

BRIEFING PAPER ON DEMENTIA DIAGNOSIS

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Foreword

This is part of a series of papers that has been commissioned by Genio to provide accessible overviews of key areas relating to the development of dementia services. The paper explores the diagnosis of dementia; what the current practice is in Ireland; a description of common standardised instruments for cognitive assessment; an overview of practices in other parts of the world and based on the evidence, some actions for consideration.

This report informed the development of the National Dementia Strategy which is due to be published shortly.

I would like to acknowledge the work of Prof Suzanne Cahill and Dr Maria Pierce in producing an excellent report and also the support of the Atlantic Philanthropies in funding this work. It represents a valuable resource for informing the development of dementia services into the future.

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1. Background

Worldwide, the prevalence of dementia is expected to reach approximately 76 million by 2030 and 135 million by 2050 (Prince et al., 2013). As dementia is a costly, chronic and progressive illness, with no effective cure, many countries across the world are being forced to face critical challenges, attempting to respond to the “rising tide” of this threatening illness (WHO, 2012). One such challenge for governments is that of planning and developing timely assessment and diagnostic services. The latter is recognised as being fundamental to the improvement of services for people with dementia because of the benefits that accrue (Bamford et al., 2004). Timely diagnosis is supported by clinical guidelines and national dementia strategies across Europe and further afield (Department of Health, 2009; DHSSP, 2011). The challenge of timely diagnosis is also currently being confronted in Ireland where the government’s recent development of its first National Dementia Strategy has heightened public debate about the preferred approach to dementia assessment, diagnosis and disclosure.

This paper has been commissioned by Genio to provide a detailed review of this key priority area, i.e. the timely diagnosis of dementia, identified for action in Ireland’s forthcoming National Dementia Strategy¹. Its purpose is three-fold. First, it describes, to the best of our knowledge, where, why and by whom dementia is diagnosed in Ireland. This section of the paper also provides information on common standardised instruments used in cognitive assessment, the diagnostic criteria recommended for use, the value of neuropsychological testing and current thinking

¹ Several other key priority areas have also been identified for this National Dementia Strategy.

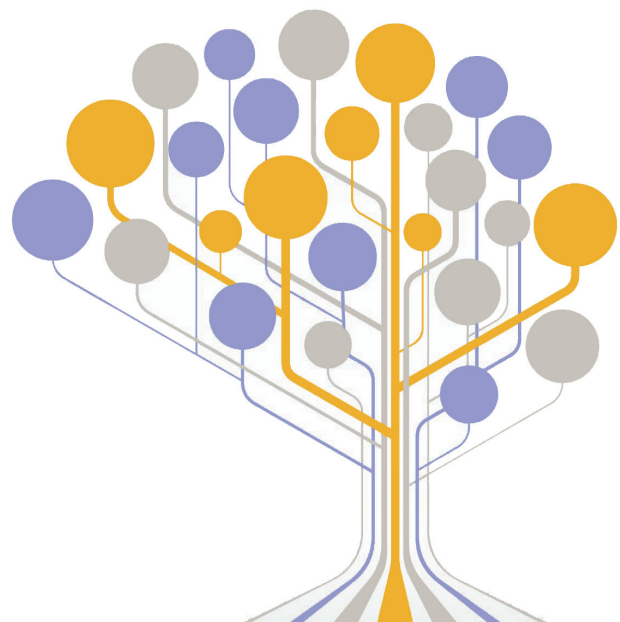
about best practice on disclosure patterns. Second, an overview is provided of approaches adopted in other countries around the world now further advanced in their planning of dementia diagnostic services. This section of the paper takes cognizance of national dementia strategies within a select number of countries and the commitment within these Strategies to improve diagnostic rates in both primary and secondary care. It includes reference to guidelines for those diagnosing and disclosing news of dementia in primary care, the referral pathways and skill sets needed. Drawing on the available research evidence, the third and final part of the paper identifies key actions for consideration in terms of the structures, systems and guidelines needed in Ireland to support the assessment and diagnosis of dementia.

At the outset, it must be remembered that diagnosis is not an endpoint in itself but merely one component of an integrated care pathway. What happens to the individual prior to and after a diagnosis of dementia, in terms of interventions, is equally important but is beyond the scope of this paper. It also needs to be acknowledged that different countries use different health service professionals in the assessment and diagnosis of dementia. For example, in Israel, France and the Netherlands, Neurologists appear to be the main medical specialists involved in diagnosis at Memory Clinics, whereas in the UK, Northern Ireland and the Republic of Ireland, Geriatricians and Old Age Psychiatrists are more likely to play an influential role in Memory Clinics (MCs). Who takes the lead in this important area depends on health care systems, professional capacity, and the interest and financial benefit in each country (Knapp et al., 2007).

Despite these differences, what is common across countries is the lack of understanding and public awareness about Alzheimer's disease and the related disorders (WHO, 2012), and that dementia remains hugely undetected and under-diagnosed (Brooker et al., 2013; Prince et al., 2011). For example, data from high-income countries reveal that only 20% to 50% of cases are routinely recognized and documented in primary care case notes (Prince et al., 2011). The UK National Audit Office (2007) concluded that only about one third of people with dementia receive a diagnosis. Similarly, the ALCOVE project, recently reported that although most countries stated they missed 40-60% of theoretical dementia diagnoses; some countries fared better (missing only 30%), but others fared worse (missing over 60%) (Brooker et al., 2013). This discrepancy between estimated and documented dementia has been referred to as the 'treatment gap' (ADI, 2011), since without a diagnosis many people live with no treatment, care or organised support (ADI, 2011; Pratt, 2006).

Dementia is difficult to diagnose (Butinex et al., 2011) and around the world even when diagnosed, significant delays often occur from symptom-onset to diagnosis. One cross-country study showed that the average time delay between when caregivers first noticed symptoms to when the person sought out a diagnosis was one year, but for others, a delay of more than two years occurred (Wilkinson et al., 2004). A pan-European study found the average length of time between symptom recognition and formal diagnosis was 20 months (Bond et al., 2005). In Australia the time gap between when symptoms were first noticed and when diagnosis was made was estimated to be 3.1 years (Phillips et al., 2011).

Despite efforts being made to improve timely diagnosis, population screening for dementia, i.e. the routine testing of a defined population even when no symptoms or signs have been reported, is categorically not recommended. Population screening for dementia is resource intensive and a recent systematic review has found it yields no benefits (Lafortune et al., 2013). Clinical guidelines are unequivocal in this regard (NICE/SCIE, 2006; see also Scotland, French guidelines).



2. Reaching a Timely Diagnosis

2.1 The Irish Context

There were an estimated 47,746 people with dementia in Ireland in 2011 and this figure is expected to rise to over 130,000 by 2041 (Pierce, Cahill and O'Shea, forthcoming). Incidence estimates by O'Shea suggest that there are approximately 4,000 new cases of dementia annually in Ireland (O'Shea, 2007). Regarding both incidence and prevalence rates, it is not known what proportion of Irish people receives a diagnosis, or indeed a differential diagnosis, nor is there any data available on where diagnosis occurs. We suspect, however, that when diagnosis occurs, this probably takes place in a variety of health settings including, primary care, community care (through community mental health teams) and secondary services including hospital outpatient's services and Memory clinics.

We also suspect, however, that, like in other countries, many of the 48,000 people estimated to have dementia remain undiagnosed and probably struggle in silence, unsure how to make sense of their presenting symptoms and who to turn to for advice. Often these people only come into contact with health service professionals when a crisis occurs, leading perhaps to a hospital admission. Even then, unless assessed by a Geriatrician or Old Age Psychiatry team, the dementia may be missed, particularly if hospital admission is due to physical health problems. This means that by the time medical help is sought, the dementia may be well advanced. The under-diagnosis of dementia is not unique to Ireland and arises for a variety of complex and inter-related reasons including stigma, the interaction of case complexity, pressure on time and the negative effects

of reimbursement systems (Hinton et al., 2007; Stoppe et al., 2007a). There is limited recent data available on Irish GPs' approaches to diagnosing and disclosing a diagnosis of dementia to their patients. Earlier research however showed that the obstacles to diagnosis encountered by them included that of differentiating normal ageing from symptoms of dementia, lack of confidence and concerns about the impact the news of the diagnosis would have on the patient (Cahill et al., 2006). It is also said that primary care in Ireland is currently dominated by an acute and episodic model of care and it is believed that the chronic care model, which encompasses both communicable and non-communicable diseases such as dementia, can provide guidance for a shift to a lifelong model of promotion, prevention, early intervention and chronic care (Draper et al., 2011)

2.2 Mild Cognitive Impairment and Early Onset Dementia

Mild cognitive impairment (MCI) refers to a transitional zone between normal ageing and dementia (Raschetti et al., 2007). It is a syndrome defined as cognitive decline, greater than that expected for an individual's age and education but that does not interfere notably with the individual's activities of daily living. Some people with MCI remain stable or return to normal but more than 50% will progress to dementia within five years (Gauthier et al., 2006). Indeed dementia is sometimes but not always preceded by MCI. It is difficult to predict who amongst those with MCI will progress to dementia (Russ & Morling, 2012).

