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# Young-onset dementia in mental health services

Recommendations for service provision

## **College Report CR217 (revision of CR135)**

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Approved by: The Policy and Public Affairs Committee

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**“No one should be alone with dementia. Don’t dwell on the losses or on the future as you have little control over either. Instead, enjoy the moment; enjoy today; and if today is a bad day, then tomorrow may be better.”**

Wendy Mitchell (author of *Somebody I Used to Know*)

# Foreword

“ Greater attention to dementia care within our health and social care service and in wider society has not always translated into attention for young-onset dementia (YOD) – dementia that develops before the age of 65 years. Those with YOD experience different, often greater, challenges than those who develop it at an older age. YOD is challenging not just for the individual and their family, but also for professionals providing care.

We therefore warmly welcome this report, the culmination of a fruitful collaboration between a team of experts, including people with first-hand knowledge of YOD. This partnership provided enormous insight into this condition and into the best approaches for meeting the needs of people with YOD and their families.

The report describes what is involved in achieving good quality YOD services for the benefit of people accessing these services. It recommends that the needs of patients with YOD are best met by a dedicated specialised service actively engaged with the wider clinical and social network of specialties.

Although the report is primarily written as a guide for psychiatrists working in mental health trusts, it will be of interest to all staff involved in the planning and delivery of YOD services.

We hope that it will promote urgently needed improvement across the UK in the quality and scope of services for younger people with dementia. We also hope it will stimulate research to improve the evidence base, guide future practice and achieve better outcomes for some of the most vulnerable people within our health and care systems.

”

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# Working group

The report was produced by a working group set up by the Royal College of Psychiatrists' (RCPsych's) Faculty of Old Age Psychiatry to update College Report 135 (Royal College of Psychiatrists, 2006). The report is endorsed by the Faculty and approved by the College's Policy Committee.

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- Members of the Young Dementia Network (YDN) (facilitated by Tessa Gutteridge): Wendy Mitchell, author and YDN steering group member living positively with dementia; Keith Oliver YDN steering group member, Alzheimer’s Society Ambassador and KMPT NHS Dementia Envoy; Des O’Sullivan, living with Young Onset Lewy Body Dementia; Peter Watson, Carer, YDN steering group member.
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# Executive summary

This report recognises that a person with young-onset dementia (YOD) and their family will often have complex diagnostic, management and personal needs and it is important that these needs are met in a timely and effective way.

The primary message is that the needs of patients with YOD in the care of mental health trusts are best met by a dedicated specialised service which actively links with the wider clinical and social network of specialties and services, signifying the diverse needs of this patient group.

A central component of these specialised services will be staff with the right combination of expertise and training. Psychiatrists have a key role in diagnosing and managing the mental health of younger people with dementia. This can best be achieved by a multidisciplinary team that works to optimise the quality and continuity of care, including information and advice. Such a team is best placed to ensure integration between National Health Service (NHS) specialists and partnership with a broad range of services (including third sector) that help to connect patients and their families with support at home and in their community.

The report offers advice to psychiatrists on job planning, continuing professional development (CPD) and training relevant to working in this area. It also recognises that more research is required to improve the evidence base and inform future practice. Looking forward, greater integration and collaboration between key stakeholders could offer much needed strategic leverage to improve the quality and scope of services for younger people with dementia across the UK.



# Recommendations and key messages

The main recommendations are summarised under four headings, with additional details provided in the subsequent relevant chapters of the report.

## 1. Access to a specialised service with expertise to provide assessment and treatment to facilitate support

### a. The patient and their family are at the centre

- i The service should be person-centred, age-appropriate and involve a person and their family from all backgrounds in decision-making and care planning; timely information and advice should be provided.
- ii Mental health trusts should actively support the involvement of patients and their families in the design and review of their service.
- iii Services need to support a person with YOD to remain as active and connected with their local community as possible (e.g. by raising awareness of initiatives such as Dementia Friendly Communities and age-appropriate services).

### b. Clinical leadership and expertise

- i Trusts should ensure that younger people presenting with suspected dementia have access to a specialist team with necessary expertise to make a diagnosis and address their needs.
- ii Younger people presenting with suspected dementia should be referred to a specialist team. Trusts should ensure referral pathways are clear and avoid unnecessary delays and uncertainties in accessing support. This will involve locally agreed YOD care pathways with clear provisions for the interface between the specialist team and other services, including primary care.

- iii Trusts should ensure there is a named local clinical lead for YOD within mental health services. They should have extensive experience and knowledge of the assessment and management of dementia, including rarer subtypes. They will usually be an old age psychiatrist (a dementia expert).
- iv The service should ensure patients have a named key worker (health or social care) who will provide guidance and be responsible for coordinating their care, as recommended for all patients with dementia by the National Institute for Health and Care Excellence (NICE) (2018).
- v Patients should have access to a full range of multidisciplinary professionals who have the necessary training and expertise to meet the needs of younger people with dementia. This should include access to a psychiatric nurse, clinical psychologist, occupational therapist, physiotherapist, social worker, speech and language therapist and dementia advisor (or equivalent).
- vi The needs of patients and their families are often complex, multiple and progressive, so it is important that the specialist team can tailor their involvement for as long as is clinically required, promoting continuity of care and a model of long-term support.

### c. Multi-agency partnership and commissioning

- i To ensure that the needs of patients and their families are addressed comprehensively over the course of their illness, there should be close collaboration between the patient, their family, the specialist team, primary care and the statutory and voluntary/third sector providers. People with YOD are likely to need help with employment, family welfare, relationships, emotional support, finances, accommodation, driving, legal and ethical matters, short- and long-term care, and palliative care.
- ii The specialist team should work with other agencies to enhance the quality and range of services in their locality, help identify any gaps and facilitate training of staff groups.
- iii Trusts should name a senior manager who can facilitate integration and collaboration between the specialist team, key local stakeholders and commissioners. The manager should help to develop a clear commissioning strategy for services within each locality that links mental health and acute NHS trusts, primary care and statutory and non-statutory services.

#### d. Optimising diagnostic and evidence-based practice

- i To optimise diagnostic accuracy, the specialist team should be able to access genetic testing and relevant biomarkers. This will include specialised neuroimaging and cerebrospinal fluid analysis, as recommended by NICE (2018). Clinicians working in mental health trusts should have access to brain scan images on relevant software platforms, e.g. a picture archiving and communication system (PACS), either in-house or through an arrangement with the local acute trust.
- ii Pre- and post-diagnostic support should be routinely offered to ensure optimised and personalised treatment and care plans for people with YOD and their carers.
- iii Pharmacological and non-pharmacological management of patients should follow NICE (2018) recommendations where possible, taking the wide-ranging nature of YOD into account.

#### e. Developing links with other medical and psychiatric specialties

- i It is important that the commissioning, provider and clinical interfaces promote cross-trust, cross-specialty working and that clear operational arrangements are in place to facilitate this. Patients with YOD will present to a wide range of NHS services, both within and outside of mental health trusts. Their psychiatric and medical needs are unlikely to be met within mental health trusts alone (or indeed by any single provider). In most localities this will require the specialist team to interface with multiple services, including neurology, genetics, neuroimaging, neuropsychiatry, neuro-ophthalmology, addiction, adult mental health, liaison psychiatry and intellectual disability services.
- ii As an initial step, YOD services in mental health trusts should identify a neurologist with an interest in cognitive disorders, with whom they can discuss/cross-refer patients, and a neuroradiologist with whom brain scans can be reviewed, preferably at joint meetings.
- iii The specialist team should develop a knowledge of the network of resources available in their locality. This will help guide patients and referring clinicians to the most relevant specialists and support.
- iv Building on these local links, the psychiatrist and team should aim to foster a clinical network that promotes the learning and sharing of best practice, such as cross-specialty imaging meetings, joint diagnostic clinics and joint educational events.

## 2. Job planning for psychiatrists

- a Job plans should reflect a minimum requirement of three programmed activities to support the service provision and development of a YOD specialist team.

Trusts should ensure this includes sufficient time for direct clinical care but also time for leadership, service development, cross-specialty and multi-agency working, supervision, training, research and CPD. More time might be required depending on local factors.

- b It is important that trusts ensure psychiatrists have time to support research and optimise patient participation in local research studies. There is need to improve the scope and quality of evidence-based practice and research in YOD.

## 3. Continuing professional development of consultants and trainees

- a Trusts should ensure access to relevant CPD for psychiatrists and other team members working with people with YOD.

This will include training in rarer dementias, interpretation of neuroimaging and use of new diagnostic markers, role of genetic testing and the different needs of younger people living with dementia.

- b Trainees in psychiatry require greater opportunities to develop competences in YOD to be better prepared to work in this area as consultants.

Training in YOD for core and higher trainees in psychiatry is often ad hoc: opportunities for placements in YOD services need expanding within training programmes along with access to cross-specialty experience, such as in neurology, neuropsychiatry and neuroradiology.

- c Opportunities for multidisciplinary training should be positively endorsed by trusts.

## 4. Future research and strategic developments

- a The recommendations of this College report should be reviewed and audited by all trusts providing services for YOD.
- b Medical and clinical directors have a key role to ensure consultant job planning supports services for YOD.

