



# PALLDEM-Homecare

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**Homecare workers providing end-of-life care for people with dementia**

Lesley Williamson, NIHR Dementia Research Fellow

Home Care Research Forum, September 2025

#PALLDEMhomecare #WorldAlzheimersMonth

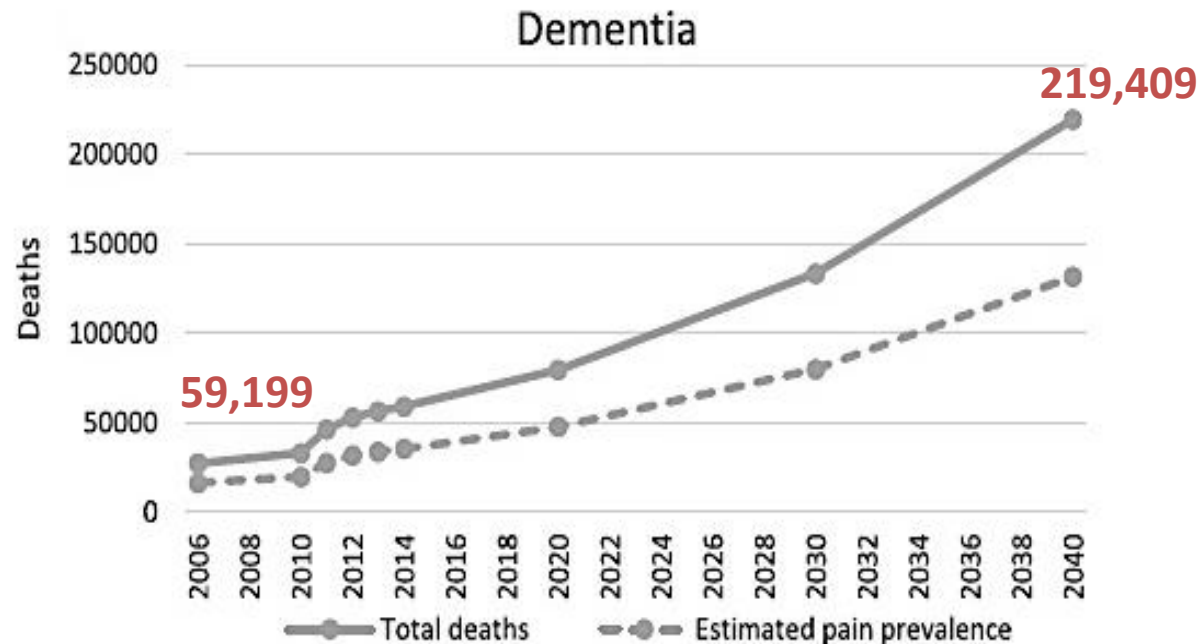
**Is dementia a terminal condition?**



58%

of the public do not know  
dementia is a terminal condition

# What is the problem?



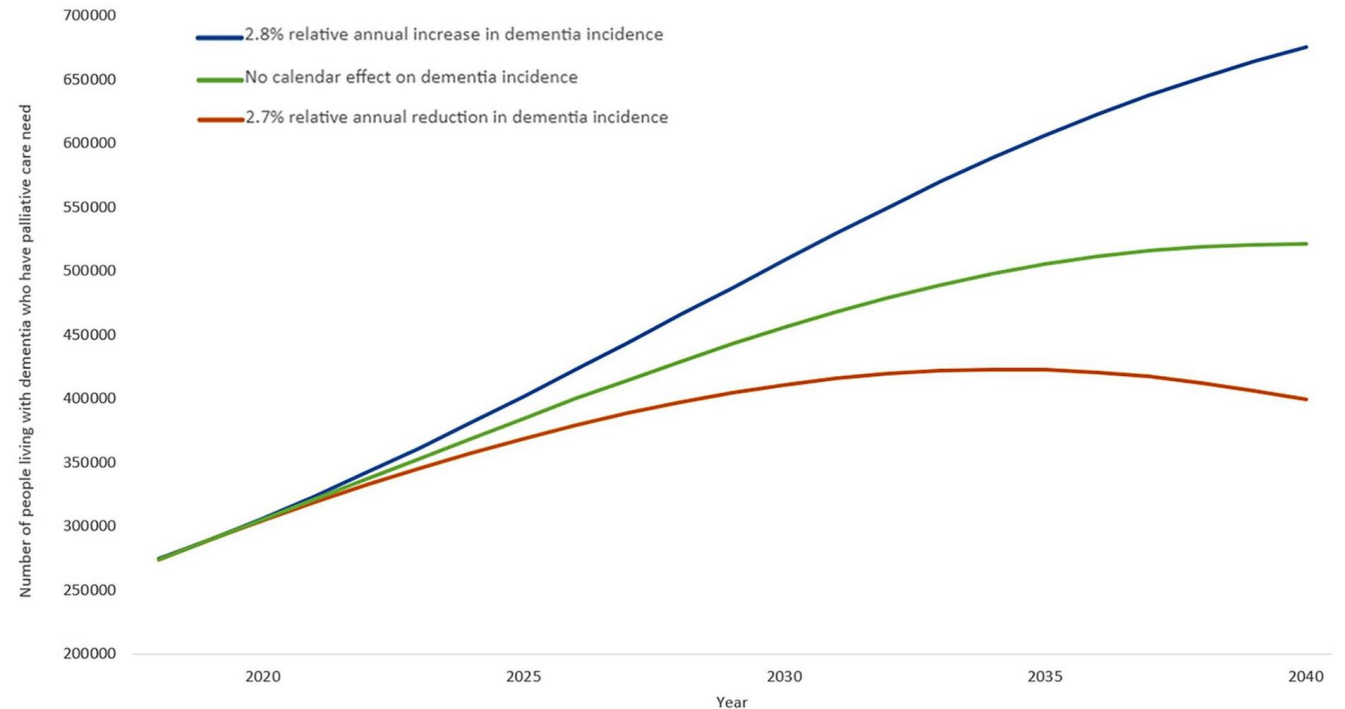
**Fig 2:** Number of people with dementia estimated to require palliative care from 2006 to 2040

