

**Executive Summary**  
**Independent Evaluation of the Marie Curie Cancer Care**  
**Delivering Choice Programme in Somerset and North**  
**Somerset**

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## Executive Summary

The national Marie Curie Delivering Choice Programme (DCP) has 18 projects running across England. The aim of the programme is to develop services so that palliative patients are cared for and die in their place of choice. The three main objectives include:

- To work in partnership with the local providers and commissioners to develop 24-hour services that will meet the local needs and ensure:
  - the best possible care for palliative care patients;
  - equity of access to services; appropriate support services for patients and carers;
  - information on choice for place of care and death is available to all;
  - improvements of coordination of care among stakeholders.
- Evaluation of the impact of the Programme on health services.
- Sharing findings and learning more widely.

From 2008 - 2011, Marie Curie Cancer Care worked with local professionals to develop palliative care services in Somerset and North Somerset. Those engaging in developing the services include professionals from the NHS and local authorities, clinicians and managers from the acute, primary and community sectors and staff from local charities such as hospices.

The Centre for Primary Health Care at the University of Bristol was commissioned to carry out an evaluation of the Somerset Delivering Choice programme by Marie Curie Cancer Care in the autumn of 2010. Although known as the 'Somerset' Delivering Choice Programme, the two counties of North Somerset and Somerset participated. The aim of this evaluation was to investigate the impact of the Somerset Delivering Choice Programme. The interventions under study included:

- End of Life Care facilitators (North Somerset)
- End of Life Care Coordination Centres (North Somerset and Somerset)
- Out of Hours Advice and Response Line (Somerset)
- End of Life Care Discharge in Reach Nursing Service (Somerset)
- Adastra electronic end of life care register and the recording of Key Worker (North Somerset and Somerset)
- Delivering Choice End of Life Care pathway and the Palliative Care Framework (North Somerset and Somerset)

The evaluation intended to report on the following outcomes agreed in conjunction with Marie Curie Cancer Care and local stakeholders:

- Emergency hospital admissions (and re-admissions) in the last 6 and 1 months of life
- A&E visits

- Hospital costs including hospital admissions and A&E visits
- Co-ordination of care
- Patient and family carer satisfaction
- Care and death in preferred place

The two primary questions of this evaluation were:

1. Who uses Delivering Choice and what happens as a result?
2. What works for whom and in what circumstances?

To answer the first question, we collected and analysed quantitative data from routine sources such as the Delivering Choice services and Primary Care Trust data on deaths and hospital service usage. To answer the second question, we used 'realistic evaluation' methodology. We interviewed 155 individuals, including 42 family carers and one patient, as well as professionals from hospices, social services, hospitals, GP practices and community wards. We also collected surveys from a further 14 people, so in total we obtained the views of 169 people: 99 from Somerset and 70 from North Somerset. In addition, we collected documentation such as local reports, Board papers and meeting minutes and analysed call logs and register data. To analyse the data, we used framework analysis.

Key findings were:

1. Family carers and professionals consistently reported **excellent quality, co-ordinated care. Family carers were highly satisfied** with all services with direct patient contact. They reported that involvement of the Delivering Choice services released them from a full time caring role and reduced their anxieties. Overall, family carers were extremely grateful for the involvement of the Delivering Choice services.
2. Those receiving a Delivering Choice intervention were 67% less likely to **die in hospital** in North Somerset, after adjusting for confounding factors such as gender, age, deprivation and condition (unadjusted rates of hospital death were 19% in Delivering Choice and 43% in non Delivering Choice users). Those receiving a Delivering Choice intervention were 80% less likely to die in hospital in Somerset compared to those who did not receive a Delivering Choice service (unadjusted rates of 14% and 43% respectively).
3. The Delivering Choice service with the greatest proportion of **home deaths** (including a care home where this was the patient's usual place of residence) was the Somerset Care Coordination Centre at 75%, followed by the Generic Support workers at 64%, the Out of Hours advice line at 59% and the North Somerset Care Coordination Centre at 44%.
4. In **North Somerset, emergency hospital admissions** in the last month of life were 51% lower amongst those receiving a Delivering Choice intervention compared to those not receiving a Delivering Choice intervention after adjusting for confounding factors (unadjusted rates 29% and 41%). Emergency admissions

were 78% lower in the last week of life (unadjusted rates (unadjusted rates 6% and 22%). The North Somerset Care Coordination Centre appearing to be the most effective component of the interventions offered.

