Independent Evaluation of the Marie Curie Cancer Care 'Delivering Choice Programme'

Structured End Evaluation Report for Lincolnshire

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EXECUTIVE SUMMARY

The Marie Curie Delivering Choice Programme was initiated by Marie Curie Cancer Care in 2004 to:

" See better planning, choice and co-ordination of high quality palliative care to patients, so more patients are cared for and die in the place of their choice" (p 10 MCCC Phase I report 2005).

Marie Curie Cancer Care stated three key objectives for the Programme to achieve in Lincolnshire:

1) "Develop patient focused 24 h service models that serve the local needs and ensure:
    - The best possible care for palliative care patients
    - Improvements in equity of access to services
    - Appropriate support services for palliative care patients and their carers
    - Choice in place of care and death is available to all
    - Information on choice is available and known to all
    - Improvements in co-ordination of care among stakeholders
2) Evaluate the economic impact to health care services of more patients receiving palliative care at home as compared to hospitals
3) Disseminate findings to other health and social care providers that leads to replication of solutions across the UK"

(MCCC Phase I report 2005)

Evidence from the baseline evaluation undertaken in 2005 identified six themes that were perceived to affect palliative care provision across Lincolnshire:

- Coordination
- Communication
- Resources
- Out of hours care
- Knowledge and skills
- Fragmentation and gaps in services

The objective of this end evaluation report is to look at change and continuity in the patterns of support to facilitate choice in end of life care for patients and their families with cancer and heart failure in Lincolnshire, in the context of the Programme. The evidence suggests that the most successful intervention was the DCLN, with mixed appraisals of the RRT and the PCCC.

The use of a mixed methods formative evaluation methodology has resulted in a rich and complex wealth of data from multiple perspectives. Synthesising the data to provide an accurate but nuanced evaluation has been challenging. As in other 'real world' research, we have endeavoured to capture the impact of complex interventions against a backdrop of changing local and national services. However, the analysis reported here has several limitations. We were asked by Marie Curie, who commissioned our evaluation, to confine our attention to the interventions that make up the Programme in Lincolnshire. However, the incorporation of other support dimensions, such as non statutory services like care homes, local self help and charitable organisations, would have given a more complete understanding of the relationship between choice and service utilisation.

There have been specific challenges in interpreting and comparing NHS and Marie Curie datasets, which are largely incompatible. We have successfully obtained data from district nurses, specialist nurses, stakeholders, family carers and bereaved carers. As in the baseline evaluation, general practitioners have not chosen to respond to questionnaires or telephone interviews in the way we had hoped. They have cited being overburden by concurrent questionnaires, including those distributed by Marie Curie. Obtaining the views of service users is very important but for dying patients who are consumers of the Programme interventions the window of opportunity to recruit and interview them is extremely small. Some patients were just too drowsy, ill and weak to be interviewed despite agreeing to participate. In these circumstances, the use of proxy data from carers and bereaved carers provides an important insight into their experiences, in addition to carers' and bereaved carers' ability to evaluate their own needs and experiences. There is an obvious trade-off between maximising the data collected and the restraints of time and resource. Overall, we are confident that there are sufficient data to draw the conclusions we have presented in the Report.

To summarise the findings, the Programme interventions will first be considered separately, followed by some broader issues on the implementation of the Programme and its outcomes.

The Delivering Choice Programme in Lincolnshire

The current population of residents registered with a GP in Lincolnshire is 720,451 (NHS Informatics 2007). This is an increase of 9352 registrations since the 1 January 2006. During April 2006-March 2007 there were 7649 adult deaths of which the cause of death was registered as cancer in 2140 cases and heart failure in 457 cases.

Rapid Response Team (RRT)

The RRT was developed to provide and improve out of hours nursing services in the Boston and Spalding areas of East Lincolnshire. There were mixed views about the RRT. Some respondents viewed the service as a significant additional support to the primary care team and importantly, to patients and carers. Evidence showed that the service was effective in providing care and support particularly at crisis points over night. It was seen as one of the key services that enabled families to keep their loved one at home until they died. Carers valued the reassurance of knowing the service was only a telephone call away and that practical physical help and symptom control could be summoned for patients.

More cancer patients than heart failure patients benefitted from the service. Evidence suggests that 35% of cancer patients compared to just 6% of heart failure patients who died between April 2006 – March 2007 in the main Boston and South Holland area received support from the RRT before death. In this area 73% (n=114) of cancer patients who died at home received RRT support. The majority of patients and families that received this support (64%) made direct contact with the service on more than one occasion. In addition 20% (n=65) of cancer patients who died in hospital received support from the RRT as did 30% of cancer patients who died in the hospice and 25% of cancer patients who died in a care home.

The evidence reveals that the RRT has improved the availability of twilight and out of hours care within the Boston and Spalding areas, however, not all of the potential patients in the selected area have accessed the service. This maybe due to inadequate information about the service and may also reflect patient choices. For those patients who have access to the services, it has enabled them to stay at home if that is their choice of place of care.

> *'It's just brilliant, it's just so good, because they're so calming'* **(Patient with heart failure P2C3H)**

The service has supported carers, and according to bereaved carers the combination of the RRT and regular night care workers enabled their relative to die at home. There was some evidence that RRT staff were unable to function to their full capacity.

There was a gap in services during the day at weekends when neither the RRT nor St Barnabas Hospice at Home Service was available. Uptake of the RRT telephone advice only service provided in the extended boundary area was poor and appeared to have little impact. The views of Macmillan nurses who were not working within the RRT areas were less positive. Concerns were expressed about the potential fragmentation of care into 'pockets' of good provision and there was a view expressed that the services provided by the RRT could be addressed equally well by additional funding for 24 hour district nursing. Data recorded by the RRT is potentially misleading as they record re-referrals by the RRT itself and this inflates the figures for utilisation.

Discharge Community Link Nurses

The DCLN service was developed to facilitate and improve the coordination of discharges from hospitals for patients with complex needs, provide support and to improve communication between hospital and community services. The role of the DCLN was perceived as successful in creating effective packages of care to enable patients to go home even at the very end of life. However, 80% of cancer patients who died in Lincoln County and Pilgrim Hospitals did not receive support from the DCLNs, the reason for this is unknown, and may be due to a range of different factors.

Evidence indicates that a combined total of 572 patients were seen by the DCLNs across both hospitals in Lincoln and Boston. Of those patients seen by these nurses, 80% had cancer, 11% heart failure and 9% other non-malignant conditions. The DCLNs in combination with the RRT and PCCC were perceived to have improved 24-hour care. The DCLN service was regarded as patient and family carer focused. Careful assessment and carefully constructed care packages were perceived to enable patients to stay at home. For the patients who were referred to the DCLN service, they appeared to access thoughtful care and greater choice of place of care.

The work of the DCLNs in Lincoln and Boston enabled 61% of patients referred to them to be discharged or transferred to their preferred place of care. Respondents who had accessed this service were overwhelmingly positive. But there are two caveats: 1) a lack of cover when the DCLNs were on leave, which delayed discharge and hampered communication; and 2) home visits by the DCLNs raised patient and carer expectations which could not then always be met by existing community services, especially district nursing services. The DCLN service was reported to improve information and co-ordination between organisations.

> *'I think [DCLN] is a really good example of intelligent prescribing in the way she constructs the package of care. And I don't think you get that with everybody else… a very competent clinician, who's really thinking about the package, and who is communicating clinician to clinician with '7a' and the team in a really effective way.'* **(SH7b)**

The DCLN initiative was thought to fulfil many of the core objectives of the Programme in terms of providing a patient focused service where people have access to information and appropriate support services in order to make informed decisions about their care. Many of those interviewed would like to see more resources put in place to extend and increase the role of the DCLN. This intervention was regarded as the most successful and provided added value to patients and hospital staff. The DCLNs had a greater impact on cancer patients because of perceptions about difficulties in recognition of end of life in heart failure patients and questions about the appropriateness of care.

The Palliative Care Coordination Centre (PCCC)

The PCCC was designed to coordinate care packages for palliative and end of life care patients. The PCCC received a mixed evaluation. According to respondents the PCCC had a difficult start as it had to liaise with social services to develop a shared pathway for highlighting where patients should be referred to for care coordination and 'brokerage'. These issues appear to remain unresolved. The PCCC was valued most by district nurses who reported that it assisted with their workload. Primary care practitioners (predominantly district nurses) made 81% of the referrals to the PCCC; cancer patients made up 87% of these referrals. Specialist nurses reported that the PCCC positively supported the work of district nurses with whom they had regular contact. However, some district nurses reported that while the PCCC improved coordination and reduced their workload, it appeared to increase fragmentation of care provision to some patients.

Evidence indicates that despite the final location of patients' deaths, the PCCC arranged care for 42% of all cancer patients and 11% of heart failure patients who died across the county between 1 April 2006 and 31 March 2007. Despite the lower than anticipated number of cancer patients referred to the PCCC, it is likely that not all of the countywide cancer related deaths were of patients with predictable palliative or end of life care needs. Cancer patients were the most frequently referred diagnostic group to the coordination centre for the arrangement of care packages. The data based recorded 12,888 requests for care on behalf of 1042 patients. Once again there are concerns about the interpretation of the data recorded by the PCCC.

However, one quarter (25%) remained 'open' at the time of cancellation or could not be booked. There is potential for misleading inferences being drawn as this inflates the figures for utilisation. The PCCC figures reflect only a proportion of the care coordination needs of the total number of patients who died from cancer and from heart failure across Lincolnshire.

Three key problems were highlighted in relation to the PCCC: 1) reduced communication between professionals and lack of continuity of care were regarded as a negative consequence of the PCCC; 2) lack of flexibility leading to instances where the service was not thought to be sufficiently sensitive to the complex needs of the client group; 3) funding issues: continuing care funding was seen as the only way to access the PCCC and was a lengthy process for patients with non cancer palliative care needs. High costs of agency care and problems with accessing care were also perceived as problematic.

Most patients, carers and bereaved carers were not aware of the centres' role in coordination the care they received. For those who were, they identified receiving a telephone call telling them about what care shifts they could expect. They reported that knowing who was coming enabled them to plan their week and increased their sense of safety when strangers entered the home.

> *'So Barnabas and Macmillan nurse did it between them in the morning; they used to come and wash him and see that he was all right ...then they got me a night [nurse] to come in then, and she'd be here until, from nine until eight, and then the district nurse would come at eight to wash him...Going back as I said that the nurses would go, my doctor's nurse, district nurse would pop in, in between, but at three o'clock then I would have my [Marie Curie RRT] nurses. ... But I couldn't have done without them* **(Bereaved Carer C2).**

Despite improving the coordination of care in respect of the provision of care workers in the home, lack of continuity and increasing fragmentation of the care provided was perceived to have increased by the DNs and specialist nurses. The reliance on agency nurses as previously discussed, has led to some reports of episodes of very poor care provision by inappropriate staff for people in extremely vulnerable situations.

Wider support for family carers

While patients, carers and bereaved carers reported individual experiences of good care and being facilitated in their preferences for place of care, overall, they were often confused about roles, systems and interventions which appeared as a bewildering array of people and services. On the whole they did not attribute the care they received to the Programme interventions or to Marie Curie, apart from the RRT. Carers often related to a particular health care professional who was key for them – who this person was varied. Care was often supported and enabled by a complex array of service providers and by family networks. This suggests the need for an individual named coordinator for end of life care to assist patients navigate the complexity of service provision.

The carer support groups funded by Marie Curie were designed to provide support and useful information through a monthly luncheon club. Two carers accessed the Carer Support Group and they reported it as helpful but were unaware that it was linked to the Programme. They reported issues about the timeliness of the educational interventions offered at the group.

Implementation of the Programme

Implementing a major change in services such as the Programme requires skills in negotiation and partnership working. In this final section, we consider broader issues about the extent to which improvements in communication and coordination between stakeholders across Lincolnshire have been facilitated or hampered. One stakeholder reported some of the more negative impacts including the view that in the Grantham and South West Lincolnshire area the Programme essentially copied their coordination centre then took over its role and moved it to Lincoln. Other criticism highlighted the perception of disadvantage felt by not funding a DCLN at Grantham Hospital. Some respondents reported feeling uncomfortable with some of the claims made by the Programme because the claims were felt to fail to recognize the team work required between different organisations and services to provide good palliative care. This has caused some bad feeling and a perception of increasing gaps in service provision across the county as a whole.

> *'I think what worries me more is that we've created slightly more gaps, because of this potential division between providers.'* **(SH11)**

Two stakeholders suggested that how the Programme was introduced has resulted in problems engaging some staff with it and there was some concern that the problems identified by the process of implementing the Programme will have long term implications on cluster based commissioning of palliative care services.

Conclusion

What broader conclusions can be drawn from these findings, particularly in the light of anticipated demographic and family changes? The population of Lincolnshire is increasing, and there are likely to be greater numbers of older people choosing to live in rural and coastal areas. Moreover, the assumption that there will be family carers available and willing to provide care near the end of life needs to be reviewed. The Programme has implemented one successful intervention – the DCLN and two interventions with evidence of partial success – the RRT and PCCC. Overall it is cancer patients who benefit most from these interventions and are more likely to have choice in place of care than heart failure patients. The assumptions underpinning current end of life care services means that heart failure patients who typically experience different patterns and trajectories of illness than cancer patients, and where prognostication is more uncertain, continue to be under served. The Programme has facilitated greater choice and greater access to 24-hour care predominantly in the Boston and Spalding areas, rather than the whole of Lincolnshire. The Programme can be considered to be a partial success for cancer patients in restricted areas of Lincolnshire, enabling them to be discharged home near the end of life.

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Glossary

A&E	Accident and Emergency
AHP	Allied Health Professional
BC (number)	Bereaved Carer (number)
C (number)	Carer (number)
CA	Cancer
CNS	Clinical nurse specialist
CS	Carer Support Group
DCLN	Discharge Community Link Nurse
DCLN-B	Discharge Community Link Nurse Boston
DCLN-L	Discharge Community Link Nurse Lincoln
DH	Department of Health
DLN	Discharge Liaison Nurse
DN	District Nurse
DS 1500	Special Rules applying to funding allowances for people with less than 6 months to live
Dr	Doctor
E	East
ECP	Emergency Care Practitioner
EMAS	East Midlands Ambulance Service
GP	General Practitioner
GSF	Gold Standards Framework
H@H	Hospice at Home
HCA	Health Care Assistant
HCP	Health Care Professional
HF	Heart Failure
HFN	Heart Failure Nurse
L2	Lincolnshire End Evaluation
LCP	Liverpool Care Pathway
LRO	Lincolnshire Research Observatory
LSS	Lincolnshire Social Services
MC	Marie Curie
MCCC	Marie Curie Cancer Care
NCRI	National Cancer Research Institute
N/Home	Nursing Home
NHS	National Health Service
NICE	National Institute for Clinical Excellence
NVIVO	Computer aided qualitative data analysis software
NE	North east
NW	North west
OOH	Out of Hours
P (number)	Patient (number)
PCCC	Palliative Care Coordination Centre
PCT	Primary Care Trust
PGD	Patient Group Directive

PPC	Preferred Place of Care
RN	Registered Nurse
RRT	Rapid Response Team
RRT-V&A	Rapid Response Team Home Visit and Advice area
RRT-T	Rapid Response Team Telephone Advice area
SE	South east
SH	Stakeholder
SLA	Service Level Agreement
SPSS	Statistical Package for Social Sciences
Sr	Sister
Jn Sr	Junior sister
SN	Staff nurse
wte	Whole time equivalent

1. BACKGROUND TO THE EVALUATION

1.1 The Delivering Choice Programme in Lincolnshire

The Programme was initiated by Marie Curie Cancer Care in 2004 to:
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Marie Curie Cancer Care stated three key objectives for the Programme to achieve in Lincolnshire:

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2. Evaluate the economic impact to health care services of more patients receiving palliative care at home as compared to hospitals

3. Disseminate findings to other health and social care providers that leads to replication of solutions across the UK"

(MCCC Phase I report 2005)

Marie Curie Cancer Care have subsequently implemented the Programme across three areas of the UK: Lincolnshire, Tayside and Leeds. The Programme has been developed in the wake of the publication of comprehensive guidance for improving supportive and palliative care for adults with cancer and other life limiting illnesses (NICE 2004), which defines the essential elements of palliative care services. The White Paper '*Our Health, Our Care, Our Say: a new direction for community services*' refers to the three pilot sites of the Programme as central building blocks of the government's focus on improving choice and end of life care within the community (DH 2006). There is increasing recognition of the necessity of providing evaluative evidence with which to underpin new initiatives to expand palliative care provision, address inequities in access, and develop models of palliative care that are both responsive to individual preferences and make effective use of scarce resources (NCRI 2004). Marie Curie Cancer Care originally commissioned the University of Sheffield to conduct an independent evaluation of this Programme. In October 2006, this independent evaluation was transferred to Lancaster University. This report presents end evaluation data from Lincolnshire. This report is intended as a complement to the previous baseline evaluation report on Lincolnshire prepared in 2006.

1.2 Aims of the evaluation

The purpose of the evaluation undertaken by Lancaster University is to measure the impact of the Programme in meeting the first of the Programme objectives, stated above. The evaluation aims to

- Establish a baseline picture of the current state of services in three sites.
- Examine, according to the following criteria, the impact of the interventions introduced to improve services:
    - Whether the Programme interventions are patient focused
    - Whether the Programme interventions improved 24 hour care
    - Whether the Programme interventions serve local need
    - Whether the Programme interventions provide best possible care
    - Whether the Programme interventions have improved access to services
    - Whether the Programme interventions have improved choice.
    - Whether the Programme interventions have improved information.
    - Whether the Programme interventions have improved coordination between local services.

- Whether the Programme interventions have been successful or not in meeting consumers needs.

1.3 Conclusions drawn from the baseline evaluation findings in 2005

1. Lincolnshire has a higher than average population over the age of 65, distributed across a large rural county, with poor transport infrastructure. The current configuration of general and specialist palliative care services is such that is relatively difficult for people to access them and for professionals to provide services where they are most required.
2. We noted particular concentrations of deprivation, areas of low population density and higher than average numbers hours of informal care provided by family carers.
3. We highlighted an apparent change in population structure, with influxes of new migrants from Europe, who are likely to require new service configuration in the future.
4. We have observed considerable diversity in the provision of generalist and specialist palliative care, and significant shortfalls are predicted**.**
5. There appears to be a shared understanding of the current challenges and difficulties among respondents including: fragmentation and uneven distribution of services, poor co-ordination, some duplication and some need to access services ‘out of county’.
6. Primary care staff highlighted concerns about ‘out of hours’ provision and the impact on patient choice, and the possibility of offering care at home and death at home as realistic options.

7. Specialist nurses were aware of the full range of key issues but felt limited by issues to do with resources, co-ordination and referral options, which limited the choices they could offer to patients.
8. Patients with heart failure and their family carers appeared unclear about the range of services available and reported mixed experiences of hospital admissions. Most regarded primary care services positively but overall relied on family and friends to provide the majority of their care. It was clear that this was difficult for some carers.

2. CONTEXTUAL INFORMATION

Health and social care services in Lincolnshire have undergone a major restructuring process since the baseline evaluation of the Programme was undertaken in 2005. This section of the report will provide an overview of the changes across the county that may have had an influence on care provision during this time period. It will also include a brief overview of the Programme interventions.

2.1 East Midlands Ambulance Service (EMAS)

In 2006, the Lincolnshire Ambulance NHS Trust was amalgamated with the EMAS as a result of the reconfiguration of ambulance services. Some components of the reconfiguration are ongoing, with procedures and protocols undergoing harmonisation. Changes in the way community paramedics work have occurred. Lincolnshire is due to benefit from an additional 59 operational ambulance staff and the control centre is getting an extra 24 ambulance staff.

In rural areas of Lincolnshire such as Woodhall Spa, local volunteers raise funds to provide emergency care or rapid response services which are counted within the ambulance response times. The volunteer service is called ‘LIVES’ and the volunteers wear similar uniforms to the ambulance service and are trained to use equipment such as defibrillators.

2.2 Lincolnshire Social Services (LSS)

Lincolnshire Social Services were undergoing a reconfiguration of their services at the beginning of 2006, which has now been completed. Access to services remains driven by needs rather than by diagnosis, and funding for care services is rigorously assessed. During the baseline evaluation, LSS were actively implementing the single assessment process as the tool for identifying client’s needs and required services. LSS had a contracting system in place, for purchasing care provision. Care services are now purchased through a ‘brokerage system’ in place since April 2006.

2.3 Lincolnshire Primary Care Trust (PCT)

Lincolnshire PCT has undergone a series of reconfigurations since the baseline evaluation. The three previous PCTs have been amalgamated and, since April 2007, the PCT has been subdivided into eight administrative 'cluster' areas. The structural changes are almost complete and there has been a substantial change in staff.

> *…we've had a lot of change of new staff, and I think we've probably less in cancer and palliative care, but we've lost some organisational memory'* **(SH11)**

However, there is currently no uniformity of service provision with models of care predominantly still based on the old three PCT provision areas. Since 2005, there are three additional heart failure community matrons in post due to sponsorship by the British Heart Foundation. They are deployed by cluster area. The community Macmillan nurses also now work within each of the cluster areas. The coordination centre for palliative care in the south west of the county was subsumed into the PCCC and relocated to Lincoln.

2.4 United Lincolnshire Hospitals NHS Trust

The hospital underwent serious financial difficulties between the baseline and end evaluation periods with the replacement of the Chief Executive. During 2006 the hospital Macmillan nurses at Lincoln County Hospital were being asked to cover nurse shortages for a short period on the hospital wards. In 2007 the general Discharge Liaison Nurses (DLN) at Lincoln and Pilgrim Hospital were disbanded.

The Discharge and End of Life Team (DELTA) based at Lincoln County Hospital, formed prior to the Programme, has been relaunched and significant work undertaken to integrate the DCLN into the team. All team members (Macmillan nurses, occupational therapist, physiotherapist, DLN and DCLN) act as key workers depending on the patients' needs, and each can refer to the PCCC. A new hospital Macmillan nurse post commenced at Pilgrim Hospital in September 2006 and one post was filled in Grantham Hospital in January 2007. These changes in themselves have added to an increased focus on palliative and end of life care issues within each of the hospitals. During the period of the evaluation the palliative care beds based at Skegness Hospital were closed, but then reopened after public pressure.

2.5 Implementation of end of life care pathways

The majority of GP practices, 87 out of 103 practices, are reported as implementing the Gold Standards Framework (GSF), either registering with the central team or through QOF and the GMS contract. All GP practices are supposed to be using the Liverpool Care Pathway (LCP). The LCP is reported as being not well used for non-cancer patients being cared for in the community. Staff from 31 practices have attended GSF training and staff from 41 practices have attended LCP training.

The LCP has been rolled out onto all wards at Lincoln County and Louth Hospitals. This has been a slower process at Grantham and Pilgrim Hospitals, which is reportedly due in part to a lack of palliative care approach on the wards. A new general palliative care pathway is currently being developed within the United Lincolnshire Hospitals Trust.

2.6 Out of hours care

During the baseline evaluation, the south west of Lincolnshire had an overnight district nursing service. This has subsequently been decommissioned, leaving a gap in overnight provision. East Lindsey residents continue to have access to twilight district nurses and the out of hours services in Louth; the latter has some information on palliative care patients. Out of hours care within the west and north- west cluster areas remain well provided for with little change since the baseline evaluation. In the west and north-west cluster areas green cards for cancer patients and blue cards for heart failure patients are used to provide pre-emptive information for the out of hours call handlers and the patients are reportedly quickly triaged though the system.

2.7 Palliative care providers

St Barnabas Hospice continues to provide an array of services including inpatient care, day hospice care with associated therapies and hospice at home. These services can be accessed from the main hospice and the five day hospices. Since the baseline evaluation a new chief executive has come into post at Gifts Hospice. The hospice offers a range of services through the day hospice and provides hospice at home in the Grantham area as far as Stamford. Thorpe Hall in Peterborough, run by Sue Ryder Care, continues to accept a small number of palliative care patients from Lincolnshire. Louth and District Hospice have developed their services since 2005. During the baseline evaluation period Louth and District Hospice worked out of a ward within County Louth Hospital. A new home support service was commenced in February 2007. Butterfly Hospice Trust in Boston has developed its fund raising since 2005. Land has been purchased near to Pilgrim Hospital to build an inpatient unit initially with 8-10 beds.

2.8 Marie Curie Cancer Care Delivering Choice Programme

Since the baseline evaluation was undertaken the Programme interventions have been developed in collaboration with provider services.

2.8.1 Discharge Community Link Nurses (DCLN) - Lincoln and Boston

Two nurses were employed, one per site from January 2006 and began taking on a caseload in February 2006. The aim of the DCLN role has been to:

> *facilitate hospital discharge, provide advice and support to patient and carers while in hospital, provide a communication and information link between primary and secondary care providers and when necessary to accompany and settle patients at their home thus providing continuity of care (MCCC report June 2006)***.**

Referral criteria included:

- *Patients who meet the Near to Death Criteria*
- *Patients who meet the Continuing Care Criteria.*
- *Patients who have the DS 1500 completed*
- *Patients who are identified as palliative and/or End of Life Care patients*
- *Patients who have expressed a wish to be cared for and die at home*
- *Patients who are able to be supported at home (MCCC Phase II report September 2005).*

The nurses have established themselves and their roles in both hospital environments. They work regular ‘office’ hours.

2.8.2 Palliative Care Coordination Centre (PCCC)

The PCCC commenced in January 2006 with a stepped rollout beginning in Boston and the surrounding area covered by the RRT. In February the centre extended to cover the rest of East Lincolnshire, followed in March by west Lincolnshire and lastly in April the centre took on the coordination of south-west Lincolnshire services. The main function of the service is to book care. The centre operates five days per week, between 0900 and 1700 Monday to Friday. It has one manager and four coordinators. There has been some turnover of the coordinators since its commencement. The main referral criteria for the centre are:

- *18 or over*
- *Registered with a Lincolnshire GP*
- *A palliative care patient (MCCC Report June 2006).*

The PCCC receives telephone calls and referrals from a range of service providers, the majority of whom are district nurses for whom the service was tailored.

2.8.3 Rapid Response Team (RRT)

The RRT is based in Boston and covers central Boston and a 15-20 miles radius outside. The RRT team manager was employed in December 2005 and the remaining staff came into post in January 2006. The service began receiving calls from January 2006. It was originally based within the A&E department at Pilgrim Hospital, but subsequently moved to an alternative location within the hospital. The service accepts referrals from all palliative care patients regardless of diagnosis.

> *The primary aim of the Rapid Response Team is the provision of a community based crisis intervention nursing service which will compliment both the District Nursing Service and the Out of Hours service and be available during Twilight and Out of Hours periods (MCCC Report June 2006)*

The RRT team provide a service seven days per week over two time periods:

- 1500 – 2230hrs (Twilight shift)
- 2200 – 0700 hrs (Out of hours)

Each shift is covered by a registered nurse and a healthcare assistant. The role of the service is to*:*

- *Respond to palliative care crisis calls*
- *Provision of home care*
- *Palliative advice on the disease and treatment*
- *Assessment and advice on physical symptoms which are not responding to current management*
- *Assessment for referral to the GP service for medical advice/treatment*

(MCCC phase III report)

2.8.4 Wider support for patients and carers - carer support groups

The Carers support group provides carer support through a monthly luncheon club meeting facilitated by St Barnabas Hospice nursing staff and supported by volunteers. Information and emotional support is offered at these sessions. Attendance is also supported by volunteers who provide transport for carers or provide care to the patient while the carer is away. The support group operates from St Barnabas Hospice Day Therapy Unit in Gainsborough where the first group met in June 2006 and expanded to the St Barnabas Hospice Day Therapy Unit in Lincoln at the beginning of February 2007. Future areas for expansion are St Barnabas Day Therapy Units in Spalding, Sutton-on-Sea and Boston. *(MCCC Phase III report).*

3. DOCUMENTARY AND EPIDEMIOLOGICAL DATA ANALYSIS

The Lincolnshire population is currently increasing at a rate greater than the national and regional average. In 2006, the death rate in Lincolnshire exceeded the birth rate and the conclusion drawn by the Lincolnshire Research Observatory is that the growth in population is due to inward migration (LRO 2007).

