

End of Life Care – Supporting Information, Data & Evidence

**September 2007 Working Draft for Clinical Chairs
Version 1.0**

Introduction

As part of the NHS Next Stage Review, groups of clinicians within each Strategic Health Authority area are being asked to focus on how to improve the quality of care provided to patients along 8 pathways:

- ❖ Staying healthy
- ❖ Maternity and newborn care
- ❖ Children's care
- ❖ Mental health
- ❖ Acute care
- ❖ Planned care
- ❖ Long term conditions
- ❖ End-of-life care

For each of the 8 pathways of care, a pack of supporting information, data and evidence has been compiled to help stimulate discussion, debate and ideas within the clinical working groups.

- **These packs are not comprehensive, nor are they deliberately exclusive.**
- **They represent an attempt to corral the publicly available information, data and evidence for each of the 8 pathways of care to support discussion.**
- **Neither the packs as a whole nor specific pieces of evidence should be taken to represent national policy.**

Chairs and members of the clinical pathway working groups are encouraged to supplement the information within these packs with any additional evidence that they are aware of as well as regional and local data.

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- Background / Introduction
- Facts and Figures
- Good practice and supporting evidence
- Questions / issues
- Annex

End of Life Care - Introduction

- Work has been underway to develop a national strategy to deliver increased choice to all adult patients regardless of their condition, about where they live and die. This work has taken into account the need to promote choice, improve quality, equality and value for money.
- In order to support SHAs with their local review of end of life care this slide pack draws on evidence which has emerged from the strategy development work on what good end of life care should look like.
- This pack sets out:
 - A definition of end of life care
 - The current issues and challenges
 - Basic facts on death, where people want to die and where they die
 - A care pathway for end of life
 - Evidence to support what good practice might look like
 - Case studies

End of Life Care - definition

- The phase 'end of life' ends in death. Definition of its beginning is variable according to individual patient and professional perspectives. In some cases it may be the patient who first recognises its beginning. In other cases the principal factor may be the judgement of the health/social care professional/team responsible for the care of the patient. In all cases, subject to patient consent, the beginning is marked by a comprehensive assessment of supportive and palliative care needs.
- End of life care helps all those with advanced, progressive, incurable illness to live as well as possible until they die. It enables the supportive and palliative care needs of both patient and family to be identified and met throughout the last phase of life and into bereavement. It includes management of pain and other symptoms and provision of psychological, social, spiritual and practical support.

(Ref: Operating Framework 2007-08: PCT baseline review of services for end of life care www.dh.gov.uk)

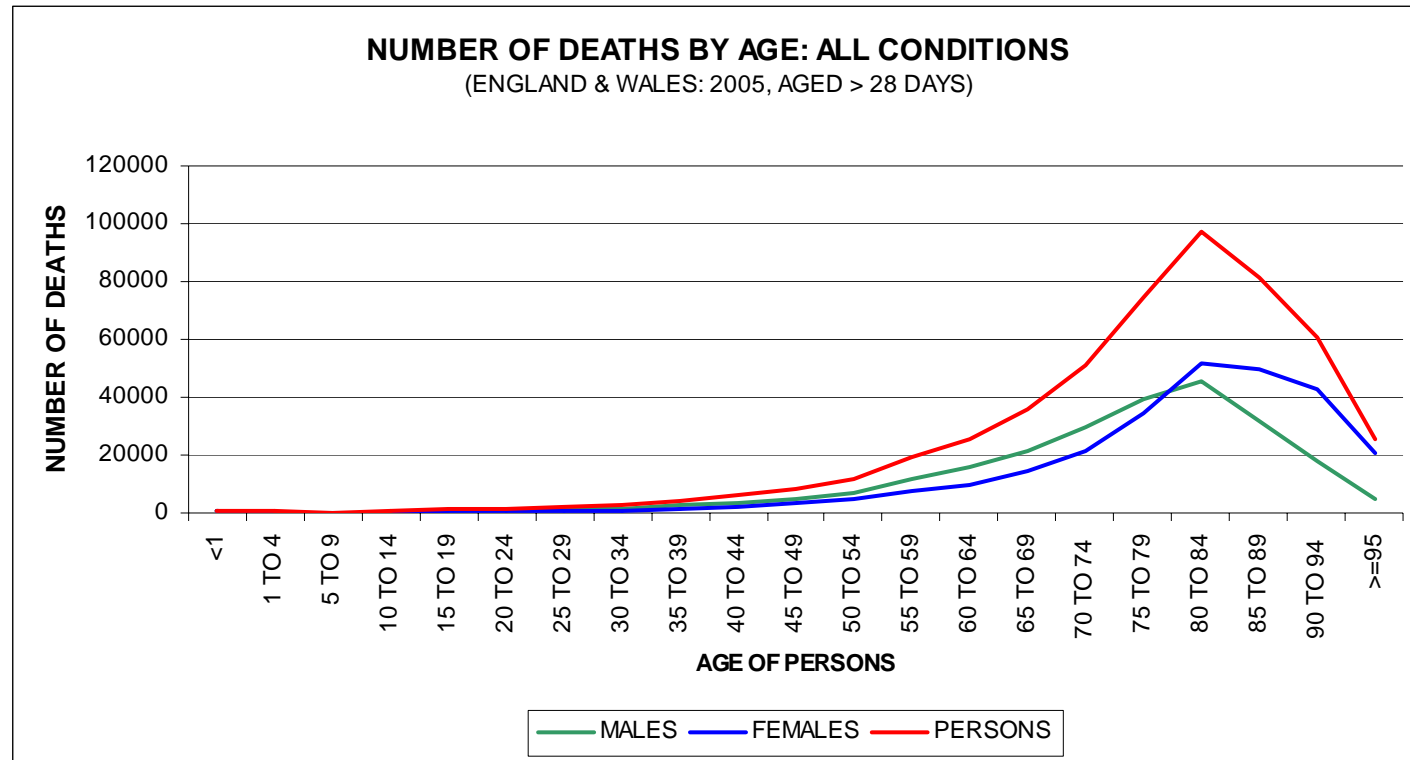
Current issues and challenges in end of life care

1. Lack of public awareness and discussion about death and dying across society as a whole
2. Low priority given to end of life care within the NHS and social care both commissioners and providers.
3. Lack of recognition in identifying people who may be approaching the end of life and initiating discussions about people's preferences for end of life care
4. Inadequate assessment and review of people's needs and preferences.
5. Poor coordination of care across the sectors, which leads to delays in setting up packages of care to meet people's needs
6. Suboptimal delivery of care in hospitals, care homes and the community
7. Poor care in the last days of life
8. Problems with verification and certification of death, viewing the body at mortuary and with return of the person's property to their family.
9. Inadequate support for carers
10. Inadequate education and training and support
11. The lack of robust measures to assess the quality and effectiveness of care
12. Inequalities in access to and provision of end of life care within a diverse population.

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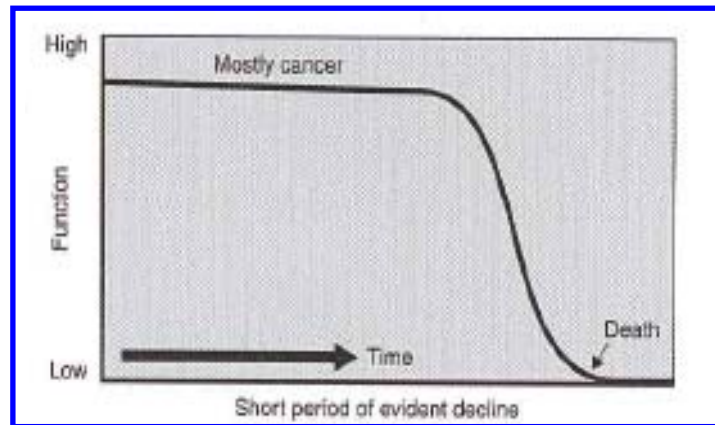
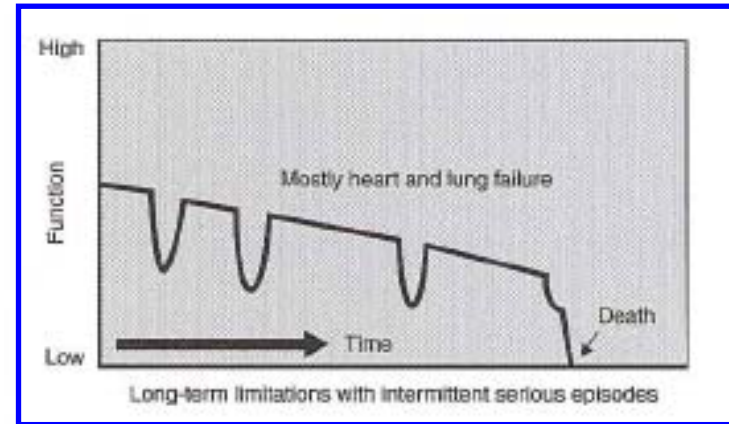
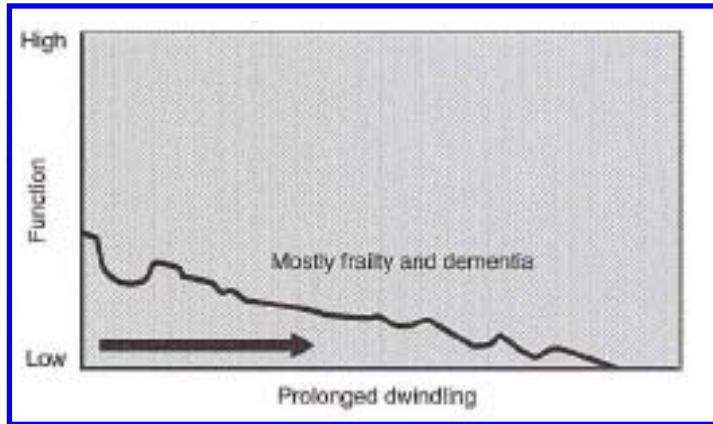
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Deaths by age and sex



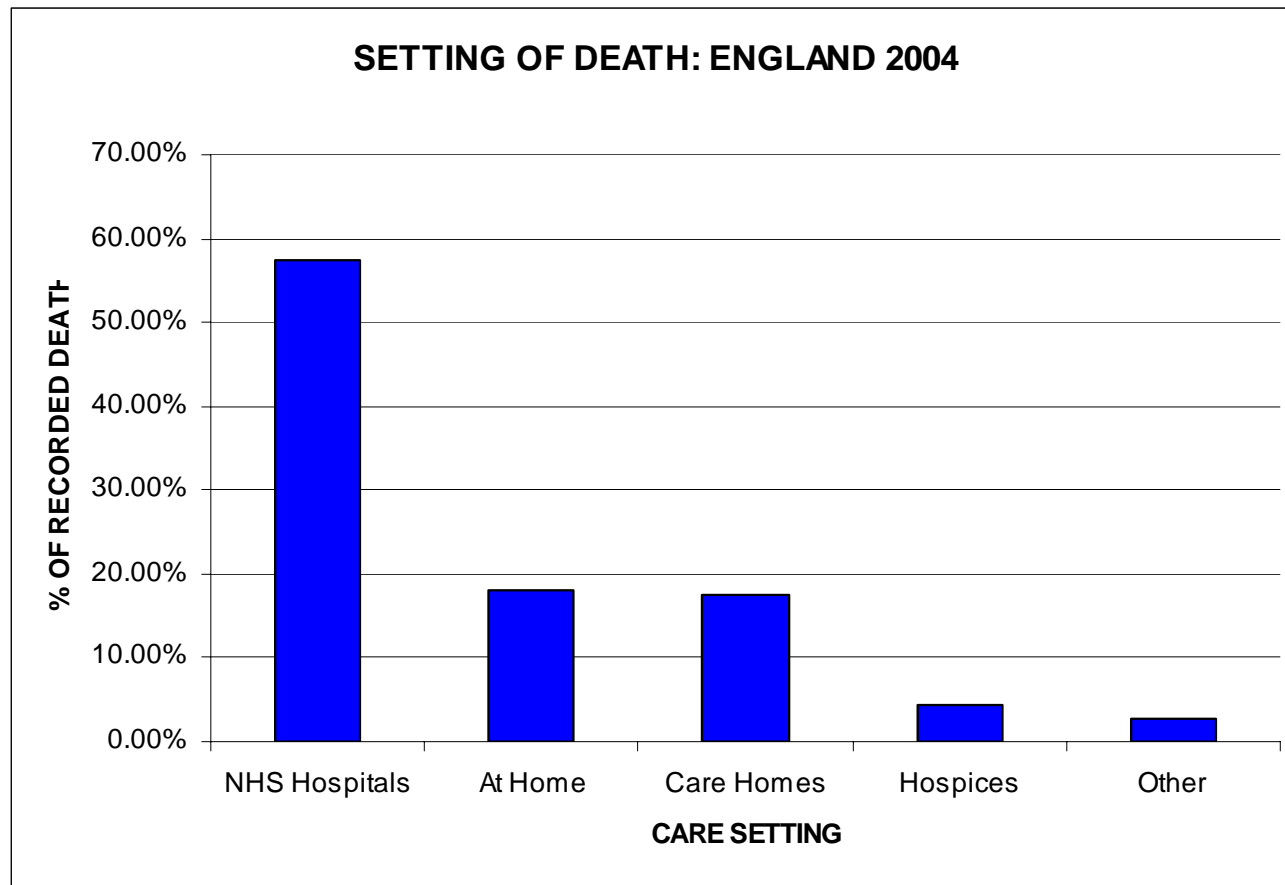
Source: Office for National Statistics, Mortality Statistics (DH2 No.32) 2005

