NATIONAL END OF LIFE CARE PROGRAMME

Evaluation of the Test Sites Commissioned to Facilitate the Implementation of the National End of Life Care Programme Social Care Framework, Supporting People to Live and Die Well

FINAL REPORT

Anwen Jones, Research Fellow, Centre for Housing Policy
Karin Lowson, Associate Research Fellow,
Centre for Housing Policy
Karen Croucher, Research Fellow, Centre for Housing Policy

January 2012

Centre for Housing Policy

THE UNIVERSITY *of* York

Contents

Tables and Figures

Executive Summary

1.   INTRODUCTION BACKGROUND

In 2010 the National End of Life Care Programme (NEoLCP) published *Supporting People to Live and Die Well: a Framework for Social Care at the End of Life*. The aims of the Social Care Framework (SCF) reflect those of the End of Life Care Strategy (DH, 2008), that is to ensure individuals and their families have choice and autonomy at the end of life. The Social Care Framework offers an invitation to all key stakeholders to work with the programme to develop an understanding of how social care practice can best support people approaching the end of their lives, and build the necessary tools and resources to promote change. Following in a competitive tender, in October 2010 NEOLCP commissioned eight test site projects, each of which addressed a number of the 10 objectives of the Social Care Framework, with the aim of improving understanding of what works in practice, and how best to facilitate the implementation of the Social Care Framework.

The eight test site projects were:
* Lancashire County Council and Rossendale Hospice - Hospice at Home Personal Budgets Pilot
* Hull and Wakefield Primary Care Trusts - Modelling End of Life Care Pathways and Key Competencies
* Sue Ryder Care Leckhampton Court Hospice, Gloucester - Mentoring Workshops for Adult Care social workers and fieldwork support assessors
* Norfolk County Council and Norfolk NHS – Implementing an Integrated Palliative Care and End of Life Service in North Norfolk
* West Essex Community Health Services and partners – Integrated Health and Social Care Discharge Planning at End of Life
* Essex County Council and partners – Integrated Health and Social Care Operational Commissioning
* Guy's and St Thomas's Modernisation Initiative and partners - Exploring the Role of a Lead in end of life care in Social Work Teams in Lambeth and Southwark
* St Christopher's Hospice, London – End of Life Intervention Skills Consultation and Education.

In March 2011, researchers at the University of York were commissioned to evaluate the eight test site projects, and assess their overall:
* Relevance to the NEoLCP and the SCF
* Impact value in relation to the 10 key objectives of the SCF
* Relevance to health and social care interface
* Value for service users
* Value for money

The evaluation also considered: the types of skills that underpinned each test site, the challenges and barriers encountered, and the wider learning offered by the test sites. The evaluation was undertaken in three phases and involved collating existing data about each

of the sites, in- depth interviews with key informants and stakeholders, and examination of final reports and project documents.

2: PROJECT SUMMARIES

Summaries of the eight test site projects are presented in section 2 of the report. All the test site projects were designed to run for relatively short periods (between three to six months) and with relatively modest funds (between £10,300 and £35,000).

3: PROCESSES FOR UNDERTAKING THE PROJECTS

Despite problems with the procurement process and receipt of funds, projects appear to have been delivered on time (including those given extensions) and on budget. Projects appear mostly to have delivered their planned activities, although one project that had proposed the development of a financial model was unable to deliver the original project plan. Only one project was subject to a formal external evaluation, two projects conducted internal evaluations whilst the remainder collected data to demonstrate outputs and/ or gathered feedback from participants and services users (although at time of writing these results are yet to be published).

4: DELIVERING THE PROJECTS

The evaluation examined how far the test sites have had any impact on raising the profile of end of life care in their local area, on commissioning of services related to end of life care provision, on workforce development, on the end of life care pathway and on the environment of care. We also consider what the test sites could demonstrate regarding benefits to service users and others. Finally, we examined what local objectives had been achieved. It should also be noted that two of the test sites' initiatives were concerned with developing strategies and structures to aid and enhance the delivery of end of life care, and the full impact of these developments cannot yet to be demonstrated. Overall the test sites appeared to have great potential for improving end of life care, as evidenced by the impact on commissioning services, developing training and improving the end of life pathway.

Although only two test sites had raising the profile of end of life care as an explicit objective for their project, all projects did raise both the profile of end of life care and the role of social care. Four test sites aimed to have an impact on commissioning. We observed test sites taking on the issues around commissioning for community, hospice and domiciliary care. Test sites commented on the lack of cross-agency commissioning strategies and how the work from their projects would be contributing to their development. Two sites also commented on the input to contractual agreements with care providers ensuring that quality standards around end of life care were included.

Four test sites worked on developing the skills and knowledge of professionals working in end of life care. Two test sites developed and successfully ran workshops for social care staff, whilst a third identified the need for training in specific areas. A fourth developed training material on competencies for key workers. The role of palliative care champions and their training needs was identified and acknowledged, as was the need for joint training strategies for the delivery of end of life care.

Although it was not an explicit aim of any of the test sites, projects did have an impact on at least some stages of the end of life care pathway, for example in identifying the role of social care, and how it could contribute to improved quality of and more holistic care. Emphasising the message that end of life care is a social care responsibility and that social care workers have a role was seen as critical.

None of the test sites explicitly addressed environments of care; however, one project addressed the issue of the home environment recognising the importance of this for maintaining individuals in their own home at the end of life. At the time of the evaluation, there was little documented evidence on the direct benefits to service users, and some respondents commented that greater involvement from service users would have benefited projects. Where service users were involved, their apparent willingness to discuss end of life issues is reassuring.

All test sites set themselves local objectives, in part as a means of addressing the Social Care Framework objectives, but also as objectives in their own right, which were mostly met. Two sites explicitly addressed training and workforce development needs, whilst others sought to implement personal budgets (with only a small degree of success, but plenty of learning). One project sought to reduce the number of deaths in hospital by implementing a model of delivery of care; however, the reduction in hospital deaths was not documented, probably due to the timescales of the project

5:   DELIVERY AGAINST THE SOCIAL CARE FRAMEWORK OBJECTIVES

The Social Care Framework has 10 explicit objectives (see Chapter 1), and all the test site projects aimed to meet some of these objectives (see Table 5, Chapter 5). Some objectives were more commonly addressed (5 and 8), whilst objective 10 was not explicitly addressed by any test site, although three sites did collect information which could contribute towards an evidence base for good practice. All test sites did raise awareness of the role of social care (objective 1), although only two explicitly addressed this. Facilitating commissioning and embedding end of life care in commissioning (objectives 2 and 3) were only addressed by four sites. Progress was made towards meeting these objectives, although problems and challenges were also recognised, and for some the experiences and findings from the projects were contributing to the development of local cross-agency commissioning strategies. Strengthening the specialism of palliative care social work (objective 4) was only addressed by two test sites: one identified their crucial role in developing the workforce and the second in developing and supporting palliative care champions.

The promotion of understanding and best practice in holistic assessment (objective 5) was addressed successfully by five tests sites. Tests sites mostly achieved this objective by awareness-raising and education. The promotion of earlier end of life care planning (objective 6) was addressed by three test sites, although the involvement of social care earlier in the pathway was a theme throughout many projects. Training and education again supported the achievement of this objective as well as the recognition of the role of the domiciliary care worker. Only one test site explicitly address education and training of social care staff (objective 7), yet as can be seen from many sections in this report, all sites recognised the key role of education, and addressed this objective in numerous ways including workshops, awareness-raising, and the development of training strategies. The

creation of a supportive work environment for social care workers (objective 8) was addressed by six test sites, again in part by training, education and awareness-raising but also by clarifying their roles, and working in partnership with other agencies. Promoting supportive communities (objective 9) was addressed by two test sites, by engaging with a range of community services, which also contributed to awareness-raising. Gaps in services were identified and mechanisms for addressing these identified.

6:   KEY ENABLERS, CHALLENGES AND LESSONS

Enablers and keys to success were identified as:

- establishing (and building on existing) working relationships and having a commitment to improving care;
- engaging and working with key stakeholders;
- having the appropriate skills to deliver the project.

Barriers and challenges comprised:

- issues around the extent of project engagement, for example as councils and social care departments faced financial constraints and job losses;
- problems with the delivery of care packages, including the availability of resources, bureaucracy and the coordination of services;
- the delivery of personal budgets, including identifying those clients who would be suitable and developing both the skills for processing personal budgets and the understanding of end of life care ;
- information sharing and communication, particularly at the point of hospital discharge;
- reluctance to talk about end of life;
- lack of a shared understanding about what end of life care means, for many social care staff (including some senior managers) end of life care was understood as palliative care or care in the very last days of life, rather than as an holistic concept.

All test sites aimed, or hoped to secure funding, to continue their projects or build on their achievements through new and related projects. Examples included joint education strategies, the appointment of a joint discharge facilitator, the development of e-learning packages, and the development of a community volunteer scheme. Project teams recognised that there would always be staff turnover and resource constraints, therefore it was important to embed end of life care in strategies, action plans, training, and commissioning.

Test sites also indicated their willingness to disseminate findings and several had already participated in conferences, as well as undertaking local awareness-raising. All test sites also made recommendations for those wishing to take forward their findings and initiatives. All project teams believed that what they had done was replicable elsewhere, for example the workshops that had been developed could be run anywhere. Key findings were mostly in respect of partnerships, training and staff development, and continual awareness-raising, embedding end of life care in local strategies, the valuable roles of different professions such

as domiciliary care workers, social care workers and preventive services, and ensuring that there is effective signposting and information to enable people to make choices at end of life.

7.   KEY MESSAGES

Importantly a key message at the outset is that these are projects which any organisation, agency or locality could replicate.

Key messages are summarised under a number of themes:

- Roles with respect of end of life care
- Understanding of end of life care and end of life pathways
- Engaging stakeholders
- Ownership of end of life care strategies
- Training and supporting staff
- Funding mechanisms
- Communicating and sharing information
- Environments of care

Acknowledgements

This evaluation would not have been possible without the generous assistance of a number of individuals and organisations.

We are especially grateful to the Project Leads and all those from the eight test sites who generously gave up their time to be interviewed.

 We are also grateful to members of the National End of Life Care Programme which commissioned the evaluation and supported the evaluation team.

Section 1:   Introduction and Background

1.1   CONTEXT

In modern industrialised societies, sudden death is relatively rare. The majority of deaths occur following a prolonged period of chronic illness related to conditions such as cardiovascular disease, diabetes, cancer, dementia, neurological and respiratory disorders that usually constrains or limits individuals' activities and life styles until death (Murray et al, 2005; DOH, 2008; NEoLCP, 2010). End of life care is increasingly being recognised as a crucial policy and practice issue as government and policy makers reflect on the challenges presented by an ageing population. The Department of Health's End of Life Care Strategy (DH, 2008) was introduced in July 2008 building on the work of the National End of Life Care Programme[1,] and reflecting concerns about the need for improvement to end of life care services. The strategy and accompanying implementation programme are intended to change the culture and experience of dying and have a number of key aims. These include raising the profile of end of life care and promoting a change in attitudes to death and dying in society; improving commissioning, care planning, and the coordination of care. According to the End of Life Care Strategy, high quality end of life care should be available wherever the person chooses to be cared for, be that at home, in a care home, in hospital, in a hospice or elsewhere (DH, 2008).

A report by the National Audit Office (NAO) on end of life care found that the majority of people would prefer not to die in hospital, but a lack of NHS and social care support meant that many people do so when there is no clinical reason for them to be in hospital. The report found that co-ordination between health and social care services in relation to the planning, delivery and monitoring of end of life care was generally poor, and that few health professionals, and even fewer social care workers, had received any training around end of life care. The NAO report suggested that there was scope for more people to die in the place they wished and that this could be achieved through improved training of all health and social care staff in understanding and awareness of end of life care needs, and the extension of palliative care services for those that need them, regardless of their condition. Improved delivery of end of life services would require more effective commissioning and partnership working between the NHS, social services, and the voluntary sector (NAO, 2008).

The National End of Life Care Programme (NEoLCP) supports the implementation of the End of Life Care Strategy, by developing, supporting and sharing good practice, in collaboration with local and national stakeholders. Key issues include:

---

[1] For more information go to: www.endoflifecare.nhs.uk

- local profile raising regarding end of life care issues;
- strategic commissioning by commissioning bodies promoting understanding and use; of the End of Life Care Pathway[2];
- workforce development;
- environments of care[3].

1.2   THE SOCIAL CARE FRAMEWORK

As noted earlier, the NAO report (NAO, 2008) emphasised the need for better co-ordination of health and social care in need of life care and, in 2009, the NEoLCP appointed two social care leads. This was in recognition of the fact that the social care sector has a vital role to play in supporting people to live and die well, and that the strategy could not be implemented without the active engagement of and input from the social care sector.

In 2010, the NEoLCP published Supporting People to Live and Die Well: a Framework for Social Care at the End of Life[4]. The Social Care Framework was developed with the involvement of a group of senior professionals and other stakeholders within social care[5]. The main aims of the Social Care Framework reflect those of the End of Life Care Strategy and the NEoLCP, that is to ensure individuals and their families have choice and autonomy at the end of life. The Social Care Framework sets out how social care can support the development and enhancement of social care at the end of life but also emphasises the need for a robust evidence base to support the development of good social care practice in end of life care.

The primary purpose of the Social Care Framework is to provide a structure that facilitates and promotes:

- the mapping of social care provision;
- stimulation of new developments and initiatives;
- co-ordination of services, including health care and other care providers, for people at the end of life;
- clear direction for social care support at the end of life that is fully commensurate with the agenda for transforming social care services.

---

[2] For more information on the End of Life Care Pathway go to: www.endoflifecareforadults.nhs.uk/care-pathway

[3] For more information on environments of care go to

: www.kingsfund.org.uk/publications/ehe_care_environment.html

[4] Available at: http://www.endoflifecareforadults.nhs.uk/publications/supporting-people-to-live-and-die-well-a-framework

[5] A full list of members of the programme's Social Care Advisory Group can be found in the report, available at: http://www.endoflifecareforadults.nhs.uk/publications/supporting-people-to-live-and-die-well-a-framework

The Social Care Framework offers an invitation to all key stakeholders to work with the programme to develop an understanding of what works best in practice and build the necessary tools and resources to promote change. It sets out ten key objectives, as shown in box 1.1

Box 1.1   The ten key objectives of the Social Care Framework

1. identify and raise awareness of the role of social care in supporting people at the end of their life among the public, the social and health care workforce and its management;
2. facilitate commissioning and delivery of person-centred, integrated care;
3. embed end of life care within commissioning and inspection frameworks and standards for practice;
4. strengthen the specialism of palliative care social work;
5. promote understanding and best practice in holistic assessment of individuals, their carers and families at the end of life;
6. promote earlier end of life care planning that builds on an holistic understanding of wellbeing;
7. educate and train social care staff to deliver high quality end of life care;
8. create a supportive work environment that enables social care workers to maximise their contribution to quality end of life care;
9. promote supportive communities through engagement with a wide range of community services;
10. work jointly with research commissioners and funders to establish a robust evidence base for good practice in social care at the end of life.

1.3   DEVELOPING SOCIAL CARE PRACTICE: THE TEST SITE PROJECTS

In order to improve understanding of what works in practice, the NEoLCP issued an invitation to tender for test site projects to address one or more of the ten objectives of the Social Care Framework in August 2010. Fourteen proposals for test site initiatives were received and eight were selected against the following criteria:

- relevance to the NEoLCP and the Social Care Framework;
- clarity and feasibility of the proposal;
- impact value in relation to the key objectives of the Social Care Framework;
- relevance to the health and social care interface;
- evidence of skills necessary to undertake the work;
- value for service users;
- value for money.

The eight test sites commissioned in October 2010 were:

- Essex County Council and Essex Community Health Services and partners – Integrated Health and Social Care Operational Commissioning
- Guy's and St Thomas' Charity Modernisation Initiative and Lambeth and Southwark Councils – Exploring the Role of a Lead in Social Work Teams in Lambeth and Southwark
- Hull and Wakefield Primary Care Trusts and Partners - Modelling End of Life Care Pathways and Key Competencies

- Lancashire County Council and Rossendale Hospice - Hospice at Home Personal Budgets Pilot
- Norfolk County Council and Norfolk NHS – Implementing an Integrated Palliative Care and End of Life Service in North Norfolk
- St Christopher's Hospice, London – End of Life Intervention Skills Consultation and Education.
- Sue Ryder Care Leckhampton Court Hospice, Gloucester - Mentoring Workshops for Adult Care social workers and fieldwork support assessors
- West Essex Community Health Services, Essex County Council Social Care, Princess Alexandra Hospital NHS Trust, West Essex Primary Care Trust and St Clare's Hospice, West Essex Community Health Services, Essex County Council and partners – Integrated Health and Social Care Discharge Planning at End of Life

Summaries of the eight test sites are presented in Section 2. A matrix summarising which Social Care Framework objectives each test site sought to address is shown in Section 5.

1.4 THE EVALUATION OF THE TEST SITES

Overview

In March 2011 the Centre for Housing Policy and York Health Economics Consortium, at the University of York, were commissioned to undertake an evaluation of the eight test sites. The project was not intended to provide a detailed analysis of each test site project but rather set out to assess their:

- relevance to the NEoLCP and the Social Care Framework;
- impact value in relation to the ten key objectives of the Social Care Framework (detailed above);
- relevance to health and social care interface;
- value for service users;
- value for money.

In addition, the evaluation considered:

- whether the test sites offer replicable models for wider service development;
- the types of skills that have underpinned each test site and what implications this has for wider service development;
- challenges and barriers to implementation that have been encountered during the test phase;
- key learning points for wider dissemination.

Methods

The research began in April 2011 and the fieldwork was conducted in May and June.

The evaluation comprised three main phases, as outlined below.

Phase 1:   Base line data collection

The aim of the first phase of the project was to collate existing data about each of the test sites in order to understand how best to select and/or design appropriate evaluation measures. The initial bids made by the test sites to the NEoLCP were reviewed to ascertain the overall objectives of each test site and how these were to be achieved. In addition, structured interviews using a generic topic guide were conducted with key informants at each of the test sites to ascertain how far they had progressed to date, what had been achieved against the original objectives, what data had been collated and for what purposes, and what - if any – had been the barriers and constraints to the development of the projects. These initial interviews and the review of project documents informed the selection of interviewees and the development of research instruments for the second phase of the research.

Phase 2:   In-depth data collection from the test sites

In addition to the in-depth interviews conducted with the eight project leads, 40 individuals were interviewed either face to face or over the telephone. Interviewees included social workers, social work managers, social care managers, nurses, (hospital and community based), hospital based nurses, discharge facilitators, a domiciliary care manager, social care operational services managers, commissioners, service user representatives[6], palliative care social workers and lecturers. Towards the end of the evaluation test sites were able to provide the research team with the final reports on their projects.

Phase 3:   Production of project reports

The final report draws on project documentation, including project proposals, information on training courses and other events (for example, content, participants and aims and objectives), notes from project meetings, evaluations of specific project activities (for example, feedback on training sessions) and the projects' mid-term and final reports, as well as the interviews with respondents.

1.5   REPORT OUTLINE

The final report comprises five further sections. **Section Two** provides summaries of the eight test site projects. **Section Three** presents a commentary on the processes for undertaking projects. **Section Four** discusses the delivery reports the delivery of the projects. **Section Five** describes the delivery of the projects against their objectives. Finally **Section Six** considers the key enablers and barriers identified and consider the sustainability and transferability of the projects. **Section Seven** concludes with some key lessons from the evaluation.

