

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

**Final report
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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.

Overview of Main Report

1.0 Introduction

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:
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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 member 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. (Pawson & Tilley, 1997) The following section gives a brief overview of the methods. Full details are available in the appendices, along with some reflections on realistic evaluation methodology.

2.0 Methods Section Summary

2.1 Quantitative Methods

2.1.1 Collection and Availability of Data

A time consuming aspect of the quantitative data collection was gaining approvals for access to service data from the service providers and/or associated gatekeepers, such as Caldicott guardians. The level of approval required for each service varied significantly and was inconsistent within each Primary Care Trust. Once approval had been granted, Delivering Choice services were contacted to initiate Delivering Choice service data collection. The Project Manager (GL) had previously piloted data collection from all Delivering Choice services in Somerset and North Somerset for the October 2011 interim report and consequently data collection for this final report was relatively straightforward.

For this retrospective cohort study our aim was to identify all patients who died from 1 September 2011 to 29 February 2012 and who were potentially eligible to receive end of life services in Somerset and North Somerset. We then determined which patients had utilised a Delivering Choice service from 1 September 2011 to 29 February 2012. Outcomes of interest were place of death, emergency hospital admission and A&E attendance. To facilitate patient identification, all Delivering Choice services were asked to collect NHS numbers, age and postcodes. These personal identifiable details were then used to link individual patient death, hospital and Delivering Choice data at the Primary Care Trusts. Data on individual inpatient

costs were provided by the Primary Care Trusts (based on National Tariff rates), A&E costs were calculated using a standard reference source and costs for Delivering Choice services were based on data reported in business cases and executive group minutes.

This process was not possible for the End of Life Care facilitators in North Somerset because this service provides support to health care professionals (i.e. GPs, district nurses, care home staff, etc.) on how to use end of life care tools (i.e. Delivering Choice pathway, Gold Standards Framework, Liverpool Care Pathway, Advance Care Planning, etc.). The End of Life Care facilitators do not have direct contact with patients. Thus it was not possible to identify the effect of this service by collecting patient level data and consequently we have not included any quantitative data on the impact of the End of Life Care facilitators in North Somerset.

Electronic records were not fully robust at the North Somerset Care Coordination Centre and in some cases GL searched paper copies of patient files for the required data. It was also the first time that data on the North Somerset Generic Support Workers had been collected. Unfortunately, the evaluation team found that service usage was incomplete for the full study period for this service. Consistent data was only available for a 101 day period at the start of the data collection period between 1 September 2011 to 29 February 2012. The paper diary for the Generic Support Workers stopped the first week of December 2011.

Data from both the Somerset and North Somerset Adastras systems were made available to the study team. However, the format of the Adastras outputs from both counties (Excel spreadsheet in North Somerset and PDF in Somerset) was such that required a significant amount of time (approx. 72 hours in total) to re-organise the data before it could be sent to the Primary Care Trust. All of the Delivering Choice services were asked to collect service usage data and forward this securely to the Primary Care Trust independently from the evaluation team, however in actuality the Somerset Care Coordination Centre was the only service able to send their service usage data directly to the Primary Care Trust. All other services were visited (between April and June 2012) by GL who hand-collected data, which was then personally delivered to the both Primary Care Trusts. This was due to stringent Caldicott agreements.

Once all data had been received by the Primary Care Trust, it took each analyst three hours to link to their pre-collected datasets and resolve inconsistencies. In total data, collection and linkage has taken the Primary Care Trust analysts approximately 20 hours. An independent statistician was then consulted to review, clean and analyse the linked datasets received from the Primary Care Trust. Statistical analysis was performed using Excel 2007 and Stata v12.

2.2 Realistic Evaluation

Realistic (or realist) evaluation starts from the point that involvement in any programme is a choice. The objective of an evaluation is to understand more about what it was that led a particular person with their particular sets of circumstances to making that choice. Realist evaluation cannot answer what 'caused' particular outcomes. Instead, the key question in a realist evaluation is: What works for whom and in what circumstances? To answer that question, data on context, mechanisms and outcomes are gathered and the relationships between the three are explored.

Given the complexity of the Delivering Choice Programme with its multiple services, stakeholders and settings, in August 2010 a dozen local stakeholders attended a research evaluation meeting to give their views on issues in designing the evaluation. In January and February 2011, we held three 'hypothesis generation' workshops with around two dozen local stakeholders, including those who set up, refer into or deliver Delivering Choice services. The aim of those workshops was to identify key 'hypotheses' or explanations for how and why particular Delivering Choice services might work and to clarify what success, or intended outcomes, might look like. The key hypothesis cutting across the entire programme was identified as:

The furnishing of relevant, reliable and timely information, advice, services (e.g. night care workers, equipment) and support to patients, carers and professionals by key regional or Delivering Choice interventions help facilitate seamless, co-ordinated care, generate high patient and carer satisfaction and contribute to patients dying in their place of choice.

To test this hypothesis, we collected data through interviews, surveys, documentation and analysis of databases. Views through interviews and surveys were collected from 126 professionals, 74 from Somerset and 52 from North Somerset. Participants included specialist community palliative care nurses, community and district nurses, hospice clinicians and administrators, GPs, GP practice managers and administrators, hospital consultants, ward sisters, paramedics, Out of Hours GPs and district nurses, care home staff, social service staff and Delivering Choice service providers. In total, we carried out 65 telephone interviews, 27 formal, face to face interviews, 22 informal interviews and analysed 14 surveys. In addition, we conducted 43 interviews with family carers and patients who had used Delivering Choice services, 25 from Somerset and 18 from North Somerset.

Interviews with Delivering Choice professionals and hospital staff took place in November and December 2011, except for the new North Somerset Care Co-ordination Centre lead nurse who was interviewed in March 2012. Interviews with family carers and patients were carried out from December 2011 to March 2012. Face to face interviews with community and primary care professionals were conducted from January to March 2012. Telephone interviews with health and social care professionals across the two counties were carried out from April to June 2012. The survey was administered in early February 2012 and again in early March 2012.

Formal observations were carried out with Delivering Choice service providers in August 2011, November/ December 2011 and March 2012. By August 2011, all services, except the Generic Support Workers, had been in operation for at least six months and by December 2011 most services had been operating for over a year. Only the Generic Support Workers were observed in March 2012, as informal observations of all of the other services continued throughout the duration of fieldwork. In total, we carried out 15 observations. Documentation such as meeting minutes, Board papers, local Marie Curie reports and Primary Care Trust audits were collected throughout fieldwork and analysed from April to June 2012.

In addition, we carried out in-depth analyses of a sub-sample of data from the Out of Hours advice line log and the Adastra electronic register in May and June 2012. For the patient experience pathways, data were drawn on from family carer interviews, Adastra electronic register, Delivering Choice services and Primary Care Trust death and hospital data.

To analyse interview, observation and documentation data, we used Framework analysis, whereby we developed a proforma which was then applied consistently across all data sources. Each team member separately analysed their own data, taking one intervention in turn, and then findings were shared and discussed at a team meeting. Draft chapters were then written up, discussed at a further team meeting and refinements made. To test 'face validity', findings were discussed with Delivering Choice providers at two meetings, one in Somerset and the other in North Somerset.

For further information about the methodology of both the realistic evaluation and quantitative components of this evaluation, please see the appendices.

Quantitative Results

Who uses Delivering Choice and what happens as a result?

3.0 Findings from routine data

3.1 Demographic and cause of death data

3.1.1 North Somerset

All tables for this chapter are presented in the appendices. Table 1 provides an overview of the demographic results for the six month study period 1 September 2011 to 29 February 2012. A total of 1022 individuals died in North Somerset, the mean age at death was 81 years and there was a slight difference in the number of deaths in females (54%) compared to males (46%). Over the six months 38% of the study population died in an acute hospital, but this was closely followed by deaths at home, including a care home where this was recorded as usual place of residence, at 31%. Overall the majority of deaths were attributable to cancer (neoplasms) (28%) and heart disease (18%). We were unable to obtain directly comparable data from the PCT for previous years in order to examine trends but the available data suggest that the proportion of deaths in acute hospitals has decreased. From the the End of Life Care Intelligence Network the average annual percentage of deaths in hospital for the whole North Somerset population for 2008-10 was 46.3% which was lower than the national average of 54.5% (<http://www.endoflifecare-intelligence.org.uk>). From the PCT data the winter period in 2008 (Quarter 4) showed 52% of all deaths were in acute hospitals, for 2009 the figure was also 52% but in 2010 the number had fallen to 43%. Data for the same quarter in 2011, during the study period, showed this proportion was 46%.

Table 2 provides a summary of the diagnostic groups in the total population during the study period and illustrates the differences between these groups. For example, a lower proportion of patients who died of cancer were in the 80-89 years age group compared with other conditions such as heart disease or cerebrovascular disease. More cancer patients accessed Delivering Choice services than any other group, specifically the North Somerset Care Coordination Centre (34%).

3.1.2 Somerset

Table 21 gives the demographic results for Somerset deaths during the six month study period. A total of 2572 individuals died in Somerset, the mean age at death was 82 years and females died (55%) compared to males (45%). The majority of deaths occurred in an acute hospital (36%), whilst 22% died at home (private residence) and a further 22% in a care home considered to be the usual place of residence. Again, we were unable to obtain directly comparable data from the PCT for previous years in order to examine trends but the available data indicates that the proportion of deaths in acute hospitals has decreased since 2009. From the the End of Life Care Intelligence Network the average annual percentage of deaths in

hospital for the whole Somerset population for 2008-10 was 49.2% which was lower than the national average of 54.5% (<http://www.endoflifecare-intelligence.org.uk>). From PCT data, the winter period in 2009 (Quarter 4) showed 45% of all deaths were in acute hospitals, data for the same quarter in 2011, during the study period, showed this proportion had fallen to 38%. This trend is fairly consistent across the three year period and is accompanied by a rise in the number of deaths in care homes. The most common cause of death was cancer at 29%, followed by heart disease which resulted in 18% of deaths.

Table 22 provides a summary of the causes of death in the total population of Somerset during the study period. For example, a lower proportion of patients who died of cancer were in the 80-89 years age group compared with other conditions such as heart disease or cerebrovascular disease. Registration on Adastra was more likely for cancer patients, with 382 patients registered and of these 125 had a Key Worker listed - this equates to 51% of cancer patients in the Somerset population. Cancer patients most commonly accessed the Somerset Care Coordination Centre (29%), closely followed by the OOH Advice Line (27%) and then Discharge in reach nurses (12%).

3.2 Data on morbidity of patients

3.2.1 North Somerset

From hospital admissions data we were able to determine information on morbidities for 66% (674/1022) of the North Somerset study population. Table 3 show that congestive heart failure (24%) and COPD (23%) were the commonest morbidities in the North Somerset palliative population. Cancer and metastatic cancer accounted for 18% and 22% respectively of medical conditions recorded. However, individuals that accessed the Delivering Choice resources were more likely to have cancer (27%) or metastatic cancer (46%). The Charlson Index score for Delivering Choice users was 4.6 and for non-Delivering Choice users it was 3.0, therefore for those patients for whom data are available this would suggest those receiving Delivering Choice services have higher morbidity.

3.2.2 Somerset

From admissions data for Somerset we determined morbidities for 71% (1834/2572) of the study population and the most common were renal disease (24%), COPD (23%) and metastatic cancer (23%) (Table 19). Yet, amongst Delivering Choice users only, these individuals were much more likely to have metastatic cancer (52%) or cancer (39%) as morbidities. The Charlson Index score for Delivering Choice users was 5.3 and for non-Delivering Choice users it was 2.9, again this would suggest those receiving Delivering Choice services have higher morbidity.

3.3 Delivering Choice interventions accessed in each PCT

3.3.1 North Somerset

The four interventions in North Somerset included in the quantitative analysis were:

- North Somerset Care Coordination Centre
- Generic Support Workers
- Adastra electronic end of life care register
- Key Worker

There were a total of 213 patients in North Somerset that accessed Delivering Choice interventions from 1 September 2011 to 29 February 2012, which gives a total uptake rate of 21%. Over two thirds (68%) of the individuals accessing Delivering Choice services in North Somerset were cancer patients (Table 1). There were a total of 131 out of 1022 people (13%) listed on the Adastra electronic register between 1 September 2011 to 29 February 2012. Of those listed, 38 (4% of 1022) had a Key Worker.

During the study period the North Somerset Care Coordination Centre was accessed by 153 patients and the Generic Support Workers provided care to 25 patients (over 101 days). Table 4 gives an overview of the combinations of Delivering Choice interventions used in North Somerset. The North Somerset Care Coordination centre was the most frequently used by people who only accessed one service and was used by 101 patients. Few patients ever used more than one and only five patients (<1%) used all four together.

For the North Somerset Care Coordination Centre, death on average occurred approximately 17.7 days after accessing this service (median 8 days; IQR 4, 21). Whilst patients using the Generic Support Worker had a mean time to death after first contact of 53.8 days (median 20; IQR 5, 64). (Table 5). This means that half of all of the users of the North Somerset Care Co-ordination Centre came into contact with this service for the first time eight days before death while half of those who had services from the Generic Support Workers came into contact for the first time 20 days before death. This was the earliest of all of the services. However, these figures suggest that North Somerset Delivering Choice services are being accessed quite late in the patient trajectory.

3.3.2 Somerset

The five initiatives included in the quantitative analysis for Somerset were:

- Somerset Care Coordination Centre
- Out of Hours Advice and Response Line
- Discharge in reach nursing service
- Adastra end of life care register
- Key Workers

A total of 616 patients accessed these interventions from 1 September 2011 to 29 February 2012. Seventy one percent of individuals were cancer patients. Patients with heart disease were the second most likely group to use these interventions, but

accounted for only 7% of users. (Table 21) There were a total of 487 out of 2572 people (19%) listed on the Adastral electronic register in Somerset and of these 156 (6% of 2572) had a named Key Worker recorded and 331 did not (Table 22).

Table 24 gives an overview of the combinations of Delivering Choice services used in Somerset. The Somerset Care Coordination Centre was the most popular standalone service and was used by 151 patients. The most popular combination of two services was the OOH line and Somerset Care Coordination Centre, which was used by 101 patients. Twenty nine patients were supported by all three services (OOH line, Care Coordination Centre and Discharge in reach nurses). Table 25 provides a more complex overview of how the three Delivering Choice services, Adastral and the Key Worker roles were utilised in Somerset. The results are comparable to those seen in North Somerset, with only 10 patients (<1%) having used all five resources together.

For the Somerset Care Coordination Centre, death on average occurred approximately 17.2 days after accessing this service (median 9.5 days; IQR 4, 20), whilst mean time to death after first contact for the Discharge in reach service was 17.8 days (median 6; IQR 2, 23) and for the OOH line 22.5 days (median 10; IQR 2, 31) (Table 26). This means that half of all Somerset Care Co-ordination Centre users came into contact with the service for the first time within 9.5 days before death; half of all Discharge in reach service users came into contact with the service for the first time within six days before death and half of the OOH advice line users came into contact with the service for the first time within 10 days before death. So, half of all of those using Somerset Delivering Choice services are first coming into contact ten days or less before death, which again suggests Delivering Choice services are being accessed quite late in the patient trajectory.

3.4 Place of death

3.4.1 North Somerset

Table 1 shows that those individuals utilising any combination of the Delivering Choice interventions were more likely to die at home (41%) compared to in hospital (19%). Only a limited number of patients (8%, 81/1022) had a preferred place of death listed on Adastral, but 60% (49/81) of those with preferred place documented actually died in their preferred place. Those patients registered with a Key Worker were more likely to die at home (61%) compared to those on Adastral without a named Key Worker (47%).

Logistic regression modelling (controlling for the effects of confounding by gender, age, deprivation and condition) provides evidence that there was a lower odds of death in hospital amongst those patients using Delivering Choice services compared to non-Delivering Choice users (OR 0.33, 95% CI 0.21-0.50, $p = <0.0001$) in North Somerset (Table 7). This means that people receiving a Delivering Choice service were 67% less likely to die in hospital compared to those who did not receive a Delivering Choice service.

Looking at individual interventions, patients accessing the North Somerset Care Coordination Centre were 58% less likely to die in hospital (OR 0.42, 95% CI 0.25-0.69, $p=0.001$) and those registered on the Adastra end of life register were 70% less likely to have died in hospital (OR 0.30, 95% CI 0.13-0.69, $p=0.005$) (Table 8).

3.4.2 Somerset

Table 21 shows that those individuals utilising any combination of the Delivering Choice services in Somerset were more likely to die in their home (44%) or a care home considered their usual place of residence (10%) compared to in acute hospital (14%). 290 patients had a known preferred place of death recorded (11%). In total 31% (193/616) of Delivering Choice users had 'home' listed as their preferred place of death and in total 44% of the study population died in their own home. Forty eight percent of patients registered on the Adastra end of life register died at home, whilst this increased to 56% if a patient was registered with a Key Worker.

Logistic regression models, after controlling for confounding, showed that there was evidence of a lower odds of death in hospital amongst Delivering Choice service users when compared to non-Delivering Choice users (OR 0.20, 95% CI 0.17-0.27, $p = <0.0001$) in Somerset. (Table 28) This means that people receiving a Delivering Choice service were 80% less likely to die in hospital compared to those who did not receive a Delivering Choice service.

Looking at individual interventions, patients accessing the Somerset Care Coordination Centre were 89% less likely to die in hospital (OR 0.11, 95% CI 0.06-0.22, $p<0.0001$), those who used the OOH advice line were 66% less likely to have died in hospital (OR 0.34, 95% CI 0.20-0.57, $p<0.0001$) and those registered on the Adastra end of life register were 78% less likely to have died in hospital (OR 0.22, 95% CI 0.12-0.40, $p<0.0001$) (Table 29).

3.5 Hospital admissions in the last 6 months, 30 days and 1 week of life

3.5.1 North Somerset

Emergency admissions were the most common type of hospital admission during the last six months of life for all North Somerset patients, with 61% (626/1022) of the study population having an emergency admission between 1 September 2011 and 29 February 2012. Those people who became Delivering Choice users had higher rates of admission (69%) versus non-Delivering Choice users (59%). (Table 5)

In the last month (30 days) of life, emergency admissions were again more likely when compared to all other admission types. Thirty nine percent of the whole study population had an emergency admission during their last 30 days of life, but Delivering Choice users were much less likely to have an emergency admission (29%) compared to non-Delivering Choice users (41%). Logistic regression analysis (controlling for the effects of confounding by gender, age, deprivation and condition) suggests that Delivering Choice users had lower odds of having an emergency admission in their last month of life compared to non-Delivering Choice users (OR

0.49, 95% CI 0.33-0.74, $p = 0.001$). (Table 10) Looking at individual interventions, patients accessing the North Somerset Care Coordination Centre were 45% less likely to have an emergency admission (OR 0.55, 95% CI 0.34-0.90, $p=0.016$). The other interventions were not individually associated with lower odds of admission. (Table 11)

For half of the patients death occurred less than 20 days after accessing the North Somerset Care Coordination Centre (median 8 days; IQR 4,21) and Generic Support Workers (median 20; IQR 5,64).(Table 5) So looking at admission up to the last month (30 days) of life may overlook the most significant impacts that accessing Delivering Choice services may have on emergency admission during the last week of life. Indeed, logistic regression analysis (controlling for the effects of confounding by gender, age, deprivation and condition) shows that Delivering Choice users were approximately 80% less likely to have an emergency admission during their last week of life compared to non-Delivering Choice users (OR 0.22, 95% CI 0.12-0.44, $p = <0.0001$). (Table 13) Again, patients accessing the North Somerset Care Coordination Centre were the least likely to have an emergency admission (OR 0.09, 95% CI 0.02-0.39, $p=0.001$). (Table 14) The other interventions were not individually associated with lower odds of admission. Indeed access to the generic support workers appears as if it may be associated with increased odds of admission (OR 6.26 (95% CI 0.81-48.6, $p = 0.079$). However this result is based on a few admission events in a small sample ($n=25$) and is not statistically significant. Therefore it should not be regarded as a substantive finding.

Patients using the Delivering Choice programme in North Somerset had 50% fewer hospital admissions in the last month of life and 80% in the last week of life than non-Delivering Choice users with the North Somerset Care Coordination Centre appearing to be the most effective component of the interventions offered. However, the findings also highlight that access to services is relatively delayed and that the impact of Delivering Choice is actually occurring very late in a patient's life.

3.5.2 Somerset

Emergency admissions were the most common, with 67% (1718/2572) of the study population having an emergency admission during their last six months of life. More Delivering Choice users had an emergency admission than non-Delivering Choice users, 77% compared to 64% respectively. (Table 26)

This finding was reversed in the last month (30 days) of life, with 43% of the whole study population having an emergency admission, whilst Delivering Choice users were less likely to have an emergency admission (38%) compared to non-Delivering Choice users (45%).(Table 26) Logistic regression analysis (controlling for the effects of confounding by gender, age, deprivation and condition) suggests that Delivering Choice users had lower odds of having an emergency admission in their

last month compared to non-Delivering Choice users (OR 0.61, 95% CI 0.48-0.76, $p < 0.00001$). (Table 31)

Patients accessing the Somerset Care Coordination Centre were the least likely to have an emergency admission (OR 0.58, 95% CI 0.42-0.80, $p = 0.001$) as were patients entered on the Adastral end of life register (OR 0.41, 95% CI 0.28 -0.60, $p < 0.0001$) (Table 32). From the data it may appear that Discharge in reach nurses are associated with increased odds of admission in the last month of life (OR 4.14, 95% CI 2.67-6.42, $p = < 0.0001$). However, it is important to highlight that the higher hospital admission rate for Discharge in reach nurses is inevitable because they work in hospitals and identify patients when they have had, or are at risk of, an emergency admission. The aim of the service was to reduce hospital re-admissions and as less than 5% (7/114) of the patients who used the Discharge in reach service were re-admitted over the study period this puts this result in context.

For Somerset first contact occurred 10 days or less before death for half the patients median 9.5 days (IQR 4, 20) for the Care Coordination Centre, median 6 days (IQR 2, 23) for the Discharge in reach nurses and median 10 days (IQR 2, 31) for the OOH line. (Table 26) So again we have also investigated the potential impact of accessing Delivering Choice on emergency admission in the last week of life. Logistic regression analysis (controlling for the effects of confounding by gender, age, deprivation and condition) suggests that Delivering Choice users had lower odds of having an emergency admission in their last week of life compared to non-Delivering Choice users (OR 0.32, 95% CI 0.23-0.45, $p = < 0.0001$). (Table 34) Again, patients accessing the Somerset Care Coordination Centre were the least likely to have an emergency admission in their last week of life compared to non-Delivering Choice users (OR 0.26, 95% CI 0.15-0.46, $p = < 0.0001$) as were patients entered on the Adastral end of life register (OR 0.57, 95% CI 0.33 -0.98, $p = 0.043$) (Table 35). Unlike the results for the last month of life, it does not appear that accessing Discharge in reach nurses is associated with increased odds of admission in the last week of life (OR 1.54, 95% CI 0.95-2.50, $p = 0.81$). Additional scrutiny of the data revealed that 20/114 patients that accessed the DIR nurses had at least one admission in the last week of life. Of these 20 patients, 15 were an index admission (i.e. the admission at which a Discharge in reach nurse was first assigned to the patient) and the remaining five patients were readmissions after a previous index visit.

This suggests that the patients using Delivering Choice in Somerset had 39% fewer hospital admissions in the last month of life and 68% in the last week of life than non-Delivering Choice users, with the Somerset Care Coordination Centre appearing to be the most effective component of the interventions offered. Being registered on the Adastral end of life register is also associated with lower risk of admission. Again, the findings also highlight that access to services is relatively delayed and that the impact of Delivering Choice is actually occurring very late in a patient's life.

3.6 A&E attendance last 6 months and 30 days of life

3.6.1 North Somerset

Table 5 shows that in the last six months of life, 64% (650/1022) of the study population had an A&E visit. Rates of A&E utilisation were similar in both groups: we found that 63% (135/213) of Delivering Choice users compared with 64% (515/809) of non-Delivering Choice users had attended A&E in the last 6 months.

Attendance at A&E in the last 30 days of life followed a different pattern, with 41% of the general end-of life population visiting A&E, compared with 36% of non-Delivering Choice users and only 5% of Delivering Choice users.

Logistic regression analysis (controlling for the effects of confounding by gender, age, deprivation and condition) suggests that Delivering Choice users had lower odds of having an A&E visit in their last month of life compared to non-Delivering Choice users (OR 0.41, 95% CI 0.28-0.62, $p = <0.0001$). (Table 16) Moreover, patients accessing the North Somerset Care Coordination Centre were again least likely to have an A&E visit in the last month of life (OR 0.46, 95% CI 0.29-0.76, $p=0.002$). The odds of an A&E visit are further lowered during the last week of life (OR 0.22, 95% CI 0.11-0.42, $p=<0.0001$). (Table 19) Again, patients accessing the North Somerset Care Coordination Centre were again least likely to have an A&E visit in the last week of life (OR 0.15, 95% CI 0.05-0.43, $p=<0.0001$). (Table 20) This suggests that patients accessing Delivering Choice in North Somerset had 59% fewer A&E attendance in the last month of life and 78% fewer in the last week of life with the North Somerset Care Coordination Centre appearing to be the most effective component of the interventions offered.

3.6.2 Somerset

Table 26 shows a similar picture for Somerset, with 56% of the study population visiting A&E within the last six months. Again, in Somerset, A&E visits were similarly likely for non-Delivering Choice (56%) and Delivering Choice users (58%) during the six months.

Approximately one third (34%) of the total study population had an A&E visit in their last month of life. We found that 36% of non-Delivering Choice and 26% of Delivering Choice users visited A&E. (Table 26) Logistic regression analysis (controlling for the effects of confounding by gender, age, deprivation and condition) suggests that Delivering Choice users in Somerset had lower odds of having an A&E visit during their last month (OR 0.66, 95% CI 0.51-0.85, $p=0.001$) (Table 37) and last week of life (OR 0.32, 95% CI 0.22-0.47, $p=<0.0001$) compared to non-Delivering Choice users. (Table 40). Patients accessing the Somerset Care Coordination Centre (OR 0.58, 95% CI 0.40-0.82, $p=0.002$) were less likely to have an A&E visit in their last month of life as were patients entered on the Adastral end of life register (OR 0.61, 95% CI 0.40 -0.92, $p=0.018$). (Table 38). Patients seen by Discharge in reach nurses were more likely to have visited A&E in the last month of life (OR 3.29, 95% CI 2.23 – 4.87, $p <0.0001$), but again this is most probably due to

identification of the patients by the Discharge in reach nurses at the time of an A&E visit. Notably, patients accessing either the OOH advice line (OR 0.34, 95% CI 0.17-0.70, $p=0.003$) or Somerset Care Coordination Centre (OR 0.24, 95% CI 0.12-0.48, $p<0.0001$) were less likely to have an A&E visit in their last week of life. (Table 41) Again this suggests that patients accessing the Delivering Choice programme in Somerset had 34% fewer A&E attendance in the last month of life and 68% in the last week of life with the Somerset Care Coordination Centre and OOH advice line appearing to be the most effective component of the interventions offered.

3.7 Indicative Costs

Using the cost data provided by commissioners and the mean difference in secondary care admission costs and A&E costs in the last month of life we calculated the mean difference in hospital service costs between patients receiving and not receiving Delivering Choice services in each PCT (see Appendix C). The total mean difference in hospital costs per Delivering Choice patient was -£355.89 in North Somerset and -£234.85 in Somerset. We then multiplied this by the number of patients utilising Delivering Choice over the six month period and then doubled it to determine the indicative costs avoided over a 12 month period in each PCT. No data were available to calculate the impact of Delivering Choice interventions on community costs.

3.7.1 North Somerset

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 (Table 42). No data were available to calculate the impact of delivering choice services 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. This is particularly relevant to the directly employed generic support workers, who delivered care to meet needs that may otherwise have been met through CHC-funded services.

3.7.2 Somerset

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 (Table 43). We were not able to calculate the impact of delivering choice services on community costs.

3.8 Conclusions from quantitative results

Key findings from the quantitative results are:

- People accessed Delivering Choice late in their end of life pathway with 50% accessing services less than 20 days before death in North Somerset and 10 days in Somerset.

- People receiving a Delivering Choice service were 67% less likely to die in hospital in North Somerset and 80% less likely to die in hospital in Somerset compared to those who did not receive a Delivering Choice service.
- Users of the Delivering Choice programmes in North Somerset and Somerset had fewer hospital admissions in the last month of life (39% and 50% respectively) and in the last week of life (80% and 68% respectively) with the North Somerset and Somerset Care Coordination Centres appearing to be the most effective component of the interventions. In Somerset, the OOH advice line and being on the Adastra end of life register was also associated with lower risk of admission.
- Users of the Delivering Choice programmes in North Somerset and Somerset had fewer A&E attendances in the last month of life (59% and 34% respectively) and in the last week of life (78% and 68% respectively) with the North Somerset and Somerset Care Coordination Centres and Somerset OOH advice lines appearing to be the most effective components of the interventions offered. In Somerset being on the Adastra end of life register was also associated with lower risk of admission in the last month of life but not the last week.
- For North Somerset the total spend on Delivering Choice was £369,000 and the indicative costs avoided were £151,609 over a 12 month period. For Somerset the total spend on Delivering Choice was £325,955 and the indicative costs avoided were £289,335 over 12 month period. No data were available to calculate the impact of delivering choice services 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 CHC-funded services.
- 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.
- 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. This could be because the Discharge in reach service proactively selects patients, rather than waiting for referrals like other Delivering Choice services.
- The system outputs from the Delivering Choice services are not all user friendly for evaluation and audit purposes.

North Somerset interventions

What works for whom and in what circumstances?

Having presented the quantitative results from routine data, the next section of this report takes each intervention in turn to learn more about what works for whom and in what circumstances.

4.0 End of Life Care facilitators

4.1 Introduction

The Delivering Choice programme has used 'facilitators' in both Somerset and North Somerset. This report only concerns the North Somerset End of Life Care facilitators, as only the North Somerset facilitators were part of the Delivering Choice programme.

Two North Somerset End of Life Care facilitators, both former district nurses, came into post in June 2010. The posts were full time and funded by the Primary Care Trust. North Somerset Community Partnership, now a community health services social enterprise, was the service provider. The cost of the End of Life Care facilitators was included in the costs of the End of Life Care Co-ordination Centre for North Somerset, which totalled £219,000 in 2010/2011 and £369,000 in 2011/2012.

To learn more about the End of Life Care facilitators, we carried out 37 interviews including 10 with community nurses at various band levels, 10 hospice staff, 4 GP practice staff and 2 GPs, 3 nurses from community hospitals, 3 care home staff and 4 Delivering Choice service providers. We also analysed two surveys and observed two training sessions in care homes. Documentation included all three Somerset Marie Curie reports, the Working Stream 7 working document and Board papers from May and August 2011.

4.2 How is it supposed to work?

Unlike the other Delivering Choice interventions, there is no mention of the End of Life Care facilitators in the Phase II report by the local Marie Curie team on suggested interventions. Instead, they first appear in the final report of the Marie Curie team (Phase III), after NHS North Somerset considered various service models and costings.

The End of Life Care facilitators were employed to address problems identified in Phase I of the project, specifically with GP practices and care homes. These were:

- Care home and primary care staff sometimes lacked confidence and skills in providing care for patients at the end of life.
- There was a lack of advance care planning resulting in crisis situations and occasionally unnecessary admission to hospital.

- A lack of skills and confidence by professionals in holding difficult conversations with patients and their families can sometimes result in ineffective communication or even avoidance in broaching difficult subjects.
- Preferred place of care was not always recorded. (Phase III report)

Identified outcomes were to:

- Increase the quality of care for patients at the end of their lives.
- Increase staff confidence and competence through enhancing knowledge and skills.
- Establish and support the use of end of life tools including advance care planning, Liverpool care pathway, Palliative Care framework, Delivering Choice pathway and Key Worker role.
- Ensure that there is a consistent approach to the use of Gold Standards Framework and other end of life tools across North Somerset.
- Bring about a reduction in the number of emergency admissions to acute hospital care in a crisis near the time of a patient's death.
- Establish and achieve patients preferred place of care. (Phase III report)

In interviews, one End of Life Care facilitator added another outcome - that of helping staff to identify end of life care patients earlier, so that care could be put in place sooner. The End of Life Care facilitator service was not condition specific and until recently their remit was focused largely with staff with minimal patient contact.

4.3 *How does it actually work?*

4.3.1 *Key functions*

Of all of the Delivering Choice interventions and tools, the End of Life Care facilitators has been the most nebulous, making it difficult to concretise and, therefore, more challenging to evaluate.

The EOL care facilitators served an important function in becoming the recognisable 'Face of End of Life Care' for North Somerset. In interviews, the two EOL care facilitators were instantly identified and widely known by a wide range of participants, possibly in part because they had worked previously in community nursing in North Somerset.

The brief of the End of Life Care facilitators was highly ambitious and arguably unachievable against the stated objectives. They were brought in to raise awareness, educate, identify and plug gaps, advise and signpost across community and primary care, care homes and hospices. The assumption appears to be that the promulgation of pathways and knowledge of tools would lead to their adoption by staff which in turn would improve the quality of end of life care.

To achieve this, the facilitators:

- Attended meetings on end of life care at hospices, GP practices and community ward bases.
- Provided specific training, primarily to care homes and community teams, on advance care planning, syringe drivers, Delivering Choice and Liverpool Care pathways, Key Worker and 'just in case' medication. A major aspect of their training role was encouraging and skilling up staff to use the Adastra end of life care register.

In educational workshops with care homes, the facilitators included additional information about services and funding available such as the out of hours teams, fast track and Continuing Health Care so that care home staff had a better understanding of the whole system. The aim was to generate a less panicked response in an emergency and thereby decrease calls to A&E.

Through this face to face contact at meetings and training sessions, the facilitators became a 'point of access' for end of life care and so their role grew to include other functions, namely:

- Offering ad hoc advice, for example a community hospital nurse rang the EOL care facilitators for guidance on medication for those patients who do not have hospice nurses.
- Signposting staff to appropriate services such as the website or other sources when they have queries (e.g. diabetic specialist nurse with clinical query).
- Identifying, agreeing and spreading good practice such as the St Peter's proforma for end of life medications to guide GP prescribing and a flowchart for setting up a night care worker.
- Represent North Somerset at South West regional end of life facilitator network events, which link into national initiatives.
- Resolving tensions and clarifying working practices between different disciplines, for example tensions arose between care staff and GPs about who should lead on registering patients on Adastra electronic register.

In regards to the last point, we observed this first hand during a workshop at a care home where the issue about when it was appropriate to call on hospital services emerged several times in the discussion with some intensity.

4.3.2 Strategic role in re-skilling district nurses in end of life care

Not only did the role of the End of Life Care facilitators encompass all of the previously listed educational and operational functions, but they appeared to have a strategic role in overseeing and modifying end of life care service provision for the county. Specifically, in 2008 when Delivering Choice was launched, there was a long standing problem of de-skilling of district nurses and GPs as the local hospice delivered excellent care at home in the southern part of Somerset.

I think in the south of the patch, it's a different hospice, it's a different relationship, and particularly in some parts of [area] they have enormous numbers of care homes and residential homes, and I think there's been a certain tendency of 'the hospice are involved, we don't need to be so involved'. So there's a bit of handing over one way or the other. So I think that potentially some of the GP community there haven't engaged as much because they haven't seen it as their day business. (GP AL)

This model was not sustainable.

It [the hospice] delivers a very good job but I think that the responsibility of any specialist service is continual training and education of the people they work with and when you've got a relatively small community and things are stable that's great if you can afford it. But I know the tsunami that's coming, and that model won't work for the future. My own population over the twenty two years I've been there, I've just seen that the population aging and so we do have far more deaths than we had twenty years ago because we've got a different age structure for our community because we're fairly elderly. That's going to escalate so we have to [be] realistic about the changes that are coming. (GP AL)

To reduce the intensity of the “tsunami”, the strategy was to increase the engagement of GPs and improve the skills of community staff through joint working with the hospice. To achieve this, working practices changed with the roll out of ‘just in case’ boxes whereby hospice nurses would note that a ‘just in case’ box was needed for a particular patient and notify the relevant district nurse. In turn, the district nurse would put the medications into the box and then deliver the box to the patient. This was a way of introducing the district nurse to the patient and family members earlier. To implement this new way of working, the EOL care facilitators carried out training in ‘just in case’ boxes with community nurses.

4.3.3 Uptake and reach

Since March 2012 both of the EOL care facilitators have been based at the North Somerset End of Life Care Co-ordination Centre (NSCCC). One now has the new role of overseeing the NSCCC while the other continues with some of the functions of the End of Life Care Facilitator role, as well as managing two of the generic support workers.

Throughout, with their ‘can do’ attitude, the End of Life Care facilitators have responded efficiently and competently to ever increasing demands as they emerged. However, the signs are that this capacity is threatened.

I think without a facilitator role I'd really be concerned about the ongoing sustainability. I can oversee and I can prompt to a certain degree, but there are only so many hours in a day.... I had a call from a palliative care nurse the other day about a concern in a nursing home about syringe driver training. I was able to email [end of life care facilitator] and say, 'Can you get in touch with this home and set up some more training?' If that role wasn't there it would be down to me to sort out with already a full role. (End of Life Care facilitator)

The geographical and professional area covered by the North Somerset EOL Care facilitators is large, hard to reach and highly heterogeneous. Nonetheless, the EOL Care facilitators attempted to cover ground. The Phase III report states that at the end of their first year by August 2011, the End of Life Care facilitators had made 2694 'contacts' with 254 community staff, 168 GPs, 48 staff working with dementia or learning difficulties patients and 33 specialist nurses¹. (Phase III report) When asked by the evaluation team for up to date figures in July 2012, for some professional groups contacts had actually decreased in the intervening year, which suggests some accuracy issues. Contacts ranged from a few minutes to repeated educational workshops, so the intensity of the End of Life care facilitator intervention was variable. Given this variability, the large remit, and the fact that for 12 of the 21 months during the study period only one End of Life Care facilitator was in post, it is perhaps unsurprising that capturing the impact of the role has been difficult. Nonetheless, the evaluation team has gathered information, using the methods outlined above, to gain an understanding of the service.

Most staff working in the community (including hospice workers) at bands 5 and 6, said they are in contact with the EOL facilitators between one and three times per month and find them "very helpful". This contact tends to take the form of phone calls to the End of Life Care facilitators at the NSCCC, although several have also received training from them in the workplace. Two who have had little or no contact were relatively junior community nurses new in post. Two community team staff at higher levels also mentioned having productive working relationships and called the End of Life Care facilitators at the NSCCC for advice.

Amongst other professionals, contact with the End of Life Care facilitators was more variable, which is a reflection of the End of Life care facilitation role. Three hospice staff members from in-patient units and Hospice at Home had no contact and did not feel they needed this. Two other respondents at one hospice however, spoke of regular contact with the End of Life Care facilitators to liaise over training. Training was also mentioned by a Community Team Head. Generally, whether or not people

¹ These numbers do not appear to add up to the total because some individuals had multiple contacts; reported directly from the Phase III report.

had regular contact with the End of Life Care facilitators, they had an idea of at least some of the work they do. Senior staff were generally more likely to meet the End of Life Care facilitators at meetings. Two respondents mentioned that now that the End of Life Care facilitators are based at the NSCCC, the remaining End of Life Care facilitator visits patients, for example if the case is difficult or the patient does not quite meet the criteria for fast track, or to respond to an emergency when no one else is available.

4.4 What prompts someone to call on the End of Life Care facilitators?

Different prompts triggered different functions of the role. For example, with regards to training, staff would contact the End of Life Care facilitators when they noticed particular knowledge gaps. Within the residential homes, the prompt could be concerns about meeting care standards.

We went into residential homes because two or three matrons in different homes had concerns about end of life care and carers haven't got the knowledge of looking after dying patients. They were still trying to feed people when they've lost their swallowing reflex because they were worried CQC [Care Quality Commission] would tell them off because they weren't feeding patients. (End of Life Care facilitator)

With respect to the other functions, once the End of Life Care facilitators were known, hospice, community and care home professionals sought out their involvement when they wanted help, advice or signposting so the 'trigger' was uncertainty and/or a lack of information.

4.5 What's its impact on the evaluation outcomes?

4.5.1 Co-ordinated care

As this was not part of the End of Life Care facilitator role, we did not collect information on the impact of this service on co-ordinated care.

4.5.2 Patient dying in place of choice

A GP who had worked quite closely with the End of Life Care facilitators around care homes stated that recently, she had found quite noticeable changes in place of death. She was not able to directly relate this to the work of the End of Life Care facilitators, but she felt they had made an important contribution. For example, she had received a thank you note from a family because of the care offered by the staff at the care home meant that their relative was able to die in their place of choice.

They've [care home staff] had a few terminal care patients and actually one of them has written to us to say thanks it all went very well and the relatives are writing to me saying that was great, thank you for letting them die at home basically. (GP GI)

She also referred to data collected by her GP practice.

I was looking at what they call a death board in the surgery where we've got all the deaths. And it used to be kind of roughly 50/50 in acute hospitals and in the community and now it's probably more like about 80-85% of our patients dying either at home or in nursing homes and so for me that's really positive. Whether you can kind of directly make the link between what [the End of Life Care facilitators] have been doing and what we've been doing with that happening or whether it's just a kind of patients just choosing that more I don't know...but I've been here for about eighteen years now and I've definitely seen that huge shift...in the last few years towards staff feeling more confident and being better prepared and anticipating patients dying at home and the quality of dying at home or their care home. (GP GI)

To test this further, we compared place of North Somerset death data from our study period of 1 September 2011 – 29 February 2012 to place of death data from 2004-2006 as reported in the Phase 1 report. Although we did not find that 80-85% of the population were dying at home or care homes as reported by the GP, we did find a 10% decrease in hospital deaths and a corresponding 10%+ increase in deaths at home. However, as many initiatives have taken place over the intervening six years and because we do not have quantitative data for the End of Life Care facilitators, we cannot say to what extent the End of Life Care facilitators contributed to that shift.

Table 44: North Somerset Place of Death

Place of death	2004-2006	1.9.11-29.2.12
Acute hospital	47-49%	37.9%
Home	18%	30.6%
Hospice	4-6%	6.3%
Care home	26-27%	14.7%
Elsewhere	3%	10.6%

4.6 What are the other positive impacts?

4.6.1 Meeting intended outcomes

The only 'hard' outcomes set for the End of Life Care facilitators were around the use of the Adastral end of life care register. We found that 169 people were registered for North Somerset, of which 59 had a Key Worker recorded. All of the community participants involved in the evaluation mentioned knowledge of the Adastral register and several community nurses reported that they had received Adastral training from the End of Life Care facilitators. A member of one community team specified that they have started naming Key Workers since the End of Life Care facilitator last visited them, sometime before Christmas 2011, although this is not supported by our data. However we also know that community teams have difficulty in accessing Adastral, and so perhaps the Key Workers are identified but not recorded on the electronic register. Please see the register and Key Worker report for further information about Adastral.

In terms of 'soft' outcomes, several participants spoke of training they'd had on the Liverpool pathway and the Framework ('traffic lights'). One community nurse said she had a copy of the 'traffic lights' that the End of Life Care facilitators had introduced, which she used to decide whether to fast track a patient. Please see the pathway and framework report for further information.

Extending end of life care services to non-cancer patients is an overarching aspiration of the Delivering Choice Programme and given the flexible and responsive nature of the role, the End of Life Care facilitators are expanding their scope to include other populations, such as the learning disabled and those with dementia.

4.6.2 Increase in confidence of staff

As one participant commented, tracing back the change in behaviour to the training sessions offered by the End of Life care facilitators is difficult, partly because the changes are so intangible. However, we received numerous reports from community and care home staff that the training offered by the End of Life Care facilitators was valued. District nurses appeared especially enthusiastic about the training in 'just in case' boxes. One said she "loved them" and described these boxes as "an idiot guide". Another district nurse mentioned appreciating that the training "provides structure to the community nurse". A third was appreciative of the recently launched documentation detailing how to access a night care worker in North Somerset, as this is a perennial problem.

In terms of care homes, one manager described an End of Life Care facilitator as "absolutely fabulous", saying not only did the facilitator come to give training but she also returned with extra information and leaflets on a second trip. Two care home matrons commented that they thought care home staff were more confident following educational workshops.

When I first started here 12 years ago the carers that used to work here, they were always frightened of going into a room if somebody was dying in case they were dead when they walked in. But now, they are a lot more confident in dealing with that, and dealing with relatives that are crying or upset. (Care home matron)

This care matron also thought staff were more respectful of the dying.

When people are dying in their bedrooms I think they're different now. They used to sort of just go rushing in and talking normally, but now it's a lot more respectful. [Is it?] Yes, I think so, after they probably thought about it. When they say they don't remember the training but when you actually see them doing the work it has changed from before [the End of Life Care facilitator] did the little course.... They're a lot more like you say empathetic, and they're more respectful to the families as well, a lot quieter in their mannerisms. They were a bit noisy before. (Care home matron)

Furthermore, she believed that the trained nurses were now kinder to junior staff.

And I think the trained nurses as well, when we've had a death, they're more empathetic to the staff, so at one time they'd have said, 'Oh just get on with the work', in the olden days, but now it's 'do you want to come and have a chat?' (Care home matron)

A GP confirmed that she believed care home staff were more confident and less likely to panic as a result of the training from the End of Life Care facilitators.

Overall, a hospice Community Palliative Care Specialist summed up the views of many by writing,

Having worked in North Somerset prior to the Care Centre and [End of Life Care facilitator] being in place I feel that since both of these services have been activated the standard of care and support not only to patients and carers, but also primary care team members has increased. (Community Palliative Care Specialist MC)

4.7 What helps to make it work?

4.7.1 Highly skilled facilitators

The characteristics of a successful End of Life Care facilitator for this model are:

- Extensive knowledge of end of life care.
- Excellent skills in presentation, generating discussions and making educational sessions interesting and interactive.
- A willingness to discuss end of life issues with reluctant staff members.
- Tenacity, resilience and passion about end of life care.
- Good organisational and project management skills.
- An ability to build good working relationships with professionals from a variety of backgrounds.
- Knowledge of hospital, community and voluntary service provision for end of life care patients.
- Personable, approachable, empathetic.
- Ideally previous experience in setting up a new service.
- A willingness to 'turn their hand to anything'

End of Life Care facilitators have to be aware of their own issues around death and dying and be able to reassure, and raise the confidence of, staff who find the subject emotionally difficult. One End of Life Care facilitator spoke of how she used her own experiences to help put people at ease.

I always tell a story about earlier this year, [we] went to a dementia study day ...And it just happened to be the anniversary of my mother's death, and I just broke into tears that afternoon. Somebody said something about families and oh, I just, and this is like 11 years on. And I do tell that story and I say, 'Look, we all have got stuff and you never know when it's going to hit you, and it's

absolutely fine to say I can't deal with this at the moment'. (End of Life Care facilitator)

The End of Life Care facilitators needed good skills in gaining commitment from staff who may be experiencing change fatigue. One mentioned she tried to simplify the change.

Change is scary to some people, yet another change is scary. We've got lots happening in the health service at the moment, people are very change fatigued, it's got to be a change that benefits sense, it's got to be someone who can show people the benefits. If you're going to go in saying, 'Oh, it's another change, we've got to do it, oh we'll make the most of it,' you're not going to get anywhere, you've got to have someone who believes in it. You've got to get somebody who is going to give them the feeling that it's not going to be such a big task that they can't do it. (End of Life Care facilitator)

Reluctance is one challenge; opposition is another. Thus, interestingly two different participants (nurse and GP) used the word “feisty” as a necessary character trait of successful End of Life Care facilitators.

The ideal professional background of the End of Life Care facilitator fostered some debate. We found that when working with hospice professionals, community nurses and care home staff, specialist palliative care and district nursing experience was useful. However, this background was less helpful when working with recalcitrant GPs. (see below)

4.7.2 Building good working relationships and responding flexibly to requests

One factor that helped the End of Life Care facilitators was getting themselves widely known and building good working relationships at the start.

Probably for the first eight months, we were constantly going to different groups, district nurse meetings, physio meetings, OT meetings, social care meetings, anybody that would have us. We literally went and did, 'this is our pathway, this is where we are and what we are,' just opened ourselves up to say, 'Ask us more, invite us back', because we were only ever allowed ten or fifteen minutes of their meeting time so it wasn't a huge amount. (End of Life Care facilitator)

Moreover, the End of Life Care facilitators were flexible about what function they performed for different staff members. For example, one GP practice initially requested help ‘sorting out’ the Adastra electronic register, which then led to a further invitation to deliver training. Another example was offered by a care home provider who mentioned that care home staff were having difficulties setting up a

syringe driver, and an End of Life Care facilitator responded with training the next day.

4.7.3 Interactive, high quality educational sessions for care home staff

To understand more about what worked well in the training offered by the End of Life Care facilitators, as well as observing two workshops, we interviewed three care home staff from two care homes. They were positive about the training, saying that they liked the interactive nature rather than working from “books”. The End of Life Care facilitators had a flair for presenting ideas and facilitating interesting, “thought provoking” discussions. For example, in one exercise participants were asked to imagine their own deaths.

I do a little training session about people thinking about their own death and dying, and that will stimulate amazing conversation. It's just a few slides, but the element of it is thinking about your own and how you will be. And if you talk about your own death and dying and your plans, it might just make it a little easier for you to talk, because if you've already expressed yours it might be easier for you then to have that conversation with somebody else if you've voiced yourself about your own death. (End of Life Care facilitator)

This exercise seems to be effective in helping staff to discuss death with others.

Yeah, I think it [discussing own death] was thought provoking because I went home still thinking about it, thinking 'What do I?' And I spoke to my husband and I told him what I wanted. [Did you?] Yes, because it's something that just goes round in your head thinking, 'Well what would I want in that place?' I mean especially if you've got dementia as well because you wouldn't be able to remember what you wanted. (Care home matron)

A member of the care home staff commented that the training created more empathy between staff and the patients and staff were more ready to respond spontaneously to patients' needs to discuss death.

Empathising, putting yourself in their shoes and seeing what they would want. Because we've known a lot of them for so long, we most probably know them much more than what their relatives do at this point in time sort of thing. So sometimes they tell us, they sit and tell us what they want. (Care home junior staff)

The End of Life Care facilitators were also happy to re-visit care homes to offer additional training to new staff, which is important given the high turnover. In addition, an End of Life Care facilitator arranged for care staff to visit a funeral parlour to find out what happens after death. This innovative educational activity was reportedly popular with care home staff.

4.8 What makes it more difficult?

4.8.1 Transient staff and commercial ethos in care homes

Several participants including care home staff, a GP and an End of Life Care facilitator, mentioned that the regular turnover in staff at the care homes means that improving the quality of care and maintaining that improvement is a constant challenge.

I think we need to update constantly to be honest, to remind people why the residents are here, what we should be doing, and ultimately dignity at the end of life. It's easy to forget, it's easy to think sometimes this is just a job when really they're the people, their lives are involved.... The dynamics of the home just change, sometimes it knocks the confidence so it's just having that refresher training constantly, reminding us. (Care home junior staff)

The evaluation team experienced the impact of this transience too. We organised three focus groups but only one took place. Lack of attendance was reportedly due to staff either not knowing the End of Life Care facilitators, because the care staff were new in post or not remembering the training. This confirmed the End of Life Care facilitators' view that the transience of the care home staff population makes it difficult to sustain impact.

The second issue is around costs. A GP commented that care homes need someone working within the care home with clout to promote the potential of training, as there was a cost implication.

I think some are more enthusiastic about improving quality of experience whereas some are there because they're making money....[An owner in the latter category] probably doesn't invest as much in their staff in terms of letting them go on courses for example or syringe drivers or end of life care because obviously that costs them to send their staff on these. (GP GI)

4.8.2 Uninterested, resistant GPs

GPs were the professional group with whom the End of Life Care facilitators had the most difficulty in reaching. Despite (or perhaps because of) their district nursing background, the End of Life Care facilitators found it difficult to engage GP practices and bring GPs on side. They reported that they offered an invitation to all GP practices, but were unable to furnish a list to the evaluation team of who had attended from each practice. This could be because so few GP practices actually took up that invitation. To learn more, we contacted three GP practices and spoke to three practice managers and one administrator and found that although the Adastral end of life care register was available in their practice, none of them had received training from the End of Life Care facilitators.

Given the poor response from GP practices to the End of Life Care facilitators in their specialist nurse role, this suggests, as one GP put forward, only GPs (rather than nurses) are likely to bring GPs around.

There's all those power politics. I've been fortunate to work with a very good PCT but there is still that [attitude that] the PCT is doing this to us, whereas, if a clinician comes along, side to side and said look guys, this is good practice and [the End of Life Care facilitators have] been great but I suspect a GP going in and saying look guys this is about good [unclear 00:08:45] it's about good experience for patients.... It's a coming alongside approach rather than the top down. Because GPs are self employed, independent practices, top down doesn't work, and that's what PCT stuff could be perceived as. So it's, I, as a practising GP and coming along and talking to you as a practicing GP and are you aware of these things? (GP AL)

4.8.3 Easy to lose sight of focus

Given that the remit of the End of Life Care facilitators was so broad and that they first approached the role with the intention of 'getting a foot in the door', the End of Life Care facilitators rapidly became over-stretched. For example, we were told that one End of Life Care facilitator had worked with the libraries to increase public awareness of end of life care issues during the Dying Matters week. Although undoubtedly valuable work, it is difficult to see how this effort might directly impact on their stated outcomes of increasing staff confidence, improving the quality of end of life care, reducing hospital admissions and increasing the chances of patients dying in their place of choice.

4.8.4 Lack of clarity around role leading to professional territorialism

We received three reports from NSCCC staff that the End of Life Care facilitators and the North Somerset End of Life Care Co-ordination Centre did not work particularly well together initially. The difficulties appeared to be around confusion about the role and responsibilities of the End of Life Care facilitators in relation to the lead nurse at the NSCCC. There has now been a change in staff, as the original lead nurse left and the Band 7 End of Life Care facilitator took over the management of the NSCCC; tension has dissipated, and these staff are now all based on the same site.

4.8.5 Lack of administrative support

The End of Life Care facilitator service had limited, ad hoc access to administrators, so much of their time was spent ringing GP practices, care homes and community teams to set up meetings, organising study days and pulling together study packs. Given that they were graded at Band 6 and Band 7, arguably these administrative tasks were not the best use of their time. If a part time administrator had been available, perhaps more comprehensive records of their contacts would have been produced. They also would have found a budget for stationery useful.

4.9 What would make it work better?

Two care home staff mentioned that they would appreciate more guidance on how to talk to families about death and dying. This could perhaps even include families, along with care home staff, in the training. A member of the evaluation team noted that to her knowledge the care home staff did not receive a list of possible training

that they could receive. We did not receive any other suggestions about how to improve the intervention of the End of Life Care facilitators.

4.10 Does it duplicate something else that's already there?

The greatest potential for duplication occurred with end of life care training offered by the hospices, two of which operated in the North Somerset area. One hospice no longer offers courses. The other hospice in the county offered a range of courses including higher education modules in Palliative or End of Life care, syringe driver training, symptom control, Advance Care Planning, Supporting People in Bereavement, end of life conversations, GP Symptom Management seminars and Adastral electronic register training for the ambulance service. Training was available for registered and unregistered practitioners, administrative staff, care home personnel and mixed audiences. Some of the training was free to practitioners, as it was funded by the Primary Care Cluster.

Thus there is considerable overlap with the training offered by the End of Life Care facilitators. The principal difference was that the training provided by the End of Life Care facilitators was always free. We also found that a GP, who was positive about the role of End of Life Care facilitators, accessed training from the hospice so as to find out more about hospice services and up-to-date information on medication.

4.11 How do the evaluation findings fit with the original hypothesis?

The original hypothesis for the End of Life Care facilitators generated by the participants in the hypothesis generation workshops in early 2011 was:

EOL facilitators in North Somerset have specialist knowledge of end of life care. They engage interested and non-interested healthcare providers to change practitioners' views and that makes them "indispensable". They empower other healthcare professionals to see the relevance of their care to people at end of life. They also enable staff to access training which builds their confidence to care for people at end of life. EOL facilitators made inroads to GP practices and care homes. Staff then see themselves as part of the larger system.

This leads to the outcomes of empowerment, trust, holistic system, information and conversations.

Our evaluation findings suggest that the EOL Care facilitators have made a valiant start. With regards to their "indispensability", the End of Life Care facilitators have fully met the implicit objective underpinning their role – that of increasing the profile of end of life care in North Somerset. They were so well known that a North Somerset out of hours community nurse mentioned one of the End of Life Care facilitators without prompting, at a chance social encounter with an evaluation team member. Moreover, we have substantial evidence of improvement in the key outcomes of empowerment, trust, information and conversations.

4.12 What are the key ingredients?

To implement this successfully elsewhere, the key ingredients are:

- Clear and focused brief to enable impact to be concentrated and outcomes achievable.
- Maintain the role as dedicated solely to end of life care.
- Employment of highly skilled nurse facilitators, to work with care home and community staff, and GP facilitators to work with GP practices with
 - Extensive knowledge of end of life care services and treatment.
 - Interactive educational style.
 - An ability to build good working relationships with professionals from a variety of backgrounds.
 - A personable, empathetic approach with qualities of resilience and 'feistiness'.
 - An ability to respond quickly and flexibly and 'turn their hand' to anything.
 - Good change management skills.
 - Background in district nursing to work with care homes, hospices and community wards. Background in general practice to work with GP practices.
- Administrative support and budget for stationery and educational materials.

4.13 Conclusion

The intervention of End of Life Care facilitators in North Somerset was diffuse, variable and wide ranging. Their ever- burgeoning role was not clearly demarcated and, arguably, was not sufficiently resourced, nor were their activities systematically recorded. Therefore, perhaps not surprisingly, teasing out and capturing their impact has been difficult. We have little outcome data to draw on, basing our conclusions almost entirely on the perceptions of the local professionals contacted.

No one expressed negative opinions about the End of Life Care facilitators while most stated that they were 'helpful' or 'very helpful'. Moreover, many professionals were grateful for the support they had received, particularly care home staff, some district nurses and one of the GPs contacted. The End of Life Care facilitator service also won the North Somerset most successful service improvement initiative in 2011.

The End of Life Care facilitators gave a face, a name and a presence to raise awareness about end of life care in North Somerset. We received reports from community and care home staff that the work of the End of Life Care facilitators has given them more confidence in working with the dying. In making that change happen, the End of Life Care facilitators are obviously highly skilled in working with a wide range of people, delivering thought provoking training and cultivating changes in attitude, which in the case of the few care home staff and some community nurses contacted, reportedly translated into behavioural adaptations.

Having laid the bedrock for changing professional behaviour, which can take years, it would be unfortunate if their funding was discontinued just when the benefits may come about. Because the intervention of the End of Life Care facilitators is hard to measure, behind the scenes, subtle and dependent on working through staff who then in turn deliver care to patients, it is easy to undervalue the importance of their work. The impetus now needs to be on honing in and focusing the role to achieve the ambitious outcomes.

However, the literature suggests that relying exclusively on the 'mechanism' of changing practice through professionals who raise awareness and provide education may not be successful. (Dopson, Locock, Chambers & Gabbay, 2001; Wye & McClenahan, 2001) In the case of the North Somerset Delivering Choice programme, the End of Life Care facilitator intervention is fortuitously coupled with the NSCCC, which offers an operational function to support the changes advocated by the End of Life Care facilitators. The impact of this combination of service interventions will be explored in a later chapter of this report.

4.14 Recommendations

1. More resources, specifically more End of Life Care facilitators with a nursing background to be contracted for a longer period of time. Consider extending the contract for the remaining End of Life Care facilitator for two years.
2. Narrow and focus the remit in terms of aims and function (operational, educational, strategic) OR target audiences (care homes, community staff, GP practices, hospices) OR outcomes and possibly geographical area (i.e. Integrated Care teams), so that the impact is more concentrated and the outcomes achievable.
3. Maintain the facilitator role as dedicated solely to end of life care.
4. Consider appointing a GP End of Life Care facilitator to work with GP practices.
5. Continue to link into the South West regional end of life care network for learning and dissemination.
6. Consider an administrative post to support the facilitators, especially if more facilitators are appointed.
7. Set up regular rolling educational programme for care homes.
8. Set up better systems to record the number, type and duration of contacts to support business cases and requests for funding.

5.0 North Somerset End of Life Care Co-ordination Centre (NSCCC)

Outcomes for patients and professionals accessing the North Somerset Care Co-ordination Centre

- Significantly lower emergency hospital admissions and A&E visits in last month of life.
- Significantly fewer deaths in hospital.
- Perceptions of greater co-ordination of care.
- High level of family carer satisfaction.
- Perception of freeing up of district nursing time.
- Reduction in district nurse and family carer anxieties around co-ordination of care.
- Release of family carers from full time caring role.
- Unintended outcome – families prefer Generic Support Workers to agency carers.

What helps this intervention work

- Flexibility of an in-house model.
- On site fast track assessor with other specialist nurses within the team.
- Personal care workers (Generic Support Workers) co-located with the NSCCC, who can keep the NSCCC and wider system updated on the families' needs through regular face to face contact.
- Co-location of the NSCCC with the Single Point of Access team in open plan offices to foster good verbal communication with social service staff.
- The right admin and clinical staff with excellent communication skills who work well under pressure.
- Regular whole NSCCC team meetings to monitor staff wellbeing and provide updates on patient and family needs.
- Ensuring that the Generic Support Worker role includes a psycho-social function as well as personal care.
- Managing the boundaries of the Generic Support Workers so that they do not become over-involved, over-stretched or poorly targeted.
- Regular meetings with hospices to market the service.
- Excellent leadership with a manager who has a community nursing background.

What stops this intervention from working as well as it could

- Patients dying at home not known to the NSCCC.
- Lack of front line caring staff i.e. Generic Support Workers and night staff.
- Poorer liaison with hospitals out of county.
- Lack of access to up to date electronic information about patient status.
- Concerns about brokerage and care agencies.
- Delays in provision of equipment.
- Budget restrictions i.e. increased number of patients dying at home through care packages but fast track budget is fixed at previous levels.

5.1 Introduction

The North Somerset End of Life Care Co-ordination Centre (NSCCC) sits within the Single Point of Access team within council premises. The NSCCC was purposely located here to take advantage of co-location with social services staff, who may identify end of life care patients earlier in their trajectory.

The NSCCC went live on 8 November 2010 and is staffed by 0.5 WTE Band 7 lead nurse, 1 WTE Band 6 nurse facilitator, 2 WTE administrators, 8.5 Generic Support Workers offering personal care and the Continuing Health Care fast track facilitator (0.7 WTE). This makes the NSCCC a 'one stop shop' for end of life care needs. The NSCCC's core opening times are Monday to Friday 8am-6pm. The shifts of the Generic Support Workers are 8am – 4pm and 1pm – 9pm.

The cost of the NSCCC was combined with the cost of the End of Life Care facilitators. This came to £219,000 in 2010/2011 and £369,000 in 2011/2012. These costs were to be covered by the anticipated release of costs from 10% fewer hospital deaths (n=100) and a 1% reduction in emergency call outs (n=23). (Service specification North Somerset)

In addition to quantitative analyses, to evaluate the NSCCC we collected the views of 47 individuals, including 17 family carers and one patient, hospice and community nurses, care home staff, community hospital staff and Delivering Choice service providers. We observed NSCCC staff formally on three separate occasions in August and December 2011 and shadowed Generic Support Workers on two shifts. We also analysed documentation such as Marie Curie reports, Board minutes, a service specification and NHS Somerset and NHS North Somerset fast track audits.

5.2 How is it supposed to work?

Many different types of North Somerset professionals can set up packages of care for terminal patients who want to remain in their usual place of residence. These include community matrons, specialist palliative care nurses, district nurses, nurse assessors from Continuing Health Care and, less frequently, social workers. The packages of care might consist of night care workers, equipment and day time care agency staff who provide personal care (ie washing, feeding etc, sometimes known as 'social' care). The working group tasked with '24 hour care' identified a lack of flexibility to provide short, long and night shifts and a shortage of care agency staff with experience in end of life care. The 'Generic Support Worker' role was one response.

Obtaining the different elements of a care package can be time consuming, as different suppliers need to be contacted for the various elements. Moreover, the timing of the delivery of the care package can often be disjointed or delayed. The Phase I report identified several other difficulties including:

- Delays in waiting for assessment by social services or the Continuing Health Care team.

- Lack of joined up working between North Somerset social services and North Somerset PCT.
- Too many different agencies involved and services going into the home.
- Geographical issues regarding coordinating care with other professionals (e.g. to set up a syringe driver; patient – base - surgery - pharmacy).
- Insufficient communication between professionals and agencies involved in providing care.
- Lack of continuity from hospital, hospice and district nurses.
- Multiple sets of records. (Phase I report)

To address these problems, both Somerset and North Somerset have developed End of Life Care Coordination Centres. The intention for the Care Coordination Centre in North Somerset was that non-fast track patients, as well as fast tracked patients, would be eligible to use the service.

The overarching aim of the North Somerset Care Co-ordination Centre was to speed up care package organisation. By installing good care packages quickly, the Co-ordination Centre intended to relieve the burden of family carers and facilitate patients dying at home. Specific objectives included:

For professionals:

- To organise and coordinate packages of care that potentially impact on avoiding hospital admissions and reducing length of hospital stay.
- To free up the time of community nurses previously spent on organising packages of care.
- To provide a central point of information on palliative care patients and local care services for health and social care professionals.
- To provide a 'helicopter' view of available resources for commissioners and service providers relating to demand and capacity of services. (Phase II report)

For patients and family carers:

- Improved continuity of care, better signposting and communication relating to packages of care between health and social care organisations and the patient and their carers/families that will potentially reduce anxiety.
- A reduction in the number of double bookings or duplication of visits to a patient through clearer planning and information sharing. (Phase II report)

To meet these objectives, in addition to organising packages of care, the tasks allocated to the End of Life Care Co-ordination Centre team included:

- Establishing and maintaining the Adastra end of life care register including information on preferred place of care and death.

- Maintaining a centrally held database capturing care provision required by palliative care patients and information relating to demand for care and unmet care.
- Maintaining and updating the palliative care website in conjunction with other providers. (Phase II report)

Funding was also allocated to create an in-house team of Generic Support Workers located at the North Somerset End of Life Care Co-ordination Centre to carry out:

- Basic personal care.
- Enhanced skills e.g. PEG feeding, wound care, foot care, stoma care.
- Domestic chores.
- Assistance with medication.
- Provision of emotional support for patient and family carer. (North Somerset Service specification)

Evaluation data suggest that the Generic Support Workers also serve an important function in keeping an eye on family carer and patient needs, which can then be relayed to the NSCCC and through the NSCCC to the wider system, including community nurses.

In line with the working party, an aspiration of the Generic Support Workers team was to provide care 24/7.

5.3 How does the NSCCC actually work?

The North Somerset End of Life Care Coordination Centre (NSCCC) initially had some difficulties around unclear roles and line management responsibilities. In March 2012, the former Band 7 End of Life Care facilitator took over the management of the Co-ordination Centre and these difficulties now appear resolved.

5.3.1 Co-location with Single Point of Access

The NSCCC is in the early stages of capitalising on the inherent advantages offered by co-location within the Single Point of Access. The Single Point of Access is a new team, which also consists of Care Connect and the Professional Assessment Team.

Within North Somerset, professionals, patients and family carers can phone the Care Connect team, staffed from 8am to 6pm. Care Connect offers signposting to a broad range of services, including, to name a few, benefits agencies, home energy conservation agencies, and transportation providers. Most importantly, for the purposes of end of life care, Care Connect provides information on home care support and care homes. All requests coming through Care Connect are logged electronically and 'work flowed' to the appropriate professional.

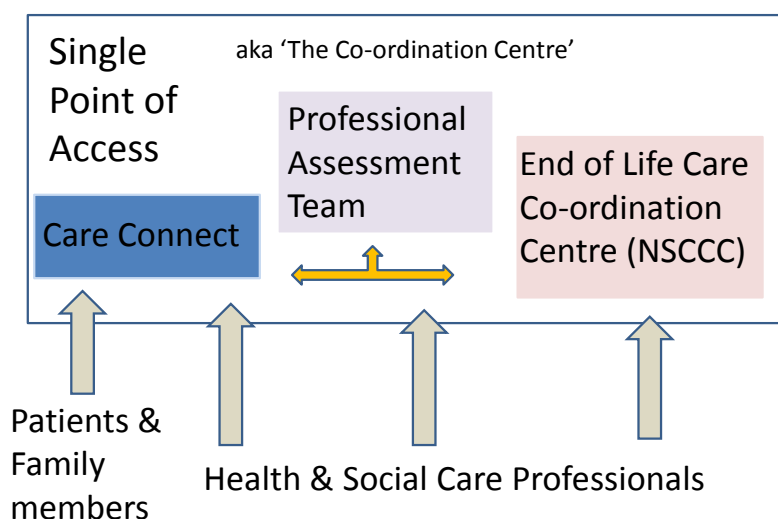
The Professional Assessment Team is made up of health and social care professionals including occupational therapists, physiotherapists, nurses and social workers. Their job is to triage, prioritise and ensure that the referrals coming from Care Connect, and elsewhere, are directed to the correct service. The nurse

manager for the NSCCC also has a half time role as the lead nurse for the Professional Assessment Team. Social care staff report on the AIS system and health professionals on the RIO system, although all electronic systems can be accessed by any professional, regardless of discipline.

The intention was that by locating the NSCCC within the Single Point of Access, palliative care patients that might have been missed will be picked up through Care Connect or the Professional Assessment team. In practice, this is happening in an ad hoc manner, mainly when a member of the Professional Assessment Team finds that the usual response does not fit and the issue is clearly health or palliative care related. In these cases, the Professional Assessment Team member (e.g. social worker, occupational therapist or physiotherapist) tends to refer up to his or her immediate line manager, who then suggests “crossing the room” to pass the referral to the End of Life Care team. For example, a junior social worker brought the case of an elderly gentleman with nutritional problems to the attention of her line manager who in turn suggested that the referral be passed on to the lead nurse of the NSCCC.

Another way to identify palliative care patients coming through Single Point of Access routes is the weekly multi-disciplinary meeting for the entire Single Point of Access team. In addition, the lead nurse for the NSCCC may help the Single Point of Access nurse whose role it is to pass on messages from patients to the district nurses, when there is a backlog. In this way, patients not previously known to the NSCCC might be identified by chance. However, these various mechanisms depend on professionals having enough time to identify, reflect and act on these cases, which is less likely during busy periods. There is no systematic way of capturing end of life care patients who come through to Single Point of Access routes. Please see the figure below for referral routes into Single Point of Access.

Figure 1: Referral routes into North Somerset Single Point of Access



5.3.2 Setting up care packages

Community and hospice professionals are prompted to contact the NSCCC to set up care packages predominately for fast track patients (those expected to die between 6-8 weeks) who want to die at home. The NSCCC is contacted because:

- Staff cannot get the equipment, night or day care workers elsewhere.
- Staff need to set up multiple elements in a care package and do not want to spend hours organising this themselves.
- Previous experience has led staff to believe that the NSCCC will set the care package up efficiently and quickly.

Patients and family carers are prompted to use the NSCCC to change care package requirements.

To set up an initial package of care, usually a community nurse or hospice clinician rings or faxes directly through to the NSCCC or telephones Care Connect which put calls through to the NSCCC. Although these data are not systematically collected, the lead nurse of the NSCCC believed district nurses to be the most frequent source of referrals, followed by hospice workers (hospice in southern patch more than the hospice in the northern patch), community matrons and then the acute hospitals. The professional making the referral will request equipment, night care workers or care agency staff as required. A four page care needs form is completed. Once the patient and family are known to the NSCCC, subsequent requests for additional care or night care may come directly from them rather than professionals.

In North Somerset, patients eligible for fast track are those considered likely to die within six to eight weeks. They are independently assessed by the fast track co-ordinator, who is part of the NSCCC team or another nurse on the team, if the fast track co-ordinator is not available. The budget for fast track has followed the fast track co-ordinator to the NSCCC team. The fast track co-ordinator will look at the RIO electronic system to review the case. Sometimes the fast track co-ordinator or another nurse on the team will also undertake a home visit, especially if the patient lives in a care home. A NSCCC staff member estimated that about 15% of patients are independently assessed, often when there is some doubt about suitability. Then a decision is made whether the patient qualifies for fast track and, if this is confirmed, the package of care is put in place. Those choosing to die at home are prioritised ahead of those in care homes, the assumption is that care home patients will already have some access to staff and equipment. The intention is to put in a package of care within 24 hours. A combined North Somerset and Somerset audit published in August 2011 reported that care packages for 80% (55/66) of patients met that target.

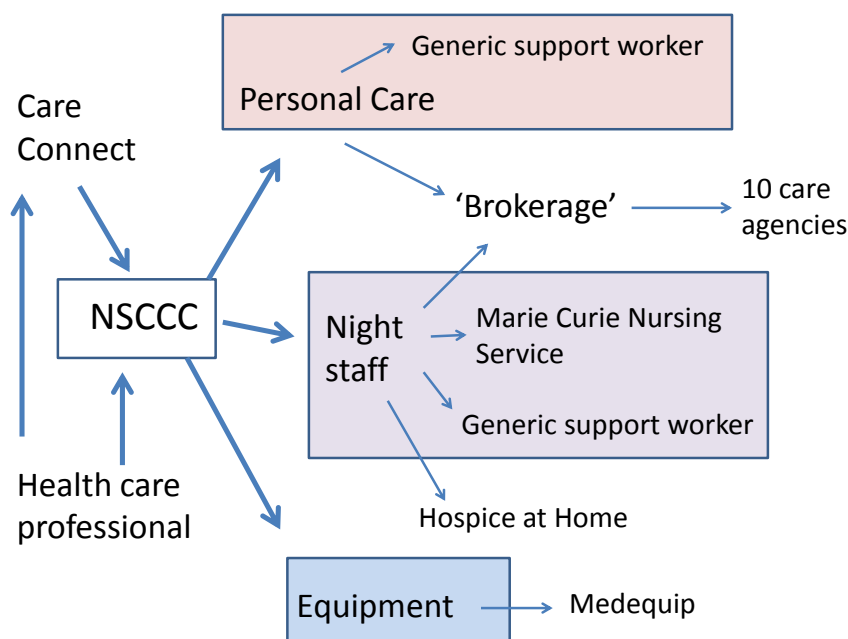
If personal care is needed, the NSCCC will first check if the Generic Support Workers have capacity, as they are part of the End of Life Care Coordination team. If not, then the request goes on to 'brokerage'. Brokerage is a team of advisors and administrators who set up care with external providers for patients with all types of

conditions not just end of life care. The brokerage team receive a 'record of needs' which they then advertise electronically via e-mail or the DCAW (domiciliary care allocation website) to all 10 potential care agencies. Once an agreement is made with a care agency, the 'order' is sent back to the 'commissioning agency' (i.e. the NSCCC). The NSCCC does not usually have much further contact with the care agencies nor does the NSCCC systematically feed back any information about the care package to the professional who originated the referral.

