



Welcome to the Research Forum 2022

Thursday, 31st March 2022 at thestudio, Leeds

[#LYPFTResearch22](#)



Time	Programme item	Presented by
08:30	Registration and refreshments	
09:15	Welcome	Max Henderson, LYPFT
	Session Chair: Dr Max Henderson, LYPFT	
09:30	<i>Community-based Behavioural Activation Training (ComBAT) for Depression in Adolescents</i>	Lucy Tindall and Emily Hayward, University of York
10:00	<i>The latest outputs from COMIC (Child Orientated Mental Health Intervention Centre)</i>	Ellen Kingsley, Megan Garside, Eleni Tsappis and Amelia Taylor, COMIC at LYPFT
10:30	<i>Fresh Start - Seeking to improve the support offered by the NHS, to people who self-harm.</i>	Max Henderson, Mat Harrison, Else Guthrie, LYPFT and Nav Kapur, University of Manchester
11:00	Break (and poster viewing)	
	Session Chair: Sarah Cooper, LYPFT	
11:15	<i>Why Mental Health staff should get involved in research</i>	Wendy Burn, LYPFT
11:45	<i>Parkinson's study</i>	George Crowther, LYPFT
12:00	Lunch (and poster voting)	

Time	Programme item	Presented by
	Session Chair: Dr George Crowther, LYPFT	
13:00	<i>New psychosocial intervention to support Independence in Dementia (NIDUS) programme: an update on our NIDUS-family and NIDUS-professional trials</i>	Claudia Cooper, University College London
13:30	<i>Empowering Better End of Life Dementia Care (EMBED-Care) programme: what we have learnt so far</i>	Professor Liz Sampson, East London NHS Foundation Trust
14:00	Workshops	
	<i>Workshop 1 Involving patients and public in research</i>	Chaired by Charlie Rust, LYPFT
	<i>Workshop 2 Embedding research into your career development</i>	Chaired by George Crowther, LYPFT
	<i>Workshop 3 Optimising recruitment</i>	Chaired by Sarah Cooper, LYPFT
14:45	Closing remarks	Sarah Cooper, Head of R&D



***New psychosocial intervention to support
Independence in Dementia (NIDUS) programme:
an update on our NIDUS-family and NIDUS-
professional trials***

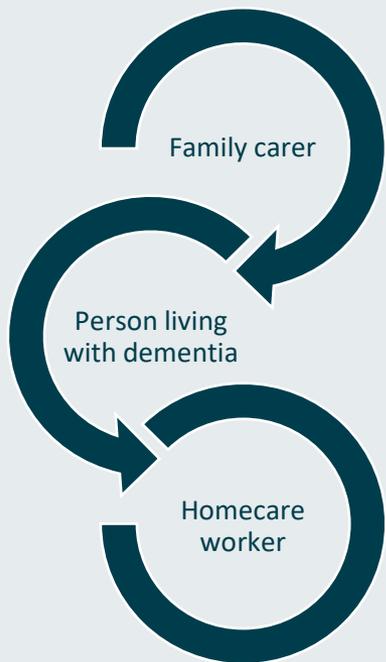
Presented by

Claudia Cooper, University College London



Supporting independence at home for people with dementia (NIDUS-Family)





NIDUS-family

NIDUS-professional

NIDUS-Family Road Map

1. We built an evidence base...



Planning and enabling meaningful patient and public involvement in dementia research

Alexandra Burton^a, Margaret Ogden^b, and Claudia Cooper^a

2. ...used it (with our PPI group lived and clinical experience) to co-produce NIDUS-family (Sept 2018 - Jan 2019)

3 ... piloted it (June 2019 – January 2020)

4. ...and are testing it in a large trial of 297 dyads (April 2020 – April 2023)

5. Putting it into practice

Our implementation group is meeting to think about how, if it works, we will ensure it is used.



NIDUS-FAMILY INTERVENTION MODEL: Description of intervention

SESSION TEMPLATE



Module	Plan ahead	Communicate	Behaviour	Physical health	Physical activity	Mood	Carer wellbeing	Managing at home	Relaxation	Sleep & diet
Psycho-education & signposting										
Communication skills										
Behavioural management (DICE)										
Behavioural activation										
Enabling										
CBT self-help										
Relaxation										

Pre-session:
Set 3-5 goals



Session 1:
Refine goals



Next 4-6 sessions:

Pick topic for each session and make plans to try out in between
Review progress on plans



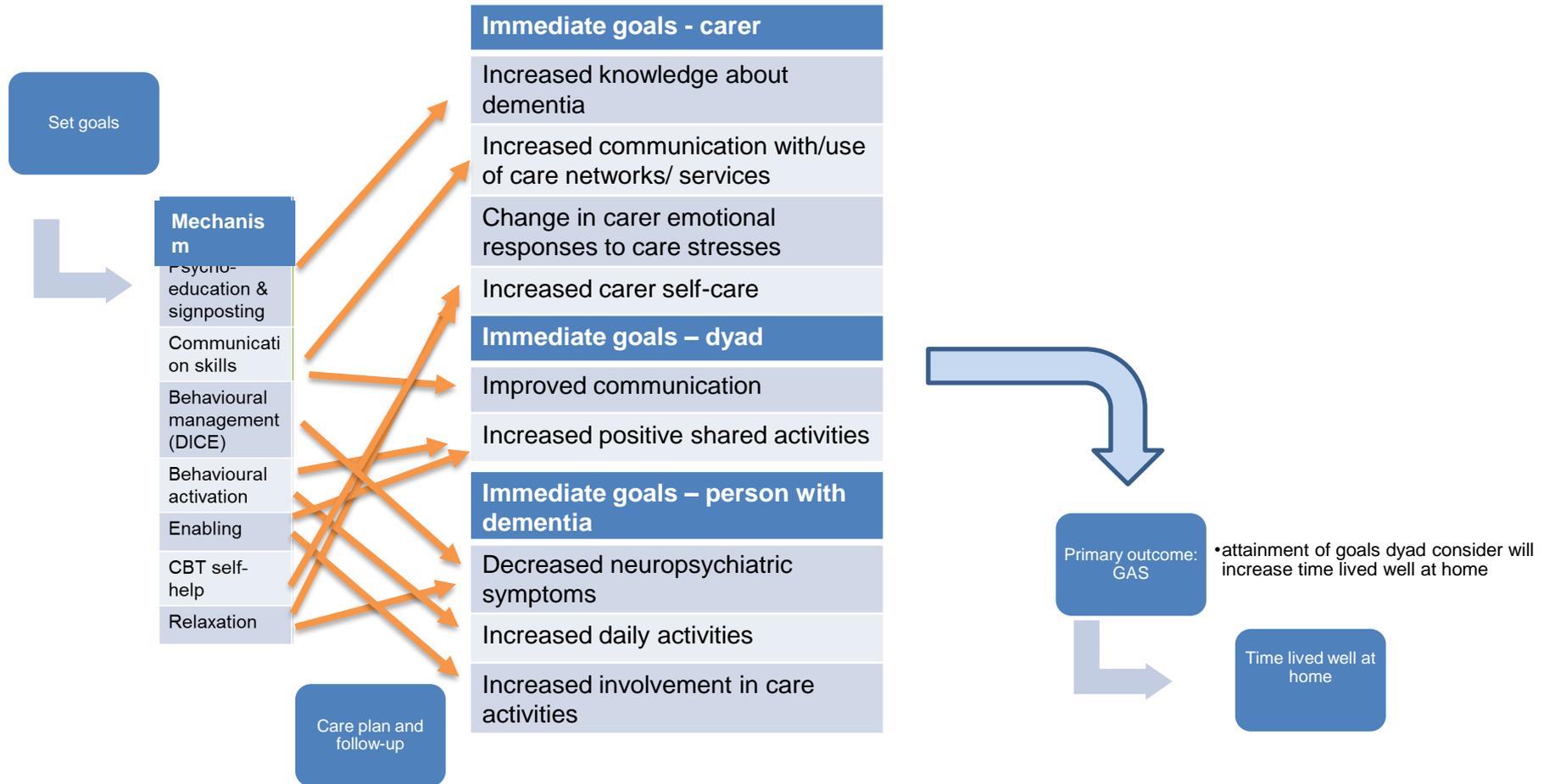
Last main session:

Putting it all together/ planning for the future



Follow-up phone calls: checking in, embedding plan

NIDUS-FAMILY INTERVENTION MODEL: Causal assumptions



Context

Covid
Dementia severity
Dyadic relationship

Reach:
Population approached, consenting

Implementation &
Mechanisms of impact

Set goals

- Ability participants to set goals
- Number/types of goals set
- Process to monitor therapeutic relationships
- Fidelity

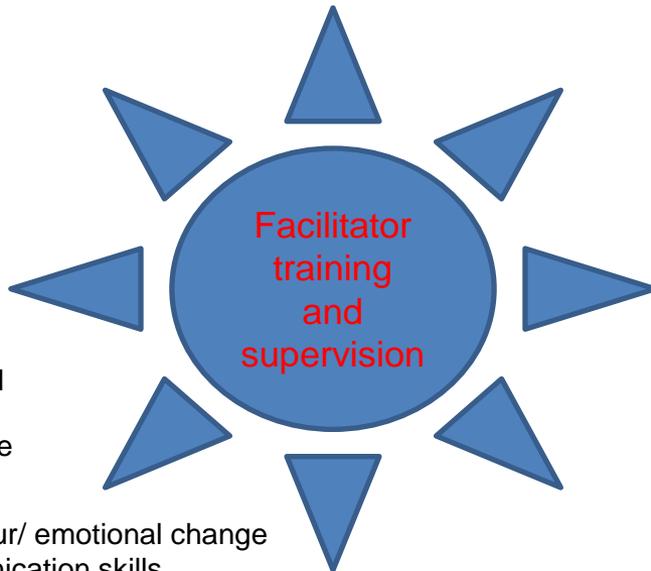
Intervention processes

- Attendance/ acceptability
- Delivery format (zoom, phone, F2F)
- Mapping goals to modules
- Psychological & physical capacity to engage
- External factors influence opportunity
- Motivation affected by dementia severity

Capability
Opportunity
Motivation of dyad

Core components
Adaptable periphery

Mixed methods process evaluation
Realist perspective



Immediate goals

- Behaviour/ emotional change
- Communication skills
- knowledge about dementia
- Increased service use/ knowledge

Primary outcome:
GAS

- attainment of goals dyad consider will increase time lived well at home

Outcome



Implementation group & study

Time lived well at home

Comments/ feedback on NIDUS-family:

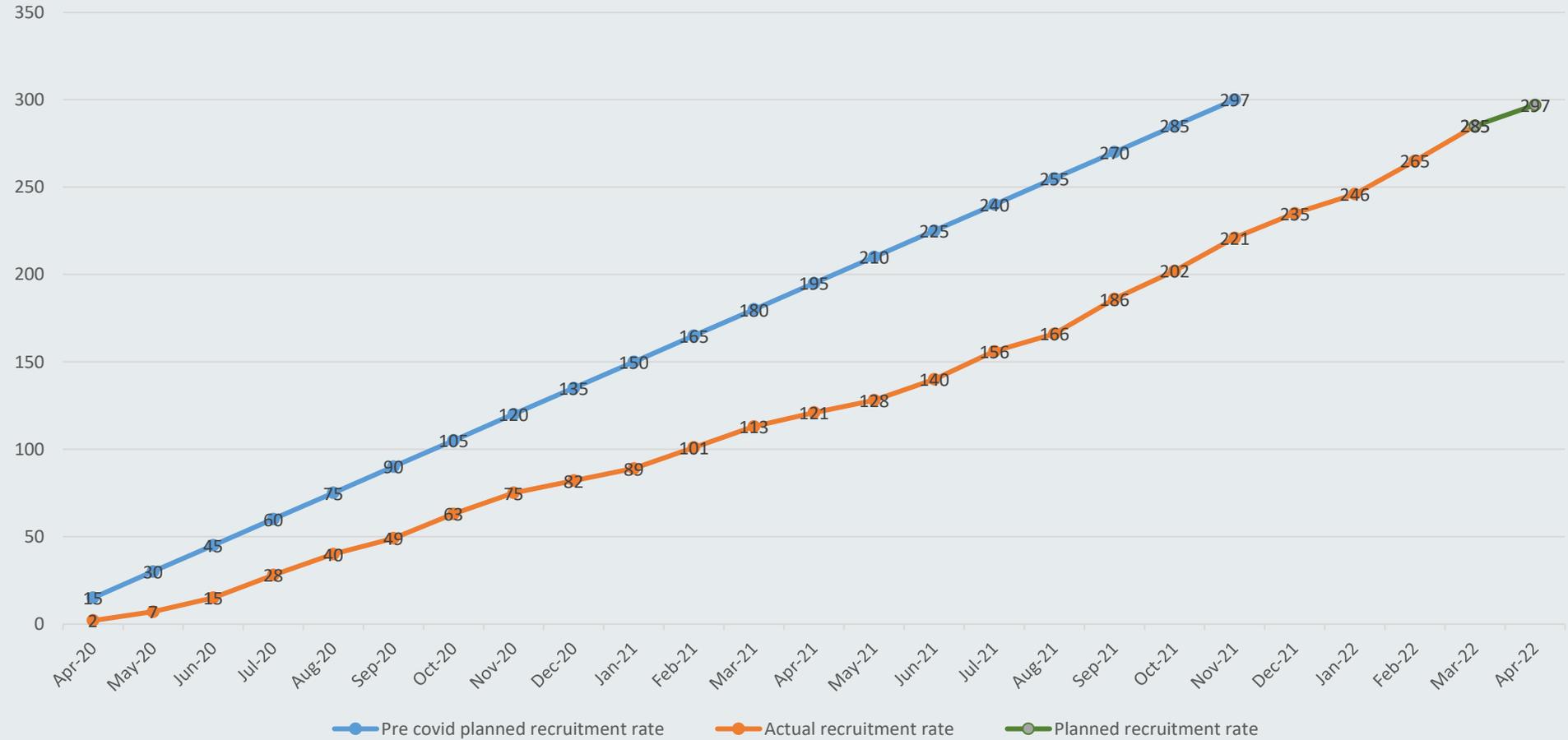
“Recently a few participants have mentioned to me how taking part in the intervention has made them more aware of the specific situations/issues (GAS goals) and therefore more proactive in finding solutions. Some felt this would not have happened without the intervention, which gives them the opportunity and space to discuss and reflect on issues.” **Amirah Akhtar, Study team researcher**



