

Scottish Partnership for Palliative Care

Palliative and end of life care in Scotland: the case for a cohesive approach

Report and recommendations
submitted to the Scottish Executive

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Executive Summary

Palliative care is an integral part of the care delivered by any health or social care professional to those living with and dying from any advanced, progressive and incurable disease. One element of palliative care is care provided at the end of life. Palliative care is not just about care in the last months, days and hours of a person's life, however, it is also about enabling someone to live with a life-threatening condition, maintaining and as far as possible improving quality of life for patients and their families.

Currently, standards of palliative and end of life care are variable across Scotland, and cancer patients are likely to receive greater support than those with non-malignant conditions as they approach the end of life. The Scottish Partnership for Palliative Care has identified a need to address these inequities by developing a cohesive approach to palliative and end of life care in Scotland.

A short-life working group was accordingly set up to make recommendations to the Scottish Executive regarding the development of such a cohesive approach. The group started by examining the tools for palliative and end of life care recommended in the Department of Health End of Life Care Programme:

- Gold Standards Framework (GSF)
- Liverpool Care Pathway for the Dying Patient (LCP)
- Preferred Place of Care (PPC) as an example of advanced care planning

and considering these within the context of *Delivering for Health* and the wider Scottish health agenda. As this work developed, the group widened its scope to include consideration of other relevant developments which quickly came to its attention. These included:

- changes to out of hours service provision
- a possible approach to joint care management
- the Marie Curie Cancer Care Delivering Choice pilot project in Tayside
- the NHS Lothian 'Do not attempt resuscitation' (DNAR) framework and policy.

Between May 2006 and March 2007 the working group heard a number of presentations and examined a range of literature relating to each of these areas. After a full discussion and examination of this information, the group undertook a consultation process involving the Partnership's members and other interested parties, and agreed the recommendations set out in section 5 of this report. These recommendations centre on:

- supporting continued and expanding use of the principles and approach of the Gold Standards Framework Scotland in all care settings
- encouraging a uniform approach to achieving the goals of the Liverpool Integrated Care Pathway for the Dying Patient in all care settings, and
- clarifying some of the issues relating to out of hours service provision, DNAR policy, and joint working by health and social care.

The Scottish Partnership for Palliative Care believes that by adopting a cohesive approach and implementing the recommendations in this report the Scottish Executive Health Department can facilitate the delivery of high quality palliative and end of life care to everyone in Scotland who needs it, on the basis of clinical need not diagnosis, and according to established principles of equity and personal dignity.

1. Introduction

This report provides recommendations to the Scottish Executive for developing a cohesive approach to palliative and end of life care in Scotland. The work was undertaken with the aim of ensuring equity in access to and standards of palliative and end of life care across Scotland on the basis of clinical need not diagnosis.

1.1 Working group remit

The Scottish Partnership for Palliative Care set up a short life working group in palliative and end of life care (PEOL) to undertake this work. The remit agreed by the group was to consider, within the context of *Delivering for Health*¹ and the wider Scottish Health context, the tools for palliative and end of life care recommended in the Department of Health End of Life Care Programme:

- Gold Standards Framework (GSF)
- Liverpool Care Pathway for the Dying Patient (LCP)
- Preferred Place of Care (PPC) an example of advanced care planning

and to make recommendations to the Scottish Executive Health Department on mechanisms for ensuring equivalent and equitable outcomes for patients in Scotland requiring palliative and end of life care.

1.2 Terminology

Palliative care is an integral part of the care delivered by any health or social care professional to those living with and dying from any progressive and incurable disease. Palliative care is not just about care in the last months, days and hours of a person's life. It is also about enabling someone to live with a life-threatening condition, maintaining and as far as possible improving quality of life for patients and their families. As well as controlling pain and other distressing symptoms, it is about helping patients and families cope with the emotional upset and practical problems of the situation, helping people to deal with spiritual questions which may arise from their illness, and supporting families and friends in their bereavement.

The World Health Organisation (WHO) defined palliative care in 2002 as: 'an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.'

End of life care is that part of palliative care which should follow from the diagnosis of a patient entering the process of dying, whether or not he or she is already in receipt of palliative care. The term 'end of life care' is used by different people to mean different things, since this phase could vary between months, weeks, days or hours in the context of different disease trajectories.

This report is entitled 'Palliative *and* end of life care: the case for a cohesive approach' to reflect the fact that palliative care includes, but is *not exclusively about*, end of life care. Palliative care is the care that should follow from the diagnosis of a progressive disease. However, the group's remit was to consider the tools recommended within the Department of Health End of Life Care Programme, so within this report the group has

focused on those elements of palliative care which are likely to be delivered in the last 12 months of life, including both general palliative care and specialist palliative care.

Some definitions of terms used within this report are available in the glossary, which includes definitions of the terms 'general palliative care', 'specialist palliative care', 'multi-disciplinary team', 'home', and 'out of hours'.

1.3 Working group process

All of the group's work was undertaken with the aim of ensuring equity in access to and standards of palliative and end of life care to all on the basis of clinical need rather than diagnosis.

The group took as its starting point consideration of the tools for palliative and end of life care recommended in the Department of Health End of Life Care Programme (see 1.1 above), but within the context of *Delivering for Health* and the wider Scottish health agenda, widened its scope to include consideration of other relevant developments which quickly came to its attention. These included:

- changes to out of hours service provision
- a possible approach to joint care management
- the Marie Curie Cancer Care Delivering Choice pilot project in Tayside
- the NHS Lothian 'Do not attempt resuscitation' (DNAR) framework and policy.

Between May 2006 and March 2007 the working group examined a range of literature and heard presentations relating to each of these areas. Sections 3 and 4 of this report summarise the information and issues the group was able to consider.

Although the group examined a range of literature relevant to the issues being considered within this report, no comprehensive literature review was undertaken. On some occasions limited evidence was available concerning the initiatives being considered, and on these occasions the group drew on its own expertise and experience, and consulted more widely among the Partnership's members and contacts, to make judgements based on the information available.

After a full discussion and examination of this information, the group undertook a consultation process involving the Partnership's members and other interested parties, and agreed the recommendations set out in section 5. A full list of documents and presentations made to the group is available in Appendix F.

The group wished to ensure that its recommendations would support implementation of the vision set out in *Delivering for Health* and ensure that palliative and end of life care services in Scotland would:

- be delivered as locally as possible
- have an emphasis on preventative, anticipatory care rather than reactive management
- support integration of appropriate health and social services.

In particular, the working group wished to make recommendations to encourage the delivery of palliative and end of life care services in a manner which supports and facilitates:

- a system of continuous, integrated and community-based care
- increased use of anticipatory care to ensure unscheduled hospital admissions are appropriate
- increased emphasis on multi-disciplinary team working, using fully the skills of the whole clinical team
- a climate of enhanced communication and respect in which patients and carers are treated as partners in the provision of care.

Appendix A provides more detail about the wider Scottish Health context within which the group considered its recommendations.

1.4 Scope

Some responses to the consultation on the draft report highlighted areas which are not covered in depth within this report, including:

- bereavement care
- psychosocial issues
- the palliative care needs of minority ethnic groups
- the need for cultural and practical changes to ensure that good palliative care and symptom management are provided concurrently in all care settings.

It was also highlighted that there are likely to be relevant developments and initiatives currently taking place in Scotland that are not considered within this report.

The group was aware that it could not conduct a comprehensive review of palliative care in Scotland, or address every possible improvement in palliative and end of life care within one report. Rather, it concentrated on recommending what it considered to be a cohesive set of changes which specifically move towards a cohesive approach and represent a level of change which the group deemed to be manageable.

2. *The need for a cohesive approach to palliative and end of life care in Scotland*

2.1 Background

Over 55,000 people die in Scotland each year, yet the quality of care received by the dying can be very variable. There is known to be inequity between those who die of cancer and those who die of other causes in that cancer patients are likely to receive greater support than those with non-malignant conditions as they approach the end of life.² The Scottish Audit for Surgical Mortality Report (2004 data) highlighted the fact that some patients benefit from better end of life care provision than others.³ A core principle of the NHS, however, is that it should provide a universal service for all based on clinical need⁴, and there is a growing recognition that this must include the provision of appropriate and high quality palliative care for all.^{5,6,7}

It is also increasingly acknowledged that patients should be able to receive care in their own home or as close to home as possible. The reality however, is that many people receive inpatient care away from their home and family. It is likely that with the provision of additional local support a proportion of these admissions could be prevented.⁸

A range of recent initiatives in Scotland and other parts of the UK have begun to address some specific aspects of these issues, but to date there has been no single comprehensive and cohesive approach to the provision of appropriate palliative and end of life care across Scotland as a whole.

A major contribution to palliative care in primary care settings has been the introduction of the Gold Standards Framework Scotland (see section 3.1), which aims to improve palliative care in the community. Between October 2003 and October 2006 the framework was offered to practices throughout Scotland, with an overall take-up of 72%.

The Scottish Partnership for Palliative Care has also encouraged a national approach to the provision and quality of palliative care in two recent publications:

- *Making good care better: national practice statements for palliative care in adult care homes in Scotland* (May 2006), which sets a new benchmark for the delivery of palliative care in Scottish care homes; and
- *Joined up thinking...Joined up care* (November 2006), which is based on the findings of an extended national consultation into ways of improving access to palliative care for people with non-malignant conditions and makes a series of recommendations which have the support of the Minister for Health and Community Care and the Chief Medical Officer for Scotland.

2.2 Policy context

While there are a great many challenges to health and social care services in providing a uniform standard of good palliative care to all who need it, there are also a range of recent policy initiatives in different parts of the UK which either address palliative care issues directly, or help to create an environment in which such challenges may more easily be overcome.

2.2.1 Policy context: Scotland

The need to make appropriate palliative care available to those with non-malignant conditions has been recognised in a series of Scottish Executive policy statements:

- *Our national health, a plan for action, a plan for change* (2000) recognised that palliative care should be available to all on the basis of need not diagnosis
- *Cancer in Scotland: Action for change* (2001) acknowledged the wider application of palliative care beyond cancer
- *Coronary heart Disease and Stroke Strategy for Scotland* (2002) stated that palliative care should be available to everyone with end stage heart failure.

More recently, palliative and end of life care has been included, either directly or indirectly, in the following developments:

- the National Framework for Service Change Action Team report *Care in Local Settings* (May 2005) recommended that Cancer Networks should collaborate with Community Health Partnerships (CHPs) to develop protocols for the delivery of palliative care in community settings
- *Delivering for Health* (October 2005) and the associated Kerr Report *Building a health service fit for the future* set out a vision for a model of care whereby people with long term conditions are cared for in the community where possible without hospitalisation, and with a shift from reactive episodic care to continuous support
- *The Future Care of Older People in Scotland* (2006) emphasised again the need for improved access to palliative care for all.

2.2.2 Policy context: England

In England, following the publication of *Building on the Best: Choice, Responsiveness and Equity in the NHS* in December 2003, the Department of Health announced the launch of its End of Life Care Programme with an allocation of £12m over three years to help promote implementation of best practice in end of life care. The Programme was set up to help health and social care professionals in England improve end of life care for their patients, regardless of their disease, through sharing good practice, evaluation, training and education. The Programme recommends three key tools for improving end of life care:

- the Gold Standards Framework (see section 3.1)
- the Liverpool Care Pathway for the Dying Patient (see section 3.2)
- the Preferred Place of Care advanced care planning tool (see section 3.3)

and is part of an overall strategy to give people greater choice in their place of care and death and to provide training for health and social care staff to help care for people at the end of their lives.