In order to ensure anonymity, where direct quotes from respondents are used these are not attributed to a named individual or area. However, wherever possible, an indication is given of the individual's role in order to provide the reader with some context.

---

[6] Because of the tight timescale for completion of the evaluation, there was insufficient time for obtaining ethics approval to interview service users. Therefore we interviewed representatives of service users where possible.

Section 2: Project Summaries

2.1 INTRODUCTION

This section provides summaries of the eight set site projects including details of the test site area, the lead organisation, partner organisations, the project aims and the Social Care Framework objectives each site sought to address, as well as some of the project outputs. It should be noted that these were relatively small scale projects with a limited timescale. The test sites received funding ranging from £10,300 to 35,000, for projects designed to take six months to complete. Their purpose was to demonstrate relatively simple and innovative approaches to support the rollout and implementation of the Social Care Framework. They also were intended to have the potential for national dissemination as well as enhancing local end of care provision.

The test sites were geographically spread: two were located in the North of England, three in the East of England, one on the South West and two in London. Two of the projects were led by NHS Commissioners (NHS Wakefield and West Essex PCT), three by county councils (Essex, Lancashire, and Norfolk), two by charitable hospices (Sue Ryder Care and St Christopher's), and one by the Guy's and St Thomas' Charity's Modernisation Initiative. The projects normally comprised partnerships across health, social care and the voluntary sector, for example, one comprised a partnership between NHS Wakefield, NHS Hull, Wakefield Council and Hull Council, another was led by Guy's and St Thomas' Charity's Modernisation Initiative which worked in partnership with the London Boroughs of Lambeth and Southwark; the West Essex test site was led by West Essex Community Health Services in partnership with Essex County Council Social Care, the Princess Alexandra Hospital NHS Trust, West Essex Primary Care Trust and St Clare's Hospice; and the Essex test site project was led by Essex County Council in partnership with Essex County Council Social Care, Acute Hospital Trusts, Essex Community Health Services and Primary Care Trust Commissioners and Providers.

Throughout this report, test sites are referenced for brevity and simplicity by either their lead organisation or their locality.

Locality : Wakefield and Hull
Project Title
Development of key worker competencies for domiciliary care workers to support an integrated pathway for end of life care
Project Lead Organisation
NHS Wakefield District
Project partners
NHS Wakefield District, Wakefield District Council, NHS Hull, Hull City Council, Dove Hospice (Hull), GPs, HICA Home Care and Elm Tree Court Residential Home,
Project Aim
The aim is to change people's experience for the better and provide an evidence base that can be disseminated widely, by looking at the core competencies required for front-line staff in end of life care.
Project History
Hull City Council had been working with their local Cancer Network[7] and a range of partners, on implementing the Living Well person-centred tools[8].
Project Summary
The project built on previous work in the two health economies in Wakefield and Hull. The project compared and contrasted the detailed circumstances in the city of Hull and Wakefield District to develop common themes. In Wakefield the project tested the idea of a domiciliary care worker (DCW) as a key worker for end of life care as part of everyday practice, including a competency analysis. In Hull, the role of DCW as an advocate for people nearing the end of life in the primary care Gold Standard Framework[9] meeting was tested. People's stories were compiled through filming of key individuals across both localities. These were used as evidence for DCW competencies, and to develop training packages.
Social Care Framework Objectives
1. Identify and raise awareness of the role of social care in supporting people at the end of their life among the public, the social and health care workforce and its management
5. Promote understanding and best practice in holistic assessment of individuals, their carers and families at the end of life
6. Promote earlier end of life care planning that builds on an holistic understanding of wellbeing
8. Create a supportive work environment that enables social care workers to maximise their contribution to quality end of life care
Project Outputs
- The stories of people nearing the end of life were collected and summarised onto DVD for training purposes   - Social care staff trained in person centred and Living Well tools   - Key worker competencies developed for DCWs
Project support agencies
Bridgesfm (project management), Skills for Health (assessing DCW competencies), Helen Sanderson Associates (implementing Living Well Toolkit) and Storywise (undertaking filming).

---

[7] Cancer Networks are the organisational model for cancer services to implement the Cancer Plan. They also ensure that all commissioners and providers of cancer care, the voluntary sector and local authorities within the network work effectively together to deliver high quality care.

[8] The Living Well toolkit is a guide to help those at the end of life think about and record what is important to them and assist them to plan for the end of their life. It is available from

http://www.helensandersonassociates.co.uk/media/38837/livingwellweb-final.pdf

[9] For more information on the GSF go to: www.goldstandardsframework.org.uk/[9]

Locality: Gloucestershire
Project Title
Mentoring Workshops for Adult Care social workers and fieldwork support assessors
Project Lead Organisation
Sue Ryder Care
Project partners
Sue Ryder Care, Gloucestershire County Council Adult Care
Project Aim
The aim is to target the social care workers who are responsible for assessment and care management of people nearing the end of life and their carers, in order to build their skills in communication and reflection on the palliative care aspects of their roles.
Project History
The Project Lead and colleagues had been working on a 4-level social care model to complement the National Institute for Clinical Excellence (NICE) models for psychological and other holistic aspects of care. The project aimed in part to test the usefulness of this model in supporting generalist social work staff.
Project Summary
Workshops, utilising the four-level social care model, were delivered to social care front-line staff and managers over a three week period. The managers were engaged to gain their support for the project and workshops. The workshops were evaluated by the University of Nottingham.
Social Care Framework Objectives
1. Identify and raise awareness of the role of social care in supporting people at the end of their life among the public, the social and health care workforce and its management
4. Strengthen the specialism of palliative care social work
8. Create a supportive work environment that enables social care workers to maximise their contribution to quality end of life care
Project Activities and Outputs
• 3 – 6 meetings were planned for operational managers, with further planned as necessary. One of their bi-monthly meetings was attended and telephone discussions held. • Six workshops were planned and delivered, and 66 staff participated • The planned evaluation by the University of Nottingham was undertaken with 64 pre- and post- workshop questionnaires completed and analysed.
Project support agencies
An independent external consultant

Locality: Lancashire: Rossendale locality
Project Title
Hospital at home personal budgets pilot
Project Lead organisation
Lancashire County Council
Project partners
Lancashire County Council, Rossendale Hospice, Help Direct
Project Aim
The aim was to offer people receiving social care support, who access hospice services, an opportunity to plan their support through the use of personal budgets
Project History   - Rossendale Hospice had moved into a new building offering the opportunity for the development and extension of their services including Hospice and Home and Day Therapy   - Links had been made with Help Direct, a signposting organisation   - Lancashire County Council, implementing personal budgets, was committed to including end of life care within their personal budget processes.
Project Summary
Service users with palliative care needs accessing the Hospice at Home service were offered a personal budget service brokered by the Hospice at Home. A considerable amount of the project time was spent briefing and raising awareness with key stakeholders.
Social Care Framework Objectives
2. Facilitate commissioning and delivery of person-centred, integrated care
5. Promote understanding and best practice in holistic assessment of individuals, their carers and families at the end of life
6. Promote earlier end of life care planning that builds on an holistic understanding of wellbeing
Project Activities and Outputs   - Project processes including a project board were planned and implemented   - Briefing sessions for key stakeholders were planned and delivered to around 50 people, including staff at Rossendale Hospice, and social workers working with people nearing the end of life   - A support plan for accessing personal budgets has been prepared; three people took up these budgets, and three expressed an interest.   - Two people accessed Help Direct Services, and seven more are considering options.   - A Help Direct Clinic has been established at the Rossendale Hospice

Locality: North Norfolk
Project Title
The implementation of an integrated palliative care service in North Norfolk
Project Lead Organisation
Norfolk County Council
Project Partners
Norfolk County Council Community Services – Adult Social Care, NHS Norfolk, primary care staff and three GP practices, North Norfolk Integrated Care Organisations, the Norfolk Hospice, three domiciliary care agencies
Project Aim
The overall aim was to identify, share and develop good practice around commissioning and delivery of person centred integrated care, access to community support services, and development of professional expertise in supporting palliative and end of life care in North Norfolk.
Project History
Norfolk County Councils Adult Social Care jointly commissioned with NHS Norfolk and NHS Great Yarmouth and Waveney the Marie Curie Delivering Choice Programme (MCDCP) Toolkit[10]. The first two phases (understanding the current state of services, and designing service models) had been completed. The project built on and complemented this previous work undertaken on the Marie Curie Delivering Choice Programme. North Norfolk, where the project was undertaken, was one of their Integrated Care Organisation test sites.
Project Summary
An investigative inquiry approach was adopted across the county and within the locality. Interviews and workshops were held, surveys were completed, and case studies were collected. The community support available to people with palliative and end of life needs in North Norfolk was mapped based on the MCDCP toolkit. .
Social Care Framework Objectives
2. Facilitate commissioning and delivery of person-centred, integrated care
4. Strengthen the specialism of palliative care social work
9. Promote supportive communities through engagement with a wide range of community services
Project Activities and Outputs
50 interviews held with a range of individuals including those working for Norfolk County Council, partners (including primary care) and stakeholders.   - CareFirst data (the Norfolk County Council social care database) was analysed identifying three clients accessing personal budgets.   - A survey based on End of Life competencies was completed by 105 people working in adult social care and 60 working across the community and primary care.   10 case studies were collected.   - The results from the surveys and the case studies were discussed in multi-disciplinary workshops.   - Recommendations emerged in respect of commissioning of domiciliary care, the delivery of person centred integrated care and the strengthening of the specialism of palliative care.   - Examples of excellent practice were identified, but practical support was not easy to access and work is progressing on a *Citizens Portal.*   - Findings are being shared with key stakeholders and agencies

[10] For more information on the Marie Curie Delivering Choice Programme and the Toolkit, go to:
http://www.mariecurie.org.uk/en-gb/healthcare-professionals/innovation/Delivering-Choice-Programme/

Locality: West Essex

Project Title
The Delivery of Integrated Health and Social Care Community Discharge Planning at the Princess Alexandra Hospital Harlow for Individuals with a Life Limiting Diagnosis who are in the Last 6 – 12 months of Life

Project Lead Organisation
West Essex Primary Care Trust Provider Service

Project Partners
Essex County Council Social Care, the Princess Alexandra Hospital NHS Trust, West Essex Primary Care Trust, St Clare's Hospice

Project Aims
To aim of the project was to improve the quality and efficiency of discharge facilitation for individuals with a life limiting illness in the last 12 months of their life, admitted for acute care through an integrated approach through discharge coordination.

Project History
Partner organisations in West Essex had been working to improve the integrated management of end of life care but it was recognised that more had to be done. In particular, the effective hospital discharge of individuals admitted with a life limiting illness needed to be improved by integrating health and social care practice.

Project Summary
A discharge facilitator was appointed to work jointly with social care. Given the problems already identified in the discharge process, the appointment of a joint discharge facilitator to work operationally across professional boundaries was felt to be the most effective way to establish a new model of working.

Social Care Framework Objectives
2. Facilitate commissioning and delivery of person-centred, integrated care
3. Embed end of life care within commissioning and inspection frameworks and standards for practice
5. Promote understanding and best practice in holistic assessment of individuals, their carers and families at the end of life
8. Create a supportive work environment that enables social care workers to maximise their contribution to quality end of life care
9. Promote supportive communities through engagement with a wide range of community services

Project Activities and Outputs
Following initial training (e.g. various IT systems) the discharge facilitator worked to raise awareness of end of life care and preferred priorities for care, the role of the joint discharge facilitator; and, actively encouraged the referral of people in the target group from the hospital and the community. The discharge facilitator also worked with agencies to expedite discharges and, in some cases, accompanied people home when they were very close to death. The project received 68 appropriate referrals (7.5 per week for the duration of the project), most of whom were discharged within 48 hours. The vast majority (nearly 90%) were discharged to their preferred place of care.

Project support agencies
The project worked with and was supported by a range of statutory and non-statutory agencies and organisations and individuals including: hospital and community medical and nursing staff; hospital social workers; the Continuing Health Care team; domiciliary care managers; transport services; Marie Curie and Macmillan nurses; palliative care teams; discharge liaison nurses; hospices; care homes; carers and relatives; and, end of life care facilitators.

Locality: Essex
Project Title
The Delivery of Integrated Health and Social Care Operational Commissioning and Delivery Plan Pan Essex
Project Lead Organisation
Essex County Council
Note: It was intended to form partnerships with health services across Essex (acute hospitals, community health services and mental health trusts) and hospices and other care providers. However, it proved difficult to fully engage health services at a time when these services were undergoing radical reorganisation. It was therefore decided to focus on developing an End of Life Care Strategy for Essex County Council.
Project partners
Essex County Council Social Care, Acute Hospital Trusts, Essex Community Health Services and Primary Care Trust Commissioners and Providers.,
Project Aims
To facilitate a streamlined, coordinated health and social care pathway which is based on competency rather than professional identity and promotes timely discharge with robust access to a range of high quality individualised care and information services, planned with the person nearing the end of life, and family, crossing where required, organisational boundaries.
Project History
Planning had begun around Quality, Innovation, Productivity and Prevention (QIPP) and New Ways of Working in Essex[11] and it seemed an opportune time to start coordinating Essex County Council's end of life care strategy.
Project Summary
The project manager worked with a wide range of organisations and agencies in the statutory and private, voluntary and independent sectors (some of which are detailed below) to promote, and disseminate knowledge, about end of life care and to ensure that end of life care is embedded in commissioning processes, strategies and delivery plans.
Social Care Framework Objectives
2. Facilitate commissioning and delivery of person-centred, integrated care
3. Embed end of life care within commissioning and inspection frameworks and standards for practice
5. Promote understanding and best practice in holistic assessment of individuals, their carers and families at the end of life
8. Create a supportive work environment that enables social care workers to maximise their contribution to quality end of life care
9. Promote supportive communities through engagement with a wide range of community services
Project Activities and Outputs
There were numerous project activities and outputs e.g. the creation of a network of 40 end of life care champions; the commissioning of end of life care training; the introduction of mandatory end of life care training for Essex CC staff and the establishment of a workforce training pathway; work with the community engagement team to develop guidance on end of life care for travellers; and, the development of a care pathway which incorporates end of life care with a local prison. The project has also produced an End of Life Care Delivery Plan and Action Plan.
Project support agencies
The project worked with a wide range of organisations including: Acute hospital trusts, Essex Community Health Services; Primary Care Trust commissioners and providers; QIPP plan managers; mental health trusts; hospices; domiciliary and residential care providers; and the prison service.

[11] New Ways of Working is a programme across Essex launched by Essex County Council aimed at modernising services whilst generating financial savings.

Locality: Lambeth and Southwark
Project Title
Exploring the Role of Leads in end of Life Care in Social Work Teams in Lambeth and Southwark
Project Lead Organisation
Guy's and St Thomas' Charity Modernisation Initiative End of Life Care Programme,
Project Partners
Community, Disability and Older Persons Service, Lambeth Council and Older People's Services, Southwark Council.
Project Aims
• To identify end of life care leads in each social care team • To identify training needs in end of life care for those leads • To clarify and test the role of an end of life lead within social care teams in Lambeth and Southwark • To cross-fertilise learning in end of life care through a facilitated learning network of district nurse leads and social care leads in end of life care • With this network of end of life leads in the social care teams to clarify the role of older/adult social care team members in the provision of end of life care • To increase multi-disciplinary information sharing.
Project History
The project lead has already been working with senior managers in adult social services in the two boroughs as part of the Modernisation Initiative (MI).
Project Summary
The project builds on the work of the Modernisation Initiative (MI), established in 2008 to examine every aspect of end of life care. The social care test site initiative provided the opportunity to develop the end of life care lead role, to identify training and support needs and to meet these needs through the training provided by St Christopher's and a range of sessions and activities arranged and/or delivered by the project facilitator.
Social Care Framework Objectives
8. Create a supportive work environment that enables social care workers to maximise their contributions to quality end of life care.
Project Activities and Outputs
• 16 social workers and social care staff End of Life Care Leads identified across older people and adult services and in a variety of setting including hospital and the community. • Identification of training needs (which were shared with the St Christopher's Hospice team which provided training) • Shared learning and networking events with a range of end of life care providers • Development of a social care End of Life Care Lead role description which also details the roles and responsibilities of managers in supporting this role.
Project support agencies
The project worked closely with St Christopher's Hospice which also ran a test site project involving the two boroughs' social care teams. The project also worked with a wide range of agencies and organisations including the Modernisation Initiative; Community Link Nurses; palliative care services; representatives from residential care services; service users; peer support volunteers from Facing the Future Service (part of the Alzheimer's Society); and, key stakeholders from the private, voluntary and independent sector.

Locality: Lambeth and Southwark
Project Title
End of Life Intervention Skills Consultation and Education
Project Lead Organisation
St Christopher's Hospice
Project Partners
None, although the project worked closely with the agencies and organisations detailed below.
Project Aims
To work towards meeting the learning and support needs of older adults social care staff in the London Boroughs of Lambeth and Southwark in term of their delivery of high quality end of life care, as identified by them.
Project History
St Christopher's Hospice has extensive experience of providing training for all professionals engaged in palliative care, including social work and social care staff and had wanted to do more training with statutory social work services for some time and to extend their work to the boroughs of Lambeth and Southwark.
Project Summary
The project worked collaboratively with the Guy's and St Thomas' team and the heads of adult services in the two boroughs to identify end of life care leads and their training needs. Although the St Christopher's team had originally proposed to focus on social work end of life care leads, it became evident that managers (including senior managers) and social work teams would also benefit from training. The project also worked with end of life care leads from a wider range of social care settings than initially proposed e.g. sheltered housing, hospitals and Care Line.
Social Care Framework Objectives
5. Promote understanding and best practice in holistic assessment at the end of life
6. Promote early engagement with end of life care planning that builds on an holistic understanding of wellbeing
7. Educate and train social care staff to deliver high quality end of life care
8. Create a supportive work environment that enables social care workers to maximise their contribution to quality end of life care.
Project Activities and Outputs
Training, consultation and support for three groups: • Managers (senior and service managers) • Other members of these social care teams (half-day sessions and 12 team visits) • End of life care leads (3 events over 2.5 days) The project also offered leads: • Free places on training courses run as part of St Christopher's programme of multi-disciplinary training • Access to St Christopher's library and the support of the librarian • A help line for support on end of life issues. The project workers also spoke to service users at Lambeth Carers' Forum and Southwark Sheltered Housing Forum following requests from a senior manager and an end of life care lead.
Project support agencies
Guy's and St Thomas' Charity Modernisation Initiative; Community, Disability and Older Persons Service, Lambeth Council; and, Older People's Services, Southwark Council. St Christopher staff including nurses, social workers and librarian, Lambeth Carers' Forum and Southwark Sheltered Housing Forum.

Section 3:   Processes for undertaking the projects

3.1   INTRODUCTION

As noted in the introduction, the NEoLCP invited proposals for projects which would be test sites to support the rollout and implementation of the Social Care Framework. Bids could come from any branch of social care practice and services including education and training. Proposals were required to identify a project lead who could be employed in a Local Authority, the NHS, an independent provider or a voluntary organisation. Although the University of York research team was not party to the decision-making around selection of successful proposals, in this section we have commented on the proposals. We also examine processes for receipt of funding and management of projects.