Trajectories towards death



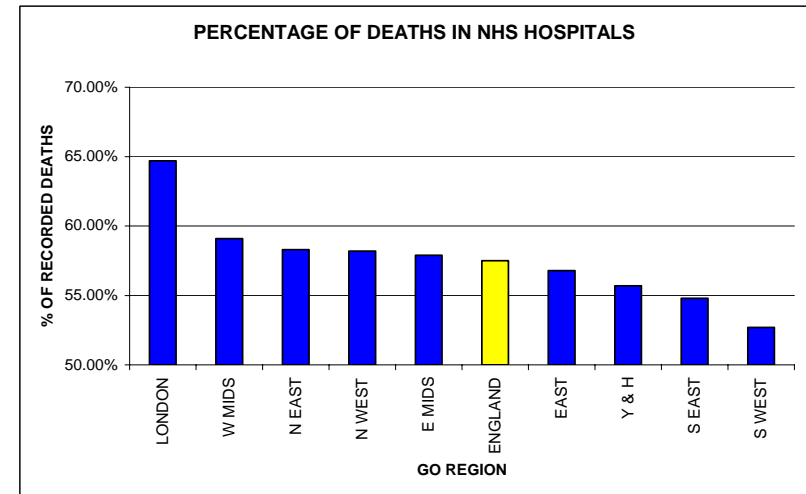
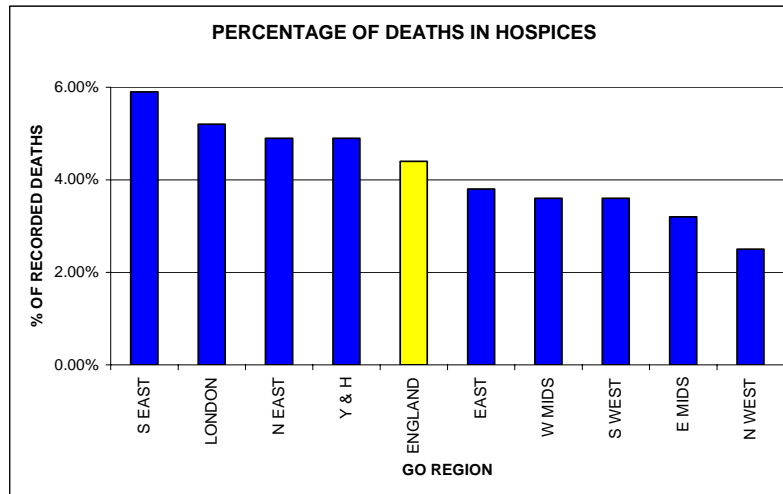
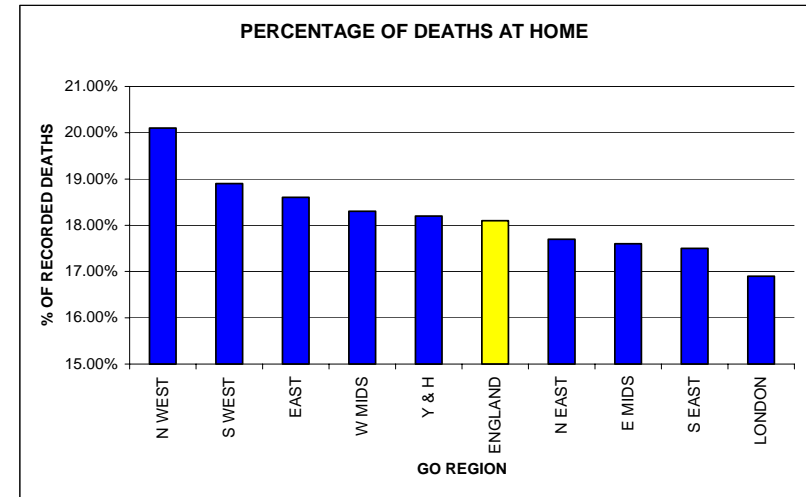
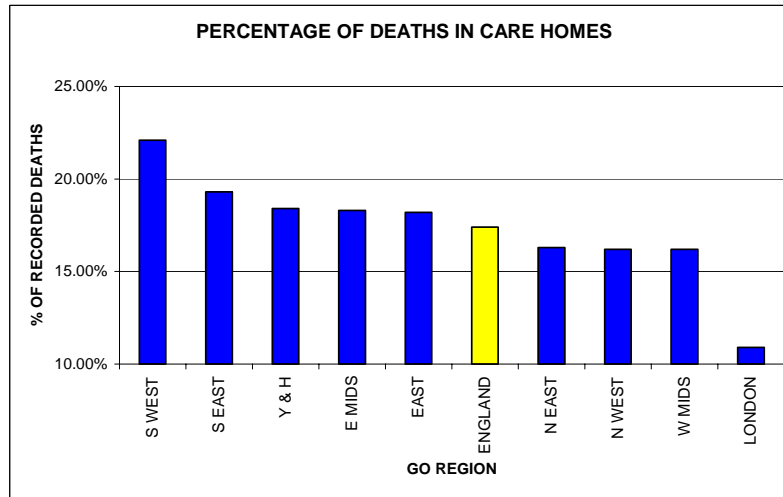
Source: Lynn and Adamson, *Living well at the end of life; adapting health care to serious chronic illness in old age*, 2003

Most people die in a hospital



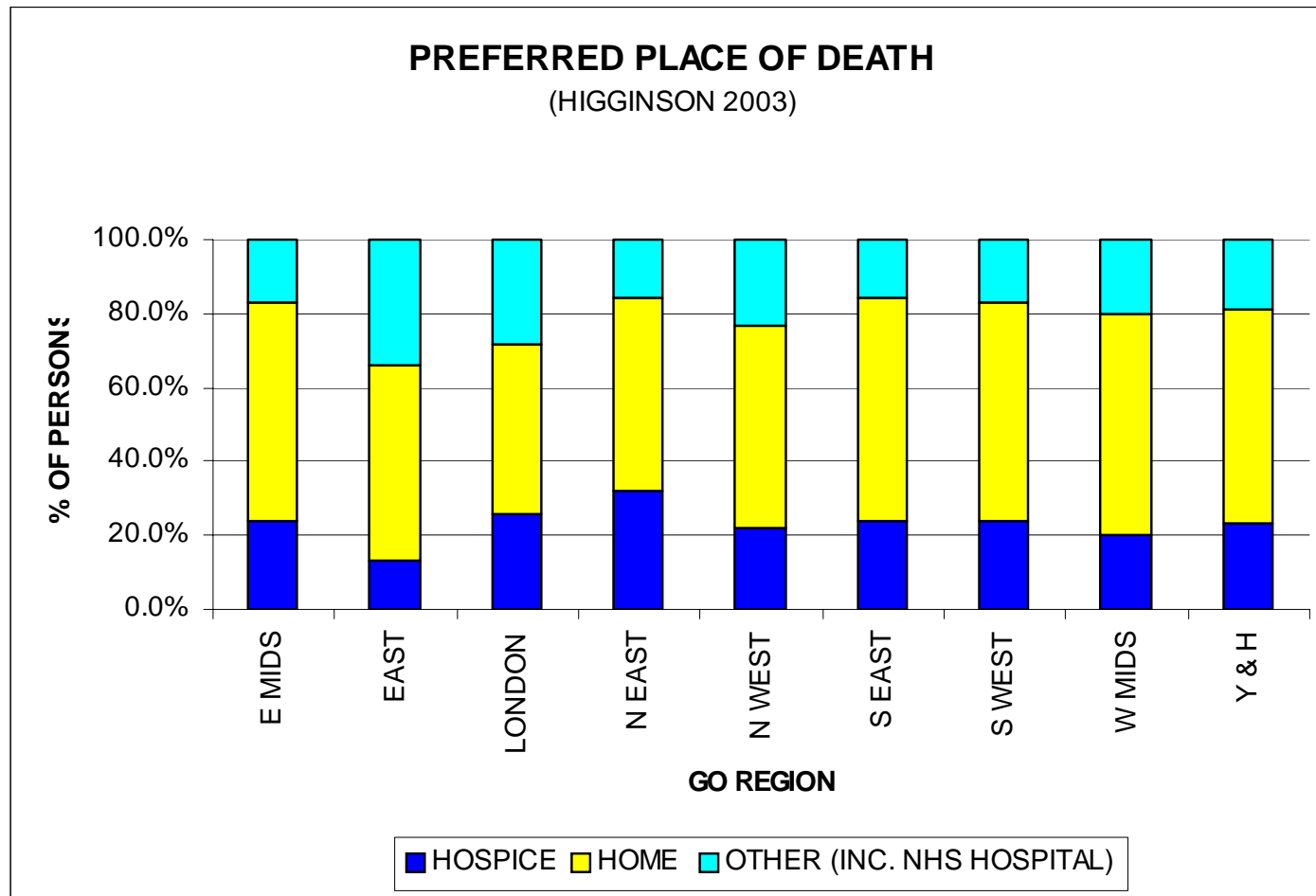
Source: Adapted from Table 19 in: Office for National Statistics, Mortality Statistics 2004

There is some variation over setting of death across the English regions, especially for death in care homes