The Department of Health is currently developing an End of Life Care Strategy, to meet the health and social care needs and preferences of all adult patients regarding where they live and die. An Advisory Board has been established to provide advice to Ministers on the overall development of the strategy and on

how it might best be implemented. Several working groups, including a Workforce Development working group, have been established to take forward work to underpin the development of the strategy and will report to the Advisory Board. The Advisory Board is expected to report to Ministers by the end of 2007.

2.3 Scottish Partnership for Palliative Care Working Group

Against this background of different initiatives and amid growing awareness of quality and equity issues, the Scottish Partnership for Palliative Care identified the need for a cohesive approach to palliative and end of life care in Scotland. Endorsement for such an approach was secured from the Partnership Council and constituent groups and from the Cross Party Group on Palliative Care in the Scottish Parliament. Agreement was also reached with the Scottish Executive Health Department (SEHD) that the Partnership's recommendations on this issue would be welcomed. A short-life working group on palliative and end of life care was established in May 2006 with a view to examining the issues and producing recommendations. This report is a summary of their discussions and conclusions. A list of working group members is attached at appendix E.

3 Department of Health (DoH) England End of Life Care Programme Initiatives

3.1 Gold Standards Framework

3.1.1 What is the Gold Standards Framework?

The Gold Standards Framework (GSF) is one of the tools recommended in the Department of Health NHS End of Life Care Programme. It is a framework of strategies, tasks and enabling tools designed to help primary care teams improve the organisation and quality of care for patients in the last stages of life in the community, so that more live and die well in their place of choice. The GSF:

- is aimed at community care. It was originally focused on primary care settings, and now includes all areas covered by primary care teams, including patients living at home, in care homes and community hospitals.
- aims to enable generalists to provide high quality general palliative care, accessing specialist input as appropriate
- originally focused on patients in roughly the last 6 months of life (eligible for DS1500 benefits) and now includes patients in the final year or so of life (year, months, weeks of life as well as those in the final days).

Core principles

The GSF is based on three main principles, all of which involve improved communication and are applicable in any care setting. Practices are encouraged to:

- a. identify patients in need of palliative/supportive care towards the end of life.
- b. assess their needs, symptoms, preferences and any issues important to them.
- c. plan care around patient's needs and preferences and enable these to be fulfilled, in particular allow patients to live and die where they choose.

The GSF was developed for primary care by primary care, initially for cancer patients, but is now being used for patients with any life limiting illness and in other settings such as care homes. Primary care teams can adopt the framework at their own pace, and in a way that suits their service.⁹

3.1.2 Use of the GSF: where are we now?

To enable effective spread and implementation of the framework in England, a GSF support programme has been running since 2001, supported by the NHS, Macmillan Cancer Support and now by the NHS End of Life Care Programme. The GSF Programme has been structured with two phases a year and is now in phase 10. In England the GSF has been introduced in 79% of Primary Care Trusts (PCTs) and in every one of the 34 Cancer Networks and 28 Strategic Health Authorities (SHAs). Several PCTs have 100% coverage and over half of the GSF practices use GSF for non-cancer patients.¹⁰

3.1.3 What is the Gold Standards Framework Scotland?

Within Scotland, funding from the Regional Cancer Networks, Macmillan Cancer Support and the Big Lottery Fund supported the Gold Standards Framework Scotland (GSFS) project. This project ran from October 2003 to October 2006

and encouraged GP practices across Scotland to adopt a version of the GSF adapted for use within NHS Scotland.

Though GP practices involved in the GSFS project tend to concentrate their initial efforts on using the tool with cancer patients, within Scotland there has been an early emphasis on the benefits that this approach can have for patients with non-malignant conditions. The principles underpinning the Scottish development remain identical to those of the original Gold Standards Framework. The differences are that the Gold Standards Framework Scotland (GSFS) initiative encouraged practices to:

- address the needs of patients from the point of diagnosis onwards
- maintain a palliative (supportive) care register as well as a cancer register, to ensure that all patients are appropriately supported at key points in their journey.

3.1.4 The GSFS: where are we now?

The GSFS Project ran over three years and saw 72% of GP practices across Scotland sign up to the principles of the GSFS. By the 12-month mark, the framework had been extended by 71% of participating practices to include all palliative care patients, not just those with cancer, and 58% of participating practices had extended use of the framework to include cancer patients from the point of diagnosis. Now that the project is completed, primary health care teams who wish to adopt the framework can use the documentation provided on the GSFS website.¹¹ The GSFS is also being considered by the 'shifting the balance of care' work stream at the Scottish Executive Health Department, and the *long-term conditions CHP self-assessment toolkit* (SEHD, February 2007) instructs CHPs to take account of the GSFS.

3.1.5 Sustainability of the GSFS: IT issues

Feedback from GPs participating in the GSFS project indicated that most of the IT systems used by practices did not have the capacity to incorporate GSFS data, so most of this information was being collected on a paper-based system that was hard to sustain.

It was felt that IT support was therefore required to ensure the future sustainability of the benefits and processes introduced by the GSFS, and the GSFS team undertook work to ensure that the Scottish Enhanced Functionality (SEF) specifications were amended to include the information required by GP practices participating in the GSFS. As a result, to remain accredited suppliers of NHS Scotland, existing suppliers of IT practice systems will have to ensure that the products they offer to GP practices deliver the following functions relating to palliative care:

- dedicated data-entry screens for the collection of palliative care/ GSFS data
- prompt collection of non-populated items and auto-populate from information already contained within the practice system, so that each piece of information need only be entered once
- plan review dates
- alert teams to imminent review dates
- generate summary lists for multi-disciplinary team (MDT) review

- generate summary information for out of hours (OOH) use.

It is hoped that an upgrade which includes these new functions will be available to GP practices from summer 2007. After such an upgrade, GPs will be able to record a patient's palliative care needs using a dedicated data entry screen and the system will enable this information to be easily accessed and used to support sustained use of the principles of the GSFS within the practice.¹² An outline of the palliative care summary information that will be available following this upgrade is included at appendix B2.

3.1.6 Are there benefits to introducing the GSF?

In considering its recommendations, the working group concentrated mainly on the evaluation report of the GSFS project¹³. However, the group was also aware that the GSFS results echoed many of the findings from the English GSF project, which had included a substantial evaluation element.¹⁴

3.1.6.1 GSFS Practice questionnaires

Practices participating in the GSFS were asked to complete questionnaires at baseline, six and twelve months after adopting the framework. Though the GSFS may not be the sole cause of improvement in GP practices over this period, results indicate that it has assisted GP practices to make a number of improvements. Information from these questionnaires has consistently shown a perceived increase in the quality of care offered to patients with palliative care needs, and an increase in staff confidence in managing this group of patients. The GSFS Final Report¹³ summarises the following changes as being the most significant for practices:

- participating practices concur that the top five gains / benefits from the framework are:
 - better care for patients / increased patient satisfaction
 - improved communication within practice / team / PHCT / with patients and carers
 - improved / increased teamwork / extended team-building
 - improved standards / service
 - more co-ordinated / structured / better organised care / integrated care pathways
- most improvements in care and processes occur within the first six months of using the framework
- an increase in the number of regular meetings being held by practices indicates their commitment to the multidisciplinary process
- improvements regarding continuous and anticipatory care in the community
- working in partnership with carers has become increasingly important in the eyes of practices
- the use of evidence-based protocols and guidelines helps practices ensure that no patient 'slips through the net'
- practices believe they are making a difference in palliative care. This is reflected in the number of practices that extended the framework to include non-cancer patients as well as cancer patients from diagnosis.

3.1.6.2 GSFS Patient interviews

In order to evaluate the impact the GSFS had on patients and carers, 10 semi-structured interviews with patients and carers were conducted by an independent researcher.

All the patients and carers interviewed felt well supported, and in possession of as much information as they felt they required. The interviews provided evidence of a holistic approach to care from the practices involved, and indicated that good support from the primary care team helped carers to feel valued and involved. The general themes to emerge from the interviews were:

- people feel supported and informed
- people are enabled to care
- proactive and ongoing contact is much appreciated
- there is a general feeling that there is a team approach to care
- bereavement contact is valued.

A powerful summary of the results of this qualitative assessment was provided by the researcher:

“Often it was not so much what the GPs or nurses did that made the difference, but knowing they are committed to their care and on hand at any time, gave patients and family carers the confidence to be, and to die, at home.”

3.1.7 Discussion

Having considered the available information, the group agreed that the GSFS project had achieved significant success, and that much could be achieved by capitalising on the momentum gained by the project. The group noted that though designed for use by GP practices, the framework encourages joint planning of care and joint working between the NHS, local authorities and the voluntary sector. The group particularly noted the effect the project had on increasing the confidence of healthcare teams, patients and carers. The group also heard anecdotal evidence that improvements in communication enabled more efficient use of time, since better co-ordination among the multi-disciplinary team result in fewer unnecessary visits and gave generalists the specialist support they required to deal with patients themselves.

The aims of the GSFS were consistent with the vision set out within *Delivering for Health*:

- The GSFS helped the entire primary care team to improve communication and to work across organisational boundaries to provide better care to people nearing the end of their life.
- The GSFS improved the confidence of patients and carers, increasing support for self-care and self-management.
- Multi-disciplinary team working was integral to the GSFS, helping practices to fully utilise the skills of the whole clinical team, and assisting teams to review care using evidence-based protocols and guidelines.
- The GSFS allowed more intensive case-management for individuals with serious long term conditions and built in anticipatory care to reduce crises and emergency admissions.

- This approach encouraged GP practices to work in partnerships with carers, and is also a step towards the integration of generalist and specialist care. The GSFS helped to ensure a consistent approach and a spread of good practice across Scotland.

The GSFS approach can support organisations to meet many of the requirements set out in regional and national policy documents, and appendix B1 gives a detailed illustration of how the GSFS relates to the wider health policy context. However, the group noted that effective introduction and sustainability of the GSFS had relied on support being available in the form of a dedicated GSFS facilitator. The group also noted that ongoing dialogue with those involved in the GSF in England is likely to result in mutual benefits, and that in future the Scottish Patients at Risk of Readmission (SPARRA) risk prediction algorithm is likely to assist and facilitate the GSFS approach^a.

3.1.8 Recommendations 1 - 5

Recommendation 1

NHS Boards and CHPs should encourage adoption of the principles, approach and documentation of the GSFS by the remaining 28% of general practices in Scotland not yet involved.

Recommendation 2

SEHD, NHS Boards, CHPs and palliative care networks should support application of the core principles of the GSFS in all care settings across Scotland.

Recommendation 3

SEHD, NHS Boards, CHPs and palliative care networks should support the ongoing extension of the principles, approach and documentation of the GSFS to patients with life-threatening and long-term conditions and to frail elderly patients with multiple co-morbidities.

Recommendation 4

SEHD, NHS Boards, CHPs and palliative care networks should commit to supporting the ongoing education and facilitation required to allow mainstreaming of the GSFS to be sustainable in all primary care settings.

Recommendation 5

CHPs and palliative care networks should encourage GP practices to make full use of the upgraded IT systems that will become available from summer 2007. This should include GPs using their upgraded existing IT system to record patients' palliative care needs, plan review dates and assist multi-disciplinary team meetings, and sharing summary information with OOH services and NHS 24.

