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Dementia assessment and referral data collection

Outcome of consultation

May 2021

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1. Summary

In January 2020, we (NHS England and NHS Improvement) launched a consultation seeking views from stakeholders on the suitability of the dementia assessment and referral (DAR) data return. The aim of the consultation was to help determine whether the data collection should remain open or be closed. This document summarises the responses received and sets out the next steps. These are to:

- Close the DAR data collection, retaining the current suspension until the end of the first quarter of the financial year 2021/22, by which time the closure will be completed.
- In collaboration with stakeholders, progress with the development of a broader, more practical way of working to support provision and quality of dementia and delirium care within trusts and to ensure appropriate transparency of this care.
- Use and collate information through sources of data already routinely collected to avoid adding additional burden to systems.

2. Background

A key commitment in the [NHS Long Term Plan](#) – building on the Prime Minister’s challenge on dementia 2012,¹ 2015² and 2016³ – is to deliver improvements in the care we provide to people with dementia and delirium. This includes early diagnosis and good quality treatment and support, whether they are in hospital or at home.

The DAR was a national commissioning for quality and innovation (CQUIN) framework, introduced in April 2012. It was intended to raise the profile of dementia case finding in acute trusts and increase identification of dementia on admission as an emergency, and to ensure appropriate assessment and referral.

¹ https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/215101/dh_133176.pdf

² <https://www.gov.uk/government/publications/prime-ministers-challenge-on-dementia-2020>

³ <https://www.gov.uk/government/publications/challenge-on-dementia-2020-implementation-plan>

When the DAR CQUIN was retired, its targets were added to the NHS Standard Contract and became a mandatory return. NHS Digital collected information on NHS activity in England through the DAR data returns submitted by trusts. We published the returns from September 2013 to February 2020.

The data collection reported on the number and proportion of patients aged 75 and over admitted as an emergency for more than 72 hours in England, who were identified as potentially having dementia, appropriately assessed, and where appropriate, referred on to specialist services.

However, data quality declined steadily. The last DAR data release was for February 2020. Thirteen trusts out of 143 were unable to submit data and the data quality of some other submissions was poor.

Recognition of this – in addition to anecdotal feedback regarding the burden of the collection, lack of resource, and the data not being utilised in full locally – led to a consultation on the value of the collection and consideration of a possible replacement.

Due to the COVID-19 pandemic, the DAR data collection was paused at the end of March 2020 and has not yet been resumed. This decision was informed by the Office for Statistics Regulation's guidance on ['Changes to statistical outputs during the coronavirus outbreak'](#).

3. Responses

3.1 Overall number of responses and types of responders

The consultation took place between 9 January and 5 March 2020. Responses were invited from all stakeholders involved in the data collection including acute trusts, foundation trusts, clinical commissioning groups (CCGs), clinical networks, commissioning support units (CSUs) and the third sector. In all, there were 93 valid responses from a range of health and information management professions.

3.2 Key responses and themes from the consultation

Fixed category questions were posed to enable respondents to select a fixed response, to facilitate a view as to whether the data collection is seen as favourable or not. To enable provision of some contextual information to the fixed categories addressed, free text fields were also included.

Key questions, responses and recurring themes include:

1. Do you think the DAR data collection should remain open or be closed?

Of all respondents, 46% thought the collection should be closed, 34% thought it should remain open and 19% indicated they did not know.

Those who thought the DAR should remain open indicated they believe it is used to maintain the focus of identifying dementia within acute settings. However, respondents who said the DAR should close indicated doubts about its relevance and impact. They also suggest there should be an alternative or something else put in place. Some responders felt that either way there is improvement required.

2. To what extent do you find the published data from the DAR collection useful or not?

52% of all respondents reported they did not find the published data useful, compared with 34% who said it was useful, and 14% who did not know.

Participants who said they did not find the DAR data useful indicated they believe there are alternatives, have concerns over the data quality and do not tend to use the data.

However, respondents who signalled they find the DAR data useful indicated believe it provides an indication of performance.

3. Do you think the DAR collection could be improved – be it the process of collecting the data or the published data itself?

66% of all respondents reported they thought the DAR collection could be improved.

