NHS
Merton
Clinical Commissioning Group

c/o 120 The Broadway
Wimbledon
SW19 1RH
Tel: 0203 668 1221

Report to the London Borough of Merton Healthier Communities and Older People Overview and Scrutiny Panel

Date of Meeting: 12th November 2014

Title of Document: Report on End of Life Care	Purpose of Report: Requested by the London Borough of Merton Healthier Communities and Older People Overview and Scrutiny Panel
Report Author: Hannah Pearson, Commissioning and Service Improvement Manager Merton CCG	Lead Director: Adam Doyle, Director of Commissioning and Planning
Contact Details: Email: hannah.pearson@mertonccg.nhs.uk	
Executive Summary: This report has been produced to provide members of the London Borough of Merton Healthier Communities and Older People Overview and Scrutiny Panel with the information requested regarding End of Life Care service provision. The report will inform the discussion that will take place during the meeting on 12th November 2014. The report explores various areas including the CCG's aims, current service provision, key achievements, future plans and salient issues with regard to End of Life Care.	
Key sections for particular note (paragraph/page), areas of concern etc: N/A	
Recommendation(s): N/A	
Committees which have previously discussed/agreed the report: N/A	
Financial Implications: N/A	
Other Implications: N/A	
Equality Analysis: N/A	
Information Privacy Issues: N/A	
Communication Plan: N/A	

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1. Background

End of Life Care is one of the most important aspects of providing and commissioning care. Accordingly, for some time in Merton, this area of service provision has received considerable attention and investment.

Significant progress has been made and many service developments have been implemented which are improving care for those approaching the end of life and for their loved ones. Merton CCG remains committed to pursuing continuous improvement and identifying new ambitions which will help to drive innovations and improvements in relation to End of Life Care service provision.

Partnership working has remained key for many years in delivering improvements in End of Life Care. The Sutton and Merton End of Life Care Network continues to be an extremely valuable forum which provides oversight and drives the implementation of new service developments. Continuing to work in a joined-up manner across health, social care and the third sector will be key to our approach as we move forward. Further, listening to patients, carers and families will remain of fundamental importance in order to enable the quality of services to be continually enhanced.

This report explores areas including the CCG's aims, key achievements, current services and next steps in relation to End of Life Care service provision.

2. Aims

Merton CCG's overarching vision for End of Life Care has remained unchanged for several years, along with the core values, goals and ways of working.

The overall goal is to make sure that the highest quality End of Life Care services are available, so that people at the end of their lives have a 'good death'. Effective and compassionate care and support should be in place for people who are approaching the end of life so that they can have a dignified, peaceful and controlled end of their life. Families and friends should be supported through this time and after their loved one has passed away.

People should, where possible, be given the opportunity and feel able to express their preferences about where and how they are cared for, are supported, and die, so that health and social care services can ensure, as far as is feasible, that these wishes are met.

The CCG is committed to designing and commissioning services and working with partners in order to provide:

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- Equitable access to services for all people needing End of Life Care.
- The best possible care for all people needing end of life support.
- Patient-centred care which is responsive to the dying person's needs and wishes.
- A choice of place of care and death, where possible.
- Appropriate support services for both the dying person and their family and friends.
- Good communication between all professionals and with the patient and those closest to them.
- End of life services based on best practice models.
- Access to information and advice.
- Improved co-ordination of care across service providers.
- Support and training for staff.
- Adequate funding, making the most of existing resources.

The following ways of working underpin the CCG's approach:

- Involving local people, patients and carers in the development and improvement of End of Life Care services.
- Working in the spirit of partnership with health and social care organisations, both statutory and voluntary.
- Reviewing regularly the services we commission in order to ensure that they reflect best practice and are responsive to the needs of and feedback from service users.

3. Demographics and Quality Indicators

In South London approximately 0.6% of GPs' registered patients will die each year. For Merton CCG, which has a population of approximately 200,000, this equates to approximately 1,200 deaths per annum.

It can be challenging to assess the quality of End of Life Care services for particular CCG populations. However, considering the proportions of deaths that occur in different settings and the usage of the Coordinate My Care system are widely recognised to be valuable.

In the 2013 National Survey of Bereaved People (VOICES), the majority of people who reported where they would like to die expressed a preference to die at home[1] although often this does not become a reality. Therefore, the proportion of deaths that occur in people's homes is considered to be a good indicator of the quality of End of Life Care provision. In Merton we have seen an increase in the proportion of

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[1] Accessed at: http://www.ons.gov.uk/ons/dcp171778_370472.pdf

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people who are able to die at home rise from ~12% in 2004 to ~19% in 2009 to ~37% to date in 2014. When considering this data it should be acknowledged that the measurement was changed in 2010 to include usual place of residence (to include care homes).