3.2 Liverpool Care Pathway for the Dying Patient (LCP)

^a SPARRA was developed by the Information Services Division (ISD) to identify patients aged 65 years and over at greatest risk of emergency inpatient readmission. It is designed to identify those patients at highest risk of

3.2.1 What is the Liverpool Care Pathway?

The LCP is an integrated care pathway that was developed to take the best of hospice end of life care into hospitals and other settings. While the GSF is used from the point of diagnosis onwards, the LCP is used to care for patients in the last days or hours of life once it has been confirmed that they are dying. The LCP is designed to facilitate effective communication within the multi-disciplinary team and with the patient and family, anticipatory planning including psychosocial and spiritual care, and appropriate symptom control and bereavement care. The LCP has accompanying symptom control guidelines and information leaflets for relatives.

The LCP is a multi-professional document which provides an evidence-based framework for end of life care. It aims to facilitate multi-professional communication and documentation, integrating guidelines into clinical practice. The LCP replaces all other documentation in this phase of care and is applicable in hospital, hospice, care home and community settings. It is designed to empower healthcare teams to deliver high quality care to dying patients and their relatives.

The originators of the LCP at the Marie Curie Palliative Care Institute in Liverpool recognise that each clinical area may have specific needs that are not included in the original LCP document. However, as long as the goals remain the same, the prompts, associated guidelines and other supporting documentation can be altered to support clinical need.¹⁵

For this reason, use of the term Liverpool Care Pathway (LCP) has been retained throughout this document to refer to any locally adapted version of this integrated care pathway which retains the same goals.

This process of localisation of the pathway by multidisciplinary teams is recognised as an integral part of the process of implementing the pathway and facilitating multi-professional communication.

3.2.2 Use of the LCP: where are we now?

The LCP is one of the tools recommended by the Department of Health NHS End of Life Care Programme, and rollout of this tool is taking place across England. The LCP is also a key recommendation in the NICE guidelines for supportive and palliative care, and is included in Phase 3 of the Cancer Services Collaborative Partnership Palliative Care Initiative, and in the NHS Modernisation Agency document *Supportive and palliative care for advanced heart failure*. A national audit of care delivered in the dying phase using the LCP in acute hospital trusts in England is currently underway. The results from this audit are due in the summer of 2007 and are expected to provide a clear picture of care delivered in participating trusts that can be used to develop benchmarks against which future care can be measured in the hospital sector. The LCP has been successfully adapted for use within hospital, community, hospice and care home settings, and the LCP Central Team is currently working collaboratively with specialist colleagues to demonstrate transferability of the LCP into more specialist healthcare settings, for example cardiac, renal and ICU.

emergency readmission, ie where the predicted probability of emergency inpatient admission in the next year is 60% and above.

The LCP is being used in various regions and care settings across Scotland. Though no comprehensive research has been carried out, appendix C2 gives an overview of the current situation regarding LCP implementation within Scotland.

3.2.3 Are there benefits to using the LCP?

Beacon status has been awarded for this framework and this national recognition has led to it being included in Phase 3 of the Cancer Services Collaborative Partnership Palliative Care Initiative. Evaluations of use of the LCP in England indicate that use of the LCP results in a measurable improvement in documented end of life care across all sectors and a measurable improvement in care.

Among the key benefits of the LCP is the role it plays in:

- facilitating multi-professional communication ^{16, 17}
- supporting measurable improvements in the documentation of end of life care ^{17, 18, 19, 20}
- supporting measurable improvements in the quality of end of life care ^{17, 19, 20, 21}
- fostering effective communication with families and improves care after death ^{18, 20, 21}
- empowering healthcare teams to deliver optimum care of the dying ^{20, 21, 22}
- discontinuing inappropriate interventions ^{19, 20, 21}
- increasing anticipatory prescribing and the anticipation of problems ^{19, 21, 23}
- informing and influencing education programmes and the role of specialist palliative care teams ^{16, 24}
- addressing equity of access to quality end of life care ^{17, 19, 20}
- informing standard setting and benchmarking in end of life care ^{23, 25, 26}
- exercising potential to inform and influence resource allocation
- supporting healthcare governance through the delivery of demonstrable and equitable outcomes ^{16, 23, 27}

The limited data available from evaluations of use of the LCP in Scotland indicates that similar benefits are being seen where the LCP is being used in Scotland. For example the report of the NHS Forth Valley pilot indicates that implementation of the LCP empowered staff to deliver optimum care and resulted in good symptom control, good communication, and improved evidence of caring for the patient after death. ^{28, 29} Implementation of an adaptation of the LCP into eight independent nursing homes across Lothian indicated that it was important in facilitating evidence-based quality end-of-life care in nursing homes. ³⁰ Within NHS Ayrshire & Arran, introduction of the LCP was perceived to empower staff to deliver high quality care to dying patients and their family, facilitate multi-professional communication, and facilitate the integration of national guidelines into clinical practice. ³¹ In 2005, LCP implementation within NHS Ayrshire & Arran was awarded a runner-up prize in the Scottish Executive Evidence into Practice Awards.

3.2.4 Discussion

The LCP is just one example of an integrated care pathway for the dying, and there are likely to be locally developed pathways and processes which are currently enabling many staff to deliver high standards of care during the last few days and hours of life. The group believed that the Scotland-wide introduction of such a pathway would play a major role in enabling these high standards to be

provided to all patients across Scotland. They also felt that using the same pathway across Scotland would have the added benefit of enabling benchmarking across sectors, and would facilitate cross-border working in NHS Board and CHP areas, thus further improving standards of care.

While it is known that alternative integrated care pathways for the dying have been developed, the LCP appears to be the most widely used, developed and adapted. The LCP also has the advantage of being designed with flexibility in mind, since the process of localisation of the pathway by multidisciplinary teams is recognised as an integral part of the process of implementing the pathway and facilitating multi-professional communication.

Some consultation responses indicated that use of a pathway such as the LCP may be viewed as being overly prescriptive or as potentially inhibiting the clinical judgment of professionals. However, the group came to the considered view that these concerns are addressed by the inbuilt flexibility of the LCP, since this pathway accepts that it is admissible for LCP 'goals' not to be achieved as long as appropriate clinical justification is documented.³² The group was also aware of a view that there is the need for a check-list to help teams ensure that appropriate decisions are made about starting patients on the LCP, and to provide a way of documenting the decision-making process. Such a check-list could be incorporated into the process of local implementation of the LCP if desired.

Having considered the information available, the group agreed that adopting the LCP should assist organisations to deliver the vision set out within *Delivering for Health* and supporting policy in the following ways:

- Implementation of the LCP helps to ensure that patients receive high standards of end of life care wherever they are, helping in the move towards continuous, integrated care, embedded in the community.
- Anticipatory prescribing using LCP guidelines allows the patient's comfort to be maintained.
- By facilitating care planning, use of the LCP can help to avoid unwanted patient transfers and hospital admissions at the end of life.
- The LCP facilitates multi-disciplinary communication, and helps to integrate specialist and generalist care.
- The LCP involves prompting good communication with the family, enabling patients and carers to be treated as partners.
- The LCP also provides a validated care pathway, and a model of outcome based care which allows for benchmarking across sectors.

The group came to the view that introduction of the LCP increases the confidence of staff in providing care to patients in the last days and hours of life, but emphasised that education and training is an essential element of effective implementation. It is important that staff are aware of the benefits and limitations of an integrated care pathway, realise that good palliative care begins long before the time period during which the LCP is applicable, and have the necessary grounding in general palliative care skills to enable them to make full use of the LCP once introduced.

3.2.5 Recommendations 6 - 7

Recommendation 6

SEHD, NHS Boards and palliative care networks should support and facilitate flexible use of the LCP in all care settings.

Recommendation 7

Dedicated resources should be made available by CHPs and NHS Boards to introduce, embed and mainstream use of the LCP across Scotland. This should take into account the need for localisation of LCP documentation to support clinical need, and for appropriate education and training to ensure staff have the necessary understanding to use the LCP successfully and appropriately.

3.3 Preferred Place of Care (PPC): an example of advanced care planning (ACP)

3.3.1 What is the 'Preferred Place of Care' instrument?

The PPC is a patient-held document designed to enable nurses, doctors and others to discuss with patients and carers their preferences relating to end-of-life care in ways that are intended to promote informed choices. The PPC plan includes the opportunity to discuss and record: (i) a family profile and carers' needs; (ii) the patient's thoughts about care choices and preferences; and (iii) the services that are available within a locality. The PPC initiative seeks to offer patients informed choice about the manner and place of their care at the end of life.

3.3.2 Use of the PPC: where are we now?

The PPC is recommended in the Department of Health End of Life Care Initiative 'Building on the Best' as an example of advanced care planning. It was first introduced into practice in December 2001, and in 2004 it formed a part of the guidance on Supportive and Palliative Care for Adults with Cancer produced by the National Institute for Clinical Excellence. The palliative and end of life care group could not find any evidence of the PPC being used in Scotland.

3.3.3 Are there benefits to using the PPC?

In March 2006 a meeting was held at Lancaster University to invite discussion on the evaluation of PPC among interested stakeholders. Delegates agreed: that: 'by recording and making information available, PPC has the potential to formalise good practice relating to communication at the end of life and offers a practical way forward, especially to nurses.'³³ However, other issues were raised which warranted further discussion, and it was acknowledged that: 'PPC is a complex intervention that needs a realistic, modular and sustained programme of evaluation, linked to a wider understanding of the end-of-life care initiative for England.'³³

3.3.4 Discussion

The group felt that the PPC may have the potential to assist advanced care planning, and agreed that there is an increasing body of evidence to indicate 'advanced care planning' as an approach has positive benefits.^{34, 35, 36} The group felt that advanced care planning is a complex and important issue, and

supported recent moves from the Department of Health to place more emphasis on advanced care planning as a process rather than focusing on the use of the PPC in particular. The group therefore widened its discussion to include advanced care planning in general.

3.3.5 Advanced Care Planning

The NHS End of Life Care Programme defines advanced care planning (ACP) as:

‘a process of discussion between an individual and their care providers irrespective of discipline. If the individual wishes, their family and friends may be included. With the individual’s agreement, discussions should be:

- documented
- regularly reviewed
- communicated to key persons involved in their care.

Examples of what an ACP discussion might include are:

- the individual’s concerns
- their important values or personal goals for care
- their understanding about their illness and prognosis, as well as particular preferences for types of care or treatment that may be beneficial in the future and the availability of these.³⁷

The outcome of ACP may be the completion of a statement of wishes and preferences or an advanced decision, but this is not mandatory

Advanced care planning was a recurring issue throughout group discussions. ACP is an integral element of the GSFS approach, and the LCP also assists healthcare teams, patients and carers to agree care plans in advance. The group therefore agreed that a recommendation for the mainstreaming of advanced care planning as an approach was implicit in its recommendations for universal usage of the LCP and adoption of the principles of the GSFS , and that a further recommendation covering a very specific element of advanced care planning (such as the PPC) was unnecessary.

4. Additional Initiatives (Scotland)

4.1 Out of Hours Services (OOH) and NHS 24

Services provided to patients out of hours are an essential part of palliative and end of life care, and issues relating to OOH service provision were therefore relevant throughout the group's discussions. Key areas discussed are summarised below.

