Caring in Death

Protocol for a Pilot Evaluation of Co-Produced Palliative Dementia Care Resources for Care Workers Hesitant to Engage with Death and Dying

Presented by: Dr Rasa Mikelyte

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King's College London
Leeds Beckett University

Project Team

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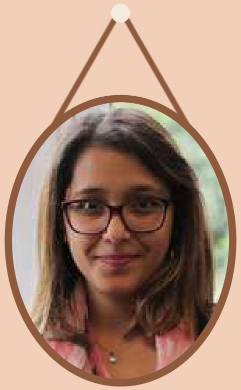
Principal Investigator



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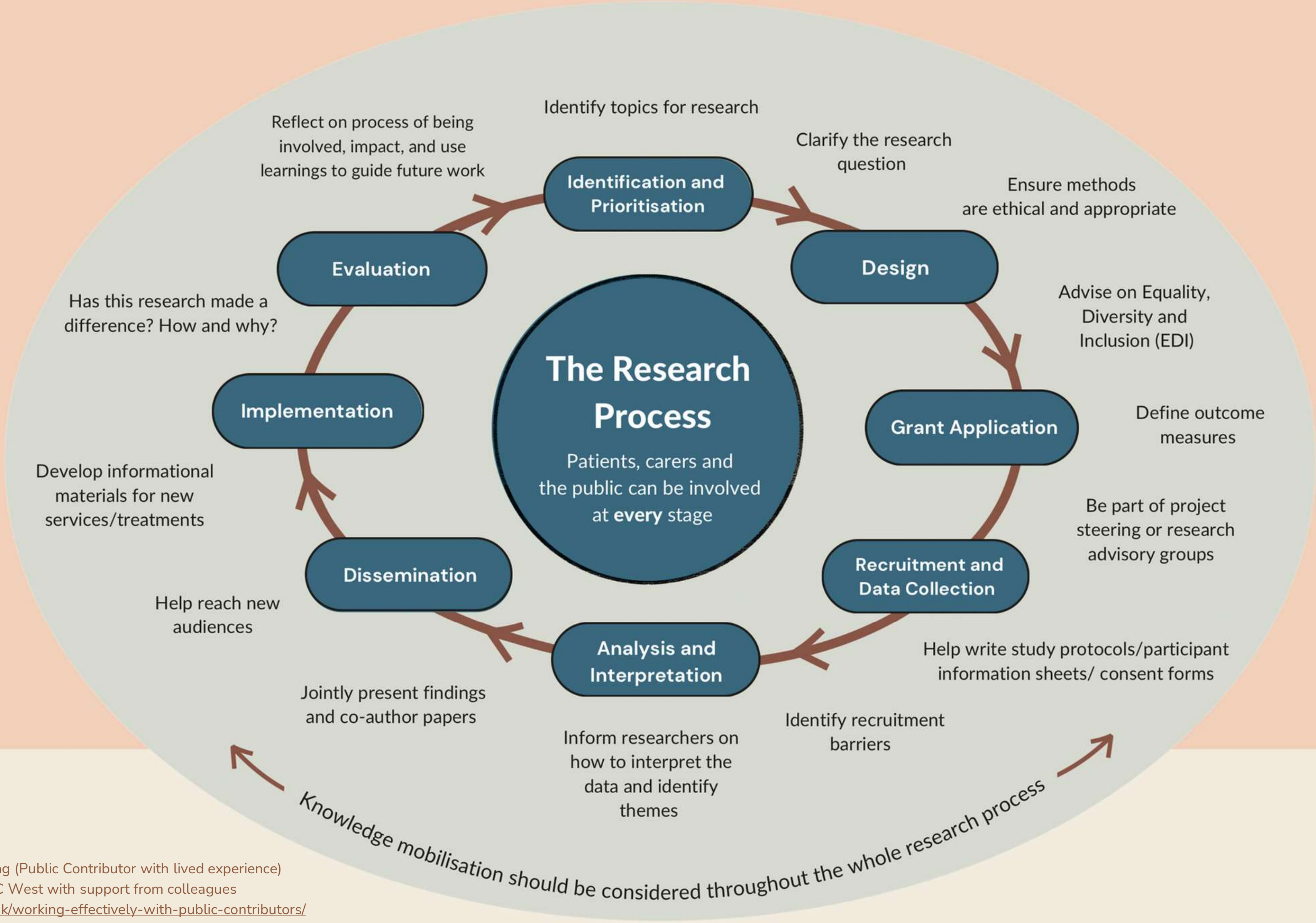

The Research Process

Patients, carers and the public can be involved at **every** stage

Identification and Prioritisation

Identify topics for research

Clarify the research question

Design

Ensure methods are ethical and appropriate

Advise on Equality, Diversity and Inclusion (EDI)

Grant Application

Define outcome measures

Be part of project steering or research advisory groups

Recruitment and Data Collection

Help write study protocols/participant information sheets/ consent forms

Identify recruitment barriers

Analysis and Interpretation

Inform researchers on how to interpret the data and identify themes

Jointly present findings and co-author papers

Dissemination

Help reach new audiences

Develop informational materials for new services/treatments

Implementation

Has this research made a difference? How and why?

Evaluation

Reflect on process of being involved, impact, and use learnings to guide future work

Knowledge mobilisation should be considered throughout the whole research process

