

MANCHESTER JOINT STRATEGIC NEEDS ASSESSMENT

ADULTS AND OLDER PEOPLE

CHAPTER: Other Topic Areas

TOPIC: End of Life Care

WHY IS THIS TOPIC IMPORTANT?

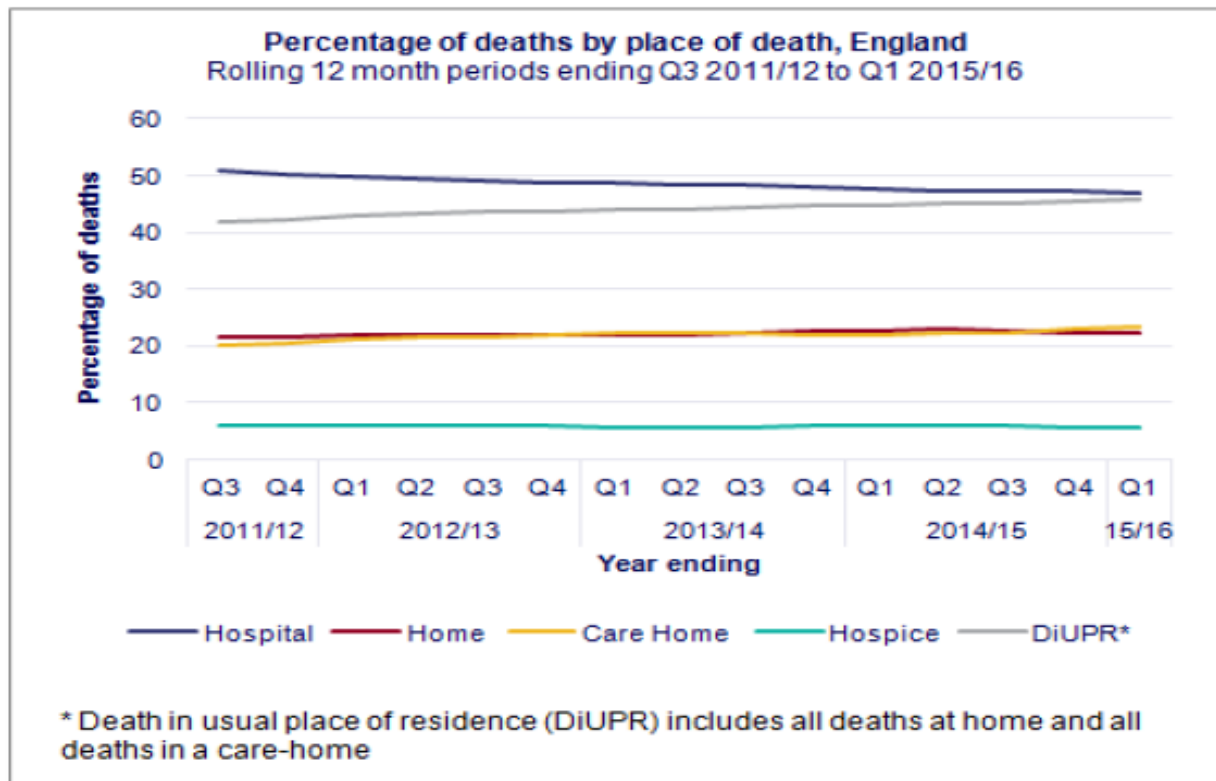
In England, approximately half a million people die each year. The number is expected to rise by 17% from 2012 to 2035. The percentage of deaths occurring in the group of people aged 85 years or more is expected to rise from 32% in 2003 to 44% in 2030.

End of Life (EoL) care describes the help and support to people in their last year of life. It has been defined by the National Council for Palliative Care as **'care that helps all those with advanced, incurable illness to live as well as possible until they die'**. It is a crosscutting area of care which incorporates urgent care, planned care and all patients with a life limiting illness. It requires cooperation between organisations that provide care for people at the end of life.

Palliative and supportive care refers to the active holistic care of patients with advanced progressive illness. Management of pain and other symptoms and provision of psychological, social and spiritual support is paramount. The goal of palliative care is achievement of the best quality of life for patients and their families.

A national survey in 2010 (Cicely Saunders International) found that 64% of respondents would like to die at home. Historically, people living in England have been much more likely to die in hospital than in their own home. However, in recent years, things have started to change and the proportion of people dying in their usual place of residence has increased. As the chart below shows, the proportions of people dying in hospital and at their usual place of residence are now fairly similar. (Note: 'Usual place of residence' includes deaths that occurred at home or in a care home/religious establishment and is often used as a proxy marker for quality of end of life care).

Figure 1: Percentage of deaths by place of death, England



Views of family members

The [National Survey of Bereaved People](#) (VOICES, Views of Informal Carers - Evaluation of Services) collects information on bereaved people's views on the quality of care provided to a friend or relative in the last 3 months of life. Data from the 2015 survey shows that:

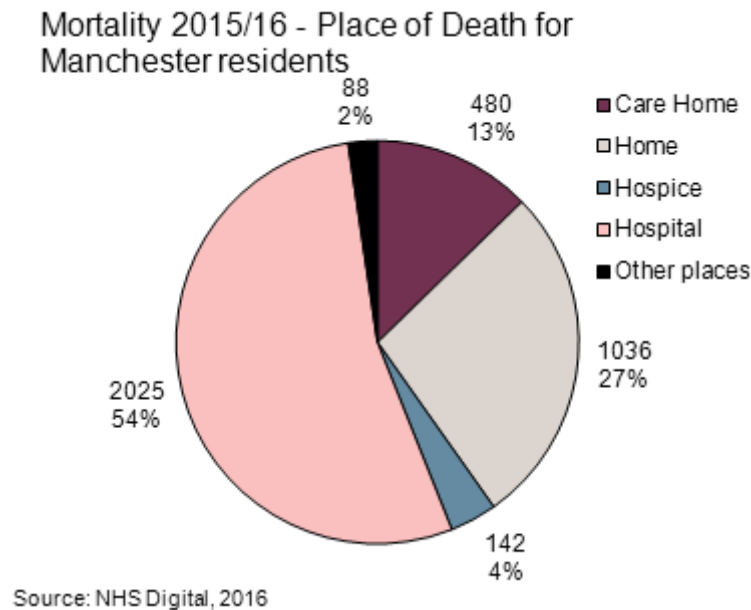
- 3 out of 4 bereaved people (75%) rate the overall quality of end of life care for their relative as outstanding, excellent or good; 1 out of 10 (10%) rated care as poor.
- 7 out of 10 people (69%) rated hospital care as outstanding, excellent or good which is significantly lower compared with care homes (82%), hospice care (79%) or care at home (79%).
- Ratings of fair or poor quality of care are significantly higher for those living in the most deprived areas (29%) compared with the least deprived areas (22%).
- Almost 3 out of 4 (74%) respondents felt hospital was the right place for the patient to die, despite only 3% of all respondents stating patients wanted to die in hospital.

