

Easy-to-read summary: Priority setting for end-of-life research

Since January 2016, the NIHR CLAHRC Greater Manchester has been working with local carers and healthcare professionals (doctors, nurses, Macmillan staff, end-of-life professionals, hospital managers etc.) from our partner NHS organisations to find out what the priorities are for end-of-life research in Greater Manchester.

What we wanted to find out

- What are the important areas for improvement in end-of-life care in Greater Manchester?
- Which end-of-life topics are we best able to investigate/research?
- Which are the most important topics for future end-of-life research in Greater Manchester for both local carers and healthcare professionals?
- Of these key topics, which are the most important research questions to investigate?

What we did

Through early discovery discussions with local healthcare professionals, we identified six topics within which we have the knowledge and skills to deliver end-of-life research in Greater Manchester:

- 1 24-hour access to care**
- 2 Planning end-of-life care in advance**
- 3 Staff and carer education**
- 4 Consistency/continuity of care**
- 5 Care at home**
- 6 Equal access for all.**

Through a number of carer organisations in Greater Manchester we invited carers with experience of or an interest in end-of-life care to take part in the project. We held group meetings and interviews with carers to find out which of the six topics mentioned above should be priorities for end-of-life research.

This work was funded by the National Institute for Health Research Collaboration for Leadership in Applied Health Research and Care (NIHR CLAHRC) Greater Manchester, a partnership between providers and commissioners from the NHS, industry, the third sector and the University of Manchester. We aim to improve the health of people in Greater Manchester and beyond through carrying out research and putting it into practice.

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We also invited healthcare professionals to take part in a half-day workshop to gather their perspectives on what the most important priority areas were.

We then compared the responses to see which were the most important topics overall and whether there were any differences or similarities between the carers' and healthcare professionals' views.

Results

1. 24-hour access to care

24-hour care and support was seen as very important by both groups as ultimately it could help to reduce carer/family strain as well as prevent crises and unplanned admissions to hospital.

There were concerns from carers that emotional and medical support was not available during the night and weekends. Having someone to provide *'holiday cover'* was also highlighted as important, as well as the need to have someone to contact for support and reassurance or professional medical advice [*"just be there when you need it"*].

2. Planning end-of-life care in advance

Planning of end-of-life care in advance was seen as important for helping patients to take control and to make decisions about their care, it also enables healthcare professionals to feel in control about the care they provide.

For carers, the importance of this planning centres on the need for healthcare professionals to have the difficult conversations as soon as possible [*"healthcare professionals need to approach difficult questions early"*].

Better knowledge of available services by the healthcare professionals and better communication between patients, carers and healthcare professionals would help to avoid crises in the home such as:

- (i) Unnecessary hospital admissions
- (ii) Poor transfers of care
- (iii) Unwanted treatments.

3. Staff and carer education

Education and training was seen as vital in ensuring that carers felt supported and empowered to carry out their caring role. Carers wanted to know what to expect when the patient was close to death and how to recognise that their loved one was dying [*"the carer and the family need to know, this is what happens when a person dies [...] and the practicalities of what that means"*].

Carers also felt that they wanted more information about the treatments being given, and up-to-date information about the patient's condition, as well as guidance on how to give certain treatments and manual handling. Carers also stated the need for information to be shared in a timely fashion [*"it's about giving information and knowledge at the right time"*].

Other areas mentioned were:

- Better training required for healthcare professionals (*“high quality compassionate staff are better than just quantity”*)
- Better directing of carers to the right information and contacts required
- Improved bereavement preparation needed.

4. Consistency/continuity of care

The lack of continuity in hospital care was a big issue for carers. It was highlighted that having a key worker or named person to contact to help coordinate care would be beneficial, as there are often a lot of different staff delivering care for the patient and having to explain the same details repeatedly to different members of staff was viewed as a source of stress. It is important for GPs, nursing homes and all healthcare professionals to have up-to-date knowledge of the patient, their condition, their necessary treatments and how to administer them.

5. Care at home

This topic was important to carers with a particular focus on how to transition from social care to palliative care [*“how quickly will the end-of-life care kick in to ensure dignity and less stress on the family?”*]. Another carer discussed how healthcare professionals could help with this decision-making, in particular if the person does not have the capacity to make that decision, as well as providing reassurance for the carer and patient [*“somebody who can come in and say, you’ve done a really good job, it’s better to go into a hospital now”*].

6. Equal access for all

This topic was mentioned throughout the discussion and was linked to a lot of the other topics. Healthcare professionals felt that there were differences in the timeliness of available services, how certain policies were used, how certain diagnoses were treated, how different areas were dealt with as well as cultural and spiritual influences.

Carers also highlighted that access to services and treatments for patients could be improved, as it currently varies by locality, for example with continuing healthcare and social care, which can have a big effect financially [*“I was having to fight for everything”*]. Other carers spoke about difficulties with decisions being made too late, and a lack of services for people with mental health issues or learning difficulties [*“there is no place for anybody with a learning disability to go, is there, at end-of-life”*]. The need for spiritual and emotional support and the impact of both of these factors was also highlighted by carers and healthcare professionals.

Conclusion

Whilst we set out to find out which of our topics were the most important, it is clear that all six of these areas are key elements of end-of-life care and therefore must be key elements of end-of-life research.

The three key topics that appear to have particular importance to both healthcare professionals and carers are:

- 1 Access to 24-hour care**
- 2 Planning end-of-life care in advance**
- 3 Staff and carer education.**

But the remaining three topics were also agreed as important. As well as our six topics, we found that our carer and healthcare professional participants also identified a number of key themes that spanned across all the topics, and these are also vital to consider for future end-of-life care research. These include:

- **The need for improved communication between patients, carers and different services and/or agencies.**
- **Better understanding of the expectations carers will have about their involvement in various aspects of care.**

Next steps

Moving forward, we have developed a number of research questions that could be used as starting points for future end-of-life care research. We will continue to work with our carer and NHS partners to use our findings to define plans for end-of-life research in Greater Manchester.



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Notes

This work builds on the [national research priority report \(2015\) by the Palliative and End of Life Care Priority Setting Partnership \(PeolcPSP\)](#) which outlined ten key areas to focus on within end-of-life care research.

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