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View over Derwentwater

National Audit of Dementia

Spotlight Audit in Community Based Memory Services 2021

Guidance for sampling and questions

Welcome to the Spotlight Audit for community-based memory services

This audit is for community-based memory services in England and Wales. A memory service for this audit is an individual service or clinic or team, or it may be more than one team if structured as one service – see organisational questionnaire for further details.

There are 3 parts to this audit:

Patient-level information or casenote audit: 50 consecutive patients seen for initial assessment from 01/01/2021 per registered service/ clinic/ team participating in the audit – see guidance **below.**

Organisational questionnaire: one per registered service – see guidance below.

Patient/ carer feedback questionnaire: an online questionnaire to be completed by 20 patients (or carers) who attended your service during the data collection period.

For any queries, please contact the project team:

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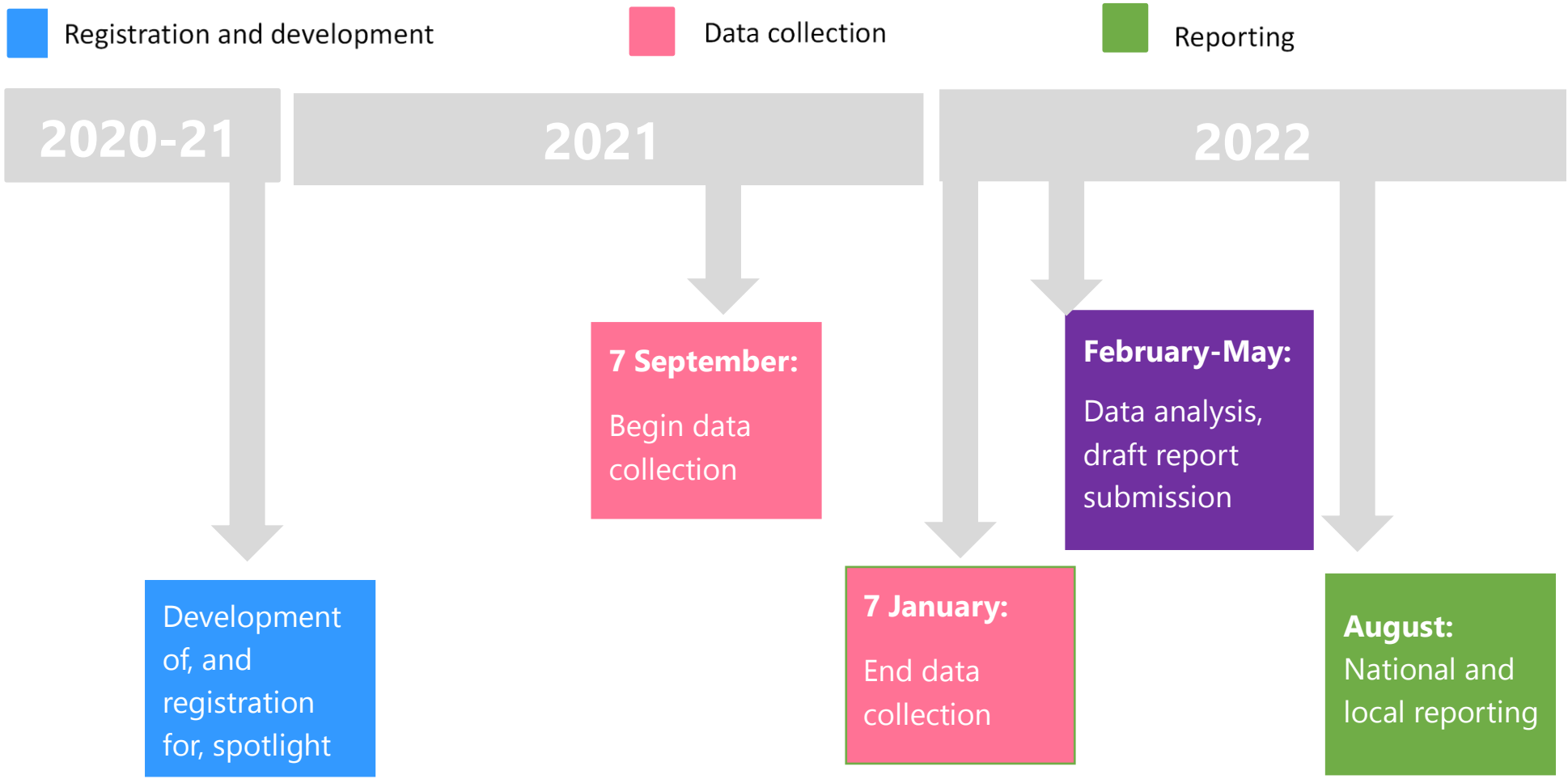
Please note that when contacting the project team about your casenotes, do not at any time include any identifiable data about patients (for example: name, NHS number, address).