THE MANCHESTER PICTURE

Local mortality data for Manchester shows that, in 2015/16:

- 54% of residents died in hospital
- 27% died in their own home
- 13% died in residential/care homes
- 4% died in a hospice
- 2% died in another place

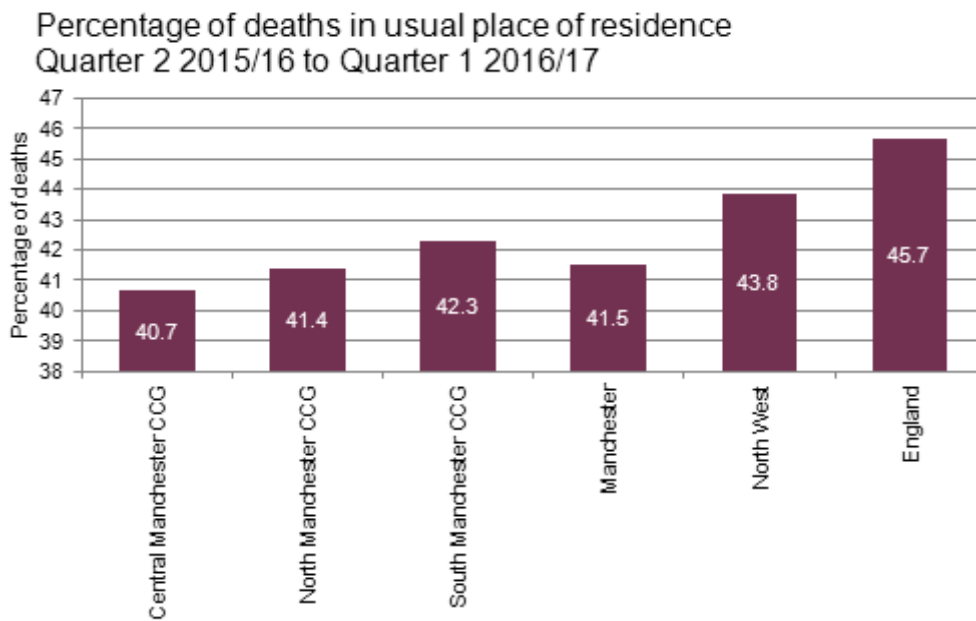
Figure 2: Percentage of deaths by place of death, Manchester (2015/16)



Compared with the national average, people living in Manchester are much more likely to die in hospital and, conversely, are much less likely to die in residential or hospice care. The proportion of deaths that occur at home is similar to the national average.

In the period between October 2015 and June 2016, 41.5% of people living in Manchester died in their usual place of residence (i.e. at home or in a care home / religious establishment). This is lower than the percentage for the North West (43.8%) and England (45.7%). The table below shows the differences between the three CCGs in Manchester in terms of the proportion of local people dying in their usual place of residence.

Figure 3: Percentage of deaths in usual place of death, Manchester

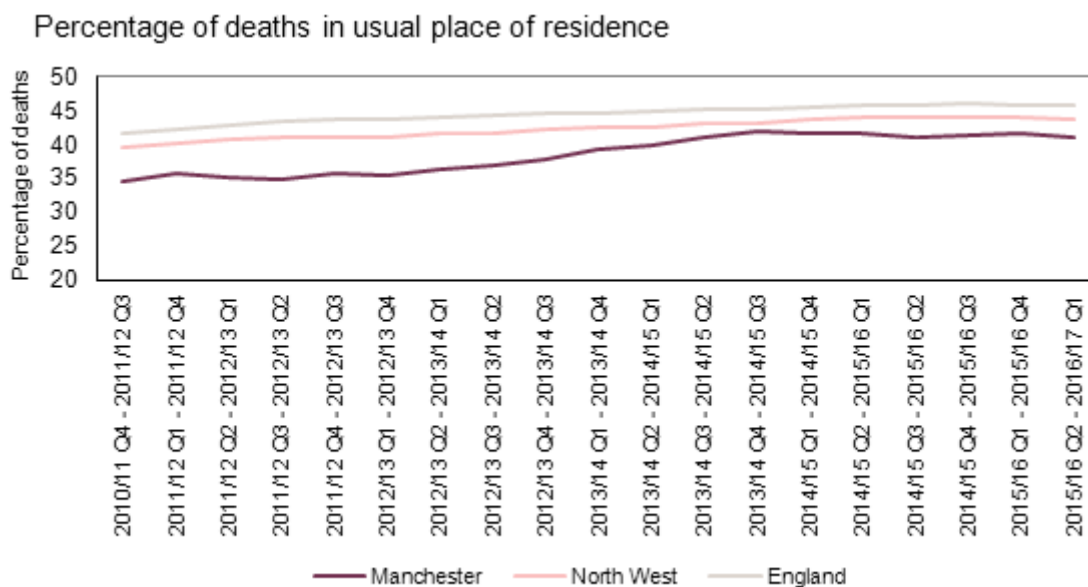


Source: PHE National End of Life Care Intelligence Network, 2017

Figure 3 (above) shows that people in South Manchester are more likely to die in their usual place of residence than those living in North or Central Manchester.

Over the last few years, the proportion of Manchester residents recorded as dying in their usual place of residence has been increasing such that the Manchester figure is now much more in line with those for the North West region and England as a whole (Figure 4).

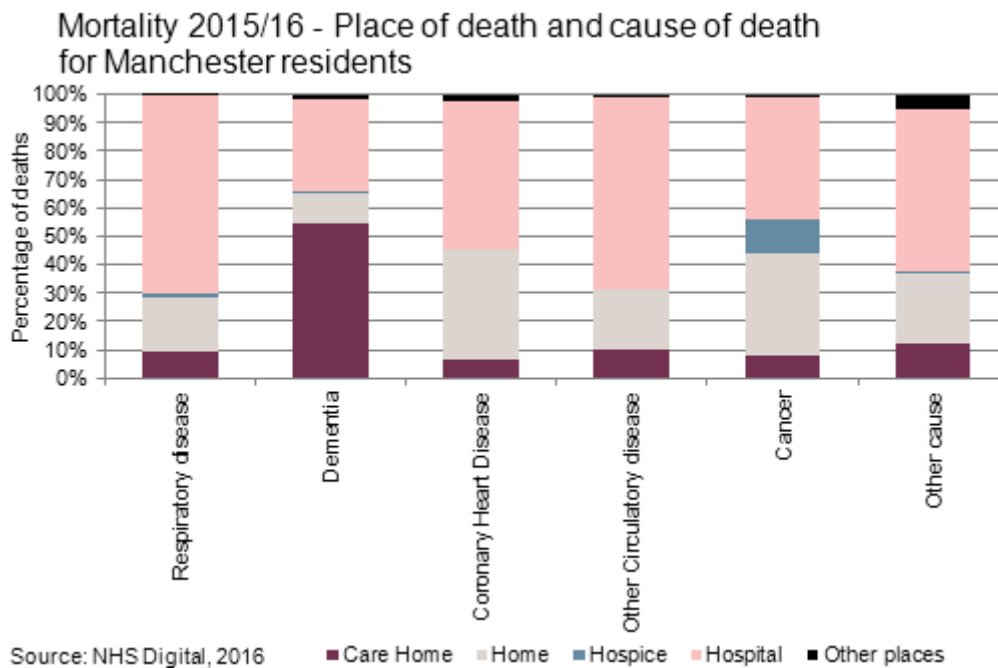
Figure 4: Percentage of deaths in usual place of death, Manchester (Trends)



