

## ‘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

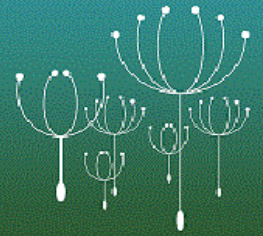
### Programme

Time	Description
10.00	Arrival and coffee
10.20	Welcome – Prof Kristina Niedderer, Prof Tom Dening
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



MinD

designing for people with dementia  
mindful self-empowerment and social engagement



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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

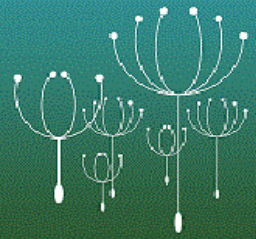
Michael Craven, Nottinghamshire Healthcare NHS Foundation Trust, UK

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.

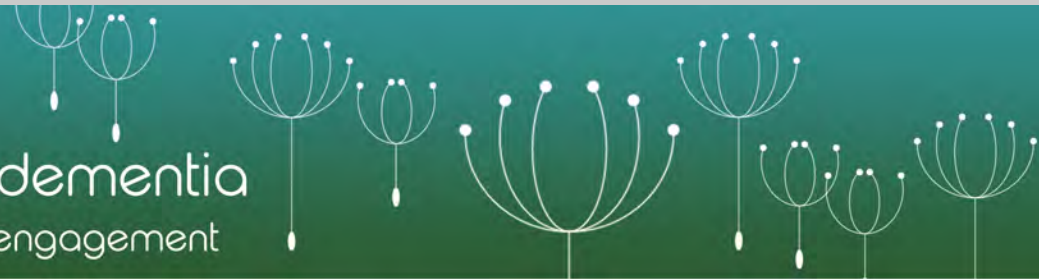
The following topics were discussed during the day:

- 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.

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[www.designingfordementia.eu](http://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.



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## The project aims

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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



## Universities



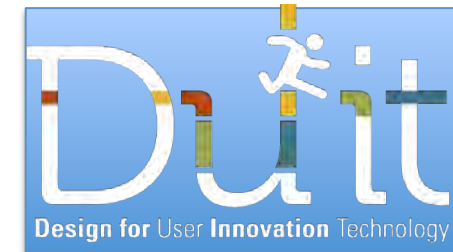
UNIVERSITY OF TWENTE.



## Dementia care & policy



## Design



# Project shape

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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

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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

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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

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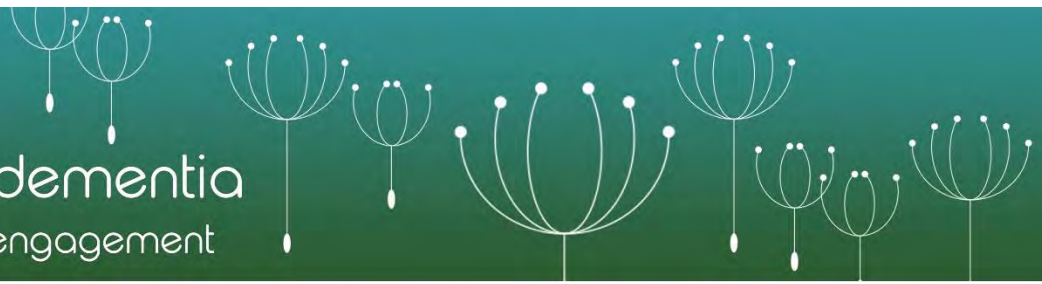
Collectively address the issue of how to evaluate designs when working with people with dementia

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

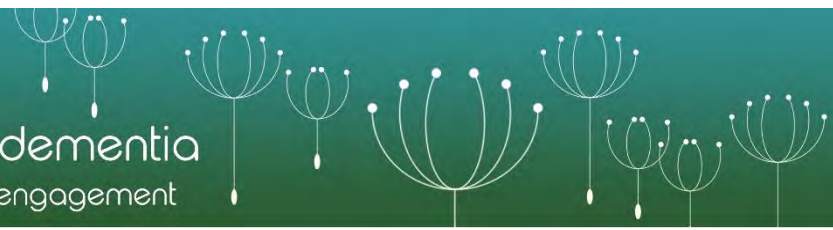
Department of Psychiatry, Psychotherapy and Psychosomatics

Alexianer Krankenhaus Hedwigshöhe, Berlin

\*Technische Universität Dresden, Medical Faculty



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- **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)

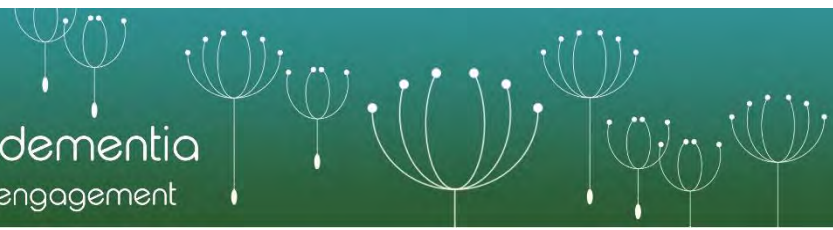
### – Caregivers

- 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)

	Germany
Focus Group <u>Caregiver</u>	2
Focus Group <u>PwD</u>	0
Interview <u>Caregiver</u>	10
Interview <u>PwD</u>	6



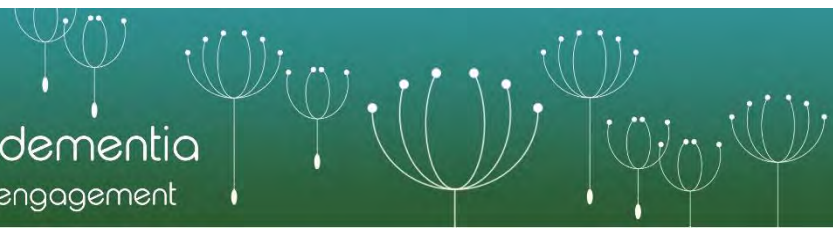
## Qualitative interviews: Categories and subcategories

### 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

The logo for MinD is displayed in a white, lowercase, sans-serif font. To the right of the text, there are several stylized, white line-art plants that resemble dandelions or similar seed-bearing plants, with multiple thin stems and small circular heads. The background of the header is a dark teal color with a subtle gradient.

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mindful self-empowerment and social engagement

## **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**



The logo for MinD is set against a teal-to-green gradient background. It features the word "MinD" in a white, lowercase, sans-serif font. To the right of the text are several stylized white line drawings of plants with multiple stems and small circular buds at the tips. Below the main text, the words "designing for people with dementia" and "mindful self-empowerment and social engagement" are written in a smaller, white, lowercase, sans-serif font.

