



Sussex Community **NHS**
NHS Foundation Trust



‘I want to live my life well and die peacefully when the time comes’: Integrating palliative care into community healthcare for older adults with dementia

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@CatherineJanee1 #embedcare

Need for palliative dementia care is great and rising

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Health

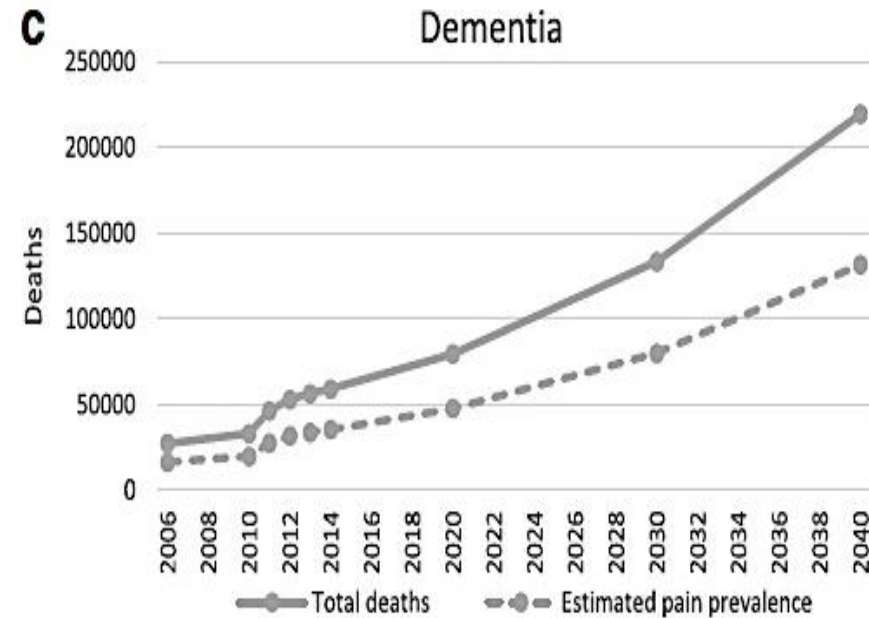
Dementia now leading cause of death

14 November 2016



There are many different types of dementia. Alzheimer's is the most common form.

Dementia, including Alzheimer's disease, has overtaken heart disease as the leading cause of death in England and Wales, latest figures reveal.



The number of people dying with dementia
x4 projected rise by 2040
Etkind et al. BMC Medicine 2017

*As a an artist, one is
merely a link in a chain*

Vincent Van Gogh

**As a nurse scientist, one is
a vital link in a chain**



Empowering better end of life dementia care: EMBED-Care

EMBED-Care Team

Prof. Liz Sampson	PI	Prof. Jason Warren	DRC-UCL (YOD)
Prof. Catherine Evans	Co-PI; WS1 Lead	Jane Ward	Expert by Experience
Prof. Katherine Sleeman	WS2 Lead; Engagement	Dr Vicki Vickerstaff	Statistician
Dr Nuriye Kupeli	WS3 Lead		
Dr Kirsten Moore	WS4 Lead	Imogen Collier	RA
Dr Nathan Davies	WS5 Lead	Tofunmi Aworinde	RA/PhD WS1
Dr Clare Ellis-Smith	WS6 Lead	Emel Yorganci	RA/PhD WS2
Prof. Richard Harding	Social Scientist	Sophie Crawley	RA/PhD WS3
Prof. Rumana Omar	Statistician	Juliet Gillam	RA/PhD WS5
Dr Anna Gola	Health Economist	Ali-Rose Sisk	PhD – YOD
Dr Janet Anderson	Implementation Science	Sharon Novara (UCL)	Project Coordinator
Dr Bridget Candy	Systematic Reviewer	India Tunnard (KCL)	Project Coordinator
Prof. Rob Stewart	Large data epidemiology	Dr Charlotte Kenten	Programme Manager
Prof. Simon Mead	UCL- National Prion Unit		

The EMBED-Care team



Aims to...

