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Telford & Wrekin COUNCIL

Shropshire Council

Addenbrooke House Ironmasters Way Telford TF3 4NT

JOINT HEALTH OVERVIEW & SCRUTINY COMMITTEE

Date	**Thursday, 15 April 2021**	Time	**2.00 pm**
Venue	**Remote Meeting**		

Enquiries Regarding this Agenda		
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Committee Membership:	**Telford & Wrekin**	**Shropshire**
	Councillor Stephen Burrell Councillor Stephen Reynolds Councillor Derek White, Telford & Wrekin Health Scrutiny Chair	Councillor Karen Calder, Shropshire Council Health Scrutiny Chair Councillor Heather Kidd Councillor Madge Shineton
Co-Optees	Hilary Knight Janet O'Loughlin Dag Saunders	David Beechey (Shropshire Co-Optee) Ian Hulme (Shropshire Co-Optee)

AGENDA

4. **End of Life Care Update** 3 - 14
   To receive an update on End of Life Care from Tracey Jones, Deputy Director Partnerships, Shropshire, Telford & Wrekin CCG.

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Shropshire, Telford & Wrekin
Sustainability and Transformation Partnership

Paper Title	**System Review of End of Life Care and Experience Feedback on Completion of Phase One and Identification of 4 key Focus Areas for System Intervention**
Paper Details	**Paper for : Joint Health Overview and Scrutiny Committee** **Date : 15/04/2021** **Author (s) : Tracey Jones Deputy Director Partnerships** **Lisa Cliffe Deputy Director Transformation** **Alison Massey Transformation Partner** **Purpose** **Update outcomes of Phase 1** **Links to local , Regional and National EOL Initiatives** **Update re Next Steps**

1. Background to System End of Life Care Review

1.1 This review is one of the early pieces of work that we as a system have come together to collaborate on. It signifies a move away from a traditional commissioner led review with a focus on data to a collaborative review which seeks to reflect, in its priorities, the issues that stakeholder, including system providers, have identified for themselves

1.2 It does not replace individual organisations responsibility to listen to and respond to patient or formal CQC / CCG feedback about care. This will continue under the governance of each organisation.

1.3 At the heart of the review is a desire to improve experience locally in Shropshire, Telford and Wrekin in relation to End of Life Care (EoLC). This is the experience of the individual, those important to them and the wider community of staff in statutory and non-statutory organisations who deliver and support care at the end of a person's life.

1.4 The review had two distinct phases

Phase One ; Collate areas for focused system improvement/transformation

Phase Two ; Implement through system working groups changes to pathways and approaches that will transform positively the experiences around End of Life Care

1.5 The original ambition was that both phases would be addressed within a 6-9 month timescale however the resurgence of covid 19 has impacted upon these timescales. Additionally the bringing together of the two CCGs and resultant appointments has transferred the senior leadership of the project to Lisa Cliffe as the CCG Deputy Director for Transformation who will lead Phase Two.

1.6 Further to the commencement of Phase One, NHSEI has established a Regional Palliative and End of Life Network which places responsibilities on the system to deliver against the National Ambitions for Palliative and End of Life Care.

1.7 This report will

* Summarise the process of the review undertaken in Phase One and present the four areas that have been collaboratively agreed as priorities for focus
* Cross map these four areas with other key End of Life Review Recommendations including Regional NHSEI requirements
* Provide details of next steps

2. Summary of Methodology for Phase One

2.1 The priorities for intervention that are identified in this document have been developed through Phase One of the review. In the initial phase of the review(Nov to mid-December 2020) a range of stakeholders were asked to feedback what improvements they felt would improve care across the system, recognising that for many individuals they will be receiving care from multiple providers.

2.2 The range of stakeholder approached covers individuals with lived experience, patient representative groups such as Healthwatch, providers from Health and Social care and the non-statutory sector such as Hospices, Care Homes and CCG Commissioning and Quality leads

2.3 During the collation of feedback, there was an extremely strong theme in all of the lived experience accounts around the need to get symptom management right at the end of life. This was spoken about in both positive terms when it had happened and conversely the lasting distress this caused when it had not been so. A decision was taken that this would be selected as one of the four areas of focus.

