

# Dementia and Imagination Research Methods

Dr. Gill Windle, Dementia Services Development Centre  
Dr Carys Jones, Centre for Health Economics and Medicines  
Evaluation

School of Healthcare Sciences  
Bangor University



DEMENTIA AND IMAGINATION  
DEMENTIA A'R DYCHYMYG



# Introduction

Internationally, there is a growing interest regarding the potential of arts programmes in dementia care.

Researchers wish to embrace the contribution people with dementia can make, however undertaking research with people living with dementia brings some unique challenges.

Memory and communication difficulties involve careful exploration and interpretation to understand experiences. This can be further complicated when trying to tease out 'what is so special' about creative interventions.

Taking part in creative approaches may have unique benefits, but how can researchers 'measure' this?

What is the potential of the arts for raising awareness and challenging the assumptions of living with dementia?

# Rationale – address limitations

*Journal of Aging, Humanities, and the Arts*, 4:352–367, 2010  
Copyright © Taylor & Francis Group, LLC  
ISSN: 1932-5614 print/1932-5622 online  
DOI: 10.1080/19325614.2010.533396



## Impact of Arts Participation on Health Outcomes for Older Adults

MELISSA CASTORA-BINKLEY and LINDA NOELKER  
*Katz Policy Institute, Benjamin Rose Institute, Cleveland, Ohio, USA*

*International Journal of Ageing and Later Life*, 2014 9(1): 7–34. © The Author

The participative arts for people living with dementia: a critical review

By HANNAH ZEILIG<sup>1</sup>, JOHN KILLICK<sup>2</sup> & CHRIS FOX<sup>3</sup>

## “Shall I Compare Thee to a Dose of Donepezil?”: Cultural Arts Interventions in Dementia Care Research

Kate de Medeiros, PhD,<sup>\*,1</sup> and Anne Basting, PhD<sup>2</sup>



## The Journal of DementiaCare Research Focus

This section aims to provide a channel of two-way communication between researchers and practitioners in the expanding field of social, psychological and nursing research in dementia care, including all aspects of nursing and care practice, communication and the environment.

## Arts programmes and quality of life for people with dementia – a review

*Do we know enough about the potential of visual art programmes to improve the quality of life and well-being of people with dementia? Katie Salisbury, Katherine Algar and Gill Windle review the literature on use of the arts in dementia care, with a specific focus on visual arts*

## Aging & Mental Health

Publication details, including instructions for authors and subscription information:  
<http://www.tandfonline.com/loi/camh20>

## The impact of community-based arts and health interventions on cognition in people with dementia: a systematic literature review

Rhea Young<sup>a</sup>, Paul M. Camic<sup>a</sup> & Victoria Tischler<sup>b</sup>

## Art therapies and dementia care: A systematic review

Renée L. Beard

*Dementia* published online 20 September 2011

DOI: 10.1177/1471301211421090

## Viewing and making art together: a multi-session art-gallery-based intervention for people with dementia and their carers

Paul M. Camic <sup>a</sup>, Victoria Tischler <sup>b</sup> & Chantal Helen Pearman <sup>b</sup>

**Mixed-methods exploratory pre-post design (N=24 dyads)**

---

## An Art Gallery Access Programme for people with dementia: “You do it for the moment”

Sarah MacPherson <sup>a</sup>, Michael Bird <sup>a b</sup>, Katrina Anderson <sup>a b</sup>, Terri Davis <sup>a</sup> & Annaliese Blair <sup>a</sup>

**Mixed methods exploratory, including behavioural observation (N=15)**

---

Ullán, A. M., et al. (2013). Contributions of an artistic educational program for older people with early dementia: An exploratory qualitative study. *Dementia*, 12(4), 1-22.

**Qualitative, exploratory, including observation (N=21)**

- Visual arts programmes are by their nature ‘complex’ in that they contain several interacting components
- there is no ‘gold standard’ outcome measure for arts programmes - explore different approaches
- longitudinal mixed-methods design

# Mixed methods longitudinal design

- 1) a structured questionnaire including validated outcome measures and qualitative, open-ended questions
- 2) self-evaluation of impact of sessions
- 3) behavioural observation with an active control condition
- 4) semi-structured interviews with a sub-group of participants

# Quantitative outcome measure – which one?

- The role of standardised, validated and reliable measures in visual arts interventions have yet to be fully investigated
- QoL was measured with the Dementia Quality of Life (DEMQOL, Smith et al., 2007).
- Five domains of quality of life including positive and negative emotions, memory, loneliness and daily activities. It uses both self-reporting (twenty-nine items) and ratings by family carer or staff member as proxy (DEMQOL-Proxy; thirty-two items).
- Challenges of administering to people living with dementia?

# Observed well-being 'in the moment'

Article

## Measuring the quality of life and well-being of people with dementia: A review of observational measures

Katherine Algar, Robert T Woods and Gill Windle  
Dementia Services Development Centre (DSDC), Bangor University, Wales, UK



Dementia  
0(0) 1–26  
© The Author(s) 2014  
Reprints and permissions:  
sagepub.co.uk/journalsPermissions.nav  
DOI: 10.1177/1471301214540163  
dem.sagepub.com  
The SAGE logo, consisting of a stylized 'S' inside a circle followed by the word 'SAGE' in a bold, sans-serif font.