Source: Office for National Statistics © Crown Copyright 2016

The graph(s) below show the number (and proportion) of deaths from different causes occurring in different settings

Figure 5: Percentage of deaths by cause and place of death, Manchester (2015/16)



In 2015/16, people dying from cancer were the most likely to have died in a hospice setting. This reflects the fact that end of life care services have traditionally been orientated towards cancer care. However, people with a range of other life limiting conditions including cardiovascular, respiratory, and neurological disorders and dementias should also be fully accommodated. Although non-cancer related deaths accounted for over 70% of deaths in Manchester in 2015/16, the number of people with non-cancer diagnoses accessing specialist palliative care services remains very low.

People dying from Coronary Heart Disease were most likely to die at home. This reflects the more sudden nature of these deaths rather than this being a reflection of choice of end of life care. In contrast, people dying from respiratory diseases were most likely to die in hospital. Dementia had the greatest percentage of deaths in a care home.

A Care Quality Commission national review to address **inequalities in EoL care** in 2015 found that people with a diagnosis other than cancer, older people, people with dementia, people from protected groups (see Appendix) and people who may be vulnerable because of their circumstances do not always experience good care in the last phase of their life. Action is needed to make sure everyone receives good quality, personalised end of life care regardless of diagnosis, age, ethnic background, sexual orientation, gender identity, disability or social circumstances.

WHAT WOULD WE LIKE TO ACHIEVE?

Key Standards for End of Life Care

NICE quality standards (see Links and References) define clinical best practice for EoL care. They provide 16 specific, concise quality statements, measures and audience descriptors to provide the public, health and social care professionals, commissioners and service providers with definitions of high-quality care.

The quality standards cover all settings and services in which care is provided by health and social care staff to all adults approaching the end of life. This includes adults who die suddenly or after a very brief illness. The quality standards do not cover condition-specific management and care, clinical management of specific physical symptoms or emergency planning and mass casualty incidents.

The Care Quality Commission (see Links and References) have addressed inequalities in EoL Care following their review publication in 2016. They concluded that nationally, the quality of care for some people at the end of their life is still not good enough.

They found that where commissioners and services are taking an equality-led approach that responds to people's individual needs, people receive better care.

Care in the last days

Priorities of Care for the **dying person** are defined by a document developed by the 'Leadership Alliance for the Care of Dying People' called [One Chance to Get It Right](#). This was published in 2014 and replaced the Liverpool Care Pathway.

It sets out the approach to caring for dying people that health and care organisations, and staff in England should adopt so that any action taken must **focus on the provision of care not the process behind the care or its documentation**. There is also a strong emphasis on care being driven by patients and those close to them.

This approach is based on **five equally important Priorities for Care** of the Dying Person. These are:

1. The possibility that a person may die in the next few days or hours is recognised and communicated clearly (where appropriate), decisions about care are made in accordance with the person's needs and wishes, and these are reviewed and revised regularly.
2. Sensitive communication takes place between staff and the person who is dying, and those identified as important to them.
3. 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.
4. The needs of families and others identified as important to the dying person are actively explored, respected and met as far as possible.
5. An individual plan of care, which includes food (nutrition) and drink (hydration), symptom control and psychological, social and spiritual support, is agreed, co-ordinated and delivered with compassion.

The End of Life Care Strategy (Department of Health, 2008) identified high incidences of inappropriate admissions to hospital from care homes at the end of life and highlighted a need for end of life care training for care home staff.

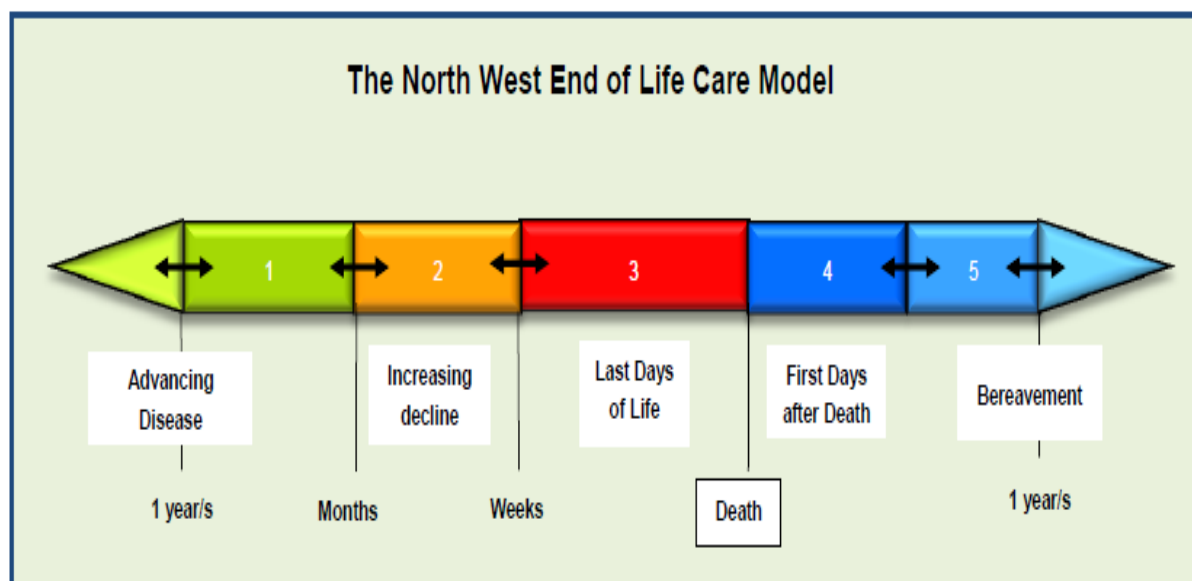
The North West End of Life Care Model

The changing demographics of an ageing population, longer chronic disease trajectories, and greater co-morbidity, provide further incentives to improve and expand palliative care and end of life care provision. In the North West alone, it is estimated that the number of people with long term conditions (LTCs) will double to 3 million by 2030.

