NHS Flourishing for the Future:

Caring for People Living with Dementia

A Scoping Report for the Arts and Humanities Research Council (AHRC)

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Current diagnosis rates sit at 46.8% with significant regional variation.

Executive Summary

This report presents the results of the NHS Fit for the Future 2025-2026 scoping project, commissioned by the Arts and Humanities Research Council (AHRC) to explore how design-led research can support the UK government's mission of increasing the proportion of people receiving a dementia diagnosis within the first 18 weeks of referral to 92% by 2029. Current diagnosis rates sit at 46.8% (UK Government, 2025) with significant regional variation (Alzheimer's Society, 2023). In order to identify the systems, services, research, methods, and interventions that are needed to reach this target, this scoping project aims to:

- Assess how UK Research and Innovation (UKRI) and AHRC-funded design-led research has contributed to the dementia landscape, from both a pre-diagnosis and post-diagnosis perspective, and identify where design-led research might achieve significant impact.
- Amplify the expert voices in dementia, including researchers and people with lived experience, to identify resources and infrastructures needed as well as opportunities to support timely diagnosis and broader post-diagnosis dementia care.

Accordingly, this executive summary outlines the principal challenges in dementia diagnosis, synthesises key findings that highlight areas requiring urgent contribution by design-led research, and concludes with actionable recommendations to address these challenges in a timely manner.

Key Problems

The following are the prominent key problems in dementia diagnosis and care. These problems were identified throughout our expert consultation and stakeholder workshops and corroborated by the literature review.

- **Limited awareness and persistent stigma delay help-seeking and dementia diagnosis uptake.**
- **Pre-diagnostic pathways are unclear, and support during diagnosis is inconsistent and fragmented.**
- **Post-diagnostic care is fragmented and difficult to navigate; people are often left to their own devices after diagnosis with little follow-up.**
- **Support systems do not sufficiently account for diverse needs (e.g., young-onset, rarer dementia subtypes, etc.).**
- **Informal carers and families lack structured support.**
- **Collaboration across organisations and sectors remains limited.**
- **Lack of a nationwide (UK) integrated dementia strategy and good practice guidelines, resulting in inconsistencies in dementia care pathways and service quality across regions.**

The identified problems indicate a strong focus on post-diagnosis interventions and limited attention to pre-diagnostic stages, young-onset, and rarer types of dementia. Where literature highlights the potential of participatory and design-led interventions, experts emphasise that integration of interventions into health systems, workforce training and national strategies remains insufficient.

Key Findings

The following key findings synthesise insights from the literature review, expert consultations and stakeholder workshops. It presents the prevailing gaps and emerging opportunities for design-led research.

- Design-led dementia research largely focuses on post-diagnosis interventions, with pre-diagnostic stages and advanced stages under-researched.
- Participatory and person-centred approaches are increasingly adopted, including interventions in assisted technology, spatial and environmental design, and well-being.
- Much research remains exploratory, with limited longitudinal evaluation and follow-up. Only a few projects translate into widely implemented outputs.
- Although there is wider recognition of dementia, there is still a need for anti-stigma work and a more informed understanding of rarer types of dementia. Stigma remains a major challenge for people seeking help.
- Culturally sensitive and integrated community-based interventions play an important part in post-diagnosis support.
- Design-led dementia research has significant potential to influence health systems and care practices, yet translation into policy and large-scale implementation remains limited.

Together, these findings show that both the growing adaptation of participatory approaches, and the persistent structural challenges limit their broader impact. In particular, they show misalignment between lived needs across the dementia journey and research focus, as well as constraints in integration and policy implementation. Design-led research has the potential to address the gaps above, particularly through creative, participatory, person-centred, and systemic approaches that bridge research, policy, and practice.

The findings led to a set of recommendations categorised into four main thematic groups. These recommendations are discussed further in detail in the relevant section of the report. The following is the summary of the recommendations identifying the components of dementia care that design-led research should actively seek to contribute to.

Summary of Recommendations

Early Identification and Diagnosis Pathways

- Awareness campaigns that aim for a more comprehensive understanding of dementia.
- Wider and targeted education of early signs and symptoms.
- Tackle dementia-related stigma through culturally sensitive programmes.
- Target early identification with the development of clear and consistent diagnostic pathways.
- Develop validated and easy-to-use screening tools for primary care.
- Develop education-, skill-, subtype-sensitive, culturally appropriate diagnosis instruments.

Collaborative, Sustainable, Long-term Impact

- Strengthen cross-organisational collaborations in the delivery of dementia diagnostic pathways.
- Develop implementation-ready policies with embedded accountability processes.
- Advocate and design for long-term, strategic, interdisciplinary funding for dementia research.
- Grow the dementia workforce.
- Support primary care to tackle the rising demand for these services.
- Develop regional dementia knowledge exchange hubs informed by emerging local needs.

Person-centred Post-diagnosis Pathways and Research

- Develop person-centred and specialist post-diagnosis services that are inclusive of carer needs.
- Design consistent psychosocial interventions.
- Improve access to dementia nurses, navigators and advisors.
- Develop new and meaningful measures of success for people with dementia.
- Create new evaluation methods for measuring quality of life.
- Adopt multi-disciplinary approaches to address late-stage dementia and end-of-life dementia care.
- Train care-home staff in recognising late-stage dementia needs.
- Design-led Methods, Sector-wide Frameworks, and National Guidelines
- Develop innovative, person-led methods of working with people living with dementia.
- Use more creative and participatory methods that are inclusive of changing and varying needs.
- Develop and deliver UK-wide clear design guidelines.
- Create a streamlined national ethics charter that is proportional to the risk.
- Advocate for recognition of people with dementia’s decision-making capacity in the guidelines
- Develop a nationwide young-onset dementia framework.

The findings and problems identified here provide a foundation for targeted actions to guide future design-led research, practice and investment to improve outcomes for people living with dementia (PLwD), their families, and carers, healthcare staff. Overall, this scoping project highlights both the potential and current limitations of design-led dementia research in supporting timely diagnosis and post-diagnostic care. While the research shows that participatory and person-centred approaches help strengthen support after diagnosis, significant gaps remain.

Particularly, the need for a wider and more integrated rollout of person-centred and place-based healthcare approaches, and for more consistent pre-, peri – and post-diagnostic support is significant. Similarly, there is a growing need for collaborative research approaches to address the significant challenge posed by the growing demand for, and strain on, services. Therefore, developing regional dementia knowledge exchange hubs with specialised design departments informed by emerging local needs is the key to addressing the multifaceted challenges mentioned. These hubs, responsive and accountable to the lived experience of people living with dementia, their carers and healthcare staff, will shape the future of dementia research. They will also support healthcare services in incorporating design-led, integrated, place-based, and person-led approaches, thereby making them more resilient to future challenges amid increasing pressures.

Significant gaps remain, particularly in pre-diagnostic and diagnostic support, young-onset dementia and the integration of research into practice and policy.

Timeline

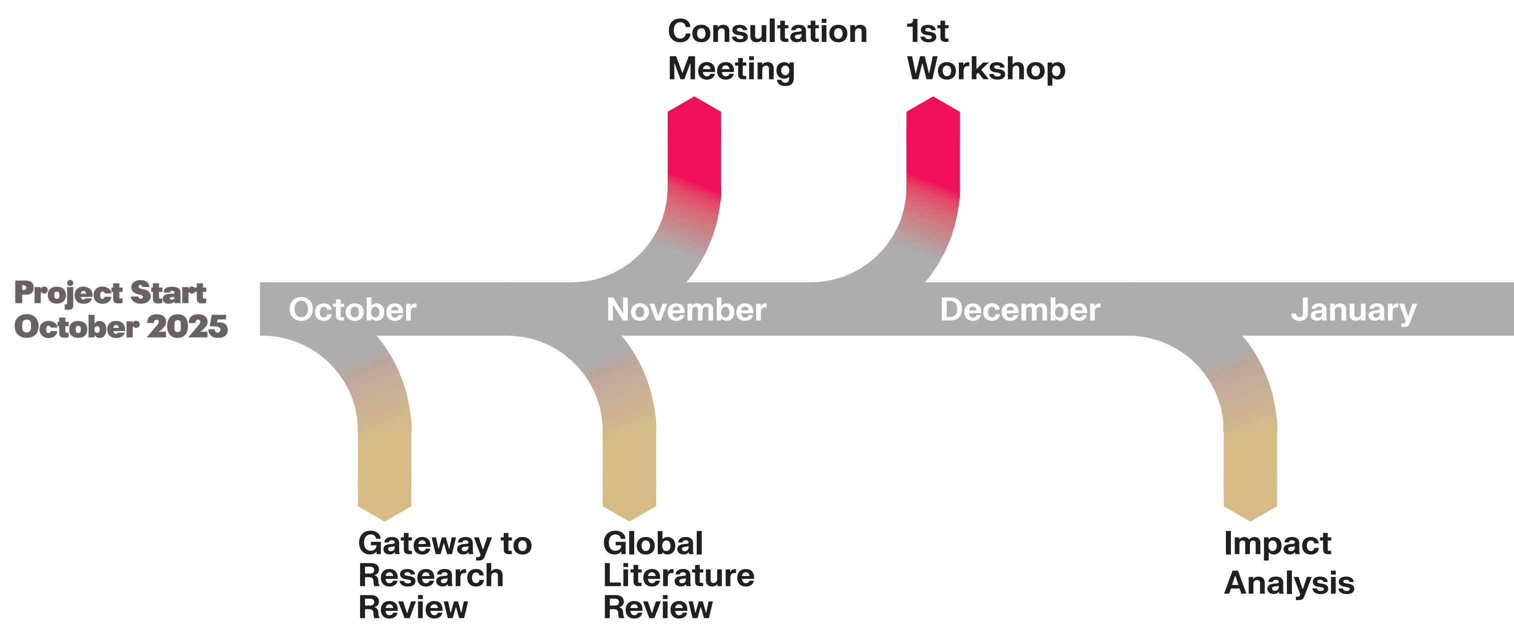
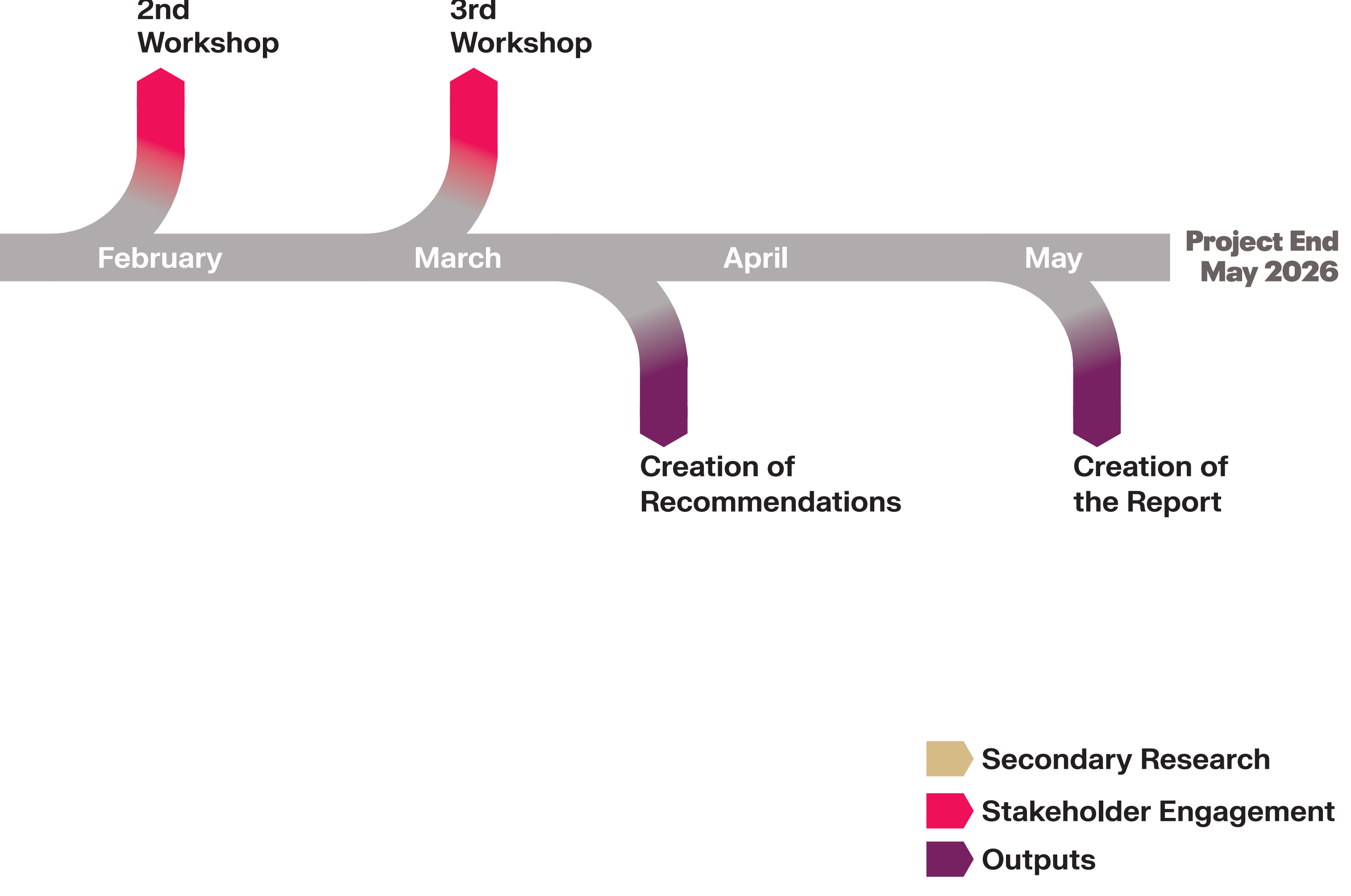


Figure 1: Project timeline


2nd
Workshop
3rd
Workshop
February
March
April
May
Project End
May 2026
Creation of
Recommendations
Creation of
the Report
Secondary Research
Stakeholder Engagement
Outputs

12
9
3
6

Introduction

Background and Context

Dementia is an umbrella term for several diseases that are mostly progressive affecting memory, cognitive abilities and behaviour. In the long term, it significantly affects a person's ability to sustain their daily activities. There are over 100 types of dementia, with Alzheimer's disease and vascular dementia currently accounting for 90% of cases (Alzheimer's Disease International, n.d.). Dementia may progress quickly or slowly, depending on factors including the type of dementia, the person's age, their general health, and their lifestyle. Although the disease trajectory may look different for individuals, it may progress through three stages: early, middle, and late (Alzheimer's Society, n.d.).

