JSNA
Joint Strategic Needs Assessment

End of Life Care: report on key themes and findings

Joint Strategic Needs Assessment (JSNA) Report for

Hammersmith and Fulham   Kensington and Chelsea   Westminster

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About this report

The overall aim of this JSNA is to provide a comprehensive evidence base and information about end of life care needs of the local population to inform future commissioning intentions and strategic approach across the three Boroughs.

Authors and contributors

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Supplemental reports

This work draws information from a range of sources and key stakeholders. Further information is contained within two supplements to this report:

- Supplement 1: Technical document
- Supplement 2: Policy and Evidence Review

CONTENTS

1   Recommendations at a glance

The overarching theme emerging from the JSNA is the need for a whole scale 'culture shift', for all practitioners that may come into contact with dying people to consider End of Life care as 'everyone's business', not just a service provided by specialist palliative care.

The recommendations identified in this section have been drawn from the evidence contained in the JSNA and in development with key stakeholders. As many of the recommendations cut across a number of different themes and service areas these they have been collated below by theme for ease of reference. The recommendations should be reviewed by commissioners and consideration should be given as to whether they are appropriate for local implementation.

Recommendation	Details
Recommendation 1: Maximise choice, comfort and control through high quality effective care planning and co-ordination.	Everyone with a life limiting long term condition should have care plans which address their individual needs and preferences, particularly as they approach the last phase of life. Their care must be coordinated, with a clear oversight of the respective roles and responsibilities of all health, social care and third sector service providers. Oversight and monitoring of the overall effectiveness of care requires development. a. **Commissioner and service providers should collaboratively develop quality indicators which are outcome based;** ▪ Personalised individual care plans including where appropriate, Advance Care Planning, symptom control, pain management, access to 24/7 advice and support for patients, carers and families. ▪ Undertake a dedicated review of existing quality indicators such as the Gold Standard Framework implementation, complaints analysis, CQC ratings across primary, secondary and specialist services, care homes and other services, as appropriate. ▪ Develop a benchmarking tool from these indicators to inform specific improvements to local services (generalist, specialist and palliative) which provides oversight of all end of life care services and are linked to local ambitions, ensuring performance is visible b. **Shared personalised care records;** ▪ Continue to work on electronic care record (Co-ordinate My Care or CMC) interoperability issues; set local improvement targets for rolling out electronic care records; publish utilisation of electronic care records at practice or network level

Recommendation	Details
	Implement a mechanism to identify where care plans have not been accessed or adhered to, the reasons why and remedial actions; develop an interagency case review model which supports system improvements c. **Facilitate choice through better information (Recommendation 4)**
Recommendation 2: Promote end of life care as 'everybody's business' and develop communities which can help support people	The overall focus of end of life care must be a community model, with input from specialist services when needed. Local leaders, commissioners, professionals and our populations should generate a culture where talking about and planning for the last phase of life is 'normal'. a. **Key local health, social care and independent sector strategies and models should explicitly reference end of life care ambitions, e.g**. - Whole Systems Integrated Care, Shaping A Healthier Future, the personalisation agenda, primary care transformation programmes, the emerging North West London Last Phase of Life programme - This should include how respective services contribute to their ambitions, how these will be achieved, and how this is monitored for improvements b. **The normalisation of end of life care;** - A culture in which dying, death and bereavement is discussed and planned for should be promoted through improved engagement with all things 'end of life' - Enable anyone who wants to have a care plan, including an electronic care (CMC) record, to have one if they so wish c. **Each community is mobilised to help and should be given a greater, more visible role in the development of end of life care services which provide practical, emotional and spiritual support;** - Commissioners and providers should specifically undertake collaborative work with third sector organisations to develop the role and contributions of the community, voluntary and independent sector, and map service provision

Recommendation	Details
Recommendation 3: Identify clear strategic leadership for end of life care across both social care, health and the independent sector	Leadership should reflect a community based model across a range of services, with a clearly articulated end of life care vision and ambitions. a. **Health and Wellbeing Boards, Clinical Commissioning Groups and local authorities should be clear on strategic leadership;** ▪ Organisations should be visible and articulate in their commitment to improving the end of life experiences of their local communities across a range of services Identify a lead organization or group with responsibility for ensuring developments are cohesive and aligned

Recommendation 4:
 	
Develop a coordinated education and training programme for practitioners, the person dying, carers and for family and friends (if they wish)
	Formal and informal training and education programs for all frontline practitioners needs to be coordinated, systematic, visible and evaluated, in line with good practice guidelines.
	
