LOTHIAN PALLIATIVE CARE REDESIGN PROGRAMME

EVALUATION FOR

August 2017
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EXECUTIVE SUMMARY

This is an independent report commissioned by Marie Curie on behalf of the OAK Foundation to evaluate the outcomes of the Lothian Palliative Care Redesign Programme.

Background to the programme

NHS Lothian introduced its new palliative care strategy, Living and Dying Well in Lothian\(^1\) in 2010 to cover the period 2010 to 2015. The strategy recommended a number of areas for investigation, to improve the delivery of palliative care within Lothian. At the same time, Marie Curie had been working with a number of health systems across the UK, using the Delivering Choice Programme\(^2\) to improve the delivery of palliative care. Given the strong local relationships between the two organisations, Marie Curie approached NHS Lothian with an offer to explore funding opportunities for service developments which would contribute to achieving both organisations’ strategic objectives.

The result was the Palliative Care Redesign Programme - a complex partnership initiative that sought to create a whole-system approach to enhancing palliative care in Lothian. It used the Delivering Choice programme\(^2\) approach to bring together health and social care partners from the public, independent and voluntary sectors across Edinburgh and the Lothians, to examine challenges in delivering effective palliative and end-of-life care before improving existing services and implementing new services.

Marie Curie convened the programme board, led in partnership with NHS Lothian, and secured matched funding from the Oak Foundation to implement projects selected by the programme board. To maximise the impact of the investment, stakeholders prioritised six workstreams to be taken forward. These were:

1. Expansion of Marie Curie services, including redesign of the Edinburgh Hospice and Lothian Marie Curie Nursing Service alongside the introduction of the Lothian Helper Volunteer Service.
2. Improving the provision of palliative care in care homes through:
   - Introduction of a training and education programme for local authority care home and home care staff across Lothian
   - Establishing a Care Home Centre of Excellence, Innovation, Training and Research\(^3\)
3. Identification of patients including:
   - The evaluation of an Anticipatory Care Questionnaire (ACQ) within a care home setting
   - The Early Identification of patients in a primary care setting utilising existing IT infrastructure
4. Public engagement and awareness raising through Health Promoting Palliative Care and the Compassionate City
5. Focus on carers through a review and improvement of workplace policies for carers working in the local area
6. Local improvements in delivery of palliative care across Lothian including:
   - Development of methodology to pro-actively capture feedback on palliative and end of life care
   - Introduction of the Lothian approach to care in the last days and hours of life

\(^1\) [http://www.nhслоthian.scot.nhs.uk/OurOrganisation/Strategies/ladwinlothian/Pages/default.aspx](http://www.nhслоthian.scot.nhs.uk/OurOrganisation/Strategies/ladwinlothian/Pages/default.aspx)

\(^2\) The Delivering Choice Programme is a methodology developed by Marie Curie based on a whole systems thinking approach. Using this approach, the focus is on localised and sustainable solutions that address issues and barriers across the entire system of service delivery. Working together with local care providers and organisations to examine existing care service needs, Marie Curie then designs, pilots and evaluates new service improvements.

\(^3\) A feasibility study into this project was supported by the programme with funding obtained from external sources.
Aims of the programme

The programme sought:

- an increase in the number of people with identified palliative care needs
- earlier identification of people with palliative and end of life care needs
- increased numbers of carers with needs identified and effectively assessed
- reduced avoidable hospital attendance / admissions
- patients spending more time in their preferred place of care
- patients and families being happier with the provision of care and support
- stronger links between community and acute services in developing effective patient pathways
- more patients having up to date Anticipatory Care Plans
- increased time knowledge and skills for health and social care workers and volunteers, to provide high quality care and support for palliative care patients and their carers and families
- increased / improved public and professional awareness of palliative and end of life care issues and of available support along with increased community involvement.

Evaluation methodology

The evaluation used a mixed methods approach, combining the following data sources:

<table>
<thead>
<tr>
<th>Quantitative</th>
<th>Qualitative</th>
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<tbody>
<tr>
<td>Service data collected by Marie Curie about patient usage and uptake of Marie Curie Hospice services and the Marie Curie Nursing Service (MCNS)</td>
<td>Semi-structured interviews with programme board members and other strategic level stakeholders, to examine partnership effectiveness</td>
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<tr>
<td>Patient and carer satisfaction data collected by Marie Curie in relation to the MCNS and the community-based Clinical Nurse Specialist (CNS) services</td>
<td>Semi-structured interviews with project leads and other operational-level stakeholders</td>
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<td>A comparative dataset of service usage and key outcome measures, for comparable patients cared for by Marie Curie Hospice, MCNS and St Columba’s Hospice before and towards the end of the redesign period (procured from NHS Scotland Information Services Division (ISD))</td>
<td>Semi-structured interviews and focus groups with participants in the Care Staff Development Programme</td>
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This was complemented by synthesis and analysis of internal project evaluations for workstreams 2-6.

Programme achievements

The programme has achieved a number of important outcomes, both as a result of individual workstreams and at a programme level. We provide an overview of the main achievements below:

Expansion and redesign of Marie Curie Hospice services and MCNS
The redesign process completed at the end of March 2017, and has resulted in a redesigned and revitalised Marie Curie Hospice and MCNS, with a stronger community focus and more integrated and co-ordinated ways of working across the services and with St Columba’s Hospice. Key features of the redesign include:

- Increased capacity for community-based services, facilitated by a reduction in in-patient beds
- Local coordination and integration across MCNS and CNS services, ensuring patients receive a range of community-based services seamlessly
- Integrated approach to bed management across the two hospices
- Introduction of the Marie Curie Helper Volunteer Service, providing befriending and support to patients and carers
- Enhanced day care provision

Early results show these changes have led to important outcomes for patients:

- Fewer days spent in hospital during the last six months of life, suggesting more time spent at home during this period
- Reduced hospital admissions
- Shorter lengths of stay for hospital admissions
- Reduced hospital bed days
- Reduced A&E attendances
- Improvements in the appropriateness of A&E attendances and subsequent admissions
- More patients receiving care from the MCNS (MCNS involvement means that patients are more likely to be able to die at home)

Not only do these outcomes indicate a better quality of experience for patients and carers, they are also likely to translate into economic savings for the health system.

**Care staff development programme**
Across Lothian, 514 local authority-employed care staff participated in the study day at the core of this development programme. 49 of them also completed an in-depth online module to extend their learning.

The evaluation shows that the programme has been very effective in improving care staff’s knowledge, understanding and confidence in relation to providing and talking about care for people towards the end of their lives. This has led to reported changes in practice, with care staff being more able to identify patients approaching end of life, more able and willing to discuss this sensitive issue with family members, and more able to work with other members of the multidisciplinary team to contribute to planning and providing care that meets patients’ and families’ wishes. The programme has also led to improvements in understanding about the importance of timely Anticipatory Care Planning, and some staff reported appreciating the concept of a ‘good death’ in a way they hadn’t done before.

Amongst the small sample of staff involved in qualitative focus groups and interviews, we noted a deep commitment to ensuring people approaching the end of their lives had as high a quality of life as possible and dignity and care in their final days and hours. Those staff indicated that the course had enabled them to put that commitment into practice in a more meaningful way.

**Evaluating an Anticipatory Care Questionnaire (ACQ)**
An ACQ was developed and tested in two care homes in Edinburgh, to find out more about what contributed to effective anticipatory care planning for residents, families, care home staff and other health professionals, and how problems with the process could be overcome.
The ACQ acts as a simple tool to support planning, and having it in use in a care home helps create a culture of anticipatory care planning. In those homes trialling the ACQ, 64% of acute events were managed appropriately and in line with the resident’s Key Information Summary (KIS).

The ACQ trial pre-dated the care staff development programme, and interestingly found that staff felt they needed more support to be able to have conversations about anticipatory care planning with residents and families. The outcomes of the development programme evaluation show that this support need has been addressed amongst those who attended the programme.

**Early identification of patients with palliative care needs through existing IT infrastructure**

Edinburgh University developed an IT tool called AnticiPal, which identifies patients on GP databases with possible palliative and ‘pre-palliative’ care needs. The tool was trialled in eight GP practices across Lothian. On average 0.82% of patients on a GP list were identified as having potential palliative care needs. Practices then reviewed those patients’ records, and found that approximately one third had not already been identified as having palliative or pre-palliative care needs. Anticipatory care plans were put into place for these patients.

NHS Lothian has confirmed that AnticiPal will now be rolled out across Lothian. If this is successful, Scottish roll-out is planned thereafter. A trial is also underway in Northern Ireland with 20 practices.

**Improving awareness of palliative care**

Through the Health Promoting Palliative Care project, a number of outputs have been achieved:

- Development of a resource library that can be accessed by health and care professionals and community leaders
- Development of a resource based on the Australian resource, ‘Dying to Know’, available to all through the Good Life Good Death Good Grief website
- Training and awareness raising in palliative and end of life care delivered to a range of health professionals
- Testing new approaches to community engagement with sports clubs, leading to the adoption of Remembrance and ‘To Absent Friends’ activities at Edinburgh Rugby and Hibernian FC

**Supporting carers in the workplace**

Marie Curie is providing specialist palliative care expertise to VOCAL, a local carers’ organisation, to ensure that palliative care is a core part of VOCAL’s ongoing work with employers about carers’ needs.

**Strategic added value**

Alongside these practical and tangible changes, the programme has delivered significant Strategic Added Value (SAV) in terms of:

- **strategic leadership & catalyst**: setting direction, articulating and communicating needs, pursuing opportunities and solutions, creating the ground swell of support, enthusiasm and collaboration that ensured partner buy-in
- **engagement**: building mechanisms and incentives for effective and deliberative engagement of stakeholders in the design and delivery of priorities and programmes

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Stakeholders continue to implement strategic and operational changes that have been stimulated as a result of the programme, meaning there is likely to be an increasing SAV effect over the next twelve months to two years, in terms of:

★ **strategic influence:** carrying out or stimulating activity that defines the distinctive roles of partners, gets them to commit to shared strategic objectives and to behave and allocate their funds accordingly

★ **leverage:** providing financial and other incentives to mobilise partner and stakeholder resources – equipment and people, as well as funding

★ **synergy:** using organisational capacity, knowledge and expertise to improve information exchange and knowledge transfer and coordination and/or integration of the design and delivery of interventions between partners

**Partnership**
Partnership has been at the heart of the programme from the very beginning. All the key organisations and recognised experts in palliative care in the region have been involved in shaping and governing the programme, convened and led by Marie Curie. This partnership has been one of the crucial enablers of the achievements listed above.

However, a deepening of that partnership has also been one of the programme’s important outcomes. The partnership has created a new working culture between these organisations; one of collaboration and common purpose. This in turn creates the conditions for joined up working to continue to grow and develop in future, and is an important legacy of the programme.

It will be important to continue this partnership now that the programme has ended. Without the regular focus of the programme board there are fewer opportunities for individuals to come together except for specific tasks. Sustaining the relationships and the space for thinking, strategic discussion and knowledge-sharing will be essential, to maintain a healthy and productive partnership, particularly in relation to implementing the priorities of the Strategic Framework for Action on Palliative and End of Life Care. Furthermore, the continuation of the partnership will help sustain momentum on embedding the strategic and operational changes that are underway and ensure the programme’s learning is adopted as widely as possible.

**Recommendations**

1. The partnership should be continued, for example through a community of practice; this will require continued leadership
2. The ACQ should be further refined, then rolled out (with appropriate support and guidance) to care homes across the region
3. The home care staff training course should be adapted for use in alternative settings, for example private care homes and non-registered healthcare staff, to enable an increased understanding of palliative care and importance of anticipatory care planning
4. A follow-up evaluation of the Marie Curie Hospice and MCNS Redesign should be conducted in one to two years
   - The ISD linked data extraction should be expanded to include acute and community services, alongside capturing data relating to lay carers
   - Economic assessment (cost-effectiveness should also be included)
1 INTRODUCTION

The Lothian Palliative Care Redesign Programme is a whole-system partnership venture. It uses the Marie Curie Delivering Choice programme approach to bring together health and social care partners from the public, independent and voluntary sectors across Edinburgh and the Lothians, to examine challenges in delivering effective palliative and end-of-life care before improving existing services and implementing new services.

NHS Lothian introduced their new palliative care strategy, Living and Dying Well in Lothian\(^5\) in 2010 to cover the period 2010 to 2015. Within the strategy, a number of areas were recommended for investigation to improve the delivery of palliative care within Lothian. Alongside this, Marie Curie has been working with a number of health systems across the UK, using the Delivering Choice Programme to improve the delivery of palliative care. Based on strong local relationships, Marie Curie approached NHS Lothian with an offer to explore funding opportunities to enable service developments that would assist with achievement of both organisations’ strategic objectives.

Early discussion highlighted the importance of partnership working and Marie Curie and NHS Lothian agreed to co-sponsor the programme, which would be a needs-based scheme of work, looking at the delivery of palliative care in all settings within Lothian. Buy-in was sought from local partners including acute and community care providers, local authorities, academia and other third sector organisations.

Marie Curie convened the programme board, led in partnership with NHS Lothian, and secured matched funding from the Oak Foundation to implement projects selected by the programme board.