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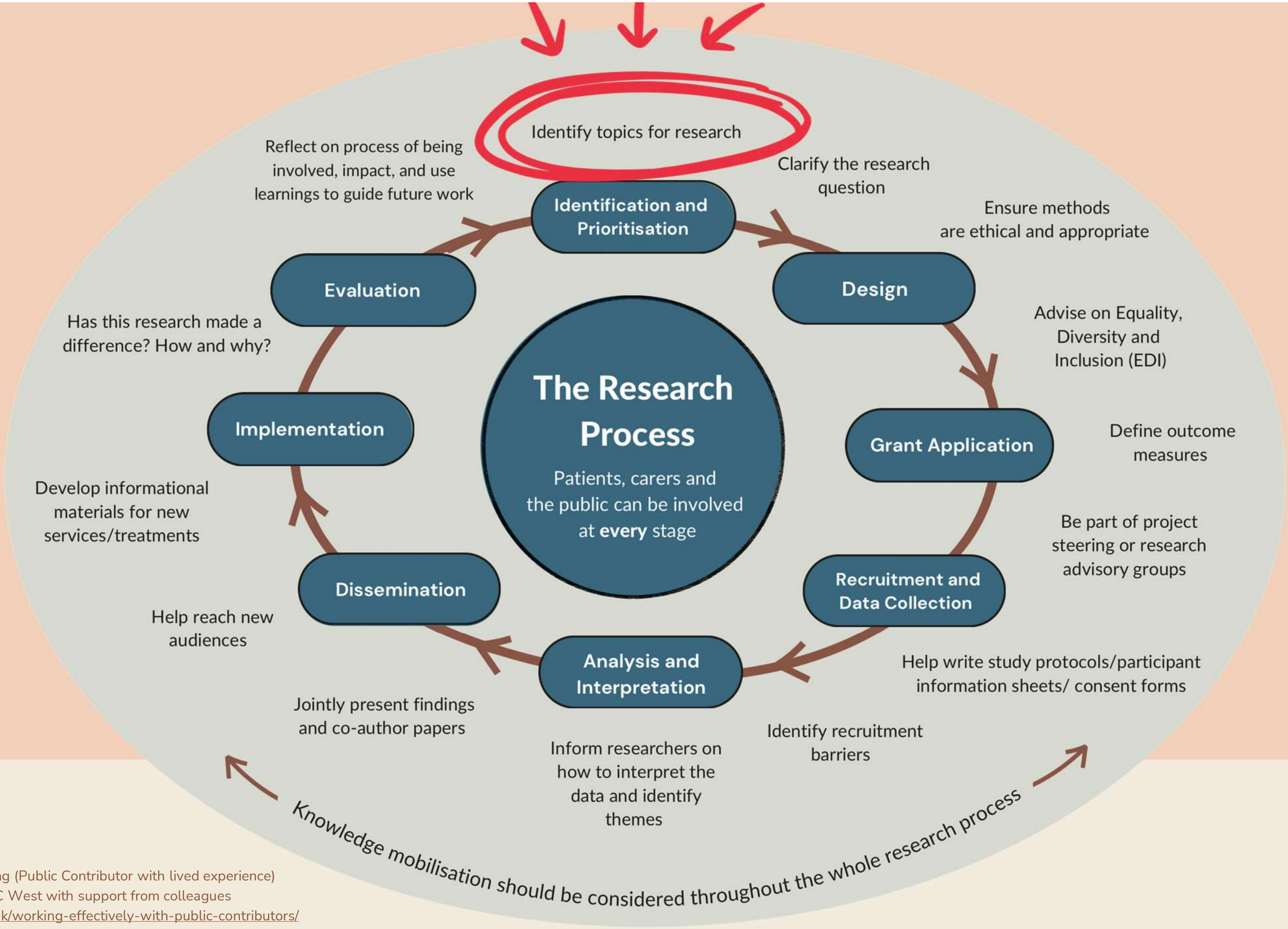

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Setting Research Priorities

This presentation is based on independent research funded by the National Institute for Health and Care Research (NIHR) School for Social Care Research (SSCR).
The views expressed in this presentation are those of the authors and not necessarily those of the NIHR SSCR, the NIHR or the Department of Health and Social Care.

What are research priorities for living with dementia in Kent?

Twenty-two people living with dementia from Kent-based involvement groups have set the following research priorities. The approach for prioritising was developed by a smaller working group of four people living with dementia. While these activities were supported by volunteers, NHS staff and researchers, only people living with dementia had a say in what the research priorities should be.

These are the top 3 research priorities for living with dementia in Kent.

1st Training & Awareness

Research Areas Proposed:

- Benefits of people living with dementia being involved in dementia training for health and social care professionals, especially medical doctors
- Benefits of learning from interactions with people living with dementia (versus formal training)
- Research on the 'best' way to train professionals
- People living with dementia raising public awareness of dementia via varied and considerate media representations
- Educating service providers and commissioners on the benefits of arts for dementia
- Educating on different dementias (and dementia is not just about memory)
- Capturing behaviour change resulting from training (not solely attitude change)

2nd Information

Research Areas Proposed:

- Increasing information accessibility for people with a more advanced dementia
- Personalising provision of information (i.e. avoiding a "carrier bag of leaflets")
- Stereotypes and dementia representations in the media (including the role of people living with dementia consulting on or co-creating media portrayals)
- 'Right' time of providing different kinds of information
- Increasing opportunities to seek information at different timepoints following a diagnosis

3rd Support

Research Areas Proposed:

- Evaluating benefits of peer support
- Enabling continuity of support and integration of care
- Supporting family/friend carers with dementia-specific care
- Increasing opportunities for intergenerational dementia support
- Enabling greater access to social care
- Creativity as a form of treatment/support for dementia
- Support aimed at maintaining "quality of life, not just life"
- Increasing availability of and access to financial support

WHY was this project carried out?

The voice of people living with dementia is crucial in dementia care research. However, people living with dementia often become involved after researchers have already determined the topic of their research. While various approaches, tools, and methods have been developed for setting priorities in health and social care research, few have been successfully applied in priority-setting work with people living with dementia. Our work, therefore, focussed on research priorities set specifically by people living with dementia. We also used an approach to set priorities which was developed by a smaller group of people living with dementia.

WHICH other research areas were identified?

In addition to the 3 most pressing priorities overleaf, people living with dementia said that the following research areas were important:

Fairness
- Living alone and dementia progression
- Isolation and/vs living alone
- Rare dementias
- Dementia and (other) disabilities
- Postcode lotteries in support

Help-Seeking
- Understanding who is likely to seek support, who is less likely, and why
- Ways to encourage more people living with dementia to accept available support

Participation
- Staying in employment with dementia
- Expanding lived experience influence on research
- Lived experience in training, education and service delivery

Also:
- Cretivity and/for dementia
- Impact and reduction of stereotypes and stigma
- Accessibility (of spaces, services, information, etc)

WHAT have people living with dementia said?

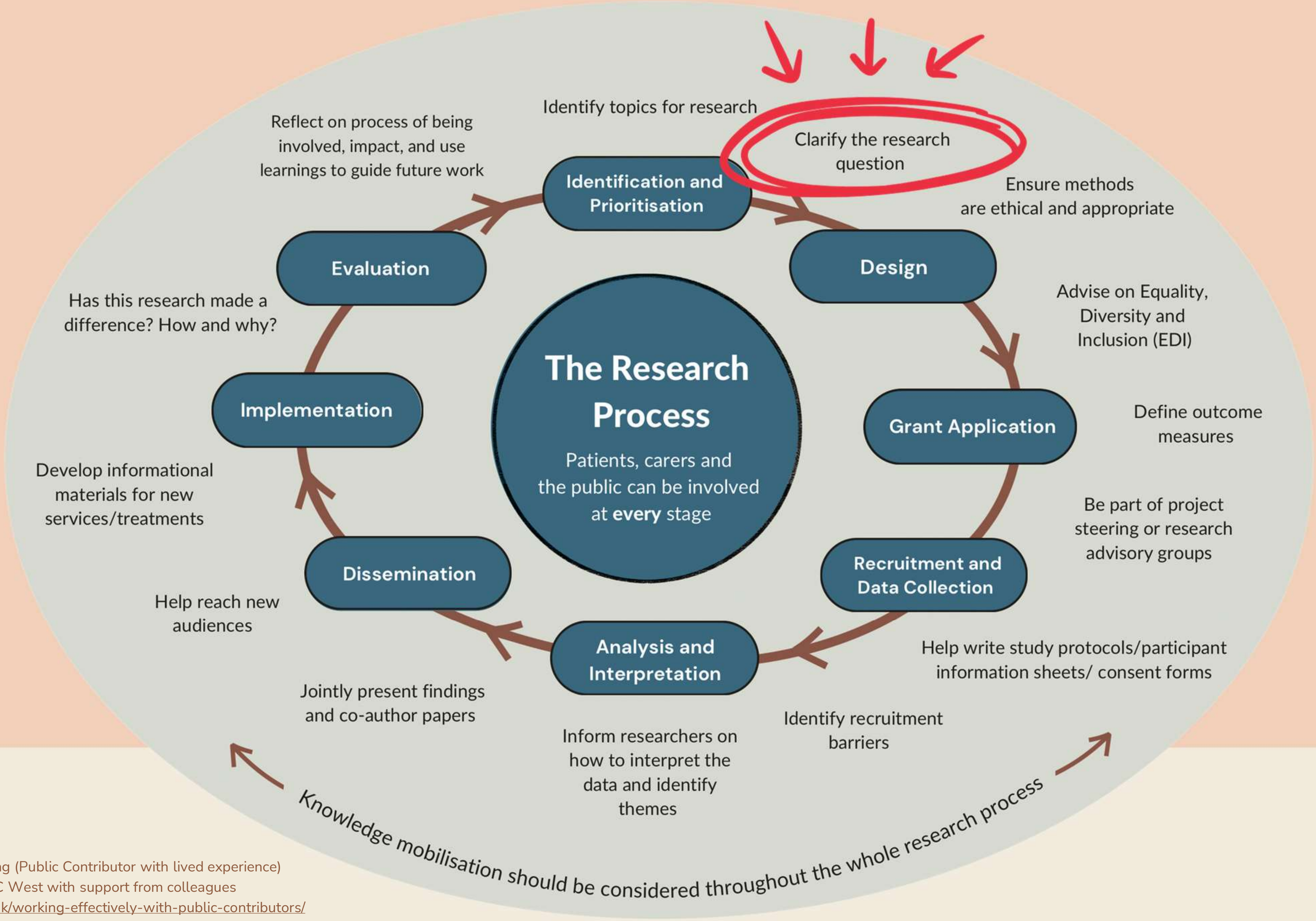
"I would want the research to look at leadership and how it changes professional behaviours, because so often people will change attitudes through training. Very hard to change behaviours. And if we change behaviours, we've won."

