NHS Digital

Indicator Supporting Documentation

IAP00427 Dementia: 65+ Estimated Diagnosis Rate

Application Form

Section 1. Introduction / Overview

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| **1.1 Title** | Dementia: 65+ Estimated Diagnosis Rate |
| **1.2 Set or domain** | 1. NHS England: Dementia diagnosis monthly workbook (EAS1) 2. Public Health Outcomes Framework / Dementia profiles 3. CCG Outcomes Indicator Set 4. CCG Improvement and Assessment Framework |
| **1.3 Topic area** | Dementia, Primary Care |
| **1.4Definition** | The indicator value is the estimated diagnosis rate for dementia in persons aged 65 and over, defined as the number diagnosed with dementia divided by the number estimated to have dementia given the characteristics of the population, expressed per 100 persons estimated to have dementia.  More precisely, applying the estimated age and sex-specific 65+ prevalence rates of the reference population (the Cognitive Function Aging Study II (CFAS II) sample) to the age and sex structure of the subject population (all 65+ patients under the care of a given organisation extracted from the General Practice Extraction Service (GPES)), yields the number of people 65+ one could estimate to have dementia within the subject population regardless of diagnosis. Dividing the actual number of cases recorded for said organisation (again extracted from GPES) by the estimated number yields the estimated diagnosis rate.  The indicator reports a monthly snapshot of the final day of the month, at:   1. Clinical Commissioning Group (CCG), NHS Commissioning Region, NHS Commissioning Sub-Region and England level, aggregated from GP practice level data mapped by commissioning organisation of responsibility. 2. Local Authority, Public Health Region, Public Health Comparator Organisations and England level, aggregated from GP practice level data mapped by postcode of GP practice 3. Clinical Commissioning Group (CCG) and England level mapped by commissioning organisation of responsibility 4. Clinical Commissioning Group (CCG) mapped by commissioning organisation of responsibility |
| **1.5 Indicator owner & contact details** | Kathryn Salt, Primary Care Domain, NHS Digital  [Primarycare.domain@NHS.net](mailto:Primarycare.domain@NHS.net) |
| **1.6 Publication status** | Not currently in publication |

Section 2. Rationale

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| **2.1 Purpose** | NHS England: EAS1To monitor performance in increasing England’s dementia diagnosis rate, and to categorise the diagnosis rate of individual organisations as significantly higher, significantly lower, and neither significantly higher nor lower than the target 66.7% diagnosis rate.Whilst the national target has been achieved, variation still exists across the country and is now the focus of improvement plans at various local levels. The indicator will be used by NHS England, NHS Commissioning Region Teams, NHS Area Teams and Clinical Commissioning Groups for improving dementia diagnosis rates.   1. PHOF / Dementia Profiles   To provide Public Health England, Local Authorities, other organisations and the public with information about the estimated rate of diagnosis of dementia in general practice, as part of PHE’s public health surveillance role. The indicator has been selected for the PHOF because of the importance of dementia in determining quality of life for older people and the scarcity of information on the topic.   1. CCG OIS   The purpose of this indicator is to measure the estimated dementia diagnosis rate, allowing CCGs to compare their indicator value to the national target, and where population characteristics are similar, to peer CCGs.   1. CCG IAF   Assessment of CCGs performance in meeting and maintaining the national ambition of a diagnosis rate of two thirds of local prevalence. |
| **2.2 Sponsor** | Carl Child, NHS England |
| **2.3 Endorsement** | NHS England and Public Health England both favour the use of CFAS II, allowing for a unified approach across two sections of the health system with a single indicator methodology.  CFAS II support use of their prevalence data in local planning (as stated in their research). CFAS II finds no heterogeneity between the six study sites (two in each of Cambridge, Newcastle and Nottingham) from which prevalence rates were derived, implying that the results can be scaled up to larger populations and used in the manner described. |
| **2.4Evidence and Policy base**  Including related national incentives, critical business question, NICE quality standard and set or domain rationale, if appropriate | Then Prime Minister David Cameron launched the Dementia Challenge in 2012 (<http://dementiachallenge.dh.gov.uk/>), to build on the 2009 National Dementia Strategy. A key component of the challenge is to improve diagnosis rates for dementia, so that more patients suffering from dementia are given a formal diagnosis so that they can receive the appropriate post-diagnostic care and support.This commitment was further supported by the NHS 2014-15 mandate which set a target of increasing the Estimated Dementia Diagnosis Rate to two-thirds by March 2015 and to sustain this throughout 2015/16 (<https://www.england.nhs.uk/2013/05/dementia-targets/>). This Mandate commitment had continued since then as it remains a key priority for NHS England. Continued monitoring is important to maintain focus on dementia. Timely diagnosis and intervention is a key objective of the National Dementia Strategy and has been reinforced as a priority in the Prime Minister's Challenge on Dementia, published on 26 March 2012. Diagnosis rates for dementia vary across the country. Too often, diagnosis comes too late - during a crisis or beyond the point at which people can plan for the future and make informed choices about how they would like to be cared for. For example, a fall leading to admission to hospital. NHS England has set the first ever national ambition to improve dementia diagnosis rates. By 2015, the aim was that two-thirds of people with dementia should have a diagnosis, with appropriate post diagnosis support. Although this aim was achieved at a national level, regional variation still exists.  This indicator acts as a gateway to ensuring that appropriate post-diagnostic support is made available to all who require it. It is also a metric in the CCG IAF and a key indicator for our dementia well-pathway. There are a range of outcomes targeted for people with dementia and their carers as set out below. Improving diagnosis rates has a key role to play in the ability to achieve these outcomes:   * Slower progression of the condition which might be possible with early diagnosis and the prescription of appropriate drugs for certain types of dementia (e.g. Alzheimer’s); * Improved ability to cope with symptoms of dementia and the consequential deferred institutionalisation which might be deliverable through early diagnosis and better information, support and treatment; * Avoidance of side effects associated with inappropriate medication which might be deliverable through better detection of dementia, better training of staff working in hospitals and care homes, and dramatically reduced reliance upon anti-psychotic drugs; * Reduction in the amount of time that people with dementia spend in hospital, both in terms of avoidable admissions/readmissions and reduced length of hospital stay for those with dementia who are hospitalised for whatever reason. |

