ISLE OF WIGHT
END OF LIFE CARE REVIEW 2013/14
REPORT
DRAFT

Thoreya Swage

March 2014

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EXECUTIVE SUMMARY

1. This is a report of a review and evaluation of the Isle of Wight Clinical Commissioning Group (IOW CCG) commissioned end of life care (EoLC) services against:

- National Guidelines
- Local End of Life Strategy
- Provision of local hospice care
- Current pathways of care

2. A range of stakeholders were interviewed together with an analysis of data and information relating to the Isle of Wight end of life care services and examination of good practice elsewhere

3. Overall there was a willingness to work together across the agencies (hospital, community, social care, hospice and care homes) to improve the care for people nearing the end of life although over 47.6% of people were still found to be dying in hospital rather than at home

4. The review found that there were the following areas of good practice including:

- The use of the Amber Care Bundle in the hospital setting
- The use of the Older Persons Anticipatory Care Plan in the community setting
- The ACP is placed on the 111 Adastra electronic records system
- A co-ordination centre for rapid response based at the 111 hub
- The integration of palliative care nursing
- The use of 'Just in case' drugs
- The support, advice and information provided by the third sector (e.g. Wessex Cancer Trust)

5. Areas where there were there were concerns about end of life care included:

- There is no formal link between the ACB and the ACP
- There are elements of an end of life care pathway but no overall picture of how the service should be delivered across agencies
- The continuation of occupational therapy services across the hospital trust, community, hospice and social care is fragmented and there is the potential for duplication of work
- The co-ordination of response to a referral for end of life care is not clear
- Training for health and social care professionals on end of life care is inconsistent

6. A number of recommendations have been made to improve end of life care services for the Isle of Wight including:

    I.   A holistic and co-ordinated pathway across community, social and secondary care should be developed in order to improve the consistency of care of people with end of life care needs on the island.

          a.   In the first instance there should be the continuation of care using the Anticipatory Care Plan in the primary setting and the Amber Care Bundle in

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the acute sector through the mechanism of consistent electronic records. This also needs to link up with social care records

    b. The availability of the 'Just-in-case' drugs packages should be improved to ensure that these are accessible in a timely manner when required

    c. The pathway once developed should be embedded into the end of life care contracts

II. A specific service specification for palliative care and end of life care Occupational Therapy services across acute and community settings should be developed to clarify the input of this therapy to the end of life care pathway

III. There should be clarity on the input and role of the district nursing services to the end of life care pathway paying specific attention to the capacity of the current service to meet end of life care needs

IV. In conjunction with the development of an island wide end of life care pathway consideration needs to be made to the appropriate training and education needs of all the professionals looking after people with end of life care needs in the hospital, community and care homes sector. Ideally the training should be multi-disciplinary in nature.

V. There should be an appointment of a key worker to co-ordinate and review the management of a patient referred for end of life care.

VI. There should be a dedicated role to support the case managers in identifying and fast tracking people who are nearing the end of life who have a 'step down' change in condition requiring continuing health care

VII. There should be a lead provider agency for the delivery of end of life care which will hold the main contract for these services and subcontract with other providers to provide a whole end of life care package. As part of this arrangement there needs to be a service level agreement or contract for working with social care

VIII. The strategy for end of life care should link up with other initiatives such as My Life, A Full Life and the needs of people with dementia

IX. The end of life care pathway should cover not only the needs of people who have cancer but also terminal non cancer conditions such as cardiac and lung conditions

INTRODUCTION

This is a report of a review and evaluation of the Isle of Wight Clinical Commissioning Group (IOW CCG) commissioned end of life care services against:

- National Guidelines
- Local End of Life Strategy
- Provision of local hospice care
- Current pathways of care

A number of issues have arisen during 2013 which have prompted a review of end of life care services on the Isle of Wight including:

- Concerns that have been raised within Primary Care over the accessibility to the Hospice;
- Review of end of life care services Occupational Therapy support, both in the hospital and Hospice
- Review of Pharmacy support delivered to Earl Mountbatten Hospice (EMH) from the Isle Of Wight NHS Trust
- Review of the current end of life strategy to give assurance with regard to the commissioning requirements for the IOW CCG
- Pathways across the whole end of life care needing to be more robustly developed.

The aims of this Project are to:
- Identify the gaps and/or overlaps in current end of life care service provision;
- Ascertain patient and professionals accessibility to current end of life care services;
- Ascertain patient and carers views;
- Identify service developments and improvement opportunities; and
- Review current best practice and gaps in service.

The outcome of this work is to:
- Review and refresh the End of Life strategy in light of the findings of the service review including revised end of life care Pathways
- Present proposals to the CCG on improvements to the commissioning of end of Life services
- A report covering the issues above

METHODOLOGY

The review was undertaken in three parts:

1. One-to-one in-depth semi-structured face-to-face interviews with key stakeholders
2. An analysis of data and information relating to the Isle of Wight end of life care services
3. An examination of good practice with regard to end of life care services from other sources

The key stakeholders were representatives from:

- Earl Mountbatten Hospice
- Isle of Wight NHS Trust (acute and community services)

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- General Practice
- Clinical Commissioning Group
- Patients
- Social Care
- Nursing Homes
- Residential Homes
- Voluntary sector
- National End of Life Care Programme

A full list of the stakeholders interviewed is in Appendix A.

The review was undertaken from January to March 2014.

The outcomes of this piece of work include:

- A project report, covering the aims and objectives of this Project
- Proposals for end of life pathways;
- Proposed developments in end of life care for the Isle of Wight;
- A refresh of the Isle of Wight end of life care strategy.

FINDINGS

The findings of the interviews and other information collected as part of this work are presented under specific headings with a summary of the areas of good practice identified during the course of this project.

Care provided by the Earl Mountbatten Hospice

The Earl Mountbatten Hospice (EMH) is well regarded on the island and it provides, inpatient, outpatient, hospice at home, support care (physiotherapy, occupational therapy, lymphoedema, complementary and bereavement care). The hospice is currently integrating the nursing teams for palliative care in the community (see below) and has just recruited two new oncologists with one now in post.

