# BMJ Open Quality Development and pilot testing of quality improvement indicators for integrated primary dementia care

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## ABSTRACT

**Background** Implementation of integrated primary care is considered an important strategy to overcome fragmentation and improve quality of dementia care. However, current quality indicator (QI) sets, to assess and improve quality of care, do not address the interprofessional context. The aim of this research was to construct a feasible and content-wise valid minimum dataset (MDS) to measure the quality of integrated primary dementia care.

**Methods** A modified Delphi method in four rounds was performed. Stakeholders (n=15) (1) developed a preliminary QI set and (2) assessed relevance and feasibility of QIs via a survey (n=84); thereafter, (3) results were discussed for content validity during a stakeholder and (4) expert consensus meeting (n=8 and n=7, respectively). The stakeholders were professionals, informal caregivers, and care organisation managers or policy officers; the experts were professionals and researchers. The final set was pilot-tested for feasibility by multidisciplinary dementia care networks.

**Results** The preliminary set consisted of 40 Qls. In the survey, mean scores for relevance ranged from 5.8 (SD=2.7) to 8.5 (SD=0.7) on a 9-point Likert scale, and 25% of all Qls were considered feasible to collect. Consensus panels reduced the set to 15 Qls to be used for pilot testing: 5 quality of care, 3 well-being, 4 networkbased care, and 3 cost-efficiency Qls. During pilot testing, all Qls were fully completed, except for well-being Qls. **Conclusion** A valid and feasible MDS of Qls for primary dementia care was developed, containing innovative Qls on well-being, network-based care and cost-efficiency, in addition to quality of care Qls. Application of the MDS may contribute to development and implementation of integrated care service delivery for primary dementia care.

## **INTRODUCTION**

The complexity of primary dementia care, caused by the complex nature of this clinical syndrome, often associated comorbidity, and the multiple professionals involved poses a great challenge to healthcare systems.<sup>1 2</sup> As a result, dementia care is often fragmented, which leads to poor quality and inefficient care, because different professionals provide unaligned services, resulting in patients' and caregivers' low satisfaction with the services offered.<sup>3-5</sup> Care integration is considered

important to overcome fragmentation and improve quality of care.<sup>6-9</sup>

Integrated care is defined as the delivery of a continuum of care, designed to meet multidimensional needs of the population and the individual, by a coordinated multidisciplinary team of professionals.<sup>10</sup> To achieve dementia integration, a transition towards care network-based care is needed.<sup>11-13</sup> DementiaNet, a healthcare innovation consisting of 36 multidisciplinary networks of primary care professionals, facilitates such a transition.<sup>11 14</sup> The essential characteristics of DementiaNet are summarised in box 1. To evaluate the effectiveness of such an integrated care approach in practice and to identify areas for improvement, a tailored, feasible and valid set of quality indicators (QIs) is needed.<sup>15</sup> This need is based on extensive literature search and expert consensus on QIs based on patient-reported outcomes of physiotherapy and geriatric patient care showing that, when connected firmly with feedback loops to the healthcare, it can improve outcomes and efficiency on the levels of direct patient care and health services.<sup>16</sup> Several QI sets have been developed to assess quality of primary dementia care, including a set of six QIs used to assess DementiaNet networks' quality of care.<sup>17–21</sup> However, these sets do not sufficiently adopt the interprofessional context. Furthermore, existing integrated QI sets do not include well-being issues,<sup>22</sup> or their large number of indicators limits feasibility.<sup>23</sup> Therefore, the aims of this study were to construct a content-wise valid minimum dataset (MDS) of QIs to measure quality of integrated primary dementia care in co-creation with stakeholders and to pilot test its feasibility in practice.

# METHODS

# Design

Between May 2018 and July 2019, a modified Delphi method was conducted. This

# Box 1 What is DementiaNet?

DementiaNet is a Dutch healthcare innovation focusing on primary network-based care. Networks of professionals from medical, care and social disciplines, caring for the same persons with dementia (PWDs), are formed.<sup>14</sup> Currently, the DementiaNet approach is being applied in more than 40 networks. DementiaNet facilitates gradual development of self-organised primary care networks providing highquality integrated dementia care. Strategies to achieve this include clinical leadership and quality improvement cycles. With DementiaNet, we address needs of professionals (increase knowledge, skills and collaboration); PWD and informal caregivers (personalised care, integration of care and welfare, care coordination and continuity of care); and the healthcare system (local level, tailor-made, system approach, cost-effectiveness and sustainable approach). Full description can be found in the paper of Nieuwboer *et al*,<sup>14</sup> and the first quantitative evaluation of effectiveness is described by Richters et al.<sup>2</sup>

methodology is particularly useful to reach agreement on content validity and feasibility; inclusion of a large number of participants prevents domination during the consensus process.<sup>24 25</sup> In four rounds, we (1) developed a preliminary QI set, (2) sent out a survey to stakeholders, (3) discussed results during a stakeholder consensus meeting and (4) discussed results during an expert consensus meeting. Thereafter, the final set was pilottested for feasibility.