	a. **All professionals must be competent in end of life care discussions and compassionate care delivery;**
	  ▪ In accordance with guidelines, professionals must converse in informed and sensitive end of life care discussions and be able to provide appropriate emotional and psychological support. Some professionals require further training on the physical management of patients nearing the end of their lives.
	
	b. **End of life care training and education should be available to all professional groups (both generalist and specialist staff) with both formal and informal development opportunities**
	  ▪ Training should be reflected in professional development plans where appropriate.
	  ▪ Training should be systematically evaluated to assess impact
	  ▪ Training must include knowledge regarding the various faiths and implications for end of life care, including an awareness of legislation which supports individualized care, recognizing and responding to distress and alleviating this proactively
	
	c. **A community development programme for the communities, family, friends and carers should be developed to enhance community and individual capacity to support end of life care**
	  ▪ Local events and approaches which include end of life care should be developed and promoted.

Recommendation	Details

Recommendation 5:
 	
Everyone should have easy access to evidence and information
	More information needs to be easily available. Accessibility in terms of language, style, culture and ability should be reviewed. Evidence and information must be available to commissioners and providers and used to actively improve services.
	
	a. Information needs to be easier to find, useful and shared;
	   ▪ A wider, more comprehensive variety of information should be available on websites of local services, such as PeopleFirst and the respective Clinical Commissioning Groups (CCG) websites
	   ▪ Information about entitlements and benefits needs to be available and easy to locate and access
	
	b. Facilitate choice and control through better information;
	   ▪ Develop a local visual care (service) pathway to help everyone (patients, family, friends and carers, and other professionals) to understand the overall landscape of local service provision. This should include information on roles and responsibilities, benefit and entitlements, needs led care and carer assessments, and condition specific services
	   ▪ Local (non- specialist palliative care) services which are able to provide bereavement support, such as local faith groups, Age UK, and commissioned bereavement services need to be promoted further
	
	c. Recommendations for specific communities or services;
	   ▪ Dedicated reviews of the quality of end of life services for specific communities should be routine. BAME communities are less likely to experience high quality care in the last three months of life. People with learning disabilities, children and young people, and people with dementia lack specific reviews of end of life care access and quality
	   ▪ Review the ability of care homes (with and without nursing) to deliver quality end of life care services
	   ▪ Review Hospice@Home provision and consider 24hour hospice at home across three boroughs (HFCCG)
	   ▪ Consider the expansion of the EOLC Facilitator functions into WSIC models, through existing or new posts (CLCCG & WLCCG)
	   ▪ Expand Dementia Nurse Specialist service across three boroughs (HFCCG & WLCCG)
	   ▪ Expand the Trinity/St John's pilot of a dedicated Care Home Team
	   ▪ Review transport issues
	   ▪ 24/7 access. Review recent audit of specialist palliative care for implications for local services (all CCGs) regarding pain management and symptom control

2   Introduction

2.1   Background

Death and dying are an inevitable part of life, and approximately 500,000 people die in England each year (NICE, 2011). Nationally, this figure is predicted to increase over the next 15 years (Gomes & Higginson, 2008), although this is not replicated locally, where despite an increasing and aging population, the number of deaths has reduced each year over the last decade.

People are living longer due to improvements in public health, vaccinations, and advances in medical treatment. Consequently, people are experiencing longer periods of ill-health before the end of life and more people are living longer with multiple health conditions. This is expected to place further pressure on health and social care services.

People approaching the end of their life experience a range of physical symptoms, as well as emotional and spiritual needs. To manage these issues effectively requires integrated and multidisciplinary working between teams and across sectors regardless of whether the person is in their home, in hospital, a care home, or hospice. Families and carers of people at end of life also experience a range of problems and will have their own specific needs which must be addressed before, during and after the person's death.

It is recognised that while there are many high quality services, and some people experience good quality end of life care, many people do not. This variation in end of life care practice has been a feature highlighted in recent reports, including the Parliamentary and Health Ombudsman's 'Dying without dignity'(2015).

To address this variation it is vital that end of life care is seen as everyone's business and not limited to certain specialties such as palliative care services. The focus on supporting people to receive care, and be supported to die in their preferred place of care, requires a future shift in culture and in service provision from the acute hospitals to the community.

Primary care teams in the community can deliver excellent palliative care for their dying patients and enable patients to die well where they choose when complemented by good access to specialist services, support, and expertise. As demand for community care increases, it is important to maximise the potential of primary palliative care and the use of frameworks or protocols with good collaboration with specialists. Whole Systems Integrated Care (WSIC), the project to bring together different parts of the health and care system to better meet the needs of the individual is the ideal opportunity to ensure the focus on community based care embraces the best of end of life care.

