Collaboration for Leadership
in Applied Health Research
and Care Greater Manchester

NHS
National Institute for
Health Research

Next steps for end-of-life research

Research priorities defined for Greater Manchester

In partnership with:

Bury Carers Centre
Greater Manchester, Lancashire and South Cumbria Strategic Clinical Networks
Manchester Carers Forum
Salford Royal NHS Foundation Trust
University Hospitals of South Manchester NHS Foundation Trust

Foreword

I am delighted to introduce the results of our end-of-life priority setting consultation to determine the next steps for research across Greater Manchester. It has been a privilege to work with so many partner organisations, all recognising the need for more research to improve end-of-life care. The success of this work is largely thanks to our local carers and healthcare professionals for the openness with which they shared their views and experiences.

With limited funding available for end-of-life research, it is our responsibility to make policy makers aware of the knowledge gaps to highlight where the most urgent needs for high quality research lie. We hope that this report will help to focus research organisations across Greater Manchester on the end-of-life research that concerns local carers and healthcare professionals the most.

Gunn Grande,
Professor of Palliative Care,
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Funding

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. Please visit www.clahrc-gm.nihr.ac.uk for more information.

Contents

Glossary of terms

EoL	*End-of-life*
HCP	*Healthcare professional*
PeolcPsP	*Palliative care and end-of-life care Priority Setting Partnership*
CLAHRC GM	*Collaboration for Leadership in Applied Health Research and Care Greater Manchester*
ACP	*Advanced Care Planning*
CCG	*Clinical Commissioning Group*
PICO	*Population, Intervention, Comparator and Outcome*
CLIP	*Client group, Location, Improvement and Professionals*
EPaCCs	*Electronic Palliative Care Co-ordination Systems*
CHC	*Continuing Health Care*

Key messages

Palliative and end-of-life care is a largely under-researched area. There are many unanswered questions that need to be addressed and, with limited time and resources, it is vital to focus on the priorities of greatest importance that are likely to bring benefits to local patients and their families. This report sets out the research priorities in Greater Manchester within the scope of national research priorities. The consultation period was six months and involved 32 healthcare professionals (HCPs) and 26 carers. Our results define what is important for research within Greater Manchester using the national top 10 end-of-life research priorities defined by the Palliative and end of life Care Priority Setting Partnership (PeolcPSP) as a framework[1].

Consultation Process:

HCPs gave their views at a workshop with small group discussions. HCPs chose two topics that were important from six locally pertinent topics selected from the national top ten research priorities. Within these discussions HCPs developed research questions that would be important to address. Carers decided which of the six topics they wanted to discuss and this included why that topic was important to them. The detailed carer discussions were used to refine the research questions that HCPs developed, to ensure that the questions represented the interests and concerns of both HCPs and carers. We used a more flexible approach with carers, so they could decide when and how they expressed their views, due to the demands of their caring role and/or health problems.

Results:

Initial scoping with stakeholders led to the selection of six potential local priority topics from the national top ten priorities to take forward within Greater Manchester, these are:

1. Staff and carer education
2. Planning end-of-life care in advance
3. Access to 24 hr care and support
4. Care at home
5. Equitable access
6. Continuity of care

We used these topics as a basis for further exploration with carers and HCPs to understand those which were particularly relevant to local end-of-life care. Table 1 shows the top three topics and also one broad research question. The topics and questions shown below were particularly important for both HCPs and carers. The results section presents the full range of research questions.

Table 1. The top three shared priority topics and a key research question

Topic	Research question
Access to 24 hour care	*What does effective and appropriate 24 hour care look like?*
Planning end-of-life care in advance	*How can Advanced Care Planning (ACP) discussions and decisions be communicated effectively between healthcare providers in different settings?*
Staff and carer education	*What are the education and training support needs of carers across the end-of-life care trajectory?*

Conclusions:

It was clear from our consultation process that all six topics held some importance for both HCPs and carers within Greater Manchester, which validates the national findings.

However, there are a number of key issues for end-of-life research that emerged within the discussions and spanned across each topic area. We highly recommend that that the following are also considered in the design and explorations of future end-of-life care research:

(i) The need for improved communication with patients and carers, and between different services and/or agencies
(ii) The need for equal access to care across different diagnosis groups, socio-economic status and geographical location
(iii) The management of both the patient and carers, and HCPs expectations in relation to their involvement in various aspects of care

Moving forward, any one of the research questions raised within this report could be used as a starting point for future end-of-life research.

1. Background

This piece of work builds on the national research priority report (2015) by the Palliative and end-of-life care Priority Setting Partnership (PeolcPSP)[1]. PeolcPSP worked with patients, carers, health and social care professionals to identify and prioritise research questions to influence future end-of-life research in the UK. They worked in partnership with Marie Curie, NHS England and the James Lind Alliance, with a total of 30 organisations taking part. As part of PeolcPSP's work they have identified ten topics for future end-of-life research for the UK.

Since then, the All Ireland Institute of Hospice and Palliative Care have adapted these priorities to Northern Ireland and the Republic of Ireland specifically[2]. Hence we within CLAHRC GM[a] have utilised a similar approach to establish how relevant the ten nationally developed priorities are within Greater Manchester. We have also defined broad research questions within these priority topics which the local healthcare and academic community could take forward for further exploration and research.

2. Purpose

Population demographics and service provision vary by Clinical Commissioning Group (CCG) and even within CCGs, particularly for end-of-life care. This is well reported within healthcare policy[3] and the academic literature[4]. The purpose of this work is to ensure such regional variances are taken into account within future end-of-life research priorities.

The exploration of the top ten national end-of-life research topics is an essential part of developing effective and worthwhile future research for Greater Manchester.

This project addressed the following three questions:

(i) Which of the top ten UK research priorities for end-of-life care do we have the interest, knowledge and skills to take forward in Greater Manchester?
(ii) Of these topics, which of these are perceived to be important for future end-of-life research in GM for both local carers and healthcare professionals (HCPs)?
(iii) Within the important topics for Greater Manchester end-of-life research, what are the research questions that need addressing?

3. Approach

3.1 Initial scoping work

Between August 2014 and July 2015, using semi-structured discovery interviews, members of our CLAHRC GM team collected the opinions of a wide range of end-of-life HCPs from primary, community and secondary care about local end-of-life services. In total, 29 HCPs were interviewed and provided information which largely focussed around gaining an understanding about:

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[a] *Collaboration for Applied Health Research and Care Greater Manchester (CLAHRC GM):* is 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.

