



# Identification of Outcomes and Measures for Economic Evaluation

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A report for The Reader

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Elizabeth Hancock  
Fionn Woodcock  
Chris Hellmund  
David Trueman

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Acknowledgements: the authors would like to thank Ed Godber for support on project scoping and the comments from Meera Sookee during this project.

## Executive Summary

### Background

The Reader is a social enterprise that uses Shared Reading to improve wellbeing and reduce social isolation across the UK and beyond. The Charity delivers extensive activity in the health, criminal justice, and youth sectors, in conjunction with a range of partners including mental health trusts, public health departments, clinical commissioning groups, local libraries, and criminal justice settings.

### Objective & scope

The study has two objectives:

1. Identify a key outcome variable of the Shared Reading programme that is suitable for use in a future economic evaluation of the programme; and
2. Identify an outcome measure for the key outcome variable that can be monitored by The Reader to inform a subsequent assessment of the economic impact of the programme in terms of healthcare system resource use, mortality or health related quality of life.

### Key Findings

The two key outcomes that align most closely with the Shared Reading programme logic are reduced social isolation and improved psychological wellbeing. Improved health related quality of life and increased patient activation outcomes were considered relevant to healthcare decision-makers but are likely to have weaker causal links to the Shared Reading activity.

We consider that reduced social isolation is the most suitable outcome for use in a future economic evaluation of the programme for the following reasons:

- There is stronger evidence in the literature linking reduced social isolation to health system resource use than for improved psychological wellbeing.
- Reductions in self-reported loneliness provide a way to measure reductions in social isolation, and can be monitored through participant surveys using the De Jong Gierveld 6-item loneliness scale (a validated research tool).
- Existing research shows reductions in loneliness result in increased physical activity and health benefits (such as reduced depression) with associated cost savings for health services.

We therefore recommend that The Reader includes the De Jong Gierveld 6-item loneliness scale in future surveys of attendees at Shared Reading groups. To monitor the impact of the programme on participants' loneliness, this will need to be collected when someone joins a group, and again after they have attended several meetings. This data can be combined with the existing evidence linking reductions in loneliness to cost savings for health services in a future economic evaluation of the programme.

# 1. Introduction

## Overview of the charity

The Reader is a social enterprise that uses Shared Reading to improve wellbeing and reduce social isolation across the UK and beyond. Small groups of people meet on a regular basis and take it in turns to read out loud to the group. The choice of literature is designed to provide people with another perspective on life, and Reader Leaders help facilitate discussion of the issues raised by the material.

## Objectives and scope

Currently, funding for Shared Reading is provided at a local level. The Reader would like to expand their groups and secure funding in more locations, with the eventual aim of obtaining funding at a national level. Although The Reader currently receives commissions from NHS Trusts and Clinical Commissioning Groups, with increasing constraints on healthcare budgets there is increased pressure on budget holders to demonstrate that the services they commission offer good value for money.

### The study has two objectives:

1. Identify a key outcome variable of the Shared Reading programme that is suitable for use in a future economic evaluation of the programme; and
2. Identify an outcome measure for the key outcome variable that can be monitored by The Reader to inform a subsequent assessment of the economic impact of the programme in terms of healthcare system resource use, mortality or health related quality of life.

It is anticipated that this will be used to develop an economic argument for healthcare decision-makers to commission Shared Reading services from The Reader.

## Structure of the report

The remainder of this report is structured as follows:

- Section 2: Background to The Reader
- Section 3: Identification of outcomes for economic evaluation
- Section 4: Evaluation methods and measures: a targeted literature review
- Section 5: Selection of outcome measure
- Section 6: Key conclusions.

## **2. Background to The Reader**

### **Description of charity**

The Reader aims to make a Shared Reading group available in every UK town, through the development of a national network of Shared Reading practice, and the building of a large-scale, long-term Shared Reading community. This model relies on a network of volunteers ('Reader Leaders') to run community groups with the support of staff at The Reader. Operating at this scale allowed The Reader to engage with more than 8,000 Shared Reading beneficiaries in over 500 different groups in 2015/16.

The Reader receives funding from a range of sources including charitable trusts, public services, individual donations and commissions from NHS Trusts and Clinical Commissioning Groups, and through public health budgets.

