

Last Years of Life: *Factsheet*

Tower Hamlets Joint Strategic Needs Assessment

UPDATED 2015/6

QUARTER 4

Executive Summary

- “Ambitions for Palliative and End of Life Care, a national framework for local action” brings together a range of previously published guidance into six priority ambitions, which aim to achieve high quality care for all people nearing the end of life, and their families and carers.
- In Tower Hamlets the term “last years of life” has been adopted to describe the period preceding death, recognising that this time may be days, weeks, months and even years for different people.
- Effective interventions to improve the experience of care in last years of life are
 - Person centred integrated care, which includes carers and families
 - Being able to express preferences about care and place of death
 - Identifying and meeting palliative needs early
 - Improving the experience of hospital care in last years of life
 - Access to Specialist Palliative Care
 - Training and education for health and social care staff
 - Reducing inequalities in access and experience
 - Community approaches to Last Years of Life and “healthy dying”
- There are around 1,000 deaths each year in Tower Hamlets, with a lower proportion of deaths in older people, compared to the national average, reflecting the young age profile and reduced life expectancy. Around two thirds of people who die were born in the UK and Ireland, and 14% were born in Bangladesh.
- Significantly more Tower Hamlets deaths occur in hospital (59%) compared to the national average of 47%. Significantly fewer deaths occur in care homes (7%) compared to the national average of 22%, and more in a hospice (10% compared to 6% nationally).
- The proportion of people with palliative care need, which has been identified by Tower Hamlets GPs is higher than the England average of 37% and increased from just over a third in 2010/11 to almost half (48.38%) in 2012/13. However not all people identified have their preferences recorded; an audit in 2013/4 showed that only a fifth of care plans for people receiving integrated care included a ‘crisis plan.’
- Bereaved carers in Tower Hamlets are less likely to rate the care given to their relative during their last months of life as high quality, compared to England averages. However very low survey response rates make it difficult to assess specific areas of need and of good practice, and local solutions for feedback from service users are needed.
- Hospice service use reflects the ethnic profile of Tower Hamlets residents who die each year. There appears to be greater use of hospice services by people with conditions other than cancer compared to national rates.
- A range of interventions which aim to improve access to last years of life services and improve patient and carer experience have been introduced as part of the Tower Hamlets Integrated Care Programme. These include multi-disciplinary training in palliative care as well as generic care planning and navigation, shared records, crisis planning and rapid access. Evaluation measures will assess their impact.

Recommendations

Person centred integrated care

- Integrated care for people in their last years of life should include personalised care planning, care navigation, shared records, 24/7 rapid response, and discharge planning on admission to hospital
- Integrated care evaluation needs to consider information about the pathways of care received by people who have since died, and proportion/demographic data for people whose preferences were recorded and met
- Strengthen partnership working and communication between all service providers, people and their carers
- Ensure high quality and accessible support for carers and families, including bereavement care
- Assess the need for increased care home accommodation in the borough

Identifying palliative needs early and meeting people's preferences about care

- Training for all health and social care staff in having difficult conversations, to enable preferences to be met

Training and education

- Training in Last Years of Life care with support from specialist palliative care for all health and social care staff including care homes
- Ensure that all staff are trained in listening to and understanding the person, and in understanding their own role and the role of other workers

Improving the experience of hospital care in the last years of life

- Review of hospital specialist palliative care; assess how 'hospice in hospital' function can be achieved

Community approaches to Last Years of Life and "healthy dying"

- Extend 'compassionate community' approaches to engaging local people in discussion, support and planning for last years of life

Reducing inequalities in access

- Extend the equity audit of specialist palliative care services to include other services for last years of life
- Review the care pathways for groups less likely to experience high quality care e.g. people with learning disabilities, people who are homeless, people who misuse drugs and alcohol and people with certain conditions such as HIV.
- Engage with and provide training and support for staff in services which work with these groups
- Ensure training and support for staff, families and carers in meeting the needs of people with dementia

Improving experience of last years of life care to meet the expressed needs of people and their carers

- Ensure that health and social care services record carers' details and seek and respond to their views.
- Work with partners to introduce or modify services in line with findings of the 2015 local VOICES survey of bereaved carers, building on areas of good practice and addressing areas where improvement is needed.
- Work with stakeholders, including community partners to identify how best to consult regularly about experiences of last years of life care, so that local people's voices can routinely shape the way services are delivered.

1. What is care in the last years of life?

“How we care for the dying is an indicator of how we care for all sick and vulnerable people. It is a measure of society as a whole and it is a litmus test for health and social care services”¹.

In Tower Hamlets the term “last years of life” has been adopted to describe the period preceding death, recognising that this time may be days, weeks, months and even years for different people. Nationally the term ‘end of life care’ continues to be used to describe care in the last 12 months of life, acknowledging that many people are living longer with multiple long term conditions and frailty, and that care in “the last years of life” better describes their needs.

Changing the terminology to “last years of life” aims to help health and social care service providers to respond early to the care needs of patients and their families, when they are better able to express their preferences about the type and place of care and death, and when care can be tailored to their changing needs.

Last years of life care includes palliative care - an approach to care that is life-enabling and prioritises comfort and quality of life. Palliative care has often been used synonymously with ‘end of life care’ since it developed as a clinical specialty in the 1960s in response to managing the complex symptoms of advanced cancer. It is defined by the World Health Organisation as “an approach that improves the quality of life of patients and their families facing the problems 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.” The appropriateness of a palliative approach to care should be based on the person’s needs, not just on diagnosis or life expectancy.

2. What is the policy context?

National policy

Ambitions for Palliative and End of Life Care, a national framework for local action² builds on the 2008 End of life Care Strategy¹. It was developed by a partnership of 27 stakeholder groups, including health and social care organisations, patients and the public.

The new framework brings together a range of previously published guidance into 6 priority ambitions, which aim to achieve personalised, integrated high quality care for all people nearing the end of life, and their families and carers. The ambitions’ overarching vision is that “I can make the last stage of my life as good as possible because everyone works together confidently, honestly and consistently to help me and the people who are important to me, including my carer(s).”³

Figure 1. Ambitions to achieve the vision



¹ Department of Health 2008 End of life care strategy: promoting high quality care for all adults at the end of life

² Ambitions for Palliative and End of Life Care: A national framework for local action 2015-2020

³ ‘Every Moment Counts’ National Voices, National Council for Palliative Care and NHS England

Because most people when offered a choice would prefer to die at home, increasing the proportion of deaths in “usual place of residence” (DiUPR) is used a proxy measure of progress towards achieving strategic aims of choice and personalisation. In 2014, NHS England recognised that the 2008 strategy has reversed the upward trend of people dying in hospital, and that “we now need to ensure that living and dying well is the focus of end of life care, wherever it occurs⁴.”

The ambitions in the national framework are dependent on 8 ‘foundations’ (figure 2) with subsidiary ‘building blocks’ which contribute to the overarching ambitions⁵.

Figure 2. Eight foundations for ambitions for palliative and end of life care

Personalised care planning

Everybody approaching the end of their life should be offered the chance to create a personalised care plan. Opportunities for informed discussion and planning should be universal. Such conversations must be ongoing with options regularly reviewed.

Shared records

To ensure the plan can guide a person centred approach it has to be available to the person and, with their consent, be shared with all those who may be involved in their care

Evidence and information

Comprehensive and robust data are necessary to measure the extent to which the outcomes that matter to the person are being achieved. This, alongside strengthening the evidence-base, will help to drive service improvements.

Involving, supporting and caring for those important to the dying person

Families, friends, carers and those important to the dying person must be offered care and support. They may be an important part of the person’s caring team, if they and the dying person wish them to be regarded in that way. They are also individuals who are facing loss and grief themselves.

Education and training

It is vital that every locality and every profession has a framework for their education, training and continuing professional development to achieve and maintain competence and allow expertise and professionalism to flourish.

24/7 access

When we talk about end of life care we have to talk about access to 24/7 services as needed, as a matter of course. The distress of uncontrolled pain and symptoms cannot wait for ‘opening hours.’

Co-design

End of life care is best designed in collaboration with people who have personal and professional experience of care needs as people die.

Leadership

The leadership of Health and Wellbeing Boards, CCGs and Local Authorities are needed to create the circumstances necessary for action. Clinical leadership must be at the heart of individual service providers

⁴ NHS England 2014 Actions for the End of Life Care 2014-6

⁵ <http://endoflifecareambitions.org.uk/wp-content/uploads/2015/09/A-Presentation-of-the-Ambitions-for-Palliative-and-End-of-Life-Care1.pdf>

London policy

The Pan-London End of Life Care Alliance of health and social care providers, voluntary sector and lay representation has identified high impact interventions to improve the experience of care⁶. These include:

- Engagement of patients in holistic planning, which takes account of individual's needs and preferences
- Individual care plans are recorded, communicated and acted upon
- Equity of access across geographical boundaries for cancer and non-cancer patients, with a focus on marginalised, vulnerable and excluded groups (e.g. people who are homeless, LGBT, misuse substances)
- Support and empowerment by trained professionals able to meet the physical, social and emotional needs of patients and carers;
 - GPs able to identify early, and have sensitive discussions with patients in their last years of life
 - staff who are able to meet individual care needs of patients, including in care homes
- Holistic support and empowerment of carers
- Access to 24-hour responsive out of hospital care
- A supportive community which talks openly about death and end of life
- Reducing social isolation of people who are dying through networks of community support
- Recruitment of compassionate staff who are employed in a supportive management structure
- Continuity and joined-up care with good communication between services
- Pharmacy services are able to meet the needs of patients

Local policy

Tower Hamlets Health and Wellbeing Strategy 2013-16 includes the aspiration that more residents are supported to choose where they are cared for and their place of death, as a measure of choice and quality of care in their last years.