Section 3. Data

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| **3.1Data source** | Dementia diagnoses and registered patient lists collected from GP practice clinical systems: NHS Digital (NHS DIGITAL) GP Extraction Service (GPES), National Health Applications and Infrastructure Services (NHAIS)  Estimated prevalence rates: Medical Research Council (MRC) Cognitive Function Aging Study II (CFAS II). The Cognitive Function and Ageing Studies (CFAS) are population based studies of individuals aged 65 years and over living in the community, including institutions. CFAS is the only large multi-centred, population-based study in the UK that has reached sufficient maturity. CFAS II is based in England and builds upon the design and infrastructure of CFAS I. CFAS II recruitment began in 2008 and the study provides data on generational and geographical differences, including people in institutions. CFAS II is comprised of 3 centres: Cambridgeshire, Newcastle and Nottingham; with 2 sites in each centre. CFAS II baseline fieldwork was conducted between 2008 and 2011, with a follow up interview conducted with participants approximately 2 years after the baseline interview. |
| **3.2 Justification of source and others considered** | GPES is the only source of national level primary care diagnosis data from GP system suppliers.  Office for National Statistics (ONS) residential population data were considered for use, but NHAIS registered patient data were chosen to maintain consistency between numerator and denominator populations for the following reasons:  1) GPES clinical data used in the numerator do not yield individual patient postcodes and would be assigned to an ONS residence based denominator by GP practice postcode. Sourcing denominator data from GP clinical systems ensures that the numerator and denominator are taken from the same population.  2) GPES clinical data used in the numerator do not yield 100% patient coverage. Since the ONS residential data cannot be adjusted to account for this, the diagnosis rate for any given area would be inflated to some extent. Sourcing denominator data from GP clinical systems allows the definition of an identical cohort of GP practices in the numerator and denominator data.  Although numbers of registered patients can be affected by “list inflation” whereby patients remain registered at a practice after leaving the area, this is thought to have minimal effect on people aged 65 and over and will have equal effect on both the numerator and denominator.  Nine possible sources of estimated dementia prevalence data are available: |

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| O’Connor et al (1989) |
| Brayne and Calloway (1989) |
| Livingston et al (1990) |
| Clarke et al (1991) |
| Saunders et al (1993) |
| MRC-CFAS (1998) |
| MRC CFAS II (Matthews et al, 2013) |
| Dementia UK (2007) |
| Dementia UK (2014) |

