

**Policy Paper on the Case for the Inclusion of Dementia in
Chronic Disease Management Programmes in Ireland**

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Contents

Acknowledgements.....	i
Executive Summary.....	ii
Abbreviations.....	vi
Chapter 1 Introduction	1
Chapter 2 Dementia as a chronic disease.....	4
2.1 Chronic diseases.....	4
2.2 Dementia as a chronic disease.....	4
2.2 Impact of dementia.....	5
2.3 Modifiable risks factors for dementia.....	6
2.4 Dementia as a comorbid condition.....	6
2.5 Summary	7
Chapter 3 Methodology.....	9
3.1 Introduction.....	9
3.2 Literature Review	9
3.3 Stakeholder Interviews	9
3.4 Conceptual framework.....	11
3.5 Interrogation of new GP Contract using a Dementia Lens	11
3.6 Strengths and limitations	12
3.7 Summary	12
Chapter 4 Review of Irish Policy	13
4.1 Tackling chronic disease, a policy framework for the management of chronic disease	13
4.2 HSE Transformation Programme Chronic Illness Framework.....	16
4.3 Healthy Ireland (2013-2025)	16
4.4 Irish National Dementia Strategy.....	17
4.5 Sláintecare.....	19
4.6 Positioning of dementia	21
4.7 HSE re-structuring	24
4.8 Summary	25
Chapter 5 Chronic disease management models.....	27
5.1 Conceptualising chronic disease management.....	27
5.2 Chronic disease management models	28
5.3 Cost-effectiveness of CDM interventions	33
5.4 Summary	34
Chapter 6 The Chronic Disease Management Programme for GPs	36
6.1 Dementia and the new GP Contract	36
6.2 Opportunistic Case Finding Programme	37

6.3	An Annual Preventive Programme.....	40
6.4	Structured Treatment Programme	42
6.5	Summary	44
Chapter 7	Stakeholders' views on Chronic Disease Management Models and Dementia	45
7.1	Dementia as a chronic disease.....	45
7.2	Barriers and enablers to having dementia included in CDM programmes	46
7.3	CDMP for GPs vis-à-vis other programmes.....	47
7.4	Positioning of dementia in the Department of Health and the HSE.....	48
7.5	Expected Benefits and Potential Risks of including Dementia in CDMPs	49
7.6	Costs	53
7.7	Summary	53
Chapter 8	A Synthesis of Findings.....	55
Chapter 9	Conclusions	61
References	68
Appendix I:	Chronic Care Model Components	75

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Executive Summary

About 65,000 people in Ireland are estimated to have dementia. Although conventionally viewed as a cognitive brain disorder, dementia can be framed as a chronic disease, since it is irreversible and progressive, non-communicable, has a long duration and cannot be cured. This more contemporary framing offers an opportunity for individuals and their family members affected by the condition and augurs hope for governments, communities and society, since it turns the spotlight on risk reduction and on primary, secondary and tertiary prevention. In so doing it suggests ways of reducing the very significant economic, social and emotional costs that dementia poses.

In July 2019 a new Irish GP contract with a significant chronic disease management programme component (CDMP for GPs) was agreed by the Department of Health, the Irish Medical Organisation (IMO) and the Health Service Executive (HSE). The inclusion of dementia in the new bundle of chronic diseases identified for GPs was seen as a potentially useful mechanism for bringing dedicated attention to dementia in primary care. However, when the new contract was finally announced, dementia was not included. For some, this came as a surprise, since there had been an explicit commitment to progressing the inclusion of dementia in the CDMP for GPs in the mid-term review of the Irish National Dementia Strategy.

This policy paper was commissioned by the Alzheimer Society of Ireland (ASI) to investigate the feasibility of including dementia in a revised CDMP for GPs in the future. It set out to explore what it would mean for a range of key stakeholders, if dementia were to be categorised as a chronic disease. What are the likely benefits and risks for the person, family caregivers and GPs and what are the potential barriers and facilitators to having dementia included in a revised GP contract? How might this framing of dementia build on and inform policy developments currently underway through the National Dementia Office to implement the Irish National Dementia strategy?

This work included a literature review, examining Irish policy documents relevant to this brief and a review of the international literature reporting on best practice models in chronic disease management, their effectiveness and cost effectiveness and their application to dementia care. The Irish National Dementia Strategy was interrogated using a chronic disease management lens. The new GP contract was interrogated using a dementia lens and the technical aspects of including dementia in a revised CDMP for GPs were carefully considered. Governance systems and structures in place in the HSE and in the Department of Health were examined with reference to where dementia currently sits. Finally, our fieldwork involved conducting face-to-face in-depth interviews with a range of stakeholders, including people with dementia, family caregivers, clinicians including a GP, old age psychiatrist and geriatrician, a health economist and senior representatives from the Department of Health, the HSE and a NGO.

The literature review revealed that for the last decade there has been a strong and solid commitment on the part of the Irish government to use chronic disease management approaches in the development and delivery of health care services. This commitment has more recently been consolidated in the Sláintecare report that acknowledges the impact that chronic diseases have and will continue to have on an already over-burdened health

care system. Sláintecare recommends an integrated care model that reflects a shift away from a hospital-centric model of health care, to one that focuses on prevention and self-care and on primary and community care. Recommendations from Sláintecare have likely significantly influenced the more recent re-structuring of HSE clinical programmes, chronic disease management programmes and integrated care programmes all of which incorporate dementia.

We have demonstrated that the Irish National Dementia Strategy although underpinned by principles of personhood and citizenship is also guided by chronic disease management principles and that many of the building blocks for framing dementia as a chronic disease are evident in this policy document. These include primary prevention, information systems and multi-disciplinary teams. Including dementia in the CDMP for GPs could quite easily build on the on-going work being undertaken by the National Dementia Office and could strengthen earlier HSE and Irish based dementia in primary care work, such as the PREPARED project.

Regarding the three main components of the new CDMP for GPs - namely: (i) *opportunistic case finding*; (ii) *annual preventive programme*; and (iii) *structured treatment programme* - we have identified the technical recalibrations that would be required in order for dementia to fit into the requirement of the CDMP for GPs. The literature review demonstrated that there is an absence of evidence available to recommend *opportunistic case finding* by GPs for identifying people with undiagnosed dementia. However, a tool already available in Ireland would enable GPs identify people with dementia for enrolment on the *structured treatment programme*. Regarding the *structured treatment programme*, its core values align well with those of the Irish National Dementia Strategy and the inclusion of dementia in this programme would be welcomed by people living with dementia and their caregivers. However, the self-management component of this programme could pose difficulties for all key stakeholders and the programme's rigidity with planned visits scheduled at specific times might prove problematic for people living with dementia. Regarding the *annual preventive programme*, given that most of the risk factors for cardiovascular disease and diabetes are those that also place people at risk of dementia, and that it would be feasible to extend the programme to include some additional modifiable risk factors for dementia, there is a compelling case to support a focus on dementia risk reduction in primary care the future. That said, certain barriers would first need to be overcome.

In making a case for the inclusion of dementia in CDMP for GPs, we examined practices in other jurisdictions where CDM models are being implemented. In this context, collaborative dementia care models used in primary care and delivered in a range of overseas countries offer useful insights. In particular we have reviewed three well known models: (i) the Wagner Chronic Care Model (CCM); (ii) collaborative dementia care models; and (iii) the CCM for neurological conditions including dementia. We have concluded that there are elements from all three of these models that have broad application for dementia care in general practice in Ireland. In particular the collaborative dementia care models described by Heintz et al (2019) where a dementia care manager acts as a conduit between primary care, old age psychiatry, behavioural neurology, nursing and social work, has resonance for the future direction of dementia care services in Ireland. In this model, the training and support offered to the dementia care manager means that the GPs' time can be spent more

efficiently on treatment and care, while the care management aspects of dementia can be undertaken by a trusted third party.

The in-depth interviews reveal that while the majority of stakeholders believe that dementia can be viewed as a chronic disease, no consensus was found on whether or not dementia should be framed in this way; there are merits and demerits associated with such a conceptualisation. Stakeholder opinion was also divided about whether or not dementia should have been included in the bundle of chronic diseases identified for the GP contract. Nor was any consensus found regarding the extent to which dementia should be a named condition included in HSE integrated care programmes. There was no shared understanding of these programmes with some stakeholders being highly critical of same.

Many benefits along with risks were identified by the stakeholders, if dementia were to be included in a revised GP contract. Potential benefits identified by most and common across all three groups of stakeholders was the likelihood that this approach would lead to integrated care pathways. Other benefits for the individual included better access to GPs, better record-keeping and a greater emphasis on secondary prevention. Expected risks identified by many included the excessive cost of using this approach, caregiver burden and for GPs an increased workload with the prospects of sub-optimal care being delivered due to lack of specialist training in the area.

An examination of the cost-effectiveness of using a CDM approach in dementia care showed that the evidence is mixed and not compelling. For example, while one recent narrative review showed that enrolment in collaborative dementia care models was associated with less frequent use of acute medical services, the overall findings from this same study were inconclusive. Only one of the seven models described in this review showed overall savings. Another programme reviewed proved to be cost-neutral for Medicare when programme costs were considered. Evidence from an EU commissioned report investigating the impact of integrated care programmes for chronic disease was equivocal. What is clear from the experience of implementing the CCM in other countries is that redesigning the CDMP for GPs to include dementia will require investment in the short term, and it is harder to determine if there will be cost savings in the longer term.

Although the evidence base for the cost-effectiveness of CDMPs in the context of dementia care is weak, we can categorically argue that in Ireland dementia care needs more resourcing and more political attention. This is the resounding message from a wealth of economic studies on dementia care conducted in Ireland over the past ten years. Prevalence is increasing, family members, on whom the main bulk of caring falls, may in the future no longer be willing or available to care, and people with dementia and their family carers are likely to demand better quality services. In addition, philanthropic funding in Ireland has ended, and it is unrealistic to rely on Dormant Accounts grants and fund-raising campaigns to support what for some constitute basic health and social care services. Finally in identifying future directions for the development and expansion of dementia services, we must remain cognisant of the fact that recommendations for the inclusion of dementia in the CDMP for GPs will have very profound implications for priority-setting and resource allocation in other areas of dementia care.

Overall, this report has shown that making a case for the inclusion of dementia in a revised GP contract is not a straightforward exercise. We would argue that if progress is to be made, a more nuanced approach needs to be adopted. Although dementia is a chronic disease it is not a hard hitting one like stroke, coronary heart disease or diabetes where larger groups of people belonging to different age cohorts are potentially affected. We recommend that the ASI organise a forum to communicate the findings of this policy paper to people with dementia and their family carers. Further recommendations could then be developed based on their feedback and deliberations. Similarly, the findings need to be shared with GPs. We also recommend that a roundtable meeting takes place that brings together senior health and social care officials and other key stakeholders in the field of dementia care. The purpose of this meeting would be to further discuss and progress these findings.

Abbreviations

A&E	Accident and Emergency
ASI	Alzheimer Society of Ireland
CCM	Chronic Care Model
CCM-NC	Chronic Care Model for Neurological Conditions
CDM	Chronic disease management
CDMP	Chronic Disease Management Programme
CHO	Community Healthcare Organisation
CME	Continuing Medical Education
COPD	Chronic Obstructive Pulmonary Disorder
CSPD	Clinical Strategy and Programmes Division
DOH	Department of Health
GMS	General Medical Services
GP	General practitioner
GPVC	General Practice Visit Card
HSE	Health Service Executive
ICGP	Irish Congress of General Practitioners
ICIC	Improving Chronic Illness Care
ICP	Integrated Care Programme
ICPCD	Integrated Care Programme for Chronic Disease
ICPOP	Integrated Care Programme for Older People
IMO	Irish Medical Organisation
In-MINDD	Innovative Mid-life Intervention for Dementia Deterrence
MCI	Mild Cognitive Impairment
NCAGL	National Clinical Advisor and Group Lead
NCPOP	National Clinical Programme for Older People
NICE	National Institute for Health and Care Excellence
NDO	National Dementia Office
NDS	National Dementia Strategy
OCCO	Office of the Chief Clinical Officer
PREPARED	Primary Care Education, Pathways and Research of Dementia
STP	Structured Treatment Programme
TILDA	The Irish Longitudinal Study on Ageing
UK	United Kingdom
US	United States
WHO	World Health Organization

Chapter 1 Introduction

This policy paper was commissioned by the Alzheimer Society of Ireland (ASI) in November 2019 to explore the case for including dementia in the new chronic disease management programme (CDMP) for GPs. The introduction of the CDMP for GPs follows an agreement reached in July 2019 between the Department of Health, the Health Service Executive (HSE) and the Irish Medical Organisation (IMO) on the programme, as part of the new GP contract.

The broad aim of the paper is to explore the feasibility of including dementia in the CDMP for GPs, which currently caters for medical card holders and GP visit card holders. More specifically, the paper aims to describe what it would mean for individuals and their family members affected by dementia, as well as for GPs, to have the condition categorised as a chronic disease. The paper also aims to identify the technical aspects required for the inclusion of dementia in a CDM framework and how the inclusion of dementia as a chronic disease would inform and build on developments currently underway through the National Dementia Strategy (NDS). Given the clear direction provided by the ASI for this policy brief and the time constraints set down, three different methods were used to develop this paper (see Chapter 3). First, a literature review was conducted that aimed to examine relevant policy documents and models of best practice in CDM. Second, in-depth interviews were undertaken with a diverse range of stakeholders and, third, a review was conducted of the new GP contract as it pertains to chronic disease management.

The broad context to the ASI's call for this policy paper is the evidence that people living with dementia in Ireland and their family members continue to have significant unmet needs (Rochford Brennan, 2019; ASI, 2019; Fox et al, 2020), despite the substantive and transformative work that has recently taken place through the National Dementia Office (NDO) to implement the NDS (O'Shea et al, 2017, Pierce et al, 2019, Fox et al, 2020). Like in other countries, in Ireland, GPs are the first point of contact for people worried about their memory or cognitive problems and, like in other countries, government policy in Ireland decrees that GPs play a pivotal role in dementia assessment and diagnosis (DOH, 2014). At a primary care level, good dementia care takes time (Iliffe et al., 2009) but it has been noted that GPs in Ireland are not always able to devote the time required to be proactive in dementia assessment, diagnosis and support (Cahill et al., 2006; ASI, 2019). A recurrent challenge in dementia care is often the absence of physician-led, post-diagnostic follow-up (Begley, 2009, Diaz-Ponce, 2013). Categorising dementia as a chronic disease has the potential to improve access to and quality of GP care for people with dementia and their family members (ASI, 2019).

The more immediate context behind the ASI's call for this policy paper is the commitment set down in the Mid-term Review of the NDS. In the review it was stated that the NDO will: 'progress the inclusion of dementia into the CDM framework, thereby resourcing GPs to provide proactive evidence-based care ...' (DOH, 2018, 29). The commitment at the time to have dementia included in the new GP contract is not surprising given that the NDS states very explicitly that CDM principles should guide dementia policy, service delivery and development (DOH, 2014). Although we are aware that some attempt was made, through a written submission to the Department of Health, to marshal a case for the inclusion of dementia in the new GP contract, when the new agreement was finally launched in 2019,

dementia was not included. We do not know the reasons for its exclusion and can only hazard some guesses. There was also a commitment in the NDS's Mid-term Review to develop a clinical programme in dementia care and to integrate dementia into both the clinical care programme for older people and the Integrated Care Programme for Older People (ICPOP) (DOH, 2018).

To contextualise this policy paper, we have reviewed some key Irish policy frameworks and documents that have shaped and informed the development of CDM, dementia care and integrated care programmes within the health and social care system. It has also been necessary to gain a better understanding of the positioning of dementia within the HSE, and within innovative models of care particularly the integrated care programmes. We have also found it important to understand the restructuring that has taken place within the HSE including that occurring as a result of recommendations arising from the review of national clinical programmes. These are covered in Chapter 4.

To develop this policy paper, it has also been necessary to review the diverse range of CDM models that exist in order to identify an evidence base that demonstrates their effectiveness and cost-effectiveness. We have focused on the most widely known model, the Chronic Care Model (CCM). It forms the basis for many other CDM models and has been used to inform the development of CDM models for dementia care and neurological conditions more broadly. These are reviewed in Chapter 5.

This policy paper provides an opportunity to look at the new GP contract, and particularly its CDMP for GPs aspect in detail and examine it through a dementia lens. In Chapter 6, the CDMP for GPs and each of its three core components is described, then reviewed from the point of view of these components being revised/extended to incorporate dementia. Both the factors facilitating the inclusion of dementia in this programme (enablers) and those impeding its inclusion (barriers) are also identified.

Critically important too for us is that the voice of key stakeholders including people living with dementia, health service practitioners and policy makers is elicited and heard and their views on CDM and dementia are reported in Chapter 7.

The call for this exploratory piece of work has occurred at a critical juncture in the evolution of public policy on dementia in Ireland. It is now almost six years since the NDS was first launched. Much has happened for the better in Ireland on the dementia care landscape during this time (O'Shea et al., 2017). Advances have occurred in clinical and non-clinical research, in practice and service development and in community awareness and understanding of a condition that in the past was seldom talked about and rarely diagnosed. Many of these advances were long overdue as the baseline profile of dementia services in Ireland was very low.

Each of the six core prioritised areas of the NDS are relevant to this paper, but arguably the most salient one relates to 'timely diagnosis and intervention'. Within this prioritised area, a commitment was made to ensure that people will receive a timely diagnosis of dementia and its sub-type: that GPs would be supported to diagnose and provide information on brain health and on dementia and that people with dementia would know where to seek support

and access services or entitlements following a diagnosis. The PREPARED project,¹ which focused on this prioritised area, competently delivered on its agreement to: (i) train and educate GPs and primary care staff in dementia; (ii) to develop local dementia care pathways; and (iii) to develop tools and resources to support clinical decision-making (Pierce, 2019). This policy paper allows us to examine how the CDMP for GPs could potentially build on and incorporate various elements of the PREPARED project. The paper also provides an opportunity to examine the relevance of each of the NDS's other priority areas for CDM and for the CDMP for GPs, as well as a number of high-level projects led by the NDO that are currently underway. These include a diagnostic framework project, a dementia disclosure framework project, a post-diagnostic framework project and an acute hospital integrated care project.

The new CDMP for GPs is to be phased in over a protracted period. Although it does not currently include dementia, there is scope for its revision in the future. How might the inclusion of dementia in a future bundle of chronic diseases work for GPs, for the individual living with the condition and for family caregivers? What are the potential risks and expected benefits for stakeholders by having dementia framed as a chronic disease and included in a revised CDMP for GPs and what is needed to enable this to happen? How might the inclusion of dementia in a new bundle of chronic diseases build on and complement the work programmes now well underway through the NDO to implement the NDS? This paper aims to address these along with other pertinent questions relating to reframing dementia as a chronic disease.

¹ The PREPARED project was a national dementia research and education initiative aimed at developing, delivering and evaluating training and education interventions for GPs and other primary care professionals. It was funded by the HSE and The Atlantic Philanthropies over a three-year period, as part of the implementation of the Irish National Dementia Strategy.

Chapter 2 Dementia as a chronic disease

This chapter discusses the meaning of *chronic diseases*, reviews the criteria often used internationally to identify illnesses as chronic diseases and puts forward an argument as to why dementia can be considered as a chronic disease. In the chapter, we also highlight the impact dementia has, as a chronic disease, on the individual and on society and we compare and contrast this impact with other chronic diseases. The chapter also critically reviews dementia as a comorbid condition.

2.1 Chronic diseases

The term chronic disease is commonly used by health professionals, policymakers and academics, but there is much variation in the use of the term (Bernell and Howard, 2016). The Improving Chronic Illness Care (ICIC) Programme, a US national programme that aims to improve the health of people with chronic illness, by helping large numbers of health care systems, defines chronic disease as: 'any condition that requires ongoing adjustments by the affected person and interactions with the health care system'. The World Health Organization (WHO) uses the following definition: chronic diseases are 'not passed from person to person. They are of long duration and generally slow progression' (WHO, 2016). More expansive definitions include other features, some of which are included in the Department of Health's definition:

Chronic diseases are long-term conditions, lasting more than 6 months, are non-communicable and involve some functional impairment or disability and are usually incurable (DOHC, 2008).

Chronic diseases have a serious impact on the day-to-day lives of people living with the condition (Bährer-Kohler and Krebs-Roubicek, 2009) and lifestyle factors can play a significant role in their aetiology (NCHS, 2013). Chronic diseases are often preventable and are caused in part by a variety of risk factors. If one or more of these risk factors can be modified, then many of the symptoms and challenges associated with chronic disease (morbidity) and early death (mortality) can be avoided or prevented (Schmidt, 2016). However, focusing only on the individual is insufficient when identifying policies to prevent chronic disease. Large populations need to be targeted with a strong public health message conveyed to all, that lifestyle factors matter and that good health in later life is rooted in physical and mental health from early in life, so that every stage of the life cycle matters (Wu et al., 2015).

