A Systems Approach to Implementing Digital Tools for Earlier Alzheimer Detection in Scottish Primary Care Services

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Abstract

The early detection of dementia is a clinical and system priority. Technology has the potential to achieve earlier detection, however, may fail to be successfully implemented. This thesis examines how a novel digital cognitive assessment might be embedded into routine primary care workflows to support the earlier detection of Alzheimer disease (AD), using the tablet-based Four Mountains Test (4MT) as a case study. Rather than evaluating diagnostic accuracy, this research investigates the conditions shaping detection and the practical requirements for integrating a new assessment into general practice. Guided by systems thinking principles and the Engineering Better Care (EBC) framework, qualitative research generated actionable knowledge from three perspectives: (1) patient and carer journey mapping to trace lived experience and pathways to diagnosis; (2) clinician process mapping, semi-structured interviews, sketching tasks and workshops; and (3) usability testing of the 4MT prototype with GPs, followed by iterative adaptation. Data were transcribed, coded and analysed thematically to surface barriers, enablers and points of fit.

Findings show dementia detection as an emergent, distributed process shaped by community actors, relational advocacy and constraints including short appointment times and variable access to memory services. Clinicians described diagnostic practice as multiple strands with brief cognitive tests, functional assessments, collateral histories and clinical judgement, rather than relying on any single instrument. Existing typically paper-based assessment tools (e.g. MMSE, MoCA) were perceived as limited in sensitivity, time-demanding or culturally narrow. Testing the 4MT with GPs revealed cautious optimism: its design was seen as promising, but practical concerns required modification. In response, the prototype was adapted, producing a clinician-endorsed version ready for patient use.

This thesis contributes empirically by documenting distributed detection practices, practically by producing clinician-informed adaptations and implementation recommendations, and methodologically by demonstrating a systems approach to digital health implementation. It concludes that applying a systems approach can support practical integration of tools like the 4MT in Scottish primary care, with outputs grounded in frontline workflows and informing future patient testing and evaluations.

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Abbreviations and Glossary

AD	Alzheimer’s Disease
PLWD	People Living with Dementia
EBC	Engineering Better Care
CG	Caregiver
GP	General Practitioner
NHS	National Health Service
MMSE	Mini-Mental State Examination
MoCA	Montreal Cognitive Assessment
6CIT	6 Item Cognitive Impairment Test
ACE III	Addenbrooke’s Cognitive Exam 3
CFIR	Consolidated Framework for Implementation Research
NASSS	Nonadoption, Abandonment, Scale-Up, Spread and Sustainability
CL	Cluster Lead
PQL	Practice Quality Lead
IJB	Integrated Joint Board
MCI	Mild Cognitive Impairment
NICE	National Institute of Care and Excellence
TAM	Technology Acceptance Model
UTAUT	Unified Theory of Acceptance and Use of Technology
SUS	System Usability Scale
HCD	Human Centred Design
SCIMP	Scottish Clinical Information Management in Practice
EMIS	Education Management Information System

1. Introduction

1.1 Research Context

This thesis addresses the urgent need for earlier detection of Alzheimer's disease (AD) in Scottish primary care. For too many people, the journey to a diagnosis begins late – often in a movement of crisis rather than through proactive recognition in general practice. A common scenario involves a patient raising memory concerns with their GP, only to be advised they have passed the cognitive test and to return should symptoms worsen. Such delays reflect a system still oriented towards diagnosing dementia at later stages rather than identifying early, subtle changes. The demographic context underscores the urgency. Across the UK, it is estimated that 982,000 people are currently living with a form of dementia, a number projected to rise to 1.4 million by 2040 (Alzheimer's Society and Carnell Farrar, 2024). AD accounts for an estimated 62% of these cases (Prince et al., 2014), placing a growing strain on individuals, families, health and social care services and the economy (World Health Organization, 2025). In Scotland, geographical and socioeconomic inequalities exacerbate this burden, leading to disparities in both timely diagnosis and access to post diagnostic support (PDS) (Scottish Government and COSLA, 2021). Although there is no cure for AD, earlier detection is highly valuable. It enables people to make informed choices about their care while they retain capacity, improves quality of life, and provides access to support services (Rasmussen and Langerman, 2019). Importantly, emerging disease-modifying treatments are expected to be effective only in the earliest stages (Livingston et al., 2024, Wellcome and Nesta, 2025). Yet current diagnostic practices remain insufficiently sensitive to capture these early changes, leaving a critical gap in the pathway (Dumas et al., 2023). Addressing this gap requires rethinking how detection and diagnosis can be achieved in primary care. Innovation in the form of digital cognitive assessments and blood-based biomarkers have emerged as a potential solution. However, existing literature rarely explores how such tools might be integrated into real-world healthcare systems, particularly within the UK context or at the primary care level (Marwaha et al., 2022, Schroder et al., 2024). This thesis therefore explores how systems thinking could be utilised to explore how digital cognitive tools could be implemented in Scottish general practice, using the Four Mountains Test (4MT) (Hartley et al., 2007) as a case study. It argues that only by aligning clinical needs, technological potential and systems level understanding can meaningful and sustainable change be achieved. Figure one brings together three complementary dimensions: the clinical context (clinical need), the intervention (technological solutions) and the analytical lens (systems thinking approach).

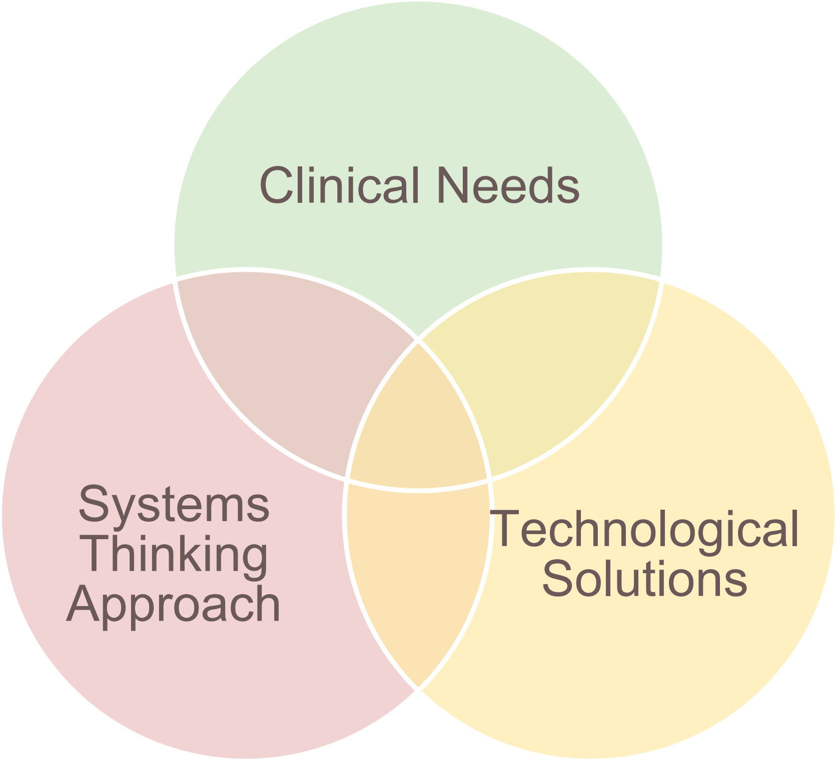


Figure 1: Conceptual positioning of the study across clinical needs, technological solutions, and a systems thinking approach.

1.2 Research Motivation

Evidence shows that digital cognitive assessment tools have demonstrated a high sensitivity and specificity for detecting Mild Cognitive Impairment (MCI) (Chan et al., 2016, Staffaroni et al., 2020). However, the implementation of such tools remains challenging – specifically in the context of Scottish primary care (Cresswell and Sheikh, 2013, Greenhalgh et al., 2017). The 4MT, although validated in research studies (Bird et al., 2010, Chan et al., 2016, Moodley et al., 2015b), has still to be tested in real-world clinical contexts. It remains unclear how tools such as the 4MT may be accepted by General Practitioners (GPs), patients and carers, or how they could be effectively integrated into complex care pathways. Current research on implementing digital cognitive tools in primary care is emerging but remains fragmented, particularly in relation to dementia (Lennon et al., 2017). There is also a lack of system-level studies that consider not only the accuracy of these tools but their practical fit within primary care services. Understanding adoption requires attention to workflows, clinician and patient needs, and wider organisational factors. This study is motivated by the need to address this gap by exploring how digital tools for earlier Alzheimer detection can be meaningfully implemented in Scottish primary care, using a systems approach to align innovation with the realities of clinical practice.

1.2.1 Clinical Needs and the Diagnostic Gap

Alzheimer Disease

AD is viewed as a progression through several stages, beginning with a preclinical phase which does not generally exhibit symptoms, followed by mild cognitive impairment (MCI) or prodromal phase, and eventually transpiring into AD dementia, which can be mild, moderate or severe (Jack et al., 2018). However, not all people exhibiting preclinical AD or MCI will progress onto dementia stages.

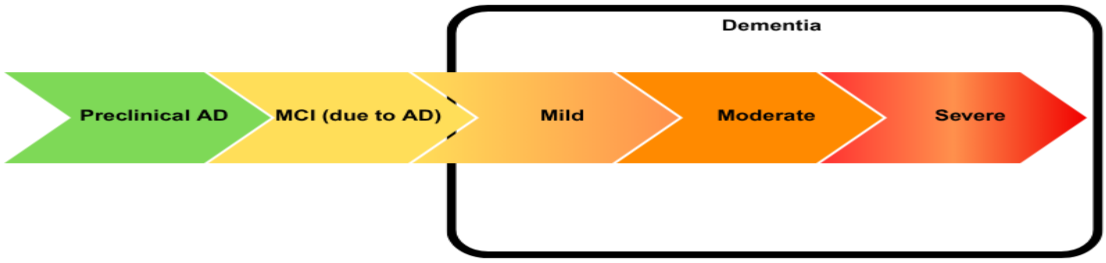


Figure 2: Alzheimer disease trajectory adapted from (Porsteinsson et al., 2021)

In the UK, the diagnostic journey is shaped by the National Institute for Health and Care Excellence (NICE) guidelines for dementia assessment (National Institute for Health and Care Excellence, 2018). For most patients, this begins in primary care, where GPs gather history, conduct physical examinations, order blood and urine tests, and perform a cognitive assessment. Yet, it is here that delays and inconsistencies frequently arise (de Levante Raphael, 2022). The steps taken by GPs are inclusive of information gathering such as: patient history, physical examination, blood and urine tests and finally conducting a cognitive test (National Institute for Health and Care Excellence, 2018). Notably, the Mini-Mental State

Examination (MMSE) and Montreal Cognitive Assessment (MoCA), which are seen as the most widely used tests, are not included in the list of brief cognitive assessments in the guidelines (Figure 3).

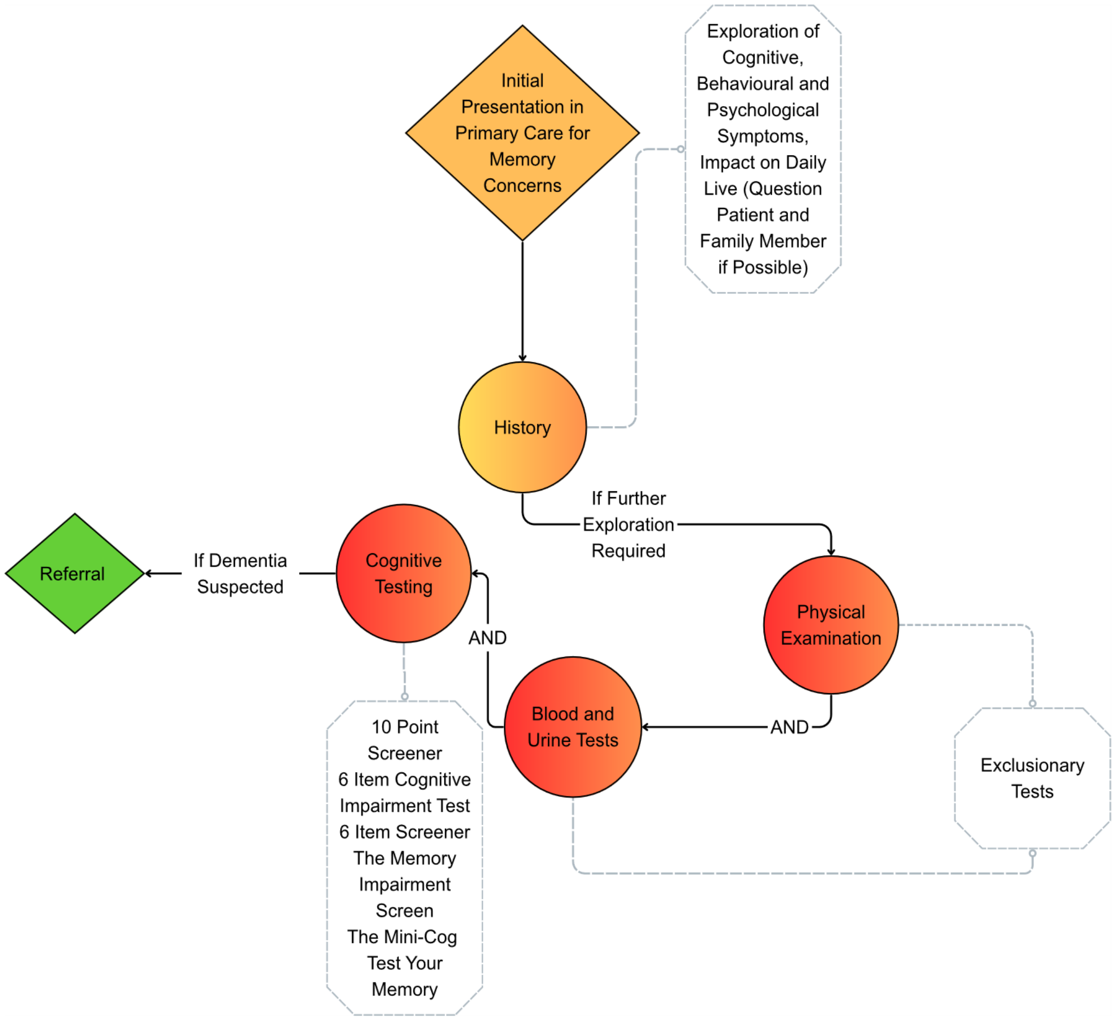


Figure 3: NICE guidelines on dementia diagnosis. Figure adapted from https://www.nice.org.uk/guidance/ng97/chapter/Recommendations#diagnosis

Current Cognitive Tests and The Difficulties Associated with Diagnosis

Existing cognitive screening tools such as the MMSE, MoCA and Six-Item Cognitive Impairment Test (6CIT) are widely used but have notable limitations (Nasreddine et al., 2005). They are not designed to detect early, domain-specific deficits such as spatial disorientation which is now understood as a potential early marker of hippocampal dysfunction associated with AD (Coughlan et al., 2018b). Moreover, these tools may not be feasible to use routinely in short consultations, and their interpretability varies.

Clinicians also express ambivalence about diagnosing dementia early when post-diagnostic support is limited (Iliffe et al., 2015). The lack of clarity over referral thresholds, the emotional weight of delivering a diagnosis, and structural pressures such as time constraints and insufficient access to secondary care services, all contribute to diagnostic inertia. Patients and carers, meanwhile, report frustration, delays and uncertainty and are often navigating the system alone until they are in a state of crisis intervention (Bunn et al., 2012). It is also important to consider the risks associated with an earlier diagnosis and the implications attached. Currently, there exists high levels of stigma and anxiety around the topic of dementia so efforts must also be made to mitigate stigma in the process of offering diagnostic solutions. Against this backdrop, new tools that can detect AD-related cognitive change earlier, in a way that fits the needs of patients and health professionals combined, are majorly required. The 4MT offers such a possibility. However, the effectiveness of any tool is contingent on more than its clinical validity; it must also have implementation potential within the constraints of the primary care system. To understand this implementation potential, consideration should be given to the needs of patients and clinicians. The usability and acceptability should be assessed alongside where it could fit best within the wider NHS ecosystem.

1.2.2 The Digital Dimension of Diagnosis

Over the past decade, digital innovation has accelerated in healthcare, offering new possibilities for the detection, monitoring and management of chronic conditions including dementia. Cognitive assessments that were once confined to pen-and-paper tools administered in memory clinics can now be digitised, enabling more scalable and accessible approaches to cognitive testing. This is particularly relevant in primary care, where time constraints and a backlog in the referrals to secondary care contribute to significant delays in the identification of AD (Iliffe et al., 2015, de Levante Raphael, 2022). Digital cognitive tools aim to address several key limitations of traditional assessments. Firstly, they can be designed to capture more domain specific cognitive changes, such as impairments in spatial navigation or memory, which are known to occur in the prodromal phase of AD (Coughlan et al., 2018b). Secondly, digital formats allow for greater consistency and standardisation across different clinical settings, reducing practitioner bias and improving reproducibility. Thirdly, with appropriate design, digital tools may enable remote or self-administered screening, potentially reducing the burden on clinical staff and increasing access for underserved populations. Despite these advantages, digital assessments also introduce new challenges. Issues of digital exclusion, accessibility and health literacy must be carefully addressed to ensure equitable use across a socioeconomically and geographically diverse population. For example, older adults may have limited digital confidence or access to devices. Moreover, clinicians must be confident not only in the tool's diagnostic utility, but also in its integration into existing workflows and patient consultations (Marwaha et al., 2022).

The 4MT is used as a case example to understand how a digital cognitive tool may be implemented within Scottish primary care. It was selected because it reflects several defining characteristics of emerging digital cognitive assessments: it is tablet-based, targets a specific cognitive domain and is grounded to neuroscientific evidence, linking spatial navigation deficits to early hippocampal degeneration in prodromal AD (Coughlan et al., 2018b). Its visual and non-verbal design may also reduce language-related bias (Chan et al., 2016) which is common in standard cognitive assessments such as the Mini-Mental State Examination (MMSE) or Montreal Cognitive Assessment (MoCA). At the same time, the 4MT does not represent all digital cognitive tools, and its use as a case example has limitations. Its evidence base, while promising, is largely derived from controlled research settings (Moodley et al., 2015b, Chan et al., 2016), and its performance within routine primary care populations remains unexplored. Furthermore, its reliance on spatial navigation tasks and digital delivery introduces potential challenges related to its usability and integration into consultations. Moreover, as with all innovations, clinical validity alone is not sufficient. Successful implementation relies on usability, accessibility and alignment with national care guidelines. Ultimately, the digital dimension of diagnosis should not be viewed in isolation. It must be considered as one part of a wider system. In this case, the system involves primary care structures, referral processes, patient experiences and organisational cultures. As such, this thesis positions digital technologies not as a standalone solution, but as a component of a system that must be co-designed, tested and adapted to ensure meaningful and sustainable change.

1.2.3 Systems Thinking

Health systems are complex and adaptive, composed of interdependent actors, workflows and cultures that interact in dynamic and often unpredictable ways (Plsek and Greenhalgh, 2001, Komashie and Clarkson, 2022). This complexity presents challenges for the implementation and uptake of new digital tools (Greenhalgh and Papoutsi, 2018). Many promising diagnostic tools fail to be adopted at scale, not because of ineffectiveness but, because they are introduced into a system without a clear understanding of how these systems work (Greenhalgh et al., 2017, Lennon et al., 2017). Applying systems thinking principles and taking a systems approach could help understand this complexity and improve the implementation and uptake of digital cognitive assessment tools. Rather than viewing implementation as a linear process of deployment, systems thinking emphasises the importance of context and continuous feedback for improvement (Meadows, 2008, Patou et al., 2020, Clarkson et al., 2017). This aligns with health system design approaches that recognise the socio-technical nature of healthcare delivery systems (Ciccone et al., 2019). The Royal Academy of Engineering proposes the Engineering Better Care (EBC) framework, which encourages a focus on four interrelated areas: people, design, systems and risk and emphasises that all areas must be considered for systems change. These areas are visualised in Figure 4 where it displays juggling the four interconnected areas, highlighting the need to consider all together for sustainable improvement (Royal Academy of, 2017).

Figure 4: Figure from Royal Academy of Engineering: Engineering Better Care report outlining four areas of systems perspectives (Clarkson et al., 2017: p 30)

This thesis utilises the Engineering Better Care (EBC) framework (Clarkson et al., 2017) as it provides a structured yet flexible approach to addressing the complexity of healthcare systems. Unlike many traditional models of implementation, which often focus on isolated interventions or assume linear change (Greenhalgh and Papoutsi, 2018, Braithwaite et al., 2018). The EBC framework integrates perspectives from systems thinking, engineering and clinical practice (Clarkson et al., 2017). This makes it particularly well suited for the introduction of new technologies into complex and adaptive environments such as the National Health Service (NHS) in Scotland. Instead of simply delivering a new tool, the EBC framework offers a series of activities, tools and questions to achieve system improvement across four stages: understand, co-design, deliver and sustain. To first act on change within a system such as the NHS, the system must be understood (Department of Health and Design Council, 2003). EBC suggests that using methods such as stakeholder and process mapping can be utilised for understanding the system in which new technologies could be embedded. Central to this framework is the cyclical model which supports the continuous process of systems improvement through asking various questions (Figure 5).

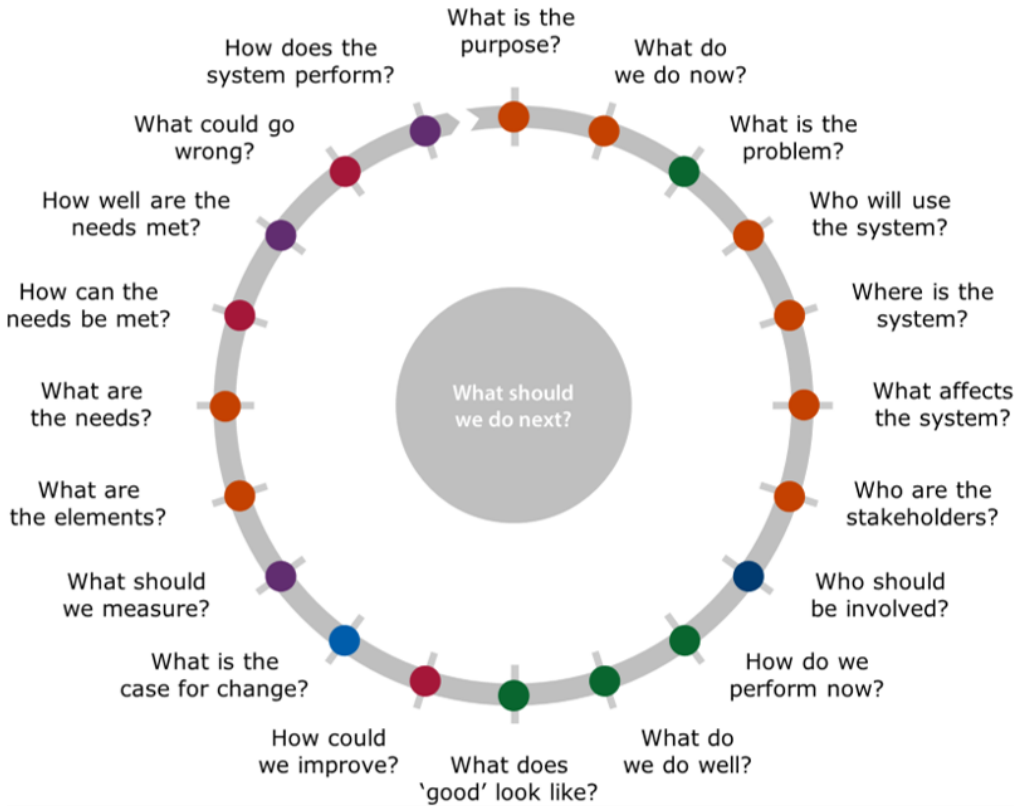
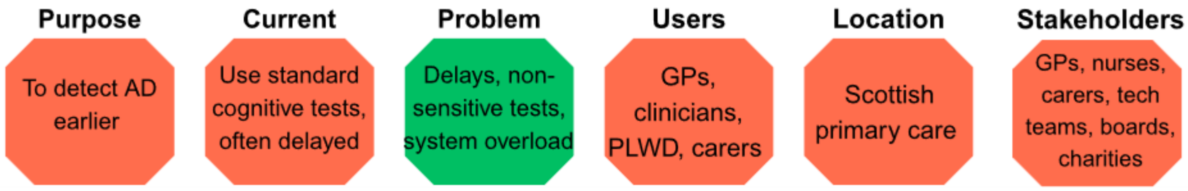


Figure 5: Cyclical model from the engineering better care framework. Image from *https://www.iitoolkit.com/improvement/ebc.html#nogo. Accessed last on 5th November 2025*

Throughout the thesis, some of these questions will be answered to support the implementation of the 4MT. With the purpose, current state, problem, users, location and stakeholders identified, six of the improvement questions can be answered (Figure 6).



Purpose	Current	Problem	Users	Location	Stakeholders
To detect AD earlier	Use standard cognitive tests, often delayed	Delays, non-sensitive tests, system overload	GPs, clinicians, PLWD, carers	Scottish primary care	GPs, nurses, carers, tech teams, boards, charities

Figure 6: Improvement questions from cyclical model from EBC with answers formulated on existing knowledge. (Clarkson et al., 2017)

1.3 Research Aims and Objectives

The central proposition of this thesis is that systems thinking, clinical needs and technology must intersect if digital cognitive tools are to have a meaningful impact on the early detection of AD. Together, this is seen as a taking a systems approach. A systems approach enables researchers to think holistically about solutions, considering every part of the wider system to ensure that tools like the 4MT are not just clinically valid, but also usable and accepted within the real-world context, addressing the clinical needs for the earlier detection of AD.

This study adopts a systems-informed, design-led approach (Maier et al., 2022) to explore how digital tools can support earlier Alzheimer detection in Scottish primary care. It adopts a focused interpretation of system integration situated at the level of clinical practice and early-stage implementation. It draws on literature synthesis, user engagement and co-design methods to identify the barriers and enablers of implementing a tool such as the 4MT. It situates the 4MT within the broader diagnostic journey, from first presentation to referral and beyond. Thus, the aim and objectives of this thesis are as follows:

Aim

To explore how the 4MT can be feasibly integrated into general practice settings within NHS Scotland to support the earlier identification of AD.

Objectives

To achieve this aim, the study is structured around four core objectives:

1. To understand the diagnostic journey of people living with dementia (PLWD) and their carers, with a focus on identifying barriers and facilitators to early diagnosis.
2. To map current GP workflows and decision-making processes around memory complaints and cognitive assessment, highlighting where and how digital tools could be integrated.
3. To evaluate the usability and acceptability of the 4MT among clinicians and members of the public, identifying design improvements and contextual factors influencing adoption.
4. To identify enablers and constraints within the wider system of staff, patients, infrastructure and workflow for the sustainable implementation of digital cognitive tools.

Broader dimensions of system integration are acknowledged as critical to full deployment within NHS Scotland but are beyond scope of this study. These factors typically arise at later stages of the technology adoption lifecycle, following initial usability and acceptability testing. Accordingly, this research is positioned within the early stages of the technology adoption lifecycle, focusing on problem-solution fit, feasibility and user acceptance within a real-world primary care setting. By doing so, it provides foundational insights into whether and how such tools could be meaningfully integrated into practice prior to a wider scale up.

1.4 Research Questions

This thesis is guided by two interrelated questions:

Q1. How might we use systems thinking to implement a digital cognitive tool for earlier Alzheimer detection in a Scottish primary care setting?

This question addresses the practical factors influencing real-world integration of the 4MT, including workflow alignment, stakeholder roles and system readiness.

Q2. How do clinicians and patients perceive the usability and accessibility of a digital cognitive tool, and what impact does this have on implementation of the tool?

This question explores the lived experiences and attitudes of end users, including both healthcare professionals and members of the public, and how these shape the uptake and acceptability of the tool.

The following chapters will explore these questions as follows:

Chapter	Study	Aim	Research Question
3	Patient and carer perspectives of the dementia journey	Understand the diagnostic process from the perspective of patients and carers	Q1
4	Clinician perspectives on dementia diagnosis and digital tool implementation in primary care	Understand the diagnostic process and perception of new digital assessment tools from the perspective of clinicians	Q1 / Q2
5	Pilot implementation of the 4MT	Understand how the 4MT may be implemented in practice and gather usability insights from end-users	Q1 / Q2

1.5 Methodology

The successful implementation of a digital cognitive assessment tool like the 4MT requires attention not only to clinical validity but also to real-world usability, accessibility and integration within the whole system. The design of the 4MT focuses on assessing spatial memory using 3D-rendered mountain landscapes. Participants are asked to identify the previously seen image from different viewpoints, a task that challenges allocentric navigation, a domain impaired early in AD. While clinically promising, the digital design of the 4MT must also meet the needs of a broad user base, including older adults and individuals with limited digital experience. This includes careful consideration of interface clarity, reading levels, font size and accessibility features – all while preserving diagnostic integrity.

Research undertaken in this thesis uses the Design Research Methodology (DRM) (Blessing and Chakrabarti, 2009). The DRM provides a structured framework for design research, comprising four iterative stages:

1. Research Criteria (RC): defining the problem space and research objectives.
2. Descriptive Study 1 (DS I): understanding the current situation through empirical investigation.
3. Prescriptive Study (PS): developing and proposing designing interventions.
4. Descriptive Study 2 (DS II): evaluating the proposed interventions in context.

This thesis situates three sub-studies within this framework:

- Literature synthesis (RC, DS I): mapping current knowledge and identifying systemic challenges in implementing digital cognitive tools (Chapter 2)
- Patient and carer journey mapping (DS I): exploring lived experiences of dementia pathways (Chapter 3)
- GP process mapping and pilot planning of the 4MT (DS I, PS, DS II): examining clinical workflows, barriers and enablers of tool integration (Chapter 4 & 5)

By organising the studies in line with the DRM framework, the research ensures methodological coherence while allowing iteration between evidence, design exploration and evaluation. This research is exploratory in nature and does not aim to evaluate the diagnostic effectiveness of the 4MT. Instead, the focus is on the feasibility of implementing such a tool within Scottish primary care. The scope is scoped to early diagnostic stages and does not extend to post-diagnostic care pathways.

Further methodological detail is provided in the results chapters three, four and five. For each chapter, the same reporting structure is adopted, which includes patient recruitment, data collection protocols and thematic analysis strategies used throughout the respective sub-study.

1.6 Contribution to Knowledge

The research makes a combined conceptual, empirical and methodological contribution to research on digital health implementation in primary care. Conceptually, it advances understanding of how a systems thinking approach can be applied to the early-stage integration of digital cognitive assessment tools. Empirically, it provides new insights into the dementia diagnostic pathway within Scotland’s primary care, highlighting the barriers and enablers to earlier AD detection from the perspectives of patients, carers and clinicians. Methodologically, the research demonstrates the value of combining design research methods such as journey mapping, process mapping and co-design with systems informed analysis to investigate implementation challenges in complex healthcare settings. By addressing a gap between research on diagnostic tool development and real-world implementation, this thesis contributes to ongoing discussions within implementation science and digital health regarding how emerging technologies can become embedded within routine clinical practice. While implementation science has increasingly moved beyond purely linear models of implementation to recognise implementation as an iterative, staged and context-dependent approach, this thesis extends these perspectives by conceptualising early-stage integration as a dynamic system of interacting components within everyday primary care practice. Rather than focusing solely on adoption as a discrete event, the studies highlight how implementation unfolds through ongoing interactions between people, processes and organisational contexts. In doing so, it contributes a systems-informed, practice level perspective to existing implantation frameworks using the 4MT as a case study for earlier Alzheimer detection. By addressing key questions around implementation, usability and integration, it contributes knowledge in three interrelated areas.

Clinical Needs

The research offers insights into how digital tools, specifically the 4MT, might be embedded into existing general practice workflows. By exploring the diagnostic journey from the perspective of GPs, it highlights where and how such tools might support earlier identification of cognitive decline and what adaptations may be required to fit within current clinical processes and time constraints.

Systems Thinking

By applying systems thinking and design frameworks to the implementation of digital cognitive tools, this thesis surfaces broader system-level barriers and enablers. It examines how primary care infrastructure; service design and inter-professional coordination shape the feasibility and sustainability of the adoption of digital tools in real-world healthcare contexts.

Digital Technology

Through direct engagement with PLWD, carers, clinicians and developers, this research gathers real-world feedback on the 4MTs usability, interface design and clinical utility. This iterative and participatory approach contributes to a growing body of work that centres user experience in the design and refinement of digital health tools, ensuring their relevance and accessibility in everyday practice.

Taken together, these contributions advance academic and practical discussions around the role of design and systems thinking in the implementation of digital cognitive assessment tools in primary care. The findings aim to inform future implementation strategies and lay the groundwork for broader scale deployment of digital cognitive tools within primary care systems. Furthermore, it contributes to wider ongoing work through the Spatial Biomarkers in Alzheimer’s Disease (SABRE) project which aims to understand whether spatial tests can be used to diagnose AD early in routine practice.

1.7 Structure of the Thesis

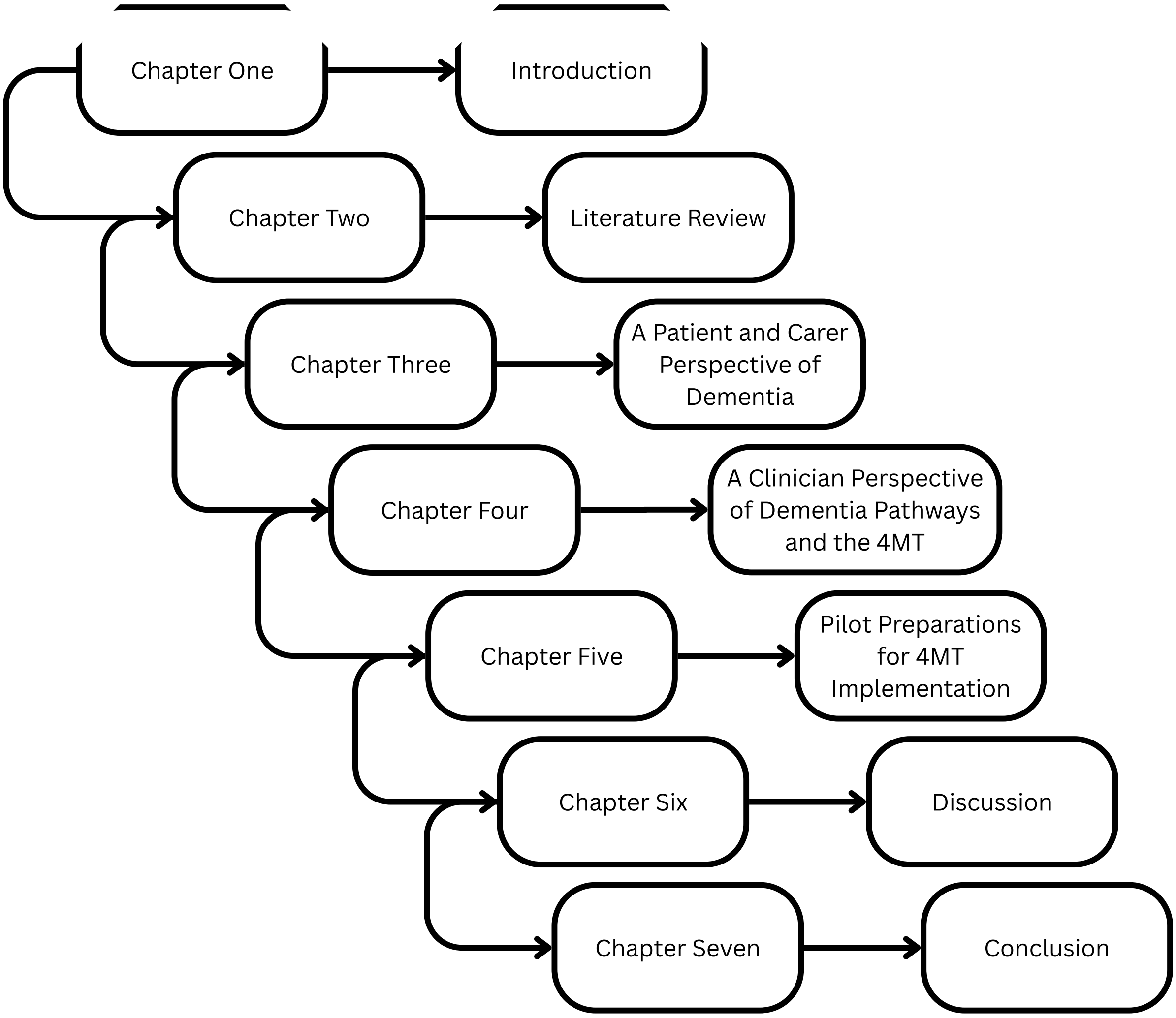


Figure 7: Structure of the thesis

This thesis is structured across seven chapters (Figure 7). Chapter one introduces the research context, outlining the clinical, technological and systems-level challenges in the early detection of AD in Scotland's primary care. It also presents the study's aims, objectives and research questions. Chapter two reviews the relevant literature on cognitive assessment tools, digital health innovation and systems thinking in healthcare, identifying the key gaps that shape the project rationale. Chapter three will present findings from patient and carer journey mapping, highlighting the systemic and lived experience barriers to timely diagnosis to set the pilot project context. Chapter four explores the dementia diagnostic pathway from a clinician perspective with early usability feedback presented. Chapter five lays the groundwork for the pilot implementation of the 4MT, looking at the systemic process to diagnosis in a GP practice in Lanarkshire and assessing the feasibility of introducing a novel digital tool in this setting. Chapter six discusses the implications of the findings, reflecting on the overall contribution to knowledge and offers recommendations for future research, and practice. Finally, chapter seven concludes the thesis with synthesising key insights, highlighting the significance of the research and providing a future perspective on the implementation of digital cognitive assessments in primary care.

2. Literature Background

The detection of Alzheimer Disease (AD) has become a clinical and system priority with an estimate of 982,000 people living with dementia in the United Kingdom (Alzheimer's Society and Carnell Farrar, 2024), a figure that will continue to rise in incidence as the population ages (Hofman et al., 1991). The implications for healthcare systems are significant with dementia care representing one of the most substantial cases in the National Health Service (NHS). Amid rising prevalence, the early detection of AD has become a central concern in the UK due to its potential to improve care outcomes, delay progression, and reduce long term costs.

Traditionally, AD has been diagnosed based on dementia symptoms which are identified through functional impairments that interfere with daily living. However, recent advances in biomarker science have shifted the conceptualisation of AD from a late-stage diagnosis to a progressive, biologically defined continuum (Jack et al., 2018). This continuum perspective divides AD into three phases: a preclinical or asymptomatic phase marked by abnormalities in biomarkers, a prodromal phase which is commonly diagnosed as Mild Cognitive Impairment (MCI), and a final stage of full dementia. Crucially, most pathological changes, including the accumulation of amyloid and tau deposition (the main pathological hallmarks of the disease), occur in during the preclinical and prodromal stages, long before overt symptoms manifest (Dubois et al., 2016a). This has profound implications for the detection and intervention of AD.

From a systems perspective, this shift challenges existing diagnostic paradigms. Primary care systems, particularly within the UK, still operate largely on syndromic definition, with GPs reluctant to refer patients for further diagnostic workups unless memory loss is visibly impacting function. This creates a lag between disease onset and diagnosis, undermining efforts toward early detection and treatment planning (Iliffe et al., 2015). Moreover, current screening tools are designed to identify general cognitive impairment rather than specific early-stage changes. They are sensitive to later stage deficits but may miss the subtle signs of dysfunction that characterise AD (Coughlan et al., 2018b). Emerging tools like the 4MT offer a path forward by operationalising the continuum view. By targeting allocentric spatial memory, they align more precisely with early pathological change. However, the implementation of such tools face inertia from legacy diagnostic systems and health professional training. Syndromic frameworks such as the DSM-5 and ICD-10 continue to define AD in functional terms, while newer biological frameworks such as the NIA-AA’s AT(N) model are not yet embedded in general practice.

This literature review explores how digital cognitive tools, and particularly the Four Mountains Test (4MT), might close this diagnostic gap. The central concern of this review is not only whether these tools are clinically valid, but whether they can be integrated meaningfully and equitably into the routine practices of primary care, particularly within the NHS Scotland context. Thus, this chapter takes a systems informed approach to synthesising literature from multiple domains, clinical, technology, and systems thinking. It aims to provide a critical foundation for implementation focussed research, foregrounding the barriers, enablers and implications of deploying novel tools for AD detection. It begins with an overview of the clinical needs, discussing the context of Scottish primary care followed by technology. It then examines the role of systems thinking and the factors influencing adoption in healthcare.

2.1 Clinical Needs

2.1.1 The Scottish Primary Care Landscape

In Scotland, the NHS provides a publicly funded and integrated system where general practice serves as the first point of contact for most people. It plays a key role in managing health needs and coordinating care across the wider system. In this context, the complexity of digital tool implementation is further shaped by regional variation and health information technology (IT). While the platform SCI Gateway links primary and secondary care nationally, individual GP practices retain autonomy over which primary care record system that they use (e.g., EMIS, Vision, GPASS). This diversity complicates attempts to integrate standardised tools (Deloitte, 2006). The National Institute for Health and Care Excellence (NICE) has acknowledged the value of integrated diagnostic pathways, but more current cognitive assessments are designed in isolation rather than co-produced with clinicians and patients (National Institute for Health and Care Excellence, 2018).

There are 14 territorial health boards in Scotland under the governance of various organisations which come under the Scottish Government (Figure 8), with GPs acting as independent contractors. They play a central role in initiating investigations, coordinating referrals, and providing continuity of care. Patients often trust GPs highly, but services face workflow shortages, multimorbidity in ageing populations and significant workload pressures (Audit Scotland, 2024). These pressures make it difficult to adopt new diagnostic tools, especially when cognitive testing can consume so much of a standard 10-minute consultation (Hayhoe et al., 2016). Moreover, introducing new diagnostic tools with the promise of earlier detection could increase pressure on the healthcare service beyond the primary care stage. For example, an increase in referrals could increase the workflow for secondary care and may place pressure on support services. Thus, it is important to ensure the integration of new tools is placed well in the system to mitigate the risks of earlier diagnosis coming with little to no support (Rasmussen and Langerman, 2019).

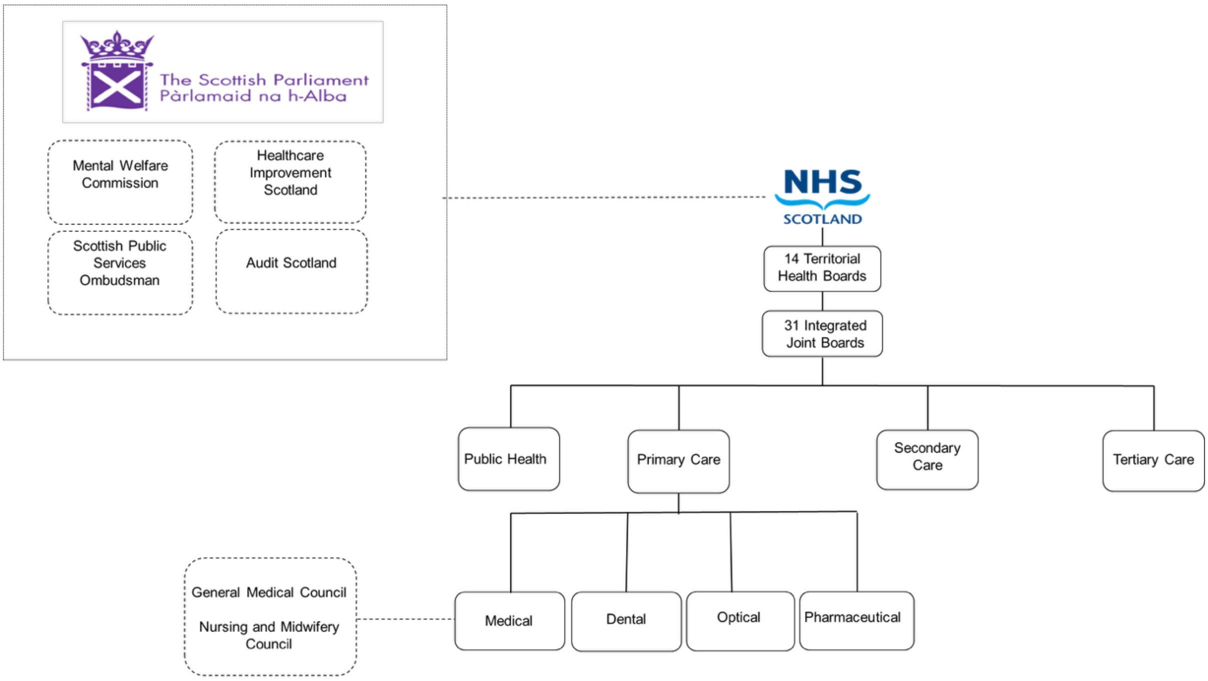


Figure 8: High level outline of the Scottish healthcare system created from information in The SPICe Briefing (Robson and Boray, 2016).