One senior healthcare assistant is available nightly in North Somerset provided by the Marie Curie Nursing Service; the NSCCC manages the referrals to this service. This is the preferred option. If this member of night staff is booked, the NSCCC can arrange for care from Hospice at Home, from a care agency via the North Somerset brokerage team, from Marie Curie Nursing Service, if the team has a second night staff member available, or through negotiation with Rapid Response. A Generic Support Worker may also be willing to take on the night caring commitment. All equipment is ordered through 'Medequip'.

Once the care package is organised, the family carer is contacted to let him or her know the particulars of the package and to communicate that it will be reviewed after six weeks. Please see the figure below.

Figure 2: Setting up care packages in North Somerset



5.3.3 Database and website maintenance

As the central access point for end of life care, the NSCCC was charged with:

- Updating the Adastra electronic register.
- Establishing and maintaining an electronic system to record demand and supply of end of life care services.

- Maintaining the website.

With regards to Adastra, a NSCCC staff member, interviewed in December 2011, stated that they did not use the electronic register because of difficulties with the password and because of concerns about putting patient details on the register without explicit patient consent. As of July 2012, with the advent of a new nurse lead, the evaluation team was told that NSCCC staff tended to ask community staff whether newly referred patients are on the register. There is no electronic system to record demand and supply of end of life care services currently in use. We do not know the extent to which the NSCCC maintains the website.

5.3.4 Generic Support Workers

In March 2012, the generic support working team was made up of a mixture of ex-NHS acute sector assistants, former hospice workers and ex-private care agency staff. The remit of the Generic Support Workers is to offer personal care to the patient, which they appear to do “sensitively” and “respectfully”.

And the people (Generic Support Workers) themselves, they must have been trained...They were splendid...They were respectful, and gave [husband] all the kindness...He had to be washed by them, and not once did he find it embarrassing or awkward. He accepted it all, because of their attitude...They were treating him gently.. with respect, right up until the end. (Family carer MP)

They also offer emotional and practical support to the family.

After providing patient care, the two Generic Support Workers sat down with the daughter to drink tea and chat. One of the Generic Support Workers had told me earlier that this patient is very close to death and has told the Generic Support Worker that she is ‘ready to die’, which the daughter knows but is anxious about. The Generic Support Workers engaged in a broad discussion of points raised by the daughter, covering social, work and family matters. This discussion appeared to help the daughter relax and then raise pressing issues, asking at one point, ‘what do I do now?’ The Generic Support Workers carefully explained about the importance of using sponges to moisten mother’s lips and clean her teeth, advice to which the daughter responded: ‘I’m glad you told me that’. The Generic Support Workers also advised the daughter not to worry about the need constantly to be doing things for her mother, that it was OK to just sit with her and have quality time. The two Generic Support Workers kissed the daughter on leaving the house, which initially surprised me, given that they have only been involved in this case for three days, and reinforced for me how quickly the Generic Support Workers can form a personal relationship with family carers. (Observation, Generic Support Workers, 21.2.12).

5.3.5 Uptake and reach of the NSCCC

Quantitative data for the NSCCC for the period of 1 September 2011 – 29 February 2012 show that 153 patients received care packages and died during that time period. This is 15% of the total number of patients who were classified as eligible for palliative care (153/1022). On average, patients come into contact with the NSCCC 17.7 days before death with a median value of 8 days (range 4-21); therefore 50% of the patients are referred to the NSCCC eight or fewer days before death.

Almost exactly equal numbers of men and women used the NSCCC. 16% of those referred to NSCCC were under 70; 20% were between 70 and 79; 48% were between 80 and 89 and 16% were 90 or more. So nearly two thirds of the patients using the NSCCC were over 80. In terms of conditions, of the 153 patients referred to the NSCCC, 65% (99/153) died from cancer; 8% (12/153) died from respiratory diseases; 6.5% (10/153) died from heart disease; 6.5% (10/153) died from dementia and 5% (8/153) died from cerebrovascular disease. All others died from various other conditions including nervous system and genitourinary diseases. So although the NSCCC predominately provides services for cancer patients, nearly a third of the patients using the NSCCC had non-cancer diagnoses.

In interviews and surveys with professionals, we found the NSCCC was largely used by:

- District nursing and hospice community teams to arrange packages of care for fast track patients.
- Hospice in-patient units to arrange discharges.
- Hospice at Home to check if the NSCCC was already working with patients newly referred to the hospice.

Of those using the NSCCC, two respondents said they were in contact at least once a week and four said they contacted the NSCCC 1-3 times a month. All of the professionals interviewed said they found the NSCCC helpful, the majority finding it very helpful. Typical comments included “I have always found the NSCCC to be prompt and efficient”; “it has been great to book equipment”; “they have been able to set up care packages quickly”.

The beneficial aspect most frequently mentioned by staff as most helpful to themselves is that the arrangement of care packages and equipment is simpler and quicker. Thus, a community nurse said that she did not have to hunt around for phone numbers and “you’re not repeating yourself, you’re not referred to somebody else”. A former community palliative care nurse said he used to have to pull over in a layby to arrange care packages, but now can simply call the NSCCC. A typical comment was made by a hospice nurse when she remarked, “There’s one place to ring and no other care agencies are involved or, if there are, they’ll tell you”. She compared this with other counties where care packages can be more difficult to arrange due to the number of agencies involved, with no central coordination. A

similarly confusing situation was described by staff who had worked in North Somerset prior to the launch of the NSCCC.

The speed with which equipment can be arranged was highlighted by several professionals, as well as family carers. Equipment was often said to be in place the day after a request. Two community nurses made a comparison with referrals to social services which they said could take up to six weeks.

Care packages can also be arranged within a day for fast track patients. If this is not possible, however, the NSCCC may provide a Generic Support Worker in the meantime. Again, the speed of putting in a Generic Support Worker compared more favourably than the packages arranged through brokerage by social services. Thus overall, community nursing and hospice staff found the introduction of the NSCCC beneficial.

5.3.6 Uptake and reach Generic Support Workers

In looking at uptake of the Generic Support Workers, we were only able to access information for 101 days of the six month study, as the paper diary that recorded Generic Support Worker use stopped abruptly in the first week of December. 25 North Somerset patients who died from 1 September – 29 February 2012 received this service. Slightly more women than men used the service (15/25). Of these 18/25 (72%) had cancer; two had heart disease; two died from respiratory disease and 1 died from dementia.

During those 101 days, 28 different patients and their family carers were supported by the Generic Support Workers. Fifteen families received support from one Generic Support Worker each visit and 13 had a team of two Generic Support Workers. . In total over this period, there were 1025 visits from Generic Support Workers over the 101 days, making 10.14 Generic Support Worker visits per day across the team for this time period. The total number of visits per patient ranged from 1 to 84. About a quarter of the families had brief contact with the Generic Support Workers and about 15% (4/28) were high users of the Generic Support Workers' service. Please see the table below for further details.

Table 45: Generic Support Worker usage

Number of Generic Support Workers (GSW) allocated	One GSW visited	Two GSWs visited			
	15 patients	13 patients			
Total number of days on caseload	One day	2-6 days	7-20 days	21-35 days	36+ days
	9 patients	8 patients	4 patients	3 patients	4 patients
Total length of visits ²	0.5 hour	1-3 hours	4-10 hours	11-20 hours	21 hours+
	9 patients	7 patients	3 patients	5 patients	4 patients

5.4 What is the impact on the evaluation outcomes?

5.4.1 Co-ordinated care

Family carers who had used the NSCCC reported that the coordination of care across the different sectors was high. For example, the patient below commented:

Everything has been set into place so smoothly...There's a team that comes in from [X], but they only come in once in the mornings...we have the district nurses which were those that come to do my driver. Then we had the other carers that come in and wash me...We've had so many people in, but everything has been done, well they couldn't have done anymore for us.
(Patient QQ and Family carer QL)

The NSCCC set up comprehensive care packages quickly which often went beyond the expectations of family carers.

In terms of the support that we got here at home, I have to say it was fantastic, it was tremendous...Somebody mentioned that they think we could get a hoist, and...two days later there was a hoist here. It was almost like my goodness, why are we being treated so well? (Family carer GS)

Within days everything I've needed seems to have arrived promptly. (Family carer NG)

Family carers also appreciated how the NSCCC have proactively anticipated needs.

They've [NSCCC] been like, 'Betty do you need a sitter?', so they've been supportive and the hospice has as well...where [NSCCC] can't [provide a sitter], [the hospice] tried to...so I've had a mixture of Marie Curie nurses [and] hospice nurses. (Family carer MB)

² Each visit estimated as 0.5 hours.

They're [CCC] also sending me some respite now... I think it was all decided as a big team thing really and they all sort of communicate and I think that they decided that it would be good for me. (Family carer NG)

Moreover, we did not receive accounts from any family carer of double bookings or duplication of care.

5.4.2 Hospital usage

Those using the NSCCC had significantly lower emergency hospital admissions and A&E visits in the last month of life. In terms of hospital usage in the last month of life, 26% of NSCCC patients had an emergency hospital admission (40/153) and 23% visited A&E (35/153). This compares to 41% (hospital admissions) and 45% (A&E visits) for non-Delivering Choice users in the last month of life. This association was even stronger in the last week of life. Looking at North Somerset Delivering Choice interventions overall, the NSCCC was the strongest component.

These findings confirmed perceptions from family carers and patients in interviews that the use of the NSCCC led to less hospital usage.

[My wife] would have to be in a hospital or hospice or something [if care package not put in place]... Yeah, I wouldn't be able to stay at home, no way... Because there's no way I can wash you [wife], I mean I do your hands and face but when it gets to everything else, because you've got to take her weight... we'd be lost to be honest with you [without care package]... I think I might do myself in then, it would be that bad. (Patient RR and Family carer MR)

I think they [NHS] pay a lot of attention to getting people out of hospital but this [NSCCC service] prevents a lot of people from going into hospitals. (Family carer JC)

5.4.3 Death in preferred place of care

Amongst NSCCC patients, 44% died at home compared to 28% of non-Delivering Choice users. Conversely, 18% of NSCCC patients died in hospital while 43% of non-Delivering Choice users died in hospital. Quantitative analyses suggested that use of the NSCCC strongly improved the chances of a death at home.

Qualitative data confirmed quantitative findings in that family carers believe that patients are more likely to die in their place of choice.

They admitted her [mother] and they said she had a chest infection... Well [after] about ten days they said she was fit enough to go home... She wasn't happy to come home, she didn't feel confident to go home and I wasn't overly happy so she said could I find somewhere for her to go for a week or two respite? So I got her into [residential care home]... she was very, very

poorly...She just went down so fast...the last few days were very, very quick... She [NSCCC lead nurse] got like a hospital bed arranged to go in and obviously the Rapid Response she got to go in because they were the only ones that could administer the morphine...She said 'I will stay on until I've got everything set up'...She came back quite later in the evening and said yes everything had been set up and yes it had been funded, so there is no problems with that...I was really pleased, I've never had any experience before but how efficient she was and got everything all set up to me so smoothly, it was quite comforting. (Family carer NR)

For some family carers, the Generic Support Workers were instrumental in allowing their dying relative to stay at home.

The daughter told me that her mother had been very clear she wanted to die at home. There is a big family to help support her, although this daughter is the only one in the family prepared to provide hands-on personal care. As a result, the daughter said that if the GSWs were not available she would 'struggle' and her mother would probably have to move to the hospice, and she added that GSWs allow the option of her mother continuing to be at home. (Researcher's notes following interview with Family carer MB)

5.5 What are the other positive impacts?

5.5.1 Freed up staff time and reduced stress

Several participants stated in interview and in the survey that the NSCCC frees up district nursing time and reduces the anxiety around organising care packages. Two participants said that the NSCCC was a good "first port of call" when they had queries and needed to "lay problems at their [NSCCC] feet". A hospice nurse also thought that the NSCCC reduces stress for family carers because care packages are better organised.

With the time that is freed up by the NSCCC, staff said they can concentrate on the "proper" focus of their job – caring and providing information for patients and family carers. However, two participants mentioned that with more individuals being treated in the community, staff workloads are greater than ever. So rather than freeing up time to give staff more time per patient, the NSCCC has provided the potential to increase the total number of patients cared for at home. However, without before and after quantitative time and motion studies, we cannot confirm this.

5.5.2 Family carers released from full time caring role

Once a good care package is in place, family carers can interact with their dying loved one differently and focus on offering emotional support.

It's enabled me to sit back and just be there...and hold her hand. (Family carer MB)

Family carers were also able to take a break.

The last six months, he [husband] didn't go out at all and then the last couple of months, he was in bed downstairs, you know, and that's where we started having, you know, the sitters from Marie Curie and we also had some from [Hospice]...so that I could, you know, get out and do a bit of shopping and, you know, a number of hours rather than sometimes you've got a sitter and they're only here for about an hour. (Family carer WJ)

5.5.3 Perception of 'helicopter' view and control

One staff member from the NSCCC also stated that she believed that the NSCCC had a 'helicopter' view and had more control over spending. However, given that community and hospice nurses can still organise packages of care and only about 1 in 7 palliative care patients are coming through the NSCCC, this sense of oversight and control may be more illusory than actual. Nonetheless, because the NSCCC sits within the Single Point of Access team, the team is in a better position to query unnecessary spend from potential duplication of effort.

Things crop up or we have queries in and we say, 'Oh yeah we know about that patient'. It could be from somebody completely different, like a social worker. And we say, 'Oh yeah we already know that patient and we're dealing with it'. And then of course we'll say, 'Well why are you getting involved?' And they'll say, 'Well because we've been asked to go and put a stand aid in'. And I'm saying, 'But they're fast track and dying. So why would you want to go out and do an assessment?' (NSCCC IF)

5.5.4 Perception that more complex cases referred

We received a report that the success of the NSCCC in helping patients to die in their place of choice has led to greater confidence of professionals in using the NSCCC for more complex cases.

We had a GP the other day phone up the coordination centre from Weston to say, 'I've got a lady in a nursing home and she wants to go home, you can't do anything about that, can you?' I went, 'We possibly can, what's the situation?' We talked about it, I went and saw her, did the fast track, everyone was like, 'She won't go home, we can't get her home,' and the nursing home was saying, 'She'll never manage, she'll never manage.' Just by doing some simple things, like overnight she was being toileted every half an hour, we put a catheter in. We got her home and she died four days later. The GP later then phoned back and said, 'I didn't think we'd do that, I was just phoning thinking I didn't know what to do with it, I'll push it to them, and you did it.' So that I think for him, he was just passing the problem he felt, but the problem was actually resolved and sorted and the lady died where she wanted to die. (NSCCC BZ)

5.6 What are the unintended consequences?

Those families that have had both care agency staff and Generic Support Workers prefer the Generic Support Workers. This can be difficult if the Generic Support

Workers are not available and the family does not want care agency staff, as the family is not convinced they will get as high a level of service.

5.7 What do family carers think?

Two members of the NSCCC staff recounted how family carers had got in touch with the NSCCC to thank them. The Generic Support Workers in particular received thank you notes and gifts. All of the family carers and the one patient interviewed were universally grateful for the Generic Support Workers, with one family carer calling them “earthly angels”.

The thing that I have felt very humble about and very grateful for was the level of absolute dedication and almost love and affection that's shown by these girls...My sister and I have been really grateful for the help and the support that we've had from them all, just tremendous...They almost became family friends almost, it was that way. (Family carer GS)

I couldn't have managed without them [GSWs], I couldn't have managed without them, without the confidence that I knew they were coming in...And I was asked, would you like more help in the evening, just to get him undressed, you see? And I could manage, actually, but it made it easier, made it easier for me. (Family carer MP)

I think they are a lovely group and they do a wonderful job both for the patient and for the relatives, I would like to stress that point...They will chat to you and help you to relax...a little bit of counselling as well.. I think it's very good, on the whole their attitude towards the relatives is very good. (Family carer CJ)

They [GSWs] were actually here when [my husband] died and they dealt with him and they were so, they were really lovely. I can't praise them enough. (Family carer Mrs P)

Family carers also reported that the Generic Support Workers operated well together as a team and were familiar with the patient's needs. Because the same care workers came in regularly, they also got to know the family well.

They [GSWs] all seemed to know what was going on and maybe it's because they all came in regularly and they all knew dad and they could keep an eye on him and knew what was going on. (Family carer PS)

I think the continuity of the same people coming all the time is good...it's a much smaller team so everybody's got to know each other. (Family carer NG)

What's been nice is it's all the same team [GSWs], so mum's not having to deal with different people every single day. There's a team of six or

eight...coming in all the time...I know all their names and mum does as well.
(Family carer MB)

They've [GSWs] got to know us... because it's the similar teams that come.
(Patient QQ and Family carer LQ)

5.8 What helps to make it work?

5.8.1 Co-location with the Single Point of Access team in open plan office

The intention of the programme developers with co-location was to increase the chances of early identification of end of life care patients. As one participant mentioned, the co-location of health and social care professionals needs to be thought through carefully to make it work.

I think single point of access is tricky depending on where you drop it. It's that communication, how social and health communicate because if you can't get that working you're going to have big hurdles and every Trust, every area is so different, that needs to be lit up very carefully I think. (NSCCC BZ)

We had presumed that this communication would occur through electronic alerts or some other systematic procedures. Instead, we found the benefits of co-location arose from the layout of the office premises. Both NSCCC and Single Point of Access staff commented that the open plan office where they could see their colleagues and be reminded to look out for end of life care patients coupled with regular multi-disciplinary team meetings increased the chances of cross referral. Moreover, instead of telephoning outside the building to hand over appropriate cases, they could now just cross the room which saved time. Given that several Social Services professionals purposely sought out the evaluation team to pass on these positive views, we can assume that they perceive the NSCCC to be a valued addition.

5.8.2 Having the right staff on the NSCCC team with regular updates

Two NSCCC staff members mentioned the importance of good communication skills for all staff members, including the administrators. Staff also need to be flexible, able to re-prioritise in a crisis, and capable of coping with challenging situations. One NSCCC staff member said that the Generic Support Workers should have good boundaries to work with the families, otherwise Generic Support Workers may provide too much support and get "burnt out". In her experience, Generic Support Workers with a health background have an advantage, in the context of these demands. NSCCC staff also have to work well under pressure with uncertainty and have a good sense of humour. Moreover, in this more in-house model, it was thought important to have skills within the team to carry out fast track assessments, especially for highly complex cases.

And as the work is so emotionally demanding, two NSCCC staff made the point that team members require ongoing support and monitoring. One mechanism for this is

provided through team briefings, which take place three times a week. Generic Support Workers are key to these briefings, as they are able to update other NSCCC staff on patients' circumstances and any changes in their care needs. Initially, these briefings were carried out by telephone, but face to face briefings appear to work more effectively.

5.8.3 Access to flexible in house support team (Generic Support Workers)

The Marie Curie reports (Phase II and Phase III) note that there was considerable discussion about where to base the Generic Support Workers: with the community ward teams or at the NSCCC. The final decision was to locate the Generic Support Workers in-house at the NSCCC, because otherwise, as two NSCCC staff members commented, the Generic Support Workers might have been absorbed and diverted from end of life care service provision. As a result, the NSCCC has an in-house team of professional care workers whom they know well and can trust. We did not collect data from community nurses to obtain their views on locating the Generic Support Workers within the NSCCC team.

Three NSCCC staff members said that the flexibility of the Generic Support Worker team, in terms of the timing and length of visits, willingness to re-prioritise quickly, and the capacity for night care, means that the NSCCC is able to respond swiftly, appropriately and flexibly to changing care needs as they arise.

We had a lady this week who's only young, 52, and her husband, we were already seeing her as a Generic Support Worker service, and she deteriorated in the week and there was a bit of a mix up with the night sits. One of our Generic Support Workers was able to do the night sit at very, very short notice. That's because we've got a flexible team. Without a flexible team, I think we'd really struggle with it. It was an unusual situation, but that lady, she'd have ended up in hospital if we hadn't have got someone in there because she died in the night. (NSCCC BZ)

The importance of this flexibility was corroborated in the family interviews (relevant extracts are cited later in this appendix).

As usual with a new service, managing supply and demand was difficult. At the start, the Generic Support Workers took on all requests, which meant that sometimes they were delivering care to those who lived for months instead of those in the last few weeks of life. To address these issues, the incoming lead manager of the NSCCC has set up a regular review process with the aim of passing non-eligible patients to brokerage sooner thus freeing up the generic support team for more terminal patients. However, as this change was brought in after March 2012, we cannot comment on its impact.

5.8.4 Having time to pull together good quality care packages

In observing the NSCCC, an evaluation team member noticed that the organising of care packages was much more time consuming than immediately apparent.

During discussions with [fast track co-ordinator] and hearing her on the phone, it is apparent that significant time is required for phone calls with relatives, to go through details of care packages, evaluate their effectiveness, as well as their costing implications. Such time is sometimes difficult to find with all the other demands on [fast track co-ordinator] and the team.

(Observation NSCCC, 21.12.11)

Moreover, we were told that without sufficient time, inappropriate care could be put in place.

5.8.5 *Raising their profile at weekly meetings with the hospice*

To encourage the hospices to use the NSCCC and to find out about patients currently not known to the NSCCC, the original lead nurse and fast track co-ordinator attended a multi-disciplinary meeting at one hospice once a week. They believed that this led to a strengthening of the relationship and the increased likelihood of hospice staff contacting the NSCCC for equipment and advice about possible fast track patients. The NSCCC attempted to arrange a similar weekly meeting with the other hospice in the county but this did not happen as they “work slightly differently”. (NSCCC staff member CK) The service mapping exercise suggests that the NSCCC receives more referrals from the hospice where they attended meetings regularly than from the other hospice on the patch. (see ‘across the initiative’ chapter)

5.9 *What makes it more difficult?*

5.9.1 *Patients not coming into contact with NSCCC*

As stated previously, 15% of those potentially with palliative care needs, who died in the six month study period, came into contact with the NSCCC and 30% died at home. Given this discrepancy, we identified several reasons why patients dying at home do not necessarily come into contact with the NSCCC:

- *Perception that the NSCCC is only for fast track patients.* All the hospice and community ward clinical staff we interviewed said they only used the NSCCC for fast track patients. This was not the original intention, but given the volume of work, the limited staff at the NSCCC, and the location of the fast track co-ordinator within the NSCCC team, the service may be seen as exclusively for fast track referrals.
- *Community and hospice nurses can and do still organise packages of care themselves,* for example they can directly order equipment through Medequip. The lead from one community ward mentioned that they mainly use the NSCCC for equipment, as they have their own support workers, while another mentioned that they use the NSCCC primarily for the Generic Support Workers and not equipment.
- *The hospices have alternatives or do not need to use the NSCCC.* A clinical staff member from the hospice in the north of the county said that they tend not to use the NSCCC, as equipment would be booked by the district nurses. Moreover, a staff member from the hospice in the south said they have

historically managed organising the care packages rather than the district nurses; it is difficult to change these patterns. The hospices have access to night care workers through Hospice at Home.

- *Nurses do not see the advantages in having care organised by the NSCCC.* Given that both community nurses and hospice staff have other ways and means to access the care and equipment needed, two nurses stated that they do not see the purpose of involving a third party.
- *Perception that use of NSCCC involves more paperwork.* A hospice nurse implied that there were “inconveniences” in using the NSCCC because of the paperwork. Another community nurse mentioned that the request form has too many questions, as this form was adapted to elicit information to order night care workers and ensure that the patient is known to the whole system.
- *Procedures to book night nurses – extra step added.* One hospice nurse said that although she would like to keep the NSCCC, she thought the previous procedures to book care were quicker. Before when a patient’s condition ‘dipped’, the hospice community team could contact their own Hospice at Home colleagues directly to set up night nurses, do the paperwork, and then ring the district nurses. With the current system, however, the hospice needed first to contact the NSCCC to check availability of the Marie Curie night care worker. If the NSCCC does not have night caring staff, the hospice nurses then have to go back to their own hospice to request night care workers. So this staff member’s perception is that an extra step has been added to the process.
- *Perception that the responsiveness of the NSCCC service may be variable.* One nurse thought that the NSCCC was short staffed; another mentioned that sometimes the NSCCC does not pick up the phone. A further community nurse said that sometimes NSCCC staff would make repeated call backs to her before the package was put in place.
- *Alternative services are more flexible.* One hospice nurse said that night care workers can only be booked for one night at a time through the NSCCC whereas we were told Hospice at Home night carers can be booked for up to three nights.
- *Little follow up information given to referrer after request received.* Information on who made the original request was not recorded routinely and consequently the NSCCC did not have mechanisms to update the member of staff who had made the request. As a result, one district nurse said that she spent a lot of time chasing the NSCCC for “updates and answers”. A hospice nurse concurred. A further hospice nurse said that after requesting delivery of medication through the NSCCC, she tends to ring the district nurse to ensure that the district nurse knows who made the original request. As a result, professionals might not be using the NSCCC because they may have concerns that the request has not been acted on.

5.9.2 *Lack of night care workers, Generic Support Workers and back office staff*

NSCCC staff and those outside the organisation, such as community nurses, believed that NSCCC is currently operating at full capacity. If they were to pick up more referrals, specifically non-fast tracked patients, then more NSCCC staff would need to be employed. One staff member stressed that when the lead nurse and the fast track co-ordinator (who is employed 0.7 WTE) were both out of the office, there was no one to approve fast track applications, which resulted in delays.

With regards to night care workers, the addition of three night care workers that rotate, so that one night care worker was available every night through Marie Curie was a boon and so the situation has improved. However, we received conflicting information. Community and hospice nurses, as well as some family carers, mentioned the shortage of night care workers, yet a commissioner said that the budget for night care workers was often underspent due to lack of district nurse requests. A NSCCC staff member also said the NSCCC has some reluctance in advertising night care workers to family carers, as they do not want to raise expectations that subsequently cannot then be met. So we are not sure if there are not sufficient night care workers or if they are just not advertised.

We also received accounts from NSCCC staff of how a lack of Generic Support Workers jeopardised the quality of the service at a critical phase.

We would like to have more of them [GSWs]... I think we need 10 to make it very workable rather than sort of workable...for example today, they've [GSWs] been visiting a patient of ours...all of a sudden last night he completely dipped and he looks as though he's really entering the terminal phase. And tonight I've had to get two bank staff that don't know the family, don't know the patient, and they're having to go in because there are not the support workers. And for me it's an absolute travesty today that that's happened, for family, and for the patient...this is just not good enough because we haven't got enough staff to do what we're supposed to be doing, seeing the patient through their whole journey. And at the critical moment today it's all fallen down. (NSCCC IF)

Family carers also noticed the shortage of Generic Support Workers.

I thought well I'll just ring up and make sure they're (GSWs) coming...Well they were in a fix, they'd had two or three very poorly patients and they were short of staff and one of the managers, I don't know whether you've met [CCC manager]. She had to come and help and they didn't get here until quarter past twelve...I can't stress too strongly that they need the support and they need more support, they definitely do. I think they are under-staffed, they can never calculate how many people they are going to be dealing with from day to day. (Family carer JC)

Without funding for 10 Generic Support Workers as originally envisaged, the NSCCC is currently unable to meet the aspiration of having care workers available 24/7.

5.9.3 Concerns about brokerage

When the NSCCC does not have capacity to meet care needs with their own in-house team, they have to call on brokerage for night staff and care workers. The NSCCC staff said that brokerage were helpful and in an emergency would proactively make calls on their behalf, but there can be long delays before an agency picks up and responds to the request.

We haven't got control over brokerage packages. We send it to them and we're just waiting for them to come back to us...their processing is they email out the requests, and you wait for agencies to email them back. ... When they've had no response and I'm desperate, I've resorted to phoning agencies, brokerage have been aware, but I've phoned them and said, 'Look, we're really, really desperate'. And then they've come up with somebody. It's that personal ... an email doesn't do anything. (NSCCC staff BZ)

Interestingly, we discussed the advantages and drawbacks with brokerage staff and were told that sending out a blanket e-mail or website message was the most equitable way of advertising the work, as all care providers could then provide the package. However meanwhile, NSCCC staff believe that patients could die with no care in place.

The request to brokerage has to be specific and there is a lack of flexibility, which may be difficult when the NSCCC does not have access to all of the information and have not directly spoken to the patient or family carer.

When you go to brokerage, you have to be specific as to times. You have to state, 8.00 am for half an hour. But sitting here in the coordination centre, we only can go by the information we have received from our referrals. So unless we went out to visit each of our people that we have referred to us, we couldn't say specifically, oh, that person wants somebody at 8.00 am. (NSCCC staff CK)

Concerns were also expressed about unknown characteristics of the care agency staff sent into homes, particularly their youth and level of experience. Such features sometimes compared unfavourably with the Generic Support Workers, whose attributes were well known, respected and valued.

It concerns me sometimes if we go out to brokerage, their level of skills and expertise. Sometimes they're young girls, I'm not knocking because of age, but sometimes, and eighteen year old, nineteen year old, who's just started in caring, how do they deal with death and dying in somebody that's young? They haven't had that experience and it's difficult for them. That's going to transfer onto the family how they cope. The brokerages, the agencies are very good, but we don't know what those individuals' experiences are and how they're going to cope in that situation, where[as] our Generic Support Workers, we know their skills, we know their strengths, we know their level of

training because we've been doing it and we know they'll cope in that situation. I think it just gives a better experience. (NSCCC BZ)

We also found that as there is limited feedback to the NSCCC from patients and Family carers who received care packages organised by brokerage, care packages may not be updated as needs change.

If JW had known about the CCC, she may have been able to access more night-sitters, thereby relieving her of care responsibilities at night and, possibly, enabling her to keep her husband at home for his final week, rather than see him move to the hospice. One possible reason why JW was not so closely involved with the CCC may have been because the GSWs were not involved; care was provided by an agency, limiting the potential for feedback to the CCC of her changing needs. (Researcher's notes following interview with family carer WJ)

5.9.4 Delays in provision of equipment

We received reports from two Generic Support Workers that delays in obtaining equipment can be frustrating and sometimes embarrassing.

[GSWs] raised the issue of slowness in provision of equipment, such as pressure mattresses and recliner chairs, which can greatly relieve problems and help patients remain comfortable at home. Sometimes patients can wait weeks, which is a critical factor when at the end of life. One Generic Support Worker told me she had initially suggested a recliner chair to Mrs R, who is finding it difficult to get herself up from her existing chair, and had subsequently put in a request to the Occupational Therapist, who was happy to support the request. However, four weeks later nothing had happened and the Generic Support Worker said she is feeling guilty for mentioning the chair and then being unable to follow it through in a timely way, although provision is beyond her control. (Observation, Generic Support Workers, 21.2.12)

5.9.5 Poorer liaison with hospitals out of county

North Somerset patients attend many different hospitals, including several outside of North Somerset county boundaries. This can make organising care difficult, as reported by this family carer.

He'd decided that no, he wasn't going to have any more chemo at all, and that was it and he therefore wanted to go home...we're now sort of four days on and they've said 'yes he can probably have CHC funding, no he can't, we'll try and get you home, no you can't, we need the bed, you've got to go off to a nursing home and we'll find you one'. So you can imagine it's very upsetting for everybody. So it was then sort of confirmed that no he wanted to go home, Friday, she [social worker] then called me in the afternoon and apologised and said that yes dad is available for CHC funding...So a whole week later, by

the end of the Friday, where have we got to? We've got to yes he is available for CHC funding, it's not going to be the social worker that's going to be dealing with it, it's going to be somebody else, it's going to be the discharge nurse, and dad's still in hospital...I saw my dad in the evening on Monday and he obviously wasn't very pleased...He said, 'they're talking about paperwork and I'm talking about breathing'...and the discharge nurse then said once we'd signed all the forms that she couldn't do anything at all because of where dad lived and because dad lived in North Somerset all his CHC funding would have to be processed by North Somerset...[as] they were a hospital in Bristol so she dealt with a different area... [CCC co-ordinator] then called me and I said, 'you know that this has all been going on since the previous Monday, so almost going on for two weeks now'.. she then phoned back later, and said 'yes we're making arrangements for Dad to come home tomorrow' so that was fantastic, it's like 'oh thank god, you know, somebody's at last listening and getting something moving'. (Family carer SP)

Several staff members of the NSCCC mentioned that they knew that discharge packages via the hospitals should and could be improved, but thus far had not had sufficient time to help address this.

5.9.6 Lack of access to up to date electronic information

To make decisions about the eligibility for fast track funding, the fast track co-ordinator needs access to up to date information about the patient. The addition of 'Toughbooks', which are hand held tools that community nurses can use while in patients' homes, would help to ensure that the available information is current. RIO, which is widely used by community nurses, was described as a "godsend" because it makes it possible to track patient deterioration. However, RIO can be "clunky", with technical problems that make it unreliable. Consequently, staff have got disheartened and important information may not always be added to RIO records. Currently, the NSCCC is overly dependent on paper but will soon become paperless because of the lack of space in their new premises. The long term goal is for the NSCCC team (i.e. fast track co-ordinator, Generic Support Workers) to detail their latest interactions on the 'progress' section of RIO, so that everyone accessing RIO will have the most up to date information.

5.9.7 Budget restrictions

The protocols and allocation of the budget also caused obstacles. For example, fast track patients who receive help from the Generic Support Workers do not have to pay, as funding comes from the NHS. But those with an income over a certain threshold who have personal carers supplied by social services do pay privately. This has caused difficulties in the past when Generic Support Workers were provided to patients who then lived on for months while other patients in similar positions paid for their own care.

Another budget issue is around authorisation, as the former lead nurse was only authorised to order equipment for care packages up to £200. She was told that at Band 7, she did not have sufficient authority to order more expensive equipment and so she had to seek out other Band 7 personnel who did have this authorisation. This would result in delay. The newly appointed Band 7 lead nurse now does have full authorisation.

The NSCCC staff also received confusing messages about spending. The NSCCC felt penalised for their success in getting more patients fast tracked as they were asked to slow down referrals because their budget has been over-spent.

I think we've been doing really well because the Fast Tracks have doubled the number of referrals we have in a month. But there was a meeting a few months ago to say the Fast Track budget was overspent and how could we look at stopping some of these referrals and look at them more carefully, not accept them for Fast Track. Back track a bit on what we're doing. Which I think is completely not what we're here for. I think if you're setting up a service, you have to actually budget for it. Apparently, the Fast Track budget was set last year and it wasn't increased. Well, it's bound to increase, isn't it? If you're setting up a new service and you want people to die at home?
(NSCCC CK)

The increasing reluctance to award fast track funding was noticed and mentioned by one hospice staff member using the NSCCC and has caused some concern.

5.10 What would make it work better?

Possible improvements to the NSCCC were:

1. Extending opening hours to include weekends (suggested by a district nurse).
2. Better Coordination of withdrawal of services after death (suggested by a GP).

A patient, a fifty year old died at home about two weeks ago and it was really slick, the only kind of criticism of it was that...when a patient dies the information seems to take a while to filter through so that they took like three days to get the bed out and it was a very small house and the beds were in the conservatory and it was all a bit traumatic for everyone seeing this empty bed lying there and...then someone tried to drop off some equipment the day after he died...I think that could be that would be nice for the relatives if that could be a little bit slicker. (GP GF)

3. More proactive communication with those referring, immediately after the care package is first put in place. The newly appointed NSCCC manager has already identified more proactive communication as a service objective.

5.11 Does it duplicate something else that's already there?

Several respondents said that the NSCCC is a unique service. A hospice nurse said that although all of the services are available individually, the NSCCC generally has better access, provides more continuity and works well with Hospice at Home.

However, the Generic Support Workers can be replaced by care agencies organised by brokerage. Professionals tended not to notice a difference between care agency staff and the Generic Support Workers, and one nurse stated that both were of a good standard. However, the family carers interviewed were clear that differences existed. They perceived that the Generic Support Workers provided more psychosocial support in their care, generally had more time and appeared less pressurised.

With agencies they come in specifically to wash and that is their remit...And that is a totally different attitude from the end of life team [Generic Support Workers]... [who] are supportive. They are very supportive and I think if one were very upset they would be able to help you a little. (Family carer CJ)

They [Generic Support Workers] took over from a private contractor that was doing the job before, although they [private agency carers] were reasonably punctual...they had to be quick, they had to go and they seemed a little bit pressured and they weren't able to give the sort of care that the [Generic Support Workers] are providing you know...They've been a very good team, they can't always be on time, and they can't in fact give precise times because of course they...won't rush, which is good. (Family carer GN)

5.12 How do the evaluation findings fit with the original hypothesis?

The original hypothesis for the North Somerset End of Life Care Co-ordination Centre was:

The NSCCC provides someone to speak to alleviate anxieties. NSCCC staff are already up to speed because they have access to relevant databases e.g. health and social care. They can organise equipment and get things organised with one call. NSCCC staff have knowledge about what equipment needed e.g. new bed. The North Somerset model is hugely replicable because the 'back office' has social worker and mental health worker [through larger Single Point of Access team] so will pick up those who may inadvertently slip through. The Single Point of Access team can capture whole system. The problem with many services is that they are dependent on people referring and if professionals don't know that the patient is at the end of life, then there is no referral. Patients may be known to social care long before health professionals, so a single point of access means services get in early.

This leads to outcomes around choice of care, trust, holistic system, resources, empowerment, conversations and information.

This hypothesis emphasises the anticipated benefit of co-location of the NSCCC with the Single Point of Access team would be greater access to multiple sources of electronic information. In actuality, we found the advantages of co-location came from the shared open plan office, whereby staff were regularly reminded, visually and verbally, to identify and pass on palliative care patients to the NSCCC. Earlier identification did occur, but in an ad hoc rather than systematic manner, usually when a member of the wider Single Point of Access team found that the usual service response did not fully answer the presenting request, the issue was clearly health or palliative care related, and the Single Point of Access team member had enough time to probe the referral and consider the case. However, the universal opinion from both NSCCC and the wider Single Point of Access team was that the co-location of the NSCCC within the Single Point of Access team was beneficial.

5.13 If this were implemented somewhere else, what are the key ingredients?

The key ingredients to making this 'in house' service model work are:

- Enhancing flexibility by having the right team with in-house fast track co-ordinator for rapid assessment, in-house care workers to deploy in crises (i.e. emergency night sits) and directly managed access to night care workers.
- 'One stop shop' for fast track applications and organisation of care packages.
- Rapid assessment of fast track applications with more than one nurse assessor on the team and good links with Continuing Healthcare.
- Flexible administrative team with good communication skills.
- Co-location with Single Point of Access team in open plan offices to foster good communication across disciplines.
- Excellent leadership from manager with community nursing background who understands community service provision, manages staff well, is methodical and personable, with excellent communication skills.
- Putting care packages in quickly and at the appropriate time.
- Good communication flows between professionals either electronically or verbally (ie via RIO, open plan office, regular whole team meetings with Generic Support Workers and wider Single Access Team).
- Good relationships with sources of referral e.g. community and hospice nurses.

5.14 Conclusion

The NSCCC, including the Generic Support Workers, offers high quality, well co-ordinated services of great value to family carers. Overall, professionals also appreciated the NSCCC, as care packages are organised speedily and efficiently, thereby freeing their time. Quantitative data suggest that proportionally more NSCCC users died at home than non-Delivering Choice users with fewer hospital admissions and A&E attendances in the last month of life. Thus, these promising findings suggest that the NSCCC has successfully met its key outcomes.

Delivering Choice programme developers believed that co-location with the Single Point of Access team would make a significant difference. Our findings suggest that although co-location was important, the 'in house' and 'one stop shop' elements of this model were key. The NSCCC team includes three nurses, including the fast track co-ordinator, with access to good quality electronic information via RIO, who can rapidly assess and make decisions on fast track applications. They also have an in-house team of Generic Support Workers whom they can deploy flexibly for emergencies, such as sudden night sits, as well as direct and prioritised access to the Marie Curie night care workers. Thus the inherent flexibility in this model to promptly and appropriately respond to rapidly changing circumstances and needs appears to be crucial. Moreover, those referring to the NSCCC need only go to one place to organise fast track approvals and initiate the organisation of care packages.

The challenge for the NSCCC is now to build on its success by extending its reach. Given that 50% of those accessing the NSCCC die within eight days of first contact, finding ways to identify end of life care patients and set up care packages earlier is a priority. Moreover, as currently two thirds of NSCCC patients die from cancer yet only just over a quarter of North Somerset residents die from cancer in total, the NSCCC could also expand to include a greater proportion of non-cancer patients. The quantitative data suggest that the NSCCC is effective in reducing hospital service usage and its related cost, so greater benefits are likely to accrue the earlier that the NSCCC has involvement. Furthermore, because they are part of a joint health and social care team, the NSCCC is well placed to introduce mechanisms for earlier detection of patients. Overall, the NSCCC has made very good progress in delivering a high quality service whose patients are less likely to have emergency hospital admissions in the last month of life.

5.15 Recommendations

1. Develop mechanisms for identifying early end of life care and non-cancer patients, perhaps through Care Connect or Professional Assessment Team.
2. Collect source of referral details and set up systematic feedback to reassure professionals that request met and as a reminder of the existence of the NSCCC. These data can also be used for marketing.
3. Consider increasing the fast track budget to meet the increasing need for care packages in usual place of residence.
4. If the objective of earlier identification receives greater priority, then further funding for the front office is needed.
5. Review the criteria for allocation of Generic Support Workers to prioritise families and patients with the highest needs i.e. patients with little family or community support and/or patients with more challenging symptoms (e.g. faecal incontinence).
6. Increase the capacity of the Generic Support Workers to the original 10 WTE, if further evaluation finds that they are better targeted.

7. Find out what needs to change so that families have greater access to night care workers. Consider the allocation of an occasional night care worker earlier in the patient trajectory (ie 5-6 weeks before death).
8. Brokerage to consider advertising requests end of life care package by telephoning care agencies rather than sending out e-mails and messages on the website due to necessity of putting in care as quickly as possible.
9. Set up systems to capture unmet need and improve the record keeping on allocation of the Generic Support Workers.
10. Increase marketing of the service to community nurses (see North Somerset map in Chapter 11) to identify community wards with low NSCCC use.
11. Carry out education and liaison work in hospitals to increase referrals of non-cancer patients.
12. Look at systems for retrieving equipment to see if they are fast enough.

Somerset interventions

6.0 Discharge in reach nursing service

Outcomes for patients and professionals accessing the Discharge in reach service

- Low hospital re-admissions.
- High family carer satisfaction.
- Perceptions of more co-ordinated care.
- Higher proportion of non-cancer patients accessed (40%).
- Perceptions of greater likelihood of non-hospital death for patients on their own.
- Hospital staff more knowledgeable about and confident in end of life care.
- Hospital staff more willing to question unnecessary treatments.
- Links between acute and community sector strengthened.
- Potential hospital complaints averted.
- Potential unintended outcome – ‘off loading’ of complex discharges to Discharge in reach service and therefore potential de-skilling of staff.

What helps to make this intervention work

- Ensuring that the Discharge in reach nurses support and challenge professionals, patients and family carers.
- Adapting the model to the characteristics of the hospital (i.e. more targeted in larger hospitals).
- Placing the service at the ‘front door’ of the hospital for rapid turn around.
- Enshrining the proactive in-reach approach.
- Employing highly skilled nurses.
- Dedicated time.
- Building relationships with staff in hospital and community.
- Good community service provision, with co-ordination centre and community nurses in place.
- Access to up to date patient information.

What stops this intervention from working

- Professional territorialism and personality conflicts between key staff.
- Poor role definition and boundaries resulting in the absorption of this role into already existing discharge and palliative care teams.
- Care packages set up too early or that break down.

6.1 Introduction

The provider of the Somerset Discharge in reach nurse service was St Margaret's Hospice and Marie Curie Nursing Service working in partnership. The six month start up cost was £47,414 and the initial annual cost for the two nurses was £86,478 for 2010-2011. The post was originally funded by the local Primary Care Trust and they are now funded by their respective hospitals. One Discharge in reach post was located in a smaller hospital and went live in June 2010 while the other was initially launched in April 2010, failed and re-launched in January 2011 from the larger hospital. One post operates 30 hours a week, from 8.30-4.30 on Monday, Tuesday, Thursday and Friday and the other operates 37 hours a week from 8am-4pm five days a week.

To evaluate the Discharge in reach service, in addition to quantitative data, we carried out 43 interviews, eight of which were with family carers and 35 with professionals including hospital clinicians, community and hospice nurses and the Discharge in reach nurses themselves. We also carried out four observations – two for each hospital – at two time points. In addition, we analysed Crosscare data for the Discharge in reach service to look at patients with multiple contacts and extracted information from the three Marie Curie Somerset reports and the May and August 2011 Board papers.

6.2 How is it supposed to work?

Previously, decisions regarding discharge were sometimes made without consultation with professionals, patients or family carers. There were also delays in appropriate assessments (by district nurses, social workers, care homes etc.), obtaining equipment and putting appropriate care packages in place, ordering medication and transport. (Phase I report)

The supposition was that having a named co-ordinator at hospitals would address these difficulties, free up the time of district nurses and bring about a speedier and higher quality discharge process. This, in turn, would have an impact on avoiding future hospital admissions while also reducing length of hospital stay. So, the two key mechanisms employed by the Discharge in reach nurse service to bring about change were:

1. Stopping unnecessary hospital admissions by turning around patients when they first present at the door.
2. Facilitating faster discharges of those who are already in hospital.

The objectives of the Discharge in reach nursing service were to:

- Facilitate and resolve barriers to individual discharges.
- Ensure multi-disciplinary proactive discharge planning.
- Act as a resource for professionals, patients and family carers and ensure an integrated and co-ordinated discharge.

- Ensure better communication and provision of information with community services both prior to and at the point of discharge and the handover of patient information to the key-worker.
- Identify and develop fast and standardised discharge processes for the transfer of palliative care patients from hospital to their preferred place of care. (Phase II report)

Having been in post for over 18 months, the Discharge in reach service has now added another objective – educating staff on good end of life care practice. Within the Marie Curie literature, unlike other services, we did not find explicit outcomes for the Discharge in reach service.

Initially, the most important aspect of the Discharge in reach nurse service was its proactive in reach component. Unlike the discharge liaison teams, who wait for referrals to come to them, the Discharge in reach nurses were expected to proactively find their own case load by attending ‘Grand rounds’ where patients over the previous 24 hours are reviewed, from A&E and Medical Assessment Units and through conversations with hospital staff. As both services are now well established, the Discharge in reach nurses report that proactive in reach is less crucial.

6.3 How does the Discharge in reach service actually work?

6.3.1 Support and challenge

The Discharge in reach service advocates for patients and family members who are facing difficult choices with little knowledge or experience of the implications. The Discharge in reach nurses know how the system works, what needs to happen, what might happen and how to make the right things happen, once a decision has been made. Although this approach helps family members and patients make more informed decisions, it may mean that patients do not die at home, once the full implications of a home death are discussed.

What triggers the Discharge in reach service to come into action is:

- Alert from community or hospital staff that potentially appropriate patient has come into hospital, possibly because the patient has complex health needs or because the staff member is at a loss as to how to proceed.
- Proactive identification by the Discharge in reach nurses of those who:
 - Have been admitted overnight “inappropriately”.
 - Have been “stuck on Medical Admissions Unit but really want to get home but have to wait”.

The questions that the Discharge in reach nurses ask in order to identify relevant patients are:

1. Does the patient want and would there be any benefits from further treatments?
2. Does this patient want to die in hospital?

If the response to these questions is 'no', then this is a suitable patient for the discharge in reach service.

The Discharge in reach nurses both support and challenge patients, family members and staff. The support function is explicit in their brief (see objectives above), however the 'challenge' aspect is less obvious yet crucial. Without challenge, the Discharge in reach service would be much less effective. For example, the Discharge in reach nurses explore family members' half formed assumptions of taking care of the dying by articulating potential real life scenarios.

And I said, 'She's taking him home to look after. Has anybody sat and talked to her about what it's going to be like and if he wakes up at three o'clock in the morning and he's breathless? How's she going to manage with that and has she got the phone calls [out of hours numbers]?'...Because what I've found since I started doing this job [is] that a lot of patients say they want to go home and relatives are frightened. Some are fine, some say, yes, that's what they want to do. Some do it because that's what their loved one wants but they don't particularly feel that they're going to be able to do it. And some of them are absolutely petrified of doing it. So [it helps] if I go in without the airy fairy stuff, and say, 'If you're thinking about going home this is what I can provide, this is what we can do for you and this is how much help we can give. You can take as much of that or as little of it as you want and if you only take a little and you find later on you want more then more can be introduced. But there are going to be times when you are going to be there alone unless you've got friends or family that are going to be here'. (Discharge in reach nurse)

Moreover, the Discharge in reach nurses also challenge hospital staff. For example, the Discharge in reach nurses bring around hospital staff reluctant to tackle end of life care discussions. Most importantly, doctors and nurses are trained to keep people alive, so a critical role for the Discharge in reach service is to help clinical staff recognise when treatments should stop and patients need to be allowed to die. This is a major cultural shift.

There was a lady came through A&E who had fallen at home, she was already at home for palliative care with her husband and she fell so GP thought she ought to come in and just be checked over and the husband said, 'Look, we want to go back home as soon as possible if there's nothing wrong with her leg.' So they x-rayed it and there's wasn't anything wrong with her leg but she was in hospital, we'd done all the bloods and everything. They found that she had a HB of five. By the time I got back to her, because I'd had to go up and see other patients, she was on MAU [Medical Admissions Unit] and about to have a blood transfusion and everything else that that entailed. And it was clearly written that that isn't what she wanted. She'd been through all of that and she wanted palliative care. But, at the same time she was at home needing symptom control as well. So I managed to speak to the consultant and say, 'When you go and see her, can you bear in mind that this lady is palliative care? And actually, to the best

of my knowledge, doesn't want a blood transfusion and if she had been at home and not had the fall you wouldn't know her HB was five.' And at the same time her daughter phoned the help line at the hospice to say that they're going to give mum a blood transfusion, she doesn't want it. And so she didn't have it, we sorted out her symptoms, put her on a syringe driver, got her back home and she died at home three days later. Whereas, if I wasn't in post that wouldn't have happened. (Discharge in reach nurse)

I was actually shadowing [Discharge in reach nurse] that day and she [the patient] was on the A&E trolley. And [the Discharge in reach nurse] said, 'Why are we doing all these tests? This lady wants to go home, there's no point in doing that, let's get her back home'. So she gave support to the nursing home, told the district nurses that this was happening and she [the patient] virtually turned round and went back not quite in the same ambulance but back out of A&E and didn't even hit the ward. (Manager LR)

6.3.2 Keeping an eye out

As part of their advocacy role, in addition to supporting and challenging hospital staff, family members and patients, the Discharge in reach nurses 'keep an eye out' for patients who are not expected to die immanently, but may be palliative care patients soon.

I have another lady who came in because she'd fallen at home so she ended up on the orthopaedic ward but she already had a known cancer of which she had been told at Christmas that she'd had twelve months to live – this was last Christmas. The F1 had asked me, because he'd been on another ward and got used to my working so he said, 'I've got a lady for you. Will you come and see her?'...And he said, 'Because I've looked at her chest x-ray and it's awful.' So I went to see her and we got talking to the daughter purely because the staff nurse introduced me fortunately... But she was then seen by the geriatrician who felt that she wasn't end of life so I wasn't able to put that care in. So she's gone home to her daughter with just what Social Services can put in and I see on Crosscare that [now] she is needing symptom control. So I'm going to keep my eye on that one to see what happens. (Discharge in reach nurse)

6.3.3 Uptake and reach

From 1 September 2011 to 29 February 2012, according to Crosscare records 207 patients came into contact with the Discharge in reach nurses. Of those 207, 144 died during the study period, giving an uptake rate of 5.6% (144/2572). Taking the figure of 207, the Discharge in reach service has an average of 33 patients a month or about 17 patients a month per caseload. On average, patients came into contact with the service 17.8 days before death with a median value of 6 days (range 2-23), so 50% of the patients using the Discharge in reach service die within six days, which is the latest of all Delivering Choice services.

Almost equal numbers of men and women came into contact with the Discharge in reach service. Fifteen percent were under 70; 31.3% were aged 70 to 79; 36.1% were aged between 80 to 89 and 17.4% were over 90 years old. In terms of conditions, 60.4% died from cancer; 9% died from heart disease; 8.3% died from respiratory conditions; 6.3% died from cerebrovascular conditions and 5.6% died from dementia. So nearly 40% of the patients using the Discharge in reach service had non-cancer diagnoses, which is the highest of any Delivering Choice service.

Hospital staff from a wide variety of backgrounds (e.g. discharge liaison, consultants, ward sisters, transport managers) have extensive contact with the Discharge in reach service, as do staff from the Central Referral Centre at St Margaret's hospice who spoke of the Discharge in reach nurses being "one of us". Specialist palliative care nurses in the community also mentioned having frequent contact, mostly in the form of information exchange about a patient discharge. The district nurses interviewed had less contact with Discharge in reach nurses with only half (3/6) mentioning previous interactions. Although one Discharge in reach nurse said that she had started to work with care homes, only one of the four care home staff interviewed mentioned working with the Discharge in reach service, perhaps because these were not the care homes in contact with the Discharge in reach service.

6.4 What is the impact of the Discharge in reach service on the evaluation outcomes?

6.4.1 Co-ordinated care

We received multiple reports from family carers, hospital and community staff on the improvement in discharge processes that have come about because of the Discharge in reach nurses.

Before [Discharge in reach nurse] arrived...there'd be lots of different people involved [in end of life hospital discharges]...Not knowing how to contact certain people...No one having the overall communication skills. There were just too many people involved and then people not knowing who'd done what...So it was a bit of a mess...So when [the Discharge in reach nurse] came, not only was she the person who had the knowledge [but] also she was that stable person that knew who to contact...and do it in a much speedier timescale. (Hospital matron AU)

Community staff commented how much quicker, co-ordinated and streamlined the discharge processes now are.

[Before]... [the] discharge would be a disaster. District nurses would be picking up probably on a Friday afternoon and saying this person's been sent home and there's nothing in place. It would be running round then. Then they'd have to be organising equipment and trying to order equipment, and because of the expense then it was no, I don't think we had CHC, I can't

remember now. Well it wasn't as quick, it wasn't so fast tracked, but they would then have to order the bed, but then it would have to go on a five day wait for a bed. So there was a bit of discrepancy there, so equipment didn't get in as quickly or it would be the district nurses going off to the local hospital to try and get a commode in, just scrabble around really. (Community palliative care nurse NL)

Community staff commented that the discharges organised by the Discharge in reach nurses were of higher quality than those organised by other hospital staff.

If you know the in-reach are involved you know that discharge will be absolutely comprehensive and the best outcome achieved. I see a great difference in the types of discharges from a ward that doesn't involve in-reach because you know that all the funding is in place, the equipment's in place, all the healthcare professions will have been informed, whereas it's not the same quality from a staff nurse, with the best will in the world, because they only work on a ward. (Community palliative care nurse RM)

6.4.2 Hospital usage including re-admissions

In the last month of life, 68% of patients using the Discharge in reach service had an emergency admission and 52.1% visited A&E. Given that the Discharge in reach service is based in hospital and the initial contact tended to occur in the last month of life, these high figures are to be expected. Of the 144 patients who died during the study period, there were 98 admissions with an average of 0.8, which suggests that a few people had several re-admissions. We have robust re-admission data for 114 patients who died during the six month study period. In the last week of life, quantitative data show that 20 patients used the Discharge in reach service of whom five were re-admissions. In total of the 114 patient for whom we have robust data, 7 (6%) were emergency hospital re-admissions after their first contact with the Discharge in reach service. This low re-admittance figure is a testament to the effectiveness of the Discharge in reach service.

To explore re-admissions further, we identified patients from the total 207 who used the Discharge in reach service during the study period who had contact with the Discharge in reach service on more than one occasion over a minimum three week gap. We found 11 patients met this criterion and looked at their Crosscare data in-depth to learn more about repeated contacts with the Discharge in reach service. Of these eleven, eight patients had cancer, one had heart disease, one had chronic respiratory disease and one had Splenic Lymphoma.

Six of these eleven were re-admissions.³ The general narrative that emerged from these case studies of re-admissions was that the patient was admitted to hospital

³ Note that total number of readmissions for those that died was 7/114 whereas 11/207 had two or more contacts over a three week period. So we are not looking at the same datasets or using the same criterion. We could not look at the data of the seven who had died as the identity of these seven was anonymised by the Primary Care Trusts.

and diagnosed with a terminal illness. They were visited by a Discharge in reach nurse and the discharge was arranged for their preferred place of care. The patient deteriorated much quicker than anticipated with insufficient care or support from family and/or the community. This culminated in a crisis point where the patient had an accident or became unwell suddenly and then was readmitted to hospital. The patient was visited by the Discharge in reach nurse again to establish what went wrong and determine future appropriate place of care. This decision was influenced by whether the family member felt they could cope with the emotional and physical demands of caring for their loved one. The patient was subsequently discharged to a hospice, nursing or residential home and there was another visit from the Discharge in reach nurse prior to or after their discharge from hospital for the second time. Subsequently, the patient died in the place where they have been discharged or back in hospital.

Of these eleven people who had repeated contact with the Discharge in reach service more than once over a three week period, there is no available evidence to show that any of them died in their preferred place of death. Three patients had no information recorded on their preferred place of death. Four patients had no information recorded on their actual place of death; however, they may not have passed away during the six month study period. Four patients, for whom we do have information on preferred place of death, did not die in their preferred place. Of these, three patients wanted to die at home, but actually died in hospital and one patient wanted to die in a hospice, but actually died in a care home. These findings fit with the general narrative of steep decline and although these patients would have preferred to die at home, due to the severe nature of their illness and the shortage of social and family support available at the time, they were readmitted to hospital.

6.4.3 Death in preferred place of care

The hospital death rate for the Discharge in reach service is not as low as the other Delivering Choice services (31.3%), but still lower than non-Delivering Choice users at 42.7%. Given that half of the patients seen by the Discharge in reach service die within six days after first contact, we could assume that a good proportion of Discharge in reach patients may either be choosing to die in hospital or are too ill to move. Instead of dying at home, Discharge in reach service patients are more likely to die in care homes (12.5% versus 8.8% for non-Delivering Choice patients) or community hospitals (11.8% versus 4.8% for non-Delivering Choice patients).

Nonetheless, the perceptions from both hospital and community staff were that patients are much more likely to die in their place of choice as a result of the involvement of the Discharge in reach service.

I know [the Discharge in reach nurse] quite well and if [a patient] said you know I want to die in a deck chair in the middle of a roundabout, [the Discharge in reach nurse] would try to do that. (Hospital matron PS)

This includes those who live on their own.

That goes along with like [the Discharge in reach nurse's] role because certainly in the past if you lived at home on your own and you appeared to be in the last few weeks of life the chances of you getting discharged must have been zero really but I've certainly seen people that [the Discharge in reach nurse] has facilitated that to happen for. (Community palliative care nurse RT)

6.5 What are the other positive impacts?

6.5.1 Hospital staff are more knowledgeable about end of life care patients

Both Discharge in reach nurses saw the education of staff on end of life care as an important, on-going part of their service and had developed training materials or hosted educational events. This may become a larger focus, given that the Discharge in reach service cannot provide for every relevant patient.

One of the nurses and I are trying to implement the preferred choice of care...So if [ward staff] have the time to talk to family and relatives of that patient, to start this and start putting down what the patient and family want and then for that to go with them just so that we can maybe get it started... And I'm doing some work with one of the doctors on a computerised discharge letter...at doing a flow chart for if you've asked the surprise question and then where would you go on this flow chart as far as discharge is concerned. (Discharge in reach nurse)

We put together a learning pack...in conjunction with the palliative care team, that we took to our academy and invited all staff to attend...And that was all around palliative care and the services that are now in place in Somerset and how they can tap into those, either with me being here or without me. They've also got on each ward an end of life file which has got all the information that they need if I'm never there, so that they can do it all themselves. (Discharge in reach nurse)

6.5.2 Hospital staff are more aware of the needs of end of life care patients

We received reports that hospital staff were apparently now more aware of end of life care patients, their needs and potential support available.

They [ward staff] are learning a lot from just seeing [the Discharge in reach nurse] doing it...They might not have even known that if a patient has got six weeks at the end of life that they get a bit more money and caring, but now they know because [of] [the Discharge in reach nurse]. (Hospital matron PS)

Dr X said that it has been useful to have a person to consult with who has specialist knowledge of end of life care issues and that [the Discharge in reach nurse] has helped him think about end of life care in a more proactive way adding that often [the Discharge in reach nurse] has "forced" such

thinking to come about...[He said that] the difference [the Discharge in reach nurse] had made to end of life care within the hospital was that junior doctors now think more readily about these issues than they once did, and that they benefit from spending time with [the Discharge in reach nurse]. Dr X added that junior doctors talk with her and that this had opened their engagement with other staff on end of life issues....Such educational work cannot be one off but needs regularly repeating so that new staff are constantly updated and educated appropriately in-situ. (Informal interview, Consultant in Care of the Elderly 7.12.11)

6.5.3 Hospital staff confidence has increased

Several participants also believed that the confidence of hospital staff in managing end of life care patients had increased.

The ward sister told me that [the Discharge in reach nurse] gives great support to staff, who sometimes go to [the Discharge in reach nurse] with problems in regard to patients requiring end of life care and that [the Discharge in reach nurse] is able to explain in an invaluable way the details of how patients can be supported in moving back into the community from hospital and receiving appropriate care there... The ward sister told me that [the Discharge in reach nurse] helps staff gain confidence, adding “she has given me that confidence and that knowledge” regarding patient discharge. (Informal interview, Ward sister 7.12.11)

This confidence has led to ward staff becoming much receptive to and capable of handling more difficult requests.

A couple of weeks ago we had another patient whose family had said, ‘...we want to take him [father] back to Brighton.’ And they [ward staff] were like...we can [organise] that, whereas a year ago...so now that they’ve been through the process they know that it can be done. (Discharge in reach nurse)

6.5.4 Hospital staff more willing to challenge treatment decisions

The evaluation team was told that some hospital staff were more willing to question the advisability of some treatments.

The ward sister added that staff are now more likely to challenge doctors about unnecessary treatment for patients who require end of life care and that this has come about because of [Discharge in reach nurse’s] contact with ward staff and her influence. (Informal interview Ward sister 7.12.11)

6.5.5 Links between hospital and community sectors strengthened

The Discharge in-reach service was reportedly viewed by some as key to bridging the gap between community services and the acute hospitals.

Dr X said that a big strength of [the Discharge in reach nurse] and her role is the interface between the hospital and the community and the knowledge that

she has of community resources that are available, and her skill to negotiate those resources. Staff in hospitals simply don't have the knowledge of community resources and cannot therefore negotiate as effectively or as precisely as [the Discharge in reach nurse] does. (Informal interview, Consultant in Care of the Elderly 7.12.11)

I know she's there if I need her and I know I can trust everything that she says and if I phone her up and say 'whilst they're in hospital, could they do this or could they just check this?' She will pass that on and it's just nice to have that person, that contact. (Community Palliative Care nurse RT)

6.5.6 Potential complaints averted

An unexpected consequence of the Discharge in reach service is that Discharge in reach nurses appeared to be informally managing family concerns about hospital care that come from community staff, before they reach the complaint stage.

If I've had a message from say the family, sometimes the family say, 'Oh I went to see my mum yesterday and I didn't think much of the care or she seemed really depressed, I don't know what to do about it.' And I say, 'Well have you spoken to the nurses?' 'Oh they were so busy'. So I would go back to [the Discharge in reach nurse] and say 'I've had this message' and she could follow it up. (Community palliative care nurse RT)

6.5.7 What are the negative consequences?

Concerns were expressed about the possible deskilling of staff. From early on (Phase II report) there was a recognised tension between the importance of having a named professional to educate and skill up hospital professionals about end of life care issues and de-skilling those same hospital staff by creating a specialised end of life care nursing role. This continues to be a concern for some.

Dr X was also keen to emphasise that as well as the benefits of [the Discharge in reach nurse's] role there is a downside in that it can be too easy to offload onto her so that hard pressed staff are relinquished from having to tackle some of the end of life care issues that they might otherwise be expected to take on, admittedly having less time to do this as effectively as [the Discharge in reach nurse] would do. (Informal interview, Consultant in Care of the Elderly 7.12.11)

The Discharge in reach nurses had to tread a difficult line between spreading their expertise and taking over.

6.6 What do family carers think about it?

A principal advantage from the perspective of family carers was that the involvement of the Discharge in reach service reduced pressures on the family.

When you're in this very extreme situation it's such a relief not to have to do battle to get things [done]. That was all taken from us. (Family member CW)

The families were very grateful for the speedy, comprehensive care packages that the Discharge in reach service set up.

She [in-reach nurse] organised everything for Dad to come home, because it was short notice, he was coming home and I said, 'I can't look after him in his bed...because...it was too low.' And by 8 o'clock that night everything we needed was there at home. And Dad was there, so it was amazing. We were really pleased. (Family member BW)

We practically had every service that was available, it certainly seemed like that. It was quite amazing to both of us...We had everything we needed... So we had equipment, carers, community nurses, 24 hour helpline and a lot of kindness and support and backup... I feel extremely fortunate because even now after however many months it is [following husband's death], I can still see a complete picture of care and support without any holes in it. (Family member CW)

The family members were also appreciative that the Discharge in reach nurses often anticipated future needs that the family members were unaware of.

She [Discharge in reach nurse] said, 'I'd like you to try the night sitters'...She was more aware than I was of how much they might be needed...It was just something she felt we should have, and very glad she did. (Family member CW)

The Discharge in reach service also provided much needed reassurance.

My concern was that [wife] would want to be at home, how was I going to cope on my own with her and also with the fact that I knew she was going to die at home and how would I deal with that from then on? And as [in reach nurse] explained...'all the care will be there, all the help will be there at any moment that you want it...You will have several telephone numbers that you can contact should an emergency arise or you feel concerned in any way about any stage in her condition'. (Family member WC)

As soon as I met her [Discharge in reach nurse] she said, 'You don't need to do anything, we'll do it.' Because I was asking, 'What we do? Do we have to do this?' 'You don't need to do anything', she said, 'don't worry about it, we'll do it all'. (Family member HJ)

The Discharge in reach nurses appeared to tailor care to the individual patient.

I think dad would have been quite insistent that he go home. He might even have discharged himself... so I think she stopped that ...she pacified dad... I think she got the measure of him...he was an intelligent man, he was

Principal at the college and a JP in the town and...an important man and I think she dealt with him like that ...and she was very good because I know she knew that I was worried that he was going to put the pressure on to go home ...and she would be very firm and say, 'This is going to be much better for you and...you can take your lap top into the home.'...All of those things that were important to dad...and she knew that. (Family member MR)

6.7 What helps to make the Discharge in reach service work?

6.7.1 Model adapted to the characteristics of the hospital

Although the objectives of the Discharge in reach service were the same for the two posts, in practice there have been different models in the two hospitals. We found that for several reasons, including the size of the hospital and support from hospital colleagues, the Discharge in reach service was established more easily at the smaller hospital.

But I guess also not to forget that [larger hospital] is twice the size of [smaller hospital] and it is much more political. It's not so friendly and people are so very, very busy and they're in their silos. I guess this is the other thing they're all in their silos, they all have their job to do so it was always going to be a harder nut to crack then somewhere like [smaller hospital] which was a lot smaller, more friendly and someone in there who had been working in there for years anyway. (Manager LR)

Despite this, we found that the Discharge in reach service did eventually become a great success at the larger hospital; it just had a more difficult start. We found that for the larger hospital, what appeared to work best is:

- Proactive in-reach, whereby the nurse actively identifies patients herself rather than wait for hospital staff to refer.
- Clarifying that the aim of the service is NOT to unblock beds but to identify and discharge end of life care patients that had been admitted to hospital who wanted to die at home.
- Modifying the eligibility criterion from 12 months to three months until expected death.
- Limiting where the Discharge in reach service targets i.e. Medical Admissions Units, Surgical Admissions Unit, particular wards, fast-track patients.
- Clearly carving a role out for the Discharge in reach service that is not absorbed by other hospital teams (i.e. palliative care or discharge liaison).

At the smaller hospital, these boundaries were looser and this did not appear to compromise the effectiveness of the Discharge in reach service.

6.7.2 Highly skilled nurses delivering the service

The nurses delivering the service are crucial to its success. The essential skills and attributes were:

- Extensive knowledge of end of life care.
- Sensitive communication skills with an ability to read body language.
- Ability to be honest and inclusive with patients and family members about prognosis and implications of decisions.
- Willingness to discuss end of life issues with total strangers possibly with minimum information and with reluctant staff members.
- Assertive, “tenacious”, “broad shouldered”, organised and passionate about end of life care.
- Ability to build good working relationships with staff from a variety of backgrounds (e.g. transport, hospital medical staff, community professionals).
- Knowledge of community service provision for end of life care patients.
- Computer literate.

We heard repeated reports from family members and professionals of the Discharge in reach nurses’ “exemplary” communication skills. The Discharge in reach nurses need to be sensitive to the level of knowledge and acceptance that patients and family carers have about the terminal diagnosis and help them move fairly quickly to a position where care wishes are established.

[The researcher] sat in when [the Discharge in reach nurse] talked to a patient and his son in regard to discharge plans. [The Discharge in reach nurse] confirmed with the patient and the son that home is the preferred choice and discussed practicalities that would enable discharge home to take place, including [the Discharge in reach nurse’s] idea that a wheelchair should be made available for the patient to have with him on discharge. [The researcher] noticed that [the Discharge in reach nurse] was clear in her communication about the patient’s condition and deteriorating health and likely scenario if he was to be alone at home when a problem occurred. The patient readily admitted that in the worst situation he would die alone and indicated that this would be an event that would have to be accepted by himself and by his family. The son listened carefully to his father, who was equally clear in saying that despite this possible scenario his greatest wish was to return to his own home. The son concluded that he would fully support the discharge and seemed reassured that [the Discharge in reach nurse] had helped put in place as good a support system as could be expected in the circumstances. (Observation 29.11.11)

These discussions may involve some difficult family dynamics.

I suppose the other key ingredient is knowing how to bring the whole conversation to a head, and to involve all the family, because there’s nothing worse than you talking to somebody and they know that they’re dying, but their daughter hasn’t got a clue and they don’t want their daughter to know,

but they want their daughter to be there. And so it's about having that skill I suppose to bring it all together so that everybody's on the same page. And sometimes that's really hard. (Discharge in reach nurse)

Moreover, the excellent communication skills of the Discharge in reach nurse are needed with hospital, community and hospice staff.

[Discharge liaison team staff member] was at pains to say that the difference [the Discharge in reach nurse] has made to the provision of good quality end of life care centres largely on the communication skills that she has and the conversations she is prepared to enter into and facilitate, saying that [the Discharge in reach nurse] picks up on body language and signals very well, capitalises on her own life experience, and is "an artist" in working in a subtle and sensitive way with families and ward staff. (Observation 7.12.11)

In addition to these skills, the personal attributes of the Discharge in reach nurses are crucial.

I think you've got to have very broad shoulders...because it is a challenging role. I think you have to be quite assertive, you really have to know what you're talking about and flexible so it's no good going in that sort of role as a bit of a shrinking violet because you're talking to all sorts of staff from all walks of life, consultants, ward staff, saying, 'Well no actually I think this patient could go home. Why hasn't this patient gone home?' Then on the other aspect trying to get the drugs sorted, the transport sorted, so it's a hard role. (Manager LR)

I mean if she was 'I'm too busy, I can't do that now or you'll have to go through the proper system' or the patients didn't take to her, [if] she wasn't a very personable sort of person it wouldn't work. But because she's lovely, the patients like her. She can talk to the nurses and perhaps guide them without making them feel like she's telling them what to do or criticising them. So I mean it's quite a difficult role I would think and equally she's confident enough that she can go to the doctors and say, 'How about doing this?' Or 'I don't think this is helping her, perhaps she needs a bigger dose'. And that takes a lot of competence because doctors don't always like to be told by a nurse anyway. (Community palliative care nurse RT)

6.8 Building relationships within and across the hospital and community

Undoubtedly as a result of their excellent communication skills, the Discharge in reach service has built up relationships so now hospital and community staff initiate contact.

It's an in-reach post so in respect that means I go looking for patients to bring back out of the trust back into the community. But I do, as time's gone by and reputation builds you do get, I get a lot of phone calls. I even get phone calls

from consultants asking me to go and see their patients, which is great. Or you get the conversations as you're walking in the building, because it's quite a small building in comparison, quite personable so you do get to see people who say, 'Oh can I just ask you about somebody or tell you about somebody?' and refer that way. (Discharge in reach nurse)

6.8.1 Dedicated time

Another key element to the success of the Discharge in reach nurse service is dedicated time for end of life care patients, which other hospital staff do not have.

Definitely the busyness, the turnover on the wards, definitely the winter pressures, all year now [are reasons] why these things [well planned discharges] don't happen. That's the biggest reason for this post being in place I believe, that there's just not the time [for ward staff] to have those in-depth conversations and all the arrangements that go with it to discharge somebody. (Discharge in reach nurse)

[Palliative Nurse] said that [the Discharge in reach nurse] is able to explain to families what is possible in regard to the options available and help families think through those options in a measured way and make an informed decision about the most practical option. She said that she and her colleagues could not have done such in depth work and have had such detailed conversations as [the Discharge in reach nurse] has managed to achieve. (Observation 29.11.11)

Patients and family members recognised that this time was essential. For example, one daughter in law replied without any hesitation that the patient would have died in hospital as "no one would have had the time to help him work through his feelings". (Family member CM) This may require several conversations or encounters over a several weeks.

