‘Soft Evaluations’ Workshop
What is it, why do we need it and how can we convince others that it is valuable?

Thursday 19 October 2017, 10.00 -16.30 h
ML120, University of Wolverhampton, UK

Programme

<table>
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<tr>
<th>Time</th>
<th>Description</th>
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<tbody>
<tr>
<td>10.00</td>
<td>Arrival and coffee</td>
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<tr>
<td>10.20</td>
<td>Welcome – Prof Kristina Niedderer, Prof Tom Dening</td>
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</tbody>
</table>
| 10.30 | 5 min. short presentations by participants + 5 min. questions:  
10.30 Prof Vjera Holthoff, Dr Berit Ziebuhr, Alexianer Hospital Berlin  
10.40 Dr Julie Gosling, Dr Mike Craven, Nottinghamshire Healthcare Trust  
10.50 Dr Isabelle Tournier and Afsaneh Abrilahij, University of Luxembourg  
11.00 Dr Jennifer Lim, University of Wolverhampton  
11.10 Dr Marta Díaz, Universitat Politècnica de Catalunya  
11.20 Dr Teresa Atkinson, Dr Faith Wray, Worcester University  
11.30 Karen Gray, Worcester University  
11.40 Dr David Prytherch, Coventry University  
11.50 Prof Cathy Treadaway, Cardiff Metropolitan University  
12.00 Prof Gail Kenning, University of Technology, Sydney |
| 12.10 | Plenary discussion of the issues emerging from the presentations |
| 13.00 | Lunch |
| 14.00 | Group work: exploration of key themes in groups |
| 15.20 | Feedback and plenary discussion |
| 16.00 | Networking and refreshments |
| 16.30 | Close |
‘Soft Evaluations’ Workshop
Thursday 19 October 2017, 10.00 -16.30 h
University of Wolverhampton, UK

Attendance list

Berit Ziebuhr, Alexianer St Hedwig Kliniken Berlin, Germany
Cathy Treadaway, Cardiff Metropolitan University, UK
David Prytherch, Coventry University, UK
Eva Galán, INTRAS, Spain
Faith Wray, University of Worcester, UK
Gail Kenning, University of Technology, Sydney, Australia
Isabelle Tournier, University of Luxembourg, Luxembourg
Irene G. Bolzoni, INTRAS, Spain
Jennifer Lim, University of Wolverhampton, UK
Julie Gosling, Nottinghamshire Healthcare NHS Foundation Trust, UK
Karen Gray, University of Worcester, UK
Kristina Niedderer, University of Wolverhampton, UK
Marta Diaz, Universitat Politècnica de Catalunya, Spain
Michael Craven, Nottinghamshire Healthcare NHS Foundation Trust, UK
Michaëlle Bosse, TU Dresden, Germany
Teresa Atkinson, University of Worcester, UK
Tom Denning, Nottinghamshire Healthcare NHS Foundation Trust, UK
Vjera Holthoff, Alexianer St Hedwig Kliniken Berlin, Germany
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Summary of the day

The rationale behind the workshop on ‘Soft Evaluations’ was to discuss in multiprofessional expert panel (designers, professionals in dementia research, PPI and scientific methodologists) how to evaluate data in dementia research. As evidence-based recommendations are the basis of health care funding we are interested in providing evidence for the variety of interventions in people with dementia and their carers at different stages of dementia disease. The understanding of the term ‘soft evaluations’ is not clearly defined. The general notion of it during the workshop is a very early stage of evaluation (developmental evaluation) including e.g. analyses of interviews, videotaping, narratives. In contrast to measuring results in a quantitative way soft evaluations does not yet have an impact on health care decision-making and policies as it is not considered evidence-based.

Participants in the order of presentation: Kristina Niederer, Tom Dening, Berit Ziebuhr, Vjera Holthoff-Detto, Julie Gosling, Mike Craven, Isabelle Tournier, Jennifer Lim, Marta Díaz Teresa Atkinson, Faith Wray, Karen Gray, David Prytherch, Cathy Treadaway, Gail Kenning.

The following topics were discussed during the day:

• Our research must be aimed at dissemination and must influence public decision making
• Transferability of our results but not generability
• Levels of evaluation, their methods and their validity
• Everybody deserves the same quality of care and activation (human equity rights)
• Misunderstandings over language lead to difficulties in communication between disciplines (particularly clinical/public health and arts/design)
• The emotional impact on researchers of conducting research with people with dementia, particularly those in advanced stages
• How the logistical requirements (resourcing, time etc) and values of researchers and the research environment itself will impact both how the evaluation is conducted and maybe also the product or intervention itself
• How do we design for constant decline
• Ethics for ‘soft evaluation’ – a different kind of framework may be necessary
• Enhance communication between the disciplines with similar challenges in measuring their intervention effects