- c The Memory Services National Accreditation Programme (MSNAP) run by the College Centre for Quality Improvement (CCQI) should include performance measures that link to the recommendations in this report. This will help drive improvements and monitor the provision of services for YOD. In trusts commissioned to provide services for YOD, a named local clinical lead for YOD should be added as a mandatory requirement for MSNAP accreditation.
- d Trusts need to actively support research in YOD and collaborate with the clinical research networks, such as the dementia and neurodegeneration specialty network (DeNDRoN). Evidence-based practice in this area is limited and barriers to participation in local and national research need addressing.
- e More active links between other professional bodies (such as the Association of British Neurologists and the Royal Colleges of General Practitioners and Nursing) and the RCPsych are highly desirable. This could be through joint educational and regular training events and publications.
- f There should be a named individual at the level of the commissioning authority (clinical commissioning groups (CCGs)) with responsibility for developing services for people with YOD, especially in order to guide the implementation of further integration. It is important that services for people with YOD develop in line with new initiatives and commissioning arrangements.
- g To inform the local planning and commissioning of services for YOD, there is a need for improved informatics on the diagnostic rates and performance of NHS services in meeting their operational requirements for this patient group. It is important that dementia indicators exist and that they reflect the impact of dementia on younger as well as older people, including improved diagnostic rates of dementia for all ages. Therefore, the College welcomes the recent addition by Public Health England (2018) of new prevalence indicators for YOD.
- h The role of the psychiatrist and specialist team supporting patients with YOD will need to involve collaboration with a diverse range of services. We recommend that within each region, trusts link with the NHS England Dementia Clinical Networks to help improve YOD services and encourage innovation. Nationally, an alliance involving key stakeholders, including (but not limited to) the Faculty of Old Age Psychiatry, the Association of British Neurologists, Alzheimer's Society, Young Dementia Network, primary care and commissioners, would offer clear strategic benefits for the future development of services for people with YOD.

# Introduction

In the UK, at least 42 000 people are living with young-onset dementia (also known as early-onset dementia) which is defined by its onset before the age of 65 years (Alzheimer's Society, 2014). The Royal College of Psychiatrists and Alzheimer's Society last co-published guidelines on the provision of services for people with YOD in 2006 (CR135). Significant changes in the intervening decade to mental health services and in the evidence base underpinning dementia diagnosis and management have necessitated a revision. This report renews the College's position on services for YOD in the context of these changes and advises on best practice.

Importantly, public awareness of dementia is growing and there have been significant policy developments to drive better care and treatment.

The National Dementia Strategy (Department of Health, 2009) followed by the Prime Minister's Challenge on Dementia (Department of Health, 2015) have been influential in raising the profile of dementia, with over 2.5 million Dementia Friends and improved detection rates across the UK. Evidence-based guidelines (e.g. from the National Institute for Health and Care Excellence, 2018) are advancing clinical standards and fostering best practice. However, there is a danger that the high prevalence of dementia in later life can overshadow the importance of its occurrence in younger patients (Rossor *et al*, 2010). Despite examples of excellent services for patients with YOD, these remain the exception rather than the rule. Overall services remain patchy across the UK, with concerns they may have contracted in scope and coverage. Arguably, the clinical practice, policy and research needs of younger people with dementia have been less visible.

A number of themes converge to shape the reason why the experience of dementia at a younger age has a different impact than it has later in life. These include clinical, genetic, psychological, family, employment, societal and service considerations.

People with YOD have a much broader range of diagnoses, including less common forms of dementia, and may present atypically or with distinctive clinical phenotypes. Dementia in younger adults is often misdiagnosed, under-recognised and inadequately managed. Genetic factors have greater relevance and biomarkers may have greater clinical utility, yet are not uniformly available. Younger people often have no defined entry point into a service and accessing the right service and support has been notoriously cumbersome and variable. The integration between different services has often been limited, making it difficult for patients, families and healthcare professionals

to navigate clinical care pathways. The untimely nature of YOD affects family life, including dependent children and potentially parents, as well as employment, causing financial hardship. Research on people with YOD can offer key insights into the nature and potential treatment of dementia for all ages (e.g. imputing amyloid therapeutics from monogenetic causes of Alzheimer's disease), but research into YOD remains underdeveloped.

The majority of people with YOD receive their diagnosis and care from old age psychiatrists, who apply their skills and knowledge as dementia experts across the age range, predominantly in mental health trusts. This report focuses primarily on this setting, but the core messages are equally applicable to psychiatrists based in acute hospitals and relevant to other psychiatric sub-specialists who may be routinely or intermittently involved in the care of patients with YOD. This will include colleagues in neuropsychiatry and general adult, intellectual disabilities and liaison psychiatry.

Emphasis is placed on forging better clinical and training links between neurology and mental health services, while recognising this is one part of a much broader alliance that is required between health services, social care and third sector groups.

This report aims to complement the important work of the Young Dementia Network and key partners, such as Alzheimer's Society. We hope it will inform the dialogue between commissioners, clinicians and managers regarding the needs of people with YOD and how best to deliver services. It aims to cover all of the UK, although the issues are not unique to the UK (e.g. Sansoni *et al*, 2014; Alzheimer Society Canada, 2016; Carter *et al*, 2018).

# 1. Access to a specialised service

## 1.1 Why access to a specialised service is important

Younger people with dementia will undoubtedly share experiences with older people with dementia, yet there are important clinical and personal differences that can have a unique or disproportionate impact on younger people. Services need to ensure they are organised and delivered to meet these needs.

These differences include clinico-pathological variations in the aetiology and presentation of YOD that require specialist knowledge and expertise to diagnose and manage. YOD occurs at a time in life when personal and family impact can be particularly hard, because it is so often unexpected; a person may still be working or have dependent children or parents. Patients and families often experience significant difficulties and delay accessing support because of the way services are configured.

We expand on these factors in this section.

### Prevalence of young-onset dementia and estimated population needs

It is estimated that there are at least 42 000 people with YOD in the UK accounting for approximately 5% of all people with dementia (Alzheimer's Society, 2014). Assuming constant prevalence, this number is projected to increase to over 50 400 by 2025 (Carter *et al*, 2018).

Estimates of YOD incidence and prevalence vary by study and have included different diagnostic groups (Teles Vieira *et al*, 2013). For the age range 45–64 years, studies suggest there would be 11.5 to 22.8 new diagnoses (all causes) per year per 100 000 (Mercy *et al*, 2008; Garre-Olmo *et al*, 2010) and a prevalence range of 83.1–132.9 per 100 000 (Ikejima *et al*, 2009; Harvey *et al*, 2003; Withall *et al*, 2014).

The onset of YOD increases with age. For example, the estimated prevalence for the 30–34 year-old age group ranges from 4.2 to 13 per 100 000, increasing to 83 to 700 per 100 000 in the 60–64-year-old age group (Teles Vieira *et al*, 2013). In contrast to older cohorts, YOD appears to be more common in men.



The Prime Minister’s Challenge on Dementia 2020 set out a vision that all CCGs and local health and well-being boards should have access to relevant local and national data on dementia so commissioning and provision of services can be improved. To address the need for national data on dementia, the Dementia Intelligence Network (DIN) was created, followed by the launch of the Dementia Profile in 2016. The profile provides health intelligence to inform the provision of care in England for people who have dementia. In 2017, the DIN added to the profile three new indicators which focused on YOD (Public Health England, 2018). The indicators were created using the dementia diagnosis data recorded by NHS Digital (2016–2017), providing information that can be utilised by local authorities, CCGs and Sustainability and Transformation Programmes (STPs). The indicator values for crude YOD prevalence and YOD as a proportion of total dementia are presented in Table 1. The distribution pattern for crude YOD prevalence in England (CCG level) is displayed in Figure 1. The indicator values highlight the variation in recorded YOD diagnosis across England based on GP practice registers. The diagnostic rates vary by location and there is a gap between the observed and expected rates recorded by this approach compared with estimates from Alzheimer’s Society (2014) and epidemiological studies. As primary care data develop, they should inform future service development.

**Table 1 Young-onset dementia indicators**

| Indicator  | England value                          | Local authority value   | CCG value  | STP value   |
|--|--|---|--|---|
| <b>Dementia: crude recorded prevalence per 10 000 (aged under 65 years)</b>                | <b>2.99 per 10 000 (2.94 to 3.04)*</b> | <i>Lowest</i><br><b>Camden</b><br><b>1.15 per 10 000 (0.8 to 1.7)*</b>          | <i>Lowest</i><br><b>Camden</b><br><b>1.12 per 10 000 (0.8 to 1.6)*</b>               | <i>Lowest</i><br><b>North Central London</b><br><b>1.79 per 10 000 (1.6 to 2.0)*</b>          |
|  |  | <i>Highest</i><br><b>Stoke-on-Trent</b><br><b>6.42 per 10 000 (5.5 to 7.5)*</b> | <i>Highest</i><br><b>Cumbria/North East:</b><br><b>7.15 per 10 000 (6.1 to 8.3)*</b> | <i>Highest</i><br><b>Durham, Darlington, Teesside</b><br><b>4.89 per 10 000 (4.5 to 5.4)*</b> |
| <b>Dementia (aged under 65 years) as a proportion of total dementia (all ages) per 100</b> | <b>3.2% (3.2% to 3.3%)*</b>            | <i>Lowest</i><br><b>Havering</b><br><b>1.6% (1.1 to 2.3)*</b>                   | <i>Lowest</i><br><b>Eastern Cheshire</b><br><b>1.3% (1.1 to 2.3)*</b>                | <i>Lowest</i><br><b>Surrey Heartlands</b><br><b>1.9% (1.6 to 2.3)*</b>                        |
|  |  | <i>Highest</i><br><b>Newham</b><br><b>6.2% (4.9 to 7.8)</b>                     | <i>Highest</i><br><b>Bradford City</b><br><b>10.4% (8.0 to 14.0)*</b>                | <i>Highest</i><br><b>North West London</b><br><b>4.7% (4.3 to 5.1)*</b>                       |

*Indicators developed by the Dementia Intelligence Network, based on NHS Digital data (April 2017).*

CCG, clinical commissioning group; STP, sustainability and transformation programme.

The table highlights two of the three YOD indicators developed by the Dementia Intelligence Network. During 2016–2017, there were a total of 443 839 people with a recorded diagnosis of dementia in England, of whom 14 199 were younger than 65. Crude recorded YOD prevalence is the number of people with dementia aged less than 65 years, recorded on GP practice registers, as a proportion of all people aged less than 65 years recorded on GP practice registers. Caution should be taken when interpreting indicators with a higher than average value, which may mean that the prevalence of the condition is high in an area, but it could also indicate better case recording and/or detection. It is intended that all indicators will be refreshed at regular intervals.