3.2   CLARITY OF PROJECTS

The proposals for test sites submitted to the NEoLCP included information on aims and objectives and proposed programme of work. Of particular interest to this evaluation are the clarity of a proposal (in particular the planned activities and outcomes), and the realism of a proposal. Projects were chosen which had clear objectives and proposed work which the NEoLCP wished to support, or presented 'a kernel of a good idea', even if this was not always fully articulated in the actual proposal.

We recognise that the amount of funding available for each test site was not very large, with a short timescale for project completion and hence we would expect the proposals to be commensurate in their length and detail with this funding. Six of the proposals were quite clear in their aims, objectives and proposed activities although two (Essex and Norfolk) made it clear that the exact approach or methodology would depend on initial fact finding activities and the support needs identified in the early stages of the project. The simplest project with the lowest budget (Gloucestershire), was very clear in respect of the proposed work, and had a very clear set of activities, which were delivered. *"We knew it would be small with limited time, so we wanted a targeted project".*

Two proposals were a little unclear as to their proposed work, however, although the description of proposed work and activities were imprecise, the resulting projects were focused and delivered a wide range of activities (which may not have been activities originally envisaged).

3.3   PROJECT MANAGEMENT

Proposals to the NEoLCP were required to indicate the management arrangements for the projects. Project management comprises a number of factors including the skills of project team (especially that of the project lead); the processes of project management including project boards, and the buy-in of partners such that they are willing and can deliver their

planned activities. One of the criteria adopted by the NEoLCP to judge the quality of the proposals was the skills of the project team.   The projects were of relatively low value (between £10,300 and £35,000) and of short duration; therefore project management arrangements needed to be fit for purpose but not too onerous. Key to the achievement of the project activities was the buy-in from the various organisations involved. Most projects had multiple partners, and indeed a key objective for the funding of these test sites was to bring together health and social care organisations.

Not all of the proposals contained detailed information about the project management arrangements. For example, the Essex County Council proposal simply stated that the post holder responsible for delivering the project would report to the Adult Social Care Board. The main responsibility for project management normally lay with the project lead. The Norfolk project appointed a dedicated project lead for the duration of the project, and the Wakefield and Hull project lead was an external consultant who had assisted in developing the funding bid Other projects utilised existing staff, who undertook the project management role alongside their usual job for the duration of the test site project. Three projects also used external support for their projects: The Gloucestershire project employed a consultant as an 'external supervisor'. The Guy's and St Thomas' project employed an experienced facilitator with a social care background to engage participants, organise activities and deliver training. The West Essex project appointed a discharge facilitator to undertake the project under the management of the project lead and with support from project partners.

Most of the test site projects were overseen, supported and advised by various steering groups or advisory boards. From the interviews and reviews of local documents, it was clear that there were a variety of local mostly cross agency groups and boards involved in palliative and end of life care. The Norfolk proposal described how the project lead would be jointly managed and supervised by the Adult Social Care and NHS Commissioning Managers for long term conditions, and the project would also report to their Adult Partnership Board. The Lancashire project described their relationship to their local Palliative Care Partnership Board and the Practice Based Commissioning Board. The West Essex project explained that their End of Life Care Steering Group would have overview of the project, with a time limited sub group comprising representatives from a range of organisations including community health services, the PCT, GPs, a local hospice and a user representative, carrying out the project board function. The St Christopher's project was advised by a steering group comprising the project lead and a number of senior representatives from the lead organisation and partner organisations.

We have no evidence that these varying arrangements had a differential impact on the success of the projects, although interviewees occasionally did comment on the valuable input of these agencies (or conversely their lack of support) and the degree of involvement of steering groups and advisory groups was not always clear. What did matter was that the agencies supported the projects in whatever way was appropriate and stakeholders did comment on the perceived value of their project management arrangements, for example:

> *Organisations were at different starting points and went down different paths.*
> *So we didn't have much of a relationship except at project meetings when we*

---

shared what each was doing. But when we came together as a project team, there was good support from both sides, and despite doing different things, we shared experiences and helped each other. (Assistant Head of Services, Social Care and Housing)

A number of respondents remarked that the project would not have succeeded without the support of their steering and advisory groups. For example, one project lead believed it was particularly important to have the support of representatives of medical professionals.

The other key person was […] who was so enthusiastic in spreading the word in the hospital. Having a medic on board still makes such a difference (Project lead)

However, we were of the view that the variability of the project governance processes in part reflected the complexity of the local commissioning and management arrangements for end of life care, as well as the partners involved. Such complexity may in itself impede progress with developing end of life care at a local level, especially when considering the complex communications required.

Project management processes also varied. Two projects (Norfolk and Wakefield and Hull) had produced project initiation documents (PIDSs) which they shared with the research team along with other internal management documents such as budget management plans, internal contracts and letters of agreement, action and delivery plans. The research team was also supplied with records of meetings with project partners and other key stakeholders, and of project related events and activities.

3.4   USE OF FUNDS

Project teams appeared to have mostly spent the funds according to the expected costs given in their proposals. Funds were spent on staff costs and activities, such as running workshops, and external support and project management. For example, the Wakefield and Hull project, spent 33 per cent of their funds on the project manager (from an external organisation), the Norfolk project spent all of their funds on the project manager and administrative support (who were both employed by the County Council on a short term basis), whilst the Gloucestershire project used 50 per cent of the funds to cover the project lead's normal role, whilst she worked on the project as lead and co-facilitator of the workshops. For the Lancashire project, the cost of the project lead was covered by the local authority and the funding was used to cover the costs of project related activities.

Some project leads, including those at the Lancashire, Wakefield and Hull, and St Christopher's test sites, told us that the full budget allocation had not been spent, but that any under spends would be used to continue the work of the project, for example, to cover the costs of further training.

3.5   INTERNAL EVALUATIONS

Proposals to the NEoLCP were required to include information about how the test site teams were going to monitor and evaluate their projects. Two projects conducted internal evaluations.

The Gloucestershire project, which focused on delivering training workshops to social care staff, worked with a University to evaluate the impact of these workshops using a tool that they had developed for evaluating the impact of workshops on end of life care that they had delivered and which was modified for the project. Participants completed a questionnaire before and after the workshops examining confidence and knowledge in respect of end of life care. The project proposal for Norfolk indicated that information that would be recorded and against which outputs and outcomes would be measured during the life of their project. For this project, performance against some of these outcomes was recorded in their final report but there was insufficient time to analyse the data in depth.

The remaining projects did not conduct formal internal evaluations but most had reviewed their progress or conducted some form of monitoring and evaluation exercise. For example, the St Christopher project evaluated every activity and training session and used the feedback to refine and amend the content and delivery of training sessions and activities whilst the Guy's and St Thomas' Charity project asked all participants to provide feedback on their experience of the project at the end of the initiative. The West Essex project collected a substantial amount of monitoring data on sources of referral, diagnosis, age profile of service users, preferred priorities of care, the number of successful end of life hospital discharges achieved and the time taken from referral to discharge. This project also planned to collect feedback from service users and their families. The Wakefield and Hull project collected information from stakeholders and participants, and evidence collected on the competencies of domiciliary care workers was externally reviewed.

3.6   SUMMARY AND DISCUSSION OF FINDINGS

We cannot comment on the process for selection of successful proposals for funding, except to note that there was variability in their clarity and adherence to criteria for selection. The projects mostly appear to have delivered their planned activities, although one was unable to use their financial model as planned and another was unable to fully engage health services at a time when these services were undergoing radical reorganisation. Only one project was subject to a formal external evaluation, others collected data to demonstrate outputs and/or gathered feedback from participants and service users. Two project leads reported that their project was too small to do anything other than an informal evaluation but results had been put into their final reports.

A key finding, however, was that despite the short timescale and the limited funding available all projects produced valuable outputs, which is testimony to the dedication of the project leads and the willingness of the project teams and their partners to embark on these challenging initiatives, in times of change and financial and workforce constraints.

Section 4:   Delivering the Projects

4.1   INTRODUCTION

This section focuses on the achievements, outcomes and impact of the test sites. The themes under which we have discussed our findings reflect those required by the NEoLCP. We examine which and how far test sites have had any impact on raising the profile of end of life care in their local area; on commissioning of services to deliver and support end of life care; on workforce development; on the end of life care pathway; and, on the environment of care. We also consider the benefits to service users and others. Finally, we examine how far they have achieved their local objectives. However, it should also be noted that two of the test site initiatives (Norfolk and Essex) were concerned with developing strategies and structures to aid and enhance the delivery of end of life care, and the full impact of these developments are yet to be demonstrated.

4.2   RAISING THE PROFILE OF END OF LIFE CARE IN THE LOCAL AREA

One objective of the NEoLCP is to raise the local profile of end of life care issues. Similarly one of the objectives of the Social Care Framework is to identify and raise awareness of the role of social care in supporting people at the end of life. Only two of the eight test site projects (Wakefield and Hull, and Gloucestershire) had awareness-raising as a specific objective in their original proposal but it was clear that all projects had raised both the profile of end of life care and the role of social care to a greater or lesser degree. A number of respondents explained there had been some recognition of the importance of, and interest in, end of life care within their organisation or area, for example, within adult social care services, local authorities and Primary Care Trusts previously. The test site initiative had provided the opportunity to further raise awareness of the issues and disseminate the importance and relevance of end of life care far more widely both within and without their organisations through a wide range of activities and interventions.

> *"It has raised the profile a lot. I think that it was something that had been floated but the project put the meat on the bones and people now have more understanding of their role and how that fits…and that has filtered down to the coal face through training etc…now people are recognising what needs to be done and who to go to [for information]." (Social care representative)*

> *"One of the really clear impacts of the project is that people are talking about it [end of life care]…a year ago there weren't a lot of people talking about end of life care in their day to day work but now they are…it isn't just about learning – it's about getting end of life as part of the everyday dialogue so when we go through anything we do what you find now is people saying 'and don't forget the dementia strategy, don't forget end of life – so it's being able to embed that…it is high profile…"(Operational manager, social services)*

> *"The project has been a real success. We have had good engagement and everyone will receive a copy of the report. The profile of end of life care has been raised and we have identified training issues." (Project lead)*

Raising the profile of end of life care and the role of social care was achieved in a number of different ways, for example, through training including workshops for managers in adult social care (see below); the use of e bulletins to publicise end of life care and provide links to learning resources; training and other relevant information; the creation of end of life leads or champions in adult social care; through meetings with a wide range of stakeholders including health services, GPs, social services, the prison service, commissioners, domiciliary and residential care providers from the private, voluntary and independent sector; and by attending meetings of various working groups and forums working with diverse client groups (including travellers in one area).

> *"…we have also set up some time to meet with the prison health service to make sure that end of life is considered right through people's prison sentences and not just for the prisoner – but also trying to work with the prison for them to consider whether a loved one, relative, friend etc. has some end of life needs and how the prison could support them with that… And actually what was really good is that it is the first time that the prison has thought about linking in with [local authority] for a, full community care assessment and b, thinking about end of life care…" (Operational services manager, social services)*

One test site (Wakefield and Hull) produced a DVD about people nearing the end of life which not only fulfilled project objectives for identifying competencies, but also contributed to raising awareness about the experiences of people (indeed their final report was entitled *Real Stories: Real Insight*). Test sites also provided information about plans for dissemination of learning and outputs from their projects following completion of the projects. These were envisaged, *inter alia,* as contributing to raising awareness of end of life care. Examples included running a seminar and becoming more involved with local training initiatives on end of life care.

4.3   IMPACT ON COMMISSIONING

Four of the test sites (Essex, Lancashire, Wakefield and Hull, and West Essex) aimed to have a direct impact on the commissioning of services related to end of life care provision, having as one of their Social Care Framework objectives *the facilitation of commissioning and delivery of person-centred integrated care,* whilst two projects (Essex and West Essex) aimed to *embed end of life care within commissioning and inspection frameworks and standards for practice.* In one test site area, Essex, new services had been, or were about to be commissioned as a result of the project, for example end of life care training for all social care staff.

In the Lancashire test site, the County Council's Social Services department commissioned the Hospice at Home service (which was part of the local hospice's suite of services). The

project lead for this test site was also the Social Service's lead commissioner. Therefore, for this project, commissioning services was a crucial part of the project. This was further reinforced by the recognition of the important role played by the Help Direct signposting services (also commissioned by the County Council).

> *"In the project, we recognise that some people are getting social care services and some continuing health services, yet there is no single place that captures all of this, and certainly from a Social Care perspective, that there are other services involved with that person. A lot of what we have been doing is to reflect the 'wholeness' of these services." (Project lead)*

On their achievement of the Social Care Framework on commissioning, the project lead commented:

> *"[we ensure that] what's commissioned from the hospice meets person centred integrated care criteria. But, looking at wider commissioning, e.g. for all services to be delivering the same standards of care, there's a lot of work to be done here. It's about how we commission integrated end of life care." (Project lead)*

One of the objectives of the project in Norfolk was facilitating commissioning and delivery of person centred care. Two commissioning managers were involved in the project, from the perspective of commissioning for long term conditions and older people and the commissioning for the integrated health and social care team, as was the NHS commissioning lead for end of life and palliative care. The project also undertook a review of the commissioning of domiciliary care provision. The project team recognised that collaborative working with GP commissioners and integrated care organisations would facilitate improved end of life care and would inform future commissioning. The intention was that an integrated end of life model would offer commissioners a framework for the delivery of locally based end of life care. A finding of the project was that commissioning was problematic due to the rurality of the local area, limited numbers of care agencies and difficulties in recruiting staff for domiciliary care provision. This resulted in inconsistent support for people with palliative and end of life care needs and inappropriate referrals to the Social Services intensive person-centred Home Support services, emergency services, and rapid response teams. The project team made recommendations to address these problems for commissioning.

Three test sites, Essex, St Christopher's and Guy's and St Thomas', reported that end of life care was now embedded in contractual agreements with providers of services such as domiciliary and residential care. The Essex test site had disseminated the NEoLCP *Route to Success*[12] publications on achieving quality in end of life care, to inform providers of the standards expected in domiciliary care, care homes and services for people with learning disabilities. Southwark council, as a result of the St Christopher's and Guy's and St Thomas

---

[12] Available at: http://www.endoflifecareforadults.nhs.uk/publications

projects, was ensuring that contractors recognised the need to address end of life care issues by including this requirement in contracts.

> *…what we have also done is looked at the residential and domiciliary contracts that we have with providers which did not have reference specifically to end of life care and to all the quality and standards we required from them – that has now changed and we have amended the contracts so that there are 10 key points around the provision of end of life care and what is required of them" (Project lead)*

Whilst some test site areas, such as Essex, had contributed to the development of more strategic end of life commissioning, other localities, had no strategic end of life commissioning plans. A respondent from one of these test sites commented:

> *" For all sorts of reasons we don't have a strategic approach to commissioning, and certainly don't have an integrated approach re end of life care." (Project Lead)*

However, positively, this project was seen to be contributing to the strategic discussions, and outputs from the project would be featuring in the renewal of the project plan for end of life care within social care. The project (along with another of the test sites, which had been contacted by the project lead) had also informed a review of the role of palliative care social work. For this locality, the palliative care workers were funded from a variety of sources; one was funded by the PCT, another by a hospice, and a third by another source. This was not seen as ideal.

Findings from the projects indicate that positive changes to commissioning for those at end of life will take time. We have noted elsewhere the complex nature of the boards, bodies and organisations that have the strategic overview, commission and provide end of life care. A fundamental question must be: who takes responsibility for the strategic commissioning of end of life care, and how to ensure the involvement of social care? As a key stakeholder in the Wakefield and Hull project commented:

> *"If we are to work towards more people having the confidence to choose home as their preferred place of death, we will need to think very differently about the services we commission and how they are provided" (previously a commissioner)*

4.4   IMPACT ON WORKFORCE DEVELOPMENT

Only one project, the St Christopher's Hospice project had the specific objective of *educating and training social care staff to deliver high quality end of life care*, although four further projects specifically worked to develop the skills and knowledge of professionals working in end of life care in different ways. It should be noted, however, that all projects in some way educated social care staff.

The Gloucestershire project, building on the 4-level model of social care[13], ran a series of workshops aimed at encouraging specialist palliative care social workers, who were involved in care management or assessment, to reflect on and pro-actively develop their role. Sixty six people attended the workshops, although there were differences in the take up of training across localities, in part as a result of the localities varying in size, and the perceived differences in the level of commitment of the locality managers. Interestingly, the project lead during the planning of the workshops became aware of generic training for health and social care staff which was run by the End of Life Care facilitator working for the local PCT; although it appeared that none of the workshop attendees were aware of or had received any training from this source. This is a key finding, as it is crucial that agencies share knowledge and information about available training and information across their localities.

Although the Norfolk project did not explicitly provide training as a project activity, during workshops run during the project, the need for more training on tools on end of life tools, for example the Gold Standards Framework[14] (GSF) was identified. Their staff survey revealed that very few social care staff had attended GSF training, and hence their level of confidence in applying the framework and associated end of life tools was low. On the other hand, clinically trained nurses and staff working in nursing homes and some domiciliary agencies had attended such training and showed more confidence. Feedback from their survey included: *"I feel that all workers require on-going training in areas alongside medical staff as there does appear to be a gap between social and medical staff."* Palliative care champions were also seen to need access to and support from specialist palliative and end of life training. One recommendation from the project was the need for a joint health and social care training strategy: this is another key finding from the evaluation.

The Wakefield and Hull project focused on the development and identification of key worker competencies, working with a member of Skills for Health who mapped common core end of life care competencies from the filming of people's stories. This person identified where competencies were being delivered and then mapped these against national occupational standards. Before this project, the Director from Skills for Health had worked on the end of life care development pathway for the North of England developing the common core competencies. Out of the 48 competencies, 42 were being delivered and it was felt that:

> *…social care workers were much better at delivering competencies than was the NHS. Clinical solutions were offered from the NHS, but for people on the end of life care pathway, they were not appropriate as they missed the holistic approach and did not display end of life care competencies (Training and Education External Expert)*

As a by-product of the filming of people's stories, which were used to identify the competencies, a shortened DVD will be made available for e-learning purposes. At the time

---

[13] See Hearn F et al (2008). Re-emphasising the social side: a new model of care. European Journal of Palliative Care, 15, 6 pp276-278

[14] For more information go to: http://www.goldstandardsframework.org.uk/

of interviewing and writing up the test sites evaluation, this product was in the planning stages. Under spending from the project contingency was available to develop these training materials.

Positive recommendations in respect of training needs emerged from projects. For example in the Gloucestershire project which ran the series of workshops, links were made with others working in training and the Project Lead has been invited to a meeting on end of life care training for the county, in part to update members on the outcomes from the project. Because of the positive feedback from the workshops, the project lead is attempting to find funding to continue the workshops focusing on mentoring. A concern was the sustainability of future training as, to support roll out, they would need to train the potential trainers

The Norfolk project had recognised the need to create a joint health and social care strategy and training plan for enhancing palliative and end of life expertise, and a recommendation was made that training should be delivered in localities to multi-disciplinary audiences, in small chunks, embedded in meetings and workshops, and backed by access to e-learning. Essex had started to develop a 'training pathway' for its workforce. This comprised three elements, basic, intermediate and expert. The basic training, which is based on eight e learning modules, will give staff a basic understanding of the Social Care Framework objectives and their role in relation to end of life care. The basic training is now mandatory for all members of staff, which is seen to be a major achievement.

