




# Primary Care Dementia Data: Consultation Response 2026

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## About Primary Care Dementia Data

The Primary Care Dementia Data (PCDD) publication contains data about people with dementia at each GP practice in England, to enable NHS GPs and commissioners to make informed choices about how to plan their dementia services around patients' needs. Data includes, but is not limited to, statistical calculations for dementia diagnosis rates, demographic and dementia type breakdowns, antipsychotic prescribing and comorbidity data. The latest PCDD publication can be found at <https://digital.nhs.uk/data-and-information/publications/statistical/primary-care-dementia-data>.

## Introduction

The primary care dementia data consultation ran from Thursday 19<sup>th</sup> March to Wednesday 15<sup>th</sup> April 2026, and sought feedback on a range of proposed changes to PCDD publication. A link to this consultation can be found [here](#). This consultation response then goes on to document the responses received and explain the decisions made and next steps.

## Proposals and Rationale

The changes proposed in this consultation aimed to streamline the publication process, and outputs to ensure operational efficiency whilst ensuring that user priorities are accounted for, and that NHS England still meets statutory obligations regarding publication of data.

NHS England engaged with key stakeholders ahead of the consultation to determine the fundamental requirements of the PCDD publication and aimed to incorporate this feedback into the proposals.

In line with the consultation aims, any final decisions or changes made as a result of/following feedback aim to balance operational efficiency, quality of the publication and public utility.

Furthermore, NHS England and the Department for Health and Social Care (DHSC) are working with stakeholders to identify additional routes to provide expanded analysis of dementia data as part of a wider re-design of the way that intelligence on dementia will be produced and disseminated. We will provide an update on this as and when further information is available.

This consultation proposed:

- a reduction in publication frequency
- a reduction in publication scope and complexity

The proposals included within the consultation are summarised below; please refer to the [consultation webpage](#) for further detail relating to each proposal.

### Proposal 1 – Reduction in frequency

It was proposed that from 2026/27, the PCDD publication will be published on a quarterly basis (April/July/October/January) rather than a monthly basis. Due to a change in the

collection frequency of the underlying dataset, this proposal was a **MUST** and could not be avoided.

## Proposal 2 – Removal of time series

It was proposed that only data for a single quarter would be published with each release of the PCDD publication, as opposed to the 13 month time series previously published with every release.

## Proposal 3 – Removal of National Excel Summary

It was proposed to no longer publish the national excel summary file which contained selected statistics about demographic characteristics and delivery of care.

## Proposal 4 – Removal of Dementia Diagnosis Rate indicator at Local Authority level

It was proposed to cease production of the Dementia Diagnosis Rate (DDR) indicator at Local Authority (LA) level, and to only produce this for select NHS geographies.

## Proposal 5 – Aggregation of Practice Level Data and Removal of Disclosure Control

Subject to approval from the Disclosure Control Board (DCB) within NHS England, it was proposed to publish all data at sub ICB level only and to remove all disclosure control from the publication outputs with no rounding or suppression applied.

## Proposal 6 – Consolidation of CSV files

It was proposed to reduce the number of data CSV outputs from 12 CSV files to 2, with 2 additional CSV files which provide mapping and data dictionary information being retained.

## Methodology for consultation

A form was created with the following 18 questions to understand the needs of data users, and collate feedback in relation to the proposed changes:

**Q1.** What sector do you work in? if you work across multiple sectors, please select your main sector in which you use Primary Care Dementia Data.

*Choices taken from: DHSC, Government Partners, Local Authority, Member of the public, NHS England, NHS Organisation, Royal College, Third Sector Organisation or Other*

**Q2.** How do you use primary care dementia data? E.g. within service planning, research. Please give as much detail as possible.

*Free text responses.*

**Q3.** Are there data on dementia subgroups such as dementia subtype, age band, ethnicity etc. which you use? (tick all that apply)

*Choices taken from: Dementia subtype e.g. Alzheimers, Age/sex, Ethncity, Residential type, None, Other*

**Q4.** Do you rely on Primary Care Dementia Data to monitor variation and inequalities in your service planning?

*Choices taken from: Yes, No, N/A*

**Q5.** What additional dementia measures or breakdowns would be most helpful to support you in commissioning and service planning?

