

# BMJ Open Minimum clinically important difference of the Social Functioning in Dementia Scale (SF-DEM): cross-sectional study and Delphi survey

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## ABSTRACT

**Objectives** Good social functioning is important for people living with dementia and their families. The Social Functioning in Dementia Scale (SF-DEM) is a valid and reliable instrument measuring social functioning in dementia. However the minimum clinically important difference (MCID) has not yet been derived for SF-DEM. This study aims to define the MCID for the SF-DEM.

**Design** We used triangulation, incorporating data from a cross-sectional study to calculate the MCID using distribution-based and anchor-based methods, and a Delphi survey.

**Setting and participants** The cross-sectional survey comprised 299 family carers of people with dementia. Twenty dementia experts (researchers, clinicians, family carers) rated whether changes on clinical vignettes represented a meaningful change in the Delphi survey.

**Primary outcome measures** We calculated the distribution-based MCID as 0.5 of an SD for each of the three SF-DEM domains (1—spending time with others, 2—communicating with others, 3—sensitivity to others). We used the carers' rating of social functioning to calculate the anchor-based MCID. For the Delphi survey, we defined consensus as ≥75% agreement. Where there was lack of consensus, experts were asked to complete a further survey round.

**Results** We found that 0.5 SD of SF-DEM was 1.9 points, 2.2 and 1.4 points in domains 1, 2 and 3, respectively. Using the anchoring analysis, the MCIDs were 1.7 points, 1.7 points, and 0.9 points in domains 1, 2 and 3, respectively. The Delphi method required two rounds. In the second round, a consensus was reached that a 2-point change was considered significant in all three domains, but no consensus was reached on a 1-point change.

**Conclusions** By triangulating all three methods, the SF-DEM's MCIDs were 1.9, 2.0 and 1.4 points for domains 1, 2 and 3, respectively. For individuals, these values should be rounded to a 2-point change for each domain.

## INTRODUCTION

Social functioning is important to human experience including for those with dementia. Decline in social functioning—how individuals interact in society and their own personal environment<sup>1</sup>—is a diagnostic criterion for dementia<sup>2</sup> and social

## Strengths and limitations of this study

- This is the first study which aims to derive the minimum clinically important difference (MCID) for the Social Functioning in Dementia Scale; this has useful implications for future research aiming to improve social functioning in dementia.
- This study triangulates the MCID from three established methods, which are the distribution-based, anchor-based and Delphi-based methods.
- The cross-sectional study comprised a large research sample, which was diverse in terms of gender, ethnicity, background and severity of dementia.
- A diverse range of dementia experts were recruited onto the Delphi survey, including family carers, doctors, researchers and therapists.
- The study took place in the UK so it is not clear if the findings are applicable to populations outside of the UK.

functioning impairments are distressing to people with dementia and their families.<sup>3</sup> As well as increasing the risk of dementia onset, loneliness and social isolation have lasting psychosocial effects on those living with dementia and their caregivers.<sup>4–7</sup> Conversely, increase in social interaction has been associated with improvement in cognition,<sup>8,9</sup> and improved quality of life for individuals with dementia.<sup>10</sup>

Accurate measurement of social functioning in dementia is essential for research aiming to understand the causes of decline in social functioning in dementia, effects of different lifestyles and to assess whether interventions are effective in maintaining or improving social functioning. There are few instruments designed to assess social functioning in dementia.<sup>11</sup> We, therefore, developed and psychometrically tested the Social Functioning in Dementia scale (SF-DEM) scale showing it to be acceptable, reliable and valid<sup>12</sup> and establishing its factor structure.<sup>13</sup>

SF-DEM has, therefore, been recommended for research into social functioning in dementia.<sup>11</sup>

A statistically significant difference between or within groups on an instrument may not equate to a clinically important difference.<sup>14 15</sup> An important metric of a scale is therefore the minimum clinically important difference (MCID), defined as ‘the smallest change or difference in an outcome measure that is perceived as beneficial and would lead to a change in the patient’s medical management, assuming an absence of excessive side effects and costs’.<sup>16</sup> To our knowledge, no MCID has been reported for the SF-DEM or any other instrument that measures social functioning in dementia. The MCID is subjective and there are several ways to calculate it, including statistically based approaches based on distribution of data or anchoring score changes to another measure, and seeking expert opinion via a Delphi survey.<sup>17</sup> In this study, we aimed to derive the MCID of the SF-DEM using all of these approaches. By utilising three established methods to calculate the MCID and subsequently triangulating the results, we aim to mitigate any potential biases which may arise from the different approaches.