> *"...we have mandatory e learning …we have the end of life strategy as part of our appraisal system now which is brilliant so we have clear smart measurable outcomes that we expect people to comply with and develop and work with the end of life care strategy in their work with service users…and that goes right through the organisation – from my level right down to the frontline staff – so it has impacted on what we do." (Manager, social services)*

This test site area was in the process of assessing specific training needs and commissioning training from local hospices and other providers for the more advanced courses. This area was also planning to assess the training needs of workers in the Private Voluntary and Independent (PVI) sector through their Providers' Consortium, (which comprises 840 domiciliary and residential care providers) and to offer training on end of life care as required.

> *"…the senior managers are going to bring me the training requirements of their relevant staff in the different localities across [area] and we are hoping that we will get a lot of end of life care need – training needs – from that and then we can target those people for training…And then obviously if we have more then we can commission more training" (Manager, social services)*

> *"We are actually going to commission with a local hospice …who are going to provide some taster or awareness sessions – two day sessions and then eight day sessions – and then we are going to commission another hospice to deliver their bespoke Connected course which is their high level*

*communication course for the end of life and we are going to open it up to the
PVI sector [private, voluntary and independent sector] as well so it's our own
internal staff and the PVI staff…" (Manager, social services)*

Three of the test site areas, Guy's and St Thomas', Essex and Norfolk, had identified end of
life care leads or 'champions' who would help raise awareness of end of life care and
disseminate knowledge to their colleagues, professionals and service users and their
families. These end of life care leads described how they had benefited from the projects
with which they had been involved, for example:

> *"…we talked about dementia and the impact on family members as well as
> the service user, so we talked about how to support someone with
> dementia...and also the Advance Care Planning – that was good, to think with
> the person and the family what they might want before it gets too late for them
> to express what they want…what their wishes are… despite being on the
> course I still find it a difficult topic to initiate really – but doing the course –
> even though it is still difficult and uncomfortable – you know that it is
> essential, important and you have to find a way of talking through it – to get
> people talking about it." (End of life care lead)*

> *"It certainly has had an impact on me – I am more knowledgeable and
> confident – end of life care is something social workers are not unfamiliar with
> because we deal with it on a day to day basis but it is nice to have had the
> training and guidance that we can refer back to so it certainly has helped me
> to be more confident and it is good to be able to talk to colleagues and they
> can ask questions – I might not be able to answer them all but I know where I
> can ask or look…it is still difficult to initiate end of life discussions but I am
> more confident." (End of life care lead)*

Not all end of life care leads interviewed had provided formal training for their colleagues but
all said they were planning to do so and had begun to share their knowledge in less formal
ways.

> *"…we have had discussions and I may do small presentations – we were well
> prepared by the training – we did presentations - I will do something on
> Advance Care Planning and Gold Standard…What I have done is – well I will
> always discuss the issues – but I have gathered information on end of life
> care and put it all together so that people can access it." (End of life care
> lead)*

In other test site areas for example, Lancashire, West Essex and Essex, workers had also
developed knowledge around end of life care issues in a less formal or structured way, for
example through discussions with colleagues about a specific case, or through the project
briefings. A number of respondents felt that the project had been successful in changing
people's perceptions of end of life care and what could be achieved (see also raising local
profile).

> *"Sometimes when you talk to doctors about what we are trying to achieve it is like a light being switched on and talking to ward staff and explaining that people can get good end of life care in the community and that they don't have to be in a hospice or a hospital – and about having the conversation earlier rather than later." (Discharge facilitator).*

A number of project partners and even project leads also remarked that they had not only learned more about end of life care, but that they had benefited from the test site initiative in other ways. Some professionals who had been working in the same area for many years explained that they too had learned from the experience and found it rewarding.

> *"For me it has been a significant learning experience and has had an impact for me as a professional and I have been practising for 26 years… I have developed through it… …I think we have been valued as a key partner in the discharge process more than we used to be…" (Social care manager)*

> *"…of course we do very different work and if we do need something from social services we don't have any power so we need to communicate well – so this was an opportunity…Another added benefit was learning more about their roles, staying in touch with what is going on out there – you can live in a kind of hospice bubble if you like – learning more about the culture out there. ..It is quite difficult to keep in touch with what's going on" (Project lead)*

One of the unintended benefits identified from this project had been within the educational needs in the community around the Gold Standards Framework[15]. One interviewee commented that joined up working had improved.

> *"Education and training for both health and social care and SWIFT[16] around end of life care; tools have been developed around this, and now it's a case of ensuring this is widely available to all team members in both organisations." (NHS Commissioner for Long Term Conditions)*

Another project explained that by looking at the training needs across both health and social care it would be possible to make a difference in coordinating care and preventing crises by aiding communications for people with palliative care needs

Whilst there were many positive outcomes in respect of training and development from the projects, problems were also encountered. Several sites found that there was a problem with releasing staff for training and one way they worked round this was to utilise more e-learning. One manager commented that *"the recent budget cuts have had an impact on the*

---

[15] For more information on the Gold Standards Framework go to: http://www.goldstandardsframework.org.uk/

[16] SWIFT was the Strategic Workforce Innovation for Education and Training scheme, comprising a pool of money that devolved down from the Strategic Health Authority to local organisations. It is for all professional groups and all agencies.

teams as all teams have lost staff which has caused significant pressures when trying to release staff to attend workshops". A palliative care coordinator in another test site explained how they were working closer to provide learning to social care staff but a problem they encountered was these staff only get two study days a year which meant that training had to be incorporated into meetings so that their two study days were unaffected. There was also an issue around training agency staff who provide care at home and who funds and trains them around end of life care   One response is to link this to the commissioning and contracting process of services from the PVI sector.

4.5   IMPACT ON END OF LIFE PATHWAY

Steps of the End of Life Care Pathway

The End of Life Care Pathway has six steps, which are shown in box 4.1. This pathway offers a structure for planning services, although, as emphasised in the Social Care Framework, this pathway is not a neat linear process. The whole pathway is also underpinned by social care, spiritual care, and information and support for people nearing the end of their lives, their carers and families. Although this was not an explicit aim of any of the eight test sites it was evident that all the projects, through their various activities, had an impact on at least some stages of the End of Life Care Pathway[17] and the Essex project's End of Life Care Delivery Plan notes that the End of Life Care Pathway could be used as a model for service planning and delivery. The training offered by St Christopher's Hospice included sessions on 'Challenging Conversations' which covered talking about dying and planning for the end of life. The West Essex project sought to improve care planning by encouraging people to discuss their Planned Place of Care and also worked to improve the co-ordination of care by liaising with relevant agencies. A number of respondents from these test sites also reported that they had recognised the importance of considering and addressing the needs of carers. In these and other areas, the importance of domiciliary care and the work of various other health and social care agencies in the delivery of high quality care were implicit in their work. It appeared that the final step of the end of life pathway received the least attention although a few social care End of Life Care leads said they felt more able to talk to clients who had been bereaved.

---

[17] The End of Life Care Pathway comprises six steps and was developed to help anyone providing health and social care to people nearing the end of life. The Care Pathway aims to ensure that high quality, person-centred care is provided which is well planned, co-ordinated and monitored while being responsive to the individual's needs and wishes. More information is available at: http://www.endoflifecareforadults.nhs.uk/care-pathway

Box 4.1   The Six Steps of the End of Life Care Pathway

- Step 1: Discussions as the end of life approaches
- Step 2: Assessment, care planning and review
- Step 3: Coordination of care
- Step 4: Delivery of high quality services in different settings
- Step 5: Care in the last days of life
- Step 6: Care after death

What is End of Life?

As noted above, respondents in some areas made the point that they were more aware of end of life care and what this meant following the training they had received and were thus more confident and able to deliver good end of life care (see below). However, it should be noted that evidence emerging from the test sites points to confusion over what exactly end of life care is and hence what is the pathway of care, and who contributes and at what point. This was the case even amongst some of the respondents who had received training yet still tended to associate 'end of life' with terminal diagnoses and/or the very end of life. This was a major concern for many of the project leads and key stakeholders.

> *"Staff thought that end of life work was literally the last few weeks of life….[I was] quite surprised so many staff didn't realise they were working in end of life care." (Co-facilitator, workshops)*

Who is responsible for End of Life?

A common observation was that social workers may not see that end of life care is part of their remit. A key stakeholder from Adult Social Care commented:

> *"Social care staff had very little involvement at end of life and particularly with individuals living in the community. It appeared that when someone was diagnosed with a life limiting illness, health took over – rightly in terms of the health care needs but social care was missing especially as we recognised that there were things that could be done to help and support the individual which health was ignoring." (Assistant Head of Services)*

A commissioner of adult social care services observed:

> *"…if you look at teams across the board there has been a disconnect between their understanding about the needs of patients with long term conditions, as we have a lot of active social work for people with long term conditions, and the need to plan for end of life care. There have been some difficult discussions including one social work manager telling me 'it wasn't their job." (Project lead)*

Coordination of Care

The Norfolk test site ran a workshop at which they discussed the findings from a series of case studies, commenting on the people's pathways and end of life and coordination between agencies. Numerous weaknesses emerged in the management of these people including confusion of roles within social care and between social care and other agencies, a lack of coordination of services (including too few and too many), and inconsistent quality of care. Interestingly, despite issues raised here and in other test sites about 'health taking over', this test site also identified as one of their successes, their Continuing Health Care Fast-Track Process, which included the involvement of domiciliary care (there being an agency specialising in working with end of life and palliative care) thus enabling people to die at home.

In West Essex, the project team had worked closely with the Continuing Health Care Team and negotiated some changes to administrative procedures. These and the fact that one person took responsibility for these procedures, had helped expedite the discharge process. West Essex had also developed an integrated health and social care discharge pathway, and an operational framework to facilitate and expedite appropriate hospital discharge.

Supporting Service Users

Respondents across a number of test sites explained how they felt their involvement in the projects had enabled them to support service users at the end of life. A number of respondents explained that they had little understanding of end of life care prior to being involved in various test site initiatives as this hospital based social worker explained.

> *"…to be frank, at the time I really did think that it was about the last few days, in the hospital they talk about the Liverpool Pathway…but in my mind it was about the last few days and how you work with people and their carers and relatives – but then I came to realise that there is a sort of lead in…you start when people are relatively well and then you work along and the Liverpool Pathway is at the end of it." (End of life care lead)*

At the time of the evaluation few had actually put their newly acquired skills and knowledge into practice but many said they felt more confident about raising the topic of end of life care; discussing choices with their clients; advising other professionals about good end of life care; and in liaising with the various services and agencies whose support was required to meet the service user's wishes. They also felt more knowledgeable about the practical support and resources available to service users, their partners, carers, and family members.

> *"I am now more likely to talk to them, carers and relatives, about end of life. I have been able to raise the topic with people who have a terminal illness…and I have spoken to an Extra Care manager who was worried about*

providing end of life care and I was able to advise him about available resources" (End of life care lead)

"Before the course I didn't feel comfortable about talking about end of life care – the course gave me the confidence to talk about it. I learned more about the skills used in challenging conversations …" (End of life care lead)

In West Essex, a joint health and social care discharge facilitator post had been created as part of the project and here a dedicated worker discussed options with service users including their Preferred Priorities for Care[18] (PPC) and was able to arrange for these preferences to be met towards the very end of life, including the last few days. The West Essex project succeeded in discharging almost 90 per cent of people to their preferred place of care.

"I talk to the patient, find out whether they have an existing PPC and whether this has changed – do they want to go home, do they want to go to a hospice, do they want a care package – what do they want, do they have any fears or worries? Talking about the fact that they are dying because a lot of people I see may have been told that they are going to die they haven't had a chance to talk about it because they have been putting on a brave face for the family…and of course I speak to the family, explain things, talk about their concerns." (Discharge facilitator)

Using the Gold Standards Framework

Two sites (Wakefield and Hull, and Norfolk) discussed the role of the Gold Standards Framework (GSF) within their project (having a GSF flag on a person indicated that they were expected to die within a year). It was evident that social care workers, including senior managers, were often unaware of the GSF or other relevant structures, frameworks or pathways. A lead partner from adult services in one test site felt their greatest achievement had been the involvement in GSF clinics they knew GPs were holding for people nearing the end of their lives.

"Certainly the leads and the managers have learned about the resources available and what is happening – some of the structures and frameworks e.g. Gold Standard…that some of the service users they work with may be on Gold Standard or registered with GP practices or known to district nurses…" (Project lead)

In another area, one unintended benefit had been the changes made to how referrals came into the service and these now included people on the GSF onto their database, highlighting that people would be flagged whenever the person with end of life care needs came into

---

[18] More information on Preferred Priorities for Care is available at:

http://www.endoflifecareforadults.nhs.uk/tools/core-tools/preferredprioritiesforcare

their system. The Norfolk project also highlighted how the GSF flag might be used for managing end of life care.

> *"…a finding was that if we could share these GSF registration details [from GPs] and this can be done in the integrated care setting with our social care database, it will make a significant difference as we will know earlier and we can make an earlier intervention so we won't be working with people at the last minute." (Project lead)*

4.6   IMPACT ON ENVIRONMENT OF CARE

The issue of the environment for end of life care can be overlooked. However, a series of initiatives is seeking to address this.. NHS Estates in 2005 issued guidance on health care design and the hospital environment for end of life care, following which the Kings Fund undertook a pilot with eight sites across hospitals and hospices to examine how to improve the environments for end of life care. A report was published in 2008. More recently, a further programme was undertaken, the report from which was published in 2011[19]. Coinciding with the launch of this and two other publications, the theme of the End of Life Care Programme Newsletter for August 2011 is the environment.

Equally importantly, work undertaken elsewhere has demonstrated the importance of the environment for older people living in their own homes, where the majority of people experience end of life care and wish to die. For example, the funding of handyperson services, which tackle not just cosmetic improvements such as gardening and decorating, but also undertake preventive work such as repairing flooring, repairing lights, and installing grab rails to prevent falls, which can be vital in supporting older people at the end of life.

Although test sites addressed issues of caring for people in their own and care homes, and addressing their social care needs, none of the test sites were explicitly concerned with environments of care. However, the Lancashire test site indirectly addressed the issue of the home environment. This test site, having a hospice at home as one of the partner organisations, worked with a signposting agency which directed people nearing the end of their lives and their carers to services they required and which would improve their well-being. Services to which service users and carers were directed included, for example, ones which helped to make the home more comfortable, to move furniture and to undertake roof repairs. The organisation recognised that the home environment was important for maintaining individuals in their own home at the end of life.

Improving the home environment and ensuring that it is suitable for managing a person at end of life is crucial. They may be admitted to hospital for social care reasons that are associated with the home environment, or conversely not be discharged from hospital for simple reasons such as their bed not being in the most suitable room, or a bed rail not having been fitted. Whilst not criticising the test sites for not addressing the home environment, we are concerned that there appear to be no initiatives to address this aspect

---

[19] Available from http://www.kingsfund.org.uk/publications/ehe_care_environment.html?&bought=22530

of care, especially as the Kings Fund initiatives have exclusively focused on hospitals and hospices.

4.7   BENEFITS TO SERVICE USERS AND OTHERS

Most test site projects had involved those who were using their services and their families, or representatives of service users in different ways, although there was little formal evaluation of the benefits to service users. Due to the time constraints of undertaking the evaluation, we did not interview or collect evidence from service users although we did collect evidence about the involvement of service users and families in the test sites.

In one area the project lead also ran a service user support group (Gloucestershire), another test site had a service user representative on the Project Board (Norfolk), in other areas service users participated in focus groups and surveys (Norfolk, Wakefield and Hull, and West Essex), and briefing sessions (Guy's and St Thomas'. The discharge facilitator employed as part of the West Essex test site project had direct contact with people nearing the end of their lives, their families and carers.

West Essex was able to demonstrate its success in meeting people's preferences for care. Central to this project was the creation of a joint health and social care discharge facilitator. Its success was attributed to the work of this facilitator, who liaised with all relevant services, and, importantly, discussed preferences with people nearing the end of their lives, their families and carers. A number of respondents remarked that they would have liked service users to have had more involvement in the project and to have gathered feedback from service users, their carers and families but that this had not been possible within the timescale of the project. West Essex had commissioned a survey of service users which was to be conducted at the end of the test site initiative but the data was not available at the time of writing.   In two areas the issue of end of life care had been raised with older people living in sheltered housing and discussions facilitated around decision making and planning.

In the Guy's and St Thomas' project, an end of life care lead working in sheltered housing had asked one of the project team to speak to a local sheltered housing forum.

> *"…we have brought the end of life framework to our residents as we have a Sheltered Forum we use to share information with our residents and they were so open to it – I invited [project manager] to speak to them and it was almost as if 'why weren't you here before?' it was like they just wanted someone to broach the subject and since then they have been asking for information, for leaflets – even if it is just to give their families." (End of life care lead)*

The Wakefield and Hull project focused on the voice and experiences of people nearing the end of their lives. . They had previously worked with the Living Well Toolkit, which was used by a wide range of staff groups, including domiciliary care workers, and which was seen as benefitting people nearing the end of their lives and staff. They also tested the role of domiciliary care workers speaking for people nearing the end of their lives in the Gold

Standard Framework clinics held by GPs. As one interviewee from Adult Social Care commented:

> "We knew that this was where they made decisions about patients particularly around continuing care and how to manage them towards their end of life. We knew they were held with just medical input and no input from the patients themselves. So a success for the pilot where we tried this was to show the GPs and the health team that although the patient doesn't actually have to be in these meetings…we can give the patients a voice and hence can take into account their wishes about how they want to be treated and cared for, and what was important to them.…Patients didn't want to keep repeating their stories nor how they wanted to be cared for…..These staff [domiciliary care workers] started to go to GSF meetings and become a spokesperson for the patient…For some patients the decision-making about their care was changed." (Assistant Head of Services)

Respondents from both these projects remarked how open these service users had been to discussing their preferences and experiences. Project workers were surprised, but pleasantly so, that users and carers would be prepared to share their stories so willingly.

> "…we were surprised at how eager people were as it would be of benefit to others. We are continuing to ask people 'can we share this example of good practice?'" (Assistant Head of Services)

This test site also involved the Patient and Public Involvement Manager who had ready access to a variety of groups to undertake focus groups with people who had experienced end of life care and carers.

> "Through engagement, carers and the voices of staff were able to influence changes and ensure that their voices were heard…Experience based design was used as a tried and tested method of user involvement…It helps to identify good practice. A bank of people were utilised to join in two focus groups for end of life care." (Patient and Public Involvement Manager)

The Gloucestershire project, although they worked entirely with staff (and hence had no direct involvement with service users) nonetheless was able to receive input from service users, as their project lead also ran a service user support group at their local hospice, and their input to the workshop programmes was taken into account.

At the Norfolk test site, a local service user representative (and who was chair of the local Carers Council) was a member of their project board and participated in several of the project activities, including making a site visit to a local care home. This person also fed back information from the project to the Carer's Council.

The Lancashire project, which involved a signposting organisation enabling users and carers to access what they termed 'low level interventions' were very clear that their involvement

had had a real positive impact on users and carers, and gave numerous examples of small things that contributed enormously to the quality of life of people who were nearing the end of their lives, for example organising for someone to attend a remembrance service. They commented:

> ”…it's unlikely that the lack of medical or clinical input will put [the patient] in hospital, unless there's an emergency, it's the lack of practical support. What's likely to tip the carer over is the fact that they haven't been out of the house for several weeks or that there's no one to do the shopping. Where we have started to address these things, these have been the unintended benefits.” (Hospice Day Therapy Manager).

