UNIVERSITY OF CAMBRIDGE

MANCHESTER 1824
The University of Manchester

How can carers be supported better at end-of-life? A mixed methods study to identify recommendations for change in organisational structures /processes.

Dr Gail Ewing

Professor Gunn Grande

Background: current policy guidance

Ambitions for Palliative and End of Life Care:

A national framework for local action 2015-2020
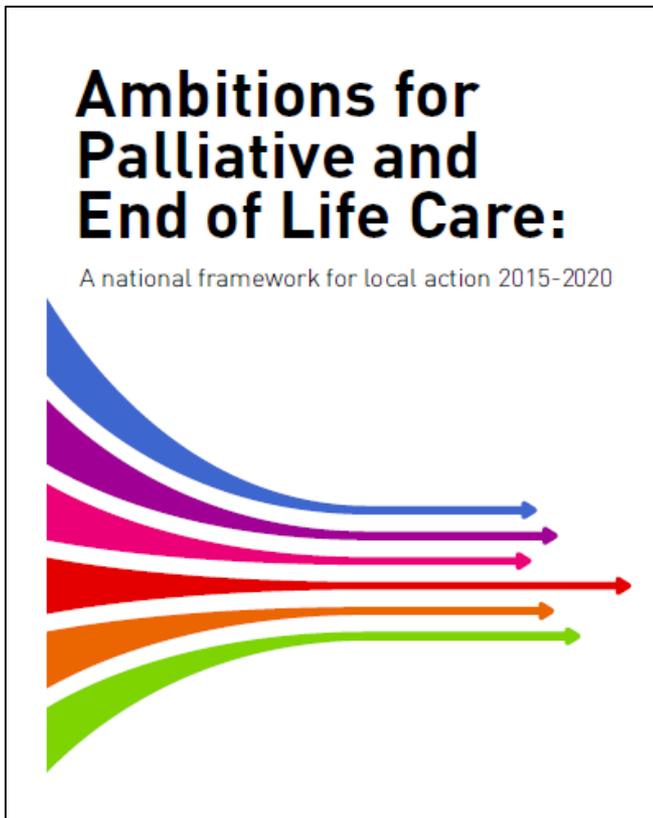
- Ambitions for carers, families and those important to the dying patient
- Core recommendation for care and support to be
  - *comprehensive*
  - *person-centred*
  - *holistic*

Our research question

"What are the structures and processes that need to be in place within services to provide comprehensive, person centred assessment and support for carers in end of life care?"

Study aim

To provide recommendations for services for key structures and processes

The study process

1. Secondary analysis of existing implementation data

2. Expert consultation through focus groups

3. Stakeholder consultation through workshops and online survey with health and social care professionals, carers, policy leads and academics

Results: 10 recommendations

1. Identification of carers
2. Data on carers
3. A method/protocol for assessing carers & responding
4. A recording system for carers
5. A process for training staff
6. Available time/workload capacity
7. Senior management support
8. Role models/champions
9. Pathways for communication
10. Monitoring/auditing processes and outcomes