2.2   Population analysis of deaths across the three Boroughs

A comprehensive analysis of deaths across the three Boroughs has been undertaken to inform this JSNA. This analysis is described in full in the End of Life Care Technical Document. Below is a selection of the headline findings. Further analysis has been included where it supports the key themes described in section 2.

Population and number of deaths

The percentage of either gender at all ages over 65 for the three boroughs is significantly low compared with England. The exception is in RKBC for those aged 85+ for both genders, with the percentage of women over 85 years close to the England average, but with a significantly higher percentage of males older than 85 years because of the Royal Hospital Chelsea, a home for retired soldiers.

The death rate is low compared to other areas, even when taking into account the age distribution of the population. There have been an average of 2,815 deaths per year between 2006 and 2014. Despite an increasing and aging population the number of deaths has reduced by 19 each year.

The median age at death is 83 years for women and 76 years for men, compared to national figures of 85 for women and 82 for men. Median age at death varies from 66 years in Earl's Court to 88 years in Pembridge.

The number of deaths that occur is not likely to change significantly over the next ten years. This takes into account the small increase in the ageing population predicted by ONS and the expected reduction in death rates.

Cause of death
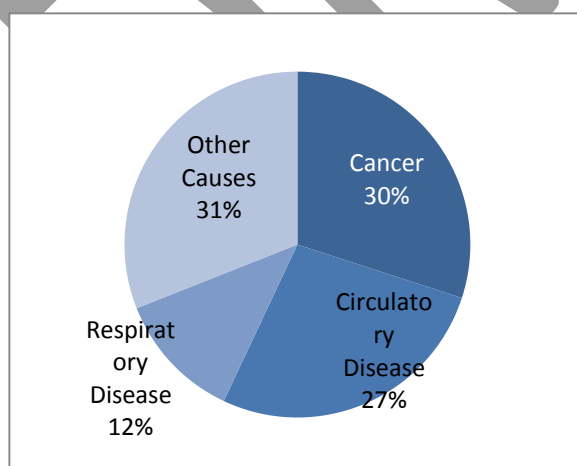
On average there are 844 (30%) deaths per year due to cancer, 768 (27%) due to circulatory disease, 341 (12%) deaths due to respiratory disease and 863 (31%) deaths due to other causes. The percentage of deaths due to cancer is significantly higher in the north of WCC and is significantly associated with an older median age at death.

Examination of deaths in the three boroughs is complicated by the geography and the different populations of the organisations responsible for providing services. There are a number of different populations to examine: Resident, Registered, Residents who are Registered, and Registered who are not Resident. Additionally, those who die may do so anywhere in the country.

2.3   Definitions of End of Life and Palliative Care

The terminology for end of life and palliative care is not always used consistently and does require clarity. For the JSNA the following definitions have been used.

End of Life Care

The term end of life care is commonly used when patients are identified as being likely to die within the next 12 months.   This includes those people whose death is imminent and expected within the next few hours or days.

Palliative care

The World Health Organisation define palliative care as, "an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual."[1]

NICE uses a similar definition, referring to "the active holistic care of patients with advanced progressive illness".

Specialist palliative care

To enable this active and holistic approach to palliative care, specialist palliative care is provided by a multidisciplinary team who have received appropriate training. The team's aim is to facilitate the physical, psychological, social and spiritual support required by people approaching the end of life.

The relationship between specialist palliative care and end of life care is shown in figure 1 below[2].

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[1] WHO http://www.who.int/cancer/palliative/definition/en/
[2] Consultant Nurse in Palliative Care Reference Group, Marie Curie Cancer Care, National Council for Palliative Care, and Palliative Care Section of the Royal Society of Medicine, London, UK. Accessible at: www.ncpc.org.uk/sites/default/files/CommissioningGuidanceforSpecialistPalliativeCare.pdf