Early onset dementia, also known as young onset dementia, is conventionally considered to include people who have experienced the onset of dementia before 65 years of age (Fossor et al., 2010). Accordingly, although the prevalence of dementia increases with age (Alzheimer Europe, 2009; Jorm & Jolley, 1998; Ziegler-Graham et al., 2008), Alzheimer's disease and the related dementias are not a normal part of ageing and dementia is not simply age-related. In fact the assessment and diagnosis of people with early onset dementia, an illness now affecting some 4,000 Irish people, is an area gaining increasing attention at some Memory Clinic services in Ireland (Cahill, Moore and Pierce, 2012). At St James's Hospital in Dublin, a Cognitive and Behavioural Disorders Clinic has recently been established. This service reviews people with early onset dementia and those whose cognitive disorders are associated with other neurological diseases (Hutchinson, 2013). We suspect that in Ireland, like in other countries, these younger people with dementia are also being assessed at other outpatient hospital-based neurological clinics around the country.

Early onset dementia can present in people as young as in their 30s, 40s or 50s. It tends to have an atypical presentation, with inherited phenotypes leading to causative genes (Hutchinson, 2013). It is a challenging dementia subtype for both those diagnosed and their family caregivers, as they are more likely to have young families, more financial responsibilities and are more likely to be working (Brodaty and Donkin, 2009). There is a distinct lack of ownership of early onset dementia by any one medical speciality (Hutchinson, 2013) and those experiencing it are also likely to undergo multiple referrals to different specialists and travel

lengthy pathways before arriving at a differential diagnosis. Their symptoms may be more challenging than those of older cohorts (Hutchinson, 2013). If linked into appropriate services (of which there are extremely few), these people usually receive more time and resources including advanced neuro-imaging (Hutchinson, 2013).

Dementia associated with Down syndrome is another common form of early onset dementia and the prevalence of Alzheimer's disease in this group of people is much greater at a younger age, compared to the general population. Because of the intellectual disability, and communication difficulties, diagnosis of this type of dementia can be extremely difficult and may require very specialist input (Coen, 2008). In Ireland today it is estimated that about 700 people have Alzheimer's disease related to Down syndrome (Cahill et al., 2012; Pierce, et al., 2013).

2.3 The need for a timely diagnosis

Whilst there is no clear consensus in the literature about which if any one discipline within the medical profession should take responsibility for diagnosis, earlier diagnosis and treatment are widely advocated (Prince et al., 2011; Waldemar et al., 2007) and, despite the absence of a cure, there is convincing evidence pointing to the benefits of a timely

diagnosis.² Diagnosis has been referred to as the gateway to care (Knapp et al., 2007) and differential diagnosis the gateway to appropriate medical and drug treatment (Iliffe et al., 2009). Assessment and diagnosis can mark an important transition: it reflects a shift from the uncertainty and ambiguity of symptoms (Iliffe et al., 2009) to a phase in which the individual can learn to adapt to loss of function (Woods et al., 2003).

Other benefits of early diagnosis include clarifying the cause of memory and cognitive problems and sometimes other unusual behaviours (Cahill & Shapiro, 1997), allowing access to suitable service supports (ADI, 2011; Bamford et al., 2004), promoting positive coping strategies (Derksen et al., 2006), reducing caregiver distress (ADI, 2011; Bamford et al., 2004), and facilitating planning for the future and long-term goal setting (Bamford et al., 2004). Increasingly, there is also the potential for using anti-dementia drugs as they may slow functional decline and delay nursing home placement (Geldmacher et al., 2003; Hatoum et al., 2009), reduce caregiver burden (Lingler, Martire & Schulz, 2005), empower the individual (Rockwood et al., 2004; NICE, 2011)

² While early diagnosis is broadly accepted to be a prerequisite to enhancing the diagnosis of dementia, the term 'timely diagnosis' is sometimes used in preference to the term 'early diagnosis', where timely diagnosis is defined as 'the time when the patient or caregiver and the primary care physician recognize that a dementia syndrome may be developing' (De Lepeleire et al., 2008). The preference for timely diagnosis implies that methodologies should concentrate not on population screening not on making the earliest possible diagnosis using currently available technology, but on a speedy response to the first reported signs of changed behaviour and functioning in the patient, (De Lepeleire et al., 2008; Prince et al., 2011). Timely diagnosis has been the goal of many national dementia strategies and advocacy organisations.

and promote quality of life (Diaz-Ponce & Cahill, 2012). There is also evidence that anti-cholinesterase inhibitors (AChEIs) are of some benefit in terms of improvements in cognition, ADL and behavioral symptoms (Rodda and Waler, 2009). Timely diagnosis may also be cost-effective as it can save health care costs by delaying institutionalization (ADI, 2011; Banerjee and Wittenberg, 2009).

“All too often, diagnosis occurs quite late, often after the illness has taken its toll on family life, and after it has caused huge distress to the individual and all those around him/her.”

Despite these benefits, Iliffe and Manthorpe (2004) have also highlighted the risks associated with making an early diagnosis of dementia. These include risks to the individual, to family members and to service systems. Risks to the individual include false positives, with the under-treatment of other illnesses such as depression, the risk of medication side effects and loss of autonomy. Risks to the family include labelling relatives prematurely as carers, and assigning them with new roles including that of monitoring medication compliance, and lengthening the period of the illness. Some of the service risks include lack of resources to deal with the demands generated by an early recognition policy and the accumulated risk of services needing to support more people for longer periods without significant changes occurring in primary care. Other experts have also provided very helpful overviews of the benefits and risks of early diagnosis (see, for example, Sheaff et al., 2011).

Despite this cautionary advice about risks, a recent survey of physicians found that most agreed that the majority of patients will benefit from a timely diagnosis through increased eligibility for pharmacological interventions (Alzheimer Society, 2012a). However, not all GPs appreciate the value of making an early diagnosis and not all patients recognize the value of discussing their concerns about memory and cognition at an early stage. The upshot is that all too often, diagnosis occurs quite late, often after the illness has taken its toll on family life, and after it has caused huge distress to the individual and all those around him/her.

2.4 Criteria for diagnosis

It is usually recommended that the diagnostic criteria set out in the Diagnostic Statistical Manual DSM-IV³ (APA, 1994) or other diagnostic criteria⁴ be fully satisfied in order for dementia to be diagnosed. In this context, three main criteria should be met. First, the presence of multiple cognitive deficits that include evidence of memory impairment as reflected in memory testing. Second, at least one of the following symptoms must be present: (a) aphasia, (b) apraxia, (c) agnosia or problems with executive functions, or (d) disturbances in cognitive deficits. Third, at least one of the above-mentioned symptoms should be

3 DSM SM-IV has recently been updated to DSM SM-V. Here dementia is referred to as a significant cognitive impairment.

4 For example, in the US, the diagnosis of AD is today usually based on the National Institute of Neurological, Communicative Disorders and Stroke–Alzheimer Disease and Related Disorders Association (NINCDS-ADRDA). According to these guidelines, a diagnosis is classified as definite (clinical diagnosis with histologic confirmation), probable (typical clinical syndrome without histologic confirmation), or possible (atypical clinical features but no alternative diagnosis apparent; no histologic confirmation) (ref).

sufficiently severe to cause significant problems with employment or social functioning. This latter statement is significant as there are situations where people experience cognitive, communication, and executive function problems yet can still continue to work or function socially. Dementia, therefore, refers to the “development of multiple cognitive deficits, which are severe enough to impair occupational or social functioning” (Coen, 2008).

2.5 The diagnostic process

Different countries use different systems and approaches for the diagnosis of dementia. However, by and large, medical doctors, either General Practitioners, usually undertake diagnosis alone or by medical specialists such as Geriatricians, Neurologists or Old Age Psychiatrists or by General Practitioners in collaboration with medical specialists. This clinical diagnosis is based on an examination of all the signs and symptoms of the illness and requires clinical judgment, along with information obtained from the patient and a collateral history obtained from family members.

It is noted that specific attention should be paid to mode of onset, course of progression, pattern of cognitive impairment and presence of non-cognitive symptoms such as behavioural disturbance, hallucinations and delusions. Differential diagnosis needs to be considered with reference to treatable causes of cognitive impairment such as depression, hypothyroidism and certain vitamin deficiencies (Foley, 2013). Timely diagnosis also requires screening tests and where relevant, referral to geriatricians or other specialists including MC staff. In the UK it is

argued that general practitioners tend to engage in a “watchful waiting process” when patients first present with suspicious symptoms, (Iliffe et al, 2009a). As a result of this, Bamford et al. (2007) argue that these patients are not referred early enough to specialist physicians.

Whilst it is beyond the scope of this paper to outline in detail the hierarchy of investigation involved, and what by way of physical examination is required including the screening tests that are used (e.g. laboratory tests such as ECGs, Cerebro Spinal Fluid testing, blood tests), and medical history and imaging (e.g. x-rays, MRI, EEG, PET) are requested, the literature suggests that the first step in diagnosis is to establish the presence of significant cognitive impairment and the second is to exclude any potentially reversible condition (Iliffe et al., 2009). In addition to this, validated assessment tools are often used.