*Free text responses*

**Q6.** Do you support proposal 2 to remove the time series from the publication?

*Choices taken from: Yes, No*

**Q7.** Please provide a reason why you don't agree with this proposal (this is really helpful or us to assess the impacts of the change on users).

*Free text responses*

**Q8.** Will the removal of the time series within each publication impact your ability to monitor progress in improving services?

*Choices taken from: Yes, No, N/A*

**Q9.** Do you support Proposal 3 to remove the national excel summary file from the publication?

*Choices taken from: Yes, No*

**Q10.** Please provide a reason why you don't agree with this proposal (this is really helpful or us to assess the impacts of the change on users).

*Free text responses*

**Q11.** Do you support Proposal 4 to remove the Dementia Diagnosis Rate indicator at Local Authority Level?

*Choices taken from: Yes, No*

**Q12.** Please provide a reason why you don't agree with this proposal (this is really helpful or us to assess the impacts of the change on users).

*Free text responses*

**Q13.** Do you support Proposal 5 to aggregate all data to sub ICB level and remove disclosure control?

*Choices taken from: Yes, No*

**Q14.** Please provide a reason why you don't agree with this proposal (this is really helpful or us to assess the impacts of the change on users).

*Free text responses*

**Q15.** Are there any areas where the removal of GP practice level data would negatively impact your commissioning and service planning?

*Free text responses*

**Q16.** Do you support proposal 6 to consolidate the 12 CSV files in 2 CSV output files?

*Choices taken from: Yes, No*

**Q17.** Please provide a reason why you don't agree with this proposal (this is really helpful or us to assess the impacts of the change on users).

*Free text responses*

**Q18.** Please add any further comments you would like to feed into this consultation below.

*Free text responses*

To support the form a web page was also created with further details regarding the consultation proposals and is available [here](#), and a mailbox was available to post any further questions that people had as the consultation was in progress.

The consultation was promoted using a prominent note added to both the publication and series pages. Interested parties were also targeted by contacting ~20 known stakeholders including NHS England dementia policy teams, OHID, DHSC and third sector organisations.

Halfway through the consultation period a reminder was sent out to encourage more responses, and additional ‘sample’ outputs were published on the same webpage as the consultation to provide clarity regarding the proposals.

By the end of Wednesday 15<sup>th</sup> April 2026, a total of sixteen responses (15 via the survey, and 1 email) had been received. These responses are described in the Results section below.

## Results

An overview of the responses to the consultation questions are provided below. Where appropriate, NHS England have provided a response to each question and in some cases responses have been grouped as to not repeat information.

1.What sector do you work in? If you work across multiple sectors, please select your main sector in which you use Primary Care Dementia Data.

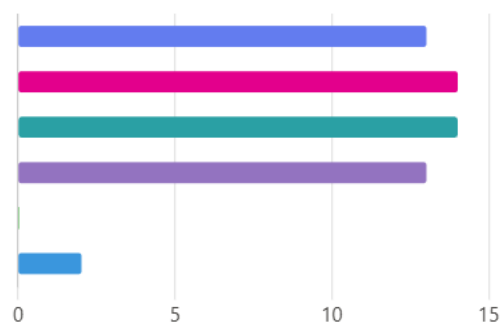
Sector	Responses
DHSC	1
Local Authority	8
NHS England	1
NHS Organisation	5
Third Sector Organisation	1

2.How do you use the primary care dementia data? e.g. within service planning, research. Please give as much detail as possible.

Respondents mainly use the primary care dementia data for service planning and commissioning, monitoring trends and performance over time, and identifying variation/inequalities. Several also use it in dashboards (e.g., Tableau/interactive reporting), audits/service evaluation and quality improvement, and to model demand/capacity and resource allocation. A smaller number referenced policy/advocacy and national/local benchmarking for accountability.