The current population of residents registered with GPs within the eight PCT clusters is 720,451 (see Table 1). This is an increase of 9352 registrations from the 711,099 registered on the 1 January 2006.

Table 1 - Lincolnshire PCT GP population data 2007

Cluster population	Males	Females	Total
Boston	37,696	38,539	76,235
East Lindsey	42,186	43,630	85,817
Lincoln South	53,050	55,870	108,920
Mid Kesteven	61,562	63,561	125,123
North West Lincs	52,133	53,400	105,533
Skegness & Coast	35,099	35,611	70,711
South Holland	34,294	35,232	69,526
Welland	38,540	40,046	78,586
Grand Total	354,560	365,889	720,451

These data need to be considered in relation to the NHS mortality figures for 1 April 2006 - 31 March 2007 presented in the following section.

3.1 Findings from the analysis of the NHS mortality data

3.1.1 Introduction

To evaluate the effectiveness of the Programme in meeting its stated objectives, analysis of mortality data for 1 April 2006 – 31 March 2007 is required. It must be noted that the Programme initiatives were established during the spring and early summer months of

2006 and therefore the numbers of patients accessing the services would have been increasing as the services became embedded during this time. Greatest access to the services is believed to occur from September 2006 onwards. The figures in relation to the referral and service provision of the Programme services presented throughout the evaluation are likely to be lower than figures taken from a later time period.

The following data indicated the population mortality for cancer and heart failure, and will be used to base the remaining quantitative component of the evaluation upon.

Table 2 - Total number of deaths for Lincolnshire residents over 18 years old from 1 April 2006 – 31 March 2007

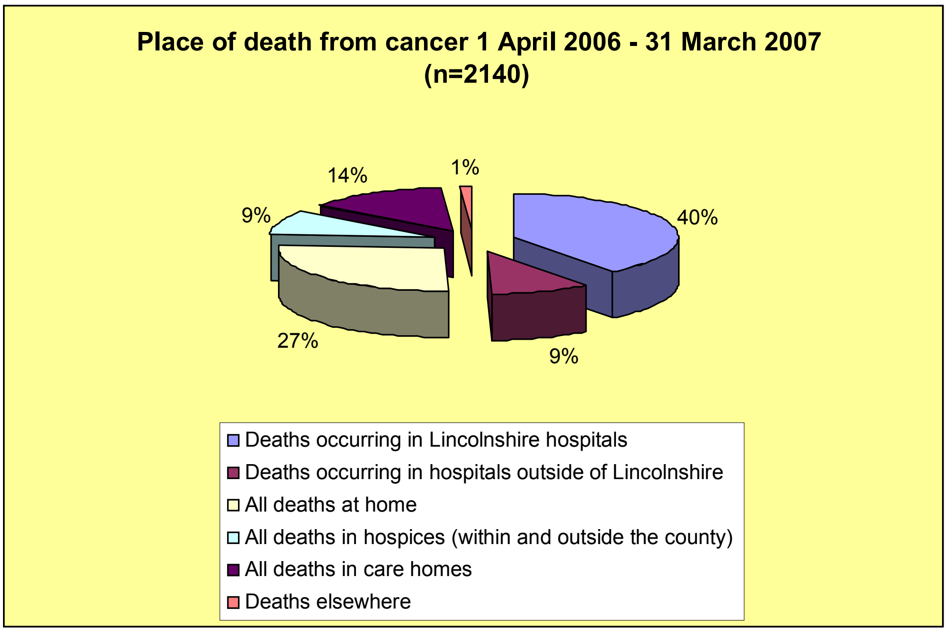
Data April 06 – March 07	**Total number of deaths (Percentage %)**
All deaths of Lincolnshire residents	7649 (100%)
All deaths occurring in hospital (within and outside the county)	4293 (56%)
Deaths occurring in Lincolnshire hospitals only	3455 (45%)
Deaths occurring in hospitals outside of Lincolnshire	843 (11%)
All deaths at home	1440 (19%)
All deaths in hospices (within and outside the county)	198 (3%)
All deaths in care homes	1543 (20%)
Deaths elsewhere	174 (2%)

Table 2 shows that 7649 Lincolnshire residents over the age of 18 years old died from a range of different conditions during this period. For 56% of Lincolnshire residents' death occurs in hospital whilst just 19% of deaths occur at home. Table 2 also shows that for 49% of residents who died of cancer (n= 1056) and 66% who died from heart failure (n= 302), death occurs in a hospital situated either within or outside of the Lincolnshire county boundaries. Deaths occurring outside of the county boundaries include deaths at major treatment centres for cancer and cardiovascular diseases in Nottingham and Leicester. Some deaths of residents living in the very north or south of the county occurred across the county boundary in Kings Lynn and Grimsby.

3.1.2 Location of deaths from cancer and heart failure

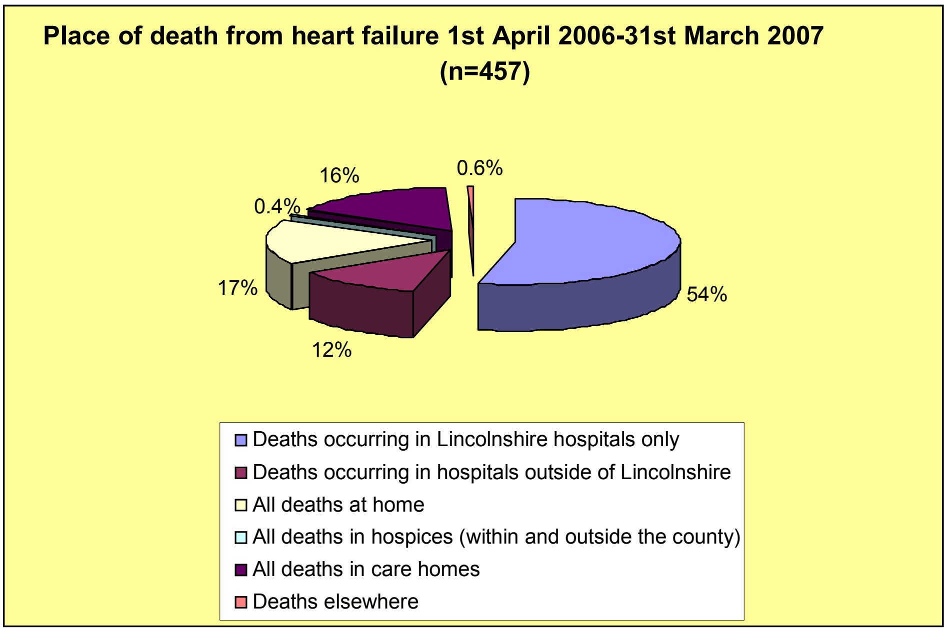
Analysis of the NHS data, as shown in Figure 1, indicates that the majority of deaths from cancer occurred in Lincolnshire hospitals (n=852, 40%), followed by deaths at home (n=575, 20%), then by deaths in other hospitals and care homes.

Figure 1 – Place of death from cancer NHS mortality data 1 April 2006 – 31 March 2007



In depth analysis of the mortality data for cardiovascular disease which identified recorded heart failure deaths (see Figure 2) reveals that the majority of deaths from heart failure occurred in Lincolnshire Hospitals (n=245, 54%), followed by deaths at home (n=76, 17%) and deaths in care homes (n= 74, 16%).

Figure 2 – Place of death from heart failure NHS mortality data April 2006 - March 2007



It is clear from Table 3 that there are different patterns in place of death between disease groups. Countywide, fewer cancer patients died in hospital than heart failure patients and, conversely, more cancer patients died at home than heart failure patients. Proportionally more heart failure patients died in a care home or hospital outside of the county and two heart failure patients died in a hospice. Identifying whether this difference in place of death could be attributed to access to the Programme interventions, requires further examination.

Table 3 – Place of death for patients with cancer and heart failure 1 April 2006 – 31 March 2007

Data April 06 – March 07	Total number of deaths from cancer	Total number from deaths from heart failure
All deaths of Lincolnshire residents	2140 (100%)	457 (100%)
All deaths occurring in hospital (within and outside the county)	1056 (49%)	302 (66%)
Deaths occurring in Lincolnshire hospitals only	852 (40%)	245 (54%)
Deaths occurring in hospitals outside of Lincolnshire	204 (9%)	57 (12%)
All deaths at home	575 (27%)	76 (17%)
All deaths in hospices (within and outside the county)	189 (9%)	2 (0.4%)
All deaths in care homes	296 (14%)	74 (16%)
Deaths elsewhere	24 (1%)	3 (0.6%)

4. COUNTYWIDE EVALUATION OF PALLIATIVE CARE PROVISION

4.1 Introduction

The baseline evaluation undertaken across Lincolnshire in 2005 identified a range of issues related to palliative care provision across the county. Six key themes were consistent across the stakeholder evaluation, which included the GP and DN survey, interviews with service providers and focus groups with specialist nurses.

- Coordination
- Communication
- Resources
- Out of hours care
- Knowledge and skills
- Fragmentation and gaps in services.

This chapter will compare findings in relation to the six themes highlighted from the baseline evaluation with those obtained during the end evaluation. During the baseline evaluation we collected interview data from four heart failure patients, but no carers or bereaved carers. The perspective of these patients indicated a lack of information and access to services. Tables 4 and 5 compare the GP and DN responses to two key questions from the 2005 and 2007 survey.

Table 4 – GPs and district nurses perceived top three priorities to improve the standard of palliative care provision in their practice

Responses of district nurses

	Factor 1	Factor 2	Factor 3
2005	Coordination	Resources	Communication
2007	Communication and Coordination	OOH and continuity	Resources

Response of GPs

	Factor 1	Factor 2	Factor 3
2005	Communication	Coordination	Resources
2007	Communication and Coordination	Access to Macmillan nurses and hospice care	Education and skills training

Table 5 – GPs and district nurses perceptions of factors that prevent them from delivering good care to their patients with palliative care needs

	Factor 1	**Factor 2**	**Factor 3**
2005 combined GP and DN	Lack of resources	Lack of out of hours provision	Poor coordination and fragmentation
2007 GP	Out of hours care	Communication and coordination	Access to Macmillan nurses and hospice care
2007 DN	Lack of Resources including staff	Poor out of hours services Difficulties accessing medication	Lack of knowledge/interest by GP

4.2 Coordination

Coordination was considered to have improved since 2005. Poor co-ordination was highlighted by all stakeholder groups in the baseline evaluation as detrimental to the provision of palliative and end of life care. This was highlighted by difficulties in the coordination of care provision at home and inadequate information about discharges from the acute services. Thus creating overlaps in services being provided by one or more organisations to patients in their homes or in contrast to gaps where no services were arranged for patients who required them.

There were much fewer comments about poor coordination in the 2007 GP and DN surveys, and in the interviews with stakeholders, nurse specialist focus groups or in the interviews with patients, carers and bereaved carers. Some DNs commented directly about the benefits of the palliative care coordination centre, but others identified lack of resources and poor out of hours care and lack of knowledge as preventing good palliative care provision and reducing patient choice. The loss of the south- west Lincolnshire coordination centre in 2006 was viewed as detrimental to care provision in the area by reducing the flexibility of moving carers and filling potential gaps in services. Since 2005 changes in focus away from coordination as a predominant concern from the participants, would suggest that this is no longer a key issue in Lincolnshire indicating a countywide improvement.

4.3 Communication and teamwork

Communication and teamwork – in 2005 intersector and interagency communication was perceived to be poor and by 2007, there was evidence of improvement.
Communication between the acute care sector and primary care was deemed poor on the whole, during the baseline evaluation, with inadequate information being provided to district nurses, GPs and specialist nurses by the acute services about patients. Communication was noted to be poor at times between primary care team members, particularly between some DNs and GPs and between health professionals and their patients. In the 2007 end evaluation survey, only the GPs identified poor communication as a contributing factor in preventing the provision of good palliative care. Instead, good communication and team working were seen to contribute to good care:

> *'Good teamworking with district nurses – good communication. The district nursing team having the skills to deal with situations and the knowledge of calling on resources/agencies'.* **(GP20 W)**

Communication remained in the top three priorities for improving palliative care countywide by both GPs and DNs. Lack of reference to poor communication by DNs might indicate an improvement across the county. However there was a perception by other key stakeholders and specialist nurses that important direct communication between service providers about patients had been lost since the baseline evaluation. It was felt that the palliative care coordination centre had detrimentally affected the level of direct communication about patients and their personal situations.

One of the areas of difficulty was how different organisations relate to each other within the PCT. Duplication in note keeping within patients' homes concerned stakeholders and specialist nurses in terms of regulation and in terms of communicating information between services. This is an ongoing concern from the baseline evaluation.

> *' our staff would go into somebody's house, there would be the notes from the district nurse, there would be the notes from, say, an agency, there would be our notes, and you've got all these different sets of notes. And there was a requirement that everybody has their own assessment and everybody has their own notes and writes them up. And I think this is also where the medication fits in as well, because actually what it should be is that the district nurse is classed as the key worker, but organisations and the legislation, though in light of the Commission for Social Care Inspection, isn't set up to deal with this. And they have a very, very blinkered approach; they don't look at the big picture.* **(SH6a)**

Little information was available from the baseline evaluation about communication from the perspectives of patients, carers and bereaved carers. The end evaluation interviews identified several experiences of good communication. When communication and coordination were working well it was perceived as enhancing care:

> *'I'm more than impressed in the way that the link between the district nurses and the things that social services do, because we're talking about Thursday the nurse will come and she'll see something, she'll say, "Oh, I'll get in touch with social services." I can guarantee the next day at the latest, isn't it, someone says, "Oh, your nurse has said you want this doing, can I come over and have a look?" and that's it.'* **(Family carer H3)**

Family carers reported needing good communication in advance about which care workers were coming to their homes. They also wanted to know that the person coming knew about their particular circumstances:

> *'They come from all over the place late at night, don't they - you don't know where they're coming from. And I would be worried as well because they wouldn't know any of the circumstances. They wouldn't know his history at all. And, with his history, then I'm afraid people really have got to know.'*
>
> **(L2 C2 H)**

Some family carers found that while their relative was still on the hospital wards, it was difficult to get information or to find someone with whom they could talk to meaningfully. Once the process of discharge started, communication was much better. One carer talked of being kept in the dark over a long period until the Discharge Community Link Nurses became involved:

> *'[DCLN] was helpful - you could speak to her, you could talk to her . . . basically how he was and what the actual prognosis was, and what the outcome was because you're kept in the dark for so long.'* **(L2 BC4 H)**

The availability of information booklets were perceived to be invaluable to help coping:

> *'They've always laughed because [daughter] read every page and she knew every word . . . we looked at the book and said, well, this is what we've got to do, we phoned Rapid Response.*' **(L2 BC3a3b C)**

What family carers seemed to want were both reliable systems in place and people with empathy who could be flexible in varying situations. Good communication and coordination were regarded as key to achieving this.

Since the baseline, there appears to be improved communication between acute services and community practitioners and improved communication about arranging care. However, this is possibly at the loss of some communication between specialist service providers:

> *I understand why the Centre's there, and I understand it's got a place, and I acknowledge that, and I think the idea behind it is good, I don't understand why two clinicians can't talk together (Stakeholder 7a).*

4.4 Resources

In 2005, lack of community staff and lack of care workers were perceived to be main resource problems, however, by 2007 this changed to lack of weekend services and poorly trained agency staff. Inadequate resources were perceived to impinge on the provision of good palliative care in 2005. These resources included not having enough staff to provide care in the community and particularly for DNs and GPs not having enough time to spend with palliative care patients. Lack of resources also included access to equipment and home care workers, particularly in rural areas and near the borders of Lincolnshire. The baseline findings also identified that there was an unequal distribution of care resources across the county. DNs and GPs ranked improving access to resources as second and third priorities to improve palliative care.

At the end evaluation in 2007, DNs and GPs continued to regard adequate staff and better transport as important for providing good palliative care despite the investment in Lincolnshire by the Programme access to adequate resources. DNs and family carers highlighted the lack of hospice at home service over the weekends as preventing the provision of good palliative care:

> *'The Hospice at Home team were unable to cover seven days per week, so care was fragmented. Agency staff sometimes were inexperienced and short of time for the care they needed to give because of firms reduced staffing levels at weekends'*
> **(DN30 no location stated).**

4.5 Out of hours care

There has been an improvement in out of hours services in the Boston and Spalding areas of East Lincolnshire due to the presence of the RRT since 2005. Lack of out of hours care was a concern raised by stakeholders, primary care practitioners and specialist nurses in East Lincolnshire during the baseline evaluation. In the end evaluation, the same issue was also identified by specialist nurses, GPs and DNs as preventing the delivery of good palliative care. The need to improve access to out of hours care was ranked in the top three priorities of GPs and DNs at the end evaluation. This is a change in priorities from the baseline. Distribution of out of hours services remains unequal across the county, with the west and north west clusters and the Boston areas having better access to out of hours support than the north east and south west of the county.

> *'OOH failed to attend when patient terminal and in pain. Was no service midnight – hand over at 8.00am'. (***GP1 SW)**

> *'No seamless care for palliative care patients in the out of hours. Emergency care practitioners who have no experience of palliative care needs'.* **(GP26 E)**

The provision of care in the home at night was often reported as invaluable by family carers and bereaved family carers in enabling patients to stay and eventually die home. It is likely that improvements in coordination of night care has contributed to this:

> *'I had somebody to stay at night because [wife] died so quick at the end, well, nearly at the end - she went downhill very quick. And we had an agency nurse two nights I think, or three, it's a bit hazy to me now. But then we had a Macmillan nurse. I think she came one or two nights. And the last night we had a Marie Curie and that was the only time we had a Marie Curie. And they were all absolutely marvellous.'* **(Bereaved family carer C1)**

> *'The night service, particularly those first few nights when we were so panicky and upset, and what if anything happened in the night, what on earth will we do, has been, well I think, as far as I'm concerned, probably the best of the services, because we do need our sleep, and we would not have been getting it. I mean even with the sitters at night, to start with it was very difficult, you're still kind of listening out for every little sound or call. But I think now, certainly I, and well dad will tell you, but I mean I do now sleep better knowing that there's somebody there.'* **(Family carer C5)**

District nurses and bereaved carers commented that out of hours care workers sometimes have no palliative care training. Some of the care provided by agencies was perceived to be poor and workers were not sympathetic to patients and carers concerns and needs.

> '*Yes, but one walked out, one of these agencies, walked off at half past three one morning. The nurses and everybody, well they put in terrible complaints, so did the doctor… They haven't got the people, these agencies. The girl came, she was fair enough and I supplied everything for her. She had this chair out there which you pull down like a bed. And I came in here to sleep and the door went and I could hear, I'm going now, and I thought, she left me at half past three in the morning*

> *with nobody. That's not on. That was the only thing I could complain about, was the agencies.'* **(Bereaved family carer C1)**

Family carers living in areas not covered by the Rapid Response Team were reluctant to call the emergency services because they believed that the emergency services were unfamiliar with their dying relatives' circumstances. They feared that emergency services would transfer their relative to hospital, often in contrast to the wishes of the dying person and their carer. However, there were instances where carers had called the emergency services, and they found them *'Very reassuring and very good'* **(Bereaved family carer C8).**

It is apparent that despite geographical improvements in out of hours care in the Boston and Spalding areas of East Lincolnshire through the implementation of the Programme, the county-wide view reveals a mixed picture with areas of good and poor access to out of hours services. The increased focus on out of hours care suggests there is a perception that this area of care needs to improve. Direct evaluation of the RRT, which provides out of hours care in the Boston and Spalding areas, is reported in Chapter 5.

4.6 Knowledge and skills

Improving palliative care knowledge and skills, particularly symptom control and anticipatory prescribing, continue to be perceived as important in 2007. Inadequate knowledge and skills were identified as important factors preventing the delivering of good palliative care across the county in 2005. Further education in palliative care and in symptom control was felt to be important by all stakeholder groups, particularly GPs and DNs who welcomed the opportunity to have more training in the baseline evaluation. Data from the end evaluation in 2007 indicates that GPs still rank the need to increase skills and symptom control training in their top three priorities to improve standards of palliative care. DNs also rank a lack of skills and knowledge as preventing good palliative care across the county.

Lack of anticipatory prescribing and access to medication were ranked by DNs as important factors that prevent the delivery of good palliative care in the 2007.

> *'Obtaining controlled drugs, especially at weekends. Work in a rural setting - sometimes families have to travel miles to get medication'.* **(DN12 NW)**

Seven DNs attributed a lack of interest or knowledge in palliative care to their GP colleagues at the baseline evaluation.

4.7 Fragmentation of services

Fragmentation of service provision and continuity of care are perceived to have worsened since the baseline evaluation. In 2005 concerns were raised by the different stakeholder groups and related issues were raised by patients about the fragmentation of services and the use of numerous agencies to provide palliative and end of life care. Patients were confused about what support was available to them and how this could be accessed. For the stakeholder groups, perceived fragmentation led to gaps in provision undermining continuity of care and sometimes duplication. Fragmentation was worse for those working near the Lincolnshire border areas. In 2007 fragmentation remains a concern for all stakeholder groups. It is perceived by specialist nurse that the Programme has contributed to the fragmentation of services, creating pockets of good practice but excluding many non- cancer patients.

> *'I just think it's causing a fragmentation of inequity almost to non-palliative care patients' (***Macmillan nurse** 7*).*

Out of hours care and the use of care agencies are also currently perceived by GPs and DNs to add to the loss of continuity of care and increase fragmentation. It would appear that concerns over fragmentation have remained consistent since the baseline.

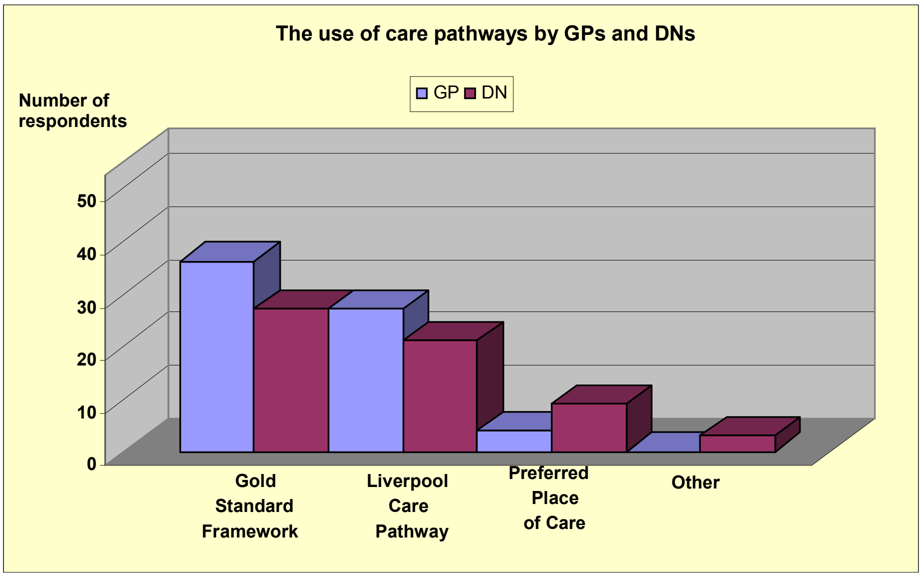
4.8 Care pathways

Care pathways have increased in use within the acute and community sectors since 2005. The baseline evaluation explored the use of care pathways in facilitating palliative care in hospital and community settings. At the time there were mixed views about the use of care pathways by stakeholders, with care pathways being seen as both a help and a hindrance in the provision of care. District nurses appeared to be more orientated to the use of pathways than GPs (see Figure 3), who at times made negative comments about their use. There were also regional differences in their utilisation, with West Lincolnshire appearing to use these pathways more than other areas.

Evidence from the end evaluation indicates that care pathways have become integrated within the work of most GP practices across Lincolnshire. The LCP has been rolled out onto most wards across ULHT. In 2007 GPs and DNs identified care pathways as a positive contribution to providing good palliative care. There were few negative comments.

> *'The Gold Standard Framework is successful in providing good quality palliative care, especially with the prescribing of anticipatory drugs and the LCP'.* **(GP10 NW)**

Figure 3 – The use of care pathways by GPs and DNs in 2007



4.9 Preferred place of care

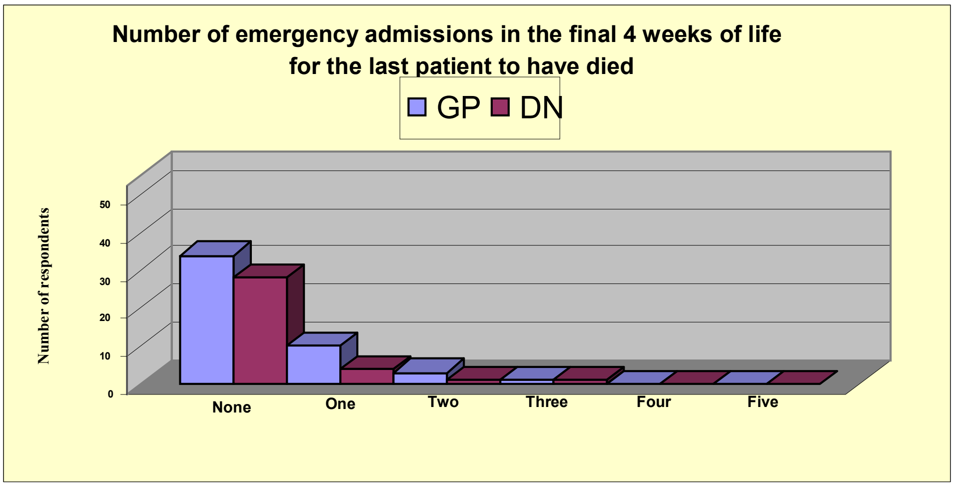
Choice for the preferred place of care was achievable for those patients receiving the Programme initiatives, but has probably changed little since the baseline evaluation for the remaining patients. One of the major thrusts of the Programme is to facilitate choice in place of care and death and equip patients, carers and professionals with the necessary information to make this possible. For some, this has been successful:

> *Oh absolutely. I mean I think it's the subjective elements of the Delivering Choice Programme that undoubtedly are having a great effect as well because Lincolnshire was always quite reasonable really in the amount of people that were being managed at home or at least out of hospital. I think, whenever we did a little bit of analysis, there were about 60% of patients were dying within the Acute Trust and I think we're starting to materially affect that to the extent that, I mean I suppose also one of the things that has to be said is it's almost like an urban myth, 80% of patients prefer to die at home, 20% actually only do, but the Delivering Choice Programme actually did validate that that 80% would prefer to die at home and only 20% were actually managing to achieve it, I think, nationally ……..so, I mean I don't have the up to date figures but I think that we have made quite a material*

impact on the amount of patients that are being managed now better at home. **(Stakeholder 3)**

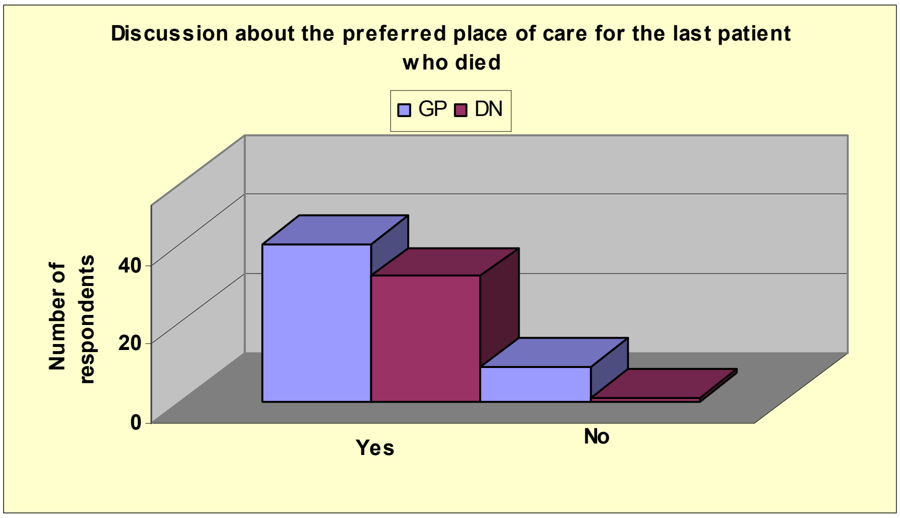
Specialist nurses perceived that choice was achievable for those patients receiving the Programme initiatives, but they thought it has probably changed little since the baseline evaluation for the remaining patients. None of the patients interviewed recalled being directly asked about where their preferred place of care was. However, this was something that four of the six patients had considered, with home being their preferred place of care. Questions added to the 2007 GP and DN survey sought to identify whether patients across the county were being asked about their preferred place of care and whether this was being achieved. The GPs and DNs were asked whether their last palliative care patient was admitted as an emergency to hospital in the last four weeks of life. Figure 4 shows the majority of respondents reported that their patients did not get admitted into hospital during this time however a small number of patients had one or more admissions.