We plan a second workshop for the year 2018.
‘Soft Evaluations’ Workshop

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www.designingfordementia.eu
The project aims

Support people with early-mid stage dementia and their carers
Support and improve self-empowerment & social engagement
Using design and mindfulness theory/practices

Two foci:
• designing to help with personal difficulties
• Designing the environment to support persons with dementia
Project shape

4 year project

**Year 1:**
Data collection with persons with dementia and with carers (completed May 2017)

**Year 2:**
Design development and realisation based on results
Decision making and development through co-design with people with dementia and healthcare experts

**Year 3:**
Evaluation of (experiential) prototypes
Where we are now

Completed data collection phase

Working through design phase

This exchange (visit 18: Wolverhampton/Nottingham) launches the evaluation phase (WP6), including

- public involvement event 18.10.17
- soft evaluation workshop 19.10.17
Soft evaluation

Idea for today’s event came from the MinD symposium, December 2016

Hard versus soft evaluation: **4 issues**

1) Level and approach of evaluation
2) Tools for evaluation and validity
3) Considering culture and context as part of evaluation
4) KIS: evaluation appropriate for people with dementia (e.g. verbal, non-verbal indicators)
Aims for today

Collectively address the issue of how to evaluate designs when working with people with dementia

Short presentations on researchers’ experience

Use workshops to explore emerging themes

Next steps, for example drafting a consensus statement
MinD data collection in Germany: methodology & initial results

Berit Ziebuhr, MD
Resident
Vjera Holthoff, MD, PhD*
Professor of Old Age Psychiatry

Department of Psychiatry, Psychotherapy and Psychosomatics
Alexianer Krankenhaus Hedwigshöhe, Berlin
*Technische Universität Dresden, Medical Faculty
• **Design of interview guideline with open-ended questions**
  – Literature search for qualitative interviews in persons with dementia
  – Expert group without dementia (caregivers, researchers, Alzheimer Europe)
  – **Quality assurance through expert with dementia, caregivers**
  – Interview guideline: PwD, caregivers (with single interviewee, focus group)

• **Qualitative Interviews**
  – Audiotape -> Transcribed verbatim

• **Structured Content Analyses of Transcripts**
  – Material processing using a mixed deductive-inductive approach
• **Recruitment of participants**
  – Alzheimer-Gesellschaft Berlin e.V
  – Department Old Age Psychiatry St. Hedwig Kliniken

• **Patient and Caregiver characteristics**

  – PwD
    • Mean age: 80.5/78.5
    • Gender (male): 33% (2)/68% (19)

  – Caregivers
    • Mean age: 69
    • Gender (male): 32% (7)

  – Dementia types:
    • Alzheimer’s disease
    • Vascular dementia
    • Frontotemporal dementia 0% (0)/32% (9)
    • Mixed dementia; Not specified: 68% (19)
Qualitative interviews: Categories and subcategories

Level 1:
- Activities of Daily Living (ADL)
- Social interaction
- Use of (technical) devices

Level 2:
- Decision-making
- Sense of empowerment (have something expected of them)
- Live perspective Caregiver and PwD
- Staying connected
- Honouring identity
- Adaption to their evolving life
Data collection: qualitative interviews in PwD

Observations

• Feel that restrictions in everyday life come from age
  – e.g. restrictions in mobility are age-related
• Feel that restrictions in life come from the caregivers’ worries
• Rarely attribute restrictions to symptoms of dementia or use the word ‘dementia’
  – Have difficulties thinking of what changed since the diagnosis although they described those changes responding to other questions and realize them
• Often think that existing assistive devices could be useful but they don’t need them now, maybe later
PwD: activities of daily living/social activities

Loss of meaningful activities

Joy in learning new things

Feeling of importance and being needed

I would like to do things of my own and on my own
PwD: loss and fear

Losing ability to take care of themselves

Losing the sense of belonging somewhere
working with picture, touch, mime, music and hugs
Notting Hill Housing Trust Peer-Led Tenant Evaluation

‘there is a voice – the voice is us’
Kevin Chettle; Inmate Balderton Hospital 1960 - 1980
Special Lecturer; University of Nottingham 1998 - 2013

I’ve come a long way
older researchers feed back their recommendations to care providers

a taste of care
‘- a moving, engaging and often deeply funny exploration of exile, memory and loss - ‘ Jon McGregor
The Guardian: April 2011

Arise You Gallant Sweeneys
Looking at Irish film and the Irish in film

SPECIAL SCREENING

ARISE, You Gallant Sweeney's

(Produced by Outaside Films)

I'll be coming home shortly. I haven't been home in fifty years.

Arise, You Gallant Sweeney's is a remarkable documentary in both its stories and its storytelling. Its observational style follows a group of ageing Irish migrants from Nottingham care home, as they take a coach trip home to Ireland. A Banal enough premise for a film but when it's known that some of the men haven't been back since emigrating in the 1950s and 60s, we see in the people a mix of estrangement and familiarity. Confused by the euro currency, disoriented by their surroundings, they appear like fishes out of water. Yet their memories and insights are poignantly revealed.