MinD

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## **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'*

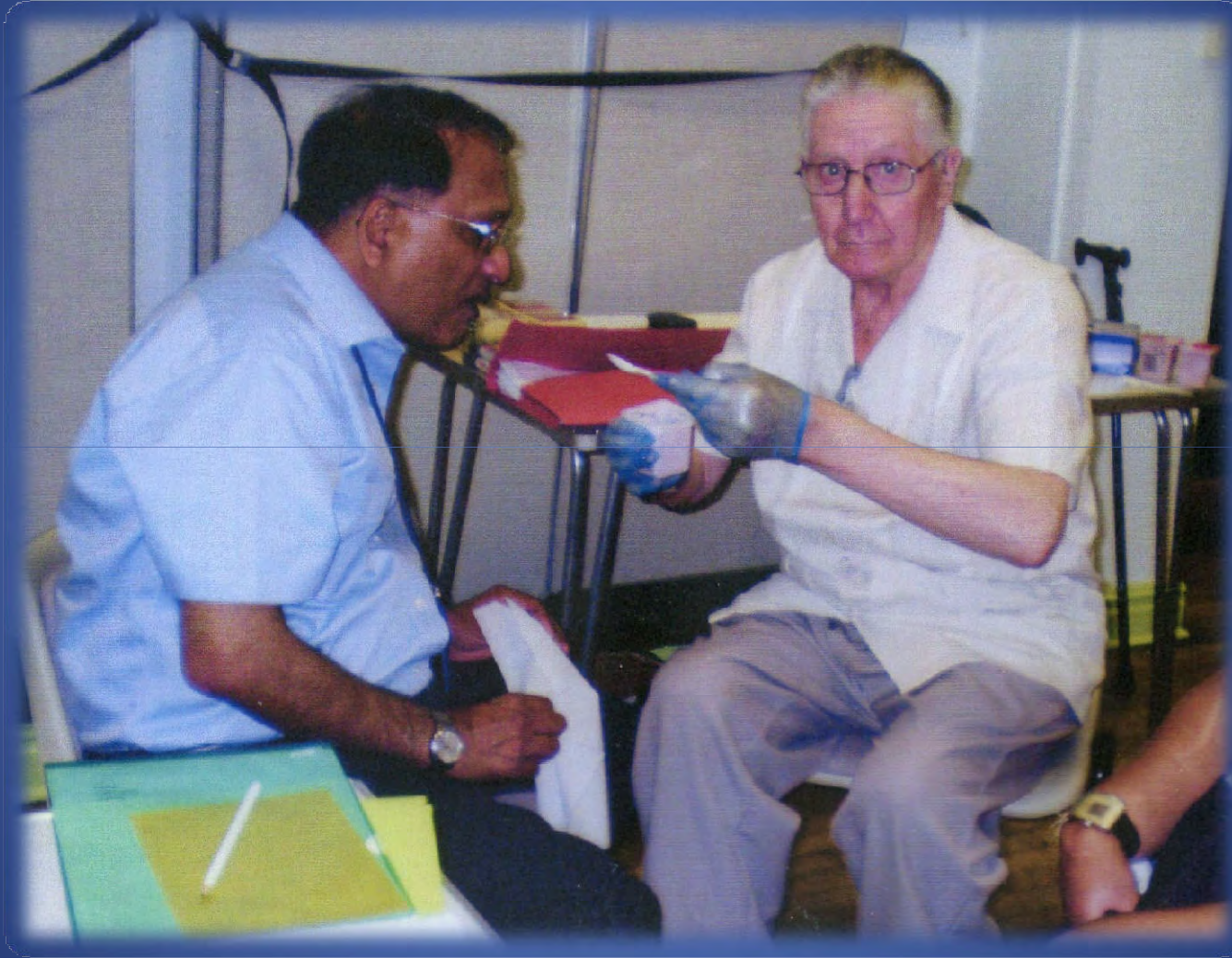


Kevin Chettle; Inmate Balderton Hospital 1960 - 1980  
Special Lecturer; University of Nottingham 1998 -2013





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**





# IRISH FILM GROUP

Looking at Irish film and the Irish in film

SPECIAL SCREENING

## ARISE, You Gallant Sweeneys

(Produced by Outside Films)

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



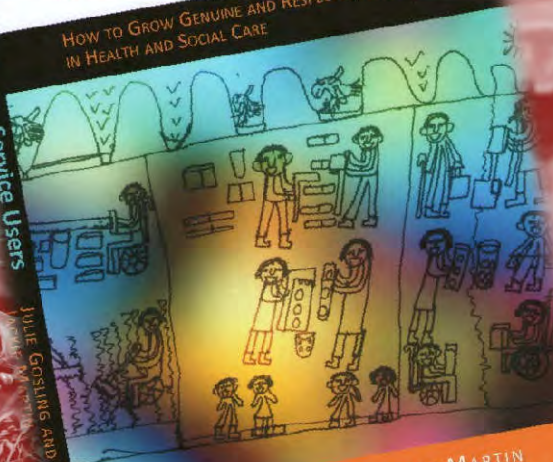
*Arise, You Gallant Sweeneys* is a remarkable documentary in both its stories and its storytelling. Its observational style follows a group of ageing Irish emigrants from a Nottingham care home, as they take a coach trip home to Ireland. A banal enough premise for a film but when it's known that some 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, disorientated 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)**

Making Partnerships with Service Users

## Making Partnerships with Service Users and Advocacy Groups Work

HOW TO GROW GENUINE AND RESPECTFUL RELATIONSHIPS  
IN HEALTH AND SOCIAL CARE



JULIE GOSLING AND JACKIE MARTIN

Services meeting  
out / slide / film

## Arise, You Gallant Sweeneys!

A Long Distance Gang and OutsideFilm production

The story of a long road home to Ireland.  
A film made by the men who built the motorways  
of post-war Britain.

"A moving, engaging and often deeply funny  
exploration of exile, memory and loss"  
- Jon MacGregor, The Guardian

**SHOWING AT:**  
Irish Heritage Birmingham Area  
Museum Room at The Irish Centre, Digbeth  
Wednesday 6th July 2011 at 7.00pm  
All welcome - no charge


Film Night at The Spotted Dog, Digbeth  
Monday 11th July 2011 at 8.00pm  
All welcome - no charge  
Free tea and buns!

Screened at The Long Distance Gang - Richard Bodwin, Kathy Butler, Chris Cassidy, Julie Cassidy, Tony Colley, Pat Kelly, Sean Lynch-Jones, Joe McElroy, Ian McLean  
Screened at The Long Distance Gang - Richard Bodwin, Kathy Butler, Chris Cassidy, Julie Cassidy, Tony Colley, Pat Kelly, Sean Lynch-Jones, Joe McElroy, Ian McLean



Arise, You Gallant Sweeneys!




The image is a collage. In the center is a photograph of a white, scruffy-haired dog wrapped in a crinkled red plastic bag. Surrounding this central image are four photographs of older men. Top-left: A man with grey hair and blue eyes, looking slightly to the right. Top-right: A man with grey hair, looking down. Bottom-left: A man with grey hair and blue eyes, looking forward. Bottom-right: A man with grey hair, looking forward. The text is overlaid on the collage.

