

NHS East Midlands

Next Stage Review

Regional Workstream Final Report

End of Life Care

January 2008

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1. Overview and Vision for End of Life Care Services across the East Midlands

The regional workstream agrees with the definition of end of life care (EOLC) outlined in the national evidence base. For the purpose of this report the scope of EOLC is that expressed in the Department of Health (DH) working paper in relation to the End of Life Care Strategy (2006) and reiterated in the Emerging Themes paper (2007), which states that EOLC should encompass:

- Adults with **any** advanced, progressive, incurable illness
- Care given in **all** care settings
- Care given in the last year(s) of life*
- Patients, carers and family members including care given after bereavement

This work excludes care given outside the current legal framework such as assisted suicide and voluntary euthanasia.

The scope does include young adults from the age of 18 onwards. EOLC for children and teenagers up to 18 will be covered by the East Midlands childrens' clinical workstream. The EOLC workstream does recognise a link in relation to several of the other workstreams particularly, long term conditions, acute care and mental health.

The operating framework for 2007/08 published in December 2006, set out local action for PCTs to begin to lay foundations for future improvements in EOLC. This includes undertaking a local end of life care service baseline review. Due to the timescale it has not been possible to include supporting data in this report, as it has not as yet been collated. Some data is however likely to be included in the county reports as a result of evidence gathered by the individual PCTs for this review, although it is unlikely to be complete as the original submission date for this work was March 2008.

The workstream has engaged service users in this process via the county clinical task groups. Some groups have had patients/carers on the membership whilst others have consulted a variety of user and voluntary sector forums, sharing with them the initial evidence gathering templates and subsequently giving them opportunity to read and comment on the East Midlands EOLC workstream draft report.

The overall vision of the regional workstream for EOLC is:

To develop end of life care services that are patient focused and able to meet individual need (including the needs of carers), particularly enabling choice in decisions about care and preferred place of death. Services should be equitable, safe and able to meet the needs of a diverse population.

*As this is a retrospective definition and not possible to manage prospectively, this should be defined as any patient who would be picked up through the 'trigger' question as part of the Gold Standards Framework outlined on page 8 of this report

Care at the end of life should be supported by standards and outcome measures to ensure it is effectively meeting the needs of the local population and helping to build and maintain public confidence in the services provided. The key outcome is to achieve a 'good' death for all patients and their families/carers whatever the care setting.

2. Current Issues

The East Midlands EOLC clinical workstream agrees with the issues and challenges outlined in the national evidence base provided in relation to end of life care.

Two of the areas identified nationally were immediately recognised as being areas of concern for the East Midlands. One is the low priority given to end of life care by the majority of commissioners and providers across the UK. EOLC should be considered as 'core business' for the National Health Service (NHS) but many services, particularly hospices often rely on substantial funding from charitable sources to maintain their service provision.

The second is the inequity of provision in relation to diagnosis with many patients with long-term and chronic conditions not receiving the same level of care and intervention as patients with cancer.

The workstream agreed to identify current issues across the East Midlands by highlighting them under the six stages of the pathway outlined in the national evidence base plus a section on carer support. These were then compared with the national evidence to clarify if all the issues were the same and highlight any additional challenges pertinent to the East Midlands.

2.1 Public Awareness

Death and dying are not topics openly discussed by the general public in the UK and the East Midlands is no exception. The East Midlands also has the added complexity of having a multi-cultural population, which brings with it further challenges when attempting to raise public awareness. The difficulty in knowing how to engage with the public and meet such a wide range of diverse needs often prevents any progress being made in this area.

There is a general lack of knowledge about palliative care and what services are available across the 5 counties. This applies to many health/social care professionals as well as the general public.

There is no regional public awareness strategy about death and dying, although an inevitable situation for everyone. Awareness campaigns are often linked to other sections of health and any available budget is therefore currently consumed in these areas.

2.2 Assessment and Care Planning.

Despite the national End of Life Care Programme, which outlined recommendations and provided additional resource for 3 years, there remains inequity of service provision across the East Midlands.

The End of Life Care tools (Gold Standards Framework (GSF), Liverpool Care Pathway (LCP) and Preferred Priorities for Care (PPC)) are not being fully implemented in all care settings in the region. Advanced care planning (ACP) is not happening in most areas, as it is not embedded in the general patient assessment process. This incorporates the discussion with patients regarding their preferences for types and places of care at various stages throughout the EOLC pathway and about decisions to refuse treatment culminating in preferred place of death. The majority of health care professionals do not currently have the appropriate skills to enable them to initiate these types of discussions with patients and education provision is variable across the East Midlands in relation to EOLC issues. The teaching programmes that are provided are not always well attended suggesting it may not be seen as a priority area.

There is no agreement within the counties or across the region in relation to a holistic assessment tool for patients and carers and no formal lever to help implement the national guidance recently published by the Cancer Action Team (CAT) in January 2007.

2.3 Coordination of Care

The main problem within the East Midlands is the fragmentation of service provision between the different sectors particularly health, social care and the voluntary sector and also between primary and secondary care. This often leads to poorly coordinated care where patients end up being admitted to hospital in a crisis situation or are not able to be discharged promptly due to a delay in organising care packages in primary or community care.

The lack of robust 24/7 services is a major contributor to this problem as is the poor advanced care planning, limited resources for both generalist and specialist palliative care and the absence of an identified key worker in primary care. There is also no regional wide approach to the coordination of services through one central point in each county.

Currently many practices are not aware of the number of patients they have with long-term conditions who are reaching the end of life stage. They are therefore not placed on the palliative care (EOLC) register and fail to have early enough discussions about PPC. The trajectory of most cancers makes this group of patients generally much easier to identify.

There is also a lack of communication between primary and secondary care with acute and mental health trusts not being aware that patients are on an EOLC register and often correspondence from the hospital not getting to GPs in a timely fashion.

Health and social care are segregated in many areas with separate budgets and a lack of coordination between the sectors when planning a patient's care package. There is often little knowledge of the services that the voluntary sector can provide and limited partnership working between statutory and voluntary organisations.

A particular issue has been raised in relation to the often poor coordination of transitional care for those with chronic conditions reaching the end of life, who transfer from paediatric to adult services.

2.4 Delivering High Quality Care

Specialist palliative care services were originally established and commissioned for cancer patients across the East Midlands, as in the whole of the UK. There has been little investment in these services to meet the ever increasing demand of non-cancer patients. The current reliance on charitable funding to provide many of these services also puts them at considerable risk. This type of funding has the potential to fluctuate and any significant decrease can affect the long-term sustainability of service provision.

Additional services, often only provided by voluntary sector organisations, such as complementary therapy and counselling support are also being stretched trying to meet increased need and again are often reliant on charitable funding.

There is presently a limited number of specialist palliative care beds and not enough expertise in community hospitals and care homes to enable palliative and end of life care to be offered in different care settings. Respite care is inadequate often leading to patients requiring hospital admission.

There are also issues with continuing care funding with recent changes to the framework.

The delivery of 24/7 services is very limited across the East Midlands with inconsistent access to specialist support, advice and intervention out of hours. Access to equipment and medication is also variable.

There is no formal governance framework to evaluate the implementation of GSF and LCP across the region. There are no regionally agreed outcome measures for practices to demonstrate their usage of the tools and the potential benefits.

The provision of training programmes in all aspects of palliative and end of life care varies across the region with differing degrees of input on pre and post registration courses for medical, nursing and other health and social care professionals.

There is limited availability of services to meet the needs of other sections of the region's population such as black and minority ethnic (BME) groups, those with learning or mental health disabilities and prisoners.

Patients often undergo unnecessary diagnostic investigations at the end of life due to ACP and Advanced Decisions to Refuse Treatment (ADRT) not being in place and medical staff not always having the skills to diagnose the dying phase or the confidence to implement the dying pathway and rationalise active interventions.

The issue of smoking raises a challenge for the provision of care for dying patients across the East Midlands. Due to the recent smoking ban it is difficult to provide appropriate facilities within organisations to enable patients to smoke towards the end of their lives if not in their own homes, whilst protecting carers and staff from exposure to second hand smoke. Staff are also exposed when visiting patients at home if they or their carers smoke.