Despite these operational challenges, Scotland has developed a progressive dementia policy environment. Since the first National Dementia Strategy in 2010, successive policies have prioritised timely diagnosis, post-diagnostic support and integration across health and social care (Figures 9-10) (Scottish Government and COSLA, 2021). Unlike England, where the Quality and Outcomes Framework (QOF) has intermittently incentivised dementia diagnosis, Scotland abolished QOF in 2016, relying instead on GP cluster quality improvement and Primary Care Improvement Plans (PCIPs)(British Medical Association, 2025). This creates both challenges and opportunities: while GPs operate under intense pressure, there is strong national support for the earlier diagnosis of Alzheimer disease (Scottish Government and COSLA, 2021) which could be achieved with tools such as the Four Mountains Test (4MT). Given the short administration time of the 4MT and automated scoring feature, GPs could potentially benefit from tools that meet their needs within the clinical time constraints. Nonetheless, diagnostic practice across Scotland still relies heavily on syndromic definitions of dementia, with referrals only triggered only after clear functional decline. Referral criteria remain complex and inconsistent, resulting in long waits that can be as long as 55 weeks (Puttick, 2025). On average, the time from symptom onset to official diagnosis exceeds 3.5 years (Kusoro et al., 2025). Almost half of people with dementia in UK primary care have no recorded cognitive concern or diagnosis (Aldus et al., 2020), highlighting systemic under-detection. Contributing barriers include GP confidence, patient help seeking behaviour and referral pathway design (Bradford et al., 2009)

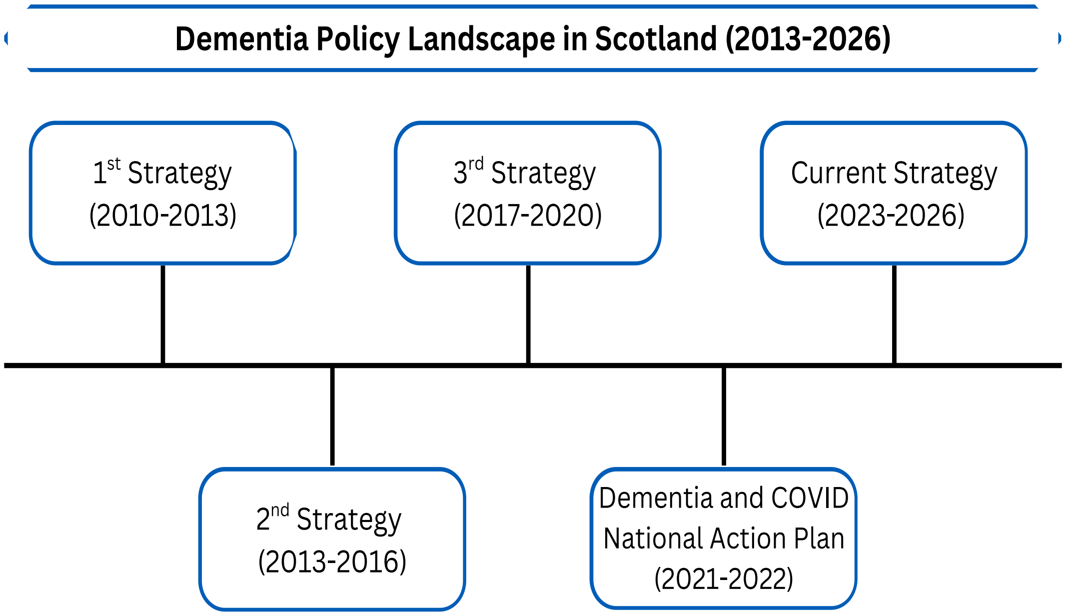
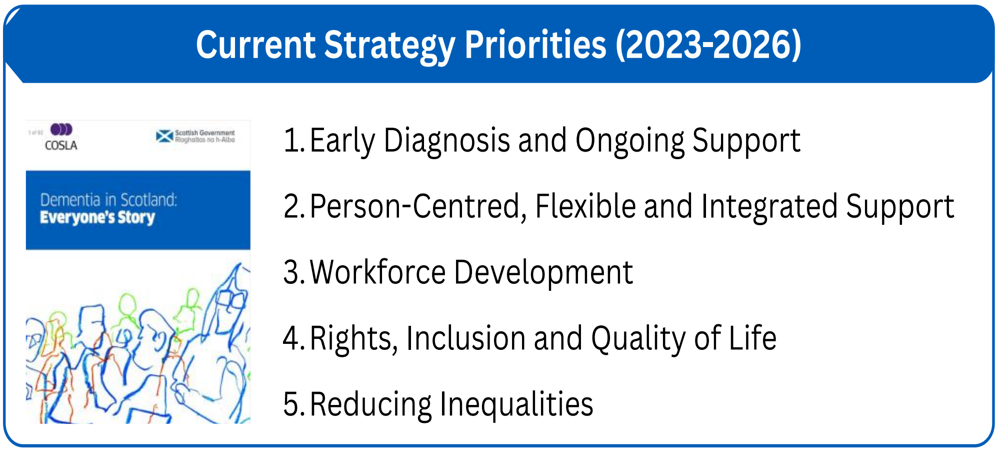


Figure 9:Outline of dementia policies in Scotland from 2013-2016 adapted from (Alzheimer Europe, 2025).



Current Strategy Priorities (2023-2026)

1. Early Diagnosis and Ongoing Support
2. Person-Centred, Flexible and Integrated Support
3. Workforce Development
4. Rights, Inclusion and Quality of Life
5. Reducing Inequalities

Figure 10: Outline of the current policy priorities for dementia in Scotland (Scottish Government and COSLA, 2021)

2.1.2 The Biological Continuum of Alzheimer Disease

Traditionally, AD has been diagnosed once dementia symptoms are evident. However, advances in biomarker science have reframed AD as a progressive continuum (Jack et al., 2018). This model identifies three phases: a preclinical stage marked by biomarker abnormalities, a prodromal stage usually recognised as mild cognitive impairment (MCI), and symptomatic dementia. The pathological hallmarks known as amyloid-beta plaques and tau tangles accumulate during the preclinical and prodromal stages, long before overt symptoms (Dubois et al., 2016a). Hippocampal atrophy, particularly affecting spatial and episodic memory, occurs early and is strongly associated with subtle symptoms such as disorientation (Burgess et al., 2002).

The Braak and Braak staging system describes six phases of neurofibrillary tangle progression, from the transentorhinal region (stages I-II), through the limbic system (III-IV), to widespread neocortical involvement (V-VI). spatial disorientation and episodic memory loss emerge in the earlier stages, supporting the rationale for targeting hippocampal function in detection strategies (Braak and Braak, 1991).

Biomarkers have advanced diagnosis in specialist settings, with cerebrospinal fluid (CSF) analysis, positron emission topography (PET) imaging and emerging plasma assays providing biological evidence of pathology (Palmqvist et al., 2020, Janelidze et al., 2020). Yet these methods are costly, invasive and impractical for primary care. Practical cognitive tools are therefore needed to operationalise the biological model of AD within everyday clinical workflows.

2.1.3 Spatial Disorientation as an Early Marker

Spatial disorientation, or difficulty navigating familiar environments, is increasingly recognised as an early and specific cognitive deficit in AD and MCI (Guariglia and Nitrini, 2009, Monacelli et al., 2003). These impairments are linked to hippocampal and entorhinal dysfunction (Figure 11) (de Toledo-Morrell et al., 1984, Nedelska et al., 2012). Allocentric navigation, which is the ability to form environment-centred representations, is disproportionately affected in early AD, while egocentric navigation (self-referenced) remains relatively preserved until the later stages (Serino et al., 2014, Weniger et al., 2011). Experimental tasks such as the human Morris Water Maze and landmark-based wayfinding confirm reduced accuracy and strategy use among MCI patients compared to controls (Morris, 1981, Lester et al., 2017, Lithfous et al., 2013). Because these deficits occur independently of general memory decline, they offer a disease-specific avenue for early detection (Hartley et al., 2007)

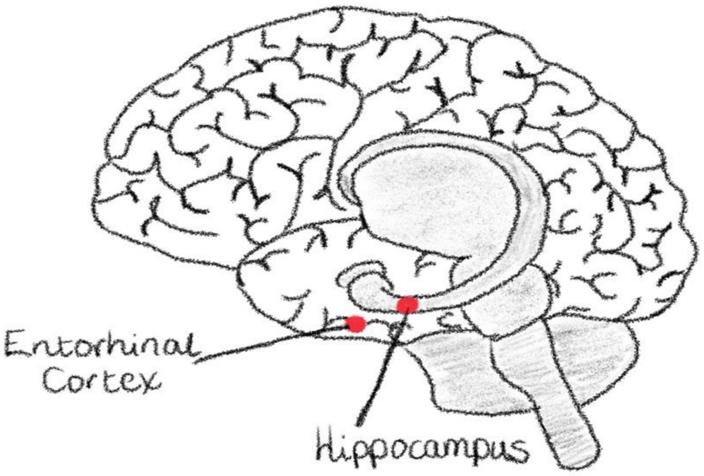


Figure 11: Own illustration of the brain highlighting the entorhinal cortex and hippocampus (Hamilton, 2025)

2.1.4 Existing Cognitive Assessment Tools and the Four Mountains Test

The Mini-Mental State Examination (MMSE), Montreal Cognitive Assessment (MoCA), and Six-Item Cognitive Impairment Test (6CIT) remain the most commonly used cognitive screening tools in UK primary care. They are brief, inexpensive, and easy to administer, making them well suited to time-constrained clinical settings. However, they also have notable limitations.

In terms of clinical sensitivity, the MMSE demonstrates good reliability for moderate to severe dementia but has consistently been shown to have low sensitivity to MCI (Nasreddine et al., 2005) The MoCA improves sensitivity to MCI and earlier cognitive decline, although this is accompanied by increased administration times and the susceptibility to educational and language related bias (Carson, 2018). The 6CIT takes under five minutes but is less extensively validated (Creavin et al., 2016). Across all three tools, a common limitation is their reliance on language based and memory tasks, which are not specific to AD-related pathology (Greenhalgh and Papoutsi, 2018). Importantly, none assess spatial disorientation, limiting their ability to detect disease at its earliest stages (Creavin et al., 2016, Coughlan et al., 2018b).

The 4MT differs in both cognitive focus and intended position within the diagnostic pathway. Rather than functioning as a general cognitive screening tool, it is designed to assess allocentric spatial memory, making its targeted domain more closely linked to early hippocampal changes in AD. As such, it’s demonstrated sensitivity to prodromal AD in experimental settings (Coughlan et al., 2018b). However, unlike established screening tools, its usability and acceptability within routine primary care workflows remain unexplored.

Taken together, this comparison suggests that while existing tools may be well-suited to identifying established cognitive impairment within a primary care setting, they are limitied in their ability to detect the earliest stages of AD. The 4MT therefore represents a complementary approach, with the potential to address this gap, but with distinct implementation challenges that must be considered. Table 1 presents a structured comparison of these tools across clinicial sensitivity, domain and key limitations.

Table 1: Existing cognitive assessment tools in Scottish primary care compared with the 4MT

Tool	Delivery Mode	Targeted Cognitive Domain	Sensitivity	Time	Training Required	Language Reliance	Key Limitations
MMSE	Pen and Paper; Administered by clinician	Multiple domains targeted including memory, language and attention	Low	5-10 mins	No	Yes	Poor sensitivity to MCI, biased by education
MoCA	Pen and Paper; Administered by clinician	Multiple domains targeted including executive function, attention, language	Moderate to high	10-15 mins	Yes	Yes	Longer to administer, scoring complexity
6-CIT	Pen and Paper; Administered by clinician	Multiple domains targeted including memory, orientation and attention	Low – limited to subtle deficits	<5	No	Yes	Narrow scope, low specificity for subtle impairments
4MT	Online tablet based; can be self-administered at home or by clinician	Spatial disorientation, early marker of AD	High	10-15	No	No	Not yet implemented in clinical practice, usability in practice untested

2.1.5 Patient and Carer Perspectives

The diagnostic journey is shaped by emotional and relational factors as much as clinical ones. Patients frequently delay help-seeking, attributing symptoms to ageing or fearing stigma (Bunn et al., 2012). Misconceptions about dementia equating to immediate memory loss persist (Corner and Bond, 2004), and stigma can deter disclosure or prompt denial (Giebel et al., 2022). Carers often serve as advocates, encouraging consultations, but report difficulty convincing clinicians to act in the absence of overt memory problems (Bunn et al., 2012). Following, diagnosis, they face fragmented services, inconsistent guidance and significant emotional and financial strain (Turner et al., 2004, Dementia Carers Count, 2025). Patients and carers value empathetic listening and validation from GPs (Godbee et al., 2022), yet short consultation times frequently limit these interactions. Variability in post-diagnostic support further compounds inequalities (Morgan et al., 2011). Digital cognitive tools could help validate concerns and facilitate continuous monitoring, but their design must prioritise usability and acceptability, especially for older adults with limited digital literacy (Han et al., 2023). Co-design with patients and carers is essential to ensure these tools support, rather than complicate, the diagnostic journey.

2.1.6 The Case for Early Detection

Earlier diagnosis benefits patients, families and health systems. It allows individuals to understand the symptoms, make informed decisions and plan ahead (Brodaty and Donkin, 2009). It provides access to interventions that may slow progression and offers entry into clinical trials for emerging disease modifying treatments such as Lecanemab and Donanemab, (Alzheimer's Society, 2025) which are most effective in early stages (Cummings et al., 2022). For carers, timely diagnosis provides clarity, reduces uncertainty and facilitates access to resources and support (Bunn et al., 2012, Leifer, 2003). At the system level, early detection enables better resource allocation and may delay institutionalisation, reducing costs projected to rise from £34 billion to £55 billion annually by 2040 (Alzheimer's Society and Carnell Farrar, 2024, Prince et al., 2016). However, critical literature warns against assuming that earlier is better. Overdiagnosis is a risk, as not all individuals with biomarkers or MCI progress to dementia (Mitchell and Shiri-Feshki, 2009, Dubois et al., 2016b). While the 4MT offers potential for early identification, its use must be balanced against the psychological and social consequences for patients and families. In a context already laden with stigma and anxiety around dementia, early detection without adequate support may cause distress or unintentionally reinforce negative narratives around brain health (Le Couteur et al., 2013, Iliffe et al., 2015). These considerations highlight that the utility of the 4MT cannot be judged solely on diagnostic or efficiency grounds; its integration must also account for patient experience, ethical considerations and the wider sociocultural context of dementia. A balanced approach emphasises “timely and meaningful” rather than a universal early diagnosis, grounded in person-centred values. There is the consideration that not everyone would want to receive a diagnosis but embedding the option for early detection would mean that individuals can make an informed consideration to receive that diagnosis earlier should they wish to receive it.

2.2 Digital Technology

Technology is playing an increasingly important role in the early detection of AD. Digital cognitive tools range from simple digitised versions of established tests to innovative platforms employing artificial intelligence (AI), virtual reality (VR), or passive monitoring. Their appeal lies in scalability, standardisation, automation and potential for remote delivery, which are qualities particularly valuable in primary care settings where time, resources and specialist access are constrained (Costa and Milne, 2024).

2.2.1 Digitised Versions of Traditional Tests and Novel Innovations

One branch of innovation focuses on digitising established paper tools, such as the MMSE, MoCA and Addenbrooke’s Cognitive Examination (ACE-III). Digital versions maintain the structure and scoring of their originals while adding features such as automatic timing, integrated data storing and electronic scoring. This improves standardisation and reduces human error. However, digital replication does not resolve the limitations of original tools: low sensitivity to prodromal AD, ceiling effects, reliance on language and poor specificity to AD pathology (Arevalo-Rodriguez et al., 2015, Tsoi et al., 2015, Greenhalgh and Papoutsi, 2018). Thus, while digitisation enhances usability and efficiency, it does not fundamentally advance diagnostic precision.

A more transformative strand of development involves tools that are purpose built to capture early, disease specific cognitive changes. Recent years have seen the development of a diverse range of digital tools aimed at improving early detection of AD, particularly in scalable and non-invasive formats suited to primary care (Table 2).

Table 2: Analysis of Digital Cognitive Assessments showcasing strengths, weaknesses, threats and opportunities of each tool

Tool	Strengths	Weaknesses	Opportunities	Threats
4MT	- Validated in >13 academic studies - Assesses allocentric memory, linked to prodromal AD - Quick to administer - Language independent	- Not yet tested in a primary care setting - Research tool, has not been medically validated	- Can be used in practice or at home - Earlier identification of AD - Differentiate AD from other dementias	- Integration with electronic health records - Patient / clinician acceptance
Sea-Hero Quest	- Assesses spatial navigation, linked to prodromal AD - Large normative dataset	- Not clinically validated	- Can be offered as at home testing - AI and big data insights	- Demographic bias - Gaming bias - Data protection threat
Altoida's Digital Neurosignature	- Multimodal biomarkers - High sensitivity - Quick to complete	- No FDA clearance and can only be used for investigational purposes only - Cannot be used for clinical diagnostics	- Potential for regulatory approval - Telehealth integration - Earlier Detection	- Delays in approval or no approval - High cost if commercialised - Data protection threat
Integrated Cognitive Assessment	- Quick to complete - Independence of language - CE-marked	- Narrow domain	- Scalable population - Primary care usage	- False negatives or positives - Clinician trust
Neurocatch	- Objective EEG data - Detects subtle change	- Requires equipment - Complementary to behavioural tests	- Biomarker integration - Primary care use - Disease monitoring	- Cost - Workflow disruption

Among these is ‘Sea Hero Quest’ which is a mobile game co-designed with neuroscientists to assess spatial navigation abilities. Spatial navigation abilities are closely linked to hippocampal integrity which can be often impaired early in AD (Burgess et al., 2002). The game generated an unprecedented normative dataset on spatial cognition and demonstrated the ability to differentiate between individuals with hereditary risk for AD from healthy controls (Coutrot et al., 2019). Other novel tools include Altoida’s Digital Neuro Signature, which assesses digital biomarkers by combining eye-tracking, motor and augmented reality-based tasks. Although this tool may be a promising tool for practitioners, it has not yet received clearance in the US (Meier et al., 2021, Altoida, 2024) Similarly, the Integrated Cognitive Assessment (ICA), a five-minute task independent of language conducted on a tablet which tests processing speed has demonstrated strong diagnostic performance and has received CE-marking for clinical use (Kalafatis et al., 2022). NeuroCatch provides rapid, EEG-based objective assessments of brain function, offering physiological insights that could complement behavioural tests (Ghosh Hajra et al., 2016). These emerging tools exemplify the expanding possibilities of digital technology for scalable, early cognitive screening, though their integration into routine care remains contingent on systems compatibility, usability and clinical validity.

Beyond direct testing, digital tools increasingly utilise passive and wearable monitoring. Smartphones and wearable devices can track behaviour continuously, generating ecological data on movement, sleep, speech and mobility. This approach allows subtle cognitive decline to be inferred from deviations in daily routines. For instance, fitness tracker data from a pilot study perfectly distinguished MCI from healthy controls (Xu et al., 2024). Longitudinal analysis of 83,000 biobank participants linked disruptive circadian rhythms with higher AD risk and accelerated decline (Winer et al., 2024). Gait analysis using wearable sensors has shown associations between slower walking speed, reduced stride length and poorer cognitive outcomes in amnestic MCI (Xie et al., 2019}. These modalities offer the advantage of continuous and unobtrusive monitoring but raise significant ethical concerns. Issues of privacy, consent and surveillance are particularly acute for older and potentially vulnerable populations. Furthermore, most passive tools lack a robust clinical evaluation, limiting their immediate applicability in routine primary care (Costa and Milne, 2024).

2.2.2 Usability and Acceptability

As the population ages, there will be more familiarity with technology among the elderly population, although it has been demonstrated that experience is not conditional for perceived usability (Thorpe et al., 2016). Accuracy alone does not determine the success of digital tools. Usability and usefulness are a critical factor (Bharucha et al., Davis). According to the principles of user-centred design (UCD), technology adoption among older adults is most successful when tools are developed iteratively around the user's context, capabilities and motivations (Maier et al., 2015, Thorpe et al., 2019). From a UCD perspective, usability is more than the simplicity of an interface as it reflects the degree to which a system enables the user to achieve meaningful goals with effectiveness. Acceptability is shaped by how well technology aligns with the values of its user and their everyday routine. Studies emphasise that willingness to use technology is shaped by interface simplicity, clarity of instructions and perceived relevance (McMurray et al., 2024). Tasks delivered in familiar and intuitive formats, such as digital card games, have been shown to enhance engagement (Ciesla et al., 2024, Gielis et al., 2021). Thorpe et al (2019) emphasise that perceptions of usefulness depend on the type of device and how well it meets user needs. These insights underline that usability and acceptability are inseparable from lived experience and expectations of older adults. Importantly, usability extends beyond interface design to system-level alignment. Successful implementation depends on coherence between patient motivation, tool design and clinician workflow. Ciccone et al. (2019) describe this as part of a "techno-behavioural framework", positioning usability at the intersection of human behaviour, systems and technology. Without this alignment, even well-designed tools risk abandonment. Thus, UCD principles are critical, not only for designing accessible interfaces but also for embedding technologies within real-world systems that support meaningful use.

2.2.3 Digital Exclusion and Equity

Digital innovation risks exacerbating health inequalities if issues of access, literacy and cultural appropriateness are overlooked. Older adults with limited digital literacy or access to technology may be excluded (Han et al., 2023). Variations in hearing, literacy and language also require careful adaptation (Sewell et al., 2013, Cherbuin et al., 2008). Studies caution that systemic barriers, such as device access or broadband availability, can undermine even the best designed tools (Bloniecki et al., 2021, Liu et al., 2024). Equity requires intentional strategies. Garcia Basalo et al. (2017) recommend tailoring visual cues for individuals with lower literacy, while others highlight the risk of under-diagnosis when tools are not culturally adopted (Wild et al., 2008). Frameworks such as the CLEARS framework (Culture, Limiting Conditions, Education, Age, Residence, Socioeconomic status), recently proposed in a systematic review of qualitative studies, categorises sociodemographic factors that contribute to digital exclusion. CLEARS emphasises that these factors often intersect as someone could be older, have a low education, live in a remote area and have sensory loss, each compounding the risk of exclusion (Wilson et al., 2023). Equity requires intentional strategies such as designing interfaces that account for sensory impairments, language and literacy and engaging users from CLEARS defined groups in co-design to ensure tools are usable, trusted and relevant.

2.2.4 The Four Mountains Test

The 4MT is a digital spatial memory task that measures allocentric (environment referenced) and egocentric (self-referenced) navigation abilities which are domains that are typically impaired early in AD. The test was initially designed by Hartley et al (2007) to evaluate hippocampal dependent spatial memory through a series of trials in which participants must identify a previously viewed landscape scene from a rotated viewpoint. Unlike traditional memory tests, which assess verbal or working memory, the 4MT taps into the brain's ability to form and retrieve spatial representations of the environment. The theoretical underpinning of the 4MT is rooted in the known progression of AD. One of the earliest brain regions affected in AD is the medial temporal lobe, inclusive of the hippocampus and entorhinal cortex which are regions essential for allocentric spatial navigation (Bird et al., 2010, Burgess et al., 2002). The specificity of the 4MT to this brain region makes it a promising tool for early detection, especially since spatial disorientation often precedes significant verbal memory loss in Alzheimer pathology (Allison et al., 2016).

Unlike general cognitive screeners, the 4MT targets a specific and relevant domain of impairment in AD. While tools like the MMSE and MoCA offer a broader picture of cognitive functioning, they may overlook or misinterpret early spatial deficits which are characteristic of prodromal AD (Mitolo et al., 2013, Welsh et al., 1991). The 4MT complements these tools by offering a focused and sensitive measure of hippocampal function, which is often compromised long before traditional markers of memory loss emerge. Additionally, the 4MT compares favourably with existing tools due to its administration and ease of use. It typically takes 10 minutes to complete, requires minimal training to administer and does not demand advanced clinical interpretation, thus making it a promising candidate for widespread use in primary care settings. The 4MT is brief, non-invasive and designed to be user friendly for older adults. It involves presenting participants with an image of a mountain landscape, followed by a choice of four options from varying viewpoints. Participants must select the image that represents the same landscape, testing their ability to mentally rotate and recall spatial features (Figure 12). This format makes the test relatively immune to language and cultural bias, thereby enhancing its suitability for diverse populations.

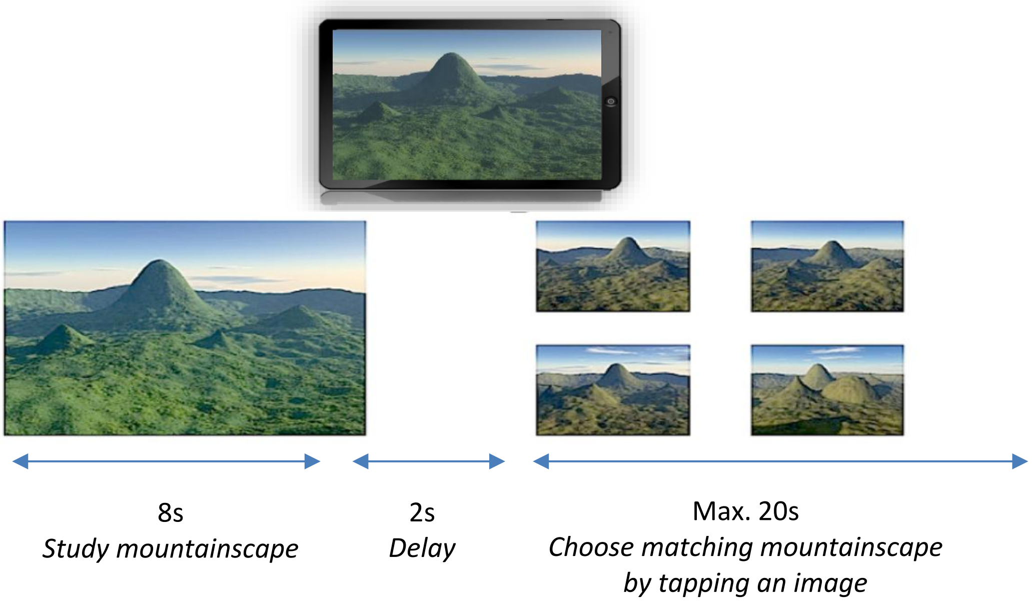


Figure 12:Top: An image of the 4MT, which is presented on a touchscreen tablet. Bottom: an overview of a single test trial format. Each tests comprises 15 trials lasting around 8 minutes. (Newton, 2024)

Its digital interface allows for automatic scoring and data capture, making it potentially well suited for integration into electronic health records or digital referral platforms. The 4MT does not require verbal responses or fine motor skills, further improving its accessibility for individuals with language or physical impairments.

Several studies have evaluated the 4MT's diagnostic utility. In its original validation, Hartley et al (2007) demonstrated that the test could distinguish healthy participants from those with selective hippocampal damage. Follow up studies have shown that performance on the 4MT is significantly impaired in adults with MCI who are amyloid positive, suggesting its specificity for Alzheimer related cognitive decline (Moodley et al., 2015a). Wood et al 2016 further demonstrated that 4MT performance could predict conversion from MCI to AD, outperforming traditional tools such as the MMSE and MoCA. Moreover, 4MT scores have been shown to correlate with hippocampal volume on MRI (Hartley et al., 2007) suggesting that the test may serve as a proxy for structural brain changes (Coughlan et al., 2018a).

These findings position the 4MT as a robust, biologically grounded tool for identifying early cognitive changes linked to Alzheimer pathology. It also demonstrates its predictive nature which is one of the four characteristics identified in the P4 healthcare model (Patou et al., 2020).

Despite diagnostic promise of the 4MT, it has not yet been widely adopted in a routine clinical practice. Several barriers remain, including the need for integration into existing clinical workflows, clinician training and further validation in real-world settings. Primary care poses challenges due to limited time for appointments and competing clinical demands (Greenhalgh et al., 2017). Nevertheless, the 4MT aligns well with the principles of person-centred care and systems informed healthcare. Its short duration and digital format make it amenable to use in brief consultations. It may also serve as a useful triage tool, helping GPs decide which patients require referral for more comprehensive neuropsychological testing or biomarker analysis. Importantly, implementing the 4MT requires more than technical validation. Adoption depends on its perceived value by clinicians, ease of integration into IT systems and patient acceptance. These factors highlight the importance of applying systems thinking and implementation science frameworks, as explored in subsequent sections of this review.

In summary, the 4MT offers a scientifically grounded approach to earlier Alzheimer detection. Its unique focus on spatial memory differentiates it from traditional cognitive tests and positions it as a valuable addition to primary care screening pathways, if system level barriers are addressed.

2.3 Systems Thinking Approach

Systems thinking offers a philosophical and practical toolkit for working within complexity rather than against it. Meadows (2008) defines a system as “an interconnected set of elements that is coherently organised in a way that achieves something”. Systems thinking, then, is about seeing interdependencies, feedback loops, and the unintended consequences of an intervention. It encourages a shift in design questions from “what will this tool do?” to “what will this tool do for the system?”. In healthcare, this perspective is particularly valuable. Clinical interventions, especially digital tools, rarely act in isolation. Introducing a cognitive test might affect not only patient assessment, but also referral rates, administrative workload, electronic medical record usage and the perception of a clinical role. The unintended consequences of technology, whether positive or negative, are often shaped by these systemic interactions (Plsek and Greenhalgh, 2001, Greenhalgh et al., 2017).

In recent years, systems thinking has been increasingly applied to healthcare (Clarkson et al., 2017, Patou and Maier, 2017, Ciccone et al., 2019, Komashie and Clarkson, 2022). In health, systems thinking has been used to understand how interventions interact with complex environments (Adam and de Savigny, 2012). At its core, systems thinking shifts the focus from isolated interventions to the dynamic relationships and feedback loops that define system behaviour (Meadows, 2008, Checkland, 1999). It emphasises the importance of understanding context and interdependence which are features that are especially present in the diagnosis of dementia. In contrast to the mechanistic view of healthcare as a controllable delivery pipeline, systems thinking encourages a more holistic perspective (Clarkson, 2018). As Clarkson et al. (2017) argue in the Engineering Better Care (EBC) framework, designing effective health interventions requires a consideration of four interrelated areas: people, systems, design and risk. This integrative approach reflects the need to move beyond tool development to reimaging the service processes. In dementia care, this is particularly critical as the success of a digital cognitive tool is not determined solely by its diagnostic performance, it is also determined by how well it aligns with the environment, organisational structures and the needs of its users.

2.3.1 Healthcare systems

Healthcare can be understood as a system: a set of connected parts that work together to achieve the common goal of keeping people healthy and providing care when needed. Healthcare systems have often been conceptualised through a mechanistic lens: as delivery systems designed to perform specific functions in a linear and controllable manner. However, this framing fails to reflect the dynamic, context dependent and deeply human character of health systems, especially in primary care settings. Plsek and Greenhalgh (2001) argue that healthcare is best understood as a complex and adaptive system, one which is composed of multiple interacting agents, whose behaviours are interdependent and emergent.

Primary care illustrates this complexity. It is shaped by high levels of uncertainty, time pressures and relational continuity. In this environment, small changes, such as introducing a new digital cognitive assessment tool, can reverberate across multiple levels, affecting not just clinical practice but also referral pathways and patient expectations (Sturmberg and Lanham, 2014). In such systems, change is non-linear. Small interventions can have large and unintended effects (Clarkson, 2018). This is particularly relevant for digital cognitive assessment tools in dementia care, where a tool's effectiveness is not defined solely by its clinical accuracy. Instead, success depends on how well the tool integrates into the surrounding system. Lennon et al. (2017) introduce the concept of system readiness, a concept that extends beyond user acceptance to include organisational capacity, policy alignment, technical infrastructure and receptiveness to change. Readiness, in this view, is not a passive backdrop but an active determinant of success. Even well-designed tools will fail if introduced into systems that are unprepared to accommodate them. As (Braithwaite et al., 2018) argue, implementation must be conceived not as a simple act of dissemination but as an iterative and adaptive process, shaped by context, feedback and learning. This calls for a shift in focus: from tool-centric evaluation to systems-informed implementation. In the context of digital cognitive tools for dementia, this means implementation cannot be treated as a simple act of dissemination. It must be reimagined as a process of iterative and context sensitive co-evolution between the tool, users, workflows and infrastructure. Understanding primary care as a complex system is especially important for dementia detection, where cognitive concerns often arise in ambiguous and emotionally loaded consultations. Digital tools, no matter how accurate, must be designed and implemented with the underlying complexities of primary care in mind if they are to be successfully adopted.

2.3.2 Barriers and enablers of implementation in primary care

Despite strong evidence that digital cognitive tools could improve the early detection of dementia, the implementation of such tools comes with challenges (Greenhalgh et al., 2017). This reflects the broader complexity of general practice, which involves time-pressured consultations, diverse patient needs and layered organisational governance (Creavin et al., 2021, Greenhalgh et al., 2009). Within such environments, the success of a tool is determined less by its intrinsic diagnostic accuracy and more by how well it aligns with the surrounding system. GPs are unlikely to adopt tools unless they can be used confidently, embedded quickly and linked to strong follow-up pathways (Fowler et al., 2015, Wilson et al., 2023). Furthermore, barriers often arise at multiple levels simultaneously, making adoption dependent on system-level coordination rather than isolated interventions (Lewy, 2015).

Table 3 summarises the key barriers and facilitators identified across implementation studies.

Table 3: Barriers and enablers to adoption of digital cognitive tools in primary care

Factor	Barrier/Challenge	Facilitator/Enabler	Source
Workflow Alignment	Tools underused if they disrupt GP workflow	Integration with existing processes and support structures	(Fowler et al., 2015, Giaquinto and Parnetti, 2006)
Clinician Confidence	Uncertainty in diagnosis reduces use	Clear follow-up pathways and training increase confidence	(Wilson et al., 2023, Jerjes, 2024)
Time Constraints	Short consultations limit tool use	Nurse-led triage or caregiver assisted screening can reduce GP burden	(Assaf and Tanielian, 2018 2017, Elliott et al., 2008)
System Integration	Lack of EHR compatibility hinders uptake	Seamless EHR integration improves usability	(Lester et al., 2017)
Usability	Tools seen as time-consuming or complex	Tools must be clinically valid, quick and easily embedded	(Welsh et al., 1991, Lester et al., 2017)
Patient Acceptance	Low acceptance limits use	Involving patients and carers improves acceptability	(Wilson et al., 2023)

2.3.3 The role of co-design

Co-design is a central tenet of systems informed innovation, particularly in complex and user centred domains like dementia care. Rather than developing solutions in isolation and delivering them top-down, co-design involves the meaningful inclusion of end users which, in this instance, applies to clinicians, patients, carers and administrators. The meaningful inclusion of end users should apply throughout the whole design, testing and implementation process. In healthcare, co-design has evolved from experience-based models to more advanced participatory systems mapping and service design approaches. It has been emphasised that engaging users early and continuously is not only ethically sound, but also more likely to result in solutions that fit real-world constraints and values (Greenhalgh and Papoutsi, 2018). For tools like the 4MT, this includes shaping everything from test interfaces and data presentation to how feedback is given to patients and how it aligns with GP workflows. Co-design also helps to uncover the emotional and relational factors that shape adoption. For instance, involving people living with dementia (PLWD) and their carers can illuminate concerns about stigma, test anxieties and the need for trust-building communication. From a systems lens, co-design supports emergence and adaptation (Patou et al., 2020). By embedding feedback loops into the design process, tools can evolve in response to changing needs, shifts in policy and clinical innovations

2.3.4 Implementation frameworks

To support implementation in complex settings, several frameworks have been proposed. These include: the Consolidated Framework for Implementation Research (CFIR) (Damschroder et al., 2009), the Nonadoption, Abandonment, Scale-up, Spread and Sustainability (NASSS) (REF) (Greenhalgh et al., 2017) framework, the Technology Acceptance Model (TAM) (REF), (Davis, 1989), the Unified Theory of Acceptance Model (UTAUT) (Venkatesh et al., 2003) and the Engineering Better Care (EBC) framework (Clarkson et al., 2017). These frameworks reflect different traditions within implementation science and related fields. As outlined by Nilsen (2015), they can be broadly categorised into process models, determinant frameworks and evalutation frameworks. Importantly, many of these approaches already conceptualise implementation as a dynamic and staged process rather than a purely linear progression. For example, process models describe phases such as exploration, adoption, implementation and sustainment, while determinant frameworks such as the CFIR emphasise the interaction between intervention characteristics and organisational context. Similarly, the NASSS framework explicitly foregrounds complexity, non-linearity and adaption over time.

The CFIR categorises implementation into five domains: the intervention, the inner setting, the outer setting, the individuals involved, and the process (Damschroder et al., 2009). The NASSS adds a complexity lens, asking not just what matters, but how complexity accumulates across seven domains: the condition, the technology, the value proposition, the adopters, the organisation, the wider system and adaptation over time (Greenhalgh et al., 2017). NASSS is useful for anticipating why a seemingly simple intervention might succeed in one setting but fail in another. The TAM explains technology adoption through two constructs: perceived usefulness and perceived ease of use (Davis, 1989). UTAUT builds on this by integrating elements from multiple acceptance models, proposing four key determinants of intention and usage (performance expectancy, effort expectancy, social influence and facilitating conditions) and highlighting the role of moderating factors such as age, gender, experience and voluntariness (Venkatesh et al., 2003).

While the frameworks discussed above originate largely from implementation science, the EBC complements these by offering a structured design-engineering methodology focused on iterative improvement. Its emphasis on people, systems, design and risk aligns closely with co-production.

Each framework has unique strengths and limitations (Table 4), but together they offer a layered and complementary understanding of how to move from tool development to sustainable adoption.

Table 4: Comparison of frameworks

Framework	Key Strengths	Limitations
TAM	• Simple and easy • Focuses on perceived usefulness and ease of use • Useful for early stage understanding of user attitudes	• Does not consider broader organisational or system level factors • Ignores context, workflow integration and policy influence • Mainly predictive or initial acceptance
UTAUT	• Builds upon TAM with social influence and facilitating conditions • Offers more comprehensive behavioural predictors • Often used in healthcare to evaluate intention and actual use	• Still individual centric, overlooking system complexity • Limited guidance on design or implementation strategies • May require adaptation for clinical contexts like dementia screening
CFIR	• Comprehensive • Widely used in healthcare for planning and evaluating complex interventions • Allows tailoring to specific settings	• Can be overwhelming due to its size and detail • Requires experience to apply effectively • More descriptive than prescriptive

NASSS	• Specifically developed for health technology in complex systems • Considers the lifespan of innovation • Addresses complexity, co-evaluation with context and system resistance	• Still relatively new • May require deep understanding of sociotechnical systems to apply well • Less focused on individual level behaviour
EBC	• Systems orientated and holistic • Practical for co-design and service improvement in real world health settings • Encourages interdisciplinary thinking	• Not yet adopted in academic health research • Lacks a large body of valuated tools or empirical studies • May need adaptation for specific evaluations

In addition to the frameworks summarised above, other influential approaches further reflect the field's shift away from linear models of implementation. For example, Normalisation Process Theory (Murray et al., 2010) focusses on the work required to embed interventions into routine practice, while process models such as the EPIS framework (Aarons et al., 2011) conceptualise implementation as unfolding across staged phases from exploration to sustainment. Evaluation oriented frameworks such as the RE-AIM framework (Glasgow et al., 1999), and broader theories such as Diffusion of Innovations (Rogers, 2003) similarly emphasise the dynamic and multi-level nature of implementation over time.

Overall, while existing implementation frameworks offer important insights into the factors, processes and stages shaping implementation, they are less well suited to capturing how implementation emerges in the early stages of integrating novel technologies into routine practice. In particular, although many frameworks within implementation science conceptualise implementation as an iterative, staged and context dependent process, they are often applied at organisational or system levels, or at later stages such as scale up and sustainability. Therefore, adopting a systems-thinking approach could complement these perspectives, focusing on the granular and practice-level dynamics through which implementation unfolds in everyday primary care. Doing this could extend existing frameworks rather than replacing them, providing a more detailed account of how interactions can shape the early integration of digital cognitive assessment tools.

Implementation science literature emphasises that clinical tools cannot succeed based on accuracy alone. Factors such as training, time constraints and digital literacy all influence uptake (Greenhalgh et al., 2017). In the UK context, where GPs are under increasing pressure, even brief cognitive tests can be perceived as burdensome unless clearly beneficial and seamlessly integrated into consultations (Canevelli et al., 2020). Several studies have identified barriers to implementing cognitive screening in primary care. Turner et al., (2004) reported that GPs were reluctant to use new tools without clear guidelines, particularly if results did not lead to faster referral or improved care options. Digital tools also raise concerns about equity and digital exclusion. For instance, online cognitive tests that require tablets or smartphones may inadvertently disadvantage older adults from lower income or rural backgrounds (McDonough, 2016, Gitlow, 2014). Any tool designed for widespread use in primary care must therefore be robust, quick and intuitive, while also adaptable to diverse user needs.

Taken together, these perspectives highlight that successful implementation of digital cognitive tools depends not only on understanding behavioural and organisational factors but also on designing interventions that align with system dynamics and professional practice. Implementation science identifies the determinants of uptake, design methods shape technologies around user and workflow needs and systems thinking builds on existing implementation frameworks by providing a lens to understand how these interact across different levels of care. This thesis therefore adopts a systems-oriented implementation approach, integrating insights from implementation science and design to explore how tools could be implemented within Scottish primary care. The principles of P4 medicine (predictive, preventative, personalised, participatory) further reinforce this direction (Patou et al., 2020). Digital cognitive tools such as the 4MT exemplify predictive and preventative healthcare, while co-design and user engagement reflect the participatory approach that underpins personalised care.

2.4 Preliminary summary

2.4.1 Clinical needs

Earlier detection of AD is clinically valuable, aligning with both patient priorities and health system goals. However, current primary care practices are constrained by syndromic definitions, time-limited consultations and tools that are not sensitive to the earliest changes in AD. This results in a significant diagnostic delay and under-detection, despite policy emphasis on early diagnosis. The potential for an earlier diagnosis lies with more sensitive detection tools that align with the early markers of AD.

2.4.2 Digital Technology

Digital cognitive assessment tools offer appealing benefits such as standardisation and scalability. Although tools like the 4MT demonstrate high diagnostic accuracy and offer a promising route to operationalise advances in AD detection, factors such as usability, equity and acceptability can significantly hinder the rate of adoption in primary care. This suggests that the need for early detection and potential solutions to address this challenge are not enough to make change. This is where a systems thinking approach becomes imperative.

2.4.3 Systems Approach

Systems thinking does not view solutions in isolation of the world they are to be placed in. It looks at the whole system to achieve change. The implementation of digital tools must be viewed as a system-level intervention. Scotland's dementia policy landscape supports innovation, but real-world adoption is shaped by structural, organisational and cultural factors. Variation in referral pathways, uneven access and digital readiness across practices complicate a standardised rollout. A systems thinking approach is essential to identify barriers and embed new tools sustainably.

Taken together, the literature highlights a clear and urgent need for earlier, more precise detection of AD, supported by advances in digital technology and grounded within real world systems. however, it also reveals significant misalignments between emerging technologies and the current structure of primary care. While tools like the 4MT offer a strong theoretical promise, their practical integration into general practice remains poorly misunderstood and under-reached.

To address this gap, this thesis adopts a systems-informed research design that builds on insights identified in the literature. The empirical strand of this work comprises a series of interlinked studies, each examining a different dimension of the implementation challenge. The first of these, presented in the following chapter, maps the diagnostic journey from the perspective of patients and carers. This study explores how memory concerns are currently recognised, communicated and acted upon within Scottish primary care, and identifies the critical touchpoints, barriers and enablers that shape diagnostic access and experience. In doing so, it provides a foundation for understanding where and how digital tools like the 4MT might be meaningfully introduced into routine practice.

3. A Patient and Carer Perspective of Dementia

3.1 Introduction

This chapter presents the first study of the thesis, which aims to build an understanding of the patient and carer pathway for the implementation of a digital cognitive tool by addressing the following question: "*How might we use systems thinking to implement a digital cognitive tool for earlier Alzheimer detection in a Scottish primary care setting?".* Using a qualitative approach, this study conducted journey mapping workshops to explore the barriers and facilitators across three phases of the dementia journey: noticing symptoms, getting a diagnosis and life after a diagnosis. Thematic analysis was used to interpret the data and identify key themes that reflect the lived experience of patients and carers navigating dementia support systems in Scotland. This chapter is positioned as the groundwork phase to understand how the journey is experienced by the people living with dementia (PLWD) and their carers. As major stakeholders in the diagnostic journey, the experiences of PLWD and carers are critical for implementing new digital cognitive assessment tools in primary care.

Note: Some works from this chapter have been incorporated in a manuscript uploaded to a preprint depository called Research Square (Appendix 12), while preparation for full journal submission is currently being planned (Newton et al., 2025). Notably, the workshop format and data analysis process used in this thesis and chapter based on Scotland were replicated in three workshops in England as part of a wider research programme.

Dementia profoundly reshapes the lives of those diagnosed, as well at the people who care for them. While dementia is often described as a "journey", the pathways people navigate from first noticing symptoms, through receiving a diagnosis, to life after diagnosis remain highly complex and inconsistently supported. Previous research has highlighted delays in recognition, fragmented diagnostic processes, and significant gaps in post-diagnostic support (Bunn et al., 2012, Giebel et al., 2022). However, comparatively little work has centred the perspectives of people living with dementia (PLWD) and their carers using participatory, visual methods that make lived experiences tangible for system redesign (Feldman et al., 2020). This chapter addresses that gap by presenting a qualitative journey mapping study conducted with PLWD and carers. The study had two aims (1) to deepen understanding of the dementia journey across three key phases through the voices of those directly affected; and (2) to co-create visual artefacts that communicate these experiences in ways that are accessible and actionable for policy, practice and design audiences. As part of my master's research contribution, I was responsible for designing and conducting the journey mapping study in Scotland, including developing study materials, recruiting participants and carrying out semi-structured interviews with PLWD and carers. A mirrored study was conducted in England, and I subsequently analysed the combined dataset. Positioned within the 'Understand' phase of the Engineering Better Care (EBC) framework (Clarkson et al., 2017), this chapter establishes the lived experience context for the subsequent studies presented in this thesis. By surfacing the challenges, emotions and system interactions that shape the dementia journey, the findings provide a foundation for later process mapping with GPs and pilot preparations of the 4MT. In doing so, this chapter contributes both empirical insights and practical tools for embedding lived experience into the design of more responsive and effective dementia diagnostic pathways.

3.2 Methods

3.2.1 Study Design

This qualitative study used semi-structured interviews with PLWD and carers to explore experiences across three stages of the dementia journey: noticing symptoms, seeking a diagnosis, and life after diagnosis. The study design was pilot tested with members from the Department of Design, Manufacturing and Engineering Management at the University of Strathclyde. The aim was twofold: (1) to enable better understanding of the patient perspective among the research and innovation community and (2) to produce an open-source information overview to reduce the uncertainty among people right at the start of their own journey by showing what they might expect to happen. The study was situated within a wider project exploring the implementation of early diagnostic tools and hopes to provide a contextual understanding of how memory concerns are first recognised and acted upon.

3.2.3 Researcher Characteristics and Reflexivity

Data collection and primary analysis were conducted by myself (SH- female) and a member of the supervisory team (CN, Post-Doc -female). Researchers had combined experience in neuroscience, psychology and counselling (BSc) and this study was part of the MPhil (SH). Both researchers have also completed the Good Clinical Practice and the Join Dementia Research training. I had prior involvement with the wider project on early diagnostic tools but no prior relationship with participants before recruitment. The study motivation and aims were shared with the participants alongside credentials and organisation. To support reflexivity, I engaged in regular peer debriefing sessions with the supervisory team throughout data collection and analysis, these discussions included debriefings on field notes. These discussions enabled critical reflection on assumptions and positionality in line with COREQ guidance. Field notes were recorded following interviews to capture observations and emerging analytic insights.

3.2.2 Participants

Participants were recruited in Glasgow using a multi-channel approach. Recruitment materials were circulated via Join Dementia Research (JDR), the Scottish Dementia Research Consortium (SDRC), and the Tayside Partners in Research (PIR) group. In addition, flyers (Appendix 1) were distributed through local dementia support groups, and short presentations were delivered at Alzheimer Scotland community meetings to raise awareness of the study. In total 22 people responded to adverts, of which 7 did not respond to follow up emails to organise a suitable date/time for the study, and 1 cancelled on the day and declined to reschedule. A purposive sampling strategy was used to capture diversity in gender, role and ethnicity. Eligibility criteria were:

1. People with memory concerns or mild cognitive impairment
2. People who have supported someone through a dementia diagnosis
3. People who are English speaking (1st or 2nd Language)
4. People between 18 and 99 years old.

In total, seven sessions were conducted in Scotland, with a mix of individual and group interviews. Some were held in person across the University of Strathclyde Living Lab and Alzheimer Scotland offices, while others were conducted online to accommodate participant preference. Table 5 presents participant demographics.