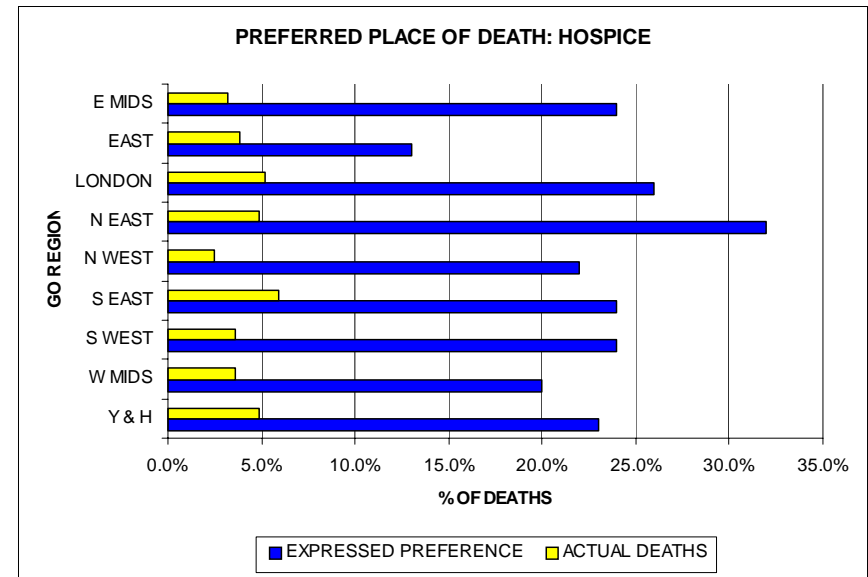
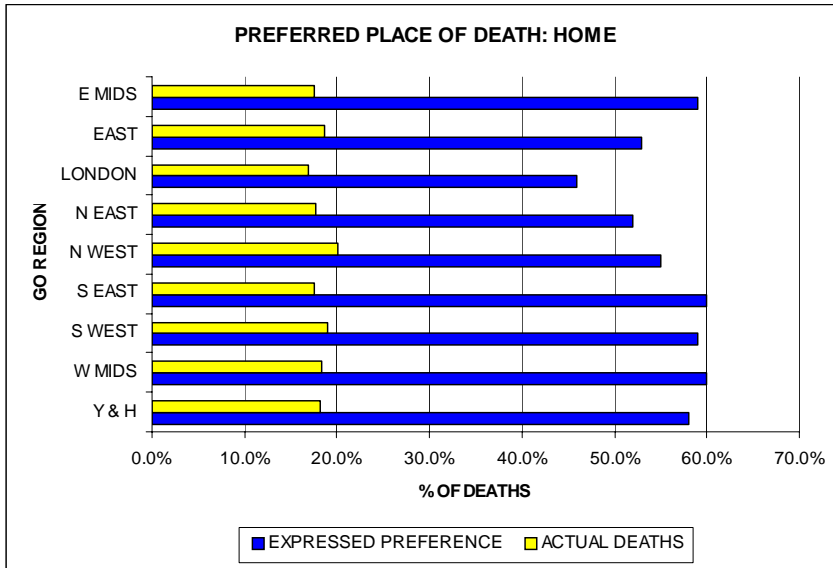
Source: Adapted from Table 19 in: Office for National Statistics, Mortality Statistics 2004

The majority of people would prefer to die in their own home



Source: I.J. Higginson, "Priorities and preferences for end of life care in England, Wales and Scotland", National Council for Hospice and Specialist Palliative Care Services, 2002

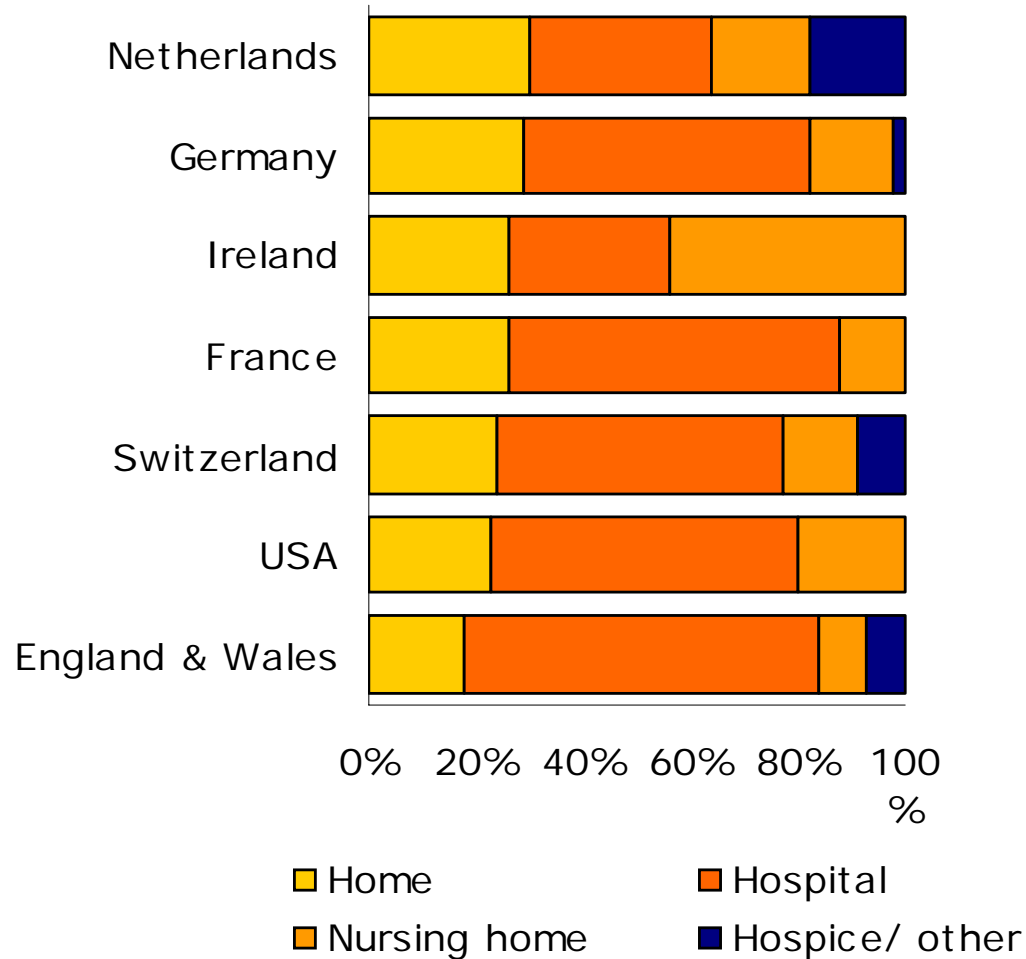
However, only a minority of people manage to die in their preferred setting



Source 1: I.J. Higginson, "Priorities and preferences for end of life care in England, Wales and Scotland", National Council for Hospice and Specialist Palliative Care Services, 2002

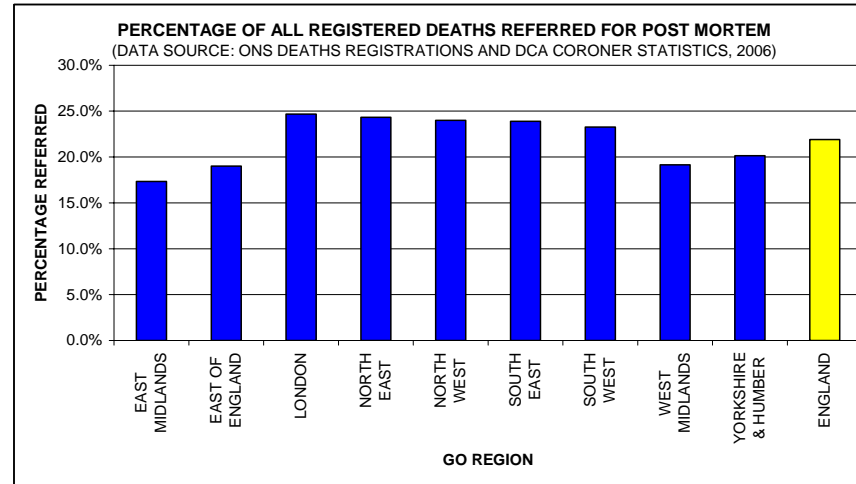
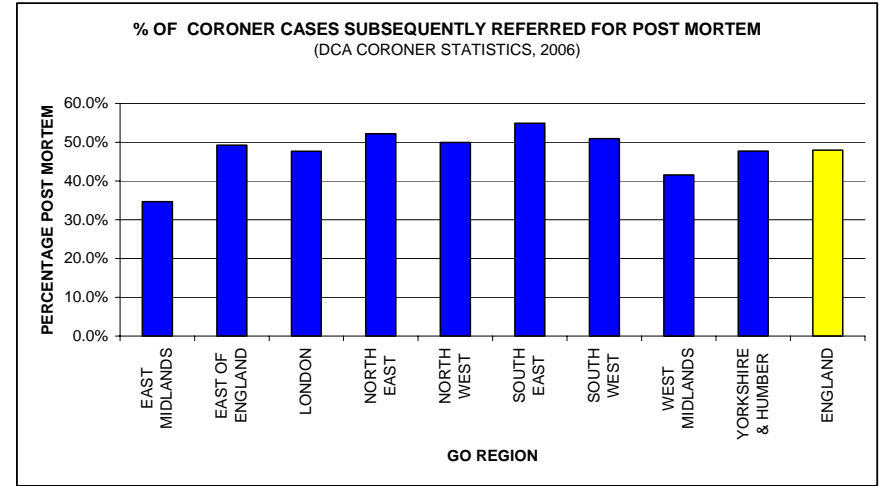
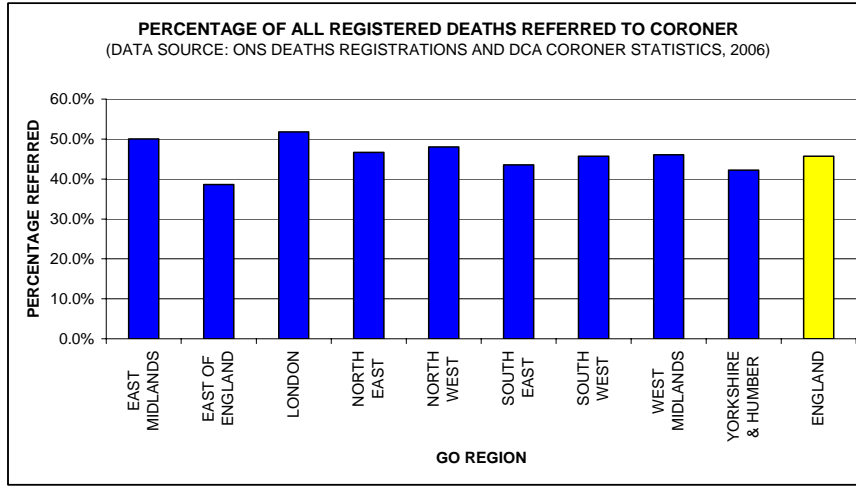
Source 2: Adapted from Table 19 in: Office for National Statistics, Mortality Statistics 2004

Other countries are much more successful in allowing patients to die outside the hospital setting



Source: World Health Organisation, *Better Palliative Care for Older People*, 2004

Referrals to Coroners and post mortems – Should there be so many referrals?



Caring for patients who die in hospital costs the NHS upwards of £200m every year

Costs of Final Episode of Hospital Care for Patients Dying in Hospital in England, 2005/06	£ Millions
Final hospital FCE resulting in death in hospital (all diagnoses)	755
Final FCE in Hospital resulting in Death for primary diagnosis that could be considered 'End of Life Care' conditions*	222
Final FCE in Hospital resulting in death with a Primary Diagnosis of Cancer	149

- Detailed work is under way to estimate costs of dying in other settings, and of cumulative resource use in the year prior to death – but these results are not yet available
- The costs shown above therefore present a very restrictive view of hospital resource use at the very end of life amongst patients dying in hospital – further analyses will provide a more comprehensive view that will probably indicate a much greater cumulative consumption of resources in the months before death
- * chronic, progressive and eventually fatal conditions (including cancer)
- Footnote: other costing analyses were considered but were felt to be not robust enough to be included here, nor sufficiently complete

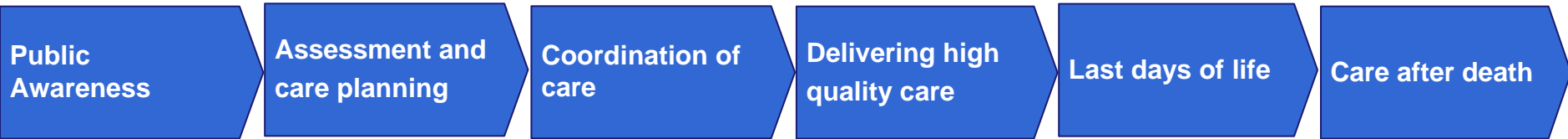
Establishing a baseline for end of life care provision

- It is not yet possible to make comparisons between SHAs or PCTs in their provision of end of life care services. It is, however, possible to establish a baseline from which future performance can be measured
- The operating framework for 2007/08 published in December 2006, set out local action for PCTs to begin to lay foundations for future improvements. This included undertaking a local end of life care service baseline review of end of life care services. Guidance on conducting the review was published in April 2007
- It was suggested that PCTs and Local Authorities may find it helpful to share the data with local partners and any gap analysis and plans for development with relevant SHAs. In future, the Healthcare Commission may draw on information about end of life care services, including the baseline review, as part of its Annual Health check
- Key evidence to support local baseline reviews of End of Life Care Services are summarised in *population based needs assessment for end of life care - a compendium of data for SHAs and PCTs, 2006*, The National Council for Palliative Care: www.ncpc.org.uk. This document will provide a useful overview and give key indicators of need for given populations. Many of the statistics within this publication are derived from NCHOD publications, should you wish to access disaggregated statistics these are available at: www.nchod.nhs.uk

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End of Life Care Pathway – addressing the challenges



• Public awareness

- Open, honest communication
- Identifying triggers for discussion
- Agreed care plan and regular review of needs and preferences
- Assessing needs of carers

- Strategic coordination
- Coordination of individual patient care
- Rapid response services

- High quality care provision in all settings
- Hospital, community, care homes, hospices, community hospitals, prison, secure hospitals and hostels
- Ambulance services
- Spiritual care

Last days of life

- Identification of the dying phase
- Review of needs and preferences for place of death
- Support for both patient and carer
- Recognition of wishes regarding resuscitation and organ donation

Care after death

- Recognition that end of life care does not stop at the point of death.
- Timely verification and certification of death
- Care and support of carer and family, including emotional and practical bereavement support

Support for carers

Public awareness should be promoted through open discussion about death and dying



What does good look like?