There have been some concerns over access to specialist medical advice as well as admission to the hospice for patients with cancer from the community. The admission process follows an assessment at the medical assessment unit at the hospital prior to admission to the hospice. This developed as the hospice was short of consultant input. The situation is being addressed with the appointment of the new consultant who is investigating the current system.

The hospice is focussing on the improvement of medicines management and has developed an enhanced clinical pharmacology service operating on the wards. This process is being facilitated by the new consultant oncologist who was appointed in January 2014.

The hospice has also opened a day centre, the John Cheverton Centre, in the past year where there are 15 places for patients from the community to be assessed by clinical nurse specialists for palliative day care. Currently it is open 4 days a week and the plan is to extend this to 5 days and eventually to weekend opening.

Care provided by the Isle of Wight NHS Trust

The hospital trust provides inpatient care for patients with palliative care needs. The service is provided by clinical nurse specialists who support other staff. The two oncologists based at the hospice are shared with and paid by the hospital trust. The trust uses the Amber Care Bundle (ACB), a multi-disciplinary tool used for the assessment and management of people at the end of life.

For community nursing services see section on palliative care in the community below.

Residential and social care

There is a fast track process for people nearing the end of life who require continuing health care. For this to take effect there needs to be a 'step down' change in the patient's condition, such as severe weight loss, a change in pain administration to a syringe driver, requiring nursing in bed. The referral is assessed by nurses who gather information about the patient including a report from the GP. Agencies who provide a sitting service are also contacted as part of the fast track process are asked to respond within an hour and a half and care is arranged within 24 hours.

There are eight agencies who provide a sitting service on the island however this is not enough capacity to met needs and the CCG is going out to tender for more providers later this year.

Joint training is provided to health and social care staff twice a year in September and March to explain the continuing health care process.

There is a perception that there is limited access to the fast track process to meet the needs of people requiring continuing health care and specifically end of life care. This is in part due to a delay in reviewing care packages and not identifying people in need quickly enough, and also to poor understanding of the criteria for fast track assessment, i.e. the 'step down' change in condition, that determine access to continuing health care.

There was the input of a specialist worker on the continuing health care panel who had the role of supporting the case managers to make fast track referrals and to identify people who fit the criteria for such care. This role has since ceased three years ago. The manager for continuing health care at the CCG is available to discuss potential referrals for fast track assessment.

The role of the residential and care homes is varied with respect to the management of people with end of life care needs due to the high turnover of staff and limited training on this subject matter. This has improved with the piloting of the Anticipatory Care Plan (ACP) in the north- east part of the island.

Pathway

The Leadership Alliance for the Care of Dying People has published a joint statement in January 2014 following a report of the independent panel on the Liverpool Care Pathway. It states that there will be no replacement for the Liverpool Care Pathway once it is phased out by 14th July 2014. In its place individually tailored plans are to be used at the end of a person's life.

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There are different elements of a pathway for the management of people nearing the end of life at work on the island. In the hospital setting patients are placed on the Amber Care Bundle if they are considered to be towards the end of life. This is a process, originally developed at St Thomas' Hospital in London, which involve the following steps; assessment, management, best practice, engagement and recovery uncertain to ensure that patients receive the appropriate management.

Benefits of the ACB include:

- improved decision making
- a positive impact on the multi-professional team and communication and working
- an increase the confidence of nurses about when to approach medical colleagues to discuss treatment plans
- patients are treated with greater dignity and respect
- greater clarity around preferences and plans about how these can be met
- lower emergency admission rates

In the community the Anticipatory Care Plan has been developed and implemented for general practice to use. The ACP has been developed further into a frail older person's ACP.

After piloting in the north-east of the island, ACPs have been rolled out. To date 406 ACPs have been recorded across the GP practices island-wide in response to a QP –QOF target of 0.3% of the practice population for 2013/14.

The ACP is used mostly for people with cancer who are nearing the end of life. However there are other conditions that people have which require support at the end of life including chronic cardiac and respiratory conditions as well as dementia. There is a need to include these people with these conditions on the ACP.

There is no formal link between the ACP in the community and the ACB in the hospital setting.

Occupational Therapy

The occupational therapy service for people with end of life care needs is fragmented. The NHS trust has two acute palliative care occupational therapists (OTs): one Whole Time Equivalent (WTE) and one 0.67 WTE to manage hospital patients.

If patients require OT input following discharge, referrals are made from the acute service to the community service for a screening assessment using Fair Access to Care criteria. As the demand for these services is high once patients assessed they are often put on a waiting list which may not be timely enough for their deteriorating condition. This is linked to delays in ensuring that people have the appropriate equipment for their needs. There is a lack of clarity over who is responsible for palliative care in the community with respect to occupational therapy.

In order to ensure that the service is as effective as possible hospital OTs initiate a weekly discussion with the hospice OTs to discuss handovers of patients who are known to EMH to prevent duplication of input. There are concerns over differing standards the trust OTs and

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hospice OTs (for example on clinical supervision of the hospice OT by a physiotherapist). The hospice has developed a proposal for the appointment of another OT.

A business case was developed by the hospital trust for more OT capacity in 2009, however with little data to support this the work did not progress far. Since then data collection on activity has started and 187 referrals have been made to the service between April 2013 to January 2014, making a total caseload of 120 clients.

There currently is no service specification for end of life care OT services.

Guidance to commissioners from the British Association of Occupational Therapists and College of Occupational Therapists on improving hospital to home services for older people suggest that a possible method for reducing such delays is to set up a mechanism for the up-front payment for equipment and adaptations through the following means:

- Pooled or dedicated budgets
- Providing a loan facility for patients allowing them to repay the cost of repairs and adaptations over a set period
- Signposting to a expert or agency who can advise or assist patients/carers to make arrangements for repayments

A checklist for commissioning better services is in Appendix B

Co-ordination of care across different settings

The multi-agency management of people requiring end of life care is located the 'hub', a centre based at the Ambulance Station which facilitates the response of the 111 service, the Anticipatory Care Plan and Hospice at Home. The ACP records are placed electronically on the Adastra information system held at the hub so that it is clear that healthcare professionals have had discussions about end of life care with patients and their carers.

It is not clear how the end of life care register, located in general practice, is completed and how this information is shared with other agencies.