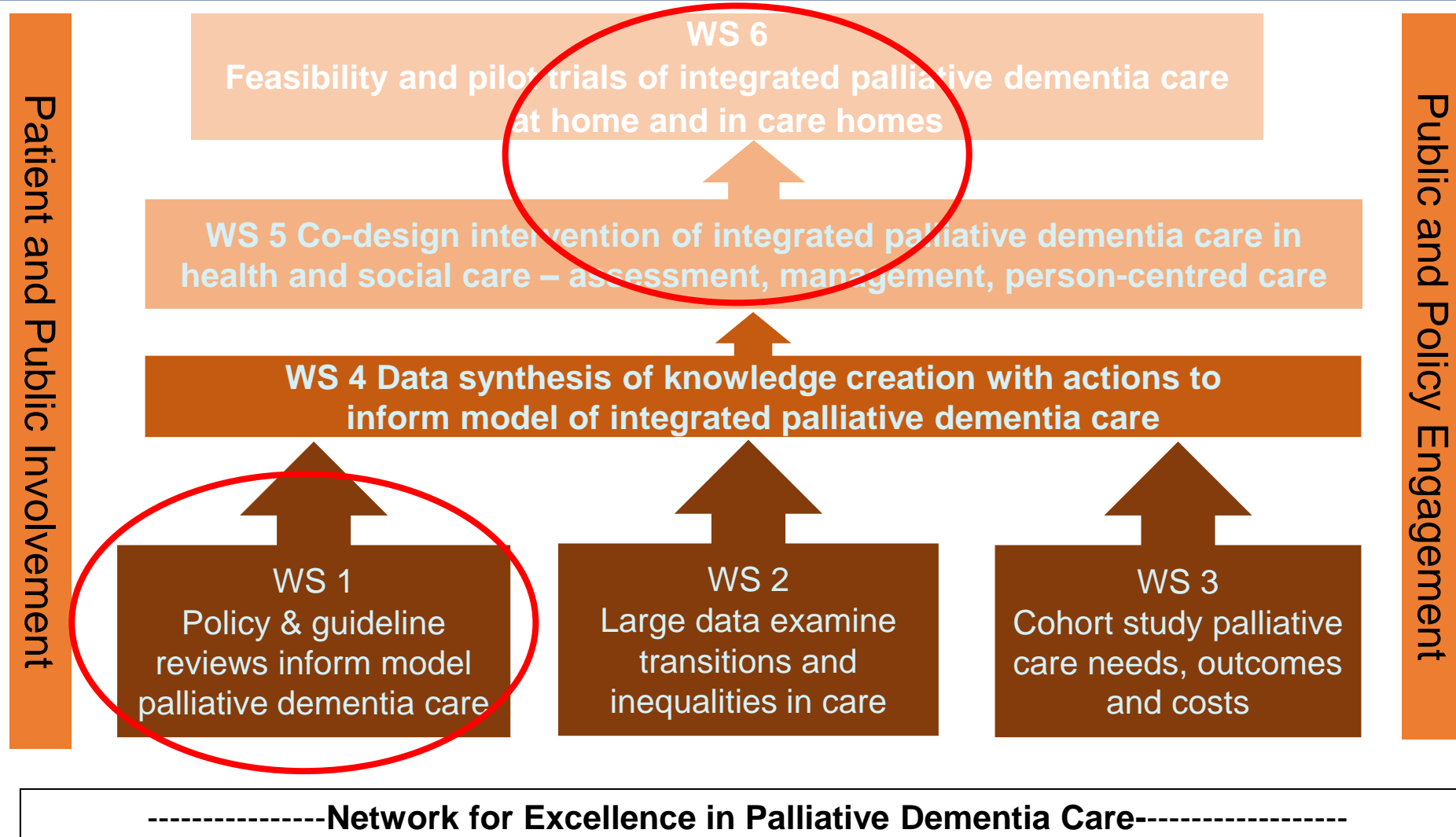
EMBED-Care

Empowering Better End
of Life Dementia Care



1. **Lever a step-change in palliative dementia care**, generating new knowledge and a network for care, engagement and research
2. **Co-design and evaluate the EMBED-Care Framework to empower people with dementia, carers and staff**, to identify and act upon changing needs, in the community
3. **Build research capacity in dementia care**
4. **Collaborative Patient and Public Involvement with people affected by dementia** across the programme

EMBED-Care programme overview



Work Stream 1: Meta-review to construct system-based logic model of integrated palliative dementia care.