(i) the roles of individuals and groups of practitioners
(ii) the HCPs which were key to end-of-life care
(iii) the remit and capacity of specific end-of-life services
(iv) the referral pathways
(v) areas that are important to develop further

The interviews were not transcribed, but detailed field notes were collected. The data were analysed using a framework analysis to identify key themes and areas of common linkages. As table 2 below shows, five clear themes were identified.

Table 2. Local end-of-life care themes identified

Themes	Quotes
Integrated approach to community care, involving care planning and communication	*"The integration of health and social teams is beneficial to cross-team communication"* *"A care pathway could prove useful for improving in-home care"* *"Communication between nursing homes and hospitals needs to improve"*
Importance of building relationships with carers throughout care into bereavement	*"Building a pre end-of-life relationship with patients and carers"* *"Other aspects of good end-of-life care include providing support for carers"* *"Carers would like reassurances they are doing the right thing"*
Rapid efficient discharge with 24 hour access to services	*"The main complaint [from patients] is inappropriate hospital admissions"* *"Discharge done efficiently and correctly is crucial"* *"Issues with [ordering] equipment sometimes delay discharge"*
Consistency and continuity of patient care with a single point of contact	*"Lack of co-ordination between teams can lead to a lack of continuity of care for patients"* *"A named contact for each patient to ensure continuity, communication and trust"* *"A key worker for each patient would be useful"*
Awareness and better utilisation of the services available	*"Good practice is knowing the area and district nurses well and liaising with them successfully"* *"The Marie Curie night service is particularly useful but needs to be planned and it is not possible to arrange within 24 hours"* *"District nurses are key for end-of-life care"*

This initial scoping work provided insights into local end-of-life care, and helped to focus the more detailed HCPs research priority workshop, and our discussions with carers around their priority topics for future end-of-life care research. We used the data collected and themes identified in combination with ten national PeolcPSP research priorities[1], to streamline the national priorities down to the six most relevant for the local area, as displayed in table 3.

Table 3. The six most locally important end-of-life research topics from the national 10

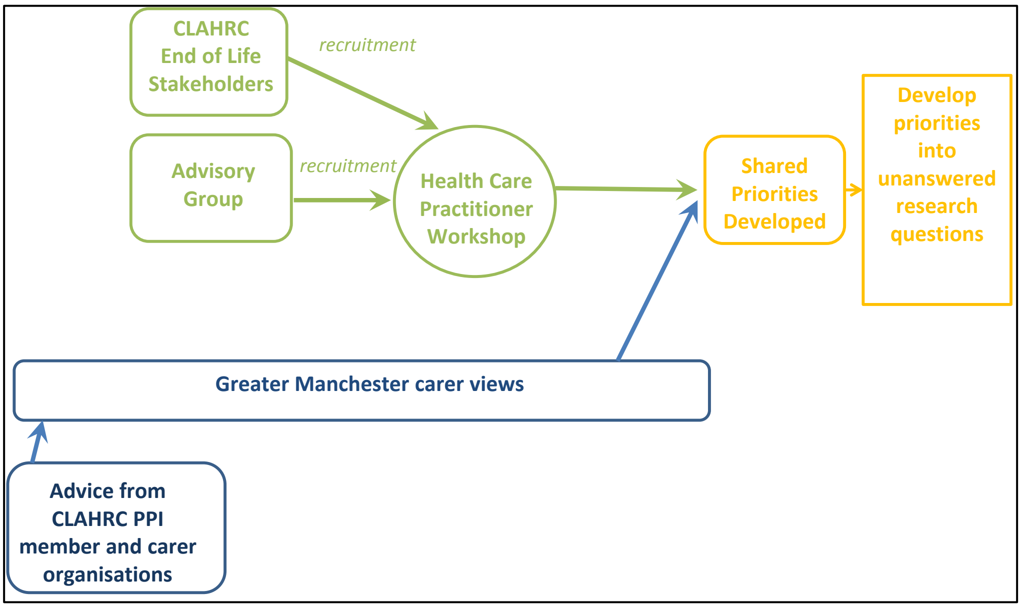
Topic	National research questions developed by PeolcPSP
Education	*What information and training do families and carers need to provide the best care for their loved ones who are dying, including training for giving medicines at home? What are the best ways to ensure that all staff are adequately trained to deliver end-of-life care, no matter where the care is being delivered?*
Access to 24 hr care and support	*What are the best ways of providing care outside of working hours to avoid crises and help patients to stay in their place of choice? This includes help with symptoms, counselling and advice, GP visits for patients, carers and families.*
Equitable Access	*How can access to end-of-life care services be improved for everyone regardless of where they live?*
Advance care planning	*What are the benefits of planning end-of-life care in advance? Who is best to help patients and families plan in advance?*
Care at home	*What are the benefits of providing care at home and what are the best ways of doing this? How can home care be maintained as long as possible and would good co-ordination of services affect this?*
Continuity of care	*What are the best ways to make sure there is continuity for patients at the end-of-life, in terms of the staff they have contact with? Does this improve quality of care? Would having a person to coordinate care for patients and families help?*

As discussed in more detail throughout this report, we relied on the six topics displayed in table 3 for further exploration with carers and HCPs, to identify which of these were seen to have the most importance and relevance.

3.2 Consultation process

Figure 1 shows how our ongoing engagement process with carers and the HCP workshop have contributed to the development of the shared priority topics for future end-of-life research.

Figure 1. Overview of the consultation process



As figure 1 illustrates, we have integrated carer consultation (in blue) and HCP consultation (in green) to develop this report which identifies the shared local priorities for end-of-life research (in gold/orange). The specific elements of the consultation approach are explained further in the following sub-sections of this report.

3.2.1 Encouraging a range of people to take part

We identified and approached HCPs and carers in different ways to encourage a good mix of involvement.

HCP involvement:

As part of our initial scoping work (see section 2.1) we established relationships with stakeholders across the end-of-life care spectrum spanning primary, community, secondary and tertiary care. We relied on these relationships to develop a key list of end-of-life HCPs to invite to our workshop. We were keen to ensure that we had representation from various care delivery settings and organisations.

