Dementia Diagnostic
Services for Ireland:
a literature review

Foreword

The Irish National Dementia Strategy emphasises the importance of timely diagnosis as the first step in a person's journey with dementia. Equitable access to assessment and timely diagnosis of dementia across Ireland requires the alignment of referral and diagnostic pathways at primary, secondary and tertiary care settings.

The review of memory clinics carried out by the National Dementia Office (NDO) and Dementia Services Information Development Centre (DSIDC) in 2017 identified considerable variability in the structure, availability and function of memory clinics across the country and highlighted that there were no national guidelines on the role and function of memory clinics. In addition to geographical variability in terms of service availability across the country, there were major differences between services in terms of staff composition, frequency of operation and post diagnostic support and evidence that people under the age of 65 and those with intellectual disability had difficulty accessing services.

To address the priority actions around timely diagnosis within the National Dementia Strategy and the findings of the memory clinic review, the Dementia Diagnostic Project was established by the NDO in 2017, with a remit to develop a national framework for an integrated diagnostic pathway for dementia in Ireland. The purpose of the review of international best practice was to provide the evidence needed to plan and develop equitable dementia diagnostic services in Ireland.

This literature review highlights that there is no one 'size fits all' when it comes to creating the best approach and pathway; however, it is clear that a modern approach to timely diagnosis must emphasise flexibility and fluidity between assessment at primary, secondary and tertiary levels, with regional specialist assessment readily accessible for atypical and hard to diagnose cases. The modern concept of diagnostic pathways for dementia should also take into consideration the importance of prevention, the imperative to address modifiable factors in at-risk populations and the importance of brain health education and advice.

This literature review makes a significant and welcome contribution to the evidence needed to inform the creation of an equitable system of assessment and diagnosis of dementia as part of the advancement of the Irish National Dementia Strategy.

I would like to acknowledge the work of the National Dementia Office who commissioned this report, and the Centre for Gerontology and Rehabilitation in UCC who produced this valuable and informative document. Finally, I would like to thank the members of the National Dementia Project Steering Group for their support and dedication in progressing the development of a national dementia diagnostic framework for Ireland.

Prof. Brian Lawlor,
Conolly Norman Professor of Old Age Psychiatry,
Co-Director, Global Brain Health Institute,
Trinity College Dublin

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i.   List of Acronyms

6CIT	Six Item Cognitive Impairment Tool
AD	Alzheimer's Disease
BPSD	Behavioural and Psychological Symptoms of Dementia
CDAMS	Cognitive Dementia and Memory Service
CMHT	Community Mental Health Teams
CPD	Continuing Professional Development
DLB	Dementia with Lewy Bodies
ECF	Eldercare Facilitator
EOD	Early Onset Dementia
FTD	Frontotemporal Dementia
ICT	Information and Communications Technology
GP	General Practitioner
GPCOG	General Practitioner Assessment of Cognition
GPwSI	General Practitioner with Special Interest
MAS	Memory Assessment Service
MDT	Multidisciplinary Team
Mini-Cog	Mini-Cog© Assessment Instrument (cognitive tool)
MIS	Memory Impairment Screen
MMSE	Mini-Mental State Examination
(A)MTS	(Abbreviated) Mental Test Score
POA	Psychiatry (psychiatrist) of Old Age
QALY	Quality Adjusted Life -Year
RCT	Randomised Control Trial
VaD	Vascular Dementia

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1. Introduction

This literature review was commissioned by the National Dementia Office in December 2017 to inform the planning of dementia diagnostic services in Ireland, by providing evidence to support decisions by a Dementia Diagnostic Project Steering Group regarding recommendations and implementation of enhanced dementia diagnostic services for Ireland. This literature review aimed to describe existing models of dementia diagnostic services and provide the evidence for each model, where it exists, particularly where alternative models have been directly compared, or where an economic analysis or economic comparative analysis has been performed. Given the clear direction from Slaintecare[1], a particular emphasis was placed on searching for evidence for GP-led diagnosis and diagnosis within the community, rather than in hospital-based clinics. Another significant focus was dementia diagnosis disclosure, as a crucial part of the overall diagnostic process, and a key link between diagnosis and post-diagnostic support.

1.1 Dementia Definition and Clinical Syndrome

Dementia is commonly used as an umbrella term to refer to a range of progressive conditions affecting the brain[2] that result in structural and/or chemical changes in the brain, with shrinkage in the volume of the brain and damage or death of neurons[3]. It is characterized by a decline in one or more cognitive domains (learning and memory, language, executive function, complex attention, perceptual-motor, social cognition), interfering with daily function and independence. [Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition (DSM-5)]. The process of dementia beginning (triggers) and its speed of progression are complex, with multiple factors including genetic predisposition, socio-demographic factors and environmental influences playing a role[4]. Dementia is a chronic and incurable condition, ultimately causing severe functional impairment and death[5].

It is estimated that there are several hundred sub-types of dementia[2-4,6]. The most common sub-type of dementia is Alzheimer's Disease (AD), accounting for over 60% of all diagnosed cases of dementia[6-8]. Other common types include Vascular Dementia (VaD), Dementia with Lewy Bodies (DLB), frontotemporal dementia (FTD), alcohol-related dementia/Korsakoff's syndrome[4], and Mixed Primary Neurodegenerative dementia-Vascular Dementia. Other sub-types include Creutzfeldt-Jakob disease, Huntington's disease, Corticobasal Degeneration, and AIDS dementia complex (ADC).

1.2 People living with Dementia: estimates and projections

The rising prevalence of dementia in many countries across the world means that dementia is now a global health issue. It is believed that the total number of people with dementia worldwide is currently over 45 million[7,9,10], and the number of new cases every year is approximately 9.9 million. These figures are expected to rise significantly in the coming years in developed countries due to the continued 'aging of the population' as life expectancy continues to rise, with even more dramatic increases in dementia prevalence due to increased life expectancy in developing countries, namely in China and India[10]. Current projections indicate that by 2050 there will be over 131.5 million people living with dementia worldwide[11].

In Ireland, current estimates on the prevalence of dementia suggests that there are over 55,000 people living with dementia in the country and projections propose that this may rise to 94,000 by 2031 and 152,000 people by 2046[12].

1.3 Timely diagnosis of dementia

Over recent years there has been a welcome change in reframing the focus of dementia care on the retained abilities and capabilities of people with dementia rather than on lost abilities. Timely diagnosis provides people with dementia time to plan for the future, potentially slow down the progression of the condition and also play a more active role in the design and provision of services through participation and feedback[3,13]. Thus, timely diagnosis of dementia is a common theme in a number of national dementia strategies, and some, such as the UK's *'Living well with dementia'*, and Ireland's *'The Irish National Dementia Strategy'*, have set specific goals to address the current diagnosis gap, which is seen to hinder clinical pathways of care[14-17]. Part of this process is seeking to dispel the myth that cognitive impairment is an inevitable and normal part of the ageing process[18].

Linked to this, there is a growing interest in appropriate dementia diagnostic pathways for 'minority groups' such as people with Young Onset Dementia (YOD), people with intellectual disabilities (Down's Syndrome in particular) and migrant groups[19-23]. Similarly, there is a growing interest in understanding how structural, cultural or institutional obstacles can inhibit the process of dementia diagnosis[5]. Recognizing potential differences and needs in ethnic minorities in dementia diagnostic services is vital given the considerable rise in migrant communities in the last 30 years in the country. For example, VaD is believed to be the most common type of dementia among minority ethnic groups in the UK[22].

Greater recognition of the particular diagnostic process needs of people with YOD is also an area of growing interest in recent years. In people with YOD, symptoms are frequently misdiagnosed and the correct diagnosis is often delayed for several years. The effect of this delay on the patient and family includes elevated stress, confusion and a rise in family conflict[24]. Significantly, YOD is also more common among minority ethnic groups[22,25].

1.4 The case for new models of diagnostic services

Service provision for people with dementia is itself challenging due to the complexity of the disease but a major obstacle is the fact that at present less than 50% of people receive a formal diagnosis. An Irish study of 600 older people admitted to six hospitals in Cork county found that only 36% of people diagnosed with dementia in the research study had a prior formal diagnosis of dementia[26]. This is well below the current status in the UK, where diagnostic rates have significantly increased due to diagnostic service expansion and national diagnostic targets (currently 70% of people in England and Scotland with dementia have a formal diagnosis)[26a].

Delayed diagnosis is a significant problem in dementia, with reasons including delays in seeking medical advice at the onset of dementia symptoms, and under-diagnosis from GPs and other healthcare professionals[8,14,27-30]. A qualitative thematic analysis of 20 case studies of carer experience, in the UK, indicates that the median timeframe between becoming aware of initial dementia symptoms and receiving a medical diagnosis is 1.5 years[14]. Crisis events continue to be a main trigger for initiating the diagnosis process[28]. Thus, national dementia strategies seek to support timely diagnosis of dementia by raising awareness and highlighting the need for proactive services.

The 2013 English National Memory Clinics Audit found that the average waiting time from receipt of referral to assessment was 5.2 weeks (range 1-25 weeks)[31]. In Ireland, the self-reported waiting time in January 2017 across 19 memory clinics ranged from four weeks to one year. In the UK, case-finding in primary care has been promoted and financially incentivized in recent years[32].

A significant challenge to diagnostic services relates to the projected large increase in the number of people with dementia over the coming years, which naturally will impact on diagnostic service waiting times and responsiveness. Increasingly there is a call for innovative models of care for diagnosing and treating dementia which improve health outcomes for patients, and prevent morbidity and hospitalization, in a manner that is cost beneficial and uses resources efficiently[33,34]. Devolved forms of health provision, which move away from hospital-based care and towards primary care settings, are also promoted[35]. The following chapters will explore the evidence for different models of diagnostic services, and their cost evidence, where available.

2. Methodology

The main work presented in this report is based on a review of literature looking at diagnostic pathways to dementia care. This work was funded by the HSE in order to provide evidence (Irish and international) to the Dementia Diagnostic Project Steering Group to support decisions with regard to recommendation or implementation of potential dementia diagnostic services/pathways for Ireland. This report is complementary to an earlier report commissioned by the HSE looking at post-diagnostic supports in dementia, authored by O'Shea et al. in 2018[36].

This review used a scoping review methodology so as to allow exploration of a broad topic, including key concepts, theories, and multiple types of evidence. We used the framework described by Arksey and O'Malley[37]. With a scoping review methodology, the underlying research question has a broad focus, and a limitation is that there may be a risk that the researcher might miss a relevant study. However, in the current instance we used a systematic search strategy, and the broader research question allowed us to pragmatically explore and answer a number of relevant related topics.

This literature review involved a defined and systematic search of all relevant materials, conducted by a single reviewer, without formal appraisal of the quality of the evidence, given the expectation that there would be few if any high quality randomised control trials (RCTs) or similar in this area. The search was undertaken between December 2017 and May 2018 and progressed in a staged manner involving a number of steps, which included the development of a broad research strategy, the creation of a review protocol, the identification of key bibliographical databases, retrieval and management of information, review of key materials and write-up of results using a narrative synthesis approach. Preliminary results were shared with and interpreted by the Dementia Diagnostic Project Steering Group in January and May 2018, leading to refinement of search priorities based on their needs in planning dementia diagnostic services in Ireland. In particular, a decision was made as the review progressed that the diagnostic needs of people with intellectual disability or YOD would require detailed separate literature reviews, and would no longer be within the scope of this current review.

Three distinct searches were carried out to address the main areas of research interest. These were:

1) Dementia diagnostic service models (with a key focus on 'memory clinics')
2) Diagnosing dementia in primary care settings
3) Dementia diagnosis disclosure.

Similar eligibility criteria were used for these three distinct reviews. The initial parameters used for retrieval of information included sourcing all available literature written in English between the dates of January 2000 and May 2018. Retrieval of information included a broad range of materials, including published articles, commissioned reports and other grey literature.

Key bibliographic databases were identified in consultation with the all members of the research team. A short list was compiled of the most important databases likely to include relevant articles, reports and other materials relevant to the study of diagnostic pathways for dementia care, as well as the three sub-themes linked in this report. The key databases used to source information were PubMed/Medline, Cinahl, Scopus, Embase, NCBI and, Cochrane.

Additionally, supplementary sources were reviewed, including the following databases: the Campbell Collaboration Library, the Australian National Health and Medical Research Council, the Medical Research Council (UK), the National Guideline Clearinghouse (US), the Agency for Healthcare Research and Quality, and Prospero.

Each review used a distinct search strategy and these were, at times, refined and adapted to specific databases depending of the range of options available to help create a more targeted and contained search for the literature. Further details on the search terms used and total number of article hits for each theme can be found in the Appendices at the end of the report.

2.1 Literature Selection, Review and Analysis

Following retrieval of materials from different bibliographical databases, the subsequent steps in the review included the selection of literature, the review of the information and the analysis of main findings. After duplicates were removed, a manual selection of texts was performed. This entailed looking initially at titles and abstracts to identify further texts for elimination. The process of literature selection was based on a set of inclusion and exclusion criteria, which was refined along the way. One significant limit that was set in this process was excluding materials that dealt specifically with post-diagnostic pathways, as the key focus of the review was to identify literature pertaining to diagnostic pathways of care (see table 2.1 below for a detailed list of eligibility criteria applied in the literature selection process).

As the systematic literature review process entailed three distinct reviews that dealt with different elements of diagnostic pathways to dementia care there was also some internal criteria to consider to avoid overlap and repetition. However, a degree of flexibility was incorporated in the eligibility criteria applied in order to avoid over-limiting the literature search and selection and increasing the risk of omitting significant materials. A degree of repetition therefore was expected and dealt with during the write-up stages of the report. The review was conducted by a team of three researchers, with a different team member performing each of the three reviews; subsequently the materials were drawn together and analyzed by one of the team members.

Table 2.1 Inclusion and Exclusion Criteria applied in the review

Inclusion	Exclusion
• Literature limited to the last 18 years	• Focussed exclusively on post diagnostic supports
• No age limit	• Non-English language
• Any type of study	• Service for a highly selected patient group only e.g. HIV dementia, oncology patients only
• Any type of diagnostic service, any setting	
• Any outcome measure used	
• Any evaluation type	
• Any report of user and/or referrer preference or service feedback	
• Any cost analysis, modelling and/or cost comparison	
• Any evidence that related to 'disclosure'	

Of the three distinct reviews performed, the first, which looked at dementia diagnostic service models, entailed a broader search remit. The other two themes, which looked at diagnosis disclosure and diagnosis in a primary care setting, had more narrow remits. However, there was a high degree of complementarity between the three search strategies.

A narrative synthesis approach was adopted to assess and summarise the materials selected for review. This approach is widely utilised in the health sciences in the synthesis of mixed data, derived from qualitative and quantitative data sources[38]. As the term suggests, narrative analysis makes use primarily of words and text to offer a summary and an explanation of the key findings derived from the systematic literature review[39], recounting the main findings of the review in narrative format, and offering an exploration of the links between different data sources encountered[39].

3. Diagnostic Service Models

Before discussing the evidence to support various diagnostic service models, it is necessary to briefly describe these in some way. There are many variations between similar-sounding services and between service types but they can be categorised generally to support description and evaluation.

3.1 Categorising diagnostic services

We have chosen to divide services firstly into those based in the community and those based in hospital clinics.

Community based diagnostic services can be further divided into:

• GP-provided diagnosis as part of usual care, where the GP diagnoses their own patient during a consultation and then refers to other services as needed for post diagnostic support

• GP-led memory clinics, where a GP within a practice or region has a special interest in dementia and sees other GPs' patients for diagnosis, usually with MDT support

• Outreach memory clinics, where a specialist service comes regularly to provide a memory clinic in the community, often based in GP practices or health centres

• Community-based Psychiatry of Old Age (POA) services, typically providing domiciliary visits as well as community-based clinics.

Hospital based diagnostic services

• Generic out-patient clinics provided by geriatricians, POA, or neurologists where a person with suspected dementia is referred by their GP for diagnosis, or the diagnosis is suspected during review of another condition (e.g. falls assessment, Parkinson's disease)

• 'Cohorted clinics', where all patients attending a certain generic clinic once a week, fortnight or month have suspected or known dementia, but there is limited MDT dedicated support to the clinic and the clinic would not meet criteria (see Chapter 5) for being a memory clinic

• Memory clinics, where all patients attending have suspected or known dementia and there are established diagnostic protocols and good MDT input, often with enhanced diagnostic assessment capabilities (genetic testing, imaging and cerebrospinal fluid analysis).

