

# Prevalence of all cause young onset dementia and time lived with dementia: analysis of primary care health records

Numbers of people with young onset dementia have been severely underestimated and prevalence is likely to be much higher than previously thought. **Janet Carter** and colleagues report on the findings of their study, which has significant implications for service provision.

**T**here are no routinely published statistics of the current number of people with a diagnosis considered as young onset dementia (YOD).

Recent figures from the Recorded Dementia dataset indicate that 3.4% of all people with dementia are currently aged under 65 (NHS Digital 2022), the group commonly identified as having young onset dementia (YOD) in its various forms. But this does not give a complete picture of the numbers of people diagnosed with YOD.

The figures in this national dataset are broken down by age according to those currently aged “64 and under” or “65 years and over”, ie, the data relate only to the current age of individuals and omit any mention of age at diagnosis. Figures identifying current numbers of people diagnosed with dementia under the age of 65 who have now transitioned to the over 65 age group are lacking. This is important because people living with YOD - whatever their current age - have specific needs related to atypical forms of dementia and because of the stage of life at diagnosis.

YOD is poorly recognised and often misdiagnosed (Konijnenberg *et al* 2017, Salem *et al* 2014) because presenting symptoms are complex. Common neurodegenerative conditions leading to a YOD diagnosis include Alzheimer’s disease, accounting for a third of cases, but presentation is frequently atypical characterised by non-memory impairment, such as language, visuo-spatial, executive, behavioural or motor-led dysfunction (Graff-Radford *et al* 2021, O’Malley *et al* 2019, Koedam *et al* 2010).

Chaotic pathways to assessment and care, poor knowledge from key professionals and limited access to specialist expertise all militate against timely and accurate diagnosis (Van Vliet *et al* 2013, Carter *et al* 2017) and increase carer burden. People with a YOD can benefit from a multidisciplinary team approach to their diagnosis and care, with collaborative working across specialities, key workers who provide continuity of care and access to age appropriate and meaningful activities (Stamou *et al* 2020a). The integrated approach set out in the NHS Long Term Plan should help facilitate enhanced care for people with YOD.

Young people with dementia consider themselves as distinct from those with late onset conditions in that their care needs relate directly to their dementia impacting on their work and social roles, causing financial or legal difficulties, changes in family roles, loss of social identity and disruption of future prospects for individuals, children and family supporters.

A recent UK-based survey of services for those with YOD highlighted the lack of age-appropriate post-diagnostic support, the lack of meaningful social and recreational activities, and lack of respite and long-term care facilities (Rodda & Carter 2016). New evidence from

## Key points

- People living with YOD have specific needs related to atypical forms of dementia and because of the stage of life at diagnosis
- Current national data underestimates numbers of those with YOD as it takes no account of those who have grown older (i.e., now aged over 65) with their diagnosis
- New figures estimate that 7.5% (33,454) of all those currently alive with dementia, were diagnosed under 65
- 55% of those currently aged between 65 and 69 were diagnosed under the age of 65
- Of those in this 65-69 age group, 25% have lived with dementia in excess of five years and 5% in excess of 12 years
- Routine availability of data on the prevalence of YOD and the time lived with a diagnosis, would allow local health and social care commissioners to understand better the proper extent of local services.

national surveys (O’Malley *et al* 2020, Stamou *et al* 2020b) confirms that those with young onset dementia currently receive few services, use few resources after diagnosis and age-appropriate activities are lacking.

Limited availability of age-appropriate activity leads to social isolation and loss of identity. Studies show that those with YOD are generally cared for at home for longer than those with late-onset disease, yet carers who are often working have limited opportunities for respite mainly because services are not age appropriate, are costly or have inconvenient opening hours.

## Numbers with YOD

Recent global prevalence figures for young onset dementia (Hendricks *et al* 2021), derived from a meta-analysis of existing studies worldwide, indicate an estimated age-standardised prevalence of 119 per 100,000 population in the age range 30-65 years. This compares to an estimated prevalence in the UK, based on census data (Harvey *et al* 2003), of 54 per 100,000.

Recorded Dementia Diagnosis data (aggregated from all GP practices in England) published by NHS Digital in September 2020 reported that there were 441,909 individuals with a formal diagnosis of dementia in England, of which 3.4% (15,172) were people currently aged under 65 years.

However, this number does not fully represent those with YOD because it does not include people who received a

YOD diagnosis that have now transitioned to being older than 65 years of age. The lack of provision in current data systems to enable identification of those living with young onset dementia, obstructs the planning, education and development needed for effective care pathways that can address the needs of this under-served group.