Awareness

- Open discussion about death and dying as a normal process
- Plans in place such as wills, funeral arrangements, organ donation
- Open days by Funeral Directors, Crematoria, hospices
- Life cycle and loss included in local school curricula.
- Local PCTs and LAs promoting awareness and developing locally available awareness raising tools/programmes

Evidence base

- ICM/Endemol/BBC Poll (2005) Survey of General public – UK study of 1027 participants
 - 67% of people over 65 have made a will
 - 51% had discussed how they would like to die
 - 8% prepared advance decisions
- ICM/Endemol/BBC (2005) Bereaved Sample
 - 42% relatives did not know preference for care setting
 - 66% had never discussed with patient
 - 21% had prior to illness and 13% during illness
- How we manage death and dying in Norfolk County and Waveney. Report of the Norfolk Health Overview and Scrutiny Committee in partnership with Norfolk and Waveney Cancer Network (2005)
http://www.norfolk.gov.uk/consumption/groups/public/documents/committee_report/norhealth290905item6pdf.pdf



Case study – St Christopher’s Hospice, South London

Description

- St Christopher’s Hospice Creative Living Centre and the Candle project run a partnership project with primary schools within the hospice’s catchment area. The aim of the project is to introduce the hospice to Year Five school children in a creative and non-threatening way and to promote healthier attitudes to death and dying amongst themselves, their teachers and school peers and also to parents and carers.

This programme has also been extended to a local city academy working with Year 12 students.

- www.stchristophers.org.uk

Benefits

- Death and dying is a subject which is often avoided in society today. This project has demonstrated how a local hospice can have a wide and positive influence in awareness raising. **Significantly the number of schools involved has doubled to twelve and 80% of local schools refer children to the Candle Project** which provides specific support to bereaved children
- A number of children and parents are now involved in talking about the work of the hospice and in fundraising
- Funding has been received from The Daisy Foundation and the Arts Council



Good assessment and planning requires open communication between patients and professionals

What does good look like?

Assessment and planning

- Recognition by professionals that death does not represent failure and that enabling people to die as well as possible is a core function of health and social services.
- Open, honest communication between health and social care professionals with patients and carers about end of life care.
- People given the opportunity to consider the care they wish to receive based on the best information available.
- Every person [and carer] to have a care plan which sets out their needs and preferences and is documented electronically and reviewed regularly
- People's preferences about where they wish to be cared for and die should be elicited and recorded and carers and families should be aware of this.
- Recognition of the MCA which sets out provisions for people to state in advance what they would like to happen should they be unable to make decisions in the future.

Evidence base

- Higginson I (2003) Priorities and preferences for end of life care. Published by NCPC
 - Telephone survey of 1,000 adults
 - Home preferred place by older people
 - 24% preference for hospice care
- Advance Care Planning: A guide for Health and Social Care Staff. (February 2007) University of Nottingham www.endoflifecare.nhs.uk
- Mental Capacity Act.
- 'What if' communication between consultants and people nearing the end of their lives' Paper from Macmillan Care Support by Dr Jane Maher. April 2007
- The Preferred Priorities for Care (formally Preferred Place of Care). www.cancercumbria.org.uk/leaflet 'When I die' – Booklet developed by Sunderland People First for people with learning disabilities, which sets out in pictorial form the choices 'Tony' has made for care for his end of life care and after his death. www.sunderlandpeoplefirst.org.uk/Accessibleinformationpage



Case study - Cedar Court, Leicester

Description

- Cedar Court, a care home in Leicester, has established a register in order to identify, assess and plan for the future needs of their residents. The staff complete an advance care plan with each resident and family. The results have been striking in terms of improving communication between staff, fostering greater teamwork, and in the quality of care and coordination with the GP practice, which in turn has led to fewer hospital admissions in the last stage of life.
- Contact:
Tel: 0116 257 1330
Email: cedarcourt2@shealthcare.co.uk

Benefits

- In fostering an open and facilitative approach with all new residents staff have been able to find out what their hopes and preferences are for their future care. In so doing this organisation has broken down the barriers in talking about end of life.
- Families feel that their loved one is being looked after in a safe and caring environment.
- Improved communication between staff has led to a reduced number of hospital admissions.
- **100% of residents achieved their wish to remain in the home until their death.**
- **PCT funding for training and facilitator support.**



Case study – St Oswald’s Hospice and Northumberland Tyne & Wear NHS Trust

Description

Providing end of life care for people with learning difficulties

Partnership service between Northumberland Tyne and Wear NHS Trust and St Oswald’s Hospice. Outputs from this programme have included:

- Disability Distress Assessment Tool (DisDAT) www.disdatt.co.uk
– a tool to identify and manage distress in people with severe communication difficulties
- What can we do? A guide to offering care and support to people with a learning disability at the end of life.
- Downs Dementia Assessment Tool (DoDAT)
– currently being piloted.
Contact: Claud Regnard, St Oswald’s Hospice
claudregnard@stoswaldsuk.org

Benefits

Outcomes from the initiatives have included:

- Empowered both carers and staff to better identify and communicate the patient’s distress
- Enabled people to stay in their own home
- **Improved education and support for professionals caring for learning disability people with life-threatening illness.**
- **Reduced the need for acute hospital admission – resulting in cost savings.**
- Increased the involvement of hospice and community palliative care services.
- NHS fund two posts including an honorary contract with Palliative Care Consultant.

Successfully coordinating care requires a single point of access, supported by end of life care registers



What does good look like?

Coordination

- End of life care services across boundaries should be coordinated at a strategic level to enable PCTs, social services, ambulances, hospital and voluntary sector to work in partnership to deliver a 'seamless' service.
- All relevant services should be coordinated at an individual patient level to ensure the person receives care in the location of their choosing
- A single point of access should be established through which all services are coordinated.
- Locality-wide end of life care registers should be established which would trigger access to OOH services, 24hr helpline, rapid response services and ensure wishes about DNAR, advance decisions and preferred place of death are known to all relevant services.

Evidence base

- Hampshire County Council. A review of care at the end of life in Hampshire. (January 2007)
- Marie Curie 'Delivering Choice' programme. www.mariecurie.org.uk
- Gold Standards Framework www.goldstandardsframework.nhs.uk
- Prognostic Indicator Guidance (June 2006) www.goldstandardsframework.nhs.uk
This enables GPs to identify patients for inclusion on the palliative care register which attracts QOF points.
- Making decisions. A guide for people who work in health and social care. (February 2007) National Care Association. www.dca.gov.uk/legal-policy/mental-capacity/publications.htm



Case study – Marie Curie Cancer Care

Description

- The Marie Curie Cancer Care Delivering Choice Programme was initiated in 2004 with the aim of improving services to allow all palliative and end of life patients to be cared for, and die, in the place of their choice.
- The programme aims to develop patient-focused 24/7 service models to effectively meet local needs. The first programme was established in Lincolnshire, and consists of a number of components, including:
 - A board, with high-level representation from local health, local authority and independent and voluntary sector organisations, to oversee the development of the programme
 - Palliative Care Co-ordination Centre, providing a single port of call for booking home care for patients across the full range of providers
 - A community-based Rapid Response Team, providing twilight and out of hours rapid response nursing care for patients, their families and carers
 - Discharge Community Link Nurse, ensuring the proactive management of the process of discharge from hospital

Benefits

- The benefits of formal high level stakeholder involvement in the programme to achieve effective cross –agency co-ordination.
- The programme, specifically the rapid response service, has already had a significant impact on the number of hospital admissions. **Between January and June 2006, out of 745 referrals for 250 patients, 280 admissions to A&E were avoided.**
- Further programmes have been established in Leeds and South East London. In each case there is high level support and involvement from local health, local authority, independent and voluntary sector organisations.



Case study – Knowsley Health and Social Care

Description

Integrated NHS & social care palliative care at home

- The team is led by a nurse with support from a team of health and social care workers who are trained in palliative care. Using single assessment, the care and support needs for both the patient and carer are identified and services put in place to support choice, empowerment and independence
- People referred to the service are those in the last months of life, are local residents and in receipt of Disability Allowance (DS1500)
- Currently the case mix is 90% cancer, 10% non-cancer
- Contact:
 - Karen Jones, Knowsley PCT
karen.jones@knowsley.nhs.uk
 - Carole Bayliss, Knowsley Health and Social Care
Carole.bayliss@knowsley.gov.uk

Benefits

The benefits of this jointly funded service include:

- Reduction in emergency admissions. In the period 1 Jan 05 to 31 July 07, 139 people avoided emergency admission to hospital
- This led to a saving of 4,216 bed days over the same period
- From 1 January 05 to 31 July 07, respite care was provided to 98 carers. In 5 of these patients were given a short stay in a nursing home. The other 93 had carers breaks at home, including help with shopping, household chores, bathing the patient etc

Hospital care

Hospitals that provide good quality end of life care have specialist teams and clear protocols for dying patients

Delivering high
quality care



What does good look like?

- There should be high level commitment and leadership from PCT and NHS Boards and senior NHS managers and clinicians to ensure high quality end of life care is delivered in acute hospitals
- Hospitals should recognise that one of their core roles is to provide care for the dying and therefore should:
 - Establish a specialist palliative care team who provide care based on needs rather than disease, and provide education for staff throughout the hospital
 - Ensure that relevant professionals have appropriate skills to elicit the needs and preferences of patients
 - That care plans are recorded, communicated and accessible to all relevant health and social care staff.
 - Establish a framework to ensure delivery of appropriate care for people who are in the dying phase.
 - In collaboration with other agencies have processes in place to ensure rapid discharge for those who wish to die at home

Evidence base

- Healthcare Commission – Spotlight on complaints. January 2007 www.healthcarecommission.org.uk
- Rogers A, et al “*All the services were excellent. It is when the human element comes in that things go wrong*”: dissatisfaction with hospital care in the last year of life. *Journal of Advanced Nursing* 2000; **31**: 768-774
- Higginson IJ, et al. *Do hospital-based palliative care teams improve care for patients or families at the end of life?* *Journal of Pain and Symptom Management* 2002; **23**: 96-106
- Liverpool Care Pathway for the Dying www.mcpcil.org.uk/liverpool_care_pathway
- NICE Guidance on supportive and palliative care for adults with cancer. www.nice.org.uk
- Marie Curie ‘Delivering Choice’ Programme. www.mariecurie.org.uk



Case study – Marie Curie Cancer Care

Description

The Rapid Discharge Pathway for the Dying Patient

- The LCP Central Team UK within the Marie Curie Palliative Care Institute Liverpool has developed the Rapid Discharge Pathway for the Dying Patient.
- This supports coordinated care, to enable patients, where possible, to be discharged from the acute hospital to home in the last hours / days of life, if this is what the patient wants. This model of care provision can be adapted by other organisations as part of a continuous quality improvement programme for care of the dying, in support of the patient and carer choice agenda.