Figure 1: Relationship between specialist palliative care and end of life care
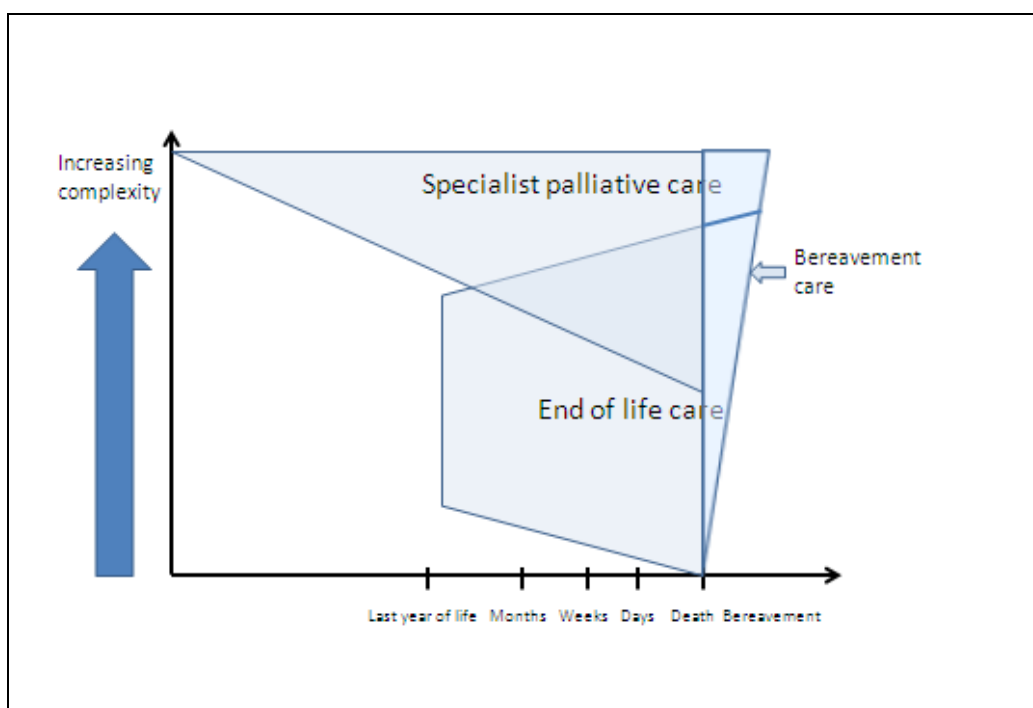
2.4 Overview of End of Life Care and Palliative Care Services

End of life care can take place in a number of settings such as care homes, hospices, hospital, or at home. Services are delivered by a range of health and social care professionals but is generally provided by two different types of health and social care staff:

- Generalist staff providing day-to day care to patients and carers in their homes and in hospitals e.g. hospital doctors and nurses, GPs, community nurses, and social workers.

- Specialist palliative care staff such as Consultants in Palliative Medicine and Clinical Nurse Specialists. These can be NHS or social care staff, or specialists working for charities such as hospices, Macmillan, or Marie Curie.

Care is usually delivered by a combination of generalist and specialist staff through multidisciplinary teams. Planning and coordination is key to providing good care and the Gold Standards Framework highlights the importance of practices holding multidisciplinary team meetings to consider the needs of people approaching the end of life. These meetings should involve a range of professionals, including GPs, district nurses, and social workers, with specialist palliative care staff to provide support and expertise. The level of care is set by the needs of the patient, with escalation of care as appropriate.

2.5   National Guidelines and Standards

The findings and recommendations of this JSNA have been developed with reference to two key pieces of national guidance and best practice in implementing high quality end of life care:

- End of Life Care Strategy
- NICE Quality Standards for End of Life Care for Adults

During the latter stages of developing this JSNA, the National Palliative and End of Life Care Partnership published their national ambitions[3], calling for collective action to improve end of life care. The Partnership comprises statutory bodies and charities, such as NHS England, Public Health England, Association of Directors of Adult Social Services, MacMillan and Marie Curie, and these ambitions need to be considered as a key driver in delivering end of life care locally. These are described in more detail below.

The National End Of Life Care Strategy 2008

The Government strategy recognised that while some people received good end of life care there was still a considerable number who did not have a 'good death'.

One of the key themes identified was the importance of whole systems working, and a number of key areas for action were identified, such as

- Raising the profile of end of life care and changing attitudes to death
- Strategic commissioning
- Identifying people approaching the end of life
- Care planning
- Coordination of care
- Rapid access to care
- Delivery of high quality services in all locations
- Last days of life and care after death
- Involving and supporting carers
- Education and training and continuing professional development
- Measurement and research
- Funding

