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**Independent Evaluation of the Marie Curie Cancer Care
'Delivering Choice Programme'
CHESS and CAPCCS work streams**

End Evaluation Report for Leeds

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**Professor Sheila Payne, Professor Jane Seymour, Dr Christine Ingleton,
Dr John Chatwin**

**International Observatory on End of Life Care
Division of Health Research
Lancaster University**

EXECUTIVE SUMMARY

This report is the result of an independent process evaluation of two service improvement initiatives implemented by Marie Curie Cancer Care as part of their Delivering Choice Programme. The programme seeks to increase choice at end of life, and this report focuses on aspects of the project in Leeds.

At the request of MCCC, we focus on two of the eight work streams that are being piloted in the region. These are: *Care Homes End of Life Supportive Services (CHESS)*, and *Complex and Palliative Continuing Care Service (CAPCCS)*. These two work streams address different aspects of end of life care: CHESS focuses on end of life care in care homes, and CAPCCS is concerned with the provision of a community based support service closely linked to the District Nursing Service. Therefore, the aims of the analysis are slightly different for each workstream.

For CHESS, our objective was to explore whether or not the service worked; the impact it had on the internal systems and processes within participating care homes; the impact it had on access, support and communication for stakeholders (i.e. care home staff and outside healthcare professionals; whether or not it was a sustainable initiative; and the impact it had on users – the patients and families involved.

Our evaluation of the CAPCCS workstream addressed aspects of service delivery and integration including information flow and the effectiveness of the ‘generic worker’ model that the initiative utilises; the impact that CAPCCS had on patients and families; and workforce implications including the training and skills that might need to be addressed if the service were to develop further.

Findings and recommendations: *CHESS*

- As a pilot initiative, CHESS has demonstrated that a multi-layered approach which combines a course of training workshops with facilitated support via smaller local meetings and a degree of ‘on demand’ contact with training staff is an effective way of improving quality of end of life care in a range of care homes. It has been able to enhance the quality of care in homes where effective end of life

provision was already in place, but more importantly, it has enabled those homes which were less well organised in this respect to develop highly effective systems and procedures from the ground up.

- Participating homes have seen a positive impact, both on residents (in terms of facilitating their wishes in relation to their end of life care), and care home staff at all levels (in terms of greater levels of professionalism, knowledge, awareness of end of life issues, and confidence in dealing with external healthcare professionals, relatives and other staff).

- The programme does appear to have addressed all of the major areas relevant to end of life care in care homes, and the training programme is flexible enough to accommodate additional themes as and when they arise. However, continued care needs to be taken to ensure that existing services and initiatives in the city (such as those supplied to care homes by Community Nurse Specialists or District Nursing teams) are acknowledged and learned from so that key palliative care agencies are not alienated.

- In care homes that have embraced the CHESSE ethos there have been positive developments in the organisation of internal systems. Specifically, it is evident that the formalisation of processes and documentation (such as Advance Care Planning) has greatly facilitated the carrying out of residents wishes in relation to their end of life care – particularly by making it easier for them to stay in the care home if this is their preferred place of death.

- In parallel with this, the greater confidence that care home staff have reported in dealing with end of life issues now that procedures and processes are clearly defined and synchronised with the requirements of outside agencies, is very encouraging. CHESSE has enabled the often undervalued members of the care home workforce (in particular, care assistants and other unqualified staff) to develop a greater sense of professional identity and worth.

- A key aim of CHES was to improve communication between care home staff and outside healthcare professionals – particularly out of hours GPs. In many care homes this is not a major issue, and good professional relationships between home staff and outside healthcare professionals already exist. However, in participating homes that hitherto experienced problems in this area (high levels of inappropriate call-outs, for example), a greater awareness of how to put effective systems and planning into place has meant that information routinely required by visiting healthcare professionals – from accurate recording of the resident’s ongoing condition, through to the Advance care plan – is now readily available to them. This has facilitated communication and in some cases fostered more collegial relationships with care home staff. Similarly, CHES provides care home staff with a deeper knowledge of the medical and bureaucratic processes that accompany end of life care, so instances of inappropriate call-out to various agencies are reduced.

- The issue of the sustainability of CHES is complex. Although reports from participating homes have been very positive, there have been concerns expressed regarding the actual benefit (in terms of systemic and cultural change within the citywide care home arena) that the relatively small number of participating homes actually represents. Similarly, there has been some expression of concern among stakeholders that the homes that would have benefited most from the initiative are the ones least likely to have engaged with it. If CHES is to continue, and have a tangible citywide impact, the issue of recruitment and involvement (of homes) needs to be addressed. It is acknowledged, however, that considering the realistic limitations of time and resources that CHES in its present form is under, this will be a very challenging aspect of its development.

Findings and recommendations: CAPCCS

- Overall, the CAPCCS programme does appear to have had a significant positive impact on the way end of life care is delivered to patients who choose to die in their own home (or care home). The CAPCCS service as a whole is very popular with carers and DNs, and the personal approach and good communication skills of the HPCAs were particularly noted.
- The method of referring patients to CAPCCS appears to be satisfactory in terms of the way it is integrated into existing computerised systems (i.e. RIO). There were some concerns expressed about the speed at which the system could be updated in the light of fast changing patient conditions. However, these were not regarded as particularly significant due to the close telephone contact that DNs usually maintained with HPCAs.
- Referral pathway issues were raised by some stakeholders. In particular, it was suggested that opening up referral access to groups of healthcare professionals other than DNs would be advantageous. However, much of the success of the pilot programme has been due to the simple and straightforward way in which the service has been meshed with the particular organisational needs of the DN service. This has allowed the activities of the programme to be relatively streamlined and focused, with lines of accountability and the demarcation of roles clearly stated. While it may be that opening up the referral pathway is a valid proposition, at present the relatively limited resources available to CAPCCS would make this difficult.
- Communication between DNs (i.e. case holders) and HPCAs is reportedly very good, with a degree of mutual respect on both sides – HPCAs deferring to the DNs whenever necessary, and DNs voicing few complaints about the abilities and professionalism of the HPCAs.
- Some higher level inter-agency communication issues have been raised. These relate mainly to contacts between CAPCCS administrators and joint care

managers. It has been suggested that systems and procedures for withdrawing CAPCCS services from patients - in cases where a patient's condition has improved and they are no longer regarded as 'fast track' - need to be reviewed so that relevant personnel are always informed before HPCAs are pulled out.

- Similarly, it appears that although CAPCCS is designed to work closely with DN services on the ground, there needs to be closer synchronisation of lead-out times with other agencies so that withdrawal of CAPCCS dovetails with the provision of alternative care arrangements.
- The organisation and implementation of care plans works well from the perspective of HPCAs. Similarly, most DNs regarded the system as adequate. However, an issue of concern to some DNs was the number of different care plans that HPCAs need for a given patient, and the level of detailed instruction that they appear to require. The implementation of 'generic' care plans for commonly used interventions (such as the use of lifting hoists) could be a means of reducing the administrative burden on DNs.
- In general, the current level of training and support available to HPCAs appears to be well suited to the tasks they are asked to perform. Further training might focus on more 'medical' issues, such as the giving of medication.
- The selection and training of HPCAs is regarded as a crucial element in the success of CAPCCS. The level of attention given to making sure that applicants for HPCA posts have the right mix of social and communication skills for end of life care - along with the routine caring skills that are required - has meant that the current team of HPCAs are seen as extremely professional and effective. If CAPCCS is developed further, it is crucial that this element of the service is not neglected.
- It appears that the 'generic worker' model is likely to be the most effective way of supplying the type of care that the CAPCCS service provides. Certainly, none of our respondents were able to suggest a model that might be more suitable. It was generally acknowledged that without this form of targeted, yet versatile,

intervention, far fewer people would be able to die at home – particularly those who have little or no family or carer support.

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1 BACKGROUND TO THE EVALUATION

Marie Curie Cancer Care implemented the Delivering Choice Programme in a number of areas across the UK. The Programme aims to provide patients with more choice at the end of life. A key objective of the Programme is to help providers and commissioners of care to redesign services in order for patients to have choice for place of care and death.

The Delivering Choice Programme has involved a range of bespoke regionally informed initiatives (focusing on Lincolnshire, Leeds, Tayside (Scotland) Barnet (North London), South-east London, Somerset, and Northumberland (Tyne and Wear)). Within each of these regions there have been multiple discrete ‘work streams’ addressing areas of end of life care that have been highlighted by local scoping exercises. These range from the provision of respite care for terminally ill patients, through to IT infrastructure support and information management systems for palliative care health professionals. As a high profile national initiative, the programme has also been instrumental in providing guidance for improving supportive and palliative care for adults with cancer and other life limiting illnesses (Dept. of Health, 2008), and the white paper *‘Our Health, Our Care, Our Say: a new direction for community services’* (Dept of Health, 2006) refers to the three pilot sites of the Delivering Choice Programme (Leeds, Tayside and Lincolnshire) as central building blocks of the government’s focus on improving choice and end of life care within the community.

Marie Curie Cancer Care originally commissioned our team to undertake an independent evaluation located in three sites: Lincolnshire, Tayside and Leeds. In October 2006, this independent evaluation was transferred to Lancaster University. Baseline evaluations for Lincolnshire, Tayside and Leeds were completed by 2007, along with an end evaluation for Lincolnshire (2008). The end evaluation for Tayside is scheduled to begin early in 2009, and this report represents the end evaluation for Leeds.

