MHPF
National Alliance of Voluntary Sector Mental Health Providers

The interface between dementia and mental health

An evidence review

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Together with 21 other "not for profit partners", they link strategically with t he Department of Health, NHS England and Public Health England undertaking specific agreed work programmes aimed at benefiting the strategic development of the "not for profit mental health sector".

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Executive summary

While there has been considerable and welcome attention in the area of dementia over recent years, the mental health of people in later life, and specifically the complex relationship between dementia and mental health problems, is a neglected area in public discourse, policy and service provision. In this paper we explore the relationship between dementia, mental health and mental health problems.

To do this, an evidence review was carried out to explore the extent that people living with dementia have co-existing mental health problems. The review initially examined the limited available literature on the incidence and experiences of comorbidity of dementia and mental health problems. Several interviews were then undertaken to get a clearer idea of the real world experiences of those working with people living with dementia and mental health problems, to help fill some of the current gaps in literature on comorbidity.

It begins with a section discussing the similarities and differences between dementia, cognitive impairment and mental health problems, followed by a section on the identification issues. We then discuss the current policy in relation to mental health and dementia, and the social and economic costs associated with both. Care, service provision and treatment methods identified through the review are then discussed, followed by gaps and resources. The review ends with some recommendations based on the findings of the review.

The main finding of this review is that comorbidities are underdiagnosed in people living with dementia, not extensively researched and therefore not understood fully. The relationship between dementia and mental health problems is not well documented, and extensive searching found relatively little literature on the challenges or experiences associated with living with this co-morbidity. There was also an overwhelming lack

of literature on the care needs of those with dementia who develop a mental health problem or for those with a pre-existing mental health problem with develop dementia. This translates into a lack of understanding within service provision and an absence of specialised services for people living with both mental health problems and dementia, which was confirmed through the interviews with people working as service providers.

Based on our review of the available information, we have produced the following recommendations:

Policy level

- Co-produce a mental health and dementia research programme with people with lived experience of this co-morbidity, their families and carers.
- Develop data systems to ensure mental health and dementia data can be analysed in an integrated and strategic manner to inform provision, policy and research.
- Develop policy and practice guidance on the mental health needs of people living with dementia.

Organisation level

- Develop relationships between mental health and dementia representative organisations and the wider disability movement; and advocate for the inclusion of people living with mental health problems and dementia within the UN review of the UK's compliance with the Convention on the Rights of Persons with Dementia.
- Develop a rights based approach to health and social care provision for people living with mental health problems and dementia, and their families and carers.

Programme level

- Develop a programme to pilot social inclusion and community based interventions, and to scale and test promising approaches.
- Develop programmes of provision, guidance, policy and research for people with early onset dementia; and scale and test promising approaches.

Cross-cutting

- Ensure that co-production principles and approaches are adopted across all provision, policy, research developments and resource the work of representative organisations such as the Dementia Engagement and Empowerment Project and the Dementia Alliance for Culture.
- Develop programmes of provision, guidance, policy and research for members of BAME communities; and scale and test promising approaches.

Introduction

The population of the UK is ageing, with the average age of the population on the rise and the number of older people increasing, due in part to ageing of large cohorts born after both World Wars and the 'baby boomer' generation of the 1960s. The UKs population over the age of 50 makes up over a third of the population, with latest statistics putting it at 23.2 million.[1] The number of people aged 75 and over has increased by 89% since 1974.

An ageing population presents new health challenges for the health and social care systems to manage. One such challenge is the increasing number of people living with dementia, including the sometimes forgotten proportion of people who develop early onset dementia. Another is the number of older people living with mental health problems. A third, but often overlooked challenge is the population of people living with a comorbidity of both dementia and poor mental health.

Although there has been considerable and welcome attention in the area of dementia in recent years, mental health in later life is a neglected policy brief. As a result the prevalence of comorbidity has receive little of the attention it deserves, both in the general population and in marginalised communities.
The aim of this report is to provide a comprehensive, equity focused review, that equips those working in or interested in dementia, later life and mental health problems with a clear understanding of the relationship between dementia and mental health.

Methodology

The Mental Health Foundation is an independent UK charity working across both dementia and mental health. This review has been undertaken to identify: what is known about people living with dementia and mental health problems, what policy exists in relation to this comorbidity, and what services and resources exist for those working with people living with a comorbidity of dementia and mental health problems. The review gathered evidence from a selective literature review and interviews. Annex 1 contains the full methodology followed for this evidence review.

Terminology

Later life is broadly defined as starting at 50 years for this report. While we recognise that most do not self-define as 'older people' at this stage in their lives, many people will begin to experience a physical decline or deterioration in their 50s, many begin to seriously plan for their retirement, take early retirement or find it difficult to secure employment. Those in society who face inequalities such as poverty and poor mental and physical health are also more likely to experience the effects of ageing earlier in their life course, and a later definition does not recognise and accommodate these factors.[2]

Although there are variations on how the term 'comorbidity' can be used, it is defined here as two or more conditions (physical, mental or neurological) and recognises the possibility of interactions and competing risks between conditions

meaning that comorbid conditions and their treatments can have effects greater than the sum of the individual conditions.[3]

There are concerns and objections to the various terms used to describe poor mental health on the grounds that they medicalise ways of thinking and feeling and do not acknowledge the many factors that can prevent people from reaching their potential. We recognise these concerns and the stigma attached to mental ill health, mental illness and others. However, as there is no universally acceptable terminology that we can use as an alternative, we have chosen to use 'mental health problems' through this report.

Distinguishing between mild cognitive impairment, dementia and mental health problems

There are advantages and disadvantages to the separating out of dementia, cognitive impairment and mental health problems, given the overlaps in symptoms and the marked similarities between the experiences of people living with dementia and people living mental health problems. A number of historical and contextual factor impact the experiences of people living with dementia, cognitive impairment and mental health problems.

- Dementia and mental health problems occur in all populations, but the prevalence and impacts of these conditions vary due to differential access to information and support; therefore, diversity and intersectionality need to be accounted for when addressing the needs of those living with either, or with both.
- It is widely recognized that both people living with dementia and people with mental health problems are frequently denied their human rights, despite legislation in place to protect their rights.[4, 5] For this reason, these is a shift towards addressing dementia and mental health problems through a human-rights based approach and locating people's experiences within the broader disability movement, to reinforce the obligations of all to protect the rights of people living with dementia and mental health problems.
- Both dementia and mental health problems have traditionally been viewed from a medicalised treatment model, but there is growing evidence that prevention is possible by addressing risk factors and wider determinants of health.
- Historically, both dementia and mental health have been treated within psychiatric services because they are conditions which affect the brain (unlike other neurological conditions).

The relationship between all forms of dementia, mild cognitive impairment (MCI) and mental health problems is complex. Some symptoms of dementia and depression for instance- including withdrawal from social activities and general apathy- are very similar. The forgetfulness experienced during mild cognitive impairment and early stage

Alzheimer's disease (the most common form of dementia) are easily confused. This can sometimes lead to misdiagnosis. Two conditions can be present concurrently, which can also complicate identification. It is important to highlight MCI as a stand-alone condition from dementia and mental health problems, and below we distinguish between the three terms, but moving forward this literature review will focus on dementia and mental health problems only.