Note: As part of the wider collaborative project, parallel workshops were also conducted in London by trained facilitators. While I later contributed to the analysis of those data for a joint publication, the methods and findings reported in this thesis focus solely on the Scotland strand, which I directly conducted. Findings of both strands of the project are incorporated on a manuscript uploaded to the depository called Research Square (Newton et al., 2025).

Table 5: Participant Demographics

	Carers (n=11)	**PLWD (n=3)**
N Female	9	1
N White **(White British or any other White background)**	11	3
N Black **(Black British, or any other Black background)**	0	0
N Asian **(British Asian or any other Asian background)**	0	0
N Other Ethnic Group (Arab or any other background)	0	0

3.2.4 Ethical Considerations and Consent

Ethical approval for this study was granted by the University of Strathclyde Ethics Committee (Ref: UEC24/94). All participants received a participant information sheet (Appendix 2) in advance and had the opportunity to ask questions before consenting. Written informed consent was obtained prior to participation, either on paper (for in-person sessions) or electronically (for online sessions). At the start of each interview, capacity to consent was confirmed through a brief discussion and teach-back approach (participants were asked to explain the study in their own words). Participants were reminded that involvement was voluntary and that they had the right to withdraw at any time without reason. All data was anonymised and stored securely in accordance with GDPR and the University of Strathclyde data management policies.

3.2.5 Data Collection

Semi structured interviews were conducted either in person or via video call depending on participant preference. Interviews lasted around 60 minutes, and a topic guide was used (Appendix 3), structured around three phases of the dementia journey (symptoms, diagnosis, life after diagnosis) but applied flexibly to allow participants to shape the conversation (Appendix 4). The guide was informed by a pre-existing dementia journey map generated from thematic analysis of Alzheimer’s Society online forum posts (Appendix 5) (Bodnarova, 2024), which surfaced common themes in public accounts of dementia experiences. The topic guide was used flexibly to encourage participants to share experiences in their own terms. This balance allowed interviews to remain anchored in key points of comparison while retaining openness to emergent issues (Kallio et al., 2016). Particular attention was given to creating space for participants to reflect not only on practical challenges but also on emotional and relational dimensions of their experience. Moments of adaptation, resilience and identity work were explicitly welcomed, recognising the value of both difficulties and coping strategies in understanding the dementia journey. All interviews were audio-recorded following written informed consent, in accordance with ethical approval (Ref: UEC24/94). Transcripts were produced verbatim to preserve the richness of participants’ narratives.

3.2.6 Data Analysis and Visual Mapping

Data analysis followed a two-stage process. First, interview transcripts were analysed thematically using Braun and Clarke (2006) reflexive thematic analysis framework. Coding was conducted inductively, with initial descriptive codes iteratively grouped into broader themes relating to decision making, emotional responses, interactions with health services, and shifting identities. NVivo software (Version 14.24.2), was used to support data management, coding and theme development.

As focus groups were conducted in two different locations by different researchers (Glasgow – SH, London -CN), additional steps were taken to ensure there was consistency across the dataset. All transcripts from both sites were coded by myself, with a subset independently reviewed by the supervisory team. Codes and themes were regularly discussed and refined to reach analytic consensus, supporting rigour and consistency in interpretation. Comparison of the two datasets did not reveal substantial differences in the themes identified; however, the analysis presented in this thesis emphasises insights relevant to the Scottish healthcare context, reflecting the primary focus of the study.

Regular peer debriefs within the supervisory team helped ensure reflexivity and transparency in the analytic process, consistent with COREQ guidance on maintaining credibility in qualitative research (Tong et al., 2007). All interview transcripts were analysed thematically by the data controller (SH) and then confirmed with a lead researcher (CN) to ensure consistency and depth of interpretation across both sites. In the second stage, findings were synthesised into visual representations to aid interpretation and cross-stakeholder communication. These artefacts included a rich picture diagram, which illustrated the overall dementia journey as a non-linear, interconnected system and three stage specific journey maps corresponding to the phases of noticing symptoms, seeking a diagnosis and life after diagnosis. Importantly, these visual artefacts were not used during interviews but were developed during the analysis phase to synthesise participant narratives. They were subsequently refined following feedback sessions with original participants, enhancing the trustworthiness of interpretation through member reflection.

3.3 Results

This section presents findings from the thematic analysis of interviews with PLWD and CGs. Eight overarching themes were derived from the data: caregiving, diagnosis journey, feelings, healthcare experiences, life adjustments and impact, public perception and stigma, support and unmet needs. To complement these thematic findings, participants' experiences were also structured visually across three key phases of the dementia journey: noticing symptoms, seeking a diagnosis and life after diagnosis. The visual maps (Figures 13-16) were designed both to reflect participant narratives and to support communication of findings to policymakers and the public. The results are therefore presented in two layers: first, a visual representation of the dementia journey across phases, and second, a thematic exploration of participants' experiences.

3.3.1 Visualising the Dementia Journey

While the following sections present results thematically, a series of visual journey maps were created to capture participants' experiences across the dementia pathway. These include an overall rich picture map and three phase-specific maps. Together, they provide a high-level overview of the dementia journey and highlight the transition points that shaped participants' experiences.

Complete Journey Map

A rich picture diagram was created following interviews with participants to visualise the whole journey from noticing symptoms right through to life after diagnosis (Figure 13). This was then shown to participants to obtain feedback on the output. Participants noted it was too high level and would prefer broken down maps with more in-depth information pertinent to each stage. In response, three phase-specific maps were developed to provide more in-depth accounts of experiences at each stage.

Noticing Symptoms

The noticing symptoms map illustrates the early experiences of noticing something that was ‘not quite right’ (Figure 14). Participants described subtle signs like memory lapses, emotional changes, or shifts in personality, that were often dismissed or misattributed to aging, stress, or physical health issues. Both carers and PLWD spoke about the internal uncertainty and external stigma that shaped delayed health seeking. A recurring theme was the lack of awareness among both the public and health professionals relating to symptoms.

Diagnosis

The diagnosis map illustrates the complexity and emotional turbulence of navigating the diagnostic process (Figure 15). Many described it as fragmented, slow and dependent on persistent advocacy by carers. Experiences of being dismissed by professionals were common and even when the diagnosis was received, the process often felt cold and unsupported. Participants noted relief in finally having answers but also frustration with poor communication for dementia type clarity and little follow up. The comparison to cancer care was frequently raised with dementia described as lacking structure or continuity.

Life After Diagnosis

The life after diagnosis map shows how life changed after diagnosis, often dramatically (Figure 16). Participants reported shrinking social worlds, loss of independence, increasing care needs, and emotional exhaustion. Carers described assuming new roles with little preparation or support. Access to services varied significantly by location, and most felt that post-diagnostic support tapered off to quickly. Nonetheless, there were also moments of resilience, humour and connection through hobbies, peer support and positive encounters with professionals. The journey after diagnosis was framed as long and lonely, often navigated without a map

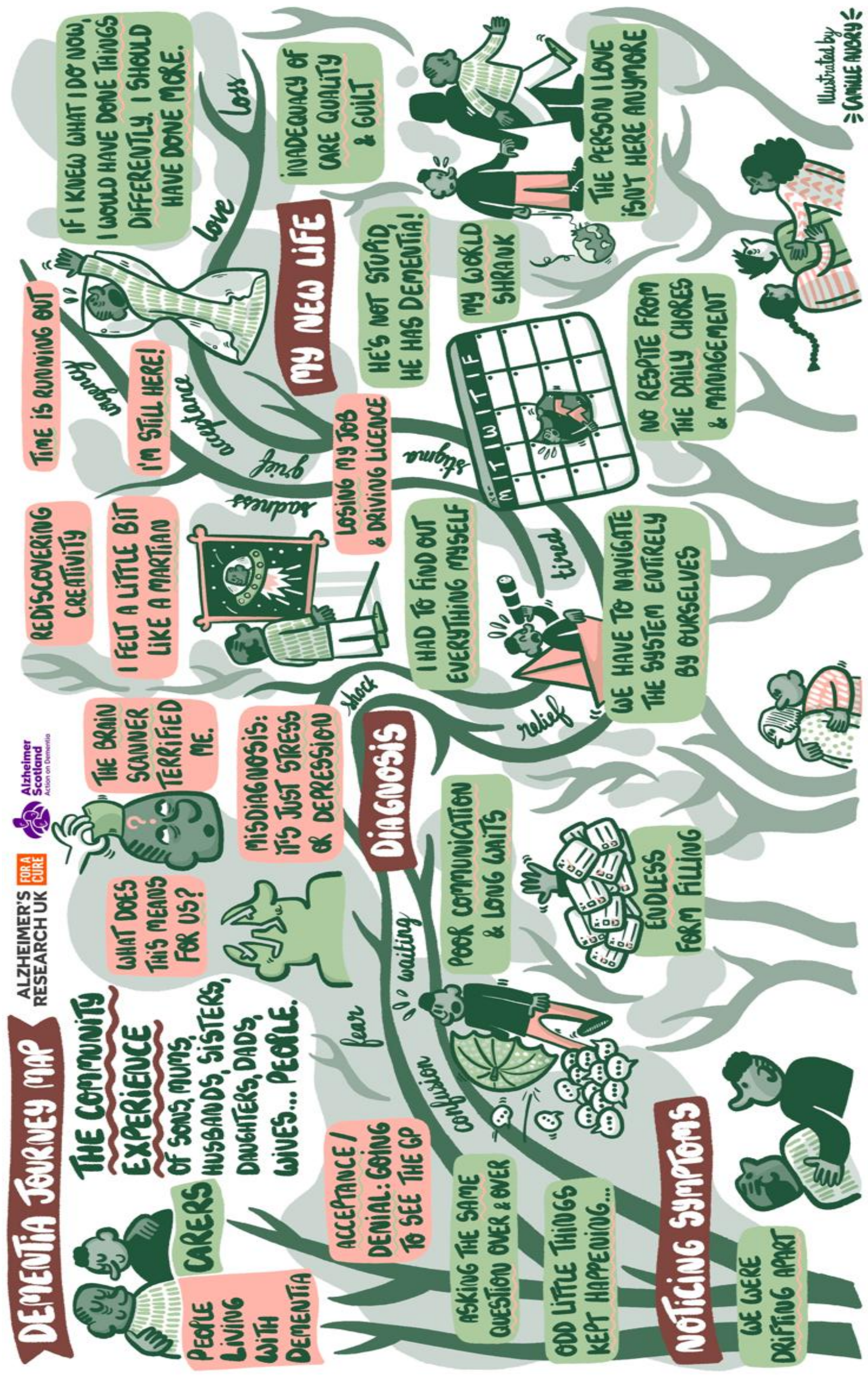
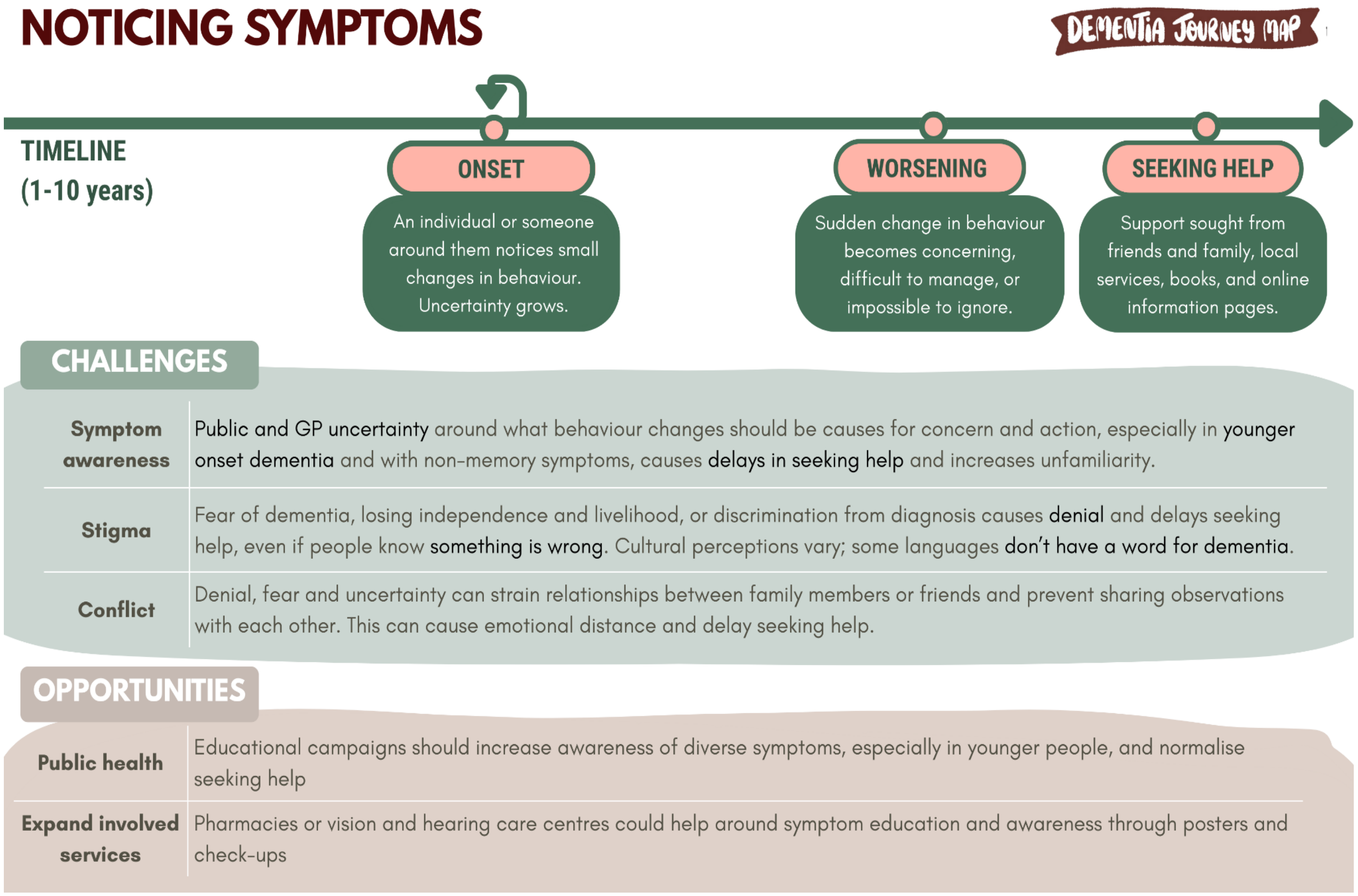


Figure 13: Rich picture diagram of the dementia journey illustrated by Camille Aubrey based on findings from chapter 3 (https://www.camilleaubry.com/) (Newton et al., 2025)



NOTICING SYMPTOMS

DEMENTIA JOURNEY MAP

TIMELINE
(1-10 years)

ONSET
An individual or someone around them notices small changes in behaviour. Uncertainty grows.

WORSENING
Sudden change in behaviour becomes concerning, difficult to manage, or impossible to ignore.

SEEKING HELP
Support sought from friends and family, local services, books, and online information pages.

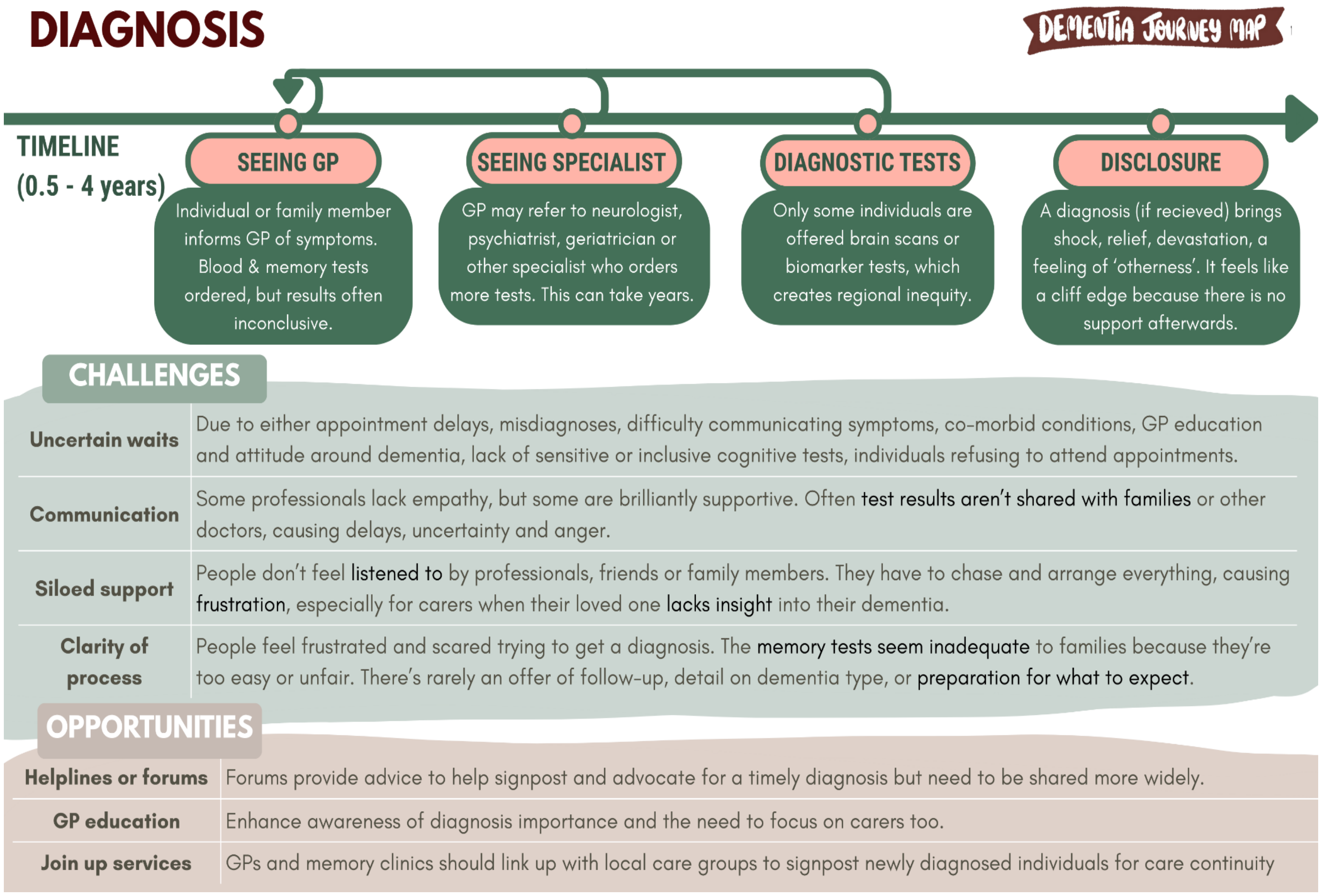
CHALLENGES

Symptom awareness	Public and GP uncertainty around what behaviour changes should be causes for concern and action, especially in younger onset dementia and with non-memory symptoms, causes delays in seeking help and increases unfamiliarity.
Stigma	Fear of dementia, losing independence and livelihood, or discrimination from diagnosis causes denial and delays seeking help, even if people know something is wrong. Cultural perceptions vary; some languages don't have a word for dementia.
Conflict	Denial, fear and uncertainty can strain relationships between family members or friends and prevent sharing observations with each other. This can cause emotional distance and delay seeking help.

OPPORTUNITIES

Public health	Educational campaigns should increase awareness of diverse symptoms, especially in younger people, and normalise seeking help
Expand involved services	Pharmacies or vision and hearing care centres could help around symptom education and awareness through posters and check-ups

Figure 14: Noticing Symptoms Stage of the Dementia Journey Map. Created from journey mapping interviews (Newton et al., 2025)



SEEING GP: Individual or family member informs GP of symptoms. Blood & memory tests ordered, but results often inconclusive.

SEEING SPECIALIST: GP may refer to neurologist, psychiatrist, geriatrician or other specialist who orders more tests. This can take years.

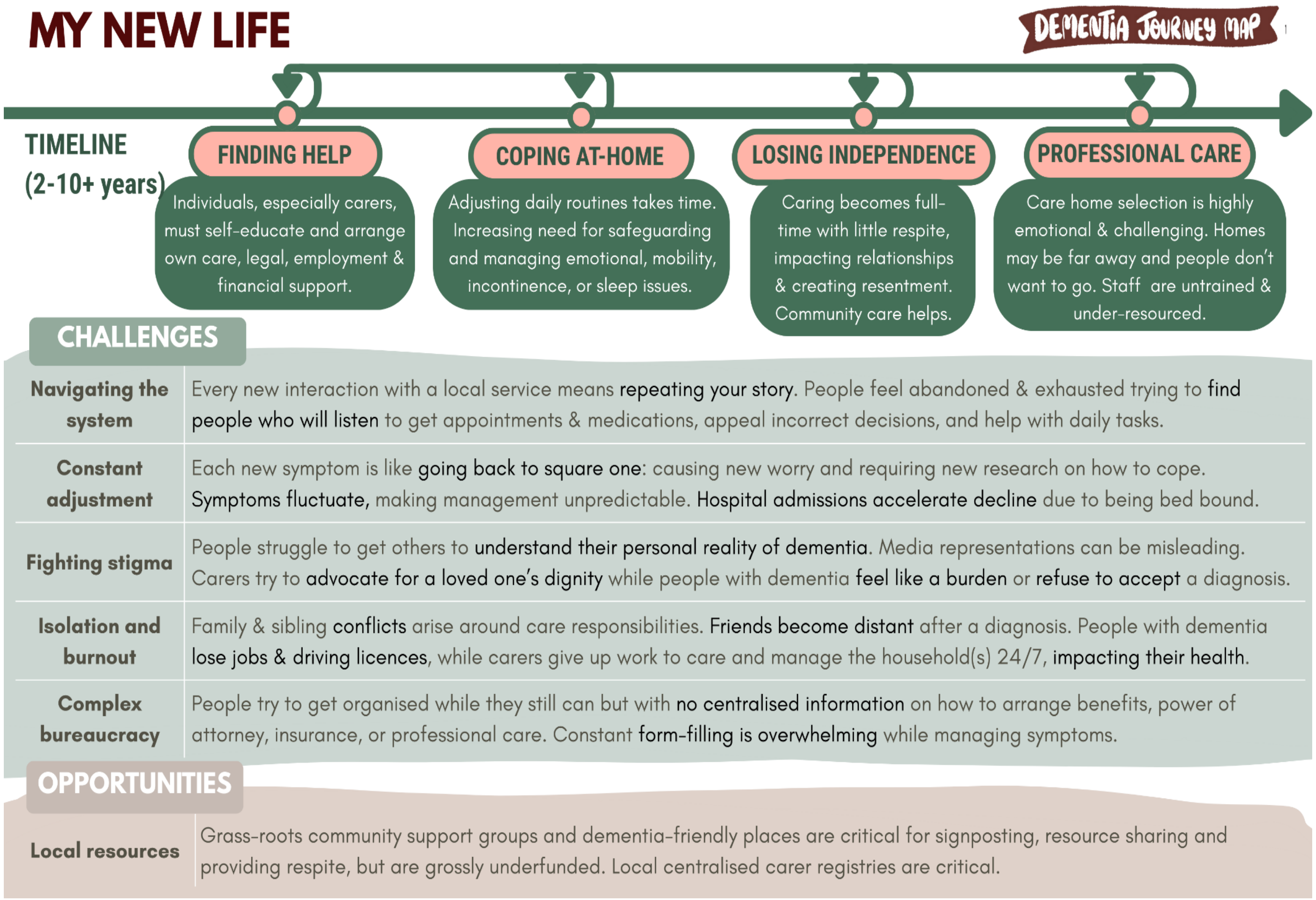
DIAGNOSTIC TESTS: Only some individuals are offered brain scans or biomarker tests, which creates regional inequity.

DISCLOSURE: A diagnosis (if recieved) brings shock, relief, devastation, a feeling of 'otherness'. It feels like a cliff edge because there is no support afterwards.

CHALLENGES	
Uncertain waits	Due to either appointment delays, misdiagnoses, difficulty communicating symptoms, co-morbid conditions, GP education and attitude around dementia, lack of sensitive or inclusive cognitive tests, individuals refusing to attend appointments.
Communication	Some professionals lack empathy, but some are brilliantly supportive. Often test results aren't shared with families or other doctors, causing delays, uncertainty and anger.
Siloed support	People don't feel listened to by professionals, friends or family members. They have to chase and arrange everything, causing frustration, especially for carers when their loved one lacks insight into their dementia.
Clarity of process	People feel frustrated and scared trying to get a diagnosis. The memory tests seem inadequate to families because they're too easy or unfair. There's rarely an offer of follow-up, detail on dementia type, or preparation for what to expect.

OPPORTUNITIES	
Helplines or forums	Forums provide advice to help signpost and advocate for a timely diagnosis but need to be shared more widely.
GP education	Enhance awareness of diagnosis importance and the need to focus on carers too.
Join up services	GPs and memory clinics should link up with local care groups to signpost newly diagnosed individuals for care continuity

Figure 15: Diagnosis Stage of the Dementia Journey Map. Created from journey mapping sessions. (Newton et al., 2025)



MY NEW LIFE

TIMELINE
(2-10+ years)

FINDING HELP
Individuals, especially carers, must self-educate and arrange own care, legal, employment & financial support.

COPING AT-HOME
Adjusting daily routines takes time. Increasing need for safeguarding and managing emotional, mobility, incontinence, or sleep issues.

LOSING INDEPENDENCE
Caring becomes full-time with little respite, impacting relationships & creating resentment. Community care helps.

PROFESSIONAL CARE
Care home selection is highly emotional & challenging. Homes may be far away and people don't want to go. Staff are untrained & under-resourced.

CHALLENGES

Navigating the system	Every new interaction with a local service means repeating your story. People feel abandoned & exhausted trying to find people who will listen to get appointments & medications, appeal incorrect decisions, and help with daily tasks.
Constant adjustment	Each new symptom is like going back to square one: causing new worry and requiring new research on how to cope. Symptoms fluctuate, making management unpredictable. Hospital admissions accelerate decline due to being bed bound.
Fighting stigma	People struggle to get others to understand their personal reality of dementia. Media representations can be misleading. Carers try to advocate for a loved one's dignity while people with dementia feel like a burden or refuse to accept a diagnosis.
Isolation and burnout	Family & sibling conflicts arise around care responsibilities. Friends become distant after a diagnosis. People with dementia lose jobs & driving licences, while carers give up work to care and manage the household(s) 24/7, impacting their health.
Complex bureaucracy	People try to get organised while they still can but with no centralised information on how to arrange benefits, power of attorney, insurance, or professional care. Constant form-filling is overwhelming while managing symptoms.

OPPORTUNITIES

Local resources	Grass-roots community support groups and dementia-friendly places are critical for signposting, resource sharing and providing respite, but are grossly underfunded. Local centralised carer registries are critical.

Figure 16: New Life Stage of the Dementia Journey Map (Newton et al., 2025)

3.3.2 Themes derived from conversations

Themes were generated through reflexive thematic analysis (Braun and Clarke, 2006), drawing on inductive coding approach. I led the coding process for the Scottish data and subsequently analysed the combined dataset of Scotland and England, reading and re-reading transcripts to identify patterns in experience. Initial codes were generated manually, capturing significant features of the data. These codes were then grouped into themes, which were refined through an iterative process involving regular discussion and reflection with my supervisor. The eight themes are represented as drawings below (Figure 17). Following this, each theme is broken down, highlighting the participants lived experiences across the dementia journey, cutting across the three mapped phases described above.

Figure 17: My own illustrations of themes throughout the dementia journey (Hamilton, 2025)

Theme 1: Caregiving

Carers consistently described the "fight" required to advocate for their loved ones, particularly in navigating health and social care systems. Many reported repeated struggled with GPs, social workers and services: *"We had to fight tooth and nail with the GP surgery … we were constantly fighting" (P4, Carer, Scotland).*

The burden of care extended beyond advocacy. Carers reflected on exhaustion, disrupted sleep and the invisibility of their struggles. One participant highlighted the lack of respite for even basic activities: *"One of the hardest things is going to the toilet for a carer... It's silly things that it's not the great big dramatic stuff" (G1, Carer, Scotland).* Others described masking their distress to protect their relative: *"I tried my hardest not to let him see me getting upset" (P2, Carer, Scotland).*

Alongside these challenges, carers described coping strategies from brief moments of escape – *"I would go and sit by the sea for 10 minutes just to calm myself"* – to distraction techniques such as going for drives of engaging in hobbies. Underpinning these narratives was both a profound sense of love and responsibility, and anxieties about their own futures with dementia: *"I'm terrified that every little memory loss… that's it (G4, Carer, Scotland).*

This section illuminates the emotional, physical and systemic challenges faced by carers, who often found themselves advocating persistently for their loved ones while struggling with their own wellbeing. The 'fight' for recognition, diagnosis and support was a recurring theme, alongside the invisible toll of caregiving, manifested in disrupted sleep and emotional suppression. Carers shared the burden of feeling lost in a fragmented system and highlighted the need for clearer pathways and consistent support. Despite these challenges, many developed personal coping strategies, such as distraction techniques, demonstrating resilience in the face of ongoing uncertainty. Underpinning all accounts was a deep sense of love, responsibility and fear; not only for the person they cared for, but also for what the future may hold.

Theme 2: Diagnosis Journey

Participants described the diagnostic pathway as complex, frustrating and, for many, deeply emotional. They recounted a series of 'trigger points' that prompted help seeking, often following noticeable changes in memory, behaviour or orientation. However, this journey was rarely straightforward. Many noted that the process was lengthy, uncertain and filled with inconsistencies in how their concerns were received in primary care. For some the decision to seek help was driven by personal awareness of cognitive change: *“I was aware that I was forgetting more things than I expected to… names of people you knew quite well”. (G2, PLWD, Scotland)*. For others, sudden behavioural changes raised alarm: **“***it was like he was hallucinating … he would be talking as if he was part of the story in the book (G3, Carer, Scotland)*. A recurring frustration was the perception that concerns were dismissed or minimised in general practice, contributing to long delays: *“So, I went to the GP … I think I got a bit dismissed. You know, it was just it was just like … it's probably just his heart attack and he probably is down about the work.” (P3, Carer, Scotland).* Some carers felt penalised for challenging a medical opinion: *“From that moment on … our name was blackened because we had dared to challenge the medical profession and we found our journey after that very, very difficult to have” (G1, Carer, Scotland)*

For some, a diagnosis brought relief and a sense of validation: *“And when I got the diagnosis oh my goodness…I was relieved It's not me… There is something wrong with [my partner].” (P2, Carer, Scotland)*. For others, it provoked feelings of shock and despair, particularly in the absence of empathetic communication: *“’I'm sorry, Mr G, you have a dementia and there is no cure’. And my father's response was ‘oh, find me in the river.’” (G2, Carer, Scotland)*. With some noting a sense of alienation stemming from receiving the diagnosis: *“At the time I was given the diagnosis I felt a bit like a marsian” (P1, PLWD, Scotland)*

Participants contrasted dementia with other illnesses, emphasising the absence of coordinated care: *“If it had been cancer … I'm sure they wouldn't just go, ‘Oh, by the way, you've got a huge tumour in your brain… off you pop.’” (G2, Carer, Scotland).* Stigma shaped how participants processed the diagnosis, with some resisting disclosure**:** *“You don't introduce yourself and say ‘hello. I'm a diabetic’, so why should you feel you have to go, ‘Hello. I'm got dementia?’” (G1, Carer, Scotland).*

Concerns also centred on the timing of diagnosis with some feeling it came too late, with others fearing the implications for independence: *“You're losing [independence] and I'm not ready to lose that yet.” (P1, PLWD, Scotland).*

Across accounts, the diagnostic journey was characterised by uncertainty, fragmented pathways, and inconsistent communication. While a diagnosis could validate concerns, the absence of clear information and post diagnostic support often left families feeling abandoned. Stigma and fears of lost independence further complicated how individuals processed and lived with the diagnosis.

Across these experiences, the diagnostic journey was described as emotionally taxing, filled with uncertainty and often lacking the clarity, communication and compassion participants felt were needed.

Theme 3: Feelings

Participants described dementia as an emotionally turbulent journey, characterised by grief, uncertainty, guilt and loneliness. Reactions to diagnosis were often conflicting. For some, the news was devastating, with one carer recalling how her partner “really struggled to identify” with being someone living with dementia at a relatively early age (G1, Carer, Scotland). For others, receiving a diagnosis provided temporary relief, confirming that their concerns were valid: *There was a bit of relief when we got a diagnosis…but that was fairly short lived” (P4, Carer, Scotland*. Beyond the initial moment of diagnosis, emotions of ongoing loss and heartbreak became central to daily life. Carers described dementia as “eternal heartbreak” that never fully subsided (G2, Carer, Scotland). PLWD echoed this sense of isolation noting that *“It is a lonely disease because nobody else… really understands.” (P5, PLWD, Scotland)*. These accounts highlighted how dementia reshaped relationships, often leaving carers and PLWD feeling emotionally disconnected from the wider world.

Guilt and exhaustion were recurrent themes. Carers reflected on the tension between their devotion and the personal toll of care, with one admitting: *“I remember speaking to one of my friends and saying how trapped I felt… I felt so guilty for saying that” (P2, Carer, Scotland)*. Others emphasised the strain of managing their loved one’s vulnerability, describing situations where confusion placed them at physical risk. Alongside this was the continual challenge of adapting to unpredictable memory lapses, which left carers feeling drained: *“you left the visit thinking -exhausted- because you had to keep remembering about the things that she remembered and didn't remember” (G3, Carer, Scotland)*

Despite these challenges, moments of resilience, love and humour were woven throughout participants’ accounts. Carers emphasised that their role was not only a burden but also an expression of deep connection, one reflecting simply: *“I loved looking after him” (P2, Carer, Scotland)*. PLWD also resisted stigma by asserting their dignity: *“We are still human even with our diagnosis” (P1, PLWD, Scotland)*. Alongside these emotional experiences, participants voiced frustration at the lack of answers in dementia care and research. Families described the disappointment of unanswered questions about causes or progression, and some expressed a sense of hopelessness about the limited progress of dementia strategies.

This frustration deepened the emotional weight of navigating the journey, compounding feelings of grief and isolation. Taken together, these accounts show that dementia was lived not as a single emotion but as a shifting and often contradictory landscape. Families balanced devastation with love, guilt with pride, and exhaustion with resilience. The emotional impact of dementia extended beyond the condition itself, shaped by the responses of services, the persistence of stigma and the absence of clear answers.

Theme 4: Healthcare Experiences

Participants described striking inconsistencies in their healthcare journeys, with access to support often dependent on geography. Families reflected on the "postcode lottery" of services, where two people living only miles apart may receive entirely different levels of care: *"I would say because I had experience with two different local authorities the assistance you get can very much depend on where you live yeah post code lottery" (G1, Carer, Scotland).*

Primary care was often the first point of contact, yet many participants found this stage particularly challenging. Securing a GP appointment could feel like an uphill battle, especially when continuity of care was lacking: *"Trying to get a face-to-face appointment, trying to get a GP to listen to the concerns long enough … the GPs don't really know all the patients these days it's really difficult to get somebody to take concerns seriously" (P4, Carer, Scotland)*. Such barriers left carers feeling dismissed at the very moment they sought validation for their concerns.

The quality of interactions with healthcare professionals varied widely. Some families spoke positively of empathetic consultants or proactive GPs, but others described encounters that left them feeling ignored and marginalised. Carers reflected on situations where the professionals failed to address their loved ones directly, eroding the persons sense of dignity: ***"****They didn't want to speak to him. They would speak to me. They would ignore him completely. It was as though he didn't exist." (G1, Carer, Scotland)*. One participant also reflected on the stigma that still lingers in clinical practice: *"Lot of clinicians see dementia it's like there's a schism" (P1, PLWD, Scotland)*

Experiences with diagnostic testing further highlighted systemic shortcomings with some participants passing memory tests despite showing clear symptoms, raising concerns about their sensitivity: "*My dad actually got very high scores … numbers are his thing spelling was his thing, and he even knew what a marsupial was" (P4, Carer, Scotland)*. Others criticised the design of the tools themselves, questioning both the fairness and relevance of them: *“I thought it was a rubbish test … I was waiting for them or for better ones to come in and they never did” (P2, Carer, Scotland)*. For some, even basic tasks became exclusionary: *“I was told to draw, and I had said to her at the time I can’t draw but I had to copy whatever shapes were there” (P1, PLWD, Scotland)*.

Where care needed escalating, participants’ experiences in hospitals and care homes revealed deep concerns about quality and oversight. Accounts of neglect and poor practice were particularly stark. One carer described how their wife returned from respite bruised and injured: *“My wife was put into a care home for four days… they lost half her clothes… she came out really bruised all over. She fell, had a big lump in her head… it turns out that three people, including the manager of the care home, were charged with abuse.” (G1, Carer, Scotland)*. Others spoke about inappropriate interventions, poor hygiene and basic dignity being compromised: *“He gets lucky if he gets two showers a week in the hospital and part of that is because there's no staff” (P2, Carer, Scotland)*. These experiences fuelled wider frustrations with regulatory bodies, with carers questioning whether organisations such as the care inspectorate were fulfilling their responsibilities: *“I think the care Inspectorate need to get their act together and start really doing something. Somebody needs to have a proper overview” (P2, Carer, Scotland)*.

Medication was another area of divergence. While some participants expressed relief at avoiding unnecessary prescriptions, others felt let down when treatments were unavailable or withheld: *“My mum she didn't get particular meds … they weren't particularly available for her at that point” (G3, Carer, Scotland)*. For some the absence of treatment options compounded feelings of neglect.

Participants’ accounts revealed healthcare experiences that were profoundly uneven, shaped as much by geography, workforce shortages and systemic gaps as by the disease itself. At best, care was compassionate and proactive, giving families a sense of being supported. At worse, it was fragmented, impersonal and unsafe. These narratives illustrate the urgent need for more consistent, coordinated approaches to dementia care across the system.

Theme 5: Life Adjustments and Impact

Participants described the profound adjustments required following a diagnosis of dementia, both for themselves and those around them. These changes unfolded gradually, often reshaping everyday routines, identities and relationships. Loss of mobility and independence was felt acutely, symbolising both restriction and disconnection: *“The driving thing has hit me more, a lot harder. I’m more upset about that because I feel that you’re losing your independence bit by bit” (P5, PLWD, Scotland)*. Carers also reflected on how their lives had contracted as responsibilities increased: *“Our lives suddenly became much smaller like from being like the world our lives became smaller became Britain became Glasgow became [hometown] became our house became not even in the garden became literally in our house” (P2, Carer, Scotland)*. Adjusting to new roles and identities was central to participants’ accounts. Carers spoke about the difficulty of moving from equal partner to caregiver: *“The relationship between us is not of equal partnership … It's more the teacher and the child, and then he struggles with that. He really struggles with that.” (G1, Carer, Scotland)*. Others reflected on the personal impact of having to leave work or redefine a role they once cherished: *“I am struggling at times to accept my new role because I love work. I absolutely loved work” (G1, Carer, Scotland)*. Planning became a practical and emotional necessity. Conversations around Power of Attorney (POA) and end-of-life planning underscored both the need and the urgency of preparation. As one participant explained: *“POA is obviously essential … but I think that it has to be fully explained to people because it's not always clear just what the legal implications are” (G1, Carer, Scotland)*. Others described the weight of form filling and the emotional strain of funeral planning.

Physical and cognitive changes also became visible markers of life after diagnosis. Carers highlighted the toll of disturbed sleep, emotional exhaustion and subtle but significant declines: *“He used to make the dinner for me … and then it's all of a sudden he couldn't follow a recipe” (P2, Carer, Scotland)*. Such everyday moments were often remembered as early indicators of dementia in hindsight.

Despite these challenges, many participants also described ways of adapting and holding onto sources of meaning. Music, bobbies and social groups provided continuity and joy: *“Music's always been important to him…you can't go past the charity shop without going in and getting a bit of vinyl.” (P3, Carer, Scotland)*. Others described walking groups, clay work, or continued efforts to attend concerts and meet with friends as vital outlets of identify and connection.

Maintaining independence was a strong thread across the interviews. Small acts such as making a cup of tea or navigating a familiar train route carried profound symbolic value: *“I noticed that there was a train station about 50 yards from the centre… so I said, well its 2* *trains I take to go to the café" (P1, PLWD, Scotland)*. These acts were framed not as trivial, but as essential ways of retaining control and dignity.

This theme highlights how life after a dementia diagnosis is characterised by a continual renegotiation of roles, identity and the future. While participants acknowledged the pain of loss and restriction, their stories also revealed resilience, creativity and determination to live meaningfully amidst change.

Theme 6: Public Perceptions and Stigma

Stigma and public misunderstanding emerged as powerful barriers throughout participants' experiences. Participants highlighted the widespread misconception that dementia is only an illness of old age, which delayed recognition and diagnosis for many: *"a lot of people put memory problems down to old age and they ignore the signs and symptoms …until they're a lot further down the road" (P5, Carer, Scotland).* For PLWD, challenging these stereotypes was a priority, with one participant reflecting: *"I think it's about time they changed the perceptions that it's not only in older persons" (P1, PLWD, Scotland)*.

Despite advocacy efforts through working groups and peer networks, stigma continued to shape everyday interactions. Some participants described reluctance to disclose a diagnosis because of the way others might respond: "*It took me quite a long time to tell anybody because there is a stigma about dementia because purely people don't understand it and that's what we need to get rid of" (P2, Carer, Scotland).*

Public spaces and services were often experienced as inaccessible, reinforcing exclusion. Participants emphasised that dementia-friendly environments required calmness, awareness and sensitivity: *"To me dementia friendly means not being noisy … calmness and you need people that [understand dementia]" (P2, Carer, Scotland)*. Even small design features could create major barriers, such as dark flooring being mistaken for holes. These practical details shaped whether people felt able to participate in community life with dignity and safety.

Underlying many reflections was the struggle to maintain identity in the face of public and personal misconceptions. Carers and PLWD alike challenged the notion that the diagnosis defined them: *"I've got dementia, but it doesn't mean I'm stupid." (G1, Carer, Scotland)*. Participants stressed the importance of humour, holidays, hobbies and shared experiences as ways of living well and resisting stigma.

Media portrayals were seen as a double-edged sword. While some depictions resonated with participants, others were described as fear-inducing or misleading. One carer commented positively on an advert showing figures navigating a dark forest, while another criticised campaigns that framed dementia solely in terms of loss and despair. Participants also expressed frustration with misleading claims about cures or miracle preventions, which they felt offered false hope.

Workplace experiences illustrated the damaging consequences of stigma in institutional contexts. Several participants described being excluded, overlooked or even forced to leave employment following a disclosure of a diagnosis. One PLWD reflected: *“If I had cancer or any other illness, they would have kept me … but no” (P5, PLWD, Scotland).* Carers also recounted discriminatory attitudes towards PLWD in recruitment and care settings, where they were judged according to whether they were “a quiet type” or someone who “might cause trouble” (G2, Carer, Scotland).

These accounts reveal how stigma permeates social, professional and healthcare contexts, compounding the challenges already faced by PLWD and their carers. While advocacy and awareness initiatives are gradually shifting narratives, participants emphasised that deeper cultural change is needed to foster dignity, understanding and inclusion.

Theme 7: Support

Participants described a wide range of experiences with support networks following diagnosis, highlighting both the value of support when present and the significant gaps in provision that left many feeling isolated and underprepared. Charities such as Alzheimer Scotland and the Alzheimer’s Society were praised for their practical advice, emotional reassurance and confidence boosts, particularly when staff demonstrated dementia-specific knowledge. As one carer reflected, “*when I phoned Alzheimer's or Dementia UK, they said … ‘ask the GP or psychiatrist if you can try sertraline’” (P3, Carer, Scotland).* Others described daycare services as “terrific” and “very very helpful”, with one PLWD noting the “confidence boost from people who understand” (P1, PLWD).

Post-diagnostic support (PDS) was another key point of discussion, with experiences ranging from coordinated-high quality care to what participants described as tokenistic or dismissive encounters. One carer reflected positively that *“Dad had a year of psychiatric support… where dad was, they were very good” (G3, Carer, Scotland).* However, others recalled: *“Someone from the post diagnostic support team … and said to me ‘go away and get your affairs in order because this is a progressive disease’ and that was the amount of* *support we got." (P3, Carer, Scotland).* For many, the service resembled a postcode lottery, with access and quality varying dramatically.

In the absence of clear pathways, carers often assumed responsibility for researching symptoms and planning care: *"I personally had to do all the research to find out what was going on, what was wrong with my wife. No one could tell me." (G1, Carer, Scotland).* Others described the overwhelming process of searching "every website", which could be terrifying (P3, Carer, Scotland). This sense of being left to "piece it together" fuelled frustration and highlighted a wider system gap: *"There's something really, really wrong in the way in which healthcare social care is delivered" (P2, Carer, Scotland).*

As needs progressed, in-home care services were described as inconsistent. Positive accounts depicted carers who offered dignity, companionship and practical help: *"They sent a wonderful lady … she would even give me a lift down to the station so I could go out and meet my friend for a couple of hours…She was absolutely wonderful." (G1, Carer, Scotland).* Yet others reported mismatched staff, poor continuity and a lack of dementia understanding: *"Carers would come in say 'have you had your breakfast?' and he would say 'yes', and then they would walk back out again. They weren't told in advance he had dementia" (P4, Carer, Scotland).* Such inconsistencies meant services could either relieve or intensify stress.

Across all experiences, relationships and peer networks were seen as essential sources of support. Group activities and contact with others facing similar challenges offered relief and a sense of belonging: *"He's got comfort from understanding that there were people the same as him, of the same age group" (G1, Carer, Scotland).* Trusting relationships with individual clinicians were also valued, often described as more impactful than formal structures: *"The doctor was brilliant… he kind of seemed to understand" (P2, Carer, Scotland).*

Overall, experiences of support following diagnosis were deeply mixed. While some participants described sustained and meaningful connections with charities, clinicians or carers, others reported feelings of abandonment, confusion and the burden of navigating services alone. Despite national policy guarantees, PDS was viewed as inconsistent and uneven, reflecting a postcode lottery of access and quality. Participants repeatedly emphasised that the most effective support came from genuine human connection where moments of empathy and understanding alleviated the isolation of living with dementia.

