“Good support isn’t just about ‘services’ – it’s about having a life.”

Supporting People Affected by Dementia to Live Well: The Role of Dementia Hubs and Dementia Navigator Services

Evidence Review

IMPACT DEMONSTRATOR PROJECT

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INTRODUCTION

This review explores evidence from the scholarly and policy- and practice-relevant research literature focusing on the role that community-based dementia support hubs and dementia navigator services can have in helping support people with dementia (PWD) and their family members who care for them to live well. The review has been conducted for the *Supporting People Affected by Dementia to Live Well IMPACT Demonstrator Project*, which aims to develop a social rather than clinical pathway for providing support to improve the lives of those affected by dementia. Focusing on defining what constitutes a community-based support hub and a dementia navigation support service, outlining the core characteristics of different models of each type of service and their associated outcomes, as well as the facilitators and barriers to their implementation and delivery, this review synthesises and provides a descriptive overview of the evidence available.

Background Context

Dementia is a progressive condition that commonly results in degenerative brain function, memory loss, difficulties with communication, and declines in reasoning, analytical abilities and other cognitive thinking skills that interfere with daily life and functioning (Abrams et al. 2024; Alzheimer’s International, 2025). The most common type of dementia is Alzheimer’s disease, with other types including vascular dementia, Lewy body dementia, mixed dementia (Anthonisen et al. 2023), and frontotemporal dementia (NHS UK, 2025). Dementia mainly affects older people, with the likelihood of developing dementia doubling every five years after the age of 65 (NHS England, 2025). However, dementia can also develop earlier, presenting different issues for the person affected, their caregiver and their family (ibid).

According to the World Health Organization, approximately 50 million people throughout the world are living with dementia, with 10 million new cases diagnosed every year (Alzheimer’s International, 2025). In the UK, the number of people with dementia is approx. 850,000, with 676,000 of these living in England (NHS England, 2025). Dementia presents a major global health challenge because, in the near future, the number of people living with dementia worldwide is predicted to increase rapidly (Abrams et al. 2024). By 2030, global dementia rates will be approximately 78 million, with the numbers in England and Wales being expected to rise to 1.7 in England and Wales by 2040 (ibid). By 2050, the number of people worldwide expected to be living with dementia will rise to approximately 139 million (ibid).

The rising rate of dementia means that planning for and ensuring appropriate dementia care is a priority for the NHS and the UK government (ibid). Dementia services are also expected to align with the National Institute of Clinical Excellence (NICE) recommendation for service users to have a single point of contact (ideally a health or social care worker) for all their dementia-related care needs (ibid). In addition, it is also expected that community services and informal care will form a substantial part of how UK future care needs will be met (Jitendra and Bokhair, 2024). However, many carers also feel undervalued and unrecognised, with 57%

saying that they need better understanding and recognition of their role from the general public (Carers UK, 2025: 18).

Research reveals that dementia care and support often remains fragmented, uncoordinated, and difficult to navigate (Anthonisen et al. 2023; Abrams et al. 2024; Kelly and Innes, 2016). In particular, people with dementia and their caregivers often report a lack of knowledge of dementia and about available support services, in addition to difficulties accessing relevant health and social care services (Giebel et al. 2021). This can contribute to unmet needs and poor health outcomes for people with dementia and their caregivers (Anthonisen et al. 2023; Gelmon et al. 2025; Giebel et al. 2021). In addition, research has also shown that many carers for those with early onset or rarer types of dementia may have greater difficulties obtaining information and accessing relevant support services (Giebel et al. 2021). Those from systematically marginalised communities may also be at greater risk of poor outcomes, owing to greater difficulties accessing information and support that aligns with specific linguistic, socio-cultural, and disability-related needs (Gelmon et al. 2025; Kelly and Innes, 2016; Bowes et al. 2009).

These concerns have cumulatively led to increased interest in improving the pathways by which people with dementia and their caregivers can obtain access to support and information within the community to enable them to live well (Kelly and Innes, 2016). Two ways of achieving this are via dementia hubs and dementia navigation services.

Objective and Aims

As this review was conducted for the *Supporting People Affected by Dementia to Live Well IMPACT Demonstrator Project*, its objectives were to understand how dementia hubs and navigator services help support people with dementia and their caregivers to live well and how these services can be implemented and delivered.

Therefore, the aims of this review were five-fold:

1. To synthesise the research and policy-relevant evidence available focusing on community-based dementia hubs and navigation services to define what constitutes a community-based dementia hub and dementia navigation service and to outline the core components of each of these services,
2. To explore the potential outcomes associated with these services,
3. To identify different models of each of these services,
4. To identify the facilitators and barriers to implementing and delivering each of these services,
5. To identify shortcomings in the evidence and identify possibilities for future research.

Research Questions

Given its aims, this review is centred upon answering five research questions for both dementia hubs and dementia navigation services:

1. What constitutes a dementia hub and dementia navigation service and what are the core components of each of these services?
2. What potential outcomes are associated with the provision of each of these services?
3. What different models of these services are available?
4. What are the key facilitators and barriers to the implementation and delivery of these services?
5. What gaps in evidence remain?

Structure of Review

This review has been divided into several sections. The following section presents the methodology used to conduct the searches, review, and synthesis of the available evidence. This is followed by a narrative description of the findings for each type of service and for each of the research questions. The final section consists of a concluding discussion, highlighting key evidence gaps and suggestions for further research, along with a statement about the limitations of this review.

DESIGN AND METHODS

The review methodology consisted of five components: 1. Initial scoping to gauge the availability of existing evidence already synthesised in published systematic reviews; 2. Full search and review of the evidence captured in the existing published academic research synthesis literature (systemic reviews, scoping reviews, evidence reviews, and rapid realist reviews) 3. Search and review of the evidence from the primary academic research literature; 4. Search for relevant published grey literature consisting of policy- and practice-based evidence reports and policy reports not available through the academic research literature databases; and 5. Application of a backwards citation search to identify additional key literature referenced in the research synthesis publications. This approach was based upon a combination of systematic, rapid review, and narrative techniques to review the literature in a way that broadly aligns with the key principles of systematic and rapid reviewing (Bryman, 2016), while simultaneously allowing for subjective evaluation of the evidence presented in the literature to determine relevance (Snilsveit et al., 2012).

Search Strategy

Searches for relevant publications were conducted between June and July 2025, following initial scoping of the evidence available. The searches covered academic, policy- and/or practice-relevant ‘grey literature’ containing evidence and insights from research, policy, practice-based and lived experience. Research synthesis literature and primary research literature was located through keyword searches using the following databases: Web of Science, Scopus, Medline, and Social Care Online. Key words relevant to the research question were identified to enable keyword searches of the databases to be performed using multiple combinations of keywords. These searches were supplemented with a keyword search using Google Scholar and the Google search engines to try to identify relevant ‘grey’ literature.

Keywords included to perform the database and grey literature searches included combinations of the following: Dementia Navigator; Navigation Programs Dementia; Dementia Navigation; Dementia Coordinator; Dementia Coordination; Alzheimer’s Navigation; Alzheimer’s Coordination; Dementia Care Coordinator; Dementia hub; Dementia Community Support; Dementia Carer Support; Dementia Coordinated Support; Dementia Support Integration; Dementia Information Access; Dementia UK; Dementia England; Scotland; Wales; Northern Ireland; Australia; Norway; Sweden; Denmark; Netherlands; Europe; Canada; Australia; United States; Outcomes; Delivery; Implementation; Barrier; Facilitator; Challenge; Intervention; Strategy; Pathway; Model; Approach; Agency; Voice; and Lived Experience.

Application of Inclusion/Exclusion Criteria

A pre-determined inclusionary /exclusionary criterion was then applied to the initial database and web search results. Literature published prior to 2015 was removed on the basis that research older than 10 years could be deemed dated given economic, political and demographic changes in recent years. Duplicates were also removed.

To be eligible for inclusion, publications needed to address one or more of the research questions and: be published in English between 2015 and 2025; and focus on the UK, one or more of the four UK nations, one or more European countries, or include evidence from socio-cultural, economic and political contexts bearing similarity to the UK neoliberal context, namely the United States, Australia, New Zealand or Canada.

Given the focus of the project is on support provided within the community setting and on providing a social rather than clinical pathway for providing support, publications that focused on navigation and support provision that did not explicitly focus on people with dementia and their caregivers were excluded. Publications that focused solely on case management were excluded. Publications focusing solely on countries in low- and middle-income countries were excluded due to the potential differences between the socio-cultural, political, and economic contexts of these countries being too different to align with the UK context.

Quality Assessment and Evaluation of Relevance

Quality assessment was undertaken of the sources selected for inclusion. Academic sources were assessed as high quality on the basis of academic peer-review. Grey literature was considered high quality when peer-reviewed or when published by government departments or reputable third-sector organisations.

After quality screening of the titles and abstracts, texts were read to check eligibility against each research question. A total of 38 documents were selected for inclusion in the final selection. Findings and insights from the final selection of sources were selected and coded descriptively by hand against each of the questions.

FINDINGS

Theme 1: Dementia Navigation Services

Thirty documents in the sample contained evidence about dementia navigation services.

What constitutes a dementia navigation service and what are its core components?

