Appendix 1

Report of the Health Scrutiny Panel

Review of End of Life Care

Tower Hamlets Council
May 2009

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Chair's Foreword

It is rarely easy to speak about death and dying. But every year around 1200 people die in Tower Hamlets and these people and their loved ones are entitled to the best possible care the Council and its partners can provide. We need to talk together about end of life, and think through the findings and recommendations of this report, for the sake of all those who live and die in our community.

Sadly not all people who die in Tower Hamlets receive the care they want and need. Many residents who would choose to die at home, instead, end their life in hospital. Delays in arranging transportation or equipment can cause distress to families and carers who want to look after the dying at home. More support to give carers confidence, skills, training and equipment is vital and this requires a greater degree of co-ordination across agencies.

If there is one single recommendation from this report that has the potential to really make a difference in improving the care of the dying in this Borough it is the establishment of a single joint post that will be responsible for ensuring the healthcare of the NHS is better integrated with the social services provided by the local authority. Clearly some of these recommendations have a financial cost, but if we can improve care of those at the end of their life, enabling those who wish to die at home to do so, there will be savings in reduced length of hospital admissions. However, regardless of cost, end of life care must reflect the choices made by the dying person.

This report looks at end of life care from a Tower Hamlets perspective and identifies areas where care and support services can be improved in our Borough. A great number of local people have contributed to this report and I was struck by the care and compassion of the many professionals and unpaid carers who look after those who are at the end of their life. I also noted, and I hope this report reflects, the frustration and sense of urgency of colleagues who identified where things are not working well. All these contributions have been valuable and I thank everyone who contributed to the review for sharing their expertise and experiences. In particular I wish to thank the Scrutiny officer, Shanara Matin, for co-ordinating the review and collating the evidence upon which the findings were based.

Whether a person dies in hospital, a care home or their family home, a peaceful, dignified, private death should be the natural end to life. One aspiration of the Tower Hamlets community strategy is to make the Borough a great place to live. We can only achieve this if our community is supportive, responsive and caring when a person reaches the end of their life. I hope and believe this report contributes to turning that aspiration into a reality.

Councillor Dr Stephanie Eaton
Chair, Health Scrutiny Panel

Chapter 1 – Introduction

Background

1. The Health Scrutiny Panel is the statutory body in Tower Hamlets established to respond to duties placed on local authorities by the Health and Social Care Act 2001. This includes having in place an Overview and Scrutiny function that can respond to consultation by NHS bodies on significant changes and developments in health services and to take up the power of Overview and Scrutiny on broader health and wellbeing issues.

2. The overarching aims of health scrutiny are to:

    - Identify whether health service provision reflects the views and aspirations of the local community
    - Ensure all sections of the community have equal access to health services
    - Ensure that all sections of the community have an equal chance of a successful outcome from health services.

3. These specific powers and duties are achieved by putting patients and the public at the centre of health services.

4. Each year the Health Scrutiny Panel undertakes an in-depth review of a health and or social care issue identified as a local priority within the context of a four year work programme focused on reducing health inequalities (2006/10). This document is the report of the health scrutiny review of 2008/09 into End of Life Care in Tower Hamlets.

The review process

5. End of life care as a potential health scrutiny review subject was discussed with local health trusts during the induction programme for Health Scrutiny Panel members in June and July 2008. The Tower Hamlets Primary Care Trust (NHS Tower Hamlets from 1 April 2009), Barts and the London NHS Trust and the East London NHS Foundation Trust welcomed the proposed review.

6. During the scoping period for the review, the Primary Care Trusts' adopted the Delivering Choice Programme which pilots the Marie Curie toolkit to redesign and improve end of life care services.

7. The Health Scrutiny Panel was keen to ensure that the scope of the review would add value to the Delivering Choice Programme and would avoid duplication over lines of inquiry and investigation.

8. It was agreed that the review would complement the pilot of the Delivering Choice Programme. While this programme has a strong focus on health service provision, the health scrutiny review undertook to

investigate more fully the relevant social care services and other related services for which the Council has primary responsibility. During the scoping process members heard anecdotal evidence that there were challenges in providing a seamless service for recipients of end of life care and there was a clear role for the Health Scrutiny Panel in identifying improvements in the integration of health and social care to meet an individual's needs and choices.

9. Members also identified the challenge of making discussion of death and dying more acceptable across the community and the role of community leadership in raising the concept of a planned or good death.

10. The review did not consider end of life care provision for children and young people. Death and dying of young people is particularly traumatic and it was felt that a review in this area would pose different challenges. We felt that end of life care of the young would benefit from a specialist investigation and therefore consideration of this group was excluded from the scope of this review.

One Tower Hamlets considerations

11. The review focused on how local people from all communities experience and access end of life care. As expected, a large number of recipients of end of life care are older and for many, their care is influenced by the need to manage illness and disability. The take up of end of life care services is lower for BME communities especially hospice services. The number of older Black and Minority Ethnic (BME) people is set to grow as the historically younger age profile of these residents' changes over time. Members considered how service improvements would meet current and projected needs in the Borough and considered the role of the faith community work in improving awareness and access to end of life care services. The Council's Equalities team commissioned a report in 2008/09 on the health and social care needs of older lesbian and gay people living in the Borough which was reviewed for information related to end of life care.

Aims of the review into end of life care

12. To review how social care provision of end of life services meets the needs of local people and; to examine the co-ordination of health and social care at end of life. The review considered the policies, practices and systems that determine the provision of these services and identified solutions to the barriers faced by local people in accessing end of life care.

Review Objectives

13. The objectives of the review were:

1. To scrutinise and contribute to the Tower Hamlets PCT End of Life Care Services Improvement Programme, “Delivering Choice”
2. To investigate the barriers to choice, and equality of access to social care provision of end of life care services amongst equalities groups
3. To assess the co-ordination of health and social care in end of life care services
4. To investigate the needs of carers of people at the end of life
5. To examine the role of the voluntary, community and faith sectors in end of life care provision
6. To identify improvements to the commissioning process as a lever to improving end of life care
7. To consider ways to improve the availability of information on services for patients, carers and professionals.

