



National Audit Office

A Review of the Provision of End of Life Care Services in City and Hackney Primary Care Trust



National Audit Office

2008

WHOLE SYSTEM REVIEW

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Part 1: Introduction

The NAO is carrying out a value for money study looking at the delivery of end of life care

1. Over the course of two days, four staff from the NAO health value for money team (the Review Team) conducted a qualitative review of end of life care services in City and Hackney.

2. The visit forms one strand of the study team's work on end of life care which will result in a full value for money report to Parliament in November 2008. Our work involves a range of methodologies including:

- (a) System reviews of end of life care provision at Herefordshire, Sheffield, and City and Hackney PCTs;
- (b) Surveys of PCTs, care homes, hospices and clinicians;
- (c) Focus groups of patients and carers; and
- (d) Economic and financial modelling.

3. Alongside these methodologies we are also working with the Balance of Care group on a retrospective review of the patient records of all patients who died of cancer, chronic disease, or frailty or who died unexpectedly in Sheffield in October 2007. This is a valuable piece of unique work which will provide demographic information on patients dying of these conditions, but will also examine how many hospital deaths might have been avoidable had alternatives been available and given due consideration.

4. Our study of end of life care services in England is currently in the analysis and drafting stage and its findings are due to be reported to Parliament's Public Accounts Committee in November 2008. The team would like to thank City and Hackney PCT and all those involved for agreeing to participate in this work for their support, knowledge and advice. We hope the findings prove useful in developing future end of life care services for the people of City and Hackney.

The Review Team met with staff and stakeholders to analyse the current situation and look ahead.

5. To gain an understanding of the strengths and challenges of end of life care in City and Hackney we interviewed over 30 people involved in the commissioning and delivery of services, including:

- (a) senior staff and managers from City and Hackney PCT;
- (b) acute care staff;
- (c) GPs and nurses;
- (d) Senior staff and managers from Hackney Council and City Council;
- (e) hospice staff;
- (f) care home staff; and
- (g) the Chair of the local Health and Social Care Forum.

6. The feedback and findings from these meetings were collated and analysed in conjunction with facts and figures taken from both internal and external sources including the PCT baseline review, ONS mortality data for 2007 and information presented during the visit.

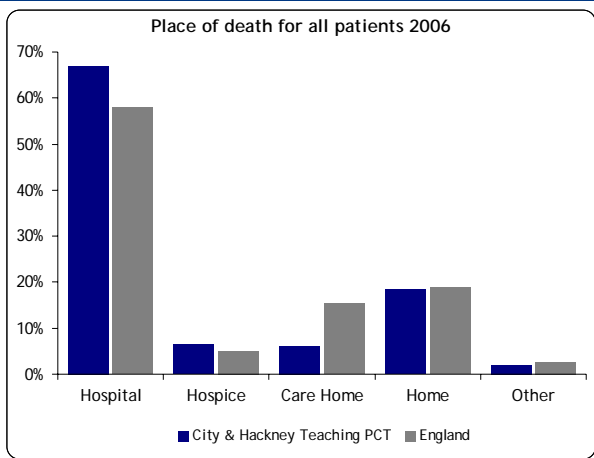
The Review Team recognises that end of life services in City and Hackney operate in a complex and changing environment.

7. Advances in medical care and changes in lifestyles mean that the average age of the population is increasing and patients with significant complex illnesses are living longer. As a result there is an increasing need for palliative and end of life care services.

8. End of life care is likely to receive greater media and public attention in the near future. The Department of Health published a National End of Life Care Strategy led by Mike Richards, National Director for Cancer, in July of this year. End of life care is also one of the eight care pathways included in Lord Darzi's review of the NHS.