\*Numbers in brackets denote 95% confidence interval.

## Diversity of clinical diagnoses

The diagnostic assessment of patients presenting with suspected YOD needs to consider the broad and varied aetiology of dementia in younger people. Approximately one in three people with YOD has a rare or uncommon underlying cause. This includes dementia associated with Huntington's disease and rarer genetic disorders; movement disorders (e.g. progressive supranuclear palsy, corticobasal degeneration, multiple system atrophy); prion diseases (e.g. Creutzfeldt–Jakob disease (CJD)); inflammation (e.g. cerebral vasculitis, limbic encephalitis); metabolic encephalopathies; the central nervous system (CNS) infections (e.g. HIV-related, syphilis, Lyme disease, Whipple's disease); demyelinating disorders; certain intellectual disabilities (e.g. Down's syndrome); head injury and trauma; types of brain cancer; alcohol-related brain damage (ARBD), which includes Korsakoff's syndrome, cerebellar syndrome and frontal lobe dysexecutive syndrome. For further information on ARBD see College Reports [CR185](#) and [CR212](#) (Royal College of Psychiatrists 2014, 2018).

The pattern of common neurodegenerative disorders also varies. Alzheimer's disease contributes proportionately less to the cause of YOD than later in life, accounting for approximately one third of diagnoses. Conversely, frontotemporal dementia (FTD) is recognised as the second commonest form of degenerative dementia in YOD.

Patients who experience cognitive difficulties due to pre-existing mental illness, such as schizophrenia or affective disorders, or patients with intellectual disabilities, will often require very careful diagnostic appraisal over time to discern whether or not a type of dementia is developing.

## Variations in clinical presentation

Although Alzheimer's disease remains the most common single cause of YOD, its clinical phenotype in younger people can be different than in older people. Non-amnesic presentations can be more prominent, including dyspraxia, visuospatial and language dysfunction, as can neurological changes, such as myoclonus. Posterior cortical syndromes are more common in younger patients with Alzheimer's disease and can present with apparent visual difficulties that are related to visual agnosia.

Age-related variations in the type of pathology that can cause vascular dementia are also recognised. Conditions such as cerebral autosomal dominant arteriopathy with subcortical infarcts and leukoencephalopathy (CADASIL), amyloid angiopathy and cerebral vasculitis are more commonly found in younger patients than in older people. Although vascular dementia is an uncommon cause of YOD overall, it is a significant contributor to cognitive decline in some younger groups, for example people with poorly controlled vascular risk factors such as diabetes and hypertension.

## Prognosis and natural history

Evidence suggests that degenerative conditions such as Alzheimer's disease and FTD are associated with a faster rate of cognitive decline and shorter life expectancy in younger patients. The median duration of survival after diagnosis is 4–5 years, possibly shorter in FTD, especially when complicated by motor neurone disease. Also, many of the rarer diseases that cause YOD can be rapidly progressive. Advance care planning and the palliative care needs of patients need to be considered early on in the course of the disease, often in the context of dependent children and surviving parents, which requires skilful intervention by healthcare professionals.

## Higher prevalence of genetic and familial risk factors

There are recognised genetic abnormalities associated with YOD that are usually inherited but can occasionally occur spontaneously. Examples include CADASIL (*NOTCH3*), Huntington's disease (*HTT* gene CAG trinucleotide repeat) and genetic forms of FTD (primarily *MAPT*, *GRN*, *C9orf72* expansion) and Alzheimer's disease (*APP*, *PSEN1*, *PSEN2*). However, it should be borne in mind that the majority of patients with early-onset Alzheimer's disease will not have an identifiable genetic abnormality. Genetic factors may also affect how the illness presents and progresses.

These genetic factors have significant personal and family implications and services will need to offer (or facilitate access to) genetic advice, counselling and, where appropriate, diagnostic testing.

## Application and role of biomarkers for subtyping dementia diagnosis

Certain biomarkers have an established clear evidence base for their use in diagnosing YOD, such as cerebrospinal fluid (CSF) analysis in the diagnosis of CJD. The evidence that neuroimaging and CSF biomarkers can improve diagnostic accuracy in other types of dementias is advancing, and age-related factors can modify their clinical utility. For example, in the assessment of Alzheimer's disease, hippocampal atrophy seen on magnetic resonance imaging (MRI) or computed tomography (CT) can be a disease marker, and this can have greater clinical relevance in younger people as age-related atrophy is less likely to confound the interpretation of this change. Likewise, if the diagnosis of Alzheimer's disease is suspected but uncertain, NICE guidance (2018) states that CSF measures of tau and amyloid-beta should be considered (with a caveat that the specificity of these tests is lower in older people). The added value of amyloid positron emission tomography (PET) imaging is likely to follow a similar pattern of offering greater discriminatory value in younger people (noting this form of imaging is currently largely restricted to research studies and clinical trials). The Edinburgh Consensus (Ritchie *et al*, 2017) and

Alzheimer's Research UK (2018) provide further commentary on the application of new biomarkers in dementia.

Given the diagnostic difficulties in assessing YOD, the potential influence of age on the diagnostic utility of biomarker tests and arguably their superior acceptability in younger people, there is a need for services to embed these tests in the clinical assessment of people with suspected YOD. To implement the NICE recommendations effectively and safely, close collaboration between mental health and acute trusts is required and psychiatrists are likely to need additional training in their application and interpretation. For example, although old age psychiatrists regularly request brain imaging and rely on the report when making a diagnosis, it is highly unusual for psychiatrists working in mental health trusts to have access to the images. Given the frequent need in YOD to reinterpret scans as the clinical picture changes, this discrepancy will increasingly be a barrier to the delivery of an efficient diagnostic pathway and training. Most memory assessment services in mental health trusts do not have access to a PACS, so the clinicians are unable to see the scans they are ordering and have to rely on the report. Therefore, it is incumbent on providers and commissioners to facilitate access by psychiatrists to the PACS of the imaging provider, most typically a nearby acute trust (assuming the majority of mental health trusts are unlikely to invest in an in-house PACS).

Developing a professional network would facilitate the joint discussion of complex diagnostic issues and help explore the best ways to introduce newer investigatory techniques into clinical practice. A useful first step would be for YOD services in mental health trusts to identify a neurologist with a specialist interest in cognitive disorders with whom patients can be discussed and cross-referred (including for CSF examination), and a neuroradiologist with whom imaging can be reviewed. Whether these specialists are based in the local acute provider or the regional neuroscience centre will vary according to geography and availability.

## **Delays and difficulties in accessing diagnosis and support**

Delays accessing a diagnostic assessment have been widely reported, with numerous accounts of patients and their families moving from 'pillar to post' before accessing the relevant services (Williams *et al*, 2001). On average, a person may see between two and five different consultants before a diagnosis is made and it is estimated to take twice as long for a patient with YOD to be diagnosed compared with late-onset dementia (Burns *et al*, 2017). Indeed, delays in diagnosis can often be measured in years (van Vliet *et al*, 2013). This is particularly evident in FTD and rarer dementias. It can take on average 4.4 years to receive a diagnosis of YOD, so closer partnership with GPs to facilitate more timely referrals is important.

The longer time to reach diagnosis can have a knock-on effect on family stress, work sickness and loss of earnings, delays in treatment,

increased cognitive problems and functional decline, depression or anxiety and missed opportunities to participate in research, such as clinical trials that often require participants to have mild symptoms.

## Diagnostic rates and accuracy

In addition to delays in diagnosis, rates of misdiagnosis have been a concern – as high as 30–50% (Werner *et al*, 2009; Carter *et al*, 2018).

Under-detection and under-investigation have also been reported. Nationally, diagnostic rates for dementia have steadily improved, reaching 67% by 2018 (NHS Digital, 2018). However, the diagnostic rate for YOD remains suboptimal and is subject to significant regional variation.

A number of factors, such as the inherent complexity of the differential diagnosis of YOD, atypical presentations, the lack of specialist services, limited awareness and training of staff are likely contributing to the relatively high rates of under- and mis-diagnosis. Changes in how memory clinics are functioning could also be relevant. Nationally, memory assessment services are operating to shorter timeframes of more episodic patient contact. This approach in the context of YOD could lead to premature decision-making and have negative consequences for patients and their families. It is often prudent to ensure there is time to monitor and review a patient before making a diagnosis: making a false positive diagnosis of YOD can have significant unintended consequences. Where diagnostic uncertainties persist or emerge it is important to be open about this and plan care accordingly.

Referrals of younger people to memory assessment services are increasing and there is a growing need for practitioners to have the necessary expertise to diagnose mild cognitive impairment and non-organic amnesic disorders in younger patients (Sikdar *et al*, 2016). Understanding the relationship between psychiatric comorbidities and YOD is often complex and requires expertise and time. This can be particularly challenging for patients with co-existing severe mental illness who have cognitive under-performance, sometimes in the context of neuroimaging changes that require careful interpretation.

Salem *et al* (2012, 2014) reported a high rate of overdiagnosis of dementia in young patients often associated with incomplete diagnostic work-ups. They suggested this tendency to overdiagnose dementia, particularly in the context of depression or alcohol abuse, could stem from the differing symptom profile of dementia in young patients, lack of knowledge among clinical physicians and the wide range of conditions that may be misinterpreted as dementia. Further, the diagnostic assessment of YOD in acute hospital admissions is usually not recommended due to the brevity and often incomplete nature of the assessment window, potentially compounded by the lack of collateral history, investigations and the co-existence of physical illness that may confound the assessment. Other factors complicating

diagnosis include prominence of neuropsychiatric features compared to the nature of the cognitive deficits (Mendez 2006).