14. The Panel's work programme is outlined below:

Stage 1 (Oct 08)	• Defining scope of review • Consideration of national and local policies • Delivering Choice Programme Objectives
Stage 2 (Oct 08 – Jan 09)	Evidence Gathering from: • Care-Plus Project: Carers Centre Tower Hamlets • Interim findings of the Delivering Choice Programme • National Audit Office Report on End of Life Care • Care Homes • Adult Health & Wellbeing Directorate • Older LGBT Matters
Stage 3 (Dec 09 – Feb 09)	Visits • Older People’s Panel • Royal London Hospital Chaplaincy Visit / Interfaith Forum • Older People’s Reference Group Meeting and Focus Group
Stage 4 (Mar 09)	• Draft report and consultation

Chapter 2 - National Policy Context

15. Each year around half a million people die in England. The care provided to these people, their families and carers, is a significant component of the workload for many health, social care, and voluntary sector staff. However, too often care for this people at the end of their life is not co-ordinated effectively across the different service providers, and is not designed around people’s expressed wishes and preferences about their care.

16. In response to these challenges, the government has put in place a number of initiatives to improve care for people at the end of life. These

include: the development of National Institute for Health and Clinical Excellence guidance for supportive and palliative care for adults with cancer (2004), the NHS End of Life Care Programme, and the NHS Next Stage Review which have all contributed to the national End of Life Care Strategy launched in July 2008. The strategy recognises that improvement is required to ensure that people can access high quality care at the end of their life, irrespective of age, gender, ethnicity, religious belief, diagnosis or care setting, and that this care respects each individual's needs and preferences.

17. The End of Life Care Strategy is supported by £286 million of funding to improve the quality of care for all adults approaching the end of their life. Its aim is to provide more choice to people about where they would like to live at the end of life and where and how they would like to die. The strategy champions a growing national momentum towards improving end of life care within primary care, care homes, and considers care for patients with all end-stage illnesses in the final months and years of life. The ten year strategy is the first of its kind.

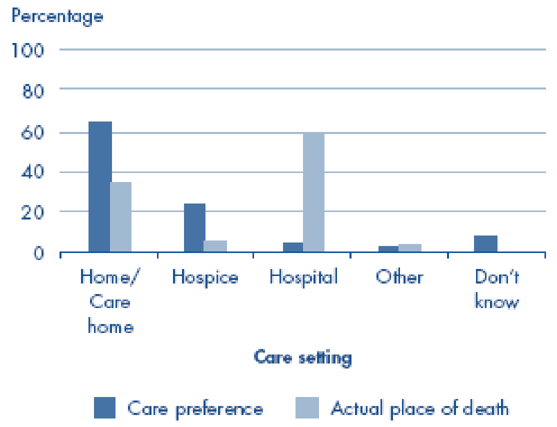
18. The National End of Life Care Strategy will include:

- **Improved community services** – working with PCTs and Local Authorities to ensure that rapid response community nursing services are available in all areas at all times. This is to enable more people to be cared for and die at home if they wish
- **Workforce training and development** – to train health and social care professionals in assessing the needs of patients and carers to provide the best possible quality of care at the end of life.
- **Development of specialist palliative care outreach services** – encourage PCTs and hospices to work together to develop specialist services in the community, to support all adults regardless of their condition
- **Setting up a national End of Life Research initiative** – to further understand how best to care for those at the end of their lives.
- **Quality Standards** – to develop quality standards against which PCTs and providers end of life care provision can be assessed.

19. The strategy notes that implementing end of life care pathways requires a major organisational commitment to the goal of improving care of the dying, and may require specific resources and local leadership.

20. The National Audit Office produced a comprehensive report on resourcing and challenges facing end of life care provision following the publication of the National Strategy in July 2008. The report is discussed in more detail within the review findings. Some of the national level data from the report is included below which demonstrate the current challenges faced within this care sector.

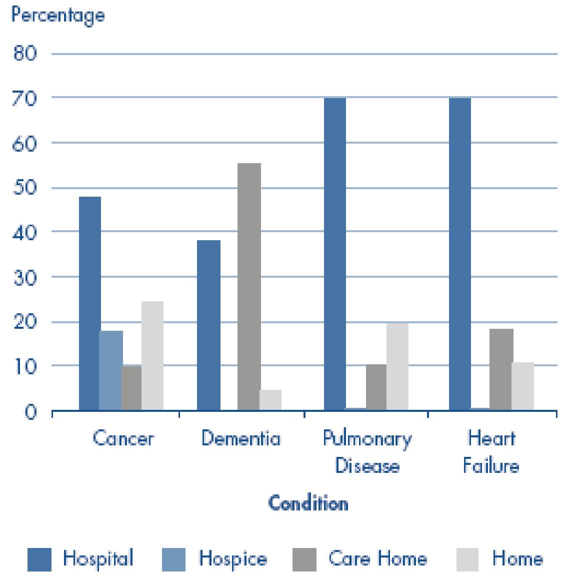
1. Comparison between people's preferences and actual place of death



Source: "Views About Dying at Home", survey commissioned by Marie Curie in 2004 of 2,453 people in Great Britain, carried about by You Gov and 2006 Office for National Statistics Mortality Statistics for England

NOTE

As 'care home' was not an option in the 2004 You Gov survey, but is recorded as a place of death in the 2006 Mortality Statistics, these categories have been merged for the purposes of this comparison.



Source: National Audit Office analysis of 2006 Mortality Statistics for England

2. Place of death varies by condition

21. Fig.1 presents the comparison between people's preferences and actual place of death. This suggests that many more people choose to die at home than are able to and suggests that Hospitals are one of the least likely preferences.

22. Fig 2 highlights the way medical condition influences people's place of death with heart and pulmonary disease patients most likely to die in Hospital.

Next Stage Review of Healthcare for London

23. Lord Ara Darzi's report 'Healthcare for London: A framework for action' set out radical changes to health service provision in London which, if implemented, will have a significant impact on London's health economy. Overview and Scrutiny Committees across London established the Joint Overview & Scrutiny Committee (JOSC) to review the plans within the report including the work of the End of Life Care Working Group.

24. Members of that working group provided evidence to the JOSC and the key points from their evidence is set out below. The information provides an insight into the challenges currently facing end of life services in London, including:

- 80% of the NHS workload relates to supporting people with chronic conditions.