SCREENING WEDNESDAY, 30 NOVEMBER - 7.30. (ADMISSION £5)
significant positive outcomes explored and recorded through personal and group reflection and lived experience narrative

retrieving control
‘ - I have worked with this man for nine years but I never knew until now that he feels exactly the same about death and dying as I do – ‘

- a dramatic change in organisational culture in their ‘wet’ hostel - from warehousing to opportunity-building

seeing other and self anew
Thank You 😊

julie@makingwaves.org
Advocacy in Action – members of the Making Waves Lived Experience Network.

A worker collective of people with very challenging behaviour who won many awards for it! We have developed service-user and carer partnerships within public services provision and education, locally and internationally for 25 years and have evaluated services all over the UK. We are gentle activists and also advocate for and with people in crisis situations. We provide safe spaces and friendly listening ears for anyone who needs us. We support one another and we are committed to supportive partnerships.

Our co-productions with two local universities Nottingham Trent / University of Nottingham.

- Local and national development of both the DipSW and the New Degree in Social Work
- New social work student recruitment and selection procedures and academic tutor training in their applications.
- New frameworks for assessment of readiness to practice skills and values
- Complete design, delivery and assessment of MA/BA module ‘Social Work With Adults’
- National conference presentations, awards, strategic policy development in social work
- Management of student placements (90’s)
- Joint publications with students and tutors & production of distance learning resources.
- Development / delivery on CPD module Risk Management in Social Work and research framework to evaluate programme
- Teaching and moderation within CPD Families and Children Modules
- Specialist pre- and post-reg teaching on values, diversity, advocacy, human rights
- Course development and GCCC validations
- New compact for collaborative partnership
- Peer-led research with 60 to 90 year old partners, including people with dementia
- Collaborative action research and capacity building with communities least well heard and least well served and promoting their role within all teaching and assessment.
- Honoured with associate lectureships, special lecturer appointments and a Doctorate in Social Sciences for our work.
Making Waves – A lived experience network of ‘well-being’ educators, researchers, advocates and activists!

We work with public agencies, authorities and educators to protect and promote the rights, well-being and opportunities of people who use services. Present teaching and development is conducted through the social, economic and political lens of neoliberal and austerity aftermaths on social work. We support collaborative partnerships between academics, agencies, practitioners and people using social, health and welfare services to build resilient communities of survival and growth. Making Waves presenters all live with the impact of past or present mental distress or difference and are affiliated with the Institute of Mental Health (IMH) through their unique peer-led research group OPEN FUTURES.

Our work with local universities, public agencies and institutes of mental health and well-being

- community based open dialogue on death and dying – new standards in palliative care
- Teaching on all pre- and post reg courses for mental health social workers and nurses
- Co-production of experiential assessment framework for mental health nurses
- validation, delivery and moderation on post-reg Best Interest Assessor programme and teaching on post-reg AMHP courses
- Representation on domestic violence, safeguarding, equality/diversity forums
- Strategic membership of School Council and Public Engagement task groups
- Collaborations in new dementia research and new law and mental disability network
- Distance learning mental health educational films, clips and podcasts – eg Talking Heads co-produced with both students and tutors
- Voices From The Crowd – taking mental health learning out of the classroom – experiential learning with communities
- Nottingham MAD studies network and Carnival MAD – cutting edge constructs in mental health research and education - led by lived experience and interdisciplinary partnerships between academics, activists, mental health survivors and their allies
- Publications and presentations at national conference and policy forums
- Volunteer advocacy and benefits activism for and with individuals in mental distress
- Peer support and community development capacity building for involvement and for survivor action-research

Keep in touch with Making Waves - julie@makingwaves.org
DEVELOPING AND USING SOFT OUTCOMES

Julie Gosling

'ARISE YOU GALLANT SWEENEYS ' - https://vimeo.com/67628782

Road trip and film to discover old and new meanings of home, made by and with older and disabled Irish migrant survivors of the construction industry who needed / chose to street drink. Three participants had early dementia.

'This one of the most haunting films I have ever seen. It is a piece of social history that should not be relegated to a dusty shelf but should be shared with anyone interested in the 'human condition'.

The film merited a five page review in Guardian Weekend in May 2011, has been shown all over the UK including 3 showings at Nottingham Broadway, was been purchased by an Irish television network for showings in 2012.

'LISTEN TO ME - I LIVE HERE!'

A peer-led evaluation of home-based support, developed and conducted by older researchers (65 - 84 yrs) from diverse ethnic communities and lived experience backgrounds. Two researchers and a number of the research participants (60 - 93 yrs of diverse ethnicities and lived experience backgrounds) had been diagnosed with early stages of dementia.