## Delphi method

#### Participants

Participants were stakeholders and experts in the field of primary dementia care. Stakeholders were healthcare professionals, informal caregivers, and care organisation managers or policy officers. Experts were professionals and researchers, including all authors, specialised in research or care. Professionals from each discipline were balanced for each round.

Stakeholders for the first physical meeting (round 1) and survey (round 2) were invited by email and recruited via the DementiaNet newsletter database to ensure their familiarity with integrated primary dementia care. Additional caregivers for the survey were recruited via the outpatient clinic or through project contacts. Stakeholders interested to participate in round 1 and participants who showed interest during round 2 were invited for the second physical meeting (round 3). Purposeful sampling was used for the meetings (rounds 1 and 3); we made sure all relevant primary care disciplines were represented, and the representatives were seen as experts by their colleagues. To include non-expert opinions as well, random sampling of a large group of stakeholders was used for the survey (round 2).

Participants for the expert consensus meeting (round 4) were selected based on their involvement in the DementiaNet project; all were employees at the Radboudumc Alzheimer Centre or at the General Practitioner Organisation of Nijmegen.

## Delphi rounds 1. Development of the preliminary set

In a brainstorm session with stakeholders, relevant and easy-to-implement indicators were pre-selected, covering three predefined topics: (1) quality of dementia care (process indicators, patient level); (2) well-being of person with dementia (PWD) and their caregiver (outcome indicators)<sup>15 26</sup>; and (3) network-based care (process indicators network level).<sup>27</sup> Additionally, the existing quality of care indicators used by DementiaNet networks were included in the discussion.<sup>11 21</sup> Afterwards, the authors reviewed previous QI sets developed by their group<sup>17 21</sup> and subsequently composed the preliminary set for the stakeholder survey.

## 2. Survey to stakeholders

In an electronic survey, the preliminary QI set was presented to stakeholders. Consent was asked at the beginning of the survey. Caregivers were only asked to comment on quality of care and well-being indicators. A glossary was included to explain medical jargon. Caregivers could request a paper version of the survey.

Stakeholders were asked to rate all indicators individually on relevance by using a 9-point Likert scale from 1 (not relevant) to 9 (highly relevant), to identify the three most important indicators per topic and to add missing indicators. Professionals were also asked to assess QIs on measurement feasibility (yes/no).

Coded questionnaire responses of professionals and caregivers were analysed separately to determine the mean relevance, top 3 indicators and feasibility of all indicators. An indicator was judged feasible when over 50% of respondents indicated the data feasible to collect.<sup>28</sup> Descriptive analyses were performed using IBM SPSS V.25.0.

## 3. Stakeholder consensus meeting

Survey results, for professionals and caregivers separately, were presented to a stakeholder panel for their judgement of content validity. Inclusion of additional indicators, revision of QIs, and exclusion based on relevance and feasibility were discussed.

## 4. Expert consensus meeting

Results of the survey and stakeholder consensus meeting were distributed to the experts a week prior to the meeting. The expert panel composed the MDS for pilot testing, based on the rated relevance, arguments from the consensus meeting, content validity, feasibility and correspondence with current guidelines.

# **Pilot testing**

#### Participants

DementiaNet networks were selected to pilot the new set of indicators (MDS) based on their proactive attitude and timing of their networks' yearly assessment.<sup>11</sup>

| Table 1  | Participants  | ' backgrou | und and y | ears of ex | xperience |
|----------|---------------|------------|-----------|------------|-----------|
| in numbe | ers (and perc | entages fo | r round 2 | ) defined  | per round |

| · · ·  | 0       |           | /       | •       |
|--|---------|-----------|---------|---------|
| Characteristic                                       | Round 1 | Round 2   | Round 3 | Round 4 |
| Number of participants                               | 15      | 114       | 8       | 7       |
| Female, n (%)  | 11      | 100 (88%) | 6       | 6       |
| Dominant background,<br>n (%)                        |         |           |         |         |
| Researcher   | -       | 1 (1%)    | -       | 3       |
| Healthcare professional                              | 8       | 94 (82%)  | 5       | 2       |
| General practitioner                                 | 1       | 10 (9%)   | 1       | 1       |
| Practice nurse                                       | 1       | 12 (11%)  | -       | -       |
| Case manager   | 2       | 21 (18%)  | 1       | -       |
| Community nurse                                      | 1       | 29 (25%)  | 1       | -       |
| Other  | 3       | 22 (19%)  | 2       | 1       |
| Manager/policy officer                               | 5       | 7 (6%)    | -       | 2       |
| Informal caregiver                                   | 2       | 12 (11%)  | 3       | -       |
| Years of experience<br>dominant background,<br>n (%) |         |           |         |         |

| 5–10 | 5 | 25 (27%)* | 3† | - |
|------|---|-----------|----|---|
| >10  | 5 | 51 (56%)* | 3† | 6 |

\*Years of experience of professionals and managers/policy officers; n=92. †n=7.