2.5 Last Days of Life

The actual process of identifying the dying phase has been highlighted as a key issue particularly for non-cancer patients where the disease trajectory is more variable.

Despite dedicated facilitators helping to implement the LCP in all the counties across the East Midlands there are still many care settings where it is either not being implemented or not necessarily implemented for all patients. There is a particular issue in nursing and care homes and for some acute and mental health trusts. This is also no agreement across the region on how this tool can be embedded long term to ensure sustainability once each facilitator's contract has ended.

Although all counties have 'hospice at home' type services these are rarely 24 hour and are not resourced adequately enough to provide care for all patients at the end of life.

There are often difficulties in getting patients discharged from hospital to die at home due to the delays in setting up appropriate care packages.

The lack of integrated advanced care planning (ACP) across the region adds to problems at the end of life and often leads to hospital admissions if the relevant support services cannot be put in place. In the absence of ACP poor communication can result in patients' wishes regarding their Do Not Resuscitate (DNR) status or Advanced Decisions to Refuse Treatment (ADRT) not being followed. This can be particularly difficult for ambulance crews answering 999 calls who in the absence of relevant information are obligated to resuscitate patients and/or transfer them to the nearest A&E department.

Patient choice is also an issue in relation to place of death. Although home is often the place where patients initially say they wish to die, preferences or circumstances may change as they approach death. They then may wish to be in a more secure environment such as a hospital, community hospital or hospice. In addition unavoidable admissions do sometimes result in hospital deaths. End of life care should therefore continue to be as important in the hospital setting as in any other and there is a general view that the present standard of care in most acute and mental health trusts across the East Midlands is not as good as it should be.

This can be a particular issue when patients die following an acute episode of care such as a trauma, surgery or a medical emergency. Care leading up to and following death in these circumstances differs, as the initial intention is to preserve life. Maintaining the dignity and respect of these patients is challenging and the support of their families and carers is not always as robust at the time of, and following death as it is for those whose deaths are expected.

In addition there is a lack of robust recording and communicating systems to keep pace with the evolving patient choice agenda.

2.6 Care After Death

There is no single recognised bereavement policy across the East Midlands with varying degrees of service provision being offered across the 5 counties. There also appears to be a lack of widespread comprehensive written information for carers to prepare them for the death and to support them in the initial time period after the patient has died.

Verification of death by nursing teams is not in place in all counties and there are not robust systems in place to remove equipment and/or drugs from patients' homes in a timely manner following the death, according to carers' wishes.

There is currently no unified approach across the East Midlands for referring cases to the coroner when there is an expected death and the team that know the patient are not available. Such referrals can be distressing for families, carers and professionals due to the lack of awareness of the role of the coroner. The requirement to inform the police when there is an unexpected death is not usually a problem, however the inability to exercise any professional discretion in occasional circumstances can be an issue.

Cultural needs are not being met as well as they should be given the diverse population mix in the East Midlands. It is also difficult to cater for the needs of more unusual cases, such as larger patients, in a dignified manner.

Facilities and support for carers at the time of, and in the hours following death are variable across the region and there is no agreed standard of what should be available/offered to carers at this time.

2.7 Support for Carers

Some of the issues have been covered under specific steps of the pathway. In addition the lack of a comprehensive holistic assessment across the East Midlands, which should encompass carer support, means there is currently no formal mechanism to identify the needs of carers at the end of life.

There are limited respite services of all types particularly for non-cancer patients and inadequate support particularly out of hours. The educational needs of carers are also not being assessed and met, with inadequate written support available e.g. there are no formal training programmes relating to manual handling and the usage of equipment.

There is an issue not specifically linked to supporting carers but actually about the availability of carers themselves. Public health data shows the steady rise in the numbers of older people across the East Midlands. This trend will continue to increase over the next 20 years. The number of younger people however is expected to fall. This may well result in a lack of carers to provide the level of input that is seen at the moment. This could have serious implications for the delivery of health and social care in the future.

2.8 Conclusion

Following the local baseline of current issues it is apparent that the issues and challenges identified in the national evidence base are very similar to those identified in the 5 counties across the East Midlands. There are certainly no conflicting views. A number of additional issues have also been highlighted such as the population growth and the controversial topic of smoking facilities for dying patients.

All of the key issues raised nationally have been covered in more detail by using the stages of the pathway to identify local issues within the region.

The next part of the report will use the stages of the pathway again to look at the areas of good practice outlined nationally plus additional areas of good practice identified by the East Midlands workstream members.

3.0 What Good Practice Looks Like – review of the evidence base national/local

The national evidence base outlined what good practice should look like for each of the six stages of the pathway and also for carer support. This was followed by a number of case studies from around the country, where initiatives have been introduced and patient experience improved in relation to each stage of the pathway. These examples have been included as Appendix 1 along with a number of local initiatives from across the East Midlands.

This section will outline the national view on what good practice should look like for each stage of the pathway as outlined in the supporting evidence and will include additional areas, which have been raised by the East Midlands EOLC workstream. Under each stage a locally implemented example of good practice will be outlined in greater detail to highlight the potential benefits.

3.1 Public Awareness

National

Open discussion about death and dying needs to be encouraged as a normal process. Individuals should be encouraged to have the relevant plans in place in relation to their will, funeral arrangements and views on organ donation.

Funeral Directors, Crematoria and hospices should be encouraged to have open days and sessions on life cycle and loss should be included in local school curricula.

Local PCTs and LAs should promote awareness by developing locally available awareness raising tools and programmes.

East Midlands - additions

Patient and public websites and information centres within acute hospitals can be used to help raise awareness of EOLC. Information hubs in GP surgeries, community hospitals and possibly libraries could be developed as a way of promoting this concept further.

Staff education programmes should be developed to raise awareness amongst healthcare professionals, which in turn will help increase public awareness of the issues.

Local example of good practice - Cancer Network Website

The Leicestershire, Northamptonshire and Rutland (LNR) Cancer Network Website was launched in September 2007. In the patient information section of the website there is a specific section on palliative care including EOLC, which contains general information and enables access to a number of local and national information resources. It gives details of where palliative care services are available across LNR including hospitals and hospices and there is also a help and support database which outlines national and local resources that are available including details of support groups and where people are able to access advice on benefits or obtain equipment. There are also details about respite services that are available across the network.

There is further information on palliative and EOLC on the healthcare section of the website with details of local work programmes, national initiatives and agreed policies and guidelines in relation to the delivery of equitable services across LNR. Initial feedback on the site has been very positive and there are plans to further develop the palliative care content with a view to developing a specific palliative care website to help raise awareness and benefit patients with long term conditions.

3.2 Assessment and Care Planning

National

There needs to be recognition by professionals that death does not represent failure and that enabling people to die as well as possible is a core function for health and social services. There should be open, honest communication between health and social care professionals with patients and carers about end of life care. Individuals should be given the opportunity to consider the care they wish to receive based on the best information available.

Every person (and carer) should 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 made aware of this. There needs to be recognition of the Mental Capacity Act (2005) 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.

Recent update: Mid Trent Cancer Network have developed Mental Capacity Act compliant Advance Decision to Refuse Treatment Specialist Guidance document and education programme (www.adrtnhs.co.uk) commissioned by Department of Health, Help the Hospices and East Midlands Ambulance Service. This programme is being further developed to be adopted by the National End of Life Programme and will become an End of Life Tool.

East Midlands – additions

An agreed holistic assessment tool (the holistic common assessment of supportive and palliative care needs for adults with cancer – assessment guidance January 2007 could be adapted. This incorporates general information plus physical, social (occupational), psychological and spiritual needs) should be developed for all patients, which incorporates advanced care planning and is undertaken at various stages along the care pathway. A component of this would be a patient held record to assist with communication between health and social care professionals and involve patients and carers in the process.

It is proposed that the Quality and Outcomes Framework (QOF) be better employed to provide more comprehensive coverage of patients within their last year(s) of life and to provide better quality of care with more measurable outcomes. For example, include those patients identified by the one-year trigger question (would you be surprised if this patient were to die within one year?) but include elements of EMAS 'end of life care decisions' forms and Out of Hours (OOH) PPC forms to ensure that advanced care planning has been discussed as appropriate.

It is recognised that these discussions are not always possible or necessary with all patients so a standard could be set at around 70% for the QOF. A flag system would need to be employed so that primary and secondary care providers involved would be aware of what had already been covered for any given patient.