- Surveys consistently reveal that the majority of people want to die at home or in a hospice. However, 70% of deaths in London take place in hospital, which is much higher than the rest of the country.
- End of life care in London is fragmented. The report proposes establishing five commissioning zones to achieve greater co-ordination of services. PCTs would be tasked to produce a specification of the required services to meet the needs of their population and commission providers for that zone. The providers would arrange for discussions to take place with individuals to find out their wishes for end of life care and then arrange for these services to be delivered (as far as possible). Service providers could be drawn from the NHS, or may be from the independent or voluntary sectors. Marie Curie deliver a similar service to fill gaps and improve services in Lincolnshire and this demonstrates the plans should roughly be cost neutral given the anticipated reduction in the number of people dying in hospital.

- The proposals will require people to overcome the taboo of talking about death. It will also require decisions to be taken to identify when someone is approaching the end of their life. It is not always straightforward to accurately predict life expectancy, although one option would be for people to be referred to end of life services when diagnosed with terminal illnesses.

- The proposals could impact on social care services, and like other aspects of chronic disease management it would be vital to ensure that the service specification for the end of life care providers include both health and social care.

- It was highlighted that these proposals (like other aspects of Healthcare for London) could provoke a debate about entitlement given that social care services are increasingly means-tested while health services are universal.

- Some London residents live in very poor quality accommodation and it is essential to ensure that these people are not forced to die at home. It was agreed that protections would need to be built into the system so that people who want to die at home are able to do so, while those wishing to die in hospital are able to also.

- It can be very difficult to find a terminally ill patient a place in a hospice, and an individual may be too poorly to be transferred by the time a space is available. Care homes often refuse to take a very ill resident back after hospital treatment despite this being the person’s home. This may be because the care homes do not feel they have the expertise to support a very sick resident or because they feel the death of a resident will affect their reputation. It was agreed that any proposals must address this situation.

25. In relation to palliative care for Cancer Patients the following points were made by the JOSC and are :

- Any reform must ensure appropriate out of hours care services are in place. Often when faced with severe pains or complications many patients currently attend Accident & Emergency (A&E) as other health services are closed.

- Further work is required to develop palliative care skills within general practice, and doctors may require additional training on how to offer emotional support to patients diagnosed or living with cancer. Carers must be identified and their views incorporated into end of life plans.

- Hospices do not receive guaranteed funding from PCTs and donations account for much of their income.

- The end of life proposals could impact on carers. It is vital to identify the needs of carers early on and ensure they have the support to cope in their role. Government policy currently means that carers receive less state financial support once they reach pensionable age.

- Disagreements between organisations as to what is ‘health’ and what is ‘social’ care can undermine the quality of care provided to individuals. Very sick people may not have time to wait for lengthy discussions to be resolved.

- Clinicians must be encouraged to start discussions with their patients about their life expectancy and end of life care when patients are diagnosed with a terminal illness.

- The proposals for end of life care will require additional community nursing staff. This will not happen overnight and has a financial cost. However, a failure to ensure that staff are in place will increase the burden on carers and lead to increased hospital admissions.

Chapter 3 - Local Policy Context

26. In Tower Hamlets around 800 people die in hospital each year, nearly 2/3 of all deaths in the Borough. Approximately 11% of hospital spend is on unplanned admissions which accounted for 21,000 emergency bed days in 2006/07. There is not enough anticipated planned care for people in the Borough even though most deaths are related to long term conditions.

27. On average there is one complaint a fortnight about end of life care arising from concerns about privacy, dignity and communication.

28. There are significant inequalities in access to end of life care, with people who have conditions other than cancer and people from BME groups tending to benefit least from specialist palliative care services. Strikingly, people living in care homes are even more likely to die in hospital than older people living in the family home.

29. The 2007 End of Life Care Baseline Review identified many services provided by health, social care, voluntary and community providers in the Borough. However it was difficult to get a clear sense of the quality and capacity of what is available and how to best access these services.

Baseline Review

30. Tower Hamlets Primary Care Trust baseline review of end of life care included the audit results of the Liverpool Care Pathway and the Gold Standards Framework. These are key tools, frameworks and pathways to guide staff and utilise the various assessment processes to recognise people who are at the end stages of life, identify their palliative care needs and support carers. The baseline review concentrated on Trust commissioned services and that of known established providers such as Hospices and Marie Curie nursing services.

31. Of the1200 deaths a year in Tower Hamlets nearly 75% of deaths were amongst people over 65. 47% of all deaths are at the Royal London Hospital with people in their last year of life accounting for 20% of emergency and 13% of planned hospital bed days. Lengths of stay for people in their last admission ranged from 15 days where the stay was elective to 24 days in emergencies.

32. The baseline review looked at social care provision to carers. The findings in this area concluded that assessment criteria would not identify many carers in need but that very basic support services could make a real difference to their quality of life.

33. The final place of care was revealed to be influenced more by disease, provision and resources rather than the patient's / carer's wishes. A number of contributing factors were identified by the review:

- Inequalities in accessing available care
- Difficulties in navigating and choosing appropriate services
- Poor knowledge of available services amongst generalist staff who are involved in providing end of life care.

The Delivering Choice Programme

34. Following on from the Baseline Review, Tower Hamlets Primary Care Trust implemented the Marie Curie Delivering Choice Programme to assess and deliver service improvements to the way end of life care services are provided locally. The programme focuses on engaging leaders, managers, clinicians and frontline staff, service users and wider communities – in short all stakeholders in the process of understanding needs and the current state of services and redesigning models of care.

Conclusions

35. There are a number of high profile national and local programmes looking at how to deliver patient choice at the end of life. Members of the working group discussed the scope of the scrutiny review in the context of these broader programmes of activity. The working group concluded that it would be appropriate to focus the review on end of life services provided by the Council. This included looking at the integration of health and social care but also supplementary services that are key to supporting and managing dying and death in the community. The working group also undertook a critical friend role to the Delivering Choice Programme.