(Solid lines represent total estimate, Dotted lines represent estimates of pain prevalence)

# What is the problem?

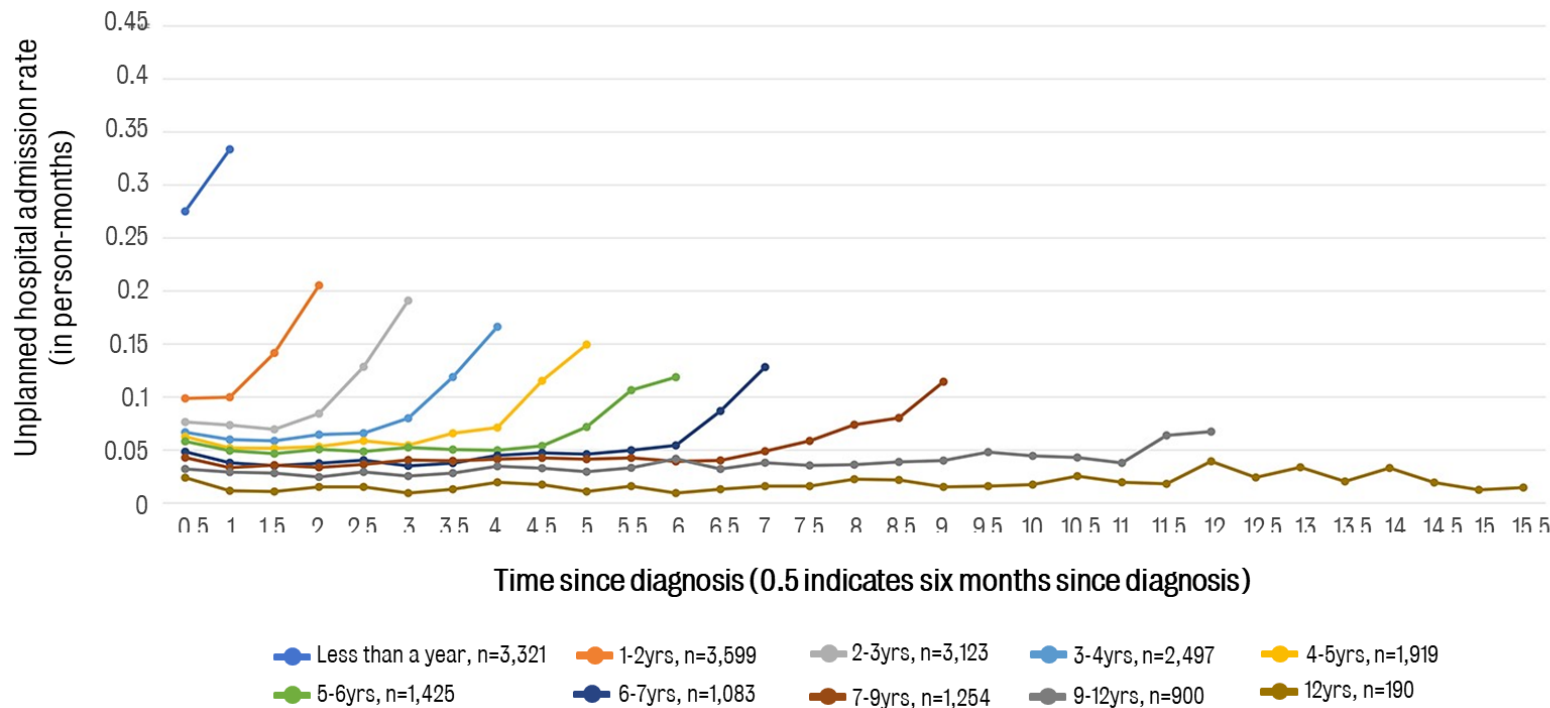


- 40% would benefit from palliative care<sup>1</sup>
- Projected to increase substantially by 2040<sup>2</sup>



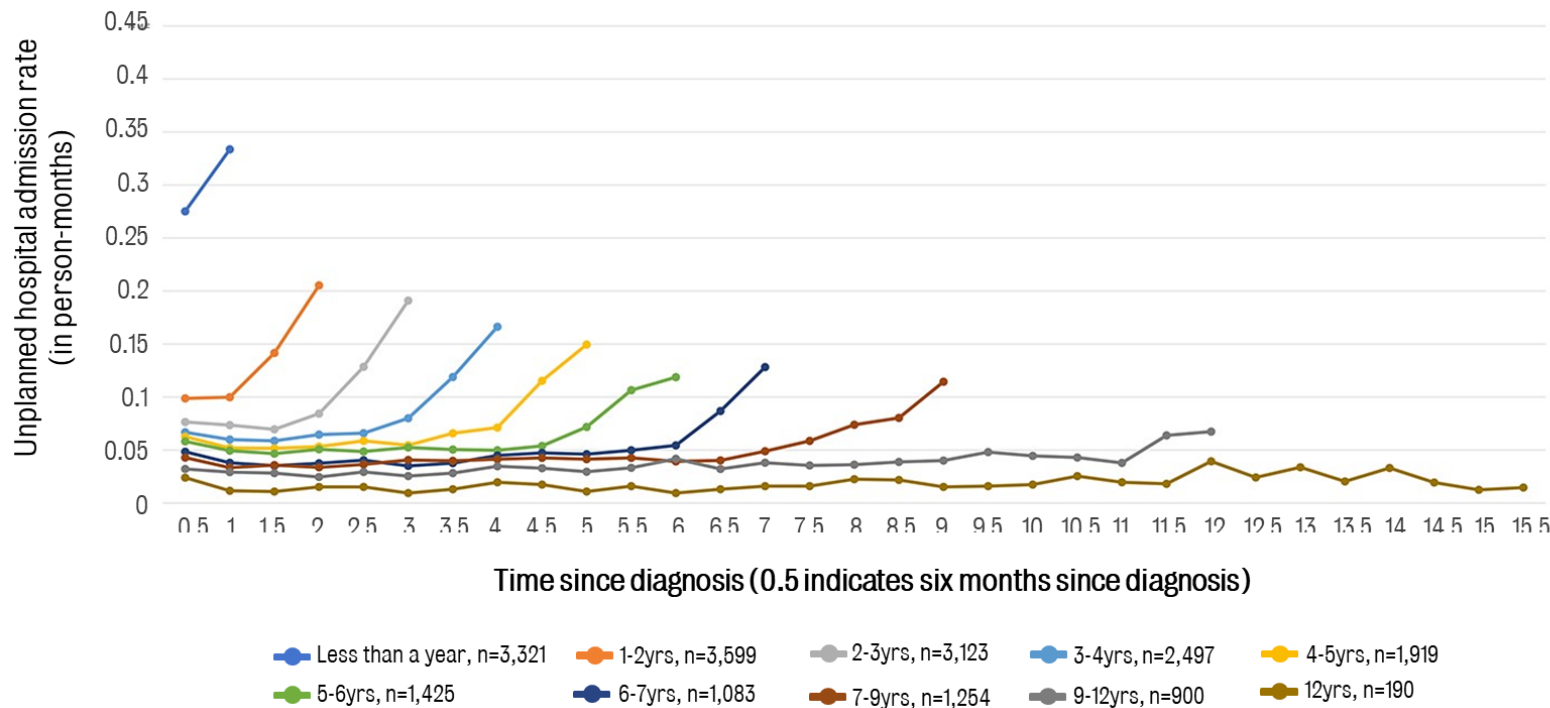
**Fig 1:** The projected number of people living with dementia in England and Wales who have palliative care need<sup>2</sup>