Benefits

- In 2006/7 1.2% of people who would have previously died in hospital were able to return home to die
- **Collaboration and successful integration between hospital, community, social services, voluntary sector and ambulance services**

Community care

High quality community services involves GPs identifying those with end of life care needs and triggering other services

Delivering high quality care



What does good look like?

- Health, social care and voluntary sector services should be coordinated to enable people to stay in their preferred place of care. This should include access to primary care, district nursing, social care, pharmacy, occupational therapy, physiotherapy, equipment and out of hours services.
- The identification, assessment and care coordination of all those who need end life care should be routine within all general practices
- Support for carers should be an integral part of service delivery.
- Rapid response and 'hospice at home' services should be in place enabling people to be assessed out of hours in their own homes and services provided which otherwise might require admission to A&E.
- OOH services should have immediate access to an up-to-date end of life care plan for the individual, including information about DNAR wishes.

Evidence base

- Audit Commission 1999: 1st Assessments: a review of District Nurse services in England and Wales. Audit Commission, London
- Gold Standards Framework – see slide 52 www.goldstandardsframework.nhs.uk
- Nursing care services in Southend Essex. Hospice at Home services. Rosalindmatty@spdnsnurse.co.uk – see case study
- Evaluation of the DH programme to train district nurses in palliative care. July 2006 www.dh.gov.uk – Over 25% of all district nurses received training
- A new deal for carers in primary care. The Princess Royal Trust for Carers. 2006. www.info@carers.org
- Raising standards for patients: New partnership in out-of-hours care. DH (2000)
- A practical guide for PCTs and organised providers. DH (2004)



Case study - Southend Borough Council

Description

Community services

- SPDNS* Nurse Care provides nursing and social care support in Southend, Essex, on behalf of Southend Borough Council. It also provides a Hospice at Home service, in partnership with Fair Havens Hospice. The service provides ongoing respite and crisis support to informal carers as well as 24/7 support to very ill patients and their families to prevent unplanned admission to hospital.
- Contact: Director of Hospice at Home. SPDNS House, 449 London Road, Westcliff on Sea, Essex SSO 9LG
- * Used as title it is no longer used as an acronym

Benefits

- This service demonstrates the value of partnership schemes in providing comprehensive care for people in the setting of their choosing
- Through organising personal care provision on behalf of Southend Borough Council, and with the Hospice at Home based in their offices, SPDNS Nurse Care are able to deliver a joined up, collaborative service. **This has been of direct benefit in supporting patients to remain at home and the financial benefit of avoiding any unnecessary hospital admissions.**

Care homes

To deliver high quality care staff need to be trained and supported to ensure that residents can be confident in dying in their care home if that is their preference

Delivering high quality care



What does good look like?

- Care home residents should be confident that they can remain at the home until they die if that is their wish.
- There should be a culture which values equally the dying and living of residents
- Staff should be trained and supported in being able to discuss end of life care with residents and plan care needs and preferences in advance
- The care should be person-centred, ensuring that the dignity of the person is maintained.
- There should be supporting services from district nursing, primary care, out of hours and community palliative care teams which are integrated and accessible.

Evidence base

- Around 100,000 people die in care homes each year (20% of all deaths)
- Accumulating evidence that residents are transferred from care home to acute hospitals in the last days of life. – see annex
- Liverpool Care Pathway for the Dying
http://www.mcpcil.org.uk/liverpool_care_pathway
- Gold Standards Framework
www.goldstandardsframework.nhs.uk
- The Preferred Priorities for Care (formally Preferred Place of Care www.cancercumbria.org.uk/leaflet)
- The whole of me. Meeting the needs of older lesbians, gay men and bisexuals living in care homes and extra care housing. Age Concern, February 2006.



Case studies in care homes (1/2)

Description

Innovative practice in Care Homes

- Five care homes managed by Risedale Estates in the North West of England have introduced the Gold Standards Framework, Liverpool Care Pathway for the dying and the Preferred Place of Care with benefits for both staff and residents.
- Anchor homes instituted a 3 day training programme in end of life care for 300 staff over two years.
- A BUPA home in Bexley, Kent has found that introduction of the LCP has led to a sharp drop in hospital admissions at the end of life. Death rate of residents in hospital has dropped from 30% to under 20%

Benefits

Risedale Estates

- Staff, residents and families work together to agree advance care plans.
- Residents and carers feel they are more in control and care is personalised.
- Staff feel more confident.
- **Number of emergency hospital admissions reduced (leading to a saving for acute trust of £2.5k per admission).**

Anchor homes.

- Families feel care is centred around their loved one and are supported after death
- **Staff and residents are able to talk about death more openly.**
- Greater support from PCT and specialist palliative care teams.

BUPA home, Bexley.

- Staff feel more confident about discussing issues around death and dying. **Residents feel more confident about the care available** in the care home and are less anxious.



Case studies in care homes (2/2)

Description

Innovative practice in Care Homes

- Sussex Health Care, a group of homes catering for the elderly mentally infirm and people with learning and physical disabilities have introduced a coding system depending on whether the likely prognosis is measured in years (A), months (B), weeks (C) or days (D). Residents coded C and D are reviewed weekly, while those coded A and B are reviewed monthly to agree individual care plans.
- St Christopher's Hospice are working with in excess of 17 care homes to implement end of life care 'tools' in local care homes. In addition clinics have been introduced in care homes. Staff from the hospice work with care homes in teaching and on-the-job training and support.

Benefits

- Sussex Health Care. This has led to better partnership with GPs, OOH services and specialist palliative care services and has led to more residents dying where they wish to die. Positive feedback received from families. **The coding has provided useful information for reviewing staffing levels and skill mix.**
- St Christopher's Hospice. A hospice nurse is allocated to the home and has a caseload that is specific to that home. **In one home there has been no hospital deaths since the programme started.** PCTs fund 38% of the nurse and associate training and mentoring. The reported confidence of staff in supporting residents and families has increased considerably.

Hospice care

Hospices should act as centres of excellence that provide direct care for people with complex problems

Delivering high
quality care



What does good look like?

Centres of excellence which provide:

- direct care for people with complex problems on the basis of need rather than diagnosis.
- advice to GPs and district nurses as well as education and training for staff who wish to specialise in palliative care.
- leadership in research, development and evaluation related to end of life care.
- support to enhance the care provided in care homes including providing 24 hour telephone advice
- bereavement care.
- schemes with local communities in raising awareness of end of life care

Evidence base

- Hospice and Palliative Care Directory United Kingdom and Northern Ireland 2007.
www.hospiceinformation.info.



Community hospitals should be integrated into the end of life care pathway, supporting others services with trained staff

What does good look like?

- Community hospitals should be integrated into end of life care services enabling those who require respite or 24 hour nursing care to receive it near to home.
- Staff should be provided with additional support and training in end of life care enabling more patients and carers to benefit from the environment and proximity to their homes.

Evidence base

- NHS Institute for Innovation and Improvement. Community Hospital Survey 2007. http://www.institute.nhs.uk/quality_and_value/productivity_series/survey.html
- Payne S et al. *Healthcare workers skills: perceived competence and experience of end of life care in community hospitals*. (2007). In Progress in Palliative Care, 15,(3), 118-125
- Payne S et al. *End of life care in community hospitals: the perceptions of bereaved family members*. (2006) Palliative Medicine; 20;541-547
- Payne S et al. *Community Hospitals: an under-recognised resource for palliative care*. (2004) Journal of The Royal Society of Medicine; 97, 428-431
- Payne S et al. *Healthcare workers' skills: Perceived competence and experiences of end of life care in community hospitals*. (2007) Progress in Palliative Care. 15, 118-125

Ambulance services

In order to deliver high quality care ambulances must have access to local end of life care information systems

Delivering high quality care



What does good look like?

Ambulance services should:

- Ensure that JRCALC national clinical guidelines on resuscitation and terminal illness are being followed.
- Enable staff to have access to patient care plans and be aware of any stated preferences particularly in relation to DNAR requests.
- Ensure that staff feel confident in dealing with end of life care issues.

Primary Care Trusts should:

- Ensure that their contracts for emergency ambulance services and/or non-emergency patient transport services include sufficient capacity to respond quickly to requests to transport terminally ill patients who wish to die at home.
- Provide information systems which facilitate the sharing of information between agencies.

Evidence base

- JRCALC Clinical Practice Guidelines, October 2006 www.library.nhs.uk/emergency
- Transport of patients with palliative care needs, London Ambulance Service (LAS) South East London (SEL) SHA. Extract from NHS End of Life Care Programme Progress Report March 2003 www.endoflifecare.nhs.uk
- Marie Curie 'Delivering Choice Programme' www.mariecurie.org.uk
- Central Cheshire PCT, Mersey Regional Ambulance NHS Trust & Cheshire & Merseyside SHA. *A strategic review of the provision and commissioning of ambulance services* 2005 June



Case study – ambulance service

Description

Transport of patients with palliative care needs- London Ambulance Service and (formerly) South East London SHA

A new policy has been developed to provide:

- Timely transfers between hospital and home and other settings
- Clarity about the patient's wishes regarding resuscitation and interventions
- Information to support decision making in the home particularly to prevent inappropriate transfer to hospital. Such as:
 - Sticker placed on patients phone with OOH service contact details for specialist palliative care teams
 - Crew able to contact HQ or OOH services, GP service for up-to-date information on the patient and appropriateness of possible transfer to hospital
 - Patient information kept in small bottle in fridge

Benefits

- Patient is able to document their preferences about place of death and DNAR.
- Patient and families are involved in decision making, particularly around transfer to another setting.
- **Undesired resuscitation or inappropriate transfer to hospital avoided by ambulance crew.**
- Number of admissions to hospital reduced.

Prisons and secure hospitals should work with the local NHS to ensure that the standard of care for prisoners is the same as for other people

Delivering high quality care



What does good look like?

- Those who are approaching the end of life in prisons or secure hospitals should receive services that are designed to treat people with dignity and respect and are provided with as much choice as possible.
- Such institutions should work in partnership with local NHS and voluntary sector providers to ensure that assessments of needs and preferences are documented and reviewed, and that services are coordinated to ensure that the wishes of the person are respected.

Evidence base

- Kings Fund – Health care environments in prisons project. *Health care environments in prisons in London to be transformed for benefit of prisoners and staff*. Press release 04.06.07 www.kingfund.org.uk
- Norwich Prison – see case study
- Watson R et al (2004) *Prison Health Care: a review of the literature* International Journal of Nursing Studies. Vol 41, Issues 2, 119-128



Case study - Norwich

Description

Norwich Prison

- Recently the prison established a 15-bed unit for older people serving a life sentence. The intention is to provide care until they die, recognising that as death approaches the person may wish to choose whether to be cared for in familiar surroundings, or in the local hospital or hospice.
- Working in partnership with the PCT, local hospital, hospice, ambulance service and local coroner, the unit are able to provide appropriate care to the person. The staff have all been trained by the local hospice in the basic principles of end of life care and are able to refer to hospice medical and nursing staff for advice and additional support. The GSF and LCP are established within the unit. Personal preferences about care are discussed with the person and, where appropriate, with families, about resuscitation, who they would like with them and where they would prefer to die. Families and friends are able to visit regularly as death approaches and to spend time quietly with the person after death to pay their last respects.

Benefits

- This example demonstrates that it is possible through local partnerships to achieve high quality care irrespective of the setting.
- **This service is funded by the PCT and is actively supported by local hospital and hospice services.**
- Since the unit opened in August 2004 there has been 10 deaths. Three prisoners chose to be transferred to Priscilla Bacon Lodge Hospice to die.

Homeless people

Health and social care staff must be trained to enable them to understand the particular issues associated with homelessness

Delivering high quality care



What does good look like?