Tower Hamlets Clinical Commissioning Group strategic vision is to improve care in the last years of life through

- Equitable access to dignified care, independent of diagnosis, age or ethnicity
- Integration with shared records across statutory and voluntary sector health and social care, including hospice community and in-patient services
- A strong primary care system to support people in the community
- "Goals of care" which are transparent and individually negotiated, and include social participation
- Dignified care - control and choice about place of death, symptom relief and when treatment is stopped
- Support for carers and families
- Access to care 24 hours a day, 7 days a week, 365 days a year
- Access to specialist palliative care
- 'Healthy Dying' promoting health in the face of death and enabling age-friendly communities

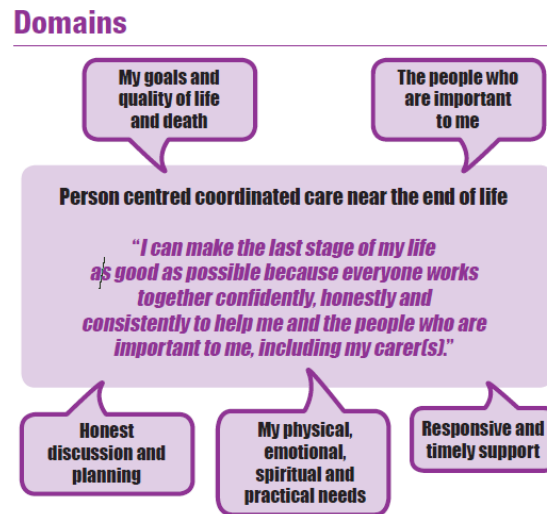
⁶ Pan-London End of Life Care Alliance (2014): actions to improve experience of care

3. What are the effective interventions?

(i) Person-centred integrated care

- Every Moment Counts³, the narrative for person-centred coordinated care, bases its recommendations on the experience of bereaved carers and published evidence. It identifies five domains enabling the last stage of life to be “as good as possible because everyone works together confidently, honestly and consistently to help me and the people who are important to me, including my carers.” Each domain lists a series of standards expressed through the eyes of the dying person (figure 3).

Figure 3. Every Moment Counts



Source: National Voices, the National Council for Palliative Care, NHS England 2015

- The number of deaths in people aged 85 and over, and in people with more than one long term condition is increasing nationally. These groups have a greater likelihood of frailty and multi-morbidities, in particular dementia, conditions which may extend over months or years with gradual deterioration and increasing needs.
 - This has implications for health and social care services in providing holistic person-centered integrated care which meets people’s needs, avoids focusing only on treatment for specific diseases (with multiple medication and appointment schedules) , avoids unplanned and unnecessary hospital admissions, and enables people to discuss their preferences while they are able to make informed choices, so that this can be recorded, shared appropriately and acted upon.
- #### (ii) Expressing preferences about care and place of death
- Meeting people’s preferences for care and place of death is an important measure of the quality of end of life care. While most people, when asked, state that they prefer to die at home there is variation in this and it should be recognised that people’s preferences may change over time and depend on their experience. For example, people who have experience of hospice care are more likely to choose a hospice as their preferred place of death.
 - An advance statement is a written statement that sets down preferences, wishes, beliefs and values regarding future care⁷. It aims to guide anyone who might have to make decisions in someone’s best interest if they have lost the capacity to do so themselves, or to communicate them. Although not legally binding, anyone who is making decisions about another person’s care must take it into account.

⁷ <http://www.ncpc.org.uk/sites/default/files/AdvanceCarePlanning.pdf>

- An advance decision (also known as a living will, or advance decision to refuse treatment) is a decision to refuse specific treatments in the future. An advance decision is legally binding, as long as it meets the necessary criteria for it to be considered valid and applicable. This includes the decision not to resuscitate (Do Not Resuscitate /DNR). In Tower Hamlets this terminology is being replaced with “allow natural death.”
- Electronic palliative care co-ordination systems (EPaCCS) provide the facility to assess whether people’s preferences for place of care are met. ‘Co-ordinate My Care’ is a system in London which links primary care records for people in last years of life with the London Ambulance Service, who are then better able to respond appropriately to peoples’ preferences in a crisis.

(iii) **Identifying and meeting palliative needs early**

- Not all deaths are expected, however evidence suggests that care can be planned for around 75% of people who die each year from causes which ultimately result in death⁸.
- The Quality Outcomes Framework (QOF) is a voluntary scheme which rewards General Practice for 'quality care' and helps to fund further improvements in the delivery of clinical care. Relevant QOF standards are for GPs to maintain registers of people whose death may be anticipated and to conduct multi-disciplinary reviews of people on the register in order to provide appropriate care. Nationally, around a quarter of people with palliative care need are identified by primary care.
- The proportion of GPs reporting they had never initiated a conversation with a patient about their end of life wishes fell from more than a third (35%) in 2012 to a quarter (25%) in 2014, showing improvement.
- There is evidence to support the benefits of systematic evidence-based approaches, such as the Gold Standard Framework (GSF) to improve end of life care through earlier identification, more person-centred assessment and effective care planning for people with end stage renal disease, chronic heart failure and chronic obstructive pulmonary disease. GSF accredited organisations reduce their proportion of deaths in hospital and support more people to die in the place of their choosing⁹ for example:
 - following GSF accreditation care homes have reduced hospital deaths by two thirds
 - in primary care, GSF accredited practices the proportion of people dying in their preferred place of care increased from 43% to 72% and in some case studies hospital deaths have halved.

(iv) **Improving the experience of hospital care in last years of life**

- National surveys show that less than 5% of people wish to be cared for at the end of their life and to die in hospital. Although some people change their minds nearer the time of death, being part of planning is an important aspect of quality.
- In reality, during the last year of life people in England tend to have multiple hospital stays, often following emergency admission. Hospital remains the most common place of death, and in almost 90% of cases, this follows an emergency admission with an average length of stay in hospital of 13 days¹⁰.

⁸ Murtagh FEM, Bausewein C, Verne J, Groeneveld EI. How many people need palliative care? A study developing and comparing methods for population-based estimates Palliat Med <http://pmj.sagepub.com/content/early/2013/05/20/0269216313489367.abstract>

⁹ www.goldstandardsframework.org.uk/ cited in PHE National End of Life Care Intelligence Network What We Know Now 2014 June 2015

¹⁰ Public Health England 2013 What we know now 2013 New information collated by the National End of Life Intelligence Network

- 'Actions for the end of life care' recognises the need for a shift in focus from 'place of death' to the broader experience of end of life care. Hospital deaths are unavoidable for a number of reasons including people's choice. While people's preference about place of death has been important in the drive to increase the proportion of deaths that occur at home, it is not the only important factor. Population surveys show that having as much information as they wanted and choosing who makes decisions about their care were equally important.
- This means that we need to improve the way that dying people and their families are cared for in hospital at the end of life; although pain relief is better achieved in hospital, the overall reported experience of care at the end of life is as not good for people who die in hospital compared to those who die at home or in a hospice¹¹. Achieving high quality person-centred care in hospital requires systems which ensure robust co-ordination and communication with primary health and social care, supported by trained staff with expertise and confidence to support dying people and their families.

(v) Provision of Specialist Palliative Care

- Specialist Palliative Care (SPC) is defined as "the active, total care of patients with progressive, advanced disease and their families. Care is provided by a multi-professional team who have undergone recognised specialist palliative care training. The aim of the care is to provide physical, psychological, social and spiritual support"¹². SPC services should be available to all patients with cancer and non-malignant diseases on the basis of need.
- Specialist palliative care services are largely provided by hospices and include in-patient and community support for people in the last years of life, their carers and families. Increasing access to specialist palliative care for people who are dying in hospital can improve experience during the last months and weeks of life.

(vi) Training and education for health and social care staff

- Caring for and supporting people approaching the end of their life is considered among the most challenging work any health and social care worker faces. It can also be the most rewarding - if they have the right knowledge, skills and attitude to provide the care and support they need. Training and continuing support is needed for all health and social care staff, not just those who work in palliative care settings.
- Experience has shown that training which brings people from different roles together can also enable a greater understanding of how everyone can work together with the person in receipt of care and support in order to provide excellent end of life care¹³.
- In response to the Cavendish review, the Care Certificate has been developed jointly by Skills for Care, Health Education England and Skills for Health. It has been designed with the non-regulated workforce in mind in order to ensure an effective induction of new staff which gives everyone the confidence that workers have the same introductory skills, knowledge and behaviours to provide compassionate, safe and high quality care and support.
- A national audit found that training in care of the dying was mandated for doctors in 19% of acute hospital trusts and for nurses in 28%¹⁴. While 82% of acute hospital trusts reported that they had provided some training on care of the dying in the previous year, 18% had not provided any formal training in care of the dying. Training included a communications element for doctors in 61% of trusts and in 69% for nurses.

¹¹ National Survey of Bereaved People (VOICES) 2013; 2014 ONS <http://www.ons.gov.uk/ons/rel/subnational-health1/national-survey-of-bereaved-people--voices-/2013/stb---national-survey-of-bereaved-people--voices-.html#tab-Quality-of-Care>

¹² National Council for Palliative Care, 2012. Commissioning guidance for specialist palliative care: Helping to deliver commissioning objectives.

¹³ Skills for Care 2014 Understanding roles: working together to improve end of life care

¹⁴ National Care of the Dying Audit- Hospitals England 2013/14 www.rcplondon.ac.uk/sites/default/files/ncdah_national_report.pdf

(vii) **Reducing inequalities in access and experience**

- There is inequitable access to high quality end of life care for certain groups of people². Increasing access to high quality care for all population groups and for people with different conditions is essential to achieving overall improvement in services and people's experience. Although the overall proportion of all deaths that take place in hospital is reducing, there are inequalities between population groups in access to specialist services, experience and place of death.
 - Older people (with the exception of the very old), men, and people in the most deprived groups are more likely to die in hospital than other groups.
 - Homeless people die younger from complex conditions and often in hospital.
 - People who die from causes other than cancer are less likely to die at home or in a hospice than people with other conditions.
 - Nationally there is evidence of lower uptake of palliative care services by people from black and minority ethnic groups compared to people from White/majority groups, with evidence of poorer outcomes.
 - A review of SPC services in London found wide variation in the availability of out of hours services across the capital, and although improving, evidence of unmet need by people who die from non-malignant conditions.¹⁵
 - People with learning disabilities are less likely to access specialist palliative care services, to have inadequate pain relief and experience poor co-ordination of services.
 - Carers of people who died from cancer are more likely to rate care in the last 3 months as excellent or very good and to report that pain relief was adequate, compared to people who died from other conditions. Overall, less than half of people who die at home had adequate pain relief compared to 87% people who die in a hospice.
- After cancer type, marital status is the most important factor associated with place of death, and there are recommendations that people who are single, widowed, or divorced should be a focus for last years of life care improvement, along with groups with risk factors such as haematological cancer, lung cancer, older age, and deprivation.
- A third of people over 60 years old who die have dementia, and evidence shows that many receive poor quality care towards the end of life. People with advanced dementia often decline gradually and the dying process may take months, so that families and professionals often fail to recognise the terminal phase. At this point, active treatments and costly hospital admissions are almost always inappropriate as well as distressing and traumatic.
- Experience can be improved for people with dementia through the Namaste Care programme¹⁶. Namaste is a Hindu term meaning 'to honour the spirit within.' The programme is designed to improve the quality of life for people with advanced dementia by providing meaningful activities and sensory stimulation, especially through touch, in a safe and comforting environment.