Figure 1 shows the proportion of home deaths that occurred from April 2013 to June 2014. It can be seen that in this period the proportion has fluctuated from ~35% to ~43%. Work is underway to explore how service provision in the community could be enhanced in order to achieve further increases in the number of people who are supported to die at home.
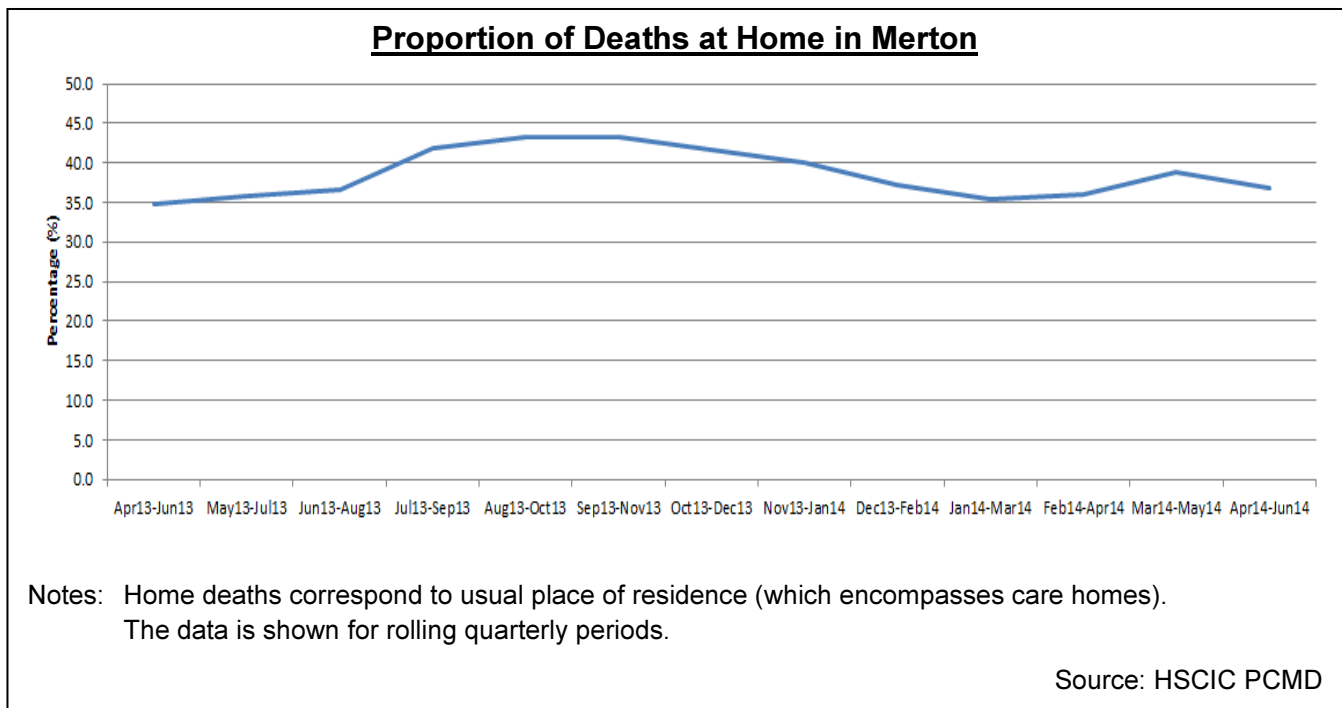
Proportion of Deaths at Home in Merton

Notes: Home deaths correspond to usual place of residence (which encompasses care homes).
The data is shown for rolling quarterly periods.

Source: HSCIC PCMD

Figure 1

Coordinate My Care (CMC) is an electronic urgent care record enabling details of a person's illness and their wishes to be shared to improve the coordination of care and allow people's choices to be known to emergency and out of hours services. CMC is being used in all 25 Merton GP practices, hospitals, hospices and community services. The most recent CMC dataset showing utilisation across London revealed that Merton CCG ranks fourth out of the 32 London CCGs in terms of the proportion of the population who are estimated to be in the last year of life having a CMC record, with 37% of this cohort having a record.

There is encouraging evidence about the effectiveness of CMC. Where Merton CCG patients have a CMC record, ~25% die in hospital (see Figure 2). However,

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nationally 54% die in hospital[2]. Further, ~72% of individuals with a CMC record die in their first or second preferred place of death (see Figure 3).