Local example of good practice – Care of cancer patients on EOLC register including Out of Hours (OOH) service

At Measham medical unit a patient held record (PHR) is issued to patients on diagnosis of cancer. Information needs are assessed at regular intervals. At the time palliative care is needed a separate section is added with clear indication of preferred place of care and all professionals make regular clinical entries. Medication is left at the patient's home in anticipation of particular symptom needs. Multi disciplinary team meetings are held regularly to discuss and learn from patient's journeys.

PHR enhances the speed and quality of communication between all health care professionals. It allows easy understanding of the roles of all the caring professionals in that patients care. The dying patients' families are given the opportunity to contact their GP out of hours by mobile telephone. A regular Saturday morning visiting service for dying patients – extended to long bank holidays weekends is also offered.

The practice has achieved a cancer deaths at home rate of nearly 60% in the last year, by using team working, patient held records and a willingness to attend patients out of hours. The major metric is the quality of feedback by independent carer survey after death.

3.3 Coordination of Care

National

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 and rapid response services and ensure wishes about PPC which include DNR status, ADRT and preferred place of death are known to all relevant services.

East Midlands - additions

7-day support services in secondary care should be implemented to help speed up the discharge process from hospital. There should be access to equipment 24/7 to help with discharge packages and to prevent unnecessary admissions to hospital. There should be a named key worker for all patients in secondary and primary care to help coordinate patients care pathways.

Gold Standards Framework (GSF) and the Liverpool Care Pathway (LCP) should be fully implemented in all care settings to ensure care is better coordinated with regular discussions within an MDT. GP out of hours services with support teams should be established to help implement care packages in the community.

There should be an adequate number of generalist and specialist EOLC beds in a variety of different care settings. This should enable patients to die closer to home if they are not able to, or do not choose to be at home.

Local example of good practice - Delivering Choice Programme

Marie Curie Delivering Choice Programme was launched in Lincolnshire in October 2004 and will complete on the 31st March 2008. The aim of the Programme is to develop and help provide the best possible service for palliative care patients allowing them to be cared for in their place of choice. The Programme has developed several high quality service models in Lincolnshire, which support the needs of patients and carers thereby enabling patients to die in their place of choice.

These services include:

Community Based Rapid Response Team. The primary aim of the Rapid Response Team (RRT) is the provision of a community based crisis and planned intervention nursing service, which complements all primary health and social care, voluntary sector Community Nursing Services and the Out of Hours Service. The RRT is available seven days per week during the twilight and Out of Hours (OOH's) periods working in conjunction with Health Care Providers in both the acute and Primary Care Sectors. Currently the service is situated in Boston Pilgrim Hospital and covers Boston and the surrounding area of Spalding and South Holland.

Palliative Care Co-ordination Centre (PCCC) The PCCC is an administrative centre arranging the booking of home care packages for palliative care patients across Lincolnshire. The Centre is situated in the East Midlands Ambulance Service Divisional HQ building in Lincoln and operates five days per week (9am – 5pm; Monday to Friday).

Discharge Community Link Nurses (DCLN). The role of the DCLN is to facilitate hospital discharge for end of life patients and provide a communication and information link between primary and secondary care providers during the discharge process. To provide continuity of care between hospital and community, and when necessary, the DCLN also meet some patients at their home on the day of discharge thus providing nursing support for patients and carers at home. There two nurses, one based in Lincoln County and the other in Boston Pilgrim Hospitals.

3.4 Delivering High Quality Care

National

Hospital

There should be high-level commitment and leadership from PCTs, 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 need rather than disease, and provide education for staff throughout the hospital.

They should ensure that relevant professionals have appropriate skills to elicit the needs and preferences of patients and that care plans are recorded, communicated and accessible to all relevant health and social care staff. They should establish a framework to ensure delivery of appropriate care for people who are in the dying phase and in collaboration with other agencies have processes in place to ensure rapid discharge for those who wish to die at home.

Community

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 and 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 DNR wishes.

Care Homes

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 the EOLC of residents as equally as enabling them to live well until this time. 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 and there should be supporting services from district nursing, primary care, out of hours and community palliative care teams which are integrated and accessible.

Hospice care

These should be centres of excellence, which provide direct care for people with complex problems on the basis of need rather than diagnosis, provide advice to GPs and district nurses as well as education and training for staff who wish to specialise in palliative care. They should lead the way in research, development and evaluation of issues related to end of life care. They should provide support to enhance the care provided in care homes and patients' own homes including providing 24-hour telephone advice and bereavement care. They should be involved in schemes with local communities in raising awareness of end of life care.

Ambulance services

They 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 and ensure that staff feel confident in dealing with end of life care issues.

Primary Care Trusts

They 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 and provide information systems which facilitate the sharing of information between agencies.

Prisons

Those who are approaching the end of life in prisons or secure hospitals must 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 symptoms, needs and preferences are documented and reviewed, and that services are coordinated to ensure that the symptoms are addressed and wishes of the person are respected.

Homeless

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.

Spiritual

There should be processes in place to ensure that spiritual care is provided and coordinated across the care pathway and recognise the need for, and enable those caring for the dying and bereaved to have a reasonable knowledge of various faiths and practice. All care settings should facilitate an environment in which those with or without faith can take part in ritual actions. Occasions of remembrance for bereaved people and staff should be organised when ever possible,

East Midlands - additions

Information prescriptions should be developed for all conditions, as this will ensure patients and carers receive the relevant information at the right time in relation to palliative and end of life care.

Advanced Communication Skills Training programmes should be rolled out for all relevant staff to ensure they have the skills to deal with discussions related to death and dying. Specialist nursing posts should also be developed for all long-term conditions.

Issues in relation to cultural differences also need to be taken into account. Cultural support workers should be accessible and involved in care planning and if there are language barriers independent interpreters and link workers should be available when discussing end of life care issues.

The 'Virtual hospital' model may be worth considering providing both generalist and specialist palliative care input across communities. This is based on Croydon's virtual wards pilot (see Appendix 4), which aims to provide integrated care within a home setting. The pilot is yet to be fully evaluated, but initial feedback has been positive.

Respite and day care services should be increased to meet demand and allow care to be delivered in a variety of settings. Care pathways also need developing for other patient groups such as travellers and mental health patients (learning disabilities covered in national good practice, Appendix 1).

A form which registers end of life care decisions has been developed by East Midlands Ambulance Service (EMAS) and should be fully implemented across the region to ensure information regarding ADRT and DNR status is communicated to the ambulance service from both secondary and primary care.

Mental health issues are important to consider in more detail as there are a number of categories which link to end of life care. Firstly there is the mental health of patients themselves. This can be in relation to their general psychological well being and may also link to the Mental Capacity Act if at any point they are unable to communicate their wishes, due for example to dementia. It also relates to those patients with mental health problems or learning disabilities who are at the end of life. The final area is the mental health needs of families and carers and the benefits of providing support in the initial bereavement phase to prevent potential long-term mental health problems.

A closer working relationship with mental health trusts may help to ensure that end of life care needs are carefully considered for every individual and to encourage partnership working between all providers of health and social care. More integrated working would also assist prisoners and those with learning disabilities at the end of life and ensure wherever possible better forward planning and coordination of care.

Local example of good practice – Long Term Conditions Team

Central Nottinghamshire have a Long Term Conditions Team with Consultant Community Geriatrician Leadership providing a comprehensive service in the community. This service has good communication with the Specialist Palliative Care Service in the joint management of patients at home.

3.5 Last Days of Life

National

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 with discontinuation of inappropriate interventions, psychological and spiritual care and care of carer and family. Health and social care staff should be trained and supported to undertake this process in accordance with existing models of care (LCP).

East Midlands - additions

A tool to help identify patients entering the dying phase should be developed (current research project in Nottingham University). There should be 24/7 hospice at home type services, rapid discharge teams and the LCP should be fully implemented in all care settings. There should be clear information for carers related to what is likely to happen in the last few days of life and who to contact in an emergency. Other issues highlighted in coordination of care are also relevant here.

Although not common there needs to be a recognition that patients do occasionally live longer than expected when placed on the LCP and that their status should be regularly reviewed. Sometimes, particularly patients with long-term conditions may be put on the pathway several times before they die.