"What difference does involving people with dementia have in the training course that's been provided?"

"We need research into the right way to get the public to understand dementia"

"I have a carrier bag full of information about dementia... There must be a way... that there's individuality in information given"

This summary was written by Keith Oliver, Anne-Marie Norris, Dawn Horne, Chris Norris, Lara Stembridge and Rasa Mikelyte. The work was funded by NIHR SSCR. Images and infographics by Slidesgo and Freepik.



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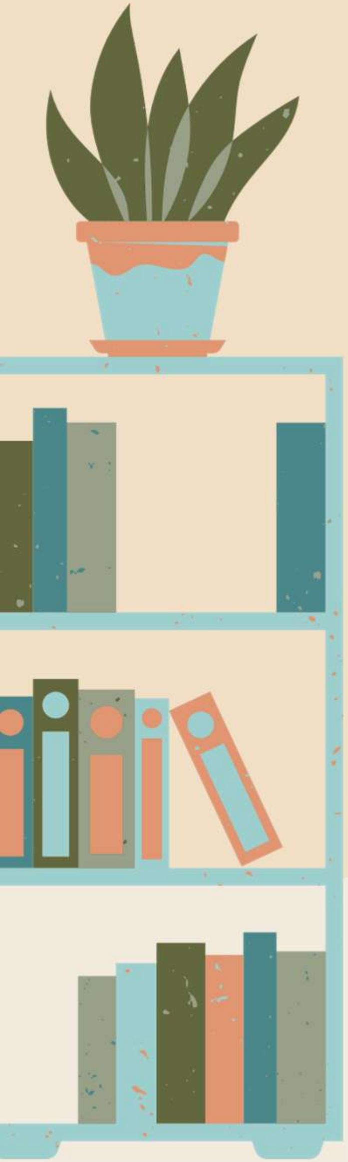
Research Question:



Underpinned by the premise that to produce effective resources for social care workers supporting people with dementia around death and dying it must:

1. be **co-produced** with people living with dementia, their families, and care workers, and
2. be underpinned by **behaviour change theory**

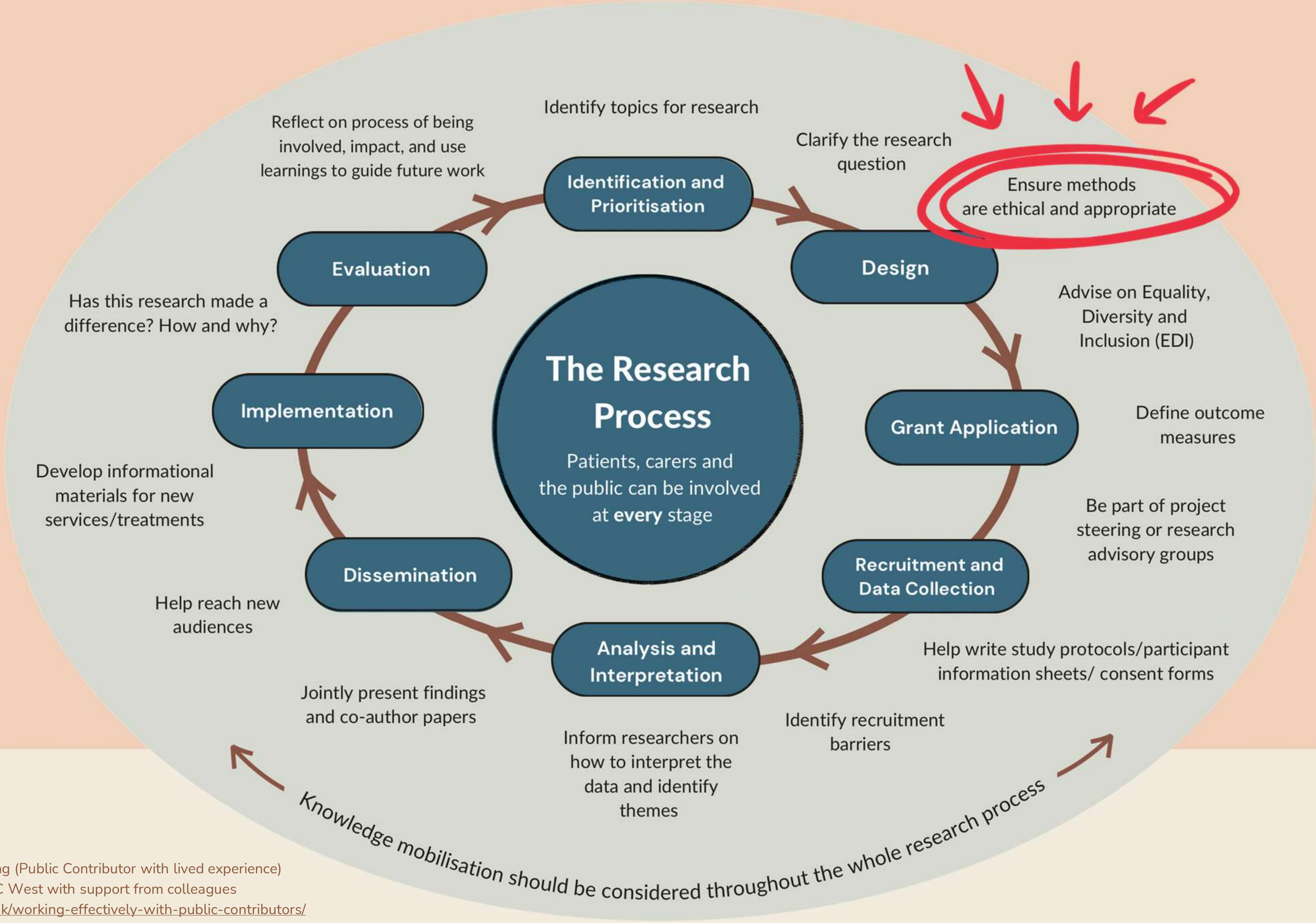
How can co-designed, behaviour change-informed resources improve care workers’ capability, motivation, and opportunity to deliver palliative dementia care?