2.6 Standardised instruments/assessment tools

Cognitive functioning tests, of which there are many, are used to evaluate cognitive function and are important in the assessment process. In general poor performance on such tests is merely indicative of a problem with cognitive functioning (Phillips et al., 2011), although a person’s performance may be affected by educational ability, language, hearing and culture. While a diagnosis of dementia cannot be made solely on the basis of the results of any of the cognitive assessment tools, these tests provide useful evidence for doctors undertaking the clinical

assessment and investigations. Many different tools are used by those involved in assessing cognitive function and in the diagnosis of dementia, and choice of tool varies considerably.

Clinician surveys show that the Mini-Mental State Examination (MMSE) is overwhelmingly ubiquitous in practice (Schulman Hermann & Brodaty, 2006) and is the most commonly used tool in general practice. The MMSE, which was developed by Folstein, measures orientation, immediate memory, attention and calculation, recall, various aspects of language and visuo-spatial skills. When used for screening, a MMSE a score of less than 24 scored out of 30 is conventionally used for the detection of significant impairment (Folstein et al., 2001). However, when the intention is illness classification, recommendations by Folstein et al. are as follows:

- i. normal cognitive function = 27-30
- ii. mild cognitive impairment = 21-26
- iii. moderate cognitive impairment = 11-20 and
- iv. (iv) severe cognitive impairment = 0-10.

Although the MMSE is relatively easy to administer, scores can be difficult to interpret and bias can arise in relation to age, race, education, and socioeconomic status (Galvin & Sadowsky, 2012). As the test can take up to 20 minutes to complete, administration of the MMSE is less practical in primary care.

The clock-drawing test is often considered to be a useful adjunct to the MMSE. It too is quick to use and tests visuo-constructive ability, executive function and numerical and verbal memory (Kirby et al, 2001).

However, it has been claimed that the scoring of this test is difficult due to the wide range of intellectual and perceptual skills being assessed (Ismail, Rijii and Shulman, 2010) and differences in interpretation of test results.⁵

A recent WHO evaluation found that a number of cognitive screening tools have been validated for use in general practice.⁶ It concluded that three tools are most suitable for routine dementia screening in general practice. These are the General Practitioner Assessment of Cognition (GPCOG);⁷ the Memory Impairment Screen (MIS)⁸ (Buschke et al., 1999) and Mini Cog⁹ (Borson et al., 2000). These instruments were found to take less than five minutes to administer, have been validated in community or general practice samples. Each is at least as valid as

5 The Alzheimer's Society makes the point that asking a simple question along the lines of "has the patient been more forgetful in the last twelve months to the extent that it has significantly affected his/her life?" is a useful risk assessment for dementia (Alzheimer's Society, 2013).

6 World Health Organisation. Mental Health. [Accessed 08.12.13; www.who.int/mental_health/mhgap/evidence/resource/dementia_q6.pdf].

7 The GPCOG is a 6-item cognitive screening tool, specifically designed for use in primary care. Taking 5 minutes to complete, it appears to perform well within the primary care setting and is psychometrically robust and free of educational bias. It includes time orientation, a clock drawing task, report of a recent event and a word recall task.

8 The MIS is a 4-item assessment test that takes approximately 4 minutes to complete. The MIS is especially appropriate for use with ethnic minorities.

9 The Mini-Cog is a brief screening tool designed for primary care use and assesses two aspects of cognition – short-term recall and clock drawing. It takes 3-5 minutes to complete and performs comparably to the GPCOG, also being free of educational bias.

the MMSE. In one UK study, these tests were shown to be as clinically and psychometrically robust and more appropriate for primary care physicians than the MMSE (Milne et al., 2008). Details of such cognitive assessment tools are well defined in the NICE guidelines on dementia (NICE/SCIE, 2006). Other tools are the Abbreviated Mental Test Score (MTS)¹⁰ and the Six Item Cognitive Impairment Tool (6CIT)¹¹.

Newer assessment tools, such as the Montreal Cognitive Assessment (MoCA), a tool used in The Irish Longitudinal Study on Ageing (TILDA) and developed to assist GPs detect mild cognitive impairment (MCI), are gaining credibility because of improvements in sensitivity and decreasing susceptibility to cultural and educational biases. Although more complex than the MMSE and Mini-Cog, the MoCA is free of charge for clinical use. It assesses multiple cognitive domains and was developed to discriminate between people with MCI and normal cognitive function (Nasreddine, Phillips, Bedirian et al., 2005). A score of 26 or above is considered normal (range = 0-30). There are many other short and simple memory tests available that can be used as first-line screening tools for use in primary care (Cullen, O'Neill, Coen & Lawlor, 2007). Each has advantages and disadvantages: the important point is that an objective measurement can provide an accurate "snapshot" of the patient's cognitive ability, and provides a quantitative measurement to inform treatment responses.

10 This is a well-established 10-item screen that samples various cognitive domains. There are only verbal items. Orientation, long term memory, recognition and short term memory are assessed

11 Designed for primary care use, the 6CIT takes approximately five minutes to complete. All items are verbally based. Orientation, short term memory and attention/concentration are assessed.

2.7 Neuropsychological testing

In the UK, the NICE guidelines recommend that, where available, referral to specialist services, should be made to confirm a diagnosis, exclude other pathologies, subtype the dementia and tailor treatments to the specific dementia subtype (NICE/SCIE, 2006; Burns and Iliffe, 2009).

Neuropsychological testing includes examining the individual's ability to encode and recall information, concentration and attention levels, orientation, language naming and visuo-spatial skills which include a wide variety of individual skills varying from recognition to identification (Gibb, 2013).

Neuropsychological testing may include a range of more detailed neuro-cognitive tests. The Cambridge Cognitive Test (CAMCOG), which discriminates against different patterns of decline, is one assessment tool often used by neuropsychologists.

In reflections about screening and assessment tools, it is argued that the impact that these will have on the individual, who may already be fearful of symptoms, needs to be given due consideration. In a UK study, Keady and Gilliard (2002) demonstrated that neuropsychological testing was particularly daunting for people presenting with memory and cognitive complaints at Memory Clinics. In this same study, patients used words like "worry", "concern" and "anxious" to reflect their experience of the process of being tested. Similar findings emerged in Ireland in a small-scale exploratory study of patients attending a national Memory Clinic for the first time (Cahill et al., 2008a).

2.8 Diagnosing dementia in primary care

Considerable differences in primary care physicians' abilities and confidence in diagnosing dementia has been consistently reported in the literature (O'Connor et al., 1988; Downs et al., 2000). Unlike several other major illnesses, no definitive test exists to diagnose dementia (Workman, Dickson & Green, 2010) and it is said that diagnosis is usually one of exclusion, undertaken by a process of elimination and conducted in two distinct stages (Lindesay, 1999).

Iliffe and colleagues, in a recent two-part excellent seminal paper on diagnosis, assessment and disclosure (Iliffe et al, 2009; Robinson et al, 2010), argue that (in the context of dementia), rather than testing for a disease, the first stage in diagnosis, the "trigger phase", usually involves the medical practitioner becoming suspicious of the possibility of a dementia syndrome. After this index of suspicion arises (Iliffe et al, 2009), dementia may be gradually identified, as other causes are excluded.¹² Once the dementia syndrome has been established, the second stage in diagnosis, involves the identification of the aetiological subtype of which there are many.¹³ The accurate diagnosis and sub-typing is important as it will determine the management strategy offered and prognosis (Tomoeda, 2001). This has become more important with the advent of treatments specifically for Alzheimer's disease, and because of the need to avoid the potentially serious side effects of antipsychotic use in people with Lewy body dementia.

12 Common non-dementia causes of cognitive decline include delirium, depression, vitamin deficiencies, thyroid problems, depression, and drug side-effects.

13 The four most common sub-types are Alzheimer's disease, Vascular Dementia, Mixed Dementia and Lewy Body dementia.



A challenge, identified by Iliffe et al. (2009), is that often physicians are reluctant to diagnose a serious non-modifiable disease, which carries a huge burden of stigma (Batsch and Mittelman, 2012) and families and patients may also be reluctant to accept such a diagnosis and such factors may contribute to significant delays. Pointing to the complexities involved in diagnosing dementia, Iliffe makes the point that there are fundamental and widespread misunderstandings about how the diagnostic characteristics of dementia syndrome diverge from the cognitive changes of normal ageing (Iliffe et al, 2009). He contends that GPs should be considerably more proactive rather than reactive to the signs and symptoms of dementia.

To improve the detection of dementia in primary care, Iliffe and his colleagues recommend three distinct approaches, namely: (i) enhancing professional skills; (ii) modifying service delivery; and (iii) appropriate remuneration and screening. A cautionary note is made by these experts about the tensions and obstacles that may arise when cross-disciplinary

collaboration is required and when efforts are made to change the way in which services operate.

Brief doctor-patient encounters concerning multiple symptoms and health conditions tend to be the norm in busy general practice surgeries, (Phillips, Pond & Good, 2011). General practice is usually a rushed setting where unless the GP has definite suspicions of dementia and is on the alert for changes associated with memory and cognitive impairment, the early signs and symptoms of dementia may not be that apparent (Turner et al., 2004). The challenge of diagnosis is often made all the more difficult for GPs as signs and symptoms can sometimes be deliberately hidden or disguised by the individual or by family members (Cahill & Shapiro, 1997). The latter usually only seek out a diagnosis after all attempts at normalising symptoms fail and the problem is seen as different from normal ageing (Krull, 2005). As mentioned, making a diagnosis is “no easy task” and requires considerable time, a resource that many GPs do not have. It also at times requires access to specialists including neuropsychologists, who are not always accessible to GPs.