# What is the problem?



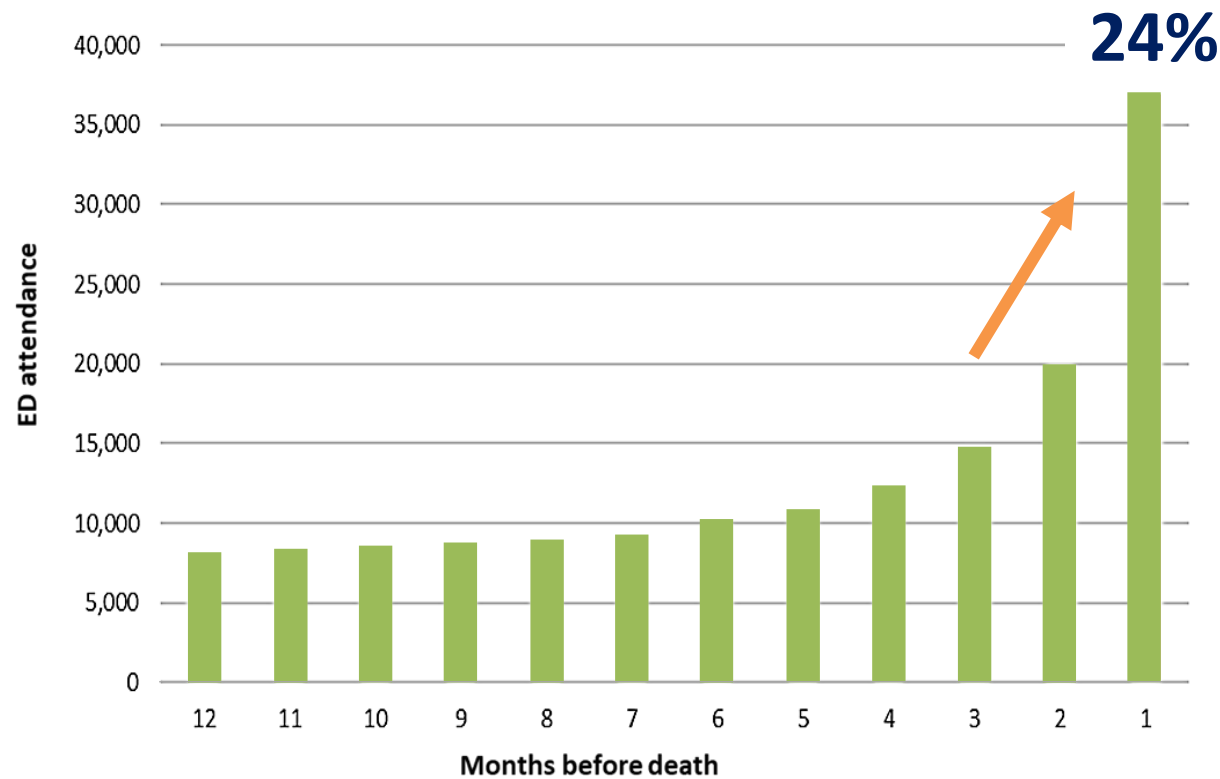
**Fig 4:** Unplanned hospital admission rates for people who died with dementia (n = 12,667) by duration of survival after diagnosis