Diagnostic accuracy will impact treatment decisions. In addition to standard treatments for neurodegenerative and vascular disorders, other causes may improve with focused treatments, for example sleep apnoea, hypothyroidism, vitamin deficiencies, epilepsy, multiple sclerosis, normal pressure hydrocephalus and other psychiatric disorders.

## **Pre- and post-diagnostic support and information**

Thorough diagnostic assessment is a crucial step, but it is rarely an end point, as many practical, emotional, health, ethical and legal issues lie ahead. Nevertheless, the way diagnostic disclosure is prepared for, shared and followed up are central steps in supporting people. Finding the right pace, information and approach to facilitate diagnostic disclosure is important. The Young Dementia Network and other charities offer useful resources for both health professionals and patients and their families (see [Table 6](#) and [Box 1](#)).

Adopting an approach more aligned to long-term conditions (such as that practised for diabetes), with greater emphasis on continuity of care, allows for individually tailored assessment and management plans that reflect the diagnostic complexity. The need to accommodate the often rapidly changing and progressive nature of YOD and high likelihood of emergent behavioural and psychological symptoms can also be addressed using a long-term conditions model. This allows for relationships to be built with a patient's family and carers, and support to be offered quickly when it is required. It will also enhance the collaboration with primary care, given that GPs have a key role in the longitudinal care of patients with YOD.

Healthcare professionals need to be mindful of the psychological effect of the language they use (Mitchell, 2018). Services also need to be cognisant that some patients and families may need time to contend with the untimely nature of changes emerging in YOD. Some patients may defer an assessment, 'fearing the worst', feel stigmatised or overwhelmed and uncertain where to turn for help, struggling to make sense of the changes and feeling 'too young' for dementia to be diagnosed. Some people may fear disclosing the diagnosis and wish to hide it from others. Others may have a sense of shock at the impact on their life expectancy. van Vliet et al (2011) analysed 92 caregivers' perspectives in the pre-diagnostic period in YOD and found several themes that influenced this process. In nearly every case, the carer was the one to seek help from the GP. Subtle changes in behaviour, often noticed by someone other than the nearest relative, took time to be noticed, and often the person with dementia had limited insight or tended to minimise their difficulties. A lack of awareness of YOD from health professionals added to the difficulties, which reinforces the need for staff training and education.

Younger people living with dementia are likely to have different information needs than those with late-onset dementia. It is important that the information is tailored accordingly and that care plans are personalised.

## Patients with intellectual disability

Certain types of intellectual disability are a risk factor for YOD. As more people with intellectual disabilities are living into older adulthood, the need for assessments related to possible dementia will increase. For example, people with Down's syndrome are at high risk of developing early-onset Alzheimer's disease, particularly in their fifties. The presentation may differ and the disease may progress more rapidly, with a high prevalence of epilepsy. The use of diagnostic criteria and neuropsychological assessments validated in patients with intellectual disabilities can help improve accuracy and aid monitoring. However, it is often difficult to diagnose dementia in people with severe disabilities. A diagnosis will often require serial assessments as well as multidisciplinary assessments and detailed collateral history. The impact of any comorbid condition and pain should be assessed. For a more detailed discussion of these issues and general further guidance, see CR196 (British Psychological Society & Royal College of Psychiatrists, 2015) and the NICE guideline on mental health problems in people with intellectual disabilities (NICE, 2016).

## Accessing support – high levels of unmet need

Young-onset dementia services are often experienced by patients and their families as fragmented, lacking continuity and not focused to address the differing needs of younger patients. For various reasons, the way younger people and their families may respond to YOD and use services differs from older people with dementia. Services often struggle to offer age-appropriate support and in the gaps that emerge there are often high levels of unmet need.

Younger people with dementia are more likely to be cared for at home for longer than those with late-onset disease, resulting in high carer burden (Bakker *et al*, 2013a). They use informal care systems more than statutory services, often because of limited opportunities to access age-appropriate respite (Bakker *et al*, 2013b).

There is evidence that people with YOD experience high levels of unmet need in many important areas of life, including daytime activities, social company, intimate relationships, eyesight and hearing/communication, memory, mobility, psychological distress and needs for information (Carter *et al*, 2018). Unmet needs can have a clinical impact and are associated with higher rates of neuropsychiatric symptoms (Bakker *et al*, 2014).

Concerns about the lack of 'age-sensitive' or 'age-appropriate' services have consistently featured in the literature. Services that are prominently used by older people, such as day care or residential care, are often experienced as inappropriate, especially in the early

stages of the illness. This can reduce their acceptance by carers who may feel an added pressure to extend the time they provide care at home. People with YOD may be more physically fit by virtue of having fewer age-related comorbidities and have preserved levels of physical activity; these needs should be anticipated in how services are delivered.

## Personal and family context and implications

Dementia in younger people is untimely and often unexpected. Patients and their families are not usually prepared for the diagnosis and its consequences, such as loss of employment and early retirement, loss of role and future opportunities, and impact on family finances.

The personal, psychological adjustment to a diagnosis of dementia will invariably generate stress and worry at any age, but it is likely (though under-researched) that the impact on identity, self-concept and personhood is influenced by contextual factors such as age and life experiences. Prevailing social attitudes, expectations and beliefs will shape how the illness is experienced, and the experience of living and coping with YOD is often strongly situated within an individual's social context (Clemerson *et al*, 2014). Patients with YOD experience difficulties in changing roles, self-esteem and lack of meaningful occupation or activity (Millenaar *et al*, 2016).

Finding ways to help people maintain their sense of independence, activity and participation is an important component of support. Remaining engaged in some form of employment confers benefits (Richardson *et al*, 2016) and maintaining positive social interactions, a sense of belonging and purpose are valued and help self-confidence (Mayrhofer *et al*, 2017). Projects that focus on active rehabilitation similar to those offered after other neurological diagnoses may prolong functional independence.

The INSPIRED study examined barriers to accessing care in YOD (Draper *et al*, 2016). Services were not universally taken up, with some patients only accessing services when the need became too great for the carer and others refused to engage. However, for those who had tried to engage with services, a number of themes emerged. This included concerns about their affordability and flexibility and how meaningful and tailored to the person they were (Cations *et al*, 2017).

Specialised services for YOD offer the advantage of being able to facilitate peer-to-peer support; the opportunity to meet with, learn from and share experiences with people in a similar situation is often highly valued by patients and their families, but it is more difficult to achieve in a dispersed model of healthcare.

The impact of YOD is felt at a different phase of the family life cycle compared with older people. Patients are likely to have a partner of similar age, who in turn may also experience difficulty maintaining employment and other family responsibilities. Carers are likely to need advice on their employment rights and a range of legal matters. It



is of concern that young carers often do not access the support to which they are entitled, and that they often feel that support is not appropriate for their age group specifically (NICE 2018).

Individuals are more likely to have dependent children living at home, as well as surviving parents. The emotional and practical impact on their children is usually significant: children are likely to feel anxious, fearful and bewildered, eventually experiencing the loss of their parent (Svanberg *et al*, 2010). Staff can feel uncertain how best to respond, and both informal and formal sources of support for children are often underdeveloped. At times, liaison with child and adolescent psychiatric services can be helpful. Where risks are apparent, child welfare and safeguarding issues will need to be addressed.

Family members and carers can experience high levels of stress, burden, depression, isolation and, at times, stigma (van Vliet *et al* 2010; Rosness *et al*, 2011). Potentially different types of dementia can mean different kinds of stresses for the carers.

Carers also describe issues related to a lack of appropriate social company, intimate relationships, sexual health and a tendency for services to focus on risk and danger issues rather than more empowering themes. Developing new skills and normalising activities are also seen as valuable.

## Employment and driving

Issues related to employment and driving are likely to feature. YOD affects performance at work and ultimately leads to loss of employment, with repercussions on income, role and social connectedness. Where necessary, patients will need support on employment rights, risks and occupational health-related matters. Unfortunately, individuals will sometimes have been dismissed from employment before a formal diagnosis or a chance to implement reasonable adjustments (Equality Act 2010) that may enable a person with dementia to continue to work (Chaplin and Davidson, 2016). Employers, human resource staff and disability employment advisors are unlikely to be aware of YOD. Chaplin (2016) and Clayton-Turner *et al* (2015) highlighted the importance of providing information on employment rights to patients and their families. Signposting patients to advice on benefit and welfare rights via organisations such as Citizens Advice can be helpful ([www.citizensadvice.org.uk](http://www.citizensadvice.org.uk)). Advice regarding personal independence payments and other benefits is often important.

A decline in driving skills will need managing. It is mandatory to notify the Driver and Vehicle Licensing Agency (DVLA) on diagnosis and in-car driving assessments can be invaluable in reconciling whether it is safe for a person to continue driving. A consensus clinical guideline on driving has been produced by the Driving and Dementia Project (2013) at Newcastle University.

## Palliative care needs and support in later stages of dementia

The majority of younger patients with advanced dementia are still likely to be cared for in settings primarily designed for and used by older people with dementia. Most palliative care services developed for younger patients have focused on the needs of patients with progressive neurological disorders such as motor neurone disease, multiple sclerosis and Huntington's disease. In relation to the last, the importance of advance directives and the anticipation of end-stage care needs have been highlighted, alongside recognising the importance of dignity, meaningful social interaction, communication, comfort, safety, spirituality, enjoyment, well-being and nutrition (Klager *et al*, 2008). It is highly likely that patients with other forms of advanced dementia, such as Alzheimer's disease, will face similar issues, but further research is required to explore these in greater detail.

## Staff training and awareness

The relatively low prevalence of YOD means that most staff groups, whether within the NHS or social care settings, are unlikely to be familiar with the needs of people with YOD. NICE (2018) highlighted this issue and included a specific recommendation regarding staff training for younger people living with dementia.

# 1.2 Current status of services for young-onset dementia in mental health trusts

Within mental health trusts, the majority of specialised services for YOD have been provided by old age psychiatry services, adopting a range of service models.