NOTTING HILL HOUSING TRUST TENANT SURVEY

A Post-Care-In The-Community-Act peer-led consultation with tenants with severe learning disabilities to establish satisfaction with community housing following discharge from long-stay residences in 'asylum' hospitals. A number of men and women interviewed by the learning-disabled researchers had dementia at various stages.
LIVED EXPERIENCE LED RESEARCH PRINCIPLES AND PROCESSES

phenomenological research
 collaborative and / or SU led
 ('involvement' will never be enough)
 mutual spaces for planning and sharing ideas
 OPEN DIALOGUE communication
 (see Mikhail Bakhtin and maybe also Carl Rogers)
 sharing of power - everyone in this space is an expert
 valuing of everyone's contribution
 process more important than task
 non-judgmental processes of individual and group reflection
 narrative and portfolio approach to reclaiming and telling the story
 observations from self and others

SOME NOTICEABLE 'SOFT' OUTCOMES

growth in mindfulness
 increased personal insight
 increased social engagement, improved relationships
 willingness to try new things and take personal risks
 (Pat's first trip on the tram / University speakers / touring the film)
 escalating self confidence, heightened self esteem
 individual and collective empowerment
 increased agency within personal and organisational settings
 better motivation, focus, alertness and concentration
 better cognition, understanding and problem solving
 more relaxed and comfortable in own skin
 physical and mental wellbeing enhanced
 reduction of alcohol consumption and other addictions
 reduction of chaotic or harmful behaviour
 acceptance and peace of mind / space for spirituality
 Consciencia - raised awareness / sense of responsibility
 validation of experience and awareness of rights
 personal and group redefinition - towards positive identities
SOME EXAMPLES OF QUANTIFIABLES FROM THE CASE STUDIES DISCUSSED

no. people communicated with
frequency + nature of communicated responses
no. frequency + nature of communications *initiated*
frequency + nature of eye contacts
frequency + nature of words, signs or sounds - existing / new
frequency + nature of body gestures - existing / new
increases in mobility
improvements in continence management
frequency + nature of falls and other accidents
frequency + nature of physical symptoms - existing / new
frequency + nature of mental/emotional symptoms - existing / new
changes in level of manual dexterity
frequency + nature of activities participated in - existing / new
improved sleep patterns
changes in appetite

EXAMPLES OF POSITIVE IMPACTS ON ORGANISATIONS AND WORKERS FROM THE CASE STUDIES DISCUSSED

change in culture
change in policy
innovation
more and better co-productions
more and better communications
willingness to take risks
improved work motivation
improved work satisfaction
reduced sickness rates
Researchers’ ‘non-functional requirements’ in healthcare design

Michael Craven
NIHR MindTech Healthcare Technology Co-operative
Research App case studies

1. **Asthma** Self-Reported Wellness (with PEF meter & Bluetooth pulse oximeter)

2. **In-Vitro Fertilisation** Self-reporting of Stress

3. **Sickle Cell Disease** Pain Monitoring

4. **ADHD** Continuous Performance Test – Snappy App
Multiple stakeholders in research projects – requirements flow

- **Research institution/Provider organisation**
  - Research governance
  - Ethics
  - Informatics

- **Researchers**
  - Clinical/Scientist
  - Engineering/Analyst
  - Involvement

- **Application Developers**

- **Users**
  - Clinical user
  - End-user

Supply and/or Produce (may also Implement)
Sickle Cell Disease self-monitoring

- **Home monitoring device**
  - Improved communication between clinician and user
  - Research on causes of sickle cell ‘crises’
  - Improve self-management and control

- **Balance needs of users and clinicians**
  - What do clinicians want to know?
  - What do users want to say?

- **Researcher/Ethics requirements**
  - Short development time
  - Use standard scales
  - Capture physiological data
  - No clinical decisions to be made by App

- **User requirements**
  - Personalisation of record of pain and breathlessness
  - Affordability - most cannot afford own phone

- **Solutions**
  - Implement on single platform and lend phones for the study
  - Implement standard questionnaire but with additional questions specified by users
Mobile psychometric assessment of Attention Deficit Hyperactivity Disorder (ADHD)

**QbTest**
- Computerised assessment of attention and activity
- Supports clinical decision making
- Provides patients with objective reports on their condition

**SnappyApp**
- Continuous ‘AX’ performance test delivered by mobile phone App
  - Measure of (in)attention & impulsivity
- In-built accelerometer and gyroscope
  - Assess levels of (hyper) activity during test

**Requirements**
- **Researcher/Ethics demands**
  - Short development time
  - Convenience sample
  - Two times a week data collection – limited burden
- **End-user demands**
  - Works on own phone
  - Aesthetics
  - Motivational aspects

**Solutions**
- Cross-platform implementation - web-app
- Send email prompts
- Gamification potential identified
Case study lessons

• Non-functional requirements influence (dominate?) platform choice
• Development time pressures
• Ethical demands – must address early on
• Researcher and user demands may be different, or have different reasons for these
• Small teams – can give fast results but good communication of requirements is vital
A general model for user requirements

Sharples, et. al


Soft assessment in dementia
Université du Luxembourg

Isabelle Tournier

Contact:
isabelle.tournier@uni.lu

http://wwwfr.uni.lu/recherche/flshase/inside/people/isabelle_tournier
• **Founded in 2003**: the only public university of the Grand Duchy of Luxembourg.