“At the end of our session, she (family carer) was really thankful for the NIDUS project which has helped bring about a change in her life; she's become more proactive by focusing on her own wellbeing, started asking others for help (especially from family) and says she has become more perceptive of her own and the plwd's feelings and behaviours.” **Ayesha Dar, Study team researcher**

“It has been such a pleasure to meet and work with you during these difficult months. Your support has been invaluable to me and allowed me to gain insight into emotions and frustrations, validate my feelings and allowing me the space to put these feelings out there. Thank you.” **Participant email to Jodie Birch, Study team researcher**

NIDUS-Family recruitment over time



Follow up assessments

6m follow ups (n=151)

- Primary outcome completed: 151/173 (87%) (for 6 only 1yr outcome (2 had died and 4 due to time restrictions))
- No outcomes: 24 (13 no contact, 2 RIP and declined GAS, 9 withdrawn)

12m follow ups (n=88)

- Primary outcome completed: 88/102 (86%) (for 13 only 1yr outcome (8 PLWD died and 5 due to other reasons))
- 17 not done (9 no contact, 3 RIP and declined, 5 withdrawn)

18m follow ups (n=23)

- Primary outcome completed: 23/41 eligible (56%)

NIDUS-Professional Road Map

1. We built an evidence base...



2. ...used it to co-produce NIDUS-Professional (Sept 2019 – April 2020)



3. ... we will pilot the intervention in one group of home carers (and 2-3 dyads they care for will receive NIDUS-family) (scheduled November 2020 - March 2021)

COVID-19 update: NIDUS-professional has been adapted to remote delivery via Zoom video call.

4. ...and test it in randomized feasibility trial (60-90 home carers from 3 agencies and 60-90 clients with dementia) (August 2021 – March 2023)



5. Analysis and Economic evaluation



NIDUS-professional

- To estimate:
- proportion of care workers adhering to intervention (expected value 75%, 95% CI = 59-87%);
- clients for whom primary proxy-rated outcomes were completed at 6 month follow-up (75%, 95% CI = 62-85%).
- Sample size: 60 HCW and 60 clients

Recruited Agencies

Agency 1
(randomised 20.1.22 to intervention)

7/40 HCW identified completed baseline

5/20 of clients/ family carers of participating HCW identified completed baseline

5 sessions of NIDUS-professional delivered to **5/7** HCW
NIDUS family underway with **1** client

Agency 2
(randomised 1.2.22 to control)

5/14 HCW identified complete baseline

2/7 of clients/ family carers of participating HCW identified completed baseline

Agency 3
(randomised 14.03.22 to intervention)

18/19 HCW identified completed baseline

6/9 of clients/ family carers of participating HCW identified completed baseline

Session 1 NIDUS-professional will be delivered next week to **17/18** HCWs
NIDUS family underway with **6** clients

In progress

8 interested agencies



***Empowering Better End of Life Dementia Care
(EMBED-Care) programme: what we have learnt
so far***

Presented by

**Professor Liz Sampson, East London NHS Foundation
Trust**

EMBED-Care

Empowering Better End of Life Dementia Care

Joint programme between KCL and UCL

PI: Prof. Elizabeth Sampson, UCL

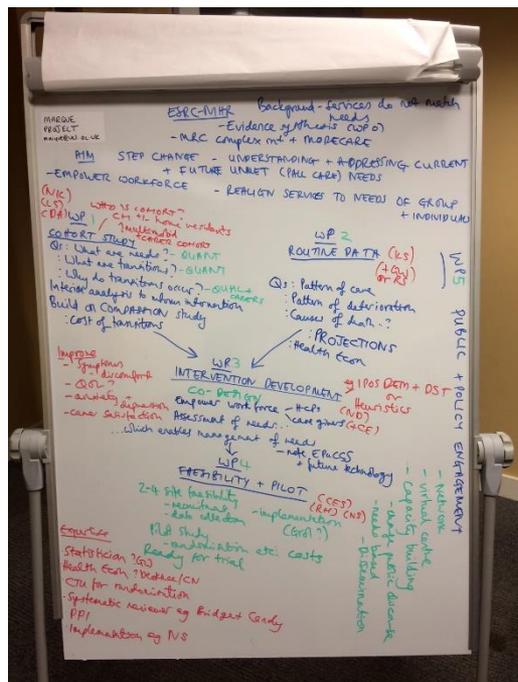
Co-PI: Dr Catherine Evans, KCL

Funder: ESRC/NIHR Dementia Research

The team



EMBED-Care
Empowering Better End
of Life Dementia Care



EMBED-Care Team

Prof. Liz Sampson	PI	Prof. Jason Warren	DRC-UCL (YOD)
Dr Catherine Evans	Co-PI; WS1 Lead	Jane Ward	Expert by Experience
Dr 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		

Why is this important?