36. Social and economic inequalities prevent many people from accessing appropriate services and dying at home when they want to. Tower Hamlets is the third most deprived local authority in England and has the third highest proportion of people living in the most deprived localities (Indices of Multiple Deprivation, 2007). One of the factors that could help mitigate against the impact of inequality is having good access to a network of carer and professional support to enable people to live as well as they possibly could. The NHS Baseline Review of long term conditions and palliative care highlights the wide range of services that exist in the Borough and suggests that these services could be well placed to overcoming the impact of inequality.

37. A large majority of deaths in Tower Hamlets follow a period of chronic illness, where people are known to health and social care providers. This suggests that services could be redesigned to trigger active consideration of end of life care issues when appropriate. However, health and social care professionals will need to be sufficiently confident to manage these discussions with individuals, and will need training to ensure they are aware of all services available to residents at the end of their life.

Chapter 4 – Findings

38. Members of the Panel held the first formal review meeting at the Princess Royal Carers' Trust Centre in Tower Hamlets. The working group received presentations from Lyn Middleton, Chief Executive of the Carers Centre Tower Hamlets on the Care-Plus Tower Hamlets project and the services the Trust provides to carers more generally. The second presentation by John Roog, Service Head, Adult Health and Wellbeing Directorate at Tower Hamlets Council focused on the points in a person's end of life care where social care interacts with health services. .

39. The Carers Trust presentation put forward key facts about carers nationally and locally, highlighting the sacrifices of carers and their support needs. There are currently 6 million unpaid carers in England and Wales saving the taxpayer £87 billion or the equivalent cost of another National Health Service. 80% of carers admit their caring role has an adverse effect on their health and the greatest worry for most carers is the concern over what would happen to the person they look after if they became ill. The number of carers is expected to increase by 50% over the next thirty years.

40. In discussing the strains that are often placed on Carers and the way people can fall between services, Lyn Middleton gave an example of a carer carrying their relative up and down stairs in their home over a long period of time and who was now in need of surgery to replace kneecaps. The carer's GP had not asked what had caused this health problem and the carer's needs were therefore not identified.

41. The issues around arranging carer's assessments identified carers as often not identifying themselves as carers. Many people see their caring responsibilities as fulfilling the role of a partner, child etc. The key challenge to enabling people to access the right services for the people they care for and themselves is recognising their role as a carer.

Care-Plus Tower Hamlets

42. The presentation covered the interim findings of the Care-Plus Tower Hamlets project, a three year research project funded by the Kings Fund. The project has been piloting an enhanced carer support service to

determine the impact of a single point of contact for care co-ordination for carers of patients with end stage heart failure. It has been identified as being good practice by the Audit Commission and the Kings Fund. The evidence showed that well supported carers can prevent unnecessary hospital admissions and identified that carers feeling unable to cope was a primary reason for taking the cared for person to hospital.

43. The services provided by the Care-Plus project included counselling, social activities that improve quality of life and support with financial issues for example benefit applications and maximising income. The project co-ordinator was also able to make applications for funding from charitable trusts when needs fell outside the remit of social care funding. A referral protocol specifically for end of life care packages has also been developed with St Joseph's hospice, enabling the co-ordinator to make direct referrals of patient and or carers into their services.

44. The Care-Plus project showed that successful fast tracking to appropriate services and tailored co-ordination of support resulted in an approach that works for the individuals who are delivering care but also for the organisations providing the goods and services.

45. In describing the key findings it was said that the Carers centre are able to be more flexible and try different routes as they do not have the same internal bureaucracies to deal with. One of the examples given included where the NHS are only able to provide patients with home nebulisers. Where these are needed all the time by patients, having a home based nebuliser can adversely affect the individual's quality of life as they become house bound. Without the same bureaucratic constraints faced by public service providers the Care-Plus project organised for a portable nebuliser for the patient and thereby dramatically improving both patient and carer mobility and quality of life. The project had also been able to respond to other specific local needs for example the project has a short term wheelchair loan facility for people waiting to receive one through the formal process of application to social care services which can take weeks to complete.

46. Members discussed the issues behind these examples and whilst they welcomed the Joint Strategic Needs Assessment approach to Commissioning it was felt that that in order for the commissioning process to be genuinely responsive to people's needs it should allow commissioned services flexibility to meet to these needs.

47. Health care professionals who have referred patients into the project have reported that they have been freed up to carry out their primary role and develop a more satisfactory relationship with patients in relation to their medical need. Clinicians and professionals interviewed as a part of the project overwhelmingly said that the service works extremely well and that they have a great deal of confidence referring their patients to the project and valued the ongoing contact with the co-ordinator.

48. The care plus project had managed 62 cases at the time of the review meeting, costing approximately £660 per person per year. The project is currently meeting expanding demand by taking on two final year nursing and social work students as volunteers. The Carers Centre Tower Hamlets has been asked to prepare a business case for continued funding. As at end of March 2009 there was not confirmed funding in place for the continuation of the project in the PCT Commissioning Intentions for 2009/2010 or from Social Care funding.

49. In subsequent meetings members discussed the role of the project in improving the quality of life of the individual and their carer through this approach. The focus on end stage heart failure reflected local community needs as coronary heart failure is a major cause of death in the Borough. The project has won a number of national good practice accolades and Members were keen that public service providers should learn from the experience of the project and the Care-Plus project be commissioned to continue and expand its work.

Recommendation 1
That the Care-Plus project be commissioned by NHS Tower Hamlets and London Borough of Tower Hamlets for a minimum of a further two years. The scope for disseminating learning from the project locally should be explored within the commissioning of the project.

50. The working group wanted to review the findings of the Older LGBT Matters report capturing the experiences of older lesbian, gay, bisexual and transgender adults in Tower Hamlets. The research project commissioned by the Scrutiny & Equalities Service at Tower Hamlets Council had been asked to include where appropriate any evidence around the experience of death and bereavement within the LGBT community. The nature of the research meant that it was not specific to end of life care but did reveal that services across the board could be much improved to meet the needs of the LGBT community and indeed the needs of residents who do not typically live in a “nuclear” or intergenerational family setting.

51. Throughout the review the working group heard anecdotal evidence of the need to recognise the role and rights of carers, partners and friends of the person coming to the end of their life. In particular there is a need to identify a way of recording an individual’s preference for who could make decisions on their behalf if they are no longer able to do so.