To supplement the design and recruitment of HCPs, we approached a number of senior and strategic end-of-life professionals from our partner organisations to form a clinical advisory group. They provided *'clinical endorsement'* for our work as well as acting as *'champions'* to encourage involvement from the appropriate and relevant HCPs. As part of this, each advisory group member shared information with the relevant people[b] within their organisation. This approach proved to be invaluable in quickly disseminating information to associated HCPs.

Carer involvement:

After consultation with our patient public involvement group and local carer group leaders, we felt that adopting a single carer workshop would make it difficult for certain carers to attend and would

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[b] *Relevant people:* includes professional who the local *'clinical champions'* believed were important to the delivery, commissioning and management of local end-of-life care.

be limited in terms of diversity. Therefore, we planned for a consultation period spanning several months.

Local carers that had experience of, and an interest in end-of-life care, were invited to take part. Through our previous end-of-life work, we have established relationships with a number of local carer organisations. These existing links were helpful in setting up facilitated workshops or interviews with carers from the following organisations:

- Bury Carers Centre
- Salford Carers Centre
- Trafford Carers Centre
- Oldham Carers Centre
- Macmillan Cancer and Information Centre
- St Ann's Hospice
- Manchester Carers Forum

To access carers who don't attend carer groups, we also invited involvement through our website and Salford Citizen Scientist.

To ensure we communicated effectively with each carer organisation, we used a multi-faceted approach to engagement. Each of the groups preferred different methods of communication and contact; we used a combination of newsletters, website stories and/or introductory talks at existing carer group meetings. Carers could also register their interest by phone, e-mail or through the organisation's group leader. However, for HCPs we decided a single workshop would be the most appropriate method for data collection.

3.2.2 Facilitated workshops and interviews

HCPs:

We aimed to involve a good mix of senior clinicians and managers and we were successful in achieving this. Of the 32 HCPs involved, 44% were clinicians, 40% senior managers and 16% managers in a quality improvement, practice development or research role. There was a wide range of clinicians involved, such as palliative care consultants, GPs, nurses and end-of-life care facilitators. Managers were generally directors or leads for services such as palliative care, community end-of-life care, nursing home services or the complex discharge service. Unfortunately there were no social care HCPs that attended the workshop.

The HCP workshop required careful planning to ensure there was enough time for small group discussions covering each topic in sufficient depth to develop research questions. Therefore, prior to the event, HCPs were asked to choose two from the six topics to discuss in greater depth. Resultantly, HCPs were allocated to discussion groups related to their chosen topics; this also enabled us to gain an indication of the topics which were cited by most HCPs as being important for further discussion. The workshop included two sessions of facilitated small group discussions on each of the six topics (see agenda in appendix 6.1). It was important that each HCP had an equal voice so each discussion group was facilitated by a member of our CLAHRC GM team who was skilled in applied healthcare research and facilitation, to be impartial and to probe appropriately. Details of these discussions were recorded on flip charts and notes were transcribed and cross checked with each facilitator to ensure the summary accurately reflected the content of the discussions.

The focus of the discussions was:

(i) What is important to HCPs about that topic?
(ii) What are the research questions HCPs want to be answered within that topic?

To assist with developing research questions, all HCPs were briefed about PICO[c] and CLIP[d] techniques[5]. Each HCP had the opportunity to put forward possible research questions to their group, and through discussions agreed on the top three questions for their chosen topics.

Carers:

Our flexible approach helped to engage a wide range of carers from diverse backgrounds, with 26 carers agreeing to be involved; 15 of these were previous carers (mainly bereaved); 11 were current carers (9 were also previous carers); with 77% of carers being between 55-84 years of age. It is important to note that whilst two of the carers identified themselves as being patients, they reflected on their role as a carer, rather than their experiences as a patient. Interestingly, the carers involved had a wealth of caring experience with 54% having been in a caring role for two or more different people, with the average time period being 12.5 years (it ranged from 8 weeks to 69 years). We also asked carers about the people they cared for and found that they were mainly older adults with 55% being between 65-84 years old.

As discussed in section 3.2.1, local carer groups were initially contacted in a number of different ways. We held a number of informal workshops at each carer organisations (70% of the data were obtained through this method of collection), along with telephone and face-to-face interviews.

The workshops were predominantly facilitated by two members of our project team. We presented an overview of the project and invited questions; this led into facilitated small group discussions on the six topics. For each carer involved, a data collection form was completed (see appendix 6.2), which was done either at the end of the workshop or during an interview. This process enabled carers to give their individual views to ensure they all had a voice, because obtaining the views of quieter carers was often difficult within the group discussions. The data collected included demographic information, followed by the six topics with a summary for why carers felt each selected topic was important. The number of carers who chose each topic was counted to identify the topics carers chose more frequently.

The discussions (where consent was gained) were recorded and subsequently transcribed verbatim, with key points being recorded on flipchart paper. A sense check at the end of the discussion was done, to ensure that everything carers wanted to discuss had been covered; this was important because some carers may have wanted to discuss other topics beyond the six presented (see table 3). All the information from the audio recordings, flip chart notes, and completed data collection forms was organised under the six main topic areas.

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[c] *PICO:* is a mnemonic (memory aid) for Population, Intervention, Comparator and Outcome. It is a framework for developing research (memory aid) questions most commonly used to compare one intervention to another.

[d] *CLIP:* is a mnemonic for Client group, Location, Improvement and Professionals. This is also a framework for developing research questions most commonly used to assess outcomes of a service or policy.