The North West vision for end of life care is for people to be supported, to be cared for and, separately, **die well in the place of their choice**, with a broad aim to reduce avoidable hospital admissions for patients at the end of life and to expedite discharge for end of life care patients who are admitted to hospital for emergency care.

The North West End of Life Care Model (see Figure 6 below) uses a whole systems approach for all adults with a life limiting illness, regardless of age and setting, moving from recognition of need for end of life care, to care after death. In order to apply the model, it is important that staff across different organisations understand the needs and experiences of people and their carers.

Figure 6: The North West End of Life Care Model



People who are reaching the end of their life rely heavily on their carers for holistic care and support at all levels, including practical help, some physical care and emotional support. Raising the topic of end of life and last wishes is acknowledged to be difficult in some circumstances.

A [qualitative research study](#) by Public Health England on public perceptions and experiences of EoL care concluded that early conversations when the patient has insight and full capacity are seen as ideal. However, these can seem premature and may be difficult to introduce, particularly when the patient has dementia which is not often conceptualised as 'terminal'. The topic feels easier to raise when a person is in the later stages of an incurable illness. Yet, if their cognitive capacity has by then been

compromised, then the conversation may be less meaningful. For people with dementia, timing is therefore seen to be particularly important.

Ensuring Equality in EoL Care

Dixon et al found that while deprivation did not limit access to support, housing and deprivation are a factor. Improving alternatives where home death is not possible or not preferred is necessary. For certain groups who are more likely to die in hospital, **alternative settings should be available** which provide a similar experience to that of the home.

Lewis et al¹ found that people from lower socio-economic groups are more likely to die in hospital due to:

- A lack of family and carer support
- Being less likely to support a death at home
- The demand for services at end of life being higher

What does the evidence say?

The Appendix, with references, to this topic demonstrates evidence of inequalities in EoL care and how these may be addressed.

Dixon et al. (2015) found a propensity for those over 80, with dementia or receiving treatment for disease management to have their pain management needs underestimated by clinicians. The recommended solution for this is education of clinicians and a structured tool for pain assessment. The research also found that people from BME groups are less likely to view the care in their last three months of life as highly as non BME groups, however they did not have the data to suggest why this may be the case and further work is required to explain this.

Josie Dixon, Derek King, Tihana Matosevic, Michael Clark and Martin Knapp. Equity in the Provision of Palliative Care in the UK: Review of Evidence. Personal Services Research Unit London School of Economics and Political Science

<https://www.mariecurie.org.uk/globalassets/media/documents/policy/campaigns/equity-palliative-care-uk-report-full-lse.pdf>

Kafetz (2002) suggested that the process of dying can be different in elderly people than young people; Cognitive dysfunction may affect their awareness. Also in relation to bereavement there is less likely to be a period 'anticipated bereavement' for the relative/carer as disease progression is less predictable. Greater awareness is required through training of impact of age and frailty amongst health and social care teams. Earlier access to hospice services would help to build relationships between patients and carers and the hospice and would also provide some support for carers.

<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC1279248/>

Kafetz, K: What happens when elderly people die? Journal of the Royal Society of Medicine, 2002

Older people are more likely to die in hospital or a nursing home than at home or in a hospice. [The Department of Health End of Life Equality Impact Assessment \(2008\)](#) suggested that an effective Electronic Palliative Care Co-ordination system should be in place to support preferred place of care and death. The assessment also found that for some recent immigrant groups, carers are more likely to have additional stress of visa

¹ Lewis et al, 2014 Social capital in a lower socioeconomic palliative care population: a qualitative investigation of individual, community and civic networks and relations

and housing issues - Health and social care staff should be more aware of this and services and pathways should be linked to support for these issues. The bereavement needs of people with learning disabilities are not always met by mainstream bereavement services - voluntary sector groups may have more expertise in this area and should be utilised as they may be able to offer a wider range of support.

<https://www.gov.uk/government/publications/end-of-life-care-strategy-promoting-high-quality-care-for-adults-at-the-end-of-their-life>

Gaffin et al. (1996) raised concern that hospices may not be supporting the cultural and religious beliefs of certain communities - Local Care Organisations should ensure that in managing contracts for hospices not only demographic data should be captured but hospices should demonstrate how they are adapting their care, and promoting themselves to BME groups. Hospice at Home services will address this gap as the service can go to the source and into people's own homes.

<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2149863/>

Gaffin, J; Hill, D; Penso, D: Opening doors: improving access to hospice and specialist palliative care services by member of the Black and Minority Ethnic Communities; Commentary on palliative care. National Council for Hospice and Specialist Palliative Care Services

Koffman et al. (2001) found that rituals and traditions of minority ethnic groups are important in death but can be ignored or unknown by health and social care professionals. Care Professionals and others such as coroners should be trained to deliver a culturally sensitive approach, particularly on faiths where burial within 24 hours is required.

<https://www.ncbi.nlm.nih.gov/pubmed/12054151>

Koffman, J; Higginson, I: Accounts of carers' satisfaction with healthcare at the end of life: a comparison of first generation black Caribbeans and white patient with advanced disease. Palliative Medicine, 2001

END OF LIFE CARE MODEL FEATURES

The following outlines the key features of an EoL care model with some considerations and outcomes to reduce inequality

Feature of End of Life model	Key Considerations
Care model provides support from terminal diagnosis and at least last 12 months of life.	This provides greater opportunity to discuss care planning and preferences, put in place support and understand the specific needs of the each individual – this should increase with opportunity to support more people with complex palliative care needs to die in their preferred place of care. Electronic Palliative Care Co-ordination should be in place.
Treatments delivered in the community, including IV antibiotics and biphosphonates, ultrasound.	A cohort of patients in Manchester will live in accommodation which is unsuitable for clinical interventions to take place; there is therefore a risk that these patients are unable to access community based

	<p>treatments. Must ensure that alternative settings in the community are identified.</p> <p>Heald Green and Little Hulton hospice sites have services currently established to deliver IV treatments including blood transfusions to outpatients.</p> <p>North Manchester patients can access a home IV therapy team who can deliver antibiotics at home and other facilities (i.e. blood transfusions and biphosphonates) in the near future.</p>
<p>Care coordination – a central coordination function bringing together all professional involved in each individual’s care. Multi- disciplinary meetings of relevant health and social care professions in the community hub.</p>	<p>Ensure translation services central to this function.</p> <p>Enables the development of a more enriched picture of each patient and their support network needs, through sharing information and identifying specific needs.</p>
<p>Specialist Support – Palliative Care Consultants, GPswSI (GP with Special Interest) and Advanced Nurse Practitioner or Consultant Nurses to provide clinical leadership and expertise across the pathway.</p>	<p>Electronic Palliative Care Coordination will be delivered through the Manchester Care Record.</p>
<p>24/7 support in the community. Specialist EoL support available 7 days a week, 8am to 8pm, with district nursing and other support available at all hours.</p> <p>24 hour helpline for professionals, patients and carers to contact which coordinates support and response</p>	<p>Sufficient MDT staff needed in the community for the seamless services.</p> <p>St Ann’s Hospice provides a 24/7 Out of Hours (OOH) specialist advice line across Greater Manchester. Spring Hill and Dr Kershaw’s Hospices also provide some OOH advice.</p>
<p>Use of and development of volunteers:</p> <ul style="list-style-type: none"> - Transport to and from appointment - Befriending for patients and carers - Supportive tasks such as dog-walking, gardening - Low-level bereavement support - Other 	<p>Provide befriending and low-level bereavement support. If recruited from a range of local communities, this can assist in ensuring service are culturally sensitive Risk that volunteers are not representative of the population that the model serves.</p> <p>Provide better access to transport for those without or unable to travel. Low car ownership in parts of Manchester.</p> <p>Learn from charities (Being There in Manchester) and hospice experience of recruiting and training volunteers.</p>