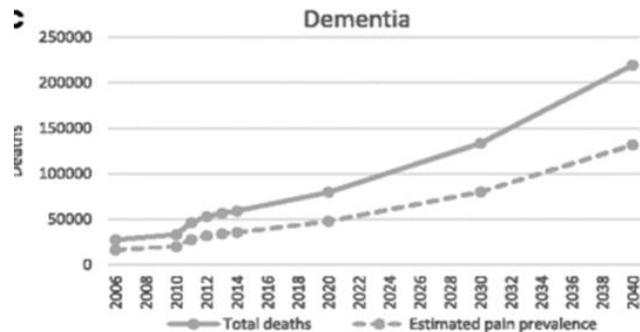
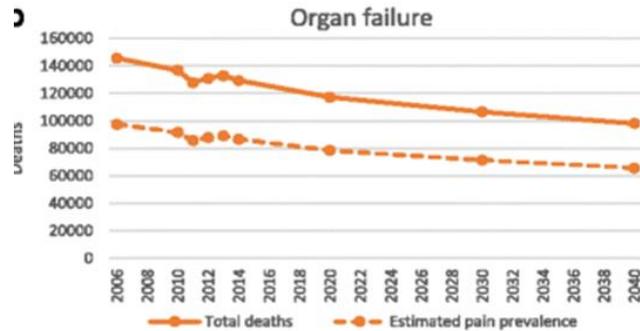
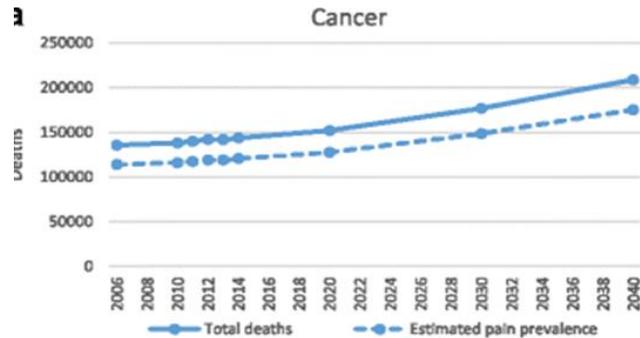
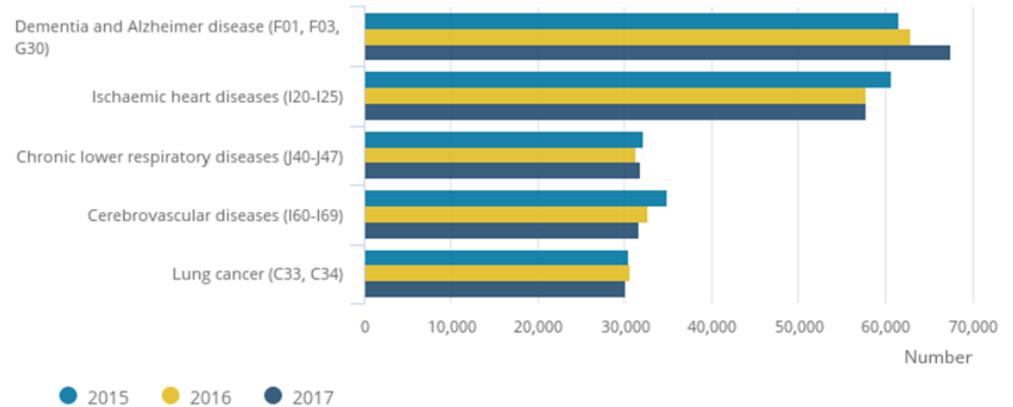


Figure 2: Number of deaths from top five leading causes, 2015 to 2017
England and Wales



Source: Office for National Statistics

Etkind et al. 2017

EMBED-Care aims to...

1. Leverage **step-change in palliative dementia care**, creating a new network for care, engagement and research
2. **Develop new knowledge and pilot a model of care to empower people with dementia**, carers and staff, to identify and act upon changing physical, psychosocial and spiritual needs, addressing these **across settings**
3. **Deliver a model of integrated palliative dementia care**, enhancing person-centred decision-making and communication to improve comfort and quality of life
4. Build capacity in dementia research
5. Deliver imaginative public engagement
6. Embed PPI at all points of the project

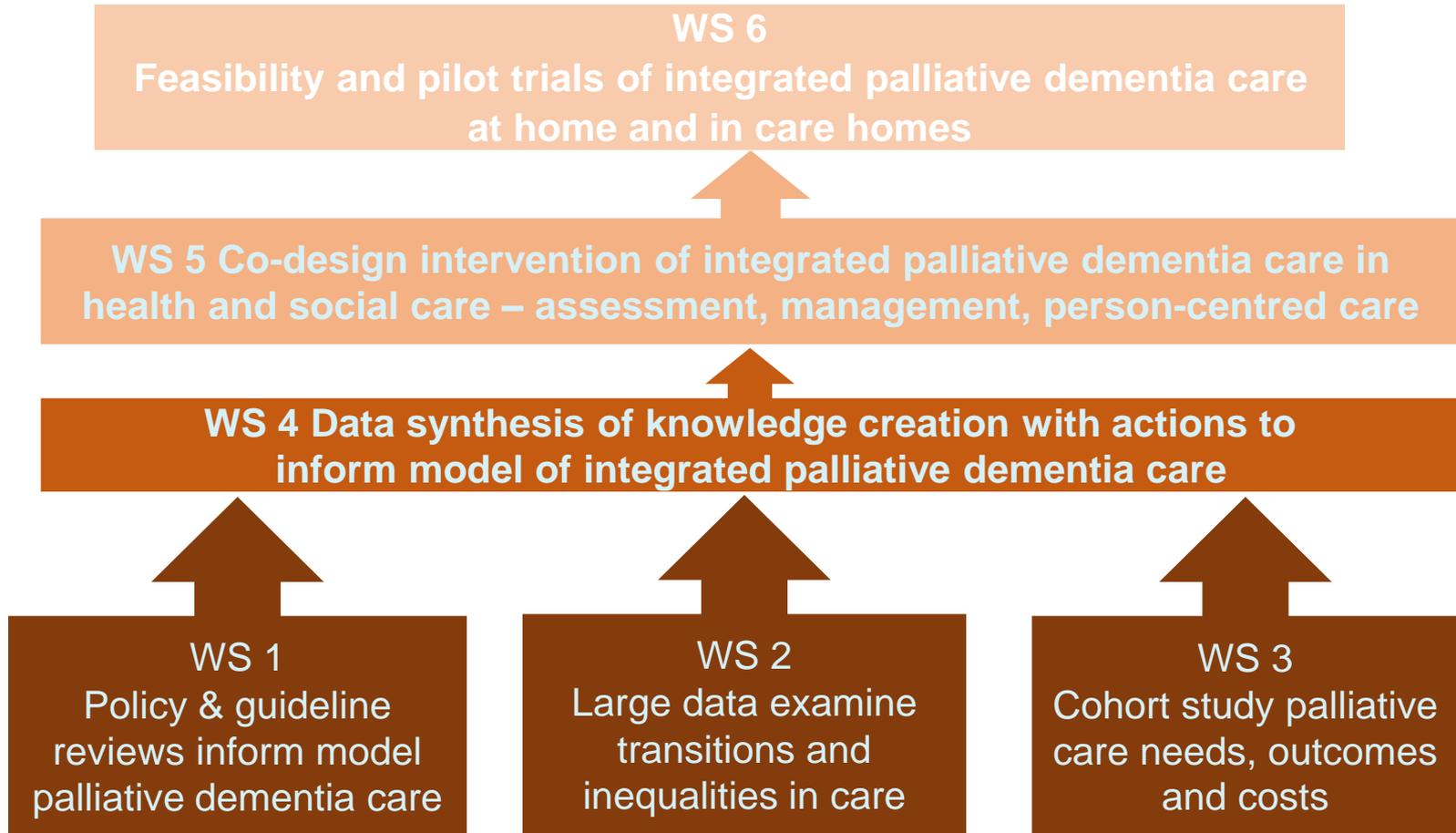
EMBED-Care
Empowering Better End
of Life Dementia Care