## METHODS

We conducted a study using data from a cross-sectional survey of family carers of people with dementia and a Delphi survey of dementia professionals and experts by experience.

### Cross-sectional survey

#### Setting and participants

This study used data collected from a previous research project<sup>13</sup> to calculate the MCID for the SF-DEM. Two hundred and ninety-nine family carers of people with mild, moderate and severe dementia were recruited across three UK National Health Service mental health trusts in Sussex and North London and gave informed consent to participate.

#### Procedures

Trained researchers conducted a single interview with the family carer participants to obtain demographic information about the person with dementia and scores for the SF-DEM. The carers also provided information for other validated carer-rated measures used to determine dementia severity, using the Clinical Dementia Rating Scale (CDR).<sup>18</sup>

Social functioning was assessed using the SF-DEM, a 20-item questionnaire administered by an interviewer. There are seventeen items covering different aspects of social functioning which are divided into three domains (‘spending time with other people’ (dDomain 1), ‘communicating with other people’ (domain 2) and ‘sensitivity to other people’ (domain 3)). These items are scored using a Likert scale (0–4 indicating frequency: ‘never’ to ‘very often’). A score is calculated for each domain; the scale scores range for each domain from 0

to 21, 0–18 and 0–12, respectively. High scores indicate better social functioning. There are also three unscored summary questions which assess overall impression of social functioning, recent change and willingness to make future changes.

### Analysis

Distribution-based methods are based on the statistical characteristics of obtained samples. They determine what magnitude of change in an outcome measure, here the SF-DEM score, is greater than what would be expected from chance alone.<sup>19</sup> Previous studies have suggested that 0.5 SD may be clinically significant.<sup>20–22</sup> We, therefore, calculated the SD of the SF-DEM score for each of the three domains, and 0.5 of the SD

Anchor-based approach determines the MCID by associating the change in the numerical scale to a subjective and independent assessment of improvement.<sup>19</sup> This allows a numerical measurement to become ‘anchored’ to a qualitative assessment which is likely meaningful to patients. In this study we used the carers’ overall impression of social functioning (four points on a Likert scale: excellent, good, fair, poor) to anchor to the SF-DEM score. We first calculated whether there was correlation between the score in each of the three SF-DEM domains and the overall impression of social functioning using Spearman’s correlation coefficient. We then calculated, for each domain, the mean difference in SF-DEM domain score, per different overall rating of impression in social functioning (excellent, good, fair, poor), as the anchor-based MCID.

All analyses were conducted using IBM SPSS V.25.

### Delphi survey

#### Setting and participants

Twenty dementia experts were recruited as participants, providing informed consent to participate in the survey. We defined experts as researchers who specialise in dementia care, healthcare professionals with experience working with people with dementia, or family members, close friends, or carers of a person with dementia with at least weekly contact.

#### Procedures

We created eight brief fictionalised anonymous vignettes for each of the three SF-DEM domains based on previous studies using the SF-DEM scale (see online supplemental appendix 1).<sup>12 13</sup> These changes corresponded to improvement and decline in SF-DEM score of 1, 2, 3 and 4 points. The study participants were asked for each vignette ‘do you consider the change described as important to the health or quality of life of the person’, and asked to answer ‘yes’, ‘no’ or ‘not Sure’. They were invited to explain more about their answer to help move to consensus by clarifying and specifying. The survey was delivered using Opinio, a web-based survey tool.

Participants were also asked to define their gender (male, female, other, prefer not to say), ethnicity (using

UK census categories), expertise (dementia carer, psychiatrist, neurologist, geriatrician, clinical psychologist, nurse, social worker, occupational therapist, researcher, other), country of residence (UK, other European country, North America, other) and years of experience in caring for or working with people with dementia (less than 5, 5–10, more than 10). The survey was piloted by two researchers prior to being circulated to the participants.

