YOUNG ONSET DEMENTIA IN LANCASHIRE-12 2014 - 2030

An assessment of population need

Gemma Jones – Joint Strategic Needs Assessment Manager|
Business Intelligence| Lancashire County Council
August 2016

Young onset dementia in Lancashire-12

Contents

Acknowledgements 3
Key points 3
Introduction and background 3
Introduction 3
Background 4
Technical information 4
Exclusions 4
Analysis 5
Headline figures 5
Types of young onset dementia 5
Estimates and projections at upper and lower tier authority level 6
Estimates for service planning areas (SPAs) 7
Estimates for clinical commissioning groups (CCGs) 7
Recorded prevalence 7
QOF records 7
Adult social care records 8
Sociodemographic profile of adult social care client group 8
Learning disabilities and young onset dementia 9
Impact on caregivers 9
Recommendations 10
Appendices 11
Appendix A – types of dementia 11
Appendix B – estimated number of people with YOD by service planning area 12
Appendix C – map of estimated number of persons with YOD by service planning area 13
Appendix D – map of number of adult social care clients with YOD by service planning area 14
Glossary 15
References 15

Acknowledgements

The author would like to thank Sue Hird and Simon Collins from Lancashire County Council for their comments and suggestions on the draft report.

Key points

- Younger people with dementia have a unique set of difficulties and opportunities compared to older people with dementia.
- Learning disabilities are a risk factor for young onset dementia, and many other risk factors relate to lifestyle and the effective management of existing conditions.
- It is difficult to establish an accurate prevalence of YOD but this report has highlighted that there is a substantial gap between estimated and diagnosed prevalence. There could be more than 800 people in Lancashire-12 with YOD and around 470 of these could be undiagnosed.
- Prompt diagnosis can help people with YOD to manage their condition and achieve a better quality of life, while, in some cases, appropriate treatment and lifestyle changes can help slow the progression of the underlying disease.
- Working and volunteering are known to promote positive mental wellbeing. Many people with YOD will still able to be economically active, so it is important to support these individuals to obtain work and remain in work for as long as they desire.

Introduction and background

Introduction

Dementia is a syndrome – usually of a progressive, long-term nature – characterised by a deterioration in a person's ability to process thought, over and above what would be expected from normal ageing. It occurs as a direct or indirect result of a number of diseases or injuries, such as Alzheimer's disease or stroke. Dementia affects memory, thinking, orientation, comprehension, calculation, language, judgement, and learning capacity (World Health Organization, 2015). Young onset dementia is dementia that occurs before the age of 65.

Risk factors for young onset dementia include genetic factors, alcohol use, history of stroke, use of antipsychotic medication, depression, having a father who has dementia, illicit drug use, pre-existing low cognitive function, low weight, high blood pressure and having a learning disability (Jervis & Prinsloo, 2008; Nordström, Nordström, Eriksson, Wahlund & Gustafson, 2013; Strydom, Chan, King, Hassiotis & Livingston, 2013).

In the UK there are estimated to be more than 40,000 people under 65 with dementia (Alzheimer's Society 2014a). This estimate has increased significantly since Alzheimer's Society published their 2007 report Dementia UK (first edition). The original 2007 figures were thought to be underestimated because they were based on referrals of younger people to services, whereas in the 2014 (second edition) report the 60–64 years old estimate was provided by the new Delphi consensus as part of late-onset dementia (Ferri, Prince, Brayne, Brodaty, Fratiglioni, Ganguli,… & Scazufca, 2005).

The National Institute for Health and Care Excellence argues that younger people with dementia have special requirements (NICE, 2006). Despite similarities in the symptoms of dementia regardless of age, every case is different, and the health and care needs of people with young onset dementia differ from those of older people with dementia because their lives are different. They are often still working, paying mortgages and looking after children, so it is important to provide support and services that are appropriate to their lifestyles and situations.

Certain interventions may delay the progression of dementia, for example interventions that address cardiovascular risk factors can help delay or prevent the onset of vascular dementia. Support tailored to the needs of the individual can help them achieve a better quality of life for longer. This report provides analysis of young onset dementia in Lancashire-12 and present some recommendations for actions to support people who are living with the condition and those who care for them.

Throughout this document links are provided to relevant pages on Lancashire Insight – the online home of Lancashire's joint strategic needs assessment (JSNA).

Background

There are a range of services for dementia sufferers in Lancashire-12 but these are predominantly accessed by older people. This report is the result of a request from the age well commissioning team at Lancashire County Council, in late 2015, to fill a gap in intelligence about people with young onset dementia. The information requested included recorded and estimated prevalence, gender differences, geographical distribution, numbers receiving support, support costs and a greater understanding of the link between learning disabilities and young onset dementia. While this report attempts to answer these questions, the quality of the intelligence is dependent on the availability and quality of data. The findings will be used, along with other information, to inform commissioning decisions about dementia services for younger people in Lancashire-12.

Technical information

The clinical term used to describe dementia that affects people under the age of 64 is early onset dementia. However, other terms used are working age dementia or young onset dementia; the latter term is used throughout this report in accordance with the expressed preference of younger people living with dementia (The Dementia Engagement and Empowerment Project, 2014).