She [the patient] had some dementia and...Social Services had got involved and they were discharging her home...She was found the very next morning; they don't think that she ever went to bed. They found her in the bathroom. They think she took all her tablets at the same time... So then they asked me to get involved then... and initially I thought it'd be easier now because she's been home and it's failed so it'll be easier to get her to go into a nursing home....And so I went merrily over to see her. Of course her short term memory's gone, hasn't it? So, no, went home perfectly alright thank you very much...So then you'd think outside the box and think, right, what are we going to do about this then because she really can't go home, she's just not safe. So would you like to go to a nursing home for some lunch? And the nursing home were (sic) really brilliant... [they said] send her over, we'll have her for lunch and everything and we'll show her the room and see how she gets on. So off she goes for lunch. She comes back. Yes, lunch was very nice but I

don't want to go there because they're all mad. There's nobody I can talk to. But the sister in the ward was really good and she kept bringing her to the computer...and people kept talking to her and when I went back and saw her two or three days later she said I think I might go to that nursing home you know. I think I might give it a try .I said well, let's just go and give it a try and if you don't like it we'll think of something else. She went there and died two weeks later. (Discharge in reach nurse)

6.8.2 Good community service provision and information

To support the service, the Discharge in reach nurses need community staff, equipment and hospice places to be in place so that patients can be discharged quickly. The Somerset Care Co-ordination Centre is key to making this happen. The Discharge in reach service also relies on the Out of Hours advice line to ensure that patients are settled once they are back at home. In addition, although sometimes not available, the Discharge in reach nurses need information about the patient to gauge how to pitch the discussion. Ideally this would be available on the Adastra electronic register, but more often the Discharge in reach nurses turn to Crosscare. In fact, we had reports as late as December 2011 that one of the Discharge in reach nurses was still unable to access the Adastra electronic register.

6.9 What makes it more difficult?

6.9.1 Personality conflicts

Early on at one of the hospitals, the Discharge in reach service initially failed as some hospital staff held concerns that the service was duplicating their remits.

There was a lot of people in the discharge team had been there for a long time, they saw it very much as a threat. The palliative nurses at [the hospital] also saw it as a threat and thought well you know why can someone come in and do the job that we're doing? And also I think people at the [cancer centre] also saw it as a threat.... (Manager LR)

To address these issues, the Delivering Choice Executive Committee minutes note that a member of the Executive committee (who was not named) had written to the Hospital Palliative Care nurses urging them to “embrace the role [of the Discharge in reach nurse]”. (Executive minutes 15.6.10) Nonetheless, the situation was sufficiently difficult that the first Discharge in reach post holder left and the post was vacant until January 2011.

After this rocky start, when the second post holder arrived, she quickly was absorbed into the discharge liaison team. This also caused difficulties as she appeared to be taking on the referrals more appropriate to the discharge liaison team such as patients “who had been in bed for six weeks” (Manager LR), rather than identifying her own caseload through proactive in-reach. Consequently, she was overwhelmed with work. In part, this situation appeared to come about because of poor line management.

However, the Discharge in reach nurse was given a new line manager. This line manager along with a key hospital staff manager worked in tandem with the discharge liaison and palliative care teams to help these teams understand how the Discharge in reach service differed from usual discharge and palliative care work. To reinforce this message, the Discharge in reach nurse moved offices and was no longer sitting in the same area as the discharge liaison team. Clearer boundaries were put in place around which patients fell into the province of the Discharge in reach service (i.e. three months to expected death, MAU, A&E and SAU only). Clinical supervision at the local hospice was instituted. In this way the Discharge in reach nurse was 'extracted' and the service was made distinct.

In addition, the personal qualities of the second post holder of the Discharge in reach nurse service helped. She was able to rapidly develop strong and productive relationships with colleagues from the discharge liaison and palliative care teams. So, it appears that the turn around was due in no small part to the efforts of the second post holder herself.

6.9.2 Care packages set up too early or break down

The timing of putting in care was problematic. Three district nurses in Somerset mentioned their concerns that patients from hospital have been put on fast track funding too early in an effort to avoid hospital usage. This led to difficult situations for the district nurses.

Some people can be fast tracked from hospital I think before they necessarily need the fast track and I am not sure if that's a thing to get them, whether the hospital put pressures to get them out, you know and then obviously you've got the problem then, well not a problem but later on they perhaps after 12 weeks actually they've been in the nursing home with all the care, they have actually improved and then they go on... So then you've got problems for families that actually they are in a nursing home that doesn't accept social services funding, and if they don't qualify under CHC normally then they might have to move and that funding may be stopped. So that's a worry for patients and families. (District nurse JK)

Likewise, if inadequate care packages are set up, then patients may bounce back into hospital, although this appeared to happen infrequently, as hospital re-admission rates were low.

6.10 Does it duplicate something else that's already there?

Like hospital staff, initially the evaluation team wondered about the potential duplication of the Discharge in reach service with the discharge liaison and palliative care teams in hospitals. One difference is that the discharge liaison service is responsible for all hospital discharges, not just those expected to die in the next three months. In comparing the Discharge in reach service with the palliative care teams, the palliative care teams appear to have a larger remit in referring patients to

specialist palliative care providers outside the hospital, rather than setting up packages for home care.

Undoubtedly, there is some overlap between the discharge liaison and palliative care teams with the Discharge in reach service. But as a community palliative care nurse made clear, with the advent of the Discharge in reach service there is now someone specifically identifiable in the hospital to both community and hospital staff focused on the rapid discharge of patients who want to die in the community. However, the previous mechanisms are still in place as not all end of life care patients can or should be discharged from the hospital via the Discharge in reach nurse.

6.11 How do evaluation findings fit with the original hypothesis?

The original hypothesis for the Discharge in reach nurses generated by the participants in the hypothesis generation workshops in early 2011 was:

Discharge in reach nurses have dedicated time to have discussions with patients and healthcare professionals that trigger awareness of options. With dedicated staff taking on this role, non-cancer patients are more likely to be identified. Conversations expand between staff, patients and family carers from wills and burials to end of life care and preferred place of care. Discharge in reach nurses enable co-ordination of previously fragmented resources with DN input, pharmacy input etc. and put in packages of care quickly, aided by the co-ordination centre. This has triggered a change of culture (partly through education on the job) so that discharge is considered on the day of admission.

This leads to the outcomes of choice of care, empowerment, trust, holistic system, conversations and inclusivity and equity.

Our evaluation findings fit relatively well with the original hypothesis. We received substantial reports that the Discharge in reach service arranged good quality discharges for end of life care patients; conversations with hospital staff around end of life care were more frequent; hospital staff were more confident; co-ordination had improved and discharges were speedier. However, we did not find evidence that hospital staff are thinking about discharge from day 1, but implicit in hospital staff interviews is greater awareness of the need for speedier discharges.

6.12 What are the key ingredients?

The key ingredients to making this intervention work are:

- Proactive in-reach with a focus on targeting end of life care patients admitted to hospital who want to die in the community.
- Employing highly skilled, approachable, personable, resilient nurses.

- Placing the Discharge in reach service 'at the front door' of the hospital to stop unnecessary hospital admissions quickly.
- Dedicated time.
- Adapting the model to the particular circumstances of the hospital.
- Carving out a clear, distinct role.
- Good, prompt community provision of care packages in the community.

6.13 Conclusions

Based on reports from family carers and professionals from hospitals and the community, the Discharge in reach nurse service appears to be much needed and appreciated, especially for the co-ordination, speed and efficiency of discharges. Most importantly, family member satisfaction with the service was high. The re-admission figure at 6% is low (7/114), so the Discharge in reach service appears to be successfully helping patients to die in the community.

Although the supportive and educational aspects to the service were highly valued, we found that a key element to making this service work was providing 'challenge'. This took the form of exploring with family carers and patients the potential implications of their choices around preferred place of care and questioning hospital staff about potentially unnecessary or unbeneficial treatments and investigations. The latter was particularly revolutionary. In addition, another crucial element to this service was the 'in reach' component, which initially allowed the Discharge in reach nurses the flexibility to identify their own caseload and educate hospital staff about the service worked until it became more established.

However given the enormous scope and potential, the service runs the risk of over-stretching the Discharge in reach nurses and/or deskilling hospital staff, if the educational remit becomes too broad or the Discharge in reach service takes on too many end of life discharges, especially those of complicated patients. This is likely to be an on-going challenge. Thus far, the Discharge in reach nurses appear to have managed that difficult balance well. In sum, the Discharge in reach nurses have made a vital and important contribution to the quality of care for end of life care patients in Somerset.

6.14 Recommendations

1. Continue with dedicated long term funding with a longer term contracts (ie two – three years).
2. Consider resourcing further posts to cover annual leave, holidays and increase the scope of the service, especially at the larger hospital.
3. Keep more consistent records with regular checks for quality. If not currently doing so, keep electronic note of all of those who decide to stay in hospital and reasons why.
4. Continue to extend the service to non-cancer patients.
5. Continue to build up links with care homes and community hospitals.

6. Continue with educational efforts to skill up hospital staff in good end of life care and smooth discharges.

7.0 Out of hours advice and response line

Outcomes for patients and professionals accessing the Out of Hours advice and response line

- Significantly fewer emergency hospital admissions in the last month of life and A&E visits in last month and week of life.
- Significantly fewer hospital deaths.
- High level of family carer satisfaction.
- Perception of greater co-ordination of care.
- Increased staff confidence.
- Perception of fewer calls to OOH District nurses (DN).
- Potential unintended outcome – perception by some OOH DNs of increased delays in reaching patients. Disputed by family carers who reported faster response from OOH DNs contacted via advice line.

What makes this intervention work

- Publicising the service.
- Prior patient contact with the hospice, so that the family member/ patient is aware of the advice line number and the advice line has patient information.
- Building on the previously existing daytime advice line service offered by the Central Referral Centre.
- Proactively phoning back family carers after the crisis to check that all is well.
- Knowledge of and good liaison with community and urgent care services.
- Close collaboration with the Somerset Care Co-ordination Centre.
- The “practical”, “sensible” and “re-assuring” approach of the nurse advisor.
- High standard of expertise and extensive experience.
- Keeping community professional caregivers up to date.

What stops this intervention from working

- Constant need to re-publicise the number.
- Duplication of advice lines and out of hours numbers leading to confusion for families about which number to ring.
- Some out of hours advice lines appear to give a poorer service, which adversely affects the reputation of this line.
- Some district nurses do not understand how the service works.
- Some district nurses are not passing the number on to patients.
- Lack of dedicated nurse on advice line from 1am may lead to calls going unanswered.
- Perception that the advice line is only for cancer patients.

7.1 Introduction

The advice and response line is manned by one registered, dedicated nurse seven days a week, from 5pm to 1am on Monday to Friday and from 8am to 1am on weekends and bank holidays. During the day all calls to the advice and response line's 0845 number are transferred through to the Central Referral Centre (CRC) at St Margaret's, which is staffed by a team of administration staff and community palliative care nurses. At 4pm the CRC switches to the out of hours advice line and for an hour it is staffed by community palliative care nurses before the dedicated out of hours line nurse comes on for his/her shift at 5pm. From 1am onwards, calls are picked up by the night time in-patient hospice staff, so calls may not be promptly answered if in-patient staff are busy or taking another call. This means that professionals, family carers and patients need only ring one advice line number at any time day or night to receive specialist end of life care advice. The Out of Hours advice line service that is reported on here, as part of the Delivering Choice Programme evaluation, operates from 5pm-1am on weekdays and from 8am-1am on weekends

To ensure that the line is always covered, including sick and annual leave, the Primary Care Trust have funded two whole time posts. Start up cost for the service was £58,565 and the annual cost for the first year was £105,606.

To evaluate the Out of Hours advice line, in addition to quantitative data, we interviewed 50 people including 14 family carers, specialist community palliative care nurses, community nurses, care home staff and a hospital nurse. We also analysed 11 surveys. We carried out two formal observations in August and November 2011. In addition, we analysed the Out of Hours log for the six month study period and read documents including the Marie Curie reports, Board papers and meeting minutes.

7.2 How is it supposed to work?

In Phase I of the Delivering Choice programme, out of hours care for end of life patients was found to be fragmented and sub-optimal in both counties. The working group suggested the introduction of a central advice and response line to give greater continuity of advice to patients, carers and professionals and act as a triaging point for palliative care patients to ensure the most appropriate response (Phase II report). Initially, this Out of Hours advice line was to cover both North Somerset and Somerset patients, but North Somerset decided to wait (for reasons not disclosed) and so only Somerset is covered. The Somerset Out of Hours advice line, which is provided by St Margaret's Hospice, went live in January 2011.

The Out of Hours nurse advisor manning the advice line offers:

- Telephone advice to patients and carers on symptom control, support services available, practical, emotional and psychological issues.
- Triaging of Out of Hours services with existing services for end of life patients (for example district nursing teams, Out of Hours GPs, ambulance service, emergency duty social worker).

- Planned or proactive telephone support to patients and carers who require reassurance or are in crisis, as identified by professionals (for example Discharge in reach nurses, community palliative care teams, Somerset Care Coordination Centre [SCCC]), or patients that have been categorised as Red, according to the Palliative Care Framework.
- Generalist palliative care advice to professionals working Out of Hours including clinical support regarding prioritisation of care.
- Linking to the coordination centre (when open) to provide details regarding packages of care (Phase II).

The key intended outcomes of the service are:

1. Increase the number of patients dying at home or closer to home.
2. Reduce the number of inappropriate hospital admissions and inappropriate contacts for patients and carers with urgent care services.
3. For patients and family carers:
 - Ensure their urgent palliative care needs are met.
 - Limit the physical and psychological suffering and maximise their quality of life.
 - Educate on self-care and the best use of services.
 - Reduce carer strain and anxiety.
 - Increase access to relevant information at the right time.
4. For professionals:
 - Provide advice.
 - Decrease length of time between professionals seeking assistance and accessing specialised palliative care services.
 - Deliver consistent response and communication with other providers (Phase II report).

Like other Delivering Choice services, an aspirational goal is to broaden its client base from cancer patients to include those with non-cancer diagnoses and to provide services for those living alone.

7.3 *How does it actually work?*

The advice line is a “life line” for those helping the dying. It offers easy access to highly experienced experts who respond professionally and quickly. The advice line nurses offer sound, practical advice to help patients, family carers and professionals who are coping with rapidly changing, and sometimes frightening, scenarios.

Although thus far the advice line is largely used by those helping cancer patients, the advice line is available for patients with any condition. However, all of the patients must be registered with a Somerset GP.

When a call comes in, the nurse on the advice line consults available information about the patient, usually located on Crosscare (an electronic information system run by St Margaret’s hospice). The helpline nurse offers advice and, where appropriate,

triages patients through to other services as needed as quickly as possible. Reportedly, calls into the advice line are recorded and all calls should be logged.

Although unusual in its complexity, the example below taken from the OOH advice line log gives a good flavour of how the advice line works and the lengths to which the advice line nurses will go to resolve problems. It starts with a wife calling about an equipment malfunction that affected her husband with motor neurone disease.

[First entry] 12.9.11 [Wife] was given the advice line number from staff at SMIY [St Margaret's inpatient unit] because [husband's] mattress had deflated and the motor appears not to be working...She has rung Huntley's who make the mattress on their 24 hour advice line but because it was not purchased from them but came from Medequip then they could not deal with the matter...

[Next entry] Said to [wife] I am not sure when we could get hold of one this late on a Friday night but I would try to contact the STARS team who cover the area and also the OOH DNs and I would get back to her...

[Next entry] Tried the STARS team but no answer on either of their numbers. Rang the OOH DN call centre who also took all the details and said they would try to sort something out. Also left a message on the OOH social workers' number...This was at 23:10.

[Next entry] Rang [wife] to say that STARS not answering and that OOH DNs were looking into it. She said she would settle [husband] down for the night in his chair...Told her to call any time if problems. 22:30 OOH DNs rang – no mattress tonight but emergency delivery tomorrow...

[Next entry 13.9.11] Request for follow up call. Spoke to [wife] they managed okay overnight. DN expected this morning...We discussed need for passive exercises. Will ring SCCC at 10:00 when they open to see if they can help. 11:47 rang SCCC but he's not known to them. However did get the OOH Medequip number out of them. 12:29 Called [wife]. She is tearful now. Gave her the number. DN has gone to [hospital] to see if she can get another pump. 13:30 [Wife] rang. Has got another mattress arriving at 5pm! (OOH advice line log)

After the situation is resolved, the advice line nurses are expected to contact other community service providers (for example community palliative care nurses, district nurses) so that all concerned were up to date. On occasion, we were told that one query could generate up to 30 further calls to ensure that all care was in place. Community palliative care nurses are often routinely informed as advice line staff speak directly to relevant staff or leave messages. Community palliative care nurses confirmed that they receive frequent messages.

Certainly on a Monday morning I come back and there's (sic) at least two or three messages, sometimes more from the Out of Hours. Every day there's always one, invariably one from the Out of Hours to say 'so and so has

phoned up in distress or someone's phoned up for such a reason', which is great because we can phone them back and sort it all out. Sometimes the advice line sorts it all out and we don't need to do anything; it's all sorted.
(Community palliative care nurse RT)

When death occurred, the advice line nurses appeared to contact a wide variety of professionals, although there was some variability of exactly whom those professionals were. Mainly, the advice line nurses contacted the Central Referral Centre (possibly just by making a note on Crosscare as both were in-house), the Somerset Care Coordination Centre, community palliative care nurses and sometimes hospital palliative care nurses.

7.3.1 Uptake and reach

Data supplied from the OOH advice line indicate that a total of 2034 calls were made to the advice line over a 12 month period from April 2011 to March 2012. The average number of monthly calls is 170, with September 2011 as the slowest month with 120 referrals and January 2012 as the busiest month with 232 (OOH advice line yearly report).

For the purposes of this study, Out of Hours advice line call log data was extracted from 1 September 2011 to 29 February 2012 for analysis by the evaluation team. Initially, these extracted data included daytime entries from the Central Referral Centre and in-patient hospice night nurses as well as for the Out of Hours advice line. We re-extracted data without Central Referral Centre calls (n=1319). Once in-patient hospice night nurse calls were excluded from the call log (n=290/1319=22%), we found that 1029 calls were made regarding 391 patients when a dedicated nurse was manning the lines. Of those 1029, 616 (60%) were made between the hours of 5pm and 1am while 413 (40%) took place on weekends and bank holidays. Once these were linked to Primary Care Trust data, we found 243 patients used the OOH advice line and died during the six month study period. These data were used for the quantitative analyses.

On average, patients come into contact with the Out of Hours line 22.5 days before death with a median value of 10 days (range 2-31); therefore 50% of the patients are referred to the Out of Hours line ten or fewer days before death. Calls were made for almost equal numbers of men (49%) and women (51%) patients. Of these, 35% were 70 years old or younger; 25% were aged between 70-79; 31% were aged between 80-89 and 9% were 90 years old or more.

Occasionally, callers may have a specific purpose in calling the Out of Hours advice line, for example care agency staff to leave a message for night care workers, or GPs to check on available beds in the hospice. Community palliative care nurses may phone to request that the advice line nurses check on a patient, while both community palliative care nurses and district nurses phone for advice on medication and symptom control. Night care workers may phone about nutrition or how to

manage symptoms, so one advice line nurse emphasised that the advice line has an important educational role.

Family carers and patients call for emotional and practical support.

The couple of times when I felt completely frazzled mentally, there was somebody on the other end of the phone who didn't mind me offloading to them, and weeping down the phone, on one occasion. (Family member VM)

Sometimes family carers were prompted by a healthcare professional who was directly on hand. But usually, patients and family carers initiated the call themselves. There is some suggestion in the qualitative data that access to the advice line may be particularly reassuring to those living in rural Somerset, far from other services.

The advice line is predominately used by those caring for cancer patients. Quantitative data for the study period linked by the Primary Care Trust showed that 17% (n=42) of those using the Out of Hours line died from non-cancer conditions. However, when we looked at the log, we found only just under eight percent (36/391). This discrepancy could be because some of those with no diagnosis details in the log may have died from non-cancer conditions or from coding discrepancies in death data. In analysing the Out of Hours log data, we found that the 36 non-cancer patients we identified included:

- 12 with heart failure (tallies with PCT data).
- 8 with COPD (PCT data = 9).
- 6 with dementia (PCT data = 4).
- 5 with motor neurone disease (PCT = 5).
- 5 with other conditions e.g. CJD, alcoholic liver disease (PCT =12).

We found that in our sub-analysis of non-cancer patients, over half the patients were referred onto other agencies, most commonly Out of Hours GPs (n=8), Out of Hours district nurses (n=7) and night sitting agencies (n=6). Callers were also triaged to other providers, including the ambulance service, hospital A&E, social workers, a respite care home and the 'STARS' team on one occasion each. Advice line nurses had the most contact with community palliative care nurses (n=9).

In interviews, all of the specialist community palliative nurses were enthusiastic about the advice line and said they received and made calls frequently. Of the community nurses, four of the six interviewed by telephone had directly used the OOH line. This is unsurprising, since three of these contacts were obtained from the OOH line call log. Two nurses who used the service worked as Out of Hours district nurses; the other two called the advice line at weekends or Bank Holidays. The two District Nurses who had not called were aware of the OOH advice line. However, one district nurse, who did not use the advice line Out of Hours, phoned in the daytime to contact the Central Referral Centre. Two district nurses commented that

having close working relationships with a community palliative nurse minimises the need for further advice.

Amongst non-nursing professionals, neither of the two Somerset GPs who had in-depth interviews had used the advice line and when analysing data using the 'caller status' field, only 28 of 1029 calls (3%) came from GPs. However caller status field is somewhat inaccurate, so more GPs could be using the advice line. Care homes tended to use the advice line infrequently. We interviewed a Deputy Manager and senior shift leader at two Residential Homes and a nurse at a Nursing Home, all of whom were logged as previously calling the OOH line but they each could only remember one call.

Given that the same telephone number is used to contact the Central Referral Centre and the Out of Hours advice line, community and primary care professionals often did not note the distinction between the two, as the same number is called throughout the 24 hour period. However, Central Referral Centre and OOH advice line staff saw the two services as distinct, in that the OOH advice line is manned by an experienced palliative care nurse who is dedicated to take calls, while the Central Referral Centre deals with all referrals and queries that come into St Margaret's Hospice for all of the hospice services. For the Central Referral Centre, offering advice is just one of their functions, whereas for the Out of Hours advice line it is the core function. In on-site observations, members of the evaluation team were also aware that the two services were separate and distinct.

7.3.2 Characteristics of users of the advice line

To learn more about the advice line, we analysed a sub-sample of calls for all patients referred to the advice line who died between September 2011 and February 2012. Using a computer generated randomisation tool, we selected 10% (n=25) of the patients. We also analysed the 36 calls from non-cancer patients. Three of the non-cancer patients were randomised into the 10%, so the total number of patients for this sub-analysis was 58 (23%).

Of the 22 cancer patients, the call chain was initiated by family carers for 10 patients, the SCCC for 3 patients, a district nurse for 2 patients and, for a single patient, one of the following: Primary Care Link Nurse, community palliative care nurse, OOH advice line, patient and paramedic. No information was given for one patient.

For the 36 non-cancer patients, the call chain was initiated by 10 family carers, two patients and 24 professionals. This higher proportion of professionals is unsurprising as non-cancer patients and family carers are less likely to come into contact with St Margaret's as it is largely a cancer based hospice. Of those 24 professionals who initiated the call chain:

- 6 were night care workers.
- 6 were GPs.
- 5 were hospital nurses.

- 2 were district nurses.
- 2 were unknown professionals.
- 1 each was from a care agency, care home manager, the Somerset Care Coordination Centre.

Thus calls for cancer patients most commonly come from family carers while calls for non-cancer patients tend to come from professionals.

In analysing data from the sub-sample further, three of the 58 call chains involved patients living on their own with no one to care for them. Those living on their own were all non-cancer patients. About three quarters of the call chains occurred over a short time period of less than three days. Of the 58 call chains, 21 were resolved with just one call; 22 with two calls and 12 with 3-6 calls. Please see the tables in appendix B for further findings from these analyses.

The longest call chain for a cancer patient involved eight calls over a one month period, largely instigated by his wife, with a further seven calls to the Central Referral Centre during the daytime. In this case, it is clear from the first call that the wife appears to be struggling with caring for her husband. The two longest call chains for non-cancer patients were quite complex cases. One involved a woman with heart failure living on her own who called nine times over several months, mostly around the Christmas period, often because she wanted to discuss care options such as in-patient hospice placement. The other concerned a man dying of alcoholic liver disease who was cared for by his ex-wife. Not only was he in a great deal of pain and sometimes aggressive, the ex-wife was also dealing with difficult dynamics with her ex-husband's family.

7.4 *What's its impact on the evaluation outcomes?*

7.4.1 *Co-ordinated care*

The call log provided ample evidence that the OOH advice line ensures that a wide variety of participants are kept up to date, especially community palliative care nursing teams, the Central Referral Centre and night care workers. In our sub-sample analysis, we found examples of the OOH advice line passing messages between the SCCC and night care workers, between community palliative care nurses and night care workers and between the Discharge in reach nurses and family carers. These data also show how often the day team from the Central Referral Centre would carry on sorting out situations that had arisen initially while the phones were manned by the Out of Hours advice line nurses and vice versa. Moreover, the OOH advice line appeared to serve an important function of organising emergency packages of care when the SCCC was closed.

7.4.2 *Death in place of choice*

Significantly more patients using the Out of Hours advice and response line died out of hospital, according to quantitative analyses. Of the 243 Somerset palliative care

patients who used the Out of Hours advice line and died during the six month study period, three-quarters (54%) died at home and 8% died in hospital. This compares to 15% of non-Delivering Choice patients who died at home and 43% who died in hospital.

7.4.3 Hospital usage

In terms of hospital usage in the last month of life, 36% of Out of Hours advice and response line patients had an emergency hospital admission and 20% visited A&E. This compares to 45% (hospital admissions) and 36% (A&E visits) for non-Delivering Choice users in the last month of life. Thus, patients who used the Out of Hours advice and response line had significantly fewer hospital admissions in the last month of life and A&E visits in the last month and week of life.

This confirms findings from the qualitative data. Some of the family carers said that they were using the advice line instead of urgent care services offered in hospitals and by Out of Hours doctors and district nurses.

I didn't ever have to phone for ambulances or anything, all that was done and it wasn't done through the GP or the district nurse... you could just phone one number [OOH Advice Line]...and then they would get you sorted. (Family member MI)

The advice line staff also believed that urgent care was used much less. For example, an advice line nurse said that less than half of the calls go through to urgent care. Our analysis of 36 non-cancer patients showed that about a quarter of the calls (20/79) resulted in further contact to urgent services.

7.5 What are the other positive impacts?

7.5.1 Increased staff confidence

A positive unexpected benefit of running the advice line has been the change in confidence of staff working on the advice line. Initially, many were reluctant to man the phones, but this has now changed.

I think from a staff point of view one of the successes has been the confidence that we've ...it's been a very steep learning curve for our staff to take on a very, very different role to that which they've been doing beforehand...but it has shown a lot of staff what they actually know, you know that they do every day, the advice we're giving, it has given them a huge amount of confidence in their own knowledge. A lot of staff who were initially, when we set up, said there was no way I'm going to put on that headset and answer those calls and deal with it all and now we've got most of the staff, inpatient trained staff who rotate and take shifts on the advice line. (OOH line staff LI)

We also received an unconfirmed report that some OOH line staff have become more confident about receiving calls referring to non-cancer patients.

7.5.2 Fewer calls to Out of Hours line district nurses

An Out of Hours district nurse mentioned that fewer patients call her as they are phoning the advice line instead, which she appreciates. She gave an example of a patient needing Midazolam who called the advice line when they did not know when they could have some more.

7.6 What do family carers think?

Family carers interviewed in relation to the advice line service were unanimously positive, using terms such as “invaluable” and “superb”. They were extremely grateful for the service for many reasons. For example, they appreciated the reassuring manner of the nurse advisors.

You have people on the other end of the phone who are sensible, practical, who've been down this route, in terms of providing support and care. They have the answers to all the questions you're likely to have, they're used to folks being emotional... to know that you're not alone, that there's always someone on the phone who's not going to panic, who's not going to be shocked, where you can discuss things which are really, perhaps, very personal, sometimes very grim, and they don't mind. (Family member VM)

They were hugely relieved to have help on hand in traumatic circumstances and were especially grateful for the call backs once the crisis had passed, as it made them feel that someone was watching over them.

On one occasion...he [husband] was in such awful pain, didn't know what to do with himself... I felt I ought to give him more morphine but I didn't like to, because I didn't understand drugs much and I thought I might kill him. So, in desperation, I rang my GP...but they were just going off duty and said...ring the [on call doctor]... and I was so unhappy about it, I thought a strange doctor will come here, they won't know his history and...I rang the hospice Out of Hours and I spoke to a lady called [X]...she went and got his records...she said 'Just hang on, I know about this case' and then she told me exactly what to give him... and then he became calmer...and he was out of this awful agony and I felt so relieved...and then what was most amazing and lovely, about an hour later, she rang me back and she said 'How are things?'.. I've never been so grateful to anyone in my life... and she said to me, 'If you're worried during the night, it doesn't matter what time it is, I'm here. You ring me' and she said, 'if necessary, I can send out a paramedic' and it was so amazing and wonderful, you see I wasn't on my own, floundering. (Family member HJ)

Moreover, patients as well as family carers found it reassuring.

[My husband (patient)] would sometimes phone [OOH Advice Line] just to say "This is happening...what should be happening? ... This is what I'm feeling" and so it was reassurance for him as well... So for him as a patient he found it useful as well. (Family member JM)

Family carers appreciated information and the fast access to professionals.

If I wanted any information or if I couldn't get hold of people like doctors or something like that because it was weekends.. I found them extremely good...I only had to phone them up. (Family member TF)

It reduced pressure on family carers at a difficult time.

It was as though I'd passed my responsibility for him [husband] to her [nurse at OOH Advice Line], it lifted a great weight off my shoulders because I didn't know what to do for the poor man; he was in such trouble. (Family member HJ)

I phoned her [OOH Advice Line] and told her the situation...about half past ten we lost [wife], I phoned the hospice, spoke to the same lady on the telephone...she said I'll deal with all the doctors...everything for you, I'll phone you back within half an hour and tell you what's happening. So it was great because they dealt with everything, they took the pressure off. (Family member CF)

7.7 What helps to make it work?

7.7.1 Publicising the service

Crucial to the success of the service is ensuring that people know it is there and have immediate access to the number when needed. The advice line markets itself to community professionals so that they use the service themselves and pass on the details to their patients' families. The advice line also directly advertised to family carers and patients that came within its sphere of influence.

To reach community professionals, we were informed of or observed a variety of strategies including:

- Stickers with the number were produced at district nurse request for district nurses to affix to the notes of patients.
- Face to face meetings with key relevant professionals such as Out of Hours GPs.
- Employment of two community nurses at the hospice with a community outreach remit including advertising the advice line service to district nurses and GPs.
- Posters on staff noticeboards.
- Cards for staff to distribute.

As evidenced in the call log and the observations of the evaluation team, family carers and patients were routinely made aware of the advice line number when the nurses contacted the family at the request of a professional. Moreover, the hospice let in-patients and day centre visitors know about the number. In addition, the SCCC gave family carers the number when first in contact and then sometimes reminded family carers when care packages were changed; this was confirmed by interviews with family carers and by the data log supplied by the SCCC.

In visiting GP surgeries and hospices for interview, the evaluation team found the advice line advertised by posters or cards at the front desk, on seven out of eight occasions. When asked, community palliative nurses replied that they give the cards out to “all” of their patients, whereas district nurses were more circumspect and are less likely to hand them out to “confused” patients or families.

RES: I've got the card that lives in my bag and we've got them dotted around and all the girls have got a card and they've all got them in their diary so they've got access to them and know who to contact, but like I say I've not had a requirement to contact them myself at the moment...

INT: So you offer those cards to patients and carers?

RES: To some, I must say we don't give them to all. Those that we feel that it's appropriate to give them to, we do give to them, there are some that are perhaps confused and wouldn't recognise quite what circumstances they should be using it but we wouldn't give the card to them. (District nurse RH)

In exploring this further, of the nine family carers whom the Out of Hours line helped identify for interview, five had definitely first heard about the advice line through St Margaret's hospice, either from a hospice nurse or a hospice social worker who visited the home (n=3) or as an hospice in-patient (n=2). In two other cases, it was probable that the family member got the number from the hospice but the interview participant was not entirely clear. In the last two cases, the source of the advice line contact number was a hospital palliative care discharge nurse and a “Macmillan nurse on the hospital ward”.

7.7.2 Prior contact with the hospice so patient details are already known

Given that most of the family carers who used the advice line were known to the hospice, prior contact with the hospice was crucial in ensuring use of the advice line.

It was probably about into the late spring early summer that we registered with St Margaret's Hospice and then we had one of the team come out to visit us regularly and she would come and assess [patient's] pain and you know come and chat to him here and see how he's getting on... And then as that progressed we used the Out of Hours service. (Family member JM)

Furthermore, this prior contact was an advantage once a call was made as the nurse advisor was able to quickly get up to speed with the case by consulting details previously entered on Crosscare.

And because that person there can look at the details on Crosscare, they know so much more about them, they can look up and say 'oh yes your husband Jeff or whatever, oh he's just come out of hospital', they know all this information. Whereas if you phone anyone from the Out of Hours, because I used to work for the Out of Hours, and you had to go to the call centre, understandably I'm not criticising it but for a patient in distress to actually go through the call centre and have to say what's wrong with whoever they're phoning about 'Yes alright, put the phone down and wait for the doctor to call back'. It's quite difficult and if you're elderly, to understand why you can't just speak to someone; they find it quite difficult. Whereas the advice line, they often do that for them. (Community palliative care RT)

Access to up to date information of the patient was a distinct advantage of the St Margaret's advice and response line over other advice lines. Previous knowledge of the patient and expertise in end of life care is very important to family carers, who in a crisis just want the right help immediately.

The reason why I think the advice line provided by the hospice was so important, was this, that the folks who were staffing it were from the hospice, so they know profoundly about dealing with the sort of situation where someone is at end of life, and all that that entails – I think a bog standard centre would be completely hopeless. And, I'll give a very good example of [this comparison]...On the very final day of Mum's life, while I was actually away, in the bathroom, Mum had rolled out of bed, and she had a syringe driver and line into her arm, and I found her on the floor...It was desperate. And I rang the NHS helpline, and there was a chap on the other end of the phone who, then, started wanting to go through all Mum's medical history...And I said, look...'All I need to have is someone medically qualified to come out and check whether this syringe driver is still in'...And a chap...rang back who was a doctor...and, again, wanted to go through Mum's medical history. And I said, 'Look, I don't want an ambulance out here. All I need is just either a doctor or a nurse to come out and check that this line is in'. And, again, [he] wasn't listening. I ended up putting the phone down...And the solution came from ringing the [OOH Advice Line]...when I rang, the person on the other end of the phone, she was brilliant, she said, 'Right,...I'm going to phone the district nurses on your behalf, there'll be somebody round in half an hour', and there was. (Family member VM)

In comparison with other 'call centres', the access to information via Crosscare means that the Out of Hours line nurse can respond with a much more welcoming, personalised approach.

As soon as I said [husband's name], 'Oh yes', and it was straight away like it wasn't just 'Oh hang on a minute, let me see what number he is' sort of thing, it was like, 'I know about this person'. And it was quite a personal sort of feel, which again gives you reassurance that you're not one of hundreds... You felt like they, that they were friends... They were always very approachable and very, it was just like me phoning a friend to say, you know, what do I do now? And they were lovely. (Family member JM)

7.7.3 Building on a previously established line

The Central Referral Centre advice line was already firmly established when the Out of Hours advice line service was set up. Because the telephone number was the same, external professionals needed only to use one number and saw the Out of Hours advice line as an extension of an already well used service. The service was well used almost immediately from the start and within five months was receiving over 200 calls monthly (OOH advice line annual log). Arguably, the Out of Hours line would not have had such good initial uptake, if it had not built on the previous success of the Central Referral Centre.

7.7.4 Proactive response

Like the other Somerset Delivering Choice services, the proactivity of this service was especially notable. We had several reports of the advice line phoning family carers back after the crisis had passed, just to make sure that the situation had stabilised, and noted from the Out of Hours data log that these follow up calls were common. Moreover, the Discharge in reach nurses and community palliative care nurses reported that the advice line would phone patients to make sure that all was well at home before any crisis might occur. We also observed how these proactive calls could result in signposting family carers through the maze of end of life care processes and services.

A woman whose kidneys are failing and was previously known to the hospice and had palliative care nurse involvement before her recent hospital admission was discharged home today. [Advice line nurse] phoned the home, while [the researcher] was present, and spoke with a family member, the daughter, who said that her mother was not yet home from hospital, was expected this evening and was being brought home by her son. [Advice line nurse] gave the daughter the number of the advice line and encouraged her to phone back if she had any further questions or any concerns. [Advice line nurse] answered immediate questions put by the daughter in respect of availability of people to provide night-sits, and said that initially the district nurse would need to do an assessment to sort out funding for this service and [Advice line nurse] added that there would probably also be a social worker who could help with sorting out funding. (Observation at Advice Line, 22 November 2011)

7.7.5 Understanding of and relationships with community providers

Over time, advice line staff have reportedly learned much more about what services are available in the community, which in turn has improved their ability to triage

effectively and offer good quality advice. The evaluation team found many examples in the call log of how the nurse advisors were working across the health and social care. The call log and reports from family carers suggest that the nurse advisors had an excellent overview of what each health and community service could provide and what 'strings to pull' to resolve a situation.

However, there may still be some confusion. An Out of Hours district nurse said that the St Margaret's advice line nurses had called GPs for 'just in case' medication instead of the district nurses. We were unable to confirm this report.

7.8 What makes it more difficult?

7.8.1 Confusion around multiple OOH telephone numbers and services

In addition to the St. Margaret's line number, family carers and patients potentially have access to several other Out of Hours advice lines, including SWASFT and those operated by Out of Hours GP and district nursing services. Other hospices also operate 24 hour advice lines via inpatient units in the area.

A district nurse suggested that this proliferation of Out of Hours services, many with 0845 numbers, could potentially be confusing to patients and family carers and this was confirmed in our interviews with family carers. One man recounted that even though he had previously used the advice line number, when his wife had a subsequent crisis he telephoned the NHS urgent care number instead of the St Margaret's line because he could not remember which number to phone (see Mrs Red in Chapter 10).

The evaluation team were also confused by the proliferation of numbers, as we did not know whether negative feedback from community professionals about out of hours advice lines related to the St. Margaret's advice line or a different Out of Hours service. For example, a district nurse mentioned that she had heard "negative reports" about the "Out of Hours line" but was unable to clarify which one. Nonetheless, this negative publicity had influenced her, as she was reluctant to hand out the St Margaret's number, partly because of a mistaken belief that the St Margaret's advice line would not get in touch with the Out of Hours District Nursing service appropriately.

7.8.2 Perception by professionals of delay in urgent care visits routed via OOH advice line

A full time Out of Hours district nurse spoke of receiving messages via the St Margaret's Out of Hours advice line, which had delayed care for patients. She explained that if patients or family carers phone the St Margaret's helpline rather than the OOH District Nursing line directly, an extra link was created in the communication chain (St Margaret's helpline → OOH District Nurse call centre → District Nurse on call). In her experience, this extra step had delayed a visit to a patient. In addition, she said that when the district nurse on call receives the message, only minimal information is given, such as name and address. When the

Out of Hours district nurse then visits, the family member has to explain the situation several times and at 2am this can be very distressing. This district nurse said she would prefer the patient or family member to call her directly.

In discussing this situation with the OOH advice line staff, the evaluation team were told that Out of Hours district nurses and GPs are advised to phone the OOH advice line directly themselves to receive further details, when receiving an urgent visit request routed through the Urgent Care call centres from the Out of Hours advice line. But apparently not all Out of Hours district nurses do contact the St Margaret's Out of Hours advice line for further information, nor does it appear that Urgent Care call centres pass on all relevant information.

However in exploring this issue further, the evaluation team received an entirely different view from family carers. Far from incurring delays, family carers who phoned through to the advice line and then received visits from urgent care staff reported that the Out of Hours GPs and district nurses arrived more promptly than if the family member had called the Out of Hours urgent care lines directly.

We'd [previously] called the NHS number or the emergency number for doctors but they get here when they can don't they?...Whereas with the Out of Hours [advice line] service you had somebody straight away, knowing [patient's] case, to be able to say right give him more oramorph..so you felt you had something more immediate whilst at the same time they were contacting a doctor with all his details to say can you prioritise?... that's what they seemed to do, you know just to say 'he needs you now' rather than wait for an hour and a half, two hours... And that was brilliant, because when you're the carer who's done everything that you can possibly do, you're left thinking oh where do I go now with somebody that's writhing around in pain?
(Family member JM)

In addition, community palliative care nurses suggested that patients who went through the advice line, as opposed to other Out of Hours call centres, were more likely to get more appropriate care. In talking about Out of Hours services available before the advice line was established, one community palliative care nurse said:

You would just tell people to phone the GP Out of Hours line, and then it's awful because then at the weekends you would come back after the weekend or a bank holiday and people would have got into real situations, or GPs would have gone in and changed medication and done some bizarre dosaging, I have to say, or bizarre drugs. You can understand it because they've gone in and they've just got to make a decision, not necessarily the decision you would have made but they had to make a decision. Whereas now at least the patient can speak to the Out of Hours advice line; they can speak to the consultants if necessary or the doctors there, and then give advice and contact the appropriate person, which is just better really.
(Community palliative care nurse NL)

Thus the data from the family carers and community palliative care nurses suggests that patients and family carers are more, not less, likely to receive a good quality, speedy service from urgent care GPs and district nurses, if they go through St Margaret's advice line.

7.8.3 Lack of a dedicated nurse manning the phone round the clock

One district nurse described a problem that a family member had with a call going unanswered. The family member called the helpline at 7.30am three times and "held and held" but nobody answered. The district nurses came into work that morning to find a message on their answer phone in which the family member was "tearful, quite desperate". The district nurse then spoke to the advice line nurse and found the advice line nurse quite defensive, saying that ward patients took priority. This district nurse saw the conflict as the hospice nurse was doing two jobs at once.

7.8.4 Need to re-publicise the number

Although a great deal of effort was put into advertising the service at its launch, there was a recognition that community, primary and hospital staff forget about the advice line and new staff need to know it is there. So the service needs to be regularly re-publicised. This needs to be carefully considered.

I think part of that is, and I think that's one of the difficulties with how you advertise the service because we can put mail shots in GP practices and put posters up, but actually you're not near the poster when you're home in distress at 10 o'clock at night. (OOH line staff LI)

As a result, the service was relying largely on word of mouth. This appeared to work well. For example, stakeholder board members were told in a presentation in May 2011 that the number of incoming calls from the launch of the service in January 2011 to April 2011 had increased 200% from 99 to 297. (Enclosure C 17 May 2011 Stakeholder Board documents)

7.9 What would make it work better?

7.9.1 Extend reach and increase funding to include more non-cancer patients

Several evaluation participants mentioned that with more funding the range of the advice line could be extended to harder- to-reach groups, such as those with dementia, motor neurone disease and heart failure. In addition to broadening the range of patients included, the service could also be extended around the clock. Currently the perception was that the Out of Hours advice line was operating at capacity, which we have limited evidence to test.

During the one observation we conducted of the advice line, for five hours on a Tuesday night in November 2011, five calls were made. Two came into the service, one from a family member at 20:45 and from a GP at 21:35. The three calls that the nurse made out were to: (1) the SCCC at the start of the shift for handover; (2) an Out of Hours GP, to follow up the first call received; (3) a family member regarding a

recently discharged patient. As the researcher involved in the observation kept the advice line nurse busy, by informally interviewing her, and as we only carried out a limited period of observation, we cannot determine whether the advice line is operating at capacity.

7.9.2 Improve the quality of the data recorded

Of all of the Delivering Choice services, the Out of Hours advice line most easily provided data to the evaluation team. Analysis of 1319 calls from their call log suggests that the majority of calls are logged. The exceptions appear to be sometimes when OOH line nurses initiate calls (see OOH Tables in the appendix B: patients 2,4,9,14 and 22). The quality of data on what prompted the call and how the OOH line responded is very good. However, improvements to record keeping would need to take account of the following:

1. Information on 'status of caller' and 'caller's name' is sometimes misleading. As a result we could not confidently determine the number of different types of callers (for example family member, district nurse, care home) nor carry out a detailed analysis of what prompted calls for each type of caller. For example we found incidences of:
 - Status recorded as 'care home' but call actually initiated by son or daughter on behalf of parent in a care home.
 - Status recorded as 'district nurse' but again family member actually initiated the call.
 - Confusion around the term 'carer', which could mean a night care worker, day care agency staff or family member.
 - Caller listed as 'GP' but caller's name clearly indicates a community palliative care nurse or night care worker.
2. Diagnosis is often missing in the 'diagnosis' field. In some cases, a reference to the patient's condition is made in the free text fields. Nonetheless, for a quarter of the patients during the study period (100/391), no information on condition was available. With such a large proportion missing, it is difficult to determine the extent to which the advice line is reaching non-cancer patients.
3. 'Lives alone' could be misleading, as sometimes sons or daughters had moved in, so although patient usually lived alone, they were now accompanied.
4. Dates were sometimes entered day/ month/ year and sometimes entered month/ day / year. This could be confusing. For example in our sub-sample analysis of 36 non-cancer patients we found two instances of calls received from family carers after the patient had died.
5. Some nurse call handlers provided quite sparse information, with a call logged but little follow up, while others provided detailed accounts.

7.10 Does it duplicate something already in place?

As stated previously, there are several Out of Hours advice lines operating in Somerset. Moreover, not all community staff members turn to the advice line as their first port of call Out of Hours, as this district nurse suggests.

I guess for me, the one I've used the least and it's been least important is the Out of Hours system, however you know End of Life team [SCCC] do work weekends, I think it's three or half past three so I've been, if I've had a problem in the weekend I've gone to them rather than the Out of Hours. So I've just not had the need to use beyond their hours, so for me that hasn't been a key part. (District nurse HR)

Moreover, we received reports that some GPs still offered patients and family carers their own mobile numbers in case of an emergency, rather than pass on the advice line number.

7.11 How do the evaluation findings fit with the original hypothesis?

The original hypothesis for the Out of Hours advice and response line, derived from the hypothesis generation meetings in early 2011, was:

The Out of Hours advice line offers reliable back up out of hours whereby questions are answered respectfully in a timely fashion. The advice line is dependable for staff and patients. The advice line provides access to specialist knowledge and practical support. It also breaks down barriers and alters perceptions. It triggers conversations with carers and patients that reduce their anxieties. Staff manning the advice line can answer carer questions such as "How will I know when she's died?" The advice line can signpost staff, carers and patients, and sometimes they are signposted to the co-ordination centre. North Somerset has several numbers, so still some way to go. Somerset has one number.

This leads to the outcomes of choice of care, resources, information, empowerment, conversations and patient/ carer satisfaction.

The fit between the evaluation findings and the original hypothesis is close.

7.12 What are the key ingredients?

The key ingredients to making this service work elsewhere are:

- The practical and re-assuring manner of the nurses advisors who have extensive knowledge and experience of end of life care, 'go the extra mile', and offer a high quality service.
- Good electronic systems with up to date information about patients.
- Proactively phoning back family carers a few hours after the crisis to check that all is well.
- Knowledge of and good liaison with community and urgent care services.

- Innovative and regular marketing of the service.
- Building on the already existing daytime advice line.

7.13 Conclusion

The St Margaret's Out of Hours advice and response line provides a high quality service of great value to family carers and professionals. They 'trouble shoot' when crises emerge, often in the last few days of life. Of special value to the family carers was the proactive call back after a crisis, to check in. Qualitative and quantitative data both suggest that patients who use the Out of Hours advice line have less hospital usage and increases the chances that family carers will be able to cope sufficiently so that patients can die at home. Thus, these promising findings suggest that the Out of Hours advice line makes a useful contribution to enhancing patient choice at the end of life.

Building on the daytime advice line service operated by the Central Referral Centre, the key components that appear to have led to the success of this service are the competency, professionalism and "reassuring" manner of the nurse advisors, and their knowledge and ability of end of life care needs and services so as to effectively navigate the wider care system and provide callers with the help required. In sum, the OOH advice line often took on an advocacy role.

The Out of Hours line now faces several challenges to build on its success. The first is to extend its reach to non-cancer patients; we found less than 20% of those referred to the advice line died from non-cancer conditions. The second is to work with daytime and out of hours district nurses to dispel fallacies about the advice line and encourage these professionals to hand out the number to potential callers and use the number themselves. A third challenge is to enhance collaborative links with urgent call centres so that maximum information is routinely transferred to the out of hours district nurses and GPs on duty. As these first two challenges involve expanding the capacity of the nurse advisors, and currently we are told they are working at maximum levels, more funding would be required.

Finally, unlike other Delivering Choice Programme Services, the Out of Hours advice line is operating in a crowded market. Moreover, with the advent of the new NHS 111, that market is about to become even more populated. The St Margaret's Out of Hours advice line has a clear 'unique selling point', offering an excellent service to end of life care patients. Given the difficulties in making the 'advocacy' aspect of the Key Worker role work, especially out of office hours when key professionals are not available, another unique contribution of the Out of Hours advice line is its ability to successfully discharge the Key Worker advocacy role, out of hours. Perhaps, this could be capitalised on. In summary, a major challenge over the next two years is to develop a marketing strategy whereby the Out of Hours advice line is able to clearly identify and bolster its strengths, clarify its differences and develop a way forward with regards to other out of hour line initiatives, to help secure its longer term sustainability.

7.14 Recommendations

1. Reduce the confusion about out of hours numbers with community nurses.
2. Explore further what information out of hours district nursing service passes on to the district nurses on call.
3. Consider allocating more funding to expand the reach of the advice line to non-cancer patients and more patients in general.
4. Identify current and known future 'competitors', their strengths and weaknesses, and clarify the 'unique selling point' of the St Margaret's Out of Hours advice line.
5. Explore ways to ensure the sustainability of the advice line either working in partnership with other 'competitors' and/or capitalising and investing more heavily in its unique selling points.
6. Consider officially allocating the 'advocacy' aspect of the Key Worker role to the advice line nurse advisors out of hours and publicising this widely to all professionals. Again, this would significantly increase the work of the Out of Hours advice line and so extra funding would be necessary.
7. Improve the quality of the information on caller status, caller name and diagnosis, to clarify who is using the advice line. In addition, data could be collected on where the advice line number was obtained for marketing initiatives.
8. SCCC to check that the OOH advice line number is available at every contact with family carers.
9. 22% of calls are received by the hospice in-patient ward nurses between the hours of 1am-9am weekdays and 1am-8am weekends. Consider if this is sufficient to warrant the funding of extra dedicated staff to cover these hours, as set out in the original business case.

8.0 Somerset Care Co-ordination Centre

Outcomes for patients and professionals accessing the Somerset Care Co-ordination Centre

- Significantly fewer emergency hospital admissions and A&E admissions in the last month of life.
- Significantly fewer hospital deaths.
- High level of family carer satisfaction.
- Perception of greater co-ordination of care.
- Perception of freeing up of district nursing time.
- Reduction in district nurse and family carer anxieties around co-ordination of care.
- Release of family carers from full time caring role.
- 7 night sits a week possible

What helps this intervention work

- Good supply of and good relationships with high quality external care providers with experience in end of life care.
- Working with external care providers to improve quality of care, for example through opening up training opportunities in end of life care, creating reciprocal relationships, and by addressing care agency staff concerns.
- Liaising with care providers via telephone to build relationships and speed up delivery of care packages.
- Employing night staff on contract rather than bank to create stable, widespread supply of night sitters.
- Regular feedback to keep professionals and family members informed.
- Helpful, approachable, 'can do' staff.
- Excellent team management, led by a former community nurse with good interpersonal and communication skills.
- Having a clear customer service focus whereby the family and patient needs take precedence.

What stops this intervention from working

- Community nurses obtaining equipment, carers and night sitters directly themselves, without going through the SCCC.
- Issues with the Continuing Health Care approval process, including delays and difficulties in getting hold of CHC team members via phones.
- Problems associated with care agencies, such as staff shortages or variable quality care provided by staff with limited experience in end of life care.
- Meeting the continually changing needs and demands of families

8.1 Introduction

The Somerset End of Life Care Co-ordination Centre was launched in May 2010. The service was provided by Somerset Community Health. The staffing includes a full time Band 6 nurse lead and 3.8 Band 3 administrators. The Centre is open from 8am-6pm Monday to Friday and from 10am-3pm on Saturday and Sunday.

Start up costs came in at about £100,000 and costs from 2010/2011 were £146,912. These were funded by the local primary care trust. The business case anticipated that use of the SCCC would result in 10% fewer hospital deaths annually (n=187) and that the SCCC would receive about 86 new referrals a month. (Phase II report)

To evaluate this service, we collected the views of 50 individuals through interviews and surveys including 18 family cares, 12 community nurses, 8 specialist community palliative care nurses and various other professionals including a GP, hospice nurses and a care home manager. Two formal observations were carried out in August and December 2011. Various documentation such as all three Marie Curie reports, Board papers and a NHS Somerset and North Somerset fast track audit dated 2011.

8.2 How is it supposed to work?

As with the North Somerset End of Life Care Coordination Centre, the Somerset End of Life Care Coordination Centre (SCCC) was set up to organise care packages for those who wanted to die at home or in residential care. The Marie Curie Phase I needs assessment report identified the underlying issue that the Somerset Coordination Centre was to address:

With multiple professionals and organisations providing care for patients in the community, coordination of care is important. Sometimes patients and carers are receiving visits from a variety of professionals in a short space of time. It appears that sometimes there is limited communication and coordination between professionals about who is providing care and support. This can lead to increased confusion for patients and carers. (Phase I report)

Packages of care can consist of any combination of day and night staff, equipment such as commodes and beds and personal care workers for washing, dressing and feeding. In Somerset, usually district nurses and specialist community palliative care nurses organised the care packages. However this process could be time consuming with district nurses estimating that it could take up to 3-4 hours, so one of the key aims of the SCCC was to free up community nursing time. (Phase I report)

8.2.1 Objectives and outcomes

The objectives for the Somerset End of Life Care Coordination Centre were the same as those for the North Somerset service, mainly to:

- Organise packages of care for palliative care patients in respect of the following services: Social care; Somerset Palliative Care Partnership; Marie

Curie Nursing Service; nursing care from a nursing agency; and care home placements.

- Provide service advice and signposting for palliative care patients and their carers/families.
- A central point of communication relating to care packages for palliative care patients and health and social care professionals.
- Establish, maintain and review the end of life care register including information on preferred place of care and death.
- Maintain and update the palliative care website in conjunction with other providers.
- Coordination of information regarding palliative care services in the county, providing a signposting function for professionals.
- Provide commissioners and providers with information relating to demand and capacity of services. (Phase II report)

The outcomes for this service were:

- Improved communication between organisations and patients and their carers/families in regard to packages of care, so as to reduce anxiety and the number of double bookings or duplication of visits.
- A reduction in the time spent by clinical staff organising packages of care, allowing time to be reinvested in the delivery of care.
- Avoidance of hospital admissions and a reduction in length of hospital stay.
- Improved continuity of care for patients. (Phase II report)

8.3 How does it actually work?

Initially, some community staff were not sure of the remit of the SCCC and there were doubts about whether the new service would free up time for community nurses.

We've obviously got this new Care Coordination centre which has probably been the biggest change out here in terms of palliative care. I must say when it first came out I didn't have much faith in it because I kind of felt that it wasn't saving us any time...Because actually Social Services were setting up the packages of care quite well before they came along, and you know it's not saving me any work, okay it's saving social services work, but we seem to just be creating jobs for the sake of creating jobs....But once it [care order] gets to them [SCCC] they do take a bigger role in care packages and equipment, and in the end, again once a patient's passed away they will stop all the packages of care and they will arrange for the transport and things to go in which does make a big difference to us. So yes, I think over time as it's sort of established itself, it's been quite a useful service, but I wasn't convinced in the first place.
(District nurse RH)

8.3.1 Meeting objectives

We found evidence that the SCCC is fulfilling all aspects of its brief. Moreover in its role of providing service advice to patients and family members, the SCCC has sometimes taken on the role of negotiator between community nurses and family members.

There were things which came up which led me to call Wells [SCCC] and say look, this is not happening, or that's not happening. And then they said, 'Right, the district nurses will deal with that'. And I said, 'Well, when we've raised it with the district nurse, they say it's not for them to do'. And Wells [SCCC] would say, 'That's rubbish, right, we'll call the district nurses now'. And then they would sort it out. So I found Wells, that [SCCC] office, extremely responsive. They seemed to know exactly what to do and what the scope of everyone's role was. (Family member NC)

A district nurse confirmed that in her experience, the SCCC helped resolve family member concerns.

8.3.2 Setting up packages of care

Community and hospice professionals are prompted to contact the SCCC to set up care packages predominately for fast track patients (those expected to die between 6-8 weeks) who want to die at home. The SCCC is contacted because:

- Staff cannot get the equipment, night care workers or care workers elsewhere.
- Staff need to set up multiple elements in a care package and do not want to spend hours organising this themselves.
- Previous experience has led staff to believe that the SCCC will set the care package up efficiently and quickly.
- Staff need to increase or change a package of care.
- A patient record needs to be added to the Adastral end of life care register.

Patients and family members are prompted to use the SCCC to change care package requirements and to liaise with health care or care provider professionals on their behalf.

Although the intention was to organise packages of care for all palliative care patients, in actuality the SCCC only sets up packages of care for fast tracked patients with Continuing Health Care funding. In Somerset, several informants reported that fast track criteria focus on patients considered likely to die within 6-8 weeks, who are in a deteriorating condition, and who have significant health needs with a specific diagnosis and a terminal condition, e.g. cancer. Those without a terminal diagnosis, those who are 'dying of old age', and those with sufficient care already in place do not qualify and consequently will not receive services from the

SCCC. The SCCC can set up a package of care in any of the nine 'federations' in Somerset, which is a largely rural county.

To set up a care package, usually the district nurse or specialist community palliative care nurse makes an assessment of patient needs and completes the relevant form. Because neither the Continuing Health Care team nor the SCCC team carries out assessment visits nor have access to patient records, they are entirely reliant on the nurses to complete the forms to a good standard and with sufficient details. Nurses working in the community and community hospitals have received training in completion of fast track applications. For equipment orders, the nurse will need to consult a catalogue to specify which equipment is required.

Once the fast track application form is complete, it has to be authorised. Specialist palliative care nurses can sign their own forms, but district nurses need the signature of GPs, consultants, ward charge nurses or specialist palliative care nurses. We did not speak to any GP, consultant or authorised nurse to ask about the level of scrutiny they apply to these requests before giving their authorisation. One district nurse we interviewed stated that in total it may take her a maximum of 30 minutes to complete the needs assessment form and get authorisation but other applications will be delayed, if no authorising staff are available.

Before the SCCC can organise the package of care, the Continuing Health Care (CHC) team, who agree fast track funding, need to approve the request. The forms can be faxed to the CHC team or sent electronically to CHC and the SCCC simultaneously. This latter option is preferred by the SCCC, so they can start organising the packages of care at an early stage, although some staff, particularly those from the Central Referral Centre at St Margaret's hospice, have concerns about the security of e-mail. The CHC team recently designated a nurse to work two days a week exclusively on processing fast track applications and there is now a dedicated telephone number for fast track applications. There are also several other nurses available in the Continuing Health Care team to approve the request. If a package of care is requested during non-office hours, the SCCC can organise this and then seek retrospective CHC approval.

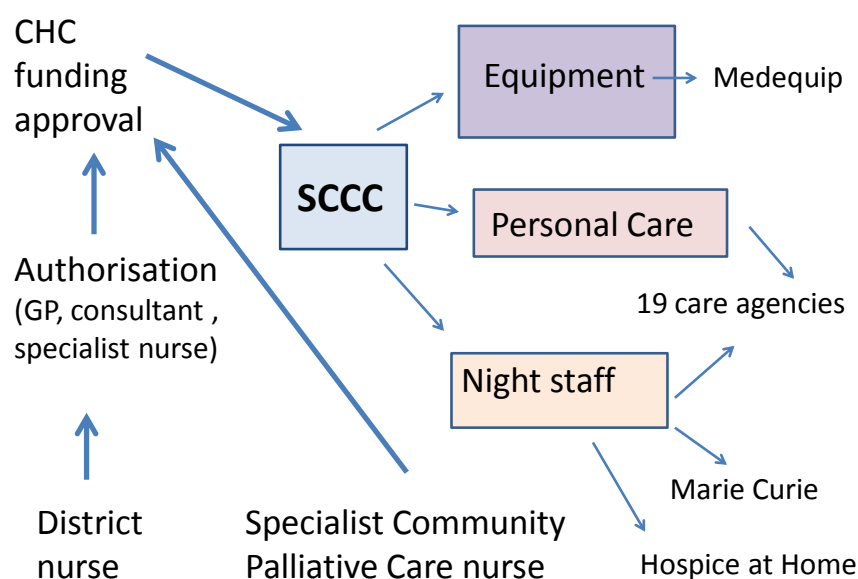
Once the SCCC receives confirmation from CHC that funding has been approved, they organise the care package. With CHC funding, the maximum package that individual patients are allowed is visits by two carers up to four times a day and up to four night sits a week. Equipment comes through Medequip and personal care and night sits can be arranged through any of 19 different care agencies. Some of the care agencies are 'strategic' providers who hold a block contract and others are 'spot' providers with negotiated rates. Night care workers, which are in the most demand, are also available from Marie Curie and Hospice at Home.

After a care package has been set up, the family member and the original referring professional are informed. Family members can directly contact the SCCC themselves, if they want to change elements of the care package. If a professional wants to change an element of the care package, they can ring the SCCC directly to make modifications up to the maximum package without requiring further approval from CHC or completing further paperwork.

After death, the SCCC activates a checklist, which details exactly who needs to be contacted so that there are no “slips”, for example a district nurse or CHC assessors contacting the family, post death, without knowledge that the patient has died. The check list also helps ensure that equipment is taken out of the home quickly. Several participants commented that the SCCC organises the retrieval of equipment particularly well.

Please see the figure below which illustrates routes for arranging care packages.

Figure 3: Setting up care packages in Somerset



8.3.3 Databases and websites

The electronic sources of information relevant to the SCCC are:

- Adastra electronic end of life register.
- Palliative care website.
- Bespoke ‘scheduling’ system to record details about the care packages.

We learned that the SCCC manages and updates the Adastra electronic end of life register, which includes:

- Adding records for newly identified patients, for community palliative care nurses who do not have direct access
- Informing community nurses about who is the 'Key Worker' for a particular patient.

The SCCC also maintains and updates the palliative care website every three months. In addition, the SCCC attempts to collect data on 'unmet need' to inform commissioners via SADIE.

For each referral, data on 'performance metrics' are collected, such as: the source of referral; whether the patient lives alone; the number of calls needed to set up care; the number of visits requested, etc. Not all these data appear to be easily available, though, as the evaluation team discovered when asking for information on postcode, 'lives alone' status and source of referral. We were told that postcode information was usually not available and status regarding whether a patient lives alone was not easily accessible because this information is only collected in free text. Source of referral is by name only, not profession, so again would require some extra analysis to be useful. We could not carry out any further checks or quality assessment of this database because fuller access was denied, due to concerns about patient confidentiality.

8.3.4 Uptake and reach

Quantitative data from the Primary Care Trust and service usage data from the SCCC, between 1 September 2011 and 29 February 2012, show that 294 patients received care packages and died during that time period. This is 11% (294/2572) of the total number of palliative patients who died in Somerset, which is comparable to the proportion of patients accessing the North Somerset End of Life Care Coordination Centre (15%). Because the SCCC only works with fast track patients and we do not know the number of fast track patients, we do not have denominator data on the number of patients who could have received SCCC services. Initial projections estimated service usage at 35%, based on a capacity and demand algorithm derived from estimates of the number of palliative care patients in a population, the current number of fast track applications at NHS Somerset and activity at Lincolnshire Palliative Care Coordination Centre. (Phase II report). However, we received reports from Continuing Health Care and SCCC staff that this 35% figure was substantially overestimated.

On average, patients come into contact with the SCCC 17.2 days before death with a median value of 9.5 days (range 4 to 20). This means that 50% of SCCC patients are referred to the SCCC 9½ days before death.

Almost equal numbers of men and women used the SCCC. Just over a quarter were younger than 70 years of age; 31% were aged between 70 to 79; 30% were aged between 80 to 89 and 13% were over 90. In terms of conditions of the 294 patients referred to the SCCC, almost three quarters died from cancer (74%); 8% died from

heart disease; 6% died from respiratory diseases; 3% died from dementia and 2% died from cerebrovascular conditions. All the rest died from various other conditions. So, overall, a quarter of SCCC patients died from non-cancer conditions.

All six of the Somerset specialist community palliative care nurses interviewed and all but one of the 10 district nurses said they had contacted the SCCC. Community nurses estimated their use of the SCCC between once and several times a week. Staff from the Central Referral Centre said they were in contact daily with the SCCC. GPs, care home staff and out of hours community nurses said they did not use the SCCC service for two main reasons: because district and community palliative care nurses set up the care package and because they believe the SCCC is not open outside normal office hours.

8.4 What's its impact on the evaluation outcomes?

8.4.1 Co-ordinated care

Family carers reported that the use of the SCCC resulted in care packages that were well co-ordinated and fast.

It [care package] was almost as if you could see a clock mechanism and everything was moving just smoothly. There was [sic] no hiccoughs, nothing...Once [wife] made that decision [to come home]...The hospice was organised, the district nurses were organised...carers were set up to come in the morning for toiletry type of things and get her up...an all singing, all dancing bed...was brought in. (Family member CP)

They [SCCC] seemed to arrange the local district nurses to do what they had to do, and obviously also arranged just routine carers for the more mundane washing and feeding and so on, and were also the link through to things like the Marie Curie nurses because on some nights, she had a sit in overnight carer... and then all the specialist equipment was delivered to the house, special beds, the hoist, and all the rest of it. All of that happened seamlessly to me. (Family member NC)

He [husband] came back home and we suddenly had all the bells and whistles...had a hospital bed, had some lifting equipment. We had a big wheelchair...we had a small wheelchair...We had a lift made available to us...We then had some speech therapy as well. (Family member JW)

The bed and all the equipment came. Yes I couldn't believe it... I couldn't believe how fast it came. (Family member BD)

Professionals were also positive about the impact of the SCCC on coordination of care, especially this particular specialist palliative care nurse who was asked which Delivering Choice intervention had made the most difference.

The end of life coordination centre, I can't sing their praises high enough I really can't, there's nothing but positives with that, it's just a brilliant, brilliant service. I don't know if other parts of the country have it but if they don't they should roll it out everywhere. (Community palliative care nurse RT)

Another district nurse commented on the impact that SCCC had on smoother discharges.

Discharges from hospital, quite often they would come out with us having to fast track them once they were out...and in terms of the End of Life Care Coordinator Centre, all those things would be replaced by different people. So for example if it was something to do with the package of care then I would contact CHC to approve the increase and I would contact extra care agencies or to even approve or to start, or maybe Social Services. The equipment, then I would have to arrange Medequip. So all the different little snippet of jobs they [SCCC] would do, would be somebody different that you would have to contact. So that's why it's nice to just go to them and say this is what I need, off you go. (District nurse HR)

Another nurse brought up how not only was care going into the home well co-ordinated, but care ceasing and equipment being retrieved from the home was well organised too.

The coordination centre is fantastic, even a year ago when somebody was ill you were fast tracking them but then you would be sorting out the care, you would be sorting out the equipment, you would be trying to sort out the nights and in a busy day it took up a lot of time. And the same when they passed away that you'd have to contact all these people and everything and they've been really, really good at sorting out the care and making sure that everything's in place and trying to get the sits and the carers and whatever and that's taken a huge weight off us and it gives us more time to go and do what we should be doing, so from that point of view. (Community palliative care nurse LC)

8.4.2 Patient dying in place of choice

Patients who used the SCCC were significantly less likely to die in hospital. Of the 294 Somerset palliative care patients who used the SCCC, and died during the six month study period, three-quarters (70%) died at home and less than 5% died in hospital. This was confirmed by qualitative data where the perception amongst health care professionals is that the use of the SCCC to organise care packages is helping more patients to die in their usual place of residence.

I think even sort of ten years ago there weren't that many people that would actually unless they really didn't have any symptoms or any problems then you couldn't actually facilitate them to actually stay at home for end of life care at all. And the equipment and things that we can get available now and get in

there to actually help them, so yeah definitely...I don't know what the statistics are but I'm sure that they must be very different ten years ago to what they are now for actually people staying at home and being cared for at home now, it must be a huge difference. (Community palliative care nurse LC)

There was a patient last week, I had all the family on the phone saying, "We can't cope, she has to go into the hospice." And I said, "But she doesn't want to, she wants to stay at home, that's her last wish. Is there no way we can increase the package of care?" So we got a couple of day sits in through the coordination centre to talk to them and say could you perhaps organise a rota so you're not all there together but you come separately so that she's not on her own, I know she had lots of friends, I'm sure they would help. So I went off for a day off thinking oh she's going to end up in hospital. I know it. And came back and thought no, she's not. And I saw the son and he said, "Oh yeah, we've sort of got a rota". And everything seemed to have calmed down and they seemed less frightened. So it does work, whereas before perhaps it wouldn't. Without the coordination centre and day sits and night sits it would not have worked at all. She would never have stayed at home. (Community palliative care nurse RT)

8.4.3 Hospital usage

Those who used the SCCC had significantly emergency hospital admissions and A&E visits one month before death. With respect to hospital usage, 32% of SCCC patients had a hospital admission within one month of death compared to 45% of non-Delivering Choice service users. 20% of SCCC patients visited A&E within one month of death compared to 36% of non-Delivering Choice service users. In the last week of life, SCCC patients were even less likely to visit hospital..

8.5 What are the other positive impacts of the SCCC?

8.5.1 Releases community nurses' time and reduces anxieties

We found widespread perception that the SCCC had freed up community nursing time previously spent organising care packages. One specialist palliative care nurse said that *"Any community nurse with any sense would go through the SCCC."* (District nurse QZ)

RES2: We were having to organise a lot more, we have to be, now we've got the coordination centre...We were spending a lot of time on the phone weren't we and ringing around to different agencies...

RES1: And Marie Curie, you know we had to ring, we had a list of people that could do so we had to ring round and book.

RES2: And that was a performance because

RES1: Had to have a half hour interview to pick

INT: And that's organising the night sits or the carers to come in?

RES1: Yes.

RES2: *And that was quite in depth. You had to know the patient quite well to know, to be able to answer all the questions to meet the criteria of them getting the care whereas now, we've got help to do it and it's easier.*

RES1: *Less time consuming.*

RES2: *Yes, takes away that pressure from us really. (District nurses JK)*

Handing responsibility for organising care packages over to the SCCC also means that the community nurses have one less worry.

You can always check with the coordination centre. And if patients phone in and say their night sit didn't turn up or carers didn't turn up, they [SCCC] will get on to the agency and if one agency can't help then they know other agencies they can go to. So yeah, that just takes a whole lot of worry out. It's a box we can tick with confidence. (Community palliative care nurse RT)

8.5.2 Taking on more complex cases

We had three reports that the use of the SCCC had resulted in catering for more complex cases. For example, an evaluation researcher observed a SCCC staff member liaising with the Discharge in reach nurse to provide care for a patient leaving a Somerset hospital to go to Devon. Secondly, a specialist community palliative care nurse recounted how the provision of care in a home setting had impressed a GP who had thought a patient was destined for a hospital admission.

I think we still shock them now, some of the GPs, with what we can organise and put in place...I actually stopped the other day this gentleman [who] wanted to go into a nursing home, he didn't want to go into hospital. I said, 'No that's fine we can get him to where he wants to be'. But he [the GP] didn't really believe me and he'd already gone through Primary Link...but the family said 'no' and they had to send the ambulance away. But he [the patient] actually got to where he wanted to be and now the GPs actually realised that we can get him to where he wants to be, he doesn't have to go into a hospital if he chooses to go into a nursing home...So it's just really that you have to keep reinforcing with the GPs what can actually be done for people at home. (Community palliative care nurse LC)

In a third example, a district nurse, who was originally sceptical about the SCCC, recounted how a patient who lived alone was able to die in her own home.

It's helped with things like people that lived in their own. We recently had a patient that lived alone and wanted to die at home and that was quite a challenge because of arranging night sits and things. Now before the End of Life Centre came I had Marie Curie. I might have been able to top up with a bit of Hospice but the chance of me getting seven days a week would have been quite slim. Whereas now we'll go out for regular nights with the care agency with the End of Life Coordinator centre and then top up in between

with the Hospice and Marie Curie and we had seven nights a week sits with that lady. A year ago I don't think, you know two years ago I don't think we would have been able to provide that for her. So we are offering a better service to people and allowing, facilitating more people to die at home.
(District nurse HR)

8.5.3 Greater quantity of equitable care packages provided

Several participants noted that the sheer volume of care available has increased, especially night care workers. A community palliative care nurse suggested that not only is more care available, but that care may be more equitably distributed because it is arranged from a central point.

And consequently care probably wasn't equitable because it was first come first served and just luck who you had on your side really. But now we all go to a central point and the care is divided up more fairly I would say. But there is a lot more of it out there to divide up so that makes it easier doesn't it?
(Community palliative care nurse BQ)

8.6 What do family carers think about the SCCC?

The SCCC offers an excellent service, praised by both professionals and family members.

We were very fortunate to get the level of care that we did, and they [SCCC] worked hard to help as much as is possible...when there were problems they worked hard to try and sort it out. (Family member CP)

[SCCC were] very good, seemed very competent, good manner (Family member EM)

If you wanted to sort out something structurally if you like with the care package, Wells [CCC] were the people. I never met them, but over the phone they were very efficient and helpful. (Family member NC)

The SCCC was also able to anticipate future patient and family member needs.

They [CCC] were able to just sort things out quite quickly and say, 'You definitely need a night carer. We'll sort one out for tomorrow night and we'll see if we can get you a few nights in a row'. (Family member JF)

8.7 What helps to make it work?

8.7.1 Good supply of and good relationships with high quality external care providers

The SCCC has no 'in house' care providing staff like the NSCCC, so it is heavily reliant on outside care provider agencies. One way to build relationships with external care providers is through telephone rather than electronic contact when setting up the care package. In addition to building relationships, telephoning has several other advantages such as more appropriate targeting (for example, avoiding

care providers who may have reached capacity through previously allocated work), ensuring that the care provider is aware of the request, more rapid turn-around, and immediate weeding out of care providers who are not able to deliver.

