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Dear Colleagues,

Dementia Diagnosis Rates- October 2016

I am writing to update you on the latest dementia diagnosis rate figures, which were published by NHS Digital on 11 November 2016. The data provides the position at the end of October 2016. The national dementia diagnosis rate at the end of October 2016 was 67.7%. To access local data, please use the following link which will direct you to the NHS England website: https://www.england.nhs.uk/mentalhealth/dementia/monthly-workbook/.

NHS Digital Data Extract

As you will know from previous correspondence, the collection of monthly dementia diagnosis QOF data is subject to a direction, and therefore mandatory. However, there are some practices that have yet to complete their CQRS applications on time and are therefore showing zero returns. Please ensure that all practices in your area are signed into the CQRS system.

The next monthly publication of dementia diagnoses, for end November data, will be published on 16 December 2016.

Join Dementia Research

Join Dementia Research (www.joindementiaresearch.nihr.ac.uk) is a nationwide service that NHS England supports in partnership with Alzheimer's Research UK, Alzheimer's Society, and the NIHR. It helps match people interested in research to appropriate studies.

Research by the charities suggests that many people with dementia want to take part in research, but do not know how to do so. To hear why research is so important to people with dementia, watch our video: https://youtu.be/RuTdO7isaWg

Join Dementia Research provides NHS clinicians with an easy way to signpost people to a full range of available studies, without the need to have an intricate knowledge of what research is going on.

A current area of focus for dementia research is on new interventions for people in the early stages of dementia, making it increasingly important to signpost people to Join Dementia Research as part of the post diagnostic pathway.

In one of the CCGs in the Care City Test Bed, where Join Dementia Research is being integrated into core clinical pathways, preliminary data shows the proportion of people with a diagnosis of dementia registered with Join Dementia Research is twice as high as the next highest CCG in the country.

A new online toolkit has recently been launched to help CCGs and NHS services integrate Join Dementia Research into their core pathways: nhs.joindementiaresearch.nihr.ac.uk

Find out how many are registered to Join Dementia Research in your region and discover what studies are open locally: nhs.joindementiaresearch.nihr.ac.uk/data-and-statistics

Music Therapy and Dementia

Music therapy plays a crucial role in the care of many people with dementia, helping minimise apathy, anxiety, restlessness and depression. Crucially, it can support people throughout all stages of dementia, from diagnosis to end of life care, as well as support those who care for them. In the UK, music therapy has been recommended as a psychosocial intervention in the National Dementia Strategy (Department of Health 2009). Leading research has shown that music therapy can significantly improve and support the mood, alertness and engagement of people with dementia, can reduce the use of medication, as well as helping to manage and reduce agitation, isolation, depression and anxiety, overall supporting a better quality of life.

As a non-pharmacological intervention, music therapy engages healthy parts of the brain to address secondary effects of the illness. Music therapists work with people with dementia to support inevitable losses and look for appropriate ways to use music to help meet their psychological needs.

Music therapy is an established clinical intervention, which is delivered by HCPC registered music therapists to help people whose lives have been affected by injury, illness or disability through supporting their psychological, emotional, cognitive, physical, communicative and social needs.

To find out how you can access music therapy for someone you feel who could benefit from it or for those who care for people with dementia, please contact the British Association for Music Therapy by visiting www.bamt.org or call 020 7837 6100.

Memory and Smell

For families of people with dementia, it is very important that constructive and engaging supported activity is organised that enables their loved one to feel safe, entertained and purposeful. Involving people with dementia, however, can be a challenge for carers and activities staff in residential care, as the disease often inhibits communication and leads to people becoming withdrawn.

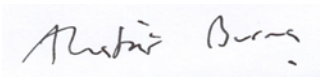
Talking and being listened to is one of the most basic human needs; a recognised mood therapy that is key to our culture where sitting with a friend for a "cup of tea" is the answer to every life problem! So how can carers and activity staff draw people into conversation?

Smell & Connect was launched at The Alzheimer's Show in London last year. National Activity Providers Association (NAPA) undertook a trial of Smell & Connect to show there's nothing like a scent to stir a memory.

If you'd like to know more about the Smell & Connect trial visit: http://smellandconnect.co.uk/news/56-national-activity-providers-association-napa-trial-of-smell-connect

With the CCG letter now being published via the CCG Bulletin monthly this will not always coincide exactly with the publication date of the dementia diagnosis rate data on the NHS Digital website. Therefore, it will be down to CCGs to check the NHS England website for the monthly workbook containing the CCG diagnosis rates and GP diagnosis count data. The workbook with publish on the NHS England website on the same day as NHS Digital release the data (usually the 2nd Friday of each month). The NHS Digital publication calendar can be found on the NHS Digital website- http://content.digital.nhs.uk/pubs/calendar.

Yours Sincerely



Alistair Burns
National Clinical Director for Dementia and Older People's Mental Health
NHS England

Annex A

Key actions that practices can routinely undertake to increase dementia diagnosis rates

- **Use the Dementia Quality Toolkit (DQT)**: Maintaining excellent data quality can only be maintained by regular cleansing. The DQT consists of a series of reports and queries run directly on GP systems to identify patients who may have dementia, but who are not coded as such within the practice. The DQT can be downloaded from the North of England Commissioning Support Unit (NECS) website: http://www.necsu.nhs.uk/dementia. **PASSWORD:** Support30

- **Secondary Care Data:** Develop standard working practices of information sharing between primary and secondary care, particularly around diagnosis.

