Journeying Together
Opening doors to the arts for people with dementia and their families

Diane Armstrong
Dementia Support Coordinator
Age UK Lancashire
Delivering Journeying Together

Essential ingredients:

• Identified need
• Committed partners
• Clear roles and remits
• Complimentary skill sets
• Active involvement in planning, design and delivery from people living with dementia and their families/carers
Delivering Journeying Together

Age UK Lancashire provided:

- Specialist knowledge around dementia and dementia friendly environments
- Guidance and support
- Awareness raising and training for staff and volunteers across both organisations
- Support for those attending events
- Additional promotion
- Management of the steering group leading the development
- Facilitation of the task group of people living with dementia and their families
Journeying Together findings

- People living with dementia and their family members enjoyed participating in film and arts events and valued being able to get out and meet people.

- People felt comfortable in the environment: and found the activities friendly and welcoming, they were able to relax and enjoy themselves, without feeling judged or awkward.

- Attending events has increased confidence and improved well being.
Journeying Together findings

- Attending events with like-minded people has enabled them to overcome feelings of isolation.

- All staff, volunteers and workshop facilitators have benefited from dementia awareness sessions, and this has enabled them to feel confident and comfortable about supporting people with dementia.

- Opening the cinema to a wider audience has enabled the community to gain a greater understanding of dementia.
Journeying Together challenges

- Reaching people
- Access
- Transport
- Length of sessions
- Risk management
- Recruiting volunteers
Journeying Together in the future

- Ensuring continuation of valued events
- Securing funding for both the arts and specialist elements of the project.
- Extending links to Lancaster University evaluating the impact of the events
- Collaborating with other theatres dementia friendly programmes e.g. The West Yorkshire Playhouse and The Lowry
- Work with the wider Dementia Friendly Community in Lancaster led by Age UK Lancashire.
Dementia Friendly Lancaster

- Involvement of people with dementia
- Challenge stigma and build understanding
- Accessible community activities
- Acknowledge potential
- Ensure an early diagnoses
- Practical support to enable engagement in community life
- Community based solutions
- Consistent and reliable travel options
- Easy to navigate environments
- Respectful and responsive business and services
Dementia-friendly communities

Empowering people with dementia to have high aspirations, confidence and know they can contribute

Becoming dementia friendly means:
- Shaping communities around the views of people with dementia and their carers
- Ensuring early diagnosis, personalised and integrated care is the norm
- Maintaining independence by delivering community-based solutions
- Appropriate transport
- Challenging stigma and building awareness
- Supporting helping people with dementia engage in community life
- Easy to navigate physical environments
- Businesses and services that respond to customers with dementia

Diagram includes illustrations of community infrastructure, including buildings, streets, and transportation options, with text annotations throughout.
Journeying Together in the future

- A Dementia Friendly Dukes all of the time

- Part of the local Dementia Action Alliance along with other businesses and community organisations.
What can you do?

• Become a Dementia Friend

• Become a member of the Lancaster, or your local Dementia Action Alliance

• Spread the word about Journeying Together

• Help us to continue the journey.
Useful Contact Details

- www.ageuklancashire.org.uk
- www.dukes-lancaster.org/
- www.ageuk.org.uk
- www.dementiaaction.org.uk
THANK-YOU

QUESTIONS
85 not out. How dependent are our oldest old?

Carol Jagger
AXA Professor of Epidemiology of Ageing

Institute for Ageing and Health
Newcastle University

Lancaster Centre for Ageing Research 10 July 2014
Apocalyptic demography?

Source: ONS 2012 Population Projections

- “Frail, vulnerable and high users of care”
- Reality is we know very little about the health of 85+
  - Thought to be hard to include in studies
  - More likely to be in institutions and not included in studies
Truth or myth?

• Those aged 85+ are difficult to recruit into studies

• Most very old people
  – Live on their own and are lonely
  – Have a poor quality of life
  – Are cognitively impaired
  – Are dependent and cannot care for themselves
Newcastle 85+ Study

A longitudinal prospective study of >1000 individuals born in 1921 to

1. Describe in biological, medical and psychosocial terms the health of >85s

2. Understand the factors associated with health maintenance in >85s?
## Demographics

<table>
<thead>
<tr>
<th></th>
<th>All</th>
<th>Women</th>
<th>Men</th>
</tr>
</thead>
<tbody>
<tr>
<td>Widowed</td>
<td>59%</td>
<td>70%</td>
<td>42%</td>
</tr>
<tr>
<td>Married</td>
<td>30%</td>
<td>16%</td>
<td>52%</td>
</tr>
<tr>
<td>Living alone</td>
<td>61%</td>
<td>73%</td>
<td>42%</td>
</tr>
<tr>
<td>Institution</td>
<td>10%</td>
<td>12%</td>
<td>7%</td>
</tr>
</tbody>
</table>
Psychological wellbeing