PARTICIPANTS (target population): People with dementia with palliative care needs and lay caregivers (family/friends)

IMPLEMENTATION

Policy UK
'personalised care'
to orientate care
towards QoL
(Sleeman et al. *BMC Pall Care* 2021)

CONTEXT

Geographical
High-income areas
(e.g. Americas 60%
Europe 29%)

INTERVENTION THEORY (*how the intervention works including overall aims*)

- **Person-centred care***, human value of person with dementia (and carers); relational care to uphold sense of self
- **Holistic person-centered assessment*** includes goal setting, advance care planning and review
- **Promote wellbeing and function***, including spirituality, independence and cognition

INTERVENTION DESIGN (*describes the "What?" of the intervention*)

Components:

- **Optimal management of symptoms*** neuropsychiatric, pain and other problems using person-centred and evidence-based interventions and minimise futile treatment. **Ongoing medical review**
- **Staff training* all members of the team (including volunteers)** on dementia care and skills to apply palliative care, including orientation and ongoing training, focus communication, teamwork and collaboration, and evaluation to drive improvement.
- **Provide information and education to person with dementia and family*** on dementia and palliative care approach, family role as proxy-decision maker and involve person with dementia. **Culturally competent care**
- **Supportive environment*** to ensure comfort, sense of community, safety, choice and meaningful engagement
- **Continuity of care and care coordination**, to enhance seamless care and communication across services e.g. case conferencing, MDT review, central coordinator/case manager
- **Support for caregivers (beyond information)** to promote wellbeing e.g. respite care, offered psychological therapy for depression i.e. CBT and grief support pre and post death
- **Diagnosis and prognosis**

Execution: Timing and duration, dose and intensity of palliative care for people with dementia

INTERVENTION DELIVERY (*"How?", "Who?" and "Where?"*)

Setting (location): Managing care transition risks associated with transfers to hospital and support for the person/family during care. **Delivery agents (who) and mechanisms (how)**

HEALTH OUTCOMES

Person with dementia

- QoL/wellbeing*
- Neuropsychiatric symptoms*
- Depression*
- Pain and comfort
- Other symptoms
- Function
- Falls reduction
- Reduction in restraint

Lay caregivers

Quality of life/wellbeing
Burden
Depression

Population-level health outcomes

- Mortality

Non-health outcomes Economic evaluation

PROCESS OUTCOMES

Palliative care activity
Quality of care*
Service use e.g. Place of death
Staff outcomes
Caregiver satisfaction with care

*Most common components identified in 5+ systematic reviews. **Red text** areas of uncertainty pursued in the programme

Work Stream 5: Co-design of the EMBED-Care Framework & app

Dr Nathan Davies and Dr Clare Ellis-Smith



Co-design EMBED-Care Framework and app:

1. IPOS-Dem tool (holistically assess concerns, needs, symptoms and goals) ✓
2. Clinical decision support tool (evidence based care at the point of care) ✓
3. Manual and training support e.g. video ✓

Iterative co-design approach with 3 groups:

1. People with mild dementia ✓
2. Current and former carers ✓
3. Practitioners across settings and specialities ✓

“Assessment as intervention”: Integrated Palliative care Outcome Scale-Dementia (IPOS-Dem). Dr Clare Ellis-Smith



IPOS-Dem

Please write clearly

Person's name:.....

Person's number

Date (dd/mm/yyyy):.....

Q1. What have been the person's main problems over the past week?



<https://pos-pal.org/>



IPOS-Dem

Q2. Please select one box that best describes how the person has been affected by each of the following symptoms over the past week.

