



# Current UK clinical practice in diagnosing dementia in younger adults: compliance with quality indicators in electronic health records from mental health trusts

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## ABSTRACT

**Objectives:** To examine current UK practice in diagnosis of patients under 65 with young onset dementia, within 5 years of date of diagnosis, identified from electronic health records of 8 NHS mental health trusts.

**Methods:** Patients diagnosed with young onset dementia were assembled from the UK-Clinical Record Interactive System, (UK-CRIS) using diagnosis of dementia as the index date. A pre-designed proforma, derived by international Delphi consensus from experts in the field in previous work, was used to assess components of the diagnostic assessment in 402 electronic health records across 8 NHS sites. Information was extracted on key aspects of clinical and physical examination according to both a minimum and gold standard.

**Results:** Percentage compliance rates analysed by NHS site and statement, including compliance for site for minimum standard (11 statements), the additional 20 statements required for Gold standard, and the complete Gold standard set (31 statements) show that the additional 20 statements in the Gold standard had consistently higher compliance rates for every site compared to the minimum set.

**Conclusion:** Findings confirmed variation in clinical practice and identified commonly missed items in examination and enquiry compared to expert consensus. This suggests that a template proforma, which contains the key indicators for comprehensive assessment of dementia in young adults according to a quality standard could help support clinicians to improve record keeping and reduce gaps in knowledge.

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## Introduction

Young onset dementia (YOD) refers to dementia diagnosed in those aged 65 years and under. YOD is poorly recognised and often misdiagnosed (Konijnenberg et al., 2017; Salem et al., 2014) because presenting symptoms are complex, conditions are heterogenous in presentation and atypical compared to those of late onset disease (LOD). Alzheimer's disease is common in YOD, accounting for a third of cases, but presentation is frequently atypical characterised by non-memory impairment, such as language, visuo-spatial, executive, behavioural or motor-led dysfunction (Graff-Radford et al, 2021, O'Malley et al, 2019, Koedam et al 2010). Frontotemporal dementia is more frequent, characterised by behavioural changes, for example inappropriate social interactions, lack of empathy, poor motivation, and reduced insight which can delay help-seeking (Kuruppu & Matthews 2013, Draper et al, 2016). Alcohol-related dementia and HIV-associated cognitive impairment require multidisciplinary and multi-agency approaches (Rao & Draper, 2018, Underwood & Winston, 2016).

Significant delays can arise in time to diagnosis from GP referral depending on service type (Hussey & Butler, 2019).

Many younger people in the UK continue to be assessed and diagnosed in memory services where there is typically limited access to other multidisciplinary professionals (Rodda & Carter, 2016). Clear evidence about the best practice approach to diagnosis is lacking. This raises concern as many dementia and memory clinics continue to employ routine procedures, screening measures and cognitive tests tailored to older patients that are often insufficient to identify the complexity of presentation in YOD and result in under-investigation with limited use of crucial supplementary investigations. Indeed, evidence suggests that under-investigation is particularly common in non-specialist settings (Eriksson et al., 2014). Providing individuals with an accurate diagnosis allows them and their families access to suitable treatments, support and research opportunities. Timely diagnosis and improved recognition were rated by those with YOD as the highest priority for service improvement, placing it above post-diagnostic support (Armari, Jarmolowicz, & Panegyres, 2013).

A UK-based study, called The Angela Project, has focused on developing guidance on best practice in diagnosis of dementia in younger adults. The Angela Project included an international Delphi study with secondary care clinical experts

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(O'Malley, Parkes, Stamou, et al., 2020a) to establish the key indicators for comprehensive assessment of dementia in this patient group. The resulting consensus created two standards, a minimum standard and gold standard, which have provided a template for assessing the UK clinical practice in the current study. A knowledge exchange event was also conducted with the participating NHS Trust clinical leads to understand further common gaps in enquiry.

Our objectives were to identify differences in compliance with the minimum and gold standard a) at and between sites b) with dementia subtypes and c) to investigate possible explanations for commonly missed items of enquiry and examination

## Materials and methods

### Study setting and data source

To undertake the audit, the platform UK-CRIS (UK-Clinical Record Interactive System) through the CRIS Network, was utilised. The data for the study was extracted using the CRIS application, which renders anonymised data from over two million electronic health records (EHR) for use for research and audit purposes (<https://crisnetwork.co>). The CRIS data have been extensively supplemented through natural language processing applications using Generalised Architecture for Text Engineering software which apply information extraction techniques allowing users to derive structured information from the text fields held in mental health records (Perera et al., 2016). This methodology was employed across the EHR from eight separate Trusts in England from both rural and urban locations.

**Ethics** The Angela Project was approved by the Health Research Authority in England and by the South Central Berkshire Research Ethics Committee (REC ref 17/SC/0296). At each UK-CRIS site, a governance process with the CRIS oversight committee took place, to review the project as a CRIS-specific project and to agree to participation.

**Sample** All patients aged 65 years or younger who had received a diagnosis of dementia were identified from eight NHS trusts between September 2018 and November 2019. The date of the first recorded diagnosis before the age of 65 served as the index date for the retrospective search for the quality indicators. Patient records were excluded if it was apparent that the person was diagnosed later than 5 years ago (before 2014), if an individual was diagnosed in another NHS Trust and had since moved, so diagnostic information was not present in the files and if diagnostic information was in an associated, attached letter that the research team were unable to access. Patient data were denoted by a unique and stable pseudonym, (BRC\_ID), consisting of a randomly generated string of characters to exclude use of any personally identifiable information from the patient records. Each individual entry record also included a document BRC\_ID. These IDs do not allow researchers to identify specific patients and cannot be linked to the patient's NHS number or individual Trust ID.