Dementia navigation is a model of care and support designed to guide and support people with dementia and their caregivers in accessing and using health and social care systems to help them meet their care and support needs (Anthonisen et al. 2023). These services seek to reduce the fragmentation of programs and services, improve access to care and support, and integrate support across settings and sectors (ibid; Giebel et al. 2023). Dementia navigators perform a variety of tasks, including providing tailored information and advice, assisting with goal setting and decision-making, and connecting people to social and health care providers and relevant support groups (Giebel et al. 2023; Kokorelias et al. 2022a; Bernstein et al. 2019, 2020; Possin et al. 2017, 2019; Abrams et al. 2024; Anthonisen et al. 2023). The support services that they help people to navigate can be psychosocial, social, emotional, financial, educational or logistical and may include sign-posting to day care centres, respite care, peer-support groups, social activities, paid home care, as well as befrienders: services that specifically focus on helping people with dementia and/or their carers maintain a good quality of life. As such, dementia navigation services fall under the umbrella of post-diagnostic support services (Giebel et al. 2023). In the UK, dementia navigators often signpost and link people up with the following sectors and services: voluntary sector, community services, informal support networks, social services, general practice, and hospitals (ibid). People with dementia and their carers can also contact their dementia navigator with specific queries (ibid). These services aim to provide support across the dementia illness trajectory, enhancing communication with various care and support providers and supporting caregivers, at each stage of the illness (Michalowsky et al. 2019; Kokorelias et al. 2022a).

Navigators do not need to be professionals, but may have backgrounds as health care professionals, social care professionals, service support personnel or as people with lived experience of supporting or caring for someone with dementia (ibid; Abrams et al. 2024). Dementia navigators work across a range of settings and are usually based within the community but may also work out of clinics (ibid). Their shared central focus, however, is to link people up with suitable support within their community or locality, and all aim provide a single point of contact who is in regular contact with the person with the condition and their unpaid carers (Giebel et al. 2023; Kokorelias et al 2022a).

According to Abrams et al. (2024) determining what qualifies as a dementia navigation service depends on the service aims and types of services provided. However, the terms ‘dementia navigation service’ and ‘dementia navigator’ are not used consistently throughout the literature when referring to the same type of service with the same aims. Other terms used to describe this type of service are ‘patient navigator’ (Abrams et al. 2024), dementia care coordinators (Giebel et al. 2023: Kallmyer et al. 2022), system navigators and team navigators (Bernstein et al. 2019, 2020; Possin et al. 2017, 2019), support navigators (Kokorelias et al. 2022a), support coordinators and peer navigators (Abrams et al. 2024; Anthonisen et al. 2023). A variety of job titles can also be used to refer to staff associated with dementia navigation services, including dementia care coordinator, dementia support worker, dementia care navigators (Giebel et al. 2023; Kallmyer et al. 2022), dementia advisors and dementia navigators (ibid). While specific roles may vary, the fundamental similarity is that the role is non-clinical (Giebel et al. 2023; Bernstein et al, 2019, 2020; Possin et al. 2017, 2019; Kokorelias et al. 2022a) even though the role can be performed by clinical members of staff or those with a background in healthcare (Giebel et al. 2023). Whilst they carry out similar functions to social prescribers, they also differ in that they focus exclusively on one condition (ibid).

Dementia navigation services differ from case management approaches to dementia care even though both may take place within the community setting. This is because dementia case management focuses on the planning and co-ordination of care and is associated with a more clinical pathway, which dementia navigation services may not necessarily be involved with. In addition, dementia navigation services aim to navigate people to services and also provide education and information, which case managers often do not (Giebel et al. 2023). Furthermore, case managers are usually social work or nursing professionals, and thus tend to be clinically qualified, whereas dementia navigators do not need to have professional qualifications (ibid). Dementia navigators also differ from Admiral nurses in that Admiral nurse services involve a named, clinically qualified individual who provides in-depth support in more nursing-based elements of dementia care (ibid).

What potential outcomes are associated with dementia navigation services?

The impact of dementia navigator services can be measured quantitively by measuring those with dementia and their caregivers’ senses of competence and functional independence using a modified Barthel Index care providers to determine a person’s ability to independently perform various self-care tasks (Cations et al., 2020). Other ways of measuring impact are by measuring improvements in self-reported problematic dementia-related symptoms (Mavandadi et al. 2017a; 2017b),and the length of time patients remain in the community between accessing the service and time of placement in residential care or death (Michalowsky et al., 2019). Impacts can also be measured and evaluated qualitatively through evidence from surveys, interviews, narratives and lived experiences (Kokorelias et al. 2022a).

Positive outcomes associated with increased ability to access services and support resulting from dementia navigation services include decreased hospital admissions and emergency visits (Giebel et al. 2023; Possin et al. 2017; 2019), lower hospital readmissions, reductions in the number of days hospitalized, shorter delays obtaining long-term care placements (Kallmyer et al. 2022; Kokorelias et al. 2022a; Michalowsky et al. 2019), reduced spending on residential long-term care settings (Giebel et al. 2023), improved quality of life for people with dementia and their carers, decreased carer burden, reduced rates and severity of depressive symptoms, and greater carer self-efficacy (ibid; Bernstein et al., 2019). Other evidence of positive outcomes linked to the use of dementia navigation services are improved dyadic relationships, decreased relationship strain, lower rates of unmet needs, and improved understanding of how to support people with dementia (ibid).

Merrilees et al. (2020) explain how the benefits of these services for carers can be divided into three categories: emotional, informational and instrumental. Improvements in carer emotional wellbeing and quality of life are linked to greater access to psychosocial support, whereas the provision of educational materials to communicate better with the person with dementia are linked to greater understanding of and access to relevant information (ibid). Wellbeing is also improved through increased access to support groups and decreased stress in having to source out and identify relevant support services (ibid). These positive outcomes were also identified in a number of the other publications (Bernstein et al. 2019; Mavandadi et al. 2017a; Mavandadi et al. 2017b; Possin et al., 2017, 2019; Kokorelias et al. 2022a). Other studies evidenced how these services were linked to improvements in carer financial planning, increased satisfaction and motivation in providing care, wider support networks and decreased isolation (Giebel et al. 2023; Possin et al. 2017; 2019; Kokorelias et al. 2022a).

Studies have also shown that those who access navigator services are more likely to experience an increase in use of and willingness to use formal services (such as social work) and other support services (such as the use of educational service support provided by local Alzheimer’s societies) (Kokorelias et al. 2022a). The use of dementia navigation services has also been linked to improvements in whole family understanding of dementia (ibid).

However, evidence is limited and inconclusive as to whether dementia navigator services targeted to those from minority ethnic groups and underserved or hard to reach populations is linked to improved outcomes for people with dementia and their caregivers (Chodosh et al. 2015; Xiao et al. 2016; Dementia Waikato, 2017).

What different models of dementia navigation services are available?

All models of dementia navigation services identified from the review provided some form of referral and/or linkage to other services, resources and information, care or support, and were provided within the community setting, either in community resource centres, day centres, memory support centres, and with one provided in a General Practitioner’s building. However, models differ in their use of protocols to assess the PWD and their caregiver’s needs, their use of resource libraries, their role in supporting individualised care planning, and in the degree to which they help to coordinate care and liaise with primary care services. Most navigation services were provided by an interdisciplinary team of staff members, which often included volunteers and people with lived experience, while others were provided by professionals. Modes of delivery included in-person, telephone-based, web-based, or a combination, with the most common approach involving a combination of service delivery by phone and in-person. Some services have age specific requirements, or require a diagnosis of dementia, while a small number are specifically aimed at PWD and caregivers from particular population groups.

An overview is provided below of the 16 different models identified from the review with Appendix 1 providing an overview of the evidence relating to those with the strongest evidence base.

MIND Dementia Care Navigation model (Giebel et al. 2023)

The MIND in Dementia (MIND) service focuses on the provision of the following core elements: assessing support needs, developing care and support plans, providing dementia education and skill building strategies, coordinating support, and referral to care and support services. Support is provided either in person or via telephone. Needs assessments are revisited at regular intervals. Services are usually run by non-clinical professionals and with a high value being placed on the interpersonal skills and/or experiences of working with people with dementia and unpaid carers amongst staff (ibid). Staff receive training in communication skills, dementia care, and general skills building. Services aim to serve the needs of local communities and focus on addressing needs gaps and may target particular population groups, such as people from minority ethnic backgrounds, and may also require a diagnosis to use the service. Navigators meet regularly with people with dementia and their carers to support them accessing services and provide general dementia education.

The MIND at Home model (Amjad et al. 2018)

This model aimed to increase access to health services amongst older adults with dementia for those already receiving dementia care and support navigation and was trialled in Baltimore, Maryland in the US. This model was composed of an interdisciplinary team of non-clinical memory care support workers who were linked to health care services specialising in dementia care. The intervention was delivered both by telephone and in person and was eligible to those age 70 years and older who resided in northwest Baltimore and who received informal care from at least one family member. Service users had to meet the diagnostic criteria for dementia as defined by the Diagnostic and Statistical Manual of Mental Disorders (DSM-IV-TR) and have one or more unmet care needs according to the Johns Hopkins Dementia Care Needs Assessment. MIND at Home aimed to delay transition to institutional care, reduce unmet care needs, improving quality of life, and decrease stress and depression. Service users were provided with information about support and how to obtain referrals, information about identifying and addressing potential environmental safety hazards, dementia care education, behaviour management skills training, informal counselling, and problem-solving. Linked partners, including health care partners, provided dementia evaluation services, treatment of cognitive symptoms and behaviour management, referral to Alzheimer’s Association, advice about medication administration, general medical/health care and safety advice and information, assistance with daily activities, information and support with legal issues/advance care planning, caregiver referrals, caregiver mental health care, and caregiver general medical/health care.