<p>Support to die in preferred place of are through night-sitting and development of hospice-type beds in community.</p> <p>Introduction of Assistant Practitioners to enable implementation of care plans and extended hours.</p>	<p>See references above to homelessness.</p> <p>If hospice-type beds are likely to be in nursing homes, ensure commissioning of specific, targeted training and education in place to consider and provide for all of the above equality factors.</p>
<p>Increase the proportion of deaths out of hospital and reduce unplanned admissions in the last 12 months of life.</p>	<p>Achieve through an effective MDT approach and care coordination in the community.</p> <p>Integrated information sharing with Ambulance Trust and OOH GP service essential.</p>
<p>Improve patient and carer experience and support for carers to improve outcomes for people approaching the end of life for carers after death.</p>	<p>For carers, death not only represents the loss of a family member, but can represent the loss of identity and purpose.</p> <p>Better identification of particular carer needs. Carers should be offered an assessment of their needs. The carer's strategy should be implemented and care tailored towards each patient, with consideration given to race, religion etc.</p>
<p>Improved psychological support – extended bereavement support, including contact beyond two weeks after death</p>	<p>Ensure this is culturally sensitive and appropriate depending on carer needs. Ensure bereavement services are available in the community and staff are trained in bereavement support.</p>

Consider further and on-going investment in Marie Curie model, with appropriate adaptation for Greater Manchester needs in order to support patients dying at home and prevent inappropriate admissions at the end of life with education and training for all staff.

<p>WHAT DO NEED TO DO TO ACHIEVE THIS?</p>
<p>NICE guidance on end of life care for adults NICE Guidance on end of life care for adults defines clinical best practice within this topic area. It provides specific, concise quality statements, measures and audience descriptors to provide the public, health and social care professionals, commissioners and service providers with definitions of high-quality care.</p> <p>This quality standard covers all settings and services in which care is provided by health and social care staff to all adults approaching the end of life. This includes adults who die suddenly or after a very brief illness. The quality standard does not cover condition-specific management and care, clinical management of specific physical symptoms or emergency planning and mass casualty incidents. The quality standards are as follows:</p>

1. People approaching the end of life are identified in a timely way.
2. 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.
3. 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.
4. 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.
5. 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 independence and social participation for as long as possible.
6. People approaching the end of life are offered spiritual and religious support appropriate to their needs and preferences.
7. 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.
8. 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.
9. 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.
10. 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.
11. 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.
12. The body of a person who has died is cared for in a culturally sensitive and dignified manner.
13. Families and carers of people who have died receive timely verification and certification of the death.
14. 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.
15. 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.

16. 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.

Amendments have been made to this quality standard following the independent review of the use of the Liverpool Care Pathway (LCP) for the Dying Patient, which reflect the phasing out of the LCP (2013).

In 2016, [plans](#) to ensure high quality, compassionate care for everyone at the end of life were announced by Health Minister Ben Gummer (<https://www.gov.uk/government/news/government-commits-to-high-quality-end-of-life-care>). As part of this, the government has made 6 commitments to the public to end variation in end of life care across the health system by 2020. These are:

- honest discussions between care professionals and dying people
- dying people making informed choices about their care
- personalised care plans for all
- the discussion of personalised care plans with care professionals
- the involvement of family and carers in dying people's care
- a main contact so dying people know who to contact at any time of day

The Vision for End of Life Care In Manchester

The vision for Manchester is for all patients and their carers across the city to have 24/7 equitable access to high quality, consistent and supportive, palliative and end of life care when they need it, with accurate identification and proactive management of all their palliative care needs: physical, social, psychological and cultural.

The Living Longer Living Better (LLLBB) End of Life Care Model has been produced by Manchester Commissioners. The care model fits with the North West End of Life Care Model and describes the offer, outcomes, measures and standards for people in their last year of life. This model has been placed in the One Team approach to local integrated care and will be delivered by the Local Care Organisation. Care integration should be seamless, so for example separate health services must be working in a fully integrated way before progressing to wider multi agency integration.

To summarise, the vision for Manchester should be delivered by:

1. **Co-ordinated care and integrated** services with effective communication between teams, and use of enhanced neighbourhood teams, as per the Living Longer Living Better End of Life Care model.
2. Effective and timely **identification of patients** who would benefit from supportive care.
3. Care planning based on the needs and wishes of those patients at the end of their lives, and the people close to them i.e. the **Right Person** getting the **Right Care** in the **Right Place** at the **Right Time** and **Every Time**.
4. Providing and delivering **choice of the type of care** they would like to receive where possible.
5. **Support for carers** and family members during the end of life and bereavement.

The new **Manchester Care Record (MCR)** will allow effective communication and care co-ordination for the one team model so people can be supported in their preferred place of care and when in their last days of life. The MCR was endorsed by the Health and Wellbeing Board in July 2016. This obliges all organisations to commit to the MCR as the best appraised system allowing faster progress on care co-ordination.

Manchester's Priority Areas for End of Life Care for 2017/18 and onwards are:

- 1 Embedding the **5 priorities of care** that replaced the Liverpool Care Pathway (LCP)
- 2 Developing city-wide **7 day services** based on the North Manchester model. This should include therapists and community based Consultant
- 3 Maintain and extend a **care home team** to cover the City
- 4 Expand the **district nursing** resource to support end of life care at home
- 5 Implement on-going **training for care home staff**
- 6 **Care home staff** should have satisfactory terms of employment and career opportunities to reduce staff turnover
- 7 Have in place sufficient local and specialist 24 hour bed based provision for **respite care** needs and the last weeks and days of life
- 8 Ensure effective and **culturally sensitive** procedures are in place following death
- 9 Enhancement of the **24 hour helpline provision** across Greater Manchester
- 10 **Single point of access** for end of life care services (LLL, EoL care model)
- 11 Development of palliative care **Lymphoedema model** and specialist care in community, as part of the Greater Manchester Priority Programme
- 12 Expansion of domiciliary **Complementary Therapy** to across the city, for patients and main carers
- 13 Substantive posts for cancer and **end of life care Facilitators**
- 14 **Electronic Palliative Care Co-ordination** System rolled out and used effectively
- 15 Development of **hospice style beds in the community** in partnership with Hospice services
- 16 Consideration of commissioning a **Hospice at Home** model
- 17 **Education and Training** of healthcare professionals: Consider further and on-going investment in Marie Curie model, with appropriate adaptation for Greater Manchester needs, to support patients dying at home and prevent inappropriate admissions at the end of life with education and training for all staff

WHAT ARE WE CURRENTLY DOING?