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|  | CFAS II is preferable as it has a more scientific, well documented and transparent methodology including well documented survey techniques, consideration of bias and use of confidence intervals to describe uncertainty in the data. The use of CFAS II by both NHS England and Public Health England also brings consistency and comparability of results. A disadvantage of the data is that it is only applicable to patients aged 65 and over. |
| **3.3 Data availability** | CFAS II reference rates remain static and are available open access here: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3906607/  GPES data are extracted from GP practices via their IT supplier on the first working day after the last day of the month and is available for analysis around 5-10 working days later. The Health and Social Care Act 2012 (the Act) gives NHS Digital statutory powers, under Section 259 (1), to require data from health or social care bodies or organisations who provide health or adult social care in England. The Department of Health (DH) (on behalf of the Secretary of State or NHS England (NHSE) may direct NHS Digital to establish a data collection. When NHS Digital receives such a direction we issue a Data Provision Notice to the appropriate providers of the required data. The data, as specified by NHS Digital in this published Data Provision Notice, is required to support a direction from NHSE to NHS Digital. On 31st July 2015 such a notice was issued for the collection of aggregated numbers of patients in England with a record of dementia diagnosis on their clinical record (<https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/450355/dpndementia.pdf>), and an update published 20th September 2016 (https://www.gov.uk/government/uploads/system/uploads/attachment\_data/file/554043/DPN\_Dementia\_Data\_2016-17.pdf)  Therefore, organisations in scope of the notice are legally required, under Section 259 (5) of the Act, to provide the data.  To agree to the above data collection, GP practices must explicitly opt in via their local IT system. As such, although 100 per cent participation should be the expected standard, it is possible that a given GP practice might not participate either passively by failure to opt in (due to technical and/or other error), or by actively choosing to disregard the Data Provision Notice. |
| **3.4 Data quality** | Completeness - this measures the degree to which data items used to produce the indicator include all expected values:  All GP data collected is complete – data is validated upon receipt to ensure that practice organisational code, dates the extract covers and all aggregated counts are populated (even if with a zero). As the data are aggregated at source, they are not affected by Type 1 or Type 2 patient opt-outs from data sharing.  The only two current, possible sources of estimated dementia prevalence data are: CFAS II and the Alzheimer’s Society Dementia UK Report 2014. CFAS II is preferable as it is has a more scientific, well documented and transparent methodology including well documented survey techniques, consideration of bias and use of confidence intervals to describe uncertainty in the data. A disadvantage of the data is that it is only applicable to patients aged 65 and over. The CFAS II study gives very wide confidence intervals around the prevalence estimates in each age group, indicating a great deal of uncertainty. A larger, more definitive study would be preferable, but the uncertainty in the CFAS II study is fully taken into account in the confidence interval methodology for this indicator.  In light of the reduction in dementia incidence found between the first CFAS study (1989–1994) and CFAS II (2008–2011), it is important to note that as CFAS II ages it will gradually become less and less representative of the true epidemiological prevalence experienced in England. Moreover, it is important to consider that CFAS II is based on three areas of England and may not necessarily be applicable to all other areas. This is clearly noted in the guide to interpretation of the indicator.  Coverage - this measures the degree to which data used to produce the indicator have been received from all expected data providers:  GPES can currently extract from 99.0 per cent of open, active GP practices (who use one of the four main GP IT systems suppliers). Currently 96.9 per cent of practices have opted-in with more expected month on month.  This indicator is published with a full coverage report, e.g.  Table 3 showing national coverage of GPES dementia extracts for England  Any patient with a code of ‘dementia’ on their record is extracted. It is possible that for some people with dementia their diagnosis is only recorded in free text, a scanned letter from another health setting or is not recorded at all, which means that we cannot extract their record. However this is in fact one of the reasons that this indicator is needed: not all dementia diagnoses are committed to record.  The data extraction is subject to continuous review, to chase up non-participating practices and improve the extraction process. Data quality is therefore expected to increase over time.  When data is not available for a GP Practice, the most recent data available for that practice would be used, either from within the monthly data collections or from the most recent annual Quality and Outcomes Framework publication.  Validity - this measures the degree to which data items used to produce the indicator satisfy the set of standards and business rules that govern the permitted values and formats for those data items:  Data returned is aggregated counts and only records with a number are loaded as data is validated upon receipt.  Default - this measures the degree to which the default values specified in applicable standards and business rules have been used in the data used to produce the indicator:  Not applicable because Data returned is aggregated counts and only records with a number are loaded as data is validated upon receipt.  Integrity - this measures the degree to which data satisfy the set of business rules that govern the relationships between the data items, records and data assets used to produce the indicator:  Data is validated once received to ensure that the age/gender breakdown counts do not add up to greater than the overall dementia register count. Occasionally the age/gender breakdown counts can add up to less than the overall dementia register count where a date of birth is not recorded on the patient record.  Timeliness - this measures the elapsed time between the start and/or end of the recording period for the data used to produce the indicator and the expected indicator publication date, e.g. if the indicator is published 18 months after the last item of data used to produce it was recorded, this may impact on its usability:  Data is extracted, processed and published within 2 weeks of real time, e.g. data as of 31 January 2017 will be published on 10 February 2017. Use of the data within all frameworks will then procede according to each domain’s publication schedule. |
| **3.5 Quality assurance** | When data are loaded they are validated within the Data Management Environment (DME) ((e.g. numerator (number of people diagnosed with dementia) not larger than denominator (practice list size), data not inflated/deflated by unrealistic amount compared to previous months)). This is automated using SAS Data Integration Studio so that validations happen automatically when carrying out the processing of the data. If practices fail these validations we would contact the system supplier to ensure data extraction was correct and then we would contact the practice to verify the results. This has never happened to date.  The indicator calculation is dual run between independent processes to verify results. The simulation will produce slightly different confidence intervals from the same source data each time, but will be accepted if identical to one decimal place.  The data extraction is subject to continuous review, to chase up non-participating practices and improve the extraction process. Data quality is therefore expected to increase over time.  Before publication data are validated for integrity and internal consistency against the XML schema and business rules, with any failures being removed from the dataset. During publication values are sense checked against long terms trends and post publication individual practices, CCGs and Area Teams regularly QA their reported figures against internally audited numbers and both practice clinical system suppliers and NHS Digital support practices in resolving discrepancies. |