Partners in Dementia Care model (Bass et al. 2015)

Like the above MIND at Home model, the Partners in Dementia Care model of dementia navigation involved attempting to better link PWD and their caregivers to dementia health care services to reduce hospital admissions and emergency department visits for veterans in four US states (Massachusetts, Rhode Island, Texas, and Oklahoma). Services were delivered by phone, email and mail and provided by an interdisciplinary team of dementia care navigators (care coordinators) from Veterans Affairs and the US Alzheimer’s Association. This model was designed to coordinate healthcare and community services, with linked partnerships aiming to promoted holistic, less fragmented care and support for both the medical and nonmedical needs of individuals with dementia and their caregivers, increased access to information and educational resources, and improved management of coexisting medical conditions. The model utilised a standardised protocol and coaching.

The US Memory Program model (Chen et al. 2020; Liu et al. 2019)

The Memory Program model involves prioritising meeting both the PWD’s and the caregiver’s needs by assisting communication with primary care physicians and professional social work services and other services for support, coaching, education and referrals. It also provides information to learn about caregiving, managing stress, and self-care. Supportive and educational events led by experts in memory and older people’s care are held regularly. Services are delivered in person and based out of memory clinic. Unlike other models, a social worker functions as the dementia navigator, with the model aiming to provide the information and communication necessary for seamless care coordination, as well as support. Each visit included a detailed interview with the PWD and their caregiver(s), medication reconciliation and review, a functional assessment, a discussion about their goals of care, information about local social support, and health literacy assessments.

Maximising Independence at Home model (Willink et al. 2020)

This model focuses on cost-effective care and support coordination for people living with dementia. This is a home-based coordination model is administered by trained, nonclinical community workers who provide the primary means of contact between people with dementia and their caregivers. The model is linked to a multidisciplinary clinical team with expertise in dementia care. It specifically focuses on addressing a broad range of unmet dementia-related care needs for people with dementia over the age of 70 and their caregivers that place older adults at risk of health disparities, high health care costs, poor clinical outcomes, poor quality of life, and caregiver burden.

The US Department of Veteran Affairs model (Dept of Veteran Affairs, 2020)

This is a US wide navigation model targets a specific population group (military veterans) with dementia and their caregivers. Services are delivered through Veteran Affairs Community Medical Centres or Veteran Affairs Community Resource Centres and provided by phone and email. Navigation services are provided by an interdisciplinary team of licensed clinical social workers and volunteers, with the care coordinators providing access to one-on-on counselling, support, and education for caregivers. They also help caregivers apply for benefits and navigate the health care systems, with the goal of reducing caregivers reduce stress and improve problem-solving skills and connect them to helpful resources.

The Dementia Care Coordination Program (Nadash et al. 2019)

This US model is a distinctive coordination program as it uses the medical system, rather than direct outreach, to identify and refer families to supports provided by the Alzheimer’s Association. Navigation support is provided by care consultants who can receive referrals from individual physicians or health plan case managers. The idea behind this model is that by identifying and referring participants in the early stages of the disease process, participants can access more appropriate medical treatment as well as social and informational supports offered directly by the care consultancy team, and indirectly through care coordinator referral to other resources. This program also facilitates communication between PWD, caregivers and health professionals, and is associated with benefits to health care service provision, as well as for the caregivers and PWD. Direct benefits associated with this model are decreased stress, lower caregiver burden and improved financial planning, which, in turn, result in improved health outcomes, including fewer preventable health events and delayed institutionalization.

The Care Ecosystem model (Bernstein et al. 2019; 2020; Merrilees et al. 2020; Possin et al. 2017; Rosa et al. 2019)

The Care Ecosystem is a dementia-capable model that provides personalised and proactive care and support for people with dementia and their caregivers. People with dementia and their caregivers are enrolled as dyads and assigned to a team navigator, who identifies needs and concerns, provides education and curated information about community-based resources, provides linkages to resources and emotional support by phone and email on a scheduled monthly basis or more frequently as required. During the initial intake, the navigator and the dyad negotiate the frequency of contact and additional contact can be provided during periods of greater-needs and can decrease during lower-need times. To respond to differential and changing needs, a ‘navigated care light’ intervention can be used where dyads can opt to be contact on a quarterly basis with handouts and reminders that support is available if needed (Bernstein et al. 2020). In this model, navigators also provide care coordination, share care planning and legal and decision-making tools, and provide tailored behavioural interventions. Behavioural interventions included providing, as needed, educational information about behaviours and help in identifying support resources, including dementia day programs and caregiver support programs. They also coordinate with clinical support as required. Care team navigators work in interdisciplinary teams with an advanced practice clinical nurse, a social worker and a pharmacist, and are dementia specialists without medical degrees but who have received training, including on how to implement the Care Ecosystem’s Care model. Care team navigators also answer case questions, discuss care protocols, and work with cases that require triage. For example, for complex behaviours, they triage to the supervisory clinical team (e.g., consultation with pharmacist about medications lists). A full navigator caseload ranges from 50–80 dyads and workflow and communication is supported by the Care Ecosystem Dashboard, which is a relationship management software uniquely adapted to the program, and which also provides a mechanism to rapidly triage difficult cases to the clinical team, who can also monitor the dashboard (Bernstein et al. 2020).

The Banjamin Rose Institute Care Consultation model (Bass et al. 2019)

The Benjamin Rose Institute Care Consultation model is delivered by health care and social care organisations working together in tandem. A Partners in Dementia Care coordination model provides a bridge between health care, social care and community services by providing PWD and caregivers with comprehensive and coordinated assistance for meeting both medical and non-medical needs, including access to services and support for mobilising social networks to form wider supportive informal care networks, and providing information and emotional support. In this model, a social worker, nurse, or other care professional from each partnering organization serves as the navigator who delivers the service. Care consultants from partnering organizations work as a team, using a single, shared electronic record that guides delivery and maintains program fidelity. PDC follows a standardized protocol that requires at least monthly telephone, e-mail, or regular mail contact between Care Consultants and PWDs and/or caregivers. More frequent contact is provided whenever needed, based on PWDs’ or caregivers’ preferences and Care Consultant’s perceptions of need. While the initial set aims to help PWD and their caregivers set up a dementia action plan, the program aims to establish a long-term relationship with families.

The ACCESS study navigation models (Chodosh et al. 2015)

The ACCESS study coordinated care program provided both a telephone-only approach or an in-person plus telephone approach for delivering an evidence-based coordination program for people with dementia and their caregivers from underserved Latino communities in the US. A Steering Committee of medical and service providers from participating organizations provided oversight for implementation and delivery of care management and support strategies, while care coordinators were bilingual social workers with previous experience in Spanish speaking populations. An additional requirement for the role was having a Latino cultural background, which helped them take a more nuanced approach to culturally specific dementia-related issues. Information was provided in Spanish and reviewed for cultural appropriateness prior to dissemination by the navigators and other volunteer native Spanish speakers. Navigators also attended community health fairs and visited local community agencies including day centres to help to identify those from harder to reach communities. Initial assessments were structured to generate a problem list, and support services were identified tailored to addressing these problems. Referrals were made to social support services, educational services, and respite services, as appropriate, including resources provided by the Alzheimer’s Association and other agencies. Navigators also undertook advanced care planning and referrals for mental health support and other medical services as required, and services for helping managing medications. Follow ups were provided to achieve greater problem solution. Navigators also provided caregivers with coaching on how to have productive visits with health care professionals and provided support for assessment information to facilitate care.

The Australian Care Coordinator model (Xiao et al. 2016)

The Australian Care Coordinator model implemented and delivered in Xiao et al.’s (2016) study in Adelaide, South Australia, aimed to provide personalised dementia support for people living with dementia and their caregivers designed specifically for people from Australian minority ethnic groups (Aboriginal and Pacific Islanders, and Black, Asian and other Minority Ethnic groups). Support navigation was provided by phone and in person. Navigators worked in interdisciplinary teams made up of 8 care coordinators, which included a registered nurse, a social worker, and Community Home Care Certificate holders, with experience in working with people from minority groups. Referrals for support aimed to address care information needs, educational and skill needs, environmental safety needs, social-cultural care needs, and self-care needs. Navigators used a Personalized Caregiving Support Plan to assess caregivers’ needs. When necessary, they also organised conferences with caregivers and care staff to discuss ongoing challenges. Scheduled caregiver support events included monthly caregiver support group meetings and information sessions that were funded by the National Respite for Carers Program.