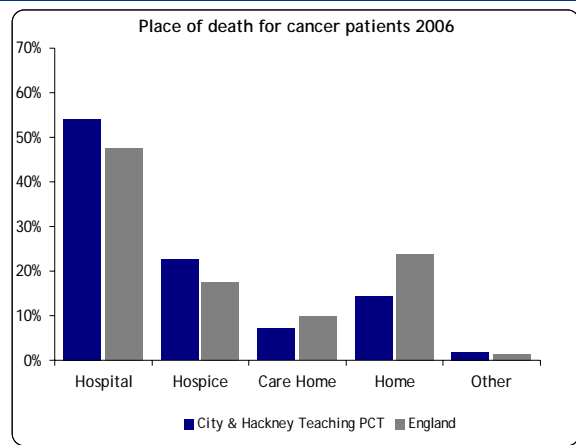
City and Hackney Facts & Figures

Place of death for all patients in City and Hackney PCT 2006



Data taken from 2006 Mortality Statistics

Place of death for cancer patients in City and Hackney PCT 2006



Data taken from 2006 Mortality Statistics

- 31% of all deaths occurred in Home, Care Home or Hospice and 67% in Hospital. City and Hackney’s national ranking for non-acute deaths across all diseases is 141st out of 152.
- City and Hackney is ranked as the sixth most deprived PCT area in England.
- City and Hackney has a comparatively low number of deaths per 100,000 residents, ranking 148th out of 152 nationwide.
- The NCPC population-based needs assessment for end of life care awarded City and Hackney a need index of 70 as compared to the national average of 92 indicating the PCT has a lower need than that indicated by the national picture.

Part 2: Strengths

This part of the review outlines the key strengths exhibited within end of life care provided in City and Hackney, as identified during the course of our interviews.

City and Hackney's end of life care providers are dedicated to their work and committed to providing the highest quality of care possible.

9. Staff providing end of life care in City and Hackney have both energy and passion for the work they do. At every level within the end of life community there is a commitment and desire to treat patients as individuals with dignity and respect and to enable them to have a good death in the absence of pain and other symptoms and in familiar surroundings. This commitment should be acknowledged as crucial to championing end of life care and driving future change.

10. Interviewees reported that the profile of end of life care within the PCT had been raised considerably during the last six months. The main driver for this was reported to be the completion of the baseline review carried out in preparation for the publication of the Department's end of life care strategy. Carrying out the baseline review was seen as a valuable process which had prompted lively debate about how different aspects of the end of life care services commissioned and provided by the PCT were working.

11. The PCT's Ongoing Care Board took on responsibility for end of life care following the completion of the baseline review. Within the PCT, the Board acts as the strategic body for planning and reviewing end of life care services across City and Hackney, and recently fed into the creation of the PCT's commissioning strategy for investing £450,000 in end of life care over the next three years. The Local Palliative Care Working Group, which has been in place for 18 months, now reports into the Ongoing Care Board. Interviewees reported that this arrangement has provided strategic direction and greater prominence for the Working Group.

End of life care services are treated with priority by the Homerton University NHS Foundation Trust, which offers holistic end of life care services.

12. The PCT has an above average level of hospital deaths (68 per cent). There are several factors which contribute to this, including:

- High levels of poor quality housing which is not always suitable as a care setting for people at the end of their life.

- The lack of residential care facilities for the elderly.
- The fact that the culture of some communities living within the PCT encourages the active treatment and use of acute care for people approaching the end of their life.
- The number of single households with no or limited carer support.

13. Given this, it is clear that the Homerton University NHS Foundation Trust has, and will continue to have, an important role to play in the delivery of end of life care services.

14. The hospital has an end of life board which is attended by the Medical Director and the Chief Nurse. The Liverpool Care Pathway is in use of four wards which represents around 50 per cent of the inpatient capacity of the hospital. There are plans to roll out this tool to all wards in due course.

15. In addition, the Hospital has a dedicated multi-disciplinary palliative care team consisting of a consultant doctor; three clinical nurse specialists; a clinical psychologist; a social worker; chaplain; and team secretary. The team carries out a range of activities including providing support with pain and symptom control, coordinating community care on discharge from hospital, and bereavement support services are provided to both out-patients and in-patients.

16. The team received 295 new referrals in 2006-07, and provided more than 2,000 nursing contacts. Less than two per cent of patients were not seen within one working day of referral. The team works across the entire hospital and around 25 per cent of patients seen have a condition other than cancer. It also works closely with St Joseph's hospice and a member of St Joseph's community team attends the multidisciplinary team meetings.

17. The Homerton University Hospital Social Work Team makes assessments of need and plans discharge services in collaboration with ward and community-based staff.

There are a range of end of life care services available to the people of City and Hackney.

18. There are a range of services for people with end of life needs:

- Thirty three GP practices provide Locally Enhanced Services for palliative care.
- District nurses assess, plan and manage the care of patients outside of hospital, including in patients' homes, GP surgeries and residential nursing homes. The support they provide seeks to avoid the need for patients to be admitted

into hospital and, where they have been in hospital, to help facilitate their discharge.