	Not at all	Slightly	Moderately	Severely	Overwhelmingly	Cannot assess
Pain	0 <input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	<input type="checkbox"/>
Shortness of breath	0 <input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	<input type="checkbox"/>

	Not at all	Occasionally	Sometimes	Most of the time	Always	Cannot assess
Weakness or lack of energy	0 <input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	<input type="checkbox"/>

Q3. Has s/he been feeling anxious or worried?	0 <input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	<input type="checkbox"/>
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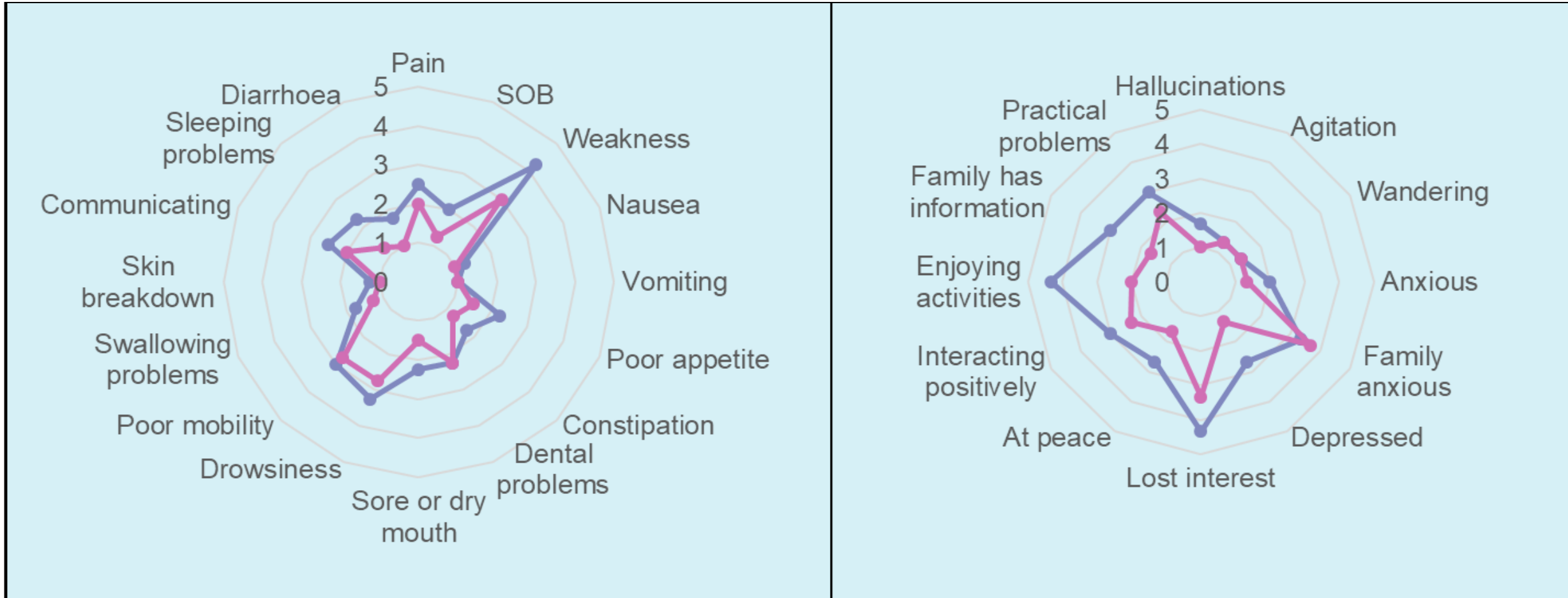
Q4. Have any of his/her family been anxious or worried about the person?	0 <input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	<input type="checkbox"/>
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Q5. Do you think s/he felt depressed?	0 <input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	<input type="checkbox"/>
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Q5b. Lost interest in things s/he would normally enjoy?	0 <input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	<input type="checkbox"/>
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Ellis-Smith, et al.....Evans CJ. Development of a caregiver-reported measure to support systematic assessment of people with dementia in long-term care: IPOS-Dem. *Pall Med* 2016

“Assessment as intervention”: Change in scores- 1 month



Kinley J, Ellis-Smith C et al.....Evans CJ A collaborative approach in dementia care to improve clinical effectiveness. *International Journal of Palliative Nursing*, 2019, 25; 12

EMBED-Care 12 decision areas:

- Overarching principles
- Emotional wellbeing of person with dementia
- Emotional wellbeing of carers
- Pain
- Mobility
- Eating, drinking & mouthcare
- Sleep
- Constipation & incontinence
- Weakness & lack of energy
- Delirium
- Skin care
- Spirituality

Davies, N. et al. Guiding practitioners through end-of-life care for people with dementia: the use of Heuristics. *Plos One* 2018.