Theme 8: Unmet Needs

Across sessions, participants identified persistent gaps in treatment, information and long-term support for PLWD and their carers. Despite awareness campaigns and national frameworks, lived experiences reflected a system still struggling to meet real-world needs. As one carer stated: *"I think there's a lot of work to be done. I don't know where to start, but I think there's still a lot to be done." (G1, Carer, Scotland).* Others described both frustration and resignation at the slow pace of change: *"Change is happening yeah, just not quick enough" (P1, PLWD, Scotland).*

A recurring theme was the lack of clear and consistent guidance at the point of diagnosis and beyond. Participants expressed a strong desire for centralised information and simplified processes, such as a single point of contact or a "tell us once" service. One carer questioned: *"Why can things not go to someone with LPA & this covers all services? Just a 'tell us once service" (P2, Carer, Scotland).* Similarly, a PLWD suggested the value of a straightforward, practical guide: *"It doesn't have to be a massive document … but just … a name, number, just steps, for a hint" (P1, PLWD, Scotland).*

Initial diagnostic support was often described as inadequate, but this tapered off quickly, leaving families without direction during the long "middle years" of dementia. Participants repeatedly emphasised the need for sustained contact to prevent crisis': *"The diagnosis journey is great. You'll get loads of folk helping at that point. You've also got the end of life and respite, but you know that journey between the diagnosis and respite might be 20 years" (G1, Carer, Scotland).* Another reflected: *"Initially, we needed support to get our heads round it and work out what we needed to do, but actually it's now, it's two and three years down the line we need the support" (P4, Carer, Scotland).*

Service availability, particularly was care homes and respite, was a consistent concern. Families described stark shortages in their local areas: *"There's zero [care homes] in [local area] to go to. It's not even that it's full it's just, there just isn't a building" (P2, Carer, Scotland)*. Even when services were available, access was patchy, with one carer noting that the "*availability of respite care"* remained one of the biggest issues *(G1, Carer, Scotland).* Participants linked these gaps to a lack of standardisation across Scotland, with significant variation in what post-diagnostic care looks like in practice.

Information sharing and communication with professionals were also highlighted as major shortcomings. Some participants felt that more detail would not have altered outcomes, but others expressed frustration at the absence of transparency around diagnoses, treatments and test results: *"When we got the diagnosis on that day... there's no drugs that can be* *used. Somebody will be in touch. Here's a booklet and that literally was the summing up of the information that we got" (G1, Carer, Scotland)*. Another described being excluded from medical knowledge: *They gave him a scan. We still don't know what the results of that scan were…they said, 'oh…you don't need to know these things'" (G3, Carer, Scotland).* Together, these accounts reveal a set of unmet needs that extend beyond medical treatment to include continuity, communication and practical support. While policy promises were acknowledged, participants described a reality where support faded too quickly, services were inconsistent, and the burden of this fell onto patients and families. For many the system felt reactive rather than proactive.

Participants described a system where urgent, practical and emotional needs often remained unmet despite entitlement to care. From patchy post-diagnostic support to poor signposting and fragmented services, families frequently felt forced to navigate complex terrain alone. Even when support was present, it was rarely sustained or coordinated, leading many to describe experiences of frustration and abandonment. Calls for system wide improvement centred around longer-term support, better communication, standardised care pathways and meaningful inclusion of people with dementia and their carers in decision making and service design.

3.4 Discussion

This study explored the lived experience of PLWD and their carers across three pivotal phases: noticing symptoms, seeking a diagnosis and life after diagnosis. Through thematic analysis and participatory visual mapping, I identified a range of emotional, relational and systemic challenges that illustrate the deeply fragmented and person-dependent nature of dementia care in the UK, particularly within Scotland. These findings reinforce existing literature on the diagnostic and care gaps in dementia pathways (Bunn et al., 2012, Iliffe et al., 2015, Giebel et al., 2022, Wiersma et al., 2024) while extending it through a visual and systems-orientated lens grounded in lived experience.

Navigating Caregiving and The Emotional Toll

Carers described not only the practical burden of coordinating appointments, medication and daily routines, but also the profound emotional strain that accompanied these tasks. Many spoke of masking their own distress to protect loved ones, often putting on a cheerful front while managing feelings of grief, frustration or exhaustion privately. This emotional suppression was frequently coupled with guilt – both for harbouring negative thoughts and for occasionally feeling resentment toward the demands of caregiving. In addition, several carers expressed fear for their own future, worrying about whether they might also develop dementia and what that would mean for their families. These accounts align with findings from Giebel et al. (2021), who argue that the emotional complexity of caregiving is frequently underrepresented in service design, which tends to emphasise logistical and practical support. Brodaty and Donkin (2009) similarly note that carers are at heightened risk of anxiety, depression and social isolation, not only due to the physical demands of caregiving but also because of the emotional labour involved in constantly balancing their own needs against those of their relative. Carers were rarely prepared for the depth of change that dementia imposed on their relationships, and many spoke of assuming care roles informally and without training. These accounts reinforce critiques of the ‘invisible carer’, where the formal system relies on unpaid labour while offering little structural support (Dementia Carers Count, 2024).

The Diagnostic Experience: Delay, Dismissal and Disruption

Delays and dismissive interactions were prominent across accounts of the diagnosis journey. Participants frequently had to fight for referrals or second opinions, a finding supported by studies highlighting primary care as a common bottleneck in dementia detection (Turner et al., 2004). The experience of being disbelieved or referred to depression rather than memory services was common, particularly when initial symptoms were subtle or behavioural. This reflects wider research showing that early dementia symptoms are often misattributed, especially among women and younger adults (Bunn et al., 2012). Even after diagnosis, communication was often rushed or unclear. PLWD and carers described being left in the dark with little information about dementia subtype, trajectory, or next steps which is a far cry from the structured pathways provided in cancer or stroke care. These findings underscore that technical diagnosis alone is not sufficient and must be accompanied by meaningful communication and follow up.

Reconsidering Cognitive Assessment in Dementia Diagnosis

A prominent area of frustration in participants’ diagnostic experiences involved the use of standard memory tests, which many described as irrelevant and reductive. Individuals with high cognitive reserve such as strong English or mathematical skills often passed traditional cognitive assessments like the MMSE or clock drawing tests, despite exhibiting clear functional changes. These accounts reflect wider concerns in the literature about the limited ecological validity of many traditional memory tests (Creavin et al., 2016).

Some participants described instances where tests failed to detect their symptoms or led to misdiagnosis. For example, scoring well on tests led to delayed referrals and assumptions of depression, even when it was insisted that something more serious was occurring. This issue was particularly acute in conditions like frontotemporal dementia (FTD) which may present without memory loss and therefore evade detection by memory heavy tools (Rascovsky et al., 2011). This reinforces a key theme in the data that the diagnosis process often over-prioritises test scores and under-prioritises carer insights or behaviour-based cues. This underscores the need for more sensitive and inclusive tools, especially in primary care where time and expertise are limited. However, as participants' accounts suggest, introducing new tests alone will not resolve systemic problems; they must be embedded within relationally supportive and contextually aware pathways (Borson et al., 2013).

Adapting to Life After Diagnosis

Post-diagnostic life was described as a long period of adjustment and emotional navigation. Participants reflected on shrinking social worlds, changing roles and a loss of independence. There narratives reinforce the concept of 'biological disruption' in chronic illness where personal identity and everyday life are permanently altered (Bury, 1982). A major source of distress was the lack of ongoing support following diagnosis. Although Scotland's National Dementia Strategy promises one year of post-diagnostic support, participant' experiences varied widely. Some reported excellent care, while others received only leaflets. These findings reveal a gap between policy intent and practice, echoing critiques of implementation inconsistency across health boards (Godbee et al., 2022). Participants called for longer-term check-ins, better signposting and relational continuity, rather than reactive crisis-driven responses.

Public Attitudes, Stigma and Social Disconnection

Stigma remained a significant barrier throughout participants' journeys. Dementia was often seen as shameful, misunderstood or associated only with old age. Participants noted that public responses often defaulted to pity, creating further isolation. These experiences align with global evidence showing that stigma reduces help-seeking, erodes identity and undermines wellbeing for both PLWD and carers (Tingley et al., 2024, Werner et al., 2011). Participants also critiqued media representations with some feeling that awareness campaigns reinforced fear rather than understanding however, it was shared that some representations were well received. Others highlighted the importance of dementia friendly spaces, not just in physical design but in communication and culture. These insights suggest that stigma is not just a personal barrier, but a structural issue embedded in how dementia is represented and supported.

Implementation Gaps and System Fragmentation

Across the dementia journey, participants described services as disjointed, inconsistent and difficult to navigate. These accounts mirror wider critiques that dementia care in the UK lacks integration and continuity (Iliffe et al., 2015). A common frustration was the need to repeatedly retell their story at every new point of contact, which left many participants calling for a clearer pathway, a central point of coordination and a consistent professional to guide them through key transitions.

For those with multiple health conditions, the challenges were even greater. Participants with complex comorbidities often felt poorly served by systems designed around single conditions, an issue also highlighted in the literature (Stirland et al., 2019). This fragmentation meant that important contextual factors such as physical health, social support or caregiving capacity were frequently overlooked in care planning.

Rather than asking for entirely new services, participants expressed a strong desire for existing policy commitments to be meaningfully delivered. The gap, in their view, was not one of vision but of execution: strategies and promises were in place but lived experience revealed striking inconsistency in how they were implemented.

Implications for Policy, Practice and 4MT Integration

This study highlights the urgent need for dementia strategies to move from policy rhetoric to delivery. Participants' accounts point to implementation gaps rather than an absence of guidance, underscoring the importance of supporting clinicians in practice. Participants stressed that there was no lack of strategy, in fact there was a lack of implementation of strategy. This could be something to look at more in depth in future work. There is a clear demand for targeted training to help GPs recognise early, non-memory symptoms and communicate sensitively about the diagnostic process. Equally, extending post-diagnostic support beyond the current one-year model, with provision that adapts to the evolving needs of PLWD and their carers, would address a major service gap. Greater continuity could also be achieved through a named contact role, while the use of visual methods such as journey maps or rich pictures could foster shared understanding across professionals, patients and carers. This gap in service delivery also relates directly to the ethical dimensions of an earlier diagnosis. For an earlier diagnosis to be meaningful, it must be embedded within a wider support system.

For the 4MT specifically, the findings underline the importance of aligning innovation with the lived priorities of PLWD and carers. Participants wanted assessments that were less stressful, more dignified and able to capture difficulties beyond abilities. A tool such as the 4MT, with its focus on spatial memory, could address these gaps if designed with sensitivity to the testing experience. Integration into practice should therefore be shaped not only by technical validity but also by its acceptability to patients and carers, particularly in terms of clarity and accessibility. Ensuring that such tools reduce, rather than add to, the burden of assessment will be critical for uptake and trust. These implications suggest that system improvements and novel tools will only succeed if they are attuned to the realities of the patient and carer journey, offering both earlier detection and a more humane experience of diagnosis and support.

3.5. Limitations

This study has several limitations. First, participants were primarily drawn from those willing and able to take part in co-creation sessions, which means the voices of individuals with more advanced dementia, or those without access to support networks are underrepresented. Second, as with most qualitative research, findings are not intended to be statistically generalisable; instead, they provide rich, contextualised insights into lived experience. Third, while journey mapping provided a powerful means of visualising the dementia trajectory, it inevitably simplified and condenses what are highly individual and variable experiences. Nonetheless, the participatory approach employed here generated ecologically valid and richly textured accounts that foreground the voices of PLWD and carers. Importantly the use of visual mapping helped translate fragmented and emotional narratives into systems insights that are actionable for service redesign.

3.6 Future Research

This work also lays the foundation for the subsequent stages of this thesis. Chapter four shifts focus to GP perspectives through process mapping, while chapter five explores the practicalities of piloting the 4MT in primary care. Understanding where and why diagnostic pathways break down from the perspective of those most directly is essential for designing earlier and more meaningful interventions.

3.7 Chapter conclusion

This chapter has used participatory journey mapping to foreground the lived experience of Scottish people affected by dementia and to surface systemic gaps that persist despite over a decade of strategic reform. Through thematic analysis and co-created visual tools, it revealed a consistent pattern of emotional burden, diagnostic delay and fragmented support. Standard memory assessments were frequently described as reductive and unrepresentative, particularly for non-memory led dementias. By grounding these findings in participant narratives and aligning them with existing literature, this study makes a strong case for reorienting dementia services toward more relational, anticipatory and inclusive models of care. Crucially, the proposed implementation framework offers a bottom-up scaffold for bridging the gap between strategy and delivery. By translating lived experience into actionable recommendations, it points to practical mechanisms for enhancing GP awareness, improving continuity of support, and addressing systemic inequities. These insights set the stage for the next phases of this thesis: GP process mapping and the pilot implementation of the 4MT, both of which build directly on the lived experience evidence presented here.

4. Clinician Perspectives on Dementia Diagnosis and Digital Tool Implementation in Primary Care

4.1 Introduction

Building upon the patient and care perspectives explored in chapter three, this chapter shifts the focus to the clinician’s role within this system, seeking to understand how primary care practitioners perceive and navigate the diagnostic process in their day-to-day work. Dementia diagnosis in primary care is a complex and iterative process that is shaped by fragmented service pathways, variable clinical practices and evolving patient needs. Despite growing recognition of the importance of an earlier diagnosis for patient outcomes and service planning (Scottish Government and COSLA, 2021, Alzheimer's, 2024), diagnostic pathways often remain poorly defined inconsistently applied and difficult to navigate for both clinicians and patients.

Healthcare systems are frequently characterised as a complex socio-technical system, where interactions between people, processes, technology and the organisational environment shape the delivery of care (Aarts et al., 2015). Systems engineering offers established approaches for making sense of these interactions and identifying opportunities for improvement (Clarkson et al., 2017). One such approach - process mapping - allows frontline clinicians to visualise complex care processes, identify gaps and reflect on opportunities for improvement. Rather than prescribing linear solutions, it encourages teams to explore how clinical work is actually done whilst capturing the real-world complexity often lost in top-down service plans (Checkland, 1999, Royal Academy of, 2017). This approach aligns with the broader systems thinking shift in healthcare improvement which advocates working with frontline clinicians to understand challenges and identify sustainable change opportunities.

Existing diagnostic pathways, both in Scotland and internationally, are often presented as simplified linear routes: a patient presents with memory concerns, the GP assesses them, and a referral to specialist services follows (National Institute for Health and Care Excellence, 2018). However, the reality is far more nuanced. Concerns may be raised by family members or third parties; GPs must balance limited appointment time with sensitive conversations; and diagnostic processes are shaped by local resources and patient readiness (Bunn et al., 2012). To implement a new cognitive screening tool such as the 4MT into this context, it is essential to understand where and how cognitive testing fits into workflows, what factors influence GPs to assess, refer or monitor and how technology could support, rather than disrupt patient care. This chapter addresses these questions by engaging GPs in an exercise that not only captures the as-is journey but encourages them to reflect on potential improvements.

4.2 Methods

4.2.1 Study Design

This qualitative study used a systems engineering approach to explore the dementia diagnostic pathway in Scottish primary care. Drawing on process mapping and human-centred design principles, this study combined three components:

1. Walkthrough of the 4MT: clinicians were guided through a demonstration of the digital 4MT and asked to comment on clarity of instructions, usability, clinical relevance and potential fit within primary care.
2. Process mapping exercise: participants were presented with the draft dementia diagnostic pathway created by the SABRE team in England (Figure 18). The SABRE pathway had been iteratively created by the research team in consultation with clinicians as part of their wider work on 4MT implementation. In the present study, the SABRE map was used as a stimulus for reflection: Scottish GPs were invited to critique areas that diverged from their practice and suggest modifications. In group sessions, participants also produced hand-drawn maps of their own diagnostic pathways, enabling comparison between proposed national models and lived realities within Scottish general practice.
3. Semi-structured interviews and group discussions: these explored participants' current diagnostic practices, use of cognitive tests, perceived barriers and ideas for service improvement.

The design aligned with the EBC framework, which emphasises engaging frontline staff in reflecting on systems, processes and opportunities for innovation.

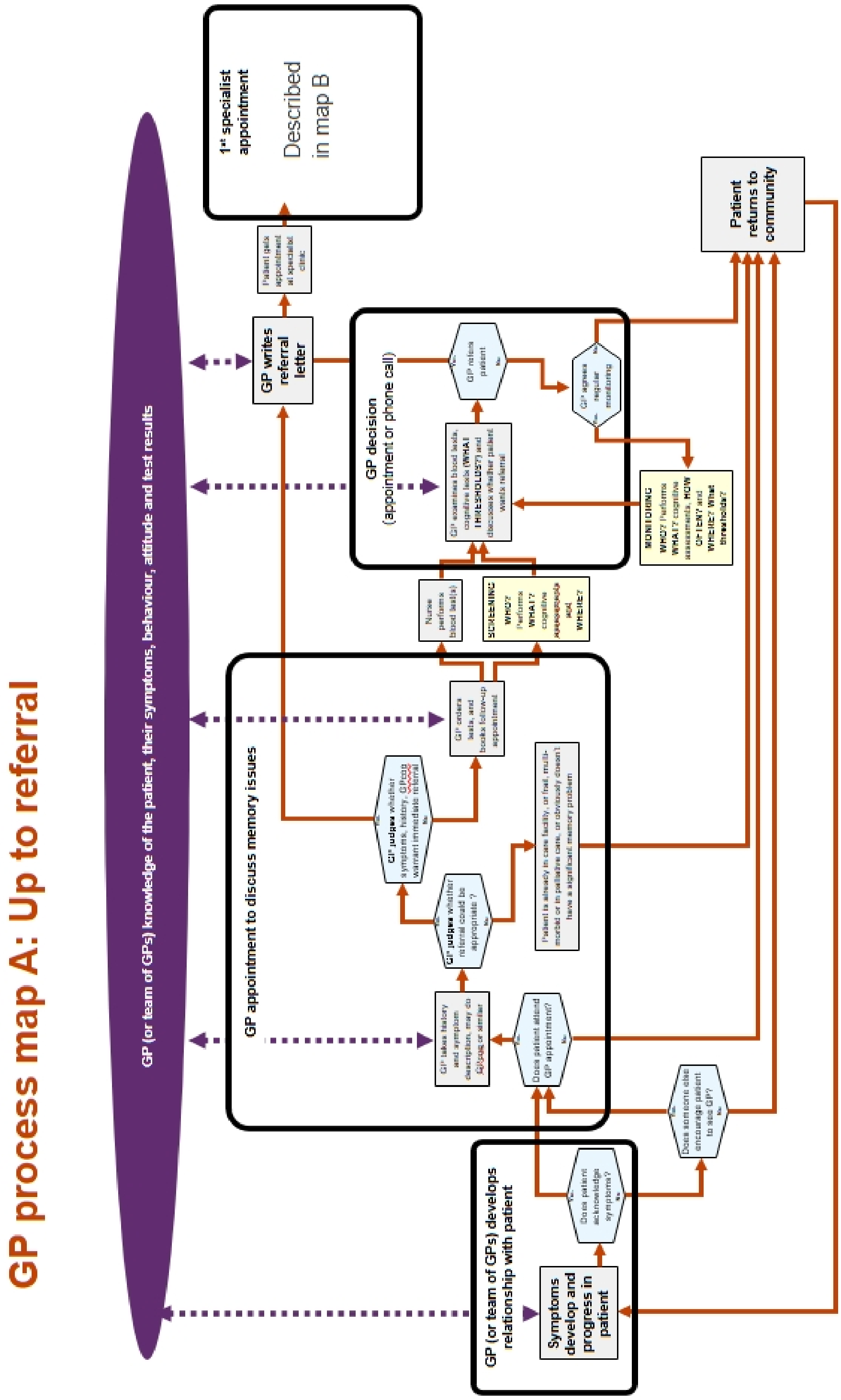


Figure 18: Draft dementia diagnostic pathway created by the SABRE team in England (SABRE, 2024)

4.2.2 Participants and Recruitment

Eleven primary care clinicians across NHS Tayside, NHS Lanarkshire, and NHS Ayrshire and Arran took part in the study (Table 6). Recruitment took place through several channels:

- Presentations at GP forum and cluster meetings to introduce the study and invite expressions of interest.
- Flyers (Appendix 6) emailed via primary care leads to local GPs, outlining the study purpose and participation details.
- Direct conversations with primary care leads, who acted as gatekeepers and facilitated introductions.
- Peer referrals with GPs who had already participated sharing the study with colleagues.

Recruitment combined purposive and convenience sampling: purposive in seeking clinicians with experience or interest in dementia diagnosis, and convenience in including those who responded to invitations.

The final sample included three individual interviews, one group interview (n=4) and one group feedback session (n=4). Participants represented a mix of urban and rural practices, covering diverse populations and service contexts (Table 7). Each participant completed an anonymous demographic questionnaire (Appendix 7) to characterise the sample while preserving confidentiality.

Table 6: Participant demographics

Participant	Age	Gender	Experience (Yrs)	Region
P001	31	Woman	5-10	Tayside
P002	-	Woman	10-15	Lanarkshire
P003	36	Woman	5-10	Ayrshire and Arran
P004	29	Woman	1-5	Ayrshire and Arran
P005	44	Woman	20+	Ayrshire and Arran
P006	56	Woman	20+	Ayrshire and Arran
P007	36	Woman	5-10	Lanarkshire
P008		Man	20+	Lanarkshire
P009	55	Woman	20+	Lanarkshire
P010	42	Woman	10-15	Lanarkshire

P011	Woman	Lanarkshire

4.2.3 Data Collection and Analysis

Table six outlines the activities that each participant took part in followed by an explanation of what each activity involved.

Table 7: Participant activities

Participant	4MT walkthrough	SABRE Map feedback	Semi-structured interview	Process map creation and feedback
P001	x	x	x	
P002	x	x	x	
G001 (P003-P006)	x	x	x	x
P007	x	x	x	x
G002 (P008-P011)	x	x	x	x

Walkthrough of the 4MT

Each participant was guided through a working version of the 4MT on a laptop or tablet. They completed a demonstration of the task while commenting on clarity of instructions, usability, and potential fit with primary care workflows. Prompts were used to elicit reflections on patient acceptability, time requirements, and comparability to other cognitive tests. Feedback was captured through audio recordings in individual sessions through field notes in group settings.

Process Mapping

A draft dementia diagnostic pathway developed by the SABRE project was used as a stimulus. In this study, the SABRE pathway was either presented on screen or as a paper copy to clinicians to annotate or comment on. Participants commented on areas that aligned or diverged from their own practice, noted barriers and suggested adaptations. In one group session, participants also produced hand-drawn maps of their own diagnostic practices. These annotated and hand-drawn maps were collected as artefacts for analysis. In the group feedback session, I was guided through the process while producing a co-created visual which was then reviewed by the clinicians in the group.

Semi-structured interviews and group discussions

An interview guide explored topics including current diagnostic pathways, use of cognitive tests, referral practices, barriers to timely diagnosis and opportunities for innovation. Individual interviews and one-group interview were audio-recorded and transcribed verbatim. Other group interviews and feedback sessions were documented through detailed field notes and supplemented by the annotated and hand-drawn maps produced during the sessions.

4.2.4 Data Analysis

Data from transcripts, field notes and mapping artefacts were analysed thematically using Braun and Clarke (2006) inductive approach. Coding was conducted across the full dataset, identifying recurring patterns in diagnostic practice, barriers within the system, and perceptions of innovation. Triangulation across the three data sources (4MT walkthrough, process mapping and interviews) enhanced the robustness of the findings and allowed a systems-level understanding of the dementia diagnostic pathway in Scottish primary care.

4.2.5 Ethical Approvals

The study received ethical approval from the Nottingham Research Ethics Committee via the Integrated Research Application System (IRAS, Ref: 24/EM/0280). all participants were provided an information sheet (Appendix 8) and gave written informed consent prior to participation. Interview recordings and field notes were stored securely on encrypted drives. Demographic data were collected anonymously. Identifiable details have been removed or pseudonymised to protect confidentiality.

4.3 Results

4.3.1 Clinician Perceptions of the Dementia Diagnostic Pathway

GPs described a diagnostic process that was both structured and adaptive, shaped by local service contexts, patient presentation and individual clinical judgement. Across interviews, GPs reflected on the practical realities of recognising and responding to memory concerns. Key themes included: initiating concerns and early encounters, working within constraints, and the role of others in the system.

Theme 1: Concerns Often Begin Elsewhere

GPs consistently described how cognitive concerns were rarely raised by the patient themselves with family members, carers or third parties such as reception staff, pharmacists or social workers often being the first to voice concerns. Participants emphasised that many individuals with cognitive decline lacked awareness of their symptoms or did not recognise them as significant.

"Often people with dementia are oblivious to their condition so they're quite often brought by a family member, or sometimes they're picked up by the reception staff" (GP 7, Lanarkshire)

"Sometimes people will come in off the street and say, 'I am really concerned I've seen such and such up the square'" (GP, Ayrshire & Arran)

However, some GPs described cases where patients did present themselves, often because they were experiencing subtle difficulties with memory, confusion or function and wanted reassurance. These individuals were sometimes described as the 'concerned well', or people who were simply seeking clarity or peace of mind:

***"**Occasionally it's the patient themselves" (GP 2, Lanarkshire)*

"You do sometimes get relatives who are very worried about dementia. A son or daughter who's really, really worried about dementia." (GP 7, Lanarkshire)

In these instances, GPs took care to assess and reassure, while managing expectations about what a diagnosis might or might not provide; especially given the lack of treatment options for early-stage memory loss. This early stage of the pathway was therefore shaped by both external observation and internal concern with GPs balancing clinical listening and risk-based decision making across diverse starting points.

Theme 2: Time, Tools and Triage

Participants described varying approaches to cognitive assessment, with all using a brief screening tool, which was most commonly the 6CIT or MoCA, in combinations with patient history and functional observations. Several GPs referenced avoiding the MMSE due to licensing restrictions, and a few used mood scales or blood tests to rule out other causes:

“We would do baseline bloods for most people unless it was clearly not an issue. Just looking for any physical conditions that could be dementia. And we would do a memory score of some kind, a short one, just to give us some idea … memory score is OK. We would still refer them because obviously it's only a basic score… doesn't test every bit of the brain.” (GP 2, Lanarkshire)

“Blood test, GP appointment, that I would get the history, 6CIT and then do the referral if there was an issue at that point” (GP, Ayrshire & Arran)

It was noted that, if patients had recent blood tests, then these would not necessarily be repeated:

“I'll get the patient back another time to get their blood test check if they haven't already had them done, you know, within the last six months or … if it's been a gradual onset of symptoms, then they have all their blood's done three months ago. I'm not going to repeat them.” (P1, Tayside)

Appointment lengths varied, with GPs describing 10,15, or 20-minute appointments depending on practice systems. Some mentioned the ability to book double appointments or follow ups when needed:

“The standard appointment’s 10 minutes. People can request double, but they tend to come in and 10-minute appointments” (GP 7 Lanarkshire)

“20 minutes. Depends, if they need longer, they get longer you’re just late for the next one” (GP, Ayrshire & Arran)

This flexibility was essential when GPs needed to involve carers, explain test results or navigate more sensitive discussions about driving, capacity or referral. One participant noted how language and literacy challenges often extended consultations and impacted the patient’s understanding of testing:

“What we are saying would take a couple of minutes to run through would maybe take them, I don't know, 10-15 minutes” (GP 2, Lanarkshire)

GPs also mentioned the emotional strain some patients experienced during memory testing, particularly when they were aware of potential diagnoses, and described strategies such as breaking assessments into smaller steps or reviewing over several visits.

Theme 3: The Role of Others in the System

Many participants described a shared sense of responsibility within the wider primary care team and community. GPs frequently credited carers, district nurses, pharmacists, reception staff and mental health colleagues as key to raising concerns or providing the fuller picture necessary for diagnosis:

“You quite often get contacted by family members. Or occasionally… hospital specialties or social work or someone else to say; ‘Have you checked in on that patient's memory?’” (P1, Tayside)

Cases were shared where non-clinical staff first noticed unusual behaviours, such as missing appointments, medication errors or navigation difficulties. Family members were often pivotal in flagging concerns or providing collateral history about changes in function, behaviour or safety:

“it’s likely the chemist will phone us like they’re mixing up their medication” (G1, Ayrshire)

Carers were also described as critical allies during appointments. Several GPs emphasised that having carers present made assessments more effective, particularly when patients had poor insight or memory. Carers could often fill in gaps, offer timelines, and validate or challenge patient accounts, giving clinicians a richer and more accurate understanding of the situation:

“*I'm happy to have the relative there and actually to be honest it's usually helpful because they sometimes give a slightly different perspective to what the patient does so.” (P2, Lanarkshire)*

Theme 4: Referrals and Reviews

Decisions around referral to memory services were not always immediate. GPs described monitoring patients with mild symptoms or uncertain presentations, sometimes over multiple visits, before referring. Others described how concerns were raised but a decision to refer was deferred if the patient or family were unsure:

"I guess not everyone wants to be given the diagnosis … so, we would just have a discussion about what their thoughts and wishes were and kind of try to go along with that, providing obviously there's no sort of major safety concerns or safeguarding concerns" (P2, Lanarkshire)

"Unless the problems are very prominent, you would give that a few months …You redo the memory score and see if it improves things like that." (P7, Lanarkshire)

Referrals were made via SCI Gateway, although the content of the referral varied. Some included detailed cognitive scores and mood assessments; others focussed more on functional changes or carer input. Several GPs expressed frustration with waiting times, particularly for patients under the age of 65 or those with more subtle symptoms. In some cases, referrals were returned, delayed or bounced between services:

"Elderly get seen between 2-4 weeks 60 and under can be anything up to 18 months. I had an early under 60 referred and he was well over a year, and it was only because I kept pushing that he eventually got seen and by the time he was seen it was too late (G1, Ayrshire)

4.3.2 Perceptions of the 4MT

As part of the anonymous questionnaire provided prior to study start, participants were asked: "Do you think tests for cognitive impairment in general practice could be improved? If yes, why?". Out of the 11 participants who were given the question, 9 responded with yes and 2 left the question blank. Some of the answers included that tests could be "simplified" and "less time-consuming" with some participants commenting on the accessibility and specification of existing tools, showing that there is scope for an improvement on existing cognitive tests.

GPs were introduced to a prototype version of the 4MT and asked for feedback on its clarity, usability and potential role in the diagnostic pathway. Most participants welcomed the idea of a digital tool that targeted hippocampal function, noting that it might offer something distinct from existing brief cognitive screeners. Several saw potential value in using the 4MT as an early screening or rule out tool, particularly for patients experiencing general forgetfulness or anxiety.

“It would be great for screening because we need to pick it up quicker” (G1, Ayrshire)

However, another theme which arose was the ethical tension between screening and treatment, suggesting that diagnosis without care pathways could cause harm, particularly to patients who may not yet be functionally impaired. One GP expressed concern about the emotional impact of diagnosing early when few interventions were available:

“But I think the way medications [are] at the moment, early pickup’s probably not as worthwhile as it sounds, it always sounds good if you pick things up early… you can pick up early and say… you found out five years earlier then that's lead time bias. It's not actually progress. So, I think you have to be careful.” (P7, Lanarkshire)

While the clinical instinct to detect early was strong, GPs weighed it against the reality of stretched memory services and limited post-diagnostic support.

In terms of practical use, participants raised concerns about the language complexity, digital interface and the stress some patients might experience, especially when tasks were timed or perceived as difficult:

“I think they would even panic with the prospect of trying to do that task with the time limit” (G1, Ayrshire and Arran)

“I think it's quite a difficult test. It's a bit nerve-wracking to do it. You're kind of wondering what your score is going to be.” (P7, Lanarkshire)

4.4 Discussion

This chapter reflects on the findings of the process mapping work with GPs, situating them within wider literature on dementia diagnosis, systems-based care and digital tool implementation in primary care. The data gathered across individual and group interviews reveals a nuanced portrait of current diagnostic practice, which is a practice shaped by professional intuition, community ties, structural limitations and the relational dynamics between patients, carers and clinicians. The findings suggest that dementia diagnosis in general practice is not a straightforward or linear event, but rather an emergent and distributed process involving multiple actors, evolving information and variable timing. While GPs operated within a broadly recognisable framework consisting of initial concern, brief screening, functional assessment and referral, this framework was adapted in real time, often informally and collaboratively. This discussion draws together key insights around 5 themes identified throughout interviews. It also reflects on the barriers and enablers identified in this study and considers their implications for future implementation of digital cognitive assessments, particularly in resource limited settings like Scottish primary care. Clinicians noted various barriers and enablers that shape the feasibility of introducing digital cognitive assessments in primary care (Table 8).

Table 8: Barriers and enablers that shape the feasibility of introducing new tools

Barriers	**Enablers**
Limited consultation times	GPs openness to innovation when tools are brief and evidence based
Variability in patient literacy, language and digital comfort	Carers’ willingness to contribute to collateral histories
Emotional sensitivity of raising dementia concerns	The potential for tools like the 4MT to streamline reassurance and triage
Long waiting times and inconsistent service availability	Alignment with policy calls for integrated and system wide dementia care (Scottish Government and COSLA, Godbee et al.)
Risk of ethical tensions if testing outpaces support pathways.	

The findings reinforce that dementia diagnosis rarely begins in the consultation room. Concerns often originate externally, through family, carers, pharmacists, reception staff or other community actors before reaching the GP. This mirrors (Bunn et al., 2012) and (Iliffe et al., 2015), who argue that dementia recognition is socially constructed and reliant on networks of observation and advocacy. In this sense, GPs are not the sole gatekeepers of diagnosis, but rather central nodes within a distributed detection system. A notable insight is that the potential value of the 4MT may lie not only in detecting impairment but also in reassuring the “worried well”, reducing unnecessary referrals and preserving clinical capacity, though this must be balanced against risk of false reassurance.

GPs consistently framed diagnosis as a process of triangulating cognitive tests, medical history, functional observations and collateral accounts. Commonly used tools included the 6CIT and MoCA, with avoidance of the MMSE due to licensing restrictions (Martin and O'Neill, 2009). While these tools provided structure, they were seen as limited, time consuming, culturally narrow or insufficiently sensitive to subtle deficits. These findings echo the work of (Stirland et al., 2019), who emphasise that comorbidities and contextual factors complicate test interpretation, and Brodaty and Donkin (2009), who highlight the emotional weight carried by families throughout testing. Appointment constraints exacerbated these challenges, with 10-15 minutes often inadequate for nuanced conversations, especially when language barriers or emotional reactions required additional time.

The accounts underscored the central role of carers and wider teams in both recognition and assessment. Carers provided essential collateral histories, often offering details that patients could not, while non-clinical staff were sometimes first to detect unusual behaviours such as medication errors. This confirms findings from Werner et al. (2011) and Giebel et al. (2021), who highlight carers as both partners and emotional labourers in the diagnostic process. From a system perspective, diagnosis is thus relational, clinicians rely on input from multiple sources to build a coherent understanding of patient function and risk.

Referrals to memory services were not automatic but shaped by timing, patient wishes, and service availability. GPs described monitoring patients over months, repeating tests, or delaying referral where patients or families were hesitant. Ethical tensions emerged as clinicians sought to respect autonomy while also weighing safety, capacity and the potential value of early diagnosis. Waiting times, particularly for younger patients, created frustration and in some cases, compromised timely diagnosis. These findings align with Borson et al. (2013), who caution that early detection must be accompanied by responsive service pathways to avoid creating “diagnostic limbo” for patients.

When introduced to the 4MT, GPs expressed cautious optimism. They valued its novelty in targeting hippocampal function and saw potential for use as an early screening or “rule out” tool. However, concerns were raised around patient anxiety, language complexity and the ethics of diagnosing without adequate support services. These perspectives echo wider debates in the literature (Turner et al., 2004; Wiersma et al., 2024), which stress that innovation in cognitive testing must be balanced against issues of feasibility, patient accessibility and system readiness. Importantly, feedback from this study directly informed revisions to the 4MT prototype. Specifically, instructions were simplified to reduce language barriers, task framing was adjusted to minimise patient anxiety, and interface elements were refined to fit within the constraints of primary care workflows. These adaptations, described further in chapter five, ensure that the pilot implementation of the 4MT is grounded in the realities of practice.

Taken together, these findings underline the importance of seeing dementia diagnosis as a system-wide endeavour, not an isolated clinical act. GPs operate within structural and relational constraints, negotiating uncertainty across patients, carers and services. Tools like the 4MT may have promise, but their adoption will depend on fit with workflows, brevity, accessibility and linkage to meaningful referral pathways. More broadly, the findings support calls for integrated models of dementia care (Scottish Government and COSLA, 2021, Godbee et al., 2022), where early recognition is coupled with responsive post-diagnostic support.

4.5 Chapter Conclusion

This study demonstrates that dementia diagnosis in primary care is an emergent, negotiated process shaped by social networks, resource constraints, and clinical judgement. Existing tools are used pragmatically but often fall short of providing clarity within the realities of short appointments and diverse patient needs. The 4MT was viewed with interest but also caution, particularly around feasibility and ethical implications. Ultimately, sustainable innovation in this space requires not only better tools but also systemic improvements in care coordination and support. These insights provide the foundation for the pilot implementation of the 4MT (Chapter 5), ensuring that its design and testing are informed by frontline realities.

5. Pilot Implementation of the 4MT

5.1 Introduction

The preceding chapters have mapped the dementia diagnostic journey from two complementary perspectives: that of people living with dementia (PLWD) and their carers (chapter three), and that of primary care clinicians (chapter 4). Together, these studies illuminated the real-world complexity of detection and diagnosis in Scottish primary care, a process shaped by relational networks, patient and carer advocacy, variable access to memory clinics and the adaptive problem-solving of clinicians within a constrained system. Across both perspectives, a consistent need emerged for timely, practical and accessible cognitive assessment tools that could support general practitioners (GPs) in identifying possible early-stage dementia, particularly in cases where symptoms were subtle. Clinicians expressed interest in innovations that were quick to administer, easy to interpret and suitable for patients with diverse language and literacy backgrounds, while also integrating smoothly into time-limited consultations.

The Four Mountains Test (4MT) was identified previously by our research team as a potential candidate to meet these needs. Research has demonstrated the 4MTs ability to detect hippocampal dysfunction in the prodromal stages of Alzheimer disease (AD), offering a window into cognitive change that is less reliant on verbal skills or cultural familiarity than many established screeners. However, the test has not yet been explored in the context of routine GP consultations, nor evaluated for usability, acceptability and fit within primary care workflows. Informed by the system insights generated in earlier chapters, a pilot implementation study was developed to assess the 4MTs practical use in Scottish general practice. This chapter outlines the rationale, design and early implementation activities of that pilot. Preliminary indicators are included here to provide an initial view of acceptability and inform the next phase of development. The preliminary pilot activities were therefore designed to explore the practical feasibility of introducing the 4MT into general practice. Specifically, the pilot aimed to assess its usability for clinicians within the constraints of short consultations, its acceptability to patients and carers and its overall fit within existing diagnostic workflows. In doing so, the pilot sought to generate early insights to inform further refinement of the tool and shape the design of a larger scale implementation study. Thus, this chapter seeks to answer both research questions: ‘How might we use systems thinking to implement a digital cognitive tool for earlier Alzheimer detection in a Scottish primary care setting?’ and ‘How do clinicians and patients perceive the usability and accessibility of a digital cognitive tool, and what impact does this have on its implementation?’.

5.2 Methods

5.3.1 Study Design

The pilot followed a formative, exploratory design to examine the usability, acceptability and workflow integration of the 4MT in a real-world general practice context. The primary focus was to gather practical feedback from clinicians and identify barriers and facilitators to adoption, rather than evaluate diagnostic performance. The approach was informed by principles of human centred design (HCD) and the Engineering Better Care (EBC) framework, which emphasise co-design, contextual adaptation and early user feedback before scaling up. Intermediate conversations built on the earlier process mapping chapter (Chapter 4) where clinicians shared their thoughts on the 4MT conceptually. A staged series of activities enabled iterative refinement of the tool (Table 9). All study activities were conducted under full ethical approval from the University of Strathclyde Ethics Committee, the Nottingham Research Ethics Committee (via IRAS), and NHS Lanarkshire R&D.

Table 9: Study activities and description

Activity	Description
Education Day	Initial walkthrough of 4MT with clinicians to obtain early-stage feedback.
Cluster Meeting	Follow up demonstration with broader group of GPs.
Meeting with CL and PQL	In-depth hands-on feedback with cluster lead and practice quality lead.
Feedback Review	Revised 4MT presented based on earlier feedback; partner clinic identified.
4MT Training	Three sessions in which small groups of clinicians trialled the 4MT on each other, followed by completion of the System Usability Scale (SUS).
Drop-in Sessions	Weekly check-ins with the practice team to discuss patient uptake and emerging issues.

*CL = Cluster Lead, PQL – Practice Quality Lead

5.2.2 Ethics and Consent

Ethical approval for the study was obtained in stages. Initial approval was granted by the University of Strathclyde Ethics Committee (Ref: UEC24/89), followed by review and approval through the Nottingham Research Ethics Committee via the Integrated Research Application System (IRAS, Ref: 24/EM/0280). As the participating clinic was located within NHS Lanarkshire, final approval was obtained from the NHS Lanarkshire Research and Development office (Ref: L24079).

All participants were provided with a written information sheet (Appendix 9) detailing the study aims, activities, data handling procedures and right to withdraw at any stage without consequence. Written informed consent was obtained prior to participation in formal activities, including permission for audio recording of one interview. For informal feedback and drop in discussions, verbal consent was affirmed before data capture in field notes. All data were anonymised, and participants are referred to throughout using unique study codes (P001 – P007)

5.2.3 Recruitment and Participants

Participants were recruited via GP cluster meetings, education days and direct in-person invitations to practices that had expressed prior interest in the 4MT. Recruitment was supported by pre-existing networks from the process mapping study. This approach represents a combination of convenience sampling through existing contacts and purposive sampling by targeting one partner practice committed to dementia innovation.

One clinic within NHS Lanarkshire was purposively selected for the pilot, based on prior engagement and willingness to support early-stage testing. The practice team itself consisted of five GPs, one locum GP, one trainee doctor, one practice nurse, one link worker, one occupational therapist and a small reception team. A study flyer (Appendix 10) was circulated within the clinic to invite participation. In total, seven clinicians took part in the pilot activities (Table 10).

Figure 19: Map of the United Kingdom with coordinates of partner clinic identified with red information graphic: own graphic made with google collab

Table 10: Participant Demographics

Participant	Age	Gender	Experience (Yrs)
P001	36	Woman	5-10
P002	-	Male	20+
P003	55	Woman	20+
P004	42	Woman	10-15
P005	-	Woman	
P006	-	Woman	
P007	27	Male	1-5

5.2.4 Procedure

The procedures described here correspond to the structured pilot activities listed in Table 7.

- Demonstration and training: clinicians were introduced to the 4MT through a live demonstration, which included an overview of its scientific background and potential role in detecting AD. In training sessions, clinicians trialled the prototype in pairs, experiencing both administrator and patient roles.

- Usability rating: after the final interaction, participants completed the System Usability Scale (SUS).
- Structured feedback discussion: Group discussions followed, focussing on clarity of instructions, digital interface, patient suitability and workflow integration. Feedback was also sought on potential documentation pathways within the Vision EHR system.
- Drop-in sessions: Weekly informal check-ins provided an opportunity for emerging issues to be shared and recorded.

5.2.5 Data Collection and Analysis

Data was gathered through a combination of qualitative and quantitative methods. One GP provided in-depth feedback during a process mapping interview, which was audio-recorded with written informed consent, in line with the approved study protocol, and transcribed verbatim. All other pilot interactions, including demonstrations, training sessions and informal discussions with clinicians were documented through contemporaneous field notes These notes captured navigation behaviours, verbal comments, questions and non-verbal cues during test use.

Qualitative data were analysed thematically following the inductive, reflexive approach described by Braun and Clarke (2006). initial line-by-line coding focused on usability issues, contextual barriers and suggestions for adaptation. Codes were not grouped solely based on frequency; rather, they were developed into broader themes through interpretive synthesis, considering both explicit statements and the underlying meanings conveyed by participants. This involved repeated cycles of comparison between the raw data, emerging codes and developing theme structures, to ensure that the themes captured both the surface content and the deeper patterns of meaning relevant to usability and workflow integration. documentation.

SUS responses were scored according to standard methodology, producing a score between 0 and 100 for each participant. These were summarised descriptively to provide an initial indication of usability.

5.3 Preliminary Findings

Preliminary findings are drawn from a combination of field note observations, one transcribed interview, and SUS responses. While qualitative data provided rich insight into usability and system fit, SUS offered a standardised measure of perceived usability. Together, these findings give an early indication of how the 4MT was received in practice.

5.3.1 Mapping the System from a Clinician Perspective

Early conversations with clinicians revealed important contextual factors shaping how new tools such as the 4MT might be adopted. Unlike many surgeries, the partner practice did not operate an online appointment booking system or the so-called “8 o’clock scramble” in which patients compete for limited slots by phoning as lines open. Instead, the practice operated on a more personalised, patient facing approach, with reception staff available to help patients book appointments or request prescriptions throughout the day. One GP compared the booking process to a parent-child relationship, where reassurance, compassion and guidance were as important as medical expertise in shaping patient experiences. Clinicians described their patient population as diverse, with a substantial proportion of older adults and individuals with multiple long-term conditions. These contextual details influenced their evaluation of the 4MT: they wanted tools that could be delivered efficiently within existing consultation structures while maintaining the strong relational ethos of the practice. Discussions also touched on the use of the Vision clinical system. While there was interest in coding 4MT results using SCIMP codes for integration into EHRs, GPs noted that this would currently require a temporary workaround. For the pilot phase, clinicians agreed to record results in free-text notes, but these conversations provided useful insight into how formal integration might work in the future. Insights from these conversations were used to build upon findings from chapter 4 and develop a practice-specific process map (Appendix 11). This map has been broken into three phases for ease of reading (Figures 20-22) capturing how patients move through the system and where potential touchpoints for introducing the 4MT may exist – once created, clinicians reviewed the map and highlighted any required changes.

