

**Supporting Family Caregivers  
in the Transition between Hospital and their  
Relative's Preferred Place  
for End of Life**

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**Department of Health disclaimer**

The views expressed are those of the authors and not necessarily those of the NHS,  
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## **STUDY PURPOSE AND DESIGN**

# Rationale

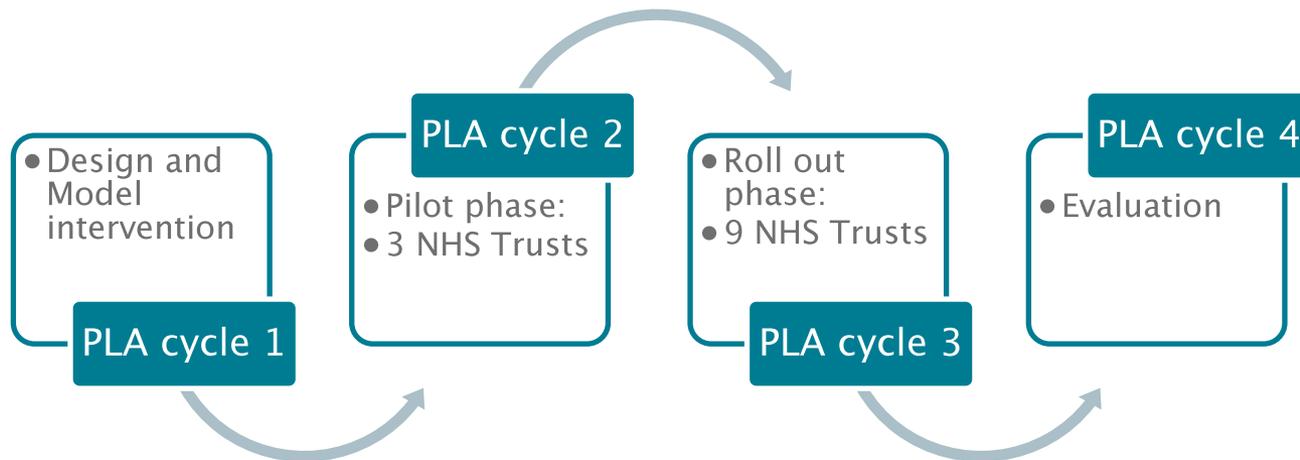
- Transitions at the end of life are emotionally laden – often signalling the severity of the family member’s illness (Penrod, 2012)
- Characterised by uncertainty and psychosocial distress (Payne and Morby, 2013)
- Exacerbated by discharge process, experienced as chaotic and haphazard (Waring et al, 2014)
- Focus on patient and organisation needs, not family needs (Ewing et al, 2019)
- Family support rarely provided (Hanratty et al, 2014)

# Study aims

- To co-construct a support intervention for family members during the transition of care from hospital to home or nursing home for end of life care
  - With a social (family) care orientation
  - To be delivered by health care professionals in hospital
- To assess the usability, acceptability and accessibility of the intervention and the factors influencing implementation

# Study Design

## Participatory Learning and Action Research



# Co-researchers

- Members of public with experience of caring for a dying family member n= 5
- Clinical co-researchers – nurses and occupational therapists working in hospital end of life care teams n=45
- Social and health care experts n=7