Mild cognitive impairment

MCI is a clinical diagnosis used for a condition in which someone has minor problems with their mental abilities, such as memory, attention or language that are worse than normally experienced by a healthy person of that age, but the symptoms do not interfere significantly with daily life. There is no test or procedure to demonstrate conclusively that a person has MCI. For some people it's a precondition for Alzheimer's, although it doesn't proceed in all forms of dementia, seen less in the forms of dementia that develop suddenly, such as Lewy body dementia. For others it's a treatable condition, caused by physical health problems, poor eyesight, vitamin deficiency or as a side effect of certain medication.[6]

Mental health and mental health problems

Mental health is more than an absence of symptoms of distress, it includes a positive experience of self, individual resources included self-esteem and optimism, the ability to sustain relationships and resilience. Mental wellbeing in later life enhances people's functionality and adds life to their years, as well as years to their lives.[7]

Mental health problems[i] is an overarching term which covers the range of negative mental health states including, mental disorder – those mental health problems meeting the criteria for psychiatric diagnosis, and mental health problems which fall short of a diagnostic criteria threshold. Mental health problems can be further categorised into the common mental problems such as anxiety and depression which may be transient (relapsing, remitting and recovered); and severe mental health problems such as schizophrenia and bipolar disorder; and the various behavioural disorders. Three quarters of people with a mental health problem do not receive ongoing treatment.[8]

Mental health in later life is shaped by the experiences lived through to this point, the social, economic and physical environments in which people live and is influenced by pressure points and experiences such as retirement, bereavement or a deterioration of physical health.[9] Identifying and treating older people's mental health problems, rather than incorrectly assuming they are part of the natural process of ageing, is an issue that needs to be addressed. Annex 3 contains full definitions of the mental health problems referred to in this paper.

[i] Psychological disability is a term being used increasingly to describe a spectrum of mental health problems that influence our emotions, cognitions, and/or behaviors, used when the problems significantly interfere with the perform of life activities such as learning, working and communicating. We acknowledge its validity but will for ease of understanding will use mental health problems throughout the report.

Dementia

Dementia is an umbrella term which defines organic disorders or syndromes where changes to the physical structure of the brain is the cause of the illness, including the death of brain cells or damage in parts of the brain that deal with thought processes. This leads to a decline in mental ability which affects memory, thinking, problem-solving, concentration and perception. Each person's experience with dementia is unique.

Early onset dementia is the term used for any dementia diagnosis received before the age of 65. There are an estimated 40,000 young people with dementia across the UK.[10] Sub-typing dementia is important in guiding treatment and prescription decisions. **Alzheimer's disease**, the most common form of dementia making up 60% of cases, is degenerative, and its exact causes are unknown. Annex 2 contains an outline of the sub-types.

Table 1 highlights some of the main characteristics and statistics around dementia, mild cognitive impairment and mental health problems.

Table 1: Dementia, mild cognitive impairment and mental health problems

Dementia	**Mild cognitive impairment**	**Mental Health problems**
Age is the key known risk factor for dementia- although between 2-10% of cases start before the age of 65 years. After 65 years the prevalence doubles every five years. Symptoms include short-term memory with recall and progressive loss of functional abilities including speech, recognition and sequenced action. There are approximately 850,000 people with dementia in the UK- 40,000 of which are younger people.[11] There are approximately 60,000 deaths each year directly attributable to dementia. Approximately 50% of people living with dementia in England and Wales will receive a diagnosis. On average people live for 6 years after being diagnosed with dementia.[12]	Between 5-20% of people aged over 65 have MCI. There are numerous causes for MCI, from depression and anxiety to physical illness, deficiencies or side effects of medication. For some, MCI is a pre-dementia condition, with the brain diseases that causes dementia already established. Not all cases of MCI leads to the development of dementia, but people who have MCI are at an increased risk of developing dementia (10-15%). Almost all cases of Alzheimer's start with MCI. A healthy lifestyle can lower the risk of a person with MCI developing dementia. MCI often occurs alongside depression but it's unclear what the relationship between them is.[13] There is a grey area between MCI and early onset Alzheimer's as currently available testing make them difficult to distinguish.	Depression is the most common mental health problem in later life, affecting 20% of older people in the general community, and up to 40% of older people in care homes. Its estimated that 85% of older people with depression receive no help at all from the NHS. Studies of depressed adults show they have poorer functioning, comparable to or worse than that of people with chronic medical conditions such as heart disease and arthritis. The percentage of older people aged 50 and above who reported feeling anxious or depressed ranged from 14-22%. People experiencing severe mental health problems die on average 15-20 years earlier than the rest of the population.

Comorbidity of dementia and mental health problems

Dementia and mental health problems are not mutually exclusive, and there is a subset of the English population living with both. This group consists of people living with existing mental health problems who develop dementia, and people living with dementia who develop mental health problems.

The exact size of this group is unknown, as recording is difficult for various reasons[i] , but small scale studies, given the prevalence levels of dementia and mental health problems in later life, it is reasonable to estimate there are a significant number of people living with dementia who are also experiencing a mental health problem. Demographic and social factors are important to keep in mind also, as the experiences of dementia and mental health problems vary across populations in England. Below is a summary of the available research on comorbidity of dementia and specific mental health conditions.

Dementia and depression

The relationship between dementia and depression is complicated because some of the expressions of dementia and depression overlap and the epidemiology and mechanisms are unclear.[14] A systematic study from 2010 found that in old age there was a definite association between depression and dementia.[15] One study estimated that 40% of people with dementia are also experiencing depression.[16] Depression can occur with all forms of dementia but is most common with vascular dementia.[17] It is unclear whether specific subtypes of depression correspond to specific types of dementia.

There are a body of longitudinal studies, examining whether depression was a risk factor for the onset of dementia which have found that depression was a major risk factor for incidence of dementia including Alzheimer's disease, vascular dementia and mild cognitive impairment.[18, 19, 20, 21, 22] A 2013 systematic review and meta-analysis of 23 community-based cohort studies undertaken to evaluate the risk of incident of dementia in people with late-life depression found depression was associated with an increased risk of dementia, and suggested that it would be valuable to design clinical trials to investigate the effect of late-life depression prevention on risk of dementia.[23]

Depression in earlier life increases the risk of dementia in later life by approximately twofold.[24] A large Danish study has found that the rate of a subsequent diagnosis of dementia was significantly correlated with the number of prior depressive episodes with, on average, the rate of dementia increasing by 13% with every depressive episode that led to an inpatient admission.[25] Some recent studies have suggested that long-term treatment with anti-depressants may increase the risk of developing some types of dementia.[26] Further studies are required to determine the impact of depression treatment on dementia progression.[27]

i There are growing bodies of evidence around both the costs of poor mental health and dementia for society and (for mental health primarily) the case for investment in prevention .

Depression in older people can often go undiagnosed despite the prevalence of risk factors including bereavement, loneliness and deteriorating physical health. On occasion someone experiencing depression may be misdiagnosed as having dementia. Individuals dealing with both will be struggling with two sets of difficulties and may be more confused and have greater memory loss. The double experience may also result in more extreme behaviour and or aggressive reactions. This can compound isolation, disempowerment as well as cognitive decline.

Dementia and anxiety

Anxiety is more common in individuals with dementia that those without. Defining anxiety in people living with dementia is complicated due to the overlap in symptoms of anxiety, depression and dementia. The prevalence of people with dementia experiencing anxiety disorders has formed the basis of several recent studies and results range from 5% to 21%.[28, 29] Anxiety may be higher in vascular dementia than in Alzheimer's Disease, and it decreases in the severe stage of dementia. It is associated with poor quality of life, behavioral disturbances and limitations in activities of daily living.[30] In the later stages of dementia chemical changes in the brain may increase bouts of anxiety and depression.[31]

Dementia and bipolar disorder

About 90% of cases of bipolar disorder have a reported onset prior to the age of 50. Elderly people living with bipolar are heterogeneous and general consists of at least two types: (1) those experiencing a late-life manic episode whose bipolar illness began in young adult life; and (2) patients without any manic episodes before late life but may only have a history of depression.[32] Late onset bipolar disorder may be caused by dementia.[33]

It can be hard to identify bipolar disorder in people living with dementia. The two conditions demonstrate similarities with respect to their clinical expression (agitation, psychotic, mood and cognitive symptoms) and structural brain neuroimaging.[34, 35, 36] However there are important differences, with cognitive symptoms prevailing in dementia and mood symptoms in bipolar disorder, a lack of brain structural abnormalities in bipolar that are seen in dementia, and both presenting different abnormalities in functional brain neuroimaging.[37] More specific tests are needed to improve diagnosis.[38]

Dementia and Schizophrenia

Early studies of the progression of dementia over the lifespan in people living with schizophrenia showed inconsistent results.[39] However, there is a growing body of evidence showing that people with schizophrenia are at an increased risk of developing dementia, with one study reporting the rate of dementia at twice that of people who did not have a diagnosis of schizophrenia [40] although the most common type of dementia in people living with schizophrenia differs from Alzheimer's in its clinical features.[41, 42]

The diagnosis and management of dementia in schizophrenia is challenging.