Figure 4 – Emergency admissions in final four weeks of life in 2007



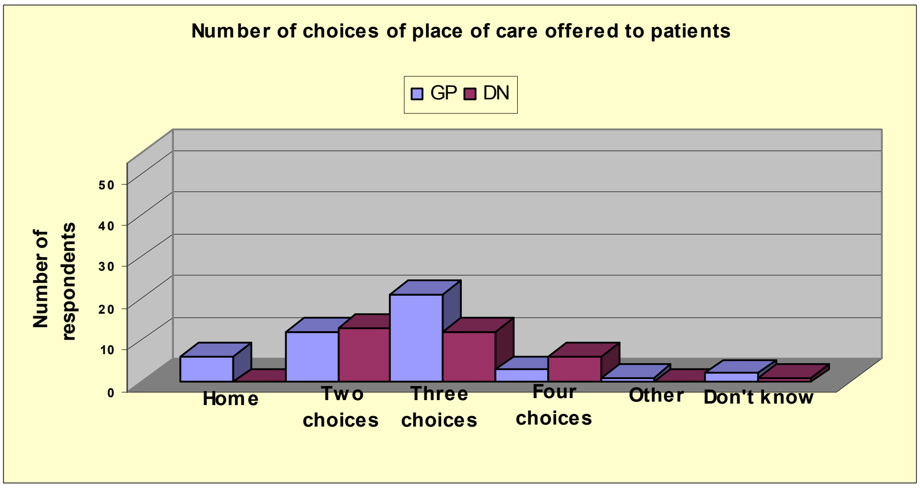
The majority of respondents stated that they had discussed with the patient their preferred place of care (Figure 5).

Figure 5 – Comparison of GPs and DNs reported discussion of preferred place of care with their last patient who had died



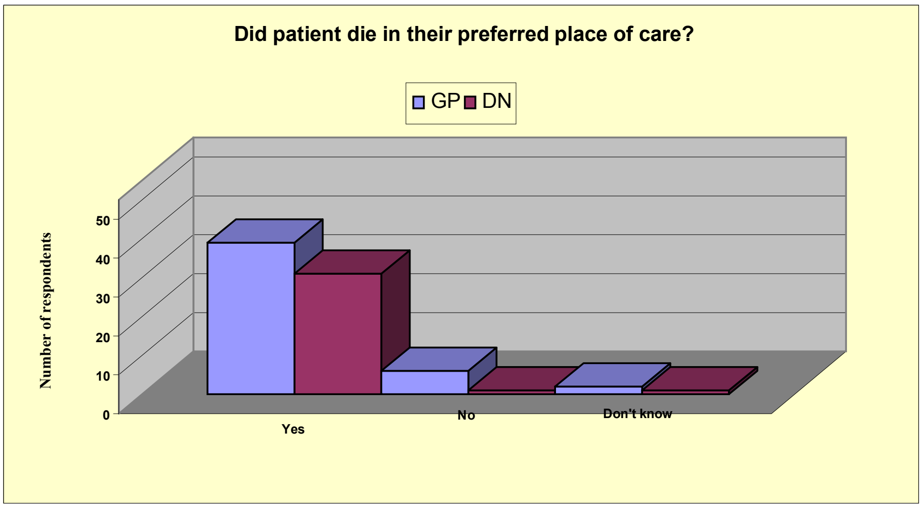
A range of choices was being offered to patients at the end of life, including home, care home, hospice, hospital or other. The practitioners were asked to list how many choices were offered, as shown in Figure 6.

Figure 6 – Number of choices offered



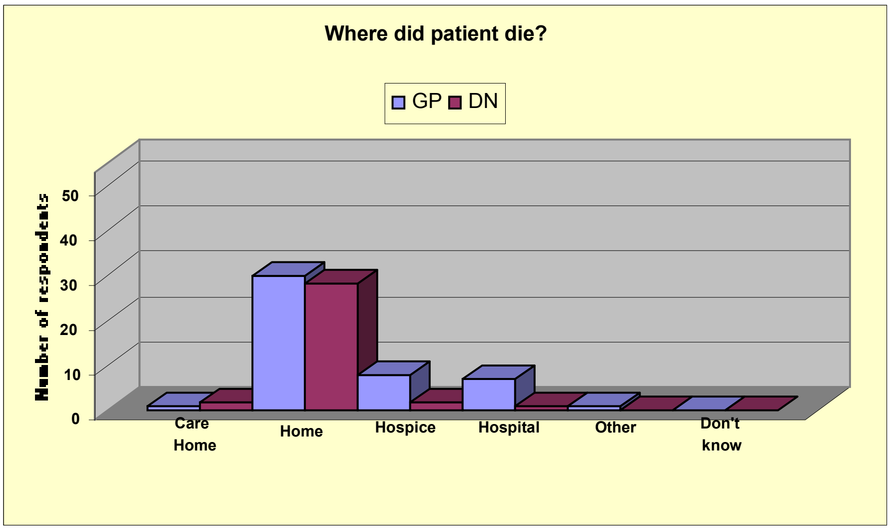
When asked if the patient died in their place of their choice, most did (see Figure 7).

Figure 7 – Deaths in preferred place of care



When asked where their patient had died, the most common response was ‘home’ (see Figure 8).

Figure 8 – Actual place of death



It is apparent from accounts of GPs and DNs that the patients are being offered a range of choices about where they wish to be cared for and many are achieving their choices and also dying at home.

4.10 Transport

In 2007, ambulance transport services for patients at the end of life were reported as not meeting the needs for safe, skilled and rapid transfers home or across county borders to neighbouring hospice services. Transport has emerged as a new concern from stakeholder interviews, focus groups and during interviews with patients, carers and bereaved carers. From the stakeholders' perspective, lack of flexibility in arranging transport for patients at the end of life near a weekend is preventing rapid transfers home:

> *'I heard something a couple of weeks ago where somebody hadn't got home, and it felt like the weekend had been a bit of a weak spot, that had it been a normal working day then probably things would have happened…if things haven't happened by Friday afternoon it's obviously Monday before and things can change very rapidly for some people can't they?* **(Stakeholder 10)**

Problems transferring patients across county borders were specifically highlighted by GPs. For example, a GP stated that to transfer a terminally ill patient from the south west of the county to Thorpe Hall Hospice in Cambridgeshire required the patient to be delivered by Ambulance to the A&E department of Peterborough Hospital first, since the local ambulance service would not take the patient to the hospice.

Transport for patients with syringe drivers is problematic and one participant described how they felt obliged to use subversive tactics to resolve the dilemma:

> *'We also had a bit of a problem with syringe drivers. You have to have - is it a paramedic or something if you have a syringe driver, going on something stupid like that. We've had to take batteries out of syringe drivers until they've got to the other end. We have hidden them. But how stupid, you know, from here to the hospice…But we've had to have district nurses at the other end waiting to put the battery in.'* **(Stakeholder 1)**

Carers and bereaved carers reported difficulties with transport, particularly the lack of skills needed in transferring ill or dying patients' home. These skills are perhaps somewhat different from skills needed in other transport situations. One carer described how the transfer home was both unsafe and not patient-focussed:

> *'She [wife] was extremely distressed – what's the words – disorientated, she was blue, they'd run out of oxygen on the way home, and the guy in the back couldn't reconnect it properly. She panicked. She was just a wreck, a complete wreck [. . .] it took her a long, long time to get over just that transfer. That's another reason she doesn't want to go back to hospital, she doesn't want to have to do the journey. [. . .] They were not caring at all, they just dumped her in, asked me and [daughter] to lift her into bed, and there you are then, cheerio, off they went, oh is it that, and she was terrible.'* **(Family carer C5a)**

Where volunteer drivers are used the quality of transport in moving patients and carers was often reported as excellent:

> *'Usually, it's the same driver that picks [husband] up, usually, just depends, but I mean our usual driver was on holiday, but they're all volunteer drivers - wonderful people.'* **(Family carer C2)**

The end evaluation has highlighted current concerns about the inflexibility of patient transport and about the lack of skills of ambulance crews countywide in caring for terminally ill patients being transferred between hospital and home.

4.11 Summary of findings in relation to the countywide evaluation

- Coordination was considered to have improved since 2005.
- Communication and teamwork – in 2005 intersector and interagency communication was perceived to be poor and by 2007, there was evidence of improvement.
- In 2005 lack of community staff and lack of care workers were perceived to be main resource problems, however, by 2007 this changed to lack of weekend services and poorly trained agency staff
- There has been an improvement in out of hours services in the Boston and Spalding areas of East Lincolnshire since 2005 due to the presence of the RRT, however, there has been a loss of our of hours nursing care in South West of the county since 2005.

- Good out of hours care remains unequally distributed across the county.
- Improving palliative care knowledge and skills, particularly symptom control and anticipatory prescribing, continue to be perceived as important in 2007.
- Fragmentation of service provision and continuity of care are perceived to have worsened since 2005
- The use of care pathways has increased within the acute and community sectors since 2005.
- For patients receiving the Programme, initiatives facilitating their preferred place of care was believed to be achievable, but for the remaining patients it has probably changed little since the baseline evaluation.
- In 2007, a new concern was identified that ambulance transport services for patients at the end of life are not meeting the needs for safe, skilled and rapid transfers home or across county borders to neighbouring hospice services.

5. RAPID RESPONSE TEAM

5.1 Introduction

There was clear evidence from the baseline evaluation in 2006 that East Lincolnshire had very poor out of hours provision compounded by its large rural landscape. There was no night time nursing service, unlike South and West Lincolnshire, and long delays were experienced across the whole area when calling the out of hours GP service. This was perceived to impact on patient choice and the possibilities of maintaining care at home as a realistic option.

5.2 Experiences and perceptions of patients

In 2007, patients in the RRT area were aware of the input the team had had on their care at home. For two of the three patients who had the RRT attend, their memory of the number of times the RRT had called conflicted with that of their spouse. This was because their spouse had called the team out when the patient and carer were in crisis:

> *'It was, if you like, a quietening down operation. That's not really the word I'm looking for, but I can't think of anything else, but just to give us reassurance that everything was okay. I've got to be quite honest with you, and I think this is true of the people I've spoken to in the hospice, that when you've got a combination of age and illness, the one thing that you need is support. You don't want medical attention, you don't want doctors giving you drugs, it's just that you want someone to hold your hand, be it only mentally, you don't have to ..., but you need to know there is someone there who's caring and will help you.* **(Patient with heart failure)**

One patient had the RRT regularly visit or make telephone calls for a period of time after she stopped having regular night care:

> *I think for about, I suppose two or three weeks, they used to ring me at night and say, 'Do you want us to come tonight?' and I thought well, you know, it's not going to go on forever so I got to saying, 'Well I'll be okay tonight' and I got used to being on my own…There was a nice sort of feeling that I could have someone if I wanted to.*

> ***And did they ever come out to see you?***
> *…they used to say, 'What time do you want to go to bed?' and I always said, 'Midnight' and they used to say, 'Okay we'll be there at midnight.' And they used to be here at midnight. All the way from Boston they used to come just to put my leg in bed. They were all very nice, you know. Usually there'd be two of them.*
> **(Patient with heart failure)**

Other reasons for RRT visits included: to give pain control injections over night, to change blocked catheters, and help clear up when a patient became incontinent. For the patients outside of the RRT area, their first place of help is the out of hours services, although none of the patients had needed to contact them.

The precarious nature of end stage heart failure was clear listening to a patient who lived alone and was reliant on the carer workers identifying changes in her condition and accessing help. Another heart failure patient, who had had several near death episodes in recent months and had had RRT input on several occasions to help both him and his wife, also illustrated these difficult experiences.

5.3 Experiences and perceptions of family carers

The RRT was reported to be of great value to many carers who were interviewed. According to them, it made a very significant difference to their ability to care at night and at weekends, providing reassurance on the end of the telephone, as well as symptom control and hands on care:

> *'It's just brilliant, it's just so good, because they're so calming. And they will say, because they know the situation. All right, they've got a computer in front of them they can look it up, but they do just that. And they calm you down and just relax you a bit really to be able to talk to them.'* **(Family carer H3)**

> *'They were just helping me to literally clean [patient] up each night because he was obviously incontinent at that stage and it was very difficult to try and keep everything clean.'* **(Bereaved family carer C5)**

> *'3a: dad was not well and I didn't quite know what to do. So I rang, the district nurses rang them and they came out, two of them.'*
>
> ***So the district nurses rang the Rapid Response for you?***
>
> *'3a: Yes. Because they all go off duty you see. And Rapid Response come on at three o'clock so we'd always get somebody, and two of them came out that afternoon. And, if you remember, they brought that morphine for your dad, didn't they?... The little sachets at first didn't they, little bottles, little tiny bottles. But then [husband] had to go on, he had two syringe drivers. But there was always somebody there who we could phone because we had to phone them several times didn't we - are we doing the right thing? Well, do you want us to come and we said well, we'll see if we can cope, then we'll ring you if we do need you, you know. But they were so good, they really were.'* **(Bereaved family carer C3a)**
>
> *'I'd like Rapid Response to be full time, 24 hours a day, seven days a week because it's a fantastic service. They are there at the end of a phone. If nothing else, they can keep you calm and they'll say to you well we're at a job now but we'll be there as soon as we can and if it's more important, more urgent, they sort things out. They keep somebody talking to you to calm you down. [. . .] Their manner, there wasn't one nurse that you could have said a bad word against them. They were just superb from the moment they walked in. Well even before that because they were on the phone.'* **(Bereaved family carer C5)**

One carer reported being advised by the RRT to phone for an ambulance after her husband had had a fall:

> *'So I rung my son who lives the other side of town and between, me and C got him up with a big, big struggle before my son arrived and I rung the Rapid Response and they said I had to get an ambulance to get him into hospital. Well that was the bogie word wasn't it, we'd promised him he wouldn't go to hospital. So we thought*

> *about it and my son said, "We've promised him, mum.'* **(Bereaved family carer C4)**

Two carers were interviewed who lived in the RRT telephone only advice areas, but they had not heard about the RRT. Carers who lived nearer to Lincoln were not able to receive any support from the service.

When asked what the carers would have done without the RRT, in areas where they were available, the following quote expressed what both the carers and bereaved carers commonly said:

> *'3b: I think I'd have muddled through till the morning. Unless it was an emergency, then I'd have, you see I wouldn't have wanted to phone an ambulance because I know for a fact they just, he'd be in hospital. I've nothing against hospitals but, do you know what I mean, they'd just whip him in hospital and that I didn't want because all we wanted was, I knew if the situation we phoned them was whether he could give him certain medication so it wasn't life threatening. I knew he wasn't, well if you see what I mean - it was only just peace of mind really.'*
>
> *'3a: And that's worth a lot, you know. To know someone's at the end of that phone. I don't know. I suppose had he'd have gone we'd have had to phone a doctor but we wouldn't have got our own doctor probably. I don't know. You see every time the district nurses went in the afternoon and the Hospice went they'd say, now don't forget to ring Rapid Response. Every time, didn't they?'* **(Bereaved family carers C3a and 3b)**

5.4 Perceptions and experiences of specialist nurses

There was overwhelming appreciation of the RRT by the specialist nurses who have had patients cared for by the team. For patients within the RRT area where previously there had been no out of hours nursing provision, the RRT has made a significant difference.

> *'Marvellous, yes I do get a lot of feedback from patients, constantly, constantly, who've had them go out to them and just how impressed they've been, and I think*

> *people almost sort of get into the mind set of just not expecting anything, you know, at that time of night, and to have such a good supportive response has made them feel sort of so much better about things…you know the fact that they've stayed with them and in some circumstances have stayed because somebody's been close to death and they've been able to remain there, I know they can't promise that on every occasion depending on the demands on the service, but where they can they do, and that's been a big comfort, or they've called back again'.* **(Macmillan nurse 9)**
>
> *'I had a chap who's now died, who was on two syringe drivers because he was so bloated and oedematous so that any medication was, it was struggling to get him to control his pain and symptoms and things, and obviously they went in to sort that out in the night and things'.* **(Heart failure nurse 5)**

The RRT was seen as an essential service for palliative care patients by specialist nursing staff as it provided a range of supportive care approaches:

> *'What makes them marvellous is the patients can ring them obviously out of hours, and they will either advise over the phone, or they will go out, and it may not be a specific heart failure problem, it could be the catheter's bypassed at two in the morning, and the bed's flooded, or the patient's fallen, but essentially they're palliative with heart failure, and they're just very supportive, and they will feed back to us if there's problems. And it's, I think, an essential number now, out-of-hours is so up in the air really, I think it's an essential number when our patients become palliative really'.* **(Heart failure nurse 5)**

For the Marie Curie nurses, the RRT provide additional help or advice over night, where in any other circumstances their nurses would have to call out of hours services or wake the relative when help was needed to move a patient:

> *'I've used them several times, and often it has just been on the phone, but I've pre-warned them if I've sensed something might happen, if there isn't the equipment there or something, and they've often said, look, don't worry, we'll come out if we*

> *need to, but I've not had to actually get them out. But we've got the Rapid Response if I work in Boston, so I know I can call them if I need extra help physically, or haven't got the equipment or a catheter or something, you know'.* **(Marie Curie nurse 3)**

Unfortunately the rural nature of some areas delayed the RRT arriving:

> *'Immediately, it's actually getting the physical bodies to the home that can take the time, depending whether the Rapid Response team is out already, as well as the time factor to travel from Pilgrim to wherever they've got to go to, which in this area can take quite a bit of time.* **(Marie Curie nurse 5)**
>
> *Sometimes you can't get them, because I had to put a gentleman on the floor for safety, and I had to call his wife, because the Rapid Response wouldn't be there in time to help me.* **(Marie Curie nurse 1)**

The RRT is seen by the nurses to have improved the family's ability to manage at home. This was particularly true for the heart failure nurses, who have small number of patients using the RRT. For these patients, the RRT team were perceived to have prevented admissions to hospital:

> *'I think it's given families confidence in looking after their loved ones at home'.* **(Marie Curie nurse 7)**
>
> *'I have had a couple of patients because they cover ...have been absolutely marvellous, and you know, some cases they have had to come out a couple of times a night, but it's definitely averted hospital admission, and definitely enabled the patient to stay at home, and invariably die at home, without a doubt, ... I think he[patient]got a bit disorientated and a bit unsettled, and the family obviously felt they needed some support during his disorientation. And they offered support to the family as well as him, and he went back to bed, but otherwise, it would have been an ambulance job because they wouldn't have known what to do.* **(Heart failure nurse 4)**

> *'I think that's important, it is, it's support for the family, I've only had to use them once, and this was a gentleman who was in and out of hospital quite frequently, and yes, it's that support for the family, so they knew that he didn't have to go to hospital'.* **(Heart failure nurse 6)**

Being able to provide the RRT with information pre-emptively is seen as beneficial to patient care during the crisis period:

> *'I do try and make sure that whenever I give out the Marie Curie number I do fax information about those patients so that Marie Curie have a got a point of reference and some knowledge so that patient then doesn't have to give a lot of information, so if they are ringing in a distressed state it's easier on both sides.'* **(Macmillan nurse 9)**

The respondents appreciated that the service was not just for crisis response. They also valued the opportunity to arrange for the RRT to telephone families to prevent a crisis:

> *'I've seen to someone one day and been a bit worried about them, they're not very stable, you've given them your advice, but I've actually asked Rapid Response to give them a call that night. And they've rung and just checked things are all right, and obviously said, you know, if you need to ring us during the night, so I've used them that way as well, as a sort of pre-emptive, and they've been fantastic'.* **(Heart failure nurse 5)**

The RRT were perceived to have closed a gap in care in the evenings between the daytime DN and twilight services. However, there remains a gap in the morning between the end of the RRT service and the start of the DN services.

The views of the Macmillan nurses not working within the RRT areas were somewhat more sceptical. There was a general sense that the RRT highlighted the fragmentation of care in to 'pockets' of provision. It was felt that much of what the RRT was providing was relevant to non-palliative care patients and could be overcome by having 24 hour district nursing:

> *'I just feel that you're getting lots of little pockets of people doing little things, you almost need to invest some of this money into the bigger teams, or the bigger picture, if you like, because palliative care's everybody isn't it. And I think the problem is that, you know, would you be better investing some of this into social care in some areas, or would it be better going into district nursing teams in some areas'.* **(Macmillan nurse 7)**

> *'I must say I think my personal opinion is that 24 hour district nursing would benefit, not just palliative care, but everybody'.* **(Macmillan nurse 6)**

For one Marie Curie nurse the presence of the RRT service had made her re-evaluate how the role of the RN at night might be better used to provide more care:

> *'with what I've seen of Rapid Response, it makes you sort of think more about the way that we work at night, and maybe ways that the service could be changed in the future, so that maybe, you know, because I've been at houses all night where really I've felt that my resource, the resources I'm providing aren't being put to their, you know, because I know there's other patients in that area that might not have a Marie Curie nurse that night, and I wonder sometimes whether that nine hours could be used a bit more effectively, not in every case, because there are nights you go to and you're needed that nine hours.'* **(Marie Curie nurse 3)**

It is clear that for those professionals working within the RRT area, the service has made a great impact on improving care at home and indeed in some instances is felt to have prevented admission to hospital. Specialist nurses believed that out of hours care has improved for those who have had access to the service. However not all patients are provided with the RRT telephone number. The Macmillan nurses within the area and the heart failure nurses make informed decision about to whom they give the telephone number:

> *I tend to sort of give them where their health is more precarious, where I think there are more symptom problems, and anybody where there is the potential for symptom difficulties and even those with psychological problems so that there is somebody that they can speak to, and would suggest the ones I'm not giving them out to probably are the patients that ... perhaps it's all a bit too premature for them.* **(Macmillan nurse 9)**

5.5 Stakeholder perspectives of the Rapid Response Team (RRT)

There were mixed views on how well the RRT was working and not all stakeholders were aware of its existence:

> *I mean the Rapid Response Team sounds great but I don't know very much, I didn't even know it existed.* **(Stakeholder 2)**

Some questioned how well it had been publicised but at the same time were cognisant of the teething problems that are likely to occur when introducing a new initiative:

> *I suppose one question that now; or doubt that is in the back of my mind is just how well publicised it was, but I guess when you're starting something new what you don't want to do is be overwhelmed. You need it to pick up gradually and to be able to know what the limits are I suppose in a sense, rather than being overstretched and then perhaps not being able to meet the need. I am disappointed that; I mean I can remember people were interested in hearing about, particularly about the Rapid Response Team, and I'm sad really that in a sense it doesn't seem to have been remembered.* **(Stakeholder 12)**

More generally, the re-structuring of the PCT was raised as a possible cause of lack of knowledge of the RRT and the service it offers:

> *Well, one of the gaps I think is definitely in communication and, you know, because predominantly the Rapid Response is only in the Greater Boston area, then not many other people will be aware of it other than those that actually directly benefit from it. I think, actually, when we're just talking about the Rapid Response, I think one of the impediments really to the development of the Delivering Choice*

> *Programme has been, funnily enough, the restructuring of the PCT.* **(Stakeholder 3)**

Nevertheless some viewed the service as a significant additional support to community services and importantly, to patients:

> *I just think it's another additional support structure for the palliative care patient, and I think that's invaluable, because they must feel quite isolated sometimes as patients.* **(Stakeholder 6a)**

For some interviewees, the introduction of the RRT provided continuity of care, enabling the appropriate grade of staff to be deployed and ultimately changing how the Hospice at Home team worked; as illustrated by the following two excerpts:

> *And I think what it's doing is actually enabling us to put healthcare support workers into patients [homes] that might otherwise have had to have a trained nurse in there……. I would say, you don't really need a trained nurse with the patients overnight, from my experience anyway, because you've got Rapid Response on call. And yes, they do cover quite a wide area, but when you ring the office number, it's automatically linked into their mobile that they carry with them, so you can always talk to somebody.* **(Stakeholder 7a)**

> *I think what it's doing for me, from Hospice at Home on days, is it's actually giving the patient continuity, and it's actually closing the loop, whereas before I didn't think it did, I think we stopped at one o'clock, three o'clock, whatever, and then you've got 12 hours then before somebody actually comes back into work, probably longer, you're coming into work, you can go into a patient, all sorts has happened overnight you didn't even know, like patients may have [died] or been admitted, now we know that, we can be prepared then, and if the patient's died overnight, we will still go in and do that visit. So really it has changed the way we work.* **(Stakeholder 7b)**

Some of those interviewed who were familiar with the RRT services had reservations about whether the right service users had been targeted and the seemingly inflexible criteria that were being employed:

> *I think inflexible referral criteria. I think the targeting was wrong. I agree with (other interviewee), I really feel that they should have targeted healthcare out in the community to support, and by that I mean the nursing residential homes, you know, GP practices, because I don't think the message quite got across. Because I remember talking to one GP who was sending a patient in, who wasn't well analgesed, and didn't seem to know anything about the Rapid Response Team, and by then had no interest in actually doing anything actively about it anyway - he just wanted the patient sorted thank you very much. So that, for me, is the issue, because I think the wrong people were targeted. I mean, because they spent a lot of time in hospital and they spend a lot of time with use, and we had lots of meetings and lots of presentations about what it was about, but it wasn't so, we weren't going to be the main users as such, I didn't see us as the users; I saw people out on communities as the people that require the help* **(Stakeholder 4a).**

Some stakeholders spoke of how well they had been supported by the RRT but felt that through circumstances outside their sphere of responsibility RRT staff was unable to function to their full capacity. Two areas of concern were highlighted: Patient Group Directives (PGDs) and verification of death:

> *Oh they're [RRT staff] brilliant……… Because I think they're a nice group of girls, anyway, and boys, sorry, because there is a fella there. I think they're a good support because we've just set up down there so our knowledge of palliative care probably isn't as up to date as theirs, but we support each other very well. I think the downside is that they can't carry out the job to their capacity because they can't verify death and they don't have any PGDs.* **(Stakeholder 5)**

The same interviewee explained how PGDs operated in practice:

> *Right. We have PGDs, so if I come to see you, and I say you have a chest infection, you're not allergic to anything, I can prescribe you some amoxicillin. We have strict guidelines of the PGDs that we hold - we can work to those. If we want to*

> *give a drug that's not within the PGDs, we then have to contact the GP and say this is what I found, this is what I want to give and why I want to give it and they'll say yes, no, yes that's fine, you can do it. We have to have their permission to give it; we can't just give any drug we want. Unless we're nurse prescribers, then with nurse prescribers, you have a larger remit of medication.* **(Stakeholder 5)**

It was reported that the RRT staff are, however, not permitted to set up medication prescribing and this leads to time delays for patients and frustration for RRT staff who are experienced nurses:

> *Like I say, they [RRT staff] go to the patient, the patient is agitated. Now, they're experienced nurses, they know what they want to give, but because they haven't got that PGD in place, they then contact us. We then go out and see the patient and say yes, that's fine, and we'll give it.* **(Stakeholder 5)**

The interviewees felt that more groundwork in terms of staff development before introducing the RRT service may have ameliorated some of the present difficulties relating to verification of death:

> *And it's like they can't verify death. And they've been seeing these patients for weeks and months at a time sometimes and then they have to call a total stranger into these relatives, who are besides themselves because they've just lost their loved one, and we then go out and we have to verify. I do feel that it's a good service but they didn't set the groundwork very well. Because if you say Marie Curie to anybody, they will say cancer, treatment, dying, and yet they didn't put the groundwork in so the nurses could have gone onto a nurse verification course straightaway so they can verify their patients.* **(Stakeholder 5)**

It was unclear whether there had been any interaction between the ambulance service and the Programme and so it was difficult to ascertain if there had been a change in the number of calls for people nearing the end of life since the introduction of the RRT.