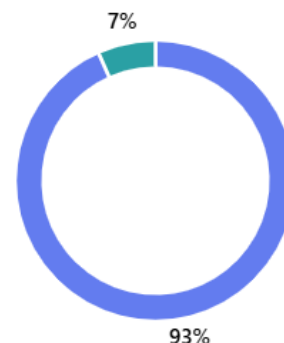
3. Are there data on dementia subgroups such as dementia subtype, age band, ethnicity etc. which you use? (tick all that apply)

● Dementia subtype e.g. Alzheimers	13
● Age/sex	14
● Ethnicity	14
● Residential type	13
● None	0
● Other	2



4. Do you rely on Primary Care Dementia Data to monitor variation and inequalities in your service planning?

- Yes 14
- No 0
- N/A 1



5. What additional dementia measures or breakdowns would be most helpful to support you in commissioning and service planning?

Overall, respondents most often asked for more granular geography options (e.g., local authority/district and GP/PCN level, or bespoke areas), plus additional pathway and utilisation measures such as GP to diagnosis waiting time, hospital admissions/length of stay and delayed discharges. Several also requested added clinical breakdowns (frailty, severity/stage at diagnosis, place of diagnosis and imaging/biomarkers). 5 respondents said no additional measures were needed.

**Response:**

Table 1 below is a collation of the requests for additional dementia measures and/or breakdowns which were provided in response to question 5 of the survey. NHS England have provided a response to each of these requests within table 1 below.

**Table 1: Survey responses to Q5 regarding desired additional dementia measures of breakdowns**

Information requested for inclusion in the publication	Response
Frailty	<p>The following measures will be included at sub ICB level from 2026/27:</p> <ol style="list-style-type: none"> <li>1. Count of patients on the QOF Dementia Register who experienced a fall within the last 12 months</li> <li>2. Count of patients on the QOF Dementia Register who experienced fractured neck of femur (NOF) in the past 12 months</li> <li>3. Count of patients on the QOF Dementia Register who are living with mild frailty.</li> <li>4. Count of patients on the QOF Dementia Register who are living with moderate frailty.</li> <li>5. Count of patients on the QOF Dementia Register who are living with severe frailty.</li> </ol> <p>Please see the <a href="#">business rules</a> for further details regarding the frailty measures which will be introduced.</p>
Wider demographic data such as sexual orientation, gender identity, language data, additional disabilities/conditions	<p>This information will be considered for inclusion in future publications. There are however some limitations which may impact whether these can be included within future extracts*.</p>