Cognitive impairment and delirium are common features of schizophrenia, present in more than 80% of older people with schizophrenia.[43] Because of this, some have argued that it may not always warrant an additional diagnosis of dementia, but studies have shown dementia is a real entity in people with schizophrenia.[44]

Dementia and psychosis

Psychosis is common in older people, with 20% of people over 65 developing psychotic symptoms by age 85.[45] Often but not always, psychosis develops in people living with dementia as a feature of the progression of the disorder and can be expressed through, delusions, aggression, hallucinations, apathy and sleep disturbance. The prevalence of psychotic symptoms in patients with Alzheimer's disease is 41.1%.[46] These behaviours can be particularly distressing for both the individual and their carer's and may result in a break down in family structures when family members feel unable to provide the necessary support. It was unclear from the literature reviewed what number of people with psychosis go on to develop dementia. People from African American or black ethnicity groups have been found to have a higher rate of psychosis. Psychosis is also associated with more rapid cognitive decline.[47]

Profiling the population living with dementia and mental health problems

Dementia and mental health problems are conceptualised primarily as cognitive and psychological issues, with little attention given to the wider factors and conditions that influence their development- although this is changing slowly for both. The prevalence of dementia and mental health problems differs across gender, age groups and population groups, so although there was no literature found which dealt with intersectionality in relation to a comorbid experience of dementia and mental health problems, it's probably accurate to assume these factors influence the prevalence rates.

Intersectionality is a concept that seeks to explore how social locations and identities converge to create conditions of inequality and privilege, acknowledging that we cannot usefully understand individuals in terms of single identity categories as everyone occupies multiple social locations that intersect to give more or less social capital and privilege.[48] A significant body of work by Dr. Wendy Hulko over the last decade has helped to highlight the heterogeneous nature of people living with dementia and to challenge prevailing ideas of what it is like to live with the condition.[49, 50] The Marmot Review investigated the intersectional relationships between mental health, other social identities and inequalities.[51]

Here are some of those intersecting factors:

Gender: Dementia is an issue that disproportionately affects women, with two-thirds of people living with dementia in the UK being women,[52] and three quarters of carers for people with dementia being women.[53] This is partially explained by the fact that women outlive men on average. However, there

is a limited body of research literature concerned with gender and dementia, suggesting that dementia is a category not marked by gender.[54] In relation to the prevalence of mental health problems across genders, women are more likely to experience anxiety or depression.

Black and Ethnic Minority communities: The Irish population in England have the highest estimated prevalence of dementia of any ethnic group,[55] due in part to the older mean age of this community. The black African-Caribbean population experience more prevalence of early onset dementia and have greater risk factors for vascular dementia[56, 57] and also twice as likely to experience psychotic disorders compared with their White British counterparts.[58]

People with learning disabilities: It is estimated that 1 in 5 people with learning disabilities will develop dementia and 1 in 50 people with Down's Syndrome will develop dementia in their 30s.[59] A 2007 study in the UK found that 54% of people with learning disabilities had a mental health problem.[60] The assessment of cognitive impairment in people with learning disabilities needs special care, paying attention particularly to existing mental health problems, and less reliance on standard tests.[61, 62]

People with long-term physical health conditions: People with long-term physical health conditions have higher prevalence of mental health problems and in the case of older people, dementia. These co-morbid problems, the prognosis for their long-term condition and the quality of life they experiences can both be negatively affected.[63]

People from a disadvantaged background: Socio-economic circumstances, education levels and adverse childhood experiences may all play a part in the genesis of conditions that lead to dementia.[64, 65, 66] Traumatic events and adverse experiences, poor housing or homelessness, or having multiple and complex needs place people at higher risk of experiencing mental health problems.

Prevention

Until relatively recently it was thought that prevention of dementia was not possible. However, there is emerging evidence that physical health plays a significant role in the development of mental health problems and some cares of dementia. Emerging research has shown that keeping vascular risk factors under control can prevent a proportion of new cases of dementia, as cardiovascular disease and diabetes are risk factors for the development of mild cognitive impairment, as well as Alzheimer's disease and vascular dementia.[67, 68, 69]

Lifestyle changes, such as a healthy diet and regular exercise can help reduce the risk of stroke and hypertension,[70] as well as having a positive impact on mental wellbeing. These changes can be supported through population wide policies targeting sugar in food, smoking and alcohol consumption. It has been estimated that if it was possible to delay the onset of dementia by as little as 1 year, that would reduce the prevalence

of dementia by 12 million fewer cases worldwide in 2050.[71]

The NHS Health Check programme offers advice and support to help people aged 40-74 make changes that can reduce the risk of dementia.[72] Unfortunately, the programme does not currently extend into addressing mental health problems. There is a clear need to increase knowledge of the risk factors associated with vascular dementia and how positive lifestyle changes can make a difference, through public awareness raising and establishing dementia friendly communities.[73]

In terms of preventing mental health problems in people living with dementia, research on care homes has shown that those that met the residents physical health needs effectively had lower rates of depression.[76] A 2014 survey in the UK on people with dementia found that less than half felt part of their community, and nearly 10% had left the house only once a month,[77] this is a worrying statistics as loneliness and isolation are linked to poor mental health.[78] However, this is an area requiring more research to explore mechanisms and causation as well as measures to implement.

Dementia friendly communities

Dementia friendly communities is a movement developing across Europe, and has been shown to be an effective way to improve awareness of dementia and reduce the stigma and discrimination experienced. It is a key part of the Prime Ministers Challenge. In 2012 a nationwide campaign was run to improve understanding.

Public Health England and the Alzheimer's Society then launched Dementia Friends, a major social movement aimed at improving understanding of dementia and changing attitudes toward people with the condition. Their aim was to get communities across England signed up to the foundation-stage recognition process, and to develop a publically available specification for dementia friendly communities.[74]

However, the current communities in existence do not explicitly address co-existing mental health problems, although this may change in the future.[75]

Policy context

Dementia is now the responsibility of the Parliamentary Under-Secretary of State of Public Health, currently Jane Ellison MP. Mental Health is held by the Minister of State for Community and Social Care, currently Alistair Burt MP.

People with dementia or mental health problems have the same rights as everyone else under the Human Rights Act and European Convention on Human Rights. However, for various reasons, extra protection mechanisms exist within policy and legislation for those living with dementia and mental health problems to ensure their rights are protected and their needs are met.

Cross-cutting policy related to both dementia and mental health

United Nationals Convention on the Rights of People with Disabilities
The Convention on the Rights of Persons with Disabilities (CRPD) is an international treaty, ratified by the UK in 2009, which promotes and protects the rights of the person with a disability. The Convention defines disability as including "those who have long-term physical, mental, intellectual or sensory impairments in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others", which means that people living with dementia and mental health problems should be afforded the protections available under it. The UK's compliance will be reviewed in 2017 by the UN Disability Committee and under the UN Universal Periodic Review process.