4. Results

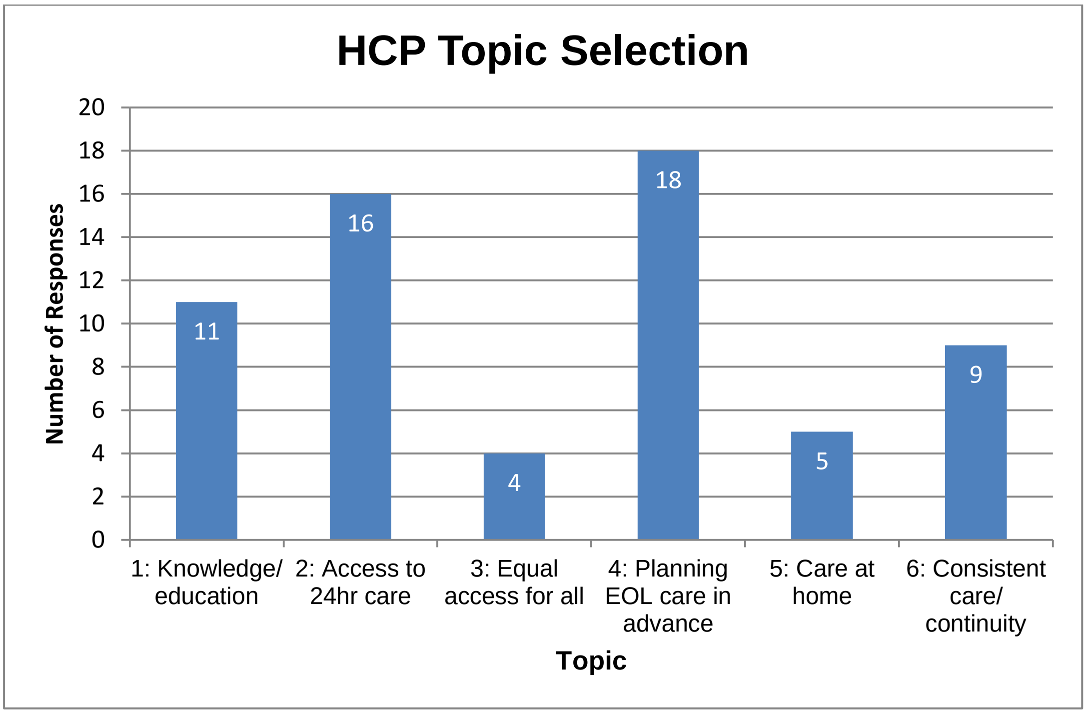
4.1. Topic selection

HCPs and carers chose their topics in different ways so it is difficult to directly compare the specific numbers across groups. However, it is possible to identify which topics were perceived by both groups as being the most important for future end-of-life research.

Whilst it is clear that all of the six topics for future end-of-life research are important and that overlaps exist between them, for the purpose of research prioritisation it was helpful for HCPs to choose two of the six topics to discuss in greater depth to develop research questions.

As figure 2 identifies, the three most selected topics of discussion for HCPs were: Topic (4) Planning end-of-life care in advance, Topic (2) Access to 24 hour care, and Topic (1) Knowledge and education.

Figure 2. HCPs topic selection



Carers were also asked to identify the topics most important to them, however unlike the HCPs who were limited to two choices, there was no restriction on the number of topics that carers could select, as they had more time available to explore topics. Interestingly we found that on average carers chose between three and four topics, which they believed to most important to future end-of-life research.

Figure 3. Carers' topic selection

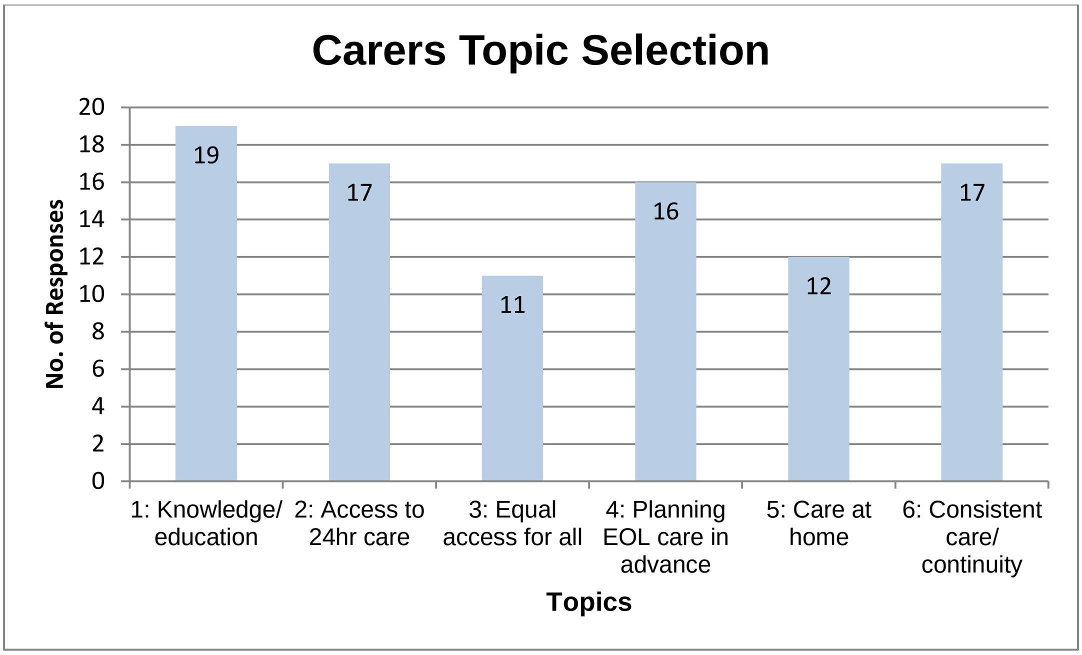
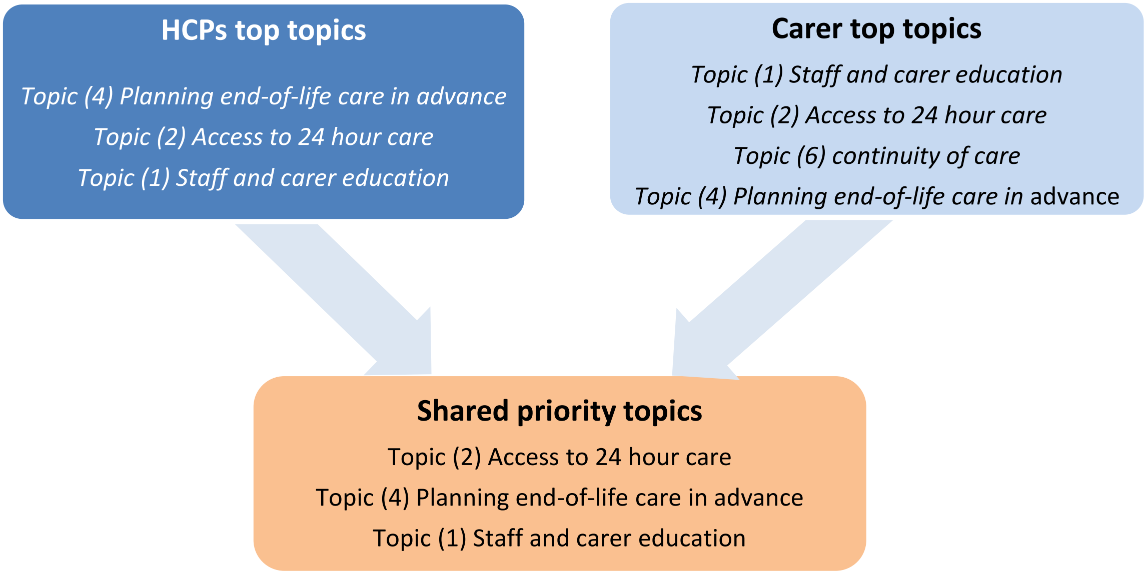