Recommendation 2
That the needs and rights of carers, partners, single sex partners and friends be recognised within the context of end of life care. In particular the tools used to facilitate discussion with families at end of life be extended to cover these groups.

National Audit Office report on End of Life Care

52. The working group reviewed the recently published National Audit Office Report (NAO) on End of Life Care (November 2008) as part of the discussion during the review meeting. The report states that:

> *"Provision of end of life care services has become increasingly complex: people are living longer and the incidence of frailty and multiple conditions in older people is increasing. As a result, people approaching the end of their life require a combination of health and social care services provided in the community, hospitals, care homes, or hospices."*

53. Members discussed the suggestions within the report for learning from the hospice movement and how skills could be disseminated through outreach services and training. Councillor Stephanie Eaton described her experience of visiting St Joseph's Hospice as part of the evidence gathering work for the review.

54. St Joseph's is the only local provider of hospice services to residents of Tower Hamlets. The hospice is a tremendous success story in the range and quality of services it is able to provide to people at end of life. During the visit Councillor Eaton discussed some of the challenges faced in promoting further uptake of these services, particularly by ethnic minority communities. In part this was attributed to the way that hospices are perceived as places where "you go to die", a service specifically for Christians or a perception that hospice support is Cancer specific. St Joseph's Hospice is tackling these issues by promoting the facility as a pain and symptom management service. St Joseph's is keen to deliver more community services through outreach work. Members were keen that the NHS Trusts in Tower Hamlets and the Council work in partnership with the Hospice in relation to the training of health and social care staff and the potential for joint outreach work in the community. Planned services include a new self-management facility and refurbishing of an area of the hospice that will be available to anyone who wishes to know more about end of life care. The new centre will offer information, advice, support and services, including a public education programme, available to schools and other community groups. The hospice is currently piloting the education programme with a Tower Hamlets Primary School.

55. Members of the working group pointed out that there were many 'tools' and methods being discussed as ways to improve end of life care services for example the Liverpool Care Pathway, Gold Standards Framework for use in primary care and Preferred Priorities of Care. They concluded that there was a need to simplify the model of care for people at end of life. This would benefit the individual patient but also simplify the process for the professionals using these tools. It was suggested that having one model with four or five criteria to identify and facilitate care across health and social services during end of life would be beneficial.

Recommendation 3
That the Council and NHS Trusts work in partnership with St Joseph's Hospice to extend hospice care in the community; and train health and social care and care home staff on managing end of life care discussions.

Coordinating Health and Social Care

56. John Roog, Service Head for Older People & Homelessness at Tower Hamlets Council, delivered a joint health and social care presentation that set out the patient pathway at end of life and the points at which health and social care interact.

57. The NAO report on End of Life Care states:

> *"Coordination between health and social care services in relation to the planning, delivery and monitoring of end of life care is generally poor and is hampered by different funding streams. It can be difficult to determine what proportion of patients' needs are medical and fall under the NHS budget, or non-medical (social care) and are funded, in part, by local authorities and by the patient based on a needs assessment. A lack of integrated services and an absence of a single point of contact to coordinate care can lead to particular frustration."*

58. Amongst the challenges that were discussed in coordinating care at end of life the key factors that Members commented on were the need to prioritise improving the discharge process. Members felt that it was important to get transport and appropriate equipment into place and organised as part of the discharge process. Members were disappointed to hear that transport from the Royal London Hospital, needs to be booked twenty-four hours in advance and that this could be the sole factor keeping a dying person in hospital.

Recommendation 4
That the NHS Trusts in Tower Hamlets and London Borough of Tower Hamlets prioritise co-ordination across health and social care during discharge from hospital and as a part of this work that the major Hospitals in Tower Hamlets explore options to prioritise the transport needs of those at end of life.

59. Members asked questions about the usefulness of Advance Directives and wills to prevent conflict between an individual's wishes and those of the family during what can be a highly emotional time. A number of the working group members expressed concern about the potential for financial abuse of people that are cared for by friends or family and the need to have in place warning systems that prevent elder abuse.

Recommendation 5
That the Council provide signposting and advice services on how to make wills and put in place Advance Directives and that these

should be linked to information provided by the Births, Deaths and Marriages Registry services in the Borough.

Improving information share

60. Members attended the Older Peoples Panel which co-ordinates packages of care across health and social services for older people as a result of which the panel decisions also includes co-ordinating services and products for people for those who may also be at end of life. The working group welcomed the individualised approach taken to deciding care and the shared responsibility across service providers which prioritised the needs of residents before the decision about whether the Council or the PCT would be funding that care.

61. Members felt this was a valuable start to taking an integrated approach to care whilst formal processes are being developed to achieve better coordination of services. Members' key observations were that the method for sharing information about individual cases could be improved and that this should be looked at immediately to improve the efficiency of the Panel. The current approach is ad-hoc and reliant on individual professionals 'completing the picture' of a case. The benefits were apparent in that it provided a genuinely person-centred approach. However it was felt that this process could be more efficient and consistency of through having key information about patients e.g. medical history or diagnosis, names of key people involved including carers and professionals, and, the current services they patient was accessing as standard information to be shared ahead of the meeting. Members recognised that currently there is no administrative support to the Panel to enable this to happen.

62. It was unclear whether there is an audit trail of the decisions that are taken or that there is an evaluation process for the outcomes achieved. These would be important considerations if the Panel is a long-term approach to coordinating care for end of life care patients amongst its wider client base. Members asked questions about how issues such as Adult Protection were managed and whether there were any warning systems in place for professionals to raise concerns about an individuals care.

63. Social care services are provided on the basis of needs in terms of wellbeing and quality of life. This is a different organisational and cultural approach to the way health services identify end of life care needs. Members felt that a common approach should be agreed if integrated provision is to become a reality. Members discussed the role that a common definition could play in integrating care. It was felt that a definition was an important starting point and could benefit the commissioning process, by highlighting the need to recognise that an individual's end of life experience is likely to affect their level and type of needs in the context of possible rapid decline, the needs of carers and families and how healthcare and medication is administered to them. A

common definition will not necessarily deliver integration of care as a working reality – it would however help social care service provision to consider the need to have services that respond very quickly to changes in need.