(viii) **Community approaches to Last Years of Life and "healthy dying"**

- A reluctance to talk about death, dying and bereavement in our society can impact on the way people experience death. Talking about dying and planning for death makes it more likely that people die as they wish and also supports families and carers.
- There is growing recognition of the importance of community engagement in supporting people at the end of life and their families and that death, dying and bereavement is everyone's business.

¹⁵ Marie Curie, London Cancer Alliance and PallE8, 2015 A review of Specialist Palliative Care provision and access across London: Mapping the capital

¹⁶ <http://www.stjh.org.uk/our-services/community-services/namaste>

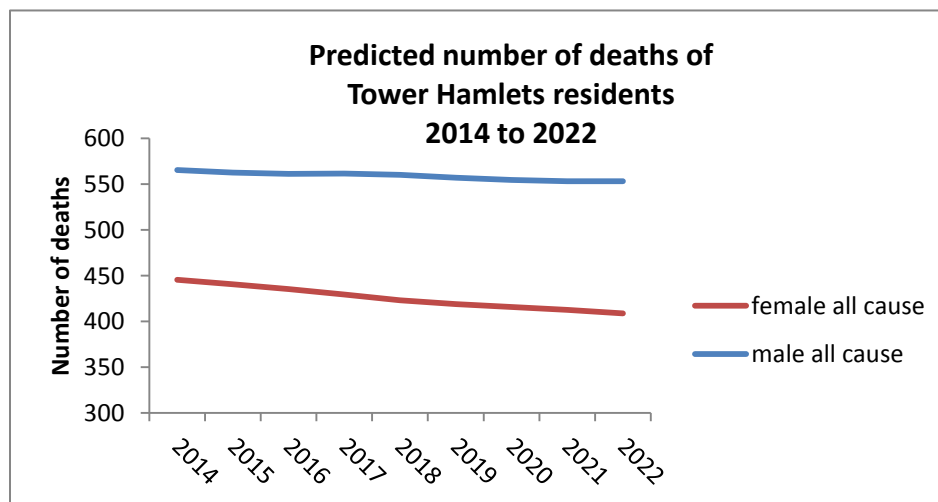
- More than half of the public (51%) who have a partner say they are unaware of their end of life wishes, which highlights the lack of open discussion even among family members.
- Only 36% of British adults say they have written a will, just over a third (34%) that they have registered as an organ donor or have a donor card, 29% that they have let someone know their funeral wishes and just 6% that they have written down their wishes or preferences about their future care, should they be unable to make decisions for themselves¹⁷.
- The Dying Matters Coalition was set up to help people talk more openly about dying, death and bereavement, and to make plans for the end of life. It provides a whole systems model of community engagement to build a “compassionate community” to support people to have conversations and make plans for their own care in last years of life¹⁸.

4. What is the local picture?

(i) Deaths in Tower Hamlets

- Tower Hamlets has a particularly young age profile. Around 6% of the population is aged over 65, the lowest proportion in England, and this is not set to change over the next 10 years. The number of deaths in the borough is therefore relatively low compared to boroughs with older populations, and a higher proportion of all deaths occur in younger and middle aged people.
- Changes in the population structure and increased life expectancy mean that the rate and number of people who die each year has fallen each year over the last 2 decades nationally and locally. Although the total annual number of deaths amongst Tower Hamlets residents is not expected to change very much over the next 5 years, modelling suggests that there will be reduction in the number of deaths amongst females (from 441 in 2014 to 409 in 2022) with less change in deaths of males (from 566 in 2014 to 553 in 2022) (figure 4). In the longer term rates and numbers are predicted to rise over the next 2 decades, and this will impact on last years of life services.

Figure 4.



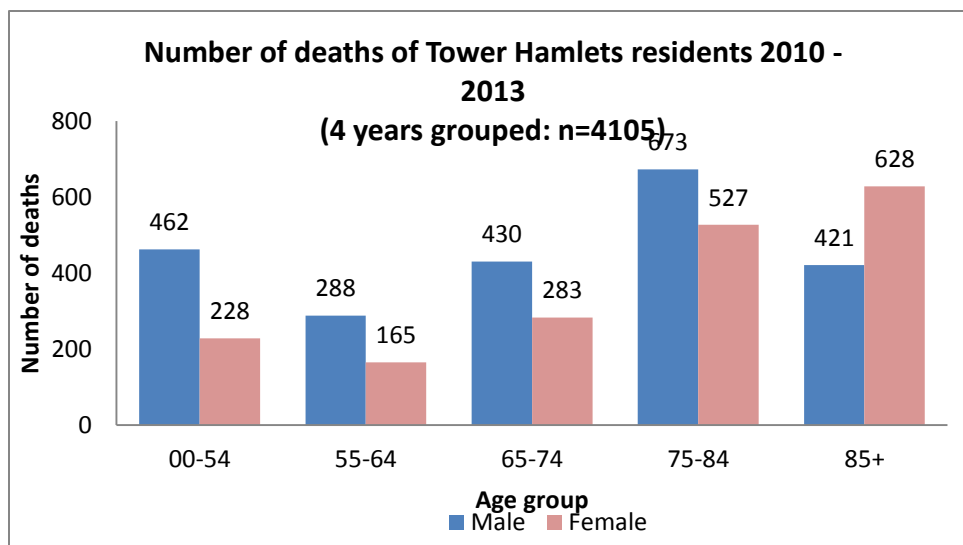
Source: ONS Primary Care Mortality Data (analysis by Geoff Mole, Public Health Analyst)

¹⁷ NCPD Dying Matters Survey May 2014 cited in PHE 2015 What we know now 2014

¹⁸ <http://www.dyingmatters.org/sites/default/files/user/documents/Resources/Community%20Pack/1-Introduction-1.pdf>

- During the four years between 2010 and 2013, there were 4,105 deaths amongst Tower Hamlets residents, an average of 1026 deaths each year. Overall, 28% of deaths occurred in people under 65 years old, compared with the England average of 16% in 2013 (figure 5) reflecting the young age profile of the Tower Hamlets population, as well as reduced life expectancy and worse premature mortality rates compared to the England averages.
- There are differences between the proportion of men and women who died at different ages. Amongst males, a third of deaths (33%) occurred before the age of 65, with 20% of all male deaths before 55 years. A smaller proportion (21%) of female deaths occurred in people under 65 years old.
- Although a third (34%) of female deaths in Tower Hamlets were women over the age of 85, this proportion is lower than the England average; nationally almost half of all female deaths (48%) in 2013 were women over 85. In males, 21% of Tower Hamlets deaths were men over 85 years old.
- An average of 32 deaths in the borough each year (3% of the total deaths) during these 4 years were children and young people up to the age of 19. Just over half of these were deaths in the first year of life, often related to prematurity.

Figure 5.



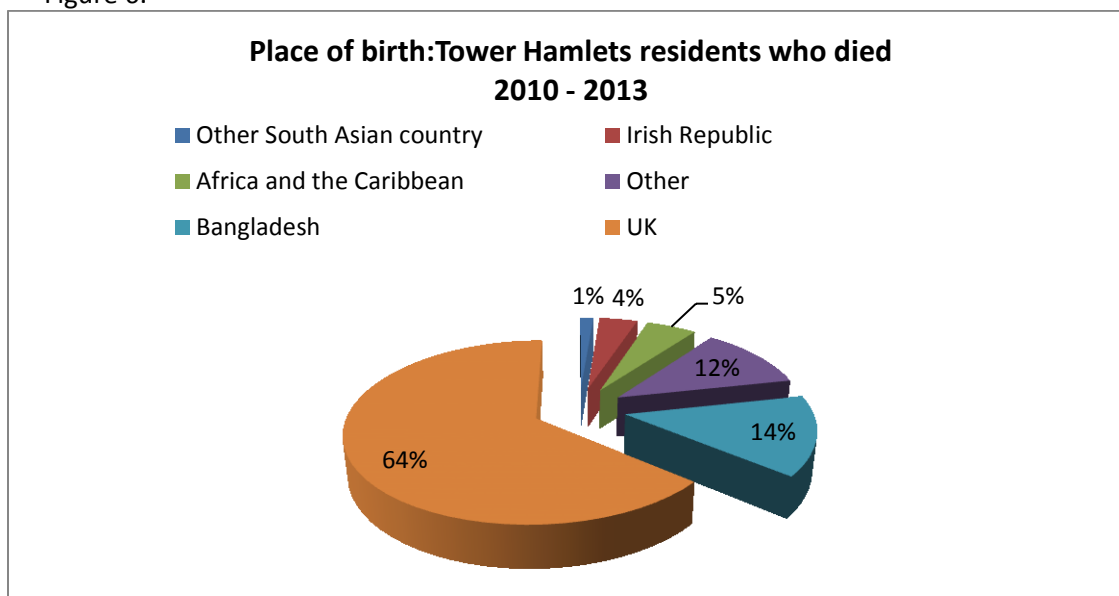
Source: ONS Primary Care Mortality Data (analysis by Geoff Mole, Public Health Analyst)

- The main causes of death in Tower Hamlets were cancer (30%), cardiovascular disease, including heart disease, stroke and diabetes (28%) and respiratory disease (14%). The overall proportion of people who die from different causes and at different ages is not significantly different from the England average. However,
 - a significantly higher proportion of women of all ages in Tower Hamlets die from cancer (31.12% compared to the England average of 26.08%)
 - a significantly lower proportion of men and women under the age of 65 die from cancer 32.49% compared to the England average of 39.12%)¹⁹
- Data relating to other conditions mentioned on death certificates reflects high levels of multiple morbidity and complex care needs in the local population during their last years of life
 - significantly more people of all ages in Tower Hamlets have respiratory disease mentioned on their death certificate as another condition compared to the England average (39.54% compared to 34.85%).