Following an extensive engagement exercise with over 200 professionals and public representatives consulted on, a significant number of proposals were presented to the programme board. In order to maximise the impact of the investment, Programme Board members prioritised six work streams to be taken forward. These were:

1. Expansion of Marie Curie services, including redesign of the Edinburgh Hospice and Lothian Marie Curie Nursing Service alongside the introduction of the Lothian Helper Volunteer Service.
2. Improving the provision of palliative care in care homes through:
   - Introduction of a training and education programme for local authority care home and home care staff across Lothian
   - The evaluation of an Anticipatory Care Questionnaire (ACQ) within a care home setting
   - Establishing a Care Home Centre of Excellence, Innovation, Training and Research\(^6\)
3. Identification of patients including:
   - The Early Identification of patients in a primary care setting utilising existing IT infrastructure
4. Public engagement and awareness raising through Health Promoting Palliative Care and the Compassionate City
5. Focus on carers through a review and improvement of workplace policies for carers working in the local area
6. Local improvements in delivery of palliative care across Lothian including:
   - Development of methodology to pro-actively capture feedback on palliative and end of life care
   - Introduction of the Lothian approach to care in the last days and hours of life


\(^6\) A feasibility study into this project was supported by the programme with funding obtained from external sources
Members of the programme board and the project boards are shown at Appendix 1.

The aim of the programme was that successful implementation of the six workstreams would result in:

- an increase in the number of people with identified palliative care needs earlier identification of people with palliative and end of life care needs
- increased numbers of carers with needs identified and effectively assessed
- reduced avoidable hospital attendance / admissions
- patients spending more time in their preferred place of care
- patients and families being happier with the provision of care and support
- stronger links between community and acute services in developing effective patient pathways
- more patients having up to date Anticipatory Care Plans
- increased time knowledge and skills for health and social care workers and volunteers, to provide high quality care and support for palliative care patients and their carers and families
- Increased / improved public and professional awareness of palliative and end of life care issues and of available support along with increased community involvement.

In order to achieve these aims, work was undertaken to ensure the aims and the measurable outcomes would fit in with agreed programme objectives:

- To increase capabilities to identify patients and to plan care in anticipation and in advance of needs
- To raise public awareness of, and promote community involvement in death, dying and bereavement
- To increase community based care service provision
- To improve co-ordination of care within and across settings to support patients and families with complex and unstable palliative and end of life care needs

1.1 Purpose of the evaluation

This evaluation provides an overview of the progress the programme has made towards its intended outcomes, along with a summary of the outcomes of the individual projects funded by the programme.

In order to address the pre-defined objectives of the programme, the programme team identified six key evaluation questions as follows:

- What is the profile of the patients being identified, registered on a palliative care register, having an anticipatory care plan in place and accessing Marie Curie services and has this changed since the programme was introduced?
- What is the profile of Marie Curie service provision to patients before and after the changes to the MCNS and MC Hospice were introduced?
- What is the impact of the programme on working relationships, communications and joined up working across acute and community providers in the area?
- What impact does the programme have on the ability of health and social care workers to deliver appropriate care with knowledge and confidence?
- What is the experience of the patient and their carers through the end to end process of the care delivery model?
- Overall, are the appropriate services in place in order to prevent avoidable hospital admissions and attendances at Accident and Emergency (A&E) for patients at the end of life?
2 METHODOLOGY

All workstreams except the Hospice and MCNS Redesign project had internal evaluations conducted by their project teams. Service activity data and Hospice and MCNS performance data was also provided for analysis. Our role was to undertake a programme level evaluation by:

- synthesising the findings of these internal evaluations
- conducting fieldwork to investigate programme level effectiveness and impact, and to supplement the findings of the project evaluations
- analysing service data to enable an evaluation of the Hospice and Marie Curie Nursing Service Redesign project

The table below provides a summary of the evaluation approach

<table>
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<tr>
<th>Activity</th>
<th>Tasks involved</th>
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<tbody>
<tr>
<td>Project set up and scoping</td>
<td>• Meetings with programme and evaluation team to scope the work and agree objectives</td>
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<td></td>
<td>• Production of project plan</td>
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<td></td>
<td>• Design of stakeholder interview discussion guides</td>
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<td>• Agreement of discussion guides and stakeholders for interview with MC programme and evaluation teams</td>
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<tr>
<td>Synthesis and analysis of internal project evaluation reports</td>
<td>• Initial review of each report, to check understanding and raise queries</td>
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<td>• Synthesis and analysis of all reports (summaries and full reports), to assess project effectiveness and also identify cross-project themes</td>
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<tr>
<td>Synthesis and analysis of MCNS and CNS patient satisfaction questionnaires</td>
<td>• Analysis of data from patient and carer surveys collected from users of the MCNS and Marie Curie Hospice CNS services, to understand the impact of the redesign on patient and carer experience</td>
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<td></td>
<td>• Consideration of themes in light of other datasets</td>
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<td>• Provide graphs and spreadsheets to Marie Curie, for use in documents and communications</td>
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<tr>
<td>Synthesis and analysis of Marie Curie Hospice service activity data</td>
<td>• Analysis of service activity data collected by the Marie Curie Hospice, to assess impact of Hospice and MCNS Redesign project on how services are used</td>
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<td>• Consideration of themes in light of other datasets</td>
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<tr>
<td></td>
<td>• Provide graphs and spreadsheets to Marie Curie, for use in internal documents and communications</td>
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<tr>
<td>Analysis of ISD comparison data</td>
<td>• Analysis of data extracted by ISD, to assess impact of Hospice and MCNS Redesign project on wider health service usage</td>
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<tr>
<td></td>
<td>• Consideration of themes in light of other datasets</td>
</tr>
<tr>
<td>Stakeholder interviews (n=21)</td>
<td>• Interviews with strategic leads, such as programme board, to gather programme level and Strategic Added Value (SAV) perspectives</td>
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<td>• Interviews with operational project leads</td>
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<td>• Thematic analysis of stakeholder interviews</td>
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2.1 Quantitative data sources

We were provided with data from three sources to support the evaluation of the Hospice and MCNS Redesign project:

- service usage data collected by Marie Curie about patient usage and uptake of Marie Curie Hospice services and the Marie Curie Nursing Service (MCNS), provided in a pre-analysed format
- customised patient satisfaction data collected by Marie Curie, specifically relating to the redesigned services within the MCNS and community based Clinical Nurse Specialist (CNS) services in Lothian
- a comparative dataset, of service usage and key outcome measures, for comparable patients cared for by Marie Curie Hospice, MCNS and St Columba’s Hospice in the period before the redesign and towards the end of the redesign; this was procured from NHS Scotland’s Information Services Division (ISD)

Upon receipt of patient Community Health Index (CHI) number, ISD extracted patient Scottish Morbidity Record (SMR) data relating to patients’ healthcare system usage. Extracted data included:

- number of hospital admissions and whether or not the admission was an elective or an emergency admission
- number of Accident & Emergency attendances of each patient
- total length of stay of all hospital admissions for each patient
- length of each patient’s hospital stay
- percentage of time within the last 6 months of a patient’s life that the patient spent in hospital and community settings
- average number of hospital admissions per patient
- place of discharge from hospital
- patient place of death defined by home, care home or acute hospital
- number of hospital admissions by speciality name

Where available, baseline data referred to the 12 month period prior to the programme implementation.

2.2 Data limitations

2.2.1 Internal project evaluations

The internal project evaluations were of varying length, level of detail and focus. Some provided an assessment of outcomes and impacts, whilst others focused predominantly on activities and outputs. We were able to supplement the reports with our findings from interviews with project leads and other stakeholders, but it is important to note this variability in quality and its influence on our ability to draw robust conclusions on impact of every project.

2.2.2 Time lag from implementation to impact

The redesign project completed at the end of March 2017, and some of the performance data supplied for the evaluation was captured at the very end of the programme. Therefore it is unlikely to represent the full potential impact of the programme’s work.

7Questionnaires were customised for the purposes of the evaluation, however a number of questions were adapted from standard Marie Curie surveys, allowing for future benchmarking of services.
In its report on Evaluating Integrated Community Care\(^8\), The Nuffield Trust highlights the growing evidence base that both the delivery and visible results of redesign take time. The authors note:

“two years of initial development, followed by a minimum of one year of ‘live’ working, and almost certainly longer, is required to show the initial effects of major changes to service organisation and provision, particularly financial savings”

The data presented in chapter 4 already shows promising indications of change, but further collection of data over the next 12 months will be needed to fully evidence the changes the programme has achieved.

2.3 Report structure

The following report is structured as follows:

- Programme level findings
- Project findings, examining the effectiveness of the eight projects included in the programme
  - Edinburgh Hospice Redesign/Redesign of Lothian MCNS
  - Training for Lothian care home and local authority care at home staff
  - Evaluation of an Anticipatory Care Questionnaire (ACQ) within a care home setting
  - Early identification of patients in a primary care setting, utilising existing IT infrastructure
  - Health Promoting Palliative Care and Compassionate City
  - A review and improvement of workplace and employment policies for carers working within the Lothian area
  - Capturing feedback on palliative and end of life care\(^9\)
  - Care in the last days and hours of life: the Lothian Approach\(^10\)
- Conclusions and recommendations
- Appendices providing additional data used to inform the evaluation

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\(^9\) This project has been delayed and is not in scope of the evaluation, but we do provide a short progress report.

\(^10\) This project has been delayed and is not in scope of the evaluation, but we do provide a short progress report.
3 PROGRAMME LEVEL FINDINGS

We carried out semi-structured telephone/face to face interviews with members of the programme board (n=22) and other key strategic and operational stakeholders, to gain their perspectives on the programme: it’s progress to date, the benefits, challenges and learning from working as part of a whole system venture and partnership programme, and the strategic added value generated by the programme. A list of interviewees can be found at Appendix 1.

The themes from these interviews are discussed below.

3.1 Early stages of the programme

3.1.1 Initial Recruitment Process

The first stage of the redesign programme was the recruitment of the Programme Board. From initial high level discussions between Marie Curie and NHS Lothian to ensure executive level buy in, a number of roles were identified and recruited to, ensuring representation from across health and social care. Stakeholders noted significant buy in and commitment to the process from senior individuals.

3.1.2 Consultation process

The consultation process at the beginning of the programme was seen to be wide-ranging and inclusive. Stakeholders reported that it took a long time, but was an important process to go through, to really understand the landscape and where the big challenges and opportunities were. The process helped to spread awareness of the programme, and to ensure that individuals’ and organisations’ knowledge of delivering palliative and/or end of life care across all parts of the health and social care system was used to inform the programme.

Whilst lengthy, the consultation process was a critical step in both securing engagement with the programme, and in identifying and selecting projects.

3.1.3 Agreeing priorities

A number of priority areas emerged from the consultation process, and these informed the design of the programme. Most stakeholders described the process of selecting successful projects robust and transparent, with a prioritisation process applied. A small number of stakeholders questioned whether the programme had been bold enough in its project selections, and whether focusing on some easy win projects might have been a missed opportunity.

However, the majority of stakeholders considered the resulting projects to be well-aligned with what was heard throughout the consultation process, and equally well-aligned with partner organisations’ strategic priorities.

3.2 Leadership and the Programme Board

3.2.1 Programme leadership

The interviews with programme board members and key stakeholders revealed a contrast between the programme’s leadership in the earlier and later stages of the programme, with notable improvements when there was a change of programme manager and senior sponsor within Marie Curie Lothian Redesign Programme Evaluation.
Curie part way through the programme. They reported that this brought a welcome focus on moving the projects forward and making the programme board a more inclusive and productive forum, and created a sense of momentum and positive progress.

In the earlier stages of the programme, some stakeholders reported a perception that the ‘real business’ was done behind closed doors rather than with the programme board, and that communication with programme board members was very limited between meetings. This was combined with a feeling of unnecessarily slow progress. They welcomed the change of leadership, describing it as ‘like a breath of fresh air’, and said this brought a new energy to the programme.

3.2.2 Programme board effectiveness
Stakeholders reported that the programme board became increasingly effective as a forum as the programme progressed. They credited much of this to the change in leadership, but also acknowledged the role of time in strengthening relationships and trust between partners, which led to them feeling that they could talk more openly about shared challenges.

3.2.3 Part of a wider community
A number of stakeholders described partners becoming increasingly collaborative at the programme board, with an approach of shared problem-solving rather than protecting their own agendas or ‘turf’. They reported that this was a key shift, and that it led to them beginning to feel that they were part of a wider palliative care community.

3.3 Progress to date
The majority of stakeholders report being happy overall with the progress of the programme. Stakeholders recognise the complexity and changing nature of the environment in which the projects are being delivered, and its influence on projects’ progress, including delays in some cases. With hindsight, they acknowledge that programmes working across all parts of a dynamic health and social care landscape probably require more lead in and development time. It has now been recognised that perhaps some of the timeframes were too ambitious, a key learning point going forward.

Importantly, all are pleased with what has been achieved. They felt that they were kept updated on progress during programme board meetings, and that challenges were discussed and ideas for overcoming them were put forward. Opinions were mixed about the adequacy of communication between programme board meetings – some felt they had enough information whilst others felt they didn’t hear enough between meetings. No stakeholders thought they received too much information.

Stakeholders had varied levels of oversight of the programme as a whole, with some having more in-depth views on particular projects due to the nature of their involvement. In these instances progress was described in the context of that project rather than at a programme level.

