Young onset epidemiology

We need to really understand our young onset dementia population

Background

In May 2018 the London Assembly Health Committee held an investigation into young onset dementia in London. The key findings included issues around data including diagnosis rates and prevalence, an unclear picture for marginalised groups and variation in support available across London. The Health Committee's recommendations to the Mayor of London set out areas for action on specific issues under his remit, notably transport and employment. Other recommendations included the need for greater inclusion of young onset dementia in wider discussions on dementia, a stronger evidence base to inform a truer understanding of need and to help to make the case for action in other policy areas. In response to the recommendations the London Dementia Clinical Network was asked to convene London's research community to identify what research would be most helpful to improve understanding on prevalence and incidence, and how the Mayor and others can best support it to happen.

Young onset dementia epidemiology meeting

On 17th January 2019 a meeting was held at the Alzheimer's Society headquarters.

Meeting attendees

- Jeremy Isaacs; Consultant Neurologist and Effective Diagnosis Lead, London Dementia Clinical Network (chair).
- Carol Brayne; Professor of Public Health Medicine. University of Cambridge
- Marcus Richards; Professor of Psychology and Epidemiology, Programme Lead at the MRC Unit for Lifelong Health and Ageing, UCL
- Tessa Gutteridge; Director, Young Dementia UK, Young Dementia Network
- Naaheed Mukadem; Clinical Research Fellow and Consultant Psychiatrist, Division of Psychiatry, UCL
- Janet Carter; Consultant in old age psychiatry, North East London NHS Foundation Trust, Division of Psychiatry, UCL. Young Dementia Network
- James Pickett; Head of research, Alzheimer's Society
- Laura Cook; Programme Lead London Dementia Clinical Network

- Susan Mitchell; Policy manager ARUK
- Michael Jackson; Dementia Intelligence Network, Public Health England
- Jacqui Hussey; Consultant Psychiatrist, Berkshire Healthcare
- Lucy Brant; Scrutiny manager, London Health Assembly
- Gus Wilson; London Health Board Secretariat Manager
- Jo Baxter; Policy officer, Alzheimer's Society

Meeting presentations

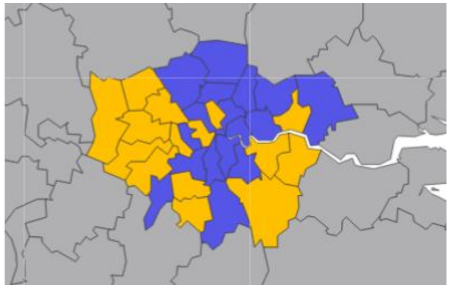
The meeting attendees were given an overview of the London Health Committee report by Lucy Brant. The Health Committee undertook their investigation because the Mayor of London has committed to making London a 'dementia friendly' capital city and young onset dementia is a minority group within the dementia population. The investigation focused on the lived experiences of people with young onset dementia, highlighting real-life experiences which underpin the need for greater public and clinical awareness of young onset dementia, including strengthening the evidence base to make a case for action. Gus Wilson presented an overview of the dementia friendly London ambitions which have wide sector involvement including housing, transport and health. Gus highlighted that there needs to be some consideration as to how success is measured for people with young onset dementia, for example employment considerations.

James Pickett presented the findings of stakeholder interviews on prevalence data that was conducted by Solutions for Public Health for Alzheimer's Society and ARUK. Participants highlighted that they wanted three prevalence estimates; people aged 65 and over living with dementia, people with young onset dementia and cognitive decline in the younger population (such as mild cognitive impairment). Participants also highlighted that they wanted to understand local prevalence and incidence and have information on different groups, such as ethnic minority populations. Participants felt that population based studies may not the right approach due to the relatively low numbers of people with young onset dementia and new funding models may need to be considered to ensure that the highlighted research areas are investigated.

Carol Brayne spoke about what we currently know about the epidemiology of young onset dementia. In Cambridge, John Hodges identified the local incidence of young onset dementia by working with primary, secondary and tertiary care systems to identify people diagnosed with dementia before the age of 65. One study has been completed in London with similar methodology. Research suggests that the prevalence of dementia in the 30-64 age group is 38-260 per 100,000 population. Carol highlighted that any research would need to use triangulation of data between various sources (e.g. primary care QOF registers, secondary care databases) with deep dives into localities and that there would need to be consideration to cohorts such as progressive supranuclear palsy, HIV dementia, drug and alcohol misuse, Down syndrome and other learning disabilities. New cohorts would also need to be considered, for example people being identified prior to symptoms through biomarkers.

Other considerations for research include social drift, and that young onset dementias have a more genetic causation attribution and people have a longer life expectancy then older people with dementia.