As part of the Delivering Choice Programme, MCCC are currently piloting eight distinct work streams in the Leeds area. These include:

Work stream 1: Support for patients & carers

Palliative Care Co-ordinator for Patients and Carers. The Leeds Project has appointed a Palliative Care Co-ordinator for Patients and Carers. The post holder will work to develop recommendations and take forward actions for the provision of support to palliative care patients and their carers across all communities in Leeds.

South Leeds Day Hospice. A day care facility has been introduced at St George's Centre in South Leeds. Referrals into this service are via the normal referral route for hospice day care.

Work stream 2: Timely and coordinated discharge of palliative care patients from hospital and hospice

Palliative Care Discharge Facilitator. The Palliative Care Discharge Facilitator works across acute trusts and the community to support the discharge of patients at the end of life from hospital to their preferred place of care.

Meet & Greet Scheme. This service offers support for patients and carers for the first 24 hours after discharge from hospital.

Work stream 3: Transportation of palliative care patients

Palliative Care Ambulance. Operated by the Yorkshire Ambulance Service, this provides transport for patients at the end of life who are discharged from hospital. It also transports patients to urgent admissions and appointments..

Work stream 4: Community teams that will provide care to patients at home in a responsive, flexible manner that is based on need, to mitigate crisis

Complex and Palliative Continuing Care Service (CAPCCS). This initiative provides support for district nurses by supplying additional health and social care for patients who have chosen to die at home.

Work stream 5: Improving access to palliative care services for ethnic minority patients

Black and Minority Ethnic Palliative Care Link Worker. The aims of this work stream is to improve access to palliative care for communities from various ethnic and religious backgrounds in Leeds.

Work stream 6: Education and development for all professionals that provide care for palliative care patients

Education & Development Facilitator & Administrator. The Palliative Care Training and Development Facilitator & Administrator work with key stakeholders to coordinate the delivery of palliative care training to all groups of staff that provide care for palliative care patients.

Work stream 7: Palliative care within care homes

Palliative Care Facilitators in Care Homes. The Leeds Project has two Palliative Care Facilitators employed to roll out Care Homes End of Life Supportive Services (CHESS). This service aims to support care home staff in providing palliative care to their residents through training workshops and better links to local community services.

Work stream 8: Identification of palliative care patients

Systems Integration Analyst. A Systems Integration Analyst has been commissioned to investigate the current IT systems in place in the various health and social care organisations in Leeds and make recommendations for ways in which information can be accessed and shared between these organisations in the form of a Palliative Care Register.

At the request of MCCC, this report focuses on two of these work streams: *Care Homes End of Life Supportive Services (CHESS)*, and *Complex and Palliative Continuing Care Service (CAPCCS)*.

1.1 Evaluation objectives

The two work streams that this evaluation is concerned with address different aspects of end of life care: CHESS focuses on end of life care in care homes, and CAPCCS is concerned with the provision of a community based support service. As discrete entities, they do not share any particular administrative or organisational structures beyond being part of the Delivering Choice Programme. The specific evaluation objectives for each stream are therefore slightly different. Importantly too, it should be noted that the themes which form the basis of the analysis presented in this report reflect issues of organisation and process which were of particular interest to MCCC. These were arrived at after close discussion with MCCC representatives at a local and national level.

1.2 CHESS

Care Homes End of Life Supportive Services (CHESS) builds on a palliative care programme originally undertaken by Leeds Primary Care Trust as part of the Gold Standards Framework in Care Homes (GSFCH) initiative. It is fundamentally a service improvement initiative which aims to support care homes in the delivery of palliative care to their residents, and improve the resident and family experience of care delivery during the last 6 -12 months of life.

This evaluation focuses on exploring the following aspects of the CHESS initiative:

i) Does it work? Is CHESS an effective and efficient way of improving end of life care in care homes? Does CHESS address all the areas that influence provision of end of life care?

ii) Internal impact. What impact has CHESS had on systems, procedures and processes within participating care homes?

iii) External connections. What impact has CHESS had on access, support and communication received by and from community services? Are there improved levels of common understanding between community services (i.e. Community Palliative Care Nurses / GPs) and care homes?

iv) Sustainability. What are the levels of commitment displayed by care home management? Is participation perceived to improve care home status (i.e. in terms of statutory accreditation).

v) Impact on users. What impact does CHES have on patients and their families in terms of quality of care, choice, involvement and decision making?

1.3 CAPCCS

CAPCCS is a service improvement initiative which has been designed to deliver an additional health and social care workforce based on the use of Health and Personal Care Assistants (HPCAs or ‘generic workers’). It was re-configured from two existing services within the city – the North West District Nursing Relief Team, and the East Leeds Integrated Palliative Care Service (ELIPCS).

For the CAPCCS evaluation, the following elements of the work stream were addressed:

i) Service delivery and integration. How efficient is the service in terms of: access by professionals; referral and delivery; information flow between professionals; effective use of care plans; and flexibility of service? Does the ‘generic worker’ model maximise the impact on patients and families while minimising the resource utilisation needed to deliver that impact?

ii) Impact of the service on patients and families. What impact does CAPCCS actually have on patient and carer experiences of care? Continuity of care – what does this mean to families, and what aspects are important to them? Does CAPCCS facilitate continuity? How do patients and carers want to access the service (i.e. via District Nurses or Support Workers)? Does CAPCCS facilitate choice (i.e. place of death)? Support – do families who engage with CAPCCS feel satisfied with the level of support etc? What else could be done to improve the experience?

i) Workforce implications. Is there a workforce willing to provide the mix of tasks required? What mix of training is required? What ongoing support might be needed?

2 METHODS

2.1 Ethics and Research Governance Approval

Multi-site research ethics approval was gained from Huntingdon Research Ethics Committee on the 17th 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 this end stage evaluation, however an amendment was granted in March 2008 to cover changes in project personnel, as well as a change of host institution (from the University of Sheffield to Lancaster University). For the baseline evaluation in Leeds, NHS Research Governance approval was originally obtained from Leeds Teaching Hospital Trust, and Leeds PCT. As with ethics approval an amendment to the local governance arrangements for this end evaluation was granted in August 2008. An honorary contract for Dr Chatwin, as the researcher for this part of the evaluation, was also obtained from Leeds PCT.

2.2 Methods of data collection (CHESS work stream)

CHESS was a pilot initiative, and as such, involvement was restricted to 33 out of a possible 174 in the Leeds area (20% or 1/5 of all the care homes in Leeds). In an attempt to facilitate equality of access to the pilot, in July 2007 MCCC sent out introductory letters to all 174 care homes in the Leeds area at the time. These outlined the expected benefits to each care home, criteria for participation in the programme, and the cost of participation. Reminder letters were sent out in August 2007, and these were followed up by telephone calls and face to face visits by MCCC facilitators.

MCCC state that a multi-disciplinary approach was taken for the selection of the final 33 care homes into the programme (*Internal MCCC communication, 2008*). It is not clear exactly what this actually involved, however, they do acknowledge that a degree of overt selection was utilised. It was reported that funding for facilitators and training was limited, so there was a desire to focus resources where they would be most effective. The programme was originally run by three facilitators, however, by the onset of our evaluation, one of these had left the project and the workload was being

shared between the remaining two. The often transitory nature of care home organisation (particularly in terms of management and staff retention) was also described as an issue that could potentially undermine the ongoing training model MCCC were proposing. One significant requirement for participation, therefore, was that a care home had retained the same manager for at least a year. The cost of participation in CHESS was £350 for a single participant care home, with a reduction for 2 or more participants. For this one-off fee, the two facilitators provided a series of training workshops which the nominated representative of the care home (the ‘champion’) could attend. It also covered ongoing (and to some extent, on demand) facilitator support, and inclusion in regular facilitated meetings where ‘champions’ from care homes local to one another could meet and discuss relevant issues. Initially, 35 homes signed up to participate in CHESS, and 2 subsequently dropped out of the programme after non-attendance at the first training workshop in October 2007.

Since the Care Standards Act came into force in 2000, care homes are no longer classified as residential or nursing homes and all homes are now registered as care homes. The Care Standards Act, however, provides for three classifications:

Care homes – Care homes for people who can no longer manage to live independently. In these establishments, GPs and other professionals continue to provide health care for residents in the same way as if they were in their own homes.

Care Homes with Nursing – This type of home provides 24 hour nursing care by qualified nurses and health care assistants. The manager or person in charge of the home must be a qualified nurse or doctor, and there must always be nursing staff on duty.

Dual registered homes – These provide both functions.

The methods utilised for the collection of data in the CHESSE evaluation included:

2.3 Postal survey of participating care home 'Champions'

A postal survey of care home workers who had been nominated to take a lead role in the implementation of CHESSE within their individual homes - was carried out in July 2008 (n=33). (These individuals are referred to by MCCC, and throughout this report as 'champions'). The questionnaires contained a mix of closed and open questions (i.e. questions requiring only a yes / no answer) along with ones which enabled respondents to give longer free text replies. (See appendix 1 for a copy of the survey, and appendix 2 for details of the sample makeup.) Completed questionnaires were coded and the qualitative elements were analysed thematically with the aid of NVIVO v7 (computer aided qualitative data analysis) software. Answers to closed and multiple choice questions were collated into an EXCEL spreadsheet for analysis.

As key individuals dealing with the practical day to day implementation of CHESSE, we wanted to gain the perspectives of 'champions' on the programme and ascertain, among other things, how effective they considered it to be. Elements of data from the survey will be presented throughout this report in the relevant thematic sections.