There can be crossover between services, such as where a hospital based-generic clinic or memory clinic also provides a community outreach service, and/or a domiciliary service (especially in geriatric and POA services).

3.2 Memory clinics - always the answer?

The National Dementia Strategy highlights the role of memory clinics in timely diagnosis. However, given the expected rise in the number of people at risk of dementia due to population ageing, and better awareness of the benefits of timely diagnosis, the demand for services will be greater than ever before. Therefore, we would require a large investment in memory clinics to meet current demand, and a huge investment to meet future demand.

Inequitable provision of, and access to, memory clinics in Ireland has been noted for several years[40]. A review of memory clinics performed in 2011 (n=14 in operation at the time) found that most were consultant led (POA slightly outnumbering geriatrician leads); 80% had nursing input; half saw less than 100 new patients per year; less than half had dedicated Allied Health Professionals (AHPs) for the clinic; and less than half of the clinics were involved in research[41].

If given extra funds, most of the directors would have preferentially employed more AHPs, while some would have preferred better access to imaging.

A recent mapping exercise of memory clinics performed in 2017 by the National Dementia Office and the Dementia Services Information and Development Centre (DSIDC) showed marked city-centricity, with almost no clinics west of the Shannon (Figure 3.1)[42,43]. It is estimated that there are currently about 25 'memory clinics' in Ireland, although many are cohorted clinics for people with memory complaints rather than true 'memory clinics' (see chapter 5). Within these, one memory clinic assesses patients on an in-patient basis, funded by health insurance[44].

Figure 3.1 Geographical spread of memory clinics in Republic of Ireland (ROI)
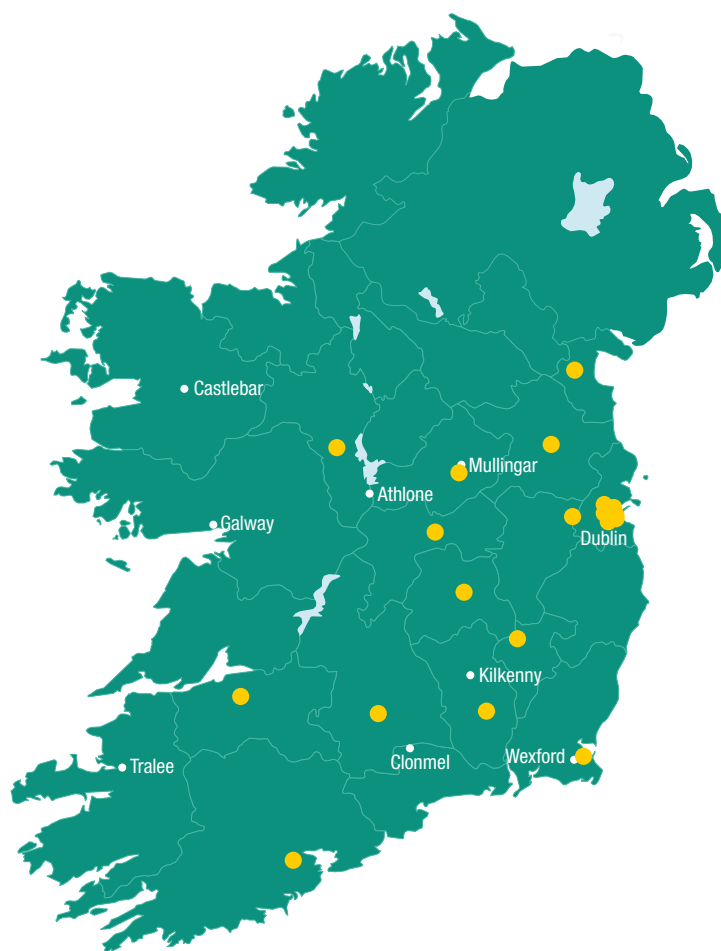
Ideally, people with dementia should be diagnosed close to home, but in very rural communities this may not be feasible through the provision of memory clinics alone, even if many more clinics were developed. In addition, those with dementia as a co-morbidity rather than the main complaint may already being attending a specialist service that can diagnose dementia outside of a memory clinic setting, and there is clearly a case for not overburdening a person or the system with multiple clinic visits. Equally, all people need equitable access to a service that can accurately and speedily diagnose their dementia, and also the type of dementia, and this often requires the type of process found in memory clinics rather than other models.

Thus it is important to consider all models of diagnostic services, anticipating that a combination of services may best fit the needs of the population and the particular person. The following chapters will explore each model in turn, as evidence permits. We will first explore the model of the person's usual GP making the diagnosis, and then a very different model, the specialist memory clinic, and finally we will look at more intermediate models (GP led memory clinics, outreach memory clinics in the community, and community mental health services).

4. Community Based Diagnostic Services:
diagnosis by the person's usual GP

Taking on a more central role in dementia diagnosis can be a daunting proposition for GPs, given the complexity of the disease, and the large number of the population at risk of developing dementia[45]. However, GPs are key stakeholders in the timely detection of dementia, usually knowing the person's health, preferences and social context very well, and having an existing healthcare relationship, with the potential to provide continuity of care across the pre-diagnostic to post diagnostic transition.

4.1 Delays in diagnosis

GPs have extensive clinical remits including the screening of conditions such as diabetes, heart conditions and some forms of cancer, chronic disease management, minor injury care, maternity, paediatric and gynaecology care, provision of vaccination services, etc. In terms of the diagnosis and management of dementia this broad remit presents a challenge. Several studies have shown that dementia disorders, in mild to moderate stages of the disease, are diagnosed in only 50% of cases in primary care[8,46-53]. In some studies, up to 80% of cases went undiagnosed in primary care[54,55]. Two systematic reviews of the accuracy of GP diagnosis at different stages of dementia concluded that many individuals with dementia are not recognised or not diagnosed as such. Mild dementia in particular is under-diagnosed[56,57], with a dementia diagnosis documented in less than one-third of mild cases and in less than two-thirds of moderate-severe cases[57].

A postal survey conducted in Ireland in 2006[58] revealed that GPs in Ireland experience difficulties in the screening, diagnosis and disclosure of dementia. On average, GPs diagnose only four new cases of dementia per year, meaning that it is hard to maintain diagnostic competency.

Delays in diagnosis in primary care are common and may occur even when a suspicion of dementia is raised by family and/or when it is detected by positive cognitive screening results[46,59,60]. According to a number of survey-based studies from Canada, Europe and Australia[46,61-65], from the initial presentation of symptoms, the confirmation of a dementia diagnosis takes several months to years in primary care. In the UK, this delay is estimated at between 18 and 30 months, but can be up to 4 years[66]. A relatively recent Irish study from 2008[67] specifically asked GPs whom they 'blamed' for delayed dementia diagnoses: 35% of GPs attributed blame to themselves, with 20% attributing blame to the family and 11% attributing blame to the patient.

Furthermore, a number of international research studies point to the high rates of referrals of suspected cases of dementia from GPs to specialists, indicating poor confidence in diagnosing dementia[41,61-64,68-70]. These referrals are not always preceded by adequate diagnostic investigations and they are not always deemed to be appropriate referrals by specialists[46,68,70-73].

4.2 Poor disclosure and post-diagnostic support

Although disclosure will be dealt with in more detail in chapter 9, it is worth noting here that evidence indicates that even when dementia is detected and documented in healthcare records, GPs withhold the diagnosis in a significant number of cases, and often fail to follow up with the person with dementia/caregivers[30,46,68,74-80]. Several review papers, surveys and qualitative studies of family caregivers reveal some level of dissatisfaction with the manner in which the diagnosis is disclosed, the transference of critical information, as well as the post-diagnostic guidance and support provided in primary care[46,69,74,75,81-83]. Specific shortcomings during these post-diagnostic encounters from carers' perspectives include inadequate

discussion of treatment and management options (including guidance on symptom management, safety, legal issues, and caregiver stress), and the lack of targeted interventions, such as referrals to support services[46,61,68-70,84,85].

4.3 Barriers to GP-led Dementia Diagnosis

4.3.1 Difficulty recognising symptoms

In general, GPs report a number of difficulties in diagnosing dementia, with the existing literature indicating that these barriers are manifest in many countries. The most common difficulties identified in the literature include[5,12,18,21,22,24]:

• Lack of knowledge concerning diagnostic criteria

• Lack of time

• Lack of resources

• Having a negative view of the benefits of early diagnosis

• Risk avoidance

• Scepticism regarding a post-diagnostic pathway of care for people with dementia

There is evidence that many GPs have difficulty recognizing the early symptoms of dementia and/or tend to overlook their importance[46,48,52,55,58,61,66,86,87]. Many GPs express low confidence in making a diagnosis of dementia particularly in the early stages of the disease, and in differentiating between dementia subtypes[46,57,58,87-93]. Interestingly, some GPs feel that the doctor-patient relationship is an important factor in their ability to diagnose dementia; for those they know well, and hence have a better sense of their baseline ability, they feel they can make better estimations of decline in cognitive and functional ability[94].

4.3.2 Patient/family-related factors

Another barrier to GP-led dementia diagnosis relates to the role of family members in recognising symptoms and pursuing a diagnosis. GPs have reported that while family members have a pivotal role in recognising dementia symptoms, it is often difficult for families to distinguish between 'old age' and symptoms of dementia until symptoms become more severe; this leads to delayed presentation to the GP[94]. Furthermore, GPs have noted in some families a masking of dementia-related symptoms, either through lack of awareness, lack of understanding of what these symptoms mean, or because family members may have internalised the cultural stigma of dementia and want to protect their family member from this label[94]. The lack of family members may also lead to difficulties in diagnosis for the GP, as some people do not have family members who can give a rich collateral history.

4.3.3 Lack of training/education

Lack of training and education is a commonly identified barrier. Many GPs feel that their training has been insufficient to prepare them for this task[46,67,86,87,95-98] and express a strong desire for a specialist consultation[46,85-87,93,99,100]. This perception is further exacerbated by the views of some GPs that the diagnosis and management of dementia disorders is more complex than other chronic conditions, both biologically and psychosocially[46,86,98,101-104]. An Irish survey of GPs' experiences in 2006 revealed that the vast majority of GPs (90%) had never undergone specialist training in dementia, and 83% would welcome training in the area. Since the time of this survey, continuing professional development (CPD) has become mandatory for GPs in Ireland who must now engage in 50 hours of educational activity per annum, although there is no mandatory inclusion of dementia training. A more recent Irish study[105] involving interviews with 14 GPs reported their voiced need for training and education around diagnosis and disclosure in particular.

4.3.4 Lack of knowledge regarding post-diagnostic supports/services

GPs can have great difficulty managing the broader quality of life and psychosocial needs of people with dementia/caregivers in terms of post-diagnostic support[46,68,70,81-86,90,97,106-110], thus discouraging a formal diagnosis by the GP. Indeed, while there are perceived difficulties in making a diagnosis, some GPs have expressed greater confidence in their diagnostic competence, compared to their ability to provide adequate post-diagnostic support to people with dementia/caregivers[46,69,97,100].

In a number of international studies, GPs admit that they are insufficiently informed about the available support services for people with dementia/caregivers in their locality and this presents a considerable barrier to providing appropriate and acceptable support following diagnosis4[6,69,85,86,98,100,110-114].

4.3.5 Poor awareness of clinical practice guidelines

Although clinical practice guidelines have been shown to be useful tools in enhancing the knowledge and confidence of GPs in the diagnosis and management of people with dementia[102,115,116], many GPs report that they are either unaware of any existing guidelines or are not familiar with the specific content of guidelines around dementia diagnosis[46,52,115-117].

One potential way of overcoming this barrier is to develop guidelines targeting primary care in more explicit terms. For instance, a paper in 2008 drawing from a multinational expert consensus group[117] highlighted the need for the development and implementation of guidelines in this area. In particular, the authors noted that just three out the eight participating countries had national guidelines which spoke to dementia diagnosis in primary care, and within these three countries, the guidelines were infrequently used by GPs to guide diagnostic practices. In Ireland, a recent guidance document from 2014[118] details current guidelines and clinical evidence in the management of dementia in general practice, entitled *'Dementia: Diagnosis and Management in General Practice'*.

4.3.6 Underlying beliefs and attitudes regarding dementia and early diagnosis

While some GPs believe early diagnosis is worthwhile/beneficial, others have more negative attitudes towards pursuing a timely diagnosis. There is an abundance of literature showing that diagnostic and management practices of GPs can be influenced by negative underlying beliefs and attitudes[46,52,58,63,74-76,86,87,90,93,95,97,111,119-125].

For instance, it is reported that GPs commonly believe that there is a lack of real therapeutic benefits of early diagnosis and this is combined with concerns over the lack of effective pharmacological treatment[94,98]. Another perception relates to concerns about the potential harmful effects of diagnosis due to the societal stigma of dementia[88,94,98,123]. A recent small-scale exploratory cross-country study between Ireland and Sweden found that Irish GPs still consider dementia to be a stigmatizing illness[126].

Other negative perceptions include GPs giving low priority to dementia symptoms compared to physical health problems, thinking that the care of another person with dementia could strain the already stretched health and social care system, and also acting on the belief that many people with dementia do not wish to know their diagnosis[55,127].

However, other authors have argued that the diagnostic approach of GPs may differ from specialists and/or clinical practice guidelines, not because of negative attitudes or poor confidence, but because they prefer to take a more holistic, individualized, and solution-focused approach. This approach is influenced by the fact that their older patients often have multiple comorbid conditions (and so dementia is not deemed a priority), as well as other non-medical factors including moral/ethical considerations, the patient/family wishes and unique circumstances, as well as the physician's own values and past experiences[46,59,77,87,102,120,128,129].

4.3.7 Perceptions of available screening and diagnostic tools

There are a range of subjective complaints and impairments in a person with possible dementia, which makes the formal diagnosis of dementia difficult. Early diagnosis in particular can be challenging, as differentiation from mild cognitive impairment, wherein there are cognitive impairments but the person retains the ability to carry on daily activities[118], can be subtle.

Thus, assessment tools are important to aid in diagnosis. However, research has shown that the majority of GPs believed that available tools were not created to diagnose dementia, but rather served to highlight or 'red flag' symptoms to facilitate a formal diagnosis being made in secondary care[94]. Some GPs also felt the tools lacked flexibility and were not applicable to the range of different cultures and languages of people presenting to them[94].

4.3.8 Health systems barriers

From a macro-level perspective, GPs have also expressed difficulties rooted in the wider health system. A very immediate challenge stems from the context of strained primary care services struggling to cope with large workloads. This is further compounded by lack of funding and financing of primary care services[46,55,94]. Numerous articles have identified time constraints as a very significant barrier to optimal dementia diagnosis and management in primary care[46,52,82,85,96-98,100,102-104,111,114,120]. Furthermore, it seems that this time barrier has worsened over recent years[94], with GPs in the UK now being limited to spending on average just 8-10 minutes with each patient[130].

Inadequate payment models are also cited by many GPs in western countries. This includes reimbursement structures that inaccurately reflect the time required to effectively respond to the needs of older persons in general, and those with dementia in particular. These are seen to prevent GPs from committing adequate time to the care of these complex patients[46,67,86,98,100,104,106,111,114]. They are also perceived to promote reactive, time-limited care systems that reward brief medical encounters. Such conditions thus present significant barriers to timely dementia diagnosis and optimal management[52,86,106].

Service integration is another problem for GPs, and the lack of coordination with secondary care services and memory clinics, coupled with a perceived inefficient referral management system, has been noted as a particular barrier for GPs pursuing a dementia diagnosis[94].

4.4 Factors which could enable the diagnosis and management of dementia in primary care

There is a large body of literature exploring ways to facilitate dementia diagnosis in primary care, often based on increasing GPs' confidence and skills in diagnosing dementia.