Recommendation 6
Health and social care services develop a common definition of end of life care to be understood by all staff working with older people in particular. The definition should agree the trigger for health and social care services to consider the end of life care needs of the individual.

Recommendation 7
A joint health and social care post be created to lead on the integration of health and social care services for end of life. The remit of the role would include creating a joint protocol for information share across health and social care including for the Older People's Panel and for co-ordinating care at the key points where health and social care interact.

Supplementary Services

64. In Tower Hamlets there is a much higher than national average of people ascribing to a faith. The diversity of faiths is also a particularly important feature of the communities that make up the hyper-diverse profile of the Borough. Members were keen to explore the faith needs around end of life care and the challenges that poses to service provision.

65. A visit to the Royal London Hospital Chaplaincy team was carried out on 9th February 2009 to which members of the Tower Hamlets Interfaith Forum were also invited.

66. The group highlighted some of the faith related needs around end of life care and in the immediate period following death. For example as part of their religious beliefs the Orthodox Jewish Community need to stay with the body before burial. Similarly friends and family needing to stay with patients, have needs around kosher food provision and to factor in that they are unable to use transport services during the Sabbath. A common feature for both Muslim and Jewish communities was the need to avoid post mortems and for rapid release of bodies where possible to enable quick burials.

67. A question was raised about the Council's position on the Coroners Bill and whether the options to introduce MRI scanning as an alternative to post mortems would be supported. Councillor Eaton attending the visit on behalf of the working group stated that there were no specific plans for the local authority to comment on the Bill that she was aware of, but she would highlight the value placed by faith communities on alternatives to post-mortems through the review.

68. The group also discussed the need for a rapid death certification service in Tower Hamlets. In the past the service had been piloted to cover the weekend closure period but was subsequently closed. Members of the Chaplaincy team were currently exploring what the service needs are and the group discussed the scope for an inter-borough approach to a rapid death certification service because of the nature of people moving across borough boundaries to access acute care and whether it would be more cost-effective through a wider geographic coverage funded by pooled resources.

69. Currently local residents can obtain emergency burial certificates on Saturdays between 12.00pm and 4.00pm through the Registrar and on Sundays and Bank Holidays there is a standby service for emergency burial certificates only between 9am and 10am (information from the Council Website). There is also a fast track certification service available through Barts and the London NHS Trust hospitals but not well known. Members who attended the visit heard anecdotal evidence that communities found it difficult to access existing services in some cases because they are not widely publicised.

70. In discussing the social care needs of individuals at end of life the group highlighted a number of cases where care was not in place when a patient was due to leave hospital. This was hampered by the limited scope of the role of hospital social workers to co-ordinate care as well as the difficulties caused by an increasingly stringent means tested approach to providing care.

71. The people attending the visit raised the need to be careful about the diversification of service delivery with partners so that individuals do not get ‘lost’ in the system. At a number of points in the review Members discussed the end of life care directories (professional and patient variations) that had been commissioned by the Tower Hamlets Primary Care Trust and questioned the capacity of the organisations listed to be able to cope if the raised profile of organisations led to increased demand. They also questioned the accessibility of a written directory given the vulnerability of people at end of life and the challenges posed by the demographic profile in Tower Hamlets.

72. In reviewing the evidence from the visit the working group considered the Council’s responsibility over some services that can facilitate and ease pressure on carers, families and individuals at end of life and in dealing with death. These supplementary services include information on writing wills and Advance Directives (as captured in Recommendation 4) to protect vulnerable adults but also to provide clarity about peoples wishes. It was also agreed that the current Registry services for death certification meant that some families of individuals could be significantly delayed in arranging the burial of their loved ones. This is seen by communities not only as a key religious priority but key to people’s cultural attitudes to bereavement and coping with the loss when a family member of close friend dies.

73. This reinforced the need for early discussion about end of life care and the need to prevent invasive treatment where this was against the wishes of the individual. The working group also considered the impact of housing conditions and overcrowding in the Borough on peoples choices over where they wanted to die but also of problems getting equipment into accommodation with restricted access. It was said that given the condition of some of the housing stock and the lack of data available on how people living in Tower Hamlets view end of life, it would be wrong to assume that people want to die at home especially on an extrapolation of national data as the basis of this.

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Recommendation 8
That the NHS Trusts and the Council review their provision of rapid death certification services to take account of local community needs including that of faith and explore the options for an inter-borough service to ensure 24 hour coverage. The service that is developed as a result of this will need to include a community engagement plan to publicise and improve access to the service.

Challenge of talking about death and dying

74. The working group were keen to explore community views about end of life care provision and sought to get these views in a number of ways. This included an editorial article in East End Life and requests to community organisations to invite people to participate in the review. The challenge in generating these responses led to the working group opting to seek views in alternative ways. It did however also highlight the innate challenge of gauging community views around death, dying and the care needs related to that. The experience of the review discussions has been that it can be very emotionally charged and rooted in diverse cultural taboos around talking about death and dying.

75. The working group visited the Older Peoples Reference Group to discuss the review objectives and emerging findings. The subject was very emotive and difficult to separate out a discussion of the objectives of the review and peoples views that were on principle against having the consultation with the group on this subject. There were a number of people who did want the discussion to take place and were keen to see the taboo of talking about death and dying being addressed and there was a great deal of internal challenge within the group. The difficulties of the discussion within the group in many ways reflect the wider challenges around making talking about death and dying more acceptable in order to improve end of life care and the need for professionals to be highly skilled in managing these discussions. It was agreed that a follow up workshop would be held to look at the findings more closely and to give people the space to think about issues in a less formal setting. Councillor Ann Jackson who attended the reference group on behalf of the working group agreed to support a further discussion.

76. Unfortunately, the two participants who had found discussion most difficult failed to attend the workshop. It did however include participants who felt ambivalent about the subject or had questioned the review objectives and the reference group being asked to comment on this subject in particular. There was an enormously rich diversity of opinions about the challenge of talking about death, how dying should be managed and the needs of carers. "A wide range of issues were raised and discussed addressed elsewhere in this report such as the difficulty for people in facing and discussing death and end of life issues; "Living Wills"; making a will, dying at home; role of and impact on carers; the need for a directory of end of life services for families."