4. Do you experience any problems in carrying out the DAR data collection?

63% of acute trust respondents indicated they had problems carrying out the collection.

5. Has the DAR been used to improve practice/outcomes?

44% of acute trust respondents said the DAR had been used to improve practice/outcomes, 37% said it had not and 19% did not know.

6. Do you think the benefits of the DAR collection are worth the effort of collection?

63% of acute trust respondents did not agree that the benefits were worth the effort.

3.3 Alternatives to the DAR data collection

To enable a deeper understanding of the views of respondents regarding consideration of the closure of the DAR, we asked:

If the national DAR data collection was stopped what do you think would help to ensure that dementia and delirium case finding, assessment and referral continue as usual?

A large number of respondents suggested alternatives. These have been broken down into key categories including:

- 1. Change the focus of the data collection:** 62.5% of respondents who indicated the focus of the data collection should be changed, suggested that delirium should be addressed.
- 2. Improve assessments and recording of information:** for example, a mandatory 4AT (a rapid clinical assessment for delirium), adhere to NICE quality standards, screen for frailty on admission, ensure the information is part of discharge letters, joined up working with quality reporting that reflects the standard of care and supports assurance.
- 3. Extend the age criteria for assessment:** for example, identifying delirium and dementia in younger patients, extending the DAR criteria to include those under 75 years of age.

4. **CQC assessments and inspections**
5. **National or local audits** to highlight assessments and care provided
6. **Change the setting of assessments:** for example, primary care for dementia and acute care for new or acute confusion.

4. Next steps

4.1 Closing the DAR data collection and developing an alternative approach

In summary, the majority of respondents support the closure of the DAR, and many have found the data collection problematic and burdensome. The majority of those who do not currently find the DAR useful believe there are better ways to drive up quality of assessments.

We will therefore formally close the DAR data collection as of June 2021.

In collaboration with stakeholders, we will progress work to develop a more practical, quality-focused, less burdensome alternative to the DAR, to support the provision of care for people with delirium and dementia in hospital.

Delirium and dementia care in hospital is of critical importance, so action will be taken to ensure an alternative brings appropriate transparency and increases focus, with overall aim to improve provision.

4.2 Considerations in developing an alternative to the DAR

A clinical task and finish group has been established to consider the suggested alternatives offered by respondents in the consultation, to support the provision of appropriate, high quality care for people with delirium and dementia in hospital locally and ensure appropriate transparency of and focus on dementia care. Key stakeholders are also engaged as part of this process.

A broad, quality-focused approach has been agreed rather than a simple direct replacement of DAR indicators. Priorities identified to progress include:

- Establish a renewed emphasis on the identification of delirium.
- Focus on drawing together measures that help to signal the quality of care for people with dementia and delirium aligned with the [Dementia Well Pathway](#), as part of a suite of measures in the context of dementia and delirium care in the wider system, long-term.
- Capture and use existing data, already routinely collected, to minimise burden on the system and take a staged approach to address short to medium term and longer-term requirements.

4.3 Implementing an alternative to the DAR

A number of existing data sources and processes have been identified for investigation, to bring the required focus and accountability around dementia and delirium care in hospital. These include:

- [4AT](#), a rapid clinical assessment for delirium used in trusts.
- Measures provided in the [Secondary Uses Service \(SUS\) database](#) that address the identification and care of people with dementia and delirium.
- Use of the [Royal College of Psychiatrists National Audit of Dementia](#) which will include questions on delirium screening and follow up, to help address the quality of care for people with dementia and delirium in general hospitals.

On completion of investigation and confirmation of appropriate measures, we propose to:

- Collect and monitor metrics from existing data sources at a national level to ensure visibility and to inform further action. This will include consideration of metrics for equalities monitoring such as age, gender and ethnicity.
- Collate a benchmarking data set to provide view of variation in care for people with dementia and delirium, and identify priority areas requiring action and support.

- Share data via Dementia Clinical Networks and regional teams to ensure visibility at a local level and facilitate local accountability and action to identify areas of best practice and address issues of concern for improvement.
- Outline further metrics that may be useful to collect, monitor and act upon at a local level with expectations on local data usage.
- Explore publication of metrics as a future, longer term step.

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