### **Description of specific programmes**

Shared Reading activity is delivered in a range of settings, including schools, prisons, care homes and community libraries, among small groups led by a trained Reader Leader. Groups are free, open to all, and place no pressure on people to contribute or step outside of their comfort zone.

Shared Reading has been demonstrated to be an effective tool for addressing social isolation and poor mental wellbeing across a diverse range of individuals. Groups who have been found to particularly benefit from Shared Reading include:

- Older people, often who are at a point of transition having recently retired or been bereaved
- Older people in care homes including individuals living with dementia
- Adults with long-term physical health conditions and/or at risk of, or experiencing, mental ill health
- People coping with, or recovering from, addiction
- Individuals in the criminal justice system
- Children and young people, particularly from targeted groups such as Looked after Children and those accessing mental health services

### **Programme logic, outcomes and existing outcome measures**

Several published studies have considered the link between social isolation, psychological wellbeing, mortality, morbidity and healthcare resource use. A summary by Valtorta and Hanratty (1) reports that the effect of poor social relationships on mortality is greater than that of other established risk factors such as obesity, and is comparable with cigarette smoking. They also report that social isolation and loneliness have been linked with earlier admission to residential or nursing care and have been identified as significant factors in physician utilisation. Existing outcomes data collected by The Reader using measures such as the ONS4 and Ryff scales of psychological well-being have already demonstrated the positive impact that Shared Reading groups have on patient self-reported well-being across a range of settings.

### **Findings of previous studies for the charity**

The Reader has conducted previous research studies in partnership with the Centre for Research into Reading, Information and Linguistic Systems (CRILS) and Health Sciences at the University of Liverpool.

The majority of studies conducted in partnership with CRILS have assessed the effectiveness (generally in terms of improvements in psychological wellbeing) of the Shared Reading programme, but only one previous study assessed the economic impact of Shared Reading.

### 3. Identification of outcomes for economic evaluation

Economic evaluations of healthcare interventions are typically conducted as cost-effectiveness analyses, with the outcome of interest being the cost per unit of health benefit gained. This health benefit can be any relevant measure of health: for example, years of life, number of symptom-free days or the commonly used 'quality-adjusted life-year' (QALY), which combines both length of life and (health-related) quality of life. Unfortunately, the QALY is not always sensitive enough to pick up the benefit of interventions like Shared Reading, which aim to improve an individual's overall wellbeing as opposed to their health-related quality of life specifically. As such, any economic evaluation must establish a causal link between appropriate proxy outcomes (such as reduced social isolation or improved psychological wellbeing) and the more commonly used measures of health value (such as QALYs).

The remainder of this section sets out a rationale for selecting a single outcome from within The Reader's Shared Reading programme logic as the basis of a future economic evaluation of health benefits.

#### Identifying outcomes of interest

Initial consultation with The Reader identified a range of outcomes that could potentially be used as the outcome of interest in an economic evaluation, including:

- Reduced social isolation
- Improved psychological wellbeing
- Improved health-related quality of life
- Increased patient activation

Reduced social isolation and improved psychological wellbeing are the outcomes that align most closely with The Reader's Shared Reading programme logic. Improved health related quality of life and increased patient activation are outcomes that were considered relevant to healthcare decision-makers but are likely to have weaker causal links to Shared Reading activity.

#### Healthcare decision-maker perspectives

Ten healthcare decision-makers were invited to complete an online survey designed to determine the outcome(s) of greatest interest to healthcare decision-makers, and the associated measures (research tools) that could be used to gather credible evidence (see Annex B). Unfortunately, only three decision-makers responded which limits the insights that can be gained. However, the three respondents indicated that reduced social isolation and improved psychological wellbeing were the outcomes of most interest.

#### Selection of outcome

Based on a review of the programme logic, internal consultation with The Reader, a targeted literature review (see Section 4) and survey responses from healthcare decision-makers it was determined that the outcome of interest in any future economic evaluation should be *reduced social isolation*.

## 4. Evaluation methods and measures: a targeted literature review

A targeted review of 12 existing studies was undertaken with two key objectives:

1. to identify methods and outcome measures that have been previously used to generate an economic case for programmes similar to The Reader; and
2. to identify which outcome measures (or research tools) can be used to establish a link between the Shared Reading outcome and resource use, mortality or health-related quality of life.