3.4 Partnership / whole system working

3.4.1 Benefits
Stakeholders saw the partnership as essential to the programme’s achievements. They could not see how any single organisation could have embarked on a programme of this scale, and across the different health and care settings and parts of the region, alone. Whilst acknowledging the crucial role of funding, obtained by Marie Curie through the OAK Foundation, they recognised that the programme needed the buy-in of the all the key partner organisations.
The fact that it was a partnership was also crucial in securing the buy-in of each partner. It wasn't a single organisation trying to impose its will or approach, it was a partnership delivering a range of both practical and evidence-building initiatives which were based on wide consultation. Managing them under the umbrella of a programme was seen as a unifying and co-ordinated approach to service improvement.

That said, a small number of stakeholders did wonder whether having a local organisation in the lead (for example NHS Lothian), with lead executive responsibility, might have embedded some of the projects more fully in the mainstream and enabled them to progress more quickly. However, given the turbulence in the system at the time, with the transition of health and social care into the Integration Joint Boards (IJBS), they also acknowledged that this probably wouldn’t have been realistic.

Feedback also suggests that partners now have much greater clarity about each other’s roles and priorities, and the challenges that different parts of the health and social care system are dealing with. Some stakeholders described also feeling that their perspectives and roles were better understood by others. For example, the role of care workers was better understood and appreciated. With understanding has also come trust. Many stakeholders described now having positive working relationships with partners at the programme board, where they didn’t before, and that this has led to them working together outside of the programme setting.

3.4.2 Challenges

Stakeholders described a rapidly changing landscape during the time the programme was being developed and implemented. They acknowledged that change in health and social care was the norm, but that the period in question was especially dynamic. In particular, changes to senior staffing in local authorities and across NHS Lothian, alongside the creation of the IJBS meant key people involved in projects sometimes changed or their line managers changed, and with them their priorities and understanding of the issues. Key programme decision makers were also focused on managing wider changes, which sometimes led to difficulties in retaining a focus on programme priorities.

They acknowledged that even without turbulence in the systems, partnership working took longer than expected, to build relationships, wider service understanding and trust. However, they reported that partnership was the right way forward, as the benefits were worth the extra time investment.

3.5 Marie Curie’s role in the partnership

We have already described the prevailing view that the programme’s success depended on all the partners. However, we also explored whether Marie Curie’s role in particular added value. Stakeholders acknowledged the practical resources brought by Marie Curie and leveraged by Marie Curie from the OAK Foundation:

- funding for the programme’s management
- funding towards the projects
- programme leadership staff
- programme management disciplines and systems

These were seen as crucial in catalysing the creation of a coherent programme of activities, all supporting a common goal at the same time. Whilst stakeholders had mixed views on whether some of the projects might have taken place anyway, they were consistent in their view that the projects...
would not have happened as quickly, or alongside other complementary projects, without Marie Curie’s role as a convenor and funder.

As well as these practical contributions, stakeholders cited Marie Curie’s reputation as a national charity and policy influencer as offering added value. Marie Curie’s interest and investment caught the attention of local organisations and gave confidence that the programme was worth becoming a part of. There was also a perception amongst stakeholders that Marie Curie had the reputation, skills and connections to promote the Lothian programme’s successes on a wider stage, enhancing partners’ reputations and influencing national uptake of good practice developed in Lothian.

3.6 Lessons learned

The lessons learned during the programme are described in the sections above, but can be summarised in these statements:

“It’s not just our organisation. We are part of something bigger.”

“It takes much longer than you expect to achieve anything. Be patient.”

“In a changing system, nothing is straightforward. Give yourself more time to get your project off the ground.”

“You need someone in the background, managing it and making sure we all stay on track.”

3.7 Strategic Added Value

The creation, strengthening and extending of partnerships was a fundamental part of this programme, as important as the projects that would deliver practical benefits to people with palliative care needs. However, the benefits and impact of the partnership aspect are less easy to define in tangible terms. We therefore included an investigation of Strategic Added Value as part of our methodology for assessing the success of the programme.

Strategic Added Value (SAV)\(^1\) was first introduced as a means to evaluate the English Regional Development Agencies’ impact that came not from programme and project spend, but on their influence on stakeholders’ and partners’ behaviours and performance. SAV has since been adopted throughout numerous public and government agencies, and provides a very helpful lens through which to view the impact of the partnership aspect of the Lothian programme. It allows for articulation of impact where the end outcome (such as more joined up communication between community care services, hospitals and palliative care specialist services) has been delivered by others but enabled, facilitated or supported by the partnership’s activity (in this context, the improved understanding and relationships between different parts of the system, enabled by the partnership, alongside the tools and skills to communicate more effectively enabled by the projects).

SAV includes a number of different categories of impact:

★ **strategic leadership & catalyst**: articulating and communicating needs, opportunities and solutions to partners and stakeholders

★ **strategic influence**: carrying out or stimulating activity that defines the distinctive roles of partners, gets them to commit to shared strategic objectives and to behave and allocate their funds accordingly

★ **leverage**: providing financial and other incentives to mobilise partner and stakeholder resources – equipment and people, as well as funding

★ **synergy**: using organisational capacity, knowledge and expertise to improve information exchange and knowledge transfer and coordination and/or integration of the design and delivery of interventions between partners

★ **engagement**: setting up the mechanisms and incentives for more effective and deliberative engagement of stakeholders in the design and delivery of priorities and programmes

Stakeholders spontaneously described all of these aspects of SAV to varying extents during their interviews. We also asked a number of questions to gain a more quantitative measure of their perspectives on key aspects of SAV.

The figure below shows the average scores for each of the six questions asked, using a scale of 1-10, where 1 is to no extent at all and 10 is to a very large extent:

**Figure 1 – The programme scores highly on partnership relationships**

Scores across most other dimensions of SAV are also relatively high

n=11 for each question except for Q5 which has one extra response

When evaluating programmes that are expected to deliver SAV, we would normally see only one or two dimensions scoring highly. However, this programme scores highly across all but one of the dimensions, which indicates strong SAV. Furthermore, although question 4 was rated lower, a number of key delivery partners reported that they expected that their score for this dimension would be much higher in another six to twelve months’ time, as the changes initiated within their organisations had not yet been fully implemented.

Other areas in which stakeholders described the programme’s SAV, which have not yet already been discussed, were:
Marie Curie Lothian Redesign Programme Evaluation

3.8 Legacy

We asked stakeholders what they believed the legacy of the programme would be. The most commonly cited legacy was the enhanced relationships formed between individuals and organisations to enable continued future collaborative working. By creating conditions where inclusive, multi-agency collaborative approaches to service improvement can take place, the legacy of the programme will continue.

The programme is perceived to have shown what can be achieved by bringing partners together under a shared agenda, using a collaborative and integrative approach. A shared understanding that no single partner has all the answers and solutions, has come from drawing on the knowledge and expertise of all people across the health and social care landscape.

Part of the programme legacy will also be through the sustained benefits that will continue to be delivered as a result of some of the projects, for example, the physical redesign of the Marie Curie Hospice and the resulting increase in day care capacity, alongside strong partnership working between Marie Curie and St Columba’s Hospice and the delivery of an enhanced Helper Volunteer service, building on a public health approach to service delivery. In addition, foundations have been put in place to allow more patients with palliative care needs to be identified.

The training and education project has increased the skills and confidence of the care workforce who participated in the project. However, there were also questions asked about the sustainability and wider adoption of what had been piloted through the projects. For example, who drives and leads the activity after the programme has finished?

3.9 The future

Stakeholders expressed uncertainty about what happens now that most of the projects in the programme have ended. As described above, there are some lasting changes that will remain, such as the core of the redesigned MCNS and Marie Curie Hospice services and the changes in the local authority-employed care workforce. Funding of Marie Curie services has reverted to agreed pre-
redesign levels, however programme developments have enabled a legacy of more efficient service delivery.

Stakeholders are concerned about how the learning and benefits generated by the programme can be continued and built upon, but also recognise that additional external funding cannot be provided in the long term – service changes need to be embedded in the mainstream of commissioned services if they are to be sustainable. Marie Curie continues to be in a position to drive this work forward.

The relationships and partnership approach will certainly be sustained, although changes in roles in various organisations do pose a threat to continuity of relationships in some quarters. Finding a way to maintain a sense of community, even when staff change, was important to stakeholders. Outside of the changing landscape of statutory health and social care organisations, the partnership between Marie Curie and St Columba’s has been cemented with clear commitment to a joint model of working.
4 PROJECT FINDINGS

In this chapter, we present the findings of evaluation of each of the projects, based on internal evaluations provided to the programme by each of the project leads, and data provided to us by Marie Curie and NHS Scotland's Information Services Division (ISD). We have also incorporated feedback from our interviews with project leads. We discuss each project in turn:

1 Expansion of Marie Curie services, including redesign of the Edinburgh Hospice and Lothian Marie Curie Nursing Service alongside the introduction of the Lothian Helper Volunteer Service.
2 Improving the provision of palliative care in care homes through:
   I. Introduction of a training and education programme for local authority care home and home care staff across Lothian
   II. The evaluation of an Anticipatory Care Questionnaire (ACQ) within a care home setting
3 Identification of patients including:
   I. The Early Identification of patients in a primary care setting utilising existing IT infrastructure
4 Public engagement and awareness raising through Health Promoting Palliative Care and the Compassionate City
5 Focus on carers through a review and improvement of workplace policies for carers working in the local area
6 Local improvements in delivery of palliative care across Lothian including:
   I. Development of methodology to pro-actively capture feedback on palliative and end of life care
   II. Introduction of the Lothian approach to care in the last days and hours of life

4.1 Edinburgh Hospice Redesign / Redesign of Lothian MCNS

This project sought to deliver a new model of care for hospice based specialist care services across Lothian, including:

★ refurbished day therapies provision within the Marie Curie Hospice Edinburgh
★ working with St Columba's Hospice on the expansion of community services to introduce seven-day working and community based AHP and CNS support in both hospices, resourced in part by a reduction of five beds in the in-patient unit
★ introducing local clinical co-ordination of the Marie Curie Nursing Service (transferring from co-ordination by the Referral Centre in Pontypool), offering tailored patient centred packages care, with a view to greater integration between community-based hospice services and the Marie Curie Nursing Service, with a focus on weekends
★ introduction of a Helper Volunteer service to provide companionship and emotional support to patients and carers

The purpose of doing so was to help more people living with a terminal illness, through increasing capacity in community services. Through improved integration and closer team working, the project also aimed to improve patients' experience of their care.

The outcomes the project aimed to deliver were:

★ 10% increase in the number of patients supported by Marie Curie in Lothian
Marie Curie Lothian Redesign Programme Evaluation

- increased identification of carers and assessment of carer and family support needs
- reduction in avoidable hospital admissions
- patients spending more time in their preferred place of care
- patients and their families happy with the provision of care and support
- stronger links between community and acute services

The redesign project ran from October 2015 to March 2017, and the data for the evaluation runs to end of March 2017.

4.1.1 Changes in Marie Curie services usage

Unique patients across community and inpatient services
Numbers of unique patients accessing in-patient and community nurse specialist services from the Hospice decreased slightly in the calendar year 2016 compared with 2015. Whilst overall numbers decreased, the balance of patients receiving the various services remained the same. For example, the percentage of patients receiving in-patient care only remained roughly the same (19% in 2015 and 17% in 2016), as did the percentage receiving community care only (56% in 2015 and 57% in 2016), and those receiving a combination of both (25% in 2015 and 26% in 2016).

Table 3 – total unique patient numbers decreased in 2016
Proportions of patient receiving each type/combination of services remained broadly the same

<table>
<thead>
<tr>
<th>Location</th>
<th>Number of patients</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>2015</td>
</tr>
<tr>
<td>Inpatient only</td>
<td>174 (19%)</td>
</tr>
<tr>
<td>Community only</td>
<td>510 (56%)</td>
</tr>
<tr>
<td>Inpatient and Community</td>
<td>227 (25%)</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>911</strong></td>
</tr>
</tbody>
</table>

Referrals remained steady over the project period, as did the balance between referrals of patients previously known to the Hospice and those that were new to the Hospice.

In-patient average length of stay has remained steady (at a six month rolling average of between 15 and 16), although it appeared to be reducing in the last two months of the project (monthly average of 11 in each of the last two months of the period). This is confirmed by stakeholders, who also report that the complexity of patient needs and the intensity of support required have both increased, as the reduced bed numbers have led to a more concentrated focus on patients with the greatest need for complex hospice-based care. In-patient occupancy as a proportion of commissioned bed days has remained steady throughout the project.

Looking at community interventions, there has been a shift in the balance of interventions over the last 10 months of the project. During that period, whilst the number of referrals remained constant, the number of Clinical Nurse Specialist (CNS) interventions decreased, whilst Allied Health Professional (AHP) interventions increased. This reflects an increasingly multi-disciplinary approach in the delivery of community-based services. CNS support for carers increased in the early part of the project, but from June 2016 appears to have decreased.

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12 As part of the redesign, the number of hospice beds was reduced from 25 to 20 from October 2015.
13 Data provided for this table was for each calendar year, rather than the April-March period to which the other data in this section relates.
The numbers of patients supported in the Day Unit have remained steady, despite the enhanced services now available in the refurbished unit. Stakeholders reported difficulties in promoting the transformed service following the refurbishment. There was organisational restructuring within the Hospice and its services, as well as restructuring in the health and social care system as a result of health and social care integration. These factors caused challenges in communicating the changes in the service and in identifying and engaging commissioners and potential referrers.