2.4 Interviews with stakeholders

In-depth semi-structured interviews were conducted with a range of stakeholders (see appendix 3 for a breakdown of respondents). These included care home managers from participating and non-participating homes; 'Champions' from participating homes; facilitators who provided training and support for the CHESSE programme; and healthcare professionals from the community who had been involved with CHESSE participating homes. Where possible, interviews were audio recorded (with the permission of the participant) and were conducted either face to face or over the telephone. Interviews for the CHESSE work stream lasted between 10 and 50 minutes. Transcripts and field notes were analysed thematically with the aid of NVIVO v7.

2.5 Interviews with bereaved carers

In-depth semi-structured interviews were conducted with bereaved carers who had engaged with participating and non-participating care homes. These interviews were aimed at exploring the experiences of these individuals as they navigated the various stages of end of life care. Data consisted of face to face, and telephone interviews of between 20 and 60 minutes duration. One participant who did not wish to be interviewed supplied a written account of her experience. Data were analysed thematically with the aid of NVIVO v7.

2.6 Site visits (care homes) and informal group interviews

As opportunities arose, informal interviews and observations were carried out during visits to care homes to interview managers and ‘champions’. Informal participant observation and group interviews were also conducted at CHESS training workshops and the ‘cluster meetings’ for care home representatives regularly held by MCCC facilitators.

2.7 Residential case studies

Case studies of 2 deceased residents based in CHESS participating care homes were obtained. These focused on the progression of specific residents as they engaged with CHESS protocols, the examination of any written records that were available, and where possible, informal interviews with relevant staff, and bereaved relatives.

2.8 Documentary analysis

This included examination of MCCC resources, workshop training materials, internal / public reports, and any independent user feedback that was available.

2.9 Recruitment

The majority of data for the evaluation of the CHESS work stream was collected between May and August 2008 (see appendix 4 for the project timeline). A small amount of supplementary material was collected during September and October 2008.

2.10 Methods of data collection (CAPCCS work stream)

CAPCCS is a service improvement initiative which has been designed to deliver an additional health and social care workforce, and was re-configured from two existing services within the city – the North West District Nursing Relief Team, and the East Leeds Integrated Palliative Care Service (ELIPCS). Additional funding to expand the resource has been provided on by the Marie Curie Delivering Choice Programme (£170,000), and the Continuing Care Service within the city (£170,000).

CAPCCS was launched as a pilot initiative in May 2008, and works in conjunction with the Service Delivery Framework for Level 6 palliative (‘fast track’) care patients via the District Nursing service. Essentially, the service provides dedicated Health and Personal Care Assistants (HPCAs) who can take on many of the routine and non-medical caring tasks which form a significant part of the workload for DNs caring for patients who choose to die at home. DN’s can access the service when they have reached maximum capacity and local teams are unable to meet the demand for personal care.

The methods utilised for the collection of data in the CAPCCS evaluation included:

2.11 Postal survey of District Nurses

A survey was conducted to obtain the views and experiences of District Nurses who had utilised the CAPCCS service (see appendix 5). The names of relevant nurses were obtained via the MCCC administrators of the CAPCCS service in Leeds.

2.12 Interviews with stakeholders

Face-to-face interviews were conducted with a range of stakeholders (see appendix 3). These included NHS commissioners, managers and administrators, MCCC staff and facilitators, District Nurses, nurse managers, HPCAs, and other relevant healthcare professionals. Where possible these interviews were audio recorded. Interview data were analysed thematically with the aid of NVIVO v7 software.

2.13 Interviews with bereaved carers

Interviews with bereaved carers who engaged with the CAPCCS process were conducted. These individuals were recruited via participating District Nurses and MCCC contacts.

2.14 Documentary analysis

As with the CHESS evaluation, this corpus included relevant MCCC internal and public documentation, service delivery protocols, usage figures, and any independent user feedback that may be available.

2.15 Recruitment

Data for the evaluation of the CAPCCS work stream was collected between September and November 2008 (see appendix 3 and 4). Recruitment of stakeholder participants was initially made via MCCC contacts. Carers, bereaved carers, and patient respondents were recruited with the help of participating DNs, and HPCAs.

2.16 Limitations of the study

There are two main limitations that need to be acknowledged in this study. Firstly, it should be noted there is the issue of isolating two discrete initiatives (CHESS and CAPCCS) from an overall Leeds programme which consists of eight work streams (see section 1, above). While the eight work streams are to a large degree independent of each other on an operational basis, they are routinely categorised together as linked components of the Delivering Choice Programme in the city. It is important, therefore, that conclusions drawn from this examination of CHESS and CAPCCS are not taken as applying to the Delivering Choice Programme as a whole.

The second limitation which needs to be considered relates to the relatively small sample sizes we were able to obtain for the postal surveys which made up a part the data set (the 'champions' survey in the CHESS evaluation, and the District Nurse survey for CAPCCS). Considering that these surveys only represented a small part of the data collected, however, we are confident that this has not had a significant impact on our findings.

3 FINDINGS

3.1 Care Homes and End of Life Support Services (CHESS)

3.2 *Context of the initiative*

The CHESS initiative was effectively one strand of a dual workstream aimed at improving standards of care in care homes. CHESS was concerned largely with the provision of training relating to end of life care provision in care homes. A parallel initiative *Improving End of Life Care in Care Homes* was developed to address broader community support issues. While there is some crossover here (particularly in terms of communication improvements between care homes and outside healthcare agencies) this report focuses specifically on the CHESS related aspects of the workstream.

CHESS was tested in 33 care homes in Leeds during 2007 / 2008. As a local initiative that has developed within and around the city, it has necessarily needed to adapt to the various idiosyncrasies of the region (in terms of recent PCT reorganisations, healthcare delivery, systems and processes etc.). However, due to the nature of care home provision generally, it may be assumed that many of the themes that formed the basis of the programme are likely to be applicable to other parts of the country.

When CHESS was initiated in 2007 there were 174 homes in Leeds providing around 4,850 places for care in a mixture of residential and nursing care settings. Of these around 3000 were designated for older age people (over 65 years), but homes in the city cater for a wide variety of other client groups, ranging from mental or physical disability, through to old age. There are currently 70 registered places for terminal care.

3.2.1 *Aims of the work stream*

Figures 1 and 2 (below) are taken directly from MCCC project reports and internal documentation and illustrate the issues identified for the care home initiative (fig 1), and the intended outcomes that were subsequently developed from them for CHESS (fig 2).

Fig 1: Care homes – themes identified.

- 1) Care homes need to understand [original wording] that for some residents the care home is the only home they have. If a patient is admitted to hospital and wants to return to die at home (the care home), they should be entitled to.
- 2) Improve retention and recruitment of staff to care homes.
- 3) Improve provision of nursing care by care homes to palliative care residents including IV medication or sub cut fluid.
- 4) Re-examine referral criteria for space allocation of care homes for end of life patients.
- 5) Continuity of care is important. Care homes should allow residents to be cared for by their own GP.
- 6) Improve relationships and communication between community professionals and care homes e.g. GPs and community CNS to attend MDT meetings.
- 7) Out Of Hours (OOH) GPs should provide service for care homes
- 8) Address administration and storage of medication within care homes
- 9) Recognition by care homes of palliative care needs in patients with mental health conditions.
- 10) Improved access to equipment within care homes.

(MCCC Leeds Project – Phase 1 report, 2006)

Fig 2: CHESS – themes identified.

- 1) An improvement in the quality and organisation of care delivery in the last 6 – 12 months of life for care home residents
- 2) The implementation of the CHESS framework and tools in the participating care homes.
- 3) The promotion of preferred place of care / death for care home residents
- 4) An improvement in communication between care homes, care home staff, residents, families, GPs, other specialist services and professionals, and out of hours services.
- 5) An increased awareness and use of community support for care homes.
- 6) A reduction in the number of residents admitted to hospital at the end of life unnecessarily.
- 7) Support for residents, relatives and care home staff with end of life issues
- 8) Improved public relations for each care home.

(Internal MCCC documentation, 2008)

According to MCCC, the overall aim of CHES is to improve end of life care for residents and families by equipping staff with the skills and confidence to support the care home's residents in their normal care environment (MCCC internal documentation). Initial scoping and development work carried out by MCCC in Leeds during 2006 identified a number of issues that influenced the quality of care that care home residents received during the end of life phase. The underlying structure of the CHES programme was developed to incorporate and address these as far as possible.

3.2.2 Processes and structure

The training programme that formed the basis of the CHES programme focused on utilising existing staff members within the care homes. Before attending the first workshop, participating homes were invited to nominate a 'champion' who would take the lead within the home for the co-ordination and implementation of the programme. Two CHES facilitators (employed by the PCT, but paid for by MCCC) were responsible for providing training, along with an employee of Leeds PCT who represented the Gold Standards Framework. According to MCCC (internal documentation), this mix of personnel reflected a desire to promote partnership between organisations, and a number of stakeholders we were able to interview confirmed that there had initially been some tension over the provenance of the ideas behind CHES during the early stages of its development. These issues now appear to have been largely resolved.

The main focus of the CHES training was a series of workshops held between October 2007, and October 2008. These were attended by 'champions' from all participating homes and aimed to 'improve, maintain and increase the knowledge, skills and confidence of the care home champions in order for them to cascade their knowledge to their respective teams' (*Internal MCCC communication, 2008*). For the purposes of the training the participating care homes were divided between the three facilitators and grouped geographically into 'clusters' of 3 – 6 care homes. In terms of the relevance of the programme, this was generally thought to be pitched at the right level. In our champions survey of, for example, 17 of the 19 respondents thought the training addressed all of the major palliative care issues likely to be encountered in

care homes. And a similar number (17 out of 19) thought that the delivery of the training was efficient and effective.