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](mailto:julie@makingwaves.org)



## Advocacy in Action – members of the Making Waves Lived Experience Network.

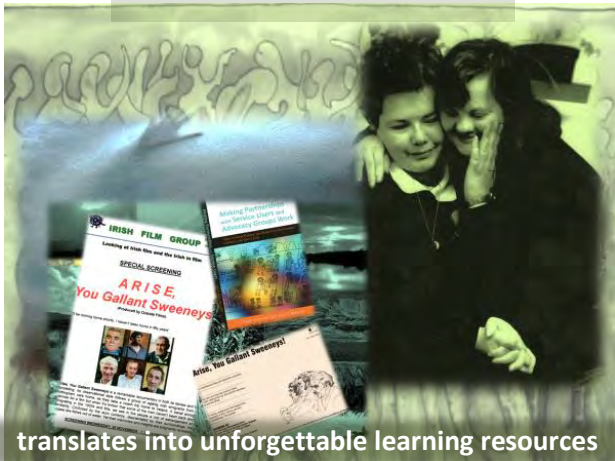
A worker collective of people with very challenging behaviour who won many awards for it! We have developed service-user and carer partnerships within public services provision and education, locally and internationally for 25 years and have evaluated services all over the UK. We are gentle activists 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.

### Supporting You to Support Us!



growing confidence as teachers and assessors

### The Power of Personal Stories



translates into unforgettable learning resources

### The Long Distance Gang



build the foundations for palliative care research

### 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 GSCC 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.

### Experts By Experience



### Voices From The Crowd



### Carnival MAD 16



### 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



## 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

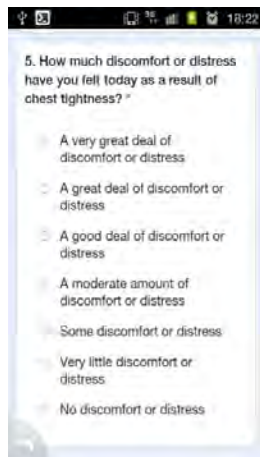
change in culture  
change in policy  
innovation  
more and better co-productions  
more and better communications  
willingness to take risks  
improved work motivation  
improved work satisfaction  
reduced sickness rates

# Researchers' 'non-functional requirements' in healthcare design

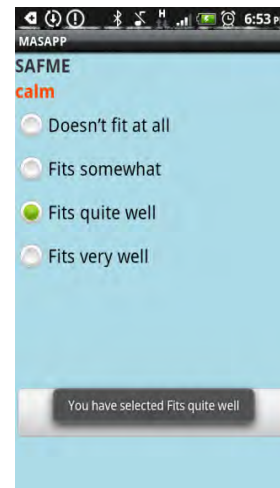
Michael Craven

NIHR MindTech Healthcare Technology Co-operative

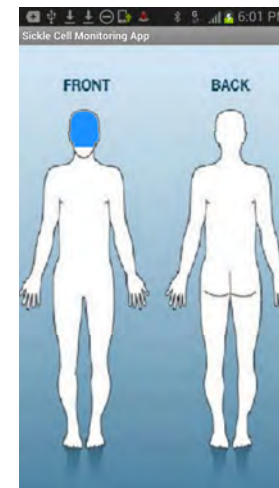
# Research App case studies



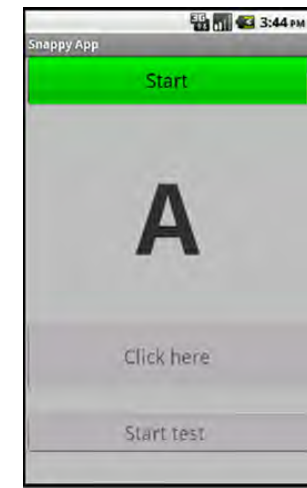
**1. Asthma** Self-Reported Wellness (with PEF meter & Bluetooth pulse oximeter)