| **3.6 Quality improvement plan**  If appropriate | A list of non-participating practices is sent to NHS England for chase-up on a weekly basis and after every publication.  NHS England disseminates this to regional analysts who then follow up locally. Additionally, the national team shares this information with the clinical networks so that they can also take action locally to encourage practices to sign up. |
| **3.7 Data linkage** | Linkage of GPES, NHAIS and Reference data is undertaken at practice level only, by practice NACS (**National Administrative Codes Service)** code. These codes are based on the prescribing cost centre assigned to the practice by NHS Business Services Authority. |
| **3.8 Quality of data linkage** | All practices are always linkable to the reference data as GPES would not have extracted their data if it were not a live GP practice. |
| **3.9 Data fields** | CFAS II  SEX: Sex of reference rate  AGE\_BAND: Age band of reference rate  PROPORTION: Reference rate with 95% confidence intervals  GPES  PRACTICE-ID: GP practice identifier  ISSUE-DATE-TIME: Extract timestamp  AGGREGATE-RECORD: Number of patients  RID: Values denoting combinations of sex and age band of patients  DESCRIPTION: Labels for combinations of sex and age band of patients  Patients with following clinical codes on their clinical record are counted. These codes comprise the Quality and Outcomes Framework dementia cluster, a set of clinical definitions agreed by an expert group including GPs and lay representatives.  (READ v2):  A4110 Sporadic Creutzfeldt-Jakob disease  E00.. Senile and presenile organic psychotic conditions  E000. Uncomplicated senile dementia  E001. Presenile dementia  E0010 Uncomplicated presenile dementia  E0011 Presenile dementia with delirium  E0012 Presenile dementia with paranoia  E0013 Presenile dementia with depression  E001z Presenile dementia NOS  E002. Senile dementia with depressive or paranoid features  E0020 Senile dementia with paranoia  E0021 Senile dementia with depression  E002z Senile dementia with depressive or paranoid features NOS  E003. Senile dementia with delirium  E004. Arteriosclerotic dementia  E0040 Uncomplicated arteriosclerotic dementia  E0041 Arteriosclerotic dementia with delirium  E0042 Arteriosclerotic dementia with paranoia  E0043 Arteriosclerotic dementia with depression  E004z Arteriosclerotic dementia NOS  E00y. Other senile and presenile organic psychoses  E00z. Senile or presenile psychoses NOS  E012. Other alcoholic dementia  E0120 Chronic alcoholic brain syndrome  E02y1 Drug-induced dementia  E041. Dementia in conditions EC  Eu00. [X]Dementia in Alzheimer's disease  Eu000 [X]Dementia in Alzheimer's disease with early onset  Eu001 [X]Dementia in Alzheimer's disease with late onset  Eu002 [X]Dementia in Alzheimer's dis, atypical or mixed type  Eu00z [X]Dementia in Alzheimer's disease, unspecified  Eu01. [X]Vascular dementia  Eu010 [X]Vascular dementia of acute onset  Eu011 [X]Multi-infarct dementia  Eu012 [X]Subcortical vascular dementia  Eu013 [X]Mixed cortical and subcortical vascular dementia  Eu01y [X]Other vascular dementia  Eu01z [X]Vascular dementia, unspecified  Eu02. [X]Dementia in other diseases classified elsewhere  Eu020 [X]Dementia in Pick's disease  Eu021 [X]Dementia in Creutzfeldt-Jakob disease  Eu022 [X]Dementia in Huntington's disease  Eu023 [X]Dementia in Parkinson's disease  Eu024 [X]Dementia in human immunodef virus [HIV] disease  Eu025 [X]Lewy body dementia  Eu02y [X]Dementia in other specified diseases classif elsewhere  Eu02z [X] Unspecified dementia  Eu041 [X]Delirium superimposed on dementia  F110. Alzheimer's disease  F1100 Alzheimer's disease with early onset  F1101 Alzheimer's disease with late onset  F111. Pick's disease  F112. Senile degeneration of brain  F116. Lewy body disease  (CTV3)  A410. Kuru  A411. Creutzfeldt-Jakob disease  E000. Uncomplicated senile dementia  E001. Presenile dementia  E0010 Uncomplicated presenile dementia  E0011 Presenile dementia with delirium  E0012 Presenile dementia with paranoia  E0013 Presenile dementia with depression  E001z Presenile dementia NOS  E002. Senile dementia with depressive or paranoid features  E0020 Senile dementia with paranoia  E0021 Senile dementia with depression  E002z Senile dementia with depressive or paranoid features NOS  E003. Senile dementia with delirium  E004. Arteriosclerotic dementia (including [multi infarct dement])  E0040 Uncomplicated arteriosclerotic dementia  E0041 Arteriosclerotic dementia with delirium  E0042 Arteriosclerotic dementia with paranoia  E0043 Arteriosclerotic dementia with depression  E004z Arteriosclerotic dementia NOS  E00z. Senile or presenile psychoses NOS  E041. Dementia in conditions EC  Eu00. [X]Dementia in Alzheimer's disease  Eu002 [X]Dementia in Alzheimer's dis, atypical or mixed type  Eu00z [X]Dementia in Alzheimer's disease, unspecified  Eu011 [X]Dementia: [multi-infarct] or [predominantly cortical]  Eu01y [X]Other vascular dementia  Eu01z [X]Vascular dementia, unspecified  Eu02. [X]Dementia in other diseases classified elsewhere  Eu020 [X]Dementia in Pick's disease  Eu021 [X]Dementia in Creutzfeldt-Jakob disease  Eu022 [X]Dementia in Huntington's disease  Eu023 [X]Dementia in Parkinson's disease  Eu02y [X]Dementia in other specified diseases classif elsewhere  F110. Alzheimer's disease  F111. Pick's disease  F11x7 Cerebral degeneration due to Creutzfeldt-Jakob disease  F21y2 Binswanger's disease  Fyu30 [X]Other Alzheimer's disease  X002w Dementia  X002x Dementia in Alzheimer's disease with early onset  X002y Familial Alzheimer's disease of early onset  X002z Non-familial Alzheimer's disease of early onset  X0030 Dementia in Alzheimer's disease with late onset  X0031 Familial Alzheimer's disease of late onset  X0032 Non-familial Alzheimer's disease of late onset  X0033 Focal Alzheimer's disease  X0034 Frontotemporal dementia  X0035 Pick's disease with Pick bodies  X0036 Pick's disease with Pick cells and no Pick bodies  X0037 Frontotemporal degeneration  X0039 Frontal lobe degeneration with motor neurone disease  X003A Lewy body disease  X003G Progressive aphasia in Alzheimer's disease  X003G Progressive aphasia in Alzheimer's disease  X003H Argyrophilic brain disease  X003I Post-traumatic dementia  X003J Punch drunk syndrome  X003K Spongiform encephalopathy  X003L Prion protein disease  X003M Gerstmann-Straussler-Scheinker syndrome  X003N Familial fatal insomnia  X003P Acquired immune deficiency syndrome dementia complex  X003R Vascular dementia of acute onset  X003T Subcortical vascular dementia  X003V Mixed cortical and subcortical vascular dementia  X003W Semantic dementia  X003X Patchy dementia  X003Y Epileptic dementia  X00R2 Senile dementia  Xa0lH Multi-infarct dementia  Xa0sC Frontal lobe degeneration  Xa0sE Dementia of frontal lobe type  Xa1GB Cerebral degeneration presenting primarily with dementia  Xa25J Alcoholic dementia  Xa3ez Other senile/presenile dementia  XaA1S New variant of Creutzfeldt-Jakob disease  XabVp Sporadic Creutzfeldt-Jakob disease  XaE74 Senile dementia of the Lewy body type  XaIKB Alzheimer's disease with early onset  XaIKC Alzheimer's disease with late onset  XaKyY [X]Lewy body dementia  XE1aG Dementia (& [presenile] or [senile])  XE1Xs Vascular dementia  XE1Xt Other senile and presenile organic psychoses  XE1Z6 [X]Unspecified dementia  NHAIS  PRACTICE\_CODE: GP practice identifier  EXTRACT\_DATE: Extract timestamp  AGE\_BAND: Age bands of list size pivoted with values below |
| **3.10 Data filters** | GPES  Only use data for patients aged 65 and over.  Only use PRACTICE-ID listed in reference tables as active GP practices with a total list size > 0  Only aggregate higher organisations from practices with both denominator and numerator data available. |
| **3.11 Justifications of inclusions and exclusions**  and how these adhere to standard definitions | Reference rates are only available for ages 65 and over so only these patient data are used. |
| **3.12 Data processing** | Data are loaded; validated, transformed and released using DME automated and tested jobs in SAS.  Validated data are joined to reference tables and reference rates in SAS Enterprise Guide for calculation (as well as being dual-run in Excel for verification).  GP practices are to be mapped to Local Authorities by postcode of the main practice site mapped to LA. |