End of Life Care services

There is no hospice geographically located within Manchester and access to hospice care for Manchester patients can depend on availability. Inpatient and day hospice care for Manchester is commissioned from St Ann's Hospice sites at Heald Green and Little Hulton, Dr Kershaw's at Oldham and Springhill Hospice Rochdale.

The table below lists some of the key services (local or citywide) that are available to support patients in their last year of life.

Acute Specialist Palliative Care	Community Specialist Palliative
<ul style="list-style-type: none">• Macmillan/specialist palliative care team (7day)• Consultant in Palliative Medicine• Complex discharge team• Macmillan Benefits Advisor• Bereavement centre / team• Spiritual care team• Specialist Palliative Care Outpatient Clinic	<ul style="list-style-type: none">• District nursing 24 hour service• Therapy services• Community Macmillan team• Active Case Management (Long Term Conditions)• Community IV Therapy• Care Home Support Team• Marie Curie Night Service• CCG Funded Nursing Care /Continuing Health Care• Hospice 24 hour telephone advice line for patients, carers and health professionals• Hospice in-patient and Outpatient Services

A fast track discharge process from hospital is in place for end of life patients to be considered for Continuing Healthcare Funding so they can be discharged to their preferred place of care / death in their last days of life.

Care Homes

Life expectancy for care home residents has been estimated as averaging between 8 months and two years. They experience a high number of A&E attendances and admissions, a lot of which are avoidable. Their needs are often complex with multiple morbidities and many will suffer from a degree of dementia. There can be a high turnover of staff that may be underpaid and insufficiently resourced for the challenges they face in providing 24 hour care.

Training for care home staff is critical to achieving good quality EoL care. The [Six Steps to Success](#) is a North West EoL care programme for care homes, delivered through 8 workshops. Each workshop is aligned to the North West End of Life Care Model.

Central Manchester Care Homes Team

The care home team in Central Manchester is a project commissioned through Better Care Funding to ensure that frail, older people with non-cancer diagnoses have access to the right services. The team comprises a GP led specialist community nursing service that provides responsive and timely health provisions for patients living in nursing and residential care homes.

The service provides a single point of coordination for the delivery of health care, including multi-disciplinary assessments to meet the needs of care home patients registered and living in a Central Manchester care home.

The project has delivered training to care home staff to enable them to be more confident in discussing people's preferred place of death and advance care planning, and in dealing with a crisis more effectively. As a result, **admissions to hospital have reduced by 68%**.

North Manchester Community Palliative Care Model

As part of the MacMillan Cancer Improvement Programme (MCIP) in Manchester, a pilot project was launched in North Manchester in April 2015. This includes a new **community-based hub** through which all palliative care is coordinated. The model is based on the principles of the Midhurst Model and built upon the existing Community Macmillan services. Benefits include:

- Operating 7 days a week 8am – 8pm with support from Nurses, Therapists and Assistant Practitioners
- Multidisciplinary team that crosscuts multiple providers with a coordinated approach, promoting high quality care.
- Daily Triage to ensure quicker response times
- Daily MDT Meetings with the palliative care team and District Nurses
- Weekly MDT attended by community and hospital teams
- Treatment closer to home
- One point of contact for patient & carers
- 24 hour helpline linked to St Ann's Hospice

The hub is led by a Community Consultant in Palliative Care, with support from a GP with Special Interest (GPwSIs) in Palliative Care and a hospital-based Consultant in Palliative Medicine, and is situated in a building based in the community. This acts as both staff headquarters and referral centre for staff and patients involved in end of life care. Community clinics are also run from the base including Lymphoedema, Dietetics, Physiotherapy, Occupational Therapy and Speech and Language Therapy. **This service was commended as outstanding by a CQC inspection in 2015 /16.**

OPPORTUNITIES FOR ACTION

The Wider Vision for Health and Social Care In Manchester

The Greater Manchester Strategic Plan describes the importance of aligning health and social care reform. The Manchester Locality Plan is the commissioning plan for joining up – or integrating - health and social care services in Manchester which are affordable and sustainable.

A single Hospital service merging the three Hospital Trusts in North, Central and South Manchester will be commissioned by a single commissioning organisation integrating City Council and the Clinical Commissioning Group (CCG) commissioners.

Integrated care local to home - One Team/Place Based Care

Opportunities for Manchester exist in the commissioning of new organisations under the One Team / Place Based Care model.

In the future care will be organised through a **One Team** approach around the place in which people live. Care will be joined up with different health and social care professionals working together and focused in the community, to keep people well enough not to need reactive and expensive hospital or long term social care. In Central Manchester, generic palliative care is a core function of district nursing services which are located in neighbourhoods and Macmillan nursing team members are aligned to one of four neighbourhood teams.

A Local Care Organisation (LCO) will be commissioned for the population of Manchester bringing together a range of services delivered in the community. The LCO will ensure services meet the needs of the local population by:

- Delivering care at a neighbourhood level, at home or in a community setting
- Delivering integrated community services in local places
- Aligning hospital and community based services, so they are integrated and accessible

The outcome will mean less pressure on permanent admissions into residential/nursing care and less people needing hospital based care.

The new **Manchester Care Record (MCR)** will allow effective communication and care co-ordination for the one team model so people can be supported in their preferred place of care and when in their last days of life. The MCR was endorsed by the Health & Wellbeing Board in July 2016. This obliges all organisations to commit to the MCR as the best appraised system allowing faster progress on care co-ordination.

REFERENCES AND LINKS

CQC national themed review of Inequalities in End of Life care

<http://www.cqc.org.uk/content/different-ending-end-life-care-review>.