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

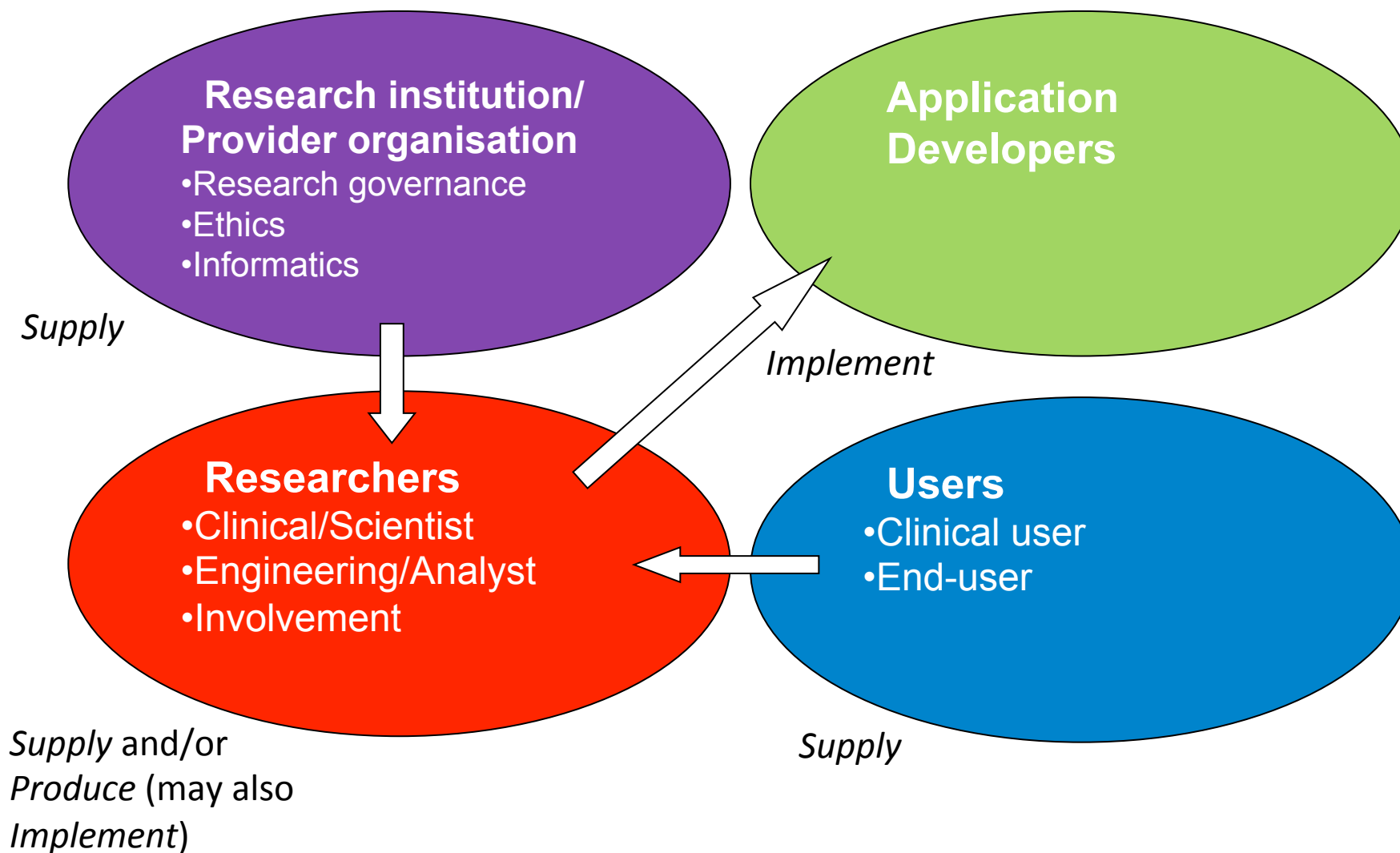


**3. Sickle Cell Disease** Pain Monitoring



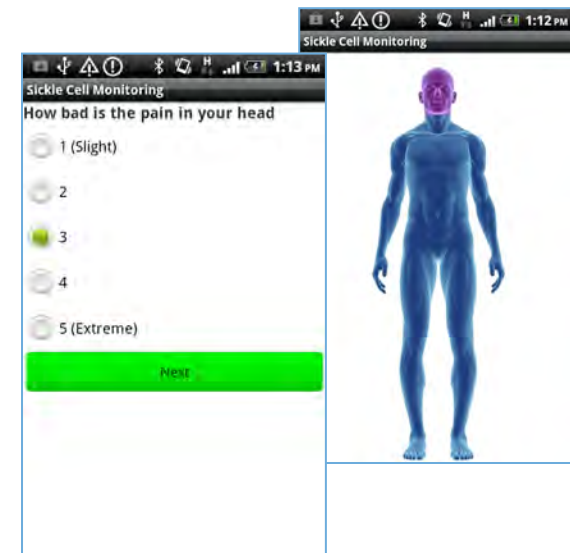
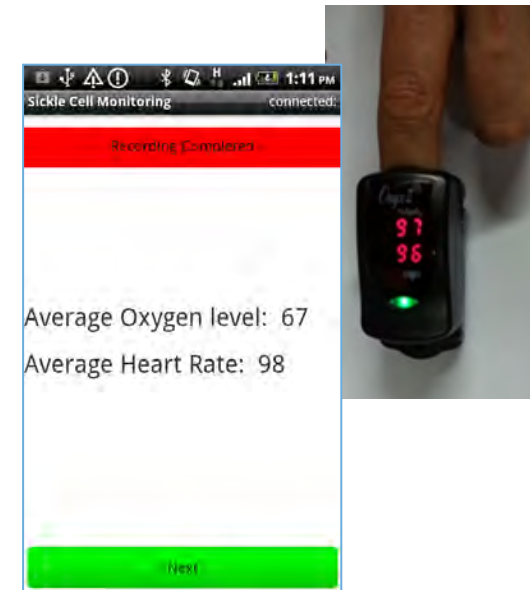
**4. ADHD** Continuous Performance Test – Snappy App

# Multiple stakeholders in research projects – requirements flow



# 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)

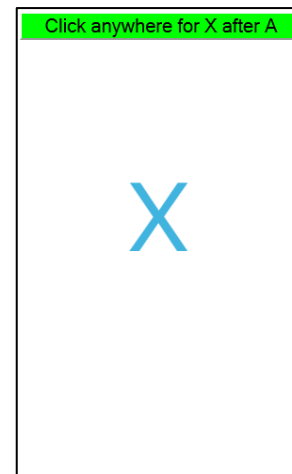
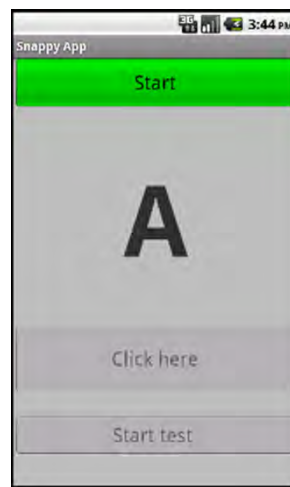
## QbTest

- 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

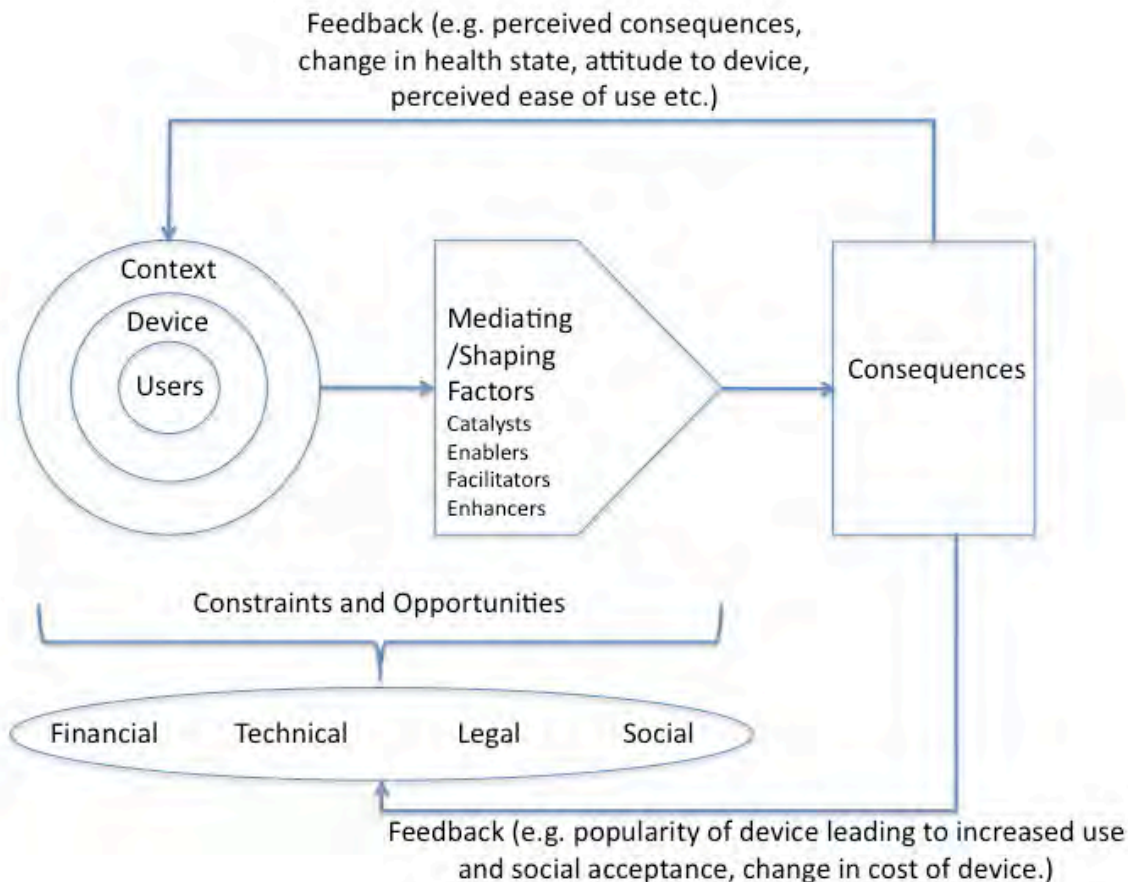
# Case study lessons

- 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

[Medical Device Design in Context: A Model of User-Device Interaction and Consequences](#), Displays, Vol. 33, Issue 4-5, October 2012, 221-232.