Timeline for data collection and reporting:



Organisational questions guidance

ONE organisational questionnaire should be returned for each service/ clinic taking part in the audit. If your organisational units are designated "teams" but each has differing responses due to their structure or commissioning, then each one may be eligible to participate. The deadline for submission is **7th January 2022**.

Question (15 total England, 18 total Wales)		Useful information/ definitions
Organisational Questionnaire		
	Please enter your organisation code	This will be provided by the project team in the form AAAAA001
	My service or clinic is in England/ Wales	Some questions differ slightly according to the country where the service is located
1	Was your memory service closed or paused for new assessments during the first national lockdown (23rd March-July 2020)?	Answer yes if new assessments were "paused"
2	**Approximately** what percentage of staff were unable to work during the first national lockdown? This includes those were shielding or redeployed.	
3	Is your service accredited with the Memory Services National Accreditation Programme (MSNAP)?	Answer should relate to the unit receiving accreditation, see above re eligibility
4	What organisation provides the memory service?	This is about the organisation which provides this memory service or clinic i.e. is it provided by Mental Health Trust or other type of organisation
5	Do you have a named research champion / lead	This does not need to be someone who conducts research, for example a research champion might talk about local studies in team meetings or keep a "consent for contact" database
6	Do you have a named lead for young onset dementia (under 65)	Only use NA if under 65s are not normally seen at the memory clinic (e.g. seen in neurology)
7	Which patients do you request ECGs for prior to commencing cholinesterase inhibitors?	
8	Are CT and MRI scans reported by neuroradiologists	Select yes if usually reported by neuroradiologist. Select no if usually reported by a general radiologist.
9	Can you view scan images (e.g. using medical imaging technology such as PACS)?	Select Yes if you can view scan images electronically in clinic or at the team base. Select No if you can only see the report

10	Is attending imaging appointments facilitated by the memory service	E.g. phoning relatives to attend with patients, phone call reminders, taking the patient.
11	Are you able to refer patients for: PET scans DAT scans CSF examination SPECT scans	
12	Is there an opportunity for joint working with: Neurology Neuroradiology Geriatrics Parkinson's disease clinic	Select the closest option to current practice. Ad hoc may include occasional emails/ phone calls
13	Do you offer a post diagnostic follow up monitoring service?	This means, that the service can provide appointments to patients after they have been diagnosed, to monitor their care/ treatment
14	Is there an offer of a named contact for emotional support throughout the assessment period?	Wales only
15	Is there an offer of a contact for emotional support following receiving a diagnosis and over the next 48-hour period?	Wales only
16	Is there a "Dementia Diagnosis – providing emotional support" education package provided as part of all MAS staff induction? (If Yes) How many staff have completed this package?	Wales only
17	Do you provide or offer any of the following post diagnostic services? (list provided)	England only. Directly provide, or refer on for provision
18	Are these services commissioned? (question asked if any of the services in Q17 ticked)	England only - "Via another provider" response – provided elsewhere whether commissioned or not
19	Do you provide or offer any of the following post diagnostic services?	Wales only – different response options – if in Wales you will not see Q17 and 18
20	Are these services commissioned? (question asked if any of the services in Q19 ticked)	Wales only – different response options – if in Wales you will not see Q17 and 18

Completing the casenote audit

Each memory service or team should submit notes for 50 consecutive patients seen for initial assessment from 01/01/2021. This excludes patients referred for initial assessment who declined to attend the service, or patients who were referred and then did not attend.