### Quality indicators

Information was extracted relating to thirty-one key indicators from text fields of CRIS EHR of 402 anonymised patients with a diagnosis of dementia under the age of 65. Demographic data including gender, age at diagnosis, dementia type and time since diagnosis were also collected. The thirty-one indicators,

highlighting key components of the comprehensive assessment of dementia in young adults were derived from an international Delphi study with expert secondary care clinicians in the field of young onset dementia. The Delphi study resulted in two standards that experts deemed as critical and essential. The minimum standards represent red flag indicators that were rated by all experts in the Delphi study as being absolutely essential or very important to diagnosis. The gold standard consists of a more comprehensive list of indicators that were rated as very important or absolutely essential by at least 80% of experts in the Delphi study.

Upon review, four statements from the original minimum and gold standards were deemed unascertainable from the free text case notes and others which had commonality were combined into one statement as indicated in Appendix 2. Some exceptions were made to the original scoring schedule.

For some indicators an intermediate score of 0.5 was assigned as indicated below

- ACE-III – if the clinician used another screening tool, such as the Montreal Cognitive Assessment (MoCA) or Rowland Universal Dementia Assessment Scale (RUDAS) and provided appropriate reasons for using it, this was scored as 1.
- MRI as initial assessment – if there was a contra-indication to MRI e.g. metal implants/pacemaker obesity or claustrophobia, then this was scored as 0.5

For complete list of 31 indicators see [table 5](#) in results section

### Data extraction

The key indicators were scored as present (1) or absent (0) in the text record according to a final template ([Table 1](#)).

Information about the quality indicators was extracted from the EHR, primarily from unstructured free text case notes. No access was available to correspondence or investigations reported elsewhere unless recorded in the clinical notes.

### Data collection

Data collection took place directly through an on-site NHS device, and through the virtual desktop interface (VDI). The pilot phase of the audit took place between September 2018 and January 2019. During this pilot phase period the query and search terms were refined. Data collection from all eight sites took place between January 2019 and November 2019.

### Stage 1

A Structured Query Language (SQL) script was inputted into the local SQL client of UK-CRIS to produce a list of anonymised identifier codes for the patient records that met our inclusion and exclusion criteria. The SQL output also provided demographic information from the anonymised patient records.

### Stage 2

The web client of UK-CRIS interrogates the anonymised patient records using key text terms for each of the indicators which are automatically highlighted to aid identification (see [Table 1](#) for key terms). Only EHR records from patients referred to and diagnosed in memory or cognitive disorders clinics in mental health trusts were included in the audit, to ensure the findings reflected the usual Trust care pathway.

**Table 1.** Minimum and Gold Standards that have been transformed into indicators. Please see the table below for more details, key words, and scoring information:

| Statement 100%                    | Official Statement   | Minimum Standard Statements   |   |                   |
|-----------------------------------|--|---|---|-------------------|
|                                   |  | Key words for search query  | Types of Questions  | Scoring           |
| Collateral history                | To ask an informant (e.g. wife/ husband) for a collateral history  | INFORMANT/corroborative/<br>Collateral hx<br>/corroboration/third party/witness/wife<br>concerned/husband concerned/seen with   | Yes/no<br>Has a clinician spoken to an informant<br>for a collateral history?   | 0 or 1            |
| Symptom type and<br>mode of onset | To understand the symptom type<br>and the mode of onset  | Symptoms/mode of onset/symptom profile/<br>chronology/progression   | Yes/no<br>Have symptoms been investigated or<br>described?  | 0 or 1            |
| More info about<br>(FTD criteria) | To ask for information about loss of<br>sympathy/empathy towards<br>others, disinhibited behaviour,<br>change in food preferences and<br>changes in personality              | Disinhibition/sweet foods/personality/<br>over-familiar/empathy<br>OR function for each of these?   | Yes/no<br>Has the clinician asked about loss of<br>sympathy/empathy towards others,<br>disinhibited behaviour, change in<br>food preferences and changes in<br>personality? | 0 or 1            |
| Physical health                   | To enquire about changes in<br>physical health   |   | Yes/no<br>Have there been any changes in physical<br>health?  | 0 or 1            |
| Full medical history              | To have a full medical history<br>(including cardiovascular history)   | Medical history/ Med Hx/cardiovascular risk/<br>CV risk/ CVS  | Yes/no<br>Has a medical history been taken?   | 0 or 1            |
| ADL                               | If there have been any changes in<br>activities of daily living  | ADL/activities daily living/<br>i.e. comments on ability to drive, make meals,<br>pay bills, wash and dress etc   | Yes/no<br>Has there been a change in ADL?   | 0 or 1            |
| Behaviour change                  | To ask about changes in behaviour  | Behaviour change<br>meaning e.g. verbal or physical aggressive,<br>acting out of character  | Yes/no<br>Have there been changes in behaviour?   | 0 or 1            |
| First degree relative<br>with YOD | To ask if a first degree relative has<br>had young onset dementia  | FHx dementia/FHx YOD<br>FHx EOD/POSITIVE Fhx<br>Genetic testing/genetic mutation  | Yes/ partially /no<br>Has the clinician asked if the patient has<br>a first degree relative with YOD?   | 0<br>0.5<br>or 1  |
| Praxis                            | Neurological Assessment –<br>Praxis  | Praxis  | Yes/no<br>Has Praxis been assessed?   | 0 or 1            |
| Parkinsonism                      | Neurological Assessment –<br>Parkinsonism  | Parkinsonism OR EPSE  | Yes/no<br>Have Parkinsonism OR EPSE been<br>explored?   | 0 or 1            |
| Rapport                           | Establishing rapport to enable open<br>reporting of symptoms   | Rapport   | Yes/partially /no<br>Has the clinician established a rapport/<br>relationship with the patient?   | 0,<br>0.5<br>or 1 |
| <b>Statement</b>                  | <b>Official Statement</b>  | <b>Gold Standard Statements</b><br><b>Possible Key word for search query</b>  | <b>Types of Questions</b>   | <b>Scoring</b>    |
| Neurological<br>symptoms          | To assess neurological symptoms,<br>including Eye movements,<br>Cerebellar signs<br>Tongue or limb fasciculation<br>Frontal signs<br>Extrapyramidal features<br>Motor Skills | all neurological symptoms listed verbatim.<br>motor symptoms/fasciculation/frontal signs<br>or frontal release signs<br>Could include weakness, gait, tremor, or<br>absence of abnormal movements | Yes/no<br>Have neurological symptoms been<br>reported and noted?  | 0 or 1            |
| Alcohol history                   | To take an alcohol history   | Alcohol/etoh/ETOH/ substance misuse   | Yes/no<br>Has the clinician asked/explored the<br>patient's alcohol history?  | 0 or 1            |
| Drug history                      | To take a drug history   | Drugs/illicit drugs/ substance misuse   | Yes/no<br>Has the clinician asked/explored the<br>patient's illicit drug history?   | 0 or 1            |
| Risks                             | To evaluate risks, for example<br>driving or in the workplace  | Risk assessment<br>Risk/s/safety/driving/ fire/wandering/<br>Exploitation/<br>financial abuse   | Yes/no<br>Has the clinician evaluated the patient's<br>risks, for example driving or in their<br>place of work or home  | 0 or 1            |
| Structural imaging                | To conduct baseline structural<br>neuroimaging   | CT/MRI<br>Structural imaging<br>MRI brain<br>MRI Head<br>Dementia protocol<br>MRI atrophy<br>MTA atrophy<br>CT/MRI/MTA atrophy/ protocol/ structural<br>imaging                                   | Yes/no<br>Has baseline structural neuroimaging<br>been done   | 0 or 1            |
| Mood                              | To exclude symptoms of mood<br>disorder  | Depression/low mood<br>geriatric depression scale/GDS/<br>mood inventory/dishevelled appearance/<br>anhedonia/affective disorder/ Formal<br>mood inventory/mood screening                         | Yes/no<br>Has the clinician mentioned symptoms<br>of a mood disorder or indicated their<br>absence?   | 0 or 1            |
| Psychosis                         | To exclude psychotic symptoms  | Psychosis/hallucinations/NPI/psychotic/<br>organic psychosis<br>Perceptions, abnormal beliefs, delusions, VH<br>– visual hallucinations   | Yes/no<br>Has the clinician asked about psychotic<br>symptoms?  | 0 or 1            |
| Medical conditions                | To consider previous medical<br>conditions   | Medical history<br>If you can see that the patients' other<br>conditions have been noted in the<br>assessment or it states that there are no<br>other conditions.                                 | Yes/no<br>Have previous medical conditions been<br>asked about or absence indicated (e.g.<br>no significant medical history/hx)   | 0 or 1            |

(Continued)

**Table 1.** (Continued)

|  |  |   |  |                   |
|--|--|---|--|-------------------|
| Past psychiatric symptoms                | Ask about past psychiatric symptoms  | Search psychiatric/psychiatrist/<br>Past psychiatric hx/PPH<br>Mental health<br>They have noted that the patient has had depression or another psychiatric symptom/condition.   | Yes/no<br>Has the clinician asked about past psychiatric history/symptoms?<br>Abbreviations Eg hx bipolar affective disorder - BAD, Sz schizophrenia                                   | 0 or 1            |
| Physical examination                     | To conduct a physical examination  | PE or physical examination<br>This includes ECG, checking blood pressure, pulse or comments on chest/heart sounds etc   | Yes/no<br>Has the clinician conducted a physical examination?  | 0 or 1            |
| Sleep                                    | To ask about sleep   | Sleep   | Yes/no<br>Has the clinician asked about sleep?   | 0 or 1            |
| Three generation history                 | To obtain a three-generation history of young onset dementia from the patient  | Family tree/genetic/3 generation/maternal/paternal<br>? use of symbols??  | Yes/no<br>Has a three-generation history of YOD been taken from the patient?   | 0 or 1            |
| MRI is initial investigation             | MRI should be the initial imaging investigation  | MRI – to determine if first imaging done. If MRI was the first imaging done, rather than a CT.  | Yes/partially/no<br>Was MRI the initial imaging investigation undertaken?  | 0,<br>0.5<br>or 1 |
| ACE-III                                  | The profile of results is important on the ACE-III   | ACE-III or depending on circumstance – MoCA or RUDAS or other screening tool.<br>If the clinician has used another screening tool, such as the MoCA or RUDAS and have provided their reasons for using it (see below for more info) | Yes/no<br>Has the pattern/profile of the ACE-III scores been discussed rather than just including the score itself?  | 0 or 1            |
| MRI                                      | MRI dementia protocol incorporating T1, T2 and Flair images  | Term dementia protocol with MRI<br>T1, T2 and Flair images  | Yes/no<br>Has the MRI protocol incorporating T1 and Flair images been included?  | 0 or 1            |
| Counselling                              | The assessment should start with counselling to ascertain what patient and supporters require  | Pre-diagnostic counselling<br>Or diagnostic counselling   | Did the assessment start with counselling to ascertain what the patient and supporters/carer understanding is of the procedure and what information they may receive e.g. a diagnosis? | 0 or 1            |
| History of LD                            | Establish if there is a known history of learning disability   | LD/Downs syndrome/Down syndrome/<br>learning disability/trisomy 21  | Has the clinician established if there is a known history of learning difficulties?  | 0 or 1            |
| Mental state examination                 | To include a mental state examination  | MSE or mental state.<br>Usually starts with comments on appearance and behaviour, comments on speech and then mood, e.g. Euthymic, dysthymic, thought content, and abnormal beliefs and perceptions                                 | Has a mental state examination been conducted?   | 0 or 1            |
| ACE-III use for cognitive profile        | An ACE-III is useful to understand the cognitive profile<br>Patterns of cognitive deficits provide clues to disease aetiology on the ACE-III | ACE-III or ACE-III with pattern/profile/<br>domains/deficits  | Has the ACE-III been conducted?<br>And is the breakdown of results on each section given e.g. language, memory, attention, visuospatial skills – usually scored out of 100             | 0 or 1            |
| Screening and neuropsychological testing | Detailed neuropsychology testing should be considered if there is under performance on screening measures                                    | Neuropsychology +/- assessment/testing<br>Neuropsychology and ACE-3<br>Neuropsychology and MOCA<br>“Neuropsychology”  | Yes/no<br>Has detailed neuropsychological testing been considered or conducted if there has been under performance/low scores on screening tools (i.e. the ACE-3)?                     | 0 or 1            |