4.4.1 New/Augmented Models of Primary Care for Dementia

Despite the above barriers to enhancing dementia diagnostic practices in primary care, there is a growing interest in the development of local and community-based models of care[46,102,106,131], often with the GP in centre stage. These models are seen to provide a more comprehensive and coordinated care management approach, and they tend to offer intensive dementia specific services in primary care[132-139]. Features of these more intensive services in primary care settings have included:

- The use of MDTs of healthcare professionals with relevant expertise (as opposed to the traditional models of primary care in which the GP takes complete responsibility for the patient)

- On-going care management, typically coordinated by a nurse working closely with the Person with dementia/caregiver, their attending GP, and other care providers

- The provision of formal dementia training for GPs (and other clinic staff), including access to an advanced nurse practitioner in geriatric medicine

- The use of standard tools, protocols, and guidelines to ensure active case finding and consistent care processes

- Access to various types of information technology resources (e.g. electronic patient records, medical record prompts, decision support tools, internet-based care management systems)

- The provision of post-diagnostic education and support for people with dementia/caregivers in collaboration with community agencies, such as local Alzheimer Societies

- Regular patient follow-ups to monitor care processes and outcomes.

4.4.2 Dementia Education Interventions for GPs

Another means to enhance the role of GPs in dementia care is the development of education interventions targeting the knowledge needs of this cohort. However, research has shown only limited success in some of the existing programmes, with many educational interventions and knowledge transfer approaches evaluated, with variable success[86,96,108,116,140-152].

In a systematic review of educational interventions conducted by Perry et al. in 2010[153], the authors concluded that only educational interventions for GPs that require active participation show evidence of improving dementia detection, and that ideally education would be combined with adequate reimbursement or other incentives at the organisational level.

On-site, outreach academic detailing (by other physicians and/or interdisciplinary clinicians) is one approach proposed in a number of studies. This is seen to provide more contextualized dementia training to GPs, facilitate the adaptation of guidelines, and/or promote the use of local resources[116,150-152]. Positive outcomes of this approach include: increased referral to local community agencies; self-reported positive effects on knowledge, confidence, skills, and motivation to work with people with dementia; and improved adherence to guidelines[150]. The main barriers to the outreach academic detailing approach were perceived time constraints and the reluctance of some GPs to receive education from non-physician clinicians[46,150].

Similar educational interventions have been fostered in Ireland. Foley et al. in 2018[154], developed and evaluated peer-facilitated dementia workshops (39 held in total, median attendance number per workshop = 4, range 2-9) with 104 GPs. The authors concluded that peer-facilitated workshops that focus on practice-relevant, case-based discussion, and are tailored to meet educational needs, can enhance participants' self-reported knowledge and confidence in dementia care. Evaluation feedback obtained from a post-workshop questionnaire shows that:

- 95% felt that they had improved knowledge of when to make a timely diagnosis of dementia

- 99% stated that the workshop enhanced their view of the benefits of making a timely diagnosis

- 91% stated that their confidence in providing post-diagnostic care had improved

- 77% said that their knowledge of how to access local services and supports for dementia had improved.

However, just two cluster RCTs to date have found that GP education increased the diagnosis of suspected dementia cases[140,145]. Downs et al. in 2006[140] reported that both decision support software (p= 0.01) and practice-based group workshops (p=0.01) significantly improved GP dementia detection (n=36 GP practices). Of note, there was no improvement in concordance with guidelines regarding the diagnosis of dementia, indicating that guidelines may not be a significant mechanism for promoting diagnosis. Rondeau et al. in 2008[145] also found that 2-hour group educational interventions (plus training on the use of four neuropsychological test batteries), delivered by other physicians/specialists (peers), increased the likelihood that GPs (N=681 GPs altogether; 352 randomised to intervention group) would suspect dementia (adjusted OR=1.99, p<0.001) and would correctly detect dementia (adjusted OR=2.24, p=0.01), compared to the control group.

In contrast, three later cluster RCTs found no significant change in dementia detection/practice based on educational interventions. An RCT by Donath et al. in Germany[143] of 129 GPs found that GP diagnostic practice did not alter post training in terms of the frequency of performing a physical examination, or arranging imaging procedures and laboratory testing. However, referral to a specialist did reduce, possibly suggesting more confidence post training. A GP education cluster RCT with 12 control practices and 11 intervention practices, with pre-post design, by Iliffe et al.[142] in the UK, showed no change in diagnostic "good practice" after the intervention. This was defined by blood tests being requested, cognitive testing completed, informant history taken, referral to consultant, nursing or secondary care, depression and/or psychosis considered, carer concerns recorded, behavioural and psychological symptoms related to dementia recorded, anti-dementia medication prescribed, medication review undertaken, and computed tomography (CT)/magnetic resonance imaging (MRI) scan requested. There was also no increase in diagnostic rates in the intervention GP practices. An RCT by van den Dungen[144] involving 8 control GP practices and 8 intervention GP practices in the Netherlands found a non-significant increase in case-finding of MCI and no difference in case finding of dementia after an education intervention.

4.4.3 Computer-based learning and decision-support systems

Information and communications technology (ICT) is increasingly promoted as a means of improving dementia diagnosis and care. A variety of computer-based learning methods (e.g. computer-assisted learning packages, computer decision-support systems, and computer-based audit and feedback tools) have been developed and tested[155-158]. These are low cost and are adaptable. However, emerging international research on their feasibility and effectiveness for dementia training in various primary care settings reveals continued pragmatic challenges (e.g. lack of access, time and skills in using them) and only modest results so far, with some accuracy and reliability issues to be teased out[55]. More research is needed in the area of ICT platforms to aid diagnosis and decision-making for GPs[55].

4.4.4 Brief, psychometrically-sound tools

The development of adequate tools to support GPs' diagnosis of dementia in what are often extremely busy working conditions is a critical way of addressing some of the time and procedural constraints experienced by GPs. Evidence suggests that there are a number of psychometrically-sound tools suitable for use by GPs.

The General Practitioner Assessment of Cognition (GPCOG)[159], as well as the Mini-Cog Assessment Instrument (MiniCog)[160] and the Memory Impairment Screen (MIS)[161], have been found to be as clinically and psychometrically robust and more appropriate for use in primary care than the Mini Mental State Examination (MMSE). In a similar vein, Cordell et al.[162], points out that while the MMSE is the most widely adopted tool, there are known limitations in terms of language, education and culture bias, whereas the Mini-Cog and the MIS have less language and culture bias. Equally, a systematic review by Mitchell et al. in 2011[57] suggests that if tool length is not a major consideration, the MMSE may remain the best tool for primary care clinicians who want to make a diagnosis.

The GPCOG is estimated to take five to seven minutes to complete, with questions for both the patient and carer to answer, making it more relevant for primary care physicians[163].

An alternative, developed in primary care, is the Six Item Cognitive Impairment Test (6-CIT), which performs as well as the MMSE but is easier to use[164]{O'Sullivan, 2016 #113577}.

In Ireland a guidance document for the management of dementia in general practice from 2014[118] stipulates five dementia screening tools as being appropriate in a primary care setting: MMSE; GPCOG; Mini-Cog; MIS; Abbreviated Mental Test Score (MTS); and 6-CIT. The document further notes that at least over 50% of GPs routinely utilize the MMSE in Ireland, because of its accessibility and professional habit. Based on an analysis of available research at that time, the document suggested that the three best cognitive screening tools for primary care are the GPCOG, the Mini-Cog and the MIS.

4.5 Summary

There are many barriers that prevent the GP of the person with dementia making the diagnosis, including factors relating to the GP (attitudes and beliefs, skills and training), the patient/family (poor awareness or masking of symptoms, stigma) and the health service (reimbursement methods, time constraints and lack of integration of services). GP education and training are key facilitators of GP-led diagnosis, but do not appear to be sufficient in isolation to change practice.

In chapter 6, we will explore the evidence for GP-led diagnosis, and GP-supported diagnosis in a more formalized community memory clinic model.

5. Hospital based diagnostic services:
the memory clinic model

Memory clinics originated in the USA in the 1970's and were initially set-up as research centres, focused primarily on gaining information about Alzheimer's Disease and on conducting drug trials[165-167]. As a result of the high level of specialised knowledge of dementia, memory clinics offered outpatient diagnostic, treatment and advice for people presenting with cognitive difficulties[15], and they were specifically focused on cognition, unlike generic neurology, geriatric, or POA clinics[15]. However, there was more emphasis on the research objective rather than providing a clinical service for the diagnosis of cognitive conditions[6,15]. The clinics were usually hospital based and the model of care was distinctive from more traditional community-based POA services[168-170]. The clinics were usually provided on a part-time basis and the term 'memory' was chosen to overcome any stigma with the use of the word 'dementia'[15].

5.1 Memory Clinics: Evolution over Time

Due to substantial gaps in the diagnosis of dementia in other health care settings, memory clinics have come to occupy a significant place in the diagnosis and management of the condition[166]. The UK was early to establish the use of these clinics and some memory clinics have been operating in the region for over 30 years[171]. The number of clinics grew substantially in the region. The first memory clinic was established in 1983; 20 new clinics were identified by 1995; and 102 by 2002[15,172,173], and there are more than 200 clinics now[31]. In 2002, 72% of memory clinics operated from a hospital base[172]. The drive behind the substantial growth in memory clinics in the UK was attributed to its provision of diagnostic services for dementia and the provision of expert information regarding the condition[173]. A visible shift is observable in the focus of memory clinics with time, namely a move away from a research centered approach and towards a diagnostic service focus[172,174].

The use of memory clinics has since expanded across the world. In Australia, memory clinics have been operating since 1998[175]. In Spain there is evidence of memory clinics operating since 1991[167]. In the Netherlands, the number of memory clinics increased from 12 in 1998, to 43 in 2004 and to 63 in 2009[174]. In Ireland, the first memory clinic was set-up in 1991 and recent figures suggest that there are over 25 clinics now operating in the country[42].

With the advent of anti-dementia medications in the 1990s, the focus on early diagnosis grew substantially as did the way in which dementia services were structured, in order to deliver new pharmacological therapies[7,9,11]. The substantial growth and support for memory clinic services has been linked in the literature with the advent of these new medications[11], with UK memory clinics acting as gatekeepers of expensive anti-dementia medication[171]. Similarly, research from Germany notes that anti-dementia therapies are largely delivered by specialised services, such as memory clinics, rather than GPs[17,18]. It is worth noting that in Germany, memory clinics are bound by protocols which stipulate they cannot prescribe anti-dementia medications until a formalised diagnosis is made, while GPs are not bound by these protocols. Similarly in Australia, access to subsidized anticholinesterase medication requires a referral from a medical specialist[175].

Early critics of memory clinics argued that they assumed a medical approach towards diagnosis which led to limited provision of information and social supports for coping with a diagnosis[6,171]. Questions also arose on whether the memory clinic model was just redirecting patients that were already receiving care from POA, thus further fracturing and fragmenting existing health services[169,171]. In response to some of these early criticisms, memory clinics now tend to operate using a multidisciplinary model with a broader remit of service provision from assessment to investigation and provision of supports and information[176].

Memory clinics are seen as a means towards achieving the goal of reduced time between symptom onset and diagnosis, and are viewed as improving attitudes towards dementia, by re-framing the means by which the disease is diagnosed and understood[139,177]. They are seen to overcome a number of biases about old age and cognitive decline, and to challenge the stigma of a dementia diagnosis[178]. Memory clinics are also widely supported for their ability to provide a more accurate and detailed assessment of dementia, leading to differentiated diagnosis, including sub-types of dementia or other pathologies, which are important to correctly identify[175,179,180]. Support for memory clinics is often reinforced by concerns that GPs and other health professionals are unwilling or lack the capacity to pursue an early diagnosis of dementia[28,30,45,181-183].

One of the most pressing issues now is responding to the sharp rise in the incidence of dementia linked to the aging of the population. Thus, although there was a substantial growth in the number of memory clinics in the UK over a short period, these clinics saw a sharp increase in referral rates and 87% of the clinics surveyed had waiting lists for initial assessments in 2000[172]. A number of distinct strategies have emerged to deal with these emerging challenges which include, for instance, the development of shared care initiatives, the separation between assessment and treatment clinics, the development of coordinated care models and the growing role of a specialist nurse in the provision of memory service care[173].

5.2 Memory Clinic typical characteristics

Memory clinics have evolved substantially and it is difficult to provide a fixed definition of the service, as they are not circumscribed to one particular setting or bound to a specific set of clinical targets. There are multiple variations in the models of care provided in a memory clinic setting[177,178].

The memory clinic service is usually composed of an MDT, with different levels and types of expertise[165,177,184]. The exact professionals involved is varied, including physicians, social workers, pharmacists, occupational therapists, researchers, nurses, psychologists and voluntary/community workers. The survey of memory clinics in the UK in 2002[172] demonstrated the wide range of staffing profiles but also indicated that the most common profile was of a team with a POA, a nurse, and a psychologist, with one-in-five clinics collaborating with voluntary and community organizations. Referrals to the memory clinics commonly came from GPs, psychiatrists or geriatricians. In Australia, most memory clinics are run by geriatricians, neuropsychologists, and nurses[185]. Most Dutch memory clinics are led by neurologists and geriatricians, and actively involve the general practitioner[174].

Considerable variation is also found in the structure and purpose of the memory clinic. Some clinics have an emphasis on diagnosis and assessment, and others focus on treatment, and some both[173]. In response to various challenges, different clinics have focused on different sets of objectives[18,165,180].

An early study conducted by Luce et al. in 2001[169] described the population characteristics of 100 consecutive people referred to a memory clinic compared to 100 consecutive referrals to a generic POA service. The memory clinic attendees were younger, with less cognitive impairments and on average being assessed two years earlier in the course of the disease[169]. Despite this, the memory clinic had good levels of diagnostic accuracy. It has been reported that nearly five clinical hours are spent on each Australian memory clinic patient[185].

5.3 Criteria and Standards for calling a service a 'Memory Clinic'

The growing expectation for memory clinics is that they should provide rapid and specialist assessment of patients, which would lead to an accurate diagnosis, followed by carefully managed disclosure of diagnosis, and the provision of other relevant post-diagnostic information for patients and their carers[4].

Banerjee[186] lists some features of a "good" memory service, based on text of the UK National Dementia Strategy:

• Rapid assessment

• Competent specialist assessment

• Accurate diagnosis

• Communication of the diagnosis in a sensitive manner to the person with dementia and their carer

• Provision of post-diagnostic treatment, care and support

• Doing this for all incident cases in the area served.

In England, The Memory Services National Accreditation Programme (MSNAP) has defined a set of standards for memory service performance which specify fair access and person-centered care as guiding principle[187].The standards involve the following domains:

• Management systems for the service

• Resources available to support assessment and diagnosis

• Assessment and diagnosis

• Pharmacological interventions

• Signposting to ongoing care management and follow up

• Psychosocial interventions.

However, an audit of memory services by the NHS Information Centre carried out in 2011 suggests a weak level of adherence to these standards. Although 94% of primary care trusts and health boards commissioned memory services, only a small percentage of these were accredited, and at least 25% of all services lacked some of the features established by the MSNAP[188].

5.4 The Evidence to support typical, hospital-based memory clinics

There is at present a growing body of research and academic debate exploring the value and qualities of memory clinics as ideal diagnostic and post-diagnostic pathways for dementia care[28,91,168,169,171,175,177,180,189-194]. Some of the themes include on-going questions concerning the benefits of early diagnosis, the accuracy of diagnosis, service satisfaction from patients and health professionals, health outcomes for patients, post-diagnostic support and effective resource allocation. A previous review of existing evidence appraising the value of memory clinics offered by Melis et al. in 2009[193] concluded that there is not enough evidence to provide a complete evaluation regarding the effectiveness of memory clinics. In particular, the authors highlighted the lack of robust evidence based on RCTs which look at memory clinics as a whole, as opposed to an evaluation of particular components of the memory clinic. The same problem applies to this current review, as most of the research available has focused on specific elements of a memory clinic service and therefore piecing together these elements brings some limitations in terms of providing a complete overview of the memory clinic service.

Our review of the literature on memory clinics yielded a number of publications, based on qualitative and quantitative studies.

