



Sussex Community **NHS**  
NHS Foundation Trust



# Applying for NIHR Funding

**Cross-sector Partnerships for Palliative and  
End-of-life Care Research, 13<sup>th</sup> October 2022**

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# Overview: three elements

**Ask important questions  
'what makes a difference  
for patients and families'  
generated from priorities  
for patients/family, clinical  
care and policy**

**Outstanding  
multidisciplinary team  
with the expertise to  
deliver the research  
Outstanding environment  
with active patient and  
public involvement and  
research track record**

**Collaborative robust  
research with pathway  
to be truly impactful  
changing outcomes for  
patients and families**

# Element 1: Ask important question(s) and justify why

## Public priorities for people affected by serious illness



NIHR Palliative and End of Life Care Research Partnership for Northern Ireland

### Palliative and end of life care Top 10

1. What are the best ways of providing palliative care outside of working hours to avoid crises and help patients to stay in their place of choice? This includes symptom management, counselling and advice, GP visits and 24-hour support, for patients, carers and families.

### Teenage and Young Adult Cancer Top 10

1. What psychological support package improves psychological well-being, social functioning and mental health during and after treatment?

### Community Nursing Top 10

1. How can community nurse teams better meet the complex needs of patients with multiple health conditions?

<https://fundingawards.nihr.ac.uk/award/NIHR135291>



- Build research capacity in PEOLC
- Build sustained collaborative research programme on key areas of need in NI

# Partnership working to identify public priorities

## Used in Covid research to quickly gain missed views



### Reduced professional support

Anxieties around delays and disruptions

A need for clear and accessible information

Identifying inequalities and those most at-risk



### Risk of reduced quality of care

Fears around rationing of care

Concerns about communication of care preferences

Maintaining a holistic approach with diminished resources



### Strains on informal care networks

Increased responsibilities for informal carers

Fears around caring and risk of infection

Loss of informal care due to isolation measures



### Increased loss, grief and bereavement

Heightened risk of complicated grief

Providing sufficient bereavement support

Impact of societal grief on mental health

Johnson H, Brighton LJ, Clark J, Roberts H, Pocock L, Ogden M et al. Experiences, concerns, and priorities for palliative care research during the COVID-19 pandemic: A rapid virtual stakeholder consultation with people affected by serious illness in England. 2020. <https://doi.org/10.18742/pub01-034>

- **Palliative care echoes policy priorities:** integrated care, personalised care and support for unpaid carers
- **Condition specific** – multimorbidity, dementia
- **Context specific:** social care, community care
- **Population specific** –underserved by palliative care e.g. children and young people; racialised/ethnic groups

## ARTICLE

## Open Access



### Priorities and opportunities for palliative and end of life care in United Kingdom health policies: a national documentary analysis

Katherine E. Sleeman<sup>1\*</sup>, Anna Timms<sup>1</sup>, Juliet Gillam<sup>1,2</sup>, Janet E. Anderson<sup>3</sup>, Richard Harding<sup>1</sup>, Elizabeth L. Sampson<sup>4,5</sup> and Catherine J. Evans<sup>1,6</sup>

#### Abstract

**Background:** Access to high-quality palliative care is inadequate for most people living and dying with serious illness. Policies aimed at optimising delivery of palliative and end of life care are an important mechanism to improve quality of care for the dying. The extent to which palliative care is included in national health policies is unknown. We aimed to identify priorities and opportunities for palliative and end of life care in national health policies in the UK.

**Methods:** Documentary analysis consisting of 1) summative content analysis to describe the extent to which palliative and end of life care is referred to and/or prioritised in national health and social care policies, and 2) thematic analysis to explore health policy priorities that are opportunities to widen access to palliative and end of life care for people with serious illness. Relevant national policy documents were identified through web searches of key government and other organisations, and through expert consultation. Documents included were UK-wide or devolved (i.e. England, Scotland, Northern Ireland, Wales), health and social care government strategies published from 2010 onwards.