In the coming years further efforts will be directed to increasing the use of CMC and making better use of the functions that are available, for example the opportunity for the development of robust cross-organisational care plans to become more commonplace. This will be supported by the CCG's wider work on integration which forms part of the Better Care Fund plans.
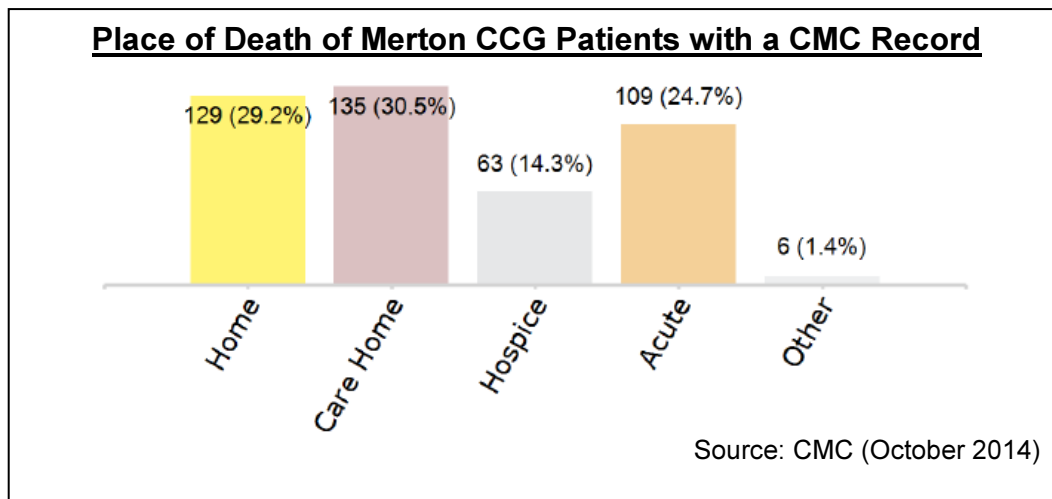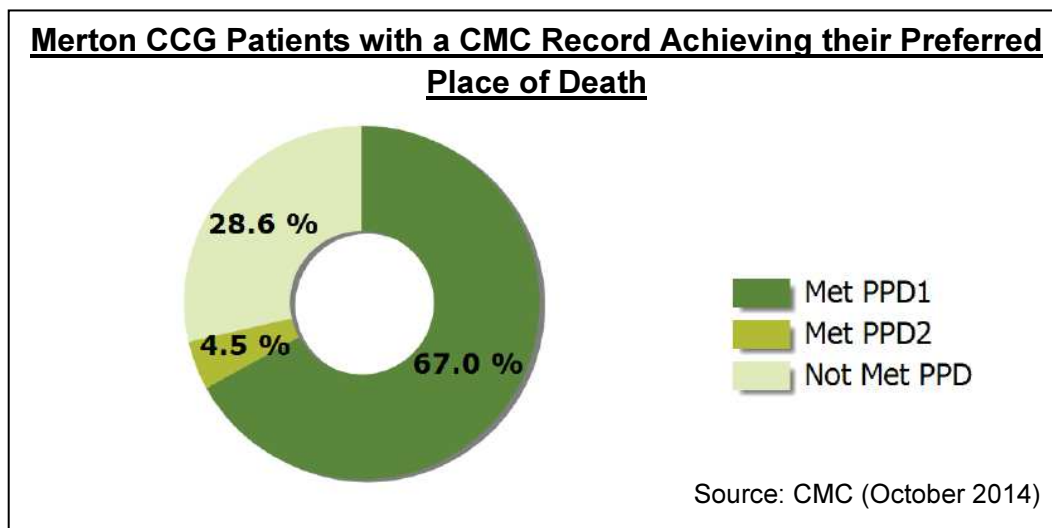

Figure 2

Figure 3

Historically, palliative care services tended to focus on patients with cancer. Increasing efforts are being made in order to ensure that service provision meets the needs of people dying from all causes. In Merton, we have undertaken focussed work in order to ensure that all patients, regardless of their health condition, have access to equally high-quality services at the end of life. The outcomes of this are