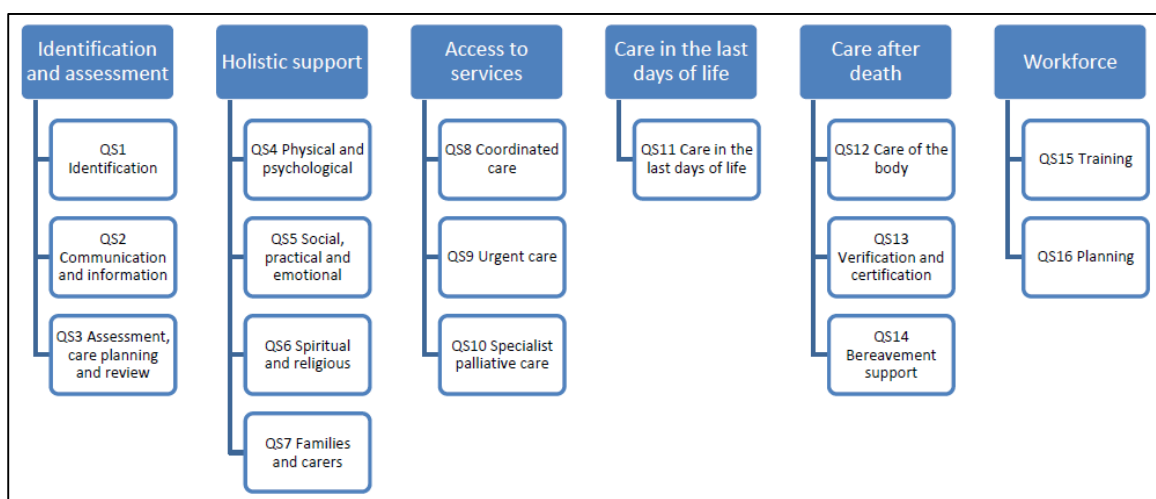### *NICE Quality Standards for End of Life Care for adults*

These standards provide a comprehensive picture of what high quality end of life care should look like. This is described through 16 quality statements. In the table below the statements are summarized and mapped to the relevant areas of care.

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[3] National Palliative and End of Life Care Partnership http://endoflifecareambitions.org.uk/

Figure 2: NICE Quality Standards on End of Life Care mapped to areas of care

Identification and assessment	Holistic support	Access to services	Care in the last days of life	Care after death	Workforce
QS1 Identification	QS4 Physical and psychological	QS8 Coordinated care	QS11 Care in the last days of life	QS12 Care of the body	QS15 Training
QS2 Communication and information	QS5 Social, practical and emotional	QS9 Urgent care		QS13 Verification and certification	QS16 Planning
QS3 Assessment, care planning and review	QS6 Spiritual and religious	QS10 Specialist palliative care		QS14 Bereavement support	
	QS7 Families and carers				

Ambitions for Palliative and End of Life Care: A national framework for local action 2015-2020

Person-centred care is a key theme of this recent report, with the focus very much on improving care for the individual and those around them. The report sets out six positive ambitions to create a new impetus for end of life care, with eight foundations required to achieve these ambitions:

Ambitions	Foundations
➢ Each person is seen as an individual ➢ Each person gets fair access to care ➢ Maximising comfort and wellbeing ➢ Care is coordinated ➢ All staff are prepared to care ➢ Each community is prepared to help	➢ Personalised care planning ➢ Shared records ➢ Evidence and information ➢ Involving, supporting and caring for those important to the dying person ➢ Education and training ➢ 24/7 access ➢ Co-design ➢ Leadership

Implementation needs to be locally led and the report is a call for action for collaboration and cooperation by local agencies **This requires leadership and the Partnership asks specifically for Health and Wellbeing Boards, CCGs, and Local Authorities (or a composite) "to publicly designate an organisation to lead on making these ambitions the reality for the communities you serve."**

2.6   Relation to local commissioning

The JSNA will support the integration of end of life care into local strategy development and models of care, in particular Whole Systems Integrated Care, as well as supporting the adoption of End of Life Care into the Adult Social Care home care contracts, and inform targeted investment in services where it will have the greatest impact.

It is an opportunity to understand the whole landscape for people approaching end of life, and their carers' and to highlight areas of improvement to be addressed in joint strategic planning.

The local commissioning and strategic context is one of increasing focus on 'Whole Systems Integrated Care' and 'Out of Hospital' commissioning. Local End of Life Care programmes are designed to increase the number of patients who die where they would wish to (whether this is in their own homes, care homes, hospital, or hospice care) and to reduce the number of unplanned admissions that end of life care patients have within the final year of their life, through more proactive and coordinated care.

Coordinate My Care

To enable patients preferences to be met and reduce unplanned admissions the CCGs have adopted the **Coordinate My Care (CMC)** online tool to record the treatment and place of death preferences of patients. Coordinate My Care (CMC) is a clinical service that allows health professionals (with a legitimate reason) to have access to a patient's care plan outlining their condition, treatment, key contact details, and wishes and preferences, as they approach the end of their life. This is particularly helpful for emergency situations.

3 Key themes and findings

This section explores findings from the JSNA. Evidence is drawn from relevant guidance and standards, local data, the views of local clinicians, commissioners and providers, and policy and evidence to reach an informed view on where there are gaps in the system. These gaps have informed the development of the recommendations.