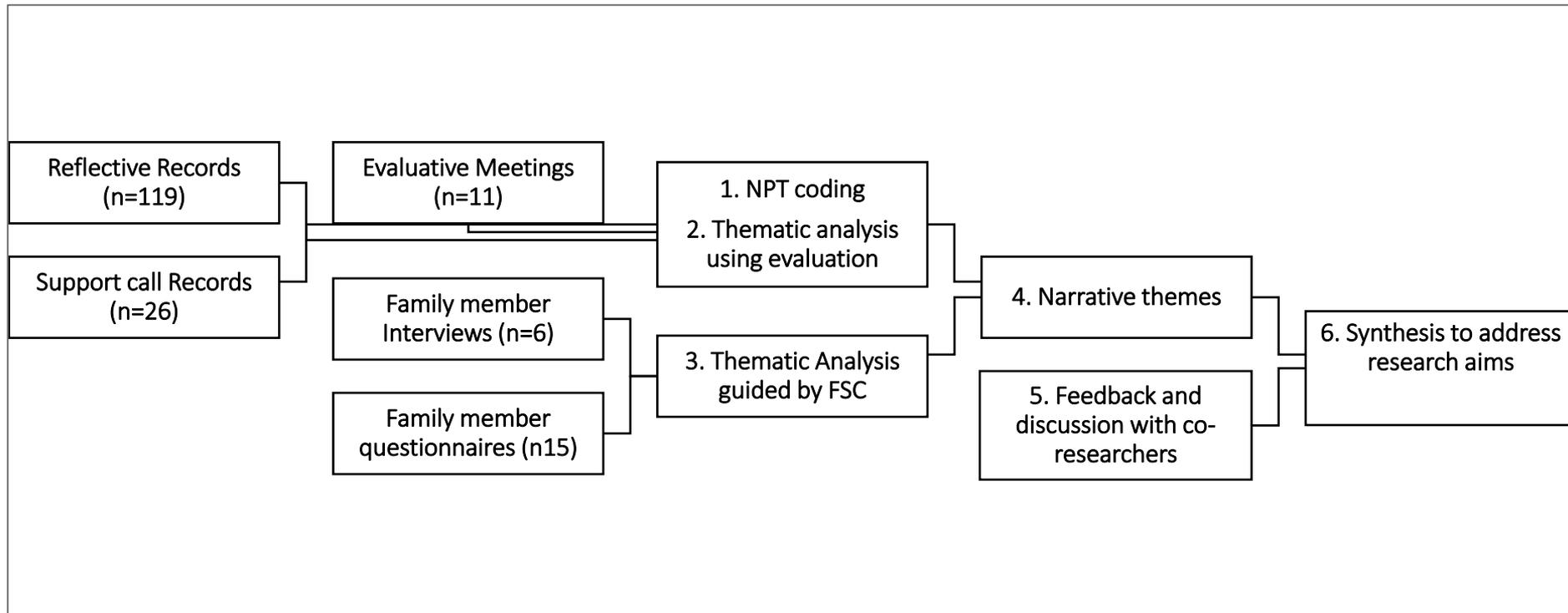
# Theoretical frameworks for study

Normalisation Process Theory – social processes of implementation (May and colleagues 2010)

Intervention = time and space bounded activities and patterns of behaviour, influenced by roles, relationships, resources (Hawe and colleagues, 2009)

Potential for an intervention to change a systems dynamics

# Data sets and analysis



**PLA CYCLE 1:  
Intervention development**

# Identifying mechanisms and intervention design

Thorough review of RCT tested interventions focused on psych-social support at the end of life (n=103 studies) and intervention manuals n=2)

Identification of intervention mechanisms:

- Asking about concerns

- Coaching problem solving

- Facilitating action planning

Co-researcher discussion and modelling using performative theatre

# Foundations of the intervention

EOL Discharge is a significant care transition characterised by uncertainty

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graph TD; A[EOL Discharge is a significant care transition characterised by uncertainty] --- B[Appropriate support can positively influence coping with uncertainty and family resilience];
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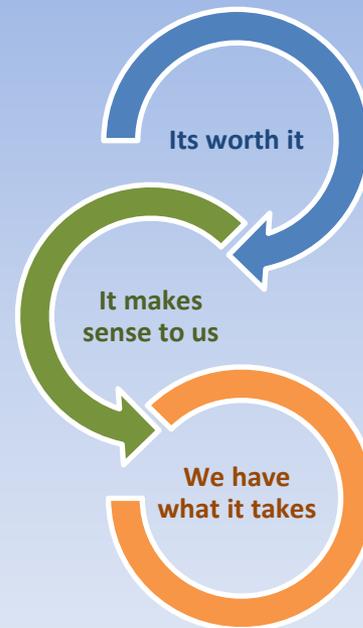
Appropriate support can positively influence coping with uncertainty and family resilience

# Family Sense of Coherence

theoretical underpinning of the hospital to home intervention

A family's resilience (their ability to cope with stressful events) is influenced by:

- **Being motivated to respond to family challenges (meaningfulness)**
- **Wanting to try to make sense of the situation (comprehensibility)**
- **Being able to utilise available resources (manageability)**