> " **How do we ensure that everyone knows how to access the information and support that enables individuals to have their symptoms managed at end of life and how can we ensure we are monitoring this is happening and provide support where it is not?"**

2.4 As a result of this decision to allocate the above as one of the 4 focus areas, this reduced the remaining areas of focus to 3.

2.5 The initial feedback was reviewed and themed into 9 key areas which matched to the different themes and messages from stakeholders. These nine key areas were then shared back with a selected group of key individuals as a cross checking process (Person with lived experience, carer, clinician and manager/commissioner).

2.6 The next step was to agree which 3 of these 9 areas would be selected, which then along with the pre-selected area of symptom management (see 2.3) above would be taken forward for intervention in Phase 2 of the review.

2.7 To undertake this, a process known as paired comparison was used. This process is subjective, ie the person competing asked themselves which question they feel, if addressed by the system would most improve experience around End of Life Care. They were asked to base this on their own knowledge, thoughts and experience.

2.8 The process involved comparing each of the questions in turn and selecting the one they felt would most impact on improving EoLC experience in comparison to other questions

2.9 The full methodology was presented to Community and Place Based Board in January 2021 and members of the board were requested to complete and encourage others in their organisation to complete. It was also shared with all those who had provided feedback for the initial nine themes. Written instructions and a video explanation were provided to assist in this process. The concept was to allow individuals to be able to complete the process at a time that suited them.

2.10 This step of Phase One was planned to be conducted from Mid-December to Mid-January .ie a period of four weeks. However with the resurgence of covid a decision was taken to taken the completion window until mid-February.

2.11 Feedback was also incorporated from individuals who choose not to complete the formal template but who wished to identify their one /two key themes.

3 Four Areas of Key Focus : Shropshire , Telford and Wrekin EOL Collaborative Review

1	How do we ensure that everyone knows how to access the information and support that enables individuals to have their symptoms managed at end of life and how can we ensure we are monitoring this is happening and provide support where it is not ?"
2	How do we support staff to better recognise EOL and engage in conversations about this with individuals?
3	How do we ensure that generalists i.e. non palliative care health and social care staff can access the level of information and support they need to deliver an improved experience of care for individuals at end of life?
4	How do we improve our approach to ensuring we are able to proactively identify anticipatory care needs?

3.1 Number 1 is the area identified through individuals with lived experience. Numbers 2-4 above are the areas that scored the highest in the paired comparison exercise.

3.2 The full results are shown in Appendix One. The area that scored joint 4th highest were related to EOL care plan documentation and the commissioning of more personalised care pathways.

3.3 In addition to the results of the local qualitative collaborative review shared above, further work was undertaken to consider the results of other national and local reviews. This was part of the commitment to ensure we considered learning collaboratively as part of the review.

3.4 The feedback from surveys undertaken by Telford and Shropshire Healthwatches relating to Experiences of End of Life and Palliative Care (Healthwatch Telford & Wrekin: Dec 2019 .Healthwatch Shropshire: Jan 2020) had already been considered as part of the initial feedback to develop the nine question areas.

3.5 An additional survey relating specifically to the Palliative Care line run by Shropdoc was undertaken by Telford and Shropshire Healthwatches. . The full report can be accessed here. https://www.healthwatchshropshire.co.uk/report/2020-01-14/experiences-end-life-and-palliative-care-services-shropshire. The relevance of the feedback to this review is that the public and professionals valued timely feedback and support. This aligns with the initial priority area of ensuring patients and those supporting them are able to access timely support for symptom management at the end of life.

3.6 The other reviews these outcomes were considered against were

a) National Audit at End of Life Care (NaCEL) NHS Benchmarking
b) Strategy Unit Review Health Services in the Last Two years of life, Shropshire, Telford and Wrekin
c) Findings of Shropshire Community NHS Health Trust Learning from Deaths Review (2020)

3.7 Appendices 2- 4 provide the detail of the mapping of the priorities identified in Phase One of the local review with these reviews. There is a high degree of correlation from the collaborative feedback and paired comparison approach and the recommendations from the above review

3.8 The gap analysis would indicate that Nutrition and Hydration should be specifically considered when addressing symptom management. The other area related to care planning and there is work locally on care plans which include care planning for End of Life .The Advance Care Planning work is being led by the current clinical EOL group chaired by Professor Derek Willis.