[2] National End of Life Care Intelligence Network (NEOLCIN), 2008-10

reflected by the fact that 57% of the diagnoses for patients with CMC records are for non-cancer conditions (see Figure 4).
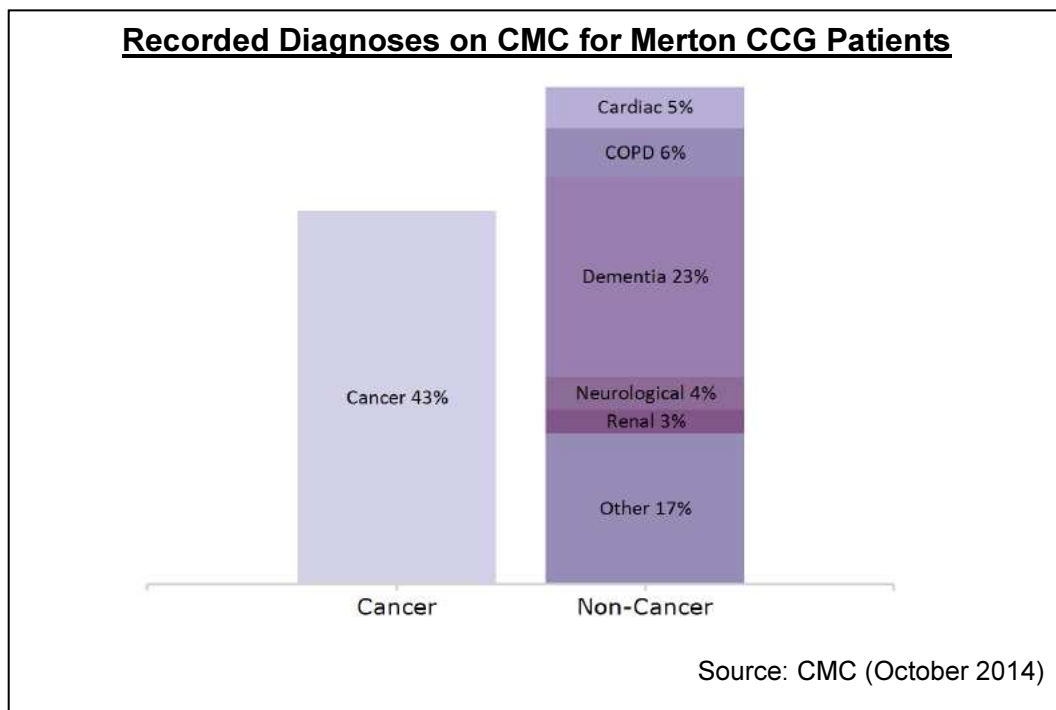

Recorded Diagnoses on CMC for Merton CCG Patients

Cardiac 5%
COPD 6%
Dementia 23%
Neurological 4%
Renal 3%
Other 17%

Cancer 43%

Cancer   Non-Cancer

Source: CMC (October 2014)

Figure 4

4. End of Life Care Services

End of Life Care is provided by a range of professionals and services and is delivered in a range of settings. Figure 5 shows the range of organisations that can be involved in the care of those approaching the end of life. Bearing this in mind, collaborative working is of fundamental importance in order to meet patients' needs and wishes during the final stages of their lives.
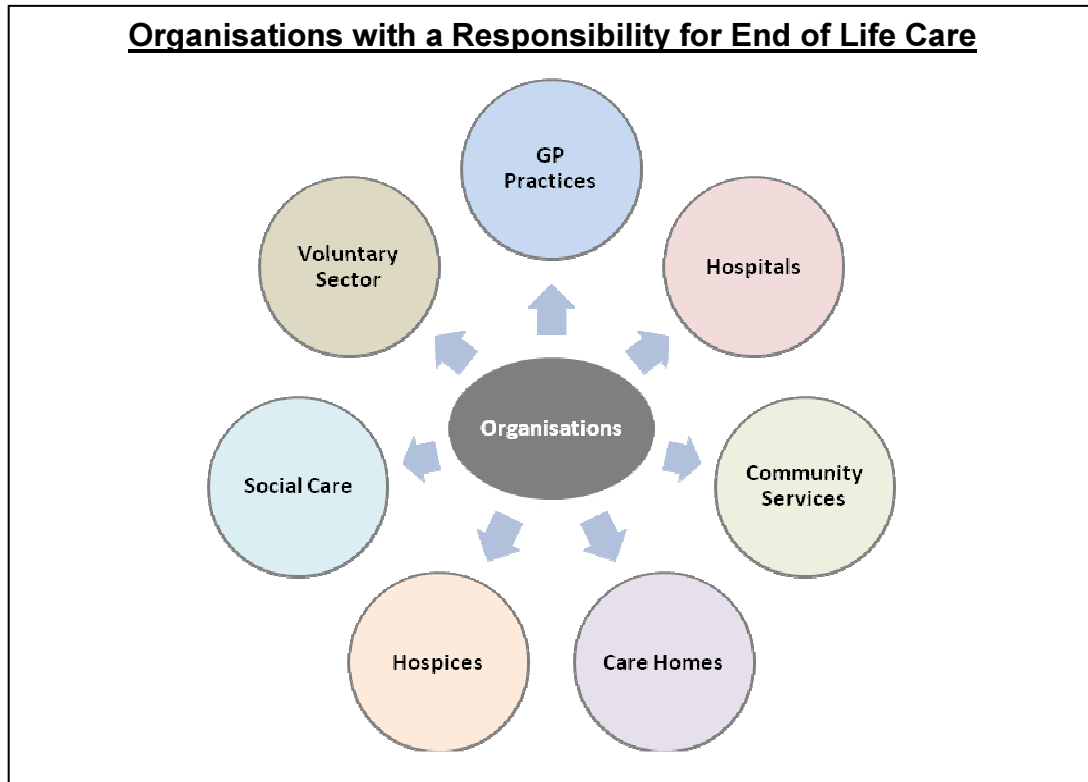
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Organisations with a Responsibility for End of Life Care