During the early 1990s there was growing concern regarding the quality and availability of services for younger people with dementia, with only 4% of hospital and community trusts in England having a dedicated service and 14% with an identifiable consultant with responsibility for YOD (Barber, 1997). Patients and their families, expressing their voice through organisations such as Alzheimer's Society, advocated access to a comprehensive, integrated, specialist service from diagnosis to long-term care or death. Furthermore, services for patients with YOD with comorbidities, such as intellectual disability and substance misuse and services for patients from minority groups have historically been underdeveloped.

Over the recent years, despite the emergence of several excellent services for people with YOD, concerns persist that services remain patchy with variable geographical coverage. Examples of innovative services include those profiled by [Alzheimer's Society](#) and the [Young Dementia Network](#).

Rodda & Carter (2016) surveyed members of the Young Dementia Network, old age psychiatrists, neurologists and members of the MSNAP about YOD services. They collected responses from 189 old age psychiatrists covering 76 UK trusts. Over half of trusts had no specialist consultant lead for YOD and had limited access to age-specific post-diagnostic interventions. Less than 15% had access to any age-appropriate cognitive stimulation therapy (CST), with 43% having no access to CST of any kind. There were very low levels of age-appropriate respite or long-term care.

For this report, consultant old age psychiatrists were surveyed in 2018. We received 100 responses from consultants working in England, Wales, Northern Ireland and Scotland. For most providers ( $n=78$ ) the assessment of YOD was conducted by mental health services for older people. A minority of providers ( $n=12$ ) used generic memory assessment services and two undertook assessments within adult mental health services. For eight responders, the assessments took place within neurology services rather than mental health services.

Overall, the survey revealed that access to specialised services remains patchy and underdeveloped nationally, and is potentially becoming less available. Of 100 responders, there was no multi-disciplinary YOD service in 71% of localities. Of the 29 respondents that had a multidisciplinary service, most reported that they were supported by a generic older people's community mental health team (CMHT) service, often limited to nursing staff without access to other healthcare professionals. A small number of services reported access to age-appropriate CST (10%) and post-diagnostic care (16%) and offered forms of social care for younger people.

There was very limited evidence of active links between mental health services and neurology, though access to specialised scanning was widely available: 97% could access MRI, 83% could access dopamine transporter (DaT) scans and over half could access PET scans, including 15% who were using amyloid PET scans. Importantly, a third of respondents reported changes over recent years in how services for YOD are delivered – reduced and moved into generic memory services or mental health services for older people. Separately, only 6% had seen expansion. Integration within and between trusts appeared low and arguably not aligned with the needs of people with YOD.

There is, however, evidence that the overall picture is mixed. There are exemplar services with notable practice (e.g. see [Young Dementia Network website](#) for details) and data from the MSNAP show a more positive picture. The MSNAP is a quality assurance programme of memory services overseen by the Royal College of Psychiatrists' Centre for Quality Improvement (CCQI). It sets standards to accredit memory service, incorporating five standards (6th Edition, 2018) relating to YOD following submission of evidence by the Young Dementia Network. (Only one standard – the processes of assessment and diagnosis – is currently mandated for accreditation.)

As part of the MSNAP accreditation process, services report whether they are meeting these standards. Of the 56 memory services across the UK using MSNAP standards since 2016, 89% had a named lead within the team for people with YOD. Totals for each standard are shown in Table 2.

| Table 2 Memory Services National Accreditation Programme (MSNAP) standards for young-onset dementia [Royal College of Psychiatrists' Centre for Quality Improvement (2018) 6th edition]  |                               |
|--|-------------------------------|
| Standard <sup>a</sup>  | Services meeting the standard |
| <p><i>Service planning and commissioning</i></p> <p><b>Health and social care commissioners, in consultation with local partners, people with dementia/suspected dementia and carers, have a local integrated care pathway based on best practice, which includes referral to national or regional specialist centres and exit from the service, where appropriate.</b></p> <p><b>Guidance: This includes specifically a pathway for young-onset dementia, people with intellectual disabilities and people with rarer types of dementia where diagnosis is more complex and likely to be delayed.</b></p> | 93%                           |
| <p><i>Staffing for the memory service</i></p> <p><b>There is a named lead within the team for people with young-onset dementia.</b></p>  | 89%                           |
| <p><i>Assessment and diagnosis<sup>b</sup></i></p> <p><b>The service has access to in-depth assessment of occupational functioning and neuropsychological assessment as required (e.g. for young-onset dementia, complex or abnormal presentations).</b></p>   | 96%                           |
| <p><i>Care management</i></p> <p><b>The service can refer on to specialist services for rare or young-onset dementia and/or complex care needs (e.g. regional/ tertiary neurology/ neuropsychiatry services).</b></p>  | 100%                          |
| <p><i>Psychosocial interventions</i></p> <p><b>The team signposts younger people with dementia to structured activities such as work, education and volunteering.</b></p>  | 96%                           |

a. Data available from 2016 provided by MSNAP.

b. Mandated for accreditation.

c. Further details on the MSNAP standards can be found at [www.rcpsych.ac.uk/workinpsychiatry/qualityimprovement/qualitynetworks/memoryservices/memoryservicesaccreditation/msnapstandards.aspx](http://www.rcpsych.ac.uk/workinpsychiatry/qualityimprovement/qualitynetworks/memoryservices/memoryservicesaccreditation/msnapstandards.aspx)

Despite the fact that exemplarily specialised services exist and have demonstrated positive outcomes, and despite the wide support from patient groups for dedicated services, the variation in the availability of specialised services continues to be a concern.

## 1.3 Role of specialised services for young-onset dementia in mental health trusts

The Royal College of Psychiatrists recommends that, where mental health services have responsibility for it, the diagnosis or care of people with YOD should be provided by a dedicated YOD service. There are some excellent services which have already established a dedicated team, but this needs expanding to ensure the same standards of care independent of location.

As outlined earlier, the experience of dementia can vary by age at onset. Taken together, these elements dictate why the clinical needs of patients with YOD and their families are best met by a dedicated team with the relevant expertise and skills mix. This team should function to improve the quality of services for YOD and reduce the risk that patients' needs go under-detected and unmet.

The knowledge, expertise, focus and leadership of a dedicated service can help inform and address the 'whole-picture' of practice, policy, commissioning and research needs of people with YOD.

The relatively low prevalence of YOD (compared to late-onset dementia) means that providers need to evaluate the feasibility and cost-effectiveness of services. Although evidence is limited, additional health economic factors that favour focusing resources in dedicated teams are as follows.

The catchment population of mental health trusts is usually large (often between 500 000 and 1.4 million), so the number of patients with YOD within their area makes it feasible and more cost-effective to provide a dedicated service.

The prevalence of YOD means that patients are likely to be dispersed over the 9300+ GP practices in the UK. This can make it difficult for individual GPs to develop their expertise in this area and to determine the collective needs of patients with YOD in a locality. In contrast, mental health trusts (of which there are far fewer – for example, 54 in England) serve much larger populations and arguably are better positioned to consolidate and focus their resources and expertise on the needs of those with YOD).

Referral and care pathways often lack clarity. Patients are often referred to a range of secondary care specialists, both within mental health services and acute trusts, which generates unnecessary costs and duplication. A dedicated team allows care pathways within the NHS to be streamlined and gaps to be identified and remedied.

As discussed further in chapter 4, the quality and depth of evidence to inform best practice is limited. Very few studies have used robust, quantifiable clinical or health economic outcome measures. Most

have used qualitative designs with small sample sizes, although these descriptive studies can provide insights and opinions that otherwise would be difficult to obtain.

Evidence is more aligned to outcomes about ‘perceived effectiveness’ (Mayrhofer *et al*, 2017). These qualitative outcomes often relate to how people rate service satisfaction, their health, well-being and quality of life, and have been explored via concepts such as social connectedness, participation and inclusion, adjustment, normalisation and support for caregivers.

Despite the lack of empirical evidence to define how best to design services, we know from a myriad of sources (case reports, feedback from carers – individually or collectively via charities or various studies, clinical contact with patients and their families, and expert consensus) that the way services are organised is unsatisfactory. There have been significant concerns about diagnostic fidelity and delays, a sense of feeling ‘pushed’ between different services and personnel with no clear pathway, and difficulties accessing the right kind of support.

Examples of existing YOD teams and services can be found on the Young Dementia Network website and the Alzheimer’s Society website.

This section outlines the key elements that pertain to the structure and function of a specialised team for YOD, set out in two parts:

- core features of a specialised team (Table 3)
- core clinical functions of a specialised team (Table 4, Table 5).

## Core features of a specialised team

| Table 3 Core features of a young-onset dementia service |   |
|---|---|
| Feature   | Comments  |
| Named local clinical lead                               | A named local clinical lead** with extensive experience of working with patients with dementia. In a mental health trust this will most likely be an old age psychiatrist (a dementia expert; see chapter 2 for advice on job planning).  |
| Named key worker and multi-professional care            | Each patient has a named key worker.<br>The YOD team is multidisciplinary, ideally co-located.<br>There is a core set of healthcare professionals that the patient has access to: a psychiatric nurse, clinical psychologist and occupational therapist**, as well as a physiotherapist, social worker, speech and language therapist and dementia advisor (or equivalent).   |
| Patient centred   | The team involves people living with dementia in decisions about care.***<br>Interventions are individually tailored, reflecting a whole-family approach and the diverse nature of YOD.   |
| Networked   | The team are highly networked, reflecting the complex needs of people with YOD from diagnosis to treatment and longer-term care: the team help to coordinate these services and work in partnership with primary care/GPs, other agencies and secondary care providers.<br>The team are able to signpost younger people with dementia to structured activities such as work, education and volunteering.**<br>The team are able to refer on to specialist services for rare forms of dementia.**<br>The team have an identified liaison neurologist with an interest in cognitive disorders with whom patients can be discussed or to whom they can be referred.<br>The team have access to specialist advice when interpreting investigations and assessments. They have access to relevant neuroimaging and can discuss the results of complex diagnostics on a regular basis with neuroradiologists and other relevant specialists in a joint meeting. |
| Continuity and long-term support                        | The specialist team tailor their involvement for as long as is clinically required, promoting continuity of care and a model of long-term support. Services are delivered flexibly to support patients and their families. The needs of carers who provide 24-hour care at home are addressed.  |
| Trust leadership  | The trust has a named manager to support the development, design, commissioning and integration of the service. The service sits within a clear management framework of the trust.  |

\*\*MSNAP standards.