'Lancashire-12' refers to the 12 authority Lancashire area. This term will be used throughout the report. See the glossary at the end of this report for more information about this and other specialist terms and abbreviations used throughout.

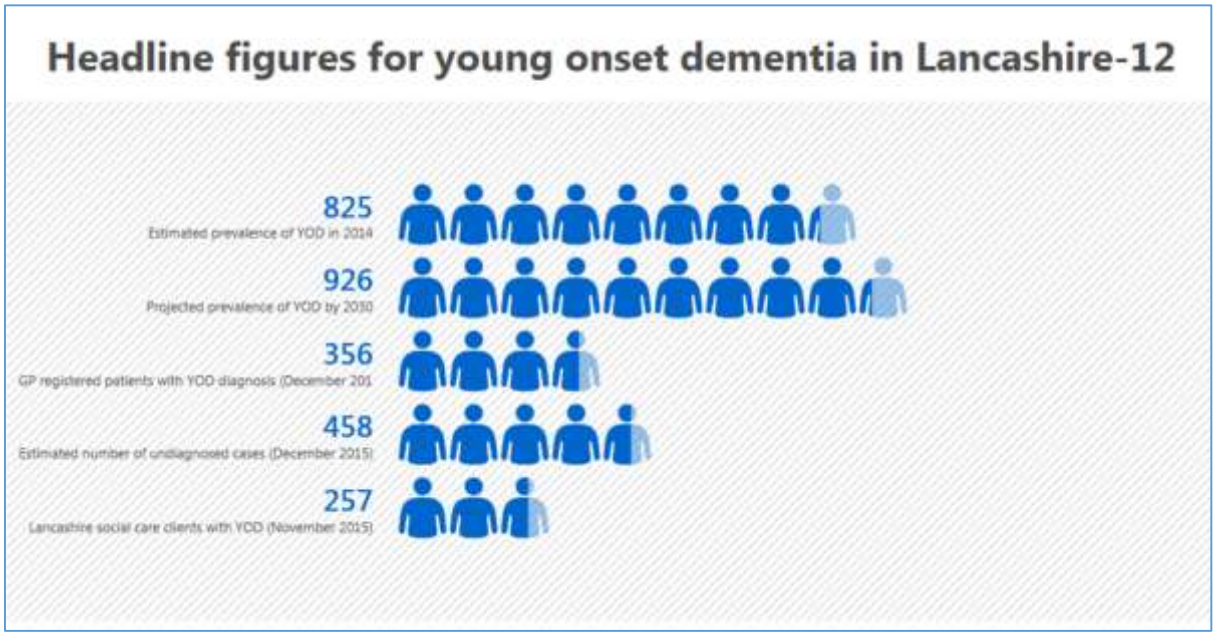
Exclusions

This report is not intended to offer further intelligence about dementia in people aged 65 and over. Please see the JSNA page for dementia on the Lancashire Insight website for information relating to dementia among the older population.

Analysis

Headline figures

Figure 1: headline figures for young onset dementia in Lancashire-12



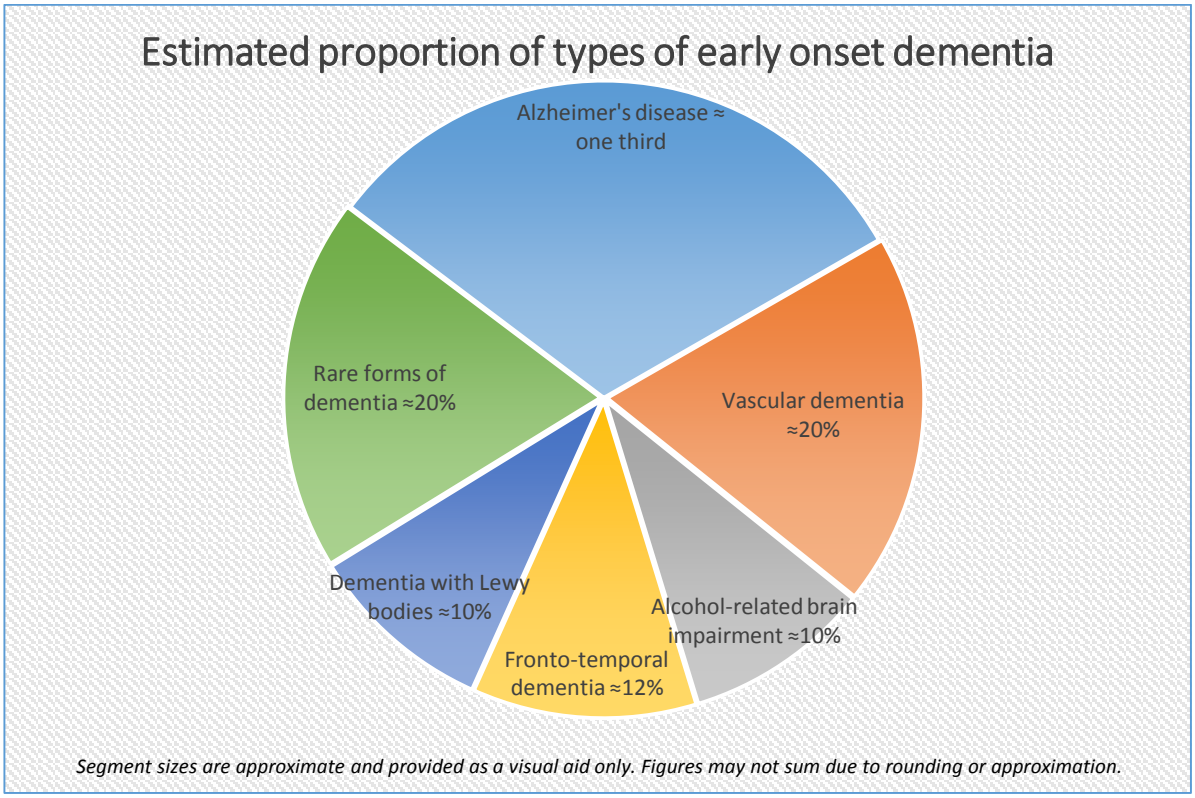
- There were an estimated 825 people with young onset dementia (YOD) in the Lancashire-12 area in 2014.
- This figure could rise to 926 by 2030 with a static prevalence rate.
- In December 2015, 356 people aged 0-64 on GP practice registers were recorded as having YOD.
- There could be around 458 undiagnosed cases of YOD in Lancashire-12.
- A minimum of 257 people on adult social care records for Lancashire-12 have YOD.
- 1 in 4 of the adult social care YOD client group also has a learning disability.