What is the issue being addressed?

- Most people with dementia in the UK are supported by social care workers at the end of life (ONS, 2023).
- Care workers are well-placed to provide good-quality, generalist end-of-life care (Handley et al, 2022),
    - but many feel underprepared and hesitant to discuss or support dying and death (Delvin & McIlfatrick, 2010)
- Current initiatives focus mainly on training and knowledge, which alone don’t change behaviour.

Why is it important?

- Palliative and end-of-life care in the UK has become increasingly specialised and medicalised (Clark et al. 2015).
- However, people living with dementia remain:
    - underserved by specialist palliative care teams (Leniz et al, 2021) and
    - significantly less likely to be referred for hospice care (Tobin et a, 2021).
- Existing end-of-life care resources and training focus mainly on general palliative care and knowledge-building (e.g. Vandrevala et al, 2017).
- None are simultaneously dementia-specific, co-produced, or evaluated for behaviour change impact.



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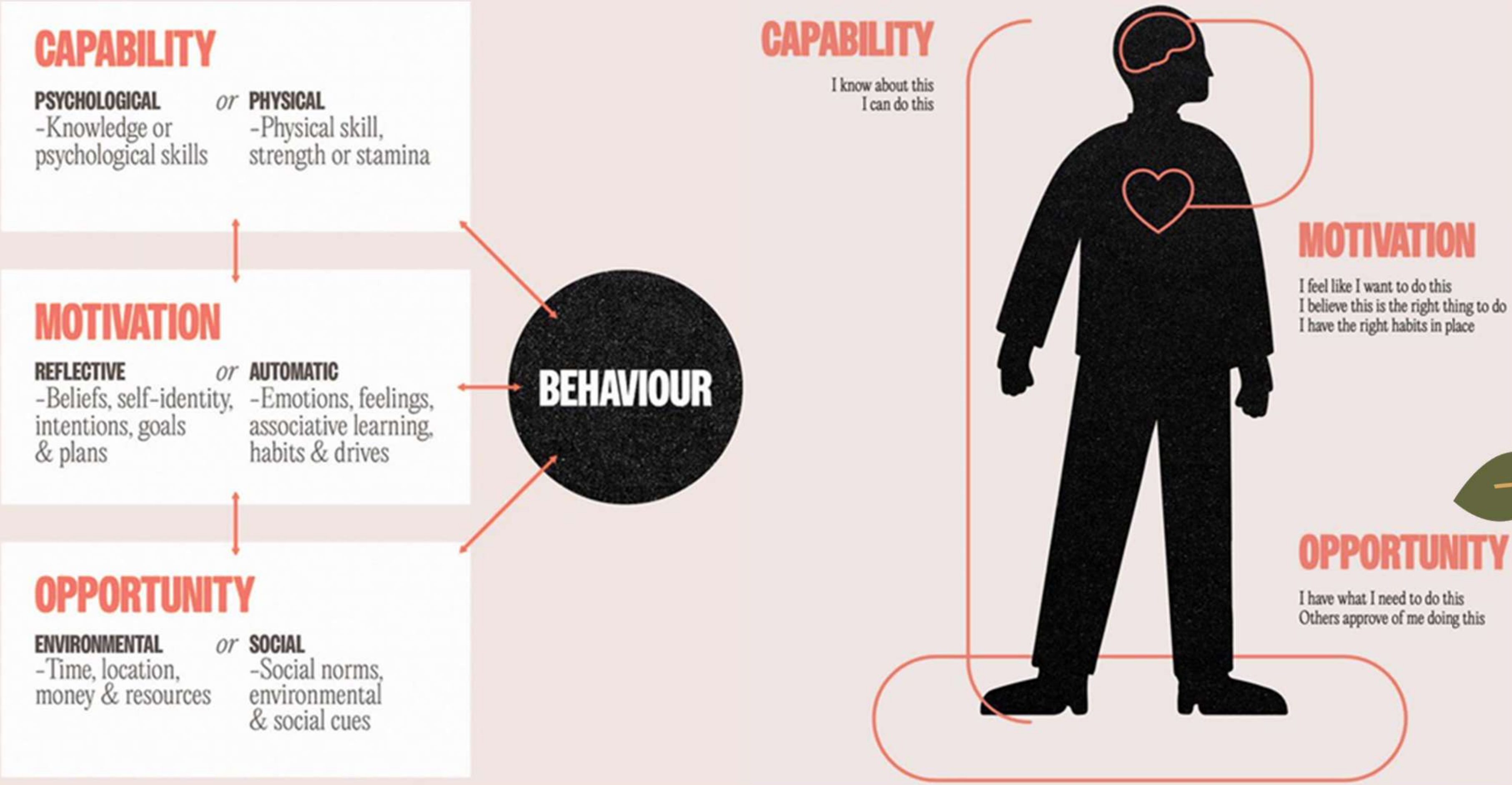


CAPABILITY

PSYCHOLOGICAL *or* **PHYSICAL**

-Knowledge or psychological skills

-Physical skill, strength or stamina

MOTIVATION

REFLECTIVE *or* **AUTOMATIC**

-Beliefs, self-identity, intentions, goals & plans

-Emotions, feelings, associative learning, habits & drives

OPPORTUNITY

ENVIRONMENTAL *or* **SOCIAL**

-Time, location, money & resources

-Social norms, environmental & social cues

BEHAVIOUR

CAPABILITY

I know about this
I can do this

MOTIVATION

I feel like I want to do this
I believe this is the right thing to do
I have the right habits in place