The needs of patients who die following an episode of acute care must also be considered. Whenever possible the LCP should still be implemented (such as in an ITU setting) and families and carers should be able to expect the same level of support at the time of death and during the bereavement phase as they would if the patient's death was expected.

Local example of good practice – Decisions at Life's End (DALE) project

This Partnerships for Older People Project is being implemented by Leicestershire & Rutland County Councils and Leicestershire County & Rutland Primary Care Trust. Its aim is to reduce the increasing number of older people who die in hospital by providing the infrastructure in primary and community care that enables older people the choice of being cared for in their own home or closer to home in the last few days of life.

It is not a new service, it is a pathway and aims to integrate existing services. It will be coordinated by District Nurses, Community Matrons and Care Home Matrons working with existing staff and with some additional capacity in the form of 11 new 'DALE' nurses, 22 new 'DALE' support workers and 10 'Befriender' volunteers. There will be a phased roll out over 2 years in Nursing / Care Homes, Sheltered Housing, own home with carer support and own home alone.

The additional staff will assist existing teams to support elderly patients in their 'home' in the last few days of life and will prevent unnecessary admissions to hospital and also improve the quality of care for these patients and their families/carers at the end of life.

3.6 Care After Death

National

End of life care should not stop at death and should include handling the body in a culturally sensitive way and accommodating the needs and wishes of carers and family. There should be 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 should also be in place.

Staff should be 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.

East Midlands - additions

There should be appropriate facilities for families and carers at the time of death and shortly following to enable privacy. A recognised care pathway for bereavement should be developed and implemented across the East Midlands which includes responsibilities for GP practices in providing bereavement support and access to specialist support as required. Local directories outlining bereavement support should be available on websites and in hard copies from GPs and libraries etc and include services for all ages. Training programmes should be developed for staff to raise their awareness and knowledge base in relation to supporting families following bereavement.

Information is required for professionals and carers in relation to the handling of drug waste – especially controlled drugs after a death, including whether to keep for the coroner or return to a licensed person.

Local example of good practice – Bereavement services

The Bereavement Support Service at Treetops Hospice in Derbyshire provides a professional support and counselling service to any individual over the age of 18 who feels they may be experiencing difficulties with their grief reaction.

The service is accessed through self-referral by anyone living within the Southern Derbyshire and Nottinghamshire borders. Following initial contact from the person, they are seen for assessment within ten working days and referred to a member of the team immediately. This results in the person receiving support within a maximum of three weeks from first contact. Sessions take place on a once-weekly basis either in the person's home or at the hospice following an assessment by the Bereavement Support Worker (assessments always take place in the person's home). The number of sessions is not time-limited but the regular supervision enables the support worker to facilitate the work such that the ending is achieved in a timely and

appropriate manner in response to the level of difficulty the person may be experiencing. Treetops Hospice operates an open-door policy whereby people may re-refer themselves at any time in the future should they feel they might benefit from further support.

The hospice also facilitates two bereavement support groups, again for people over the age of 18; these take place at the hospice on a once-monthly basis during the afternoon and evening with a maximum of eight people per group.

3.7 Support for Carers

National

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. This should include the appropriate initial and ongoing support for any children of patients who are at the end of life.

East Midlands - additions

Carers training needs should be assessed and delivered by the relevant health/social care professional. Respite services should be increased in a variety of care settings from home, care homes, community hospitals and hospices.

Local example of good practice – Carers support group

As part of the Marie Currie Delivering Choice Programme in Lincolnshire they have developed a Carers Support Group: The objectives of this service are to increase carer confidence, enhance coping strategies, and reduce feelings of fear and isolation. This is achieved by providing support to carers away from the patient in the form of Support Groups which is a monthly meeting with lunch facilitated by nursing staff and supported by volunteers. Information and emotional support is offered at these sessions. Attendance is also supported by volunteers who provide transport for carers or provide care to the patient while the carer is away. These groups are held in the St Barnabas Hospice Day Therapy Units across Lincolnshire. In June 2006 the first group was held in Gainsborough and has since expanded to Lincoln, Sutton-on-Sea, Spalding and Boston.

3.8 Conclusion

Many of the areas highlighted as good practice in the national evidence were also identified in the 5 counties across the East Midlands. A number of additional areas were also raised.

The examples of where good practice has been implemented demonstrate the potential benefits to patients at the end of life and to their carers.

The next section of the report will use the stages of the pathway and analyse the barriers that currently prevent or have the potential to prevent full implementation of good practice across the East Midlands. It will also identify some enablers to help these barriers to be overcome.

4. Barriers and Enablers

The challenge now the key issues have been highlighted and the good practice identified is understanding the barriers that are preventing or have the potential to prevent implementation of good practice across the East Midlands. It is also important to outline possible enablers to overcome these, and initiate the provision of high quality end of life care services, which can also demonstrate effective use of resources and best value for money.

4.1 Public Awareness

Death and dying are not discussed openly by society and there can be a reluctance to accept that people die, as medical technology and intervention has advanced greatly in recent years and with it there has been a rise in public expectation. Even the medical profession themselves can struggle with the concept of death as their role is associated with saving lives and healing people and patient deaths can be viewed as a failure.

There are obvious resource and capacity issues in relation to developing and delivering education programmes and undertaking awareness campaigns. There is also difficulty in providing comprehensive information resources unless sufficient funds are available.

Influencing school curricula requires partnership working between organisations and authorities, which do not traditionally link. Some LEAs may also view introducing the topic of death and dying as controversial.

Enablers

- National campaign to raise death and dying awareness outlining local responsibilities and promoting partnership working. This should take into account the particular needs of local populations

- Mandatory EOL competencies in communication and symptom management to be embedded in undergraduate and post graduate training programmes
- Use of websites to promote EOLC and help distribute the cost of printed resources following initial development costs

4.2 Assessment and Care Planning

In general the current IT infrastructure is not robust enough to enable the development of community wide electronic records allowing the implementation of the Single Assessment process (e-SAP). Cross boundary working and effective joint working between health and social care and the voluntary sector is not sufficiently developed to ensure a coherent process in relation to assessment and care planning. There is no regional or even county wide agreed holistic assessment tool for patients in the last year(s) of life to assist with this issue.

A number of good practice initiatives require potential additional resource but the main challenge is obtaining engagement from key stakeholders to implement them. Examples are ensuring there is an identified key worker in all care settings for patients at the end of life and initiating patient held records.

Enablers

- Joint commissioning and pooling of resources between health/social care and the voluntary sector possibly via a partnership board to enable cross boundary service planning and delivery to be implemented for EOLC
- Practice based commissioning used as an incentive to engage GPs
- Effective integrated IT systems
- Agreed holistic assessment tool that incorporates ACP, ADRT and is an integral part of the patient assessment process
- Agreed key worker policy covering all care settings

4.3 Coordination of Care

It is difficult to identify all patients that are eligible to be placed on a palliative care (EOLC) register as due to the trajectory of many long-term conditions it is not always possible to identify when they are entering the last year of life. The issues of cross boundary working, key worker and patient held records are also relevant barriers here. Engagement can be a challenge when trying to implement GP led OOH services and there are obvious resource implications in establishing coordination centres and ensuring 24/7 service provision including access to equipment.

Enablers

As for 4.2 plus:

- Practices to use GSF trigger question to identify those patients with Long Term Conditions likely to die within one year to ensure all relevant patients are placed on the EOLC register
- Use baseline assessments of EOLC services to begin to identify how services can potentially be reconfigured to establish coordination centres and supporting teams and ensure gaps are fed into local LDPs

4.4 Delivering High Quality Care

Delivering the same level of care for all patients is not occurring in many areas due to a lack of knowledge of many health care professionals and in some cases a limited level of resource that historically has been utilised by cancer patients and is becoming increasingly stretched now other patient groups are accessing it.

Many GPs are not prepared to take on additional workloads or provide OOH cover to meet the needs of patients at the end of life. Although many practices are claiming to be implementing GSF there is currently no comprehensive system to ensure they are doing it properly beyond the QOF points currently associated with EOLC.

Some service provision is currently not captured under clinical activity and is not included in proposed palliative care tariffs for PbR e.g. telephone advice.