2.2 Dementia as a chronic disease

Historically, definitions of chronic disease included the main chronic conditions such as cardiovascular diseases (heart attacks and stroke), diabetes, asthma and chronic obstructive pulmonary disease (COPD) and these definitions tended not to include dementia (O'Neill, 2011). While chronic disease is usually discussed in relation to these four main conditions, it would be hard to deny that dementia is a 'chronic disease', as the key characteristics that delineate chronic diseases are certainly present in dementia (Fillit et al., 1999). For example, dementia is irreversible; it has a long duration, it is generally slowly progressive and is not amenable to a curative treatment. Dementia is a degenerative condition and lifestyle factors can play a significant role in the development of the condition. There are many

different ways of framing dementia, from it being seen largely as a cognitive brain disorder to nowadays it being framed as a disability and human rights issue (Cahill, 2018). However, the chronic disease or public health framing of dementia is relatively new and although definitions have expanded to include cancer as a chronic disease, dementia still lags behind in this classification (O'Neill, 2011).

2.2 Impact of dementia

As mentioned, chronic diseases have a profound impact on the daily lives of people living with the condition and their family members and dementia is no exception. It is estimated that there are between approximately 39,000 and 55,000 people with dementia in Ireland (Pierse et al., 2019) and the impact that dementia has on these people's biological, psychological, social, emotional and economic lives is very significant. The impact on the individual will differ according to the cognitive domain affected, the severity of the impairment and the complexity of self-care tasks required. Experiences will also differ from one individual to the next, in accordance with age, gender and ethnicity and in many other ways (O'Shea et al., 2017). Like other chronic diseases, dementia impacts most heavily on people from less advantaged socio-economic backgrounds.

In Ireland, most of the care and support provided to people with dementia is delivered by informal carers of which it is estimated that there are more than 60,000 (Pierce, Cahill and Carney, 2017). The care provided by informal caregivers is wide-ranging and varied and there is extensive evidence to show that although rewarding for some, caregiving can be physically and psychologically demanding (Pierce et al., 2017) and can adversely affect carers' own health (Brennan et al., 2017). Cost of illness studies provide an estimate of the magnitude of the economic cost of dementia. In Ireland, this cost has been estimated at €1.69bn per annum, 48% of which is attributable to informal community-based care provided by family and friends (Connolly et al., 2014). The disaggregated cost of dementia care stands in stark contrast to other chronic diseases. For example, worldwide informal care costs make up 10% of cancer care costs (Luengo-Fernandez, et al., 2012). In addition, a recent analysis has found that in the last five years of life, out of pocket expenses for dementia were significantly higher than those associated with other chronic conditions such as cancer and cardiovascular disease (Kelley et al., 2015).

The impact of dementia on health systems is also significant (Pierse and O'Shea, 2017). Cost of illness studies in Ireland show that residential long-stay care accounts for 43% of these total costs, but only 9% can be attributed to the formal health and social care system (Connolly et al., 2014). The latter is an indication of the low level of expenditure on treatments and therapies, and the paucity of provision in primary and community care for people with dementia (Pierse and O'Shea, 2017). One UK study found that the health care costs of dementia were lower than for other chronic health conditions such as cancer, coronary heart disease and stroke. However, social care costs for dementia were much higher than for these other chronic diseases. When the costs of dementia to the health and social care systems are combined, these are found to be higher than the combined costs for cancer, coronary heart disease and stroke (Luengo-Fernandez et al., 2015). The acute care costs of dementia are also extremely high (Connolly and O'Shea, 2015).

Dementia is not restricted to older people, although age is by far the strongest risk factor for the condition (Prince et al., 2014). About 7% of people aged 65 years and over have dementia (Prince et al., 2014), but this percentage increases very significantly with increasing age so that, for example, about 40% of people aged 90 years or over will have dementia. This means that in the absence of a cure, population ageing drives dementia prevalence up. By 2036 the number of people with dementia is expected to grow to 115,426 and by 2046 to 157,883 (Pierce and Pierse, 2017). While these figures may be disputed, the upward trend is incontrovertible, and the increased numbers will have profound implications for Ireland's health and social care system, as well as for individuals and their family members (O'Shea et al., 2017). While the prevalence of dementia in Ireland is significant, it is lower than the prevalence of many other chronic diseases including asthma (123,383), chronic lung disease (185,002), diabetes (182,833), cancer (167,500) and chronic heart disease (114,415) (Kenny et al., 2020). This is sometimes used as a rationale to explain why dementia does not receive more political and budgetary attention.

2.3 Modifiable risks factors for dementia

Since dementia is a very costly public health issue, preventing or delaying its onset would be hugely beneficial for ageing societies. There is growing evidence of an association between modifiable risk factors in mid-life and the likelihood of developing dementia in later life. This evidence comes from a range of international studies (Kloppenborg et al., 2008; Plassman et al., 2010; Deckers et al., 2015). Target risk factors have been identified as being associated with an increased risk of dementia in later life. These include: depression, midlife obesity, high cholesterol, midlife hypertension, diabetes, physical inactivity and smoking with evidence relating to diet, cognitive inactivity, coronary heart disease and renal dysfunction less conclusive. An authoritative report on dementia prevention, intervention and care extended existing models of risk to include hearing loss, social isolation and educational level (Livingston et al., 2017).

The link between modifiable risk factors and development of dementia at later ages is less well known. The majority of people in older age groups will not have dementia, but will be at high risk of developing dementia. Approximate estimates from a US study suggest that between 27% and 31% of 70-year-old males without dementia and between 35% and 37% of 70-year-old females without dementia will develop dementia before they die (Fishman, 2017). Using scenario simulations, this study also demonstrates that interventions that delay dementia onset, or slow the acceleration of dementia incidence with age, can greatly lower the percentage of people who will ever develop dementia at an older age. It highlights the widespread need for interventions to delay or reduce dementia risk at older ages (Fishman, 2017).

2.4 Dementia as a comorbid condition

Most older people will, because of their age, have comorbidities and it is noted that after the age of 75 years, a person is likely to have at least one chronic health problem (Healthy Ireland, 2019). Data from The Irish Longitudinal Study on Ageing (TILDA) shows that almost three-quarters of older people in Ireland have two or more co-existing chronic health conditions (Kenny et al., 2020). While TILDA does not include dementia among its list of chronic diseases, a recent small-scale community-based study (N=42) drawing on a non-representative sample of people with dementia who availed of Intensive Home Care

Packages, revealed a high level of co-morbidity among this cohort. In this study only two people had no other health condition apart from dementia and more than one-third (n=16) had three or more health conditions (Keogh et al., 2018b). International studies support these findings. They have shown that people with dementia, including those attending general practice have high levels of co-morbidity, the magnitude of which is at least similar but may be higher than for people without dementia (Schubert et al., 2006; Bunn et al., 2014; Connolly et al., 2012).

Co-morbidity presents particular and complex challenges for people with dementia and their families (Schubert et al., 2006; Sanderson et al., 2002; Browne et al., 2017; Bunn et al., 2014; Bunn et al., 2017; Poblador-Plou et al., 2014). International studies show that dementia is far from simply another diagnosis on the list of chronic diseases that a person may have (Schubert et al., 2006; Prince et al., 2016; Bunn et al., 2014). As Prince et al. (2016: 124) state: 'dementia changes everything'. Dementia complicates the management of other chronic diseases in primary care settings in a number of ways. People with dementia report fewer symptoms during medical consultations than those without dementia. This is not surprising as dementia may impair an individual's ability to recognise and communicate the onset of new physical or psychological symptoms. Dementia may also impair the person's ability to seek assistance/care in the face of changes with respect to other chronic conditions and their condition overall. As dementia may impair an individual's ability to manage other chronic conditions, self-management and following treatment plans becomes very challenging. For example, the person with dementia and diabetes can have problems understanding their condition, managing medication and monitoring their blood glucose levels (Bunn et al., 2014). The person with dementia who has other comorbid conditions will often have complex medication regimes that needs to be managed (Schubert et al., 2006). Dementia also changes the nature of other chronic conditions and responses to treatment for these conditions (Prince et al., 2016).

Managing comorbid chronic conditions in people with dementia is particularly challenging because of disease progression, since as the disease progress, the ability to self-care reduces and the role of family carers increases. In addition, the course of the condition, and the emergence of complications, is not easy to predict. This is all the more reason why people living with dementia, and their family carers need regular reviews for managing comorbidity to optimise physical and mental health and wellbeing. Such reviews are also needed for a range of other reasons including monitoring changes in cognitive and functional ability, attending to nutrition and hydration, identifying, assessing and managing the emergence of behavioural and psychological symptoms, and reassessing unmet needs for care and support (Prince et al., 2016). The need for comorbidity to be managed in a holistic manner, accounting for the preferences of people with dementia and their family carers has also been highlighted (Prince et al., 2016). Poor communication on the part of primary care practitioners, however can be a barrier to good management of chronic diseases in dementia (Bunn et al., 2014).

2.5 Summary

This chapter has introduced the reader to the meaning of *chronic disease* and has shown the way in which organisations like the WHO, ICIC and the Department of Health have defined and conceptualised chronic disease. Based on these definitions, we have argued that

framing dementia as a chronic disease is justifiable since dementia meets all the criteria required for such a definition. But, given the emergence of alternative models for understanding dementia that put the person at the centre stage and focus on citizenship (Bartlett and O'Connor, 2009), personhood, empowerment and human rights (WHO, 2017), is defining dementia as a chronic disease restrictive? What are some of the unintended consequences of the chronic disease framing of dementia? Dementia has a significant impact on the individual, their families and health systems and the wider society, but it impacts differently than other chronic diseases. What are the implications of this for policy making and policy implementation? These along with other questions will be explored in the chapters to follow.

Chapter 3 Methodology

3.1 Introduction

A literature review, semi-structured interviews with key stakeholders and an in-depth analysis of the CDM for GPs pertaining to the new GP contract were used to develop this policy paper. This chapter describes the methodology. It gives a detailed account of the literature review undertaken for the project, including the relevant databases accessed; how the stakeholders were identified for interview; how the interview schedule was designed and the in-depth interviews conducted and how data collected was analysed and synthesised. It also describes how each of the components of the new GP contract were interrogated using a dementia lens. The conceptual framework used to guide how the work was undertaken is also briefly described in this chapter.

3.2 Literature Review

The literature review included a review of a broad range of international and national literature including Irish-based policy documents, peer-reviewed journal articles and grey literature. The broad aim of the literature search was to identify the best available evidence on CDM with respect to dementia and specifically to provide the evidence base required to address the key research question, namely: is there a case for the inclusion of dementia in the chronic disease management programme in Ireland?

Journal articles were identified using a systematic approach, which involved undertaking electronic searches of the following standard databases: (i.e. PUBMED/Medline, PsychInfo, CINAHL, Embase, The Cochrane Library, Google Scholar) using a pre-defined search strategy. The search strategy consisted of developing a systematic search-string that was later applied to all relevant databases, thereby ensuring exhaustive coverage and overall consistency. For Dementia/Alzheimer's disease, Mesh/Thesaurus search terms used were: (TI dementia OR pre-senile dementia OR Alzheimer's disease OR Pick's disease OR vascular dementia OR front temporal dementia OR Huntington's disease OR Parkinson's disease dementia OR Lewy bodies OR Lewy body dementia OR Korsakoff's syndrome OR Korsakoff's dementia). The search terms used for CDM were: chronic disease prevention, chronic disease prevention, integrated care models, models of care, self-management and case management. LENUS and Irish institutional repositories, for example TARA and RIAN, were also searched as well as online resources of a range of international and national institutions such as Alzheimer Disease International and Alzheimer Europe. The literature search was conducted in a staged manner between November 2019 and March 2020. Since a large volume of literature was identified, only materials directly relevant to the exercise at hand were finally extracted and reviewed.

3.3 Stakeholder Interviews

A qualitative design was used to obtain the perspectives of stakeholders. In-depth semi-structured interviews were undertaken with a diverse range of health service professionals along with senior staff in the HSE, the Department of Health and other key stakeholders. Participants were selected on the basis of their experience and expertise in the area of dementia, chronic disease or both. Data was collected on a comprehensively designed interview schedule.

3.3.1 Recruitment of stakeholders

A preliminary list of 16 potential stakeholders was drawn up. This list was reviewed with staff from the ASI to ensure inclusion of key relevant stakeholders. It included people with dementia and a broad range of health service professionals including a GP, old age psychiatrist, geriatrician, psychologist and nurse and senior staff in the HSE and the Department of Health. Interviews were also conducted with a dementia researcher and health economist. An email outlining the study's main aims and objectives was sent out to potential participants some weeks in advance of the interview inviting stakeholder participation in interviews. Participation in a stakeholder interview was entirely voluntary.

We had initially intended to interview 16 stakeholders, but only 12 interviews were successfully completed. One stakeholder formally declined to participate and in three other cases we received no response to our invitations, perhaps due to heavy workloads or lack of interest in the topic. Our efforts to pursue these people or recruit other stakeholders were then impeded by the emergence of the COVID-19 crisis. As soon as the first case of COVID-19 was confirmed in Ireland and the present corona virus crisis began to quickly escalate, a decision was reached to discontinue recruitment since several of the potential stakeholders identified for interview were engaged in crucial work related to the COVID-19 crisis.

3.3.2 The Interview Schedule

Literature findings informed and shaped the design of the interview schedule which followed a logical structure and contained 13 broad open-ended questions. This interview schedule was divided into five sections. The first section covered the topic of policy frameworks on chronic disease management. The second dealt with the expected benefits and potential risks to different groups of people, especially the individual, their family members and health service professionals particularly GPs, in adopting a CDM approach to dementia. The third section dealt with CDM in relation to the new CDMP for GPs as well as in the context of the HSE's national clinical programmes and its integrated care programmes since all three areas are relevant to the topic under review. The fourth section of the schedule explored the economic case/implications for governments in adopting a CDM approach for dementia. The final section dealt with future directions and importantly what process would be required to ensure the inclusion of dementia as a chronic disease in an Irish health policy context. Here enablers and barriers to adopting this approach were explored as were the steps needed to make this a reality.

3.3.3 Data collection

In-depth interviews were used to collect the perspectives of stakeholders. All but one of these interviews were conducted face-to-face in a location convenient to participants, usually but not always at their workplace. One interview was conducted by telephone. The interviews lasted on average one hour. Themes to guide interview topics were developed from the literature, but as the process was iterative, additional themes identified in earlier interviews were re-visited when relevant and during later research interviews. None of the interview material was recorded but rather extensive notes were taken during interview. Immediately after interviews were completed, the information collected was typed in word documents. In addition, and immediately following interview, both researchers made a brief summary of the key points highlighted in the interview.

3.3.4 Data analysis

Qualitative content analysis was used to analyse the data. Broadly speaking, we followed the Bengtsson (2016) four distinct phases of qualitative data analysis, namely: (i) decontextualization; (ii) recontextualization; (iii) categorization; and (iv) compilation. During the decontextualization phase, the two researchers read through the notes carefully to obtain a sense of wholeness before breaking down the data into smaller meaning units (sentences or paragraphs answering key questions). During the recontextualization phase, the original notes were re-read alongside the list of meaning units to ensure exhaustive coverage. We counted the number of times the coded material emerged, as for example, the number of times barriers or enablers were mentioned. During the third phase - categorization - that coded material was divided into domains with themes and categories identified. During this phase, triangulation by the two researchers took place. In the final phase – compilation - the information was organized to elicit meaning from the data and to draw a realistic and non-biased conclusion.

3.4 Conceptual framework

Many different conceptual frameworks are used in health policy analysis. However, for the purpose of this report, the principles of CDM, as detailed in the Department of Health's (2008) seminal document on CDM and referred to in the NDS, were used to interrogate dementia from a CDM perspective (Box 1).

Box 1

Key principles underpinning a chronic disease management approach

1. The national focus on population directed disease prevention and health promotion
2. The need to develop structured, planned care for patients with long-term chronic conditions
3. The use of information systems and registers to plan and evaluate care for individuals with chronic disease
4. The requirement to support and strengthen self-care
5. The need to develop a model of shared care that is integrated across organisational boundaries
6. Provision of supportive clinical decision systems such as guidelines for the management of chronic disease
7. Planning care that is delivered in the appropriate setting
8. Using multidisciplinary teams in the provision of care
9. Providing a monitoring and evaluation framework for chronic disease programmes.

3.5 Interrogation of new GP Contract using a Dementia Lens

In order to explore the feasibility of including dementia in the CDMP for GPs, the following steps were taken. The programme and each of its three components – the Opportunistic Case Finding Programme, the annual Preventive Programme and the Structured Treatment Programme - were first described. Each component was then reviewed from the point of

view of being revised/extended to incorporate dementia. Enablers facilitating and barriers impeding the inclusion of dementia in this programme currently or in the future were also identified. The review was guided by the CDM principles (Box 1), which were used as a conceptual framework. It was also informed by the review undertaken for this paper of CDM models (Chapter 5) and by the literature on dementia risk reduction, case-finding and management of dementia in general practice. The perspectives of stakeholders interviewed were taken into account.

3.6 Strengths and limitations

There are a number of strengths associated with the methods chosen to conduct this work. First, the mixed methods approach adopted meant that three different but equally important approaches were used to generate the information needed. Secondly, although the numbers of interviews conducted were small, the stakeholders who agreed to be interviewed came from a broad range of disciplines and gave of their time generously. This resulted in a wealth of rich data being collected that shed new light on an important topic. The paper also brings together for the first time, Irish policy on chronic disease management and Irish policy on dementia and examines these two areas of policy using different lenses. It includes for the first time, a review of the new CDMP for GPs applying a dementia lens. It also examines the views of stakeholders in Ireland on taking a CDM approach to dementia care for the first time. One limitation however is that the work needed to be completed over a relatively short timeframe (December 2019 to end April 2020) during which time a national pandemic had broken out. This limited the number of interviews undertaken.

3.7 Summary

This chapter has reported on the methods used to address the topic, of making a case for the inclusion of dementia in a chronic disease management programme. In the chapter we have detailed how the literature search on both Irish health policy and CDM models was conducted and how the reviewed literature shaped and informed the design of the interview schedule used to collect the qualitative data. We have also shown how and by whom the list of potential stakeholders was drawn up and how and where the in-depth interviews were conducted. In the chapter we have also explained how the interview data was written up and analysed and the conceptual framework used to make sense of the data. The chapter has also shown how and why the new GP contract as it pertains to CDM was interrogated using a dementia prism. The chapter finishes with a brief overview of the strengths and limitations of undertaking this type of policy work, especially during a period of global and national crisis.

Chapter 4 Review of Irish Policy

The purpose of this chapter is to review a number of policy frameworks and documents that have shaped and informed the development of chronic disease management programmes, integrated care programmes, and dementia care programmes in the Irish health and social care system. Ireland has a rich policy landscape and a detailed review of all relevant health and social policy pertaining to dementia and chronic disease is beyond the scope of this chapter. The chapter includes a review of some of the key seminal documents including the Department of Health's policy framework on chronic disease management, the HSE's chronic illness framework and Healthy Ireland.

In the chapter, the NDS is also interrogated (DOH, 2014) applying a CDM lens to assess the extent to which CDM principles are in evidence. The Sláintecare report, which will continue to have a very profound impact on Irish health and social care policy, is also reviewed. The chapter also examines where dementia is currently positioned both in relation to the Department of Health and the HSE. But first to a review of some seminal Irish reports on CDM.

4.1 Tackling chronic disease, a policy framework for the management of chronic disease

Since the beginning of this century, the WHO has recommended that chronic disease management (CDM) guide the reform of health care systems (WHO, 2002). Developed over a decade ago (2008) by the Department of Health and Children (DOHC), the document titled: 'Tackling chronic disease, a policy framework for the management of chronic disease', targets decision-makers and planners involved in the prevention and care of chronic disease at all levels of the public health system (DOHC, 2008).

In this document, chronic diseases are defined as: long-term conditions, lasting more than six months, [that] are non-communicable and involve some functional impairment or disability and usually incurable. Anyone can be affected by chronic diseases; however, they usually occur in older people and constitute a significant contribution to disease burden in society. Examples of chronic diseases given in this document include cardiovascular disease, diabetes, cancer, musculoskeletal conditions and osteoporosis, mental disorders, asthma and chronic bronchitis. Dementia is not included as an example.

It is argued that in the context of CDM, episodic reactive interventions taking place in hospitals, cost a lot and should be replaced with more structured and integrated care that places a greater emphasis on prevention and are delivered in primary care settings. The policy document claims that population ageing in Ireland along with the adverse impact of lifestyle factors like poor diet, smoking, lack of exercise, obesity and other risk factors will result in an increase in chronic diseases over coming years. The costs of controlling and preventing these diseases can potentially be reduced if Ireland were to change from its more conventional approach.

The DOHC's policy document is concerned with addressing the challenges of chronic disease so as to reduce the burden for individuals, their carers and the health system. CDM programmes are defined in the document as: 'initiatives which are designed to address the systemic elements relating to how care is provided for patients with chronic disease so that

outcomes can be improved” (p, 16). Reference is made to the international literature and the evidence that shows that a chronic disease model enables the delivery of better care. It results in a reduction in hospital admissions and also reduces health care costs.