GP Practices

Voluntary Sector

Hospitals

Organisations

Social Care

Community Services

Hospices

Care Homes

Figure 5

Outlined below are the key End of Life Care services which are currently commissioned by Merton CCG.

Community Nursing Service: This service is commissioned to provide End of Life Care. All district nurses are likely to have an important role in the delivery of end-of-life care. The Service provides on-going holistic assessment of a patient's condition, pain management, symptom control and nursing care for palliative care patients and works in conjunction with other service providers which offer specialist end of life and palliative care services.

Inpatient Hospice Services: Inpatient beds provide specialist person-centred palliative care to patients for a range of reasons. Inpatient services have an important role in symptom control, respite care, and for some patients care in the last few days of life.

Outpatient and Daycare Hospice Services: A range of services are offered which seek to provide physical, emotional, social, psychological and spiritual support.

Community Palliative Care Service: This service is delivered by Clinical Nurse Specialists and a Community Consultant who provide symptom control and advice to enable patients to remain comfortable and independent at home.

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Hospice at Home Service: This service provides personal care and support for patients and their carers to help them stay in their own homes.

Night Sitting Service: This service cares for individuals in their own homes and supports people to remain in their preferred place of care.

Community End of Life Nursing Service: This service is delivered by End of Life Care Nurses who provide specific support to nursing homes, their residents and their families. The nurses also provide support and education to community nurses and local GP practices.

End of Life Fast Track Discharge Service: This service speeds up discharge from hospital for people in the last days of life so they can return home or to a preferred place of care such as a care home or hospice if this is their wish.

There are close working relationships between the various providers which deliver end of life care services for Merton patients. Care coordination is of fundamental importance and mechanisms to support effective joint working are explored at Contract Review meetings. Further, the Sutton and Merton End of Life Care Network brings providers and commissioners together to explore issues which span organisational boundaries in order for solutions to be collectively established and taken forward.

5. Education and Training Opportunities

The CCG endeavours to support a range of training and education initiatives. With regard to End of Life Care, it is recognised that staff need to have high quality training and support to enable them to care effectively for patients who are approaching the end of life.

In Autumn 2011 Sutton & Merton PCT was successful in applying for Workforce Education Initiative funding to support a small pilot project which focussed on delivering education which could help improve end of life care for people with dementia; this training was provided in GP practices and care homes. Various positive outcomes arose from this work, for example, at the end of the project, all of the care homes involved had reviewed their documentation and the implementation of advance care plans and were implementing, or planning to implement, screening using a recognised pain assessment tool.

The CCG recently supported a successful bid to the South London Membership Council for Innovation and Excellence in Health Care which enabled St Raphael's Hospice to deliver an End of Life Care course. This course is for staff who work in care homes, social services professionals and those who work for agencies which

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provide community care, and includes areas such as physical assessment, communication skills, caring for people with dementia, advanced care planning and spiritual awareness.

6. Strategy Development and Future Plans

Currently Merton CCG is developing a five year End of Life Care strategy for 2014-19. A range of factors are influencing the strategy's development including national and local guidelines and policies, best practice models, feedback from patients and carers and insights from health and social care professionals. An important part of this strategy will be the core priorities which will guide the key areas of work and initiatives over the coming years.