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Under 65 diagnosis rates	<p>This information will be considered for inclusion in future publications.</p> <p>However please note that, the reference rates from the Cognitive Function and Ageing Study II (CFAS II) which are used for estimated diagnosis rate calculation are based on patients aged 65+ and should only be applied to equivalent populations to ensure statistical accuracy. Therefore, additional research would be required to calculate diagnosis rates for populations under 65 years old.</p>
Information on secondary care e.g. hospital admissions (psychiatric and acute), length of hospital stays, delayed discharges	<p>The underlying data source for this publication is an aggregate collection from primary care records; no patient level data are extracted therefore it is not possible to link this dataset with record level secondary care data.</p>
Additional diagnosis information e.g. length of time for diagnosis, severity of dementia, place of diagnosis, info on those receiving diagnostic imaging	<p>This information will be considered for inclusion in future publications. There are however some limitations which may impact whether these can be included within future extracts*.</p>
Satisfaction measures from service users	<p>This information will be considered for inclusion in future publications. There are however some limitations which may impact whether these can be included within future extracts*.</p> <p>Please note that patient satisfaction or experience measures are not routinely recorded in structured GP clinical records and therefore cannot be extracted within this dataset. If reported, such information would need to be sourced from separate data collections (e.g. surveys), rather than primary care data extracts.</p>
Practice level data of breakdowns e.g. ethnicity	<p>Please see response to Question 14 of the survey.</p>
Further breakdown of data to additional geographies e.g. LA, parliamentary constituencies	<p>Due to resource limitations and risk of disclosure control, it is not feasible to accommodate every geography type that may be beneficial to users. As such, strategic choices are required to prioritise geographies and breakdowns that are most valuable and commonly used by the majority of users. Please also see response to question 14 of the survey as this is also applicable to geographies which result in more granular data.</p>
Further breakdown of 'other' dementia type	<p>This information will be considered for inclusion in future publications. There are however some limitations which may impact whether these can be included within future extracts*.</p> <p>In 2025/26 the 'Other dementia types' subtype was divided into 'Other specified dementia types' and 'Other unspecified dementia types'. The current subtype groupings do contain several SNOMED codes which could potentially be further grouped, however, creating new categories requires meeting specific criteria, having defined inclusion standards, and ensuring that appropriate SNOMED codes are available and are actually used in primary care records. Where further breakdowns are not sufficiently coded, the resulting data would likely be subject to disclosure control measures due to small numbers and issues regarding patient confidentiality, thus in turn affecting the quality of the statistics. The interactive dashboard within the <a href="#">PCD Refset Portal</a> provides a user friendly method of understanding which SNOMED codes are included within each dementia type breakdown (including 'Other specified' and 'Other unspecified', and can be used in conjunction with the <a href="#">SNOMED Code Usage publication</a> to understand how frequently SNOMED codes are used within primary care records.</p>

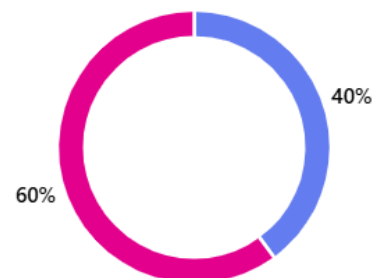
<p>More granularity of comorbidities e.g. specific comorbidities rather than grouped, intersection with learning disabilities</p>	<p>This information will be considered for inclusion in future publications. There are however some limitations which may impact whether these can be included within future extracts*.</p>
<p>Stable time series data</p>	<p>This is something we are aiming to provide with simplified, consolidated publication outputs as proposed in Proposal 6. A simplified output enables the structure of the data to remain consistent regardless of whether the contents of the dataset are changed to meet requirements i.e., measures are added/removed/altered, which in turn makes it easier to collate data across several time points to create a time series.</p> <p>Due to annual updates of the underlying data source for this publication, it has historically been necessary to revise publication outputs each year, resulting in frequent modifications to both content and format. These updates have typically involved collaboration with key stakeholders to balance their data needs with available analytical resources for development. As the dataset continues to expand, it is no longer practical to produce and publish several months of data per release given current analytical capacity therefore the approach of simplified outputs has initially been prioritised.</p> <p>Where measures are introduced or altered, it is also not possible to provide a consistent stable time series as it is not feasible to retrospectively collect data for these measures.</p>

\*There are several reasons for which it may not be possible to collect or disseminate data including:

- poor recording of certain characteristics within primary care records i.e., it is possible for this information to be recorded within clinical systems but completion or consistency of recording is poor
- limited clinical coding for certain/specific diagnoses in primary care records e.g., patient may have a generic clinical code for dementia, but the specific type of dementia they have, or the severity of their dementia is not coded
- absence of a legal framework supporting the collection of data, such as information on protected characteristics.

6. Do you support Proposal 2 to remove the time series from the publication?

- Yes 6
- No 9



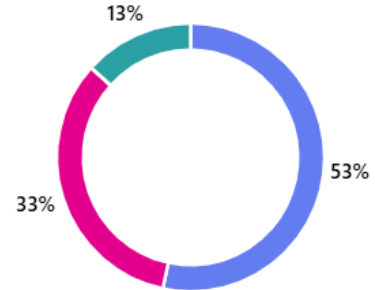
7. Please provide a reason why you don't agree with this proposal (this is really helpful for us to assess the impacts of the change on users).