Data collection opens 7th September with a **deadline of 7th January 2022**.

Each service will be asked for:

1) The total number of patients completing the pathway to diagnosis between 1st January and 31st August 2021. We will ask for this information on a separate form.

2) An audit return of eligible casenotes, for which the **minimum sample will be 50, and the maximum 100 patients**. This will give services the opportunity to return a larger sample if they wish. If your service cannot identify 50 patients seen for initial assessment in January, you may continue with patients seen in February.

Input will be required from:

Staff working at the service, and this can include students and unqualified/ junior staff working under supervision. The audit does not need to be completed/ submitted by the same person, e.g. 5 staff can audit 10 sets of notes each.

Data can be completed using the PDF form and then submitted online by persons other than the auditors. All data must be submitted online.

Estimated time to complete:

We predict that 2-3 hours will be required to identify the sample and each casenote will take between 15 minutes and 25 minutes to submit. The time taken to complete will be dependent on your electronic records system and how it is organised, with the first couple of sets taking the longest to do.

Organising your sample

1) The casenotes identified should be from a single service - and not trust wide. The patients should be the first 50 consecutive seen for initial assessment. You do not need to enter them in this order.

2) Submit the total number of patients identified via the short online form "Total N patients identified for casenote audit". You will be asked to enter the total number who completed the pathway to diagnosis between 1st January and 31st August. This data should be submitted online from 1st November onwards.

3) Organise your list so that the patients identified are listed in date order that they had their initial assessment.

4) Allocate each casenote a number, from 1 to the total number of casenotes identified. This is the number you will use when entering "audit patient number" on the data collection form.
   Please note: This is not the memory service patient number or NHS number. Please do not enter this information anywhere on the data collection form.

5) Online entry for each set of notes must be completed and submitted separately.

6) If, after patient number allocation, a set of notes is found to be ineligible for this audit (e.g. it is later understood that they never attended for initial assessment), exclude this set of notes from data entry. You should then go on to the next set of notes in the sequence, but **do not reallocate the number**. E.g. if number 2 is ineligible, go on to enter data for number 3 (so your inputted casenote patient numbers will follow as 1, 3, 4 and so on).

7) Continue to skip excluded records and move on to the next consecutively initially assessed and numbered patients in the series until you have reached your return total of 50.

8) Identify casenotes for the inter-rater reliability check (see below).

9) Please keep a copy of your list of audited patients. You will need this for any queries that arise during data analysis so that you can identify the notes again.

Inter-rater reliability check

As part of the reporting process for this audit, we are asking sites to collect inter-rater data to establish reliability.

The process requires two different people to extract and enter the data from the **first five** casenotes in order of initially assessed date onto the data collection forms.

The process for identifying casenotes for audit is described earlier in this document.

Inter-rater reliability check

Identifying the cases to be double audited:

- Follow instructions in "Organising your sample" and select the first five casenotes eligible to be entered into the data collection system (first five initial assessments). These casenotes will be re-audited.

Extracting the data:

- Identify two separate people ('first' and 'repeat' auditor) who will extract information from the casenotes and enter data via the online casenote audit data submission form.

  First auditor on their data collection form:
  - Ticks "Yes" to "*Is this an inter-rater reliability check?*"
  - For the first case, enter "1" in the box which says, "*Enter number for this patient*"
  - Collect all the information for this patient
  - Do not involve the repeat auditor(s)
  - Repeat the process for patients 2, 3, 4 and 5.