4.1.1 Changes to OOH service provision

Recent changes to the General Medical Services (GMS) contract shifted the responsibility for OOH service provision from GP practices to NHS Boards. This has changed the way in which patients access care outside normal working hours. The establishment of NHS 24 has introduced a new model where 24-hour telephone advice is the single point of access to all OOH services. Patients are now unlikely to receive OOH care from a doctor who knows them, and the importance of continuity and home visiting to palliative care patients means that they are likely to be particularly affected by these changes.³⁸

A recent consultation conducted by the Scottish Partnership for Palliative Care at the request of the Chief Medical Officer highlighted concerns within the palliative care community that these changes have resulted in a poorer service for patients, and problems accessing controlled drugs during OOH periods.³⁹

4.1.2 Out of Hours community nursing services

Some areas provide out of hours community nursing services whereby patients and their carers can be given a dedicated telephone number they can call during out of hours periods. This number allows them to speak directly to a local qualified nurse who will triage the call and respond appropriately by offering either telephone advice, a home visit or a medical consultation.

Although these OOH services are not exclusively for palliative care patients, information about them is generally made available to patients with palliative care needs. The health professional is required to complete a handover information proforma about the patient which is then faxed or e-mailed to the out of hours base. The handover sheet is also designed to stimulate anticipatory planning and thus reduce the likelihood of problems arising out of hours. An example of good practice relating to OOH community nursing services was identified in NHS Borders, where the patient and/or carer is given a leaflet and an explanation detailing how and when to access the OOH service.

4.1.3 NHS 24

The group held discussions with a senior representative of NHS 24 about some of the current difficulties identified by patients and professionals using the service. Issues identified included:

- the common misconception that NHS 24 has access to a patient's medical records. This means that patients do not prepare for calls by having the information required by NHS 24 staff quickly available, leading to potentially avoidable difficulties or delays. In particular, patients are likely to omit vital information, potentially affecting the advice they receive.

- a lack of understanding among patients of how NHS 24 works, in particular that call-backs may be passed on to the local OOH service.
- for professionals calling NHS 24, it can take a substantial amount of time to be called back by the relevant individual. Call-backs usually begin with the gathering of basic standard information, which some professionals see as an inefficient use of valuable time.

Any delays or difficulties caused by these issues are likely to have a significant effect on palliative care patients, for whom time is of the essence and a rapid response and appropriate care according to individual need is paramount.

4.1.4 Emergency Care Summary

Currently, the best way of informing NHS 24 of a particular patient's palliative care needs is by informing NHS 24 directly, by means of a 'special note' which is then manually attached to a patient's NHS 24 record. However from May 2007 all NHS 24 centres should be able to access a patient's Emergency Care Summary (ECS), providing they first obtain the patient's permission.

The Emergency Care Summary (ECS) is a relatively new system which allows information on a patient's medication and allergies to be automatically extracted from their GP's records. This should improve the quality of OOH care by ensuring OOH providers have accurate information.

4.1.5 Palliative Care Summary

Section 3.1.3 of this report outlined details of an upgrade which will be available to GP practice systems in May 2007. As part of this upgrade GPs will be able to record a patient's palliative care needs using a dedicated data entry screen. This screen will include a question asking whether the patient has given their permission for an extract of their palliative care information to be made available OOH. If the answer is 'yes', the system will automatically extract a critical subset of this information and send it to a dedicated palliative care section of the 'Emergency Care Summary Store'.

The key differences between the ECS and the Palliative Care Summary are that in the latter:

- the cohort of patients is specific to palliative care as opposed to the whole population
- the information is more comprehensive and targeted at their clinical situation
- the summary will only be sent if explicit consent is gained from the patient.

It is planned that from summer 2007, NHS 24 and OOH providers will be able to access the Palliative Care Summary via the ECS Store, as long as the patient in question has given their permission for them to do so. A template of the palliative care out of hours summary that will be available is included at appendix B2.

4.1.6 Discussion

Recent changes to the GMS contract have fundamentally changed the way in which OOH services are provided. In this quickly evolving context, it is important to ensure that staff providing OOH services have the training and skills necessary to enable them to provide high standards of palliative care to patients OOH.

Audit Scotland's Forward Work Programme for Spring 2007 and beyond includes a study which is likely to examine how different NHS boards are providing out-of-hours services and how they are working with NHS24. It will also look at the impact of the new arrangements on the cost of out-of-hours services and on patient access and quality of care. The group felt that such a study was extremely worthwhile and that the findings are likely to be relevant to palliative and end of life care.

The group agreed that IT solutions such as the Emergency Care Summary and Palliative Care Summary would improve OOH services by ensuring that OOH providers and NHS 24 have accurate information, but that IT systems also need to consider the secondary care to primary care interface. They also felt that the service provided by NHS 24 was gradually improving. However, research indicates that there are many factors that patients and carers perceive as barriers to obtaining out-of hours care, and that many of these are associated with their anxieties and uncertainties and with lack of information⁴⁰.

Continuity of care is difficult under the new arrangements, and many areas have set up 'professional to professional' lines whereby professionals in specified units can contact unscheduled care directly. The group felt that the OOH community nursing services are absolutely essential for the provision of appropriate palliative and end of life care. Concern was expressed that not all areas have such services available. It was felt that having rapid access to 24-hour nursing support was also likely to assist the ability of services to transfer people home for their last days of life, and that OOH services need to be staffed at a level sufficient to allow staff to spend time with individual patients when necessary.

The importance of effective anticipatory care and advanced care planning outlined in previous sections of this report was considered particularly relevant in helping to avoid unnecessary reliance on OOH services.

4.1.7 Recommendations 8 - 12

Recommendation 8

All NHS Boards should ensure that systems are in place which allow timely and easy 24-hour access to medication for patients with palliative care needs

Recommendation 9

Further guidance should be provided to patients and professionals, clarifying when and for what purposes it is appropriate to contact NHS 24, and what information they will be required to provide.

Recommendation 10

Ongoing efforts should be made at a local level to work with NHS 24 to learn from recent experiences to improve services within a local context.

Recommendation 11

All NHS Boards should work towards early implementation of a 24-hour community nursing service to support existing medical OOH arrangements.

Recommendation 12

SEHD should ensure that changes in out of hours provision do not adversely affect the provision or quality of palliative care to patients in the community.

4.2 Scottish Borders: an approach to joint working and care management

4.2.1 Joint care management in the Scottish Borders

The Scottish Borders Palliative Care at Home Service was developed in 1998 in response to NHS MEL (1996) 22 which stated that:

'all patients, including those with non-malignant disease, who meet the criteria for palliative care will have their care funded by health services'.

Following this, Scottish Borders Council and NHS Borders worked together to produce a policy to support this MEL. This policy set out that:

'people in receipt of domiciliary services who are known to be terminally ill and expected to die within 6 months will be exempt from charges. This provision would not extend to residential or nursing home care including a period of respite'.

Health and social services continued to work together and produced a joint document entitled 'Borders Health Services and Scottish Borders Council – Agreed Responsibilities and Protocols for Providing Palliative Care Services (1999)'. To implement this policy a joint health, social and voluntary sector working group was established to develop referral criteria, oversee the delivery of palliative care at home services and manage the joint budget. This group continues to function and provides an operational lead.

4.2.2 Are there demonstrable benefits of the Scottish Borders approach?

In 2005, approximately 24% of cancer patients in Scotland died at home.⁴¹ However, between April and November 2006, the Scottish Borders palliative care at home service has enabled 50% of palliative care patients to die at home.⁴² Though these figures aren't directly comparable, they give a strong indication that the Scottish Borders approach is having a positive impact on enabling patients to die at home.

The delivery of palliative care within the home setting can reduce hospitalisation during the last three months of life, preventing avoidable admissions close to death. The delivery of co-ordinated care, particularly palliative care, involving practice-based teams, specialists and social care can reduce avoidable hospital admission.⁴³

4.2.3 Discussion

The Scottish Borders approach was introduced as a practical solution in response to NHS MEL (1996) 22. It was not designed to be a research project, and therefore little evidence has been gathered regarding its outcomes. However, the number of patients dying at home in the Scottish Borders appears to be well above the national average, and the group felt that this fact coupled with anecdotal evidence was strong indication of the worth of the Scottish Borders approach.

Although the introduction of this approach preceded the publication of *Delivering for Health*, anecdotal evidence indicates that its outcomes are very much in-keeping with the themes of *Delivering for Health* and other more recent policy developments:

The Scottish Borders palliative care at home service supports the patient to remain at home until the end of life wherever possible, allowing for the provision of continuous, integrated care, embedded in the community. It emphasises multi-disciplinary team working and integrates health and social care, for example, assessment of patient and carer need is based on a team assessment looking at all aspects of need and ability. Although the patient is deemed to be in the last six months of life preventative care remains an issue and care planning takes account of the patients' and the carers' needs.

The care at home approach has worked well to deliver a high quality service to palliative care patients in the Scottish Borders. However, it is important to bear in mind the fact that the Scottish Borders has a relatively 'neat' composition, with a small population and only one Local Authority. The introduction of such an approach may present more difficulties in larger or more complex NHS Board areas, but could be an option worth considering by Local Authorities and Community Health Partnerships.

Group discussions also indicated that MEL (1996)²² is open to interpretation: within the Scottish Borders this MEL prompted a move towards an exemplar approach to partnership working. However, within other NHS Board areas, it has been felt that this MEL has presented a barrier to good partnership working, by allowing Local Authorities to deny funding responsibilities by emphasising the funding responsibilities of NHS Boards. The working group felt that revising MEL (1996)²² to make it more clearly emphasise joint responsibility for planning and financing palliative care would assist NHS Board areas where more than one Local Authority is involved in providing care to achieve similar results to those demonstrated in the Scottish Borders.

The group also felt that MEL (1996)²² reinforces the common misconception that the term 'palliative care' refers only to care provided during the last months, weeks and days of a person's life, and that any review of this MEL should include clear definitions of terminology.⁴⁴

4.2.4 Recommendations 13 - 14

Recommendation 13

The Scottish Executive should conduct an investigation into the implementation of NHS MEL (1996) 22, with a view to clarifying the joint Health Board and Local Authority responsibility for funding palliative and end of life care.

Recommendation 14

NHS Boards, Local Authorities and CHPs should consider adopting/adapting the principles of the NHS Borders model when developing their own approach to joint working and joint care management.

4.3 Marie Curie Delivering Choice programme

4.3.1 What is the Delivering Choice programme?

Marie Curie Cancer Care set up the *Delivering Choice* programme with the objective of providing services which enable all patients to make a free and informed choice regarding their place of care at end of life.

The programme aims to achieve this through improved planning, co-ordination and uptake of existing local services, working in partnership with local organisations to apply best practice in health and social care. The *Delivering Choice* programme seeks to make care in the community a genuine option, reducing the level of treatment and death in hospital, and replacing it with increased levels of care in the community.^{45, 46}

4.3.2 Current situation

Marie Curie Cancer Care is running flagship programmes in Lincolnshire, Tayside and Leeds. The Tayside project team identified the following areas for improvement:

- identifying patients with palliative care needs
- lengthy hospital discharge processes
- ambulance transport
- lack of continuity of care for patients
- communication between secondary and primary care and within the community teams
- the need to arrange home care quickly and effectively
- crisis response in the community
- education and training in palliative care
- support to patient and carers and information on services available.

The Tayside team is working towards providing solutions which will bring improved palliative care services to the people of Tayside.⁴⁷

4.3.3 Evidence

Running alongside this project is an independent evaluation by the University of Lancaster looking at qualitative aspects of the new models of service delivery. Findings of this evaluation will not be available until 2009. An economic evaluation of the project will also be undertaken, and the Kings Fund is conducting 'action research' alongside the project, responding to problems identified by the project as they arise.