Types of young onset dementia

The Alzheimer's Society (2014b) provides estimates of the proportion of different types of young onset dementia. These figures are approximate and therefore do not sum.

The most common type of young onset dementia is Alzheimer's disease, making up an estimated third of all cases. Vascular dementia is the second most common type accounting for around a fifth of cases. This occurs due to problems with the blood supply to the brain, sometimes but not always related to a stroke or transient ischaemic attack, (sometimes referred to as a mini stroke). Different types of dementia manifest themselves and progress in different ways. Alzheimer's disease, vascular dementia, fronto-temporal dementia and dementia with Lewy bodies are all progressive types of dementia. Appendix A provides an overview of the main types of dementia.

Figure 2: estimated proportion of different types of young onset dementia



Source: Alzheimer's Society (2014b).

Estimates and projections at upper and lower tier authority level

The table below shows the current and future estimated prevalence of dementia at upper and lower tier local authority level. The figures were calculated by applying the current prevalence estimates for males and females for five year age bands between 30 and 64 years of age from the Alzheimer's Society (2014b) report *Dementia UK: Second edition* to the most recent (2012) subnational population projections from the Office for National Statistics (ONS). These estimates therefore only show what prevalence might look like now and in the future if the current prevalence estimates remain the same.

Table 1: persons aged 30-64 predicted to have young onset dementia by local authority

Area	2014	2015	2016	2017	2018	2020	2025	2030
Burnley	59	58	58	58	59	60	62	60
Chorley	80	79	79	80	82	85	95	95
Fylde	60	59	60	62	63	65	71	69
Hyndburn	53	52	52	53	53	55	58	58
Lancaster	92	93	92	93	95	99	108	105
Pendle	62	61	61	62	62	63	66	65
Preston	82	81	82	84	85	89	98	95
Ribble Valley	44	44	45	46	46	48	53	51
Rossendale	50	50	50	51	51	52	57	57
South Ribble	78	77	78	78	79	81	90	87
West Lancashire	81	81	80	81	82	85	92	87
Wyre	84	84	84	86	87	90	98	96
Lancashire-12	**825**	**819**	**822**	**834**	**843**	**872**	**947**	**926**

Source: calculated using prevalence estimates from Alzheimer's Society (2014b) and sub-national population projections from ONS (2012).

Estimates for service planning areas (SPAs)

In order to calculate estimated numbers of YOD cases by service planning area (SPA), prevalence estimates published by the Alzheimer's Society (2014b) were applied to the latest (2014) mid-year population estimates from the ONS, and aggregated up from lower super output areas (LSOAs) to service planning areas.

The analysis shows an estimated number of cases between 4 and 20 per SPA with an average of 12 cases. Estimates for SPAs cannot currently be projected forward. See appendix B for the complete SPA data table and appendix C for a map of this data.

Estimates for clinical commissioning groups (CCGs)

The same Alzheimer's Society estimates were applied to GP registered populations within the six Lancashire-12 CCGs to produce estimated numbers of people with YOD. Table 2 shows these figures.

Table 2: estimated number of people aged 30-64 with YOD by clinical commissioning group

Clinical commissioning group	Males	Females	Persons
NHS Chorley and South Ribble	65	61	127
NHS East Lancashire CCG	134	120	254
NHS Greater Preston CCG	70	63	133
NHS Lancashire North CCG	54	51	105
NHS West Lancashire CCG	41	39	80
NHS Fylde & Wyre CCG	59	56	115
All six Lancashire-12 CCGs	**424**	**390**	**814**

Source: calculated using prevalence estimates from Alzheimer's Society (2014b) & GP registered population data from HSCIC, December 2015 (published January 2016).