The Waikato Dementia Navigation Service model (Dementia Waikato, 2017)

This is a New Zealand model of a dementia navigation service that provides services by phone and in person to all people with dementia who have received a diagnosis and their caregivers who reside in the Waikato District Health Board area. Service users must be eligible for public health services, which may help to reduce socio-economic inequalities in ability to access support. Navigation is provided within an interdisciplinary team of registered nurses, occupational therapists, social workers, and dementia navigators. Navigators provide initial information and education following diagnosis and then ongoing support, advice, and assistance to live well with dementia at home. Education is also provided about dementia symptoms and how to manage them. Navigators also make referrals for professional assessment for any additional funded services and help PWD and caregivers plan for the future and navigate through the health system services.

The Norwegian Live@Home.Path Coordination model (Fæø et al. 2020)

This Norwegian model provides services by phone and in person to people living at home with dementia and their informal caregivers on a dyadic basis. Although the coordination role is provided by two specialist nurses the LIVE@Home.Path is a multicomponent, multidisciplinary intervention that aims to bridge across health, social care and social and community support services to support dyads of people with dementia and their informal caregivers to live safely and independently at home. The program’s core components are learning, innovation, volunteers, and empowerment (LIVE). The education component included an optional educational course, while the empowerment component involved the dementia coordinator coordinating the LIVE components and ensuring that the individual with dementia is empowered throughout the LIVE intervention process. The coordinator acts as a safety net, a pathfinder, and a source for emotional care and support and also provides participants with access to health and social care and support that aligns with their personal needs and wishes.

The Holistic Dementia Navigator Service model (Wood et al. 2020)

This is a UK-based model that aimed to provide a holistic service for everyone with a dementia diagnosis within the Islington areas of London. Services were delivered by mail and in person for PWD and their caregivers through an interdisciplinary team made up of dementia navigators, 3 full-time assistant practitioners, and with a specialist practitioner as team leader. The model was built on the existing Dementia Advisors Model operated by the Alzheimer’s Society to provide signposting to services and assistance to navigate the health and social Support coordinator care systems. This service aimed to reduce social isolation, monitor and manage risk, promote effective communication and partnerships by working between health and social care and third sector providers, and by providing a person-centred responsive service to everyone in the local area to enable PWD and their caregivers to access the services they needed to avoid crisis. Most referrals were received following diagnosis by the Memory Assessment and Treatment Service.

The Kent Model of Dementia Care Coordination (Bridge-Builders) (Abrams et al. 2024)

The Dementia Care Coordination service was jointly commissioned by the Kent County Council and the Kent and Medway Integrated Care Board (ICB) to serve the population of Kent and Medway in the south-east of England in 2022. The dementia care coordinator’s role is non-clinical and aims to provide consistent long-term support tailored to individuals’ needs. Coordinators receive referrals from health and care workforces across the ICS and self-referrals and conduct needs assessments, make referrals to other local services (such as dementia cafes or respite care) and work with healthcare professionals including GPs, admiral nurses and psychiatrists to support and improve quality of life for PLWD and their caregivers. This model particularly focuses on providing information and support during periods of transition.

The Alzheimer Scotland’s 5 Pillar Model of Post-Diagnostic Support, 8 Pillar Model of Integrated Support, and Advanced Dementia Practice Model (Scottish Government, 2017)

The Alzheimer Scotland’s 5 Pillars Model of Post-Diagnostic Support is a model for post-diagnostic support that provides a framework for people living with dementia, their families and caregivers, and which offers strategies, connections and resources on how to plan living as well as possible with dementia and to prepare for the future. Since 2013, everyone newly diagnosed with dementia in Scotland is entitled to a minimum of one year’s worth of post-diagnostic support, coordinated by an appropriately trained Link Worker or navigator. Those diagnosed with dementia are able to receive support from their link worker using the 5 pillars model and which can continue for the duration of their time living with dementia, or until their needs change to the extent that they require greater care coordination or residential care. The development of the 5 Pillars Model and the post-diagnostic service offer was originally aimed at people receiving an early diagnosis and living at home or in the community, with little formal health or care service support. Link workers provide support to PWD and their caregivers and families during this early stage to plan for future decision making and future care, make connections within the community, obtain access to peer support services and information about dementia and managing the condition.

The Alzheimer's Scotland 8 Pillars Model of Integrated Support differs from the 5 Pillars Model in that it is aimed at catering for the needs of PWD during the moderate and severe stages of the condition and those of their caregivers and families. It provides a platform for coordinated care to support people with dementia living at home in the community and uses a Dementia Practice Coordinator instead of a Link Worker who provides tailored post-diagnostic support while at the same time increasing the level and focus of integrated care coordination. Dementia Practice Coordinators offer information and linkages to a range of carer support services, personalised dementia care services, community connections services, dementia friendly environments, mental health care and treatment, physical health care and treatment, and for therapeutic interventions to tackle behavioural symptoms of the condition. By using this model, dementia support can be integrated within the existing support being delivered by the established health and social care team.

The Alzheimer Scotland's Advanced Dementia Practice Model combines the 8 Pillars model and practice coordinator role with an Advanced Dementia Specialist team to provide care and support during the advanced stages, including palliative care and end of life care. The Dementia Practice Coordinator retains primary responsibility for the direction of the care and also coordinates input from the advanced team. The coordinator also plays a critical role in supporting the person with dementia to die in their place of choice and to provide support those closest to the person during the bereavement process.

What are the key facilitators and barriers to the implementation and delivery of dementia navigation services?

Twenty-three documents within the sample of publications reviewed contained evidence about the facilitators and barriers to the implementation, delivery and success of dementia navigation services.

Facilitators to implementation and delivery

Collaboration and communication between stakeholders and formal partnerships between community organisations and health and social care services were identified in a number of publications as facilitators for the development and implementation of dementia navigation services (Anthonisen et al. 2023). It is also beneficial if program organisers, caregivers, and program site partners demonstrate an equal willingness to actively support and participate in the programs (ibid). The use of flexible and adaptable delivery models that allow for both frequent and flexible communication were also associated with the successful delivery of the service (ibid), as was the importance of the navigator’s listening skills and ability to form positive relationships with PWD, their caregivers, and the providers of a wide range of services (Abrams et al. 2024). Financial facilitators to the implementation and delivery identified were having an adequate source of funding to cover the initial costs of implementation as well as a sustainable source of funding to sustain delivery of the service over the longer term (Anthonisen et al. 2023; Giebel et al. 2023). The employment of non-professionals or the use of volunteers to deliver the services helped lower the costs both in the initial and longer-term period (Anthonisen et al. 2023). Logistical and administrative tools that can help to facilitate service implementation and delivery include the use of shared computer systems and databases to provide coordination, access information and share information, as well as tools and protocols for data security (Anthonisen et al. 2023).

While having a diagnosis is a requirement for accessing some of the different types of dementia navigation services available, evidence also suggests that outcomes are also often linked to being able to obtain support during the diagnosis stage as well as being able to access continued support throughout the progression of dementia (Giebel et al. 2021). Efforts to raise awareness of the service and of how to access it was also linked to improved satisfaction and greater positive outcomes (ibid). Moreover, as carers can also experience difficulties identifying as carers and in acknowledging their needs owing to internalisation of socio-cultural norms surrounding familial care and concerns about stigma, early interventions to provide information and address the issue of stigma and accepting help is linked to increased update of the service, improved engagement with linked services, positive outcomes, and greater satisfaction with the service (ibid; Kokorelias et al. 2022b). Having a one regular navigator or point of contact was also linked to greater satisfaction and decreased carer stress (Giebel et al. 2023; 2021). Interventions to help people communicate their needs to the navigator was also associated with greater access to care and increased satisfaction with the service (ibid 2021). In addition, the extent to which navigator services enable bridge building across communities, services, professionals, systems and one another is also linked to their success in achieving positive outcomes (Abrams et al. 2024)

One publication in the sample drew on evidence from the findings of a systematic review of the research on the outcomes of navigation services alongside evidence from expertise from lived experience to devise a set of guidelines based on *Freeman’s Principles of Navigation* to help facilitate their success (Kallmyer et al. 2022). According to Kallmyer et al. (2022)’s *Guidelines for Success*, navigation services should aim to be person and family-centered to enhance engagement and directed by the particular needs and goals of the individual or dyad. Navigators should also help the person with dementia and their caregiver identify the particular challenges they face (including but not limited to medical, social, financial, emotional, relational, and spiritual) in order so support and information can be more specifically tailored (ibid). The amount of information provided, and the frequency and intensity of support offered should also be adapted to the person with dementia and their caregiver's specific needs and readiness for engagement (ibid). Support and information should also be culturally responsive and focused on what is available within the local community (ibid). Services should also focus on the family unit as defined by the patient. Coaching, education and coordination should be provided in a way that is empowering, solution-focused and strengths-based to help maximise the independence, confidence and resources of service users. Navigators should also reassess care needs and capacities over time and offer at least monthly contacts, but with options for higher or lower frequency dependent on the needs and wishes of the person and their caregiver(s) (Abrams et al. 2024). Communications should be delivered in multiple formats and include over email, in person, via telephone or via virtual meetings. Development and implementation of quality indicators can also help to ensure services remain responsive over time, with possible methods of monitoring standards including electronic tracking systems and service user satisfaction surveys and evaluation tools that aim to assess performance over a wide range of outcomes, e.g. quality of life, unmet safety and legal needs, depression, stress and strain, embarrassment, behavioural and psychological symptoms of dementia, family/friend help, satisfaction with family support, service contacts, emergency department or hospital use) (ibid). Specific tailoring of information, linkages and referrals for meeting the needs of people with different type of dementia, including young-onset dementia, and for those from particular socio-cultural groups, was associated with lower concerns about service suitability or dissatisfaction with the service (ibid; Abrams et al. 2024; Chodosh et al. 2015).