- Hackney Council's First Response Duty Team (FRDT) seeks to prevent unnecessary hospital admissions and facilitate discharge from hospital where patients have been admitted. Services are provided to a range of service users, including those requiring palliative care support. The FRDT is based at Homerton University Hospital.
- Hackney Council's First Response Provider Team (FRPT) provides the first six weeks of input for all new home care packages, including those put in place for individuals over the age of 18 nearing the end of life. The FRPT receives £200,000 of funding annually from the PCT and operates from 7.30am to 10pm, seven days a week. The team consists of two managers, four co-ordinators, two administrative staff, and 60 carers (30 in-house, 30 agency staff). Nursing support is also provided by the PCT's Adult Community Nursing Team and a specialist palliative care nurse.
- The City and Hackney Adult Community Rehabilitation team provides specialist assessments and therapy for adults with neurological conditions and physical conditions. The team consists of occupational therapists, physiotherapists, speech and language therapists, and a disability counsellor. Additional support is provided by rehabilitation assistants, a consultant allied health professional and a consultant neurologist. Around 20 per cent of the people seen by the team are end of life care patients.
- St Joseph's Hospice, founded in 1905, is one of the largest hospices in the country with 48 beds and 300 staff. The Hospice's specialist palliative and end of life care services include inpatient care; outpatient services; community care; and bereavement support before and after death. St Joseph's Hospice also provides all of its patients and the health professionals supporting them with access to clinical support and advice 24 hours a day.
- TLC Care Services, a voluntary sector organisation, provides personal care and respite support for carers 24 hours a day. TLC services are available to people over the age of 50 whose diagnosis is non-cancer. TLC also provides a night sitting service which has received very positive feedback.
- Marie Curie provides nursing and personal care support to patients, including those with a non-

cancer diagnosis. The service is available over night.

- Bereavement services are commissioned by Hackney Council and are provided to residents over the age of 50.

A number of noteworthy cases of good practice were brought to the attention of the Review Team.

19. Interviewees highlighted a number of examples of good practice in service delivery which they believed had been particularly successful. These included:

- (a) The pooled budget arrangement for Hackney Council's First Response Provider Team, which receives £200,000 of funding annually from the PCT, was working well.
- (b) The Locally Enhanced Service for palliative care provided by 33 GP practices was viewed as a positive development. Interviewees spoke of the commitment of the GPs and the value of the additional services they offer. Each practice delivering enhanced services appoints one GP and one administrator to be responsible for end of life care. The practices meet as a group every two months, either as a clinical teams or administration teams, or jointly. Since the introduction of the enhanced service, the number of practices utilising the Gold Standards Framework tool has increased from three to 33. Participating practices also provide data on end of life care patients (for example, medication needs) to the out of hours provider, Camidoc.
- (c) Interviewees spoke highly of the specialist palliative care services offered by St Joseph's hospice. The hospice also carries out a range of community outreach activities in order to learn more about the needs of its diverse local population and to raise awareness of its services. This work has included hosting lunches with local population groups; commissioning a public health analysis; and working with a community development agency to send health guides into local communities to seek their views on the hospice and issues around death and dying. More recently the hospice has started engaging with schools in order to access and raise awareness in communities where the adult population may not understand what a hospice is or speak English.
- (d) The First Response Provider Team has two occupational therapists (OTs) in its team which carry out assessment's of patient's caring needs. The introduction of the OTs has sped up

equipment provision and facilitated the delivery of more flexible care packages.

- (e) One of the care homes we visited, Acorn Lodge, encourages all of its residents to register with a single GP upon entry to the home. The GP visits the home at least three or four times a week and prescribes any medication required by the residents. Although it was initially difficult to identify a GP willing to take on this role, it has simplified the arrangements for residents accessing GP services and medication. The Chief Executive of the Agudas Israel Housing Association which runs a Jewish care home in Hackney also told us that it has an arrangement for its residents to be treated by a single GP.
- (f) Hackney Council has social workers who specialise in palliative care.
- (g) Adult Community Rehabilitation team. One fifth of the patients the team deals with are at the end of their life. The team recognises the need to react quickly and works with organisations such as the Motor Neurone Disease Association to gain speedy access to specialist equipment.
- (h) St Joseph's Hospice has recently recruited a locality focussed manager for the City and Hackney Team of the Community Palliative Care Team. They also have a triage nurse who specialises in expediting referrals appropriately. Both of these are service improvements which have been identified within the last year.
- (i) Hackney Council funds a carers centre which is run by a voluntary provider and the PCT funds a night-sitting service provided by Marie Curie. Interviewees did, however, report that there is scope for take-up of the night-sitting service to be increased. The PCT is currently taking steps to raise awareness of the service amongst GPs and district nurses.
- (j) The PCT is funding a post for a palliative care psychologist based at the Homerton Hospital within the cancer team. Funding has been provided for three years and the service will be available to both cancer patients and palliative care patients. The aim of the post is to provide continuity of care and avoid the need for patients to be reassessed as they move between care settings.