### Analysis

The Delphi method aims to obtain a consensus regarding what would constitute a meaningful change from a panel of experts in the field, using a questionnaire.<sup>23</sup> There is a range of recommendations for Delphi study sample sizes,<sup>24</sup> including that 10–15 participants would be sufficient to reach consensus.<sup>25</sup> Several rounds may be required before the process ends, in order to reach overall agreement.<sup>26</sup> We, therefore, aimed for 15 respondents<sup>21</sup> and anticipated an attrition rate of approximately 20%–30% over two or three rounds<sup>27</sup>; thus we recruited 20 experts for the Delphi study. There are no existing guidelines for establishing consensus within a Delphi study, however, many Delphi healthcare studies define consensus as a 75%–80% agreement.<sup>28</sup> We, therefore, defined a consensus as an agreement of  $\geq 75\%$  (75% agreement that the change is either considered meaningful or not meaningful).

We analysed the Delphi results by calculating the percentage consensus for each vignette, which corresponded to a change (improvement or decline) of 1, 2, 3 or 4 points in each SF-DEM domain. We then calculated the overall consensus for each point of change by calculating the proportion of study participants who judged that the vignettes reflected a meaningful difference (averaged across the vignettes which described improvement and decline). We judged any level of SF-DEM change as having reached consensus if 75% of participants judged it as being either clinically meaningful or not clinically meaningful. For levels of SF-DEM change where consensus was not reached in the first Delphi round, we wrote new vignettes using feedback and comments provided by the participants in the first round and presented these to study participants for round 2. We determined the MCID using the Delphi method as the minimum agreed meaningful points of change, as decided by a consensus among the Delphi participants. For example, if an overall consensus is reached that a 1-point change is not meaningful or no

consensus can be reached, and a 2-point change is meaningful, the MCID would be calculated as 2 points.

### Triangulation

We present MCIDs derived from the three methods separately and, as it is common practice to triangulate values from the methods used in order to determine an overall MCID,<sup>20 21 29 30</sup> we present a triangulated MCID for each SF-DEM domain by calculating the simple mean (the values summed and divided by three) from the three methods.

### Patient and public involvement

No patients involved.

## RESULTS

### Cross-sectional survey

#### Demographics

Of the 299 carers, the mean age was 63 (SD 14, min 21, max 90) years and 218 (73%) were female. The mean age of the people with dementia was 81 (SD 8, min 55, max 98) years and 179 (60%) were female. Half (148) of the family carers were spouses or long-term partners of the person with dementia and the majority of those remaining 128 (43%) were children of the person with dementia. There was a range of dementia severity as scored on the CDR (very mild=31 (10%), mild=108 (36%), moderate=99 (33%), severe=61 (20%)). Alzheimer's disease was the most common dementia subtype (159, 53%).

#### Distribution method

The mean SF-DEM score was 6.8, 5.9 and 8.3 for domains 1, 2 and 3, respectively. [Table 1](#) details the values of the mean, SD and 0.5 SD for each of the three domains. The MCIDs, defined as 0.5 SD, were calculated as 1.9, 2.2 and 1.4 points for domains 1, 2 and 3, respectively.

#### Anchor method

As is reported in [table 2](#), we found a moderate correlation of SF-DEM score vs overall impression in social functioning in domain 1, and a weak correlation in domains 2 and 3. We then calculated the MCID as the mean difference in score per different level of overall impression of social functioning. The MCIDs were 1.7, 1.7 and 0.9 points for domains 1, 2 and 3, respectively.

**Table 1** Distribution-based minimum clinically important difference on SF-DEM scale

| Domain                              | N   | Mean SF-DEM score | SD  | 0.5 SD |
|-------------------------------------|-----|-------------------|-----|--------|
| 1 (Spending time with other people) | 296 | 6.8               | 3.9 | 1.9    |
| 2 (Communicating with other people) | 291 | 5.9               | 4.4 | 2.2    |
| 3 (Sensitivity to other people)     | 293 | 8.3               | 2.9 | 1.4    |

SF-DEM, Social Functioning in Dementia Scale.