There are currently estimated to be nearly 1 million people living with dementia (PLwD) in the UK, which will rise to almost 1.4 million by 2040 (Alzheimer's Society, 2024). Over 200,000 people in the UK will develop dementia this year, which represents one person diagnosed every three minutes (Alzheimer's Society, 2026). There are also over 70,000 people under 65 with dementia in the UK (Dementia UK, 2022). The projected rise in dementia prevalence poses a significant healthcare, social care and economic challenge, and highlights the urgent need to prioritise it as a health and care concern.

The total cost of dementia care in the UK is currently £34.7 billion, forecast to rise to £94.1 billion by 2040 (Wittenberg et al., 2019). The cost of unplanned hospital admissions in the final 12 months of life alone was £6664 on average for someone with dementia (Leniz et al., 2025). Additionally, a further 700,000 people act as informal carers in the UK (Alzheimer's Research UK, 2019). Informal carers in the UK are unpaid, untrained, and often have no formal networks of support. Informal carers shore up significant gaps in health and social care services. In the complex system of dementia care and support, the contributions of these informal carers are vital but often overlooked. Unpaid carers supporting someone with dementia save the UK economy £13.9 billion a year, with two-thirds of the cost of dementia paid by people living with dementia and their families (UK Government, 2022).

Diagnosis

A dementia diagnosis is based on a combination of tests and varied assessments. These are usually done by a GP or specialist at a memory clinic or hospital. These assessments vary from taking a patient history to cognitive assessment tests for checking memory and cognition, which are usually done by a GP or a specialist. GPs will also arrange for a blood test to help rule out other symptoms that might be causing memory problems. If the initial tests rule out other problems, the person would be sent to a memory clinic, and brain scans (CT and MRI) would be arranged as part of the wider assessment alongside further cognitive tests, as scans cannot diagnose dementia on their own. Other types of scans, such as SPECT or PET scans, may be recommended if the results of other tests remain uncertain; these are usually less common (NHS, n.d.). It is important to recognise that diagnostic pathways vary, and that individuals may follow different routes to receiving a diagnosis. A key challenge is the lack of standardisation in dementia services, which vary significantly across the UK (Alzheimer's Research UK, 2025).

Accurate and Timely Diagnosis Challenges

Early and accurate diagnosis can enable people to access person-centred care early, help them plan, and prevent unnecessary acute hospitalisations. However, workforce strain, limited diagnostic capacity, and a lack of investment in memory services prevent timely access to diagnosis. Currently, services lack the capacity to meet the increasing demand (Alzheimer's Research UK, 2025).

It is clear that the demand for innovative and effective health and social care services will only continue to increase due to the intersection of an ageing population, the growing prevalence of chronic conditions, and a surge in complex needs.

Complex Pathway Navigation

Despite the high disease prevalence, current dementia diagnosis and care reportedly remains underfunded, fragmented, and too complex to navigate. Many individuals report feeling unsupported, with too many questions left unanswered due to long waiting times and no clear pathways for what happens after diagnosis. Referral pathways may vary by individual, adding complexity to diagnostic pathways (Alzheimer's Research UK, 2025).

Inconsistent Post-diagnosis Support

After receiving a diagnosis, people will be discharged from the memory services to their GPs. However, there is no clear and consistent delivery for post-diagnostic support. In addition, there are significant regional differences in access to care. People who live in rural and deprived areas have significantly more limited access to services and post-diagnosis support (Alzheimer's Society, 2022). While the type of support the individual needs depends on the type and stage of dementia, single-point-of-contact coordinators are key to providing continuous, high-quality support (Royal College of Psychiatrists, 2025).

Inequalities

While these figures demonstrate the scale of the challenge, they also mask substantial disparities in access to care. The Office of Health Economics reports that there are currently more than 100 inequalities that are impacting people living with dementia and their carers, mostly linked to location, deprivation, socioeconomic status, age, culture, and ethnicity (Hodgson et al., 2024). Currently, there is more than 20% difference between the highest and lowest diagnosis rates in Integrated Care Systems (ICSs) in England (Alzheimer's Society, 2023). Underserved communities currently face more delays and uncertainty, thus perpetuating the cycle of inequality. There is also a significant gender disparity; women are more likely to develop dementia compared to men, and, reportedly, long life expectancy is not enough to explain this gender gap. Women are more likely to become carers and more likely to care for someone with dementia. Hence, women make up around two-thirds of unpaid carers (Alzheimer's Research UK, 2022). To add to this disparity, Black and South Asian populations are more likely to be diagnosed at an earlier age and also die earlier when compared to the White population (Mukadam et al., 2022).

Scope and Focus of this Research/Report

Globally, the World Health Organisation recognises dementia as a public health priority (WHO, 2017), with a target of developing national policies, strategies, or frameworks by its member states by 2025. Currently, the UK does not have a nationwide dementia strategy. The UK government's current dementia mission aims to increase the proportion of people receiving a timely diagnosis within the first 18 weeks of referral, from approximately 46.8% to 92% (UK Government, 2025). Because everyone's journey can look different, there is no one standard test to diagnose dementia. Depending on the subtype and tests available, some diagnoses can take a few weeks (Alzheimer's Society, n.d.). However, one systematic review suggests that the average time to diagnosis across all types of dementia can take up to 3.5 years

(Kusoro et al., 2025). Regional variation remains significant, with many people waiting over a year for a formal dementia diagnosis and memory clinic wait times exceeding two years in some areas (Care England, 2025). Healthcare professionals also identify problems in initial recognition and assessment in primary care. This leads memory clinics to be overloaded with referrals for mild memory concerns, often for people who do not have dementia (Alzheimer's Research, 2025).

In consideration of what is listed above, this project was intentionally scoped to complement existing UKRI investments in dementia research by applying design-led research methods to explore unmet needs and identify future innovation pathways in dementia care, thereby helping to identify the necessary steps to help achieve the government's 2025 dementia mission of diagnosing 92% of people within 18 weeks of their first referral (UK Government, 2025). Our approach focused on clarifying what is needed to support people living with dementia (PLwD) and their carers across pre – and post-diagnostic stages, improving experiences, services, systems, and environments, while contributing to the quality and sustainability of dementia health and care services. Situating the research within this main target, we undertook a detailed review of design-led dementia-related literature and talked to more than 30 experts. This exploratory work examined:

- Existing care pathways, informed by conversations with dementia experts and sector-wide guidelines.
- Art and design-led interventions in dementia, identified through research databases such as Gateways to Research, REF2021, DRS Digital Library, Scopus and ProQuest.
- Insights, drawn from workshops with experts and lived experience participants, recent dementia research, sector guidance and policy documentation.

The Need for Design-Led Dementia Research

It is clear that the demand for innovative and effective health and social care services will only continue to increase due to the intersection of an ageing population, the growing prevalence of chronic conditions, and a surge in complex needs (NHS England, n.d.) These challenges will require innovative ways of supporting people, including those with dementia, to live well from the early stages of their diagnosis. People will need highly effective forms of support from the point of diagnosis to come to terms with this life-altering diagnosis, to ensure that they remain connected to their community and are able to live well with this long-term illness.

Design-led research differs from traditional observational approaches by generating knowledge through active intervention, using design practices as a mode of inquiry. It foregrounds collaboration, co-design, and co-production with stakeholders, including people with lived experience, practitioners, and subject experts. Within dementia research, design-led methods offer particular value through empathy-building, iterative sense-making, and the development of tangible outputs that can surface hidden assumptions, reveal systemic gaps, and reframe complex challenges in actionable ways. This report provides a clear picture of how design-led research can meaningfully address the gaps identified by both the literature and experts.

By combining literature review insights with expert consultation, this report provides a clear picture of how design-led dementia research can address gaps in care pathways, public awareness, stigma reductions, workforce capacity, and person-centred holistic support. The following sections outline key findings, problems, and recommendations derived from this integrated approach, offering a roadmap for design-led interventions in dementia care.

WEDNESDAY
25TH
APRIL

Design-led Dementia Research

This overview explores two decades of dementia research (2006-2025) from a design-led perspective. We conducted a targeted review of UK-based and global research to identify:

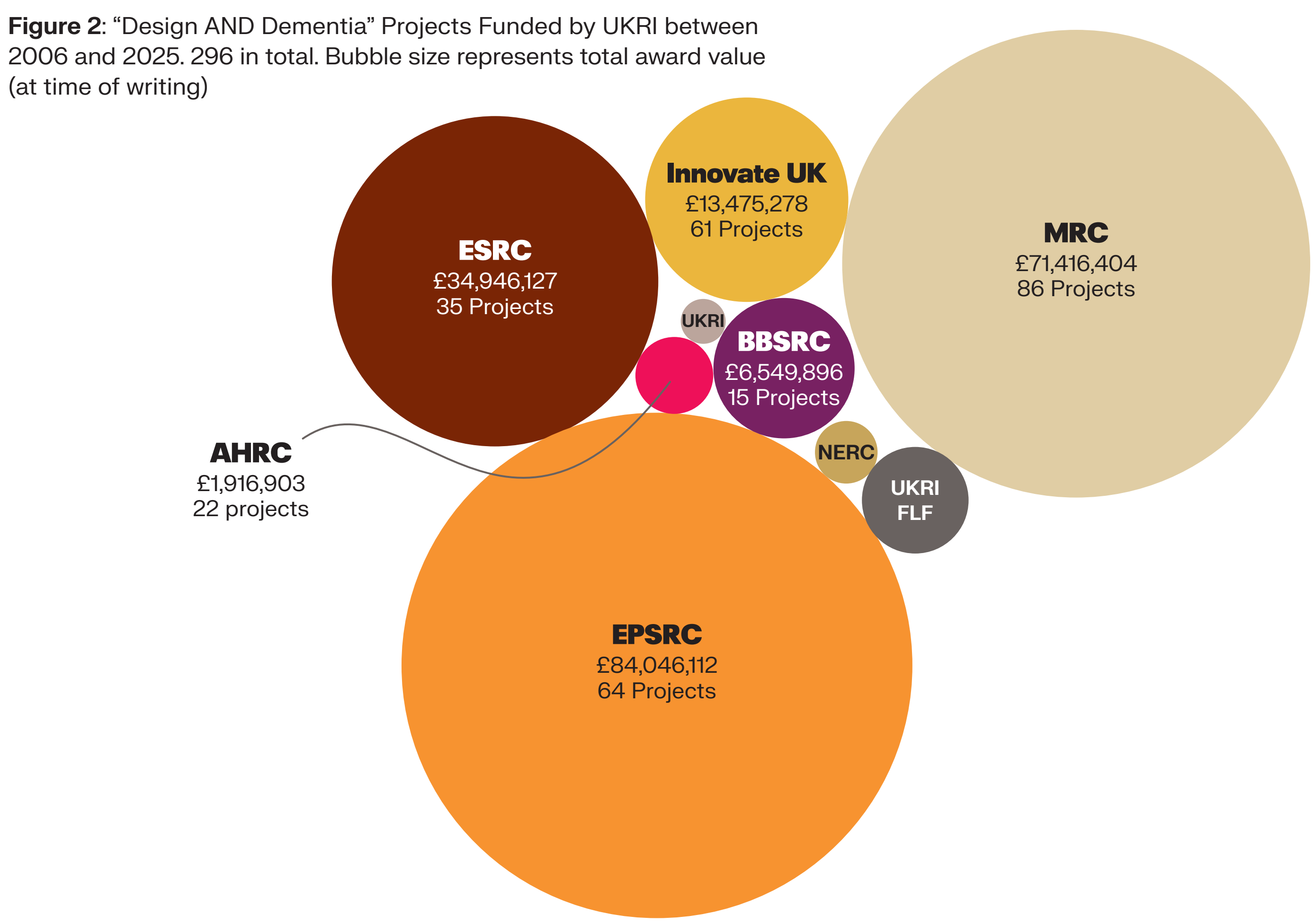
- How does design-led dementia research contribute to the wider dementia research landscape, and what impact has it achieved?

UKRI Gateway to Research

To explore UK-focused research, we analysed the Gateway to Research (GtR) database to offer a detailed picture of the landscape of design-led dementia research from 2006-2025.

Here, the search term "Design AND Dementia" was used, which finds projects indexed that have both the words "design" and "dementia" in the project abstract and/or title. Figure 2 shows the distribution of the 296 (at the time of writing) projects across funders, after filters were applied to focus on UKRI-related funders only. The overall size of the funder bubble represents the total award value.

Figure 2: "Design AND Dementia" Projects Funded by UKRI between 2006 and 2025. 296 in total. Bubble size represents total award value (at time of writing)



To further narrow down the projects and to consolidate the design focus, a design-related filter was manually applied by the researchers to each of the 296 projects, based on two selection criteria:

1. Does the project have a direct and identifiable design output to it, such as products, services, systems, environments, and toolkits?
2. Does the project apply or contribute to design-based research methodologies such as co-design and participatory design workshops?