Part 3: Challenges

This part of the review outlines the key challenges and limitations of end of life care in City and Hackney, as identified during the course of our interviews.

City and Hackney PCT serves one of the most diverse and deprived populations in England.

20. City and Hackney PCT serves an extremely diverse population including White, Turkish, Kurdish, Black African, South Asian and Jewish residents. As a result, end of life care services within the area need to meet a wide range of needs and traditions around death and dying. The population is, however, relatively young with fewer people over 75 than the national average. The diversity of the local population means that English is often not a first language or, indeed, not spoken at all. With around 16 different languages spoken in the community, there is an increased need for translation services to overcome barriers in communication.

21. In some cases, young family members act as both translator and carer, either because they are the only person in the family that speaks English, or because those of working age are unable to carry out the role due to work commitments. In some cultures caring for elder family members is also seen as being the responsibility of the young. Some interviewees suggested that there is a higher than average high number of young carers in the community, although they were unable to quantify the extent to which this is the case.

22. Whilst the development of the City of London and Docklands have brought some wealth into the area and there is considerable regeneration taking place in preparation for the 2012 London Olympics, the City and Hackney is the sixth most deprived PCT area in England. Interviewees told us that people from deprived communities are less likely to access health and social care services and, as a result, present for care nearer to the end of life.

23. In certain circumstances, local living conditions can be unsuitable for providing end of life care in the home. For example, difficulties can be encountered in attempting to fit equipment into small rooms or within high rise flats. With patients lacking the resources to make alterations to their own properties and the Council having insufficient capacity to deliver alternative housing arrangements at short notice, such problems are difficult to overcome and can lead to barriers in the effective delivery of end of life care in the home.

24. Interviewees also spoke of an increasing number of people living alone in Hackney due their families having moved out of London to nearby counties such as Essex and Kent. As a result, such people do not have any family to care for them near the end of life and may have a greater need for services if they express a preference to die at home or be more likely to be admitted to hospital.

25. The PCT area also covers the City of London, which is the smallest local authority in London with a population of around only 8,000. During 2007, end of life care services were required by only four patients. The population within the area is predominantly white, although there is a large Bangladeshi population. Whilst there is a relatively wealthy population living in privately owned properties in the Barbican area, this contrasts starkly with two council housing estates and a housing association estate.

26. Interviewees noted the relative absence of care homes in City and Hackney and attributed this to a lack of economic viability due to location costs and fewer people over 75 than the national average. This potentially results in reduced care for end of life care patients due to fewer places in care homes being available. One care home we visited described difficulties in recruiting and retaining suitably qualified staff as a result of only being able to pay the minimum wage.

27. Several interviewees spoke highly of the services offered by St Joseph's hospice, however, some expressed concern that it is perceived to be an organisation that caters only for Roman Catholic or Christian members of the community. The Hospice was fully aware of this perception and also noted that some groups do not fully understand the role of a hospice. In order to address this, St Joseph's has been engaging widely with communities in its area to raise awareness of its services and its desire to meet their religious and cultural needs.

28. The services provided by St Joseph's Hospice are provided at no cost to service users. However, the Hospice costs around £12 million a year to run. In recent years the Hospice's expenditure base has increased substantially, in part due to the need to remain competitive in terms of securing the specialist staff it requires by matching local NHS Agenda for Change pay rates for its entire staff. The nine PCTs for which St Joseph's provides services contribute around 40 per cent (£5 million) of its funding, with the remaining £7 million having to be raised through fundraising events, donations and legacies. However, the unpredictable and non-repeatable nature of legacies and donations which, due to the fact that people are living longer and spending more, are decreasing, mean that without

developing other fundraising strategies the Hospice will increasingly struggle to maintain services.

Communication with patients and between service providers could be improved

29. Interviewees highlighted the need to improve the confidence and competence of staff in beginning the discussion about death and dying with patients and their families. Early discussions and decisions regarding when a person is approaching the end of life can improve the planning and integration of services and enable better care plans to be put in place. This issue was also identified by the baseline review, particularly in relation to patients with conditions other than cancer. In order to tackle this issue, the PCT's commissioning strategy for 2008/09 includes provision for training which aims to raise awareness of conditions with defined end of life phases, support staff in identifying patients with such conditions, and improve the communication of this information about death and dying to patients.