¹⁹ http://www.endoflifecare-intelligence.org.uk/end_of_life_care_profiles/ccg_profiles

- significantly more people in Tower Hamlets aged between 65 and 84 years have cardiovascular disease mentioned on their death certificate compared to the England average (53.43% compared to 47.22%).
- Ethnicity is not recorded on death certificates, so place of birth is used as a proxy, recognising that this is an inaccurate measure. Just over two thirds of deaths (68%) were amongst people born in the UK or Ireland. Of the remainder, 14% of deaths were people born in Bangladesh, 5% were people born in Africa and in the Caribbean and 12% were people born elsewhere including other European countries (figure 6).

Figure 6.



Source: ONS Primary Care Mortality Data (analysis by Geoff Mole, Public Health Analyst)

(ii) Place of care and death

- The National End of Life Care Intelligence Network End of Life profiles summarise key indicators benchmarked against England averages²⁰. The profiles give an overview of variations in cause and place of death, by age and sex, for each clinical commissioning group (CCG) in England. These profiles are designed to give commissioners and providers of end of life care a clearer picture of the needs of their local populations, to help with the planning and delivery of services and support drives locally towards improving end of life care. Key data from the most recent profiles reflecting data from 2011 to 2013 are in table 1.

Table 1

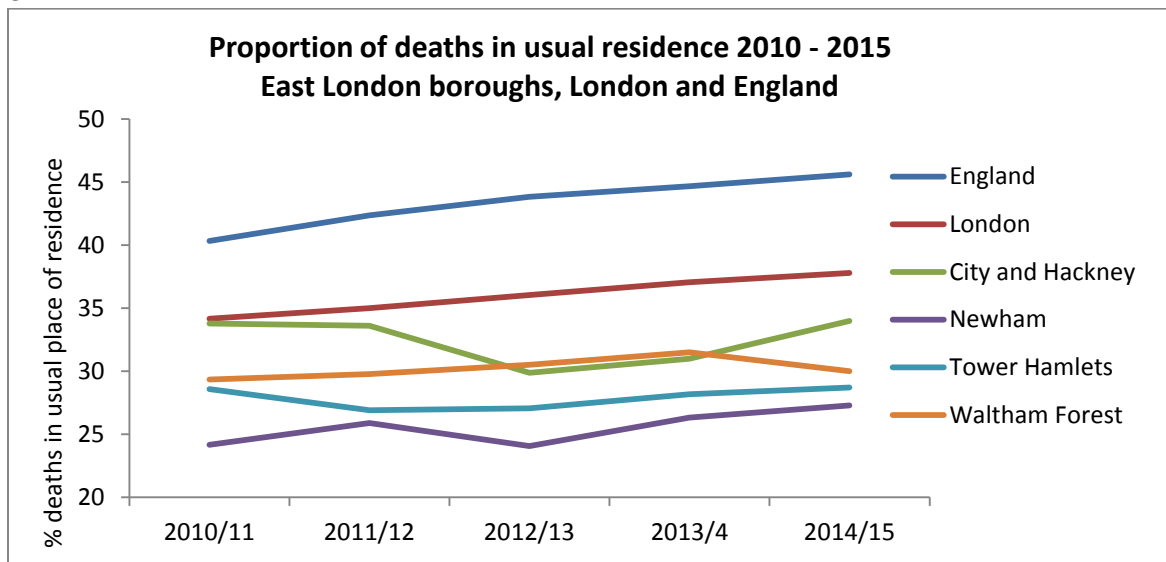
1. Place of death	Tower Hamlets	England average	England lowest	England highest	Compared to England average
Deaths in hospital	59.06%	49.3%	36.8%	66.8%	Significantly higher
Deaths at home	22.09%	22.16%	16.4%	28.6%	Similar
Deaths in care homes	5.8%	20.74%	5.1%	32.4%	Significantly lower
Deaths in hospice	9.99%	5.65%	0	12.3%	Significantly higher

Source: National End of Life Care Intelligence Network 2015 End of Life Profiles

²⁰ http://www.endoflifecare-intelligence.org.uk/end_of_life_care_profiles/ccg_profiles

- Hospital remains the most common place of death in England, but the proportion of deaths that occur in hospital is falling, and nationally was less than half of all deaths by March 2015 (47%). The proportion of deaths at home or in a care home (termed “usual residence”) has been increasing annually, from 40.3% in 2010 to 45.6% in March 2015²¹.
- In London, the proportion of deaths in usual residence remains lower than the national average and has increased at a lower rate (from 35% to 38% between 2010 and 2015). In East London rates are particularly low and do not show an overall increase during the same period. Between 27% and 29% of Tower Hamlets residents died at home or in a care home (figure 7) during this period.

Figure 7

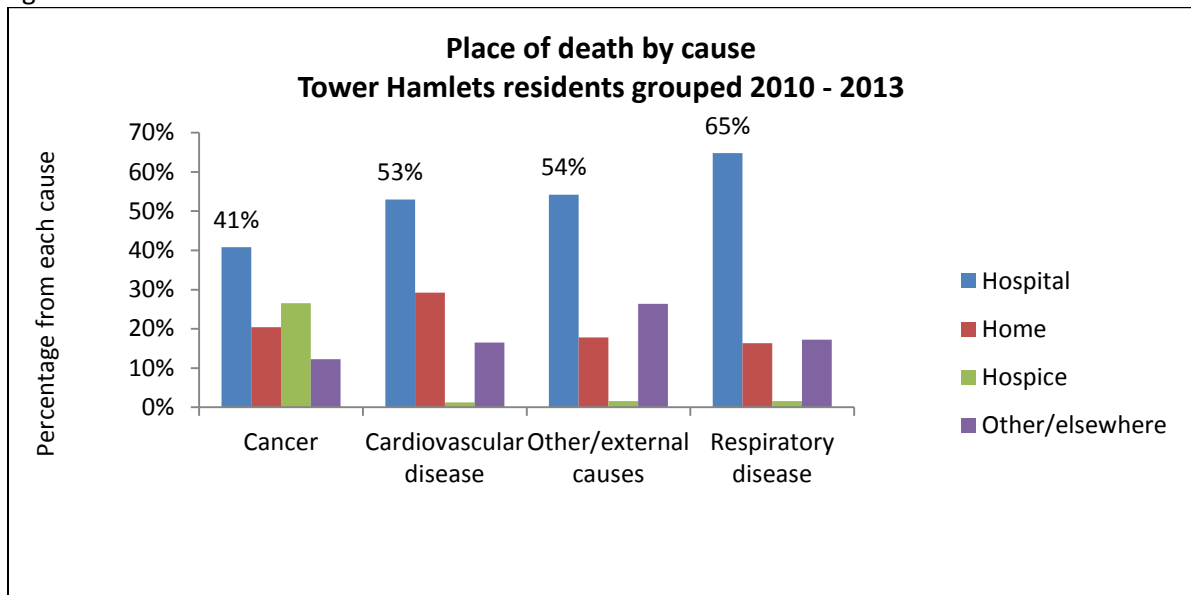


Source: ONS, National End of Life Care Intelligence Network

- Although gradually decreasing, the proportion of deaths in Tower Hamlets that occur in hospital remains higher than the national average. The most recently published data for 2014/15 shows deaths in hospital for Tower Hamlets residents at 59% compared to London (54%) and England (47%).
- There are differences in place of death related to the underlying cause (figure 8). In Tower Hamlets, amongst people who died from the commonest causes, the highest proportion of deaths at home between 2010 and 2013 was amongst people who died from cardiovascular disease (38% of home deaths), followed by deaths from cancer (28% of home deaths). People who died from respiratory disease were more likely to die in hospital (two thirds/65% of this group).

²¹ ONS, National End of Life Care Intelligence Network

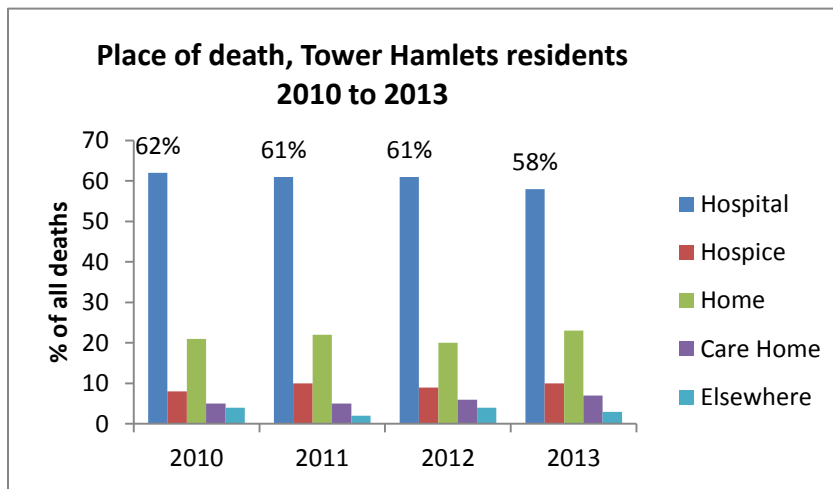
Figure 8.



Source: ONS Primary Care Mortality Data (analysis by Geoff Mole, Public Health Analyst)

- Tower Hamlets residents who die are more likely to die in a hospice than elsewhere (10% compared to 6% average in England). Nationally people who die from cancer are more likely to die in a hospice than people who die from other causes, and this is reflected in Tower Hamlets where 27% of deaths from cancer were in a hospice compared to less than 2% of deaths from other causes between 2010 and 2013. Cancer deaths accounted for 89% of all hospice deaths amongst Tower Hamlets residents during this period.
- There is a national trend for more deaths to occur in care homes and although increasing, this is less evident in Tower Hamlets where 6% of deaths between 2011 and 2013 were in a care home compared to 22% England average in 2013 (figure 9). This is likely to be related to the small number of care homes in the borough (6 in total, of which 2 offer nursing care). Some people with residential care needs may move to other boroughs to receive this care, and subsequent deaths are not recorded in Tower Hamlets data. A higher proportion of deaths occur in people under 65 in Tower Hamlets than the England average, and this group may not have the same needs as “frail elderly” people, who are more likely to use care homes.

Figure 9.