If the answer to either of these was yes, the project was included in the final list of design-led projects. Once studentships were removed, this narrowed the UKRI projects to 67, enabling in-depth analysis of what has been addressed in the field so far and what needs more urgent attention. The search process is visualised in Figure 3.

Figure 4 illustrates the outcome of applying these selection criteria to the GtR search and shows the total value each funder has awarded over the years (represented again by the size of the bubble) and across how many projects. It highlights that while the AHRC and Innovate UK have the smallest funding contributions they fund the greatest number of design-led projects – 21 each. The Economic and Social Research Council (ESRC), meanwhile, funds 12 projects relevant to design, however, at a total cost of over £17.5M – the highest of the UKRI councils and at the highest average cost per project.

In line with the government's early diagnosis mission, the 67 projects were categorised based on which stage of the dementia journey the project aimed to address. Alzheimer Scotland's Dementia Diagnosis Journey model (Alzheimer's Society, n.d) was used for this categorisation, which has the following stages: early signs and memory concerns, seeking a diagnosis, early stage and late stage.

Figure 5, which visualises the results of this categorisation, shows that the majority of projects (53/67) focused on the post-diagnosis stages, with only 5 on early signs and 2 on the diagnosis-seeking stage. The most densely populated category was the early stages, with 30 of the 67 projects falling into it.

Figure 3: Visualisation of the search process stages

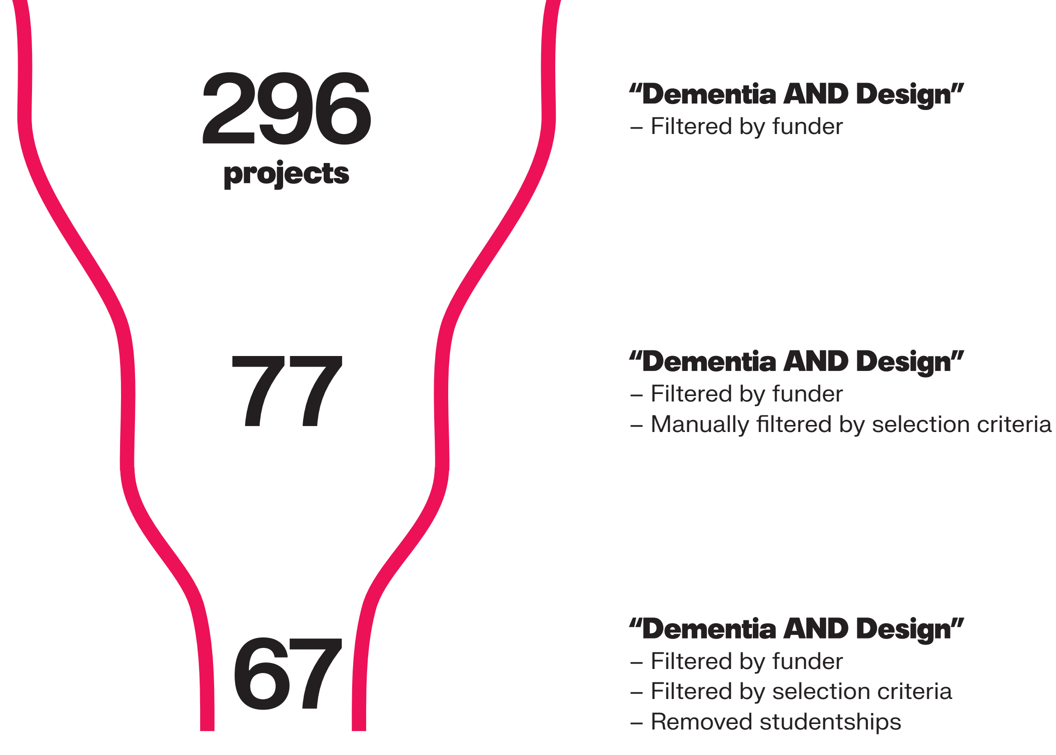


Figure 4: Gateway to Research (GtR) landscape under the search "Design AND Dementia", with the design specific criteria applied. Bubble size represents total award value. (At the time of writing)

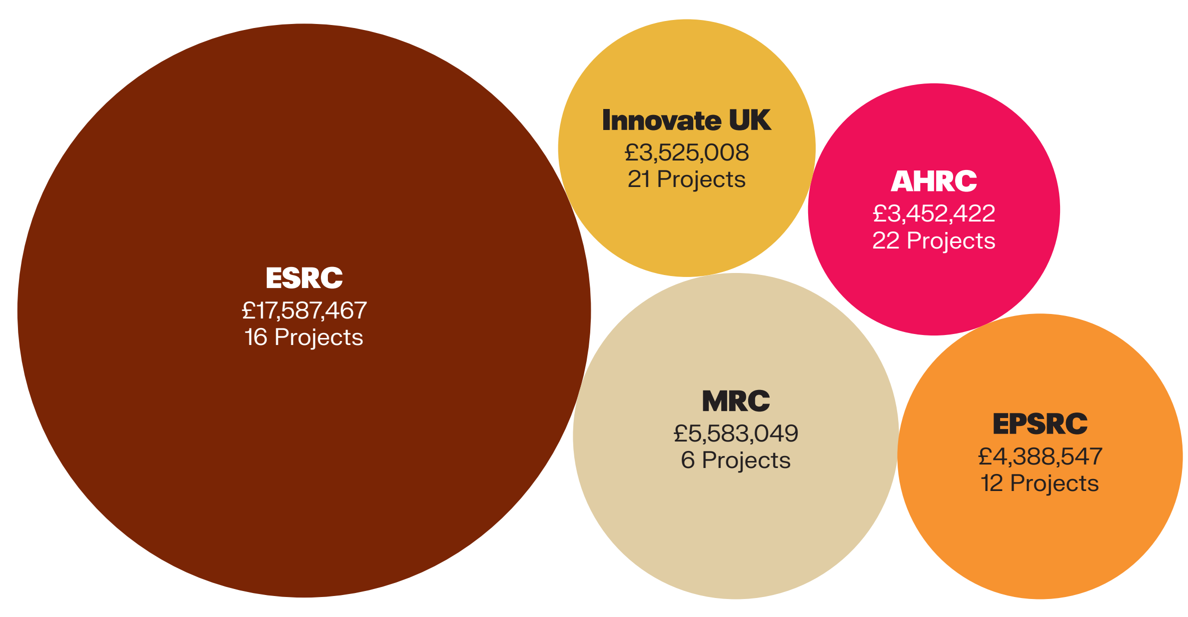
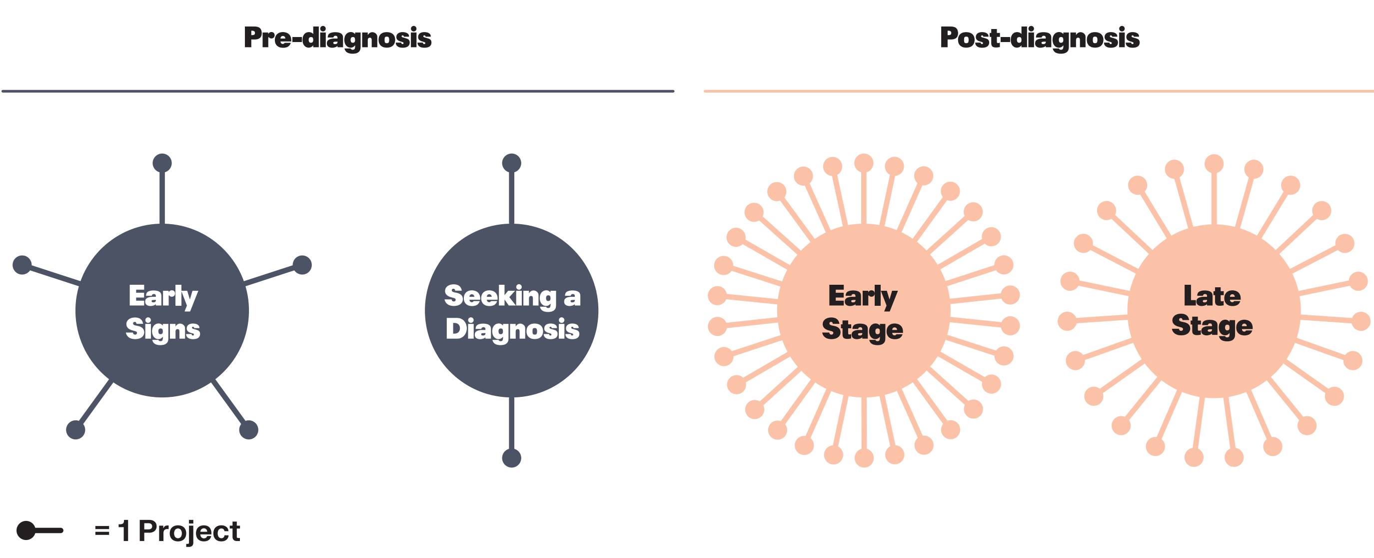


Figure 5: 67 Gateway to Research projects categorised by where in the dementia diagnosis journey they focus



7 projects could not be clearly categorised into a single stage, mainly because their scope was broad and could be relevant for any/all stages, and so are not included in the following diagrams. Figures 6 and 7 on the following pages provide a detailed look into each of the projects being done in each of the stages of dementia, and who is funding it. In these Figures, the project is represented by its GtR title or a shortened version where appropriate.

In the section below, the overview of projects by council is discussed to identify what these projects contribute to in design-led dementia research.

AHRC-funded work foregrounds the role of arts, culture, and participatory design. Projects which look at the early stages of dementia such as *IMAGINED* (Warren, 2023), and *Dementia and Imagination* (Windle, 2013), or *GOALDen Memories* (Haynes, 2023) which focuses on the late stages, demonstrate how community codesign, creative methods, and reminiscence-based interventions can shape well-being, identity, memory, and social inclusion during the post-diagnosis stages of dementia. These studies emphasise the value of lived experience, and use design tools such as digital reminiscence packs, artistic installations, and sensory craft-based work to challenge stigma and enhance connection, along with a commitment to improve well-being through the advanced stages of dementia with projects such as *Ludic Artefacts (LAUGH)* (Treadaway, 2015).

ESRC-funded research examines dementia through social, environmental and policy lenses. Large studies such as *DETERMIND* (Banjerjee, 2019), *EMBEDCare programme* (Sampson, 2019), and *APPLE Tree* (Cooper, 2019), which examine the early stages, late stages and early signs of dementia, respectively, provide insights into inequalities, post-diagnostic support, palliative care, and prevention. Meanwhile, late-stage projects like *Dementia-friendly Architecture* (Wiener, 2015) and *Seeing What They See* (Crutch, 2014) investigate spatial disorientation, visual perception, and environmental adaptations, demonstrating how design and the built environment shape daily experience and independence for PLwD. ESRC's body of work also highlights underserved groups, including those with rare dementias and the Deaf British Sign Language community.

The Engineering and Physical Sciences Research Council's (EPSRC) research

Figure 6: Gateway to Research projects focusing on the 'early signs' and 'seeking a diagnosis' stages of a dementia diagnosis