30. A number of interviewees highlighted the need for provision of information to carers and patients regarding what end of life care services are available to them, and what benefits they are entitled to receive. Confusion regarding funding rights and access to benefits can be a cause of stress for patients and their carers. Interviewees noted that some support is provided (for example, by care home staff or the First Response Provider Team), but that this is provided informally and on the basis of particular staff happening to have a knowledge of funding and benefit entitlements.

31. In City and Hackney, out of hours services are provided by Camidoc. Out of hours GPs do not always have a detailed knowledge of the patients they are called to treat and have to rely on the patient records being up to date. Some interviewees raised concerns about the continuity of care for patients out of hours, particularly in relation to the prescription of pain medication and death certification.

32. The baseline review identified the need for access to and delivery of end of life care services to be better co-ordinated. During our interviews the integration of acute and community services was specifically highlighted as being in need of attention.

33. Whilst there was generally seen to be a good level of communication between the PCT and Hackney Council, some interviewees suggested that there was a need for improved interaction with City Council. Indeed, there was an awareness that City can sometimes be forgotten about as a result of its small population; lower

need for end of life care services; and the perception that funding is not needed due to the relative wealth of some residents.

There are a number of valuable services offered which might benefit from expansion.

34. Interviewees highlighted several examples of good practice in service delivery which they believed could be expanded. These included:

- The district nursing service is not available 24 hours a day. However, following a review of district nursing services, the PCT has signalled its intention to develop a plan for delivering such a service, taking account of any recommendations from the review. Interviewees also highlighted the need for the district nursing service to be more proactive in making sure they are aware of patients who have end of life care needs.
- End of life patients often require medication to be administered during the night but the PCT does not have a 24 hour pharmacy and, whilst the out of hours service provider has a license to carry opioids it is still in the process of getting controlled drugs in place. The PCT has plans to develop a service for providing 24 hour access to end of life care drugs, including injectable opioids. Some interviewees, however, indicated that staff had concerns about the safety of carrying such drugs out of hours in City and Hackney. Pre-emptive prescribing is encouraged as an alternative means of addressing the need for drugs out of hours but some interviewees noted that there can be issues about leaving injectable drugs with certain families due to drug problems in the community.
- Interviewees stated that there were too few syringe drivers and staff trained to use them. Increased availability of syringe drivers and staff able to use them could lead to fewer admissions to acute care. A pilot study with two syringe drivers in the community is currently underway.
- Interviewees spoke highly of the bereavement services offered to the families of patients at St Joseph's Hospice but expressed a need for better provision of bereavement services for the families of those cared for in an acute setting or within the community. For example, the Hackney Bereavement Service commissioned by Hackney Council is only available to those over the age of 50. A service for residents of the City of London and those under 50 is expected to be in place by October.

Part 4: Recommendations

35. This part of the report outlines our high-level proposals and our suggestions for improving the provision of end of life care services in City and Hackney.

36. We realise that the limited duration of our visit means that we are not going to address all of the challenges facing the area. Our aim is for our ideas and suggestions to contribute to City and Hackney PCT's own internal work to improve its

end of life care services and we hope they are valuable.

37. The Review Team is happy to discuss further any of the recommendations it has put forward. These recommendations should be considered alongside those which will be made in our full study of end of life care services when it is published in November. We will also be producing individual feedback reports for each PCT to enable them to assess their data against other PCTs and prioritise areas for improvement.

1. The PCT should gain an understanding of the costs and benefits of its various end of life care services to enable it to better evaluate potential savings. For example, the potential costs and benefits of developing a service for providing 24 hour access to end of life care drugs; increasing the availability and use of syringe drivers in the community; and delivering a 24 hour response service.
2. Both the baseline review and this review have identified that improved coordination between providers could lead to more efficient and accessible end of life care services. The PCT should seek to identify any barriers to the coordination of end of life care services and identify any groups either not accessing services or with unmet needs.
3. The PCT should continue to explore the possibility of providing a support and information service for patients and carers to assist them in identifying and accessing the services and benefits available to them. In exploring this possibility, the PCT could draw on experiences of the telephone support which St Joseph's Hospice presently provides to its patients and their respective health professionals.
4. The PCT should continue in its efforts to raise awareness and take up of the night sitting service provided by Marie Curie.

ANNEX 1: Review Team Membership

The NAO Review Team consisted of the following members:

- Karen Jackson
- Tom McBride
- Kirsten Payne
- Colin Ross