

## **Representations and Adjustment Index (RADIX)**

**Catherine Quinn, Robin Morris and Linda Clare**

### **Background**

The RADIX assesses elements of Dementia Representations. Dementia Representations reflect a person's understanding of dementia. They have five components. The first of these is the identity the person ascribes to the condition; this is captured in the term the person uses to describe the condition. The other elements of DRs concern beliefs about cause, timeline, possibilities for cure/control, and consequences.

### **Administration**

The RADIX is designed to be administered to people with mild to moderate dementia (any type), having been validated for people in this severity range.

### **Step 1: RADIX Screening Checklist**

Questions 1 to 9 form the screening checklist.

First administer the screening checklist to identify whether it is appropriate to administer the rest of the questionnaire. If the person responds 'no' to all of the questions in the checklist then the RADIX should be discontinued. If the person responds 'yes' to one or more of the screening questions continue to Step 2.

### **Step 2: RADIX Questionnaire**

The questionnaire clusters the questions according to the five main Dementia Representations components as follows:

#### **Identity**

Questions 10-11 provide a profile of the way the person views the condition.

Question 10 elicits the term the person uses to describe the condition

Question 11 explores whether the person is aware of a diagnostic term that describes the condition.

From the responses to these two questions, ascertain the main term the person prefers to use when referring to the condition (e.g. 'memory problems' or 'Alzheimer's') and then use this term where you see [identity label] in all subsequent questions. If the person cannot provide a term that describes the condition, please use "condition" or "difficulties" instead.

## **Cause**

Question 12 explores the person's beliefs about the causes of the condition.

The person is asked "What do you think caused or causes your [identity label]?" Record the response, even if it is 'don't know.' If the person does not spontaneously provide a response, ask him/her to choose from the list of possible causes which is provided in Q12a. If the person selects more than one option, you then need to ask him/her to select the most important one and record this response in Q12b.

## **Timeline**

Question 13 explores the person's beliefs about the duration of these changes.

The person is asked "What do you think will happen to your [identity label] over time?" There are 4 fixed-choice response options, and the person should select one response.

## **Control**

Question 14 explores the beliefs about possibilities for controlling or managing the condition. In response to the statement "There is a lot which I can do to control the effects of my [identity label]", there are 4 fixed-choice response options to select from and the person should select one response.

## **Consequences**

Questions 15-18 explore the person's perceptions of the practical consequences of the condition, and Questions 19-23 explore the emotional consequences.

There are 4 fixed-choice response options to select from for each question, from which the person should select one response.

## **Scoring**

The responses to the open ended questions on Identity and Cause can be categorised using the lists in Appendix A and B (pages 7-8). Questions on Timeline and Control are single items and the scores are recorded individually. For Practical Consequences, responses to the questions can be summed to give an overall score and then divided by 4 to give the mean score for Practical Consequences. For Emotional Consequences, responses to the questions can be summed to give an overall score and then divided by 5 to give the mean score for Emotional Consequences.

## **Citing the RADIX**

The development and validation of the RADIX is described in: Quinn, C., Morris, R. G., & Clare, L. (in press). Beliefs about Dementia: Development and validation of the Representations and Adjustment to Dementia Index (RADIX). *The American Journal of Geriatric Psychiatry*. doi:10.1016/j.jagp.2018.02.004 [please use the most up-to-date citation details when citing the RADIX paper]

# Representations and Adjustment Index (RADIX)

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Did the person answer 'yes' to one or more questions in the screening checklist? No Yes

Was the RADIX administered? No Yes

## Dementia Representations Profile

Please use this section to record a summary of the person's responses to the questions

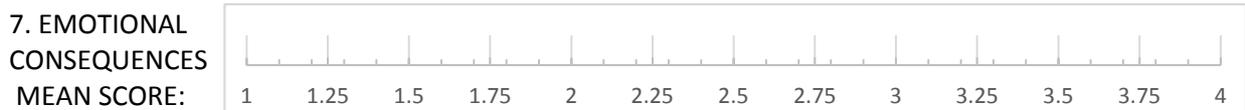
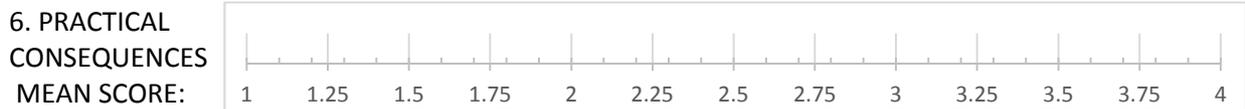
1. IDENTITY: \_\_\_\_\_