DH National End of Life Care Strategy (2008)

https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/136431/End_of_life_strategy.pdf

DH guidance on EoL care for Transgender and Transsexual people

<http://www.gires.org.uk/assets/DOH-Assets/pdf/doh-bereavement.pdf>

Enhanced Health in Care Homes

<https://www.england.nhs.uk/wp-content/uploads/2016/09/ehch-framework-v2.pdf>

Gov.uk

<https://www.gov.uk/government/news/government-commits-to-high-quality-end-of-life-care>

Leadership Alliance for the Care of Dying People

https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/323188/One_chance_to_get_it_right.pdf

Lewis J et al, 2014: Social capital in a lower socioeconomic palliative care population: a qualitative investigation of individual, community and civic networks and relations

<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4067081/>

NICE standards for EoL care

<https://www.nice.org.uk/guidance/service-delivery--organisation-and-staffing/end-of-life-care>
<https://www.nice.org.uk/guidance/qs13/chapter/List-of-statements>

ONS: National Survey of Bereaved People (2015)

<https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/healthcaresystem/bulletins/nationalsurveyofbereavedpeople/voices/england2015#quality-of-care-by-deprivation>

Public Health England: Public Perceptions and Experiences of Community-Based End of Life Care Initiatives: A Qualitative Research Report

https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/569711/Public_Perceptions_of_Community_Based_End_of_Life_Care_Initiatives_Research_Report.pdf

Public Perceptions and Experiences of Community-Based End of Life Care Initiatives: A Qualitative Research Report

Research and analysis: End of life care: research into community-based initiatives

The Six Steps to Success programme for Care Homes

http://www.endoflifecumbriaandlancashire.org.uk/six_steps/usefull_links_steps.php

Summary of the Midhurst Macmillan Community Specialist Palliative Care Service

[http://www.macmillan.org.uk/Documents/AboutUs/Research/Researchandevaluationreports/MidhurstSummary\(2\).pdf](http://www.macmillan.org.uk/Documents/AboutUs/Research/Researchandevaluationreports/MidhurstSummary(2).pdf)

OTHER RELATED JSNA TOPICS

[Manchester Joint Strategic Needs Assessment](#)

http://www.manchester.gov.uk/info/500230/joint_strategic_needs_assessment

includes related topics on

- [Adults with Complex Lives](#)
- [Respiratory Disease](#)

Date: February 2017

It is hoped that you have found this topic paper useful. If you have any comments, suggestions or have found the contents particularly helpful in your work, it would be great to hear from you.

Responses can be sent to jsna@manchester.gov.uk

Appendix: Summary of evidence of inequalities in end of life care

AGE / DEMEMENTIA / LONG TERM CONDITIONS			
Evidence	Group affected	Findings	Recommended local service solution
Dixon et al ²	Propensity for those of 80, with dementia or receiving treatment for disease management to have their pain management needs under-estimated by clinicians		Education Structured tool for pain assessment
AGED GROUPS			
Evidence	Findings		Recommended local service solution
Kalman Kafetz ³ in DH End of Life Equality Analysis	Process of dying can be different in elderly people than young people; cognitive dysfunction may affect their awareness. Also in relation to bereavement there is less likely to be a period of 'anticipated bereavement' for the relative/carer as disease progression less predictable.		Greater awareness through training of impact of age and frailty amongst health and social care team. Earlier access to hospice services to build relationships in the months over patients decline, this can also provide a support for carers.
DH End of Life equality analysis	Older people more likely to die in hospital or nursing home than at home or in a hospice.		An Effective Electronic Palliative Care Co-ordination system should be in place to support preferred place of care and death.
BME GROUPS			
Evidence	Findings		Recommended local service solution
Dixon et al	People from BME groups less likely to view the care in their last three months of life as highly as non BME groups, however they did have the data to suggest why.		Require more work to understand why.
DH End of life equality impact assessment	For some recent immigrant groups, carers are more likely to have additional stress of visa and housing issues.		Health and social care staff should be more aware of this and services and pathways should be linked to support for these issues.

² Equity in the Provision of Palliative Care in the UK: Review of Evidence Josie Dixon, Derek King, Tihana Matosevic, Michael Clare and Martin Knapp Personal Services Research Unit London School of Economics and Political Science

³ Kafetz K What happens when elderly people die? Journal of the Royal Society of Medicine, 2002

Gaffin et al ⁴	Hospices not specifically addressing cultural and religious beliefs of certain communities.	Any Local Care Organisations should ensure that in managing contracts for hospices, not only demographic data should be captured but hospices should demonstrate how they are adapting their care, and promoting themselves to BME groups. Hospice at Home services will address this gap as the service can go to the source and into people's own homes.
Koffman et al, 2001 ⁵	Rituals and traditions of minority ethnic groups are important in death but can be ignored or unknown by health and social care professionals.	Care Professionals and others such as coroners should be trained to deliver a culturally sensitive approach, particularly towards faiths where burial within 24 hours is required.

PALLIATIVE PATIENTS WITH NON-MALIGNANT DISEASE

Evidence	Findings	Recommended local service solution
Dixon et al ⁶	Other non-cancer deaths increasing in hospice care, but still relatively low compared to cancer patients, and prevalence of non-malignant disease.	Importance of links and integration with specialist teams (eg St Anne's Hospice has good links with the Heart Failure team increasing interaction)
Murray S, 2006 ⁷	COPD Experience for patients with COPD had a differential experience to those with end of life lung cancer – worse quality of life, reduced activity, higher levels of anxiety and depression and more likely to die in hospital.	Importance of hospices commissioned to deliver palliative care support regardless of condition. Palliative care registers should reflect all incurable diseases. Palliative Care registers should be regularly audited appropriately populated.

⁴ Gaffin J, Hill D, Penso D – Opening doors: improving access to hospice and specialist palliative care services by member of the Black and Minority Ethnic Communities; Commentary on palliative care. National Council for Hospice and Specialist Palliative Care Services

⁵ Koffman J, Higginson I, Accounts of carers' satisfaction with healthcare at the end of life: a comparison of first generation black Caribbean's and white patients with advanced disease. Palliative Medicine, 2001

⁶ The changing demographics of inpatient hospice death: Population-based cross sectional study in England, 1993-2012 Katherine E Sleeman¹, Joanna M Davies¹, Julia Verne², Wei Gao¹ and Irene Higginson.

⁷ Murray S, Palliative care for people with COPD: we need to meet the challenge, Primary Care Respiratory Journal

<p>DH End of Life Equality Impact Assessment</p>	<p>Motor Neurone Disease, and carers in general Carers of patients with MND may have need for respite support much sooner in the palliative care pathway than cancer patients. Hospices are also less prepared for this group, and could be less willing to offer beds when funding is mainly received from cancer charities.</p> <p>While MS is not a terminal condition, the symptoms of the disease can make it difficult for the patient to communicate their needs.</p> <p>DH consultation found the importance of ensuring that patients with end stage renal disease are included on palliative care registers.</p>	<p>There is a monthly specialised joint Neurology and MND running in collaboration with SRFT developed at Heald Green hospice (commenced September 2016)</p> <p>EoL Facilitators can assist with Palliative register audit and practice compliance.</p>
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PEOPLE IN CARE HOMES

Evidence	Findings	Recommended local service solution
	<p>People in care home may have a life expectancy of about eight months. They are frequently conveyed to A&E unnecessarily and often admitted and are risk of dying in hospital shortly after admission.</p>	<p>Mandatory and on-going training for all care home staff. Ensure the six steps or Gold Standard Framework educational programme is completed by all care homes and annually reviewed.</p>