## Pilot test

Networks reported their experiences via an open-ended questionnaire, including QI relevance, feasibility of data collection and added value of outcomes.

The authors narratively analysed the questionnaires and evaluated the collected data to determine measurement feasibility. Acceptable measurement feasibility was defined as data collection per QI completed for over 80% of the cases. Thereafter, the set of indicators was adjusted accordingly.

## RESULTS

We invited 312 stakeholders for round 1; 19 were willing to participate, and 15 were able to participate. Thirty-one were invited for round 3; 8 were able to participate. Four stakeholders participated in both rounds. Diversity in stakeholders' characteristics was large, with general practitioners, practice nurses, case managers, community nurses and caregivers being most represented. All invited experts agreed to participate. Table 1 describes participants' characteristics.

## **Indicator development**

Figure 1 summarises the process of QI development.

## 1. Development of the preliminary set

Fifteen stakeholders developed the preliminary QI set. The meeting yielded a set of 40 indicators; 11 for quality of care, 12 for well-being of PWD and their caregiver and 17 for network-based care, including all 6 QIs previously used by DementiaNet.<sup>11 21</sup> No indicators were added by the authors after reviewing previously developed QI sets.



Figure 1 Subsequent stages of the QI development process for integrated primary dementia care. QI, quality indicator; QoC, quality of care.

## 2. Stakeholder survey

Eighty-four stakeholders fully, and 30 stakeholders partly completed the assessment of the 40 QIs (table 1). Mean relevance scores per indicator ranged from 6.0 (SD=2.1) to 8.5 (SD=0.7) for professionals and from 5.8 (SD=2.7) to 8.3 (SD=0.9) for caregivers. Professionals considered collection of 25% of the indicators feasible. Table 2 shows relevance, top 3 and feasibility scores per indicator.

