10 questions to ask if you are scrutinising end of life care for adults

Introduction

This guide is one of a series designed to help Health Overview and Scrutiny Committees (OSCs) carry out their scrutiny work around various health, healthcare and social care topics. Other Centre for Public Scrutiny 10 questions guides look at:

Adult Social Care Transformation
Assessing evidence
Child and Adolescent Mental Health (with LGA)
Community Pharmacy (with NPA)
Promoting physical activity (with NICE)
Local Hospitals
Healthcare for People with Learning Disabilities (with FPLD)
Service re-design and reconfiguration
Eye health
Arrangements to support effective Local Involvement Networks

The Centre for Public Scrutiny (CfPS) http://www.cfps.org.uk promotes the value of scrutiny in modern and effective government, not only to hold executives to account but also to create a constructive dialogue between the public and its elected representatives to improve the quality of public services. The Centre received funding from the Department of Health to run a three-year support programme for health overview and scrutiny committees of social services authorities as they develop their power to promote the well-being of local communities through effective scrutiny of healthcare planning and delivery and wider public health issues.

The National Council for Palliative Care (NCPC) http://www.ncpc.org.uk is the charitable umbrella organisation for all those who are involved in providing, commissioning and using palliative care and end of life care services in England, Wales & Northern Ireland. NCPC promotes the extension and improvement of palliative care services for ALL people with life-threatening and life-limiting conditions. NCPC promotes palliative care for all who need it across all sectors and settings.

In 2008, it was asked by Government to set up and lead a new Coalition, entitled Dying Matters, to raise public awareness about dying, death and bereavement as a key part of implementing the first ever end of life care strategy [i]. Dying Matters aims to help all to have conversations about wishes and plans and to make dying well a more natural part of living well in all communities. www.ncpc.org.uk/dyingmatters

The NCPC is a subscription organisation. It offers a range of evidence based policy analysis, practical guidance and training material. www.ncpc.org.uk/subscribe

What is end of life care?

End of life care helps all those with advanced, progressive, incurable illness to live as well as possible until they die. It enables the supportive and palliative care needs of both patient and family to be identified and met throughout the last phase of life and into bereavement. It includes management of pain and other symptoms and provision of psychological, social, spiritual and practical support. [i]

Why is it important for OSCs to review end of life care for adults?

Caring for people at the end of their life is an expression of how we value people.

"How we care for the dying is an indicator of how we care for all sick and vulnerable people. It is a measure of society as a whole and it is a litmus test for health and social care services." End of Life Care Strategy, 2008, p10 [i]

"You matter because you are you and you matter until the last moment of your life". Dame Cicely Saunders

The current situation

Each year, around 500,000 people die in England. The number of deaths is predicted to continue to decrease until 2012 but from that date they are set to rise by approximately 16.5% by 2030 which equates to some 90,000 additional deaths each year (590,000)[ii]. Clearly the supply of hospital and hospice beds will not keep pace with that rate even if that were the appropriate response. Will residential/nursing home or community care services be equipped?

By 2030 those aged over 65 will account for 86.7% of all deaths with those over 85 accounting for 43.5% (a marked increase from 32% in 2004) (2). A significant proportion will have multiple conditions[iii] with approximately 29% also having dementia[iv]. Around 70% of people express a wish to die at home. This means that by 2030 we need either 20% more institutional beds or we need to develop new ways to meet people's needs, for example community based models and end of life care training for all, so that needs can be met as part of everyone's practice. At the same time informal carers will also be becoming older with possibly multiple conditions which may well affect their ability to fulfil their carer role. The ability of local areas to respond to this growth in need will be critical. How do we avoid what is an already traumatic and emotional time becoming a series of challenges to responsibility and skills that result in delays to help, care and support? The consequent damage to public confidence and perception of the service if we fail would be longstanding.