The Equality Act (2010)
People living with mid-late stage dementia or long-term mental health problems are covered by the full protection of this Act, due to the substantial and long-term negative effect on their ability to do "normal daily activities" meaning they are covered under the definition of disability. This includes protection from all forms of discrimination that are unlawful based on their disability. From an intersectional perspective, the Act can also be used to ensure that culturally appropriate support and care be provided to people living with dementia or mental health problems. In 2015 a Select Committee undertook a review of the impact of the Equality Act on people living with a disability. It recommended that the Government make a commitment to give due consideration to the provisions of the UN convention on the Rights of Persons with Disabilities when formulating new policy and legislation which may have an impact on people living with disability.[79]

The Mental Capacity Act (England & Wales only)
The Mental Capacity Act 2005 introduced protections for people with dementia or certain mental health problems, to ensure they have the ability to make decisions for themselves where possible and to protect their rights in instances where decisions are

being made for them when they lack capacity. It is seen as an empowering piece of legislation that supports the rights of people to make decisions for themselves whenever possible, although it has sometimes been used in ways that reinforce overly protective risk-averse cultures that undermine autonomous decision making and self-determination.[80] Questions have been raised about the Act's compliance with CRPD.[81]

The Care Act (England only)
The Care Act 2014 brings together existing local authority responsibilities for providing social care into a single piece of legislation, as well as some new responsibilities. The legislation is concerned with personal dignity, protection from abuse, control by the individual over their day-to-day life, physical health, mental health and emotional wellbeing, and the individual's contribution to society. The Care Act obliges local authorities to enable the individual to participate as fully as possible in decisions about them.

Mental Health policy

There is currently no specific policy for mental health in later life in England. The Department of Health's National Framework for Older People included a chapter on mental health, with a section on Dementia, but this came to an end in 2011.[82] No Health without Mental Health, the 2011 cross-government strategy is age inclusive and specifically seeks to improve mental health outcomes for people across all age groups.[83] The Mental Health Taskforce did not include dementia in its five year forward view for mental health due to the work already being done on dementia through the Prime Ministers Challenge, resulting in no comorbidity recommendations being developed.[84]

Age inclusive mental health series have been developed because age thresholds were discriminatory under the Equality Act 2010, which makes it illegal to discriminate on the grounds of age in the provision of services including health and social care services. However, one concern that has arisen from this move is that there are particular aspects of mental health in later life which require specialist services, including the complexity of a mental health/dementia comorbidity for example, and this focus and expertise is being lost as services become more age inclusive.

National Institute for Health and Care Excellence guidance related to mental health

The National Institute for Clinical Excellence in England has produced several relevant publications including public health guidance on mental wellbeing and older people and on promoting the independence and mental wellbeing of older people:

NICE (2015) Home care: delivering personal care and practical support to older people living in their own homes [NG21]

NICE (2015) Older people with social care needs and multiple long-term conditions (NG22)

NICE (2015) Older people: independence and mental wellbeing (NG32)

NICE (2016) Community engagement: improving health and wellbeing and reducing health inequalities (NG44)

Dementia policy

In 2009, The Department of Health launched the first National Dementia Strategy for England, proposed to support people diagnosed with dementia and their carers to 'live well' with dementia, to raise public awareness of dementia, reduce stigma and facilitate early diagnosis.[85] This was done on the back of a report by Alzheimers Society and Mental Health Foundation that highlighted the stigma experienced by people living with dementia.[86] There are clear gaps in the current dementia strategy in terms of supporting mental health needs.

Prime Ministers Challenge

In 2012, the Prime Minister's 'challenge' on dementia was announced, stating that 'we must ensure that every person gets the treatment and support which meets their needs and their life'.[87] The challenge superceded the national dementia strategy. The main focus of the challenge are to improve diagnosis, provide better support for carers, develop dementia friendly communities and improve research-primarily into find a cure. The only mention of mental health with the policy document is in relation to key areas highlighted for improvement in relation to care in hospitals and care homes, stating that 'aspects of variable or poor care regarding how the care met people's mental health, emotion and social needs' needed to be improved (p32).

The challenge was updated in 2015 with the Prime Minister's dementia '2020 vision' An implementation plan containing details of how the vision will be met was published in 2016, which contains a section on mental health and wellbeing. It stages that 'recognising the links between dementia and other programmes of work is key, particularly those focused on mental health' (p36). For people living with dementia and their carers affected by depression or loneliness the IAPT programme plays a key role and increasing access will be key focus over the coming years. It also recommends that older people with dementia who are admitted to hospital should have access to specialist mental health liaison services, including expertise in psychiatry of older adults, as part of their package of care.[88]

The National Dementia Action Alliance, formed of national and local organizations with an commitment to transforming the lives of people with dementia and their carers, is a key part of dementia policy implementation in England, shaping policy and attitudes at a national level.[89]

National Institute for Health and Care Excellence guidance related to dementia

NICE have published the following dementia related guidance:

NICE (2006) Dementia: supporting people with dementia and their carers in health and social care (CG42)

NICE (2010) Dementia: support in health and social care (QS1)

NICE (2013) Dementia: independence and wellbeing (QS30)

NICE (2015) Dementia, disability and frailty in later life- mid-life approaches to delay or prevent onset (NG16)

A human rights based approach to dementia and mental health problems in policy and practice

Dementia and mental health discourse has historically been dominated by the highly 'medicalised' view of disease and illness. However, increasingly they are both being viewed as having a rights-based dimension. Although both dementia and long-term mental health problems are considered disabilities under the Equality Act 2010, neither are readily recognised as a disability in current policy and practice terms.

There are now calls for a practical and systematic change to take place to embed a social model of disability, and viewing dementia and mental health problems from the social model perspective has several implications for policymakers and service providers. This would progress people living with dementia and mental health problems being viewed as a legitimate part of mainstream society, living in communities as equal citizens with their value recognised (MHF, 2015).[90]

The most recent policy statement on dementia in England refers to the human rights of people with dementia, but does so only in relation to older people, which is an issue for those under the age of 65 experiencing early onset dementia (DoH, 2015).[91] Scotland has moved ahead of the rest of the UK by incorporating a human rights based approach into its national dementia strategies, practice guidance, standards and other relevant documents.

A human rights based approach can be implemented using the 'PANEL' principles. PANEL provides a framework of the important elements that strategies and policies should include:

- Participation: Dementia and mental health problems should not exclude people from participating in society.
- Accountability: Those responsible for protecting the human rights of people living with dementia and mental health problems should be held accountable for any human rights violations.
- Non-discrimination: Education is needed to increase understanding of these conditions to reduce stigma experienced.
- Empowerment: People living with dementia and mental health problems should be empowered to participate in decision making processes
- Legality: All measures related to dementia, including policies, legislation and systems, adopted by states or stakeholder should be linked to the Universal Declaration of Human Rights and other human rights instruments.

Identification of dementia and mental health problems

Current research and evidence base

Within the UK, England has the strongest mental health data administered through Public Health England's National Mental Health Intelligence Network (NMHIN). The NMHIN manages the mental health, neurology and dementia 'fingertips' online resource which offers access to data gathered across England at a local level. However, there is a need for more detailed and better quality data to be collected and shared, as many data sets are not comparable making it difficult to generate comprehensive overviews of current relationships and trends.

One consequence of the welcome attention increasingly being given to early intervention for mental health is that less attention is given to later life interventions. More research is needed in order to understand which interventions will work best at preventing and improving the health and lives of people who are experiencing (or at risk from) mental health problems and dementia.

Measurements of mental health and dementia need to be part of a broader suite of measurements that relate data to the wider determinants of health, taking in the social, economic and environmental factors.

The current funding for research into mental health or dementia does not reflect the costs of disease burden to society. The causes of both mental health problems and dementia remain under researched, despite acknowledgement that to prevent either those causes and contributing factors need to be identified and understood. To combat this, the government has pledged to increase annual funding of dementia research to £66 million,[92] and to develop a mental health research strategy.[93] However, it is unclear whether either of these will include dedicated research on co-morbidity of dementia and mental health problems.