2. DIAGNOSTIC IDENTITY: \_\_\_\_\_

3. CAUSE: \_\_\_\_\_

4. TIMELINE: GET BETTER STAY SAME GET WORSE UNSURE

5. POSSIBLE TO CONTROL: STRONGLY AGREE AGREE DISAGREE STRONGLY DISAGREE



## **SECTION 1: SCREENING CHECKLIST**

I would like to talk to you about any changes that you have been experiencing.

**1. Have you, a family member or doctor noticed that you have been having difficulty with concentration?**

No    Yes

**2. Have you, a family member or doctor noticed that you have been forgetful?**

No    Yes

**3. Have you, a family member or doctor noticed that you have been having difficulty with remembering (e.g. recent events)?**

No    Yes

**4. Have you, a family member or doctor noticed that you have been having difficulty with thinking?**

No    Yes

**5. Have you, a family member or doctor noticed that you have been having difficulty with your ability to say what you want to say?**

No    Yes

**6. Have you, a family member or doctor noticed that you have been having difficulty with your ability to manage your day-to-day activities?**

No    Yes

**7. Have you, a family member or doctor noticed that you have been having difficulty with planning ahead?**

No    Yes

**8. Have you, a family member or doctor noticed that you have been having difficulty with making decisions?**

No    Yes

**9. Are you different in some way to how you used to be?**

No    Yes

Instructions for the researcher: Did the participant identify one or more changes? No    Yes

If YES you can continue with the RADIX

**SECTION 2: RADIX**

**10. What do you call [this difficulty/these difficulties, or condition] that you have?**

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**11. Are you aware of a specific diagnosis? What does the doctor call it?**

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Instructions for the researcher: Record the person's label for the condition. How does s/he refer to the condition; does s/he call it dementia or something else e.g. short-term memory problems, forgetfulness. Use this term, referred to as [identity label] in all subsequent questions. If the participant does not give a label, replace [identity label] with "condition" or "difficulties" instead.

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**POSSIBLE CAUSES OF MEMORY DIFFICULTIES**

**12. What do you think caused or causes your [identity label]?**

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a) Instructions for the researcher: If no instant response then follow up with: **These are some of the things that other people say causes their problems; which one do you think applies to you?**

Instructions for the researcher: Please cross all that the participant says applies to him/her.

- Ageing
- Changes within the brain (e.g. something in your brain dies off)
- Illness or disease or physical condition (e.g. diabetes)
- Hereditary condition (e.g. genetics)
- Lifestyle/life events (e.g. stress, bereavement)
- Don't know (record if given as a spontaneous response)

b) Instructions for the researcher: If more than one cause identified, ask him/her to nominate the most important one and cross the appropriate box below:

- Ageing
- Changes within the brain (e.g. something in your brain dies off)
- Illness or disease or physical condition (e.g. diabetes)
- Hereditary condition (e.g. genetics)
- Lifestyle/life events (e.g. stress, bereavement)
- Don't know (record if given as a spontaneous response)

**DURATION OF THESE CHANGES** *(Timeline)*

**13. What do you think will happen to your [identity label] over time? Will it/they**

Get better (1)                  Stay the same as it is now (2)                  Get worse (3)                  Unsure (4)

## CONSEQUENCES OF THESE CHANGES

Please indicate how much you agree or disagree with the following statements. There are no "right" or "wrong" answers. Answer according to your own feelings, rather than how you think "most people" would answer.