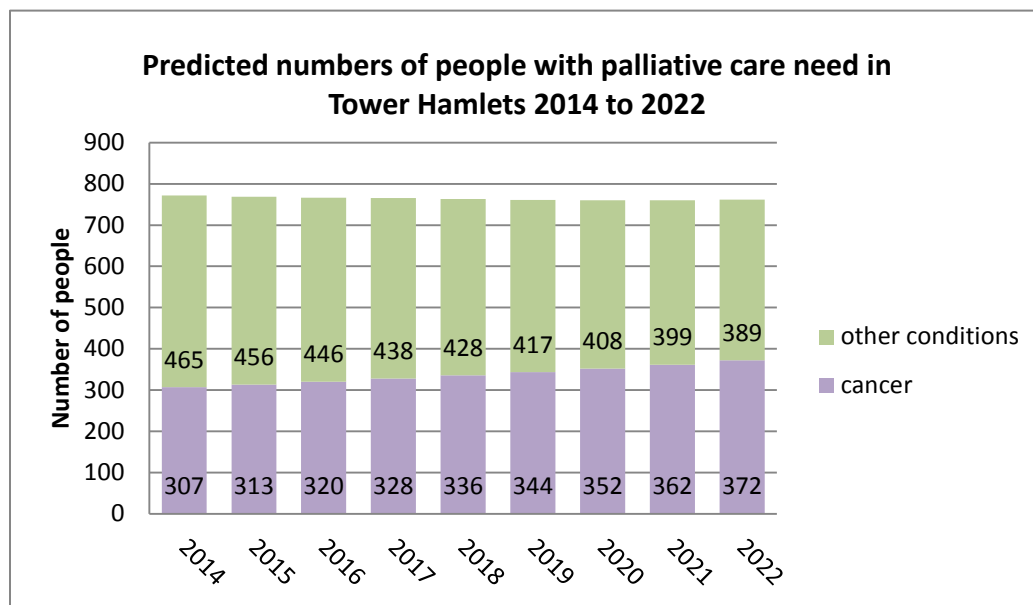
Source: ONS Primary Care Mortality Data (analysis by Geoff Mole, Public Health Analyst)

- Tower Hamlets residents who died in hospital spent more days in hospital than the average number of days for London and England. Local data shows that Tower Hamlets residents spent an average of 20 days in hospital during the admission leading to their death in 2013 and 2014, compared to the London average of 14 days. They had on average 3 previous admissions during the previous 2 years, spending a further 17 days in hospital during these admissions²².

(iii) **Identifying palliative care need**

- Not all deaths are anticipated and palliative care needs cannot always be planned. The number of people expected to require palliative care each year is estimated by summing the average number of deaths from cancer and two thirds of deaths from other causes. Around 780 people each year are likely to require palliative care in Tower Hamlets and although this number is not set to increase over the next 7 years, the proportion of those who die from cancer is likely to increase (figure 10).

Figure 10.



Source: ONS Primary Care Mortality Data (analysis by Geoff Mole, Public Health Analyst)

- In line with the young population profile, fewer people are expected to have palliative care need each year in Tower Hamlets compared to the average number for all UK boroughs. The proportion of people with palliative care need which is identified by Primary Care in Tower Hamlets and recorded in QOF data is higher than the England average and has increased from just over a third in 2010/11 to almost half (48.38%) in 2012/13 (table 2).

Table 2 Palliative care need identified by Primary Care in Tower Hamlets

Year	2012/13		2010/11	
	UK average	Tower Hamlets	UK average	Tower Hamlets
Indicator				
Estimated number of people with palliative care need	1796	781	-	829
% of people with palliative care need identified	37.03%	48.38%	26.8%	35.1%

Source: Marie Curie End of Life Care Atlas

²² Peter Allen (NELCSU) 2015 Analysis of death related admissions and previous patient relative admissions, Tower Hamlets residents 2013 and 2014 combined

- Baseline analysis of care plans for people eligible for integrated care, and who are likely to be in their last years of life in 2013/4 found that only 20% of care plans included a 'crisis plan' recording preferences for place and type of care at the end of life²³. This suggests that although need is being identified for nearly half of people in last years of life, not all have their preferences discussed and recorded.

(iv) Quality of care: reported experience

- National research into the quality of patient experience of end of life care identified²⁴
 - variations and ineffective use of best practice tools and processes for end of life care
 - more people dying with multiple, complex, non-cancer conditions
 - how people enter the care system directly impacts on the subsequent quality of their experience
 - patient choice is not prevalent and consequently care is not personalised
- Each year since 2011 the Department of Health has commissioned the Office for National Statistics (ONS) to carry out annual postal surveys of bereaved relatives using the National VOICES survey (Views of Informal Carers - Evaluation of Services). The survey aims to assess the quality of care delivered to people in the last three months of their lives and to assess variations in the quality of care delivered in different parts of the country and to different groups of patients.
- Nationally response rates are lowest for people from the most deprived groups and from Black and Minority Ethnic groups. Because response rates at a local level are generally too low to enable reliable comparisons, data is no longer published at local level. By combining results for 2 years (2011 and 2012) for 8 of the 59 questions, some local data has been made available. Tower Hamlets results are reported below.

National responses 2014

- The main findings at national level from the most recent (2014) survey were²⁵
 - 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 people (10%) rated care as poor.
 - 7 out of 10 people (69%) whose relative or friend died in a hospital, rated care as outstanding, excellent or good. This is significantly lower than the same ratings for those who died in a hospice (83%), care home (82%) or at home (79%).
 - Ratings of 'fair' or 'poor quality' of care are significantly higher for those living in the most deprived areas (30%) compared to the least deprived areas (21%).
 - 1 out of 3 people (33%) reported that the hospital services did not work well together with GPs and other services outside the hospital.
 - More than 5 out of 6 bereaved people (86%) understood the information provided by health care professionals, but 1 out of 6 (16%) said they did not have time to ask questions
 - 7 out of 10 (73%) 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.

Tower Hamlets responses 2011/12

- The 8 questions reported cover 3 sections: Overall Quality of Care, Dignity and Respect and Support for the carer and family. Tower Hamlets results are based on responses from just 47 people over the 2 years surveyed, and for some questions the number of responses is much lower. The small numbers mean that results need to be interpreted with caution, as these can cause differences in percentages to appear greater than they are, shown by the wide confidence intervals in figures 11 to 14 in the appendix.

²³ Tower Hamlets Integrated Care Programme: personal communication Julie Dublin

²⁴ Paget, A & Wood, C (2013), Ways and Means cited in Public Health England 2015 What we know now 2014

²⁵ ONS 2015 National Survey of Bereaved People (VOICES) 2014

- Responses to 5 of the 8 questions place Tower Hamlets within the lowest scoring 10 of 211 CCGs in England. Results are similar in neighbouring East London boroughs.
- Less than a third (30.7%) of Tower Hamlets respondents rated overall quality of care as outstanding or excellent, below the England average of 43.2% (figure 11). Rating of dignity and respect shown by hospital and community nurses, and support for family and carers also placed Tower Hamlets in the 10 lowest scoring CCGs in the country (figures 12, 13 and 14 in the appendix).

5. What is being done locally to address these issues?

(i) **Person-centred, integrated care**

- Tower Hamlets Integrated Care Programme (using the Better Care Fund) brings together health and social care services around the needs of patients and carers. Taking a person-centred approach, the programme aims to improve all aspects of quality of care for service users with complex needs, their families and carers; and to give them an improved health and social care system so that they can stay at home more and be in hospital less²⁶. People in their last years of life are a key group in the Programme, and will benefit from holistic, joined up and needs-led care delivered wherever possible in their own homes.
- Integrated care aims to
 - empower patients and their carers
 - provide responsive, coordinated and proactive care, including sharing information between providers
 - enhance the quality of care and to ensure consistency and efficiency of care

(ii) **Identifying and meeting palliative needs early and in accordance with people's preferences**

- Historically palliative care services were seen as those which address dying people's needs during their last days and hours of life. This perception can act as a barrier to ensuring that all people in their last years of life are offered adequate holistic palliative care wherever their care is delivered, during what is often a protracted period when care needs increase with the progression of life-limiting conditions.
- Tower Hamlets Integrated Care Programme centres on personal care planning with people and their families, which includes working in partnership to identify early and record preferences about the type and place of care at the end of life.
- Through integrated care, there is a move to increase partnership working between Specialist Palliative Care services, primary and secondary health care and other services, so that people with palliative care needs and their level and complexity of need can be identified and met.
- A key measurement of integrated care programme effectiveness is the proportion of people with up to date care plans, aiming to ensure these are reviewed at least every 6 months. Evaluation includes measures which assess whether people in their last years of life were given choice and control about their care, and whether their preferences were met.
- Central to integrated care is good communication through shared records between health and social care providers. This avoids people and their carers having to repeat themselves and ensures that preferences for care are shared and respected across providers. The Integrated Care Programme includes an IT solution enabling up to date records of consenting service users to be viewed between health and social care providers. This is in the pilot phase, and aims to provide the same function as 'Co-ordinate my Care' for people in last years of life, once the London Ambulance Service has to access to records.

²⁶ Integrated Care in Tower Hamlets accessed 15 May 2015

<http://www.towerhamletscg.nhs.uk/gp/Integrated%20Care/Guide%20on%20integrated%20care%20in%20Tower%20Hamlets%20final.pdf>

- To ensure that care is discussed and planned early and delivered appropriately for people with dementia, a quality enhanced payment (CQUIN) is included in the contract with mental health services, so that Advance Care Planning is recorded for people within 3 months of a diagnosis of dementia.
- A specialist Occupational Therapist for dementia is supporting Care Homes through staff training and improving activities offered for people with dementia.
- Tower Hamlets Care Homes are working towards the Gold Standards Framework. During 2014, 5 of the 6 Tower Hamlets home managers participated in a survey about care in last years of life. Four homes reported that they were currently working towards achieving GSF, and one planned to resume the programme²⁷.
- St Joseph's Hospice is providing the "Namaste care" programme in partnership with Age UK East London, to support people with dementia and their families through meaningful activities and sensory stimulation, especially through touch, in a safe and comforting environment. The service aims to help people with dementia to remain in their own homes wherever possible by supporting them and empowering their carers to look after them, particularly as their illness progresses and they move towards the end of their life²⁸.