Section 4 Construction

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| **4.1 Numerator** | Monthly count of the number of registered patients aged 65+ with a recorded diagnosis of dementia at any point in their clinical history, as of the last day of the month. |
| **4.2 Denominator** | Number of people aged 65+ estimated to have dementia, given the age and sex distribution of the registered patients and the CFAS II reference rates. |
| **4.3 Computation** | 1. Calculate the estimated number of cases of dementia for each organisation (denominator) by applying the age and sex-specific reference rates to the age and sex structure of its population:  Where:  is the estimated value for the subject organisation *k*  is the population (65+ patient list size) for each combination of age band *i* and sex *j* in subject organisation *k*  is the binomial proportion for each combination of age band *i* and sex *j* in the reference population (CFAS II)  2. Calculate the estimated diagnosis rate for each organisation (indicator value) by dividing its observed dementia diagnoses by its estimated value and express this as a percentage:  Where:  is the estimated diagnosis rate for the subject organisation k  is the recorded 65+ dementia diagnoses in the subject organisation k  is the estimated value for the subject organisation k |
| **4.4 Risk adjustment or standardisation type and methodology** | **Indirect Standardisation**  Expected values are calculated by gender & five year age bands (≥65), derived from the analogous stratified prevalence rates calculated in the CFAS II study applied to the actual stratified populations:  Men  65–69 years 1·2% (95% CI: 0·6–2·3)  70–74 years 3·0% (2·0–4·4)  75–79 years 5·2% (3·8–7·0)  80–84 years 10·6% (8·2–13·7)  85–89 years 12·8% (9·0–18·0)  ≥90 years 17·1% (10·6–26·4)  Women  65–69 years 1·8% (0·9–3·6)  70–74 years 2·5% (1·6–3·9)  75–79 years 6·2% (4·5–8·4)  80–84 years 9·5% (7·3–12·3)  85–89 years 18·1% (14·5–22·2)  ≥90 years 35·0% (28·4–42·3)  (Matthews FE, Arthur A, Barnes LE, et al. A two-decade comparison of prevalence of dementia in individuals aged 65 years and older from three geographical areas of England: results of the Cognitive Function and Ageing Study I and II. Lancet. 2013;382(9902):1405-1412. doi:10.1016/S0140-6736(13)61570-6.)  All sub-populations (five year age bands by gender) are non-overlapping.  After summing over age and sex, the ratio of recorded dementia diagnoses to expected gives an indirectly standardised diagnosis rate. |
| **4.5 Justification of risk adjustment type and variables**  or why risk adjustment is not used | A diagnosis rate measures how many patients with a condition have been given a formal diagnosis for the condition. By definition, however, the actual number of patients with the condition is not known, as they do not all have a formal diagnosis. Indirect standardisation allows an estimate to be made of the actual number, by applying standard age and sex specific prevalence rates (the CFAS II prevalence rates) to the age and sex structure of a subject organisation, to give the estimated number of patients one would expect to have the condition if the subject organisation experienced the same age and sex specific rates as those in the CFAS II study.  The same calculation would not be possible using direct standardisation, where a subject organisation’s age and sex specific recorded prevalence rates are applied to the age and sex structure of a standard population, to give the number of recorded diagnoses that would be observed if the standard population experienced the same age and sex specific recorded prevalence as the subject population. As this calculation does not make an estimate of the actual number of patients with the condition, it cannot produce a diagnosis rate.  Direct standardisation is often preferable as it allows comparisons to be made between subject populations, however here it is not possible and indirect standardisation is used with the caveat that no comparisons should be made between subject organisations. |
| **4.6 Confidence interval / control limit use and methodology** | Confidence Intervals  Estimated by simulation. The observed counts are subject to the usual stochastic (random) variation assumptions and are assumed to be observations from an underlying Poisson distribution.  The expected number of cases is calculated as a sum of age-specific expected numbers, each of which is calculated by applying CFAS II published prevalence proportions to the local age-sex specific population. The published proportions have confidence intervals, and these need to be reflected in the confidence intervals for the overall proportion.  Simulation allows us to capture all these separate elements and calculate approximate confidence intervals for the overall indicator: the indicator is calculated 100,000 times. On each repetition, each of the age-specific expected (binomial) distributions, and the observed (Poisson) count distribution, are randomly sampled and the indicator is calculated based on those sampled values. Hence a distribution of 100,000 random samples from the overall indicator distribution is obtained. From this distribution we can take the 2500th smallest and the 2500th largest values as robust estimates of the 95% lower and upper confidence limits respectively.  This is repeated for every organisation in the indicator, every time the indicator is produced.  100,000 repetitions is sufficient to ensure that, to one decimal place, the estimates of the upper and lower confidence limits are robust and replicable.  Please see FILE Dementia Indicator CI MT Macro for a template calculation. |
| **4.7 Justification of confidence intervals / control limits used** | Conventionally, the uncertainty in an indirectly standardised rate is summarised based on the number of observations alone, as the expected values are usually based on such a large population that any uncertainty is considered negligible. Here this is not the case, as the expected values are derived from a relatively small sample (the CFAS II study), comprising 12 reference rates, each with a confidence interval reflecting the uncertainty in the study results. These 12 elements of uncertainty in the denominator, plus one element of uncertainty around the observed count of dementia diagnoses (the numerator), combine to make the statistical distribution underlying the indicator itself (the ratio of observed to expected) too complex to define in a static formula.  By creating theoretical distributions for each of the 13 variables, the indicator can be simulated by repeating the calculation 100,000, each time randomly sampling the variables from their possible distributions of values, such that the overall distribution of the indicator value is closely approximated and can itself be sampled and/or summarised to give the confidence intervals to a limited but defined level of precision. |

Section 5. Presentation and Interpretation

Presentation

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| **5.1 Presentation of indicator** | a)  Values are given at all organisational levels as follows:  table showing number of people with dementia  b)  For the [PHOF](http://www.phoutcomes.info/) and [Dementia Profiles](https://fingertips.phe.org.uk/profile-group/mental-health/profile/dementia), the indicator will be presented using the Fingertips platform, with the same range of presentations as current indicators in those collections. However, because of the indirect standardisation, RAG ratings cannot be applied to comparisons with benchmarks.  <http://www.phoutcomes.info/> and <https://fingertips.phe.org.uk/profile-group/mental-health/profile/dementia>  c)  CCGOIS: CCG OIS would likely signpost to more regularly published data.  d)  In the following format on My NHS:  https://www.nhs.uk/service-search/scorecard/results/1173?metricGroupId=612&radiusInMile=0&recordsPerPage=10 |
| **5.2 Contextual information provided alongside indicator**  with justification | Alongside the indicator value (the rate) is given the number of people on dementia register (numerator) and estimated number of people with dementia (denominator).  A time series of preceding months’ indicator values shows rate of change.  Figures for patient and practice coverage are also given as explained in section 3.4 |
| **5.3 Calculation and data source of contextual information** | Coverage is calculated from the TRUD data on open and active GP practices, the Exeter registered patient list sizes, and the data contained in the GPES extract used in the indicator as follows:  Extracted practices / active practices  Patients registered to extracted practices / patients registered to active practices  Estimated dementia cases in extracted practices / estimated dementia cases in active practices |
| **5.4 Use of bandings, benchmarks or targets**  with justification | Indicator values with robust 95% confidence intervals allow comparison with the benchmark set by NHS England of 66.7% |
| **5.5 Banding, benchmark or target methodology**  if appropriate | Significance is determined using confidence intervals  As this indicator is indirectly standardised, comparisons between values for different areas/organisations cannot be made. Data will be presented in the context of other organisations but won’t be presented as significantly ‘better’ or ‘worse’ than each other. |