### Stage 3

A scoring proforma containing the minimum and gold standard indicators was prepared. The authors (MOM, JC) manually read through the records and used the proforma to score whether each indicator was met. Records were read retrospectively from date of confirmed diagnosis to point of referral. Only information available on the UK-CRIS platform was used when conducting the audit.

### Statistical analysis

IBM SPSS v26 software was used in all statistical analyses. The threshold for null hypothesis significance testing was taken as  $p=0.05$ .

**Sample size.** The sample size calculation was based on the requirement to estimate the compliance rate for each standard to within  $\pm 5\%$  (95% confidence intervals). As there was no *a priori* information relating to the expected compliance estimates, the most conservative value of 50% was taken. Observed compliance rates greater or smaller than 50% will have smaller confidence intervals.

### Inter-rater reliability

Two raters independently extracted the data and scored the standards for the first 50 records examined. As the selected two raters constituted a fixed effect and they each rated all of the random selection of 50 records (random effect), a two-way, mixed effects Intraclass Correlation Coefficient (ICC(3,1) (Shrout & Fleiss, 1979) absolute agreement) was used to assess overall agreement. This showed good to excellent reliability for both the gold (ICC = 0.851 (95%CI 0.751-0.912) and minimum (ICC = 0.858 (95% CI 0.763-0.917) standards with the residuals evenly distributed above and below the line of equal scores. Agreement between the two raters for each of the 31 items was analysed using a weighted Kappa coefficient. The mean weighted Kappa scores for all 31 items was 0.77 (sd = 0.15) and the lowest percentage agreement was 92%, indicating good consistency in the scoring between the two raters. The remaining records were therefore scored by one of the raters.

### Tests of normality

Kolmogorov-Smirnov tests of normality indicated strong evidence for non-normality for both compliance percentages for

the minimum standard ( $D(403) = 0.128, p' < .001$ ), and the gold standard ( $D(403) = 0.063, p < .001$ ), therefore non-parametric tests were used.

### Analysis of variation in compliance across groups

Independent-samples median tests (k-groups) were performed to examine compliance with the minimum standard at each of the sites. If the omnibus test showed a statistically significant difference, then pairwise comparison between sites, adjusted for multiple comparisons (28 comparisons), were conducted using a Bonferroni correction. Multiple regression analysis was used to investigate associations between the compliance rates and age, gender, years since diagnosis and diagnosis group (AD (including mixed dementia), Vascular dementia, Dementia in Pick's disease, Other).

## Results

### Characteristics of cohort

A total of 402 records from the eight sites met the inclusion criteria and were included in the audit. Appendix 3 highlights the number of records collected from each of the sites.

### Descriptive demographics

Demographic variables collected included gender, age, numbers of years since diagnosis, time from referral to service to diagnosis and dementia subtype as indicated by clinician-assigned ICD codes (see Tables 2 and 3).

Percentage compliance rates analysed by site and statement, including compliance for site for minimum standard (11 statements), the additional 20 statements required for Gold standard, and the complete Gold standard set (31 statements) were calculated (Table 4 see below).

**Diagnosis Subtypes:** 18 different ICD-10 codes were identified by the SQL query and 14 different dementia subtypes (See appendix 1 for the breakdown). For the purpose of the analysis, diagnoses were group into one of four broad categories: Alzheimer's disease (including mixed dementia), Vascular dementia, Dementia in Pick's disease and 'Other'

**Table 2.** Descriptive demographics from the 402 audited records (across all sites).

| Variables (Across all sites) | Frequency (%)                        | Median (inter-quartile range) |
|------------------------------|--------------------------------------|-------------------------------|
| Gender                       | 193 Female (48.0%); 209 Male (52.0%) |                               |
| Age                          |                                      | 61 years (58-64)              |
| Time since diagnosis:        |                                      | 2 years (2-4)                 |
| Diagnosis type:              |                                      |                               |
| Alzheimer's disease          | 272 (67.7%)                          |                               |
| Vascular dementia            | 83 (20.6%)                           |                               |
| Dementia in Pick's disease   | 33 (8.2%)                            |                               |
| Other                        | 14 (3.5%)                            |                               |