The children's perspective

The National End of Life Care Strategy, published in 2008[i], focuses on services for adults. A separate review of children's palliative care services, undertaken by Professor Sir Alan Craft and Sue Killen, was published in May 2007. The review drew attention to the challenges facing palliative and end of life care services for children and set out a number of recommendations for government, as well as for the development of services at a local level. The recommendations were endorsed by the government and a first ever national strategy for children's palliative care – Better Care, Better Lives – was published in February 2008.
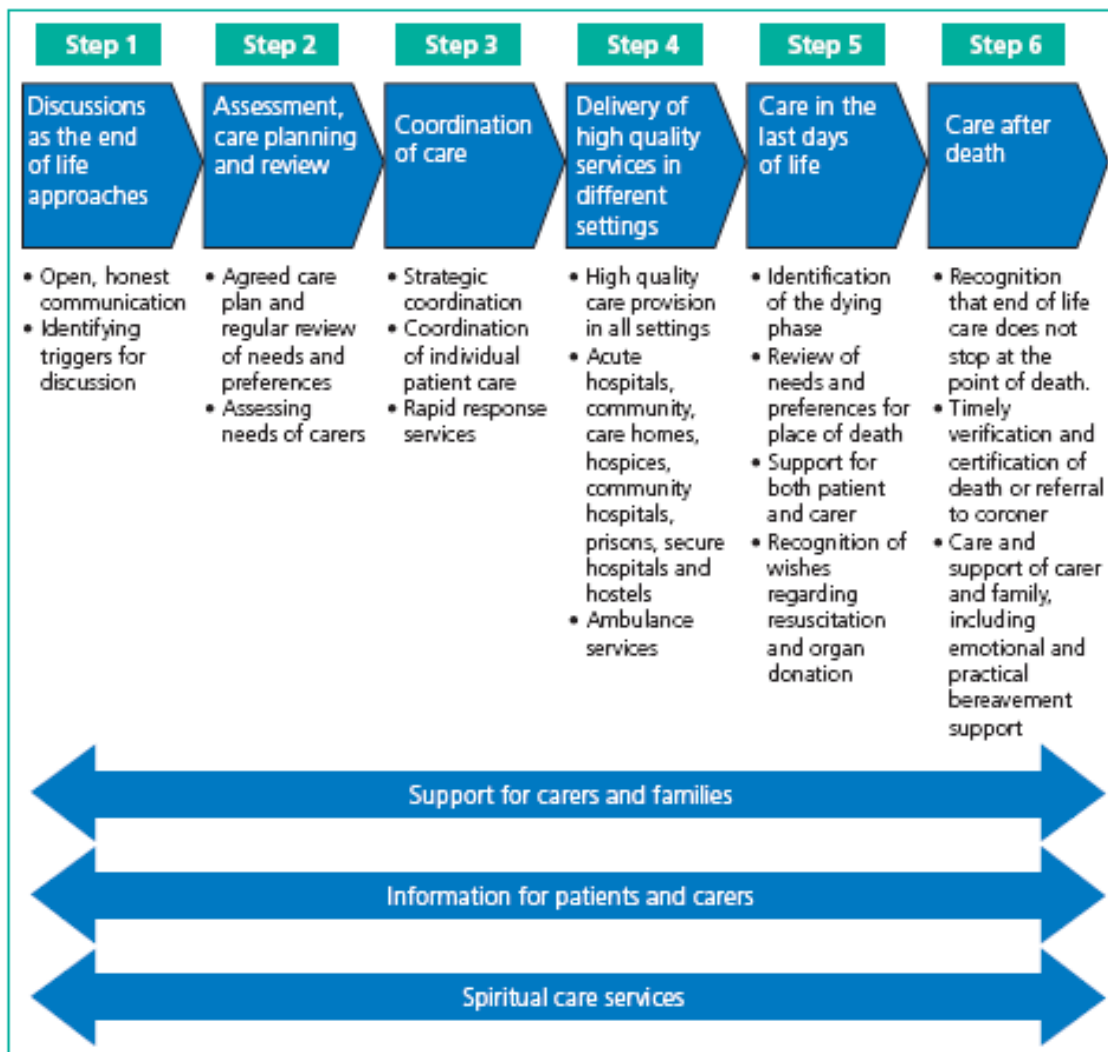
Whilst it is acknowledged that some parallels can be drawn between the principles applying to end of life care services for adults and those for children, it needs to be emphasised that there are also significant differences. For example, there are a wide variety of childhood conditions causing death before adulthood, many of which are rare. The time span of children's illnesses may also be different from adults, meaning that palliative care extends over many years.

Moreover, children continue to develop physically, emotionally and cognitively, and this affects both their medical and social needs, as well as their understanding of disease and death. Above all, a child's death remains particularly emotionally difficult, unnatural and unexpected for families and healthcare providers alike.