**Table 2** Anchor-based minimum clinically important difference on SF-DEM scale

| Domain                              | N   | Impression of social functioning* | N per impression of social functioning | Mean SF-DEM score | Spearman's Correlation: SF-DEM score vs impression of social functioning | P value | Mean SF-DEM points difference per impression of social functioning (Anchor-based MCID) |
|-------------------------------------|-----|-----------------------------------|--|-------------------|--|---------|--|
| 1 (Spending time with other people) | 296 | Excellent                         | 7                                      | 9.4               | -0.58  | <0.001  | 1.7  |
|                                     |     | Good                              | 77                                     | 9.8               |  |         |  |
|                                     |     | Fair                              | 93                                     | 7.3               |  |         |  |
|                                     |     | Poor                              | 119                                    | 4.4               |  |         |  |
| 2 (Communicating with other people) | 291 | Excellent                         | 7                                      | 9.7               | -0.29  | <0.001  | 1.7  |
|                                     |     | Good                              | 78                                     | 7.7               |  |         |  |
|                                     |     | Fair                              | 92                                     | 5.5               |  |         |  |
|                                     |     | Poor                              | 114                                    | 4.8               |  |         |  |
| 3 (Sensitivity to other people)     | 293 | Excellent                         | 7                                      | 10.4              | -0.13  | 0.025   | 0.9  |
|                                     |     | Good                              | 80                                     | 8.5               |  |         |  |
|                                     |     | Fair                              | 93                                     | 8.8               |  |         |  |
|                                     |     | Poor                              | 113                                    | 7.7               |  |         |  |

\*Response to question 'Thinking about their social life as a whole, how is it now?' on Likert scale (1=excellent, 2=good, 3=fair, 4=poor). MCID, minimum clinically important difference; SF-DEM, Social Functioning in Dementia Scale.

## Delphi survey

### Demographics

In the first round of the Delphi study, there were twenty participants. [Table 3](#) details the demographic information

**Table 3** Delphi study participants' demographic information

| Category             | Demographic information | Delphi round 1 | Delphi round 2 |
|----------------------|-------------------------|----------------|----------------|
|                      |                         | N (%)          | N (%)          |
| Gender               | Female                  | 13 (65)        | 10 (71.4)      |
|                      | Male                    | 7 (35)         | 4 (28.6)       |
| Ethnicity            | White                   | 15 (75)        | 10 (71.4)      |
|                      | Asian or Asian British  | 4 (20)         | 3 (21.4)       |
|                      | Other                   | 1 (5)          | 1 (7.1)        |
| Primary role         | Psychiatrist            | 10 (50)        | 6 (42.9)       |
|                      | Academic researcher     | 6 (30)         | 5 (35.7)       |
|                      | Social worker           | 1 (5)          | 0 (0)          |
|                      | Family carer            | 1 (5)          | 1 (7.1)        |
|                      | Clinical psychologist   | 2 (10)         | 2 (14.3)       |
| Years of experience  | Less than 5             | 4 (20)         | 3 (21.4)       |
|                      | 5–10                    | 7 (35)         | 4 (28.6)       |
|                      | More than 10            | 9 (45)         | 7 (50)         |
| Country of residence | UK                      | 19 (95)        | 13 (92.9)      |
|                      | Other                   | 1 (5)          | 1 (7.1)        |

of the participants in rounds one and two. Approximately two-thirds of the participants were female. The majority of the participants were either psychiatrists (50%) or researchers (30%). They had a varied level of experience, and the majority (95%) were based in the UK. There were 14 participants in the second round of the Delphi survey. Seventy-one per cent of the participants in round 2 were female, and the majority were psychiatrists (43%) or researchers (36%), as in round 1. 93% of participants were based in the UK.

### Round 1

[Table 4](#) reports the results of both Delphi rounds. In the first round of the Delphi process, a consensus was reached for eight out of the twelve levels of change represented by the vignettes. For domains 1 and 3, there was consensus that 2-point, 3-point and 4-point changes were considered significant but no consensus with regard to a 1-point change. For domain 2, a consensus was reached that 2-point and 4-point changes were considered significant, but no consensus for 1- or 3-point changes.