**Results:** Fifteen policy documents were included in the final analysis. Twelve referred to palliative or end of life care, but details about what should improve, or mechanisms to achieve this, were sparse. Policy priorities that are opportunities to widen palliative and end of life care access comprised three inter-related themes: (1) integrated care – con-



# Need for palliative dementia care is great and rising

BBC Your account News Sport Weather iPlayer Sounds

## NEWS

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### Health

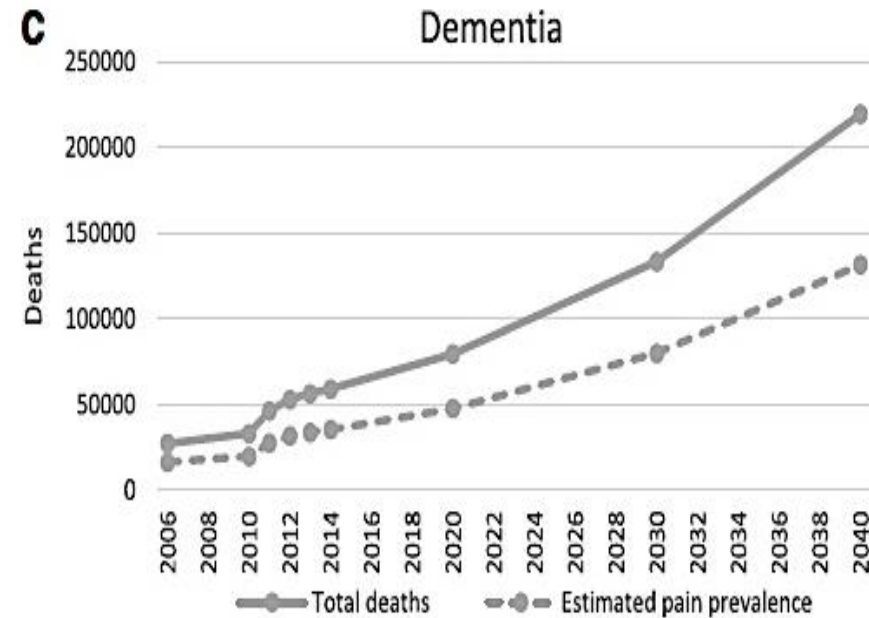
#### Dementia now leading cause of death

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*

# Element 1: Top-tips

1. Identify research priorit(ies) and justify from the perspectives of the public, policy and the evidence base - 'the gaps'
2. Identify the funding programme for your question and area
3. Know the funding guidance inside out
4. Understand what the fund funds, what are their priorities
5. Use the funder's language to show how your work amplifies the priorities

## Element 2: Outstanding multidisciplinary research team

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

Vincent Van Gogh





# Element 2: Outstanding multidisciplinary research team

## 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		

**EMBED-Care**  
Empowering Better End  
of Life Dementia Care



FUNDED BY

**NIHR**

National Institute  
for Health Research

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ECONOMIC  
& SOCIAL  
RESEARCH  
COUNCIL

UK Research  
and Innovation

**UCL**

Celebrating 20 years  
of our UCL palliative care research department

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Cicely Saunders  
International  
Better care at the end of life

# Element 2: Outstanding environment for meaningful public and community involvement

**Inclusive and diverse public and community involvement that moves beyond consulting to collaboration and partnership working**



**Better public involvement for better health and social care research**



[Find](#)



## About Inclusive Involvement

Involvement activities enable people to have a say in policies and services that affect their lives. It can mean sharing experiences of using services, of being part of a diverse community or of having an impairment or long-term health condition.

However, not everyone has an equal chance to be involved. Inclusive involvement is about positively enabling people from marginalized communities to be heard.

[Get help to Involve Users in your Organisation](#)

[Get help to Take Part in Involvement Activities](#)

[Find current Involvement Opportunities!](#)