Given the very limited changes in Hospice service usage patterns over the period, we have not provided data visualisations in the main body of the report. However, a dashboard of the key measures can be seen at Appendix 2.

**Marie Curie Nursing Services**

Before the redesign, stakeholders told us that the community CNS service and the Marie Curie Nursing Service (MCNS) didn’t work in an integrated way. The redesign involved bringing co-ordination of the MCNS under local clinical control, to introduce a patient centred approach, ensuring better co-ordination and alignment with other local services. It would appear from the data that this has led to increased uptake of MCNS services. The total number of patients accessing the Marie Curie Nursing Service (MCNS) has increased over the period of the redesign.

**Table 4 - Number of patients has increased for both Fast Track and Managed Care aspects of the MCNS**

<table>
<thead>
<tr>
<th>Service</th>
<th>Number of unique patients seen by the Marie Curie Nursing Service</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Oct 14 - Mar 15</td>
</tr>
<tr>
<td>Fast Track</td>
<td>86</td>
</tr>
<tr>
<td>Managed Care</td>
<td>133</td>
</tr>
<tr>
<td>Total (unique patients across both services)</td>
<td>186</td>
</tr>
</tbody>
</table>

Both the Fast Track and Managed Care aspects of the service have seen increases in numbers of patients, with Fast Track increasing more than Managed Care. This indicates that increased numbers of patients have been discharged from hospital and/or avoided admissions, enabling more patients to be cared for in the setting of their choice.
Figure 8 – Number of patients has increased for both Fast Track and Managed Care aspects of the MCNS

Conversely, the number of MCNS visits per patient has decreased over the same period, with the number of Fast Track visits per patient decreasing more than Managed Care. This indicates a substantial improvement as a result of local coordination, ensuring that resources are allocated appropriately to care for increased numbers of patients. Prior to the redesign period, care was provided on a first come first served basis, but local coordination ensures appropriateness of care delivery.

Figure 9 – Number of visits per patient has decreased over time

* Note that Oct – Mar 15 is half as long as the other periods.

Helper Service
Within the redesign, funding was provided to launch the Marie Curie Helper Volunteer service in the Lothian area. Launched in early 2016, the service provides befriending support for patients and their families through a process of matching volunteers. In the period to end of March 2017, the service had recruited 44 volunteers and provided support for 34 households. In doing so, the service has achieved the target levels for the first year.
4.1.2 Preferred place of care

One of the core goals of the project was to increase the amount of time patients spend in their preferred place of care. We have two sources of data to inform our assessment of this goal. Firstly, the survey of patients using the Marie Curie Nursing Service, and secondly the linked NHS data supplied by ISD. Survey data shows that, after the redesign, more patients strongly agreed that having Marie Curie services, working alongside community nursing and GP teams, had allowed them to be cared for where they wanted to be.

**Figure 10 – Most MCNS patients strongly agreed that Marie Curie services enabled them to be cared for in their preferred place**

<table>
<thead>
<tr>
<th>Strongly agree</th>
<th>Agree</th>
<th>Neither agree nor disagree</th>
<th>Disagree</th>
<th>Strongly disagree</th>
<th>Not applicable</th>
</tr>
</thead>
<tbody>
<tr>
<td>74%</td>
<td>62%</td>
<td>23%</td>
<td>8%</td>
<td>0%</td>
<td>21%</td>
</tr>
</tbody>
</table>

Period 3: Apr 16 – Mar 17  
Period 1: Oct 14 – Mar 15

Respondents: n1=13, n3=19

The linked NHS data shows there is a decrease in the proportion of time spent in hospital in the six months before death and the final month before death. This applies to all groups except patients using Marie Curie Hospice services only. As a result of the redesign, this may reflect the increasingly complex nature of patients now seen in the hospice.

The reduction observed is larger in the final month of life, highlighting the importance of community based services in helping patients to remain in their own homes. We believe it is reasonable to infer that a reduction in the proportion of time spent in hospital also equates to an increase in the time spent in the preferred place of care.
Figure 11 – Percentage of time spent in hospital in the one and six months before death has reduced with the exception of the “MC Hospice only” cohort

Percentage of time spent in hospital - 1 and 6 months prior to death

<table>
<thead>
<tr>
<th></th>
<th>1 month before death</th>
<th>6 months before death</th>
</tr>
</thead>
<tbody>
<tr>
<td>MCNS only</td>
<td>5% 10%</td>
<td>1% 3%</td>
</tr>
<tr>
<td>MC Hospice only</td>
<td>32% 30%</td>
<td>8% 8%</td>
</tr>
<tr>
<td>MCNS &amp; MC Hospice</td>
<td>15% 19%</td>
<td>4% 7%</td>
</tr>
<tr>
<td>St Columba's</td>
<td>34% 40%</td>
<td>10% 12%</td>
</tr>
</tbody>
</table>

Number of total patients:
- MCNS only: n1=224, n2=271
- MC Hospice only: n1=593, n2=593
- MCNS & MC Hospice: n1=80, n2=131
- St. Columba’s: n1=611, n2=634

The data shows an overall reduction in the numbers of patients dying in hospital, whilst involvement of the MCNS increases the proportion of patients dying at home. These are shown in the figure below. Whilst we don’t have details of these patients’ preferred places of care, we believe it is reasonable to assume that in most instances they preferred to be at home.

The closer working between the MCNS and Hospice has allowed a more effective use of organisational resources, moving towards a model where patients receive the right care in the right place, and where appropriate, ensuring hospice beds are available for patients with more intensive care requirements, whilst continuing to provide a high level of care for all patients in the setting of their choice. This is further indicated by the reduction in hospital time for patients receiving both services.
Table 5 – An increasing proportion of patients receiving MCNS care (or MCNS and Hospice combined) die at home

<table>
<thead>
<tr>
<th>Cohort Group</th>
<th>Place of Death</th>
<th>Period 1: Sept 14 – Aug 15</th>
<th>Period 2: Jan 16 – Dec 16</th>
</tr>
</thead>
<tbody>
<tr>
<td>MCNS only</td>
<td>NHS Acute Hospital</td>
<td>7%</td>
<td>7%</td>
</tr>
<tr>
<td></td>
<td>Home/Private Address</td>
<td>76%</td>
<td>83%</td>
</tr>
<tr>
<td></td>
<td>Hospice</td>
<td>16%</td>
<td>9%</td>
</tr>
<tr>
<td></td>
<td>Care homes/homes for the Elderly</td>
<td>0%</td>
<td>0%</td>
</tr>
<tr>
<td>MC Hospice only</td>
<td>NHS Acute Hospital</td>
<td>24%</td>
<td>21%</td>
</tr>
<tr>
<td></td>
<td>Home/Private Address</td>
<td>24%</td>
<td>24%</td>
</tr>
<tr>
<td></td>
<td>Hospice</td>
<td>48%</td>
<td>51%</td>
</tr>
<tr>
<td></td>
<td>Care homes/homes for the Elderly</td>
<td>5%</td>
<td>4%</td>
</tr>
<tr>
<td>MCNS &amp; MC Hospice</td>
<td>NHS Acute Hospital</td>
<td>8%</td>
<td>5%</td>
</tr>
<tr>
<td></td>
<td>Home/Private Address</td>
<td>61%</td>
<td>73%</td>
</tr>
<tr>
<td></td>
<td>Hospice</td>
<td>30%</td>
<td>23%</td>
</tr>
<tr>
<td></td>
<td>Care homes/homes for the Elderly</td>
<td>1%</td>
<td>0%</td>
</tr>
<tr>
<td>St Columba’s</td>
<td>NHS Acute Hospital</td>
<td>17%</td>
<td>17%</td>
</tr>
<tr>
<td></td>
<td>Home/Private Address</td>
<td>24%</td>
<td>23%</td>
</tr>
<tr>
<td></td>
<td>Hospice</td>
<td>57%</td>
<td>58%</td>
</tr>
<tr>
<td></td>
<td>Care homes/homes for the Elderly</td>
<td>2%</td>
<td>2%</td>
</tr>
</tbody>
</table>

Number of total patients:
- MCNS only: n1=224, n2=271
- MC Hospice only: n1=593, n2=593
- MCNS & MC Hospice: n1=80, n2=131
- St. Columba’s: n1=611, n2=634

Whilst these changes are modest, they suggest that the redesign is beginning to enable more patients to remain in their preferred place of care for more of the time, at and towards the end of their lives. It is important to acknowledge that, whilst providing care at home is the right thing to do for many patients, it requires significant support from community based services.

4.1.3 Admissions and A&E attendance

The linked NHS data from ISD allows us to look at admissions and A&E attendance before and towards the end of the redesign. In all patient groups, except those in receipt of Marie Curie Hospice services only, the number of patients with one or more admission\(^\text{14}\) or A&E attendance decreased. This decrease was most marked for patients in receipt of MCNS services only and St Columba’s Hospice.

\(^\text{14}\) Elective and non-elective admissions
Figure 12 – A smaller proportion of patients had one or more hospital admission or A&E attendance, with the exception of the MC Hospice only cohort

<table>
<thead>
<tr>
<th>Percentage of patients with one or more admission or attendance</th>
<th>Accident and emergency admissions</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>MCNS only</strong></td>
<td><strong>MCNS only</strong></td>
</tr>
<tr>
<td>14%</td>
<td>5%</td>
</tr>
<tr>
<td>27%</td>
<td>8%</td>
</tr>
<tr>
<td><strong>MC Hospice only</strong></td>
<td><strong>MC Hospice only</strong></td>
</tr>
<tr>
<td>82%</td>
<td>23%</td>
</tr>
<tr>
<td>79%</td>
<td>22%</td>
</tr>
<tr>
<td><strong>MCNS &amp; MC Hospice</strong></td>
<td><strong>MCNS &amp; MC Hospice</strong></td>
</tr>
<tr>
<td>56%</td>
<td>23%</td>
</tr>
<tr>
<td>60%</td>
<td>19%</td>
</tr>
<tr>
<td><strong>St Columba’s</strong></td>
<td><strong>St Columba’s</strong></td>
</tr>
<tr>
<td>76%</td>
<td>27%</td>
</tr>
<tr>
<td>84%</td>
<td>39%</td>
</tr>
</tbody>
</table>

**Elective admissions**

<table>
<thead>
<tr>
<th><strong>MCNS only</strong></th>
<th><strong>MCNS only</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td>6%</td>
<td>8%</td>
</tr>
<tr>
<td>15%</td>
<td>13%</td>
</tr>
<tr>
<td><strong>MC Hospice only</strong></td>
<td><strong>MC Hospice only</strong></td>
</tr>
<tr>
<td>23%</td>
<td>15%</td>
</tr>
<tr>
<td>22%</td>
<td>12%</td>
</tr>
<tr>
<td><strong>MCNS &amp; MC Hospice</strong></td>
<td><strong>MCNS &amp; MC Hospice</strong></td>
</tr>
<tr>
<td>11%</td>
<td>15%</td>
</tr>
<tr>
<td>18%</td>
<td>17%</td>
</tr>
<tr>
<td><strong>St Columba’s</strong></td>
<td><strong>St Columba’s</strong></td>
</tr>
<tr>
<td>48%</td>
<td>41%</td>
</tr>
<tr>
<td>59%</td>
<td>48%</td>
</tr>
</tbody>
</table>

**Non-elective admissions**

<table>
<thead>
<tr>
<th><strong>MCNS only</strong></th>
<th><strong>MCNS only</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td>8%</td>
<td>6%</td>
</tr>
<tr>
<td>13%</td>
<td>8%</td>
</tr>
<tr>
<td><strong>MC Hospice only</strong></td>
<td><strong>MC Hospice only</strong></td>
</tr>
<tr>
<td>23%</td>
<td>20%</td>
</tr>
<tr>
<td>22%</td>
<td>15%</td>
</tr>
<tr>
<td><strong>MCNS &amp; MC Hospice</strong></td>
<td><strong>MCNS &amp; MC Hospice</strong></td>
</tr>
<tr>
<td>11%</td>
<td>15%</td>
</tr>
<tr>
<td>18%</td>
<td>17%</td>
</tr>
<tr>
<td><strong>St Columba’s</strong></td>
<td><strong>St Columba’s</strong></td>
</tr>
<tr>
<td>48%</td>
<td>41%</td>
</tr>
<tr>
<td>59%</td>
<td>48%</td>
</tr>
</tbody>
</table>

Number of total patients:
- MCNS only: n1=224, n2=271
- MC Hospice only: n1=593, n2=593
- MCNS & MC Hospice: n1=80, n2=131
- St. Columba’s: n1=611, n2=634

ISD performed Fisher’s Exact Test on the admissions data above, and found the changes between period 1 and 2 were statistically significant in the following cases:

- **MCNS Only:** All Admissions (p=0.0005) and Elective Admissions (p=0.0025)
- **St Columba’s Hospice:** All Admissions (p=0.0009), A&E Admissions (p=0.0000), Elective Admissions (p=0.0001) and Non-Elective Admissions (p=0.0303)

15 With a 95% confidence interval
Average length of stay for elective admissions also decreased for all patients except those using St Columba’s Hospice. This may be explained by the presence of more integrated and responsive statutory care packages being available in some parts of the community to allow them to return home more quickly.