• **INSIDE → Integrative Research Unit on Social and Individual Development.**

• **4 Institutes:**
  - Generations and Family

  *Lifespan changes (psychological, cognitive, social, etc.)*
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<th>Year</th>
<th>Project</th>
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<tbody>
<tr>
<td>2017-2020</td>
<td><strong>ARPA</strong> – How to improve European mental health networks for older adults? (UE, Erasmus + strategic partnerships)</td>
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<td>2016-2020</td>
<td><strong>ROSEnet</strong> - Reducing Old-Age Social Exclusion: Collaborations in Research and Policy (UE, COST action)</td>
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<td>2016-2019</td>
<td><strong>MinD</strong> – Designing for people with dementia: Mindful self-empowerment and social engagement (UE, H2020)</td>
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<td>2016-2018</td>
<td><strong>FEELSAFE</strong> – At home safety and feeling of safety of older adults: which impact of assistive technologies? (Lux, University of Luxembourg)</td>
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<td>2015-2017</td>
<td><strong>CONNECT</strong> - Creation of a dementia-related Internet forum in Luxembourg (Lux, Fondation du Grand-Duc et de la Grande-Duchesse)</td>
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CONNECT

- An Internet platform (questionnaires and a forum) about dementia
- Users: people with MCI, mild dementia or worries about it; caregivers, relatives, all citizens
- Luxembourgish dementia healthcarers will answer to question on the forum

How make it user friendly for people with cognitive changes? How assess this user friendliness? How assess psychological benefits linked to the forum (i.e., social support, less isolation and dementia-related stigma)?
- Socially assistive robots: how are they perceived by older adults?
- Usefulness, attractiveness, etc.
- Older adults living at home or in nursing home (with or without dementia), professional caregivers

How measure assistive robots attractiveness? Existing scales are quite complex even for older adults without cognitive problems. Which behaviours will be interesting to observe with people with dementia and interactions with professional caregivers?
MinD
‘Soft evaluations’ Workshop

Dr. Jennifer N W Lim
University of Wolverhampton
19th October 2017
Comparison of data in qualitative multi-centre study:

- **Methodological design**: recruitment (sample characteristics, sampling technique, sample size), data collection (field tool - questions, data saturation), data analysis and interpretation

- What are the *standardisation mechanisms* in place to ensure validity and reliability of study?

- *Steps to achieve validity and reliability* i.e. attempts made to meet methodological design
A2. Publication and funder’s scientific expectations/requirements

*Conceptual/theoretical framework/models applied:*

- MinD’s over-arching conceptual framework
- Qualitative study s theoretical framework
B. Design for intervention

Considerations:

- Needs assessment vs. determinants of dementia
- Theoretical model driving designs and interventions
Evaluating QoL Technology Effectiveness

Dr. Marta Díaz Boladeras

Research Center for Dependency Care and Autonomous Living
Technical University of Catalonia

www.designingfordementia.eu

This project has received funding from the European Union’s Horizon 2020 research and innovation programme under the Marie Skłodowska-Curie grant agreement No 691001. This document reflects only the author’s view and the Research Executive Agency is not responsible for any use that may be made of the information it contains.
Empowerment
Self-esteem
Mood
Autonomy
Social engagement
Optimism
Confidence
Perception of health
Attitude and judgements
Likeness
Perception of usefulness/cost
Desirability
Performance
Accuracy, Ease of use / learn/ remembering
Subjective Experience
Engagement, amusement, enjoyment, satisfaction
Social involvement

Product/Device
Robust and easy to maintain
Effective and efficient
Accessible and usable
Non stigmatizing
Scalable and customizable

Quality in (of) use
Technical and usability Validation
Attitude and judgements
Effect on user/ user’s environment

Impact
Qualiy of life / (Clinical) Assessment
MinD ‘Soft Evaluations’ Workshop
19th October, 2017

Teresa Atkinson &
Faith Wray

University of Worcester
Association for Dementia Studies
The Association for Dementia Studies
Changing Hearts and Minds in Dementia Care

An innovative, active research centre
We have an outstanding track record over a wide portfolio of dementia related research. From small scale literature reviews and evaluations to large scale international research programmes, we provide a professional and person-centred approach to all our work.