4.3.4 Discussion

At the time of writing, the Delivering Choice project was still in its early stages and little evidence was available regarding its outcomes. However, the group expected this programme to yield some interesting findings, and looked forward to seeing the evaluation of the Lincolnshire Project in September 2007, and of the Tayside project in September 2008. In the meantime the group felt the time was not yet right to make any recommendations regarding this programme.

4.4 Do Not Attempt Resuscitation (DNAR): NHS Lothian Policy and Documentation

4.4.1 Background to introduction of the NHS Lothian DNAR Policy

NHS HDL (2000) 22 placed a responsibility on NHS Trusts to ensure that appropriate resuscitation policies are in place which:

- respect patients' rights
- are understood by all staff
- are accessible to those who need them
- are subject to appropriate audit and monitoring

In response to this HDL the DNAR section of the resuscitation policy of NHS Lothian was reviewed in several clinical areas and found to be inadequate. A spot audit and collection of incident reports was undertaken which revealed frequent examples of:

- inappropriate resuscitation attempts in hospitals and the community
- ambulance crews transporting patients with insufficient DNAR documentation
- incidents where a death at home that had been expected by the family and healthcare team was treated as a 'suspicious death' by police (due to the inability of the out of hours medical service to provide death certificates)
- nursing staff putting out resuscitation calls in hospitals when they know it is not appropriate
- dying patients or their relatives being asked if they want resuscitation to be undertaken, despite the knowledge that this procedure would be unsuccessful.

Misinterpretations of guidelines⁴⁸ were also common, leading to mistaken beliefs that:

- all patients (including those clearly dying) must be asked if they would like resuscitation to be attempted
- cardiopulmonary resuscitation (CPR) is always the default position in the absence of a DNAR order.

Various attempts were made at a local hospital level and at individual unit level to improve clinical practice but the lack of a consistent and integrated approach caused significant problems and confusion. In addition to this, a request from the Scottish Ambulance Service to provide a minimum standard of information for the transport of patients with DNAR orders led to an effort to resolve this issue at a pan-Lothian level.

4.4.2 Aims of the NHS Lothian DNAR Policy

The pan-Lothian DNAR policy and associated documentation was introduced to address the issues outlined above, and with the aims of:

- reducing inappropriate resuscitation attempts to 0% in hospitals and in the community
- improving practice regarding DNAR decision-making and communication
- improve communication with the ambulance service to facilitate transfer of patients with DNAR orders
- avoiding inappropriate police input at expected community deaths
- meeting the HDL requirements for Lothian's integrated health service

It was hoped that introducing a consistent approach to such a complex issue across all care settings in Lothian would provide an opportunity for:

- increased awareness among patients and relevant others about resuscitation issues
- resuscitation issues to be part of discharge planning where appropriate
- DNAR orders to be initiated or continued at home where appropriate.

4.4.3 What is the Lothian DNAR policy and documentation?

NHS Lothian developed a DNAR policy which clarifies medical and nursing responsibilities in the DNAR decision-making process, and an associated framework to assist medical and nursing staff in all settings to make appropriate resuscitation decisions. A patient information booklet was also developed based on an existing British Medical Association (BMA) booklet. The new documentation was brought into use in May 2006, and is now the only DNAR documentation to be used for NHS Lothian patients.

The framework includes guidance on when it is appropriate to fill in a DNAR form. The DNAR form is a single, high visibility form designed to be easily recognisable and self-explanatory. The form is used to communicate the information that a patient is not for resuscitation, should be filed in the front of the patient's notes, and should be transferred with the patient between healthcare settings. The form can also be sent with a patient when they are discharged home from hospital or hospice providing the patient and family want this. If a patient who is terminally ill dies at home and the family panics and calls 999 the paramedics will not be obliged to initiate resuscitation if the form is there. In this situation the police would also recognise the DNAR form and would no longer regard this as a police-death.

NHS Lothian has plans to review and amend the current documentation, and implementation of the policy has revealed:

- a steady but slow uptake of the policy among GPs
- evidence of poor implementation of the policy on discharge of patients from hospital
- the need for education regarding communication skills around resuscitation issues
- resistance by one national nursing home group to adopting the NHS Lothian documentation in favour of using their own documentation
- the need to embed the policy into the discharge planning process at an early stage
- the need to emphasise the requirement for discussion with the patient/carer on discharge
- the need to embed the policy into the induction and continuing education programmes of medical and nursing staff.

4.4.4 Are there benefits to introducing the Lothian DNAR policy?

Audit data concerning this policy is currently being collected and analysed. Anecdotal evidence indicates that the policy is having a positive impact, and it has received strong support from the SAS, who have requested that this is 'model' documentation that should be used across Scotland and linked with DNAR guidance for ambulance crews. NHS Lothian has also been successful in

negotiating a change in the Police & Procurator Fiscal procedure for investigating a death when a DNAR form exists.

Since May 2006, further developments have included:

- support from the Chief Medical Officer (CMO) to recommend that other NHS Boards across Scotland consider the Lothian documentation as a potential solution to ensuring good DNAR decision-making and documentation practice
- indications from Information Statistics Division (ISD) that if there is wide uptake of the Lothian documentation by other NHS Boards, it may be possible to incorporate the form into the ECS.

4.4.5 Discussion

The group noted the view that some may find the language used on the DNAR form surprisingly blunt given the sensitive nature of its purpose. However, it was agreed that this wording was entirely appropriate in fulfilling the form's primary purpose of being quick and easy to understand, and that the 'harsh' effect of such a form is reduced if it is included as one part of a wider advanced care plan. This issue does however highlight the importance of ensuring appropriate communication with the patient and their family before sending a form home with a patient or leaving a form in the patient's home.

The working group agreed that though in the early stages of its implementation, the NHS Lothian policy seemed to be an effective means of addressing many of the issues and uncertainties currently associated with the DNAR decision-making process. It was particularly interested to note the positive response of SAS, and their wish for this documentation to be used across Scotland. Given NHS Lothian's success regarding the negotiation of a change in the local Police & Procurator Fiscal procedure for investigating a death when a DNAR is present, and the future possibility of the documentation being incorporated into the ECS, the group felt that the DNAR policy had real potential as a Scotland-wide initiative. It was emphasised that for the benefits of Scotland-wide implementation to be realised, there would be no scope for local adaptation, since SAS training and ECS incorporation would rely on exactly the same documentation being used in all areas.

4.4.6 Recommendation 15

Recommendation 15

The DNAR policy and associated documentation developed by NHS Lothian should be adopted by all NHS Boards, along with education to support the effective and appropriate application of the documentation and procedures.

5. Discussion, conclusions and recommendations

5.1 Discussion

5.1.1 Education

The Partnership consulted widely on these recommendations before presenting them to the Scottish Executive. Consultation responses indicated that many areas were already working with some of these initiatives and approaches, but that while there is widespread enthusiasm at the prospect of being able to embrace these tools and initiatives, they can only be implemented successfully, effectively and appropriately if supported by education and training provision. The issues involved in palliative and end of life care are complex, and much of this care is provided by staff who are not specialists in palliative care. It is therefore paramount that individuals have a full understanding of the tools they are using and how they should be used appropriately.

This need for education and training has been reflected in individual recommendations relating to the GSFS, LCP and DNAR documentation. However, consultation respondents were clear that the need for education underpins all of the recommendations if staff are to be enabled to be champions of care and to introduce these tools for the benefit of patients.

5.1.2 Resources

Progress towards some of the improvements outlined within this report can be made by re-design of services and reallocation of existing resources. However, it has become increasingly clear throughout the report and from consultation responses, that full implementation of these recommendations is reliant on the availability of additional resources, both to enable appropriate education and training, and in terms of dedicated support to facilitate the introduction and sustainability of these improvements.

5.1.3 Recommendation 16

Recommendation 16

SEHD, NHS Boards and CHPs should make available additional resources to enable appropriate education and training, and to enable dedicated support to facilitate the introduction and sustainability of the improvements outlined in this report.

5.1.4 A cohesive approach to health and social care

Throughout the group's discussions it became increasingly clear that there are still many barriers to cross-organisational working between health and social care, but that professionals from both areas must work closely together in order to provide high quality palliative and end of life care services to patients. The group was aware that the idea of social care involvement in the provision of palliative care is something that is often overlooked, and that a future challenge for the Partnership is in improving links with local councils. However, the group was clear that for any approach to palliative and end of life care to be truly cohesive, it must recognise and facilitate social care as an integral part of palliative care.

5.1.5 Liverpool Care Pathway

The consultation process revealed strong support for most of the initiatives outlined within this report. However, some respondents had reservations regarding the recommendations relating to the Liverpool Care Pathway. Most of these concerns related to the quality of supporting evidence, the flexibility and applicability of the pathway, and the need for education to support its appropriate use. The group weighed these concerns carefully alongside other consultation responses which voiced their support for these recommendations. Having strengthened references to the importance of flexibility, education and facilitation to support appropriate use of the pathway, the group agreed the recommendations that are now contained within this report.

5.1.6 Audit and research

Recent research has indicated that there is a need for a wider evidence base for palliative care in Scotland, particularly in the areas of user involvement/patient experience; psychosocial care and support; bereavement care and support and complementary therapies.⁴⁹ The group felt that adopting a cohesive approach to care delivery would help to address this, by providing a good basis for future collaborative audit and research across settings and geographical areas.

5.2 Conclusions

Having carried out its remit of:

- considering the Department of Health End of Life Programme tools for palliative and end of life care and
- developing recommendations for achieving equivalent outcomes within the context of *Delivering for Health* and current Scottish health policy,

the working group has reached the considered view that the time is right for a cohesive approach to palliative and end of life care in Scotland.

The group has proposed several recommendations which it believes will begin the development of an integrated and cohesive approach. These centre on:

- supporting continued and expanding use of the principles of the Gold Standards Framework Scotland in all care settings
- encouraging a uniform approach to achieving the goals of the Liverpool Integrated Care Pathway for the Dying Patient in all care settings, and
- clarifying some of the issues relating to out of hours service provision, DNAR policy, and joint working by health and social care.

The group believes that implementation of the recommendations set out within this report will make a major contribution to the implementation and effectiveness of existing health policies, helping to accelerate the pace of change, and removing unnecessary uncertainty and confusion.

The principles of the Gold Standards Framework Scotland can be applied from the point of diagnosis onwards to improve the general and specialist palliative care of all patients regardless of diagnosis or care setting. The GSFS approach includes an emphasis on forward-planning and communication with the patient and their family to

ensure that steps are taken to anticipate future events and help things to run as smoothly as possible. This emphasis on advanced care planning enables patients and families to participate more effectively in managing their own care. The Liverpool Care Pathway is used to guide care in the last days or hours of life once it has been confirmed that a patient is dying, empowering healthcare teams in all settings to deliver high quality care to dying patients and their relatives.

Taken together, these tools have the potential to ensure a consistency of process across Scotland, facilitating equitable improvements in palliative and end of life care. Education and resources are required to enable proper introduction and support of these tools, and the ease with which professionals are able to provide good palliative care will be increased by removing some of the existing confusion and anomalies around issues such as out of hours service provision, DNAR policy, and joint working.

The group believes that by adopting a cohesive approach and implementing the recommendations in this report the Scottish Executive Health Department can facilitate the delivery of high quality palliative and end of life care to everyone in Scotland who needs it, on the basis of clinical need not diagnosis, and according to established principles of equity and personal dignity.