Because I do think there's nothing better than talking on the phone to a care provider. You can give an overview, you can get a response, maybe not instantly, they'll say, "Well I think we'll be able to do it. I'll get back to you in 10 minutes". Whereas an email can stay in their inbox for as long as they like, and we could give them a time factor... You could say, "Can you get back to me in an hour?" Well what if they don't get back to you in an hour? We could have made those phone calls and sorted it out in an hour. (SCCC staff GL)

Frequent personal contact also leads to better understanding of the niches of each care provider.

There's a small one [care provider agency] that developed with night sitters, and they've got a lot of male night sitters, which some people like and we've needed to use male night sitters in some instances specifically for things. So we know, they seem to be able to come up with the goods all the time, and it's good quality care. So we are building up care providers that maybe before didn't have the work to get established. And I think that will show through. (SCCC staff GL)

Interestingly, this in-depth work with care providers has been noticed by some of the community palliative care nurses. One mentioned that she has contributed her own feedback on the quality of care agency staff to the SCCC. The SCCC also carries out regular informal reviews of care providers with family members by ringing up to ask 'how is it going?' at regular intervals.

To improve the quality of care offered by care providers, many of whom have transient staff inexperienced in end of life care, the SCCC has arranged places for care providers to attend end of life care training through Care Focus. The SCCC has also signposted to other educational sources of information, such as the website and Marie Curie training videos on syringe drivers.

The SCCC has offered reciprocity in other ways, such as addressing some of the concerns of the care staff. For example, the SCCC provides night care workers with the OOH advice line number for emergencies. They have also set up a policy with care provider supervisors, whereby night care workers who were asked to leave by the families before a shift was over could inform the OOH advice line instead of their supervisors, who were often unobtainable. The OOH advice line, in turn, would let the OOH district nurses know. The result of this effort is that the SCCC perceives a mutually beneficial relationship with almost all of their providers.

8.7.2 Employing night care workers on contract rather than as bank

Night care workers were reportedly the most in demand. Night care workers on contract get paid whether they work or not, whereas casual bank staff are only paid

for the hours they do. Previously, night nurses were available from Marie Curie and Hospice at Home on a contract and bank basis. However, once night care workers were put on contract, this increased the number of night nurses available. This means that the SCCC can cater much more effectively for patients living on their own. As we discovered with the patient experience pathway analysis (see Chapter 10), it is sometimes possible to allocate night care workers seven nights a week.

Although this increase in night nurse supply is welcome, it requires tactical manoeuvring, in order to juggle the stipulations of the various night sitting agencies (for example, Marie Curie night staff only work within a 25 mile radius from home) with CHC funding restrictions. One SCCC staff member said that organising night sits has become almost a full time job in itself. A family member agreed that the organisation of night care workers was complicated.

Certainly having that coordination [centre] makes it a lot simpler for everybody I think, because as I say, we were having them [night sitters] from three different sources. (Family member EM)

8.7.3 Constant feedback to keep everyone informed

Another way that the SCCC liaises with referring professionals and families is by keeping everyone informed. In interviews, the SCCC staff stated that there is a constant flow of information “every step of the way” (SCCC staff GL) between the SCCC, the district and palliative care nurses and the families when a package is set up or changed. This was confirmed by several district nurses, one of whom said that the SCCC is so specific that they will provide information such as “Tracey will be coming in at ten o’clock” (District nurse VC). One family member said that he received a timetable with details on who was coming and when. When the SCCC was first set up this type of exchange appears to have been less common, which caused the district nurses some concern.

They are in contact with us a lot more now, regular calls, just little updates you know we’ve changed this or we’ve done that or the family have rung about this and keeping us more informed about what’s going on. Whereas at first that wasn’t happening quite so much and you felt a little bit like, because as District Nurses we’re used to managing that and taking charge of it, it was suddenly like oh I’ve completely lost control and I don’t know what’s going on with this care package and it’s quite scary. But they are much better now at telling us this has happened and that’s changed and that’s changed so we’re aware of the needs of the patients and the family and what we need to do to adapt to that. So that’s improved. (District nurse HR)

But another palliative care nurse said that she does not have much information about the care package.

I think the system’s changed, but I think part of it as well is there is an element that goes on that we’re out of the loop on, that whereas we knew before,

that's the only thing is, whereas before somebody would phone to say okay this agency, whether it was Hospice at Home or Marie Curie were going in, and who would be going in, and so you knew who was going on. Now we're removed from that, so all of that goes on, we go in to do our symptom control or whatever's needed, but we don't tend to know about the logistics so much on the actual care package. (Community palliative care nurse NL)

This discrepancy in views could be because only some of the SCCC staff are providing regular feedback or because the information is relayed to the nursing team, perhaps in messages left on the phone, but not reaching the relevant nurse.

8.7.4 Offering an excellent service

The adjectives most frequently used by family members and community staff to describe the SCCC staff were “lovely” and “helpful”. The SCCC offers a personalised service where each client feels that *“it's only you they're looking after, as if they're doing nothing else which is very nice”* (District nurse VC). The SCCC also gives the impression that *“nothing is too much trouble”* (District nurse JK). This high standard of service provision means that the SCCC is likely to be used again in the future.

They were really lovely women that I always spoke to there [at SCCC] who were just great actually. (Family member JF)

That [SCCC] is brilliant, it is just so superb, they're all so lovely there when you phone them up and compared to the old days when you had to set up a care package and you'd go through social services and they wouldn't know who you were. You can just phone them [SCCC] up and the care's there...It just works brilliantly and if it wasn't there we would all just be floundering honestly. (Community palliative care nurse RT)

INT: Okay, and thinking about the Care Coordination Centre.

RES1: Yes, really good.

INT: Okay, what makes you say that?

RES1: They are just really helpful aren't they?

RES2: They are so helpful and you just ring them and it just takes all that pressure away and the communication is good....

RES1: Yeah it's really good.

RES2: And nothing's too much, you just ring up, most of the time you get what you ask for...

RES1: But they try very hard, you know they try, you know, so yes I think the service we get from them is really good. (District nurses JK)

8.8 What makes it more difficult?

8.8.1 Professionals not using the service

Some community nurses appear to not be using the SCCC when they could. The data suggest that this could be for several reasons including:

- *SCCC eligibility criteria are clear that the service is only for fast track patients.* Although 2572 palliative patients in Somerset died during the six month study period, a much smaller proportion of those would meet the eligibility criteria for fast track funding.
- *Community nurses do not know enough about the SCCC.* We found that there was widespread awareness of the SCCC, but a lack of clarity about what it offered. For example, one community and one out of hours nurse were not aware of the weekend hours.
- *Community nurses can and do still organise packages of care themselves,* for example they can directly order equipment through Medequip, and contact care providers via social service and the Central Referral Centre for patients who do not qualify for fast track funding. One district nurse commented that as the community palliative care nurse attached to their team organised the care packages for all of the fast track patients, she had forgotten about the existence of the SCCC. (District nurse H)
- *Nurses prefer to organise care packages themselves.* Given that community nurses have other ways and means to access care and equipment, they may not see the purpose of involving a third party or be happy to pass over responsibility for patients. The perception amongst some community nurses is that the SCCC creates an extra loop that delays care packages. For example, one district nurse said that *“If you want to do something, do it yourself”*. She said when she has a palliative care patient and time is short, she does not want to go back to the office *“to call Peter to call Paul”*. (District nurse H) Another district nurse stated that the SCCC often calls the district nurses to clarify information on the needs assessment form which would be unnecessary if the community nurse was organising the care independently. (District nurse A)
- *Perception that the Care Needs form is too detailed.* Because the SCCC team is almost entirely administrative, they cannot carry out any of the assessment need or decide when the care package should be put in place. But one nurse (specialist community palliative care) suggested that providing this level of detail can be irksome.

It's a pity that we need to open the Medequip catalogue and individual items of furniture required because you think to yourself oh well I may as well just fax that off myself. But there's a slight sense of are we really cutting out the middle man here by doing that? What we physically do on the form is write out, we might want a glide about commode which might be TOI438, and we'll then need to put that on the form which then goes across to the end of life care coordination centre. And there's just a feeling that you could cut to the chase with that. Is there much purpose in us writing it all out laboriously for then somebody at the other end to then repeat that exercise? I'm of a school whereby doing something twice in terms of management is not positive in my view. (Community palliative care nurse RT)

8.8.2 Process of getting authorisation and CHC funding

Before submitting the Continuing Health Care application for fast track patients, the form needs to be authorised by a GP, consultant or specialist nurse. According to one district nurse, some GPs see this as an additional task and are not “on board”. (District nurse A) This authorisation step can create a delay and another nurse argued is not necessary, as district nurses are suitably qualified clinicians in their own right. The Continuing Health Care team believe that the authorisation stipulation needs to remain in place to meet Department of Health guidelines and state that this requirement has already been relaxed by adding GPs and community palliative care nurses to the authorisation list along with consultants.

Another difficulty is the responsiveness of the Continuing Health Care team, whereby some fast track applications are approved rapidly and similar requests are delayed. This causes difficulties for the SCCC team, which may have been contacted by the district nurse early in the day to alert the SCCC team, but the SCCC cannot deliver in a timely manner when CHC approval is not forthcoming. However, with the recent designation of one member of the CHC team as fast track co-ordinator, for two days a week, three nurses commented that the delays have decreased. A 2011 audit of combined Somerset and North Somerset patients for fast track found that 80% of fast track applications were approved the same day (52/65). (Gray et al, 2011)

Sometimes the CHC team does not answer their phone, so community nurses do not know what stage their request is at in the process. The evaluation team experienced this personally, when the evaluation team phoned five different numbers for the CHC team, all going to voicemail, before someone picked up the phone. When feeding this back to the Continuing Health Care team, we were informed that if a CHC staff member is on the phone, the caller will get an out of office voicemail. This leads callers to believe that no one is working, when actually they are otherwise engaged.

8.8.3 Issues with care agencies

There were several potential difficulties with care agency staff which can affect the organisation of care packages including:

Shortages:

- Of care agency staff over the weekends, bank and summer holidays and at times of illness epidemics.
- Of care agency staff available to start during a weekend as care agencies arrange their rotas on Friday afternoon.
- Of care agency staff in certain rural villages. Also if the care staff member lives 30-40 minutes from the patient, and the patient needs care four times a day, those particular carers do not have capacity for other clients.
- With smaller care providers who cannot take on the initial package of care, or do not have capacity, when care needs are increased.
- Of experienced care staff in end of life care, with few new carers coming on board.

Issues with individual care staff such as:

- Fluctuating quality. A district nurse noted that some care staff did not know how to turn sheets or carry out “mouth care”. A family member recounted how she had asked care staff not to wash out toileting cloths in the kitchen sink and to remove toileting gloves before preparing food.
- Care staff reluctant to look in patient notes for Do Not Resuscitate orders, as these notes “belong” to the district nurses.
- Care staff insensitive to family needs. For example, a community palliative care nurse recounted how a carer “sat and did the crossword” while the patient deteriorated and the family wanted the carer to leave.
- Replacement of experienced Marie Curie night nurses with less experienced care agency night care workers who might fall asleep.
- Care staff not authorised to meet all of the patient needs. For example, a family member told the evaluation team of a carer who could not help the patient shower as “*I haven’t had all the assessments and the tick sheets done*”. (Family member JW)
- Care agency staff who have never seen a death before.

8.8.4 Meeting the needs and demands of families

The evaluation team were told that some families have unrealistic expectations, believing that ‘24 hour care’ means that a community nurse will be in the home continuously. For example, one family carer was confused about the “random” level of night care provision, because as the patient was assessed as requiring night sits for four nights, surely one should be allocated for seven. (Family member NJ)

Once these assumptions are clarified and worked through, the SCCC has to dovetail the care available with the family needs. This requires constant, on-going negotiation with the care provider.

When the family are saying, ‘Well actually, can they come in at half past seven? It’s a bit late to come at nine o’clock in the morning, so and so is already up’. So you go back to the care provider, ‘Well [we] can’t really [go in earlier] because we’re down in Eddington at that time, so the only time we can get to them is nine o’clock’. So they try and shift it around and then we get back to the family and say, ‘Well really sorry but they can’t, but maybe next week they might be able to’. So you’ve got a lot of placating to do, because a lot of people think it’s a bit like ordering your shopping from Tesco, that if they want it at half past seven, they’ll get it at half past seven. And as lovely as that sounds, it’s sometimes just not possible because the carer’s not going to be in that vicinity at that time. But the care agencies do try and bend over backwards, I wouldn’t like their job, I think their patterns are even more complicated than ours. (SCCC staff GL)

Once these arrangements are made, the families may cancel or change requirements.

Then phoning the family and saying, 'We've got Monday, Tuesday, Wednesday sorted out'. And they'll say, 'Well we're all right for the rest of the week' or 'I really wanted Thursday not Wednesday because I've got somebody else coming in'. So then you've got to get back to the care provider and say, 'Sorry, really sorry, don't need Wednesday now, could you do Thursday? Okay, we'll go somewhere else'. So there's a lot of that because we are tailoring it to the family needs, because we want to do what they want, not just what we think they should have. And sometimes it's so frustrating, you can spend an hour maybe getting some night sits and then you find that the family say, 'Oh we don't want them now'. You just have to say, 'Okay, well I'll phone you next week and see if things have happened'. And then that weekend the family ring and say, 'We're not coping, we're not coping. Can you get those night sits?' You're thinking oh they've all been cancelled now, but you put a smile on your face and you say, 'We'll see what we can do'. And try really hard because you can't say sorry, you've missed the boat. (SCCC staff GL)

8.9 What would make it work better?

Two suggestions for improving the SCCC service were made. One came from a community palliative care nurse working in the Central Referral Centre who would like secure e-mail channels to transmit information, rather than faxing.

The other came from the SCCC itself. If more funding were available, they would like to expand their service to cover weekends from 8-6, instead of just from 10-3 as it currently stands.

8.10 Does it duplicate something else that's already there?

In terms of duplication, community nurses can and do organise care packages themselves. This can sometimes cause problems if the package breaks down and the SCCC needs to sort out replacement care. With community nurses organising their own packages, it is also harder to keep track of unmet need, for example when care cannot be arranged because care providers are short of staff. In addition, SCCC staff believe this undermines the credibility and reputation of the SCCC because they do not know what is happening. However, one advantage that the SCCC has over district nurses is inside information on care providers.

And they [district nurses] haven't got those relationships and if they were doing it all in their own little groups they wouldn't have the overall view, because we know that sometimes Lifeline will come down a little bit further than their zone if we ask them. And we know that CL Lifestyle have got carers who live in Yeovil. So although they're based in Minehead, you wouldn't think to ask them to do something in Yeovil....And I think it would probably, if the district nurses had to do it themselves, or even if they went into the

federations and did it, they probably wouldn't get as much care going in as quickly as we do. (SCCC staff GL)

Another form of duplication is that there are other agencies that might be confused with the SCCC, such as the Central Referral Centre which manages hospice referrals but sometimes organises care for patients who do not qualify for fast track funding. For example, we heard accounts of two professionals (GP, specialist community palliative care nurse) who were “muddled” about the difference between the SCCC and the Bridgewater Hub.

You know I always use the analogy - it's like when the buses got de-nationalised, you had all these bus routes going at you, and it feels like that at the moment, the way all these different things are coming at you for people grabbing the funding, and nobody quite knows who's doing what. Because we've got the end of life coordination centre, then you've got the Hub doing something else in Bridgwater, and then there's other things that are popping up and nobody actually knows who's doing what. (Community palliative care nurse NL)

8.11 How do the evaluation findings fit with the original hypothesis?

The original hypothesis for the Somerset End of Life Care Co-ordination Centre, generated in the hypothesis generation workshops in early 2011, was largely explicitly developed for the North Somerset Care Co-ordination Centre, except for the follow excerpt.

The Care Coordination Centres provide someone to speak to alleviate anxieties. They can organise equipment and get things organised with one call. Staff have knowledge about what equipment needed eg new bed.

This leads to outcomes around choice of care, trust, holistic system, resources, empowerment, conversations and information.

We found that use of the SCCC led to all of those anticipated outcomes.

8.12 What are the key ingredients?

To successfully implement this model, of the Somerset Care Co-ordination Centre, elsewhere, key ingredients include:

- Good relationships with the Continuing Health Care team and rapid assessment of fast track applications.
- Excellent relationships with, and a good supply of, external care providers with knowledge of end of life care.
- Employing night care workers on contract to build up supply.
- Continual feedback to clients (for example community nurses, patients and family members) on changes in care packages.

- Employing 'lovely', 'approachable', customer focused administrative staff who do their utmost to meet family member and patient needs.
- An experienced and effective manager, from a community nursing background, who understands community service provision, manages staff well, is methodical and personable, and with excellent communication skills.
- Putting care packages in quickly and efficiently.
- Good working relationships with sources of referral, for example community and hospice nurses.

8.13 Conclusion

The SCCC offers a valuable, highly appreciated service, which is clearly popular with both family carers and those professionals who use it regularly. They are grateful for the excellent quality packages that are assembled quickly, with minimum fuss, by helpful staff. Quantitative data suggest that proportionally SCCC users have fewer hospital admissions and A&E attendances in the last month of life when compared to non-Delivering Choice service users. Moreover, an impressive 70% of those using the SCCC die at home. Thus, these promising findings suggest that the SCCC has successfully met its key outcomes.

Although both the NSCCC and the SCCC models have successfully delivered their intended outcomes, the SCCC model differs from the NSCCC in several respects. At about £150,000, compared to about £370,000 a year, the SCCC is cheaper than the NSCCC, as it has fewer staff overall and most SCCC staff are at administrator rather than nursing level. Most notably, without an in-house fast track co-ordinator, team based nurse assessor or its own personal care staff, the SCCC is much more dependent on developing good external relationships, especially with the Continuing Healthcare team and the care agencies. Given the importance of relationship building, the appointment of the manager is crucial. Therefore, a key element that appears to have made this model a success is the combination of attributes held by the nurse manager leading the SCCC.

Undoubtedly, the SCCC is serving well those fast track patients that fall within its orbit. The challenge now is for the SCCC to build on its success by extending its reach. As well improving its current uptake rate of 11%, serious consideration should be given to include non-fast track patients. Given the evidence of impact by the SCCC on hospital service usage, the earlier that the SCCC sets up packages of care for patients, the greater the reduction in hospital costs. Moreover, since 50% of those accessing the SCCC die within nine and a half days after first contact, finding ways to identify end of life care patients to set up care packages earlier is a priority. In addition, as currently three quarters of SCCC patients die from cancer yet only 30% of Somerset residents die from cancer in total, the SCCC could also expand to include a greater proportion of non-cancer patients. Nonetheless, the SCCC should be congratulated for such excellent progress in less than two years since its launch.

8.14 Recommendations

1. Consider amending the eligibility criteria of the SCCC to include non-fast track patients.
2. Identify and provide services for more non-cancer patients.
3. Develop mechanisms to identify end of life care patients (and put in relevant care packages) earlier.
4. Increase the fast track and SCCC budgets to meet the above recommendations.
5. If staff capacity is sufficient, advertise the SCCC widely to remind community staff of its existence.
6. Continue to work with care agency staff to improve the quality of care offered to end of life care patients.
7. Continue to employ night care workers on contract to ensure regular supply.
8. Continue to improve relationships with Continuing Health Care team and ensure availability of dedicated fast track nurse(s).
9. Re-consider whether authorisation of fast track approvals by GPs or consultants is useful and more than a 'box ticking' exercise. If the latter, then permit community nursing requests to be self-authorised.

Across the initiative

9.0 Adastra electronic register and Key Worker

Outcomes for patients on the Adastra electronic register

- Fewer hospital deaths in North Somerset and Somerset.
- Fewer hospital admissions in the last month of life in Somerset.
- Stimulated conversations across professional boundaries.

What helps the register work

- Dedicated 'drivers' with small patches (e.g. Somerset EOL facilitators).
- Previous benefit from register.
- Identifying a lead GP within the practice with responsibility for end of life care and specifically the end of life care register.
- Clearly nominating one named person within a GP practice and/or district nurse team to be responsible for handling the *administrative* aspects of the register.
- "Cold calling" to obtain patient consent.
- Putting the electronic register on laptops for staff to use at their convenience.

What helps the recording of Key Worker

- Helping staff to see that they are already performing as 'Key Workers'.
- Assuaging fears that the Key Worker role will entail more work.

What stops the register from working

- Some staff do not see the relevance.
- Major difficulties in obtaining passwords and gaining access, especially in North Somerset.
- Perceptions that the register consigns patients to no further care and therefore is not in the patient's best interest.
- Reluctance of professionals to have advance wishes conversation to gain consent.
- Difficulties in knowing when to time advance wishes conversation to gain consent.
- Host of technical problems e.g. crashing, moving between screens, extracting data, .
- Lack of clarity about who is responsible for registering, maintaining and deleting records. Everyone is responsible so no one is responsible.
- Paramedics unable to access (North Somerset) or receive information too late (Somerset) to influence decision making.
- Change fatigue and implementation

What stops the recording of Key Worker

- Staff reluctance to be recorded as Key Worker because of confusion about the role, a belief that the informal systems work well and/ or a perception of 'tick boxing'.

9.1 Introduction

The Adastra End of Life care electronic register is region-wide in the South West and so not exclusive to the Delivering Choice programme. The aim of the electronic register is to record patient advance care wishes so that professionals across organisational boundaries (for example hospital, community, primary care sectors and hospices) can update and access information when in contact with end of life care patients. All patients who might die within the next 12 months are eligible for registration, regardless of condition.

This section covers two interventions: the electronic end of life care register and the recording of Key Worker, which is a field in the register record. Before beginning, however, a note on terminology, as the Adastra end of life care register is known colloquially as 'Adastra', for the company that developed and launched this product, but we have referred to it interchangeably as 'Adastra' and 'the electronic register'.

The costs of the electronic register for a minimum three year contract were an initial £10k for the set up fee with an ongoing cost of 2p per head of population per annum (Phase I report). As part of its QIPP strategy, the Strategic Health Authority expected that use of the electronic register would account for a savings of 10%, although no further information was available about where these expected savings would be made (Executive Board minutes 15.6.10).

To learn more about the register and Key Worker, we obtained the views of 85 professionals, 71 in interviews and 14 in surveys, including community nurses, specialist palliative care nurses, hospice nurses, GP surgery staff, Delivering Choice service providers and hospital staff. We also read documentation such as the Marie Curie Phase I, II and III reports, Board meeting minutes and papers.

9.2 How are the register and Key Worker supposed to work?

9.2.1 Register

We did not find explicit objectives and outcomes for the register in any documentation. Key fields in the electronic end of life register include Key Worker, preferred place of death, advance care wishes, 'do not resuscitate' (DNR) status and anticipatory prescribing ('just in case' boxes). The assumption appears to be that access to this information increases the likelihood of meeting patient wishes and improves coordination of care across discipline and organisational boundaries. The intention was to shift end of life care from reactive to more proactive responses from professionals, with earlier identification of appropriate patients.

The electronic register was intended to be especially helpful to Out of Hours and emergency staff, who often have no way of accessing the records of daytime doctors and nurses. So, for example, if paramedics attend an end of life care patient, they could access details on the patient held on the electronic register to find out if the patient has a 'do not resuscitate' order in place.

The two Care Coordination Centres in Somerset and North Somerset held responsibility for “establishing, maintaining and reviewing the end of life care register, including information on preferred place of care and death” (Phase I report), although, as this account suggests, discharging this responsibility can sometimes be taxing.

This part time GP sent through what we call the additions form, but the patient hadn't given consent, she hadn't ticked the consent box, and we're not supposed to put it on without the patient knowing. So I phoned [the GP], she was part time, she wasn't in surgery until the next week. So I said, 'Well can you ask one of the other GPs?' Oh, they didn't know anything about it. Then the patient went into Bridgwater Community Hospital, so I thought okay, they still use the urgent out of [hours] care services. 'Could a doctor please have this conversation?' Well I asked the nurses. They said, 'Oh we don't do advance care planning'. So I said, 'Well could one of the doctors?' 'Oh well there won't be one in now until Monday; they'll only be called in if it's emergencies'. I thought, we're not getting anywhere here. So I phoned on the Monday, oh yes the doctor would do it that day [and then] didn't. So another week went by. So this patient still wasn't on the register. Then I phoned, I think I might have been out of the office a couple of days. I thought oh still not on the register, this would be sod's law wouldn't it that this patient gets called 999, gets resuscitated. And the GP had gone on holiday, and it was just a series of errors. There wasn't a Key Worker identified, nobody wanted to take responsibility. Then the patient was discharged home and eventually, I can't remember, it went on for what seemed like weeks, I got the doctor saying, 'Oh yes the patient would give consent'. And so I put the patient on the register. (SCCC, GN)

9.2.2 Key Worker

The electronic register includes a 'Key Worker' and 'associate Key Worker' field, ideally one of whom is a community nurse. The purpose of the Key Worker is to “navigate and co-ordinate care” for families and patients across organisational boundaries (Phase I report). Ideal Key Worker characteristics are that the Key Worker is someone that the patient and family members trust, the Key Worker knows about services available and the Key Worker is a member of the multi-disciplinary team (Executive and Stakeholder Board report May 2011). Ideally, the Key Worker should be assigned when the patient is placed on the electronic end of life care register or at a Gold Standards Framework or multi-disciplinary team meeting (Executive and Stakeholder Board report May 2011). Initially, the Key Worker field just contained a professional discipline (for example district nurse) but the name of the Key Worker with contact details are now recorded in both counties. The roles and responsibilities of the Key Worker were identified as:

- Register the patient on end of life register (as per the first step of the Delivering Choice pathway – see Chapter 10).

- Act as a main contact for patient/carer.
- Carry out basic recognition of patients needs to be assessed.
- Identify associate Key Worker to act as a deputy in their absence.
- Coordination of assessments, referrals, information, equipment, medication and care package, support to Out of Hours.
- Provide advice information and guidance to the patient and their family member and to other professionals regarding the patient.
- Ensure that the family member / significant others needs have been assessed and met.
- Ongoing monitoring to ensure the patients' needs are being met effectively.
- Ensure necessary risk assessments are completed in a timely fashion.
- Bereavement follow up. (Executive and Stakeholder Board report May 2011)

9.2.3 Gaining access and consent

Professionals from a variety of backgrounds including district nurses, paramedics and hospice workers received training in using the electronic end of life care register. To access the system, professionals need to apply for and obtain a valid, current password. The system was intended to be available in hospices, GP practices and community team bases, A&E departments, ambulance services and some hospital wards.

To be registered on AdastrA, a professional and the patient have a conversation about end of life care wishes and the patient gives consent to be registered. This discussion is often initiated by a community or hospice nurse or sometimes a GP. Previously, patients could be put on the register without giving their consent but now, when registering, the rest of the record will not advance without completing the consent box.

9.2.4 Roll out and costs

To roll the register out in North Somerset, the End of Life Care facilitators offered training to different professional groups and worked directly with GP practices on request. In Somerset, Marie Curie Cancer Care funded nine End of Life Care facilitators, one for each federation to improve uptake of the register amongst community staff and GP practices from the summer of 2011. In addition, the Somerset Quality Improvement Facilitator worked with Somerset health professionals to help implement the register.

9.3 How does the register actually work?

9.3.1 What prompts professionals to use the register?

To be clear, 'use' of the register consists of two possible actions: (1) entering or updating information on to the electronic register including initial registration or (2) viewing the record to inform decision making. Participants reported that they entered data:

- As a matter of routine (two community hospice nurses).

- To ensure that the wider health and social care community was kept up to date with decisions, care plans and latest treatments, usually soon after recent contact with the patient, carer or when in contact with another service on behalf of the patient (two community hospice nurses).

Participants recounted that they viewed data on the electronic register for decision making when:

- They came across a patient unfamiliar to them and they wanted to be fully informed before progressing with the case. (Discharge in reach nurse).
- They wanted to know the patient's advance care wishes (various professionals).
- To check to what extent GP surgeries were using the register (community palliative care nurse).
- To prepare for multi-disciplinary meetings (community hospice nurse).
- To support discharge planning (hospital palliative care nurse).

For example, one community palliative care nurse, who could not actually access the register herself, was keen to ensuring that other professionals knew patient wishes.

I find if I've got a patient who I know is really poorly and I know doesn't want to be resuscitated I can't wait to get them on there just to get that information out there. (Community palliative care nurse RT)

9.3.2 What influences patients to give consent?

The main role patients have is in giving consent to go on the register. We did not talk to patients about registration but a community palliative nurse who 'cold called' patients to ask if they wanted to go on the register recounted that she had experienced a range of responses from "almost hostile" to welcoming.

People who were very receptive to the idea and could understand the merits of it, and perhaps they didn't want to have unnecessary admissions, they wanted to avoid that, and they were very up for people such as a the ambulance service understanding what their diagnosis was. They could see the merits of that and they would very much wish to be included. (Community palliative care nurse RT)

This same nurse went on to say that she carried out the registration process in the patients' presence with their input.

Because she [a patient] knows it's a database and she wants to know what's going out there and I thought that was great because you can help me do it. If there's something else that I hadn't thought of that you want to put in the message bit. (Community palliative care nurse RT)

9.3.3 Uptake and reach

Our figures suggest that annually about 2000 patients in North Somerset and 5000 in Somerset are suitable for palliative care. For North Somerset, data from the Adasta electronic register were extracted on 13 April 2012 in Excel format, which was easy to use and manipulate. For Somerset, data from the electronic register were extracted on 19 April 2012 in PDF format and were much more difficult to manipulate. The table below gives information on levels of recording.

Table 46: Proportion of patients on electronic register in North Somerset and Somerset

	North Somerset		Somerset	
Total on register	169		1054	
Total with Key Worker recorded	59	(35%)*	454	(43%)^
Total patients in study	1022		2572	
Registered	93	(9%) [∞]	331	(13%) [#]
Key Worker recorded	38	(4%) [∞]	156	(6%) [#]
Preferred place of care	81	(8%) [∞]	290	(11%) [#]

* = denominator of 169

^ = denominator of 1054

∞ = denominator of 1022

=denominator of 2572

This table shows that for North Somerset, 169 patients in total were registered on the end of life care register, of whom 59 (35%) had Key Worker recorded. In looking at the study period 1 September 2011 – 29 February 2012, in North Somerset 93/1022 (9%) were registered and died during that time period, of whom 38 (4%) had Key Worker information and 81 (8%) had information about preferred place of care. In Somerset, 1054 patients were registered, of whom 454 (43%) had Key Worker information. During the study period 1 September 2011 – 29 February 2012, of the 2572 Somerset patients eligible that died, 331 (13%) had records on the register, of which 156 (6%) had information about Key Worker and 290 (11%) had information about preferred place of care. Thus, overall about 1 in 10 eligible patients in both counties are recorded on the Adastra electronic end of life care register. Preferred place of care is more likely to be recorded than Key Worker.

9.3.4 Delivering Choice service providers

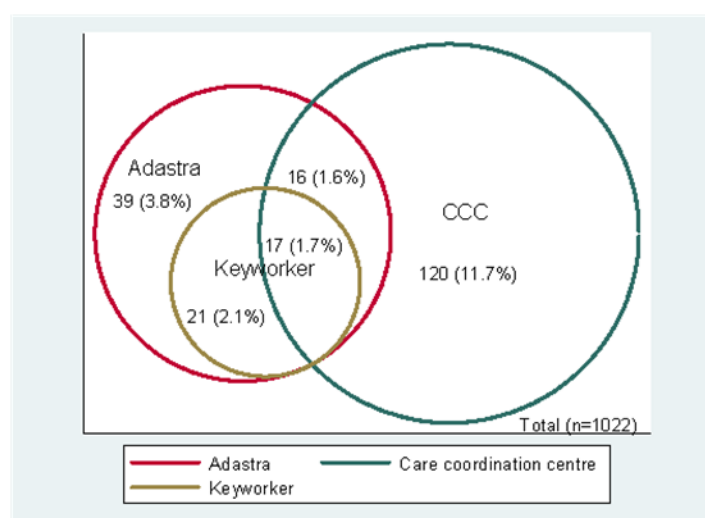
Some Delivering Choice service providers were positive about the register, commenting on its great potential to link up professionals both within organisations and across organisational boundaries. Others were less enthusiastic. For example, one Delivering Choice service provider commented that registration on the register is a first step on the Delivering Choice pathway, yet that rarely happened. In interviews with and observations of Delivering Choice services, we found that all but one DCP

service provider mentioned that they regularly used the electronic register; the exception had yet to receive a password. However, we did not actually observe anyone using the system.

However, quantitative data suggests the register is not as widely used by Delivering Choice Service providers as anticipated. Data from the study period for 1 September 2011 to 29 February 2012 shows that of the 1022 patients eligible for palliative care in North Somerset that died during these six months, 3.3% (1.7%+1.6%) of NSCCC patients were registered on the electronic register of whom 1.7% also had a Key Worker recorded.

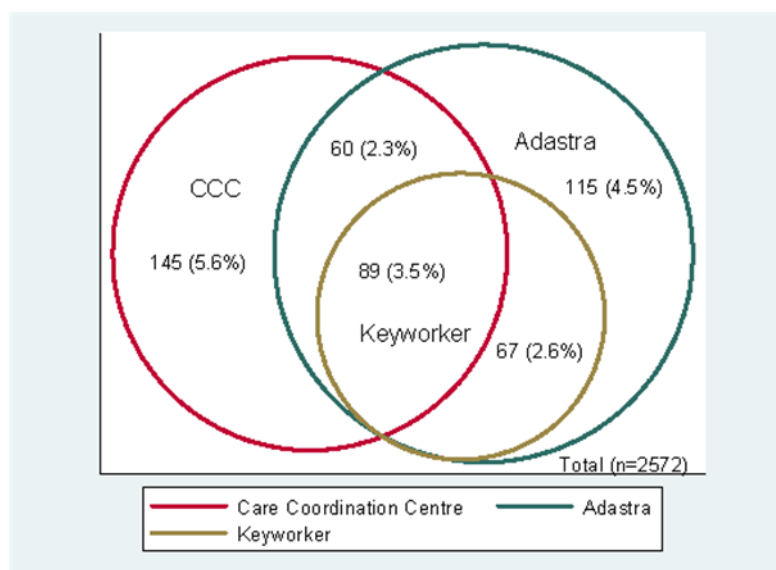
In analysing data just for the 153 NSCCC patients who died during the study period, 33 (21.5%) were registered on the electronic register of whom 17 (11%) had a Key Worker. Perhaps this is unsurprising, as the previous lead for the NSCCC had some hesitation about consent and so did not systematically register patients. As of July 2012, we have been assured that the NSCCC now routinely asks referrers if patients are on the register.

Figure 4: North Somerset Care Co-ordination Centre and register usage



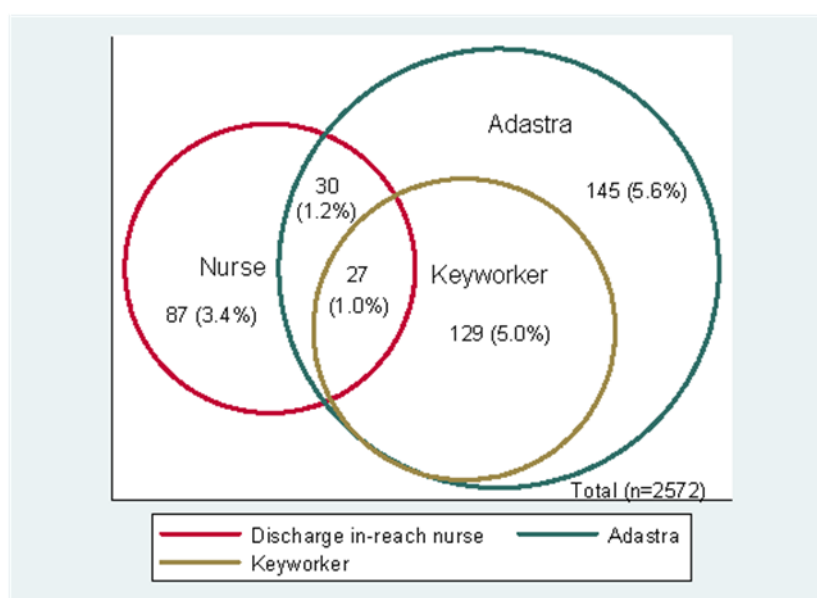
For the Somerset Care Co-ordination Centre, data from the study period for 1 September 2011 to 29 February 2012 shows that of the 2572 patients eligible for palliative care that died in Somerset during these six months, 5.8% (2.3% + 3.5%) of SCCC patients were registered on the electronic register of whom 3.5% had a Key Worker recorded. In analysing data for the 294 patients who received SCCC services and died during the study period, 149 (50.6%) were recorded on Adastra of whom 89 (30.2%) had a Key Worker.

Figure 5: Somerset Care Co-ordination Centre and register usage



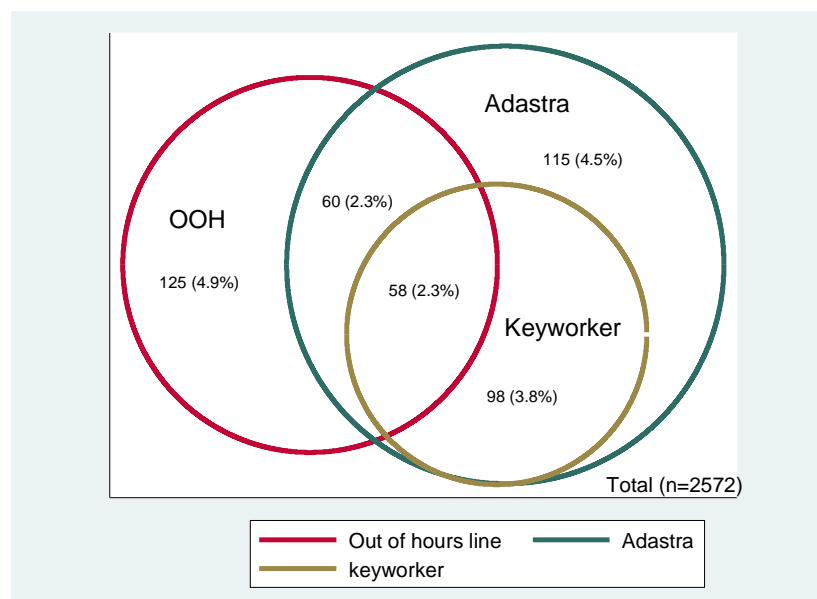
For the Discharge in reach nursing service, data from the study period for 1 September 2011 to 29 February 2012 shows that of the 2572 patients eligible for palliative care that died in Somerset during these six months, 2.2% (1.2% + 1%) were registered on the electronic register of whom 1% also had a Key Worker recorded. In analysing data for the 144 patients who used the Discharge in reach service and died during the study period, 57 (39.4%) were recorded on Adastra of whom 27 (18%) had a Key Worker recorded.

Figure 6: Discharge in reach nurse service and register usage



For the Out of Hours advice line, data from the study period for 1 September 2011 to 29 February 2012 shows that of the 2572 patients eligible for palliative care that died in Somerset during these six months, 4.6% (2.3% + 2.3%) were registered on the electronic register of whom 2.3% also had a Key Worker recorded. In analysing data of the 243 patients who received input from the Out of Hours line who died during the study period, 118 (48.6%) were registered on the electronic register of whom 58 (23.8%) had a Key Worker.

Figure 7: Out of Hours advice line and register usage



Thus, in looking at those who died in the six month study period eligible for palliative care in the two counties, of the total population (1022 for North Somerset and 2572 for Somerset), the proportion of patients who were registered ranged from 2.2% (Discharge in reach nurses) to 5.8% (SCCC). In looking just at the patients who died and used the services, the proportion who were registered ranged from 21.5% (NSCCC) to 50.6% (SCCC). The recording of Key Workers amongst those who died and used the services ranged from 11% (NSCCC) to 30.2% (SCCC). So the Somerset Care Co-ordination Centre was the most likely to have patients registered with Key Workers recorded, although almost half of the Out of Hours advice line patients were also registered. The North Somerset Care Co-ordination Centre was least likely to have registered patients. Given the remit of the Care Co-ordination Centres to maintain the register, NSCCC may need to focus more attention in this area.

9.3.5 Specialist community palliative care and hospice nurses

In moving further afield from Delivering Choice services to the hospice sector, the electronic register reportedly was systematically and frequently updated in North Somerset. We heard accounts from hospice workers in both North Somerset hospices that frontline clinical hospice staff used it daily, as did senior clinical staff. For example, one hospice nurse that worked across the two counties said he inputted new records, updated details for patients regularly and checked the electronic register for all patients on the caseload once a month in preparation for multi-disciplinary palliative care meetings. Another clinical hospice nurse stated that all the details might not always be updated immediately, such as Key Worker, however medication changes were prioritised. Some hospice staff said they used the electronic register to “get figures” or to view the information and facilitate decision-making (for example for advance care, Do Not Resuscitate and planning). However, not everyone in North Somerset hospices reportedly was a daily user as a hospice Education Lead, in-patient hospice staff and a Hospice at Home manager reported that they did not access the register because of no need or an expired password.

We received reports that some Somerset community palliative care nurses did not have direct contact with the electronic register, because they did not have access to the database. However, they did take on responsibility for registering patients by completing a proforma and sending it to the Somerset Care Coordination Centre for entering. A Somerset community palliative care nurse also said she phoned the Somerset Care Coordination Centre when she wanted information back on a particular patient. Another community palliative care nurse stated that although she updated the register, she did not check it much herself, probably because she worked “Monday to Friday, nine to five type hours when information is readily available” (CPCN RM). Another specialist community palliative nurse said she consulted the electronic register when organising discharge planning.

9.3.6 District and community nurses

Use of the register was sporadic amongst district and community nurses, with less use in North Somerset, because community nurses tended not to have passwords. Another nurse, who headed a community team, said that while she had access and some members of her team had passwords, the electronic register was not a priority but she sometimes “look[ed] at patients [to] see who’s on there, how long, any queries”. (DN VI) The North Somerset district and community nurses said they would be happy to use the system, if they could get access.

In Somerset, we found that three of the eight community nurses interviewed accessed and inputted data into the register. A district nurse said she found the electronic register useful for keeping track of patients. Another community nurse with a specialist role as an End of Life Care facilitator in Somerset did not enter patients on the register herself, but she did check on the GP practices in her federation. Four others had applied for passwords but had not yet received them, although one of

these, an Out of Hours district nurse, pointed out that she would not have access anyway, as she does not have a base.

9.3.7 GP surgeries

During the study period April – June 2011 of the interim evaluation report, we were unable to access Adastra data from Somerset. In North Somerset, at that time only two GP surgeries had patients registered on Adastra. During the study period of the final report, from 1 September 2011-29 February 2012, only three of 28 GP practices in North Somerset did not have patients registered. This is definite progress.

In interviews, GPs in both Somerset and North Somerset said they rarely register patients themselves and delegated this task to administrators. One GP commented that this approach worked well as he found Adastra “frustrating” and “cumbersome” (Somerset GP case 8). A community nurse commented that she had observed that younger doctors were more “proactive” than the older doctors who “need prompting”. (CPCN RT) This suggestion of an older/ younger doctor split was also mentioned by a Somerset Discharge in reach nurse who reported that a GP stated that he did not want to put a patient on the system as he was “old fashioned”. This nurse also reported that a different GP stated that he never registered any nursing home patients as they would all be expected to die in with next 12 months, so it was pointless. In contrast, a North Somerset GP stated that they registered all of their elderly patients on the electronic register, regardless of end of life care status.

Two community nurses said that the electronic register was accessed to prepare before Gold Standards Framework or multi-disciplinary team meetings on end of life care patients or after these meetings to update records. In terms of register maintenance, one GP with a special interest in end of life care, who was clearly familiar with the electronic register, stated that she would update all medication changes and delegated the entering of other data to an administrator. This GP added “another place to add history, more pressures on time”. (GP RU)

9.3.8 Community and acute hospitals

Within the acute hospitals, informal discussions with ward sisters at two hospitals revealed that neither used Adastra, as the updating and maintaining of the register was perceived as the responsibility of the Discharge in reach nurses. However, a sister with a palliative care role at another hospital, said she consulted the electronic register to see “who had been added to the register and what had been set up for the patient”. Telephone interviews with three other hospital-based staff nurses (one in North Somerset, two in Somerset) found that they did not access the register, although one had received a password but been unable to use it. A hospital doctor believed that the electronic register was more appropriate for community services.

9.3.9 Urgent care

To understand more about the use of the electronic register by ambulance staff, the two ambulance services for each county (GWAS in North Somerset and SWASFT in Somerset) were contacted. In North Somerset, GWAS staff reportedly only had

minimal contact with the electronic register in that an alert is passed to ambulance crews via the in-vehicle communication system, indicating that somebody at the postcode is on the Adastra register. However, remote access to Adastra was not available for the ambulance crews and often the North Somerset Clinical Support Desk did not have access to the electronic register, so information from the register could not be passed on to the attending paramedics.

In Somerset, paramedics reportedly had better access to the electronic register. They received similar alerts to those in North Somerset and then could apparently obtain further information by contacting the clinical supervisor at the Clinical Hub who logged onto the electronic register. However, the timing of information to the team on duty could be problematic. Sometimes paramedics arrived before the alert was received or before they were able to read it or information from the clinical supervisor might not reach the paramedics on call until too late. The possibility of the Adastra system being down when needed was also a reason to continue with the paper based system, as well as the fact that information – when it is present for a patient - is dependent on address, and this was not always updated. SWASFT are currently trialling an interface developed with Adastra in Dorset and Somerset so that the electronic register and the emergency IT systems can talk directly to each other.

9.3.10 Care Homes

The three respondents in Residential and Nursing Homes indicated that they do not use the electronic register, although one, the registered manager of a Residential Home can access it. A Somerset End of Life Care facilitator commented that Care Homes can access the electronic register via the Care Coordination Centre.

9.4 How does the Key Worker intervention actually work?

Having discussed the electronic register, the next few sections cover the Key Worker intervention.

9.4.1 Uptake and reach

As stated previously, we found that a total of 35% (59/169) of North Somerset and 43% (454/1054) of Somerset patients registered on Adastra had Key Worker information. Thus, the majority of patients on the register did not have Key Worker recorded.

There appeared to be two reasons for the recording of Key Worker. The first was so that professionals from different organisations involved in the care of a particular patient knew who to liaise with and update patient status. The second was the premise that if a specific professional was identified, then the Key Worker tasks were more likely to be carried out. We were unable to test the validity of this latter assumption as it was beyond the brief of the evaluation, but we do have substantial evidence on the extent of the recording of Key Worker, the experiences of Key Workers and some data on contacting of Key Workers by external professionals.

What prompts someone to record themselves as Key Worker is:

- Routine recording of self as Key Worker for all patients on caseload.
- Previous acceptance of clinical responsibility for the patient.
- Belief that they are best placed for the role.

According to interviews, district and community nurses in North Somerset are apparently happy to be recorded as 'Key Worker' but they have limited access to Adastra. In Somerset, community and primary care professionals do have access to Adastra, but there is some reluctance to taking on the official 'Key Worker' title for the purposes of the Adastra register.

The GPs say, 'Well I don't think it [Key Worker] should be me'. The district nurses say, 'Well, we don't know them [patient]'. And the district nurses might say, 'Well, the community palliative care nurse is going in, so maybe it should be them'. Well community palliative care nurses are saying, 'We don't do weekends'. People have got a real hang up about it, whether they think they're going to be phoned at home because the patient gets admitted in the middle of the night, and they're the Key Worker, I don't know, but they don't understand it. (SCCC staff member)

Many professionals reported that the Key Worker functions are taken on informally, although findings from the patient experience pathway work suggests that sometimes there were gaps. In some cases, professionals nominated themselves as Key Workers for recording on the electronic register and sometimes staff were assigned Key Worker status by others. For example, a Discharge in reach nurse reported that she always put the relevant district nurse down as Key Worker. One Somerset community nurse said she would not be happy if someone recorded her name as Key Worker without her permission.

When Key Worker was not recorded, palliative care and district nurses said that they informally knew which colleague (nurse or GP) was leading on the care and approached that particular person with any updates or queries. OOH line staff said they would probably contact the local community palliative care nurse. Thus, unsurprisingly, the majority of patients on the register did not have Key Worker recorded.

9.4.2 Key Worker disciplines

To learn more about the recording of Key Workers, we first analysed their disciplines. In looking at North Somerset electronic register records, we found that community hospice nurses were the most likely to be recorded as Key Workers for patients who die in their preferred place of care, which fit with telephone interview findings that hospice workers regularly and systematically input data. The table below only includes details of the 15 patients who died during the study period in their named preferred place of care in North Somerset, who were registered with a named Key Worker.

Table 47: Key Worker disciplines in North Somerset

Key Worker discipline	N
Community Hospice Nurse Specialist	6
Community Palliative Care Specialist	2
District Nurse	2
Director of Nursing at hospice	1
Respiratory Nurse	1
Head of Community Team	1
“Clinical Lead”	1
Ward Sister	1

In Somerset, of the 102 patients registered with a named Key Worker with contact details who died during the study period in their preferred place of care in Somerset, 49 (48%) of Key Workers were General Practitioners (GPs), 32 (31.3%) were District Nurses, 16 (15.6%) were Community Palliative Nurse Specialists and the rest were a variety of care home and hospital staff. The increased number of GPs and district nurses that were Key Workers in Somerset, in comparison to North Somerset, probably reflects differing access levels to the Adastral register, rather than the willingness of professionals to take on the Key Worker role.

Table 48: Key Worker disciplines in Somerset

Key Worker discipline	N
General Practitioner	49
District and Community Nurses	32
Community Palliative Nurse Specialist	16
Care home staff	3
Discharge in reach Nurse	1
Deputy Matron	1

9.4.3 Key Worker experiences

To learn more about professional experiences as Key Workers, we sampled ten (three from North Somerset and seven from Somerset) Key Workers. Four were Key Workers for only one patient who died in his or her place of choice; four were Key Workers for three to six patients and two were Key Workers for nine or more patients. We also sampled to get a range of professionals including three specialist palliative care nurses, three community nurses, two GPs, one hospital respiratory nurse and one mental health liaison nurse.

Of the three **specialist palliative care nurses**, one from North Somerset was Key Worker for one patient, another from North Somerset had three patients and a third from Somerset had nine patients. Two of the three nurses said they had access to the electronic register and recorded themselves as Key Workers, one of whom said

she automatically defined herself as Key Worker for all patients on her caseload. These three nurses listed the functions of the Key Worker as: symptom control; psychological support to, and liaison with patients and family members; signposting to other organisations; completion of fast track Continuing Health Care applications; facilitation of equipment; advance care planning; and gaining consent for patients to share their information on the register. Two of the three said they were never contacted externally in their role as Key Worker and one said she had received one external call. The nurse who was Key Worker for only one patient said a negative consequence of Key Worker status was that she believed that patients and family members expected her to be available twenty four hours a day, seven days a week. The nurse who was the Key Worker for nine patients was more positive, saying that the Key Worker approach joined up a once fragmented information system.

The three **community nurses** contacted were all from Somerset. One district nurse was Key Worker for one patient, one nurse had six and another had ten. The district nurse with one patient did not usually register patients, although she is the Key Worker for all care home patients. The nurses with six and nine patients respectively both regularly added patients to the electronic register, one of whom treated it like a standard 'checklist'. The district nurse with nine patients negotiated Key Worker status with the GP, but often the GPs preferred the district nurse to take on this role as it was "not a good use of their time". The Key Worker functions listed were the same as those named by the specialist palliative care nurses with the additional tasks of: liaising with care managers, social workers, occupational therapists, physiotherapists, the hospice and GPs; explaining services available to patients; and contacting the GP for pain control. The nurse who was a Key Worker for 10 patients said that if the Key Worker recording did not exist, her role would not be any different. She added that no one outside the organisation had ever contacted her in her Key Worker role.

Both of the **GPs** were from Somerset, one was listed as Key Worker for four patients and the other for six. Both said that administrative staff within the GP practice entered and updated patient details. One GP defined the role of Key Worker as liaising with the district nurses and other nursing staff while the other said he completed fast track applications and 'Do Not Resuscitate' forms and was responsible for updating colleagues at multi-disciplinary meetings. One GP said he wanted to be the Key Worker for his palliative patients because he had already accepted clinical responsibility, but he said he always named a district nurse as associate Key Worker.

The **mental health nurse** worked in Somerset and was Key Worker for one patient. This nurse was based within a community mental health team and she saw individuals on hospital wards. Generally, with regards to end of life patients, she was brought in to assess capacity for decision making. No one had ever contacted her as a Key Worker for an end of life patient.

The **respiratory nurse** in North Somerset was Key Worker for one patient. This nurse reported that she started off as the point of contact for patients with lung cancer or tuberculosis and when the patient move towards the end of their lives, the Key Worker status was transferred to the hospice. As a Key Worker, she added other tasks to those mentioned previously including arranging tests, diagnosing the patient, advising on treatments at the initial stages and arranging appointments. She did not have access to AdastrA.

So in summary, we found that the professionals who were recorded as Key Worker for more patients tended, personally or through an administrator, to routinely enter their own name when adding new records. They also seemed comfortable with Key Worker responsibility and believed that it formalised an existing, previously accepted role. In North Somerset, given that community nurses cannot access the electronic register, hospice nurses have taken on Key Worker status while in Somerset GPs were much more likely to be the named Key Worker, although community nurses were closely involved. Key Worker tasks according to community professionals tended to focus on liaison and support; the tasks identified by GPs included liaison, support and clinical responsibility, while the hospital nurse thought the Key Worker role had a more clinical focus. This confirms the view of one GP, who said that the role of Key Worker can and should change as circumstances alter and be dictated by the personal characteristics of the patient.

9.5 What is the impact of the register and recording of Key Worker on the evaluation outcomes?

9.5.1 Meeting intended objectives

The recording of Key Worker is only as good as registration on AdastrA in general. One of the rationales for the Key Worker intervention is to provide a consistent, reliable contact for liaison and coordination of care. We found that only one of the seventeen professionals interviewed about their Key Worker role had ever been contacted as Key Worker via the register by an external professional. Moreover, we were told that local staff tended to informally identify the Key Worker. So this suggests that this aspect of the Key Worker role is neither well used nor particularly necessary, although the findings from the patient experience pathways somewhat contradict this.

A key aim of the register is to inform decision making in urgent care situations. Although we were not able to confirm reports, several evaluation participants recounted hearing of situations where the register was consulted in a crisis and made a difference.

You hear stories for individual patients where it's made a difference so you know when an ambulance crew have gone out, they've had the information that someone is on the register, they've understood what that's about and they've managed the patient quite differently and there's been a 'just in case' box in the

house and the paramedic has administered something from the 'just in case' box and kept the patient at home. (GP ZB)

One Somerset district nurse cited a recent example when she had updated a patient's records on the register to record preferred place of care as the hospital. Apparently, when the ambulance service arrived the district nurse said the paramedics accessed this information and the patient's wishes were respected.

But we were also given reports of the register not being used.

And there was a patient for instance who had been told 'do not resuscitate', I don't know that the form was in the house but it was certainly or they just couldn't find the form but it was certainly on the end of life care register in big capital letters and when the ambulance crew arrived they said, "oh we haven't accessed that. We didn't know anything about it" and started to resuscitate. (Community palliative care nurse RT)

The anecdote above comes from Somerset.

9.5.2 Coordinated care

The end of life register and Key Worker intervention appear to have little impact on co-ordinating care, largely because the majority of patients are not on the register, Key Worker recording is often missing, and few professionals appear to view the database to inform their decision making. When asked which aspect of the Delivering Choice programme was the least helpful, the most common response was 'Key Worker'.

In contrast, several participants commented that they thought the register was the most helpful, although they then went on to identify the potential of what the register could do rather than provide first-hand accounts of its successful actual use. Instead, we received reports such as the following, about how poor information flows between hospital and community service providers impacted negatively on care.

My father was however having a number of seizures [at home]...my mother would panic and she would need help, and of course it's a 999 call. The guys come and they take him off to hospital. And you start again, you start again, because A&E don't have a clue, they don't know, they don't have the records, they don't understand, so it's a complete starting from scratch thing again. And we go to the point of saying to our GP, we tried to say to everybody, "Can we find a way if my dad has a seizure that we find some way of not having him transported to hospital as an automatic thing? Can we deal with the circumstances here at home where he's being well looked after?"...Surely there needs to be a level of understanding, and the notes need to be clear so that when the medical professionals arrive here they go ah right, you know the score, we're not going to take Mr C into hospital, we're going to deal with the situation here because we understand what the issues are. (Family member GS)

However, we also heard one account that perhaps the register is having more of an impact than it appears, as suggested by a Somerset GP who indicated that if the register was not regularly updated then she noticed that the coordination of care becomes patchier.

RES: We're quite proactive about it...If we do it that way then we can pre-empt problems and get 'just in case' boxes in so on and make sure that they're all on the Adastra and it seems to go smoothly. If you let that slip for a couple of months you end up having problems, we have ended up, or the patients have ended up and relatives have ended up having problems.

INT: And what do you mean by problems? What kind of problems?

RES: Calling Out of Hours and nobody knows anything about them, there's then the usual kerfuffle with from going into hospital or trying to stop going into hospital and drugs not being available and stuff. So we've been much more proactive than we used to be before we started doing it all. (GP RK)

9.5.3 Death in preferred place

Very early on in the Delivering Choice programme, before any services had been set up the Executive Committee were told that the use of the register and advance care planning had already showed a 15% reduction in hospital deaths (Delivering Choice Executive Board minutes 15.6.10). However, although that reduction may have occurred, it may be premature to attribute this to the register and advance care planning, as many other factors might have contributed to this decrease.

In both counties, we found that significantly fewer patients registered on Adastra died in hospital. For North Somerset, we found that 13% of patients registered on Adastra died in hospital compared to 43% of non-Delivering Choice patients. In Somerset, 7% of patients registered on Adastra died in hospital compared to 43% of non-Delivering Choice patients. However, in interviews we found that community professionals are more likely to use the register than hospital staff, especially for those who prefer to die in the community. Moreover, the patient experience pathway analysis suggested that in some cases patients who have died at home are registered after death, which would bias results. So it is unsurprising that quantitative analyses found that patients registered on Adastra were more likely to die at home.

To learn more about the impact of the register on realising preferred place of death, from Adastra records we identified all patients in both counties who had information on preferred and actual place of death. We compared where these patients had actually died against their preferred place of care. In both counties, we found that between 58-69% of patients who wanted to die at home realised that preference; 37-71% of those who wanted to die in a care home did so and 33-40% of those who wanted to die in a hospice died in hospice. In combining the results across the two counties, 59% (175/297) died in their preferred place of their home; 42% (40/102) died in their preferred place of a care home and 38% (16/42) died in their preferred place of the hospice. Although these data are not completely reliable, this suggests

that identifying a Key Worker and setting out advance care wishes are just two of the steps necessary to make that preference a reality.

Table 49: Comparison actual place of death to preferred place of care for both counties

Preferred place of death	North Somerset (actual/preferred)	Somerset (actual/preferred)	Total (actual/preferred)
Home	69% (24/35)	58% (151/262)	59% (175/297)
Care home	71% (5/7)	37% (35/95)	39% (40/102)
Hospice	33% (4/12)	40% (12/30)	38% (16/42)

9.5.4 Hospital usage

In North Somerset in the last 30 days of life, 27% of those registered on Adastra had an emergency hospital admission and 25% visited A&E compared to 41% and 45% of non-Delivering Choice patients. In Somerset in the last 30 days, 30% of those registered on Adastra had an emergency admission and 23% visited A&E compared to 45% and 36% of non-Delivering Choice patients. After controlling for confounders, patients registered on Adastra were found to have significantly fewer hospital admissions.

9.6 What are the other positive impacts of the register?

9.6.1 Stimulating conversations across professionals

Sometimes, the use of the register stimulated conversations amongst different professional disciplines about end of life care. A specialist palliative care nurse reported that discussions with GPs about the electronic register opened up into larger conversations about end of life care. A staff member from Somerset Care Coordination Centre recounted how she used the register as a vehicle to help educate the GPs and raise awareness of end of life care. A Discharge in reach nurse reported how she contacted the relevant district nurse when registering the patient, which again provided an opportunity for relationship building and discussions around end of life care. A further impact reported by a specialist palliative care nurse was that GPs and district nurses were more conscious of asking questions about resuscitation and were less likely to ask a patient the same information twice, once it had been recorded in the electronic register.

9.7 What are family carers' views on the Key Worker?

To explore family carers' views on Key Workers, we asked 'If you had a query or needed some advice or information in regard to the care, is there one particular person you would turn to?' A range of different professionals were named. Four family carers cited district nurses because they had a "good grasp on things" (Family carer PS) and "knew how to coordinate and pull things together" (Family carer CS). Two family carers named the GP, one because of the importance of pain management and the other because the GP was very supportive with daily visits on

the way to and from the surgery. Two mentioned a hospice nurse, because “you could always get hold of her” (Family carer PC) and the hospice nurse had “some clout” with the GP and consultant, who responded more quickly at the instigation of the hospice nurse (Family carer WJ). One mentioned a home dialysis centre nurse. A final person named three people – the Discharge in reach nurse, the community palliative care nurse and one of the hospital sisters.

The positive aspect to these findings is that from the family carers’ perspective the flexibility of who takes the Key Worker role works well, as the programme developers intended. It is also reassuring that most family carers were clearly able to identify a professional who had adopted the Key Worker role.

9.8 What helps to make the register work?

A North Somerset End of Life Care facilitator said the register needed dedicated ‘drivers’. In North Somerset, this largely fell to the North Somerset End of Life Care facilitators, who were stretched to cover such a big patch. ‘Drivers’ were also employed in Somerset with the deployment of nine End of Life Care facilitators with district nursing or palliative care backgrounds for 15 hours a week each. An additional resource was a Quality Improvement Manager in Somerset who visited GP practices on request. A large part of the role of the driver is giving staff

...the feeling that it's not going to be such a big task that they can't do it [and to]...keep drip-dripping and updating people, new staff come in all the time, unless you keep people updated they don't know about Adastra”. (NSCCC staff)

Given that the overall number of records for Somerset was 1054 compared to 169 for North Somerset, this suggests that the deployment of the nine End of Life Care facilitators attached to local federations and the visits of the Quality Improvement manager may have had an effect. The Somerset Adastra service map in Chapter 11 provides information on which Federations took up Adastra most readily. In comparison, although the two North Somerset End of Life Care facilitators were also charged with spreading the use of the register, they appeared to have less success, perhaps because their patch was too big.

Other strategies mentioned included:

- Identifying a lead GP within the practice with responsibility for end of life care and specifically the end of life care register. For example, a Somerset GP ensured that all of the eligible patients within the practice were on the register. A North Somerset GP extended this role to check death data from the PCT against those registered on the electronic register to monitor two GPs working at nursing homes. This latter GP also regularly reminded her colleagues to register “unstable patients”.
- Clearly nominating one named person within a GP practice and/ or district nurse team to be responsible for handling the administrative aspects of the register. In

some places, this person was an administrator who used a proforma completed by healthcare professionals.

- “Cold calling” to obtain patient consent.
- Putting the electronic register on laptops for staff to use at their convenience.

9.8 What makes using the register more difficult?

9.8.1 ‘End of life’ term off putting

A community specialist palliative care nurse said that the name of the tool (‘end of life’) causes consternation and this deters professionals from asking patients for consent. Another suggested that the term ‘end of life register’ meant that the register was perceived as more of a ‘death’ than ‘care’ register, signifying that care will be withdrawn.

I do wonder whether some people feel if you’re on the end of life register...that’s it and then they’re not going to get any more treatment, they’re not going to get any more care and whether that’s why they’re a bit resistant to use it. (Hospital nurse)

Further discussion of this point is made in Chapter 11.

9.8.2 Some GPs are reluctant or do not know enough to engage in end of life care

Two community nurses, a GP and one Delivering Choice service provider, commented that GPs can play a major role in registering and maintaining the register, but there is a perception that GPs often do not know much about end of life care or the role of the register in improving practice. A major contribution of GPs towards palliative care is identification of who is coming to the end of their life but “we know we’re not good enough at doing that”. (GP ZB) This same informant said that GPs are “wary” about having “those conversations” with end of life care patients.

9.8.3 Timing conversations and gaining consent

The timing of “those conversations” is critical. Patients are eligible to go on the register from 12 months of expected death and professionals are encouraged to make early identification to plan for appropriate services. But because patient consent is needed, the professional needs to broach the possibility of end of life when the patient is ready. This is much more likely to happen in the few weeks just before death when someone is deteriorating. A GP said that it is harder having those conversations with people suffering from heart failure because “people don’t really believe that heart failure kills you” (GP ZB), whereas there is more of an acceptance of death with cancer.

Having had the conversation with the patient and registered the details, some patients, on further reflection, change their minds, which required re-inputting the data. In addition, a community hospice nurse said that register entries may be only partially complete as patients may not wish to talk about preferred place of care at the first conversation.

The issue of gaining consent before registration has advantages and disadvantages. An advantage is that any healthcare professional accessing a record on the register knows that the patient and carers are aware of and has accepted their terminal status. This information is useful for staff meeting the patients for the first time, as it determines the content and structure of ensuing conversations. However, there are also disadvantages, such as the prior need for consent deters staff who are reluctant to have conversations about end of life care from registering patients. A North Somerset hospice worker reported that since the consent box has become mandatory, the register is used less frequently.

9.8.4 Difficulties with passwords and access

As stated previously, we identified Somerset community palliative care nurses who did not have access to the electronic register. A Somerset district nurse also said that she and her team do not have access, as they are waiting until the team is re-organised into a 'hub'.

Another difficulty was around passwords, as they can take months to receive by which time they can be invalid. This was particularly true for North Somerset, where one Out of Hours community hospital nurse reported that she had been waiting for a password for two years.

Passwords also often appeared to expire quickly and needed regular updating. Moreover, staff can work on multiple systems with other passwords and they cannot remember which password applies to each system. For example, an Out of Hours GP reported that she had been told that the ambulance service needed seven different passwords to serve the different health communities. Two community hospice nurses confirmed that several passwords are required to log on via the hospice/ hospital links.

9.8.5 Technical problems

Once a professional obtains a password and patient consent, there are a host of technical problems that might be encountered. Several participants called the system "old fashioned" or "clunky" (Delivering Choice service providers, GP, district nurse), although we also received reports that the system now worked better (GP administrator, hospice worker). As a Somerset hospice worker recounted

We had a separate link to it [register] there which was umpteen passwords and once you're on it you could only stay on it for a certain length of time before it just phased out. So you'd be halfway through a patient, you might sort of have several to do. We save up because it was such a long time to get on it and it was very complicated. (Community palliative care nurse RT)

Two North Somerset community hospice workers, who said they used the electronic register frequently, gave similar reports saying that the system is down at least once a week. One added that she dreads using the register, as so often it is not working.

Apparently, there are other technical deterrents to use. A GP surgery administrator commented that the users have to jump between screens. So, when a new patient is added, the name, address and date of birth are all on one screen, but then to note if a third party is involved, to record if the patient is aware of their diagnosis and so on, the user needs to go to another tab. She also said that if she searched on the patient's full name or by surgery, their details may not come up so she ends up creating duplicate entries or looking through the entire list. A district nurse said that she can sometimes edit a patient record and a 'diagnosis' flag will appear, even though this is already there or it will say the GP details have not been added when they are already recorded. She has also noticed occasional duplication and she was aware that sometimes patients who are registered do not show. So not only are there difficulties in recording patients on to the register, there appear to be some challenges in getting information out.

Other technical problems included:

- The electronic register does not link into the other local systems (for example RIO in the community, EMIS and other GP systems, Crosscare in Somerset hospices etc) so there is duplication of effort and each system is less likely to be complete.
- A community specialist palliative care nurse said that the technology does not "reach" to places without a main server, for example Minehead, Bridgwater and Glastonbury, although a different community nurse spoke of using the system in Glastonbury.
- The register suffered from several 'bugs', especially early in its implementation such as GPs being able to view all patients registered not just those in their practice (Executive committee minutes 15.6.10). This still happens, according to a North Somerset GP surgery administrator responsible for entering onto the electronic register, who was interviewed in June 2012. She can see all entries on the register and would prefer only to access those for the patients at her surgery.

So although several participants said that the register was easy to use, there were also multiple technical problems that may dissuade busy professionals from accessing the system.

9.8.6 Lack of clarity about responsibility for the register

Because the register developers did not want any particular professional group to colonise and take ownership of the register, there is a vacuum when no one takes responsibility.

The protocol for registering patients is not uniform or clear. For example, in Somerset some professionals said that the individual registering the patient has to be the same person who obtained consent, whereas others said this was not the case. In addition, early on, some professionals were reluctant to register patients without checking first with a GP.

If a procedure has not been put in place and since any professional can register, for each patient, responsibility for registration needs to be negotiated. In Somerset these discussions usually occur between GPs and district nurses, but other staff can get involved. For example, care home staff reported an incident where they called on the North Somerset End of Life Care Facilitator to adjudicate. Although the actual registration process is quick, the discussions before and about registration can be time consuming.

It isn't actually the putting it on that I find time consuming, it is more about communicating at GSF [Gold Standards Framework] meetings and things and finding out is this person on, who's going to put it on, who's got the information for it, that could be a full-time job in itself. And some surgeries it's very effective and others where you have less commitment to it that is more difficult. (CPCN RT)

Sometimes when healthcare professionals did accept responsibility, they then found that another professional had already registered these patients.

The responsibility for updating the register is also unclear, for example adding death data and taking patients off the register after death. In addition, some GP practices using the electronic register to support their multi-disciplinary team meetings, often only meet every 8-12 weeks and so the system could be up to three months out of date. One community palliative care nurse said poor updating may be a deterrent to use as *"It's only as good as the updates, isn't it?"* (CPCN RM)

9.8.7 Change fatigue and implementation issues

We received reports in Somerset and North Somerset that the timing and strategy of implementation was problematic. In Somerset, we received one report that initially the register was seen as largely a top/down initiative from the local Marie Curie Delivering Choice team and so local professionals did not have ownership. This was addressed when local district and community palliative care nurses became federation EOL facilitators in the summer of 2011. In North Somerset, roll out was delayed in some places and so professionals had received training but did not have passwords and so were not using the system.

When [End of Life Care facilitator] and I came into post that was one of my really early messages to get out there about Adastra. By then, people had done the training, forgotten about it, had thought I can't be assed, I tried to do that before, what's the point, I couldn't get on it, couldn't get logged on, I'd forgotten my password. So there was a lot of negativity about it in the beginning. Again, part of our role was going out going, 'This is Adastra, it's really easy, it's really simple, it's really useful', but we need to sustain that message. Unfortunately, at the very beginning it wasn't fantastic because they had no one driving it and you just have to have someone pushing all the time. When people use it, they see the benefit. (End of Life Care facilitator)

Change fatigue also affected professionals' willingness to take the electronic register on board, because there were already lots of systems in place and professionals think *Oh God, another system, because we've had so many systems and ...life changes so quickly, you just think have I really got time for that at the moment?* (NSCCC staff member). In addition, a community palliative care nurse thought that implementation could be affected because some health professionals did not see the benefits. He had noticed that when local professionals had received a direct benefit from using the register, they were much more likely to update records in the future.

9.9 What would make the register work better?

Apart from addressing the password and access problems in North Somerset amongst community staff and paramedics, one suggestion made by a Somerset community hospice nurse was to have satellite access so that community nurse could use the electronic register on their laptops and then update immediately when out on visits. This could also be useful for OOH district nurses.

Another suggested strategy was to introduce day staff to Out of Hours working, so that day staff would better understand the importance of the register.

Day staff are in their bubble and they think that's all that happens is in the day, unless you've done Out of Hours working you don't appreciate how long Out of Hours is, how lonely and how vulnerable people feel Out of Hours. It wouldn't do any harm for every member of staff to go and do some Out of Hours because you learn a huge amount. (NSCCC staff member)

In her patch, day nurses on the community wards have extended their shifts to seven pm, which may help foster understanding of the pressures of Out of Hours. A GP agreed that day time staff, including GPs, need to shift their perception to have a greater understanding of the needs of Out of Hours staff.

GP's just work inside the box most of the time and they don't think about the fact that the week has a hundred and sixty eight hours and actually we're only open for, I don't know, seventy two hours of those, so they don't necessarily think about what happens at three o'clock on Sunday morning, and don't think about how the Out of Hours work and the ambulance and things like that. (GP AL)

9.10 What helps to make the Key Worker role work?

9.10.1 Helping staff to see that they already are Key Workers

Given that reluctance to be named is the major problem, one End of Life Care facilitator recounted an incident of when she was able to work with community nurses to address their fears around recording of Key Worker.

They'd [community ward] had a very traumatic situation with a young man dying with a baby and wife. They had managed his care brilliantly, but it had been very traumatic. An incident had happened during the Out of Hours and it was around

medication I think. That was resolved, but it just tipped into the days because the night staff left a message for the days, it was all a bit of miscommunication. The patient didn't come to any harm, but it left the nurses feeling, "We thought we told them," and the night staff were saying, "We didn't know that". There was just this miscommunication, which is where RIO would be brilliant because then you'd be able to see it. What I did in that instance, I actually got all the team together with the night staff, the evening staff and the day staff and we had a debrief, about what worked, what didn't work, and out of it, there were two key people in there. I said, "What we need to work at is the key role here, the Key Worker role". I said, "I've listened to all of you, and you're doing the Key Worker role". They went, "How are we doing that?" I said, "Well you and you, you're being the Key Workers, you've just told me exactly everything. You've told me that you told so and so. You told me that they came to you because they knew you, you were doing the Key Worker role". It was like a light bulb moment for them... They weren't concerned about being a Key Worker because they could see that they'd been doing it for this chap and what they needed to do was do that for everyone, not just for one that was problematic... So yeah, it works, but it just needs that backup of telling them that they're doing it right. (End of Life Care facilitator)

9.11 What makes it more difficult to record Key Worker?

9.11.1 Reluctance to take on Key Worker role

With regards to the recording of Key Worker, the major challenge is getting staff to take official responsibility via recording on the electronic register. We found that a few specialist community palliative care nurses and district nurses were willing to take on this role, although one specialist palliative care nurse who regularly assigned herself Key Worker status talked about not wanting to "lumber" others. Other nurses interviewed actively avoided it.

INT: What's been your experience of the Key Worker?