The process of co-ordination and timings of the response to end of life care referrals is not clear both in and out of hours as no case worker is assigned with the responsibility to carry out such a role.

There are other island wide strategies such as 'My Life a Full Life' and work addressing dementia services which impact on the development of end of life care services. Links between these pieces of work are not clear.

'Just-in-case' boxes

Access to medication that might be required by a patient nearing the end of life out- of- hours has been facilitated by the introduction of "Just-in-case" boxes, which include a set-stock of palliative drugs which can be utilised by an out-of-hours doctor. The information on the drugs for necessary for palliative care is located on GP systems for ease of reference.
There is some concern that there are some delays in obtaining access to the 'Just-in-case' boxes both in hours and out of hours.

Palliative care in the community

There are three key community services based at Earl Mountbatten Hospice for the care of people with end of life care needs:

- The Macmillan Nursing Service. This provides 7 days a week nursing care from 9.00am to 5pm for people in the hospital as well as the community
- The Hospice at Home. This has been running for 10 years and provides End of life care, crisis response and out-of-hours care 7 days a week from 7.30am to 9.30pm. The team has both nursing and healthcare assistants
- The Mountbatten service (previously Marie Curie Cancer Care). This is a night sitting service provided by healthcare assistants

A bid to set up an integrated palliative community care team funded by a Macmillan grant for two years has been successful and the service is due to begin in April 2014. The aim is to integrate the hospice and community teams using extra healthcare assistant, occupational therapy and administrative input facilitating faster discharge from hospital and to use electronic communication. In order to improve the effectiveness of the project it is necessary for EMH to join the electronic records (Adastra) at the hub. This £250,000 project will be evaluated by Nottingham University.

Prior to the success of this bid there was an intention to integrate the different community teams and this initiative will facilitate this process.

Other community services

Community Crisis Response Team

In January 2014 a pilot Community Crisis Response Team was set up to respond to referrals within 4 hours with the aim of preventing admission to hospital. The service is co-ordinated through the 111 / single point of access system at the hub and provides crisis care for 72 hours after which the patient is handed over to other services. Although the remit of this team is not specifically for palliative care it is not clear how it interacts with other community palliative care services.

District Nursing Service

The District Nursing (DN) Service for the Isle of Wight provides end of life care from all causes to patients at home. The DN service works with the Hospice at Home Team and MacMillan Nursing service to deliver care for those at the end of life in the community on shared care of people with cancer. Daytime DN cover runs from 8.00am to 8.00pm seven days a week whilst night time cover runs from 8.00pm to 8.00am. After 8.00pm there is only one district nurse on call for the whole island to cover all district nursing needs including end of life care.

Across the island the DNs meet regularly with the general practitioners of their locality to identify the patients on the end of life care register. This information is held on the DN database and the hub so that the healthcare professional that is providing the care in the community is up to date on the patients' situation with regard to end of life care. The Hospice co-ordinates the collation and dissemination of the information on the register

The National Bereavement Survey (Voices) in 2011 showed that more than half of deaths in England and Wales occurred in hospital (53%) although the majority of the bereaved said that their loved ones would have preferred to die at home (71%). Local end of life care profiles for the Isle of Wight (2012) show that the percentage of deaths ion hospital is 47.6% (see table 1 below)

Education and training on end of life care for health and social care professionals

In January 2010, approximately £19000 was awarded to the Isle of Wight PCT in order to provide end of life care training for staff working in residential and nursing homes by the Strategic Health Authority. This was modified to setting up training for multi-disciplinary (MDT) clusters consisting of GPs, District Nurses, Community Matrons, residential homes and nursing homes centred around GP practices.

A pilot MDT cluster was set up to try out this model of training and was found to be effective.

Up to April 2013 there was an end of life care Clinical Facilitator whose role was to devise and run a programme of end of life care training for health and social care professionals. Although the programme was designed to be self sustaining the momentum has gone. The end of life care Facilitator, who has returned to her original role as modern matron in the district nursing team, continues to provide a reduced programme of end of life care education in addition to her other duties, however this is perceived as not enough to maintain levels of skills and knowledge.

There is a particular issue relating to the training for residential and nursing home staff in that this needs to be done regularly as there is a high turnover of staff in these organisations.

Information and support for patients and their carers

The island has a cancer support centre located in Newport run by Wessex Cancer Trust. The centre provides information, befriending and a range of complementary therapies, e.g. aromatherapy, reflexology and reiki to people who have cancer.

From February to October 2013 Penny Brohn Cancer Care ran three 'Living Well with the Impact of Cancer ('Living Well')' courses for residents on the Isle of Wight as well as training one local Island-based facilitator. Information on these courses is disseminated through the John Cheverton Centre, the Wessex Cancer Trust, Macmillan Nurses, the Counselling and Bereavement team at the hospice and Clinical Nurse Specialists(CNS) at St Mary's Hospital. Community Action Isle of Wight and Penny Brohn Cancer Care provided joint funding for the project.
Funding has been secured for courses in 2014, and funding is being sought for courses for 2015 and beyond.

Contracting issues

end of life care profiles

The table below compares information on end of life care profiles between the Isle of Wight and Torbay (2012)

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Table 1

Indicator	IOW	Torbay
Percentage aged over 65 yrs (All)	Almost identical	
Percentage aged over 85yrs	3.7%	4.0% (England highest)
Percentage increase in population aged 85+ (Projected to 2033)	151.7%	139.7%
Percentage settlement in urban settlements	67.9%	100%
Crude death rate	1.2%	1.3% (England highest)
Percentage deaths in care homes	22.5%	32.1% (England highest)
Number of care home beds per 1,000 population aged 75+	139.6	166.4 *(England highest = 169.6)*
Percentage deaths in hospital	47.6%	42.2% (England lowest)
Percentage of deaths from Alzheimer's, dementia and senility	26.9% (England highest)	21.7%
Percentage of terminal admissions that are emergencies	93.9% *(England highest = 97%)*	87.8%
Percentage of terminal admissions aged 85+	46.1% *(England highest = 49.4%)*	43.7%
Average number of bed days per admission ending in death	12 *(England highest = 16)*	8 (England lowest)
Total spend on hospice services per death (£)	£1,212	£988
Total spend on end of life care per death (£)	£1,254	£1,045
(Social Care) Persons receiving Self Directed Support (per 100,000 aged 65+)	1,299	2,535
(Social Care) Persons with completed assessment (per 100,000 aged 65+)	1,343 (England lowest)	4,772
(Social Care) Persons with care package delivered (per 100,000 aged 65+)	768 (England lowest)	2,644
voices Survey	(SHIP) All Amber (Average)	All green except 2 amber (Patient expressed preference where to die/ support for carers able to discuss worries with GP)