### Round 2

We presented amended vignettes for the levels of SF-DEM change which did not reach consensus in round 1. The second round led to a consensus that a 3-point change in domain 2 was clinically significant. However, no consensus was reached with regards to a 1-point change in all three domains with 71%, 43% and 39% viewing 1-point change as meaningful for the three domains (see [table 4](#)). Therefore, the Delphi consensus MCIDs are defined as 2 points in all three domains.



**Table 4** Delphi survey results

|                        |          | Delphi round 1 (n=20) |   |          |    |         |   |          |      |   |                    | Delphi round 2 (n=14) |   |             |    |   |   |          |   |                     |                    |   |   |          |  |
|------------------------|----------|-----------------------|---|----------|----|---------|---|----------|------|---|--------------------|-----------------------|---|-------------|----|---|---|----------|---|---------------------|--------------------|---|---|----------|--|
| No of points of change |          | Improvement           |   |          |    | Decline |   |          |      | Total (combining improvement and decline) |                    |                       |   | Improvement |    |   |   | Decline  |   |                     |                    | Total (combining improvement and decline) |   |          |  |
|                        |          | Y                     | N | Not sure |    | Y       | N | Not sure |      | % agreed meaningful                       | Consensus reached? | Y                     | N | Not sure    |    | Y | N | Not sure |   | % agreed meaningful | Consensus reached? | Y   | N | Not sure |  |
| 1                      | Domain 1 | 18                    | 2 | 0        | 11 | 5       | 4 |          | 72.5 | N   | 12                 | 2                     | 0 | 8           | 4  | 2 |   | 71.4     | N |                     |                    |   |   |          |  |
| 2                      |          | 17                    | 2 | 1        | 20 | 0       | 0 |          | 92.5 | Y   |                    |                       |   |             |    |   |   |          |   |                     |                    |   |   |          |  |
| 3                      |          | 18                    | 0 | 2        | 20 | 0       | 0 |          | 95   | Y   |                    |                       |   |             |    |   |   |          |   |                     |                    |   |   |          |  |
| 4                      |          | 19                    | 0 | 1        | 19 | 0       | 1 |          | 95   | Y   |                    |                       |   |             |    |   |   |          |   |                     |                    |   |   |          |  |
| 1                      | Domain 2 | 11                    | 4 | 5        | 5  | 13      | 2 |          | 40   | N   | 11                 | 2                     | 1 | 1           | 11 | 2 |   | 42.9     | N |                     |                    |   |   |          |  |
| 2                      |          | 18                    | 0 | 2        | 18 | 0       | 2 |          | 90   | Y   |                    |                       |   |             |    |   |   |          |   |                     |                    |   |   |          |  |
| 3                      |          | 19                    | 0 | 1        | 7  | 11      | 2 |          | 65   | N   | 14                 | 0                     | 0 | 14          | 0  | 0 |   | 100      | Y |                     |                    |   |   |          |  |
| 4                      |          | 18                    | 1 | 1        | 20 | 0       | 0 |          | 95   | Y   |                    |                       |   |             |    |   |   |          |   |                     |                    |   |   |          |  |
| 1                      | Domain 3 | 9                     | 9 | 2        | 7  | 10      | 3 |          | 40   | N   | 7                  | 5                     | 2 | 4           | 9  | 1 |   | 39.3     | N |                     |                    |   |   |          |  |
| 2                      |          | 14                    | 4 | 2        | 17 | 0       | 3 |          | 77.5 | Y   |                    |                       |   |             |    |   |   |          |   |                     |                    |   |   |          |  |
| 3                      |          | 18                    | 0 | 2        | 13 | 5       | 2 |          | 77.5 | Y   |                    |                       |   |             |    |   |   |          |   |                     |                    |   |   |          |  |
| 4                      |          | 17                    | 1 | 2        | 18 | 0       | 2 |          | 87.5 | Y   |                    |                       |   |             |    |   |   |          |   |                     |                    |   |   |          |  |



## Triangulation results

The mean MCIDs from the three methods are 1.9 points for domain 1 (range 1.7–2), 2.0 points for domain 2 (range 1.7–2.2) and 1.4 points for domain 3 (range 0.9–2).