For the purposes of presenting these findings and developing the recommendations, this information was mapped to a number of headings, largely based on the End of Life Care Pathway[4].

The overarching theme emerging from the JSNA is the need for a whole scale 'culture shift'; for all practitioners who may come into contact with dying people to consider End of Life care as 'everyone's business', and not just a service provided by specialist palliative care.

Overall, individual services are generally perceived as good, but improvement is needed to identify patients who are in their last year of life and create a care plan in order for their wishes to be met (and met consistently) when they come into contact with several different services.

3.1 Identification of people approaching the end of life

Identification of people approaching the end of life is key to providing good quality end of life care. The NICE Commissioning Guide for End of Life Care describes a lack of open and honest communication between health and social care staff and individuals which can hinder this identification. This barrier is related to the taboo around discussing death and dying.

Having a Coordinate My Care plan is an indicator of identification and appropriate conversations being had. In Hammersmith and Fulham CCG, 3.9% of the patients aged 65 years and over (542 patients) are recorded on CMC. A lower proportion of patients are recorded on CMC in the other two CCGs: 2.0% in West London CCG (469 patients) and 2.2% in Central London CCG (763 patients).

Table 1: Proportion of patients aged over 65 on CMC

	Number on CMC list	Total practice population aged over 65 years	% of patients aged over 65 on CMC list
H&F CCG	763	19484	3.92%
WL CCG	542	27448	1.97%
CL CCG	469	21453	2.19%

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[4] It is acknowledged that following the review and phasing out of the Liverpool Care Pathway (LCP) that references to the "pathway" often have negative associations

Of the patients with a CMC record who died, and for whom the place of death and preferred place of death are recorded, approximately 65% died in their preferred place of death. The proportion of patients recorded on CMC who died in hospital is lower than the average for all CCGs patients. The majority of patients on CMC are diagnosed with cancer (H&F CCG: 53%, WL CCG: 51%, CL CCG: 58%).

Identified gaps and issues
• Practitioners do not always identify people approaching end of life until shortly before death, resulting in patients referred too late in their trajectory
• CMC patients mainly have a cancer diagnosis, and so people with cancer are more likely to have a CMC record. Identification of the end of life care needs for patients with a non-cancer diagnosis needs to improve
• There is variation in identification across community and acute settings

3.2   Discussions as the end of life approaches

Communication is a theme that recurs in all guidance, best practice, strategy and policy written on end of life care. The Dying without Dignity report highlighted poor communication as a key theme of complaints, while the NICE End of Life Care Commissioning Guide advises that communication is a core competency for end of life and palliative care.

Locally, the BME Health Forum cited 'honest and open communication' a key aspect of what a 'good death' looks like in a workshop undertaken during this JSNA.

Identified gaps and issues
• In order to create consistent good communication with patients and their loved ones, a 'culture shift' is needed which addresses the taboos on death and dying and reluctance to initiate these conversations
• There is a need to support professionals to develop confidence in initiating end of life discussions
• Information needs to be available in range of formats and accessible to patients, service users and their families and carers

3.3   Assessment, care planning and review

Following identification, having a care planning discussion and regular review is a key element of good end of life care. The communication of plans between and among health and social care teams, other professionals and the persons personal network can help to ensure the persons wishes are respected and accommodated.

One way of monitoring this is through the number of uploaded CMC records (see local CMC take up information in 3.1). However there are other relevant indicators

such as place of death and personalised social care plans, as well as carers receiving support.

Social Care support

Table 3: Persons (65+) receiving Self Directed Support, per 100,000, average annual for 2008-10

	Number receiving support	**Indicator (per 100,000 aged 65 years and over)**
LBHF	585	3,346
RBKC	1,375	5,660
WCC	475	1,757
England average		2,935

*Source: ONS. From NI 130, 2010/11, HSCIC. 2010, ONS.*

The rate of people aged 65 years and over who receive self-directed Social Care support (direct payments and individual budgets intended to offer clients and carers' greater flexibility and independence in how support is provided) is relatively high in RKBC, similar to the England average in LBHF and low in WCC. A higher rate may indicate a greater need for services or a more developed use of self-directed support or better access to services.

In LBHF, 605 carers receive social care support (3460/100,000 aged 65+), in RKBC 350 (1440/100,000 aged 65+ and in WCC 220 (814/100,000 aged 65+). However, the majority of carers do not receive social care support and are not known to the council. In the 2011 Census, 12,334 people in LBHF reported that they provide unpaid care, 10,978 in RKBC and 15,878 in WCC.