**Table 3.** Number of days from referral to diagnosis (all sites).

| No. of days to diagnosis | Diagnosis group            | Median (inter-quartile range) |
|--------------------------|----------------------------|-------------------------------|
|                          | Alzheimer's disease        | 155 days (58 – 389.5)         |
|                          | Vascular dementia          | 117 days (51 – 384)           |
|                          | Dementia in Pick's disease | 154 days (78 – 344)           |
|                          | Other                      | 117 (40 – 397)                |

### Variation in percentage compliance with minimum and gold standard between sites

Minimum standard: Independent-Samples Median tests showed that there were statistically significant differences ( $p < .05$ ) between three pairs of sites: site E had lower Minimum Standard compliance than Site D ( $p_{adj} = .032$ , effect size  $r = 0.31$ , small) and Site G ( $p_{adj} = .001$ ,  $r = 0.55$ , large), and Site C's compliance was lower than Site G ( $p_{adj} = .016$ ,  $r = 0.34$ , small).

**Gold standard:** There were statistically significant differences between some sites; site E has lower median compliance percentage than all other sites ( $p_{adj}$  from  $< .001$  to  $0.036$ , effect sizes  $r = 0.58$ , large to  $r = 0.28$ , small) and there was also a statistically significant difference between the percentages for sites H and C, with C having the higher compliance ( $p_{adj} = .002$ ,  $r = 0.38$ , medium). See Figure 1 for variation in percentage compliance with minimum and gold standard at sites.

### Variation in percentage compliance for minimum and gold standard between dementia types

**Minimum Standard:** An Independent-Samples Median test was conducted which showed there were statistically significant differences in the percentage compliance between dementia types (test statistic = 9.09,  $df = 3$ ,  $p = .028$ ). Pairwise comparisons showed that there was a difference between those with Alzheimer's disease and Dementia in Pick's disease ( $p_{adj} = .043$ , effect size,  $r = 0.17$ , very small), with Pick's disease being associated with higher compliance. There were no significant differences between the other dementia diagnoses. See Figure 2 for percentage compliance for minimum and gold standard across dementia types.

**Gold Standard:** There were no statistically significant differences between diagnostic groups and percentage compliance with the gold standard.

### Associations between compliance rates and patient factors

As the Minimum standard compliance rate had been to vary between sites, a multi-level linear model, with site as the random, level 2 variable, was constructed to investigate associations between the compliance rates for the Minimum standard statements and age, gender, years since diagnosis and diagnosis

**Table 4.** Median and interquartile range quartile scores for compliance on the Minimum and Gold Standard, for the eight anonymised sites removed and replaced as below.

|                  | Site identifier | Median (inter-quartile range) |
|------------------|-----------------|-------------------------------|
| Minimum Standard | A               | 36.36 (27.27 – 45.45)         |
|                  | B               | 36.36 (29.55 – 45.45)         |
|                  | C               | 36.36 (27.27 – 40.91)         |
|                  | D               | 36.36 (27.27 – 45.45)         |
|                  | E               | 27.27 (18.18 – 36.36)         |
|                  | F               | 36.36 (27.27 – 45.45)         |
|                  | G               | 45.45 (36.36 – 54.55)         |
|                  | H               | 31.82 (27.27 – 40.91)         |
| Gold Standard    | A               | 44.35 (38.71 – 50.00)         |
|                  | B               | 41.94 (35.48 – 49.19)         |
|                  | C               | 48.39 (37.10 – 54.84)         |
|                  | D               | 45.16 (38.71 – 53.23)         |
|                  | E               | 32.26 (25.81 – 35.48)         |
|                  | F               | 40.32 (33.87 – 51.61)         |
|                  | G               | 47.58 (41.94 – 51.61)         |
|                  | H               | 38.71 (32.26 – 45.16)         |

group, clustered by site. Assumptions of multicollinearity, homoscedasticity and normality of residuals were tested and met. Only diagnosis group was a significant predictor ( $F(3,391.24)=4.126, p=.007$ ). This confirms the results from the Independent-Samples Median test reported above.

This was repeated for the full Gold standard (31 items) which showed no associations with any of the predictor variables.

In summary, there were statistically significant compliance rates between the sites and there were also differences in the Minimum standard compliance rate between patients with different diagnoses, after age, gender and time since diagnosis had been accounted for. Gold standard compliance rates were not associated with any of these personal variables.

**Percentage compliance with individual indicators**

Percentage compliance rates analysed by site and statement, including compliance for site for minimum standard (11 statements), the additional 20 statements required for Gold standard, and the complete Gold standard set (31 statements) were calculated (Table 4). This clearly shows that the additional 20