Due to advances in medical care, many children and young people living with life-limiting conditions likely to require palliative care are nowadays living longer, and many of them can maintain a good quality of life if they and their families are properly supported by services. However, they do require increasingly complex levels of support and it therefore becomes much more important that transitions to adult care are carefully considered by commissioners in planning end of life care services.

What does good end of life care look like?

The End of Life Care Strategy[i] outlined a pathway which represents broad stages involved in care at the end of life. Good end of life care requires quality at all stages:

Step 1	Step 2	Step 3	Step 4	Step 5	Step 6
Discussions as the end of life approaches	Assessment, care planning and review	Coordination of care	Delivery of high quality services in different settings	Care in the last days of life	Care after death
• Open, honest communication • Identifying triggers for discussion	• Agreed care plan and regular review of needs and preferences • Assessing needs of carers	• Strategic coordination • Coordination of individual patient care • Rapid response services	• High quality care provision in all settings • Acute hospitals, community, care homes, hospices, community hospitals, prisons, secure hospitals and hostels • Ambulance services	• Identification of the dying phase • Review of needs and preferences for place of death • Support for both patient and carer • Recognition of wishes regarding resuscitation and organ donation	• Recognition that end of life care does not stop at the point of death. • Timely verification and certification of death or referral to coroner • Care and support of carer and family, including emotional and practical bereavement support

Support for carers and families

Information for patients and carers

Spiritual care services

Benchmarking for any scrutiny review

- The national End of Life Care Strategy[i] http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_086277 sets out a national implementation plan with identified national support around improving end of life care which has been founded on the available evidence including expert opinion. This has then been used and developed in each Strategic Health Authority (SHA). They have all published their vision, priorities and plans for implementing End of Life Care as part of their activities in relation to the NHS Next Stage Review. These plans should include both health and social care services.

- The National Audit Office conducted a review of end of life care services in 2008[v]. In particular, it carried out detailed work in Sheffield highlighting the number of people that were in hospital who potentially did not need to be.

- Each Strategic Health Authority has been given new funding for workforce development as part of the End of Life Care Strategy[i] implementation.

- Each Primary Care Trust (PCT) is developing end of life care plans to clearly show how they will spend the £286m of funding allocated over the next two years. Although not ring fenced these monies will be closely monitored and how they are deployed must be transparent.

- The NHS Operating Framework 2009/10 clearly states that these plans should be aligned to Local Area Agreements. Local Area Agreements (LAAs) set out the priorities for a local area agreed between central government and a local area (the local authority and Local Strategic Partnership) and other key partners at the local level. They simplify some central funding, help join up public services more effectively and allow greater flexibility for local solutions to local circumstances. [vi]

- End of life care is also included in all recent national strategies including the Dementia Strategy, Stroke Strategy and the Carers Strategy. Joining all of these up and linking priorities is very important.

- Raising public awareness about issues around dying, death and bereavement is a key in the implementation of the End of Life Care Strategy[i]. See www.ncpc.org.uk/dyingmatters for further details of the national awareness raising coalition.

Possible partners and/or contributors for a review of end of life care

End of life care is part of care for all, regardless of condition, age or place of care and should be everybody's business. Therefore, it is impossible to provide a conclusive list of partners. However, the End of Life Care Strategy[i] outlined three broad categories of staff involved in end of life care.

Group definition	Members of staff
Group A – Staff working in specialist palliative care and hospices who essentially spend the whole of their working lives dealing with end of life care	Physicians in palliative care Palliative care nurse specialists and allied health professionals Hospice pharmacists Chaplains All health and social care staff working in or with hospices
Group B – Staff who frequently deal with end of life care as part of their role	Secondary care staff working in A&E, acute medicine, respiratory medicine, care of the elderly, cardiology, oncology, renal medicine, long term neurological conditions, intensive care, hospital chaplains, and some surgical specialities Primary care staff including GPs, district nurses, community matrons, some care home staff, ambulance staff and community based carers Specialist nurses such as heart failure nurses, based in primary or secondary care Community pharmacists
Group C – Staff working as specialists or generalists within other services who infrequently have to deal with end of life care	Other professionals working in secondary care or in the community. For example, care home staff and extra care housing staff, day centre and social care staff not involved in hospices. Domiciliary care, homeless projects, and prison services staff

There will also be people who are involved in end of life care who are not part of NHS organisations:

Nursing and social care staff

Coroners

Funeral directors

Faith and spiritual leaders

Carers' organisations

Benefits advisors

Voluntary organisations and volunteers

Directors of public health

Children's services

Primary Care Trust and Strategic Health Authority end of life care leads or commissioners

Patient and public involvement leads in Primary Care Trusts or Strategic Health Authorities

Local area agreement partners

Local area agreement partnership boards

Local strategic partnership boards

The key is to think first of the person needing end of life care, and imagine the people who might be involved in supporting them and meeting their needs in every area of their lives

Tips for scrutinising end of life care

- Try to think outside the box. End of life care is not solely about hospice care or care for people with cancer, and most of us want to die in our own homes. We all die and want good care whatever our condition.
- End of life care is a vast and cross cutting area, affecting virtually all conditions and places of care. In view of this, you may wish to focus on one aspect at a time, such as support for carers at the end of life, or end of life care for people with dementia.
- It is important not to overlook the key role played by GPs and community nurses, who are the first point of call for most people.
- You will find definitions of end of life care, palliative care and supportive care below.
- Refer to NCPC's website www.ncpc.org.uk for access to resources about various aspects of palliative and end of life care. Subscribing to NCPC will give you free access to all our

publications which will provide you with current trends and examples of good practice. Its population based indices of need will help with benchmarking (www.ncpc.org.uk/subscribe).

- The CfPS library already contains some reviews such as Hampshire County Council 'Care at End of Life'. http://www.cfps.org.uk/scrutiny-exchange/library/health-and-social-care/?id=1638 and 'Review of End of Life Care in Warwickshire' http://www.cfps.org.uk/scrutiny-exchange/library/health-and-social-care/?id=2463.

Definitions

The terms palliative, end of life and supportive care are all used in this area and have considerable overlap. Definitions are shown below.

Palliative care is the active holistic care of patients with advanced progressive illness. Management of pain and other symptoms and provision of psychological, social and spiritual support is paramount. The goal of palliative care is achievement of the best quality of life for patients and their families. Many aspects of palliative care are also applicable earlier in the course of the illness in conjunction with other treatments (National Institute for Clinical Excellence [NICE], 2004).[vii]

Palliative care incorporates end of life care, but, as these terms are sometimes used interchangeably, the following definition is provided:

End of life care helps all those with advanced, progressive, incurable illness to live as well as possible until they die. It enables the supportive and palliative care needs of both patients and family to be identified and met throughout the last phase of life and into bereavement. It includes management of pain and other symptoms and provision of psychological, social, spiritual and practical support ('End of Life Care Strategy', Department of Health 2008, p47)[i].

Supportive care helps the patient and their family to cope with their condition and treatment of it – from pre-diagnosis, through the process of diagnosis and treatment, to cure, continuing illness or death and into bereavement. It helps the patient to maximise the benefits of treatment and to live as well as possible with the effects of the disease. It is given equal priority alongside diagnosis and treatment.

Supportive care should be fully integrated with diagnosis and treatment. It encompasses:

- Self help and support
- User involvement
- Information giving
- Psychological support
- Symptom control
- Social support
- Rehabilitation
- Complementary therapies
- Spiritual support
- End of life and bereavement care

10 questions to help you review End of Life Care

1. What is the need in your area?

The questions below aim to help you to get a sense of the areas of greatest need in your area.

- How many people die in your locality every year?
- What do they die from?
- What age and social class are they?
- What is their ethnic background?
- Where do they die? E.g. home, acute hospital, community hospital, hospices, sheltered housing, care homes (nursing or personal care).
- Has a baseline review of your population needs been carried out in your area?
- Did this identify any gaps in the available data/information?
- What are the priorities and how are these gaps being addressed to inform end of life care commissioning and planning?

More information:

Access to statistics:
NCPC has published two helpful guides, both available free for subscribers from www.ncpc.org.uk/publications :
'Population based needs assessment for palliative and end of life care: a compendium of data for SHAs and PCTs' [viii]
'Benchmarking Analysis: Needs, resourcing, outputs and outcomes' [ix]

Statistics are also often available in public reports around the health of specific geographical areas and some public health support can be valuable in providing additional information. It should be possible to access this information in partnership with your PCT, or if needs be, to commission your PCT to do so on your behalf.