# What is the problem?



**20%**  
last six months  
of life in hospital

# What is the problem?

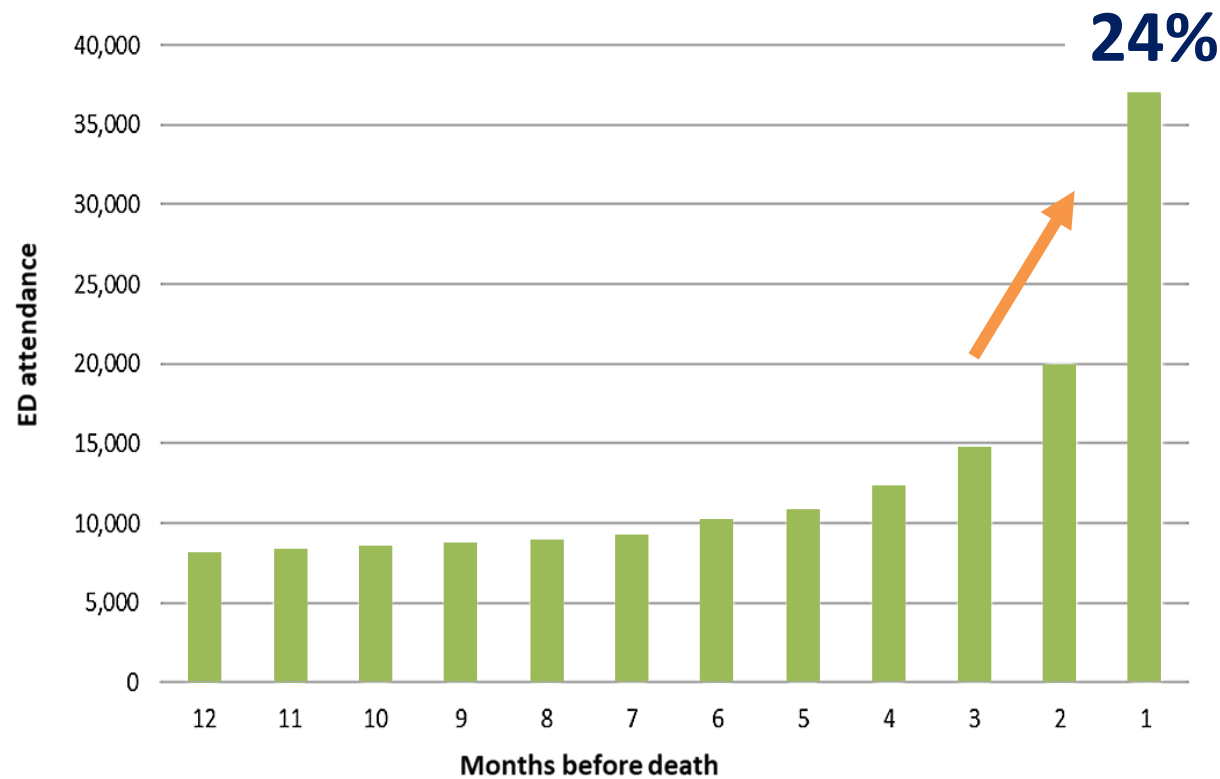


**Fig 5:** The number of emergency department attendances in the last year of life among people with dementia

(n=154,508 ED visits)



# What is the problem?



**83%**  
will visit the ED in  
the last year of life

# What is the problem?



*"Hospital isn't any place for someone with dementia. We need to be in our own environment.*

*...because you go in the hospital, you don't come out at the same level as you were when you went in. I have seen it with so, so many of my friends.*

*Just the noise, the lack of routine, lack of knowledge, lack of understanding, makes it just an alien environment."*

Person with dementia



# What is the problem?



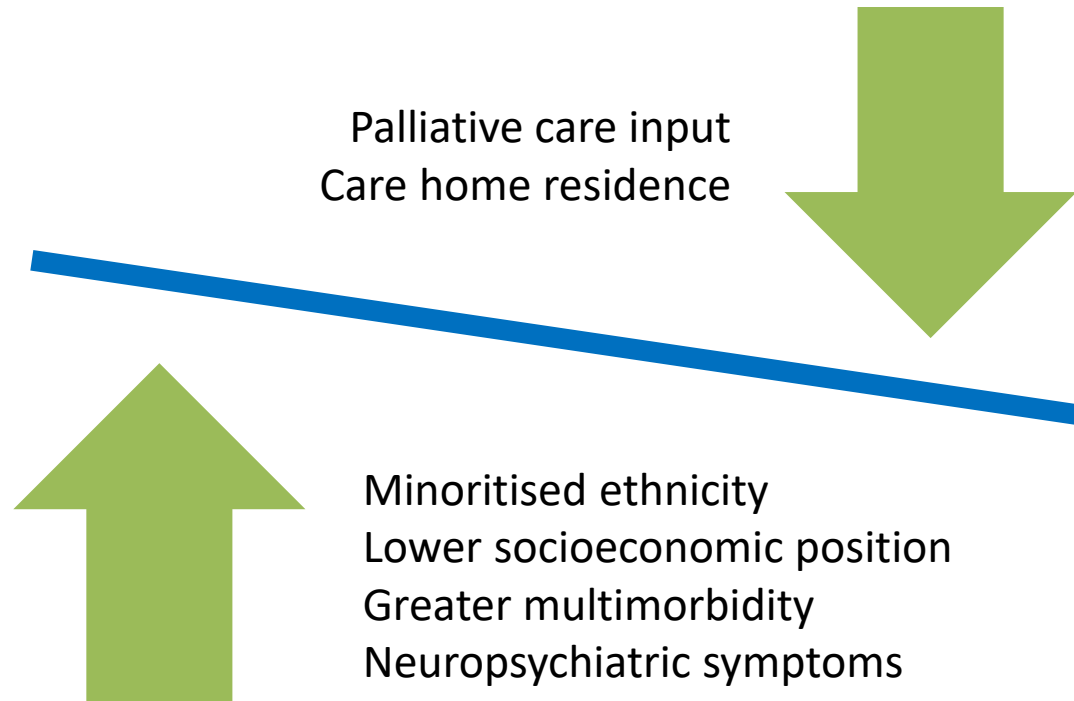
*"...we were [in the emergency department] all day basically, waiting around for this, that and the other... we had nothing to eat, nothing to drink.*

*...I just remember it as a totally miserable day, when there was nobody, nobody sort of taking care of us."*

Bereaved caregiver



# What is the problem?



**Fig 1:** Factors associated with the likelihood of attending the emergency department towards the end of life

# What is the problem?




- 90,000 people with dementia live at home and receive formal social care<sup>1</sup>
- Including homecare workers
- **Under-supported, under-trained and under-appreciated<sup>2</sup>**