- **Other searches:** This involves reviewing lists of people:
  - Who have **ever** been prescribed cholinesterase inhibitors (donepezil, galantamine, rivastigmine), or memantine.
  - 65 years and over **and all** those in care homes who have been prescribed antipsychotic medication.
  - Previously coded with local dementia codes, that is codes that are not part of the QOF Dementia Indicator Set.
  - Coded with conditions suggestive of dementia.
  - Resident in Care / Nursing homes. This review includes review of patient notes especially letters where text may refer to the possibility or diagnosis of dementia.

- **Seek support from your Clinical Network:** specific clinical advice and support is available through a network of clinicians with an interest in Dementia. Working closely with Regional Team, the Clinical Network colleagues will provide targeted support, tools and resources to aid better understanding and improvements in local dementia diagnosis rates and post diagnostic care and support. Please contact england.domainteam@nhs.net if you wish you be put into contact with one of the network contacts.

- **Additional Alzheimer's Society Support**: The Alzheimer's Society continues to provide additional support in some CCGs areas which includes public awareness activities, supporting diagnosis in care homes and improving post-diagnostic support with more Dementia Advisers. For further information on this additional support please contact england.domainteam@nhs.net or George McNamara at george.mcnamara@alzheimers.org.uk

- **Public Health England Fingertips tool**: NHS England commissioned Public Health England to develop a Dementia Intelligence Network (DIN). The DIN is a catalogue of data relating to dementia that acts to measure the outcomes set out in the Well Pathway for Dementia. Access the Fingertips tool here- http://fingertips.phe.org.uk.

- **The Mental Capacity Act (MCA)**: An estimated two million people in England lack the mental capacity to make a specific decision at a specific time. MCA established the legal framework for how these individuals are supported. The MCA describes clear principles of supported decision-making, least restrictive care and best interests decisions that consider closely the unique wishes and preferences of the individual. It provides protection for professionals that abide by the Act. It allows us all to plan ahead for the future – through advance decisions to refuse treatment and Lasting Powers of Attorney (LPAs).

Annex B

FAQs – Dementia Diagnosis Rate

1. **How is the dementia diagnosis rate calculated?**

   The definition of the 2016-17 dementia diagnosis indicator is the same as 2015-16 and was published in January 2016 as indicator E.A.S.1 of the CCG planning guidance. The detailed specification can be found on page 10 of the "Technical Definitions for Commissioners 2016/17" found at:

   https://www.england.nhs.uk/wp-content/uploads/2016/02/technical-definitions.pdf

2. **Why does the indicator only include people aged 65 and over?**

   Until April 2015, dementia diagnosis rates were calculated using estimates of dementia prevalence reported in the 2007 Alzheimer's Society study "Dementia UK"[1]. Following a consultation with other stakeholders, NHS England now believes that the best scientific evidence of rates of dementia prevalence in England are those reported in 2013 by the Cognitive Function and Ageing Study II (CFASII).

   The CFAS II study only examined dementia prevalence in older people and did not produce prevalence estimates for people aged under-65. Estimates of prevalence for early onset dementia are available, most notably in the 2014 update of the Alzheimer's Society study. This however did not update the estimates of dementia prevalence for the under-60 age groups from those given in the 2007 study. The CFAS II results indicate that dementia prevalence rates have altered since 2007.

   The disadvantages of using potentially outdated information and of mixing studies were weighed against the negative of excluding people aged under-65 from the indicator. A key factor in the decision was that the vast majority of people living with dementia are aged 65 or over; the October 2015 data from NHS Digital shows that 97% of all dementia diagnoses are for people aged 65 and over.

   NHS Digital publishes dementia register counts for people aged under-65 each month and these are available on their website. In addition, the monthly letters to CCGs from NHS England include the total number of diagnoses for all ages.

3. **If one sums the number of people on the dementia registers for a CCG as given in the NHS Digital publication, the count is lower than the number of diagnoses given for the CCG in NHS England's letter. Why?**

[2] http://www.alzheimers.org.uk/site/scripts/download_info.php?fileID=2

The monthly dementia data collection has never succeeded in obtaining data from all practices. For example, in October of the 7,754 active practices in England, NHS Digital published dementia registers for 7,421 practices. To avoid understating the diagnosis rate for a CCG, when a practice's data are not available for the latest month the CCG total in annex A includes that practice's most recently available data instead. For example, a practice for which October's data are not available would have their September register count included in the CCG total as the best estimate of their current position.

4. Why are dementia diagnosis rates no longer published for GP practices?

The publication of the results of the CFAS II study gave confidence intervals around their estimates of dementia prevalence. CIs were not available for the Alzheimer's Society 2007 prevalence rates as they had been produced from a Delphi consensus approach. Hence this year, for the first time, it was possible to assess the confidence intervals around the dementia prevalence estimates. The majority of GP practices have counts of registered patients too low for their dementia prevalence estimates to have sufficiently tight confidence intervals that their diagnosis rates could be considered meaningfully distinguishable from a norm.