- Looked at various measures that might capture the immediate effects of an arts programme
- Recommended an adapted version of the Greater Cincinnati Chapter Well-being Scale

Interest, sustained attention, pleasure, negative affect, sadness, self-esteem, disengagement and normalcy

Observed well-being among individuals with dementia: Memories in the Making®, an art program, versus other structured activity  
Jennifer M. Kinney and Clarissa A. Rentz  
AM J ALZHEIMERS DIS OTHER DEMEN 2005 20: 220  
DOI: 10.1177/153331750502000406

Does not rely on the people living with dementia, their carers or the researcher to recall feelings and details. Enables a way of quantitatively capturing 'in the moment' reactions that might otherwise be overlooked, or prove difficult to articulate.

Training challenges and lots of data!

# Qualitative

- Understanding the subjective, individual experience
- Capture deeper meaning that could be overlooked by standardised measurement tools
- Understand the impact on concepts such as quality of life and well-being (de Medeiros & Basting, 2014)
- Challenges of administering to people living with dementia?

# BMJ Open Dementia and Imagination: a mixed-methods protocol for arts and science research

---

Gill Windle,<sup>1</sup> Andrew Newman,<sup>2</sup> Vanessa Burholt,<sup>3</sup> Bob Woods,<sup>1</sup> Dave O'Brien,<sup>4</sup>  
Michael Baber,<sup>5</sup> Barry Hounsome,<sup>6</sup> Clive Parkinson,<sup>7</sup> Victoria Tischler<sup>8</sup>

# Valuing the benefits

- NHS funding decisions: evidence based, clinical effectiveness and cost-effectiveness
- Cost-effectiveness typically focuses on the benefits to the person undertaking the activity
- Social Return on Investment (SROI) analysis: a method that seeks to establish the wider social value generated by an activity

# SROI methods- overview

1. Establishing scope and identifying stakeholders
2. Mapping outcomes
3. Evidencing and valuing outcomes
4. Establishing impact
5. Calculating the SROI
6. Reporting the SROI ratio of £X of value generated for every £1 invested

# Who were our stakeholders?

## **Included:**

- People living with dementia
- Their families
- Staff working at the hospital and care homes sites
- 'The state'

## **Not included:**

- The artists

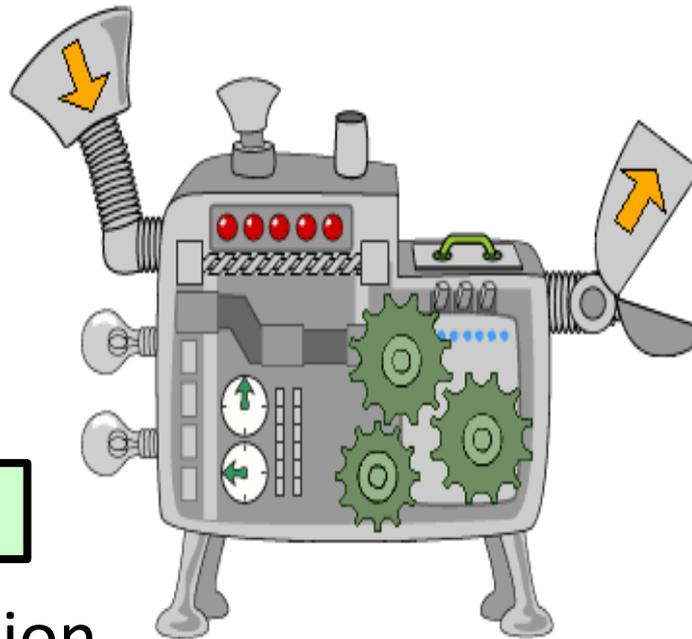
# Mapping outcomes- the theory of change

## 1. INPUTS

- Time

## 2. MECHANISMS

- Social interaction
- Shared experiences
- Creativity



## 3. OUTCOMES

- Enjoyment
- Sense of belonging

# Some of the outcomes that we valued

## **Participants:**

- Improved mood
- Increased engagement with art
- Increased confidence
- Feeling of control over the environment
- Increased sense of belonging to a community

## **Families/ staff carers:**

- Increased social support network
- Change in attitude towards people with dementia

# Resulting SROI ratio

- Our analysis estimated a social return on investment of between £2.97 and £6.34 is generated for every £1 invested in Dementia and Imagination
- Identifying which outcomes from Dementia and Imagination generated the most value means that we have a better understanding of what to include in future arts programmes for people living with dementia and those who support them

# Acknowledgements

- Dementia and Imagination was funded as ‘Dementia and imagination: connecting communities and developing well-being through socially engaged visual arts practice’, Grant Ref: AH/K00333X/1, by the AHRC and ESRC as a part of the Cross-Council Connected Communities Programme. (Principal Investigator G. Windle; Co-Investigators A. Newman, C. Parkinson, V. Burholt, M. Baber, V. Tischler, B. Hounsome, D. O’Brien, B. Woods, R.T. Edwards). Many thanks to B. Hounsome for his role as co-investigator in the first year.
- Regional and national collaborating partners in Dementia and Imagination: Age Watch, Alzheimer’s Society, the Arts Council of Wales, Denbighshire County Council, Engage Cymru, Derbyshire Community Health Service NHS, Equal Arts, the BALTIC Centre for Contemporary Art, Tyne & Wear Archives and Museums, NIHR CLAHRC and Nottingham Contemporary Ltd.



Arts & Humanities  
Research Council