## Specific challenges:

- Limited information<sup>3</sup>
- Role ambiguity<sup>3</sup>
- Negotiating family expectations<sup>4</sup>
- Disempowered to advocate for their clients<sup>4</sup>

# What could help?






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	Over-whelmingly	Cannot assess
Pain	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/>
Shortness of breath	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/>
Weakness or lack of energy	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/>
Nausea (feeling like being sick/vomiting)	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/>
Vomiting (being sick)	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/>
Poor appetite	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/>
Constipation	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/>
Dental problems or problems with dentures	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/>
Sore or dry mouth	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/>
Drowsiness (sleepiness)	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/>
Poor mobility (trouble walking, cannot leave bed, falling)	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/>

WHO Collaborating Centre for Palliative Care, Policy and Rehabilitation




- Integrated Palliative care Outcome Scale for Dementia (IPOS-Dem)<sup>1</sup>
- Holistic assessment of needs and concerns
- Physical, psychological, social and spiritual
- Acceptable in care homes<sup>1,2</sup>
- Facilitates best practice in delivering person-centred care

<sup>1</sup>Ellis-Smith *et al.*, 2017; Gillam *et al.*, 2023


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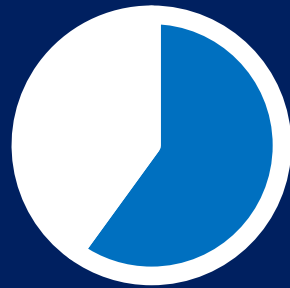
WHO Collaborating Centre for Palliative Care, Policy and Rehabilitation 

## Specific challenges:

- ✓ Provides more information
- ✓ Informs person-centred care
- ✓ Facilitates shared decision-making<sup>1</sup>
- ✓ Promotes communication between practitioners<sup>2</sup>



**How many innovations fail  
in health and social care?**



**60%**  
on average

# PALLDEM-Homecare



**Aim:** To explore, as a proof of concept, the *implementation* of the IPOS-Dem in homecare settings.

## Objectives:

1. To test the implementation of the IPOS-Dem by homecare workers
2. To garner support for homecare workers providing end-of-life care to people with dementia



# PALLDEM-Homecare



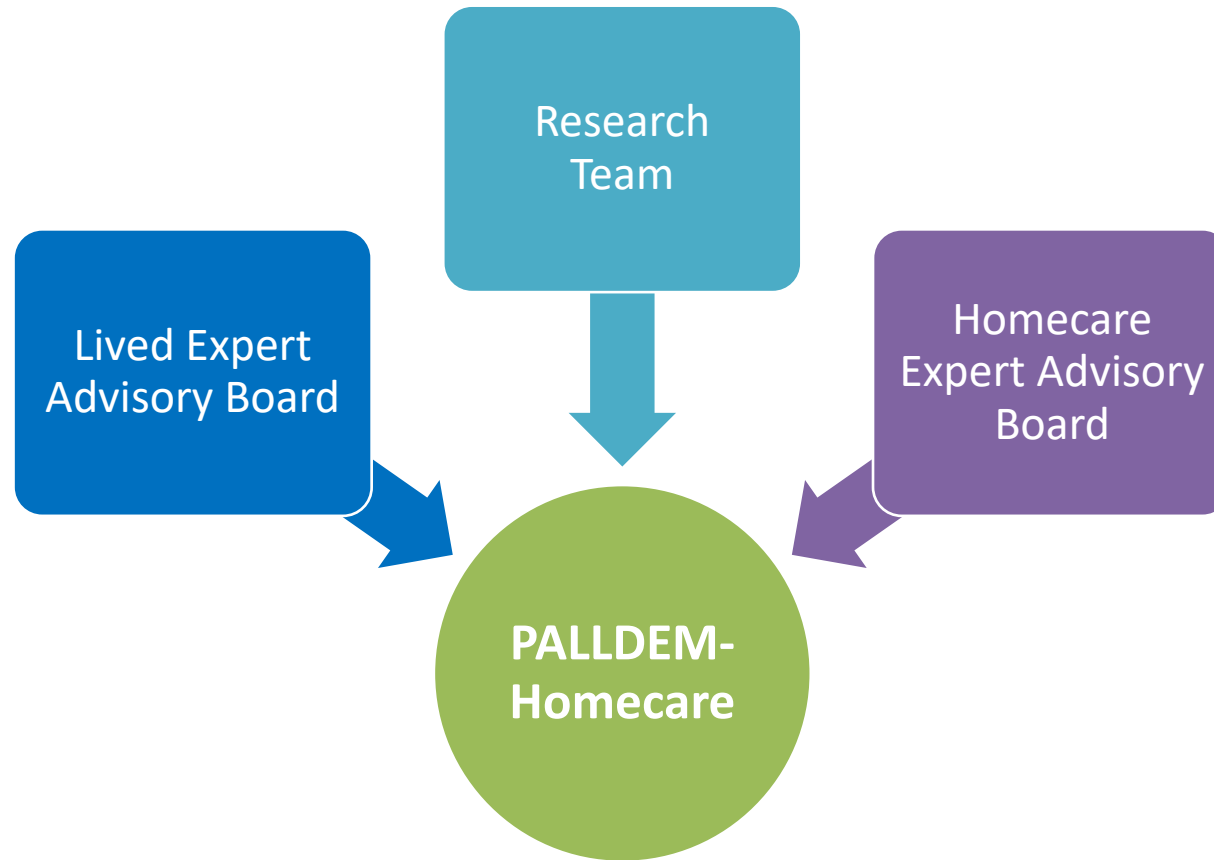
**WORKSTREAM 1:**  
Implementation planning



**WORKSTREAM 2:**  
Implementation testing

**WORKSTREAM 3:**  
Stakeholder engagement

# PALLDEM-Homecare



**What have we done so far?**

# What have we done so far?

PRELIMINARY



- Scoping review – *in progress*
- **Objectives:** To find out what evidence there is on:
  - 1) interventions to support homecare workers provide palliative and end-of-life care
  - 2) the contextual factors that may affect whether an intervention is used or not