NURSE1: Not myself.

*NURSE 2: Everybody's stepping backwards quickly when you try it.
(Community palliative care nurses RM)*

One community palliative care nurse questioned how useful the role was as she was not available out of hours. A district nurse said that staff did not want extra work. Most commonly, participants mentioned that this reluctance was partly due to poor understanding of the role and responsibilities, partly because current informal systems appeared to work well and partly because of resistance to "tick boxing". (GP RK)

Sorry to be very sceptical about this particular thing, it's like in a ward setting if you see, I don't know, Fanny Adams who's the named nurse above the bed, I just think well are they going to be here? Are they on holiday? Are they off

duty? What are they actually doing for this person? It just seems a bit like a slight publicity PR exercise to me. (District nurse UC)

9.12 Do the Key Worker and registers duplicate something else that's already there?

There is nothing that duplicates the Key Worker intervention, although the term is used in other contexts such as in care homes.

But the functions of the register are duplicated in both paper and computer systems. With regards to paper systems, one End of Life Care facilitator in Somerset mentioned that there are currently three forms capturing the same information and professionals do not want to “let go” of any. Another community palliative care nurse in Somerset mentioned that the GPs feel they are duplicating effort as they record much of the information the same information on the electronic register and ‘special messages’. North Somerset also has its own ‘white’ and ‘yellow’ paper forms. A practice manager mentioned that there are two other reporting tools for notifying ‘Do Not Resuscitate’, including the Primary Care Data Reporting Tool (PCGR). In one area of North Somerset, the electronic register became the default tool when the “letters they send out when someone is poorly” were “taken away” and staff were told only to use the electronic register.

With respect to electronic systems that are likely to capture data on dying patients, we have an account from a fast track facilitator in North Somerset that she turns to RIO, not Adastra, to get the information she needs. In Somerset the hospice IT system Crosscare had good quality data, but only hospice staff and the Discharge in reach nurses (and increasingly the hospice staff in North Somerset) had access. As a result, non-hospice patients (e.g. non-cancer) were not included. Nonetheless, the Crosscare system appeared to be functioning as the Adastra system was intended to, albeit on a smaller scale. A community hospice nurse, in comparing CrossCare with Adastra, described Adastra as factual and very concise. Although not confirmed, we were told that Crosscare has just bought out Adastra and so this may have an impact on the usability and spread of Adastra.

There are a host of other service specific electronic information systems in hospitals, GP practices, community services and hospices that system owners prefer and/or insist are kept up to date. Given that the majority of these systems do not ‘talk’ to the Adastra system, it was time consuming for professionals to ensure that all of these systems are kept up to date.

9.13 How do the evaluation findings fit with the original hypothesis?

There was no original hypothesis for either the electronic register or the recording of Key Worker developed in the hypothesis generation meetings.

9.14 What are the key ingredients?

To implement the register successfully elsewhere, the key ingredients are:

1. Eliminating technical hitches before rolling out.

2. Carrying out change management work with local professionals to gain acceptance that there is a problem that an electronic register will successfully address.
3. Employing dedicated 'drivers' with a small enough patch, so that they can work intensively across GP practices, community teams and hospices.
4. Rolling out training at the same time as putting drivers in place.
5. Ensuring that the process for obtaining passwords is smooth and quick.

9.15 Conclusion

The implementation of the electronic register and recording of Key Worker has been challenging. Although patients registered on Adastra were significantly more likely to die in the community in both counties, this could be because the register was almost exclusively used by community professionals and/ or because of post-death recording of home deaths which would bias results. Patients registered on Adastra were also likely to have fewer emergency hospital admissions in Somerset. The number of patients registered was low (93/1022 for North Somerset and 331/2572 for Somerset) with many possible confounding factors.

Given the on-going necessity to have good quality information available to all professionals who work with end of life care patients, regardless of discipline or organisational base, and the struggle to roll out the Adastra electronic register, we believe there are two options. The first is to move to the implementation of a system such as Crosscare, which has fewer technical problems, does not suffer from negative branding as an 'end of life' register, works well in both inputting and retrieving data, and appears well supported by staff. The second is to continue with the implementation of the Adastra electronic register, but with substantially more resource investment.

If this second option is taken, to encourage the uptake of the electronic register and record Key Worker, professionals need:

1. To be convinced that registration is in the best interests of the patient, have first or second hand experience of the positive impact that the register can make and accept their pivotal role in contributing information to the wider collective.
2. To have clarity about who is responsible for consenting patients and the systems in place for entering and updating records.
3. To be clear about and comfortable with the clinical responsibility of a Key Worker and accept the need for a named Key Worker.
4. To have a conversation with a patient who is willing to discuss their terminal diagnosis to obtain consent.
5. To have direct access to the database that is obtainable in a crisis, with a password that they know.
6. To have confidence that the electronic records are reliable, available and up to date.

We found that the professionals who tended to register and update the database are usually day staff and that their efforts largely benefit those working out of hours. Moreover, day staff often already had perfectly good electronic systems that met their own needs and they prioritised updating their preferred system, perceiving that the administration of another electronic register doubles their workload. So, those who need to put in the most effort to make the electronic register work are not the ones who reap the major benefits.

Thus, one of the principal difficulties that the electronic register faces is that professionals place their boundaries of responsibility around small, immediately known groups rather than the wider health and social care economy. This is a perennial problem within complex, overlapping organisational systems and not unique to end of life care. The successful uptake of the electronic register requires a major cultural shift for all those involved in end of life care to think collectively, and will require substantial effort.

With regards to Key Worker, at present many professionals are not clear about the nature of the 'problem', nor convinced that a problem exists, much less understand how the 'solution' of the recording of Key Worker will help. Therefore, taking on the responsibility of being recorded as Key Worker has many more perceived disadvantages than benefits.

However, the recording of Key Worker is different from enacting the Key Worker role, which seems to work best when professionals volunteer, rather than become reluctantly nominated. While the recording of Key Worker appears almost counterproductive, the actual role itself seems vital, given the findings from the patient experience pathways (see Chapter 10).

Broadly speaking, the enactment of the Key Worker role breaks down into three areas: assessment, co-ordination of care, and advocacy. Interviews with family carers and service records suggest descending levels of professional involvement; so assessment is quite common, good co-ordination of care less so, and advocacy happens most rarely. However, having an advocate to navigate the patient and their family through the system, as demonstrated by the Discharge in reach service, especially in a crisis out of hours, is critical to ensuring as 'good a death as possible'. Given that family carers often feel unequipped for these responsibilities, that centrally placed professionals, such as specialist community palliative care nurses do not work out of hours, and that the Out of Hours advice line team appears already to be successfully incorporating advocacy into their role, perhaps consideration could be given to broadening the scope of the Out of Hours advice line team to include the important Key Worker responsibility of advocacy outside of working hours.

9.16 Recommendations

1. Consider allocating further resources to the implementation of the Adastra register to eliminate technical problems, to provide salaries for register 'drivers' and to invest in mechanisms to electronically 'translate' information from Adastra to other systems such as EMIS, RIO, Crosscare and ambulance services' systems so that information need only be entered once.
2. Re-brand Adastra to eliminate the 'end of life' term and maximise the 'care' aspect e.g. Continuing Care Register.
3. Given that professionals said they viewed the register for advance care wishes, consider focusing effort on building up this aspect, with the intention of demonstrating the usefulness of the register.
4. Raise awareness of out of hours information issues with day staff.
5. Set up a smoother, quicker process to obtain passwords in North Somerset. Consider dropping the requirement to have password applications signed off by the lead commissioner.
6. Re-consider the need for patient consent as this might lead to earlier identification of patients.
7. Although the Somerset Care Coordination Centre has registered the largest proportion of patients, both Care Coordination Centres could consider systematic levers to boost registration levels.
8. Work closely with ambulance services to find out how to facilitate access to the register so that the effort of inputting the data is worthwhile, in terms of urgent care decision making.
9. Consider expanding the role of the Out of Hours advice line to formally include advocacy for patients and their families out of hours.
10. Improve technical aspects so that data are easier to input and extract in usable formats.

10.0 Pathways, Frameworks and Patient Experience Pathways

10.1 Introduction

The aims of this chapter are:

- To provide feedback on the use of the Delivering Choice pathway and Palliative Care Framework.
- To compare best practice end of life care service provision against the experiences and trajectories of 10 patients whose family members took part in interviews.
- To explore what Delivering Choice interventions contribute to making the death is 'as good as it could have been'.
- To begin to explore how the programme works as a whole.

Given these aims, this chapter has a different structure from previous chapters. The first part focuses on feedback about the pathway and framework and the second on patient experiences of the end of life care services.

To learn about pathways and frameworks, we carried out interviews with 72 professionals including specialist community palliative care nurses, district and community nurses, hospital doctors and nurses, hospice staff and GPs. We also looked out for use of the pathway when carrying out formal and information observations.

For the patient experience pathways, we drew on interviews with 10 family carers, Adastra electronic data, Delivering Choice service usage data and Primary Care Trust death and hospital admission data.

10.2 Feedback on the pathway and framework

10.2.1 Overview

Clinical pathways have been popularly employed with the aim of increasing quality, standardising clinical practices in health care and aligning clinical, management and patient concerns (Allen, 2009; Appleton and Cowley, 1997; Hunter and Segrott, 2008). The Department of Health's (2008) End of Life Strategy advocated a care pathway approach.

The [End of Life] strategy was developed over a period of a year by an advisory board and six working groups and over 300 stakeholders were consulted. From this process a consistent message has emerged that a whole systems approach is needed. Within this, a care pathway approach both for commissioning services and for delivery of integrated care for individuals has been strongly recommended (2008: 10).

The Delivering Choice Programme pilot work by Marie Curie Cancer Care was integral to the development of by the Department of Health End of Life strategy in

2008. The 24 Hour Care Working Group from Somerset Delivering Choice developed an End of Life care pathway (hereby referred to as the 'Delivering Choice pathway') which was introduced in June 2009. A key tension, however, when implementing clinical pathways is getting the balance between standardising clinical practices and tailoring care to the individual where appropriate (Hunter and Segrott, 2008). Some health care professionals have subsequently resisted this type of approach and instead argue that professionals need to be trusted to make the right decisions based on individual patient needs (Allen, 2010).

Supporting documentation for the Delivering Choice pathway called the Palliative Care Framework (also known as the 'traffic lights') was also developed by the Somerset Delivering Choice working group. The purpose of the Palliative Care Framework was to provide a tool accessible by any health or social care professional to assess the status of any end of life patient, regardless of condition. The information arising from application of the framework could then inform application of the Delivering Choice pathway and the decision making of the professional. The expectation was that the status of the patient would fluctuate throughout the trajectory and through regular application of the framework, professionals would be triggered to respond appropriately in line with the agreed standards.

So for example, patients classified as green were stable but should have undergone assessments, been registered on Adastra with a Key Worker and been known to their relevant Care Coordination Centre. Patients classified as amber were slowly deteriorating but managing and 'just in case' medications should be organised. Patients classified as red were rapidly deteriorating in the dying phase and all appropriate equipment and medications should be in place.

10.2.2 Objectives

The Delivering Choice pathway was developed as a mechanism for health and social care staff "to provide care in a flexible and responsive way whilst still maintaining high quality care throughout the 24 hour period". (Phase II report) Unlike the Liverpool Care Pathway, which was only initiated a few days before death, the Delivering Choice pathway could be employed much earlier. The Delivering Choice pathway was devised for all palliative care patients, regardless of condition, with the aim of ensuring that "patients and their carers/ families receive seamless care with a coordinated multi-professional approach". (Phase II report) A key step in the pathway is the registration of the patient on the Adastra end of life care register and allocation of a Key Worker; our findings on these two interventions are included in the chapter on the Adastra electronic end of life care register.

10.2.3 The Delivering Choice pathway

The pathway has eight steps, which are organised chronologically, each with standards attached. Crucially, the first step is the point where preferred place of care discussions are intended to take place.

1. End of life register
2. Allocation of Key Worker
3. Assessment
4. Care plan
5. Coordination of care
6. Delivering high quality care
7. Care in last days of life
8. After death care

10.3 Roll out of the Delivering Choice pathway and Palliative Care Framework

The assumption of the roll out strategy in both Somerset and North Somerset appeared to be that by raising awareness of the pathway and framework and by introducing staff to their potential use, community, hospital and primary care professionals would be more likely to adopt them.

Within North Somerset, the End of Life Care facilitators were charged with the remit of rolling out the Delivering Choice pathway and Palliative Care Framework. In Somerset, the local Marie Curie project team initially took on responsibility for implementation. In the summer of 2011, the Somerset End of Life Care facilitators then took on the role of promoting the use of the pathway and framework.

10.4 Use of the pathway and framework

Delivering Choice staff were understandably the most positive about the pathway and framework, as they could see benefits of the practical application. For example, a staff member from the North Somerset Care Coordination Centre said that they use the framework to determine the status of a patient when considering fast track funding. This participant also said that she continues to raise awareness of the pathway when talking to community staff referring into the Care Coordination Centre.

I'm constantly saying, 'This should have been in four weeks ago. You're now at syringe driver stage, 'Just in case' you've missed the boat for 'Just in Case'. So I'm having those conversations with district nurses. I'm prompting the use of getting 'Just in Case' in early. So we're using the pathway, but not from beginning to end, we're dipping in and out of it. (NSCCC staff member)

10.4.1 Hospital use

Within the hospitals, we spoke to 14 staff, of whom five said they had found the pathway helpful. A hospital matron mentioned that the pathway is a useful tool to prompt staff about equipment.

What's fantastic about it [pathway] is we have had patients with the internal defibrillators that it gives them [hospital staff] a prompt to remember to get someone to turn them off, pacemakers and such like that that they are more aware of. (Hospital matron)

A cardiologist agreed that the tool was useful, partly because of its adaptability.

[The researcher] asked about the use of the End of Life Care Pathway, and [Consultant] said, "I like it". He elaborated that not all elements of the pathway were always needed, saying that it could sometimes be, "a blunt tool", and also adding that it was a good instrument in that it can be adapted to suit people that he deals with in the Cardiology Department who have End of Life Care needs. (Informal interview Consultant Cardiologist Yeovil hospital 29.11.11)

However, there was an awareness that use of the pathway and framework was not widespread within hospitals, partly because non-end of life care specialists did not believe that the tool applies to their patients.

I don't think [staff] in the hospital are aware of it [Framework or Delivering Choice Pathway] to be truthful... when I gave that to a couple of the doctors they went, mm, I think this is more for palliative care than it is for us....I don't think [hospital staff] follow it [Delivering Choice Pathway]. Well, definitely they don't follow it because the first step is to put them [relevant patients] on the end of life register and in my experience it tends to be the last step. (Discharge in reach nurse)

Moreover, as one matron pointed out, clinical staff may not apply the pathway and framework because of their reluctance to accept that nothing more can be done.

It is getting them [patients] on it [Delivering Choice Pathway] that still remains a problem... A lot of our doctors would love to save everybody and still have that feeling, that belief, that they can get them a bit better. (Matron)

She also said that there was a common misconception that the Delivering Choice pathway only applied to patients with an estimated four weeks or less to live.

10.4.2 Community usage

Many hospice and community team staff interviewed said that they do not apply the Delivering Choice End of Life pathway (n=18). Instead, most use the Liverpool Pathway (n=14) and/ or the Palliative Care Framework (n=11). Amongst those that had used the Delivering Choice pathway, eight community nurses and community palliative care nurses said they had found it useful. For example, two Somerset community nurses said that they use the pathway "from step 1" when they ask the surprise question. We did not find any pattern amongst professional community nurses, as some community nurses found the pathway useful and some did not. The same was true for the specialist community palliative care nurses. The manager of a Residential home, currently working towards Gold Standards Framework accreditation, mentioned using the Framework together with the community nurses, giving an example of a current resident who is in her last days and has advance care

planning. A hospice manager spoke of using the pathway in a novel way - for the purpose of “teaching and encouraging GPs to use the Adastra system”.

In North Somerset, community staff described receiving training from the End of Life Care facilitators in the use of the Adastra register, ‘just in case’ medication, the Liverpool pathway and the framework – but not the Delivering Choice pathway. This could suggest that they have forgotten about the Delivering Choice pathway amongst the many others already in existence or were not aware of it. Those that valued the pathway said that it gave people, especially those less experienced, more confidence. Two community nurses said that the pathway provided more structure.

Community staff identified several barriers to using the pathway including:

- *Profusion of different pathways.* A Somerset community palliative care nurse said that her community team used Liverpool pathway. But on the ward at St Margaret’s hospice, a different pathway from the Delivering Choice or Liverpool was in use. This perception of different pathways as more suitable in different contexts was confirmed by four community nurses who said that they thought the Liverpool care pathway was less useful for community patients. Three hospice workers commented that the Liverpool pathway is much more widely known and established and more likely to be introduced to inexperienced and community staff by hospices. Community nurses from mainly, but not exclusively, Somerset spoke of using the Liverpool pathway “forever” and three seemed especially familiar with it. A GP also noted that the multiplicity of pathways was “a bit of a muddle”. (GP GI)
- *Lack of access to Adastra.* Only one of the North Somerset community nurses contacted (n=9) was able to access Adastra because they do not have passwords. So they can neither register patients nor add updates. Most Somerset community nurses, except for out of hours staff, have more access.
- *Pathway not applicable for patient group.* Three Somerset community nurses mentioned that they tend to work with patients in the last days of life, after many of the earlier steps should have occurred. One pointed out that sometimes even the Liverpool pathway is too late.
- *Too many new initiatives.* One community nurse said that as ‘generalists’ they are regularly receiving new guidelines and pathways to improve practice for a range of conditions (she specifically mentioned continence). So it is hard to remember them all.
- *Perception that pathway already embedded in practice.* Two community specialist palliative care nurses and one community nurse said that they did not refer to the pathway, as the steps were already part of their practice (“you’re teaching me to suck eggs here.” (Community nurse H)). However, this community nurse had the pathway on her wall for reference.

- *Not used by enough clinicians.* One district nurse, who had previously used the Delivering Choice pathway, was now more ambivalent as she had found that “other health professionals, namely GPs, don’t tend to use it”. (QR)

The Palliative Care Framework was widely known as ‘traffic lights’ and appears fairly commonly used. For example, a community nurse who had received training from the End of Life Care facilitators explained how she applied the framework when considering a Fast Track application by asking ‘Is this person Green or urgent?’ Two community nurses also mentioned having an A5 laminated copy of the framework in their bag, although one, who is newly qualified, says she doesn’t yet know how to use it. Two Somerset community nurses and two specialist community palliative care nurses spoke of using the framework in multi-disciplinary Gold Standards Framework meetings. Another community nurse reported that as soon as the team is aware of a palliative care patient, the framework is incorporated into the care plan. A Community Team Lead spoke of preferring the framework to the Delivering Choice pathway as it ‘looks at the patient’.

Overall, we found that community staff reported valuing and using the Palliative Care Framework more than the Delivering Choice pathway. This was borne out in our findings in the next section as of the ten patients analysed in depth, none followed the pathway as proscribed but records for half of the patients included information about red/ amber / green status, which suggests application of the Palliative Care Framework.

10.5 Patient experience pathways

This next section looks at the extent to which the Delivering Choice pathway is applied in practice. To recap, one of the aims of this section is to explore the extent to which the death was ‘as good as it could have been’.

First, we outlined the steps of the ideal trajectory, as set out by the pathway. Next, drawing on data from several sources including interviews with family members, Delivering Choice service usage data, routine NHS data and data from the Adastral end of life care register, we mapped the experiences of 10 patients across North Somerset and Somerset. These ten patients were chosen because they were the only ones who died during our study period of 1 September 2011-29 February 2012, so all data sources were available. The ten patients came from our original sample of 42 who were selected for interview by the Delivering Choice services. Nonetheless given the difficulties that some experienced, the narratives suggest that Delivering Choice service providers did not purposely pick only those with positive outcomes.

The aim of this painstaking work was not to produce generalisations about all patients using Delivering Choice services, but to learn in-depth about the experiences of a small number of individuals to better understand possible trajectories. Thus, these ten cannot be said to be ‘representative’.

Of the ten patients selected, five were from North Somerset and five were from Somerset. Eight were identified through their respective Care Coordination Centre, one was identified via the Discharge in reach service and one via the Out of Hours advice line. Four patients were female and six were male. Seven patients died of cancer, one patient had cancer but his death certificate stated that he died of heart problems, one patient died of a respiratory illness and one patient died of liver disease. Three patients lived alone and seven patients lived with their spouses. Seven patients died in their preferred place and three did not.

The interview transcripts from family members were mapped chronologically against the Delivering Choice End of Life care pathway. Other data from the Adastral register and the Delivering Choice services were then mapped alongside. The data sources were colour coded and organised along the care pathway in the most appropriate place. This process was not always easy, because in practice patient care does not flow in a standard chronological, linear way. However, once this process was complete, the different data sources were examined against the clinical care pathway and 'variance analysis' was completed (Hunter and Segrott, 2008). There are many different types of 'variance analysis', but the way it was applied here was by identifying the deviations of actual events from expected events and identifying discrepancies between different data sources. Each Patient Experience Pathway is presented then discussed and overall themes and concluding thoughts are discussed at the end of this chapter.

10.6 Intended trajectory

Before presenting these data, it is useful to clarify how Delivering Choice Programme developers conceptualised the 'ideal' trajectory. So, if a patient were to transverse along the pathway as intended then the following should occur in this order:

End of life register

1. Patient has been diagnosed with a life limiting or life threatening illness and the response is 'no' to the 'surprise' question of 'Would you be surprised if this individual died in the next 12 months?'
2. Patient consent is sought to add details to the Adastral end of life care register. Preferred place of care determined.
3. Professional adds patient details to Adastral.

Allocation of Key Worker

4. Professional placing patient on Adastral allocates him or herself as temporary Key Worker.
5. At next Gold Standards Framework or Multi-disciplinary team meeting, Key Worker and associate Key Worker status are discussed and assigned. Ideally, one of these roles should be occupied by a community nurse. Allocation of Key Worker should take place within three months of first registration on Adastral.

Assessment

6. Patient is assessed according to the Palliative Care Framework (Red/Amber/Green). The assumption appears to be that the Key Worker carries out this assessment. Depending on classification, varying timelines are given for assessment, fast track decision, care plan and financial assessments. For example, a patient classified as 'red' should have a holistic assessment within 12 hours, fast track decision within one working day, care plan completed the same day and financial assessment completed within 5 working days. Key other professionals receive the assessment documentation.

Care plan

7. On the basis of the information from the assessment, a care plan is drawn up.

Coordination of care

8. Once funding is agreed, the Coordination centres sets up a care package. Again the Palliative Care Framework or 'traffic lights' is employed to provide guidance on the timing of placement of care packages.

Delivering high quality care

9. The Key Worker oversees the quality of care provided using the Palliative Care Framework as a prompt.

Care during last days of life

10. Patient classified as 'red'.
11. The Key Worker carries out daily holistic review.
12. Out of hours services notified by Key Worker about patient status.
13. Family members informed what to do in case of death.

Care after death

14. Death verified within 4 hours.
15. Relevant authorities notified, ideally by the Coordination centre within one hour of verification.
16. Bereavement counselling offered, ideally by Key Worker within one day working day.

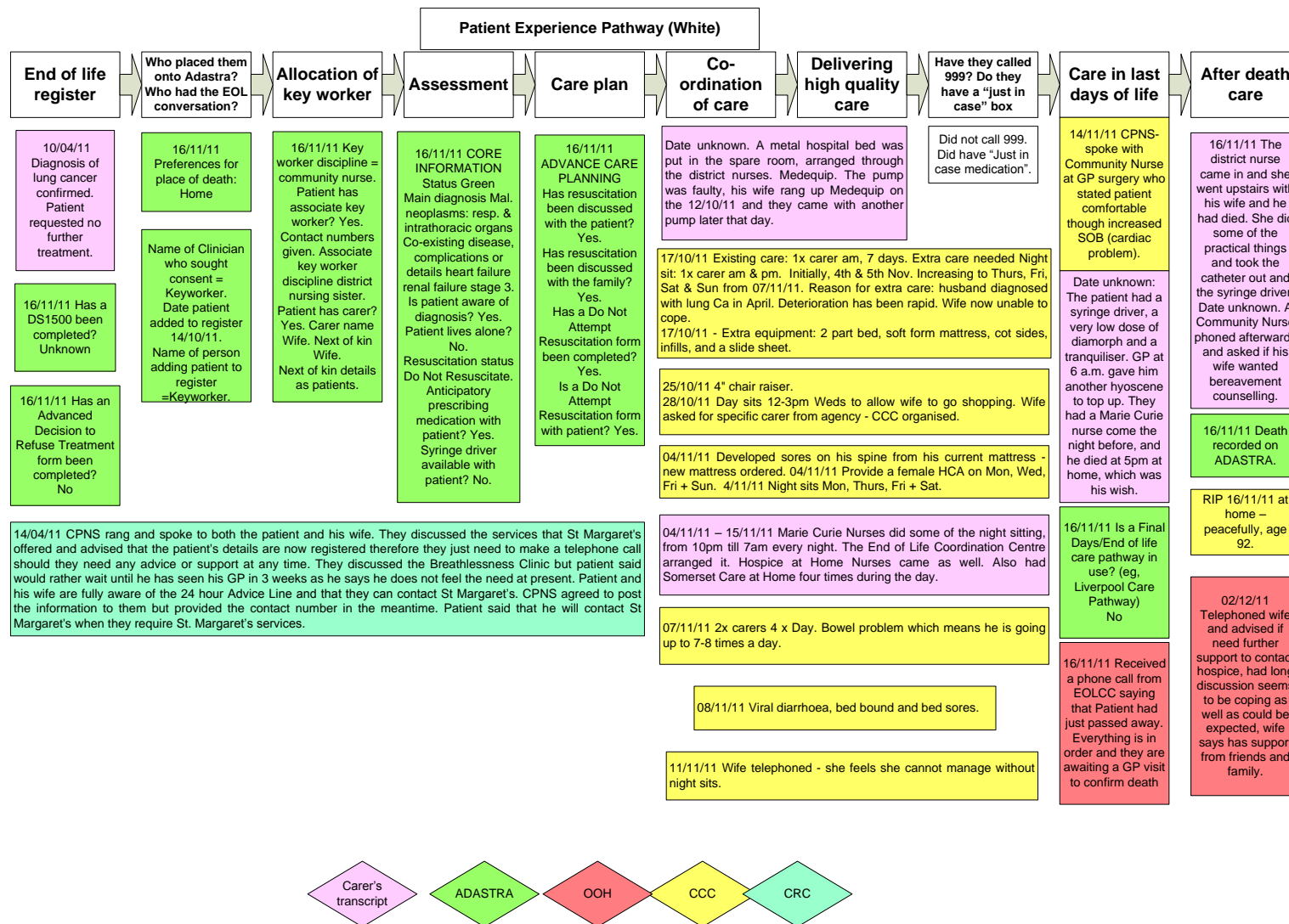
The follow ten accounts compared the pathway plan against actual experiences. Please note that OOH stands for the OOH advice line, CCC is for the respective Care Coordination Centre and CRC is for Central Referral Centre, which runs the daytime advice line number as well as handling all referrals to St Margaret's hospice.

10.7 Patient Experience Pathway 1: Mr White

Mr White lived in Somerset with his wife and died at home at age 92 years. He used services from the Somerset Care Coordination Centre, but the OOH advice line also called Mrs White after Mr White's death to offer bereavement support. The family did not ring the OOH advice line while Mr White was alive, but we assume they had the telephone number as on 14 April 2011, Central Referral Centre records report that a community palliative care nurse had discussed the services available from the hospice and mentioned that they could "just make a telephone call should they need advice or support at any time". His wife was interviewed.

Mr White died of lung cancer and he was put on Adastral end of life care register in October 2011, five months after his terminal diagnosis and a month before his death on 16 November 2011. A community palliative care nurse was recorded as Key Worker and Mr White had a named associate Key Worker as well. The Key Worker role, in terms of coordination of care, appears to have been partially taken on by the community nurses, who ordered equipment and visited on the day of death. SCCC records suggest there was good liaison between the community nurses and community palliative care nurses. The SCCC arranged a highly comprehensive package of care including night sits, day sits, maximum personal care and equipment such as a hospital bed and mattress which appear to have supported the patient and his wife well.

Mr White died in his preferred place of death and the care received seemed to be of good quality. But because no information about this patient was available on Adastral until the last month of his life, had there been a crisis in his care, NHS out of hours staff would not have had information about the preferred place of care or 'just in case' medication. The family member's transcript also documents how Mr White and his wife wanted to talk about his life expectancy in April 2011. Thus, when the specialist community palliative care nurse telephoned on 14 April 2011, she missed an opportunity to plan care in advance, register the patient on Adastral and prevent any possible crises at a later date.



10.8 Patient Experience Pathway 2: Mr Pink

Mr Pink was diagnosed with liver cancer and died aged 88 years. He used the Discharge in reach service. He lived alone in Somerset as his wife had Alzheimer's and had been placed in a nursing home. His daughter was interviewed.

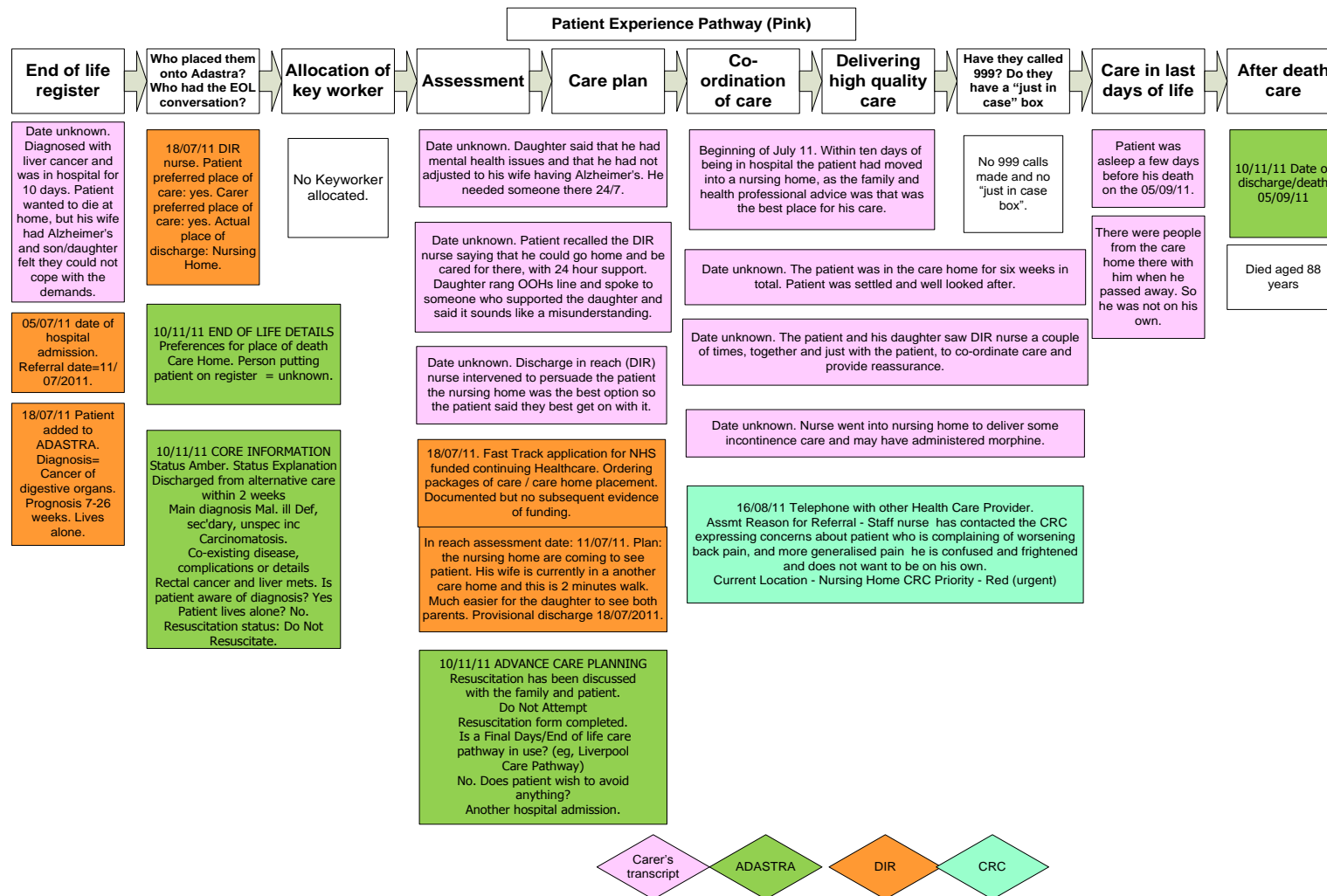
Mr Pink was identified fairly early after his terminal diagnosis and added to Adastra by the Discharge in reach nurse four months before his death. The Discharge in reach nurse discussed the options of care with the patient and family; the patient wanted to be cared for at home and the family did not feel they could fill the gaps in care services, so preferred the care home option. Subsequently there was some confusion and Mr Pink's daughter said she called the Out of Hours advice line (although we do not have a record of this call) to query the patient's belief that he would remain at home, where he was initially discharged. Eventually, Mr Pink went into a care home where he stayed for six weeks. This case illustrates the difficulty in negotiating preferred place of care, when the patient and family wishes differ, and the confusion over the term 'preferred place of care', as the preferred place of care recorded for this case was that of the family not the patient.

Although a fast track application for a home care package was made, there is no further information about whether this application was awarded but as the SCCC did not get involved and as the patient went into a nursing home ten days after discharge, presumably the application was withdrawn.

In terms of coordination of care, although no Key Worker was recorded, the Discharge in reach nurse appeared to take on this role initially, as she visited the patient and his family a couple of times post-discharge to "co-ordinate care and provide reassurance". A "nurse" (presumably a community nurse) went into the nursing home to deliver incontinence pads and possibly provide morphine. Otherwise, the patient was largely cared for by nursing home staff.

Pain was an issue, as about three weeks before death a staff nurse from the nursing home called the Central Referral Centre because the patient was experiencing back pain. There was no record on Adastra of 'just in case' medication, but if this had been available in the care home, his symptom control might have improved.

Adastra records are inaccurate about date of death, as it was recorded as 10 November 2011 not 5 September 2011. The Discharge in reach nurse appears to have provided an excellent service, with comprehensive follow up. Thereafter, we have few details about the quality of care for this patient. It is not clear whether discussion took place about, or whether it was possible to, discharge Mr Pink to the same care home as his wife, but this may have been a better option.



10.9 Patient Experience Pathway 3: Mrs Black

Mrs Black died of breast cancer at home, aged 63 years. She had services from Somerset Care Coordination Centre, but the husband also contacted the Out of Hours advice line four times for pain advice, to get a commode out of hours, in an emergency situation and to report death. Her husband was interviewed.

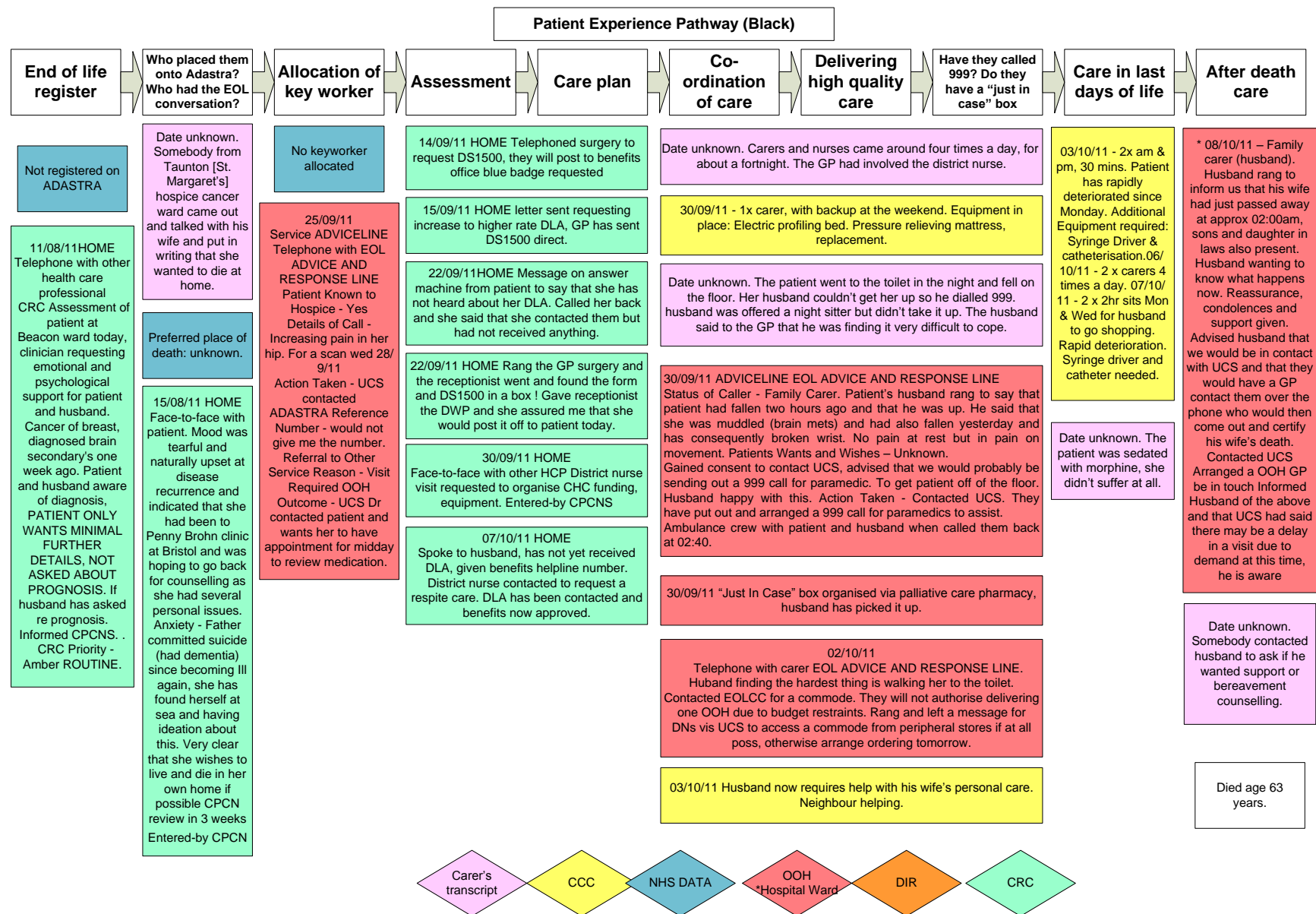
Mrs Black's preferred place of death was at home, but this was not recorded on Adastra nor was any advance care planning recorded. This is because Mrs. Black refused to give permission. If Mrs Black had consented to sharing information on Adastra, perhaps the professionals would have been able to provide a planned approach to her care and information would have been available out of hours.

Although Mrs Black was not registered on Adastra, so no Key Worker was officially assigned, early on in the trajectory community palliative care nurses took on this role by offering emotional support to the patient, making requests for equipment, liaising with the GP surgery to organise the DS1500 and contacting community nurses to organise fast track funding and respite care. From eight days prior to death, the SCCC provided equipment, day sits and personal carers, whose visits increased in frequency closer to the death. A 'just in case' box was provided eight days before death and a syringe driver was set up two days before death. The husband reported that pain control was very good. The GP was also involved. Overall, the coordination of this patient's care appears good.

On one occasion, Mrs Black fell and her husband could not get her up, so her husband called the Out of Hours advice line, who then called UCS and the paramedics which led to a hospital admission. The OOH advice line subsequently rang the family back later that night to check that the paramedics had arrived.

The two main difficulties for this patient were around funding and equipment. The couple waited three weeks for a DS1500 to be sent on to the relevant agency from the GP practice, despite repeated promptings. In contrast, Continuing Health Care funding was in place for the last two weeks of her life and the application was approved within 24 hours. However, budget restraints at the SCCC meant that obtaining a commode out of hours was difficult.

Mrs Black died peacefully at home and this was probably a death that was 'as good as it could have been' in the circumstances. The Out of Hours advice line played a key role in providing additional emotional and practical support for this family.



10.10 Patient Experience Pathway 4: Mrs Red

Mrs Red had lung and brain cancer and lived with her husband. She died at home aged 54 years. The husband rang the Out of Hours advice line several times. Mrs and Mr Red also received services from Somerset Care Coordination Centre and the Discharge in reach service. Her husband was interviewed.

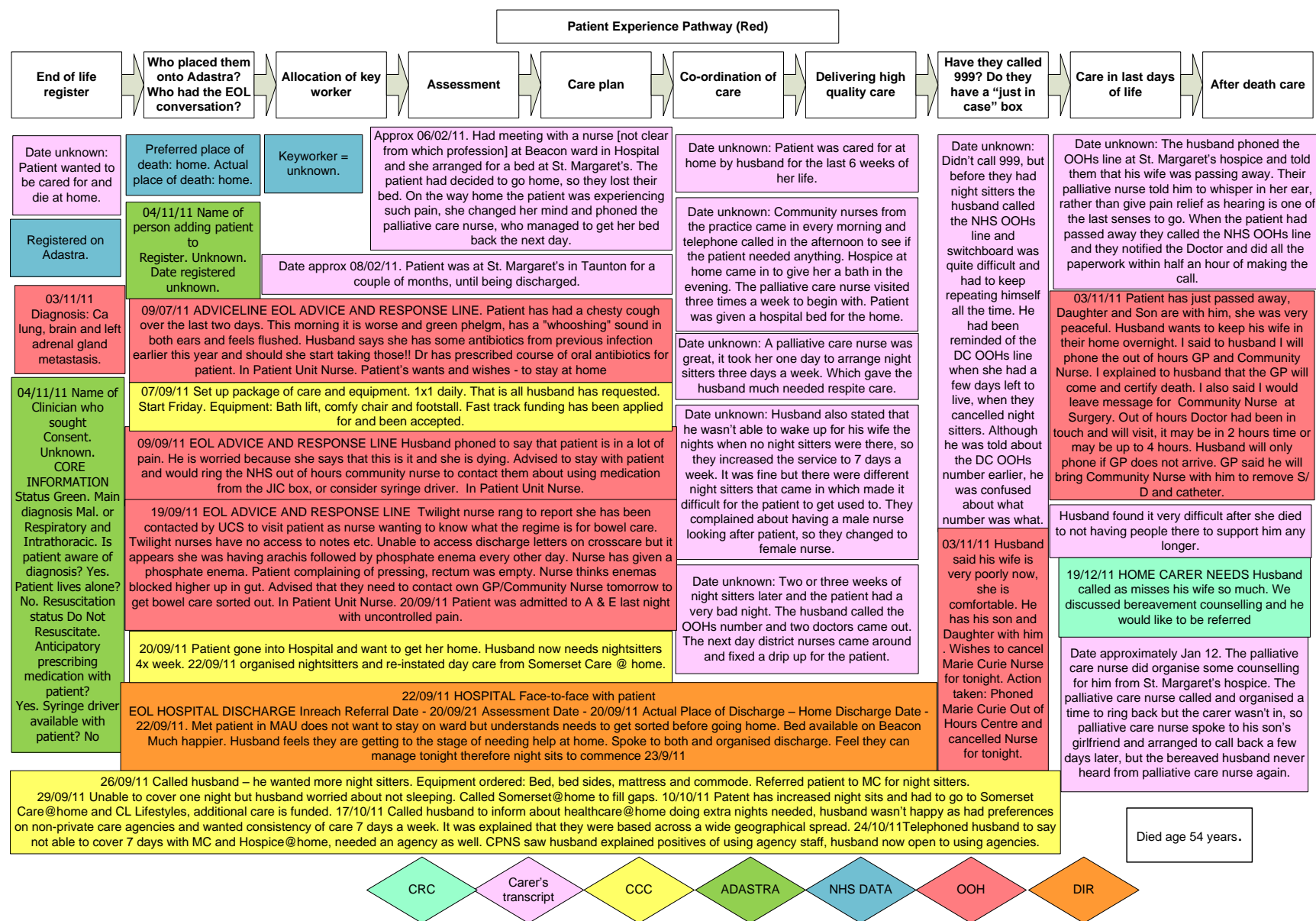
Mrs Red first went into hospital in February 2011 and then to St Margaret's Hospice as an in-patient where she stayed for two months. In July 2011, her husband called the hospice in-patient unit for symptom advice. The OOH advice line number was called twice more in September 2011 when there were crises in pain management. On one of these occasions, a twilight nurse had already been called out by UCS, rather than the OOH advice line, presumably at the request of the patient. Mrs Red had severe abdominal pain, although a 'just in case' box was in the home. The twilight nurse rang the OOH advice line because she did not have Mrs Red's notes, but the in-patient hospice nurse was unable to access the discharge letters on Crosscare. An enema treatment was recommended, but this appears not to have worked so the patient was admitted to hospital with uncontrolled pain. This may have been prevented if adequate bowel care had been provided and if the NHS and hospice out of hours teams had had access to Mrs Red's notes.

Mrs Red received fast track funding and from 7 September 2011, the SCCC organised equipment and visit from one carer daily. After discharge from hospital on 20 September 2011, the care package increased with night care workers, apparently organised by the Discharge in reach nurse who saw the patient in hospital. Mr Red was not happy about having a male nurse and wanted hospice night care workers rather than private agency staff. He also wanted the same night care workers every night, which was not possible 7 nights a week. A community palliative care nurse, working with the SCCC, persuaded Mr Red to change his mind about private care agencies.

The SCCC had reminded Mr Red about the OOH advice line when night care workers were re-arranged shortly before Mrs Red's death. Although Mr Red had rung the OOH advice line several weeks previously, he had forgotten about its existence and called the NHS OOH line instead.

Mrs Red was registered on Adastra but, it is unclear when as there is no date of registration. No Key Worker was assigned, although the community palliative care nurse and community nurses gave a lot of support and visited frequently. Mrs Red died at home on 3 November 2011. Mr Red was offered bereavement counselling by the Central Referral Centre, but no-one called back to arrange it even though he called the Central Referral Centre six weeks after his wife's death for help.

Although there were several instances of where care could have been improved (e.g. access to notes, pain control, bereavement counselling), overall this case demonstrates the proactive, collaborative approach adopted by all three of the Somerset Delivering Choice services working in partnership with specialist palliative care and community nurses. Arguably, given the tendency towards hospital admissions and the long trajectory of decline, without the help of the SCCC, OOH advice line and the Discharge in reach nurse, Mrs Red might have had greater numbers of hospital admissions and died in hospital.



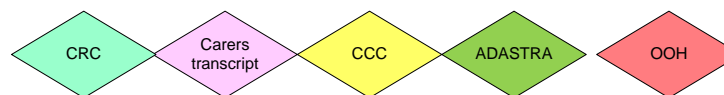
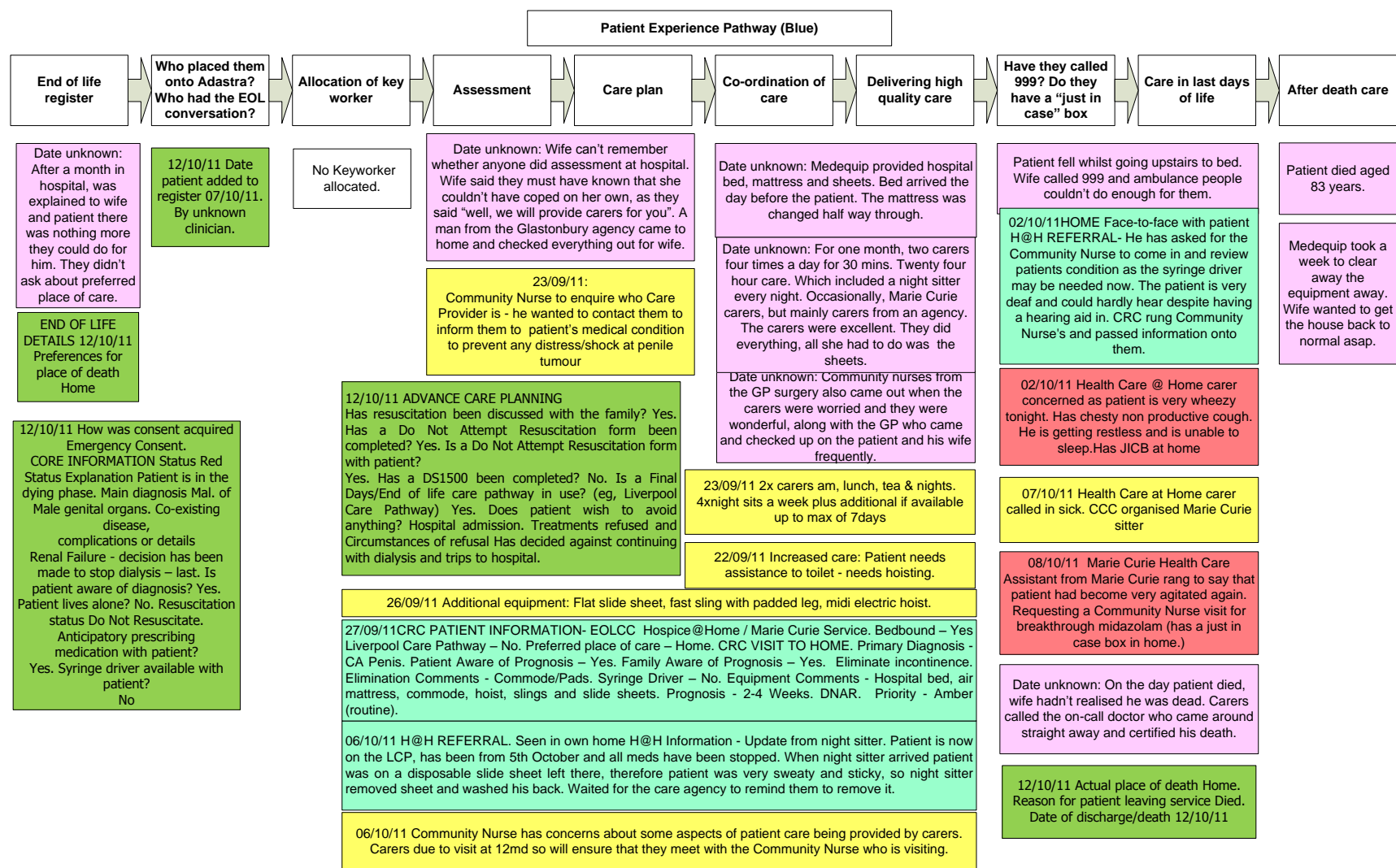
10.11 Patient Experience Pathway 5: Mr Blue

Mr Blue died from cancer of the penis at home aged 83 years. He lived with his wife, who was interviewed. Somerset Care Coordination Centre organised care agency staff, equipment and night care workers from three weeks before death.

Mr Blue was registered on AdastrA and had a lot of information recorded, including core information, advance care planning and his end of life details. Mr Blue was assessed at 'red status', when he was entered onto AdastrA five days before his death, which may have influenced the superior quality and quantity of information recorded. Two weeks earlier, he had been assessed at 'amber' status, which suggests that the Palliative Care Framework was used at least twice in his care, apparently appropriately. Mr Blue was not allocated a Key Worker although a community nurse appeared to take on this role by contacting the SCCC to find out which care agency was working with the patient early on when the patient was discharged home. Although Mrs. Blue praised the high quality of the care delivered by care agency staff, the community nurse had some concerns and it is reported that the community nurse planned to meet with the care agency staff, which suggests that the community nurse was acting in an advocate role.

On one occasion, Mrs Blue called 999, rather than the OOH advice line number, as her husband fell when going to bed. Although the SCCC reports that it passes on the OOH advice line number to all patients and family members, it is unknown whether Mrs Blue had the OOH advice line number, or whether she would have called 999 anyway. But we do know that the night care worker had the OOH advice line number because, a night care worker called the OOH advice line to ask for an OOH community nurse visit to administer increased pain medication four days before death from the 'just in case' box available.

In general, Mrs Blue thought this patient's care was of good quality, apart from when the community nurse called the Somerset Care Coordination Centre because the slide sheet had not been removed from his bed. Additionally, the equipment was slow to be removed after Mr Blue died, which was distressing for Mrs Blue. Except for speedy equipment removal, the SCCC did all it could, the community nursing service was actively involved in the case and reportedly the ambulance service was helpful. However, given that the patient spent a month in a hospital where the Discharge in reach service was available, his care might have been improved if a Discharge in reach nurse had been aware of his situation. Moreover, the patient could have been registered on AdastrA earlier in the trajectory rather than just a few days before death.



10.12 Patient Experience Pathway 6: Mrs Yellow

At the age of 97, Mrs Yellow stopped eating because she wanted to die. She lived alone in North Somerset and her granddaughter was interviewed. Mrs Yellow had some contact with North Somerset Care Coordination Centre and the Generic Support Workers. She died from pneumonia in a care home.

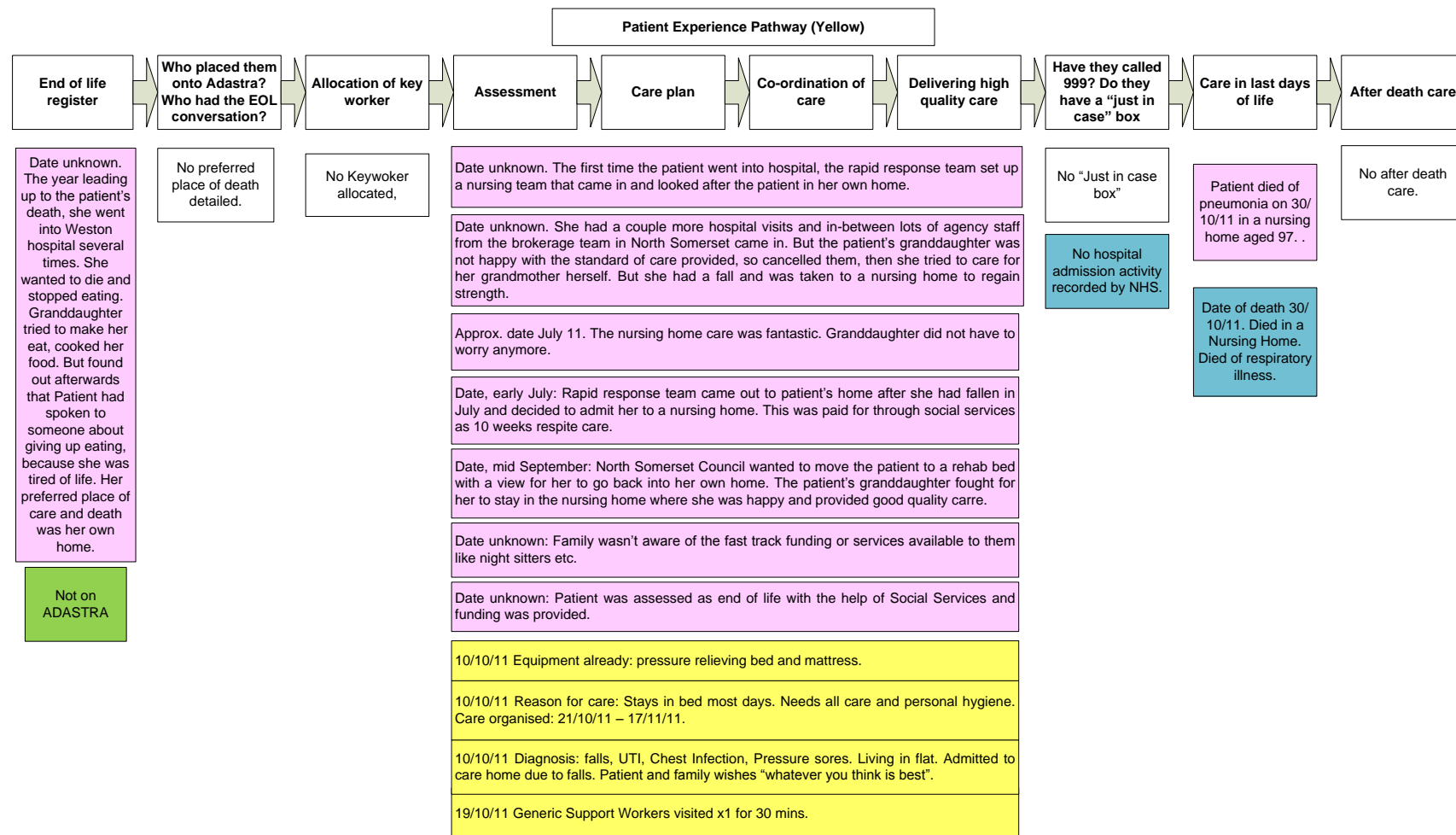
For a year before death, Mrs Yellow went into hospital several times. Unbeknownst to her granddaughter (until after she died), Mrs Yellow had had conversations with other friends about her desire to stop living. Mrs Yellow was not registered on Adastra so there are no details of her preferred place of care or death recorded, although early on her granddaughter knew that she wanted to die at home.

After discharge from hospital at an unknown date, the rapid response team arranged personal carers through an agency. Mrs Yellow's granddaughter, however, was not happy with the quality of care provided. The granddaughter then tried to care for the patient on her own, but could not be there enough of the time and was worried about her grandmother's safety. In July 2011, Mrs Yellow had a fall and the rapid response team organised respite care through social services. In mid-September 2011, Mrs Yellow was still in the care home and North Somerset Council tried to move her into a rehabilitation bed with the intention of discharging Mrs Yellow back home, but the granddaughter was happy with the care provided in the care home and fought for her grandmother to remain there.

It is unclear how North Somerset Care Coordination Centre found out about this patient, but according to the granddaughter's interview transcript, it could have been through a referral from Mrs Yellow's social worker. We do not have records on whether fast track funding was applied for or whether social services continued to pay for the care of this patient. In October 2011, the NSCCC organised some equipment and one visit from the Generic Support Workers. Given that it appears that Mrs Yellow was in nursing care home, the allocation of Generic Support Workers is a bit perplexing.

There is no record of a 'just in case' box being allocated or pain relief offered in the care home. More importantly, we have no evidence from the granddaughter's transcript or NSCCC records that any community or palliative care nurse was involved in the care of this patient. Not only was no Key Worker recorded, it seems that no one informally took on the important Key Worker roles of assessment, coordination of care or advocacy, in the year before her death when she had frequent hospital admissions. For example, Mrs Yellow may have benefited from assessment for depression by a geriatric psychiatrist, given her desire to stop living, but this was not arranged.

Mrs Yellow needed twenty four hour care and it is unlikely that even with night care workers or better quality day care, it would have been in Mrs Yellow's best interests to be cared for in her own home. However, with limited family support, high health needs and no Key Worker, Mrs Yellow was even more unlikely to realise her wish of dying in her own home. A further sign of less than optimal care was that once Mrs Yellow was happily settled in a care home, North Somerset Council wanted to move her back home. Overall, in this case it appears that the family and Mrs Yellow were largely left to struggle on their own with relatively poor quality care, despite the involvement of the NSCCC and the Generic Support workers.



10.13 Patient Experience Pathway 7: Mr Brown

According to the death certificate issued by the doctor, Mr Brown died of heart problems aged 88 years. However in early 2011 after multiple hospital tests, Mr Brown suspected that he had cancer and refused all medical interventions. He did not want confirmation of the cancer diagnosis. Mr Brown lived alone in North Somerset and died in a care home. North Somerset Care Coordination Centre was marginally involved. His daughter supplied interview data.

In mid-June 2011, Mr Brown went to hospital for six weeks and was discharged as he wanted to go home. About two weeks later, he recognised that he was not able to cope. Approximately on the 14 August 2011, which was a Sunday, there was a crisis situation when he could not get out of bed. His daughter came to help, rang “the medics” (presumably OOH GP service) and a community matron came round.⁴ The community matron requested personal carers and a night care worker. Because the NSCCC is not open on Sundays, presumably the community matron organised this care via other routes.

On this Sunday visit, the community matron and Mr Brown discussed his advance care wishes and Mr Brown opted for Nursing Home (A). According to the daughter’s transcript, initially the patient wanted to die at home however the family felt they could not cope with the care of their father. His wife had Alzheimer’s disease, had already been placed in a care home and no longer recognised her husband, which “broke his heart”. Although advance care planning was carried out, the family’s preferred place of care was recorded and not Mr Brown’s original preference of home. The family’s perception was that Mr Brown was placed in the care home arranged by the community matron, however this was not documented.

Mr Brown was registered on Adastral the next day (15 August 2011) by an “unknown clinician”, who was probably the community matron given that interviews with North Somerset staff suggest that community matrons are amongst the few community nurses in North Somerset who do have access to Adastral. NSCCC records note that Mr Brown was assessed on the same day (15 August) and a further entry records his desire for admittance to a nursing home. This entry also notes that a ‘just in case’ box will be issued for the nursing home and that Mr Brown had stopped eating or drinking. However, as Mr Brown went into a care home, there was little other involvement by the NSCCC.

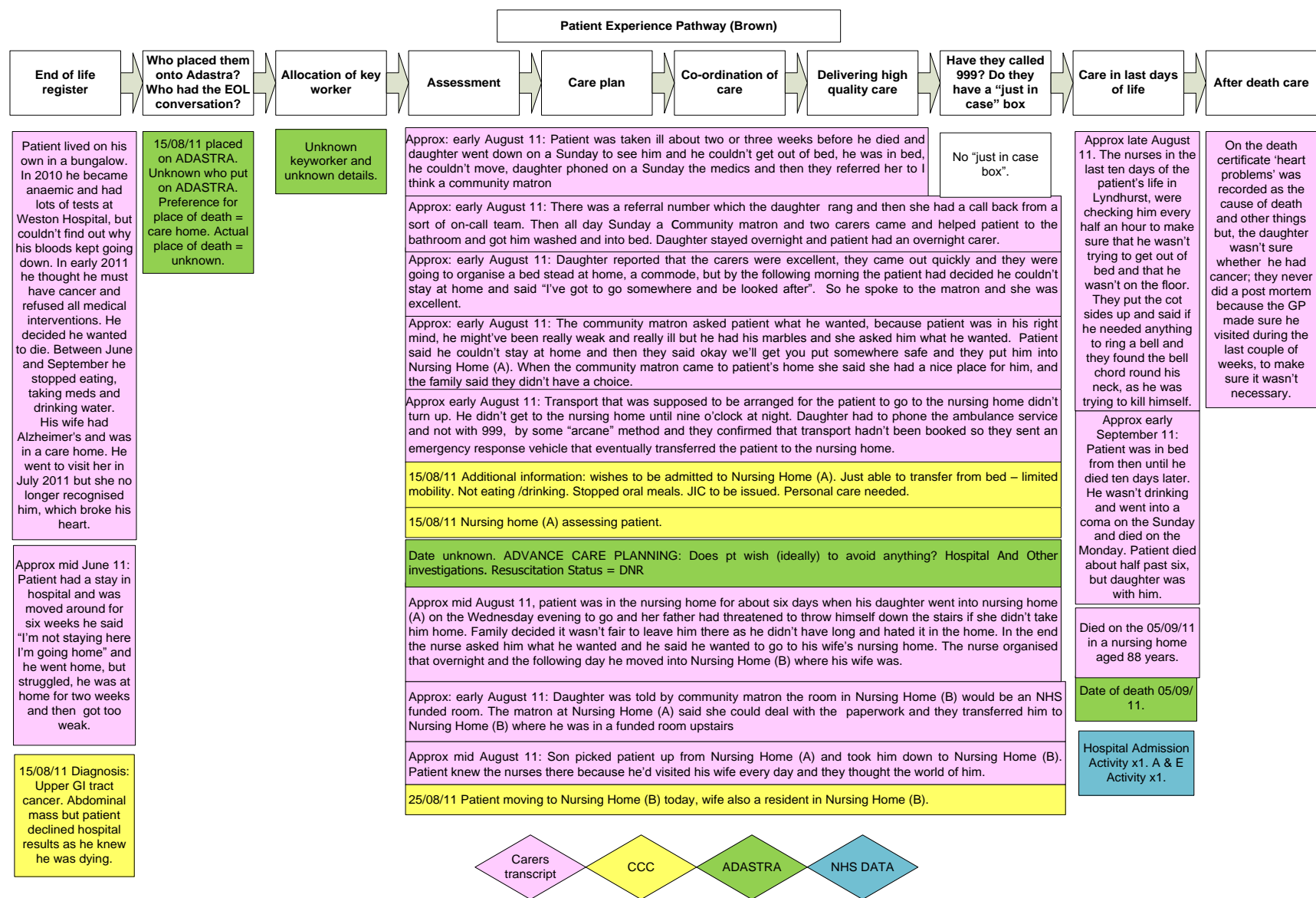
In moving from home to care home, the expected transport vehicle did not arrive; the daughter called and was told it had not been booked. So an emergency vehicle was dispatched to transfer Mr Brown to Nursing Home (A) which resulted in a 9pm

⁴ Community matrons do not usually work on Sundays, but we received corroboration from the notes.

arrival. Within a week, Mr Brown wanted to leave Nursing Home (A) and threatened to throw himself down the stairs unless his daughter took him home. The nurses at the home arranged his discharge to the same nursing home (B) as his wife and he was speedily discharged on 25 August 2011. The son had to transport his father to the new nursing home. At the nursing home (B), Mr Brown kept getting out of bed so the care home staff had to check on him every half hour. He was also found with a cord round his neck. He died eleven days after transfer to the nursing home (B) with his daughter present on 5 September 2011.

In terms of quality of care, the daughter praised the efforts of the community matron and the personal carers and this is one of only two cases where registration on Adastral appeared to occur as intended, although Key Worker was not recorded. Nonetheless, the community matron clearly acted in Key Worker capacity early on in the case and later the GP also acted as Key Worker by regularly visiting and checking on the patient in his last few days of life. But again, this was not recorded. We do not know whether a more proactive Key Worker with continuous engagement for the entire trajectory of three weeks might have led to improvements in care.

The major difficulties appear to be around transport to and between nursing homes, the difficulties in finding the right nursing home and Mr Brown's frame of mind, as he was clearly unhappy and no longer wanted to continue living. Although staying in his own home would have been difficult, if not impossible without family support, he could have been given the option to go to the nursing home with his wife earlier and again there is no evidence his mental health was assessed by a specialist team.



10.14 Patient Experience Pathway 8: Mr Purple

Mr Purple died of liver disease aged 82 years and was from North Somerset. He lived with his wife and died at home. He had services from the North Somerset Care Coordination Centre and Generic Support Workers. His wife was interviewed.

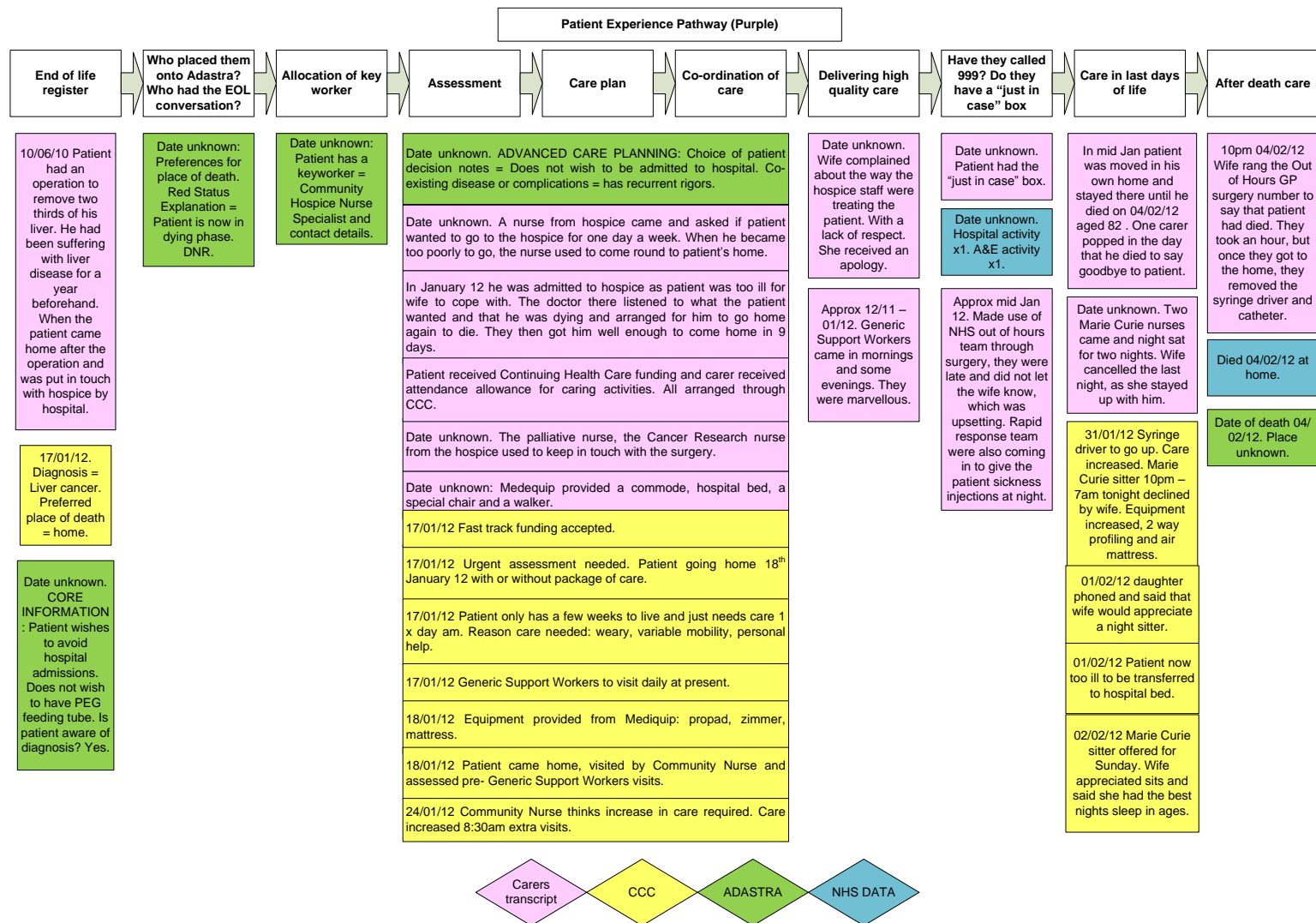
In June 2010, Mr Purple was discharged from hospital following an operation and put in touch with the hospice. At some point, they received a visit from a hospice nurse who suggested that Mr Purple attend the hospice once a week for a day visit. In January 2011, he was admitted to the hospice because his wife could not cope. Mrs Purple was not completely happy with the hospice, however, as she complained about how hospice staff spoke to her husband and received an apology.

After nine days in the hospice, Mr Purple was discharged on 18 January 2011. The first entries for the NSCCC appear the day before with a request to the community nurse for urgent assessment for fast track funding and details of the prospective care package. This included Generic Support Workers once a day and equipment, which started the next day when Mr Purple arrived home. Mrs Purple thought the Generic Support Workers were “marvellous”.

In terms of coordination of care, in addition to the equipment and Generic Support Workers, Mr Purple received visits nightly from the rapid response team to receive anti-nausea injections who often arrived late without letting Mrs Purple know, which she found upsetting. Five days before his death, Mr Purple received extra equipment and Marie Curie night care workers for two nights. Mr Purple died at home on 4 February 2012. There is no record of bereavement care offered.

Mr Purple was put on Adastra in the very late stages of his illness, when he was at ‘red’ status instead of in June 2010 when he knew he was terminal. So at least six months passed while Mr Purple remained unregistered, although he had considerable contact with the hospice. Once registration took place, a community hospice nurse was recorded as Key Worker along with core information, care and death preferences, advance care planning and date of death. Moreover, the community nursing team appeared to act in Key Worker capacity as they assessed Mr Purple for fast track funding and suggested an increase in personal care visits.

This death was as good as it could have been, apart from late registration on Adastra and the complaint about hospice staff. However, it is unlikely that earlier registration would have changed the trajectory substantially. Moreover, the NSCCC and the Generic Support Workers appeared to play a pivotal role in ensuring that Mr Purple remained at home.



10.15 Patient Experience Pathway 9: Mr Orange

Mr Orange had oesophagus cancer and lived in North Somerset with his wife. He received services from the North Somerset Care Coordination Centre and Generic Support Workers. His son was interviewed. Mr Orange died at home aged 80 years.

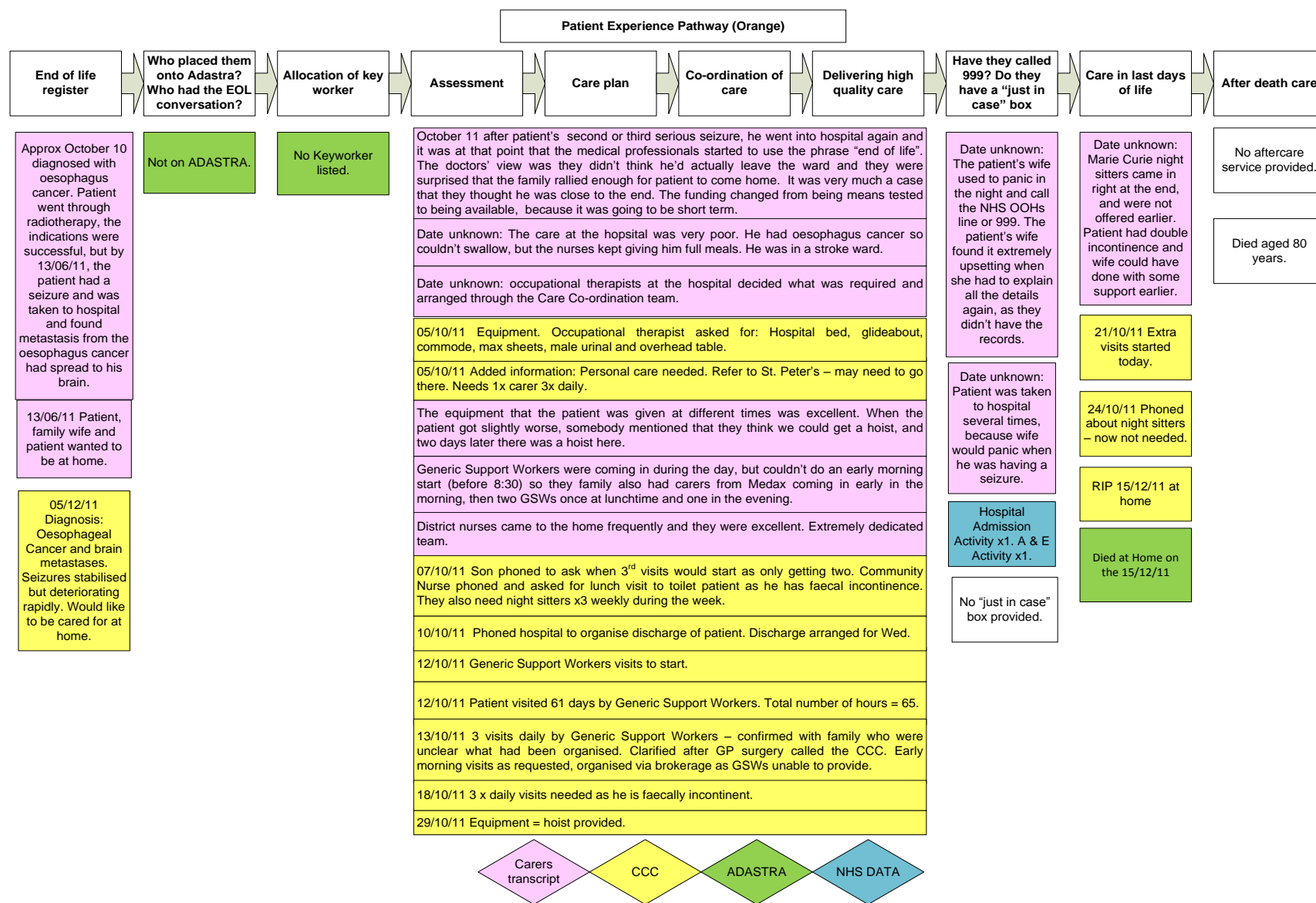
In October 2010, Mr Orange was diagnosed with oesophageal cancer and by June 2011 the cancer had spread to his brain. He suffered from seizures and was re-admitted to hospital in October 2011. At this point, clinicians began to use the term 'end of life'. His son said that the care in hospital was poor as Mr Orange was in a stroke ward and kept being given full meals, although he could no longer swallow. According to the son, hospital staff expected Mr Orange to die in hospital, but the family and the patient wanted to take him home.