5.6 Perceptions of general practitioners and district nurses

After the county wide postal survey of district nurses and general practitioners, 12 GPs working within the area covered by the RRT were invited to participate in a telephone interview. Two GPs agreed to be interviewed. They were asked about their experiences of providing palliative care and their perception of the RRT. It was clear that both GPs were keenly interested in palliative care within their practices. Both commented on the importance of communication and regular meetings with other members of staff.

> *'It's just an awareness meeting really, so that, I mean the Macmillan or someone else will come up with a name that I'll have on my cancer list, but who I don't go and see regularly and haven't got as a palliative, but they're perhaps deteriorating, they have seen that, and then after the meeting, I set up several visits, just to review the patients and how they are'.* **(GP2)**

Planning ahead and having anticipatory medication prescribed was seen as an essential component of providing care at the end of life, and was similar to the survey responses.

> *'I do this on a personal basis, making others aware for out of hours and for weekends of any needs, just making sure that we have got enough diamorphine or enough nozinan or whatever, so that should Marie Curie or Macmillan or anybody come out, then all of the various drugs and things are in place, so that others don't have to be bothered.* **(GP2)**

Both GPs commented that they had been a little sceptical of the nurse led RRT service in the beginning.

> *'But the Rapid Response system, that does appear to work really quite well…Marie Curie came in. And we were all very, we all thought that, oh dear, this will lead to a huge increase in the number of calls, you know, people going out and finding problems for us, but actually it didn't, and it seemed to work very well. And they're very sensible, working out of hours every now and again, and whenever I come across them, they're always out doing sensible things, asking sensible questions, providing support that either wouldn't otherwise be provided, or would otherwise be provided by a different person, therefore freeing them up. And I've been very, very impressed with the way things have run, to the point whereby I even, as a*

> *cluster lead, even interested in taking their model and trying to apply it to other diseases… they've certainly improved the care, and its timely delivery, and the amount of care that can be delivered, I honestly don't know if they've reduced admissions, but for me, that doesn't really matter'.* **(GP1)**

5.7 Documentary evidence

5.7.1 Deaths from cancer and heart failure within the Rapid Response Team intervention area

The NHS mortality data were scrutinised by postcode to assess the impact of the RRT on the care of cancer and heart failure patients before death within defined postcode inclusion zones (see Table 6). The RRT provided full care including home visits within a 15 mile radius around Boston to Spalding, with a smaller additional area where only telephone advice was available. Using NHS mortality data adapted by Marie Curie to highlight patient access to the Programme services, the identification of deceased patients' use of the RRT was possible. To evaluate the access to the two levels of RRT service the data analysis will focus upon the number of cancer deaths and heart failure deaths calculated within the RRT postcode boundaries surrounding Boston and the Greater Boston area. The data when represented as percentages will be a proportion of deaths of residents in the Greater Boston and Spalding postcode areas covered by the RRT rather than as a proportion of the Lincolnshire-wide deaths, since this was a 'local' intervention.

Within the first postcode inclusion zone covering Boston, Spalding, Holbeach and the surrounding areas the RRT provides home visits and telephone advice (RRT-V&A). Within the second post code inclusion zone the RRT provides telephone advice only (RRT-T). Table 6 identifies the total number of deceased cancer and heart failure patients within the two RRT postcode inclusion zones and the number of patients who received support from the RRT.

Table 6 – Proportion of cancer and heart failure deaths within the RRT response zones

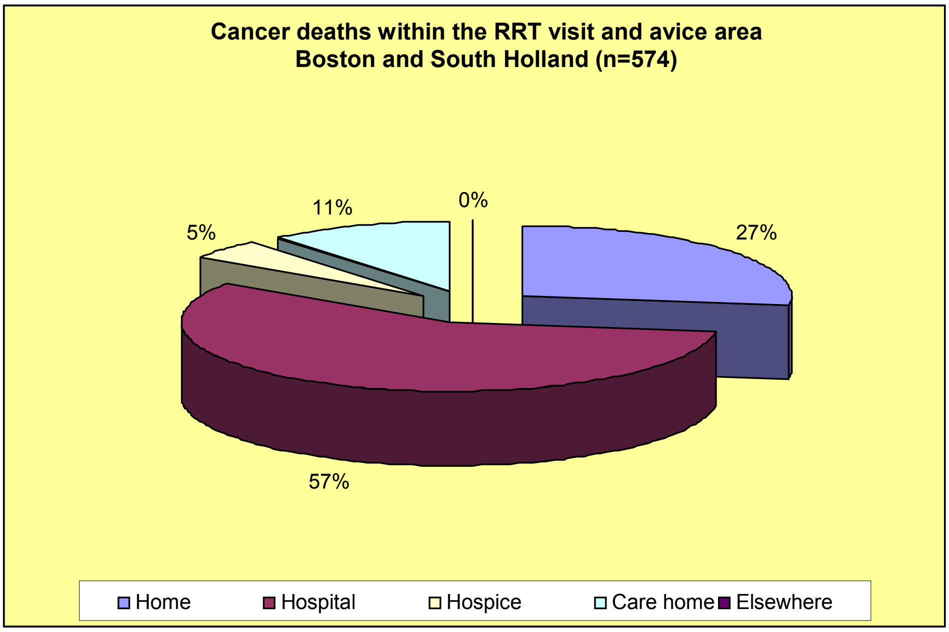
	RRT visit & advice area		RRT telephone advice only area	
	Cancer	**Heart failure**	**Cancer**	**Heart failure**
Total deaths across area	574	131	216	63
Total home deaths	157	24	53	14
Home death with RRT support	114	4	6	1
Total hospital deaths	327	93	132	37
Hospital deaths RRT support	65	3	5	0
Total hospice deaths	26	1	8	0
hospice deaths RRT support	8	0	0	0
Total care home	64	12	21	12
RRT support	16	1	0	1
Total deaths elsewhere	0	1	2	0
Deaths elsewhere RRT support	0	0	0	0

Hospital deaths include only those within and outwith the county

Thirty seven per cent of all cancer deaths (n=790) and 42 % of all heart failure deaths (n=194) in Lincolnshire occurred within the Boston and South Holland area postcode boundaries for all RRT interventions between April 2006 and March 2007. Of these 27% of cancer deaths and 27% of heart failure deaths occurred within the RRT visit and advice postcode areas.

Figure 9 identifies the location of all cancer deaths within the RRT-V&A area. It is clear that the majority of these deaths (47%) occurred in the 4 local hospitals: Pilgrim Hospital, Holbeach and Elloe Community Hospital, Skegness Hospital and Welland Hospital. Twenty-seven per cent of the deaths within this area were in the patients' own homes.

Figure 9 – NHS mortality data breakdown of cancer deaths within the RRT home visit and advice area Boston and South Holland



There were less cancer deaths overall within the extended region covered by the extended RRT-T telephone only advice area than the RRT home visit area (see Figure 10). However the location of these deaths reveals a slightly different picture. In this area, more cancer patients, 60%, died in hospital. This is greater than the countywide figure of 56%. Cancer deaths at home were similar to those in the RRT-V&A area at 25% with 10% in care homes.

Figure 10 – NHS mortality data breakdown of cancer deaths within the RRT home telephone advice area

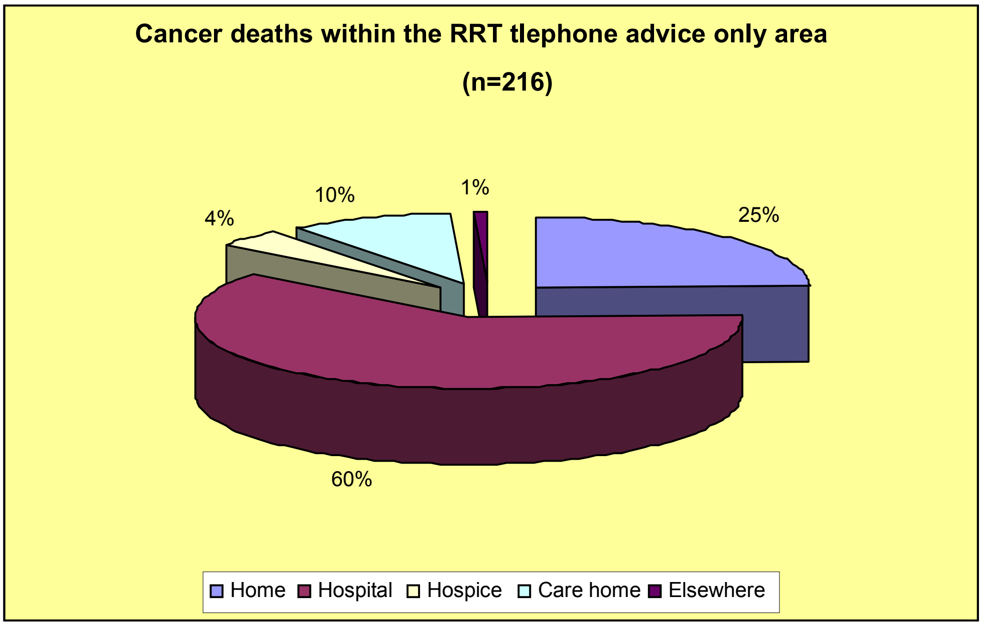


Figure 11 shows that deaths from heart failure within the RRT-V&A occur predominantly in local hospitals (71%). This is followed by 18% of patients dying in their own homes and 9% of deaths occurring in care homes.

Heart failure deaths within the RRT-T area occurred less often in local hospitals (59%) compared to the RRT V&A area (see Figures 11 and 12). There was also an increase in the number of deaths at home (22%) and deaths in care homes (19%). Four per cent more heart failure patients died at home and 10% more died in care homes within the RRT–T area than in the RRT-V&A area.

Figure 11 - NHS mortality data breakdown of heart failure deaths within the RRT home visit and advice area

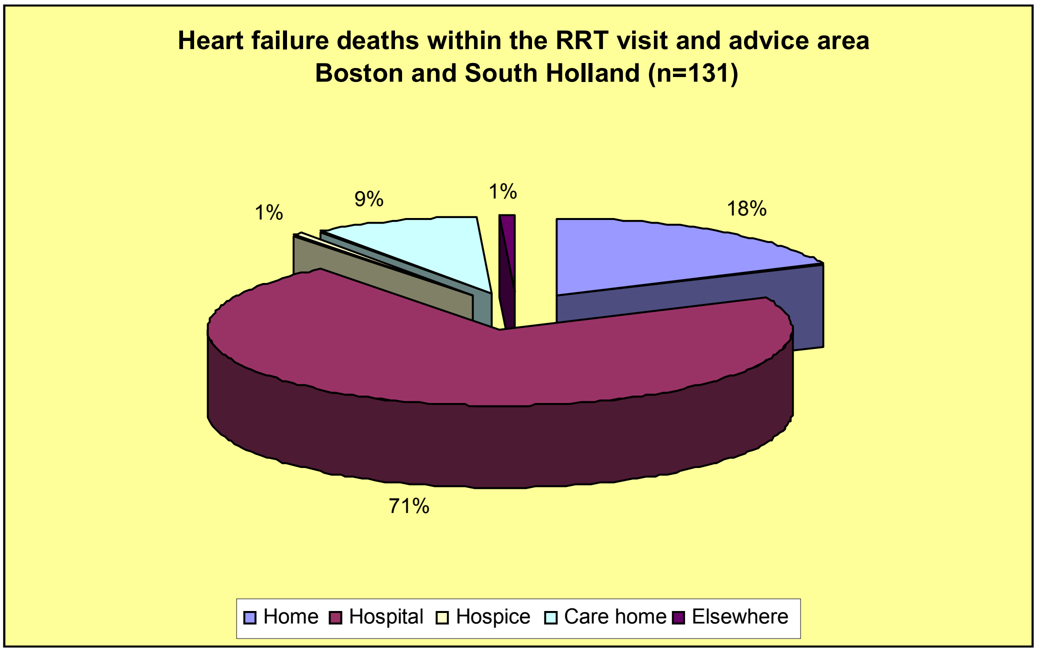
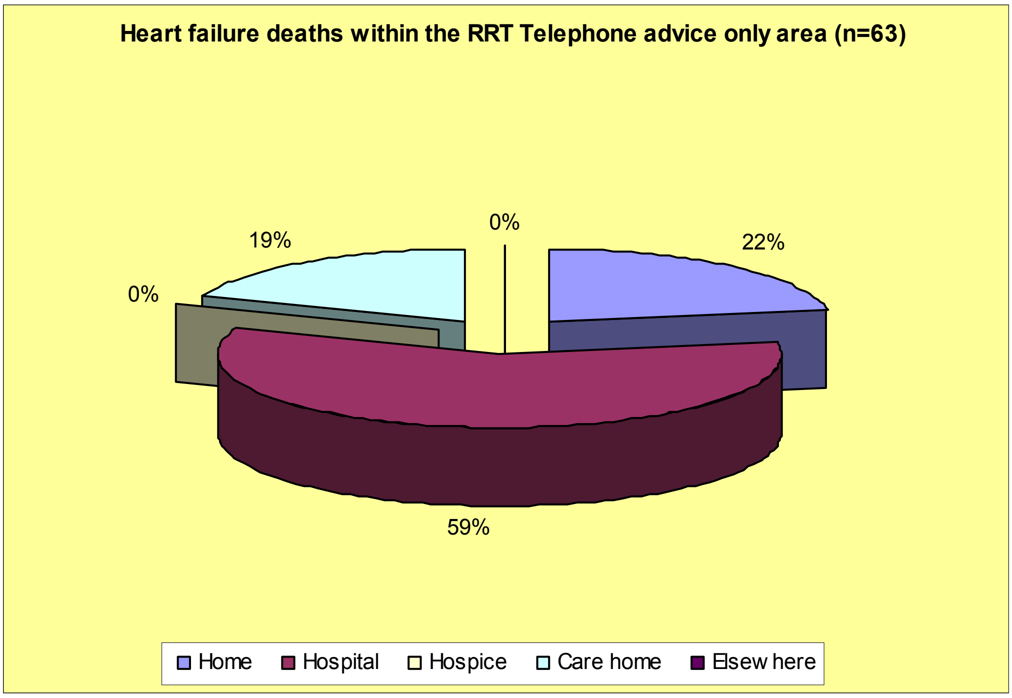


Figure 12 – NHS mortality data breakdown of cancer deaths within the RRT telephone advice area



5.7.2 Proportion of patients supported by the Rapid Response Team as reflected by the NHS data

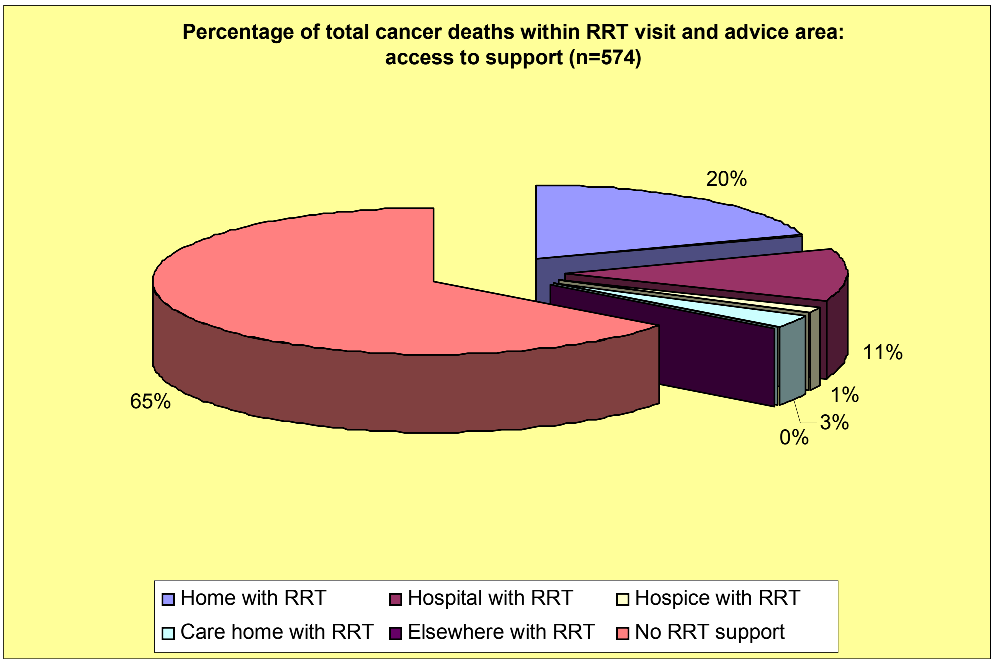
5.7.2.1 Cancer patients

Of the cancer deaths at home within the area where RRT-V&A services were available, support was provided to 114 (73%) of patients. However, 27 % of cancer patients who died at home did not receive this support before death.

Of the 327 deaths from cancer in local hospitals, only 65 of these patients (20%) received RRT-V&A support. This finding suggests that 80% of patients who died in hospital did not receive support from the RRT before death.

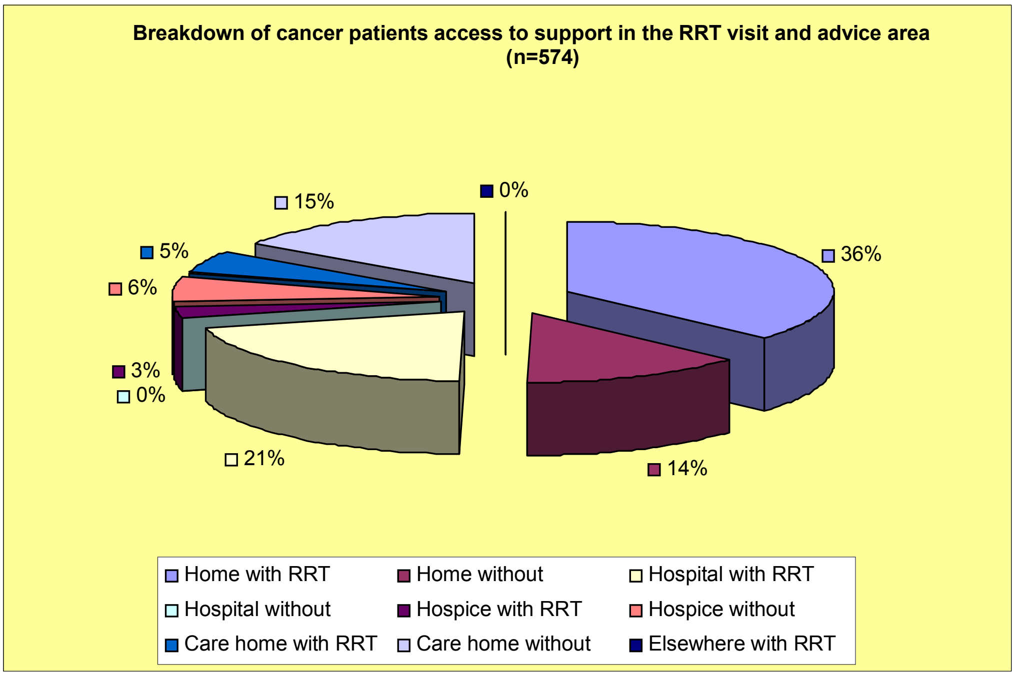
Of the 26 hospice deaths within this area, eight cancer patients (30%) received RRT-V&A support. RRT support was also received by 16 (25%) of the 64 patients dying in care homes.

Figure 13 – Cancer patient access to support within the RRT visit and advice area by place of death (percentage of total deaths)



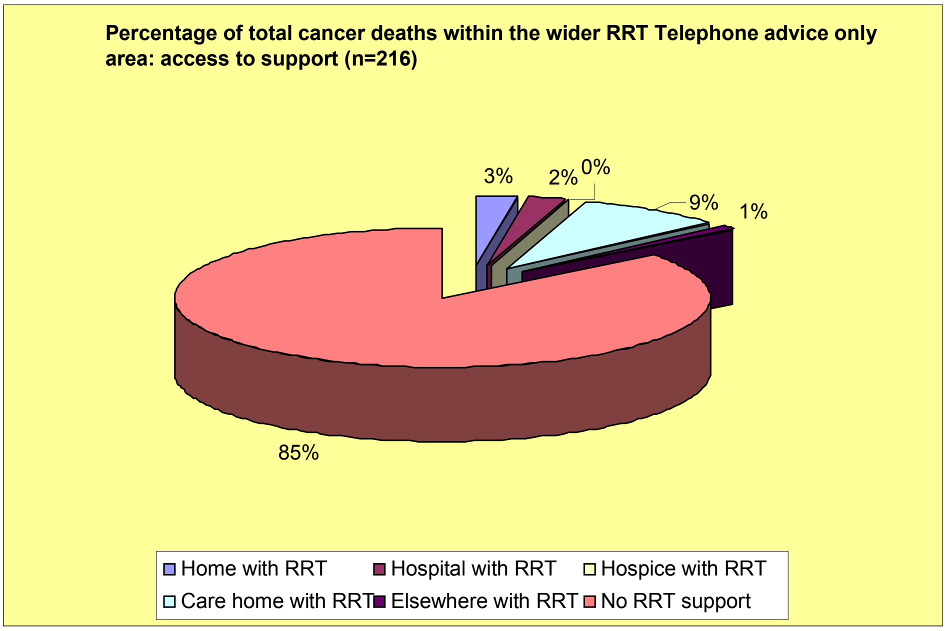
Despite the success of the RRT visit and advice service enabling the majority of referred cancer patients to die at home, in contrast, the local picture of cancer deaths across the Boston and South Holland areas indicates that the majority of cancer patients (65%) were not referred nor had access to the service before they died (see Figures 13 and 14).

Figure 14 - Breakdown of cancer patient access to support within the RRT visit and advice area (percentage of total deaths)



For those cancer patients in the RRT-telephone advice area, six patients out of a total of 53 home deaths (11%) accessed RRT for telephone support (see Figure 15). This suggests that 89% of these patients were not referred to or did not receive any of the RRT–T support available. This became further reduced when considering support accessed by those patients with cancer who died in hospital. Only 4% (n=5) of the 132 cancer patients, who eventually died in hospital, received telephone support from the RRT.

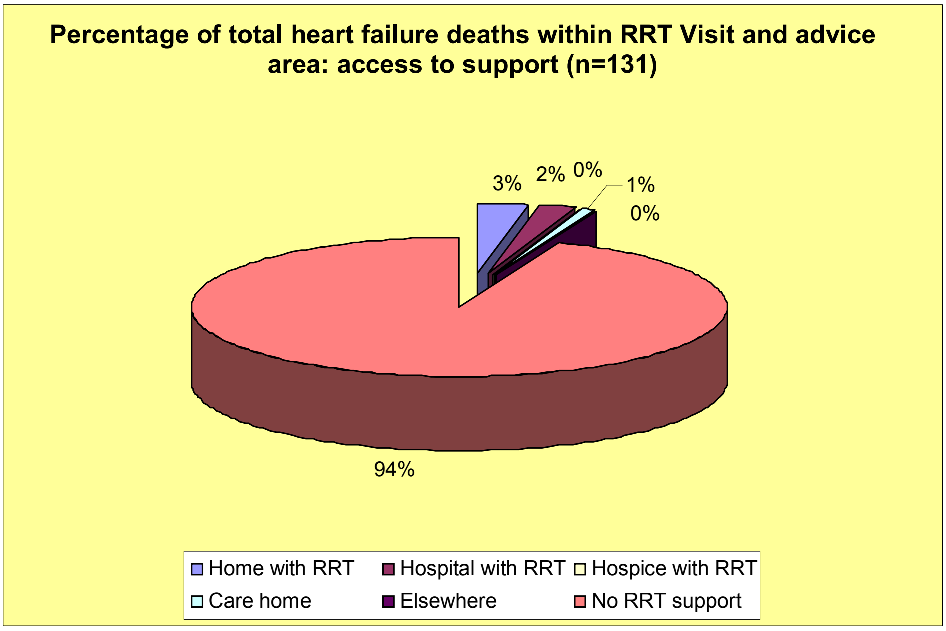
Figure 15 - Cancer patient access to support within the RRT telephone advice area (percentage of total deaths)



5.7.2.2 Heart failure patients

Of the heart failure patients who died at home within the RRT-V&A area, four patients (17%) received support from the RRT, with 83% of patients not receiving any RRT support (see Figure 16). Of the 93 hospital deaths from heart failure, three patients (3%) received RRT-V&A support. These findings suggest that the majority of patients who died at home or in hospital (or elsewhere) within the RRT-V&A area were not referred to or did not access the RRT before death.

Figure 16 - Heart failure patient access to support within the RRT visit and advice area (percentage of total deaths)



For those heart failure patients in the RRT-T area one patient from the 14 who died at home (7%) accessed RRT, receiving telephone support. None of the heart failure patients who died in hospital accessed RRT telephone support. It is evident that heart failure patients failed to access the RRT services.

The figures presented here are from the NHS mortality data set 2006-2007 and differ slightly from those received from the Marie Curie RRT database. However, this does not prevent the use of the data to examine the effectiveness of the RRT service in meeting the key objectives of the Programme. This will be discussed in relation to the array of data presented in later sections.

The majority of cancer patients within the RRT-V&A postcode area had access to and received support from the RRT. Lack of access to this support is apparent for heart failure patients in both RRT post code areas. Where the RRT has failed to provide support of any substance is within the RRT-T area, where only telephone advice is available. The cause of this is unclear.

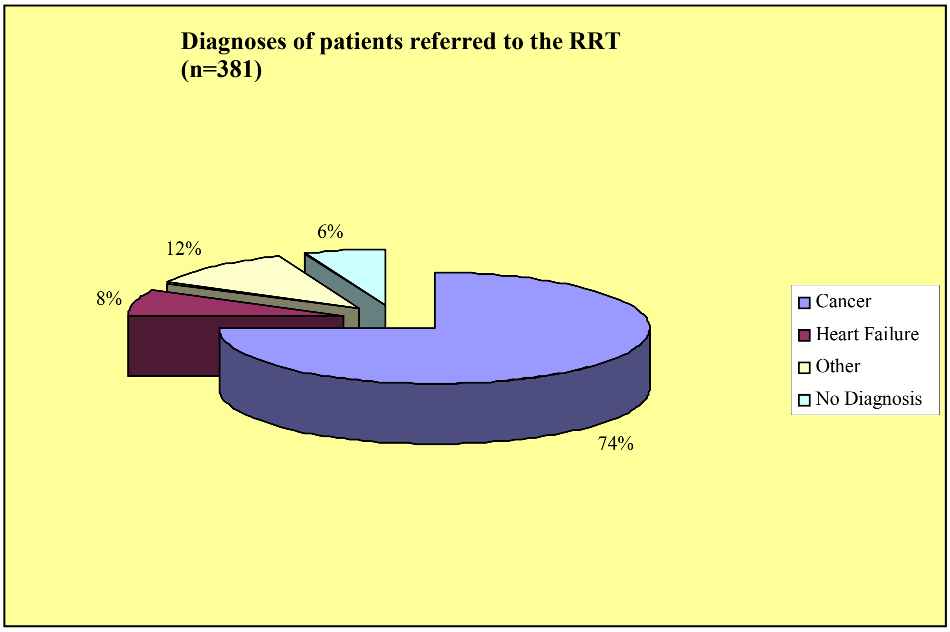
5.8.1 Assessment of the Delivering Choice Programme intervention data

Data were provided by the Programme team in Lincolnshire for three interventions: RRT, the DCLNs in Boston and Lincoln and the PCCC. These data were analysed systematically and findings will be reported below.