# What have we done so far?



PRELIMINARY

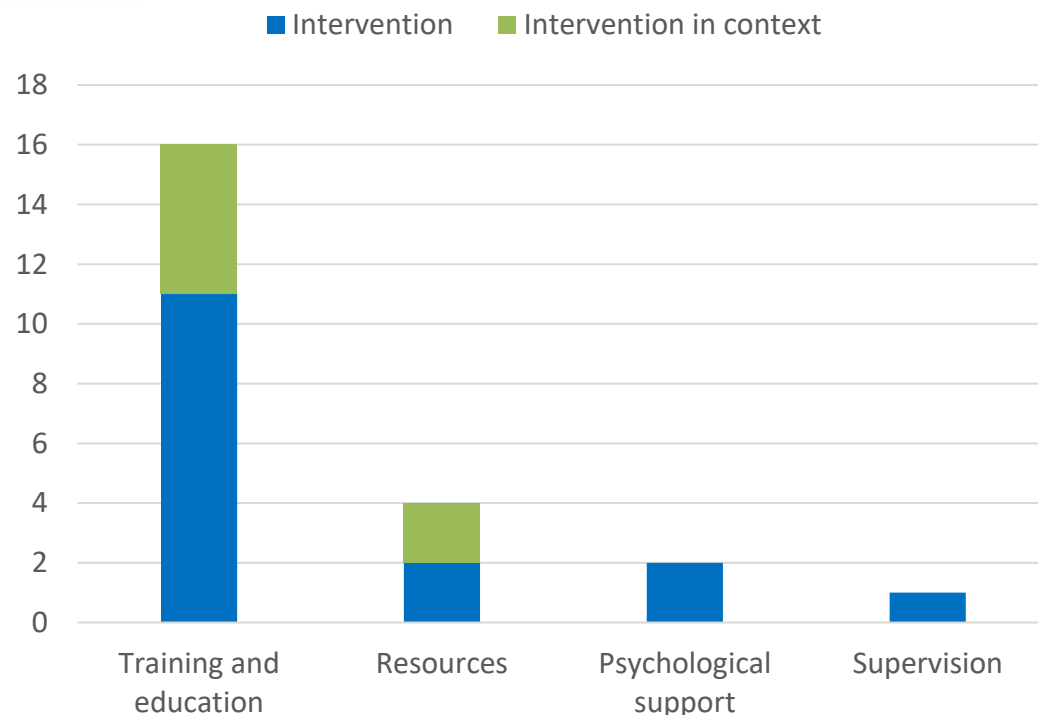


Fig 1: Intervention types (n=22)

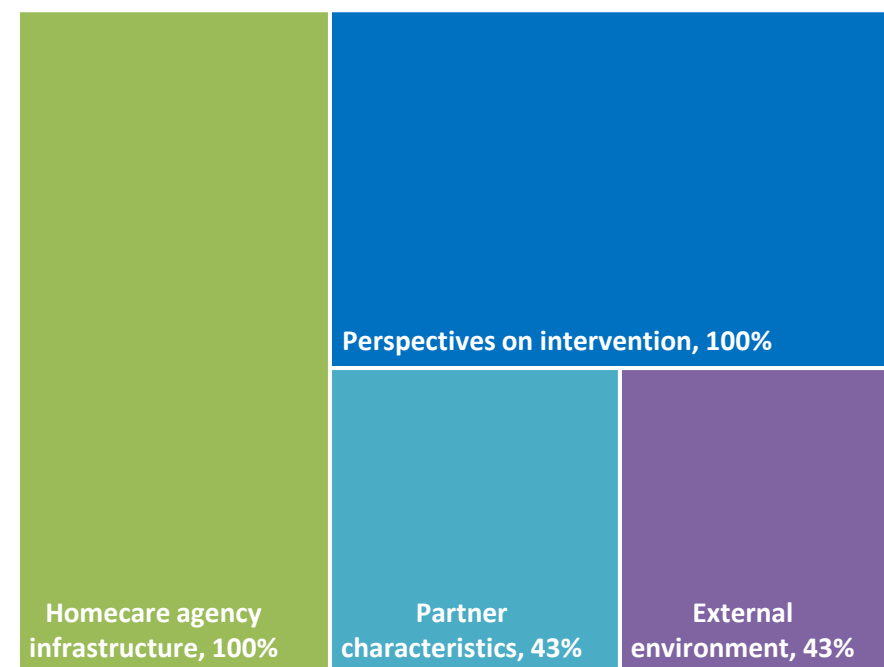


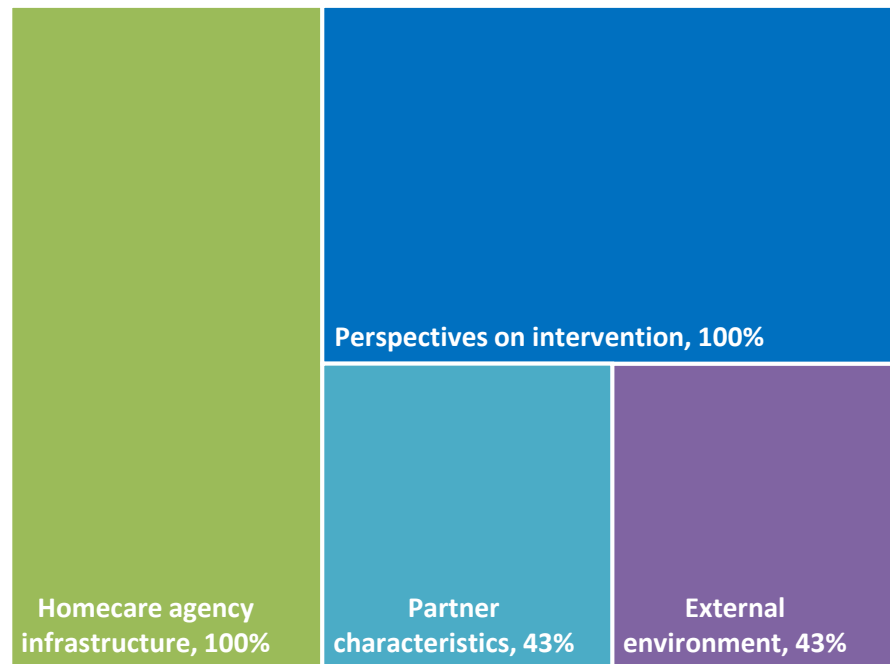
Fig 2: PRISM domains (% of papers; n=7)