1 **Consistent identification of carers within the care setting**

- **Systematic and consistent process**
  - *".. the key word is consistent …"*

- **Pro-active - by practitioners**

- **Awareness of carers see themselves in relationship terms**
  - Should not be a barrier to identification and support
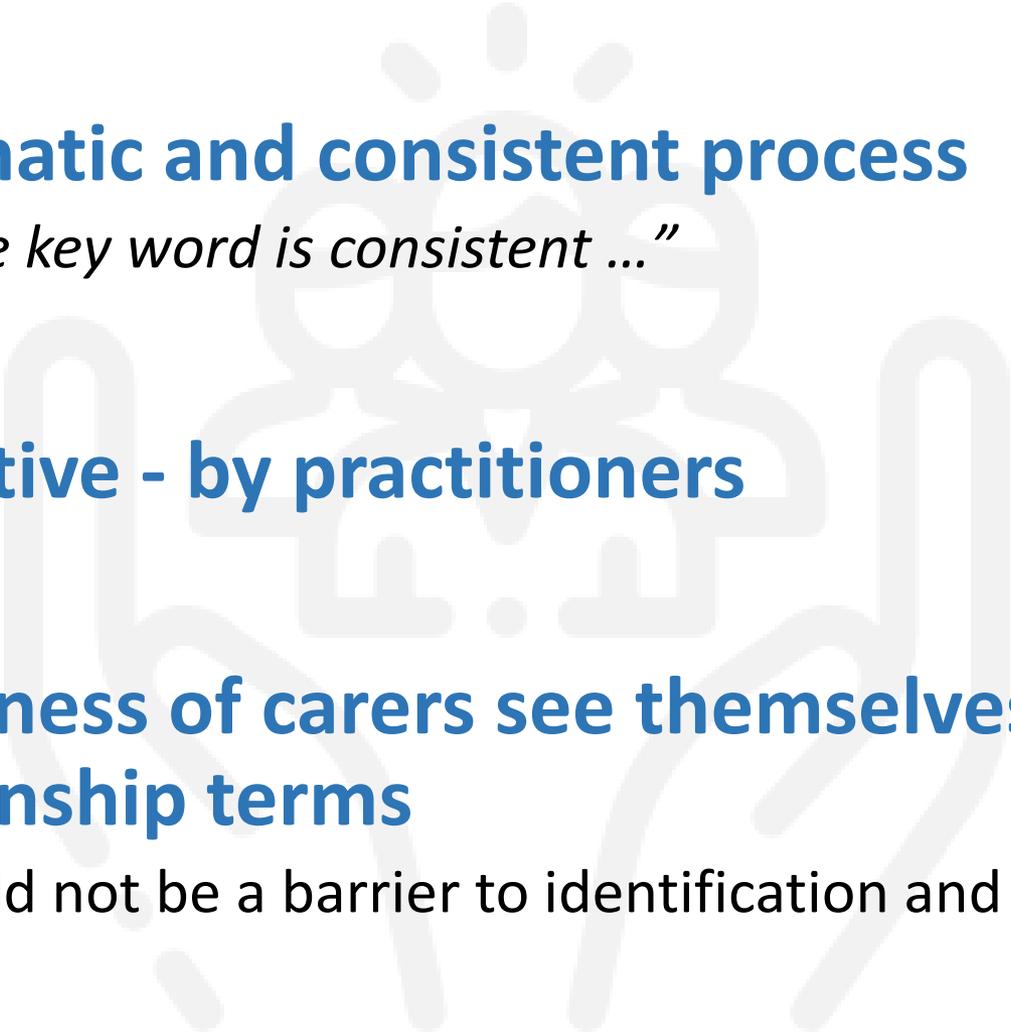
2 **Demographic & contextual data on who the carer is & their situation**

- **To aid awareness of carers; underpin assessment and support**

- **Currently a lack of data**

  "Well, it's interesting, because I'm always asked how many carers are we supporting, and everyone always knows how many patients were referred last year. But we have no data on exactly how many carers we are supporting."

- **Systems to be put in place across all settings**

3

A protocol for assessing carers and responding to the assessment

- **Moving from informal and practitioner-led to a carer-centred approach**

- **Current processes described as**
  - *'inconsistent'*
  - *'narrow in focus'*
  - *'ad hoc'*

- **Consistent, comprehensive process**
  - Recognises and values the role of carers in EOLC

4 A recording system for carer information separate from patient data

- **To support identification of carers and underpin assessment and support**

- **Significant challenge across settings – where do carer assessment details go?**
  - Separate records in primary care – linked??

- **Where carer records – need for consistent completion**

A process for training practitioners about carer assessment & support

- **Comprehensive, person-centred carer assessment and support – a change in practice**
  - requires training and support