‘Champions’ from the homes within the various clusters attended regular meetings with facilitator support. Facilitators also conducted one-to-one site visits to care homes to give additional training or advice as required.

In general, the ‘champions’ we were able to interview found cluster meetings to be extremely effective and helpful – particularly in the way that they fostered and maintained informal communication between care homes. This was reportedly a useful by-product of the programme in that rather than always contacting outside agencies (such as district nursing services, or specialist community teams) for help, participating care homes were now much more likely to contact each other for informal advice and support. It was suggested that prior to involvement in CHESS, there was little in the way of networking between homes, and that the sharing of common experiences and problem solving in the course of cluster meetings had facilitated this.

However, the system of nominating a ‘champion’ to take responsibility for the end of life organisation at a care home came in for some criticism. Notably, it was observed by one care home manager that, for a variety of reasons, the nominated ‘champion’ in some homes might not necessarily be the most effective person to implement the programme:

[Respondent is talking about a recent cluster meeting]. . . I went to one that was just all residential but they were all care assistants there, cos they’d been nominated to go on it. . . They’ve no idea what they’re on about and then there was an administrator and I’m thinking what am I doing here? What’s she doing on it? What she’s going to implement in her home? . . . I just couldn’t believe it.

(MA-CH-08-07 – care home manager)

While this does highlight the issue of whether or not it is appropriate to encourage ‘champions’ to be drawn from any section of the care home staff (i.e. they need not have any nursing or medical qualifications), and it is perhaps significant that just over half of the respondents to our survey did in fact have some form of medical training: 10 of the 19 champions who responded were registered nurses.

Throughout the course of the training, facilitators were required to be responsive to feedback from champions and other participants, and to some extent this was evident. In the final workshop, for example, funeral arrangements were suggested as a topic by participants, and a funeral director was asked to speak at this event. The material eventually covered in the 07 / 08 workshop series included topics such as:

- Identifying the skills and qualities of a 'champion'
- Professionals involved in palliative care
- Awareness of prognostic indicators and End of Life tools
- The Mental Capacity Act
- Advance care planning for residents
- The benefits of the out of hours tool and DNAR forms
- The phases of dying; symptom management at end of life
- The benefits of using Liverpool Care Pathway
- Bereavement support following death.

3.3 CHESS within care homes

3.3.1 *Employment factors in care homes*

In terms of employment kudos, care homes and nursing homes are perceived by many nursing staff at least, to be an undesirable place to work:

“Yes, I know for a fact I’ll never be out of a job. I’ll always get a job in a nursing home, you know, it’s not an aspirational place to work unless you own it or you’re the manager. . . its one of these places where you go when you just need some extra cash and you want to do a couple of nights extra. This is the culture these poor girls [care home assistants] are working under.”

(DN-CH-24-07 – Community Matron)

This negative perception of the ‘kind of staff’ that care homes employ has undoubtedly been one of the big cultural issues that CHESS has needed to address. In many ways, although the focus of the programme has obviously been the improvement of care for residents at end of life, the training process and support that CHESS has provided has had just as much tangential impact on the self image, self esteem, and wellbeing of care home staff – particularly those lower down in the hierarchy. Two of the ‘champions’ we were able to interview, for example, commented:

“We actually say that’s it’s given us so much, such a boost doing this CHESS programme, I can’t even begin to tell you because we’ve felt - it’s given us a lot more confidence. The confidence to know what we’re talking about. And I think if you know what you’re talking about you obviously, you know, you can feel more confident, and the fact that we can approach relatives, we know - I’ve never found it a problem talking to people about death, but this has made it easier. You know it’s made it easier.”

(CM-CH-15-07 – Care home ‘champion’)

“Its been difficult but you know the CHESS programme’s really helped, cos obviously it’s given me more confidence to sort of question GPs and district nurses - you know, what are you doing? Why aren’t you doing this? Why aren’t you doing that? Whereas before you just, you know, you daren’t overstep the mark in case they said well they need to be in a nursing home, or they need to be in hospital.”

(MA-CH-08-07 – Care home ‘champion’)

Other ‘champions’ were similarly enthusiastic in their evaluation of the programme, and with 17 of the 19 respondents to our survey reporting that participation had made a difference to the level of care in their care home, it is clear that many of them found that it had been of benefit.

This was particularly evident in care homes that had not previously provided any focused training in end of life issues. Specifically, champions reported much higher levels of confidence; increased levels of knowledge and understanding; and a more pro-active approach to managing end of life issues.

Only two ‘champions’ indicated that the programme had made little or no impact on the way in which end of life care was provided in their care homes. However, it appears that in one case this was because the home already provided its own in depth training, and had a strong commitment to palliative care (‘champion’ no. 10). In the other, the situation appeared to be much the same, with the ‘champion’ reporting that:

‘It has not made any difference to the care we already gave at the end of life - but the paperwork has changed
(‘champion’ survey respondent no. 11).

This newfound confidence of the many participating care home staff in issues surrounding end of life care has similarly had a positive impact on the professional healthcare staff who need to work with them. Where previously there often appeared to have been a kind of resigned acceptance that dealing with certain care homes (or sometimes, particular staff within them) would be problematic, the post-CHESS home could be a very different experience. Describing how things had improved in one of the more ‘difficult’ care homes on her caseload, this community matron related how she had gone to see a dying patient, and needed to ask one of the care staff to organise his medication:

“I mean I know a year ago, if I’d have said that, I’d have gone back after I’d finished what I was doing knowing full well nothing would have been done. I went back up there and there were 2 nurses with him. They’d just given him an injection, they’d just given him his oromorph, so they’d literally gone and checked it and gone straight up. They’d not gone ‘yes I’ll do it when I’m ready.

The junior staff, the non trained staff, completely embrace the CHES programme - a completely different attitude. They work on a different planet completely, because they don't have the same responsibilities from a nursing point of view as the trained staff do, so they have embraced it because to them it's just caring for people who are very, very ill, and its making them feel like they've more worth. Cos outside they've got people coming in and saying you're doing a really good job."

(DN-CH-24-07 – Community Matron)

3.3.2. Staff turnover

We were not able to reach any firm conclusions about the impact of CHES on staff turnover. It is well known that the issue of staff turnover is problematic in the care home arena (see, for example: Castle et al, 2005). The high staff turnover which is endemic in many care homes can be seen to have a direct impact not only on the delivery of consistent end of life care, but also on the way in which initiatives such as CHES are implemented on a day to day basis. In the context of CHES, the transmission of good practice, effective therapeutic and communicative routines, and the reinforcement of practical aspects of care, are fundamentally dependent on staff continuity. This continuity is often not found – particularly in some of the larger 'chain' homes. Although interestingly, none of the managers we interviewed actually said this about their own homes - it was always 'other', and by implication, less well run homes that suffered in this respect. In one home we visited, for example, the manager gave a glowing account of how staff turnover was very low in her home and carers '... stayed for years.' However, when referring to the same home in a separate interview, a District Nurse who had worked with it for some time painted a different picture: one in which care staff of a reasonable quality had been difficult to recruit, and turnover was as high as any other home. This inconsistency may simply be a question of relative perspectives on what constitutes a high level of staff attrition. But it also highlights the way in which perceptions of what is required can be very different depending on who you talk to, and what their vested interests are.

3.3.2 Impact on systems, procedures and processes

As with initiatives such as the Liverpool Care Pathway and the Gold Standards Framework, a key element of the CHES programme has been the formalisation and clarification of procedures and processes in relation to end of life care. While the

majority of homes that became involved in CHESS already had at least rudimentary procedures and routines in place to deal with residents at end of life (and many had extremely comprehensive ones), there appeared to be little or no uniformity across homes: any systems that were in place were very much 'in house', and were not necessarily set up in the most effective way. On one level this is not really an issue because different homes are rarely going to need to share this kind of information. But on another, it might be suggested that encouraging a standardised system of record keeping that is specifically designed to address the contextual requirements of the home, the resident, their relatives, and the multitude of outside agencies which may become involved has been one of the most useful aspects of the CHESS programme:

"It's all documented [now]. So that's been a huge improvement. . . What the CHESS programme's done is empowered the care home staff . . . they've formalised it and it's almost a checklist thing, which then you know everything is down to on an individual basis. It just acts as a prompt really to trigger what should be happening.

(DN1-SI-18-07 – District Nurse)

At an early stage in the training programme, care homes were provided with a resource file which included a selection of standardised forms. These could be customised by the individual homes as required, but essentially represented all of the paperwork required to effectively facilitate the wishes of residents as they approached end of life, along with forms to cover the relevant medical information routinely required by any outside healthcare professionals who might become involved. Probably the most significant of these from the resident's point of view (and in terms of the end of life care decision making that the Delivering Choice Programme aims to champion) is the Advance Care Plan. Where possible, this is completed by a resident well before the onset of end of life care and formalises their wishes: where they would like to be cared for should their condition deteriorate, for example, or who they would like to have involved if they are unable to make decisions for themselves.

The following case study illustrates the way in which the protocols and advance planning provided by CHESS had an impact on the end of life care received by one care home resident:

Case study 1

Mrs X was an 87 year old resident in a medium sized (37 bed) CHES participating home offering residential care. It has a CSCI rating of 2, putting it into the 'good' category. She had lived at the home for two years and was very settled. Following a chest infection and a minor fall, she was admitted to hospital for observation and further treatment for her chest infection. She then developed swallowing problems and was given intra venous fluids. Mrs X then refused all further treatment and pulled out her intra venous line.