# What have we done so far?



PRELIMINARY

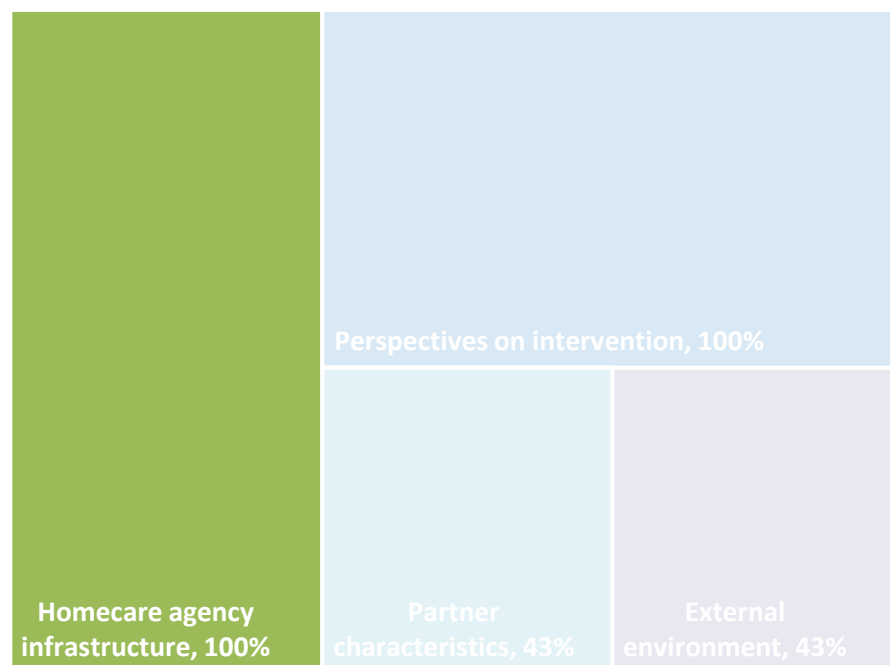


**Fig 2:** PRISM domains (% of papers;  $n=7$ )

# What have we done so far?



PRELIMINARY



**Fig 2:** PRISM domains (% of papers;  $n=7$ )

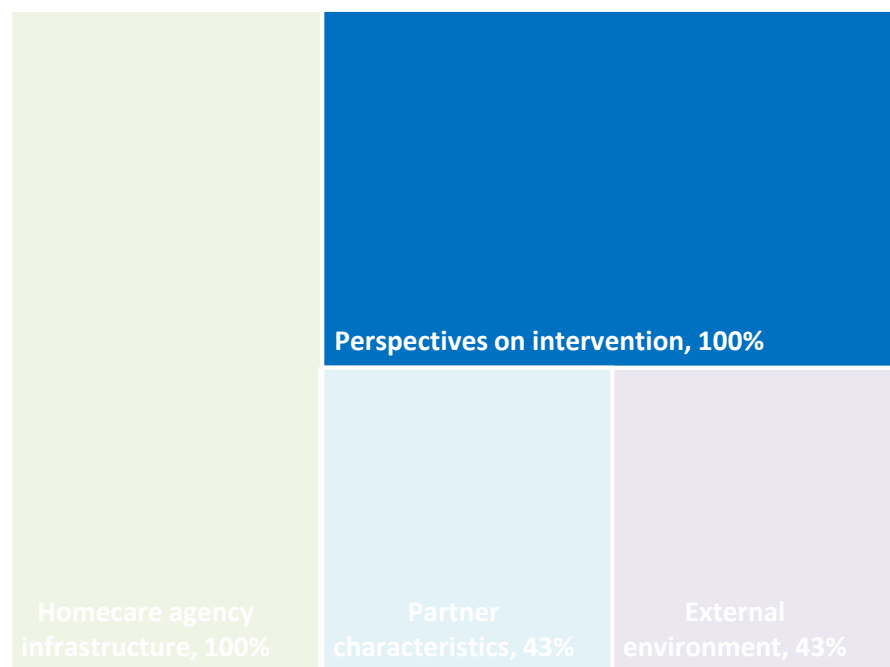
## Homecare agency infrastructure:

- Culture (learning and staff development)
- Procedures (multi-agency working, peer support)
- Need for resources (scripts, checklists)
- Workforce (workload, shift patterns, turnover, inconsistent management, limited role flexibility)