- Health and social care staff working in partnership with organisations supporting homeless people should ensure that a comprehensive assessment of the person's needs and preferences for end of life care is undertaken and communicated to all relevant agencies.
- Comprehensive discharge plans should be coordinated between the acute trust, primary care and hostel.
- There should be comprehensive education and training awareness sessions for health and social care staff to enable them to understand the health and social issues associated with homelessness.

Evidence base

- St Mungo's Opening Doors for London's Homeless. <http://www.clicknow.org.uk/mungos>
- Podymow T. *Shelter-based palliative care for the homeless terminally ill.* (2006) *Palliative Medicine*. 20. 81-86

Spiritual care

End of life care must include opportunities for people to access spiritual services

Delivering high quality care



What does good look like?

Services should:

- Have in place processes to ensure that spiritual care is coordinated across the care pathway,
- Recognise the need for, and enable those caring for the dying and bereaved to have a reasonable knowledge of various faiths and practices
- Facilitate an environment in which those with or without faith can take part in ritual actions
- Organise occasions of remembrance for bereaved people and staff

Evidence base

- NHS Chaplaincy: Meeting the religious and spiritual needs of patients and staff- Guidance for managers and those involved in the provision of Chaplaincy-spiritual care. DH 2003
- Multi-faith group for healthcare chaplaincy – www.mfghc.com/standards
- Standards for Hospice and Palliative Care Chaplains, London, AHPCC, 2003 www.ahpcc.org.uk/standards
- Marie Curie Cancer Care. The Spiritual and Religious Care – Competencies for Specialist Palliative Care. 2003. www.mariecurie.org.uk
- Further references can be found at: www.endoflifecare.nhs.uk/eolc/Resources/spiritual_care_references/

It is important that health professionals recognise when a person is entering the last days of life and so adjust their actions accordingly

Last days of life



What does good look like?

- When someone enters the dying phase it should be recognised by health and social care staff, and a care plan should be put in place that supports both the patient and family which includes:
 - Establishing measures to ensure dignity and comfort
 - Review of drugs
 - Discontinuation of inappropriate interventions
 - Psychological and spiritual care
 - Care of carer and family
- Health and social care staff should be trained and supported to undertake this process.

Evidence base

- Liverpool care pathway for the dying
www.mcpcil.org.uk/liverpool_care_pathway
- National care of the dying audit- hospitals (NCDAH) – summary report 2006/07. Marie Curie Palliative Care Institute, Royal College of Physicians
 - Ninety four hospital trusts participated with over 2672 patient cases.
 - Over half of cases had a non-cancer diagnosis
 - Demonstrated applicability to wide range of conditions
 - Helped hospitals recognise areas of high and low achievement

Appropriate care after death should focus on the sensitive handling and support of family and friends



What does good look like?

- End of life care that does not stop at death but should include:
 - Handling the body in a culturally sensitive way, accommodating the needs and wishes of carers and family
 - Timely verification and certification of death with procedures in place for OOH services, and appropriate referral to the coroner.
 - Robust procedures for return of personal property and identification of the body.
 - Staff who are confident and skilled in providing initial emotional and practical support including organ donation and sudden death
 - Information, and access to comprehensive bereavement care, including information on the role of the coroner.

Evidence base

- Healthcare Commission – Spotlight on complaints. 2006 Study showed that over half of complaints related to end of life care in hospitals
www.healthcarecommission.org.uk
- When a person dies – DH 2005 www.dh.gov.uk
- DH consultation on Improving the Process of death certification. July 2007 www.dh.gov.uk
- Bereavement: A guide for Transsexual, Transgender people and their loved ones. DH/NHS 2007.
http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_074259
- Allen R. Statistics on deaths reported to coroners, England and Wales, 2006. London: Department of Constitutional Affairs, London, England (2007)



Case study - Methodist Homes for the Aged

Description

- ***'The final lap' - improving end of life care in Methodist Homes for the Aged Care Group***
- Staff at Methodist Homes for the Aged (MHA) Care Group have introduced a number of changes aimed at humanising the process of death and dying following a series of 'Final Lap' training days.
- These include - depending on the residents' choice - having flowers and music during the final days as well as making the room welcoming for relatives after death. Residents are also encouraged to talk about death and discuss how they would like to spend their last days.
- In addition, MHA has reviewed its policy regarding a death during the night. In most circumstances it is unnecessary to call out an undertaker and remove the deceased there and then. Instead these arrangements are now left until the morning, allowing staff and residents to pay their last respects.
- Thanksgiving services in the home are more common and many homes have introduced funeral teas and some encourage residents to raise a toast to the deceased resident after the funeral service.

Benefits

- Residents are also remembered through memory books of poems and photos, their names are mentioned at the next service in the home and memorial gardens have been created, and trees planted, to commemorate those who died. Some homes also send bereavement cards to families. A total of 240 staff have now taken part in the initial training.
- Rev Dr Keith Albans Director of Chaplaincy and Spirituality Epworth House

Benefits:

- **This example helps to normalise death, enabling residents to talk freely and to openly discuss and remember those who have died.**
- Families commented that their loved ones were treated with dignity and respect
- Helpful information provided to families about planning a funeral and/or memorial services



Case study - The Radcliffe Hospital in Oxford

Description

Care after death in an acute trust

- ‘Care of the deceased patient and the bereaved’ is a written resource for multidisciplinary teams that contains comprehensive guidance on all aspects of care after death. The aim of the resource is to improve continuity between clinical and bereavement staff and includes:
 - How to communicate news of a death to families and how to care for the body; a flow chart on last offices; referral form from ward staff to bereavement services; contact details of carers and family; care and release of bodies [particularly relating to different faiths]; information on Coroners and Post Mortem
- Contact: Rev’d Philip Sutton, Head of Chaplaincy and Bereavement Services Oxford Radcliffe.

Benefits

The benefits of this programme include:

- Greater team work and communication between clinical and bereavement staff
- Improved communication between staff and the bereaved family
- **Early recognition and referral to bereavement services**
- **Improved communication and partnership working between staff and coroners**
- Adoption by the Acute Trust

The needs of carers should be addressed at each stage of the pathway



What does good look like?

Support for carers

- Service should recognise the vital role carers play in enabling someone to die in the place of their choice and acknowledge that they are central to the caring team
- Carers have a right to an assessment of their own needs as carers independently of the person they care for and this should be reviewed at regular intervals
- Systems should be in place to ensure services to support the assessed needs of both carers and patients are available when required and, in the case of equipment, collected promptly following death
- Councils should ensure that in addition to supporting carers in a planned way, they also have systems in place to support carers who, because of a crisis or emergency, are temporarily unable to care
- Bereavement care and support should be available for all carers, family members and close friends

Evidence base

- Department of Health. New Deal for Carers. 2007. www.dh.gov.uk
- Department of Health. Expert Carers Programme (ECP) August 2007 www.dh.gov.uk
- Princess Royal Trust for Carers. www.carers.org
- Crossroads – Caring for Carers. www.crossroads.org.uk
- The Children's Society – Young Carers Initiative. August 2006 www.childrenssociety.org.uk
- Cruse Bereavement Care. www.crusebereavementcare.org.uk

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- Background / Introduction
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- Good practice and supporting evidence
- Questions / issues
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Questions for clinical working groups

- Does the material shared reflect current view of best practice?
- Is this being implemented in the area?
 - What examples of best practice are there?
- If not universally implemented, why not?
 - Cultural issues – death viewed as failure
 - Structural problems e.g. configuration of services
 - Design problems e.g. access to diagnostic services
 - Incentives and financial arrangements
 - Lack of information
 - Lack of IT
 - Workforce issues
- What should change to bring about required changes?
 - Who should be responsible for bringing these about? E.g. local commissioners versus national policy change

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Detail on evidence base

- **Key evidence for public involvement and awareness raising**

- ICM/Endemol/BBC Poll (2005) Survey of General public
 - Prepared for BBC 2 programme on end of life care
 - 1027 participants 45% male; 55% female
 - Broad social mix from England, Scotland and Wales.
- ICM/Endemol/BBC (2005) Bereaved Sample
 - 500 people who had suffered a significant bereavement in previous 5 years
 - 41% male; 59% female
 - Partner/spouse 10%; other family member 80%; friend 10%
 - England, Scotland and Wales.
- How we manage death and dying in Norfolk County and Waveney. Report of the Norfolk Health Overview and Scrutiny Committee in partnership with Norfolk and Waveney Cancer Network (2005)
 - Comprehensive review supported by a survey of 1101 members of the public
 - Recommended that death and dying should be discussed more freely as a natural part of life particularly with children.
- Every child matters – Change for Children – supporting children and families coping with change – work based on Elizabeth Kubler-Ross (1969) On death and dying. New York: Macmillan. From www.everychildmatters.gov.uk 2006
- Phyllis Rolfe Silverman (2000) Never too young to know death in children's lives. ISBN- 13: 978-0-19-510955-9
- Childhood bereavement network – organisation to provide information, guidance and support to help children to manage the impact of death on their lives. www.childhoodbereavementnetwork.org.uk



Detail on evidence base

- **Key evidence for assessment**
- **Both of the following papers can be applied to conditions other than cancer.**
- Richardson A et al *Holistic common assessment of supportive and palliative care needs for adults with cancer* (January 2007) Report produced for Cancer Action Team. www.kcl.ac.uk
- This guidance is for practitioners and managers providing or coordinating the care of adults with cancer. It is intended to enable managers and practitioners to adopt a unified approach to the assessment and recording of patients' needs. It is designed for healthcare teams to employ as a benchmark against which current local processes of assessment can be appraised. Although primarily for cancer patients the core component of the approach can be applied to other conditions.
- United Health Europe. *Integrated Cancer Care Programme 2004-2006* for Department of Health. (2007). www.dh.gov.uk
- This two year programme aimed to improve the patients' experience of care through better coordination and access and seek to reduce NHS expenditure related to unnecessary care and duplication of effort; and to improve staff satisfaction with the care delivered to cancer patients. One of the most significant findings was the value of the 'care tracker' role. Care trackers linked with patients by telephone to undertake a systematic health and risk assessment and provide effective coordination of care. There has been almost universal recognition of the benefits of the role, particularly in relation to improving the patient's experience of care and in freeing up community nurses' time to devote to clinical care. As this role can be applied generically, Skills for Health have developed a nationally agreed set of core competencies for the role. www.Skillsforhealth.org.uk



NHS End of Life Care Programme – Gold Standards Framework (GSF)

- This approach has significantly improved care for people with advanced, progressive incurable illness, mainly in the primary care setting. It enables GPs to identify patients for inclusion on the palliative care register which attracts QOF points. The approach helps primary care teams to work together in ensuring continuity of care, setting in place advance care planning, symptom control and patient, carer and staff support. The programme has been running since 2001, was recommended as one approach in NICE guidance (2004) and supported as a component in the NHS End of Life Care Programme 2004- 07.
- Full details are at: www.goldstandardsframework.nhs.uk
- Uptake by NHS - See slides 56 - 59
- *Evaluation*
- Each stage of development the programme has been evaluated. At present this is being led by Prof Collette Clifford, Birmingham University working with GP practices and PCTs to demonstrate changes and identify areas for future development.



NHS End of Life Care Programme – Liverpool care pathway for the dying (LCP)

- This evidence-based framework enables clinical staff to deliver high quality care as death approaches, providing guidance on comfort measures, anticipatory prescribing, psychological, spiritual care and family support. It is mainly used by staff in hospitals and hospices but is increasingly being adopted for use in other care settings. It was recommended as one approach in NICE guidance (2004) and supported as a component in the NHS End of Life Care Programme 2004- 07.
- Full details are at: www.mcpcil.org.uk/liverpool_care_pathway
- Uptake by NHS - See slides 55 - 59
- *Evaluation*
- The Marie Curie Palliative Care Institute Liverpool and Royal College of Physicians are undertaking a national audit of care delivered via the LCP in acute hospitals. The aim is to measure the uptake and use in acute hospitals, undertake a retrospective audit of the goals included in the LCP and provide organisations with data comparing their performance. The final report is expected in Autumn 2007. Additional studies include; qualitative research of views of health care professionals regarding use of LCP in other care settings and developing a questionnaire to evaluate the views of relatives and carers on death and dying.