Figure 3 shows that four out of the six topics appear to be of most importance to local carers, these being: Topic (1) Knowledge and education, Topic (2) Access to 24 hour care, Topic (3) Consistent/continuity of care, and Topic (4) Planning end-of-life care in advance.

Consequently, the data illustrate that there are three topics which appeared to have importance locally both to HCPs and carers, as represented in figure 4. As shown, the topics of priority are highly similar for each group:

Figure 4. Developing the top three shared priority topics



Identifying the most important topics for future end-of-life research in Greater Manchester is essential and the three shared priority topics identified will aid future research. In the following section we detail why HCPs and carers believed the three shared topics to be important. However, as previously outlined it is clear that HCPs and carers believed that all six research topics were important for future end-of-life research, so in section 4.3 these remaining topics are also explored in more detail.

4.2 Shared Priority Topics

4.2.1 Topic 2 - Access to 24 hour care and support

For HCPs, access to 24 hour care and support was important as ultimately it could help to reduce carer/family strain and subsequently prevent crises and unplanned admissions to hospital. Managing carer expectations about the level of involvement with such care, and what services were available within their location was highlighted as being important. It was also discussed that access to 24 hour care and support would enable the patient to be cared for in their preferred place, whether that was at home or in hospital, and could help ensure patients had a shorter length of stay in hospital as a result of the rapid discharge process.

There was some overlap with the '*Equal access for all'* topic as it was reported that improvements could be made to 24 hour care, in particular, specific inequities of care were highlighted according to:

(i) diagnosis type and consultant availability
(ii) locality
(iii) socio-economic status of the patient

The topic of inequities in care was raised by a HCP who was also a carer, however the rest of the HCPs within the group were in agreement with the points made in relation to this. In addition, the need for improved communication between different services, HCPs, and between HCPs and carers was highlighted. In particular, this applied to care and treatment decisions, as well as signposting to the available services that carers could access.

Carers raised concerns about access to both emotional and medical support during the night and at weekends. There was some overlap with the *'Education and knowledge'* topic as, for example, it was reported that it was important to know what was happening when someone was dying and to know what to do if your loved one has a fall within the home, in particular how to lift them back up and who to call for help [*"We haven't like you said had training in lifting*"]. Having someone to provide *'holiday cover'* was also highlighted as important. Similarly to HCPs, improved communication with regards to involving patients and carers in decision making was discussed, particularly in relation to transitions between different services, and discharge from hospital. It was felt that 24 hour care did not necessarily mean access to around the clock 24 hour services in the home, but rather being able to contact someone for support and reassurance or professional medical advice ["*Just be there when you need it*"].

Refinement of the research questions:

As represented in table 4, six main questions were developed by HCPs in relation to this topic, with carers' views supporting the inclusion of question 1 in particular.

Table 4. Access to 24 hour care and support research questions

Question 1	*What does effective and appropriate 24 hour care look like:* - *For carers?* - *For professionals?* - *Across all settings?*
Question 2	*What resources are required to deliver 24 hour care?* - *What is the specialist/generalist mix required?*
Question 3	*How does the need for 24hr care vary:* - *by disease diagnosis?* - *by demographic/socio-economic factors?* - *By locality?*
Question 4	*Does the Electronic Palliative Care Co-ordination Systems (EPaCCs) impact on any variations identified?*
Question 5	*What are the barriers to delivering 24 hour care across different disease groups at different points in the end-of-life pathway and how can these be overcome?*
Question 6	*Can comparable locality specific service models be identified in order to generate evidence of effectiveness of 24 hour care?*

4.2.2 Topic 4 - Planning end-of-life care in advance

HCPs discussed how Advance Care Planning (ACP) was important as it was suggested that it could help carers to feel more supported, enable them to be more aware of their loved one's wishes, and/or be more involved in the decision making process. ACP was viewed as important for helping patients to take control and make decisions about their care and planning for their preferred place of death, but also for enabling HCPs to feel in control about the care they provided. It was felt that ACP would help with a number of issues including the avoidance of unnecessary:

(i) hospital admissions
(ii) transfers of care
(iii) treatments and procedures

ACP was also believed to help with communication across different agencies and healthcare workers and therefore aid continuity of care. It was reported that it could also help identify what services were available in the local area, and help with avoiding crises in the home. However, it was suggested that a clear definition of ACP is required, including when it is best to initiate ACP conversations, who is responsible for it, and who documents it, as it was felt that currently there is a lack of clarity around these areas. Further information was also required on how the use and quality of ACP varies across services, including evidence of its effectiveness. Indeed, the need to *'do it right'* was highlighted, particularly with regards the psychological impacts ACP could have on patients and their families.

For carers, the importance of ACP centred on the need for HCPs to have the difficult conversations as soon as possible ["*Healthcare professionals need to approach difficult questions early*"]. It was felt this would help empower the patient to make important decisions, e.g. about funeral plans, making a will, their preferred place of care/death, and enable signposting to sources of support to help with these decisions. It was also felt it would enable any religious beliefs to be taken into consideration much earlier on. However, it was highlighted that such conversations around ACP needed to be with someone who was compassionate and that HCPs needed to communicate this sensitively. Having a named person to help co-ordinate the planning for caring at home was highlighted as something which would make the process easier. Furthermore, carers discussed that it was important that the plan put in place matched what had been discussed with the patient and the carer.

Refinement of research questions:

As displayed in table 5, four main questions were developed by HCPs, with the views of carers' supporting the inclusion of questions 2 and 4 in particular.