The priorities will be structured around the sixteen Quality Statements which were set out in the 2011 NICE Quality Standard for End of Life Care for Adults. Adopting this approach will enable the CCG to have assurance that the care and support for patients and carers will be improved throughout the End of Life Care journey.

A number of priorities have been identified so far and these are set out in Appendix A. However, at this stage these can only be considered to be draft priorities as they, and the strategy as a whole, will be further shaped by information and feedback that the CCG receives from residents and service users.

Useful information has already been gleaned from the recent 'Joining Up Health and Social Care' and 'Engage Merton' Events. The former was co-ordinated by Healthwatch and took place on 11th September 2014; at this event End of Life Care was one of the six main themes explored. The latter was led by the CCG and took place on 16th October 2014; the second half of the event was an engagement 'marketplace' at which there was a stand for End of Life Care and the opportunity to provide feedback.

Further insights will be gained from a dedicated engagement event regarding End of Life Care which is taking place on 6th November 2014. Attendees will be asked questions such as:
- What services and support are needed by people who are approaching the end of life?
- What services and support are needed by carers of people who are approaching the end of life?
- What would be important to you towards the end of your life and after you die?
- What do you think our priorities for End of Life Care should be in Merton?

Information will be shared about Merton's journey in relation to End of Life Care, including details of important developments and progress so far. The key priorities that have been identified for the coming years will also be shared. Attendees will then have the opportunity to contribute to group discussions about some key issues and topics. They will be asked to consider whether there are any 'gaps' and which areas should be prioritised bearing in mind that there are limited resources.

Feedback received at the engagement event will help the CCG to find out what is most important to Merton residents, refine the strategy and shape the next steps in relation to End of Life Care service provision.

7. Challenges and Opportunities

There are various challenges and opportunities associated with End of Life Care service provision. A few of the key issues are identified below.

Ensuring that further improvements are made in terms of supporting people to be cared for and die in their preferred setting. It has been identified that the proportion of home deaths appears to be plateauing. It is possible that community teams are reaching their existing capacity which will impede their ability to meet the needs of more people who wish to be supported to die at home or in a care home. It will be necessary to review current service provision in the community and assess how this could best be enhanced. In alignment with this, it will be important to ensure that the principle of funding following the patient (in this case from acute to community) can be appropriately applied; this will be supported by improved integration across the local healthcare economy.

Supporting providers to achieve the priorities set out in 'One Chance to Get it Right'. In response to the Neuberger review, the Leadership Alliance for the Care of Dying People (LACDP) developed a new approach for the care of those in the last few days and hours of life, which is explored in the 'One Chance to Get it Right' report, published in June 2014. There are challenges associated with delivering the priorities, particularly in community settings, and it will be important for these to be addressed, perhaps through introducing new models of service provision.

Responding to anticipated changes in commissioning arrangements for palliative care services. NHS England is leading the development of a palliative care currency[3] and it is likely that this will significantly shape the commissioning mechanisms for palliative care services. It will be important for the CCG and local providers to remain abreast of and responsive to developments in this field.

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[3] In the initial document produced by NHS England it is noted that "a currency is made up of consistently identified units of care that can be used as the basis for payment between commissioners and providers". The palliative care currency being proposed is based on the needs of the patient; it has been recognised that an approach based on other units, such as procedures, would not be appropriate. At the outset no national prices will be associated with the currency and therefore it would not be accurate to refer to it as a tariff.

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Appendix A: Draft Priorities for End of Life Care Strategy

Note: The NICE Quality Statements, around which the priorities are framed, are also included in this Appendix.

Our Priorities for 2014 – 19

QS 1: Identification

No	Priority
1.1	Increase the identification of patients who are approaching the end of life across all healthcare settings, regardless of health condition.

QS 2: Communication and Information

No	Priority
2.1	Improve the availability of locally and nationally produced End of Life Care information and resources for patients, carers and families.
2.2	Support the provision of consistent information and signposting in order to make it easier for patients and those close to them to benefit from relevant information and support services which address their needs.

QS 3: Assessment, Care Planning and Review

No	Priority
3.1	Encourage the use of high quality advance care planning across all health settings.
3.1.1	Increase the number of individuals with advance care plans in nursing and residential homes.
3.2	Promote the recognition of carers' needs and the provision of support for carers to enable them to contribute to the care planning process.
3.3	Commission providers to develop tools and techniques to assess carer satisfaction in a meaningful way.