On 5 October 2011, a hospital occupational therapist liaised with the NSCCC to set up the care packages of equipment and personal carers. Fast track funding was awarded. Mr Orange was faecally incontinent so from 13 October 2011, the Generic Support Workers visited three times a day and a care agency came in once early in the morning as Generic Support Workers were not available. As Mr Orange continued to live for two more months, a significant level of Generic Support Worker resource was expended on his care as the family were visited over 60 days for a total of 65 hours.

During the night, especially when Mr Orange had seizures, Mrs Orange had a tendency to panic and called 999 or the out of hours services. The NSCCC offered night care workers, which could have helped reduce these calls, but ironically the nights when staff were arranged were when Mr Orange was fine and did not need "watching", so the night care workers were sent away. When Mrs Orange rang the NHS out of hours number, she found it frustrating that she had to keep repeating all of the patient's details, as they did not have his records to hand.

Mr Orange was not registered on Adastra and had no Key Worker, although community nurses came to the home frequently, were "excellent" and could have taken on the Key Worker role officially. As there is no Adastra record, we do not know if a 'just in case' box was issued, but the son did not mention problems with pain relief.

The quality of care in this case is high. Without the input of the NSCCC and the Generic Support Workers, it is unlikely that Mr Orange would have died at home. Moreover, Mrs Orange was well supported by her children.



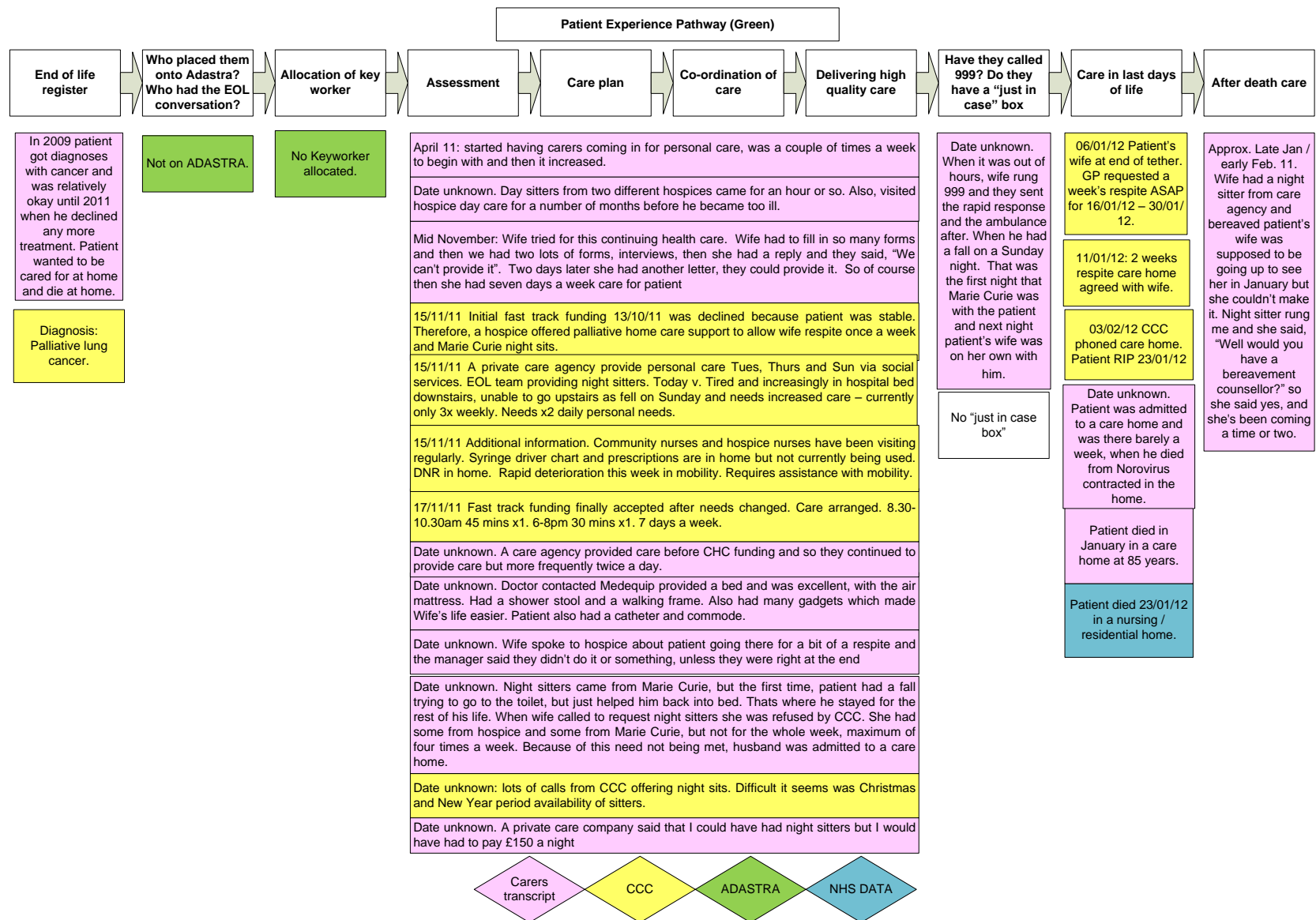
10.16 Patient Experience Pathway 10: Mr Green

Mr Green was diagnosed with lung cancer in 2009 and began to deteriorate in 2011. He lived with his wife in North Somerset. He received services from the North Somerset Care Coordination Centre. We do not know Mr Green's preferred place of care, but every attempt was made to keep him at home. Unfortunately, he died in a care home, aged 85 years. His wife was interviewed.

In April 2011, Mr Green began to receive personal carers from care agencies a couple of times a week via social services. It is not clear whether social services or the Green family paid for this care. He sometimes went to the hospice for day visits and day care workers from the hospice sometimes came. On 13 October 2011, a fast track funding application was made which was refused as Mr Green was stable. On 15 November 2011, NSCCC records note that the patient had a fall, was unable to get out of bed and needed an increase in personal care visits from thrice weekly to twice daily. Two days later, a fast track application was accepted. A doctor arranged for equipment, although this does not appear on NSCCC records and so might have been obtained directly from Medequip.

The main problem for the Greens was the lack of night care workers. Night care workers were requested seven nights a week, but the maximum allotment was four. Mrs Green was told further night sits would cost £150 a night. Although the NSCCC did make several attempts to organise night sits, sometimes night care workers could not be arranged as it was Christmas. Moreover, the first time a night care worker came, Mr Green fell out of bed and did not get out again. The rapid response team and an ambulance were called to help. Eventually Mrs Green reached the "end of her tether" and asked that Mr Green go into a home so she could get some respite. This was agreed five days later on 11 January 2012 for two weeks. The patient died on 23 January 2012 from a virus contracted in the care home. Mrs Green has since had some bereavement support organised by a night care worker.

Mr Green was not registered on Adastra and so had no recorded Key Worker. Although Mrs Green had substantial contact with the hospice, neither hospice nor community nurses are found in her account. Only the GP appears in a Key Worker role, to request equipment and respite care. Given the strain on Mrs Green, perhaps a community nurse could have helped Mrs Green to continue to care for her husband at home. On the other hand, as the main difficulties were around night care and the Green family were allocated the maximum night care workers, perhaps a Key Worker would not have helped. The NSCCC attempted to step into the breach, but their efforts were constrained by funding stipulations. This suggests that despite the maximum support package and the valiant efforts of the NSCCC, if patients need intensive care for a sustained period of time, in this case over months, elderly spouses without support from family and friends will struggle.



10.17 Discussion of Patient Experience Pathway

Using a clinical care pathway to compare the patient and family carer's experiences alongside service data from various health care data sources has been useful in answering the following questions:

- Was this death as good as it could have been?
- If not, what stopped this death from being as good as it could be?
- What did Delivering Choice services and other health and social care professionals contribute to providing good quality end of life care to patients in Somerset and North Somerset?

10.18 Adastra register and Key Worker

Although all of the patients were known to Delivering Choice services, and sometimes to hospices for many months, only six were registered on Adastra, one refused consent (Mrs Black), leaving three patients who could have been registered and were not. Named Key Workers were invariably absent from Adastra; only two patients had a named Key Worker recorded (Mr White and Mr Purple). In both cases, this appeared to be formalising already good care, although for Mr Purple the involvement of the Generic Support Workers was an additional boost. For several patients, largely in Somerset, the Key Worker was not named, but the Key Worker function was discharged by community palliative care and/or community nurses working together (Mr Orange, Mr Blue, Mrs Red and Mrs Black). The Key Worker function became especially important when either the patient lived alone (Mrs Yellow, Mr Brown, and Mr Pink) or where an elderly spouse had little family or community resources to draw on (Mr Green). For those living alone, care in a home was almost inevitable while for those with elderly spouses, the ultimate place of care depended largely on how long the patient continued to live. If the patient lived for much longer than expected, even with maximum care packages in place, the spouse and care package could break down. These accounts suggest that sometimes the Care Coordination Centres or the Discharge in reach service attempted to step into the Key Worker breach.

More generally, Adastra end of life register appears problematic, as there are issues about the timing, quality and quantity of information entered. Only five had core information and advance care planning completed. Furthermore, there were many lost opportunities where patients could have been registered onto Adastra and were not (Mrs Yellow, Mr Green and Mr Orange) or could have been added to Adastra much earlier when initially contacted by a hospice nurse (Mr White, Mr Blue, Mr Purple). It is also unclear in many circumstances when patients were entered onto Adastra as the 'date entered' field was not completed, which makes it difficult to know from what point patients' details were available and accessible to NHS out of hours teams. However, we do know that Mrs Red's record was added the day after her death, which rather negates the main purpose of the register – to inform decision making.

Another significant issue is that even when patients were entered onto Adastra, documenting advanced prescribing and advance care planning is inconsistent and this makes it particularly difficult for out of hours clinicians to make appropriate decisions. This can lead to unnecessary hospital admissions (Mrs Red). Those patients who would have benefitted from having a 'just in case' box of medication in their usual place of residence, but were not recorded as having one available included Mr White, Mr Pink, Mrs Yellow, Mr Brown, Mr Orange and Mr Green. The use of a 'just in case' box to control end of life patients' symptoms whilst at home can be vital in preventing urgent hospital admissions, as was the case for Mrs Red.

Importantly, the information entered onto Adastra needs to be accurate; date of death was incorrect for one patient. Moreover, if the patient's original preference for place of care or death was at home, but this was not possible, their preference could be recorded along with an explanation. For example, in Mr Brown and Mr Pink's case their original preference was to die at home and for understandable reasons (e.g. not being able to ensure twenty-four seven care) it was not possible for these patients to be safely cared for at home. But their original preference could still have been recorded rather than that of the family. Arguably, not recording the patient's preferred place of care or death rather than the family's preference undermines the notion of 'patient choice' and distorts data on 'unmet' need.

In all however, there does not appear to be much relationship between registration on Adastra, the quality or quantity of information or the recording of Key Worker with the overall standard of care. The high or low quality of care for the patients in this sample tended to be dependent on other factors.

10.19 Quality of care provided

Three of the ten patients in our sample received standards of care that could probably not have been improved, given the circumstances (Mr Orange, Mrs Black and Mr Purple). We also found numerous examples of how Delivering Choice services had gone beyond expectations (Mr Pink, Mr Purple, Mr Orange, Mrs Black, Mrs Red, Mr White), often with key support from community palliative care nurses in Somerset (Mr Blue, Mrs Red, Mrs Black) or community nurses in North Somerset (Mr Orange, Mr Purple).

The OOH advice line in Somerset was involved in the care of four patients and this service seemed to make a difference to family members, particularly those who were caring for their spouses at home (for example Mrs Red). Mrs Red's account suggests that the SCCC needs to regularly remind patients and family members about the OOH advice line, as they can become easily confused between the NHS OOH lines and the St Margaret's OOH advice line. The Central Referral Centre appeared in some of the patient experience pathways, especially when carers and family members made calls to the OOH advice line which were picked up during the

hours of 8am – 5pm by the Central Referral Centre (Mrs Black, Mrs Red and Mr Blue). Although in some circumstances opportunities were missed to have the ‘end of life’ discussion (see Mrs Black, Mr White and Mr Blue), in general Delivering Choice services complemented the Central Referral Centre.

There were some circumstances in which care was less optimal. For example, Mr Pink and Mr Brown suffered from the choice of nursing home. Mrs Yellow was clearly not identified early enough, despite her advanced age of 97 and frequent hospital admissions. In Mr Blue’s case, Mrs Blue reported that equipment was not removed quick enough, which she found distressing, and the slide sheet was not removed appropriately. In Mrs Black’s case a commode was not available, due to budget constraints and Mrs Green also suffered with the cap on night care workers. Mrs Yellow and Mr Brown appeared to need mental health assessments. Furthermore, Mrs Yellow’s granddaughter and Mr Red were not happy with the quality of care agency staff allocated. Nevertheless, many of the family members reported that aspects of care they received were very good. Those who received Generic Support Workers were particularly satisfied (Mr Purple and Mr Orange) and arguably Mr Green might have remained at home if Mrs Green had been allocated Generic Support Workers.

10.20 Fast track funding and the Palliative Care Framework

In terms of accessing funding, in Somerset three of the four patients identified via the SCCC were recorded as receiving Continuing Health Care funding. In Mr White’s case this is probably a lack of documentation. In North Somerset four patients received Continuing Health Care funding before they passed away. It is unclear if Mrs Yellow actually received Continuing Health Care. Nonetheless, Mr Green’s and Mrs Black’s case provides an example where fast track funding was applied too late and the assessment parameters could be too narrow. Finally, in terms of funding benefits, the DS1500 for Mrs Black was delayed for three weeks.

The Delivering Choice Palliative Care Framework was utilised in five patient pathways. Mrs Red’s status was recorded as ‘Green’ a day after she died and in Mr White’s case, the framework was updated on the date of his death as ‘Green’, which suggests that the framework was not being updated regularly, as all patients in their last days of life should be recorded as ‘Red’. For Mr Pink, his framework status was updated circa two months after his death and did not change from the previous status of ‘Amber’. In Mr Blue’s case his last status is ‘Red’ on the day he died. Mr Purple’s status on an unknown date is ‘Red’. That said, it is unclear how many times these statuses have been updated. Thus, according to the information entered on AdastrA, recording of use of the framework is not being updated regularly as the intended.

10.21 *Death in preferred place of care*

To learn more about what made the difference to death in preferred place for this very small group of ten patients, we found the key factors that increase the likelihood of a 'good enough' home death were:

- *Support from family and friends.* Given the importance of this factor, those that lived alone suffered from a disadvantage from the start (Mrs Yellow, Mr Brown and Mr Pink). For those who lived with a spouse willing to provide care, sources of informal support such as other family members or neighbours became very important. Every extra person appeared to make it more likely that the patient would stay at home (Mrs Red, Mr Orange).
- *A shorter trajectory from the introduction of the first care package.* For example, the spouses of patients who died within three weeks were more able to cope than those where the patients lived for two or more months from the introduction of the care package. However, if enough family and informal support is on hand, longer trajectories appeared manageable. (Mr Orange)
- *Night care workers.* Even four nights a week may not be enough, especially with a long trajectory. For example, Mrs Green was unable to cope with four s a week over a two month period whereas Mr Red managed for two months with seven nights a week night sits and frequent calls to the Out of Hours advice line.
- *Possibly a brief period of respite care.* After nine days respite at the hospice Mrs Purple was able to care for Mr Purple until he died at home, although he died within three weeks of the introduction of the care package.
- *Generic support workers.* In the case of Mr Purple and Mr Orange, night care workers were limited or not used, so daily visits from Generic Support Workers appeared to offer the required levels of support. In the case of Mr Orange, who was faecally incontinent and received three daily visits for 61 days, the services of the Generic Support Workers combined with family support appeared to make the difference in difficult circumstances.

However, these findings should be taken with some caution as they are only based on a sample of ten patients. Further research should explore these more.

10.22 *Influence of the Delivering Choice pathway*

A key challenge with mapping different data sets against a clinical pathway like the Delivering Choice pathway is a lack of detailed information about professional's decision making, therefore it is very difficult to know if best practice has taken place and not documented, or just not happened. Furthermore, clinical pathways are a blunt analytical tool, for example, in some cases patients such as Mrs Black understandably struggled to come to terms with their terminal prognosis and regardless of the services provided and information given, they will perhaps only

access care services when absolutely necessary. When comparing the trajectory of these patients along a clinical pathway, the professionals look like they are failing to provide a 'good quality' service, however for the patient and/ or family member, this could be how they want to be cared for. Thus, although in many circumstances applying a clinical care pathway to patient's care would ensure a consistently good standard of care, what is considered 'good quality' is subjective. In evaluating the influence of the Delivering Choice pathway, since few of the actual trajectories matched the linear planned pathway and good quality care took place regardless, arguably the contribution of the pathway to improving the quality of care was limited.

10.23 Concluding points

So overall in considering the impact of the Delivering Choice pathway, we found that professionals did not appear to find the pathway particularly helpful, as it was viewed as largely formalising what happened anyway. However, when combining service usage and interview data, 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. Data from Adastra records suggest that the framework is in somewhat sporadic use, but sometimes it is used incorrectly and changes in patient status are not updated in the Adastra electronic register.

Given these overall findings, we would recommend that:

- The Delivering Choice pathway may need to be re-designed, perhaps as a flowchart or in another less linear model.
- Further roll out and implementation of the Palliative Care Framework could be considered.

11.0 The programme as a whole

11.1 Introduction

The aim of this chapter is to provide findings relating to the entire programme. This chapter will include:

- Cross cutting findings that emerged across the programme.
- The role and impact of the local Marie Curie team.
- The integration of Delivering Choice services with each other and the wider health and social economy.
- Maps of Delivering Choice service usage, including use of the electronic register and recording of Key Worker, for North Somerset and Somerset.

11.2 Cross cutting findings

We found a number of themes repeatedly mentioned by professionals and family members across the two counties. The first four are ‘enabling’ contextual factors that help the programme to work, the next two are ‘constraining’ and the final two are unintended negative outcomes of the programme as a whole.

11.2.1 Funding

An obvious but often overlooked essential factor is money. The local Marie Curie team required funding from the national charity. All of the services needed additional funding to continue. The uncertain nature of the funding has particularly affected the End of Life Care facilitators and the Discharge in reach service, as nurses from both of these services experienced short term contract renewals. The Care Coordination Centres could not function without access to fast track funding for the care packages. Without funding, it is doubtful that many of the successes of this programme would have come about.

11.2.2 Excellent managers running the Delivering Choice services

Another obvious but essential factor was excellent leadership and management. Leadership was needed to create a vision for the service and to work with internal and external staff to deliver that vision. Management skills were needed to create new teams, re-skill staff and set practical, useful systems and procedures in place. We found several examples of where good leadership and management rescued the services when they faced difficulties, for example when one of the Discharge in reach nurses was in danger of becoming absorbed by the existing discharge liaison team, and in the early days of the NSCCC when roles and responsibilities were not clarified. Having spent an extensive period in the field, we found that all of the services benefited from excellent leadership and management.

11.2.3 Engaged NHS commissioner

One of the counties had a highly engaged commissioner with a passion for end of life care. Although this does not seem to be a crucial pre-requisite to making Delivering Choice succeed, it does help.

You go to other areas and they [say], “We haven’t got a commissioner really who’s interested”, so they have struggled from day one because they haven’t got anyone driving it. So I think without that, they’re up against it. (NSCCC staff)

11.2.4 Personal contact with professionals who refer into the service

Both of the Coordination Centres had regular face to face meetings with professionals who could refer into the service, such as hospice and community palliative care nurses. These meetings helped to develop relationships and foster understanding of what the Coordination Centres could provide.

Well I think when the Care Coordination Centre was being set up I went to [Community Hospital] and met the folk there [names CCC staff] and that was nice. And having met them face to face I have a better understanding of the reality of the place if you know what I mean. (Community palliative care nurse RW)

11.2.5 Professional territorialism

All of the Delivering Choice services experienced some suspicion from local professionals when their service was introduced. This particular excerpt is taken from an interview about the Discharge in reach service, but it could equally have applied to any other service.

Yes, so we used to have to do it all and when this first came in I will tell you that, and I mean I was probably ... you know “we do it all very well thank you”. It was almost like they were saying they could do it better than we could but I think we’d really, really miss it if we didn’t have it now. (Community palliative care nurse RT)

All of the services worked hard to reassure existing professionals that the new service was to enhance the capacity of local staff. As most of the services have now been in place for over two years, the initial disquiet has largely ebbed.

11.2.6 ‘End of life’ is an off putting term

Some of the services have ‘end of life’ in their title, as does the Adastra end of life electronic register. This is a highly potent term which can disturb patients, family carers and professions. A hospital nurse commented that she thought an important contributing factor to the reluctance amongst professionals to register patients was that on some level they worried that this would be perceived as ‘giving up’ and relegating the patient to either no or sub-standard care. A community nurse also remarked on the difficulties of an ‘end of life’ register.

RES: Some people are negative about the end of life care register and I think partly because of the type and the name. I mean who wants to say to someone would you like to go on the end of life, how would you feel if I said that to you?

INT: Yeah, not great.

RES: I appreciate that you've got to be open and honest with people but if you've got cancer and you're dying how many more times do you have to be told? I don't know, I just think it's a bit unnecessarily blunt and then people start being woolly about it and calling it Adastra and then no one knows what they're talking about. (Specialist palliative care nurse RT)

To resolve the problem, one family carer made up her own term to avoid upsetting her husband.

When [husband] was sitting there and End of Life [Care Coordination Centre] were on the phone, he used to say "who was that?" And I would say, "Oh it was E of E"... I couldn't tell him it was End of Life. I wish you would give it a nicer name... it was so soul destroying. (Family member VK)

One Delivering Choice service provider talked about how they had worked around this issue.

Now we sometimes drop the 'end of life' when we're introducing ourselves to people...[as] some families have got very upset with us. Medequip, we used to send over our order and it had Somerset End of Life Care Coordination on it. We had two husbands who just were really upset and distressed that anybody would write that on an order... They knew that their wives were at end of life but they didn't want it written down in the house. And so we've learned to pull back a little bit... Some people feel more comfortable about it than others, and I think when you phone, when you're making phone calls we always answer it, "Somerset End of Life Care Coordination Centre", but people don't always listen to what it is anyway. But when we make the outgoing call, it's easier to say it's Somerset Care Coordination Centre, and then if we feel that person's okay, you might say, "Oh by the way we are really called Somerset End of Life Care Coordination Centre, so don't be surprised if we answer the phone with that". (SCCC staff member)

So there was widespread recognition that attaching 'end of life' to the title of a service or tool was not helpful, and some had found a way of circumventing that term. Perhaps a more neutral term could reduce this barrier.

11.2.7 Homes turned into a mini hospital

A negative consequence of helping people to die at home is that their homes can become 'mini-hospitals'.

At the home of JP there was a discussion between the occupational therapist and the generic support workers about assisting Mr P to get from bed to chair. A 'stand-alone hoist' may be better as it is safer for carers to use compared to a 'patient turner', given Mr P's mobility problems. Mrs P is not that happy at the prospect of the hoist being installed, as it is said to be quite large, too big

to install in the bedroom upstairs, and so would require her husband sleeping downstairs. After we left the house the Generic Support Workers explained that the hoist will make their work safer and will allow Mr P to be less bed bound, but they admitted that it will impact on Mrs P's house and will also mean that Mrs P will have to go up and down stairs to see to her husband in the night. (Observation notes, 11.2.12)

Although family members were grateful for the equipment and professional staff, there was also some dismay. A Discharge in reach nurse also mentioned this difficulty.

It's all very well saying people can go home to die but then we turn their homes into little mini hospitals and we do that sometimes for the [benefit of] care agencies that are coming in...Because somebody's dying doesn't mean to say they can't share a bed with their wife...Ambulance men now won't carry patients upstairs so beds have got to come downstairs...We turn front rooms into little mini hospitals... and some poor wife sleeping upstairs or on a couch while her husband's downstairs. (Discharge in reach nurse)

11.2.8 Bereavement compounded by sudden withdrawal of all services

Another unanticipated negative outcome of the programme was that some family members found the sudden lack of access to services following the patient's death difficult.

I'll tell you a thing I find a little bit strange and hard...You have all this tremendous help and everything is great and then it all just stops...I've got myself in such a state...being home you've got the doctor coming in, you've got the district nurses, you've got the palliative care, you've got the contact with the hospice, you've got the night sits, everything is going on around you all time, you're going, going, going, going and then all of a sudden you've lost [wife] and everything else has stopped...It doesn't help to the next stage of life...but I know I'm not the patient really and truly... in a hospital you're not quite so involved are you because there are so many nurses and that's their place but when you're at home you're so involved with it. (Family member CF)

You miss the people. You make friends with all these people you see as well and suddenly they are not there. (Family member VK)

This difficulty about withdrawal of services is not particular to Delivering Choice.

11.3 Role and impact of local Marie Curie team

All of the factors listed above except the last two are contextual. A 'mechanism' that helped to drive the whole programme forward was the local Marie Curie team. Funded directly by Marie Curie Cancer Care, the local team was made up of a project manager, an operations manager and an administrative assistant who came into post in 2008. They carried out the initial needs assessment exercise (Phase I

report), facilitated the seven working groups that drew up the proposals for change (Phase II report, Business Phase II report), helped to implement changes, convened and participated in the regular board meetings and wrote the final report for the project (Phase III).

To learn more about the role and impact of the local Marie Curie team, the evaluation team contacted 41 members of the stakeholder and executive boards by e-mail to ask three questions:

1. What do you think the local Marie Curie team did that was helpful, as regards to the Delivering Choice Programme?
2. What could the team usefully have done differently?
3. Could the Delivering Choice initiative have taken place without the Marie Curie team? Please briefly explain the reason(s) for your answer.

We received ten replies with usable data. The low response rate is perhaps unsurprising as we gave a deadline of less than a week. Of the ten respondents, two came from North Somerset and eight from Somerset. Participants were at senior (and very senior) level and included professionals from hospices, social services and NHS commissioning and provider organisations.

11.3.1 What do you think the local Marie Curie team did that was helpful, as regards to the Delivering Choice Programme?

Responses to this question could be grouped into two areas:

- Good liaison and cohesion
- Expertise and effective project management

With regards to liaison and cohesion, respondents referred to the team's effectiveness in forging a link between the stakeholders, and in the process providing the "glue", as one put it, that helped keep everyone moving forward 'in the same direction at the same time (ZI). In providing this liaison, the team were said to have responded well to the differences in geography/demography/local responsibilities of North Somerset and Somerset, answered queries promptly, dealt with any issues as they emerged and engaged in a great deal of regular communication about the progress of the programme, using a variety of methods, including e-mail, telephone, and consultation group meetings. The team was also said to have exercised skill in building good working relationships and negotiating "around barriers", thereby "winning hearts and minds" when putting forward the case for change (GI). One respondent cited the constructiveness of the programme manager in operating objectively in respect of the contributions of the various stakeholders, managing the interfaces between them with skill. (AZ)

In terms of expertise and project management, the value of having an expert, dedicated resource was cited as a "key reason" for success that had helped "secure the deliverables" (FI). Such expertise was evident in the Marie Curie team's "wealth"

of resources, including their experience and “learning” from other areas and the good practice they could cite that helped reduce the potential to reinvent the wheel (MB). Another respondent pointed out that whereas good project management is always important, the key ingredient that made the local Marie Curie team invaluable was their specific expertise in end of life care and their “forward thinking”. (DS)

The Marie Cure local team was also described with attributes such as “leadership”, “vision” and “drive”. The Marie Curie team’s effectiveness in project management was defined in terms of their organisational skills, which included: “diplomacy”, political awareness, ability to stay focused and meet timescales, good approach to negotiation, attention to remaining “patient centred throughout” and enthusiasm. As a result, the team was seen to have “followed a structured, well thought out process in a timely manner” and their “knowledge and expertise in project management, change management and palliative care was appreciated by all they worked with” (KZ). The respondents appreciated their effectiveness in facilitating meetings and in “doing the background organisation that allowed things to happen” (LS). One clinician commented:

Clinicians and carers may have good ideas but don't have the time to execute things. The Marie Curie team by providing project manager support enabled things to turn from ideas to deeds. (NS)

An important aspect of the team’s successful project management strategy was the ability to raise the profile of the project in the wider health and social care economies of the two counties, with the result that commitment to delivery by all parties and agencies was more readily secured. Thus, progress was greatly facilitated, as one respondent said:

The service redesign process and implementation of the end of life care strategy was accelerated in Somerset. We would not have made the progress in commissioning pilot schemes for end of life care and redesigning the end of life care pathway so fast without this support. (VK)

This clinician went on to cite the “considerable administrative support” the team had provided, ensuring “very successful training sessions”, including the Advance Care Planning days. This element of back-up support was emphasised by others, for example one praised the very high level of support to the chairs of the stakeholder and executive groups through timely generation of agendas, minutes and forward plans (ZI). Another participant valued the support that involved ensuring documents were produced and actions chased and completed, all of which “made things happen promptly” (MB).

Another summed up attributes many respondents mentioned when she said

The local Marie Curie team was helpful [in] managing all aspects of the operational management of the programme very effectively. (GI)

11.3.2 What could the team usefully have done differently?

Seven of the ten respondents said that there was nothing the team could have improved on, summed up with phrases such as 'Nothing to add'. Those that did offer suggestions touched on issues of delay, reach, incremental growth (one participant) and contingency planning (one participant).

As regards to delay, one respondent from a health background thought that Phase 1 of the programme could have been significantly reduced, as the in depth mapping process "did not really tell us anything we did not already know" and had involved a lot of work. She went on to suggest that the project methodology could be revised "to provide a faster, pithier mapping process taking a care pathway approach" and that there could usefully have been fewer work streams in phase 2 "to consolidate the work and streamline the involvement of clinicians and partners". In terms of reach, this participant thought there should have been "a stronger focus on involvement of social care in end of life care planning". In respect of incremental growth, this respondent advocated more consideration of how current end of life care services already commissioned "could be redesigned to address the identified gaps in service rather than just putting in place new services". (VK)

The need for contingency planning was highlighted by another participant who talked about "a clear succession plan with the local providers and commissioners". The respondent said the local Marie Curie team should have stayed for longer, as the programme struggled to maintain momentum once the local Marie Curie team had left.

[The] same wonderful project management also allowed a relative vacuum to form in the local health providers and it was very challenging to keep the momentum going after the project ended... This would have helped in the latter stages of the project when many of the executive team seemed to lose interest with imminent end of the project. The upheavals of reorganisation haven't helped but many of the executive team have moved on to other challenges and the collective memory has been weakened (e.g. Somerset Care Coordination Centre was envisaged as supporting patients all along pathway currently only supporting CHC patients [for] last 3 months). (LS)

11.3.3 Could the Delivering Choice initiative have taken place without the local Marie Curie team?

In the main, respondents considered that the Delivering Choice Programme could not have happened, certainly not as successfully, if the local Marie Curie team had not been in place. Those who added further information highlighted the benefits of independence, accelerated progress and national profile.

One participant thought that the local team helped ensure a level playing field, bringing "independence and external validation" in a field where services were "fragmented" and the NHS had "dominance". The local Marie Curie team was

important in ensuring that “everyone had a voice”. (KZ) Another participant echoed this saying that from his perspective such an effective coalition could not have been formed without the Marie Curie local team input as

It gave a neutral ground which allowed everyone to come to table as an equal... I think there was still the opportunity for agendas to be proposed which were in an organisation's interest rather than the patient's however the setting and balance of the group made this less likely. (LS)

The ability of the team to remain impartial and independent was important to another respondent and the result was the ability to “move the delivery of the programme forward and gain consensus from the stakeholders because of this”. (GJ)

As well as independence being jeopardised, respondents considered that the speedy progress of the Delivering Choice Programme would have been lost without the involvement of the local Marie Curie team. A respondent mentioned how “the Delivering Choice Programme would not have kept to the same timescales, nor with the level of detail it had”, without the team, as it would have been “cumbersome” and time consuming to undertake such a large project “as part of the day job”, which is already beset with pressures and delays due to “changing priorities and distractions” (MB). Timescale was also raised by a third participant who said:

We would not have achieved anything like as much progress and change with the limited management team in the PCT [Primary Care Trust]. So whilst we could have applied the same methodology, the outcomes and outputs would not have been the same nor delivered in the same timescales. (FI)

The profile of the project would also have suffered.

The resources, drive and structure that the local Marie Curie team brought to the programme took the work to a significantly higher level in terms of visibility, executive and clinical support, and commitment to implementation. This has been a very positive programme in both Somerset and North Somerset, and is frequently cited as a case study to illustrate good practice. (GI)

Another raised the point that credibility for the project, and therefore cooperation to participate, was secured because the Marie Curie organisation was behind it. A prestigious national project was a useful lever to secure commitment and maintain momentum. “Working with Marie Curie engendered a level of respect that other projects haven't [got]” (MB).

While not exactly a dissenting voice, one respondent made the point that some end of life care initiatives did take place without the team, citing the Gold Standards Framework in care home programmes project, which one participant said had already been underway, adding that “the education and training strategy would have happened anyway due to the national funding to support this”. (VK)

11.3.4 Concluding remarks about the local Marie Curie team

Although only ten participants responded, there was a general consensus that the local Marie Curie team was important to the overall success of the project in several ways, mainly by providing:

- Leadership, vision, drive and diplomacy.
- Effective project management to meet targets and maintain momentum.
- A 'level', neutral playing field across disparate organisations so that one organisation did not dominate.
- Knowledge of how major end of life care re-design programmes had worked elsewhere.
- Dedicated time and staff which created an on-going focus for the work so it did not get lost in the latest re-organisation.
- A national profile via Marie Curie which created a useful change lever.

Presumably, these ten respondents were among the most positive of our sampling frame. Although they were all senior level professionals, they found the time to respond to our request for feedback on the local Marie Curie team. However, the evaluation team attended several stakeholder and executive board meetings throughout the course of the evaluation and had many informal chats with board members and the general impression was that the local Marie Curie team was highly valued. So, in summary, and without evidence to the contrary, the general consensus appeared to be:

The expertise and capacity of the Delivering Choice Marie Curie team was crucial to the success and speed of implementation in Somerset. We learned a great deal from them. (RB)

11.4 Integration of Delivering Choice services

11.4.1 Integration between Delivering Choice services

In exploring the issue of integration, to recap the five Delivering Choice services under study were:

- For North Somerset, the End of Life Care facilitators and the North Somerset End of Life Care Co-ordination Centre (NSCCC).
- For Somerset, the Discharge in reach nurses, the Somerset End of Life Care Co-ordination Centre (SCCC) and the Out of Hours advice line.

Within North Somerset, the relationships between the End of Life Care facilitators and the NSCCC were somewhat fractured initially, as there was considerable confusion over roles and responsibilities. However since March 2012 when an End of Life Care facilitator took over the lead nurse role at the NSCCC and the other facilitator moved to the NSCCC offices, the two services work much more harmoniously together. For example, the NSCCC lead nurse may hear that a care home needs extra training and this request is then passed on to the End of Life Care

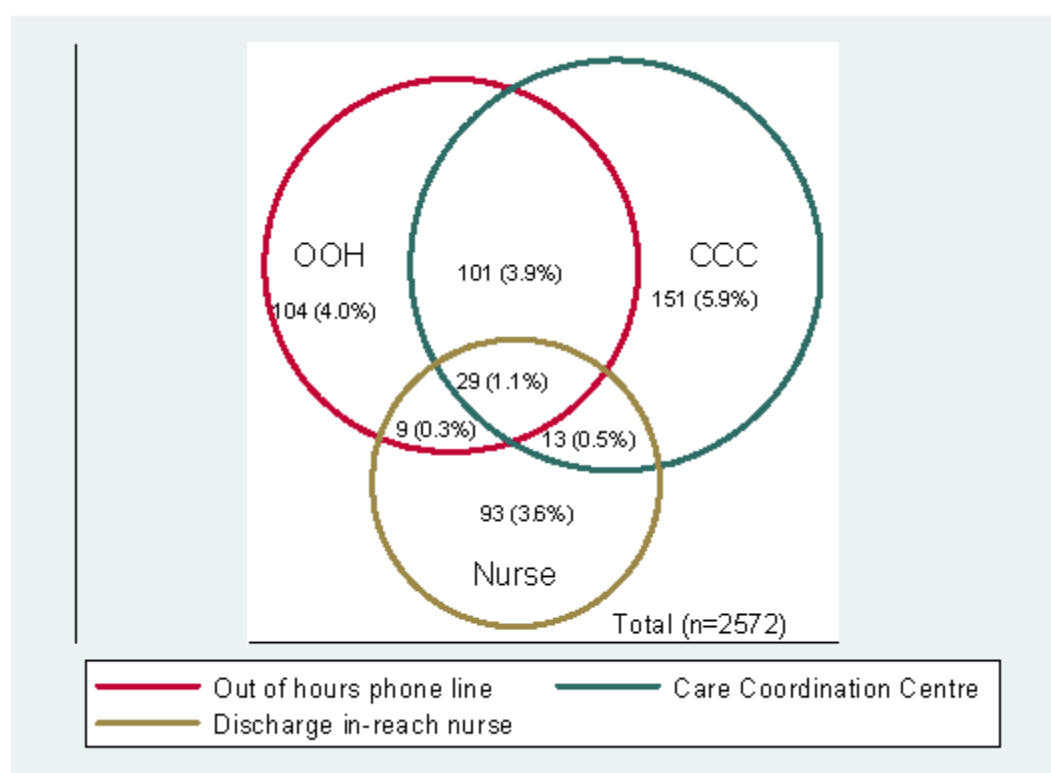
facilitator. In turn, the End of Life Care facilitator promotes and advertises the NSCCC to community nurses, hospice staff, care homes and GP practices. The NSCCC serves an operational function while the End of Life Care facilitators have an educational role that includes marketing the NSCCC. Because staff forget about services available, this regular re-advertising of the NSCCC by the End of Life Care facilitator is potentially quite powerful. It is somewhat doubtful whether either service as a stand alone would be as effective.

Within Somerset, we found ample evidence that the three Delivering Choice services worked well together. For example, we found:

- The Out of Hours line log documented regular calls from the Discharge in reach service to request that nurse advisors check up on recently discharged patients. The Out of Hours log also documented liaison between the Out of Hours line and SCCC staff over care packages.
- The Discharge in reach nurses reported regular contact with the SCCC to arrange care packages on discharge.
- Family members recounted how contact with the Discharge in reach nurses resulted in subsequent arrival of equipment or care agency staff organised by the SCCC.
- The SCCC reported that they routinely pass on the Out of Hours line number to the family members of new referrals which was confirmed by family carers and documented in SCCC records.

To explore the overlap between services further, we analysed data from all 550 Somerset patients using any Delivering Choice service who died from 1 September 2011- 29 February 2012. To interpret the diagramme below, the closer the circles are to overlapping, the greater the collaboration between services. The denominator for this figure is the total number of those who died in Somerset with potential palliative care needs (n=2572). The percentages relate to this denominator. So in interpreting this, 3.9% (101/2572) of the total number of people who died in the study period with palliative care needs accessed both the OOH advice line and the SCCC while 1.1% (29/2572) of the total number of those with palliative care needs who died in the study period accessed all three Somerset services. Given the synergy between the three Somerset services, they appear to be quite interdependent.

Figure 8: Integration between Delivering Choice services



In exploring the figure further, the Discharge in reach service would struggle to discharge patients quickly without the rapid placement of care packages organised by the SCCC, although interestingly only 29% (29+13=42/144) of Discharge in reach patients were SCCC service users. This was almost the same proportion of patients that overlapped between the Discharge in reach and OOH advice line services (29+9=38/144 or 26%). The OOH advice line takes on the role of organising emergency care packages during the non-business hours of the SCCC, as the SCCC is only open for 5 hours on Saturday and Sunday. We found that 53% (101+29/243) of the OOH advice line patients used SCCC services and 44% (101+29+13/294) of SCCC patients called or prompted a call to the OOH advice line. This suggests that there is substantial cross referral between the SCCC and the OOH advice line with less input from the Discharge in reach service. Overall, these data suggest high levels of collaboration. As one specialist palliative care nurse said

They're all part of the same jigsaw aren't they? So just on their own, they wouldn't be as effective. (Specialist community palliative care nurse RM)

11.4.2 Integration between Delivering Choice and the wider health and social care economies

In looking at the extent to which the Delivering Choice Programme has been normalised into routine care, the Adastra electronic register, Palliative Care Framework, recording of Key Worker and Delivering Choice Pathway do not appear

as well embedded. The register and framework seem to have made more progress than the pathway or recording of Key Worker.

More positively, in North Somerset, the NSCCC and the End of Life Care facilitator appeared well on their way to becoming an integral part of the Single Point of Access team, which includes health and social care professionals. In North Somerset generally, the push is for integrated health and social care teams and the NSCCC and End of Life Care facilitator appear to be in the vanguard of that movement. More widely, the NSCCC has good connections with the two hospices and growing relationships with the community teams. For example, induction for newly appointed Generic Support Workers includes time at the hospices. However, concentrated effort is needed to embed the NSCCC more firmly with community teams and begin to foster links with acute hospitals, especially those outside the county.

In Somerset, the three Delivering Choice services are well embedded within the hospice community, which is unsurprising as the hospice provides two of the three services. Within the NHS, both Discharge in reach nurses are well integrated within their respective hospitals; in fact a past danger was ensuring the on-going autonomy of the role. The SCCC has begun to develop relationships with NHS community nurses, although further work is necessary so that community nurses are more likely to delegate the organisation of care packages to the SCCC. The SCCC also reportedly has good relationships with care agencies. The Out of Hours advice line could further build relationships with urgent care and daytime NHS staff, but they have begun to develop good relationships with agencies that provide night care workers.

These growing links between the Somerset Delivering Choice service providers and wider health professionals were described by a palliative care nurse.

I think the end of life care tends to be linked together quite well really with the hospital because the hospital [Discharge in reach service] link with the end of life coordination centre in Wells [SCCC]. They [SCCC] link very much with us [community palliative care nurses] and they are very communicative so the message seems to get through to everybody so we all know what's happening. If I need to speak to one of the nurses, if a patient of mine goes in I'll speak to one of the [Discharge in reach] nurses and they'll go and visit them and come back to me and let me know what's happening, so that's good. I know when someone's coming home for instance, it's very well someone going to hospital but they come home and no one knows about it. And also, sometimes there's things that perhaps aren't in the notes that you want to explain to people, about the family or social circumstances. You can hand over that side of things, which can be helpful just to get you a bigger picture. (Specialist palliative care nurse RT)

11.5 Maps of service use

To get a better understanding of pattern of uptake of the programme across the two counties and how elements of the Delivering Choice Programme worked together, we identified the GP practices where Delivering Choice patients are registered and mapped Delivering Choice usage by community ward for North Somerset and by federation for Somerset. It was not possible to obtain denominator data of total number of palliative care deaths. There is one map for North Somerset which includes Delivering Choice service usage, the register and Key Worker. There are two maps for Somerset: the first Somerset map plots Delivering Choice service usage and the second maps usage of Adastral electronic register. As we have used data from the six month study period ending in February 2012, these patterns may have changed.

11.5.1 North Somerset Delivering Choice service usage

For North Somerset during the study period, we found the majority of the North Somerset Delivering Choice service users congregated around the community wards in the southern part of the county, which corroborates data from interviews with professionals. Knightstone, Pier View and Baytree had a combined total of 120 patients compared to 71 patients from community wards inland (Tyntesfield, Marina, Strawberry Line). Patients referred to the NSCCC were most likely to be resident in the southern community wards of Knightstone (n=52) and Pier View (n=38) and least likely to be resident in the community wards of Tyntesfield (n=12) and Clevedon (n=16). During the study period, no patient from Tyntesfield and only one patient from Clevedon were allocated a Generic Support Worker, while patients in the southern community wards, especially Knightstone (n=9) and Pier View (n=7), received services from the Generic Support Workers most frequently. So if these referral patterns continue to hold true, this suggests that the NSCCC and the Generic Support Workers are well embedded in the southern part of the county and future efforts could target the services to the Tyntesfield, Clevedon, Marina and Strawberry Line community wards.

In looking at the Adastral electronic register, the community wards with the most patients registered were again in the southern part of the county in Pier View (n=32) and Knightstone (n=26), although many patients from Marina also had Adastral records (n=24). The community wards of Baytree (n=11), Clevedon (n=15) and Strawberry Line (n=15) had registered some patients, while Tyntesfield had the fewest (n=3). Knightstone (n=9) and Marina (n=9) had the most records with Key Worker details, which could be due to their close proximity to the two hospices, while Baytree (n=3) and Tyntesfield had the least (n=1). This suggests that although uptake of the electronic register and Key Worker could be better across the entire county, Tyntesfield, Baytree, Clevedon, Strawberry Line and Pier View could be prioritised for renewed educational efforts.

As mentioned previously, the NSCCC is responsible for the updating and maintenance of the Adastral end of life register. In looking at combined use of the

NSCCC and the register, the results suggest that there is substantial scope to improve the uptake of Adastra, as a large proportion of patients across the county who are in contact with the NSCCC are not registered. For example, Pier View, which had the most patients using the NSCCC and on the register with nine, had a further 23 patients that had used the NSCCC without Adastra registration. Please see the North Somerset map below.

11.5.2 Somerset Delivering Choice service usage

The first Somerset map shows usage of the different services, and combination of service usage, by the nine Somerset federations. For the six month study period of 1 September 2011 to 29 February 2012, we found that patients from East Mendip were least likely to receive Delivering Choice services (n=22) while those from South Somerset were the most likely (n=167).

The reach of the SCCC stretched across the entire county, although the highest number of patients came from Taunton (n=49), South Somerset (n=48) and Bridgewater (n=44). Patients using the Discharge in reach service were most likely to reside in South Somerset (n=63) or Taunton (n=17), which corresponds to the location of the Discharge in reach nurses in hospitals in Yeovil and Taunton. The Discharge in reach service did not work with any patients from West Somerset, North Sedgemoor or East Mendip, possibly because patients from the northern part of the county are more likely to go to out of county hospitals. The OOH advice line, which is located in Taunton, was most frequently used for patients residing in Taunton (n=66), followed by South Somerset (n=48) and Bridgewater (n=45). The OOH advice line did not receive any calls for patients residing in East Mendip.

These results suggest that for all services, the most activity occurs in close proximity to their geographical base. For the Discharge in reach service, little can be done to change this, as the service is dependent on which hospital patients choose to visit. To expand their reach, the Out of Hours line could target East Mendip (n=0), Central Mendip (n=14), West Somerset (n=15), North Sedgemoor (n=19) and Chard, Crewkerne and Ilminster (n=20). Although it has got good coverage across the county, the SCCC could consider increased marketing of its services to East Mendip (n=22), West Somerset (n=22) and West Mendip (n=23).

Please see the Somerset service uptake map.

11.5.3 Somerset register and Key Worker uptake

In looking at the second map for Somerset on the usage of Adastra electronic register and the recording of Key Worker, East Mendip again has the lowest use (n=13), closely followed by West Somerset (n=20) while patients residing in South Somerset were the most likely to be registered (n=76). The recording of Key Worker was least likely for patients from West Somerset (n=5), Taunton (n=7), East Mendip (n=9), West Mendip (n=15) and Central Mendip (n=16). Please see the Somerset map on Adastra and Key Worker uptake.

Figure 9: North Somerset Delivering Choice usage

For Baytree, to calculate the total number of CCC users, we add (CCC only n=18) + (GSWs=2) + (CCC+Adastra=3) = 23 total CCC patients. For Adastra, we add (Adastra only=5) + (Key Worker=3) + (CCC+Adastra=3)= 11 total on Adastra.

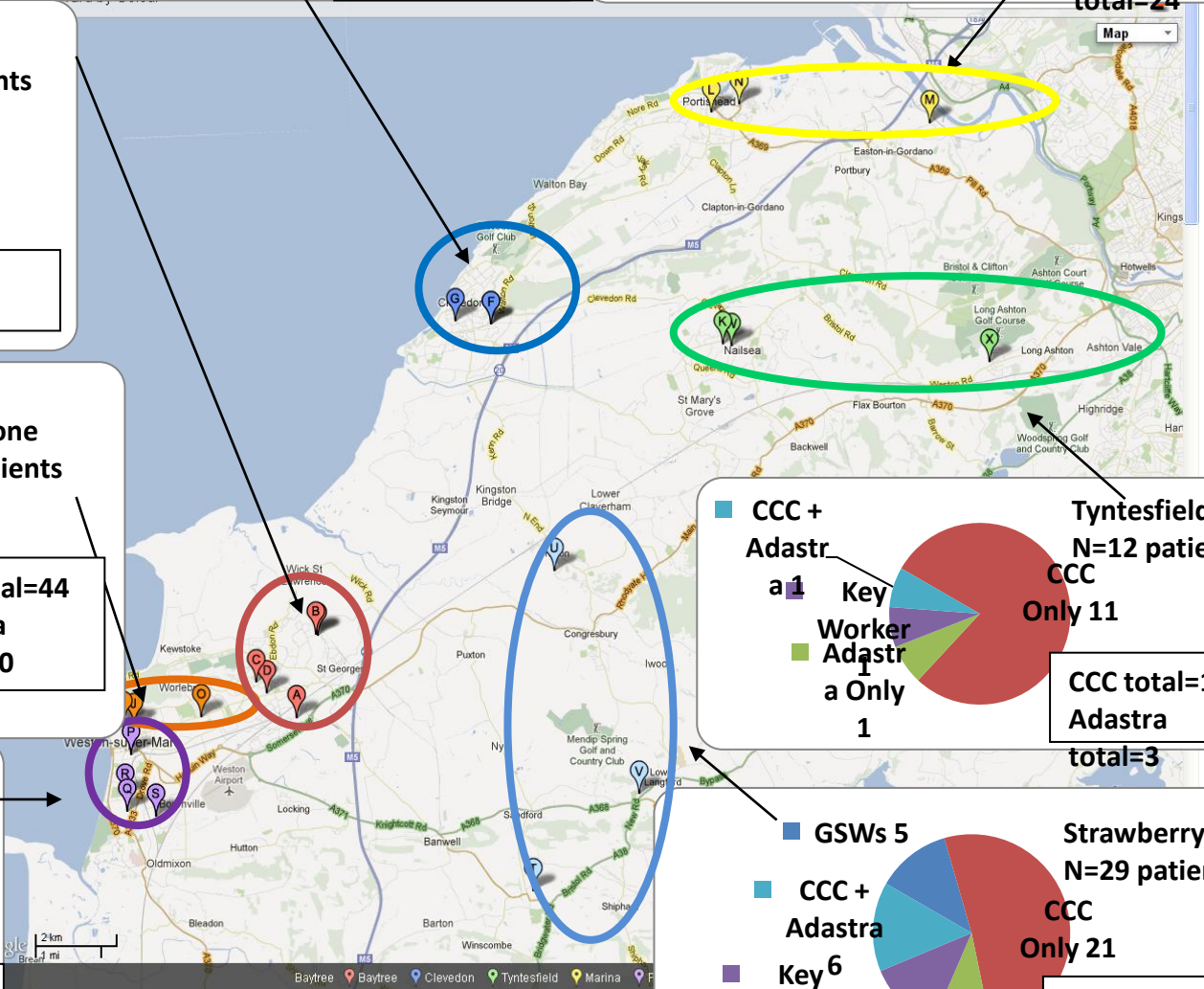
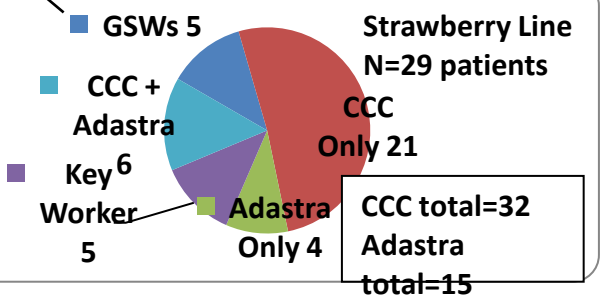
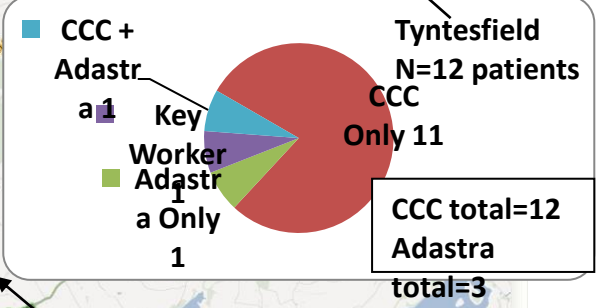
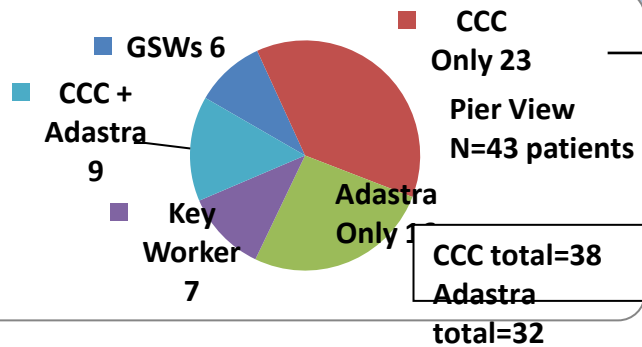
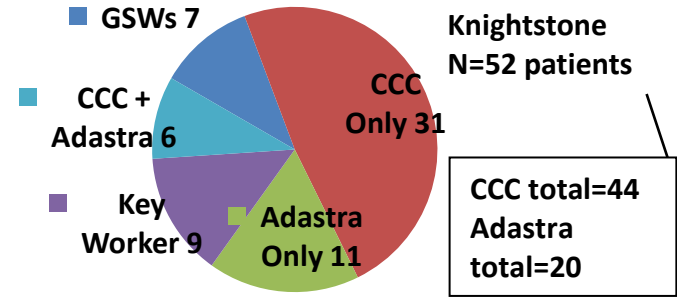
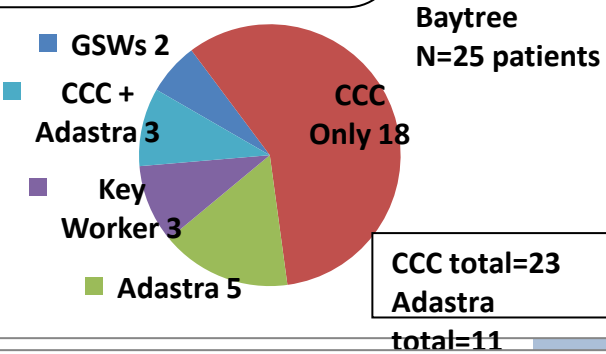
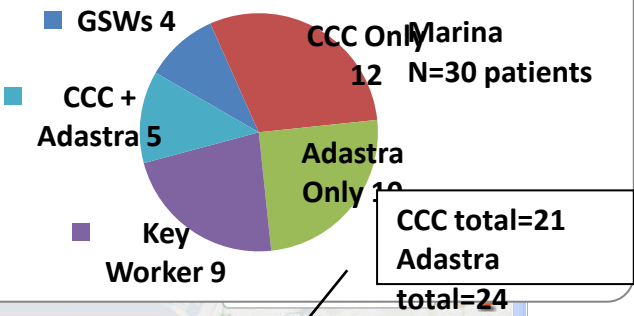
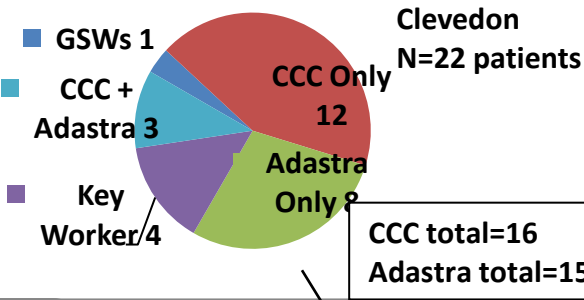


Figure 10: Somerset Delivering Choice Service Usage

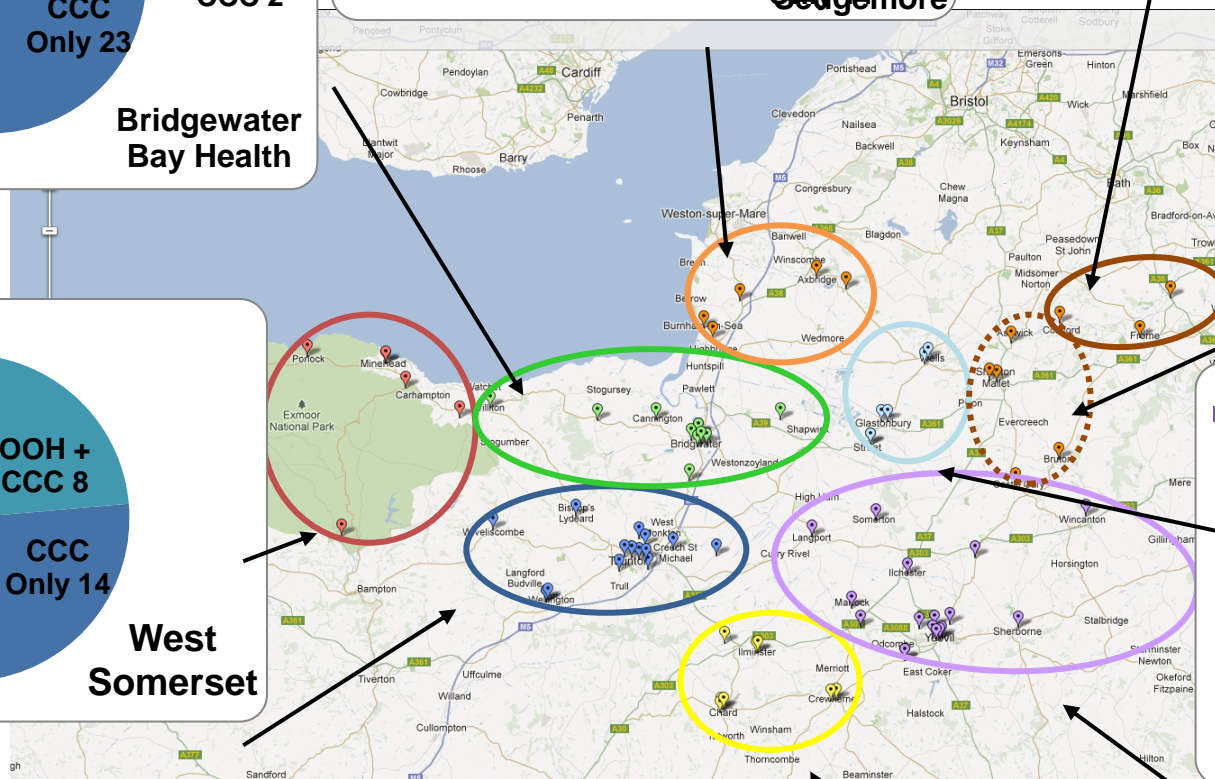
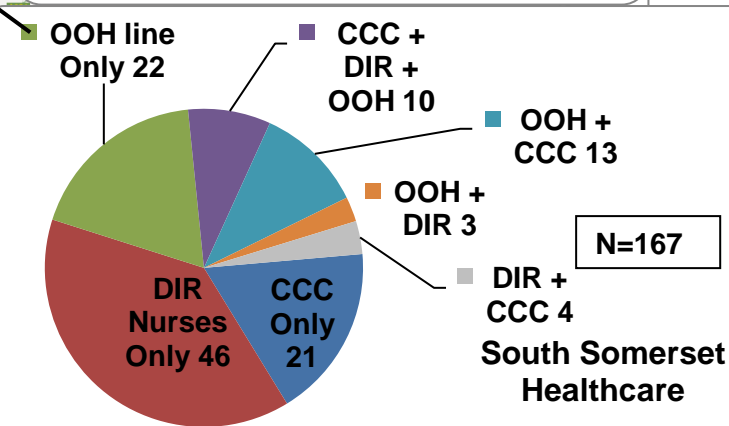
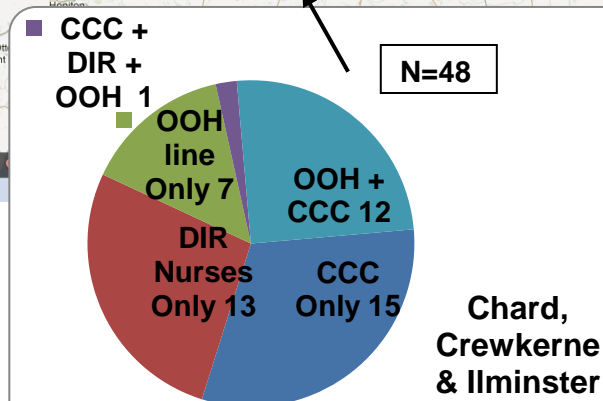
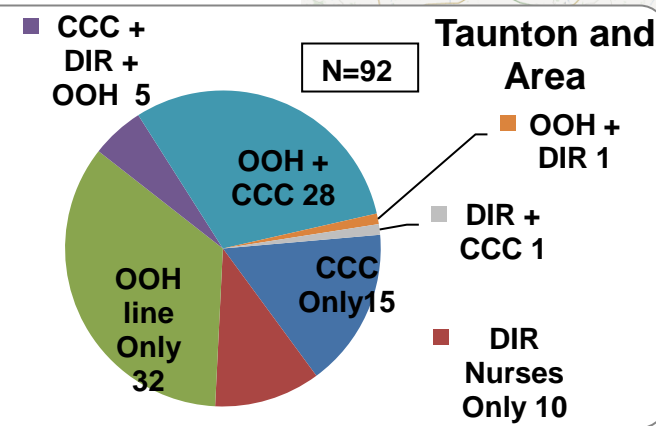
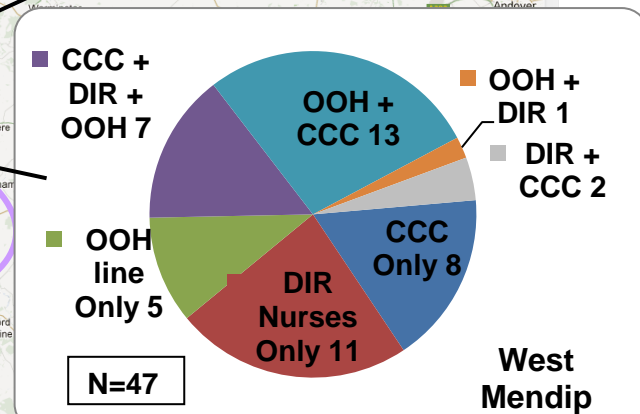
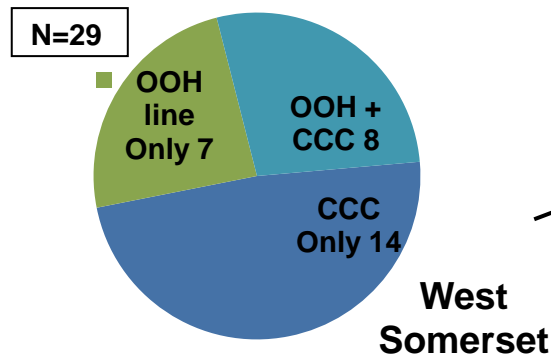
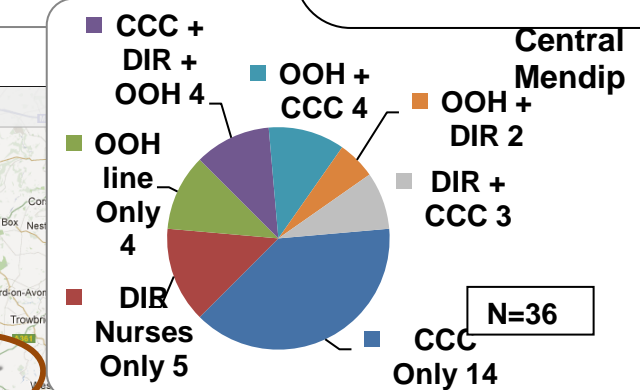
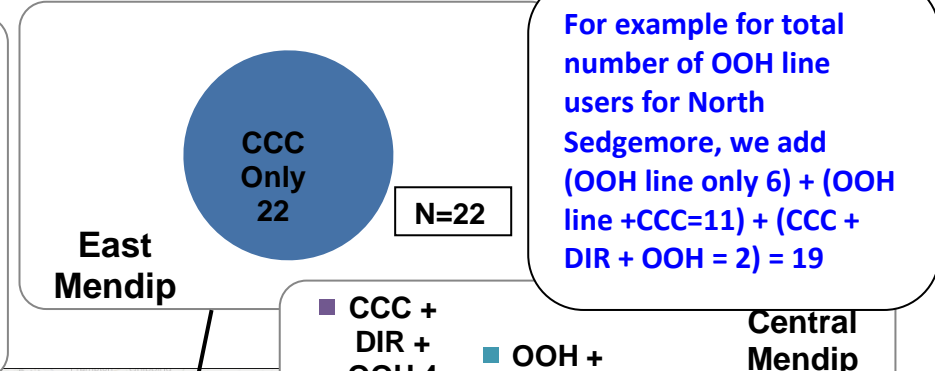
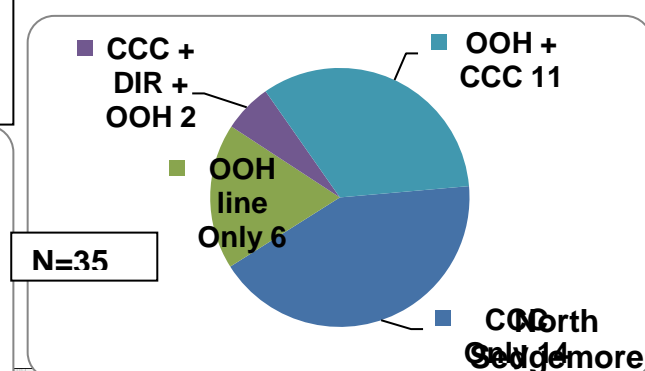
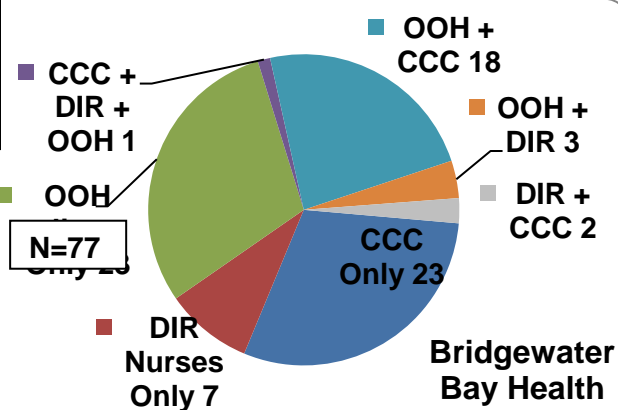
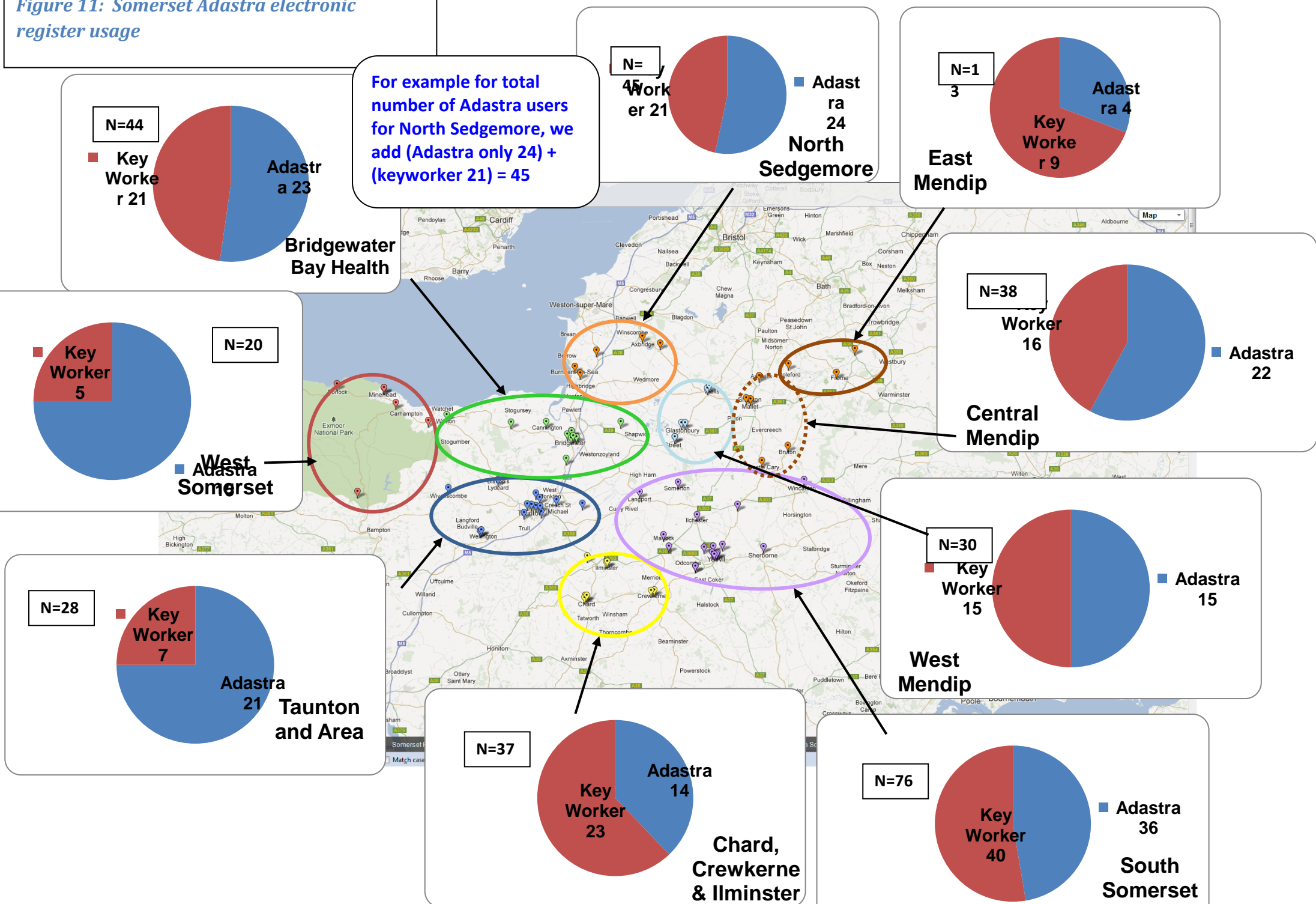


Figure 11: Somerset Adastra electronic register usage



11.6 *Concluding remarks*

In considering the programme as a whole, we identified several cross-programme contextual factors that helped including:

- Sufficient funding for the local Marie Curie team, Delivering Choice services and fast track patients.
- Excellent leadership and management across Delivering Choice services.
- An engaged commissioner interested in end of life care.
- Personal contact with professionals who refer in to the service.

Certain barriers also re-surfaced regularly including:

- Professional territorialism.
- 'End of life' term can be disturbing.

We also identified two negative consequences of the programme mentioned by family members and professionals specifically: a) homes becoming mini-hospitals for the convenience of professionals, and b) the sense of bereavement compounded for family carers as they lose contact with caring professionals. This chapter also discussed the crucial role played by the local Marie Curie team in making the initiative happen.

In looking at the interplay between the different components of the Delivering Choice Programme, we found that the services in North Somerset (End of Life Care facilitators and NSCCC) were highly dependent on each other to maximise the effectiveness of each. This is also true for Somerset services.

More widely, the NSCCC and End of Life Care facilitators appear on their way to becoming embedded in the North Somerset health and social care economy, helped no doubt by co-location within the mixed health and social services Single Point of Access team. The service usage map for North Somerset suggests:

- Uptake of Delivering Choice services is good in the southern part of the county.
- The greatest number of patients registered with Key Worker were recorded in Knightstone, Pier View and Marina.
- The Greatest opportunities for growth lie with Tyntesfield, Clevedon, Baytree and Strawberry Line.

In Somerset, the Delivering Choice services have made great inroads into the hospice, which is unsurprising as two of the three Delivering Choice services are provided by the hospice. The Discharge in reach service is well embedded in the two hospitals. The OOH advice line has begun to foster good relationships with night sitting agencies. Reportedly the SCCC has good links with the care agencies and we found substantial

evidence that the SCCC is popular with community nurses. The service usage map for Somerset suggests:

- The SCCC is relatively well used across the county; the Discharge in reach service is largely based around the two hospitals where the nurses are posted and the OOH advice line tends to be more heavily used where Delivering Choice services are geographically located.
- South Somerset Federation has the greatest uptake of all services with good overall levels of uptake in Taunton and Bridgewater.
- Greatest opportunities for OOH line lie with East Mendip, Central Mendip, West Somerset, North Sedgemore and Chard, Crewkerne and Ilminster Federations.
- Greatest opportunities for the SCCC are with East Mendip, West Somerset, West Mendip, North Sedgemore and Central Mendip.
- Uptake of the Adastra electronic register and recording of Key Worker is highest in South Somerset while further effort is needed in East Mendip.