**Figure 13 – The average length of stay for elective admissions has decreased notably, with the exception of the St Columba’s cohort**

<table>
<thead>
<tr>
<th></th>
<th>Elective</th>
<th>Non-elective</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>MCNS only</strong></td>
<td>11.9</td>
<td>11.0</td>
</tr>
<tr>
<td><strong>MC Hospice only</strong></td>
<td>14.7</td>
<td>11.4</td>
</tr>
<tr>
<td><strong>MCNS &amp; MC Hospice</strong></td>
<td>8.9</td>
<td>13.3</td>
</tr>
<tr>
<td><strong>St Columba’s</strong></td>
<td>19.0</td>
<td>12.7</td>
</tr>
<tr>
<td><strong>St Columba’s</strong></td>
<td>22.1</td>
<td>9.1</td>
</tr>
<tr>
<td><strong>St Columba’s</strong></td>
<td>16.3</td>
<td>7.7</td>
</tr>
<tr>
<td><strong>St Columba’s</strong></td>
<td>18.3</td>
<td>10.4</td>
</tr>
<tr>
<td><strong>St Columba’s</strong></td>
<td>11.8</td>
<td>11.8</td>
</tr>
</tbody>
</table>

Total number of admissions:
- MCNS only – elective: n1=44, n2=17 / non-elective n1=49, n2=23
- MC Hospice only – elective: n1=144, n2=148 / non-elective n1=496, n2=526
- MCNS & MC Hospice – elective: n1=21, n2=16 / non-elective n1=79, n2=82
- St Columba’s – elective: n1=542, n2=385 / non-elective n1=523, n2=452

In line with the overall length of stay for elective admissions reducing in most cases, the overall number of bed days for elective patients has also reduced in all cases, as has the number of bed days for non-elective admissions for MCNS and St Columba’s patients. This is shown in Figure 15 below.
Figure 14 – The total number of bed days decreased for both elective and non-elective admissions

Bed days for elective admissions have reduced across all patient groups, and non-elective bed days have decreased for MCNS only and St Columba’s patients.

<table>
<thead>
<tr>
<th></th>
<th>Period 1: Sept 14 – Aug 15</th>
<th>Period 2: Jan 16 – Dec 16</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Total elective</strong></td>
<td>12,670</td>
<td>12,724</td>
</tr>
<tr>
<td>MCNS only</td>
<td>203</td>
<td>837</td>
</tr>
<tr>
<td>MC Hospice only</td>
<td>2,178</td>
<td>2,523</td>
</tr>
<tr>
<td>MCNS &amp; MC Hospice</td>
<td>142</td>
<td>464</td>
</tr>
<tr>
<td>St Columba’s</td>
<td>7,045</td>
<td>8,846</td>
</tr>
<tr>
<td><strong>Total non-elective</strong></td>
<td>13,601</td>
<td>13,801</td>
</tr>
<tr>
<td>MCNS only</td>
<td>253</td>
<td>557</td>
</tr>
<tr>
<td>MC Hospice only</td>
<td>7,021</td>
<td>6,284</td>
</tr>
<tr>
<td>MCNS &amp; MC Hospice</td>
<td>746</td>
<td>607</td>
</tr>
<tr>
<td>St Columba’s</td>
<td>4,704</td>
<td>6,153</td>
</tr>
</tbody>
</table>

As well as the overall number of patients presenting at A&E decreasing after the redesign, the proportion being discharged home also decreased, especially amongst patients receiving the MCNS. After the redesign, most were admitted into the same acute hospital where they attended A&E. This suggests that when patients did present at A&E, it was an appropriate attendance and at the appropriate time, rather than being a result of a lack of access to other services in the community. It indicates that A&E attendance and admission were as a last resort, which also suggests that admission was not any longer than necessary, all amounting to more time spent in the preferred place of care, and less time spent in hospital. Whilst economic assessment was not in scope of the evaluation, we know that reduced number and length of admission offers cost savings to the NHS.
4.1.4 Patients’ experience of their care

We have two sources of feedback about changes to patients’ experience of their care: a survey of patients using Hospice community-based CNS services and a survey of patients using the Marie Curie Nursing Service. Furthermore, we can draw inferences from the findings of the service usage data about what these might mean for patient experience.

For patients using Marie Curie Hospice’s community-based CNS service, satisfaction levels were already very high, and remained so after the redesign. Ratings did dip a little during the period in the middle of the redesign, which might reflect the fact that service provision can be affected in the midst of delivering change. However, the ratings remained high, and recovered in the survey period at the end of the redesign. Levels of awareness of the service being available seven days per week during the daytime did not change over time, but numbers of patients reporting that they accessed this support did increase.

In all measures of MCNS patient satisfaction, ratings were already very positive. However, we do note a shift towards more patients giving the service the highest ratings after the redesign, and increases in patients agreeing strongly that they were involved in decisions about their care and that
they received enough information. This probably relates to the increased local coordination. We also note that MCNS patients reported accessing a wider range of services after the redesign, rather than only overnight care. This reflects the wider range of services available as a result of the redesign.

The survey data does not show marked changes in already-high satisfaction levels, and we see this quite commonly in evaluations of services supporting people during the most difficult times in their lives. The support provided is deeply appreciated and valued, and changes in service level often do not affect levels of satisfaction. However, the emergent changes in admissions and time spent in patients’ preferred place of care do indicate that patient experience is beginning to improve. However, we can reasonably assume that patients remaining in their preferred place and avoiding admissions, whilst feeling well-supported, will have a better experience even if it does not show up in a survey.

Given the minimal changes in satisfaction levels, we have summarised the survey data in Appendix 3, rather than presenting it in the main body of the report.

### 4.1.5 The future

Stakeholders report that, whilst Marie Curie Nursing Service seven-day working has now come to an end, the principles developed during the redesign continue to be upheld. There is more CNS resource and capacity available to support patients in the community, the Hospice CNS team and the MCNS work much more closely now and there is a more integrated approach to supporting patients. The day unit has refurbished modern and attractive facilities now, and a wider range of services to support people at different stages on their journey. The challenge with day services is to promote it to the right commissioners and referrers, so that more patients can benefit. Obviously there is some frustration that the enhanced seven-day MCNS community-based service has not continued at the same level, but the organisation is committed to spreading the available resources as effectively as possible. Conversations are ongoing with local commissioners to explore innovative methods of building upon this enhanced service.

### 4.2 Training for Lothian care home and local authority care at home staff

This project sought to provide consistent and high quality training and development in palliative care, for care workers in care homes and in home care services, across all four local authorities in Lothian, building upon previous Lothian Macmillan Care Home & Care At Home project alongside NHS Lothian internal training programmes. The objectives for the project were to:

- increase social care workers' knowledge, confidence and ability to recognise clients with unmet palliative and end of life care needs
- raise social care workers’ awareness of the wider multi-disciplinary team involved in the care of a client living with a terminal illness and their families, and what other local community and acute services are available
- ensure the social care workers were able to provide high quality end of life care for clients who are dying, thereby improving the provision of care and support for people living with a terminal illness and their families

The project consisted of:

- a palliative care study day (one day)
- an online module providing more in-depth learning on palliative care
- mentoring for staff who undertook the online module
Marie Curie recruited a programme manager to design, deliver and manage the project, and she did this in partnership with all four local authorities.

The effectiveness of the project was evaluated using post-completion and follow-up surveys, and qualitative interviews and focus groups with a small sample of participants. Response rates were very high for the post-completion surveys (96% for study day and 81% for online module).

### 4.2.1 Project reach

The study day was completed by 514 people and the online module by 4916 people. The figures below provide detail of where staff worked:

<table>
<thead>
<tr>
<th>Local authority</th>
<th>Study day</th>
<th>Online module</th>
</tr>
</thead>
<tbody>
<tr>
<td>City of Edinburgh Council</td>
<td>193</td>
<td>19</td>
</tr>
<tr>
<td>East Lothian Council</td>
<td>118</td>
<td>21</td>
</tr>
<tr>
<td>Midlothian Council</td>
<td>87</td>
<td>9</td>
</tr>
<tr>
<td>West Lothian Council</td>
<td>112</td>
<td>-</td>
</tr>
</tbody>
</table>

**Table 1 – breakdown of participant employers**

*Figure 2 – Most participants in the study day were in frontline17 roles*

N=492 (respondents to evaluation survey at end of study day)

### 4.2.2 Increasing knowledge, understanding and confidence

Survey responses indicate that both the study day and the online module had a positive impact on participants’ knowledge, understanding and confidence about dealing with end of life and palliative care needs.

---

16 71 started the module, but not all completed
17 By frontline roles, we mean those which involve providing care to clients on a day-to-day basis; by non-frontline roles we mean those involving management, administration and supervision, rather than practical care provision.
Figure 3 – Study day participants reported increases in knowledge, understanding and confidence. They also rated the practical applicability of their learning highly.

Attendees scores on knowledge and confidence areas

<table>
<thead>
<tr>
<th>Statement</th>
<th>Entirely True</th>
<th>Partly True</th>
<th>Not True</th>
</tr>
</thead>
<tbody>
<tr>
<td>I was provided an overview of current concepts within palliative care.</td>
<td>482</td>
<td>453</td>
<td>471</td>
</tr>
<tr>
<td>I have an increased understanding of the assessment, planning and treatment of pain and dyspnoea.</td>
<td>10</td>
<td>36</td>
<td>21</td>
</tr>
<tr>
<td>I was provided with an overview of ACP and how it can impact practice.</td>
<td>1</td>
<td>68</td>
<td>421</td>
</tr>
<tr>
<td>I have increased understanding and confidence in caring for a person and their family.</td>
<td>35</td>
<td>453</td>
<td>421</td>
</tr>
<tr>
<td>I can take this learning back into the practice setting.</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

n=492

Figure 4 – online module participants showed marked improvements in their understanding of palliative care issues*

<table>
<thead>
<tr>
<th>Topic</th>
<th>Pre module survey (n=79)</th>
<th>Post module survey (n=30)</th>
<th>Impact survey (n=9)</th>
</tr>
</thead>
<tbody>
<tr>
<td>The core principles of palliative care.</td>
<td>62%</td>
<td>93%</td>
<td>93%</td>
</tr>
<tr>
<td>The range of life limiting conditions that palliative clients are living with.</td>
<td>78%</td>
<td>97%</td>
<td>97%</td>
</tr>
<tr>
<td>The common symptoms associated with these terminal conditions.</td>
<td>68%</td>
<td>97%</td>
<td>97%</td>
</tr>
<tr>
<td>The process of advance care planning or anticipatory care planning.</td>
<td>56%</td>
<td>93%</td>
<td>93%</td>
</tr>
<tr>
<td>How dyspnoea is assessed and managed using a palliative approach.</td>
<td></td>
<td></td>
<td>33%</td>
</tr>
</tbody>
</table>

*Combined ‘agree’ and ‘strongly agree’ ratings that they had a good understanding of the listed issues.
The online module was reported as being practically applicable in the workplace, as can be seen in the following survey responses:

Figure 5 – online module participants describe marked improvements in practical ability to address palliative care issues

<table>
<thead>
<tr>
<th>Statement</th>
<th>Pre module survey (n=79)</th>
<th>Post module survey (n=30)</th>
<th>Impact survey (n=9)</th>
</tr>
</thead>
<tbody>
<tr>
<td>I could locate a client's advance care plan or anticipatory care plan in my work setting</td>
<td>69%</td>
<td>100%</td>
<td>100%</td>
</tr>
<tr>
<td>If a client was experiencing uncontrolled symptoms such as pain, I would know who in the team to contact to ensure a complete pain assessment is carried out.</td>
<td>83%</td>
<td>97%</td>
<td>68%</td>
</tr>
<tr>
<td>I can recognize if someone has spiritual care needs that are unmet, and I know who to contact in my team to support them.</td>
<td>97%</td>
<td>97%</td>
<td>93%</td>
</tr>
<tr>
<td>I can provide examples of common psychological and social symptoms experienced for someone living with a terminal illness and their family.</td>
<td>47%</td>
<td>97%</td>
<td>97%</td>
</tr>
<tr>
<td>I am confident in providing care for someone who is in the last days and hours of their life.</td>
<td>75%</td>
<td>100%</td>
<td>100%</td>
</tr>
<tr>
<td>In communicating with clients who are approaching end of life, and their families.</td>
<td>67%</td>
<td>100%</td>
<td>100%</td>
</tr>
<tr>
<td>I could raise a potential issue with the multidisciplinary team if a client or their family requested this.</td>
<td>78%</td>
<td>100%</td>
<td>100%</td>
</tr>
</tbody>
</table>

*Combined ‘agree’ and ‘strongly agree’ ratings for the listed statements

It is important to be mindful that the data presented in figures 4 and 5 for the impact survey relate to a very small sample (n=9), however, the post-module survey results show an impressive improvement in understanding.

Qualitative feedback confirmed these positive ratings in relation to knowledge, understanding and confidence, with staff reporting feeling much more confident in caring for clients with palliative care needs, and in raising palliative care issues with colleagues as a result of the courses. They highlighted how effective the courses’ delivery methods were, and reported that these were critical to them being able to absorb and retain such a lot of useful information.

The key learning points retained by participants varied, but the more consistent aspects included:

- ★ importance of the care plan and ensuring it reflects a client’s wishes
- ★ new insights into what a client and family members are feeling and thinking, and how this can impact on behaviour
- ★ the importance of seeing things from a client’s/family members perspective – putting themselves in their shoes
- ★ the little things that can be done to ensure a client is as comfortable as they can be
- ★ understanding more about how personal experiences shape how we approach things
finding out about the different support that is available to families following bereavement, and how they can be there for the family

- the range of different conditions and how common some of the illnesses were

- how to recognise the signs of pain and discomfort, and the different ways of managing these

A few participants also spoke about the concept of a good death being new to them, and said they found this idea very thought-provoking.