Interpretation

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| **5.6 Interpretation guidelines** | The indicator gives the ratio of the actual to estimated number of dementia diagnoses, expressed as a percentage.  Values close to 100 per cent are desirable as they indicate that the observed value is close to the estimated value, indicating by proxy that most people who have dementia have also received a diagnosis.  Indicator values significantly lower than 100 per cent indicate the possible under-diagnosis of dementia whilst values over 100 per cent indicate possible over-diagnosis.  Significance is defined with reference to confidence intervals as follows:  If the confidence interval for an organisation’s rate does not overlap the benchmark, the difference between the two rates is considered to be statistically significant. If the confidence interval for an organisation’s rate does overlap the benchmark, the significance of the difference between the rates is not determined. However, organisation’s’ rates cannot be compared with one another as indirect standardisation does not necessarily preserve the consistency of the populations under comparison. |
| **5.7 Limitations and potential bias** | The indicator is intended to identify areas with a diagnosis rate falling outside of a given range warranting closer investigation. There are many factors that affect the true prevalence and the recorded prevalence of dementia which cannot be factored into the calculation, meaning areas fall into a spectrum of greater or lesser compatability with the CFAS II study findings, themselves based on a limited sample from three areas scaled up to England level. This may be the cause of the sharp increase and decrease at either end of the rate distribution shown in section 5.9. It is important to interpret the indicator accordingly, and also note that the 66.7% benchmark is a national target, which is also monitored at lower levels.The indicator can only report on people aged 65 and over because reference rates are only available for these ages in the CFAS II reference population. CFAS II reference rates are given with confidence intervals expressing the levels of uncertainty involved.  GPES extracts data for practices that were open on the relevant date, that being the last day of the month being reported upon. The GPES extract is not instantaneous; it runs over a number of days known as the “extract window”. Depending on the length of this window, GPES may not manage to collect data for all potential practices. There is, therefore, limited potential for the misreporting of dementia diagnoses. However, the extent of any such problem will be indirectly quantified by the inclusion of the coverage figures (see section 3.4)  The extract only includes practices that are defined as a ‘GP Practice’ in the organisational reference data (TRUD). Practices defined as walk-in centres, out of hours clinics, or prison prescribing cost centres are excluded. As are ‘shared’ and ‘dormant’ GP practices.  Data are only extracted where the diagnosis of dementia is ‘coded’, i.e. a Read/CVT3 code is on the patient record. Some patients may be considered by their GP as having dementia but it could be recorded in free text or could be a scanned letter from an outpatient clinic, for example. This is however one reason why the indicator is needed – not all diagnoses of dementia are formally recorded.  The data for the denominator which is from CFAS II is research based on just 3 areas (each with two sites) in England (Cambridge, Newcastle and Nottingham). However, once adjusted for age, sex education and social class, CFAS finds no heterogeneity between the six sites, implying that although the results can be scaled up to larger populations, there is no implication that the results can be scaled down to smaller areas. In fact, the significant associations listed above would imply this should not be done. The original cohort consisted of 7,796 people. The smallest organisation in the indicator is larger than this. |
| **5.8 Improvement actions** | Practices can increase their diagnosis rate by converting existing informal diagnoses into clinically coded recorded diagnoses, and by identifying patients at risk of dementia with the dementia toolkit: <https://toolkit.modem-dementia.org.uk/> |
| **5.9 Evidence of variability** | The indicator values for December 2016 shows 47 CCGs significantly higher than the target rate of 66.7% and 21 significantly lower:  Graph showing variability of diagnosis rate for CCGS |

Section 6. Risks

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| **6.1 Similar existing indicators** | E.A.S.1: Estimated diagnosis rate for people with dementia and the CCG IAF indicator are currently published using a different methodology, however these will be replaced by the new indicator. This is likely to report changes to the diagnosis rates for two reasons:  1. Not everyone registered to a GP lives near to it, and not everyone living near a GP is registerd to it. The change will therefore have different effects on areas with different registration characteristics, for example university towns or areas with high emigration rates. This effect is nevertheless reduced by the focus on ages 65+ and serves to ensure the numerator and denominator are taken from the same population.  2. Expected numbers of people with dementia will not take into account people registered to practices for which no diagnostic data are received. This will mitigate the deflation of diagnosis rates caused by dividing an incomplete numerator by a complete residence-based denominator.  NHS Outcomes Framework 2.6.i Estimated diagnosis rate for people with dementia also used a different methodology, however is not currently being updated. The methodology will be reviewed pending the outcome of assurance. |
| **6.2 Coherence and comparability** | NHS Outcomes Framework 2.6.i Estimated diagnosis rate for people with dementia used annual QOF data as the numerator (total number of people diagnosed with dementia according to GP records) and the Dementia UK 2007 report estimated diagnosis (total number of people estimated to have dementia) as the denominator.  CFAS II is the best available research to base the indicator on as has the most scientific, well documented and transparent methodology including well documented survey techniques, consideration of bias and use of confidence intervals to describe uncertainty in the data.  The use of CFAS II by NHS England and Public Health England also brings consistency and comparability of results and CFAS II support use of their prevalence data in local planning (as stated in their research). |
| **6.3 Undesired behaviours and/or gaming** | Until recently, a financial incentive was paid to GPs for each new diagnosis of dementia. The cessation of these payments now makes gaming less likely; however it could be argued that over-diagnosis of marginal cases could occur in order for the expected prevalence rate to be met, especially if political pressure is put on GPs via NHS England; or vice versa to under-diagnose where a benchmarked rate is already attained. It is also possible that any over-diagnosis that occurred during the incentive period has a residual effect due to this indicator being based on recorded prevalence, not incidence, of dementia. |
| **6.4 Approach to indicator review** | Indicator will be reviewed annually by NHS Digital coinciding with each potential recommissioning of the data collection underpinning to consider whether the methodology is still appropriate to any changes in policy. |
| **6.5 Disclosure control** | All raw data are publicly available at GP practice level, no further disclosure risk is added in the creation of the indicator. |
| **6.6 Copyright** | Copyright ©2017 Health and Social Care Information Centre  The Health and Social Care Information Centre is a non-departmental body created by statute, also known as NHS Digital.  © 2013 MRC CFAS |