<table>
<thead>
<tr>
<th>Good or better self rated health</th>
<th>Basically satisfied with life</th>
<th>Happy most of the time</th>
<th>Never feel lonely</th>
</tr>
</thead>
<tbody>
<tr>
<td>Women</td>
<td>Men</td>
<td>Women</td>
<td>Men</td>
</tr>
<tr>
<td>75.8</td>
<td>80.7</td>
<td>82.8</td>
<td>86.6</td>
</tr>
<tr>
<td>90.3</td>
<td>92.2</td>
<td>90.3</td>
<td>92.2</td>
</tr>
<tr>
<td>47.3</td>
<td>68.7</td>
<td>47.3</td>
<td>68.7</td>
</tr>
</tbody>
</table>
Loneliness after age 85

- Fluctuating Loneliness: Women 12.0, Men 12.7
- Always Lonely: Women 9.7, Men 17.3
- Improving Loneliness: Women 9.7, Men 23.6
- Worsening Loneliness: Women 11.3, Men 11.5
- Never Lonely: Women 35.9, Men 56.4
High prevalence of disease …… but not just one

- 58% Hypertension
- 52% Osteoarthritis
- 47% Cataract
- 47% Atherosclerosis
- 17% COPD
- 13% Diabetes
- 8% Dementia

Median count: 4 (men), 5 (women)

28% (men) and 32% (women) had 6+ diseases

Multimorbidity is the norm for very old people – contrary to single disease-based healthcare delivery
Prevalence of geriatric conditions

- **Hearing impairment**: Women 56.9%, Men 63.9%
- **Visual impairment**: Women 40.7%, Men 31.6%
- **Pain last month (lasting 1+ days)**: Women 53.0%, Men 45.0%
- **Fall(s) (1+ in last year)**: Women 38.2%, Men 38.4%
- **Urinary Incontinence (severe or profound)**: Women 26.6%, Men 12.6%

Source: Collerton et al BMJ 2009
Mental functioning

- 3% scored 10 or less
- 10% (81) scored 11-21
- 16% (137) scored 22-25
- 70% not impaired (26-30)
- 16% scored 30!
Physical functioning

- 20% able to perform without difficulty all 17 activities of daily living (ADLs)
Functional decline is predictable!

... but not at a specific age

Source: Kingston et al PlosONE 2012
### Need for Care

<table>
<thead>
<tr>
<th></th>
<th>Men</th>
<th>Women</th>
<th>All</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Critical</strong></td>
<td>6</td>
<td>9</td>
<td>8</td>
</tr>
<tr>
<td><strong>Short-interval</strong></td>
<td>26</td>
<td>47</td>
<td>39</td>
</tr>
<tr>
<td><strong>Long-interval</strong></td>
<td>58</td>
<td>31</td>
<td>41</td>
</tr>
<tr>
<td><strong>Independent</strong></td>
<td>10</td>
<td>13</td>
<td>12</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td>99</td>
<td>99</td>
<td>100</td>
</tr>
</tbody>
</table>

- 75% in care homes
- If at home main carer child
- 33% in care homes
- If at home main carer spouse (34%), child (31%)
- 4% in care homes
- If at home main carer child (37%), no-one (18%)

**Critical** (requires 24-hour care)
**Short-interval** (requires help at regular times daily)
**Long-interval** (requires help less than daily)
**Independent**

Source: Jagger et al. BMC Geriatrics 2011
Implications of care needs

Projected numbers in E&W aged 80+ by dependency, 2010-2030

- 79% (302k to 541k)
- 80% (215k to 384k)
- 76% (1.02m to 1.8m)
- 91% (1.05m to 2.01m)

Source: Jagger et al. BMC Geriatrics 2011
FINAL THOUGHTS
Myths shattered!

