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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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Young onset dementia;
UK CRIS;
case note audit;
UK practice;
quality indicators

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 (O'Malley, Parkes, Stamou, et al., 2020a) to establish the key indicators for comprehensive assessment of dementia in this

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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 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:

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

(Continued)

Table 1. (Continued)

Past psychiatric symptoms	Ask about past psychiatric symptoms	Search psychiatric/psychiatrist/ Past psychiatric hx/PPH Mental health They have noted that the patient has had depression or another psychiatric symptom/condition.	Yes/no Has the clinician asked about past psychiatric history/symptoms? Abbreviations Eg hx bipolar affective disorder - BAD, Sz schizophrenia	0 or 1
Physical examination	To conduct a physical examination	PE or physical examination This includes ECG, checking blood pressure, pulse or comments on chest/heart sounds etc	Yes/no Has the clinician conducted a physical examination?	0 or 1
Sleep	To ask about sleep	Sleep	Yes/no 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 ? use of symbols??	Yes/no 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 Was MRI the initial imaging investigation undertaken?	0, 0.5 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. 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 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 T1, T2 and Flair images	Yes/no 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 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/ 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. 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 Patterns of cognitive deficits provide clues to disease aetiology on the ACE-III	ACE-III or ACE-III with pattern/profile/ domains/deficits	Has the ACE-III been conducted? 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 neuropsych-ological testing	Detailed neuropsychology testing should be considered if there is under performance on screening measures	Neuropsychology +/- assessment/testing Neuropsychology and ACE-3 Neuropsychology and MOCA "Neuropsychology"	Yes/no 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 ±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 (see Table 4).

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).

	Diagnosis group	**Median** (inter-quartile range)
No. of days to diagnosis	*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.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 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.

Table 4. 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

The 31 indicators included in the Gold standard were ranked in order of percentage compliance across all sites and dementia types 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 indicators included assessment for neurological signs, preassessment 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

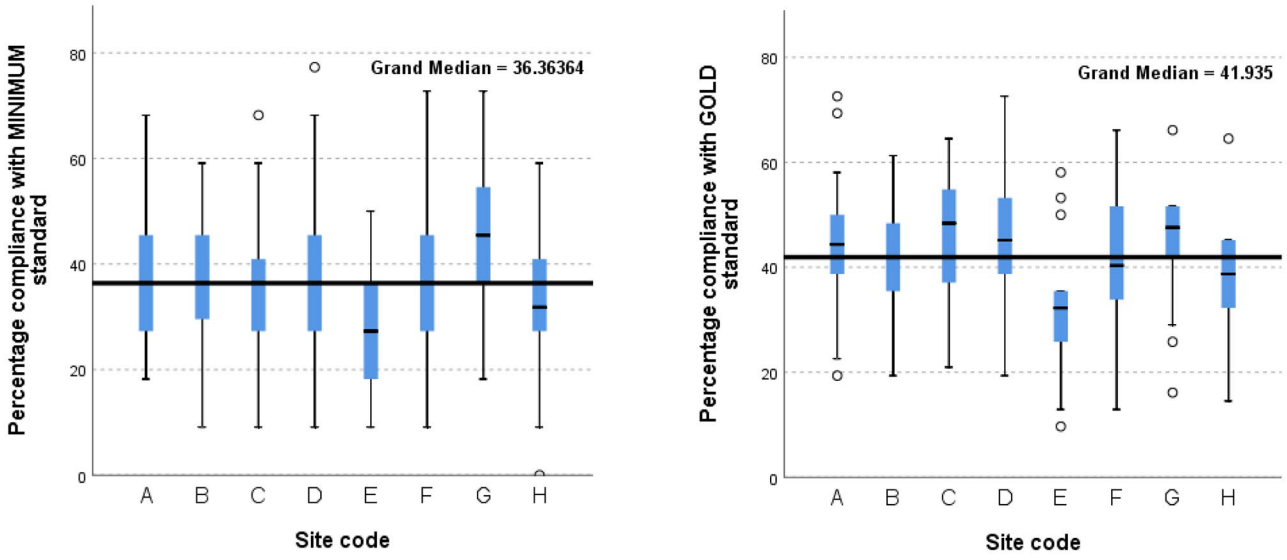

Figure 1. Variation in percentage compliance with minimum (left) and gold (right) standard at sites.

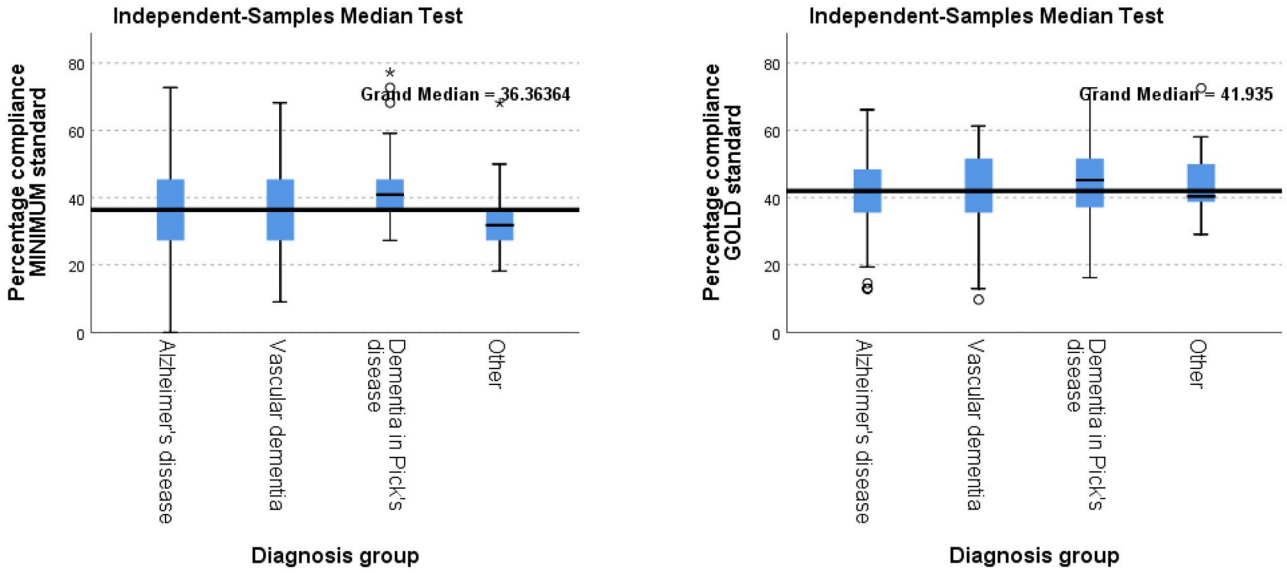

Figure 2. Variation in percentage compliance for minimum (left) and gold (right) standard across dementia types.

Table 5. 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

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 the 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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Disclaimer

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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

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 Eye movements Cerebellar signs Tongue or limb fasciculation Frontal signs Extrapyramidal features 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.

		Frequency of records (percentage)
Site identifier	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%)