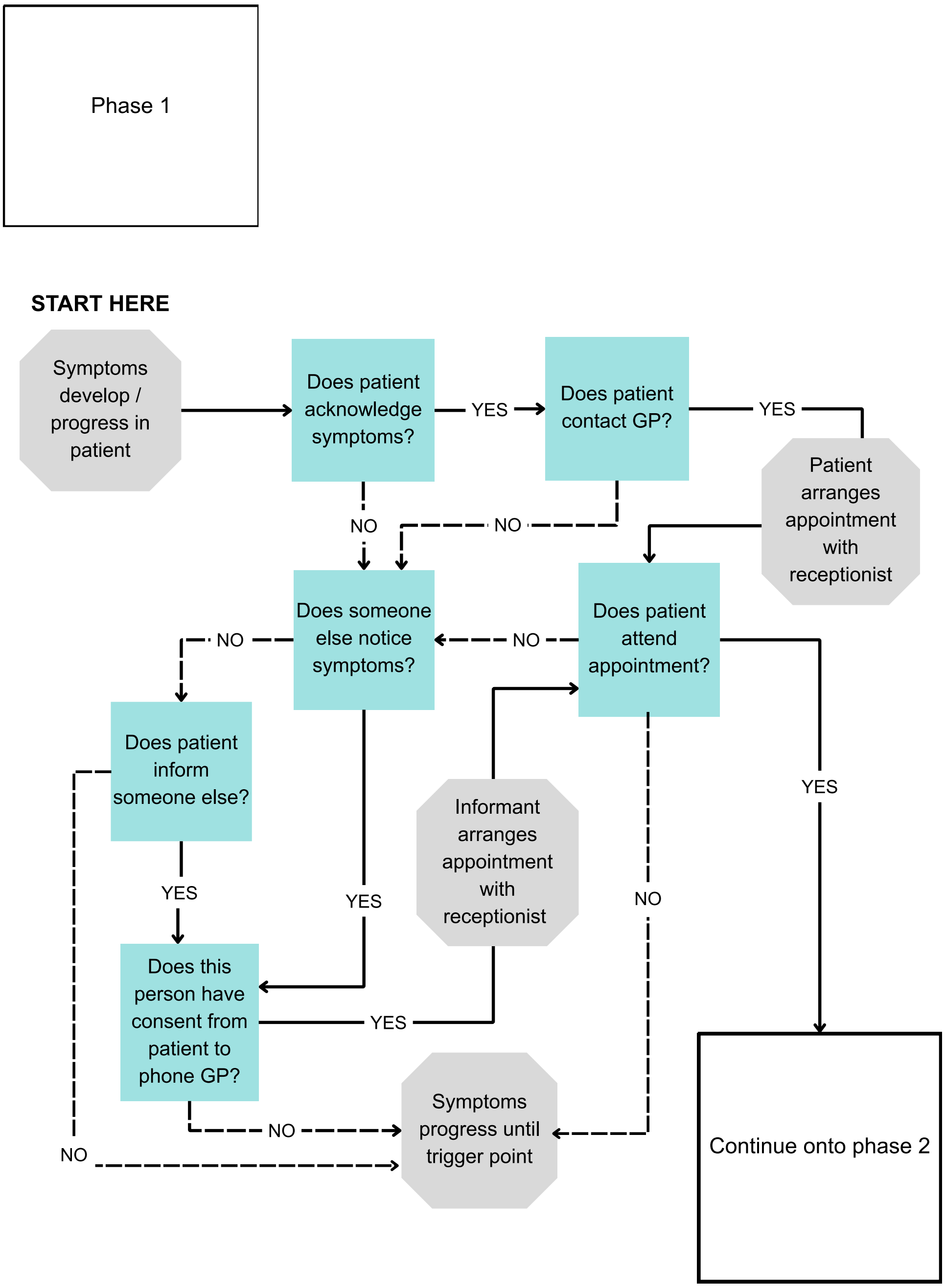


Figure 20: Practice specific process map phase 1 of 3. Made on CANVA from conversations with the practice and reviewed by clinicians within (Hamilton et al, 2025)

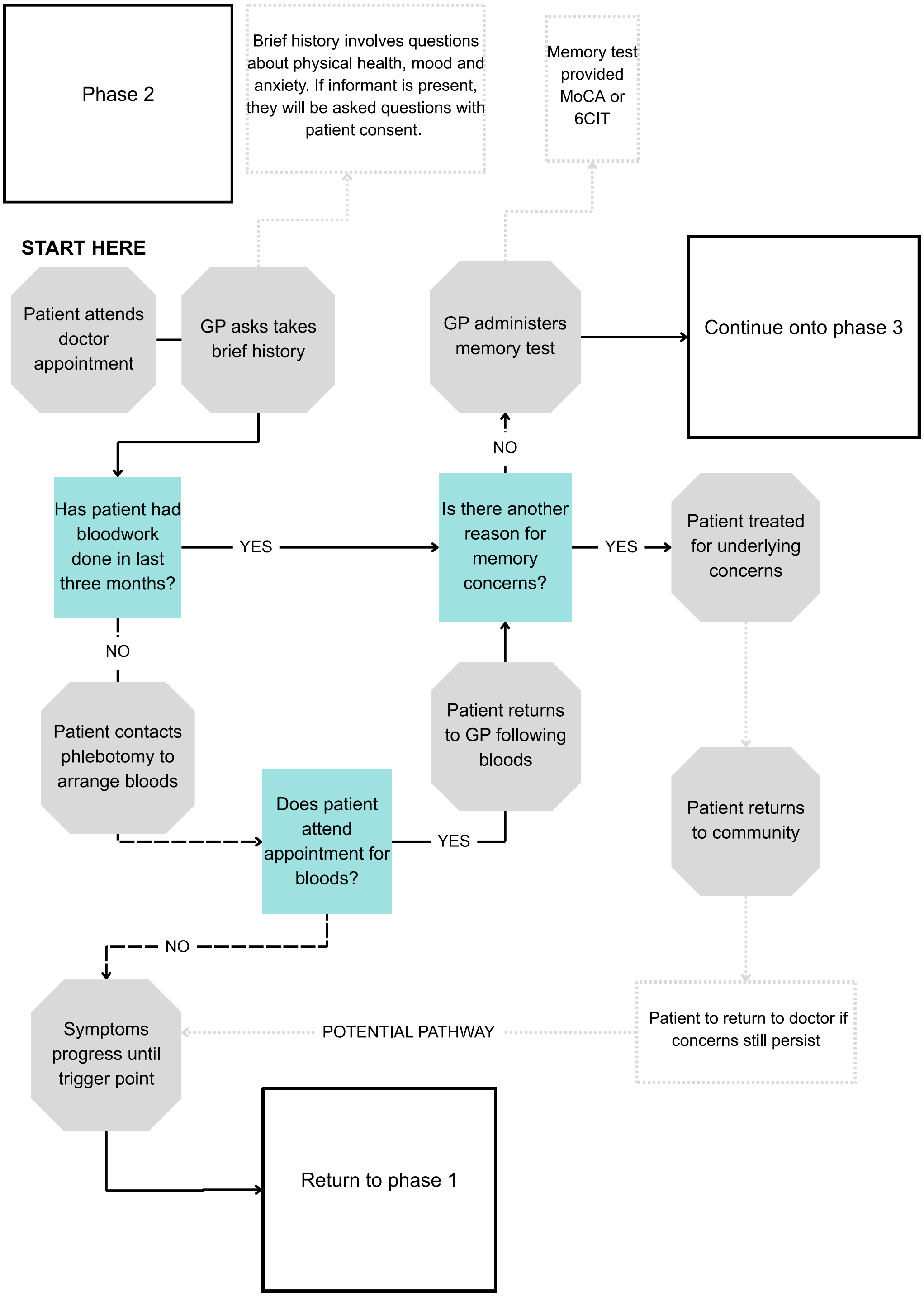


Figure 21: Practice specific process map phase 2 of 3. Made on CANVA from conversations with the practice and reviewed by clinicians within (Hamilton et al, 2025)

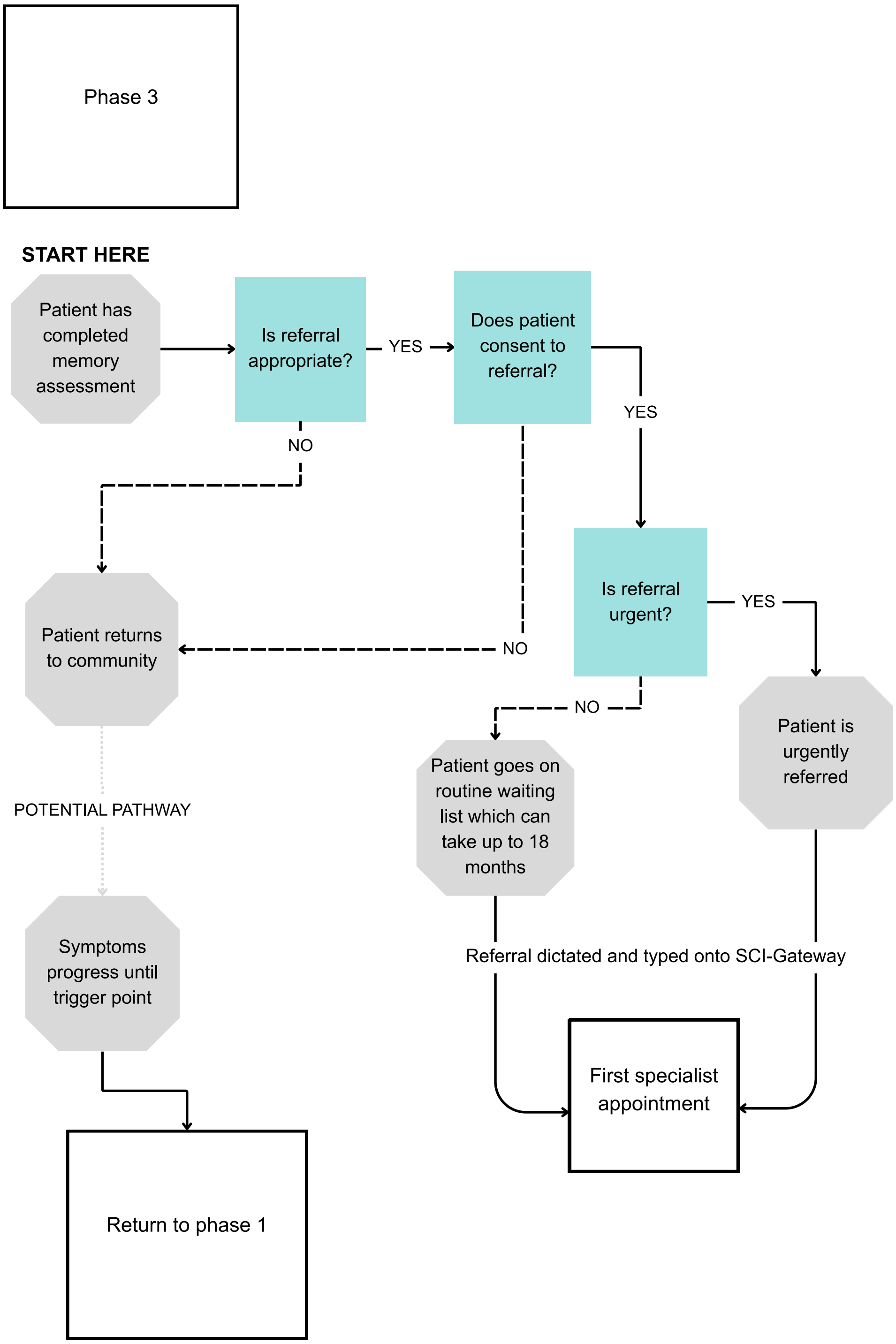


Figure 22: Practice specific process map phase 3 of 3. Made on CANVA from conversations with the practice and reviewed by clinicians within (Hamilton et al, 2025)

5.3.2 First Feedback Round: Direct Changes to the 4MT for Suitability in Practice

The first structured feedback round focused on the initial version of the 4MT presented at cluster meetings and education days. This version was patient-led, featuring written instructions on screen, 15 test trials (plus three practice trials, and no embedded feedback mechanism). Clinician raised three main concerns:

- Written instructions could confuse or overwhelm patients with lower literacy or digital confidence.
- The test length (15 trials) was incompatible with the realities of a 10–15-minute consultation.
- The absence of a structured feedback mechanism limited opportunities to capture clinician perspectives systematically.

In response, the 4MT was iteratively adapted (Table 11). The revised version adopted a clinician-led format, replacing on-screen text with a short GP script, reducing the number of trials to 10, excluding the three practice rounds, and embedding a short questionnaire at the end for structured feedback. When this version was demonstrated to the wider clinical team at the partner practice, it was broadly accepted. GPs noted that the revisions improved clarity for patients, aligned better with workflow and preserved the scientific intent of the test while enhancing feasibility.

Table 11: Adaptations to the 4MT comparison of initial version and revised version with rationale for change

Feature	**Initial Version**	**Revised Version**	**Rationale for Change**
Instruction Delivery	Written instructions on-screen	GP script delivered verbally with option to be supported for other languages by clinic translator service	Reduce confusion, improve clarity and patient reassurance
Test Length	15 trials + 3 practices	10 trials + 3 practices	Align with 10–15-minute consultation; reduce burden
Feedback Mechanism	None	Embedded clinician questionnaire	Capture usability and integration feedback

Overall Design	Independent, patient-driven test	Guided, clinician supported test	Better fit with practice workflow and relational practice

5.3.3 Second Feedback Round: Usability and System Integration

To further assess usability, clinicians completed the SUS after using the new version of the 4MT (Figure 23) which incorporated changes made by the clinicians themselves. Scores ranged from 47.5 to 100, with a mean score of 75.8, indicating above-average usability. Four out of seven respondents rated the tool within the “good-excellent” range, while two respondents reported notably lower scores (47.5 and 52.5), reflecting individual variation in perceptions of ease of use. Most clinicians reported feeling confident using the system and appreciated that it did not require technical support. Concerns did emerge centred on language complexity for patients and the potential stress induced by time-limited tasks.

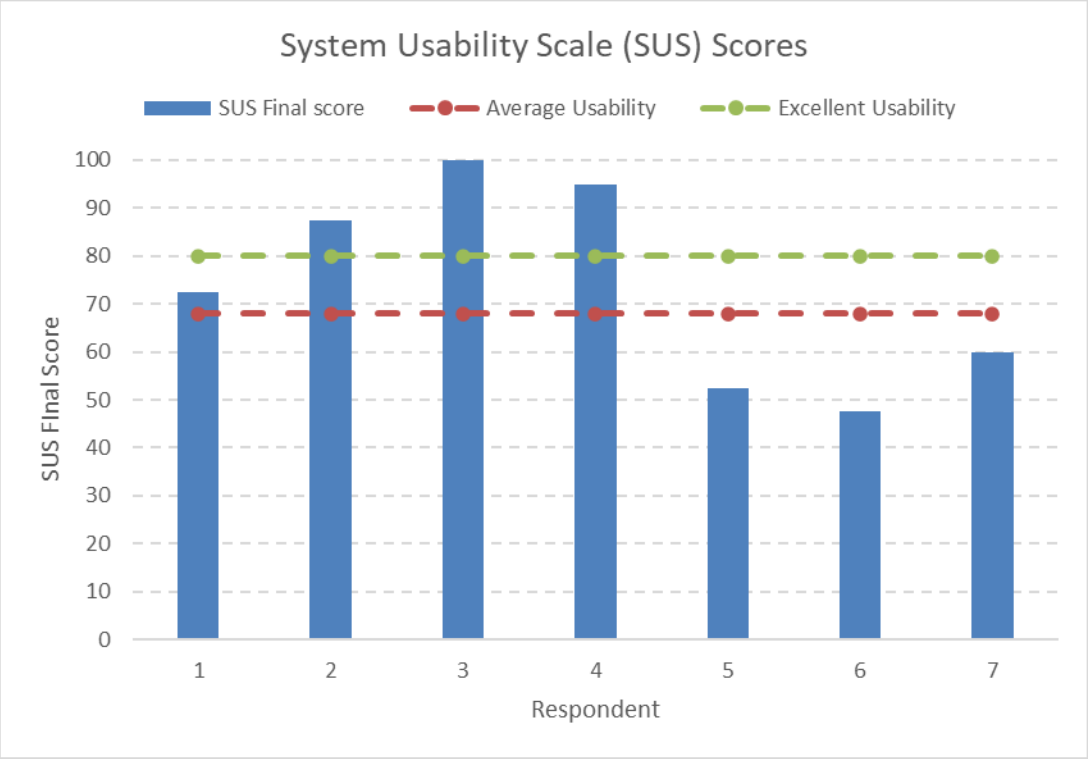


Figure 23: System Usability Scoring for the 4MT following adaptations

5.3.4 Summary

This pilot implementation of the 4MT within NHS Lanarkshire highlighted both the opportunities and practical challenges of introducing new cognitive screening tools into routine primary care. Initial demonstrations of a patient-led version revealed concerns around test length, clarity of instructions, and lack of structured feedback, which were addressed through an iterative redesign process. The revised, clinician-led version was perceived as better aligned with the realities of consultation time, patient needs, and the relational ethos of the practice.

Contextual insights underscored that the success of new tools depends not only on their diagnostic value but also on their fit within specific practice workflows and systems. Clinicians valued the 4MT's brevity and clarity but also noted the importance of integration with EHRs to support long-term adoption. Preliminary SUS scores suggested that the revised version achieved good usability, reinforcing the qualitative feedback that the tool was feasible for use in primary care.

5.4 Discussion

The pilot implementation of the 4MT offers valuable early insights into the opportunities and constraints of embedding novel cognitive assessment tools within primary care. While the full evaluation with patients lies beyond the scope of this MPhil, the iterative adaptation process and clinician feedback highlight important themes regarding usability, workflow integration and system readiness.

A key finding was the importance of co-design and iteration. The initial patient-led version, developed from the research context, was quickly judged unworkable in practice due to length, reliance on written instructions and the lack of a structured feedback mechanism. Through engagement with GPs during cluster meetings, education days, and practice-based training, the 4MT was reconfigured into a clinician-led, streamlined format with 10 test trials, a short verbal script, and an embedded questionnaire. This aligns with evidence that successful implementation of digital tools in healthcare depend not only on their diagnostic accuracy but on their ability to align with local workflows and time pressures (Greenhalgh et al., 2017). By grounding revisions in real-world clinician input, the pilot reflects human-centred design approach consistent with the principles of the EBC framework.

The findings also highlight the relational context of general practice. Clinicians emphasised that consultations are not solely technical encounters but rely heavily on reassurance, compassion and continuity. The move from a patient-led to a clinician-guided 4MT reflected this ethos, ensuring that the tool supported, rather than disrupted, the therapeutic relationship. This echoes wider critiques that many screening tools fail when they overlook the tacit, relational dimensions of primary care (Iliffe et al., 2015).

From a systems perspective, the pilot underscored the need for integration with EHRs. Conversations about documenting the 4MT in Vision and the potential use of SCIMP codes illustrate the infrastructural challenges of embedding new assessments into routine practice. While clinicians agreed to record results in free-text notes for now, the absence of a standardised coding mechanism limits data visibility, consistency and opportunities for audit. This reflects broader barriers to digital innovation in healthcare, where technical feasibility often precedes system level integration strategies (Greenhalgh and Papoutsi, 2018).

The SUS results, though preliminary, reinforce the qualitative feedback that the clinician led version of the 4MT was broadly usable and acceptable. Four out of five respondents rated the tool within the “good-excellent” range, while one respondent reported a notably lower score (52.5), reflecting individual variation in perceptions of ease of use. According to established benchmarks, SUS scores above 68 are considered above average, and scores above 80 suggest excellent usability (Bangor et al., 2009). The results therefore suggest that the 4MT, in its clinician-led form, is broadly intuitive, efficient to administer and well-integrated into the clinical context. This resonates with findings from other digital cognitive tools where clinician engagement and perceptions of ease of use strongly influence adoption (Borson et al., 2013). The combination of high perceived usability and willingness to incorporate the test into practice workflows suggest that the 4MT holds promise as a feasible option for primary care, provided further patient-facing evaluation supports its acceptability and diagnostic value.

Taken together, this pilot demonstrates that iterative, co-designed adaptation is essential when translating research-based tools into real-world practice. The work laid important groundwork for future patient-facing evaluation while also offering broader lessons on the processes and conditions required to integrate innovations within the constrained and relationally complex environment of general practice.

5.4.1 Limitations

This pilot study has several limitations that must be acknowledged. First, the evaluation was restricted to clinician-facing feedback within a single general practice and did not involve patient participants. While this provided valuable insights into usability and workflow integration, it limits the ability to assess patient acceptability, accessibility and use in practice. Future work must therefore extend to patient facing data collection to explore how the 4MT is experienced by people with suspected cognitive impairment, particularly in relation to anxiety, digital literacy and cultural or linguistic diversity.

Second, the feedback data was primarily collected through field notes and informal discussions, with only one recorded session for detailed thematic analysis. Although the iterative, co-design process was well situated to this exploratory phase, it introduces the potential for selective interpretation and limits the depth of qualitative analysis. The inclusion of SUS scores provided a structured complement, but more rigorous mixed method evaluation will be needed in subsequent stages.

Third, the study was situated within a single practice using the Vision EHR system, and findings may not be directly transferrable to practices using alternative systems such as EMIS. While discussions around SCIMP codes highlighted the importance of integration with digital infrastructure, these insights remain preliminary. Broader exploration of interoperability, coding and audit pathways will be critical for wider implementation.

Finally, the pilot was designed as a formative study and did not evaluate the diagnostic validity of the adapted 4MT in the primary care context. Establishing clinical utility in general practice will require careful comparison with established screening tools, assessment of predictive value and consideration of ethical implications for patients and carers.

5.4.2 Future Work

Future research should therefore prioritise three strands:

1. Patient-facing evaluation to assess acceptability, anxiety and diagnostic contribution.
2. System level integration studies, exploring interoperability with EHRs, coding frameworks and referral pathways.
3. Pathway aligned trials, situating the 4MT alongside post-diagnostic support to ensure that earlier detection is meaningfully linked to timely care.

By addressing these areas, future work can build on the promising indications from this pilot to evaluate the 4MT not only as a usable tool for GPs but as part of a sustainable and patient-centred diagnostic pathway.

This pilot represented the first exploration of the 4MT within Scottish general practice. By working closely with clinicians through an iterative, co-design process, the study adapted the tool from its research orientated format into a version better suited to time-limited consultations. Key adaptations included shortening the test, shifting from written on-screen instructions to a clinician-led script and embedding a structured feedback questionnaire. These changes were well received, with preliminary usability scores suggesting that the adapted version was acceptable and feasible within routine practice.

Importantly, the pilot demonstrated the value of grounding innovation in real-world system insights. Conversations with clinicians highlighted not only the strengths of the 4MT but also the practical constraints, infrastructural considerations and ethical concerns that must be addressed for meaningful implementation. While this study was limited to a single practice and clinician facing perspectives, it provides a critical foundation for the next stage of work: patient-facing evaluation and system-level integration.

Overall, this chapter has shown how a promising research tool can be translated into a clinically feasible prototype through collaboration with end-users. In doing so, it sets the stage for subsequent discussion chapter, where the findings across journey mapping, process mapping and pilot implementation will be integrated to reflect the broader implications for early dementia detection in primary care.

6. Discussion

6.1 Answering the research questions

This chapter draws together the findings from chapters three to five (Table 12), interpreting them in relation to the study's original research aims and the wider literature.

Table 12: Summary of studies conducted in the thesis

Study	Methods	Key Findings
Patient and carer perspective of the dementia journey	Qualitative, thematic analysis, semi-structured interviews and journey mapping	1. Many participants experienced cognitive assessments to not pick up symptoms until later in the disease. 2. Post-diagnostic support was extremely varied. A lot of participants received little to no support following diagnosis. 3. Participants called a central service they could speak to so that repetition was minimised.
Clinician perspectives on dementia diagnosis and digital tool implementation in primary care	Qualitative, semi-structured interviews and process mapping	1. Clinicians noted that concerns regarding memory often arise elsewhere (i.e. family, social work, pharmacy, reception staff). 2. Appointment times varied in each setting. This ranged between 10,15 and 20 minutes. 3. Most GPs noted that current cognitive tests could be improved but noted the 4MT would need further iteration for it to fit in practice.
Pilot implementation of the 4MT	Mixed-methods, qualitative (interviews, field notes) and quantitative (system usability scores)	1. Clinicians raised concerns regarding the 4MT's length and written instructions on screen. 2. Clinicians preferred a GP prescribed test to maintain the person-centred relationship in the consultation. 3. Following iterations, four out of seven clinicians rated the test within the 'good-excellent' range on the system usability scale.

This thesis explored the dementia diagnostic pathway in Scottish primary care from multiple perspectives with a specific focus on the potential role of the Four Mountains Test (4MT) as an innovative digital cognitive assessment tool for earlier Alzheimer detection. The research was guided by two overarching questions, with a short overview of findings provided for each:

Q1. How might we use systems thinking to implement a digital cognitive tool for earlier Alzheimer detection in a Scottish primary care setting?

The findings indicate that understanding the implementation of the 4MT is contingent upon alignment between clinical workflow, stakeholder engagement and system readiness. Adopting a systems thinking approach highlights how these elements are interdependent rather than discrete. GP process mapping (chapter four) revealed variability in dementia diagnostic pathways, significant time pressures on standard consultations and reliance on relational knowledge and collateral history. These factors do not operate in isolation but collectively influence when and how a new tool can be introduced into practice. These insights informed an implementation approach emphasising integration into existing appointment structures (including double appointment times where available), involvement of carers during testing to provide context and reassurance, and iterative design refinements to enhance usability and minimise patient anxiety. Preparatory pilot work (chapter five) reinforced the importance of relationship building with practices, early exposure at GP cluster meetings, and co-design with clinicians. These activities supported initial system readiness and acceptance. However, while these activities established a foundation for integration, a full evaluation in live patient pathways will be required in future research to understand how these interacting components influence sustained implementation over time.

Q2. How do clinicians and patients perceive the usability and accessibility of a digital cognitive tool, and what impact does this have on its implementation?

Clinician feedback during process mapping (chapter 4) and pilot activities (chapter 5) indicated that the 4MT was valued for its brevity, non-verbal design and potential sensitivity to early AD. SUS responses indicated that there was an overall acceptance of 4MT, with the majority scores indicating an excellent or above average usability score. Prior to iterative changes to the 4MT, clinicians were reluctant to consider adopting the tool. Patient evaluation will be considered in future works. Both the journey mapping study and process mapping study revealed that both clinicians and patient/carer end users do not think highly of current cognitive assessments, underscoring the need for this research project. Collectively, these findings provide a novel, systems level understanding of how dementia diagnosis operates in Scottish primary care, identifying actionable opportunities for the earlier detection of AD. This MPhil contributes new evidence on how digital cognitive tools such as the 4MT can be iteratively integrated into GP workflows and how systems thinking can bridge the gap between technology and implementation.

6.2 Implications for research

6.2.1 Clinical needs

Journey mapping with PLWD and carers (Chapter Three) highlighted a fragmented and inconsistent system, often reliant on personal advocacy. Carers described the emotional and logistical burden of navigating unclear referral routes, experiencing delays, and fighting for recognition of symptoms. Early signs of dementia were usually first noticed in everyday contexts rather than clinics, suggesting missed opportunities for earlier assessment. These findings are in line with existing literature on the fragmentation of services for those living with dementia (Giebel et al., 2022, Bunn et al., 2012). Additionally, PLWD and carers pointed to the need for improvement in cognitive assessment tools with many describing ‘passing the test’ despite receiving a diagnosis later down the line, this further exemplifies the need for more sensitive and specific cognitive assessment tools such as the 4MT. Process mapping with GPs (chapter four) provided a complementary view. Clinicians characterised diagnosis as adaptive and relational, drawing on tools such as the 6CIT or MoCA, collateral histories from carers, and long-term familiarity with patients. Cognitive testing was often constrained by consultation length, comorbidities and patient readiness. These findings underline systemic challenges: time limitations, reliance on relational knowledge, variation in referral thresholds, and inequities in tool accessibility for patients with language, literacy or atypical presentations. Furthermore, clinicians echoed the need for better cognitive assessments pointing to a lack of time in practice with a need for simple, accessible tests.

The presence of carers during assessments was repeatedly highlighted as beneficial, both in process mapping and in the pilot, reflecting broader evidence that collateral history and relational support enhance the accuracy of dementia assessment (Iliffe et al., 2015, Brodaty and Donkin, 2009). This suggests that any implementation of the 4MT should consider embedding opportunities for carer involvement, whether in providing contextual information or supporting patients through the test process.

Beyond technical feasibility and workflow integration, the findings underscore the ethical and psychosocial dimensions of implementing the 4MT. Early-stage adoption cannot be evaluated in isolation from the potential for unintended harm, particularly in a context of societal stigma and heightened anxiety around dementia. Implementation strategies must therefore be co-designed to include not only clinical support but also mechanisms to mitigate distress, empower patients and normalise conversations around cognitive health. The ethical dimension of early detection was also evident. While some GPs welcomed the possibility of identifying AD earlier, others expressed concern about the implications of delivering such information in the absence of disease-modifying treatments. This ethical between the clinical utility of early identification and the psychosocial implications for patients, is a recurring theme in dementia policy and practice debates (Bunn et al., 2012, Stirland et al., 2019). The 4MT may therefore be most impactful when implemented as part of a broader and well supported pathway that ensures patients receive timely follow-up, clear information and access to post-diagnostic support.

While the exploration of the 4MT was an established aim of this project, the journey and process mapping findings helped to contextualise its potential value in addressing the clinical needs for earlier detection. Clinicians, PLWD and carers pointed to gaps in current practice such as limited time and barriers linked to language or literacy. In this way, the mapping activities reinforced the rationale for piloting the tool in Scottish primary care.

This research adds to the existing evidence base by empirically mapping both patient, carer and GP experiences within the same study, offering a rare dual perspective on where diagnostic inefficiencies and inequities arise. By combining these insights, the thesis extends understanding of how relational, time and ethical constraints shape dementia diagnosis, and how this can contribute to informing meaningful design changes of digital cognitive tools.

6.2.2 Digital technology use

The 4MT emerged as a promising candidate to address several of the constraints and needs identified in Scottish primary care for the diagnosis of dementia. Its non-verbal, allocentric spatial memory task is grounded in robust neuroscientific evidence, demonstrating sensitivity to early hippocampal dysfunction, which is a hallmark of prodromal AD (Chan et al., 2016, Bird et al., 2010, Hartley et al., 2007). The tests brevity, minimal language demands and tablet-based delivery align with GP calls for tools that are both time efficient and accessible across diverse patient populations.

However, the preliminary feedback from clinicians during the pilot phase (chapter five) underscores that diagnostic potential does not automatically translate into clinical usability as qualitative feedback pointed to important refinements needed for real-world integration. Key areas included instruction clarity, interface design for patients unfamiliar with touchscreen technology and the potential stress caused by timed tasks. Clinicians noted that some patients may feel rushed or pressured, which could affect performance and engagement. These concerns are consistent with previous literature on digital health implementation in older populations, which highlights the importance of clear guidance, intuitive interfaces and minimising cognitive load during assessments (Ge et al., 2025). Importantly, the feedback in this study was not generated in a vacuum. Many of the themes raised in the pilot had already surfaced in the process mapping interviews, when GPs were first introduced to the 4MT. For example, initial concerns about patient anxiety, integration into short consultations, and the need for clinician guidance were later confirmed when the tool was used in a simulated or observed setting. This continuity illustrates the value of iterative, multi-stage engagement with end-users, which is a process central to both the EBC framework and HCD principles.

Overall, the preliminary findings suggest that the 4MT holds genuine potential as an adjunctive tool in primary care, but its adoption will depend on iterative refinement, alignment with workflow and embedding within an ethically and logistically robust pathway. The feedback from this pilot provides an actionable roadmap for these refinements for future work and reinforces the importance of sustained co-design with clinicians.

6.2.3 Systems thinking

A defining feature of this research is the continuous engagement with clinicians from the earliest stages of system mapping through to the pilot implementation of the 4MT. This process embodied a co-design and systems thinking approach, where end users acted as partners rather than passive recipients of new technologies. Process mapping provided a conceptual testing ground for the 4MT, where GPs offered initial reactions to the 4MT, surfacing concerns about patient anxiety, consultation length and the need for clinician guidance. The subsequent pilot translated these ideas into practice, allowing those concerns to be revisited in context and converted into concrete design recommendations. This progression allowed for a feedback loop in which conceptual insights were tested against practical experience, and design recommendations could be immediately captured and acted upon. The first feedback round during the pilot generated actionable design changes such as simplified instructions, a decrease in trials and a complementary script for GPs to guide patients through the process. These suggestions were in direct alignment with the EBC framework's emphasis on understanding needs, designing with users and iterating solutions (Clarkson et al., 2017). In this sense, the pilot phase functioned less as a one-off evaluation and more as a live design workshop, embedded into the realities of primary care practice. This iterative model also aligns with broader systems engineering principles in healthcare, where complex interventions are best introduced through small scale, adaptive cycles that test feasibility, surface emergent barriers and enable ongoing refinement (Carayon et al., 2014). By integrating feedback within routine practice, the thesis demonstrates how systems thinking can make digital cognitive assessment tools more implementable. Rather than treating usability as a technical issue, the research reframed it as a property of the wider care system, this MPhil therefore contributes a practical example of systems thinking in action, showing that sustained stakeholder engagement and iterative refinement are central to the successful integration of technology in primary care.

6.6 Implications for practice

The findings provide practical guidance for primary care practitioners and service managers seeking to integrate technology into clinical practice. First, early engagement and co-design with GPs is critical to align tools with workflow and consultation length. Second, embedding carer involvement during assessments can enhance contextual understanding and patient comfort. Third, iterative feedback loops between practice staff and technology developers should be institutionalised, ensuring that usability insights translate into design refinements before large-scale rollout. Finally, appointing local "champions" or linking new tools to existing quality improvement structures during cluster meetings could strengthen the pathway to implementation.

Together, these practice implications position the 4MT, as well as other tools, as feasible adjuncts to existing dementia assessment pathways when implemented through a relationship-centred and system aware approach.

6.7 Implications for policy

Although policy translation was not a primary focus of this MPhil, the findings speak directly to national priorities within the Scottish National Dementia Strategy and the Digital Health and Care Strategy. They provide early evidence to inform future policy guidance on implementing digital technology into dementia care pathways and addressing inequities in diagnostic access. By evidencing system-level barriers and co-design processes, this research lays the groundwork for policy recommendations that are both evidence-based and realistic.

6.8 Strengths and limitations

This project aimed to explore how we might leverage a systems thinking approach to implement digital cognitive tools for the earlier detection of AD in Scottish primary care. It combined patient and carer journey mapping, GP process mapping and a preparatory pilot of the 4MT. A central strength of this MPhil has been the diversity of stakeholder voices engaged across the three stages. This multi-stakeholder approach not only enriched the data but also reflected a systems thinking perspective, recognising that dementia detection and diagnosis involve a network of interconnected actors from policy through to point of care.

1. People Living with Dementia and Carers
   Through journey mapping workshops and interviews (chapter three), PLWD and carers shared detailed accounts of recognising symptoms, navigating the diagnostic process and living with the consequences of delayed or fragmented support. Their contributions grounded the research in lived experience, highlighting moments in the pathway where earlier and more accessible cognitive testing could be impactful. Carers provided insight into the practical and emotional labour involved in seeking a diagnosis and the role they play in supporting assessments.

2. Clinicians and Health Service Providers
   General practitioners (GPs) contributed both in process mapping interviews (chapter four) and in the pilot testing of the 4MT (chapter five). They offered detailed descriptions of real-world diagnostic workflows, identified practical and organisational constraints and trailed the 4MT in practice to provide usability scores and direct feedback. Practice managers and other health service staff also advised on scheduling, resource use, and operational feasibility. This group’s input directly informed tool refinements and strategies for aligning the 4MT with primary care workflows.

By weaving together these contributions, the research was able to create a holistic picture of the dementia diagnostic pathway and the potential role of the 4MT within it. The inclusion of diverse perspectives ensured that recommendations emerging from this project are both contextually grounded and reflective of the needs and priorities of those directly involved in, or affected by, dementia diagnosis in primary care.

Another strength lies in the iterative engagement with clinicians. By introducing the 4MT concept during process mapping interviews and revisiting it in the pilot context, the study enabled a continuous feedback loop, aligning with co-design and system engineering principles. This approach not only produced richer data but also generated actionable design recommendations that have already informed tool refinement. The use of field notes, semi-structured interviews and the SUS provided complementary forms of data, capturing both measurable usability perceptions of the nuanced reasoning behind them. The incorporation of EBC principles gave the work a clear system framing, helping to situate specific tool related feedback within broader considerations of pathway design and service delivery.

However, there are also important limitations. The pilot phase did not involve patient participants, meaning that the perspectives gathered reflect clinician usability and feasibility assessments only. As such, findings cannot yet speak to patient acceptability or accessibility in real-world use. Similarly, the sample sizes were modest, and the participating clinicians were drawn from practices already engaged with dementia-focused improvement work. This may have introduced a degree of positive selection bias, with feedback potentially more favourable or innovation orientated than in the broader GP population. Geographically, while recruitment covered multiple Scottish health board areas, most of the engagement occurred in contexts where existing professional relationships facilitated access. This strengthens trust and data richness but may limit the generalisability of findings to practices less familiar with the researcher or the topic area.

Finally, the scope of the MPhil stage necessarily meant that the full pilot results and patient facing evaluation were beyond the remit of this thesis. These elements will form a substantial component of future work, alongside a more formal evaluation of the 4MTs integration into the dementia diagnostic pathway.

6.9 Next Steps

Foundations established in this MPhil enable follow on studies, moving from a preparatory, clinician-focused pilot to a comprehensive mixed methods evaluation of the 4MT in primary care. For example, expanding on both the scale and scope of the research to include patient-facing trials, larger sample sizes and deeper system-level analysis. Although patient perceptions could not be directly assessed at this stage, journey mapping with PLWD and carers (chapter three) identified important accessibility considerations, including low language demands, culturally appropriate materials and supportive communication during testing. These areas should be explored directly through patient facing pilot trials in future phases.

Taken together, the findings underscore the central role of early, iterative stakeholder engagement in supporting both implementation and acceptability. They also demonstrate that usability extends beyond interface design to include the context, the relational support provided during testing, and the perceived value of the tool within the wider diagnostic pathway. Future work can build directly on the foundations established in this MPhil, moving from preparatory, clinician focused pilot work to a comprehensive, mixed-methods evaluation of the 4MT in primary care. This next stage will expand both the scale and scope of the research to include patient-facing trials, larger sample sizes and deeper system-level analysis.

Follow-on work can include:

1. Patient-facing pilot testing to evaluate the acceptability, usability and accessibility from the perspective of PLWD, those with MCI and their carers.
2. Longitudinal implementation study tracking integration of the 4MT into GP workflows, including appointment scheduling, decision-making processes, and referral patterns. Scaling up to other clinics.
3. Co-design workshops with clinicians, patients, carers and system stakeholders to refine supporting materials, training and integration pathways, ensuring alignment with person-centred and ethical principles.
4. Policy translation activities to align findings with national dementia strategies, including briefings for health boards and relevant Scottish Government working groups.

The MPhil demonstrates how a systems-informed, stakeholder engaged approach can be used to explore the implementation of digital cognitive tools within primary care. Using the 4MT as a case study, the research generated context-specific insights into the interplay between technology, clinical needs and systems thinking. It highlighted barriers, enablers and practical considerations for implementing digital cognitive assessments into routine workflows. By combining journey mapping, process mapping and pilot preparations, this MPhil demonstrates a replicable, systems informed pathway for exploring complex interventions in healthcare, which can be applied to other implementation plans for digital technology beyond cognitive assessments.

7. Conclusions

7.1 Summary of Key Findings

This thesis has explored how a systems-thinking approach can inform the implementation of digital cognitive assessment tools to support earlier detection of AD in Scottish primary care. Using the 4MT as a case study, the research examined the dementia diagnostic pathway through the perspectives of PLWD, carers and clinicians. It also identified the complex interdependencies that shape the real-world adoption of digital tools within healthcare systems.

At its core, this work demonstrates that the implementation of digital tools is not determined by the quality of the technology alone but by the system into which it is introduced. Applying a systems approach guided by the EBC framework made it possible to uncover the relationships, feedback loops and tensions that influence uptake and sustainability. The project's three empirical strands illustrated this in practice: journey mapping revealed patient and carer needs and system blind spots; process mapping captured the operational realities and pressures within primary care; and pilot preparation work identified practical enablers such as workflow fit and digital infrastructure. Together, these strands demonstrate how systems approaches can be used to anticipate and address barriers before implementation occurs.

7.2 The Integration Across Clinical Needs, Technology and Systems Thinking

The insights generated extend beyond the 4MT. They provide a transferable framework for embedding any digital cognitive tool within a complex care pathway. Specifically, the research shows that system-aware implementation requires alignment across three interconnected domains:

1. Clinical Needs - Ultimately, technology must respond to the priorities of clinical practice. In this sense, the need is to improve diagnostic accuracy, support clinicians in a time-sensitive manner and offer meaningful benefit to PLWD and their carers. This study found that digital cognitive tools are most valuable when they address clear unmet needs, compliment clinical judgement and enhance early detection in ways that are acceptable to both clinicians and patients.

2. Technology - The 4MT exemplifies how well-designed digital tools can provide ecologically valid and scalable measures of early detection suited to a primary care context. However, technology alone is not enough; usability, integration with current systems and accessibility for diverse patient groups are critical to its success.
3. Systems thinking - Health services operate as a complex adaptive system, where even small changes can ripple across the whole workflow. Systems mapping revealed that introducing a new digital assessment tool requires alignment with service structure, capacity and data sharing and protection policies. Systems thinking offers a way to anticipate the consequences of change and design for best fit within the existing care pathway.

7.3 Contributions to Knowledge and Practice

This thesis contributes to knowledge in three ways. First, it provides empirical evidence on the contextual challenges and opportunities for implementing digital cognitive assessments in primary care. Second, it demonstrates how systems thinking can be practically applied to map, analyse and guide the implementation process. Third, it establishes a model that integrates journey mapping, process mapping and pilot preparations as a cohesive approach for understanding complex interventions.

7.4 Strengths and Limitations

A key strength of this thesis lies in its integration of multiple perspectives across the dementia care pathway. The inclusion of patients, carers and clinicians allowed for a systems-level understanding that reflects the lived and professional realities of diagnostic practice. The use of visual mapping techniques supported accessibility and co-production, aligning with systems thinking principles of inclusivity and collaboration. Another strength is the focus on implementation preparedness, which bridges the gap between theoretical evaluation and real-world deployment. By engaging with clinicians early in the process, the study identified barriers and enablers that could inform future pilot testing and service design. However, limitations of this study include its exploratory scale, and its focus on a single practice for implementation. However, these boundaries allowed for depth of insight into system-specific dynamics. Future research should expand this systems-based approach to larger studies, testing generalisability across different health systems and exploring integration with EHRs, referral pathways and national dementia strategies.

7.5 Future Directions

Future research should extend this systems-based approach across larger and more diverse primary care settings to test scalability. Key questions include:

- Evaluating digital integration: how can data from cognitive assessments be linked to EHRs for continuity of care?
- Co-designing clinical pathways: how can clinicians and patients be involved in shaping workflows for implementing digital tools without adding burden?
- Exploring equity and access: how can it be ensured that digital tools are accessible across digital literacy levels, socioeconomic backgrounds and geographical contexts?
- Monitoring longitudinal impact: how does the implementation of digital tools for earlier detection influence long-term outcomes such as care planning, treatment and support, and quality of life?

7.6 Final Reflections

In conclusion, this thesis argues that sustainable implementation in healthcare depends on the alignment of systems, clinical needs and technology. Digital cognitive assessment tools like the 4MT hold significant promise for supporting the earlier detection of AD but their success hinges on system readiness rather than technological strength.

By applying a systems approach, this research has demonstrated how complex interactions across people, processes and technology can be mapped, understood and designed for. The broader significance of this work is that it provides a transferable framework for evaluating and aligning digital health technologies with existing clinical system. While the 4MT was adapted to fit current workflows, the lessons learned about system readiness, clinician needs, and patient experiences I believe apply to other digital cognitive assessments.

Ultimately, this thesis reinforces that sustainable implementation in healthcare is grounded in understanding the system, not simply in developing new technologies. By analysing how tools interact with existing workflows, resources and clinical priorities this work offers a roadmap for introducing technologies in ways that are feasible, acceptable and patient-centred: providing actionable insights for researchers, clinicians and service designers seeking to improve early detection.

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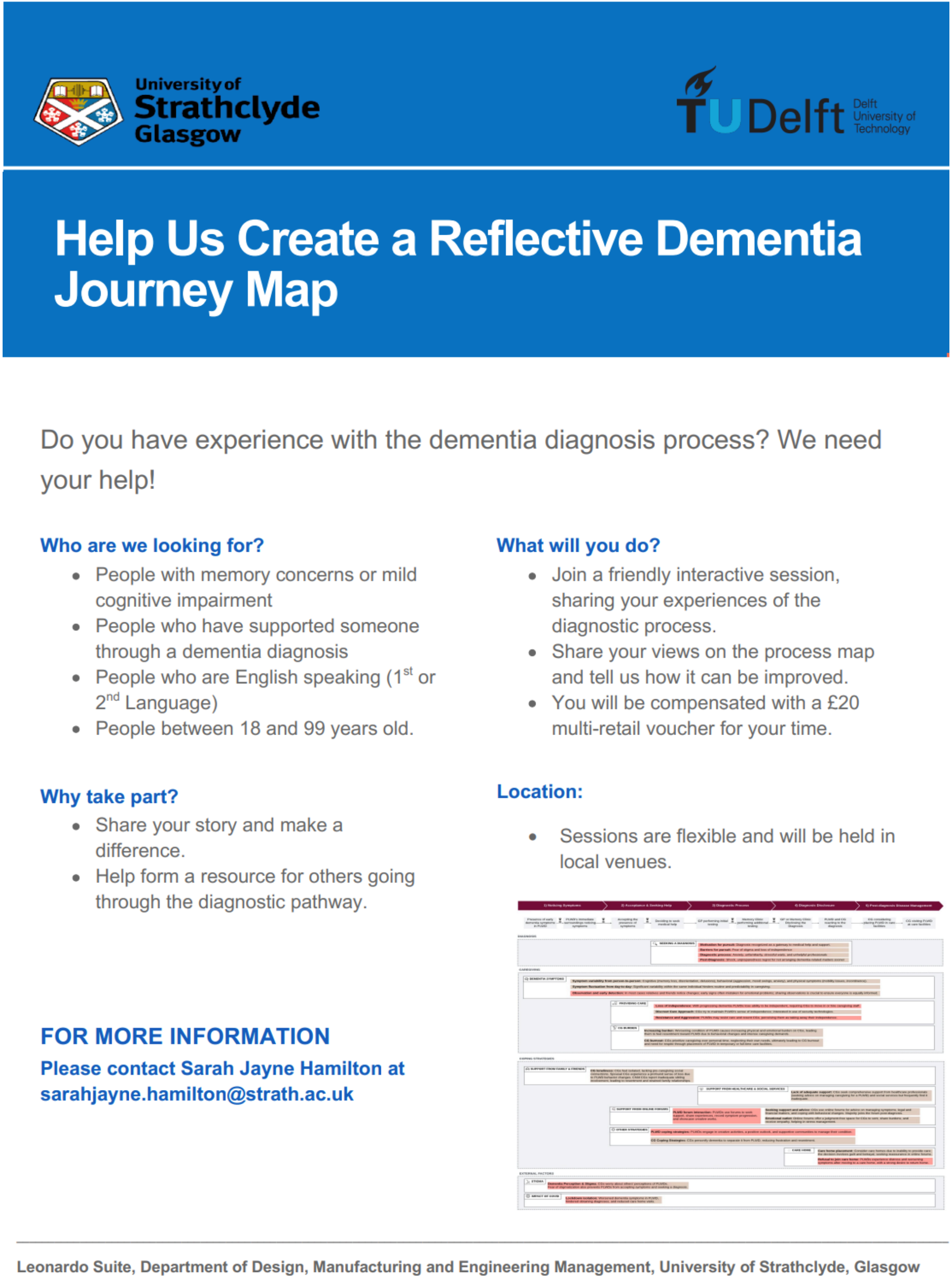
9. Appendices

A1: Flyer distributed for dementia patient journey mapping study (chapter three):



University of Strathclyde Glasgow

TU Delft Delft University of Technology

Help Us Create a Reflective Dementia Journey Map

Do you have experience with the dementia diagnosis process? We need your help!