5.4.1 Experiences and perceptions of memory clinic services

In Australia, in 2004[175], GP satisfaction with the Cognitive Dementia and Memory Service (CDAMS), a network of 13 memory clinics in Victoria, was assessed via telephone interviews with 35 GPs who had referred to the clinics. The CDAMS was designed as a specialist service for people with cognitive issues to provide assessment, early diagnosis, advice and referral services. Of note, CDAMS does not provide ongoing post-diagnostic care management. GPs were largely positive about the clinic service and perceived the assessment and diagnosis process to be comprehensive and useful, with 32% of GPs 'very satisfied' and 52% 'satisfied' with the service. The majority of GPs believed the memory clinic offered an appropriate amount of information to patients, and a smaller percentage (62%) believed adequate information was given to support carers and family of people with dementia. Some areas for improvement identified included accessibility and waiting list times and better coordination with primary care services.

A subsequent study carried out in West Yorkshire, UK in 2007[168] compared memory clinics to a community-based service, from the perspectives of service users and their carers. Interviews with five dyads (service user and carer) of a hospital-based memory clinic or a community-based nursing service indicated overall satisfaction with both services. However, some reported raised levels of anxiety when having to travel to a specialised service as opposed to receiving care at home from a nurse. Receiving treatment at home was thus a preferred option in four out of five dyads, with people perceiving that they could maintain a greater degree of control of their own treatment and be better able to communicate their preferences when not overwhelmed by the medical setting of the hospital-based clinic.

5.4.2 In-depth service evaluations

The *Croydon Memory Service* model was developed in South London in England. A service audit of this model is offered by Banerjee et al. in 2007[165]. This is a mixed method study that included a descriptive account and follow-up of a group of patients (n=290). The evaluation was carried out using six predefined goals, which included: high acceptability (target below 10% refusal rate); high appropriate referral rate (below 20%); effective engagement with people from minority ethnic groups; successful engagement with people with young onset dementia (10% target); engagement with mild cases with a focus on early intervention (60% target); and an increase in number of new cases of dementia assessed (50% target).

The Croydon memory service was the first to introduce the term 'memory service'[15]. The service started as the collaboration between a team of health care professionals working on the grounds of a psychiatric day hospital. The new terminology used was chosen as a way of designating the formation of a service designed to serve people with dementia and their carers[165]. This was developed in contrast to the idea of a 'clinic', which it was perceived by the founding members as being more suggestive of catering for the needs and working practices of clinicians[165].

The Croydon memory service is designed to work in collaboration with local systems of health and social care. The model aims to provide a low-cost, high-yielding service based on generic service provision to enable early diagnosis and intervention in dementia[165]. Local health care providers have joint ownership of the service and the main stakeholders include health services, social services and the voluntary sector. Some unique components of the model include a more horizontal structure of team work, whereby all the team members are provided with the skills to undertake initial diagnosis and assessment of patients. Profession-specific skills are deployed only when they are needed. Another component of the service is that initial assessment and care is provided in the patients' own homes.

The service was successful in meeting all the stated goals. Namely, the service refusal rate was low, at 5%, and the inappropriate referral rate was also low at 11%. Thirdly, 18% of referrals were from non-white European ethnic groups, which compares well with census projections for the area of 11% of the population for those over 65. Referrals for early stage dementia were

also within range with 77% of all referrals being mild in terms of severity of impairment. Young onset dementia referral rates also exceeded expectations at 18% of the overall population seen. Finally, the Croydon memory service increased the number of new dementia cases diagnosed through their service, with a rise from 255 to 416 in the 2004-2005 period. This represents a 63% increase. The authors highlight the ability of such memory services to obtain referrals from patients with mild early onset dementia and also to see more cases of young onset dementia. This had been previously noted in another study conducted by Luce et al. in 2001[169].

Another model operating in a secondary care setting is the *Dementia Service Centre* model introduced in a small rural town in Bad Ischl in Austria. The development of this service model is described by Auer et al.[195]. The authors state that the service was developed in 2001 as a response to the lack of dementia care services in the area. The model also seeks to respond to a gap in service provision in rural areas. A needs assessment with patients and caregivers helped form the initial development of the service. Initially the service started with the service of a clinical psychologist (one of the authors of the article) offering cognitive screening, counselling and support to caregivers. The service evolved to a model of care based on an MDT of professionals that included a social worker, a psychologist and a group of 'trainers'. The novel element of the Bad Ischl model is primarily the provision of pre-diagnosis counselling and support, and the role of trainers.

The training component in particular is a significant innovative element of the model. The foundational principles for this initiative were informed by a theoretical framework of retrogenetics, that generally focuses on the ability of people to continue to learn and to retain capacities as the disease progresses. The authors report on findings from a longitudinal database, which collected observations on patients from diagnosis onwards, from 2002 to 2013. Findings from this data indicate a 16% institutionalization rate from all referrals which is perceived to be low compared with other models and to be a direct outcome of the training programme offered.

5.4.3 Comparative service evaluations

A relatively recent review of pathways to dementia diagnosis in the South West of England offers a valuable comparative analysis of different memory clinic models operating in the region. The work produced by Minghella in 2013[32] made use of audit methodology, interviews, and focus groups and was commissioned by the NHS to support the refinement of diagnostic pathways in the area. Part of this work involved the in-depth review of five different memory clinic services operating in the area. The services were diverse and included two services operating from a secondary care setting (nurse led), two services operating from a primary care setting and a service operating from a tertiary care setting. While the services appeared to be similar at a glance, the in-depth review showed the models have distinct differences stemming from how they are commissioned, how they interact with primary care and how they function. It is noted that these distinctions lead to specific challenges, strengths, and opportunities to learn. No one model was superior to the others, with all of them having benefits and drawbacks. Overall the study found high levels of satisfaction from patients and GPs in all the services provided. There was an overall median 30-day wait from referral to assessment. The skill set of the teams was also seen as adequate in all the models.

The study reported that overall the services had a large "inappropriate referral" rate, at 60%, which they felt adds burden to the service and creates delays for those who do have dementia. However, the authors considered a person with an ultimate diagnosis of MCI or depression to be an "inappropriate referral", suggesting that it would be useful to create specific pathways of care for people with MCI, who usually represent a significant share of referrals to memory services. We would argue that it is perfectly appropriate for a memory clinic to be referred a person who may or may not have dementia, as this can be challenging to diagnose without MDT input and specialized testing. Indeed, it would seem more appropriate than referral of a person with an obvious or advanced dementia, who could be readily diagnosed by the GP and fast-tracked to post-diagnostic supports.

The author adds a note of caution in terms of overly standardizing the memory service process by adding that this could make services unnecessarily complex, resource intensive and repetitive in terms of assessments. The risks identified for memory services in the future were waiting times and high rates of inappropriate referrals, diverting resources away from people with dementia.

A recent study (2018)[37] selected 80 random memory clinics (termed memory assessment services, MAS) from those identified in a previous national survey[196] and compared the structural and the process characteristics of the MAS (i.e. skill mix, workload, volume of patients seen, provision of clinical assessments and provision of psychosocial support, waiting times, length and number of appointments, anti-dementia drug prescription and the employment of psychosocial interventions) with the patient and carer outcomes at 6 months, in terms of health related quality of life. Only the presence of AHPs was associated with a higher quality of life score, and this association disappeared in the subset of people who had been diagnosed with dementia. This benefit may relate to the AHP role, or may reflect some other confounding service factors.

5.5 Summary

Memory clinics have evolved since inception, from a primarily research focus to a more clinical focus, supported by a full MDT, with a more recent focus on rapid, specialist assessment, and early diagnosis of dementia. There remains considerable variation within this model, despite available standards and an accreditation programme in the UK; a key differentiation between clinics is whether the clinic is diagnostic only, or also provides post-diagnostic support, with pros and cons to both models.

Studies have shown overall GP satisfaction with memory clinics, but some concerns about waiting lists, while patients and carers are similarly overall satisfied, but may prefer to be assessed and treated at home if possible. Formal evaluation of a UK memory (clinic-based) service has shown it to be effective in meeting key service targets, and those targets are themselves useful to consider in planning diagnostic services.

A direct comparison of memory clinics versus other diagnostic models in the UK found them to be overall equivalent, and that study introduces a note of caution about making memory services overly standardised and overly complex. Chapter 7 will also compare diagnostic service models, this time from a cost analysis perspective.

6. Community Based Diagnostic Services:
Memory clinics and other diagnostic services

Memory clinics are increasingly shaped by a drive towards devolving care to primary and secondary care settings[35]. A number of service models are emerging, which provide novel primary-care based pathways to dementia diagnosis and care. These can be broadly described as memory clinic type services, which are based in a primary care setting.

6.1 A Canadian primary care-based memory clinic: service led by GPs

A study conducted in Canada evaluated a model of a GP-led multidisciplinary memory clinic, which was first established in 2006 to address dementia care gaps within primary care and to reduce the reliance on geriatrician-provided diagnosis. Of note, the GP leading the service was not necessarily the patient's usual GP. The memory clinic operates on a monthly or bi-monthly basis and has a designated geriatrician or 'geriatric psychiatrist' available to provide telephone or e-mail support to the GP in the memory clinic and/or to provide direct patient review when necessary. Two specific surveys were conducted to evaluate the service, published in 2010[202]. The first survey was conducted with patients and their carers looking at service satisfaction levels (n=55). The survey used a 5-point Likert scale (strongly disagree to strongly agree) and respondents were asked to rate a number of aspects of the clinic, such as timeliness and quality of information offered. Service users indicated they were very satisfied with the service, with all respondents perceiving that they had received adequate information. Service users were also satisfied with the timeframe from the point of referral to the point of access.

A second smaller survey was conducted with local GPs (n=8), looking at their experience and level of satisfaction with the service. Results from this survey also show that GPs were largely satisfied with regards timeliness and quality of assessment offered. Furthermore, the survey shows that half of the GPs surveyed reported being more confident with regards their own skills to assess dementia issues and to communicate with patients and carers about dementia. A majority of GPs also agreed that the quality of service available for patients with dementia issues had improved after the formal memory clinic was set up.

A similar extended version of the survey was conducted by Lee et al. in 2014, this time based on an expanded service with 16 memory clinics, all using the same service model but with varying staff composition (1-4 GPs and 1-5 nurses per clinic, nine clinics had social worker input, five had pharmacy input, one had occupational therapy input). One clinic ceased after initial commencement due to infrequent referrals. Of note, only 9% of the patients seen at the remaining fifteen clinics required referral onto specialist services (mainly cases with suspected frontotemporal dementia, or with Down's Syndrome or Parkinson's disease). The average delay from referral to assessment was 1.4 months, which was significantly shorter than the cited six-to-twelve month waiting time for specialist review locally.

Similar to the first study, patients and their carers (n=95) showed high levels of satisfaction with the service in terms of timeliness and level of service. Furthermore, 86.3% of respondents stated they understood the condition better as a result of the service provided by the memory clinic. Local GPs (n=27) were largely satisfied with the clinic model. Over 63% perceived that they had a greater awareness of dementia care as a result of working within the service and that the service was useful. Over 67% of GPs agreed that their patients received better information from engaging with this service. Geriatrician-performed chart audits revealed a high level of agreement with diagnosis categorisation (50 consecutive charts across five clinics). The study also included group interviews with staff members of the memory clinic, namely nurses (n=13), GPs (n=13); representatives from the Alzheimer Society (n= 5); social workers (n= 4); and mental

health counsellors (n=2), and focused on perceptions of the benefits of locating a memory clinic in a primary care setting. The most salient benefit identified was the more efficient use of resources, linked to the potential for increasing rates of early diagnosis and intervention, ultimately reducing crisis events leading to institutionalisation.

6.2 The Gnosall Primary Care Memory Clinic model: specialist outreach with a local facilitator

The *Gnosall Primary Care Memory Clinic* is another example of a memory clinic working in a primary care setting (a single GP practice with 8000 patients). This model was initially developed in the USA and adapted for the UK; it has been operating in the UK since 2006[197]. The Gnosall model seeks to strengthen the key role of primary care providers in the early identification and management of memory related conditions[198]. It is further suggested that the establishment of the memory clinic in a primary care-based setting helps address some of the stigma involved in referral to specialised services[197]. This recent study by Greaves et al. in 2015[197] provides a rich description and reflection of the everyday work in the Gnosall memory clinic. The clinic runs on a monthly basis in a primary care setting, administered by a POA who also provides in-between telephone support to the practice as needed[197,198]. The patient record, with both GP and consultant entries, remains in the GP practice, and the GP retains primary responsibility for the care of the person with dementia.

A key member of the team in the Gnosall model is the 'eldercare facilitator' (ECF) which is a healthcare worker within the practice who has a robust knowledge of dementia and who coordinates dementia care from investigation to treatment and support, for both the person with dementia and their family. The process of diagnosis starts with the GP. If there are concerns raised by the person or their family that the GP considers require formal assessment, the ECF will make a domiciliary visit for further assessment, and following this the person under assessment may be referred to the clinic[194,197]. The provision of domiciliary care by the ECF matches traditional forms of service provision (by POA services in the UK), which have an added value for people with dementia and their carers[173]. This constitutes a departure from the more fixed 'clinic' service of other models. The ECF coordinating function also has a significant value, underpinned by a collaborative process of dementia care from diagnosis to post-diagnosis, in order to enhance services for the person with dementia and their carers. This role also aligns to recent NICE guidelines that recommend that a single care coordinator/case manager for people with dementia[199].

The ECF role provides a greater level of support following diagnosis and ensures continuity of care, liaising with community care services and other local agencies as needed, which was an area where GPs had felt they lacked the necessary knowledge and skills[198,200], while also facilitating access to specialist services when needed. A recent comparative evaluation of different models of diagnostic services conducted by the NHS   suggests that the ECF role as used in the Gnosall service leads to a decrease in delay to assessment and almost no non-attendances for planned clinic reviews. Levels of diagnosis are also exactly in line with incidence estimates for the population. In addition, comorbidities are dealt with in a proactive manner and service user and carer satisfaction is high[32,197,198].

6.3 The Bristol Primary Care Memory Clinic model: memory nurses working with local GPs

Another interesting model emerged from a primary care led service located in Bristol[194,201]. Dodd et al. carried out a qualitative participatory evaluation based on peer and professional panels. Data collection entailed interviews with service users, carers and health professionals. The service was initially piloted between 2012 and 2013 and focused on the provision of a memory service by three memory nurses, seconded to offer their services in 11 GP practices. The GPs in these practices also availed of training on cognitive assessment and diagnosis skills.

The pilot service was compared with conventional service provision in the area, which usually entailed initial consultation of the patient with their GP and subsequent referral to a memory clinic located in a secondary care setting. The findings from the pilot were largely successful and

the model was subsequently implemented across the region. Main points of interest included the fact that GPs felt cautious about diagnosing dementia and preferred to rely on the nurse for consultation and advice. The feedback from service users from the pilot and from the conventional pathway of referral to secondary services indicated no significant difference in patient satisfaction, with service users being generally happy with both service models. The most valued aspect of care for patients was contact with the memory nurse in both settings[194].

6.4 The Northumberland, Tyne and Wear 'Memory Protection Services': a specialist care led service with primary care support

The *Memory Protection Service* was commissioned in 2012 as a diagnostic service for people of all ages, including people with learning disabilities. The service uses GPs with Special Interest (GPwSI) to work alongside secondary care for approximately 84,000 residents of South Tyneside, Gateshead and Sunderland, where there are 155 GP practices of varying size and three different Community Mental Health Teams. Prior to referring to the MPS, the patient's GP completes cognitive screening. All referrals are first screened and triaged at the MPS single point of access by one of the nurse practitioner duty workers. At this point, a small number of patients may be redirected to the secondary care Community Mental Health Team if the person's needs appear complex. Of note, people can also self-refer and the duty nurse will liaise with the GP for further information to support the assessment.

The person is assessed by the nurse and a consultant at a clinic in the primary care setting, or at home if they prefer, with imaging arranged for a later date, as needed. Once all results and assessments are complete, a diagnostic appointment occurs with either a Consultant or the GPwSI, where the diagnosis is disclosed, and treatment and support options are discussed, as well as issues such as power of attorney, driving, etc. The duty nurse follows up with patients by phone after three weeks to check their medication adherence. If indicated, the consultant will write a new prescription which is sent to the patient. Titration is managed through this contact. If the patient's condition has changed or they are not tolerating the medication well, the patient will be brought in to clinic, or seen in their home. Twelve weeks after the diagnostic review all patients are offered a post diagnostic appointment with the nurse.