Recorded prevalence

QOF records

As part of the Quality Outcomes Framework (QOF) general practices are required to keep records of the number of people on practice lists with various conditions. One of these conditions is dementia. The latest QOF records, obtained from the Health and Social Care Information Centre (HSCIC), show that, of all people aged 0-64 registered with a GP practice in Lancashire-12, 356 were recorded as having dementia as at 31 December 2015.

Table 3: Quality Outcomes Framework (QOF) recorded dementia diagnoses for people aged 0-64 as at 31st December 2015

CCG	Dementia register 0-64[1]	GP registered population 0-64[1]	Recorded prevalence per 100,000 reg. pop
NHS Chorley and South Ribble	40	144,824	27.6
NHS East Lancashire CCG	123	298,409	41.2
NHS Greater Preston CCG	49	176,925	27.7
NHS Lancashire North CCG	47	128,652	36.5
NHS West Lancashire CCG	44	86,901	50.6
NHS Fylde & Wyre CCG	53	112,025	47.3
All six Lancashire-12 CCGs	**356**	**947,736**	**37.6**

Source: [1]HSCIC, December 2015 (published January 2016);

West Lancashire CCG has the highest recorded prevalence of YOD, followed closely by Fylde and Wyre CCG. It is important to note that higher recorded prevalence of YOD doesn't necessarily mean higher prevalence of YOD. It merely represents a higher rate of diagnosis. Recorded prevalence may be skewed by population characteristics such as age and gender which vary by CCG area. It is not advisable to directly compare the recorded and estimated CCG figures because they apply to different age groups. However, dementia prevalence for the 0-29 age group is likely to be minimal, so it is reasonable to assume, looking at the two datasets, that there are potentially a large number of undiagnosed cases within the registered population, possibly around 450.

It was not possible to provide information about number of people receiving support from CCGs or about the nature or cost of any CCG services received by people with young onset dementia in Lancashire-12. This data was requested from Staffordshire and Lancashire Commissioning Support Unit (CSU) but the response was that they do not hold this information.

Adult social care records

Lancashire County Council's adult social care records include numerous individuals listed as having dementia, however due to the ways in which this information can be recorded it is difficult to pick up every case when querying the dataset.

The total number of cases of YOD found in the system on 27 November 2015 was 257. These included people aged 30-64 who are receiving support for YOD or are receiving support for other reasons but also have a diagnosis of YOD. 83% of this client group were aged 50 or over. The table below breaks these down by age group.

Table 4: Social care YOD cases by age

Age range	30-34	35-39	40-44	45-49	50-54	55-59	60-64
YOD cases	7	6	7	23	41	66	107

Source: Lancashire County Council, November 2015

A map of SPAs showing the number of YOD cases from the adult social care records can be found in appendix D.

Sociodemographic profile of adult social care client group

Mosaic software was used to create a sociodemographic profile the current Lancashire County Council adult social care YOD client group. The results show that the dominant groups were:

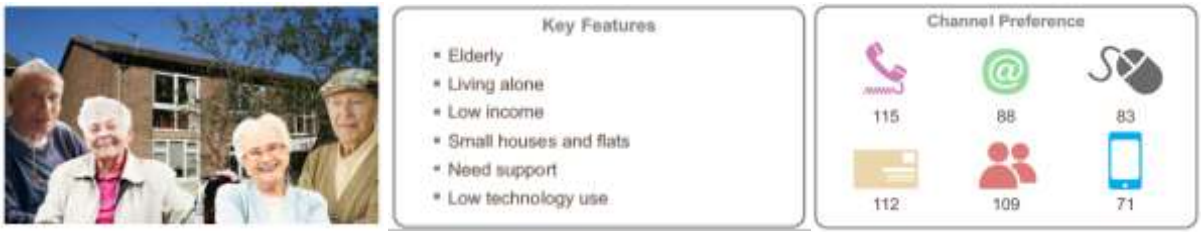
F "senior security" – (15% of client base); and

N "vintage value" – (15% of client base).

Figure 3: Key features of dominant Mosaic groups for the social care YOD client group

GROUP F, SENIOR SECURITY – ELDERLY PEOPLE WITH ASSETS WHO ARE ENJOYING A COMFORTABLE RETIREMENT:

GROUP N, VINTAGE VALUE – ELDERLY PEOPLE RELIANT ON SUPPORT TO MEET FINANCIAL OR PRACTICAL NEEDS:



Source: Experian, 2014

The dominant groups have some similarities (an older than average age profile) and some clear differences. The senior security group who often have additional pensions above the state pension are more comfortably off than the vintage value group who are on low incomes. The preferred communication channels for both groups are post and landline telephone. The senior security group may reside as couples whereas vintage value are more likely to be living alone. Lancashire Insight provides more information and analysis about Mosaic groups including an interactive atlas showing the distribution of them across Lancashire-14.

Learning disabilities and young onset dementia

Strydom, Chan, King, Hassiotis and Livingston (2013) found that older adults (aged 60+) with learning disabilities have up to five times the risk of developing dementia as those without learning disabilities. People with Down's syndrome have additional genetic risk factors that can cause them to develop dementia as early as their 30s or 40s (Jervis & Prinsloo, 2008).