5.8.1.1 Evaluation of the Rapid Response Team (RRT) service data

The RRT provided home visits and telephone advice to 381 individuals between 1 April 2006 and 31 March 2007 (see Figure 17). During this time 2104 episodes of care were provided, an average of 5.5 episodes of care per patient. Some patients received one episode of care where as others received more. Not all patients were deceased on the 31 March 2007. Of the 381 patients supported by the RRT between April 2006 and March 2007, the majority of patients, 368, were within the RRT-V&A postcode areas. There were 13 patients within the RRT-T postcode areas.

Figure 17 - Breakdown of diagnosis of patients referred to the RRT



The majority of patients supported by the RRT had cancer (n=285). Twenty-nine patients were diagnosed with heart failure and 44 had a range of other non-malignant conditions including multiple sclerosis and dementia. Twenty-three had no recorded diagnosis.

5.8.1.2 Referrals to the RRT

Evidence from the aggregated service data for April 2006 – March 2007 provided by Marie Curie identify the reasons for referrals made to the RRT. Although it is not possible to break this data down by the number of individual patient referrals and re-referrals, table 7 presents an indicator of the key support needs that assistance was requested for. Marie Curie defined the headings and subcategories. The category headings do not clearly reflect the reasons for referral. Further detail was sought about what each component involved and is presented in italics. The category Symptom Control covers a very broad range of general and specific physical, psychological and nursing issues. What is apparent is that pain accounted for 15.4% of referrals and personal care 13.5% within the category. If the category groupings were presented differently a clearer picture of the type of referrals to the RRT would be evident; these can be seen to fall within three distinct reasons for referral (see Table 7):

Symptom management, **Psychological care**, **General nursing care.**

Table 7 - Marie Curie service data: reasons for referral to the RRT

Symptom Control	**Number**	**Percentage**
Pain	217	15.4%
Personal Care *(bed bath/wash, change of clothes)*	191	13.5%
Other *(A range of different symptoms and causes)*	145	10.2%
Blocked catheter	137	9.6%
Wound care	117	8.2%
Nausea & Vomiting	94	6.6%
Loss of bowel control *(change of incontinence aids)*	81	5.7%
Syringe driver	81	5.7%
Agitation	65	4.6%
Breathlessness	56	3.9%
Pressure Area Care	50	3.5%
Loss of bladder control *(change of incontinence aids)*	44	3.1%
Constipation	42	3.0%
Terminal restlessness	29	2.0%
Anxiety *(patients')*	24	1.7%
Mental confusion	20	1.4%
Loss of appetite	10	0.7%
Oxygen flow	9	0.6%
Low blood sugar	4	0.3%
Sleeplessness	3	0.2%
Depression	1	0.1%
Total	**1420**	**100%**
Psychological reasons	**Number**	**Percentage**
Carer *(Listening, support, advice provision)*	503	75.2%
Patients*(Listening, support, advice provision)*	166	24.8%
Total	**669**	**100%**
Social reasons		
Manual Handling *(Move patient in bed or lift after a fall)*	154	55.4%
Patient dying *(support visits provided up to three nights before death)*	124	44.6%
Total	**278**	**100%**
Other		
Unmet Need *(Where the PCCC is unable to provide care, they ask RRT to offer and provide help over night)*	129	47%
Service Awareness	84	30.5%
Medication Advice	62	22.5%
Total	**275**	**100%**

The RRT received these referrals from a range of different sources, including patients and family care givers. Table 8 shows that the greatest number of referrals is by patients themselves or members of their families (n=794, 38%). These referrals were on behalf of 242 individuals. These figures suggest that a number of families were directly contacting the service on three or more occasions.

Table 8 - Referrals to the RRT 1 April 2006 – 31 March 2007

Referred by	**Number of referrals**	**Number of patients referred (n=381)**
Patient	794 (38%)	242
Rapid Response Team	292 (14%)	99
Other heath care practitioner	234 (11%)	99
District nurse	209 (10%)	90
N/A (client update call rather than care provision)	196 (9%)	157
Palliative Care Coordination Centre	180 (8.5%)	79
Emergency Care Practitioner	70 (3%)	65
Hospital staff (inc DCLN's)	62 (3%)	55
Out of hours call centre staff	38 (2%)	36
Macmillan nurse	14 (0.7%)	14
Clinical Nurse Specialist (inc heart failure nurses)	6 (0.3%)	3
Out of hours general practitioner	5 (0.3%)	5
General practitioner	4 (0.2%)	4
Total	2104	948(= more than one referral per patient from multiple sources)

The RRT are the highest referring professional service (n=292), referring 99 individual patients back to their own service between two and three times. In addition 40% (n=838) of all referrals were made by a combination of different primary and secondary care health professionals (excluding members of Marie Curie PCCC) (see Table 9).

Table 9 - Outcome of the referrals to and referrals made by the RRT

Outcome of RRT interve ntion	Planned Visit	Urgent Visit	Planned Telephone call	Urgent Telephone call	Information only Telephone call (NA)
No further referral	495	667	362	174	-
Referral to A&E	-	27	1	7	
Referral to DN/GP	-	-	1	-	-
Referral to Emergency Care Practitioner (ECP)	3	50	7	22	-
Referral to ECP and Hospital	-	-	-	1	-
Referral to ECP and Other HCP	-	-	-	1	-
Referral to GP	6	43	2	7	-
Referral to Hospital Staff	-	1	-	-	-
Referral N/A	-	-	-	-	7
Referral to OOH GP	-	11	-	3	-
Referral to OOH and Hospital Staff	-	1	-	-	-
Referral to Other	-	1	2	2	-
Referral to Paramedics	-	-	-	1	-
No Information	2	3	1	-	-

5.8.1.3 Referral by RRT to other services

For 1888 episodes of care provided by the RRT, the team made no referrals to additional health care services (see Table 9). This suggests that in 90% of contacts with patients and families the RRT team are able to effectively manage the situation. However, there were occasions when further assistance was required. Eighty-four (4%) referrals were made to the ECPs, 58 (3%) to a GP with an additional 14 (1%) specified to the out of hours GP, and 35 (2%) to the A&E department. Comparison of referrals to the RRT and referrals made by the RRT, indicate a degree of collaborative working between the RRT, the ECPs and out of hours services.

Table 10 - Referrals for planned and unplanned care

	Number of contacts	**Number of individual patients**	**Mean number of contacts (Range 1-52)**
Planned visit	507	140	4
Urgent visit	803	266	3
Planned telephone call	374	173	2
Urgent telephone call	218	121	2
Other	202	162	1
Total	2104	862	2.4

Analysis of the outcomes of RRT interventions identified that 60% (n=1260) of planned and unplanned episodes of care resulted in a home visit being made. Forty-two of the referrals made to the RRT by the Emergency Care Practitioners (ECPs), were responded to by the RRT undertaking an urgent home visit. The outcome of these indicated that five patients were referred back to the ECP, five referred to the A&E department and one to the out of hours GP. The outcome of care for 179 patients is recorded as death. Analysis identified that the RRT was involved in supporting bereaved families via a telephone call or with a home visit to attend to last offices. The RRT nurses are however not able to certify death and this required a referral to the ECPs or Out of Hours GP service.

5.8.1.4 Planned and urgent care provision

Further analysis of planned and unplanned care data identified that 266 patients and family carers each required three urgent visits (see Table 10). From the baseline data it is apparent that some patients received a combination of urgent and planned visits and telephone calls before death. For example, one patient received 52 episodes of care by the RRT with a combination of planned and unplanned visits and calls.

5.9 Summary of findings from the Rapid Response Team (RRT)

- The RRT was felt by patients, carers and family carers who had experienced the service to provide friendly, timely and professional support at home.
- There were mixed views on how well the RRT was working by stakeholders and professional groups from both those who were and were not able to access the service. Most adverse comments came from those who could not access the service.
- Some viewed the service as a significant additional support to community services and importantly, to patients.
- 73% of cancer patients who accessed the RRT visit and advice service in the Boston and South Holland postcodes died at home.
- Just 17 % of heart failure patients who received support from the RRT visit and advice service died at home.
- There were some reservations by stakeholders and professionals about whether the right service users had been targeted and the seemingly inflexible criteria that were being employed.
- 65% of cancer deaths in the RRT in the Boston and South Holland postcodes were not referred to or did not receive support from the RRT.

- 94% of heart failure deaths in the RRT in the Boston and South Holland postcodes were not referred to or did not receive support from the RRT.
- It was reported that RRT staff could have performed better if they had training in PDGs and verification of death.

6. DISCHARGE COMMUNITY LINK NURSES

6.1 Introduction

Poor communication between the acute care sector and community care services and poorly coordinated discharges were key concerns raised by stakeholders, general practitioners, district nurses and specialist nurses across Lincolnshire during the baseline evaluation in 2005. The end evaluation in 2007 sought to identify whether the DCLNs had met the outcomes required in Objective 1 and improved the discharge process from Lincoln County Hospital and Pilgrim Hospital Boston. This included the identification and communication of patient and family carers' needs to primary care services.

6.2 Perceptions and experiences of patients

Four patients who were interviewed had been admitted to Lincoln County Hospital or Pilgrim Hospital, Boston within the previous year. However, none could recall meeting the DCLN at either hospital.

6.3 Perceptions and experiences of current family carers and bereaved family carers

Bereaved family carers appreciated the DCLNs work in improving communication with family carers and patients about their choices:

> *"She [DCLN-L] was going around the wards introducing, I think she was reading case notes, and she asked if she could speak to both of us. So after that, things started moving up a gear really [. . .] offered this care at home [. . .] It all slotted into place, and I think without her, it probably all would have happened but it would have taken longer and been more disjointed.*"
>
> **(Bereaved family carer - C8)**
>
> *'Well she [DCLN-B] was the one that found the homes and everything for me. She brought a list, which area or wherever we wanted it, and which was suitable for mother-in-law to go in [. . .] I think she'd been talking to mother-in-law when I weren't there but I think with mother-in-law with her breathing and her hearing problems they left it more or less up to me [. . .] I mean they were very good at*

> *sorting it out. They got her moved in and everything. They rang me up to say when they'd got her moved in and, yes, it was very good.'* **(Bereaved family carer - H2)**

Regular contact by the DCLN to establish how the carer would manage and to identify what equipment was required was felt to have been very helpful:

> *'This was about a fortnight before he died, so we went down and - is it X? She arranged for me to have a special bed and everything brought in and this was all going to be arranged by 12 o'clock this particular day, which it did, so I was down the hospital, brought X back home in the ambulance ... Once or twice she'd come up and just discuss with me about things, but it was actual, the latter part when she said to me, once we knew he was coming home, she said, "Oh I'll get everything set up for you now"***(Bereaved family carer – C6)**

There was a perception that the DCLN involvement not only speeded up the discharge process but made the care experience more seamless:

> *'I think because she [DCLN-L] got it all in place before we came home, or before he came home, it worked like a dream. I think if she hadn't been there, he would have been discharged, and I'm desperately trying to remember, I'm sure it's the Macmillan nurse, she came, and I think she would have organised the Marie Curie. And the occupational therapists were saying that we needed the Walnut Care for moving him about and getting him up and washing and helping. What we did was I was the second carer when they came. One came so we could bed bath him and what have you. I think it would have been a lot more disjointed until it got going [DCLN-L] also organised the Walnut Care .... I just had to sign the form and we didn't pay anything and if we would have had to have been means tested, I think, and then we would have paid and that, so. I think it all slotted into place, and I think without her, it probably all would have happened but it would have taken longer and been more disjointed.'* **(Bereaved family carer - C8)**

According to one bereaved carer, good communication and collaborative working between DCLN and other professionals helped fulfil their loved one's choice to die at home:

> *'She'd [heart failure nurse] see him in hospital with [DCLN-B], and [DCLN-B] got him out of there as quick as possible, because all he wanted to do was be at home, he wanted to die at home.'* **(Bereaved family carer- H3)**

Some family carers had found that while their patient was still on the hospital wards it was difficult to get information or to find someone with whom they could talk meaningfully. Once the process of discharge started, communication was perceived to be much better. One carer talked of being kept in the dark over a long period until the DCLN became involved:

> *'[DCLN] was helpful - you could speak to her, you could talk to her . . . basically how he was and what the actual prognosis was, and what the outcome was because you're kept in the dark for so long.'* **(Bereaved family carer- H4)**

6.4 Perceptions and experiences of specialist nurses

The Macmillan nurses working within Lincoln County Hospital and the Macmillan nurses and HFNs working in the community areas across the county reported a great improvement in the organisation and discharge of patients from hospital to home.

> *'I had a patient recently who [DCLN-L] got involved with, and managed to get the patient home within 24 hours to die, because that's what they wanted to do. He'd been admitted to hospital with urine retention actually, but then his condition worsened quite dramatically, and he was end stage heart failure anyway, but he came the last few days of life and she managed to get him home by 2pm, I think on a Monday, after having known about him from a message that was left on the Sunday'.* **(Heart failure nurse 3)**

The DCLNs challenged the preconceived assumptions of hospital based staff about the possibilities of getting very sick patients home:

> *'3:we had a chap didn't we last week, or was it the week before, who was virtually unconscious, but his wish, and his family's wish was to get him home. And we did manage that, and that's where I think [DCLN-L], again, comes into her own, because probably if she hadn't been there, it wouldn't have happened...*

> *5… there's been a couple of cases where she's got them home, and I've looked at the patient, and I just think, well I'm surprised she's got them home, because I wouldn't have thought they would have gone, they should have gone to a nursing home'.* **(Macmillan nurses 3 and 5)**

The capacity to arrange quick and safe discharges was an important aspect of the new role. This was complemented by the DCLN skills and capacity to analyse and anticipate care needs:

> *'it really has been good I really feel because of [DCLN-B] insight and her knowledge and her background she's got such a clear grip, she's very good at anticipating problems and it just seems to be a much more comprehensive approach and getting the patients home, and you always know she will have thought of ensuring that the just in case and anticipatory drugs are coming out with the patients. So you just have a greater sense of confidence… when she's been on holiday. You notice the difference.'* **(Macmillan nurse 9)**

One Macmillan nurse reported transferring patients to Lincoln County Hospital from Louth County Hospital in order to get them cared for by the DCLN there:

> *'Right, well as far as [DCLN-L] concerned, the service is absolutely brilliant. There needs to be more than one of her, because it just collapses when she's not there. I have to juggle patients from Louth to get them into Lincoln County, so she can look after them, and I've done this, because I think people do tend to stay at home longer when she's been involved…'.* **(Macmillan nurse 5)**

Heart failure nurses perceived that patients stayed at home longer after the DCLNs assessed and organised their care required. A key problem identified by these nurses is not having cover when the DCLNs are on leave, which delays discharge and communication:

> *I think the only problem is, there is only one [DCLN-L] and that's a really big issue, because when she had jury service…there's nobody, and then suddenly*

> *people begin to lose a bit of faith, because they ring in and they don't get a reply. Then she comes back and she's got a backlog, so I mean it is, it's a typical lone worker sort of situation, there's nobody to take up that caseload, I think it needs to be properly resourced if it's to carry on in the future for her to make a significant difference'.* **(Heart failure nurse 1)**

> *'obviously [DCLN-B] tries to leave things in place as much as she can but is always those last minute issues, if there's a transport problem you know the Ward hasn't really thought it through as closely it could've, but [DCLN-B] had been there on the day you know she would've been on the case and it would've got covered a bit better, and things like that, and if even there'd been a change of medications between the time that [DCLN-B] had gone off on holiday and the patient actually leaving hospital again you know the adjustment may perhaps not …taken place on the TTO's as well'.* **(Macmillan nurse 9)**

Despite some initial difficulties integrating the DCLN roles in both hospital sites, the DCLNs are now considered essential team members. Evidence of collaborative working was discussed by the HFNs. In Boston one HFN had worked quite closely with the DCLN and found her input with heart failure patients extremely supportive

> *'I mean I've found [DCLB-B] invaluable in specific cases, I had one real problem patient, and if you like, member of staff as well, where I had really attitude problems to be honest towards whether somebody was palliative or not, and by me and [DCLN-B] and sort of the manager discussing and pull one together, we did resolve that, so it was good to have her as an ally, if you like, as well.'* **(Heart failure nurse 5)**

The DCLN's working practices have change since the role commenced. Both nurses used to follow patients out to their homes. The DCLN's work has become increasingly focused on patients at the end of life, rather than those with palliative care needs:

> *5: I think there is a bit of flexibility, but I know, same with [DCLN] at Boston, that '6' and I have done a lot of work with, when she was first in post, obviously*

> *workload was lighter, so she did take more palliative patients as opposed to end of life patients, whereas now she'll only really take the ones that are end of life. Now there is flexibility with that, and one of my ladies recently, who's now died, deteriorated, but again, it's the same scenario, is this a sort of final deterioration, or is this just a deterioration and she'll pick up? But I saw her twice in hospital, and the second time she was much worse, so although I'd discussed her with [DCLN] and she didn't take her on the first discussion, she did actually see her and we got continuing care and everything in the second discussion. And she probably, she might have been alive for three months rather than two months, but you know, so there is that flexibility, but yes, I mean because of workload now, and they're also not, in the early stages, [DCLN] used to visit people sort of the day or the day after discharge, whereas she doesn't tend to do that now I would say or it's on much rarer occasions.'* **(Heart failure nurse 5)**

Macmillan nurses raised concerns about how the home visits by the DCLNs have raised patient and carer expectations, which is having unintended negative consequences on community provision:

> *I think there are a couple of things that I think I've noticed, is that one thing is that when [DCLN-L] goes home with a patient, is that sometimes, and this isn't [DCLN's] fault, expectations are raised that can't be met in the community, (Macmillan nurse 6 agrees) that is a resource issue. And secondly, I do know, but I wouldn't know the exact figures, that obviously if you fill need or want, that you will overspend on the resources, and that's what's happened I believe quite considerably. However, saying that, if people have a need and a want, then that's what you've got to do, haven't you, that's not [DCLN-L] fault, but it's raising expectations. ... because [DCLN] will book care for a certain number of days, and then if that can't be continued, then the district nurse has to pick up and say, well, we can't get someone tonight or, and that is quite challenging I think, both for the patient, because they've been, if you like, cushioned over the last two weeks that [DCLN-L]'s booked the care.* **(Macmillan nurse 7)**

Questions were raised as to whether choice and meeting the patients' preferred place of care was being improved overall. The hospital based Macmillan nurses noted that not all patients who might be considered as suitable are referred to the DCLN or to themselves. If the patients are referred just for symptom management there are times when the Macmillan nurses are not involved in the discharges, since ward nurses undertake this. They also raised the important point that not all patients want to be at home:

> *'They say people don't want to die in hospital, but actually quite a number of people do want to die in hospital because they get so frightened, they don't feel they can manage at home. They can see the strain they're putting on their family. They can't get into the hospice, so the hospital is the next best thing. But then there's going to be people that aren't, don't get referred to her. I don't think preferred place of care is any better generally than it was before, it's the ones where [DCLN-L] is involved. Now if [DCLN-L] and we know she is, having to limit her caseload for what she can physically do, then there are going to be people out there who aren't getting that preferred place of care.* **(Macmillan nurse 4)**

It was acknowledged, however that for the patients who had been referred to the DCLNs, choice had been improved.

6.5 Perceptions and experiences of key stakeholders and service managers

Respondents who had accessed this service were overwhelmingly positive. There was a perception that the time the DCLN was able to dedicate to patients and their families took some of the pressure off overstretched hospital staff:

> *Well, the ward, as I've explained, nurses hardly have time to do what they're supposed to do….. She then comes to the ward, has a good read of the notes, and then has, she's got the time that we haven't got to spend talking to the family and the person and make sure that they do understand where they're at. Because I think that's important, that she totally knows that they know that they've been informed well by the doctor.* **(Stakeholder 1)**

The service was considered to be improving information and coordination between services:

> *And equally, if any of our patients, for any reason, have got to go into hospital, [DCLN-B] will be our link with the wards. We will say we've got [DCLN-B] in hospital, please can you find out what's happening, these are their wishes, you know, they really didn't want to be there, it was whatever happened, they want to go home as soon as possible, we're happy to continue or increase our care. She's say, right, no problem at all, I'll find out what's happening, I'll keep you posted and I'll get back to you, and that's how it works with her.* **(Stakeholder 7a)**

The professional background and skills of the DCLNs in palliative care were believed to be crucial in ensuring the best possible care and facilitating choice of place of care and death and promotion of inter-agency working:

> *'[DCLN-B] is a nurse as well, which helps, she's got some palliative understanding as well, and I think that's what makes it works'.* **(Stakeholder 7a)**

> *We work very closely with [DCLN-B], and that's often people working in partnership to arrange packages of care, so [DCLN-B] might take on some of the tasks and the social work staff will take on identifying some of the services as well. We also produce a care plan, so a written summary of the services that are going in which we give to [DCLN-B] so that she can pass that on to the PCT. I gather that helps them in terms of finance and budgeting. The staff work very closely with* [DCLN-B]. **(Stakeholder 10)**

> *We work quite closely with [DCLN-B] since she's been in post. [DCLN-B] will see all of the end of life patients who are admitted to the hospital, and whose choice is to come out and die at home. She will then phone us direct, and we do have an agreement for complex patients that we take the direct referral from [DCLN-B], particularly as it's nurse to nurse, because some of these patients are quite sick, and are coming on quite complex care packages. And we will arrange with [DCLN-B] what care is needed, and we'll be guided by her whether it's five visits a*

> *week, or night visits, or can you pop in the day following discharge, which is what we try to do if we possibly can.* **(Stakeholder 7b)**

Most stakeholders believed that there were fewer incidents where care broke down:

> *Yes, I'm sure. Again, I mean I haven't got evidence but I suspect that fewer people end up with a situation breaking down and the need for an alternative plan. So people going home and then finding that they're not coping and families struggling, I'm not seeing that.* **(Stakeholder 10)**

> *Yes, I'm sure. ………..a lot of people want and choose to go home but I think they need to be assured, and carers need to be assured, that there are people there who are going to make sure that they get the support that they need. And I think [DCLN-B] role has enhanced that. And certainly making the link between the hospital and the community I think has been an important one.*
> **(Stakeholder 10)**

Importantly the role of the DCLN was seen as enhancing what was previously available, rather then supplanting or displacing established provision. In particular, patients were thought to be seen earlier in their illness trajectory and given more information:

> *It is good. I mean the work was already being done, because we have discharge liaison nurses at the moment, and so that end of life was always picked up and it was part of the work that the DLNs really enjoyed doing anyway. But before [DCLN-B] come in, and she'll engage sooner, obviously the DLNs do that very end of life phase, whereas [DCLN-B] will try and see them earlier on, and I feel they've got more information, so they make better decisions further down the line because they've been better prepared by [DCLN-B] in her role.* **(Stakeholder 4a)**

Not all members of the team felt comfortable, nor indeed felt they had the time or skills to initiate discussions about people's choices at the end of life; for some, the DCLN has been important in enabling dialogue to take place:

> *Not so much, I don't think, because you can't just waltz in and do that, you've got to spend time to do that. But often families, when people are given diagnosis, some families sort it all out and know exactly what they want but there are others that don't talk to one another. And I think [DCLN-L] a very good communicator, I think she had a hospice background which I think helps as well, and I think the majority of us feel that [DCLN-L] is much more skilful than we. Because we're trying to do control drugs, we're trying to do chemotherapy. I think to be fair to us as well, we haven't got, because we're trying to do so many things, we haven't got that time. Which sounds bad but it's a fact, that we're trying to do too many other things to be able to focus and do that as well as we believe [DCLN-L] does. (***Stakeholder 1)**

For some stakeholders, particularly those working within acute settings, the opportunity to discuss choices with patients and families were limited and they were uncertain as to whether people were getting their choices met:

> *No, I would say very rarely actually… I don't know…..if we were a ward that gave some ongoing care, they'd, they would be things that we'd be involved with more but. Well, you know, the turnover on here is quick, so it's, you know, we don't intend to keep patients here for a long time. I mean I think the ones that do stay, for whatever reason, particularly, we often have delays moving patients who require side wards on, and that, you know, if it was a sort of terminal palliative care patient, they would be someone that we might try and nurse in a side ward. I think if they are going to be staying with us, then we do tend to start addressing more of the.* **(Stakeholder 2)**

The main reason preventing people achieving their preferred choice of care was thought to be access to services overnight:

> *Well usually the choice is around where the service is provided and certainly if people are within the near to death criteria an option they do have is to remain in hospital. But the choices are generally being staying in hospital, moving out into a 24 hour care situation or returning to their own home. So I suppose they're fairly traditional choices aren't they. They're fairly conventional choices. But the thing*

> *that often stops people going home is access to services overnight, and I think this service actually clearly will meet some of that need.* **(Stakeholder 10)**

For many stakeholders, a busy work schedule and other competing demands meant that they had insufficient time to spend on what could be a long and complex process in facilitating patient choice. The input from the DCLN was mentioned frequently by stakeholders as crucial in achieving care choices for both patients and their families:

> *Yes, and then [DCLN-L] will often spend ages and ages and ages trying to sort out, and the majority of these people like to go home. Some go into nursing homes, because a busy ward like this isn't the place to die, in my opinion, and I think most people would agree.* **(Stakeholder 8)**

An innovative component of the DCLN work was seen in the A&E department where the DCLN was able to avert a hospital admission

> *Yes, she'll pick, she'll even pick them up from A&E. [DCLN-B] actually turned a discharge that she'd arranged home, was failing and came back to A&E, and [DCLN-B] picked it back up, sorted it all out and sent her out from A&E. So [DCLN-B], to me, they've got the investment wrong - we should have more of those type of roles, or people who don't just do the access part, let's do the whole system.* **(Stakeholder 4a)**

In short, the DCLN initiative was thought to be fulfilling many of the core objectives of the Programme in terms of providing a patient focused service where people have access to information and appropriate support services in order to make informed decisions about their care:

> *Most go out to a nursing home or home, and we've had quite a lot go home successfully, and [DCLN-L] does a lot of that. I mean [DCLNl-L], the OT, they get in the equipment but [DCLN-L] does a lot of that work for us in organising that part very successfully, and she sort of steers that voice. I don't know what we'd do now if we didn't have [DCLN-L]* **(Stakeholder 1)**

6.5.1 Gaps and barriers in relation to the DCLN role

Stakeholders were asked if they could identify gaps in provision or barriers that prevent them achieving the best quality of care for patients and their families:

> *I think it's because Marie Curie's own service is split, if it was one team and they, whereas they all have their own caseloads and if that patient became unwell, or a new one came in, it was added to the caseload, rather than this bit of the team deals with this and [DCLN-B]will deal with that and if you need this you need to ring this number, it's all just too much extra really. You know, as a ward nurse, you're trying to get somebody home or, if you're in A&E trying to get, turn somebody around, you just need to ring a number and you get a response - not you have to work it out.* **(Stakeholder 4b)**

Stakeholders from the emergency assessment unit in Lincoln explained some of the problems of breakdown in interagency working with particular reference to patient notes and the potential for omissions in patient care due to the volume of documentation:

> *[DCLN-L] was really involved with the family but, while he was with us, we weren't aware that [DCLN-L] was involved, there was nothing, we couldn't find anything documented in her notes at all……….although we've got the patient notes in front of us, there's lots of documentation, we don't routinely go through the notes as soon as the patient if referred, as there's stacks of stuff to read.* **(Stakeholder 2)**

In spite of the problems with documentation many stakeholders would like to see more resources put in place to extend and increase the role of the DCLN to reach more patients:

> *Because there's people out there being diagnosed all the time on different wards with cancer, and some of them never get to chemotherapy because it's too far when it's diagnosed. And [DCLN-L] doesn't just cover our ward; [DCLN-L] does cover the whole hospital. I mean what you need is time to organise things for people, and be able pick people up. I know [DCLN-L] has always got a busy workload, and the Macmillan nurse. I mean we've got [DCLN-L] and we've got [DCLN-L], the Macmillan nurses, and [name] who's the lung specialist. I mean we've got [name]*

> *in the Haematology. But these people don't do the same job as XXX [DCLN-L]. She's more specific in the discharge. So I guess, you know, just more people supporting that because the nurses are really, yes, we'd like to do it but, with the best will in the world, we haven't got time to do that and everything else as well. So I guess, you know, to fill any gaps, I guess more people specialising in that particular area.* **(Stakeholder 1)**

> *And I think that's the bit as well, that we seem to be missing. It's like [DCLN-B] role, if there was money around [DCLN-B] role and she could in-reach to the community, but she doesn't have time to do any home visits or anything like that, so I think that would be a big benefit to us, because they could probably pick up signs early and, you know, sort them out in the community, rather than wait until it gets to a crisis point.* **(Stakeholder 4b)**

6.6 Documentary evidence of the outcomes of the DCLN roles

6.6.1 Referrals to the DCLN service - Boston

During the period of analysis, 291 referrals were made to the service for 259 individual patients. Of these, 22 patients had two referrals to the service, three patients had three referrals and one patient had five referrals. In total 9% of patients were readmitted and re-referred to the service on more than one occasion.