Mrs X's relatives contacted the care home and told the staff that the focus was now on end of life care and that she wouldn't be receiving any further treatment. When asked when she would be returning to their care, the relatives said that as Mrs X didn't know where she was, she may as well stay in hospital.

However, the care home had been implementing the CHES programme for the previous 10 months, and had an advance care plan in place for Mrs X. In this plan she had recorded her wishes, and specified the care home as her preferred place for end of life care.

This presented a delicate situation for the care home staff – on the one hand they wanted to be respectful of Mrs X's wishes, and on the other there were the wishes of Mrs X family to be considered – so they discussed the situation with the hospital and the advance care plan was faxed through to them. Given the authority that the care plan represented, the hospital then took the lead in discharging Mrs X back to her care home. They also spoke to her relatives. On her return to the care home, when welcomed by the staff Mrs X reportedly said 'thank god'.

Mrs X was discharged back to her care home on a Friday afternoon, and staff anticipated deterioration in her condition over the weekend. They ensured that the GP involved was made aware of the situation. He then completed an out of hours handover form, and a DNAR (do not attempt resuscitation) form. The District Nursing Team worked with care home staff to ensure that Mrs X's symptoms were effectively managed over the weekend, and she died peacefully two nights later. Care home staff were with her when she died.

In this case it is clear that had the protocols and advanced planning that the care home staff undertook as they engaged the resident and her family in the CHES process had the desired effect. These not only ensured that the wishes of Mrs X in relation to her place of death etc. were carried out, they also enabled the various agencies and professionals involved (the care home, the hospital, the District Nurses, the GP and so on) to work smoothly together to achieve this for her. The care home staff involved in this case also reported that prior to their involvement in the CHES programme, they would have "just accepted what the relatives had said about Mrs X staying in hospital", and would not have questioned their decision. Having everything formalised, out in the open and written down gave them much more confidence in their abilities to handle her end of life care in the way that she had requested, and they reported feeling proud of how they dealt with the situation.

The formalisation of protocols and the clarification of processes to care staff, relatives and outside healthcare professionals has clearly been one of the major improvements that CHES has facilitated. However, it is not only directly through this formalisation

that benefits may be observed. In many ways it can be said that the very process of a care home choosing to engage with a programme such as CHESS has positive tangential effects. In particular, by bringing the issue of end of life care out into the open and fostering an environment for staff where well entrenched perceptions, ways of coping, and attitudes towards the dying might be more consciously challenged. Even experienced and long serving staff reported that they had started to think differently about the way they worked with residents since engaging with the programme:

“I do find it interesting because I think the lasses [residents] will start opening up a bit more and maybe talking about their preferences. You don’t want to go in saying ‘well how do you want to die?.....’ you know what I mean? You can’t do it like that, you’ve got to be - it’s got to be sentimental I think sometimes.... it’s like you don’t realise, you know, it’s your job and that’s how you sort of look at it, you come and you look after them, but then it’s like you never sort of opened up and said to them, you know, some times it’s hard to say to them ‘where would you like die’ or ‘and what would you like music or flowers or friends’ you know, you just don’t know what they want, and it’s hard to sort of [ask] unless they bring it up with you first, you know what I mean?”

(CAS CH 15 07 – care assistant)

3.4 *Impact on communication with community services*

An important theme arising from the baseline evaluation of Leeds care homes carried out by MCCC (MCCC, 2006) was the need to improve communication between homes and external healthcare services in relation to palliative and end of life care. Out of hours GP services were singled out as of particular concern, but the problem extended into other services as well. The reason why problems have arisen in this area are complex but can often be traced back to the entrenchment of negative perceptions about particular homes based on previous bad experiences (i.e. repeated erroneous call outs and ‘time wasting’). One of our Community Matron respondents, for example, told how a home which was part of her case load had gained a particularly bad reputation:

“I’d been noticing a lot of call outs to the GPs, they’re being called out by [care home name] nearly every day and they were having real issues in there with communication and various other issues. And when I was training I said to my GP mentor, I actually said to the girl concerned, would it be useful to go in? And she said, ‘I wouldn’t inflict that on you.’”

According to this respondent, part of the problem could be traced back to the level (in terms of training, qualifications and experience) of the staff that some care homes tend to employ, and the cultural perspectives that these individuals may have:

“ . . . because they attract a certain level of staff - trained [nursing] staff - the staff find it very difficult to take ownership of problems and things that they shouldn't be calling GPs out [for], which I would never ever consult my GPs about as a district nurse. . . but they will call the GP out because their culture, the culture of the nursing home and the culture of some of the staff because of their backgrounds, is that they come, they get a doctor, because the doctor is god and you do not challenge the doctor. So therefore when the doctors are getting called out for patients who have - for instance you might get a patient who's got a really bad in-growing toenail, that's not infected but it's just in-growing. What's a GP going to do? It's a waste of GP time, so if they're constantly calling them out for inappropriate things the GPs get completely naffed off and say they are completely incompetent in this role and let's just shove them to the bottom of the pile . . .”

(DN2-CH-24-07- Community matron)

Although it might be suggested that issues of staff training and cultural attitudes are not going to be changed over night, it does appear that in participating care homes where communication and interaction with community healthcare professionals was a problem, the situation has reportedly improved. The manager of one of the larger homes in the programme reported how participation in CHES had dramatically changed the way that she and her staff perceived themselves in a professional context. Although she acknowledged that CHES had been relatively costly in terms of the extra work it involved on a day to day basis, the benefits of the tightly managed protocols that she and her 'champions' (this particular home nominated two) had put in place resulted in a far more proactive approach to their interactions with outside agencies – particularly GPs:

“When liaising with GPs and nurses, more power and control is always good, but it's more about what we're able to do and what you can demand. [We're no longer] a 'silly little care home that doesn't know what to do'”

(4L-21-05 – Care home manager)

This type of report was echoed by a number of other stakeholders:

“We are now more confident to request anticipatory medication, and speak with patients and families re their needs and wishes about death.”

(Respondent 4 – ‘champions’ survey)

“CHES has given us structure to our care for the dying, the ability to access resources and the confidence to care for our residents to the end of their lives without sending them to hospital to die. Relationships with GPs, residents' families have improved and now we are planning in advance for their final weeks and days.”

(Respondent 9 – ‘champions’ survey)

“I think the teams, as in the staff that are there - because obviously there’s a lot of part-time staff, I think they feel more of a team. Even the other day on Thursday I was doing a presentation, and someone from nights came in and said “oh I’ve never met you before” even though they work in the same care home, they’ve just never met because of the shift patterns. So in a way that’s good. The communication between days and nights, for example, with the advance care planning, they can see what’s sort of gone on during the day and things. Yes, more team work I think, people are talking about things. . . you know, it’s just that communication really. And for people to realise that they were actually giving quite a lot of good care in the first place . . .”

(MA-CH-08-07 – Care home manager)

3.5 *The impact of CHES on users*

Obviously, the fundamental aim of the CHES programme is to make the experience of end of life care in care homes better for residents. Unfortunately, due to the plethora of complications which can affect a person at the end of their life, the majority of residents who get to the point of engaging with the initiative are unable to comment directly. It therefore falls to the families and carers of these people to articulate how CHES might have influenced the quality of care that was received.

Overall, the responses we obtained from bereaved relatives of residents who engaged with CHES care homes were very positive. The following comment, for example, comes from a gentleman who was closely involved in the end of life care his father received at a participating care home:

“. . . the fact that it recognises the right of the person being cared for to determine their future pattern of care and the extent of any medical intervention. We’ve had discussions with care home staff as well as the GP. I wholeheartedly endorse the scheme and its objectives.”

(HH-CS-00: relative of CHES care home resident)

In this case, there were no significant difficulties for the family and care home to deal with – the resident’s death involved a gentle decline over a series of weeks, rather than any period of illness or hospitalisation – and in this respect it might be regarded as a model example where processes and procedures flow easily together and the comprehensive contingency plans which are put in place are not required.

In some cases however, it is clear that the additional levels of planning and formalisation that CHES covers are very useful. The following case study, for example, (related by the District Nurse involved) illustrates how effective the implementation of CHES protocols can be in facilitating the wishes of a dying person – even when that person is no longer able to speak for themselves:

Case study 2

“Right now one of the good examples is in the residential home that I’m attached to which is EMI [Elderly Mentally Ill], it’s got EMI status, so there’s a lot of dementias and others such as heart failures, renal failures. But one gentleman that we’ve got in there is gradually deteriorating.”

“For this gentleman his mobility became very poor, he became bed bound essentially, but they’d got the advance care planning, the family involved, the care home staff had discussed the DNAR status, which was very important, and what his wishes would be - where he would want to end his life basically. It’s such a gradual deterioration because it’s taken really, weeks and months. This started in February, this dying process and being nursed in bed by the care home staff who did a fantastic job, and again they’ve had the [CHES] teachings as well, their knowledge has been underpinned. They understand the importance of the turning, recording all that down, giving the fluids and they feel a lot more confident and lot more knowledgeable as well - able to support this gentleman.”