Furthermore, a fuller understanding of the actual lived experience, prognosis and symptom progression is required in order to support appropriate planning of services, particularly as the needs of the individual change with time. There is no routinely available data that directly captures the lived experience, prognosis and symptom progression of people with dementia of any age.

As dementia is a degenerative disease, a proxy for the level of severity or symptom progress could be length of time since diagnosis. A greater understanding of the length of time lived with dementia would broaden the options for preventive health strategies that help people manage long term health conditions in order to improve as much as possible their ability to function, their quality of life and their life expectancy.

Conflicting information currently exists on length of time lived following a diagnosis of YOD (Rhodius-Meeter *et al* 2019, Koedam *et al* 2008). A recent longitudinal cohort study (Gerritsen *et al* 2019) found that 39% of the study population were still living with their dementia six years after diagnosis.

Our objectives for this study were:

1. To provide a more accurate estimate of the number of people living with YOD in England, and
2. To ascertain the length of time those with a diagnosis of dementia have lived with the condition.

## Methods and data extraction

Two data sources were used in this study. First, the CPRD Aurum dataset is a sample of anonymised primary care records from GP practices in England. Permission for the study was granted via application to Public Health England (21\_000420) to comply with the governance process for access to the database.

The study cohort extracted from the Aurum database comprised those with a formal diagnosis of dementia, registered with a practice for over six months and still alive at the reference date. For this cohort the difference between year of birth and year of first recording of diagnosis was calculated to determine age at diagnosis. Current age was calculated as the difference between year of birth and year of data extraction (2020).

The second data source is the Recorded Dementia Diagnosis dataset, published by NHS Digital, which is a summary national dataset from GP practices records that only includes the count of people with dementia in England by current age.

## Findings

The cohort data from the Aurum dataset was tabulated into five-year age bands according to age at diagnosis and current age. To identify the *percentage* of individuals in each current age band by age at diagnosis, the number of patients in each of the age at diagnosis groups were calculated as the proportion of the total for the current age multiplied by 100 (see table 1).

As can be seen from table 1, for all current age groups over 40 years, more than 50% were diagnosed prior to their current age status; for example, in the 65 to 69 years current age group, 55.1% were diagnosed under the age of

		Current age (years)											
		Under 40	40 to 44	45 to 49	50 to 54	55 to 59	60 to 64	65 to 69	70 to 74	75 to 79	80 to 84	85 to 89	90+
Age at diagnosis (years)	Under 40	100.0%	52.3%	20.6%	6.9%	1.7%	0.3%	0.0%					
	40 to 44		47.7%	35.3%	10.0%	2.0%	0.8%	0.2%	0.1%				
	45 to 49			44.1%	36.4%	8.4%	2.9%	0.6%	0.2%	0.0%	0.0%	0.0%	0.0%
	50 to 54				46.7%	40.2%	10.7%	3.1%	0.8%	0.2%	0.0%	0.0%	0.0%
	55 to 59					47.7%	40.9%	11.2%	3.3%	0.9%	0.2%	0.1%	0.0%
	60 to 64						44.4%	40.1%	10.0%	2.6%	0.9%	0.3%	0.1%
	65 to 69							44.9%	37.4%	9.8%	3.2%	1.3%	0.4%
	70 to 74								48.2%	40.8%	12.2%	5.4%	2.2%
	75 to 79									45.6%	43.5%	16.7%	8.5%
	80 to 84										39.9%	43.8%	21.2%
	85 to 89											32.5%	36.6%
	90+												31.0%

Table 1: People with dementia: percentage of current age group by age at diagnosis (Orange boxes signify percentage in current age band diagnosed under the age of 65. Source: OHID Neurology Dementia Intelligence using CPRD Aurum database 2020 (21\_000420))

		Current age (years)												
		Under 40	40 to 44	45 to 49	50 to 54	55 to 59	60 to 64	65 to 69	70 to 74	75 to 79	80 to 84	85 to 89	90+	Grand Total
Age at diagnosis (years)	Under 40	298	123	113	106	70	22	5						738
	40 to 44		113	194	154	80	72	24	22					659
	45 to 49			243	559	346	242	99	71	25	7	0	1	1,593
	50 to 54				718	1,649	901	480	303	153	37	12	2	4,255
	55 to 59					1,960	3,456	1,744	1,248	614	234	87	11	9,353
	60 to 64						3,752	6,248	3,735	1,779	882	281	68	16,746
	65 to 69							6,996	13,995	6,674	3,317	1,395	374	32,750
	70 to 74								18,033	27,662	12,455	5,962	2,062	66,174
	75 to 79									30,926	44,502	18,428	7,893	101,749
	80 to 84										40,837	48,311	19,770	108,919
	85 to 89											35,879	34,166	70,045
90+												28,927	28,927	
QOF Grand Total		298	236	551	1,537	4,105	8,445	15,595	37,407	67,833	102,272	110,355	93,275	441,909