A review of the research evidence in Ireland some years back revealed that Irish GPs reported they diagnosed on average four new cases of dementia annually (Cahill et al, 2006). Whilst most GPs held themselves responsible for the late presentation of dementia in primary care and not their patients or the health care system (Cahill et al., 2008b), many were reluctant to diagnose. Reasons for this included therapeutic nihilism, stigma, diagnostic uncertainties, lack of confidence, risk avoidance and concerns about their clinical/professional competencies. Several GPs reported that they had significant difficulties differentiating age-associated memory problems from the signs and symptoms of dementia. Some feared damaging the doctor-patient relationship by disclosing a diagnosis. Time limited consultations were also an additional barrier (Cahill et al., 2006).

Cahill et al. (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. However, CPD for GPs is not subject-specific and there is no requirement that GPs engage in educational activities focusing on dementia. A recent small-scale exploratory cross-country study (Ireland and Sweden) found that Irish GPs still consider dementia to be a stigmatizing illness and are only equivocal about the value of dementia training (Moore & Cahill, 2012).

There is a need to develop the capacity of Irish GPs to proactively assess, diagnose and disclose dementia. To date, medical education in Ireland has not equipped GPs with the full range of clinical and psychosocial

skills required for dementia diagnosis and disclosure. As noted by Vernooij-Dassen et al. (2005), educational initiatives need to take cognizance of not only clinical issues, but also the values, attitudes, experiences and behaviours of those committed to being trained. It has been suggested that the content of training programmes needs to be varied and approaches need to be multi-faceted drawing on problem based learning, role play and other experiential learning (Iliffe et al., 2002). Guidance for the timely diagnosis of dementia is also needed in Ireland.¹⁴ Although professional education about dementia in primary care is associated with more positive attitudes to its detection (Renshaw et al., 2001), tailored educational interventions for GPs aimed at improving quality of care by facilitating the diffusion of clinical guidelines and knowledge into practice does not in itself lead to significant improvement in case identification by GPs (Wilcock et al., 2013). It seems that the organisation of health care (e.g. time, incentives, GP registers and decision support software) may be a more significant factor contributing to the under-diagnosis of dementia in primary care than education. In this context, a widely adopted approach to improving primary care services is the chronic care model (CCM),¹⁵ which requires practices to work differently, not just to refer patients to external support. Practices based on the CCM integrate changes in multiple areas including self-management support, decision support, delivery system design, clinical information systems, health care organisation and community services (Coleman et al., 2009).

14 In this context the recent pioneering and excellent work of some experts needs to be acknowledged including the soon to be launched ICGP reference Guide to dementia (Foley & Swanick, forthcoming).

15 For further information about the Chronic Care Model, see http://www.improvingchroniccare.org/index.php?p=The_%20Chronic_Care_Model&rs=2

2.9 General Practitioners' role in disclosing the diagnosis to patients

Some evidence now exists that disclosing the news of dementia to patients is not always that well handled with complaints voiced about limited information being provided and lack of follow up (Clare, 2003). A systematic review of the literature about the sharing of the diagnosis reveals that non-disclosure or the communication of vague information is experienced

“Some evidence now exists that disclosing the news of dementia to patients is not always that well handled”

as confusing, upsetting and difficult (Bamford et al., 2004). It is recommended that during the assessment and diagnostic process, people should routinely be asked if they would like to know their diagnosis and with whom this should be shared (Pratt & Wilkinson, 2001; Pinner & Bowman, 2003). Interestingly, from the perspective of GPs, research has shown that disclosing news of dementia is one of the most difficult aspects of diagnosing dementia (Adams et al., 2005), especially when disclosing the information to patients themselves rather than to their primary caregivers (Bridges-Webb, 2002).

Carpenter's US work published some ten years back yielded a broad list of arguments both for and against diagnostic disclosure (Carpenter et al., 2003). Carpenter's work demonstrated that practice guidelines and professional opinion regarding disclosure appear to depart from the actual experience reported by clinicians, patients, and family members. At a more detailed level, the issues of who is told, how and what they are told, and the impact of disclosure, are poorly understood. Sensitivity to individual differences may promote an optimal approach to disclosure. They concluded that research in this area was sparse and often contradictory.

More recent work suggests that early disclosure seems to be preferred by most but not all people presenting with symptoms of dementia, reinforcing the need for disclosure to be person-centred. In the UK, it has been reported that 92% of patients diagnosed with mild dementia when asked about disclosure preferences reported that they would in principle have welcomed being told their diagnosis (Pinner & Bourman, 2002). In another study (Dautzenberg et al., 2003), almost 100% of patients and their caregivers referred to a MC believed it was important for patients to be told their diagnosis. The benefits of sharing a diagnosis include: (i) confirming suspicions; (ii) ending uncertainty; (iii) giving access to support; (iv) making possible the promotion of positive coping strategies; and (v) facilitating planning and fulfilment of short term goals (Husband, 1999, 2000; Smith and Beattie, 2001).

In a recent qualitative study of 27 patients attending MCs in the UK, several patients were highly critical of the systemic process of assessment and diagnosis

disclosure. Some criticised the process by which the diagnosis was imparted and claimed that this was the reason for their heightened shock. The overwhelming majority wanted to know their diagnosis and prognosis. However, they believed that a staged process of diagnostic disclosure would have better enabled them take the news of their dementia on board (Samsi et al., 2013). In this same study encounters with GPs were generally rated positively by patients, however, assessment in secondary care was reported as less favourable with participants feeling lost in the labyrinth of tests, score sheets, scans and appointments and little knowledge about what constituted a good memory performance amongst the battery of neuropsychological tests.

2.10 Disclosure practices in Ireland

A well-cited Irish study, conducted during the 1990s and published in the British Medical Journal, found that the majority of family caregivers (N=100), whose relatives were attending a MCs with Alzheimer's disease, claimed that if they themselves had Alzheimer's disease, they would want to know their own diagnosis. Ironically, only 17% wanted their relatives with Alzheimer's disease to be told their diagnosis (Maguire et al., 1996).

In the first survey of Irish GPs (Cahill et al., 2006), findings showed that only 19% of those surveyed (N=300) reported that they often or always disclosed a diagnosis to a patient and 41% reported that they never or rarely disclosed the diagnosis to their patients. GPs' perceptions of their ability to comprehend the diagnosis emerged as the main reason why they

opted not to disclose (Cahill et al., 2006). These low Irish disclosure rates at the time contrast sharply with those reported elsewhere. For example, a Norwegian study showed that two thirds of GPs often or always disclosed the diagnosis (Braekhus & Engedal, 2002) whilst a British study showed that 40% of GPs often or always told their patients the diagnosis (Vassilas & Donaldson, 1998).

A small-scale British study on dementia disclosure patterns conducted amongst community mental health nurses and psychologists showed that uncertainty about whether the person with dementia would want to know the diagnosis was one of the main reasons identified for professionals withholding information about the diagnosis to the patient. In the same study, these professionals also expressed a strong sense of hopelessness and helplessness when confronted with dementia (Keightley & Mitchell, 2003).

In Ireland up until 2007, the disclosure policy at the national MC at St James's Hospital was that diagnosis was withheld unless a patient specifically requested that a diagnosis be disclosed. Since 2008, the MC's disclosure policy has changed significantly and is now patient-guided. On first meeting, patients' preferences are explored and staff members now ask patients explicitly if they wish to know their diagnosis. Relatives are advised that where a patient wishes to know his/her diagnosis this will not be withheld from them. Upon returning for feedback, patients are given the opportunity to receive their diagnosis on their own or with family, according to their preference (Cahill et al., 2008a).

2.11 The role of memory clinics and memory assessment services in diagnosing dementia

Memory clinics (MCs), specialist services for the assessment and diagnosis of dementia, have been in existence in the United States since the 1980s (Maher, 2009). Although no comprehensive definition of MCs exists, it is broadly accepted that MCs can play a lead role in the identification, investigation and treatment of dementia (Jolley et al., 2006). Across the world, there has been a very significant growth in numbers of MCs in recent years. However, there is much variability across MCs regarding whether they are assessment or diagnostic services, the degree to which they are multidisciplinary and the post-diagnostic services that are on offer (Cahill, Pierce and Moore, in press).

Some positive opinion has been voiced about the value of MCs (van Hout et al., 2001). It has been demonstrated that an integrated multidisciplinary approach to diagnosing dementia can contribute to an improved quality of life (Wolfs et al., 2008). In a recent review, Melis et al. (2009) concluded that the evidence suggests that state of the art multi-disciplinary MCs will in the future be cost-effective services for providing dementia diagnosis and guidance. Despite such positive opinion, some criticism has also emerged, particularly in the UK about the post-diagnostic value of MCs. This criticism has been voiced around the issue of whether MC services are effective in providing post-diagnostic services when compared with the usual care offered by GPs. A recent randomized control trial has shown that at follow-up the benefits of MCs compared with routine GPs services are negligible. In fact in this

study no evidence emerged about the differences in effectiveness between MCs and GPs services in relation to post-diagnostic treatment and coordination of care for patients with dementia (Meeuwssen et al., 2012). Furthermore, in one study, GPs have been found to be as proficient as MC staff at making the diagnosis (van Hout et al., 2000).