77. The experience of engaging communities to talk about end of life care for this review highlighted the challenge faced by health and social care professionals in beginning these sensitive discussions. People taking part in the discussions suggested that the Council should explore funding organisations such as Age Concern to facilitate community discussions around end of life care.

78. St Joseph’s Hospice also submitted information on their work to engage with ethnic minority communities as further ways of facilitating discussions around end of life. The Hospice has been working with Social Action for Health, a local community development organisation to work with mosques, local community centres, social clubs and schools to talk about the work of the hospice. They have opened up discussions about people’s experiences, anxieties and aspirations with regard to end of life care, which have been fed back to hospice staff enabling them to consider how to develop services which are sensitive to the needs of the wider population.

Recommendation 9
the Council consider piloting a programme of community based discussions on end of life care.

The importance of an advocacy role

79. In Tower Hamlets there are many services that could be used by people and their carers at end of life that would improve their quality of life and mitigate against the adverse impact of poverty and inequality in the Borough. Members welcomed the proposals within the Delivering Choice programme to understand this provision more fully and how it can be better co-ordinated.

80. Across all the review evidence sessions and visits there was an ongoing theme of the positive role advocates can play in the context of end of life care. The National Audit Office report, Care-Plus project and the challenges people spoke of and seen by the working group of knowing what services there are and accessing the right services in time was the most significant challenge to good end of life care. Carers and

individuals at end of life often did not have the time, confidence or knowledge about who and how to contact the services they need.

81. The working group also reviewed the findings of Phase 1 of the Delivering Choice Programme. Members welcomed the honest and open way in which local challenges to providing good end of life care were addressed and welcomed all the proposed workstreams in the report. Members felt that in arriving to many comparable and similar conclusions through the health scrutiny review process, that this reinforced the value of the research and investigative work that the Delivering Choice Programme had delivered.

82. There are a number of workstreams related to improving communication across services which must underpin any redesign of services and key to enabling a single co-ordinator to pull together different service as one care package. Members agreed that the approach to managing care for an individual at end of life should be led by an advocacy approach.

Recommendation 10
n the basis of a common definition of end of life care being agreed by the Council and NHS Trusts, individuals should be assigned a single point of contact for co-ordinating all subsequent care.

Staff Training and Confidence

83. Staff training and confidence had been identified as a key issue by the early work that Tower Hamlets Primary Care Trust had done to begin improving end of life care services. It is also a key feature of the findings of Phase 1 of the Delivering Choice Programme. During one of the review meetings members of the working group received presentations from Care Home representatives which highlighted some of the challenges faced by staff in the care home context. This included issues of non medical staff being trained to administer medication to enable people to die at home wherever they consider home to be. The discussion also explored some of the cultural challenges faced by staff in responding to the diversity of needs and views around death and dying in their day to day caring role.

84. Tower Hamlets commissions care across six local care homes. They deliver services independently and commissioning is done predominantly on a case by case basis with some contracts. There is a need to explore how these services are commissioned more strategically and for commissioning to be used to influence or incentivise service providers positively around training and development of staff confidence around managing end of life care issues. As part of the Single Status negotiations covering staff providing Home Care services a new agreement adding the administration of medicine to the cared for has just been agreed.

85. The care home representatives also highlighted issues around access to resources such as syringe drivers which often hampered staff ability to administer medication and respond to out of hours needs as much as possible within the care home. This type of equipment can represent significant costs to privately run businesses and they would welcome consideration of how access to these resources held by health care services could be shared. Members were keen that options be explored for care homes to purchase or have access to syringe drivers so that this did not prevent or delay treatment for individuals in care homes.

86. Members welcomed the range of options currently in use to improve end of life care provision such as the Gold Standards Framework, Liverpool Care Pathway and tools such as the Preferred Place of Care. Members felt that it would be important to ensure however that there was a balance between having a range of tools in place and whether this supported or hampered improved training and staff confidence and for example which tool would best be suited to a care home setting.

87. The working group discussed the evidence that there are a greater number of people at end of life living in care homes who die in hospitals than those living independently. The care home representatives acknowledged the challenges and underlying lack of staff confidence in dealing with these issues but highlighted the pressures on care home staff in terms of the wide range of training they are expected to complete of which end of life care is one part.

88. The proposed quality markers for care homes set out by the Care Quality Commission indicate a much more demanding performance regime around end of life care which was welcomed by the working group. The working group felt that it was important that health and social care service commissioners take into account that care homes identified time and resourcing as key barriers to achieving better trained, resourced and more confident staff able to deal with end of life care.

Recommendation 11
That a strategic approach to commissioning care homes be developed taking into account the need to deliver high quality and efficient services but also in a way that ensures there are sufficient resources and flexibility for care home staff to take up training to meet the end of life care needs of residents.

Chapter 5 – Conclusion and Recommendations

89. This section draws together the recommendations emerging from the review which it is hoped will help to contribute to improving provision and co-ordination of end of life care for local people. Some of the recommendations build on each other and it is important that they are viewed in the whole by the organisations asked to respond to these to achieve the anticipated outcomes.

90. The working group recognise that end of life care is a very broad field of care provision and were clear from the outset that given the health service focus on improving provision through the Delivering Choice Programme it was important for the health scrutiny review to focus on areas that would add value to this programme. For this reason the health scrutiny review did not explore issues that were being extensively addressed through the Delivering Choice Programme. For example the needs of children with terminal illnesses, the needs of mental health patients or the specific health care services e.g. palliative care, out of hours services etc that are key to delivering good quality end of life care services.

91. In reviewing the progress of the Delivering Choice Programme, Members are very supportive of all the proposed workstreams in the Phase 1 report and commend the programme team for the honest, frank and comprehensive way in which the challenges have been mapped and described in the report. Members are keen that the findings are used to seek the appropriate funding from the Department of Health and from within Primary Care and Council resources that will deliver the step change required in end of life care provision in Tower Hamlets.