Barriers to the implementation and delivery of dementia navigation services

Barriers associated with the implementation and delivery of these services included a lack of clear communication and initial and/or ongoing difficulties linking and coordinating with health care providers and other key partners or partnering organisations (Anthonisen et al. 2023). Services that operate exclusively or mainly on a referral basis, especially those that operate from a health care referral basis, can also experience greater difficulty recruiting service users (ibid). Another barrier to recruitment is that many require a formal dementia diagnosis even though many people with dementia do not have and never receive a formal diagnosis (ibid). Identifying resources for people on low income, who do not speak English or who live in more remote areas can also act as a barrier to delivery (ibid). The lack of an established standardised protocol to implement these services was another barrier to their implementation and delivery (Kokorelias et al. 2022b). In addition, as navigation programs tend to be multi-component, their implementation can be complex (ibid). Services also need to align with national policies and the policies of multiple organisations, which can further add to the complexity associated with their implementation. External service providers also have to have the capacity to accept new referrals (Anthonisen et al. 2023) An additional barrier program implementation and sustainability of delivery was funding: both the initial costs of implementing the service and the longer-term affordability of the service. While governmental support can facilitate program success, changing regulations and priorities can negatively affect advocacy for particular programs which in turn, both negatively may affect their implementation and delivery (Kokorelias et al. 2022b).

Furthermore, although having a dementia support navigator is helpful for overcoming barriers to care, the geographic care and support landscape can also limit the potential for these services to achieve their potential outcomes. If there is a dearth of linked services within a particular local area, this results in navigators being unable to link people with dementia and carers to the services that they require (Giebel et al. 2021). Receiving too much information at the start of contact when people may already be overwhelmed emotionally with diagnosis or when already struggling can result in information overload, increased confusion and feelings of loss of control (ibid). Costs of accessing the linked services or lack of clarity about how costs would be met was associated with lower levels of satisfaction (ibid). The financial side of utilising dementia services was also a personal barrier to improved outcomes and associated with inequalities in ability to access support (ibid). Low levels of trust in the professionals or volunteers providing the services were associated with increased unmet needs and greater caregiver concerns over the suitability of services for relatives with dementia (ibid). Limitations in the range of activities on offer and with the mode of delivery (whether in group settings or face-to-face or over the phone) were also associated with barriers for these services to fulfil their aims and potential (ibid; Anthonisen et al. 2023).

Facilitators and barriers associated with the implementation and delivery of particular models of dementia navigation services

Specific facilitators and/or barriers to the implementation, delivery and outcomes associated with 13 of the particular models of dementia navigation services were also identified from the review. The key facilitators and barriers identified are listed in **Table 1**. However, no specific facilitators and barriers to implementation, delivery and outcomes that were particular to the Waikato Dementia Navigation Service model, the US Department of Veteran Affairs model, and the MIND Dementia Care Navigation Program could be identified from the sample of publications reviewed.

What are the key evidence gaps?

While the evidence identifies the potential benefits associated with dementia navigation services, as well as a range of facilitators and barriers to the implementation and delivery of these services, the review also identified a need for further research to provide more evidence about the relationship between implementation, delivery and impact (Abrams et al. 2024). In addition, more evidence is required about how the different models available compare in terms of their outcomes (Giebel et al. 2023). Also, less is currently known about the barriers associated with the implementation and delivery of particular models compared to what is known about the facilitators. There is also limited published evidence about the impacts of dementia navigation services that includes evidence from the voices and perspectives of those with lived experience of dementia and providing care for family members with dementia (Giebel et al. 2023). Further qualitative research with those with lived experience would help provide a more nuanced understanding of how access to and use of this type of service affects their lives. This is also especially important given that it is also known that traditional outcome measures have limited capacity to capture the true impact of these services over longer periods of time (Kallmyer et al. 2022). In addition, few models are implemented with a formal evaluation being put in place (Kokorelias et al. 2022b). Identifying ways of evaluating services and of measuring outcomes that are meaningful to service users would therefore represent another possible area for future research.

Table 1: Facilitators and Barriers to the Implementation and Delivery of Particular Models of Dementia Navigation Services

Model	Associated Facilitators	Associated Barriers
MIND at Home *(Amjad et al. 2018)*	• Integration, communication, and collaboration between the MIND care team and health providers.	• Difficulties establishing contacts with health providers.
Partners in Dementia Care *(Bass et al. 2015)*	• Formal partnership for better networking and coordination	• Not evidenced
US Memory Program *(Chen et al. 2020; Liu et al. 2019)*	• Provision of a protected space for parties to express their concerns.	• PWD and caregivers do not reach out to navigators as their first line of help and support.
Independence at Home *(Willink et al. 2020)*	• Cost-effective form of collaboration	• Not evidenced
The Care Ecosystem *(Bernstein et al. 2019; 2020; Merrilees et al. 2020; Possin et al. 2017; Rosa et al. 2019)*	• Adaptability of the programme; • Use of non-licensed specialists makes it a more affordable option.	• Difficulties identifying resources for dyads who are low income, do not speak English or live in rural areas • Unclear triage protocols
Dementia Care Coordination Program *(Nadash et al. 2019)*	• Minimalist model of dementia-specific support, that can be further supplemented via more focused outreach and education;	• Difficulties with information sharing systems • High caseloads
The Australian Care Coordinator model *(Xiao et al. 2016)*	• Support Plans and a "caregiving diary" facilitates identification of needs and through which support effectiveness can be evaluated.	• Not evidenced
Norwegian Live@Home.Path *(Fæø et al. 2020)*	• Flexibility and accessibility of delivery	• Not evidenced
Holistic Dementia Navigators *(Wood et al. 2020)*	• Facilitating access in a timely manner helps prevent crises.	• Not evidenced
The Banjamin Rose Institute model *(Bass et al. 2019)*	• Low-cost delivery • Partnership provides formal bridging structure.	• Not evidenced
DCC Kent Model *(Abrams et al. 2024)*	• Single point of contact enhances trust and provides continuity • Knowledge of availability of local services	• High caseloads, understaffing and low salaries • Limitations and inequalities in locally available services.
The ACCESS study navigation models *(Chodosh et al. 2015)*	• Greater familiarity with socio-cultural needs of specific population groups • Delivery intensification	• Difficulty reaching underserved population groups • Lower baseline levels of PWD and caregiver trust.
Alzheimer Scotland models *(Scottish Government, 2017)*	• Open ended and flexible approach to delivering support; • Adoption of a quality measurement framework	• Challenges in service users' ability obtaining early diagnosis affects delivery of timely interventions.

Theme 2: Dementia Hubs

Although less evidence could be obtained from the searches, 8 documents in the sample contained evidence from research about dementia hubs.

What constitutes a dementia hub and what are its core components?

According to Gelmon et al. (2025), a dementia hub or a dementia care partner hub is a ‘one-stop shop’ to connect people with dementia and their caregivers with different service providers and with information and resources. Like dementia navigation services, a dementia hub or dementia care partner hub offers a systematic solution to network PWD, caregivers, and existing community resources and services.

Dementia hubs are similar to dementia cafés in that both aim to reduce social isolation, facilitate social network development and peer support, and provide information and education to people with dementia and their caregivers to address the need for greater psychosocial and informational support to address support gaps. However, they also differ in that they aim to connect people with a much wider range of multiple types of care and support service providers (Innes et al. 2022) and for which a hub serves as the focal point within this network, rather than focusing more directly on providing social connectedness and/or educational support services for PWD, their caregivers and family members like dementia cafes do, or dementia day services which have a more limited focus on directly providing activities for PWD and day respite and support for carers (ibid). Like dementia navigation services, dementia hubs seek to reduce the fragmentation of services and make it easier for people to find and access a variety of care and support services at different stages throughout the trajectory of the condition, and to help better integrate support from different providers and services (ibid; Kokorelias et al. 2022a). In particular, dementia hubs provide information about dementia and caregiving, navigation and care and service coordination, and information access to psychosocial support services, leisure activities, financial assistance, day services, transportation services, legal services, and health services (Gelmon et al. 2025).

Dementia hubs are normally located within the community setting and ideally, in accessible locations, such as near health centres or community centres. However, more recently online virtual versions of dementia hubs have now also begun to emerge (Blackberry et al. 2023). Community-based dementia hubs may offer a number of services in-house, such as activities and day centre services, peer support cafes, caregiver meeting sessions, and information sessions, while also linking people with dementia and their caregivers to appropriate locally based care and support services and partner organisations. Virtual hubs aim to provide social connections, support and education virtually, while also linking people to external services and partner organisations (ibid). The single-sited focus of dementia hubs also means that hubs can be designed with the needs of specific racial and minority ethnic groups in mind and, as such, offer the potential for helping to reduce existing inequalities in access to care and support (Gelmon et al. 2025). Furthermore, given that dementia hubs aim to function as the focal node within an existing network for services that complements, rather than duplicates, these services, their local or regional focus helps to ensure they can maintain current information on relevant resources for the specific socio-cultural, informational and linguistic needs of local BAME groups (ibid).