So, overall, we found that the Delivering Choice services work well with each other and are on their way to becoming embedded in their respective health and social care economies.

Conclusion

12.0 Conclusion

12.1 *What is different now?*

To recap, 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 Co-ordination Centres (North Somerset and Somerset)
- Out of Hours Advice and Response Line (Somerset)
- Discharge in Reach Nurses (Somerset)
- Aadastra electronic end of life care register and the recording of Key Worker (North Somerset and Somerset)
- Delivering Choice pathway and the Palliative Care Framework (North Somerset and Somerset)

The evaluation reports 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 visit
- Hospital costs including hospital admissions and A&E visits.
- Co-ordination of care.
- Patient and family member satisfaction.
- Care and death in preferred place.

Overall, we found that users of Delivering Choice services had lower rates of secondary care use than non users and that there were high levels of satisfaction with care and the coordination of care delivered by Delivering Choice. We could not investigate the contribution of Delivering Choice to care and death in preferred place, as these data were not available for sufficient patients to carry out robust statistical analyses.

12.2 *Limitations*

There were a number of limitations to this evaluation. It was not a randomised controlled trial and all findings are subject to potential confounders. We have adjusted the quantitative outcomes for potential confounders such as age, gender, deprivation and cause of death. However, there are other ways in which the groups may have differed that we were unable to account for such as whether a person lived alone. Data on comorbidities were only available for those patients admitted to hospital. Although

this was the majority of patients we were unable to include co morbidities in the logistic regression analyses.

Because of the timing of the evaluation within the roll out of Delivering Choice data from the time period preceding Delivering Choice were not available. A before and after study would have provided more robust evidence of changes in rates of secondary care use and place of death.

Moreover, we cannot state that there is a causal relationship between the use of Delivering Choice interventions and the outcomes. However, Delivering Choice services appear to be making an important contribution to improving end of life care in North Somerset and Somerset.

12.3 Key findings

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 (Discharge in reach service, both Care Coordination Centres, Out of Hours advice line). 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 and many believed that use of Delivering Choice services had contributed significantly to realising as 'good a death as could be'.
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%. The hospital based Discharge in reach service had the lowest proportion of home deaths.
4. In **North Somerset, emergency hospital admissions** in the last month of life were 50% 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 6%.
6. In **North Somerset A&E attendance** rates in the last month of life was 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 including directly employed generic support workers was £369,000 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 services 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 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. This could be because the Discharge in reach service proactively selects patients, rather than waiting for referrals like other Delivering Choice services.

For professionals, qualitative data suggests that the introduction of the Delivering Choice services, especially the End of Life Care facilitators and Discharge in reach service, has led to increased staff confidence in delivering good quality end of life care while perceptions of community professionals are that the Care Coordination Centres have freed up staff time previously spent on organising care packages. This released time can now be spent on helping more patients die in the community.

Staff across both North Somerset and Somerset commented that the introduction of the Delivering Choice services had changed the delivery of end of life care. A hospice nurse in North Somerset said

Having worked in North Somerset prior to the Care Centre and [End of Life Care facilitator] being in place I feel that since both of these services have been activated the standard of care and support not only to patients and carers, but also PHC team members has increased. (Hospice nurse MC)

In Somerset, a specialist palliative care nurse agreed that the changes brought about through the Delivering Choice programme have had an important effect on the quality and quantity of end of life care service provision.

[The] services that are available out in the community and how they're accessed has increased phenomenally and actually I was a district nurse before I worked on the inpatient unit so I can remember from when there wasn't anything other than the district nursing service really. So the increase in care provision and also being able to access it then through the end of life coordination centre, which really has been pivotal, which means that once people are eligible for continuing healthcare funding then the size of care package you can put in is large by comparison to what used to be happening and you can support people for the best part of 24-hours, 7-days a week. So there's that difference and then the role like [Discharge in reach nurse is] doing, which enables people to be discharged

very quickly, although that is dependent on all this care being provided out there because I can certainly remember when people couldn't come home because the care just wasn't available out there. If the district nursing service couldn't supply it through the day then really it didn't exist, certainly night-sits and things like that.
(Specialist community palliative care nurse RM)

So overall, the Delivering Choice services appear to be making a valuable difference to family carers and professionals. However, the interventions of the Delivering Choice pathway, Palliative Care Framework, recording of Key Worker and use of Adastra electronic register appear to have had patchier success. The following section gives an overview of these interventions, in addition to detailing key findings for every component of the Delivering Choice programme under study.

12.4 What works for whom and in what circumstances?

12.4.1 Adastra electronic end of life care register and recording of Key Worker

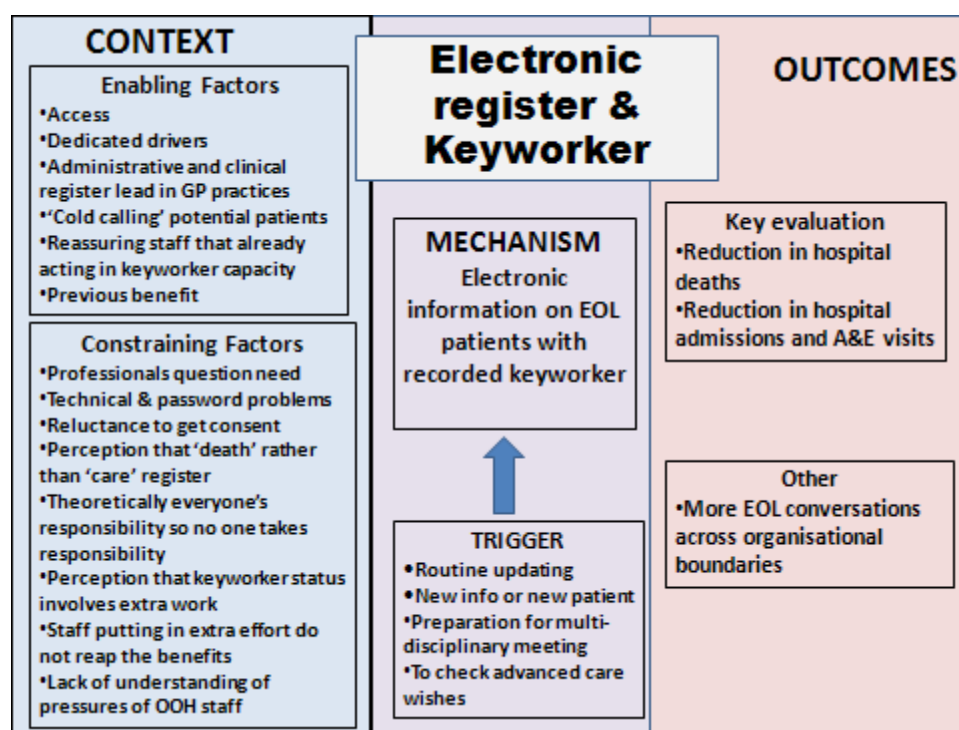
'Use' of the Adastra register can take the form of registration of patients or consultation to inform decision making. We found that more patients were registered for Somerset (n=1054) than North Somerset (n=169) overall. However, during the six month study period, only 12.9% of Somerset patients and 9% of North Somerset patients who died were registered. Amongst Delivering Choice services during the study period, Somerset Care Coordination Centre had the greatest number of patients registered with just over 50% while North Somerset Care Coordination Centre had the least at 21%. The recording of Key Worker is dependent on Adastra registration, so unsurprisingly we found that Key Worker was only recorded for 6% of Somerset and 3.7% of North Somerset patients who died during the study period.

Quantitative analyses found that registered North Somerset patients were less likely to die in hospital. Qualitative interviews found that North Somerset staff from both hospices routinely entered patients into Adastra. This was confirmed with the North Somerset service usage map, as Adastra registration is highest in the southern part of the county and in the Marina ward, both areas where hospices are active. So perhaps the association between Adastra and deaths at home is more attributable to the confounding factor of good quality care delivered by local hospices.

Quantitative analyses found that Somerset patients who were registered were less likely to die in hospital or have a hospital admission. Qualitative data revealed that during the study period each of the nine Federations had an 'End of Life Care facilitator' whose remit including increasing Adastra registration. So again, perhaps the association between Adastra and fewer deaths in hospital and hospital admissions owed more to the increased focus on good quality end of life care generated by the Somerset End of Life Care facilitators.

Given the array of potential confounders that could explain these outcomes, we are not confident about the extent that the Adastra register is contributing to changes in hospital deaths and admissions. The figure below gives an overview of the key findings for the Adastra electronic register and the recording of Key Worker.

Figure 12: Key findings Adastra electronic register and recording of Key Worker



In both counties, uptake is highest amongst hospice and community palliative care nurses who understand the importance of providing good quality information on end of life care patients, especially to urgent care services. To be successful, the register must surmount many challenges including persuading non-specialist staff that the register resolves a problem rather than creates extra work. Moreover, to justify the effort, it needs to be used by and inform urgent care staff. Overall, many are not convinced about the usefulness of the register.

Given the importance of providing good quality information across organisational boundaries, we would suggest consideration of two options. The first is to expand the Crosscare system, which appears to function well, from the hospices to NHS organisations. The second is to continue with the implementation of the Adastra system, but with considerably more resource investment. If the decision is made to continue with the Adastra system, technical improvements to both inputting and extracting data are needed.

Recording of Key Worker suffers from many of same difficulties as the register. However although recording of Key Worker on the register is low, the patient experience pathway work suggested that professionals do actually take on and discharge Key Worker responsibilities as a matter of course. Broadly speaking, the Key Worker function can be broken down into three areas: assessment, coordination of care and advocacy. Of the three, the advocacy role, whereby knowledgeable experts champion

patients and families to ensure that they get the help needed (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 are especially important for patients living on their own or with limited family support and when crises occur out of hours.

As obvious professionals, such as specialist community palliative care nurses, do not work out of hours, a key question is who should take on the Key Worker title and role out of hours. The evaluation team observed that the Out of Hours advice line team appear to be successfully acting as advocates already, for example the Out of Hours log recorded numerous examples of the nurse advisors negotiating with other care providers to ensure that patient and family needs were met. Perhaps consideration could be given to broadening the scope of the Out of Hours advice line team to include the important Key Worker responsibility of advocacy outside of working hours for greater numbers of patients. As the Out of Hours advice line staff currently state they are at capacity, this would necessitate increased funding.

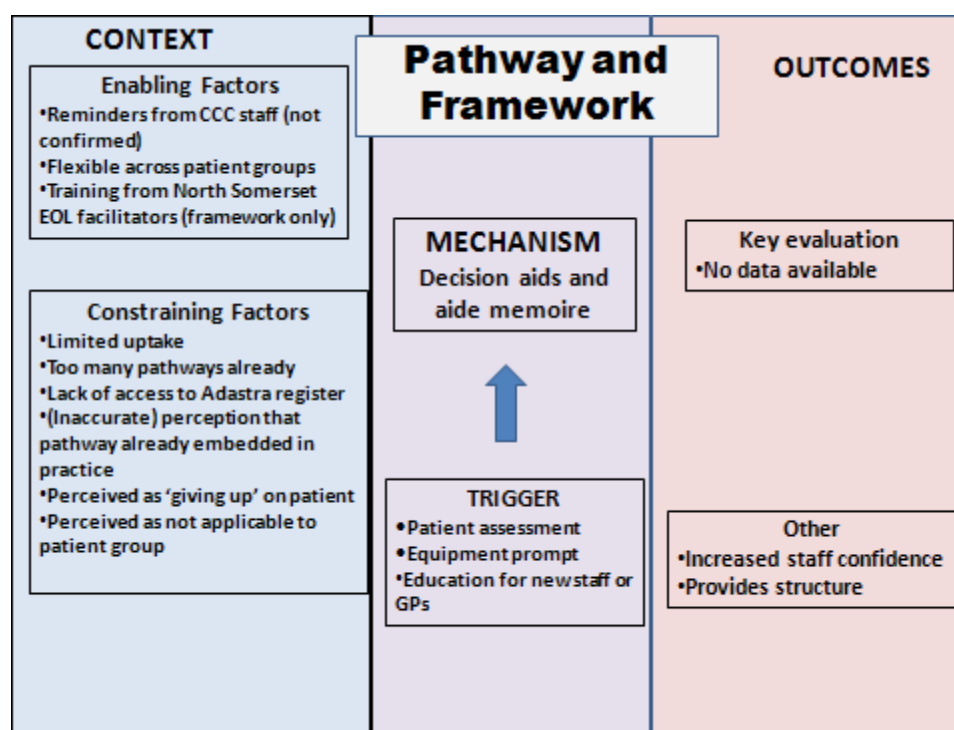
12.4.2 Delivering Choice pathway and Palliative Care Framework

The Delivering Choice pathway sets out the eight steps of the ideal end of life care patient trajectory. The Palliative Care Framework is also known as the 'traffic lights' system (red/ amber/ green) and is a tool to help staff assess patient status. Both the pathway and the framework are aide memoires designed to remind staff of what and when actions need to be carried out.

The first step of the pathway is registration on Adastra and the second is allocation of Key Worker. The analysis of the pathways of ten patients (see Chapter 10), qualitative interviews with staff and Adastra service usage data suggest that the first and second steps of the pathway rarely take place. Some experienced professionals report that the pathway is already embedded into practice, although the patient experience pathway analysis suggests this is not the case. Less experienced staff reported finding the pathway more useful. A major difficulty with the pathway is that it is designed in a linear fashion, whereas the patient experience pathway findings suggested that patient trajectories are much more iterative and unpredictable.

With regards to the Palliative Care Framework, the patient experience pathway analysis identified some use of this tool, but not always correctly. For example, patients who were in their final days were assessed as 'green' or stable, when clearly they were not. Nonetheless, several district and community palliative care nurses mentioned that they found the Framework tool useful, especially when assessing patient status in multi-disciplinary team meetings.

Figure 13: Key findings Delivering Choice Pathway and Palliative Care Framework



Given these overall findings, we would recommend that:

- The Delivering Choice pathway may need to be re-designed, perhaps as a flowchart or in another less linear model.
- Further roll out and implementation of the Palliative Care Framework could be considered, including training for non-specialist nurses.

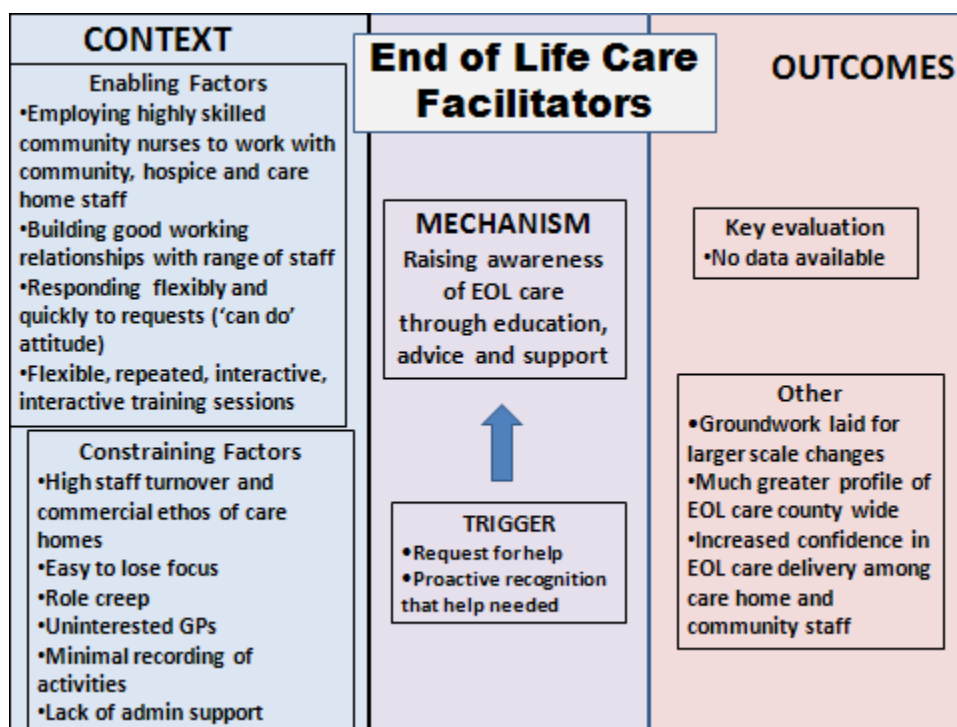
12.4.3 North Somerset End of Life Care facilitators

The End of Life Care facilitators gave a face, a name and a presence to raise awareness about end of life care in North Somerset. Their geographical scope covered the entire county. They were brought in to work with professionals across the organisational boundaries of hospices, care homes, GP practices and community wards. Their remit included delivering interactive training sessions, signposting and advising staff, resolving professional disputes, overseeing the implementation of 'just in case' boxes with community nurses and even setting up syringe drivers for patients in an emergency. The outcomes for this service were just as ambitious and wide ranging. Yet dedicated capacity was limited as the service consisted of one Band 6 nurse for 21 months and one Band 7 nurse for 9 months.

Nonetheless, the End of Life Care facilitators had a 'can do' attitude, which was appreciated by community professionals and care home staff who reported increased

levels of confidence in end of life care. They were both obviously highly skilled professionals able to work successfully with a wide range of individuals. The remaining End of Life Care facilitator also now works closely with the North Somerset Care Coordination Centre, which means that professionals are regularly reminded of the existence of the Care Coordination Centre.

Figure 14: Key findings North Somerset End of Life Care Facilitators



The sustainability of this service is in question, as at the time of writing (July 2012) on going funding has not been secured. Having laid the bedrock for changing professional behaviour, which can take years, it would be unfortunate if funding was discontinued just when the benefits may come about. Because the intervention of the End of Life Care facilitators is hard to measure, behind the scenes, subtle and dependent on working through staff who then in turn deliver care to patients, it is easy to undervalue the importance of their work. The impetus now needs to be on honing in and focusing the role to achieve the ambitious outcomes. The service also needs to develop ways to systematically record the nature and duration of 'contacts' with professionals to justify continued spending in business cases and to facilitate evaluation of impact.

12.4.4 North Somerset Care Coordination Centre

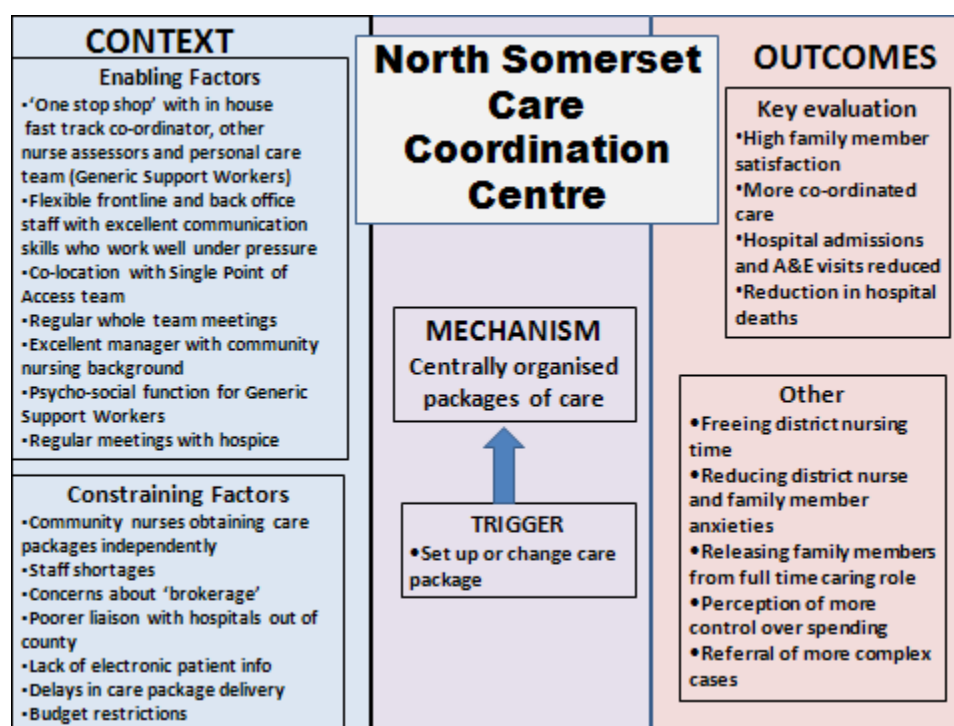
The North Somerset Care Coordination Centre (NSCCC) organises packages of care consisting of equipment, personal care agency staff and night care workers for all those who want to die in the community, regardless of condition or fast track status. This service has been crucial to the success of Delivering Choice in reducing hospital

deaths, admissions and A&E visits and associated hospital costs in North Somerset. The NSCCC has a lower proportion of home deaths (44%) than the Somerset Care Coordination Centre (70%) probably because nearly twenty percent of North Somerset Care Coordination Centre patients are in care homes. This may be a result of the training in care homes that the End of Life Care facilitators have conducted. Fifteen percent of potential palliative care patients received care packages organised by the North Somerset Care Coordination Centre during the study period (153/1022).

The 'in house' and 'one stop shop' elements of this model were key. The NSCCC team includes three nurses, including the fast track co-ordinator, with access to good quality electronic information via RIO, who can rapidly assess and make decisions on fast track applications. They also have an in-house team of Generic Support Workers (personal carers) whom they can deploy flexibly for emergencies, such as sudden night sits, as well as direct and prioritised access to the Marie Curie night care workers. Thus the inherent flexibility in this model to promptly and appropriately respond to rapidly changing circumstances appears to be crucial.

The NSCCC was popular with community and hospice nurses, who said that it released their time and reduced their anxieties relating to organising care packages. Reportedly, this time was now spent working with greater numbers of people who wanted deaths at home. Family carers were also grateful for the input of the NSCCC as it alleviated their anxieties. The Generic Support Workers were particularly appreciated by family members; one spouse called them the "earth angels".

Figure 15: Key findings North Somerset Care Coordination Centre



The challenge for the NSCCC is now to build on its success by extending its reach. Given that 50% of those accessing the NSCCC die within eight days of first contact, finding ways to identify end of life care patients and set up care packages earlier is a priority. Earlier contact would then probably have a larger impact on reducing hospital spend.

12.4.5 Somerset Care Coordination Centre

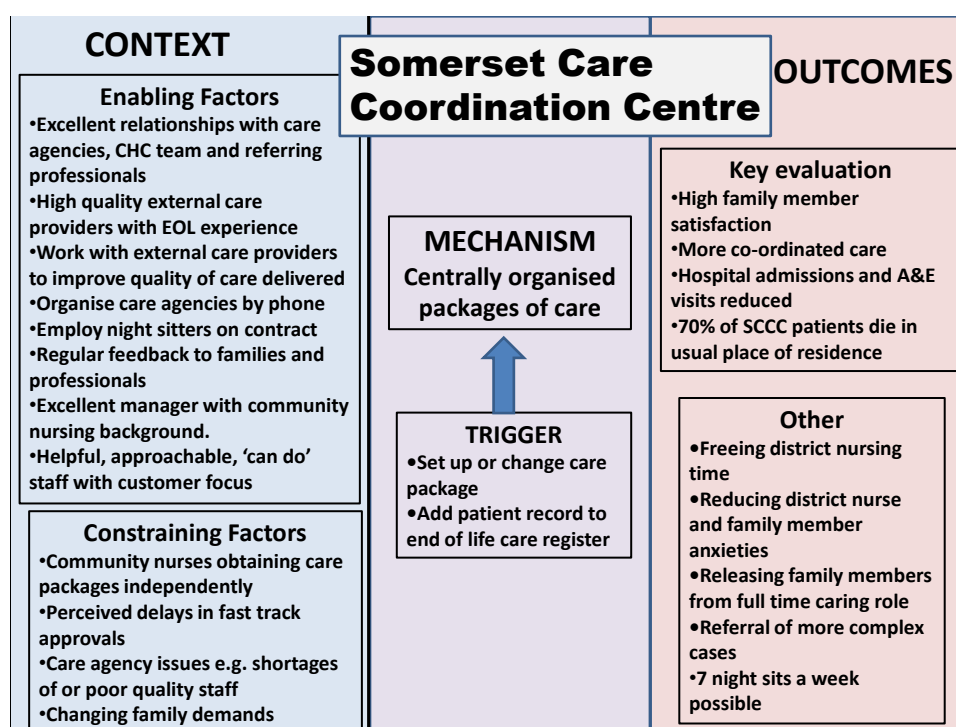
Like the North Somerset Care Coordination Centre, the Somerset Care Coordination Centre (SCCC) organises packages of care only for fast track patients who want to die in the community. Again like the NSCCC, the SCCC had the largest impact on reducing hospital deaths, A&E visits, emergency admissions and associated costs. The SCCC is also the Delivering Choice service associated with the highest proportion of home deaths (70%), which is a tremendous achievement. Another major achievement has been brought about through the use of night care workers on contract. This means that the quantity of night care workers has dramatically increased and the chances of allocating 7 night sits a week improved, which is vital to those living on their own who want to die at home. Eleven percent of those who died during the study period with palliative care needs used the SCCC (294/2572).

The SCCC was popular with specialist community palliative care nurses and community nurses and was most frequently named as the key service to 'keep'. Family carers were also universally grateful for the service, many of whom said that death at home would

not have been possible without the input of the SCCC. The patient experience pathway analysis and qualitative interviews with family carers suggest that the SCCC can act in a Key Worker role beyond the coordination of care packages by resolving tensions arising between family carers and professionals such as night staff, personal care agency staff and community nurses. The SCCC and the OOH advice line work particularly closely together with the highest proportion of joint patients. Analysis of the OOH advice line call log suggests that the OOH line takes on the organisation of care packages when the SCCC is closed.

The Care Coordination Centre model in Somerset does not have in house staff, and so relies heavily on good relationships with external teams such as the Continuing Health Care fast track assessors, personal care agencies and night sitting services.

Figure 16: Key findings Somerset Care Coordination Centre



Undoubtedly, the SCCC is serving well the solely fast track and largely cancer patients that fall within its orbit. The challenge now is for the SCCC to extend its reach by amending the eligibility criteria of the SCCC to include non-fast track patients and devising ways to promote the service to those caring for those dying from heart disease, respiratory conditions, dementia and other non-cancer related conditions.

12.4.6 Out of Hours advice line

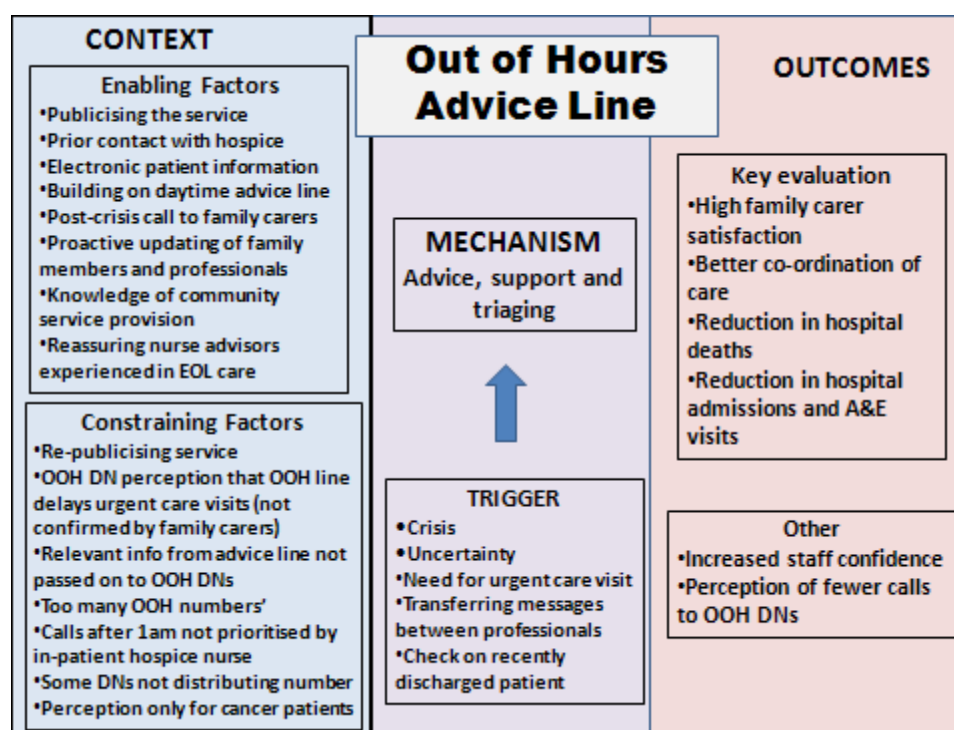
The St Margaret's Out of Hours advice line provides advice, triaging and support to professionals, patients and family carers from 5pm until 1am on weekdays and from 8am to 1am on weekends and bank holidays. They effectively 'trouble shoot' when crises emerge, often in the last few days of life, to help patients stay out of hospital. Quantitative analyses found that those who rang the Out of Hours line were 66% less likely to die in hospital and 40% less likely to visit A&E. Nine percent of patients with palliative care needs who died during the study period accessed the OOH advice line (243/2572).

The service maps suggest that the heaviest use of the OOH advice line is in Taunton, where the service is based, although calls were received from all other Federations except one.

The OOH advice line was highly valued by family carers, especially the proactive call back initiated by the OOH advice line post-crisis. Family carers also reported that urgent care services requested through the OOH advice line route arrived more promptly and were better informed than on call district nurses and GPs requested directly from the Urgent Care Service call centres, although this was disputed by a few out of hours district nurses.

Building on the daytime advice line service operated by the Central Referral Centre, the key components that appear to have led to the success of the OOH advice line are the competency, professionalism and "reassuring" manner of the nurse advisors and their knowledge of end of life care needs and services. They help to navigate patients and family members through the system to get callers the help required. In sum, the OOH advice line often took on an advocacy role.

Figure 17: Key findings Out of Hours Advice Line



Unlike other Delivering Choice Programme Services, the Out of Hours advice line is operating in a crowded market. Moreover, with the advent of the new NHS 111 service, that market is about to become even more populated. The St Margaret's Out of Hours advice line has a clear 'unique selling point' of offering an excellent service to end of life care patients. So to ensure its sustainability, a major challenge over the next two years is to develop a strategy whereby the Out of Hours advice line is able to clearly identify and bolster its strengths, clarify its differences and develop a way forward with regards to other out of hour line initiatives.

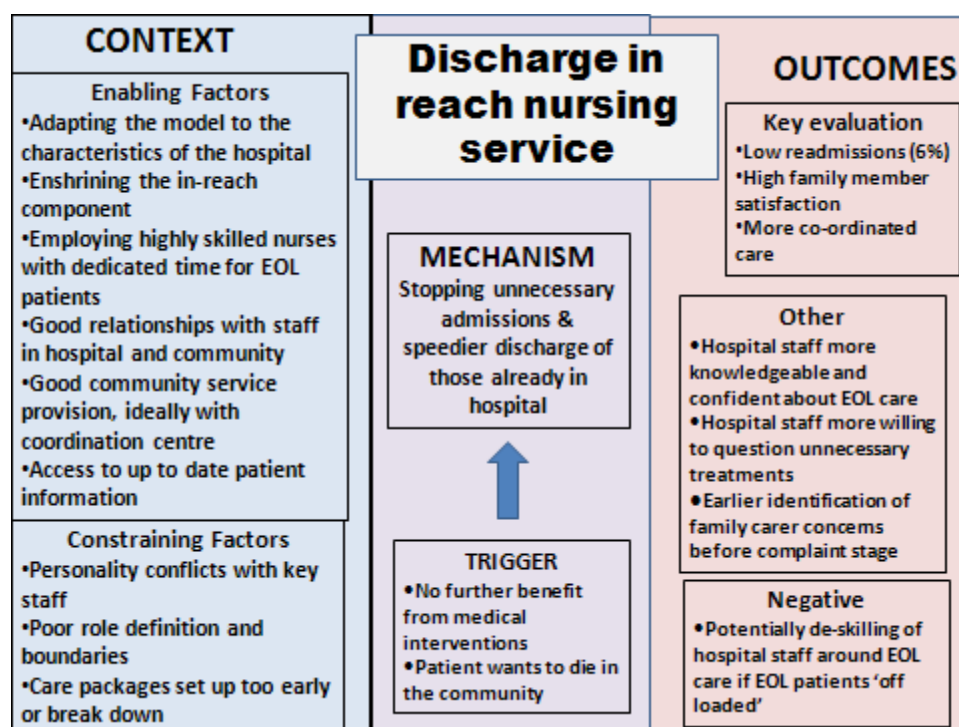
12.4.7 Discharge in reach nurses

The Discharge in reach nurse service consists of two nurses, with extensive end of life care knowledge and experience, based in two different hospitals. They identify those who want to die in the community with no further treatment at the 'front of house' in Medical Admissions and Surgical Admission Units. They select their own caseload. Initially this proactive in-reach element was important to making the service a success, but as the service became embedded and relationships with hospital and community staff grew, the Discharge in reach service has begun to take more referrals. The re-admission rate is low at 6% (7/114), so the Discharge in reach service appears to be successfully contributing to helping keep patients out of hospital. Overall uptake of the service was 5.5% of patients with palliative care needs who died during the study period (144/2572).

Although the supportive and educational aspects to the Discharge in reach service were highly valued, we found that a key element to making this service work was providing 'challenge'. This took the form of exploring with family carers and patients the potential implications of their choices around preferred place of care and questioning hospital staff about potentially unnecessary, unwanted or unbeneficial treatments and investigations. The latter was particularly revolutionary, as doctors and nurses are trained to save lives rather than allow people to die.

Given the enormous scope and potential, the service runs the risk of over-stretching the Discharge in reach nurses and/or deskilling hospital staff, if the educational remit becomes too broad or the Discharge in reach service takes on too many end of life discharges, especially those of complicated patients.

Figure 18: Key findings of the Discharge in reach service



Funding for both posts has now been secured from their respective hospitals, so the longer term sustainability of the service seems relatively favourable.

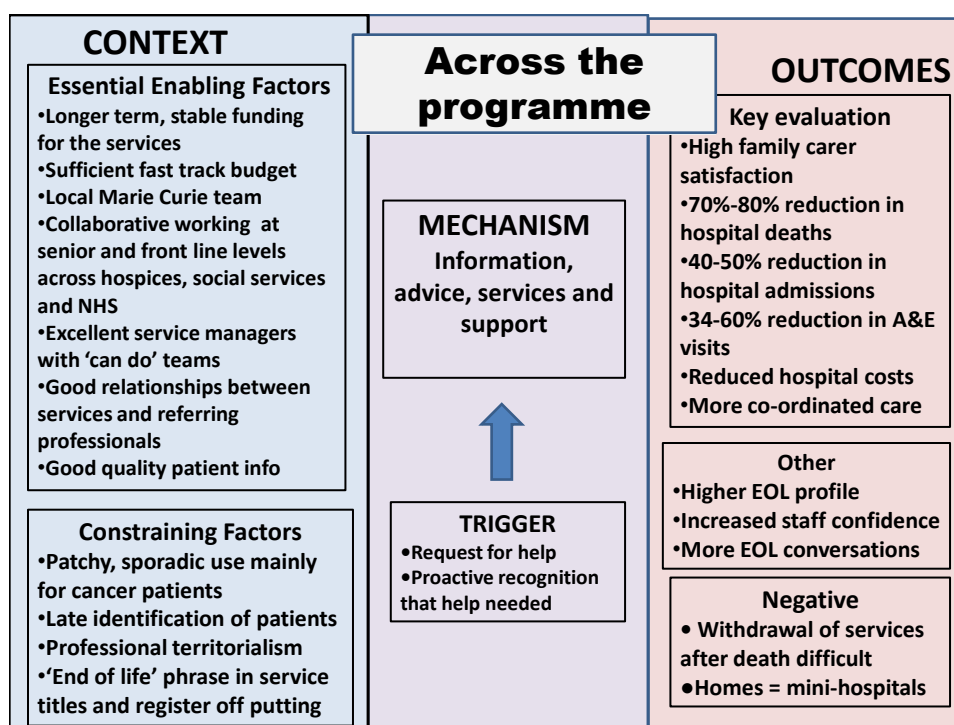
12.5 What worked overall and what still needs to change?

The key message of this evaluation is that the Somerset Delivering Choice Programme is a success. Emergency hospital admissions, A&E visits, hospital deaths and hospital costs in the last month of life are significantly lower for DCP users than for non-users. Professionals and family carers report that the coordination of care has improved. By and large, professionals find the new services helpful. Most importantly, family carers

report high levels of satisfaction, as Delivering Choice services have helped their relative die in his or her preferred place of care.

Bringing these outcomes about was a collective effort amongst senior and front line professionals across hospices, the NHS and social care services, facilitated efficiently and effectively by the local Marie Curie team. All of the Delivering Choice services benefited from excellent managers, highly skilled clinicians and committed administrative teams. Furthermore, Primary Care Trusts were willing to put forward the initial, and sometimes on-going, funding to finance the initiative.

Figure 19: Key findings for the Somerset Delivering Choice Programme



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. This then would help more North Somerset and Somerset residents experience 'as good a death as possible'.

Appendices

Appendix A Quantitative results tables

Table 1: Demographic and place of death data for North Somerset

Variable	Total population		Non-DCP service users		DCP service users		Generic Sup. Worker		Care Co-ord. Centre		Key Worker		Adastra	
N	1022	100%	809	79%	213	21%	25	2%	153	15%	38	4%	93	9%
Age (Years)														
≤40	9	1%	8	1%	1	0%	0	0%	1	1%	0	0%	0	0%
41-49	21	2%	18	2%	3	1%	0	0%	2	1%	0	0%	2	2%
50-59	41	4%	33	4%	8	4%	1	4%	4	3%	3	8%	6	6%
60-69	95	9%	71	9%	24	11%	4	16%	17	11%	8	21%	14	15%
70-79	195	19%	139	17%	56	26%	5	20%	31	20%	14	37%	36	39%
80-89	409	40%	321	40%	88	41%	10	40%	74	48%	9	24%	24	26%
90-99	236	23%	204	25%	32	15%	5	20%	23	15%	4	11%	11	12%
100+	16	2%	15	2%	1	0%	0	0%	1	1%	0	0%	0	0%
Gender														
Male	470	46%	361	45%	109	51%	10	40%	77	50%	21	55%	50	54%
Female	552	54%	448	55%	104	49%	15	60%	76	50%	17	45%	43	46%
Quintile of Dep. Score														
Least Deprived	309	30%	242	30%	67	31%	12	48%	55	36%	7	18%	24	26%
Below Average Deprivation	292	29%	229	28%	63	30%	6	24%	49	32%	12	32%	24	26%
Average Deprivation	152	15%	119	15%	33	15%	1	4%	22	14%	7	18%	16	17%
Above Average Deprivation	75	7%	65	8%	10	5%	2	8%	6	4%	3	8%	6	6%
Most Deprived	176	17%	139	17%	37	17%	4	16%	19	12%	9	24%	22	24%
Patients not linked	18	2%	15	2%	3	1%	0	0%	2	1%	0	0%	1	1%
Place of death														
Acute Hospital	387	38%	347	43%	40	19%	2	8%	28	18%	4	11%	12	13%
Home*	313	31%	225	28%	88	41%	16	64%	68	44%	23	61%	44	47%
Care home	150	15%	116	14%	34	16%	2	8%	29	19%	2	5%		
Hospice	64	6%	30	4%	34	16%	5	20%	18	12%	5	13%	21	23%
Elsewhere	108	11%	91	11%	17	8%	0	0%	10	7%	4	11%		

*Home includes a care home where this was recorded as usual place of residence

Table 1 continued

Variable	Total population		Non-DCP service users		DCP service users		Generic Sup. Worker		Care Co-ord. Centre		Key Worker		Adastra	
N	1022	100%	809	79%	213	21%	25	2%	153	15%	38	4%	93	9%
Preferred place of death														
Care Home	16	2%	0	0%	16	8%	0	0%	3	2%	6	16%	16	17%
Home	42	4%	0	0%	42	20%	6	24%	24	16%	24	63%	42	45%
Hospice	21	2%	0	0%	21	10%	0	0%	4	3%	7	18%	21	23%
Hospital	2	0%	0	0%	2	1%	0	0%	0	0%	1	3%	2	2%
Unknown	12	1%	0	0%	12	6%	0	0%	2	1%	0	0%	12	13%
Not recorded	929	91%	809	100%	120	56%	19	76%	120	78%	0	0%	0	0%
Death in preferred place														
No	16	2%	0	0%	16	8%	0	0%	4	3%	6	16%	16	17%
Yes	49	5%	0	0%	49	23%	6	24%	20	13%	23	61%	49	53%
Unknown	957	94%	809	100%	148	69%	19	76%	129	84%	9	24%	28	30%
Cause of death (ICD 10 codes)														
Neoplasm	287	28%	142	18%	145	68%	18	72%	99	65%	33	87%	76	82%
Heart disease	185	18%	170	21%	15	7%	2	8%	10	7%	2	5%	7	8%
Cerebrovascular	87	9%	78	10%	9	4%	0	0%	8	5%	1	3%	1	1%
Respiratory	156	15%	142	18%	14	7%	2	8%	12	8%	1	3%	2	2%
Dementia	157	15%	145	18%	12	6%	1	4%	10	7%	0	0%	3	3%
Other:Neoplasm	7	1%	6	1%	1	0%	0	0%	1	1%	0	0%	0	0%
Other:Endocrine	19	2%	18	2%	1	0%	0	0%	1	1%	0	0%	0	0%
Other:Nervous system	28	3%	22	3%	6	3%	1	4%	3	2%	1	3%	3	3%
Other:Circulatory Sys	24	2%	24	3%	0	0%	0	0%	0	0%	0	0%	0	0%
Other:Digestive system	40	4%	36	4%	4	2%	0	0%	4	3%	0	0%	0	0%
Other:Skin &subcutan	1	0%	1	0%	0	0%	0	0%	0	0%	0	0%	0	0%
Other:Musculoskeletal	10	1%	9	1%	1	0%	0	0%	0	0%	0	0%	1	1%
Other:Genitourinary	15	1%	11	1%	4	2%	1	4%	4	3%	0	0%	0	0%
Other:Congenital abn	1	0%	1	0%	0	0%	0	0%	0	0%	0	0%	0	0%
Other: Not class. Elsewhere	5	0%	4	0%	1	0%	0	0%	1	1%	0	0%	0	0%

Table 2: Diagnostic groups of the total study population and utilisation of DCP in North Somerset

Variable	Neoplasm		Heart Disease		Cerebro-vascular		Respiratory		Dementia		Other	
N	287	28%	185	21%	87	9%	156	15%	157	15%	150	1%
Age (Years)												
≤40	3	1%	2	1%	0	0%	1	1%	0	0%	3	2%
41-49	7	2%	4	2%	2	2%	0	0%	0	0%	8	5%
50-59	21	7%	7	4%	0	0%	4	3%	0	0%	9	6%
60-69	47	16%	20	11%	5	6%	8	5%	3	2%	12	8%
70-79	89	31%	36	19%	13	15%	21	13%	6	4%	30	20%
80-89	96	33%	75	41%	42	48%	72	46%	66	42%	58	39%
90-99	23	8%	39	21%	23	26%	48	31%	74	47%	29	19%
100+	1	0%	2	1%	2	2%	2	1%	8	5%	1	1%
Gender												
Male	144	50%	107	58%	37	43%	70	45%	45	29%	67	45%
Female	143	50%	78	42%	50	57%	86	55%	112	71%	83	55%
Place of death												
Home	96	33%	52	28%	24	28%	38	24%	56	36%	47	31%
Hospice	61	21%	0	0%	0	0%	2	1%	0	0%	1	1%
Care Home	31	11%	14	8%	17	20%	24	15%	46	29%	18	12%
Acute Hospital	83	29%	89	48%	37	43%	86	55%	20	13%	72	48%
Elsewhere	16	6%	30	16%	9	10%	6	4%	35	22%	12	8%
Key Worker	33	11%	2	1%	1	1%	1	1%	0	0%	1	1%
Care Co-ordination Centre	99	34%	10	5%	8	9%	12	8%	10	6%	14	9%
Generic Support Worker	18	6%	2	1%	0	0%	2	1%	1	1%	2	1%
Adastra	76	26%	7	4%	1	1%	2	1%	3	2%	4	3%

Table3: Comorbidities of DCP users in North Somerset

Condition	DCP resource used?					
	No		Yes		All	
N	506	100%	168	100%	674	100%
Acute Myocardial Infarction	46	9%	13	8%	59	9%
Congestive Heart Failure	133	26%	27	16%	160	24%
Peripheral vascular disease	33	7%	14	8%	47	7%
Cerebrovascular Dementia	88	17%	17	10%	105	16%
Dementia	80	16%	18	11%	98	15%
Chronic obstructive pulmonary disease	120	24%	38	23%	158	23%
Rheumatoid Disease	36	7%	7	4%	43	6%
Peptic Ulcer (PUD)	8	2%	5	3%	13	2%
Mild liver disease	15	3%	5	3%	20	3%
Diabetes	91	18%	26	15%	117	17%
Diabetes & Complications	16	3%	0	0%	16	2%
Hemiplegia or Paraplegia	18	4%	2	1%	20	3%
Renal Disease	94	19%	22	13%	116	17%
Cancer	73	14%	46	27%	119	18%
Moderate Liver disease	11	2%	1	1%	12	2%
Metastatic Cancer	71	14%	78	46%	149	22%
AIDS	0	0%	0	0%	0	0%

Table 4: Combination of DCP resources used in North Somerset

Group	GSW	CCC	Key Worker	Adastral	Number	%
1	No	No	No	No	809	79%
2	No	No	No	YES	39	4%
3	No	No	YES	YES	21	2%
4	No	YES	No	No	101	10%
5	No	YES	No	YES	15	1%
6	No	YES	YES	YES	12	1%
7	YES	YES	No	No	19	2%
8	YES	YES	No	YES	1	<1%
9	YES	YES	YES	YES	5	<1%

Table 5: Secondary care admission data for North Somerset

	Total population		Non-DCP service users		DCP service users		Generic Support Worker		Care Co-ord. Centre		Key Worker		Adastra	
N	1022	100%	809	79%	213	21%	25	2%	153	15%	38	4%	93	9%
Admissions in last 6 months														
Emergency / individuals	626	61%	480	59%	146	69%	11	44%	104	68%	21	55%	58	62%
Mean admissions	0.96		0.93		1.06		0.80		1.07		0.95		0.98	
Elective / individuals	86	8%	57	7%	29	14%	3	12%	22	14%	5	13%	14	15%
Mean admissions	0.1		0.08		0.17		0.16		0.16		0.13		0.22	
Day case/ individuals	144	14%	91	11%	53	25%	5	20%	34	22%	14	37%	31	33%
Mean admissions	0.57		0.52		0.77		0.36		0.69		1.11		1.12	
Bed-days (Non-Elective)/mean	11.7		11.1		13.9		10.1		15.6		7.6		9.1	
Bed-days (Elective inpatient)/mean	1.1		1		1.2		1.7		1.4		1.2		1.0	
Cost (Non-Elective)/ £	2539.31		2476.35		2778.47		1185.16		2712.1		2872.74		2883.73	
Cost (Elective)/ £	239.62		205.23		370.25		500.92		361.57		267.58		358.11	
Admissions in last 1 month														
Emergency / individuals	396	39%	335	41%	61	29%	3	12%	40	26%	8	21%	25	27%
Mean admissions	0.44		0.47		0.31		0.12		0.27		0.28		0.31	
Elective / individuals	18	2%	15	2%	3	1%	0	0%	2	1%	0	0%	1	1%
Mean admissions	0.02		0.02		0.02		0		0.01		0		0.03	
Day case/ individuals	30	3%	25	3%	5	2%	0	0%	2	1%	2	5%	4	4%
Mean admissions	0.05		0.06		0.03		0		0.01		0.05		0.05	
Bed-days (Non-Elective)/mean	3.30		3.37		3.04		0.28		3.14		2.08		2.34	
Bed-days (Elective in-pat)/mean	0.17		0.17		0.18		0		0.18		0		0.12	
Cost (Non-Elective)/ £	1095.53		1169.26		815.47		276.12		692.31		867.79		907.47	
Cost (Elective)/ £	74.67		69.75		93.34		0		46.22		0		137.74	
Admissions last 6 months same condition as cause of death														
Emergency / individuals	342		263		79		6		62		7		25	
Mean admissions	0.41		0.41		0.43		0.24		0.46		0.26		0.33	
Admissions last 1 month same condition as cause of death														
Emergency / individuals	235		204		31		3		24		2		9	
Mean admissions	0.24		0.26		0.15		0.12		0.17		0.05		0.10	

Table 5 continued.

	Total population		Non-DCP service users		DCP service users		Generic Support Worker		Care Co-ord. Centre		Key Worker		Adastra	
N	1022	100 %	809	79%	213	21%	25	2%	153	15%	38	4%	93	9%
A&E attendance last 6 months														
Individuals	650	64%	515	64%	135	63%	12	48%	97	63%	22	58%	55	59%
Mean number	1.03		1.05		0.96		0.88		0.96		0.92		0.88	
Mean cost/ £	106.8		108.7		99.7		87.64		99.34		92.3		89.9	
	4		1		8						4		4	
A&E attendance last month (30d)														
Individuals	417	41%	363	36%	54	5%	3	0%	35	3%	8	1%	23	2%
Mean number	0.47		0.52		0.27		0.12		0.24		0.29		0.29	
Mean cost/ £	49.99		55.34		29.6		14.04		25.8		26.2		29.2	
					5						1		4	
Charlson Index														
Individuals (% of total)	674	66%	506	63%	168	79%	15	60%	121	79%	30	79%	73	78%
Weighted total score	3.4		3.0		4.6		4.8		4.6		4.3		4.8	
Access to Service														
Number individuals (with data)							15		119					
mean time before death/days							53.8		17.7					
median time before death							20		8					
(IQR)/days							(5,64)		(4,21)					

Table 6: Deaths in hospital for North Somerset

		Death in Hospital	
		No	Yes
DCP	No	462	347
	Yes	173	40

Table 7: Odds Ratio (OR) for death in hospital for North Somerset DCP versus non DCP group (adjusted for gender, age, deprivation, condition)

Hospital Death	Odds Ratio	P	[95% Conf.Interval]	
DCP	0.33	<0.0001	0.21	0.50

Table 8: Odds Ratio (OR) for death in hospital by individual for North Somerset by DCP service versus non DCP group (adjusted for gender, age, deprivation, condition)

Hospital Death	Odds Ratio	P	[95% Conf.Interval]	
Key Worker	0.74	0.679	0.18	3.05
Care Co-ordination Centre	0.42	0.001	0.25	0.69
Generic Support Workers	0.34	0.30	0.04	2.64
Adastra	0.30	0.005	0.13	0.69

Table 9: Emergency admission in last month of life for North Somerset

		Emergency Admission (1m)	
		No	Yes
DCP	No	474	335
	Yes	152	61

Table 10: Odds Ratio (OR) for emergency admissions in last month of life for North Somerset DCP versus non DCP group (adjusted for gender, age, deprivation, condition)

Emergency Admission (1m)	Odds Ratio	P	[95% Conf.Interval]	
DCP	0.49	0.001	0.33	0.74

Table 11: Odds Ratio (OR) for emergency admissions in last month of life for North Somerset by DCP service versus non DCP group (adjusted for gender, age, deprivation, condition)

Emergency Admission (1m)	Odds Ratio	P	[95% Conf.Interval]	
Key Worker	0.60	0.33	0.21	1.69
Care Co-ordination Centre	0.55	0.016	0.34	0.90
Generic Support Workers	0.35	0.175	0.08	1.59
Adastra	0.65	0.225	0.33	1.30

Table 12: Emergency admission in last week of life for North Somerset

		Emergency Admission (1wk)	
		No	Yes
DCP	No	630	179
	Yes	200	13

Table 13: Odds Ratio (OR) for emergency admissions in last week of life for North Somerset DCP versus non DCP group (adjusted for gender, age, deprivation, condition)

Emergency Admission (1wk)	Odds Ratio	P	[95% Conf.Interval]	
DCP	0.22	< 0.0001	0.12	0.44

Table 14: Odds Ratio (OR) for emergency admissions in last week of life for North Somerset by DCP service versus non DCP (adjusted for gender, age, deprivation, condition)

Emergency Admission (1wk)	Odds Ratio	P	[95% Conf.Interval]	
Key Worker	1.13	0.898	0.18	7.03
Care Co-ordination Centre	0.09	0.001	0.02	0.39
Generic Support Workers	6.26	0.079	0.81	48.65
Adastra	0.39	0.136	0.11	1.34

Table 15: A&E attendance in last month of life for North Somerset

		A&E attendance (1m)	
		No	Yes
DCP	No	446	363
	Yes	159	54

Table 16: Odds Ratio (OR) for A&E attendance in last month of life for North Somerset DCP versus non DCP group (adjusted for gender, age, deprivation, condition)

A&E attendance (1m)	Odds Ratio	P	[95% Conf.Interval]	
DCP	0.41	<0.0001	0.28	0.62

Table 17: Odds Ratio (OR) for A&E attendance in last month of life for North Somerset by DCP service versus non DCP group (adjusted by: gender, age, deprivation, condition)

A&E attendance (1m)	Odds Ratio	P	[95% Conf.Interval]	
Key Worker	0.71	0.515	0.25	2.02
Care Co-ordination				
Centre	0.46	0.002	0.29	0.76
Generic Support Workers	0.45	0.295	0.10	2.01
Adastra	0.57	0.097	0.29	1.11

Table 18: A&E attendance in last week of life for North Somerset

		A&E attendance (1wk)	
		No	Yes
DCP	No	596	213
	Yes	200	13

Table 19: Odds Ratio (OR) for A&E attendance in week life for North Somerset DCP versus non DCP group (adjusted for gender, age, deprivation, condition)

A&E attendance (1wk)	Odds Ratio	P	[95% Conf.Interval]	
DCP	0.22	<0.0001	0.11	0.42

Table 20: Odds Ratio (OR) for A&E attendance in last week of life for North Somerset DCP versus non DCP group (adjusted for gender, age, deprivation, condition)

A&E attendance (1wk)	Odds Ratio	P	[95% Conf.Interval]	
Key Worker	1.16	0.878	0.17	7.84
Care Co-ordination Centre	0.15	<0.0001	0.05	0.43
Generic Support Workers	2.39	0.437	0.27	21.61
Adastra	0.38	0.116	0.12	1.27

Table 21: Demographic and place of death data for Somerset

Variable	Total population		Non-DCP Users		DCP Users		OOH Line		Care Co-ord. Centre		Discharge in reach		Key Worker		Adastra	
N	2572	100%	1956	76%	616	24%	243	9%	294	11%	144	6%	156	6%	331	13%
Age (Years)																
≤40	10	0%	5	0%	5	1%	4	2%	1	0%	0	0%	2	1%	3	1%
41-49	36	1%	23	1%	13	2%	8	3%	5	2%	1	1%	3	2%	5	2%
50-59	105	4%	66	3%	39	6%	20	8%	17	6%	6	4%	7	4%	22	7%
60-69	267	10%	170	9%	97	16%	54	22%	54	18%	15	10%	32	21%	58	18%
70-79	516	20%	348	18%	168	27%	61	25%	90	31%	45	31%	43	28%	93	28%
80-89	995	39%	794	41%	201	33%	74	30%	89	30%	52	36%	47	30%	104	31%
90-99	602	23%	515	26%	87	14%	20	8%	36	12%	22	15%	22	14%	46	14%
100+	41	2%	35	2%	6	1%	2	1%	2	1%	3	2%	0	0%	0	0%
Gender																
Male	1165	45%	864	44%	301	49%	118	49%	148	50%	70	49%	69	44%	157	47%
Female	1407	55%	1092	56%	315	51%	125	51%	146	50%	74	51%	87	56%	174	53%
Quintile of Deprivation																
Least Deprived	353	14%	259	13%	94	15%	39	16%	47	16%	24	17%	20	13%	47	14%
Below Average Deprivation	844	33%	631	32%	213	35%	75	31%	91	31%	54	38%	66	42%	131	40%
Average Deprivation	807	31%	629	32%	178	29%	76	31%	92	31%	41	28%	38	24%	82	25%
Above Average Deprivation	445	17%	345	18%	100	16%	37	15%	50	17%	17	12%	25	16%	56	17%
Most deprived	109	4%	80	4%	29	5%	15	6%	13	4%	8	6%	6	4%	13	4%
Patients not linked	14	1%	12	1%	2	0%	1	0%	1	0%	0	0%	1	1%	2	1%
Place of death																
Acute Hospital	920	36%	836	43%	84	14%	20	8%	12	4%	45	31%	8	5%	24	7%
Home	559	22%	286	15%	273	44%	132	54%	204	69%	30	21%	88	56%	158	48%
Care home (usual residence)	557	22%	493	25%	64	10%	11	5%	18	6%	14	10%	13	8%	40	12
Care Home (not usual res)	231	9%	173	9%	58	9%	16	7%	10	3%	18	13%	17	11%	39	12%
Hospice	153	6%	55	3%	98	16%	52	21%	38	13%	18	13%	23	15%	54	16%
Community Hospital	125	5%	94	5%	31	5%	9	4%	6	2%	17	12%	4	3%	12	4%
Community (MH) Hosp	2	0%	2	0%	0	0%	0	0%	0	0%	0	0%	0	0%	0	0%
Elsewhere	25	1%	17	1%	8	1%	3	1%	6	2%	2	1%	3	2%	4	1%

Table 21: Continued

Variable	Total population		Non-DCP service users		DCP service users		OOH Line		Care Co-ord. Centre		Discharge in reach		Key Worker		Adastra	
N	2572	100%	1956	76%	616	24%	243	9%	294	11%	144	6%	156	6%	331	13%
Preferred place of death																
Care Home	58	2%	0	0%	58	9%	6	2%	7	2%	14	10%	25	16%	58	18%
Community Hospital	6	0%	0	0%	6	1%	2	1%	0	0%	2	1%	2	1%	6	2%
Home	193	8%	0	0%	193	31%	85	35%	118	40%	31	22%	104	67%	193	58%
Hospice	33	1%	0	0%	33	5%	17	7%	16	5%	7	5%	14	9%	33	10%
Unknown	41	2%	0	0%	41	7%	8	3%	8	3%	3	2%	11	7%	41	12%
Not recorded	2241	87%	1956	100%	285	46%	125	51%	145	49%	87	60%	0	0%	0	0%
Death in preferred place																
No	40	2%	0	0%	40	6%	15	6%	16	5%	7	5%	19	12%	40	12%
Yes	205	8%	0	0%	205	33%	85	35%	119	40%	39	27%	105	67%	205	62%
Unknown	2,327	90%	1956	100%	371	60%	143	59%	159	54%	98	68%	32	21%	86	26%
Cause of death (ICD 10)																
Neoplasm	754	29%	314	16%	440	71%	200	82%	218	74%	87	60%	125	80%	257	78%
Heart disease	474	18%	430	22%	44	7%	12	5%	23	8%	13	9%	4	3%	17	5%
Cerebrovascular	237	9%	218	11%	19	3%	5	2%	6	2%	9	6%	1	1%	8	2%
Respiratory	340	13%	308	16%	32	5%	9	4%	18	6%	12	8%	5	3%	11	3%
Dementia	346	13%	316	16%	30	5%	4	2%	9	3%	8	6%	6	4%	15	5%
Other:Neoplasm	10	0%	7	0%	3	0%	1	0%	3	1%	0	0%	1	1%	1	0%
Other:Endocrine	28	1%	25	1%	3	0%	2	1%	2	1%	1	1%	0	0%	1	0%
Other:Nervous system	82	3%	60	3%	22	4%	5	2%	7	2%	3	2%	9	6%	15	5%
Other:Circulatory Sys	73	3%	68	3%	5	1%	0	0%	2	1%	2	1%	0	0%	1	0%
Other:Digestive Sys	134	5%	126	6%	8	1%	4	2%	3	1%	4	3%	1	1%	1	0%
Other:Skin & sub.	3	0%	2	0%	1	0%	0	0%	0	0%	0	0%	1	1%	1	0%
Other:Musculoskeletal	33	1%	30	2%	3	0%	0	0%	0	0%	2	1%	1	1%	1	0%
Other:Genitourinary	45	2%	40	2%	5	1%	1	0%	2	1%	3	2%	2	1%	2	1%
Other:Congenital abn.	1	0%	1	0%	0	0%	0	0%	0	0%	0	0%	0	0%	0	0%
Other: Not class. else	10	0%	9	0%	1	0%	0	0%	1	0%	0	0%	0	0%	0	0%
Not recorded	2	0%	2	0%	0	0%	0	0%	0	0%	0	0%	0	0%	0	0%

Table 22: Diagnostic groups of the total study population and utilisation of DCP in Somerset

Variable	Neoplasm		Heart Disease		Cerebro-vascular		Respiratory		Dementia		Other	
N (2570)	754	29%	474	18%	237	9%	340	13%	346	13%	419	16%
Age (Years)												
≤40	5	1%	2	0%	0	0%	1	0%	0	0%	2	0%
41-49	19	3%	3	1%	2	1%	1	0%	0	0%	10	2%
50-59	61	8%	11	2%	2	1%	7	2%	0	0%	24	6%
60-69	138	18%	43	9%	17	7%	29	9%	1	0%	39	9%
70-79	205	27%	91	19%	37	16%	55	16%	33	10%	94	22%
80-89	246	33%	193	41%	122	51%	145	43%	137	40%	152	36%
90-99	79	10%	125	26%	54	23%	95	28%	156	45%	93	22%
100+	1	0%	6	1%	3	1%	7	2%	19	5%	5	1%
Gender												
Male	384	51%	237	50%	84	35%	157	46%	112	32%	190	45%
Female	370	49%	237	50%	153	65%	183	54%	234	68%	229	55%
Place of death												
Acute Hospital	183	24%	201	42%	104	44%	183	54%	37	11%	212	51%
Care Home	86	11%	18	4%	25	11%	23	7%	50	14%	29	7%
Community Mental Health Hosp.	0	0%	0	0%	0	0%	1	0%	1	0%	0	0%
Community Hospital	36	5%	29	6%	15	6%	20	6%	10	3%	15	4%
Elsewhere	8	1%	12	3%	0	0%	1	0%	2	1%	2	0%
Home	243	32%	153	32%	17	7%	44	13%	21	6%	80	19%
Hospice	136	18%	4	1%	1	0%	4	1%	0	0%	7	2%
Usual Place of Residence (excl.Home)	62	8%	57	12%	75	32%	64	19%	225	65%	74	18%
OOH	200	27%	12	3%	5	2%	9	3%	4	1%	13	3%
Care Coordination Centre	218	29%	23	5%	6	3%	18	5%	9	3%	20	5%
Discharge in reach Service	87	12%	13	3%	9	4%	12	4%	8	2%	15	4%
Adastra	257	34%	17	4%	8	3%	11	3%	15	4%	23	5%
Key Worker	125	17%	4	1%	1	0%	5	1%	6	2%	15	4%

Table 23: Comorbidities of DCP users in Somerset

Condition	DCP resource used?					
	No		Yes		All	
N	1321		513		1834	
Acute Myocardial Infarction	121	9%	17	3%	138	8%
Congestive Heart Failure	294	22%	65	13%	359	20%
Peripheral vascular disease	111	8%	25	5%	136	7%
Cerebrovascular Dementia	228	17%	35	7%	283	15%
Dementia	267	20%	40	8%	307	17%
Chronic obstructive pulmonary disease	309	23%	109	21%	418	23%
Rheumatoid Disease	71	5%	16	3%	87	5%
Peptic Ulcer (PUD)	20	2%	13	3%	33	2%
Mild liver disease	33	2%	17	3%	50	3%
Diabetes	240	18%	96	19%	336	18%
Diabetes & Complications	24	2%	9	2%	33	2%
Hemiplegia or Paraplegia	36	3%	8	2%	44	2%
Renal Disease	331	25%	113	22%	444	24%
Cancer	192	15%	199	39%	391	21%
Moderate Liver disease	23	2%	9	2%	32	2%
Metastatic Cancer	152	12%	267	52%	419	23%
AIDS	0	0%	0	0%	0	0%

Table 24: Combination of DCP resources used in Somerset

Group	OOH Line	CCC	DIR Nurse	Number	%
1	No	No	No	2,072	81%
2	No	No	Yes	93	4%
3	No	Yes	No	151	6%
4	No	Yes	Yes	13	1%
5	Yes	No	No	104	4%
6	Yes	No	Yes	9	0%
7	Yes	Yes	No	101	4%
8	Yes	Yes	Yes	29	1%
All				2,572	100%

Table 25: Combination of DCP resources and tool in Somerset

Group	OOH Line	CCC	DIR Nurse	Adastra	Key Worker	Number	%
1	No	No	No	No	No	1,956	76%
2	No	No	No	Yes	No	74	3%
3	No	No	No	Yes	Yes	42	2%
4	No	No	Yes	No	No	70	3%
5	No	No	Yes	Yes	No	12	<1%
6	No	No	Yes	Yes	Yes	11	<1%
7	No	Yes	No	No	No	85	3%
8	No	Yes	No	Yes	No	24	1%
9	No	Yes	No	Yes	Yes	42	2%
10	No	Yes	Yes	No	No	5	<1%
11	No	Yes	Yes	Yes	No	5	<1%
12	No	Yes	Yes	Yes	Yes	3	<1%
13	Yes	No	No	No	No	66	3%
14	Yes	No	No	Yes	No	27	1%
15	Yes	No	No	Yes	Yes	11	<1%
16	Yes	No	Yes	No	No	4	<1%
17	Yes	No	Yes	Yes	No	2	<1%
18	Yes	No	Yes	Yes	Yes	3	<1%
19	Yes	Yes	No	No	No	47	2%
20	Yes	Yes	No	Yes	No	20	1%
21	Yes	Yes	No	Yes	Yes	34	1%
22	Yes	Yes	Yes	No	No	8	<1%
23	Yes	Yes	Yes	Yes	No	11	<1%
24	Yes	Yes	Yes	Yes	Yes	10	<1%
All						2,572	

Table 26: Secondary care admission data for Somerset

	Total population		Non-DCP service users		DCP service users		OOH Line		Care Co-ord. Centre		Discharge in reach		Key Worker		Adastra	
N	2572	100%	1956	76%	616	24%	243	9%	294	11%	144	6%	156	6%	331	13%
Adm. last 6 months																
Emergency / individual	1718	67%	1246	64%	472	77%	187	77%	210	71%	143	99%	106	68%	244	74%
Mean admissions	1.29		1.21		1.55		1.6		1.52		2.03		1.49		1.55	
Elective / individual	201	8%	114	6%	87	14%	48	20%	49	17%	16	11%	27	17%	54	16%
Mean admissions	0.10		0.07		0.18		0.27		0.2		0.13		0.19		0.19	
Day case/individual	394	15%	210	11%	184	30%	101	42%	97	33%	31	22%	57	37%	105	32%
Mean admissions	0.44		0.28		0.96		1.50		0.99		0.65		1.34		1.07	
Bed-days (Non-Elec)/mean	15.0		14.5		16.2		14.8		13.4		24.9		12.8		13.9	
Bed-days (Elec.in-pt)/mean	0.84		0.81		0.95		1.2		1.3		0.9		1.5		1.3	
Cost (Non-Elec.)/ £	3643.41		3476.91		4175.21		4176.75		3791.13		5766.37		3998.73		3998.71	
Cost (Elective)/ £	194.78		159.57		306.59		451.66		352.95		219.61		407.12		345.92	
Adm. last month (30days)																
Emergency / individual	1108	43%	875	45%	233	38%	88	36%	94	32%	98	68%	47	30%	100	30%
Mean admissions	0.51		0.53		0.45		0.42		0.38		0.80		0.37		0.37	
Elective / individual	45	2%	30	2%	15	2%	8	3%	10	3%	1	1%	5	3%	7	2%
Mean admissions	0.02		0.02		0.03		0.03		0.04		0.01		0.03		0.02	
Day case/individual	93	4%	64	3%	29	5%	18	7%	14	5%	6	4%	11	7%	17	5%
Mean admissions	0.05		0.04		0.06		0.09		0.07		0.04		0.13		0.08	
Bed-days (Non-Elec.)/mean	4.0		4.1		3.6		3.1		2.9		6.6		2.5		2.5	
Bed-days (Elec.in-pt.)/mean	0.13		0.11		0.20		0.21		0.29		0.01		0.44		0.27	
Cost (Non-Elec.)/ £	1387.45		1444.32		1206.85		1099.17		990.79		2203.81		1004.12		968.68	
Cost (Elective)/ £	55.46		53.59		61.4		69.32		83.09		14.07		81.25		45.44	
Adm. last 6m same condition as cause of death																
Emergency / individual																
Mean admissions	900	35%	632	32%	268	44%	101	42%	112	38%	97	67%	63	40%	137	41%
Adm. last 1m same condition as cause of death	0.47		0.42		0.62		0.59		0.58		0.96		0.64		0.61	
Emergency / individual	584	23%	465	24%	119	19%	37	15%	47	16%	58	40%	31	20%	60	18%
Mean admissions	0.25		0.26		0.23		0.17		0.19		0.48		0.23		0.21	

Table 26 Continued.