- Those aged 85+ are difficult to recruit into studies
- Most very old people
  - Live on their own and are lonely
  - Have a poor quality of life
  - Are cognitively impaired
  - Are dependent and cannot care for themselves
Unpleasant truths

In a population of 85 year olds

• Over 50% of women feel lonely some or all of the time

• High levels of disease and geriatric syndromes
  – 25% of women have severe or profound incontinence

• Multimorbidity is the norm:
  – implications for current single disease-based healthcare delivery
Being 85 is not all bad

- High quality of life - >80% satisfied with life
- Functional status (I/ADL) surprisingly good – and for some men maintained over 5 years
- Good cognitive function
- Low proportion (8%) requiring 24 hr care
- Most time from age 85 spent requiring help less than daily
- Functional decline follows a predictable course – **but not at a specific age**
Acknowledgements

Newcastle 85+ team
Research nurses
The Newcastle 85+ Study academic stakeholders
National Health Service organizations
Newcastle 85+ participants
Thank you
‘Homesharing’ as an intervention in patterns of social isolation and labour mobility

Mr. Harris Kaloudis
2nd Year PhD Candidate
Department of Sociology
Lancaster University
What is homeshare?

The exchange of:

Accommodation in one’s own home

for

Practical support of about 10 hours
Practical support can be:

• Shopping
• Preparing meals
• Cleaning
• Small repairs
• Gardening
• Taking care of pets
• Driving
Practical support CANNOT be:

• Health care
• Nursing care
• Social care
• Live-in housekeeper
• Live-in carer
• Live-in servant
The role of a Homeshare agency

• Advertise
• Recruit
• Assess
• Identify needs and preferences
• Suggest possible matches
• Support the start of a Homeshare
• Monitor and support a Homeshare
• Support the end of a Homeshare
Homeshare benefits

• **Householder**: instrumental, emotional, social, financial, health

• **Homesharer**: instrumental, emotional, financial, social

• **Public finances**: savings on health and social care

• **Urban planners**: housing stock utilisation, social capital, labour mobility
Renewed interest in Homeshare

• New schemes started or expanded within the last two years:
  – Cumbria
  – Manchester
  – Derbyshire
  – Oxford
  – Bristol
  – Buckinghamshire
The Big Question

• Can Homeshare deliver on its promises?
Maggie Kuhn - Founder of the Grey Panthers
Homeshare in the USA & Canada

• Boom in the early 1980s

• Decline since?
  – USA: 1986 to 2009: 60% decline
  – Canada: 1980 – 2001 – 2013: from 35 programs to 10 to 1

  • But: 2010 – 2013: 4 new schemes
Why didn’t Homeshare thrive?

• Meagre and unstable finding
• Increased housing affordability
• Counter-normativity of shared housing
Counter-normativity in the USA

•“American value system places a premium on privacy, autonomy and self-sufficiency.” (Jaffe 1989: 6)

•“Americans do not want to live with individuals unrelated by blood, marriage, or romance, unless circumstances offer them
Counter-normativity in the USA

• Living with strangers is counter-cultural
• Receiving care may not be a positive consumer choice
• We do not plan very well for the possibility of needing the care of others
What about England? (Heath 2011)

• Peer-shared households are:
  – “tolerable in youth when one may have fewer options but rarely tolerable or explicable beyond”
  – “difficult to think about” ... “within societies which have traditionally equated the attainment of adulthood with the establishment of an independent household on one's own.”
Norms: dynamic & adaptable?
The perceived advantages and disadvantages of Homesharing “can be seen as a mirror image of the pleasures and problems of living alone” (Doyle 1989: 8).
Conclusion

• History and norms excluded from policy literature?
  – Consequences for decision-making

• What is at stake: the direction of change of the social care system in England
Thank you!
References

Slide 12:

Slide 14:

Slide 15:
Narratives of care: exploring the experiences of older male caregivers

Christine Milligan, Centre for Ageing Research, Faculty of Health and Medicine, Lancaster University.
Carers by Gender: England and Wales (from 2010 Census Data)
‘George’ (mid-70s)

- ‘George’ has cared for his wife ‘Ella’ for more than seven years. Ella has a progressive physical disability and is now unable to walk unaided. A minor stroke a few months ago has now made it difficult for her to hold a sustained conversation. Prior to Ella’s illness, she undertook most of the household tasks although George helped out from time to time. Now George undertakes all the household tasks, including cooking, cleaning, shopping etc. as well as helping Ella to get up and dressed and to get ready for bed at night. He feels he cannot leave Ella alone for any length of time as she cannot get to the toilet unaided and if she fell she would be unable to get back up without support. George does not receive any help from social services – he has never asked as he has always felt it was his role to provide for his wife. With the exception of visits to the GP, he has no contact with health care providers. George’s mother-in-law is in her 90s and lives alone, and though she has a care package in place, he still needs to check on her daily.
George drew on his previous work skills as a tradesman to adapt the environment to maximise his wife’s independence. He has built wheelchair ramps, adapted doorways, the bathroom and kitchen to make it possible for his wife to do as much as she is able on her own. He even went to sewing classes to learn how to adapt clothing to make it easier for his wife to dress herself, but as the only man there felt out of place – as if what he was doing was not quite ‘manly’.