The test site initiatives appeared to have great potential for improving the end of life care experiences of service users, their carers and family members. For example, those who had received trainingfelt that the training and support they had received had made them more confident, knowledgeable, and skilled and, therefore, more able to provide the emotional and practical support their clients required.

4.8 ACHIEVEMENT OF LOCAL OBJECTIVES

All the test site projects not only sought to meet objectives from the Social Care Framework, but also set local objectives. During discussions with test sites, we sought to collect evidence as to how far these local objectives had been met. End of project reports also contained information on the achievement of local objectives.

The Wakefield and Hull project aimed to test whether domiciliary care workers could be key workers on the end of life care pathway and whether it would be possible to develop key worker competencies for this staff group's role in the end of care pathway. The project team demonstrated that it was possible for domiciliary care workers to have an active role in the multidisciplinary end of life care pathway, and this was already happening in what was termed *"an informal way".* They also demonstrated, through the collection of evidence on DVD which was mapped to key worker competencies by an external expert from Skills for Health, that domiciliary care workers maintained key worker relationships. As documented in their final report:

> The success of the project lies in the fact that we have seen how domiciliary care workers can be utilised to support people at end of life, that they see it as their role and that they believe that dignity, respect is an important part of care. Their pride in their work is achieved through their relationship with the person and their inherent values as well as their competency.

The Lancashire project aimed to offer service users with end of life care needs the opportunity to use personal budgets. The project also sought to test the personal budget support planning tool as a holistic planning tool, and to use the process associated with personal budget planning to help with advanced care planning. Finally, the project sought to enhance partnership working around care planning. The project was partially successful in

that service users did have the opportunity to be involved in planning aspects of their care through support planning and satisfaction with these planning processes was high but take up of personal budgets was very low (their original proposal envisaged supporting 40 users but only three took up the opportunity). Service users were also able to access a a wide range of resources via a signposting service. . Partnerships and knowledge around end of life care have been developed and enhanced. The Gloucestershire project aimed to engage social care operational managers and assessors in the support of their field work staff to deliver high quality end of life care through their participation in a series of workshops. The model for these workshops was innovatory and the project also aimed to test the model, content and effectiveness through a formal evaluation. The project was entirely successful in that managers and a range of social care workers attended the workshops and the project team had positive engagement with managers and a range of staff groups. The evaluation provided positive evidence of the effectiveness of the workshops, and the model for the workshops was also found to be successful, emphasising the role of supportive and reflective practice.

The local objectives of the Norfolk project were indistinguishable from the objectives from the Social Care Framework, in that they sought to facilitate commissioning and delivery of person centred care, to promote supportive communities, and strengthen the specialism of palliative care social work. Their final report comments on the degree of success in meeting these objectives, which are discussed in more detail in Section 5. Their report also highlights other successes of the project including the enthusiasm from a wide range of stakeholders, and how significant gains can be made by practitioners working under a shared umbrella. The report also comments on "a lasting success" which would be the inputting of the Gold Standard Framework status on individual care records on the Care First System Social Care client database.

The West Essex project had as one of its overall aims the reduction of deaths in hospital. It set out a range of detailed objectives to meet this aim and the Social Care Framework objectives. These are discussed in some detail in the test site project's final report and are summarised here. These objectives included improving joint working and commissioning across partner agencies, and developing a shared framework, in order to facilitate hospital discharge; raising awareness of end of life care and educating staff in partner organisations about key policies; undertaking monitoring and evaluation; and, developing a post-project plan. This test site had gone some way to meeting these achievements and reported particular success in working with partners; reflective practice teaching; raising the profile of end of life care; collecting monitoring and evaluation data. These, the final report suggests, helped achieve the aim of reducing the length of hospital stays and facilitating discharge to people's preferred place of care.

The Guy's and St Thomas' project set out to identify end of life care leads in social care teams and to identify their training needs and to clarify and test the role of end of life care leads. The project also had as an objective the 'cross-fertilisation' of learning in end of life care through a facilitated learning network of district nurse leads and social care leads in end of life care and to increase multi-disciplinary information sharing. The project was successful in meeting these objectives; end of life care leads were identified and the role developed and

a range of multi-disciplinary events were held. This project also worked collaboratively with another project (see below) which delivered training to the social care end of life care leads.

The St Christopher's Hospice project, which worked in collaboration with the test site project described above, set out to identify the training and support needs of the social care end of life care leads, and to deliver a flexible training and support programme in end of life care for adult social care workers. This project delivered on these objectives but also provided training sessions for managers and social work and social care teams as well as sessions for service users.

The Essex project's main aim was to develop an end of life care strategy. Its more detailed objectives included establishing a model of integrated care with the potential for implementation across the organisation and partners and improving inter-agency knowledge and confidence and ability to ensure access to good quality end of life care. The project also aimed to establish joint working and single point of entry to health and social care with common processes and support mechanisms across the local authority area; to identify the potential for joint contracting arrangements between social and healthcare with care providers for end of life care; and, to establish systems for evaluating end of life care from the service user perspective and forums for reflective practice. The Essex project had produced an end of life care strategy and had gone some way to meeting its objectives, these achievements are discussed in the following section.

4.9 SUMMARY AND DISCUSSION OF FINDINGS

Although only two test sites had raising the profile of end of life care as an explicit objective for their project, all projects did raise both the profile of end of life care and the role of social care. Four test sites aimed to have an impact on commissioning. We observed test sites taking on the issues around commissioning for community, hospice and domiciliary care. Test sites commented on the lack of cross-agency commissioning strategies and how the work from their projects would be contributing to their development. Two sites also commented on the input to contractual agreements with care providers ensuring that quality standards were included.

Four test sites worked on developing the skills and knowledge of professionals working in end of life care. Two test sites developed and successfully ran workshops for social care staff, whilst a third identified the need for training in specific areas. A fourth developed training material on competencies for key workers. Interestingly the role of palliative care champions and their training needs was identified and acknowledged, as was the need for joint training strategies for the delivery of end of life care.

Although it was not an explicit aim of any of the test sites, projects did have an impact on at least some stages of the end of life care pathway, for example in identifying their roles and how they could contribute to improved quality of and more holistic care. Emphasising the message that end of life care is a social care responsibility and their staff had a role was seen as critical.

None of the test sites explicitly addressed environments of care; however, one project addressed the issue of the home environment recognising the importance of an appropriate environment for maintaining individuals in their own home at the end of life. All sites in some way involved or represented service users, often indirectly. However, some respondents commented that greater involvement from service users would have benefited projects. Nonetheless, test sites appeared to have great potential for improving end of life care, as evidenced by the impact of commissioning services, developing training and improving the end of life pathway.

All test sites set themselves local objectives, in part as a means of addressing the Social Care Framework objectives, but also as objectives in their own right, which were mostly met. Two sites explicitly addressed training and workforce development needs, whilst others sought to implement personal budgets (with only a small degree of success, but plenty of learning). One project sought to reduce the number of deaths in hospital by introducing a discharge facilitator who worked closely with the hospital social work team (however, the reduction in hospital deaths was not documented, probably due to the timescales of the project).

Section 5: Delivery against the Social Care Framework and NEoLCP Criteria

5.1 INTRODUCTION

This section discusses the relevance of the delivery of the projects against the objectives of the Social Care Framework and NEoLCP criteria, as well as other high level criteria such as their relevance to the social and health care interface and value for money. All test sites indicated in their proposals which of the Social Care Framework objectives they were seeking to achieve, but during our collection of evidence, we discovered that test sites also delivered unintended achievements against others.

5.2 RELEVANCE TO NATIONAL END OF LIFE CARE PROGRAMME (NEOLCP) AND SOCIAL CARE FRAMEWORK

As noted in Section 1, in seeking to achieve the overall aim of the End of Life Care Strategy, to improve the quality of end of life care and to ensure that individuals and their families have choice and autonomy at the end of life, the National End of Life Care Programme and the Social Care Framework have a number of detailed objectives Each of the eight test site areas sought to meet at least one of the Social Care Framework objectives (see below) but also proposed meeting other overarching aims such as the reduction of deaths in hospital (meeting local objectives was discussed in section 4.8).

5.3 OBJECTIVES FROM SOCIAL CARE FRAMEWORK

The purpose of the Department of Health's End of Life Strategy and the accompanying implementation programme, addresses in part, a desire to change the 'culture' and experience of dying. The Social Care Framework addresses the social care aspects of these changes, and importantly the way that social care supports people at the end of life. All test site proposals indicated which Social Care Framework objectives they were seeking to achieve. These are given in the test site summaries in section two, but are also shown in Table 5 below. What became obvious during our collection of evidence from the test sites was that many, although they had not originally targeted an objective, did deliver unintended achievements against these framework objectives. We summarise our evidence of achievement by objective as below

Table 5: Social Care Framework objective by scheme

	Scheme Social Care Framework Objective	Lancashire	Wakefield & Hull	Gloucester	Norfolk	West Essex	Essex	Guy's & St Thomas'	St Christopher's Hospice
1	Identify and raise awareness of the role of social care in supporting people at the end of their life among the public, the social and health care workforce and its management		√	√					
2	Facilitate commissioning and delivery of person-centred, integrated care	√			√	√	√		
3	Embed end of life care within commissioning and inspection frameworks and standards for practice					√	√		
4	Strengthen the specialism of palliative care social work			√	√				
5	Promote understanding and best practice in holistic assessment of individuals, their carers and families at the end of life	√	√			√	√		√
6	Promote earlier end of life care planning that builds on an holistic understanding of wellbeing	√	√						√
7	Educate and train social care staff to deliver high quality end of life care								√
8	Create a supportive work environment that enables social care workers to maximise their contribution to quality end of life care		√	√		√	√	√	√
9	Promote supportive communities through engagement with a wide range of community services				√	√			
10	Work jointly with research commissioners and funders to establish a robust evidence base for good practice in social care at the end of life								

***OBJECTIVE 1: IDENTIFY AND RAISE AWARENESS OF THE ROLE OF SOCIAL CARE
IN SUPPORTING PEOPLE AT THE END OF LIFE***

A key starting point for the implementation of the End of Life Care Strategy is raising
awareness of the contribution social care already makes to meeting the needs of individuals
and families at the end of life, among the social care workforce, other healthcare workers
and the general public. According to the Social Care Framework, there is low awareness
among social and health care professionals of the role of social care support at the end of
life. This objective is also underpinned by a series of five recommended actions. This
objective therefore appears to be long term and addresses cultural and contextual issues.

Only two test sites, Gloucestershire, and Wakefield and Hull explicitly addressed this
objective, however, as discussed in the previous section, all the test sites did in some way
raise awareness of the role of social care in end of life care. Wakefield and Hull focused
more on the identification of the role rather than the raising of awareness. They commented
that they ascertained that domiciliary care workers could have the skills and competency to
work as a key worker for people at the end of life, which is more effectively done when part
of a multi-disciplinary approach to planning care. Gloucestershire believed that they had met
this objective in their project showing that they needed the skills of specialist social workers
to run workshops. They also commented that this was an important finding if their workshops
were to be rolled out. Test sites appeared to focus on raising awareness among the
workforce and key stakeholders in partner agencies, and with other forums such as a
Sheltered Housing Forum and a Service Users forum. However, there is little evidence from
test sites of raising the profile with the wider public.

It appears that, whilst the majority of test sites did not explicitly address this objective, during
the course of their projects, they implicitly engaged a variety of stakeholders and in so doing
raised the awareness of the role of social care. As stated earlier, this is a long term
objective, and will not be resolved quickly.

***OBJECTIVE 2: FACILITATE COMMISSIONING AND DELIVERY OF PERSON-CENTRED
INTEGRATED CARE***

The Social Care Framework highlights the need for effective commissioning and delivery of
integrated health and social care services. It particularly identifies potential problems
associated with disconnected interventions by agencies, and the structural barriers between
agencies. Improvements in integrated care also require improved information sharing and
funding arrangements. A theme throughout this report is the complexity and variety of
agencies and organisations working at strategic and operational levels.

Four test sites, Essex, Norfolk, Lancashire and West Essex, addressed this objective. The
Lancashire test site, working with a hospice, was clear that the services commissioned by
Adult Social Care from the hospice met the person centred integrated care criteria. However
they also recognised, looking at commissioning from a wider perspective, that more work
was required, especially ensuring that all services are delivering to the same standards of
care. Their focus was on commissioning integrated end of life care, as indeed was that of a
second site. The Norfolk test site addressed this objective in an extensive way. They

examined the role of the social worker in commissioning and delivering person centred care and identified barriers to effective commissioning. They found that commissioning was problematic due to the rural location, limited numbers of care agencies and difficulties in recruiting staff. From the project and their workshops emerged four recommendations on commissioning:

- encouraging agencies to set up specialist palliative care and end of life teams which are specially trained and available for emergency care;
- building in GSF training and palliative and end of life expertise as a contractual requirement;
- enabling care workers to work with community health staff and link workers and to join in joint training activities;
- ensuring the quality of provision through quality assurance and quality review procedures.

One of the test site projects (Essex) which had this as a specific objective had not yet facilitated the commissioning and delivery of person-centred care but was working towards meeting this objective. This test site project had developed a delivery and action plan which sets out a range of different objectives to improve commissioning and delivery of services, for example, to work with partners to offer more personalised services; to explore opportunities for joint commissioning with PCTs, local councils and the PVI sector, to provide services that are responsive to personal budgets; and to work more closely with GP consortia. The delivery and action strategy also sets out plans to consult people at the end of life and their carers to inform future developments. Further, this test site intervention had made a good deal of progress in embedding end of life care in commissioning practices.

Another test site project, (West Essex), which had the facilitation of commissioning as a specific objective, appeared to have had some impact on the delivery of services through its efforts to improve co-ordination of services and partnership working between health and social care and a range of other statutory and PVI sector providers, including addressing joint funding and joint contracting. This project had also sought to improve holistic assessment and expedite discharge to preferred place of care. There was little evidence of any direct impact on the facilitation of the commissioning of services, although the project will inform the Transformation Agenda[20] (the changes in health and social care which include moves towards personalisation) and is therefore expected to have some influence on the commissioning of services in the future.

The efforts of the test sites demonstrated the problems in working in complex environments with a wide range of agencies which are differentially engaged with end of life care. The test sites certainly succeeded with particular aspects of commissioning and delivering person centred and integrated care. Addressing barriers in funding, together with the need for flexibility, is likely to be particularly problematic. Lessons from the test sites illustrated the need for engaging all key stakeholders and agencies, which again are unlikely to be resolved in the short term.

---

[20] For more information go to: http://www.idea.gov.uk/idk/core/page.do?pageId=6103970

***OBJECTIVE 3: EMBED END OF LIFE CARE WITHIN COMMISSIONING AND
INSPECTION FRAMEWORKS AND STANDARDS FOR PRACTICE***

According to the Social Care Framework, there is evidence of widespread and costly
complaints about end of life care. Their recommendation is for organisations to routinely
seek views and experiences from service users and families, as well as implementing a
preventive approach to complaints by using regulation and inspection frameworks. Although
only two test site projects (Essex and West Essex) explicitly addressed this objective, it was
evident that other test site projects had begun to influence and have an impact on
commissioning practices and standards of practice.

For example, as discussed in Section 4, Lambeth adult social services department, which
had worked closely with Guy's and St Thomas' and St Christopher's, had written end of life
care into new domiciliary care contracts. Another test site (Norfolk) addressed this objective
as part of facilitating commissioning under Social Care Framework Objective Two. The
recommendations made by this test site, as described above, could equally apply to this
objective, especially their recognition of the need to address the quality of provision through
quality assurance and quality review procedures. Wakefield and Hull had developed a group
of domiciliary care workers (in the Hull locality) to be key workers, but subsequently had to
make redundancies across this staff group and was moving to the provision of domiciliary
care workers through external agencies. However, as a result of the project, they recognised
the need to build in to future contracts quality assurance and standards of training in end of
life care for these care workers. Essex had had explicitly addressed this objective and had
amended domiciliary and residential care contracts to include 10 key points around the
provision of end of life care and the standards expected of providers. This project was also
working to educate providers about end of life care and to consult with health commissioners
including PCTs and GP consortia around end of life care issues.

Test sites have addressed mechanisms for improving commissioning, but there appears to
have been less emphasis in tying the commissioning to a regulatory and quality driven
process. Local regulatory processes can exist, for example including quality standards in
local contracts for services. Quality assurance and review processes can also be delivered
through contracts, for example by building in the requirements for training and end of life
expertise. It is unlikely that quality assurance processes are not in place across
organisations for services that are either commissioned or delivered. However, it is likely that
end of life care is not explicitly addressed, although financial incentives (by reducing the
costs, both financial and social associated with problems of delivering end of life care) may
be one mechanism for driving through improvements.

***OBJECTIVE 4: STRENGTHEN THE SPECIALISM OF PALLIATIVE CARE SOCIAL
WORK***

According to the Social Care Framework, palliative care social workers based in hospices
and hospital have an important role, both within these specialist units and mainstream
services, in ensuring high quality end of life care. They can provide education and support to

community based social workers, as well as to users and families. However, of concern is their patchy provision, especially where there may be only a single specialist.

Only two test sites, Gloucestershire and Norfolk, addressed this objective. Adult Social Care services at Norfolk had made the decision not to invest in a team of specialist palliative care social workers and instead had developed a network of palliative care champions (which could be from any profession). The project addressed the needs of this group, including undertaking competency surveys. A finding from the project was the need to develop this group of staff by clarifying their role and allowing them access to specialist palliative and end of life training. This approach addresses the need for specialists in an alternative way.

The Gloucestershire test site saw the delivery of their workshops as a means of opening up the specialism of palliative care to mainstream social workers. During the provision of their workshops, they identified major education issues for social workers in respect of knowledge and attitudes about end of life care. A key finding was that a targeted workshop delivered with a mentoring approach was effective in educating and building confidence in a mixed group of social care staff. Another finding was in respect of the attitudes of the social worker managers and hence their influence on the role of the social workers.

The Adult Social Care Services at the Lancashire test site, whilst not explicitly addressing this objective, employed a model of locality based specialist palliative care social work, and findings from their project would contribute to a review of the role of specialist palliative care social work.

Test sites thus recognised the need for specialist support, but did not always address this need through specialist social workers, but through a range of training and development and support mechanisms. Thus, it appears that specialist support can be delivered in a variety of ways. It may not be possible, certainly in the short term and due, for example, to financial and workforce constraints, to have in post several specialist palliative care social workers. Test sites have demonstrated that alternative mechanisms for delivering this objective are possible.

OBJECTIVE 5: PROMOTE UNDERSTANDING AND BEST PRACTICE IN THE HOLISTIC ASSESSMENT OF INDIVIDUALS, THEIR CARERS AND FAMILIES AT THE END OF LIFE

Social care has a key role at each of the six steps of the end of life care pathway (summarised in section 4.5) and in promoting quality of life throughout, including the final phase of life. The future care of family members is also of concern.

Five of the test sites (Essex, Lancashire, St Christopher's Hospice, Wakefield and Hull, and West Essex) addressed this objective. Lancashire was very eloquent about their observations and achievements in respect of this objective, highlighting their awareness-raising:

"We have done a lot of promotion here, a lot of awareness-raising across health and social care…. This has been a theme throughout the project, trying to be holistic". (Project lead)

The Wakefield and Hull test site, in their focusing on the role of domiciliary care workers in respect of this objective stated in its final report:

In using person centred thinking and planning tools, domiciliary care workers have gained a more in-depth understanding of the needs of people and their families at end of life. This is based on listening and supporting people.