Influenced by the WHO, the DOHC’s framework for chronic disease prevention and management is also outlined in this document. Its broad aims are twofold: (i) to promote and to improve the health of the population and reduce the risk factors that contribute to the development of chronic diseases; and (ii) to promote structured and integrated care in the appropriate setting that improves outcomes and quality of life for patients with chronic conditions. Accordingly, the framework embraces both disease prevention and disease management programmes (DOHC, 2008).

The policy framework states that:

There are proven strategies to prevent and reduce the burden of chronic disease. For many individuals with a chronic condition, care is episodic, reactive and takes place within hospitals. It is generally now accepted that care should be structured and importantly that care is integrated with a greater emphasis on prevention. This new approach will put disease management programmes in a central position to treat and delay the onset of complications for those with a chronic condition. Much of this care can and should take place within the primary care setting. With the appropriate level of support, unnecessary hospital admissions can be avoided and quality of life improved for patients with chronic conditions. It will also involve the development of programmes to support self-care which is key to managing these conditions successfully (DOHC, 2008).

The document emphasises that the issues facing Ireland are similar to those that have faced other developed countries some of which were ahead of Ireland in terms of policy response. Lessons to be learned from other countries’ CDM programmes include:

1. The health system should shift away from medical curative models of health care towards more structured planned approaches for patients with long term conditions
2. The chronic care model requires better integrated care across institutional boundaries between primary care and the acute setting
3. The chronic care model should emphasise prevention and operate in an environment that promote health opportunities
4. Chronic disease programme requires standards, clear objectives and quality assurance mechanisms.
5. Chronic disease programmes should be supported by networks and clinical pathways that cut across the traditional boundaries of health care delivery.

Drawing on the international evidence the key principles that should be applied for effective and efficient care in the management of chronic conditions were identified. These same principles underpin Ireland’s new approach to chronic disease prevention and care and have been identified in Chapter 3 (see Box 1). The key policy requirements identified by the DOHC are listed below (see Box 2).

Box 2**Overall policy requirements for the future prevention and care of chronic disease in Ireland**

- Chronic disease programmes and initiatives should operate within the overall policy requirements established by the Minister and the Department of Health and Children
- Department of Health and Children will support the development of intersectoral working to deal with the preventative aspects of chronic disease
- Health service delivery should provide structured and integrated care for patients with long-term chronic conditions
- Programmes should be developed for the major disease groups in the form of *disease management programmes*.
- Disease management programmes should be evidence based, recognise the nature of the interdisciplinary work concerned and comprise the total course of the disease.
- Criteria should be established for the definition, diagnosis and stratification of the major chronic diseases
- Clinical decision systems such as guidelines for the management of the major chronic diseases should be developed
- Models of shared care should be developed within disease management programmes and that describe the nature of tasks between primary care and specialist services
- The primary healthcare sector should play a central role in the care of patients with chronic disease. Primary healthcare should be strengthened to meet the needs of patients with chronic conditions.
- Patients should actively participate in the management of their condition
- Clinical information systems should be further developed to support chronic disease management programmes.
- Quality assurance should be established as part of the disease management programmes for chronic diseases
- Evidence-based methods and research on chronic disease programmes should be supported
- Chronic disease programmes should be monitored and evaluated on an ongoing basis

Reflecting the close linkages between CDM and integrated care, the DOHC policy framework also highlights the importance of integrated care strategies. It references the range of organisations that have responsibility for implementing CDMPs such as the HSE; the Health Information and Quality Authority; the Institute for Public Health, health professional training bodies, health service professionals, the academic sector and other government and non-governmental organisations. There is an implicit assumption that these statutory, voluntary and tertiary organisations should be working collaboratively to tackle the challenges chronic diseases pose for Irish health and social care services.

4.2 HSE Transformation Programme Chronic Illness Framework

Published the same year as the Department of Health's policy framework on CDM (2008), this HSE sister document discusses **chronic illness** as opposed to **chronic diseases** (HSE, 2008). Chronic illnesses are defined as long-term conditions that can be treated but not cured. Interestingly in this document, **dementia** is listed as an example of a chronic illnesses. Key features of chronic illnesses include the fact that they: (i) have complex and multiple causes; (ii) usually have a gradual onset; (iii) can occur across the life course; (iv) cluster in individuals because of common risk factors; (v) can compromise quality of life; and (vi) are the most common causes of premature death.

This HSE Chronic Illness Framework was produced to provide a roadmap to prevent, detect, minimise and manage the impact of chronic illness on individual and populations. Like its sister document (DOH, 2008), the HSE framework outlines how chronic diseases place excessive demands on the health care system: people with chronic disease are more likely to attend GPs - 80% of GPs visits are due to chronic illness. They are more likely to present at A&E (66% of all people at A&E have chronic illness). People with chronic illnesses also use more in-patient days in hospital and have greater morbidity. This document also highlights the importance of integrated services, in the context of CDM. Integrating health promotion, primary prevention, secondary prevention and specialist services is considered to be essential. The document discusses both chronic illness prevention and management, the importance of addressing determinants of health, engaging the public about getting involved in their own health (self-management) and engaging working with other sectors to improve health.

4.3 Healthy Ireland (2013-2025)

The goal of Healthy Ireland (DOH, 2019) is to increase the proportion of healthy people at all stages of life in Ireland, reduce health inequalities and protect the public from threats to health and wellbeing. Ultimately, the aim is to create an environment where everyone can play their part in achieving a healthy Ireland. This policy is guided by the ethical principles of equity, fairness, proportionality, accountability, solidarity and sustainability. Its vision is for everyone to enjoy full physical and mental health and well-being to their full potential.

Throughout Healthy Ireland there are multiple references to chronic diseases, their increasing prevalence and the parallel increasing costs these diseases are likely to place on health services. Between 2010 and 2020 it is claimed that the numbers of adults in Ireland with chronic diseases will have increased: diabetes by 30%, COPD by 23%, hypertension by 28% and coronary heart disease by 31%. It argues that estimates for the growth of chronic conditions over the next 30 years highlight a problematic and extremely costly and unsustainable future for health services. Chronic diseases and their risk factors are major drivers of health care costs as well as other economic costs.

The document also discusses health inequalities. It highlights how risk factors for chronic diseases are more common among people from certain socio-economic groups and those who live in deprived areas and shows how health inequalities are linked to social and economic inequalities. The guiding principles for the implementation of this policy are better governance and leadership, better use of people and resources, better partnerships, better systems of health care, better use of evidence, better measurement and evaluation

and better programme management. According to Healthy Ireland, investment in population level interventions is both fair and wise.

4.4 Irish National Dementia Strategy

Published six years after the development of the policy framework for the management of chronic diseases and underpinned by principles of personhood and citizenship, the NDS states that dementia policy, service delivery and development should also be guided by the principles of CDM as set out by the Department of Health (Department of Health, 2014). Interestingly and to date, no review has taken place on how these principles have informed the implementation of the NDS: an observation that might suggest their relative unimportance and a point that will be returned to in a later chapter. But for the moment, attention now turns to a more in-depth critical review of the NDS using a CDM lens. In particular, the section to follow examines the alignment of the NDS with CDM principles (Box 1, Chapter 3) and identifies priority areas where these principles are already embedded in the NDS. This exercise is being undertaken to demonstrate how the reframing of dementia as a chronic disease for the purposes of the CDMP for GPs can ostensibly build on and complement the NDS.

Principle 1 - Dementia prevention and health promotion

As a policy plan, the NDS is concerned with both dementia prevention including primary prevention - policies reducing risk and increasing cognitive reserve; secondary prevention - policies aimed at detection and screening; and tertiary prevention - policies aimed at slowing down deterioration once dementia is diagnosed (Wu et al., 2015). Direct reference to primary prevention is made in the NDS with reference to the first priority area (public awareness and understanding) where it states (p, 14) 'the programme will include public education about the modifiable lifestyle and cardiovascular risk factors which can beneficially impact on risk and time of onset of dementia'. There is also reference to primary prevention when the NDS cross references the Department of Health's Future Health (A Strategic Framework for Reform of the Health Service 2012- 2015) and its health promotional principles such as keeping people healthy throughout their life course and treating patients at the lowest level of complexity in a safe timely and efficiently as close to home as possible. The NDS states that all of those involved in designing and delivering services for people living with dementia and their caregivers must take account of these principles. Although the NDS is ostensibly a policy plan about dementia prevention and management, it has been noted (especially with reference to the Dementia Understand Together campaign) that insufficient attention has been focused on dementia prevention in Ireland (O'Shea et al., 2017).

Principles 2, 5 and 7 - The development of structured, planned and integrated shared care, delivered in the right setting for patients with long-term chronic conditions delivered in the right setting

The NDS is also explicit in its policy commitment to planned and integrated care delivered in the right setting for people living with dementia. Regarding the latter, the policy commitment to home-based community care over long-stay residential care is evident in priority action area three, where it states that 'people with dementia should be facilitated to remain living in their own homes' (p 24). Its commitment to structured planned care is also seen with reference to the linkages it notes need to be developed between primary and

secondary care services and between community and acute care services. For example, with reference to Memory Clinic services, it states: 'where Memory Clinics are available, referral pathways will be clarified, with agreed GP work-up, use of common referral templates and appropriate triage of referrals' (p, 21).

The NDS sets out to provide clear clinical pathways and guidelines to all those responsible for dementia care. Section 6 (p, 24) highlights the importance of integrated care services across the entire illness trajectory. It explicitly refers to the importance of creating: 'smoother transitions between primary, secondary, mental health, community care, acute, long term and palliative care services.'

Principles 3 and 9 - Information systems and registers

An important finding emerging from the review underpinning the NDS (Cahill et al., 2012) was that existing information systems were sometimes patchy with some national databases containing limited or no dementia-specific information. It is not surprising therefore that the NDS has made a commitment to address this deficiency in record keeping on dementia. Priority area six, for example, commits to improving data collection methods on dementia to provide the evidence to inform service delivery. This priority action area details the role of the HSE, highlighting its remit regarding the development of practice-based dementia registers in primary care and the better recording and coding of dementia in the acute care sector including the accurate capturing of information about dementia in Hospital In-Patient Enquiry (HIPE) data. In addition, a commitment is made that the HSE will ensure that data from the Single Assessment Tool will be used in research to inform dementia care in Ireland. Monitoring and evaluating any new service initiative has also been an integral aspect of all of the NDS programmes.

Principle 8 - Multi-disciplinary teams

Reference is made in the NDS to the pivotal role primary care teams play in the assessment, diagnosis and follow up of people living with dementia and their family members. For example, in relation to priority action area three, the NDS states that: 'caring for a person at home will require an increasing range of individually tailored and integrated responses from the old age psychiatry service and the primary care team including allied health professionals' (p, 25). The importance of multidisciplinary input into dementia care is also emphasised with reference to primary care, mental health care and care in the community.

Principle 6 - Provision of supportive clinical decision systems such as guidelines for the management of chronic disease

The importance of clinical guidelines is reiterated throughout the NDS and even highlighted in the foreword written by Minister Lynch. Regarding priority action area two - timely diagnosis and intervention - the importance of clinical guidelines is emphasised (p, 20). Regarding the support and care of people with dementia in the acute care sector, the NDS states: the HSE will develop guidelines on dementia-friendly ward specification to be taken into account the design stage of all refurbishments and new builds.

Principle 4 – the requirement to support and strengthen self-care

Remarkably, the NDS, in listing the principles of chronic disease management, omitted the principle of self-management / self-care.

NDS principles of personhood and citizenship

The NDS is also underpinned by the overarching principles of personhood and citizenship: principles described by Hennelly and O'Shea (2017) as a major breakthrough in the effort to develop a counter-frame to the traditional biomedical model that has dominated dementia care in Ireland. By embedding the principle of personhood in dementia policy, the NDS commits to seeing 'the person' in every individual irrespective of how advanced the dementia is and to ensuring that the person remains central to how dementia care services are developed, designed and delivered (Hennelly and O'Shea, 2017).

Of much relevance to making a case for the inclusion of dementia in a CDM framework is one specific requirement set out by the Department of Health under the policy framework on the management of chronic disease (see point one, Box 2, p. 15). This requirement is that chronic disease programmes and initiatives should operate within overall policies developed by the Department of Health. Hence, the development of any CDMP specifically on or including dementia such as that agreed in the new GP contract must take account of the NDS. This also aligns well with the policy framework for the management of chronic diseases, which states that 'current and future initiatives on chronic disease should be patient-centred' (Department of Health, 2008: 18). This has implications for the development and delivery of CDMPs, as the aspiration of personhood and a person-centred approach must be at the heart of any CDMP that applies to dementia.

4.5 Sláintecare

Aims, units for service delivery and chronic disease management

Published three years after the NDS, the "Sláintecare" report sets out a high-level ten-year roadmap for health care reform (Oireachtas Committee on the Future of Healthcare, 2017). Sláintecare is notable because it provides a cross-party consensus on a long-term vision to reform Ireland's health and social care systems and make it fit for purpose (Keogh et al., 2019). Sláintecare has two key aims. The first is the phased introduction of universal health care, that it claims can only be delivered through integrated care. The second is the reorientation of the health system towards 'integrated primary and community care', which includes a restructuring of primary and community care services.

The Oireachtas Committee acknowledges the impact of chronic diseases such as diabetes, COPD, heart disease, dementia and stroke on the health system and the increasing pressure they will place on already stretched and finite health resources and it is interesting in this context how dementia is included as a chronic disease in Sláintecare's listing. It concludes that a new approach is needed reflecting a shift away from a hospital-centric model. In relation to the management of chronic diseases, it stresses that there should be an emphasis on primary and social care delivered in the community, and on prevention and enabling self-care. It agrees that primary care, general practice and CDM would come under universal health care.

Integrated care and underpinning principles

According to the Oireachtas Committee, a single-tier universal healthcare system can only be delivered through integrated care, one of five inter-related components in Sláintecare,². Integrated care it is claimed is the glue that binds the different elements of a health care system together enabling it to achieve common goals and optimal outcomes. The policy document clarifies the meaning of integrated care models and emphasises the importance of there being a common understanding of the term. Integrated care is defined in the Sláintecare report as follows:

‘Healthcare delivered at the lowest appropriate level of complexity through a health service that is well organised and managed to enable comprehensive care pathways that patients can easily access and service providers can easily deliver. This is a service in which communication and information support positive decision-making, governance and accountability; where patients’ needs come first in driving safety, quality and the coordination of care.’ (Oireachtas Committee on the Future of Healthcare, 2017: 20).

The Sláintecare report contends that the integrated care model puts the person at the centre of the system. It suggests that the delivery of integrated care is both horizontal, (meaning that care must span professional and departmental boundaries such as interdisciplinary teams) as well as vertical (meaning there must be coordination between primary, secondary and tertiary care domains). Recalibrating the system to build up primary and social care capacity is paramount to the integrated care approach.

The Oireachtas Committee also envisages a system that is integrated in terms of all stages of an individual’s life, and in terms of a comprehensive continuum of care from health promotion and disease prevention to diagnosis, treatment, disease management, rehabilitation and palliative care. It uses the WHO health system building blocks framework (WHO, 2007) to set out the core elements needed for Sláintecare to deliver on an integrated and well-functioning health system. It makes recommendations for systematically modelling an integrated health care system under five headings: Leadership and governance; Healthcare and funding mechanisms; Healthcare workforce; Medicines and medical technologies; and Information and research. The new framework will improve care, improve health and reduce costs.

The Sláintecare report endorses the principles which drive the integrated care model. They are as follows: (i) all care is planned and provided so that the patient is paramount ensuring appropriate pathways and seamless transition backed up by full patient record and information; (ii) there is timely access to all health and social care according to medical need; and (iii) patients access care at the most appropriate cost-effective service level with a strong emphasis on prevention and public health.

Implementation of integrated care

The Oireachtas Committee (2017: 75) recommends that integrated care in Ireland is implemented through three implementation streams: (i) system strengthening; (ii) service

² The others are population health; entitlements and access to healthcare; funding; and implementation.

co-ordination; and (iii) network building. Pertinent to all three streams are the work of communicating and enabling a new culture of collaboration, empowerment, co-ordination and shared goals.

Sláintecare sees the new GP Contract as an opportunity ‘to facilitate new ways of working so that GPs are incentivised to carry out health promotion/public health work, disease prevention, delivery of integrated care and management of chronic diseases including mental health and multi-morbidities’ (Oireachtas Committee, 2017: 22). CDM and integrated care are therefore to be at the heart of the new GP contract. The additional costs and extra GP and primary care staff requirements resulting from this new way of working are acknowledged.

Based on submissions made by various organisations, Sláintecare references the approach to dementia care being implemented in Scotland that reflects pathways of integrated care coordinated by link workers. Sláintecare also acknowledges that people living with dementia and their family caregivers confront serious barriers in equity of access and outcomes through the entire illness trajectory.

Leadership and governance are identified in Sláintecare as critical functions of the health system (Oireachtas Committee, 2017). Strengthening of governance and accountability in health structures are seen as a way of ‘enabling integrated care to develop’. Integration will lead to efficient and cost-effective health services which meet patients’ needs in a timely manner.

The Oireachtas Committee also recommended changes to HSE structures and probably as a consequence of this along with other reasons, some significant restructuring of HSE services has occurred over recent years. As some of this restructuring is particularly relevant to the work programme of the NDO and to having dementia included as a chronic disease for GP purposes, the final part of this chapter will provide an overview of these changes. First it is necessary to look at where the NDO is positioned at the time of writing within HSE structures.

4.6 Positioning of dementia

4.6.1 Positioning of dementia within the HSE

The National Dementia Office (NDO) was established in 2015 to oversee the implementation of the NDS and to help integrate the different elements of Ireland’s dementia policy into the wider health and social care system. It is beyond the scope of this review to provide a comprehensive overview of the implementation of the NDS. However, a Mid-term Review, an external review and a number of other evaluations of various workstreams delivered since its implementation are available (Department of Health, 2018; Keogh et al., 2018a; Keogh et al., 2018b; Pierce, 2019; Pierce et al., 2019). Another comprehensive report commissioned by The Atlantic Philanthropies that looked at developments in dementia policy, research and practice in Ireland since the development of the NDS has also been published (O’Shea et al., 2017).

From an organisational and health policy perspective, where the NDO is positioned in the DOH and the HSE is important. It is particularly important in relation to discussions about the inclusion of dementia in CDM programmes for GPs, or integrated care programmes (ICPs) including ICPOP and the integrated care programme for chronic disease (ICPCD). In the DOH, responsibility for dementia rests mainly in Social Care but dementia is also spread across a number of other divisions including Sláintecare and Primary Care. In the HSE the NDO has been situated in the HSE's Social Care Division. This division was established to support ongoing service requirements of older people and people with disabilities. The NDO has a National Lead and a Clinical Lead, and after restructuring remains in the Social Care Division, which now reports to the newly formed Office of the Chief Strategy and Planning Officer.

In Chapter 6 we look in depth at the new GP contract with particular reference to its CDMP for GPs, an area of policy development that has emerged since the launch of the NDS. We endeavour to make a case for including dementia in future revisions of this new contract for GPs, and accordingly where responsibility for the new GP contract lies in the HSE is also of critical importance. At the time of writing, the new CDMP for GPs is positioned in the National Contracts Office, which is situated in the Primary Care Division. The latter reports to the newly formed Office of the Chief Operations Officer.

As argued earlier, the boundaries between discrete disease categories, chronic diseases programmes and integrated care programmes are often blurred. Therefore, it is worth noting the positioning of the long established national clinical programmes (NCPs) especially those pertaining to chronic disease and the more recently established (ICPs) in the HSE, as these programmes can also impact on people who have dementia.

Since 2010, 36 NCPs have been developed. These have been spread across different HSE Divisions. Of direct relevance to this policy paper, is the National Clinical Programme for Older People (NCPOP), which was originally situated in the Social Care Division. Other clinical programmes with a focus on chronic disease such as asthma, COPD, diabetes and heart failures are also relevant. These were situated in the Health and Wellbeing Division. In addition, the NCPs for stroke, epilepsy and rare diseases were situated in the Acute Hospitals Division of the HSE and the NCP for Palliative Care situated in the Primary Care Division.

Of further relevance to this policy paper are two of the five ICPs, namely, an ICP for the Prevention and Management of Chronic Diseases (ICPCD) and the ICPOP, established in 2015 and 2016 respectively. They are relevant as if dementia is to be made part of a revised bundle of chronic diseases for GPs, one would assume it will also need to be included in the ICPCD. In addition, as we will show in section 4.6.2, a workstream on dementia is now part of the ICPOP. Accordingly, the section to follow will now briefly review these programmes, with a particular focus on where they are strategically positioned within HSE structures.