(iii) Improving the quality of care

- Low response rates to the National VOICES survey from carers of deceased people born outside the UK and from the lowest socio-economic groups may mean that the national survey does not reflect experiences of all patients and carers in the borough. To improve the way that services are provided, a local solution is needed to capture and act on the views of the all sections of the community, particularly those whose voices are not always heard.
- Between April and July 2015, the CCG and the Local Authority carried out a local survey using an 'assisted survey model' to complete the VOICES questionnaire, supplemented by in-depth interviews which followed up themes identified by respondents. This aimed to overcome inequalities in response rates linked to lower levels of health literacy and other language and communication barriers²⁹.
- In total, 107 carers of 97 residents who had died between 4 and 11 months earlier were invited to participate anonymously in the survey. Carers of just under half of the deceased residents (41 responses; 47%) replied to the invitation. Of these, 19 carers declined to participate and 22 said they would complete the survey. However, responses from only 14 carers were obtained - 12 through a written survey and 2 by 'assisted completion.' These 2 carers also participated in in-depth interviews.
- The overall response rate of 13% was disappointing, and was lower than the 2014 ONS survey response of 27% in Tower Hamlets (24 of 89 invited carers completed the survey). A key finding of the local survey was that the assisted survey model did not improve response rates from carers invited to participate by a main service provider, when compared to the conventional postal survey administered nationally. More focused methods, such as targeted sampling and participatory models of engagement working with community organisations may obtain better representation of perceived quality of end of life care.
- The sample was opportunistic, and therefore was not representative of all people who die in the borough. It was not stratified, by gender, age, underlying cause of death or ethnicity.
- Of the 14 responses received, 6 were from carers of White UK residents who had died, 3 from people of "other White" origin, 4 were Asian (of which 3 were Bangladeshi) and one was Black Caribbean. The majority of people who had died (12) were more than 80 years old.

²⁷ London Borough of Tower Hamlets Public Health 2014 Report on Last years of Life Care in Tower Hamlets Care Homes

²⁸ <http://www.stjh.org.uk/our-services/community-services/namaste>

²⁹ Health Focus Research 2015 Report on a pilot of a local VOICES survey in Tower Hamlets

- Most of the respondents (12) reported that their loved one had been ill for more than 6 months. In 9 cases this was more than a year.
- Only 2 carers reported that their loved one had expressed a preference about place of death (both at home) and of these, 1 reported that healthcare staff had a record of this. However most carers believed their loved one had died in the right place (11) and only 1 carer did not think this.
- For most questions responses ranged from excellent to 'poor.' Because the number of responses is too low to draw inferences, it is presented numerically in the final report. Feedback from free text in the survey and interviews provides qualitative data which may be more useful in shaping services.
- Themes identified from carers' feedback are
 - When care and support was provided at home, it was rated as very good. However, some carers had managed for considerable periods (often years) before this was provided during the final months.
 - There were specific examples of good practice; a social worker was mentioned as providing an excellent service and the quality of care in residential care homes was rated well, although 2 respondents mentioned that more staff are needed.
 - However there were also examples of poor service, such as lack of co-ordination and bureaucratic confusion which contributed to one person being prevented from dying at home.
 - One respondent reported poor hospital services, resulting in a formal complaint and agreement that services had not reached the required standard and caused unnecessary suffering.
 - A family that had provided care for their loved one (aged 90) for many years at home were distressed by his death being classed as 'unexpected' resulting in delay in releasing his body for burial.
 - One carer mentioned that her loved one's emotional and psychological needs could have been better addressed, perhaps by providing companionship and activities.
 - There was one example of lack of timely response by a GP practice who advised 'calling 999 if no-one turns up' and another of excellent services "she went into a hospice at the end of her life for 16 days. She never went into a home as I looked after her. Tower Hamlets look after older people very well...my mother's GP was fantastic"

(iv) Improving the experience of hospital care in last years of life

- NHS Tower Hamlets CCG commissions Barts Health to provide specialist and hospital based palliative care across the Trust through a multi-professional team, which gives specialist advice about symptom control as well as psychological and social support to patients, families, carers and staff. A review of the service is being carried out by the CCG during 2015/6.
- A palliative care social worker based at the Royal London Hospital works with people admitted to the hospital and their families to provide specialist support
- A healthy prescribing guide for people in the last years, months or days of life has been developed by the CCG for use by clinicians in primary and secondary care; this aims to ensure that patients receive the most appropriate medication for symptom relief, and are not treated unnecessarily.

(v) Specialist Palliative Care

- NHS Tower Hamlets CCG commissions Specialist Palliative Care (SPC) services from
 - St Joseph's Hospice (including inpatient, outpatient, carers and bereavement support)
 - Barts Health Specialist Palliative Care Service (detailed above)
 - Marie Curie night sitting service
 - Richard House Children's Hospice
 - The Mildmay Mission Hospital (specialising in neurological and HIV related conditions)
- Information provided by St Joseph's hospice indicates that the annual number of Tower Hamlets residents who used SPC services between 2010 and 2015 increased from 359 to 525 each year. Further analysis is needed to understand whether this represents an increase in the overall number of service users, and/or whether some people are accessing and using services earlier and for longer periods.

Training and education

- A Foundations of Palliative Care education programme has been commissioned through the Tower Hamlets Community Education Provider Network (CEPN) to provide comprehensive multi-agency training for improving the skills and confidence of those supporting frail and complex patients, including all those in the last years of life. A dedicated programme manager is working with education leads from each of the Tower Hamlets Integrated Care Provider Partnership (THIPP) organisations (health, social care, mental health, third sector) to determine educational needs. The aim is to embed this training into “business as usual” practice within organisations in future years.
- As part of the 2015 Care Act, a training framework for social care staff has been introduced to enable services to meet revised “fundamental standards.” The Care Certificate is a set of standards that health and social care workers adhere to in their daily working life. Designed for the non-regulated workforce, the Care Certificate gives everyone the confidence that workers have the same introductory skills, knowledge and behaviours to provide compassionate, safe and high quality care and support. Competencies include skills to work with people in their last years of life, with training designed in partnership with Skills for Health³⁰.

(vi) Reducing inequalities in access and experience

- A health equity audit is being undertaken by Public Health, working with the main provider of specialist palliative care, St Joseph’s Hospice (SJH), to identify and address differences in access to specialist palliative care between population groups and people with different health conditions. The findings will be used to inform outreach and education, to reduce inequalities and to ensure equity of access and uptake across the population.

Data provided by SJH suggests that compared to national rates, there is less inequality of access to SPC services in Tower Hamlets by people from different ethnic groups and by those with non-cancer conditions.

a) Ethnicity

- Service use reflects the ethnic profile of people who die in the borough each year recorded by the Office for National Statistics (ONS). More than a third of the total number of residents who used SJH services between 2010 and 2015 were of non-White ethnicity (between 34% and 37% each year), similar to the proportion of deaths in the borough amongst people who born outside the UK and Ireland (32%).
- The largest group of non-White residents who used SJH services between 2010 and 2015 were people of Bangladeshi origin (between 14% to 17% each year). This is similar to the number of residents who die each year who were born in Bangladesh (14%; average 142 per year).
- Analysis of national data shows that in 2013, on average only 7% of people accessing palliative care were non-White. Public Health England reports that this is lower than would be expected given that 14% of the population in England is of a non-White ethnicity³¹. (PHE does not provide an estimate of the proportion of deaths in people of non-White ethnicity; this is likely to be lower as the non-White population is generally younger).

b) Underlying condition

- Cancer was the main underlying condition for 59% of Tower Hamlets residents who used the SJH services each year between 2013 and 2015 (64% to 70% of males and 49% to 52% of females). 41% of SJH service users each year had a non-cancer diagnosis.
- This is favourable compared to national rates, which show that the proportion of people with conditions other than cancer seen by SPC services, while increasing, varies from between 12% and 27% of new patients³¹.

³⁰ <http://www.skillsforcare.org.uk/Document-library/Skills/End-of-life-care/>

³¹ PHE National End of Life Care Intelligence Network What We Know Now 2014 June 2015

- Further analysis will be undertaken using other demographic and clinical information, to assess access for residents at greater risk of poor access and experience, and to help identify how these can be reduced; for example for people who are single, widowed, or divorced (and particularly those that live alone), with dementia, who misuse drugs and alcohol, or who have learning disabilities.
- Similar equity audits on hospital SPC and support services for people in last years of life and their carers will help identify and reduce potential inequalities.
- The CCG plans use findings from the local VOICES survey to commission continuing consultation with service users, with a focus on exploring community engagement models to increase reach.

(vii) **Community approaches to Last Years of Life**

- St Joseph’s Hospice is working with a local community partner, Social Action for Health in the neighbouring borough of Hackney to engage with the diverse local communities using the Compassionate Communities model. Developing a joint intervention, they support community champions to engage local people in in-depth dialogue about end of life care, and to support people to establish Compassionate Communities ‘hubs’ addressing issues around serious illness, death and bereavement, with training and support from the hospice³². It is hoped that the pilot will enable extension into other areas of East London including Tower Hamlets.
- In Tower Hamlets, Link Age Plus, a consortium of 5 community partners provides support and social opportunities for people over 50 years old. Their ‘healthy lives programme’ includes opportunities for people to have conversations about their current and future needs, including a healthy death – for example, a “Down to Earth” workshop provided by Quaker Social Action on planning a funeral on a low income³³ and stimulating discussions about ‘putting your house in order’ using Age UK’s Lifebook³⁴
- Support for patients and their families is commissioned by the CCG and the Local Authority, and provided by third sector community organisations. This includes a Befriending Service provided by Age UK East London, the City and East London Bereavement Service, Tower Hamlets Carers Centre, and St Joseph’s hospice bereavement support. Marie Curie also provides a befriending service for Tower Hamlets residents.
- Compassion in Dying, a national charity working to inform and empower people to exercise their rights and choices around end of life care has set up an outreach service called My Life, My Decision. It has run several well attended awareness sessions in Tower Hamlets engaging with community partners such as Imams in the East London Mosque and Asian elders groups. The charity is keen to work with other groups to offer training, resources and support for local people³⁵.

6. What evidence is there that we are making a difference?

More needs to be done to ensure that people in Tower Hamlets have high quality care that meets their needs during their last years, weeks, days and hours of life.

The Association of Directors of Adult Social Services End of Life Care Charter³⁶ summarises “how we will know we have been successful” when we:

- **listen** to the person and their carers; create opportunities for them to express their views and concerns. Understand how their culture and lifestyle affects their choices and how they wish to be treated

³² http://www.compassionatecommunities.org.uk/files/PDF/CC_Report_Final_July_2013-2.pdf

³³ <http://www.quakersocialaction.org.uk/Pages/Category/down-to-earth>

³⁴ <http://www.ageuk.org.uk/home-and-care/home-safety-and-security/lifebook/>

³⁵ <http://compassionindying.org.uk/services-near-me/>

³⁶ <http://londonadass.org.uk/wp-content/uploads/2014/12/LSCPFinalCharterEoL.pdf>

- **develop care plans** around the stated priorities of the person, keep them up to date and share them across the care and support team. Goals will be clear, roles understood and there is a named co-ordinator
- **share**, as appropriate, information important to the person's care and support and keep it up to date. Everyone, including the person and their carers, know about and understand any changes and how they affect the care plan
- **value and understand everyone's role** and contribution (the person, their family/carers and health and social care colleagues)
- **support each other** (the person, their family/carers and health and social care colleagues), listen, share expertise, be comfortable asking for support or information; and
- **use ordinary language** and speak in ways that are easily understood taking account of the situation and the person you are talking with.