5.3 Recommendations 1 - 16

Recommendation 1

NHS Boards and CHPs should encourage adoption of the principles, approach and documentation of the GSFS by the remaining 28% of general practices in Scotland not yet involved.

Recommendation 2

SEHD, NHS Boards, CHPs and palliative care networks should support application of the core principles of the GSFS in all care settings across Scotland.

Recommendation 3

SEHD, NHS Boards, CHPs and palliative care networks should support the ongoing extension of the principles, approach and documentation of the GSFS to patients with life-threatening and long-term conditions and to frail elderly patients with multiple co-morbidities.

Recommendation 4

SEHD, NHS Boards, CHPs and palliative care networks should commit to supporting the ongoing education and facilitation required to allow mainstreaming of the GSFS to be sustainable in all primary care settings.

Recommendation 5

CHPs and palliative care networks should encourage GP practices to make full use of the upgraded IT systems that will become available from summer 2007. This should include GPs using their upgraded existing IT system to record patients' palliative care needs, plan review dates and assist multi-disciplinary team meetings, and sharing summary information with OOH services and NHS 24.

Recommendation 6

SEHD, NHS Boards and palliative care networks should support and facilitate flexible use of the LCP in all care settings.

Recommendation 7

Dedicated resources should be made available by CHPs and NHS Boards to introduce, embed and mainstream use of the LCP across Scotland. This should take into account the need for localisation of LCP documentation to support clinical need, and for appropriate education and training to ensure staff have the necessary understanding to use the LCP successfully and appropriately.

Recommendation 8

All NHS Boards should ensure that systems are in place which allow timely and easy 24-hour access to medication for patients with palliative care needs.

Recommendation 9

Further guidance should be provided to patients and professionals, clarifying when and for what purposes it is appropriate to contact NHS 24, and what information they will be required to provide.

Recommendation 10

Ongoing efforts should be made at a local level to work with NHS 24 to learn from recent experiences to improve services within a local context.

Recommendation 11

All NHS Boards should work towards early implementation of a 24-hour community nursing service to support existing medical OOH arrangements.

Recommendation 12

SEHD should ensure that changes in out of hours provision do not adversely affect the provision or quality of palliative care to patients in the community.

Recommendation 13

The Scottish Executive should conduct an investigation into the implementation of NHS MEL (1996) 22, with a view to clarifying the joint Health Board and Local Authority responsibility for funding palliative and end of life care.

Recommendation 14

NHS Boards, Local Authorities and CHPs should consider adopting/adapting the principles of the NHS Borders model when developing their own approach to joint working and joint care management.

Recommendation 15

The DNAR policy and associated documentation developed by NHS Lothian should be adopted by all NHS Boards, along with education to support the effective and appropriate application of the documentation and procedures.

Recommendation 16

SEHD, NHS Boards and CHPs should make available additional resources to enable appropriate education and training, and to enable dedicated support to facilitate the introduction and sustainability of the improvements outlined in this report.

6. Appendices:

Appendix A: Policy context

A.1 Delivering for Health

Delivering for Health sets out a vision for a health service where:

- services are delivered as locally as possible
- there is an emphasis on preventative, anticipatory care rather than reactive management
- there is greater integration within the health service and with social services and voluntary organisations.

A.2 Policy Context 'Pre- Delivering for Health'

In deriving its recommendations, the group was mindful of the fact that much of the palliative and end of life care services that are currently in place have been influenced by policies published prior to *Delivering for Health*:

- **NHS MEL(1996)22: NHS Responsibility for continuing healthcare** emphasises the importance of service level agreements and shared service planning between health and social work, to provide a co-ordinated strategy for the organisation and provision of care. It also sets out the responsibilities of NHS Boards with regard to palliative care provision, including funding and patient-choice.
- **Partnership for Care: Scotland's Health White Paper** was published by the Scottish Executive in 2003, and saw a central role for primary care teams in Community Health Partnerships, working with hospital services and in new relationships at community level between NHSScotland and Local Authorities. This document crystallised the principle of patient-focused services.
- the **Joint Future** initiative aiming to provide faster access to better and more joined up services through improved joint working across organisational boundaries.
- **Single Shared Assessments (SSA)** were introduced as part of the Joint Future initiative, and aimed to eliminate duplication in assessment and ensure that information is shared across agencies.
- **Better Outcomes for Older People: Framework for Joint Services**, was published in May 2005 as a further part of the Joint Future initiative. It provides a framework for designing, commissioning and evaluating joint services for older people.
- the **Unscheduled Care Collaborative Programme** was launched in May 2005, aiming to improve patient and carer experience and satisfaction through improving access and reducing waits and delays across unscheduled care patient flows.
- The **Quality and Outcomes Framework (QOF)** is a component of the General Medical Services contract for general practices, introduced from 1 April 2004. The QOF is designed to reward practices for the provision of quality care, and help to fund further improvements in the delivery of clinical care.
- The **Adults with Incapacity Scotland Act (2000)** provides ways to help safeguard the welfare and finances of people (aged 16 and over) who lack the capacity to take some or all decisions for themselves, because of a mental disorder or inability to communicate. It allows other people to make decisions on their behalf.

The group recognised that many of these policies paved the way for the vision set out within *Delivering for Health*.

A.3 Policy Context 'Post- *Delivering for Health*'

Since its publication, *Delivering for Health* has been underpinned by policies and initiatives which re-emphasise the messages of *Delivering for Health*, and look at implementation in more detail:

- **The future care of older people in Scotland** was published in May 2006 and sets out a vision for care with the emphasis on helping older people to stay at home; enabling people to be cared for in the least intensive setting possible; and a whole systems approach. One of its recommendations is that: '*consideration should be given to additional investment in improving palliative care services in Scotland, building on the success of the Gold Standards Framework and of the NHS End of Life Care Programme in England, and the effectiveness of such end of life care initiatives in Scotland should be evaluated.*'
- **HDL(2006)12: Delivering for Health; guidance on implementation** offers guidance on implementation of the action plan set out in *Delivering for Health* (DfH). This HDL states that priority should be given to actions which will achieve a shift in the balance of care, and reiterates DfH's emphasis of the importance of Community Health Partnerships (CHPs) in leading implementation and engaging with local partners to ensure a whole systems approach to rebalancing services and managing people with long-term conditions.
- **Changing Lives: Report of the 21st Century Social Work Review** was published in February 2006, and highlights the need for social work services to work closely with other universal providers to find new ways to design and deliver services across the public sector.
- **The Future of Unpaid Care in Scotland** was published in September 2006, and included an emphasis on the rights and needs of unpaid carers, their importance as partners in care, and the need to strengthen independent living and self-care.
- The **National Strategy for the Development of the Social Services Workforce in Scotland 2005-2010** sets out a plan for developing the social service workforce over the next five years.
- **Co-ordinated, integrated and fit for purpose: A Delivery Framework for Adult Rehabilitation in Scotland** is designed to give strategic direction and support to all health and social care services and practitioners who deliver rehabilitation services to individuals and communities. It reiterates many of the key messages of *Delivering for Health*, including the importance of patient participation, the need to deliver services as locally as possible, and the need for communication and co-operation between health and social care professionals. The document focuses on three target groups, one of which is adults with long-term conditions, and sets out a number of recommendations for action.
- *Delivering for Health* emphasises the increasing role of **Community Health Partnerships** (CHPs), and the Scottish Executive recently published a long-term conditions CHP self-assessment toolkit to enable CHPs to assess the way in which they manage long term conditions. Work is also currently underway at the Scottish Executive to produce a HDL explaining the relationship between Managed Clinical Networks (MCNs) and CHPs.
- **All Our Futures: Planning for a Scotland with an Ageing Population** was published in March 2007, and looks at ways of ensuring that services and

infrastructure fully reflect the changing demographic picture of Scotland. This document reiterates the importance of good palliative care with the option of remaining at home for as long as possible.

During the course of its work, the group maintained communication links with:

- The Royal College of General Practitioners long-term conditions group
- The Long Term Conditions Alliance Scotland (LTCAS)

The group also maintained an awareness of developments relating to:

- Scottish Executive strategy for the care of long-term conditions
- Department of Health (DoH) End of Life Care Strategy.

Appendix B1: How the Gold Standards Framework Scotland relates to the wider health policy context

B1.1 Delivering for Health

The aims of the GSFS were consistent with the vision set out within *Delivering for Health*:

B1.1.1 Continuous, integrated care, embedded in the community ('shifting the balance of care')

The GSFS helped the entire primary care team to improve communication and work across organisational boundaries to provide better care to people nearing the end of their lives:

- Each PHCT had a nominated co-ordinator (eg District Nurse) to ensure good organisation and co-ordination of the multidisciplinary process.
- Systems and protocols were developed to ensure continuity of care delivered by inter-professional teams and out of hours providers.
- Information was passed on to other relevant services, for example hospice/oncology department/ NHS 24/ out of hours services.

B1.1.2 Anticipatory care, reducing the rising trend of unscheduled hospital admissions and providing care in the least intensive setting

- The GSFS encouraged more intensive case-management for individuals with serious long term conditions. This helps the primary care team to monitor patients more closely, allowing them to target resources and anticipatory care to reach out to those at greatest risk.
- Practices transfer information to the out of hours service for palliative care patients using the locally agreed system. This builds in anticipatory care to reduce crises and inappropriate admissions.

B1.1.3 Multi-disciplinary team working, fully using the skills of the whole clinical team

- The GSFS encouraged the maintenance of a supportive care register to record, plan and monitor patient care, and this is discussed at regular multidisciplinary team (MDT) meetings.
- Members of the wider team are included in this process, eg social service or clinical nurse specialist.
- This helps practices to fully utilise the skills of the whole clinical team, and increases understanding among team members of the roles and responsibilities of others.

B1.1.4 Carers will be treated as partners in the provision of care

- The GSFS approach encourages GP practices to work in partnerships with carers and to maintain a carers' register which includes the contact details of carers.
- The GSFS approach encourages practices to consider the emotional and practical needs of carers, and their needs in bereavement.

B1.1.5 If patients require care urgently, they will be able to see the right person, with the right skills, at the right time

- Practices transfer information to the out of hours service for palliative care patients.
- The GSFS approach encourages practices to record and minimise the number of professionals involved with each patient, freeing up staff to see those more in need of their skills.

B1.1.6 Enhance primary care and enable GPs to access shared resources, facilities and expertise

The GSFS improved communication across the primary care team, providing networking opportunities, and enabling GPs to more easily access the expertise of other healthcare professionals. The GSFS website provides documentation that can be used in general medical practices throughout Scotland, and a list of recommended reading. (www.gsfs.scot.nhs.uk)

B1.1.7 Ensure a consistent approach and a spread of best practice across Scotland

Over 70% of GP practices in Scotland adopted the GSFS, encouraging a consistent approach and a spread of best practice across Scotland.

B1.1.8 Review care using evidence-based protocols and guidelines

According to the GSFS approach, each patient should have their symptoms, problems and concerns (physical, psychological, social, practical and spiritual) assessed, recorded, discussed and acted upon, according to an agreed process. As well as pain management checklists, the GSFS documentation has shared bereavement and terminal phase protocols, and encourages the use of integrated care pathways and significant event analysis.

B1.1.9 Integrate generalist and specialist care

Use of the GSFS documentation educates the multi-professional primary care team of their responsibility to provide good general palliative care, and improves continuity when collaborative and co-ordinated care shared between specialist and generalist is required.