"...whatever is diagnosed first drives the care the person receives"- Interviewee from Croftland

Mental health research received 5.5% of health funding. The Five Year Forward View on Mental Health (the report of the Mental Health Taskforce) recommended the development by 2017 of a ten year mental health research strategy and a five year data development plan. The strategy and data development plan will be informed by the European Roadmap for Mental Health Research in Europe (ROAMER).[94]

Mental health problems

There are various valid and reliable screening tools that are useful in detecting mental health problems, but they require training to ensure they are used efficiently. The Geriatric Depression Scale is a useful tool for screening older people for depression, with 30, 15 and 4 item versions

available.[95] NICE recommend set questions for screening general patients with a physical health problem.[96]

There is widespread under-treatment of depression in older persons.[97] Left untreated, mental health problems can lead to increased mortality, longer hospital stays and institutionalisation, physical dependence and reduced general health, with depression associated with experiencing more pain.[98, 99]

Dementia

The diagnosis rate for dementia in England is only 51%- lower than Scotland and Northern Ireland. To improve this, NHS England published a Dementia toolkit aimed at helping GPs to make more timely diagnosis and offering them advice on how to provide vital post-diagnostic support.[100]

There is a dementia Commissiong for Quality and Innovation (QUIN) framework, which since its introduction has raised the profile of the condition in general hospitals and is now successful is locating 90% of people with possible dementia (DoH, 2012).[101] Given its success, there are now plans to develop a new CQUIN to improve the recognition and treatment of depression in older people to be introduced (NHS, 2016).[102] The Mental Health Taskforce has made a recommendation for a new CQUIN that ensures people being supported in specialist older-age actue physical health services have access to liaison mental health teams, but this needs to take an integrated approach to cover both mental health and dementia in later life to be effective.[103]

Dementia is often difficult to diagnose in BAME communities, due to insufficient knowledge within families and communities, fear of exclusion and in people with Learning Disabilities due to communication problems and its early onset in the community. Another factors is that most cognitive tests are developed and standardized in one ethnic group, which may not transfer appropriately to another ethnic group due to cultural, education, language and other factors.[104]

Identification of a mental health/dementia comorbidity

To identify a person with dementia's mental health or wellbeing, previous best practice was by observational or proxy (for example, asking a family member who knew the person well) measures.[105] Although these are still useful for people living with dementia who find it difficult to communicate, it is now deemed more appropriate wherever possible to have the person with dementia tell you directly about their quality of life, using self-report measures.[106] Depression and anxiety have been found to directly correlate with a person's self-report quality of life, with low scores on measures of both related to higher quality of life.[107]

The National Institute of Mental Health [in the United States have established a formal set of guidelines for diagnosing depression in people with Alzheimer's, which could be used to aid this process, as they reduce emphasis on verbal expression and include irritability and social isolation in their assessment.[108]

Carers are an integral part to ensuring an accurate diagnosis of a mental health problems, alongside a review of the people's medical history and a physical and mental examination.[109] However, research from CQC in 2014 showed that in 33% of care homes and 66% of hospitals in the UK this was failing to happen.[110]

"...anecdotally, care service providers can generally say when a person has dementia and provide support. But it is more difficult to pick up on a mental health issue..its a blurry line between the two."- Interviewee from Skills For Care.

Identification of early onset dementia and mental health problems

- Early onset dementia does not have a distinct set of symptoms, but the repercussions of developing dementia at an earlier age are significantly different, as dementia is predominantly seen as an issue exclusive to older people. There are a number of particular features of early onset dementia worth noting:[111]
- It's more difficult to diagnose as presentations can be atypical
- There is often a higher rate of neurological disorders causing symptoms
- The physical fitness of most younger people
- The markedly different social impact of the diagnosis if they have younger families at home

The economic and social cost

There are growing bodies of evidence around both the costs of poor mental health and dementia for society and (for mental health primarily) the case for investment in prevention[i].

Poor mental health carries an estimated economic and social cost of £105 billion in England per year. The national cost of dedicated mental health support and services across government departments in England amounts to £34 billion each year, and this is excluding support and services for dementia (NHS, 2016).[112]

The estimated cost of dementia is £26billion in England per year; £17.4billion of this being incurred by people living with dementia and their families, and £8.8billion by the state.[113] There is approximately £7 billion spent by the Government on mental health services for dementia, broken down as £.6billion on NHS mental health services, £.8billion on mental health in other NHS settings and 5.5billion on other government mental health services.[114]

The cost to the UK economy of services for people living with dementia is far higher than all other conditions combined, currently making up 66% of all mental health service costs and estimated to increase to 73% by 2026.[115]

The economic impacts of both are wide ranging and long lasting because of the characters of the conditions and the lack of early and effective interventions. They are associated with losing the ability to work (particularly in relation to early onset dementia or severe mental health problems) and increased utilization of health, social care and other support services. These impact on the individual, on their family and friends and on society.

Banerjee and Wittenberg (2009) set out a clear argument on cost savings from early diagnosis of dementia.[116] However, from the available literature there doesn't appear to be any estimates for the cost savings resulting from preventing or early intervention for comorbid mental health problems.

i An overview of the economics evidence base for mental health across the life course can be found in Elliott, I. (2016) Poverty and mental health: a review to inform the Joseph Rowntree Foundation's Anti-Poverty Strategy. London: Mental Health Foundation

Care and services provision for dementia and mental health problems

It's a misconception that rights to health and social care are the same. While there is a universal right to free healthcare at the point of need across the UK, rights to publicly funded social care, housing, and welfare benefits are more conditional rights that depend on the severity of need and the individual's financial situation. Depending on the severity of dementia, people may be entitled to free NHS 'continuing care', means tested local authority social care, or a combination of both.

Health and social care services in England are not currently set up in a way which promotes an integrated response to the needs of people living with both mental health problems and dementia. Increased sub-specialisation, the decline of generalism in hospital settings and a continued gap between mental health professionals and primary care all contribute to the ongoing lack of co-ordination and oversight of peoples multiple and complex needs.[117]
There is a tendency within services to view people with dementia and people with mental health problems as homogenous groups. There is a need for a intersectional focus to counter this and explore the heterogeneous nature of people living with a single or dual diagnosis.[118]

One issue raised during the interviews is that the NHS and health services are free at the point of use, but social care services are means tested. Mental health problems are dealt with under health, whilst dementia comes under the social care budget. This can lead to significant barriers to getting appropriate care. Local government budgets have been cut significantly, by around 60% in real terms, and this has impacted on the funding available to adult social care services for later life.[119] Many local authorities have prioritised social care.[120] This has resulted in eligibility thresholds being tightened, so that only the most severe needs are often met through state-funded social care. In total, around 400,000 fewer people accessed care from local authorities in the last parliament. Demand for social care services are expected to grow on a similar scale to the NHS in the next parliament. The social care system will cost more by 2020-21. Estimates from the Association of Directors of Adult Social Services (ADASS) put this cost pressure at £4.3 billion a year by 2020-21.[121]

Care at home and informal care

Carers play a key role in the quality of life of a person with dementia. However, the needs of carers need to also be assessed, separately to those of the person with dementia, and this is often overlooked. Stress experienced by the carer can negatively impact the relationship between them and the person with dementia, so approaches to reduce this should be adopted. There are approximately 5 million carers in England, and this number continues to rise- it rose 11% between 2001 and 2011.[122]

There are 1.4 million people providing over 50 hours of unpaid care per week in the UK. This is often combined with working, caring for other family members and traveling to provide the care, so it can have a serious impact on their life.[123, 124]

Carers can be under tremendous pressure at all stages of the progression of dementia, and their health and support needs should be separately assessed alongside those they are caring for.[125] The Mental Health Foundation produced a Carers Checklist as a simple outcomes based tool for people with dementia and their carers.[126] Evidence suggests that providing carers with better information, training and coping strategies, including mental and emotional support, can improve their quality of life. START, Strategies for Relatives, is a manual based coping strategy programme that has been proved effective in promoting the mental health of carers.[127]

Carers are often still very involved in the care of a person with dementia even after care has been moved from the home to another setting, and the associated stress can be compounded with guilt, so this needs to be addressed.[128] It's important that when a person with dementia is moved to a hospital or care home setting, the family and support network are encouraged to continue involvement, and a relationship centred approach to dementia is promoted.[129] [needs to say something about professional care at home; social/domiciliary care, Admiral nurses, memory clinics and primary care, etc.]