Interrogation of Lancashire County Council social care data shows that one in four of the 257 people with young onset dementia also has a learning disability. Ethnicity adjusted prevalence of learning disability in the general population aged 30-64 is estimated to be around 2.4% (Emerson & Hatton, 2004). This means that prevalence of learning disabilities among the Lancashire-12 adult social care YOD client group is 11 times higher than for the general population of the same age. This ratio is unlikely to be as pronounced in the general population with YOD in Lancashire-12 and reflects the probability that those receiving adult social care are more likely to have greater and/or more complex needs than those not receiving support.

What all of this means for service planning is that particular attention needs to be paid to the unique needs of people with YOD who also have learning disabilities. Kenney (2013) provides several examples of reasonable adjustments that can be made in dementia services for people with learning disabilities.

Impact on caregivers

As well as affecting the health and life of the person with dementia, the syndrome can have a considerable impact on those caring for them. A literature review of the impact of young onset dementia on caregivers (van Vliet, de Vugt, Bakker, Koopmans & Verhey, 2010) found that they face high levels of burden, stress and depression. Compared to carers of older people with dementia, the results were inconclusive but it was clear that those caring for younger people with dementia experience high levels of psychological suffering and specific problems related to their phase of life. A study published a year later (Rosness, Mjorud & Engedal, 2011) found that YOD caregivers' quality of life corresponded positively with increased carer age and with the person with YOD gaining insight into their condition. Being married, having children and caring for people with comorbid cardiovascular disease were associated with increased symptoms of depression in caregivers. Reductions in depression were seen in caregivers when the person with YOD received domiciliary care.

Recommendations

This report should influence the way we support people with dementia and the new dementia strategy for Lancashire needs to take the findings into account.

1. Use existing dementia services to meet the needs of younger people with dementia. For example, providing a separate room and activities/support for younger people at day centres.
2. Work with voluntary sector providers to see what can be done in partnership for people with young onset dementia. The younger people with dementia factsheet (Alzheimer's Society, 2014a) details the types of support that might be needed by people with young onset dementia or their caregivers.
3. The local dementia campaign in May 2016 helped to raise awareness of dementia. It is important to keep collaborating with public health colleagues on dementia campaigns and to use these to highlight the particular issues and risk factors associated with young onset dementia.
4. We are reaching the national target for dementia diagnosis set by central government but need to put more emphasis on young onset dementia.
5. Health and social care practitioners should be made aware, or reminded of the risk factors for young onset dementia, such as learning disabilities, stroke, alcohol abuse, illicit drug use, high blood pressure and depression; and to monitor and offer diagnostic services to individuals with multiple risk factors where appropriate.
6. Public health, primary care and community services should continue taking action to reduce lifestyle risk factors by encouraging and enabling healthy lifestyles and achieving good management of existing high-risk conditions.
7. Improve access to consultants with specific responsibility for younger people with dementia.
8. Liaise with young people to see what they need. Using the example of employment support this could involve working at a macro level by producing campaigns for employers, and at a micro level by working with individual employees to ensure they are aware of reasonable adjustments that can be made.
9. Ensure linkage with Lancaster University to make sure we are working with them on any research on young onset dementia.
10. CCGs to ensure that appropriate treatments are available to all, as per NICE guidelines.
11. There has been a reduction in the prescribing of antipsychotic drugs for those with dementia (these drugs are contraindicated) and the prescription of treatment for those with dementia is monitored regularly by clinical commissioning groups and reported through the multiagency steering group on dementia (DERG).
12. Carry out primary research with local people with young onset dementia, their caregivers and families to ascertain their self-perceived needs.
13. Younger people with dementia should be made aware of the wellbeing benefits of being economically active and advised that there is legislation to prevent discrimination against people with long-term conditions.
14. Encourage people with young onset dementia to use a personal budget to meet their individual needs so that they can remain independent for as long as possible.

Appendices

Appendix A – types of dementia

Alzheimer's disease – the most common cause of dementia in the all-age population and in people under 65. During the course of the disease, the chemistry and structure of the brain changes, leading to the death of brain cells.

Dementia with Lewy bodies – this form of dementia gets its name from tiny spherical structures that develop inside nerve cells. Their presence in the brain leads to the degeneration of brain tissue.

Fronto-temporal dementia - in fronto-temporal dementia, damage is usually focused in the front part of the brain. Personality and behaviour are initially more affected than memory.

HIV-related cognitive impairment – people with HIV and AIDS sometimes develop cognitive impairment, particularly in the later stages of their illness.

Korsakoff's syndrome – a brain disorder that is usually associated with heavy drinking over a long period. Although it is not strictly speaking a dementia, people with the condition experience loss of short term memory.

Mild cognitive impairment – mild cognitive impairment (MCI) is a relatively recent term, used to describe people who have some problems with their memory but do not actually have dementia.

Rarer causes of dementia – there are many other rarer causes of dementia, including progressive supranuclear palsy and Binswanger's disease. In Creutzfeldt-Jakob disease (CJD) infectious agents known as prions attack the central nervous system and then invade the brain, causing dementia. People with multiple sclerosis, motor neurone disease, Parkinson's disease and Huntington's disease can also be at increased risk of developing dementia.