OPPORTUNITY

I have what I need to do this
Others approve of me doing this

The COM-B model of behaviour change

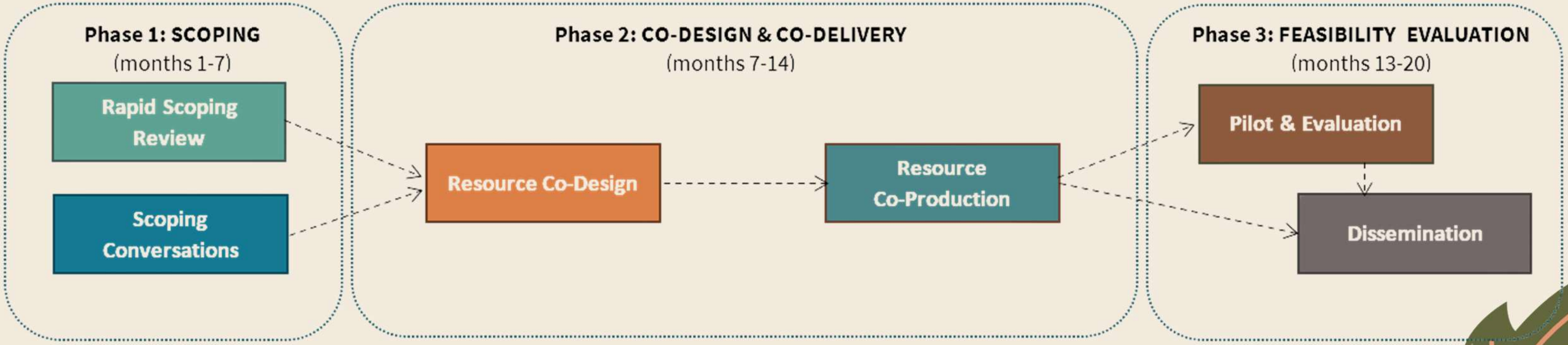
(Bru Garcia, 2024)

Study Flow

Identify barreirs and needs

Co-create resources

Pilot and evaluate



Phase 1: SCOPING
(months 1-7)

Rapid Scoping Review

Scoping Conversations

Phase 2: CO-DESIGN & CO-DELIVERY
(months 7-14)

Resource Co-Design

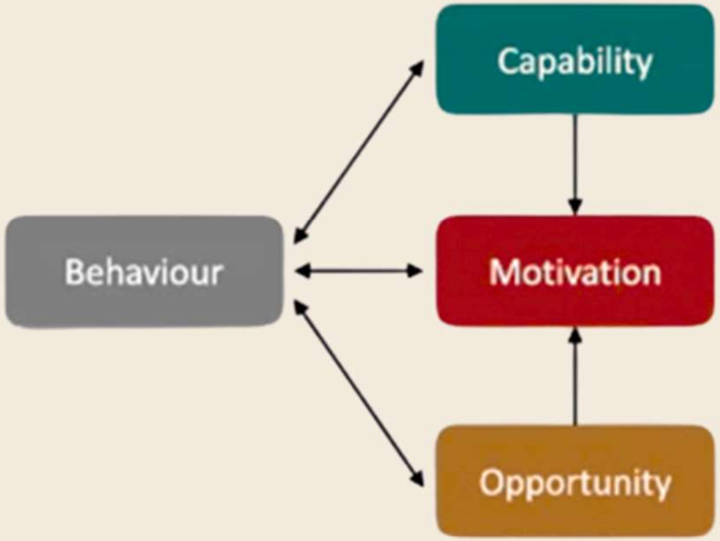
Resource Co-Production

Phase 3: FEASIBILITY EVALUATION
(months 13-20)