Overall, respondents who commented said the time series is essential for tracking dementia diagnosis trends and monitoring progress over months/years, supporting evaluation, strategy and benchmarking. Several highlighted that removing the published time series would reduce usability and accessibility, forcing organisations

to compile data themselves (increasing time, risk of error and inconsistencies) and potentially disrupting automated reporting (e.g., Power BI). A small number were unsure what the proposal meant or gave very brief responses, and one suggested retaining a consolidated extract (e.g., annual/quarterly) or providing a simple multi-period CSV at publication.

8. Will the removal of the time series within each publication impact your ability to monitor progress in improving services?

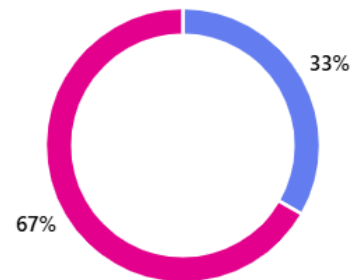
- Yes 8
- No 5
- N/A 2



**Response:** NHS England is upholding this proposal as it will still be possible for users to determine a time series and monitor progress over quarters/years using the outputs within each individual publication release; time series data from previous releases will still be available and there are no plans to remove this.

9. Do you support Proposal 3 to remove the national excel summary file from the publication?

- Yes 5
- No 10



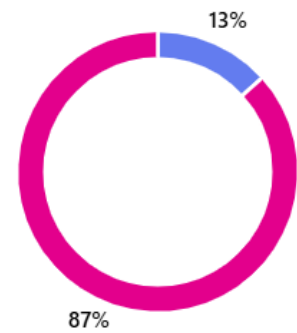
10. Please provide a reason why you don't agree with this proposal (this is really helpful for us to assess the impacts of the change on users).

Overall, respondents who commented said the national Excel summary provides an accessible, trusted snapshot that supports benchmarking against national/local baselines and monitoring performance. Several emphasised that removing it would reduce usability for non-analysts and force organisations to recreate consistent views themselves - adding time/resource burden and increasing the risk of inconsistency. Some also highlighted the importance of having a single place to view key performance/clinical measures (e.g., diagnosis rates and antipsychotic prescribing). A small number gave very brief or unclear responses (e.g., "not sure").

**Response:** NHS England is upholding this proposal and will cease production of the national excel summary as currently, a significant portion of resource is allocated to updating and verifying the code to produce the national Excel summary, resulting in a resource demand that exceeds available capacity. It will still be possible to calculate all of the figures currently in the national excel summary from data published in the CSV files.

11. Do you support Proposal 4 to remove the Dementia Diagnosis Rate indicator at Local Authority Level?

● Yes 2  
● No 13



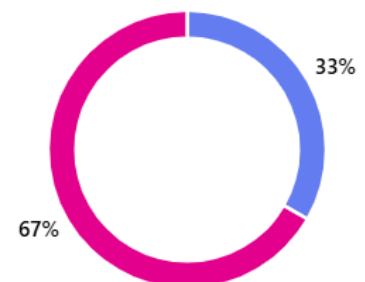
12. Please provide a reason why you don't agree with this proposal (this is really helpful for us to assess the impacts of the change on users).

Most respondents emphasised commissioning/contracting and provider model management (resource alignment, locality/provider differences). Another frequent theme was geographic granularity whereby users need varying local authority level data (LA / District). Overall, comments stress that LA level DDR is needed to manage commissioning locally, spot variation/inequalities, and hold systems to account; several suggest improving the production process (automation) rather than removing the output.

**Response:** NHS England will withdraw this proposal and continue to produce and publish the Dementia Diagnosis Rate indicator at Local Authority level.

13. Do you support Proposal 5 to aggregate all data to sub ICB level and remove disclosure control?

● Yes 5  
● No 10



14. Please provide a reason why you don't agree with this proposal (this is really helpful for us to assess the impacts of the change on users).