Hubs can be designed, implemented and governed by coalitions of dementia care partners and personnel from relevant local organizations, with coalitions providing the opportunity for people with lived experience and organisations that serve marginalised communities to take a central role in the design and delivery of services (Gelmon et al. 2025). Hubs are usually run by a small team of staff who may or may not be social care professionals, but who are knowledgeable about dementia and local services, and who have experience of caring and supporting people with dementia (ibid; Innes et al. 2022; Blackberry et al. 2023).

What are the potential outcomes associated with dementia hubs?

While less is known about the potential outcomes associated with dementia hubs compared to what is known and evidenced about the potential impacts and outcomes associated with dementia navigation services, the review identified several ways that dementia hubs can potentially contribute to positive outcomes for people with dementia and their caregivers.

Firstly, research has shown that the increased access to information, resources and services facilitated through both community dementia hubs and virtual dementia hubs is associated with positive outcomes in alleviating caregiver depression, anxiety, care burden, demand and stress, and in enhancing carer self-efficiency, sense of independence, and quality of life (Blackberry et al. 2023; Henderson et al. 2021; Gelmon et al. 2025; Evans et al. 2023; Innes et al. 2022). Virtual hubs also offer additional advantages. For example, in situations where stigma can prevent caregivers or PWD from seeking support, in that they can also offer anonymity. They also offer the benefit of convenient access at any time for caregivers who work alongside their caring role (Blackberry et al. 2023).

Both community dementia hubs and virtual dementia hubs have also been shown to help reduce caregiver social isolation, including when caregiving intensifies as the functioning of the person with dementia deteriorates and which is a time associated with decreased caregiver access to wider social support networks (Blackberry et al. 2023; Henderson et al. 2021). Research findings have also evidenced that caregivers who benefit the most from virtual dementia hubs in terms of measurable reductions in social isolation are those who are on average 55 years of age and in their first to three years of caring (Blackberry et al. 2023).

For people with dementia access to dementia hub support has also been linked to increased positive mental wellbeing, greater social connectedness fewer care home admissions and delayed admissions by an average of seven months, improved quality of life, reduced risks to personal safety, reductions in neuropsychiatric symptoms and increased feelings of support (ibid; Innes et al. 2022; Gudnadottir et al. 2021; Henderson et al. 2021). Other potential outcomes facilitated by this service are more timely access to equipment and environmental adaptations (Henderson et al. 2020).

Evidence from interview research suggests that community hubs are associated with increased nutritional health for PWD and increased social interaction for caregivers, and greater awareness of and participation in dementia friendly leisure and recreational activities (Henderson et al. 2021; Evans et al. 2023). Furthermore, access to dementia hubs is associated with facilitating programs of caregiver support and access to appropriate health and social care services which helps to reduce unmet caregiver needs as well as unmet needs amongst people with dementia. It also provides a way of facilitating access to resources and support services that are more responsive to the specific needs of PWD and their caregivers from particular socio-cultural and linguistic backgrounds (Gelmon et al. 2025). Research also demonstrates that greater responsiveness to the needs of BAME groups can help reduce inequalities in unmet needs resulting from cultural tradition, multiple systemic inequalities, and legacies of structural racism (ibid).

What different models of dementia hubs are available?

Seven specific models of dementia hubs were identified from the documents reviewed. However, although evidence about the modes of delivery and aims of the model could be obtained, it was less clear how each of these models were staffed compared to the amount of detail that was obtainable about the staffing of the specific models of dementia navigation services outlined in the previous section.

The Dementia Care Partner Hub (Gelmon et al. 2025)

The Dementia Care Partner Hub is a US-based model aimed at addressing unmet social and health needs of PWD and their caregivers through a virtual ‘one-stop-shop’ to connect PWD and their caregivers with service and support providers and information and sources through a virtual platform. The platform offers access to resources via a single site and was designed to address the needs of specific racial and ethnic groups and communities that are historically/currently underserved and underrepresented in dementia service. Information, services and resources are provided in culturally and linguistically accessible formats. The hub provides information about dementia and caregiving to help to provide early, accurate and ongoing information about dementia, caregiving for people with dementia, and self-care. The hub service also provides navigation towards appropriate health and social care providers and information about accessing services. Access to financial management services ensures that affordable support can be obtained and which also helps ensure that people are protected from financial abuse and exploitation. Daily living and respite and peer-to-peer support is also offered, as appropriate. In addition, the hub provides assistance with coordination of care and services directly. As diagnosis is not required to access the service, it also provides support, information, and resources to those waiting for a definitive diagnosis. This model was developed co-productively based on the findings from research with those from underserved and marginalised populations with lived experience to address specific areas of unmet care and support needs amongst these population groups.

Community-Based Dementia Care Re-defined model (Gudnadottir et al. 2021)

This is an Icelandic model of community-based support where a community day-service program functions as a co-ordinating hub or one-stop-shop for ongoing support, information and resources and access to health, social care and support services during the period of one year + following diagnosis. In Iceland, when a person starts showing memory difficulties, a GP refers them to the memory clinic at the National University Hospital of Iceland to obtain diagnosis. Upon diagnosis, the PWD is offered regular follow-up with a geriatrician and nurse every six months, who at this stage coordinate care and support for managing dementia symptoms and support for caregivers. As the condition progresses and the PWD’s care needs intensifies or when caregivers become overwhelmed, the person with PWD is provided with a placement on a dementia day program where their medical needs are met by in house staff. However, at this stage, the responsibility for co-ordinating all services, resources and access to support for caregivers as well as social care also shifts from the memory clinic to the directors of the day programs. Caregivers are provided with bimonthly meetings with staff from the day centre to connect them to a wide range of support services based on a relational understanding of the caregiver and their families’ situation with the aim of reducing unmet caregiver needs through local sources of support, including peer support and counselling to manage emotions, education in caregiver to increase caregiver confidence and resiliency, and temporary respite to reduce strain and stress.

The Alzheimer’s Iceland model (Gudnadottir et al. 2021)

As part of a pioneering movement in the Nordic countries, the Alzheimer’s Iceland model aims at increasing knowledge and understanding of dementia and providing access to support. This model is run by volunteers who provide a hub or access point from which PWD and their caregivers can obtain educational material, access to individual family consultation services, and access to support groups. These support hubs are often provided on an informal basis in specialised day program centres and aim to provide personalised access to support, recognising dementia as a family illness. No referral process is required, and families can turn to it on their own terms and no formal pathway directs families in need to seek this support. However, although the service provides connections to family support services, it provides no connection with primary health care or social services.

The Verily Connect model (Blackberry et al. 2023)

The Verily Connect model is a Virtual Dementia-Friendly Rural Communities-based model that was codesigned to provide an integrated website and mobile application, videoconferencing and technology learning point to decrease fragmentation in the health and social care systems and improve access to support services and resources for PWD and their caregivers in rural areas who may face challenges accessing care and support services and often must travel long distances to reach them and who may also be more reluctant to seek support owing to social stigma. This model shows how technology provides possibilities to address accessibility gaps in services and social connections. The Verily Connect model involves providing online resources (via the Verily Connect App and facilitated videoconference meetings) and links to location-specific resources (localised information, training for volunteers, and Verily Connect Hubs) to build both online and geographically specific dementia-friendly communities. It is run by volunteers with lived experience who provide support to caregivers, including technological-skill support, to improve the ability of caregivers to engage with the technologies.

The Integrated Health and Social Care model (Henderson et al. 2021)

This is a dementia hub model that aims to promote the maintenance of health and wellbeing amongst PWD and their caregivers through resources and information about health and social care and support services to help PWD and caregivers feel better able to cope with the changing needs of PWD. The hub provides access to information and resources to facilitate social inclusion, functionality and quality of life. The Hub functions as the central node of a network of existing health, social care, legal, financial and spiritual services, and maintains current information on relevant local resources for the caregivers and PWD that it serves, and provides specific information and resources aimed at particular racial and ethnic groups living in the area to foster connections with culturally-specific resources for service users from these groups. The Hub is designed, implemented, and governed by a guiding coalition of dementia care partners and leaders of relevant local organisations and which also provides the opportunity for organisations that serve marginalised communities to be central players in The Hub. This model can be implemented in different national, regional and local contexts to suit the needs of local population groups. The model is funded through a combination of government, charitable and philanthropic organisational funding, with attention paid to ensure that funders are ethnically responsive to the needs of the cultural communities it serves. Civic organisations that provide social opportunities for people to gather and connect also help support and promote The Hub, as well as create opportunities to meet directly with care partners. The Hub is staffed by a small team with skills in website development and maintenance, communications, community outreach and engagement, and information management. A community advisory group provides guidance from individuals with lived experience and knowledge of the local area.

The Belgian model (Tokovska et al. 2022)

This model is based on the Dementia Plan for Flanders (2016-2019) which provides a vision for dementia care that involves all of society. To increase the informal caregiver’s capacity and quality of life, a tailored psychoeducation package is offered to all informal caregivers and caregivers are also given access to a dementia coordination platform or hub which includes virtual psychoeducation, buddy assistance and facilitates contacts with other caregivers, as well as provides links to respite services, day services, home care and residential care facilities provided by dementia experts.