92. The working group recognise that responding to the varying and individual needs of people at end of life and the needs of their carers is challenging for both health and social care. Members are keen to see greater use of voluntary and community sector provision that can ease the pressure on health and social care provision. The lessons learnt and good practice emerging from the Care-Plus project also has potential to inform the action plan in relation to Recommendation 9 and how the Primary Care Trust and Council could develop care to be coordinated through a single point of contact.

Recommendation 1
That the Care-Plus project be commissioned by NHS Tower Hamlets and London Borough of Tower Hamlets for a minimum of a further two years. The scope for disseminating learning from the project locally should be explored within the commissioning of the project.

93. Advance Directives are documents which set out an individuals choices should they become unable to voice them through illness or reduced capacity at end of life. These are discussed further in Recommendation 5 which should support longer term planning of end of life care. There is however a need also for service providers to take into account the role of carers, single sex partners who may not have had a civil partnership or marriage ceremony and friends in determining end of life care provision for an individual.

Recommendation 2
That the needs and rights of carers, partners, single sex partners and friends be recognised within the context of end of life care. In

particular the tools used to facilitate discussion with families at end of life be extended to cover these groups.

94. The Hospice movement has a history and rich diversity of knowledge on facilitating discussion and managing the delivery of end of life care services which should be tapped into by health and social care professionals who are likely to work with individuals at end of life. The level of training and awareness required by professionals will vary and should be agreed by the services managing these staff.

Recommendation 3
That the Council and NHS Trusts work in partnership with St Joseph's Hospice to extend hospice care in the community and train health and social care and care home staff on managing end of life care discussions.

95. Discharge from hospital is a key point at which coordination of health and social care needs to come together effectively. There are cultural and procedural barriers to change which need to be addressed now to ensure that vulnerable people are neither dying in hospital waiting to go home, nor are going home to die without the adequate care arrangements being made.

Recommendation 4
That the NHS Trusts in Tower Hamlets and London Borough of Tower Hamlets prioritise co-ordination across health and social care during discharge from hospital and as a part of this work that the major Hospitals in Tower Hamlets explore options to prioritise the transport needs of those at end of life.

96. Members discussed at length the benefits that supplementary advice and signposting services could have in facilitating end of life care discussions but also avoid family disputes and prevent the financial abuse of elderly people who may have reduced capacity to make decisions at end of life.

Recommendation 5
That the Council provide signposting and advice services on how to make wills and put in place Advance Directives and that these should be linked to information provided by the Births, Deaths and Marriages Registry services in the Borough.

97. Two thirds of deaths in the Borough are "expected", in that they are generally people nearing the natural end of their lives or have been diagnosed with a chronic or terminal illness. Social care provision is broadly age and means tested which is in contrast to health care provision which is universal and free at the point of delivery. These are significant organisational differences that need to be overcome to achieve genuine integration. Members were keen however to include ideas for developing a common definition under which integration could be secured at critical points in the end of life care pathway.

Recommendation 6
Health and social care services develop a common definition of end of life care to be understood by all staff working with older people in particular. The definition should agree the trigger for health and social care services to consider the end of life care needs of the individual.

Recommendation 7
A joint health and social care post be created to lead on the integration of health and social care services for end of life. The remit of the role would include creating a joint protocol for information share across health and social care including for the Older People's Panel and for co-ordinating care at the key points where health and social care interact.

98. The working group recognised that there were a number of areas where the Council and NHS services could work to improve the experience of death and dying for individuals and their families by providing culturally or faith sensitive services, giving them confidence that their spiritual needs following death will be met.

Recommendation 8
That the NHS Trusts and the Council review their provision of rapid death certification services to take account of local community needs including that of faith and explore the options for an inter-borough service to ensure 24 hour coverage. The service that is developed as a result of this will need to include a community engagement plan to publicise and improve access to the service.

99. The focus group discussion with members of the Older Peoples Reference Group highlighted the difficulty and challenges of talking about death and dying. It also raised a number of issues around the impact of a lack of dignity and respect for the dying individual and their families' wishes can have on how people cope with dying and bereavement. Members would like to see greater consideration of bereavement needs through the Delivering Choice Programme and the key role that voluntary and community sector organisations are able to play in this area. Although this was not a specific area of investigation as part of the scrutiny review, Members were keen to ensure that work is undertaken to facilitate discussion about death and dying and removing the taboos around the subject, seeing it as key to planning for end of life care.

Recommendation 9
That the Council consider piloting a programme of community based discussions on end of life care.

100. Members welcome the suggestions within the Delivering Choice Programme report for better coordination of care including ideas for have

a one stop shop approach for accessing the wide range of services available. The evidence that has been looked at as part of this review indicates that a single point of contact for individuals and their carers is key to effective coordination. Members are keen that future health and social care workstreams to improve end of life factor this in as a priority.

Recommendation 10
That on the basis of a common definition of end of life care being agreed by the Council and NHS Trusts, individuals should be assigned a single point of contact for co-ordinating all subsequent care.

101. The working group felt that it was important to recognise care homes as the ‘home’ of the person living there and that it be treated as such in line with an individuals wishes. This should preface training and staff confidence building measures particularly in care homes and with professionals responsible for discharging patients from hospitals. Members believe that much greater results could be achieved by taking a strategic lead on commissioning care homes and that there is scope for working in partnership with care homes on sharing good practice and providing training.

Recommendation 11
That a strategic approach to commissioning care homes be developed taking into account the need to deliver high quality and efficient services but also in a way that ensures there are sufficient resources and flexibility for care home staff to take up training to meet the end of life care needs of residents.

102. On the final recommendation it is useful to reflect on the National Audit Office report conclusion on the scope and possibilities for delivering improvements through service redesign and better commissioning.

> *“Given the potential to redistribute resources identified in our work, there is scope for PCTs to improve services in all settings by deploying existing and future resources more efficiently and effectively in supporting people in their preferred place of care. To achieve this improvement, there will be a continuing need for the Department to support PCTs as they reconfigure services and redeploy resources to better meet the needs of their local population.”*

103. This highlights an opportunity to get processes and services underpinning end of life care right and future proofed to meet the increasing needs of an ageing population. The working group puts forward these recommendations as a way of supporting this overarching objective.

Scrutiny in Tower Hamlets

To find out more about Scrutiny in Tower Hamlets

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