**Related references:** Craven, M. P., Selvarajah, K., Miles, R., Schnädelbach, H., Massey, A., Vedhara, K., Raine-Fenning, N., Crowe, J. [User requirements for the development of Smartphone self-reporting applications in healthcare](#), in Kurosu, M (Ed.): Human-Computer Interaction, Part II, HCII 2013, LNCS 8005, 36-45, 2013.

Craven, M. P., Lang, A. R., Martin, J. L. (2014) [Developing mHealth Apps with researchers: multi-stakeholder design considerations](#). In Marcus, A. (ed.) Design, User Experience, and Usability: User Experience Design for Everyday Life Applications and Services, Lecture Notes in Computer Science, Vol. 8519, DUXU 2014 / HCII 2014, Part III, Springer, pp. 15-24. Doi: 10.1007/978-3-319-07635-5\_2

# Soft assessment in dementia

## Université du Luxembourg

**Isabelle Tournier**

**Contact:**

[isabelle.tournier@uni.lu](mailto:isabelle.tournier@uni.lu)

[http://wwwfr.uni.lu/recherche/flshase/inside/people/isabelle\\_tournier](http://wwwfr.uni.lu/recherche/flshase/inside/people/isabelle_tournier)

INSIDE

INTEGRATIVE RESEARCH UNIT  
ON SOCIAL AND INDIVIDUAL  
DEVELOPMENT



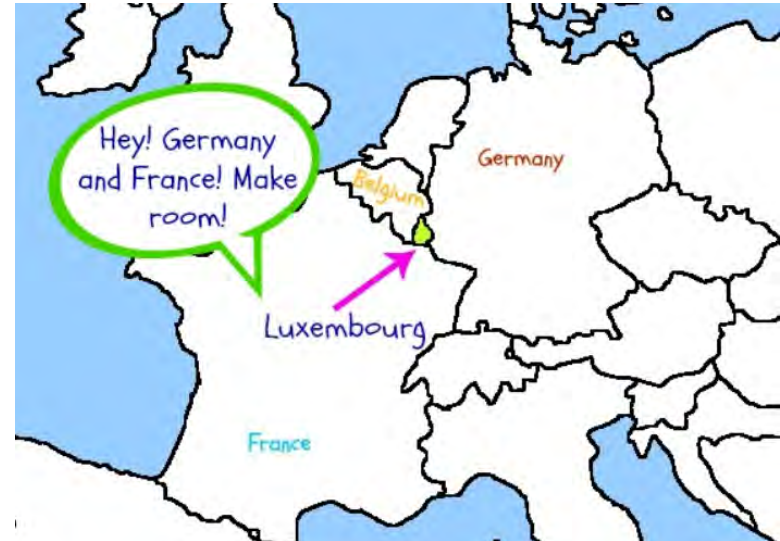
# University of Luxembourg

- **Founded in 2003:** the only public university of the Grand Duchy of Luxembourg.
- **INSIDE** → Integrative Research Unit on Social and Individual Development.
- **4 Instituts:**

Generations and Family



*Lifespan changes (psychological, cognitive, social, etc.)*



INSIDE

INTEGRATIVE RESEARCH UNIT  
ON SOCIAL AND INDIVIDUAL  
DEVELOPMENT

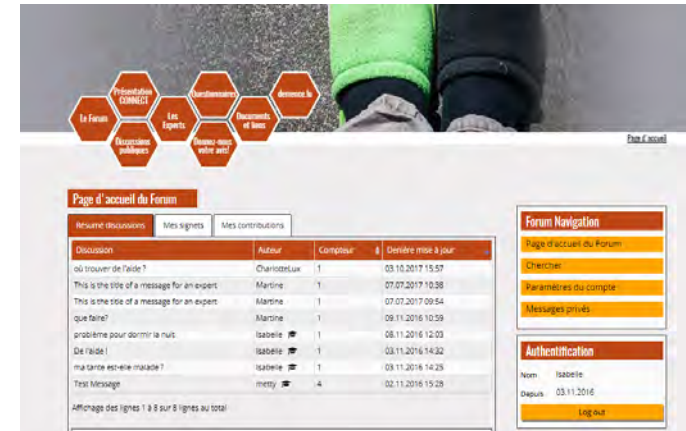
  
UNIVERSITÉ DU  
LUXEMBOURG

# Aging-related projects

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

# 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) ?*



# FEELSAFE

- 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 Wolverhampton1**  
**19<sup>th</sup> October 2017**

## ***A1. Publication and funder's scientific expectations/requirements***

### ***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

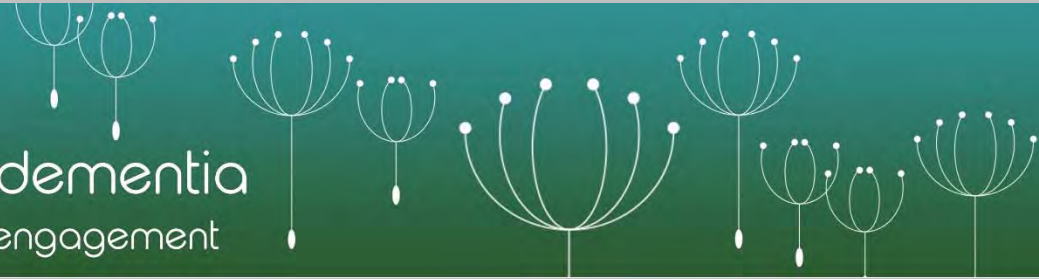
## ***B. Design for intervention***

### ***Considerations:***

-  Needs assessment vs. determinants of dementia
-  Theoretical model driving designs and interventions

minD

designing for people with dementia  
mindful self-empowerment and social engagement



# Evaluating QoL Technology Effectiveness

Dr. Marta Díaz Boladeras

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

[www.designingfordementia.eu](http://www.designingfordementia.eu)