Data in this needs assessment will form a baseline from which improvements will be measured over coming years.

- A key long term outcome measure is the proportion of residents whose death could be anticipated, and whose preferences about their care were met. We will measure this using care planning data. For example, the Integrated Care Programme metrics include tracking the proportion of people in the programme who died in hospital and had a recorded care plan; and those who had expressed a preference to die at home.
- A shorter term outcome measure is the proportion of people in the integrated care programme whose preferences about their care are discussed and recorded, in a way that can be shared appropriately. We will also assess whether there are differences in these outcomes between different population groups, and between people with different underlying conditions, aiming to reduce inequalities between groups.
- We will continue to monitor rates of death in hospital, hospice and in usual place of residence, seeking to continue the downward trend in deaths in hospital.
- In order to know whether we are on track to improve outcomes, we will measure service outputs such as the number of people from different groups who access specialist palliative care services and the number of people from different organisations and staff groups that participate in training about last years of life care.
- We will continue to monitor the number of avoidable admissions to hospital and the number of days spent in hospital for people in their last years of life, by measuring these rates amongst people currently receiving integrated care, and retrospectively for people who died from different causes and from different population groups.
- We will share the findings of the 2015 local VOICES survey of bereaved carers with key stakeholders, including people in their last years of life and their carers. We will use the findings to identify areas of good practice which need to be extended and areas where improvement is needed; we will work with partners to introduce or modify services accordingly.
- We will work with stakeholders, including community partners to identify how best to hear experiences of last years of life care, so that local people's voices can routinely shape the way services are delivered.

7. What is the perspective of the public?

- Understanding public perceptions, experiences and priorities is essential to inform end of life care services. International evidence shows that most people's priority if faced with serious illness is improving the quality of life for the time they have left, with low priority for extending life regardless of health status. People are also concerned about being a burden to family and informal caregivers.
- A UK study showed that people's priorities were being pain free, surrounded by loved ones, having dignity and privacy and being in familiar surroundings³⁷. People's top priority – being pain free – is recognised as something care at home cannot always provide as well as other locations. Nonetheless, dying at home is the most popular choice. This suggests people are sacrificing their top priority for the combined achievement of several of their other priorities. People feel that medical and practical forms of support are better in hospitals and care homes, while personal and environmental support are better in the home.
- The same report looked at perceptions of dying in different locations, comparing the opinions of people with and without experience of end of life care.
 - People expected a medical experience in care homes but this was not the case; personal and environmental factors were stronger than expected
 - People did not expect hospitals to provide a calm, dignified, loving death - and this was confirmed with experience
 - Those with experience of loved ones dying at home were slightly less positive, compared to people who had not had that experience, mentioning that dying at home led to unanticipated complications and difficult experiences
 - Perceptions about hospice care were very different between those with and without experience. Some aspects were more positive than expected (calm, peaceful atmosphere surrounded by loved ones), and some more negative (availability of medical and professional support).
- A recent study suggests that although religious and spiritual beliefs may increase marginally as death approaches, they do not affect levels of anxiety or depression in patients with advanced cancer receiving palliative care³⁸.
- Feedback from a small sample of bereaved carers using a locally administered version of the national VOICES survey is reported in section 5 (iii) above.
- Feedback through Healthwatch from Tower Hamlets residents receiving integrated care has been used to directly influence integrated care and last years of life programme areas
 - patients felt a loss of control of their lives, exacerbated by their medical condition and by an element of fatalism, with regard to the provision of their care.
 - there was a call for greater 'support' but the nature and level of support was rarely clarified. Partly this was because the deterioration of the medical condition could not be predicted but it was also hard for patients to think beyond their immediate concerns which were more pressing. What appeared to be critical was the need for support to enable patients to articulate and communicate what they needed and at what point

³⁷ Sue Ryder, A time and a place: what people want at the end of life, July 2013 cited in PHE 2015 What we know now 2014

³⁸ King et al (2013), Spiritual beliefs near the end of life: a prospective cohort study of people with cancer receiving palliative care cited in PHE 2015 What we know now 2014

8. What more do we need to know?

- How can we improve knowledge about Tower Hamlets patients' and families' perspective on quality of care, to enable services to meet people's needs?
- Are there differences in access to last years of life services by different population and groups and people with different health conditions? (including integrated care, specialist palliative care from acute trusts and from hospices, befriending and bereavement services from commissioned community organisations)? How can GP registration data which includes ethnicity, be used to measure equity of access to services?
- What are the factors which lead to differences in quality of experience, including avoidable hospital admissions, for different population groups and people with different underlying conditions? What can we do to reduce inequalities?
- How can the hospice care model be extended so that people who die in other settings (particularly in hospital) have the same experience of care as those who die in hospices?
- How can we strengthen resources in the community so that healthy dying can be discussed more openly, and local people are enabled and supported to voice their own preferences for future care?

9. What are the priorities for improvement?

Current State	Evidence for Effective Intervention	Recommendation
High rate of deaths in hospital High number of days spent in hospital preceding death	Reduction in unplanned admissions, delayed discharges and readmissions through personalised care planning and co-ordination of health and social care services	<ul style="list-style-type: none"> • Care planning, shared records, care navigation, 24/7 rapid response, discharge planning on admission • Strengthen partnership working and communication between all service providers, people and their carers • Assess the need for increased care home accommodation in the borough • Evaluation of integrated care to include information about the pathways of people who have since died
Need to improve quality of services in last years of life	<ul style="list-style-type: none"> • Person-centred care for people and their carers and families • Improve quality of care in hospitals • Better pain relief for people who die at home 	<ul style="list-style-type: none"> • Training in Last Years of Life care with support from specialist palliative care for all health and social care staff including care homes • Training should centre around listening to and understanding the person, understanding their own role and the role of other workers • Review of hospital palliative care; assess how 'hospice in hospital' function can be achieved • Ensure high quality and accessible support for carers and families including bereavement care
Low proportion of people have their preferences about end of life recorded and shared	<ul style="list-style-type: none"> • Early identification of palliative care need by primary and social care • Care planning with people and their families/carers • Shared records • A supportive community which talks openly about death and end of life 	<ul style="list-style-type: none"> • Training for all health and social care staff in having difficult conversations • Shared records including with people and their families/carers • Evaluation to demographic data for people whose preferences are/were recorded and met • 'Compassionate community' approaches to engaging local people in discussion, support and planning for last years of life
Inequalities in experience and access to palliative care between people with some conditions e.g. dementia, HIV ... and between different groups e.g. people with learning disabilities, homeless people, people who misuse drugs and alcohol	<ul style="list-style-type: none"> • Identifying people less likely to experience high quality care and to access services • Target services, to make them more accessible to these groups and support access to services 	<ul style="list-style-type: none"> • Extend the equity audit of specialist palliative care services to include other services for last years of life • Review the care pathways for groups less likely to experience high quality care e.g. people with learning disabilities, people who are homeless, people who misuse drugs and alcohol and people with certain conditions such as HIV. • Engage with and provide training and support for staff in services which work with these groups • Training and support for staff, families and carers in meeting the needs of people with dementia
We need to hear more from the perspective of service users to enable services to better meet local needs	<ul style="list-style-type: none"> • Consulting bereaved carers enables services to be benchmarked and identifies areas for improvement 	<ul style="list-style-type: none"> • Work with partners to introduce or modify services in line with findings of the 2015 local VOICES survey of bereaved carers, building on areas of good practice and addressing areas where improvement is needed. • Work with stakeholders, including community partners to identify how best to hear about experiences of last years of life care, so that local people's voices can routinely shape the way services are delivered • Ensure that health and social care services record carers' details and seek and respond to their views.

10. Contacts / Stakeholder Involvement

Ruth Bradley: Director of Care, St Joseph's Hospice
Margaret Clifford: Consultant in Palliative Medicine, St Joseph's Hospice
Claire Dow: Consultant Community Geriatrician and Clinical Director, Community Health Services Barts Health
Barbara Disney: Commissioning Manager Adult Social Care Commissioning LBTH
Brian Turnbull: Service manager Hospital social work team LBTH
Julie Dublin: Transformation manager, Tower Hamlets Clinical Commissioning Group (CCG)
Savitha Pushparajah: Clinical lead for Complex Care, Tower Hamlets CCG
Victoria Tzortziou Brown: Clinical Lead for Integrated Care, Tower Hamlets CCG
Folake Abayomi-Lee: Transformation Manager Tower Hamlets CCG
Dianne Barham: Tower Hamlets Healthwatch
Dave Barnard: Tower Hamlets Linkage Plus
Abigail Knight: Associate Director, Public Health
Richard Fradgely: Director of Integrated Care, East London Foundation Trust
Ali Rusbridge: Locality Manager (London and South East), North East London Skills for Care

	NAME	CONTACT DETAILS
UPDATED BY	Judith Shankleman Senior Public Health Strategist, LBTH	judith.shankleman@towerhamlets.gov.uk
SIGNED OFF BY	Abigail Knight, Associate Director of Public Health	abigail.knight@towerhamlets.gov.uk