Care in hospitals and nursing homes

The Care Quality Commission have a key role to place in making sure that health and social care services provided to people with dementia and mental health problems are safe, effective, compassionate, high-quality, and they have a mandate to ensure care services improve by monitoring and regulating.[130]

Very few people with dementia are cared for in hospital although many people with dementia spend time in hospital for other health reasons. At a general hospital, a shared care ward can treat patients with equally demanding mental and physical health needs. Shared-care wards have been found to be an effective model for delivering care to this complex patient group as the wards offer shared decision making between disciplines and patients spend less time in hospital.[131, 132] Liaison older people's mental health teams exist in some general hospitals, comprised of nurses, social workers, consultants, registrars, PTs and psychologist. Their role is to assess the mental health needs of older people, provision of interventions and advising on treatment. These teams and their existence vary hugely across the country, with some hospitals having no provision of organised mental health support and others having well developed teams according to a 2012 study.[133]

A third of all people with dementia are cared for in care homes and nursing homes in the UK. An Alzheimer's Society investigation in 2016 found that almost half of care home managers felt the NHS wasn't providing residents with

dementia adequate and timely access to vital services, including mental health services. One manager reported 'A resident who was saying she felt suicidal had to wait over eight weeks to be referred to mental health services'.[134]

One interviewee noted that it is often care home staff that will notice a person with dementia developing a mental health problem, but will be unsure how to deal with this as dementia care is often prioritized. Care home staff who exhibited hopeful attitudes regarding dementia, recognising the responses and achievements of people living with dementia, can contribute to better quality of life for people living with dementia and research shows these attitudes can be enhanced through appropriate training.[135]

Skills for Care is a charity who provide practical tools and support to help adult social care organisations in England to develop an efficient workforce. They share best practice, raise quality and standards and make sure dignity is at the heart of service delivery to people receiving care. This work includes programmes around mental health and dementia awareness.[136]

Care and service provision by the third sector

Voluntary organisations provide huge resources for both people living with dementia or mental health problems, or their carers. Dementia charities have vast libraries of information online on their websites, run Memory Cafes and peer groups, have support workers and run Dementia Awareness sessions. Likewise, mental health charities have huge amounts of information online about mental health problems, run awareness training, self-management and peer groups. However, there is little crossover between these groups, with only a handful of organisations, such as Mental Health Foundation and Age UK, running both mental health and dementia programmes.

"(Making Space) started as a mental health organization which later on moved to provider dementia services... our approach has been to maintain a person-centred focus, so our staff are able to provide or refer people to the right services..what we are doing is trying to look at more than just dementia"- interviewee from Making Space.

One example given during an interview of a programme aiming to improve the quality of life for people with dementia by looking at wider issues, including mental health, is the Dementia United programme in Greater Manchester (GM), which has been launched in 2016 as part of their devolution ambition to make GM the best place for people with dementia and their carers to live. Although it's not clear to what extend this programme will target people living with a comorbidity, partners include some mental health organisations and it aims to improve the lived experience, reduce social isolation (a key risk factor for poor mental health) and to take a co-production approach.[137]

Services for those living with early onset dementia and mental health problems

There is a dearth in services for people under 65 currently. There is currently no standard provision of care for younger people with dementia and their families in the UK and there is little involvement of families in care provision. Specialist services for early onset dementia are consistently called for but continue to be overlooked in English policy and service development (Roach and Keady, 2012).[138] One organisation highlighted in an interview that is trying to change that is Young Dementia UK, who have developed some resources online.[139]

"They (services) need to take a 'whole life' approach rather than a disease management approach"- Interviewee from Race against Dementia

Support for mental health problems in people living with dementia

Appropriate and timely treatment for mental health problems can significantly increase the quality of life of a people living with dementia. Modified treatments used for those without dementia can be effective:

Medication: Although recent research has found that two commonly prescribed antidepressants do not work on the depression of people with Alzheimer's disease,[140] the current NICE guidelines on dementia addressing depression recommends that people who have dementia and a major depressive disorder should be offered antidepressant medication.[141] Therefore, there is a need for more research into which antidepressants are most effective and it is vital that the prescribing of antidepressants be monitored closely for effectiveness and any negative effects or interactions with other medications.[142]

Psychological interventions: A range of therapy treatments are supported by evidence and the NICE guidelines on dementia. Cognitive behavioural therapy (CBT), which can be adapted to involve participation of carers, has been shown to be effective in treating depression in people living with dementia,[143] as has music therapy, recreation therapy animal-assisted therapy and reminiscence therapy- even in those in the later stages of dementia.[144, 145] However, access to therapies is limited, both by the demand on services from the general population and the prioritization of dementia over mental health problems by medical professionals.[146]

Social interventions: Interventions, including multisensory stimulation and exercise, should be made available people living with dementia who have a comorbidity of depression and/or anxiety. Forbes et al. (2013) conducted a systematic review across the globe that found that exercise programmes may have a significant impact on improving cognitive functioning, and that these programmes may have a significant impact on the ability of people with dementia to perform daily activities.[147] One study found that older adults with dementia are sedentary for most of the day, not achieving the minimum recommended 30 minutes of activity a day.[148] For those at the most advanced stages of dementia, carers make take on a crucial role in the undertaking of activities that support good mental health, such as helping the person to exercise, finding ways to let the people continue to contribute actively to family life or by scheduling activities that the person enjoys such as gardening.[149,150] The Seattle protocols encourage caregivers to engage the person with dementia in pleasurable activities and this has been found to reduce depression.[151] In an evaluation carried out by the Mental Health Foundation on peer support groups for people with dementia living in extra care housing with 21 tenants, it was found that people with early stage dementia who participated in the groups showed improvements in wellbeing, social support and practical coping strategies.[152]

Early treatment for mental health problems or dementia can have a beneficial effect on other existing conditions. The NHSE Dementia toolkit advises that 'improving the skills of primary care in relation to cognitive problems may also have secondary benefit in improving the detection and treatment of depression in older people' (p6). A strong message that came through from the interviews was that services must be commissioned on the basis of need and not age alone, to ensure that those experiencing early onset dementia, or older people experiencing a mental health problem will have their specific, distinct needs met- ie a personalization of care approach. Services need to be collaborative and interdisciplinary while working with statutory and voluntary services to provide a needs-based service for people complex needs, such as living with mental health problems and dementia.[153]

"It's like people (living with dementia) with a set of problems only come to the attention of services late in the day if they were not already known to mental health services. This means many aspects of their daily life have deteriorated by the time they reach the attention of services...their life problems may be so complicated that no service can deal with all of them"- interviewee from Race against Dementia

Gaps and resources identified

There is a lack of research regarding the prevalence of mental health problems in people living with dementia, with most research currently focused on depression, and much less is known about the prevalence and development of other common mental health problems- such as anxiety- and severe mental health problems- such as psychosis or schizophrenia.

Dementia navigators, who provide support to people living with dementia and help them to find their way around the health and social care system, have been identified as a key resource for people with dementia[154] and one interviewee suggested this service could be adapted, through training, to provide additional support for those who also have mental health problems that need addressing.

There is limited of research into stigma, information needs and support issues of 'other' communities within England with it comes to comorbidity, including into the Irish and black African-Caribbean populations (for reasons discussed above), the Jewish population (who have an aging population with over 20% in the 65+ age category)[155] and all other culturally diverse communities and populations.