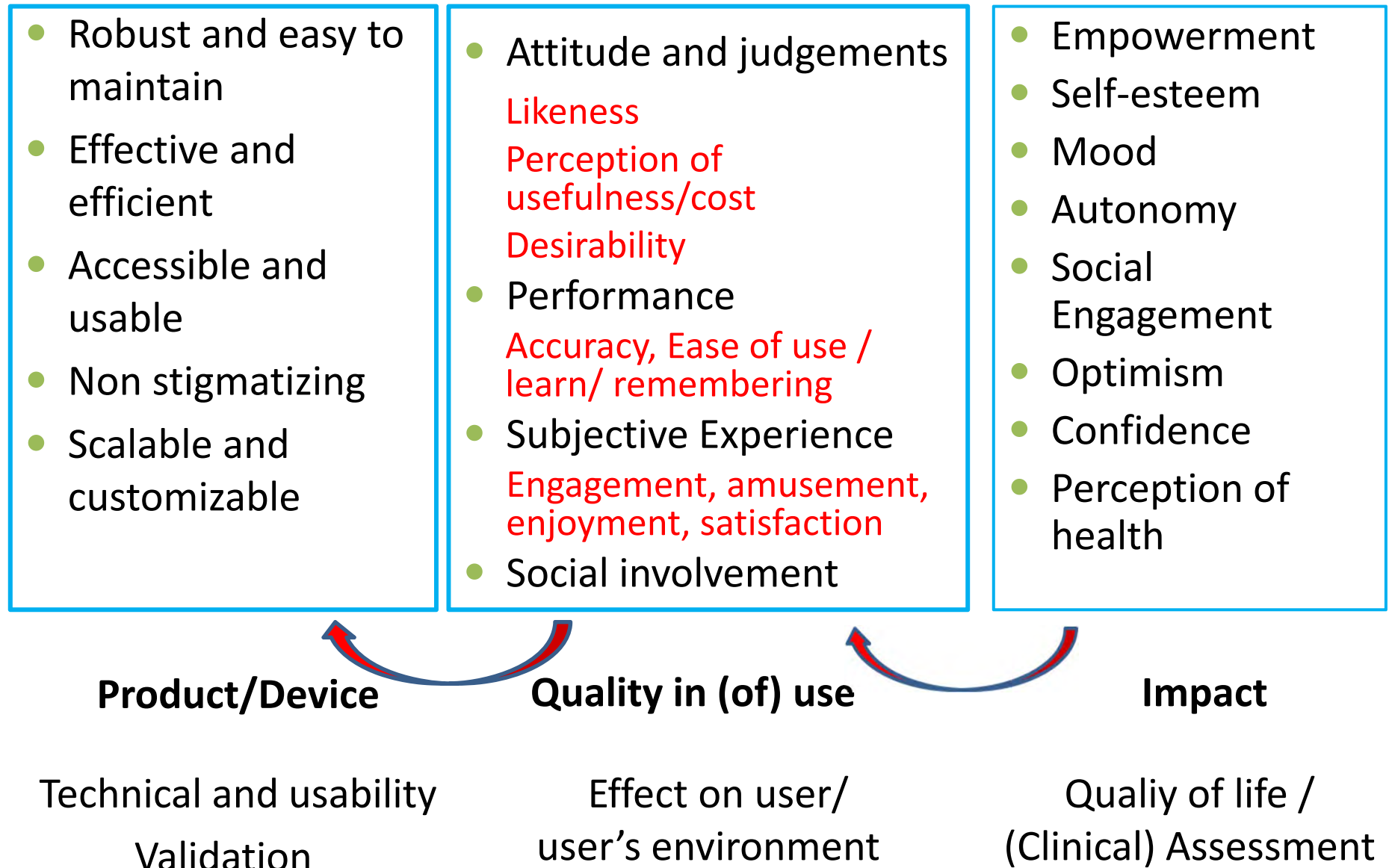


This project has received funding from the European Union's Horizon 2020 research and innovation programme under the Marie Skłodowska-Curie grant agreement No 691001. This document reflects only the author's view and the Research Executive Agency is not responsible for any use that may be made of the information it contains.



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**WOLVERHAMPTON**  
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# **MinD 'Soft Evaluations' Workshop**

## **19<sup>th</sup> 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.

## **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"*

### **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](mailto:dementia@worc.ac.uk)  
or join our mailing list <http://www.worcester.ac.uk/discover/dementia-get-in-touch.html>

### **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.





# 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

# 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](mailto:t.atkinson@worc.ac.uk)

[f.wray@worc.ac.uk](mailto: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  
19<sup>th</sup> 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



University  
of Worcester



*“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?

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





# 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**

[karen.gray@worc.ac.uk](mailto:karen.gray@worc.ac.uk)

@kcrgray / @TAnDem\_DTC





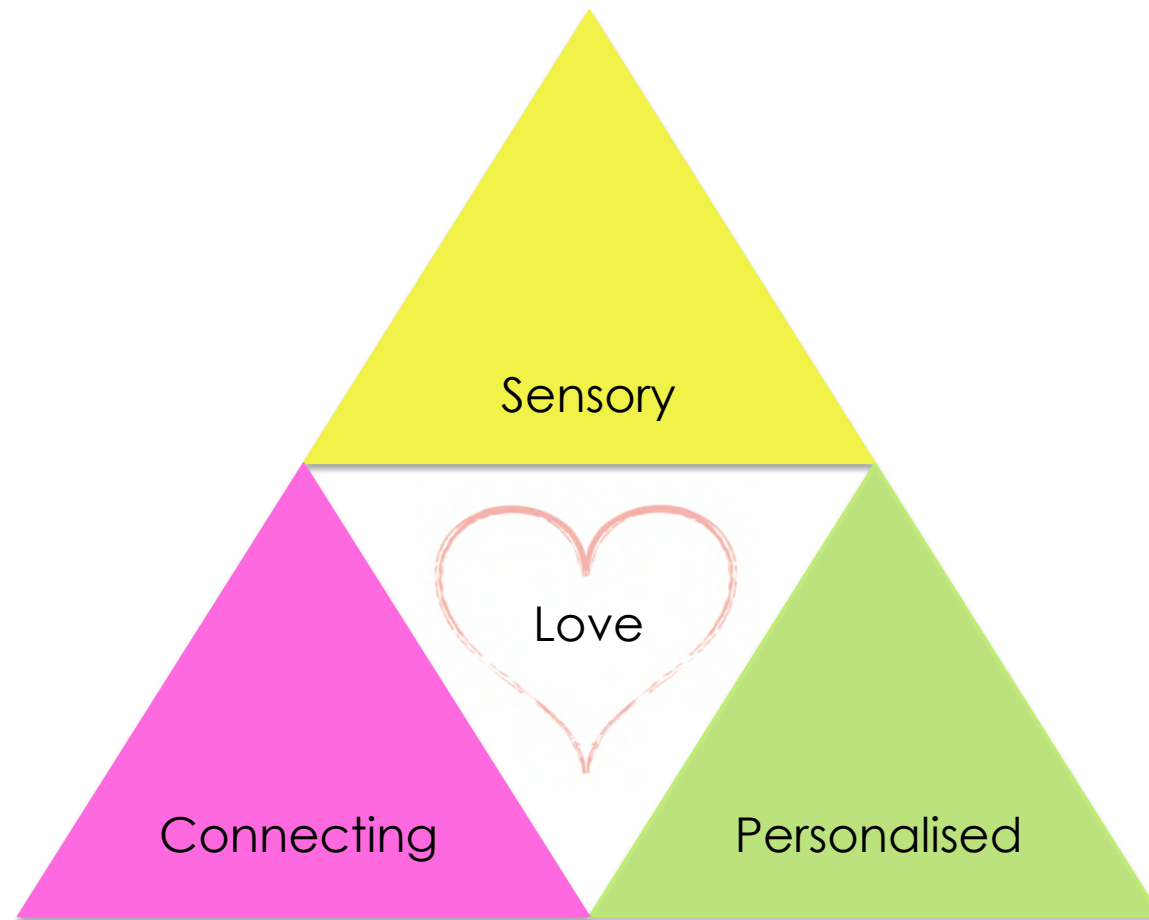
## LAUGH: designing playful objects for people living with advanced dementia