4.6.1 Integrated Care Programme for Prevention and Management of Chronic disease
The Integrated Care Programme on the Prevention and Management of Chronic Disease (ICPCD), first established in 2015, was designed to provide better care to people with chronic diseases and to improve their quality of life and independence by providing access

to integrated care and support that is planned around their needs and choices (Jennings, 2014). The objective was to “provide a full spectrum of care including prevention, early detection, management in Primary Care and appropriate Secondary Care services”. Care was to be delivered at “the lowest level of appropriate complexity”.

Like its sister programme, ICPOP, the HSE’s ICPCD builds on pre-existing NCPs but in this case on chronic diseases such as asthma, COPD, diabetes and heart failure. Its purpose is to develop a series of integrated solutions that will treat care for and support individuals with chronic disease that is best provided by an integrated team which spans professional and service boundaries. The ICPCD is intended to improve the quality of life and independence for individuals with chronic diseases by providing access to integrated care and support that is planned around their needs and choices. Supported by an Integrated Model of Care, it is expected to create change in how health and social care providers and their local partners will work with people with chronic disease to plan and deliver services needed to improve quality of life. Despite dementia being referred to as a chronic disease in Sláintecare and despite a commitment being made in the Mid-term Review of the NDS (DOH, 2018) to progress the integration of dementia into this programme, at the time of writing dementia, although a chronic disease, is not included in the ICPCD.

4.6.2 Integrated Care Programme for Older People (ICPOP)

The Integrated Care Programme for Older People (ICPOP) was established in 2016 to build on the work of the National Clinical Programme for Older People (NCPOP).³ The programme brought together two divisions within the HSE (the Social Care Division and the Clinical Strategies and Programme Division⁴), with the aim of introducing a change in the model of service provision and service delivery to older people. This change would be achieved through integrated care and more specifically through active collaboration with clinicians and managers.

Informed by two rapid reviews of the literature evidence (Harnett and Kennelly, 2018; Harnett, 2018), a 10-step framework was developed, to serve as a conceptual map outlining the vision and the key elements that needed developments. Interestingly a key element of ICPOP is to facilitate the contribution of older people to developing models of best practice. A consumer-led approach would be accomplished through listening to the voices of older people within local communities. A practical guide was developed to inform the implementation of ICPOPs at local level. The adoption of a case management approach is a key tenet of ICPOP, and guidance based on a review of case management models (Hopper et al., 2018) was prepared to support the development and implementation at a local level. A report outlining the lessons learned from the implementation of ICPOP (2015-2018) has been published (HSE, 2018).

This programme is currently in gestation but to date, thirteen sites have been identified, at least one in each CHO area to test the ICPOP model of integration with a case management approach (HSE, 2018). While there is an overall ‘blueprint’ to guide implementation, ICPOP

³ The NCPOP was established in 2010 and developed an acute care model for older people referred to as the Specialist Geriatric Services Acute Model of Care.

⁴ See Section 4.7 for an overview of structural changes within the HSE.

is a complex intervention, being implemented in a complex health system. Furthermore, at each of the 13 sites, ICPOP has been adapted and has evolved differently and dynamically.

Interestingly the inclusion of dementia in ICPOP was explicitly mentioned in the NDS under the Leadership priority action area where it is stated:

The Clinical Strategy and Programmes Division of the Health Service Executive will establish a Workstream on Dementia Care as part of its Integrated Care Programme for Older Persons, in recognition of the complexity of the illness and the need for leadership and integration across all relevant Health Service Executive Directorates (Department of Health, 2014)

This inclusion of dementia in the ICPOP was later acknowledged in the Mid-term Review of the NDS (DOH, 2018) where it was noted that a Workstream on Dementia Care had been established by the HSE's Clinical Strategy and Programmes Division (CSPD) as part of ICPOP. Links between the NDO, ICPOP and the NCPOP have also been established through the Clinical Lead on Dementia and a representative from the NDO sits on the steering group for ICPOP and on the working group for the Clinical Care Programme for Older People (CCPOP). Getting dementia prioritised in the ICPOP however has not been easy and has been identified as a challenge due to competing agendas such as frailty and stroke (Department of Health, 2018).

Apart from taking cognisance of these integrated care programmes and their relationship with the NDO's workstreams, it is also important to reflect on the recent restructuring that has occurred in the HSE and the potential this has in terms of governance structures and the positioning of dementia. The final part of this chapter now addresses this topic.

4.7 HSE re-structuring

As part of Sláintecare, the HSE's CSPD (see section 4.6.1) has undergone major change and has been restructured around three interrelated components - the NCPs and ICPs and the Office of the Nursing and Midwifery Services Director. The main goal of this recalibration has been to rethink the delivery of health and social care in order to integrate, improve and standardise patient care across all healthcare settings, by bringing together clinical disciplines and enabling them to share evidence-based solutions in order to provide improved person-centred care.

At the time of writing, the main HSE changes relevant to the current policy paper are as follows:

1. As part of the restructuring of the functions of the HSE, the Office of the Chief Clinical Officer (OCCO) was established in 2018. Its objective was to develop clinical leadership across the health care system and ensure that it remains central to the design and implementation of policy (OCCO, 2019). The CSPD now reports to the OCCO and has been renamed Clinical Design and Innovation. It works in close collaboration with Sláintecare.
2. The NCPs are to be the primary reference point for providing cross-service solutions including models of care for chronic disease and frailty ensuring that the hub of

healthcare delivery lies within primary and community care. The NCPs, all of which now function within the OCCO, are required to work closely with the Hospital Groups and CHOs.

3. Integrated care is to be a key component of all NCPs, Accordingly, ICPOP is to be amalgamated with the NCPOP. To facilitate this overall integration a National Lead for Integrated Care has been appointed (OCCO, 2019), who has responsibility for ensuring that health and well-being reform priorities (prevention, early detection, self-care / self-management for patients with chronic diseases) are prioritised and embedded across the programme work of all National Clinical Advisor and Group Leads (NCAGLs) and the NCPs.
4. There are five National Clinical and Group Leads (NCAGLs) including a NCAGL for Chronic Diseases, a NCAGL for Older Persons, and a NCAGL for Primary and Community services.⁵ The five NCAGLs have been brought into the OCCO and their role is as internal consultant to the HSE across three core pillars of clinical excellence, strategic development and operational delivery.
5. The work of the NCAGL for Primary and Community Services will include a focus on harnessing the elements of the new GP contract to deliver benefits to patients and align this with Sláintecare and the Chronic Disease Programmes and the work of the NCAGL for Chronic Diseases will include examining key linkages and opportunities for alignment of programmes of work across all other NCAGL work programmes.

This restructuring of the central functions of the HSE have relevance for dementia policy as the powerhouse for future health policy implementation appears to rest within the OCCO.

4.8 Summary

This chapter has reviewed a number of frameworks and documents published over the last decade that have informed the development of public health policy on chronic disease management and prevention and policy on dementia in Ireland. In the chapter, reference has been made to the key requirements of a CDM approach as identified by the Department of Health, and using a CDM lens, the NDS has been interrogated to ascertain the extent to which it takes cognisance of the DOHC's principles as detailed in Chapter 3. In so doing, we have shown how many of the building blocks for reframing dementia as a chronic disease are already in evidence. Another central focus in the chapter has been on the cross-party Sláintecare report. We have shown that several of its recommendations have been implemented. One of these is in respect of the HSE's clinical and integrated care programmes, where a gradual shift is being witnessed away from stand-alone clinical programmes to programmes reflecting models of integrated care.

The chapter has also shown that there are a range of programmes of work currently in progress in the HSE. One of these is the ambitious work currently being pursued by the NDO in relation to dementia. However, the NDO's present position - where it sits in the HSE's Social Care Division and reports to the Office of the Chief Strategy and Planning Officer - means that to some extent it is outside what appears to be the new main powerhouse of the HSE – the OCCO that is driving change and innovation. The chapter has shown that, although there have been efforts on the part of the NDO to integrate dementia into other

⁵ There are five NCAGLs in total. There are also NCAGLs for Mental Health and Acute Operations.

programmes of work such as the new GP contract and its CDMP for GPs and ICPOP, progress on these fronts has been slow. This is probably for a variety of reasons not least the NDO's organisational positioning within the HSE. If dementia is to be successfully integrated into key programmes of work such as the CDMPs for GPs and ICPOP, forging stronger links between the NDO and other key offices in the HSE will be critical. This point will be returned to in the final chapter of this report.

Chapter 5 Chronic disease management models

One of the fundamental challenges we faced in undertaking this review is the lack of a common definition for the term *chronic disease management*. In addition, the term is used interchangeably with other terms such as integrated care, chronic care and case management, to name but a few. Each of these other terms also lack a common definition. The boundaries between these terms are also unclear and reflect, as Nolte and McKee (2008: 65) put it, ‘the polymorphous nature of a concept that is applied from several disciplinary and professional perspectives and is associated with diverse objectives.’ This chapter examines conceptualisations of CDM. It also presents an overview of the key CDM models that have been developed and implemented.

As noted in Chapter 2, the costs of dementia as a chronic disease are high and impose a significant economic burden on the individual, families, the community, governments and on society. The high economic cost of dementia does not in itself necessarily imply that investment in CDM models for dementia is an economically sensible or viable way forward. Such an assessment depends not so much on the costs of dementia, but on the costs that can be averted through intervention (i.e. the cost benefits of the intervention). The final part of this chapter examines the evidence that we have found on the cost-effectiveness of chronic disease management models.

5.1 Conceptualising chronic disease management

The concept of ‘chronic disease management’ originated in the US in the 1980s. When first adopted as a model, CDM traditionally targeted people with a single chronic disease or condition and typically those with conditions such as asthma, diabetes or coronary heart disease. CDM programmes were narrowly tailored, and mainly used to promote adherence to medication and lifestyle behavioural change. CDM was originally seen as a means to control costs, by reducing hospital admissions, readmissions and length of stays in hospital. Initially spearheaded in the US by the pharmaceutical industry, CDM went on to become more widely embraced, including by governments in the US (Nolte and McKee, 2008; Geyman, 2007). This occurred as more evidence emerged of the potential cost savings in treatments for those with chronic conditions.

Scope of CDM, locus of delivery and evolution over time

The nature and scope of CDM initiatives vary widely. They range on a spectrum from small initiatives focusing on a narrow subset of people with chronic disease to widespread programmes targeting vast swathes of people with chronic diseases (Nolte and McKee, 2008). The locus of CDM programmes is also important, and a distinction has been made between those that are ‘on-site’ and those ‘off-site’ or ‘carved out’ (Geyman, 2007; Nolte and McKee, 2008; Spenceley et al., 2015). ‘On-site’ programmes are directed by primary providers and delivered within primary care settings, whereas ‘off-site’ or ‘carved out’ programmes that focus on specific processes of care and clinical outcomes, mostly patient education and self-management based on information systems. In contrast to on-site programmes, off-site programmes are not generally integrated with primary care and normally involve only minimal contact with primary care providers. In addition, they often lack focus on patient outcomes, or concentrate on short-term outcomes only. In the US, carved out programmes tend to be delivered by private health care providers (Nolte and McKee, 2008).

Over time, CDM programmes have evolved from those focusing on single conditions or diseases such as diabetes or stroke to others, providing a more integrated approach and addressing the multiple needs of patients with co-morbidities and multi-morbidities. This has led to the development in some countries of disease registration systems to identify at risk individuals (Geyman, 2007; Nolte and McKee, 2008). There has also been a trend towards the development of population-based approaches to chronic disease management (Nolte and McKee, 2008).⁶ The many definitions of CDM are a reflection of how CDM programmes have developed over time, and the variation among them in terms of scope, focus, purpose and components.

5.2 Chronic disease management models

The most effective interventions for improvements in chronic disease care, according to a Cochrane review (Renders et al., 2001), include the combination of multi-pronged strategies and CDM models are a good example of this approach. A large variety of CDM models exist and it is beyond the scope of this review to cover all of these models, which have been reviewed in-depth elsewhere (Savage et al., 2015; Grover and Joshi, 2015). However, we have chosen to present an overview of the Chronic Care Model (CCM) as it is most widely known and forms the basis for many other CDM models. The chronic progressive and irreversible nature of dementia makes it amenable to the core principles of the CCM (Jagdal et al., 2014), which forms the basis for other models such as Collaborative Dementia Care Models, and the Chronic Care Model for Neurological Conditions (CCM-NC), which are also reviewed in this chapter.

5.2.1 The Chronic Care Model (CCM)

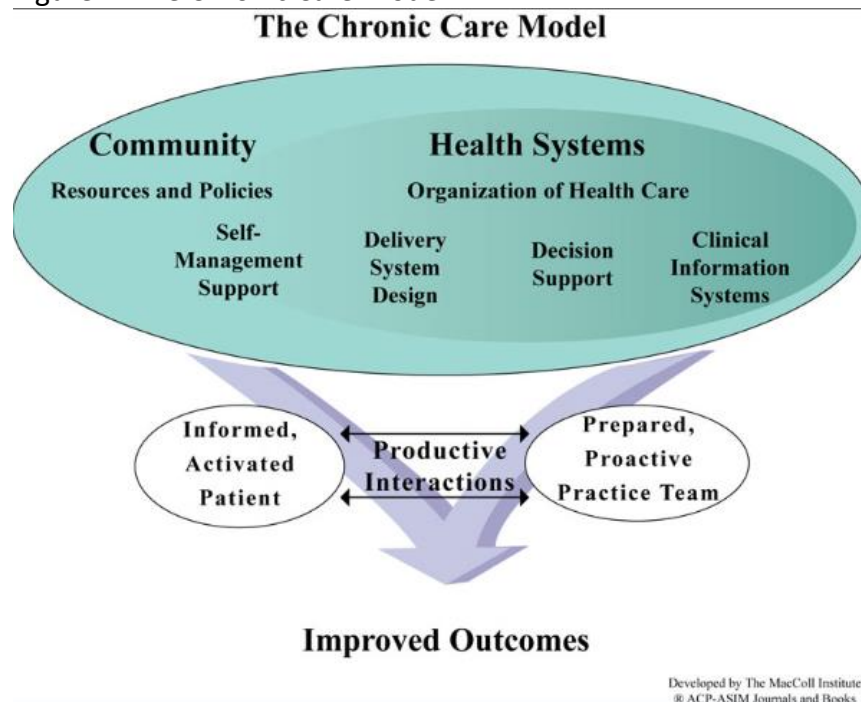
The CCM was developed in the US (Wagner et al, 1998) as an organising framework for improving chronic disease care and as a guide to quality improvement initiatives. The impetus for its development was recognition of the inadequate care people with chronic illnesses were receiving at the time in the US. It was noted that the traditional didactic approach had minimal impact and there was a need for change (Wagner et al, 1996; Wagner, 2019). There was also a recognition that care systems that are successful in improving outcomes of people with chronic diseases share common characteristics for change. These include changes to how care is delivered, changes to the support of patients, changes to information systems and interventions for the education of care providers (Wagner, 2019). This finding applied to both newly designed intervention programmes and those involving the reorganisation of existing care systems (Nolte and McKee, 2008). Wagner et al. (1998) organised these characteristics into a heuristic model of care improvement, and called it the CCM. As mentioned, the CCM is the most widely known and cited model on how to organise chronic care programmes, especially in primary care (Grover and Joshi, 2015). Like most CDM models, the CCM although a generic model and taking a health systems approach, targets individuals with a single chronic disease or condition. The CCM model was refined in 2003 by the ICIC programme in the US.⁷

⁶ see HSE <https://www.hse.ie/eng/about/who/population-health/population-health-approach/>, approach taken by Healthy Ireland, Understand Together)

⁷ http://improvingchroniccare.org/index.php?p=Contact_Us&s=96

The CCM incorporates the person, the provider, and the systems level factors and interventions. It has a series of inter-related elements (see Figure 1).

Figure 1: The Chronic Care Model



First at a **health system or health care planning level** for chronic illness, its elements are: (i) ‘the delivery system design’, that has a focus on team work; (ii) ‘decision support’, or the integration of evidence-based guidelines into everyday practice and (iii) ‘clinical information systems’ or developing information systems on patient populations to provide relevant data. Secondly, at the **community resource and policy level**, that entails the development of partnerships with community organisations, ‘self-management support’ is the key element and the emphasis is on the central role the individual has in the management of their own care.

The CCM suggests that elements of the model such as self-management support help to create informed activated patients and other elements such as clinical information systems help to ensure prepared and proactive teams. According to this model, when combined, improved outcomes and evidence-based care arise as a result of productive interactions between informed patients, who take an active part in their care, and prepared, proactive practice teams of clinicians and health care professionals who are adequately resourced and have expertise.

Improved outcomes expected from the application of this model are healthier patients, more satisfied providers, and cost savings. The CCM model has been adopted as a blueprint for health system reform in many health care settings and in most developed countries including US, Canada, across Europe and Australia (Jagdal et al., 2014; Savage et al., 2015). In Ireland, with respect to dementia care, the PREPARED project drew on the principles of the CCM.

There are several challenges and shortcomings associated with CCMs. For example, earlier in its evolution it was noted that the mechanisms by which the recommended changes could improve patient outcome needed further clarification (Wagner, 2019). In addition, it has been noted that the 'community resources and policies' component is inadequately defined, and since CCM is geared to clinically oriented systems, it is not very useful for practitioners concerned with prevention and health promotion (Barr et al., 2002). In response to such challenges, the CCM has been developed, adapted and expanded. The section to follow reviews two of these revised models, namely, the collaborative care model with particular reference to dementia and the CCM-NC, which includes dementia.

5.2.2 Collaborative Dementia Care Models

Collaborative care models were developed in response to some of the shortcomings of the earlier CCMs. These shortcomings include: lack of communication between GPs and specialists, minimal coordination of psychosocial support for caregivers, and poor management of comorbidities. Stated simply, collaborative care models aim to improve quality of care for chronic illnesses through a person-centered, team-based approach. They seek to address the complex needs of those with chronic illnesses through multidisciplinary care teams which actively involve patients and caregivers in shared healthcare decision-making (Heintz et al., 2019).

A number of collaborative care models embedded in a primary care setting have been developed for people with dementia and their family carers and implemented around the world. Examples include the ACCESS intervention in the US (Vickrey et al., 2006; Duru et al., 2009; Chodosh et al., 2006), DementiaNet in the Netherlands (Dreier-Wolfgrmm et al., 2017), and DeLPHi in Germany (Thyrian et al., 2012). Heinz et al. (2019) identified seven different collaborative dementia care models in the US, Canada, Germany and the Netherlands. In their narrative review, they examined the key components and core outcomes of interventions based on these collaborative dementia care models, and identified facilitators and barriers to their wider implementation.

Heintz et al. (2019) found that the effective management of the complex issues that people with dementia present is achieved by communication and shared decision-making. This should be accomplished across specialities and between different healthcare providers. This interdisciplinary collaboration with shared decision-making constitutes the central tenets of the collaborative dementia care model. Heintz et al. (2019) explain the way in which the model works. People with dementia and their family carers are identified for enrolment to programmes through a review of practice medical records. This enrolment is usually facilitated by a staff member referred to as a dementia care manager (DCM), often a nurse or a social worker. The DCM conducts the initial assessment, undertakes a lot of the information gathering for work up, and with the GP, tailors the care planning and referrals to service providers. After a care plan has been developed, the DCM continues to support the person with dementia and family caregiver (dyad) throughout the course of the disease by facilitating ongoing communication between members of the care team, promoting use of community-based resources, and conducting behavioural activation and other therapeutic interventions. Ongoing collaboration between the DCM, the GP and specialists is considered crucial to the management of people with dementia (Heintz et al., 2019). In this way the DCM acts as a conduit between the person with dementia and the GP and

allows for more frequent contact with the dyad and coordination of individualised treatment, and as a result increases the quantity of care without placing additional burden on the GP (Heintz et al., 2019).

Interventions informed by the collaborative dementia care model have been aimed at improving quality of life and providing a satisfactory care experience while also containing costs. Controlled trials of interventions based on the model have shown that people with dementia reported high satisfaction with quality of care and showed decreases in functional and cognitive severity. They also had fewer GP visits and had fewer visits to A&E or admissions to acute hospital. Through the intervention, caregivers received psychoeducation and used significantly more community-based supports. Caregiver burden was reduced: carers had more time to look after their own medical and psychosocial needs and were more confident when supporting their relative with dementia. There were also benefits for GPs who were able to consult with a collaborative care team. This gave them more confidence in diagnosis and management of dementia. Challenging behaviours were also more appropriately managed (Heintz et al., 2019).

Reflecting the interdisciplinary and integrated nature of this approach, Heintz et al. (2019) concluded that the successful implementation of this model required champion leaders from primary care, geriatric psychiatry, behavioural neurology, nursing and social work. All must work together to convince their leadership of quality of care improvements and the health care savings that are achievable by timely and coordinated evidence based collaborative dementia care models. However, they emphasise that on a national basis, integrating dementia care management within primary care requires transformation of the entire healthcare system, including the restructuring of payment systems to adequately support providers and reduce costs for caregivers. It also requires cooperation between multiple branches of the health care system and good leadership (Heintz et al., 2019).