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| Symbol for Indicator Governance Board |
| Indicator Assurance Report |
| **Dementia: 65+ Estimated Diagnosis Rate** |
| **IAP00427** |



**Final Assurance Rating from the Indicator Governance Board - Click here to enter date**

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| --- | --- |
| **Reason for assessment** |  |
| **Iteration** |  |

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| --- | --- |
| **Ratings Against Assessment Criteria** |  |
| Clarity |  |
| Rationale |  |
| Data |  |
| Construction |  |
| Presentation and Interpretation |  |
| Risks and Usefulness |  |
| **Overall Rating** | Choose an item. |

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| **Outcome** | Choose an item. |

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| **Key findings from Assurance** |
| * Key finding 1 * Key finding 2 * Key finding 3 |

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| **Approval date** | Click here to enter a date. |
| **Review date** | Click here to enter a date. |

**Details of Methodology Appraisal – 26/01/2017**

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| **Methodology appraisal body** | Indicator & Methodology Assurance Service |
| **Reason for assessment** | Initial assurance |
| **Iteration** | 3rd MRG meeting\* |

\*This indicator was previously discussed at MRG in 2015 – records of these discussions can be found in the repository.

***Suggested Assurance Rating by Methodology Appraisal Body***

|  |  |
| --- | --- |
| **Ratings Against Assessment Criteria** |  |
| Clarity | **Fit for use** |
| Rationale | **Fit for use** |
| Data | **Fit for use with caveats** |
| Construction | **Fit for use** |
| Presentation and Interpretation | **Fit for use** |
| Risks and Usefulness | **Fit for use with caveats** |
| **Overall Rating** | **Fit for use with caveats** |

**Summary Recommendation to Applicant:**

MRG would like to thank the applicants for submitting a good quality application to the group for consideration. On the basis that updates are made to the paperwork to ensure all the methodology is transparent and justified fully, the group are pleased to give the indicator a rating of “Fit for use with caveats” and recommend to IGB that it is included in the National Library of Quality Assured Indicators. They are assuring the indicator based on the following:

* That it is not used for performance management purposes, including financial incentives. The indicator should rather be used as a flag for further investigation and improvements.
* That it is not reported at any lower level than CCG, including GP practice level.
* Any framework already publishing an indicator value make it clear to users that the figures produced by the old methodology are not comparable with the new methodology figures.

**Summary Recommendation to IGB:**

MRG would like to recommend that the indicator is included in the Library of Quality Assured Indicators with the rating “Fit for use with caveats”. These caveats being:

* The estimated dementia prevalence is based on the CFAS II study which has a small sample size. It is acknowledged that this is currently the best prevalence estimates available, however the indicator should be interpreted with caution given that these prevalence estimates from three areas of England have been used to estimate prevalence for all areas in England.
* That CFAS II measured the prevalence of dementia in a set point in time and will increasingly become out of date.

MRG are providing this provisional assurance rating also based on the following:

* That this indicator is not used for performance management purposes, including financial incentives. The indicator should rather be used as a flag for further investigation and improvements.
* That it is not reported at any lower level than CCG, including GP practice level.
* Any framework already publishing an indicator value make it clear to users that the figures produced by the old methodology are not comparable with the new methodology figures.

**Please find a detailed description of recommendations and actions in the appraisal log at the end of the document.**

**What do the Assurance Ratings mean?**

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| **Rating** | **Description** |
| **Fit for use** | This indicator can be used with confidence that it is constructed in a sound manner that is fit for purpose. |
| **Fit for use with caveats** | The indicator is fit for use, however users should be aware of caveats and/or recommendations for improvement that have been identified during the assurance process. |
| **Use with caution – data quality issue** | The indicator is based on a sound methodology for which the assurance process endorse the use, however issues have been identified with the national data source which have implications for its use as an indicator. |
| **Not fit for use** | Issues have been identified with the indicator which have resulted in the assurance process currently not endorsing its use as a quality indicator. |
| **Not enough information provided** | There has not been enough information supplied to the assurance process to be able to accurately give the indicator a level of assurance. |

**Appraisal Log**

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| **Clarity** |

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| ***Rec. no*** | ***Issue or recommendation*** | ***Raised by / Date*** | ***Response or Action taken by applicant*** | ***Response date*** | ***Resolved*** | ***Sign off by / Date*** |

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| No issues or recommendations to date. |

Rationale

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| ***Rec. no*** | ***Issue or recommendation*** | ***Raised by / Date*** | ***Response or Action taken by applicant*** | ***Response date*** | ***Resolved*** | ***Sign off by / Date*** |
| 2a | MRG are of the opinion that this indicator is not robust enough for the purpose of performance management. Therefore, it is recommended that NHS England reconsider the wording of their purpose (for EAS 1) to ensure it is only used for improving dementia diagnosis rates. | 26/01/2017 | Amended as per recommendation | 30/01/2017 |  |  |
| 2b | In section 2.4 second paragraph: the increase should be *to* two-thirds, rather than *by* two-thirds. | 26/01/2017 | Corrected as per recommendation | 30/01/2017 |  |  |
| 2c | Please reconsider the wording around the graph presented in the purpose (section 2.1) as it is unclear as to whether this drop in dementia prevalence can be attributed to the cessation of monitoring. | 26/01/2017 | Graph and wording removed | 30/01/2017 |  |  |