| Derive the function of   |                 |  | Health | hcare profession        | als and man | agers/policy officers |      |                      | Informal careç | jivers                  |    |                 |                          |               |
|--|-----------------|--|--------|-------------------------|-------------|-----------------------|------|----------------------|----------------|-------------------------|----|-----------------|--------------------------|---------------|
| Americation (a)         Gal (a)  | Category        | Short notation QI*   |        | Relevance,<br>mean (SD) | ٤           | Priority, n (%) n     | цщ у | easibility,<br>∍s/no |                | Relevance,<br>mean (SD) | ٤  | Priority, n (%) | Final consensu<br>yes/no | s,<br>Remark  |
| Generative of the second of the sec  | Quality of care | Assessment of the caregivers' care                             | 101    | 8.2 (1.1)               | 66          | 28 (9%)               | 87   | Yes                  | ÷              | 7.8 (0.8)               | 36 | 4 (11%)         | No                       |               |
| International decision of the state of the stat  |                 | Case manager involved  | 102    | 8.3 (0.9)               | 66          | 53 (18%)              | 06   | Yes                  | ÷              | 7.3 (2.9)               | 36 | 6 (17%)         | Yes                      |               |
| Generation of the constraint of the constra  |                 | Future treatment wishes<br>discussed with PWD and<br>caregiver | 101    | 7.9 (1.2)               | 66          | 39 (13%)              | 88   | Yes                  | £              | 8.1 (0.7)               | 36 | 3 (8%)          | Yes                      |               |
| Gale of the POD classing<br>of a control for the POD classing of a control for the POD classing of a control for the POD classing<br>of a control for the POD c |                 | Geriatric assessment   | 102    | 7.0 (1.8)               | 66          | 16 (5%)               | 88   | No                   | 11             | 7.4 (1.6)               | 36 | 4 (11%)         | No                       |               |
| Gale for brond draumed         (0         (51,6)         (6         (10)         (51,6)         (6         (10)         (6)         (10)         (6)   |                 | Goals of the caregiver discussed                               | 100    | 8.0 (1.0)               | 66          | 17 (6%)               | 87   | No                   | 1              | 6.1 (2.9)               | 36 | 0               | No                       |               |
| Modelection         02         7.61         See 14/9         Se  |                 | Goals of the PWD discussed                                     | 100    | 7.6 (1.5)               | 66          | 29 (10%)              | 87   | Yes                  | 1              | 5.9 (3.0)               | 36 | 1 (3%)          | No                       |               |
| Productionationalizationa  |                 | PWD discussed in a multidisciplinary meeting                   | 102    | 7.6 (1.5)               | 66          | 42 (14%)              | 88   | Yes                  | Ŧ              | 7.0 (2.9)               | 36 | 4 (11%)         | Yes                      |               |
| Model         10         71(5)         80         8(%)         6         6         7(%)         80         7(%)         80         8(%)         80         8(%)   |                 | PWD discussed in a pharmacotherapeutic meeting                 | 102    | 7.05 (1.9)              | 66          | 6 (2%)                | 88   | 8                    | ÷              | 7.0 (2.2)               | 36 | 3 (8%)          | Yes                      |               |
| Support leaded or angle of the field of the fie  |                 | Psychoeducation offered to caregiver                           | 100    | 7.7 (1.5)               | 66          | 18 (6%)               | 87   | N                    | 12             | 6.5 (2.7)               | 36 | 4 (11%)         | No                       |               |
| Openational constraints         Mathematical constraints         Mathemat  |                 | Support offered to caregiver                                   | 66     | 7.8 (1.4)               | 66          | 26 (9%)               | 86   | Yes                  | 12             | 6.7 (2.3)               | 36 | 2 (6%)          | Yes                      |               |
| Witheling         Caragiver feets supported         85         61(7)         85         4(11%)         No           Caragiver involved in care PWO         83         22 (9%)         80         10         12         53 (0.9)         35         6 (17%)         No           Caragiver involved in care PWO         83         21 (9.0)         83         10 (4%)         80         10 (4%)         80         10 (4%)         No         No         No         No           Caragiver involved in care PWO         83         81 (1.0)         83         10 (4%)         80         No         <   |                 | Changing relationships<br>discussed with PWD and<br>caregiver  |        |                         |             | AN                    |      |                      |                | NA                      |    |                 | N                        | Added round 3 |
| Caregiver involved in care PWD         5         82 (13)         83         2 (93)         85         6 (173)         No         No           Caregiver involved in own care         83         81 (13)         83         10 (33)         83         10 (33)         83         10 (33)         No         No           Caregiver involved in own care         83         81 (10)         83         10 (33)         80         10 (33)         83         10 (33)         No         No         No           Formulated goal carefield         83         70 (16)         83         10 (3)         80         10 (3)         80         10 (3)         No   | Well-being      | Caregiver feels supported                                      | 83     | 8.5 (0.7)               | 83          | 48 (19%)              | 80   | N                    | 12             | 7.8 (1.0)               | 35 | 4 (11%)         | N                        |               |
| Caregiver knowled in own care         81         1(1,4)         83         10(4%)         80         No         No         No         No           Caregiver knowled in own care         81         81(1,0)         83         16(9%)         80         No         12         7.7(1,3)         35         3(9%)         No           Caregiver knowled         83         7.0(1)         83         16(9%)         80         No         12         7.7(1,3)         35         3(9%)         No           Funduated goal caregiver         83         7.0(1)         83         16(9%)         80         No         No         16         No           Funduated goal caregiver         83         7.0(1)         83         3(1%)         80         No         No         No         No           Funduated goal caregiver         83         8.0(1)         83         3(1%)         80         No         No         No         No         No           PUD reveal         83         8.0(1)         83         21(9%)         80         No         No         No         No         No           PUD reveal         83         8.0(1)         83         21(9%)         80         12 <t< td=""><td></td><td>Caregiver involved in care PWD</td><td>83</td><td>8.2 (1.2)</td><td>83</td><td>22 (9%)</td><td>80</td><td>No</td><td>12</td><td>8.3 (0.9)</td><td>35</td><td>6 (17%)</td><td>No</td><td></td></t<>   |                 | Caregiver involved in care PWD                                 | 83     | 8.2 (1.2)               | 83          | 22 (9%)               | 80   | No                   | 12             | 8.3 (0.9)               | 35 | 6 (17%)         | No                       |               |