Summary:
- Almost identical age profile, with highest number of people over 85yrs in Torbay
- **Higher number of deaths in care homes in Torbay, with more beds being**

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> - **available in Torbay**
> - **The IOW has the highest percentage of deaths from Alzheimers, dementia and senility in England**
> - **The IOW has a high number of emergency terminal admissions, and also for people over 85yrs**
> - **The IOW has a high LOS for patients who have died in Hospital, with Torbay having the lowest**
> - Torbay has 51% more people per 100,000 of population 65+ who have received Self Directed Support
> - **The IOW has the lowest number of people in England per 100,000 of population over 65yrs who have a completed Social Care assessment and care package delivered**
> - The IOW spends more on EOLC than Torbay

The profiles support the picture with regard to emergency admissions to hospital for people with terminal conditions. In terms of the amount of expenditure, the Isle of Wight spends more than Torbay for a similar population on end of life care, however the numbers of people receiving self directed support, having had a completed assessment and care package delivered are less.

Contract incentives

a. Amber Care Bund le

For 2013-14 the Amber Care Bundle was the subject of two key performance indicators as a CQUIN incentive for the hospital trust:

KPI 1 – number of agreed wards using the Amber Care Bundle

KPI 2 – Number of patients on the Amber Care Bundle

This has raised the profile of the use of the ACB although this is not as good as it could be as this there is fragmentary training of hospital clinicians

b. Anticipatory Care Plans

In the past year practices have been incentivised to identify the patients on their list who are in the last year of their life and to talk to them about their preferences (the 'find your 1% campaign)

The intention for 2014-15 is to embed this further by making this activity a contract requirement for GPs.

National review of funding of palliative care

A review into the funding of palliative care published by the Department of Health in 2011 recommended that a palliative care tariff be developed in order to deliver better outcomes for patients. This tariff would operate as a top up to any other tariffs that may already cover the non-palliative aspects of a patient's condition.

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Through the tariff the NHS would fund the following:

- An assessment, on a regular basis, of the needs of a patient
- All the clinically assessed palliative care needs of a patient irrespective of setting, as in any other branch of clinical care
- A co-ordinator for the patient who will guide them through their journey, signposting patients and families to the full range of services including those provided by society and not funded by the state
- At the end of life, as an addition to the tariff, the social care needs of a patient after they are added to an end of life locality register

In 2012 seven pilot sites across England were identified to take part in collecting essential cost and activity data from the main providers of palliative care over a two year period. The main providers included in this project include hospitals, the voluntary sector, Clinical Commissioning Groups, Local Authorities, nursing home providers and community health trusts. It is anticipated that the tariff would be identified in time for implementation from April 2015.

SUMMARY OF AREAS OF GOOD PRACTICE ON THE ISLAND

In summary there are a number of areas of good practice that are currently in place for the management of people with end of life care on the island including:

- The use of the Amber Care Bundle
- The use of the Older Persons Anticipatory Care Plan
- The ACP placed on the 111 Adastra electronic records system
- A co-ordination centre for rapid response based at the 111 hub
- The integration of palliative care nursing
- The use of 'Just in case' drugs
- The support, advice and information provided by the third sector (e.g. Wessex Cancer Trust, Penny Brohn Cancer Care)

EXAMPLES OF GOOD PRACTICE/ EVIDENCE FROM ELSEWHERE IN ENGLAND

In this section some examples of good practice from elsewhere in England are described

1. Marie Curie Nursing Service

In 2012 Marie Curie Cancer Care commissioned an evaluation of the impact of the Marie Curie Nursing Service (MCNS) nationally on the place of death and hospital use at the end of life.

The use of hospital care rises significantly and, in particular unplanned admissions, towards the end of life. This study by the Nuffield Trust showed that people who had care from the MCNS were significantly more likely to die at home (76.7%) than those who received standard care (34.9%). In areas where there was a MCNS only 7.7% died in hospital compared to 41.6% in areas where there was only standard care.

The study also showed a reduction in emergency care admissions for those who had MCNS care compared to standards care (activity of 11.7% compared to 35%)

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Similar patterns were observed for elective admissions and outpatient and A&E attendances. For patients receiving MCNS care who did not have a recent history of cancer there was a greater reduction in the use of unplanned hospital care (A&E attendances and emergency admissions)

The differences in hospital use were reflected in the differences in the costs of hospital care between MCNS patients and those who had standard care. The unadjusted costs of hospital care for people who received MCNS was £1,140 less per person than for those who had standard care. The lower costs of unplanned care (emergency admissions and A&E attendances) accounted for three-quarters of this difference.

2.   Marie Curie Cancer Care Delivering Choice Programme in Somerset and North Somerset

In this study two Marie Curie Cancer Care Delivering Choice Programmes in Somerset and North Somerset were evaluated by the University of Bristol.

The key interventions studied were:

- Care Coordination Centre
- Generic Support Workers
- Out of Hours Advice and Response Line
- Discharge in reach nursing service
- Adastra electronic end of life care register
- Key Worker

The services followed a 'Delivering Choice Pathway' (see number 4) which enabled good co-ordination of care and improved the proportion of people dying at home

The establishment of a co-ordination centre ensured that there was a rapid and flexible response to patient and family needs which was made more effective with the allocation of a specific key worker.

The discharge in-reach nurses played a valuable role in supporting patients and their families as well as education on end of life care for health professionals. Furthermore the nurses were able to challenge potentially unnecessary treatments, were able to identify their own caseloads through the in reach approach to the local hospital and were well placed at the 'front of house' Medical Assessment Units, Surgical Admission Units and Accident and Emergency Departments to turn around patients quickly who wanted home deaths.