Who are we looking for?

- People with memory concerns or mild cognitive impairment
- People who have supported someone through a dementia diagnosis
- People who are English speaking (1st or 2nd Language)
- People between 18 and 99 years old.

What will you do?

- Join a friendly interactive session, sharing your experiences of the diagnostic process.
- Share your views on the process map and tell us how it can be improved.
- You will be compensated with a £20 multi-retail voucher for your time.

Why take part?

- Share your story and make a difference.
- Help form a resource for others going through the diagnostic pathway.

Location:

- Sessions are flexible and will be held in local venues.

FOR MORE INFORMATION

Please contact Sarah Jayne Hamilton at sarahjayne.hamilton@strath.ac.uk

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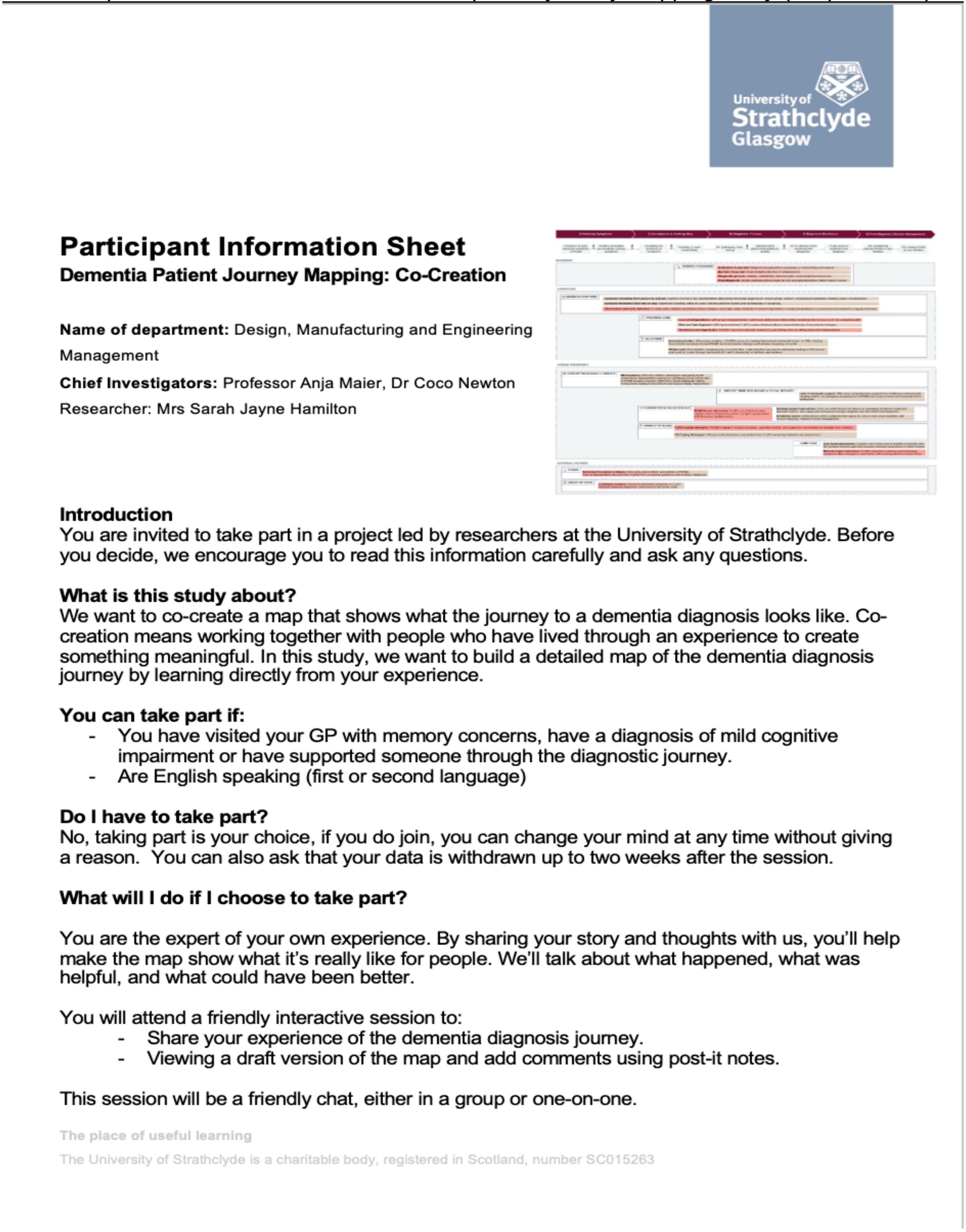
Leonardo Suite, Department of Design, Manufacturing and Engineering Management, University of Strathclyde, Glasgow

A2: Participant information sheet for dementia patient journey mapping study (chapter three):



Participant Information Sheet

Dementia Patient Journey Mapping: Co-Creation

Name of department: Design, Manufacturing and Engineering Management

Chief Investigators: Professor Anja Maier, Dr Coco Newton

Researcher: Mrs Sarah Jayne Hamilton

Introduction

You are invited to take part in a project led by researchers at the University of Strathclyde. Before you decide, we encourage you to read this information carefully and ask any questions.

What is this study about?

We want to co-create a map that shows what the journey to a dementia diagnosis looks like. Co-creation means working together with people who have lived through an experience to create something meaningful. In this study, we want to build a detailed map of the dementia diagnosis journey by learning directly from your experience.

You can take part if:

- You have visited your GP with memory concerns, have a diagnosis of mild cognitive impairment or have supported someone through the diagnostic journey.
- Are English speaking (first or second language)

Do I have to take part?

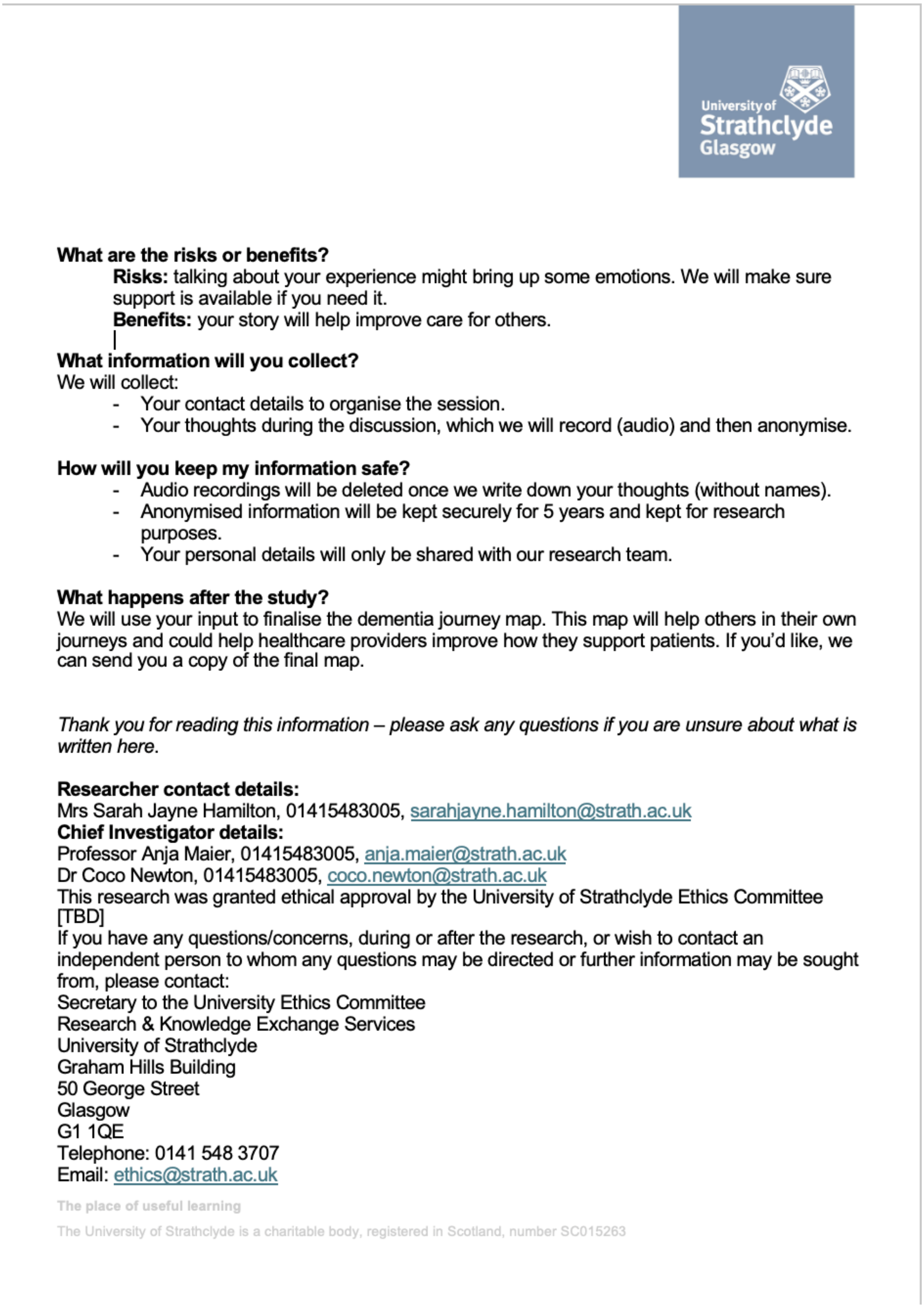
No, taking part is your choice, if you do join, you can change your mind at any time without giving a reason. You can also ask that your data is withdrawn up to two weeks after the session.

What will I do if I choose to take part?

You are the expert of your own experience. By sharing your story and thoughts with us, you'll help make the map show what it's really like for people. We'll talk about what happened, what was helpful, and what could have been better.

You will attend a friendly interactive session to:
- Share your experience of the dementia diagnosis journey.
- Viewing a draft version of the map and add comments using post-it notes.

This session will be a friendly chat, either in a group or one-on-one.



What are the risks or benefits?

Risks: talking about your experience might bring up some emotions. We will make sure support is available if you need it.

Benefits: your story will help improve care for others.

What information will you collect?

We will collect:

- Your contact details to organise the session.
- Your thoughts during the discussion, which we will record (audio) and then anonymise.

How will you keep my information safe?

- Audio recordings will be deleted once we write down your thoughts (without names).
- Anonymised information will be kept securely for 5 years and kept for research purposes.
- Your personal details will only be shared with our research team.

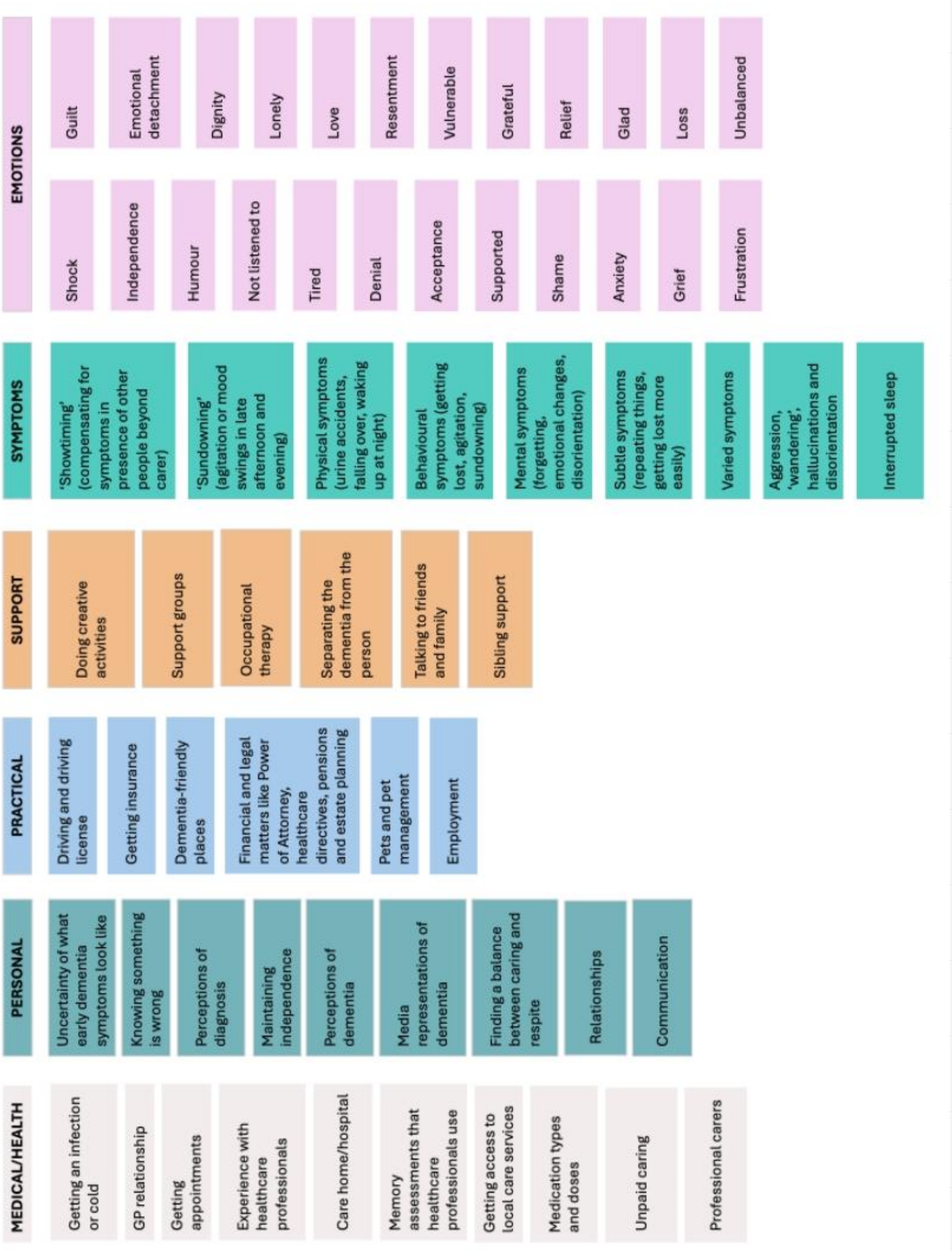
What happens after the study?

We will use your input to finalise the dementia journey map. This map will help others in their own journeys and could help healthcare providers improve how they support patients. If you'd like, we can send you a copy of the final map.

Thank you for reading this information – please ask any questions if you are unsure about what is written here.

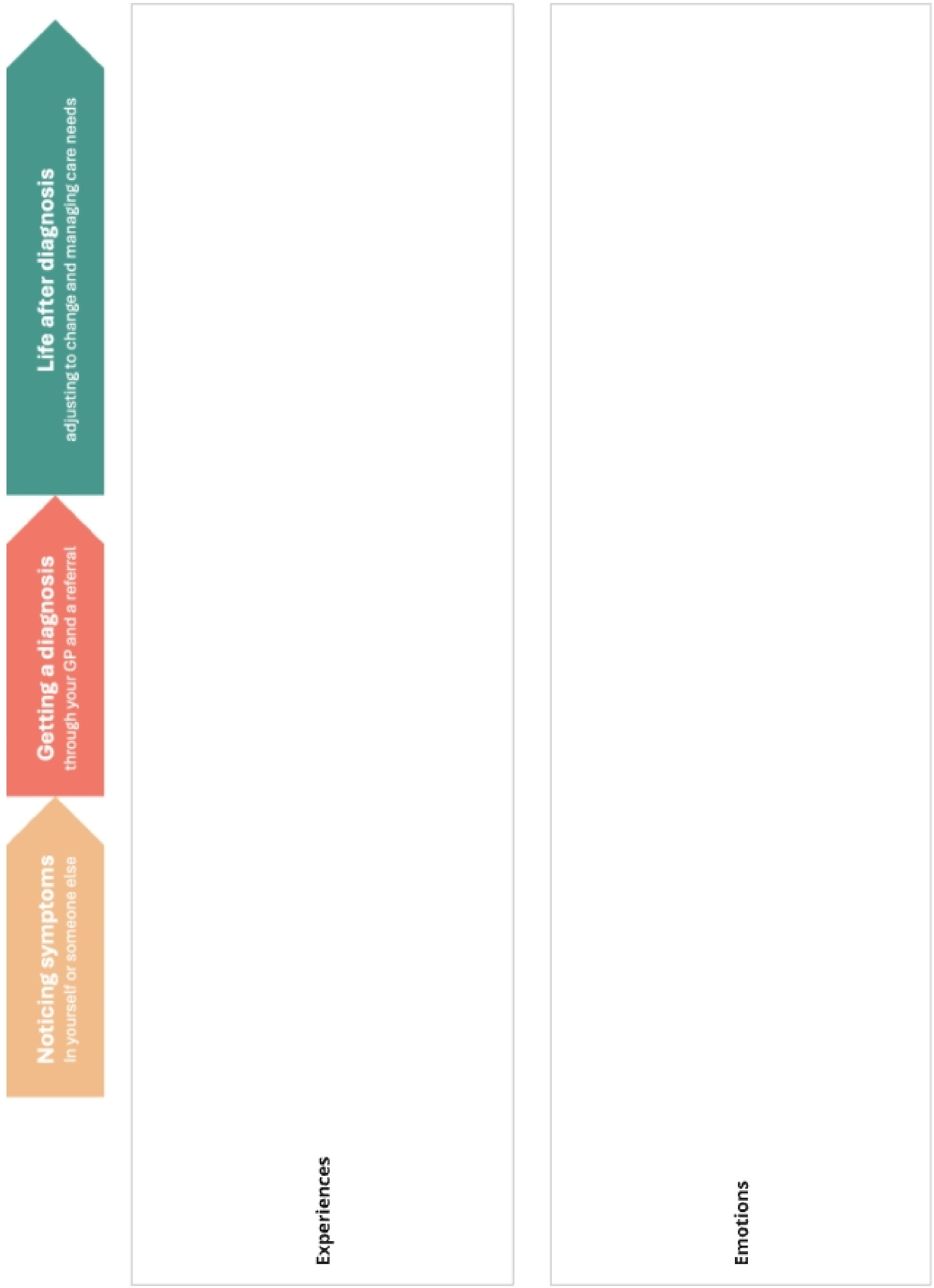
Researcher contact details:
Mrs Sarah Jayne Hamilton, 01415483005, sarahjayne.hamilton@strath.ac.uk
Chief Investigator details:
Professor Anja Maier, 01415483005, anja.maier@strath.ac.uk
Dr Coco Newton, 01415483005, coco.newton@strath.ac.uk
This research was granted ethical approval by the University of Strathclyde Ethics Committee [TBD]
If you have any questions/concerns, during or after the research, or wish to contact an independent person to whom any questions may be directed or further information may be sought from, please contact:
Secretary to the University Ethics Committee
Research & Knowledge Exchange Services
University of Strathclyde
Graham Hills Building
50 George Street
Glasgow
G1 1QE
Telephone: 0141 548 3707
Email: ethics@strath.ac.uk

A3: Topic guide used in dementia journey mapping chapter (chapter three):

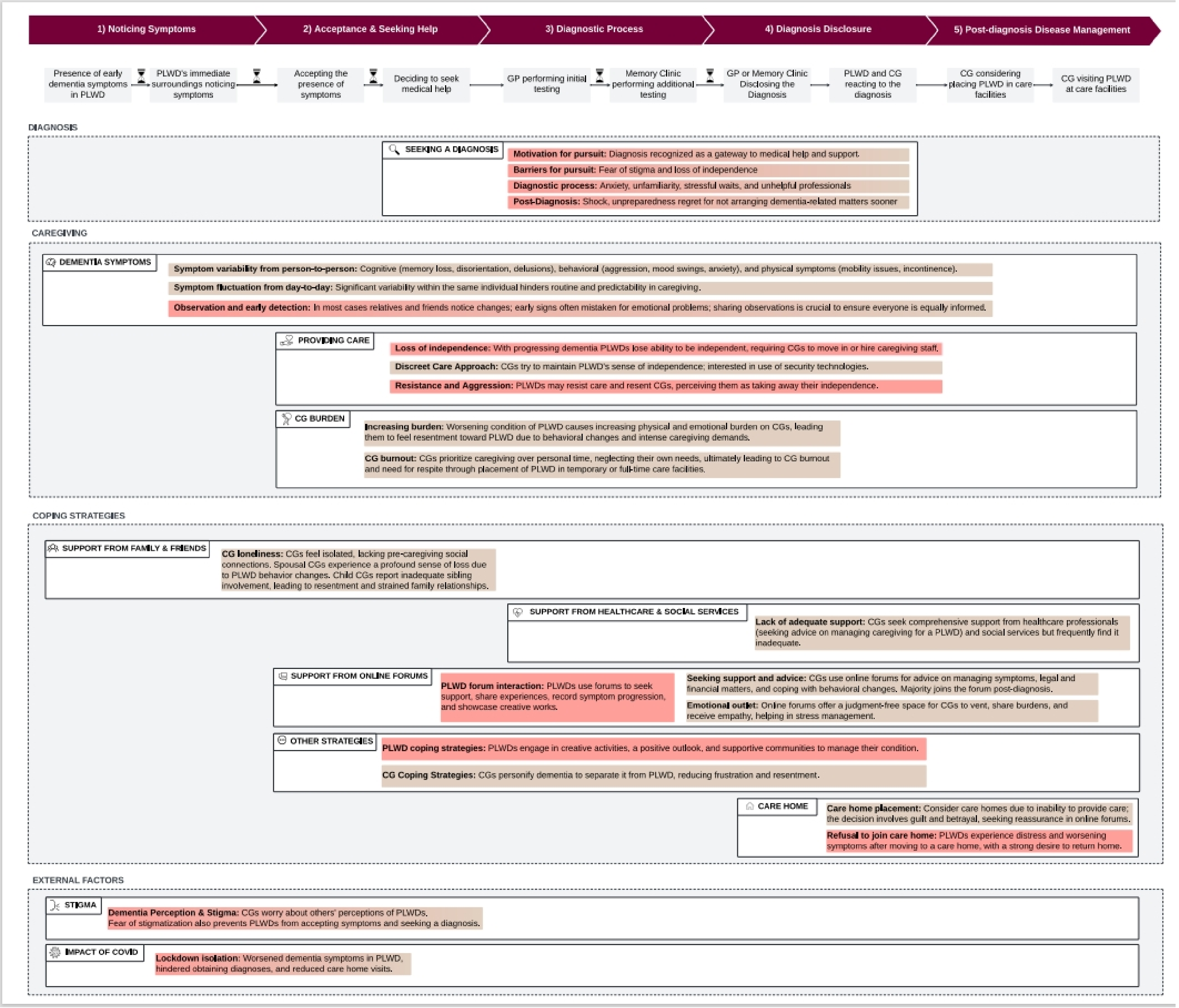


MEDICAL/HEALTH	PERSONAL	PRACTICAL	SUPPORT	SYMPTOMS	EMOTIONS	
Getting an infection or cold	Uncertainty of what early dementia symptoms look like	Driving and driving license	Doing creative activities	'Showtiming' (compensating for symptoms in presence of other people beyond carer)	Shock	Guilt
GP relationship	Knowing something is wrong	Getting insurance	Support groups	'Sundowning' (agitation or mood swings in late afternoon and evening)	Independence	Emotional detachment
Getting appointments	Perceptions of diagnosis	Dementia-friendly places	Occupational therapy	Physical symptoms (urine accidents, falling over, waking up at night)	Humour	Dignity
Experience with healthcare professionals	Maintaining independence	Financial and legal matters like Power of Attorney, healthcare directives, pensions and estate planning	Separating the dementia from the person	Behavioural symptoms (getting lost, agitation, sundowning)	Not listened to	Lonely
Care home/hospital	Perceptions of dementia	Pets and pet management	Talking to friends and family	Mental symptoms (forgetting, emotional changes, disorientation)	Tired	Love
Memory assessments that healthcare professionals use	Media representations of dementia	Employment	Sibling support	Subtle symptoms (repeating things, getting lost more easily)	Denial	Resentment
Getting access to local care services	Finding a balance between caring and respite			Varied symptoms	Acceptance	Vulnerable
Medication types and doses	Relationships			Aggression, 'wandering', hallucinations and disorientation	Supported	Grateful
Unpaid caring	Communication			Interrupted sleep	Shame	Relief
Professional carers					Anxiety	Glad
					Grief	Loss
					Frustration	Unbalanced

A4: Blank map used in chapter 3 for plotting journey topics



A5: Preliminary dementia journey map informing topic guide (chapter 3)



DIAGNOSIS

SEEKING A DIAGNOSIS

Motivation for pursuit: Diagnosis recognized as a gateway to medical help and support.

Barriers for pursuit: Fear of stigma and loss of independence

Diagnostic process: Anxiety, unfamiliarity, stressful waits, and unhelpful professionals

Post-Diagnosis: Shock, unpreparedness regret for not arranging dementia-related matters sooner

CAREGIVING

DEMENTIA SYMPTOMS

Symptom variability from person-to-person: Cognitive (memory loss, disorientation, delusions), behavioral (aggression, mood swings, anxiety), and physical symptoms (mobility issues, incontinence).

Symptom fluctuation from day-to-day: Significant variability within the same individual hinders routine and predictability in caregiving.

Observation and early detection: In most cases relatives and friends notice changes; early signs often mistaken for emotional problems; sharing observations is crucial to ensure everyone is equally informed.

PROVIDING CARE

Loss of independence: With progressing dementia PLWDs lose ability to be independent, requiring CGs to move in or hire caregiving staff.

Discreet Care Approach: CGs try to maintain PLWD's sense of independence; interested in use of security technologies.

Resistance and Aggression: PLWDs may resist care and resent CGs, perceiving them as taking away their independence.

CG BURDEN

Increasing burden: Worsening condition of PLWD causes increasing physical and emotional burden on CGs, leading them to feel resentment toward PLWD due to behavioral changes and intense caregiving demands.

CG burnout: CGs prioritize caregiving over personal time, neglecting their own needs, ultimately leading to CG burnout and need for respite through placement of PLWD in temporary or full-time care facilities.

COPING STRATEGIES

SUPPORT FROM FAMILY & FRIENDS

CG loneliness: CGs feel isolated, lacking pre-caregiving social connections. Spousal CGs experience a profound sense of loss due to PLWD behavior changes. Child CGs report inadequate sibling involvement, leading to resentment and strained family relationships.

SUPPORT FROM HEALTHCARE & SOCIAL SERVICES

Lack of adequate support: CGs seek comprehensive support from healthcare professionals (seeking advice on managing caregiving for a PLWD) and social services but frequently find it inadequate.

SUPPORT FROM ONLINE FORUMS

PLWD forum interaction: PLWDs use forums to seek support, share experiences, record symptom progression, and showcase creative works.

Seeking support and advice: CGs use online forums for advice on managing symptoms, legal and financial matters, and coping with behavioral changes. Majority joins the forum post-diagnosis.

Emotional outlet: Online forums offer a judgment-free space for CGs to vent, share burdens, and receive empathy, helping in stress management.

OTHER STRATEGIES

PLWD coping strategies: PLWDs engage in creative activities, a positive outlook, and supportive communities to manage their condition.

CG Coping Strategies: CGs personify dementia to separate it from PLWD, reducing frustration and resentment.

CARE HOME

Care home placement: Consider care homes due to inability to provide care; the decision involves guilt and betrayal, seeking reassurance in online forums.

Refusal to join care home: PLWDs experience distress and worsening symptoms after moving to a care home, with a strong desire to return home.

EXTERNAL FACTORS

STIGMA

Dementia Perception & Stigma: CGs worry about others' perceptions of PLWDs.
Fear of stigmatization also prevents PLWDs from accepting symptoms and seeking a diagnosis.

IMPACT OF COVID

Lockdown isolation: Worsened dementia symptoms in PLWD,
hindered obtaining diagnoses, and reduced care home visits.

A6: Flyer distributed as part of the process mapping study (chapter four)

University of Strathclyde Glasgow

Are you a clinician in Scotland with experience in dementia?

Take part in our research study!

Participation Involves:

A 45-minute interview about

- your processes for referring or diagnosing someone with dementia
- your views on a new digital cognitive test for dementia

Potential Benefits:

Help us improve service quality for dementia in Scotland, get involved with research, and get a £20 voucher

You Qualify If:

You are any type of clinician (current or retired) with experience of cognitive assessment, memory complaints or dementia diagnostic pathways working in Scotland

Looking For More Information?

Please contact Sarah Jayne Hamilton at
sarahjayne.hamilton@strath.ac.uk

Research project: *A Systems Approach to Implementing Digital Tools for Earlier Alzheimer Detection in Scottish Healthcare Systems*

Ethics approval: *NHS Research Ethics Committee East Midlands - Nottingham 1 (REF 24/EM/0280)*

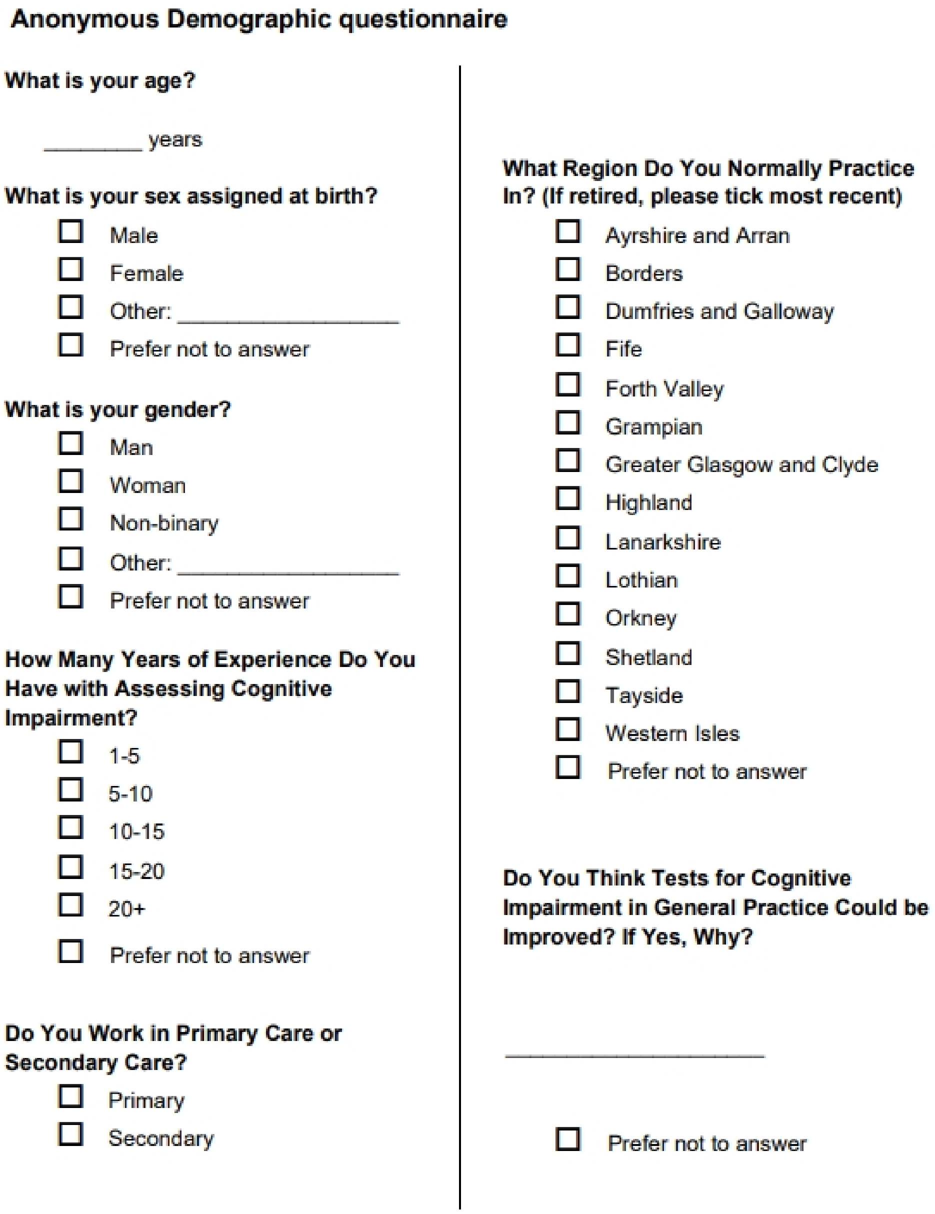
University of Cambridge

UCL

NIHR | National Institute for Health Research

Alzheimer Scotland
Action on Dementia

A7: Anonymous demographic questionnaire (chapter four)



Anonymous Demographic questionnaire

What is your age?

________ years

What is your sex assigned at birth?

- ☐ Male
- ☐ Female
- ☐ Other: __________________
- ☐ Prefer not to answer

What is your gender?

- ☐ Man
- ☐ Woman
- ☐ Non-binary
- ☐ Other: __________________
- ☐ Prefer not to answer

How Many Years of Experience Do You Have with Assessing Cognitive Impairment?

- ☐ 1-5
- ☐ 5-10
- ☐ 10-15
- ☐ 15-20
- ☐ 20+
- ☐ Prefer not to answer

Do You Work in Primary Care or Secondary Care?

- ☐ Primary
- ☐ Secondary

What Region Do You Normally Practice In? (If retired, please tick most recent)

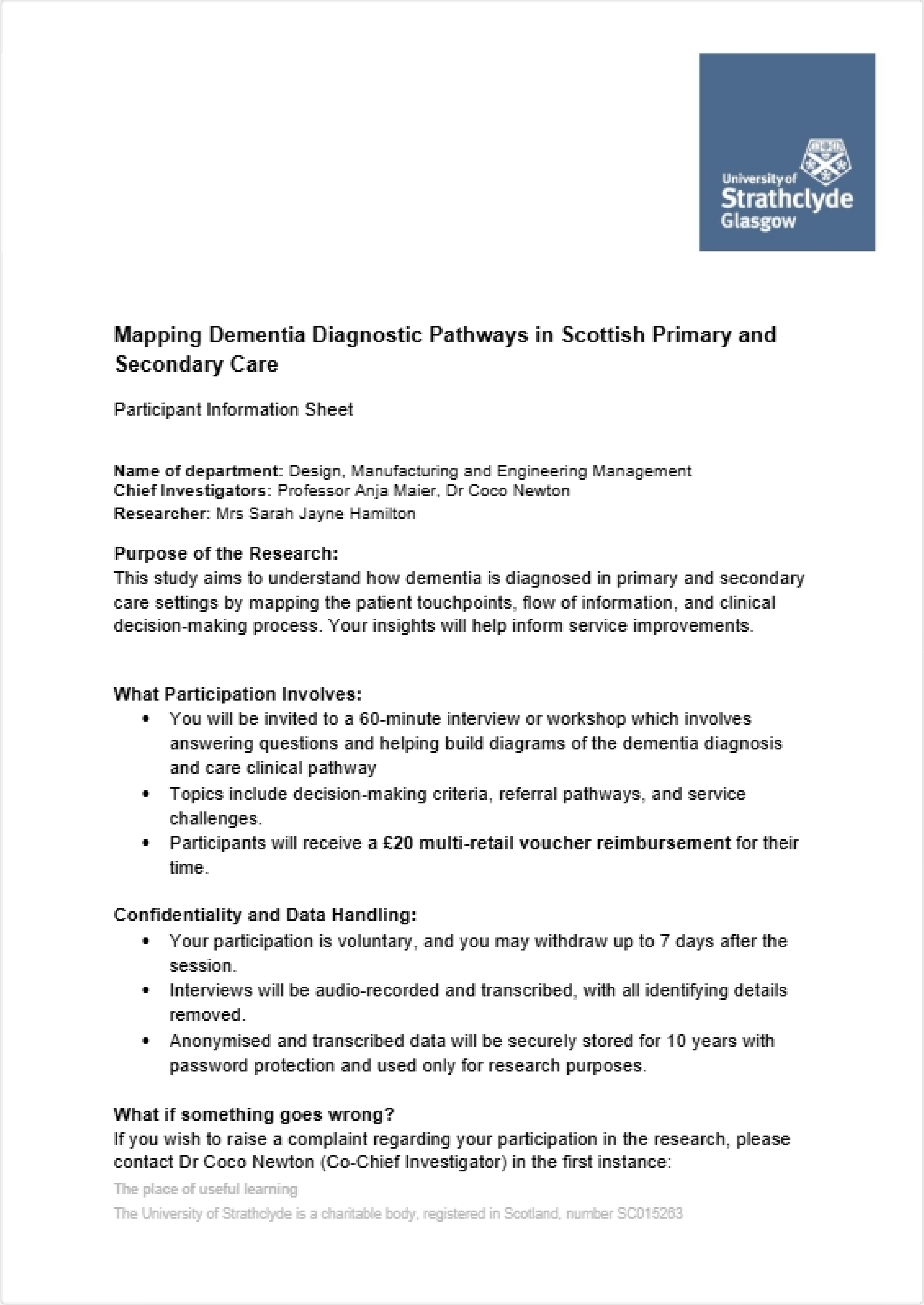
- ☐ Ayrshire and Arran
- ☐ Borders
- ☐ Dumfries and Galloway
- ☐ Fife
- ☐ Forth Valley
- ☐ Grampian
- ☐ Greater Glasgow and Clyde
- ☐ Highland
- ☐ Lanarkshire
- ☐ Lothian
- ☐ Orkney
- ☐ Shetland
- ☐ Tayside
- ☐ Western Isles
- ☐ Prefer not to answer

Do You Think Tests for Cognitive Impairment in General Practice Could be Improved? If Yes, Why?

____

- ☐ Prefer not to answer

A8: Information sheet for the process mapping study (page 1 of 2) (chapter four)



University of Strathclyde Glasgow

Mapping Dementia Diagnostic Pathways in Scottish Primary and Secondary Care

Participant Information Sheet

Name of department: Design, Manufacturing and Engineering Management
Chief Investigators: Professor Anja Maier, Dr Coco Newton
Researcher: Mrs Sarah Jayne Hamilton

Purpose of the Research:

This study aims to understand how dementia is diagnosed in primary and secondary care settings by mapping the patient touchpoints, flow of information, and clinical decision-making process. Your insights will help inform service improvements.

What Participation Involves:

- You will be invited to a 60-minute interview or workshop which involves answering questions and helping build diagrams of the dementia diagnosis and care clinical pathway
- Topics include decision-making criteria, referral pathways, and service challenges.
- Participants will receive a **£20 multi-retail voucher reimbursement** for their time.

Confidentiality and Data Handling:

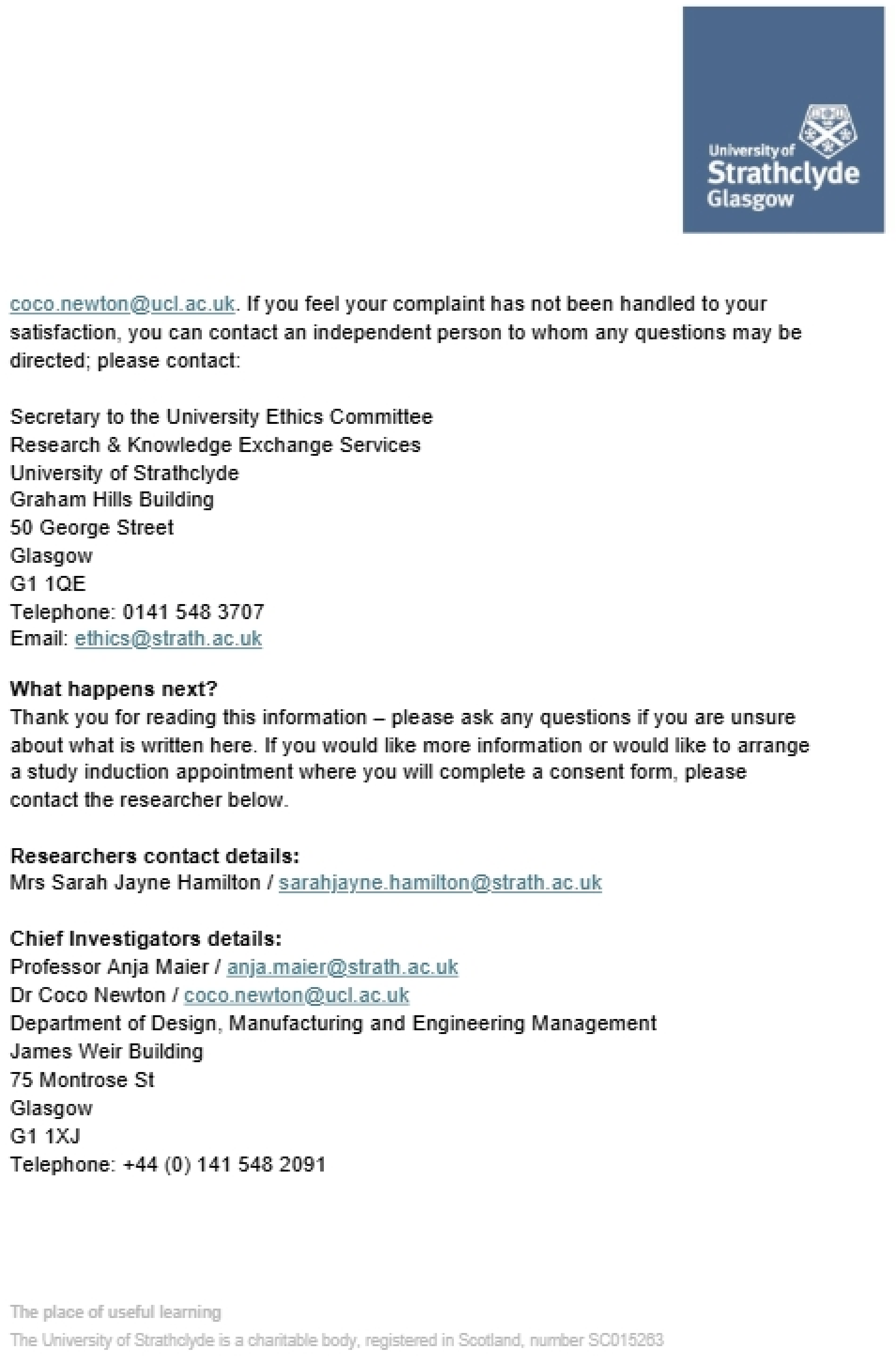
- Your participation is voluntary, and you may withdraw up to 7 days after the session.
- Interviews will be audio-recorded and transcribed, with all identifying details removed.
- Anonymised and transcribed data will be securely stored for 10 years with password protection and used only for research purposes.

What if something goes wrong?

If you wish to raise a complaint regarding your participation in the research, please contact Dr Coco Newton (Co-Chief Investigator) in the first instance:

The place of useful learning

A8: Information sheet for the process mapping study (page 2 of 2) (chapter four)



coco.newton@ucl.ac.uk. If you feel your complaint has not been handled to your satisfaction, you can contact an independent person to whom any questions may be directed; please contact:

Secretary to the University Ethics Committee
Research & Knowledge Exchange Services
University of Strathclyde
Graham Hills Building
50 George Street
Glasgow
G1 1QE
Telephone: 0141 548 3707
Email: ethics@strath.ac.uk

What happens next?
Thank you for reading this information – please ask any questions if you are unsure about what is written here. If you would like more information or would like to arrange a study induction appointment where you will complete a consent form, please contact the researcher below.