Challenges have included retention of the GPwSI as they have other clinical commitments, and the availability of the consultant to travel to multiple primary care practice locations. There was a ten-fold increase in the predicted referral rate to the MPS as a result of case finding and promoting the service. Not all referrals have been deemed appropriate. Many very early-stage patients have been seen, due to the promotion of the service locally and the ability to self-refer, and these patients have needed detailed neuro-psychological assessment to eventually reach a diagnosis.

6.5 Other evidence for primary care memory service models

A rapid review appraisal conducted by Wells and Smith in 2017[194] identified a number of initiatives centered around diagnostic care pathways involving primary care services in England. Based on the literature reviewed, the authors found that there is evidence to support the premise that primary-care led services can reduce referral times and address existing diagnostic gaps and delays. The study expands on the issue of appropriate diagnostic pathways for different cohorts by highlighting the fact that GPs tend to be the first point of access for the diagnosis of older and more frail patients. It is felt that primary care is particularly appropriate for this cohort, bypassing more time-consuming and complicated assessment pathways in secondary and tertiary care. However, it was also noted that rapid assessment targets and efficiency rates need to be balanced with the need to follow a pathway pace where patients and their carers feel they have time to process the diagnosis. This issue was particularly highlighted in the Berkshire Memory clinic, which designed a primary care based 'one-stop shop' service, with service user feedback highlighting the need to design a service that matches the pace of the service-user[32].

6.6 Community Mental Health Teams

Although not a specific focus in our literature review, it must be noted that Community Mental Health Teams (CMHTs) often provide a dementia diagnostic service in the community. Community Mental Health Teams (CMHTs) for older people in the UK were developed in the 1970's[203]. Their initial focus was to provide home-based psychiatric treatment to mental health patients, but that has evolved to include providing support for people with dementia living at home.

Of note, the mental health-led Croydon memory service model (discussed under hospital-based clinics) could equally be viewed as a community-based memory service, in that initial assessments are carried out in the person's own home.

A survey of CMHTs in the UK in 2008 reported that over 93% of teams had a single point of access for all referrals, and teams had a broad range of disciplines (80% had an occupational therapist, 67% a social worker, and 50% a psychologist), making them well placed to diagnose dementia[204]. A survey of 51 NHS trusts in 2015 focused more on dementia services, and found that while some CMHTs and memory clinics were combined, they were usually separate services[203]. Compared to memory clinics, CMHTs had more staff (especially "assistant" staff) and more often included social workers, OTs and physiotherapists as team members. They provided a wider range of activities (such as accompanying patients to appointments, assessing meal preparation safety), and provided longer term support for people beyond diagnosis.

6.7 Summary

There is good evidence to support memory clinics based in primary care. The evaluated models range from a memory clinic provided by a special-interest GP working with an MDT, with only modest specialist support (the Canadian model); to a specialist outreach clinic in primary care working closely with a non-GP member of the primary care team (the Gnosall model); to a local GP-memory nurse joint model (the Bristol model; although the latter heavily relies on the memory nurse); to the complex outreaching specialist/special interest GP model in Northumberland, Tyne and Wear. The evaluation of this latter model is complicated by its self-referral pathway and thus targeting of very early cases, who require extensive assessment, thus increasing its cost relative to other similar-appearing models. A key factor in all these models is having a GP or GPs with a special interest in dementia, and some element of specialist support. However, this may be an inherent vulnerability of this overall model, without sufficient resourcing.

7. The cost-effectiveness of dementia diagnosis and dementia diagnosis services

This literature review identified over 20 publications which addressed the cost-benefits of dementia care, including some comparative cost assessments between memory clinic models[9,12,28,33,34,74,133,190,205-221]. Appraisal of this evidence is complicated by the fact that evaluations have used different sets of cost criteria and baseline assumptions. Therefore, while the literature offers some indicative findings of the potential cost benefits of early diagnosis in memory clinics, there is not robust cost comparison evidence for memory clinics compared with other diagnostic models.

From a global perspective, cost appraisals suggest that the worldwide cost of dementia in 2005 was £315.4 billion (approx. €360 billion)[28,206], and in 2016 was €784 billion[9]. In the US, the cost of providing for people with dementia in 2010 was $109 billion, estimated to rise by $1.2-$1.6 trillion by 2040[221]. In the UK, projections predict a sharp increase in dementia related costs from £17 billion per year in 2007, to £26 billion in 2015 and to projections of over £50 billion a year by 2040[200,205]. A relatively recent study by Connolly et al.[211] estimates that the overall cost of dementia in Ireland is approximately €1.7 billion per annum, with nearly half of this cost burden falling to family and friends providing informal care to patients with dementia. A breakdown of this cost indicates that the average annual cost of care per person with dementia is €41,470. There are at present no specific evaluations of the cost of dementia diagnosis in Ireland.

One of the main reasons for the high cost of dementia relates to the nature of dementia, which leads to a progressive loss of capacity and cognitive abilities necessary for carrying out basic self-care activities[221]. It follows that dementia care entails high costs associated with institutionalization and supportive care and these represent a substantial financial burden for both health providers and carers of people with dementia.

Some of the studies described below look at the link between early diagnosis and reductions in costs in terms of healthcare resource use, prevention of hospitalization, and delay of institutionalization of people with dementia[210,219]. Some papers have also looked at the merits of commissioning memory clinics to achieve these outcome based cost avoidances[28]. A brief summary of results of different cost evaluations studies is offered below.

7.1 Does formally diagnosing dementia affect healthcare expenditure?

In response to growing concerns regarding the high healthcare costs for people with dementia, a number of studies were conducted looking at the cost-benefits of early-stage diagnosis as a strategy to tackle some of the high costs associated with dementia care. In the US, Weimer and Sager[219] conducted a Monte Carlo analysis looking at the potential cost-benefits of early diagnosis of Alzheimer's disease (AD), based on estimates of the reported cost effects of available pharmacologic and non-pharmacologic interventions. This analysis suggests that early diagnosis of AD has the potential to generate cost savings, particularly for those with mild AD (MMSE score of 28), and when early diagnosis was combined with drug therapy and caregiver interventions programmes. The authors suggest that these indicative findings should be explored in long-duration RCTs.

A study by Banerjee et al. in 2009[28] in the UK assessed the cost-benefit of commissioning memory services with an emphasis on early diagnosis and intervention for dementia. Cost savings were associated with projected delayed admission to institutionalised care over a 10-year period, with two scenarios based on proposed hypothetical reductions in institutional care of 10% and 20%. The cost was modelled on commissioning of new services at an annual

incremental cost of £220 million, based on the Croydon Memory Service Model (described in section 5.4.2, with home visits by a POA secondary care service). In the 10% reduction scenario, the study estimates cost avoidance of approximately £120 million in public/social care expenditure and £125 million in informal expenditure over 10 years. In the 20% reduced institutionalised care scenario, within 6 years the savings accrued would offset the annual cost of commissioning these new services.

Another study looking at the potential cost benefits of early-stage diagnosis of Alzheimer's disease, by Getsios et al. in 2012 in the UK[207], used a discrete event simulation of AD progression to assess the effect of treatment interventions. Information was derived from patient-level data from donepezil trials and a 7-year follow-up registry. This data was complemented with other epidemiological and health services data, including estimates of undiagnosed dementia and delays in diagnosis. The study found substantial benefits accrued for both patient health outcomes and cost savings derived directly from a program of early-stage diagnosis and treatment. Figures from this study show that even though early-stage assessment of AD does entail costs averaging approximately £4100 per patient diagnosed with AD as well as treatment-related expenses of £2400 per patient, these costs are redeemed by savings in patient care later in the disease. Direct costs of AD are reduced by more than £3600 per patient compared to no treatment patients. The largest contributor to savings is the reduced cost of institutional care with a 9.5% reduction in time spent in nursing homes compared with no treatment (i.e. if the patient is never diagnosed and treated) and a 7% reduction compared with diagnosis and treatment in later stages of AD. The study also indicates savings accrued from delaying the progression of AD while still living in the community.

However, a study by Michalowsky et al. in 2016 based in Germany[210], questions the idea of substantial cost savings due to a formal diagnosis of dementia. The authors conducted a cross-sectional analysis looking at actual healthcare resource use and utilisation patterns between community-dwelling patients formally diagnosed with dementia and those who screened positive but did not receive a formal dementia diagnosis (n=240). The results show no substantial difference in total healthcare costs between both patient groups. The patients formally diagnosed with dementia received more treatment by a neurologist, availed of more anti-dementia drug therapies, received more frequent day care support and used more acute in-hospital treatment. In contrast, those without a formal diagnosis had higher total costs for outpatient care, higher costs for planned in-hospital treatments, and had higher expenses for other medications beside anti-dementia therapies.

The most recent NICE Guideline on Dementia (2018) cautions that although some studies offer promising evidence concerning the economic benefits of early diagnosis, most of these studies are based on modelling rather than clinical trial evidence[191].

7.2 Influences on the cost of diagnosis

Research conducted in England by Gomes et al. in 2017[208] looked at the cost effectiveness of memory assessment services with different characteristics and in different patient subgroups. This large study was based on observational data collected from 944 carers and 1318 patients who had been referred to 69 different memory assessment services (MAS) across England. The observations collected from patients and their carers pertained to the period between first referral to a MAS and subsequent 3 and 6 months observations. The results indicated that the service provided by MAS in terms of diagnosis, treatment and follow-up care seemed to be effective in terms of outcomes for the patient but that it was not cost-effective over the 6-month period from initial referral. However, there were differences in gains accrued by patients using the service, with results indicating that patients aged 80 or older achieved higher gains compared with younger patients.

In terms of cost-effectiveness indicators, the study indicates that services with a higher number of new referrals per month (75 or more) were more cost effective. It also indicates that MAS services with lower clinic cost per new referral (below £2500) were also relatively more cost-effective. Larger MAS services with a more varied range of staff offering psychosocial support

demonstrated higher net benefits. The authors add that further evidence is needed that looks in detail at the longer-term cost-effectiveness of MAS.

A recent study looking at the cost of diagnosing dementia in memory clinics was conducted by Michalowsky et al. in 2017[9]. This German based study prospectively analysed the cost of diagnosing dementia using a sample of 120 patients with suspected dementia referred to a memory clinic. One of the most significant findings from this study was the presence of substantial variation in the cost of diagnosing different dementia disorders. The study shows that on average the cost per patient presenting with suspected dementia in the memory clinic was €501 (breakdown of €110 for the clinical consultation and €391 for technical procedures). From the total sample of 120 patients, only 44% received a diagnosis of dementia, at an average cost of €659, compared with those who received a diagnosis of MCI averaging at €376.

Differences in cost resulted from the use of more complex diagnostic processes and higher frequency of imaging and biomarker-based diagnostic procedures. The most costly diagnosis was that of unspecific dementia, which was given to 5 patients in the sample and averaged at a cost of €705. Diagnosis of AD was found to cost on average €649 and VaD was found to cost €662. The authors suggest that reimbursements of these services by health insurers should be adjusted for different dementia diagnosis, to ensure that the full cost of the diagnostic process is covered and safeguard the financial viability of memory clinic services, which are often based on a flat-rate payment deemed insufficient to cover the real cost of diagnosis.

7.3 Direct comparisons of the costs between different service models

A number of studies offer a direct comparison of the cost of dementia diagnosis in different healthcare settings, such as memory clinics, primary care and traditional community mental health services. One of these studies was conducted by Wolfs et al. from 2009, which offers results from an RCT, appraising the economic merits of providing an integrated diagnostic service for dementia patients. The research based in the Netherlands compared the benefits for patients who were diagnosed in a multidisciplinary diagnostic facility (n= 137) to those patients who received diagnostic services in 'usual care' (n=93). Usual care referred to a service provided primarily by a GP and with the chance of referral to a memory clinic. The results did not show any significant cost differentials between the two types of services. Although the multidisciplinary diagnostic service was marginally more expensive it was associated with a number of improved health outcomes for patients, namely better Quality Adjusted Life-Years. Other outcome measures such as improvements in cognition and behavioural issues were inconclusive.

Another comparative study by Meeuwsen et al. in 2013[209] looked at the cost benefits of dementia care in a memory clinic and a primary care setting. The care provided in the primary care setting entailed usual care service received by a general practitioner which was informed by Dutch general practice and homecare dementia guidelines. The study consisted of a multi-centre RCT with a follow-up period of 1 year and the sample size consisted of 175 outpatients. The authors conclude that at present there is no robust evidence to determine the cost-effectiveness of one service type over the other although memory clinics appeared to be marginally less costly than the GP service. However earlier studies by Wimo et al. (2013) and Jedenius et al. (2010) provide conflicting evidence as they found that diagnosis in secondary care is substantially more expensive than diagnosis in primary care. In Wimo's Swedish study, the average cost for all diagnostic procedures was SEK11,492 (approx. €1,170) and it was more costly (80% higher) in secondary care than in primary care.

Rubinsztein et al. published research in 2015[190] comparing the cost and the quality of a memory clinic type service with the service provided by a traditional community mental health team in England. This study made use of retrospective data collected routinely in both services. Over a four-month period, 34 consecutive referrals to the memory clinic and 33 consecutive referrals to the mental health team were included. Overall, the study found that memory clinics provided a

more comprehensive service for patients, which included a greater level of multidisciplinary supports, pre-and post-diagnostic counselling, and more systematic screening for reversiblecauses. They were also relatively less costly than the traditional community mental health team service (£742 versus £807 per patient). Of note, where a consultant had to travel to see a patient at home, this added significantly to the costs in the community mental health team model. The study assumed that the consultant returned to base between patients, whereas travel time and hence costs may be less in practice, as a consultant may "cohort" visits in an area.

Where authors have discussed differences between their results and other studies[9,189,190,210], they have cited significant differences in terms of patient characteristics, particularly age and health status.

A relatively recent report from the NHS in England provides a detailed description and offers indicative prices for the establishment of three different models of memory assessment (and commissioning). The first is a primary care-managed service with specialist outreach support and a dedicated eldercare facilitator (the Gnosall service described in section 6.2), which costs £396 per diagnosis. It is also associated with subsequent reduced acute hospitalisation costs (as the GP practice also covers a rota of emergency home reviews of ambulance call outs for their patients with dementia). The second is a specialist care-managed service provided in a primary care setting with support of GPwSI (in Dementia; the Northumberland, Tyne and Wear 'Memory Protection Services' described in section 6.4), but heavily reliant on a consultant service, which costs £877 per patient diagnosis. The third is an entirely specialist service, by a small team within the Older People's Mental Health Services in the Rotherham, Doncaster and South Humber NHS Foundation Trust (RDaSH). There is a single point of referral, and wherever possible patient are seen at a clinic with the full MDT, rather than at home. GPs are expected to have completed a cognitive screen, and bloods prior to referral. The average cost is £491 per diagnosis. This report does not favour any one model, instead recognising that different models are likely to be needed in different areas, taking into account the resources available and maximizing cost savings through the identification of prevailing skills and the expertise of existing professionals in the area .

7.4 Summary

Although effective, memory assessment services may not be cost-effective within the first six months post diagnosis. Longer term cost models using the actual costs of existing memory services, and cost avoidance based on either extrapolated long-term results of clinical trials, or simulation models of potentially reduced long-term care due to better care, indicate that early diagnosis may be cost neutral or slightly cost-avoidant in the longer term. In contrast, an actual (observational) cost of care study indicated that when a person screens positive for dementia, whether they are subsequently formally diagnosed or not does not substantially impact on subsequent costs. Clearly, simulation models and observational studies do not give a perfect picture, but given the complexity (and ethical issues) in performing a long-term RCT of early diagnosis versus delayed or no diagnosis, it is unlikely that RCT data will be forthcoming. Thus, there is not a compelling cost argument for early/timely diagnosis as yet, but it seems that diagnostic costs may to some degree be offset by later cost avoidance due to earlier and integrated care.

With regards to the optimum service model in cost terms, it is not possible to provide a blanket cost comparison between memory clinics and primary care based services or traditional community mental health services as the available studies describe quite different services under "primary care-based" or "secondary care-based" services. Thus, the Gnosall primary care model is half the cost per patient of the Northumberland primary care model, noting that the former relies heavily on a practice-based facilitator for initial assessments, and the latter appears to rely more heavily on consultant input and includes very early stage, and hence costly-to-assess patients. The evidence from direct comparisons in the RCTs shows that costs are pretty similar between memory clinics and primary care diagnostic services.