George is exhausted, he has had no respite and is finding it difficult to sleep, but when he mentioned this to his GP, he felt ignored - saying his GP was only really interested in his wife’s condition. He has had to give up most of the hobbies he enjoyed prior to his wife’s illness, and with the exception of the odd visit, he has had little support from friends and family. When he goes out with his wife, people talk to her and almost completely ignore him. His family seem to think he sits at home all day doing nothing, which angers him and he is feeling extremely lonely and isolated.

His wife, who has always been an extremely private person is now finding difficult to wash herself and go to the toilet on her own, George now has to help her but he finds it difficult and though he does not want to give up, he feels he is unable to cope on his own anymore and is seriously considering residential care options for his wife.
Older Male Carers – some key findings

- Often reluctant or resistant to identifying as a ‘carer’ & seeking support – assume it is the man’s role to provide.

- Age and previous career can make a difference re finding practical solutions to managing challenges of caring; harnessing existing skills and experiences can present OMCs supportive strategies and role affirmation.

- Many OMCs experience profound sense of loss: of futures, plans, relationships and friends. Many experience deep social isolation – can be cut-off from many previous (work-related) friendships. Often exacerbated by feeling ignored, undervalued by family friends etc. Support available (e.g. support groups etc.) generally female dominated.

- Report mixed experiences of statutory health & social care support. Service assessments tend to focus on domestic roles and tasks, and areas less relevant to older male carers. GPs often first port of call re support for OMCs but often feel their needs ignored or subordinated to those of cared for.

- First contact with care support services often at crisis point - often precipitated by cared-for’s need for personal and intimate care which many OMCs can find difficult.
Older male carers key findings contd.

**PRACTITIONERS**

- Through the research process, care practitioners developed growing awareness of significant gender features to their work.

- Gendered nuances subtly underpin care provider’s experiences of older carers and their assessment of needs.

- Research process often generated surprise at how few male carers known to service providers.
Who Cares?

Older family carers of relatives nearing the end life

Dr Hazel Morbey
International Observatory on End of Life Care
Faculty of Health and Medicine, Lancaster University
Outline

- Changing and ageing profile of family carers.
- Department of Health / Age UK funding programme that shifted the focus to older carers of those nearing the end of life.
- Lancaster University evaluation research of 6 local Age UK pilot projects in England.
Who Cares at the end of life?

- Ageing demographics
- Policy drivers
- Advances in clinical care and technology
- Enduring, life-long, disabling conditions.

Death is now an event of older age, and needs for care and support have become more complex.

(Hanratty, 2013)

- 6.5 million / 500,000.
- Older carer profile.
- Ageing carer population with significant health needs.
- Family carers have a dual experience as providers and receivers of care.
# Pilot study recipients

<table>
<thead>
<tr>
<th>6 Local Age UK pilot projects</th>
<th>Kingston upon Thames, Lancashire, Leeds, Leicester, Shire and Rutland, Oxfordshire, and South Tyneside.</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Stakeholder</strong></td>
<td>Totals in Supporting Older Carers Programme (n)</td>
</tr>
<tr>
<td>Older carers</td>
<td>243</td>
</tr>
<tr>
<td>Cared-for person</td>
<td>249</td>
</tr>
<tr>
<td>Volunteers</td>
<td>73</td>
</tr>
</tbody>
</table>
Key findings

• Complex, multiple, mutual needs & reciprocal caring relationships

• End of life support: emotional dimension

• Timely coordinated services

• Older carer perceptions of support received

• Volunteer services for end of life support
Older carer’s often have complex and multiple needs that co-exist with their cared-for relative’s complex health and welfare circumstances:

- **Reciprocal** and **changeable** caregiving often exists within same household and caring relationships.

- Older carers may have **lifelong** carer roles for aged family members who have **enduring** health conditions or disabilities.

- **Multiple** caregiving roles exist whereby older carers can be supporting spouses, siblings, their children or their sibling’s children, within their own households and in other households.