Table 5. Planning end-of-life care in advance research questions

Question 1	*How are ACP discussions held with patients and carers?*
Question 2	*How can ACP discussions and decisions be communicated effectively between healthcare providers in different settings?* - *How effective is EPaCCs*[e] *in communicating and sharing ACP to a variety of HCPs across different services/settings?*
Question 3	*What resources are needed to provide general nurses with the skills to have ACP discussions?*
Question 4	*What are carers' and patients' views and understanding of ACP?* - *Who do they feel should be initiating ACP conversations?* - *Do they feel ACP discussions are effective?* - *When is the most appropriate time to have ACP discussions?* - *Is ACP the most applicable name?*

4.2.3 Topic 1 - Staff and carer education

For HCPs, education and training was seen as vital in ensuring that carers felt supported and empowered to carry out their caring role. Ensuring that staff were adequately supported and appropriately trained was felt to be beneficial for enhancing their professional development and confidence, which in turn could improve staff morale. Subsequently, this could help to improve and standardise the care provided by the wider organisation. It was suggested that one potential outcome of such improvements would be a reduction in the number of complaints.

Similarly to HCPs, carers highlighted that education and knowledge was important to enable them to carry out their caring role and feel supported. Carers highlighted that the education and knowledge topic seemed to be applicable to all the others topics with the exception of *'Equal access for all'* and therefore was of particular importance for them. 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*"]. Information about the treatments being given to the patient, how to give certain treatments, manual handling training, and receiving up-to-date knowledge about the patient's current condition, were all highlighted as important. One carer reflected that this needed to be delivered in a timely manner [*"It's about giving information and knowledge at the right time*"]. Carers also highlighted a need for signposting to appropriate information, knowing who to contact in certain situations including emergencies, and the need for

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[e] *Electronic Palliative Care Co-ordination Systems (EPaCCS):* enable the recording and sharing of people's care preferences and key details about their care at the end-of-life.

aftercare for loss and bereavement [*"end-of-life care does not end with death"*]. One group discussed how an advocate for carers could provide information on what services were available to them as currently there are too many services to keep track of and they often came across information *'by mistake'* rather than being directed to it by HCPs. Carers also reported that training for HCPs was important ["*High quality compassionate staff are better than just quantity*"], which corresponds with HCPs views. In particular, they felt that communication between HCPs and carers could be improved to be more individualised, in particular when making decisions about treatments and ACPs for the patient ["*We're talking about collaborative decision making*"].

Refinement of research questions:

Table 6 shows the main research questions that the HCPs developed, with the views of carers (as discussed above) emphasising the importance of question 1.

Table 6. Staff and carer education research questions

Question 1	*What are the education and training support needs of carers across the end-of-life care trajectory?*
Question 2	*What further training is required for HCPs working within end-of-life care?*
Question 3	*What is the most effective way of engaging staff in further training/education?*

4.3 Remaining topics

As previously outlined, it is also important to understand why all of the six topics are important to local HCPs and carers, not just the three topics which seem to be of greatest importance. As identified in figures 3 and 5 we can see that for carers in particular *'Consistent/Continuity of care'* was a very important topic for future research, with both HCPs and carers valuing the importance of research around both *'Care at home'* and *'Equal access for all'*.

4.3.1 Topic - 6 Consistency/continuity of care

The consistency/continuity of care topic was one of the top priorities for carers. The lack of continuity in hospital care was a substantial issue. It was highlighted that having a key worker or named person to contact to help coordinate care would be beneficial as there is often quite a large network of HCPs involved in the care of the patient. Having to explain the same details repeatedly to different members of staff was viewed as a source of stress. Therefore, improved communication between different HCPs, the carer and the patient was highlighted as important. It was considered important for GPs, nursing homes, and all healthcare staff to have up-to-date knowledge of the patient's condition. Improved coordination between GPs and nurses visiting the home was also considered important to ensure nurses were aware of current treatments and how to administer them. An additional source of stress identified by carers was the lack of support they received for the patient after leaving the hospital. One carer reported that long waits for certain essential equipment also made things very difficult for them (e.g. 3 week wait for a colostomy bag). Another carer reflected on the inconvenience of the patient having to travel across the country in ambulances for specialist care in other settings.

HCPs felt that good communication across services 24 hours a day is key to ensuring more collaborative working and the sharing of good practice, as currently they were not aware of what other services were delivering (in relation to services within their own organisations and those further afield). In addition, it was suggested that improved coordination of discharge planning across all settings was required, as it was currently quite disjointed. This reinforced the importance for HCPs to know what is available in other settings and localities. A more seamless delivery of care was seen as something which would benefit the patient. HCPs also reported that it was important for all patients to receive the same standards of care. This linked with the *'Equal* *access for all'* topic as the need for equity of care across various diagnosis types and locations was also highlighted. It was also discussed that there was a need to ensure that the increased presence of *'specialist centres'* did not have any negative consequences, for example, on the discharge process or when repatriating patients to their local areas.

There were some clear differences in why this topic was important to HCPs and carers; however both groups mentioned that *improved communication* was key.

Refinement of research questions:

As table 7 demonstrates, six main questions were developed by HCPs, with the views of carers supporting the inclusion of questions 1, 2, 3, 4, and 6 in particular.

Table 7. Consistency/continuity of care research questions

Question 1	*What are the benefits of key workers in end-of-life care?* - *What tasks and activities does this role require?* - *What skills are required by the professional who takes on this role?*
Question 2	*Do carers believe they have received consistent care? How could this have been improved?*
Question 3	*What happens to patients with various diagnoses at the point of discharge from specialist centres?* - *How can continuity of care be promoted at the point of discharge?*
Question 4	*What does 'good' continuity of care look like from service, professional and patient/carer perspectives?* - *Can continuity of care be measured in end-of-life? How can this be benchmarked to best support best practice?*
Question 5	*How can care planning documentation be standardised across services and organisations to promote continuity?*
Question 6	*How can communication be improved across various agencies and services in order to promote continuity of care and what would enable this?*