“And the thing with it, it’s been quite intensive in there, he would have been transferred, it would have been an example of somebody that would have been transferred to a nursing home, because of the nursing needs he had but this gentleman has no pressure damage, he’s nursed on a profiling bed, powered mattress, we go in twice a week to really liaise with the staff, just to check that everything’s OK, that they’re coping OK which they are doing. And the family are kept involved, he’s very well symptom controlled, and pain’s not an issue. He’s maintained his nutrition levels, he’s very good. They’ve got the music playing for him that he likes to play, and the family, they come in, they’re very familiar, very comfortable with what’s happening, and certainly the care home staff are a lot more relaxed about it. . . . it’s all been discussed, the leadership has come from the management, and I think they’ve been empowered with the CHES programme - in symptom management, in communicating with families, having things documented so that everybody knows.”

(DN-S1-18-07 – District Nurse)

In a similar vein, the respondent below related how her mother, who had been a long term resident of a participating care home, became quite ill suddenly and required admission to hospital. Due to the fact that her mother had been able to complete an Advance Care Plan sometime earlier, in which she specified her preferred place for end of life care as her care home, she was transferred back there as soon as was practical:

“ . . . there was just this nice room, and mum knew when the carers came in to turn her or to change her – she knew their voices, and she let me know when somebody came into the room and she didn’t care for them – I got ‘the look’, and I knew she was thinking ‘bloody hell why is she here?’ So she was conscious of what was happening, and I found it rather nice. And of course the staff were wonderful, they asked me did I want any special music playing or flowers or anything. . . . And I could say to mum ‘this is what we wanted isn’t it’. And I felt that she was calm, and that she was at peace, but in an atmosphere where everybody knew her, and we all felt comfortable with the situation.”

(BC-02-CH - relative of CHES care home resident)

As with the case study given earlier, in this extract it is evident that had there not been an Advance Care Plan in place, the respondent’s mother may well have remained in hospital, or might have been transferred to an unfamiliar nursing home – both options being against her wishes. As it was, having the required paperwork and authorisations in place well before they were needed meant that she was quickly returned to the place she regarded as ‘home’, where she died peacefully in familiar surroundings – a situation which was clearly reassuring for her daughter as well.

This way in which the CHES approach actively incorporates the addressing of the concerns of family members has also been highlighted by respondents. Having a relative who is approaching end of life is not an easy situation for anyone to be in, so the practical and open approach which the programme has encouraged care homes to adopt – including holding informal meetings where they can explain the end of life process to families, for example – has been particularly useful. The healthcare professionals who become increasingly involved at the end of life stage were particularly encouraged by this development – particularly as their contact with family members might be infrequent:

“What the CHES programme’s been able to do is speak to families . . . the advance care planning has really promoted the involvement of families. Whereas the home would not previously do that. The home would discuss it with the families as and when they came in. There’s like sort of a formality to that now. They’ve done group meetings - the care home has sent out letters to invite them to have a discussion either on a one to one basis or in a group. So I think they’ve taken that up, more on a one to one basis. . . . From a district nursing point of view, often when we go we miss the families, and it’s the care home staff that are actually doing that.”

(DN1-SI-18-07 – District Nurse)

In terms of the impact that CHES is having on users then, it would appear that in those homes where the initiative is embraced there is a definite sense that it is resulting in high levels of user satisfaction. While dying residents themselves may be unable to express directly how they feel about the care they receive via CHES, it is clear that having close relatives and carers who perceive the experience in a positive light is just as valid. After all, they are likely to be well placed to judge whether or not the end of life experience was satisfactory. On a practical level too, they may well have been directly involved in the drafting of an Advance Care Plan, and so will be aware of what the deceased actually wanted, and whether or not this was provided.

3.6 Uptake and sustainability of the programme

The sustainability of the CHES programme is a thorny issue. On the one hand the pilot does appear to have confirmed that this type of integrated approach to improving end of life care in care homes certainly can have a positive impact on multiple levels - not only on residents, but also on care home staff, families and the various outside healthcare agencies that may be involved. Certainly, in the homes where the CHES protocols are being implemented there is evidence of improved co-ordination, greater efficiency and heightened awareness of issues around end of life care. However, there is a potential issue here – one that was highlighted by a number of respondents. Namely, the possibility that many of the homes which would most benefit from the programme (i.e. ones where standards are generally low across the board – not just in end of life care) are the ones which are least likely to have engaged with it.

“...it hasn't captured perhaps the ones that would've benefited more from it. There's already good practice going on in those homes probably. It's just sort of pulled it all together for them. . . It would've been good if it'd involved more homes, and I don't know if that was because there was a cost to enrol on it.”

Interviewer: “Do you think that might have put them off?”

“I'm absolutely sure it did, because even for our nursing home educations, they're free [training] days and people still don't turn up. We actually now go into the homes to deliver it, and people say they'll come and they don't. So I think the cost – unless you engage and get the enthusiasm of the managers, then I think it's difficult.”

(com2-ch-08-10 – Community Nurse Specialist)

In defence of the way CHES was organised, this situation was probably difficult to avoid when resources were limited to enabling only 20% (1/5) of Leeds care homes to participate. As an essentially experimental initiative, it would perhaps have been unreasonable to expect MCCC (and Leeds PCT) to provide CHES for free at this stage. However, there was a perception among some community healthcare professionals that the cost of participation was likely to be too high, and that this contributed to a selection of predominantly 'decent' homes taking part.

If rolled out as a full scale initiative, it is evident that issue of participation needs to be addressed – whether by somehow targeting those homes which are clearly in need of support rather than those which already provide a high standard of care, or by completely reassessing the rationale behind publicity, training and validation. Both of these options are likely to be problematic in terms of the way CHES is subsequently developed because of the cost and organisational implications they may have. Similarly, there is currently no statutory requirement for a home to take part in this type of staff training and development, so in the eyes of many of the non-participating establishments, the trade-off between the cost of funding a representative and the perceived 'added-value' to the care home may be marginal.

It is evident that MCCC did a large amount of groundwork in preparation for the CHES initiative (see the *Phase I report "Understanding the current state of services", 2006*) – however, it is also apparent that some elements of the field were overlooked or given insufficient attention. In particular, the expertise and detailed local knowledge available from the community palliative care teams based at the two main city hospices appears not to have been fully exploited during the initial phases of planning. The structuring and focus of the training programme, for example, was one area that came in for some criticism:

'I think one of my concerns about a lot of the Marie Curie stuff, not just the CHES, is that sometimes they haven't always seen the bigger picture. . . predominantly in Leeds. With both community teams, we've provided care home education for years and tried different ways of doing it. We tried running a programme in the care homes and there were pros and cons of that. Then we tried running a programme based within both hospices and there were pros and cons in that. Then we were obviously involved in the [MCCC] care home workstream. And in an attempt to try and work more closely with them – the feedback coming from the care homes signed up to CHES initially was that they wanted education in the care homes not [workshops and big events]. So we were a bit hesitant about doing that because we'd been there before. But we've agreed to do that so we've completely re-vamped our care home education and we now have a monthly programme across the city.

(COM1-30-09 – Community Nurse Specialist)

While perhaps not a significant flaw, this does appear to have resulted in some confusion and duplication of information provision – at least initially. This 'ruffling of feathers' in some quarters is perhaps understandable though, and may be an illustration of the difficulties that a large national organisation such as MCCC could face when attempting to integrate the new service into a well entrenched local environment.

“ . . .if it's to continue [CHES], It's about looking at a bigger picture I think. You know, it's great for those few homes who are involved, but it's such a massive problem across the city, and until you encompass as many of those as possible it's only going to be a drop in the ocean really. . . And you're aware of all the other little things that are going off. You know, community matrons going into nursing homes looking at end of life care issues, and you just think, well you know, we're all getting a bit bitty again. The end of life strategy is about engaging with everybody isn't it, not just doing it in pockets. It's about seeing the bigger picture, and the CHES thing – it's not the fault of the facilitators at all – but I think we've got to be careful if it goes forward that we do look at the bigger picture.”

(com2-ch-08-10 – CNS manager)

What I would say about CHES is - in a nutshell - It's got lots of positive aspects. I think facilitators going into the care homes and, for want of a better way of putting it, hand holding is what they need. I think before we had CHES we had [name] going in and trying to set up Gold Standards in half a dozen care homes. And what [name] found was that she could practically live in those care homes, and almost needed to to make a difference. So I think being in the care homes day in, day out definitely makes a difference. That's obviously got resource implications hasn't it, in terms of how many more homes could be brought into CHES. . . . but having that face to face, and having that consistent input I think helps - especially in terms of the frequent change over of staff.

(COM1-30-09 – CNS Manager)

3.7 Commitment and the perceived value of participation

In relation to levels of commitment, it is evident from our ‘champions’ survey that this is generally very high in the homes where CHES is in operation. Asked to rate the management commitment to CHES in their care home on a scale of 1 to 5 (with 1 being ‘highly committed’ and 5 being ‘not committed’) Thirteen of the nineteen ‘champions’ who responded to the survey rated their care home management as ‘1’. Three rated it as ‘2’, with only two giving lower scores (‘3’ and ‘4’). Similarly, the scores rating the level of commitment from other staff in the care home were also encouragingly high: eight of the champions considered the other staff in their home to be ‘highly committed’. Scores for the commitment of GPs to CHES varied more widely, but still included five homes that rated them as ‘highly committed’ (‘1’), while eight homes gave them a score of ‘2’, and five as ‘3’. One champion registered a score of 4, noting that in her case although the GP knew of CHES, he was reported as not being particularly interested until residents reached the point where they could be considered as ‘level 6.’