# Element 2: Build sustainable environment for meaningful public and community involvement



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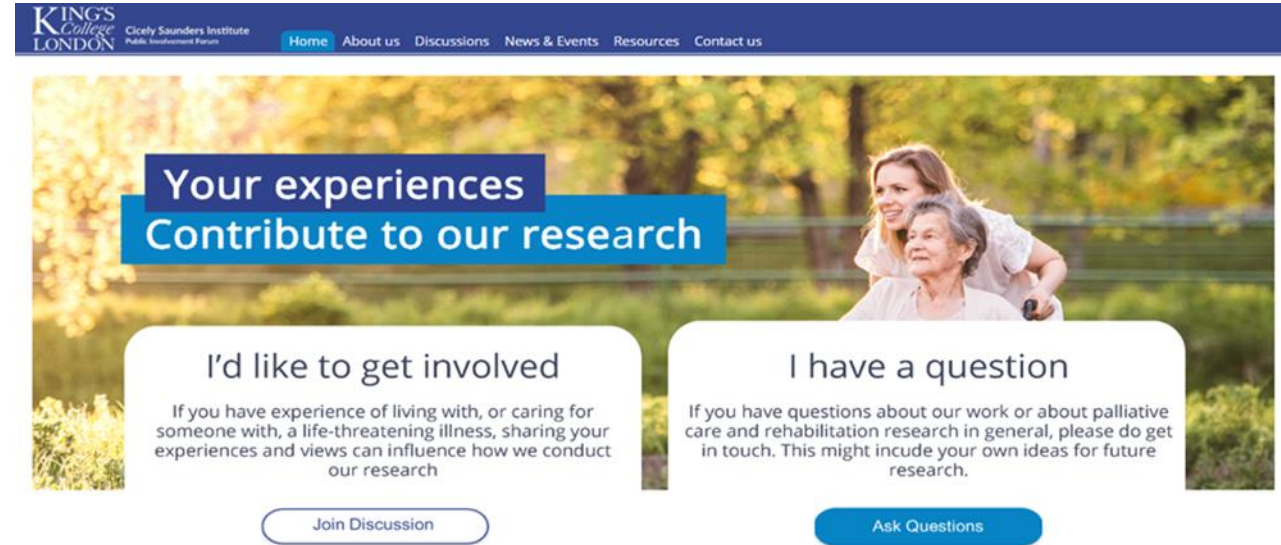
## Cicely Saunders Institute Public Involvement Strategy

January 2021 – December 2023

This strategy outlines our ambition, principles and goals for public involvement at the Cicely Saunders's Institute over the next three years. It details what we want to achieve, how we will deliver these and how we will evaluate our impact.

This strategy document was put together by our Strategy Development Team, made up of CSI staff and public members\* (in alphabetical order):

Lisa Brighton, Catherine Evans, Juliet Gillam, Halle Johnson, Rashmi Kumar\*, Margaret Ogden\*, Pam Smith\*, Marion Sumerfield\*, India Tunnard



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Cicely Saunders Institute  
Public Involvement Forum

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## Your experiences Contribute to our research

**I'd like to get involved**  
If you have experience of living with, or caring for someone with, a life-threatening illness, sharing your experiences and views can influence how we conduct our research

**I have a question**  
If you have questions about our work or about palliative care and rehabilitation research in general, please do get in touch. This might include your own ideas for future research.

Join Discussion Ask Questions

1. Build trusting collaborative community partnerships
2. Inclusive and diverse
3. Support and learning for public contributors, like 'peer buddies'
4. Resources - how evaluate impact

[www.csipublicinvolvement.co.uk](http://www.csipublicinvolvement.co.uk)