Thus, we conclude that the cost of diagnosis depends heavily on the assessments and imaging required which is driven partly by the service provider/setting but mainly through the patient characteristics and clinical need. The provision of the best service for a region is not likely to be heavily influenced by cost evidence, but by the feasibility of provision of the necessary resources for the model in question.

8. Alternatives to existing models

Although memory clinics, in whatever setting, are an established model of care, there are other models emerging as direct responses to providing care in specific settings or delivering care under low resources. This issue is particularly relevant in remote areas where resources and availability of skilled medical professionals is more scarce[222]. Service provision in remote and rural areas is of specific interest in the Irish context, given our geographical landscape, with some evidence indicating that GPs in Ireland perceive that their rurally based patients had poorer access to specialised services compared to urban-dwelling patients[67,222].

A number of articles were identified which advanced alternative models of dementia care at a diagnostic level. These innovative services are proposed as alternatives to more conventional service models which have proved to be either too demanding on limited resources or too onerous in terms of securing skilled staff to be feasible options in more remote areas. However there is little evaluative work offered for these alternatives and the tangible benefits of some of these models remain undefined[168].

8.1 Mobile memory clinics

The 'Memory Van' is an example of this type of service, which has been established in remote areas of New Zealand and Australia in response to difficulties regarding access to more conventional memory services[222]. The mobile van has the ability to travel around accessing more remote areas and providing information and screening along the way. There isn't any research which evaluates the effectiveness of this form of service for dementia care, but mobile clinics have been widely utilised in screening and delivering health care for decades. In Ireland, a mobile clinic model was proposed by McCarron and Lawlor in 2003[29] as a way of providing dedicated dementia care to people with intellectual disabilities which would incorporate a range of multidisciplinary skills including POA and specialist ID nurses.

8.2 Information and communications technology (ICT)-aided diagnosis

ICT has been increasingly promoted as a way of delivering dementia screening and diagnostic programmes, using tools such as videoconferencing, telementoring and peer support[133,223-226]. ICT can potentially overcome some of the obstacles of accessing skilled health professionals remotely as well as providing guidance, training and mentoring to local GPs[226]. To date, however there is little research conducted on the merits of these technologies as an alternative to traditional diagnostic services[226].

A recent model was proposed by Satoh et al. in 2018[223] in Japan. The model, termed Dementia IT Screening System (DITS), aimed to provide a screening programme in the community using IT technology and leveraging the skills and expertise of GPs as well as memory clinic specialists. The service was mediated through a Dementia Network Promoter (DNP) working as a 'go-between' with patients, GPs and memory clinic specialists. The promoter would screen a patient using an iPad device and this information would be transmitted to the specialist, who would provide the diagnosis and further information. The DNP would pass on this diagnostic information to the GP who would communicate with the patient on the outcome of the assessment and other treatment indications.

The service was piloted in four locations and the results showed that this model could facilitate early consultation with a specialist and could be particularly valuable for very vulnerable patients who may find it difficult to access a secondary care memory clinic service. In a similar vein, the use of iPad devices by memory clinic nurses performing initial home based assessments prior to memory clinic review has been piloted in Manchester, with the study showing more accurate scoring, and also less time required than

with traditional paper based tests, which had required results to be transcribed into several different documents[227].

Another interesting model is 'Rural and Remote Memory Clinic' which incorporates telehealth videoconferencing with a one-stop interdisciplinary assessment in a tertiary care centre, in the Canadian province of Saskatchewan, based on the challenges of people in the very low density population northern part of the region having to travel a long distance to the tertiary care centre[228]. Originally implemented as a research study, it now continues as a clinical service. Most users were satisfied with the telehealth, unless they had to travel some distance to use it also. Some still considered it "face-to-face" contact and a "personal interaction". Of note, more people asked to switch to having future appointments by telehealth than the other direction. Eventually, the clinic switched to all telehealth follow-up visits unless a person specifically requested face-to-face visits.

A similar telemedicine memory disorder clinic in a rural community has been evaluated in Ontario, this time where all patients had first been seen in person, and then were potentially suitable for tele-consultation for reassessment, medication review etc[229]. In total, 99 patients were followed up this way, in 32 clinic sessions, provided over four years. Of note, both these services used a local facilitator (nurse) who generally stayed with the patient during the consultation, and a remote physician. In the second study, a minority stated they would have preferred to have been alone during the consultation. In this study, most participants felt the tele-consultation was as valid as a real life assessment, while 30% felt more anxious with the video session than an in-person visit. Overall, 28% would have preferred to see their doctor in person. Physicians also rated it highly, although they too sensed some patient anxiety related to the technology, or occasionally patient-family tension that could have been handled better in a face-to-face session (i.e. seeing the patient and the family member separately, which couldn't easily happen with the tele-conference).

8.3 Allied Health Professional (AHP)-provided diagnosis model

Many memory services in this literature review were led by specialist nurses, with nurses performing the cognitive assessments and the necessary fact-finding from referrers and families, as well as peri-diagnostic support, while the medical input was mainly in making the formal diagnosis, based on the nursing assessments, other MDT inputs, and the imaging results etc. Similarly, neuropsychologist assessment is a key part of complex dementia diagnosis. However, an interesting memory service model is where the AHP performs the actual diagnosis of the patient.

In a diagnostic accuracy study, where two memory service nurses in Manchester made a provisional diagnosis in 404 consecutively referred patients over an 18-month period, and then the person was diagnosed as usual in the full MDT memory service, the diagnostic accuracy of the nurses was 94% (Kappa = 0.88) for dementia/not dementia and 86% (kappa = 0.76) for the exact dementia sub-type[230].

A similar study was published in 2012, where nine members of a newly established memory service in Wigan, involving three disciplines (nurse, occupational therapist and social worker) made a provisional diagnosis in 10 consecutively referred patients each (total n=90)[170]. The diagnostic accuracy for each professional group ranged from 88% to 93%, with overall 91% accuracy (Kappa 0.81). The diagnostic accuracy for the dementia sub-type was 87-96% across disciplines (Kappa 0.67-0.77). Of note, this study was performed following a specific training programme, and the team members used a standardised diagnostic framework, with assessments including the MMSE plus an object learning test. The authors suggest that trained AHPs could lessen the burden on physicians for routine diagnoses of dementia (but not dementia sub-types or challenging cases).

It has been argued that relying on AHP-provided diagnosis may compromise the process of diagnosis, and it is added that further research is needed on the possible impact of this form of

service delivery[190]. Equally, there are some nurse-led memory clinics in the UK[231,232] and Australia (apart from the more common practice of initial nurse screening, or assessment, and then physician-provided diagnosis).

8.4 Allowing self-referrals for earlier diagnosis

Open referral policies (allowing self-referral, or non-physician referral) have been proposed as a means for people and concerned healthcare professionals to by-pass the GP and thus allow a timely diagnosis for a person[233]. The 'Memory Protection Service' in Northumberland, Tyne and Wear, UK (section 6.4) promoted their service locally and allowed self-referrals and described the consequent issue that many people were assessed for very early cognitive symptoms, requiring much more complex assessment and investigations, at greater cost.

Another, Australian-based, weekly nurse-led memory clinic also had an open referral policy[232]. In total, 60% of attendees were self-referred, of whom 30% were diagnosed with mild cognitive impairment or dementia. The authors suggest that open referral policies may overcome some of the current barriers to early diagnosis, citing some patients being more comfortable discussing subtle, mild cognitive issues with a nurse than a doctor (whom they wouldn't want to "bother"). A question raised however is whether, given that over half of the patients were not diagnosed with dementia, MCI, or depression, this memory clinic format is 'worthwhile'. Even though many attendees did not require imaging or other MDT input, and many only required a single visit, there is still a cost to the clinic in terms of the nurse's time, and administration and venue provision.

The benefit of facilitating self-referrals may thus depend on whether the cost of assessing people with a lower risk of dementia is offset by a benefit of earlier diagnosis for some. An independent study with some attendees at this clinic indicated that they had wanted to 'benchmark' their cognition against their peers in society, or reassure themselves that their memory issues would not affect their independence, thus seeking reassurance primarily that things 'weren't too bad', rather than planning for future decline[234].

8.5 Summary

There is some evidence to support remote assessment provided by a tertiary care based memory clinic to more rural regions using telehealth or facilitator-transmitted electronic data, but realistically this model may be most useful in truly remote regions (e.g. in Canada and Australia), which are not typically found in Ireland. There may be a role for tele-health where a large, regional memory clinic supports a more local memory assessment service. Thus, rather than the patient being referred to the larger unit for a second opinion, the larger clinic might review the patient remotely, or provide advice on already performed assessments and test results. Nurse or therapist-provided memory assessment services may be worth exploring for local service provision in Ireland, as long as these are fully integrated into a more formal diagnostic service for ready access and support with more complex diagnoses and for the healthcare professional's ongoing continuous professional development.

9. Dementia Diagnosis Disclosure

An intrinsic part of the dementia diagnostic process is the disclosure of the diagnosis to the person with dementia. Without this, many aspects of post-diagnostic care are intrinsically hindered, such as the involvement of the person with dementia in decisions about their care, and the opportunity for them to fully inform themselves about their dementia status to make decisions about their future care. Effective, personalised, goal-focused care such as cognitive rehabilitation is also hard to envision if the person lacks the crucial information that they have a progressive and incurable cognitive condition.

Thus, a dementia diagnostic service needs to incorporate dementia disclosure in its model of care. The following sections will summarise the evidence describing people's wishes for dementia disclosure and their experience of dementia disclosure, as well as healthcare professional views and knowledge and education needs, before finally describing the evidence that disclosure practice can be improved.

9.1 Attitudes and preferences about receiving a diagnosis of dementia

The majority of people with or without a memory complaint would like to be informed of the diagnosis if they had dementia. Eight research papers addressed this particular issue; including three systematic reviews, four quantitative studies and one qualitative study.

Bamford et al.[74] published a systematic review of 59 papers in 2004 that included studies with people with dementia, carers and clinicians. There was variability both within and between groups in their attitude towards diagnostic disclosure, ranging from 17%-100% positive attitudes in the studies involving carer groups, and 33-96% positive attitudes in studies involving people with dementia. Of note, attitudes to dementia disclosure were more negative in people with concurrent depression.

By the time of the second published literature review by Robison et al. in 2011[235], which represented an update of Bamford's review, with a total of 35 papers reviewed, the majority of people with potential dementia were favourable to receiving a diagnosis. Specifically, the study has found up to 92% of people with dementia were in favour of disclosure. Of note, although 90% of carers would want to know their own diagnosis if they were the patient, only 39-97% wanted the person with dementia they cared for to know that they had dementia.

A more recent systematic review and meta-analysis published in 2014 by van den Dungen et al.[236] reviewed 23 articles with results divided into four distinct subgroups: i) the general population; ii) relatives of people with dementia; iii) physicians; iv) people with cognitive impairment, people with dementia or people referred to a memory clinic. Where individuals did not yet have cognitive impairment (groups i-iii), overall 90.7% favoured disclosure (95% confidence interval (CI): 83.8-97.5%). Patients in group (iv) also favoured disclosure, although slightly lower rates at 84.8% (95% CI: 75.6-94.0%). The top three reasons why people favoured disclosure were 'to plan for the future', 'it's my right to know' and 'to look for treatment'.

Thus, attitudes towards disclosure appear more favourable in recent years. A post hoc analysis of the data in van den Dungen et al.[236] specifically explored the influence of date of publication on preferences in terms of disclosure. Overall, studies published prior to 2003 showed lower rates of favourable attitudes towards disclosure compared with more recent studies.

More recent studies, published after van den Dungen's systematic review, reinforce the general

finding that the majority people, with and without a memory complaint, favour disclosure of a dementia diagnosis. Table 9.1 below provides a brief summary of preferences to dementia diagnosis disclosure in these studies.

Table 9.1 Summary of preferences to dementia diagnosis disclosure (papers published since 2013)

Population / focus (All questionnaires unless stated otherwise)	Type of preference				
	PwD/PwCI Would want to know	General Public Would want to know	Carer would want to know	Patient preference to tell relatives	Carer preference to tell patient
China; carer study			96%	98%	
Korea; carer and PwD study, hospital clinic	97%		98%	95-97%	
Australia; PwCI/ carer (respondents referred to a memory clinic)	92%				86%
Italy; national, general public		83%			Male 76% Female 67%
Galway, Ireland; Older hospital in-patients (excluded PwD and PwCI)		86%			
Paris, France; PwCI (respondents referred to a memory clinic)- direct questioning by the doctor	85%				

PwD = person with dementia
PwCI= person with cognitive impairment

Overall, 95.7% of 175 Chinese caregivers of people with dementia would like to know if they were diagnosed with Alzheimer's disease, and 97.6% would like their doctor to tell their relatives[237]. Of note, a lower proportion (82.9%) favoured disclosure to a patient if it was not them, but their family member who was being diagnosed with the AD. 'Cognitive impairment' was the most acceptable term among caregivers in disclosing AD diagnosis.

Similar findings were reported from Korea (98 patients and 62 family members) where 96.9% of patients and 98.4% of families would like to know their own diagnosis of dementia[238]. Furthermore, 94.8% of patients and 96.8% of family members would like to inform their family members of their dementia diagnosis.

A larger study of 1,111 people in the region of Brescia in Italy by Riva et al.[239], shows that overall 83% would want a hypothetical diagnosis of dementia to be disclosed to them. Women and caregivers were less likely to favour disclosure of diagnosis to a potential patient. The top reasons for favouring a diagnosis disclosure were 'facilitating planning' (49%); 'patient's right to know a diagnosis' (42%); and 'physician's duty to communicate the diagnosis' (9%). The main reasons for not wanting a diagnosis were 'risk of causing emotional distress and depression' (52%); 'inability of the patient affected by AD to understand/or retain diagnosis' (29%); and 'uncertain diagnosis and lack of cure or effective treatment' (19%).

Similarly, in Australia, of 47 patients with cognitive impairment attending a memory clinic, 92% were favourable to a diagnosis disclosure, and so were 86% of their attending family carers (Paterson 2009)[240].

A very recently published large study of 1005 patients attending a single memory clinic in Paris from 2004-2010 (of whom 480 were subsequently diagnosed with dementia), reported that 85% of them wished to be informed of an AD diagnosis, whereas 7.2% didn't and 7.5% were not sure[241]. Of note, older age and degree of cognitive impairment were independently associated with a preference to not be informed.

A recent Irish study conducted in Galway by Robinson et al. in 2014[242], looked at preferences for diagnosis, disclosure and screening for Alzheimer's disease before and after providing 132 older hospital in-patients (without cognitive impairment or dementia) with information about the potential benefits and hazards of diagnosis. At baseline, the percentages with a positive attitude were 79.6% for diagnosis, 85.7% for disclosure and 59.3% for screening. After counselling, there was no significant change in disclosure responses (12 more positive, 18 more negative, 102 unchanged (p = 0.2); overall 78.1% positive attitude) while there were significant declines in attitudes towards actual diagnosis (11 more positive, 27 more negative, 94 unchanged (p = 0.03); overall 69.1% with positive attitude) and towards cognitive screening (10 more positive, 35 more negative, 87 unchanged (p < 0.0001); overall 42.1% positive attitude).

To summarise, especially in recent years, most people want disclosure of a diagnosis of dementia for themselves, including healthy people, those with cognitive impairment or dementia, and carers for people with dementia.

9.2 Patient experiences of dementia diagnosis disclosure

A range of factors is highlighted in the literature as having an influence on whether a dementia diagnosis is received either positively or negatively by a patient. This includes stigma associated with cognitive decline, the way in which disclosure is delivered, access to diagnostic information, and physical and mental health status[74,243].

Experiences of diagnosis disclosure can be complex, as patients and their carers are faced with a whole range of emotions, uncertainty for the future and practical problems of coping and adapting to living with a dementia diagnosis. Eleven studies were identified that looked at experiences of dementia diagnosis disclosure. These consisted of four literature reviews, seven qualitative studies and one study involving a survey.