Baseline review:
http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_074108
Examples:
http://www.crusebereavementcare.org.uk/BPPResearch/ReviewEOLCare.pdf

and
http://www.plymouthpct.nhs.uk/findinginformation/Documents/Disclosure%20Log/foia325(1i).pdf

2. Is there a clear strategy, supported by dedicated resources, for meeting end of life care needs in your locality, covering different settings and sectors of care?

Strategy
NB: All references to "strategy" in this section refer to local strategies.

- Does the strategy clearly arise from the assessment of population need including e.g. ageing population, those with multiple conditions and those with dementia?
- How is population need measured? Is this a part of Joint Strategic Needs Assessment? For more information on population based needs assessment including your local area visit www.ncpc.org.uk/publications .
- Who do you think the key stakeholders should be in developing this strategy and do you feel that all have been involved? For example: health, social care (including care homes) and housing (see above list of partners).
- How is the strategy reviewed and by whom?
- Does the strategy include all of the elements defined as important within the national End of Life Care Strategy, such as Commissioning, User Involvement, Workforce Planning and Development, Measurement, Care Pathway Across Settings/Sectors of Care, Co-ordination of Care, 24/7 access to services, Rapid Response, Care at Home, Single Point of Contact.
- Does the strategy clearly link with other local strategies such as the NHS Next Stage Review Long Term Conditions and Mental Health Workstreams, Dementia Strategy, Stroke Strategy and Carers Strategy? The National Council for Palliative Care has developed guidance on the way in which different policy agendas can be joined up. To find out more visit www.ncpc.org.uk/policy and www.ncpc.org.uk/publications.

Resources

- What resources are dedicated to end of life care locally?
- Funding for specialist palliative care such as hospices is often provided by voluntary donations. What is the situation in your area?
- How is the use of resources monitored?
- PCT plans for spending the additional funds allocated to end of life care should align with Local Area Agreements – do they in your area?
- Do the PCT plans reflect the strategy (above)? Do the plans and funding include all stakeholders across health and social care?
- Have lead commissioners for end of life care been identified? Who are they?
- Do they have the necessary knowledge to commission end of life care effectively?
- Do they link their work with commissioners of other services such as long term conditions and mental health?

3. **Is there a clear structure for workforce development and training across settings and sectors of care?**

- Does your locality/region have a clear plan for identifying the staff who deliver end of life care including community and care home staff, and then a strategy for workforce planning and development that includes all key stakeholders?
- Does your locality have an identified lead for end of life care workforce planning and development?
- Does your local workforce development plan include the key skills of communication, symptom control, assessment/care planning and advance care planning?
- Do care homes in your area have a training programme in end of life care in place, for example, NCPC's *Care to Learn* materials? http://www.ncpc.org.uk/training/index.html

- Does your local workforce development plan include details for commissioning and meeting their training and educational needs?
- Does your local workforce strategy include details of how workforce planning and development will be monitored and reviewed? For details of the specialist palliative care workforce visit http://www.ncpc.org.uk/policy/index.html .
- Don't forget that workforce development and training include staff attitudes. Two key things that patients and carers value is compassion and empathy. How do you foster these in your area?
- Assessment, care planning and advance care planning including end of life care all require a skilled and competent workforce (see below). The leaflet entitled 'Planning for your future care' provides helpful advice for patients and carers. http://www.ncpc.org.uk/publications/freedownloads.html and "Good Decision Making - the Mental Capacity Act and End of Life Care" provides guidance for professionals (available free for subscribers from www.ncpc.org.uk/publications).

4. Is there a clear structure for monitoring end of life care?

- Does your locality monitor outcomes?
- How does this inform planning and decision making?
- Do the different provider settings each monitor end of life care at Board level?

Example 1: gathering case studies or personal stories of people dying in your locality.

- How are these captured and by whom?
- How are these used to review and improve services?
- How is the learning disseminated?

Example 2: Examples of good practice

- Are there examples of good practice in your area?
- How are these evaluated?
- How is the learning disseminated to inform others?

5. Practical support for patients, families and carers

Patients, families and carers will all have needs when the patient is nearing the end of life. How are these met? Some important issues are listed below:

- *Financial assistance*: What fast track financial assistance is available for families who will have a great deal of additional expenditure associated with care of a very sick relative? Is there access to a specialist benefits advisor who can give them timely access to available benefits?
- *24 hour advice and support:* Is there a 24 hour telephone number that patients, families and carers can call for advice or support, especially during the final stages of the illness?
- *Support:* Are carers adequately supported? Do they receive a formal assessment, time out (respite), access to training and suitable support with employment? Do they have a "life of their own" as well as their caring role? Do

patients and carers have access to peer support such as buddy systems and patient or carer support groups?