Vascular dementia – if the oxygen supply to the brain fails, brain cells may die. The symptoms of vascular dementia can occur either suddenly, following a stroke, or over time, through a series of small strokes.

Source: Alzheimer's Society, 2016

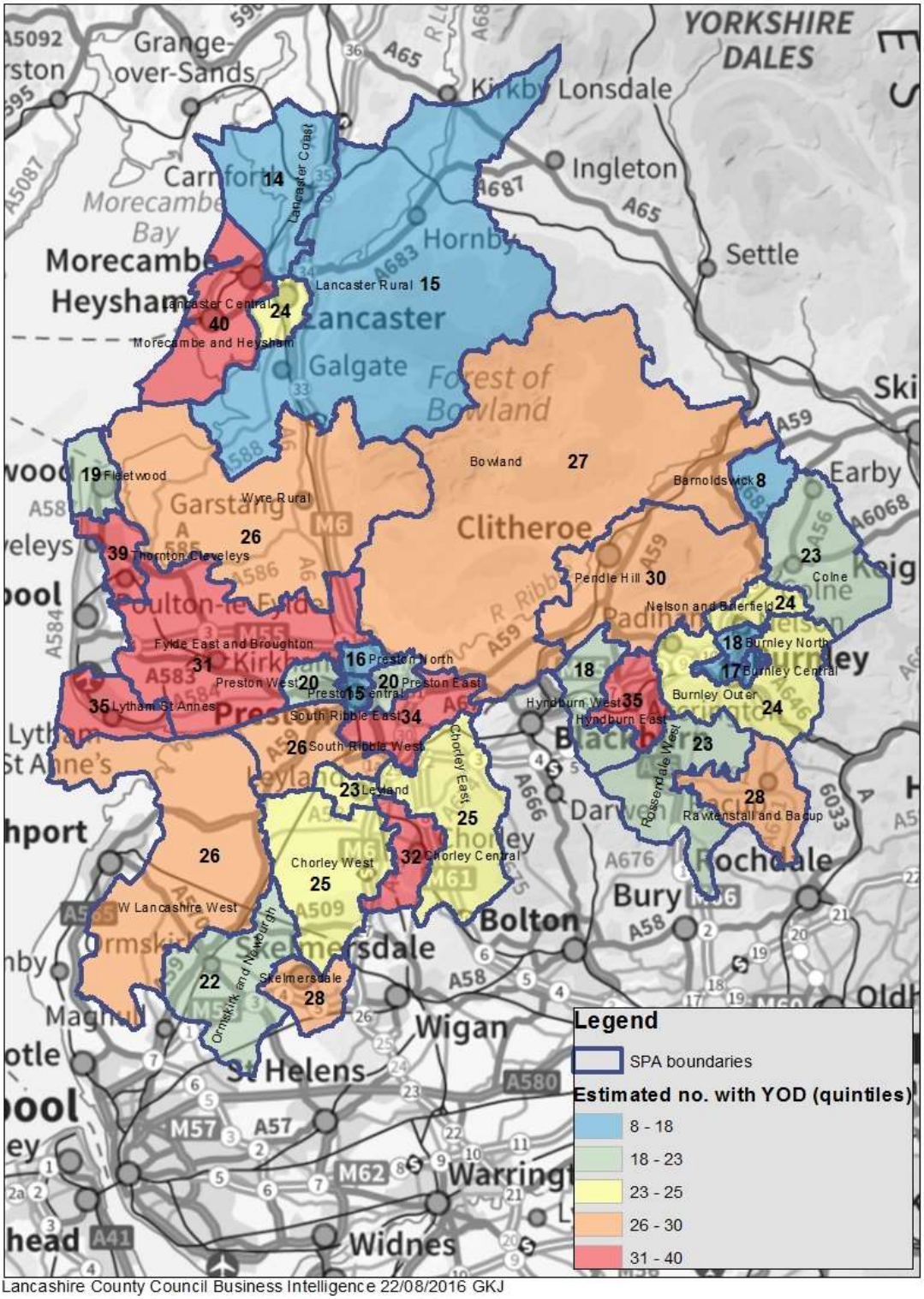
Appendix B – estimated number of people with YOD by service planning area

SPA Number	SPA Name	Males	Females	Persons
1	Burnley Central	9	8	17
2	Preston East	11	10	20
3	Burnley North	9	8	18
4	Nelson and Brierfield	13	11	24
5	Fleetwood	10	9	19
6	Hyndburn East	18	17	35
7	Preston Central	8	7	15
8	Skelmersdale	14	14	28
9	Morecambe and Heysham	20	20	40
10	Rawtenstall and Bacup	14	14	28
11	Colne	12	11	23
12	Burnley Outer	12	12	24
13	Hyndburn West	9	9	18
14	Lancaster Central	12	12	24
15	Chorley Central	17	16	32
16	Preston West	10	9	20
17	Leyland	12	11	23
18	Barnoldswick	4	4	8
19	Rossendale West	12	11	23
20	South Ribble East	18	17	34
21	Lytham St Annes	18	17	35
22	Thornton Cleveleys	20	19	39
23	W Lancashire West	13	13	26
24	Wyre Rural	13	13	26
25	Lancaster Coast	7	7	14
26	Lancaster Rural	8	7	15
27	Fylde East and Broughton	16	15	31
28	Pendle Hill	15	15	30
29	Chorley East	13	12	25
30	Ormskirk and Newburgh	11	11	22
31	Preston North	8	8	16
32	Bowland	14	13	27
33	Chorley West	13	12	25
34	South Ribble West	13	13	26

Source: Alzheimer's Society (2014b) & ONS (2012). Figures may not sum due to rounding.