Scores for the levels of commitment displayed by family and friends of resident were similarly varied, and although five ‘champions’ considered the individuals they had worked with to be ‘highly committed’ to CHES, it was also noted that (for a variety of reasons) families often did not complete the required forms: four homes rated the commitment of this group at only ‘4’.

In general, it appears that levels of commitment to a fairly intensive programme such as CHES really depend on the immediate and ongoing perceived benefits. In homes where CHES has quickly proven to be of direct practical use it can be said that commitment is likely to be high: staff can see the payoff that, say, the formalised protocols have in terms of making end of life care run more smoothly. But some homes actually deal with very few residents who require end of life care, and so the potential for the programme to prove itself does not occur so often. Similarly, in the case of outside HPs such as GPs and District Nurses, commitment to a programme like CHES only really solidifies once ‘successful’ cases start to be encountered. As we have illustrated elsewhere in this report, this does appear to be happening. Even in homes which previously may have had a questionable reputation among healthcare

professionals in terms of communication and professionalism, it only takes a couple of good experiences for the attitudes of healthcare professionals to begin to change.

Although twelve out of the nineteen care homes involved in our survey stated that taking part in CHESS had directly enhanced the reputation of their care home, in general it appeared that levels of commitment (whether in terms of simply wishing to participate in the programme, or maintaining momentum once enrolled) might be even higher if a more formalised system of accreditation was in place – especially one which would count towards the routine official assessments that care home are subject to.

‘I know the issue of accreditation, there’s still some debate about that, cos I think people were hoping that it’d have the same kudos as investors in people or that sort of thing, but I’m not so sure that that’ll be the case. . . . I think it depends on what they’re trying to sell really. I’m sure some of them would like some form of accreditation, and I think families may get some sense of security from that.’

(COM1-30-09 – CNS Manager)

This issue of how any accreditation relating specifically to end of life care might be presented in terms of care home publicity or advertising material, however, was something a number of care home managers commented on. In particular, it was felt that making a special feature out of CHESS on care home information fliers or websites could, in business terms, be counterproductive. Much care home marketing focuses on promoting the quality of facilities and the surroundings where residents will live. And as many people in the market for a residential home are not necessarily completely infirm or close to death, they (or their relatives) might be put off by overt references to end of life care. So although participation in CHESS was seen as enhancing the reputation and kudos of a home, it was really considered more as a hidden incidental which added value to the care already provided in a home, rather than something with its own marketing potential.

3.8 Summary and recommendations (CHESS)

- As a pilot initiative, CHESS has demonstrated that a multi-layered approach which combines a course of training workshops with facilitated support via smaller local meetings and a degree of ‘on demand’ contact with training staff is an effective way of improving quality of end of life care in a range of care homes. It has been able to enhance the quality of care in homes where effective end of life provision was already in place, but more importantly, it has enabled those homes which were less well organised in this respect to develop highly effective systems and procedures from the ground up.

- Participating homes have seen a positive impact, both on residents (in terms of facilitating their wishes in relation to their end of life care), and care home staff at all levels (in terms of greater levels of professionalism, knowledge, awareness of end of life issues, and confidence in dealing with outside healthcare professionals, relatives and other staff).

- The programme does appear to have addressed all of the major areas relevant to end of life care in care homes, and the training programme is flexible enough to accommodate additional themes as and when they arise. However, in line with the objectives of the wider work stream for care homes, continued care needs to be taken to ensure that similar initiatives currently attempting to provide training within homes (such as those supplied to care homes by Community Nurse Specialists or District Nursing teams) are acknowledged and learned from so that key palliative care agencies are not alienated.

- In care homes that have embraced the CHESS ethos there have been positive developments in the organisation of internal systems. Specifically, it is evident that the formalisation of processes and documentation (such as Advance Care Planning) has greatly facilitated the carrying out of residents wishes in relation to their end of life care – particularly by making it easier for them to stay in the care home if this is their preferred place of death.

- In parallel with this, the greater confidence that care home staff have reported in dealing with end of life issues now that procedures and processes are clearly defined and synchronised with the requirements of outside agencies, is very encouraging. CHESS has enabled the often undervalued members of the care home workforce (in particular, care assistants and other unqualified staff) to develop a greater sense of professional identity and worth.

- A key aim of CHESS was to improve communication between care home staff and outside healthcare professionals – particularly out of hours GPs. In many care homes this is not a major issue, and good professional relationships between home staff and outside healthcare professionals already exist. However, in participating homes that hitherto experienced problems in this area (high levels of inappropriate call-outs, for example), a greater awareness of how to put effective systems and planning into place has meant that information routinely required by visiting healthcare professionals – from accurate recording of the resident’s ongoing condition, through to the Advance care plan – is now readily available to them. This has facilitated communication and in some cases fostered more collegial relationships with care home staff. Similarly, CHESS provides care home staff with a deeper knowledge of the medical and bureaucratic processes that accompany end of life care, so instances of inappropriate call-out to various agencies are reduced.

- The issue of the sustainability of CHESS is complex. Although reports from participating homes have been very positive, there have been concerns expressed regarding the actual benefit (in terms of systemic and cultural change within the citywide care home arena) that the relatively small number of participating homes actually represents. Similarly, there has been some expression of concern among stakeholders that the homes that would have benefited most from the initiative are the ones least likely to have engaged with it. If CHESS is to continue, and have a tangible citywide impact, the issue of recruitment and involvement (of homes) needs to be addressed. It is acknowledged, however, that considering the realistic limitations of time and resources that CHESS in its present form is under, this will be a very challenging aspect of its development.

3.9 Complex and Palliative Continuing Care Service (CAPCCS)

3.9.1 Background to CAPCCS

CAPCCS is a service improvement initiative which has been designed to deliver an additional health and social care workforce. It was re-configured from two existing services within the city – the North West District Nursing Relief Team, and the East Leeds Integrated Palliative Care Service (ELIPCS). Additional funding to expand the resource has been provided by the Marie Curie Delivering Choice Programme (£170,000), and the Continuing Care Service within the city (£170,000).

CAPCCS was launched as a pilot initiative in May 2008, and works in conjunction with the Service Delivery Framework for Level 6 palliative (‘fast track’) care patients via the District Nursing service. Essentially, the service provides dedicated Health and Personal Care Assistants (HPCAs) who can take on many of the routine and non-medical caring tasks which form a significant part of the workload for DNs caring for patients who choose to die at home. DNs can access the service when they have reached maximum capacity and local teams are unable to meet the demand for personal care.

3.9.2 Aims of the CAPCCS work stream

According to CAPCCS operational policy, the agreed overall aim of the Leeds Care Services CAPCCS team is to: ‘Increase choice both at end of life, and for individuals with highly complex on-going continuing care to enable care delivery to be supported within the home environment.’ (Leeds NHS trust, 2007). Within this, the agreed objectives of the programme are quoted as:

- To increase choice at end of life and support individuals to remain within their home environment as a positive choice.
- To prevent inappropriate admissions and readmissions to acute hospital care
- To support the District Nursing workforce to deliver palliative care as outlined in the DN service delivery framework
- To prevent inappropriate admissions to long term care for individuals with highly complex needs.

(Leeds NHS trust, 2007)

Referrals to CAPCCS are made via the computerised patient information system (known as 'RIO'). At present, as the initiative is aimed specifically at supporting the DN service, only DNs are able to make referrals. A referral form 'CAPCCS 1' is completed by the referrer, and then followed up with a phone call to a customer support officer (CSO) at the central CAPCCS office. Once the CSO has received the phone call, the referral is placed on the patient's case record (within RIO), and passed to a Senior Nurse for triage.

A senior Nurse from the CAPCCS team then contacts the referrer to discuss the patient's care requirements, and if the patient is accepted under the eligibility criteria (see below), the Senior Nurse completes a 'CAPCCS 2' form (again, on the RIO system) to confirm acceptance. If the patient is not accepted, the referring DN is informed and the patient is recorded on RIO as being discharged from CAPCCS under the appropriate discharge reason.

A diagram of the referral pathway for continuing care patients, and the slightly different process undertaken for patients requiring ongoing complex continuing care is given in appendices 6 and 7.

To be eligible for the CAPCCS service, a patient must fulfil the following criteria:

- Aged over 18.
- Registered with a Leeds GP.
- Meet continuing care criteria for fast track (level 6) status.
- Have an individual business case written and agreed (for patients requiring on-going complex continuing care).

(Leeds NHS trust, 2007)

Referral figures for the period between January 2008 and February 2009, along with a breakdown of referral allocation are given in appendix 6.

3.10 Impact on service delivery and integration

3.10.1 Access to the system

Overall, it appears that the present system of referral works reasonably well, and has been successfully integrated into the existing computerised referral procedures that DNs and other NHS staff are familiar with. There were really only two issues which cropped up in relation to how referrals were made: Firstly, it was highlighted that due to the community based nature of DN work, once a patient was input into the system there were sometimes delays or difficulties in updating their details during periods when their condition began to change quickly.

‘ . . . the only problem is that you don’t ever update it on RIO then, so what... sometimes if you see the patient on the ward, you key in all their details on RIO, and then you ring them to say it’s on RIO and they can look at it. Sometimes things have changed a bit by the time the patient comes home, and so far as I’m aware there’s no way you can update.’

(Respondent: DN-CAP-4-11 – District Nurse)

This can be seen as a technical limitation of the RIO system itself, rather than one caused by the CAPCCS interface being badly designed, however. And in practice, it appears that the open and frequent phone communication that usually develops between CHAs and DNs in charge of patient’s care plans (see section 3.10.2) means that anything that is not clear can be dealt with quickly.