- *Equipment:* Is equipment readily available? All too often people request a hospital bed and it arrives after the person has died.
- *Information:* Is there a one stop shop for information, for example about how to navigate through the "system" signposting people where necessary. Where is this and how can people access it?
- *Single point of contact:* Who is the main point of contact for the patient?
- *Palliative social worker:* Is there a palliative social worker available to arrange palliative care and provide for support needs, thus taking the strain off the family?
- *Basic care:* This includes hydration, nutrition, pain control, and being cared for with dignity amongst many other things. Two examples are:

  In hospitals and care homes, how are staff made aware of people who need additional help with eating? Is there a universal sign to indicate this? Is there appropriate mouth care?

  Is there easy access to effective pain control for people in the community and is it available 24/7? Do pharmacists and GPs work together to ensure to ensure that they are readily available?

- *Bereavement care:* What support is available for bereaved adults and children?

6. Place of care

- If the patient dies on a hospital ward, what privacy and dignity can be expected?
- How many people are transferred from their home (which could include care home) to hospital in the last weeks of life?
- How many people transfer from hospice to home at the end of life?
- How many people's choice in place of care is fulfilled?

7. Is there a clear process in your locality for assessment of needs, care planning and advance care planning for end of life care?

- What process is in place for assessment of needs which includes end of life care? For the patient? For the carer?
- Is it joint across health and social care?
- Is this standardised across (a) settings of care and (b) sectors of care?
- If not, are there plans to place to review this and implement new processes?
- How are these to be monitored/ reviewed?
- Is there a clear process for assessment of need to lead to a review of the care plan including end of life care, both for the individual and for the carer?
- Is there a clear process for discussing advance care planning and end of life care wishes with the individual and their carer? How will patients and carers be reassured that their plans will be met and that all professionals involved will have access to this information?

8. Co-ordination of care

Owing to the variety of professionals involved in end of life care, co-ordination is vital.

- Is there a clear process for information sharing about people in the end of life phase across sectors and care settings i.e. a register?
- Who leads a multidisciplinary team, in particular when both health and social care providers are part of it?
- To what degree are settings able to share information?
- How are out of hours services informed of people's end of life care needs?
- To what degree are sectors (for example health, social care, independent and third sectors) able to share information?
- Is this being reviewed?

9. Do you know what local patients and carers want from services?

- Does your locality involve service users and carers in planning, developing, monitoring and evaluating end of life care services?
- Do you have a strategy for this?
- Does your Patient and Public Involvement lead have a remit for end of life care?
- Is your Local Involvement Network doing any work around end of life care?
- Do you have a plan in place to support service users, carers and staff who are carrying out user involvement in this area?
- Do you consistently and routinely provide feedback to service users and carers who are involved?
- Have you mapped out user involvement in other organisations to learn from this? To learn more about user involvement in end of life care visit www.ncpc.org.uk/users.
- What stops you from involving service users and carers?
- Do you log your lessons learned so that you can continually build on user involvement and share these within the organisation and outside?
- Have you accessed NCPC's free guide: A guide to involving patients, carers and the public in end of life care. Available from http://www.ncpc.org.uk/users/index.html[x]

10. Raising public awareness

- Do you have local public awareness plans and any campaigns around the issues of dying, death and bereavement?
- How is your locality linked to Dying Matters, the national coalition on dying, death and bereavement led by the NCPC? Sign up your organisation to get regular updates and resources. Visit www.ncpc.org.uk/dyingmatters to find out more.

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Emily Sam – Deputy Director of Policy Development, National Council for Palliative Care

Jo Black – User Involvement Project Manager – National Council for Palliative Care

Members of NCPC's service user advisory group

Avril Davies - CfPS Health Scrutiny Programme Advisor, The Centre for Public Scrutiny

Denise Holden – Corporate Scrutiny Manager, Hampshire County Council

Alwin McGibbon - Health Scrutiny Officer, Warwickshire County Council

Martin Coombs – Scrutiny Officer, Hampshire County Council

Shaun Gordon - Expert Adviser, Centre for Public Scrutiny and Director, Shaun Gordon Associates

Heather Richardson – Clinical Director, St Joseph's Hospice, London

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