4. NHSEI Regional Palliative and End of Life Care Network (PEoLC)

4.1 From April 2021, the existing Palliative and End of Life care (PEoLC) regional networks which were established in November 2020 will become PEoLC strategic clinical networks. (SCNs) which will have clinical leadership as a key priority.

4.2 These SCNs will work across the boundaries of commissioning and provision, as engines for change, and reducing variation in the modernised NHS. The emphasis is on SCNs being one element of the new system that will support commissioners and providers with their core purpose of quality improvement and ultimately the achievement of ambitions for PEoLC patients of all ages.

4.3 There is a requirement for the Shropshire , Telford and Wrekin shadow Integrated Care System to have a local steering group which will both address local priorities in addition to the Regional asks from the PEoLC SCNs which in turn will be reflecting the National Asks within the Long Term Plan.

4.4 To support delivery of the NHS Long Term Plan (LTP), the national transformation strategy for PEoLC care will be developed and led by the national PEoLC team. This approach is endorsed by the Minister of State for Care. It is anticipated that this strategy will be published in September 2021

4.5 Locally Shropshire, Telford and Wrekin have a well-established EOL group led by Professor Derek Willis. In order to ensure continuity for this group and to establish NHSEI requirements around End of Life Governance within our shadow ICS it is suggested that this group be formally approached to become the local PEoLC steering group. Informal conversations have been undertaken with the chair to date. The STP/ICS PEoLC 'Steering' groups will reflect wider membership in line with NHSEI guidance

- Voluntary, Community and Social Enterprise representation (VCSE)
- ICS/STP Senior Responsible Officer
- Commissioning/Contracting Lead PEoLC and Clinical Lead PEoLC
- People with lived experience of palliative and end of life care (patients and carers)
- Social Care
- Pharmacy
- Public Health
- Administrative support

4.6 Each STP/ ICS across the region should nominate a Senior Responsible Officer (SRO), Contracting and Commissioning Lead (CCL) and Clinical Lead (CL). (It may be that the SRO is also the CL). Members must be able to drive delivery of PEoLC outcomes across their local geographies. The Shropshire , Telford and Wrekin membership of the Regional PEoLC will need to be reviewed and refreshed as system roles have changed

4.7 The Regional PEoLC SCN will have a focus on delivering the National Programme of work however the lead regional manager is aware of the local EoLC review and close working will continue to align the outcomes achieved by addressing our 4 local priorities and the Regional Delivery Plan requirements.

4.8 A key alignment between our local work and the Regional Delivery Plan requirements will be a system level focus on data and measurement of outcomes. Locally we have been clear that the working groups that will set up to address the areas of focus will have a requirement to establish how they will measure impact. Working together with the Regional SCN will support this aim.

5. Next steps to implement Change Locally in Shropshire , Telford and Wrekin

5.1 It was agreed by the system that the review in the first instance would focus on 4 areas of priorities that cut across the system. It was agreed that we would utilise working groups of front line staff and others, supported by lead clinicians with managerial support, to deliver change, adopting and carrying forward the learning during Covid which has resulted in greater system collaboration to the benefit of those receiving care. This includes the principle to have those with lived experience or representing the patients voice actively involved within the groups developing service improvements.

5.2 These working groups will require commitment from system partners if they are to affect the level of collaborative change committed to at the start of the EoLC review by the Community and Place based Board. A reconfirmation of system partners to this approach was given at the Community and Place based board on April 7th 2021.

5.3 Shropshire, Telford and Wrekin have established leaders for End of Life within its provider organisations and wider community stakeholder's .Collectively these leaders are members of the End of Life Group under the chair of Professor Derek Willis which has led and overseen the delivery of improvements in End of Life locally.

5.4 These working groups should be chaired by clinician's who should assume leadership for the specific area under focus, however in order to deliver system change , it is important that membership and commitment to the group is cross organisational and multi professional both in terms of clinical and managerial engagement.

5.5 There is a requirement as described in section 4 to establish a system PEoLC group that reports upwards into the regional SCN and NHSEI. This system level PEoLC will be the programme board for the work streams addressing the four priority areas and this will form part of the refreshed Terms of Reference of that group.

5.6 The timescales for intervention would be between April and September 2021 with a stock take of progress presented to September 2021 Community and Place Based Board ahead of the expected launch of the National Strategy in September 2021.