Pilot & Evaluation

Dissemination

The relationship between the COM-B model and Behaviour Change Wheel

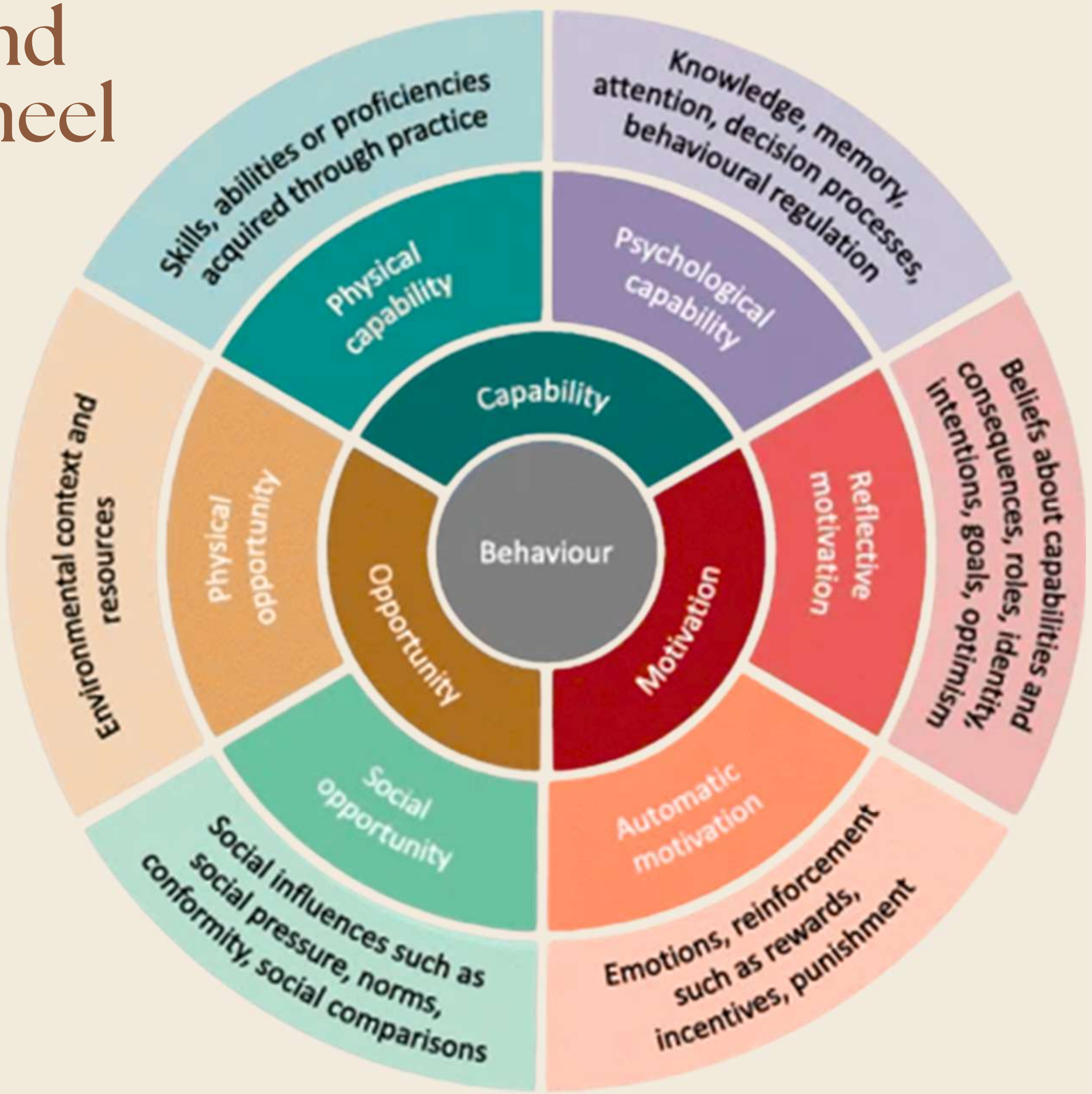


Capability

Behaviour

Motivation

Opportunity



Behaviour

Capability

Opportunity

Motivation

Physical capability

Psychological capability

Reflective motivation

Automatic motivation

Social opportunity

Physical opportunity

Skills, abilities or proficiencies acquired through practice

Knowledge, memory, attention, decision processes, behavioural regulation

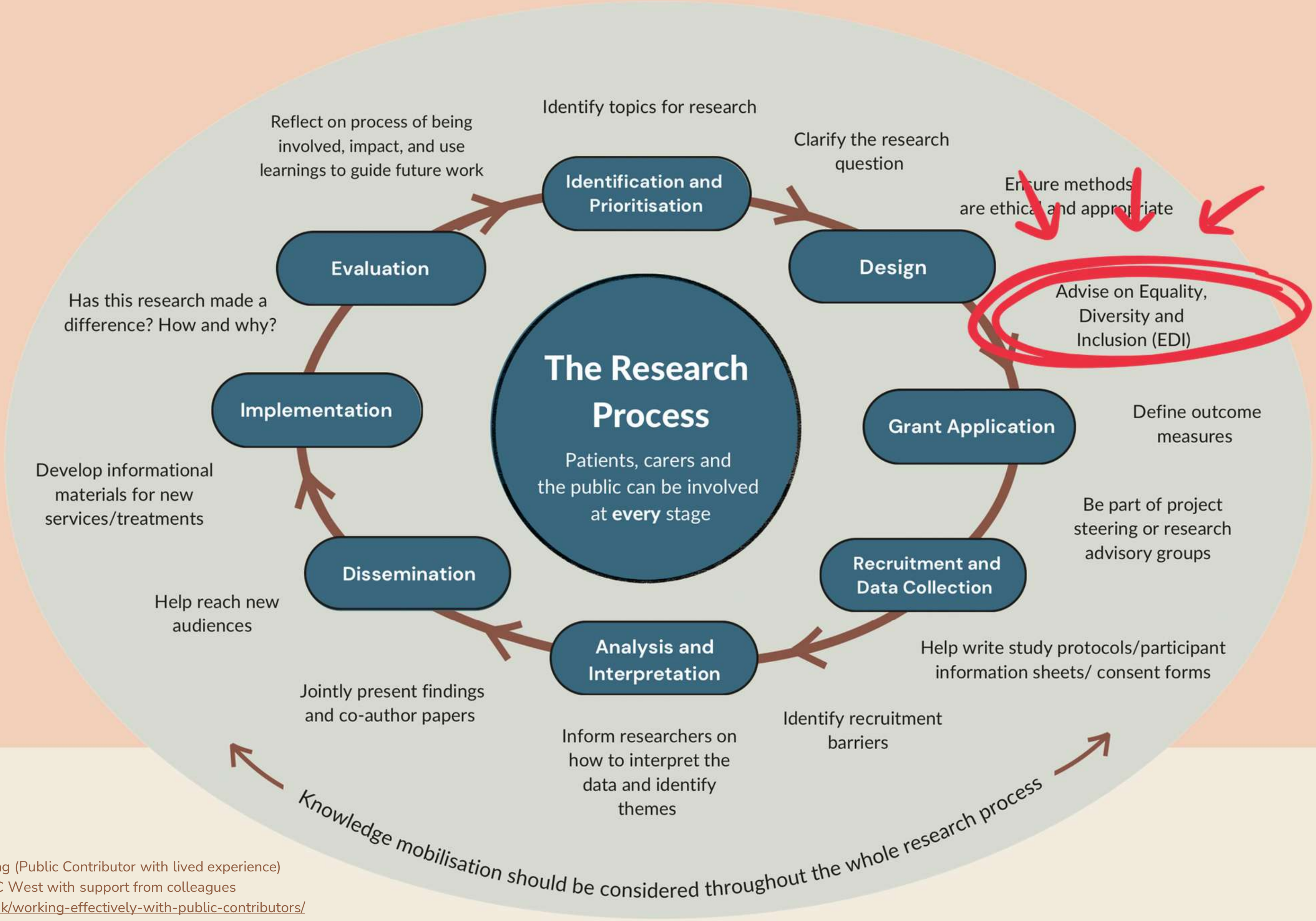
Beliefs about capabilities and consequences, roles, identity, intentions, goals, optimism

Emotions, reinforcement such as rewards, incentives, punishment

Social influences such as social pressure, norms, conformity, social comparisons

Environmental context and resources

(Mitchie et al, 2013)



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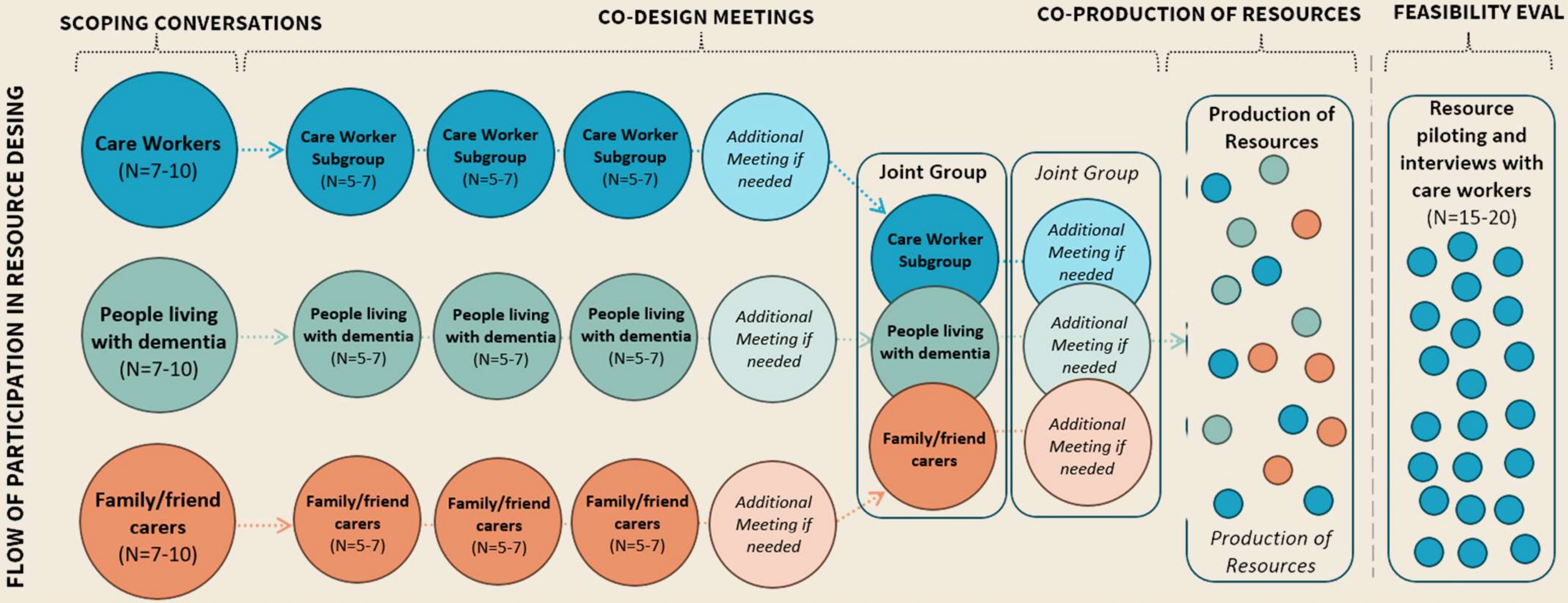
Resource Design



FLOW OF PARTICIPATION IN RESOURCE DESING

SCOPING CONVERSATIONS

Care Workers (N=7-10)