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



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



Email:

[ctreadaway@cardiffmet.ac.uk](mailto:ctreadaway@cardiffmet.ac.uk)

[jfennell@cardiffmet.ac.uk](mailto:jfennell@cardiffmet.ac.uk)

[www.laughproject.info](http://www.laughproject.info)

[www.compassionatedesign.org](http://www.compassionatedesign.org)

@LAUGHCardiffmet

## 'Soft' Developmental evaluation<sup>i</sup>

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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**

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# The LAUGH Project: Ludic Artefacts Using Gesture and Haptics

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(see <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

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(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

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(see <https://www.artgallery.nsw.gov.au/media-office/living-with-dementia/> and a copy of the report is available here <http://bit.ly/2x9ZuVA>)



# Making it Together

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Report available from <http://bit.ly/2goAjYr>

## Making It Together

**Reciprocal design to promote positive  
wellbeing for people living with dementia**



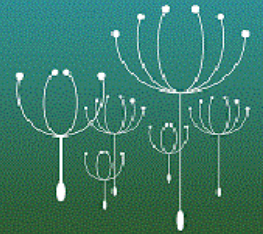
# Mixed methodology approach as the 'gold' standard

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- Logic models
- Participatory action research
- Grounded practical theory
- Ethnographic Quantitative

---

<sup>i</sup> 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?**

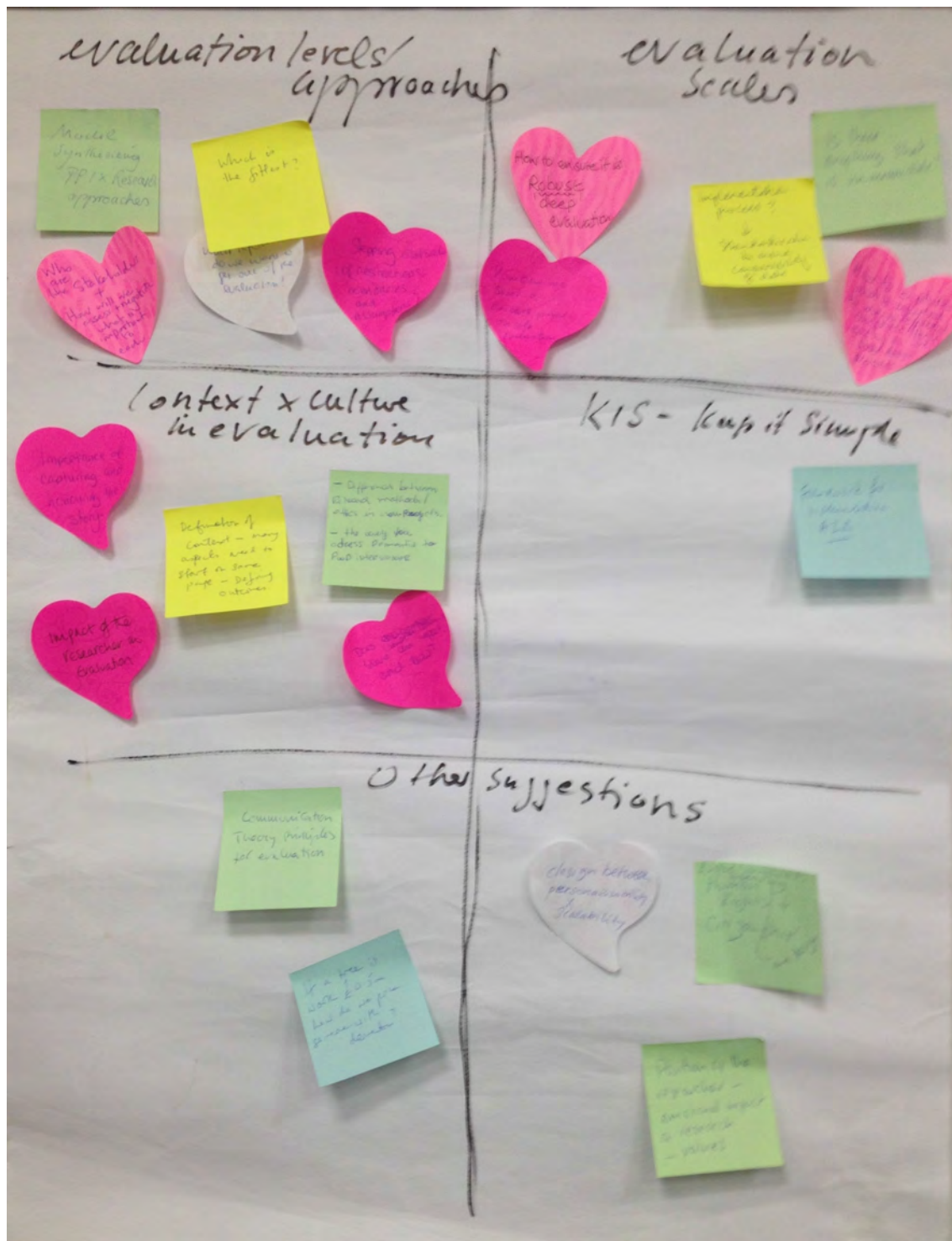
#### **Group 2: Theme 4**

- 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 extent** 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?

## **MinD ‘Soft Evaluations’ Workshop Theme 2**

### **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**

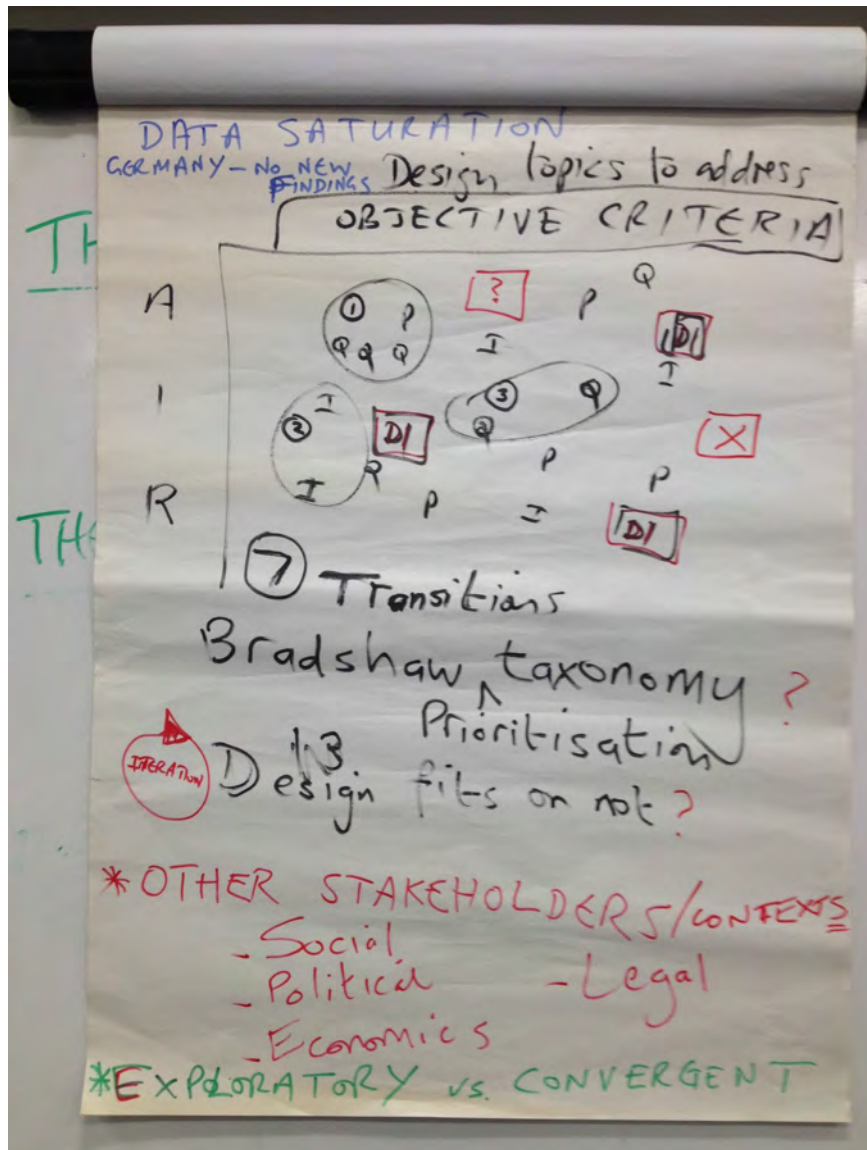
Have you previously tried to manage the kind of situations described above?