Appendix C – map of estimated number of persons with YOD by service planning area

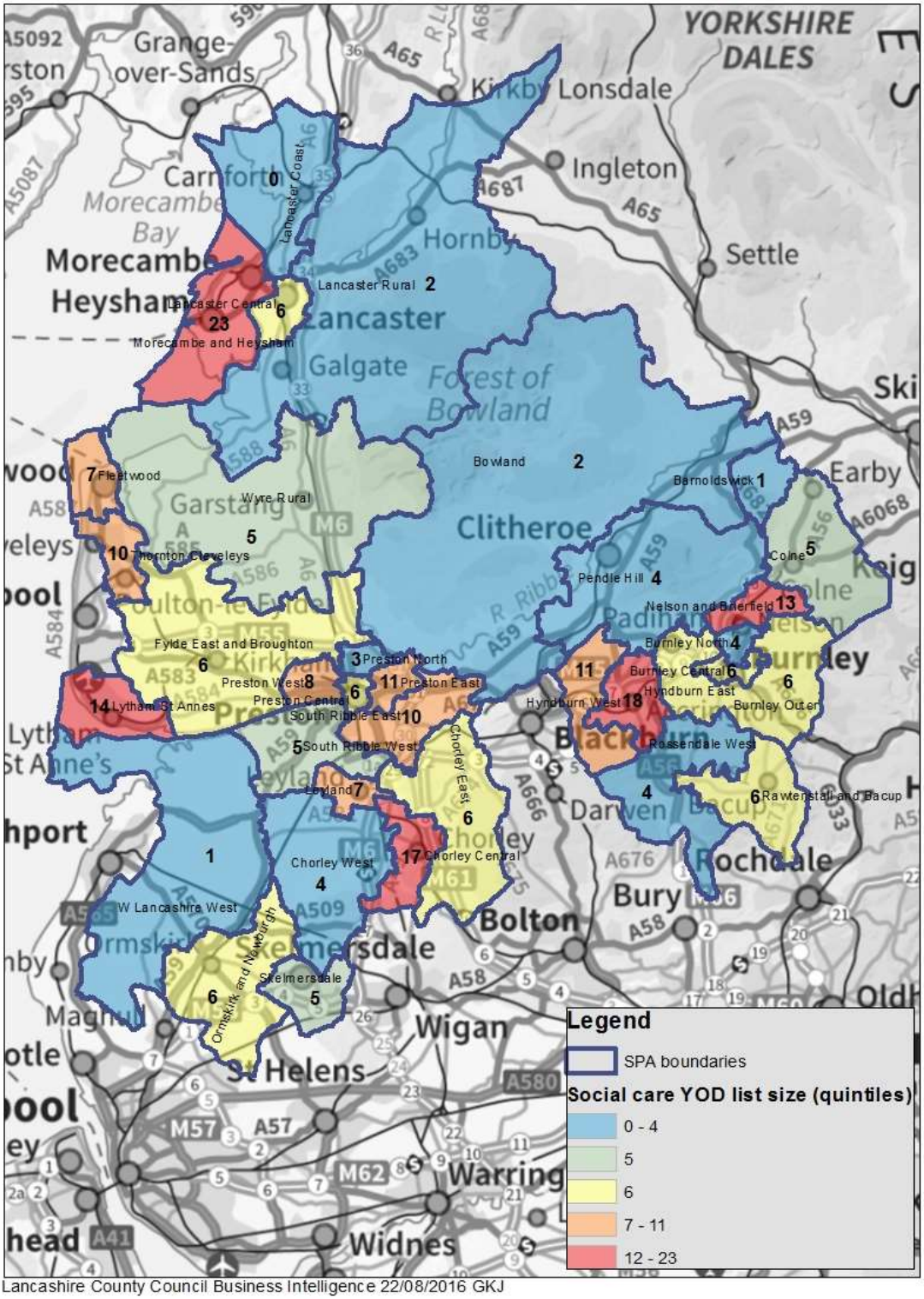
Estimated number of persons 30-64 with young onset dementia in Lancashire County Council service planning areas



Lancashire County Council Business Intelligence 22/08/2016 GKJ

Appendix D – map of number of adult social care clients with YOD by service planning area

Number of social care clients 30-64 with young onset dementia in Lancashire County Council service planning areas