Practice Development
We draw on the international evidence base to deliver education programmes, online resources and publications that empower staff to provide skilled, competent and compassionate care.

PhD study
We support and active PhD and doctoral studies programme including TAnDem, one of eight national doctoral training centres supported by the Alzheimer’s Society.

Partnership working
We work in partnership with care providers, NHS trusts, local authorities and third sector organisations who are committed to person centred care. People living with dementia inform our work at all stages.

The LINK Group: Experts by experience.

Can we help you?
Based on our research we can offer a range of consultancy, bespoke support packages and service development activities.

Led by Professor Dawn Brooker, the Association for Dementia Studies is a multi-professional university research centre. We make a cutting edge contribution to developing evidence-based practical ways of working with people living with dementia, their families, friends and carers that enable them to live well.

University of Worcester
Association for Dementia Studies
DAA Dementia Action Alliance
Care Fit for VIPS
Achieving excellence in dementia care – the tools for change

Stand By Me
We offer a range of education and development opportunities for organisations, teams and individuals.

The Association for Dementia Studies provides a broad spectrum of development and education opportunities, ranging from short continuing professional development (CPD) sessions, one day Masterclasses and workshops to 6-day courses, as well as providing academic modules held within the University of Worcester.

We work from a position of evidence-based practice. We bring to all our workshops and courses the latest and most up-to-date evidence from research and best practice.

**Bespoke courses at a venue of your choice**

- Person-centred and personal leadership focussed
- Delivered using Action Learning Set approach
- Tailored to your needs
- Delivered at a location convenient to your staff

“Absolutely amazing course, very interesting”

“One of the most worthwhile courses I have been on”

**University-based courses**

**Level 6 degree modules** aimed at staff working in a hospital setting and a community setting.

**Level 7 master’s modules**

- Advanced Practice in Delivering Person-Centred Care
- Admiral Nurse specific module

Modules are taught in two blocks in Worcester and involve a written assignment. You can attend these courses without completing the assignment and receive a certificate of attendance.

**Masterclasses, Seminars and conferences**

We offer a wide variety of 1 day Masterclasses, workshops, seminars and events.

**Get in touch/Join our mailing list**

To find out more please email dementia@worc.ac.uk or join our mailing list http://www.worcester.ac.uk/discover/dementia-get-in-touch.html

For further information please contact us: dementia@worc.ac.uk or 01905 542531

www.worcester.ac.uk/dementia

Sept 2017 Quote code ADS1115
Research

ECO – The Provision of Social Care in Extra Care Housing

Green Dementia Care Project - Green dementia care in Extra Care and Residential Care settings – opportunities, barriers and good practice.

Namaste Care Intervention UK – delivering excellent care every day for people living with advanced dementia

Find out more about our research: https://www.worcester.ac.uk/discover/dementia-recent-current-research.html
Our Research Challenges

Involving people living with dementia in qualitative interviews:

• Longitudinal research
• Ethics, consent
• Reliability of information

• Is there a better way?
Thank you

Contact us:

t.atkinson@worc.ac.uk
f.wray@worc.ac.uk
Arts and dementia: Methodological challenges

Karen Gray
Association for Dementia Studies, University of Worcester
TAnDem Doctoral Training Centre

‘Soft Evaluations’ Workshop
19th October 2017
My research

What is it about arts-based activities for dementia that might cause us problems when we try to describe, explain and justify the methods we use to evaluate them?

A navigational aid for evaluators – showing relationships and connections between challenges, local contexts and wider structures
“When people ask me what work I do, I end up talking in stories [...] For instance, this woman Ruth, she’s screaming and shouting, trying to scratch me, calling me Hitler [...]. Everybody was upset with her and, you know, shouting at her, telling her to shut up. And so I pulled out of my bag a great big bouquet of red roses, plastic red roses, and I said to the group, ‘Shall we give Ruth these roses because I think she’s probably very upset about something?’ And they all said ‘yes’, and I gave her the roses. A big smile came over her face and she held on to the roses and she was quiet. That act of yielding to somebody’s anger, not taking it personally, giving her a bit of love through the exchange of some plastic red roses, changed the atmosphere....”

[From interview with artist practitioner. Participant pseudonym]
What does this story tell us about the challenges of evaluating arts practice?

<table>
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<tr>
<th>The arts activity</th>
<th>Evaluation challenge</th>
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<tbody>
<tr>
<td>Is adaptive, flexible, intuitive by nature</td>
<td>Replicability? Generalisability or contextual knowledge?</td>
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<td>Invites participants to make choices</td>
<td>Ethics and recruitment</td>
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<td>May have effects at unexpected times and places</td>
<td>Getting a study design that can capture this</td>
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<td>Sometimes ‘atmosphere’ is the thing that changes</td>
<td>Finding a suitable measure</td>
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<td>Every individual taking part has a story, personal and clinical</td>
<td>Finding out about, controlling for, and reflecting these stories</td>
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<tr>
<td>Involves range of different individuals, groups and organisations</td>
<td>Establishing aims for evaluation</td>
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Every individual taking part has a story, personal and clinical
Questions about value

Differing views about…

Quality of evidence or research rigour

The role of the arts and culture within society as a whole and for individuals within it

The role the arts should play within health and social care and dementia care practice

raise the questions

What is the evidence for?