5.2.3 CCM for neurological conditions, including dementia (CCM-NC)

So far, we have discussed the well-known Wagner model - CCM (1998) - and the collaborative dementia care model that built on Wagner's model and has more recently been used in some countries around the world. Yet another model that also builds on the CCM is the Expanded CCM (Barr et al, 2002). The latter was introduced to better integrate aspects of prevention and health promotion into the CCM and to expand on its 'community resources' component (Barr et al., 2002; Barr et al., 2003). Of particular note here is that version called the CCM for Neurological Conditions (CCM-NC) where Canadian researchers have used the Expanded CCM as a framework to develop a model for neurological conditions that is inclusive of dementia (Jagdal et al., 2014).

The CCM-NC is similar to the Expanded CCM in that it aims to achieve improved well-being and better health outcomes for persons with dementia and other neurological conditions. In the model, this is considered achievable through having: (i) an activated and informed person and family member; (ii) a practice team of service providers; and (iii) a person-centered health system and healthy public policy. The model is strongly user-led and was developed following research conducted with a large group of stakeholders including health care professionals, non-health care professionals, individuals with neurological conditions and policy makers. Interestingly, proponents of this model stress the importance of

emphasising different CDM components and different interventions to achieve optimal outcomes for people with dementia and other neurological conditions.

The CCM-NC identified three key elements - (i) the socio-economic and political context; (ii) community integration; and (iii) health systems issues – that need to be emphasized for improving the quality of life of people with dementia and other neurological conditions. These areas have resonance for the care and support of people living with dementia in Ireland and for future policy development and will be briefly described in the section to follow and returned to in a later chapter of the report.

The socio-economic and political context

The socio-economic and political context, covers a range of themes. One is public acceptance and openness to an illness as, for example, dementia. Another is that policies should be needs-based rather than condition-specific, encouraging individual engagement and autonomy, and supportive of seamless transitions and integration into the community. The requirement for investment to enhance health and community-based services and interventions and support training for staff and caregivers is also part of the socio-economic and political context.

Community integration

Community integration is the second key element of the CCM-NC. It includes the themes of supported transitions, caregiver support and life-enhancing resources. Supported transitions are identified as a major need, and there is recognition that transitions between care settings are often common (community, hospital and long-stay residential care). This is particularly important for people with dementia. However, transitions are not always positive due to a lack of continuity of care within and between health sectors and government departments. GPs may not always be included, and community-based interventions to respond to the complexity of dementia may not be available. Caregiver support is needed, given the role that family carers play or are expected to play in supporting people with dementia, and the demands it places on their time, especially in the context of the care and support they already provide and the range of unmet needs among family carers. The theme of life enhancing resources highlights that dementia care is much broader than health care and extends to the policy areas of work, housing and transport. Failure to invest in life enhancing resources has implications for the management of dementia as a chronic disease.

Health systems

Health system issues is the third element of the CCM-NC and themes included here are knowledge and awareness among service providers of the chronic illness and availability and access to service. A significant lack of knowledge and awareness about dementia among service providers can be a contributing factor to less than optimal care. Service providers need to be aware of the potential episodic and chronic nature of dementia. A key issue identified is the lack of knowledge and understanding about self-management support for dementia among service providers. Under the latter theme, key issues included the need for person-centred care requiring a shift away from diagnosis to functional requirements and needs, the need for multi-disciplinary teams, and integrative care planning as well as the availability of community-based services and supports, particularly for those in rural areas

and the particular demands that living in rural areas places on family carers. The CCM-NC highlights the need for intersectoral collaboration within and between settings, since lack of intersectoral collaboration results in negative outcomes.

A number of important lessons can be learned from the development of the CCM-NC especially in the context of dementia care. These include the fact that first, interventions to improve knowledge and awareness of dementia and availability and access to services are a prerequisite for the implementation of components associated with the health system (self-management, delivery system design, decision support, and information systems). Secondly, and as a key priority, there is a need to address the knowledge-gap among service providers about what self-management means including in the context of dementia. Thirdly there needs to be less emphasis on decision support and information systems and a greater emphasis on promoting equitable care and optimal outcomes through the development of standardised referral criteria, protocols, care pathways and guidelines.

Proponents of the CCM-NC posit that an intersectoral collaboration between the health system, the community and the socio-political environment is needed in order to achieve its goal. This model has not yet been implemented, but future work is now needed to develop and evaluate interventions guided by the model to improve quality of care, health outcomes and well-being for individuals with dementia (Jaglal et al., 2014). Further work is also required to assess the cost implications of applying each of these models in primary care as there is a paucity of good evidence-based findings on this topic. The section to follow will now provide a brief review of the relevant literature identified on this topic.

5.3 Cost-effectiveness of CDM interventions

As mentioned, the literature on the cost-effectiveness of interventions based on the CDM models and dementia is very sparse. However, insights for dementia can be gained from cost-effectiveness studies of interventions for other chronic diseases. An EU commissioned report (Nolte and Pitchford, 2014) that provided an overview of the economic impact of integrated care approaches for chronic diseases identified 19 relevant papers based on a systematic search. The three outcome measures used to examine the economic impact of integrated care were: (i) health service utilisation; (ii) cost-effectiveness; and (iii) costs. Most of the papers that were reviewed focused on outcomes such as hospital admissions, readmissions or attendance at A&E and findings were very mixed.

Of the 19 studies, 17 reported cost data in some form and there was some evidence of cost reduction in a number of reviews. However, these findings were based on a small number of studies. Only eight out of 19 studies reported on cost-effectiveness. There was evidence of cost-effectiveness of a selected integrated care approach but the evidence was weak. Six studies reported on cost as a measure of cost utility suggesting increased cost associated with the integrated care approach in question. Overall, the researchers concluded that there are considerable complexities involved in interpreting the evidence from these studies; findings were mixed within the topics reviewed based on different definitions of components of care – and based on divergent understandings of integrated care. The researchers also questioned the meaning of integrated care and whether it should be understood as an intervention that by implication should be cost-effective or whether it

should be seen as a complex strategy to innovate and implement long lasting change in how services are delivered.

The collaborative care model for dementia care in primary care settings discussed at length in this chapter (Heintz et al., 2019) also makes a useful contribution to the literature on costs of CDMs. For Heintz and colleagues, a review of initial data from several models suggests that enrolment in a collaborative care model is associated with less frequent use of acute medical services. In particular cost savings arise from fewer in-patient admissions, fewer visits to A&E and fewer out-patient service appointments. The authors of this narrative review claim that, if implemented widely, these models could result in overall reduction in total medical expenses. Interestingly, however, in looking carefully at their findings, only one of the seven models they describe, the Healthy Aging Brain Centre in Indianapolis, showed overall cost reductions amounting to \$1.05 million or between \$980 to \$2856 per year. One other model described – the Alzheimer’s and Dementia Care (ADC) based in California – proved to be cost neutral for Medicare when programme costs were taken into consideration.

A UK based study published by the NHS and based on the collaborative dementia care model has provided a cost comparison between primary care managed dementia services with specialist outreach support and two other specialist led dementia assessment and diagnostic services (NHS, 2015). The Gnosall primary care led services, was shown to cost about half the cost of a specialist care managed service with primary care delivery. Comparison of costs were £396 versus £877. The ethos for this service was to add specialist skills and knowledge within primary care teams. The specialist consultant allocated 3.5 hours session on site every month and on-going advice and liaison was available by phone. Dementia assessment and diagnosis was a shared responsibility between GP and consultant. The service used an elder facilitator (nurse co-ordinator) who undertook home visits. To avoid or minimise acute hospital admission the service also offered additional visits for emergency incidents.

A systematic review of randomized controlled trials on dementia case management and its effectiveness on health care costs has shown no evidence for savings in health care expenditure or a reduction in hospitalisation (Pimouguet et al., 2010). A large-scale study titled D-Care has recently commenced in the US. The study is being conducted across four different clinical sites and will compare the effectiveness and cost-effectiveness of health system-based dementia care provided by dementia care specialists with community-based dementia care provided by a care consultant who work at community-based organisations.

5.4 Summary

This chapter has argued that the nature and scope of chronic disease management initiatives vary widely. It has examined different conceptualisations of CDM and has presented an overview of three distinct but inter-related models. Two of these models have been developed in the US and implemented in different countries around the world over the last two decades. The most widely used model – the CCM developed by Wagner (1998) – has been reviewed in depth and we have shown how this model has helped to shape and inform later models such as the collaborative dementia care model and more recently the CCM-NC. Given that many definitions of CDM exist, it is not surprising that different CDM

programmes have developed over time reflecting these different definitions. Models vary in relation to focus, purpose, scope and components. The chapter has also reviewed a scant and difficult to collate literature on the cost-effectiveness of CDM models. We have found there is a scarcity of literature that provides any compelling evidence of the cost-effectiveness of applying CDM models in primary care. The literature that has been identified shows that the application of CDMs does not automatically result in cost savings. Therefore, the hope that interventions based on CDM models will reduce costs may be overly optimistic. Indeed, costs may actually increase as better quality of care is provided to patients previously undertreated for chronic conditions (Geyman, 2007). In the context of increased costs, it is important to consider where these costs will fall, especially when dementia care is shared. This issue about the expected cost savings a CDM approach might yield in dementia care will be revisited in Chapter 7 where our stakeholders' view on the topic will be reported.

Chapter 6 The Chronic Disease Management Programme for GPs

This policy paper provides an opportunity to review the new GP contract, and particularly its CDMP component, interrogating it through a dementia lens. The main purpose of the chapter therefore is to describe the current format of the CDMP for GPs and detail each of its three core components. These components are then individually reviewed from the point of view of identifying how dementia would best fit and be incorporated within each. We also highlight what is needed to revise/extend these components to enable dementia to be included in future revised GP contracts. Factors facilitating the inclusion of dementia in this new programme (enablers) and those impeding its inclusion (barriers) are also identified.

Negotiations between the IMO, Department of Health and the HSE on a new GP Contract commenced around February 2017.⁸ At a policy level, these negotiations were seen as an opportunity to incentivise and reward GPs to work in new ways, including with respect to the delivery of integrated care and the management of chronic diseases (Oireachtas Committee, 2017: 22). CDM is a key focus of the newly agreed GP contract and core to the contract is the Prevention and Management of Chronic Disease Programme for General Practitioners. The new contract was established in 2019. Formally titled: A Chronic Disease Management Programme for GMS/GPVC⁹ patients, it commenced in January 2020. For the purposes of this report, we refer to the programme as the CDMP for GPs.

The goal of the CDMP for GPs is to take a population level approach to prevent and manage chronic diseases. This programme aims to improve patients' own ability to manage their chronic diseases through: (i) structured reviews with the GP and practice nurse; (ii) personalised care plans developed and agreed with GPs; (iii) regular reviews of care plans and medication; and (iv) opportunities for structured education and self-management supports.¹⁰ The intention is for the Programme to be rolled out to 430,000 adult patients over a four-year period with a target uptake rate of 75%. So how might the CDMP in the new contract currently impact on people living with dementia? Given government policy that decrees that chronic disease programmes should operate within the overall policy requirements of the Department of Health, has the NDS made any commitment to deliver on the CDMP for GPs? Does the programme in its current format have the capacity to accommodate a chronic disease like dementia? If not, what is needed and, when the contract is being reviewed, how easy might it be to incorporate within it another chronic disease like dementia? These questions will be addressed in this chapter.

6.1 Dementia and the new GP Contract

The new GP contract was not mentioned in the NDS, a finding not at all surprising given that the NDS was launched in 2014, years before negotiations on the new GP contract ever commenced. However, reference to the inclusion of dementia in the new GP contract was identified in the Mid-term Review of the NDS (DOH, 2018) as a way of progressing the

⁸ These negotiations are held under the 2014 Framework Agreement which is the agreement between the IMO, Department of Health and HSE to allow the parties to deal with all aspects, including resources, of the GMS and other publicly funded GP Contracts.

⁹ General Medical Service / GP Visit Card patients.

¹⁰ <https://www.hse.ie/eng/about/who/gmscontracts/2019agreement/chronic-disease-management-programme/chronic-disease-patient-leaflet.pdf>

timely diagnosis of dementia and intervention (priority action two of the NDS). In the Mid-term Review, a future plan itemised under priority action two was to progress the inclusion of dementia into the chronic disease management framework. This was envisaged as a way of allowing: ‘GPs to be resourced to deliver proactive dementia care, a model that has been shown to improve diagnosis rates, improve prescribing habits and lead to better outcomes for people with dementia and their family carers’ (DOH, 2018, p 29).

Importantly, the inclusion of dementia in the new GP contract was to be explored by the NDO in consultation with stakeholders in the HSE and the Department of Health (Department of Health, 2018: 29). The Department of Health (2018: 45) anticipated that getting dementia included in the GP contract negotiations would be a leadership challenge, and to address this, work with HSE Procurement and primary care was identified as a priority (Department of Health, 2018: 65). A submission was made by the NDO outlining a rationale for including dementia in the CDMP for GPs.¹¹ However, when the new GP contract was announced dementia was not listed in the bundle of chronic diseases included. The diseases listed were: (i) asthma; (ii) coronary obstructive pulmonary disease; (iii) diabetes; and (iv) cardiovascular disease.

The CDMP for GPs comprises three core components:

- (1.) Opportunistic Case Finding Programme;
- (2.) An Annual Preventive Programme for patients at high risk of cardiovascular disease or diabetes;
- (3.) A Structured Treatment Programme (STP) for those diagnosed with the Chronic Diseases included in the Programme.

The next section provides an in-depth exploration of each of these three components. First, the potential use of the Opportunistic Case Finding Programme for identifying both people at risk of developing dementia and those with dementia is examined. Second, the case for including dementia in the annual Preventive Programme is explored and barriers and enablers to its inclusion are identified. Third, to examine the STP, two questions are asked: (i) how might the current programme be enhanced for those people with dementia already included since they have as a co-existing illness at least one of the listed chronic conditions? and (ii) if the current STP were to be expanded to include dementia, how might it be revised to meet the needs of people with dementia?

6.2 Opportunistic Case Finding Programme

In the new GP contract, the purpose of the Opportunistic Case Finding Programme is twofold: (i) to identify patients at high risk of cardiovascular disease or diabetes for entry to the Preventive Programme, and (ii) to identify those with undiagnosed listed Chronic Disease for enrolment on the STP. The new GP contract defines opportunistic case finding to mean the identification of patients either with a chronic disease or at high risk of chronic disease, when a patient attends the GP with another issue, and when risk criteria can be applied and appropriate assessments/tests carried out. In its first year, the Opportunistic Case Finding Programme is expected to target people aged 75 years and over with a

¹¹ Communication from NDO, 24.02.2020.

GMS/GPVC. Those with a high-risk profile will be offered a case finding assessment and if they consent will be assessed against risk criteria. This programme is to be introduced in 2021. It will be phased in over three years and will gradually extend to all adults aged 45 years and over with a GMS/GPVC.

6.2.1 Identifying people at high risk of developing dementia for Preventive Programme
Dementia shares many of the same risk factors with cardiovascular disease and diabetes. In addition, cardiovascular disease and diabetes make a contribution to dementia risk (WHO, 2019). It is not surprising therefore that many of the risk criteria selected for the Opportunistic Case Finding Programme, for example, current smoking, obesity, high cholesterol, chronic kidney disease, are risk factors that also place people at a higher risk of dementia. Accordingly, many people identified through the Opportunistic Case Finding Programme will also have modifiable risk factors for dementia and will be identified for enrolment onto the Preventive Programme.

There are, however, a number of additional risk factors for dementia that are not included among the risk factor criteria for the listed chronic diseases. These include sedentary lifestyle, heavy alcohol consumption, a diet with high saturated fats, midlife hypertension, deficiencies in vitamin B6, B12 and folate (Winblad et al., 2016). The question then is whether the risk criteria for the Opportunistic Case Finding Programme should be extended to include assessment for these other modifiable risk factors for dementia. This would be feasible to do, as dementia risk algorithms have been developed using data routinely collected in primary care including sociodemographic variables, lifestyle factors and pre-existing health conditions (Walters et al. 2016; Schiepers et al., 2017; Vos et al., 2017). For example, the LIBRA score developed by the In-MINDD project for people in mid-life aged 40-60 years was designed to focus primarily on individual's dementia potential. It consists of modifiable risk factors that are promising targets for preventive strategies for dementia risk reduction (Solomon et al., 2017). Given the competing demands on GP's time and the length of time required to offer in-depth primary prevention and risk reduction advice, the acceptability of dementia risk scores for GPs and practice nurses would need to be explored (Foster and O'Donnell., 2015). If found acceptable, the template that has been developed for the Opportunistic Case Finding Programme, and that will be available in all GP software systems, could potentially be reworked to take account of additional risk factors relevant to dementia.

6.2.2 Identifying patients with undiagnosed dementia for STP

The Opportunistic Case Finding Programme is also intended to identify people who are eligible for enrolment onto the STP. Currently, people identified with any of the four diagnosed listed chronic diseases along with those with hypertension are eligible. If people with a dementia diagnosis were to be included as eligible for treatment, then critical to this discussion is the fact that many people who have dementia may never have received a diagnosis (Brooker et al., 2014). In Ireland for example less than 50% of people receive a formal diagnosis or receive a diagnosis of dementia at the late stages of the disease (Revez et al., 2018).

In this context, it is worth considering whether it would be appropriate to use the Opportunistic Case Finding Programme to identify people with undiagnosed dementia. A

systematic review of dementia case-finding by Ranson et al. (2018) is particularly helpful in this regard. Ranson et al. (2018) provide a formal definition of dementia case-finding, and outline its key features. They differentiate case finding from population screening and from other routes to diagnosis such as recognising clinical signs and symptoms and investigating subjective concerns. They pay particular attention to the subtle but important differences between dementia case-finding and population screening, and they use two case studies (one from the UK and the other from the US) to illustrate the difference. Based on their systematic review, Ranson et al. (2018) conclude that case-finding for dementia offers the potential to identify more people for whom a diagnosis may otherwise be missed or delayed. However, they warn that it must be used cautiously to minimise the potential risk from harm both from false negative and positive diagnoses, and stress that case-finding initiatives should be individualised and patient-focused.

Case finding initiatives should also be subject to evidence requirements, but, as Ranson et al. (2018) demonstrate, the evidence requirements proposed for dementia case-finding have not yet been met and there remain gaps in the evidence at each of five stages in the dementia case-finding process. These include gaps in relation to criteria for targeting high-risk groups, identification of those likely to benefit from case-finding, and validation of an effective, acceptable dementia case-finding question or initial enquiry. These are areas that require further research to inform evidence-based dementia case-finding practice and protocols. Based on these findings, Ranson et al. (2018) conclude that they cannot currently recommend the implementation of dementia case-finding in clinical practice.

Identifying patients with dementia: Some enablers

If case finding is not to be recommended to identify people with dementia, how else might the individual be identified in general practice? It is worth mentioning here that there exists a suite of electronic dementia audit tools developed, as part of the PREPARED project, to support GPs identify patients with dementia attending their practice.¹² These tools were not designed for case-finding of undiagnosed dementia, but to support GPs to audit the care of people with dementia by:

- Enabling easy identification of people with a current diagnosis of dementia (the Register)
- Allowing for the identification of people who may not be coded for dementia on practice software systems but where other indicators (e.g. anti-dementia medication) recorded for the patient suggest that they should be included (the Finder)

The tools also allow GPs to upload their data anonymously to a central database and in return receive their practice report, which they can use to compare their own practice with other practices. If dementia were to be included in the CDMP for GPs, the Register and Finder from this suite of tools could be useful. The Register could be used to identify people with a diagnosis of dementia and the Finder could be used to identify people who have dementia but are not coded as such for dementia. These tools have already been

¹² The suite of tools was developed by the PREPARED team in association with the ICGP and the Irish Primary Care Research Network. GP software providers were commissioned to build these tools into their medical records software systems, for GPs to use and easily extract lists/registers of patients with dementia.

incorporated into GP practice management software systems. Information about the tools and dementia coding has been communicated to GPs and other practice staff who have participated in dementia education workshops such as those delivered through PREPARED and to GPs accessing the ICGP eLearning modules and through the dementiathroughways.ie website. GPs use IT systems to a significant extent in their practice, and the usage is relatively high in Ireland in comparison to other European countries (Darker et al., 2011; Darker et al., 2015; De Rosis and Seghieri, 2015). However, some GPs have indicated that they would not be inclined to use the dementia software tool in practice (Pierce, 2019), and hence its acceptability and current use would need to be explored further.

To summarise this last section, a review of this first component of the new CDMP for GPs has shown that many of the individuals identified through the Opportunistic Case Finding Programme as being at high risk of cardiovascular disease and diabetes will also have modifiable risk factors for dementia. Dementia risk profilers are already available to identify the presence or absence of risk factors for dementia. It has also been shown that although the use of opportunistic case finding by GPs to identify patients with dementia cannot be recommended, if dementia is to be included in a future bundle of chronic diseases, there are tools already developed in Ireland that could be used by GPs. These tools would enable GPs to quickly identify people with dementia who might benefit from enrolment in the STP. The next section will now address the second component, i.e. the Preventive Programme.