The systematic review conducted by Robinson et al. in 2011[235] shows that while the majority of people favour disclosure, the process of diagnosis and disclosure has a significant influence on the patient experience. The term 'Alzheimer's disease' appears to have more negative connotations than the term 'dementia' for people receiving a diagnosis. Over half of carers for a person with dementia recounted negative experiences related to pathways of dementia diagnosis which included instances of discrimination, lack of caring from professionals, and fragmented or unsatisfactory diagnosis processes (for instance when no formal diagnosis was ever given). From the perspective of the person with dementia, the greatest difficulty with disclosure was coping with the perception of loss on multiple levels - psychologically, socially and functionally. For the carers, challenges included internalising the knowledge of having to deal with increased responsibility, while also trying to maintain an 'emotional status quo'.

A more recent thematic review of five observational studies, by Dooley et al. in 2015[244], offers insights on the significance of communication around disclosure in dementia, where dynamics between clinical professionals, patients, and their companions during diagnosis disclosure were directly observed. The two main results of this review pertain to the effects of this dynamic in terms of emotional impact and understanding of diagnosis. In relation to emotional impact, it was noted that more negative impact was observed in patients in response to a disclosure of Alzheimer's disease, compared with other forms of dementia. Furthermore, it was noted that there was a level of avoidance by the clinician in terms of engaging with and exploring the emotional impact of the diagnosis on the person, and this was reflected in the uneasy way in which diagnosis was delivered to patients. The authors posit that healthcare workers usually prioritise diagnosis comprehension and treatment compliance ahead of emotional support.

In terms of understanding the diagnosis, consensus on the actual diagnosis among patients, companions, and physicians after the diagnosis was disclosed was only considered 'moderate'. It was significantly lower for those receiving a diagnosis of 'mild' dementia. This was seen to be a consequence of healthcare workers rarely checking for patient understanding when delivering a diagnosis.

This same group later analysed 81 video-recorded diagnosis feedback meetings with 20 physicians across nine UK memory clinics[245]. In this study all doctors "named dementia", with 60% giving the diagnosis indirectly (i.e. 'this is dementia' rather than 'you have dementia'). The physicians emphasised that the dementia was mild and generally downplayed its progression.

A third thematic review of literature was published by Mitchell et al. in 2013[246]; focusing on relevant literature from 2006, or later, relating to the impact of disclosure. The review included one study that formally assessed 90 patients for anxiety and depression pre- and post-diagnosis and found depressive symptoms to remain stable, while anxiety symptoms actually reduced[247]. It was also noted that disclosure had many positive outcomes for patients, for example in terms of future planning and a greater sense of relief that a recognised disease was the cause of the symptoms they experienced as opposed to being associated with a normal process of aging.

A further prospective survey with 100 newly-diagnosed dementia patients and their caregivers (n=200 in total), conducted by Mormont et al. in 2014[248], supports the premise that dementia disclosure does not lead to higher incidence of depression, anxiety and suicide ideation in the majority of people. The study found that at 3-months following diagnosis disclosure, there was no substantial alteration in depression scores for most patients. From the viewpoint of caregivers, the overall effect of disclosure on the patient was viewed negatively in 7%, neutral in 71%, and positive in 21%. A possible explanation for the high neutral score reported by caregivers could be the poor diagnosis recall rate following disclosure, where only 44% of patients at follow-up could remember being given a diagnosis of dementia. Similar to the study by Carpenter et al, anxiety symptoms were seen to significantly reduce in a large proportion of the respondents. This prospective study also found that none of the newly-diagnosed patients surveyed reported suicide attempts or other very severe negative reactions to receiving a diagnosis of dementia.

One recent study by Milby et al. published in 2017[249] indicates that both clinicians and patients use avoidance as a coping strategy in relation to the diagnosis of dementia. The authors highlight the need for follow up interventions that recognise the difficulty in coping with a dementia diagnosis and positively counter some of the strategies that patients may develop to avoid dealing with a diagnosis of dementia. Emphasis on the 'social environment' as an influential factor in the experience of dementia diagnosis was seen to be important for both physicians and for dementia patients. For physicians this was linked to the support of the MDT, resources to support the diagnosis and the patients themselves, which assisted or hampered clinicians to support to their patients through the process of diagnosis. For the patients, this was linked to family and friendship ties, marital relationship and perceptions of healthcare professionals, to help them cope with diagnosis and disclosure.

Another study by Samsi et al. in 2014 involved interviews with 27 people with cognitive impairment and 26 carers (20 performed as dyadic interviews) before and after diagnostic disclosure. Many participants felt supported by practitioners and said that details of their condition had been explained to them adequately. However, a minority were critical of the process of disclosure and implicated this as the reason for their heightened experience of shock. A number of areas for improvement emerged, including the need to provide pre-diagnostic support or counselling to help patients and their carers navigate the diagnostic process and to flag the potential long timeframe of this process. Additionally, many respondents reported having little time to discuss emerging concerns and feeling uncertain regarding accessing support systems following diagnosis. Other studies have echoed similar ideas

regarding difficulties navigating the dementia diagnosis process.

In terms of dealing with information, Mastiwyk et al. in 2014 interviewed patients and their carers at the two clinic visits that followed the first diagnosis visit. The authors found that recall of information offered was variable. While over 94% of patients and 97% of carers in the study were informed of the patient's diagnosis, only 19% of patients and 61% of carers recalled the diagnosis when they were interviewed at the subsequent clinic visits. The principal factors attributing to this recall gap were the nature of the disease and difficulty in absorbing information due to the high emotional impact of receiving the diagnosis in the first instance. The authors further note that while carers were able to recall a diagnosis of AD they had difficulties in recalling a differentiated diagnosis such as vascular dementia, frontotemporal dementia, or primary progressive aphasia. Opinions among the respondents on whether all the information should be given all at once, or in stages, was divided.

A similar qualitative study carried by Lee et al. in 2014[177] illustrates the significance of helping patients unravel and make sense of a dementia diagnosis. Based on interviews with 10 people with mild AD, the study highlights the need to support patients through the initial stages of diagnosis where experiences of loss and uncertainty are considerably heightened. This study recommends that supports should include the promotion of positive adjustment strategies and highlights the benefits of disclosure as a way of providing a frame of reference to the very real and everyday life implications of living with dementia. The 'meaning-making' coping model suggested in this study is recommended as a positive alternative to non-disclosure, wherein people with dementia might struggle to understand the physiological and psychological changes they are experiencing.

Looking in more depth at experiences of support mechanisms, Manthorpe et al.[250], carried out a series of interviews with 27 people experiencing memory problems and 26 carers or supporters. The experience of dementia diagnosis was characterized by a high degree of uncertainty and distress. The detached manner in which assessments were made, and the intimidating clinical setting where these took place were often associated with alarm and a sense of stigmatisation. Furthermore, the provision of information and methods of communication were seen as variable, with some respondents highlighting the fact that they did not receive adequate assistance to help the person with dementia and their carer make sense of their experiences and their diagnosis.

Finally a systematic review of the literature published by Werner et al. in 2013[251] highlights the development of conceptual thinking around disclosure. The authors reviewed articles between 2000 and 2010 and noted that an earlier emphasis on the merits and ethical aspects of disclosure had evolved to a greater interest in examining the actual process of disclosure (i.e. from 'should we disclose?', to 'how best do we disclose?'). Despite this evolution, the authors identify a number of deficits in the development of clear and adequately-tested protocols for disclosure and appropriate communication strategies within these.

To summarise, there is strong evidence to suggest that disclosure does not have a significant lasting negative effect on patients and their carers. Disclosure does not lead to higher incidence of depression and suicidal ideation, and may actually be linked with a decrease in anxiety levels for patients. The process of disclosure is an important influencer of the impact of a dementia diagnosis disclosure, including a need for forewarning of the person and their carer of the likely duration of the whole diagnostic process, more focus on the emotional impact of the disclosure, and strategies to allow, or positively overcome, avoidance behaviours in the person diagnosed with dementia.

9.3 Healthcare worker attitudes, practices and experiences

Our literature review highlights that the value attached to disclosure is varied among health care professionals and this has implications for the promotion of a coherent and agreed-upon strategy of early-diagnosis pathways with an emphasis on disclosure.

Firstly, there is evidence that disclosure is often withheld from patients. A review paper summarizing studies published prior to 2002 estimated that about 50% of physicians routinely withheld a dementia diagnosis[46-76]. A mixed-method study which entailed a questionnaire of 116 GPs in Nova Scotia published in 2005 found that while up to 72% of GPs reported disclosing a dementia diagnosis to carers, just 31% reported disclosing this to the patient themselves[104]. A study from van Hout et al. in the Netherlands from 2006[84] similarly reported that GPs disclosed diagnosis to 74% of carers and 42% of people with dementia.

In comparison, a postal survey of Irish GPs published in 2006 revealed that only 6% of GPs claimed that they always disclosed a diagnosis of dementia to their patients and a marginally higher percentage (13%) stating that they often did so[58]. Further insights based on a rapid appraisal review carried by Koch and Illife[252] suggest that from a GP's perspective, disclosure was felt to be difficult and was often met with denial. GPs say they sometimes use 'euphemistic' language to overcome this, and reframe the situation.

More recent studies report relatively higher rates of disclosure in primary care (at least to family caregivers)[46]. However, a survey involving a nationally representative sample of GPs in France published by Somme et al. in 2013[253], found that GPs often reveal the diagnosis to the patient's family members (70.6%), but seldom disclose the diagnosis to the patients themselves (8.2%). Younger and male GPs were more likely to disclose a diagnosis than their older or female peers. A national survey of GPs in Malta in 2014[254] indicated that dementia disclosure was not a routine practice, despite GPs displaying a general awareness of the potential benefits of disclosure for patients and their carers.

A recent qualitative study carried out by Vince et al. in 2017[255] with eleven UK based psychiatrists involved in diagnostic disclosure demonstrates that they linked the experience of well-being in dementia diagnosis pathways to: ability to sustain continuity with life pre-diagnosis, retaining a sense of self, and accepting the dementia diagnosis. However, the authors believed that nihilistic attitudes prevent psychiatrists from integrating issues relating to well-being into diagnostic communication strategies.

Interviews with five Irish and four Swedish GPs study conducted by Moore and Cahill in 2013[126] show that even when there is awareness of the importance of diagnosis and there is access to dementia-specific training, most GPs still experience some reluctance in disclosing a diagnosis to patients. There were several instances of avoidance of using the word 'dementia' with patients. Although Swedish GPs had greater access and exposure to dementia training and were significantly more satisfied with existing post-diagnostic services than Irish GPs, respondents reported avoidance and barriers towards disclosure from both countries. A more recent study conducted in Ireland by Foley et al.[105] describes some of the challenges experienced by 14 GPs when offering a diagnosis. Their self-identified knowledge deficits related to: diagnosis, disclosure, signposting of local services, counselling and the adequate management of behavioural and psychological symptoms (BPSD).

9.4 Empirical evidence for improved disclosure practice

Unfortunately, there is a dearth of research into improving disclosure practice. A study by Lecouturier et al. in 2008[23] aimed to identify a list of target disclosure behaviours to inform a planned intervention. The authors used data from a literature review, interviews with people with dementia (n=4) and their carers (n=6), and a consensus panel with health/social care professionals (n=8). From these sources, the authors drew a wide range of potential behaviour targets, which were subsequently grouped into eight categories, namely: preparing for disclosure; integrating family members; exploring the patient's perspective; disclosing the diagnosis; responding to patient reactions; focusing on quality of life and well-being; planning for the future; and communicating effectively. While the exercise highlighted several optimal behavioural practices, it also found that complexity undermined a more staged process of disclosure. The authors therefore suggest the need for a more tailored process of disclosure, which addresses the specific needs of each patient and carer.

Based on this study, an RCT published by Eccles et al. in 2009[22], looked at the outcomes of three particular interventions applied to members of old-age mental health teams in England. One was a theory-based intervention including the aforementioned behaviour change techniques, and two were pragmatic/'common-sense' interventions involving either the provision of evidence-based information, or a patient information leaflet, to be sent to the patient prior to clinic attendance, respectively. The outcome was the 'treatment intentions' of a random sample of the team. The three interventions largely failed to change intention or behavioural simulation scores compared to a control arm. The authors explained these limited effects by the possibility of participants not adequately engaging with the interventions proposed, by possible limitations in the method of delivery (in hindsight the delivery of the behaviour change was unlikely to succeed), and by potential ceiling effects from disclosure intention already being relatively high (the issue possibly being post-intention, actual performance of good disclosure practice, not the intention to perform it as such).

9.5 Diagnosis disclosure for preclinical dementia state

Apart from the issue of disclosure of a diagnosis of dementia, a more ethically complex issue is the disclosure of potential or preclinical dementia. A scoping review recently carried out by Hughes et al. in 2017[256] revealed that there are a number of unresolved ethical concerns in the diagnosis of very early stage dementia or preclinical dementia. The biggest concerns revolve around the stigma associated with diagnosis, the potentially unnecessary burden of disclosure based on biomarker status, and the deficit of good communication strategies to overcome these issues. The authors contend that further research is needed in this area to overcome the many ethical issues identified.

9.6 Summary

To summarise, although most people want disclosure of their dementia diagnosis, current practice is that many healthcare professionals simply avoid disclosure altogether (at least to the patient), and the whole pathway of diagnosis-disclosure can be long and fraught for the patient and their carer. The importance of the healthcare professional gauging and responding to the emotional impact of disclosure is as important as the imparting of knowledge at the time of disclosure, and this process requires time and a conducive social environment. Many people and their carers don't fully recall the exact diagnosis after disclosure, especially if it is a less common dementia sub-type diagnosis.

Complicating this need for more explicit and effective knowledge transfer is the need to allow avoidance by the person with dementia if this is their coping strategy, or more ideally to facilitate the gradual and positive replacement of avoidance by hope and empowerment. Knowledge transfer and emotional support are not at all mutually exclusive, and we believe that if the initial focus is on the emotional needs of the person (and their family), this allows a therapeutic relationship to develop, such that knowledge acquisition and the resultant empowerment of the person and their family should naturally follow, at a pace dictated by the person, not the service.

Although the resultant RCT was negative, due to significant methodological issues, we believe the disclosure behaviours identified by Lecouturier et al. can serve as a useful framework for education for Irish HCPs around disclosure, and possibly future pragmatic trials of disclosure practice and process.

Figure 9.1 The key elements of good disclosure practice.

Adapted from findings of Lecouturier 2008 by S Timmons, 2018

| Integrating family members | Preparing for disclosure | Disclosing the diagnosis | Communicating effectively |
| Exploring the patient's perspective | Planning for the future | Focusing on well-being | Responding to patient reactions |

Finally, it must be noted that this review of disclosure practices did not explore post-diagnosis interventions, but clearly, relatively immediate post-diagnosis interventions could have a significant impact on the overall diagnosis-disclosure experience of the person and their carer.

10. Conclusion

At a time when the population over 65, and especially over 80, continues to rise year on year, such that the incidence and prevalence of dementia also rises year on year, we need to carefully consider the best model for dementia diagnostic services in Ireland to match current and future predicted demand. The literature review has shown the complexity of dementia diagnostic services and hence the likely complexity of a national diagnostic pathway. The very nature of dementia as an umbrella term for multiple diseases, and its varied initial manifestation from person to person is a challenge in terms of early detection and diagnosis. In addition, it is apparent that lack of awareness, stigma, and lack of familiarity with, or trust in, existing post-diagnostic care also present significant challenges to timely diagnosis.

10.1 Diagnostic process, especially disclosure

The first step towards improving dementia diagnosis pathways, regardless of a final service model, is improving overall public perceptions about dementia and the value of a diagnosis. The next step is having good disclosure practices, noting that people in general, whether they are experiencing cognitive problems or not, would welcome the disclosure of a dementia diagnosis if they had dementia, with a notable shift towards pro-disclosure in the last 10-15 years. The literature demonstrates that current issues around dementia disclosure practice may increase the stress to a person and their family member[239].

The important components of good disclosure practice have been illustrated herein[257], and should form the basis for future healthcare professional training in this area. Equally, evidence shows that people attending memory services (the patient and the family member) have difficulties in retaining information and recalling knowledge, especially for more complex sub-type diagnoses[239,258]. The need to "impart information" must be balanced with the demonstrated need to address the emotional impact of the disclosure on the person[239,244,258], with the latter being of more immediate importance in our opinion, and the former then following. Thus, there is a need for flexibility in disclosure, planning, and early post diagnostic support, allowing the person to decide when they are ready for more information or engagement with services.