6 Recommendations

6.1 To note the completion of Phase One of the Review and the collaborative identification of the 4 areas of focus

6.2 To note the change of CCG leadership of the End of Life Review as it enters Phase Two and the continued commitment of system partners to engage in the improvement workstreams to address the four key areas, including clinical leadership for all four key areas.

6.3 To note the regional NHSEI requirements re a local system PEoLC group whose membership will include representatives from the voluntary sector and people with lived experience.

6.4 To note the agreement that this refreshed PEoLC will act as the programme board for the four key improvement projects and report into the Community and Place based Board which in turn will report directly to the shadow ICS Board, thus ensuring prominent line of sight on the progress of the 4 working groups.

6.5 To agree for JHOSC to receive a report on the EOL task and finish group progress in September 2021.

Appendix One Results of the Paired Comparison Exercise

1. Process for Template Completion

1.1 The template and instructions below were shared in written format, alongside a link to a video explanation and the contacts details of how further support could be obtained. The written format also contained a briefing around the methodology for the review.

1.2 In red at the top of the document is the key prioritisation rationale that we are seeking to address and the exercise is designed to assist in collaboratively agreeing addressing whish areas of focus will make the most impact on improving EoLC experiences in our local Shropshire, Telford & Wrekin System. This is done by considering the nine questions below it.

	Which question if successfully answered would make the most impact on improving EOL experiences in our local Shropshire , Telford & Wrekin System											
1	How do we develop a system agreed EOL care plan that is flexible enough to be used across care settings and enable individuals receiving care / and those close to them to input should they wish to?	1	1	1	1	1	1	1	1	1	=	
		2	3	4	5	6	7	8	9			
2	How do we ensure transition of care between providers through aligned policies and procedures?	2	2	2	2	2	2	2		2	=	
		3	4	5	6	7	8	9				
3	How do we work together from a workforce perspective as a system to enhance a hospice at home approach?	3	3	3	3	3	3			3	=	
		4	5	6	7	8	9					
4	How do we support staff to better recognise EOL and engage in conversations about this with individuals?	4	4	4	4	4				4	=	
		5	6	7	8	9						
5	How do we improve the consistency of offer in relation to ReSPECT conversations and documentation?	5	5	5	5					5	=	
		6	7	8	9							
6	How do we ensure that as a system we are learning from death reviews together and not as silo organisations?	6	6	6						6	=	
		7	8	9								
7	How do we improve our approach to ensuring we are able to proactively identify anticipatory care needs?	7	7							7	=	
		8	9									
8	How do we ensure that generalists i.e. non palliative care health and social care staff can access the level of information and support they need to deliver an improved experience of care for individuals at end of life?	8								8	=	
		9										
9	How do we change the commissioning and delivery of the EOL care pathway locally to ensure greater levels of personalisation?									9	=	
										Total	=	
										Total must be	36	

1.3 Individuals were asked to challenge themselves if the system focusing on question 1 would make more impact on improving EoLC experience compared to question number 2, then question number one or question 3 and question 1 or question 4 (working across the template). Below is an example of a completed row.

1	How do we develop a system agreed EoLC care plan that is flexible enough to be used across care settings and enable individuals receiving care / and those close to them to input should they wish to?	1	1	1	1	1	1	1	1
		2	3	4	5	6	7	8	9

1.4. The individual in this example has indicated that they judged answering question 1 will have more impact than addressing question 2, however, when comparing question 1 with question 3 they have indicated that question 3 will have more impact on improving EoLC experience and so on.

1.5 Participants were instructed that there were no right or wrong answers. The selection of one question over the other is based on what they thought would make the most difference based on their own, knowledge, thoughts, learning and experience.

1.6 Once they have considered question 1 against all the other questions in the row, repeat the exercise with question 2. Again asking, which of these questions would lead to the most impact on improving EOLC experience?

1.7 So, they were asking themselves which out of question 2 or 3 if addressed would have most impact on improving the experience of EOLC, question 2 or question 4 and so on
In this example the marker has chosen question 2 as having greatest impact when compared to question 3, and then when considering question 2 or 4 has selected question 4 and so on. The process gets shorter as individuals move down the questions.