Rule of thumb

Pain

1. Assess

Talk

- Ask them if they are in pain?
- Where is the pain?

Look

- Are they looking sad or frightened?
- Are they frowning?

Observe

- Are they more confused?
- Are they whimpering?
- Are they groaning or crying?
- Are they eating and drinking less?
 - Are they agitated?
- Has behaviour changed?
 - Are they sweating?

Body Language

- Are they rigid, clenched fists, knees pulled up, protecting a body part?
- Are they trying to move or push you away?

Talk to a family member or advocate if the patient cannot respond or remember

2. Causes

Talk

- When did the pain start?
- What does it feel like?
 - How severe is it?
- Ask family or advocate.

Look

- Check skin and pressure areas?
- Encourage gentle supervised mobilization.
- Check oral hygiene, mouth care and possible teeth problems.
 - Are they sitting in an awkward position?
 - Have they taken their medication?
- Is the environment causing discomfort?

History

- Do they have a known pain condition such as arthritis?
 - Are they constipated?
 - Are they passing urine more?
 - Are there signs of an infection?
 - Have they had a recent fall?
- When was medication last reviewed?
- Have they had previous fractures?
 - Do they have chronic pain?
- Use a pain monitoring chart or diary to record episodes.

3. Treat

Talk

- Seek help from care team (GP, clinical staff or senior staff in care home setting)
 - Reassure the person.
- Try using distraction techniques to improve comfort.

Act

- Move position.
- Consider non-pharmacological methods such as massage or heat.
 - Consider over the counter pain medication i.e. paracetamol.
- Ensure that regular pain medications are being taken if prescribed, consider prescription if helpful.

Refer

- Once cause is established and reversible causes managed consider referral to pain specialist or palliative care.
- Referral to OT and Physio may also benefit if pain is related to movement or function.
 - Discuss with pharmacist for alternative options.

Once treatment in place reassess to ensure pain is managed.

Considering implementation from the start

PhD Student: Tofunmi Awonrinde

Design and feasibility evaluation using the IPOS-Dem as an intervention for shared decision-making for people with dementia, family carers and practitioners

PhD Student: Juliet Gillam

Design and feasibility evaluation of an implementation plan for the EMBED-Care eHealth framework to optimise person-centred assessment and decision-making for people with dementia in care homes

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DOI: 10.1002/trc2.12304



REVIEW ARTICLE

How do person-centered outcome measures enable shared decision-making for people with dementia and family carers?—A systematic review

Jesutofunmi Aworinde¹ | Clare Ellis-Smith¹ | Juliet Gillam¹ | Moïse Roche² | Lucy Coombes^{1,3} | Emel Yorganci¹ | Catherine J. Evans^{1,4}