3. The Greenwich Care Partnership

In May 2011 the Greenwich Care Partnership (GCP) was set up to deliver a service similar to the Marie Curie Delivering Choice Programme (see above).
The aim of the service is to enable people to die in the place of their choice by ensuring that there is appropriate health and social care services input together with sufficient practical and emotional support for their families and/or carers.
The Greenwich Care Partnership comprises three providers, Greenwich & Bexley Community Hospice (GBCH), Marie Curie Cancer Care (MCCC) and Greenwich Community Health Service Directorate (GCHS, part of Oxleas NHS Foundation Trust) and is designed to

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operate alongside and support established core services (GPs, district nurses, specialist nurses and so on)

There are four key elements of care:
1. Care co-ordination through a Palliative Care Co-ordination Centre
This acts as the main point of contact and access to the GCP service. This element consists of a registered nurse acting as a team leader and three part time administrators. The service is open on Monday to Friday from 8.00am to 6pm and on Saturday, Sundays and Bank Holidays from 8.00am to 1.00pm.
The co-ordination centre maintains an up to date end of life care register, co-ordinates packages of care, acts as a central contact for patients, carers and professionals and pro-actively calls patients and carers at home to ensure they feel supported. If an admission to a care home is required the centre provides assistance to patients and their family/friends to find a suitable placement. This part of the service is based at the hospice.

2. Out of hours Rapid Response Service
This service operates out-of-hours from 5.00pm to 8.00am Mondays to Fridays and through the whole weekend and is provided by Greenwich Community Health Service Directorate and the Marie Curie Nursing Service. Help is provided by nurses at the end of the telephone for unplanned and urgent support plus home visits if necessary. The team can administer medicines as well as provide personal care and offer emotional support to patients and their carers. The aim of the service is to avoid hospital admissions and support patients and their carers through crises.

3. Multi-visit personal care and support
This service is managed by the GCP team leader through the co-ordination centre and provides specially trained healthcare assistants who deliver personal care to patients in the last few weeks of their life.
This service, which is based at the hospice, operates between 8.00am and 8.00pm 365 days a year.

4. Planned night care service
This element is a planned night care service managed by the Marie Curie Service and is delivered by a healthcare assistant who will provide care to a patient if they do not have a carer or the carer needs a break. The healthcare assistant will attend the patient between the hours of 10.00pm and 8.00am staying the whole night if necessary and is supported by registered nurses in the rapid response service.

5. Overall management
In addition to the management support provided by each organisation for the different elements of the service, there is a lead nurse for the Hospice Outreach Services who provides operational support and clinical leadership to the GCP service ensuring liaison between the individual organisations.

Training and development is provided to staff working in the GCP.

Essential to this service is the identification of a key worker from the core team (e.g. district nurse, GP, specialist palliative care nurse, community matron etc) who is assigned to the patient and co-ordinates their care.
The main roles and responsibilities of the key worker are to:
• be the main point of contact for the patient and their carer
• co-ordinate assessments and referrals, and initiate and review packages of care
• provide information and guidance relating to the patient and carer to other professionals
• ensure that the carer's needs have been assessed and met

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- monitor the patient and care package to ensure that the patient's needs are being met
- provide bereavement follow up and referrals to other professionals as appropriate

The hospice (GBCH) acts as the lead or prime contractor with Marie Curie Cancer Care (MCCC) and Greenwich Community Health Service Directorate (GCHS) working as subcontractors.
A joint governance structure was established and a joint operational policy was agreed.

By having a prime contractor arrangement there are gains including efficiencies in management, flexibility in the use of personnel and the appropriate sharing of information. This leads to better continuity and quality of care for patients and their families. In addition, the prime contractor has an overview of the service and can identify areas for improvement.

The financial arrangement for the contract includes block funding together with an incentive payment of 12.5% if the Key Performance Indicator (reduction in the total number of deaths in hospital) is met. The block payment and incentive funding is apportioned to each of the three providers according to the cost and volume of each element of service delivery. Other KPIs included advanced care planning, presence of a key worker and preferred place of death being achieved.

4. Delivering Choice Pathway

The development of the Delivering Choice pathway was facilitated by Marie Curie Cancer Care as a process for health and social care staff "to provide care in a flexible and responsive way whilst still maintaining high quality care throughout the 24 hour period". The pathway was devised for all palliative care patients, regardless of condition, in order to ensure that "patients and their carers/ families receive seamless care with a coordinated multi-professional approach".

The pathway has eight steps organised chronologically. The first step is the point at which where preferred place of care discussions should take place. The eight steps are summarised below (further detail in Appendix C) and the pathway is mapped out in Appendix D:

1. End of life register
2. Allocation of Key Worker
3. Assessment
4. Care plan
5. Coordination of care
6. Delivering high quality care
7. Care in last days of life
8. After death care

This pathway, unlike the Liverpool Care Pathway which is initiated a few days before death, can be used much earlier. The pathway is most effective when the patient is placed on the end of life care register and a key worker is allocated.

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NATIONAL RESOURCES TO SUPPORT END OF LIFE CARE

National End of Life Care Intelligence Network

The National End of Life Care Intelligence Network run by Public Health England aims to improve the collection and analysis of information on quality, volume and costs of care provided by the NHS, social services and third sector to adults nearing the end of life.

In addition to providing information on research, publications and data and analytical tools the website also has a link to the End of Life Care Quality Assessment (ELCQuA) Tool which has been developed by the National End of Life Care Intelligence Network, to help commissioners and providers of end of life care monitor the quality of services.

Progress can be assessed against a set of core measures that are structured around the following:

- NICE Quality Standard for end of life care for adults (2011)
- Care Quality Commission regulations
- NHS, social care and public health outcomes frameworks
- the National Cancer Peer Review Programme's Specialist Palliative Care Measures.

The tool also links to the NHS Quality, Innovation, Productivity and Prevention Challenge (QIPP), and the metrics for the NHS Improving Quality's Transforming end of life care in Acute Hospitals (2012).