5. In **Somerset, emergency hospital admissions** in the last month of life were 39% lower amongst those receiving a Delivering Choice intervention compared to those not receiving a Delivering Choice intervention after adjusting for confounding factors (unadjusted rates 38% and 45%). Emergency admissions were 68% lower in the last week of life (unadjusted rates (unadjusted rates 24% and 10%). The Somerset Care Coordination Centre appearing to be the most effective component of the interventions offered. Adastra end of life registration is associated with lower risk of admission in the last month of life and the OOH advice is associated with lower risk of admission in the last week of life only. **Re-admissions** for the Discharge in reach service were low at 6%.
6. In **North Somerset A&E attendance** rates in the last month of life were 59% lower amongst those receiving a Delivering Choice intervention after adjusting for confounding factors (unadjusted rates 5% and 36%). A&E attendance rates were 78% lower in the last week of life (unadjusted rates 6% and 26%). The North Somerset Care Coordination Centre appearing to be the most effective component of the interventions offered.
7. In **Somerset A&E attendance** rates in the last month of life was 34% lower amongst those receiving a Delivering Choice intervention after adjusting for confounding factors (unadjusted rates 26% and 36%) and were 68% lower in the last week of life (unadjusted rates 7% and 22%). The Somerset Care Coordination Centre and OOH advice line appearing to be the most effective components of the interventions offered with Adastra end of life registration being associated with a reduction in the last month but not the last week of life.
8. For **North Somerset** the total additional spend on Delivering Choice was £369,000 including directly employed generic support workers and the **indicative hospital costs** avoided were £151,609 over a 12 month period. No data were available to calculate the impact of Delivering Choice interventions on community costs. This is particularly relevant to the directly employed generic support workers, who delivered care to meet needs that may otherwise have been met through continuing healthcare (CHC) funded services.
9. For **Somerset** the total additional spend on Delivering Choice was £325,955 and the **indicative hospital costs** avoided were £289,335 over 12 month period. We were not able to calculate the impact of delivering choice services on community costs.
10. **Patients accessed Delivering Choice late** in the trajectory with 50% accessing services less than 20 days before death in North Somerset and 10 days in Somerset.
11. People who used Delivering Choice services came from all levels of **deprivation** and the distribution of deprivation scores was similar for Delivering Choice intervention users and non users in both North Somerset and Somerset.

12. **Cancer was the most common cause of death** for Delivering Choice users across both areas. This did not reflect the population cause of death, with other chronic conditions including cardiovascular and respiratory diseases being under represented amongst Delivering Choice users in both North Somerset and Somerset. However, 40% of the Discharge in reach service patients did not die from cancer related causes.

The Somerset Delivering Choice Programme was a success. Underpinning this success was a whole system approach which relied on the collective effort of senior and front line professionals across hospices, the NHS and social care services, facilitated efficiently and effectively by the local Marie Curie team. The intervention teams worked together to deliver care that was well coordinated and highly valued by family carers.

With regards to the individual interventions, we found that:

The **North Somerset End of Life Care facilitators** served an important function as the 'face of end of life care' for professionals delivering end of life care in North Somerset. Their diverse role included identifying and plugging educational and service provision gaps across a variety of organisations including hospices, care homes and NHS primary and community care. Having laid the bedrock for changing professional behaviour, future efforts should focus on narrowing their remit to a more manageable set of objectives.

The effectiveness of the educational remit of the End of Life Care facilitators was enhanced by close collaboration with the **North Somerset End of Life Care Co-ordination Centre** (NSCCC), which had an operational function in co-ordinating care packages (e.g. equipment, personal carers, night staff). The NSCCC had an in-house model which includes the fast track co-ordinator, nurse assessors and its own team of personal care workers (Generic Support Workers). This maximised their flexibility to respond to patient and family needs. Co-location with social service staff as part of the Single Point of Access team means that the NSCCC is well placed to set up routine procedures to identify potential end of life care patients earlier.

The **North Somerset Generic Support Workers** were highly valued by family carers and served an important function in keeping the NSCCC, and thereby the wider healthcare system of healthcare professionals, up to date with patient and family carer needs. Future efforts should ensure that Generic Support Workers are carefully allocated based on patient and family need (i.e. vulnerable patients wanting a home death with limited family support or highly challenging symptoms) rather than Generic Support Worker availability.

The **Somerset Discharge in reach nursing service**, which operated in two hospitals, was characterised by highly skilled nurses who supported patients, family carers and professionals, through advocacy (patients and families) and education (professionals). Importantly, they also offered challenge, for example by questioning

potentially unnecessary treatments. With the proactive 'in reach' component, whereby the nurses identified their own caseload, this service helped the highest proportion of non-cancer patients (40%). Moreover, they were well placed at the 'front of house' in Medical Admissions Units, Surgical Admission Units and emergency departments to quickly turn around patients who wanted home deaths.