## DISCUSSION

We used three different methods, the distribution, anchor and Delphi methods, in order to establish the MCID for the SF-DEM, which measures social functioning in people living with dementia.

The mean MCIDs from the three methods are 1.9 points for domain 1, 2.0 points for domain 2 and 1.4 points for domain 3. If using the MCID for an individual patient, it would be appropriate to consider 2 points as the MCID in all three domains. However, in a research study such as a clinical trial, the triangulated values may be more useful. The MCIDs calculated from the three methods have also been reported separately in this study, and the most applicable value could be used with the researcher's judgement and prespecified in the study protocol.

For the distribution method, we chose to use the value of 0.5 SD to define the MCID. An influential systematic review demonstrated a consistency of 0.5 SD among the MCIDs reported in health-related quality of life measures in chronic diseases.<sup>22</sup> Several studies have since used 0.5 SD as the value to calculate the MCID using the distribution method.<sup>20 31–33</sup> The data in the cross-sectional survey<sup>13</sup> find a significant correlation between SF-DEM scores and carers' impression of social functioning. This allowed us to successfully anchor the SF-DEM to the subjective opinions of the family carers and calculate MCIDs using this method. The results of the Delphi survey led to a consensus on 2, 3 and 4-point changes, but to no consensus with regards to a 1-point change in all three domains with some experts judging it as important and others not. Interestingly, in round 2, there was a 71.4% agreement (close to the required 75% consensus) that a 1-point change in domain 1 was significant, in contrast to domains 2 and 3, which had 42.9% and 39.3% agreement for a 1-point change respectively. Nonetheless, we conclude that it would be appropriate to consider a 2-point change in domain 1 as clinically important, particularly when using the MCID to compare the scores of individual patients, given it is the most conservative estimate and so most appropriate in this context.

In other long-term conditions, similar methods have been used to determine an MCID to measure social functioning.<sup>34 35</sup> One study used the distribution and anchor method to establish the MCID for a scale measures quality of life (including social functioning) in children with cerebral palsy. Another used the anchor method to determine the MCID for a scale which measures quality of life (including social functioning) after total knee replacement.

## Strengths and limitations

Strengths include the fact that no previous study has established an MCID for the SF-DEM. This innovation is therefore useful for future research which uses the SF-DEM as an outcome measure. We also used three different methods in order to calculate the MCID, each of which have their specific benefits and limitations. The distribution and anchor methods were determined using data from the cross-sectional survey which took place in 2019.<sup>13</sup> This study used a large research sample, which was diverse in terms of gender, ethnicity, background and severity of dementia. The distribution method is a standardised method of statistical analysis which has been demonstrated to be consistent.<sup>22</sup> However, this method is not recommended as a first line means for determining MCID due to the lack of an anchor value which links the scores to a value that is meaningful to patients.<sup>19 36</sup> We have mitigated this potential drawback by also using the anchor method, which anchors the score to the subjective views of the family carers, and the Delphi method, thus taking expert opinion into account (in this study encompassing the views of clinicians, researchers, social workers, psychologists and family carers).

A limitation of the anchor-based method is that the results will differ depending on the choice of the anchor.<sup>15</sup> The anchor used in this study enabled us to factor in the subjective views and experiences of family carers for people with dementia. These are the individuals who spend the most time with people with dementia, and arguably may have the most insight into a clinically important change. There were 20 participants in first round of the Delphi survey, and 14 participants in the second round. We had a diverse research sample with an appropriate sample size for a Delphi survey. However, the participants were mostly UK-based which renders the results less applicable to populations outside of the UK.

## CONCLUSIONS

The results of this study specify that the MCID values for the SF-DEM are 1.9 points for domain 1, 2.0 points for domain 2 and 1.4 points for domain 3. These values are derived from the distribution-based, anchor-based and Delphi methods. Given the lack of consensus regarding a 1-point change for all three domains in the Delphi survey, it would be appropriate to round the MCID to a 2-point change as a more conservative value. As the SF-DEM is the only validated scale for measuring social functioning in dementia,<sup>13</sup> these results are of potential value for future research in this field. The calculation of the MCID will allow future researchers to identify a change which is of clinical benefit to patients, when using the SF-DEM as an outcome measure and therefore enable research into the important person-centred domain of social functioning for people with dementia.