Clear gaps have been identified in addressing the dementia and mental health needs of marginalised communities. According to the Policy Research Institute on Ageing and Ethnicity(PRIAE), barriers faced by minority communities include:[156]

- Members of BAME communities sometimes have little confidence that services will meet cultural, linguistic or religious needs.
- Interpreting services are in short supply, are inadequately advertised and often have limited funding.
- Poor access to services: potential clients may be unaware that services exist, or uncertain whether they may use the services.
- Public sector providers assuming, often incorrectly, that minority ethnic communities have strong community/family support networks.

These also came through in the interviews, with service providers overwhelmed when it comes to the needs of the general population, meaning the needs of marginalized communities often get overlooked especially people with learning disabilities and people from BAME communities.

Conclusions and recommendations

'Population ageing is one of humanities greatest triumphs, It is also one of our greatest challenges'- WHO.[157]

Dementia and mental health problems are now recognized as two of the key public health issues of the 21st century, yet there is still a dearth in research on the causes of both or the relationship they place when present together. The prevalence of comorbid dementia and mental health problems is unknown. Policy guidance on the mental health needs of people living with dementia are poor in the UK.

Recommendation: co-produce a mental health and dementia research programme with people with lived experience of this co-morbidity, their families and carers.

Recommendation: develop data systems to ensure mental health and dementia data can be analysed in an integrated and strategic manner to inform provision, policy and research.
Recommendation: develop policy and practice guidance on the mental health needs of people living with dementia.

Neither dementia nor mental health problems are readily recognised as disability issues by mainstream society, often discussed using the dominant medical model. The wider disability movement has not effectively involved people with mental health problems and dementia. This is due to a number of issues, such as the low rates of diagnosis, the invisibility of the conditions, older people being less involved in activism, the dominance of carers voice, the framing of mental health as an issue of old age, and the portrayal of people with dementia and mental health problems as 'victims'. For those people with a co-morbidly of dementia and a mental health problem the issue is even more complex, but people with complex conditions must not be forgotten when trying to advance people's rights to health and social care services.

Recommendation: develop relationships between mental health and dementia representative organisations and the wider disability movement; and advocate for the inclusion of people living with mental health problems and dementia within the UN review of the UK's compliance with the Convention on the Rights of Persons with Dementia.
Receommdneation: develop a rights based approach to health and social care provision for people living with mental health problems and dementia, and their families and carers.

A holistic, integrated approach is vital to addressing the needs of people in later life. Possible mechanisms for the delivering a holistic approach include achieving parity of esteem for mental health including integration of services, and through the remodeling of health service. But looking at the learnings from the learning disability movement, it could be argued that a better model may be to move away from health care

defining and leading the agenda, with social inclusion and support in the community the mean focus. Those living with dementia should be provided with the same opportunities as others which promote a mentally healthy later life. Support to keep active and engaged in communities should be provided for all. This should use a rights-based, citizenship and community inclusion approach whereby older people are valued as equal citizens and community based, collective solutions are provided. The move towards 'age friendly' communities and cities (e.g. Manchester, Bristol) as part of the World Health Organisation age friendly movement provide examples of putting this into practice as well as opportunities for learning. Initiatives can range from flexible volunteering and employment, to participatory arts to physical activities.

Recommendation: develop a programme to pilot social inclusion and community based interventions, and to scale and test promising approaches.

Recommendation: develop programmes of provision, guidance, policy and research for people with early onset dementia; and scale and test promising approaches.

The importance of involving older people in decisions about their own lives and about how policy and services are shaped is becoming recognised. More must be done to harness the assets of people in later life to influence policy and practice and to support one another. Focused work must be undertaken to give voice to seldom heard groups including those who are unheard due to factors such as dementia/mental health comorbidity. It's vital that people with dementia affected by mental health problems are directly involved when research is being done on the needs and what works for them, recognising the importance of people's lived experience.

Recommendation: ensure that co-production principles and approaches are adopted across all provision, policy, research developments and resource the work of representative organisations such as the Dementia Engagement and Empowerment Project and the Dementia Alliance for Culture.

Recommendation: develop programmes of provision, guidance, policy and research for members of BAME communities; and scale and test promising approaches.

Annex 1: Methodology

This Annex describes the methodology followed for the evidence review. For the literature review a selective approach was used by the team. Key high-quality research publications, published since 2010, from England and other countries where the activities and learning are culturally transferable- the rest of the UK, Europe, USA and Canada will therefore be included.

Exclusion criteria: articles focused on treatment or symptom reduction, articles that cannot be not be accessed online, articles that cannot be accessed in full using the NHS Knowledge Network, books, small qualitative/quantitative studies focused solely on medical factors, research that is from non-transferable social contexts, newspapers articles and duplicates.

Peer reviewed published literature

The team performed an independent literature review using Boolean operators in the following combinations: (dementia OR Alzheimer disease) in All AND ("mental health" OR "mental illness" OR distress OR depression)' in the Title, for the date range 2010-2015, on the following databases:
ASSIA, Barbour Index, CINAHL, Cochrane Library, EMBASE, Emerald, Health Business Fulltext Elite, OVID databases (includes Medline), RefWorks, Transfusion Evidence Library, TRIP: Turning Evidence Into Practice, Web of Science, EBSCO Psychinfo, WHO Health Evidence Network, Wiley CCTR, Wiley CDSR, UK Journal of Dementia Care, Journal of Quality in Ageing and Older Adults and The Journal of Public Mental Health special issue focused on older age.

Step 1: Search in the NHS Knowledge Network

The table below shows the number of results per year in each of the aforementioned journals NHS found using the NHS Knowledge Network.

Database	No. of Results
EBSCO PSYCINFO	2015 (72 results)
	2014 (91 results)
	2013 (113 results)
	2012 (101 results)
	2011 (95 results)
	2010 (0)
ASSIA	2014 (9)
	2013 (26)
	2012 (14)
	2011 (17)
	2010 (20)
OVID Medline	2015 (15)
	2014 (115)
	2013 (128)
	2012/2011/2010 (0)
CINAHL	2015 (12)
	2014 (60)
	2013 (66)
	2012 (55)
	2011 (53)
	2010 (0)
Ovid	2015 (126)
	2014 (50)
	2013 (30)
	2012 (5)
	2011 (1)
	2010 (1)

Database (cont.)	No. of results (cont.)
Wiley CCTR	2015 (4)
	2014 (18)
	2013 (26)
	2012 (14)
	2011 (15)
	2010 (5)
OVID HMIC	2015 (1)
	2014 (2)
	2013 (13)
	2012 (8)
	2011 (8)
	2010 (7)
Health Business Fulltext Elite	2015 (0)
	2014 (4)
	2013 (2)
	2012 (4)
	2011 (2)
	2010 (0)
Wiley CDSR	2015, 2013, 2012, 2011, 2010 (0)
	2014 (1)

Note: journals not mentioned in this table yielded 0 results for the years 2010-2015.

Step 2: Exclusion
The first column of the table below shows the total number of articles. The second column shows the number of articles minus those that were excluded by screening titles, place, and whether there was a full access to PDFs. The third column shows the final number, one we came to after excluding articles by reading the extract.

Total number (sum of all the results above)	Total number left after initial exclusion	Total number after second exclusion
1409	51	23

Grey literature

As there is no standalone policy around later life, current policy documents, guidelines and reports, mainly from England but including some key international resources, with relevant elements on dementia in relation to mental health will be identified- through online searches and references from other stakeholders- and studied. The review will build on the work undertaken previously by Public Health England with Strategic Partner Programme partners- including a briefing on mental health developed in 2014 by the Mental Health Providers Forum that was included in an equalities based dementia guidance document for commissioners.