Analysis of referrals to the DCLN service (n=291) (see Table 11) reveal that the highest proportion of referrals, 30% (n=88) were made by the generic DLNs, whose roles have been subsequently decommissioned during 2007 across the NHS Trust.

Table 11 - Referrals by profession to the Boston DCLN

Referrals made by	Number of referrals (%)
DLN/Discharge facilitator	88 (30%)
Macmillan (inc Lung & Haem CNS)	54 (19%)
Ward (matron, SR, Jn Sr, SN)	49 (17%)
Other	39 (13%)
Heart failure nurse	27 (9%)
Social worker	13 (4.5%)
St Barnabas	13 (4.5%)
District nurse	8 (3%)
Total	291 (100%)

It is apparent that nurses in a range of roles predominantly made other referrals across the hospital. Referrals were also received from social workers, from other professionals and from community service providers indicating a two-way flow of information sharing about patients. Referrals were made to the DCLN in two main areas: continuing care and palliative care. Table 12 shows that 59.2% of referrals were for patients with continuing care needs (patients at the end of life) and 40.2% for patients with palliative care needs.

Table 12 - Type of referral to DCLN Boston

Continuing care	Palliative care	Non-palliative	N/a	Total
172 (59.2%)	117 (40.2%)	1 (0.3)	1 (0.3)	291

The majority of referrals (n=222, 76%) were made for patients with cancer. Forty referrals were for patients with heart failure (14%) and 29 (10%) for other non malignant conditions, as shown in Figure 18.

Figure 18 - Diagnostic breakdown of patient referred to DCLN Boston

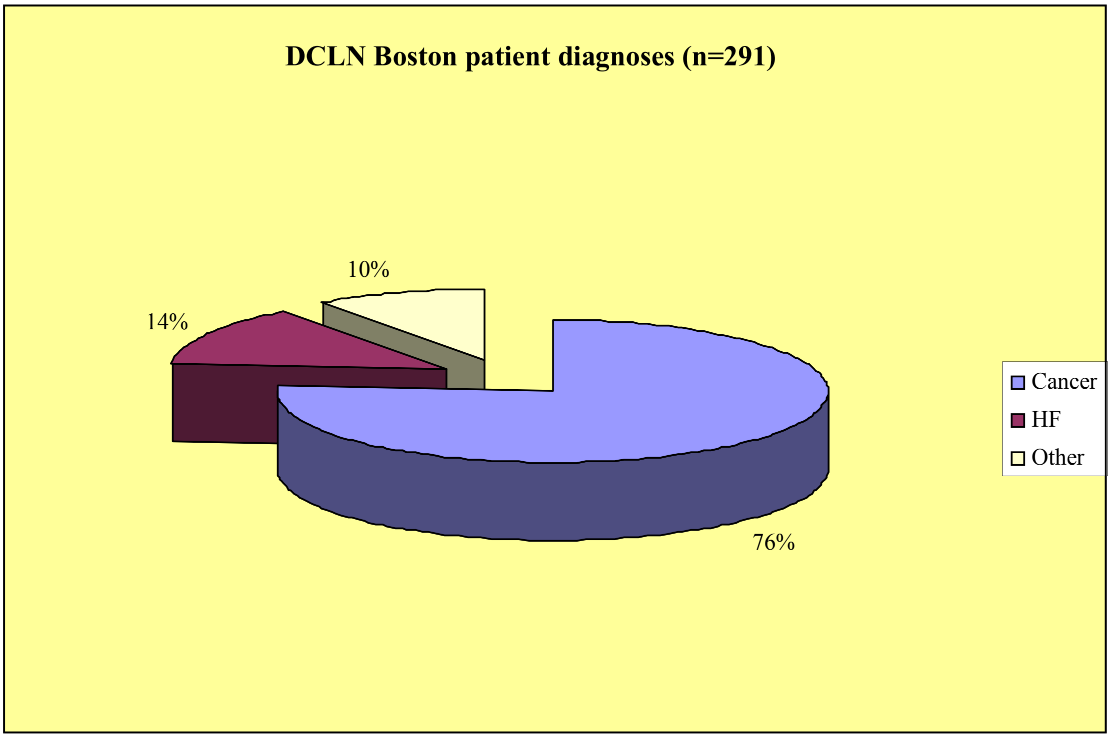


Table 13 shows reasons catalogued for patient referrals in the DCLN records at Boston.

Table 13 - Reasons for referral to DCLN

Reason for referral	Number of patients referred
Arrange community support services	109
Discharge coordination	91
Follow through	43
Transfer/information nursing home	17
Transfer to community hospital	7
Transfer to hospice	3
Provide information	3
Assessment	1

6.6.2 Outcome of DCLN Boston interventions

A key component of the DCLN role is to identify a patient's preferred place of care and preferred place of death where possible. The preferred place of care for 185 patients seen by the DCLN was home or a family member's home and, of these, 64% achieved their preferred place of care (see Table 14). A further 24 patients wished to be cared for at home, but died in hospital before discharge. For 42 patients, their preferred place of care was to remain in hospital, including community hospitals: this was achieved in all 42 cases. The reasons provided by the patients who wished to stay in hospital included not wanting to return home and the family's inability to cope.

Table 14 – Number of patients achieving their preferred place of care - Boston

	Home	Hospice	Hospital	Nursing home	Unknown
PPC	185	6	42	40	14
Achieved	116	0	42	16	-

6.6.3 Referrals to the DCLN service - Lincoln

The Lincoln DCLN data set came in two parts, which were not compatible. It was not possible to compare the reason for referral in the same way as the Boston data. Analysis of the 298 referrals to the DCLN Lincoln reveals that the highest proportion of referrals (see Table 15), 45% were made by ward nurses followed by generic discharge nurses at 14%.

Table 15 - Referrals to the DCLN Lincoln

Referrals made by	Number of patients
Nurses	133 (45%)
Discharge coordinator or DLN	43 (14%)
Allied health professionals	40 (13%)
CNS	32 (11%)
District nurse	15 (5%)
Social worker	8 (3%)
Patient family/friends	8 (3%)
Medical staff	7 (2%)
Other HCP's	6 (2%)
PCCC	2 (0.7%)
DCLN	2 (0.7%)
GP	1 (0.3%)
Unknown	1 (0.3%)
Total	298 (100%)

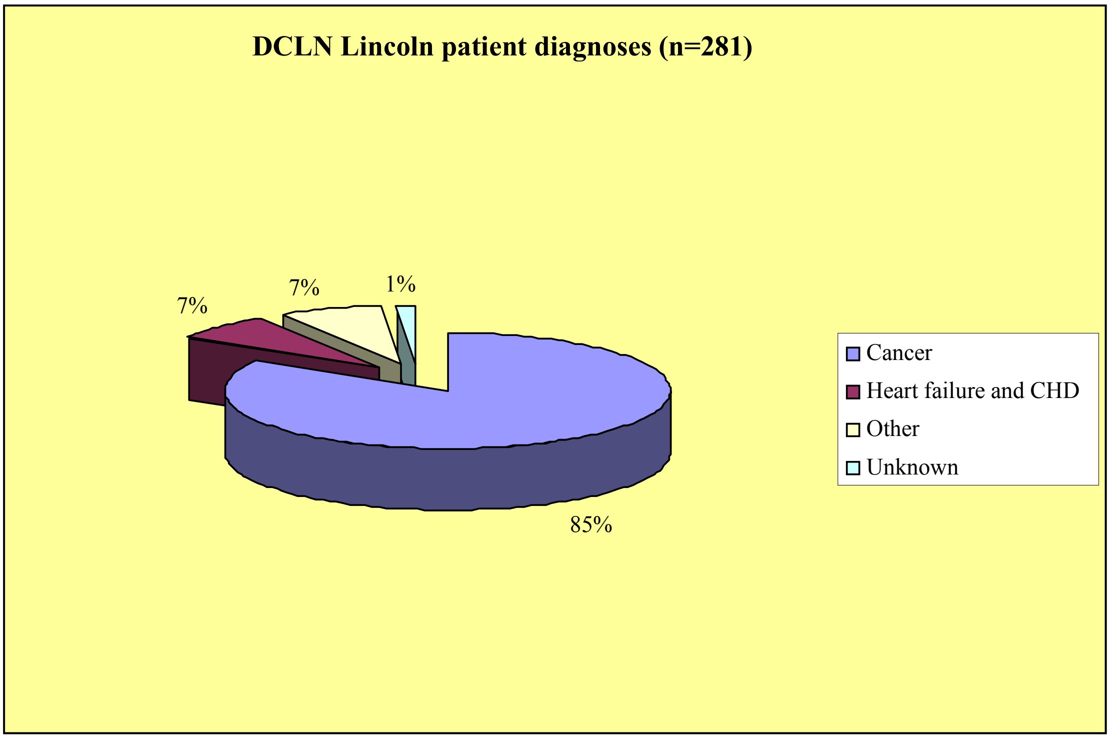
The total number of individual patients referred was 281, suggesting that 17 patients (6%) were readmitted and re-referred to the DCLN on two occasions. This is less than was experienced in Boston. The type of referrals fell predominantly into two main groups: continuing care and palliative care (see Table 16).

Table 16 - Type of referral

Continuing care	Palliative care	Other	Missing information	Total
203	84	8	3	298

Figure 19 shows that the majority of referrals (n=235, 85%) were made for patients with cancer. This is not unexpected as Lincoln County Hospital is a cancer treatment centre. Twenty-one referrals were for patient with heart failure, 21 for other non-malignant conditions and four had no recorded diagnosis.

Figure 19 – Diagnostic breakdown of patients referred to DCLN Lincoln



6.6.4 Outcome of DCLN Lincoln interventions

The key roles of providing information and coordinating discharge are also informed by the identification of the patients preferred place of care or death. Table 17 identifies the patients' preferred place of care and place of death.

Table 17 – Number of patients achieving their preferred place of care - Lincoln

	Home	Hospice	Hospital	Respite then home	Unable to verbalise/ unknown	N/Home	Other
PPC	189	13	8	1	24	40	4
Achieved	134	7	5	1	-	25	-

Where the preferred place of care was not achieved this was recorded by the DCLN as due to: family needs and dynamics (n=18), delays trying to get hospice or nursing home placements (n=9) and changes in the patients' condition.

6.7 Summary of findings for the Discharge Community Link Nurses (DCLN)

- Patients are often confused about roles, systems and interventions – they are not always able to differentiate between the different health professionals that they meet and the roles they undertake on their behalf.
- Family carers and bereaved carers found the DCLN very helpful in discussing patient and family wishes, identifying needs, coordinating equipment and discharge home.
- Macmillan nurses felt the DCLNs were very effective at communicating and coordinating successful discharges of even the sickest of patients.
- Macmillan nurses noted that the success of the DCLNs meant that delays in communication and coordination of discharges were evident when the DCLNs were on leave.
- Stakeholders and service managers who had accessed the DCLN service were overwhelmingly positive.
- The DCLN service was considered to be improving the discussion of choices and preferred place of care for patients and their families and improving information and co-ordination between organisations.
- The DCLNs appear to enhance choice relating to place of care at home by speeding up and making more efficient the transport there.
- The DCLNs overwhelmingly provide care to patients with cancer (76% of patients in Boston and 85% of patients in Lincoln).
- 71% of patients, seen by the DCLN in Lincoln, who preferred to be cared for at home achieved this.
- 63% of patients, seen by the DCLN Boston, who preferred to be cared for at home achieved this.
- The DCLN initiative appears to fulfil many of the core objectives of the Programme in terms of providing a patient focused service where people have access to information and appropriate support services in order to make informed decisions about their care.

7. THE PALLIATIVE CARE COORDINATION CENTRE

7.1 Introduction

Lack of coordination of care services leading to lack of provision or duplication of services and poor communication were key themes raised by stakeholders, general practitioners, district nurses and specialist nurses during the baseline evaluation in 2005. Concerns were also raised at the time about the fragmentation of services across the county. One of the main aims of this service was to save time for district nurses who were spending many hours on the telephone trying to facilitate packages of care for patients wishing to go home. The end evaluation sought to identify whether the PCCC had met the outcomes required in Objective 1 and improved the coordination and communication of care services for patients being cared for at home.

7.2 Experiences and perceptions of patients

Of the six patients who were interviewed, five patients remained unaware of the role of the PCCC in coordinating their care packages. The following patient highlights this lack of awareness that is associated with ill health and meeting numerous health professionals and the reliance on community carer workers:

> *'I've been in twice [Pilgrim hospital] since Christmas, that's right. I think it was a week. I suppose it was something to do, both mornings I woke up and felt peculiar and that was when they had somebody staying over night and they sent for the doctor and off I went into hospital [Pilgrim] for a week, much to my disgust…'*
> **(Heart failure patient H1)**

This patient had also been transferred to Welland Hospital where she became infected with MRSA and was very ill. Despite several admissions and discharges from hospital she had no idea how her care package had been arranged for her. She had a number of care workers from different organisations that contributed to her uncertainty:

> ***'Do you remember how many times a week you might have had them [care workers] for?***

> *Well no because, you know, sometimes it would be twice a week. I don't think it was more than three times a week. But then in between I used to get ones from agencies or something.*
>
> ***Do you know who organised all of that for you?***
>
> *Well it all seems to be the district nurses that, that it was all them that used to come and tell me I shouldn't be having them, nobody had ever had them so long before they said. I was amazed, I mean I didn't know I was going to have them, I came out of hospital and when they told me somebody was coming to stay all night, I was amazed - I didn't know anyone ever did that.'* **(Heart failure patient H1)**

There was a general sense that patients were surprised that care was available to them, and so they were generally grateful for what they received, despite not knowing how it had been arranged:

> *'I personally think that we're doing very, very well. I'm very happy with what we get. It's much more than I expected it would be to be honest. I mean they're excellent helpers during the day. I'm not always mad on the night one, but there you are, you can't have everything.* **(Cancer patient C2)**

7.3 Experiences and perceptions of family carers and bereaved carers

Family carers reported quite different routes through which care in the home was initiated and maintained. Often not understanding the systems in place, family carers tended to latch onto a particular person in the system to whom they turned for help and trusted. This person might be their or the patient's GP, a DN, a nurse specialist, a DCLN or someone else. In one case, the first place a carer, in need of help, turned to was the Citizens Advice Bureau.

Family carers appeared to be largely unaware of the PCCC even when they were getting weekly calls from them notifying them of the care in the week to come. Family carers tended to see their key contacts as the DN, DCLNs, nurse specialists or GPs who, as they saw it arranged the care. Although carers did value receiving the weekly notification of who was coming, they had little idea how the care was coordinated. One family carer, referring presumably to the PCCC, reported that:

> *'They ring on a Friday; I get all the details for the next week that's from a call centre that's doing it for the National Health and then from Allied, they ring me back and say through who they're sending... I know they're all coming at ten o'clock at night. I know that everybody's going away at seven in the morning, except the Barnabas nurse who goes away at six. And then she goes away at six and we make [relative] comfortable and then I go back to bed, we both go back to sleep.'* **(Family carer C4)**

A bereaved family carer reported finding the "organiser" very helpful - although difficulties in care at weekends was also apparent:

> *'Because I knew who was coming, and I knew most of them that did come because they did on a rotation, and I knew, you know, they were absolutely brilliant, they really were. [. . .] The only problem was at weekends, but that's the thing you see, the weekends were the worst, because I never used to know who was going to come. They'd just turn up, and you know, that was the worst.'* **(Bereaved family carer H3)**

Examples of miscommunication by the PCCC producing gaps and overlaps in care were reported:

> *'We were normally told on a Friday but obviously there was a lot of mix up. There was a change over of staff, apparently, one person had left who was on switchboard and the other one took over, and she didn't contact us for the first couple of weeks. We had one turn up and we didn't even know. And then we'd have one who was supposed to come sometimes and didn't turn up.'* **(Bereaved family carer H4)**

Overall information provided by the PCCC appeared to enable family carers to plan their week, and to know when help was available.

7.4 Experiences and perceptions of specialist nurses

The Marie Curies nurses, whilst not involved directly with the work of the PCCC were able to comment on it using the feedback by the patients they have cared for at home. The Marie Curie nurses report that family carers and patients find the telephone calls from the PCCC giving information about which care workers to expect and on what day/night, very helpful:

> *'I think they're more supported with and make decisions at the end of the phone, whoever they want… And with the coordination of the care being a lot better now, they actually know when the nurses are going in sort of day and night, they feel more supported, the feedback I've had from the relatives and the patients. And they don't feel as if they can't phone them either, you know, they don't hesitate now'.* **(Marie Curie nurse 5)**

> *'The other thing that I've heard, it's from the patients and the carers themselves, that that is their lifeline as well, they have a communication with the call centre'.* **(Marie Curie nurse 1)**

Each group of specialist nurses expressed an awareness of how the PCCC was positively affecting the work of their DN colleagues with whom they had regular contact and shared information:

> *'I think it's made huge difference to particularly to the district nurses I would say, who have multiple calls to make to different agencies and some of them they may draw blank anyway, and that's all clinic care time lost to them, so it's certainly a lot better from that point of view'.* **(Macmillan nurse 9)**

> *' It's saving them a lot of time, because now they, you know, they don't have to be ringing several people, they just ring the Coordination Centre, and they organise the total package, which may include Marie Curie, St Barnabas and Agency, if the patient's on continuing care'.* **(Marie Curie nurse 6)**

For the Macmillan nurses who made referrals to the PCCC, they reported having to talk to their DN colleagues first, because the funding for services comes from primary care:

> *'And it has to come off the DN budget, so they have to ring the DN anyway, so if we make a referral, they then have to ring the DN to check that what you've said is okay.'* **(Macmillan nurse 7)**

However, despite the benefits, the specialist nurses and Marie Curie nurses highlighted three key problems:

1. **Reduced communication between professionals** and lack of continuity were highlighted as a negative consequence of the PCCC by the Macmillan nurses and heart failure nurses:

> *'If there is a negative I think we have quite close working relationship with our local Hospice at Home team and I think very often patients that we know are known to them suddenly tip over into care needs, and sometimes you think it would be so easy just to sort of say you know can you girls you know sort of follow up Mr so-and-so or whatever. So I think it's not a huge negative… just for the continuity for the patient and often because the Hospice at Home team works out of the Hospice Day Care they often know and recognise some of the patients as they become more poorly, so just from the continuity point it would be nice.* **(Macmillan nurse 9)**
>
> *You can't ring Hospice at Home up anymore, if you feel, say somebody's in the last year of life, and you feel that they just, that they need some input from Hospice at Home, you can't just do that direct. You can't do it unilaterally with Hospice at Home, it has to be - I'm not sure how we get to Hospice at Home to be honest, if the patients aren't in the last few days of life now.* **(Heart failure nurse 3)**

The PCCC is seen to have detrimentally affected some of the close working relationships and exchanges of information betweens services, which were previously perceived to enable better communication and continuity of care.

The experience of poor communication by the PCCC itself and some overlapping of roles was raised. This apparently resulted in some DNs no longer using the service and making referrals directly to care providers:

> *'we've had issues whereby because of the problems some of our district nurses had with the Coordination Centre, and the delays we talked about for the Coordination Centre referring onto intermediate care ... part of my understanding of having a Coordination Centre was to build up a picture of exactly what the need is, and so therefore you've got these figures that are falling down gaps because people, district nurses are going straight to Gifts [Hospice], for example, there's quite a high percentage of district nurses that put their care straight from Gifts…they're avoiding the Coordination Centre, so therefore the actual, one of the purposes of it isn't being met.* **(Macmillan nurse 2)**

2. **Lack of flexibility** was raised by two of the Macmillan nurses who had worked with a local coordination centre previously, which had adapted and developed flexible processes to swap staff between locations and between different levels of need:

> *'the Coordination Centre has replaced a service that was better, and we've had huge problems with, I mean we've had some very good service, don't get me wrong, but we've also had issues that we'd already identified as issues and had ways round them that have gone backwards…. we'd already identified as gaps, pockets, where it was difficult to get care, so we had those within our Coordination Centre highlighted, so that the swap in was there to, you'd use what we did have available there went there first choice. Well of course that doesn't happen now, so we have particularly one area where they just say, sorry, we can't get care, and we have had huge numbers of patients where they've just been told, sorry, we can't get you anything, anything at all.* **(Macmillan nurse 2)**

> *'The flexibility is not built in, where probably our old system, the administrator would juggle…she could get an alternative service in, she would renegotiate, there doesn't seem to be that flexibility'.* **(Macmillan nurse 1)**

The heart failure nurses also raised lack of flexibility in relation to differing guidelines. They reported added problems in relation to their patients' conditions dramatically changing and not being able to reinstate services when awaiting discharge from hospital:

> *The Coordination Service is really good. The only problem that I've come across with it is the fact that you can't, when the patient's in hospital, the hospital can't phone and rebook care, so I had a lady who came into hospital recently, they got her sorted out, and then we wanted to go home, but we wanted some extra evening care initially until we were either sure she was back on her feet, or to continue if not. And they wouldn't accept the hospital phoning up to book that care, it had to come through either, you know, when she was home with the district nurses…So we had to get the lady home, then phone once she got home and said, can we have the care in the evening'?* **(Heart failure nurse 1)**

3. Continuing care funding is perceived as almost the only way to access PCCC support for patients. For non-cancer patients the process is more bureaucratic and requires extra authorisation for financing the care:

> *'I rang the Palliative Care Coordination Centre, got the continuing care paper faxed through, the district nurse was involved anyway, knew that he was deteriorating, and he managed to die at home. So that, you know, they did manage to get that night care for them seven nights a week in the end, at a push, although we do still have to sign some extra paperwork to get our cluster team lead to sign some extra paperwork for that, because it's non-malignant'.* **(Heart failure nurse 3)**

The high cost of agency care and swapping between providers for reasons of cost has had very unfortunate consequences and challenges the principles of providing patient led best possible care:

> *'The strange thing is, something with the Coordination Centre it very much seemed to be patient led, you know, get the care you need, we'll put you on continuing care to achieve that, but I've had an incident recently where a patient was on continuing care, was in his last two weeks of life, actually he was in his last week when it*

> *happened, and the Coordination Centre found a new agency out of Melton. Fantastic, this agency bent over backwards for what was a really difficult patient. The bill went into continuing care, it was too expensive, it was pulled three days before he died, and a new agency put in'.* **(Macmillan nurse 2)**

> *'I know at some point as well last year, one of the nurses from Gifts was saying that with continuing care, the Marie Curie Coordination Centre were going out to agencies before seeing what Gifts availability was. Which doesn't make sense at all, the care's there for free, and they're paying for it'.* **(Macmillan nurse 8)**

There is general consensus that the PCCC has reduced the workload of the DNs and improved the coordination of care. Continuing care funding, lack of flexibility and reduced local knowledge are seen to combine to produce a service that buys in care without due consideration of cost and local needs, thus, fragmenting care further for some patients at the end of life.

7.5 Experiences and perceptions of key stakeholders and service managers

The stakeholders presented mixed views about the PCCC. One interviewee described the centrality of the PCCC in care provision and the frequency of the liaison between services:

> *A lot, we liaise daily, sometimes several times a day, depending on whether, I don't know, we've had a change of shift pattern, I don't know, or a change of patient pattern, or a change of patient condition, or increased services, or we've had a direct referral from somebody. Yes, sometimes we can liaise three or four times a day.* **(Stakeholder 7a)**

For some interviewees because the service replaced an existing one, they described the PCCC service as merely an adaptation:

> *Unfortunately, in this area, the Coordination Centre, to some extent, replaced a local facility that was already running here. Macmillan had established the coordination system in the south west, so probably, you know, I don't know how*

> *much, Marie Curie's obviously higher profile, so obviously probably increased the awareness because of their Delivering Choice Programme. But, if you like the system was still available in the south-west before that, so it's been a sort of, an adaptation of that system.* **(Stakeholder 6b)**

This interviewee went on to describe some of the difficulties that were encountered when one service could be perceived as supplanted an existing one, though these problems appear to be abating:

> *Disadvantages I know you've got a little bit of rivalry really, that's the only way I can describe it, because Macmillan obviously established the previous one. Marie Curie did that, and I think, initially, hugely I'm afraid, because I wasn't here, I think there was a bit of friction, which has taken some time to work through. But certainly now I don't think we planned, I think it's working quite well.* **(Stakeholder 6b)**

In some instances the service was not thought to be sufficiently sensitive to the complex needs of the client group and was perceived to result in inequity of care, as illustrated by the two excerpts:

> *I'm not going to slate the call centre, yes, we've had teething problems, but I'll speak honestly from a clinician on the floor – when a district nurse requests a package of continuing care, the first thing the Coordination Centre thinks, right, I've got 21 hours, brilliant, I can book agencies, and agencies are automatically booked because they almost feel as if they've got that permission to use that 21 hours of care via the agencies, whereas a patient on continuing care, end of life continuing care, in my opinion, should be here first, for the best possible care for the patient, and for continuity. And that doesn't happen, because I mean obviously the Coordination have got a job to do, they've got to book this care for these patients that the district nurses are bringing, and they want to do it as quickly as they can. You know, they've got a lot of patients to cover, they've got a lot of visits to meet, and they want to do that. Very often you find that calls have been put out to the agencies, and they've been pre-booked, and we've been left out of the loop,*

> *and sometimes quite inappropriately, so in that way it doesn't always, the equity of care isn't always.* **(Stakeholder 7a)**

> *Things like moving and handling in particular, right equipment's in place, you know, that's important information, family dynamics, that's important to us going out to a patient. To the Coordination Centre that's not, they want to know name, address, GP, postcode, NHS number, but we want to know.* **(Stakeholder 7b)**

There was an acknowledgement that whilst the aims of the PCCC were laudable, that is, to save district nursing time, it has not always had the desired effect:

> *Yes, I think so, and it was very difficult for us, and it still is to a certain extent, for us not to take a direct referral from a colleague, a clinician or, I still wouldn't, you know, even to this day. And I don't know whether I will ever get my head round it completely. I understand why the Centre's there, and I understand it's got a place, and I acknowledge that, and I think the idea behind it is good, I don't understand why two clinicians can't talk together. I still never, we'll never work that one out, will we?* **(Stakeholder 7a)**

> *Right well my main involvement has been with the processes around the Palliative Care Coordination Centre. And what we've tried to sort out, an agreed process, because it's been quite difficult. Because they're acting as a brokerage team and I understand what they're trying to do, they're trying to take away the worry of arranging the care package, if you like, away from district nurses and away from hospital nurses and just put them into place. But that has caused quite a few difficulties with regard to the way that we operate. And we're still trying to sort out the most effective flowchart.* **(Stakeholder 8)**

Although work is ongoing to try and establish better inter-agency working, improvements have been made in some areas, particularly with reference to continuing care:

> *Well, I don't hear of as many issues, so I think people are clearer about the sorts of things that should happen. I mean I think, I was talking to Palliative Care*

> *Coordination Centre, they're clear that they have to go back to district nurses and say does it meet continuing care needs, you know, do you need to refer for continuing care? So I think that bits probably clearer. I suppose, you know, part of the issues are around continuing care bit because, although there's an agreed Lincolnshire Health and Social Care Plan, they don't seem to, nurses don't seem to be filling that in for purchasing of services.* **(Stakeholder 8)**

The same interviewee suggested an alternative to the PCCC in which the brokerage system is expanded with concomitant support and resources for DNs to engage in the care planning process:

> *Because the district nurse knows what's required, and if they could write a care plan and have the procurement abilities through PCT processes, to just go through our brokerage and we set up our brokerage to do the right invoicing and that sort of thing, you know, we surely could have worked it out. So maybe, instead of Palliative Care Coordination Centre, you know, the answer maybe is to expand the brokerage somehow across, and develop it across health and social care, but give district nurses more support in terms of time, resources to be able to do that care planning process - that's what I would see as the answer really.* **(Stakeholder 8)**

> *But when you're sending somebody out at night, you need to know what all the risk assessment is, absolutely vital. And that's not that they haven't responded, but I think it's taken a while, and again it's that learning process, if you were setting it up again. If you were going to another area, these are the learning points, aren't they, don't forget about this, get a system in place for that.* **(Stakeholder 7b)**

There were also thought to be some difficulties with information flow and communication:

> *Yes, and yet it is absolutely vital to understanding, because one thing I would say is, whilst the Palliative Care Coordination Centre was supposed to gather a lot of information, I don't know whether it's that it doesn't always receive that information, or it doesn't, the onward communication of that information isn't*

> *always as good as it might be, but we've had to work quite hard at getting a lot of that information. And again, that's really important stuff that would have been asked when the direct referrals happened.* **(Stakeholder 7b)**

7.6 Survey responses for general practitioners and district nurses

It is apparent from the survey data that as expected the DNs are the main referrers to the PCCC, but that some GPs have either used the service or were aware that it was being used on behalf of their patients. Some district nurses made specific reference to the PCCC when responding to the survey, highlighting its benefits in changing their workloads:

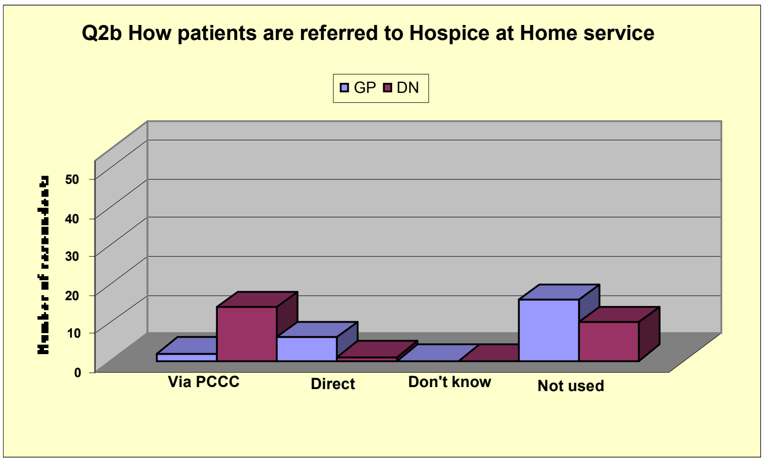
> *The Palliative Care Coordination Centre has been extremely useful and time-saving for district nurses but since its launch less communication has been forthcoming from hospitals and hospices. This may be due to previously they had relied on DNs to arrange packages of care therefore info is now minimal.* **(DN5 NW)**
>
> *Palliative Care Coordination Centre a godsend! We used to have to organise all care ourselves.* **(DN7 NW)**

However, there was also an impression that whilst the PCCC is improving coordination and reducing the workload of DNs it is increasing the fragmentation of care provision to some patients.