### Review of previous economic evaluations

Table 1 summarises the 5 economic evaluations reviewed and sets out the key relevant findings. Full references for each study can be found in Annex A<sup>1</sup>.

**Table 1: Summary of previous economic evaluations**

Study title	Relevant findings
Effects of Psychosocial Group Rehabilitation on Health, Use of Health Care Services, and Mortality of Older Persons Suffering From Loneliness: A Randomized, Controlled Trial (4)	<ul style="list-style-type: none"><li>• There is qualitative support for interventions similar to Shared Reading</li></ul>
Cost-effectiveness of a befriending intervention to improve the wellbeing and reduce loneliness of older women (3)	<ul style="list-style-type: none"><li>• Links between the De Jong Gierveld measure of loneliness/social isolation and resource use/health-related quality of life are used to quantify an economic argument</li><li>• The analysis was funded by NICE, a world leader in economic evaluations of healthcare interventions</li></ul>
Economic impact of visiting and befriending (5)	<ul style="list-style-type: none"><li>• Not directly applicable</li></ul>
Public health interventions to promote mental well-being in people aged 65 and over: systematic review of effectiveness and cost-effectiveness (6)	<ul style="list-style-type: none"><li>• The analysis uses a cost per QALY approach, suggesting that this may be of use to decision-makers</li></ul>
Dementia carers – Effective information, support and services to meet their needs (7)	<ul style="list-style-type: none"><li>• The analysis uses a cost per QALY approach, suggesting that this may be of use to decision-makers</li></ul>

Abbreviations: NICE, National Institute for Health and Care Excellence; PANAS, Positive and Negative Affect Schedule; QALY, quality-adjusted life-year; RCT, randomised controlled trial.

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<sup>1</sup> The number in brackets at the end of each study title in Table 2 indicates the relevant reference in Annex A.

We consider that the study assessing the cost-effectiveness of a befriending intervention to improve the wellbeing and loneliness of older women is particularly relevant to the Shared Reading programme. This analysis was funded by the National Institute for Health and Care Excellence (NICE), a world leader in the economic evaluation of healthcare interventions, and used to inform their guidelines on independence and mental wellbeing in older people. It links the De Jong Gierveld measure of loneliness to a range of health outcomes, including depression, stroke and coronary heart disease. These health outcomes are then linked to resource use, mortality and health-related quality of life, allowing for the calculation of total costs and total quality-adjusted life-years (the standard outcome used by healthcare decision-makers). Box 1 gives more detail on the NICE study.

### Box 1: Further detail on NICE study of befriending scheme<sup>2</sup>

#### Background

Good mental wellbeing is important throughout the life course, including in older ages. This study aimed to assess the cost-effectiveness of friendship programmes to improve wellbeing and reduce loneliness of older people.

#### Methods

A descriptive cost-consequence analysis and a cost-utility analysis were used to assess the cost-effectiveness of a friendship enrichment programme for older women (53–86 years) comprising 12 lessons that focused on friendship-related topics such as self-esteem (n=60), versus no intervention (waiting list [control], n=55).

#### Outcome Measures (Research Tools)

The study used a series of validated tools to assess; negative affect (Positive and Negative Affect Scale); self-esteem (Assertiveness Scale [Brinkman]); life satisfaction (Satisfaction with Life Scale); and loneliness (De Jong Gierveld Loneliness Scale).

#### Findings

After 9–10 months, the intervention generated statistically significant improvements in mean scores for negative affect ( $p=0.027$ ), self-esteem ( $p=0.001$ ), life satisfaction ( $p=0.012$ ) and loneliness ( $p=0.041$ ). For loneliness, the mean declines in loneliness in the intervention and control groups were not significantly different (ANOVA 0.86 vs 0.25,  $p=0.51$ ). On the basis of an evidence review linking this reduction in loneliness (calculated at 3% over the control group) with health benefits, the friendship programme is expected to reduce depression by 1.04%, reduce the early onset of dementia by 0.21%, and increase physical activity by 1.93% (thus reducing diabetes by 0.13%, stroke by 0.15%, and coronary heart disease by 0.27%). Against an intervention cost of £120, discounted future cost savings to the health service were estimated to be £391 and quality-adjusted life-years gained of 0.035 per person.