Programme summary

Patient and Public Involvement

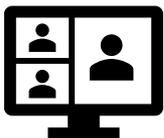
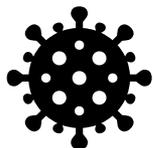
Engagement and impact



-----**Network for Excellence in Palliative Dementia Care**-----

Challenges

Solutions



COVID

Remote
assessment

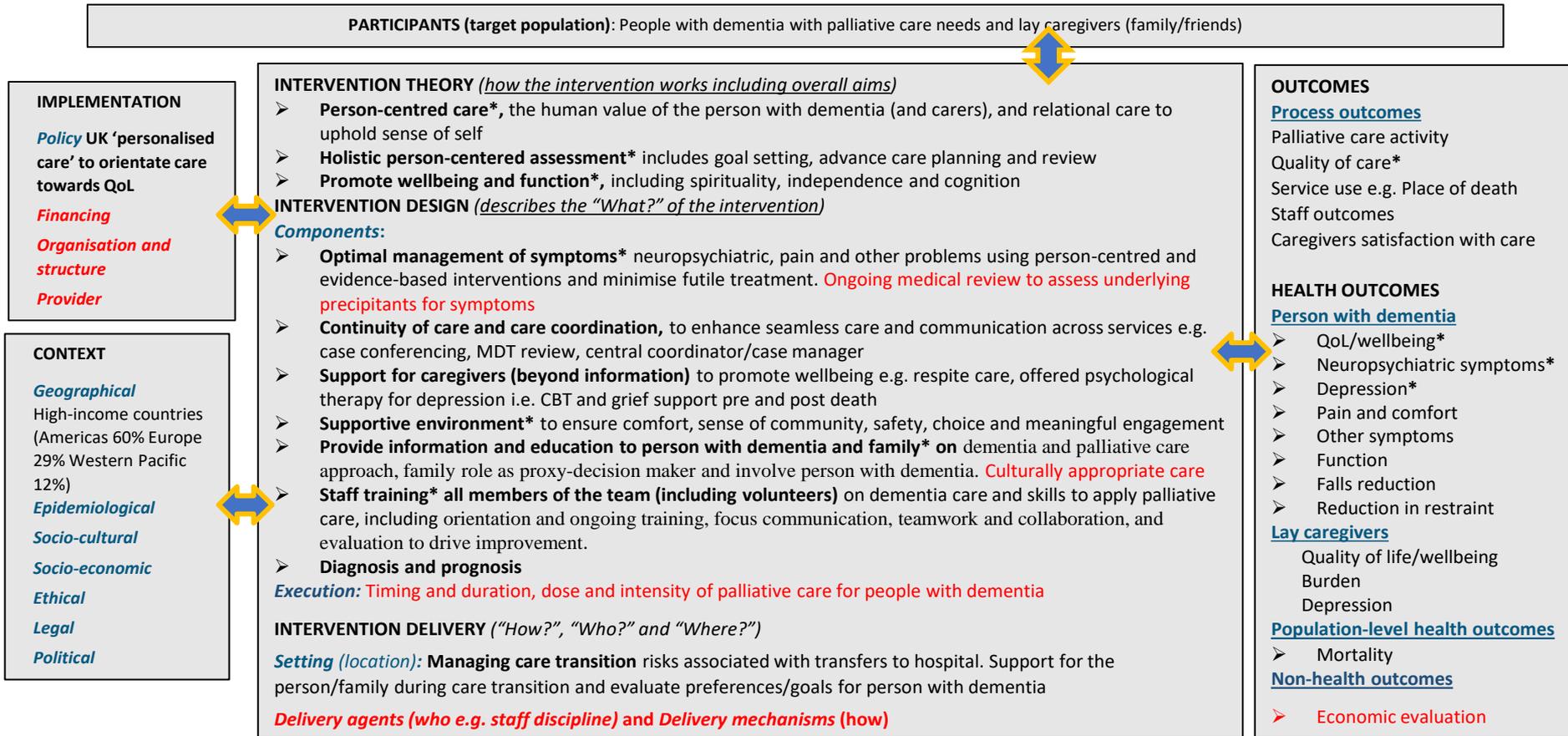
Zoom PPI &
engagement

Extra
funding



Work Stream 1: System-based logic model

Prof. Catherine Evans



*Most common components identified in 5 or more systematic reviews. **Red font denotes** areas of uncertainty with no evidence identified to pursue in the work streams

Sleeman et al. Priorities and opportunities for palliative and end of life care in United Kingdom health policies: a national documentary analysis. BMC Palliat Care. 2021

Work Stream 2: New knowledge on service use, inequalities and future population

Prof. Katherine Sleeman

Aim & Objectives

To study health service use and transitions in people with dementia in the last two years of life using large linked datasets, and use this to calculate projections of future need.

- 1: What key factors link to health service use in the last two years of life for people with dementia?
- 2: How are these predicted to change in the future?
- 3: How does community palliative care involvement influence acute hospital use?

Design

Retrospective observational study using the South London and Maudsley National Health Service (NHS) Foundation Trust Biomedical Research Centre (SLaM BRC) Case Register and its Clinical Record Interactive Search (CRIS)