What impact? What outcome? Instrumental? Economic? What if access to the arts is simply a ‘moral good’?

What’s valuable for a person with dementia? For a healthcare professional? For an artist?
Thank you for listening

Karen Gray

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LAUGH: designing playful objects for people living with advanced dementia

Prof Cathy Treadaway
Dr Gail Kenning
Dr David Prytherch
Dr Jac Fennel
Prof Andy Walters
Dr Amie Prior
Aidan Taylor
CARIAD
Cardiff Metropolitan University
Evaluation Perspective

- Qualitative
- Advanced dementia
- Subjective wellbeing
Sensory

Connecting

Personalised

Love

Compassionate Design
Issues we are dealing with:

- Small numbers
- Participants are mainly non-verbal
- Family and care staff are essential
Difficulties:

- End of life
- Emotionally distressing
- Attrition
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www.laughproject.info
www.compassionatedesign.org
@LAUGHCardiffmet
‘Soft’ Developmental evaluation
Dr Gail Kenning,
Faculty of Arts and Social Sciences, University of Technology Sydney
Design Architecture and Building, University of Technology Sydney
Honorary Reader in Ageing and Dementia, Cardiff Metropolitan University Technology Sydney
Design United Fellow, Technology University, Eindhoven
Embracing evaluation and analysis: Scaling the bespoke and other complexities:

- Preserved in perpetuity
- Evaluation as creation not reporting
- Evaluation as ‘In’ formative rather than summative
- ‘Borrowing’ and ‘stealing’ from other fields and disciplines
- Research and evaluation methodologies as process
Projects that inform the development of this framework and approach include
The LAUGH Project: Ludic Artefacts Using Gesture and Haptics

(see [https://www.laughproject.info](https://www.laughproject.info)) Playful sensory objects with people with advanced dementia

Image: ‘Hug’ a sensory textile with embedded electronics to simulate a beating heart)
Arts engagement for Liveable Communities

(findings will be published in April)

A project that takes arts engagement (viewing and the creation of arts practices) beyond the gallery and into regional, rural and remote places in Australia to spread creativity and creative thinking.
Image: Tools designed with Art Gallery New South Wales to encourage arts engagement
Evaluation of the arts access program of Art Gallery of New South Wales

Reciprocal design to promote positive wellbeing for people living with dementia
Mixed methodology approach as the ‘gold’ standard

- Logic models
- Participatory action research
- Grounded practical theory
- Ethnographic Quantitative
The approach taken here recognizes the philosophical approaches in the Developmental Evaluation (DE) field (Quinn Patton, 2010) of exploring possibilities and innovation, but does not adhere to the methodologies and approaches that focus on systems thinking and complexity science etc. Our methodology is currently being written up and will likely be published under a different nomenclature.
‘Soft Evaluations’ Workshop

What is it, why do we need it and how can we convince others that it is valuable?

Thursday 19 October 2017, 10.00 -16.30 h
University of Wolverhampton, UK

Afternoon Workshops in three groups:

Group 1: Themes 1 & 2

1) Layers of evidence-based evaluation
2) Quantitative assessments and scales: how should we maximise the validity of evaluation?

Group 2: Theme 4

4) Culture and Context: Put It In Place

Group 3: Theme 5 (new – developed from the plenary discussion in the morning)

5) Design evaluation and impact

Theme 3 “KIS (Keep it simple): evaluation appropriate for people with dementia” was felt at this point not to be a priority and was not discussed.
Discussion points from the plenary discussion in the morning for deliberation for the group discussions in the afternoon.
MinD ‘Soft Evaluations’ Workshop Theme 1

Layers of evidence-based evaluation

Evaluation is a complex process and an elusive concept, but in general can be defined as the measurement of success (or the lack of it) by a thorough process that produces a well-founded assessment on whether and to which extend predetermined goals have been achieved.

The evaluation plan should address unavoidably the following questions: What is to evaluate? (Process / outcomes; personal / social outcomes); What for? (Inform / Monitor / Motivate/ Validate / Demonstrate); When? (During the Design cycle / at the end); Who is involved? (Expert based / End user based / Other stakeholders); How? (Qualitative / Quantitative forms of evidence; Observational / Self-report; Standardised instruments / Ad-hoc instruments).

Questions

Provided the proposed design solutions focus mainly on influencing (improving) end-users’ affective states (e.g. feelings of empowerment and competence, social engagement) rather than in capabilities or performance, how can we grasp the impact of the solutions on the end-users?