Researchers contact details:
Mrs Sarah Jayne Hamilton / sarahjayne.hamilton@strath.ac.uk

Chief Investigators details:
Professor Anja Maier / anja.maier@strath.ac.uk
Dr Coco Newton / coco.newton@ucl.ac.uk
Department of Design, Manufacturing and Engineering Management
James Weir Building
75 Montrose St
Glasgow
G1 1XJ
Telephone: +44 (0) 141 548 2091

The place of useful learning
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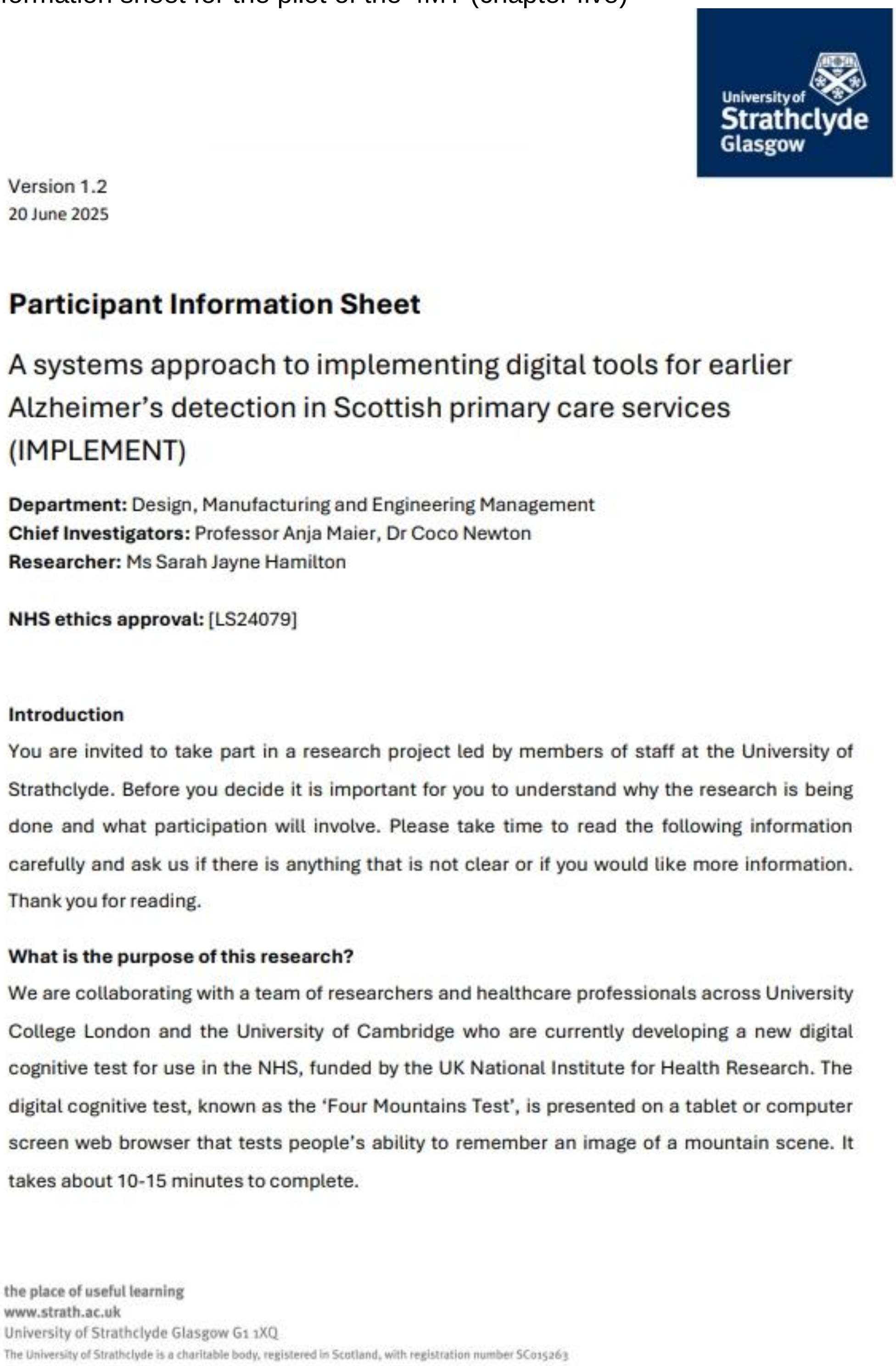
A9: Information sheet for the pilot of the 4MT (chapter five)



Version 1.2
20 June 2025

Participant Information Sheet

A systems approach to implementing digital tools for earlier Alzheimer's detection in Scottish primary care services (IMPLEMENT)

Department: Design, Manufacturing and Engineering Management
Chief Investigators: Professor Anja Maier, Dr Coco Newton
Researcher: Ms Sarah Jayne Hamilton

NHS ethics approval: [LS24079]

Introduction

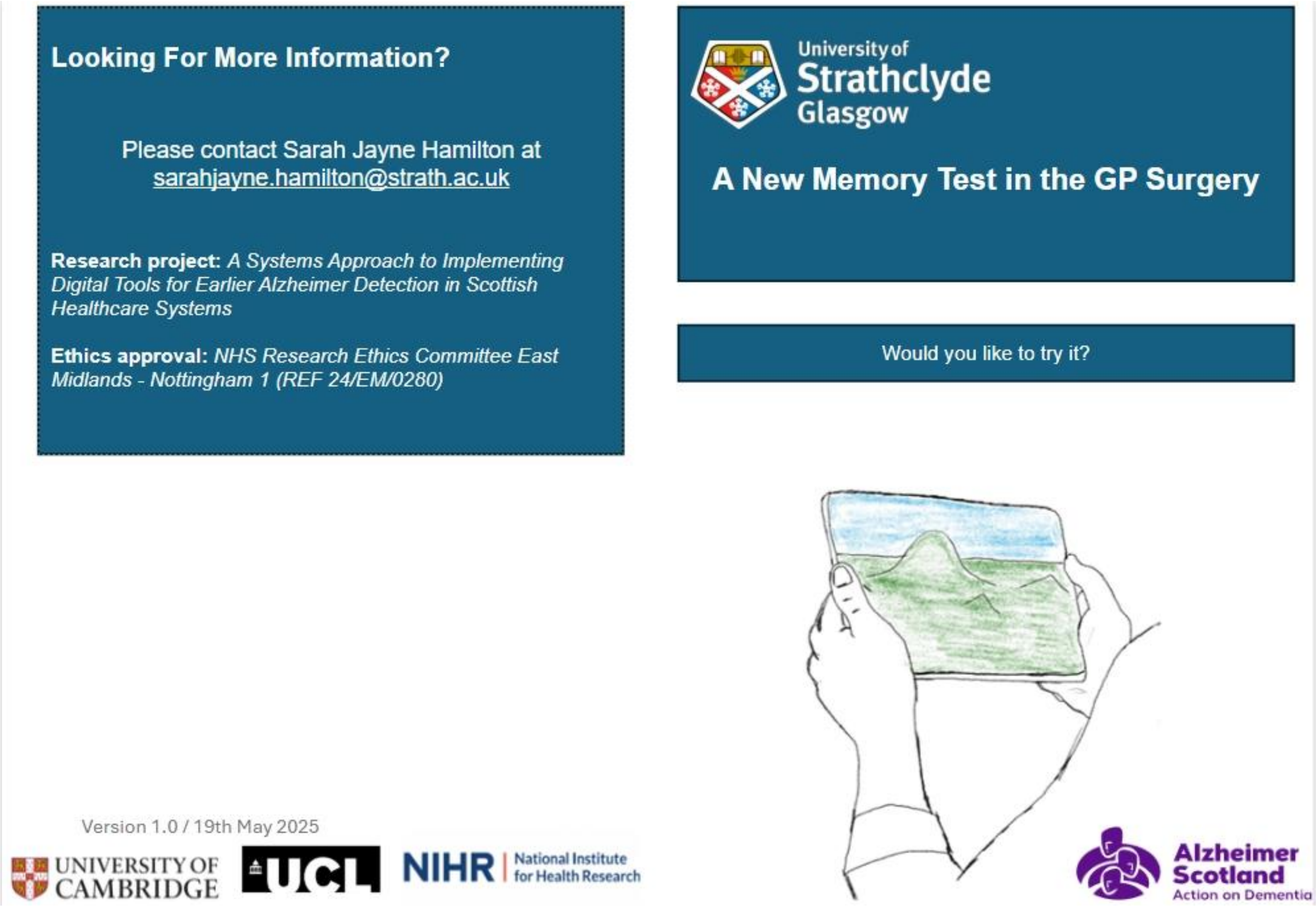
You are invited to take part in a research project led by members of staff at the University of Strathclyde. Before you decide it is important for you to understand why the research is being done and what participation will involve. Please take time to read the following information carefully and ask us if there is anything that is not clear or if you would like more information. Thank you for reading.

What is the purpose of this research?

We are collaborating with a team of researchers and healthcare professionals across University College London and the University of Cambridge who are currently developing a new digital cognitive test for use in the NHS, funded by the UK National Institute for Health Research. The digital cognitive test, known as the 'Four Mountains Test', is presented on a tablet or computer screen web browser that tests people's ability to remember an image of a mountain scene. It takes about 10-15 minutes to complete.

the place of useful learning
www.strath.ac.uk
University of Strathclyde Glasgow G1 1XQ
The University of Strathclyde is a charitable body, registered in Scotland, with registration number SC015263

A10: Flyer distributed as part of the 4MT pilot study (page 1 of 2) (chapter six)



Looking For More Information?

Please contact Sarah Jayne Hamilton at
sarahjayne.hamilton@strath.ac.uk

Research project: *A Systems Approach to Implementing Digital Tools for Earlier Alzheimer Detection in Scottish Healthcare Systems*

Ethics approval: *NHS Research Ethics Committee East Midlands - Nottingham 1 (REF 24/EM/0280)*

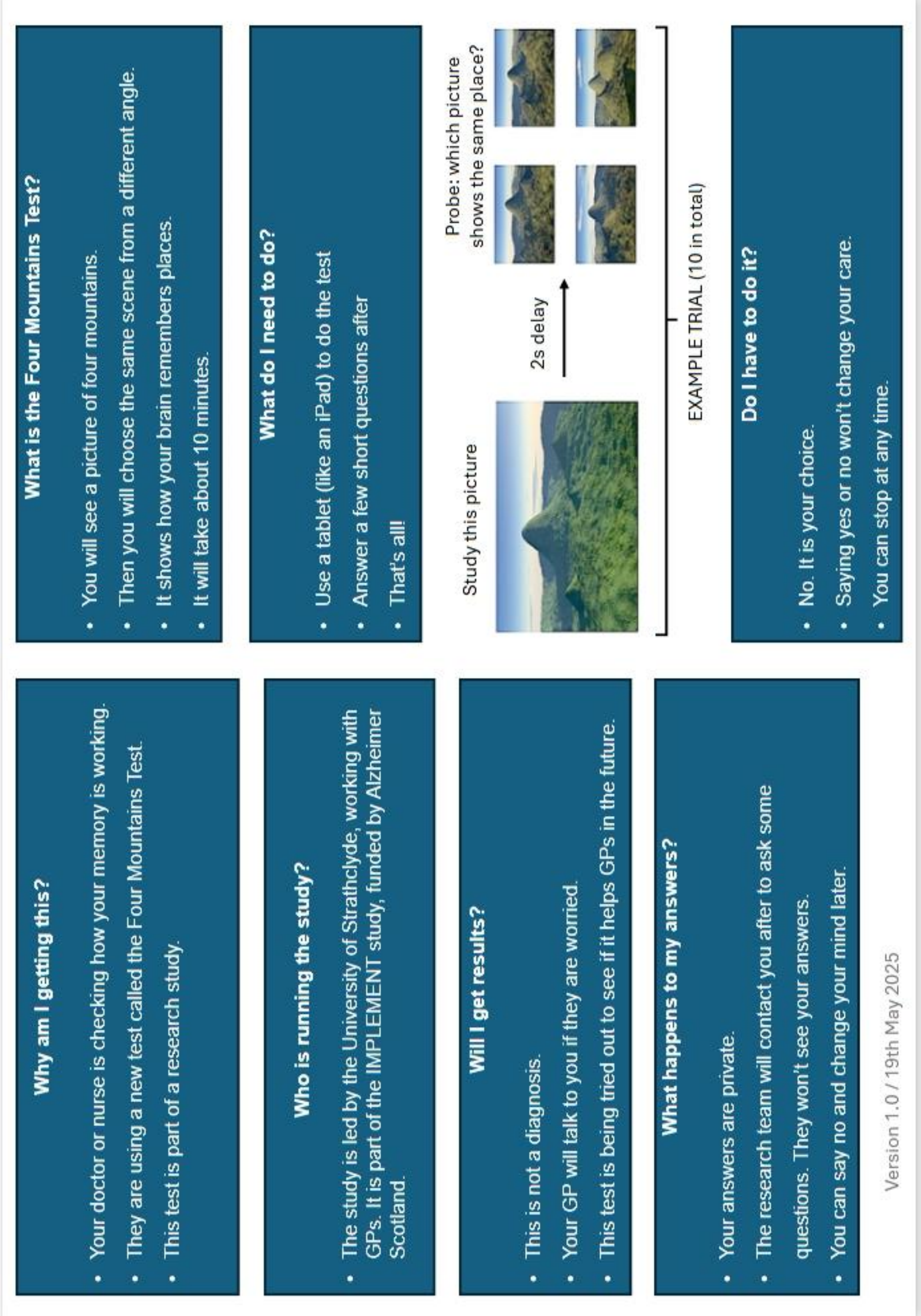
Version 1.0 / 19th May 2025

University of Strathclyde Glasgow

A New Memory Test in the GP Surgery

Would you like to try it?

A10: Flyer distributed as part of the 4MT pilot study (page 2 of 2) (chapter six)



Why am I getting this?

- Your doctor or nurse is checking how your memory is working.
- They are using a new test called the Four Mountains Test.
- This test is part of a research study.

Who is running the study?

- The study is led by the University of Strathclyde, working with GPs. It is part of the IMPLEMENT study, funded by Alzheimer Scotland.

Will I get results?

- This is not a diagnosis.
- Your GP will talk to you if they are worried.
- This test is being tried out to see if it helps GPs in the future.

What happens to my answers?

- Your answers are private.
- The research team will contact you after to ask some questions. They won't see your answers.
- You can say no and change your mind later.

Version 1.0 / 19th May 2025

What is the Four Mountains Test?

- You will see a picture of four mountains.
- Then you will choose the same scene from a different angle.
- It shows how your brain remembers places.
- It will take about 10 minutes.

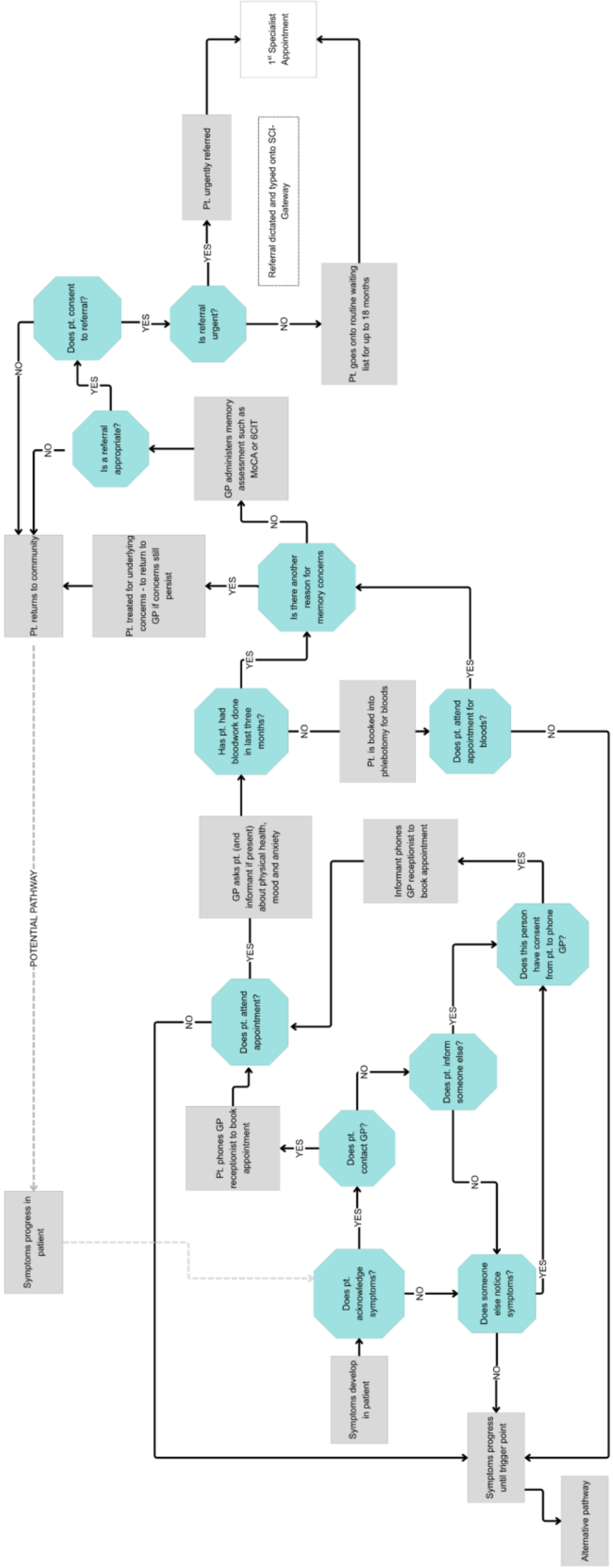
What do I need to do?

- Use a tablet (like an iPad) to do the test
- Answer a few short questions after
- That's all!

Do I have to do it?

- No. It is your choice.
- Saying yes or no won't change your care.
- You can stop at any time.

A11: Practice specific process map (full map – chapter 5)



Dementia Patient Journey Mapping: Co-Creation

Codebook

Name	Description	Sources	References
	Caregiving		
Advocacy	Caregivers often need to advocate or fight on behalf of their loved ones, whether this be in public settings or with healthcare professionals.	5	17
Coping	Caregivers can find it difficult to cope, ask for help and often use distraction techniques as a way of coping.	6	14
Difficulties	Caregivers experience difficulties such as having to accept their new role or give up the life they once lived.	6	26
I Know Something Is Wrong	The sense of knowing something is wrong.	1	4
I Lied To My Dad Everyday	Caregivers may lie to PLWD as a way of keeping the conversation in a happy tone.	1	1
Need To Protect	The desire to protect a loved one from danger, keep them free from harm and have their best interests in mind.	5	20
No Time To Feel	No time to feel	1	1
Not Having Time To Yourself	Caregiving takes up a lot of time and even going to the bathroom can be a struggle.	5	9
Offering Guidance	Signposting PLWD to help them maintain independence.	1	2
Putting On A Mask To Protect A Loved One	Dealing with difficulties privately and not sharing this with PLWD – acting as if everything is okay.	4	5
Safeguarding - 3 Steps Ahead	Thinking and planning ahead as a way of safeguarding.	1	1
Self-Care In A Caring Role	Not maintaining own health and wellbeing due to focusing on PLWD.	1	4

Name	Description	Sources	References
Splitting Yourself In Two	The feeling of having to be in multiple places at once.	2	2
Stepping Into Their World Keeps Them Calm	Caregivers describe it being useful to step into the PLWD world as they are no longer present in the current life.	2	2
Will This Happen To Me Too	The worry that it may happen to caregiver one day too.	1	1
Diagnosis Journey			
Challenging Professional Opinion	Asking for second opinions can be difficult but necessary.	1	2
Comparison Of Dementia To Other Diseases	Support and treatment for dementia is compared to other illnesses such as Cancer and Diabetes.	5	12
Description Of Dementia	How PLWD and CG describe the disease in the metaphorical sense.	2	2
Diagnosis Reaction	Reactions such as relief, shock and denial. Relief stems from now being able to access support or make sense of the symptoms.	8	16
Diagnosis Takes Time	Getting a diagnosis can be time consuming with waiting lists and not being referred on first presentation.	5	9
Diagnostic Pathways	Descriptions of the pathway such as ‘trigger point’ for seeking help and what happens en route to diagnosis such as MRI scans.	8	20
Dont Ignore The Signs	PLWD urge those with worries to seek medical advice.	1	1
Falling Through The System	Symptoms being dismissed or not being contacted when advised.	4	7
Forget Appointments	PLWD forgetting appointments, therefore delay occurs.	1	1
Genetic Links	PLWD and CG link dementia to genetics on numerous occasions.	4	11
Get Things Organised Early While I Still Can	PLWD discuss future planning while they have capacity.	1	2
Health Problems Speeding Up Illness	Decline in overall health has ‘sped up’ the dementia.	2	3
I Became Unwell Overnight	The feeling of things changing overnight.	1	1
I Could Have Been Diagnosed Earlier	PLWD discuss the possibility of earlier diagnosis if they attended GP upon first concerns.	1	1

Name	Description	Sources	References
Im Not Ready To Lose My Independence Yet	Independence is important to PLWD and they don’t feel ready to lose this.	1	1
Its Not A Diagnosis Of Death	CG discuss the apologetic response from others as if they would respond to a death.	1	1
Misdiagnosis And Delay	Incorrect diagnosis such as depression, other form of dementia, underlying health conditions masking dementia.	3	14
No Cure	PLWD discuss there is no cure.	2	4
Not Feeling Listened To	CG and PLWD do not feel listened to by their peers or health professionals.	4	13
Post Code Lottery Of Access And Support	CG and PLWD discuss variances in location for what care and support you receive. Some areas are better than others.	4	6
Symptom Recognition	Symptoms such as memory decline, bowel issues, large money withdrawals, hallucinations, loss of interest and fixation with TV or book characters.	7	52
Taking Part In Research	PLWD taking part in research studies but some are not eligible to do so.	2	3
Underlying Health Conditions	Underlying health conditions having an impact on dementia pathway as mimicking symptoms or speeding up disease.	6	11
Feelings			
Acceptance	Variance in acceptance of dementia although majority find it hard to accept.	5	11
Alienation	‘Feeling like a martian’ and being different to those around you.	3	4
Anxiety	Anxiety within CG and PLWD as a result of uncertainty.	5	14
Awareness	Lack of awareness of dementia In those experiencing it.	8	25
Confusing	Confusing pathway – things don’t make sense.	4	10
Control	Wanting to be in control of things (CG and PLWD)	2	2
Denial	Denial from PLWD that something is wrong.	4	4
Devastation	CG describe feeling devastated	1	1
Encouragement	Providing or receiving encouragement from peers	0	0

Name	Description	Sources	References
Fluctuating Emotions	Emotions are not linear, changing everyday.	2	5
Frustration And Anger	Feeling frustrated and angry with the situation.	5	22
Gratitude	Grateful to those who have provided support.	3	4
Grief And Loss	Sense of grieving the person who once was.	3	7
Guilt	Guilt stemming from initial frustrations with PLWD or due to putting family members into care.	6	9
Helpless	Not being able to do anything about it.	1	1
Home Is A Feeling	Home is not a place; it is a feeling where the individuals memories are (childhood etc)	1	2
Home Was Where Her Memories Were		1	1
Hope Of Not Being Diagnosed	Not wanting to be told it was dementia.	1	1
I Am Too Young	PLWD describe feeling too young to have this.	1	1
I Lost Hope	Losing hope as nothing is changing.	2	2
I Want To Get Better	The desire to get better instead of getting help.	1	1
It Was Horrible - Bad	Description of the experience itself.	2	3
Loneliness And Isolation	Feeling lonely and isolated from peers but also in the relationship.	5	17
Love	Still maintaining love for them.	2	5
Neglect	Feelings of neglect at the hands of healthcare professionals	2	2
Optimism	Being optimistic about the future	1	1
Overwhelming	A lot of information, a lot of change	1	1
Personhood	Maintaining personal identify and traits, dementia doesn’t define you	4	11
Relief	Relief from diagnosis, some describe relief at EOL	5	7
Resentment	Resenting what has happened	2	5

Name	Description	Sources	References
Sad And Upset	Difficult to see change in a loved one or yourself	1	1
Shock	Shocked at diagnosis	1	3
Something Inside I Cant Get Out	Quote	1	1
Stress	Stressful journey looking after PLWD	3	4
Tired - Exhausted	Tiring	4	9
Trapped	CG describe feeling trapped as they can't do simple things such as go to the shop for milk.	1	3
Trauma		1	1
Uncertainty	Uncertainty about what comes next	5	16
Unsupported	Lack of support from peers, support networks and healthcare professionals	1	2
Vulnerability	Feeling vulnerable or seeing someone else as vulnerable	2	5
Why Is This Happening	The question of why, people want to know why	3	7
Worry	Stems from uncertainty about the future	1	10
Healthcare Experiences			
Access To Care And Appointments	Where to access support but also variances in location affecting what is offered.	6	12
Bypassing The Patient To Speak To CG	CG describe professionals ignoring PLWD and not speaking to them even when they can speak for themselves.	1	1
Care Homes And Hospitals	Varied experiences with Care Homes and Hospitals – some speak highly whereas others have had very negative experiences. Choosing a care home is difficult and comes at a high cost.	6	19
Differences In Healthcare Approaches	How healthcare professionals approach cancer vs dementia – lack of empathy	2	3
GP Attendance	Attending the GP for initial concerns or new symptoms – some GPs are really informed but some CG note not feeling listened to	7	19
Increase In Care Requirements	As decline happens, there is an increase of care requirements	3	7

Name	Description	Sources	References
Medication	How PLWD manage medication varies depending on current ability. Some note frustration that no medication is available to help them.	7	19
Memory Tests	Experiences of memory tests and although passing, still showing signs of dementia.	9	28
Need For Inclusive Tests	You can pass the test and still have dementia – highly intelligent people will do better and be missed.	2	2
Previous Experience Impact On Testing	Some note that CT can be scary and thus will not have another one due to fear.	3	4
Regulation	CG notes a need for more regulation in care homes and medication goes missing	1	1
Understaffing	Places are understaffed so PLWD aren't getting what they need	2	6
	Life Adjustments And Impact		
Alcohol	No longer able to drink alcohol or alcohol negatively impacts	1	1
COVID	Impact of COVID – higher incidence of isolation for CG and PLWD – decline in available support, higher waiting times. PPE at bedside for EOL.	7	15
Decline	PLWD decline and how this impacts them and CG.	5	17
End Of Life Planning And Care	Discussions of EOL and planning in advance for this. Some experienced EOL during COVID where this was traumatic	2	3
Financial And Legal	Organizing things such as POA and Guardianship. Better to get in place early as it can take a lot of time. Looking after finances and checking insurances.	8	27
Giving Up Job	PLWD being paid off and this has been traumatic. CG having to give up job or drop hours to manage caring responsibilities.	5	9
Groundhog Day	Quote	1	1
I Just Got On With It	PLWD discuss just getting on with it as there is nothing they can do.	2	2
Incontinence	Experiencing incontinence and not knowing how to manage this.	1	2
Life Changes Completely	Quote	1	1

Name	Description	Sources	References
Lots Of Forms	Lots of forms required to be filled out – in relation to financial and legal, care homes etc.	1	1
Maintaining Independence	The desire to remain independence but gradual decline – difficult for PLWD and CG	5	10
Meaningful Activity	Doing activities such as jigsaws, crafts and wordsearches has been helpful during the journey	7	13
New Hobbies	Going to support groups and trying new things to find out you like them	1	4
Not Recognising Familiar Places	Unable to recognize home despite living there for a long time	3	3
Push Harder	The feeling of having to do more	1	1
Relationships	Emotional toll of relationships and changing roles within.	6	18
Senses	Loss of senses such as taste and smell	1	1
Sleep Disturbances	Waking up during the night / disturbed sleep	6	10
Still Doing Things You Love	Doing what you love such as listening to music	4	6
Technology	Enjoying using technology, technology as an aid, unable to use it	2	4
The 'New Self'	Takes time to adjust	1	1
The Dementia Affects All Of Us	Dementia doesn't just affect PLWD, affects the whole network (ie family, friends)	1	2
The World Becomes Smaller	The world slowly becomes refined to your own home because of safety	2	3
Time	Not having much time left	1	1
Transport Restrictions	Unable to use public transport, stopping driving, relying on others to get places	6	13
UTI	Suffering from UTIs	1	1
What Worked Then Doesnt Now	Needs change	1	1
Public Perception And Stigma			
Age Perception	Its not just something old people get and dementia isn't just old age	5	7
Attempts To Reduce Stigma	Speaking to professionals to advocate for others	1	3
Dementia Friendly Places	Places need to be more dementia friendly, places youd expect arent	1	4

Name	Description	Sources	References
Does Dementia Define You	To an extent it does define you	1	3
Having Dementia Doesnt Make You Stupid	Quote	1	3
Its Difficult To Explain Or Share	Difficult to explain symptoms or share difficulties with peers	1	3
Lack Of Understanding	No-one understands what it is like unless they have been through it	5	7
Media Representations	Mixed opinions of media, some find it should be better and say it carries negative perceptions whereas others believe media is doing a good job at raising awareness	8	11
My Family Blame Me	Quote	1	1
Not All Dementia Is The Same	Dementia varies from person to person, different types of dementia, everyones experience is different and unique	7	18
Pity	People pity those with dementia, it isn’t what we want	1	2
Police	Experiences with police due to accusations made from PLWD – trying to explain situation – most have been understanding	2	2
Sharing Own Experience	Sharing own experience can be helpful	3	5
Stigma	Lack of awareness increases stigma – ‘he’s lost his marbles’	5	13
Workplace Reactions	Losing job instead of trying to accommodate, lack of compassion	3	8
You CAN Live Well	Quote	1	1
Support			
Burden	The sense of burdening others by sharing too much or asking for too much help	1	1
Care At Home	Experiences with care at home (varies dramatically with really good and really bad experiences of carers in the home.	5	10
Community Engagement	Engaging with others in the community boosts support	3	8
Confidence From Support	Gaining confidence	1	4
Family And Friends Support	Speaking to friends and family. Family caregiving roles. Shared roles within families.	8	34

Name	Description	Sources	References
Having People You Can Relate To	Speaking to those who have been through similar is supporting.	3	3
Helplines	Using helplines for advice instead of GP so as not to be dismissed.	2	4
Peer Networks And Support Groups	Going to support groups such as Alz Scotland and doing various activities.	7	29
Pets And Animal Therapy	Awareness of calming effects of pets	1	1
Positive Clinical Relationships	Having a good GP or psychiatrist or nurse is supportive	5	12
Post Diagnostic Support	Lack of post diagnostic support	6	23
Self Education	CG and PLWD self-educating on dementia to make sense of it / try support a loved one. Many taking part in courses.	4	12
Symptoms		0	0
Behavioural Changes	Changes to behaviour such as extreme fixation or ignoring a loved one	4	8
Hallucinations	Perceiving fiction characters as family members	1	1
Personality Changes	Out of character responses, changes such as lack of hugging	3	9
Showtiming	compensating for symptoms in presence of other people beyond carer	1	2
Sundowning		2	3
Unmet Needs			
A Lot Needs To Be Done	PLWD and CG feel as though more work is needed but unsure of what	3	3
Better Support For Young Onset	Lack of support available for younger onset	2	5
Care Comes In Patches	Quote	1	3
Change Is Slow	Things are not right, the system isn’t changing quick enough	2	2
Gaps In Professional Support Network	Interactions with GP, Psychiatry, Social Work and other professionals is not joined up. Having to explain more than once. Care home managers are not available.	5	13
Having Answers Wont Make A Difference	Knowing why won’t change anything	1	1

Name	Description	Sources	References
Health Boards Are Not Aware Of Research	Taking part in research and healthcare providers being shocked by information instead of offering research opportunities	1	1
Lack Of Information For Post Diagnosis	After diagnosis, PLWD and CG feel left alone and unsure of where to turn to	7	16
Lack Of Services	Not enough facilities to look after 24/7	1	1
Not Enough Resources	Hospitals not having suitable number of bedding, towels etc	3	7
Not Getting What Youre Entitled To	Entitled to 1-year PDS but some not getting this	3	3
Not Sharing Information With Patient Or Caregiver	Going for scans and not being informed about what results are or what this means. Not including CG in conversations so things are being missed.	4	11
One Stop Shop For Support	There needs to be somewhere you can go to find everything you need.	1	1
Respite Is Not Available	Availability of respite care is not good	1	2
Signposting	Lack of signposting to help centre or informing of next steps	2	5
Untrained Staff	Staff untrained in how to deal with PLWD and their CG	3	6
We Need Support Once Things Progress More	Beyond 1-year PDS is when support is really needed as this is when things tend to get worse	1	1
You Feel Abandoned	Abandoned from support networks	1	4

COREQ (COnsolidated criteria for REporting Qualitative research) Checklist

A checklist of items that should be included in reports of qualitative research. You must report the page number in your manuscript where you consider each of the items listed in this checklist. If you have not included this information, either revise your manuscript accordingly before submitting or note N/A.

Topic	Item No.	Guide Questions/Description	Reported on Page No.
Domain 1: Research team and reflexivity			
Personal characteristics			
Interviewer/facilitator	1	Which author/s conducted the interview or focus group?	
Credentials	2	What were the researcher's credentials? E.g. PhD, MD	
Occupation	3	What was their occupation at the time of the study?	
Gender	4	Was the researcher male or female?	
Experience and training	5	What experience or training did the researcher have?	
Relationship with participants			
Relationship established	6	Was a relationship established prior to study commencement?	
Participant knowledge of the interviewer	7	What did the participants know about the researcher? e.g. personal goals, reasons for doing the research	
Interviewer characteristics	8	What characteristics were reported about the inter viewer/facilitator? e.g. Bias, assumptions, reasons and interests in the research topic	
Domain 2: Study design			
Theoretical framework			
Methodological orientation and Theory	9	What methodological orientation was stated to underpin the study? e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis	
Participant selection			
Sampling	10	How were participants selected? e.g. purposive, convenience, consecutive, snowball	
Method of approach	11	How were participants approached? e.g. face-to-face, telephone, mail, email	
Sample size	12	How many participants were in the study?	
Non-participation	13	How many people refused to participate or dropped out? Reasons?	
Setting			
Setting of data collection	14	Where was the data collected? e.g. home, clinic, workplace	
Presence of non-participants	15	Was anyone else present besides the participants and researchers?	
Description of sample	16	What are the important characteristics of the sample? e.g. demographic data, date	
Data collection			
Interview guide	17	Were questions, prompts, guides provided by the authors? Was it pilot tested?	
Repeat interviews	18	Were repeat inter views carried out? If yes, how many?	
Audio/visual recording	19	Did the research use audio or visual recording to collect the data?	
Field notes	20	Were field notes made during and/or after the inter view or focus group?	
Duration	21	What was the duration of the inter views or focus group?	
Data saturation	22	Was data saturation discussed?	
Transcripts returned	23	Were transcripts returned to participants for comment and/or	

Topic	Item No.	Guide Questions/Description	Reported on Page No.
		correction?	
Domain 3: analysis and findings			
Data analysis			
Number of data coders	24	How many data coders coded the data?	
Description of the coding tree	25	Did authors provide a description of the coding tree?	
Derivation of themes	26	Were themes identified in advance or derived from the data?	
Software	27	What software, if applicable, was used to manage the data?	
Participant checking	28	Did participants provide feedback on the findings?	
Reporting			
Quotations presented	29	Were participant quotations presented to illustrate the themes/findings? Was each quotation identified? e.g. participant number	
Data and findings consistent	30	Was there consistency between the data presented and the findings?	
Clarity of major themes	31	Were major themes clearly presented in the findings?	
Clarity of minor themes	32	Is there a description of diverse cases or discussion of minor themes?	

Developed from: Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *International Journal for Quality in Health Care*. 2007. Volume 19, Number 6: pp. 349 – 357

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Human-AI co-creation to map dementia lived experience at scale

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Human-AI co-creation to map dementia lived experience at scale

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ABSTRACT

Dementia healthcare systems must transform to meet contemporary demands. Communicating lived experience of people with dementia and carers at scale is essential to driving this. Using over one million anonymised posts from the online UK Alzheimer's Society Dementia Support Forum, we identified key experience clusters via topic modelling, large language models and content analysis. Resulting topics were corroborated and mapped onto personal timelines by people with lived experience during co-creation workshops. Through participatory synthesis we identified eleven key stages and associated challenges from symptom onset to professional care, which we visualised into a journey map. This communicates dementia as a social and systemic challenge beyond a medical condition. It also provides participant-identified opportunities for change, including diagnostic equity, carer recognition, and localised support. Our hybrid method offers an approach to engaging healthcare lived experience at scale, while the map provides an accessible communication tool to inform UK dementia policy and service design.

1 INTRODUCTION

Healthcare services for dementia currently face competing complex tensions. On the one hand, they must shift towards earlier diagnosis and prevention of dementia as new evidence emerges of disease-slowing drugs and incidence reduction through healthier lifestyles (Frisoni *et al.*, 2020; Steyaert *et al.*, 2021). But there is no consensus on what 'earlier diagnosis' means (Van Der Molen *et al.*, 2025). On the other hand, rising rates of dementia are prompting a care crisis with up to 85% of people with dementia worldwide unable to access post-diagnostic support (Gautheier *et al.*, 2022). This will only be exacerbated if systems shift towards increasing rates of earlier diagnosis.

Innovation in both health and care services is critically needed to address these tensions. Yet despite the development of medical technologies like blood tests, digital assessments or wearables capable of enhanced detection and remote assistive caring, they remain underutilized in practice (David *et al.*, 2023; Öhman *et al.*, 2021; Schindler *et al.*, 2024). This inability to integrate state-of-the-art methodologies underscores systemic issues in healthcare policy and implementation rather than a limitation in research and innovation.

Lived experience, or the knowledge acquired through first-hand involvement in clinical contexts, can help make sense of complex healthcare systems and help identify the right problems to focus policy on (Lamé *et al.*, 2023). Also known as 'PPI' (Patient and Public Involvement), lived experience inclusion in dementia research has gained momentum through initiatives such as the European Working Group of People with Dementia which have contributed to the design of clinical trial outcomes and research protocols (Dreves *et al.*, 2023; Stoeckel *et al.*, 2025). Involving patient and carer experience leads to more impactful and inclusive outcomes, with fewer practical challenges around recruitment and retention (Doyle *et al.*, 2013; Greenhalgh *et al.*, 2016; Walter *et al.*, 2025).

However, lived experience involvement has gained comparatively less traction in health service design, despite patients and carers being the only ones who experience the entire system and all services (Feldman *et al.*, 2020; Oertzen *et al.*, 2022). The most recent expert convening on dementia care pathway transformation had no lived experience representation (Snider *et al.*, 2025). Part of this may be difficulty in communicating a collective lived experience community voice to decision-makers. In dementia, qualitative study outputs frequently comprise text-only reports and case-studies on abstract themes of lived experience, working with small numbers of participants, and usually focusing on a specific dementia type or stage (e.g. Bernstein Sideman *et al.*, 2022; Campbell *et al.*, 2016; Chen and Lin, 2022; Pigott *et al.*, 2024). While these much-needed studies capture richly detailed data, and while acknowledging that no one experience is the same, decision-maker stakeholders require digestible evidence with a systemic lens to best evaluate competing factors when enacting healthcare change (O'Meara, 2024; Whitty, 2015). Lived experience evidence must be accessible and representative to be put on equal footing with clinical, operational and economic evidence (Bate and Robert, 2006).

In pursuit of this evidence gap, we drew together methods from social science, artificial intelligence (AI) and design to develop a community-level dementia journey map. Journey mapping as a method evolved from consumer service design, and now is a foremost tool used by designers for healthcare applications to facilitate a person-centred approach (Ben-Tovim *et al.*, 2008; Davies *et al.*, 2023). These diagrams visually communicate the behavioural, social and psychological factors that influence people's experiences of entire healthcare pathways, defined as the sequential interactions with clinicians, procedures and learning of new information (McCarthy *et al.*, 2016).

To identify a collective voice, we leveraged a data-enabled approach using topic modelling of online text in the UK Alzheimer's Society (AS) Dementia Support Forum, one of the largest globally with over two million posts and 100,000 users. Online support forums offer an accessible public community messaging space to exchange experiences, form friendships, share advice and seek solace, especially around dementia (Tahami Monfared *et al.*, 2022). Given the wealth of freely volunteered experience available within forums, unbiased by researcher interview guiding questions and less labour-intensive to acquire, these data are increasingly valued for generating new behavioural insights (Feuerriegel, 2025), especially for patient-centred healthcare innovation (Bourgeois and Kleinsmann, 2023). After identifying key topics within the AS forum, we worked together with lived experience volunteers - both unpaid carers and people with dementia – to validate and map these topics into a community journey map (Jung *et al.*, 2023). We show that AI-based modelling of online forum data can provide trustworthy community-level insights into dementia healthcare experiences and behaviours, while co-creation mapping workshops with lived experience volunteers can help craft these insights into an accessible communication tool to identify pressing healthcare system needs.

2 METHODS

This study involved a mixed method explanatory sequential design, with (i) quantitative topic modelling of data sourced from the online Alzheimer's Society Dementia Support Forum (Figure 1A); (ii) interpretive qualitative analyses of outputs from co-creation workshops using these topics (Figure 1B); and (iii) visualisation of the qualitative findings into a community journey map with respondent validation (Figure 1C).

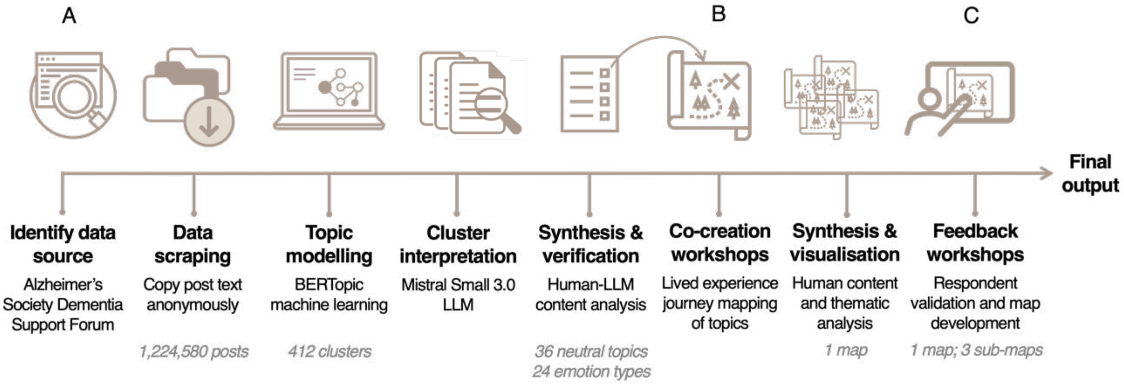


Figure 1. *Overview of method. A: analysing Alzheimer's Society Dementia Support Forum key clusters of discussed experience. B: lived experience co-creation workshops involving mapping of forum topics into personal journey diagrams which we synthesised into one single community map. C. Respondent validation and development of the final community maps. LLM = large language modelling.*

A representative from the Alzheimer's Society and all workshop participants gave written informed consent to take part in the study, and data was collected in accordance with the Declaration of Helsinki and British Psychological Association guidelines for internet mediated research (The British Psychological Society, 2021). Methods are reported according to the COREQ (COnsolidated criteria for REporting Qualitative research) guidelines (Tong *et al.*, 2007) and followed recommendations for transparent, rigorous and reproducible use of natural language processing for behavioural science (Feuerriegel, 2025). Ethical approval for the work was granted both by the Technical University of Delft Human Research Ethics Committee (ref. 3969) and University of Strathclyde Ethics Committee (ref. UEC24/94) where the research was sponsored.

2.1 Research team positionality statement

Our qualitative approach was guided by a constructivist epistemology, which assumes that meaning is socially constructed and co-produced through researcher-participant interpretation (Guba and Lincoln, 1994). We therefore describe aspects of our backgrounds, assumptions and research design that could influence the analytic process. The research team ranged from having minimal to extensive personal lived experience of dementia, either as family members or carers, but none as clinicians. We shared decision-making of the protocol design and co-produced the study materials with someone living with dementia (MB). Several researchers had extensive prior knowledge of dementia through previous research studies or employment as a professional carer (SJH, NB, MRA, AM, CN). Researchers carrying out data analysis (SJH, NB, HV, VN, RF, MAR, CN) individually had backgrounds in clinical cognitive neuroscience, psychology and counselling, user experience design, computer science and human-computer interaction. In addition, a pilot of this study was carried out as part of a Master's project in industrial design engineering (NB), which involved a background literature review and topic modelling on a subset of the forum. These perspectives and background knowledge will have contributed an interdisciplinary and background-literature informed lens to the data interpretation, and researchers with caring experience may have been more sensitive to themes around this.

2.2 Topic identification

Data source and preparation

We used the UK Alzheimer's Society Dementia Support Forum due to the large number of messages dating back to 2003 (permitting machine learning analysis approaches), the type of users (people living with dementia, carers or family members), and English language content about experiences of dementia. The website was structured into five forum categories (e.g. 'Support from other members'; 'Information and resources'), each with individual sub-forums that altogether totalled 26 (e.g. 'I have dementia'; 'Memory concerns and seeking a diagnosis'). Inside each sub-forum were discussion threads. A discussion thread comprised an initiating post by one member to which other members replied via individual posts. Some threads had no replies, and some had over 100. Post lengths ranged from single words to several paragraphs. We used all sub-forums apart from two dedicated to general Alzheimer's Society information and news. Text was retrieved and relevant data extracted as csv files on 22 January 2025 using Python v3.13.1 with the library BeautifulSoup4 version 4.12.3 (see final list and subforum sizes in Table SX). All code for this project is available at https://github.com/glarajung/PatientX.AI.

Topic modelling and interpretation

We performed topic modelling using the unsupervised machine learning framework BERTopic (Bidirectional Encoder Representations from Transformers), which cleaned text and clustered topics in the forum (Grootendorst, 2022). This is a popular customisable method for exploratory content analysis of large datasets as it leverages transformer-based embeddings to capture semantic and contextual meaning of words. These representations allow for more effective handling of short, informal, and slang-filled text and allows the model to capture nuance in forum posts. Embeddings-based methods overcome limitations in other approaches such as Latent Dirichlet Allocation which use a bag-of-words probabilistic model to analyse word co-occurrence pattens, which although more interpretable, are less meaningful as word order and context is disregarded (Feuerriegel, 2025). BERTopic is also more usable as an end-to-end framework which doesn’t require a pre-set number of topics to search for, or extensive preprocessing, as the embeddings inherently account for stopwords and syntax. All analysis was performed using Python version 3.13.0.

Our BERTopic model was partially customised, consisting of a specialised medical and health domain sentence-transformer for generating vector embeddings which was pre-trained on articles from PubMed and fine-tuned on the MS-MACRO dataset (Deka *et al.*, 2022). This encodes posts to a 768-dimensial dense vector space. In addition, we used the SpaCy count vectoriser to remove standard English stop words in addition to some custom stop words identified from early results piloting (see SX.X). We then ran default recommended Unified Manifold Approximation and Projection dimensionality reduction and Hierarchical Density-Based Spatial Clustering of Applications with Noise clustering algorithms. Finally, we used a multi-step process for interpreting these clusters, firstly consisting of C-TF-IDF scores for establishing the representativeness of keywords per topic cluster and to de-emphasize frequent but less specific words. Subsequently, with the Mistral Small 3.0 large-language model (LLM), we interpreted the meaning of each cluster post-hoc using few-shot prompting. We provided a context prompt: "*I am sending you a lot of scraped text from a forum online. Once I am done sending chunks, you will summarize everything I sent. After each chunk tell me you receive it and track how many I sent you*". Per cluster, we then provided an instruction prompt: "*Here are documents:* [insert top ten associated posts per cluster as free text]. *The topic is described by the following keywords:* [insert cluster keywords]. *I need you to write 'The topic is:' then print a short description of the documents in markdown format*".

Topic synthesis

We synthesised these interpreted clusters using a combination of the Mistral Small 3.0 LLM and manual researcher analysis. We selected Mistral Small due to it being open-source and more computationally efficient relative to other models in its category (Mistral Small AI Team, 2025). Two researchers (CN, SJH) read all cluster descriptions and the top ten associated forum posts, and removed clusters appearing non-sensical or highly specific (e.g. clusters of forum posts defined by users thanking each other, or defined by conversations repeatedly involving specific usernames). This filtered cluster set (including both the cluster descriptions and top ten associated posts) was provided altogether to the LLM as a single csv file with the prompt: "*I'm giving you a spreadsheet with clusters of text from an online dementia support forum. The clusters were generated using BERTopic. The columns give you the top keywords per cluster and the top 10 associated posts from the forum. Please summarise the themes that all the different clusters cover, with detailed descriptions of each*". This outputted seven major themes with bullet point content descriptions (see SX.X). The two same researchers decomposed these chunks of text into sentiment-neural topic categories using three iterations of inductive manifest content analysis, which involved a process of divergent open coding at the surface level of the text, synthesis through active discussion, and constant comparison to the original set of BERTopic-derived clusters to achieve a broad set of topics reflected across the forum (see Figure 2). This process was repeated to separately identify all the types of decontextualised sentiments expressed, with the prompt instead being to list all the types of emotions mentioned in the document. If some topics or emotions were missing from the synthesised list but present in the original cluster set, we included them in the final topic set. We validated this final topic set with lived experience feedback (MB) to ensure completeness and appropriate language use before progressing to the co-creation workshops.

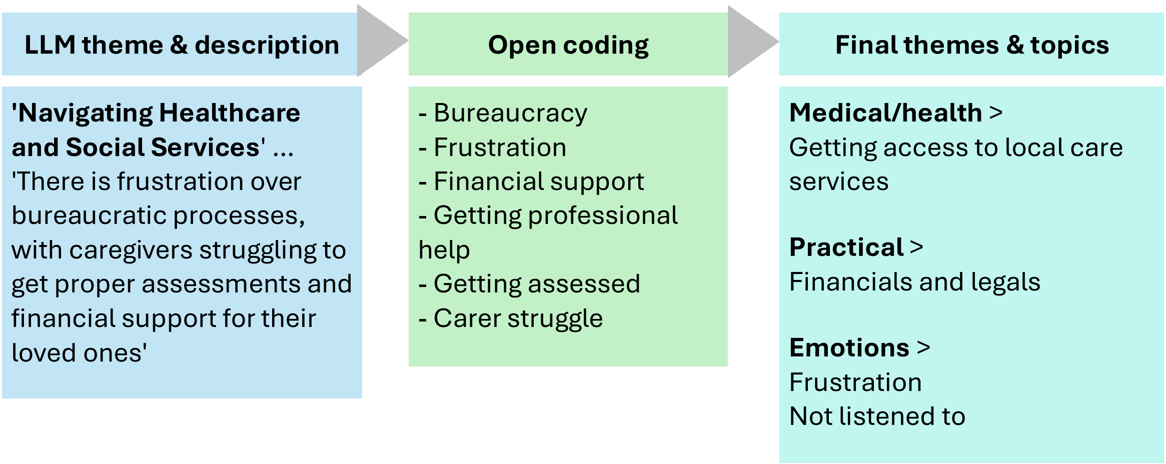


Figure 2. *Example synthesis of an LLM theme and section of emotionally-biased content description into neutral categories and topics. Categories emerged inductively across all themes and content descriptions generated by the LLM.*

Robustness checks

First, we experimented with different topic modelling approaches (Latent Direct Allocation vs BERTopic) as described above, as well as different tailorable parts of the BERTopic framework (see discussion of these outputs online here). Secondly, we repeated our finalised BERTopic modelling and LLM interpretation framework with different minimum thresholds of cluster sizes (n=50, 100 and 200 documents) to check that the results remained qualitatively consistent. Final results are reported using clusters with minimum n=100 documents which yielded the optimum balance of topic number and nuanced insight. Thirdly, in a pilot validation analysis, a researcher randomly selected 500 forum posts and performed manual manifest content analysis until code saturation was achieved, which occurred at around 100 posts (for more detail, see (Bodnárová, 2024)). The resulting code themes validated many of the LLM interpreted topics, except for two uniquely researcher derived themes around the impact of COVID and the benefits of interacting with the forum. Finally, we experimented with different types of LLM prompting, comparing the default Mistral-small LLM prompt with more tailored descriptive prompts including context of the study aims and design. The outputs were qualitatively consistent, and we opted for the default prompting to enhance reproducibility.