QS 4: Holistic Support – Physical and Psychological
QS 5: Holistic Support – Social, Practical and Emotional
QS 6: Holistic Support – Spiritual and Religious
QS 7: Holistic Support – Families and Carers

No	Priority

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4-7.1	Encourage the provision of holistic support, encompassing physical, psychological, social and spiritual needs, across all care settings.
4-7.2	Promote spirituality in End of Life Care to raise awareness and embed ensuring patients beliefs and wishes are respected and supported.
4-7.3	Engage with carers in order to gain a better understanding of how they could be better supported locally and to respond bearing in mind the insights gained.

QS 8: Coordinated Care

Note: There are several priorities which specifically relate to Electronic Palliative Care Coordination System (EPaCCS) usage and development. (The system currently being used is Coordinate My Care (CMC)). This is because there is strong evidence that Coordinate My Care improves the chances of people receiving the type of care they want and in their preferred place.

No	Priority
8.1	Improve multi-disciplinary working and communication across organisations and settings (such as Acute Trusts, Community District Nursing Teams and Social Care) so that patients experience smooth transitions.
8.2	Reduce duplication through the development of integrated and effectively coordinated services across health and social care to increase productivity and avoid unnecessary repetitions of assessments and interventions for patients.
8.3	Ensure night and day services align effectively in order to achieve effective and seamless handovers.
8.4	Simplify and streamline the processes which enable patients to access social and nursing care at the end of life.
8.5	Promote and encourage Electronic Palliative Care Coordination System (currently Coordinate My Care) usage across health and social care settings in order to increase the number of CMC records created for EOLC care patients.
8.6	Champion the benefits of improving the quality of CMC record entries across primary care, secondary care, social care and voluntary sectors.
8.7	Support the development of EPaCCs interoperability with other primary, secondary and social care IT systems.

QS 9: Urgent Care

No	Priority
9.1	Review the effectiveness of the rapid identification of CMC records in A&E settings.

No	Priority
• 9.2	Identify whether the Community Prevention of Admission Team supports End of Life Care patients to remain in their preferred place of care.

QS 10: Specialist Palliative Care

No	Priority
10.1	Monitor equity of access to specialist palliative care for patients with malignant and non-malignant conditions and take appropriate action if any issues are identified.

QS 11: Care in the Last Days of Life

No	Priority
11.1	Support providers to achieve the priorities set out in 'One Chance to Get it Right' (published by the Leadership Alliance for the Care of Dying People in June 2014) in order to improve people's experience of care in the last few days and hours of life.
11.2	Increase the number of patients with individualised care plans for the last days of life in all care settings.

QS 12: Care After Death – Care of the Body

No	Priority
12.1	Ensure any wishes in advanced care plans are respected and are met in a culturally sensitive way.

QS 13: Care After Death – Verification and Certification

No	Priority
13.1	Encourage GPs to certify death in a timely way.
13.2	Agree a policy for the verification of death by suitably trained staff to improve support to families and carers.

QS 14: Care After Death – Bereavement Support

No	Priority
14.1	Provide bereavement support services for Merton residents who are bereaved.

QS 15: Workforce – Training
QS 16: Workforce Planning

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No	Priority
15-16.1	Determine whether the Gold Standard Framework accreditation represents Value for Money and should be adopted as the preferred local standard for nursing homes by comparing outcomes from non-accredited and accredited homes.
15-16.2	Identify End of Life care training needs locally through a training needs analysis and work with strategic and local partners to develop and deliver training programmes.
15-16.3	Champion and support training in advanced communication skills to support clinical and care staff to have difficult conversations.
15-16.4	Evaluate the effectiveness of the 5 day RCN accredited End of Life Care Course for care home staff and paid carers.
15-16.5	Use the learning from the evaluation of the aforementioned 5 day RCN accredited End of Life Care Course to guide future plans for training and development of formal carers.
15-16.6	Support education initiatives to improve the skills of workforce in the effective and compassionate delivery of end of life care.
15-16.7	Identify different types of training and education delivery methods which could be introduced to increase uptake of professional development opportunities.