	Total population		Non-DCP service users		DCP service users		OOH Line		Care Co-ord. Centre		Discharge in reach		Key Worker		Adastra	
N	2572	100%	1956	76%	616	24%	243	9%	294	11%	144	6%	156	6%	331	13%
A&E attendance last 6 month																
Individuals	1448	56%	1092	56%	356	58%	137	56%	152	52%	118	82%	87	56%	187	56%
Mean number	0.93		0.91		1.01		0.95		0.97		1.45		1.04		1.05	
Mean cost/ £	22.39		22.91		20.73		5.41		20.57		2.64		28.86		27.64	
A&E attendance last month(30d)																
Individuals	871	34%	712	36%	159	26%	49	20%	60	20%	75	52%	36	23%	75	23%
Mean number	0.38		0.41		0.39		0.22		0.23		0.56		0.26		0.24	
Mean cost/ £	10.11		11.35		6.16		1.44		7.06		0		7.87		6.89	
Charlson Index																
Individuals (% of total)	1834	71%	1321	68%	513	83%	210	87%	233	79%	144	100%	125	80%	272	82%
Weighted total score	3.6		2.9		5.3		5.8		5.7		5.1		5.1		5.3	
Access to Service																
Number individuals (with data)							274		294		114					
Mean time before death/days							22.5		17.2		17.8					
Median time before death (IQR)/days							10 (2,31)		9.5 (4, 20)		6 (2, 23)					

Table 27: Deaths in hospital for Somerset

		Death in Hospital	
		No	Yes
DCP	No	1,120	836
	Yes	532	84

Table 28: Odds Ratio (OR) for death in hospital for Somerset DCP versus non DCP group (adjusted for gender, age, deprivation, condition)

Hospital Death	Odds Ratio	P	[95% Conf.Interval]	
DCP	0.20	<0.0001	0.17	0.27

Table 29: Odds Ratio (OR) for death in hospital by individual service for Somerset (adjusted for gender, age, deprivation, condition)

Hospital Death	Odds Ratio	P	[95% Conf.Interval]	
OOH Line	0.34	<0.0001	0.20	0.57
Care Co-ordination Centre	0.11	<0.0001	0.06	0.22
Discharge in reach Nurses	1.60	0.06	0.98	2.60
Adastra	0.22	<0.0001	0.12	0.40
Key Worker	0.73	0.524	0.27	1.95

Table 30: Emergency admission in last month of life for Somerset

		Emergency Admission (1 month)	
		No	Yes
DCP	No	1,081	875
	Yes	383	233

Table 31: Odds Ratio (OR) for emergency admission in last month of life for Somerset DCP versus non DCP group (adjusted for gender, age, deprivation, condition)

Emergency Admission (1m)	Odds Ratio	P	[95% Conf.Interval]	
DCP	0.61	<0.0001	0.48	0.76

Table 32: Odds Ratio (OR) for emergency admission in last month of life for Somerset by DCP service versus non DCP (adjusted for gender, age, deprivation, condition)

Emergency Admission (1m)	Odds Ratio	P>z	[95% Conf.Interval]	
OOH Line	0.78	0.159	0.56	1.10
Care Co-ordination Centre	0.58	0.001	0.42	0.80
Discharge in reach	4.15	<0.0001	2.68	6.43
Adastra	0.41	<0.0001	0.28	0.60
Key Worker	1.13	0.642	0.68	1.87

Table 33: Emergency admission in week of life for Somerset

		Emergency Admission (1wk)	
		No	Yes
DCP	No	1,489	467
	Yes	556	60

Table 34: Odds Ratio (OR) for emergency admission in last week of life for Somerset DCP versus non DCP group (adjusted for gender, age, deprivation, condition)

Emergency Admission (1wk)	Odds Ratio	P	[95% Conf.Interval]	
DCP	0.32	<0.0001	0.23	0.45

Table 35: Odds Ratio (OR) for emergency admission in last week of life for Somerset by DCP service versus non DCP (adjusted for gender, age, deprivation, condition)

Emergency Admission (1wk)	Odds Ratio	P	[95% Conf.Interval]	
OOH Line	0.44	0.005	0.25	0.78
Care Co-ordination Centre	0.26	<0.0001	0.15	0.46
Discharge in reach	1.54	0.081	0.95	2.50
Adastra	0.57	0.043	0.33	0.98
Key Worker	1.04	0.934	0.45	2.40

Table 36: A&E attendance in last month of life for Somerset

		A&E attendance (1 month)	
		No	Yes
DCP	No	1,244	712
	Yes	457	159

Table 37: Odds Ratio (OR) for A&E attendance in last month of life for Somerset DCP versus non DCP group (adjusted for gender, age, deprivation, condition)

A&E attendance (1 month)	Odds Ratio	P	[95% Conf.Interval]	
DCP	0.66	0.001	0.51	0.85

Table 38: Odds Ratio (OR) for A&E attendance in last month of life for Somerset by DCP service versus non DCP (adjusted for gender, age, deprivation, condition)

A&E attendance (1 month)	Odds Ratio	P	[95% Conf.Interval]	
OOH Line	0.60	0.007	0.41	0.87
Care Co-ordination Centre	0.58	0.002	0.40	0.82
Discharge in reach	3.29	<0.0001	2.23	4.87
Adastra	0.61	0.018	0.40	0.92
Key Worker	1.23	0.454	0.71	2.13

Table 39: A&E attendance in last week of life for Somerset

		A&E attendance (1 week)	
		No	Yes
DCP	No	1,524	432
	Yes	573	43

Table 40: Odds Ratio (OR) for A&E attendance in last week of life for Somerset DCP versus non DCP group (adjusted for gender, age, deprivation, condition)

A&E attendance (1 week)	Odds Ratio	P	[95% Conf.Interval]	
DCP	0.32	<0.0001	0.22	0.47

Table 41: Odds Ratio (OR) for A&E attendance in last week of life for Somerset by DCP service versus non DCP (adjusted for gender, age, deprivation, condition)

A&E attendance (1 week)	Odds Ratio	P	[95% Conf.Interval]	
OOH Line	0.34	0.003	0.17	0.70
Care Co-ordination Centre	0.24	<0.0001	0.12	0.48
Discharge in reach	1.25	0.41	0.74	2.11
Adastra	0.79	0.427	0.44	1.41
Key Worker	0.85	0.73	0.32	2.20

Table 42: Indicative cost for North Somerset Services over 6 months (Sept 2011- Feb 2012) and indicative cost avoided over 12 months

Service	Indicative costs 2010-11	Estimated indicative cost Sept 2011-Feb 2012
Co-ordination Centre, GSW & EOL facilitators	£369,000	£184,500
Total	£369,000	£184,500

Total cost of service (6 months)	£184,500
Number of patients (6 months)	213
Mean difference in secondary care admission costs in last month of life (DCP - No DCP)	-£330.20
Mean difference in A&E costs in last month of life (DCP - No DCP)	-£25.69
Total difference in costs	-£355.89
Indicative cost 2010-11	£369,000
Indicative cost avoided (12 months)	£151,609

Table 43: Indicative cost for Somerset Services over 6 months (Sept 2011- Feb 2012) and indicative cost avoided over 12 months

Service	Indicative costs 2010-11	Estimated indicative cost Sept 2011-Feb 2012
OOH Advice line	£105,606	£52,803
Co-ordination Centre	£133,871	£66,935
Discharge in reach	£86,478	£43,239
Total	£325,955	£162,977

Total cost of service (6 months)	£162,977
Number of patients (6 months)	616
Mean difference in secondary care admission costs in last month of life (DCP - No DCP)	-£229.66
Mean difference in A&E costs in last month of life (DCP - No DCP)	-£5.19
Total difference in costs	-£234.85
Indicative cost 2010-11	£325,955
Indicative cost avoided (12 months)	£289,335

Appendix B Out of Hours Tables

Table 50: OOH Line information for a random 10% sample of patients with cancer/ unknown diagnosis

Entry number	Condition	No. of calls	Who initiated the call(s)	What prompted call(s)	What happened next
1	Unknown	1	Family member	Bereavement support	Message left for bereavement officer, social worker and CPCNS; caller advised she could call back anytime
2	Breast cancer with metastases	1 logged and one reply noted within text	Primary Link nurse	Caller contacted by DN to arrange carer for next morning; caller called OOH line to check for Hospice at Home availability	Unable to arrange Hospice at Home due to lack of notice; OOH line returned call after checking Crosscare to say STARS were aware of possible need to go in and suggested calling them
3	Lung cancer	2, one month apart	1) CPCNS 2) Family carer	1) Support call requested, and query re. whether a DN had visited that evening (concern over urinary output); caller unable to visit 2) Concern that patient sleeping a lot, fell out of bed and caller struggled to help her back in bed; realises time may be short and patient wishes to die in hospice	1) Call made – spoke to daughter. DN has visited – no UTI. Support given to daughter who is coping, but sounded quite low. Call also made to CPCNS caller to update. GP visiting tomorrow and CPCNS the following day. 2) Support given, discussion re patient's illness progressing and to allow her to sleep; if she falls out of bed again, to call paramedics; advised caller she'd contact CPCNS to visit and assess if patient needs to be admitted for SCCC; advised caller to phone back anytime; message left for CPCNS
4	Breast cancer with metastases	1 logged, 1 reply inferred w/in 15	DN	Medication query	Spoke to on-call Dr and called DN to confirm action (DN to request that OOH Dr make necessary medication changes and reprime driver)

Entry number	Condition	No. of calls	Who initiated the call(s)	What prompted call(s)	What happened next
5	Bowel cancer with liver and pelvic lymph-adenopathy	8 calls made within a one month period (final 3 made over 4 hours) – although several others recorded within text. N.B. A further 7 calls were logged picked up by Central Referral Centre, as not 'OOH'	1) OOH line (erroneously logged as 'family carer') 2) Unknown. Appears to be contact with DN or with family carer 3) Family carer (wife) 4) Family carer (wife) 5) Family carer (wife) 6) Family carer (wife) 7) OOH line 8) OOH line	1) Planned support call requested by hospice professional to check whether CSCI set up and to offer support to family 2) Update on patient. 3) Advice sought – husband unable to sleep, Oromorph hasn't helped 4) Advice sought – husband unsettled, with hiccups, Nifedipine started yesterday but not helping 5) Advice sought - patient in pain 6) To advise DN hasn't made contact 7) Update sought 8) Planned call to offer support and check if DN had visited	1) Chat with wife who is exhausted, suggested she rest while her husband is tired; and to call the OOH line anytime she has concerns or for a chat 2) Recent DN input recorded, and updates on patient (recent deterioration) and family (PPOC/ PPOD not discussed, keen to keep patient home with support) 3) Request made for DN to give Midazolam 4) 'just in case' box present, with Haloperidol, Urgent Care Services contacted for GP call and DN visit; GP called OOH line, confirmed Haloperidol could be given and would contact DN; OOH line updated wife, asked her to call if further problems; DN called OOH line, Haloperidol had prescribed for syringe driver, so will contact GP to give PRN, asked for correct dose, OOH line advised; DN to call back if any problems 5) Advised to call own GP who should still be working, OOH GPs don't take calls until 6.30pm; OOH line called wife back for update, symptoms unchanged, awaiting GP visit; wife rang to say GP gave Midazolam and contacted DN to visit to increase dose in syringe driver; emotional support given to wife 6) Advised Urgent Care Services contacted for DN to administer from 'just in case' box, patient symptoms checked, caller advised to call again if DN doesn't make contact
Entry number	Condition	No. of calls	Who initiated the call(s)	What prompted call(s)	What happened next
5 (cont)					7) Wife informed patient still waiting for medication, she'd called OOH GP in distress, patient dying; emotional support given to wife; wife did not want to call 999 as wanted to keep

					him home to die; urgent request made to Urgent Care Services for DN visit 8) DN had visited and given 'just in case' medication; patient died 30 mins later, DN and family present; awaiting OOH GP to certify death; wife appreciative of call; death advised to CRC, CPCNS and SCCC
6	Unknown	1	DN	Medication advice – could another dose of Oxycodone and some Midazolam be given	Advice given – confirmed both could be given but small dose of Midazolam as patient hadn't had this before
7	Gall bladder cancer	2, two weeks apart	1) Patient 2) Family carer	1) Advice for relieving burping symptom which is preventing sleep 2) Patient in pain and very agitated, no urine passed for 24 hours; family distressed	1) Suggestions given: drink warm water, use more pillows, get Windeze 2) DN visit requested urgently. Family carer called back after 30 mins to say they'd received no call. Call made to Urgent Care Services and they'd left two messages as phone engaged – family informed. Call from family to say own GP attending.
8	'Undiagnosed' lung cancer	1	Family carer	Caller felt patient nearing end of life so was requesting a CPCN visit to arrange a bed as had been previously suggested	Message left for CPCNS team, advised caller CPCNS would call tomorrow; advice given to call OOH line again if patient being symptomatic as a DN visit could be arranged overnight

Entry number	Condition	No. of calls	Who initiated the call(s)	What prompted call(s)	What happened next
9	Prostate cancer	3, within a 3 hour period. The first two may have been entered erroneously;	1) No details given of this call, other than logging of date and time 2) No details given of this call,	1) No details given of this call, other than logging of date and time 2) No details given of this call, other than logging of date and time 3) Advice. Patient had	1) No details given of this call, other than logging of date and time 2) No details given of this call, other than logging of date and time 3) Urgent Care Services contacted for GP visit; carer called OOH line to advise GP had called and advised to call DNs as 'just in case' box

		call 3) gave evidence of 6 further calls within the text	other than logging of date and time 3) Carer	been vomiting (approx, 11 that day), agitated. Dr had given Maxalon previous day, catheter draining small amounts.	present; OOH line called OOH DN, and called carer to update; OOH line called carer, DN present; carer called OOH line to advise cyclizine given and this was effective, OOH line asked her to call back if any further problems; OOH line left message for DN and CPCNS
10	Ovarian cancer with secondaries	2, within 6 hours (another 2 calls were made over the following 2 days, but not 'OOH').	1) Family carer (daughter) 2) OOH line	1) DN or GP requested as patient had deteriorated over 24 hours and was agitated, SOB and in pain. Felt death imminent. 2) Update sought and to offer support to family.	1) OOH line advised they'd contact a clinician to call to assess whether a DN or GP should visit; asked daughter to call back if she hadn't heard within an hour; arranged for a clinician to call 2) Update obtained. OOH GP had visited, suspects UTI but unable to obtain a specimen. Family hesitant to assist with bedpan due to pain caused. Has not passed urine for 7 hours. Suggested a DN visit to assess needs as may need urinary catheter. Family struggling and OOH line called STARS for nightsitter but she was allocated. Urgent Care Services contacted for DN visit.
11	Muscle invasive bladder cancer	2, six weeks apart	Family carer	1) Has run out of Oramorph, which wasn't on the prescription dispensed today	1) Call to practice for GP to write prescription. Phoned caller to advise to collect prescription.
Entry number	Condition	No. of calls	Who initiated the call(s)	What prompted call(s)	What happened next
11 (cont)				2) Emotional support, patient deteriorating; caller was asked about PPOC or PPOD today and was unsure; finds these discussions difficult	2) Support given – agreed decision didn't have to be made that day and caller would call GP next day to update and ask for a visit to review patient; caller advised to call OOH line anytime; OOH line to call CPCNS to follow up after the weekend
12	Bowel cancer	2	SCCC	1) Liaison: informed that night sitter had been arranged and requested OOH DN be informed 2) Information given: main	1) Message left for OOH DN 2) Nothing

				carer has been rude to carers –nightsitters due in this weekend and caller wanted to advise	
13	Non small cell lung cancer	2, one day apart	1) Family member 2) Family member	1) Daughter had received call from patient's neighbour to say she seemed very anxious, muddled and in pain; they were also trying to phone patient 2) Daughter unhappy with hospital care and asked if she could be moved to hospice or elsewhere	1) Advised caller to go with sister to patient and see if they could calm her; patient no longer takes her medication for anxiety; consent obtained for GP visit to review social situation and pain relief, they will contact caller rather than patient to minimise distress; requested caller to call back with outcome 2) Advised she'd request a visit to patient by hospital palliative care team in the morning; message left with this team

Entry number	Condition	No. of calls	Who initiated the call(s)	What prompted call(s)	What happened next
14	Unknown	1 logged, 2 further calls indicated within 24 hours	Family carer	Medication had been changed previous day, but hadn't helped; patient in pain and vomiting overnight; caller very upset	Advised on medication which could be given and reassured; called Urgent Care Service to arrange for OOH GP to visit; OOH line phoned caller same day for update – GP visited and feels patient is constipated; OOH GP called by hospice and requested CPCNS arrange respite.
15	Unknown	1 (3 calls made in 4 preceding days, but not 'OOH')	Paramedic	To advise of death of patient and to check what he should do next. Husband had called 999 as he had been waiting 3 hours for a GP to attend.	Advised OOH line would call Urgent Care Services to check why GP had not attended, and would request a GP attend to verify, and a DN to attend to support family who were very upset. Call made to Urgent Care Services for DN and GP; call made to paramedic to update.
16	Unknown	1 (one further call made	Family carer	Assistance needed. Patient had collapsed on floor, wife unable to get	Advised caller help to be arranged immediately; 999 call made by OOH line, stating DNAR, will attend acute hospital for reversible cause; son-

		within 24 hours, but not 'OOH')		him up; son-in-law had also come to assist but patient unresponsive and breathing laboured, family very distressed.	in-law rang requesting a hospice nurse attend immediately, OOH line explained this not possible; ambulance arrived within minutes and called OOH line to report death imminent, OOH line advised he be gently placed in bed and call would be made to Urgent Care Services; OOH line called Urgent Care Services and updated; paramedic called to update - patient recovering from vaso vagal episode and they will update Urgent Care Services, family would like support call later, OOH line requested paramedic check blood sugar; OOH line called family for update, patient has chest pain, daughter has spoken to OOH GP and would like to call them back now to inform, OOH line advised to call back.
Entry number	Condition	No. of calls	Who initiated the call(s)	What prompted call(s)	What happened next
17	Stomach cancer with metastases	5 calls, the first four over a 24 hour period, one a week later	1) Family (daughter) 2) OOH line 3) Family (daughter) 4) Unknown, appears to be family or OOH GP 5) Family (son)	1) Help requested, patient had deteriorated over previous week, in constant pain (Buscopan not helping), nauseated and fatigued, says he wants to die; talked through medication 2) Update. Daughter reported medication taken but patient still in pain and looked very poorly. 3) 8 am call, as suggested by OOH line. Medication taken, pain not improved. 4) Update. Reviewed by OOH GP, patient constipated, medication changes recorded, and	1) Options given: to call OOH GP, or to try giving Tramadol, but OOH line concerned that advice would have been given to give Tramadol regularly; daughter unable to decide so OOH line suggested giving Tramadol and Cyclizine and, if not effective, to call back in an hour and OOH line would call Urgent Care Services to request GP visit; daughter happy with this suggestion 2) Suggested GP visit, but daughter said patient didn't want this until the morning. Daughter felt GP visit a good idea, OOH line suggested she speak to him and say that the nurse felt it would be best if a GP saw him, but he still wanted to wait until morning. OOH line said they respected his wishes and advised on overnight medication. Advised daughter to call again if she was worried or there was a change, otherwise to call after 8am and OOH line would request a GP visit. 3) Advised to keep taking maximum pain relief,

				<p>follow up next week by CPCNS team.</p> <p>5) To relay information. CPCNS visit due the following day, but son will be away and wanted to inform them that patient does not always admit to pain and they feel pain control is inadequate at present</p>	<p>OOH line would request OOH GP visit; Urgent Care Services contacted for OOH GP visit to review pain control, as discussed with S/N; call to daughter asking her to call if she doesn't hear from OOH GP, or to call to update after review; CPCNS team contacted to review next week</p> <p>4) Family advised to call OOH line over the weekend if they need anything.</p> <p>5) Advised message would be passed on to CPCNS to obtain Crosscare information before visiting patient</p>
Entry number	Condition	No. of calls	Who initiated the call(s)	What prompted call(s)	What happened next
18	Unknown	2 within 24 hour period	1) Family 2) OOH line	<p>1) Patient has not had bowels opened for 6 days</p> <p>2) To update family</p>	<p>1) Advised would request a DN visit to give an enema and do a PR; called Urgent Care Services to request DN visit</p> <p>2) Family member advised GP was going to visit</p>
19	Lung cancer	<p>2, within 24 hours</p> <p>N.B. Paramedic also called OOH line 4 days later at 07.49 to advise of patient death (but not 'OOH')</p>	<p>1) Family member</p> <p>2) GP</p>	<p>1) Advice needed regarding what to tell patient's young grandchildren; caller expressed concern about his wife; expressed wish for a nurse to offer support and advice to wife re. this</p> <p>2) Information required regarding whether patient was in hospice or at home, as pharmacy had received request for 'just in case' box</p>	<p>1) Suggested various books and websites; advised OOH line would request a CPCNS contact wife next week; also advised that crying was a normal part of grieving and it was good his wife could do this</p> <p>2) Information given that patient is at home and the 'just in case' box should be located there</p>
20	Unknown	1	SCCC	To inform of patient death	Informed CRC, CPCNS
21	Unknown	1	SCCC	To inform of patient death at home	Informed CRC, Hospice at Home nurse
22	Unknown	1 call logged, 3	Family carer	<p>Caller barely coping; patient had bad night,</p>	<p>Call to OOH line to request visit by GP to assess patient; call to carer to inform GP would be in</p>

further
calls
indicated
within 24
hours

becoming more
confused and agitated,
so unable to give
medication

contact; further call made to carer for update –
patient had UTI; OOH spoke to Dr who feels
patient needed admission to acute bed; OOH
contacted Urgent Care Services to advise;
patient going into hospital

Table 51: Out of Hours Line Call information for non-cancer patients between 1 September 2011 – 29 February 2012

Entry number	Condition	Where got OOH number	No. of calls	Who initiated the call(s)	What prompted call(s)	What happened next
1	COPD	Professional initiated (hospital pall nurse request)	2 calls different nights	1) OOH line 2) family member	1) Check settled after hospital discharge 2) Wanted OOH DN visit b/c of distressed breathing	1) Checked that carer had OOH line number (carer didn't). Given number. 2) Rang OOH DNs to set up visit
2	COPD	NK	2 calls same night	1) Family member 2) OOH line	1) Carer wanted info on handling distressed breathing 2) Checking patient's condition	1) Given advice. 2) Community palliative care nurse informed of calls.
3	COPD	Professional initiated (Discharge in reach nurse request)	1	1) OOH line	1) request to check settled after hospital discharge 2) Check settled after hospital discharge	1) Rang the patient's daughter who said patient was comfortable.
4	COPD	NK	2 calls same night	1) Family member 2) OOH line	1) Distressed breathing needs OOH GP 2) Check if OOH GP arrived	1) Contacted Devon OOH GP & tried to track down Devon community palliative care nurse 2) Referral made to Devon hospice for community palliative nurse to visit

Entry number	Condition	Where got OOH number	No. of calls	Who initiated the call(s)	What prompted call(s)	
5	COPD	Already known to hospice	2 calls different nights	Patient both times. Lives alone.	1) what to bring into hospice respite care 2) pain in chest	1) advice given 2) OOH GP visit requested
6	COPD	NK	2 calls same night	Family member both times	1) Query re: needing oxygen at home 2) update following OOH GP contact	1) OOH GP asked to phone family member
7	COPD	Professional initiated	2 calls different nights	1) Night sitter 2) care agency	1) Request for OOH DN visit 2) Request for night sitter.	1) OOH DN visit requested. 2) Night sit set up.
8	COPD	Professional initiated	6 calls on different nights over 3 night period	1 st 4 calls initiated by night sitters, 5th by OOH line and final call by family member	1) what do as patient sleeping? 2) Patient screaming in pain. 3) Update OOH line 4) Patient not slept 5) OOH line checking on patient 6) OOH line informed of death	1) advice 2) OOH DN visit requested 3) Nothing 4) Advice 5) Ask GP to refer to Community Palliative Care 6) Informed Central Referral Centre, Community Palliative Care, EOL Coordination Centre

Entry number	Condition	Where got OOH number	No. of calls	Who initiated the call(s)	What prompted call(s)	What happened next
9	Motor neurone disease	Hospice in patient nurse	3 calls over 24 hour period	1) Family member 2) OOH DN 3) OOH line	1) Mattress not functioning. 2) No new mattress tonight. Emergency delivery tomorrow. DN will go over to hospital tomorrow to get new pump. 3) Check situation.	1) Rang STARS team. No response. Rang OOH DNs. Rang OOH social worker. 2) Rang family member with update. 3) Got OOH Mediquip number. New mattress arriving at 5pm.
10	Motor neurone disease	NK	2 calls over 24 hour period	Family member both times	1) feeding problems 2) reassurance re: giving injection (daughter is a nurse)	Advice and reassurance given both calls.
11	Motor neurone disease	Professional initiated	5 calls over 3 day period	All calls from OOH district nurse	All calls relating to medication, specifically maximum morphine	Advice given
12	Motor neurone disease	Professional initiated	1	GP	Discharge advice as patient's husband has dementia	GP advised to refer to Community Palliative Care team.
13	Motor neurone disease	Professional initiated	1	GP	Looking for hospice place rather than acute hospital admission	Urgent hospital admission arranged.

Entry number	Condition	Where got OOH number	No. of calls	Who initiated the call(s)	What prompted call(s)	What happened next
14	Heart failure	NK	10 calls from 12.10.11-22.1.12	Patient lives alone. 9 calls from patient. 1 call from GP.	Queries about hospice waiting places, "wanting to chat", help thinking through different options	Advice/ reassurance given and after 6 calls community palliative care nurse informed.
15	Heart failure	Professional initiated	5 calls from 11.2.11 to 24.11.11.	Patient lives alone. 1) Night sitter 2) OOH DN (entry of yellow form) 3) Night sitter 4) night sitter 5) Night sitter	1) Can't leave patient alone when shift ends 2) DN can't cope as rats/ mice in house 3) Pressure sores 4) catheter problems 5) informed of death	1) Advised to ask GP for social worker to assess for nursing home.EOL Care Coordination Centre and Central Referral Centre informed. 2) Arranged for OOH Hospice @ Home nurse to go to home to calm DN. Environmental health assure no more rats or mice. 3) OOH DN visit requested. 4) OOH DN visit requested 5) Informed Community Palliative Care, Hospital Palliative Care, Central Referral Centre and district nurses.
16	Heart failure	Professional initiated	3 calls within 24 hour period	Patient lives alone. 1) Night sitter 2) OOH line 3) Night sitter	1) Can't leave patient on own at end of shift. 2) check in the morning 3) Informed of death	1) Told night sitter to call OOH DNs and give patient 999 number 2) No further action needed 3) Contacted Central Referral Centre, SCCC and Community Palliative Care

Entry number	Condition	Where got OOH number	No. of calls	Who initiated the call(s)	What prompted call(s)	What happened next
17	Heart failure	Professional initiated	5 calls 4 within 24 hour period, 1 month later	1) 'Keith' (professional?) 2) 'Anna' (professional?) 3) OOH line 4) OOH line 5) Professional	1) DN visit needed 2) Need night sit 3) Update to OOH prof and patients 4) check if night sit needed 5) Night sit needed	1) OOH DNs contacted 2) Rang SCCC & PCT but both shut as too late 3) Patient told to phone advice line if problems 4) Night sit arranged 5) Night sit arranged
18	Heart failure	NK	2 calls 25.9.11 13.10.11	Family member both times.	1) advice about diarrhoea 2) informed of death	1) advice given 2) OOH line asked to inform community palliative care nurses but no info if they did Advice given
19	Heart failure	Central Referral Centre	1	Care home nurse	Options for former nursing home patient currently in hospital	
20	Heart failure	Professional initiated?	1	Patient lives alone. "Julie" rang professional known to OOH line?	Informed of death and cancel night sitter	Rang night sitting agency and left message for community palliative care nurses
21	Heart failure	Professional initiated	2 within 24 hours	1) Hospital professional (NK who) 2) OOH line	1) Request to check on discharge 2) Checked that patient settled	1) Rang patient. 2) Gave out advice line number

Entry number	Condition	Where got OOH number	No. of calls	Who initiated the call(s)	What prompted call(s)	What happened next
22	Heart failure	Professional initiated	3 over 3 months	1) Care agency 2) Night sitter 3) Night sitter	1) Falls risk so let night sitter know 2) Needs hospice bed 3) Informed of death	1) Night sitter informed 2) Bed at hospice sought – none available. No further info 3) Contacted OOH DNs, Community Palliative Care, Hospital Palliative Care, Central Referral Centre, SCCC
23	Heart failure	Professional initiated	4 calls – 3 over same night; final call next day	1) night sitter 2) night sitter 3) night sitter 4) family member	1) Pre-terminal, needs meds 2) Update OOH line on OOH GP visit 3) Patient aggressive, needs more meds 4) Informed of death	1) OOH GP contacted & visited 2) nothing 3) OOH DN contacted & visited 4) Contacted Central Referral Centre and Community Palliative Care
24	Heart failure	Professional initiated	1	GP	Opiate use	Advice given
25	Heart failure	Professional initiated	1	Hospital nurse	“Patient wants to die”	No other information given.
26	Heart failure	NK	1	Family member at behest of ‘Natalie’ (professional?)	Informed of death	Ambulance sent for as unexpected death

Entry number	Condition	Where got OOH number	No. of calls	Who initiated the call(s)	What prompted call(s)	What happened next
27	Dementia, Multiple sclerosis	NK	1	Family member	Wants to book respite care	Call back arranged from respite home after the weekend
28	Dementia	Professional initiated	1	GP	Advice needed on medication	Advice given
29	Dementia	Professional initiated	1	Hospital nurse	Advice needed on medication	Advice given
30	Dementia	Professional initiated	2 within 24 hours	1) Night sitter 2) Night sitter	1) No info available on patient about to night sit 2) Informed of death	1) Suggestion to call nursing home 2) no further information
31	Dementia	Professional initiated	1	GP	Advice needed on medication	Advice given.
32	Parkinson's, dementia	NK	1	Family member	Help with shower.	Given Somerset Care number. Arranged for assessment.
33	Pulmonary fibrosis	NK	5 in 3 day period	1) Family member 2) family member 3) family member 4) family member 5) OOH line	1) short of breath, advice needed 2) patient no better 3) short of breath, advice needed (2 nights later) 4) patient no better 5) checking that OOH GP arrived	1) advice given including medication 2) OOH GP contacted 3) advice given including medication 4) OOH GP contacted 5) No one answered the phone.
34	Chest infection	Professional initiated	1	District nurse	Night sitter needed	Night sitter set up.

Entry number	Condition	Where got OOH number	No. of calls	Who initiated the call(s)	What prompted call(s)	What happened next
35	Alcoholic liver disease	Professional initiated	9 calls over 2 month period, sometimes several in short space of time	1) GP 2) Community palliative nurse 3) OOH line 4) OOH line 5) family member 6) family member 7) family member 8) Community palliative nurse 9) OOH line 10) family member 11) family member	1) Medication advice & to notify system of patient 2) Request to check on patient 3) Checking on patient 4) Checking on patient 5) Emotional support 6) Emotional support 7) Emotional support 8) Request to check on patient 9) Checking on patient 10) Patient in pain 11) Patient has chest infection	1) Advice given 2) Responded to request 3) Rang and no answer. 4) Rang and gave info on OOH line and other services available 5) Listened 6) Listened. 7) Listened. 8) Responded to request 9) Rang family member. 10) Requested OOH GP to phone. 11) Requested OOH GP to contact.
36	CJD	Professional initiated (SCCC)	2	1) SCCC 2) OOH line	Request to check after discharge	OOH line rang no further information

Appendix C Full methods report

Background

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 the evaluation was to investigate the impact of the Delivering Choice Programme, which consisted of several new services underpinned by electronic information tools, documentation and the 'Key Worker' concept. The services under study included:

- End of Life Care facilitators (North Somerset)
- End of Life Care Co-ordination Centres (North Somerset and Somerset)
- Out of Hours Advice Line (Somerset)
- Discharge in Reach Nurses (Somerset)

The information tool rolled out across both counties was the Adastral electronic register, which was available across the whole of the South West of England. This electronic tool could be accessed across hospice and NHS organisations (e.g. community teams, GP practices, A&E services) and recorded information on 'Key Worker' for each patient as well as details on advance care wishes. Documentation under study included the Marie Curie End of Life Care pathway and the framework, also known as the 'traffic lights', which aimed to identify fast track patients.

The evaluation outcomes from this initiative included:

- Co-ordination of care
- Patient and family carer satisfaction
- Care and death in preferred place
- Hospital admissions (and re-admissions) in the last 6 and 1 months of life
- A&E visits in the last 6 and 1 months of life
- Costs

The evaluation was split into two concurrently running workstreams. The first focused on routine data, primarily service usage data from the Delivering Choice services, hospital usage and death data from the Primary Care Trusts and advance care wishes data from the Adastral electronic register. The second workstream employed realistic evaluation methodology (Pawson & Tilley, 1997) to explore the mechanisms and contextual factors behind each intervention more fully.

Routine data

Ethical approvals, Caldicott permission and obtaining routine data

Because this study was classified as a service evaluation and not research, we did not need NHS ethics approval. Instead, we submitted the protocol, topic guides and participant information sheets to the ethics committee of the Faculty of Medicine at the University of Bristol. The University ethics committee stated that we did not need ethical approval for the routine data workstream, as these data were anonymised, but ethical approval was required for the realistic evaluation. This approval was received 23 September 2011.

To collect routine data, we needed Caldicott guardian permission. We found this much more difficult to obtain, as reported in the interim report. Many of the Delivering Choice services were reluctant to supply data due to concerns around patient confidentiality and patient consent. Negotiation around data release varied for each Primary Care Trust and Delivering Choice service, but often required numerous telephone and/or email discussions to facilitate release of the data. The level of approval required for each service varied significantly and was inconsistent within each Primary Care Trust i.e. some gatekeepers reviewed all supporting documents (protocols, ethical approvals, Caldicott statement, etc.) and other DCP services were happy after a brief discussion. For example, GL spent over a month liaising with the Acting Director of Nursing and Patient Safety about the finer details of a Caldicott statement in order to access the Care Coordination Centre data in Somerset. Once approval was finally granted, it was no longer valid because this service had moved under the remit of the Somerset Partnership NHS Foundation Trust. GL needed to reapply for Caldicott approval from a different member of staff and this took nearly three weeks.

Delivering Choice Data collection For this retrospective cohort study our aim was to identify all patients who died from 1 September 2011 to 29 February 2012 and who were potentially eligible to receive end of life services in Somerset and North Somerset. We then wished to determine which of these people utilised a Delivering Choice service.

To facilitate patient identification all Delivering Choice services were asked to collect NHS numbers, age and postcodes. These personal identifiable details (PID) would then be used to identify the Delivering Choice service users by linking data at the Primary Care Trust (PCT) against Somerset and North Somerset outcome data (see 'Data Linkage' section below).

Outcomes of interest were collected for all patients that died in the two PCTs of a predefined set of causes of death in the period 1 September 2011 to 29 February 2012. These patients were deemed 'palliative' and therefore had the potential to have received Delivering Choice services in the six month period preceding their death. The eligibility criteria for the predefined group of patients included were those recommended and used by the National End of Life Care Intelligence Network

(www.endoflifecare-intelligence.org.uk). The PCTs provided information on the cause of death for the relevant population during the study period. This categorisation was used to identify each patient's diagnostic group and consequently what types of patients are utilising Delivering Choice interventions.

The process of linking Delivering Choice services to individual patients was not possible for the End of Life Care facilitators in North Somerset because this service provides support to health care professionals (i.e. GPs, district nurses, care home staff, etc.) on how to use end of life care tools (i.e. Delivering Choice pathway, Gold Standards Framework, Liverpool Care Pathway, Advance Care Planning, etc.). The End of Life Care facilitators did not have direct contact with patients. Thus it was not possible to identify the effect of this service by collecting patient identifiable data and consequently we have not included any quantitative data on the impact of the End of Life Care facilitators in North Somerset.

Data availability

The Project Manager (GL) had previously piloted data collection from all Delivering Choice services in Somerset and North Somerset for the interim report published in October 2011. Therefore data collection for this final report was relatively straightforward. Nevertheless, it was the first time that data on the usage of the North Somerset Generic Support Workers had been collected. Unfortunately, the evaluation team found that service usage was recorded in a paper diary and was incomplete for the full study period. Consistent data was only available for a 101 day period between 1 September 2011 and 29 February 2012.

All Delivering Choice services provided the evaluation team with access to relevant databases and paper records. Some Somerset services were concerned about storage and transport of patient identifiable data prior to pseudonymisation, but this was resolved by passing all data via information managers at the Somerset Partnership NHS Foundation Trust

Data Collection

All of the Delivering Choice services were asked to collect service usage data and forward this securely to the PCT, however the evaluation team knew from the interim report that this was unworkable. In actuality the Somerset Care Coordination Centre was the only service able to send their service usage data directly to the PCT. All other services were visited (between April and June 2012) by GL who hand-collected data, which she personally delivered to the both PCTs.

Computer records were robust for five of the Delivering Choice services and data collection was relatively uncomplicated. For the Care Co-ordination Centre in North Somerset, since the pilot study, efforts had been made to update computer records and consequently NHS numbers were available for most patients, however some (approx.10%) could still only be found by hand collecting from the patient's paper service usage record.

Data from both the Somerset and North Somerset AdastrA systems were made available to the study team. However, the format of the AdastrA outputs from both counties (Excel spreadsheet in North Somerset and PDF in Somerset) was such that required a significant amount of time (approx. 72 hours in total) to re-organise the data before it could be sent to the PCT. Individuals were considered 'On' the AdastrA EOL register if they were listed and could be linked via name, date of birth and/or NHS number to the PCT data.

Data linkage

All data obtained from the Delivering Choice services were linked by dedicated data analysts at Somerset and North Somerset PCTs. Patients using Delivering Choice services were linked to data extracted from the Primary Care Mortality Database, In-patient hospital data and Accident and Emergency data obtained from NHS Connecting for Health.

Each Delivering Choice service was asked to collect data from 1 September 2011 to 29 February 2012. The PCT analysts used the Primary Care Mortality Database to identify people who had died of conditions potentially amenable to palliative care during the study period and then linked data on Delivering Choice eligible patients within this subset. All patient data was pseudonymised during linkage at the PCT and returned to the University of Bristol evaluation team for analysis. The University team linked Lower Super Output census areas supplied by the PCT to deprivation scores. In order to compare the relative levels of morbidity in Delivering Choice and non-Delivering Choice populations we used data from those patients who had a hospital admission during the study period and who therefore had data on morbidities available to derive a Charlson score. (Charlson et al 1987) The Charlson score is an index of morbidity, derived initially to predict death in hospital. However, it is now used more widely as an index of multimorbidity. NHS Tariff data were made available by the PCTs allowing costing of individual inpatient episodes and visits to the accident and emergency department (A&E) were costed at a standard NHS tariff rate.

Statistical analysis

An independent statistician reviewed and cleaned the data and analysed the datasets received from the PCT.

Descriptive Analysis

Data cleaning and descriptive analysis were performed using Excel 2007 and STATA v12. Descriptive analysis aimed to include the following results:

- i) The demographic and cause of death data and development of summary statistics for each PCT.

- ii) Demographic and cause of death data on patients receiving all Delivering Choice services in each PCT compared with those who did not receive any components of the Delivering Choice Programme.
- iii) Data on patients receiving the individual components of the Delivering Choice Programme in each PCT compared with those on/and off the Adastra end of life care electronic register who do not receive the components.
- iv) Data on how many patients used which combination of interventions in each PCT
- v) Data on certain diagnostic groups and their utilisation of services.

Logistic Regression

Statistical modelling was undertaken using the logistic regression functions in STATA v12 to investigate the different outcomes between Delivering Choice users and non-Delivering Choice users, namely:

- Hospital deaths over the six month study period.
- Emergency admissions during the last 6 months and one month (30 days) of life.
- A&E attendances during last 6 months and one month (30 days) of life.

Logistic regression models were also used to investigate the impact of gender, age, deprivation and condition causing death on hospital deaths, emergency admission and A&E attendance for Delivering Choice users during the last month and week of life. These potential confounders were treated as follows:

- Gender - female or male (reference group)
- Age –reference group <40, then decade increments
- Deprivation – Index of multiple deprivation quintiles with least deprived as reference group
- Cause of death – neoplasm (reference group), heart disease, cerebrovascular, respiratory, dementia, other

Economic analysis

The following cost data were available:

Cost	Data	Source of data
Hospital admission	NHS tariff cost for each individual patient admission (based on national NHS Tariff and admission HRG)	Somerset and North Somerset PCT admission data
A&E visit	Reference cost for NHS A&E visit	NHS Schedule of Reference Costs 2010/11 ¹
North Somerset Delivering Choice services (including generic support workers)	Indicative costs for 2010-11	North Somerset PCT
Somerset Delivering Choice services	Indicative costs for 2010-11	Somerset PCT

¹ NHS Schedule of Reference Costs 2010/11 available from:
http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_131140

We undertook the following calculations for each PCT based on these data:

- Based on individual patient costings from PCT admissions data (NHS Tariff costs) we calculated mean costs for Delivering Choice users vs. non-Delivering Choice users for secondary care admissions (including elective and non-elective admissions) and A&E utilisation over the last month of life. This time period was selected as most patients did not access Delivering Choice services until the last month of life.
- The mean difference in costs between patients in the Delivering Choice/non-Delivering Choice groups was then calculated for each PCT
- This figure was multiplied by the number of patients who accessed Delivering Choice services to estimate indicative costs avoided from potentially averted emergency and A&E attendances resulting from Delivering Choice over a 6 month period
- Indicative costs avoided for Delivering Choice vs. non-Delivering Choice were then extrapolated to a 12 month period.
- Indicative costs for the Delivering Choice services in each PCT were added together (where required)

Additional Analysis

In addition to the original analysis planned we undertook the following analyses:

- 1) Length of time between date of first contact with a Delivering Choice service and date of death
- 2) As a result of the findings of 1) we undertook modelling of the impact of Delivering Choice on emergency admissions and A&E attendances in the last week of life. We did not undertake modelling of admissions in the last six months of life as few patients received services prior to one month before death.

Realistic evaluation

To explore the 'black box' of the Delivering Choice interventions, initially we considered two methodological approaches: theories of change and realistic evaluation (also known as 'realist' evaluation). After reading a helpful paper comparing the two (Blamey & Mackenzie, 2007), we opted for realistic evaluation, as this approach appeared to better fit the commissioning brief.

Realist evaluation starts from the point that involvement in any programme is a choice. The objective of an evaluation is to understand more about what it was that led a particular person with their particular sets of circumstances to making that choice. Realist evaluation cannot answer what 'caused' particular outcomes. Instead, the key question in a realist evaluation is: What works for whom and in what circumstances? To answer that question, data on context, mechanisms and outcomes are gathered and the relationships between the three are explored.

Outcomes are defined as intended or unintended consequences that have come about as a result of the intervention. Examples of outcomes for the Delivering Choice Programme are seamless, co-ordinated care and fewer hospital admissions. Mechanisms activate a change in behaviour and enshrine the theory of the programme makers about how particular interventions might bring about change. An example of a mechanism for Delivering Choice is that the out of hours advice line offers advice, support and triaging to other services.

Context can be defined as everything outside of the intervention that may affect whether and to what extent the mechanism is triggered. (Ovretveit, 2011) When examining context, researchers look for the essential ingredients that lead to the activation of the mechanism and when this is less likely to happen. So, for example, a Context-Mechanism-Outcome configuration for the Out of Hours advice line is:

Knowledge of community service and urgent care provision (Context)

Facilitates the ability of the OOH helpline to offer advice, support and triaging to other services (Mechanism)

Which contributes to co-ordinated, seamless care and a reduction in hospital admissions (Outcome)

Thus, these Context-Mechanism-Outcome configurations are mini-hypotheses which can be tested by collecting qualitative and quantitative data from the field. Once tested, the findings generated from these hypotheses can then meet an over-riding aim of a realist evaluation, which is to identify what can be replicated elsewhere.

Local involvement in designing the evaluation

Given the complexity of the Delivering Choice Programme with its multiple services, stakeholders and settings, we enlisted the help of local stakeholders to develop the evaluation. In August 2010, a dozen local stakeholders attended a research evaluation meeting to give their views on issues in designing the evaluation. In January and February 2011, we held three ‘hypothesis generation’ workshops with around two dozen local stakeholders, including those who set up, refer into or deliver Delivering Choice services. The aim of those workshops was to identify key ‘hypotheses’ or explanations for how and why particular Delivering Choice services might work and to clarify what success, or intended outcomes, might look like. Over a dozen hypotheses were put forward, in addition to 10 intended outcomes such as empowerment, trust and greater choice in place of care. Each of the outcomes was also defined.

On 17 May 2011, at a combined stakeholder and executive board meeting for the Delivering Choice Programme, we presented the findings from the hypothesis generation meetings. The stakeholder and executive board members limited the focus of the evaluation to a reduced number of interventions and three outcomes of key interest. After that meeting, Marie Curie Cancer Care, the main client of this evaluation, made a final decision on the scope of the evaluation.

Key hypothesis

Having read the literature for Somerset Delivering Choice, gathered the views of a wide range of stakeholders and discussed our emerging ideas with local and national staff from Marie Curie Cancer Care, the key hypothesis cutting across the entire programme was identified as:

The furnishing of relevant, reliable and timely information, advice, services (e.g. night sitters, equipment) and support to patients, carers and professionals by key regional or Delivering Choice interventions help facilitate seamless, co-ordinated care, generate high patient and carer satisfaction and contribute to patients dying in their place of choice.

Research questions

Given that over-arching hypothesis, we developed questions in several areas:

Context

- What are the essential contextual factors that enable or constrain the triggering of the mechanisms for each of the interventions under study?

- How do the different aspects of the DCP programme work together?

Mechanisms

- What are the mechanisms for each intervention and the triggers that prompt the use of those mechanisms?

Outcomes

- Do carers and family using the interventions under study feel that the death 'went as well as it could have'?
- Did those using the study interventions die in their place of choice?
- Is/ was care for Delivering Choice patients perceived by patients, carers and professionals as seamless or have there been gaps and duplications?
- What other outcomes, intended or unanticipated, have come about?

Transferability

- What can be replicated elsewhere?

Sustainability

- How do the interventions under study change (if at all) after the disbanding of the Somerset Marie Curie team in summer 2011?

Data collection

To answer our research questions, we divided this aspect of the study into three parts:

- Preliminary work
- Service delivery
- Patient journey

Preliminary work (July – September 2011)

Mapping services

To understand more about how the landscape had changed with the advent of Delivering Choice to the two counties, we needed to know about previous and current service provision. To identify end of life care services, we developed two maps for each county, one for before Delivering Choice (pre-2008) and post-Delivering Choice (2011-2012). We drew on Delivering Choice literature and telephone and face to face interviews with local staff. These data were then inputted into NVIVO and the relationships between the services indicated by arrows. These maps gave us a good understanding of the topography of end of life care services in the two counties. This was useful for purposive sampling for interviews, but we did not find them terribly helpful in the analysis phase.

Initial observations

To get an overview of the programme, the project manager (GL) carried out a series of initial visits to all of the Delivering Choice services under study in August 2011. These included the Out of Hours advice line (Somerset), Care Coordination Centres

(Somerset and North Somerset), Discharge in reach service at two hospitals (Somerset) and End of Life Care facilitators (North Somerset). The aim of these visits was to start to build relationships with local professionals, to collect data for the 2011/2012 service map, to understand more about how the services work especially referrals, to feed information into the development of this research proposal and to get a 'baseline' reading of the intensity of the services (i.e. number of staff in post and working, number of referrals). This information was also useful to make sense of routine data on Delivering Choice service utilisation, hospital admissions and preferred place of care.

The Delivering Choice service visits began the first week of August 2011. GL spent approximately two hours at each service, chatting to staff, collecting documentation and observing interactions. She took notes while speaking to staff and wrote these up immediately after the visits. Later in the study, these baseline readings were compared to mid-study visits (see below).

Testing the feasibility and appropriateness of realistic evaluation design

Given the complexity of the Delivering Choice Programme and the sensitivities around conducting end of life research with dying patients and their families, we thought it wise to test the feasibility and appropriateness of the proposal with patients, carers and professionals. GL and LW spent a morning in August 2011 at St Margaret's hospice, where they discussed this proposal with the managers of the advice line and the Discharge in reach service and four patients and family carers. The appropriateness and sensitivity of the topic guide for the patients and family carers was tested.

Collecting and analysing Delivering Choice literature

The local Somerset Marie Curie team kept excellent records charting the development of this initiative. There were a host of useful reports, meeting minutes, business cases, formal presentations and so forth. These data were helpful in providing contextual information about the initial picture of end of life care services, the problems that the subsequent study interventions were meant to address, the decision-making that shaped the services, the challenges that local stakeholders faced and how those challenges were addressed. Most importantly, from a realistic evaluation perspective, these documents gave glimmers of understanding of the contribution and impact that programme developers anticipated for each intervention.

From the literature, we initially planned to develop timelines for each intervention. But this was not necessary, as the local Marie Curie team produced useful timelines for each intervention at the final stakeholder and executive board meeting in August 2011. Instead in addition to extracting data for service maps, we drew on the Somerset Delivering Choice literature to develop each 'intervention' report, constantly comparing the intentions of the programme developers against the actual functioning and impact of each intervention.

Service delivery (October 2011-May 2012)

To re-cap, the interventions under study were:

- End of Life care facilitators (North Somerset only)
- Discharge in reach nursing service (Somerset only)
- Out of Hours advice line (Somerset only)
- Coordination centres (North Somerset and Somerset)
- Documentation, specifically the pathway and framework i.e. 'traffic lights' (North Somerset and Somerset)
- Adastra end of life care register (North Somerset and Somerset)
- Key Worker role (North Somerset and Somerset)

Observations of Delivering Choice interventions

We carried out observations of all five Delivering Choice services at two time points: 1) baseline and 2) mid-study. We had intended to carry out a final set of observations in April 2012 to explore sustainability, but as funding for all of the services extended beyond March 2012, further formal observations to assess sustainability seemed superfluous. So, this third set was dropped.

The aim of the first set of observations was to build relationships with local Delivering Choice staff, observe how the services functioned, identify staff and staff roles, clarify referral routes and collect documentation such as referral forms. The aim of the second set of observations was to explore more fully how the services operate, particularly what works well and what does not. GL carried out the first set of observations in August 2011 and JP conducted the second set from November to December 2011. Informal observations continued long after these dates, however as both GL and JP made repeated visits to each of the services until the end of data collection in May 2012 to carry out interviews and collect service data. Thus, there was regular monitoring of changes and fluctuations in the services.

The formal observations varied in length from two hours (e.g. training session delivered in a care home) to five hours (e.g. 5-10pm shift at the Out of Hours advice line). In total, we carried out 15 formal observations, nine of which fell into the second set and six into the first.

Table 52: Observation

Service	Who observed	Dates	Observer
Dischage in reach Hospital A	Discharge in reach nurse on wards x2	11.8.11	GL
		29.11.11	JP
Discharge in reach Hospital B	Discharge in reach nurse on wards x2	15.9.11	GL
		22.11.11	JP
Out of Hours Line	Lead manager	5.8.11	GL
	Nurse advisor during 5-10pm shift	22.11.11	JP
Somerset Co- ordination Centre	Lead nurse x2	11.8.11	GL
		13.12.11	JP
North Somerset Co- ordination Centre	Fast track co- ordinator x2	4.8.11	GL
		19.12.11	JP
End of Life Care facilitators	End of Life Care facilitator in office	3.8.11	GL
		9.11.11	JP
		16.11.11	JP
Generic support workers	Generic support workers half day x2	21.2.12	JP
		13.3.12	JP

To guide formal observations, the researchers had a proforma with a list of queries and areas of interest that the evaluation team had previously agreed. Researchers took notes while carrying out observations or recorded their observations into an audio recorder. These were typed up either by the researcher or an external transcriber.

Collecting the views of professionals

We wanted to collect the views of five professional groups:

1. Staff delivering or leading on the Delivering Choice services
2. Professionals using the interventions
3. Professionals not using the interventions or using the interventions infrequently

4. Staff working with or displaced by Delivering Choice (e.g. hospital palliative care teams)
5. Members of the Executive and Stakeholder Boards

The aim of collecting data from Delivering Choice frontline and managerial staff was to obtain their perceptions of how the study interventions functioned both individually and as a collective, the triggers that brought about change, the impact on service users and the wider health economy. To collect the views of this first group, we conducted formal, semi-structured face to face interviews. These interviews were carried out by GL or JP. A topic guide was developed and reviewed regularly throughout the data collection period. The interviews were recorded and transcribed by an external transcriber. In total, we carried out 12 interviews with professionals that fell into this group. Through the observations and interviews, we reached saturation with those delivering or managing frontline Delivering Choice services.

With respect to the professionals referring to or using the Delivering Choice interventions, the aim in collecting their data was to explore what led to use of the intervention, what helped and hindered and consequences of using the intervention. The aim in collecting data from those who did not use Delivering Choice services was to test out emerging theories about what did and did not work. The aim in collecting the views of the final group of professionals, those who might work closely with Delivering Choice professionals or might be displaced by the implementation of Delivering Choice services was to find out more about the impact of the Somerset Delivering Choice Programme on the wider health economies in the two counties. To collect the experiences of all these professional groups, we used a variety of methods including formal, informal, group and telephone interviews and surveys.

We found interview candidates through a variety of methods. Using snowball sampling, we asked the professionals delivering or managing the Delivering Choice services to identify professionals within hospital or community sectors with whom they came into frequent contact. In hospital, we took advantage of the formal observations of Delivering Choice to identify staff for interview. We tended to conduct informal interviews with hospital staff and formal, face to face interviews with professionals in the community.

We also identified potential interview candidates through the survey responses. The initial aim of the questionnaire was to gather 'representative' data on uptake and quality of Delivering Choice services. But the response rate was so poor, that after two attempts (n=20) we abandoned this method for telephone interviews. However, these surveys did furnish the names and contact details of community staff, which were our first starting point in the telephone survey.

For North Somerset, to gather the views of those who may not have used any of the services, we obtained a list of the seven community wards, their leads and telephone numbers. LD systematically went through this list until she had talked to at least one (and preferably two) members from each of the community ward teams. As specific gaps became more apparent through concurrent analysis, for example information on use of Adastra by paramedics, we sometimes drew on personal connections such as an academic GP known to SP currently carrying out a study on ambulance crews in North Somerset.

For Somerset, we had much more in-depth interview data. Nonetheless, we wanted to hear the views of less frequent users of Delivering Choice interventions from a range of professional backgrounds including community nursing, care homes and out of hours services. Using the list of callers to the OOH advice line as a sampling frame, we identified those who had made one call. To get the views of ambulance crews, we contacted SWASFT (Somerset) and a GP and an end of life care trainer working with GWAS (North Somerset).

Initially, the topic guide for these telephone interviews was based on the questionnaire, but as we reached saturation with various areas of enquiry, we deleted questions and added others. The majority of telephone interviews were conducted by LD in April and May 2012, although LW carried out several with social services staff.

In total, we collected the views of 126 professionals – 52 from North Somerset and 74 from Somerset. Please see the table below.

Table 53 Professional participants in Somerset Delivering Choice Evaluation

Role	Phone	F2F	Informal	Survey*	N Som	Som	Total
DELIVERING CHOICE SERVICE PROVIDERS							
DCP service providers	2	9		1	4	8	12
COMMUNITY AND COMMUNITY HOSPITAL NURSES							
Community & district nurses	16	6		3	10	15	25
Community hospital nurses	1		2		3	0	3
SOCIAL SERVICES							
Social services	9		2		6	3	9
Care home staff	5	2		1	3	5	8
HOSPICE RELATED							
Community palliative care nurses	7	4		1	5	7	12
Hospice clinical and admin staff	14			5	10	9	19
GENERAL PRACTICES							
GP	1	3		1	2	3	5
GP surgery staff	5				4	1	5
HOSPITAL STAFF							
Ambulance and related staff	2		2		2	2	4
Hospital nurses and allied professionals	3	2	13	2	3	17	20
Hospital Consultant			2			2	2
Hospital other		1	1			2	2
Total	65	27	22	14	52	74	126

*Survey total does not add up to 20 because if we received a survey return and interviewed a professional, then that counted as an interview.

On reflection, we reached saturation in North Somerset with hospice staff, community nurses and members of the Single Point of Access team. Despite repeated efforts, we were unable to interview more care home staff and urgent care staff. In Somerset, we reached saturation with community palliative care specialists, care home staff and staff from the Central Referral Centre. Because Somerset is such a big county, we would have liked to have interviewed more community staff from rural areas.

Documentation and databases

In addition to interviews and observations, we collected two types of documentation: 1) electronic and paper documents and 2) databases. Documentation was used to corroborate accounts in interviews and interpretations from observations, to identify those for sampling and to track the development of the different interventions.

Examples of electronic and paper documents include:

- Referrals forms to the Coordination Centres
- Service specifications and board papers for North Somerset
- Advertising literature
- Monthly returns from April 2011-March 2012 for the Out of Hours advice line
- Phase I, II and III and Phase II business reports from the local Marie Curie Team
- Documents for stakeholder and executive board meetings from June 2010 to August 2011 including Powerpoint presentations, meeting minutes and interim reports

From databases, data from Crosscare and Adastral were extracted on our behalf. Crosscare held data for the Out of Hours advice line and for the Discharge in reach service. The Adastral electronic register held data on Key Worker and preferred place of care. For the Out of Hours advice line, we asked for all information for all calls from 1 September 2011 to 29 February 2012, excluding those to the Central Referral Centre. We carried out several analyses of these data including:

1. Extraction of two sub-samples including a 10% sample selected randomly by a computer generated tool (n=22) and all non-cancer patient related calls (n=36). We carried out in-depth analysis on reason for call, number of calls, what happened and who initiated the call. We also used these samples for quality assurance to check for potential bias in the family members suggested by the Delivering Choice staff for interview.
2. To check the quality of the database, we sorted the caller status field (i.e. carer, GP, care home) and analysed the calls from GPs. We found several quality issues reported in the OOH advice line chapter.

From Crosscare, we also extracted data for 11 patients who had more than one contact over a three week period with a Discharge in reach nurse to understand more about possible re-admissions. The records of these 11 patients were read and drawn into an 'overall narrative'.

With regards to Adastral, we extracted data for both North Somerset and Somerset. In addition to feeding into routine data analysis, for each county we identified those patients who had recorded preferred place of care, where died and a Key Worker recorded with contact details. We then sampled Key Workers based on county,

number of patients recorded as Key Worker and professional role. We carried out telephone interviews with 10 Key Workers – 3 from North Somerset and 7 from Somerset.

Patient journey (November 2011-March 2012)

Family carer and patient interviews

To understand more about the patient experiences at end of life, and explore the use of Delivering Choice, we interviewed family carers. The initial invitation to take part was made on our behalf by DCP staff who telephones patients and their families who had received Delivering Choice services in 2011. If interest was expressed, the Delivering choice staff member sent a letter of invitation, an information sheet about the study, and a consent form. On receipt of signed consent forms, the qualitative researcher telephoned to arrange the interview.

42 interviews were carried out with family members who had provided informal care to their (now deceased) relative, and only one with a patient. This was partly because patients identified by Delivering Choice staff died before the interview could be arranged, or take place, and also because most of those who returned signed consent forms were family carers of patients who had died.

At interview, family carers were asked about a number of issues, including: how they heard about DCP; what prompted use of the particular service (s); views on the quality of the service (s); and, apart from the one patient interview, whether the patient died in his or her preferred place of care and the contribution that DCP made to facilitating death in place of choice.

Interviews were conducted face to face, except for three carried out by phone, at the interviewee's request, and were carried out by an experienced qualitative researcher. In addition, we checked if the patient has been put on the end of life care register and analysed any updates to his or her record. We also checked other electronic data sources for details about these patients.

As well as contributing to the overall analysis (see below), we used these data to inform patient experience pathways. The transcripts were selected of ten family carers of patients. Selection was based on the date of death as all died in the six month study period of 1 September 2011 to 29 February 2012, so all sources of data were available. The carers' interview transcripts were mapped chronologically against the Delivering Choice End of Life care pathway. Other data from a variety of sources were then mapped alongside the carer's transcript. These data sources included: NHS data, data stored on Adastralink and service usage data available from Delivering Choice services. The different types of data sources were colour coded and organised along the care pathway in the most appropriate place. This process was not always easy as in practice patient care does not flow in a standard

chorological and linear way. However, once this process was complete, the different data sources were examined against the clinical care pathway and 'variance analysis' was completed. There are many different types of 'variance analysis' (Hunter and Segrott, 2008), but the way it was applied here was by identifying the deviations of actual events away from expected events and identifying discrepancies between different data sources.

Analysing and writing up the data

So at the close of data collection we had:

- Interviews with family members and patients
- Observations of Delivering Choice services
- Formal, informal and telephone interviews with professionals
- Surveys
- Data from documentation and databases

In considering analytical approaches, we took several factors into account including: the large quantity of heterogeneous data from various sources, the multiple researchers who had collected the data, the short time frame for analysis (12 weeks in total) and our desire to draw on the principles of realist evaluation. After a couple of attempts using thematic analysis, we settled on framework analysis. (Ritchie & Lewis, 2003)

Framework analysis is a deductive approach whereby researchers develop a proforma of topics of interest and only extract data relating to those topics. We designed the proforma for this study, using realist evaluation concepts. For example, to draw out contextual factors, we developed two questions: What helps this intervention to work? What stops this intervention from working? The questions on the proforma were revised and refined several times by the team to ensure that all pertinent data were captured. Each researcher then completed a separate proforma report for every intervention, extracting data that he or she had personally collected across the multiple data sources.

Each week team members submitted reports on one of the nine Delivering Choice interventions (e.g. Discharge in reach nurses, Adastra electronic register, etc.). Researchers used different techniques and tools to pull together their reports. For example, GL used NVIVO and included large, continuous sections from transcripts under the different proforma headings. JP printed all the transcripts out, read to identify key themes and then included the theme with supporting quotes from the transcripts and observations. BS used Word to cut and paste, while LD read across the telephone notes and surveys and wrote a summary of key findings. Once completed, LW then compiled the four mini-reports for each intervention into a 'master' document, returning to original source data when needed, for example to

better understand discrepancies in the data. At the end of this process, each of the interventions had its own master document.

The whole team, including SP, then met to discuss the emerging findings. The key questions at these discussions were: what are the key points about this intervention? As different team members shared their understandings, commonalities, discrepancies and gaps were identified. This then led either to the collection of further data by LD, who continued to conduct telephone interviews until the end of May 2012, or to re-appraisal of data already collected.

After these discussions, LW re-drafted the 'master' reports and key findings were synthesized into 'summary' reports. Both the master and summary reports were distributed to all team members including SP. The team then met again for a longer discussion. The key questions at this second discussion were:

- Is the emphasis of this report right?
- What are the key ingredients of this intervention?
- How integral is this intervention to Delivering Choice?
- What recommendations should we make?

LW then re-drafted the master and summary reports.

So in terms of integrating the data, the data across the multiple sources were compared, contrasted and combined at three points: 1) when each researcher analysed the data that s/he had personally collected, 2) when LW combined the master reports, 3) at team meetings.

To obtain 'face validation', LW and GL presented preliminary findings to Delivering Choice service providers at two meetings, one in Somerset and one in North Somerset. The sections of the master report entitled 'How is this supposed to work?' and 'How does this actually work?' were also sent to frontline service providers and their managers for comment and assurance of factual accuracy. The master and summary reports were re-drafted to include their comments and emerging quantitative findings.

Quantitative protocol

Aims:

Who is using Delivering Choice services?

Determine if patients who are entered onto the EOL pathway and who access the components of the EOL care framework will:

- be more likely to have died and been cared for in their place of choice
- be less likely to have been admitted to hospital for care in the last 6 months of life
- have fewer emergency and elective bed days in the last 6 months of life

- have different diagnoses or conditions than those who do not access the components of the EOL framework.

Study design:

Retrospective cohort study of all patients in Somerset and North Somerset PCTs (data to be collected separately to same protocol).

a. Population inclusion criteria

From the Primary Care Mortality Database (PCMD), ONS identify:

- 1) All patients who died between 1st September 2011 and 29th February 2012
- 2) Registered with a Somerset or North Somerset GP (rather than resident in Somerset/North Somerset)
- 3) Over 18 years of age (i.e. DOB is before 1.4.1993)
- 4) After discussion we have decided to use the following operational definition:
Deaths amenable to palliative care.
 - a. This excludes deaths attributed to the following ICD10 chapters: A, B, O, S, T (based on NHS Somerset QIPP End of Life Care targets and Marie Curie Cancer Care End of Life Care monitoring template (see appendix 1).
 - b. Also excludes the following ICD10 chapters V, W, X, Y (based on Operating Framework SQU02. Department of Health, Technical Guidance for the 2011/12 Operating Framework. Leeds, January 2011.
- 5) Who died of the following causes, based on Underlying Cause of Death code (as used by NHS Somerset and SWPHO [1]):
 - a. Malignant neoplasms = ICD 10 codes C00-C97 (do not include in situ or benign neoplasms or Neoplasms of uncertain or unknown behaviour D00-48 – recently included by SWPHO in their dataset www.endoflifecare-intelligence.org.uk). Put D00-48 in 'other' deaths
 - b. Heart disease = ICD10 codes I0-5 (ref SWPHO)
 - c. Cerebrovascular = ICD10 I60-69 (ref SWPHO)
 - d. Respiratory = ICD10 codes J00 to J99
 - e. Dementia = ICD10 codes F01, F03, G30, R54 (SWPHO)
 - f. Other = all remaining ICD10 codes

b. Population characteristics

From PCMD extract following data:

Item	Data extracted by PCT	Use of data	Data provided to UoB
1	NHS Number	Matching to HES/DCP by PCT	Will be allocated unique study ID number
2	DATE OF BIRTH		Age at death in months
3	DATE OF DEATH		
4	PLACE OF DEATH		Coded e.g. Acute trust, community hospital, nursing or residential home, usual place or residence* and elsewhere. (*May include residential home, if this was where the individual's "home" was prior to death)
5	DECEASED USUAL ADDRESS		
6	DEC USUAL ADDRESS POSTCODE		LSOA
7	PCT OF GP REGISTRATION		
8	GP Practice Code		Yes
9	UNDERLYING CAUSE OF DEATH		Yes
10	SEX		Yes
11	CAUSE OF DEATH ICD CODE 1		Yes
12	CAUSE OF DEATH ICD CODE 2		Yes
13	CAUSE OF DEATH ICD CODE 3		Yes
14	CAUSE OF DEATH ICD CODE 4		Yes
15	CAUSE OF DEATH ICD CODE 5		Yes
16	CAUSE OF DEATH ICD CODE 6		Yes
17	CAUSE OF DEATH ICD CODE 7		Yes
18	CAUSE OF DEATH ICD CODE 8		Yes
19	PLACE OF DEATH CODE		Yes

Having defined our population and found out what they died of and where, their demographic characteristics and which GP practice they were registered with, we need to know what happened to them in the last six months of their lives. To do that we will link to the following sources using NHS number (etc) to determine service use.

c. In patient hospital data

Using NHS number, postcode etc to link to inpatient hospital admission data from Secondary Uses Service (SUS) data from NHS Connecting for Health (linkage at PCT). Extract data on admissions. Include all admissions in previous 6 months before date of death. N.B. Including any admissions during which death occurred.

Item	Data extracted by PCT	Use of data	Data provided to UoB
1.	NHS Number	Data linkage	No
2.	Postcode		
3.	Provider_3		
4.	Sex		Yes
5.	Date of Death		Yes
6.	Admission Method (Hospital Provider Spell)		1) Day cases 2) Elective Inpatients 3) Regular Elective (e.g. dialysis) 4) Emergency 5) Other non-elective (e.g. hospital transfers, maternity)
7.	Discharge Destination (Hospital Provider Spell)		Yes
8.	Discharge Method (Hospital Provider Spell)		Yes
9.	Source of Admission (Hospital Provider Spell)		Yes
10.	Start Date (Hospital Provider Spell)		Yes
11.	Discharge Date (From Hospital Provider Spell)		Yes
12.	Episode Number		Yes
13.	Start Date (Consultant Episode)		Yes
14.	End Date (Consultant Episode)		Yes
15.	Main Specialty Code		Yes
16.	Treatment Function Code		Yes
17.	Diagnosis Primary (ICD)		Yes
18.	Diagnosis 1st Secondary (ICD)		Yes
19.	Diagnosis 2nd Secondary (ICD)		Yes
20.	etc		Yes
21.	Primary Procedure (OPCS)		Yes
22.	2nd Procedure (OPCS)		Yes
23.	etc		Yes
24.	Practice Code of Registered GP		Yes
25.	Age		Months
26.	HRG		Yes
27.	Dominant Episode		Yes
28.	Spell LOS		Yes
29.	Tariff_Total		Yes

d. Accident and emergency data

Using NHS number, postcode etc to link Accident and Emergency data to Secondary Uses Service (SUS) data from NHS Connecting for Health (linkage at PCT). Extract data on A&E attendances. Include all attendances in previous 6 months before date of death. N.B. Including any A&E attendance on date of death or during which death occurred.

Item	Data extracted by PCT	Use of data	Data provided to UoB
1.	NHS Number	Data linkage	No
2.	Postcode		
3.	Sex		Yes
4.	Date of Death		
5.	Practice Code of Registered GP		
6.	A&E Arrival Mode		
7.	A&E Attendance Category		
8.	A&E Attendance Disposal		
9.	Arrival Date		
10.	Accident And Emergency Diagnosis - First		
11.	Accident And Emergency Diagnosis - Second		
12.	Accident And Emergency Diagnosis - Third		
13.	etc		
14.	Accident And Emergency Investigation - First		
15.	Accident And Emergency Investigation - Second		
16.	Accident And Emergency Investigation - Third		
17.	Accident And Emergency Investigation - Fourth		
18.	Accident And Emergency Investigation - Fifth		
19.	etc		
20.	Accident And Emergency Treatment - First		
21.	Accident And Emergency Treatment - Second		
22.	Accident And Emergency Treatment - Third		
23.	Accident And Emergency Treatment - Fourth		
24.	Accident And Emergency Treatment - Fifth		
25.	etc		
26.	HRG Code		
27.	HRG Version Number		
28.	Age at CDS Activity Date		

e. Delivering choice data

All services delivered by the EOL care pathway will record patient's NHS number. Linkage of patients who have died to services received will be undertaken at the PCTs by matching NHS number. In the case of non-matching, then age and part postcode will be used. Utilisation of each part of the EOL pathway by those patients who died will be recorded. This will include the EOL register and whether advance care planning and preferred place of care is recorded.

In addition, in Somerset we will focus on use of:

- Key Worker
- Discharge in reach nurses
- Coordination centre for EOL care
- Out of hours advice and response line

In North Somerset we will focus on:

- Single point of access for coordination of care
- Access to generic health workers
- EOL facilitators

By using NHS number we will track patients across health and social care wherever possible e.g. we will work with the PCTs and local organisations such as GP out-of-hours services to map use of services across interfaces in health and social care.

Outcomes

The outcomes that will be collected for each patient, using NHS number as unique identifier will be:

- a. Place of death
- b. Whether died and been cared for in their place of choice – if known
- c. Admitted to any hospital, including community hospitals, in the last 6 months of life (emergency and elective)
- d. Admitted to any hospital, including community hospitals, in the last 1 month of life (emergency and elective)
- e. Total bed days in last 6 months of life
- f. A&E use in last six months and one month of life

In addition, based on the costs of commissioning services and the number of hospital admissions and bed days in patients receiving different services, we will undertake economic modelling of the costs of the new services and the savings from any reduction in admissions.

References

1. National End of Life Intelligence Network. Deaths in Older Adults in England. South West Public Health Observatory, Bristol, October 2010. www.endoflifecare-intelligence.org.uk

Reflections on using realistic evaluation

Advantages

Overall, the methodology of realist evaluation worked well, bringing particular strengths to the evaluation.

Firstly, staging several hypothesis generation meetings across the two counties added an important conceptual step that often is skipped in service evaluations – that of understanding where the programme came from, why and what programme developers hoped to achieve. Most importantly, it allowed the evaluation team to learn about and tease out the aspirations and challenges of the programme developers and an opportunity to unearth, consider and reflect on explicit and implicit assumptions. This helped to identify clear priorities and potential areas for enquiry. On a practical level, the workshops provided a way for the evaluation team to meet and develop relationships with key programme participants, including local stakeholders and the national Marie Curie team, which may have helped facilitate future access.

Secondly, the Context-Mechanism-Outcome configuration was useful in helping the evaluation team to keep focused. As the programme was so wide ranging with a plethora of different stakeholders across a multitude of organisations, each with its own culture and ways of working, there were many fascinating alleys to distract the evaluation team. But by keeping the realist evaluation framework in mind, the evaluation team found easier to regularly bring the focus back. Repeating the key question of ‘what works for whom and in what circumstances?’ was particularly helpful.

Thirdly, the realist evaluation approach allows for regular testing and re-testing of assumptions and findings. Realist evaluation comes from the critical realism stable, which holds that there is a fixed ‘truth’, with variations in perspectives of that truth (Pawson and Tilley, 1997:21). Because an aim of realist evaluation is to identify the key ingredients to successfully transport the initiative elsewhere, it is important to weed out opinions on what is interesting, but not necessary, from what is essential. This meant that the evaluation team could not take any particular viewpoint at face value and constant corroboration of emerging findings was crucial. So, for example, when we were told by an End of Life Care facilitator that a ‘mechanism’ that changed care home staff behaviour was discussing their own deaths, we interviewed several care home staff to ascertain whether this indeed did have the impact suggested. By continually testing the findings, we found that this approach was highly iterative, much more so than other qualitative approaches.

Fourthly, and closely related to the point above, the realist evaluation approach permitted the researchers to continually drill down into real examples to help unpick contextual factors and mechanisms. For example, when a hospice nurse said that she used the Adastral register to update patient details, we asked for a specific example of the last time she used the register for this purpose. This provided extra

information on the characteristics of the patient, the working habits of the hospice nurse and the challenges in using the system; information that we could then test in future interviews to build up a grounded picture. It was not enough to know that something was used, we needed to know the sequence of events leading to that use to understand more about why and when the intervention 'worked'. Asking for examples of when the intervention 'worked' was also more successful than asking participants the question of 'what works for whom and in what circumstances?', as this conceptual question tended to baffle.

Finally, using a realist evaluation approach was a refreshing change with its positive emphasis on 'what works?' Many evaluations (and evaluators) focus on what is wrong or needs improvement, and indeed there was a tendency in the hypothesis generation workshops for participants to veer towards the negative. But focusing on what is not happening does not help us to understand what could happen, if particular contextual factors changed. Thus even for interventions that are plainly 'not working', the realist evaluation approach can pull out useful lessons which can then be applied when considering the transferability of the programme.

In applying a realist evaluation methodology, the process that the evaluation team adopted for each intervention was:

1. Find out what is happening.
2. Identify where the intervention is working best
3. Discover why the intervention might be working best in that particular context
4. If useful, identify some examples of where it is 'not working' to test emerging findings

Challenges

Using a realist evaluation approach also brought some challenges. Firstly, the hypothesis generation workshops and the development of the research design was over-laboured. Partly, this was due to the inexperience of the evaluation team in using this methodology. However in discussing our experiences with other researchers using realist evaluation, we found this is a common pitfall.

Secondly, this approach is not underpinned by theoretical frameworks to help explore and deepen understanding of the findings. Realist evaluation is highly pragmatic, and probably therefore appeals more to those coming from a positivist perspective.

Thirdly, realist evaluation methodology requires highly proactive methods to data collection. We found surveys largely unhelpful. Apart from the poor response rate, the information collected was often too generic to be of use. For example, participants would state that they contacted the End of Life Care facilitators for 'advice', but there was no further information on what prompted that contact, what advice was needed or what happened once the advice was offered. Moreover, when LD contacted survey participants for further information, she often found that the

data on the surveys were misleading. For example, a participant said that she contacted that End of Life Care facilitator several times a week, but this was because the End of Life Care facilitator often picked up the phone at the North Somerset End of Life Care Coordination Centre not because the participant wanted the End of Life Care facilitator in particular. This skewed information could have led the evaluation team to over-estimating and under-estimating the uptake of particular services.

Instead, we found that the combination of in-depth face to face interviews with a variety of professionals, informal face to face interviews, telephone interviews and observations much more helpful. These methods allowed the researchers to pursue lines of enquiry until exhausted.

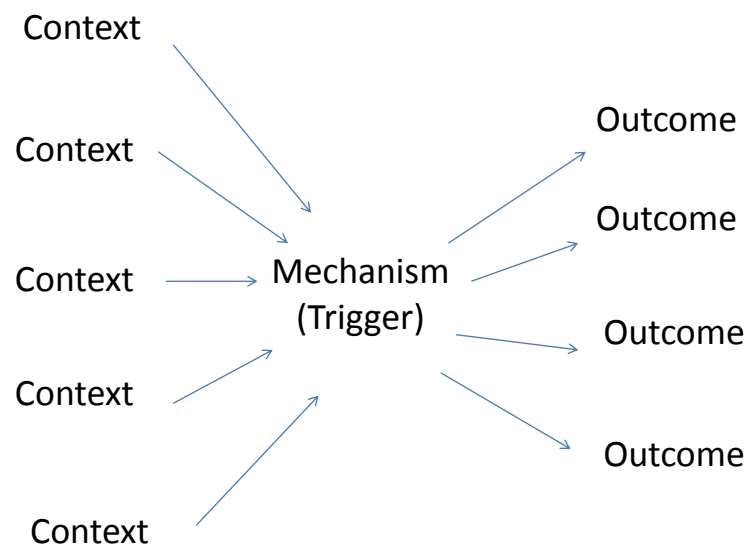
Fourthly, we had considerable difficulty in defining and applying the realist evaluation terms. For example, JP, LW and GL all independently analysed the same transcript to tease out context, mechanisms, triggers and outcomes. Although there was widespread agreement on outcomes, defining and agreeing context, mechanisms and triggers was murkier. We often found that a factor that one person identified as a 'context' would be viewed as a mechanism by another. Mechanisms and triggers were particularly difficult to isolate. Instead, we found that developing the more general questions of 'what helps?' 'what hinders?' and 'what is working?' were more helpful.

We also found it difficult to draw together linear CMO configurations. Usually the mechanism and the trigger for that mechanism were constant for every configuration, but we found multiple contextual factors and outcomes. Thus, it was difficult to follow a straight line of trajectory from one contextual factor to the mechanism through to a specific outcome. So instead of the configurations looking like this:

Context → Mechanism → Outcome

The configurations for each intervention more closely resembled this:

Figure 20: Context Mechanism Outcome Configurations



Given this, we could explore the relationship between contextual factors and the mechanism and between the mechanism and outcomes, but looking at the connections between a specific contextual factor and a particular outcome was elusive.

Conclusion

Given our experiences using realist evaluation methodology, we would recommend applying this approach in further evaluations of complex programmes. However, we would suggest that the choice of methods is crucial and would advise future evaluators to opt for more interactive data collection techniques. We would also suggest ‘stepping lightly’ over definitional matters associated with realist evaluation terminology. Having a broad definition of context, mechanism and outcome was important, but circular discussions attempting to classify and label particular findings as context, mechanism or outcome were unproductive. If these pitfalls are avoided, we believe that this methodology can make a useful contribution.

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