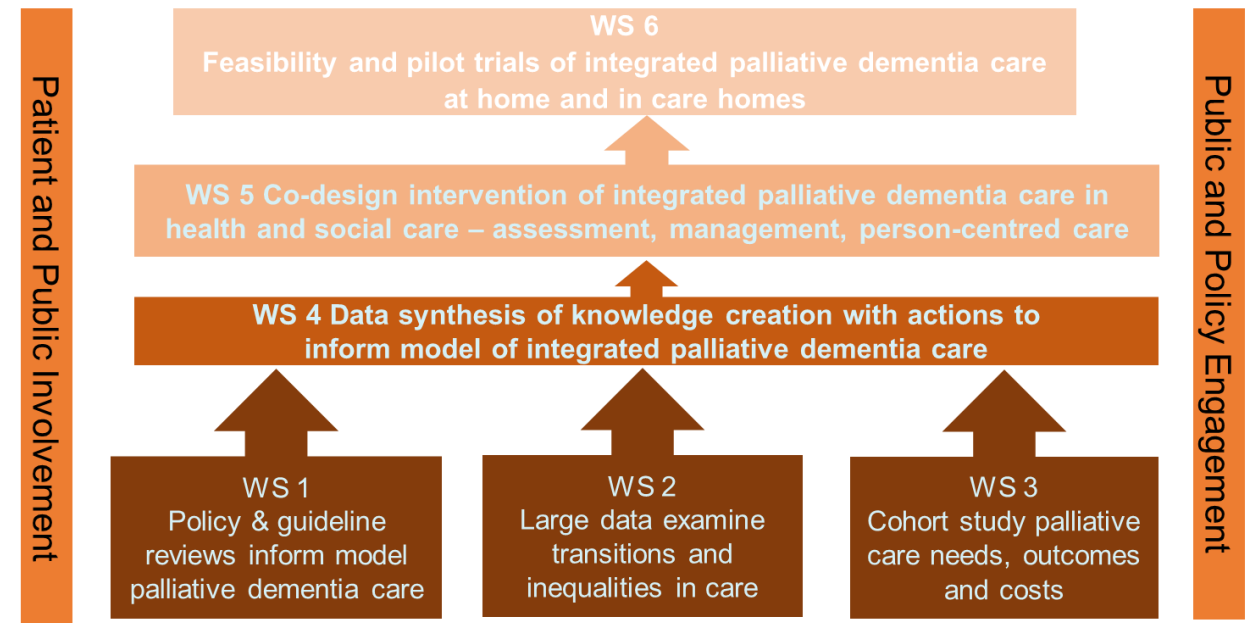
# Element 3: Collaborative robust research

**Study design:** is a coherent robust 'story' to deliver the statement aim

**Methods:** vital bricks that clearly fit together to form a whole

**Applied and accessible concepts and technical terms:** clear rationale for how and why using

Aim to lever a **step-change in palliative dementia care**, generating new knowledge and model of integrated care



--Network for Excellence in Palliative Dementia Care--

*Sampson et al. EMBED-care protocol. Int J Geriatric Psychiatry 2019*

**EMBED-Care**  
Empowering Better End of Life Dementia Care

# Element 3: Pathways to be truly impactful on patient care and outcomes, and policy

**PATHWAYS TO IMPACT:** a visionary and novel programme of **public and policy engagement** targeting different sections of society to maximise knowledge exchange.

## Impact & Engagement Facilities



Celebrating 20 years  
of our UCL palliative care research department



## Change the conversation

- YouGov Survey ✓
- Digital content ✓
- Co-creation workshop
- Art installation
- Public workshops x 3
- Public debate
- Social media campaign
- Public engagement consultants guide and evaluate ✓

## Impact on policy & practice

- Policy Summit ✓
- Parliamentary engagement ✓
- Knowledge exchanges ✓
- Academic conferences ✓
- Project ECHO superhub
- Industry conferences