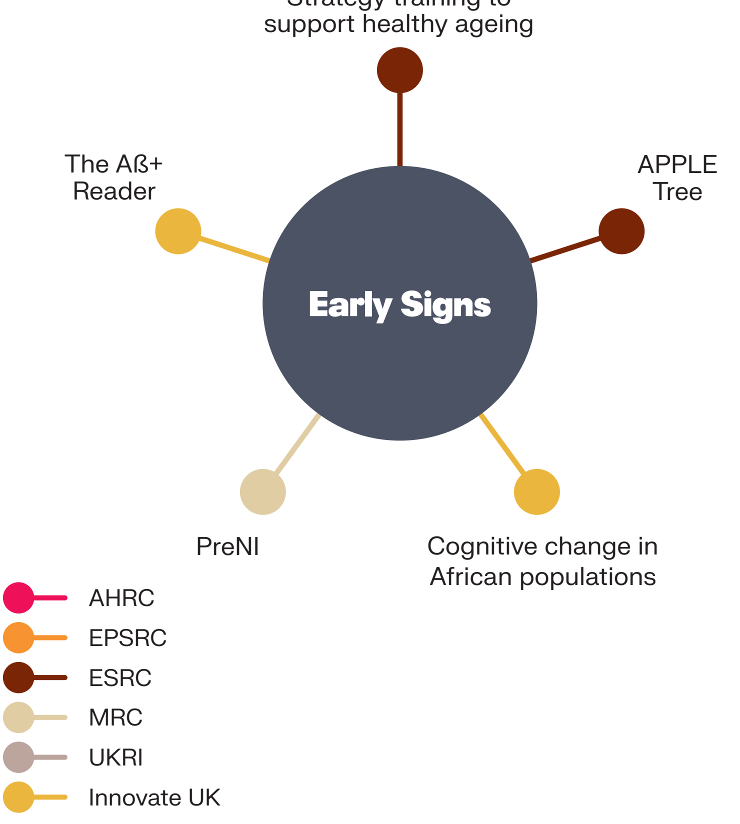
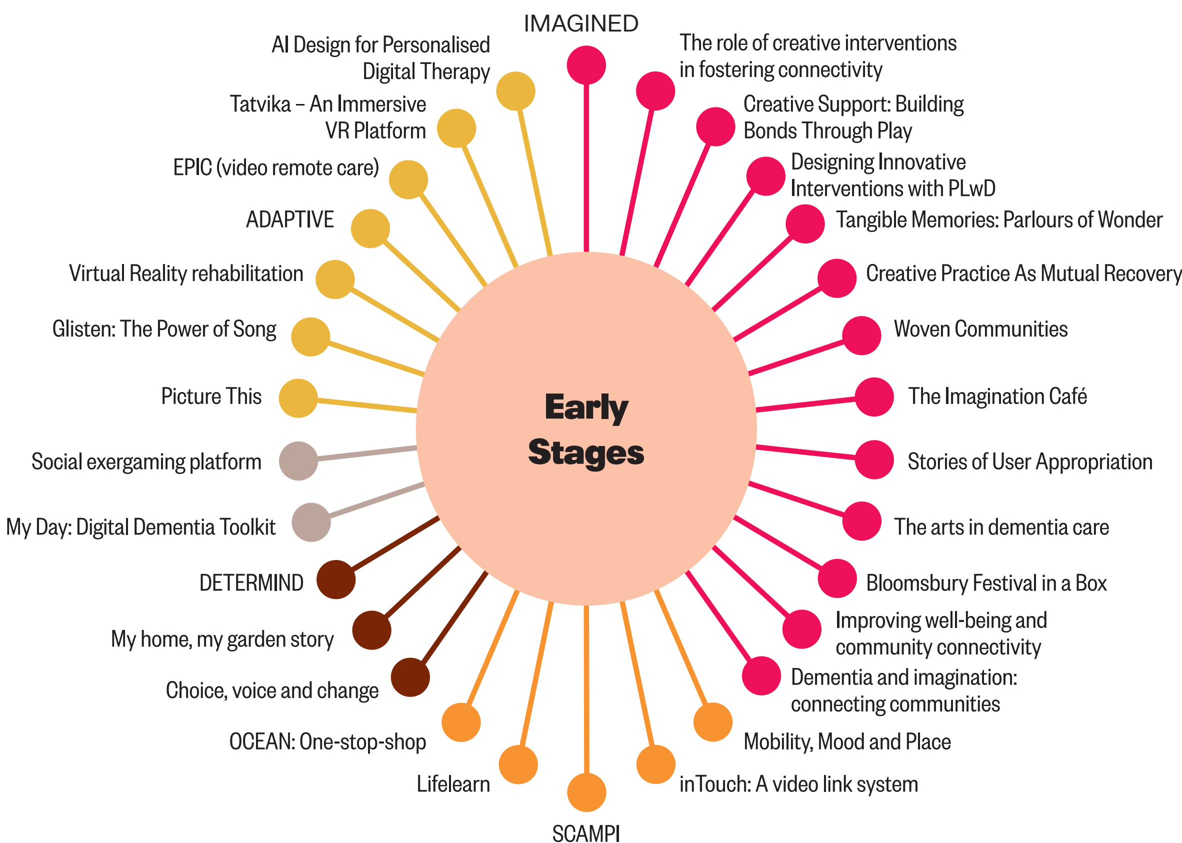
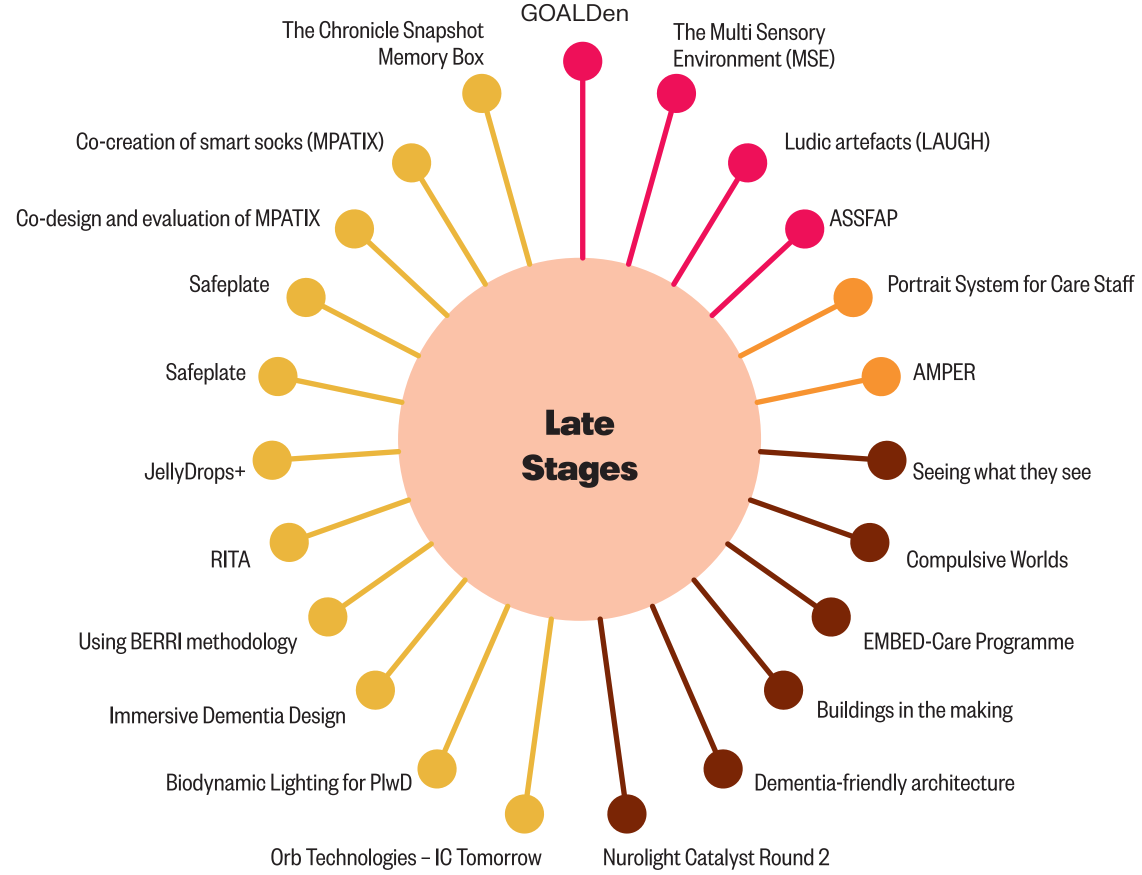


Figure 7: Gateway to Research projects focusing on the 'early stages and 'late stages' of a dementia diagnosis





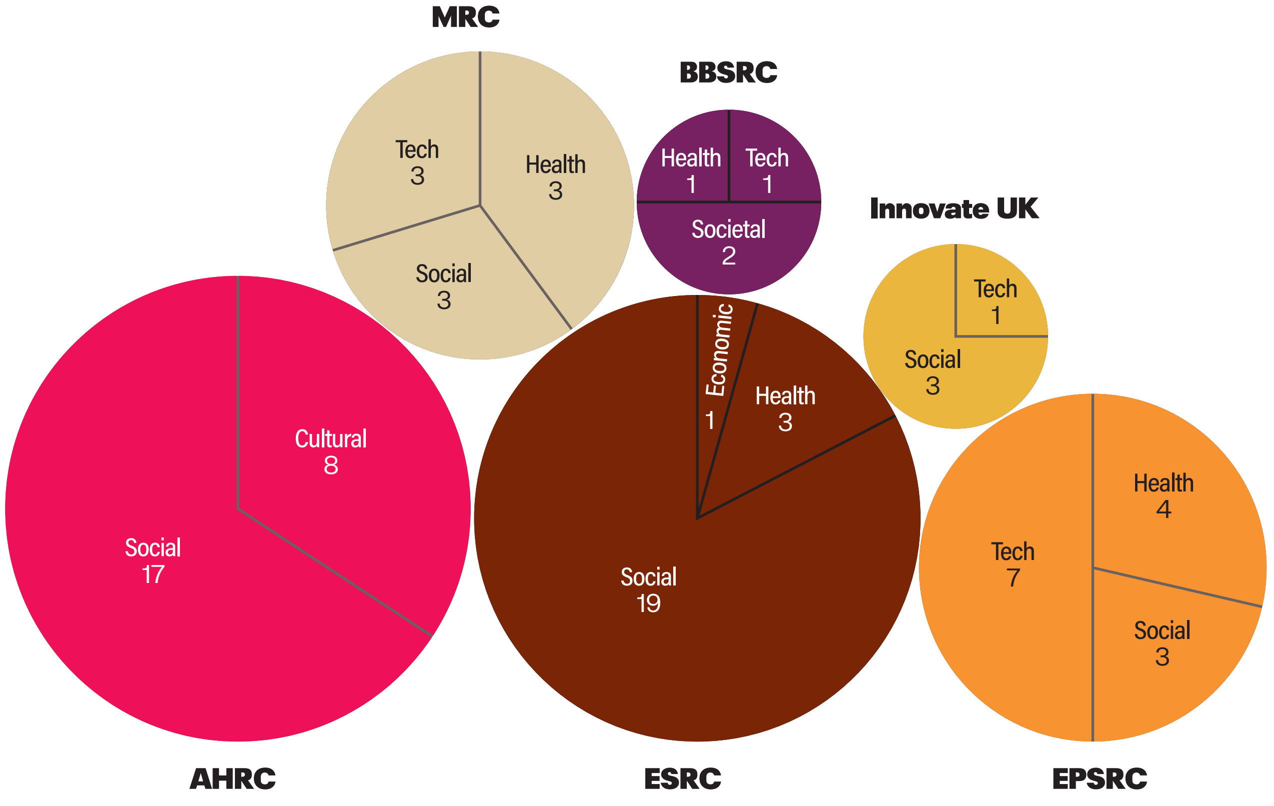
strengthens the technological and engineering dimension, focusing on AI-enhanced interaction, behavioural modelling, and sensor-enabled care. The *AMPER* project (Aylett & Aylett, 2022) explores support for autobiographical memory via conversational agents for people in the late stages of dementia, while SCAMPI (Maiden, 2017) and other wearable technology projects develop digital self-management systems and context-aware assistive devices for those in the early stages of the condition. These studies integrate user-centred design with advanced computational methods to support independence, memory, and social participation.

The Medical Research Council (MRC) programmes anchor the biomedical and early detection domain, spanning neuroimaging, biomarker discovery, pre-symptomatic research, and global diagnostic harmonisation. Major investments such as MRC *Dementias Platform* (Gallacher, 2014), which looked at diagnosis, and projects like *EPOCH* (Prina & Matthews, 2020) which analysed how the built environment influenced health behaviours across the stages of dementia, extend the research landscape by linking biological, environmental, and societal factors, providing evidence that complements design-oriented interventions.

Innovate UK-funded projects including *SmartSocks* (Milbotix Ltd., 2024), the *Aβ+ Reader* (Occuity Ltd., 2024), *Tatvika – An immersive VR platform* (Inclusys Ltd., 2024), and The *Chronicle Snapshot Memory Box* (Chronicle Digital Storytelling Ltd., 2024) illustrate a strong emphasis on marketable products, from wearable agitation detection systems and immersive VR therapeutics to novel diagnostic imaging devices and multisensory memory tools, each focusing on a different stage of the dementia journey. These projects reinforce a shift toward real-time behavioural monitoring, personalised interaction, and scalable digital therapeutics.

Across councils, several crosscutting themes emerge: the centrality of codesign with PLwD and carers; deeper attention to sensory, spatial and environmental quality; and a strong drive to support carer capability, independence, and well-being while showing increasing interest in digital and data-driven technologies. Together, these projects show a field steadily transitioning from isolated interventions to the integrated design of products, services, and systems that combine creativity, technology, behavioural evidence, and person-centred principles to improve life with dementia.

Figure 8: REF2021 impact case studies under "Dementia" categorised by UKRI funders and impact type



REF Impact Case Studies

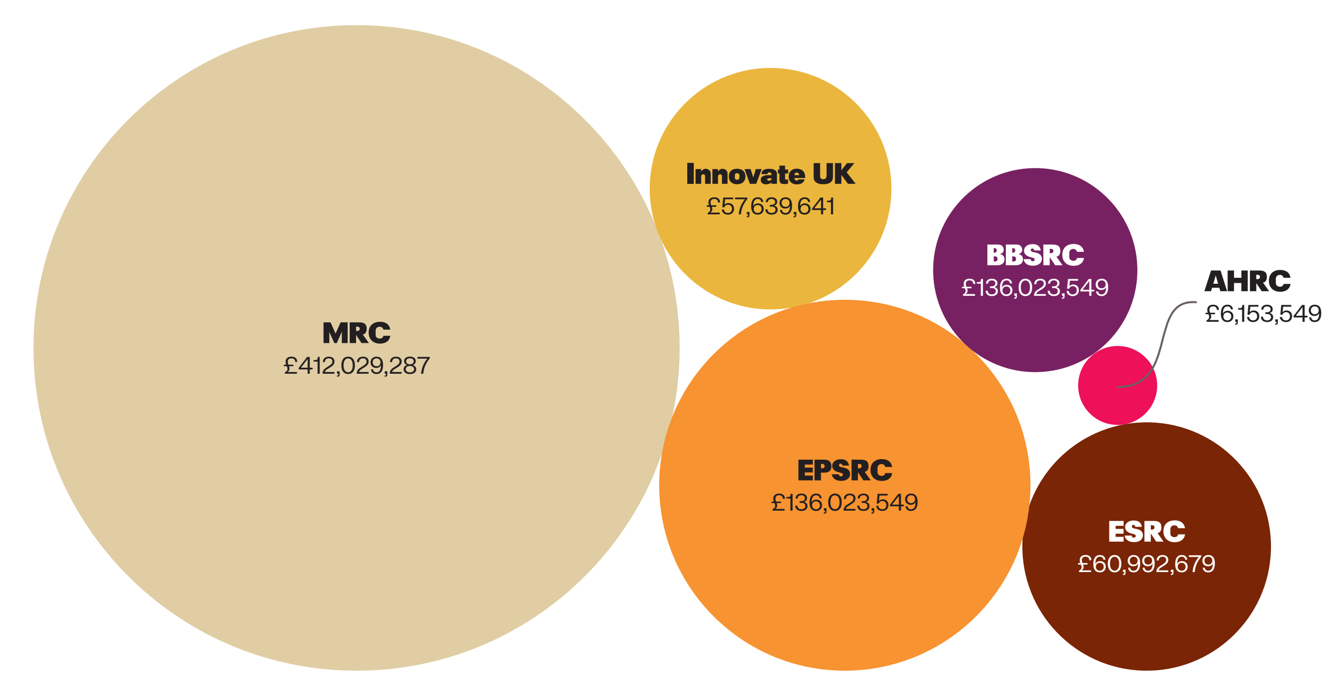
Having identified design-led research in dementia, the impact being made in the space was investigated. REF2021 was used for this, looking specifically at the impact case studies (Research England, n.d.). 181 impact case studies were found under the "Dementia" search with no other filters applied. The researchers reviewed the 181 and extracted any that were at least partially funded by one of the UKRI councils, leaving 72 UKRI-funded projects. The results are shown in Figure 8, displaying the funders and impact type for every project as pie graphs within the overall bubbles. The larger the bubble in Figure 8, the greater the number of projects the funder has funded. In cases where a project was funded by more than one council, a point was awarded to each funder.