People living with dementia (N=7-10)

Family/friend carers (N=7-10)

CO-DESIGN MEETINGS

Care Worker Subgroup (N=5-7) → **Care Worker Subgroup** (N=5-7) → **Care Worker Subgroup** (N=5-7) → *Additional Meeting if needed*

People living with dementia (N=5-7) → **People living with dementia** (N=5-7) → **People living with dementia** (N=5-7) → *Additional Meeting if needed*

Family/friend carers (N=5-7) → **Family/friend carers** (N=5-7) → **Family/friend carers** (N=5-7) → *Additional Meeting if needed*

Joint Group: **Care Worker Subgroup**, **People living with dementia**, **Family/friend carers**

Joint Group: *Additional Meeting if needed*, *Additional Meeting if needed*, *Additional Meeting if needed*

CO-PRODUCTION OF RESOURCES

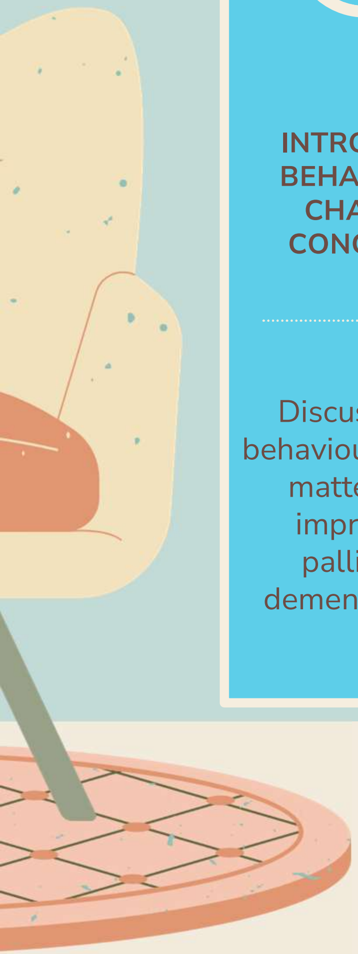
Production of Resources

Production of Resources

FEASIBILITY EVAL

Resource piloting and interviews with care workers (N=15-20)

Scoping conversations - 2hrs per person; co-design meetings (4-6 meetings, 2hrs for attendance plus 1hr each for preparation / document review per participant) – approx. 15hrs per person; Co-production of resources - participants can choose how much to engage, but we have budgeted for an average of 10hrs per person. Scoping conversation participants will be invited to stay in the project throughout its duration, but if participation dips below expected numbers, we will recruit additional stakeholders not previously involved in the project. Care workers participating in the pilot will be recruited separately and will not have taken part in any previous study activities.



Integrating Behaviour Change Techneques in Co-Design

1

INTRODUCE BEHAVIOUR CHANGE CONCEPTS

Discuss why behaviour change matters for improving palliative dementia care.

2

EXPLORE COM-B: CAPABILITY, MOTIVATION, OPPORTUNITY

Discuss skills and knowledge care workers need (e.g. confidence in discussing dying).

3

CO-DEFINE CAPABILITY, MOTIVATION & OPPORTUNITY

Participants share what each means in their own experience.

4

INTRODUCE BEHAVIOUR CHANGE TECHNEQUES (BCTS)

Explain and match BCTs to COM-B components through interactive tasks.

5

PRIORITISE & OPERATIONALISE BCTS

Groups choose key techniques (eg social support) and suggest how they could look in the resources.

6

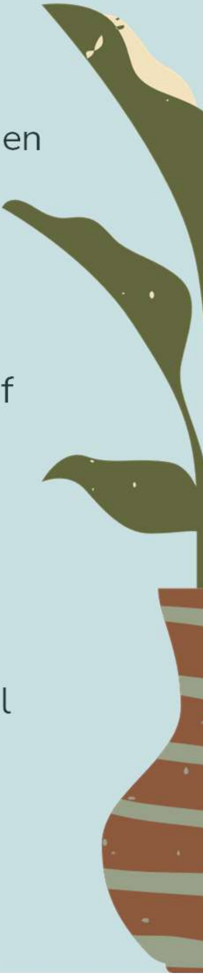
REFINE WITH EXPERTS & PARTNERS

Specialists (e.g. Dementia UK) review and guide application of chosen techniques.