There are challenges involved in increasing service provision, changing working patterns and establishing more effective partnership working between organisations and sectors.

There is a conflict between allowing patients to smoke in the terminal phase of their disease whilst in hospital/hospice premises and the legal position in relation to smoking in public places.

There is no unified DNR policy across the East Midlands, which can lead to confusion, repetition of assessment processes and unwanted attempts to resuscitate patients at the end of life.

Enablers

As for 4.2 & 4.3 plus:

- Use baseline assessment to better utilise current resource and identify specific areas which require additional investment to meet growing demand and feed into local LDP
- Increase the indicators for QOF in relation to EOLC and incorporate a requirement to demonstrate positive outcome measure
- PCTs should identify Quality Indicators to be included in contracts/service level agreements (SLA) with providers which could be used to manage performance
- Unified DNR policy across the East Midlands

4.5 Last Days of Life

There can be delays in discharging dying patients due to poor discharge planning including transport issues and the difficulties in setting up packages of care in the community.

The high turnover of staff particularly in care homes and amongst junior medical staff makes it difficult to sustain the use of the LCP. Limited resource is not enabling training programmes to be sustained long-term.

There is limited palliative care in-patient resource and palliative care beds are not being fully utilised in community hospitals due to a lack of expertise and the reluctance of GPs to take responsibility for patients in this setting.

There are numerous legalities in relation to the administration of drugs particularly for ambulance crews, which can result in the need for a hospital admission near to the end of life to provide symptom control.

Enablers

- Practice based commissioning used as an incentive to engage GPs
- Coordination centre established to arrange home care packages – infrastructure in place to meet demand
- LCP ‘champions’ at a senior level and clinical link workers established in acute trusts and PCTs with a responsibility to ensure the pathway is implemented within their organisations. This should be linked to an outcome measure regarding number of patients placed on the pathway
- Incentives for care homes to use LCP
- National policy related to drug administration at EOL

- Strategy to utilise community beds with associated training programmes and links with specialist palliative care teams

4.6 Care After Death

There are obvious funding and capacity issues in providing facilities for relatives up to the time of death and shortly after. This also includes the provision of information resources and staff training programmes.

Removing equipment from a patient's home can also be difficult to initiate within a 24-hour period particularly at weekends and there can often be a charge for providing this service. The removal of drugs is also an issue with staff and carers not always being aware of correct procedures.

There is currently no mandatory requirement to provide bereavement services and no incentives for GPs to help enable this, as such provision is variable. The lack of a common bereavement policy also prevents equitable practice.

Enablers

- Agreed bereavement policy which includes a minimum standard for provision and facilities
- Robust SLAs developed with equipment providers and clear information available in relation to the disposal of drugs
- Practice based commissioning used as an incentive to engage GPs plus possibly QOF

4.7 Support for Carers

The lack of an agreed holistic assessment incorporating support for carers results in differing levels of intervention.

Resource and capacity is again an issue in relation to providing respite services, facilities and training for carers.

Enablers

- Agreed holistic assessment tool that incorporates carer support
- Use baseline assessments of EOLC services to begin to identify what services are currently available and how some may potentially be reconfigured to increase the provision of respite services. Additional need for provision to be fed into LDP
- Training needs assessment for carers included as integral part of holistic assessment

4.8 Conclusion

There are a number of significant barriers preventing the implementation of good practice, which highlight how complex the issues are in relation to delivering high quality care at the end of life.

This complexity also highlights the reasons why many of the good practice initiatives have not as yet been implemented to date across the East Midlands due to the barriers outlined in this section. The enablers do prove however, that with the right level of engagement from key stakeholders the care of patients and their families/carers can be greatly improved.

The next section will briefly look at current and potential workforce issues in relation to EOLC.

5. EOLC Workforce Issues (provided by East Midlands SHA)

5.1 Existing Workforce

An extensive range of staff currently provide different aspects of care for individuals with palliative care needs:

- Community Matrons/ Specialist Nurses/ Advanced Nurse Practitioners
- Ambulance Emergency Care Practitioners / Community Paramedics
- Intermediate Care Teams / Rapid Response Teams
- Pharmacists
- Therapists eg, Physios / OTs
- Voluntary Sector
- GPs / District Nurses / Practice Nurses
- Macmillan / Marie Curie Nurses
- Consultants and Palliative Care Specialists
- Other Specialists eg, Lymphodema Therapists
- Social Workers
- Care Home Staff
- Clinical Psychologists

5.2 Specific Workforce Issues:

- Workforce issues related to new legislation eg, Mental Capacity Act: Advanced Decisions to Refuse Treatment will be significant.
- The main workforce capacity issues tend to be related to inequity of workforce at the specialist end with particular shortfalls around numbers of Consultants in Palliative Care, Neurology and Specialist Nurses eg, Heart Failure, Renal and Neurology.

- Clinical psychologists are becoming increasingly involved with patients with palliative care needs. However, commissioning arrangements for services for these conditions tends to be in disease specific categories and often does not include support required from other specialities.
- A Whole Systems Modelling project was undertaken in Leicestershire, which looked specifically at the shift of unscheduled care activity from secondary to primary care and the impact on the workforce as well as bed capacity. The project explored the impact of the introduction of Community Matrons, EOLC tools such as LCP and GSF and the impact of 'first responders' eg, Emergency Care Practitioners. The final report found, not surprisingly, that the desired outcomes were better achieved through a combination of new ways of working and the coordination of services and resources rather than simply through the introduction of specific new roles.
- It is important to plan EOLC workforce across the entire pathway with collaboratively working between health, social care and the voluntary sector.

5.3 Specific Education and Training Needs

The quality of death and dying needs to have a much higher profile in multi-professional education and training. The national End of Life Care Strategy Advisory Board recommends that we through education commissioning ensure 'that health and social care staff at all levels have the necessary knowledge, skills and attitudes related to care for the dying. For this to happen end of life care needs to be embedded in training curricula at all levels and for all staff groups.' There also needs to be access to national training events and commissioned local events. It is therefore important to:

- Map existing palliative care training via HEIs and other providers
- Identify gaps and feed into education commissioning processes (pre and post basic)
- Ensure GSF, LCP, PPC underpin all palliative care training and the principles underpin pre and post registration training
- Maximise the impact of these and other education/training programmes, eg, nurse prescribing, community matrons, ECPs

Another pertinent issue in relation to EOLC workforce is an appreciation of the challenges of working with patients at the end of life and the need to ensure there are a variety of different support mechanisms available for staff working within this area.

The final sections of this report will put forward some key priorities/recommendations to the East Midlands SHA and to the national review panel to outline what needs to happen locally to deliver the optimal pathway for EOLC within the region. It will also provide examples of what could be the first achievable 'next steps' in relation to the implementation phase of the review.

6. Key Priorities/Recommendations

A number of key initiatives as outlined below need to be taken forward in able to deliver the optimal pathway for all patients at the end of life across the East Midlands.

a) Coordinated (cross boundary) care pathway for EOLC (Potential care pathway attached as Appendix 3)

This could be developed by current (clinical) palliative care network groups or equivalent and ratified by a partnership board in each county established with broad representation to ensure the implementation of coordinated care across organisational boundaries.

The pathway would incorporate the areas of best practice outlined in this report.

b) Joint (PCT/LA) commissioning along patient pathways informed by EOLC baseline review

The partnership panel would be responsible for commissioning care along this pathway using the PCT baseline assessments to identify current service provision and to highlight gaps for inclusion in future LDPs.

Having a full picture of what services are currently available in all sectors may enable resources to be redirected or better utilised to meet the need of all patients at EOL.

c) Support for families/carers at all stages of the pathway including bereavement

This should be incorporated in the care pathway outlining best practice as highlighted in this report

d) Workforce strategy including education and training needs for EOLC in pre and post registration training programmes for all disciplines

Some elements of EOLC training should be made mandatory particularly for medical staff. A policy outlining the development needs should be developed by the HWD with a view to introducing increased levels of EOLC training within curricula over a set time period

e) Integrated IT systems

A strategic plan to integrate IT systems across organisational boundaries including the voluntary sector should be outlined with phased timescales to allow the implementation of e-SAP and enable coordinated care by improved communication systems

f) Agreed standards and outcome measures for each stage of the pathway (Potential standards and outcomes attached as Appendix 2)

Any implementation plans to improve EOLC must be accompanied by outcome measures to enable the evaluation and monitoring of initiatives and performance and to demonstrate improvements and benefits to patients/carers experience. Suggested measures are outlined in section 6.

g) Senior level 'champions' responsible for monitoring EOLC outcomes in every organisation which is fed back to the SHA

Identifying organisational champions with defined areas of responsibility should help ensure high quality EOLC for all patients.

h) Regional cross boundary EOLC public awareness strategy

Ideally led nationally, an East Midlands public awareness strategy should be developed using the good practice outlined in this report ensuring the diverse needs of local communities are addressed. This should over time, help to change societies attitude towards death and dying.