Quality Statements in the 2011 NICE Quality Standard for End of Life Care for Adults

Area	Description
QS 1: Identification	People approaching the end of life are identified in a timely way.
QS 2: Communication and Information	People approaching the end of life and their families and carers are communicated with, and offered information, in an accessible and sensitive way in response to their needs and preferences.
QS 3: Assessment, Care Planning and Review	People approaching the end of life are offered comprehensive holistic assessments in response to their changing needs and preferences, with the opportunity to discuss, develop and review a personalised care plan for current and future support and treatment.
QS 4: Holistic Support – Physical and Psychological	People approaching the end of life have their physical and specific psychological needs safely, effectively and appropriately met at any time of day or night, including access to medicines and equipment.
QS 5: Holistic Support – Social, Practical and Emotional	People approaching the end of life are offered timely personalised support for their social, practical and emotional needs, which is appropriate to their preferences, and maximises

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	independence and social participation for as long as possible.
QS 6: Holistic Support – Spiritual and Religious	People approaching the end of life are offered spiritual and religious support appropriate to their needs and preferences.
QS 7: Holistic Support – Families and Carers	Families and carers of people approaching the end of life are offered comprehensive holistic assessments in response to their changing needs and preferences, and holistic support appropriate to their current needs and preferences.
QS 8: Coordinated Care	People approaching the end of life receive consistent care that is coordinated effectively across all relevant settings and services at any time of day or night, and delivered by practitioners who are aware of the person's current medical condition, care plan and preferences.
QS 9: Urgent Care	People approaching the end of life who experience a crisis at any time of day or night receive prompt, safe and effective urgent care appropriate to their needs and preferences.
QS 10: Specialist Palliative Care	People approaching the end of life who may benefit from specialist palliative care, are offered this care in a timely way appropriate to their needs and preferences, at any time of day or night.
QS 11: Care in the Last Days of Life	People in the last days of life are identified in a timely way and have their care coordinated and delivered in accordance with their personalised care plan, including rapid access to holistic support, equipment and administration of medication.
QS 12: Care After Death – Care of the Body	The body of a person who has died is cared for in a culturally sensitive and dignified manner.
QS 13: Care After Death – Verification and Certification	Families and carers of people who have died receive timely verification and certification of the death.
QS 14: Care After Death – Bereavement Support	People closely affected by a death are communicated with in a sensitive way and are offered immediate and ongoing bereavement, emotional and spiritual support appropriate to their needs and preferences.
QS 15: Workforce – Training	Health and social care workers have the knowledge, skills and attitudes necessary to be competent to provide high-quality care and support for people approaching the end of life and their families and carers.
QS 16: Workforce Planning	Generalist and specialist services providing care for people approaching the end of life and their families and carers have a multidisciplinary workforce sufficient in number and skill mix to provide high-quality care and support.

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Appendix B: Invitation for End of Life Care Engagement Event

Please Help Us Improve End of Life Care in Merton

An Invitation to Take Part....

We would like to invite you to an engagement event so that we can hear your views on End of Life Care services in Merton.

At the event we will share some information about our journey, including details of important developments and progress so far. We will also discuss various key priorities that have been identified for the coming years.

You will then have the opportunity to contribute to group discussions about some key issues and topics. Your input will help us shape the next steps in relation to End of Life Care service provision and help us to find out what is most important to Merton residents.

Date	Thursday 6th November
Times	4.00 – 6.00pm or 6.30 – 8.30pm We are running two identical events. Refreshments will be provided from 6.00 – 6.30pm for the attendees of both events.
Location	Drake House, 44 St. George's Road, Wimbledon, London, SW19 4ED.
RSVP	Please RSVP to Leeca Perrett and indicate which event you wish to attend. Email leeca.perrett@mertonccg.nhs.uk or call 020 8251 0605. Please let us know if you have any specific dietary requirements.

Appendix C: 'One Chance to Get It Right' Priorities

The five Priorities for Care set out in the One Chance to Get It Right report are outlined below. These apply when it is thought that a person may die within the next few days or hours. They are transferable across settings and should be adopted and delivered regardless of where someone dies. The primary focus is on the needs and wishes of the dying person and their loved ones, who should be at the centre of decision-making regarding treatment and care.

Priority 1: Recognise
This possibility [of dying] is recognised and communicated clearly, decisions made and actions taken in accordance with the person's needs and wishes, and these are regularly reviewed and decisions revised accordingly.

Priority 2: Communicate
Sensitive communication takes place between staff and the dying person, and those identified as important to them.

Priority 3: Involve
The dying person, and those identified as important to them, are involved in decisions about treatment and care to the extent that the dying person wants.

Priority 4: Support
The needs of families and others identified as important to the dying person are actively explored, respected and met as far as possible.

Priority 5: Plan & Do
An individual plan of care, which includes food and drink, symptom control and psychological, social and spiritual support, is agreed, co-ordinated and delivered with compassion.

Leadership Alliance for the Care of Dying People (2014)

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