# **Family-Focused Support Conversation**

# Family-Focused Support Conversation - Intervention components

## **Meaningfulness:** significance

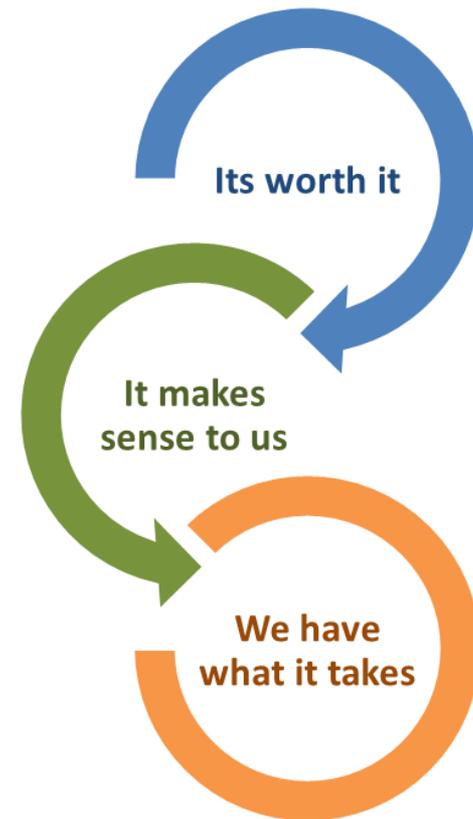
‘We know this is often a difficult time for families (pause)’

## **Comprehensibility:** Concerns and implications

‘Have you talked as a family?...what concerns were raised?...

## **Manageability:** Plan

‘Have you any thoughts as a family how you might manage these concerns?’



## **PLA CYCLES 2 and 3: Implementation**

# Pilot implementation (3 months)

Aim: to assess the potential to use the intervention in practice and whether it caused unexpected or undue disruption

Implementation sites: 3 NHS Trusts (3 acute hospitals, 3 hospital palliative care teams)

Implementation undertaken by n=7 clinical co-researchers (specialist nurses n=6 and occupational therapist n=1)

Assessed by practitioner reflective analysis of interventions provided (n=22), support calls with implementation teams (n=3) and evaluation meetings (n=2)

# Roll out implementation (6 months)

Aim: to assess usability, accessibility and acceptability and factors influencing implementation

Implementation sites: 7 NHS Trusts (9 acute hospitals, 12 hospital palliative care teams); included populations with diverse economic and ethnic populations across England

Implemented by: 45 clinical co-researchers, specialist nurses (n=42) and occupational therapists (n=3)

Assessed by practitioner reflective analysis of interventions provided (n=105), support calls with implementation teams (n=26) and evaluation meetings (n=9); family questionnaires (n=15) and interviews (n=6)

# PLA CYCLES 4: Evaluation

# Pilot implementation key results

Intervention was implemented, took no more time than usual practice

Intervention *'pulled practice apart', 'flipped conversations to focus on the family' – from 'something done to families', 'to a focus on family concerns'*

# Roll out implementation key results

Intervention was usable, accessible and acceptable by practitioners and family members

Changed the nature of family support – family members felt valued and supported and equipped them to provide care

Influenced by relationships between specialist and ward teams

Intervention was sufficiently flexible to take account of case load pressures and conflicting priorities

# Changed the colour of family support

*It 'changed the colour of family work', 'Previously [we] had focused on the patient, [we] had a paternalistic/arrogant approach of what [we] could offer as a team and professionals, and what the family needed to do. Now [we] ask family members their concerns'*

It changed interactional practice with family members *'how I deliver lines like a script'*

It challenged practitioner assumptions about family needs *'made (us) listen to what the family have been thinking about and to their thoughts about solutions'*

# Family members:

Felt valued and supported

- *They were, they were concerned about us... a couple of times we...started crying when they ... started to involve us...that someone was caring about us (S001)*

Intervention informed family decision making, to think through concerns and facilitated conversations with other family members

*'It's that awful torment, isn't it? You want to know what you don't want to know' (Family member D)*

*'It's difficult to say but the fact that my mum was dying sort of wasn't in my mind anymore. What was in my mind was to get her home and start to look after her at home. I wanted her to be at home. I wanted her to be in her own bedroom' (Family member A).*

# Influencing factors

Intervention was readily implemented, took no more time than usual practice and often saved time

The intervention was sufficiently flexible to take account of case load pressures and other priorities -

Relationship between specialist and ward teams influenced whether the intervention was considered legitimate work – dependent on previously agreed roles in discharge

Has potential to enhance sustainability of discharge and distribution of health and social care resources

# Conclusion

The Family-Focused Support Conversation is useable, accessible and acceptable

Enabled hospital health care practitioners to provide family-centred support during end of life care transitions from hospital to home or nursing home

Importantly it focuses on meaning-making – practitioners supporting family members to understand the significance of end of life care discharge and to make informed decisions about their role in care