JOURNAL OF MEDICAL INTERNET RESEARCH

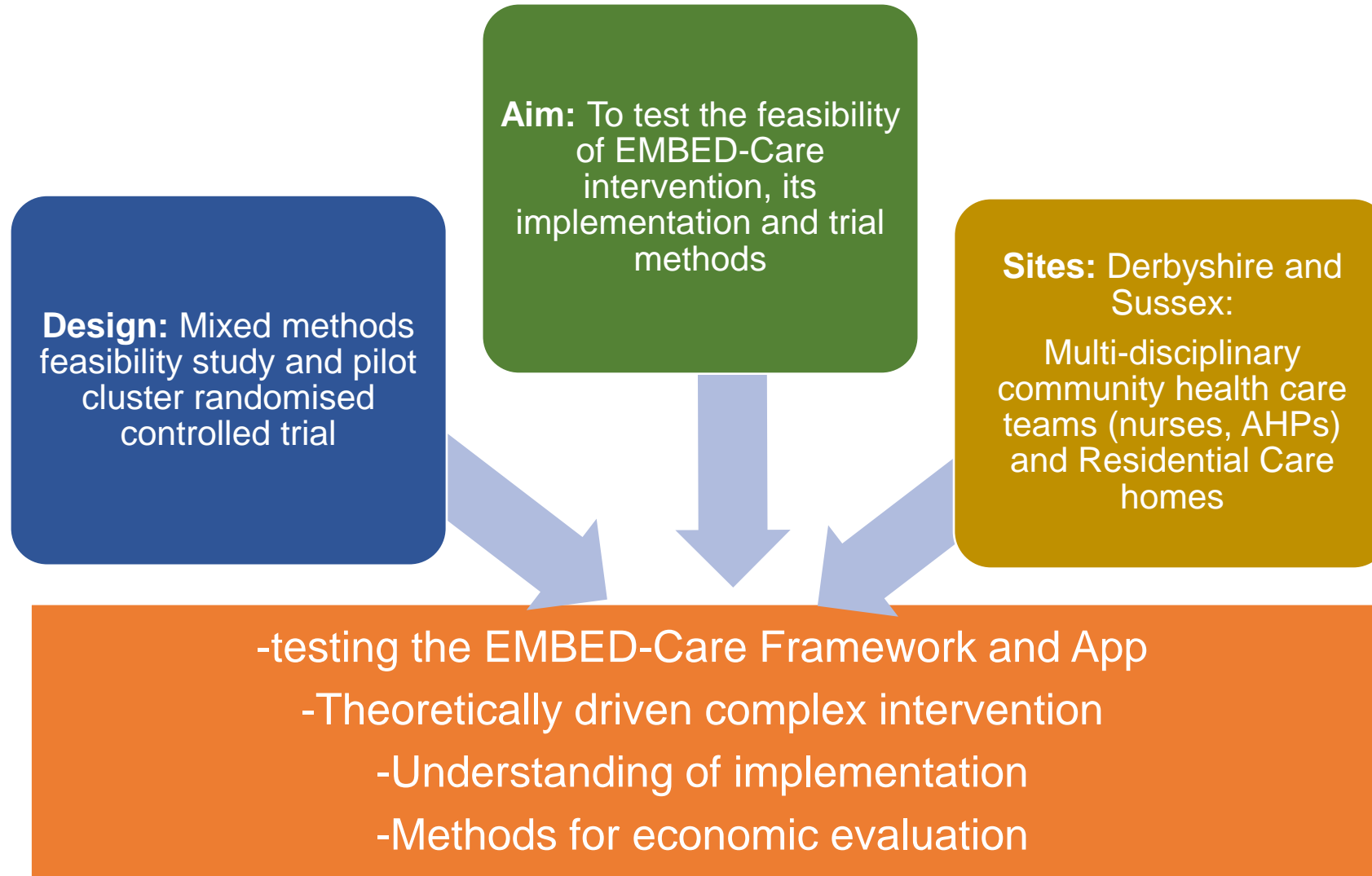
Gillam et al

Review

Implementation of eHealth to Support Assessment and Decision-making for Residents With Dementia in Long-term Care: Systematic Review

Juliet Gillam¹, BSc (Hons), MSc; Nathan Davies^{2,3}, BSc (Hons), MSc, PhD; Jesutofunmi Aworinde¹, BSc (Hons), MSc; Emel Yorganci¹, BSc, MSc; Janet E Anderson⁴, BBSoc, MPsych, PhD; Catherine Evans^{1,5}, BSc (Hons), MSc, PhD

Work Stream 6: EMBED-Care Framework and App feasibility evaluation and pilot testing. Dr Clare Ellis-Smith



EMBED-Care: Network for Excellence in Palliative Dementia Care

A Network for Excellence in Palliative Dementia Care

Email: dop.embedcare@ucl.ac.uk

Webpage: www.ucl.ac.uk/embed-care

EMBED-Care
Empowering Better End
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