Table 2: People with dementia: estimated numbers of current age and age at diagnosis for England September 2020. (Orange boxes signify numbers in current age band diagnosed under the age of 65. (Source: PHE Neurology Dementia Intelligence using dementia QOF and CPRD Aurum database 2020 (21\_000420))

65 years. In the 70-74 age group, 14.4% were diagnosed under the age of 65 years, and so on.

To estimate a national prevalence figure for young onset dementia, the number of those with a diagnosis given prior to their 65<sup>th</sup> birthday was modelled. The percentages in each age at diagnosis group calculated from the Aurum database sample were applied to the Recorded Dementia Diagnosis dataset to calculate an estimate of the overall number of all cases where age at diagnosis is less than 65 years of age (table 2).

The calculation demonstrates that, of the total number of people living in England who currently have a formal diagnosis of dementia (441,909), 33,345 (7.5%) received the diagnosis prior to their 65<sup>th</sup> birthday (see table 3)

In order to make a direct comparison to available global prevalence figures the number of individuals diagnosed between the ages of 30 and 64 was also calculated (33,104). This equates to a prevalence figure of 92 per 100,000 population (see table 3) based on mid-year population estimates for 2020 in England.

Age at Diagnosis	
Under 65 years	33,345 (7.5%)
Over 65 years	408,564 (92.5%)
<b>Prevalence</b>	
Count of diagnosed cases between 30 and 64 years of age and still living with dementia	33,104
Mid-year population estimates 2020 - 30 years of age and over	35,975,768
Estimated prevalence of young onset dementia per 100,000 population	92

Table 3: Estimated numbers currently living with a diagnosis of dementia by age at diagnosis and estimated prevalence of diagnosed YOD in England, September 2020 (source: OHID Neurology Dementia Intelligence)

	Age Group	Median (Years)	75th Percentile	95th Percentile	Maximum
Current age	40 to 44	3	9.25	18.7	22
	45 to 49	3	6	14	21
	50 to 54	3	6	14.1	29
	55 to 59	3	5	11	30
	60 to 64	3	6	12	27
	65 to 69	3	5	12	28
	70 to 74	3	6	12	29
	75 to 79	3	5	9	30
	80 to 84	3	6	7	34
	85 to 89	4	7	14	35
90+	9	15	23	57	

### Time living with dementia

For the purpose of this study, duration of time living with dementia in years was defined as the time between age at diagnosis and current age. Using the tabulated 5-year age bands from the CPRD Aurum dataset, the maximum length of time in years since diagnosis was calculated (see table 4).

The results demonstrate that for people with dementia currently aged between 40 and 84 years of age, half have lived with dementia for up to three years. Looking more narrowly at those currently aged 45 to 49 years of age, 25% have lived with a diagnosis for over six years with 5% living in excess of 14 years (albeit a relatively small sample).

Table 4: People with dementia: length of time since formal diagnosis by current age. (Orange boxes signify current age band diagnosed under the age of 65). (Source: PHE Neurology Dementia Intelligence using CPRD Aurum database 2020 (21\_000420))

## Summary

Our objectives were to calculate the prevalence of YOD – defined as dementia diagnosed under the age of 65 – using primary care electronic health records in England, and to determine the length of time lived with dementia in relation to current age.

We found that, of 441,909 people in the Recorded Dementia Diagnosis dataset for England at the end of September 2020, an estimated 33,345 (7.5%) were individuals living with a diagnosis of young onset dementia. Estimated prevalence of YOD (those aged between 30 and 64) was 92 per 100,000 of the general population.

Our findings show that 55.1% of those currently living with dementia aged between 65 and 69 years were diagnosed under the age of 65. Of this age group, half have lived with dementia for three years or less, 25% for more than five years, and 5% in excess of 12 years to a maximum of 28 years.