Commissioning guide for commissioners for end of life care for adults

The commissioning guide for commissioners for end of life care for adults is a resource produced by the National Institute for Health and Care Excellence to assist commissioners, clinicians and managers to commission high quality and evidence based services across England. The guide links to the Quality Standards for the end of life care in adults published by NICE (2011) and covers the following:

1. Commissioning services for end of life care for adults
2. A pathways approach to commissioning high-quality integrated end of life care for adults
3. Assessing service levels for adults needing end of life care services
4. Specifying end of life care for adults
4.1 Identification and assessment (quality statements 1, 2 and 3)
4.2 Holistic support (quality statements 4, 5, 6 and 7)
4.3 Access to services (quality statements 8, 9 and 10)
4.4 Care in the last days of life (quality statement 11)
4.5 Care after death (quality statements 12, 13 and 14)
4.6 Workforce (quality statements 15 and 16)
4.7 Service models
5. Service specification for end of life care for adults
6. The commissioning and benchmarking tool

Considerations for contract specifications for end of life care are set out in further detail in Appendix E

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CONCLUSIONS

There is a recognition that patients at the end of life prefer to die at home although there is still some way to go to realise this desire.

The pathway for the management of patients with end of life care needs is fragmented with the Amber Care Bundle operating in the hospital setting and the Anticipatory Care Plan operating in primary care. There is some joining up of different elements in the pathway with the Anticipatory Care Plan being placed on the 111 Adastra information system so that a co-ordinated response is enabled. However it is not always clear whose responsibility it is to response to a referral for end of life care.

There has been much work in primary care to develop and implement the Advance Care Plan with incentives to encourage practices to 'find their one percent' of patients who are nearing their end of their life

Similarly in secondary care the use of the Amber Care Bundle is being promoted through the use of CQUINs.

There is a good service with respect to the various teams that provide nursing care for people with end of life care needs and the establishment of an integrated palliative community care team will act to improve the co-ordination of response further.

Other elements of good practice include the use of 'Just in Case' drugs, the inclusion of older people's needs on the Anticipatory Care Plan and a sharing of the ACP and end of life care register with the Adastra 111 information system.

The input of occupational therapy and social care into the end of life care pathway needs to be defined more clearly.

Multi-disciplinary training and education on end of life care matters in the community and hospital setting is inconsistent and this has, for example led to uncertainty as to how to manage such patients in care homes.

Support for patients and their carers by the voluntary sector is good with the provision of not only advice and information but also a range of complementary therapies.

RECOMMENDATIONS

1. A holistic and co-ordinated pathway across community, social and secondary care should be developed in order to improve the consistency of care of people with end of life care needs on the island.
    - In the first instance there should be the continuation of care using the Anticipatory Care Plan in the primary setting and the Amber Care Bundle in the acute sector through the mechanism of consistent electronic records. This also needs to link up with social care records
    - The availability of the 'Just-in-case' drugs packages should be improved to ensure that these are accessible in a timely manner when required

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- o The pathway once developed should be embedded into the contracts for end of life care
2. A specific service specification for palliative care and end of life care Occupational Therapy services across acute and community settings should be developed to clarify the input of this therapy to the end of life care pathway
3. There should be clarity on the input and role of the district nursing services to the end of life care pathway paying specific attention to the capacity of the current service to meet end of life care needs
4. In conjunction with the development of an island wide end of life care pathway consideration needs to be made to the appropriate training and education needs of all the professionals looking after people with end of life care needs in the hospital, community and care homes sector. Ideally the training should be multi-disciplinary in nature.
5. There should be an appointment of a key worker to co-ordinate and review the management of a patient referred for end of life care.
6. There should be a dedicated role to support the case managers in identifying and fast tracking people who are nearing the end of life who have a 'step down' change in condition requiring continuing health care
7. There should be a lead provider agency for the delivery of end of life care which will hold the main contract for these services and subcontract with other providers to provide a whole end of life care package. As part of this arrangement there needs to be a service level agreement or contract for working with social care
8. The strategy for end of life care should link up with other initiatives such as My Life, A Full Life and the needs of people with dementia
9. The end of life care pathway should cover not only the needs of people who have cancer but also terminal non cancer conditions such as cardiac and lung conditions

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Appendix A

List of people interviewed

Name	Role/organisation
Alan Sheward	Executive Nurse, Isle of Wight NHS Trust
Anita Hayes	NHS IQ, End of life care
Chloë Longmore	Service Design Manager - London and South East, Marie Curie
Chrissie Dawson	Lead Commissioner Palliative Care, Southampton Clinical Commissioning Group
Daphne Williams	Patient Representative Isle of Wight CCG Frail Older Persons Group
Dawn Berryman	Adult Continuing Health Care Manager, Isle of Wight Clinical Commissioning Group
Dr David Isaac	GP Lead for End of life care, Isle of Wight Clinical Commissioning Group
Dr Mark Pugh	Executive Medical Director, Isle of Wight NHS Trust
Dr Michelle Legg	GP Lead for Frail Elderly and Dementia
Dr Paul Howard	Consultant, Earl Mountbatten Hospice
Georgia Diebel	Acting Head of Living Well Services
Jackie Hazeldine	Modern Matron/Practice Educator, District Nursing Service, Isle of Wight NHS Trust
Jackie Raven	Commissioning Manager – Adult Social Care, Isle of Wight Council
Jill George	Community Nurse Manager, Earl Mountbatten Hospice
Julie Gurney	District Nurse Team Leader, North East Locality
June Ring	Wessex Cancer Trust
Karen Morgan	Head of Quality, Isle of Wight CCG
Kevin Dannatt	Scio Health Care Representing Isle of Wight Nursing Homes
Liz Arnold	Director of Nursing Services and Education, Earl Mountbatten Hospice
Lucy Sutton	Associate Director for Clinical Senate and Strategic Clinical Networks. Formerly South of England end of life careLead
Maggie Bennett	Chair of Care Homes Association, Isle of Wight
Pat McCamley	Operational Manager - Clinical Lead Community Nursing
Sara Quarrie	Occupational Therapy Service Lead for acute and community services
Tami McMahon	Penny Brohn Cancer Care

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Appendix B

Checklist for commissioners (equipment and adaptations)

(British Association of Occupational Therapists and College of Occupational Therapists)

1. Are you developing joint commissioning arrangements for hospital discharge across health, care and housing? And across the hospital-community boundary?