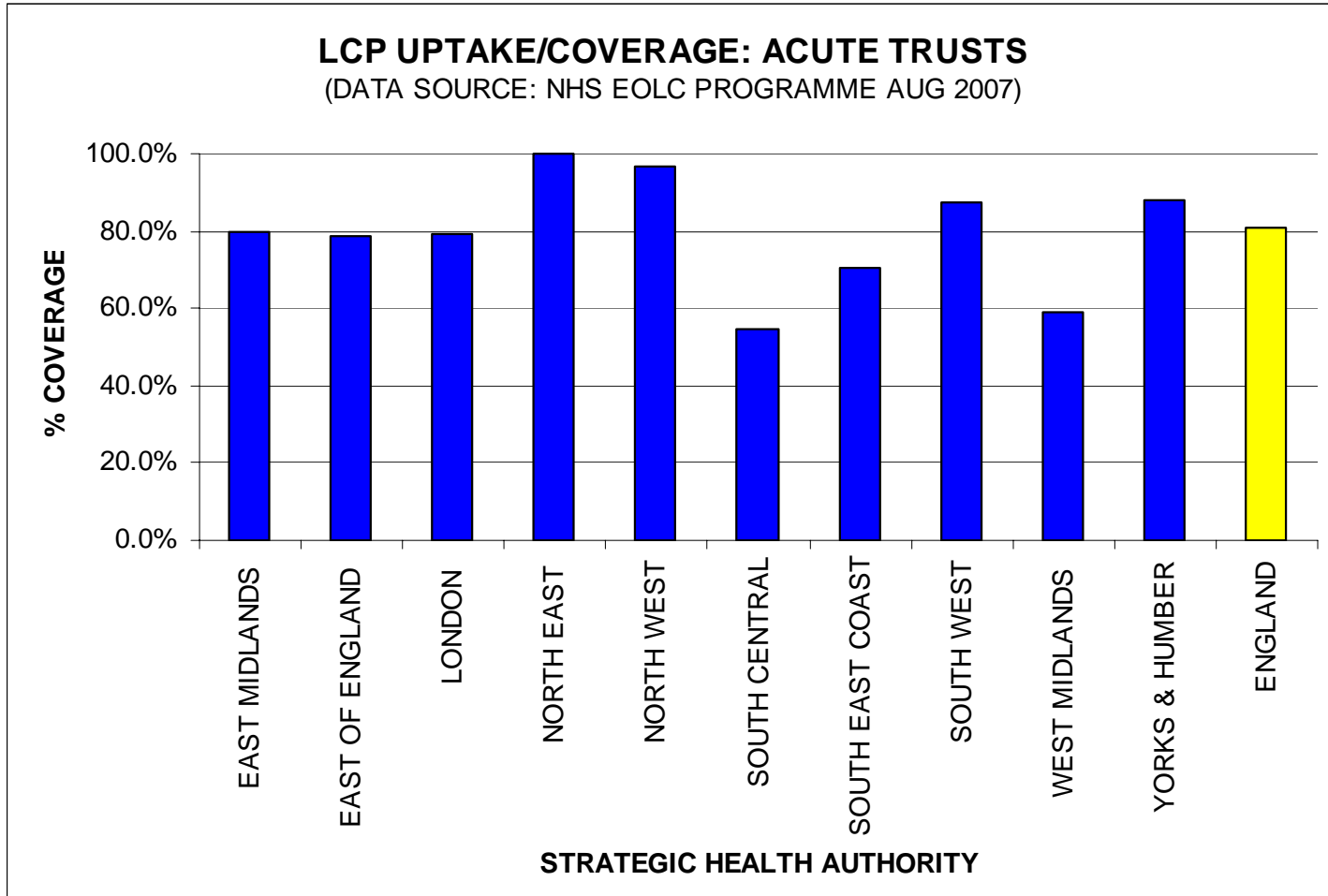


NHS End of Life Care Programme – Preferred Priorities for Care (PPC, formerly preferred place of care)

- This is an example of advance care planning. It is a patient held document designed to support patient choice, ensuring that the information is shared with all health and social care professionals involved in their care. The explicit recording of preferences and wishes of patient and carer helps to direct the planning and continuity of care and service delivery by the multidisciplinary team and other agencies. Originally developed by Lancashire and South Cumbria Cancer Network for use in primary care, it has been developed and broadened. Recommended by NICE guidance (2004) and supported as a component in the NHS End of Life Care Programme 2004- 07, it now being adopted across the country in care homes and acute hospitals.
- Full details are at: www.cancercumbria.org.leaflet
- Uptake by NHS - See slides 56 - 59
- *Evaluation*
- Early evaluation suggests that patients are more likely to receive care in their preferred place of care.

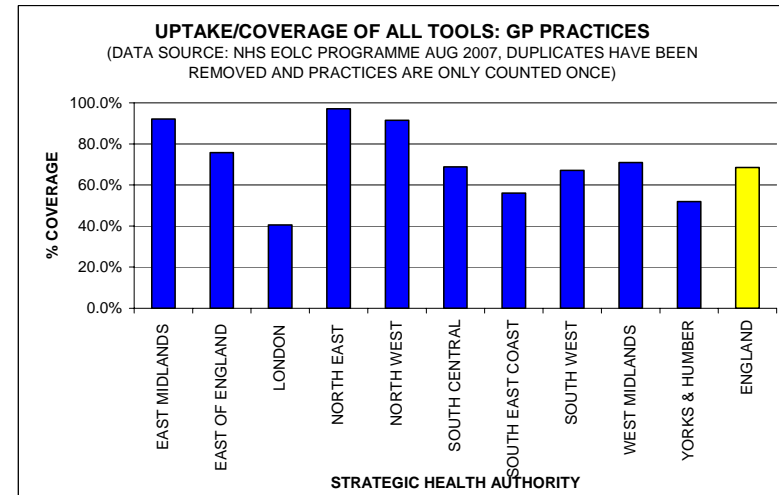
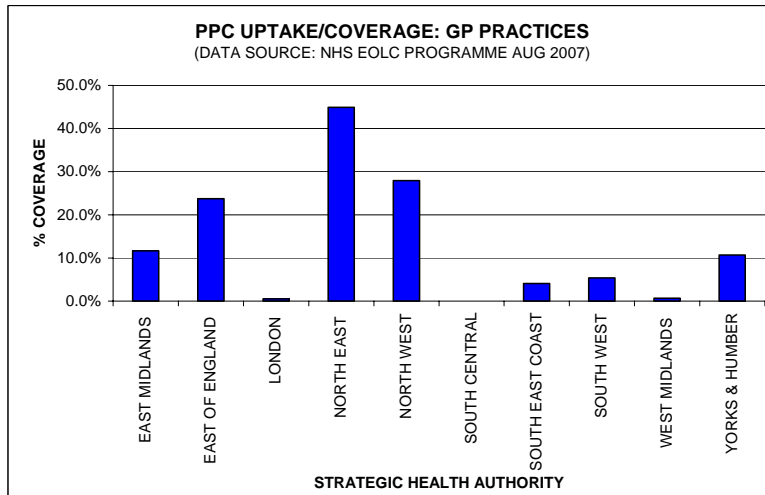
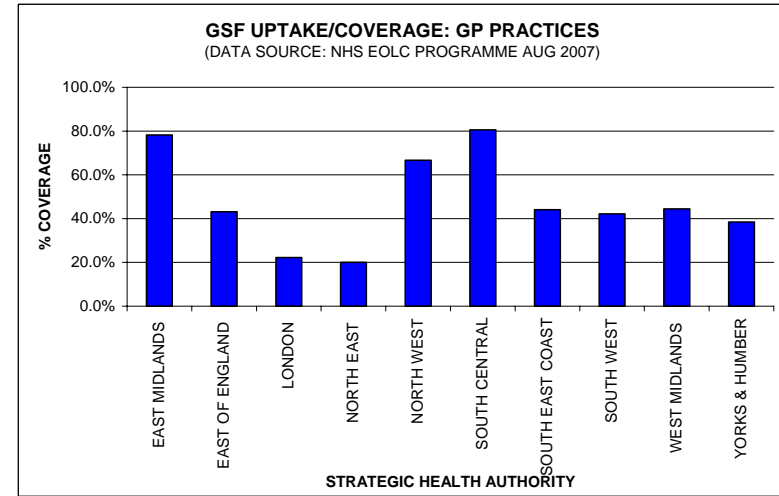
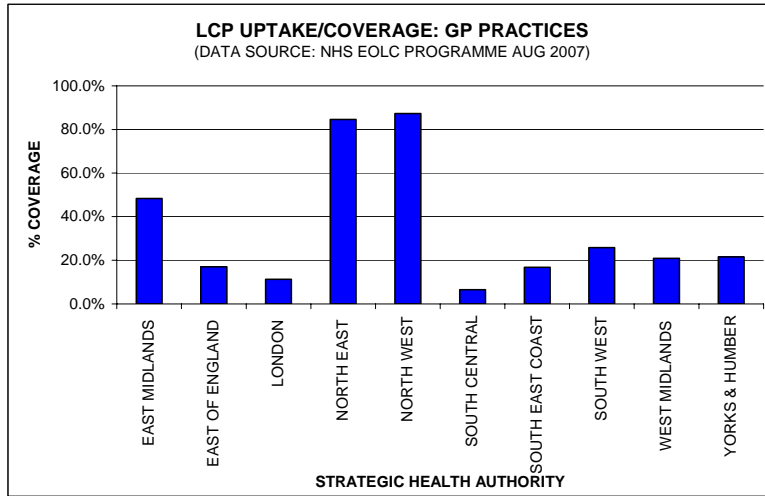