6.3 An Annual Preventive Programme

The Preventive Programme focuses on people at high risk of cardiovascular disease and diabetes, who have been identified as such through the Opportunistic Case Finding Programme. These patients will receive an annual GP and practice nurse consultation. They will be given health promotion advice, along with advice on lifestyle modification and will have their risk factors and interventions recorded. Accordingly, should the Preventive Programme also address dementia risk reduction and what might be needed if the programme were to do so in the future?

6.3.1 Including dementia risk reduction in the Annual Preventive Programme

A potential benefit of incorporating primary prevention of dementia into this element of the CDMP for GPs is that it could also serve as a vehicle to enhance awareness among GPs of the inter-connectedness of dementia prevention with that of the prevention of other more readily recognised chronic diseases, such as diabetes and cardiovascular disease. In this way, it may provide opportunities for GPs to address dementia risk in a timely and appropriate way (O'Donnell et al., 2015).

There is a compelling case for incorporating dementia risk reduction into the annual Preventive Programme and in so doing so, this would help to incentivise GPs and practice nurses to discuss dementia within consultations targeting primary prevention and risk factor reduction.

We know from the Dementia Understand Together campaign that knowledge of risk factors and protective factors for dementia among the general public is extremely low (Glynn et al., 2017). It has also been noted, especially with reference to the Dementia Understand Together campaign, that insufficient attention has been focused on dementia prevention in

Ireland (O'Shea et al., 2017). Like in other countries (Foster and O'Donnell, 2017), GPs involvement in dementia care in Ireland has largely focused on diagnosis and post-diagnostic management, with limited attention paid to primary, secondary and tertiary prevention. Guidelines cannot cover all topics and although helpful guidelines have been produced for GPs on dementia diagnosis and management and more recently revised (Foley, et al., 2019), primary prevention of dementia was not covered in these Guidelines. Nor was primary prevention addressed in the PREPARED Educational Programme, currently being delivered through the ICGP Continuing Medical Education (CME) small group meetings. Likewise, in the ICGP web-based eLearning Programme on Diagnosis and Management of Dementia in Primary Care there is limited coverage of dementia prevention.

General practice can play an important role in ensuring that patients are made aware that there are potentially modifiable and interlinked risk factors for dementia, which, if addressed, may reduce the risk of developing dementia in later life, or at least delay its onset. The idea is not new. This was the concept behind the In-MINDD project, which promoted the idea that GPs can play a role in supporting people with modifiable risk factors for dementia to make the necessary lifestyle changes to address these risks (O'Donnell et al., 2015). While In-MINDD focused on people in mid-life (i.e. aged 40-60 years), there is no reason why the concept cannot also be customised for people in older age groups with a risk of developing dementia.

General practice is a suitable setting for public health education and advice on the prevention of dementia. GPs are usually in close contact with their patients whose life circumstances become well known to them often over a long period of time. While they often have to deal reactively with the conditions their patients present with, they can also act proactively and are well placed to instigate primary prevention. This issue is well supported in the literature. For example, Foster and O'Donnell (2019) argue that in order to tackle risk factors for dementia, it is important to find an arena that routinely addresses modifiable risk factors, social conditions and coexisting chronic diseases such as cardiovascular disease and diabetes, and suggest that primary care, particularly general practice, is arguably that setting. This is in keeping with the WHO, which has recognised that, within the health system, prevention of dementia is best addressed within primary care (WHO, 2016).

In the context of this discussion on primary prevention risk reduction and dementia in primary care, it is important to note that a new working group for dementia risk reduction has recently been established by the HSE involving the NDO and staff from other HSE divisions. The incorporation of dementia risk reduction into the Annual Preventive Programme would complement and strengthen this new HSE awareness-raising programme and signal a more joined-up strategy to dementia prevention in Ireland. It would also concur with the policy objective endorsed by both the WHO and NICE of incorporating dementia into existing programmes focusing on risk reduction (O'Donnell et al., 2015).

6.3.2 Barriers and enablers to the inclusion of dementia

If dementia risk reduction is to be included in the Annual Preventive Programme, specific requirements will need to be met. GPs must understand the role of modifiable risk factors in dementia (Foster and O'Donnell, 2019) and know how they can best support their patients

to address and incorporate the necessary health-related behaviour change into everyday life (O'Donnell et al., 2015). Therefore, the training needs of primary care professionals on primary prevention of dementia may need to be elicited and addressed. One potential barrier to the inclusion of dementia in the Preventive Programme is that GPs and practice nurses may find talking about dementia with their patients stigmatizing and they may also be reluctant to enter into discussion with their patients on sensitive lifestyle related topics that might be perceived as intrusive when linked with dementia. Another issue is that in busy and resource-stretched general practices and other primary care settings, it may be difficult to achieve health behaviour change and hard to deliver support face-to-face.

These potential barriers could be overcome to some extent by promoting dementia risk reduction in other ways as for example in practice waiting rooms or by social prescribing to 'off-site' programmes. Social prescribing is being advocated as an important way to provide GPs with a non-medical referral option that can be delivered alongside existing general practice services to improve individuals' health and well-being. In this regard, there may be a role for link workers who, based in primary care, support people to develop and achieve a personalised set of health and social goals by engaging with community resources. The link worker approach, which is gaining popularity in the UK (Husk et al., 2020; Wildman, 2019) and currently being tested in primary care in Ireland for people with complex multimorbidity in socially deprived areas (Kiely et al., 2019), could potentially be applied to dementia risk reduction. Referral options include those that aim to prevent dementia and other chronic diseases through targeted life-style interventions (for example physical activity, healthy eating). One example of an 'off-site' programme is Mjinbreincoach in the Netherlands, a mobile health intervention, which allows people to identify areas in which their brain health can be improved and how the risk of dementia can be reduced. It provides practical information and advice on lifestyle changes, which not only help people to achieve better brain health but to reduce risk of diabetes, obesity and cardiovascular disease.¹³

6.4 Structured Treatment Programme

The third component of the new CDMP for GPs - the Structured Treatment Programme (STP) - is for people already diagnosed with chronic disease. The STP initially targets people over 75 years but then extends in year two to those aged over 65 years and by 2022 to all adults with a medical card or GP visit card. The emphasis here is on supporting patients to manage their own chronic disease(s) through planned visits to GPs twice per year. Each of the two GP visits should be preceded with a practice nurse consultation where patient education, preventive care, medicine review and physical examination are the focus.

In Section 6.4.1, the current programme is reviewed to see how it could be enhanced for people with dementia already included in the programme by virtue of having at least one of the chronic conditions as a co-existing illness. Section 6.4.2 takes the programme and examines how it might meet the needs of people with dementia, if the programme were to be expanded to include dementia in the bundle of conditions. There are issues that cut across both the current STP programme and an expanded STP programme. Current

¹³ Mjinbreincoach is an evidence-based intervention with its roots in the In-MINDD project, which uses the LIBRA risk score, MjinBreincoach is being used as a part of a broader dementia prevention awareness raising campaign in Limburg, a province in the Netherlands, and its usefulness and acceptability is being tested.

diagnostic rates of dementia are low (Timmons et al., 2015), stigma may still pose challenges both in terms of people coming forward for diagnosis as well as GPs being proactive in diagnosing. This would have serious implications for the STP. Scheduled reviews are a core feature of the STP, but the appropriateness of the review for people with dementia needs to be considered. Self-management is at the core of CDM and at the core of the STP, but unlike the other chronic diseases, self-management poses particular challenges for people with dementia. Dementia implies that self-management support must be available, and this raises many issues in relation to caregiver supports and has the potential to place additional burden on family caregivers. These issues are discussed in section 6.4.3.

6.4.1 The STP and dementia as a co-existing condition

As discussed in Chapter 2, people with dementia have high levels of comorbidity. This means that even though dementia is not currently included in the new bundle of chronic diseases, a sizeable proportion of people with one or more of the four chronic diseases enrolled onto the programme will also have dementia. However, the coexistence of dementia with one or more of the four other listed chronic conditions is not currently addressed in the STP. We would argue that this is a major oversight because of the ways in which dementia complicates the management of other chronic diseases for people with dementia and the challenges this presents for family carers and clinicians in primary care settings, as discussed in Chapter 2.

6.4.2 Including dementia in its own right in the Structured Treatment Programme

There are factors that facilitate the inclusion of dementia in the STP. Nationally we know that people with dementia and their family members welcome having regular contact with GPs (Begley, 2009; Diaz-Ponce, 2014). The planned GP and Practice Nurse led reviews that form part of this new CDM programme would allow for this. The NDS (DOH, 2014), also strongly advocates for the preservation of personhood, empowerment, autonomy and the individual's own participation in decision making, core values reflected in the STP component of the CDMP for GPs. For example, the STP involves the development of personalised care plans and opportunities for self-management support. Self-management may work well for people at the earlier stages of dementia and for people with certain dementia sub-types where insight remains intact.

Potential barriers to the inclusion of dementia in the STP

However, there are also barriers that might impede the inclusion of dementia in the STP. In particular the self-management component of the programme could pose a significant obstacle for people with certain dementia sub-types or at particular stages in their journey through dementia. For example, a person with more moderate to severe dementia will, it is likely, experience major difficulties supporting themselves and this component of the programme could potentially place further strain on family caregivers. Likewise, the STP is supposedly an integrated model yet there is no provision within the model for secondary primary care liaison over more complex patient cases or how costs would fall if primary secondary care responsibilities were shared.

A further potential barrier from the point of view of dementia care is that the current focus in the STP is limited with only four core areas addressed: (i) patient education; (ii) prevention care; (iii) medicine review; and (iv) physical examination. In terms of self-

management and to address the needs of a person with dementia, the focus in this programme would need to expand to include topics directly relevant to the person with dementia such as ways of coping better with cognitive and memory functioning, advanced care planning, communication techniques and dealing with responsive behaviours. A final barrier that needs to be carefully considered is the planned and schedule visit component of the STP. One of the hallmarks of dementia is that the illness is progressive and unpredictable and, certainly with more advanced dementia, health and social care needs are constantly changing. For this reason, planned scheduled visits at set intervals may not be appropriate for people with more severe dementia.

6.5 Summary

This chapter has reviewed the three main components of the new CDMP for GPs that forms a central part of the new GP contract, namely: (i) the Opportunistic Case Finding Programme; (ii) the Annual Preventive Programme; and (iii) the Structured Treatment Programme. In critically reviewing these three programme components, the chapter has highlighted the technical aspects required to have dementia categorised as a chronic disease and the actions required to enable dementia fit into the requirements of the CDMP for GPs.

First, in relation to opportunistic case finding, we have argued that many of those individuals identified through the Opportunistic Case Finding Programme for enrolment onto the Preventive Programme will also have risk factors for dementia and for this reason it would be feasible for this programme to be extended for the assessment of a range of modifiable risk factors for dementia. Based on the literature we have shown that, opportunistic case finding cannot be recommended for identifying those with undiagnosed dementia for the STP. Despite this caveat we have identified a tool already in existence that can be utilized by GPs to enable them readily identify patients with dementia for enrolment onto the STP.

Using a dementia prism, we have also interrogated the second component of the CDMP for GPs, namely the Annual Preventive Programme. Here it is shown that given the risk factors that dementia shares with cardiovascular disease and diabetes¹⁴, there is a strong argument to support a focus on dementia risk reduction in the future. However, given that most GPs and practice nurses are not thinking about dementia from a public health perspective, training programmes to upskill them in the area of dementia prevention will be a prerequisite. The final part of the chapter critically reviewed the new STP. We have argued that where there is a diagnosis of dementia, this will shape the focus and approach to management of all other chronic conditions. We also put forward suggestions as to how this programme could be further revised and expanded to be inclusive of dementia as a condition in its own right. Here the obstacles along with enablers to the inclusion of dementia in the programme are reviewed.

¹⁴ These are the two chronic diseases that the programme targets.

Chapter 7 Stakeholders' views on Chronic Disease Management Models and Dementia

This chapter reports findings from in-depth interviews conducted with stakeholders in the area of dementia or CDM. Twelve stakeholders - seven females and five males - participated in these in-depth interviews. Three were clinicians (a GP, an Old Age Psychiatrist and a Geriatrician); two were people living with young-onset dementia; two were Department of Health officials; three were academics (a nurse, an economist and psychologist) two of whom were also family caregivers; one was a policy officer employed by a voluntary organisation and one person was a HSE employee with a specific dementia remit.

The chapter opens with a discussion from a stakeholders' perspective about the value of conceptualising dementia as a chronic disease. It then progresses to an analysis of factors (enablers and barriers) likely to impact on the inclusion of dementia in chronic disease management programmes. The third section of the chapter focuses on the potential risks and expected benefits of including dementia in chronic disease management programmes: these findings are reported as they pertain to the individual, family caregiver and the GP. The final part of the chapter addresses the topic of the cost ramifications arising from the inclusion of dementia in CDMPs.

7.1 Dementia as a chronic disease

Amongst the 12 stakeholders, broadly speaking, there was a shared understanding that dementia *could* be framed as a chronic disease, and of what aspects of the chronic disease management approach would be of most value for dementia care. The following five characteristics were commonly raised by stakeholders:

- *Shared and structured care* – '[we] hear all the time that the type of [dementia] care is unstructured ... what there is at the moment is not working ... [with a CDM approach there would be] a clear pathway and structured care' (R7).
- *Primary and secondary prevention and health promotion* - 'A good starting point for making a case for including dementia in the CDMP for GPs is the focus of the programme on prevention as many of the risk factors for dementia are shared with those for other chronic diseases covered by the programme' (R 11)
- *Registries*: While registries were deemed important for CDM, mixed opinions were expressed as to what would be the best approach to take and how exactly the approach taken might work in practice. The main issue giving rise to these mixed opinions was the different patient registries that are either already in existence or in the process of development (e.g. National Dementia Registry, Chronic Disease Registry), and whether a registry should be a practice-based or a national registry. One person felt there was no political buy-in for a national dementia registry despite the modelling work currently underway (R12). Reference was made to the shift away from registers for individual chronic disease to a chronic disease registry encompassing several chronic diseases, that there was little clarity as to whether dementia would be included or not, and concern was expressed that the minimum data in a chronic disease registry would not be sufficient to assist health

professionals planning and evaluating care for individuals with dementia. One respondent also believed that a barrier to the inclusion of dementia in a chronic disease registry is that most GPs had very limited interest in dementia care (R12). Reference was also made more broadly to a HSE e-health system (R5). One person felt that, in the absence of e-health, patient registers were probably a useful start (R3).

- *Co-morbidities*: Several respondents referred to the fact that people who have dementia usually have other comorbidities
- *Self-management or empowerment* - considered by some as: ‘hugely important as it promotes greater independence of people with dementia’ (R2)

However, this shared understanding that dementia *could* be framed as a chronic disease did not necessarily mean that dementia *should* be positioned in the HSE’s CDMP or in the CDMP for GPs. Some believed that by positioning it within a CDM framework, dementia could become medicalised even with the best of intentions. There was also concern that dementia might become dislodged, squeezed out by other chronic diseases that have a higher prevalence; a higher public health and political impact and that affect younger people ‘other chronic diseases that affect younger people and young people’s needs gain better traction’ (R9). In contrast, others believed it would be a veritable ‘game changer’ as currently GPs are unable to give their patients with dementia the time required: ‘the CDM approach would pull things together ... incentivise GPs to take an interest in the area of dementia’ (R 7). Among those who favoured the inclusion of dementia in CDM programmes, similar examples of expected benefits were cited. These included: (i) a well-informed primary care workforce: good dementia required time and GPs would have more time available for their patients; (ii) a reduction in financial strain with reimbursement of out-of-pocket costs through medical card and long term illness booklet, access to social welfare entitlements; and (iii) more clear-but pathways through care.

7.2 Barriers and enablers to having dementia included in CDM programmes

Questions were asked about the main barriers and enablers to having dementia included in CDMPs. A total of 24 different barriers and 14 enablers were identified. The main barriers are grouped below under five main themes in order of frequency:

- *Funding and resourcing*: specifically, the availability of funding to support a very costly model of care that would involve building a well-resourced and supportive eco-system. Such a model might detract from other under-resourced areas such as home care services - crucial for supporting people with dementia to live well in the community
- *Complexity of dementia*: Concerns were expressed about the complexities of dementia which sets it apart from other chronic diseases. It was noted that it was a lot easier to diagnose and manage the other listed chronic diseases. For example, a consultation with a person with diabetes it was stated, might involve a quick check but for a person with dementia, it would involve reviewing medical, psychological and social aspects and would require a tailored response with at times, intensive

intervention. To adequately assess and respond to each individual's situation may require the involvement of a range of health professionals straddling general practice, nursing, occupational therapy, physiotherapy, pharmacy, geriatric medicine, old age psychiatry, disability, neurology, social work, social care, and so on. There were also concerns expressed about the difficulties of moving a complex disease into a CDM programme where it might not be prioritised.

- *Structural resistance and lack of support*: specifically lack of support and buy-in from the Department of Health, Geriatricians, Old Age Psychiatrists, from Health and Social Care professionals and from Integrated Care Teams in an already complex system.
- *Lack of evidence of impact and effectiveness*: reference to the fact that there is an absence of compelling evidence about the cost-effectiveness of CDMPs and challenges involved in demonstrating cost utility and cost-effectiveness - what outcome measures should be used and for whom should the programme be effective?

The main enablers identified by stakeholders are grouped below under three main themes and in order of frequency:

- *Support and buy in from relevant groups*: Support and buy-in was identified as an enabler by stakeholders in several interviews. However, stakeholders offered different opinions as to who could exert most power and influence in this context. Some believed that responsibility rested with the Department of Health, while others saw the HSE as being the key player. There was much uncertainty too about who or which division within the HSE would be best placed to ensure that dementia was included in CDMPs. Some interviewees specified the Assistant National Director of Older Peoples' Services, while others believed that, with the recent restructuring within the HSE, staff in the OCCO with a remit for integrated care were better positioned to do this. The importance of 'buy in' for CDM from the public especially from the very start was also mentioned.
- *Economic evidence of effectiveness*: specifically, if it could be proven that the approach would reduce hospital admissions. There was recognition here that demonstrating cost-effectiveness might prove very challenging.
- *Co-morbidities*: people with dementia often have co-morbidities including other chronic diseases
- *Doing it anyway*: more specifically through the implementation of the NDS

7.3 CDMP for GPs vis-à-vis other programmes

Questions were asked about the inclusion of dementia in the CDMP for GPs, vis-à-vis its inclusion in a range of other programmes that currently exist and are being developed by the HSE - i.e. clinical care programmes (CCPs), integrated care programmes (ICPs) and CDM programmes (CDMPs). ICPOP was praised by about one third of all stakeholders. Most who

favoured this programme saw ICPOPs as the way forward: the model was valued for its potential to build partnerships between hospital and community care staff (R 9) and between primary care and secondary care including memory clinic staff (R, 5). These stakeholders saw no merit in having dementia positioned in the HSE's CDM programmes.

However not everyone shared such positive views and some stakeholders were highly critical of the ICPOP, especially for its role in usurping primary care resources. One respondent - also a family caregiver (R8) - claimed that if primary care teams were adequately resourced then there would be no need for integrated care – 'integrated care teams [are] taking ownership at crisis times ... primary care teams are not properly staffed and therefore cannot take ownership ... [there is] lots of expertise in primary care system but [it's] not being tapped into'. A clinician (R6) working in dementia care stated he was not familiar with the ICPOP model. He reported that GPs had little knowledge or understanding of ICPOPs, and he had not been informed by the HSE about where or when they were introduced. He said 'I did not know, that's [ICPOPs] over my head'.

Data analysis also revealed that there was no shared understanding of the role of or focus within ICPOPs. Some stakeholders were of the view that ICPOPs were concerned primarily with dementia. Others believed that their key focus was on frailty and/or falls. One stakeholder with this latter understanding, commented that because of its focus on older people, ICPOPs would disadvantage people with young-onset dementia, if dementia were to be included (R10). He talked about the real lack of integration in the field of dementia care generally: GPs were working in silos and specialists were pitted against one another; psychiatrists versus geriatricians; geriatric assessment teams versus community mental health teams (R10). Another stakeholder although aware of and supportive of the development of ICPOPs stated: '[you] very rarely hear about dementia from those involved in ICPOP even when they are asked to focus on dementia' (R11). In discussions about ICPOP reference was also made to the number of multi-disciplinary teams that can potentially deliver services to people with dementia in Ireland. These included primary care teams, community mental health teams, memory clinic teams, geriatric assessment teams, and integrated care teams. This same respondent claimed that the role or location of the MDT in the ICPOP model is unclear (R12).