  Repeat auditor on their data collection form:
  - Using the **same five cases** in the **same order** as the first auditor(s)
  - Ticks "Yes" to "*Is this an inter-rater reliability check?*"
  - Add "R" at the end of the number (so number 1 of the first auditor's casenotes, is numbered 1R by the repeat auditor)
  - Collect all the information for this patient
  - Do not involve the first auditor(s)
  - Repeat the process for patients 2, 3, 4 and 5, numbering them 2R, 3 R etc.

N.B. If you have excluded any notes from your list as found to be ineligible, so that (for example) your notes are numbers 1, 3, 4, 5, 6, then your second auditor notes should be numbered the same: 1R, 3R, 4R, 5R, 6R

Questions and guidance

Question (39 in total)		Useful information/ definitions
Casenote Audit		
	Please enter the org code provided by the project team	Unique identifier for your service for this audit. This will be in the form AAAAA001.
	Please enter the audit patient number	The number you have allocated for the set of patient notes you are auditing – please see above for how to do this.
	Is this an inter-rater reliability check?	See IRR guidance above.
	My service or clinic is in England/ Wales	There are some additional/ differing questions for services in Wales aligning with Welsh Government guidance.
1.	Age at referral	Age in whole years at the date of referral Age calculator available at: https://www.calculator.net/age-calculator.html?today=05%2F07%2F1939&ageat=01%2F04%2F2021&x=55&y=19

		Or https://www.calculatestuff.com/miscellaneous/age-calculator Many others are available.
2.	Sex	Please respond with sex assigned at birth.
3.	Gender	Please select option patient most identifies with.
4.	Sexual Orientation	
5.	Ethnicity	Responses are standard listed NHS ethnicities. Select unknown/ not documented if no ethnicity recorded.
6.	Is English the patient's first language?	
7.	Did the patient need an interpreter	
8.	Does the patient live alone	
9.	Lower Super Output Area - Name Field	To find the LSOA, **England** go to: *https://www.fscbiodiversity.uk/imd/index.php?p=PO15+6TN%0D%0APO15+6BJ%0D%0APO15+6EW&d=#data* Enter the postcode and this will give you the LSOA Name. E.g. SW1A 0AA will give you the name field Westminster 020C – enter this information in the online form. DO NOT submit the postcode.
		Wales go to: Welsh Index of Multiple Deprivation (gov.wales) and click on Postcode to WIMD rank look up to download the spreadsheet. Enter the postcode in column A WITHOUT a space and this will give you the LSOA name. E.g. entering CF105AL will return the name Butetown 4.
Referral		
10.	Who was the patient referred by?	
11.	Date referral received	must be in format dd/mm/yy
12.	Date seen for initial assessment	must be in format dd/mm/yy
Assessment		
13.	Place of assessment	Select usual place of residence if assessed at home or in a care home.

		Other - inpatient rehabilitation unit, short stay unit etc.
14.	Was the video call facilitated by someone else? e.g. children or spouse	
15.	Reported alcohol consumption per week	
16.	Is there evidence of a discussion about: a) The patient's eyesight/ vision b) The patient's hearing	e.g. does the patient wear glasses, last opticians appointment. e.g does the patient wear hearing aids.
16c	The individual's general current health status and any current difficulty	Wales only
17.	Was the patient referred to occupational therapy for a functional assessment?	
18.	Was a falls history taken	e.g. number of falls last 12 months, fear of falling
19.	Was the patient referred to diagnostic neuropsychological assessment?	
Investigations		
20	Was a brain scan requested by memory service?	
21.	Date scan requested?	Must be in format dd/mm/yy
22.	Who requested scan?	If request goes through the GP but requested by Memory Service (due to local pathways) please select Memory Service
23.	Was a scan performed?	
24	What scan was performed?	
25.	Reason scan was not performed:	
26.	Date of scan:	Must be in format dd/mm/yy
27.	Were specialist investigations performed? e.g. PET/DAT/SPECT scan/CSF examination	
28.	What specialised investigations were performed?	
Diagnosis		
29.	Recorded diagnosis:	