Usage of LCP – NHS acute trusts





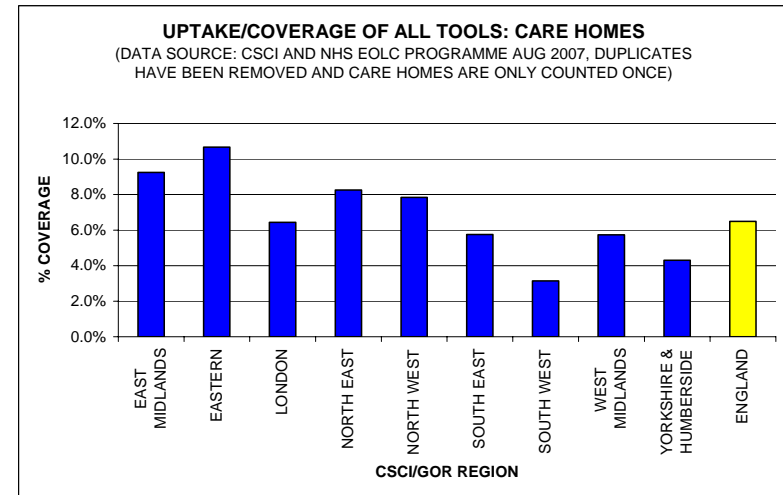
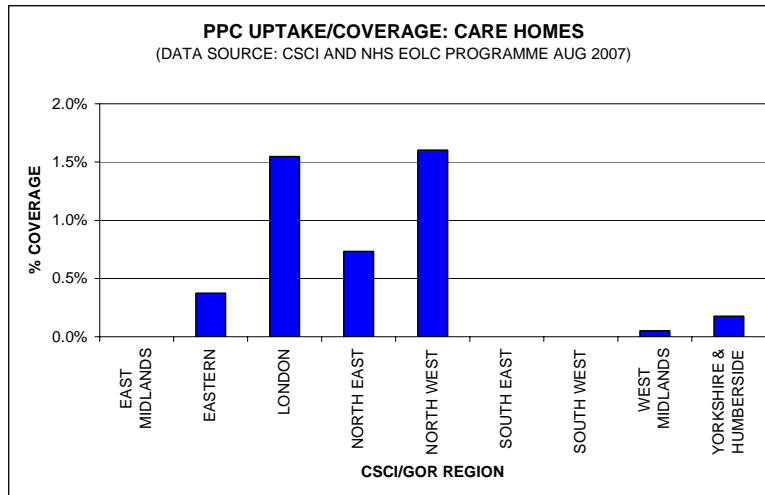
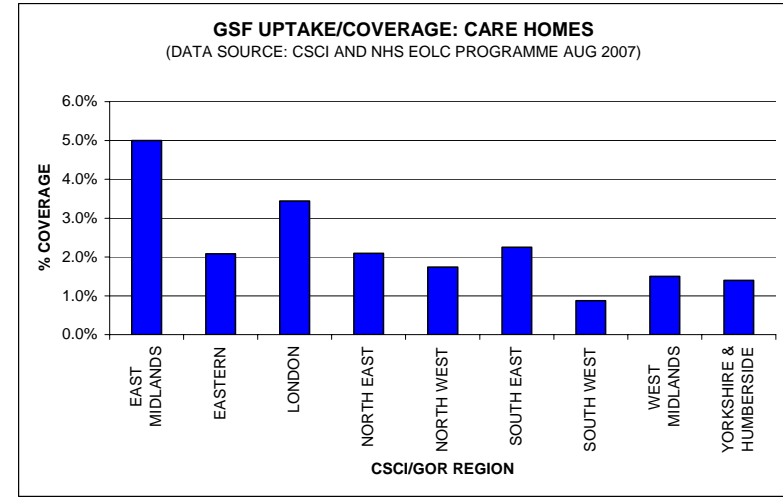
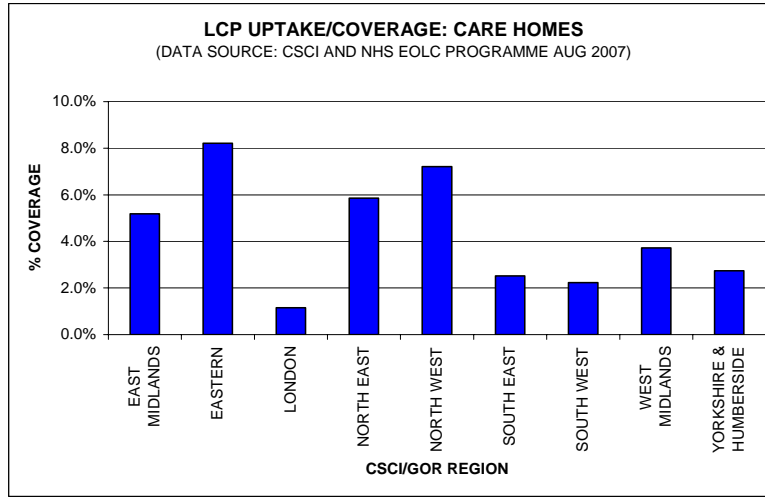
Usage of EOLC tools – GP practices



“ALL TOOLS” includes locally developed models of care



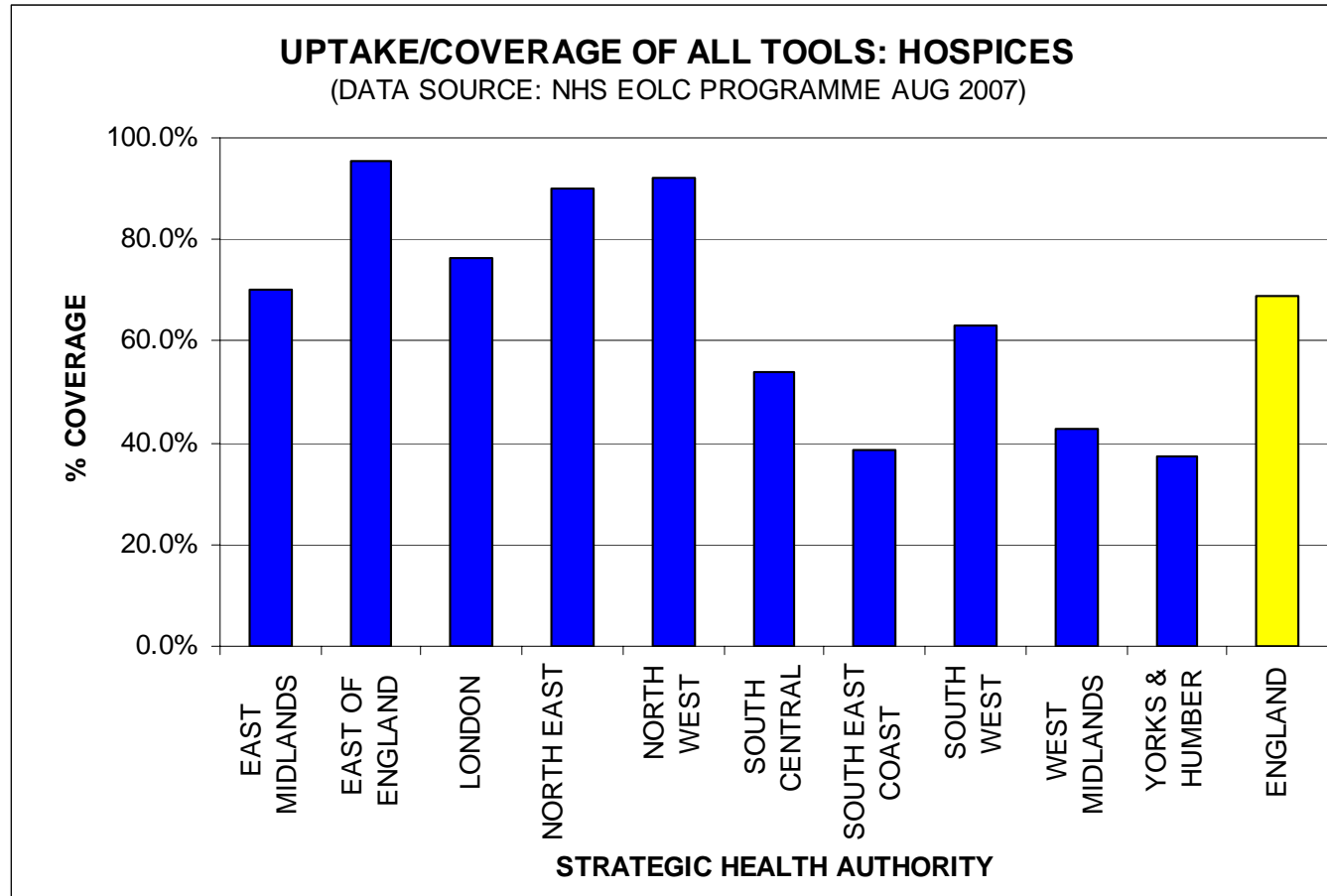
Usage of EOLC tools – care homes



“ALL TOOLS” includes locally developed models of care



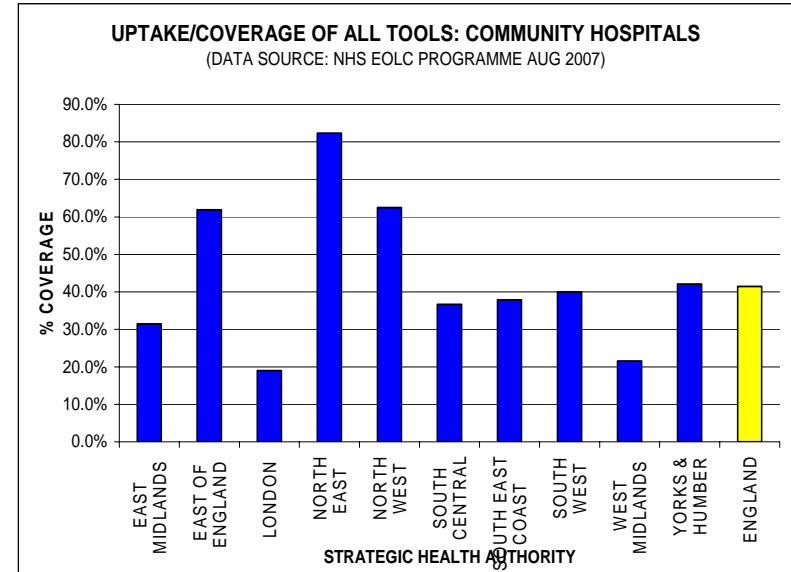
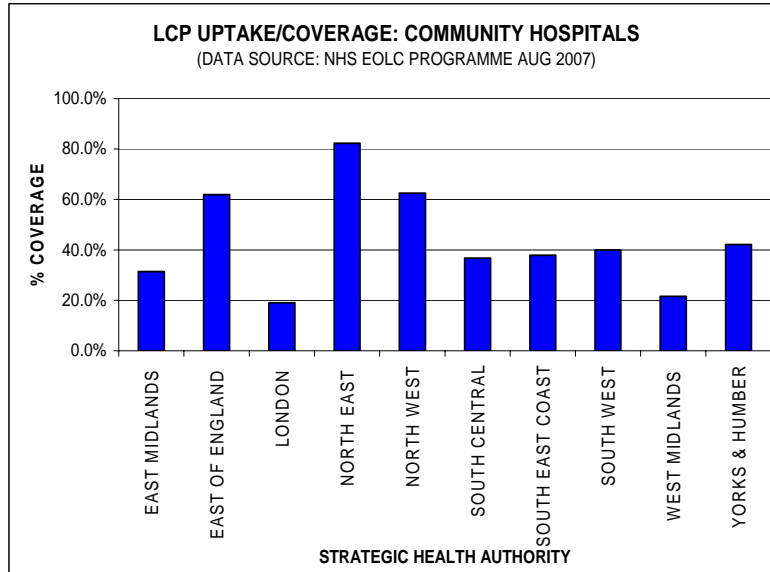
Usage of EOLC tools – hospices



“ALL TOOLS” includes locally developed models of care



Usage of EOLC tools – community hospitals





Detail on evidence base

- **Key evidence for care provided by primary care and community services**

- Audit Commission 1999: 1st Assessments: a review of District Nurse services in England and Wales. Audit Commission, London.
 - This demonstrated that palliative and terminal care patients take up to 40% of DN time but only 8% of DN workload.
- KA Sullivan et al *Exploring district nurses' experience of a hospice at home service* International Journal of Palliative Nursing. 2005 Sep; 11(9): 458, 460-6
 - Hospice at home is believed by district nurses to be a valuable service
- Addington-Hall et al. Evaluation of the Education and Support Programme for District Nurses and Community Nurses in the Principles and Practice of Palliative Care. March 2006. www.nursingandmidwifery.soton.ac.uk
 - The results of the evaluation strongly suggest that the programme has led to improvements in DN confidence in their competence and knowledge of palliative care.
- CJ Todd et al *General practitioners and district nurses views of hospital at home for palliative care*. Palliative Medicine 2002; 16:251-254
- F Tyrer & C Exley. *Receiving care at home at end of life: characteristics of patients receiving hospice at home care*. Family Practice 2005; 22:644-646
 - These papers provided evidence that people can be enabled to die at home
- A Grady & E Travers. *Practice development hospice at home2: evaluating a crisis intervention service*. International Journal of Palliative Nursing. 2003 Aug; 9(8): 326-356
 - This demonstrated evidence about how to prevent admission to and facilitate discharge from, institutional care.



Detail on evidence base

- **Key evidence on factors affecting transfer from care home to hospital in last days of life**
- Some studies in UK and US have found that hospitalisations for dying patients may be both unnecessary and inappropriate. In regions where care homes have sought residents' wishes about transfer to hospital and end of life care, there were lower levels of hospitalisation.
 - Mezey M et al *What impact do setting and transitions have on the quality of life and end of life and the quality of the dying process.* Gerontologist, 2002. 42 (Special Issue LLL), 54-67
 - Komaromy C et al. *The quality of terminal care in residential and nursing homes.* 2000. International Journal of Palliative Nursing, 6 (4), 192-200
 - Travis S et al *Hospitalisation patterns and palliation in the last year of life among residents in long-term care.* Gerontologist, 2001. 41 (2), 152-160