In some parts of the world, MCs offer a more remote or virtual service. For example, in rural parts of Canada (Saskatchewan) a rural and remote memory clinic service offers pre-assessment services to clients via telehealth video-conferencing (Morgan et al., 2009). Later, patients and carers attend a MC in person for assessment and diagnosis and the visit ends with feedback being provided on the same day. Follow-up appointments are then arranged by telehealth videoconferencing at six weeks later and at three and six months later. A full in-person follow-up occurs at twelve months and thereafter on-going review takes place. This model of service has application in large countries where populations are dispersed and access to specialist service may otherwise be limited.

Ireland's first MC was established at St James's Hospital in 1991 and like other countries, Ireland has also witnessed a significant expansion in MC services since then. There are now some 16 MCs in operation across the Republic of Ireland (Gibb, 2013). However, like in other countries, there is much regional variation across these clinics, regarding services offered and the financing and resources of such services. A small minority of these MCs are very well resourced, and provide a truly multi-disciplinary service daily, whilst others depend on community-based allied health practitioners and offer fragmented and merely skeleton-style services.

A national survey of Irish MCs was conducted in 2011 when efforts were made to investigate the numbers of patients assessed annually (Cahill, Pierce and Moore, in press). Although data about patient throughput was only available in eight of the then 14 clinics surveyed, findings revealed that an average of 126 patients were assessed and reviewed at MCs that year, i.e. a total of 1,764 patients (Cahill et al., in press). Given that many of these people probably failed to receive a diagnosis (some were probably assessed as the “worried well”/subjective complainers; others were definitely review patients and others again had mild cognitive impairment (MCI)), it is likely that circa one quarter (450 patients) of patients in attendance, will have received a diagnosis of dementia at these clinics. Allowing for the fact that there is probably circa 4,000 new cases of dementia in Ireland annually these figures are small.

It needs to be remembered that apart from diagnosis occurring in MCs, dementia assessment and diagnosis also occurs in hospital outpatient clinics and diagnosis is also undertaken by Old Age Psychiatrists attached to Community Mental Health Teams. Dementia diagnosis can also occur in Neurology outpatient services as, for example, at the cognitive and behavioural disorder clinic at St James’s Hospital. Within MCs in Ireland, there is no consensus on pre-assessment work-up, no referral templates and no timelines around assessment, investigation, diagnosis and feedback to primary care. In other words referral pathways and communication between primary care and Memory Clinic services needs much more clarity with more adequate service integration. This was an issue highlighted by some of the participants in the recent national survey of MCs in Ireland (Cahill et al, in press).

“The evidence reveals that most people (but not everyone) favour disclosure, but in a staged process, thereby allowing them time to take on board the information provided.”

2.12 Summary

So far, this paper has reviewed the recent literature on the topic of dementia diagnosis and disclosure. It has argued that, despite a consensus existing on the value of timely diagnosis; the identification and diagnosis of dementia, especially in primary care is complicated, takes times and is generally considered to be a two-staged process. Timely diagnosis of more atypical dementias including early onset dementia and dementia in people with Down syndrome has been shown to be exceptionally challenging. Regarding the disclosure of dementia to patients, the evidence reveals that most people (but not everyone) favour disclosure, but in a staged process, thereby allowing them time to take on board the information provided. The paper has also described in lay man’s terms how dementia is diagnosed, the diagnostic criteria required, the protocols followed, including the standardised instruments/assessment scales that are administered. The next section of this paper moves on to discuss the issue of dementia assessment and diagnosis in a number of countries outside Ireland.

3. Approaches to Diagnosing Dementia in Five Countries

In this next section an overview is provided of what happens in other countries across the world now further advanced than Ireland in their planning and delivery of dementia assessment and diagnostic services. The paper will compare and contrast policies, procedures and practices in relation to the diagnosis of dementia in five countries namely: England, France, the Netherlands, Norway and Australia. In this cross national review, every effort will be made to identify within the countries selected, the extent to which the assessment and diagnosis of dementia is conducted in primary care, secondary care services or within other specialist services such as MCs. At the outset it must be kept in mind that the approaches outlined are not representative of global approaches adopted to dementia assessment and diagnosis and where relevant, reference to other countries will also be made.

3.1 Country selection

These five countries have been selected for specific reasons. First, service initiatives for the diagnosis of dementia in these countries are now well established and promoting a timely diagnosis is a priority area in most of these countries' National Dementia Strategies or National Plans. Secondly, we are interested in comparing a range of different countries where policies and approaches have been published in English. Other reasons for the selection of these particular countries include the fact that England has close geographical/historical ties with Ireland; its population has a similar age structure, and England has a clear vision with respect to dementia diagnosis. The French National Plan for Alzheimer's disease is on its third iteration and therefore France has had the opportunity to reflect on the outcomes emerging from its first and second Dementia Plan and service initiatives. Norway, which

has a population similar in size to Ireland, has well-defined benchmarks developed for best practice in dementia care, an interdisciplinary approach to dementia diagnosis and pathways for all those affected by dementia which are clear to both lay people and health service professionals. The Netherlands and Australia have been selected as in both countries an emphasis is placed on encouraging GPs to broaden their knowledge base and to be on the alert for the signs and symptoms of dementia and to make relevant referrals to specialist services.

3.2 England

The English National Dementia Strategy - Living Well with Dementia (NDS) focuses on a few key objectives including the need to diagnose dementia earlier. It aims to 'make early diagnosis and treatment the rule rather than the exception' (Department of Health, 2009: 21). A priority objective (also an objective of Quality Outcomes for People with Dementia (Department of Health, 2010)) is of having good quality early diagnosis and intervention available to all. In short, the English Dementia Strategy makes a clear case for adopting this objective.

Acknowledging that under-diagnosis of dementia is currently the norm, in England, the NDS states that:

All people will have access to a pathway to care that delivers a rapid and competent specialist assessment; an accurate diagnosis, sensitively communicated to the person with dementia and their carers; and treatment, care and support provided as needed following diagnosis. The system needs to have the capacity to see all new cases of dementia in the area (DoH, 2009).

A core aim of the NDS is to ensure that effective diagnosis and intervention services are available to all at a national level. However, it has been noted (DoH, 2009) that a constraint of the English system has been the lack of clarity around the critical issue of where and by whom a formal diagnosis of dementia should be made. Traditionally in England, diagnosis of dementia occurred mainly within specialist secondary services. This may have been since the NICE guidelines advised that: "Only specialists in the care of people with dementia (that is, psychiatrists including those specializing in learning disability, Neurologists, and Physicians specializing in the care of the elderly) should initiate treatment" (NICE/SCIE, 2006). The guidelines may have legitimated GPs reluctance to involve themselves in assessment and diagnosis.

In England, MCs have today been identified as being well positioned to offer early diagnostic services and the NDS has called for the commissioning of larger numbers of MC services for early diagnosis and intervention. These MCs are structured to receive referrals from primary care physicians and work locally with other specialists. In fact the NDS stipulates that every specialist mental health service for older people should have a MC (Department of Health, 2009). Despite the expansion that has occurred in MCs in England, today availability varies widely.

Some criticism has been voiced about MCs in the UK for their failing to offer continuity of care, particularly as patients' cognitive functioning declines (Pelosi et al., 2006). The argument marshalled, is that clinics have confined themselves to the easy parts of the management of neurodegenerative disorders; patients are assessed and then discharged or else reviewed

until such time as their cognitive deterioration and behavioural disturbances become problematic when they are referred to general old age psychiatry teams. The latter are then obliged to arrange "proper" management plans which some critics suggest involves undoing that done by clinicians who may lack experience of people with dementias' long term care needs. The task it is said is not made easier when potential members of the multidisciplinary team have been recruited to MCs.

An emerging debate in England, and one pertinent to Ireland, surrounds the role of GPs in the diagnosis of dementia. In the UK, the GPs role remains somewhat ambiguous as the NICE Guidelines favours not merely making a diagnosis of dementia but also identifying the sub-type of dementia where possible. If this is the case then the involvement of specialist physicians, including specialist GPs (consultant GPs with expertise in dementia) is required. Setting out the process and referral pathways required, the NICE Clinical Guideline 42 (NICE, 2006) states:

Diagnosis of a dementia syndrome can often be made in primary care, though if diagnosis is in doubt, referral to a specialist (old age psychiatrist, neurologist, physician in healthcare of older people or specialist GP, as deemed appropriate) should be undertaken. In most cases, subtype-specific diagnosis of the type of dementia will be required and people should be referred to a specialist with expertise in the differential diagnosis of the condition.