# What have we done so far?



PRELIMINARY



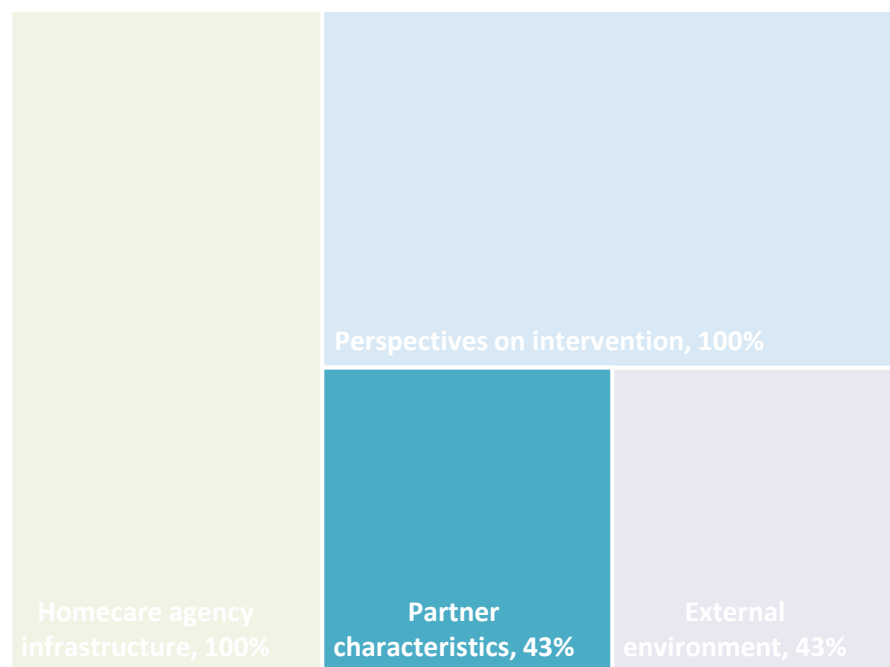
**Fig 2:** PRISM domains (% of papers;  $n=7$ )

## Perspectives on intervention:

- Homecare workers:
  - Risk of added burden of work
  - Positive features (feasible, relevance to role, engaging with other professionals)
  - Differences between homecare workers
- Clients:
  - Positive; more support
  - Careful messaging

# What have we done so far?

PRELIMINARY



**Fig 2:** PRISM domains (% of papers;  $n=7$ )



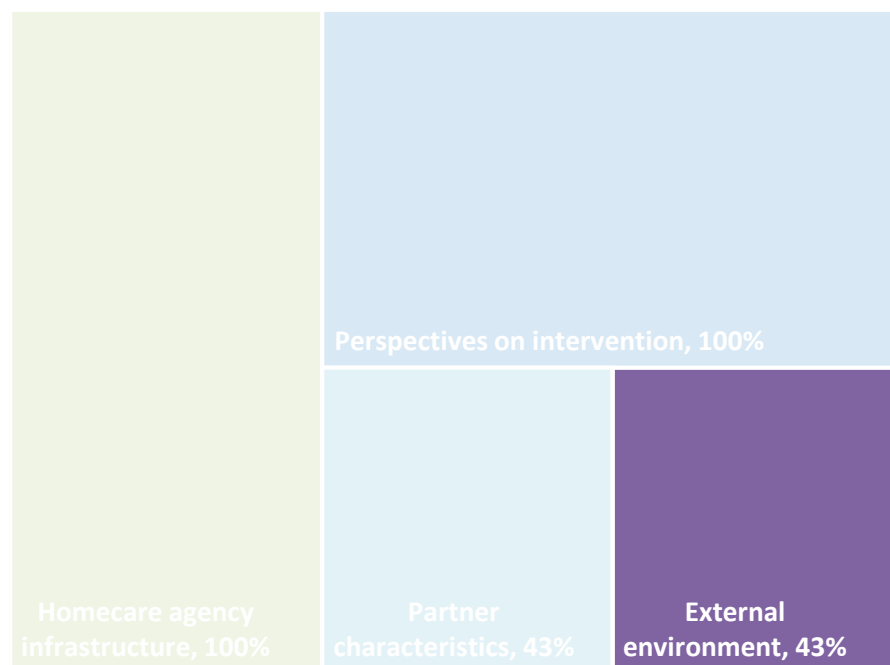
## Partner characteristics:

- Homecare workers:
  - Job satisfaction, stress or burnout
  - Previous educational experience
  - Differences between homecare workers
- Homecare managers:
  - Supportive
- Clients:
  - Medical conditions
  - Cultural differences

# What have we done so far?



PRELIMINARY



**Fig 2:** PRISM domains (% of papers;  $n=7$ )

## External environment:

- General financial and staffing constraints
- Limited accredited training
- Limited scope of practice

# What have we done so far?



**PRELIMINARY**

## Limited evidence on how we can implement interventions to support homecare workers:

- External environment
- Characteristics of managers and families
- Perspectives of managers, clients and families

## What we do know:

- Tailor to different levels of experience and expertise among homecare workers
- Clear messaging about relevance, feasibility and purpose – mitigate burden
- Clear messaging for clients and families
- Prepare for limited infrastructure and availability of staff to engage

**What's next?**

# You're invited to join us!



- **Homecare Expert Advisory Board:** 2 homecare workers to join the Board (4hrs over 2yrs; £40 gift)
- **Workshops:** Express interest (not yet open to recruitment)
- **Implementation trial:** Express interest (not yet open to recruitment)
- **Engagement opportunities:** Support activities and events, in any way you choose (e.g. webinars, short articles, blogs, talking heads, public outreach events, etc.)



***Interested to know more or just stay connected?***

Email: [Lesley.Williamson@kcl.ac.uk](mailto:Lesley.Williamson@kcl.ac.uk)





# Acknowledgements



- **Funders**, Marie Curie and Alzheimer's Society (Grant Ref. MC-24-017)
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- **Co-applicants**, Ms Mair Graham, Dr Clare Ellis-Smith, Dr Abigail Burgess, Dr Monica Leverton, and Professor Katherine Sleeman
- **Other colleagues**: Dr Emel Yorganci, Dr Cat Forward



# PALLDEM-Homecare

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THANKS FOR LISTENING

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#PALLDEMhomecare



# IMPACT CENTRE FOR PALLIATIVE AND END OF LIFE CARE

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Cicely Saunders  
International  
Better care at the end of life

KING'S  
College  
LONDON

- Aims to improve outcomes for people affected by dying, death and bereavement by **bridging the gap between evidence and practice**.
- Survey to understand the **current needs, challenges and priorities** across the health and social care system.
- Need to hear from **social care practitioners** to understand how the Impact Centre can best support the sector in providing palliative and end-of-life care.
- For more information on Impact Centre:  
<https://shorturl.at/TQVKI>



**ACCESS SURVEY**  
(<https://shorturl.at/4pr5J>)