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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NHS Foundation Trust

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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
Methods

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

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:
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
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<th>Member Involvement (Manchester lead)</th>
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<td>Generating Neighbourhood Profiles of Cognitive Ageing and Service Use Using Nationally Representative Population (Manchester lead)</td>
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<td>Development of a Dementia Core Outcome Set (Lancaster lead)</td>
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<td>Personal digitised life story tools for Deaf sign language users with dementia (Manchester lead)</td>
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<td>Work Programme 8:</td>
<td>Staff and Member Health and Wellbeing Service (Manchester lead)</td>
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**Study website:**
[www.neighbourhoodsanddementia.org](http://www.neighbourhoodsanddementia.org)

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

Richard Ward, Andrew Clark, Sarah Campbell, Barbara Graham, Agneta Kullberg, Kainde Manji, Kirstein Rummery and John Keady

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2School of Nursing, Midwifery, Social Work and Social Sciences, University of Salford, Salford, Greater Manchester, United Kingdom of Great Britain and Northern Ireland
3School of Nursing, Midwifery and Social Work, University of Manchester, Manchester, United Kingdom of Great Britain and Northern Ireland
4Institute for Medicine and Health, Linkoping University, Linkoping, Sweden

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

Caroline M Swarbrick
Division of Nursing, Midwifery and Social Work, University of Manchester, UK

Open Doors
Greater Manchester West Mental Health NHS Foundation Trust, UK

Scottish Dementia Working Group
Alzheimer Scotland, UK

EDUCATE
Penneine Care NHS Foundation Trust, UK

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

John Keady
Division of Nursing, Midwifery and Social Work, University of Manchester, UK. Greater Manchester West Mental Health NHS Foundation Trust, UK

Study website:
www.neighbourhoodsanddementia.org
@nbdem
HELEN PUSEY:
MANCHESTER CAMERATA AND
PORTRAITS OF A PLACE

www.manchestercamerata.co.uk
‘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

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<td>Enhancing well-being</td>
<td>Increased confidence and self-worth</td>
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<td>Improved mood</td>
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<td>Taking risks</td>
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<td>The Journey</td>
<td>Self-Discovery</td>
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<td>Building a community</td>
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<td>Defying expectations</td>
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‘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

- 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
- 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