| Caregivers known involved         B         11(1)         B3         16(%)         B0         No         17         13         3 (9%)         No           Formulated goal caregiver         83         70(14)         83         0         80         1         10         10         10           Formulated goal caregiver         83         70(14)         83         0         80         1         10         10         10           Formulated goal caregiver         83         60(21)         83         3(1%)         80         1         10         10         10           Formulated goal caregiver         83         80(11)         83         3(1%)         80         1         10         10         10         10           PWD Involved in om care         83         80(11)         83         21(8%)         80         10 <td< td=""><td></td><td>Caregiver involved in own care</td><td>83</td><td>8.1 (1.3)</td><td>83</td><td>10 (4%)</td><td>80</td><td>No</td><td>6</td><td>8.2 (0.8)</td><td></td><td>NA</td><td>No</td><td></td></td<>   |                 | Caregiver involved in own care                                 | 83     | 8.1 (1.3)               | 83          | 10 (4%)               | 80   | No                   | 6              | 8.2 (0.8)               |    | NA              | No                       |               |
| Formulated goal caregive         83 $70(16)$ 83 $70(16)$ 83 $70(16)$ 83 $70(16)$ 83 $70(16)$ 83 $70(16)$ 83 $31(16)$ 83 $31(16)$ 83 $31(16)$ 83 $31(16)$ 83 $31(16)$ 83 $31(16)$ 83 $31(16)$ 83 $31(16)$ 80 $10(16)$   |                 | Caregivers knows involved professionals                        | 83     | 8.1 (1.0)               | 83          | 16 (6%)               | 80   | No                   | 12             | 7.7 (1.3)               | 35 | 3 (9%)          | No                       |               |
| $ \begin{array}{llllllllllllllllllllllllllllllllllll$  |                 | Formulated goal caregiver                                      | 83     | 7.0 (1.6)               | 83          | 0                     | 80   | No                   |                | NA                      |    |                 | No                       |               |
| PWD feets supported         83         8.1(1)         83         60(24%)         80         No         7.5(2.3)         35         7(20%)         No           PWD involved in own care         83         8.0(1.1)         83         21(8%)         80         No         12         7.5(2.3)         35         7(3%)         No           PWD involved in own care         83         7.8(1.5)         83         20(8%)         80         No         12         7.1(2.2)         35         2(9%)         No           PWD knows contact         83         8.2(1.3)         80         No         12         7.1(2.2)         35         3(9%)         No           Presevarace time of the         83         8.2(1.3)         80         No         12         7.7(2.2)         35         6(17%)         Yo           Propositional         83         6.0(2.1)         83         33(13%)         80         No         12         7.7(2.2)         35         6(17%)         Yo           Propositional         83         6.0(2.1)         83         5(2%)         80         Yo         Yo         Yo           PWD satisfied with his/her dialy         No         12         5.8(2.7)         35         <  |                 | Formulated goal for PWD  | 83     | 6.0 (2.1)               | 83          | 3 (1%)                | 81   | No                   |                | NA                      |    |                 | No                       |               |
| PWD involved in own care         83         80 (1.1)         83         21 (8%)         80         No         12         7.0 (2.3)         35         2 (6%)         No           PWD knows contact         83         7.8 (1.6)         83         20 (8%)         80         No         12         7.1 (2.2)         35         3 (9%)         No           PWD knows contact         83         8.2 (1.3)         83         3 (13%)         80         No         12         7.1 (2.2)         35         6 (17%)         Yes           Persevenance time of the         83         8.2 (1.3)         83         33 (13%)         80         No         12         7.7 (2.2)         35         6 (17%)         Yes           Persevenance time of the         83         6.0 (2.1)         83         5 (2%)         No         Yes         Yes           Psychoactive medication for         83         6.0 (2.1)         83         5 (2%)         80         Yes         7.7 (2.2)         35         1 (3%)         No           Psychoactive medication for         83         6.0 (2.1)         83         5 (2%)         80         Yes         Yes         Yes           PWD satisfied with his/her daily         Mo         Yes  |                 | PWD feels supported  | 83     | 8.3 (1.1)               | 83          | 60 (24%)              | 80   | No                   | 12             | 7.5 (2.3)               | 35 | 7 (20%)         | No                       |               |
| PVD knows contact         83         7.8 (1.6)         83         2.0 (8%)         80         No         12         7.1 (2.2)         35         3 (9%)         No           Professional         Persevenance time of the<br>caregiver         83         8.2 (1.3)         83         3 (3%)         80         No         12         7.7 (2.2)         35         6 (17%)         Yes           Persevenance time of the<br>caregiver         83         6.0 (2.1)         83         5 (2%)         80         Yes         7.7 (2.2)         35         6 (17%)         Yes           Psychoactive medication for<br>more than 2 weeks         83         6.0 (2.1)         83         5 (2%)         80         Yes         7.7 (2.2)         35         1 (3%)         No           PND satisfied with his/her daily         Na         Na         Na         Na         Yes         Added round           Well-being related on for PWD         Made for PWD         Made for PWD         Made   |                 | PWD involved in own care                                       | 83     | 8.0 (1.1)               | 83          | 21 (8%)               | 80   | No                   | 12             | 7.0 (2.3)               | 35 | 2 (6%)          | No                       |               |
| Persevenance time of the         83         8.2 (1.3)         83         8.2 (1.3)         80         No         12         7.7 (2.2)         35         6 (17%)         Yes           caregiver         Psychoactive medication for<br>more than 2 weeks         83         5 (2%)         80         Yes         72         35         1 (3%)         Yes           Psychoactive medication for<br>more than 2 weeks         83         5 (2%)         80         Yes         12         5 (2%)         35         1 (3%)         No           PWD satisfied with his/her daily         NA         NA         NA         Yes         Added round           Vell-being related goal for PWD         MA         NA         NA         Yes         Added round  |                 | PWD knows contact<br>professional                              | 83     | 7.8 (1.6)               | 83          | 20 (8%)               | 80   | No                   | 12             | 7.1 (2.2)               | 35 | 3 (9%)          | No                       |               |
| Psychoactive medication for         83         6.0 (2.1)         83         5 (2%)         80         Ves         12         5.8 (2.7)         35         1 (3%)         No           more than 2 weeks         More than 2 weeks         NA         NA         Yes         Added round           PWD satisfied with his/her daily         NA         NA         NA         Yes         Added round           Well-being related goal for PWD         NA         NA         Yes         Added round  |                 | Perseverance time of the caregiver                             | 83     | 8.2 (1.3)               | 83          | 33 (13%)              | 80   | No                   | 12             | 7.7 (2.2)               | 35 | 6 (17%)         | Yes                      |               |
| PWD satisfied with his/her daily     NA     Yes     Added round added round       with test     MA     Yes     Added round       Viell-being related goal for PWD     NA     Yes     Added round   |                 | Psychoactive medication for<br>more than 2 weeks               | 83     | 6.0 (2.1)               | 83          | 5 (2%)                | 80   | Yes                  | 12             | 5.8 (2.7)               | 35 | 1 (3%)          | No                       |               |
| Vell-being related goal for PWD NA Ves Added round   |                 | PWD satisfied with his/her daily activities                    |        |                         |             | AN                    |      |                      |                | NA                      | _  |                 | Yes                      | Added round 3 |
|  |                 | Well-being related goal for PWD                                |        |                         |             | NA                    |      |                      |                | NA                      |    |                 | Yes                      | Added round 4 |