### Control

#### 14. There is a lot which I can do to control the effects of my [identity label]

Strongly disagree (1)      Disagree (2)      Agree (3)      Strongly agree (4)

### Practical Consequences

#### 15. As a result of my [identity label] people treat me differently

Strongly disagree (1)      Disagree (2)      Agree (3)      Strongly agree (4)

#### 16. As a result of my [identity label] I do not go out as much as I used to

Strongly disagree (1)      Disagree (2)      Agree (3)      Strongly agree (4)

#### 17. As a result of my [identity label] I cannot do some of the things that I used to do

Strongly disagree (1)      Disagree (2)      Agree (3)      Strongly agree (4)

#### 18. As a result of my [identity label] I feel I have lost control over my life

Strongly disagree (1)      Disagree (2)      Agree (3)      Strongly agree (4)

TO GENERATE MEAN SCORE: First record the TOTAL score (SUM of Q15~Q18): \_\_\_\_\_  
Second divide (÷) the TOTAL score by 4= \_\_\_\_\_ This generates the MEAN SCORE

### Emotional Consequences

#### 19. As a result of my [identity label] I get annoyed or frustrated with myself

Strongly disagree (1)      Disagree (2)      Agree (3)      Strongly agree (4)

#### 20. As a result of my [identity label] I get very angry about what is happening to me

Strongly disagree (1)      Disagree (2)      Agree (3)      Strongly agree (4)

#### 21. As a result of my [identity label] I feel I have lost confidence in myself

Strongly disagree (1)      Disagree (2)      Agree (3)      Strongly agree (4)

#### 22. I feel low or upset when I think about my [identity label]

Strongly disagree (1)      Disagree (2)      Agree (3)      Strongly agree (4)

#### 23. I find myself worrying about my [identity label]

Strongly disagree (1)      Disagree (2)      Agree (3)      Strongly agree (4)

TO GENERATE MEAN SCORE: First record the TOTAL score (SUM of Q19~Q23): \_\_\_\_\_  
Second divide (÷) the TOTAL score by 5= \_\_\_\_\_ This generates the MEAN SCORE

## Appendix A: Identity response categories

The responses to the questions on Identity can be categorised by matching them to the list below. Select the most relevant category.

### Definitions of categories

1. **Diagnostic term:** The person uses a diagnostic term.
2. **Descriptive term describing specific symptoms:** The person uses a term which relates to the symptoms of dementia.
3. **Descriptive term describing an emotional response:** The person uses more emotive or personalised terms.
4. **Descriptive term describing general changes:** The person refers to other changes they have noticed.
5. **Ageing:** The person refers to getting older
6. **Don't Know:** The person doesn't have a term to describe the condition or simply doesn't know

Categories	Examples of types of responses
Diagnostic term	Dementia Alzheimer's disease Mixed dementia Vascular dementia Lewy bodies
Descriptive term describing specific symptoms	Memory loss/problems/difficulties Short-term-memory problems Forgetfulness Confusion Poor concentration
Descriptive term describing an emotional response	Frustration Annoying/irritating Anxiety/stress/worries Lacking confidence Going mad
Descriptive term describing general changes	Slowing Withdrawn Laziness Reliance Tiredness
Ageing	Getting older Old age Senior moments Age-related problems An age thing
Don't Know	Person doesn't know

## Appendix B: Cause response categories

The response to the open-ended question on Cause can be categorised by matching it to the list below. Select the most relevant category.

### Definitions of categories

- 1. Ageing:** The person refers to the cause being ageing.
- 2. Changes within the brain:** The person refers to either biological or structural changes in the brain.
- 3. Illness or disease or physical condition:** The person refers to the cause being illness or disease or due to his/her physical condition.
- 4. Hereditary condition:** The person refers to the condition being hereditary.
- 5. Lifestyle/life-events:** The person refers to the cause being lifestyle, life-events, or emotional problems.
- 6. Don't know:** The person does not know what the cause is

Categories	Examples of types of responses
Ageing	Old age Getting older My age The ageing process General ageing
Changes within the brain	Shrinking of the brain Deterioration of the brain Brain not functioning correctly Brain cells dying Build-up of plaques
Illness or disease or physical condition	Illness Health problems Diabetes Thyroid problems Hearing loss
Hereditary condition	Genetic It's in my genes Bad genes Inherited Runs in the family
Lifestyle/life-event	Work environment Retirement Sleep deprivation Bereavement Stress
Don't know	Person doesn't know