Overall, respondents mainly argued that aggregating outputs to sub-ICB level would remove the geographic granularity and multiple area definitions (e.g., local authority, district/constituency, and GP practice-level) needed for targeted interventions, commissioning and tender/bid work. Several also stressed the importance of benchmarking and monitoring local trends against the national picture. A smaller number referenced transparency/disclosure-control considerations, and one suggested a compromise approach (e.g., only aggregating low-count practices) rather than removing granularity entirely. A couple of responses indicated uncertainty about what the proposal entailed.

**Response:** The majority of measures within the publication are currently published at sub-ICB level only therefore users would experience no difference in the granularity of these measures.

All published data require an approved risk assessment and/or approval from the Disclosure Control Board regarding potential breaches of patient confidentiality and proposed disclosure control measures to account for this.

The decision regarding the geography level at which measures are published is largely dictated by the principles set out in the [Code of Practice for Statistics](#) which make it unsuitable to share more granular data (e.g. practice level) for certain measures due to disclosure control and patient confidentiality guidelines. The code states that producers of statistics must balance the need to produce **quality** statistics which add **value** whilst ensuring confidentiality within those outputs to maintain **trustworthiness** (in both the organisation and the data itself). Where practice level data is deemed to breach patient confidentiality e.g. due to small numbers or protected characteristics, it is possible to apply disclosure control measures such as rounding and/or suppression however this can be detrimental to the quality and value provided within those statistics and it becomes more beneficial to apply alternative disclosure control measures such as aggregation of data to higher geography levels. The antipsychotic prescribing measures within the PCDD publication provide an example of this whereby ~80% of values are suppressed at practice level and as part of this consultation it was proposed that this data will be more accurate and of higher value to users if aggregated to sub ICB level without rounding and suppression.

15. Are there any areas where the removal of GP practice level data would negatively impact your commissioning and service planning?

Overall, respondents who said GP practice level data matters emphasised the need to target support and improvement at specific practices/PCNs, differentiate commissioning approaches (e.g., where enhanced services apply to some practices but not others), and evaluate locally delivered services and referral pathways. Several highlighted that granular practice geography supports insight packs for bids/tenders, resource modelling, and identifying variation/inequalities (including inclusion and community access) at local authority level. A sizeable minority reported little or no current impact (they do not use practice level outputs or use alternatives such as QOF), though one noted it would limit future analysis unless access routes (e.g., DARS) are clearly supported.

**Response:** Table 2 below shows the measures which NHS England currently publish at practice level alongside our response and rationale regarding which measures will continue to be published at practice level, and which will be aggregated to sub ICB level as per proposal 5.

**Table 2: Response to practice level measures**

Measure (currently published at practice level)	NHS England Response	Rationale
Dementia Register measures: <ul style="list-style-type: none"> <li>• Aged 0-65</li> <li>• Aged 65+</li> </ul>	NHS England will withdraw this proposal and will continue to publish these measures at practice level as they were previously published.	
Antipsychotic Prescribing measures: <ol style="list-style-type: none"> <li>1. Count of patients on dementia register <b>with</b> a diagnosis of psychosis</li> <li>2. Count of patients on dementia register <b>without</b> a diagnosis of psychosis</li> <li>3. Count of patients on dementia register <b>with</b> a diagnosis of psychosis who have been prescribed antipsychotic medication</li> <li>4. Count of patients on dementia register <b>without</b> a diagnosis of psychosis who have been prescribed antipsychotic medication</li> </ol>	This proposal will be upheld for the antipsychotic prescribing measures. These counts will be aggregated to sub ICB level but will have no suppression or rounding applied.	The antipsychotic prescribing measures which are currently published at practice level are currently heavily suppressed (~80% counts suppressed) therefore data quality is extremely low.  As per the code of practice, NHS England has deemed it more appropriate to publish higher quality data without suppression at the higher geography level of sub ICB, as opposed to heavily suppressed data at the GP practice level.