St Christopher's had sought to meet this objective through a training programme for end of life care social care leads and in shorter training sessions for social work and social care teams, managers and adult social service leads (see below and Section 4). A number of respondents remarked that this training had helped them think differently and more holistically about their clients, carers and families.

"…of course you can always do more but on the whole, we are very pleased with it. I think the most pleasing thing is that when you chat to the leads they tell you things like 'oh I was chatting to a woman and she told me her husband had died and I wouldn't have really engaged in a proper conversation with her before and now I did and she really felt it was valuable and she told me it was valuable and I feel more comfortable and I will do that again'. So you know it is little things but you can see that they are doing things differently. There are lots of examples like that – of people looking at their assessment forms and thinking how they can use them more imaginatively." (Project lead)

The West Essex project reported having had some success in achieving this objective by raising awareness of the Social Care Framework and its objectives among health and social care staff (see also Section 4). This was achieved through day to day contacts and discussions with relevant staff, for example, ward nurses and hospital doctors, care providers and community nurses, as well as through attendance at meetings of established working groups e.g. the Hospital Mortality Review Group and Community Health and Social Care Mangers' meetings. Importantly however, many respondents felt that whilst these activities had helped to convey the message about holistic end of life care, another significant factor in changing attitudes was demonstrating what could be achieved in practice.

"I suppose also what has emerged is whether we could myth bust because there were lots of myths around e.g. 'you won't get people home because there will be blocks in social care'. And from a consultant 'oh, you can't get the care packages' so it was about getting the evidence to challenge those myths in the future as well as delivering the project" (Project lead)

As noted earlier, the Essex project sought to meet its stated objectives over the longer term by developing a strategic end of life care delivery and action plan. This test site project had begun to disseminate information about good practice in the provision of end of life care to a range of providers and commissioners and had initiated training for its staff (see also the findings from objective 3 and the discussion in section 4). However, at the time of the evaluation it was too early to assess the impact on this specific objective.

One project lead reflected on the problems in encouraging holistic approaches in both health and social care:

> *"A consultant said to me 'I am being holistic', but I said 'you can't be holistic on your own'. I have also had equal problems with the social work teams, 'what's that health stuff to do with me?'" (Project lead)*

Most test sites, although not explicitly addressing this objective, sought to promote understanding about assessment of need of individuals, carers, and families. Those that did address this objective also recognised the problems with delivering holistic care, probably as a result of long term barriers between organisations, as discussed elsewhere in this report. The encouragement for organisations to work together in all aspects of the end of care pathway will require the significant removal of barriers. However, as has been demonstrated by test sites, this is entirely possible.

OBJECTIVE 6: PROMOTE EARLIER END OF LIFE CARE PLANNING THAT BUILDS ON AN HOLISTIC UNDERSTANDING OF WELLBEING

According to the Social Care Framework, social care has an important role to play in linking assessment of need to advance care planning within an holistic framework. Three sites (Lancashire, St Christopher's Hospice, and Wakefield and Hull) explicitly addressed this objective, although the involvement of social care earlier in a person's end of life pathway has been a theme throughout the activities of many test sites, especially with the increasing recognition that one agency cannot deliver all needs .

One test site project lead stated:

> "*we have done a lot to promote talking to people earlier, and there has been active promotion with patients themselves. We are thinking earlier about the types of support service users and patients may need*".

The Wakefield and Hull test site, in their work with domiciliary care workers, were keen to encourage the potential for their close relationship with people nearing the end of their lives and their families, since they are likely to spend more time with them than other groups of staff or professions. Not only could these staff work with the person and their families for a longer time span, supporting the family earlier in the pathway, but also their close relationship could be of benefit in recognising the need for other support.

The St Christopher's project aimed to raise awareness of the need to promote earlier end of life care planning amongst social workers and social care staff. One participant remarked that the training and support he had received from St Christopher's and the Guy's and St Thomas' projects had impacted on the way he thought about end of life care.

> *"…to be frank, at the time I really did think that it was about the last few days, in the hospital they talk about the Liverpool Pathway…but in my mind it was about the last few days and how you work with people and their carers and relatives – but then I came to realise that there is a sort of lead in…you start when people are relatively well and then you work along and the Liverpool Pathway is at the end of it – and that I think was one of the benefits of the training and something I could communicate to my colleagues back here"*
> *(End of life care lead)*

Test sites did recognise the need for earlier end of life care planning as well as the earlier involvement of social care staff in the end of life pathway. Success is associated with a number of factors including the understanding of the role of social care in the pathway and hence a holistic approach to assessing needs for and the delivering of end of life care.

OBJECTIVE 7: EDUCATE AND TRAIN SOCIAL CARE STAFF TO DELIVER HIGH QUALITY END OF LIFE CARE

Education and training are essential in not only changing the culture around and provision of end of life care, but also in delivering the recommendations made in the Social Care Framework. However, although only St Christopher's Hospice explicitly addressed this objective, most projects identified the key role of education and training in the development and provision of high quality end of life care by social care staff.

The Gloucestershire test site, although explicitly targeting the objective of strengthening the specialism of palliative care social workers in delivering training and education to a range of qualified and unqualified social care staff, also in fact addressed this objective. Their project team identified and gave training to a group of generalist social workers and assessors, who have a crucial role in supporting those at the end of life, yet have limited access to specialist end of life training and mentorship. This test site is also seeking to extend the provision of the training by providing extra training in mentorship, subject to funding availability.

The Norfolk test site focused a great deal on workforce development, despite not explicitly addressing this objective. During their project they looked at the process of training, how well it was working and what were knowledge levels, in part through a survey and also interviews:

> *"[our] survey showed us that Social Care did not have a lot of confidence on end of life care. There was a real desire to get this knowledge…need training and e-learning and work together and get this right." (Project lead)*

St Christopher's Hospice specifically addressed this objective with their training programme for end of life care leads, managers and social work/care teams. Project leads explained that they had developed their training programme in response to needs identified by the end of life care leads and their managers. The training provided necessarily focused on some of the more basic skills and knowledge required to assess needs and preferences and deliver end of life care, in particular, communication skills and an understanding of end of life care and the role of social care in this, which the project team felt were basic social work skills. For example, how loss is managed was of great concern to them:

> " We felt like we were going right back to basics. We sort of knew but it was still a shock – astonishing that loss as an issue is not threaded through social work because it is so central – loss underpins every aspect of social work…it is not covered in training…it is quite frightening…" (Project lead)

The training introduced the Social Care Framework and covered a range of topics including sessions on Advance Planning; the Liverpool Care Pathway and the Gold Standards Framework; how to talk about difficult issues; spirituality at the end of life and loss. The project also offered participants free places on a number of more in-depth training courses including Challenging Conversations; Advance Care Planning; Visible and Invisible Dying; and, Dementia and End of Life Care. The end of life care leads also participated in the Guy's and St Thomas' project which had covered (amongst other things) multi-agency working and provided information about resources available to support people at the end of life. Respondents who had attended the training courses explained that they had learned about the importance of holistic assessment of individuals, their carers, and their families and most felt they were better equipped to support people at the end of life , their carers and their families (see Section 4) although they still felt it difficult to talk about the end of life.

> "…we talked about dementia and the impact on family members as well as the service user, so we talked about how to support someone with dementia – they could be in pain but can't explain why – so that was quite helpful also the Advance Care Planning – that was good, to think with the person and the family what they might want before it gets too late for them to express what they want…what their wishes are…"(End of life care lead)

The test sites successfully developed and used a wide range of techniques, from workshops to reflective learning, and delivered education and training to a wide range of professionals and staff. They also demonstrated how successful such training can be through their internal evaluations and how it can both raise awareness and knowledge as well as confidence. Tools and training packages are available from the test sites, and will be of value to any organisation seeking to develop training and education for their staff.

OBJECTIVE 8: CREATE A SUPPORTIVE WORK ENVIRONMENT THAT ENABLES SOCIAL CARE WORKERS TO MAXIMISE THEIR CONTRIBUTION TO QUALITY END OF LIFE CARE

According to the Social Care Framework, end of life care is most effective when those involved are working in a supportive environment. For example, they should be able to have team discussions, and have access to specialist resources and support. Good leadership and management are also seen as crucial. Six test sites (all except Lancashire and Norfolk) had this as a specific objective. However all sites demonstrated how they involved and supported staff in end of life care.

Wakefield and Hull, in seeking to create a supportive environment for domiciliary care workers, stated in their final report:

> *Supervisors and managers of domiciliary care workers recognise the contribution the workforce have [sic] to supporting people at end of life. Domiciliary care workers display many of the competences to ensure quality care is received. What is required is the system change that allows time and flexibility to meet changing needs of people at end of life and their families.*

Gloucestershire used a reflective and supportive model for delivering their workshops, the purpose being to allow their targeted group of staff time to reflect on their skills, to consult with specialist care practitioners and to clarify referral routes to specialist services. Participants were also able to complete competency surveys, which allowed them to reflect on their skills and confidence levels in a supportive environment. The project team that ran the workshops believed that the workshops were successful in achieving their aim, and were a successful model for the delivery of education and training to this group of staff.

The Guy's and St Thomas' project aimed to create a supportive work environment by identifying end of life care leads in social care teams and clarifying their role in end of life care which included educating colleagues. The roles and responsibilities of managers in supporting leads and engaging in end of life care issues were also formalised. The project worked with these leads to indentify training needs, some of which were met by the St Christopher's project (see below). The end of life care leads also participated in a networking event attended local palliative care services and people at the end of life , and joint sessions with community nurses in order to increase multidisciplinary information sharing.

As noted above (and see Section 4), St Christopher's delivered training to these end of life care leads, their teams and their managers. Whilst it was evident that end of life care leads had benefited from their participation in both these projects, there were concerns, reported in the test site project report and by end of life care leads interviewed as part of this evaluation, as to whether managers would continue to support them in their role, this concern was echoed by managers who felt they required more training.

The Essex test site project was in the process of working towards meeting this objective, as noted earlier and elsewhere in the report, their main aim was to produce a strategy which

would detail how the local authority would work with providers and commissioners to meet the more detailed objectives.

All test sites recognised the need for a supportive environment for staff and had to a certain extent sought to develop such an environment through a variety of initiatives. As discussed in the Social Care Framework, such an environment comes from not only activities and processes, but also culture, management and leadership. Useful learning has emerged from the test sites in ways of ascertaining how staff can be supported, but also examples of initiatives that can be adopted.

OBJECTIVE 9: PROMOTE SUPPORTIVE COMMUNITIES THROUGH ENGAGEMENT WITH A WIDE RANGE OF COMMUNITY SERVICES

The Social Care Framework recognises the need to address the experiences of service users and carers as well as involving a wider community in the provision of end of life care. The wider community may include the voluntary sector and independent providers, and crucial to the delivery of high quality end of life care is the development of good working relationships across the statutory sector and these organisations. Of the eight tests sites only Norfolk and West Essex sought to address this objective. These test sites worked with a wide group of stakeholders during their projects.

Norfolk looked at the capacity of local services, although others, including the West Essex project had engaged with a wide range of community services (see Section 2 for examples). In addition, the Guy's and St Thomas' project held multi-disciplinary events which it was hoped, would improve knowledge about existing services and go some way towards improving multi-agency working. During the project, Norfolk found examples of good practice across all partnership agencies; however, during a survey administered to a wide range of staff, more than 50% of respondents did not appear to be confident about the range of practical support available. They also believed that information about the support available was not easy to find. One proposal coming out of the project was the need for a 'citizen portal' (probably an e-portal) to be a central repository of information for the community and professionals. Another interesting facet of this test site was the extensive engagement with a very wider range of services and providers (probably the widest of any of the test sites). As the project administrator (who organised meetings, workshops and project activities) commented: *"everyone was really engaged throughout…it was easy to get people engaged…everyone seemed interested and passionate for the subject"*.

West Essex had been working with partner organisations on numerous initiatives before the test site initiative. . As a test site they appointed a discharge facilitator who worked operationally across professional and organisational boundaries. They also worked across organisations to negotiate and secure health and social care packages of care. As reported in their final report, two key strategic successes of the project were*: "working in partnership with shared targets [and the] development of relationships between partners with the role creating a 'bridge' engendering a genuine 'can do' attitude: this included services such as transport [and] care agencies"*.

The two test sites explicitly addressing this objective demonstrated the value of engagement with a wide range of stakeholders including the wider community. Additionally, other test sites also worked successfully with a wide range of stakeholders and agencies, for example working with hospices. To be successful and effective, this engagement will be at several levels, and not just at an individual level but also at a whole system level.

OBJECTIVE 10: WORK JOINTLY WITH RESEARCH COMMISSIONERS AND FUNDERS TO ESTABLISH AN EVIDENCE BASE FOR GOOD PRACTICE IN SOCIAL CARE AT THE END OF LIFE

The development of the Social Care Framework highlighted the need for a stronger evidence base on the need for and the impact of social care at the end of life. None of the test sites explicitly addressed this objective; however three test sites (Gloucestershire, Norfolk and Wakefield and Hull), whilst not actually working with research commissioners and funders did collect information which could contribute towards an evidence base for good practice. A fourth, West Essex, collected data on the impact of their initiatives.

Wakefield and Hull used people's stories as evidence for the competencies of domiciliary care workers. By using an experienced member of a legitimate agency (Skills for Health), the mapping of the activities of domiciliary care workers against the common core competencies has external validity. The DVD to be produced by the test site will enable other agencies to use the mapping and will illustrate these competencies (although it will not contain the full range: several hours of evidence were reviewed by Skills for Health to determine the competencies).

Gloucestershire used tools developed by the University of Nottingham, to assess changes in confidence and competencies of attendees before and after a series of workshops. The tools were amended for the purposes of the project and were also administered and analysed by the University, who had originally developed the tools to support workshops on end of life care that they run. Unfortunately, at the time of data collection by the evaluation team, the analysis of results from these workshops had not been completed, although preliminary information was available. Norfolk also collected evidence on confidence and competencies of a range of staff as a baseline during their project; however although they did not use an externally validated tool, they too have an evidence base.

West Essex collected evidence on the impact of their initiatives. Examples include the increase in the number of individuals with social care packages or new and increased continuing health funded packages.

One of the aims of the Social Care Framework is to initiate a programme of stakeholder engagement and consultation (evidenced by many of the activities from the test sites) and evidence gathering and testing of new approaches with evaluations. The extent of the test sites' own internal evaluations was variable, however, robust evidence has emerged from three of the sites, and a fourth collected data on the number of individuals benefitting from their initiative. The collection of evidence and the testing of new approaches are likely to be patchy and variable, especially being reliant on the enthusiasm of individuals and a

willingness to expose themselves to robust and possibly external evaluations. On the other hand, it is also likely that in times of financial constraints, new approaches will only be implemented when accompanied by evaluations or audits in order to demonstrate effectiveness and possibly value for money.

5.4 RELEVANCE TO THE HEALTH AND SOCIAL CARE INTERFACE

During our interviews and case studies we collected information about partnerships and examples of agencies working together. All test sites comprised teams and activities which worked across a wide range of agencies. Three project leads were from health and four from social care; and one test site employed an external consultant with a background in health purchasing and commissioning to lead its project. The project summaries in Section 2 provide information about the partners working on the projects and also details of other organisations that worked on the projects, a number on a contractual basis to do a specific task, such as project management, evaluation, or external peer review.

Several themes in respect of partnership working emerged during the evaluation, both as enablers for the success of projects, but also for the delivery of project outputs. Interviewees often commented that these were unintended benefits of the project.

Firstly strong partnerships were identified as enablers to the success of projects. Partnership working, in particular sharing information and ownership was seen to be one of the benefits and an output of the projects. One project lead commented that *"the most startling success was the enthusiasm that all stakeholders and partners showed in engaging with the project".* A number of respondents stated that the project was only successful because of partnerships.

> *"[organisations] learned from each other and created a better result" (Project lead)*

One project lead observed that there had been little involvement from the local PCT. However she was not overly concerned as the project itself reported back to a multi-agency Palliative Care Partnership Board, so they were aware of the project and its findings, but in respect of having a partnership with this organisation and clinical staff, she observed that "*It has been difficult".*

Secondly, projects enabled the development of new partnerships. It appears in most localities these partnerships have been sustained, even though the project is finished, and the recommendations from the project will be taken forward by the partners as well as continuing to support earlier work upon which the project built. A locality care manager commented:

> *"It was a short term project, but relationships will be long term now because of the project" (Locality manager)*

A second project lead commented that:

> *"We had worked with the hospital team for a while and know them but the project strengthened the relationships, and it may develop in other areas…and in other areas positive partnerships are developing".*

Thirdly, even where no new partnerships were developed, existing partnerships appear to have been strengthened: as an NHS Commissioning Manager commented:

> *"…no new relationships evolved, but existing relationships were developed and strengthened" (Commissioning manager)*

In another project, a social care manager had joined the local End of Life Care Group as a result of partnership working within the project, and is now a member of a sub-group looking at advanced care planning across health and social care.

Fourthly, project buy-in from partners and from key stakeholders was seen as crucial to ensuring the projects went well. As one project lead observed, *"we had fantastic buy-in".*

Engagement with partners was also seen as crucial for taking the findings and outputs from the projects forward. Norfolk, had seen significant partnership working, and the project lead commented in their final report that:

> *Significant gains can be made had by all practitioners working together under the shared umbrella of the integrated care organisation and the GSF. Palliative and end of life cases frequently involve close collaboration between health and social care, and the review highlighted that integrated care coordinators, multi-disciplinary team meetings and casework managers are starting to align and coordinate health and social care.*

5.5   VALUE FOR MONEY

One of the criteria against which proposals were to be judged for selection as test sites was value for money. In this section, we comment on whether test sites did demonstrate value for money, and whether the outputs from their projects contributed to a greater understanding of cost effectiveness and value for money.

The proposal from the Lancashire test site indicated that their project would be cost effective, for example by describing how some of the key infrastructure to enable the project to deliver its objectives were already in place, and emphasising the value of the planned outcomes. Two of the proposals (West Essex and Norfolk) addressed the financial costs of health and social care provision, although neither of these projects included information on financial costs in their final reports.

Wakefield and Hull had planned to test their findings on the value (and presumably cost effectiveness) of domiciliary care workers by using a financial model that had already been developed for local NHS use, and this was cited as one of the reasons why the proposal looked attractive to the NEoLCP on selecting those test sites to be funded. Unfortunately,

the project team found that the timescale of six months, plus limited resources precluded its use. The project however did deliver alternative and valuable outcomes

The West Essex project had expedited hospital discharge and believed that this would have resulted in savings, especially if their model had been rolled out. One of the aims of this project was to reduce the numbers dying in hospital but it also aimed to get people to their preferred place of care more quickly. The Wakefield and Hull project addressed, in part, the issue of inappropriate referrals to their local intensive social care home support team, as well as emergency services and rapid response teams, by reviewing the commissioning of domiciliary care provision in their locality.

Gloucestershire considered whether the workshops that they had designed and run had been cost effective. They commented in their final report that "*a significant measurable improvement in confidence in staff can be made in a cost effective time frame of half day workshops…*"

No attempt was made to quantify the costs and potential savings in any of these projects and therefore there is no quantified evidence as to these claims. On the other hand, most (but crucially not all) of the test sites' objectives were met, and even where explicit objectives were not met, the learning from these test sites (such as issues to be addressed with personal budgets for people in receipt of end of life care) are themselves of value.