- **Training at multiple levels**
  - General awareness raising of carers across workforce
  - In nurse training
  - For junior frontline staff to identify and assess
  - Advanced level practitioners – to *'up their game'*
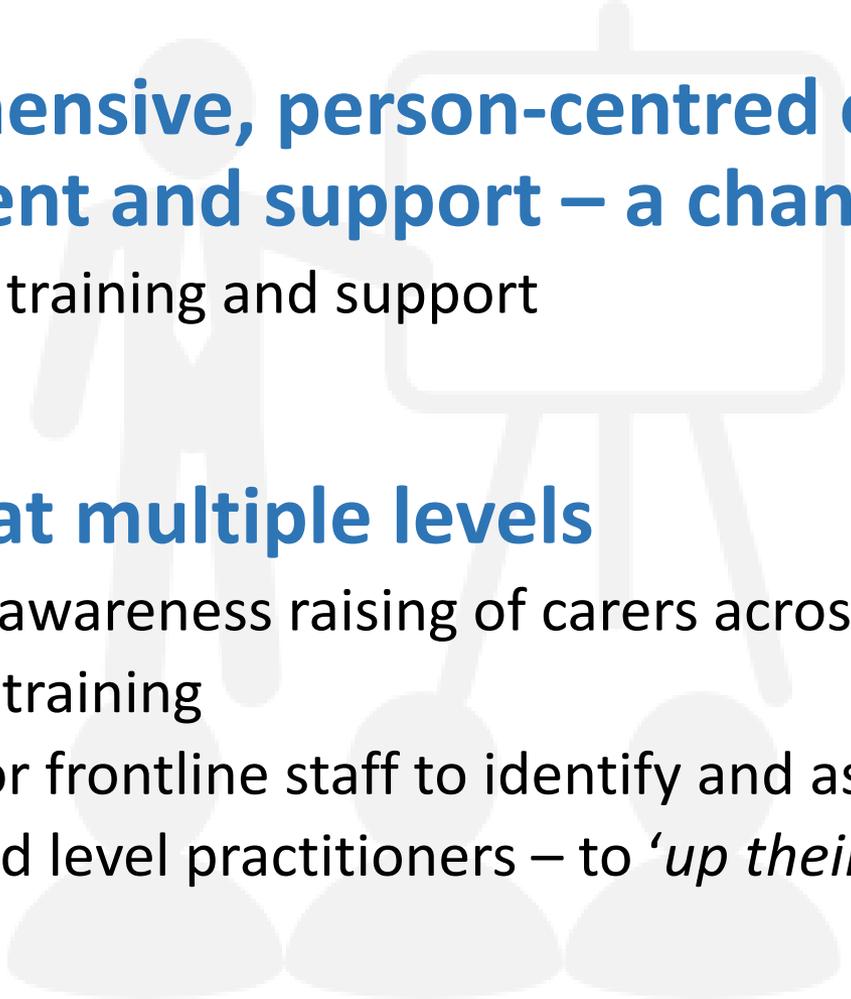
6 **Available time/workload capacity for carer assessment and support**

- **Investment of time in short term for later gains**
    - Potential to improve quality of care
    - Better outcomes for carers ⟶ patients

- **Frontline staff –** *'firefighting'*
    - positive sentiments about supporting carers not enough without addressing resource issues

- **Not just about time and resources**
    "a considerable mind-shift for practitioners from a focus merely upon the patient "

7 Support from senior managers for carer assessment and support

- **To initiate a change in practice**

- **To drive the process forward**
  - Support from commissioners needed to help managers deliver the carer agenda

- **Sustain changes longer term**
  "A dynamic input" … "If you don't refresh the vision the initiative will not keep going."

8 Role models / champions for carer assessment and support

A formalised organisational role

- Creating a positive culture

- Providing enthusiasm and drive

- Cascading training

- Providing exemplars for practice

- Peer support

- Problem solving

Pathways for communication about carer assessment and support

- **Two way communication between organisational levels**

- **Between peer practitioners**

- **Specific to carers in their own right**
  - *"sometimes they're mentioned, sometimes they're not, there's not a slot 'and what about the carers?' with each patient."*

10 **Procedures for monitoring /auditing processes and outcomes of carer assessment and support**

- **For internal purposes**
  - To assess goals on carer assessment and support being met; problems identified

- **For external communication**

  ".. our commissioners are asking us to demonstrate outcomes and how we can achieve certainly carer screening and carer assessments are something, [..] we'll have to demonstrate

Conclusions

- 10 recommendations - key building blocks
  policy ambitions ➡️ practice
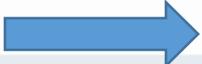
- Two key challenges

  A general challenge of embedding a different way of working (PCC) - for patients not just carers

  carer-specific challenge of resolving where carers 'fit' within palliative and end of life care

  DISCUSS

Thank you

Dr Karen Spencer, Research Fellow, University of Manchester.

Michael Spence, Programme Manager, NIHR CLAHRC, Greater Manchester.

Zoe Ashton, Facilitator, NIHR CLAHRC Greater Manchester.
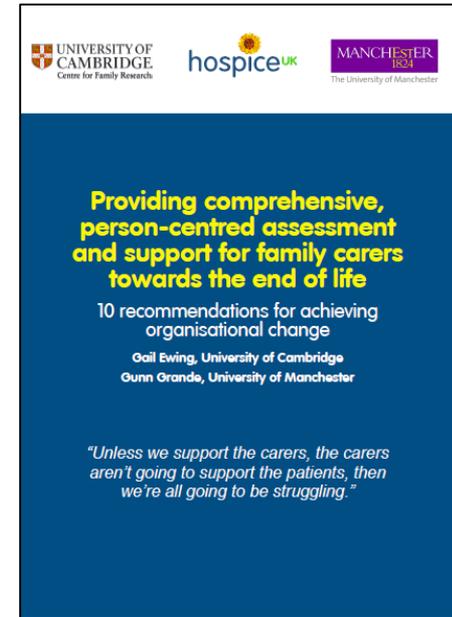
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