7. Achievable First Steps

- Complete PCT EOLC baselines – agree priority areas for initial (e.g. continued funding of LCP facilitator posts) and future investment and identify opportunities to implement/roll out good practice models across the East Midlands (ideally jointly with LAs at county level)
- Develop and distribute proposal document outlining how GPs, through PBC can offer increased services for patients in the last year of life including OOH services
- Agree a minimum number of standards and outcomes for EOLC to be measured across the East Midlands by the end of 2008, taken from those outlined in this report
- Identify 'champions' within each Trust with a clear remit for ensuring EOLC tools are used within their organisation and monitoring agreed standards/ outcomes

- Use this report, as a resource to develop overarching regional strategies for workforce/education and training needs, communication systems and bereavement care across the East Midlands to then be implemented at county level via more detailed local strategies.

8. Conclusion and Key messages

End of life care as with most other areas of health/social care is very complex. This report has identified many areas of good practice currently happening across the East Midlands but has also highlighted a number of significant barriers that prevent this area of care being as good as it could be for our local population. The enablers do prove however, that with the right level of engagement from key stakeholders the care of patients and their families/carers can be greatly improved.

If the key themes identified above are addressed, the vision as outlined at the beginning of this report should become a reality. To ensure that this report does truly influence positive improvements in-patient care will however require top-level commitment.

This clearly begins at the Department and Health and continues through the SHA to the local commissioners and providers of EOLC services across the East Midlands. This encompasses the need for a reduction on the reliance of charitable funding to support elements of specialist palliative/end of life care service provision across the region which should be viewed as 'core business' by a 21st century NHS.

Continuing engagement and consultation with local communities is also key to ensure the development and delivery of EOLC services that truly meet the needs of the East Midlands diverse and multicultural population.

9. Regional EOLC Workstream members

Jackie Booth	Marie Curie	Lincolnshire
Naomi Caldwell	GP	Northamptonshire
Sue Cohen	Assistant Director, Public Health	Derbyshire
Pat Copson	Palliative Care Professional Lead	Leicestershire
Chris Elwell	Consultant Oncologist	Northamptonshire
Mark Fallon	GP	Lincolnshire
Luke Feathers	Consultant in Palliative Medicine	LOROS
Greg Finn	Consultant in Palliative Medicine	Nottinghamshire
Philip Foster	GP	Nottinghamshire
Sarah Furley	Cancer and Palliative Care Planning Manager	Lincolnshire
Marion Gee	CSIP	East Midlands
Cheryl George	CSIP	East Midlands
Robin Graham-Brown (Chair)	Director of Older Peoples Services	UHL
Angela Howe	Palliative Care Services Manager	Northamptonshire
Ali Johnson	Derby and Burton Cancer Network Nurse Director	Derbyshire
Jo Kavanagh (Executive Lead)	LNR Cancer Network Nurse Director	Leicestershire/ Northamptonshire
Vaughn Keeley	Consultant in Palliative Medicine	Derbyshire
Andrew Kenworthy (CE Sponsor)	Chief Executive	Nottinghamshire
Jane Lindley	Care Manager	Leicestershire
Jim Murray	Clinical Lead, Cancer and Associated Services	Nottinghamshire
Judy Parsons	GP	Derbyshire
James Reid	Consultant in Elderly Medicine	Leicestershire
Nicky Rudd	Consultant in Palliative Medicine	UHL
Jill Ryalls	Area Manager, Older People's Services	Derbyshire
John Stephenson		EMAS
Carole Tallon	Consultant in Palliative Medicine	Northamptonshire
Elaine Wilson	Mid Trent Cancer Network Nurse Director	Nottinghamshire/ Lincolnshire

10. References

Advance Decisions to Refuse Treatment - Specialist Guidance (Adult) (2007), East Midlands Health and Social Care Community, Mid Trent Cancer Network.

End of Life Care - Working Paper (2006) EOLC Strategy Advisory Board, Department of Health, DH.

End of Life Care: Emerging Themes (2007), EOLC Strategy Advisory Board, (DH).

End of Life Care Supporting Information, Data and Evidence (2007), NHS Next stage Review, DH.

Holistic Common Assessment of Supportive and Palliative Care Needs for Adults with Cancer – Assessment Guidance (2007), National Cancer Action Team.

Operating Framework 2007/08: PCT baseline review of services for end of life care (2007), DH.

Mental Capacity Act Code of Conduct (2005), Department for Constitutional Affairs.

UK Ambulance Service Clinical Practice Guidelines (2006) Joint Royal College Ambulance Liaison Committee (JRCALC)

11. Appendices

Appendix 1 – Examples of national/local good practice models

Public Awareness

National examples:

An example was given where a hospice had linked with local primary schools to help raise children's awareness of death and dying.

Examples across the East Midlands include:

- Cancer information centres in Lincolnshire provide a drop in and outreach service for the general public as well as patients and carers, which includes information regarding end of life care. Other information centres across the East Midlands provide similar services
- 4 of the 5 counties have cancer network websites which include information plus help and support databases covering palliative and end of life care
- A number of the hospices across the East Midlands have annual open days for the general public and develop regular newsletters
- Nottinghamshire are using a hospice publication – 'circle of life' to help health care professionals begin to initiate conversations regarding palliative care with patients and introducing the concept of hospice care
- All counties are using national publications on end of life care

Assessment and Care Planning

National examples:

A care home in **Leicestershire** was used to highlight an example of advanced care planning which has increased the number of residents dying at the home rather than being admitted to hospital. The other example given was the development of specific assessment tools to improve the care of people with learning disabilities at the end of life.

Examples across the East Midlands include:

- Holistic needs assessment and advanced care planning is being practiced in a number of counties incorporating the advanced decision to refuse treatment initiative
- End of life care tools (GSF and LCP) being implemented to some degree in all counties
- Lincolnshire using medication boxes in patients own home
- Primary care key worker pilot being undertaken in Northamptonshire
- Palliative care MDTs occurring in most hospitals and hospices across the region
- MDT for MND patients developed in Leicestershire

- Referral system established in parts of Northamptonshire for patients with long term conditions requiring palliative care services
- Advance Decision to Refuse Treatment guidance and education in Nottinghamshire

Coordination of Care

National examples:

The **Lincolnshire** Delivering Choice Programme was highlighted which via cross boundary working, coordination through a central point and the introduction of rapid response teams managed to avoid 280 admissions to A&E in a 6-month period. Discharge community link nurses also help facilitate discharge at the end of life. Another joint health and social care initiative was outlined where a specialist team trained in palliative care helped avoid hospital admissions through providing respite care in a variety of care settings, predominately the patients own home.

Examples across the East Midlands include:

- Flexible day care provision being provided in a number of hospices across the region offering much needed respite for patients and carers
- Various levels of 'hospice at home' type services being delivered in all 5 counties enabling patients to die at home
- Good systems of communication between primary and secondary care in Derbyshire, ensuring communication with GPs within 24hours
- Practice led OOH services being practiced in Leicestershire
- 'Green card' system being implemented in Lincolnshire and Leicestershire for palliative care patients
- Registration of end of life care decisions developed by EMAS and being utilised by many trusts across the region
- Sherwood Forest Hospitals Trust have developed the patient Recurring Admissions Patient Alert (RAPA) programme to alert appropriate staff of any potential admissions and patients in casualty. This is part of the Beyond Cancer Waits Programme and is reaching into new diagnoses and the community. This programme has a national award

Delivering High Quality Care

National examples:

Many examples were given under this heading, as different care settings were included. The hospital example was a rapid discharge pathway for dying patients. The community case study referred to a 24/7 'hospice at home' service. Examples from care homes were those where the end of life care tools had been implemented – both of these initiatives had enabled people to die at home. A coding system had been used in one care home to identify those patients that were likely to die within days or weeks to allow for better planning of care.