The initial documents identified were:

- DoH: Prime Minister's challenge on Dementia 2020 and implementiation plan
- DoH: Dementia-friendly health and social care environments
- MHF: Promoting Mental Health And Well-being In Later Life
- MHF: Dementia, rights and the social model of disability: A new direction for policy and practice
- MHF: Getting on... with Life
- MHF: The Lonely Society
- AgeUK: Loneliness- the state we're in

Step 2: Google search

2 Google searches were performed:
1. (Dementia and "Mental Health") AND (Strategy or Guidelines or "Impact Assessment"). The first ten pages were reviewed.
2. ("Human Rights") AND (Dementia and "Mental Health") AND (Strategy or Guidelines). The first ten pages were reviewed.

Step 3: Exclusion

Exclusion criteria: Local Papers, News Papers, Academic Papers –as they should have come up in the peer reviewed search-, papers from non-transferable social contexts, papers published before 2009 –we include in this search papers from 2009 because this is when the Dementia Strategy for England was published.

Interview questionnaire

The below questionnaire was used to gather feedback from service providers. Five completed interviews took place.

Mental Health and Dementia: a review of evidence

The Mental Health Foundation is doing an evidence review for the Mental Health Providers Forum on mental health and dementia, and is seeking key stakeholders views to identify issues and recommended references. To this end, we would appreciate if you could take a few minutes to answer the following questions. Please return this form back to Marguerite Regan at: MRegan@mentalhealth.org.uk

Please state whether you want your answers to remain anonymous:

Date:

Question 1: Are you aware of many service users living with both mental health problems and dementia? If so, and you work closely with them, what steps do you tend to take to deal with this, what resources do you use?

Question 2: What are the difficulties facing service providers identifying and supporting people living with dementia who might also be living with mental health problems?

Question 3: Are there any gaps in resources that need to be addressed in order to provide adequate services or support?

Question 4: What changes do you think need to happen in health and social care to support people living with dementia who are also living with mental health problems?

Question 5: Do you know of any resources or references available that we should be considering for this review?

Any other comments

Many thanks for taking the time to complete this questionnaire.

Marguerite Regan
Policy Manager
MRegan@mentalhealth.org.uk

Annex 2: Sub-types of Dementia

The following descriptions were taken from the NHS England Dementia Revealed Toolkit[158] and the Guidance on Dementia Care for Designated Centres for Older people:

Alzheimer's disease
Alzheimer's disease is the most common form of dementia making up 60% of cases, is degenerative, and its causes are unknown. The key feature of AD is the deterioration in memory and other executive functions, such as reasoning, flexibility, task sequencing etc. In general the changes are gradual over time and the illness may last several years.

Vascular dementia
Vascular dementia is the second most common type of dementia. It is usually caused by mini strokes that constrict blood flow and oxygen to the brain, or an episode of illness The person may get worse quite suddenly, and then not change again until the next stroke happens. People can experience this and Alzheimer's together- known as mixed Alzheimer's/Vascular Dementia.[159]

Lewy body dementia and dementia in Parkinson's disease
These two types of dementia are related but not quite the same. In Lewy Body dementia, dementia comes first and 'Parkinsonism' often develops later - although often without tremor. In dementia in Parkinson's Disease, the Parkinson's Disease comes first, and one in six patients with Parkinson's Disease go on to develop dementia. In Lewy Body Dementia, memory may be well preserved at first, but deteriorates later. The key features are difficulties with attention, arousal at night, marked fluctuation in levels of cognition and confusion, vivid, and often highly developed, hallucinations, sensitivity to neuroleptics and REM sleep disorder.

Frontal-lobe dementia/Pick's disease
Frontal Lobe Dementia (FLD), which was previously known as Pick's Disease. Frontal Lobe Dementia is particularly difficult because it often presents in a younger age group. In the behavioural variant, it may take several years before the condition is diagnosed. The development of inflexibility and unreasonableness, blunting of social sensitivity and, sometimes, aggression may damage important relationships before the diagnosis is suspected.

Creutzfeldt-Jacob disease
Creutzfeldt-Jakob disease (CJD) is the most common human form of a group of rare, fatal brain disorders known as prion diseases. Prion diseases, such as Creutzfeldt-Jakob disease, occur when prion protein (which is found throughout the body but whose normal function isn't yet known) begins folding into an abnormal three-dimensional shape. This shape change gradually triggers prion protein in the brain to fold into the same abnormal shape. Through a process scientists don't yet understand, mis-folded prion protein destroys brain cells. Resulting damage leads to rapid decline in thinking and reasoning as well as involuntary muscle movements, confusion, difficulty walking and mood changes.

Alcohol related dementia

Korsakoff's syndrome is a brain disorder usually associated with heavy alcohol consumption over a long period. Although Korsakoff's syndrome is not strictly speaking a dementia, people with the condition experience loss of short-term memory. Korsakoff's syndrome is caused by lack of thiamine (vitamin B1), which affects the brain and nervous system. People who drink excessive amounts of alcohol are often thiamine deficient. This is because:

- many heavy drinkers have poor eating habits and their diet does not contain essential vitamins
- alcohol can interfere with the conversion of thiamine into the active form of the vitamin (thiamine pyrophosphate)
- alcohol can inflame the stomach lining, cause frequent vomiting and make it difficult for the body to absorb the key vitamins it receives. Alcohol also makes it harder for the liver to store vitamins.

Korsakoff's syndrome is part of a condition known as Wernicke-Korsakoff syndrome. This consists of two separate but related stages: Wernicke's encephalopathy followed by Korsakoff's syndrome. However, not everyone has a clear case of Wernicke's encephalopathy before Korsakoff's syndrome develops.

Annex 3: Definitions of mental health problems

Mental health problems are usually defined and classified to enable professionals to refer people for appropriate care and treatment. But some diagnoses are controversial and there is much concern in the mental health field that people are too often treated according to or described by their label. This can have a profound effect on their quality of life. Nevertheless, diagnoses remain the most usual way of dividing and classifying symptoms into groups. The following definitions come from the Mental Health Foundation website:[160]

Depression
Depression is a common mental disorder that causes people to experience depressed mood, loss of interest or pleasure, feelings of guilt or low self-worth, disturbed sleep or appetite, low energy, and poor concentration.

Anxiety
Anxiety is a type of fear usually associated with the thought of a threat or something going wrong in the future, but can also arise from something happening right now. Around 1 in 6 people in the UK will experience a mental health problem like anxiety each year, which has steadily increased over the past 20 years. It is also likely that individuals do not seek help for significant levels of anxiety, meaning many remain without diagnosis or treatment.

Schizophrenia
Schizophrenia is a diagnosis given to some people who have severely disrupted beliefs and experiences. During an episode of schizophrenia, a person's understanding and interpretation of the outside world can become disrupted and they may:

- lose touch with reality
- see or hear things that are not there
- hold irrational or unfounded beliefs
- appear to act strangely because they are responding to these delusions and hallucinations.

Bipolar disorder
Bipolar disorder, formerly known as manic depression, is a chronic disease of abnormal mood characterized by episodes of elevated mood or depression, or, less frequently, a mixed affective presentation of both. They may also experience what are called 'grandiose' ideas or delusions about their abilities and powers, and a loss of judgement. People in a high phase can be increasingly goal directed, meaning they can get themselves into difficulties that they would normally avoid – they may leave their job, spend money they don't have, engage in high-risk situations or give away possessions.

Psychosis
Psychosis describes the distortion of a person's perception of reality, often accompanied by delusions (irrational and unfounded beliefs) and/or hallucinations (seeing, hearing, smelling, sensing things that other people can't). Psychosis is a symptom of some of the more severe forms of mental health problems, such as bipolar disorder, schizophrenia,substance abuse or some forms of personality disorder.

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The Mental Health Foundation, a UK wide charity, has been in existence for 65 years. We focus on researching and evaluating fresh approaches to mental health with a view to advocating helpful policy change and the roll out of best practice more widely.

Our work is centred on prevention – we believe that there is far more scope for interventions that prevent people developing mental health problems and which sustain recovery.

Access to mental health services is critical, but as a society we also need to focus on bringing down the need for these services and developing good mental health for all.

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