Work Stream 3: Cohort study

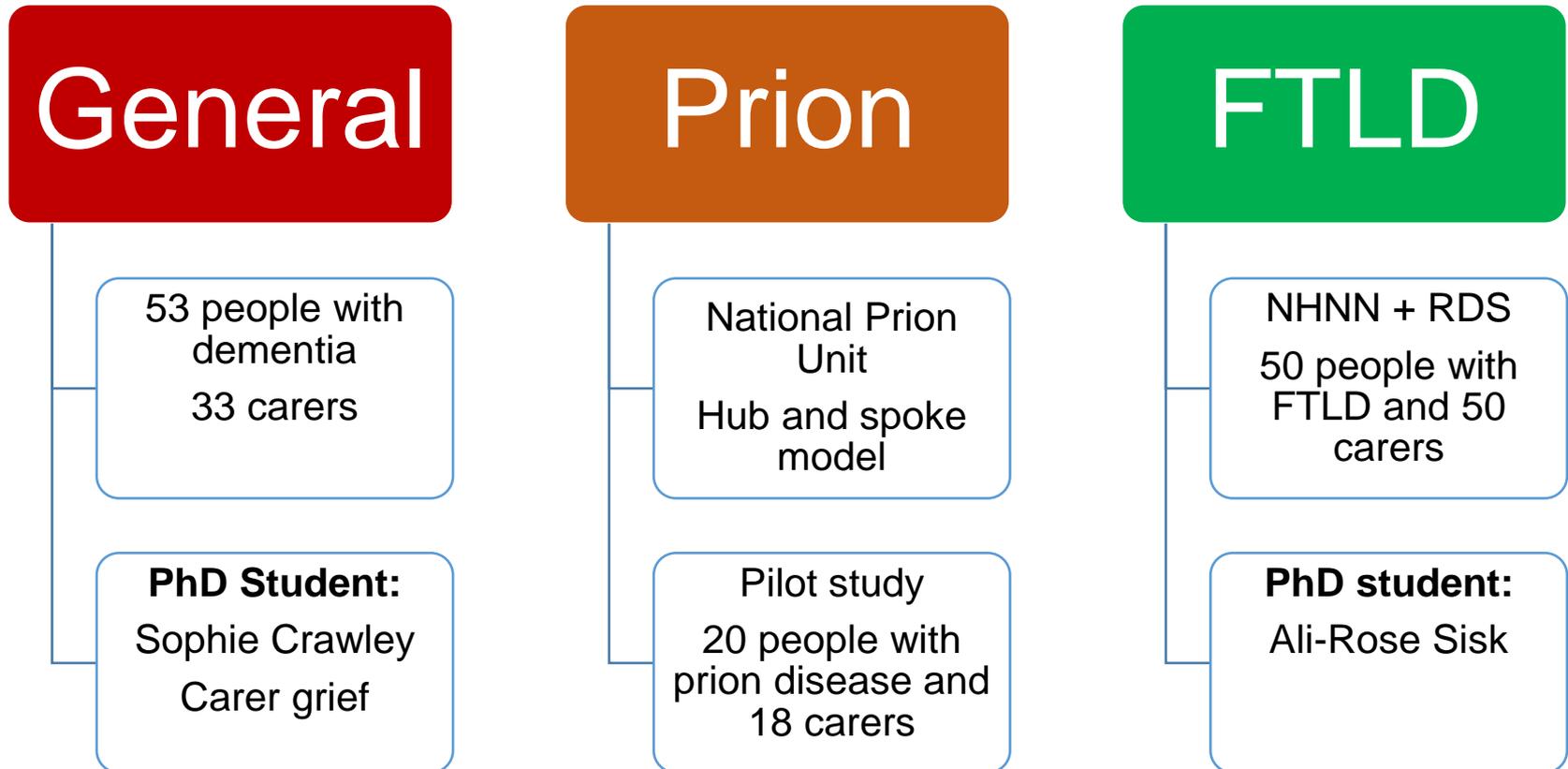
Dr Nuriye Kupeli

Aims

1. Describe the key unmet palliative care (physical, psychological, social and spiritual) and association between unmet needs and comfort, QoL, service use, care transitions, carer experiences and health and social care costs
2. Explore common strategies carers use to address unmet needs
3. Explore post-death, unmet needs of PwD and care transitions prior to death and family carer needs in bereavement
4. Sub-cohorts on Prion disease and young onset frontotemporal dementia



Cohort updates



doi:10.1017/S1041610221002787

REVIEW

Grief in family carers of people living with dementia: A systematic review

Sophie Crawley,¹ Elizabeth L. Sampson,² Kirsten J. Moore,³ Nuriye Kupeli,² and Emily West²

¹Marie Curie Palliative Care Research Department, Division of Psychiatry, UCL, London W1T 7NF, United Kingdom

²Division of Psychiatry, UCL, London W1T 7NF, United Kingdom

³Melbourne Ageing Research Collaboration, National Ageing Research Institute, Melbourne, Australia

Work Stream 4: Data Synthesis

Dr Kirsten Moore

Objective

Synthesise evidence and knowledge generated from WS1-3, to provide a foundation and inform **recommendations** and **components** for our new intervention.

- Development of synthesis methods incorporating real-world contexts, resources and mechanisms

Palliative Care Need	Outcome measure (WS1)	Evidence of unmet need (Compassion cohort, WS2&3)	Interventions (WS1, WS3, experts and co-design)	Evidence for interventions	
				Care home setting	Other settings including at home
Delirium					
Co-morbidities managed					
Vision and hearing assessed and required aids used (glasses and hearing aids)					
Pain					
Footcare					

IPOS-Dem



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.

		<i>Not at all</i>	<i>Slightly</i>	<i>Moderately</i>	<i>Severely</i>	<i>Overwhelmingly</i>	<i>Cannot assess</i>
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"/>
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"/>



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? 

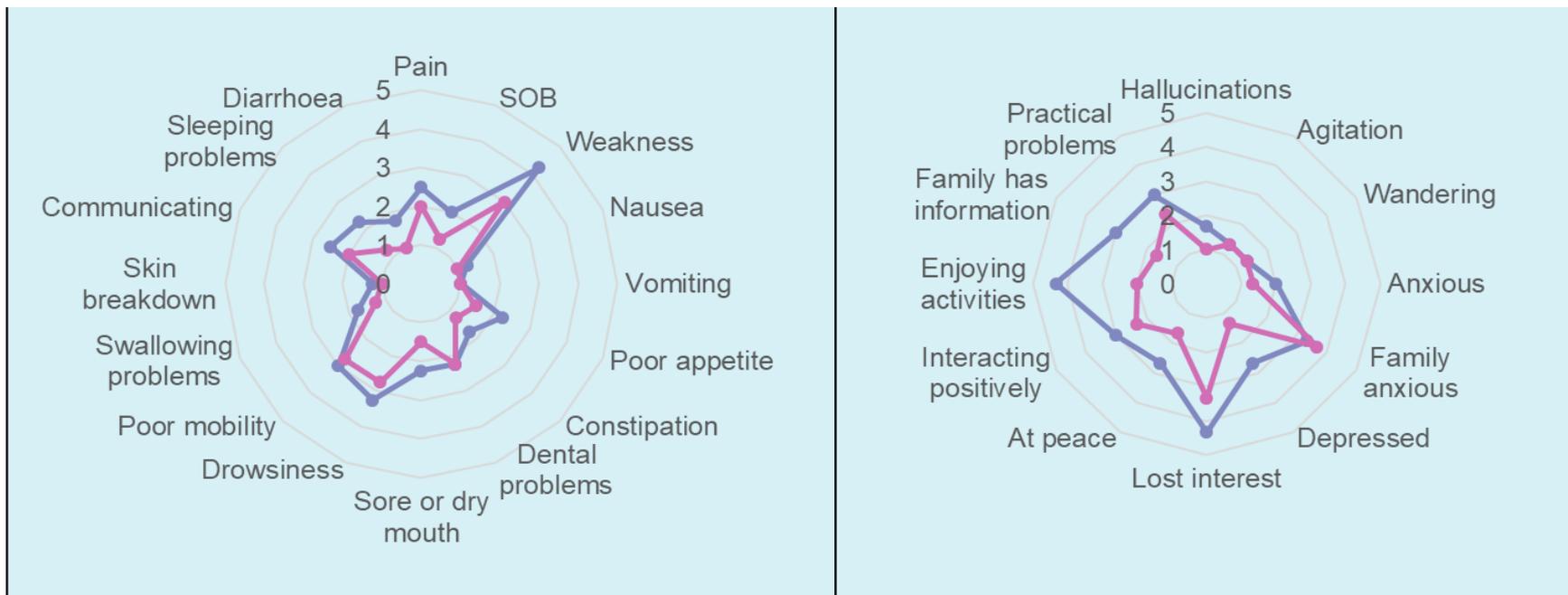
1.....