The funding awarded to test sites ranged from around £10,000 to £35,000, which were relatively small sums. The activities proposed and delivered by the test sites were extremely wide ranging, and it is not possible to comment whether one project delivered greater value for money than another. All test sites delivered important findings and learning, and in many instances, tools and methodologies, all of which are transferable for other localities. What is important is that the lessons learned from the test sites in respect of what worked, did not work and why are taken on board by those wishing to engage social care in end of life care.

5.6   SUMMARY AND DISCUSSION OF FINDINGS

Some objectives were more commonly addressed (5 and 8), whilst objective 10 was not explicitly addressed by any test site. Although none of the test sites chose to contribute to the evidence base in this way, all test sites nevertheless contributed to the knowledge base and three collected quite robust data which could contribute towards an evidence base for good practice. It was interesting perhaps that only two test sites had the explicit objective of raising awareness of the role of social care (objective 1) yet this was something all test sites did in one way or another. Facilitating commissioning and embedding end of life care in commissioning (objectives 2 and 3) were addressed by four sites. Progress was made towards meeting these objectives, although problems and challenges were also recognised, and for some the experiences and findings from the projects were contributing to the development of local cross-agency commissioning strategies. Strengthening the specialism of palliative care social work (objective 4) was only addressed by two test sites; one identified their crucial role in developing the workforce and the second in developing and supporting palliative care champions.

The promotion of understanding and best practice in holistic assessment (objective 5) was addressed successfully by five tests sites. Tests sites mostly achieved this objective by awareness-raising and education. The promotion of earlier end of life care planning (objective 6) was addressed by three test sites, although the involvement of social care earlier in the pathway was a theme throughout many projects. Training and education again supported the achievement as well as the recognition of the role of the domiciliary care worker. Only one test site explicitly address education and training of social care staff (objective 7), yet as can be seen from many sections in this report, all sites recognised the key role of education, and addressed this objective in numerous ways including workshops, awareness-raising, and the development of training strategies. The creation of a supportive work environment for social care workers (objective 8) was addressed by six test sites, again in part by training, education and awareness-raising, but also by clarifying their roles, and working in partnership with other agencies. Promoting supportive communities (objective 9) was addressed by two test sites, by engaging with a range of community services, which also contributed to awareness-raising. Gaps in services were identified and mechanisms for addressing these identified.

All test sites demonstrated in numerous ways their working together with other agencies (we have summarised partnerships and agencies in our project summaries in section 2 of this report). Project staff came from a variety of backgrounds as did members of project teams, and we noted that most projects reported to multi-agency boards and groups. The role of partnerships as an enabler for the success of projects was recognised and buy-in was seen as critical. Project teams forged new relationships and also strengthened existing relationships.

One of the criteria against which proposals were judged was value for money, however due to the wide range of outputs, from the quantifiable such as the number of workshops and attendees to the unquantifiable such as the development of a strategy, it was not possible to comment on whether one test site gave better value for money than another. Three projects did claim to be delivering cost effective solutions or developing models that would save money (such as reducing the deaths in hospital), but there was no quantifiable evidence for these claims. However, there were useful outputs and valuable learning emerged from these test sites.

Section 6:   Key Enablers, Challenges and Lessons

6.1   INTRODUCTION

This section discusses evidence on enablers and keys to success, as well as barriers and challenges faced. Most of the findings were key themes running through all projects. We also consider the sustainability and replicability of the projects and their findings, as well as drawing out and summarising the key lessons.

6.2   ENABLERS AND KEYS TO SUCCESS FOR UNDERTAKING THE PROJECT

Established working relations and a commitment to improving end of life care

One of the main enablers or keys to success highlighted by many of the test site projects was that they already had established working relations with relevant partners and key stakeholders who had an interest in, and commitment to, end of life care and the role of social care within this agenda. Broadly ensuring there was support for the project before embarking on it, was crucially seen as an enabler to its success. Five projects [Norfolk, Wakefield and Hull, Guy's and St Thomas', West Essex and Essex acknowledged that they had built on existing and well developed relationships including those developed through previous or ongoing projects and programmes such as the Modernisation Initiative, the implementation of person-centred tools including the Living Well project and the Marie Curie Delivering Choice programme; as well as a range of other end of life care and Quality Innovation Productivity and Prevention[21] (QIPP) working groups. This meant that some (although not all as will be seen below) projects were able to 'hit the ground running' and begin working towards meeting their objectives without the need for a great deal of development work, which, respondents explained, would have been difficult given the short timescale for the projects.

> " [The timescale] … would have been extremely difficult had we not had the infrastructure we had. It takes time to build up networks and relationships. But we were able to hit the ground running as we had already had contact with [another area] which had done similar work and [senior manager] had already done some work around it [end of life care]" (Project Lead).

Norfolk collected evidence from a variety of sources using several methodologies, such as questionnaires, focus groups and interviews, and recognising the potential complexity of their project, focused on collecting evidence from and using existing relationships. They

---

[21] For more information on the QIPP Agenda go to

: http://www.improvement.nhs.uk/Default.aspx?alias=www.improvement.nhs.uk/qipp

termed these 'relationships of trust'. One partner already had a person-centred programme in place, and a second had a Community Development Team and links with user groups through the Patient and Public Involvement Team. They also acknowledged that the existing relationships between partners, the project team, and links with key people within the local authority and their domiciliary care team helped enable the project team deliver the majority of their objectives.

Engaging key stakeholders

Good communication and engagement between key stakeholders and the project teams and activities was also seen as important across all projects. For example for those test sites addressing training and development, stakeholder engagement was crucial for organising workshops such as through holding discussions with operational managers. This ensured project buy-in, and hence increased uptake of workshops. Planning of these workshops was also seen as crucial to their success for Gloucestershire, including using an external consultant with whom ideas were "bounced off" The project lead believed that *"we did find that the project was innovative, there has been training in other areas, but it may not be focused on a workshop as a model or this content, nor targeted in this way."* The workshops were also held in a variety of localities which encouraged participation. Similarly (see Section 4) the Norfolk, the St Christopher's Hospice, and the Guy's and St Thomas' projects had consulted senior managers and social care staff about their training needs and then provided training sessions and other activities for senior managers and social care team managers in order both to improve their understanding of end of life care and to encourage their engagement with the project.

The support of senior managers proved important for other reasons. As noted in Section 3, due to delays in the procurement process and the funding of the test sites, a number of projects would not have commenced without the support of senior managers who agreed to cover the costs of the project had this proved necessary.

Respondents also explained how important it was to have an established infrastructure and the commitment of key stakeholders who were willing not only to give of their time, but to provide the necessary resources to meet project objectives. This included seconding staff to work with the projects and allowing staff members to attend courses as well as providing support structures and where necessary, funding for example, for training. This willingness to set aside additional resources at successful test sites demonstrated that localities and agencies valued their outcomes, and also a longer term commitment to supporting aspects of end of life care.

Having the appropriate skills to deliver the project

Another key enabler identified by respondents was having people (either existing members of staff or people appointed specifically to help deliver the initiative) with the appropriate skills to deliver the project. A number of project leads and partners as well as respondents who had participated in training programmes or other project activities remarked on this. Again, because the timescale for the test site intervention was tight it was important to

identify or appoint project workers who had the skills, experience, attitude and enthusiasm to start working towards the project objectives without lengthy training. Clearly in some test site areas training and development work was necessary (see below) but it appears that careful selection of key personnel, as well as having established relations with key stakeholders committed to end of life care, reduced this need to a minimum. Examples of observations about key stakeholders at two projects are:

> *"[Name's] role cannot be underestimated – she went to people's workplaces to meet them and talk about the project. She kept in touch with them over the 'phone and by e mail. She has a very good understanding of the realities for people in operational posts, she is a very experienced facilitator and she has a background in social work …A very skilled communicator and very, very good at engaging people. That was one of the real strengths of the project"* (Project lead)

> *"One of the really clear impacts of the project is that people are talking about it and a lot of that is down to [name] and her work…a year ago there weren't a lot of people talking about end of life care in their day to day work but now they are… A lot of us have worked with [name] before so that always makes a difference – she is so enthusiastic…she is so committed to it and driven..."* (Manager, social services)

This was also something commented on by respondents such as this social worker who had participated in training and activities delivered by two projects.

> *"The quality of the training – I was just so impressed by it…they were so well set up to communicate End of Life in their teaching and training – it was absolutely fantastic…"* (End of life care lead)

Projects which directly involved service users and their families commented on the enablers to involving users in the projects. Building trust was cited by two interviewees; "*because they feel safe…they trust what we tell them*" (Project lead)*.*

6.3   BARRIERS AND CHALLENGES

Project Engagement

The Wakefield and Hull project team commented in their final report that the problems they faced were in respect of the range of the methodologies used and balancing what could be done within the timescale. The project lead also commented that *"I have responsibility but no authority re getting the project done…need people to be willing".* This was echoed by another project lead who reflected on achieving buy-in and support from operational managers in order to enable local staff to attend the workshops. Issues discussed elsewhere in this report such as social care not recognising that end of life care was 'their' problem as well in itself creating a barrier; as one project lead commented "[there were] *issues in getting through to managers"*.

Additionally, financial problems and cuts in budget cuts were seen as a barrier as teams had lost staff which had caused significant pressures in trying to release staff to engage with or attend project activities, which were frequently seen as additional to staff day to day job. A typical comment was:

> *"..because it's not part of social work or district nurse practice, for example, it's just seen as something else to do. We're too busy and it's not relevant. It's not been high enough in any organisation…everyone is going through such significant changes". (Project lead)*

One project lead believed that there were problems in finding staff cover to enable people to attend workshops, and another that the workshops were less of a priority. This in part reflects that fact that the projects were taking place at times of uncertainty and change for health and social care, and therefore the commitment of resources to the projects may have been problematic for some localities.

Whilst most of the test projects were able to start on time (despite some problems with the commissioning process described earlier) setting up projects, engaging with partners and key stakeholders, and briefing staff was time consuming. Many commented that project activities were delayed as a result. For example, the project team using filming as a means of collecting evidence on competencies were concerned about their ability to recruit people and organisations due to initial suspicion about the purpose of the filming. In particular, one manager had concerns; however once it was explained that any DVD would be used as a training tool, filming was allowed.

The Lancashire project team acknowledged that they had seriously underestimated the awareness-raising and education needed:

> *"…there was a lot of groundwork that we probably didn't realise we needed, which took until Christmas. We certainly underestimated the amount of education needed…also there were delays over the Christmas period. If we tried to do this again, we would bid for two-year's worth of money with a six-month lead-in period for education and awareness-raising." (Project lead)*

Problems with the delivery of care packages

A number of respondents explained that securing care packages and co-ordinating services was problematic. In West Essex, community services explained that whilst the joint discharge facilitator had helped to improve matters and to expedite discharge to the preferred place of care, barriers remained. These barriers related to the shortage of resources and gaps in provision; the time taken to organise and deliver appropriate packages of care; a lack of clarity about who should be responsible for providing care; bureaucracy; and the complexity of health and social care provision and funding regimes. Added to this, a number of health and social care workers commented on the fact that procedures vary from area to area.

*"One of the problems is actually having the resources there – you might know
they are there but because of funding cuts and restrictions it is difficult and
sometimes we find that services don't really – say someone has a Continuing
Health Care Need and in the past they were getting services from social
services – there can often be a gap in provision, the transition is not always
smooth…so there are problems for people – some think that it should be up
to the NHS and others think it is up to us…not thinking about the benefit to
the person who we should be thinking about" (End of life care lead)*

*"…you are reliant on a number of different services to be put in place and it is
the resources that are quite often the problem, particularly with the care
aspects, there is the Continuing Care funding which is in my experience can
be quite difficult, not quite so if it is fast tracked but there is still a time delay
on that" (Community Matron)*

Respondents also felt that bureaucracy and a lack of uniformity in processes and
documentation across local areas (and nationally) caused delays and confusion, and also
meant that people nearing the end of life in some areas had far less choice than those in
others. Variability in language and terminology could also be problematic.

*"Discharge forms are lengthy and a pain – different ones for different areas –
no continuity - or uniformity...and we don't have the same access to care
across area boundaries – there is different provision in different areas...
People can't make choices in all areas because the care is not available, for
example, in one area a patient could not go home as she wished because the
PCT won't provide 24 hour nursing care – so she had to go to a nursing
home…It's a National Health Service but it doesn't feel very national
sometimes." (Discharge facilitator)*

Others made the point that if service users, their carers and families were to be confident
about staying at home then they had to be sure that resources were available whenever they
required them.

*"…but I think the biggest barriers are to do with care aspects…and fear as
well especially if it is a patient that is going home to family – it is that family's
fear of how they are going to manage, how can we access resources very
quickly if we need to…and unfortunately within Community Services we don't
have 24 hour nursing teams at the moment – we work from 08:30 until 22:00.
Out of hours GPs can be an issue" (Community Matron)*

A domiciliary care manager explained the importance of having correct care packages in
place and in good time:

*"You have to get discharge information in good time… Getting assessments
done – having packages in good time – it puts a lot of onus and stress on the*

> *domiciliary care workers – it is not nice for them to have to leave a patient*
> *who is ill and in great pain…"*

Personal Budgets

The Lancashire project was focused almost entirely on identifying and enabling those at end of life to have personal budgets. The Norfolk project also sought to collect information about those at the end of life on personal budgets. Both project teams were thus able to reflect on the relevance to and problems with personal budgets for this group.

The aim of the Lancashire test site was to include those receiving care from the local hospice in the personal budget process, as currently it was seen as an additional service (being block contracted by the local Adult Social Care). This test site, as one of its local objectives, sought to use the personal budget support planning tool as a holistic plan. The project team recognise, however, that this objective was only partly met. The number of people at the end of life who chose to have a personal budget was low (three during the duration of the project), although staff had discussed the possibility with a further three.

They also reflected on the complexities of personal budgets, together with the need to become engaged early in any plan in order to plan these services properly, problematic for social workers already. The concept of a personal budget can be complex to understand for social workers and service users. An issue may be that those at the end of life in receipt of treatment may not be able to manage the personal budget (although it is only a virtual budget), whilst having treatment as well:

The Norfolk test site aimed to collect information about those approaching end of life who were on the local Social Care database and who were also on personal budgets. They only found three clients that had personal budgets. Firstly, they discovered that those clients on end of life care were not well recorded on the data base, and hence were difficult to identify, and secondly that personal budgets seemed only to apply to people who were stable at end of life. As they became unstable, the continuing health pathway appeared to be the preferred option.

However, they found that the personal budget process was very slow and time consuming, and they did try to find ways of working around this. One suggested solution was to use a voluntary sector organisation which had a budget for palliative care; which would allow staff to be utilised quickly, although the funding would have to be sorted out later

In order to address these perceived problems, the project team made a series of recommendations (as detailed in their final report) to improve take up including encouraging staff to review and where feasible set up personal budgets for end of life cases, and collecting examples of good practice of where personal budgets are suitable (and possibly less suitable) to give staff more confidence in recognising and setting them up. These observations about the relevance of personal budgets for those on end of life care pathways are crucial given that there is wide encouragement for people in receipt of social care to access personal budgets.

Information sharing and communication

Although many of the test site projects had sought to overcome challenges around information sharing and communication between the various agencies involved in co-ordinating and delivering end of life care, through training, multi-disciplinary networking sessions and working with partner agencies to improve and expedite processes (see Section 4) many reported that challenges remained. A social care end of life care lead who had undertaken training from St Christopher's and attended multi-disciplinary workshops and events organised by the Guy's and St Thomas' test site also remarked that although she had learned a good deal about end of life care' people's right to choose where they were cared for and the role of social care in end of life care, in practice there remained barriers to effective working.

> "Hospital discharge team can be a problem – lack of information- they are supposed to send notifications and discharge notes etc but it doesn't always happen…that can be a problem if someone is discharged without the correct care package in place. The training has helped a bit but doesn't help overcome these barriers – what it has done is help me understand how I can help people have a good death – I used to think it was better for people to die in hospital and now I understand that the type of support people need can be provided in the community. If that is what their choice is it should be made possible."

Talking about end of life

The unwillingness of some individuals to talk about end of life care was perceived to be a problem by respondents across the test site areas and even social care workers who had undertaken training explained that they still found it difficult to broach the topic. A number of respondents explained that people's personal experiences of loss were often a barrier to their engaging with end of life care and that they too might require support. Others made the point that it is not only social care workers who find it difficult to talk about dying, but other experienced professionals including nurses, doctors and other health professionals.

> "I think end of life care is still something that is maybe a very tricky subject for some nurses; we have found this looking at PPC [Preferred Priorities for Care] – they have difficulty discussing this – I have it within my own team..., I still find it difficult especially with younger patients I have to say…(Community Matron)

The Guy's and St Thomas project (which had undertaken discussion about end of life care with residents of a sheltered housing scheme) and the West Essex project (which worked directly with people nearing the end of their lives) reported that some service users had been keen to talk about end of life care, not all were. This was a particular problem for the West Essex project which found that whilst people might be happy to talk about their wishes, they were unwilling to formalise these in written Preferred Priorities for Care documents. In this case it meant that information which may have been spoken but not

formally recorded could not be shared with other professionals and this was thought to have resulted in unnecessary readmissions to hospital.

It was also observed that several of those attending workshops may be from different cultures and healthcare systems, possibly having different communication skills and different ways of thinking about death:

> *"English culture and looking at death and why we do what we do is different to what the nurses from Africa [do] who see death all the time." (Project co-facilitator)*

A lack of understanding of what end of life care means

Although the test site projects had worked to raise awareness and knowledge of end of life care a number of respondents made the point that people working in health and social care were confused about the meaning of end of life and still tended to talk about the very last days or weeks of life. One end of life care lead who had undertaken training in end of life care explained what she understood by end of life:

> *"I think when someone is diagnosed with a terminal illness and they know that they are going to die…."*

Another respondent explained that even healthcare professionals such as nurses failed to see the relevance of end of life care and Preferred Priorities for Care for elderly people.

> *"…there are some [nurses] who think 'well, they are elderly, why do they need a PPC?' So, because, I think it is fine when they have a cancer diagnosis or when there is a very definite illness but they find it very difficult when we are dealing with frail elderly and there are some patients who don't have a specific diagnosis, they are just old and frail but that still means the end of life care should be the same" (Community Matron)*

6.4   SUSTAINABILITY AND TRANSFERABILITY

Project teams in their final reports for the End of Life Care Team were asked to comment on the sustainability and transferability of their project findings, including reflecting on the potential for wider dissemination and routine practice. We have not replicated the findings from these reports; however, we have summarised and identified in this report key themes, and have also included evidence gathered through the site visits and interviews.

Sustainability

All eight project leads described how they would seek to continue the project or build on their achievements within their locality. This was to be achieved through presentations to, and on going engagement with, key stakeholders such as local End of Life or Palliative Care Boards, operational managers, Palliative Care Champions, PCTs and GPs. The

Gloucestershire test site project was seeking funding to take forward additional workshops, following positive feedback from those participating in the workshops run during the project. St Christopher's was in the early stages of negotiating a contract with a local authority to deliver end of life care training, this was as a direct result of the test site initiative. A number of project leads stressed the importance of ensuring end of life care remained a priority, particularly during the present climate of swingeing budget cuts and reorganisation.