Lancashire County Council Business Intelligence 22/08/2016 GKJ

Glossary

CSU	commissioning support unit
DERG	dementia expert reference group
GP	general practice/practitioner
HSCIC	Health and Social Care Information Centre
Lancashire-12	The geographical area encompassing the twelve county districts: Burnley, Chorley, Fylde, Hyndburn, Lancaster, Pendle, Preston, Ribble Valley, Rossendale, South Ribble, West Lancashire and Wyre.
Lancashire-14	The geographic area encompassing the twelve county districts: Burnley, Chorley, Fylde, Hyndburn, Lancaster, Pendle, Preston, Ribble Valley, Rossendale, South Ribble, West Lancashire and Wyre plus the two unitary authorities Blackburn with Darwen and Blackpool.
LSOA	Lower layer super output area (Census geography containing between 1,000 and 3,000 people and between 400 and 1,200 households).
Mosaic	A geodemographic segmentation profiling toolkit that groups similar populations or households together based on a range of social, demographic and consumer data.
MSOA	Middle layer super output area (Census geography containing between 5,000 and 15,000 people and between 2,000 and 6,000 households).
NICE	National Institute for Health and Care Excellence
ONS	Office for National Statistics
QOF	Quality Outcomes Framework – part of the General Medical Services (GMS) contract for general practices, introduced on 1 April 2004. The QOF rewards practices for the provision of 'quality care' and helps to fund further improvements in the delivery of clinical care.
SPA	Service planning area (any of 34 geographical areas created by Lancashire County Council's business intelligence team for service planning purposes. Each SPA is made up of between three and eight MSOAs).
YOD	young onset dementia

References

Alzheimer's Society (2014a). *Younger people with dementia.* Available from https://www.alzheimers.org.uk/site/scripts/download_info.php?fileID=1766

Alzheimer's Society (2014b). *Dementia UK: Second edition*. Available from https://www.alzheimers.org.uk/site/scripts/documents_info.php?documentID=2759

Alzheimer's Society (2016). Alzheimer's Society (2016). *Types of* dementia. Available from https://www.alzheimers.org.uk/site/scripts/documents.php?categoryID=200362

Emerson, E. & Hatton, C. (2004). *Estimating Future Need/Demand for Supports for Adults with Learning Disabilities in England*, Institute for Health Research, Lancaster University. Available from http://www.improvinghealthandlives.org.uk/uploads/doc/vid_10673_IHaL2011-05FutureNeed.pdf

The Dementia Engagement and Empowerment Project. (2014). *Dementia words matter: Guidelines on language about dementia*. Available from http://www.youngdementiauk.org/sites/default/files/DEEP-Guide-Language.pdf

Ferri, C.P., Prince, M., Brayne, C., Brodaty, H., Fratiglioni, L., Ganguli, M., Hall, K., Hasegawa, K., Hendrie, H., Yueqin, H., Jorm, A., Mathers, C., Menezes, R., Rimmer, E., & Scazufca, M. (2005). Global prevalence of dementia: a Delphi consensus study. *The Lancet, 366*(9503), 2112-2117.

Jervis, N. & Prinsloo, L. (2008). How we developed a multidisciplinary screening project for people with Down's syndrome given the increased prevalence of early onset dementia. *British Journal of Learning Disabilities (36)* 13–21.

Johannessen, A., & Möller, A. (2011). Experiences of persons with early-onset dementia in everyday life: A qualitative study. *Dementia: The International Journal of Social Research and Practice, 12*(4), 410-424. DOI: 10.1177/1471301211430647

Kenney, A. (2013). Making reasonable adjustments to dementia services for people with learning disabilities. Available from https://www.improvinghealthandlives.org.uk/publications/1196/Making_Reasonable_Adjustments_to_Dementia_Services_for_People_with_Learning_Disabilities

National Institute for Health and Care Excellence. (2006). *Dementia: supporting people with dementia and their carers in health and social care*. NICE guidelines [CG42]. Available from https://www.nice.org.uk/guidance/cg42

National Institute for Health and Care Excellence. (2015). *Dementia, disability and frailty in later life – mid-life approaches to delay or prevent onset*. NICE guidelines [NG16]. Available from https://www.nice.org.uk/guidance/ng16/

Nordström, P., Nordström, A., Eriksson, M., Wahlund, & Gustafson, Y. (2013). Risk Factors in Late Adolescence for Young-Onset Dementia in Men: A Nationwide Cohort Study. *JAMA Internal Medicine, 173*(17), 1612-1818. DOI: 10.1001/jamainternmed.2013.9079

Roness; T.A., Mjørud, M., & Engedal, K. (2011). Quality of life and depression in carers of patients with early onset dementia. *Aging Mental Health (15)*3, 299-306. DOI: 10.1080/13607861003713224

Strydom, A., Chan, T., King, M., Hassiotis, A., & Livingston, G. (2013). Incidence of dementia in older adults with intellectual disabilities. *Research in developmental disabilities*, *34*(6), 1881–1885.

van Vliet, D., de Vugt, M.E., Bakker, C., Koopmans, R.T., & Verhey, F.R. 2010. Impact of early onset dementia on caregivers: a review. *International Journal of Geriatric Psychiatry, 25*(11), 1091-1100. DIO: 10.1002/gps.2439

World Health Organization. (2015). *Dementia: Factsheet no.363*. Available from http://www.who.int/mediacentre/factsheets/fs362/en/