2	How do we ensure transition of care between providers through aligned policies and procedures?	2	2	2	2	2	2	2
		3	4	5	6	7	8	9

1.8 Participants were asked to make a choice between the questions and fully complete the template, repeating the procedure above with each separate question, working across the rows

1.9 Once you have completed the template you need to add up the numbers 1, 2, 3 selected etc and record in the column at the side. When added up the column should equal 36.

Focusing on this will make the most impact on improving EOL experiences in our local Shropshire , Telford & Wrekin System

How do we develop a system agreed EOL care plan that is flexible enough to be used across care settings and enable individuals receiving care / and those close to them to input should they wish to?	1	1	1	1	1	1	1	1	1 =	4
	2	3	4	5	6	7	8	9		
How do we ensure transition of care between providers through aligned policies and procedures?	2	2	2	2	2	2	2		2 =	3
	3	4	5	6	7	8	9			
How do we work together from a workforce perspective as a system to enhance a hospice at home approach ?	3	3	3	3	3	3			3 =	3
	4	5	6	7	8	9				
How do we support staff to better recognise EOL and engage in conversations about this with individuals ?	4	4	4	4	4				4 =	5
	5	6	7	8	9					
How do we improve the consistency of offer in relation to ReSPECT conversations and documentation?	5	5	5	5					5 =	1
	6	7	8	9						
How do we ensure that as a system we are learning from death reviews together and not as silo organisations?	6	6	6						6 =	7
	7	8	9							
How do we improve our approach to ensuring we are able to proactively identify anticipatory care needs ?	7	7							7 =	3
	8	9								
How do we ensure that generalists ie non palliative care health and social care staff can access the level of information and support they need to deliver an improved experience of care for individuals at end of life ?	8								8 =	4
	9									
How do we change the commissioning and delivery of the EOL care pathway locally to ensure greater levels of personalisation?									9 =	6
									Total =	
									Total must be	36

Appendix One CONT

2. Results of Paired Comparison

Stakeholders who contributed

People with experience
Healthwatch (S, T&W)
Primary Care
Community Services
Acute Hospital
Ambulance Service
Social Care
Care Homes
CCG

For those individuals/services that sent a more narrative feedback i.e. chose not to complete the template, the scoring was weighted for the questions that most represented the response.

A total of 28* completed templates were returned and the scores for each question added up Questions were weighted to reflect the narrative/verbal feedback received from People with experience, Social Care, Care Homes and WMAS. For example an individual feedback via email of experience of staff having the lack of confidence to manage a syringe driver and another incidence of a person needing admission to a care home as care over night was not available. For this narrative feedback questions 3 and 8 were scored an 8 (8 is the highest any question could score).

No	Question	Total score
1	How do we develop a system agreed EOL care plan that is flexible enough to be used across care settings and enable individuals receiving care / and those close to them to input should they wish to?	110
2	How do we ensure transition of care between providers through aligned policies and procedures?	97
3	How do we work together from a workforce perspective as a system to enhance a hospice at home approach?	107
4	How do we support staff to better recognise EOL and engage in conversations about this with individuals?	148
5	How do we improve the consistency of offer in relation to ReSPECT conversations and documentation?	72
6	How do we ensure that as a system we are learning from death reviews together and not as silo organisations?	81
7	How do we improve our approach to ensuring we are able to proactively identify anticipatory care needs?	123
8	How do we ensure that generalists i.e. non palliative care health and social care staff can access the level of information and support they need to deliver an improved experience of care for individuals at end of life?	137
9	How do we change the commissioning and delivery of the EOL care pathway locally to ensure greater levels of personalisation?	110

* Of the 28 completed returns 9 were partially completed

Appendix Two Mapping of Shropshire , Telford and Wrekin EOL Review Priority Areas of focus and the Recommendations of the National Audit at End of Life Care (NaCEL) NHS Benchmarking