- **Decline** or crises in health can prevent older carers from fulfilling their caregiving role.
Case 1

Two brothers who live together, the younger brother Richard has a primary caring role for his older brother Stan of 73 years of age. Stan has a diagnosis of cancer and attends the local hospice regularly. Richard has diabetes, a chronic organ disease requiring surgery, and joint problems causing considerable pain, with imminent planned joint replacement surgery. He is prescribed specialised treatment that cannot be obtained from his GP or local hospital and he travels by taxi to another hospital at some distance to obtain this. Stan experiences sleep problems and feelings of being unable to cope as his own and his brother’s health deteriorates. He has been asked to complete an employment assessment form to evaluate how his illness will affect his ability to work, which is also causing him further stress and worry. Richard takes a caring role for Stan during periods of his own health improvement.

(ST, Dec 2012)
Case 2
Bill is 73 years and is primary carer for his wife Mary who is also 73 years. Bill is awaiting heart surgery and struggles with mobility because of his heart condition. Mary has terminal cancer and is diagnosed with dementia. She is in hospital awaiting discharge to their new sheltered accommodation home. Mary was Bill’s primary carer prior to the onset of her dementia symptoms. The pressures of caring have added to Bill’s own health concerns leaving him feeling very stressed, which compounds his health issues.
*(LDS, Sep 2011)*
Lifelong, shifting caring roles

Case 7
Fiona who is 88 years, is primary carer for her eldest sister Rebecca 99 years, another sister Emily of 95 years, and her nephew David of 77 years of age. Rebecca the eldest sister is currently a hospital inpatient, and will be discharged soon. She, her younger sister Emily and David live together, while Fiona resides in sheltered accommodation. Fiona is the first line carer contact for all her relatives.

(ST, Jun 2011)
Lifelong, shifting caring roles

Case 8

Nazia 71 years, cares for Sophia, her sister of 64 years, who has a diagnosis of two cancer illnesses. Sophia has learning and physical disabilities and has received life-long care from Nazia. In addition, Nazia cared for another sister, also diagnosed with a learning disability, until her death some years previously, and both parents who she more recently nursed through terminal illnesses, until their death.

(LDS, Sep 2012)
Recommendations to support older carers of those nearing the end of life

- Assessment of older carers should take account of the multiple and mutual needs that often co-exist between them and their cared-for relative.

- Recognition that for older carers there can often be complex and reciprocal components to the health and social circumstances of both older carer and cared-for family member.

- Older carers needs should be addressed alongside those of their cared-for family member. Assessments of family carer should be embedded into services delivering end of life health and social care.
Acknowledgements

• Professor Sheila Payne, Dr Katherine Froggatt, Professor Christine Milligan, Dr Mary Turner.

• National Age UK through funding from Department of Health

• 5 local Age UKs and 1 local Age Concern:
  • Kingston upon Thames (Age Concern)
  • Lancashire
  • Leeds
  • Leicester, Shire and Rutland
  • Oxford
  • South Tyneside
What do family carers do near the end of life?

Professor Sheila Payne

*Co-Director:*
International Observatory on End of Life Care,
Lancaster University
Unpacking the home study
Dying for frail older people

- Cognitive deficit (dementia)
- Socially isolated from family
- Under or over treatment
- Co-morbidities
- Lack of understanding or communication about diagnosis and prognosis
- General awareness of death as possible and even desired.
- Little perceived choice and often no real choice
- Autonomy may not be valued to the same extent as by younger people
Paul, 72, is a retired teacher who cared for his wife Shirley for 5 weeks from her diagnosis of pancreatic cancer to her death in February 2011. They had been married for 45 years and had no children. She was diagnosed in hospital, where she was given the choice of staying in hospital or going home; however, there was minimal discussion about her place of care.

She said she wanted to die at home and I wouldn’t disagree with her, no, no. I loved her a lot.
Paul acknowledged that despite their good relationship, they did not discuss Shirley’s illness and approaching death.

We didn’t talk about it you know, lots of people said ‘oh this is a time when you can talk about these things’ but we didn’t, I think we just kind of pushed it in the background.
When she was discharged from hospital, a number of different services were organised. Paul found it confusing to have so many different people come to the house:

The first problem I found was in the first few days at home, it was almost as though people were inundating us, and I got a little bit exasperated with the community nurses; somebody’d want to come, big questionnaire, fair enough to try and assess the needs. Then somebody from Marie Curie came, another questionnaire, and she went away. Then somebody from the hospice came and another one... and it went on like this and I thought, well what about the practical help of, you know, when she gets more ill, getting her to the toilet and getting her washed and things like that, which was at that stage what was worrying me more. [...] it seemed that one organisation could have come and assessed the needs.
On the whole, Paul was satisfied with the services Shirley received, but on occasion when they needed help out of hours they had to wait for people to respond:

That service I thought was quite good: it was pretty exhausting in that – I don’t know if you’re familiar with it – you phone and leave a message on an answer phone, you don’t contact them directly, so you don’t know how long they’re going to be [...] You wait for them to phone their own answer phone and then they’ll turn up an hour and a half later maybe or something like that. So there was a fair amount of sleep deprivation.
What also made it harder for Paul was that Shirley did not want any of their friends to visit:

She wanted no visitors and she wouldn’t go downstairs; it was almost as though she’d said ‘that’s it, it’s over’. That was a bit hard to take.
Paul also had to take responsibility for Shirley’s pain control at times, which he found worrying:

If she was in extreme pain I could always phone up and say that, you know, she’s having problems, and they would do their best to come. Obviously the nurses had quite a lot of people to see as you would expect, and the NHS, what can you do, so they would maybe phone me up and say ‘look, we’re stuck here with a patient who’s having problems, can you cope?’, and sometimes you just had to cope on your own, you know. I’ve had to change a patch myself, which turned out to be the right thing to do in any event, but you know because the dosage wasn’t sufficient and I had patches of different strengths so maybe I’d put another one on and hopefully that would take some of the pain away.
Key points

• The delivery of medication to a dying person at home can cause anxiety and concern to family carers.
• Family carers require support in managing and delivering medications at the end of life.
• There is potentially a greater role for community pharmacists in providing this support.
Key recommendations

Practical strategies to support family carers at home:

• There is a need for a key worker who can get to know the patient and family. The key worker could help to prepare the patient and family for the death, and act as a source of support for the family afterwards.

• Family carers (particularly older carers) often have their own care needs; these should be identified and addressed by the care-giving system. Too often professionals focus solely on the patient and overlook the carer.

• Care needs to be more responsive to the individual needs of the patient and family carers, rather than imposing professional agendas and values.

• The management of medications places a huge burden of responsibility on family carers; more support is needed and there is scope for greater involvement of community pharmacists in this.
Guidance on information:

- There is often a lack of communication between health professionals and patients/carers and **limited opportunities** to talk; information needs to be given and updated as the situation changes, with different options being discussed at different points.

- **Written information** is helpful for patients and families. A short leaflet about what to expect around the death and immediately afterwards should be given to family carers.

- Patients and family members have to tell their story repeatedly. Initiatives such as ‘**tell me once**’ should be used more widely.
Place of death:

• A distinction needs to be made between place of care and place of death; the place of care is more important than where the person actually dies, but the focus is too heavily of place of death.

• There is potentially a much greater role for the voluntary sector in providing support when someone is dying at home, both before and after the death.
Conclusion

In reality family carers are still experiencing unnecessary distress, insufficient support and poor communication.
Do you want to know more?


Neighbourhoods and dementia: a mixed methods study (2014-19)

Improving the evidence base

Chief Investigator: Professor John Keady, University of Manchester

Presentation by:

Dr Siobhan Reilly, Division of Health Research, Lancaster University
Overall Research Aims

• To understand the meanings, experiences, and structure of neighbourhoods for people living with dementia and their care partners
• To make people with dementia and their care partners core to the research agenda
• To encourage innovative technological advances in dementia studies and in the development of a neighbourhood model of dementia
• To build capacity within the research community and the networks of people living with dementia and their care partners
• To develop the evidence base, methods and measures for people living with dementia and their care partners
<table>
<thead>
<tr>
<th>CO-INVESTIGATOR ORGANISATIONS</th>
<th>PROJECT PARTNERS</th>
<th>SUPPORTING ORGANISATIONS</th>
</tr>
</thead>
<tbody>
<tr>
<td>The University of Manchester</td>
<td>Age UK, Salford</td>
<td>Manchester Academic Health Science Centre</td>
</tr>
<tr>
<td>Stirling University</td>
<td>AQuA</td>
<td>Greater Manchester Academic Health Science Network</td>
</tr>
<tr>
<td>Salford University</td>
<td>Finerday</td>
<td>Manchester Interdisciplinary Collaboration for Research on Ageing</td>
</tr>
<tr>
<td>Lancaster University</td>
<td><a href="https://www.finerday.com">https://www.finerday.com</a></td>
<td>Greater Manchester Dementia Partnership</td>
</tr>
<tr>
<td>Liverpool University</td>
<td>Greater Manchester Public Health Network</td>
<td>INVOLVE</td>
</tr>
<tr>
<td>University College London</td>
<td>NHS Greater Manchester</td>
<td>UK Urban Ageing Consortium</td>
</tr>
<tr>
<td>University of Linköping</td>
<td>Rt Hon Hazel Blears MP</td>
<td>NIHR DeNDRoN</td>
</tr>
<tr>
<td>British Deaf Association</td>
<td>Manchester City Council / NHS Manchester</td>
<td>Alzheimer’s Society</td>
</tr>
<tr>
<td>Alzheimer’s Collaborative Enterprise</td>
<td>Manchester MHealth Ecosystem</td>
<td>ESRC DTC Centres</td>
</tr>
<tr>
<td>Pennine Care NHS Foundation Trust</td>
<td>North West People in Research Forum</td>
<td>Television and media outlets</td>
</tr>
<tr>
<td>Greater Manchester West Mental Health NHS Foundation Trust</td>
<td>Salford City Council</td>
<td>Alzheimer Scotland</td>
</tr>
<tr>
<td></td>
<td>NHS SalfoR+D Acute and Primary Care Research</td>
<td>Economic and Social Data Service</td>
</tr>
<tr>
<td></td>
<td>Scottish Dementia Working Group</td>
<td>Greater Manchester Comprehensive Local Research Network</td>
</tr>
<tr>
<td></td>
<td>Alzheimer Scotland</td>
<td>NHS Forth Valley</td>
</tr>
</tbody>
</table>
Member Involvement Strategy