The Scottish Digital Support Platform model (Killin et al. 2018)

This is an internet-based, post-diagnostic support platform for families living with dementia in Scotland. This model provided access to information, support and resources for PWD and their caregivers, including information about the condition and on locally available community resources, as well as about how to access formal social care services. The platform combined three technologies to facilitate access to a wide range of information and resources: 1. Living It Up (NHS Scotland)—a well-being portal designed to provide information and advice about conditions (including, but not limited to, dementia) and relevant community resources located near the user’s location; 2. Jointly (Carers UK)—a care coordination service that defines an informal network or ‘circle’ of care for a person living with dementia (including, eg, relatives, friends and professional carers), allowing all members of the circle to communicate and access shared tools and functions, such as a calendar, address book or to-do list; and 3. ClickGo (Carr Gomm)—a support appointment scheduling interface for families with a statutory package of care in place. Appointments requested by the user or family would be confirmed or modified by the care provider. Care plans could also be shared via ClickGo, including details of remaining monthly support budget. Profiles for members of the care team and current progress on predefined outcomes were also available.

What are the key facilitators and barriers to the implementation and delivery of dementia hubs?

Four documents reviewed identified facilitators and barriers associated with the implementation and delivery of particular models of dementia hubs. A summary of the key facilitators and barriers identified is shown in **Table 2**.

What are the key gaps in the available evidence?

While the evidence available identifies some models of dementia hubs and a number of potential beneficial outcomes associated with the provision of dementia hubs, especially for those from more marginalised communities, the amount of evidence available of particular models is limited. In addition, although a number of potential beneficial outcomes associated with dementia hubs are evidenced, as well as a number of facilitators and barriers to the implementation and delivery of these services associated with the particular models available, it is not clear from the evidence how these are staffed and run. Further research comparing the benefits of in-person versus online hubs would also be beneficial for highlighting what works best and for whom.

Table 2: Facilitators and Barriers to the Implementation and Delivery of Particular Models of Dementia Hubs

Model	Facilitators	Associated Barriers
Verily Connect model (Blackberry et al. 2023)	• Volunteer face-to-face assistance for accessing online support • Low cost. • Flexible approach. • Access to support through health professionals can increase uptake.	• Time requirements in learning and using a technology-based intervention • Poor internet connectivity can reduce access to updates • Preferences for face-to-face support • Less suitable for older caregivers due to lower confidence using technology
Integrated Health and Social Care model (Henderson et al. 2021)	• Social media communications should be provided in multiple languages • Many key partners • Other local government entities are important partners for reaching caregivers • Leadership from an active coalition with lived experience • Funding via a combination of sources.	• Not evidenced • Lack of connectivity and teamworking and effective communications with service providers creates barriers to the successful delivery of the model
Community-based Dementia Care Re-defined model (Gudnadottir et al 2021)	• Model is generally rated very highly with caregivers. • Referral is automatic.	• Lack of adequate communication and poor teamworking limits potential to deliver desired outcomes • Lack of flexibility in opening times affects accessibility.
Scottish Digital Support Platform model (Killin et al. 2018)	• Cost-effective • Feedback from service users demonstrates it is highly suited to needs of those caring to PWD reaching the moderate stage of the condition	• Requires familiarity with technology.

CONCLUSION

This review identified a robust evidence base about the core characteristics of dementia navigation services and their associated potential outcomes, as well as of the facilitators and barriers to the implementation and delivery of these services. Sixteen different models of dementia navigator services were identified from review of both the national and international literature, including about how these services could be staffed and run. While barriers and facilitators to the implementation of specific models were identified for a small number of models, the majority of facilitators and barriers were general and therefore may apply across all models. However, gaps in the evidence remain about the relationship between implementation, delivery and impact. In addition, the amount of evidence that includes the perspectives, voices and narratives of those with lived experience of using or co-producing dementia navigator service is limited. Therefore, future research focusing on evidence from lived experience could help provide a more nuanced understanding of how access to, use of, and engagement with co-producing this type of service affects PWDs’ and their caregivers’ lives.

Although the amount of evidence available about dementia hub services is smaller, the limited amount of evidence on in-person and online dementia hub services provides helpful information about their purpose and core characteristics, as well as how the in-person form of this service differs from other dementia services, such as dementia meeting places, dementia day services and dementia cafes. A range of outcomes associated with in-person and virtual forms of dementia hubs are also evidenced, including how they may help to reduce socio-economically- and ethnically-based care gaps when specifically tailored to the needs of particular population groups. In addition, while only a limited number of models of were evidenced in the literature, evidence about specific facilitators and barriers to the implementation and delivery of each model were identifiable. However, how these services are staffed and run is less clearly evidenced, as is how outcomes may compare between in-person and virtual versions of dementia hub services.

One notable limitation of this review is that application of a pre-defined inclusion/exclusion criteria resulted in publications evidencing findings from contexts other than western neoliberal countries being excluded due to the potential for these research contexts to be politically, economically and socio-culturally highly distinct from that of the UK. However, inclusion of findings from research in these other countries could have widened the scope of potential models included. While this would require application of an evaluation criteria for assessing their suitability for cross-cultural application, expanding the scope of the search could prove beneficial for obtaining additional evidence. Moreover, publications that were not in English were also excluded. However, inclusion of non-English ‘grey literature’ documents about nation-specific dementia navigation and hub services could have helped obtain further evidence about additional European models of these types of services.

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Appendix 1: Summary of Evidence of Dementia Navigator Models with Strongest Evidence Base

(Thanks to Dr Claire Toomey for compiling this summary)

Model	Population/ Timeline	Study Design/ Measures	Data	Service Provider	Funding	Context	Status
MIND at Home *(Amjad et al. 2018)*	303 adults, aged ≥70 with a cognitive disorder (Average age: 84); Gender: 64% Female; 36% Male; Ethnicity: 29% non-white; 88% of participants had dementia; 12% had mild cognitive impairment. Location: Baltimore, Maryland (Between 2008–2011). Excluded: Individuals in crisis; signs of abuse, neglect, or danger to self or others. Timeline: 18 Months	Quantitative Study: Single-blind RCT evaluating efficacy of an 18-month care coordination intervention. Outcome Measures: In-person, self-report interviews administered to the study partner at baseline, 9 months, and 18 months.	Significantly increased outpatient dementia/mental health visits from 9 to 18 months (p=.04) relative to controls. Home and community-based support service use significantly increased from baseline to 18 months in the intervention compared to control (p= .005).	Multiple providers: Community-based nonclinical care coordinators, supported by an interdisciplinary clinical team.	Multiple private and public sector funders. Cost/Benefit: Increased cost of outpatient and HCBS use offset by decreased spending on long-term care. Lower costs compared to prior interventions that have used professional case managers.	Increasing cost of care for Americans living with dementia presents challenge for healthcare system. In addition to, high rates of hospitalization, nursing home stays, long-term care placement, emergency department (ED) visits, and outpatient care. Community-based services and support increasingly recognized as key components of high-quality dementia care with potential to reduce longer-term care costs.	Trial: Complete Model ongoing and evolving (John Hopkins Medicine 2025)
US Memory Program *(Chen et al. 2020)*	101 Patients with Alzheimer Disease and their caregivers (n = 63) at Greenville Health in 2012. Propensity score matching identified a	Quantitative Study: Difference- in-differences regression and segmented regression analysis on the patients' health care utilisation patterns pre- and post-intervention. Outcome Measures:	Intervention patients had fewer emergency department (ED) visits (–0.0538; 95% CI, –0.102 to –0.0052) in some analyses. Caregivers had half as many acute visits with	Health care provider: Program implemented at Prisma Health in Greenville, South Carolina (USA).	Research funded by the Institute for the Advance of Health Care at the Greenville Health Systems (now Prisma Health).	Alzheimer disease (and related dementias) are the sixth leading cause of mortality in the US. High economic and social burden and for health care systems.	Trial: Complete

	control group in South Carolina (n = 928). Timeline: 24 months- Study conducted between late 2012 and 2014.	Caregiver differences were examined via t tests of differences in means. Four Outcome Variables: Total medical charges, Emergency Department encounters, admissions, and discharge.	depression as a diagnosis (from 0.22 to 0.11, difference of 0.11; 95% CI, –0.242 to 0.0198).			Caregivers of patients experience high levels of financial and health challenges.	
US Memory Program *(Liu et al. 2019)*	Participants/ eligible patients: n = 238, age ≥65 years, between ages of 65 to 96 in the intervention group and 938 patients aged 65 to 102 in the comparison group. Most patients in the intervention group were Caucasian, female, and widowed. Location: South-eastern United States. Inclusion: Had to have visited the memory clinic at least once between 2015 and 2017 and an ambulatory or out- patient location in the health care system network in the 12 months following their index visit. Timeline: 12 months	Mixed Methods Study: Evaluated the impact of a memory clinic with an embedded dementia navigator on the experiences and health outcomes of patients with dementia and their caregivers. Embedded mixed methods design: 1) retrospective matched cohort study of health care utilization; 2) Prospective surveys of caregiver burden and patients’ QOL; 3) Qualitative interviews with caregivers, where qualitative data collection and analysis were conducted in parallel with the quantitative components.	Patients receiving memory clinic services (n = 238) had higher emergency department visits than a matched cohort with dementia (n = 938). Findings suggest that this embedded navigator model is useful for addressing caregiver needs and may have potential to reduce caregiver burden and improve patient quality of life.	Healthcare setting: Memory clinic within a large vertically integrated health care system in the South-eastern United States. More than 900 care locations including hospitals, long-term care facilities, primary care, and specialty practices. Team based approach: The care team includes a geriatric physician, nurse, nurse practitioner, and a social worker who functions as the dementia navigator.	Private foundation funding: Study was supported by a grant received from the Duke Endowment.	Dementia is a complex diagnosis estimated to impact more than 47 million people worldwide. Dementia diagnosis often occurs in primary care settings. Higher healthcare costs (for patients with the disease) compared to those without the disease. Previous work has evidenced positive effects of an interdisciplinary primary care-based memory clinic model in providing comprehensive care and management of patients with dementia. In addition to supporting the knowledge base of caregivers.	Trial: Complete