Data

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| --- | --- | --- | --- | --- | --- | --- |
| ***Rec. no*** | ***Issue or recommendation*** | ***Raised by / Date*** | ***Response or Action taken by applicant*** | ***Response date*** | ***Resolved*** | ***Sign off by / Date*** |
| 3a | The main caveat associated with this indicator is that the estimated dementia prevalence is based on the CFAS II study which has a small sample size. It is acknowledged that this is currently the best prevalence estimate available, however the indicator should be interpreted with caution given three areas of England have been used to estimate prevalence for all areas in England. | 26/01/2017 | Added in section 5.7 Limitations and Potential bias | 30/01/2017 |  |  |
| 3b | In section 3.4 (Data Quality) it should be acknowledged that CFAS II measured the prevalence of dementia in a set point in time and will increasingly become out of date. Any plans to update the prevalence estimates should be documented. | 26/01/2017 | Added as per recommendation | 30/01/2017 |  |  |
| 3c | Please supply a comprehensive list of estimations of dementia prevalence in section 3.2 as there are more available than the two currently stated. | 26/01/2017 | Added as per recommendation | 30/01/2017 |  |  |
| 3d | Sections 3.2 and 3.4 both refer to the Alzheimer’s Society Dementia UK report, but 3.2 refers to one in 2007 while 3.4 refers to one in 2014. For consistency both should refer to the same year. If 2014, then the listed benefit of the CFAS II prevalence estimates being more recent should be removed. | 26/01/2017 | Amended as per recommendation | 30/01/2017 |  |  |
| 3e | Please ensure that all acronyms used in the application form are defined. For example, RID in section 3.10 and NIACS in section 3.7. | 26/01/2017 | Amended as per recommendation | 30/01/2017 |  |  |
| 3f | For completeness, it is recommended to state that Type 1 objections do not apply to this indicator as the data extraction is an aggregate count (and type 1 objections only apply to patient-level extractions). | 26/01/2017 | Added as per recommendation | 30/01/2017 |  |  |
| 3g | Please make clear under timeliness in Data Quality (Section 3.4) that although some of the frameworks will be able to process and publish the data within 2 weeks of real time, this will not be the case for others (such as the CCG OIS). | 26/01/2017 | Added as per recommendation | 30/01/2017 |  |  |
| 3h | Please provide more details regarding the assurance of the data fields. The verbal update given during the meeting covering that they are based on QOF definitions and undergo a checking process as part of this should be documented. | 26/01/2017 | Added as per recommendation | 30/01/2017 |  |  |

Construction

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| ***Rec. no*** | ***Issue or recommendation*** | ***Raised by / Date*** | ***Response or Action taken by applicant*** | ***Response date*** | ***Resolved*** | ***Sign off by / Date*** |
| 4a | Please change the wording of the numerator and denominator to include that both are based on the registered population. In addition, please amend the denominator from reading “given the characteristics of the population” to “given the age and sex distribution of the population”. | 26/01/2017 | Amended as per recommendation | 30/01/2017 |  |  |
| 4b | Please justify the use of indirect standardisation within the application form. | 26/01/2017 | Amended as per recommendation | 30/01/2017 |  |  |
| 4c | Please provide the rationale for the confidence interval methodology, e.g. why a simulation method was chosen rather than using the confidence intervals supplied by the CFAS II study. | 26/01/2017 | Expanded as per recommendation | 30/01/2017 |  |  |
| 4d | As the paperwork currently stands, it would not be possible to replicate the confidence interval methodology. It was decided during the MRG that the easiest and most understandable way to supply this information would be to publish a spreadsheet with the calculation alongside the application form. | 26/01/2017 | An Excel / VBA template exists which can be supplied with the form (attached). | 30/01/2017 |  |  |

**Presentation and Interpretation**

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| ***Rec. no*** | ***Issue or recommendation*** | ***Raised by / Date*** | ***Response or Action taken by applicant*** | ***Response date*** | ***Resolved*** | ***Sign off by / Date*** |
| 5a | In section 5.6, it states that there will be confidence intervals for the benchmark however this will not be the case. Therefore, please amend. | 26/01/2017 | Amended as per recommendation | 30/01/2017 |  |  |
| 5b | MRG suggest that providing age and sex breakdowns as part of the presentation may be useful for users. | 26/01/2017 | Publication of more granular diagnosis data would be subject to further approvals regarding disclosivity of data and will be pursued but may not be possible. | 30/01/2017 |  |  |
| 5c | Update 5.6 to make clear that due to the indirect standardisation used in this methodology, CCGs should only be compared to the national benchmark not eachother. Therefore, comments about overlapping confidence intervals should be removed. | 26/01/2017 | Amended as per recommendation | 30/01/2017 |  |  |
| 5d | In the interpretation, it is worth stating that the study estimates of dementia prevalence may not be applicable to all areas of England. This could be the reason why in section 5.9 (Evidence of variability) there is a sharp increase and decrease at either end of the estimated diagnosis rate distribution by CCG. | 26/01/2017 | Amended as per recommendation | 30/01/2017 |  |  |

**Risks and Usefulness**

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| ***Rec. no*** | ***Issue or recommendation*** | ***Raised by / Date*** | ***Response or Action taken by applicant*** | ***Response date*** | ***Resolved*** | ***Sign off by / Date*** |
| 6a | In section 6.1, the information discusses the effect of the change in methodology. This should read “This is likely to *report* a decrease in diagnosis rate “ rather than “This is likely to *cause* a decrease in diagnosis rate” | 26/01/2017 | Amended as per recommendation | 30/01/2017 |  |  |
| 6b | In 6.3 it should be pointed out that due to previous incentivisation of dementia diagnoses there may be residual effects of potential over-diagnosis (gaming). | 26/01/2017 | Added as per recommendation | 30/01/2017 |  |  |
| 6c | Section 6.6 (Copyright) should acknowledge CFAS II. | 26/01/2017 | Added as per recommendation | 30/01/2017 |  |  |

**Any complaints or appeals against the decisions made during the assurance process should be made to the Indicator & Methodology Assurance Service (IMAS) Team at NHS Digital. Likewise, if you are unclear regarding any of the recommendations in this report, or have any queries about the assurance process in general, please contact the IMAS team.**

**Indicator and Methodology Assurance Service**

**NHS Digital**

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