• Lead: Dr Caroline Swarbrick
• ACE Club, Scottish Dementia Working Group, Open Doors, EDUCATE
• Partner Organisations: INVOLVE, Citizen Scientist project, Manchester Informatics:
• Module approach to training and involvement over duration of programme
• Changing the culture of user involvement in dementia research
Dementia User Involvement and Engagement Model

Adapted from INVOLVE (2005, p25)

Stage 1. Training and Support
- Research training and education programme
- Initiate support and peer support networks

Stage 2. Design
- Participatory research design
- Reading documents e.g. info sheet
- Designing data collection tools e.g. schedules

Stage 3. Undertaking
- Data collection
- Data analysis and interpretation

Stage 4. Dissemination
- Presentations / conferences
- Reports
- Journal papers
- Feedback for participants

Stage 5. Implementing Findings
- User-engagement outputs
- Involvement in writing further bids
- ‘Impact on Policy’ event with Rt Hon Hazel Blears and Prof Alistair Burns

Stage 6. Evaluating Impact
- Evaluating impact of Work Packages and findings
- Evaluating impact of training and support
- Evaluating impact of Committee / Group involvement
Work Package 1: Generating Neighbourhood Profiles of Cognitive Ageing and Service Use Using Nationally Representative Population Data

Team:
Pendleton (lead); Nazroo; Tampubolon; Taylor. Timeline: 36 months.

Research Question:

How can we produce Neighbourhood Profiles using existing longitudinal data bases to provide more accurate estimates of geographical variation in cognitive ageing and service use to inform policy, commissioning and practice?
Work Package 2: Development of a Dementia Core Outcome Set

Team:
Reilly (lead); Challis; Burns; Reeves; Davies; Hydén; Keady; Williamson. **Timeline: 36 months - review in year 5.**

Research Questions:

• Which outcomes should be measured from the perspective of people with dementia, carers, health professionals and policy makers?

• How should such outcomes be measured?

Team:
Ward (lead); Clark; Hydén; Rummery; Keady; Davies; Taylor; Campbell. **WP**

**Partner Organisations:** Forth Valley NHS; Alzheimer Scotland; Age UK Salford; Manchester Valuing Older People Network; Rt Hon Hazel Blears MP; Integrated Commissioning/Public Health, Salford; Finerday. **Timeline:** 60 months.

**Research question:**
How can neighbourhoods support people with dementia and their carers to remain socially and physically active?

**Sites:** Stirling, Salford and Linköping
CEDER – Center for dementia research – is based on the research program “Dementia: agency, personhood and everyday life” that was awarded funding by the bank of Sweden Tercentenary Foundation in 2011.

*Photo: Sculptures “Beatrice Granath, Secretary” by Moa Anderson*

**CEDER’s ambition** is to conduct social scientific and humanistic research around persons living with dementia diseases: their abilities, experiences and knowledge. Of particular importance is the ways persons with dementia make use of their remaining abilities in everyday social interaction and as citizens.

**NEWS**

**International conference in Norrköping**
October 15-17, 2014 CEDER organizes the international conference “Life with dementia: relations”.

**New book overviews research on dementia**
WP4: (1) Developing the evidence base for evaluating dementia training in NHS hospitals: a mixed methods design

Team: Reilly (lead); Reeves, Davies, Burrow, Keady, Leroi.