2. Are you aware of the range of housing and community services that already exist in your locality, from which you could commission relevant services?

3. Are you engaging agencies that provide housing and support services in order to improve patient care and save you money?

5. Are you working with occupational therapists and social workers to explore the range of services that can help older people live well at home following discharge and to better match local services with patient's requirements? Do you make use of any predictive modelling tools?

6. Have you identified gaps in 'home from hospital' service provision in your locality? Are you acting to fill those gaps?

7. Are you requiring service providers to work together, where appropriate, as a condition of contract?

8. Do you have a pooled or dedicated budget to pay for equipment and adaptations for those leaving hospital, to speed up discharge?

9. Do you know how long it takes to get an adaptation made or equipment fitted? Does your commissioning process allow sufficient planning time ahead of discharge?

10. Are you aware of local housing authorities' policies relating to Disabled Facilities Grants (which pay for some home adaptations)? Are you involved in shaping delivery of home adaptations and related grant policies?

11. Do you know where you can refer patients on for information and advice on housing and support services in your area?

Appendix C   Trajectory of the Delivering Choice Pathway (Marie Curie Cancer Care)

End of life register

1. Patient has been diagnosed with a life limiting or life threatening illness and the response is 'no' to the 'surprise' question of 'Would you be surprised if this individual died in the next 12 months?'

2. Patient consent is sought to add details to the Adastra end of life care register. Preferred place of care determined.

3. Professional adds patient details to Adastra.

Allocation of Key Worker

4. Professional placing patient on Adastra allocates him or herself as temporary Key Worker.

5. At next Gold Standards Framework or Multi-disciplinary team meeting, Key Worker and associate Key Worker status are discussed and assigned. Ideally, one of these roles should be occupied by a community nurse. Allocation of Key Worker should take place within three months of first registration on Adastra

Assessment

6. Patient is assessed according to the Palliative Care Framework (Red/Amber/Green). The assumption appears to be that the Key Worker carries out this assessment. Depending on classification, varying timelines are given for assessment, fast track decision, care plan and financial assessments. For example, a patient classified as 'red' should have a holistic assessment within 12 hours, fast track decision within one working day, care plan completed the same day and financial assessment completed within 5 working days. Key other professionals receive the assessment documentation.

Care plan

7. On the basis of the information from the assessment, a care plan is drawn up.

Coordination of care

8. Once funding is agreed, the Coordination centres sets up a care package. Again the Palliative Care Framework or 'traffic lights' is employed to provide guidance on the timing of placement of care packages.

Delivering high quality care

9. The Key Worker oversees the quality of care provided using the Palliative Care Framework as a prompt.

Care during last days of life

10. Patient classified as 'red'.

11. The Key Worker carries out daily holistic review.

12. Out of hours services notified by Key Worker about patient status.

13. Family members informed what to do in case of death.

Care after death

14. Death verified within 4 hours.

15. Relevant authorities notified, ideally by the Coordination centre within one hour of verification.

16. Bereavement counselling offered, ideally by Key Worker within one day working day.

Appendix D   **Example of Delivering Choice Pathway (Marie Curie Cancer Care)**

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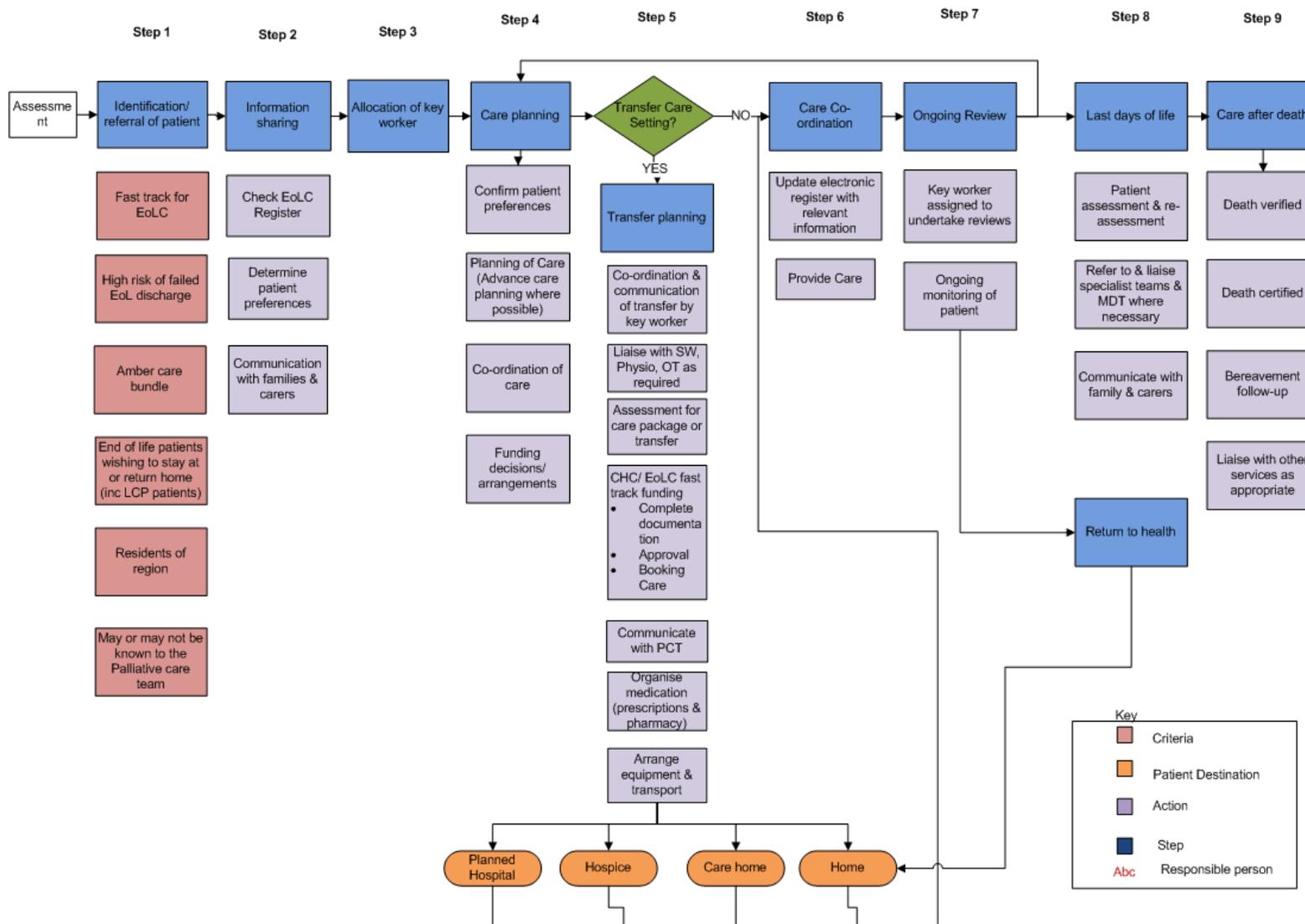
Appendix E
Considerations for contract specifications for end of life care (NICE)