The **Somerset Out of Hours advice and response line** offered a dedicated, experienced palliative care nurse on weekday evenings until 1am, on weekends and bank holidays to answer calls from patients, family carers and professionals. Of especial value to family carers was the proactive call back a few hours after a crisis. This service has capitalised on the success of the in hours line offered by the Central Referral Centre, by using the same 0845 number. Given the plethora of potential advice and out of hours lines available to patients and family carers, future efforts should prioritise developing a business strategy to market its special features. One potential selling point to consider maximising is the advocacy function that advice line nurse staff currently perform for patients and families who ring out of hours; this could possibly be extended to more patients and families.

Although the **Somerset Care Co-ordination Centre** (SCCC) had the same key function of organising care packages as the North Somerset Care Co-ordination Centre, the model was different. The Somerset Care Co-ordination Centre was led by a nurse and staffed exclusively by administrators, without any in-house care staff, additional nurses or fast track co-ordinator. Thus to make this model work, the SCCC was heavily reliant on high quality management and good external relationships, particularly with community and palliative care nurses, care agencies and Continuing Health Care. An advantage of this model is that it cost about 60% less. Given its success and effectiveness, consideration should be given to ensuring that non-fast track patients also have access to the SCCC, as despite original intentions currently only fast track patients are eligible.

Although not exclusive to Delivering Choice, the intention of the **Adastra end of life care electronic register** was to provide up to date information on advance care wishes across organisations (e.g. hospices, A&E departments, community nursing teams, Out of Hours GP and community nurses etc.). Use could comprise of inputting and updating records or accessing the register to aid decision-making. A total of 169 North Somerset and 1054 Somerset patients were registered by April 2012, from an estimated annual palliative care population of 2000 and 5000 respectively. With regards to decision-making, although out of hours GPs from both counties reported using the register, a Somerset Out of Hours district nurse, most North Somerset community nurses, North Somerset community hospitals and North Somerset paramedics reported that they had no access. Some Somerset paramedics had access, but we were unable to determine the extent of their use. Major barriers included technical difficulties (e.g. crashing, difficulties in moving between screens, problems in extracting information etc), professionals' reluctance to consent patients to an 'end of life' register and difficulties in obtaining passwords

in North Somerset. Importantly, because all professionals could take responsibility for the register, in practice sometimes no one did.

The register included a field for details on **Key Worker** for each patient. In total, 35% (59/169) of North Somerset patients and 43% (454/1054) of Somerset patients who were registered had a Key Worker recorded. Although professionals appreciate the importance of Key Workers, there was some confusion about the implications of official registration as Key Worker. Nonetheless, the patient experience pathway analysis (see Chapter 10) suggested that professionals were informally taking on the Key Worker role. This role can be broken down into three areas: assessment, coordination of care and advocacy. Of the three, advocacy, whereby knowledgeable experts champion patients and families to get the best quality care available (e.g. by putting forward a complaint about sub-standard agency care), is the least likely to be consistently enacted, yet it is essential in helping to navigate vulnerable patients and family carers through complex, confusing systems. Key Workers appear especially important during out of hours crises and for those who live alone.

Professionals did not appear to find the **Delivering Choice pathway** particularly helpful, as it was viewed as largely formalising what happened anyway. However, in the patient pathway analysis presented in Chapter 10, we found that the pathway was rarely used as indicated, usually because the first steps of registration on the Adastra electronic register and the recording of Key Worker were skipped. We also found that actual patient trajectories differed significantly from the linear pathway, which limited the usefulness of the tool.

The **Palliative Care Framework** was reportedly more popular, as professionals said that it helped with assessment of current patient status. Adastra records suggest that the framework is in somewhat sporadic use. Sometimes it is used incorrectly and changes in patient status are not updated in the Adastra electronic register.

Across the programme, several factors contributed to the success of Delivering Choice including:

- Highly collaborative working at senior and frontline levels.
- The involvement of a local Marie Curie project team.
- Sufficient funding for the Delivering Choice services, the local Marie Curie team and fast track Continuing Health Care patients.
- Well run Delivering Choice services with 'can do' teams.

However, more could still be done. In Somerset, less than a quarter of all potential patients are accessing Delivering Choice services (616/2572). In North Somerset, that drops to just over a fifth (213/1022). About two thirds of Delivering Choice service users have cancer while only about 30% die from this condition. Furthermore, half of Delivering Choice patients are coming into contact with the services just 6-20 days before death. The focus now should be on extending the

breadth and depth of the Delivering Choice Programme so that a wider range, greater numbers and earlier identification of patients is possible.

Thus **the key message of this evaluation** is that the Delivering Choice Programme provides high quality services whose users are less likely to turn to hospital services or die in hospital. Future efforts should concentrate on the expansion of services to all palliative care patients, despite their condition, earlier. This then could help more North Somerset and Somerset residents experience 'as good a death as possible' in their place of choice, while potentially also lowering hospital costs.