National Audit of Dementia
Round 4 (2018)
Guidance for the Carer Questionnaire

April 2018

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The data collection period will be staggered as shown below. This is the guidance for the carer questionnaire.

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<th>Organisational checklist</th>
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Contacting the Project Team

For any queries, please contact the NAD Project Team at:

nad@rcpsych.ac.uk

You may also find the information you need on the website:

www.nationalauditofdementia.org.uk

Or you may contact the team individually:

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**Before you begin:**

**IDENTIFY** the key people you are going to work with. This is a complex audit which should not be carried out by a single lead. The guidance for each tool gives some suggestions of colleagues who could help you to collect and co-ordinate the return of the different types of data required.

**Let us know if we can help.** We are available to answer queries within office hours, or you can email us, and we will respond as soon as we can.

We look forward to working with you.
The Carer Questionnaire was a new tool developed for the third round of the audit in conjunction with the Patient Experience Research Centre at Imperial College London. It was designed to assess carers’ perceptions of care received by the person they care for, in addition to their satisfaction with their own involvement during the patient’s admission. It will be repeated in this fourth round of audit to allow for comparison between the rounds.

The questionnaire produces two scores, the carer rating of the overall quality of care, and the carer rating of the quality of information and communication.

Each hospital site is expected to organise the distribution of carer questionnaires to informal carers/family/friends, or professional carers such as key workers, visiting patients with dementia in hospital during **July 2018**. If you would like to extend the data collection period to maximise returns, you may distribute questionnaires from 4th June until 21st September.

The questionnaires will be supplied in two packs of 100. Each questionnaire will have a prepaid envelope and a prize draw postcard attached. Also in the pack, will be promotional posters and leaflets.

**Input will be required from:**

- Your local audit lead;
- Carer experience lead/Dementia lead;
- Patient experience and PALS/quality improvement staff;
- Ward Managers on adult wards admitting patients with dementia;
- Staff working in dementia cafés or other services which support people with dementia and carers in the hospital.

**Estimated time to complete:**

The local audit lead should initially organise a meeting with the carer experience/dementia lead and staff member(s) from the patient experience quality improvement team/PALS to:

1. Discuss and organise the distribution of questionnaires to carers and publicising the questionnaire within the hospital;
2. Allocate responsibility to team members to distribute the questionnaires to carers visiting the wards during the data collection period (see below for details).

This will take up to an hour. A further 1-2 hours will need to be allocated for any follow up meetings required.

Ward team members responsible for handing out the questionnaires, will need to allocate an hour each week (probably spread over more than one day) for distribution.
Distributing your carer questionnaires

Carers of patients with known or suspected dementia (where known to family) should be offered the opportunity to complete a questionnaire if they come to visit the person in July 2018. If a hospital would like to extend the distribution period, questionnaires may be handed out from 4th June until 21st September 2018. The NAD Project Team will provide weekly updates to audit leads on the number of carer and staff questionnaires returned to us. We advise that you monitor these return rates and decide how long to distribute the questionnaires for based on this information.

The questionnaire can be given to any family members, friends or key workers and should be given in the run up to discharge or when the person is medically fit.

The questionnaire can be distributed on adult inpatient wards in the hospital from which people with dementia are discharged. You should exclude ICU, HDU etc. and any mental health and maternity wards. The questionnaire should not be distributed in A&E or outpatients departments.

We recommend that Ward Managers each nominate a Questionnaire Lead who will be responsible for distributing the questionnaire and recording the number they give out. The NAD Project Team will provide tally sheets and an overall distribution excel spreadsheet, to record the total number of questionnaires handed out. When data collection has closed, we will ask that you return the excel spreadsheet with the total number distributed to us. We will calculate your return rate using this information, so it is important that this is kept as accurate as possible. Please see APPENDIX A for the briefing for Questionnaire Leads.

The questionnaire can also be given at Dementia Cafés or advice sessions held on site during the data collection period, and distributed by patient experience leads, advice workers or PALS.

An online version of the questionnaire is available for any carers who prefer this method at www.CarerQ.org.uk. This is publicised on the leaflets and posters we will send to you.

If you have a carer questionnaire which you use in your hospital already, we are hoping that by informing you with many months’ notice that the carer questionnaire is taking place again, that you will be able to arrange to use the NAD questionnaire in July 2018 instead. You may choose however to give out both questionnaires during this time. We cannot accept a hospital’s own questionnaires – even if they ask similar or the same questions.

Return and Response rate

A return of at least 50 questionnaires should be aimed for.