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**Contributors** TL, GL and AS conceived the idea for this study and designed the analysis plan with input from all authors. TL conducted the literature search and conducted the data analysis plan, with input from AS. SB acquired funding for the cross-sectional study. The article and figures were drafted by TL and GL, SB and AS edited the manuscript. All authors read and approved the final article. AS is the guarantor, who accepts full responsibility for the work and/or the conduct of the study, had access to the data, and controlled the decision to publish.

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### Appendix 1: Vignettes used for phase 1 and 2 of the Delphi survey for calculation of the minimum clinically important difference for the Social Functioning in Dementia (SF-DEM) scale

We would now like to ask you to give your opinion on a series of fictionalised case scenarios describing people with dementia. The questions do not relate to social functioning during COVID restrictions.

Please read the following scenario and answer whether you think that the change in the amount of social contact for the person with dementia described is important to their health or quality of life.

*[The vignettes detailed below were then presented in a random order. Only the text of the vignette was shown to participants, without indication of the number of points of change each represented. After each vignette, the following question was asked:]*

Do you consider this change important to XX's health or quality of life?

- Yes
- No
- Not sure (comments can be entered below)
  - Free text box for comments

#### Phase 1 vignettes

|                               |          |             |  |
|-------------------------------|----------|-------------|--|
| Domain 1:<br>Time with others | 1 point  | Improvement | Joan lives in a sheltered accommodation and goes shopping with her daughter weekly and is visited twice a week by her grandson. She continues these activities but has also started going to the monthly coffee mornings in the shared space in her accommodation. |
|                               |          | Decline     | Peter lives with his daughter, goes to church once per week and to music concerts approximately monthly. He used to meet with a friend in his local pub once per week, but no longer does this as frequently, only going every two months.                         |
|                               | 2 points | Improvement | Marianna's son visits her twice a week, and goes shopping with her friend once a week. She has now begun to go with her friend to an exercise class every fortnight.   |
|                               |          | Decline     | Bill lives alone and would be visited by his granddaughter once a week but she has moved to another city for university so now only visits him every two months. In addition, he now rarely goes to church, having previously been a weekly attender.              |
|                               | 3 points | Improvement | Tom has lived in a care home for the past 18 months and his son and grandchildren, who live 4hour drive  |

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|   |          |             |   |
|---|----------|-------------|---|
|   |          |             | away, visit him monthly. It is arranged that he moves to a care home in the same town as his son so his family now visit him every day.   |
|   |          | Decline     | Maggie lives with her husband and they attended an exercise class together every week but difficulties with balance have stopped her from going to the exercise class. Their weekly shopping trips have also now stopped.   |
|   | 4 points | Improvement | Ola used to live with his wife and they would occasionally go to a restaurant. She had a stroke requiring hospital admission and remains in a rehabilitation hospital so Ola sees no-one at home and does not go to out to restaurants.                                 |
|   |          | Decline     | Susi used to go to her local coffee shop every morning, and to her daughter's home for dinner every Friday. In the last month, she has not been able to go to her local café and has not visited her daughter's home at all.  |
| Domain 2:<br>Communicating<br>with others | 1 point  | Improvement | Fred lives in a residential home and used to call to his son once a month, but his son now calls Fred more frequently, twice a week, to check on his safety.  |
|   |          | Decline     | When Monica met with her neighbour, she would often ask about her friend's about any concerns about her family, but now Monica only remembers to do this occasionally.  |
|   | 2 points | Improvement | Ada used to often find it difficult to follow conversations when in groups of people but her friends have noticed that she can follow the conversations if they speak more clearly and directly to Ada so she now never has difficulty being involved in conversations. |
|   |          | Decline     | Ahmed used to call his daughter every week but now only remembers to do this every few weeks, so she calls him on other occasions. He used to occasionally have difficulty following conversations but now says that this happens often.                                |
|   | 3 points | Improvement | Sarah previously could not contribute to conversations at her day centre but she now always takes part in lengthy conversations with staff at the day centre.   |
|   |          | Decline     | Andrea is called by her granddaughter Maria, who is currently studying at University abroad, once a week. She used to always ask Maria about her studies and being away from home, but now always forgets to ask about these things.                                    |
|   | 4 points | Improvement | Pauline is called by her close friend every day for a chat. She previously would not share things that were   |