> *Whilst the Palliative Care coordination service is excellent and so has reduced the amount of time district nurses spend on co-ordinating services, I have had several relatives complaining about the amount of different people, carers and agencies they see and allow into their homes at a very stressful and private time of their lives. I also wonder about the lack of continuity of care when so many different agencies are used. As one relative commented to me recently "we never saw the same carer [workers] two nights running! Over a three week period we had 23 different people in the house!"* **(DN23 NW)**

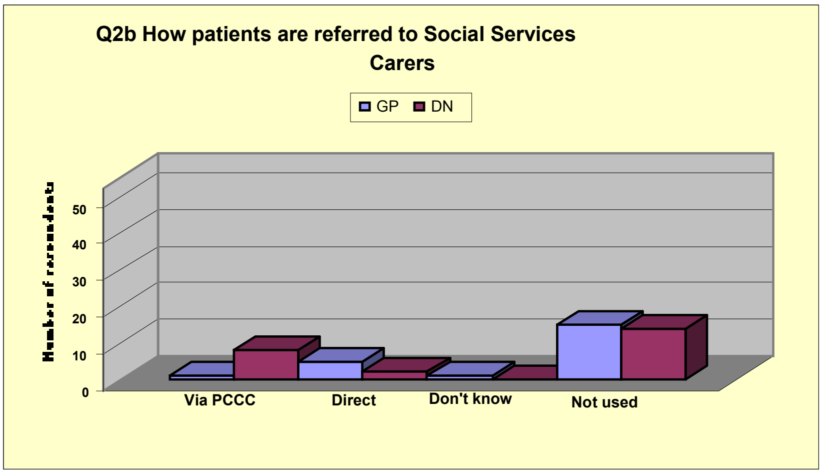
Response to the survey indicate that access to hospice inpatient and hospice day care services are predominantly being made using direct contact by primary care practitioners and the PCCC. However, as shown in Figure 20, there is a clear indication of some patients being referred to Hospice at Home services via the PCCC.

Figure 20 - Referral methods to request Hospice at Home services



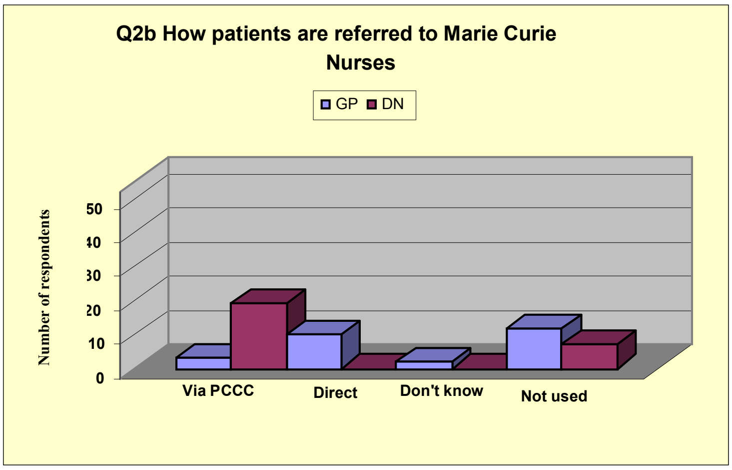
The arrangement of care by social service care workers is being undertaken both by contact with the PCCC but also by direct contact from the DNs (see Figure 21).

Figure 21 - Referral methods for social services



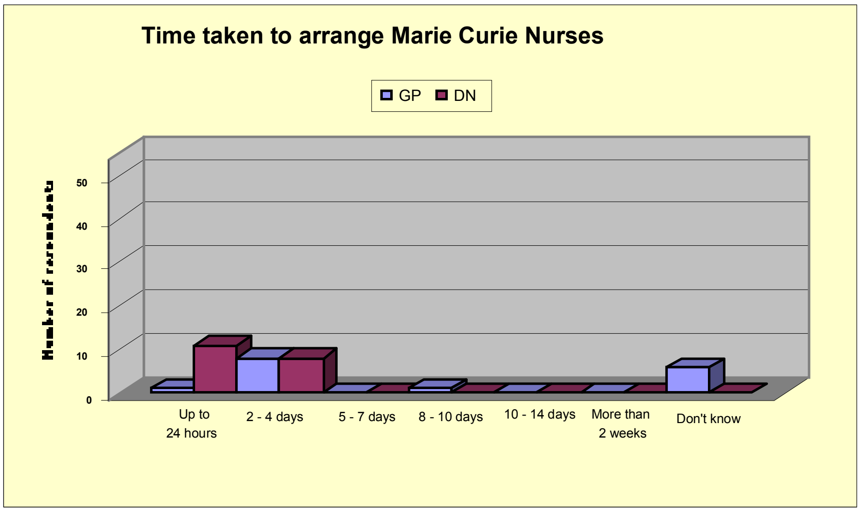
The PCCC is the main route for primary care practitioners to arrange Marie Curie nurses (see Figure 22).

Figure 22 - Referral methods to arrange Marie Curie nurses



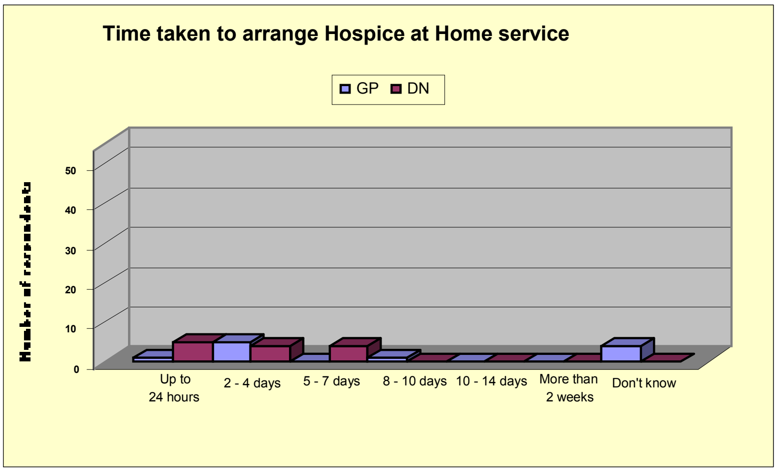
Data indicate the effectiveness of the PCCC in supporting the role of the DNs in arranging care. The data indicated (see Figure 23) that it took between 24 hours and four days to arrange Marie Curie nursing support for patients at home.

Figure 23 - Time taken to arrange Marie Curie nurses



Hospice at Home services were coordinated in a period between two to seven days as shown in Figure 24.

Figure 24 - Time taken to arrange Hospice at Home services



Overall the PCCC appears to free up DNs to care for patients.

7.7 Documentary evidence of the outcomes of the PCCC

The centre provides a countywide service with the offices based in Lincoln. Data provided by Marie Curie were extracted from the complex database used by the PCCC. Eight entries were removed after discussion with the PCCC manager because words such as ‘delete’ and ‘duplicate’ were identified next to patients’ names within the dataset.

7.7.1 Requests made to the PCCC

Requests could be made by many different health and social care professionals, although the largest users were the DNs, at whom the coordination centre was targeted. Requests were made on behalf of a total of 1042 individual patients.

7.7.2 Key issues relating to the data recorded by the PCCC

To understand the data presented it is helpful to be aware of how requests have been recorded by the PCCC.

- The high number of referrals can be seen to reflect the process of recording requests for care where each component of a care package has to be requested separately.

    - Where a patient requires a care worker to provide care in the morning, care at lunch time and care in the evening, three separate requests are recorded on the PCCC database. Where a patient requires two care workers to provide care on three occasions during the day, this will require six requests being recorded separately.

    - For each referral the number of shifts requested (day or night) is then calculated over a two week period and recorded. For example: district nurse X makes one referral for night care with one health care assistant for patient A. This is recorded as one request for 14 shifts at night over 14-days/night period. Most commonly a request would be recorded as one referral asking for eight night shifts over 14 nights, which is the equivalent of 4 night shifts per week. However for some patients, requests are made but then cancelled, perhaps due to a change in circumstances. Sometimes the requests are then rebooked, which increases the number of recorded referrals per patient.

- All booked night shifts are reviewed every two weeks and the DN makes a new referral fortnightly.

- The PCCC records only the initial request for care package components. Where social care is arranged with an agency provider or an assessment is requested for Hospice at Home:
    - After the initial 14-day period, the PCCC will communicate with the referrer regarding the continued need for the care package based on the patient assessment; updates are recorded in the patient schedule and care plan.

    - A DN will request an assessment for Hospice at Home from the PCCC. Thereafter the Hospice at Home service may supply two support visits per week, or other forms of care. Visits that are arranged in this way are communicated to the PCCC by the Hospice at Home Team and recorded in the patient schedule and care plan.

- The PCCC data does not reflect the entire care provided to a patient.

The complexity of presenting the MS Excel data filtered from the complex interactive PCCC dataset will necessitate that simply organised data are offered. The dataset was systematically filtered; however, complex computation was not possible for this analysis.

It is evident that the requests for care coordination cover a range of purposes, including the key areas of assessment, social and nursing care. The degree of success of the PCCC in coordinating care and meeting the referral requests can be assessed by considering the proportion of care requests ‘fulfilled’, ‘cancelled’ and those remaining ‘unbooked’ or ‘open’. A one off request was made for a social worker, the majority of requests can be divided into four categories of care worker: registered nurses, health care assistants, social care carers and volunteers. The following four tables provide information about the number and type of requests made:

Table 18 - PCCC number of visit requests for Registered Nursing care or assessment

<table>
<tr><th>Grade request</th><th colspan="6">Nursing Care</th><th colspan="6">Assessment</th><th colspan="6">Social care</th></tr>
<tr><td>RN</td><td>Total Requests for RN nursing care</td><td colspan="2">RN provided & request fulfilled</td><td colspan="2">HCA provided instead of RN & request fulfilled</td><td>Requests Cancelled</td><td>Total Requests for RN assessment</td><td colspan="2">RN provided & request fulfilled</td><td colspan="2">HCA provided instead of RN & request fulfilled</td><td>Requests Cancelled</td><td>Total Requests for RN social care</td><td colspan="2">RN provided & request fulfilled</td><td colspan="2">HCA provided instead of RN & request fulfilled</td><td>Requests Cancelled</td></tr>
<tr><td>Number of RN requests</td><td>389</td><td colspan="2">125</td><td colspan="2">46</td><td>33</td><td>529</td><td colspan="2">361</td><td colspan="2">32</td><td>64</td><td>1</td><td colspan="2">1</td><td colspan="2">0</td><td>0</td></tr>
<tr><td rowspan="2">No. visits provided</td><td rowspan="2"></td><td>D</td><td>N</td><td>D</td><td>N</td><td rowspan="2"></td><td rowspan="2"></td><td>D</td><td>N</td><td>D</td><td>N</td><td rowspan="2"></td><td rowspan="2"></td><td>D</td><td>N</td><td>D</td><td>N</td><td rowspan="2"></td></tr>
<tr><td>1</td><td>259</td><td>1</td><td>63</td><td>369</td><td>0</td><td>32</td><td>0</td><td>1</td><td>0</td><td>0</td><td>0</td></tr>
</table>

RN = Registered Nurse, HCA= Health Care Assistant, D= Day shift N = Night shift .

Of all 919 visit requests for an RN, 565 (61%) visit requests for RN care and assessment were fulfilled by either an RN or an HCA. Seventy-eight (8.5%) of requests were fulfilled by HCAs. Ninety seven requests (11%) were cancelled and 257 (28%) requests remained unbooked or open (see Table 18).

Table19 - PCCC number of visit requests for health care assistant care or assessment

<table>
<tr><th>Grade request</th><th colspan="6">Nursing care</th><th colspan="6">Assessment</th><th colspan="6">Social care</th></tr>
<tr><td>HCA</td><td>Total Requests for HCA nursing care</td><td colspan="2">HCA provided & request fulfilled</td><td colspan="2">RN provided instead of HCA & request fulfilled</td><td>Requests Cancelled</td><td>Total Requests for HCA assessment</td><td colspan="2">HCA provided & request fulfilled</td><td colspan="2">RN provided instead of HCA & request fulfilled</td><td>Requests Cancelled</td><td>Total Requests for HCA social care</td><td colspan="2">HCA provided & request fulfilled</td><td colspan="2">RN provided instead of HCA & request fulfilled</td><td>Requests Cancelled</td></tr>
<tr><td>Number of HCA requests</td><td>8590</td><td colspan="2">2880</td><td colspan="2">653</td><td>2383</td><td>46</td><td colspan="2">15</td><td colspan="2">16</td><td>5</td><td>3178</td><td colspan="2">651</td><td colspan="2">43</td><td>1091</td></tr>
<tr><td rowspan="2">No. visits provided</td><td rowspan="2"></td><td>D</td><td>N</td><td>D</td><td>N</td><td rowspan="2" colspan="2"></td><td>D</td><td>N</td><td>D</td><td>N</td><td rowspan="2" colspan="2"></td><td>D</td><td>N</td><td>D</td><td>N</td><td rowspan="2"></td></tr>
<tr><td>520</td><td>4358</td><td>6</td><td>835</td><td>15</td><td>0</td><td>18</td><td>0</td><td>2567</td><td>59</td><td>65</td><td>0</td></tr>
</table>

RN = Registered Nurse, HCA= Health Care Assistant, D= Day N = Night .

A total of 11,814 visit requests were made for HCA care and assessment. 4258 (36%) HCA visit requests were fulfilled with 712 (6%) of these requests being fulfilled by a RN. Twenty-nine per cent of the HCA visit requests were cancelled and 35% of HCA visits requested remained unbooked or open (see Table 19).

Table 20 - PCCC number of visit requests for Social Care Carers (SCC)

<table>
<tr><th>Grade request</th><th colspan="6">Nursing care</th><th colspan="6">Assessment</th><th colspan="6">Social care</th></tr>
<tr><td>SCC</td><td>Total Requests for SCC nursing care</td><td colspan="2">HCA provided & request fulfilled</td><td colspan="2">RN provided instead of SCC & request fulfilled</td><td>Requests Cancelled</td><td>Total Requests for SCC assessment</td><td colspan="2">HCA provided & request fulfilled</td><td colspan="2">RN provided instead of HCA & request fulfilled</td><td>Requests Cancelled</td><td>Total Requests for SCC social care</td><td colspan="2">HCA provided & request fulfilled</td><td colspan="2">RN provided instead of HCA & request fulfilled</td><td>Requests Cancelled</td></tr>
<tr><td>Number of SCC requests</td><td>11</td><td colspan="2">3</td><td colspan="2">1</td><td>0</td><td>2</td><td colspan="2">0</td><td colspan="2">2</td><td>0</td><td>108</td><td colspan="2">18</td><td colspan="2">0</td><td>45</td></tr>
<tr><td rowspan="2">No. visits provided</td><td rowspan="2"></td><td>D</td><td>N</td><td>D</td><td>N</td><td colspan="2" rowspan="2"></td><td>D</td><td>N</td><td>D</td><td>N</td><td colspan="2" rowspan="2"></td><td>D</td><td>N</td><td>D</td><td>N</td><td rowspan="2"></td></tr>
<tr><td>0</td><td>6</td><td>0</td><td>1</td><td>0</td><td>0</td><td>2</td><td>0</td><td>77</td><td>0</td><td>0</td><td>0</td></tr>
</table>

RN = Registered Nurse, HCA= Health Care Assistant, D= Day N = Night .

One hundred and twenty one requests were made for social care carers, of which 24 (20%) requests were fulfilled by HCA's and RN's, whilst 37% of requests were cancelled and 43% of visit requests remained unbooked or open (see Table 20).

Table 21 - PCCC number of visit requests for volunteers to provide care

<table>
<tr><th>Grade request</th><th colspan="6">Nursing care</th><th colspan="6">Assessment</th><th colspan="6">Social care</th></tr>
<tr><td>Volunteer</td><td>Total Requests for Volunteer nursing care</td><td colspan="2">RN provided request fulfilled</td><td colspan="2">HCA provided instead of Volunteer request fulfilled</td><td>Requests Cancelled</td><td>Total Requests for Volunteer assessment</td><td colspan="2">RN provided request fulfilled</td><td colspan="2">HCA provided instead of Volunteer request fulfilled</td><td>Requests Cancelled</td><td>Total Requests for Volunteer social care</td><td colspan="2">Volunteer provided request fulfilled</td><td colspan="2">HCA provided instead of Volunteer request fulfilled</td><td>Requests Cancelled</td></tr>
<tr><td>Number of Vol requests</td><td>15</td><td colspan="2">3</td><td colspan="2">3</td><td>0</td><td>1</td><td colspan="2">1</td><td colspan="2">0</td><td>0</td><td>4</td><td colspan="2">0</td><td colspan="2">3</td><td>1</td></tr>
<tr><td rowspan="2">No. visits provided</td><td rowspan="2"></td><td>D</td><td>N</td><td>D</td><td>N</td><td colspan="2" rowspan="2"></td><td>D</td><td>N</td><td>D</td><td>N</td><td colspan="2" rowspan="2"></td><td>D</td><td>N</td><td>D</td><td>N</td><td rowspan="2"></td></tr>
<tr><td>0</td><td>3</td><td>0</td><td>3</td><td>1</td><td>0</td><td>0</td><td>0</td><td>10</td><td>0</td><td>0</td><td>0</td></tr>
</table>

RN = Registered Nurse, HCA= Health Care Assistant, D= Day N = Night .

Twenty requests for volunteers were made of which 10 (50%) were fulfilled by RNs and HCA's. There was a deficit in the fulfilment of: 8 requests for Volunteer nursing care provision and 1 request for a Volunteer for social care provision. These are indicative of requests remaining unbooked or open (see Table 21).

Cancellation of care referrals occurred due to the death of a patient or due to the transfer of a patient from home to another care location. In Table 22 it can be observed that the PCCC was requested to arrange a vast number of care requests on behalf of the 1042 individual patients on their database.

Table 22 – Number of requests for care shifts from PCCC

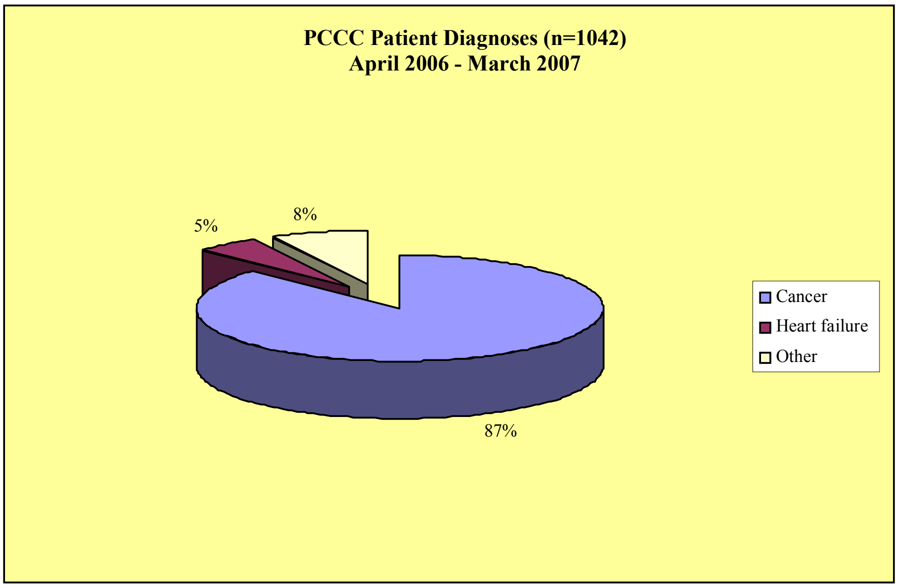
Care/shift requests	Number
Total number of care shifts requested	109076
Total number day shifts received by patients	15675
Total number night shifts received by patients	16241
Total number of shifts requests cancelled	35904
Total number care episodes received	31916

*These figures include shifts received by patients before a care visit request had been cancelled or where a request remained 'open' or 'unbooked' where only a proportion of shifts requested from a provider were fulfilled, with the completion of remaining shifts outstanding.

7.7.3 Diagnostic categories of patients

Diagnoses of the 1042 patients whose care was coordinated by the PCCC are shown in Figure 25. Eighty-seven per cent of all patients referred had cancer (n=904), 5% had heart failure (n=51) with the remaining 8% (n=81) patients having a range of other non-malignant conditions. There were 2598 deaths across Lincolnshire from cancer between 2006 and 2007, therefore it appears that 40% of potential patients were referred to the PCCC during that period.

Figure 25 - Diagnostic breakdown of patients referred to the PCCC



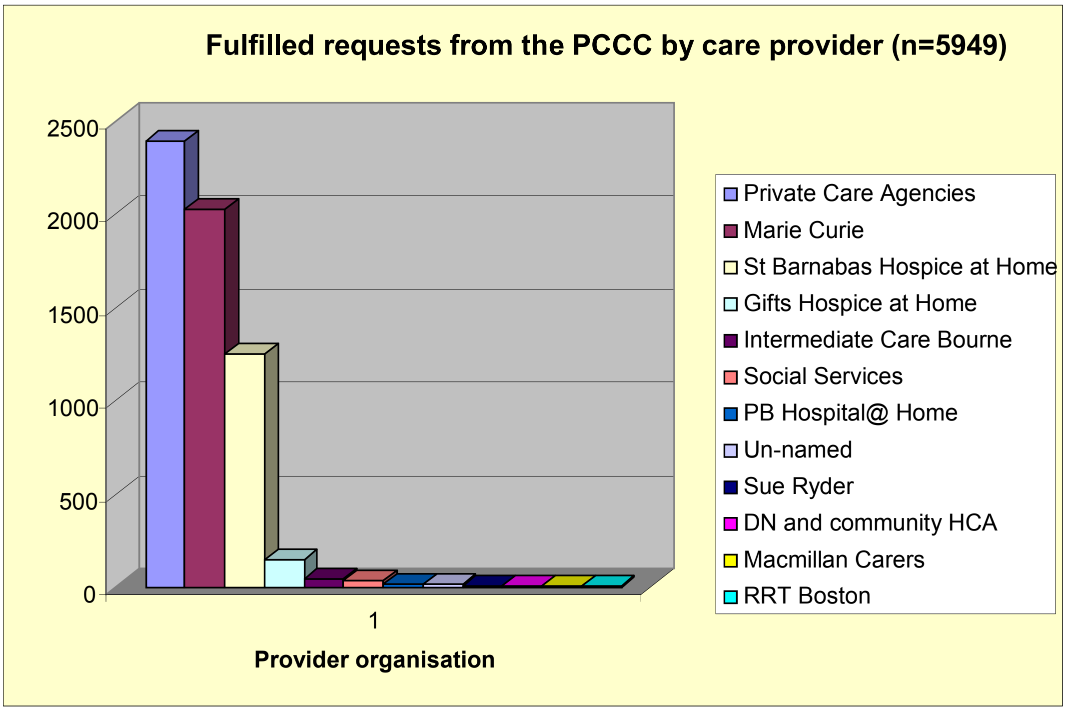
7.7.4 Coordinating care provision

Analysis of the data identified which organisation the PCCC used to provide the care workers requested. This is shown in Table 23 and Figure 26.

Table 23 - Care providers used by the PCCC

Care provider	Number of requests 'fulfilled'	
Independent Care Agencies	2391	(40%)
Marie Curie	2028	(34%)
St Barnabas Hospice at Home	1247	(21%)
Gifts Hospice at Home	150	(3%)
Intermediate Care Bourne	45	(0.8%)
Social Services	33	(0.6%)
PB Hospital@ Home	14	(0.2%)
Un-named	12	(0.2%)
Sue Ryder	10	(0.2%)
DN and community HCA	9	(0%)
Macmillan Carers	6	(0%)
RRT Boston	4	(0%)
Total	5949	(100%)

Figure 26 – Fulfilled requests to the PCCC by provider organisation



It is apparent that 40% of all fulfilled requests for care were arranged with private care agencies and Marie Curie Cancer Care provided 34%. St Barnabas Hospice at Home service provided 21% of the shift requests that were fulfilled, and Gifts Hospice at Home provided 3% of the care. In total, 58% of care requests were fulfilled by palliative care organisations.

7.8 Summary of findings from the PCCC

- The PCCC received 12888 requests for care provision on behalf of 1042 patients. However, 25% requests remained 'open' at the time of cancellation or could not be booked.
- Cancer patients made up 87% of the requests for care to the PCCC.
- There has been an inequitable balance of referrals between cancer and heart failure patients.

- Access to the PCCC is often contingent upon quick access to continuing care funding, which disadvantages patients with non-cancer diagnoses including those with heart failure.
- Although patients and some carers are unaware of the work of the PCCC, the evidence from stakeholders and specialist nurses indicated that on the whole the PCCC has improved the coordination of care services for patients at home and reduced gaps and duplication in care provision.
- Whilst communication to coordinate services is improved, there is concern that direct communication about complex patient situations between specialist service providers has been reduced.
- Some concerns were raised by the specialist nurses and the district nurses about care at home becoming more fragmented with the increasing provision of different care organisations going into patients homes at the end of life.
- Survey responses from the district nurses did not clarify if they perceived the PCCC to have reduced their work load on the telephone arranging packages of care to facilitate discharge of patients home.