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?



## **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

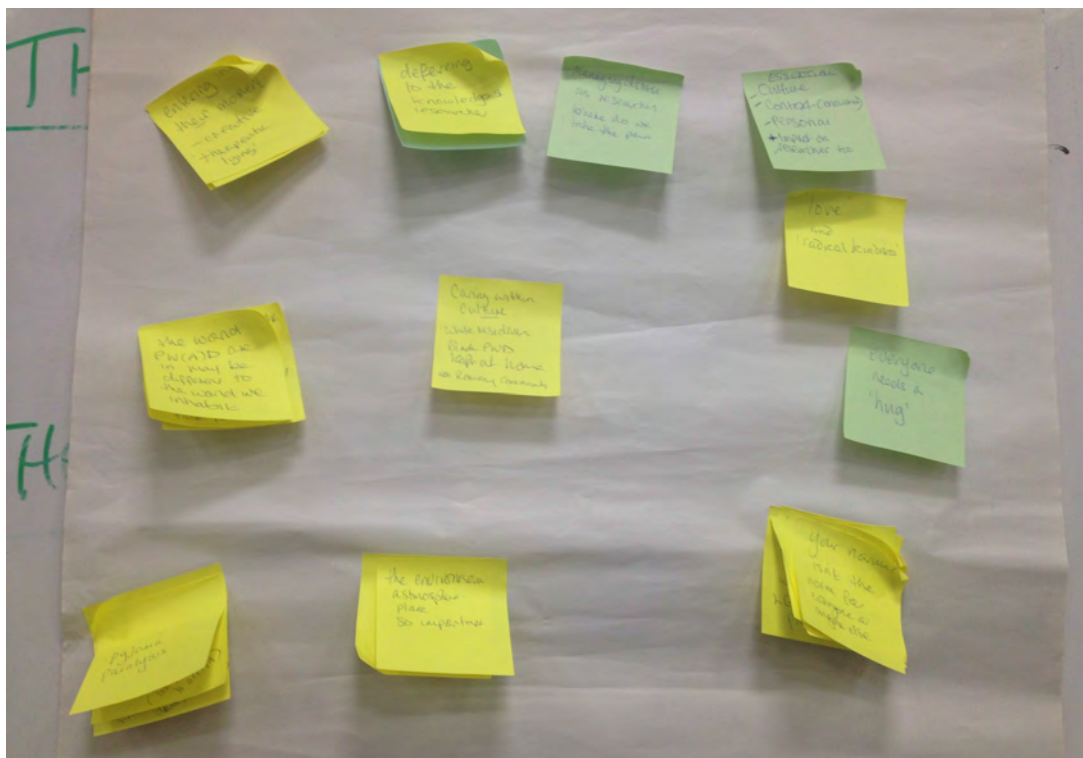
Think of interview experiences that felt comfortable or uncomfortable. What factors might have been at work - (personal and / or contextual)?

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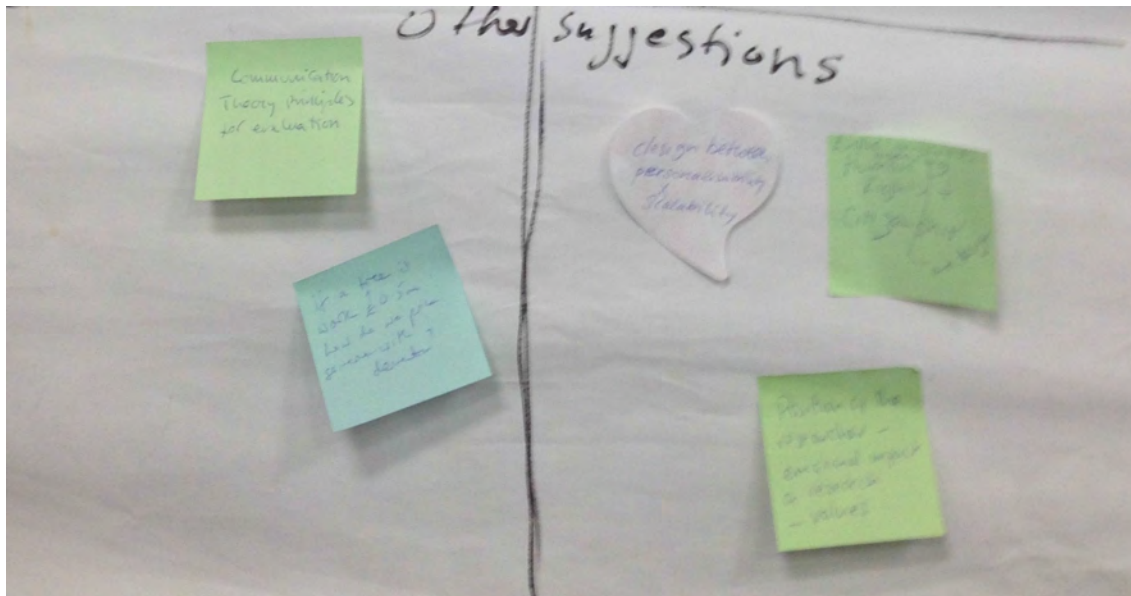
Why do people's circumstances sometimes give a misimpression?

### GROUP WORK

facilitation - issues regarding: culture / context / communication / female interviewer / flash cards / eye contact / other life events / how we address someone /



### Group 3: Theme 5 - Design evaluation and impact (developed from the plenary discussion in the morning)



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 they contribute or what they can afford.