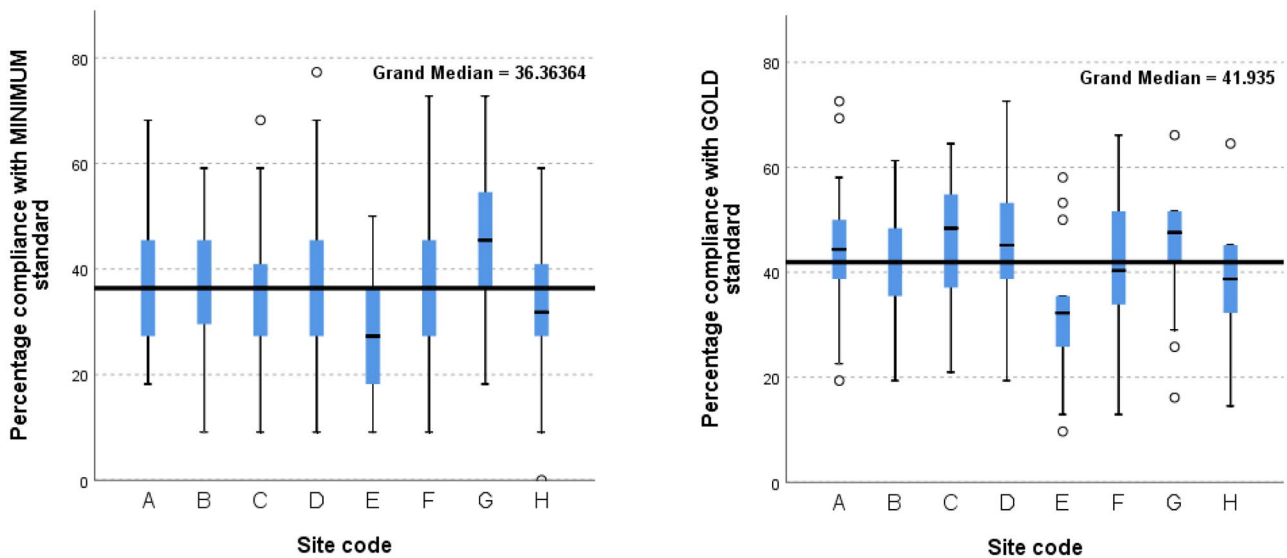
statements in the Gold standard had consistently higher compliance rates for every site than the minimum set, hence the higher compliance for Gold compared to minimum overall.

The 31 indicators included in the Gold standard were ranked and are shown in Table 5.

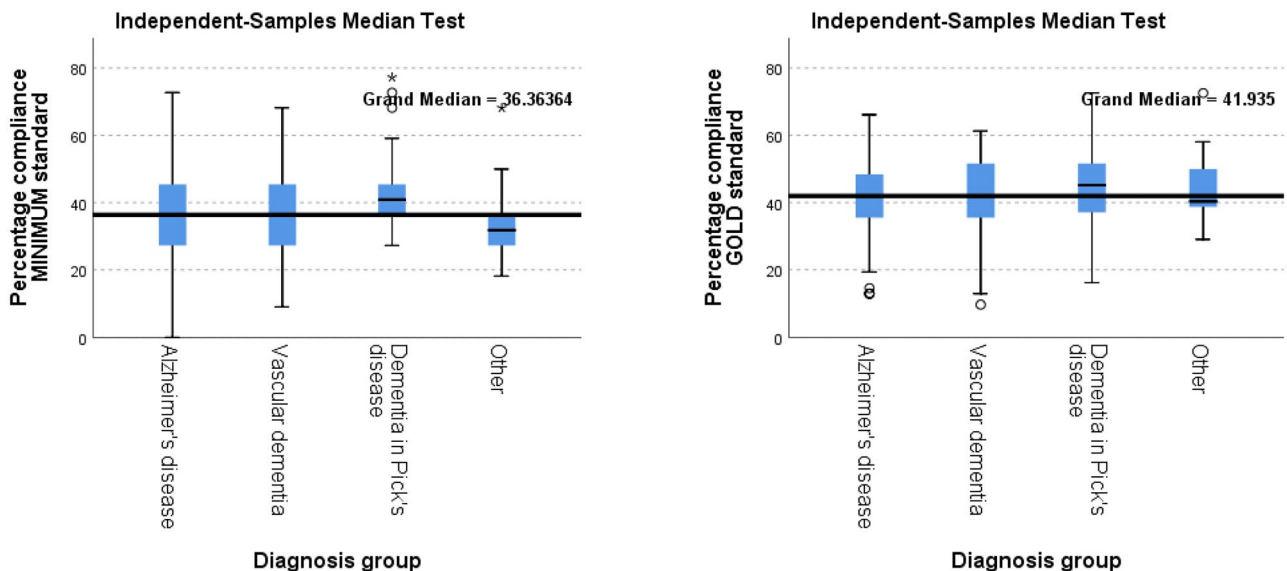
The results demonstrate wide variability in percentage compliance across the indicators regardless of diagnosis type or site with the top indicators yielding scores of over 90%. Low scoring

**Table 5.** Percentage compliance rates broken down by site and statement on the Minimum and Gold Standard.

|   | Percentage compliance per site N/11 Minimum standard (%) | Percentage compliance per site N/20 additional statements for GOLD standard (%) | Percentage compliance per site for all statements N/31 GOLD standard (%) |
|---|--|---|--|
| A | 38   | 47  | 44   |
| B | 39   | 43  | 41   |
| C | 35   | 52  | 46   |
| D | 37   | 48  | 44   |
| E | 28   | 33  | 31   |
| F | 37   | 45  | 42   |
| G | 45   | 48  | 47   |
| H | 33   | 40  | 37   |



**Figure 1.** Variation in percentage compliance with minimum (left) and gold (right) standard at sites.



**Figure 2.** Variation in percentage compliance for minimum (left) and gold (right) standard across dementia types.

**Table 6.** Percentage compliance for individual indicators of the Gold Standard across the whole dataset (402 records) ranked in order.