The estimated prevalence figure for YOD in this analysis provides a truer estimate of people living with YOD in England because it includes all people with this diagnosis irrespective of their current age. The study legitimises the view that an expansion in focus is required to identify a “hidden population” of individuals with YOD who may have been living with dementia for some years, and for whom specific health and social care needs remain unmet.

This additional insight can be achieved by improving the Recorded Dementia Diagnosis dataset, routinely published by NHS Digital, to include the age at diagnosis of the current cases with dementia.

For those in the 65-69 age group, 25% have lived with dementia in excess of five years and 5% in excess of 12 years to a maximum of 28 years. This similarity extends well up the age range: for example, among those currently aged 85 to 89 years old with dementia, 25% have lived with dementia for over seven years and 5% for more than 14 years.

The results support the finding that for those in the under 65-year age groups, there is very little difference from older age groups in length of time living with dementia. Nor is there any real difference in this respect between males and females in all age groups.

## Discussion

Current estimates of YOD prevalence are hampered by methodological limitations. Direct ascertainment of cases in the community is challenging because YOD is rare, presentations are diverse and hard to recognise and large-scale screening in a population study is therefore expensive and impractical.

This study has demonstrated that the current methodology used for routine collection of national data -

numbers of people with YOD aged under 65 - masks the true numbers of those living with YOD, and therefore underestimates the needs and support necessary for this patient population.

By combining two datasets for this study, we have been able to provide an improved estimate of 33,345 (i.e. 7.5% of the total) diagnosed under 65 and still living with dementia on the reference date (September 2020).

For those diagnosed between the ages of 30 and 64 years, this equates to a prevalence figure of 33,104 people (92 per 100,000). As we have seen, this compares to a previous estimate based on census data (Harvey et al 2003) of 54 per 100,000.

Realignment of the current datasets, using age at diagnosis as demonstrated, highlights that those with young onset dementia likely represent a far greater proportion of the diagnosed population than previously thought.

## Living well with YOD

A public health prevention approach aspires to help people manage long term health conditions, in order to improve as much as possible their ability to function, their quality of life and their life expectancy. The prospects of living well with dementia are better to the extent that health and social care needs are fully met. The needs of each individual of any age are unique and will change over time due to the degenerative nature of dementia.

If length of time lived with dementia is one proxy for current needs, this dataset has provided useful insights into disease trajectory for those with YOD. For example, 55.1% of those currently aged between 65 and 69 years were diagnosed under the age of 65 and 25% of them have lived with the condition for more than five years. Further, an estimated 9,600 individuals currently aged over 70 were originally diagnosed with YOD.

Understanding the transitions of those with YOD in the over 65 population matters if the lived experience of unusual and atypical dementias and associated different psychosocial needs is to be acknowledged. Recent evidence from a major study of YOD, The Angela Project, identified a three-tiered set of recommendations for good practice at the levels of service design, function and delivery (Stamou *et al* 2020b).

Services achieving highest satisfaction ratings were considered knowledgeable with specific expertise in YOD, provided accessibility to age-appropriate services and provided meaningful social participation. These services also gave individuals a voice, provided specialist support for children, supported employment and flexible working for carers, gave advice about benefits, social support and advance care planning, and provided opportunities to engage in research. Further advice can be found on the “Young onset dementia pathway” webpage at [www.youngdementianetwork.org](http://www.youngdementianetwork.org).

## Limitations of data

Although these figures advance our knowledge of YOD, it is likely that they are an underestimate. Our prevalence estimate is based on the CPRD Aurum database which is a

non-randomised sample of primary care records. Bias in the database will impact on the distribution of ages at diagnosis. The database is also known to under-report cases of dementia by up to 7% for ages up to 85 to 89 years, when compared to the Recorded Dementia Diagnosis dataset.

Length of time lived with dementia in the data set is necessarily derived from date of diagnosis and not age at symptom onset. The delays commonly associated with establishing a YOD diagnosis suggest that length of time lived is likely to be longer than the figures here estimate.

## Conclusions

By improving the routine availability of local data on the prevalence of YOD and the time lived with a diagnosis, local health and social care commissioners would be better able to understand the proper requirements and extent of local services. It would enable clinicians and commissioners to reduce health inequalities by strengthening diagnostic and post-diagnostic services.

Better data would also highlight the challenges in providing preventative care to people of similar age, given that their health and social care needs are heterogeneous because they have lived with a diagnosis of dementia for varying periods of time.

In summary, this study legitimises the view that the methodology used to determine numbers of people living with a diagnosis of dementia underestimates the proportion with YOD and diminishes our understanding of the differing needs they bring to the over 65 population.

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