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|--------------|---|
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| $\mathbf{U}$ | 1 |

| Table 2 Con   | tinued  |      |                         |             |                       |          |                        |               |                         |    |                 |                           |                   |
|---|---|------|-------------------------|-------------|-----------------------|----------|------------------------|---------------|-------------------------|----|-----------------|---------------------------|-------------------|
|   |   | Hea  | Ithcare profession      | als and man | agers/policy officers | <u>,</u> |                        | Informal care | givers                  |    |                 |                           |                   |
| Category  | Short notation QI*  | ٦    | Relevance,<br>mean (SD) | Ē           | Priority, n (%) n     |          | Feasibility,<br>yes/no | Ē             | Relevance,<br>mean (SD) | Ľ  | Priority, n (%) | Final consensus<br>yes/no | ,<br>Remark       |
| Network-based care  | Activity to involve broader<br>network (eg, PWD and<br>caregivers, and dementia<br>initiatives) | 78   | 7.0 (1.7)               | 77          | 5 (2%)                | 74       | °<br>Z                 | 12            | 7.5 (2.0)               |    | NA              | Ž                         |                   |
|   | Agreements with municipality on medical support indications                                     | n 78 | 7.4 (1.6)               | 22          | 11 (5%)               | 75       | No                     |               |                         | NA |                 | No                        |                   |
|   | Case review with network  | 78   | 7.0 (1.8)               | 27          | 10 (4%)               | 74       | No                     |               |                         | NA |                 | No                        |                   |
|   | Discussion of mutual interests  | 78   | 6.8 (1.7)               | 22          | 4 (2%)                | 74       | No                     |               |                         | NA |                 | No                        |                   |
|   | Discussion of mutual personal relationships   | 77   | 6.4 (1.6)               | 12          | 1 (0%)                | 74       | No                     |               |                         | NA |                 | No                        |                   |
|   | Document present with<br>expertise and contact<br>information of all professionals              | 78   | 7.9 (1.1)               | 11          | 12 (5%)               | 75       | N                      |               |                         | NA |                 | Yes                       | Merged<br>round 4 |
|   | Informal activity with network  | 78   | 6.4 (2.0)               | 22          | 1 (0%)                | 75       | Q                      |               |                         | NA |                 | Yes                       |                   |
|   | Interprofessional education together with network   | 78   | 7.1 (1.8)               | 12          | 6 (3%)                | 75       | No                     |               |                         | NA |                 | No                        |                   |
|   | Network agreements on early signalling  | 78   | 7.4 (1.8)               | 12          | 13 (6%)               | 75       | No                     |               |                         | NA |                 | No                        |                   |
|   | Network goals discussed   | 78   | 7.1 (1.7)               | 22          | 16 (7%)               | 74       | No                     |               |                         | NA |                 | No                        |                   |
|   | Network has one or two<br>network leaders   | 79   | 7.6 (1.5)               | 27          | 25 (11%)              | 75       | No                     |               |                         | NA |                 | Yes                       | Merged<br>round 4 |
|   | Network worked on at least one challenge or celebrated one success                              | 78   | 6.8 (2.0)               | 22          | 9 (4%)                | 74       | N                      |               |                         | NA |                 | Yes                       |                   |
|   | Network working arrangements discussed  | 78   | 7.2 (1.4)               | 27          | 12 (5%)               | 74       | No                     |               |                         | NA |                 | No                        |                   |
|   | PWD and caregiver consulted<br>on experience with network-<br>based care                        | 27   | 7.1 (1.6)               | 77          | 10 (4%)               | 74       | <sup>o</sup> N         | 12            | 8.2 (0.6)               |    | NA              | N                         |                   |
|   | Representative of a welfare organisation present  | 79   | 8.0 (1.3)               | 27          | 44 (19%)              | 75       | Yes                    |               |                         | NA |                 | Yes                       |                   |
|   | Representative of PWD or caregiver present in network   | 79   | 7.5 (1.7)               | 27          | 30 (13%)              | 75       | No                     | 12            | 7.7 (2.1)               |    | NA              | No                        |                   |
|   | Work agreement for the shared caseload  | 78   | 7.7 (1.3)               | 27          | 22 (10%)              | 75       | No                     |               |                         | NA |                 | Yes                       | Merged<br>round 4 |
| Cost-efficiency   | Diagnosed in the primary setting  | 3 10 | 1 6.0 (2.4)             | 66          | 23 (7.74%)            | 06       | Yes                    | 11            | 6.0 (2.8)               | 36 | 5 (14%)         | Yes                       |                   |
|   | Number of emergency<br>consultations  | 83   | 6.0 (2.3)               | 83          | 11 (4%)               | 80       | Yes                    | 12            | 6.3 (3.2)               | 35 | 3 (9%)          | Yes                       |                   |
|   | PWD care is reimbursed from<br>the long-term care finance<br>system                             |      |                         |             | NA                    |          |                        |               |                         | NA |                 | Yes                       | Added round 4     |
| *All QIs concern the past 1<br>NA, not available; PWD, pe | 2 months.<br>srson with dementia; QI, quality indicator.  |      |                         |             |                       |          |                        |               |                         |    |                 |                           |                   |