Heading	Subheading	Considerations
Purpose	Policy context	• National policy drivers for end of life care including the Department of Health (2008) 'end of life care strategy' • Evidence base, for example NICE guidance and quality standards, NHS evidence and national strategy consultation
	Local strategic context	• Local commissioning drivers (for example reducing hospital admissions and length of stay, QIPP, CQUIN) • Invest to save • Results of joint strategic needs assessment
	Aims and objectives of service	• The expected outcomes of the services
Service scope	Define service user groups	• Demographic profile of the local population (age, gender, ethnicity, socioeconomic status) • Local recorded and expected need for end of life care • Expected proportions of people needing end of life care services who have cancer and non-cancer diagnoses and, if appropriate, a breakdown of non-cancer diagnoses • Estimated prevalence of co-morbidities (for example, hypertension, stroke, heart failure, depression) • Evidence of inequalities in outcomes between specific groups • Number of wholly- attributable and partially-attributable end of life-related hospital admissions, bed days and readmissions • Number of people currently being treated in primary care, community-based and specialist palliative end of life services and other relevant services • Number of people who see their GP and are entered on the GP end of life care register • Population-groups that will be targeted
	Exclusion criteria	• Define exclusion criteria in accordance with NICE guidance and locally determined criteria.
	Geographical population	• Proportion of people living in urban and/or rural areas. • Areas of higher-than average need for example, areas with a high population of older people. • Population coverage needed or geographical boundaries
	Service description /	• Mapping existing services for people with end of life care needs

	care package	• Commissioning of core service components • Interface with other local services including social care, residential and nursing care, hospices, intermediate care services, ambulance service, out-of-hours services, community mental health services
Service delivery	Location	• Service location, defining accessibility requirements and discreet locations • Integration with other services for people with end of life needs • Home-based, locality-based services and centrally-based services
	Days/hours	• Expected hours of operation, including days, evenings and weekends. • Expected number of people for case finding, assessment, treatment, care coordination or case management, aftercare, end-of-life care, taking into account potential increased flow through the system over defined periods
	Referral processes	• Referral criteria and processes for people with end of life care needs. • Management of people who are 'unable to attend' and 'did not attend'
	Response times	• Should be needs-based and outcomes-based • Setting specific times, which may be particularly important for people identified as rapidly approaching death
	Care pathways	• Agreed clinical protocols or guidelines to support decision-making in the care pathway • Pathways for people with complex needs and co-morbidities • Use of third sector organisations • Care coordination
	Discharge Processes	• Process for discharge from end of life services, including aftercare and communication with other teams
	Staffing	• Profile of existing health and social care workforce • Staffing levels to be funded: minimum band or levels of experience and competency and expected skill mix • Skill mix and competencies of staff for specific areas of care
	Information sharing	• Define information-sharing, confidentiality and audit needs, including IT support and infrastructure

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		• Raising awareness of end of life care services. Do people with end of life needs and health and social care professionals know how to access services and know what services exist?
Quality assurance and clinical governance	Patient and public involvement	• Processes to understand service user experience of end of life services in order to develop and monitor services. See also 'Patient experience online network' • Expectations of how service user opinions, preference and experience will be used to inform service delivery for example, focus groups, representation on working groups, and surveys • Monitoring of complaints and compliments and how used to inform service • Views of informal carers – evaluation of services (VOICES) national survey of the bereaved may be adapted using the toolkit to develop a local survey
	Quality indicators	• Use NICE quality standards to define high-quality care including NICE quality standard for end of life care for adults • Satisfaction surveys and access to treatment • Define outcomes and (proxy) measures including outcomes provided in the NICE quality standard for end of life care for adults
	Performance monitoring	• Local need and demand for treatment, including brief interventions. • Impact of services on admissions to accident and emergency, inpatient hospital care and length of stay in hospital • Measurement of referrals and discharges
	Equality	• Measures to ensure equality of access to services, taking into account the risks of unintentional discrimination against groups who are often under-represented, such as people who do not speak English as a first language • Consider equity of access for people living in residential and nursing homes, those who are housebound, or those in prison
	Staff training and competency	• Training and competencies on recruitment and for ongoing development • Processes for monitoring clinical practice and competency, including professional registration and clinical supervision arrangements • Skill mix and competencies required across the care pathway. See 'Skills for health' and Core competencies for end of life • Staff development – appraisal and personal

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		development plans, and mandatory training
	Audit and surveys	• Specify expectations for audit, which may include assessment, intervention, prescribing practices and successful treatment outcomes • It may be useful to specify that providers participate in the following audits and surveys: • The <u>National care of the dying audit – hospitals</u> collects data on communication with primary care. • National Council for Palliative Care <u>specialist palliative care workforce</u> survey. • Views of informal carers – evaluation of services (<u>VOICES</u>) national survey of the bereaved may be adapted using the <u>toolkit</u> to develop a local survey
	Staff and patient safety	• Procedures for risk assessment • Formal procedures for incident reporting and monitoring • Address any safeguarding concerns and promote the welfare of children and vulnerable adults
Activity Plan		• Planned service development setting out any productivity improvements
Cost	Value for money	• Likely <u>cost of new or additional services</u> • Anticipated set-up costs • How will pricing be set? • Potential for better value for money • Are people receiving most appropriate end of life services? • Cost of facilities, for example venue hire • Cost of staff travel to services and people's homes • <u>QIPP</u>.

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