B1.1.10 Identify people with long-term conditions and place them on a general practice-based register

Part of the GSFS was to maintain a Supportive Care Register (paper or electronic) to record, plan and monitor patient care.

B1.1.11 Rural health services

The GSFS helped the primary care team to improve organisation and co-ordination, helping to maximise the efficiency of visiting clinicians, and enabling specialists to concentrate on the most complex cases while also providing support and education for local clinicians.

B1.2 Other Policy Context

The GSFS approach:

- is a way of introducing intensive co-ordinated case management for patients with the most complex health needs and vulnerability to emergency hospital admission. This is one of the local level actions outlined in HDL(2006)12

- is particularly pertinent to patient flow 5 of the Unscheduled Care Collaborative Programme, helping to ensure unscheduled hospital admissions are appropriate
- is in-keeping with the 'joint future' ideal, and supports *Better Outcomes for Older People* by suggesting a more holistic approach to care
- is a way of improving and co-ordinating care management, as recommended in circular CCD8/2004
- helps to educate the primary care team about general palliative care, helping to support the needs of carers as suggested in recommendation 5 of *the Future of Unpaid Care in Scotland*: 'we recommend that all frontline staff with direct responsibilities for supporting the needs of carers in 'first contact' agencies are properly equipped to advise unpaid carers about their rights, entitlements and available services.'
- can help teams to introduce the recommendations contained within *Co-ordinated, integrated and fit for purpose*, including addressing transitions of care for older people and those with long-term conditions, helping services to be focused on 'at-risk' individuals, and enabling more continuity of care
- can help General Practices to claim the 52 quality and organisational points relating to cancer, palliative and supportive care that are available from the Quality and Outcomes Framework (QOF) of the revised General Medical Services (GMS) Contract 2006/07
- can help to reduce emergency admissions and improve advanced care planning, contributing to the achievement of the following Ministers' key objectives, targets and performance measures for the NHS and local delivery plans:
 - *Target A.05T: By end of 2007 no patient will wait more than 4 hours from arrival to discharge or transfer for accident & emergency treatment*
 - *Target T.02T: By 2008-09, we will reduce the proportion of older people (aged 65+) who are admitted as an emergency inpatient 2 or more times in a single year by 20% compared with 2004/05 and reduce, by 10%, emergency inpatient bed days for people aged 65 and over by 2008.*⁵⁰

Appendix B2: palliative care out of hours summary

GOLD STANDARDS FRAMEWORK SCOTLAND Palliative Care OOH Summary

H2 - Date: Updated when sent

H3 - Review Date:

Section 1			
Patient and Carer Details		Patient's Own GP and Nurse	
1a – Patient Surname		1h - Usual GP name	
1b - Patient Forenames		1i - Nurse	
1c- CHI Number		1j - Practice Details	
1d – Patient Address			
1e – Patient Tel number			
1f - Carer Details			
1g - Access information including potential issues			
1k – Next of kin details			

Section 2 Patient's Medical Condition	
2a - Main Diagnoses	
2b – Other Relevant Issues	
2c - Allergies / Adverse drug reactions	
2d – Current Drugs and Doses	
2e – Additional drugs available at home	

Section 3 Current Care Arrangements	
3a – Care arrangements	
3d – Syringe driver at home	
3e – Catheter continence products at home	
3f – Moving & handling equipment at home	

Section 4 Patient's and Carer's Awareness of Condition	
4a - Patient's Understanding of Diagnosis	
4b - Patient's Understanding of Prognosis	
4c - Carer's Understanding of Diagnosis	
4d - Carer's Understanding of Prognosis	

Section 5
Advice for Out of Hours Care

5a - Care Plan Agreed	
5b – Preferred place of care	
5c – Should GP be contacted out of hours?	
5d - GP – Home Tele/Mobile/Pager	
5e - Resuscitation Status Agreed	
5f – Actual Resuscitation Status	
5g – Will GP sign death certificate in normal circumstances?	
5h – Additional Useful OOH Information	

Appendix C1: how the Liverpool Care Pathway (LCP) relates to the wider health policy context

C1.1 Delivering for Health

The aims of the LCP are consistent with the vision set out within *Delivering for Health*:

- C1.1.1 • Continuous, integrated care, embedded in the community**
- Ensure a consistent approach and a spread of best practice across Scotland
- More capacity for local diagnosis and treatment
- Use community and voluntary resources well
- Integrate generalist and specialist care
- Integrate health and social care
- Rural health services

The LCP was developed to take the best of hospice end of life care into hospitals and other settings.

C1.1.2 • Reducing the rising trend of unscheduled hospital admissions

- Provide care in the least intensive setting
- Anticipatory care
 - Patients who have previously expressed a wish to die at home may be admitted to hospital to die because carers feel unsupported and unsure about expected changes prior to death. Using the LCP gives carers the support they need to facilitate good care at home. This can also help to facilitate the discharge of patients who would otherwise have died in hospital.
 - LCP symptom management guidelines support anticipatory prescribing, helping comfort to be maintained for the patient.

C1.1.3 Multidisciplinary team working, fully using the skills of the whole clinical team

- The LCP is a multi-professional document which facilitates multi-disciplinary communication and documentation.
- The process of localising and implementing the LCP is a multi-professional process which in itself enhances and supports effective team-working.

C1.1.4 Carers will be treated as partners in the provision of care

- As part of the implementation process, supporting information leaflets for patients and relatives are developed to accompany the LCP.
- The LCP supports the healthcare team to discuss end of life care with carers and the family in a planned way. Exposure to a supportive network can improve bereavement outcomes, and engagement with carers prior to death has the potential to increase professional knowledge of issues which could lead to a complex bereavement.

C1.1.5 Treating the patient as a partner

- The LCP involves prompting effective communication with the patient.

C1.1.6 Review care using evidence-based protocols and guidelines

- The LCP provides a tried and tested care pathway, and a model of outcome based care which allows for benchmarking across sectors.

C1.2 Other Policy Context

Use of the LCP:

- helps to shift the balance of care, as emphasised in HDL(2006)12, by helping patients to be cared for appropriately wherever they are
- raises awareness of expected changes towards the end of life and increases confidence that patients are being cared for appropriately. This helps to reduce emergency hospital admissions in-keeping with the aims of the Unscheduled Care Collaborative. This also helps people to be cared for in the least intensive setting possible, in-keeping with the vision set out in *The future care of older people in Scotland*
- can help a CHP to improve its score on the long term conditions self-assessment tool, by improving palliative care services
- supports carers in line with *The future of unpaid care in Scotland*, encouraging good communication with the family and enhancing bereavement care.

Appendix C2: LCP implementation across Scotland

The working group undertook to find out about current use of the LCP across Scotland, by e-mailing chairs of regional palliative care managed clinical networks (MCNs) (or equivalent), and other contacts. Results of this informal survey are detailed below. This survey was *not* a comprehensive mapping exercise, and one NHS Board area was unable to reply in the given timescale. However, the results are helpful in providing an outline of current uptake of the LCP across Scotland.

NHS Ayrshire & Arran: An integrated care pathway inspired by the LCP is being used within the hospice, and is being used within all wards within Ayr hospital and the medical unit and the surgical specialties at Crosshouse hospital. It is also being used within care of the elderly wards at Biggart Hospital and within East Ayrshire Community Hospital. It is currently being rolled out into the community setting, and is also being used by some care homes.

NHS Borders: The LCP is used within care of the elderly wards at Borders General Hospital, and within some Scottish Borders community hospitals and care homes. There are plans to extend pilots of its use to eight further care homes.

NHS Dumfries & Galloway: All GPs and District Nurses have been informed about the LCP and have the option to use it. The LCP is being used throughout all community hospitals, most acute hospitals, and is beginning to be used in some care homes.

NHS Fife: The LCP is not currently being used in Fife although a sub group of the palliative care Group recently looked at the pathway and the implications for implementation. The sub-group's work has been forwarded to an NHS Fife strategic group to consider as to whether the LCP should be implemented across Fife.

NHS Forth Valley: The LCP has been implemented in the region's acute hospitals, and is currently being extended to the community hospitals. It is also planned that the palliative care MCN will encourage and support Care Homes to implement the pathway. One CHP has completed its base-line audit.

NHS Grampian: The group was not aware of any widespread use of the LCP in Grampian.

NHS Greater Glasgow and Clyde: A project manager has dedicated time to work with two palliative care practice development staff, a palliative care CNS for Care Homes and with palliative care teams to implement the LCP across NHS Greater Glasgow. The first phase of implementation is currently underway, focusing on the acute sector, and two partnership care homes. Future work will include the implementation of the LCP across other care settings. Marie Curie Hospice Glasgow and St Margaret of Scotland Hospice are already using the LCP, and Prince and Princess of Wales Hospice is currently developing LCP education and training for staff, with a view to implement the LCP in 2007. The Beatson Oncology Centre has also adapted the LCP for local use. Within Clyde, Accord Hospice has implemented the LCP, and there are plans to implement the LCP within St Vincent's Hospice and some CHPs during 2007.

NHS Highland: The LCP is used within Highland Hospice, Lorne & Island District General Hospital and Cowell Hospice, and has been piloted within Broadford Hospital. Introduction of the LCP within Raigmore Hospital in Inverness will commence in 2007. The palliative care team in mid-Argyll plan to undertake further implementation of the LCP during 2007.

NHS Lanarkshire: The LCP is well-established within St Andrew's Hospice Airdrie, and a pilot of the tool is running in a ward of one of the local hospitals. The Medical Director at St Andrew's Hospice has conducted a series of informal lectures/ awareness raising sessions with District Nurses and GPs, and is working to obtain Big Lottery funding for fund LCP co-ordinators for North and South Lanarkshire over a five year period.

NHS Lothian: A baseline audit has been carried out in the Older Peoples Service Astley Ainslie and Associated Hospitals Edinburgh and work is underway to adapt the LCP for local use. There are plans that the LCP will be introduced to these hospitals following a short period of consultation and an education programme. An audit of the effects of LCP will be carried out 6 -12 months following implementation. St Columba's Hospice recently undertook a baseline review and staff education with a view to implementing the LCP in the in-patient unit in 2007.

NHS Tayside: The LCP is being rolled out within primary care and community hospitals within the Perth and Kinross area.

NHS Orkney: An ICP based on the LCP is used across all clinical areas.

NHS Western Isles: The LCP is not used in the Western Isles.

Appendix C3: LCP goal definitions

More detail is available at:

http://www.mcpcil.org.uk/liverpool_care_pathway/view_the_lcp_and_associated_documentation/goal_definitions

- Goal 1:** current medication assessed and non-essentials discontinued
- Goal 2:** prn subcutaneous medication written up as per protocol
- Goal 3:** discontinue inappropriate interventions
- Goal 4:** ability to communicate in English assessed as adequate with patient and carer
- Goal 5:** insight into condition is assessed
- Goal 6:** religious / spiritual needs assessed
- Goal 7:** identify how family / other are to be informed of the patient's impending death
- Goal 8:** family / other given hospital information
- Goal 9:** GP practice is aware of patient's condition
- Goal 10:** plan of care explained and discussed with patient and family / other
- Goal 11:** family / other express understanding of planned care
- Goal 12:** GP practice contacted re patient's death
- Goal 13:** procedures for laying out followed according to hospital policy
- Goal 14:** procedure following death discussed or carried out
- Goal 15:** family /other given information on hospital procedures
- Goal 16:** hospital policy followed for patient's valuables and belongings
- Goal 17:** necessary documentation & advice is given to the appropriate person
- Goal 18:** bereavement leaflet given.