Figure 8 concludes that the AHRC had more impact case studies returned to REF2021 (25) than the other UKRI funders, and provided primarily social impact as well as cultural. Since the AHRC's focus includes design, this highlights the positive impact design-led research has been making in the dementia space.

Notable projects using design to achieve impact include *Transforming the life quality of people with advanced dementia – and their carers – with a HUG™ by* Treadaway et al. (2021) which produced HUG™, a sensory comforter that improves the quality of life of people affected by advanced dementia through reducing anxiety, agitation and enhancing social interaction. Another project which achieved impact was *Innovation in Dementia Care: Positive Impact of Visual Arts Interventions* by Windle et al. (2021) which demonstrated how arts interventions improved the quality of life of people affected by dementia, with a 518% social value return on investment. A final noteworthy project is the *Enhancing dementia care via sensory design* (Jakob, A. 2021), a project which enabled care providers to improve the facilities and service they offer by creating more appropriate multi-sensory environments in their care-homes, as well as influence suppliers and support community projects. Each of these projects employed design to improve dementia research and the quality of lived of those living with dementia.

Figure 9 shows the total award amounts for each UKRI funder between 2006 and 2025. This highlights AHRC as the smallest funder of dementia research among the UKRI councils, with a total of £6,153,549 over

Figure 9: GtR search for "Dementia" limited to UKRI funders. Representing total award amounts between 2006 – 2025



the 19-year period. This is around 1/67th (1.49%) of the total expenditure of MRC, the largest funder by a considerable margin. Despite this relative lack of funding, as just discussed and shown in Figure 8, the AHRC is funding the greatest number of impact case studies returned to REF2021 of the UKRI councils. Whether one takes this as a definitive metric or as an indicative pattern, the significance is the same: design and arts-and-humanities-informed approaches appear to generate forms of impact that are highly relevant to patient care, especially where that care depends on meaning, inclusion, communication, behaviour, environment and lived quality rather than clinical intervention alone. In other words, design research can exert disproportionate influence where care outcomes depend on how systems are actually experienced.

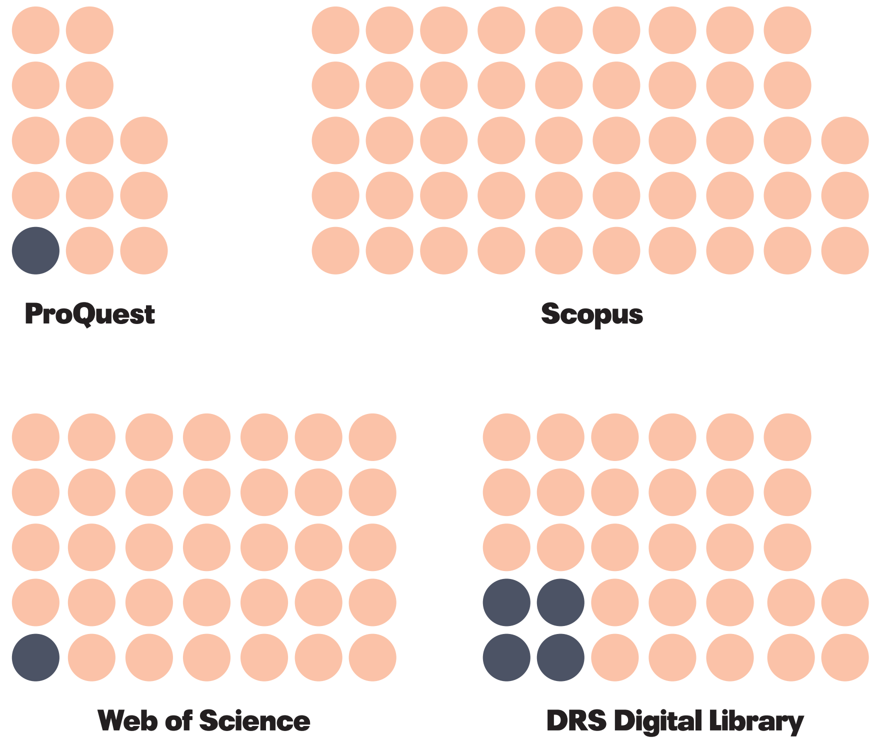
Global Literature Review

The focal points of global design-led dementia research were identified by several peer-reviewed literature searches. For global research, Scopus, Web of Science, ProQuest and Design Research Society (DRS) Digital Library were reviewed. To simplify categorisation, the dementia journey was narrowed to two categories to clarify whether the research contributed to pre-diagnostic processes or post-diagnostic care pathways. Figure 10 shows the result of this categorisation for each of the four databases used. Projects were chosen based on the selection criteria previously mentioned: whether the project has a direct and identifiable design output to it, or whether the project applies or contributes to design-based research methodologies. In the following section, an overview of the design-led projects' contribution to dementia research is provided, categorised by the themes they address.

Participatory and Co-design Methods

The literature on dementia and design (2006–2025) shows that participatory and codesign approaches were at the centre of methodological frameworks when designing with people living with dementia, particularly in post-diagnosis contexts. These studies emphasise that working directly with people living with dementia leads to more impactful and meaningful outcomes. Early work, such as Rodgers' co-designing with people living with dementia (2018), emphasises the importance of involving participants in shaping interventions and argues that transparency is the foundation of a truly symbiotic relationship. Branco et. al. (2017)

Figure 10: Pre – and post-diagnosis focus by projects identified in four databases



expand this by showing how openness, adaptability, and empathy enable designers to negotiate and personalise project briefs and methods to meet individual needs. These studies show how co-design supports agency and argue that care-focused design needs to remain grounded in lived experience. This includes frameworks that reinterpret participation as relational and dynamic (Winton & Rodgers, 2024), as well as flexible, and responsive to fluctuating capacities (Hendriks et al., 2018), supporting more equitable dementia participation. Earlier work, such as design probes used in the MinD project (Garde et al., 2018), similarly emphasises the importance of flexible, exploratory tools that enable researchers to gain varied insights about the perspectives of people living with dementia. Dankl's multidimensional design research framework (2020) offers guidance on coherence, ownership, and generative tools for cross-disciplinary dementia consortia. These studies show a shift toward more rigorous, reflective, and theoretically grounded approaches to design methodologies in dementia research.

Agency, Autonomy, Dignity and Well-being

Niedderer et al. (2019) position mindful interdisciplinary codesign as a means of enhancing agency and subjective well-being. This approach focuses on individuals' current capabilities, criticising deficiency-oriented approaches to life-limiting conditions. Kenning & Treadaway's work on sensory textiles (2018) shows how tactile objects can support well-being and emotional continuity throughout late-stage dementia and even serve as transitional memorials for families. These works together illustrate how sensory and aesthetic design can support dignity, emotional comfort, and a sense of self.

Cognitive, Social, and Emotional Engagement

Wesselink et al. (2025) demonstrate how adaptive invitation design in a music-based device can encourage engagement among people experiencing loss of initiative. Tan et al. (2022) and Peeters et al. (2016) show how e-textiles and personalised music systems, respectively, can strengthen sensory engagement, storytelling and positive affect. Anderiesen et al.'s (2015) and King & Siu's (2017) illustrate how playful interactions and cognitive gameplays can initiate meaningful engagement and sustain enjoyment when activities are well-matched to cognitive and sensory capacities. Tobiasson's (2015) exercise game research highlights how physical activity, competition, and social interaction contribute to well-being in special care units.

Sensory, Psychosocial, and Meaning-Making Interventions

Niedderer & Fung (2023) evaluate *Living the Life*, an evidence-based psychosocial intervention developed through co-design, showing how self-administered reflective tools can support well-being and meaningful activity. Research by Houben et al. (2022) on soundscapes demonstrates that personalised auditory experiences can evoke storytelling, interaction, and comfort among residents with moderate-to-advanced dementia. Similarly, Anderiesen & Eggermont (2013) explore playful design as a means of stimulation in Alzheimer's disease.

Maintaining Identity, Personhood, Connection, and Comfort

Studies such as Lima and Barreto (2025), who use life stories and cultural narratives to cocreate cognitive and sensory artefacts, highlight the importance of personal meaning in design processes. Francis & Murtha's investigation of first-person narratives in long-term care home design (2021) demonstrates how residents' stories reshape design priorities and reveal emotional relationships to place. Complementing this, Stevens et al. (2016) provide evidence of the importance of co-developing interior textiles and colours with residents, showing how aesthetics can elevate comfort and identity in everyday living environments.

Embodied, Sensory Expression

Mortati (2023) proposes multisensory immersive environments to encourage engagement and promote delight. Walker's exploration of everyday aesthetics (2022) demonstrates how visual and sensory probes help people with dementia express personal preferences in home environments, even nonverbally. Wood's musical transcription method (2020) shows how communication can be understood through tonal, rhythmic, and embodied cues beyond spoken language. These studies emphasise sensory expression not only as therapeutic but also as a means of maintaining identity, personhood and connection.

Design-led dementia research is committed to addressing a vast array of needs in dementia care systems all across the pathway.

Meaningful Spatial Cues, Supporting Orientations

Chen (2023) develops a spatial framework for creating a sense of home grounded in bodily habits and intimate spatial relationships. O'Malley et al. (2018) identify environmental design features that support orientation, showing that people with dementia prefer distinctive, meaningful spatial cues over signage-based solutions.

Creating Sense of Home and Belonging

Gramegna et al. (2023) explore community-engaged homemaking practices that help PLwD establish a sense of belonging in new care environments through meaningful objects and routines. Da Rosa et al. (2023) identify spatial and furniture priorities for therapeutic environments for people with MCI, emphasising seating arrangements, natural light, and multisensory outdoor spaces that contribute to social interactions. Earlier architectural work, such as that by Van der Linden et al. (2016), demonstrates how ethnographic case studies can inform architects in designing residential dementia environments.

Ethics by Design and Value Sensitive Design

Buhr et al. (2025) introduce empirical value-preference modelling to inform ethical AI-supported care, while Ballegaard et al. (2025) illustrate how participatory processes can help negotiate moral tensions in surveillance technologies. While fewer in number, these studies provide foundational ethical frameworks that complement the more numerous participatory and technological works. Two distinct papers (Köhler et al., 2022; Burmeister, 2016) apply value-sensitive design to assistive technologies in institutional dementia care. These works emphasise that technologies must honour autonomy, dignity, justice, and contextual understanding of lived experience as often requiring negotiation of conflicting values across people with dementia, families, and care staff.

Dementia-Friendly Environments to Support Well-being

Isaksen (2025) documents the operational realities of a Norwegian dementia village designed to promote autonomy and reduce medication use, indicating how purpose-built environments can gently support well-being. Similarly, extending this urban scale, McLaughlan et al. (2018) argue that dementia-friendly design must expand from suburban or institutional contexts into the street, public realm, and city infrastructure to genuinely support ageing in place. *De Korenbloem Sheltered Housing* (Tribillon, 2023) showcases a Belgian community integrated housing model for young-onset dementia, merging architectural care principles with urban social life.

Participation and Social Citizenship

Kelson et al. (2017) position public art as a vehicle for social citizenship, showing how young-onset dementia groups engage dynamically with outdoor public artworks. Museum-based arts education programmes (Belver & Ullán, 2019) similarly demonstrate gains in well-being, identity, and inclusion through guided cultural engagement. In parallel, *Mobility, Mood and Place* (Scott, 2017) highlights codesign as a foundational tool in age-friendly planning.

Communication, Information Tools and Practices

The codesign of tools to support communication continues in *Designing a Questionnaire for Pain Assessment* (Black et al., 2013), which demonstrates how physical and graphic design features can make clinical tools more usable for people with dementia and their carers during hospital admission. Similarly, Davies et al. (2024) introduce the EMBED Care Framework, a co-designed digital tool that structures holistic palliative dementia care, emphasising person-centred design, clarity of information, and shared decision-making to better support people with dementia and their carers.

Behaviour and Well-being in Healthcare Settings

Kirch & Marquardt (2023) show that dementia-friendly design in hospital settings improves selfcare capability and supports a shift toward more human-centred healthcare environments, while Quirke et al.'s development of the PlanEAT assessment tool (2023) offers a structured method for evaluating residential care layouts against evidence-based dementia design principles, which consider: safety; size and scale; visual access; stimulus reduction; useful stimuli; movement and engagement; privacy and social interaction; community links; and domestic activity.