4.2.3 Changes to practice

A follow-up impact survey was sent out to study day participants, three months after their participation, to find out more about how the course had changed their confidence and practice. The response rate for this survey was small at 5% of all participants (n=27), but the majority of respondents did report some changes to practice.

Figure 6 – Most respondents report changes to practice and increased confidence in dealing with palliative care needs in the workplace

This was backed up by the qualitative feedback from participants, where participants talked about the different ways in which they were working with their clients who had palliative care needs. Increased communication with clients and their families tended to be the most commonly reported changes to practice, in terms of both what they discussed and how it was discussed. Participants reported spending more time trying to understand what and how a client was feeling, and what more they could be doing to ensure they were as comfortable and happy as they could be. For some, the focus was on listening more to the client, rather than relying on what family members were telling...
them. They found that, often, clients would be more honest with them about how they were feeling and what was concerning them, than they would be with their families.

For others, it was having the confidence to include the family more in discussions, and having the confidence to deal with any questions that may arise. A few participants spoke about the conversations they now had being more honest. Several participants also felt they were communicating with greater sensitivity, empathy and patience, and doing more to understand things from the perspective of the client and family members.

Importantly, managers of the staff who had participated in the course(s) also recognised these changes in confidence and practice, and could see a difference between the staff who had participated and those who had not.

Amongst the small sample of staff involved in qualitative focus groups and interviews, we noted a deep commitment to ensuring people approaching the end of their lives had as high a quality of life as possible and dignity and care in their final days and hours. Those staff indicated that the course had enabled them to put that commitment into practice in a more meaningful way.

4.2.4 Facilitating Anticipatory Care Planning

Anticipatory Care Planning has been another focus of the programme, with two projects supporting this important process. The development programme for care workers appears to have complemented and supported Anticipatory Care Planning, by educating care staff about the purpose of Anticipatory Care Planning, and the role they can play in ensuring that all their clients have up to date and good quality plans in place. The qualitative feedback revealed a much improved understanding of how important both the process of planning and the plans themselves are for people as they approach the end of life. The feedback from surveys and interviews/focus groups also indicates an improved confidence in talking openly about Anticipatory Care Plans with clients.

Furthermore, the surveys of online module participants also show an improved understanding of the role of the multi-disciplinary team in providing and planning for palliative care, including their own role and value within that team. This was reiterated in the qualitative interviews and focus groups.
4.2.5 Future considerations

The project has shown that social care workers welcome the opportunity to learn more about palliative care, and that a single study day does provide sufficient knowledge and understanding to change social care workers’ practice back in the workplace. The fact that a number of staff from each workplace participated in the course created a common language about palliative care, which facilitated different ways of working individually and as a team.

The online module provided effective in-depth learning, to help consolidate and extend the knowledge gained in the study day. It was well-received by those that participated, but overall uptake numbers were much lower than the single study day. The time commitment to complete the online module is significant (between nine and twelve hours depending on the participant’s experience and skills), and access to IT is a prerequisite, alongside the additional resource required to provide ongoing support. Workplaces need to develop a common policy for how the time will be resourced, and they also need to ensure access to IT for participants.

The training was only available to staff employed directly by local authorities, but a large proportion of home-based care is provided by staff employed by private providers. To achieve a consistently high quality of delivery across all care services, the offer of training would need to be expanded to private providers too.

Larger scale roll-out of the online module would need a bank of mentors to support it, as the mentor’s role is crucial in supporting participants to complete the reflective aspects of the module.

*Combined ‘agree’ and ‘strongly agree’ ratings for the listed statements
4.3 Evaluation of an Anticipatory Care Questionnaire within a care home setting

The purpose of this project was to better understand anticipatory care planning and the links between medical and care home teams, to improve patient care in a care home setting and to reduce hospital admissions. The project looked at the use of an Anticipatory Care Questionnaire (ACQ) in anticipatory care planning in two different care homes in Edinburgh. It aimed to understand:

★ what makes care planning work well for residents, families, care home staff and other professionals (including NHS 24)
★ how problems can be addressed

The study ran for 12 months from April 2015 and used a mixed methods approach comprising an audit of acute events and qualitative interviews with care home staff, GPs and relatives of care home residents.

The evaluation explored how the ACQ approach could be improved, to help increase in the number of anticipatory care plans completed. It was hoped that this would also improve the standard of Key Information Summaries (KIS) for care home residents and help to reduce inequalities in the provision of care planning in care homes.

The study looked at:

★ acceptability of the ACQ, and barriers and facilitators to its use
★ how useful the ACQ was to medical staff in helping complete and update KIS for care home residents
★ how ACQs impacted on decision-making about potential hospital admissions.
★ how acute clinical events were managed, and in particular how useful KIS were in aiding decision-making about hospital admission

The key findings are discussed below.

4.3.1 ACQ facilitates effective anticipatory care planning
Having a simple tool and a culture supporting anticipatory care planning meant 64% (44 of 69) of acute events were managed appropriately and in accordance with the resident's KIS. Whilst challenges in using the ACQ were identified by relatives, care home staff and GPs, these are being addressed as ACQs are updated.

4.3.2 Support needs
Care home staff report that they would welcome further guidance and support in discussing and documenting care planning with residents and families.

Staff and relatives report that it would be helpful to have brief explanatory leaflet about the process and the decisions to be considered in anticipatory care planning that could be used alongside information from staff.

4.3.3 Effective and timely systems for care planning
Individual care homes need a systematic approach for agreeing, reviewing, recording and updating KIS anticipatory care plans and ensuring that these are easily accessible to all professionals who need them to guide decision-making.
The study reported that most people move into care homes from acute hospitals rather than from their own home, and often do so with no preparation or planning, as the transfer is usually very rapid once a place has been identified. The study concluded that anticipatory care planning should begin earlier in the process, as the move into a care home is being planned. Effective engagement with future residents and their families at this stage would enable more timely discussions about their priorities for any future care.

4.3.4 Supporting good decisions during acute episodes

During the day, care home residents are usually assessed by a GP before referral to hospital. This does not happen routinely out-of-hours. However, when a GP visit did happen, this led to more effective decision-making. Calls triaged by NHS 24, using protocols designed for urgent care, tend to result in emergency ambulance calls and potentially avoidable admissions.

Accident & Emergency staff often receive limited information about care home residents referred for urgent care. This makes it more difficult for them to make good decisions about treatment options and ongoing care.

Furthermore, the likely outcomes of hospital interventions are often poorly understood by families of residents. Whilst a hospital admission can be of benefit for some care home residents, many acute interventions fail to offer added value and can be associated with avoidable harms. NHS 24 protocols for urgent care do not reflect likely outcomes for frail people. There is a lack of clear information about the impact of such interventions, to enable relatives to make good decisions.

4.3.5 The future

The evaluation made the following recommendations:

★ effective anticipatory care planning should be available in all care homes as part of ongoing care from pre-admission to bereavement for all residents and their families
★ staff should be supported to administer ACQs effectively
★ using an Anticipatory Care Questionnaire (ACQ) provides useful input for Key Information Summaries; these in turn support effective emergency decision-making about interventions that will be of benefit to the patient and are in accordance with their and their families’ wishes
★ to make anticipatory care planning more effective and reliable, the following need to be in place:
  • robust systems
  • clear documentation
  • good communication with residents and families, and between professionals and care settings
  • support for care home staff
4.4 Early identification of patients in a primary care setting utilising existing IT infrastructure

This project built on previous work by the University of Edinburgh, and developed software to identify patients with possible future palliative care needs, through General Practice IT systems. AnticiPal software searches patients’ electronic records for combinations of Read Codes which might indicate that a patient is at risk of deterioration and could therefore benefit from Anticipatory Care Planning (ACP), and potentially from palliative care.

Through the project period, three versions of AnticiPal were tested with a sample of eight GP surgeries in NHS Lothian.

4.4.1 Refining AnticiPal

Three versions of AnticiPal were tested, each providing a greater level of refinement. Version 1 was not specific enough, and identified too many patients. Version 2 was refined to be much more specific in the combinations of conditions it searched for. This generated a more manageable size of list, with a higher success rate of identifying patients in the target group.

Version 3 was a further refinement for repeat searches, requested by the test sites, so that any future search excluded patients already identified in previous searches. This meant that future searches only identified patients who were ‘new’ to the target group.

4.4.2 Search sensitivity

Once AnticiPal has identified potential target patients, staff in the GP practice need to manually review patient files to determine whether they do indeed have future palliative care or anticipatory care planning needs. Version 1 generated large numbers of patients to review, which was difficult for the practice to manage.

The refinements in Version 2 made the search more specific and generated a more manageable list of patients for review. The table below shows the search results in each of the eight test practices.

Table 2 – Version 2 identified between 0.61% and 1.23% of each practice’s patients as having potential palliative care needs

<table>
<thead>
<tr>
<th>IP1</th>
<th>IP2</th>
<th>IP3</th>
<th>IP4</th>
<th>IP5</th>
<th>IP6</th>
<th>IP7</th>
<th>IP8</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Version 1</td>
<td>462</td>
<td>111</td>
<td>342</td>
<td>332</td>
<td>429</td>
<td>205</td>
<td>333</td>
<td>245</td>
</tr>
<tr>
<td>Version 2</td>
<td>55</td>
<td>29</td>
<td>63</td>
<td>69</td>
<td>78</td>
<td>41</td>
<td>106</td>
<td>71</td>
</tr>
<tr>
<td>List size</td>
<td>4459</td>
<td>3086</td>
<td>9971</td>
<td>10832</td>
<td>9367</td>
<td>6766</td>
<td>10847</td>
<td>7380</td>
</tr>
<tr>
<td>v2 by List size</td>
<td>1.23%</td>
<td>0.94%</td>
<td>0.63%</td>
<td>0.64%</td>
<td>0.83%</td>
<td>0.61%</td>
<td>0.98%</td>
<td>0.96%</td>
</tr>
</tbody>
</table>

Of those patients identified by the search, GP case review identified around a third where they agreed with the assessment and put Anticipatory Care Plans in place. Across all GP practices in the trial, 0.82% of patients were identified as having potential palliative care needs.

4.4.3 The practicalities of using AnticiPal

Informal interviews with stakeholders highlighted that staff involved in trialling AnticiPal were very enthusiastic about the concept. Indeed, the trial was over-subscribed, indicating that many more practices are also interested in identifying patients with palliative and anticipatory care planning needs. However, staff reported that their workload was already extremely pressured, and they were concerned about how they would manage having more anticipatory care or palliative care patients on their caseloads.
4.4.4 The service user perspective
Patients and carers were supportive of the idea of early anticipatory care planning, but had some concerns that the focus needed to be on continued quality of life for the patient and seamless communication between services, rather than on death and dying.

4.4.5 The future
The project has had interest from other parts of Scotland and elsewhere in the UK, to roll out a version of AnticiPal to help identify 'pre-palliative' patients. NHS Lothian has provided a mechanism for rolling out the software across all GP practices whereby, if successful, a national roll-out will commence. Additionally, a project has been developed in Northern Ireland with the software being trialled in 20 GP practices.

Other funders have also expressed interest in supporting further development.

4.5 Health Promoting Palliative Care and Compassionate City
Building on previous work, this project sought to encourage conversations about death, dying and bereavement, and to raise awareness of palliative care. The project worked with health professionals and with the general public, across a range of events and activities, to open up conversations about death, dying and celebration/remembrance of the lives of friends and family.

4.5.1 Gathering resources
The project reviewed and procured a variety of resources to support conversations about death, dying and palliative care. These are now made available for meetings, events, teaching sessions and workshops.

In addition, the project team identified a resource from Australia, 'Dying to Know', and gained permission to develop a Scottish version of the concept. The resource is currently being finalised, and will be available for free download from the Good Life Good Death Good Grief website.

The project also developed a photographic exhibition, It Takes a Village, which has been used in a variety of settings to engage NHS staff and the public.

4.5.2 Working with health professionals
As well as making resources available to health and care professionals, the project has worked practically with a variety of NHS staff and contributed insights to a range of NHS Lothian projects, including:

★ facilitating and presenting at in-service training sessions about palliative and end of life care
★ working with NHS staff to use the resources described above
★ contributing to the development of NHS Lothian's new procedure to support DNACPR decision-making
★ provided information for resources including NHS Inform and Support Around Death websites

4.5.3 Community engagement
The project engaged with communities in a variety of ways, including:

★ hosting and supporting events during 'ToAbsent Friends Week' and 'Dying Matters Weeks',
4.5.4 Exploring new routes to public engagement
The project wanted to test new ways of engaging the community, through non-traditional routes such as sports organisations. This led to two successful collaborations, with Scottish Rugby Union and Edinburgh Rugby and with Hibernian Football Club. Both collaborations related to ‘To Absent Friends’, and Hibernian had such a positive response that they intend to make the activity a regular, annual commemoration. Edinburgh Rugby have also begun proactively remembering people attached to the club who have died either pre-match or during half time.

These activities have shown that it is possible to engage people in the topic at sporting events, and the project is currently exploring how this could be taken further, especially in football.

4.5.5 Compassionate City
The project was also aiming to contribute to the social changes outlined in the Compassionate City Charter, however this was not achieved due to a timing mismatch between the project and the progress of the Charter.