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### 3. Stakeholder consensus meeting

Eight stakeholders discussed the survey results. Stakeholders generally agreed with the survey respondents on relevance and prioritisation. Disagreement existed on the QI 'recent pharmacotherapy check', which had a low relevance and feasibility score, though stakeholders considered the indicator crucial for assessing quality of care. They argued that polypharmacy negatively influences quality of life and morbidity. Two new well-being QIs were proposed for inclusion: 'discussing changing relationship between PWD and caregiver' and 'PWD satisfaction with daily activities'. The QI about PWDs' goals was nominated for exclusion as it was considered not specific and not feasible.

## 4. Expert consensus meeting

A geriatrician, two general practitioners, a nursing scientist, two researchers and a coordinator of General Practitioner Organisation of Nijmegen decided on the composition of the MDS for pilot testing considering primarily relevance but also feasibility. The panel agreed with the stakeholders on adding the QI on PWD satisfaction with daily activities. Three network QIs about task division and communication were merged. Experts added the QI: 'whether the network has formulated a well-being related goal for the PWD', which replaced some of the excluded network and well-being QIs. During the discussion, costefficiency was added as a separate topic, and QIs were arranged accordingly. An additional QI was included for cost-efficiency: 'whether care of PWD is reimbursed from the long-term care finance system'. Twenty-six QIs were excluded, resulting in a pilot-testing set of 15 QIs: five quality of care, three well-being, four network and three cost-efficiency QIs.

## **Pilot testing**

Three DementiaNet networks voluntarily pilot-tested the QI set. Regarding relevance and added value, they preferred the new set above their currently used OIs, as they stated that it represented more aspects of the network collaboration. This information helped them to identify new improvement goals. The QIs focusing on PWD care wishes and on support for caregivers were considered of added value. Measurement feasibility was good; it took one to two hours, depending on the size of the caseload, to complete the QIs. QIs were fully completed, except for the well-being QIs; on average, these were completed for 14% (perseverance time) and 42% (satisfaction with daily activities) of their PWD (range: 11-31). These well-being indicators were difficult to collect as they required caregiver consultation as an additional time-consuming action. Participants suggested the case manager should complete these questions. Furthermore, pilot answers suggested ambiguity of two QIs, which were therefore reformulated (table 3).