2.3 Co-creation workshops

We used co-creation as a collaborative and iterative process of knowledge construction, in which people living with dementia and carers contributed to data generation, analysis and results communication. This aligns with serveral defined types of co-creation such as co-production and knowledge/value co-creation (Greenhalgh *et al.*, 2016), whilst also drawing on principles of experience-based co-design to ensure an authentic final output (Bate and Robert, 2006).

Participants

Participants were invited to participate in co-creation workshops via convenience sampling, using adverts placed online on Join Dementia Research and emails to local care groups and dementia-focused organisations around Glasgow and London. These sites were chosen based on researcher location, and more than one site was included to increase participant regional diversity of experience. The purpose of the workshop was described as an opportunity to share personal experiences with researchers. Inclusion criteria included English-speaking (first or non-first language) adults who had either visited their GP with memory concerns, had a diagnosis of mild cognitive impairment or mild dementia, or had supported someone through their diagnostic journey. We excluded one person who had memory complaints but had not yet sought clinical help. Our sample size reflected the maximum feasible recruitment within the available timeframe, aligned with our aim of achieving representative corroboration of forum-derived topics through a novel methodological approach (Malterud *et al.*, 2016).

Overall, 22 individual participants and three care organisations responded to our invitations. A total of 59 people completed the co-creation workshops (Table 1). Not all participants that expressed interest took part due to our analysis reaching data saturation and 8 participants not responding to scheduling emails. In two workshops involving people with dementia, one was terminated early because participants realised they found it too difficult to discuss their experiences, and in another, three participants from the group refused to take part because they did not want to be identified as having a dementia diagnosis. These participants were withdrawn from the study.

Table 1. *Overview of co-creation participant demographics*

	Glasgow (n=14)	**London (n=45)**	**Total (n=59)**
	n	**n**	**n (%)**
Carers	11	31	42 (71%)
People living with dementia	3	14	17 (29%)
Female	10	36	46 (78%)

White *(White British or any other White background)*	14	34	48 (81%)
Black *(Black British, or any other Black background)*	0	2	2 (3%)
Asian *(British Asian or any other Asian background)*	0	8	8 (14%)
Other Ethnic Group *(Arab, mixed ethnic, or any other background)*	0	1	1 (2%)

For participants living with dementia, capacity to consent was determined through a 'teach back' evaluation at the start of the workshop, where researchers checked that participants could comfortably answer questions about the study purpose and aims. In most cases, carers accompanying participants with dementia helped to confirm capacity. Only one participant was known to researchers prior to study start through previous meetings at Alzheimer Scotland events. Apart from three of the group workshops in London held within local carer support organisations, no participants knew each other prior to study start.

Setting

Co-creation workshops were conducted both online via Microsoft Teams or in-person at either the University of Strathclyde Living Lab, Alzheimer Scotland Glasgow offices, or at three local care organisations in Greater London. The choice of online or in-person depended on participant preference and group size. Participant numbers per workshop varied from 1 to 18. Two researchers were present per workshop (CN with either SJH or MRA; all female with formal qualitative training and lived experience of dementia). For two of the in-person group workshops at local care organisations, between 2-4 of their professional carers also helped to facilitate the workshops. Audio recording with a Dictaphone or in-built Teams software was used for all online workshops and for in-person workshops with one or two participants in Glasgow. Large group workshops were not audio recorded. Each workshop lasted around an hour, and participants were reimbursed for their time with a £20 multi-retail voucher. One care organisation was reimbursed for the cost of the venue hire.

Co-creation workshop procedure

After introductions, participants re-read the information sheet, asked questions, and gave written consent either in person or via email. Researchers gave a short verbal overview of the study and emphasised an informal atmosphere.

The main workshop activity was a creative storytelling exercise using a blank dementia journey map and forum-derived topic prompts (Figure 2A). The map was divided into three stages (‘Noticing Symptoms,’ ‘Getting a Diagnosis,’ ‘Life After Diagnosis’) and two rows (‘What happened?’ and ‘How did I feel?’) to provide structure. Participants used printed cards or wrote/drew their own reflections to build a timeline of their experience. They were encouraged to select topics that resonated with them, with no “correct” way to participate. Researchers engaged with small side conversations with participants, sometimes sharing their own experiences of dementia. In-person workshops were self-directed or done in small groups, with researchers circulating to prompt discussion and take field notes. In two dementia-only groups, researchers facilitated the discussion more actively using a central A0 map and post-it notes. Online workshops used Miro (version 1.0.14; Miro Ltd, San Francisco, USA) to share a digital map. A researcher facilitated discussion one topic at a time, while another took live notes on-screen, checking for accuracy and placement. No field notes were taken.

Each session concluded with next-step information and Q&A. Researchers completed reflexive diary entries and debriefed to track emerging themes and workshop dynamics.

Analysis

Audio files were automatically transcribed after each workshop by Teams (version 25163; Microsoft Corporation Ltd, Redmond, USA) or Microsoft Word (version 16.97.2, Microsoft Corporation Ltd, Redmond, USA) software and validated by a researcher manually comparing the audio with the text. Our analysis took part in two stages, combining both manifest content analysis (focused on explicit surface-level content) and latent content analysis (exploring underlying meanings and assumptions) (Bengtsson, 2016). This hybrid design enabled us to capture both the frequency and depth of experience reflected in participant narratives. We followed an abductive analytic approach (Thompson, 2022), allowing us to construct codes both deductively by cross-referencing topics from the forum analysis (e.g. pre-identified challenges and journey stages) and inductively by identifying codes unrelated to the forum topics.

Stage 1: Independent Coding of Workshop Data

During the workshop period, two researchers (SJH, CN) independently coded arising data. Manifest content analysis (SJH) was conducted in NVivo (version 14.24.2; Lumivero Ltd, Melbourne, Australia), using fine-grained meaning units related to events, actions, emotions, and beliefs (for example, 'transport restrictions', 'urinary tract infection', 'increase in care requirements'). These were condensed into sub-themes with descriptions and analysed for code frequency, before being grouped into larger theme categories (e.g. 'Feelings'; 'Healthcare experiences' – see Supplementary Materials).

Latent content analysis (CN) was conducted manually and focused on identifying meaning units at the level of first-person experience statements. These aimed to reflect community-level themes tied to different journey phases (e.g. 'They said it was just stress and depression' [diagnosis stage, with themes of misdiagnosis, uncertainty, delays]; 'My world shrank' [post-diagnosis stage, with themes of isolation, carer burden]). Statements included both direct quotations and synthesised expressions using amalgamated participant language. Coding was iterative and reflexive, supported by post-workshop discussions and researcher diaries (CN, SJH, MRA). We continued this process using repeated triangulation between the different journey maps, raw transcripts and reflexive researcher diaries until themes became stable and non-overlapping.

Stage 2: Integration and Synthesis

After completing all workshops, we combined the manifest and latent analysis outputs to ensure comprehensive and trustworthy coverage of the data. Through iterative discussions and returning to raw transcripts, maps, and forum topics, we identified consensus themes and journey elements. We analysed for both the frequency of themes as well as their most common placement temporally on individual maps. This involved several collaborative meetings over a two-week period to refine the final structure. We defined frequently mentioned codes as those appearing across at least five co-creation workshops and used this to prioritise final theme selection. Where possible, latent first-person statements were edited to incorporate some manifest codes that were not captured. Because not all frequently mentioned manifest codes could be captured by the latent themes, we decided to document three levels of meaning units in the final output: (1) emotions, (2) events, and (3) first-person experience statements. These were positioned on the original map template to preserve the temporal aspects of the meaning units (see Supplementary Materials).

2.4 Map visualisation

A professional illustrator (https://www.camilleaubry.com) converted our final analysis output into a rich picture journey map through several rounds of collaborative discussions around imagery, analogies, meaning, and colours. As part of this, we reduced the content of the map due to complexity issues, using researcher reflection and the manifest codebook frequencies to make judgements about what content to include. The illustrator used professional judgement on which parts of the analysis output to depict with images vs text.

2.5 Respondent validation workshops

Participants and setting

Of participants that completed the co-creation workshops, 14 individuals and one London care organisation were invited to attend, of which 18 individuals took part (17 carers, 1 PLWD; 6 male; 13 White British). Not all London-based participants were invited to attend feedback workshops due to not being able to find a separate room and facilitator to work with people living with dementia. Reasons for individually invited participants not attending feedback workshops included no response to the invitation (n = 3) and unable to attend the date or time or take part online (n = 5). Workshops were either online or at one of the local London care organisations.

Procedure

To refresh participants' memory and create a non-judgemental atmosphere, researchers gave a short presentation of the study methods before showing the map and walking participants through the journey image and text content. This included a specific request for constructive criticism and acknowledgement that some participants to not like the map. The remainder of each workshop took place as unstructured discussion between the researchers and participants with the same two researchers (CN and SJH). Data was captured through field notes and researcher reflective diaries without audio recording to facilitate openness. Changes to the maps were made after each feedback workshop and the new iteration presented at the next workshop. This proceeded until we received no new feedback, resulting in three workshops.

Analysis

Field notes were analysed using a similar manifest content analysis procedure described previously and resulting topics were triangulated with previous co-creation output codebooks to identify and prioritise map changes. Following reflective discussions among the research team about participants' attitudes toward the study, we conducted an additional thematic analysis to explore themes related to the context and dynamics of the co-creation workshops (Braun and Clarke, 2019). We looked for codes across the field notes and previous co-creation codebooks (with associated quotes) relating to participant reflections on their participation or the wider context of UK dementia healthcare systems. We constructed themes that captured the latent, core, non-overlapping sentiments expressed in the codes through frequency counts and triangulation with the original participant journey maps and transcripts. As some of the respondent validation workshops involved unstructured discussion with researchers, participants will have been influenced by additional information volunteered by the researchers, such as anecdotes and statistics around dementia care and policymaking.

3 RESULTS

3.1 Forum topic modelling

We identified 1,224,580 eligible Alzheimer's Society Dementia Support forum posts that described aspects of the dementia experience (Figure 3A). Using the machine-learning based BERTopic topic modelling framework, we derived 412 clusters among these posts. 662,640 of the posts could not be reliably classified into clusters, but as a group were summarised by the keywords related to hospitals, care staff, visiting loved ones and the difficulty of some days. Clusters formed from the remaining posts revealed a diverse semantic range of topics (see Figure 3B). The largest topic with 91,239 associated posts related to financial and legal issues, including advice and questions around getting financial or legal help, understanding lasting power of attorney, and clarifying fees and entitlements. Other large topics with at least 5000 associated posts included issues around food and eating, driving licence authorities, donepezil or Aricept® medication, accessing continuing healthcare and social care, pet management, the passing of loved ones, getting a diagnosis, the personal reality of dementia.

To understand the clusters in more detail, we performed a principle component analysis which revealed 37 distinct groups of clusters (Figure 3C). The even and separate spacing of these groups across the two dimensions of variation indicated both a broad coverage of topic space but also some redundancy through overlapping clusters. Secondly, we assessed the explanatory power of keywords using the class-based Term Frequency-Inverse Document Frequency (c-TF-IDF) score, a measure of keyword representativeness per cluster with high scores assigned to terms that appear frequently in a single cluster but less frequently in others. This indicated that some clusters were less well defined (Figure 3D).

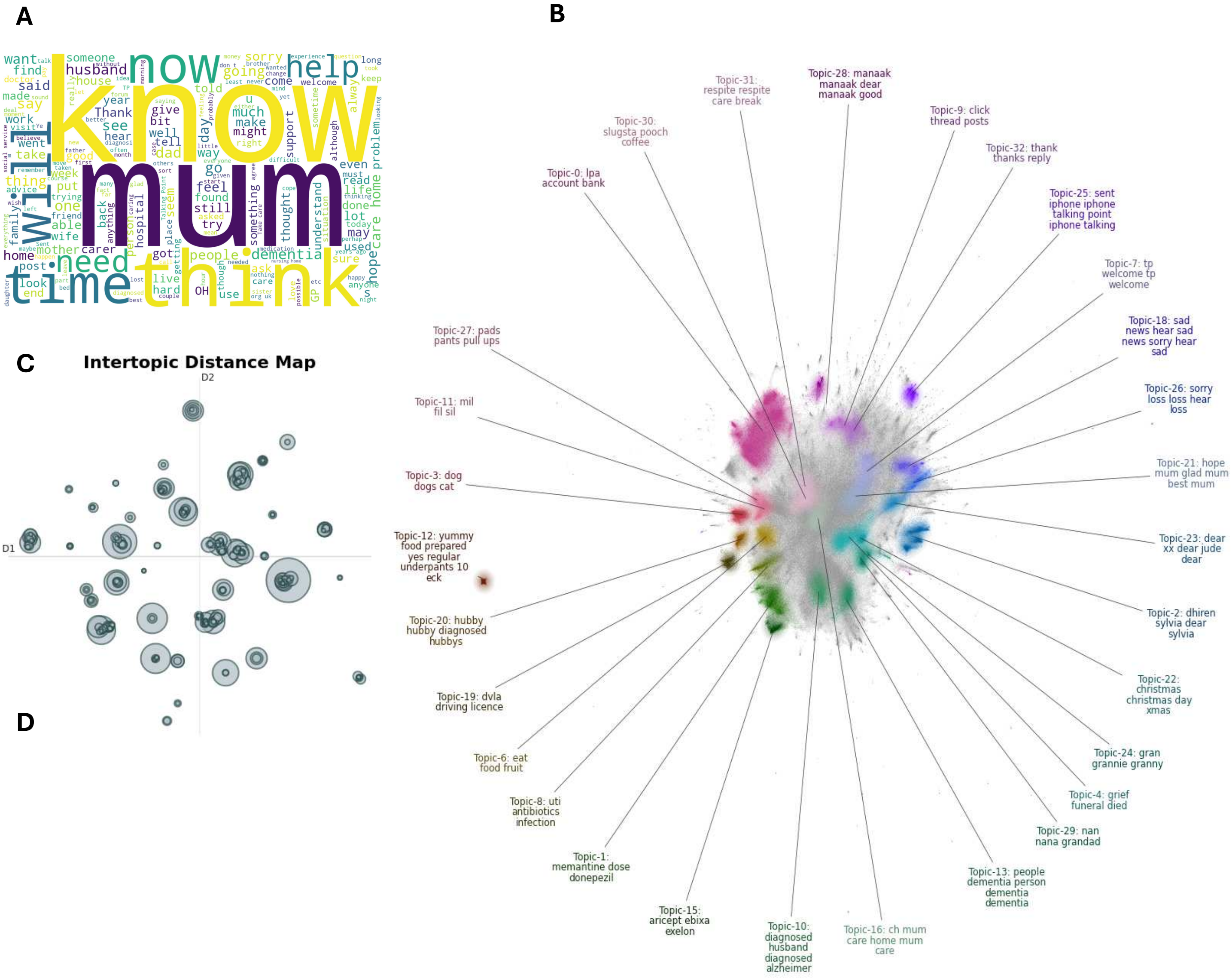
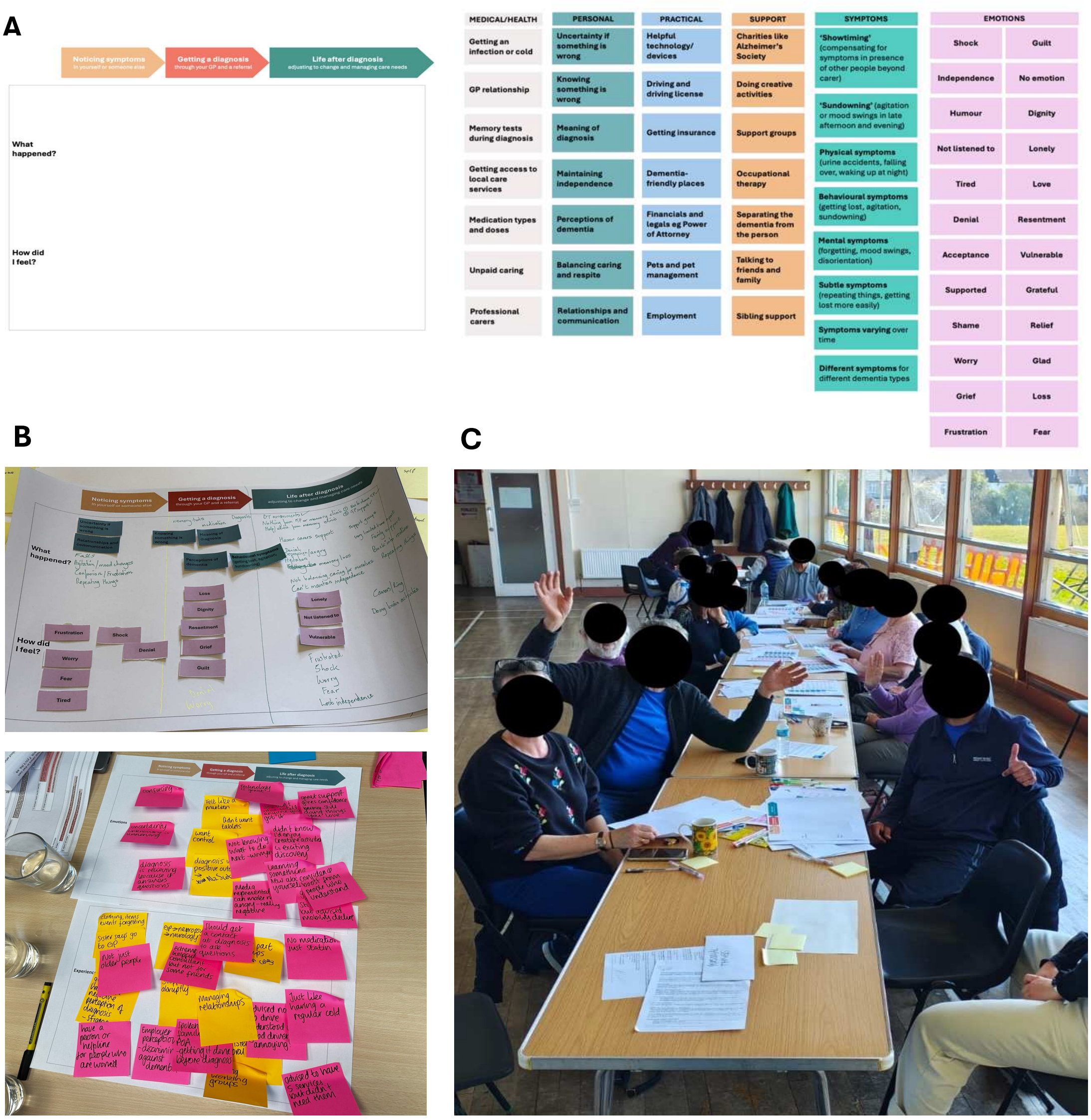


Figure 3. *Forum topic modelling results and characteristics. A. Word cloud derived from entire dataset. B. Data map plot of individual posts within their assigned cluster before filtering and synthesis. 30 of the largest clusters are visualized with first three keywords. Colours represent cluster similarity, with similar colours indicating clusters of more related semantic meaning. C. Intertopic distance map displaying two principle components of the class-based Term Frequency-Inverse Document Frequency score distribution along x and y axes. Each bubble represents a topic, and the size represents the prevalence of the topic in the forum. Minimum cluster size is 100 posts. Bubble proximity is determined by word semantic meaning overlap. D. Graph showing the trends in class-based Term Frequency-Inverse Document Frequency scores of keywords (1-10) per individual clusters, with lower scores and stable scores across term ranks indicating less uniquely described clusters. The top 30 largest clusters from B are visualised in red, reflecting the range in meaningful and noisy clusters.*

Based on these findings, we removed clusters with less meaning and synthesised overlapping ones (see Methods). To do this, we interpreted each cluster individually using an LLM and manually filtered out noisy ones with less semantic meaning related to dementia experience, leaving 209 clusters (see Supplementary Materials). Subsequently we used the LLM to extract themes appearing across these clusters, and manual researcher content analysis to decompose the LLM output into individual topics using content analysis. This process resulted in a final set of 36 sentiment-neutral topics and 24 types of emotions that captured the main topics and themes of the forum (Figure 4A). We grouped the sentiment-neutral topics into five categories: medical or health related, personal, practical, support sources or symptom features. These topics were kept separate from the types of emotions to prevent biasing them towards particular positive or negative valences in the subsequent workshops.

3.2 Mapping topics into a journey map through lived experience co-creation

We invited people with lived experience of dementia to create personal journey maps using the topics and a blank map structured around three temporal stages ('Noticing Symptoms', 'Diagnosis', and 'Life After Diagnosis') and two sections ('What Happened?' and 'How did I Feel?') to capture both objective and subjective experience (Figure 4A). We hosted 12 workshops held across London and Glasgow, and 59 participants who were either living with dementia (n = 17) or were unpaid carers of someone with dementia (n = 42) took part. Most people with dementia had recently received a diagnosis (within five years), though some experienced more moderate symptoms. The carers included partners, children or siblings of someone living with dementia presently or in the past.



MEDICAL/HEALTH	PERSONAL	PRACTICAL	SUPPORT	SYMPTOMS	EMOTIONS	
Getting an infection or cold	Uncertainty if something is wrong	Helpful technology/ devices	Charities like Alzheimer's Society	'Showtiming' (compensating for symptoms in presence of other people beyond carer)	Shock	Guilt
GP relationship	Knowing something is wrong	Driving and driving license	Doing creative activities	'Sundowning' (agitation or mood swings in late afternoon and evening)	Independence	No emotion
Memory tests during diagnosis	Meaning of diagnosis	Getting insurance	Support groups	Physical symptoms (urine accidents, falling over, waking up at night)	Humour	Dignity
Getting access to local care services	Maintaining independence	Dementia-friendly places	Occupational therapy	Behavioural symptoms (getting lost, agitation, sundowning)	Not listened to	Lonely
Medication types and doses	Perceptions of dementia	Financials and legals eg Power of Attorney	Separating the dementia from the person	Mental symptoms (forgetting, mood swings, disorientation)	Tired	Love
Unpaid caring	Balancing caring and respite	Pets and pet management	Talking to friends and family	Subtle symptoms (repeating things, getting lost more easily)	Denial	Resentment
Professional carers	Relationships and communication	Employment	Sibling support	Symptoms varying over time	Acceptance	Vulnerable
				Different symptoms for different dementia types	Supported	Grateful
					Shame	Relief
					Worry	Glad
					Grief	Loss
					Frustration	Fear

Figure 4. *Co-creation workshops and materials. A. Blank map and topic cards derived from forum topic analysis provided to participants during workshops. B. Two example participant maps, one from a carer (top) and one from a person with dementia using researcher note-taking (bottom). C. One of the co-creation workshops with carers.*

This process generated 35 maps (Figures 4B–C), four from people with dementia and the remainder from carers. Maps varied in length and depth, ranging from detailed narratives to single-word reflections. Using manual content analysis, we derived eight overarching theme categories and 171 sub-themes representing the full journey experience (see Methods).

While sub-themes detailed aspects from across all journey stages, most were concentrated in ‘Life After Diagnosis’. Categories largely mirrored the forum topics, including caregiving, diagnosis, feelings, healthcare experiences, life adjustments, public perception, support, and unmet needs. A sub-theme appearing in the maps but not the forum topics was the impact of COVID, and a forum topic not appearing in the maps included pets and pet management.

To create the final experience map, we worked with a professional illustrator and held respondent validation workshops with returning participants. We synthesised the most frequently referenced and consistently positioned sub-themes into 34 key elements across the three journey stages (Figure 5A). These were visualised through verbal statements, illustrations, and design motifs.

The design motifs conveyed deeper themes. The two intertwined paths represent the distinct but interdependent experiences of people with dementia and carers. The meandering lines reflect the non-linear nature of the journey – described by one participant as constantly 'going back to square one'. A forest backdrop with thinning foliage symbolises memory loss, inspired by a metaphor from a person with dementia who described progressive memory changes as first leaves falling, and then becoming branches. Individual figures at different entry points along the bottom signify diverse experiences within a shared narrative. First-person statements throughout reinforce the personal and co-created nature of the map.

3.3 Journey stage sub-maps

In the first respondent validation workshop, some participants reported that the map was too high-level relative to the depth of their experience, and some felt that the messaging was too negative (see Section 3.4). They also highlighted that the issue of cultural variation in terms of attitudes to dementia was missing, and that the impact on carers was not reiterated strongly enough. Consequently, we created three individual sub-maps for each of the three journey stages 'Noticing Symptoms', 'Diagnosis' and 'My New Life' (Figures 5B-D) by expanding the original 34 map elements with further sub-themes identified through our analyses. We adopted a more traditional patient journey map structure, detailing the key journey milestones and associated challenges or barriers experienced by people affected by dementia. In subsequent feedback workshops we additionally asked for participant-sourced opportunities for change. Below we present the final summary outputs for each journey stage.

3.3.1 Noticing Symptoms (Figure 5B)

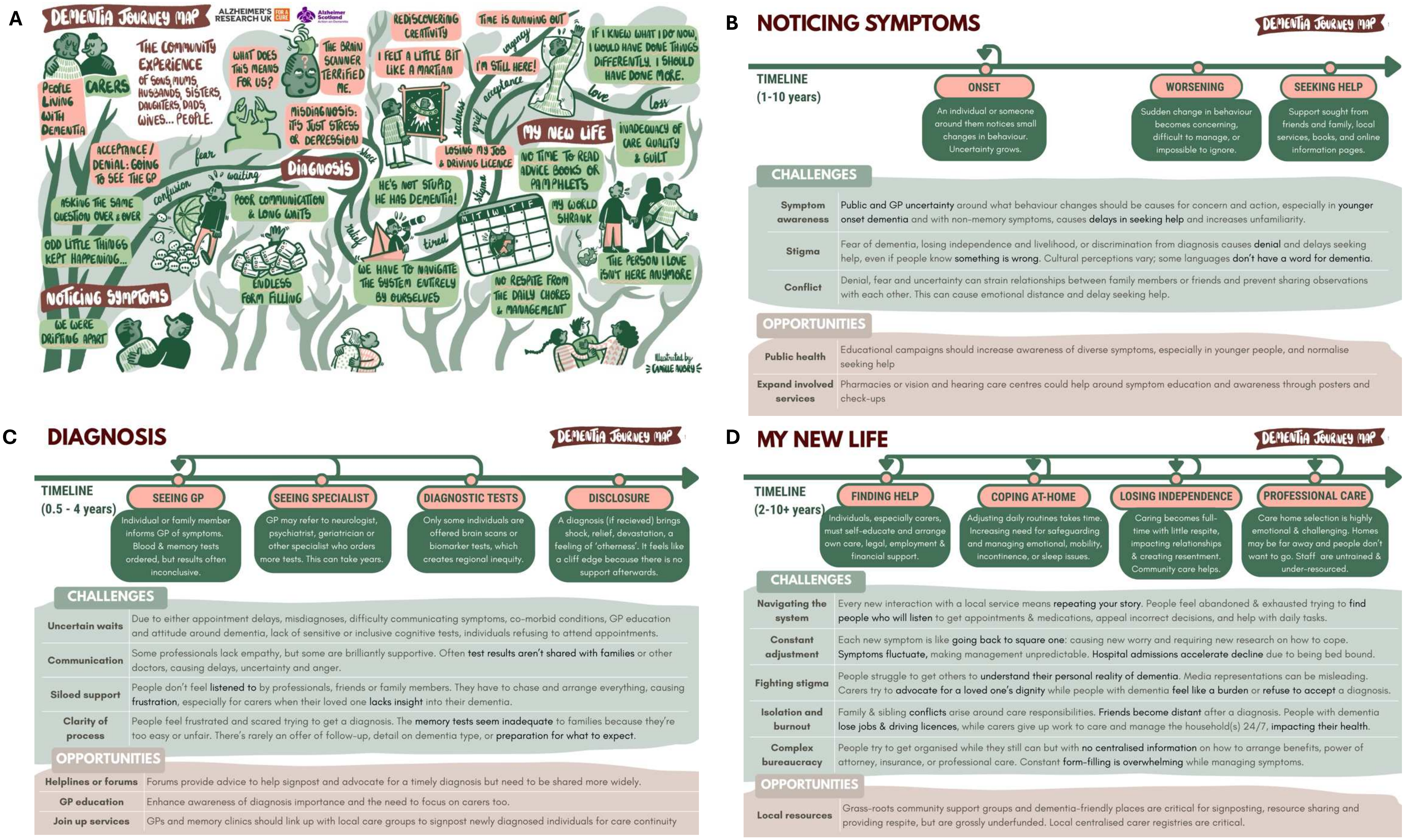
A key message was that the time taken to notice and act on symptoms depended on age, personality traits related to acceptance and denial, employment status and social surroundings of an individual. The symptoms could be very gradual and uncertain, or very rapid and aggressive if co-morbid with other health conditions. A significant medical event could either mask or unmask symptoms. Participants described subtle signs like memory lapses, emotional changes, changes in gait, or shifts in personality, that were often dismissed or misattributed to aging, stress, or physical health issues. Both carers and people with dementia spoke about the internal uncertainty and external stigma that shaped delayed health seeking. A recurring theme was the lack of awareness among both the public and health professionals relating to symptoms. Opportunities for change suggested by participants centred on symptom awareness and education through public health campaigns and involving more health check centres such as hearing and eye care.

3.3.2 Diagnosis (Figure 5C)

The duration and timeliness of a diagnosis depended on local service availability and the quality of relationships between families and clinicians. GPs were seen as the gatekeepers to help and their attitude to dementia mattered hugely in terms of diagnosis access. The map captures the complexity and emotional turbulence of navigating the process. Many described it as fragmented, slow and dependent on persistent advocacy by carers. Experiences of being dismissed by professionals were common and even when the diagnosis was received, the process often felt cold and unsupported. Participants noted relief in finally having answers but also frustration with poor communication for dementia type clarity and little follow up. People with dementia also described feeling alienated by the new diagnostic label. The comparison to cancer care was frequently raised with dementia described as lacking structure or continuity. Opportunities for change suggested by participants included GP educational interventions and making connections between primary care clinics and local care organisations to facilitate continued care post-diagnosis.

3.3.3 Life After Diagnosis (Figure 5D)

Almost all maps reported that support from health services stopped after a diagnosis. Life changes were often dramatic with little follow-up. Participants reported shrinking social worlds, loss of independence, increasing care needs, complex bureaucracy around financial or care support, feeling both overwhelmed and emotionally exhausted. Carers described assuming new roles with little preparation or support. Access to services varied significantly by location and sometimes within locations. Unpaid carers faced inner turmoil and guilt when deciding to use professional care, because although it was often deficient and away from home, they had no choice. Nonetheless, there were also moments of resilience, humour and connection through hobbies, peer support and positive encounters with professionals. The journey after diagnosis was framed as long and lonely, often navigated without a map, with all responsibility to identify needs and understand entitlement falling to individual families. Local social and health service networks were felt to never be joined up, causing huge frustration, anger, and distress. Opportunities for change suggested by participants focused on supporting local care organisations.



B NOTICING SYMPTOMS

TIMELINE (1-10 years)

ONSET	WORSENING	SEEKING HELP
An individual or someone around them notices small changes in behaviour. Uncertainty grows.	Sudden change in behaviour becomes concerning, difficult to manage, or impossible to ignore.	Support sought from friends and family, local services, books, and online information pages.

CHALLENGES

Symptom awareness	Public and GP uncertainty around what behaviour changes should be causes for concern and action, especially in younger onset dementia and with non-memory symptoms, causes delays in seeking help and increases unfamiliarity.
Stigma	Fear of dementia, losing independence and livelihood, or discrimination from diagnosis causes denial and delays seeking help, even if people know something is wrong. Cultural perceptions vary; some languages don't have a word for dementia.
Conflict	Denial, fear and uncertainty can strain relationships between family members or friends and prevent sharing observations with each other. This can cause emotional distance and delay seeking help.

OPPORTUNITIES

Public health	Educational campaigns should increase awareness of diverse symptoms, especially in younger people, and normalise seeking help
Expand involved services	Pharmacies or vision and hearing care centres could help around symptom education and awareness through posters and check-ups

C DIAGNOSIS

TIMELINE (0.5 - 4 years)

SEEING GP	SEEING SPECIALIST	DIAGNOSTIC TESTS	DISCLOSURE
Individual or family member informs GP of symptoms. Blood & memory tests ordered, but results often inconclusive.	GP may refer to neurologist, psychiatrist, geriatrician or other specialist who orders more tests. This can take years.	Only some individuals are offered brain scans or biomarker tests, which creates regional inequity.	A diagnosis (if recieved) brings shock, relief, devastation, a feeling of 'otherness'. It feels like a cliff edge because there is no support afterwards.

CHALLENGES

Uncertain waits	Due to either appointment delays, misdiagnoses, difficulty communicating symptoms, co-morbid conditions, GP education and attitude around dementia, lack of sensitive or inclusive cognitive tests, individuals refusing to attend appointments.
Communication	Some professionals lack empathy, but some are brilliantly supportive. Often test results aren't shared with families or other doctors, causing delays, uncertainty and anger.
Siloed support	People don't feel listened to by professionals, friends or family members. They have to chase and arrange everything, causing frustration, especially for carers when their loved one lacks insight into their dementia.
Clarity of process	People feel frustrated and scared trying to get a diagnosis. The memory tests seem inadequate to families because they're too easy or unfair. There's rarely an offer of follow-up, detail on dementia type, or preparation for what to expect.

OPPORTUNITIES

Helplines or forums	Forums provide advice to help signpost and advocate for a timely diagnosis but need to be shared more widely.
GP education	Enhance awareness of diagnosis importance and the need to focus on carers too.
Join up services	GPs and memory clinics should link up with local care groups to signpost newly diagnosed individuals for care continuity

D MY NEW LIFE

TIMELINE (2-10+ years)

FINDING HELP	COPING AT-HOME	LOSING INDEPENDENCE	PROFESSIONAL CARE
Individuals, especially carers, must self-educate and arrange own care, legal, employment & financial support.	Adjusting daily routines takes time. Increasing need for safeguarding and managing emotional, mobility, incontinence, or sleep issues.	Caring becomes full-time with little respite, impacting relationships & creating resentment. Community care helps.	Care home selection is highly emotional & challenging. Homes may be far away and people don't want to go. Staff are untrained & under-resourced.

CHALLENGES

Navigating the system	Every new interaction with a local service means repeating your story. People feel abandoned & exhausted trying to find people who will listen to get appointments & medications, appeal incorrect decisions, and help with daily tasks.
Constant adjustment	Each new symptom is like going back to square one: causing new worry and requiring new research on how to cope. Symptoms fluctuate, making management unpredictable. Hospital admissions accelerate decline due to being bed bound.
Fighting stigma	People struggle to get others to understand their personal reality of dementia. Media representations can be misleading. Carers try to advocate for a loved one's dignity while people with dementia feel like a burden or refuse to accept a diagnosis.
Isolation and burnout	Family & sibling conflicts arise over care responsibilities. Friends become distant after a diagnosis. People with dementia lose jobs & driving licences, while carers give up work to care and manage the household(s) 24/7, impacting their health.
Complex bureaucracy	People try to get organised while they still can but with no centralised information on how to arrange benefits, power of attorney, insurance, or professional care. Constant form-filling is overwhelming while managing symptoms.

OPPORTUNITIES

Local resources	Grass-roots community support groups and dementia-friendly places are critical for signposting, resource sharing and providing respite, but are grossly underfunded. Local centralised carer registries are critical.

***Figure 5.** Journey maps for dementia created using AI-based topic modelling, researcher content analysis, and lived experience co-creation. A. The entire journey from both the person with dementia (orange) and carer (light green) perspective, divided into three stages. B-D. Individual sub-maps of the three journey stages, with greater detail on defining journey milestones, associated challenges, and opportunities for improvement. Back arrows represent the cyclical and non-linear features of the journey, including becoming 'stuck' at certain milestones.*

3.4 Reflections on the map and dementia journey

The co-creation and validation workshops included not only discussions about map content but also deeper participant reflections on the broader value of the maps for dementia advocacy and awareness. Below, we present key contextual themes that emerged from these conversations.

Theme 1: Glad to have participated in the study, but sceptical of the impact

Most participants agreed that the content was reflective of their experience to varying degrees, and particular areas of the map resonated strongly to individuals. This included the statement of 'odd things kept happening', the 'endless form filling', and the image depicting the sailboat with a person looking ahead as a navigator of the system. Some participants reported feeling glad that they had the opportunity to tell their story and were intrigued to learn about the study method involving artificial intelligence. However, opinions both within and across workshops diverged when discussing the utility of the map. There was scepticism and frustration when discussing whether communicating lived experience would influence political will:

"I think speaking to people all over, I used to go to the Alzheimer's and dementia conferences back in the day, but I lost hope to be honest because what are we on now you know our 4th, 5th strategy?" [Carer G1, P2, Scotland]

Others were more optimistic, responding with messaging around the importance of sharing stories to drive change:

"It's not publicised enough. I don't think the government does enough and people like myself, I knew nothing about dementia as far as I was concerned Dementia was a word and Alzheimer's was a word because everybody talks about Alzheimer's being the most prolific case of dementia, and that's all I knew. Frontotemporal dementia when it was said to me, I'd never heard of and I think that's one of the major reasons that there is lack of I think urgency because there's lack of information." [Carer G1, P1, Scotland]

Theme 2: No one dementia journey is the same

Participants resonated with how the map appearance and content reflected their own experience in different ways. For one carer, the map complexity captured their journey experience which they described as a 'jungle' – hard to find their way through and see around them. Others conversely felt it was either too complex or wasn't complex enough. Some felt it didn't capture the pain of the journey, with someone describing their caring experience as:

"You feel like a single parent to a child that you know will never grow up." [Carer G1, London]

However, multiple participants, especially those either living with dementia or caring for someone with early stage dementia, pushed back on the negative connotations of the map, highlighting that they had still managed to have positive experiences:

"So yeah, you know, you can live well and have some laughs with some good coach holidays, although we kept getting lost." [Carer G1, P3, Scotland]

There were also split opinions on the portrayal of dementia in the media, with some advocating for showing how living well with dementia is possible, while others felt it was necessary to show the reality of their hardship:

"...most media outlets they talk about the really negative parts of it and I suppose the good parts of it they don't want to promote because of negative aspects of it and while yes I suppose nowadays they want to see both the good and the bad and all that sort of stuff but I think it's about time they changed the perceptions that it's not only in older persons." [Person with dementia P1, Scotland]

The atmospheres of the workshops also varied. In some cases, the mood was one of camaraderie and cathartic sharing of experience; in others, it was a mood of despair and unprocessed grief or guilt, especially when carers who had recently lost a loved one discussed the end-of-life part of the journey:

"Heartbreak. It's eternal heartbreak. It doesn't go away. It rests with you. You feel so grieved." [Carer G3, P3, Scotland]

Theme 3: Knowledge in the system is too siloed and stigmatised

The constant message emerging across all workshops was the need for better information sharing, empathy, and awareness. Participants wished that other people could understand the reality of dementia, be it workplace employers, carers, local council staff, neighbours and friends, siblings, or clinicians:

"I sent an e-mail to my boss saying that I've been eligible for this research study now. I was in this research study and then she sent me home sick when she got that e-mail and said that I had ... she had to refer me to occupational health." [Person with dementia, P5 Scotland]

"But it's ... it's always that negative connotation. 'I'm so sorry.' And then the heads goes down. And 'I'm so sorry.' And that ... that sometimes gets my partner down as they look at him. They look at him and then ultimately start to compensate for him and feel sorry for him and he doesn't like that. And neither do I, to be honest. And it does probably bring out the worst at me sometimes, but I think it's other people's opinions." [Carer G1, P2, Scotland]

"Gave me carers to look after my wife in the morning to get her out of bed to get her dressed, but they were the wrong team of carers. And they... they finally said, oh, OK, and it is the wrong team. So they sent a private company, and they were even worse. They didn't turn up at all." [Carer G1, P1, Scotland]

Other people's lack of awareness or empathy was often cited as the cause of stigma, discrimination, loneliness, frustration, and time spent navigating the system. When participants met others who seemed to understand, it felt like a 'confidence boost'. Surprisingly, most participants had not encountered the Alzheimer's Society Dementia Support Forum used in this study. This led to participants sharing their solutions to common problems experienced by the others in their group, as well as their ideas for larger system change:

"Do you know there is an infrastructure there to help the care homes but it's not ... I don't know ... It's as though even the care inspector don't really seem to be looking at it. I think the care inspectorate need to get their act together and start really doing something. Somebody needs to have a proper overview." [Carer P2, Scotland]

"I would like regular group support from [local care group], so I can express myself with others in the same boat." [Carer G1, London]

"Why can things not go to someone with LPA & this covers all services – just a 'tell us once service?" [Carer G1, London]

"... one of the biggest issues of course is the availability of respite care." [Carer G1, P1, Scotland]

4 DISCUSSION

We present journey maps of the UK dementia experience from both a carer and person with dementia perspective, created by integrating large-scale online forum data with lived experience co-creation. They reveal how dementia is a deeply interpersonal and systemic challenge beyond just a medical condition, and that current UK systems do not support the realities of living with it. Through covering the entire journey and utilising a rich-picture format to visualise content, this output intends to help drive system-level transformation in UK dementia healthcare by providing stakeholders with comprehensive and shared understanding of the community lived experience.

Prior research has documented multiple aspects of dementia lived experience through traditional qualitative methods, of which nearly all our maps capture despite arising from a novel dataset and hybrid human-AI methodology. These include barriers to accessing a diagnosis such as stigma and lack of awareness (Bernstein Sideman *et al.*, 2022), feelings of uncertainty and the lack of ongoing support post-diagnosis (Campbell *et al.*, 2016), media portrayals of dementia (Bailey *et al.*, 2021), identity in dementia (Addis and Tippett, 2004), carer guilt and advocacy (Parker *et al.*, 2022), the lack of support for managing financial and legal affairs (Giebel *et al.*, 2023), and many more. One other study also leveraging AI to analyse online data collected from North American forums and social media posts identified similar emotional and personal barriers along the dementia journey to those in our dataset (Tahami Monfared *et al.*, 2022). Our maps act as a form of 'meta-synthesis', drawing together all aspects into an accessible visual communication tool rather than purely text-based thematical output.

Visual communication of lived experience in the form of a journey map is gaining traction in health service design (Davies *et al.*, 2023). It enables a systems and person-centred approach to healthcare improvement, particularly suited for complex, multi-actor systems like dementia (Clarkson *et al.*, 2018; Patou *et al.*, 2020). Visualisation is a powerful medium for cross-boundary knowledge sharing (Stompff and Smulders, 2015), and creating shared knowledge is critical for implementing change (Rapport *et al.*, 2018). However, it has not yet been used to create knowledge around community dementia lived experience. Previous applications used journey visualisation as a qualitative device or as a tool to support family members of someone with dementia (Brookman *et al.*, 2025; Smith and Phillipson, 2022; Wiersma *et al.*, 2025).

Using AI and online data is a new approach to journey mapping, applied to-date to cancer and sarcoidosis patient journeys locally in the Netherlands (Kahlmann *et al.*, 2025; Voigt *et al.*, 2025). The novelty of our work lies not only in the application to dementia but also the triangulation of BERTopic machine learning, large language modelling, human qualitative analysis, and lived experience co-production, enabling us to develop a community level, trustworthy, and in-depth dementia journey map aimed at health service design stakeholders. Generalising this human-AI co-created approach across healthcare domains could enable scalable synthesis of real-world and organically-generated lived experience data (Bourgeois and Kleinsmann, 2023).

Although we aimed to communicate lived experience at scale, our co-creation workshops revealed conflicting realities of dementia. Some participants expressed deep pessimism, reflecting the impact of UK budget cuts, postcode lotteries, and declining social care (Ward *et al.*, 2022). Simultaneously, others were powerful advocates for system transformation. Our maps consequently go beyond communicating experience to also include participant-prioritised opportunities for change: improved public awareness, inclusive diagnostics, joined-up support, recognition of unpaid carers, and investment in local, dementia-friendly services. These represent viable system levers for policymakers to explore.

Limitations to our work include the use of forum data from self-selected contributors with unknown demographics. We mitigated this by recruiting a broad group of lived experience participants across two UK sites and using inclusive workshop formats. This uncovered cultural and language issues around dementia not evident in the forum data, and the unfamiliarity of some participants with the UK Alzheimer’s Society forum suggested we captured perspectives potentially missing from the forum data. Future work could expand to more diverse text sources including blogs, non-English forums, or anonymised clinical notes to avoid reinforcing a White Western bias in the maps. An additional limitation includes using machine learning and large language modelling approaches to content analysis, which can risk producing surface-level insights and reinforcing stereotypes and biases

(Caliskan *et al.*, 2017). We addressed this through a hybrid human-AI approach, combining quantitative methods with lived experience corroboration (Feuerriegel, 2025). However, final decisions about what to prioritise in the maps were influenced by our own positionalities, including our disciplinary backgrounds, prior assumptions about dementia, and interpretations of participant narratives – even with respondent validation in place.

In future work, large scale lived experience datasets such as this could be leveraged to develop not just community level insights but also a set of tailored dementia journey 'personas' that reflect the variation in diagnosis type, caregiving arrangement, cultural background, or local service context. Such personas could facilitate local scenario planning or service design workshops for decision-makers in regions with varying population demographics. In parallel, how journey maps impact on stakeholder shared understanding of lived experience and subsequent decision-making should be formally evaluated to help assess their utility and transferability.

Taken together, this study demonstrates the feasibility of combining large-scale data analysis with lived experience co-creation, and shows that journey mapping can transform fragmented narratives into a unified, visual tool directed towards generating comprehensive shared understanding of lived experience for health system transformation.

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Supplementary Files

- SupplementaryMaterials.docx