Place of death

The VOICES survey reported that of those who expressed a preference, the majority preferred to die at home (81%), although only half of these actually died at home (49%). Therefore the percentage of deaths occurring in usual residence (at home or in a care home) is commonly used as a proxy indicator of whether people's end of life care wishes are being met. However, concerns have been raised that the focus should be on the experience of dying regardless of location.

Figure 3: Percentage of all deaths by place of death
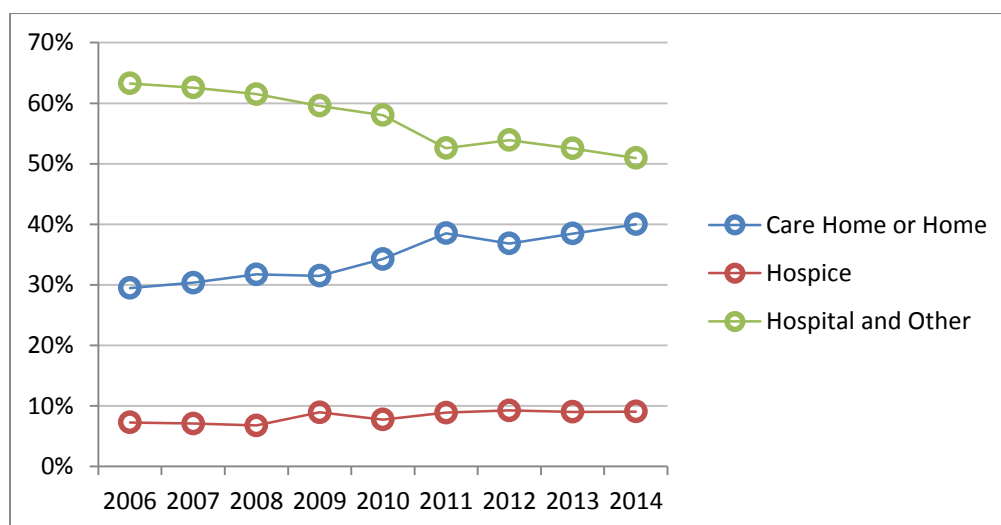
Source: Local Mortality Data; LA resident or CCG registered patients place of death

Figure 4 shows whether deaths occur in someone's usual residence (Home or Care Home), a Hospice or Hospital/Other. Over the first 6 years there was a reduction in the number and percentage (from 63% to 52%) of deaths occurring in hospital, and the percentage has remained essentially the same for the last 4 years. There was a balancing increase in deaths at people's usual residence (from 29% to 39%) over the same period, and this has also been stable for the last 4 years. The percentage of deaths in a Hospice increased by nearly a third from 7.5% to 9.5%, and has been stable for the last five years.

Identified gaps and issues
• There is a need for shared decision making and involvement of patients and the bereaved
• Electronic care plans (CMC) needs to be compatible with local systems demonstrating interoperability and enabling a user-friendly platform.
• Care plans need to be utilised and shared appropriately
• Discharge arrangements need to be designed specifically for patients who are nearing the end of their lives
• Single point of Access: some stakeholders raised issues in relation to multiple points of entry for palliative care provision, which has implications for co-ordination

3.4 Coordination of Care

Mechanisms need to be established to enable well coordinated care, in accordance with the care plan, across sectors and at all times of day and night. As a person's condition can deteriorate rapidly, there is a need to ensure that services are available 24/7 and can respond quickly and appropriately. Provision of 24/7 services can avoid unnecessary emergency admissions to hospital and enable more people at the end of their life to live and die in the place of their choice.

GPs and District Nurses play a key role in coordinating and providing continuity of care locally. Multidisciplinary teams provide a mechanism for primary care teams to deliver excellent palliative care for their patients, complemented and supported by specialist palliative care services. A number of services provide end of life care in the community throughout the day and night.

However, a recurring theme is that there is room for improvement in coordination between different professionals and the potential role of an individual having overall responsibility in coordinating a patient's care.

Identified gaps and issues
• Strategic leadership is required to coordinate care across the system. Leadership should reflect a community based model with input from specialist services. • End of Life Care presents across a range of services and it would be beneficial to have an identified lead with responsibility for ensuring developments are cohesive and aligned (case management, service development, strategic leadership) • Continuity of care • The place of End of Life Care in MDTs needs to be considered

3.5 Delivery of high quality services in different settings

End of life care is delivered across a range of settings and locations, including acute hospital and community settings, care homes, extra care housing, hospices, community hospitals, prisons, secure hospitals, hostels and ambulance services.

Equity in service provision is vital. The Policy and Evidence Review (accompanying document) highlights end of life care issues for specific communities such as BME groups, people with a learning disability, prisoners, LGBT, homeless people, and people with dementia.