The London ambulance service has developed a policy to help initiate hospital discharge and prevent undesired resuscitation and inappropriate transfer to hospital. An example of cross boundary working was demonstrated between a prison and its local PCT and acute trust to provide services for prisoners at the end of life.

Other areas covered but not supported by case studies were hospices, community hospitals, homeless people and spiritual care.

Examples across the East Midlands included:

- Decisions at Life End project for elderly patients in Leicestershire supporting them to die in their own home/care home
- 24-hour district nursing cover provided in Derbyshire plus 7 day working of hospital palliative care teams. Some other counties are providing 6 day working
- OOH GP service plus Saturday visiting service operating in one practice within Leicestershire which has helped prevent hospital admissions
- EOLC tools being implemented for non-cancer patients in some counties
- Outreach spiritual support service being offered in Leicestershire
- Urgent community OT assessment being provided for EOLC patients in Derbyshire
- Mid Trent Cancer Network are piloting a PHR called “My Little Blue Book” along the lines of maternity and paediatric models. This is currently cancer specific but the intention is that it will eventually cover all diagnoses.

Last Days of Life

National Examples:

No national case studies were included for this section.

Examples across the East Midlands:

- LCP being implemented to various levels in all counties and in most care settings
- Hospice at home services being delivered at various levels in all counties
- Registration of EOLC decisions (EMAS) being rolled out across all the counties
- Varying degrees of DN cover to support patients OOH in a number of counties
- Medication boxes being used in patients homes in Lincolnshire

Care After Death

National Examples:

A group of care homes have introduced several initiatives to try to normalise death to enable the residents themselves to talk about death and help family and staff openly discuss and remember those that have died. An acute trust has produced comprehensive guidance on all aspects of care after death to assist staff and improve the care of bereaved families.

Examples across the East Midlands:

- Bereavement services are provided in a number of the hospices across the region and also in some of the acute trusts
- Some GPS provide follow up services for bereaved families
- 24/7 mortuary service is available in a number of the acute trusts
- Verification of death by nursing staff has been introduced in several counties

Support for Carers

National Example:

No national case studies were included for this section.

Examples across the East Midlands:

- Hospital chaplaincy departments available in most trusts across the region
- Counselling and support services offered by most of the hospices and some charitable organisations such as 'coping with cancer' in Leicestershire
- Day care and respite offered by most hospices across the region
- Best practice guidelines in caring for relatives of a dying patient developed in Nottingham and Lincolnshire
- PALS still available in some trusts and most PCTs
- Children and young peoples bereavement team in Northamptonshire
- Numerous support groups in place across the 5 counties

Appendix 2 - Potential EOLC Standards and Outcome Measures

Public awareness

Standards

- Evidence of public engagement, involvement and education regarding issues related to EOLC are in your area

Outcomes

- Public and staff awareness surveys demonstrating increased levels of knowledge and understanding

Assessment and care planning

Standards

- Evidence of combined health and social care assessment taking place in a timely manner
- Evidence of combined health and social care funding for patients on End of Life Care Pathway
- Proof of mechanisms for the identification of patients who may be eligible for the GSF with both malignant and non-malignant conditions (in own homes, acute trusts and Care Homes)
- Community EOLC MDT – membership, frequency of meetings, evidence of regular review of cases for GSF and recommendations re needs
- Evidence of appropriate completion of Preferred Priorities of Care Document with patients on GSF including the use of advanced directives re resuscitation/other escalation of medical care and organ donation

Outcomes

- Patient/carer satisfaction surveys demonstrating co-ordinated care pathways
- Reduced number of inappropriate hospital admissions
- Increased number of patient being cared for and dying in their place of choice
- Documented EOLC discussions
- Number of staff undertaking communication skills training
- Reduced number of complaints related to coordination of care and communication issues

Coordination of care

Standards

- Key Worker – evidence of nominated Key Worker for every patient on GSF, clear role definition for Key Worker with advanced communication skills training
- Demonstrate functioning Single Point of Contact for patients and carers to access 24/7 when problems arise

- Robust proof with case examples that appropriate support is available 24/7 for patients and their carers both in their homes and in Care Homes, including the possible provision of medical, nursing, pharmaceutical, physical, psychological, spiritual and social support if required acutely

Outcomes

- Reduced number of inappropriate admissions
- Reduced LOS
- Increased number of patient being cared for and dying in the place of choice
- Patient/carer satisfaction surveys demonstrating co-ordinated care pathways
- Identifiable key worker at all stages of patients care pathway

Delivering high quality care

Standards

- Evidence of ongoing training and accreditation in EOLC (inc GSF, PPC and LCP) for all health and social care staff according to their level of need. This must include training of Care Home and Hospital staff.
- Percentage of deaths in Hospitals, patients home, Care Homes and Hospices in your area
- Robust proof with case examples that appropriate support is available 24/7 for patients and their carers both in their homes and in Care Homes, including the possible provision of medical and nursing care, appropriate drugs and equipment

Outcomes

- Agreed local standards met for the implementation of GSF/LCP
- Documented EOLC discussions and numbers of patients dying in their place of choice
- Patient/carer satisfaction surveys demonstrating co-ordinated care pathways and demonstrating a good patient/carer experience

Last days of life

Standards

- Proof that resources are available in hours if prognosis is estimated in days
- Evidence of adoption, appropriate training and use of the Liverpool Care pathway in community, Care Home and Hospital settings
- Evidence of anticipatory prescribing of palliative care drugs and syringe drivers for patients entering the final days of life +/- availability of drugs from pharmacy or ambulance centre 24/7 should advanced prescription not be in place
- Availability of side rooms for patients dying on LCP in acute hospitals

Outcomes

- Reduction in the number of complaints relating to EOLC
- Number of patients being cared for using the LCP
- Carer satisfaction surveys
- Numbers of patients dying in their place of choice
- Reduced number of inappropriate admissions

Care after death

Standards

- Quality assurance with proof from registrar records that unless a Coroner's Post Mortem is required certification of death occurs within 24-hours and that this can be expedited further where religious beliefs require burial before sunset of the day of death, including in the hospital setting
- Evidence that nurse verification of death is available in the community, Care Homes and Hospital

Outcomes

- Reduction in the number of complaints relating to EOLC
- Prevalence of anxiety and depression at one year post bereavement
- Reduction of referrals to mental health services following bereavement
- Carer satisfaction surveys

Support for carers (at all stages of the pathway)