Which dimensions, indicators and techniques would be privileged to be consistent with the experience-based methodology? Are they feasible? Do they bring enough evidence to demonstrate the value of the project?
Quantitative assessments and scales: how should we maximise the validity of evaluation?

Quantitative validated tools such as scales and associated research methods are often used to attest the efficiency or usefulness of assistive tools or interventions. The use of these is often necessary to support publications in peer-reviewed journals.

Validation of tools (e.g., scales) includes testing the internal validity of the measure, that is, does it measure what is intended, consistently and minimising potential experimenter bias?

Currently, validated tools dedicated to people with dementia and their difficulties (e.g., reduced attention and working memory) are not in common usage although a good number are proposed for Quality of Life and newer ones for Sense of Coherence and Positive Psychology. Scales for dementia, especially traditional Likert scales, can be quite challenging to complete as disease progresses, and may lead experimenters to reformulate questions, even at the level of the individual participant, to the detriment of a tool’s internal validity. Nevertheless, we can argue that it is “better than nothing” and may increase the external validity of the results (i.e., the extent in which results can be generalized to other people and settings) by accessing people who are not able to deal with more standardised tools.

Questions

Have you previously tried to manage the kind of situations described above?

Are you using any validated tools?

Which do you find attractive for assessment of people with dementia?

How do you deal with potential difficulties of participants to answer or fit with standardised tools?

How do you justify, in peer-reviewed publications, your choices regarding such tools?
DATA SATURATION

Design topics to address
OBJECTIVE CRITERIA

Transitions
Bradshaw taxonomy?
Prioritisation
Design files or not?

* OTHER STAKEHOLDERS/CONTEXTS
- Social
- Political
- Legal
- Economics

* EXPLORATORY VS. CONVERGENT
MinD ‘Soft Evaluations’ Workshop Theme 3

KIS (Keep it simple):

evaluation appropriate for people with dementia

People with dementia may have some difficulties when asked to evaluate products or new designs. For example, if there are several to compare, it may be difficult to keep them all in mind at once. You may require longer to process the information or to grasp what the product is intended to do. If there are complicated instructions to read or long rating scales to complete, these may be hard to deal with. Such issues need to be borne in mind when asking people with dementia to evaluate products or designs. Therefore, keep it simple – though bear in mind that ‘simple’ is not patronising, it is about giving the important information so that the user can give a proper response.

Questions to discuss

How do you understand ‘evaluation’? Should we use another form of words?

It seems to me that we want to ask certain questions about products. Such as: Do you like this? What do you think of it? Does it make sense? Would it help you? Would you use it? Would you pay money for it? Is this the right sort of language to use? What’s the best way of asking you?

What’s the best way of explaining what something is meant to do?

For example, handling it, verbal explanation, written instructions, pictures, videos?

Are there any other questions that you think are important that we should ask about the products?
MinD ‘Soft Evaluations’ Workshop Theme 4

**Culture and Context: Put It In Place**

In isolating the individual from their lived world context, research tools sometimes neglect important considerations of cultural values, customs and practice and/or the circumstances impacting upon human thoughts, feelings and actions.

Researchers should reflect upon their engagements with research subjects and what it is about or within the researcher that may impact on these interfaces.

**Questions**

Think of interview experiences that felt particularly comfortable or uncomfortable. What factors might have been at work (personal and/or contextual)?

How can race, age, gender, culture class, advantage, or life experience (etc) affect the research interface?

Why do people's circumstances and environments sometimes give a misimpression?
Putting It In Place – Workshop notes

In isolating the individual from their lived world context, research tools may sometimes neglect important considerations of cultural values customs and practice and or the circumstances impacting upon human thoughts, feelings and actions.

Researchers should also reflect upon their engagements with research subjects and what it is about or within the researcher that may impact on these interfaces.

QUESTIONS

Think of interview experiences that felt comfortable or uncomfortable. What factors might have been at work - (personal and / or contextual)?

How can race, age, gender, culture class, advantage, or life experience (etc) affect the research interface?

Why do people's circumstances sometimes give a misimpression?

GROUP WORK

facilitation - issues regarding: culture / context / communication / female interviewer / flash cards / eye contact / other life events / how we address someone /
The group discussed issues of design in supporting people with dementia: the role of design as a process of co-production, which is linked to the designer (or artist, etc) as facilitator. It can therefore be personalised to the individual, but is difficult to scale up. While design as an outcome, whether as object, service or environment becomes detached from the person and can be produced on a large scale and therefore reach many more people, it cannot therefore be fully personalised. Agency of design was discussed in this context as well as the need for design to be personalisable.

Also, the value that we attribute to an individual person’s life was discussed in relation to how much care a person receives as opposed to what the contribute or what they can afford.