The local picture

Hospices

There is good coverage of the boroughs by hospices, although less than 10% of local deaths occur in hospices. There is some overlap in the areas that are covered by the hospices, particularly by Pembridge hospice and Trinity hospice. In the areas where the coverage of the hospices overlap (e.g. in the middle of K&C) it appears that a higher proportion of all deaths are hospice patients.

Hospital

The majority of people who died in hospital are aged over 75 years and were admitted following an emergency admission. The average length of stay of the last admission before death of 16.5 days. The primary diagnosis of the last admission before death was respiratory disease for 31% of patients, circulatory disease for 20%, and cancer for 16%.

Social Care

The rate of persons discharged from hospital with the intention of rehabilitation (aged 65 years and over) is similar to the England average, although relatively high in Westminster.

Identified gaps
• There is variation in the quality of experience that people and their families and carers have across the boroughs. Equity of service provision is important and commissioners may wish to consider expanding or developing services which increase choice and allow people to be cared for at home, if this is their wish • Training on the physical management of patients nearing the end of their lives should be available to staff in different settings • There is very little co-ordination of quality issues and measures employed across settings • There is a need for access to specialist advice 24/7

3.6   Care in the last days of life

Recent NICE guidance on the care of dying adults in the last 2-3 days of life make recommendations on recognizing when a person may be in the last days of life; communication; shared decision making; maintaining hydration; pharmacological interventions; and anticipatory prescribing.

Once a patient has been identified as nearing the end of his or her life, advance care plans should be reviewed continually to confirm that all of the resources are in place to provide the preferred end-of-life care services in the preferred location. Particular consideration should also be given to the needs of carers in this time.

Identified gaps and issues
• Reported variation in service provision with regard to pain relief and control in care homes (e.g. Syringe drivers – equipment, training and confidence, maintaining competency) • Emotional and spiritual support in last days of life • Pathway documentation to provide guidance for professionals, patients and families

3.7   Care After Death

End of life care does not stop at the point of death, and timely verification and certification of death or referral to coroner is an important part, as is care and support of carers and families. This includes emotional and practical bereavement support**.**

The VOICES Survey reported that a particular area for improvement in North West London is help and support for families and carers at the time of death. The BME Health Forum highlighted that this support needs to be culturally appropriate and take into account specific cultural and religious needs, for example, the swift release of the deceased for burial within 24 hours.

Identified gaps and issues
• There is currently a lack of awareness among commissioners and providers on the full range of community and voluntary services and the extent to which they can contribute to end of life care. Further clarity on the role of community and voluntary services is required • Bereaved carers should have access to good-quality information about the practical steps they need to consider and how to access emotional support if they need it. • Help and support for family at the time of death is an area for improvement

3.8   Support and Information for Carers and Families

Family and carers should be seen as key stakeholders involved in the decision-making and planning around end-of-life care needs. Advance care planning and inclusive communication is a valuable process to make care preferences transparent and to ascertain gaps in carers' ability to deliver care themselves, including their own health care needs (and issues of bereavement).

Recognising and addressing the needs of family and carers is one of the *5 Priorities of Care for the Dying Person.* A holistic assessment of family and carer needs is required, including support for children of carers, bereavement support, and respite care. Information should be tailored to meet their specific needs, accessible and presented in a sensitive way.

The Local Picture

Unpaid carers may help reduce hospital admission and promote home deaths. The End of Life Carers Project in Westminster and Hammersmith & Fulham aims to support carers in preparing for end of life, and advanced care planning, and address their specific needs, while enabling them to fulfill their caring responsibilities and other commitments. Importantly, it allows access to respite care and an opportunity to pursue activities such as health and leisure activities, academic learning and training.

Identified gaps and issues
• Identification of the role of community and voluntary services (CVS) and lack of awareness of the full range of CVS services
• Information needs to be available in a range of formats and accessible for all
• Bereaved carers should have access to good-quality information about the practical steps they need to consider, and how to access emotional support if they need it.

3.9   Spiritual Care Services

Spiritual care may be very important to the dying person and their loved ones, and so is an important aspect of providing good all round end of life care. The NICE Commissioning Guide for End of Life Care reports that there is a widespread need for **training in all aspects of spiritual care**.

Spiritual and religious needs should be considered in the assessment and advance care planning process. Some services may be provided through local religious organisations and commissioners may wish to ensure these are reflected in the local care pathway.

Addressing the spiritual needs of patients, closely linked with cultural and religious beliefs, was also highlighted by the BME Health Forum workshop undertaken during the JSNA process.

Identified gaps
Spiritual care needs are not always documented

4 References

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