Dementia-friendly Care Ecosystems

Shen (2023) positions service design as a means to transform dementia care ecosystems, proposing systemic contributions through 'involving, connecting and fostering' across communities. A related study by Shen & Sangiorgi (2023) uses dementia-friendly communities to demonstrate how design can activate local networks of support, shifting focus from deficits to remaining capacities. These works highlight a shift from designing isolated interventions to orchestrating multistakeholder care ecosystems. Mitchell & Zhao (2024) outline the design of *FRED*, an AI-powered social robot intended to reduce caregiver burden, emphasising ethical and accessibility considerations. Similarly, research on mixed reality technologies (Desai et al., 2020) shows how older adults with dementia interact with tangible and virtual prompts, underlining the role of embodied action and multimodal cues. These studies reflect growing interest in designing technologies that are embedded in everyday care rather than replacing human relationships.

While design-led research is positively contributing to the dementia research landscape, it is important to note that the vast majority of research focuses on the post-diagnosis stage

Design Futures, Speculative Approaches for Citizen Participation

The *Mentian* design fiction project (Darby & Tsekleves, 2018) uses participatory speculation to explore future dementia policy, showing how fictional artefacts can encourage debate and citizen ownership of care futures. Mapping care networks (Carey et al., 2016) also highlights the potential of design to illuminate systemic gaps and inequalities in dementia care provision.

Acceptance of Assistive Technology

Overall, with expertise spanning the built environment and architectural design, sensory and technological design, speculative and participatory approaches, and communication, information, and ethical considerations, design-led dementia research is committed to addressing a vast array of needs in dementia care systems all across the pathway. In literature we observe a range of innovative and creative design interventions (*e.g.*, products, spaces, and services) that have been developed for disrupting the cycle of well-formed attitudes and opinions, policies, commonly-held beliefs, and ways-of-thinking and acting that often remain unopposed in the health and social care of people living with dementia. These highlight how design-led thinking, making, and doing are at the forefront of envisioning future dementia health and social care, ensuring that people living with dementia live their lives to the fullest (Rodgers, 2022).

While design-led research is positively contributing to the dementia research landscape, it is important to note that the vast majority of research focuses on the post-diagnosis stage, mirroring the work found in Gateway to Research. This reinforces the magnitude of the research gap that lacks focus on early signs and pre-diagnosis, emphasising the need for design research to pay attention to this area, particularly if it is to address the government's mission to increase diagnostic rates with accuracy and continued support.

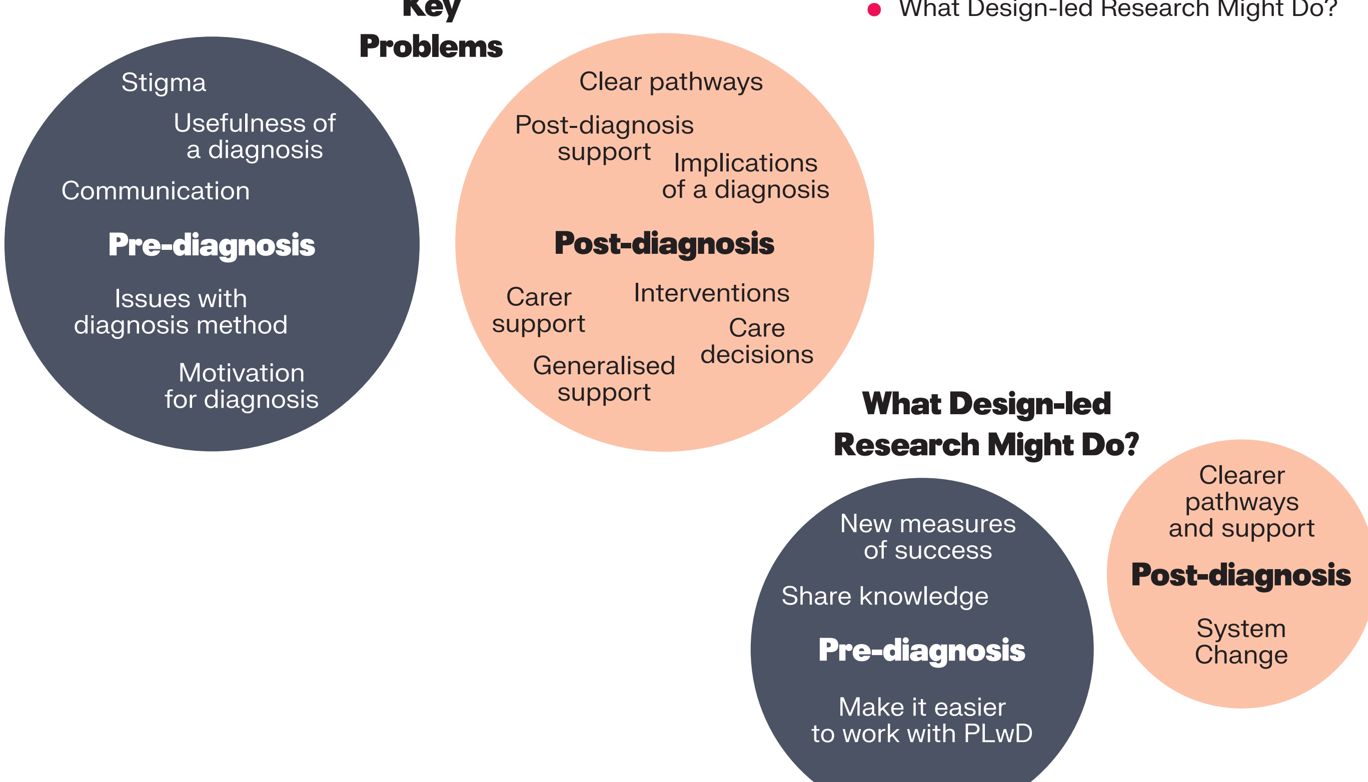
The work included the organisation of three workshops created to map the dementia research landscape through the lens of a diverse range of different disciplines. The workshops helped identify the key problems from the experts' perspectives, highlighting significant issues, weaknesses, strengths, and opportunities where design-led research might play future roles.

Workshops

Workshop 1, December 2025

The first workshop was held at the University of Strathclyde, Glasgow, on 1st of December, 2025 and included researchers and practitioners from a wide range of disciplines and expertise in digital health and wellbeing, dementia policy and practice, design, and computing. The focus of the workshop was to identify:

- Key Problems in Dementia Care (both pre-diagnosis and post-diagnosis)
- What Design-led Research Might Do?



Workshop 2, February 2026

The second workshop was held at the Helen Hamlyn Centre for Design, Royal College of Art, London on the 17th of February, 2026. Experts from disciplines such as psychology, palliative care, behavioural science, health and community sciences, and design including various Dementia Network Plus members participated in the workshop. The focus of the second workshop, building on the first workshop, was to explore and identify issues surrounding dementia diagnosis and care pathways:

- What are the Key Problems?
- What is Currently Working Well?
- What Would You do to Improve the Current Issues?
- What Needs to be Prioritised?

Key Problems

Pre-diagnosis

Lack of Awareness and Knowledge

Fear and stigma

Managing expectations (diagnosis, care and behaviour change)

Discrepancies regarding, and lack of services and support for, diagnosis

Lack of services and support for diagnosis

Choice and motivation to know

Post-diagnosis

Lack of post-diagnosis support

Accommodating different pathways and needs

Supporting informal carers and families

Care and support inequalities

What is Currently Working Well?

Pre-diagnosis

Awareness and visibility (but lacks critical understanding)

Staff (more needed)

Informal support groups

Large number of memory services

Pockets of good practice

Strategy national / international

Emerging pre-symptomatic biomedical tests for identification of Alzheimer's disease

Post-diagnosis

Creative and innovative care practices

Third sector support in navigating dementia (e.g., dementia friends, Admiral nurse, dementia coordinators, dementia advisers)

Local, place-based, and grassroots community-based support

Creative and design-led Interventions

Creative and innovative care practices

Informal peer support (through community groups)

Recognition of need for different responses to different symptoms

Figure 11: Workshop 2, Helen Hamlyn Centre for Design, Royal College of Art, London.

What Would You Do to Improve the Current Issues?

Pre-diagnosis

- Greater awareness and stigma reduction
- Young-onset pathways/ frameworks
- Joined-up approaches
- AI and tech-based solutions
- Person-centred clear pathways
- Choice on diagnosis, individual at centre

Post-diagnosis

- Creative interventions and future thinking
- Young-onset pathways and frameworks
- AI and tech-based solutions
- Shared guidelines, expertise and resources
- Person-centred, integrated, continual support and services

What Needs to be Prioritised?

Now

- Memory clinic modernisation
- Build and sustain networks
- Clinical, social and public education of rarer subtypes
- Share expertise and remove silos
- Include under-represented groups and community voices
- Make resources [for] universal/ inclusive design
- Co-create networks blending knowledge and expertise
- Design health systems/ resources that embed continuity of care (within team and over time)
- Remove the burden on the individual
- Meeting centre in every community
- Coordinate information and expertise

Mid-term

- Aligning workforce with AI
- More link workers

Long-term

- Personalised healthcare
- Risk awareness and behaviour change
- Sense of regaining control after diagnosis

Workshop 3, March 2026

The third workshop was held in Edinburgh at the Training and Conference Centre on the 24th of March, 2026. The focus of this workshop was to identify how design-led research can help address some of the key issues surrounding dementia diagnosis and care pathways. This workshop was attended by experts in architecture, design, dementia, nursing, psychology, as well as a participant from Dementia UK and an Admiral nurse. This workshop, building further on the themes explored in workshops one and two, posed the following questions:

- What are the Key Problems?
- What is Currently Working Well?
- What Would You do to Improve the Current Issues?

Once the key problems were identified by the workshop participants, we asked them to identify the key contributions that design-led research might make to these areas by asking:

- What are the Key Issues for Design-led Research to Address?
- What Can (Will) Design-led Research Do?
- What Needs to be Prioritised?

Key Problems

Pre-diagnosis

Pre-diagnosis and post-diagnosis support
Research
Awareness and stigma
Clear pathways
Accurate diagnostic tools and better diagnosis process
Decision-making, consent and choice

Post-diagnosis

Staying active and access to outdoors
Environmental design
Autonomy
Carer support
Hospital admissions
Future planning
Stigma
Clear pathways
Workforce
Multimorbidities

What is Currently Working Well?

Pre-diagnosis

Risk factors
Scan accessibility
Lifestyle improvements
Risk factors

Post-diagnosis

Post-diagnosis support
Support in community
Third sector and community networks
Holistic and person-centred support
Workplace incentives to support in workplace
Supporting autonomy and normality
Single point support and dementia hubs

What are the Key Issues for Design-led Research to Address?

PLwD-led Co-design and research

Multiple types of evidence

Inclusive and enabling environments and tools

Impact and policy influence

What Needs to be Prioritised?

Community and people-led design and research

Help with future planning

Multidisciplinary public health research

Considering different pathways

Nationwide good design principles and policy

Communicate research impact and benefits widely

Incentives to support research participation

What can (Will) Design-led Research Do?

Pre-diagnosis focus

Multidisciplinary joined-up approaches

Co-design tools for cognitive health with PLwD

Raise awareness and reduce/ remove stigma

Summary of Workshops

The workshops highlighted three key emergent issues:

- The need for clear diagnostic pathways;
- Varied and accurate diagnostic tools;
- High-quality, person-centred post-diagnosis support.

In addition to these three key issues, the importance of raising awareness, including of the rarer subtypes of dementia, to combat both fear and stigma, was frequently identified. These recurrent themes are at the core of supporting someone concerned about dementia from the very start of their journey through to diagnosis pathways and post-diagnosis support.

Some workshop participants emphasised that obtaining a diagnosis of dementia should remain a matter of personal choice. While a diagnosis can be beneficial, it may also alter how others relate to the individual. It is therefore essential to ensure that people continue to feel valued and included after receiving a diagnosis of dementia, and that they are supported well throughout their journey. Additionally, there are important aspects of living with dementia that may be less visible. People who live alone, as well as those experiencing cognitive difficulties but not actively seeking a diagnosis, should also be offered appropriate support from health and social care services.

Furthermore, concerns were raised regarding the potentially negative consequences of increased number of people diagnosed with dementia to reach the mission target of 92%. Several participants suggested that it would be irresponsible and unethical to diagnose more people if adequate post-diagnostic support cannot be provided immediately following diagnosis.

Consequently, person-centred and holistic post-diagnostic support, ideally coordinated through a single point of contact such as Admiral Nurses, community link workers, or dementia advisers, was identified as essential. This approach was suggested to facilitate navigation of complex care systems, ensure timely access to appropriate information, and support individuals and families in planning for the future.

Similarly, workshop participants stressed the need for preventative measures to reduce avoidable hospital admissions, as the acute hospital environment can be highly

The importance of a comprehensive, nationwide dementia strategy was frequently emphasised across all three workshops.

distressing for people living with dementia, often exacerbating existing symptoms

The inclusion of people with lived experience, including carers and people from under-represented groups, in co-designing and co-leading research with lived experts to increase the relevance and the impact of the research was another theme that was highlighted frequently in the workshops.

From a research perspective, increasing and encouraging participation from the general public in dementia research was highlighted. Workshop participants also emphasised the importance of more coordinated, joined-up approaches across multidisciplinary teams. Also, sustained follow-up funding was identified as essential to ensure long-term impact, alongside the development of shared platforms that connect researchers from different disciplines thus reducing unnecessary duplications and avoiding 'reinventing the wheel'.