7.4 Positioning of dementia in the Department of Health and the HSE

As mentioned earlier, at the Department of Health, dementia is currently positioned within the social care integration unit. However, responsibility with the CDMP for GPs lies in the Department's Primary Care Division (see chapter 4). In terms of governance structures, opinion was divided as to where dementia should be positioned. Some stakeholders clearly favoured its current position - 'it fits well' especially within the HSE since the clinical lead in dementia (a geriatrician) reports to the clinical lead in the ICPOP (another geriatrician) (R9). However, others believed that dementia was poorly positioned strategically - 'there are so many facets to the HSE and the key people involved in the ICPOP are connected to those in CDM, in contrast to the NDO which does not seem to be at the table' (R12). Several respondents commented about the complexities of dementia and the fact that no matter where it might be positioned, dementia would pose problems. One respondent believed that dementia should not be part of either ICPOP or the CDMP. This same respondent (R10) favoured having a dementia specific integrated care programme. This way the programme

would straddle age boundaries and be inclusive of both people with young- and late-onset dementia.

7.5 Expected Benefits and Potential Risks of including Dementia in CDMs

A series of questions were asked about the expected benefits and potential risks likely to accrue to the individual living with dementia, the family caregiver and the general practitioner (GP) in using a CDM approach to dementia. The section to follow now reports stakeholders' view on these topics.

1. For the person living with dementia

For the individual, a total of 17 expected benefits and 11 potential risks were identified. Table 1 reports on benefits and risks. In order of frequency, the 17 expected benefits are grouped under six main themes:

Table 1: Expected benefits and potential risks for the person with dementia

Expected benefits	
Better integrated care	This includes clear pathways through care and guidelines (R1, R3, R4, R6, R7, R9)
Better entitlements	These included access to medical cards, long term illness scheme and hence reimbursement for drug costs and appliances, right to disability benefit, technology access to peer support programmes and so on (R2, R11, R12)
Better GP access	An early assessment and timely diagnosis: 'this would incentivise GPs' (R7)
Improved recordkeeping	'it will mean that the electronic system in GP practices will be linked to the system in the hospital ... (R1, R2, R4)
Family benefits	Dementia did not just affect the individual but family members were affected (R8)
Primary, secondary or tertiary prevention	(R10, R2, R12)
Potential risks for the person with dementia	
Sub-optimal care due to absence of competencies	Reference here was made to the fact that dementia is complex demanding specialist skills, it requires a well-trained primary care team, GPs would need skills in knowing when to refer patients on for more specialist assessment and care (R5, R6, R9)
Over-diagnosis / misdiagnosis	The perils of GPs being incentivised and of either over-diagnosing or mis-diagnosing R6 and R11
Costs	Concerns were raised about the cost of a CDM approach by GPs and the likelihood that this model of care might take from other service systems – 'spending in one area may lead to cut backs on other area. If there is greater spending in primary care, will there be less available to spend on home care for example' (R7, R8, R11).

Resource allocation	Approach could take from other areas (R7, R11)
Co-location	Teams not always on site (R10)

For the individual, the two most frequently cited expected benefits from using a CDM approach were integrated care pathways and the perception of access to a suite of freely available medication, technologies and supports. Several respondents talked about the absence of care pathways in the current system – ‘primary care teams are working in silos’ and the dangers that can arise especially during transitions in care when information systems are patchy or disconnected.

For the individual, 11 potential risks were identified that are grouped together (Table 1) under three broad themes and in accordance with the frequency of responses. The most frequently cited risk for the individual, was sub-optimal care, arising due to the absence of competencies. Several of the stakeholders commented that dementia care was complex. One respondent said ‘clinicians in secondary services are not on top of it, then GPs are worse’ (R 9). The same stakeholder also emphasised the need for all staff training when he said: ‘All components need to have sufficient competencies [it’s] the best model on paper but ... it could all fall asunder’ (R9). It was noted that lack of specialist skills and training might result in over-diagnosing or mis-diagnosing.

2. For the family caregiver

For the family caregiver a total of seven expected benefits and eight potential risks were identified. Table 2 reports on these findings. In order of frequency the seven benefits are grouped under four main themes:

Table 2: Expected benefits and potential risks for the family caregiver

Expected benefits for the family caregiver	
Additional support	Confidence and reassurance that the caregiver is ‘not on their own’ and can be ‘signposted to the appropriate services’. Also, that there was a sense of comfort in local services (R3, R5 and R7)
Access to Benefits	Comfort in knowing that there is an automatic entitlement to a medical card – related to diagnosis rather than means. Not having a medical card places extra financial strain on families (R2, R12)
Family carers’ own needs can be assessed	Reference to the importance of assessing both the needs of the family caregiver and the person’s own needs (R10).
A structured approach	Pro-active care and a holistic approach with improved communication, better communication if staff are properly skilled with a better information flow (R6)
Potential risks for the family caregiver	
Caregiver Burden	May place additional burden - the ‘carer may have to take on the

	self-management role. Dementia is not a one-person illness but a family illness and family members suffer' (R7, R8, R11)
The Medical Model	Dementia only seen through a biomedical lens. Potential for the focus to be on health services to the detriment of community services and wider community supports. Person may get locked into custodial care with pathways of decline (R8, R12)
Stigma	The approach would mean that more people (team) would know of a person's diagnosis and this might pose problems if the person wanted exclusive ownership of their diagnosis (R1)
Increased expectations	Building up expectations in the absence of competence – 'it's a good model on paper but staffing is critical (R9)
Inflexibility/rigidity	R3

For the family caregivers, the two main expected benefits identified by the stakeholders were: the support and confidence regular contact with the GP would facilitate and the perceived automatic entitlements having a medical card would yield. Respondents talked about the fact that a CDM approach might enable caregivers to feel reassured; that there would be joined up thinking in dementia care; that people need 'hand holding' and the current system was too disjointed.

The eight potential risks for family caregivers identified by stakeholders were grouped into five main themes and in accordance with frequency of responses (Table 2). The main potential risk identified was that the approach might place further strain on already burdened family caregivers. Other risks included the medicalisation of dementia, the stigma associated with more people knowing a person's diagnosis and increased expectations in the absence of required competencies. One person talked about how the approach might lead to an overly rigid system when dementia care should be flexible.

3. For the GP

The section to follow reports on the expected benefits and potential risks likely to accrue to GPs in having dementia included in the new CDMP contract for GPs. A total of 10 expected benefits and 12 potential risks were identified. Table 3 reports on these benefits and risks.

Table 3: Expected benefits and potential risks for the general practitioner

Expected benefits for the General Practitioner	
More time	GPs would have more time to be proactive in dementia assessment, diagnosis and follow up. A belief that GPs were doing this already but would be incentivised to take a specialist interest (R1, R6 and R8)
Awareness of community interventions	GPs may be aware of other interventions in the community established for other chronic diseases and there would probably be better linkage to community services (R7, R9)

A structured approach	Making GPs' work easier, reference here to electronic records, pathways through care and guidelines for dementia management (R1, R2, R3, R5, R12)
Potential risks for the general practitioner	
Increased workload	Several spoke about the extra pressure this would put on GPs given that the latter are already under significant pressure and under-resourced. Could adversely affect their income (R1, R7, R10, R11, R12)
Lack of competencies	Dementia is a complex and specialist area and GPs would need to be upskilled, ['there are] limitations to what GPs can do' and low numbers of patients presenting with the symptoms (R1, R5, R6)
High costs	Excessive costs associated with inclusion; shared care poses challenges and who will be reimbursed for core services? (R8, R9, R11)
Too formulaic and rigid	R3

Once again, the ten expected benefits are grouped thematically and in accordance with frequency cited (Table 3). The main expected benefits associated with the inclusion of dementia in the new CDMP contract was that it would allow GPs more time to assess, diagnosis and support people living with dementia. GPs might also be familiar with other community-based interventions that would be relevant for people diagnosed with dementia and it was noted that there would be comfort for patients in attending local settings rather than attending a clinic. Once again, the structured approach the CDM model would offer GPs was also deemed important for some stakeholders, the approach would result in better record keeping and better links to other allied health professionals.

The 12 potential risks for GPs were grouped according to frequency into four thematic areas and are listed above in order of frequency of response (see table 3). Not surprisingly the main risk for GPs identified by many respondents was an increased workload. Here it was mentioned that GPs are already very busy and that good dementia care takes time; the inclusion of dementia in the CDMP would also have workforce implications. People with dementia tend to have co-morbidities which would place further demands on GPs time. Other potential risks included, GPs lack of competencies in dementia care and the exceptionally high costs associated. One respondent claimed that the CDMP approach might not be sufficiently flexible to accommodate the needs for people who have dementia.

Respondents were also asked the question: should dementia have been included in the new GP contract? Responses here were equivocal. Some believed it should have been included, while others believed it was wise that it was not included and others were very unsure. Once clinician (R6) stated that although he first regretted that dementia was not included in the GP bundle of chronic diseases, perhaps in hindsight this was beneficial since lessons could be learned from the initial trialling of other chronic diseases.

7.6 Costs

Each of the stakeholders was asked a question about how might the CDM approach lead to a reduction in health care costs? Responses to this question were equivocal: some stakeholders highlighted a potential reduction in hospital service use (days spent in hospital) but similar numbers mentioned potential delays in admission to nursing homes. Two stakeholders believed it was too early to comment on how the CDM approach might reduce costs. – ‘don’t’ have figures, it needs more evidence to make an economic case for ... inclusion’ (R4). Several respondents talked about the high costs associated with the CDM approach and the big challenges facing governments in terms of the equitable distribution of scarce resources.

In response to a question asked about potential health care costs arising from adopting a CDM approach, one respondent provided a lengthy narrative, stating: ‘as we know the more things that help means inevitably that costs will go up ... if you get it right people will live longer. I firmly believe what you can do with good tertiary care [is you] can probably squeeze most troublesome symptoms of dementia into later stages for the disease but to give support to do this is very expensive’. Another stakeholder stated that dementia as an illness is hugely under-resourced and under-prioritised in government spending but caution was now needed: it was time to review the overall situation in Ireland and plan future directions. The same stakeholder said that the inclusion of dementia in CDMP for GPs could potentially cause expenditure cuts in other very important areas already under-resourced such as home care. This stakeholder questioned the expected outcomes of such a policy decision and for whom? [is it] increased numbers with a diagnosis, improved well defined pathways of care, increased resources to GPs or budgetary implication for the state? Another clinician was somewhat dubious about the feasibility of reimbursing GPs for dementia, if dementia were to be included in a CDMP for GPs. He suggested there might be other ways of commissioning or engaging GPs in the area of dementia care, outside of the CDM model.

7.7 Summary

This chapter has reported interview findings from a diverse range of stakeholders on the merits and demerits of including dementia in chronic disease management programmes broadly and more specifically in the HSE’s new CDMP for GPs. In the opening part, it was shown that while most stakeholders believe that dementia can be framed as a chronic disease, opinion is divided on whether or not it should be included in CDM programmes. For some, the recent development of ICPOPs by the HSE work well: they are inclusive of dementia and therefore negate the need for dementia to constitute a stand-alone clinical programme or to be part of other CDMPs. However, for others this is not the case. Opinion was also divided as to whether dementia should have been included in the first phase of the new CDMP for GPs.

The chapter has also reported on both the potential barriers and enablers to having dementia included in future CDMPs. Barriers identified include: (i) the high costs associated with its inclusion; (ii) the complexity of dementia; (iii) structural resistance, including lack of buy-in from key stakeholder group; and (iv) the need for a better evidence base. Enablers identified include, (i) co-morbidities commonly associated with dementia, some of which

are other chronic diseases; (ii) buy-in from relevant parties (Department of Health, the HSE and the public; and (iii) a belief that this is being done anyway.

The second part of the chapter advanced to a discussion of the benefits and risks of including dementia in CDMPs. Interestingly, the largest number of expected benefits (17) identified were those likely to accrue to the individual. They included better integrated care, more entitlements and improvements in GP care and primary secondary and tertiary prevention. The greatest number of risks identified (12) were those likely to be experienced by GPs. These included increased workload, lack of competencies since dementia was considered a specialist area and the high costs of delivery. For family caregivers, a similar number of expected benefits and potential risks were identified. Risks here included increased caregiver burden and the medicalisation of dementia with a stronger emphasis on health services rather than on community supports. Benefits were additional supports and access to benefits. No consensus was found among the stakeholders regarding the potential economic gains likely to accrue from using a CDM approach to dementia care management.

Chapter 8 A Synthesis of Findings

The primary aim of this policy review was to examine the case for including dementia in the CDMP for GPs. Making a case for its inclusion is not a simple exercise and there were probably a number of valid reasons why the four chronic diseases identified - cardiovascular disease, diabetes, asthma and COPD - were chosen for this first phase of the new GP contract. These include the fact that these chronic diseases affect a larger number of people; diagnostic criteria are clear cut; stand-alone national clinical programmes already exist, as does a chronic disease management programme (CDMP) and early intervention appears to reflect value for money. In contrast, dementia has the potential to pose significant challenges. First, dementia is not a disease per se, but rather it is a syndrome underpinned by a whole plethora of different diseases. Nor is dementia, in terms of prevalence and political traction a 'high hitting disease' compared with the chosen bundle for the new CDMP for GPs. The chosen chronic diseases affect larger numbers of both young and older people. Third, unlike the identified bundle of chronic diseases for which there are already existing HSE national clinical programmes, there is no extant national clinical programme for dementia. There has also been a history of an absence of agreement over diagnostic criteria for Alzheimer's disease (AE, 2014).

In Chapter 6 we looked in depth at the three core components of the GP contractual reform, as agreed between the Department of Health the HSE and IMO, to explore the feasibility of including dementia. These components are: (i) opportunistic case finding; (ii) annual preventive programme; and (iii) a structured treatment programme for those already diagnosed. In Chapter 7 we reported findings from the interviews with the key stakeholders. In chapter 4 we discussed the complexities of HSE structures. This chapter aims to synthesise these findings. It starts with a return to the technicalities and logistics of the new CDMP for GPs, teasing out how easily dementia might be included in a revised version of this contract.

Opportunistic case finding programme

The first component of the new GP contractual reform is the Opportunistic Case Finding Programme. In its current format, its aims are twofold: (i) to identify patients at high risk of cardiovascular disease or diabetes for entry to the Preventive Programme; and (ii) to identify those with undiagnosed but listed chronic disease(s) for the Structured Treatment Programme. With regard to the former, we argued that people identified at high risk of cardiovascular disease or diabetes will also be at high risk of dementia and, therefore, some of the main risk factors for dementia will be addressed through this component. However, we showed that there are additional risk factors for dementia that are not currently being addressed through the programme that would be feasible for the programme to include. Before their inclusion in the opportunistic case finding programme, however, some exploratory work will need to be undertaken including the acceptability of addressing dementia risk reduction among GPs and practice nurses, and the impact this will have on general practice time.

With regard to identifying those undiagnosed for the STP and the future inclusion of dementia as a listed chronic disease for GPs, we considered the feasibility of using an opportunistic case finding approach. Based on the literature we showed that, in the context of dementia, opportunistic case finding cannot be recommended since there is insufficient

scientific evidence available pointing to its merit. However, we showed that there are tools already built into general practice IT systems that could be used by GPs to enable them to quickly identify people with dementia. These are people who might also benefit from enrolment in the Structured Treatment Programme. Accordingly, the key approaches GPs would take to identify people would not be opportunistic case-finding but rather recognition of clinical signs and symptoms and the investigation of subjective concerns. If dementia is to be included in the CDMP for GPs in the future, GPs must take account of these well-recognised approaches. They must also take account of pathways to dementia diagnosis which differ from other chronic diseases. In this context, several lessons can be learned from PREPARED project.

Annual Preventive Programme

The second component of the new CDMP for GPs is the Annual Preventive Programme. It focuses on people at high risk of cardiovascular disease and diabetes who are offered an annual GP and practice nurse visit for risk factor and health promotion advice. We have shown that this programme also offers a window of opportunity for GPs to include people who have a high-risk factor profile for dementia, for advice on risk reduction and primary prevention and we have shown that this would be feasible to do. Importantly, it would build on, complement and strengthen the HSE's current dementia risk reduction awareness-raising programme and would signal a more joined-up strategy to dementia prevention in Ireland.

However, we argued that to operationalise this, some prerequisites would need to be met. These include the upskilling of GPs and practice nurses in the area of primary prevention and dementia. In addition, and for optimal use of their valuable time and scarce resources, the development of off-site programmes such as mobile health interventions currently in evidence in other parts of Europe to which GPs and practice nurses could prescribe, would be beneficial. There is also potential for the development of a link worker approach for socially prescribing or referring people with modifiable risk factors for dementia to mobile health interventions or to community-based interventions and resources available in the area.

The Structured Treatment Programme

The third component of the new GP contractual reform - the Structured Treatment Programme - was also reviewed in relation to its capacity to accommodate dementia. This is in our view the component of the CDMP for GPs that will need to be most carefully and substantially revised if it is to accommodate people with dementia. This is because issues pertinent to dementia but not nearly as pertinent to other chronic disease will need to be addressed. These include the high level of underdiagnosis of dementia, the complexities of diagnosis, and issues around open disclosure. A Dementia Diagnostic framework project and a Dementia Disclosure Framework project are currently being developed by the NDO, and if the CDMP for GPs is to be revised to include dementia, it will need to carefully align with build on and complement these developing frameworks.

Elements of this STP such as more regular contact with GPs and practice nurses and provision for even more visits for those with multi-morbidities, align well with the needs and desires of people with dementia and their family caregivers. However, other elements may

pose a challenge. One of these is self-management. This is considered a core feature of the STP and widely recognised as a necessary and key component of CDM. Within a CDM approach, the goal of self-management is collaboration between health professionals and an informed and activated person and their family. However self-management is complex and potentially problematic for people with a diagnosis of dementia. It can also place additional burden on family carers as was highlighted in our stakeholder interviews. It also became clear through these interviews that policy makers, policy implementers, health professionals and service providers often lack basic knowledge and awareness about the principles of self-management in the context of dementia. Interestingly this potential barrier to CDM has been highlighted in the literature. For example, Jagdal et al. (2014) have argued that unless this knowledge gap is addressed, self-management will not be seen as a priority in dementia care. People with dementia are vulnerable to poorer outcomes if they are unable to negotiate self-management (Ibrahim et al., 2017).

Expected benefits and potential risks

In Chapter 7 we reported stakeholders' views on both the expected benefits and potential risks that may arise by including dementia in a CDMP. Benefits and risks were investigated for the three different groups, the individual, the family caregiver and the GP. Findings revealed that expected benefits outweighed potential risks but only marginally. Interestingly most of the expected benefits identified were likely to accrue to the individual and included integrated care, perceptions of free entitlements through medical card and long-term illness scheme,¹⁵ more ready access to GPs, better record keeping, family benefits and a stronger focus on risk reduction and secondary/tertiary prevention. Expected benefits for the family caregiver were not that dissimilar and included reassurance that the carer was not 'doing this alone', beliefs about access to reimbursement schemes, a structured approach and scope for carer needs' assessment and support.

Potential risks were many and evenly distributed between GPs (12 risks identified) and the person with dementia (11 risks identified). The issue of the complexity of dementia and the absence of a well-trained and competent workforce were identified as risks for both these two groups. Risks for the family caregiver of having dementia framed as a chronic disease included increased caregiver burden, the medicalisation of dementia with a greater emphasis on health services rather than on home and community care services and increased expectations on the part of family caregivers in the absence of a well-trained workforce.

Barriers and enablers

In the same chapter we also explored stakeholders' views about barriers and enablers that might facilitate or mitigate against dementia from being included in CDMPs. More barriers than enablers were identified by the stakeholders. Not surprisingly funding was identified by many as the main barrier. The CDM for dementia care was considered a very costly model of care that would require the development of a well-resourced supportive eco-system. A high level of investment would be required especially in primary and home-based community

¹⁵ The inclusion of dementia in the CDMP for GPs would not lead to the inclusion of dementia in the Long-term Illness Scheme (LTI). However, a review of the LTI Scheme is to form part of a review of the current eligibility framework, including the basis for existing hospital and medication charges, to be carried out under commitments given in the Sláintecare Implementation Strategy.

care services and although that investment might in time yield dividends, the return on investment would be long term. Questions were also raised about the existence of a compelling evidence base to support the CDM in the context of dementia.

Concerns were also expressed that this model might detract funding from other already under-resourced areas in the field of dementia services. In discussions about potential barriers to the inclusion of dementia in a chronic disease framework, the issue of the complexity of dementia was also raised – dementia straddled so many different disciplines: there might be difficulties moving a complex disease into a CDM programme where it might not be prioritised in relation to other ‘hard hitting’ chronic illnesses. Interestingly in terms of enablers, the support and buy-in from relevant interest groups was identified as the most important enabler but no consensus was found about who these relevant groups were. Some saw the public as being the main advocacy group to articulate the need for dementia to be included in a CDM framework, while others saw the HSE and more specifically the new OCCO and others again the Department of Health.