		<i>Not at all</i>	<i>Occasionally</i>	<i>Sometimes</i>	<i>Most of the time</i>	<i>Always</i>	<i>Cannot assess</i>
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"/>
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"/>
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"/>
Q5b. Lost interest in things 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"/>

Change in scores- 1 month

“Assessment as intervention”



Ellis-Smith et al. Development of a caregiver-reported measure to support systematic assessment of people with dementia in long-term care: The Integrated Palliative care Outcome Scale for Dementia Palliative Medicine 2016

Heuristic interventions- rules of thumb

- What's the alternative to another pathway or another guideline?
- Synthesis of best practice
- Provided a structure and broke down complexity
- “Implicit made explicit”
- Authority and permission
- Source of reassurance and validation
- Appreciated the simplicity

Facial
weakness



Arm
weakness



Speech
problems



Time
to call 999



Work Stream 5: Co-design of intervention

Dr Nathan Davies

Development of the EMBED-Care intervention :

1. IPOS-Dem tool (holistically assess and identify concerns, needs, symptoms and goals) ✓
2. Heuristic decision toolkit (enable staff and carers to put in place the right care at the right time, and place) ✓
3. Manual and training support ✓

Iterative co-design approach with 3 groups:

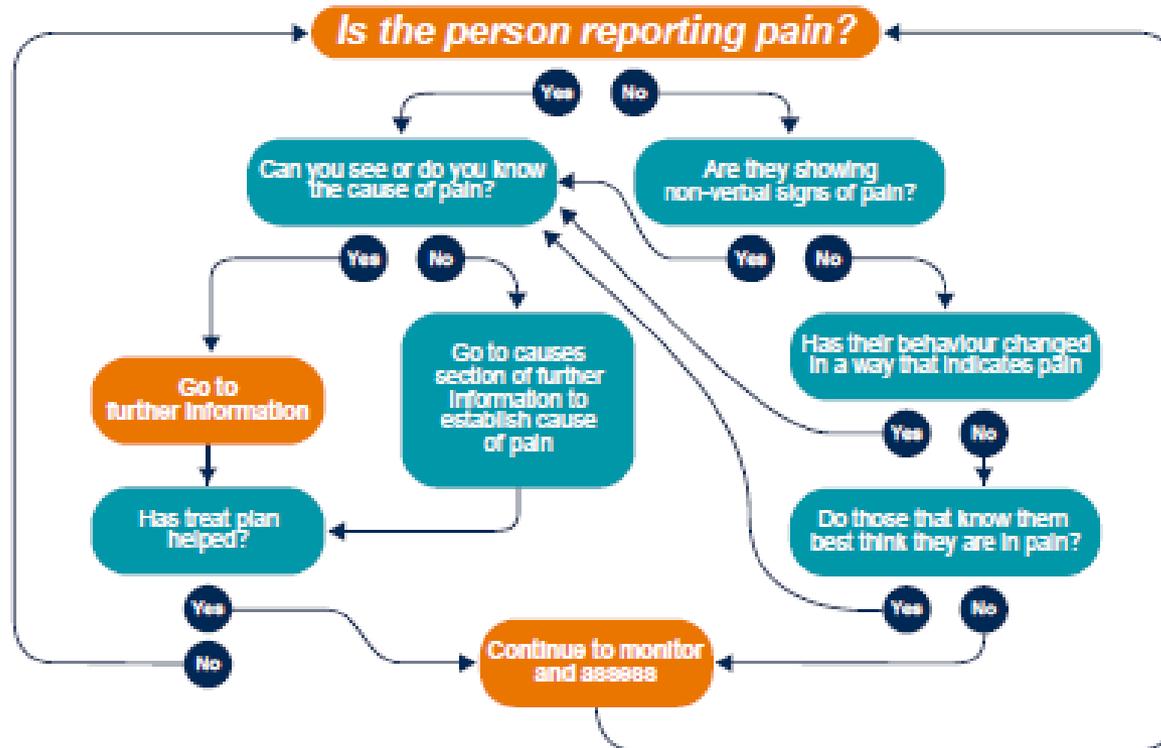
1. People with mild dementia ✓
2. Current and former carers ✓
3. Practitioners across settings and specialities ✓

Implementation process and user testing

1. Field testing with 10 professionals and carers
2. Explore barriers to use, content and design modifications for implementation or delivery

Designing heuristics

Pain



Version a

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 growling 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?
-

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.

Version b

Pain

1. Assess	2. Causes	3. Treat
Talk	Talk	Talk
<ul style="list-style-type: none"> Ask them if they are in pain? Where is the pain? 	<ul style="list-style-type: none"> When did the pain start? What does it feel like? How severe is it? Ask family or advocate. 	<ul style="list-style-type: none"> 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.
Look	Look	Act
<ul style="list-style-type: none"> Are they looking sad or frightened? Are the frowning? 	<ul style="list-style-type: none"> 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? <ul style="list-style-type: none"> Have they taken their medication? Is the environment causing discomfort? 	<ul style="list-style-type: none"> 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.
Observe	History	Refer
<ul style="list-style-type: none"> Are they more confused? Are they whimpering? Are they groaning or crying? Are they eating and drinking less? <ul style="list-style-type: none"> Are they agitated? Has behaviour changed? Are they sweating? 	<ul style="list-style-type: none"> Do they have a known pain condition such as arthritis? <ul style="list-style-type: none"> 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? <ul style="list-style-type: none"> Do they have chronic pain? Use a pain monitoring chart or diary to record episodes. 	<ul style="list-style-type: none"> 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.
Body language		
<ul style="list-style-type: none"> Are they rigid, clenched fists, knees pulled up, protecting a body part? Are they trying to move or push you away? 		
		Once treatment in place reassess to ensure pain is managed.

Digitised



Considering implementation

PhD: Tofunmi Awonrinde

How can we use the Integrated Palliative care Outcome Scale for Dementia (IPOS-Dem) to facilitate shared decision-making on care and treatment between the person with dementia living at home, and their informal and formal caregivers?