The importance of a comprehensive, nationwide dementia strategy was frequently emphasised across all three workshops. However, several participants highlighted that the mere existence of a policy or strategy does not necessarily guarantee its effective implementation. Clear design principles and guidelines emerged as another key theme reinforcing the importance of embedding good practice and high-quality care into products, services, systems and environments from the earliest stages of the design process.

Another important theme the workshop participants stressed was the ethics application processes involved in research projects. These processes were described as difficult, complex, resource-intensive, lengthy, and often risk-averse. These challenges were viewed as particularly problematic for research involving people in the advanced stages of dementia, where procedural delays can significantly restrict participation.

The consideration of young-onset dementia and the needs of people with dependants, many of whom remain active in the workforce, was identified as another critical theme. With an increasing number of individuals receiving a diagnosis at a younger age, the implications for employment and caring responsibilities of people with dementia require careful attention.

It was widely acknowledged that third-sector organisations and community groups play a crucial role in supporting people living with dementia, particularly in contexts where health and social care services are lacking or insufficient. However, these services often face precarious and inconsistent funding, raising concerns about their long-term sustainability. Improved and meaningful carer support, including access to carer respite, emerged as another central theme across the three workshops, reflecting the well-established relationship between carer well-being and the well-being of people living with dementia. Here, workshop participants highlighted the importance of community groups, community-based meeting centres, and networks supported by third-sector organisations. Embedding advocacy and sustained support within these services was highlighted as essential to ensuring continuity of high-quality post-diagnosis care.

With regards to ongoing support, participants described the transformative potential of psychosocial interventions and emphasised the importance of structured, 'prescribed' social interactions in maintaining well-being. The ability to remain at home and stay physically active, alongside access to outdoor environments, was also frequently mentioned. Risk-averse approaches and protocols within care homes and healthcare settings can restrict outdoor access, with detrimental effects on mobility and overall well-being.

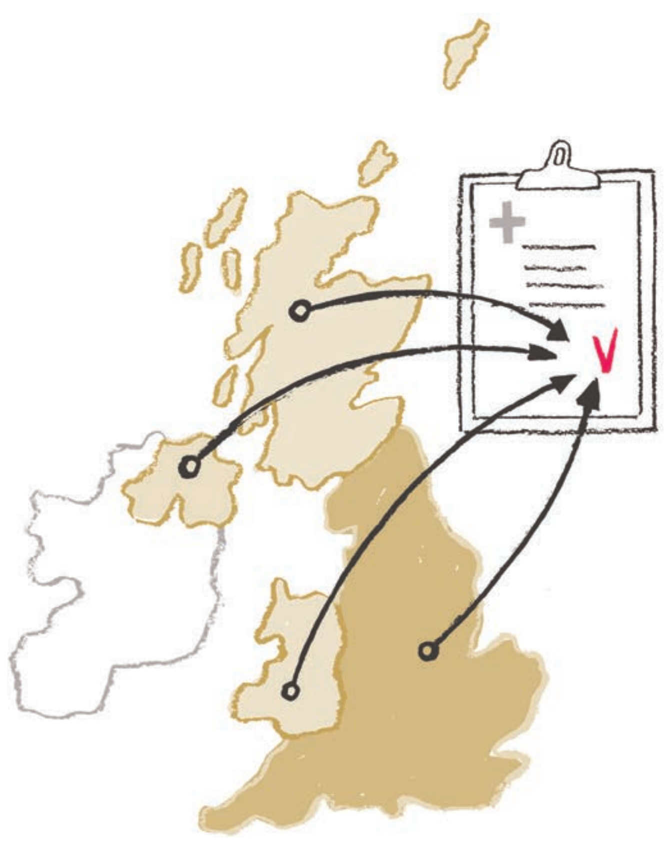
The following recommendations for design-led research are based on the scoping study's work conducted between October 2025 and April 2026, which comprised desk-based research that focused on a review of globally-published literature and UK-based impact case studies in addition to three design and dementia stakeholder workshops with over 30 participants. The recommendations set out below accurately reflect the results, insights, and findings.

Recommendations for Design-led Research

There are cross-cutting principles that apply to each of these recommendations. These are:

1. People with dementia and their carers should be involved at every stage of the research;
2. All research must be person – and community-led, culturally competent and inclusive;
3. Equity across geography, age, sex, gender, ethnicity and dementia subtypes should be sought;
4. Research and innovations should be implementation ready with clear accountability for long-term impacts;
5. All guidelines and ethics processes should be proportionate to the risk and easy to use and adopt.

Early Identification and Diagnosis Pathways



1. Design National Clear Diagnosis Pathways

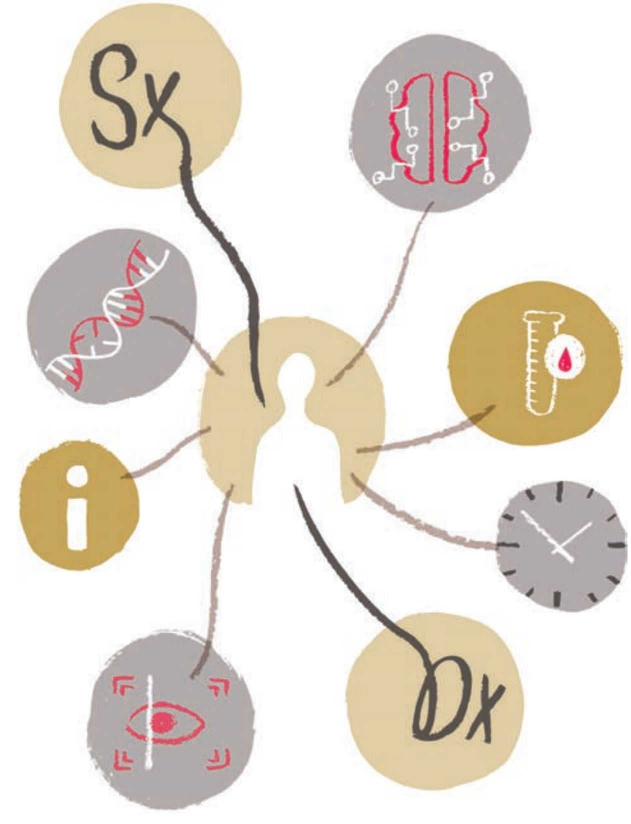
Design-led research should support the development of clear and consistent diagnostic pathways across UK geographical regions, enabling people living with dementia and their carers to better understand what to expect at each stage of the dementia journey. A national care standard must cover the entire dementia pathway, including pre-diagnosis, to help reduce regional disparities in care (Alzheimer's Research UK, 2025).

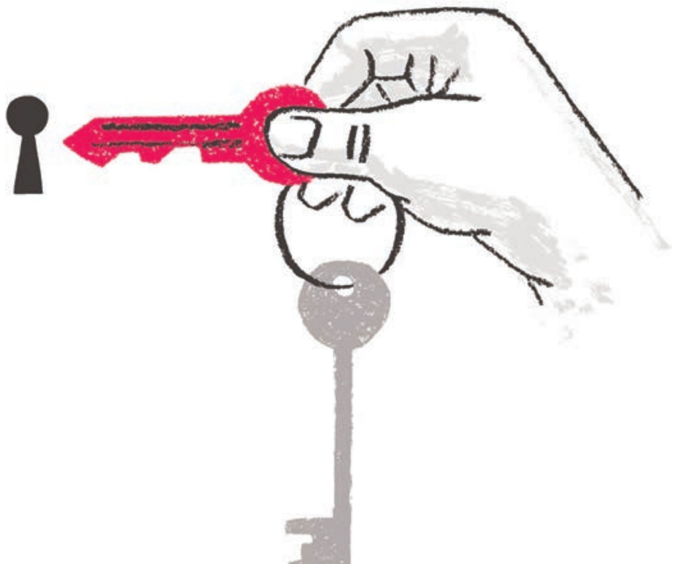
Scaling Integrated Care Systems (ICSs), alongside one-point-contact coordinators and advisers, is essential to improve access, reduce delays and lower avoidable hospital admissions. If scaled nationally, these can help tackle regional care disparities (Morris et al., 2024).

2. Design Accurate and Varied Diagnostic Tools

Design-led research should help develop validated screening tools suitable for primary care, quick enough to use within standard GP appointments, and requiring minimal training or additional resources (Alzheimer's Research UK, 2022a).

Diagnostic tools must be person-centred, subtype-sensitive, culturally appropriate, educationally sensitive, and accurate (Prince et al., 2003). Supported by investment in infrastructure that ensures readiness for future demand and long-term sustainability (UK Dementia Research Institute, 2024).





3. Design Ways to Improve Awareness of Early Signs

National awareness campaigns should be designed to educate rather than frighten, improving understanding of the early signs, symptoms and the benefits of diagnosis (Department of Health, 2009).

Conversations about brain health and dementia risk should be integrated into appropriate consultations, supported by community link workers and improved service signposting (Alzheimer's Research UK, 2019).

4. Design Ways to Eliminate Stigma across Demographic Groups

Design-led research should address dementia-related stigma by creating bespoke education campaigns, outreach programmes, and support networks that reflect the experiences of diverse groups (Siette et al., 2023).

Structural stigma should be challenged through inclusive policy and service design, with meaningful representation of people living with dementia fundamental to achieving change (Alzheimer's Disease International, 2024).

Collaborative, Sustainable, Long-term Impact

5. Strengthen Cross-Organisational Innovative Collaborations

Design-led research must involve people living with dementia alongside clinicians, researchers and the third sector, policymakers, and industry to redesign diagnostic pathways and tools (WHO, 2022).

Greater interdisciplinary funding and collaboration are required across primary care networks, ICSs, care homes, and community organisations to support continuity along the diagnostic journey (Alzheimer's Society, 2024).

6. Design for Policy Implementation and Accountability

Policy informed by design-led research should be implementation-ready, with delivery mechanisms and accountability considered from the outset (Cabinet Office, 2015).

Design-led research should support primary care to meet current challenges while planning for future demand through integrated, scalable approaches to diagnosis (Alzheimer's Research UK, 2022b).

7. Sustainable Funding for Design-led Research

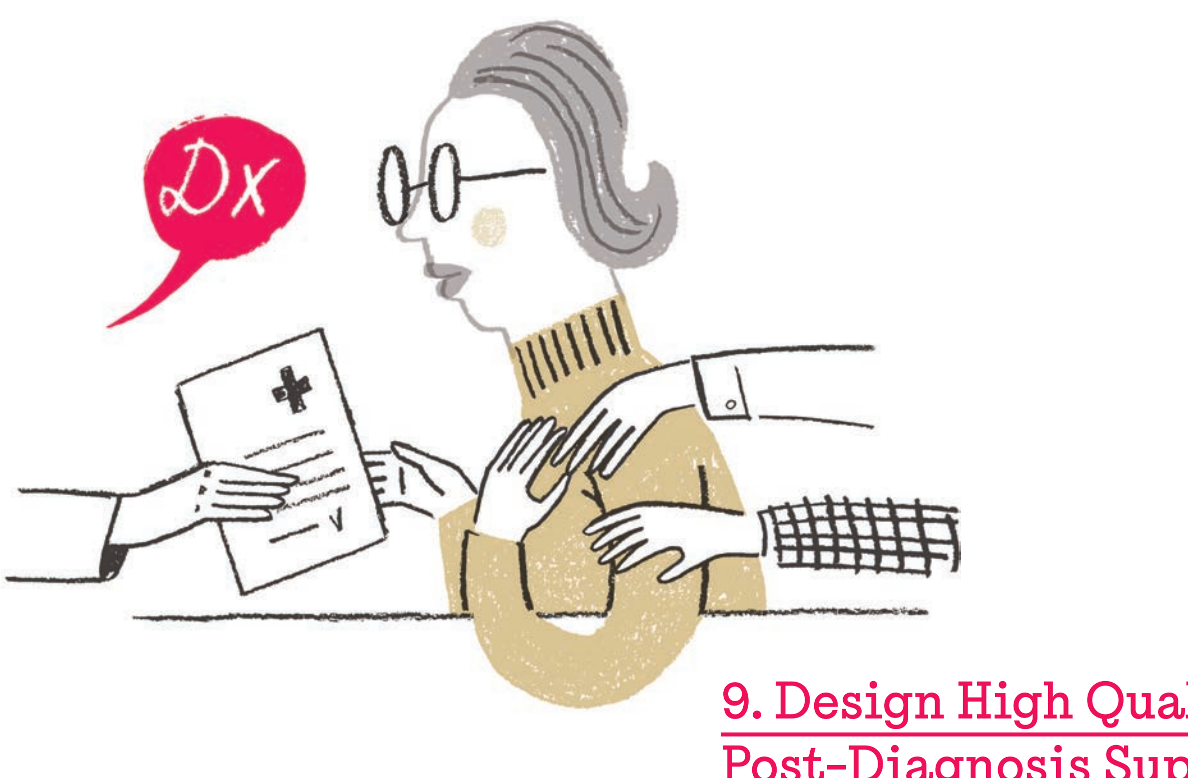
Long-term, strategic investment is needed to support design-led dementia research, grow the workforce, and embed design within wider healthcare priorities (UK Dementia Research Institute, 2024).

Investment should focus on strengthening successful institutes, labs, and place-based centres or networks of impact across the UK.

8. Establish Regional Design-led Research and Innovation Hubs

Establish regional dementia knowledge exchange hubs with distinct areas of expertise and regular cross-hub exchange. Incorporate design research into each hub to develop specialised, design-led dementia expertise informed by this multidisciplinary exchange.