#### Interpretation

The intervention is both effective and cost-saving, suggesting that friendship programmes help enhance both the health and wellbeing of older women and are a good use of public money.

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<sup>2</sup> The box is based on the abstract to the published NICE study.

## Review of studies linking outcome measures to resource use

Table 2 summarises the 7 studies linking outcome measures to resource use that we reviewed and sets out key findings. The review highlighted the paucity of studies linking improved psychological wellbeing to other outcomes of interest. By contrast, all of the studies considered focussed on social isolation as the outcome of interest.

**Table 2: Studies reviewed to establish links between outcome measures and resource use, mortality or health related quality of life**

Study	Key Findings	Measure Used
Ellaway et al, 1999 (8)	There is significant increase in GP consultations for patients that report feeling lonely most of the time or often	Single question: 'At the present moment do you ever feel lonely?'
Iliffe et al, 2007 (9)	Social isolation is associated with depressed mood and impaired memory, perceived fair or poor health, perceived difficulty with both basic and instrumental activities of daily living, diminishing functional ability, and fear of falling	Lubben Social Network Scale
Fratiglioni et al, 2000 (10)	Individuals living alone, and those without any close social ties, both had an adjusted relative risk for developing dementia of 1.5	Unclear
Molloy et al, 2010 (11)	A higher frequency of loneliness was associated with higher rates of emergency hospitalisation	Unclear
Cornwell and Waite, 2009 (12)	Social disconnectedness and perceived isolation are independently associated with lower levels of self-rated physical health	Social Disconnectedness – 8-item scale
Mistry et al, 2001 (13)	Patients who were socially isolated or at high or moderate risk for isolation, were 4-5 times more likely to be re-hospitalised within the year, than low isolation risk patients	Lubben Social Network Scale
Wilson et al, 2007 (14)	Loneliness is associated with an increased risk of dementia	De Jong Gierveld 6-item loneliness scale

Abbreviations: GP, general practitioner.

## Summary of findings

The targeted review confirmed that the chosen outcome of interest (reduced social isolation) has been used successfully in previous economic evaluations. A variety of relevant outcome measures (research tools) were identified that make it possible to link reduced social isolation to reduced resource use and better health outcomes (typically related to either improved survival or improved health-related quality of life). The three potentially relevant outcome measures that were found to link to other outcomes of interest were the De Jong Gierveld loneliness scale, the Social Disconnectedness 8-item scales and the Lubben Social Network Scale. Further discussion regarding the most appropriate outcome measure is provided in Section 5.

## 5. Selection of outcome measure

A total of 6 potential outcome measures (research tools) were identified by three sources – CEL, South Gloucestershire Council and Lancashire County Council. The only outcome measure identified by all sources was the De Jong Gierveld 6-item loneliness scale as shown in Table 3 below.

Table 3: Outcome measures – sources and research tools

Measure	CEL Measurement Tool	De Jong Gierveld 6- item Loneliness Scale	The UCLA 3- Item Loneliness Scale	Duke Social Support Index (DSSI)	Lubben Social Network Scale	Social Disconnect- edness 8- item scale
Source:						
CEL	✓	✓	✓	✗	✗	✗
South Gloucestershire	✗	✓	✗	✓	✗	✗
Lancashire	✓	✓	✓	✓	✓	✓

### Selection criteria

The criteria for determining the most suitable outcome measure were agreed in consultation with The Reader and are presented in Table 4.

Table 4: Selection criteria for the most suitable outcome measure

Criterion	Key source of evidence
1. Readily linked to resource use, mortality or health-related quality of life	Key findings from targeted review of existing research (Section 4)
2. Impact of Shared Reading programme expected to be observed	
3. Readily understood by decision-makers	Findings from review of alternative measures
4. Reliable and validated	(Section 5)
5. Simple to use	
6. No negative impact on participants	

Table 5 summarises the extent to which the six alternative outcome measures meet the selection criteria. Following discussions with The Reader the De Jong Gierveld 6-item loneliness scale was determined to be the research tool that best meets the pre-specified criteria. As noted above, this measure was used in the analysis conducted by NICE discussed in Section 4. Use of this measure would therefore potentially enable the Reader to carry out a similar analysis of the cost-effectiveness of the Shared Reading programme in the future.

