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Dear Colleagues,

Dementia Diagnosis Rates- December 2016

I am writing to update you on the latest dementia diagnosis rate figures, which were published by NHS Digital on 13 January 2017. The data provides the position at the end of December 2016. The national dementia diagnosis rate at the end of December 2016 was 67.8%. To access local data, please use the following link:

<https://www.england.nhs.uk/mentalhealth/dementia/monthly-workbook/>.

The next monthly publication of dementia diagnoses, for end January data, will be published on 10 February 2017.

Current and new NHS Digital Data Extract

As you will know from previous correspondence, the collection of monthly dementia diagnosis QOF data is subject to a legal direction from NHS England, and therefore mandatory. However, there are still some practices that have yet to complete their CQRS applications on time and are therefore showing zero returns. This is an ongoing issue but you may be aware the source data for the calculation of dementia diagnosis rates is due to change to a new extract.

NHS Digital have been setting up a new extract from GPES called the Dementia Data 2016-17 collection and all practices have received an offer to accept the new collection via the CQRS system.

The details of the new collection were described in the Data Provision Notice which was emailed out to practices by NHS Digital in September 2016.

Participation in the new extract is mandatory (it has a direction) and it will replace the current dementia extract.

Of the practices expected to participate 7,242 have approved the new extract but 210 practices have yet to accept the request on CQRS (still have an offered status) and a further 18 have rejected the extract. The level of participation for the new extract currently much lower (96.8%) than for the current extract (approx. 98%) and needs to be considerably increased before the switch is made if the calculation of dementia diagnosis rates is to remain accurate. Please could you follow this up with your local areas and please ensure that all practices in your area are signed into the CQRS system and have accepted the new extract collection.

CCG Improvement Assessment Framework (IAF) Buddy Support

The CCGIAF is a new framework of metrics that will become the principal method by which NHS England holds CCGs to account for their performance. Assessments based on the framework will be carried out annually, with ratings awarded for each of six key clinical priority areas based on a four point scale. Ratings will be moderated by national expert panels and tiered support will be made available by NHS England.

In addition to other support mechanisms NHS England would like for CCGs to support one another to improve performance against the two dementia indicators within the CCGIAF via a buddying system. Any CCG interested in having a buddy please can you contact ENGLAND.DomainTeam@nhs.net.

CFAS prevalence estimate project

A team at Newcastle University have won the tender to undertake the CFAS prevalence estimate project. They will be using the CFAS II study data to explore potential for more specificity by geography. This analytical work will explore whether additional factors (e.g. deprivation, rurality, cardiovascular risk, learning disabilities etc.) can be used to give a more accurate estimate of CCG level dementia prevalence. It will also provide an update to the CFAS estimates that takes account of these additional factors. It is intended that this project will complete by March 2017.

Solanexumab

Lilly announced the results of Solanezumab Phase 3 EXPEDITION3 Study at the end of 2016. Disappointingly, solanezumab did not meet the primary endpoint in the EXPEDITION3 clinical trial, a study of solanezumab initiated in people with mild dementia due to Alzheimer's disease. As a result, Lilly will not pursue regulatory submissions for solanezumab for the treatment of mild dementia due to Alzheimer's disease.

Despite this set back Lilly have publically emphasised their continued commitment to finding solutions for Alzheimer's disease. They intend to continue to analyse the study results and work with the external scientific community in the hopes of

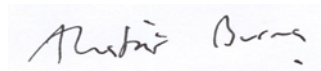
uncovering findings that will help shape and advance future Alzheimer's disease research.

CCG Bulletin

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 will be published on the NHS England website on the same day that 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>.

Finally, I would just like to take the opportunity to thank you for all your work to improve care outcomes for those living with dementia, their carers and families. I will write again in February 2017. In the meantime, if you would like any general or clinical advice with your work on dementia, or want to discuss anything further, please contact me at Alistair.Burns@nhs.net.

Yours Sincerely

A handwritten signature in black ink that reads "Alistair Burns". The signature is written in a cursive style and is contained within a light grey rectangular box.

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>. If you require a password please contact england.domainteam@nhs.net.
- **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>

The methodology used to calculate dementia prevalence is due to change in April 2017. From April 2017 NHS England will no longer apply the CFAS II prevalence estimates to ONS resident population estimates, they will instead be applied to the registered population from GP lists.

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.

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

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?

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.