We will email you a tally sheet and a spreadsheet which we ask you to use to keep track of the number of questionnaires distributed in your hospital. We can only provide you
with a response rate if you can tell us how many have been given out. This is especially important if you are a smaller hospital or if local reasons (such as demographics) will make it more difficult to achieve the target return.

It is important that this questionnaire is widely distributed as hospitals that have a return rate of fewer than 10, cannot be provided with a full report.

We will update the audit lead weekly on the number of carer and staff questionnaires we receive.

**Ideas for encouraging questionnaire returns:**

We will send you posters and leaflets to publicise the questionnaire in your hospital and we will be publicising it through social media and via our partners in the audit.

Below are some suggestions participants in Round 3 of the audit had on improving return rates locally:

- Some hospitals found it was better to encourage carers to fill in the questionnaire on site (in private) and then to offer to collect the sealed envelope and post it for them.
- Have a member of staff give the questionnaire to carers directly to explain why it is important and that it is designed to collate their views of the care received and to improve hospital care for people with dementia. Leaving questionnaires in a pile somewhere or next to bedsides sees very few returns.
- Give out the questionnaire to carers during visiting hours.
- Remind staff about the questionnaire at handovers, board rounds, 1:1s and through email. Encourage them to promote the questionnaire and achieve a high return.
- Display NAD posters (provided by the Project Team) on the notice boards on wards or on the back of toilet doors.
- Promote the survey through social media, on the hospital website or publicise via hospital newsletters. You can provide the link (www.CarerQ.org.uk) to the online questionnaire.
- Have a stand in the main entrance to the hospital, promoting the paper and online questionnaires.

**Prize Draw**

Carers completing the questionnaire will be able to enter a prize draw using the postcard attached to the questionnaire. The postcard is also prepaid and is returned to a separate address to the questionnaire, so that personal details cannot be linked to completed questionnaires.
The online questionnaire also gives the opportunity to enter the prize draw once completed, via a redirect to a separate form (details provided on the prize draw form cannot be linked to responses to the questionnaire).

**Distribution period**

The questionnaire can be distributed throughout the four month period (4th June to 21st September). **All hospitals must distribute the questionnaire in July 2018.**

You will be sent 200 questionnaires. We will not be printing anymore questionnaires for this Round of audit so please keep these packs safe when they arrive, so they are ready for the start of data collection. You may give out the questionnaire until the 21st September. We have allowed additional time for questionnaires to reach us by post.

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**PLEASE NOTE**

The carer questionnaire is intended to be completed anonymously. Each will have a pre-paid envelope attached to be sent back directly to the NAD Project Team. Any questionnaires completed on the ward should only be returned to staff to forward to the Project Team, if sealed within an envelope. Staff should not assist with completion of questionnaires, but patient/public volunteers or representatives may offer help.

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**Carer questionnaires in other languages**

We will have questionnaires available upon request in the following languages:

- Bengali
- Gujarati
- Polish
- Punjabi
- Turkish
- Urdu
- Welsh

We will automatically send hospitals located in Wales Welsh copies, so you do not need to request these.
What is the carer questionnaire and what are the benefits of completing it?

The carer questionnaire is part of the National Audit of Dementia and collects views from carers of people with dementia about the quality of care and communication in this hospital.

The role of the questionnaire lead is to identify carers of people with dementia visiting their ward or wards and give them the questionnaire with a brief explanation about what you are asking them to do. If the questionnaire is left by beds and not handed in person to the carer with an explanation, it is very unlikely to be completed.

The questionnaire is anonymous and has an information sheet, pre-paid envelope and pre-paid postcard for entry to a prize draw (to win one of five £50 vouchers for a high street store of their choice) attached. It takes about 5 minutes to complete the questionnaire.

Who should be given the questionnaire?

Family members and key workers visiting a person with known or suspected dementia during July 2018 should be offered a questionnaire to complete. Your hospital may also decide to hand out questionnaires in June, August and September.

The questionnaire does not use the term “dementia” so can be used if the person with dementia in hospital is unaware of, or does not agree with, their diagnosis. However, the questionnaire should not be given if memory problems have just become apparent and the family member may not be aware of them (i.e. there has been no discussion). It is best to offer the questionnaire to the carer during the run up to discharge, or when the person they are visiting is medically fit.

Why is it important that the questionnaire is distributed?

The carer questionnaire allows valuable insight into the quality of care provided by hospitals from the view of the carer. In the third round of audit, hospital sites returned a minimum of 1 questionnaire to a maximum of 104 questionnaires, with an average of 24. If you have any questions, contact the NAD Project Team on 020 3701 2707 or 020 3701 2681.