The Operating Framework for the NHS in England 2012/13 has also identified dementia as an

area requiring particular attention and focuses on 'improving diagnosis rates, particularly in areas with the lowest current performance'. This framework aligns itself well with the Prime Minister's Challenge on dementia which aims to 'deliver major improvements in dementia care and research by 2015' (Department of Health, 2012). The Minister has made a commitment to 'increased diagnosis rates' as part of its objective to improve dementia health and care. It stated that 'from April 2013 there will be quantified ambition for diagnosis rates across the country, underpinned by robust and affordable local plans' and committed to the inclusion of a new indicator in the NHS Outcomes Framework 2013/14 to act as an incentive to increased diagnosis rates. GPs are seen as having a key role to play in the NHS ambition to increase diagnostic rates. A new Enhanced Service for take up by GPs has been designed and introduced as part of the GP contract for 2013/14 to reward practices for having a pro-active, case finding approach to the assessment of people who may be showing the early signs of dementia. GPs are incentivised to keep a dementia register and undertake a review of the support needs of patients diagnosed with dementia and their carers. The latter includes an appropriate physical and mental health review. It also addresses carers' information needs and reviews the impact of caring on the carer.¹⁶

Further efforts to increase awareness of dementia and improve diagnostic rates are reflected in the dementia component of the NHS Health Check programme.¹⁷ Under this programme, everyone aged 65-74 who

has a NHS Health Check, although not subjected to memory and cognitive testing, should be made aware of the signs and symptoms of dementia and where appropriate told the whereabouts of their local memory services. The purpose of the intervention is to raise awareness of dementia and the availability of memory services which offer further advice and assistance to people who may be experiencing memory difficulties, including making a diagnosis of dementia. An online dementia training tool has been introduced as a component of the NHS Health Check Programme to increase awareness and understanding of dementia among general practitioners and other primary care health professionals offering the NHS Health Check and to increase signposting to assessment and diagnostic services (<http://www.healthcheck.nhs.uk/increasing-dementia-awareness-training-resource/>).

3.3 France

In 2000, a national report on Alzheimer's disease was published in France, which recommended the development of a dedicated National Dementia Strategy and highlighted the problems confronting people seeking a diagnosis marking this out as a key area of interest. Since that time, three consecutive plans for Alzheimer's disease and other dementias (2001-2004, 2004-2007, and 2008-2012) have been published. Addressing gaps in dementia diagnosis has been a key priority in all three French Dementia plans. The French Dementia plans have led to the development of improved diagnostic services for dementia across the country and the development of individualised treatment plans, including a structured

¹⁶ www.nhsemployers.org/Aboutus/Publications/Documents/qof-2013-14.pdf

¹⁷ A public health programme in England for people aged 40-74 which aims to keep people well for longer.

secondary stage (primary care physician) and the provision of necessary social support. Assistance and support to younger people with dementia has also been promoted (<http://www.centre-alzheimer-jeunes.fr>).

The overall approach adopted in France has been to facilitate access to reliable diagnosis, through the establishment of a national network of Memory Centres. These Centres encompass both MCs (consultation mémoire) and Memory Research and Resource Centres and are augmented by independent specialists, i.e. Neurologists, Geriatricians and Old Age Psychiatrists. The aim is to ensure that each health district (Territoire de Santé) has its own MC. By the end of 2006, there were 366 MCs located throughout the country and by 2007 a national network of MCs had been established. The French plan has been about both creating new MCs (65 since the plan began in 2008) (Lustman, 2011) and strengthening those already in existence (202 by June 2012).¹⁸ French MCs today employ multidisciplinary teams consisting of Neurologists, Geriatricians, Psychiatrists, Psychologists or Speech Therapists. By 2012, there were also a total of 465 hospital-based MCs covering the country.¹⁹ In France, these MCs are generally located in university hospitals.²⁰

France's third national plan for Alzheimer's disease and related diseases (2008-2012) set out to address the challenge of timely diagnosis by adopting a more

18 http://www.plan-alzheimer.gouv.fr/IMG/pdf/Plan_Alzheimer_4th_anniversary-2.pdf

19 http://www.plan-alzheimer.gouv.fr/IMG/pdf/Plan_Alzheimer_4th_anniversary-2.pdf

20 These Memory Clinics are either independent or part of other departments such as Neurology or Geriatric Medicine.

holistic approach to what Bamford (2010: 6) refers to as 'the thorny problem of early diagnosis'. The plan promised a guiding framework for initial diagnosis and referral in conjunction with a wider awareness-raising campaign. The Alzheimer Plan (2008-2012) has eleven key objectives, one of which concerns 'improving access to diagnosis and care pathways'. This same objective has eight measures for implementation, four²¹ of which deal with diagnosis. Measure eight, for example, concerns "preparing and implementing a system for giving the diagnosis and providing counselling." Ring-fenced funding was allocated through the French Strategy and a budget of €6.68 million set aside for this measure. The detailed budget allocated to each measure means that the French National Dementia Plan provides greater specificity in the implementation process in comparison to other national dementia strategies (ADI, 2012).

In the third Plan and in an effort to improve diagnostic access, specific funding was allocated to enable each region to have at least one Memory Resource and Research Centre (MRRC). The latter is a specialist centre providing diagnosis for those with suspected early onset dementia and most complex cases to reach what is considered to be a satisfactory level of facilities (Measures 11, 12 and 13). By doing so the whole country would be covered with specialized diagnostic and follow-up units. In 2013, a total of 20 of these specialist services were in operation (Guisset-Martinez, 2013).

Despite the development of a network of Memory Centres, much regional diversity exists in France in terms of access to diagnostic services. It has also been noted that there has been considerable inertia and

21 Measures 8, 11, 12 and 13.

reluctance on the part of GPs to refer patients to these clinics. The French experience is significant as it demonstrates that increasing the number of Memory Centres does not in itself lead to increased rates of early detection and diagnosis of dementia (Bamford, 2010).²²

3.4 The Netherlands

In the Netherlands it is noted that about 50% of all those with dementia receive a diagnosis and it is estimated that 27% of all new cases of people with dementia will be diagnosed mostly by Neurologists or Geriatricians attached to MCs (Ramakers and Verhey, 2011). The specialists are often assisted by (Neuro)Psychologists and specialist dementia nurses. In the Netherlands, as in other European countries, a burgeoning in MC availability has occurred and a striking development is that most MCs now tend to be better integrated with local care services, most commonly community mental health teams or long-term care facilities (Ramakers and Verhey, 2011).

The National Dementia Plan for the Netherlands states:

A patient presenting to their GP with suspected dementia or dementia-like symptoms can expect the GP to have enough knowledge to be able to recognise the symptoms. This means that the GP needs to know when to refer the patient to secondary care (outpatient memory clinic etc.) and what support can be offered.

²² It is curious that despite such a sophisticated approach to specialist service development in this area, nonetheless it is noted that compared with 15 years ago, the involvement of GPs in France in the diagnosis of dementia is now considered extremely important if people are to receive a timely diagnosis of dementia (http://www.plan-alzheimer.gouv.fr/IMG/pdf/Plan_Alzheimer_4th_anniversary-2.pdf).

Accordingly, GPs can diagnose dementia and indeed can charge extra (double consultation time) but there is no other incentive for GPs to improve or increase timely diagnosis. When cases are complex, GPs' sole responsibility is for diagnostic work-up and referral onwards to MCS. In the Netherlands these more complex cases include patients who refuse to receive care or who have co-morbidities, behavioural and psychological symptoms, or other serious problems or where specialist diagnostic equipment is required.

In the Netherlands, GPs receive almost no professional training in dementia in their basic medical education; however, they are obliged to participate in continuing professional education. The Dutch Association of GPs has also developed a programme to train GPs in the care of frail older people including people with dementia. This programme is expected to result in a growing number of GPs having specialism in the care of people with dementia.

3.5 Norway

The overall aim of the Norwegian Dementia plan (2008-2015) was to increase knowledge about dementia in society and to develop a variety of Day Care programs. The timely diagnosis of dementia was not a key priority in this clearly articulated plan. Yet, embedded within the plan, is a commitment to developing and testing models for assessment and diagnosis based on partnerships between specialist and primary/community care services. As a result, workable models of collaboration have been developed in Norway and various benchmarks set. One of these was that every municipality, of which there were at the time 430, would have a dementia community based team by the year 2015.

The Norwegian model for assessment and diagnosis of dementia assumes a division of tasks between community based and specialist hospital health services but when necessary a partnership between the specialist and primary care services. Initial responsibility for assessment and diagnosis of dementia lies at the primary and community care level. However, in cases where assessment is complicated or when primary and community care services lack the necessary expertise or resources, the person is referred to the specialist health service. Accordingly, the objective with regard to dementia assessment and diagnosis in Norway is:

“for people with a very mild degree of dementia (MMSE score 25-27), younger people with any degree of dementia and atypical cases to be assessed in a specialist health care Memory Clinic. All other patients that have clear symptoms and signs of dementia should be assessed and diagnosed in primary health care ... that’s our goal” (Engedal, 2012).

This means that in Norway, the individual’s age and MMSE score are criteria used to determine which discipline within the Medical Profession should assess and diagnose dementia. GPs for example are expected to assess those over 65 years who present with the most common types of dementia (i.e. Alzheimer’s disease, Vascular Dementia, Frontal Temporal Dementia and Dementia with Lewy Bodies). However, younger people (aged < 65 years) should be diagnosed at Memory Clinics or through Specialist services²³.

23 It is not unusual for Norwegian GPs to mistakenly suspect that a younger person has a condition such as depression, stress or burn-out when in fact their symptoms are the early signs of dementia. When this happens it is said that it can take two to three years for a younger person to get a correct diagnosis of dementia, which means that by the time a diagnosis is made the condition is often well progressed (Holth, Personal Communication, November 2013).