Partner Organisations: Advancing Quality Alliance [AQuA]; Manchester mHealth Ecosystem. Timeline: 60 months.

Research Questions:

- How do variations in implementation, content and intensity of dementia training in hospitals in England relate to health service outcomes/process measures (length of stay and emergency re-admissions) and staff outcomes (such as confidence, knowledge of dementia)?

- What components of dementia training are most strongly related to improved patient outcomes and staff confidence in knowledge and skill about dementia?

Team:
Hellström (lead); Keady, Hydén, Reilly, Davies, Reeves, Taylor, Dahlbäck. **WS Partner Organisations:** Manchester mHealth Ecosystem; Finerday. **Timeline:** 42 months.

**Research Question:**
Following a diagnosis, how can a couple orientated self-management course provided in primary care sustain and enrich everyday life and maintain neighbourhood integration?
WP4 (3): Development of personal digitised life story tools for Deaf people with dementia

Team:
Young (lead); Ferguson-Coleman, Atkinson, Buckley [British Deaf Association (BDA)], Taylor. WS Partner Organisations: Manchester mHealth Ecosystem; Finerday. Timeline: 36 months.

Research Question:
Is a linguistically appropriate and culturally sensitive personalised digitised life story tool for use by and with Deaf sign language users with dementia a feasible and acceptable intervention?
Additional Areas

• x3 ESRC PhD studentships [2 with matched funding] with access to the Doctoral Training Centres in Scotland and the North West:
  – areas – technology; co-research; discharge home from hospital
  – 1 based in Scotland and 2 in the North West

• Web/Educational materials/ Computer Science
So what impact will we have?

• If we have the evidence we can deliver....
  
  – Scientific, economic and social impact

  – Policy and practice impact

  – Make a difference to people’s lives by facilitating the changes that are needed to deliver dementia friendly neighbourhoods into communities.
THANK YOU FOR LISTENING

FOR FURTHER INFORMATION EMAIL:

s.reilly@lancaster.ac.uk
Ageing Playfully
By Emmanuel Tsekleves

Pathways to Impact Event: Caring for our older populations – 10th July
Emmanuel Tsekleves

Senior Lecturer in Design Interactions

ImaginationLab / Design / LICA / Lancaster University

Centre for Ageing Research (C4AR)

Contact
e: e.tsekleves@lancaster.ac.uk
w: http://imagination.lancaster.ac.uk/people/Emmanuel_Tsekleves
T: _Design4Change_
L: http://www.linkedin.com/in/emmanueltsekleves
Playful Design is the use of game thinking and playful elements in user experience.
Playful Design Example

https://www.youtube.com/watch?v=2lXh2n0aPyw
Working together with local community groups who look after the park, the Lancaster City Council, NHS Lancashire Public Health we are co-designing a 'health trail', which offers a new way of motivating and taking casual physical activity specific to local people in their park (Ryelands Park in Lancaster, UK).
Making the physical digital...
...and the digital physical
Co-designing

Following a number of co-design activities and workshops we work with sedentary park users and older people to co-design a phygital health trail based on their values, aspirations and activities they enjoy doing in the park.
Proof-of-concept prototype: phygital xylophone
Making of

https://www.youtube.com/watch?v=eOOcKWBdW-w

https://www.youtube.com/watch?v=d6CG1Iieq_s
Making of
Interactive Xylophone – 1st prototype

https://www.youtube.com/watch?v=HSQZ3mIIgr8
Playfulness is ageless
Fun ways of keeping active for all
Value of bridging the intergeneration gap
Feedback

IT COULD BE BETTER IF...
It was smaller so you don't have to keep running
I liked it because it was different
MORE GRASS LESS TAR/PAVING
Really cool! Really interesting idea!
I want the runner to be able to play a couple in an example!
More colourful! It's exciting to look at. Smoother
would also be easier
- give examples of songs you could play - note a number
i.e. Eye of the Tiger
- Star Wars theme tune

THE BEST THING ABOUT THE XYLOPHONE IS...
I want one at home.
It's awesome!
- how easy and engaging it is
- doesn't take long
- it was less to find the noise was very quiet
- funny novelty

I want an xylophone to make a special day feel just of making it an instrument.

Play it back afterwards on the piano.
The first part of the project is supported by the Lancaster University FASS-Enterprise Centre and the second part is supported by Catalyst, a research project based at Lancaster University and funded by the Engineering and Physical Sciences Research Council http://www.catalystproject.org.uk/