PhD: Juliet Gillam

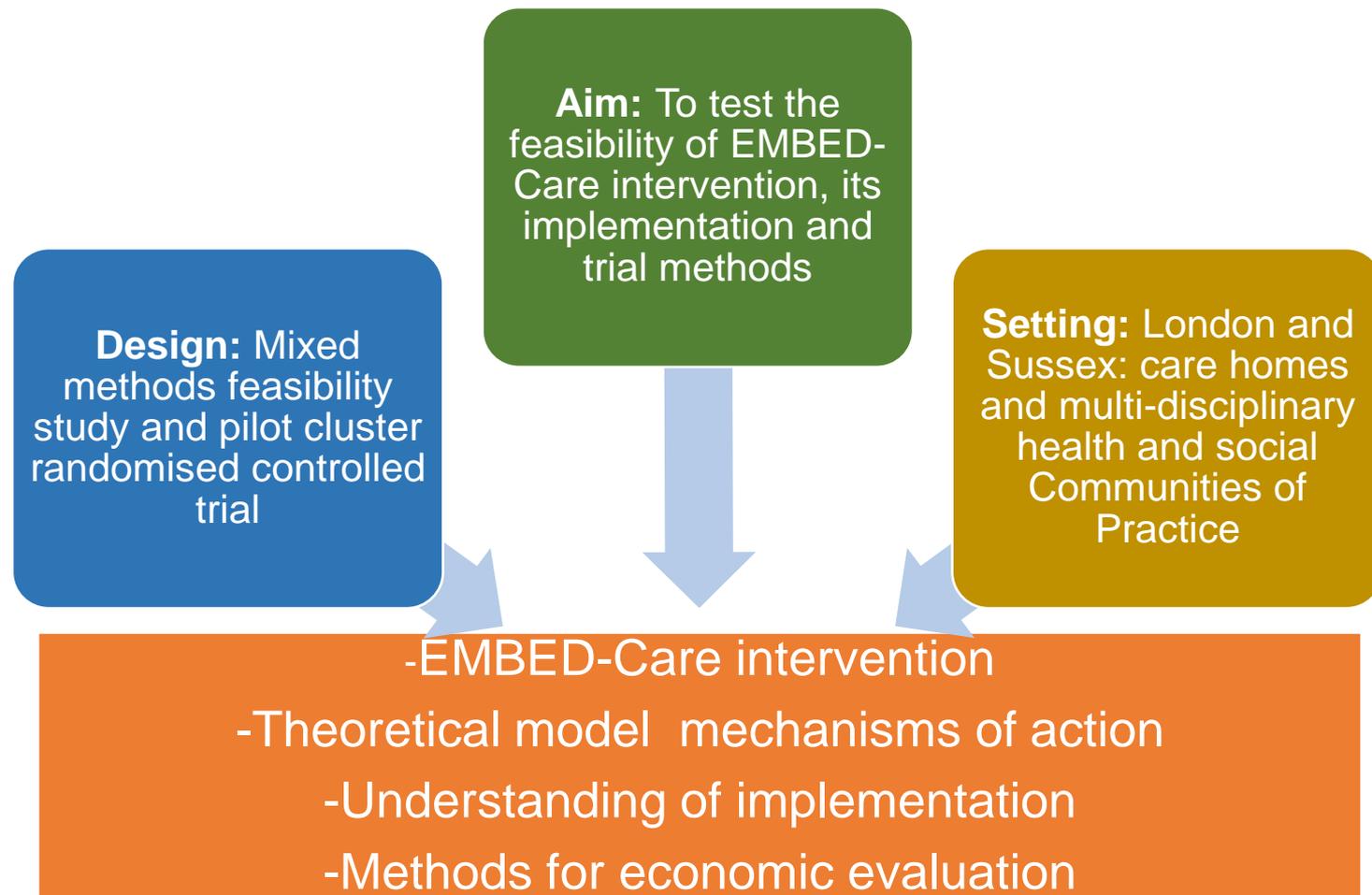
Design and feasibility evaluation of a plan to implement an eHealth intervention to optimise person-centred assessment and decision-making for people with dementia in care homes

Review

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

Work Stream 6: Intervention

Dr Claire Ellis-Smith



COVID-Supporting decision making

Decision aids

- Videos, booklets, or web-based tools
- State the decision, provide information, summarize options, benefits and harms
- Helps guide decision by clarifying values
- Increase knowledge, quality of communication, effective in reducing decisional conflict

1. West et al. Rapid review of decision-making for place of care and death in older people: lessons for COVID-19. Age Ageing. 2021
2. Aker et al. Challenges faced during the COVID-19 pandemic by family carers of people living with dementia towards the end of life. BMC Health Serv Res. 2021
3. West and Nair et al. Exploration of the impact of the COVID-19 pandemic on people with dementia and carers from black and minority ethnic groups. https://www.ucl.ac.uk/psychiatry/sites/psychiatry/files/endemic_decision_aid_26_08_20_v.2.pdf



Supporting you to make decisions while caring for someone living with dementia during Coronavirus (COVID19) and beyond

Name of person completing this document:

Relationship to the person living with dementia:

Name of person living with dementia:

Use this section to keep important phone numbers for example, care home, GP, pharmacy, district nurse, home care agency

Name	Name of key contact	Number

Supporting you to make decisions while caring for someone living with dementia during Coronavirus (COVID19) and beyond

CovPall-CareHome: Rapid evaluation of the care home response to the need for palliative care during the COVID-19 pandemic: integration, communication and workforce resilience

Aim: To examine the response of care homes in England to meet the rapidly increasing need for palliative and EoL care for residents during the COVID-19 pandemic and make policy recommendations (NIHR Policy Research Programme)

WP 1: On line rapid survey to map care home (n=400) provision of palliative and EOLC

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graph TD; WP1[WP 1: On line rapid survey to map care home (n=400) provision of palliative and EOLC] --> WP2[WP 2: In-depth care homes case studies (n=24) to explore the challenges and facilitators]; WP2 --> DT[Data triangulation focus on challenges and facilitators to improve and sustain high-quality palliative care];
```

WP 2: In-depth care homes case studies (n=24) to explore the challenges and facilitators

Data triangulation focus on challenges and facilitators to improve and sustain high-quality palliative care

PIs Drs Katherine Sleeman & Catherine Evans

Impact and engagement



Change the conversation

- Co-creation workshop
- Art installation
- Public workshop x 3
- YouGov Survey ✓
- Digital content
- Social media campaign
- Public debate
- Evaluation

Influence policy & practice

- Policy Summit ✓
- Policy labs x4
- Project ECHO superhub
- Parliamentary events ✓
- Academic conferences ✓
- Industry conferences
- Knowledge exchanges x 4

PPI

Carer Reference Panel-meets every 4 months

Social media, personal experiences

Recruitment and participation

Capacity building with MCRs and PhD students

CJD Support network
Young Dementia UK
Rare Dementia Support

Jane Ward
Co-APP
Represented on all
governance groups

Represented on
Governance Groups

DEEP Workshops x 4



EMBED-Care Programme Partners



-----Network for Excellence in Palliative Dementia Care-----

EMBED-Care
Empowering Better End
of Life Dementia Care

Thank
you...

Further information

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