The need for intersectoral working

The work for this policy paper has also required us to examine governance structures and systems within the HSE and the Department of Health especially those pertaining to where dementia is currently positioned. A key issue uncovered is that there needs to be more joined up thinking across different programmes and projects currently being developed within the HSE, and greater intersectoral working between its different divisions. For example, the NDO is currently engaged in developing a range of dementia frameworks. It sits in the Social Division of the HSE and its clinical lead reports to the Office of the Chief Strategy and Planning Officer. However, the Lead on ICPOP (of which dementia forms a component) is now part of the Clinical Design and Innovation and Design Division and reports to the Office of the Chief Clinical Officer. In addition, the responsibility for the new GP contract in the HSE (for which we are making a case for dementia inclusion) lies in the National Contracts Office, which is part of the Primary Care division and reports to the Office of the Chief Operations Office.

Based on this policy review it appears that much programme development within the HSE is taking place and occurring in parallel. Intersectoral collaboration may be considerably weakened by the (perceived) positioning of the NDO, or as one of the stakeholders succinctly said: ‘the NDO is on the margins and has poor linkages with CDM or ICPOP, except through its clinical lead’. There is a need for the integration of dementia across each of these important programmes: for integration of primary care with the two Integrated Care Programmes namely, ICPOP and ICPCD and for the full integration of these programmes with the on-going work of the NDO. There is a need for intersectoral collaboration, as recommended in the Expanded CCM for neurological disease, not just among health professionals interacting with people with dementia but also among senior officials within organisations such as the HSE.

Integration

Dementia is a complex condition that lends itself well towards integrated care pathways and the seamless system or model of care that is currently being developed by the NDO. This is not in evidence in the new model of CDMP for GPs. Throughout several of the stakeholder

interviews, reference was made to the importance of dementia care pathways and integrated care and the expected benefits this collaborative approach would yield for the individual living with dementia. It was argued that GPs could not do this alone, there was a need for better partnerships in dementia care to be developed between various health service professionals in primary, secondary and tertiary care. It was claimed that the current system of service delivery was fragmented and not working – ‘nothing was knitting together’.

While there are similarities between integrated models of care and chronic disease models, we would argue that the extant model of CDMP for GPs does not reflect the principles of integrated care or shared care. Integrated care programmes are about partnerships between the community and hospitals and in the case of dementia, between staff in primary care; memory clinics; community mental health teams; integrated care teams and those working in the residential care sector. Best practice is about holistic models of care that involve interdisciplinary teams and integrated care programmes are about overcoming disciplinary boundaries and about coordinating care between primary secondary and tertiary health service professionals.

If health care policy in Ireland is to be guided and informed by the Sláintecare recommendations, then the model of integrated care it embraces is one that values both horizontal (across disciplines and departments) and vertical (across care sectors) integration. However, this notion of horizontal and vertical integration is not in great evidence in the new CDMP for GPs. It is also one that puts the person at the centre of the system.

Summary

In this chapter we have used interview data and an interrogation of the new GP contract to make a case for the inclusion of dementia in future revisions of the CDMP for GPs. We have highlighted some of the potential barriers that might impede the inclusion of dementia in future revised GP contracts and how these could potentially be overcome. We have also shown some of the key enablers that could facilitate the inclusion of dementia in revised contracts and how its future inclusion could benefit people either at high risk of developing dementia or those who already have dementia. We have also shown some of the current complexities within HSE structures which will need attention if dementia is to be fully integrated into the range of aligned programmes. We have argued that there were probably very valid reasons why dementia was excluded in the new CDMP for GPs but that this exclusion does not necessarily mean it cannot and will not be included in future revised contracts. In this way, this chapter acts as a useful backdrop to the final chapter which will draw conclusions and make important recommendations.

The second part of the chapter advanced to a discussion of the expected benefits and potential risks of including dementia in CDMPs. Interestingly the largest number of expected benefits (17) identified were those likely to accrue to the individual and include better integrated care, better entitlements, better GP care and primary secondary and tertiary prevention. The greatest number of risks identified (12) were those likely to be experienced by GPs. These include increased workload, lack of competencies since dementia was considered by several as a specialist area and high costs of delivery. For family caregivers, a

similar number of expected benefits and potential risks were identified. Risks included increased caregiver burden and the medicalization of dementia with a stronger emphasis on health services rather than on community supports and benefits identified were additional supports and access to benefits. No consensus was found among the stakeholders regarding the potential economic gains likely to accrue from using a CDM approach to dementia care management.

Chapter 9 Conclusions

In Ireland there are somewhere between 39,000 and 55,000 people currently living with dementia and every year, approximately 10,000 people (between 7752 and 13,733) are likely to develop the condition (Pierse et al., 2019). In Ireland the total number of people with dementia is projected to reach 115,426 by 2036 and 157,883 by 2046. The magnitude of dementia therefore cannot be underestimated. Like in other countries, in Ireland, dementia leads to increased costs for the individual, for families, for communities, for society and for the government. Although for the government, the economic cost of dementia is high and of concern especially towards the end of life: for the individual and for family caregivers the social and emotional costs are also very significant and add substantially to the economic burden many people have to endure. In Ireland, the annual cost of dementia has been estimated to be €1.69 billion.

How dementia is understood and responded to is rapidly undergoing change in Ireland (O'Shea et al., 2019). From traditionally being understood as a cognitive brain disorder, informed by a disease model, public discourse on dementia has more recently shifted and expanded to incorporate broader perspectives. These perspectives are informed by social and biopsychosocial models that focus on the preservation of personhood and on a wide range of non-biological factors. Aligned with this broader focus is the reablement approach, that supports human rights, promotes choice and autonomy and is designed to, as far as possible, give the person with dementia control over their own life. How dementia is framed is important as it will inform the way in which policy makers respond to the condition and the type and quality of service designed and delivered (Cahill, 2018).

Internationally, a momentum is also now growing to frame dementia from a public health (WHO, 2012, Travers et al., 2015) and human rights perspective (WHO, 2017). The public health framing has only recently begun to be embraced by policy makers in Ireland (Sláintecare, 2017). It has yet to be taken on board by GPs, who tend to encounter people with dementia in crisis and often later rather than earlier in the course of the condition. If in Ireland, dementia was to be included amongst chronic diseases for GP management, this would mean that GPs would need to adopt a public health approach to dementia care. It would also mean that GPs would play a key role in the primary, secondary and tertiary prevention of dementia. This paper has shown how the new GP contract, currently being implemented in Ireland could, with relative ease, be revised and expanded to accommodate this new role. But a critical question here is: would there be buy-in from GPs, the Department of Health, the HSE, the IMO and other key stakeholders for this and how might the new role of GPs be best supported?

This public health framing of dementia reminds us of the value of conceptualising dementia as a chronic disease. This conceptualisation does not mitigate against dementia being framed in any other way as the complexities of dementia are such that it demands multiple responses and a broad range of different frameworks. In Chapter 2 we showed that, despite the fact that dementia has all the hallmarks of a chronic disease, it is not generally recognised as one. These hallmarks include the fact that the condition lasts longer than three months, dementia cannot be cured, lifestyle factors play a key role in its aetiology and people who have dementia also tend to have other comorbidities, at the rate of on average

2.4. The overlap and synergies between strategies for reducing dementia risk and those for mitigating the risk of cardiovascular disease and diabetes cannot be overlooked. All of this means that dementia can no longer be looked upon as a single syndrome or as an afterthought. Dementia needs to be mainstreamed into all chronic disease management programmes.

This paper has looked at the technical aspects of what it would mean for dementia to be categorised as a chronic disease. We have demonstrated that one of the core strengths of taking a CDM approach is the emphasis this would place on primary prevention. Up to about 40% of all dementias are preventable and might be averted if the individual took cognisance of lifestyle and other cardiovascular risk factors in earlier years, and even in mid-life and later years dementia risk reduction continues to be relevant. We have shown that risk reduction is already clearly built into the CDMP component of the new GPs contract, in the form of the Annual Preventive Programme. Ironically therefore, people at high risk of developing dementia will in the future be identified for enrolment onto this GP programme not by design, but more by accident, because of the modifiable risk factors that dementia shares with cardiovascular disease and diabetes.

Furthermore, there are tools (dementia risk profilers) already available that would make it feasible to readily identify people with modifiable risk factors for dementia. In this way it would be both desirable and achievable to purposely design and incorporate dementia risk reduction into the preventive programme. What shape the preventive programme would take for people at high risk of developing dementia is open for debate. However, we have suggested several options including an 'on-site' approach, using specialist trained practitioners (e.g. Link Workers), working collaboratively with general practice, or using off site, low cost options, such as mobile health interventions or community-based resources. The CDMP for GPs offers a promising window of opportunity for GPs to become more proactive in the area of dementia prevention especially in providing lifestyle and risk reduction advice.

In terms of what it would mean for GPs if dementia was included in a new bundle of chronic diseases, we have argued that opportunistic case finding cannot be recommended. This is based on the literature where currently there is insufficient evidence to justify opportunistic case finding in the context of dementia in general practice. However, as mentioned, we have shown the tools that could be used to enable GPs to quickly identify those people with dementia who might benefit from enrolment onto the Structured Treatment Programme. Our review of this component of the new contract would also suggest that if in the future, dementia is to be included as a chronic disease, careful attention must be paid to the issue of dementia diagnosis and disclosure, since GPs are usually the first point of contact for people worried about signs and symptoms of dementia. If GPs were encouraged and rewarded in this area, through a revised CDMP for GPs, this would also help to deliver on the commitment set down in the NDS to support GPs to engage in a timely diagnosis of dementia. It would also help to build on work completed by the PREPARED project and the valuable work already underway by the NDO, in relation to dementia diagnostic and post-diagnostic pathways and their more recent work programme that looks at dementia disclosure pathways.

In terms of the logistics and technicalities of including dementia in the CDMP for GPs, it needs to be remembered that dementia complicates the management of chronic diseases including cardiovascular disease, diabetes, asthma and COPD. Failure to recognise the presence of dementia in a person with one or more of these other chronic illnesses can lead to poorer outcomes. The likelihood that a sizeable proportion of people identified for the STP component of the new GP contract may either already have dementia has not been fully acknowledged in the current design of the STP. We would contend that this is a serious oversight and needs urgent attention, whether or not dementia is included at a future date in a revised version of the GP contract.

Self-management is also central to the STP component of the new CDMP for GPs, where there is a commitment to a patient centred approach. Self-management enables patients and their clinical providers to work in partnership. It means that patients are supported and empowered to be involved in their own care. If dementia is to be included in the STP in its own right, the self-management aspect of the STP will also require considerable attention and revision and we have detailed some of what we believe is needed in this context. Although people with dementia want to be involved in their own care, we know from the literature that there is a widespread absence of knowledge and understanding of the principles of self-management amongst health service professionals in the context of dementia. This finding was also strongly reiterated by several of our stakeholders. To optimise their capacity for self-management, people with dementia require strategies that are individually tailored and take account of the cognitive domains that are impaired.

In making a case for the inclusion of dementia in CDMP for GPs, we have looked at practices in other jurisdictions where CDM models have already been implemented. In this context, collaborative dementia care models used in primary care and delivered in a range of overseas countries offer useful insights. In particular we have reviewed three well known models: (i) the Wagner CCM; (ii) collaborative dementia care models; and (iii) the CCM for neurological conditions including dementia. We would argue that there are elements from all three of these models that have broad application for dementia care in general practice in Ireland. In particular the collaborative dementia care models described by Heintz et al. (2019) where a dementia care manager acts as a conduit between primary care, old age psychiatry, behavioural neurology, nursing and social work, has resonance for the future direction of dementia care services in Ireland. In this model, the training and support offered to the DCM means that the GP's time can be spent more efficiently, acting as an anchor for treatment and care, but allowing the necessary case management aspects of dementia to be undertaken by a trusted third party. In Ireland, the recent evaluation of the NDO's Post-diagnostic Support Grant Scheme showed that once a diagnosis is made, an opportunity arises to guide and appropriately refer people to community-based post-diagnostic dementia supports (Pierce et al., 2019). The latter obviously needs to be done in negotiation with the individual and their family members. The assessment, negotiation and care planning that this type of referral requires could potentially be facilitated by a DCM. In this context there is scope for the Dementia Adviser role in Ireland to be further finetuned.

There are several elements of the CCM-NC, that also have broad application for dementia care in general practice in Ireland. In particular the community integration component of the model, where recognition is given to the need for support, in transitions in care and for

the promotion of continuity of care within and between health sectors and government departments is vitally important. In many countries including Ireland, the transition between hospitals, the community and long-term care facilities for people living with dementia is not well handled. This model emphasises the need for case coordination, for protocols to be developed and for smoother transitions into long term care. The political context of this model is also noteworthy for Ireland, where it is highlighted that policies pertaining to dementia should be needs-based rather than condition-specific and should encourage individual engagement and autonomy. Also, the theme of life-enhancing resources, where there is a reminder that dementia care is broader than merely health and social care and extends to other policy areas including housing, employment, education and transport must be recognised. This same theme about the importance of greater collaboration between various government departments and agencies each committed to dementia care has recently been emphasised in the continuum of care report on dementia for Ireland (O'Shea et al., 2019).

This paper has also looked at how including dementia in the CDMP for GPs could inform and build on work currently underway by the NDO as part of the implementation of the NDS. It has enabled us to take a closer look at the NDS, interrogating it through a CDM lens. We have shown that many of the building blocks for framing dementia as a chronic disease and for taking a CDM approach to dementia care are already in evidence in the NDS. These have been discussed in Chapter 4 and include primary prevention, information systems and multi-disciplinary teams. They build on earlier HSE and Irish based dementia-specific work as, for example, the PREPARED project.

Personhood and citizenship are the core principles underpinning the NDS. Broadly speaking these principles focus on the person and differ from the principles underpinning a CDM framework where the emphasis is more on systems, settings, clinical decisions, teams and monitoring. Some stakeholders were concerned that the aspiration of personhood and person-centred care could get dislodged or worse still, cast aside, as a result of framing dementia as a chronic disease. The latter, it was argued, could potentially lead to an overemphasis on the disease rather than the person, especially if there is an over-concrete/rigid application of the CDM approach. Therefore, it is crucial that the principle and practice of personhood is embedded into a revised version of the CDMP for GPs.

The implications of a CDM approach for people living with dementia, their caregivers and GPs has also been explored. Our stakeholders identified a total of 34 expected benefits and 31 potential risks. For the individual, expected benefits included more structured dementia care pathways, better access to GPs, better record keeping and a greater emphasis on secondary prevention. There was also a perception that the approach would lead to a medical card or and/or long-term illness scheme entitlement. For GPs, one of the biggest risks identified by stakeholders, was excessive workload and sub-optimal care arising due to lack of competence in the area of chronic disease management and dementia care.

Policy makers need good information on costs and outcomes to base wise decisions on resource allocation (O'Shea et al., 2019). Accordingly, we have also looked at the topic of the cost-effectiveness of using a CDM approach in dementia care and we have shown that the evidence base here is mixed and in no way compelling. In this context, the Heintz et al.,

(2019) narrative review is probably most pertinent to our work and although it has shown that enrolment in collaborative dementia care models is associated with less frequent use of acute medical services, this has yet to be fully tested. Only one of the seven models, based in Indianapolis, reviewed by Heintz and her colleagues, showed overall savings of \$1.05 million. Another programme implemented in California, proved to be cost neutral for Medicare when programme costs were considered. We also showed that based on an EU commissioned report investigating the impact of integrated care programmes for chronic disease the evidence base was equivocal. What is clear from the experience of implementing the CCM in other countries is that redesigning the CDMP for GPs to include dementia will require investment in the short term, and it is harder to determine if there will be cost savings in the longer term.

A critical feature of health and social care systems informed by chronic disease models is effective communication and shared decision-making between health and social care professionals across an integrated system of care. Integrated care is said to be the glue that binds the different elements of a health care system together enabling it to achieve common goals and optimal outcomes. In relation to integrated care, we would regard the new CDMP for GPs as restrictive. In the context of GPs playing a significant role in dementia care from a CDM perspective some questions must be raised. These include: (i) Is it preferable to have a stand-alone CDMP for GPs that is inclusive of dementia or a model of care for people with dementia that is integrated across the whole health care system? (ii) can we combine the two? (iii) if dementia were to be included in a new bundle of chronic diseases for GPs, will it first need to be included in clinical care programmes and more explicitly spelt out in the Integrated Care Programmes? (iv) do we need, as suggested by one stakeholder, a separate programme on integrated care for dementia?

There are risks and benefits associated with any decisions that policymakers take when resources are scarce. Although, as mentioned the evidence for the cost-effectiveness of CDMPs in the context of dementia care is weak, we can categorically argue that in Ireland dementia care is under-resourced and needs more public investment. This is the resounding message from a wealth of economic studies on dementia care conducted in Ireland over the past ten years (Connolly et al., 2014; O'Shea and Monaghan, 2017; Carter et al., 2019; Walsh et al., 2019). This is because the prevalence of dementia is increasing, family members on whom the main bulk of caring falls, may not always be available to care, and people want better quality services. In addition, philanthropic funding in Ireland has run out, and we can no longer continue to rely on grants from Dormant Accounts to support what in some cases, constitute basic health and social care services for people who have dementia or those are at risk of developing dementia.

In identifying future directions for the design of dementia services, it is important to remember that recommendations for the inclusion of dementia in the CDMP for GPs will have profound implications for priority-setting and resource allocation. The CESRD has recently argued that if personhood is to be taken seriously, decision-making with regard to priority-setting and resource allocation in research and policy must include the strong and authentic voice of people with dementia and carers. This means that people with dementia and family caregivers must be directly involved in the interpretation and narration of research results for subsequent policy action (Keogh et al., 2019). Through its

“Conversations on Dementia Policy”, a series of engagements and events, the CESRD has demonstrated the use of Policy Café and Carers Assembly style events to engage and elicit the views of people with dementia and their family carers in response to research.

In line with the CESRD’s thinking, one key recommendation for future action in this area is that: the ASI organise a forum to communicate the main findings of this policy paper to people with dementia and their family carers. Further recommendations could then be developed based on their feedback and deliberations. Such recommendations might include that:

1. A round table discussion takes place that brings together senior officials from the NDO and from other key offices working in the field of dementia services in Ireland. The discussion would centre around teasing out what is needed to make the inclusion of dementia in the CDMP for GPs a reality, and to ensure its integration with the NDO’s pre-existing work programmes and other HSE clinical and integrated care programmes.
2. The findings are shared with GPs, following which the ASI could explore the acceptability among GPs and primary care staff of extending the GP Preventive Programme to include dementia risk reduction. This would entail exploring with key stakeholders the feasibility of adopting different options available for the design of such as preventive programme. It would also entail the development of an education and training module on dementia risk reduction for GPs, practice staff and other primary care professionals. Findings in relation to the inclusion of dementia in the Structured Treatment Programme could also be explored with GPs.
3. A research study is undertaken in collaboration with a small number of GPs signed up to the new GP contract. Its purpose would be to identify the prevalence of cognitive impairment and dementia among people with the known listed chronic diseases who are already enrolled on the STP. The study would also investigate how dementia complicates the management of other chronic diseases, and how GPs and practice staff can best be supported to manage chronic disease in the context of dementia. Findings would be used to inform the future development of the STP.
4. The development of an education and training module on self-management and supporting resources in the context of dementia for GPs, practice nurses and other primary care professionals.
5. Test the feasibility of embedding a collaborative dementia care model in general practice and demonstrate what a structured treatment programme based on this model would look like. This could be done thorough a stakeholder consultation led by the ASI. This would inform the feasibility and design of such a programme.
6. Consider the possibility of designing a longitudinal study in the area of dementia risk reduction using TILDA data.

In conclusion, this policy paper has explored the case for including dementia in the new CDMP for GPs as part of the GP contract agreed between the Department of Health, the HSE and the IMO in 2019. It has highlighted some of the complexities involved in making a case for dementia to be included: the obstacles that would need to be overcome; the type of buy-in that would be required; the risks that could possibly arise and the fact that in the context of dementia, a CDMP approach would require significant investment. The costs incurred will depend on what choices are made with regard to revising the CDMP for GPs. There is a risk that these costs, especially if they prove to be extremely high, might detract funding from other service sectors already under-resourced. Notwithstanding this, we have highlighted the feasibility of extending aspects of the new CDMP for GPs contract, to make it more dementia-friendly and to ultimately lead to dementia being included in a future bundle of chronic diseases. While we can only speculate as to why to date, the inclusion of dementia as a chronic disease has not happened, this policy paper has provided an opportunity to look afresh at the CDMP for GPs through a dementia lens. In so doing it has enabled us to offer policymakers and stakeholders some direction for the next iteration of this programme.

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Appendix I: Chronic Care Model Components

Chronic Care Model components

Health system – organisation of health care	Health care planning that includes measurable goals for better care of chronic illness
Self-management support	Emphasis on the importance of the central role the patient has in the management of their own care
Delivery system design	Focus on teamwork and an expanded scope of practice for team members to support chronic illness
Decision support	Integration of evidence-based guidelines into everyday practice
Clinical information systems	Developing information systems based on patient populations to provide relevant client data
Community resources and policies	Developing partnerships with community organisations that support and meet patient needs