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

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\(^1\) [http://www.nhslothian.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 services and 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:

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<th>Quantitative</th>
<th>Qualitative</th>
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<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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<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)