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|                                 |          |             |   |
|---------------------------------|----------|-------------|---|
|                                 |          |             | worrying her, but now discusses these during most conversations which is reassuring for her. She used to never initiate conversation during these phone calls and would only listen to her friend but now she often brings up new topics of conversation.   |
|                                 |          | Decline     | Magda lives alone but would speak every day by phone with her sister. After her sister died, she no longer speaks by phone to anyone and she also occasionally finds it difficult to speak to other people about her feelings.  |
| Domain 3: Sensitivity to others | 1 point  | Improvement | Jose would often be irritated during the visits of his care workers though he would not be aggressive or argue with them. He is now slightly more accepting although continues to occasionally be irritated by their care.  |
|                                 |          | Decline     | Kim was previously always friendly with her neighbours even when they would play music loudly. Their behaviour has not changed, but now she will occasionally tell them that she is annoyed that their noise kept her awake.  |
|                                 | 2 points | Improvement | Liz and her husband watch television during the evenings and she would always be irritated when her husband asked her questions which she found distracting. This would always lead to an argument. Recently, she has become more tolerant of her husband's questions and they have only occasionally argued. |
|                                 |          | Decline     | Suneeta lives alone in sheltered accommodation and would often join the group activities. Now she always excuses herself from these stating that she is not interested.   |
|                                 | 3 points | Improvement | Bert used to always find a reason why he could not attend family gatherings but now has more confidence in these settings and so always agree to join these.  |
|                                 |          | Decline     | When Norah saw her daughter and grandchildren she would not criticise her grandchildren's behaviour, but she does not disguise her annoyance and always comments on things they are doing that irritate her.  |
|                                 | 4 points | Improvement | Jan lives with his wife and used to often get irritated at his wife suggesting they go out for a walk and this would always lead to an argument. He now no longer gets irritable and they have not argued for several months.   |
|                                 |          | Decline     | Tara used to enjoy going to the cinema weekly with her friend. For the last few months, she has made  |

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|  |  |  |   |
|--|--|--|---|
|  |  |  | excuses not to go to the cinema which would lead to an argument with her friend on those occasions. |
|--|--|--|---|

### Phase 2 vignettes

|                                     |          |             | NEW   |
|-------------------------------------|----------|-------------|---|
| Domain 1: Time with others          | 1 point  | Improvement | Joan lives in a sheltered accommodation and her son visits her twice a week. In addition to this, she has now also begun to go to the group exercise class in her accommodation every fortnight.  |
|                                     |          | Decline     | Peter lives alone and is visited by his granddaughter once a week and also sees his neighbour most days. However, he now rarely goes to church, having previously been a weekly attender.   |
| Domain 2: Communicating with others | 1 point  | Improvement | Fred has mild dementia and previously always found it difficult to follow conversations when in groups of people. His friends have begun to speak more directly to him which sometimes helps him although he still often cannot follow the thread of conversations.                   |
|                                     |          | Decline     | When Monica met with her neighbour, she would always ask her friend if she had any concerns about her family, but now Monica occasionally forgets to ask about this.  |
|                                     | 3 points | Improvement | Sarah previously could not contribute to conversations with her family when they visit but she now always takes part in lengthy conversations with them.  |
|                                     |          | Decline     | Andrea lives alone but would have a long conversation every day by phone with her sister. However, since her sister died, she now only speaks occasionally to another relative on the phone and she also occasionally finds it difficult to speak to other people about her feelings. |
| Domain 3: Sensitivity to others     | 1 point  | Improvement | Jose becomes irritated almost every day when his wife tries to talk to him about their plans for the day, and this would always lead to arguments. Now, he continues to be irritated every day but this only leads to an argument about three or four times a week.                   |
|                                     |          | Decline     | Kim has always been friendly with the other residents in her nursing home. She remains friendly but has started to occasionally tell them that she is annoyed if the television is on too loud.   |