If a person is aged over 65 years yet presents with atypical symptoms or the condition is progressing quickly, GPs are required to refer these patients to a MC or a neurological or psychiatric service for further assessments. In these cases, assessment and diagnostic tools²⁴ including CT, MRI and EEG are used and medication is sometimes used. Norwegian MCs have a common register for research purposes and use similar protocols.

Accordingly, the Norwegian approach to assessment and diagnosis is well defined and clear pathways through diagnostic and support services have been delineated. It is also recognised that a full assessment often requires a collaborative effort between several different health professionals especially at the primary and community care level. In this context, it is recommended that a dementia team, consisting of a nurse, an occupational therapist and other qualified staff, work together with the GP in charge of the investigation to undertake the assessment.

Interestingly, in terms of timely diagnosis, whilst the English and French Dementia Plans seem to place a great emphasis on the proliferation of MCs, in Norway the expansion of community based dementia care teams seems to be at the fore. As a result of the Norwegian dementia plan, these dementia teams are now established in almost half (47%) of municipalities in Norway (Engedal, 2012). Professionals on the dementia team observe and assess the person at home in order to review cognitive and functional skills. The information collected is then reported to the GP, who carefully considers the case and uses the information provided to decide what further

24 See www.aldringoghelse.no

investigations are needed. Although dementia teams are responsible for undertaking these home-based assessments and reporting outcomes to the GP, teams never make a diagnosis. Indeed there is anecdotal evidence that some GPs are reluctant to consider these assessment reports and when this happens the diagnostic process takes longer.

Fagnett DEMENTIA²⁵ provides information about the Dementia plan 2015, its priority areas and includes information on community based Dementia Teams. This website also disseminates experiences from projects that have been implemented or those currently being developed within the Dementia Plan priority areas. Fagnett Dementia is intended to be a support for professionals and planners working in the area of developing supports for people with dementia and their relatives. Interestingly, the Norwegian Directorate funds the portal for Health as part of the Dementia plan 2015. The National Centre of excellence for aging and health is responsible for its professional content. The portal information can be read online or downloaded for use in professional's own work. Discussion forums have been established on the various theme areas where professionals can discuss and exchange experiences.

The use of appropriate assessment tools also appears to be an important priority in Norway in terms of the accurate and reliable assessment and diagnosis of dementia. In this context, The Norwegian National Centre of Excellence for Research, Education and Service Development (Aldring og Helse) was commissioned to develop dementia assessment tools and separate tools have been designed for community-based, allied health professionals and

for GPs in primary care. Aldring og Helse, which has produced the tools also have responsibility for training GPs to use the diagnostic tools and for designing courses on dementia diagnosis for GPs. As part of the training, diagnostic manuals have been devised and a video focusing on the topic of the assessment process has been developed.²⁶

Unlike the other Strategies reviewed here, in Norway, the Dementia Plan also places an emphasis on the diagnosis of persons with dementia resident in nursing homes and on increasing doctors' role in nursing homes. To this end, assessment tools have been developed for allied health professionals and doctors working in nursing homes.²⁷ Common across each of these assessment tools is the need for training to enable health service professionals to administer the tools. The up-skilling in dementia of both the public and professionals was also a key commitment in the Dementia Plan 2015.

3.6 Australia

In 2005, the Commonwealth Government of Australia announced a four year funding programme for its Dementia Initiative titled: Making Dementia a National Health Priority (2005-2010) (Department of Health and Ageing, 2005), which broadly speaking aimed at supporting people with dementia and their carers at home. A year later, i.e. in 2006, the National Framework for Action on Dementia 2006–2010 (NFAD) was launched. This Action plan agreed to by Health Ministers identified five priority areas for action namely (i) care and support services, (ii)

25 Fagnett DEMENTIA (roughly translated as Dementia Priority Areas online)

26 This video is now available online at www.aldringoghelse.no

27 Green sheets are to assess people at home (for GPs (leger) and for community teams) The red tool is for assessing residents in nursing home care.

access and equity, (iii) information and education, (iv) research, and (v) workforce and training strategies. Despite the Dementia Initiative and the National Framework for it, it was argued that in Australia action on diagnosis remained limited (Skladzien, Bowditch and Rees, 2011). Accordingly, the real challenge of diagnosing dementia only became a priority in Australia more recently in 2012 when an inquiry on Dementia: early diagnosis and intervention was announced by the Australian Government (DoHA 2012).

Under the terms of reference of this inquiry, the House of Representatives Standing Committee on Health and Ageing (HRSCHA) focused on the topic of how early diagnosis and intervention might: (i) improve quality of life and assist people with dementia to remain independent for as long as possible; (ii) increase opportunities for continued social engagement and community participation for people with dementia; and (iii) help people with dementia and their carers to plan for their futures, including organising financial and legal affairs and preparing for longer-term or more intensive care requirements (AIHW, 2012). The inquiry, which called for written submissions and conducted public hearings, published a report in June 2013.

In Australia today, dementia can be diagnosed in different medical and community care settings: by medical professionals or nurse specialists in a primary care; by a Specialist, such as a Neurologist, Geriatrician, Gerontologist, Psychogeriatrician, Psychiatrist, or Neuropsychologist in hospital services, or through multi-disciplinary team services such as an Aged Care Assessment Team (ACAT) or at a MC where in Australia there were circa 30 at the end of

2012 (Cahill, Pierce and Moore, in press). However, in the inquiry report, much emphasis was placed on the role primary care professionals have in the diagnosis of dementia, as the latter had heretofore received limited attention. The inquiry was informed that GPs had an important role in recognising, assessing and diagnosing dementia, but also heard that there were many barriers preventing GPs from making a timely diagnosis including system level barriers, attitudes of GPs and knowledge and skills of GPs.

After considering the evidence for the inquiry, the Committee recommended that a national evidence-based dementia-training program for GPs should be developed, with an emphasis on diagnosis. Training would include the following elements:

- Challenging stigma and misconceptions;
- Managing sensitive and difficult conversations in the context of the doctor-patient/carer relationships;
- Current best-practice and implications of latest research; and
- Diagnosis, care and support pathways for people with dementia, their families and/carers.

The inquiry also recommended the development of a training and support programme to increase the capacity of specialist nurses employed on multi-disciplinary teams to assess and diagnose dementia in primary care settings. The inquiry reported that while GPs can be equipped to make a diagnosis, in more complex cases they may require, specialist advice before a diagnosis could be made. Examples include when a person is young, or presents with early stages of the illness.

4. Guidelines for Dementia Diagnosis and Management

Several of the countries discussed in this paper, have also developed national guidelines for the diagnosis of dementia and for integrated care pathways for people with dementia. In England, the NICE guidelines first published in 2006 and revised in 2011 are extremely comprehensive and provide detailed advice about both the diagnosis of dementia, the diagnosis of sub-types, who should be referred to Memory Assessment services and who should prescribe anti-dementia drugs. The guidelines also stipulate that people assessed for possible dementia should be asked if they wish to know their diagnosis and with whom they wish this information to be shared. The NICE guidelines also emphasise the need for physicians when diagnosing to be conscious of other co-morbidities and review all patient medication. They recommend that patients be reviewed on a regular basis, probably every six months and that Memory Assessment Services should be the single point of referral for all those with a possible diagnosis of dementia

In the Netherlands, a guideline providing advice on diagnostics for GPs was first published by the Dutch College of General Practitioners (NHS Standard) in 2012. While the practice guideline for GPs is seen to strengthen their role in diagnosis, it has been criticised for discouraging GPs from prescribing anti-cholinesterase inhibitors and Memantine and for failing to address collaboration between primary care and secondary care, which it is argued would promote more effective and efficient dementia diagnosis (Olde Rikkert, Lemstra and Verhey, 2013). Another guideline for specialists specifying the tests required to diagnose dementia has also been developed and a new guideline for specialists is expected to be published by the end of 2013. It is reported that in the Netherlands, although

good awareness of these guidelines by GPs exists, they are not always followed. Curiously, in the Netherlands, there is also a national dementia care standard, which covers all professional guidelines and attempts to moderate these by addressing inconsistencies between different guidelines. Alzheimer Nederland has developed the national care standard, which was completed in May 2012. The care standard guides health insurance companies to contract regional dementia care.

The New Zealand Guidelines first produced in 1997, have undergone a second iteration and since 2003, are available online (Ministry of Health New Zealand 1997). They provide useful information for practitioners who may be unsure what to do with complicated cases of dementia. These guidelines assist GPs to decide which patients should be referred to which services - rehabilitation, mental health or aged care services. Canada's consensus guidelines were first produced in 1999 (Chertkow, 2008) and several US guidelines on dementia have been published including the US Preventive Services Task Force.

The Australian guidelines for primary care - Care of People with Dementia in General Practice Guidelines (Royal Australian College of General Practitioners 2006), which are currently under review, are prescriptive and encourage GPs to engage in case finding and not screening. These same guidelines highlight GPs role in driving assessment, medication compliance, legal capacity and other legal matters including advanced directives and enduring powers of attorney. They reinforce the view that the detection and diagnosis of dementia is a lengthy process that usually involves third parties, including family caregiver, the specialist and the individual.

5. Summary

This paper has reported on policies and practices currently in place to assess and diagnose dementia in Ireland and in a select number of other countries around the world. In the earlier part, evidence was provided as to why timely diagnosis is considered beneficial, yet why this is not always achievable. It was shown that, amongst other reasons, the ambiguity in signs and symptoms of dementia results in uncertainty and allows for a wide variety of diagnostic possibilities, which normally takes time and involves third parties.

