

Lancaster University Centre for Ageing Research Town and Gown

Conference: Dementia and the Imagination: Arts and Design for Health

Presentation:

Participatory arts and dementia: an overview from Manchester

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Special thanks to:

Dr Caroline Swarbrick

Dr Jackie Kindell

Manchester Camerata

Nick Ponsillo

**DART PhD students past
and present**

Presentation Format

- It's a double act ...
- John will provide an overview of the work of the Dementia and Ageing Research Team with special reference to creative practices
- Helen will then outline her work with Manchester Camerata and the Portraits of a Place project, a joint venture with the NHS and the young onset dementia service in Manchester city centre
- Final thoughts and time for questions

Dementia and Ageing Research Team

- DART started in 2008 and has 12 inter-disciplinary members: core group – John Keady, Caroline Swarbrick, Helen Pusey, Simon Burrow
- DART's primary research interest is in **the everyday experience of people living with dementia and their carers** and finding ways to engage those perspectives in transforming, shaping and leading our work
- Up until September 2015 DART have led, or been involved in studies, that have been funded through a range of bodies: NIHR, ESRC, HIEC, Alzheimer's Society, BUPA, Salford City Council, MICRA, Manchester Camerata
- DART is a predominantly **social research group** and we use a range of qualitative methods to conduct our work, including our PhD students

DART prizes creativity and personal knowledge ‘innovation through co-production’

We adopt a range of methods, for example:

- Visual recording: photographs, video camera
- Interviews: face to face; ‘walking’ [outdoor spaces]; biographical; sensory; appearance
- Focus groups
- Social network mapping
- Drawing and creative arts/writing

DART methodologies

We see value in:

- Narrative approaches
- The importance of biography
- Creative social research methods
- Longitudinal engagement
- Reflexivity
- Case study research
- Shared language

But ... Case study research not always seen as scientific by the academic community



Editors

John Keady, University of Manchester, UK
Penny Harris, John Carroll University, USA

Editorial Board [2002-2017]

Over 30 academics and personnel from
12 different countries, including people
with dementia

First Edition: Feb 2002; impact factor
awarded 2014 [2017: Gerontology: 14/32]

Available 8 times a year

Gloria Sterin: Vol 1; issue 1; page 1

Awareness and Time

**People can cope with this
disease. But you need time.**

(Sterin, 2002 p.9)



Reference:

Sterin, G. (2002). Essay on a word: A lived experience of Alzheimer's disease. *Dementia: The International Journal of Social Research and Practice*, 1(1): 7-10

Neighbourhoods Study: Primary Aims

- **Examples ...**
- **To learn from the process and praxis of making people living with dementia and their care partners core to the research agenda**
- **To build capacity within the research community and the networks of people living with dementia and their care partners**
- **To develop the evidence base, methods and measures for understanding the significance of neighbourhoods for people living with dementia and their care partners**
- **To create, test and evaluate interventions that are pertinent to a neighbourhood model of dementia**

Neighbourhoods Study

- People living with dementia central to the programme: EDUCATE Group; Open Doors; Scottish Dementia Working Group; Age UK Salford INSPIRE group
- 8 work programmes
- Independent Member-Led Projects: Acknowledgements to Dr Caroline Swarbrick
- UK Partners and Sweden: Center for Dementia Research
- 3 ESRC Studentships: 1 Scotland; 2 North West England, plus 2 additional PhD studentships based in Sweden


NEIGHBOURHOODS AND DEMENTIA: A MIXED METHODS STUDY

Study Reference Number: ES/L001772/1

- Work Programme 1:** Member Involvement (Manchester lead)
- Work Programme 2:** Generating Neighbourhood Profiles of Cognitive Ageing and Service Use Using Nationally Representative Population (Manchester lead)
- Work Programme 3:** Development of a Dementia Core Outcome Set (Lancaster lead)
- Work Programme 4:** Neighbourhoods: Our People, Our Places (Stirling lead)
- Work Programme 5:** Developing the evidence base for evaluating dementia training in NHS hospitals: a mixed methods design (Lancaster lead)
- Work Programme 6:** 'Living Life & Doing Things Together': couples living with dementia at home (Sweden lead)
- Work Programme 7:** Personal digitised life story tools for Deaf sign language users with dementia (Manchester lead)
- Work Programme 8:** Staff and Member Health and Wellbeing Service (Manchester lead)

Study website:

www.neighbourhoodsanddementia.org

 @nbdem

Improving
Dementia Care
ESRC·NIHR



NEIGHBOURHOODS AND DEMENTIA: A MIXED METHODS STUDY

Study Reference Number: ES/L001772/1

The lived neighborhood: understanding how people with dementia engage with their local environment

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Article

Visioning change: Co-producing a model of involvement and engagement in research (Innovative Practice)