Michael Jackson spoke about improving routine data on the prevalence of young onset dementia in England. Young onset dementia rates are included on the PHE finger tips tool. In 2018 in England 14,935 individuals under the age of 65 had a diagnosis of dementia on GP practice registers, equating to 3.07 per 10,000 population and varying across CCGs from 1.12 to 7.15 per 10,000 population. In London 1,840 individuals under the age of 65 had a diagnosis of dementia on GP practice registers, equating to 2.19 per 10,000 population and varying across CCGs from 1.12 to 3.43 per 10,000 population.



In London 15 CCGs were similar to the England rate (yellow), and 17 were below (blue)

The finger tips tool also records the proportion of dementia cases under the age of 65. In 2018 in England 3.3% of people with dementia were under the age of 65, varying between CCGs from 1.3% to 10.4%. In London 3.9% of people with dementia were under 65, varying between CCGs from 1.7% to 6.2%.

This data is collected monthly directly from GP practice records and is available via NHS digital. There are limitations with the data; mis-coding in primary care, people with young onset dementia who are now over 64 not being included in the count and practices not submitting data. In November 2018 33% of London GP practices submitted a zero return, which could be due to opting out of data collection or practices not having anyone under the age of 65 with dementia. In comparison, only 5 practices submitted a zero return in November 2018 for older people with dementia.

Since the meeting, we have discussed practice data submission with NHS digital. They confirmed that there is one submission for practices for dementia data, and practices are unable to opt out of submitting data just for people under the age of 65. There are only five practices in London that do not submit dementia data; NHS England London Region has previously reviewed these practices, and they do not submit data for appropriate reasons, for example, because they are practices attached to schools. Therefore, practices reporting zero young onset dementia data have no patients with a recorded dementia diagnosis under the age of 65. It is important to highlight that practices submitting zero may still have patients with young onset dementia who do not appear on the data submission, this could be caused by patients not having a diagnosis, or the diagnosis not being coded, or the patient is aged 65 or over. NHS digital also confirmed that once a patient is 65 and over they will move onto the 65 and over register, regardless of the diagnosis code, even if coded as Alzheimer's Disease of early onset. NHS digital are currently unable to use the submission data to report on people that received a diagnosis code before the age of 65.

Jacqui Hussey spoke about comparing memory service and primary care diagnosis registers in Wokingham. Using the Dementia UK consensus estimates of population prevalence it was predicted that locally there were 108 people living with young onset dementia. The service held a register which had 80 people living with young onset dementia; however, only 29 people were on GP practice registers with a diagnosis of dementia under the age of 65. This work further demonstrated the difficulties of basing assumptions about the prevalence of young onset dementia based on GP practice data. Jacqui highlighted that it was important to have accurate data to ensure appropriate commissioning of services, to provide a network for people living with young onset dementia and their families, and to co-ordinate services effectively.

Group Discussion

The group discussed what information was needed with regards to young onset epidemiology, suggestions were:

- Incidence and prevalence
- Specific information on different subtypes, including incidence and prevalence rate of progression and life expectancy
- How long people wait for a diagnosis, stage of dementia at diagnosis, contact with healthcare professional (number and type) prior to diagnosis and what are the differences in health resource use by dementia subtype, ethnicity and social class
- Increased understanding of needs
- Correct messaging for policy makers and commissioners
- Information on the cohort of people with a young onset dementia diagnosis who appear not to undergo decline in function post-diagnosis
- Optimise GP practice / NHS digital data

The group discussed the research methodologies that would be required to answer the above questions. It was felt that an epidemiological needs-based analysis was required. Research would need to synthesise existing data and evidence and use deep dives into a local population of people with young onset dementia. It was felt that determining the prevalence of undiagnosed young onset dementia would be too complex given the likely budget and timescale. Qualitative interviews would also be beneficial to consider the wider implications of diagnosis. The national birth cohort study or the CRIS data base, which is currently being used for the Angela project, could potentially be used to support this programme of research. James Pickett noted that a well-constructed grant proposal along these lines would fall within the remit of research supported by the Alzheimer’s Society.

Recommendations for City Hall

- Bring together the research funding community to highlight the need for epidemiological needs-based analysis for young onset dementia
- Continue to ensure that there is specific consideration for young onset dementia in the dementia friendly London ambition
- Champion the need for better data; GP practices using accurate coding and using GP practice records to get a true picture of people who were diagnosed under the age of 65 (regardless of current age)

Recommendations for NHS England (London region) Dementia Clinical Network

- To support memory services and GPs in one or two CCGs to replicate the “deep drive” performed in Wokingham to triangulate provider and GP records to provide an updated count of the number of people with a diagnosis of young onset dementia