30	Was this diagnosis confirmed/ working?	Working diagnosis option can be ticked if diagnosis is yet to be confirmed due to outstanding tests
31.	Date diagnosis was given:	must be in format dd/mm/yy. This is the date the patient/carer are **informed** of the diagnosis
Treatment and post diagnostic support		
32.	Was anti-dementia medication prescribed?	This question refers to initial prescription of medication, at time of diagnosis
33.	Which medication was prescribed	AChEI and memantine - select if prescribed a cholinesterase inhibitor and memantine This question refers to initial prescription of medication, at time of diagnosis
34	Was the patient offered cognitive stimulation therapy (CST)?	Not appropriate e.g. advanced dementia, no dementia, language barrier
35.	Was the patient offered a dementia advisor or navigation type service (either in house or referral on)?	England only. E.g. ongoing memory service care coordination, Alzheimer's Society care navigators, primary care dementia review clinic
35b	Was the patient offered a dementia advisor or navigation type service **from diagnosis to end of life** (either in house or referral on)?	Wales only, alternative to 36
36.	Was the carer offered a psychoeducation course (either in house or referral on)?	For example: START, CRISP programme
37.	What other interventions were provided? (list provided)	Either provided “in-house” or by onward referral
37a1	If your service is in Wales did you also provide: Interventions aligning to the all-Wales pathway of standards – standard 9 Offer of other socially prescribed interventions	Wales only
38.	Was the patient asked about being contacted for research?	
Primary care correspondence		
39.	Were READ or SNOMED codes in relation to diagnosis included in letter correspondence to GP?	

Patient/ carer feedback guidance

The patient/ carer feedback questionnaire was developed by Alzheimer's Society specifically to gather feedback on the experience of virtual appointments for people living with dementia attending memory assessment services. We have been permitted to use a slightly adapted version for this audit to increase the amount of information available about this, and to provide feedback at a service level (where sufficient responses are received).

The questionnaire will only be available online as it is currently not possible to process paper questionnaires. Your service will be sent leaflets explaining the questionnaire which you can give to patients when they attend for appointments, and ask them to complete it. For example, it can be given along with the Alzheimer's Society booklet. The leaflet will contain a QR code which can be scanned to give access to the questionnaire on a phone or tablet. The leaflet will also be sent as a PDF containing a clickable link which you can send to patients if you wish.

The questionnaire can be completed by the person living with dementia, or by a family member/ carer on their behalf.

The questionnaire asks for the name of the memory service, or for the area or town where the person lives, so that we can match responses to your service. It does not ask for any identifiable information and responses will be completely confidential.

Distribution of this questionnaire for the spotlight audit will be entirely via registered memory services, as above.

We are asking services to aim for 20 responses. We will send you updates on the number of patient/ carer feedback questionnaires submitted for your service during the data collection period. If we receive fewer responses, we may aggregate them with responses submitted for other services within your Trust/ Health Board, or suppress part of the information, to ensure confidentiality.

Please keep a note of the **number** of patients you have asked to complete the questionnaire, as this will enable us to provide you with a response rate. We will ask you for updates about this.

From previous audits, we know that questionnaires for patients or carers are more likely to receive a response if:

- A member of staff personally asks the person to complete it and explains that the feedback is important and will be used to help improve services locally and nationally.
- A member of staff is designated lead for this part of the audit and organises distribution of the questionnaire.

Respondents will be given the opportunity to enter a prize draw to take place at the end of the audit, with 5 prizes of £50.

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Cover image shows “View over Derwentwater” by Peter Montgomery, runner up in the NAD Art Prize 2018, for the theme Living Well.