4.3.2 Topic 5 - Care at home

This was a topic of more importance for carers, perhaps because the provision of care in the home was seen as being so important in ensuring that patient's wishes could be fulfilled. However, one carer reflected how it is important to establish if people actually want care at home and if they do, to determine if they are able to actually provide that level of care, as well as accommodate the equipment required, e.g. a hospital bed. The distinction between social care and palliative care was discussed ["*How quickly will the end-of-life care kick in to ensure dignity and less stress on the family*?], and the struggle with obtaining continuing healthcare as opposed to social care which comes at a cost to the carers financially and has implications for the levels of support available. The availability of counselling for carers was also considered beneficial when caring for someone at home. There was overlap with the *'Education and knowledge'* topic with regards to more training for staff in order to provide care at home. It was also discussed that when caring for someone at home, it was important to know when it was best for the patient to go to a hospice or hospital. One carer reflected how it "*took him to collapsing on the floor*" before realising that the hospice might be the best place for their loved one. Another carer discussed how HCPs could help with this decision making, in particular if the person does not have the capacity to make that decision *["Somebody who can come in and say, you've done a really good job, it's better to go into a hospital now"].*

For HCPs, providing care at home was viewed as a complex process involving numerous stakeholders. It was highlighted as an important topic due to the longer-term detrimental impacts that poor quality care and support can have on the family as a whole. The financial implications for the family when caring for someone at home and the various needs of carers such as access to help, particularly in times of emergencies, were recognised. Similarly to carers' views, it was felt that there was currently a lack of access to 24 hour services and that to achieve care at home the availability of hospice at home services or access to Macmillan Nurses needed to be improved. The gaps that currently existed with regards to resources were discussed including 24 hour care, night sits, day sits and respite. Concern was raised that services are currently not accessed equitably and therefore do not reflect the demographics of the Greater Manchester area. Furthermore, it was felt there was a lack of clarity on the local differences in the provision of and need for services. Gaps in service provision in some areas and the need for more community-based end-of-life support was highlighted. The importance of assessing what was actually required to enable patients to be cared for within the home was also mentioned, particularly as it was felt there were increasing numbers of end-of-life patients wishing to be cared for at home. The variation in the needs of patients depending on their condition and what this meant for service provision was also discussed, for example the needs of cancer patients may differ from patients with longer term conditions.

Refinement of research questions:

Table 8 displays three questions which were developed by HCPs (1-3), with the views of carers supporting the importance and inclusion of question 2 in particular. Question 4 was developed by the CLAHRC GM project team based on the views of carers; this was not addressed by HCPs during the workshop.

Table 8. Care at home research questions

Question 1	*How does the quality of Advance Care Planning affect the effectiveness of care at home?*
Question 2	*What are the differences in the provision of care at home across different localities within GM?* - *How can this best be investigated?* - *Is a service evaluation required?*
Question 3	*Do community specialist services improve the quality of care at home and how could this best be measured?* - *Are there differences between cancer and more chronic conditions?*
Question 4	*What are carers' and patients' views on what effective care at home is?*

4.3.3 Topic 3 - Equal access for all

The equal access for all topic was seen to be less important as a research focus in its own right, but it was frequently mentioned as part of the discussion about the other research topics, with the main reasons around its importance relating to waiting times and access to services and equipment.

HCPs felt that there were differences in the timeliness of available services; some experienced longer delays compared to others. Differences were reported in how certain policies were being applied in different areas e.g. access to Continuing Health Care (CHC) funding, and there were local variations in how the North West End of life care model was applied. Diagnosis and disease type was also believed to impact on the guidance for palliative care that HCPs utilised, and it was discussed that whilst specific guidance is available on palliative care for stroke patients, this is not the case for all disease areas. Lastly, HCPs felt that cultural and religious or spiritual factors often had a negative impact on equal access to care.

Similarly to HCPs, carers also highlighted that access to services and treatments for patients could be improved, as it currently varied by locality. One carer reflected that they often waited too long for equipment, such as a hospital bed for their loved one, and they felt that there were not enough hospice beds within their area. It was discussed that the same care should be available regardless of financial or social status. In addition, difficulties in trying to get continuous care as opposed to social care for their loved one, which impacted on them financially, was also highlighted as an important issue ["*I was having to fight for everything*"]. Delays with this process meant a carers' loved one died before they got him/her a place in a nursing home ["*That's how close to death he was when they made that decision*"]. One carer also made specific reference to problems of access for those 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*"].

Refinement of research questions:

Table 9 displays the three main questions developed by HCPs, with the views of carers supporting the inclusion of question 3 in particular.

Table 9. Equal access for all research questions

Question 1	*What can and should be measured in terms of equal access to care?*
Question 2	*How can the Care Quality Commission (CQC) gold standard of end-of-life care be achieved and what data should be collected to evidence this?* - *What enables certain areas in GM to achieve the gold standard of care*
Question 3	*How can equal choice for all best be achieved?* - *What should be the minimum level of care offered to all patients?* - *What can patients and carers expect in terms of end-of-life care? (E.g. maximum wait times to access to services such as hospice care?)* - *How can a personalised care approach be developed which takes account of patient and carer preferences, including cultural and spiritual needs?*

5. Learning from our experiences

In collaboration with the HCPs and carers involved with our local priority setting work, we have reflected on our approach and developed a number of key learning points, which might be useful for future associated work:

- Developing and obtaining support via the clinical advisory group was critical to ensuring the right HCPs attended the workshop.
- Planning for the HCPs workshop and material preparations took much greater time and resources than anticipated; however this time investment was fully justified and necessary in ensuring a successful event.
- Small discussion groups of between two - five HCPs for 45 minute sessions worked well for the task of developing research questions.
- Each of the small HCP discussion groups operated in a similar way to a focus group; with a number of different methods of sharing ideas used *(as indicated by our ethnographic observers[f]).* The use of flexible methods of facilitation seemed beneficial in achieving valuable discussion and consensus, rather than imposing a structure that some HCPs may not have been comfortable with.
- Carer organisations have often been involved with research studies and these previous experiences influence their willingness to take part. We experienced this, with some organisations suggesting that they had taken part in studies previously, but they had never had any feedback about the outcomes, impacts and/or next steps. Therefore it was imperative that we engaged carers throughout all stages of this consultation, and we emphasised that we would actively engage all carers as part of our dissemination of the findings and any future end-of-life research that we (CLAHRC GM) take forward.
- Several carers were hard of hearing and/or had visual impairment, so it was important to use large screen presentations, flyers, handouts and a microphone where possible during the various consultation activities.
- A number of carers were uncomfortable with their views being audio recorded during group discussions. We were able to accommodate their needs by using consent forms allowing them to opt out; we formed a discussion group with these carers that was not recorded, with key points recorded via flipcharts instead.
- The use of a standardised data collection form was essential for collecting data from carers; this enabled data to be obtained from carers who were uncomfortable in a group setting.
- Discussions about the end-of-life care of loved ones is an emotive and sensitive subject. During the consultation with carers it was very important to emphasise they only needed to share information which they felt comfortable with, and that all discussions were confidential. We also found that having dedicated time to debrief after each carer workshop/engagement event was advantageous.
- Carers struggled to rank the six research topics in terms of their importance, as they were reluctant to decipher between the importance of one topic over another. Consequently, we adapted our approach and asked carers to select all of the topics that mattered most to themselves around end-of-life care.