Care Ecosystem Model *(Bernstein et al. 2019; 2020; Merrilees et al. 2020; Possin et al. 2017; Rosa et al. 2019)*	Bernstein et al. 2019: Care team navigators (n=10); Caregivers (n = 269). Bernstein et al. 2020: case study analysis - three family dyads participating in the Care Ecosystem program (Case 1: 70 year old male Cantonese speaker with vascular dementia; Case 2: 83-year-old woman with Lewy body dementia; Case 3: A 68-year-old woman with advanced frontotemporal dementia). Merrilees et al. 2020: 780 family caregivers; three exemplary cases. Possin et al. 2017: 460 patients within the trial (55% female, Average age 78). Rosa et al. 2019: Sample 272, Participants 192 (aged over 45, with dementia).	Qualitative/ Mixed Methods Studies: Bernstein et al. 2019: Mixed Methods: interviews, focus groups, observations with Care Team Navigators; and Quantitative survey. Bernstein et al. 2020: Qualitative Study: Interviews, focus groups, and case study analysis. Merrilees et al. 2020: Mixed methods: Focus groups and interviews with the care team navigators. Quantitative Studies: Possin et al. 2017: Quantitative: pragmatic randomized controlled trial Rosa et al. 2019: Micro-costing analysis to calculate operational costs per-participant-month between March 2015 and May 2017	Working closely with caregivers; providing emotional support; tailoring education and resources; and coordinating with a clinical team around decision making important (Bernstein et al. 2019). Care navigators who speak the same language and have an understanding of the symptoms of different dementia syndromes may be particularly effective. (Bernstein et al. 2020): Merrilees et al. (2020) Identified three categories of Care Team Navigator intervention: emotional, informational, and instrumental support. Possin et al. 2017: the care model was revised to enhance caregiver support and to address CTN stress and burnout. Rosa et al. 2019: Start-up and Early Operations costs	Multiple providers: Team-based, multidisciplinary approach that includes both professional clinicians and trained, unlicensed navigators	Multiple funders U.S. Department of Health and Human Services, Centers for Medicare & Medicaid Services (Bernstein et al. 2019; 2020; Merrilees et al. 2020; Possin et al. 2017; Rosa et al. 2019)	Increasing economic and social burden of ineffective dementia care - US health care settings.	Trial/Study: Complete

			ranged between $581 and $142 per-participant (month during Continuing Operations). Estimated costs would range between $75 (UNMC) and $92 (UCSF) per-participant-month with the highest projected caseloads (90).				
Banjamin Rose Institute model *(Bass et al. 2019)*	The study sample included 148 caregivers and 84 persons with dementia who used ‘Partners in Dementia Care’ (services) for 12 months. Caregivers: Average age was 67.5 years, 95% were female. Most were the spouse of the person with dementia, though about a quarter were adult daughters. Persons with dementia: 84 veterans with dementia. average age was 80, and nearly all were male. 85% were living in the same household with their caregiver. Timeline: 12 months	Mixed Method Study: Translation study-implemented to mirror a non- research implementation. Research data came from 2 structured telephone interviews, one before program implementation and a follow-up after program completion. PWDs and caregivers averaged 14 telephone contacts with Care Consultants over the 12-month study period, and 12 behavioural action steps to address problems or concerns. Repeated measures ANOVAs were utilised for analysis.	Repeated measures ANOVAs showed the use of ‘Partners in Dementia Care’ (service) was related to significant improvements. Caregivers had decreased levels of isolation, physical health strain, unmet needs, and increased confidence in caregiving capacity, informal helpers, and support service use. People with dementia had decreased embarrassment about memory problems and unmet needs; and increased informal support and community service use.	Multiple providers: Community and healthcare organizations: The program is delivered through a network of partner organizations, which includes both healthcare providers and community-based organizations.	Multiple private and public sector funders. PDC was delivered via partnerships between the Louis Stokes Department of Veterans Affairs Medical Centre and the Greater East Ohio Alzheimer’s Association Chapter and the Western Reserve Area Agency on Aging.	Numerous non-pharmacological programs for family caregivers and persons with dementia (PWDs) have been found efficacious in randomized controlled trials. Few programs have been tested in translation studies that assess feasibility and outcomes in less-controlled, real-world implementations.	Study: Complete Model utilisation/ development ongoing

Australian Care Coordinator model *(Xiao et al. 2016)*	61 family caregivers from 10 minority groups completed the trial. Average age: 56 (range 26-89). Most caregivers were female. Their median duration in the caregiver role was 4 years (range 1- 25).	Quantitative Study: A randomised controlled trial was utilised to test the hypothesis. Primary outcome was caregivers’ competence measured by the SSCQ. Outcome variables were measured prior to the intervention, at 6 and 12 months after the commencement of trial. A linear mixed effect model was used to estimate the effectiveness of the intervention.	The intervention group showed a significant increase in the caregivers’ sense of competence and mental components of quality of life. There were no significant differences in the caregivers’ physical components of quality of life.	Multiple service providers: 7 across Adelaide, South Australia.	Funding was provided by 2 key funders: the Dementia Collaborative Research Centre, University of New South Wales; and Flinders University Faculty Seeding Grants.	Most caregiver interventions in a multicultural society are designed to target caregivers from the mainstream culture and exclude those who are unable to speak English. This study explores whether support provided by a team led by a care coordinator of the person with dementia would improve competence for caregivers from minority groups in managing dementia.	Pilot Study: Complete Supported the expansion of care coordination roles in Australia's mental health and aged care systems.
Verily Connect model *(Blackberry et al. 2023)*	113 total participants, who were recruited from 12 rural Australian communities. Three main cohorts: dementia caregivers, volunteers, and health service staff. Caregivers: 37 informal caregivers providing care for someone with dementia or cognitive impairment. Volunteers: 39 volunteers were recruited, with a median age of 66. Most	Mixed methods Study: mixed-methods, stepped-wedge, cluster-randomised controlled trial. Caregiver data were collected between 2018 and 2020. The relationship between post-intervention social support with age, years of caring, years since diagnosis, and duration of intervention were explored through correlation analysis and thin plate regression. Google Analytics were analysed for levels of engagement, and cost analysis was	Caregivers’ perception of social support increased over 32 weeks (p = 0.003) and there was a marginal trend of less care demand among caregivers. Better social support was observed with increasing caregiver age until 55 years. Younger caregivers (aged <55 years) experienced the greatest post-	Multiple providers: Academic research centres, rural health service providers, volunteer organisations, and national dementia and caregiver associations.	Multiple funders: Australian Government, Department of Health, Dementia and Aged Care Services (DACS).	Caring for people living with dementia often leads to social isolation and decreased support for caregivers. The study investigated the effect of a Virtual Dementia-Friendly Rural Communities (Verily Connect) model on social support and demand for caregivers of people living with dementia. The co-designed intervention entailed an integrated website and	Trial: Complete

	volunteers were female (82%). Health service staff: 37 staff members from aged care and health services participated. Timeline: 24 months (between 2018 and 2020)	performed for implementation.	intervention improvement. The Verily Connect model improved caregivers’ social support and appeared to ease caregiver demand.			mobile application, peer-support videoconference, and technology learning hubs.	
Integrated Health and Social Care model *(Henderson et al. 2021)*	Not Applicable	Literature review: integrative literature review synthesises empirical literature from six databases (CINAHL; MEDLINE; AMED; TRIP; Web of Science and Science Direct; 2007–2019). Measures: Twenty studies met inclusion criteria. Results were thematically analysed. Three themes were identified: 1) Relationships; 2) Promoting health and well-being; and 3) Difficulty understanding systems.	Findings: 1) Relationships important in integrated health and social care services (IHSC). 2) Service users feel left out of planning their care and have a lack of clarity navigating integrated systems. 3) Service user and informal carer voices are underrepresented in current literature More research required that explores the person-centred experiences and needs of IHSC service users.	Not Applicable	Funded by Robert Gordon University and NHS Grampian.	Global priority: People-centred health and social support systems Challenges: Lack of safe, effective, timely, affordable, coordinated care around the needs and preferences of people who access integrated health and social care (IHSC) services. Current international guidance for integrated care sets a precedence of person-centred integrated care that meets the health and well-being needs of people who access IHSC services.	Not Applicable