> *"... there's a lot of change and reorganisation at the moment and all we can do and what we are doing is to try to get this out and open it up to as many people as possible so that we capture the right people and groups at the right level but what we will have to do I guess at a later date within our Strategic Workforce Planning Group – at that group we have representation from mental health and the PCT and lots of representation – so if we share our information with that group then it will be disseminated more widely to all the appropriate people –there is a lot of restructuring and a lot of people are moving about and I don't know what the picture is going to look like in a few months…but I think it is about making sure that we take steps to make sure that the information gets out to the right people and that they can then share the information as appropriate" (Manager, social services)*

Another project lead was drawing on evidence from the test site intervention to build a business case for a joint health and social care discharge facilitator post.

> *"We are putting together a business case for an integrated post…people will say 'you have a Marie Curie nurse, you've got a Macmillan nurse' but they are missing the point completely because they are different. I think the data and evidence is there – but it will be down to being able to make a business case. I think we have got the evidence and material to show how this fits and that it is something different and unique." (Project lead)*

The report from the Norfolk test site described sharing findings from the competency surveys undertaken to develop a joint palliative care and end of life strategy and training plan. As a result of the project, during which problems were identified in the storing and accessing of information about services for people with end of life care needs, the Local Authority is working on updating their information portal, by creating a Citizen Portal. The Lancashire test site report described how a separate spin-off project was being developed as a result of the involvement of the signposting agency in helping people access low level support through holding regular clinics at the local hospice. Local GPs were also being encouraged to direct people to their services. Additionally members of the project team described how they were investigating a project based on 'Time Banks', whereby they would build a community network for befriending services to help people with their practical needs. This would be similar to the MacMillan scheme 'A Little Bit of Support", but instead of employing people (as do MacMillan), their scheme would use community volunteers. Initial consultation with people nearing the end of their lives and carers is currently taking place, the purpose of which, in part, enables the project team to collect information about the availability and access to community and universal services for people with end of life care needs, and hence to identify gaps in services.

The Wakefield and Hull test site described how they were intending to use under spent contingency monies from their project budget to complete and issue e-learning material complete with a DVD, to enable people to identify the required competencies for domiciliary care workers to take on some of the roles of key workers. According to their final report, in one locality, a common advanced care planning tool has been agreed and training is being developed around key worker competencies to include domiciliary care workers. In a second locality, plans to utilise re-ablement monies to develop a 24 hour end of life domiciliary care service are being developed. However, one of the key stakeholders from their local authority acknowledged that their personalisation agenda has been delayed in part due to internal restructuring, but that they have recognised the need to refocus on sharing good practice.

A number of project leads noted that if the work of their projects was to continue then this would require ongoing commitment. One project lead and a number of respondents who had participated in training programmes delivered by test site initiatives remarked that whilst management had been supportive of the initiatives and allowed staff time to attend sessions, they were concerned that this support might be difficult to sustain. A few respondents noted that whilst the public sector is subject to almost continual change, restructuring and reorganisation, the current period is one of even greater uncertainty than usual. Added to this, spending cuts were also a concern.

> *"I don't want to lose sight of end of life care in the midst of everything else that is happening at the moment, restructuring and so on...Spending cuts, reorganisation and uncertainty –there's lots of good advice about best practice – but it is difficult when there is no money, no time, no resources" (Senior manager, social services)*

Interviewees who raised the issue of constant change and staff turnover accepted that whilst it was a fact of life currently it was essential to formalise agreements around end of life care and to embed end of life care in strategies, action and delivery plan, training and commissioning.

> *"…it needs commitment from managers and operational staff re changing practice. The Social Care Framework is about this. But we are struggling with this. In this world we tend to do the must does. The Social Care Framework is a nice to do, but not a must do. Unless these project objectives become must does, they won't happen" (Project lead)*

Dissemination

Evidence was collected from test sites on plans for dissemination of the learning and the findings from their projects. The Wakefield and Hull project team produced a large document, which they believe will be a valuable asset along with a companion DVD; one of their sections in the report is entitled *"A call to action":*

> *This report is an invitation to the social and health care communities, commissioners, people and their informal carers to draw on the insight from these real stores and help change practice. The project team have plans to*

make the work sustainable within our local areas and it would be a real return on the investment if others use and build on our work.

A key stakeholder from the Lancashire project was keen to disseminate and increase awareness about their local signposting services:

…"the more staff who know what we do, such as GPs, domiciliary care workers and social workers, and who have conversations with others about what we do, the better. It doesn't have to be anything formal, it's as much about awareness-raising" (Field navigator)

Members of the Wakefield and Hull team had already presented findings from an earlier end of life project in the national End of Life Care Programme Newsletter, and it is possible that findings from the projects will feature in future editions. The Gloucestershire Team presented a poster to the European Association of Palliative Care Congress in mid-May, and presented their project at the Help the Hospices Conference in September. The Project Lead was also asked to organise a session at the Association of palliative Care Social Workers' Conference. The St Christopher's Hospice team planned to write articles for publication whilst in Essex, the test site activities and developments were reported in the Council's electronic news bulletin. Finally, the National End of Life Care Programme team is planning a national conference at which findings from the projects will be disseminated.

Transferability – key lessons

Findings from the test sites can be transferred to other localities. For example, outputs such as training and development packages and methodologies can be adopted by organisations taking on board the learning of the test sites on successful delivery of initiatives. Organisations seeking to implement certain initiatives should draw on the key learning from test sites on initiatives such as the role of personal budgets, or the value of low level preventive services.

All the test sites sought to address their Social Care Framework objectives. In section 5 we examined in some depth how far these objectives were met and the learning from them. Many of the objectives also would require a longer time scale to be met, whilst other could be met incrementally. The learning from the test sites' successes in meeting these objectives should also be of great value for those seeking to address them locally.

The test site project final reports also made a series of recommendations for those wishing to take forward findings. Recommendations covered project management issues, such as using established partnerships and partnership mechanisms, communicating with all stakeholders, and ensuring leadership and senior management buy-in.

I cannot overstress the importance of having senior social care managers who absolutely get that that social care has a place in end of life care (Project lead)

In addition to the partnerships forged within the test sites, several interviewees commented on the need to continue to build bridges, for example with their local authority (by those from healthcare) and vice versa.

> *"…I think what is really important is to support local senior managers and commissioners – to actually have some forums where they can come together to talk about end of life care…" (Project lead)*

Project leads also commented on the need to link to general practice, especially making links to Gold Standard Framework processes. Two test sites explicitly involved GPs, but recognised that these were supportive of the project and desired to improve end of life care, and a third test site involved GPs and their staff in their Project Board and in briefing sessions, especially about personal budgets and the role of the signposting services. Other respondents, including social care workers who had participated in the projects, also stressed the importance of networking and multi-disciplinary workshops and activities.

> *"If you can't do anything else, get people together to find out what people do – including service users - so that people can hear about experiences from a different perspective" (Project lead)*

All test site projects were of a relatively small scale in respect of funding and timescale. In part this allowed them to be relatively easily replicated by other localities and organisations. Whilst the projects and their teams engaged with a wide range of stakeholders, they were normally driven by a designated project lead (usually already in post) with the support of existing infrastructure to act as project board or steering group. The very act of working with the multi-agency stakeholders and project management in part address some of the Social Care Framework objectives, and is of value in itself.

6.5   SUMMARY AND DISCUSSION OF FINDINGS

Enablers and keys to success were identified as establishing working relationships and having a commitment to improving care; engaging and working with key stakeholders; and having the appropriate skills to deliver the project. Barriers and challenges comprised issues around the extent of project engagement, for example as councils and social care departments were being faced with financial constraints and job losses (many test sites lost key staff in the middle of their projects); problems with the delivery of care packages, including resources, bureaucracy and the coordination of services; the delivery of personal budgets, including identifying those who would be suitable and developing the confidence in staff; information sharing and communication; talking about end of life; and a lack of understanding about what end of life care means.

All test sites aimed to continue their projects or build on their achievements through new and related projects. Examples included joint education strategies, a joint discharge facilitator, the development of e-learning packages, and the development of a community volunteer scheme. Project teams recognised that there would always be staff turnover and resource

constraints, therefore it was important to embed end of life care in strategies, action plans, training and commissioning.

Test sites also indicated their willingness to disseminate findings and several had already participated in conferences, as well as undertaking local awareness-raising. All test sites also made recommendations for those wishing to take forward their findings and initiatives. All project teams believed that what they had done was replicable elsewhere, for example the workshops that had been developed could be run anywhere. Key findings were mostly in respect of partnerships, training and development and continual awareness-raising, embedding end of life care in local strategies, the valuable roles of different professions such as domiciliary care workers, social care workers and preventive services, and ensuring that there is effective signposting and information to enable people to make choices at the end of life.

Section 7:   Key Messages

7.1   INTRODUCTION

This section draws together and summarises the key messages from the test sites and from the evaluation. The key messages are summarised under a number of emergent themes.

Perhaps the overriding message is that these are projects which any organisation, agency or locality can replicate. The projects were small, with modest funding, and undertaken in a relatively short timescale, yet they produced valuable outputs and learning. Individual projects have demonstrated which initiatives and activities are more valuable than others or are more effective in some situations or with certain individuals. Some have developed models which could be used by others, for example, the End of Life Care Delivery Plan developed in Essex might prove a useful model for others wishing to develop a county wide strategy, similarly the various training initiatives such as that developed by St Christopher's Hospice could be adapted for use elsewhere.

Section 5 above reports in some detail how the test sites addressed the 10 objectives of the Social Care Framework. The findings of the evaluation also allow for some further reflection on the 10 objectives themselves. All the objectives are clearly relevant to improving social care practice at the end of life, but the evaluation suggests that some may need to be prioritised.

The test sites demonstrate that awareness and understanding of the role of social care in end of life care is not high generally and that buy-in from senior management from a range of different agencies, supported by end of life care champions, is key to taking the end of life care agenda forward. Those Social Care Framework objectives that focus on raising awareness (Objective 1), facilitating commissioning and delivery of person centred care (Objective 2), and improving standards of practice (Objective 3) would seem to be where the greatest effort should be directed. Other objectives, for example, developing supportive working environments (Objective 8), earlier planning for end of life care (Objective 6), to educate and train social care staff to deliver high quality end of life care (Objective 7), promoting supportive communities through engagement with community services (Objective 9) and developing an evidence base (Objective 10) will flow from a greater understanding of the role of social care in end of life care. Enhanced understanding, particularly among those who are in the position to engage with other key stakeholders and agencies and to commission and shape services, would appear to be the crucial first step.

7.2   ROLES WITH RESPECT TO END OF LIFE CARE

The test sites were successful in meeting the key objective of identifying and raising awareness of the role of social care in supporting people at the end of life but informants also emphasised the importance of reinforcing this message. As expected, many social care workers did not recognise their role in end of life care. The test sites also found a lack of awareness among other professionals including doctors and nurses. The test sites

demonstrated that all manner of people and professionals have a role in end of life care, and many of the projects included a diverse range of agencies and individuals in order to raise awareness of their respective roles and contribution to end of life care. Mechanisms to raise awareness included multi-agency workshops, meetings and training sessions. These event s included not only social workers but also for example, community nurses, support staff such as domiciliary care workers, hospital transport workers, funeral directors, and individuals who deliver preventive services such as handypersons services.

A key finding from the test sites was the importance of palliative care or end of life care leads or champions. Test sites demonstrated the value of promoting and supporting the role of palliative care champions and end of life care leads. However, it is also crucial to ensure that not only is there is clarity about what are their roles are, but that these roles are formalised, and supported by managers.
 It is also important to ensure that information and knowledge about end of life care are disseminated to social care team members at all levels on a regular on-going basis so that the end of life care issues are constantly reinforced and that new members of staff are aware of the issues and their role in end of life care. Finally, it must be appreciated that those who work with people approaching the end of life may find talking about care at the end of life difficult. This evaluation found that some individuals who had received training as part of test site initiatives still found it difficult to talk about end of life care.

7.3   UNDERSTANDING END OF LIFE CARE AND END OF LIFE PATHWAYS

Many of the test sites were successful in improving understanding about end of life care through the delivery of their various initiatives. However, it was clear that many of those involved in the test site initiatives were surprised by the lack of understanding among social care workers and other professionals, including doctors and nurses about what end of life care is and when it should begin. It was evident that many health and social care staff associated end of life care with terminal illness, palliative care, and the last few days or weeks of life. Although many of the test sites were addressing some of the steps of the end of life care pathway, respondents tended not to talk about the end of life in these terms and often still tended to think of only one or two steps, in particular, the last days of life, rather than over the longer term. The need to reiterate and reinforce the notion of the end of life pathway as a process if end of life care is to be addressed holistically is a key finding from the test sites. Anyone thinking of developing initiatives to improve and extend the contribution of social care in end of life care must be aware of this very low level of understanding amongst many key professionals including trained social workers and healthcare professionals (and not just social care workers).

Nevertheless, the test sites demonstrated the valuable contribution that social care can make to end of life care, and how the steps for an effective pathway are underpinned throughout by social care input. A key message is that social care must be engaged at an earlier stage in the end of life care pathway. Social care support takes on many forms, for example, domiciliary care workers have been shown to fulfil a key role as part of a multi-agency team, and low level preventive support is also valuable. Conversely, end of life care

must be included in social care assessment forms and other relevant documents such as hospital discharge forms to ensure that these issues are explored, recorded and acted upon.

7.4   ENGAGING STAKEHOLDERS

All the test site areas worked with a wide range of stakeholders and emphasised the importance of engaging relevant individuals, agencies and organisations in developing and/or delivering the initiative. The relevant stakeholders varied depended on the type of initiative (see Section 2 project summaries for details of the various agencies and organisations involved in each of the test site projects) but included professionals from all health and social care sectors. The test site project leads explained that an effective way to engage key stakeholders was to involve them in project planning and project management or steering groups. Multi-disciplinary training and networking events were also found to be very beneficial. These helped to raise awareness of resources available in the community, improved understanding of the roles and responsibilities of partner agencies, and facilitated improved communication between key partner agencies.

Test sites such as Guys and St Thomas's that ran such events found that they provided opportunities for social care and health workers (and other relevant agencies) to discuss barriers and challenges and seek ways to overcome these. It is important that such events or activities are undertaken on a regular and on-going basis especially in sectors where staff turnover is high.

7.5   OWNERSHIP OF END OF LIFE CARE STRATEGIES

One of the objectives of the Social Care Framework is to embed end of life care within commissioning and inspection frameworks and standards for practice. Only a few of the test sites areas had local End of Life Strategies but these were seen as essential in ensuring that end of life care was high on the planning and commissioning agenda of health and social care. Linking to incentives such as QIPP (Quality, Innovation, Productivity and Prevention) with its focus on, for example, the development of sustainable effective pathways and systems, of which end of life care is an integral part, may be one mechanism for embedding end of life care in health service commissioning.

While end of life care needs to be embedded in strategies, commissioning and contracting processes, there are issues with the complexity of relationships and the number of planning and strategy boards and groups where the "ownership" for end of life care may lie. This complexity has been clearly demonstrated in the test sites. A key question for commissioning arising from the test sites is the question of who owns end of life care, especially the delivery. If it lies in acute health care, there is a danger that home care is not supported or social care encouraged. Thus a key message is that given the complexity of commissioning and planning relationships, and the changing landscape of health and social care, it is essential to raise awareness of end of life care and keep it on the agenda because end of life care is only one of many priorities and its importance needs to be constantly reinforced.

7.6   TRAINING AND SUPPORTING STAFF

The requirement for training and supporting staff is articulated in the Social Care Framework. However a key message is that such initiatives need time and resources. Given financial and workforce constraints, training must be carefully tailored. In successful initiatives, training needs were assessed and target groups involved before the training programmes were developed. A further finding is that training must be flexible and tailored to what is needed rather than what is assumed to be needed. Test sites found that multi-disciplinary training can be very beneficial

Again test sites had some success in providing a supportive work environment for social care workers but it was clear that workers (at all levels) might require on-going support to enable them to deliver appropriate end of life care. It is important not to underestimate the barriers around talking about end of life care, even among trained social workers and healthcare professionals. It was evident that people's own experiences were often a barrier to their engagement with end of life care, and many would benefit from specific training on challenging or difficult conversations similar to the courses delivered by St Christopher's.

7.7   FUNDING MECHANISMS

Throughout the Social Care Framework is the recognition that financial barriers often militate against individuals receiving the appropriate care. Flexibility across budgets is essential and test sites did demonstrate that this is possible. Personal budgets are seen as one remedy. However, those test sites working with personal budgets found that not all those at end of life are suitable for or wish to have a personal budget. Personal budgets appear to be more suitable for some service users than others, for example for those with stable conditions. Other test sites demonstrated the value of fast-tracking continuing health care budgets.

7.8   COMMUNICATING AND SHARING INFORMATION

A key message from the test sites is that the identification of individuals who would benefit from end of life care is not always easy. Some conditions are fluctuating (for example,Parkinson's Disease). Moreover, methods for identifying people who are approaching the end of life, for example, using local social care databases can be problematic, although - as noted above - the process can be facilitated by working with GPs and using Gold Standard Framework flags. Sharing and having access to the same data across agencies is critical as those at end of life are normally managed within the healthcare system, and yet as the Social Care Framework highlights, social care is an essential component of end of life care.

Test sites identified useful and innovative ways of engaging with users and families. Valuable ways of providing information include e-portals on local authority web sites. Test sites successfully worked with people approaching the end of their lives by signposting them to different agencies. A key message is that access to a range of service needs to be well signposted and information made easily available. For example most hospitals have information counters or departments at the main entrances to hospitals, including cancer

information centres: these can be expanded or developed to include social care, and address the needs of people with a wider range of end of life conditions.

7.9   ENVIRONMENTS OF CARE

None of the initiatives on environments of care have addressed the home environment and none of the test sites explicitly addressed this aspect of end of life care. While it is understood that the focus of the test sites was on social care, the absence of a discourse on the role of the home environment in enabling end of life care choices, is of some concern. There would be some considerable value in developing our understanding of the importance of the home environment in end of life care. Consideration should be given to the role of low level preventive services such as handyperson services, as well as that of other professionals such as doctors, nurses, social workers, physiotherapists, domiciliary care providers and occupational therapists in ensuring that the home is a suitable environment with adequate facilities for end of life care. Unsuitable conditions at home may prevent individuals leaving hospital or remaining at home at end of life.

References

Department of Health (2008) *End of Life Care Strategy,* London: Department of Health. Available at: www.endoflifecareforadults.nhs.uk/assets/downloads/pubs_EoLC_Strategy_1.pdf.

Murray, S.A., Kendall, M., Boyd, K. and Sheikh, A. (2005) 'Illness trajectories and palliative care', *British Medical Journal,* 330: 1007 – 1011.

National Audit Office (2008) *End of Life Care.* London: The Stationery Office. Available at: http://www.nao.org.uk/publications/0708/end_of_life_care.aspx

NEOLCP (2010) *Supporting People to Live and Die Well: A framework for social care at the end of life,* Report of the Social Care Advisory Group of the National End of Life Care Programme. Available at: http://www.endoflifecareforadults.nhs.uk/publications/supporting-people-to-live-and-die-well-a-framework

NHS Estates (2005) *Improving the Patient Experience. A Place to Die with Dignity: Creating a Supportive Environment.* Design Brief Working Group, NHS Estates: Leeds.

Waller S, Dewar S, Masterson A, Finn H. *Improving Environments for Care at End of Life.* The King's Fund 2008