<p>Assessment/Referral measures:</p> <ol style="list-style-type: none"> <li>1. Number of patients with a record of <b>receiving an assessment for dementia</b> by the GP practice since 1 April of the reporting year who have <b>declined a memory assessment</b> in the last 12 months</li> <li>2. Number of patients with a record of <b>receiving an assessment for dementia</b> by the GP practice since 1 April of the reporting year who have <b>declined a referral to a memory clinic</b> in the last 12 months</li> <li>3. Number of patients with a record of <b>receiving an assessment</b> for dementia by the GP practice since 1 April of the reporting year</li> <li>4. Number of patients with a record of <b>receiving an assessment</b> for dementia by the GP practice since 1 April of the reporting year who have <b>also received an initial memory assessment</b> since 1 April of the reporting year</li> <li>5. Number of patients with a record of <b>receiving an assessment</b> for dementia by the GP practice since 1 April of the reporting year who have <b>also been referred to a memory clinic</b> since 1 April of the reporting year</li> </ol>	<p>This proposal will be upheld and these counts will no longer be published at GP practice level.</p>	<p>These measures have been removed from the Core GP Contract service extract which is the dataset that underpins this publication and will therefore no longer be available to publish at practice level.</p> <p>Two associated measures are being introduced:</p> <ol style="list-style-type: none"> <li>1. the number of referrals to a memory clinic within the last 12 months</li> <li>2. the number of patients referred to a memory clinic within the last 12 months</li> </ol> <p>As these are new measures being introduced to the dataset and publication it is standard practice to initially publish these at a higher geography level.</p>
<p>Care plan / medication review measures:</p> <ol style="list-style-type: none"> <li>1. Number of patients who <b>chose not to receive</b> a dementia <b>care plan</b> or dementia <b>care plan review</b> in the last 12 months</li> <li>2. Number of patients with a record of <b>receiving</b> a dementia <b>care plan</b> or dementia <b>care plan review in the last 12 months</b></li> <li>3. Number of patients with a record of <b>receiving</b> a dementia <b>care plan</b> or dementia <b>care plan</b></li> </ol>	<p>NHS England will withdraw this proposal and will continue to publish these measures at practice level as they were previously published.</p> <p>Following approval from the disclosure control board, the medication review measure will no longer have suppression or rounding applied.</p>	

<p><b>review</b> in the last 12 months, who <b>received a medication review</b> since 1 April of the reporting year</p>		
<p>Practice list size measures: 1. Aged 0-65 2. Aged 65+</p>	<p>NHS England will withdraw this proposal and will continue to publish these measures at practice level as they were previously published.</p>	

16. Do you support Proposal 6 to consolidate the 12 CSV files into a 2 CSV output files?



17. Please provide a reason why you don't agree with this proposal (this is really helpful for us to assess the impacts of the change on users).

Overall, comments suggest the file consolidation is acceptable for some users provided that no measures or breakdowns are lost and outputs remain clearly labelled. Others emphasised that disaggregated data (including protected characteristic breakdowns) is essential for analysis and there is no easy alternative source. One response highlighted that local authorities rely on this dataset for adult social care commissioning, service planning and population needs assessment. A couple of respondents had no particular opinion or did not understand the proposal.

**Response:** NHS England will proceed with the proposal to consolidate publication outputs into fewer files; however, there will be 4 data CSV files instead of the previously proposed 2. Please see the [Proposed Outputs](#) section below for further detail on which measures are contained within each file and at which geographical aggregations. Please note that the two dementia diagnosis rate CSVs (LA and NHS geographies) will continue to be published and will remain identical to what is currently published.

The majority of the data will remain in a similar format to the current CSV files in terms of column headings, datatypes, measure breakdowns and granularity i.e. data which is currently published at sub ICB level in separate CSVs will continue to be published at sub ICB level but this will be within a single consolidated CSV file, with the addition of extra columns to enable easier identification of the different measures. Fewer CSV files provides the benefit of there being a single source of the truth, as opposed to several variations of the same data (e.g., some containing breakdowns of dementia diagnoses by sex and 5 year age band, whereas others contain dementia diagnoses by wider age bands, and with no sex breakdown) across several different files.