Caroline M Swarbrick

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Open Doors

Greater Manchester West Mental Health NHS Foundation Trust, UK

Scottish Dementia Working Group

Alzheimer Scotland, UK

EDUCATE

Pennine Care NHS Foundation Trust, UK

Katie Davis

Division of Nursing, Midwifery and Social Work, University of Manchester, UK

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Dementia

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Study website:

www.neighbourhoodsanddementia.org



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www.manchestercamerata.co.uk

**HELEN PUSEY:
MANCHESTER CAMERATA AND
PORTRAITS OF A PLACE**

'Portraits of Place'



Arts Science Collaborative

- Manchester Young Onset Dementia Service
- Manchester Camerata Orchestra
- University of Manchester

‘Portraits of Place’



- ‘Portraits of Place’, sought to enhance a sense of belonging and to promote personal and wider identity.
- Art and Music workshop over 8 weeks
- People with young onset dementia and carers as composers and artists
- Observational and interview evaluation

Main Findings



Overarching themes	Sub-themes
Enhancing well-being	Increased confidence and self-worth
	Improved mood
	Taking risks
The Journey	Self-Discovery
	Building a community
	Defying expectations

'Portraits of Place'



- <https://www.youtube.com/watch?v=DGAycRyyzq0>

Final thoughts

- Importance (for us) of case study work
- Development and application of new social research methods
- Where possible, encouraging the involvement of people with dementia to research their own lives and experience
- Promoting the importance of personal knowledge
- The growing influence of public health and creative arts in dementia studies [social interventions]
- Future preparation and role of practitioners in dementia care

Some Publications from DART

- Woods, R.T., Orrell, M., Bruce, E., Edwards, R.T., Hoare, Z., Hounsome, B., Keady, J., Moniz-Cook, E., Orgeta, V., Rees, J. and Russell, I.T. REMCARE: pragmatic multi-centre randomised trial of reminiscence groups for people with dementia and their family carers: effectiveness and economic analysis. *PLoS ONE* 2016, 11(4): e0152843. doi:10.1371/journal.pone.0152843
- Campbell, S., Manthorpe, J., Samsi, K., Abley, C., Robinson, L., Watts, S., Bond, J. and Keady, J*. Living with Uncertainty: Mapping the transition from pre-diagnosis to a diagnosis of dementia. *Journal of Aging Studies* 2016, 37: 40-47 DOI: 10.1016/j.jaging.2016.03.001 (*corresponding author)
- Elvish, R., Burrow, S., Cawley, R., Harney, K., Gregory, J., Pilling, M. and Keady, J. 'Getting to Know Me': The second phase roll-out of a training programme for supporting people with dementia in general hospitals. *Dementia: the international journal of social research and practice* on-line first, February 2016: DOI: 10.1177/1471301216634926
- Roach, P., Drummond, N. and Keady, J. 'Nobody would say that it is Alzheimer's or dementia at this age': family adjustment following a diagnosis of early-onset dementia. *Journal of Aging Studies* 2016, 36: 26-32 doi:10.1016/j.jaging.2015.12.001
- Dowding, D., Lichtner, V., Allcock, N., Briggs, M., James, K., Keady, J., Lasrado, R., Sampson, E.L., Swarbrick, C. and Closs, S.J. Using sense-making theories of decision-making to aid understanding of the recognition, assessment and management of pain in patients with dementia in acute hospital settings. *International Journal of Nursing Studies* 2015, 53: 152-162 <http://dx.doi.org/10.1016/j.ijnurstu.2015.08.009>
- Ward, R., Campbell, S. and Keady, J. 'Once I had money in my pocket, I was every colour under the sun': Using 'Appearance Biographies' to explore the meanings of appearance for people with dementia. *Journal of Aging Studies* 2014, 30: 64-72. DOI: 10.1016/j.jaging.2014.03.006
- Adra, M., Hopton, J. and Keady, J. 'Constructing the meaning of quality of life for residents in care homes in the Lebanon: perspectives of residents, staff and family'. *International Journal of Older People Nursing*. 2015, 10 (4): 306–318. Doi:10.1111/opn.12094. **Winner of the inaugural 'International Journal of Older People Nursing Award' for 'Outstanding Methodological Innovation in Gerontological Nursing Research'**.
- Young, A., Ferguson-Coleman, E. and Keady, J. Understanding Dementia: effective information access from the Deaf community's perspective. *Health and Social Care in the Community* 2014. DOI: 10.1111/hsc.12181
- Kindell, J., Sage, K., Wilkinson, R. and Keady, J. Living with Semantic Dementia: A Case Study of One Family's Experience. *Qualitative Health Research* 2014, 24(3): 401-411. Open access: <http://qhr.sagepub.com/content/24/3/401.full.pdf+html>
- Keady, J., Campbell, S., Barnes, H., Ward, R., Li, X., Swarbrick, C., Burrow, S. and Elvish, R. Neighbourhoods and Dementia in the Health and Social Care Context: a realist review of the literature and implications for UK policy development. *Reviews in Clinical Gerontology*, 2012, 22, 2: 150-163. DOI: 10.1017/S0959259811000268