PEOPLE IN PRISONS

Evidence	Findings	Recommended local service solution
<p>Macmillan</p>	<p>Most common causes of death, through natural causes, in prison is cancer and heart attacks.</p> <p>Macmillan refer to research which shows limited knowledge of end of life care in prison health staff, and limited knowledge of prisoner needs amongst health staff.</p>	<p>Districted nursing and other health teams in Manchester support prisoners in Manchester prison.</p>

LEARNING DISABILITIES

Evidence	Findings	Recommended local service solution
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Stein ⁸	Professional education is a critical component to improving end-of-life care and promoting better informed medical decisions for people with intellectual disabilities. Frequently, health care professionals (physicians, social workers, nurses, clergy and others), including hospice and palliative care staff, lack training on the special needs of people with intellectual disabilities and on methods to assess their decisional capacity.	Ensure education and training covers emotional and physical needs of different patient groups, include those with learning disabilities.
Tuffrey-Wijne I, et al ⁹	Factors affecting palliative care provision for people with intellectual disabilities include social issues (home situation and family issues), emotional and cognitive issues (fear, patient understanding, communication, cooperation and capacity to consent) problems with assessment and the impact on staff and other patients. An underlying theme is the need to take more time and to build trust.	Hospice teams can include onsite social workers who deliver specialised safeguarding training and expert care. These should be supported by rigorous policies to ensure individual and specialist needs of all patients are prioritised.
Mencap ¹⁰	People with learning disabilities pain management needs may not be understood and expressed by them, resulting in delays or denial of treatment.	
DH Equality Impact Assessment	The bereavement needs of people with learning disabilities are not always met by mainstream bereavement services.	Ensure bereavement services are cognisant of the needs of people with learning disabilities. Utilise voluntary sector groups who may have more expertise and a wider range of support.
GENDER		
Evidence	Findings	Recommended local service solution
Grande G et al ¹¹	Women are less likely to die at home than men and men are less efficient carers.	Women may be more likely to need more support in place including night sittings. Training and

⁸ Stein G. Providing Palliative Care to People with Intellectual Disabilities: Services, Staff Knowledge, and Challenges. *Journal of palliative medicine*

⁹ Tuffrey-Wijne I, et al. Palliative care provision for people with intellectual disabilities: interviews with specialist palliative care professionals in London. *J Nurs Manag.* 2007 Oct; 15(7):700-2

¹⁰ Mencap, *Death by indifference*, 2007

¹¹ Grande G, Addinton-Hall J, Todd C. Place of death and access to home care services: are certain patient groups at a disadvantage? *Social Science and Medicine* 1998

		support should be available for all carers involved in EoL care.
GYPSIES AND TRAVELLERS		
Evidence	Findings	Recommended local service solution
Jesper et al, 2008 ¹²	<p>The needs of terminally ill Gypsies and Travellers are being overlooked by hospitals and GPs, according to research carried out by Jesper. None of the people interviewed in the study (regardless of accommodation status) were able to use palliative care services for their family members.</p> <p>The reasons included pride in caring for a person at home, clashes with medical staff over large numbers of visitors, and limited knowledge of the services available. Enforced mobility reduced access to GPs and made it difficult to organise programmes of palliative care to support Gypsies and Travellers who wished to die at home.</p>	A flexible approach is required to accommodate harder to reach communities.
SEXUAL ORIENTATION		
Evidence	Findings	Recommended local service solution
Age Concern, 2006 ¹³ Marie Curie ¹⁴	<p>The impact of older peoples' sexual orientation can be ignored as they are considered not to be sexually active anymore, though their sexual preference remains despite not being sexually active.</p> <ul style="list-style-type: none"> - LGBT may not access services or may delay accessing them as they assume discrimination - LGBT peoples' spiritual needs may not be given the same attention as other patients 	<p>People's sexual orientation with consent should be recorded and considered in any assessment given, and care provided if there are needs not addressed.</p> <p>There should be active engagement with The LGBT community by EoL care services.</p>

¹² Jesper et al. A qualitative study of the health experience of Gypsy and Travellers in the UK with a focus on terminal illness, Warwick University, 2008

¹³ Age Concern, The whole of me ... Meeting the needs of older lesbians, gay men and bisexuals living in care homes and extra care housing, 2006

¹⁴ Marie Curie, What are the issues? "hiding who I am" the reality of end of life care for LGBT people, June 2016

	<ul style="list-style-type: none"> - Support networks for LGBT people may be quite different, with support networks created outside of biological family. Professionals may not give these loved ones the same acknowledgement. - Bereaved partners may feel more isolated and unsupported - Increased pressure on carers as they are more likely to be accessing EoL care late 	
TRANSSEXUAL AND TRANSGENDER PEOPLE		
Evidence	Findings	Recommended local service solution
DH Equality Impact Assessment	Due to previous experience of prejudice, transsexual and transgender people are likely to conceal their identity and, in death, their friends and relatives may also conceal the deceased's status.	Recommend professionals consult the Department of Health, Bereavement: A Guide for Transsexual, Transgender people and their loved ones.
HOMELESS		
Evidence	Findings	Recommended local service solution
DH End of Life Care Strategy	Homeless Homeless peoples' behaviour or lifestyle can be difficult to reconcile with a hospice environment. Some prefer to remain in a setting such as a shelter and resist admission to a hospice which can result in receiving no treatment.	Recommendation to work with homeless shelters to support people who wish to die here. Specialist advice should be sourced from the Manchester MPATH service.
LANGUAGE		
Evidence	Findings	Recommended local service solution
Marie Curie	<p>The Marie Curie Cancer Care launched a pilot project Key Trends in 22006 (Delivering Choice Programme) which aimed to improve palliative care access to BME groups through the appointment of a link worker.</p> <p>The programme identified that interpreters felt they did not know enough about EoL care and needed support, particularly after delivering bad news and in discussing preferences fro where</p>	Training in End of Life care should be provided and be available to key workers who may have a role in EoL care.

	people wanted to be cared for and die.	
RELIGION		
Evidence	Findings	Recommended local service solution
DH End of Life Equality Analysis	<p>Different religious beliefs and rituals should be considered not only during EoL care but also at death. Human body is sacred to some religions and therefore a post mortem is unacceptable.</p> <p>There are different religious needs which professionals need to be aware such as cleaning of the body, not leaving the body alone etc.</p> <p>Chaplaincy services are sometimes restricted to the Christian faith and do not include others.</p>	<p>Restrict post mortems to cases where MRI scanning cannot achieve required results.</p> <p>Ensure multi-faith chaplaincy services exist and are actively involved in the EoL pathway, not just hospital based.</p> <p>Primary care (the GP) and care home staff should be knowledgeable of these different religious needs and their role in identifying and supporting them.</p>