Table 5: Comparison of alternative measures

	Links to resource use, mortality or health-related quality of life	Impact expected to be observed	Understood by decision-makers	Reliable and validated	Simple to use	Non-negative for the user
CEL measurement tool	✗	?	✓	✗	✓	✓
De Jong Gierveld 6-item loneliness scale	✓	✓	✓	✓	✓	?
UCLA 3-item loneliness scale	✗	✓	✓	✓	✓	✗
Duke Social Support Index	✗	?	✓	✓	✓	✓
Lubben Social Network Scale	✓	?	✓	✓	✓	✓
Social Disconnectedness – 8-item scale	?	?	?	✓	?	✓

✓ = yes, ✗ = no, ? = to an extent.

Abbreviations: CEL, Campaign to End Loneliness; UCLA, University of California, Los Angeles.

## 6. Key conclusions

On the basis of the above discussion, we consider that:

1. Reduced social isolation is the most suitable outcome for use in a future economic evaluation of the Shared Reading programme.
2. Reductions in self-reported loneliness provide a way to measure reductions in social isolation, and can be monitored through participant surveys using the De Jong Gierveld 6-item loneliness scale (a validated research tool).

We therefore recommend that the Reader includes the De Jong Gierveld 6-item loneliness scale in future surveys of attendees at Shared Reading groups. To monitor the impact of the programme on participants' loneliness this will need to be collected when someone joins a group, and again after they have attended several meetings.

The Reader will be able to use this data to inform a subsequent economic evaluation of the programme by using existing evidence linking reductions in loneliness to increased physical activity and health benefits (such as reduced depression). These generate cost savings for health services that can form the basis of an economic evaluation of the programme (as in a recent NICE study of a befriending scheme).

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## Annex B: Questionnaire

*Please note that all questionnaire responses will be anonymised prior to sharing with The Reader.*

Name:

Job title:

Organisation:

Location: (North West, South West, London, Wales, Northern Ireland, Other)

### Outcome measures

1. In an economic analysis of The Reader's shared reading programme, which of the following would you be most interested in seeing as an outcome? Please rank in order of preference.
  - a. Reduced social isolation
  - b. Improved psychological wellbeing
  - c. Improved health-related quality of life
  - d. Increased patient activation

2. Are there any other outcomes of The Reader's shared reading programme that you would consider to be valuable?

3. Would you consider any populations served by The Reader to be of particular interest?
  - a. Individuals with dementia
  - b. Individuals with mental health problems
  - c. Individuals with chronic health conditions
  - d. Other:

4. To what extent would you consider the following measures of social isolation to be useful or of value? (1 = not useful/valuable, 5 = highly useful/valuable)
  - a. Duke Social Support Index (DSSI)
  - b. Lubben Social Network Scale (LSNS)
  - c. Other:

5. To what extent would you consider the following measures of psychological wellbeing to be useful or of value? (1 = not useful/valuable, 5 = highly useful/valuable)
  - a. Warwick-Edinburgh Mental Wellbeing Scale (WEMWBS)

- b. ONS4 Subjective Wellbeing Scale
- c. Ryff Scales of Psychological Wellbeing
- d. Positive and Negative Affect Schedule (PANAS)
- e. Other:

6. To what extent would you consider the following measures of health-related quality of life to be useful or of value? (1 = not useful/valuable, 5 = highly useful/valuable)

- a. EQ-5D
- b. SF-6D (derived from the SF-36)
- c. Other:

7. To what extent would you consider the following measures of patient activation to be useful or of value? (1 = not useful/valuable, 5 = highly useful/valuable)

- a. Patient Activation Measure (PAM)
- b. Other

8. Are there any other outcome measures you would be interested in seeing?

#### Barriers to funding

1. What would you consider to be the key barriers to funding a project with The Reader? For example, cost or perceived lack of benefit.

2. Is there a specific type of funding that would be most accessible for funding a project with The Reader? For example, funding specifically designated for dementia patients, or for reducing social isolation.

#### Follow-up

1. Would you be open to a 10 minute follow-up conversation to discuss some of your answers to this questionnaire?

- a. Yes
- b. No