| Statement   | Percentage compliance across sites, and all dementia types (%) |
|---|--|
| To understand the symptom type and the mode of onset  | 94   |
| To conduct baseline structural neuroimaging   | 91   |
| To ask an informant (e.g. wife/husband) for a collateral history  | 86   |
| To evaluate risks, for example driving or in the workplace  | 85   |
| To exclude symptoms of mood disorder  | 84   |
| If there have been any changes in activities of daily living  | 74   |
| To consider previous medical conditions   | 72   |
| To ask about sleep  | 71   |
| To exclude psychotic symptoms   | 67   |
| To include a mental state examination   | 61   |
| To conduct the ACE-III  | 60   |
| To take an alcohol history  | 52   |
| Ask about past psychiatric symptoms   | 51   |
| MRI should be the initial imaging investigation   | 47   |
| To have a full medical history (including cardiovascular history)   | 45   |
| To use ACE-III to understand the cognitive profile  | 35   |
| Establishing rapport to enable open reporting of symptoms   | 30   |
| Detailed neuropsychology testing should be considered if there is under performance on screening measures   | 30   |
| To enquire about changes in physical health   | 29   |
| To conduct a physical examination   | 28   |
| To ask about changes in behaviour   | 24   |
| To take a drug history  | 22   |
| To ask if a first degree relative has had young onset dementia  | 19   |
| To obtain a three-generation history of young onset dementia from the patient   | 11   |
| To assess neurological symptoms, including Eye movements, Cerebellar signs, Tongue or limb fasciculation, Frontal signs, Extrapyramidal features Motor Skills | 10   |
| To conduct MRI dementia protocol incorporating T1, T2 and Flair images  | 9  |
| To assess Parkinsonism  | 7  |
| To ask for information about loss of sympathy/empathy towards others, disinhibited behaviour, change in food preferences and changes in personality           | 6  |
| To assess Praxis  | 5  |
| The assessment should start with counselling to ascertain what patient and supporters require   | 3  |
| Establish if there is a known history of learning disability  | 3  |

indicators included assessment for neurological signs, pre-assessment counselling and ascertaining a history of learning disability. In some circumstances although there is clear agreement about the value of specific indicators e.g. structural imaging across all sites reaching 90% compliance, execution to an acceptable 'expert consensus' standard was less common.

## Discussion

Quality of diagnosis and equity in access to specialists with expertise remains an issue for those with Young Onset Dementia (O'Malley, Parkes, Campbell, et al., 2020; Rabanal, Chatwin, Walker, O'Sullivan, & Williamson, 2018; Vernooij-Dassen, 2006). Misdiagnosis due to other causes, particularly psychiatric

disorders are common because of complexity and heterogeneity in presenting symptoms (Vieira et al., 2013). Mitigation of these issues could be achieved by increased knowledge and rigorous and systematic approach to diagnosis (Millenaar et al., 2016; O'Malley et al., 2019; Sansoni et al., 2016). No research about current UK practice is available.

In order to understand current diagnostic practice for younger people with dementia in the UK memory services, compliance with expert-defined quality indicators (O'Malley, Parkes, Stamou, et al.) in an anonymised dataset of 402 patients with young onset dementia using the UK Clinical Research Interactive System (CRIS) across eight NHS trusts was investigated. This study is currently the largest to utilise the digital platform UK-CRIS and is a component of the largest UK study of young onset dementia. The study was carried out in mental health trusts as this is where the majority of young people with dementia are diagnosed (Stamou et al., 2020).

Percentage compliance rates were analysed by site and statement for a Minimum standard (11 statements, ranges 28–45%), the additional 20 statements required for Gold standard, ranges 33–52%), and the complete Gold standard set (31 statements, ranges 31–47%). This analysis shows that the additional 20 statements in the Gold standard had consistently higher compliance rates than the minimum set at every site, resulting in higher compliance for the Gold standard compared to Minimum standard overall.

In patients with a final diagnosis of Frontotemporal Dementia (ICD coding - Dementia in Pick's Disease), percentage compliance with the minimum standard was higher than for Alzheimer's disease (and no higher than for other diagnostic groups). Examination of the components of the minimum standard suggest that this may not be surprising since it contains two indicators that are arguably more specific to Frontotemporal Dementia (FTD) than other diagnoses; international criteria for FTD and a change in behaviour. There was no statistical difference in time to diagnosis from referral to site with diagnosis subtype.

Percentage compliance with the Gold Standard did not vary across diagnostic groups suggesting that this standard may be more useful as a clinical tool. Perhaps, not surprisingly, for assessments conducted in mental health trusts, items concerned with assessment of mental state, mood and risk were convincingly assessed within this standard, while assessment and/or recording of indicators requiring neurological examination for key signs was less common. Furthermore, discrepancies were apparent. For example, although conducting structural neuroimaging scored highly for all sites, performing this to a recognised standard such as an MRI 'dementia protocol' was rare.

The variable compliance rates across sites were evaluated further in a follow-up knowledge exchange session with representatives of the clinical teams whose notes informed the audit. The goal was to identify 'on the ground' experience and to understand further the barriers and facilitators to improving practice. Clinicians advised that use of a standard proforma in the clinics to guide enquiry was rare. One site indicated that a letter template sent to GPs acted as an aide memoire for recording key elements after the assessment. Clinical teams also identified that in cases where nurses were performing assessments, the proformas were relatively rudimentary and did not distinguish between YOD and LOD with regard to specific items of enquiry at a level of detail to reach the gold standard. With regard to some indicators, for example pre-assessment

counselling, teams reported that often a scripted proforma was used to meet MSNAP (Memory Service National Accreditation Programme) standards rather than individually tailored counselling which takes account of age-specific needs.

In summary, initial analysis of anonymised data for patients with YOD using expert-defined quality indicators has provided a baseline about variation in the information that is currently recorded in EHR.