4.6 A review and improvement of workplace and employment policies for carers working within the Lothian area
The initial scope of this project was to work with employers and with carers’ organisations to:

★ examine current workplace practices to support carers who are in employment whilst caring for loved one with palliative care needs
★ identify working carers’ needs when caring for someone with palliative care needs
★ identify the resources, networks and organisations that can support individuals
★ increase awareness among both carers groups and health care professionals of the resources available to support carers

Amongst the employers engaged\(^\text{18}\), there was widespread acknowledgement and understanding of issues affecting working carers, and they were keen to engage in conversation. However, there were challenges in getting them to commit to progressing the project. Conversely, there was good commitment from local carers’ organisations who hosted focus groups to help identify the issues for working carers.

As VOCAL, one of the local carers’ organisations, was planning to initiate some wider work with employers about carers, Marie Curie offered support to provide palliative care expertise to this work. This approach ensures that palliative care is a core part of VOCAL’s ongoing work with employers about carers’ needs and thus enables the findings from the early consultation work to be progressed. VOCAL has also established a Facebook group for carers, which provides a safe environment for conversations to happen between carers and enables the development of peer support.

\(^{18}\) A total of seven employers were identified for discussion. Each organisation employed a minimum of 250 people and were a combination of organisations with a local and national presence.
4.7 Ongoing projects

Two projects in the original programme have only recently commenced. These are described below.

4.7.1 Capturing Feedback on Palliative and End of Life Care
The initial scope of this project was to improve ways of capturing feedback on end of life care. It was acknowledged that, in the current services, feedback is not routinely captured and is often only received via the complaints mechanism.

The project was to be led by NHS Lothian and has been delayed due to an approach from Scottish Government, requesting the incorporation of a VOICES\textsuperscript{19} type survey in the project. As part of this process, NHS Lothian was required to submit a funding application to Scottish Government. There was a delay in the approval process within Scottish Government, partly due to organisational restructuring.

The funding of the project is shared between Marie Curie, NHS Lothian and Scottish Government. NHS Lothian is responsible for delivering the work and employing staff to undertake the associated tasks. The organisation therefore needed to delay the start of the recruitment process until all the finances are in place. Following confirmation of funding from Scottish Government, the process to seek Public Benefit & Privacy approval commenced, with recruitment commencing in July 2017. Whilst the formal start date of the project has been delayed, significant work has been undertaken by the project lead to ensure that, when the project team is in post, they are able to build on solid foundations.

4.7.2 Lothian Approach to End of Life Care
The scope of this project is to develop and introduce the Lothian Approach to End of Life Care. This is in response to the Scottish Government mandating all health boards to introduce a local approach to delivery of end of life care following the withdrawal of previous guidance.

Initial recruitment began in April 2016, but two rounds of recruitment were unsuccessful. NHS Lothian and Marie Curie agreed that, since there was significant difficulty in identifying a single candidate with all the required skills, the role would be split across two individuals.

A secondment was agreed with Edinburgh Napier University for an individual to work 2 days per week, delivering the educational component of the project. Alongside this, a secondment was agreed with NHS Lothian for a Project Facilitator to work 3 days per week to deliver the project facilitation and clinical improvement component.

Both of the above roles were successfully recruited and the project formally commenced in April 2017.

\textsuperscript{19} \url{https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/healthcaresystem/bulletins/nationalsurveyofbereavedpeoplevoices/2015-07-09}
5 CONCLUSIONS & RECOMMENDATIONS

In this chapter we set out the conclusions we have drawn from the evaluation, and our recommendations for the future.

5.1 Programme achievements

As the programme draws to a close, most of the projects have completed. It is therefore timely to consider what is different in Lothian as a result of the programme. The programme’s key tangible achievements, which remain after the programme ends, are:

- a redesigned and revitalised Marie Curie Hospice and Marie Curie Nursing Service, with a stronger community-based focus and more integrated ways of working across the various services and with St Columba’s Hospice
- the successful launch of the Lothian Helper Service, providing befriending support to patients and families across Lothian
- a local authority care workforce with enhanced capability and confidence to support people towards the end of their lives
- a primary care tool for identifying patients in with pre-palliative care needs that can be refined to help primary care teams with anticipatory care planning; there also appears to be an appetite for such a tool
- increased understanding of how to improve the process of anticipatory care planning in care homes, and a questionnaire that can be further refined to support the process
- a suite of support resources for health professionals and the general public to enable conversations about death, dying and bereavement
- opportunities to ensure support is in place for employees in Lothian who are caring for a loved one with palliative care needs

5.2 Strategic added value

Whilst generating strategic added value (SAV) was not a core objective of the programme, it has been one of its most important achievements, alongside the practical and tangible changes described above. To date, the programme has delivered particularly strongly on:

- Strategic Leadership and Catalyst
- Engagement

Furthermore, our findings indicate that there is likely to be a continued growth in SAV, in terms of Strategic Influence, Leverage and Synergy, as organisations continue to implement strategic and operational changes stimulated as a result of being involved in the programme.

The enabler of this Strategic Added Value has been the genuine partnership between all the key organisations and recognised experts in palliative care in the region, convened and led by Marie Curie. This partnership has created a new working culture between these organisations; one of collaboration and common purpose. This creates the conditions for joined up working to continue to grow and develop in future, and is an important legacy of the programme.

There are risks to this partnership, as changes to key personnel are inevitable, and without the regular focus of the programme board there is less reason for individuals to come together except for specific tasks. Sustaining the relationships and the space for thinking, strategic discussion and
knowledge-sharing will be essential, to maintain a healthy and productive partnership, particularly in relation to implementing the priorities of the Strategic Framework for Action on Palliative and End of Life Care. Furthermore, the continuation of the partnership will help sustain momentum on embedding the strategic and operational changes that are underway and ensure the programme’s learning is adopted as widely as possible.

**Recommendation 1**  
The partnership should be continued, for example through a community of practice. This will require continued leadership.

5.3 Answering the key evaluation questions

At the beginning of the programme, the programme board agreed a number of key evaluation questions. The programme has experienced changes during its lifetime, as does any programme operating in the real world. Consequently not all of the programme’s activities are complete yet. However, the bulk of the projects (also representing the majority of the programme’s investments) have concluded, and we now reflect on each of the evaluation questions in turn.

5.3.1 *What is the profile of the patients being identified, registered on a palliative care register, having an anticipatory care plan in place and accessing Marie Curie services and has this changed since the programme was introduced?*

Due to the abolition of the Quality and Outcomes Framework during the time period of the programme, GPs are no longer incentivised to hold a register of palliative patients, leading to inconsistency in the data available from practices. Whilst this impacts on the ability to answer this question fully, we note a number of relevant outcomes from the programme:

The ACQ evaluation project has led to more patients in the two pilot care homes having up to date anticipatory care plans in place. The key to continuing this pattern, of more people having plans in place at the right time, is to roll out the learning from the ACQ evaluation across the region’s care homes.

The AnticiPal project has also led to around 170 more patients in primary care having their pre-palliative needs identified and anticipatory care plans put in place. The programme’s support for developing and testing AnticiPal has enabled the development team to secure future funding for roll-out across Lothian, which will result in more patients in primary care having their needs identified and planned for earlier.

By increasing the knowledge of social care staff relating to the importance of anticipatory care planning, we anticipate that the local authority social care staff development programme will lead to more care home residents having plans of an appropriate quality in place.

The Marie Curie service usage shows a small increase in numbers of patients accessing services. Based on trend lines and the expansion of existing services, we anticipate this will increase in future years.

**Recommendation 2**  
The ACQ should be further refined and then rolled out (with associated support and process guidance) to care homes across the region.
5.3.2 What is the profile of Marie Curie service provision to patients before and after the changes to the MCNS and MC Hospice were introduced?

Service provision has changed in the following ways:

- Fewer in-patient beds, with an increased focus on community-based care wherever appropriate
- An integrated approach to community-based services across the CNS and MCNS services, so that patients get the right combination of services in the right place in a seamless fashion
- An integrated approach to bed management across the two Lothian Hospices
- Increased capacity in the community-based CNS service
- Enhanced day care provision

Usage of MCNS services (both Managed Care and Fast Track) have increased, which indicates that more patients are avoiding hospital admissions or being discharged from hospital to home earlier. Overall, changes in the number of unique patients using the Hospice’s services appear to be limited thus far, but this shift to more patients receiving community-based services is a positive indication of care being delivered in the right place at the right time.

Given the positive early indicators we discuss below in 5.3.6, we also conclude that it is likely that patterns of service usage will continue to change and improve in the next one to two years.

5.3.3 What is the impact of the programme on working relationships, communications and joined up working across acute and community providers in the area?

There has been a notable strengthening of relationships at the leadership level, which has created a stronger partnership of palliative care leaders in the region. This partnership has enabled the delivery of the programme’s outcomes, and its development has been an important process in and of itself – building trust, understanding and a common vision for palliative care in Lothian and the relationships which facilitate productive collaboration in future. The strengthened relationships at a leadership level also provide the foundation for improving operational relationships across the system.

We also conclude that the improvements in care staff understanding of anticipatory care planning will create a bottom-up demand for improved integration between care homes and clinical service providers in both the community and acute sectors. Furthermore, further roll-out of ACQ and AnticiPal should lead to the existence of more and better quality anticipatory care plans, which in turn will facilitate improvements in the communication of patients’ and families’ wishes across the sectors.

5.3.4 What impact does the programme have on the ability of health and social care workers to deliver appropriate care with knowledge and confidence?

The programme has had a very positive impact on local authority-employed care staff, demonstrated through increased knowledge and confidence when discussing palliative and end of life care with patients and carers. The care staff development course provides a high impact and cost-effective way to develop a key part of the workforce in delivering palliative care. To maximise its benefit, the programme should be rolled out to the workforce employed by private providers.

The model appears to have worked very effectively and could be transferable. Hence there is also real potential to roll the course out to other regions within the UK, and to be further adapted for a wider range of professionals and roles.

The ACQ and AnticiPal have both helped to develop staff skills in identifying palliative care and pre-palliative care needs. In addition, both projects have also identified the need to increase support for
staff having conversations about anticipatory care planning. This is an important learning outcome from the process.

**Recommendation 3**
The home care staff training course should be adapted for use in alternative settings, for example private care homes and non-registered healthcare staff, to enable an increase in understanding of palliative care and importance of anticipatory care planning.

5.3.5 **What is the experience of the patient and their carers through the end to end process of the care delivery model?**

The patient satisfaction data collected for the evaluation relates only to patients of the Marie Curie Hospice CNS service and the MCNS. These show small improvements in satisfaction levels, but from a very high baseline position. This is not unusual: patients and carers of services provided by charitable organisations are generally highly satisfied with the care and support they receive. Therefore it is also important to look at other indicators of improvements in patient experience alongside the survey data. We can infer an improved patient and carer experience since the redesign from the following indicators:

★ patients spend more of their time at home rather than in hospital, on average have fewer acute admissions and shorter lengths of stay for these admissions
★ more patients have been supported by the MCNS and, in turn, MCNS involvement means that patients are more likely to be able to die at home

Whilst the changes are relatively modest to date, they are positive indicators of improvement. We would expect the impact of these improvements to reach more patients over time.

5.3.6 **Overall, are the appropriate services in place in order to prevent avoidable hospital activity for patients at the end of life?**

The linked comparative data from ISD providing evidence of

★ reduced admissions
★ reduced A&E attendances
★ reduced hospital bed days
★ improvements in the appropriateness of A&E attendances and subsequent admissions

As well as being indicators of an improved quality of care and experience for patients, these reductions in avoidable uptake of acute hospital services are likely to generate economic savings for NHS Lothian. If repeating the evaluation of the redesign in future years, as discussed earlier, inclusion of a cost-effectiveness assessment would be merited.

**Recommendation 4**
A follow-up evaluation of the Marie Curie Hospice and MCNS Redesign should be conducted in one to two years. The ISD linked data extraction should be expanded to include acute and community services, alongside capturing data relating to lay carers. Economic assessment (cost-effectiveness should also be included).