NaCEL Recommendation (2019)	Do the outcomes of the Shropshire Telford and Wrekin EOL review priority areas meet with this recommendation?
Put in place systems and processes to support people approaching the end of life to receive care that is personalised to their needs and preferences.	Yes
Review capability and capacity across all care settings, to provide appropriate care at the end of life, and to support people important to the dying person through to bereavement, with the aim of better meeting people's needs and preferences.	Yes
Ensure adequate access to specialist palliative care in hospitals for holistic assessment, advice and active management.	No, the priorities identified focus more on the support for the generalist workforce to, it is likely that this working group will identify any gaps in specialist provision
Create and implement an action plan to ensure the local findings and national recommendations of NACEL are reviewed, and providers of NHS funded care at the end of life in acute and community hospitals and other care settings are supported by commissioners in developing, implementing and monitoring their plans.	No, this is already in place within provider organisations
Ensure systems and processes for anticipatory prescribing for patients transferring from hospital to home or care home to die are aligned across the health and social care system.	Yes
Require and support health and care staff to gain competence and confidence in communicating effectively and sensitively with the dying person and people important to them in the last days and hours of life.	Yes
Put systems in place to ensure the needs of people important to the dying person are assessed and addressed in a timely manner, both before and after death.	Yes
As part of a strong governance framework for end of life care, report annually to the Board with a performance report and action plan.	Yes, the review process forms part of the Governance framework and a priority for the regional Palliative and End of Life Care Network
Ensure that staff have an awareness of the possibility or likelihood of imminent death, and acknowledge and communicate to the dying person and people important to them, as early and sensitively as possible.	Yes
Ensure that priority is given to the provision of an appropriate peaceful environment, that maximises privacy, for the dying person and people important to them.	Yes
Ensure that patients who are recognised to be dying	No, there was a specific question

have a clearly documented and accessible individual plan of care developed and discussed with the patient and those important to them to ensure the person's needs and wishes are known and taken into account.	about developing a standard care plan. This scored as 4 in the prioritisation process
Ensure that the intended benefit of starting, stopping or continuing treatment for the individual is clear, with documentation of the associated communication with the dying person and/or people important to them.	Yes
Ensure the dying person is supported to eat and drink if they are able and wish to do so.	Yes, although there is no specific prioritisation about nutrition and hydration this will form part of the work for the group that will be working to improve care for the person in the last days of life
Ensure patients who are recognised to be dying, and are likely to need symptom management, are prescribed anticipatory medicines and individualised indications for use, dosage and route of administration are documented.	Yes as above
Where relevant, ensure that clear explanations are given to the dying person, and people important to them, about the rationale for the use of, and medications delivered by, syringe pumps.	Yes as above

Appendix Three Mapping of Shropshire , Telford and Wrekin EOL Review Priority Areas and Findings of Strategy Unit Review Health Services in the Last two years of life, Shropshire, Telford and Wrekin

Key themes of Strategy Unit Review	**Do the outcomes of the Shropshire Telford and Wrekin EOL review priority areas meet with this recommendation?**
35% of people in S,T&W die in hospital, the most common experience is a terminal episode of 2 days	Yes, anticipating care needs and identifying people in the last year of life will support more people to die in their preferred place
Services are often reactive and uncoordinated	Yes
Too few people die in their preferred place	**Yes**
There is an inequity of experience and access	No specific prioritisation focused on equity, however all the work streams will work towards equality of access
People dying from cancer are more likely to have their access to hospital planned	Yes, anticipating care needs and identifying people in the last year of life will support more planned care
9 in 10 people access urgent care in the last 2 years of life	As above
Rates of unrelieved pain are highest for those palliative patients who die at home	As above

Appendix Four Mapping of Shropshire , Telford and Wrekin EOL Review Priority Areas of focus and the Findings of Shropshire Community NHS Health Trust Learning from Deaths Review (2020)

Key themes of Learning form Death Review	Do the outcomes of the Shropshire Telford and Wrekin EOL review priority areas meet with this recommendation?
Recognition that an individual is in the last year of life and anticipating care needs	Yes
Care in the last days of life	Yes
Care Planning and communication	No, there was a specific question about developing a standard care plan. This scored as 4 in the prioritisation process
Nutrition and Hydration	Yes, although there is no specific prioritisation about nutrition and hydration this will form part of the work for the group that will be working to improve care for the person in the last days of life
Leadership	No, there were no prioritisation questions specific to leadership however this is covered by the establishment of the system level PEoLC reporting into the regional and then national Group with a strong emphasis on clinical leadership
Training	Yes
Bereavement	No, there were no prioritisation questions specific to bereavement, however this could be an element of the working group tasked to address symptom management and care in the last days of life