### DISCUSSION

An MDS of 15 QIs was developed to measure the quality of integrated primary dementia care; QIs for quality of

| Table 3Idementia       | Final set of QI descriptions for integrated primary care   |
|------------------------|--|
| Category               | QI description   |
| Quality of care        | A case manager is involved.<br>The PWD has been discussed in a multidisciplinary<br>meeting in the past year.<br>The PWD has been discussed in a<br>pharmacotherapeutic meeting in the past year.<br>Future treatment wishes were discussed with the PWD<br>and their informal caregiver in the past year.   |
|                        | Support is offered to the informal caregiver in the past year.   |
| Well-being             | Assessment of the perseverance time of the informal caregiver.   |
|                        | Informal caregiver states that PWD is satisfied with his/ her daily activities.  |
|                        | The network has set at least one well-being related goal for the PWD.  |
| Network-<br>based care | At least one representative of a welfare organisation is part of the network.  |
|                        | <ul> <li>Task division and communication:</li> <li>1. There is a document with expertise and contact information of all the healthcare professionals available for the network in caring for frail older adults, which is updated yearly.</li> <li>2. The network has one or two network leaders.</li> </ul> |
|                        | 3. The network has composed written working agreement for their shared caseload of PWDs.   |
|                        | The network worked on at least one new challenge or celebrated one success in the past year.   |
|                        | There was an informal activity for network participants in the past year.  |
| Cost-                  | The PWD is diagnosed in the primary setting.   |
| efficiency             | Number of emergency consultations in the past year.<br>PWD care is reimbursed from the long-term carefinance<br>system.  |

PWD, person with dementia; QI, quality indicator.

care, well-being, network-based care, and cost-efficiency were included. Most QIs were overall judged positively regarding content validity and feasibility by primary dementia care stakeholders. During pilot testing, most indicators were considered relevant, of added value and feasible to collect. However, collection of the well-being QIs still needs specific attention.

## Strengths and limitations

An important novelty of this set is the inclusion of wellbeing, network-based care and cost-efficiency indicators, which supports the triple-aim ambitions; improve quality of care, population health and cost-effectiveness.<sup>29</sup> Previous sets mainly included quality of care indicators.<sup>19</sup> Moreover, this novel MDS for integrated primary dementia care is substantially shorter than existing sets.<sup>23</sup> The comprehensiveness of the set, in combination with its high relevance and feasibility, make the MDS useful for daily practice; based on the pilot test future acceptance is expected to be high.

Another strength of the set is its fit with the validated Rainbow Model of Integrated Care.<sup>27</sup> This model's four levels of care provision, the service, professional, organisational and system levels, are all represented in the MDS. QIs on quality of care and well-being refer to the service level: processes and outcomes of care for the PWD and caregiver (eg, QIs on multidisciplinary meetings and satisfaction of PWD with daily activities). Network QIs refer to the professional and organisational levels, the required collaboration between professionals and organisations (eg, QIs on task division and communication). Cost-efficiency QIs refer to the system level, the impact of regulations on collaboration between professionals and organisations (eg, QI on PWD care reimbursement).

Last, stakeholder meetings and the survey included a diverse group of participants regarding background, age and informal caregiver's roles. Their interaction and discussions created broad support for the QIs included; acceptability of the MDS is therefore expected to be high. However, the stakeholders were mainly active in DementiaNet networks; the MDS is therefore highly applicable to the Dutch network-based dementia care context. Adaptations to the MDS might be necessary when using the set for other healthcare systems in other countries.<sup>30</sup> However, because of their generic content, the QIs can be highly transferable to other populations, for example, vulnerable older adults. Collection of the well-being QIs proved difficult. Evaluation of new strategies to collect these QIs is needed since their relevance is well recognised in practice.

#### Future implications for research and practice

By addressing various levels of integrated care, the MDS is highly useful for performance feedback in an interdisciplinary setting to encourage professionals to improve the quality of services for their joint caseload. Care coordination, interdisciplinary teamwork and personalised care can be improved by setting improvement goals and assess change over time. Moreover, the complexity in dementia care is captured by clustering QIs in levels related to each other; better network collaboration leads to better quality of care, better patient and caregiver well-being and/or lower healthcare costs.

The MDS can inform policy makers on best practices to achieve (cost-)effective network-based dementia care. As most QIs in the MDS are not dementia specific, it is applicable in other populations, for example, vulnerable older adults, which will increase acceptability by preventing fragmentation due to disease-specific QIs.

Future research should include the use of the MDS in long-term follow-up evaluations of integrated primary dementia care programmes such as DementiaNet. However, first reliability testing and assessing sensitivity for relevant change are needed.

# CONCLUSION

A concise set of QIs with proven feasibility and content validity was developed to assess integrated primary dementia care. Innovative QIs on different relevant aspects of integrated care, well-being, network-based care and cost-efficiency were included next to quality of care QIs. By monitoring changes in QI scores over time and subsequent care improvement cycles, professionals in interdisciplinary primary dementia care collaborations can improve the quality of service for their joint caseload. As such, the set may contribute to the implementation of guidelines and care pathways for integrated primary dementia care.

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