A major strength of our dataset is the comprehensive inclusion of the population of interest, across eight different NHS trusts. The analysed sample therefore encompasses differing care pathways and practice allowing highly generalisable results.

Furthermore, deriving structured information directly from the text fields held in mental health records allowed accurate representation of contemporaneous records. Keywords for our search query were aimed at identifying clinician-assigned constructs, rather than descriptions of experiences.

Limitations for the study included the level of detail within the notes which differed greatly between the sites. Whilst some sites followed usual clinical clerking, which included key queries to investigate and note during the initial and subsequent assessments, other sites summarised assessments concisely in a freehand manner. It should also be noted that some of the consensus indicators required a level of subjectivity in assessment. For example, the indicator related to rapport was scored according to whether the term 'rapport' was used, or if the clinician's language suggested that questions were directed more towards the person undergoing the assessment (rather than a family supporter) and if they described the personality of the person, suggesting that they attempted to get to know the patient as well as possible. Finally, the study includes records from Mental Health Trusts, so patients with YOD assessed in neurology centres/services, would not have been included and this limits generalisability of the findings. Ideally, capturing records from those assessed in neurology and specialist services would provide greater understanding of differences in patient initial complaints and profiles between mental health and neurology services.

In other fields of medicine, introduction of interventions such as aide memoire in addition to clinical education has been valuable in improving standards of good practice (Parwaiz, Perera, Creamer, Macdonald, & Hunter, 2017). The results obtained here, suggest that a template proforma, which contains the key indicators for comprehensive assessment of dementia in young adults according to a quality standard could help support less experienced clinicians to improve record keeping and reduce gaps in examination and enquiry.

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## Author contribution

JC, JO and JP initiated, planned and co-ordinated the study for this paper. MOM and JC conducted the research, drafted and proof-read the paper and JP, JO, JLF and VS contributed to drafting, proof-reading and worked on the final draft of the paper

## Disclaimer

The views expressed are those of the authors and not necessarily those of the NHS, the NIHR or the Department of Health.

## Data sharing statement

We the authors agree to sharing data from this work, upon reasonable request.

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## Appendix 1. Dementia diagnoses included in the case note audit

| ICD-10 Code | Diagnosis   | Grouping Diagnosis         |
|-------------|---|----------------------------|
| F00         | Dementia in Alzheimer's disease                             | Alzheimer's disease        |
| f000        | Dementia in Alzheimer's disease with early onset            | Alzheimer's disease        |
| F000        | Dementia in Alzheimer's disease with early onset            | Alzheimer's disease        |
| F001        | Dementia in Alzheimer's disease with late onset             | Alzheimer's disease        |
| F002        | Dementia in Alzheimer's disease, atypical or mixed type     | Alzheimer's disease        |
| F009        | Dementia in Alzheimer's disease, unspecified                | Alzheimer's disease        |
| F01         | Vascular dementia   | Vascular dementia          |
| F010        | Vascular dementia of acute onset                            | Vascular dementia          |
| F011        | Multi-infarct dementia                                      | Vascular dementia          |
| F013        | Mixed cortical and subcortical vascular dementia            | Vascular dementia          |
| F018        | Other vascular dementia                                     | Vascular dementia          |
| F019        | Vascular dementia, unspecified                              | Vascular dementia          |
| f020        | Dementia in Pick's disease                                  | Dementia in Pick's disease |
| F020        | Dementia in Pick's disease                                  | Dementia in Pick's disease |
| F022        | Dementia in Pick's disease                                  | Dementia in Pick's disease |
| F028        | Dementia in other specified diseases classified elsewhere   | Other                      |
| G318        | Other specified degenerative diseases of the nervous system | Other                      |
| F02         | Dementia in other specified diseases classified elsewhere   | Other                      |

## Appendix 2. Statements that were not included in the audit and reasons for exclusion and combining.

| Standard that Delphi-PRO statement belongs to | Statement in Delphi consensus but not audit   | Reasons   |
|---|---|---|
| Minimum Standard                              | A thorough neuroimaging investigation should be included  | Was combined with the "baseline structural neuroimaging" statement and added to gold standard   |
| Minimum Standard                              | A thorough neurological assessment should be conducted  | Was combined with the following to make a gold standard neurological indicator/statement<br>Eye movements<br>Cerebellar signs<br>Tongue or limb fasciculation<br>Frontal signs<br>Extrapyramidal features<br>Motor Skills |
| Minimum Standard                              | Support is required from diagnosis to end of life care  | Unable to extract this from the case note records   |
| Minimum Standard                              | Diagnosis of YOD is a clinical judgement and has a profound impact on the future, so it important to convey this to patient and their family and remain open to the need to review and potentially modify opinion | Unable to extract this from the case note records   |
| Gold Standard                                 | Ensuring the patient has capacity   | Could not extract this from the case note records   |
| Gold Standard                                 | Multiple professionals are required over time to allow flexible assessment with support to end of life  | Could not extract this from the case note records   |

## Appendix 3. Frequency and percentage of records from each of the participating sites in the audit.

| Site identifier | Frequency of records (percentage) |
|-----------------|-----------------------------------|
| A               | 58 (14.4%)                        |
| B               | 52 (12.9%)                        |
| C               | 53 (13.2%)                        |
| D               | 50 (12.4%)                        |
| E               | 53 (13.2%)                        |
| F               | 50 (12.2%)                        |
| G               | 50 (12.4%)                        |
| H               | 36 (9%)                           |
| Total           | 402 (100%)                        |