8. CARER SUPPORT GROUP

8.1 Introduction

The baseline evaluation identified that district nurses and general practitioners were reliant on the provision of informal care by family carers to enable their relative to die at home. Analysis of census data also revealed that informal carers across Lincolnshire provide higher than average numbers of informal hours of care. The four patients who were interviewed relied on family and friends to provide the majority of their care and it was difficult for carers to find support. The Programme aimed to improve the wider support for patients and carers, with the specific aims to improve access to support groups and training for carers.

8.2 Carer support group

The carer support groups facilitated by St Barnabas Hospice have been financially supported by the Programme. In total, 21 carers attended the support sessions, of which two were interviewed. They regarded the carer support group lunches as a St Barnabas Hospice initiative and were not entirely clear about the involvement by Marie Curie. One carer, at first, did not like the group because she made friends with people who then stopped coming because the person they cared for had died. However, after the initial difficulties this family carer found the groups very helpful and supportive. The group provided her with the opportunity to talk with others and share experiences safe in the knowledge that her husband was being cared for at home whilst she was out.

> *'well I found it a bit distressing because, you know, you would go and talk to the other wives as well, which was the whole idea, and then the next time you went, the next month, well where's so and so, husband's died. And you'd go the next month, oh where's so, oh her husband's died. And I was finding it a bit oh dear, you know. Too close to home maybe. But, anyway, you know I do enjoy it now and a volunteer driver comes and fetches me and brings me back, and a carer comes and sits with [husband], so that I needn't worry.'* **(Family carer C2)**

The second carer had attended the lunches and has also had mixed feelings about them:

> *'I was just a bit worried about getting somebody with you because we weren't leaving you, at the moment it isn't necessary, I mean [wife] is okay now for a couple of hours. But I mean that's been very useful and we've done, we've had one or two talks about lifting and very useful things, and first aid and things that you'd perhaps wouldn't talk about. And perhaps one of the most useful, one of the Hospice cooks spoke to us about how they slip cream in the custard and cream in the soup and things, when you weren't eating it was quite a problem wasn't it'.*
> **(Family carer C1)**

At the time of the evaluation newer carer support groups were being established in Spalding and Sutton on Sea, thus extending access across the county.

The provision of information by a range of different health and allied professionals during the carers support group had the greatest impact where the information provided matched with what the family carer needed advice on at the time. Where carers are able to attend the group because a volunteer is sitting with their relative at home, this increases their confidence and enables them to attend the group.

9. DISCUSSION

The objective of this report was to look at change and continuity in the patterns of support to facilitate choice in end of life care for patients and their families with cancer and heart failure in Lincolnshire, in the context of the Programme. The evidence suggests that the most successful intervention was the DCLN, with mixed appraisals of the RRT and the PCCC. In this Discussion, we will consider the boarder context of health care policy in which the Programme is situated, acknowledge the limitations of our evaluation and summarise the outcomes of the key Programme interventions.

End of life care services have only recently become the focus of NHS and government attention (NHS End of Life Care Strategy forthcoming). This is in recognition of the public health implications of a socio-demographic trend meaning that two thirds of the 600,000 people who die each year in the UK are over the age of 75, and death usually follows a period of chronic disease such as heart disease, cancer, stroke, chronic respiratory disease, neurological disease or dementia. Most deaths across the country (58%) occur in NHS hospitals, with around 18% occurring at home, 16% in care homes, 5% in hospices and 3% elsewhere (National Council for Palliative Care, 2006). It is frequently argued that these statistics are likely to run counter to people's preferences for place of care and death: most people when asked on one occasion will express an immediate preference for home as a place of care and death (Higginson, 2003). However, it has been shown that preferences are likely to change over the course of disease, often because of family care-giving circumstances (Gott et al, 2004). For example, Gomes and Higginson (2006) have shown that 'the sustainability of keeping terminally ill people at home depends on how close their families are and how able they are to give care to their loved ones' (p 517). The NHS End of Life Care Strategy builds in part on the NHS End of Life Care Programme, in which a key aim has been to 'improve the quality of care at the end of life for all patients and to enable more patients to live and die in the place of their choice' (http://www.endoflifecare.nhs.uk/eolc, accessed 12th January 08). The Programme can be seen as a complementary initiative, focusing on addressing similar objectives and evolving from the long and respected role of Marie Curie as a major third sector player in palliative and end of life care in the UK. Lessons learnt from the Programme therefore should be incorporated into any guidance about models of service delivery that emerge from the End of Life Care Strategy.

Historically the NHS was established within a paternalistic model of professional decision-making, where the fundamental aim was to improve the health of the nation by providing equitable and accessible services (Small 2004). At this time choice in health care was not regarded as a priority or arguably as even desirable. According to Small (2004), patients' rights and responsibilities have emerged in the political and policy rhetoric since 'new' Labour reforms in the mid 1990's. The NHS emerged as a largely hospital based service, and hospital care has typically been the major expenditure that numerous policy directives have tried to curb. The last year of life is the time of greatest lifetime health care usage (Whynes 1997). There has therefore been a consistent endeavour to shift from in-patient provision to 'community care' (a largely undefined entity – generally assumed to be family caregivers, combined with primary care and social care services) in the hope of lowering costs. Examples of this shift in provision can be seen in mental health services, intellectual disability services, long term care of older people and more recently surgical services. These changes are facilitated by medical, pharmacological and technological developments with the consequence that patients tend to spend less time as in-patients. They have the advantage of saving NHS hospital expenditure but arguably there is cost shifting to primary care and increased costs, often hidden, on family carers. The Programme can therefore be seen as complying with this larger 'cost containment' agenda, although framed within the rhetoric of 'choice'.

The analysis reported here has several limitations, not least that it has been confined to the interventions that make up the Programme in Lincolnshire. It should be acknowledged that since the baseline data collection in 2005 (Payne et al 2005), there have been a number of specific changes in Lincolnshire such as PCT reconfigurations, and wider national developments, that are likely to have impacted upon end of life care services and to increase the pressure on hospitals to discharge patients as soon as possible. Marie Curie directed our focus on the Programme interventions. The incorporation of other support dimensions, such as non statutory services like care homes, local self help and charitable organisations, would have given a more complete understanding of the relationship between choice and service utilisation.

The use of a mixed methods formative evaluation methodology has resulted in a rich and complex wealth of data from multiple perspectives (Ingleton and Davies 2007). Synthesising the data to provide an accurate but nuanced evaluation has been challenging. As in other ‘real world’ research, we have endeavoured to a capture the impact of complex interventions against a backdrop of changing local and national services. There have been specific challenges in interpreting and comparing NHS and Marie Curie datasets that are largely incompatible. We have successfully obtained data from district nurses, specialist nurses, stakeholders, family carers and bereaved carers. As before, general practitioners have not chosen to respond to questionnaires or telephone interviews in the way we had hoped. They have cited being overburden by concurrent questionnaires, including those distributed by Marie Curie. Obtaining the views of service users is very important but for dying patients who are consumers of Programme interventions the window of opportunity to recruit and interview them is extremely small. In these circumstances, the use of proxy data from carers and bereaved carers provides an important insight into their experiences, in addition to carers’ and bereaved carers’ ability to evaluate their own needs and experiences (McPherson and Addington-Hall 2003). Overall, we are confident that there are sufficient data to draw the conclusions we have presented in the Report.

To summarise the findings, the Programme interventions will first be considered separately, followed by some broader issues on the implementation of the Programme and its outcomes.

The work of the DCLNs in Lincoln and Boston enabled 61% of patients referred to them to be discharged or transferred to their preferred place of care. Respondents who had accessed this service were overwhelmingly positive. But with two caveats: a lack of cover when the DCLNs were on leave. This delayed discharge and hampered communication; and secondly, home visits by the DCLNs raised patient and carer expectations which cannot then always be met by existing community services, especially district nursing services. The DCLN service was reported to improve information and co-ordination between organisations. The DCLN initiative was thought to be fulfilling many of the core objectives of the Programme in terms of providing a patient focused service where people have access to information and appropriate support services in order to make informed decisions about their care. Many of those interviewed would like to see more resources put in place to extend and increase the role of the DCLN. This intervention was regarded as the most successful and provided added value to patients and hospital staff. The DCLNs had a greater impact on cancer patients because of perceptions about difficulties in recognition of end of life in heart failure patients and questions about the appropriateness of care.

There were mixed views about the RRT. Some respondents viewed the service as a significant additional support to the primary care team and importantly, to patients and carers. Evidence showed that the service was effective in providing care and support particularly at crisis points over night. It was seen as one of the key services that enabled families to keep their loved one at home until they died. Carers valued the reassurance of knowing the service was only a telephone call away and that practical physical help and symptom control could be summoned for patients. Once again more cancer patients than heart failure patients benefitted from the service. There was some evidence that RRT staff were unable to function to their full capacity. There was a gap in services during the day at weekends when neither the RRT nor St Barnabas Hospice at Home Service was available. Uptake of the RRT telephone advice only service provided in the extended boundary area was poor and appeared to have little impact. The views of Macmillan nurses who were not working within the RRT areas were less positive. Concerns were expressed about the potential fragmentation of care into ‘pockets’ of good provision and there was a view expressed that the services provided by the RRT could be addressed equally well by additional funding for 24 hour district nursing. Data recorded by the RRT is potentially misleading as they record re-referrals by the RRT its-self and this inflates the figures for utilisation.

The PCCC also received a mixed evaluation. According to respondents the PCCC had a difficult start as it had to liaise with social services to develop a shared pathway for highlighting where patients should be referred to for care coordination and 'brokerage'. These issues appear to remain unresolved. The PCCC was valued most by district nurses who reported that it assisted with their workload. More detailed investigation of the impact of the PCCC on district nurses is warranted. Primary care practitioners (predominantly district nurses) made 81% of the referrals to the PCCC; cancer patients made up 87% of these referrals. Specialist nurses reported that the PCCC positively supported the work of district nurses with whom they had regular contact. However, some district nurses reported that while the PCCC improved coordination and reduced their workload, it appeared to increase fragmentation of care provision to some patients. Once again there are concerns about the interpretation of the data recorded by the PCCC. The data based recorded 12888 referrals on behalf of 1042 patients. However, one quarter (25%) remained 'open' at the time of cancellation or could not be booked. There is potential for misleading inferences being drawn as this inflates the figures for utilisation. Three key problems were highlighted in relation to the PCCC: reduced communication between professionals and lack of continuity of care were highlighted as a negative consequence of the PCCC; lack of flexibility leading to instances where the service was not thought to be sufficiently sensitive to the complex needs of the client group; funding issues: continuing care funding was seen as the only way to access the PCCC and was a lengthy process for patients with non cancer palliative care needs. High costs of agency care and problems with accessing care were also perceived as problematic.

While patients, carers and bereaved carers reported individual experiences of good care and being facilitated in their preferences for place of care, overall, they were often confused about roles, systems and interventions which appeared as a bewildering array of people and services. On the whole they did not attribute the care they received to the Programme interventions or to Marie Curie, apart from the RRT. Carers often related to a particular health care professional who was key for them – who this person was varied. Care was often supported and enabled by a complex array of service providers and by family networks. This suggests the need for an individual named coordinator for end of life care to assist patients navigate the complexity of service provision. Two carers accessed the Carer Support Group and they reported it as helpful but were unaware that it was linked to the Programme. They reported issues about the timeliness of the educational interventions offered at the group.

One barrier to effective care most frequently mentioned was ambulance transportation for patients. Transport at weekends was particularly problematic. Ambulance transport for patients with syringe drivers remained a problem. Bad experience of transfers may be influencing patient choice of care. The way ill or dying patients are transferred home can be unhelpfully detached from the rest of the care package – this does not enhance choice. Some carers reported difficulties getting transport for the patient to and from respite care.

Implementing a major change in services such as the Programme requires skills in negotiation and partnership working. In this final section, we consider broader issues about the extent to which improvements in communication and coordination between stakeholders across Lincolnshire have been facilitated or hampered. One stakeholder reported some of the more negative impacts including the view that in the Grantham and South West Lincolnshire area the Programme essentially copied their coordination centre then took over its role and moved it to Lincoln. Other criticism highlighted the perception of disadvantage felt by not funding a DCLN at Grantham Hospital. Some respondents reported feeling uncomfortable with some of the claims made by the Programme because the claims were felt to fail to recognize the team work required between different organisations and services to provide good palliative care. This has caused some bad feeling and a perception of increasing gaps in service provision across the county as a whole. There was some concern that the problems identified by the process of implementing the Programme will have long term implications on cluster based commissioning of palliative care services.

The Programme is based on two assumptions that family caregivers are available and willing to provide care at home and facilitate dying there, and that primary care services are able to play a key role in providing palliative care for the majority of patients in the community setting. These assumptions need closer examination. It is well recognised in the literature (Harding and Higginson 2003; Payne 2007) and in policy guidance (NICE 2004) that family carers are central to enabling home care near the end of life. However, demographic and employment trends mean that there are likely to be fewer people available and willing to provide care for increasingly older people, especially women who outlive their spouses. With increasing number of older people living alone, additional demands are likely to be placed on social and primary care services in the future. Several studies have shown either the care delivery or knowledge base of primary care practitioners to be of variable quality (Jarrett et al 1999; Barclay et al 2003). Unfortunately due to delays in implementing the educational components of the Programme in Lincolnshire, we are unable to evaluate on how well prepared community based staff were. The educational programme has the potential to raise the profile of palliative care within district nursing teams and to help practitioners better identify the needs of patients with heart failure and other conditions. There is evidence that patients with end stage heart failure remain poorly served in Lincolnshire and this confirms other research (Barnes et al 2006; Gott et al 2007).

10. CONCLUSIONS

What broader conclusions can be drawn from these findings, particularly in the light of anticipated demographic and family changes? The population of Lincolnshire is increasing, and there are likely to be greater numbers of older people choosing to live in rural and coastal areas. Moreover, the assumption that there will be family carers available and willing to provide care near the end of life needs to be reviewed. The Programme has implemented one successful intervention – the DCLN and two interventions with evidence of partial success – the RRT and PCCC. Overall cancer patients continue to benefit most from these interventions and are more likely to have choice in place of care than heart failure patients. The assumptions underpinning current end of life care services means that heart failure patients who typically experience different patterns and trajectories of illness than cancer patients, and where prognostication is more uncertain, continue to be under served. The Programme has facilitated greater choice and greater access to 24-hour care predominantly in the Boston and Spalding areas, rather than the whole of Lincolnshire. The Programme can be considered to be a partial success for cancer patients in restricted areas of Lincolnshire, enabling them to be discharged home near the end of life.

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12. APPENDICES

APPENDIX 1 - Methods

A multi-method formative model of service evaluation was employed at the baseline and end stage (see Table 1). The focus has been on collecting data on current end of life care service provision in Lincolnshire, to examine local initiatives to develop palliative care services and to assess the impact of the Programme. The following section describes the process of gaining ethical approval and the methods of data collection and analysis.

Ethics and research governance approval

Multi-site research ethics approval was gained from Huntingdon Research Ethics Committee on the 17 August 2005. An amendment to allow secondary data analysis of material collected by Marie Curie staff was obtained in August 2006. No further ethics approvals were required to undertake the end stage evaluation. NHS Research Governance approval was required from Lincolnshire teaching PCT and from United Lincolnshire Hospital NHS Trust. On this occasion a letter providing information about the return of the evaluation team and the presentation of the current research protocol document, and ethics committee documentation pertaining to the previous amendments were required. Approval were sought in April 2007 and gained in May 2007.

Methods of data collection

Table 1 - Relationship of data collection methods to the evaluation of the Programme aims

Aims Methods	Implementation of 24 hour services to serve local needs and allow more people to be cared for and die in the place of their choice.	Access and barriers to palliative care services.	Co-ordination and communication between stakeholders.	Information provision to patients and carers, and relationship to informed choices about place of care.
Documentary Analysis:				
a. NHS Mortality data	yes	yes	yes	
b. DCLN, RRT and PCCC data	yes	yes	yes	
c. Population data	yes	yes	yes	
d. Strategic documentation	yes	yes	yes	
Stakeholder Inquiry				
a. GP and DN Questionnaires	yes	yes	yes	yes
b. Interviews	yes	yes	yes	yes
c. Focus Groups	yes	yes	yes	yes
Patient and Carer Inquiry				
a. Interviews patients and carers	yes	yes	yes	yes
b. Interviews bereaved carers	yes	yes	yes	yes

Documentary analysis

Documentary data were obtained to gain current demographic and epidemiological information about Lincolnshire. Current population data and mortality data for the evaluation period 1 April 2006 – 31 March 2007 were provided by Lincolnshire PCT. Further information was obtained from the Lincolnshire Research Observatory.

Data specifically about the Programme interventions: Discharge Community Link Nurses (DCLNs), Rapid Response Team (RRT) and Palliative Care Coordination Centre (PCCC) were provided by Marie Curie Cancer Care in July 2007.

Method of analysis

Two files were provided by Lincolnshire PCT informatics department to Marie Curie:

File 1) data for April 06 – February 07 and

File 2) data for March 07.

Marie Curie staff then colour coded all patients who had been seen by the DCLNs in Boston and Lincoln and by the RRT. Both NHS files were combined and all data prior to the 1st April 2006 removed. The subsequent file contained multiple entries for patients who had one or more admission to hospital over the period. The total number of entries in the combined file was 28893. The file containing the combined data from both NHS data sets underwent a process of systematic filtering. All duplicate names and entries were removed since the number of hospital admissions was not analysed. All deaths under 18yrs of age were removed. Rules were created to identify and filter the number of cancer related deaths and the number of heart deaths and the location of these deaths. Underlying cause of death from ICD 10 Codes 'C 00 to D 48.9' for cancer were selected and ICD 10 code 'I 00- 52.8' for heart. Causes of sudden death were removed from the data. Further filtering using specific ICD 10 Heart failure codes were used to identify deaths caused by heart failure. Further filtering by post code using the RRT post code area zones for home visits and the post code area zones for RRT telephone advice enabled the calculation of cancer and heart failure deaths within these population areas.

Data provided by Marie Curie for the RRT, DCLN services and the PCCC were each systematically filtered using the same methodology.

Stakeholder inquiry

There were three elements to the stakeholder inquiry:

- Survey of general practitioners (GPs) and district nurses (DNs);
- Interviews with stakeholders;
- Focus groups with specialist palliative care and heart failure nurses (HFNs).

Survey of GPs and DNs

The baseline evaluation undertaken across Lincolnshire in 2005 identified a range of issues related to palliative care provision across the county. Six key themes were consistent across the stakeholder evaluation which included the GP and DN survey, interviews with service providers and focus groups with specialist nurses.

A survey was conducted to obtain the views and experiences of GPs and DNs about end of life care.

Recruitment of General Practitioners

Addresses of GPs were provided by Lincolnshire PCT in April 2007. The survey questionnaires were posted to individual GPs in May 2007. GPs were only identified by PCT location on the returned questionnaires. Reminder letters were sent. To supplement the survey data, 12 GPs were identified by the Marie Curie RRT and invited to participate in telephone interviews. Two GPs agreed.

Recruitment of District Nurses

The name of the lead for community services was requested from Marie Curie Cancer Care in March 2007. Contact details for district nursing leads for the new PCT clusters were provided in April 2007. The PCT cluster lead DNs agreed to distribute the questionnaires to all Level 6 and 7 DNs in May 2007. Reminder letters were distributed using this method.

Analysis of questionnaires

Completed questionnaires were labelled by the PCT clusters for DNs and GPs. Data from closed questions were coded and entered onto Statistical Package for the Social Sciences (SPSS). Answers to open ended questions were entered into NVIVO v7 (computer aided qualitative data analysis) software and were analysed thematically.

Interviews with stakeholders

The interviews with stakeholders were designed to identify key aspects of strategic service provision .

Recruitment

The recruitment of stakeholders occurred between April and June 2007. Stakeholders were identified through their association with the Programme executive committee and through discussions with local NHS, Voluntary and Social Services departments across Lincolnshire. Stakeholders were identified for their strategic and service provision positions within their organisations. Stakeholders were invited to participate and interviews were arranged.

Interviews and Data Analysis

Face-to-face interviews were conducted in May and June 2007 by Dr Sargeant and took between 10–81 minutes. An aide memoire was used to guide the interviews, which were audio recorded with permission. The interviews were analysed using NVIVO qualitative data analysis software.

Focus groups and interviews with specialist nurses

Recruitment

The recruitment of specialist nurses and Marie Curie nurses commenced in April 2007. Macmillan nurses, Marie Curie nurses, heart failure nurses across Lincolnshire were invited to attend a discipline specific focus group. The focus group participants were initially contacted via a representative from each service.

Focus groups and analysis

Four focus groups were held. The focus groups were audio recorded, transcribed and entered into an NVIVO database for thematic analysis.

Patient and carer inquiry

An investigation of the views and experiences of current cancer or heart failure patients and their carers, and with bereaved carers was undertaken (see Table 2).

Interviews with Patients, Carers and Bereaved Carers

Interviews with patients, carers and bereaved carers aimed to:

- identify what services were received by patients and their carers and any changes in delivery between 2005 and 2007
- identify access to the Programme interventions
- explore how they experienced any services received
- identify current gaps or overlaps in service provision and any changes since 2005
- identify any changes in information provision to the patients and their carers.

Recruitment

The recruitment of patients and carers began in May 2007 and was completed in August 2007. Assistance with recruitment was requested from a number of organisations across Lincolnshire. Cancer patients and carers were recruited through health professionals who acted as intermediaries to maintain patient confidentiality, as required by our ethical approval.

Interviews with bereaved carers

Interviews with bereaved carers aimed to:

- identify what services had been received by the bereaved carer and for the deceased person
- explore how these services were experienced
- identify gaps or overlaps in service provision before and after the death
- identify what information had been provided before and after the death and how helpful it had been
- explore choice and what services would have been helpful before and after the death.

Recruitment

Recruitment began in May 2007 with the identification of potential participants. Discussions were undertaken with the RRT and the PCCC during May and June and with the heart failure nurses and St Barnabas Hospice between June and July. A purposive sampling technique was employed to identify bereaved carers of individuals who had died from cancer or from heart failure in Lincolnshire. Interviews were conducted between June and August 2007 (see Table 2).

Presentation of findings

The findings will be presented in tables, figures and using direct quotes from informants. Direct quotes are illustrative of the issues identified and we have attempted to draw on a broad selection of participants. Identifiers are provided in brackets following each quotation.

Table 2 - Data collected in Lincolnshire during May – August 2007

Evaluation Data	Anticipated recruitment/ data	Details of participants and data collected	Final sample and data collected
Interviews stakeholders	10	Interviews held n= 11	11
Survey – GP	406	Returned n = 52 (13%) Reminder letters sent 12 GPs invited to telephone interview	52 2 interviewed
Survey - DNs	Sent to a total of 86 level 6 and level 7 DN's	Returned: n= 34 (39.5%) Reminder letters sent	34
Focus Groups - Macmillan nurses	1 Focus Group	1 held (n=9)	1 (n=9)
Focus Groups - HFNs	1 Focus Group	1 held (n=6)	1 (n=6)
Focus Groups - Marie Curie nurses	1 Focus Group	1 Held (n=7)	1 (n=7)
Interviews cancer patients	5-10	Patients receiving RRT, DCLN over Lincolnshire Recruitment via MCCC and St Barnabas	3
Interviews heart failure patients	5-10	Patients receiving RRT, DCLN over Lincolnshire Recruitment via MCCC and St Barnabas	3
Interviews carers of cancer patients	5-10	Carers receiving either RRT, DCLN, PCCC calls or attend support groups Recruitment via MCCC and HFN	7
Interviews carers of heart failure patients	5-10	Carers receiving either RRT, DCLN, PCCC calls or attend support groups Recruitment via MCCC and HFN	3
Interviews bereaved carers of cancer patients	5-10	Bereaved carers who received one of the following: RRT, DCLN, PCCC calls, attended support groups Recruitment via MCCC and St Barnabas	7
Interviews bereaved carers of heart failure patients	5-10	Bereaved carers who received one of the following: RRT, DCLN, PCCC calls, attended support groups Recruitment via MCCC, HFN and St Barnabas	4
OOH service data	OOH call data/ service usage	Requested to be followed up	Nil
Ambulance service ECP data	Number and type of call outs to Boston area	To be requested following recent interview	Nil
MCCC PCCC dataset		Requested	Received
MCCC RRT dataset		Requested	Received
MCCC DCLN dataset	Lincoln and Boston data sets	Received	Received
NHS Informatics data set		Requested from MCCC	Received

APPENDIX 2 - Participants

Patient interviews

	Patients	**Relationship of patient to carer**	**Age**	**Marie Curie Delivering Choice Programme services in area**
CANCER	P1 C1 C	Wife		DCLN, PCCC, No RRT, CS
	P2 C3 C	Husband		RRT DCLN,PCCC, No CS
	P3 C7 C	Husband		DCLN, PCCC, No RRT, No CS
HEART	P1 H	No carer		RRT DCLN,PCCC, No CS
	P2 C3 H	Husband		RRT DCLN,PCCC, No CS
	P3 H	No carer		DCLN, PCCC, No RRT, No CS

Carer interviews

	Carer	**Relationship of carer(s) to patient**	**Age**	**Marie Curie Delivering Choice Programme services in area**
CANCER	P1 C1 C	Husband	75	DCLN, PCCC,CS, No RRT
	C C2	Wife	64	DCLN, PCCC,CS, No RRT
	P2 C3 C	Wife	-	RRT DCLN,PCCC, No CS
	C4 C	Husband	75	DCLN,PCCC, CS, No RRT
	C5 C	Daughter	74 & 41	RRT,DCLN,PCCC, No CS
	C6 C	Husband & daughter	66	DCLN,PCCC, No CS, No RRT
	P3 C7 C	Wife	53	DCLN,PCCC, No CS, No RRT
HEART	C1 H	Wife	76	RRT,DCLN,PCCC, No CS
	C2 H	Wife & daughter	78 & -	RRT,DCLN,PCCC, No CS
	P2 C3 H	Wife	68	RRT,DCLN,PCCC, No CS

Bereaved carer interviews

	Bereaved carer	**Relationship of bereaved carer(s) to patient**	**Age**	**Marie Curie Delivering Choice Programme services in area**
CANCER	BC1 C	Husband	-	DCLN, PCCC,CS, No RRT
	BC2 C	Wife	72	RRT,DCLN,PCCC, No CS
	BC3a3b C	Wife & Daughter	76 & 47	RRT,DCLN,PCCC, No CS
	BC4 C	Wife	-	RRT,DCLN,PCCC, No CS
	BC5 C	Wife	52	RRT,DCLN,PCCC, No CS
	BC6 C	Wife	76	RRT,DCLN,PCCC, No CS
	BC7 C	Wife	66	DCLN,PCCC, No CS, No RRT
HEART	BC1 H	Husband	-	RRT DCLN,PCCC, No CS,
	BC2 H	Daughter-in-law	60	RRT DCLN,PCCC, No CS,
	BC3 H	Wife	56	RRT DCLN,PCCC, No CS,
	BC4 H	Son	46	RRT DCLN,PCCC, No CS,

DCLN - Discharge Community Link Nurses; RRT - Rapid Response Team
PCCC - Palliative Care Coordination Centre; CS - Carer Support Group
‘No’ = no service provided in the area

Focus group participants

Macmillan nurses	Heart failure nurses	Marie Curie nurses
9	6	7

Sample of stakeholders

Participating stakeholder organisations	**Number of representatives**
East Midlands Ambulance Service	1
Gifts Hospice	2
Lincolnshire County Council	2
Lincolnshire PCT	1
St Barnabas Hospice	2
United Lincolnshire Hospitals Trust – Boston Hospital	2
United Lincolnshire Hospitals Trust – Lincoln County Hospital	4