The literature review has also demonstrated the tension between aiming for a 'rapid diagnosis', i.e. avoiding long waiting times for first assessment or for specialist imaging that can draw out the whole diagnostic process for a person who is already very anxious about the possible final diagnosis, and the equal need to progress at a pace set by the person, who may need time to adjust to the possibility of a forthcoming diagnosis of dementia[32].

10.2 Models of diagnostic services - diagnosis in the community

This literature review has highlighted many different models of diagnostic services that the HSE could consider, but the evidence to support these models is still evolving and the overall conclusion from comparative reports has been that local context is probably as important as the 'evidence' to support a particular model[200]. A key area of interest is facilitating dementia diagnosis by GPs, with evidence suggesting that diagnosis and disclosure rates by GPs remain low, and rare in early stage disease[30,46,68]. A number of barriers and facilitators to GP-led diagnosis have been identified which are helpful in terms of understanding current practices and promoting more pro-active attitudes to dementia diagnosis, and which would have a relatively short time-to-gain period (Chapter 4).

Apart from diagnosis of dementia by a person's usual GP, Canada and the UK have demonstrated the feasibility of more formal memory services that are embedded in primary

care, where a lead GP with a special interest in dementia receives referrals from GP colleagues or other primary care team members, with telephone or direct support from a specialist service[133-136,138,259]. However, pragmatically, if no GP in area X has a particular interest in dementia, and local GPs are struggling to meet their existing patient caseload, then they will struggle to provide or sustain a formal GP-led memory service, even if there was a strong quality or cost case for that particular model over others.

Another "diagnosis in the community" model is the outreach memory service model, where the specialist service provides a clinic in a local GP practice, such as the much-cited Gnosall model[197] where a member of the primary care team performs the initial assessment and links closely with the outreach specialist team, which facilitates the disclosure and transition to post-diagnostic support processes, as they provide a single-point-of-contact support to the person throughout the diagnostic process. Other UK services have used out-reach "memory nurses" (i.e. dementia nurse specialists) in GP practices, with evidence to support this model, and show the dependence on the nurse by the GP[202].

A final and somewhat overlooked in the literature model of "diagnosis in the community" already exists in Ireland, namely community mental health teams. One study compared the costs of this model to a memory clinic and found the former more expensive due to the costs of travelling to the person's home[168,190]. However, people with dementia and their families particularly value assessment and care at home, and it is logical that it is usually less stressful than a clinic attendance, and importantly it can offer a diagnostic service to a person who might repeatedly refuse to attend a clinic.

A diagnostic pathway should be able to indicate to a potentially referring GP which people might particularly benefit from a mental health service-led diagnosis versus a geriatric-led service, or perhaps better than this have a central triage system where some people are automatically seen by the mental health team (e.g. pronounced psychotic features, emotional distress, etc.). Another person, for example with frailty, multi-morbidity or already known to geriatric services, may benefit more from a geriatric service-led diagnosis, where physical needs could be addressed along with the dementia needs. A final case is the person with a pre-existing mental health disorder, who is well known to community adult mental health services, but where that service may not have dementia diagnostic skills. A dementia diagnostic pathway here needs to ensure continuity of care and to limit unnecessary duplication of assessment.

10.3 Models of diagnostic services - diagnosis in a hospital clinic

A well-established model is the hospital-based memory clinic model. Studies have shown that GPs, people with dementia and families are usually satisfied with memory clinics[175] but long waiting lists and the person's preference to be assessed and treated at home if possible are issues[175]. Formal evaluation of a UK memory clinic has shown it to be effective in meeting key service targets. A direct comparison of memory clinics versus other diagnostic models in the UK found them to be overall equivalent[200].

These clinics vary significantly between and within countries, despite available standards and an accreditation programme in the UK. A key question is whether these should provide a diagnostic service only, or also post diagnostic support, with pros and cons to both models. A particular question for the HSE is whether it should develop standards for what constitutes a 'memory clinic' versus a 'memory assessment clinic' or service. For example, the former might be required to accept people of any age, and have the MDT discipline mix and overall expertise to accurately diagnose early stage, and subtle, and complex dementia, with ready access to imaging (including functional brain imaging where appropriate), cerebrospinal fluid analysis and genetic testing where appropriate, and complex neuropsychological assessment. If not provided within the core clinic, there should also be rapid and seamless access to psychological, financial and emotional support in the immediate post-diagnostic period.

If this was the standard, then most existing 'memory clinics' in Ireland would not qualify for this term. Instead these would require a new term, perhaps 'memory assessment services', where all attending patients have a memory issue, and they are run by a specialist with a special interest and skills in dementia diagnosis, supported by an MDT to some degree (nurse specialist and occupational therapist at a minimum, perhaps), but this clinic itself might need support for a complex diagnosis. Thus a few regional 'memory clinics' would support many local 'memory assessment services'. It would seem prohibitively costly to provide full memory clinics throughout Ireland, and the literature clearly indicates that making dementia diagnosis overly complex (and expensive) can lead to waiting lists, thus delaying actual intervention and support.

Additionally, not everyone with possible dementia may need to be seen at a local 'memory assessment service'. Consider the 92 year-old, frail man living one hour's drive away from his nearest level-2 hospital and three hours from the nearest 'memory clinic', whose family are pretty sure he has dementia and think it might be better to have this confirmed, although they have no particular concerns about the implications of the diagnosis. It might be reasonable to think that he could be readily diagnosed by his local GP, and ideally in his own home, with local memory assessment service support from the level-2 hospital by email/letter/telephone. Similarly, a person with complex Parkinson's disease attending a movement disorder clinic regularly, who has hallucinations and cognitive decline, may be best diagnosed within their usual clinic setting, rather than in a second service, given that cognitive impairment and dementia is an intrinsic part of Parkinson's disease.

By default, this is actually a common 'other' model of diagnostic service in Ireland, i.e. the 'diagnosis of dementia in a hospital clinic that is not a memory clinic or memory assessment clinic' model. This seems appropriate for many people, where their cognitive issue is just one of many morbidities, and where they are already well known to a service and have established relationships. The key here may be that this non-memory service needs to perform to a certain standard in relation to diagnostic process, disclosure process and access/referral to immediate post-diagnostic support. We need to consider how this could be achieved, such as by enhanced training of clinic staff, having a "memory pack" at the clinic, and a close link to the local memory service, community dementia coordinator, hospital dementia nurse specialist, etc.

10.4 Putting it all together?

It is apparent that a diagnostic pathway for Ireland needs to incorporate a range of solutions to meet current and predicted future demand, ranging across:

- a low complexity, local diagnosis with a person's own GP, or with a GP-lead in their local area

- a more complex diagnosis made by an outreach service in a local primary care centre, or by a community based mental health team

- diagnosis within secondary/tertiary care-located generic geriatric, neurology or POA clinics, or a secondary/tertiary care-based memory assessment service, where there is ready access to blood testing, imaging, and a certain range of MDT input

- diagnosis in a highly complex regional memory clinic, that can diagnose even very early-symptom dementia, and also pre-dementia or "high risk of developing dementia", recruiting such people to clinical trials of prevention and neuroprotection as these studies come on stream, and supporting local memory assessment services in the diagnosis of complex dementia, or a difficult to determine dementia sub-type.

The following schematic demonstrates some of these potential settings of diagnostic services and some benefits/limitations.

Figure 10.1 A schematic of memory diagnostic services

Regional Memory Clinics	Local Memory or Generic Clinics	Primary Care	Community Mental Health
National/regional clinic - provides an excellent diagnostic service, and access to treatment trials, but the person has to travel and the diagnostic process may be stressful (imaging, cognitive batteries, LP).	Local hospital - will have MDT and imaging facilities etc.; a little stressful but close to home. Needs to provide a certain standard of diagnosis and disclosure	Own GP surgery - not stressful, but needs access to imaging and MDT support. Needs to provide a certain standard of diagnosis and disclosure	Sometimes seen in own home - least stressful, but costly if MDT has to travel; needs good link to imaging facility.

It must also be noted that some people are first suspected to have dementia in residential care, and many people in residential care in Ireland have an as yet undiagnosed dementia. Although the literature review did not specifically focus on their diagnostic needs, and most evidence is based on a service being provided to a person living in the community, frailer people in residential care also need a clear pathway to diagnosis. This diagnosis would seem to be most appropriately provided by the visiting GP or medical officer, or by an outreach memory service in a more complex case. Residential care would seem an ideal setting for technology-assisted diagnosis, as reviewed in Chapter 8 in relation to remote-dwelling people. In this scenario, the resident would be assessed by a familiar healthcare professional in the residential care setting, with support electronically as needed from the local specialist team based on the transmitted results and/or a video-assisted review of the person remotely.

Similarly, the first hint of possible dementia is commonly seen during a hospital admission, where delirium often unmasks subtle cognitive impairment or an as-yet undiagnosed dementia[26]. An overall dementia diagnostic pathway has to facilitate a starting-point in this location also. The literature review did not include any review of in-hospital dementia diagnosis or a "discharge to diagnose" model, but the latter is more common practice (i.e. the diagnosis is suspected during the admission, but not made formally until after discharge home).

A natural pathway would seem to be out-patient assessment in a generic speciality clinic or memory assessment clinic based at that hospital, once the acute illness has subsided, but there likely will be regional variations in how this pathway would work, depending on the local context. Such referral and confirmation of scheduling would be facilitated by the hospital's dementia nurse specialist or equivalent other dementia specialist, as the risk in practice is that a referral to a speciality clinic is intended by a busy medical team but may not actually happen, or there may be an assumption that the GP will automatically follow up on making the referral. In the future, electronic healthcare records may facilitate a community based pathway, where there would be less reliance on easy access to the paper case notes for context and recent cognitive assessment results, which currently favours hospital clinic follow-up where the diagnosis is suspected in hospital.

Regarding cost-benefit, this literature review has demonstrated that the cost of diagnosis does not depend so much on the setting, as on the complexity of the process, with key cost drivers being imaging, genetic testing, and specialist time, especially if travel is involved[9,190].

10.5 Final summary

This report has described several models that could be used in dementia diagnosis pathways in Ireland. The findings overall suggest that memory diagnostic models are still evolving and have considerable complexity and there is large variability even with a model as provided in clinical practice. The key approach should be to create adaptable models which maximize the use of existing skills and resources and provide good integration between diagnosis, disclosure and post-diagnostic support, not necessarily all provided in a single service, and between the dementia assessment and management and the ongoing care of the person's other morbidities or chronic conditions.

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Appendix 1

Details of strategy used for the review of 'dementia diagnostic service models'

The main search terms used were: (TI Dementia) OR (TI Alzheimer*) AND (AB diagnos*) AND (AB memory clinic) OR (AB memory complaint*) OR (AB service model). Slight adjustments were made to suit specificities of databases used. The following table provides a breakdown of the search strategy applied to each database.

Table A.1 Search details for the review of 'dementia diagnostics service models'

Database	Date	Search Terms	Limiters	Total Hits	After Duplicates	Papers for full text review
Medline/ Pubmed	23/02/2018	Dementia or Alzheimer*/TI AND diagnos*/AB AND memory clinic/AB OR memory complaint*/AB OR service model/AB	Date of publication from 2000-2018 and, limited to English materials	4038	3643	75
CINAHL	23/02/2018	Dementia or Alzheimer*/TI AND diagnos*/AB AND memory clinic/AB OR memory complaint*/AB OR service model/AB		4,885	3389	79
Scopus	23/02/2018	Dementia or Alzheimer*/TI AND diagnos*/AB AND memory clinic/AB OR memory complaint*/AB OR service model/AB		762	346	72
Embase	23/02/2018	Dementia or Alzheimer*/TI AND diagnos*/AB AND memory clinic/AB OR memory complaint*/AB OR service model/AB		1396	681	38
Cochrane	27/02/2018	Dementia or Alzheimer*/TI AND diagnos*/AB AND memory clinic/AB OR memory complaint*/AB OR service model/AB		3508	2766	14

Appendix 2

Details of strategy used for the review of 'diagnosing dementia in a primary care setting'
For the search on 'diagnosing dementia in a primary care setting' the search terms used were: GP (general practitioner*) or General Practice or Primary (Health*) Care AND Diagnosis or Assessment AND Dementia or Alzheimer's. Slight adjustments were made to suit specificities of databases used. The following table provides a breakdown of the search strategy applied to each database.

Table A.2 Search details for the review of 'diagnosing dementia in a primary care setting'

Database	Date	Search Terms	Limiters	Total Hits	Papers for full text review[1]	After Duplicates
Medline/ Pubmed	08/01/2018	GP (general practitioner*) or General Practice or Primary (Health*) Care AND Diagnosis or Assessment AND Dementia or Alzheimer's	Date of publication from 2000-2018 and, limited to English materials	2111	242	Each search was checked so as not to add returns from previous databases. A total of 344 documents were imported into EndNote which identified a further 70 duplicates. Final count of documents screened for full text was 274 articles.
CINAHL	08/01/2018	GP (general practitioner*) or General Practice or Primary (Health*) Care AND Diagnosis or Assessment AND Dementia or Alzheimer's		188	12	
Scopus	08/01/2018	GP (general practitioner*) or General Practice or Primary (Health*) Care AND Diagnosis or Assessment AND Dementia or Alzheimer's		595	75	
Embase	08/01/2018	GP (general practitioner*) or General Practice or Primary (Health*) Care AND Diagnosis or Assessment AND Dementia or Alzheimer's		277	14	

[1]Total number before duplicates were removed in EndNote

Appendix 3

Details of strategy used for the review of 'dementia diagnosis disclosure'
The key guiding research question for this particular theme was - What is the evidence to support practices in dementia diagnosis disclosure?

For overall terms used were: TI: (MH Dementia) AND (AB: Diagnosis) AND (AB: (Disclosure OR Disclosing OR Disclose. Slight adjustments were made to suit specificities of databases used. The following table provides a breakdown of the search strategy applied to each database.

Table A.3 Search details for the systematic review search of 'dementia diagnosis disclosure'

Database	Date	Search Terms	Limiters	Total Hits	After Duplicates	Papers for full text review
Medline/ Pubmed	08/01/2018	(TI: MH "Dementia+") AND (AB: Diagnosis) AND (AB: (Disclosure OR Disclosing OR Disclose)		163	After removing duplicates automatically in Endnote (n=299) and manually in Endnote (n=50), total hits = 243	A total of 194 articles were identified for full review
CINAHL	08/01/2018	(TI: MH "Dementia+") AND (AB: Diagnosis) AND (AB: (Disclosure OR Disclosing OR Disclose))		80		
Scopus	08/01/2018	('dementia' OR 'alzheimer-disease' OR 'alzheimers') AND ABS (diagnosis) AND ABS (disclosure OR disclosing OR disclose)	Date of publication from 2000-2018 and, limited to English materials	173		
Embase	08/01/2018	(Dementia:TI OR 'alzheimer disease': TI OR alzheimer's: TI) AND diagnosis: AB AND (disclosure: AB OR disclosing: AB OR disclose:AB)		127		
Cochrane	08/01/2018	'dementia' in Record Title and diagnosis in Abstract and Disclosure OR Disclosing OR Disclose in Abstract		6		

Appendix 4

Details of strategy used for the review of guidelines and other grey literature for 'dementia diagnosis disclosure'.
A further search was carried out targeting materials such as guidelines and other grey literature materials. The following table outlines the steps undertaken and the number of sources obtained.

Table A.4 Search details for the review of guidelines and other grey literature for 'dementia diagnosis disclosure'

Source	Date	Search Terms	Total Hits	Papers for full text review
Campbell collaboration	11/01/2018	('dementia' OR 'Alzheimer-disease' OR 'Alzheimer's') AND (diagnosis) AND (disclosure OR disclosing OR disclose)	0	0
National Guideline Clearinghouse	11/01/2018	Searched 'dementia' and then filtered by guidelines category: 'diagnosis'	24	0
Agency for Healthcare Research and Quality EPC reports	11/01/2018	Searched 'dementia'	6	0