The LCP also includes auditing against the following comfort measure goals:

<i>Pain</i>	patient is pain free
<i>Agitation</i>	patient is not agitated
<i>Respiratory tract secretions</i>	excessive secretions are not a problem
<i>Nausea and vomiting</i>	patient does not feel nauseous and is not vomiting
<i>Breathlessness</i>	breathlessness is not distressing the patient
<i>Other symptoms</i>	patient is not distressed by any other symptom
<i>Mouth care</i>	patient's mouth is clean and moist
<i>Micturition difficulties</i>	patient is comfortable

<i>Medication</i>	all medication is given safely and accurately
<i>Pressure area care</i>	patient is comfortable and in a safe environment
<i>Personal hygiene care</i>	patient's personal hygiene needs are met
<i>Bowel Care</i>	patient is not agitated or distressed due to constipation or diarrhoea
<i>Other care</i>	patient's other care needs are met
<i>Communication/insight</i>	patient becomes aware of the situation as appropriate
<i>Care of next of kin/ family/ others</i>	next of kin/ family/ others are prepared for the patient's imminent death
<i>Religious and spiritual support</i>	appropriate religious and spiritual support has been provided.

Appendix D: How the Scottish Borders approach relates to the wider health policy context

D.1 Delivering for Health

D.1.1 Geared towards long-term conditions

The Scottish Borders service is available to all patients considered to be in the last six months of life irrespective of diagnosis.

D.1.2 Continuous, integrated care, embedded in the community ('shifting the balance of care')

- The palliative care at home service supports the patient to remain at home until the end of life wherever possible and according to patients wishes.
- If hospital admission is required patients are managed in the local community hospitals, again under the care of the local GP and primary care team.
- The service is available throughout a 24-hour 7-day period. Special provision has been made locally to support the patient and their carer in the out of hours period.

D.1.3 Multi-disciplinary team working

Assessment of patient and carer need is based on a team assessment looking at all aspects of need and ability. The District Nurse or Clinical Nurse Specialist manages the care in most instances although there are occasions where social work colleagues may assume the role of care manager. Allocation of this role is agreed within the team and is assumed by the most appropriate person for each individual patient.

D.1.4 Anticipatory care

Although the patient is deemed to be in the last six months of life preventative care remains an issue. Full assessment of the patient and their carer identifies actual and potential problems which they may have or encounter. Provision is then made within the care plan to pre-empt further problems thus ensuring that care is given as required and increased where necessary to prevent admission wherever possible.

D.1.5 • Carers will be treated as partners in the provision of care

• Care provided in the least intensive setting

Managing patients at home in the end of life requires a complex package of care from health, social and voluntary sectors, and in many cases the support and commitment of the carer is crucial. Care planning takes account of the patients and the carers' needs. Ensuring carers get the respite they need is part of the assessment process and the management plan reflects this. Provision is made within the budget to allow flexibility in the care provided allowing the carer time to sleep, shop or even play a round of golf if deemed appropriate to meet the carer's needs.

D.1.6 Patient as partner

- Patients are supported to take a full part in the assessment process to determine their needs, and consideration is given to the wishes of the patient towards place of care.

- Wherever possible if an existing care package is in place this will be continued to ensure patients are familiar with the care providers and existing relationships are not compromised.
- All care at this stage is free to the patient thereby relieving the patient and their carer of any financial burden caring may incur at the end of life.

D.1.7 Self-care encouraged and facilitated

Care is available to all patients in the end of life however due to financial constraints 24-hour continuous care is not an option. Patient and their carers are encouraged to work with health and social services to ensure the care package is adequate for their needs. Patients are given access to an out of hours dedicated phone line should problems arise and encouraged to use this whenever necessary. The district nurses and Macmillan nurses work with the patient and their carers to ensure they have an understanding of medication and its use and any potential problems that may arise as a result of their illness. By educating the patient they become more involved in their care and take responsibility for directing services and seeking help when necessary.

D.1.8 Integrate health and social care

- The patient and their carer are managed in the primary care setting by a team of health, social and voluntary care professionals.
- Budgets are integrated, with health services picking up any new care packages in the last six months of life and social services meeting the cost of existing packages thereby sharing the cost of care.
- All professionals taking on the care management role use the single shared assessment documentation and details are entered into both health and social services data systems.

D.1.9 Moving from 'low tech' to 'high tech'

Care management is documented on a single shared assessment document which allows details of the assessment and the care package to be entered onto both health and social work databases. The plan for the future is to link both these systems to allow ease of access and transferability of information.

D.2 Other Policy Context

The NHS Borders approach:

- was developed in response to NHS MEL(1996) 22 and there are indications that it is working well to deliver the shift in the balance of care emphasised in HDL(2006)12
- is very much in-keeping with the 'joint future' ideal
- pre-empts some of the recommendations of *Co-ordinated, integrated and fit for purpose*, mainstreaming the idea that rehabilitation teams with crossover functions need to consider how to improve the continuity of care, and helping to facilitate anticipatory care to prevent unnecessary admissions to hospital
- actively supports older people to stay in their own homes, as is emphasised in *Better outcomes for older people: framework for joint services* and re-emphasised in *The future care of older people in Scotland*.
- follows the principles of care management, joint resourcing and joint management set out in circular CCD8/2004
- respects unpaid carers as partners, as recommended by *The Future of Unpaid Care in Scotland*.

Appendix E: Palliative and end of life care group membership

Membership:

Dr Patricia Cantley	Consultant in Elderly Medicine, NHS Lothian
Dr Fiona Downs	Consultant in Palliative Care, Strathcarron Hospice
Shirley Fife	Macmillan Lead Cancer & Palliative Care Nurse, NHS Lothian
Dr Elizabeth Ireland	Lead Clinician & General Practitioner, NHS Forth Valley
Dr Jeremy Keen	Consultant in Palliative Care, Highland Hospice
Linda Kerr	CNS In Palliative Care, NHS Ayrshire & Arran
Kate Lennon	Macmillan Nurse Consultant in Palliative Care, NHS Greater Glasgow & Clyde
Aileen Eland	Area Nurse Manager (Scotland), Marie Curie Cancer Care Nursing Service (group member from August 2006)
Professor Scott Murray	St Columba's Hospice Chair of Primary Palliative Care, University of Edinburgh
Maria McGill (Chairman)	Chairman, Scottish Partnership for Palliative Care
Jim McLaggan	Caring Services Manager Scotland, Marie Curie Cancer Care (group member until July 2006)
Elaine Peace	Macmillan Nurse Consultant – Cancer and Palliative Care, NHS Borders
Dr Chris Ward	Honorary Consultant Cardiologist, Ninewells Hospital, NHS Tayside
Paul Welford	Manager, NOSCAN, NHS Grampian
Professor John Welsh	Professor of Palliative Medicine, NHS Greater Glasgow & Clyde

In attendance:

Dr Rosaleen Beattie	Scottish Executive Health Department
Rebecca Patterson	Policy Manager, Scottish Partnership for Palliative Care
Patricia Wallace	Director, Scottish Partnership for Palliative Care
Fiona Warner	Patients and Quality Division, Scottish Executive Health Department

External consultant:

Fiona Mackenzie, Chief Executive of NHS Forth Valley, in her role as NHS Scotland lead for the 'shifting the balance of care' strand of *Delivering for Health* implementation received all papers and acted in a consultative capacity.

Appendix F: List of presentations made at meetings of the palliative and end of life care group

20 June 2006:

Lothian Voices Project

Dr David Oxenham, Medical Director, Marie Curie Hospice, Edinburgh

Tayside Delivering Choice Project and Preferred Place of Care

Jim McLaggan, Caring Services Manager Scotland, Marie Curie Cancer Care

NHS Borders approach to joint working and care management

Elaine Peace, Macmillan Nurse Consultant – Cancer and Palliative Care, NHS Borders

22 August 2006:

Gold Standards Framework Scotland (GSFS)

Dr Elizabeth Ireland, Lead Clinician & General Practitioner, NHS Forth Valley

Tayside Delivering Choice Project

Aileen Eland, Area Nurse Manager (Scotland), Marie Curie Cancer Care Nursing Service

Policy context: older people's issues

John Storey, Care of Older People Division, Scottish Executive Health Department

14 September 2006:

Continuing care: the impact of current policy on services

Jane Davidson, Strategic Clinical Care & Discharge Manager, NHS Tayside
Martin Leiper, Consultant in Palliative Medicine, NHS Tayside

16 November 2006:

Palliative Care and the Scottish Executive

Dr Rosaleen Beattie, Scottish Executive Health Department

14 December 2006:

Gold Standards Framework Scotland: focus on IT Issues

Paul Welford, Manager – NOSCAN, NHS Grampian

NHS 24 and Out of Hours Services

Janette Brogan, Senior Nurse, NHS 24

'Pre-LCP' care pathway

Dr Fiona Downs, Consultant in Palliative Care, Strathcarron Hospice

23 January 2007:

DNAR: Lothian DNAR policy, and outcomes from meeting with CMO to discuss its possible introduction across Scotland

Dr Juliet Spiller, Consultant in Palliative Medicine, Marie Curie Hospice
Edinburgh

Scottish Patients at Risk of Readmission (SPARRA)

Dr Elizabeth Ireland, Lead Clinician & General Practitioner, NHS Forth Valley

Appendix G: Glossary

General palliative care

General palliative care is care that is based on the understanding and practice of palliative care principles. These include:

- a focus on quality of life which includes good symptom control
- a whole person approach which takes into account the person's past life experience and current situation
- care which encompasses both the person with the life-threatening illness and those that matter to that person
- respect for patient autonomy and choice
- emphasis on open and sensitive communication

General palliative care is provided for those who need it as part of the routine care provided by a person's usual professional carers (doctors, nurses, care assistants etc) whether at home, in a care home, or in hospital.

'Home' and 'Care Home'

Where an individual has chosen to live in a care home, the care home is seen as being their 'home'. Therefore, throughout this report, all references to 'homes' should be read as 'homes and care homes'.

Multidisciplinary team

NHS QIS defines a multidisciplinary team as:

'a group of people from different disciplines (both healthcare and non-healthcare) who work together to provide and/or improve care for patients with a particular condition.

The composition of multidisciplinary teams will vary according to many factors. These include: the specific condition, the scale of the service being provided and geographical /socio-economic factors in the local area.'⁵¹

Multidisciplinary teams are involved in providing both general and specialist palliative care, and are likely to include: chaplain; doctors; nurses; occupational therapists; pharmacist; physiotherapist; social worker; anaesthetist; bereavement specialists; complementary therapists; dentist; dietician; lymphoedema specialists; oncologist; psychiatrist; psychologist and/or counsellor; speech and language therapist.

Out of Hours (OOH)

Out-of-hours is usually defined as evenings, weekends from Friday evening to Monday morning, and public holidays. This reflects the working hours of many primary care and palliative care staff, although GP surgeries' opening hours vary within the working hours of 8 am and 6.30 pm.

Specialist palliative care

Specialist palliative care is based on the same principles of palliative care as outlined above under 'general palliative care', but can help people with more complex palliative care needs. Specialist palliative care is provided by specially trained multi-professional specialist palliative care teams and can be accessed in any care setting.

Appendix H – References

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