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[f] *Ethnography* - simply stated, is the study of people in their own environment through the use of methods such as participant observation and face-to-face interviewing

- Overall, adopting a flexible and sustained consultation approach spanning a number of months was effective in involving a wide range of diverse carers from the local Greater Manchester area in this research priority setting consultation.

6. Conclusions

It is clear that all six research topics, identified from our initial scoping work and the national priority setting work, are important to both HCPs and carers within Greater Manchester. As demonstrated in figure 4, there are three topics in particular which appear to have particular importance to local carers and HCPs, these being:

(i) Access to 24 hour care
(ii) Planning end-of-life care in advance
(iii) Staff and carer education

As noted, there are a number of key issues for end-of-life research that emerged within the discussions and spanned across each topic area. We highly recommend that that the following are therefore considered in the design and explorations of future end-of-life care research:

(iv) The need for improved communication with patients and carers, and between different services and/or agencies
(v) The need for equal access to care across different diagnosis groups, socio-economic status and geographical location
(vi) The management of both the patient and carers, and HCPs expectations in relation to their involvement in various aspects of care

Moving forward, any one of the research questions raised within this report could be used as a starting point for future end-of-life research. Further work is required to define the relatively broad questions outlined in this report, but these provide the backbone for future end-of-life research within the Greater Manchester community. However it is important to note, that as part of this report we have not conducted a literature review to ascertain the current evidence base and research which may assist with defining, answering and developing proposals for any of the research questions suggested as part of this consultation process.

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7. References

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8. Appendix

8.1 Agenda for the HCPs workshop

Time	Topic	Speakers
09:00-09:30	**Registration and refreshments**	
09:30-09:45	**Speed networking**	
09:45-09:50	**Aims of the day** **What is CLAHRC?**	Prof Gunn Grande
09:50-10:25	**National research priorities and how our projects fit with these:** The national context and our end-of-life priority setting work. 1) Supporting carers to enable patient discharge at end-of-life (5 minutes) 2) Uncovering the contribution, costs and economic value of family caregiving (5 minutes) 3) Mapping pathways of care for end-of-life (15 minutes)	Prof Gunn Grande Prof Damian Hodgson
10:25-11:10	**Group work** • What is important to you about your research topic? • What are the research questions you'd like to be answered within this topic? • What are the top 3 research questions within this topic?	
11:10-11:25	**Break and refreshments**	
11:25-12:10	**Group work** (All delegates move to new table with a new topic) • What is important to you about your research topic? • What are the research questions you'd like to be answered within this topic? • What are the top 3 research questions within this topic	
12:10-12:30	**Feedback on the top research questions**	
12:30-12:45	**Round up of the session**	Prof Gunn Grande and Tony Bonser
12:45--13:15	**Sandwich lunch and networking**	

8.2 Carer data collection form

End of Life Care Priorities for Patients and Carers in Manchester

Name		Prefer not to disclose	**Telephone**	
Are you a patient?	**Yes** ☐ **No** ☐ If yes: How old are you? ____		**E-mail**	
Are you currently a carer?	**Yes** ☐ **No** ☐ If yes: What is the age of the person/ persons you care for? ____ How long have you cared for them? ____			
Have you been a carer in the past?	**Yes** ☐ **No** ☐ If yes: What was the age of the person/ persons you cared for? ____ How long did you care for them? ____			

Which area do you live in? (please tick)

Bolton	Bury	Heywood Middleton & Rochdale	Oldham	Tameside & Glossop	Stockport	Manchester	Trafford	Salford	Aston, Leigh and Wigan

What is your age group?(please tick)

under 18	18 -24	25-34	35-44	45-54	55-64	65-74	75-84	85-94	95 and older

What is your ethnic group?(please tick)

White	Mixed/Multiple Ethnic Group	Asian/Asian British	Black/African/ Caribbean/ Black British	Prefer not to disclose	Other (Please detail below)

What is your religion? (please tick)

No religion	Christian (including Church of England, Catholic, protestant)	Buddhist	Hindu	Jewish	Muslim	Sikh	Humanist	Prefer not to disclose	Other (please detail below)

Topic	**Which topics are most important to you?** (Please tick)
1. Education/ Knowledge 1a. What information and training do families and carers need to provide the best care for their loved ones who are dying, including training for giving medicines at home?	
1b. What are the best ways to ensure that all staff are adequately trained to deliver end of life care, no matter where the care is being delivered? If there were more staff would it improve their care?	
2. Access to 24 hr care What are the best ways of providing care 24 hours a day to avoid crises and help patients to stay in their place of choice? This includes help with symptoms, counselling and advice, GP visits for patients, carers and families.	
3. Equal access for all How can access to end of life care services be improved for everyone regardless of where they live?	
4. Planning end of life care in advance Having a discussion with people near the end of life and their families and carers can help them to live and die in the place and the manner of their choosing. The main goal in delivering good end of life care is to be able to clarify people's' wishes, needs and preferences and deliver care to meet these needs. What are the benefits of planning end-of-life care in advance? Who is best to help patients and families plan in advance?	
5. Care at home What are the benefits of providing care at home and what are the best ways of doing this? How can home care be maintained as long as possible and would good co-ordination of services affect this?	
6. Consistent care What are the best ways to make sure there is reliable quality of care at the end of life, in terms of the staff they have contact with? Does this improve quality of care? Would having a person to coordinate care for patients and families help?	

Please share which of the topics from the previous page are the important issues are to you:

Your chosen topics	The important issues within this topic(s) that are important to you:

Please share with us, why these chosen issues are the most important to you?

Are there any other comments you would like to share?