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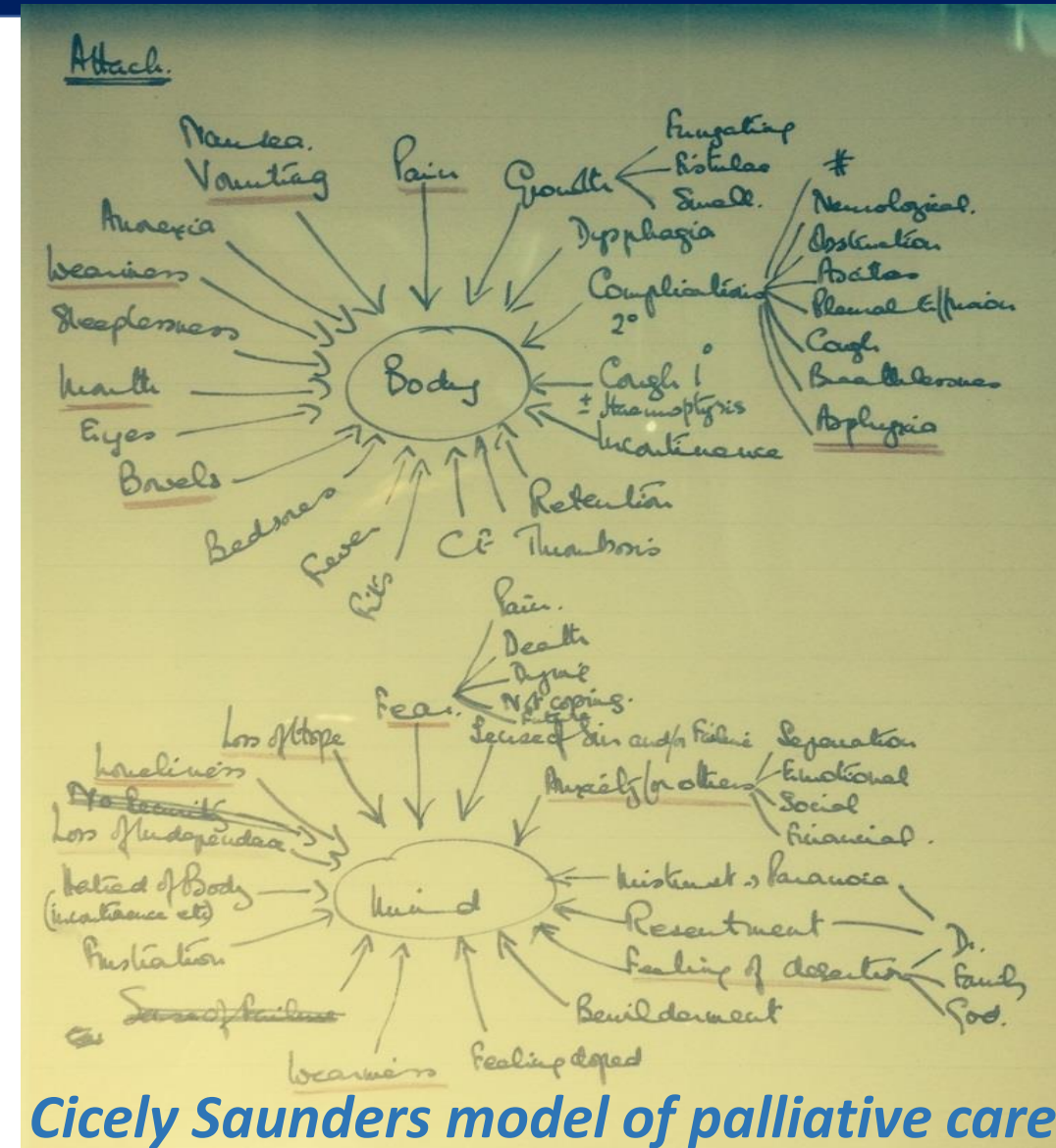
# Top-tips for applying for research funding

- **Build programmes of research and clearly message leaders/strengths** in the research area with track record e.g. publications, grants, impact
- **Clear strong vision on the research intention and why important from multiple perspectives** (Public | Policy | Evidence). Clear what doing, why and how
- **Build strong collaborations to connect with resources, expertise and sites**
- **Identify and use research resources; there are lots!** Funder guidance and reports on funded studies; NIHR infrastructures (RDS, ARCs, NIHR Schools) and resources (e.g. PPI); HEI infrastructures – costing, big grants, policy engagement....etc
- **Build research capacity | Create opportunities:** Early Career Researchers co-PI/co-lead workstream with senior researcher oversee scientific rigour. Co-apps to build expertise and integrate clinical care and research (post-docs, clinicians). Opportunities for PGR.
- **Pathways of impact** to truly engage the public to change the conversation and policy makers to construct evidence-based policy
- **Build sustainable infrastructure for public and community involvement in palliative care research**

# Take Home Messages

- Palliative care is central to the future of health and care, & understands the multimorbid population
- Put PPI at the centre; people want this
- Use the right tools – measures, methods and expertise to deliver the research and impact
- Emphasis on dissemination and impact
- Innovate, understand and evaluate
- Build research capacity, skills, infrastructure, and collaborations

*Our science is the science that puts the person before their disease and considers mind and body*



*Cicely Saunders model of palliative care*



# Thank you...

**Reach for the stars and realise policy ambition to strengthen integration of palliative care in all health and care services for people affected by serious illness from childhood to adulthood**

## Further information

[www.ucl.ac.uk/embed-care](http://www.ucl.ac.uk/embed-care)

[dop.embedcare@ucl.ac.uk](mailto:dop.embedcare@ucl.ac.uk)

**EMBED-Care**

Empowering Better End  
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