\*\*\*NICE (2018) recommendation.

## Core functions of a specialised team

Table 4 Core clinical functions of a YOD service

| Tasks   | Comments  |
|---|---|
| Comprehensive dementia diagnosis including full history, physical and mental state examination, cognitive assessment and relevant investigations (including neuroimaging and CSF) | Use validated criteria to guide clinical judgement when diagnosing dementia subtypes.<br>NICE (2018) also recommends CSF measures of amyloid and tau to improve diagnostic accuracy in Alzheimer's disease. It is highly likely that this will require a service operational policy with an acute trust to ensure the tests are conducted safely and with appropriate expertise.<br>Each service will need to determine which formal neuropsychiatric and neurocognitive tools to use in their assessment pathway (to aid diagnosis, monitor change and evaluate outcomes). |
| Assessing the role of mental and physical health comorbidities  | This may include managing risk factors such as vascular disease, diabetes, smoking, obesity and hypertension (in collaboration with GPs).<br>Evaluate the role of any mental health factors.<br>Rule out reversible causes of dementia.<br>Remain vigilant to false positive and false negative diagnoses.<br>Provide advice on medicines that might contribute to cognitive impairment.  |
| Assessment and management of any associated physical health symptoms  | These may include motor symptoms, involuntary movements, impaired gait and mobility, falls, autonomic dysfunction, epilepsy, swallowing and speech impairments, incontinence and constipation. This may involve liaising with primary care and relevant secondary care specialists  |
| Genetic testing   | Links should be formed with medical genetic services and/or cognitive neurology clinics (as per local arrangements) to facilitate advice on genetic testing.<br>The genetic tests (excluding <i>C9orf72</i> ) are run as dementia gene panel ( <a href="https://ukgtn.nhs.uk/find-a-test/search-by-disorder-gene/details/6712/">https://ukgtn.nhs.uk/find-a-test/search-by-disorder-gene/details/6712/</a> )  |
| Comprehensive needs assessment and management   | Access to a full MDT is crucial both initially and over the course of the illness.<br>Needs will need to be reviewed over the course of the illness.  |
| Pre-, peri- and post-diagnostic support with tailored information   | Examples on the Alzheimer's Society website and other third sector providers (see resources in Table 6).  |
| Care planning, review and coordination  | Every patient should have a key worker who will guide, support them and help establish links with community-based services.<br>Patients should have a personalised care plan that is regularly reviewed (NHS England, 2017a).   |
| Prescribing cognitive enhancers   | Prescribing should be evidence based where possible and aligned to key guidelines (e.g. O'Brien <i>et al</i> , 2017; NICE, 2018).   |
| Non-pharmacological interventions for people living with dementia   | Explore interventions to promote cognition, independence and well-being tailored to the person's preferences. These may include peer groups, cognitive stimulation, reminiscence therapy and cognitive rehabilitation or occupational therapy to support functional ability   |
| Managing non-cognitive symptoms   | These may include changes in sleep patterns (including REM sleep), behaviour disturbance, psychosis, low mood and anxiety, agitation, aggression, disinhibition and apathy  |



Table 4 cont.

| Tasks  | Comments  |
|--|---|
| Assessing risks (including driving)  | Consider resources such as driving guidance (Driving and Dementia Project, 2013) and referral to driving mobility centres.<br>The patient will need to inform the DVLA and their car insurer about their dementia diagnosis.  |
| Supporting informal carers (information, skills training, support accessing interventions) | This will include but is not limited to (NICE, 2018): <ul style="list-style-type: none"> <li>● tailored information about dementia</li> <li>● developing personalised strategies</li> <li>● helping carers understand and respond to changes in behaviour</li> <li>● adapting communication styles</li> <li>● looking after their own physical and mental health and emotional well-being</li> <li>● planning enjoyable and meaningful activities</li> <li>● information about relevant services</li> <li>● advice on planning for the future.</li> </ul> This needs to reflect family circumstances and preferences – including support for dependent children and surviving parents.<br>Consider advice on sexual health and physical exercise.<br>Consider role of assistive devices and new technologies in promoting independence. |
| Providing advice on legal, employment and financial issues                                 | Where appropriate, consider liaison with employers to help support patients at work, including their right to reasonable adjustments (in line with the Equality Act 2010).<br>Provide advice on personal payment and benefits as well as welfare rights, wills and lasting power of attorney ( <b>concerning both health and welfare</b> ).   |
| Supporting advanced care decisions   | This will include advance decisions to refuse treatment and any advance statements the patient may wish to make reflecting their preferences, wishes and beliefs regarding their care (NHS England, 2018).  |
| Palliative care  | Work in partnership with GPs (who often coordinate end-of-life care) and where appropriate links with local palliative care services.<br>Ensure pain management is optimised as appropriate. Advise on swallowing, nutrition, dignity and comfort, often in the context of best-interest decision-making.<br>Further general guidance on palliative care is produced by NICE (2011, 2017).  |
| Audit and quality assurance  | Undertake regular quality improvement activities and consider external review (such as MSNAP).  |
| Supervision of team  | Regular clinical supervision is key.  |
| Supporting access to research  | NICE (2018) recommends that people living with dementia (all stages) should be informed about research studies they could participate in.   |

CSF, cerebrospinal fluid; DVLA, Driver and Vehicle Licensing Agency; MDT, multidisciplinary team; MSNAP, Memory Services National Accreditation Programme.

Cont.

**Table 5 Core networking and leadership functions of a young-onset dementia service**

| Networking tasks   | Comments  |
|--|---|
| Facilitating direct clinical care  | Key role will be to help link patients with a diverse array of community services and professionals. This will involve developing a working knowledge of local age-appropriate services.  |
| Forming links between NHS specialists and third sector providers                 | YOD services in mental health trusts should identify a neurologist with an interest in cognitive disorders.<br>Formal links with neuroradiology services will assist interpretation of scans, supplemented by access to PACS (for clinical and training purposes).<br>Third sector providers typically offer a huge range of innovative and person-centred interventions including tailored information and advice, age-appropriate day care, peer and carer support groups, physical activities, volunteering, supported workplaces, leisure activities and assisted holidays. |
| Local strategic leadership   | Ensure needs of people with YOD feature in the strategic aims of the trust, including research and development committee.<br>Ensure care pathways are clear.<br>Set up joint neurology and neuroradiology interface.<br>Establish links with commissioners, clinical strategic networks and clinical research networks (DeNDRoN).<br>Work in partnership with primary care, third sector providers and local voluntary groups.  |
| Staff training and awareness with strong emphasis on multi-professional training | Actively explore opportunities to support staff training in primary and secondary NHS care as well and social care settings. NICE (2018) highlight the importance of staff training in their recommendations.   |

# 2. Job planning for psychiatrists

A psychiatrist will require time within their job plan to enable them to undertake the roles and responsibilities needed to provide senior clinical leadership to a service for people with YOD.

As a minimum, a psychiatrist will require three programmed activities (PAs) to perform the necessary clinical and service leadership functions for each team. This number of PAs is partly informed by the epidemiology of YOD to estimate anticipated workload. As referenced earlier, the prevalence of YOD in the age range most likely to use the service (45–64 years) ranges from 83.1 to 132.9 per 100 000. This gives an approximate average of 100 people with YOD per 100 000 in this age range. If the population served by the team exceeds this number, then more PAs are required.

The PAs should incorporate sufficient time for:

- direct clinical care (DCC), including the assessment, diagnosis and management of patients with YOD, and
- supporting programme activities, such as leadership, service development, cross-specialty and multi-agency working, supervision, training, research and continuing professional development.

This guidance is a minimum standard for running a safe service. Inevitably, local factors will influence how much more time is necessary. These factors include:

- population size and characteristics, including levels of morbidity
- geography
- referral patterns
- level of staffing
- the range and type of service pathways, both within and outside the mental health trust
- the amount of service development and strategic leadership required.

Importantly, the service will require access to an MDT. This staffing resource, both in terms of expertise and availability, will be key to a successful service for people with YOD and will affect job planning. The precise configuration of staffing will take these factors into consideration to meet the local needs of people with YOD.

This guidance should be seen in the context of more general guidance on job planning for psychiatrists, including [CR207](#) (Royal College of Psychiatrists, 2017).

It is important the senior leadership teams in each mental health trust (medical directors) support consultant job planning to enable specialised teams to be set up and remain viable and sustainable.

There is need to improve the scope and quality of research in YOD. It is important that the psychiatrist has time to support research and is supported by the specialist team and trust to optimise patient participation in local research studies.

# 3. CPD, resources and training

## 3.1 Continuing professional development for psychiatrists

Psychiatrists (and other team members) working with people with YOD will require training in rarer dementias, interpretation of neuroimaging, use of new diagnostic markers, genetic testing and the different needs of younger people living with dementia. In addition, given the complex interplay with neurological and psychiatric disorders, CPD for psychiatrist should cover how to identify and manage cognitive symptoms that arise in the context of enduring mental health problems, such as schizophrenia and affective disorders, as well as somatization disorders, functional neurological disorder, epilepsy, migraine, sleep disorders and motor disorders, such as Parkinson's disease.