It was also argued that timely diagnosis can be facilitated or hindered by a whole range of different factors, some individual and others systemic, including lack of diagnostic competencies, stigma and patients' own attitudes and beliefs and inadequate health care systems. The issue of disclosure practices was also discussed and some recent evidence presented on most peoples' own preferences for news of dementia to be conveyed to them in a person-centered way generally over a staggered period of time. It was argued that diagnosis and disclosure should be conveyed in a compassionate, respectful way, with news of the illness being communicated over a protracted period thereby allowing people experiencing the symptoms, along with their family members, time to take on board this important information.

Regarding the issue of which health service professional or member of the medical profession has main responsibility for diagnosing and disclosing dementia, this review has pointed to differences and ambiguities arising internationally regarding the respective roles of (i) general GPs versus specialist GPs, (those with a special interest in dementia) and

between (ii) Medical Specialists such as Neurologists, Geriatricians, and Old Age Psychiatrists and Nurse Practitioners. In France and the Netherlands, it was shown that Neurologists appear to take the lead role in MCs; whilst in England and Ireland, MCs are largely led by Old Age Psychiatrists and Geriatricians, and in Australia, several Memory Clinics are today nurse-led. The review suggests that in the absence of GP specialism, accurate sub-typing of dementia, probably requires enhanced interdisciplinary collaboration and partnerships to be developed between GPs and specialists and between community and hospital-based services including MCs (Iliffe et al., 2009; NICE/SCIE, 2006).

Efforts have also been made in this review to identify from across Europe, models of best practice in relation to dementia diagnosis, disclosure and support, where integrated care pathways are clearly in evidence. The only country reviewed in this paper, which in our view reflects extremely logical pathways of referral to diagnosis (including differential diagnosis and sub-typing) is Norway. Accordingly, whilst most Norwegian GPs are trained to diagnose straightforward cases of dementia; the more atypical cases are referred by them to specialists at MCs and later referred back to community dementia teams. At a macro level, timely diagnosis and support seems to be promoted and facilitated in Norway by a well developed health and social care system. At a micro level, it is promoted, by a series of tools and procedures designed by experts and tailored to the needs of individual health service professionals. The overall approach to assessment and diagnosis is underpinned by specialist training available to all health service professionals and by excellent information systems including a dementia-specific

web-site developed to keep health service professionals up-to-date on latest thinking. However even within such logical systems, the type of tensions described in the literature (Iliffe et al, 2009) leading to barriers in relation to interdisciplinary collaboration have also been witnessed in Norway.

“Whilst community mental health teams are in evidence in some parts of the country, Ireland has no community based dementia teams, unlike several of the countries reviewed in this paper”

Finally, it has been argued that for a variety of reasons, Ireland differs significantly from the other countries reviewed in this paper regarding dementia assessment and diagnostic services. First, the country has no Dementia Strategy, although one is promised in the near future. Second, there are no dementia-specific guidelines for GPs²⁸ and for Specialists including MC staff and good quality local and national data on dementia diagnosis is seriously lacking. Thirdly, there is no national register of people diagnosed annually with dementia in primary care (an ironic finding given that more than 80% of GPs use electronic patient records (Darker et al, 2011) and good IT infrastructure exists in primary care). Nor is there reliable data available from all MCs on numbers of people annually diagnosed (Cahill, Pierce and Moore, in press). Whilst community mental health teams are

in evidence in some parts of the country, Ireland has no community based dementia teams, unlike several of the countries reviewed in this paper. Finally there is no political leadership of dementia in Ireland, unlike the UK where national targets to address the illness have been established by David Cameron and unlike in France where former President Nicolas Sarkozy has championed the disease, and where the current President, Francois Hollande now supports the launch of a fourth French Alzheimer Plan. Overall our review leads us to conclude that the baseline profile of assessment, diagnosis and the support for people with dementia in Ireland is low; there is still much stigma, negativity and nihilism in evidence and the illness fails to receive the political and budgetary attention it deserves.

28 Guidelines for GPs, currently being completed by Dr Tony Foley and Dr Greg Swanick, are expected in January 2014.

6. Actions for Consideration

Based on this review of the research evidence and the experience of other jurisdictions, the following suggestions are being put forward as areas for immediate action in relation to education and training and for the timely diagnosis and support of people with dementia:

- The importance of the role of GPs was highlighted in the paper, along with the need for specialist training and support for GPs in diagnosing dementia. This points to the need for a range of training modules for medical education in dementia diagnosis and disclosure at undergraduate and post-graduate level and in addition, the availability of evidence-based guidelines for dementia diagnosis and disclosure in primary and secondary care services. The issue of how best GPs might be incentivized to diagnose dementia is worth further, detailed exploration.
- Learning from the experience in other jurisdictions, the ways in which capacity for assessing and diagnosing dementia could be expanded include training nurses on primary care teams in dementia assessment and case finding; encouraging primary care services to collaborate and forge partnerships with GPs who have a specialism in dementia; examining the remit of some community mental health teams (CMHTs) to explore ways in which the functions of the Community Dementia Teams in Norway could be carried out. This might include providing the necessary training to CMHTs to have the skills for pre-assessment work-up and post diagnostic support.
- Clarity around a diagnostic pathway would be particularly helpful. The collective experience from other jurisdictions suggests a system where diagnosis takes place primarily in primary care, with support from local specialists where necessary and the availability of tertiary-level specialist advice and support for a small number of cases. Effective working will require enhanced interdisciplinary collaboration and partnerships between GPs and specialists and between community and hospital-based assessment and diagnostic services including Memory Clinics. Diagnostic pathways should be designed to ensure clear access for people with early-onset dementia and others who might require additional specialisms for diagnosis.
- This review also points to the need to increase awareness of dementia and reduce stigma among the wider public and health and social care professionals. The development of educational and information resources such as dementia-specific websites for health professionals may be helpful in this regard.

7. Conclusion

In conclusion, the burgeoning numbers of people presenting with dementia in Ireland in the foreseeable future means that action is needed now to plan responsive assessment diagnostic and post-diagnostic services. We can learn from the experiences of other countries now further advanced in their planning and experience of organizing assessment and diagnostic services. This paper has argued that immediate challenges, which must now be addressed, include, timely diagnosis, sensitive communication of the diagnosis to the individual and family and mobilization of interventions and services to support the person to live well with dementia and enjoy a

good quality of life. As other experts have shown (Iliffe et al, 2009), this will require systemic change and the reconfiguration of primary care services, closer collaboration between primary and specialist care services and the development of systematic referral and care pathways. Ultimately, the goal will be to ensure that specialist assessment and accurate diagnosis including differential diagnosis is readily and rapidly available to all (irrespective of age) and that appropriate interventions (pharmacological and non-pharmacological), care and support are provided according to individual needs.



References

1. Adams, W.L., McIlvain, H.E., Geske, J.A. and Porter, J.L. (2005) 'Physicians perspectives on caring for cognitively impaired elders', *Gerontologist*, 45(2), 231-9.
2. ADI (2011) World Alzheimer Report 2011: The Benefits of Early Diagnosis and Intervention. Alzheimer's Disease International, London, [Accessed 29 Nov 2013 from <http://www.alz.co.uk/research/WorldAlzheimerReport2011.pdf>
3. ADI (2012) National Alzheimer and Dementia Plans Planned Policies and Activities: Early Detection, Access to Diagnosis, and Stigma Reduction, ADI, London.
4. Alzheimer Europe (2009) 'Number of people with dementia in Europe higher than previously thought', Alzheimer Europe Press Release, 13 July, 2009.
5. Alzheimer's Society (2012a) Dementia 2012: A National Challenge. Alzheimer's Society, London [Accessed 29 Nov 2013 from http://alzheimers.org.uk/site/scripts/download_info.php?downloadID=821]
6. Alzheimer's Society (2012b) Unlocking Diagnosis: All-party Parliamentary Group Report. Alzheimer's Society, London. Accessed 29 November 2013 from http://www.alzheimers.org.uk/site/scripts/download_info.php?fileID=1457
7. Alzheimer's Society (2013) Helping You to Assess Cognition: A Practical Toolkit for Clinicians, Alzheimer's Society, London [http://www.alzheimers.org.uk/site/scripts/download_info.php?fileID=1661; Accessed 29 November 2013].
8. American Psychiatric Association (2004) Diagnostic and Statistical Manual of Mental Disorders Fourth Edition (DSM-IV), American Psychiatric Publishing, Arlington, VA.
9. Australian Institute of Health and Welfare (2012) Dementia in Australia, Cat. No. AGE 70, AIHW, Canberra.
10. Bamford, C., Lamont, S., Eccles M. et al. (2004) 'Disclosing a diagnosis of dementia: A systematic review', *International Journal of Geriatric Psychiatry*, 19(2), 151-169.
11. Bamford, C, Eccles, M., Steen, N. and Robinson, L. (2007) 'Can primary care record review facilitate earlier diagnosis of dementia? *Fam Practice* 24: 108-116.
12. Bamford, S. (2010) A Problem Shared is a Problem Halved? Dementia: Learning
13. Opportunities from Europe - A Policy Brief, The International Longevity Centre, London.

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