This was not previously possible as the 13 month time series across all measures made the file size unmanageable, as well as the complexities involved with applying differing disclosure control rules regarding suppression and rounding to different measures. The proposal to remove suppression and rounding to measures published at sub ICB level negates the need for this complex processing across different measures thus allowing a single consolidated CSV file containing all measures aggregated to sub ICB level.

With the exception of antipsychotic prescribing data, data which is currently published at practice level will continue to be published at practice level within the practice level aggregations CSV file (see Table 2 above for further information).

Further information regarding the agreed outputs can be found in the [Outcome](#) section below.

18. Please add any further comments you would like to feed into this consultation below.

Overall, the additional comments reinforce two main messages:

(1) strong concern that reducing the dataset or removing local authority level reporting would weaken local strategy, commissioning and contract management, and could disadvantage people with dementia

(2) the need for transparency, flexibility and stakeholder involvement as dementia intelligence products are redesigned (including calls for bespoke geographies and for councils/LGA and voluntary sector partners to be involved). Two respondents considered most proposals acceptable provided that breakdowns are retained and clearly labelled.

**Response:** NHS England and the Department for Health and Social Care (DHSC) are currently working with stakeholders to identify a suitable alternative route to provide further analyses of dementia data as part of a wider re-design of the way that intelligence on dementia will be produced and disseminated. We will provide an update on this as and when further information is available.

## Outcome

After considering the feedback provided, NHS England is revising the proposed changes to effectively address users' principal concerns.

## Proposed Outputs - Final

Following approval from the Disclosure Control Board, the outputs published within the Primary Care Dementia Data publication will be as follows from July 2026:

1. Estimated Dementia Diagnosis Rates (NHS geographies) – **no change**
2. Estimated Dementia Diagnosis Rates (LA geographies) – **no change**
3. Dementia Measures (Sub ICB Level)
  - a. Dementia diagnoses (5 year age band/sex breakdowns)
  - b. Dementia diagnoses (ethnicity breakdowns)
  - c. Dementia diagnoses (dementia type breakdowns)
  - d. Dementia diagnoses (residence type breakdowns)
  - e. Referrals to memory clinic within 12 months – **new indicators**
  - f. New incidence of dementia
  - g. Young onset dementia
  - h. Dementia with delirium
  - i. Dementia with palliative care
  - j. Mild cognitive impairment (5 year age band/sex breakdowns)
  - k. Dementia diagnoses (with/without psychosis)
  - l. Antipsychotic prescribing (with/without psychosis)
  - m. Prescribing (donepezil, rivastigmine, galantamine / memantine / combination) – **new indicators**
  - n. Frailty – **new indicators**
  - o. Patient list (5 year age band/sex breakdowns)
4. Dementia Measures (Practice Level)
  - a. Dementia diagnoses (aged 0-64)
  - b. Dementia diagnoses (aged 65+)
  - c. Care plan reviews (received/declined)
  - d. Medication reviews
  - e. Patient list (aged 0-64, 65+)
  - f. Patient list (aged 0-65+)

Sample outputs can be found here: <https://digital.nhs.uk/data-and-information/publications/statistical/primary-care-dementia-data/pcdd-consultation-2026#sample-outputs>



PCDD-csv-outputs-ex  
ample.zip

## Next Steps

The proposed next steps will be:

- This document will be attached to the consultation page, as well as the series and publication pages from 2025/26. We will also circulate to the interested parties that were initially notified about the consultation.
- Technical development and testing of new analytical pipeline required to ingest, process and output data in the finalised output format.
- Collection and publication of first quarterly publication in July 2026 for Q1 2026/27 data (April-June 2026). This will be in the new publication format.
- Continue conversations with stakeholders to identify a suitable alternative route to provide further analyses of dementia data as part of a wider re-design of the way that intelligence on dementia will be produced and disseminated.

For any enquiries or additional feedback please contact our generic mailbox ([england.gpses@nhs.net](mailto:england.gpses@nhs.net)).