A key recommendation is that psychiatrists develop links with colleagues in other specialties and trusts that help not only to forge a functioning clinical network but to build opportunities for joint education and sharing of practice. These could take the form of: joint imaging meetings with colleagues in neuroradiology and medical physics; shared educational programmes with colleagues in neurology and neuropsychiatry; joint case discussion peer groups with neurologists and clinical psychologists; regional networks of MDT staff linked to services for YOD.

## 3.2 Resources

### Resources for health professionals

The Young Dementia Network have provided a helpful resource outlining the key elements of a care pathway which can be used as a blueprint for patients, services and commissioners (Young Dementia Network, 2016). They also produced a guide for GPs to help them to identify key red flags to indicate when a younger person with suspected cognitive impairment should be referred to a specialist service, and when to consider adult mental health services, neurology, counselling services, or when to 'watch and wait' (Young Dementia Network, 2017).

Examples of resources are provided in [Table 6](#) and [Box 1](#).

Table 6 Young-onset dementia resources for health professionals

|                              |  |
|------------------------------|--|
| Metrics                      | <ul style="list-style-type: none"> <li>● Three YOD metrics focused on prevalence, available on the dementia profile compiled by Public Health England (<a href="https://fingertips.phe.org.uk/profile-group/mental-health/profile/dementia/data">https://fingertips.phe.org.uk/profile-group/mental-health/profile/dementia/data</a>)</li> <li>● NHS Digital data: resource for reviewing dementia diagnostic rates (<a href="https://digital.nhs.uk/">https://digital.nhs.uk/</a>)</li> </ul>   |
| Resources                    | <ul style="list-style-type: none"> <li>● Alzheimer's Society (<a href="http://www.alzheimers.org.uk/about-dementia/types-dementia/younger-people-with-dementia#content-start">www.alzheimers.org.uk/about-dementia/types-dementia/younger-people-with-dementia#content-start</a>)</li> <li>● Alzheimer's Research UK (<a href="https://www.alzheimersresearchuk.org/about-dementia/types-of-dementia/alzheimers-disease/early-onset-alzheimers/">https://www.alzheimersresearchuk.org/about-dementia/types-of-dementia/alzheimers-disease/early-onset-alzheimers/</a>)</li> <li>● Services for Younger People with Dementia and the Role of Clinical Psychology (Briefing Paper 23) published by the British Psychological Society (<a href="http://www1.bps.org.uk/system/files/Public%20files/DCP/cat-444.pdf">www1.bps.org.uk/system/files/Public%20files/DCP/cat-444.pdf</a>)</li> <li>● An NHS blog article by Burns <i>et al</i> (2017; with additional resources and key contacts)</li> <li>● Social Care Institute for Excellence, information on young-onset dementia (<a href="http://www.scie.org.uk/dementia/symptoms/young-onset/">www.scie.org.uk/dementia/symptoms/young-onset/</a>)</li> <li>● YoungDementia UK: a national charity for younger people with dementia and their families (see <a href="https://www.youngdementiauk.org">https://www.youngdementiauk.org</a>)</li> <li>● Younger People with Dementia (Berkshire): website (<a href="http://www.ypwd.info">http://www.ypwd.info</a>) and related articles (<a href="http://www.ypwd.info/sites/default/files/JDC%20article.pdf">http://www.ypwd.info/sites/default/files/JDC%20article.pdf</a>)</li> <li>● Young Dementia Network: a collaborative group of individuals and organisations managed by YoungDementia UK (see <a href="https://www.youngdementiauk.org/young-dementia-network">https://www.youngdementiauk.org/young-dementia-network</a>)</li> </ul> |
| Books                        | <ul style="list-style-type: none"> <li>● <i>Young Onset Dementia: A Guide to Recognition, Diagnosis, and Supporting Individuals with Dementia and Their Families</i>, by Hilda Hayo, Alison Ward, and Jacqueline Parkes. Jessica Kingsley Publishers, 2018.</li> <li>● <i>Supportive Care for the Person with Dementia</i>, edited by Julian Hughes, Mari Lloyd-Williams and Greg Sachs. Oxford University Press, 2010.</li> </ul>   |
| Research                     | <ul style="list-style-type: none"> <li>● Angela Project (<a href="http://www.ucl.ac.uk/psychiatry/the-angela-project">www.ucl.ac.uk/psychiatry/the-angela-project</a>)</li> <li>● Dementia and Neurodegeneration Clinical Research Network (DeNDRoN) (<a href="http://www.nihr.ac.uk/nihr-in-your-area/dementias-and-neurodegeneration">www.nihr.ac.uk/nihr-in-your-area/dementias-and-neurodegeneration</a>)</li> <li>● Join Dementia Research (<a href="http://www.joindementiaresearch.nihr.ac.uk">www.joindementiaresearch.nihr.ac.uk</a>)</li> </ul>  |
| Specialist dementia websites | <ul style="list-style-type: none"> <li>● CADASIL (<a href="http://www.cambridgestroke.com/cadasil.php">www.cambridgestroke.com/cadasil.php</a>)</li> <li>● FTD talk (<a href="http://www.ftdtalk.org">www.ftdtalk.org</a>)</li> <li>● Familial Alzheimer's Support Group (<a href="http://www.raredementiasupport.org/fad/">www.raredementiasupport.org/fad/</a>)</li> <li>● Huntington's Disease Association (<a href="http://www.hda.org.uk">www.hda.org.uk</a>)</li> <li>● Huntington's Disease Association Northern Ireland (<a href="http://www.hdani.org.uk/cgi-bin/greeting?instanceID=1">www.hdani.org.uk/cgi-bin/greeting?instanceID=1</a>)</li> <li>● Learning (Intellectual) Disability and Dementia (<a href="http://www.learningdisabilityanddementia.org">www.learningdisabilityanddementia.org</a>)</li> <li>● The Lewy Body Society (<a href="http://www.lewybody.org">www.lewybody.org</a>)</li> <li>● Parkinson's UK (<a href="http://www.parkinsons.org.uk">www.parkinsons.org.uk</a>)</li> <li>● Posterior cortical atrophy (PCA) support group (<a href="http://www.raredementiasupport.org/pca/">www.raredementiasupport.org/pca/</a>)</li> <li>● PSP Association (<a href="https://pspassociation.org.uk">https://pspassociation.org.uk</a>)</li> <li>● Rare Dementia Support (<a href="http://www.raredementiasupport.org">www.raredementiasupport.org</a>)</li> <li>● Scottish Huntington's Association (<a href="https://hdscotland.org">https://hdscotland.org</a>)</li> </ul>  |
| Additional resources         | <ul style="list-style-type: none"> <li>● Dementia Partnerships – dementia hub for professionals rich with resources (<a href="https://dementiapartnerships.com/">https://dementiapartnerships.com/</a>)</li> <li>● Dementia Roadmap - List of resources (<a href="https://dementiaroadmap.info/category/diagnosing-well/#.Wyd7WIVKipo">https://dementiaroadmap.info/category/diagnosing-well/#.Wyd7WIVKipo</a>)</li> <li>● Dementia Action Alliance dementia statements (<a href="http://www.dementiaaction.org.uk/nationaldementiadeclaration">www.dementiaaction.org.uk/nationaldementiadeclaration</a>)</li> <li>● Centre for Health Service Development: Younger Onset Dementia Literature Review (<a href="https://ahsri.uow.edu.au/content/groups/public/@web/@chsd/documents/doc/uow176494.pdf">https://ahsri.uow.edu.au/content/groups/public/@web/@chsd/documents/doc/uow176494.pdf</a>)</li> </ul>   |

Cont.

Table 6 cont.

|                        |   |
|------------------------|---|
| Innovations (examples) | <ul style="list-style-type: none"><li>● <b>Oxford Academic Health Science Network including practice recommendations for frontotemporal dementia</b> (<a href="http://www.oxfordahsn.org/clinical-networks/dementia/">www.oxfordahsn.org/clinical-networks/dementia/</a>)</li><li>● <b>Young Onset Dementia Assessment Service (YODAS) include Young Onset Dementia app (via Apple or Google)</b> (<a href="https://improvement.nhs.uk/resources/young-onset-dementia-assessment-service/">https://improvement.nhs.uk/resources/young-onset-dementia-assessment-service/</a>)</li><li>● <b>Streamlining Memory Service Pathways: Guidance from the London Dementia Clinical Network</b></li></ul> |
|------------------------|---|

## Resources for patients and their families

### Box 1 Resources for patients and their families

- **The Young Dementia Network** ([www.youngdementiauk.org](http://www.youngdementiauk.org))
- **What is young-onset dementia? - factsheet. Alzheimer's Society** ([www.alzheimers.org.uk/about-dementia/types-dementia/younger-people-with-dementia](http://www.alzheimers.org.uk/about-dementia/types-dementia/younger-people-with-dementia))
- **Young-onset dementia: understanding your diagnosis. Alzheimer's Society** ([www.alzheimers.org.uk/sites/default/files/migrate/downloads/young-onset\\_dementia\\_understanding\\_your\\_diagnosis.pdf](http://www.alzheimers.org.uk/sites/default/files/migrate/downloads/young-onset_dementia_understanding_your_diagnosis.pdf))
- **Younger people with dementia – living well with your diagnosis. NHS Health Scotland and Alzheimer Scotland** ([www.youngdementiauk.org/sites/default/files/Younger%20people%20with%20dementia%2C%20NHS%20Health%20Scotland.pdf](http://www.youngdementiauk.org/sites/default/files/Younger%20people%20with%20dementia%2C%20NHS%20Health%20Scotland.pdf))
- **Alzheimer Scotland** ([www.alzscot.org](http://www.alzscot.org))
- **Alzheimer's Society** ([www.alzheimers.org.uk](http://www.alzheimers.org.uk))
- **Dementia Action Alliance** ([www.dementiaaction.org.uk](http://www.dementiaaction.org.uk))
- **Younger People with Dementia (Berkshire)** ([www.ypwd.info](http://www.ypwd.info))
- **Young-onset dementia support group (St George's University Hospitals NHS Foundation Trust, London)** ([www.youngdementiasupport.london](http://www.youngdementiasupport.london))
- **Join Dementia Research** ([www.joindementiaresearch.nihr.ac.uk](http://www.joindementiaresearch.nihr.ac.uk))

## 3.3 Training needs of trainees in young-onset dementia

Future workforce planning needs to include psychiatrists who will be competent working with patients who have YOD. In preparing this report, we sampled the views of senior trainees in old age psychiatry on their experiences in training in YOD. The survey, carried out in 2018, was distributed to 55 trainees and returned 20 responses. There was an even distribution of trainees across ST4 to ST6 years and most regions were represented; 70% of respondents were progressing towards a single certificate of completion of training (CCT) in old age psychiatry and the remainder were undertaking dual training in old age and adult psychiatry.