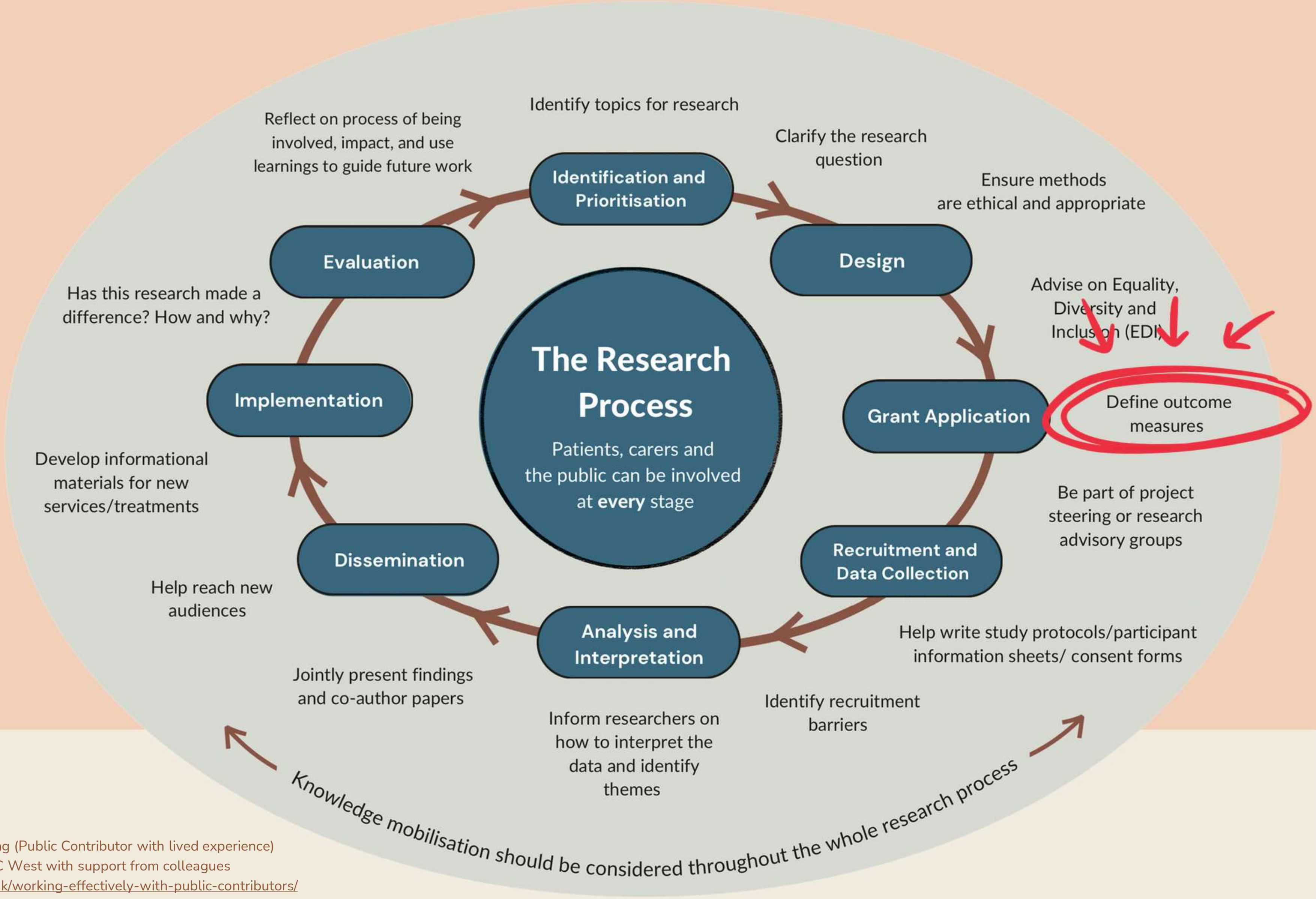
Existing Considerations

- Recruitment for maximum diversity (beyond protected characteristics):
    - e.g. young care workers, visa-sponsored workers, care workers for whom English is not the first language.
- Inclusive recruitment and data collection approaches:
    - e.g. verbal consenting processes, dyslexia-friendly formats, individual-dyad interviews for people who may find focus groups a poor fit
- Diverse dissemination of resources:
    - e.g. co-designed flyer easy-reads, practitioner-aimed events, lived experience co-applicants at conferences

Intentional Unknowns



- No idea what the resources will focus on!
    - e.g. advance care planning, regonition of when someone is approaching death, talking to families about EoL planning
- No idea of what the outputs are!
    - simulated role-play modelling, videos, set of facilitative questions
- Good idea oh how we are develping the resources, but not the specifics!
    - Behaviour Change Techneques will be prioritised by the co-design groups, who will also decide how to apply them
- Designing outcome measures to fit the intervention and the nature of PPI



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Evaluation of the Co-Production Process

- Light-touch evaluation to capture how Phase 2 is progressing and to make iterative changes for maximum inclusion:
    - The co-production process will be evaluated following an approach already used in dementia-inclusive evaluations (Giebel et al, 2023).
    - Analysis will be conducted jointly with EbyE co-applicants, ensuring they receive sufficient methodological support

Evaluation of the Resource Piloting

- Care workers will review resources using the think-aloud methodology (Szinay et al, 2021), followed by semi-structured interviews, co-adapted to fit the nature of resources, but will include:
    - **Change in the behavioural antecedents** defined by the COM-B model (capability, opportunity and motivation). Behaviour change itself would not have happened this quickly
    - **Perceived usefulness and acceptability** of the resources
- Will inform **resource refinement** and **identification of additional components** needed for a future, larger-scale intervention.

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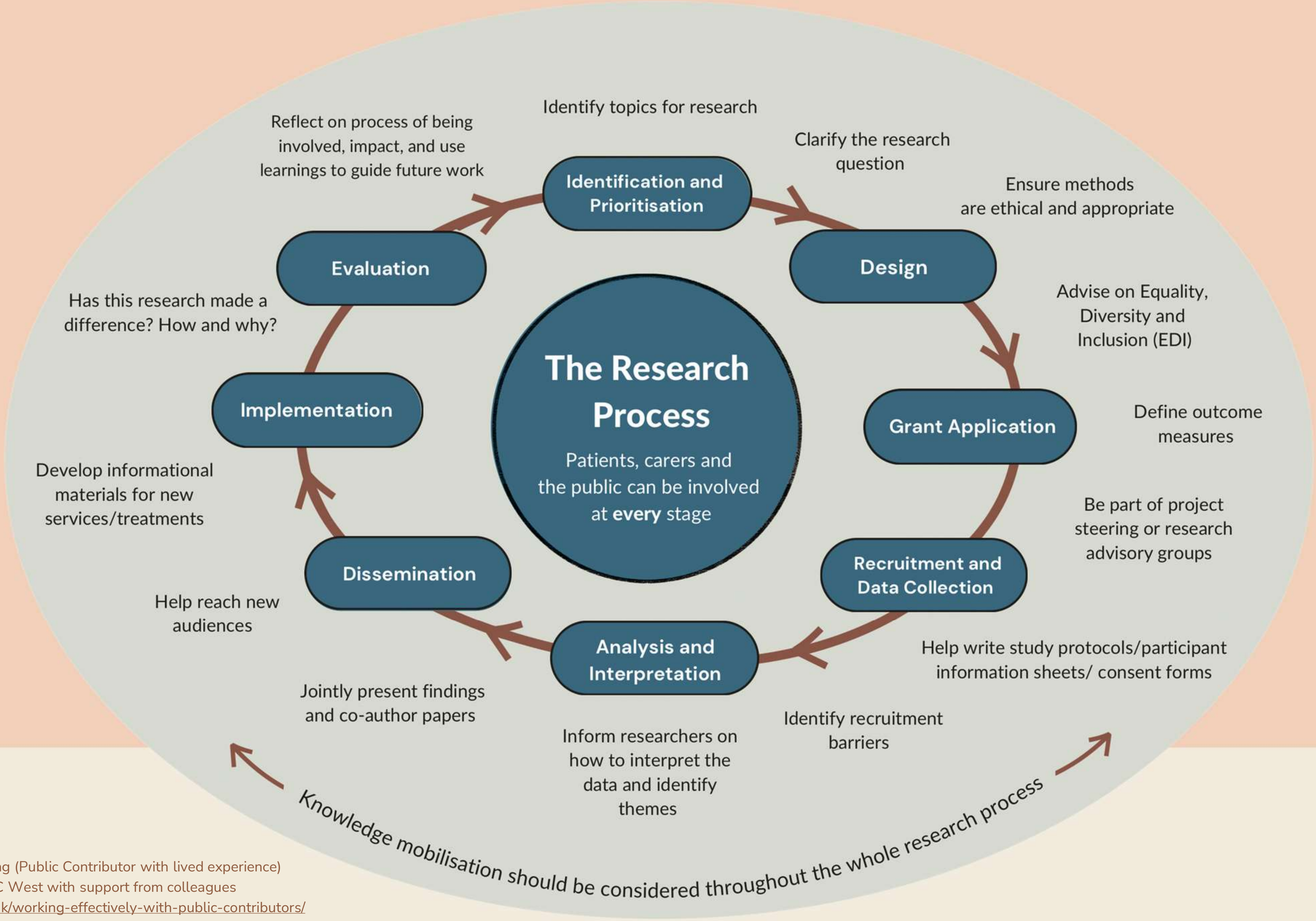
- Involved in every aspect of the study
- Will co-facilitate the co-design groups they represent
- Will co-disseminate findings

Expert by Experience Co-Applicants



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So what?

- People living with dementia are **not passive** recipients of care or mere research participants
- Many people living with and caring for someone with dementia are **keen to shape** what good care looks like, even around **a ‘taboo’ or 'sensitive' topic** like dying.
- Their **meaningful involvement** across the research cycle (as co-applicants, co-producers and co-disseminators) is possible!

Thank you!

Questions?

R.Mikelyte@kent.ac.uk