We anticipate that the ACQ and AnticiPal projects, and the care staff training course, will lead to more patients having Anticipatory Care Plans in place and to staff feeling confident and knowledgeable to act on patients’ and families’ wishes. We anticipate that this is also likely to lead to fewer avoidable admissions, and this should be confirmed by future evaluation.
APPENDICES
APPENDIX 1
PROGRAMME BOARD, PROJECT BOARDS, STAKEHOLDER INTERVIEWS
# Programme Board

<table>
<thead>
<tr>
<th>Name</th>
<th>Organisation</th>
<th>Role</th>
</tr>
</thead>
<tbody>
<tr>
<td>Andy Shanks</td>
<td>City of Edinburgh HSCP</td>
<td>Social Care Services Representative</td>
</tr>
<tr>
<td>Anne Bond</td>
<td>Midlothian HSCP</td>
<td>Social Care Services Representative</td>
</tr>
<tr>
<td>Bruce Mason</td>
<td>University of Edinburgh</td>
<td>Academic &amp; Research Representative</td>
</tr>
<tr>
<td>Diana Hekerem</td>
<td>Marie Curie</td>
<td>Lead Supplier</td>
</tr>
<tr>
<td>Dr Duncan Brown</td>
<td>St Columba's Hospice</td>
<td>Hospice Representative</td>
</tr>
<tr>
<td>Dr Hazel McCutcheon</td>
<td>NHS Lothian</td>
<td>Primary Care (General Practice) Representative</td>
</tr>
<tr>
<td>Dr Kirsty Boyd</td>
<td>NHS Lothian</td>
<td>Acute Hospital (Medical) Representative</td>
</tr>
<tr>
<td>Dr Lorna Porteous</td>
<td>NHS Lothian</td>
<td>Primary Care (General Practice) Representative</td>
</tr>
<tr>
<td>Dr Rachel Kemp</td>
<td>Marie Curie</td>
<td>Hospice Representative</td>
</tr>
<tr>
<td>Eamon O’Kane</td>
<td>Marie Curie</td>
<td>Programme Co-Sponsor</td>
</tr>
<tr>
<td>Gill Cottrell</td>
<td>West Lothian Health and Social Care Partnership</td>
<td>Social Care Services Representative</td>
</tr>
<tr>
<td>Kris Wright</td>
<td>Marie Curie</td>
<td>Project Manager</td>
</tr>
<tr>
<td>Mairead Hughes</td>
<td>West Lothian Health and Social Care Partnership</td>
<td>Social Care Services Representative</td>
</tr>
<tr>
<td>Mark Connelly</td>
<td>Marie Curie</td>
<td>Programme Manager</td>
</tr>
<tr>
<td>Neil Wilson</td>
<td>NHS Lothian</td>
<td>Programme Co-Sponsor</td>
</tr>
<tr>
<td>Niall Kieran</td>
<td>Marie Curie</td>
<td>Programme Manager / Project Manager</td>
</tr>
<tr>
<td>Nichola Summers</td>
<td>Marie Curie</td>
<td>Programme Co-Sponsor</td>
</tr>
<tr>
<td>Patricia Brooks-Young</td>
<td>NHS Lothian / Napier University</td>
<td>Acute Hospital (Nursing) Representative</td>
</tr>
<tr>
<td>Peter McLoughlin</td>
<td>NHS Lothian</td>
<td>Programme Sponsor</td>
</tr>
<tr>
<td>Professor Scott Murray</td>
<td>University of Edinburgh</td>
<td>Academic &amp; Research Representative</td>
</tr>
<tr>
<td>Shirley Fife</td>
<td>NHS Lothian</td>
<td>Primary Care (Nursing) Representative</td>
</tr>
<tr>
<td>Susan Siegel</td>
<td>Marie Curie</td>
<td>Patient and Carer Representative</td>
</tr>
<tr>
<td>Tracy Smith</td>
<td>Marie Curie</td>
<td>Education Representative</td>
</tr>
</tbody>
</table>
### Project Boards

#### Training for Lothian care home and local authority care at home staff

<table>
<thead>
<tr>
<th>Project Lead</th>
<th>Project Board Members</th>
</tr>
</thead>
</table>
| **Lyndsay Cassidy** *(Marie Curie)*  | Andy Shanks  
Patrick Jackson  
Niall Kieran  
Anne Cleary  
John Gibson  
Aileen Maguire  
Marianne Hughes  
Tracy Smith  
City of Edinburgh  
City of Edinburgh  
Marie Curie  
Marie Curie  
East Lothian  
West Lothian  
Midlothian  
Marie Curie |

#### Early identification of patients in a primary care setting, utilising existing IT infrastructure

<table>
<thead>
<tr>
<th>Project Lead</th>
<th>Project Board Members</th>
</tr>
</thead>
</table>
| **Bruce Mason** *(University of Edinburgh)*  | Professor Scott Murray  
John Steyn  
Stella McPherson  
Niall Kieran  
Kirsty Boyd  
Marilyn Kendall  
University of Edinburgh  
NHS Lothian  
Patient Representative  
Marie Curie  
University of Edinburgh  |

#### Health Promoting Palliative Care and Compassionate City

<table>
<thead>
<tr>
<th>Project Lead</th>
<th>Project Board Members</th>
</tr>
</thead>
</table>
| **Shirley Fife** *(NHS Lothian)*  | Jeannette Byers  
NHS Lothian  |

#### Evaluation of an Anticipatory Care Questionnaire (ACQ) within a care home setting

<table>
<thead>
<tr>
<th>Project Lead</th>
<th>Project Board Members</th>
</tr>
</thead>
</table>
| **Hazel McCutcheon** *(NHS Lothian)*  | Jo Hockley  
Dr Andrew Mackay  
Gill Highet  
Marion Randall  
Dr Kirsty Boyd  
University of Edinburgh  
St Triduana's Medical Practice  
NHS Lothian  
City of Edinburgh  
NHS Lothian |
### A review and improvement of workplace and employment policies for carers working within the Lothian area

<table>
<thead>
<tr>
<th>Project Lead</th>
<th>Project Board Members</th>
</tr>
</thead>
</table>
| Susan Siegel (Marie Curie) | Rosemary McLoughlin VOCAL  
Niall Kieran Marie Curie  
Carers of West Lothian  
Marie Curie Expert Voices Group |

### Edinburgh Hospice Redesign/Redesign of Lothian MCNS

<table>
<thead>
<tr>
<th>Project Lead</th>
<th>Project Board Members</th>
</tr>
</thead>
</table>
| Rachel Kemp (Marie Curie) / Duncan Brown (St Columba’s Hospice) | Hilary Ford Marie Curie  
Libby Milton Marie Curie  
Jackie Stone St Columba’s Hospice  
Dot Partington St Columba’s Hospice  
Diana Hekerem Marie Curie  
Niall Kieran Marie Curie  
Kris Wright Marie Curie  
Yvonne Owens Marie Curie |

### Capturing feedback on palliative and end of life care

<table>
<thead>
<tr>
<th>Project Lead</th>
<th>Project Board Members</th>
</tr>
</thead>
</table>
| Patricia Brooks-Young (NHS Lothian) / Shirley Fife (NHS Lothian) | Sandy Young NHS Lothian  
Jo Bennett NHS Lothian  
Jeannette Morrison NHS Lothian  
Tim Warren Scottish Government |

### Care in the last days and hours of life: the Lothian Approach

<table>
<thead>
<tr>
<th>Project Lead</th>
<th>Project Board Members</th>
</tr>
</thead>
<tbody>
<tr>
<td>Patricia Brooks-Young (NHS Lothian) / Shirley Fife (NHS Lothian)</td>
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</table>
Stakeholder interviews

The following stakeholders were interviewed as part of the evaluation:

<table>
<thead>
<tr>
<th>Name</th>
<th>Organisation</th>
<th>Role</th>
</tr>
</thead>
<tbody>
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<td>University of Edinburgh</td>
<td>Academic &amp; Research Representative</td>
</tr>
<tr>
<td>Dot Partington</td>
<td>St Columba’s</td>
<td>Director of Care</td>
</tr>
<tr>
<td>Dr Duncan Brown</td>
<td>St Columba’s Hospice</td>
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<td>Programme Co-Sponsor</td>
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<td>Hilary Ford</td>
<td>Marie Curie</td>
<td>Hospice Manager</td>
</tr>
<tr>
<td>Jackie Stone</td>
<td>St Columba’s</td>
<td>Chief Executive</td>
</tr>
<tr>
<td>Lyndsay Cassidy</td>
<td>Marie Curie</td>
<td>Programme Manager (Care Staff Training)</td>
</tr>
<tr>
<td>Neil Wilson</td>
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<td>NHS Lothian / Napier University</td>
<td>Acute Hospital (Nursing) Representative</td>
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<tr>
<td>Patrick Jackson</td>
<td>City of Edinburgh HSCP</td>
<td>Home Care Service Manager</td>
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<td>Peter McLoughlin</td>
<td>NHS Lothian</td>
<td>Programme Sponsor</td>
</tr>
<tr>
<td>Professor Scott Murray</td>
<td>University of Edinburgh</td>
<td>Academic &amp; Research Representative</td>
</tr>
<tr>
<td>Rosemary McLoughlin</td>
<td>VOCAL</td>
<td>Assistant Director of Patient Services</td>
</tr>
<tr>
<td>Susan Siegel</td>
<td>Marie Curie</td>
<td>Patient and Carer Representative</td>
</tr>
<tr>
<td>Tracy Smith</td>
<td>Marie Curie</td>
<td>Education Representative</td>
</tr>
<tr>
<td>Yvonne Owens</td>
<td>Marie Curie</td>
<td>MCNS Regional Manager</td>
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APPENDIX 2
DATA ON USAGE OF MARIE CURIE HOSPICE SERVICES
Community based support

Community interventions total - patient, Oct ’14 - Mar ’17

Number of IPU Admissions, Oct ’14 - Mar ’17

Average length of stay (days), Oct ’14 - Mar ’17

Number of Feasible bed days, Oct ’14 - Mar ’17

Occupied Bed Days, Oct ’14 - Mar ’17

Marie Curie Lothian Redesign Programme Evaluation
Community based support

Number of AHP OP (on-site) interventions - patient, Dec ‘15 - Mar ’17

Total number of carer interventions, Oct ’14 - Mar ’17

Day care

Referrals

All referrals to Marie Curie Hospice, Oct ’14 - Mar ’17

New Hospice Patients and New MCNS Patients seen per month, Oct ’14 - Mar ’17
APPENDIX 3
PATIENT SATISFACTION SURVEY DATA

This data is drawn from two different patient satisfaction surveys:

★ Marie Curie Nursing Service (MCNS) patient survey
★ Marie Curie Hospice community-based Clinical Nurse Specialist (CNS) patient survey
MCNS patient survey

Please tell us which of the services you have used

- Overnight Care
- Short episode of care (daytime)
- Short episode of care (evening/overnight)
- Care during the day
- Helper Service

N1=16, N3=18

Having Marie Curie services has allowed me to be cared for where I want to be

- Strongly agree
- Agree
- Neither agree nor disagree
- Disagree
- Strongly disagree
- Not applicable

N1=13, N3=19

Do we involve you as much as you would like in decisions about your care?

- Always
- Most of the time
- Sometimes
- Never
- Don't know

N1=12, N3=18
I have been given enough information about what to expect from the Marie Curie Nurses

N1=13, N3=17

How would you rate your overall experience of Marie Curie?

N1=13, N3=18
CNS Patient Survey

Please tell us which of our services you have used

Day Services
Outpatient appointments
At home

N not provided

How likely are you to recommend EHCS* to family and friends if they needed a similar service?

Extremely likely
Likely
Neither likely nor unlikely
Unlikely
Extremely unlikely
Don’t know

* Edinburgh Hospice Community Services
N1=106, N2=60, N3=76

When I first had support from the Hospice Community team, the timing of this was

Too early
About right
Too late
Not sure

N1=105, N2=60, N3=76
Do we treat you with dignity and respect?

- **Always**: N1=106, N2=60, N3=76
- **Most of the time**: N1=102, N2=58, N3=71
- **Some of the time**: N1=101, N2=59, N3=73
- **Never**: N1=101, N2=59, N3=73
- **Don’t know**: N1=101, N2=59, N3=73

Do we involve you as much as you would like in decisions about care?

- **Always**: N1=106, N2=60, N3=76
- **Most of the time**: N1=102, N2=58, N3=71
- **Some of the time**: N1=101, N2=59, N3=73
- **Never**: N1=101, N2=59, N3=73
- **Don’t know**: N1=101, N2=59, N3=73

Please rate the support and advice we give to relieve pain

- **Very good**: N1=106, N2=60, N3=76
- **Good**: N1=102, N2=58, N3=71
- **Fair**: N1=101, N2=59, N3=73
- **Poor**: N1=101, N2=59, N3=73
- **Very poor**: N1=101, N2=59, N3=73
- **Support not required**: N1=101, N2=59, N3=73
Please rate the support and advice we give to relieve other symptoms

```
N1=100, N2=58, N3=71
```

Please rate the emotional support that we offer you and those close to you

```
N1=104, N2=59, N3=74
```

Please rate the support we provide you as a whole person

```
N1=102, N2=58, N3=73
```
Marie Curie Lothian Redesign Programme Evaluation

Staff treat me with sensitivity, caring and compassion

N1=102, N2=58, N3=73

I am confident that staff have the right skills and knowledge to help me

N1=104, N2=59, N3=75

When I have an important question to ask, I get answers that I can understand

N1=101, N2=58, N3=74
The needs of family members, carers and friends are explored, respected, and met as far as possible

N1=103, N2=59, N3=74

I feel that I can contact the key worker when I need any urgent advice or support

N1=104, N2=59, N3=74

Were you aware you can access the CNS 7 days a week from 8:30am and 4:30pm?*

*Paraphrased from: “As part of our services, you can access the Clinical Nurse Specialist 7 days a week between the hours of 8:30am and 4:30pm. Were you aware of this?”
N1=106, N2=58, N3=75
Have you ever accessed this support?

<table>
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<th>Period 1</th>
<th>Period 2</th>
<th>Period 3</th>
</tr>
</thead>
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<td>96</td>
<td>106</td>
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<tr>
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</table>

N1=104, N2=57, N3=74

The support from EHCS has meant that an admission to hospital or a hospice has been avoided

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<th>Period 3</th>
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<tr>
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</table>

N1=96, N2=58, N3=70

How would you rate your overall experience of Edinburgh Hospice Community Service?

<table>
<thead>
<tr>
<th></th>
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<tbody>
<tr>
<td>Very good</td>
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N1=106, N2=58, N3=74