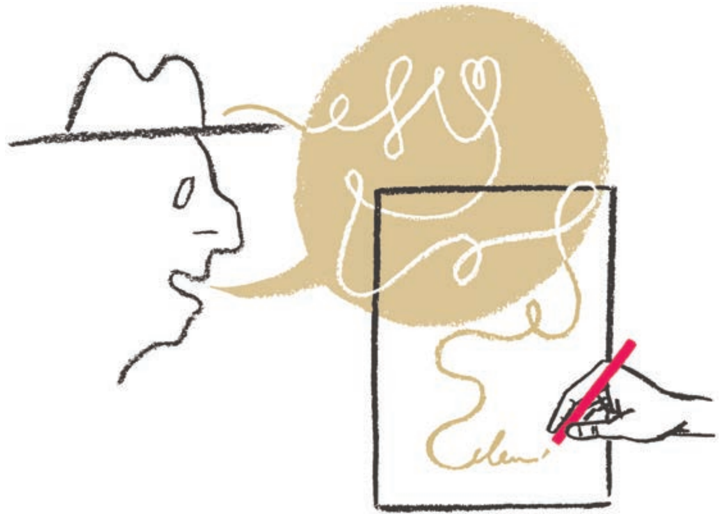
These hubs should provide regionally responsive, specialised design knowledge informed by and accountable to lived experience and emerging local care needs.



9. Design High Quality Post-Diagnosis Support

Design-led research should support person-centred specialist post-diagnosis care, including psychosocial interventions and improved access to dementia nurses, navigators and advisers. This support should consider both the needs of people living with dementia and their carers (Dementia UK, 2024; Lawrence et al., 2012).

National rollout of comprehensive annual dementia care reviews is needed to ensure joined-up health, social care, and well-being support. Design-led research must also support shaping young-onset dementia frameworks and their integration into ICSs (Dementia UK, 2024).



10. Design and Develop New Measures of Success

Design-led research should help develop new and meaningful measures of success, centred around specific, measurable, achievable, relevant and time-bound goals defined by people living with dementia (Pool & Evans, 2025).

Additionally, there is a need for larger, well-designed evaluations of these measurement instruments in care home settings, alongside the use of multiple measures that capture perspectives from both people living with dementia and those who support them, to fully represent perceived quality of life (Hughes et al., 2021; Griffiths et al., 2020).

11. More Late-Stage Design-led Dementia Research is Needed

More design-led research is needed to address late-stage dementia and end-of-life care for people with dementia, recognising that dementia is a complex, long-term condition (Aldridge et al., 2020).

Integrated, multidisciplinary approaches should be designed to support care home staff in recognising late-stage needs, when a person is nearing the end of their life, and to enable families to communicate their views on end-of-life care (Marie Curie, 2016; Crowther et al., 2022).

Design-led Methods, Sector-wide Frameworks, and National Guidelines

12. New Design-led Approaches and Ways of Working with PLwD

Design-led research should develop innovative, person-led ways of working with people living with dementia that emphasise autonomy, personal values, choice and agency. These approaches should be embedded across research and service development, promoting inclusion, participation, and social justice while ensuring that lived experience is meaningfully shaping outcomes (Wilson-Wynne, 2025; Reyes et al., 2023).

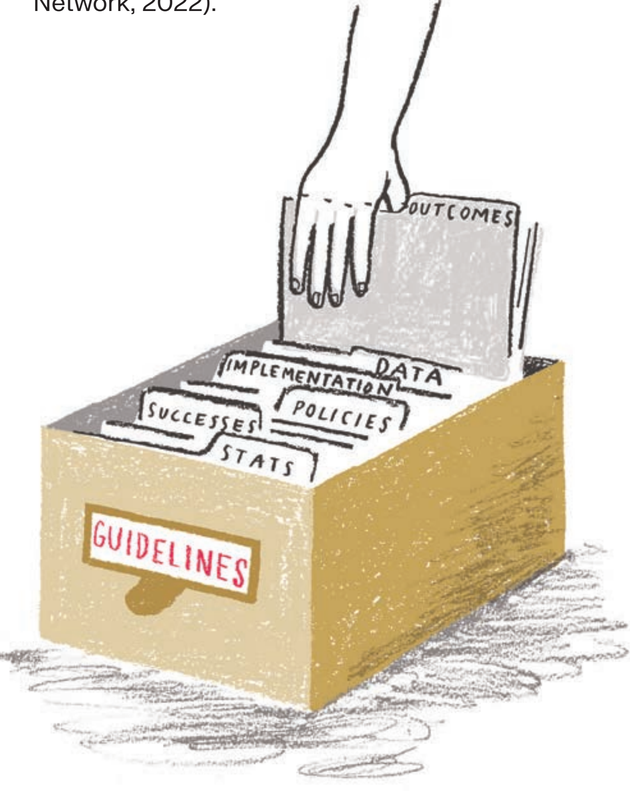
Greater use of creative and participatory design-led methods is needed to better understand the complexities of PLwD's well-being and agency over time (Zeilig et al., 2019).

13. Design National Guidelines for Designing Products, Services, Systems

There is a need for clear, UK-wide guidelines for the design of products, services and systems when designing with people with dementia to reduce duplication across projects and funding cycles.

These guidelines must adopt an empathy-first approach, drawing on lived experience and expert knowledge to ensure relevance, consistency, and maximum impact (Alzheimer's Society, 2022).

A national young-onset dementia framework should be developed to provide age-appropriate immediate post-diagnostic support, including workplace adjustments, legal and financial planning (Young Dementia Network, 2022).



14. Create National Ethics Charter

A national ethics charter should be developed to streamline processes, ensure proportionality to risk, and reduce duplication across institutions DEEP, 2023).

Design-led research should promote risk-proportional approaches, recognise the decision-making capacity of people living with dementia, and embed cultural competence and inclusive methods throughout research design and delivery (DEEP, 2023; Shatnawi et al., 2023).

People with dementia and their carers are left to navigate complex systems without continued support after diagnosis, and an accurate diagnosis itself can take years.

Conclusions

Dementia is a public health priority that is placing significant strains on health and social care services both in the UK and globally. This scoping report explores how design-led research can contribute to addressing some of the major challenges surrounding dementia diagnosis and care. This report includes a review of relevant literature and results from a series of expert stakeholder workshops that were conducted to understand what needs to be prioritised to provide continuous, holistic support to people living with dementia and their carers, to ease the strain on current services, and increase the dementia diagnosis rate.

The report highlights that current dementia services are failing to meet demands; people with dementia and their carers are left to navigate complex systems without continued support after diagnosis, and an accurate diagnosis itself can take years. Likewise, healthcare services are struggling to meet rising demand due to factors including staff shortages, training gaps, resource limitations, and sector-wide guidelines. As the report has shown, some of this is due to the complexity of dementia as a long-term, heterogeneous condition that can exhibit profound individual differences. Dementia requires a cross-service, joined-up effort including UKRI-funded research and national health and social care services. Pockets of good practice exist. However, there are stark regional differences across the UK. Third-sector organisations and other informal support initiatives play a crucial role in supporting people living with dementia and their carers, often addressing the gaps in dementia care services.

Our findings clearly indicate that person-centred approaches should be a priority, and lived experiences, both from people living with dementia, their family members, and their carers, should be at the centre of research, including setting research priorities to contribute to outputs that achieve meaningful impact. Design-led research, with its expertise in person-centred, participatory approaches, including the creation of innovative co-design methods and tools, has a key role to play in advancing the future of dementia care.

The review of the literature shows that design is not only championing co-design and participatory methods and tools but is also enabling new methodologies that enhance empathy, compassion, and participation. Design-led research shows that by placing meaningful interactions at the centre of new interventions, products, services, and systems, supporting holistic well-being is integral to establishing sustainable healthcare. Responding to an acute need, design-led projects address the common loss of initiative by encouraging cognitive, social, and emotional engagement. They expand critical understandings of continued personhood and the maintenance of one's identity through creative means, even when verbal expression is not accessible. Consequently, these projects offer crucial insights for developing new measures of success to understand the changing needs of both PLwD and their carers, as well as differences in quality-of-life goals.

Additionally, design research connecting design, policy and participation offers important insights for establishing sector-wide design guidelines that support national best practice. Related work on value-sensitive design and ethics-by-design approaches emphasises the need to embed ethics early in dementia-friendly design, which is essential for developing ethical technologies that support PLwD.

Design-led interventions are paving the way for more widespread purpose-built dementia-friendly environments, products, services and systems by centring autonomy, agency and living well.

Current efforts remain largely siloed, resulting in duplication of work and limited long-term impact. This fragmentation prevents the development of a holistic understanding of dementia that considers its medical, social, economic, and psychological dimensions together.

Similarly, introducing creative design features into otherwise verbal and text-led tools can advance the development of accurate diagnostic and measurement instruments. Embodied, non-verbal, and sensory tools extend communication beyond spoken language, supporting research on advanced-stage dementia. These also inform ethics processes by enabling the inclusion of individuals with changing capacities, irrespective of their mode of communication.

Overall, design-led interventions are paving the way for more widespread purpose-built dementia-friendly products, services and systems by centring autonomy, agency and living well. Whether it's supporting well-being through comforting tactile products or promoting autonomy through innovative spatial cues to aid orientation, design-led interventions enhance high-quality post-diagnostic support ecosystems.

Finally, it is clear that there is an opportunity to create shared hubs of knowledge exchange and joined-up approaches across disciplines and across geographical boundaries. Current efforts remain largely siloed, resulting in duplication of work and limited long-term impact. This fragmentation prevents the development of a holistic understanding of dementia that considers its social, economic, and psychological dimensions together.

Integrated approaches to health and social care will be essential for building future-resilient dementia care systems. Creative subjects, such as design, with their commitment to advancing holistic approaches to well-being, will be integral to these integrated care systems, as recognised by both the All Party Parliamentary Group on Arts, Health and Wellbeing (2017) and the World Health Organisation (2019). Integrated cross-organisational collaborations will be key to addressing rapidly increasing demands on multifaceted health and care ecosystems. These collaborations will be better suited to offer long-term, meaningful, sustainable impact.

Next Steps...

In what follows, we propose some next steps for AHRC / UKRI funding to improve both pre-diagnosis and post-diagnosis stages of dementia health and social care support. It is imperative that every future project in this space includes and involves people living with dementia and their carers at every stage of the research. Also, every project must be person – and/ or community-led and ensure equity across geography, age, sex, gender, ethnicity and dementia subtypes. Our next steps for AHRC / UKRI funding are:

UK Regional Design-led Research and Innovation Hubs

with distinct areas of expertise and regular cross-hub exchange should be established. Each Hub will be built around design-led research to develop specialised, design-led dementia products, services and systems that are regionally responsive, informed by and accountable to people living with dementia (PLwD's) experiences and emerging local care needs. Each Hub would provide place-based, responsive, and specialised design knowledge, skills and expertise informed by emerging local care needs, while also benefiting from inter and multidisciplinary knowledge exchange. Integrated design hubs will be essential for building future-resilient dementia care systems. Cross-organisational collaborations will be better placed to attract more sustainable funding by contributing to complex health and social care ecosystems rather than to short-sighted, fragmented interventions. These design-led research hubs would invest in long-term relationships with regional lived-experience communities. By grounding research and innovation in the expertise of people living with dementia, their families, carers and healthcare professionals, the design-led projects would be implementation-ready and capable of delivering sustainable, measurable, and long-lasting impact. The hubs will support interdisciplinary research excellence.

Dementia Pre-diagnosis and Post-diagnosis Pathways and Navigation Tools

need to be defined, designed and implemented collaboratively by design-led researchers, lived-experience experts, and relevant healthcare professionals. This will help show how different pathways are experienced by different stakeholders and how they can be implemented to better support people living with dementia, their carers and families, and health and social care staff. These mapping tools should be utilised to co-create future pathways with clear implementation goals to inform better pre-diagnosis and post-diagnosis navigation provision and the redesign of existing infrastructures and systems.

By grounding research and innovation in the expertise of people living with dementia, their families, carers and healthcare professionals, the design-led projects would be implementation-ready and capable of delivering sustainable, measurable, and long-lasting impact.

Validated Design-led Research Guidelines for Dementia

should be created to support better researchers when working with and/ or co-designing with people living with dementia. Joint efforts between the Design Council, dementia advocacy charities and the AHRC-funded Design | Policy Network to establish and distribute up-to-date, validated guidelines that include design-led, creative, inclusive, and accessible methods for both co-designing with PLwD and designing for dementia should be developed. These guidelines should be implemented into policy and followed by sectors that have a direct impact on how dementia-friendly the future is. These guidelines should incorporate existing creative methods, such as compassionate design, emphatic design, and mindful design, among others, that have been co-developed by people living with dementia and design researchers. These guidelines should address not only specific aspects of designing products, services, and environments but also the long-term systemic aspects of making communities more dementia-friendly.

Joint Research / Data Sharing Platforms for Design-led Dementia Researchers

is needed where researchers can connect and learn from one another more rapidly. These platforms will support the sharing of research methods, designed outputs, and impacts, as well as the formation of interdisciplinary networks amongst researchers tackling similar aspects of dementia challenges from different lenses. The platforms will prevent duplication of efforts and enable the development of more rigorous, widely tested methods, while adding to the canon of design-led research with each iteration. Similar to MRC's Dementias Platform, there is a need to establish a design-led dementia research platform.

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Conclusions

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There are currently estimated to be nearly 1 million people living with dementia in the UK, which will rise to almost 1.4 million by 2040.

The total cost of dementia care in the UK is currently £34.7 billion, forecast to rise to £94.1 billion by 2040.

It is clear that the demand for innovative and effective health and social care services will only continue to increase.

This report provides a clear picture of how design-led research can meaningfully address this issue.

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