Last Years of Life
Tower Hamlets Joint Strategic Needs Assessment
Appendix 1

Figure 11

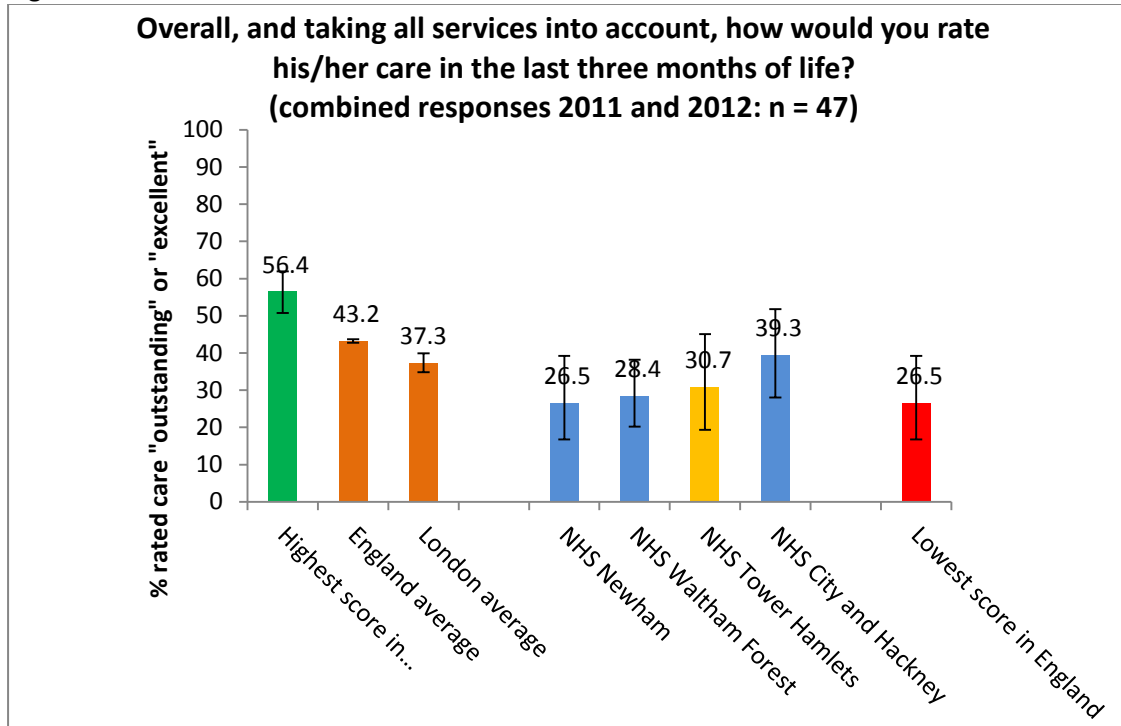


Figure 12

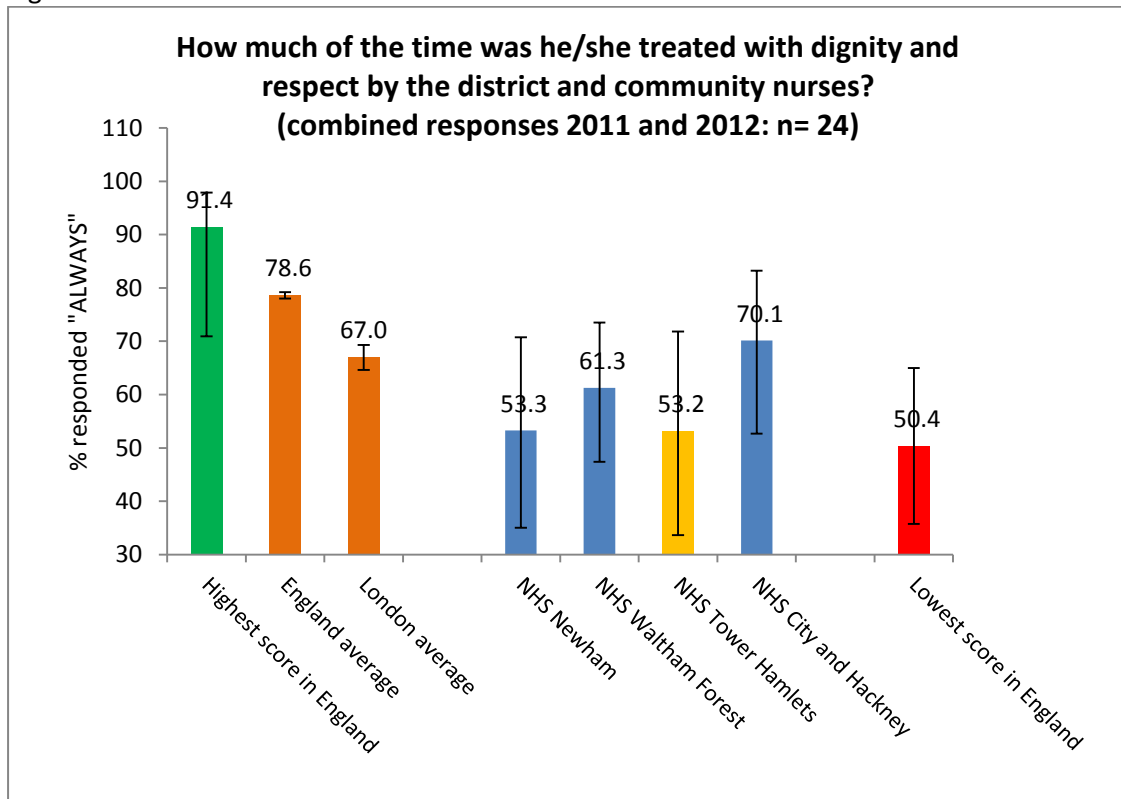


Figure 13

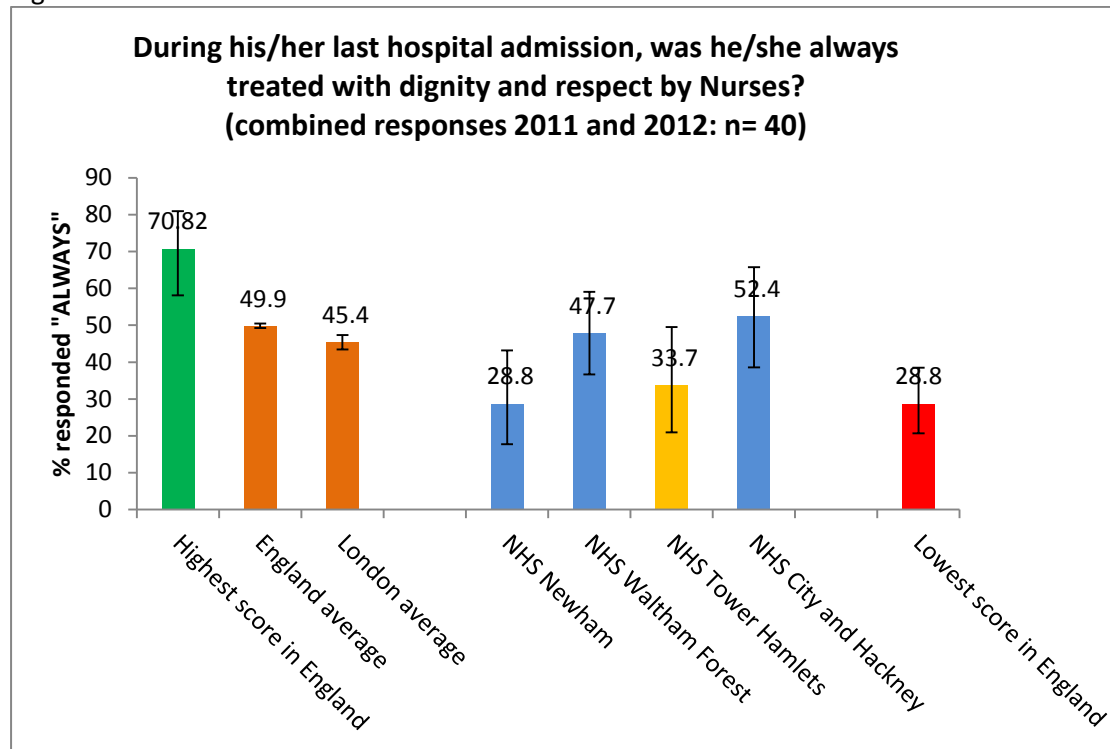
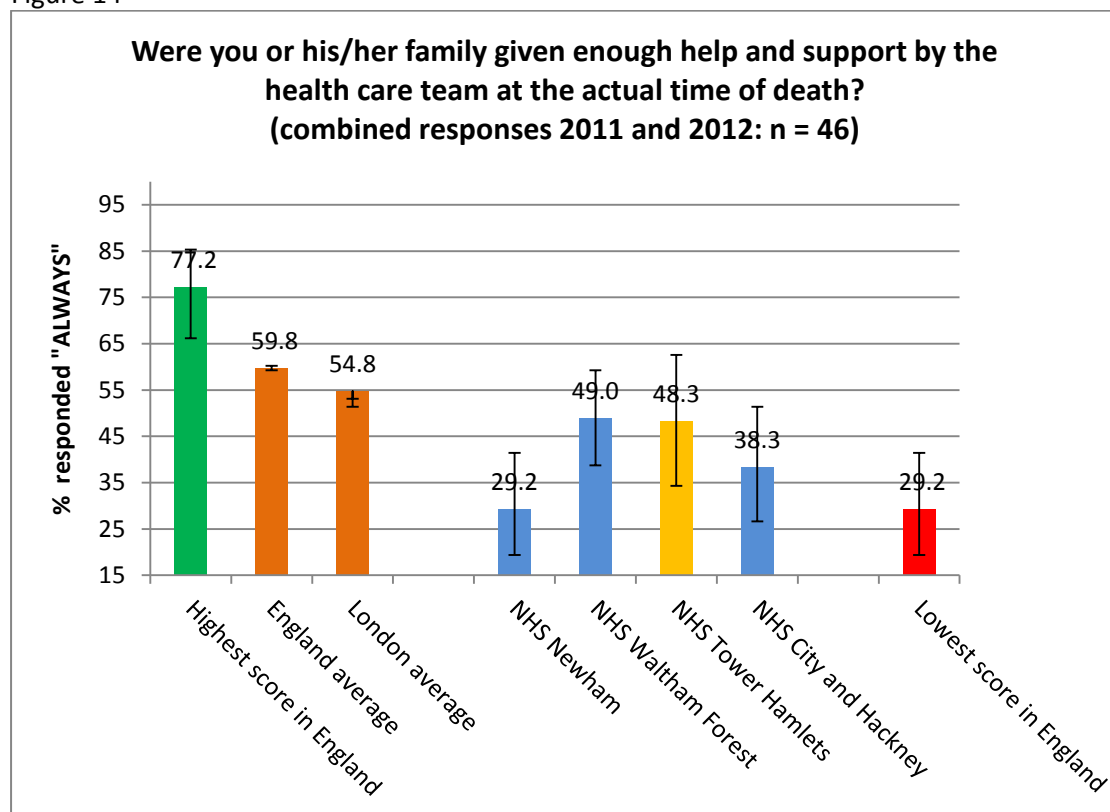


Figure 14



Source: ONS National VOICES survey of bereaved people