Overall, the findings indicated that there were potential gaps in training and a need to enhance training opportunities. The majority of trainees (60%) felt their overall training in the clinical assessment and management of YOD was limited, with only 20% rating it as satisfactory and 10% as comprehensive. This was reflected in the low number of trainees who rated themselves as being 'ready' to take on the role of consultant working with patients who have YOD: 20% felt ready, 20% felt unprepared, and the remainder saw themselves as being adequately prepared but that they would benefit from further training before taking on the role of a consultant in YOD. Only 10% rated their confidence in the clinical assessment and management of patients with YOD as good: 60% rated it as satisfactory and the remainder viewed it as being below their expectations.

A potential explanation for these findings is the limited exposure to YOD that trainees currently experience. Most gained it from working in old age psychiatry supplemented by experience in intellectual disabilities, adult psychiatry and liaison psychiatry. However, the overall amount of patient contact was low and experience was largely limited to the use of ad hoc special interest sessions. Few trainees (20%) had had contact with a consultant working in YOD and even fewer (5%) had had training experiences outside of psychiatry, such as placements in neurology, neuroradiology or clinical psychology. Three quarters of trainees had not undertaken any form of structured assessment relating to YOD.

The number of trainees who took part in the survey was low, but the findings are likely to be representative of trainee experience generally. Trainee suggestions on ways to enhance training are summarised in [Box 2](#). In addition, trainees would benefit from multi-professional training experiences that explore the differing roles of healthcare professionals and the holistic needs of patients and their families.

#### **Box 2 Suggestions to improve training in young-onset dementia psychiatry**

- **Trainers to encourage trainees to consider special interest sessions in YOD and spend more time in the community with people affected by YOD**
- **Training programmes to develop more training posts that offer experience in YOD**
- **Trainees to visit specialist YOD services in different regions or any existing national specialist groups**
- **Proactively support trainees to link with other specialists such as clinical psychologists, neuroradiologists, neurologists and palliative care professionals**
- **Trainees to be included in any local YOD leadership, peer and management groups**
- **Set up specific teaching programmes on YOD including neuroimaging workshops and joint MDT meetings**
- **Curriculum to specify clinical experience and assessment in YOD**
- **Participate in multi-professional training that explores the differing roles of healthcare professionals and holistic needs of patients and their families**



# 4. Research and strategic developments

## 4.1 Future research into the needs of patients with young-onset dementia

Research helps to improve the quality of practice and services, and research-active trusts have better outcomes. A dedicated team will have a better understanding of the feasibility of undertaking research in their locality and are best placed to facilitate the delivery of research, address barriers to participation, and help to connect patients with researchers. NICE (2018) recommends that people living with dementia (at all stages of the condition) should be informed about research studies they could participate in.

There are a number of barriers for patients with YOD to participate in research and high-quality evidence to inform best practice is limited. For example, this research gap was reflected in the NICE guidance on dementia (2018) that included only seven references after extensive screening for evidence of outcomes on the needs of people with YOD. These seven studies were all qualitative in nature, with sample sizes of five to 28, leaving the committee to conclude that the overall quality of the evidence was low or very low.

Other studies have found a similar picture. Richardson *et al's* (2016) systematic review of psychosocial interventions for people with YOD and their carers yielded only three studies. Mayrhofer *et al's* (2017) systematic review of age-appropriate services for people diagnosed with YOD identified 20 publications over a 26-year period, limited to 10 peer-review studies of which only one used quantitative analysis. Altogether, the 20 studies collated evidence from a total of just 94 patients with YOD, reflecting the small evidence base that exists.

Join Dementia Research ([www.joindementiaresearch.nihr.ac.uk](http://www.joindementiaresearch.nihr.ac.uk)) is a national portal for patients and volunteers to register their interest in dementia research in the UK. By May 2018, approximately 34 000 people had registered. Of these, nearly 700 were patients with dementia under the age of 65 years. This represents around 1.6% of the

estimated 43 000 people with dementia in this age range. Conversely, there were just over 20 000 people under 65 years without dementia who had registered as volunteers, signifying significant public interest in this issue. The [NHS Constitution for England \(2015\)](#) made access to research the core business of everyone who works in the NHS and this can benefit both patients and healthcare providers.

Patients should be offered up-to-date and timely information about research opportunities so they can judge whether and when they would like to participate.

It is important that mental health services actively support research in this area. This should be incorporated into each trust's research and development strategy and there should be active links with the clinical research network (DeNDRoN).

There are numerous areas where research could be enhanced, such as:

- epidemiological studies to better understand the prevalence of YOD
- developing an evidence base for effective post-diagnostic interventions
- effective approaches to vocational rehabilitation and reasonable adjustments at work
- improving recording methods on GP practice registers
- access to phase II and III clinical trials to develop new therapies
- how to effectively involve people with YOD and their caregivers in the design of age-appropriate services
- NICE (2018) and Alzheimer's Research UK (2018) have made a number of recommendations for future research in dementia ([www.nice.org.uk/guidance/ng97/chapter/Recommendations-for-research](http://www.nice.org.uk/guidance/ng97/chapter/Recommendations-for-research)).

## 4.2 Strategic developments

- It is important that trusts review their YOD services to identify and remedy any gaps in provision. The recommendations of this report should be reviewed and audited by all trusts providing services for YOD.
- The MSNAP should include performance measures that link to the recommendations in this report to help drive improvements and monitor the provision of services for YOD.
- This report focuses on the role of the psychiatrist and specialist team primarily working within a mental health trust. As highlighted, this will involve collaboration with a range of services, many of these third sector providers (Clayton-Turner *et al*, 2015). An alliance between the key stakeholders could offer clear strategic benefits for the future development of services for people with YOD.

- More active links between the Royal College of Psychiatrists and key professional bodies should be fostered, such as with the Association of British Neurologists, Royal College of General Practitioners, Royal College of Nursing, Royal College of Occupational Therapists and the British Psychological Society. This could be via joint educational and training events and publications.
- It is important that services for people with YOD develop in line with new initiatives and commissioning arrangements. Future opportunities for greater integration of services for people with YOD are likely to emerge as sustainability and transformation partnerships and integrated care pathways mature, and partnerships between acute and mental health trusts, primary care, local authorities and the third sector develop. Although the evidence base for the effectiveness of the integration of services for dementia is still developing, the diverse network of services for people with YOD suggests greater integration will offer clear benefits. There should be a named individual at the level of the commissioning authority (CCG) with responsibility for support developing services for people with YOD *per se*, but especially in order to help guide further integration.
- The broad policy drivers for the strategic transformation of dementia care (all ages) are summarised in NHS England's (2017b) implementation guide and resource pack for dementia care. The key drivers have been the *Prime Minister's Challenge on Dementia* (Department of Health, 2015), which complements the aims of the Five Year Forward View, published in 2014.
- These policy approaches emphasise that high-quality dementia care should encompass the five elements of the well-pathway for dementia: preventing well, diagnosing well, supporting well, living well, and dying well. The NHS *Operational Planning and Contracting Guidance 2017–2019* (NHS England, 2016) sets an expectation for an increase in the number of people being diagnosed with dementia, and starting treatment, within 6 weeks from referral; and an improvement in the quality of post-diagnostic treatment and support for people with dementia and their carers. These are reflected in the [CCG Improvement and Assessment Framework](#), which includes indicators for dementia diagnosis and post-diagnostic support. Improved standards of care planning are also advocated, with every patient with dementia having a named person who oversees the provision of personalised care and support planning (NHS England, 2017a).
- It is important that these outcomes are achieved by all people with dementia including those with YOD. It is important that the Dementia Intelligence Network continues to produce data on YOD that can inform whether NHS services are meeting these objectives for patients of all ages.
- There is a need to undertake more detailed business planning and health economic analysis of services for YOD in order to better inform their commissioning and future planning.

- At STP/regional level, the Strategic Clinical Networks for Dementia and Neurological Disorders (who may have a Dementia Advisory Group) should be approached by providers to advocate for better integration, provision and profile of services for YOD.
- At a national level, a wider partnership of key stakeholders – including (but not limited to) the Faculty of Old Age Psychiatry, the Association of British Neurologists, Alzheimer’s Society, Young Dementia Network and primary care services and commissioners – would be a vehicle to help develop national standards for services.

# Conclusions

The first core recommendation of this report is for mental health providers that offer diagnostic and/or support services for YOD to do so in a specialised service. Most, if not all, of the 54 mental health trusts in England as well the trusts in Northern Ireland, Wales and Scotland are large enough to be able to implement and organise services for YOD in this way. This will reduce the inconsistent access that characterises the services currently.

The second core recommendation is for old age psychiatrists to work with other relevant stakeholders to foster integration of care between specialties and providers. The diagnosis and care of YOD requires skills and expertise that are distributed across several clinical specialties, and cannot be delivered consistently to a high standard by mental health providers working in isolation. Old age psychiatrists and mental health providers should take a leading role in improving services for younger people with dementia, including developing local and regional clinical networks that work towards greater integration with other services. With leadership, commitment and service redesign the needs of people with YOD and their families can be significantly improved in the future.

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