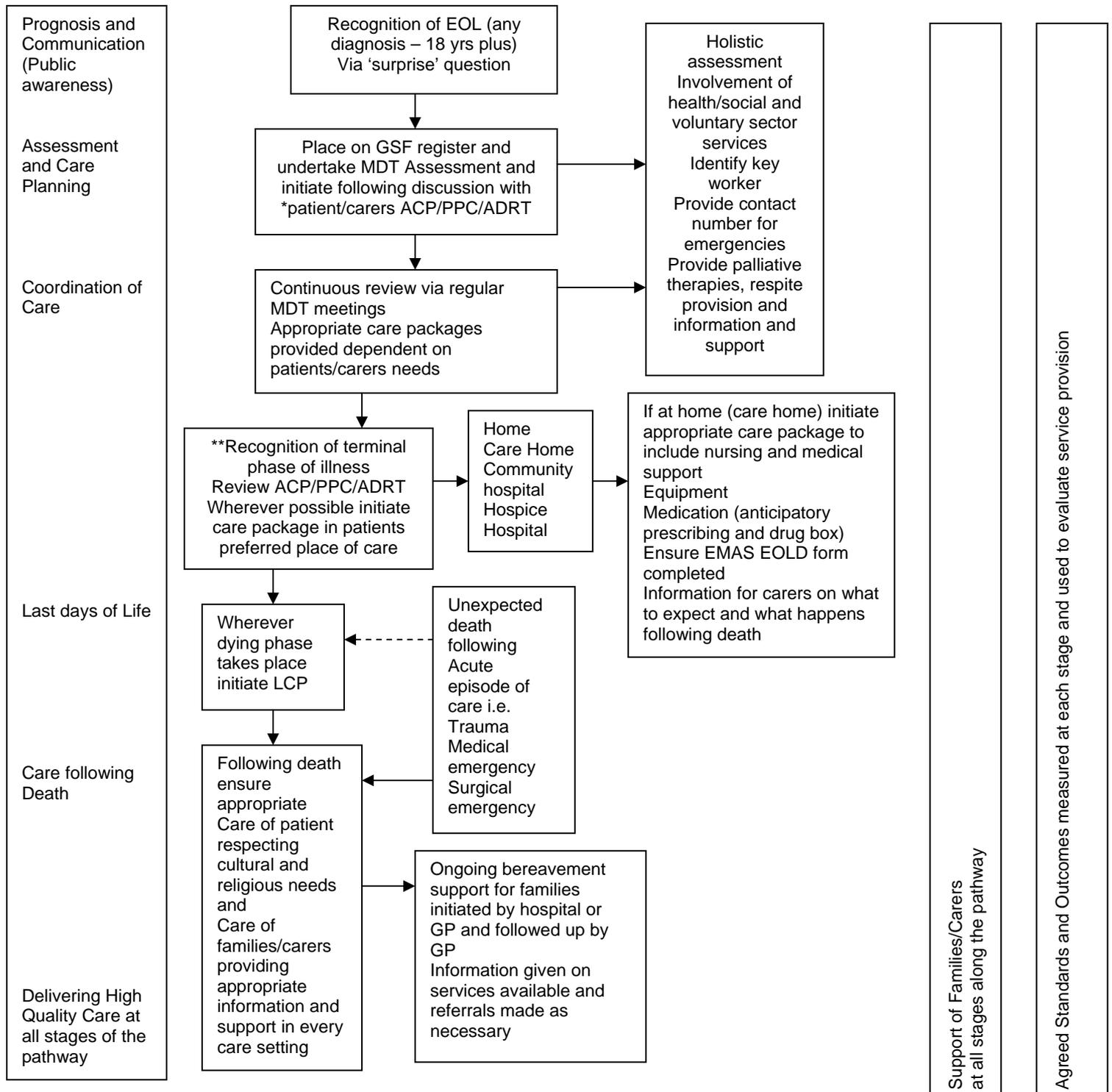
Standards

- Evidence of well organised, clearly defined and easily accessible bereavement information and support for carers
- Quiet areas, food, telephone access, free parking and accommodation available for carers of patients dying in the acute hospital setting
- Review of EOLC and bereavement related complaints over a 3-6/12 period prior to the assessment

Outcomes

- Reduced numbers of hospital admissions (carer better able to cope and better supported)
- Reduction in the psychological morbidity in carers
- Carer satisfaction surveys
- Reduced number of complaints

Appendix 3 – Potential EOLC Pathway - Approximate Time Period 12 months prior to death to 12 months post death



*and potentially staff if patient in a nursing/residential home
 ** the disease trajectory of patients with LTC may result in several potential terminal phases during exacerbations of their condition
 ----- Implement LCP when possible

Appendix 4 - Case study: Virtual wards at Croydon Primary Care Trust

Croydon Primary Care Trust (PCT) has been piloting the practical use of the Combined Model on behalf of the King's Fund and Health Dialog since May 2006. It has developed a package of care called *virtual wards* that it offers solely to people at highest predicted risk. The virtual wards project won an unprecedented four prizes at the Health Service Journal Awards in November 2006:

- Primary Care Innovation
- Clinical Service Redesign
- Patient-Centred Care
- Information-Based Decision Making

Virtual wards are now being introduced by PCTs and their equivalents in other parts of the UK.

In essence, virtual wards use the systems, staffing and daily routine of a hospital ward to provide case management in the community.

Virtual Wards

Virtual wards copy the strengths of hospital wards: the virtual ward team shares a common set of notes, meets daily, and has its own ward clerk who can take messages and coordinate the team. The term 'virtual' is used because there is no physical ward building: patients are cared for in their own homes. The only way in which patients are admitted to a virtual ward is if their name appears at highest on the predicted risk score on the Combined Model. Each virtual ward has a capacity to care for 100 patients. Using hospital parlance, each virtual ward has 100 'beds'. Croydon has plans for a network of ten wards that would care for the 1,000 patients at highest risk in the borough. The population of Croydon is 340,000 so the catchment population for each ward will be roughly 34,000 ie approximately one ward for every 15 GPs.

However one of the key strengths of the Combined Model is that it enables predicted need to be mapped across a borough. The catchment population for each virtual ward can therefore be adjusted so that in areas where there is a high level of predicted need, the catchment population will be less than 34,000 and vice versa. In this way it is possible to counter the Inverse Care Law that states that the healthcare provided in a locality is usually inversely proportional to its level of need.

A pilot of two virtual wards – both of which are in the North of Croydon – opened earlier this year. If the pilots are successful then the plan is to roll out the virtual wards project across the whole borough. There is also the possibility of opening an eleventh virtual ward for children from across Croydon. This is made possible because the Combined Model allows the predicted risk scores of toddlers and octogenarians to be compared on the same scale.

If the virtual wards are going to be successful in the long term then they need to be embedded with GP practices. Each virtual ward is therefore permanently linked to a group of GP practices (three or four large practices, or a larger number of small practices). In this way the virtual ward staff can develop close working relationships with their constituent practices. It is hoped that in future, groups of practices may wish to commission virtual wards through practice-based commissioning.

In the same way that certain hospital nurses will cover several acute wards (eg asthma specialist nurses in a district general hospital) so the specialist teams in the community will likewise cover several virtual wards.

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Ward Staff

The day-to-day clinical work of the ward is lead by a community matron. Other staff include a social worker, health visitor, pharmacist, community nurses and other allied health professionals.

A key member of staff is the ward administrator ('ward clerk'). With a dedicated telephone number and email address, the ward administrator is able to collect and disseminate information between patients, their carers, GP practice staff, virtual ward staff, and hospital staff.

Medical input is comes from daily telephone contact between the community matron and the duty doctor at each constituent GP practice. The matron is also able to book surgery appointments to see any patient's usual GP.

The virtual ward will develop close working relationships with organisations such as hospices, drug and alcohol service and voluntary sector agencies.

Medical input to the virtual wards comes in two ways:

1. The community matron for each ward will be given the bypass telephone number to the duty doctor at each of the constituent GP practices for that virtual ward.
2. Additionally, the community matron will be able to book appointments to see the patient's usual doctor.

Admission to a virtual ward

At the time of admission to the virtual ward, the community matron visits the patient at home and conducts an initial assessment. This record, and all further entries by ward staff, is entered into a shared set of electronic notes. A summary from the GP computer system is pasted into these ward notes before the initial assessment, so as to provide background information and avoid unnecessary duplication of work. The GP practice is informed of all significant changes to the patient's management.

Members of the virtual ward staff hold an office-based ward round each working day. Patients are discussed at different frequencies depending on their circumstances and stability.

Of the 100 patients on each ward, 5 patients are discussed daily, 35 are discussed weekly, with the remaining 60 patients discussed monthly. The community matron can move patients freely between these different intensity 'beds' according to changes in their clinical conditions.

Communications

Every night an automatic email containing a list of each virtual ward's current patients is sent automatically to local hospitals, NHS Direct and GP out-of-hours cooperatives. This information is uploaded onto these organisations' clinical computer systems. Should a virtual ward patient present to their services (eg to a local A&E department) then the staff working there will be alerted automatically to the patient's status. They then know that by contacting the virtual ward administrator, they can obtain up-to-date details of the patient's care. They can also arrange early discharge back to the care of the virtual ward team.

Discharge

When a patient has been assessed by all relevant virtual ward staff, and has been cared for uneventfully for several months in the 'monthly review' section of the ward, then the ward staff may feel that the patient is ready to be discharged back to the care of the GP practice. They also receive a prompt when the patient's name drops below the 100 people with highest predicted risk in the catchment area according to the Combined Model. A discharge summary is sent to the practice and a discharge letter (using lay terminology) is sent to the patient. For the first two years following discharge, the GP practice conducts quarterly –rather than annual –reviews. This not only ensures that the patient is borne in mind, but these quarterly review data are serve as positive feedback to the predictive risk modelling algorithm.