A second concern highlighted by some healthcare professionals, was the issue of basing the referral pathway solely around DNs. While DNs themselves were largely happy with this arrangement as it simplified the chain of communication, it was suggested that certain other allied healthcare professionals (such as medical social workers) would also benefit from being able to refer. The issue of other healthcare professionals being able to contact and refer independently of a DN was of particular concern because of the potential for unnecessary delays in providing care that it could lead to:

‘The fact that only district nursing service can refer to CAPCCS now is a pain. We work very closely with joint care management, and, for example, a DN might go out at 8.30 in the morning and not get back to the office till 4 o’clock. A joint care manager has got to respond to a fast track [patient] within 2 hours, and get them home if that’s required. They might need to tap the expertise of CAPCCS, but they can’t get that because there’s nobody to communicate it through. . . I can understand why the DNs are the body that we go through, but it’s about availability and communication.’

(Respondent: COM-CAP-20-11: Senior Clinical Service Manager)

This concern was also echoed by another senior manager:

‘I think the intention’s really good. But I think that there’s quite a bit more work to do to make the whole thing flow. And one of the frustrations – and I think it’s maybe correct, but it just needs better understanding in the whole system – one of the frustrations for people out there, care managers, is they can’t get at CAPCCS. They have to go through district nurses.’

(Respondent: SH-CAP-16-10: Service Commissioner)

It was further noted by respondent COM-CAP-20-11 that in previous initiatives (i.e. the ELIPCS service out of which CAPCCS was developed) it was not only DNs who could refer patients, and this reportedly made ‘life a hell of a lot easier’. On a related issue, one of the DNs who responded to our survey noted that in the current system, there was often the need to contact people from several different services (i.e. joint care, continuing care, and CAPCCS) before a decision on CAPCCS involvement was made. This respondent (who was one of the few DNs who reported that she had had difficulties accessing CAPCCS) said she felt the referral system was too long winded and:

‘. . . a complete waste of my time. I prefer the old [ELIPCS] system of speaking to the same one person only.’

(DN survey: respondent 7)

From the perspective of the patients and carers we were able to interview, there were no significant issues raised relating to the way they accessed the CAPCCS service. Once contact with the family had been made – usually via the case holding District Nurse – times and frequency of visits were negotiated as required with active input from the carer, and emergency contact numbers were given. It was standard CAPCCS

procedure to ensure that the first visit by their CHAs was facilitated by the DN. This was aimed at lessening the impact of the often overwhelming number of healthcare professionals and others who can descend on the home of a dying patient who requires a high level of care.

Carers particularly valued the way in which CAPCCS was closely integrated with all of the other services that were involved – from the DNs through to social services. It was felt that HPCAs could be asked about virtually any aspect of care, and if they did not know the answer, they would quickly be able to contact someone who did:

‘It was all integrated you know. Whoever came through the door, I could say I’m a bit worried about this you know. And it would... I didn’t have to do any more, they would say well I think we’d do this, or they would say well we’ll do this, and if it hasn’t worked by the time we’re going you know we’ll pass it upstairs. It was wonderful. It just took so much of a load off me you know. They kept saying look we’re not just here to look after [bereaved] we’re here to look after you. . . .They were very easy to talk to, because I mean they were like family, it was more than just someone coming in and doing a job.

(Respondent: CAP-BC-10-11 - bereaved carer)

3.10.2 Communication between professionals

Efficient information flow between the myriad of healthcare professionals involved in home based end of life care is vital if services are to be synchronised and responsive to the needs of the dying patient. In terms of the way in which CAPCCS has been integrated into existing channels of communication, there appear to be two distinct areas to consider:

Firstly, there is the issue of inter-professional communication on the ground. This is largely between DN case holders and the HPCAs who are attending a patient, but also includes communication between DNs and the Staff Nurses who administer CAPCCS. In general, we found that DNs were happy with the contact they had with HPCAs, and regarded them as very competent in judging what information was relevant to act on (i.e. pass on to the DN).

‘They just feed back any worries, any concerns they’ve got. And the fact that sometimes they’re putting in the first visit, which can be anytime between eight o’clock and nine o’clock, they’re actually phoning us up to say oh so-and-so was okay, or so-and-so wasn’t okay. So we’re getting a much earlier we can act on that then.

(Respondent: DN-CAP-4-11 – District Nurse)

Similarly, the HPCAs we spoke to reported that they felt the DNs listened to what they had to say:

‘[Communication is] quite good. We’ve got their phone numbers [the DNs], and they’ll either phone us back or we can speak to them direct. But they do, they do tend to listen.’

(Respondent: GW-CAP-21-10 - HPCA)

It was seen as a definite advantage by HPCAs to have immediate access to their DN case holder should they need it. Similarly, DNs who utilised the service appeared to have developed good working relationships with the medically trained staff who coordinated CAPCCS operations:

‘It’s about communication and having trust, and I think from their point of view, their coordinators, who are all very experienced nurses, feeling confident to ring me up and say ‘well actually I think blah, de, blah, de, blah...’ do you know what I mean? ‘I think this person’s pain is poorly controlled this morning.’ And I’m not going to say ‘oh well, who are you to say that.’

(Respondent: DN-CAP-4-11 – District Nurse)

Comparisons were also made between the positive interactional dynamics that had developed between the CAPCCS team and DNs, and the strained relations that sometimes developed between DNs and outside agency staff who, prior to CAPCCS, were brought in to undertake the health and social care now covered by the HPCAs.

‘I mean I don’t want to compare them to that [the agencies], but well, I suppose if I do use a comparison, we had a level six patient who went on for quite a while and who was in [care home name]. And we were getting... it were like point scoring with the agency. And [we’ve had] nothing like that. The [HPCAs] people I’ve spoken to have always been lovely and very helpful. And it’s like we’re on the same side. But I feel with the agencies sometimes, they’re just unhelpful. And we had them where they wouldn’t tell us that they’d rung an ambulance and got somebody into hospital, and never let us know. Things like that you know. The next thing you’re getting casualty ringing you up, and you don’t know anything about it. Yes, so I’d say that’s definitely better. communication... and as I say they just put her [the HPCA] through to my mobile phone.

(Respondent: DN-CAP-1-14-10 – District Nurse)

It should be noted that not all stakeholders reported negative experiences with agency staff, and although one DN reported that - almost as a matter of honour - her team would never resort to using agency care workers, and would somehow make up the extra hours required themselves, a senior manager at Leeds PCT offered a slightly more balanced perspective. She emphasised that negative attitudes towards the use of agency staff are sometimes due to culturally entrenched attitudes within the NHS about the superiority of their services, and she had regularly commissioned some excellent agency services in the Leeds area. There was general consensus among stakeholders, however, that resorting to expensive agency cover is not the preferred option. Because of the way the CAPCCS service was integrated directly into the palliative care system, and utilised HPCAs specifically trained in end of life care, the continuity of care it offered (and by implication, the quality of care) was generally regarded as superior.

The second area of interest in relation to communication concerns the way in which CAPCCS integrates with broader commissioning agencies at the PCT. This was one of the few areas where serious criticisms about the service were raised - particularly from senior managers. Specifically, it was reported that:

‘Professionals [joint care managers] are tending not to rate them [CAPCCS]. It’s poor communication is one of the factors. They might communicate with the District Nurses, but they certainly don’t communicate with us as well as they might.’

(Respondent: COM-CAP-20-11: Senior joint care manager)

This criticism appears to be focused on system and procedural processes, rather than quality of care *per se*. One particular issue which cropped up with senior managers in joint care was the way in which CAPCCS dealt with fast track cases that had been rescinded – a situation that might occur, for example, if a patient’s condition improved and health and social care support was no longer required. It appears that there have been several cases where CAPCCS support had been withdrawn suddenly, without the relevant joint care managers being informed. Although this may well simply be due to communication misalignments and teething problems with a new service, it does need to be addressed as it appears to be happening often enough for one manager to describe it as ‘a real pain’. Similarly, and more significantly, there

appear to be issues around the lead out procedure that CAPCCS adopts when they withdraw from this type of case:

‘Just as an example, if we have a fast track rescinded we [joint care] then give Social Services 28 days to reorganise the care – from a funding perspective. Now CAPCCS occasionally say ‘ok, fast track’s rescinded, we’re pulling out.’ Well you can’t! Cos you’re working for us and we say it’s 28 days, or up to 28 days. Now I can understand their frustration, cos the patient doesn’t need it - well pull out appropriately, sure. But if he still needs some care, we need to wait until the care is transferred to someone else.’

(Respondent: COM-CAP-20-11: Senior joint care manager)

While it was acknowledged that this type of procedural issue probably arose because of the limited capacity that CAPCCS has in its present state, it was also emphasised that if the service is going to work effectively alongside the District Nursing Service and their palliative framework, lead out times need to be synchronised.

These two communication issues are by no means insurmountable. However, they do appear to have had a disproportionately negative effect on the professional image of the CAPCCS organisational structure in the eyes of some management and senior management personnel. And while, as one commissioning manager put it: ‘. . . there’s a lot of embedding in, and a lot of learning still to go through.’, neglecting to address this aspect of the service could lead to unnecessary tensions developing between CAPCCS and some of the palliative care networks it needs to work with.

3.10.3 The effective use of care plans

Comprehensive care plans are at the heart of the activities that a HPCA is asked to perform, and although popular with HPCAs, they appear to be a slightly contentious issue with some DNs. As case holder, it is the responsibility of the DN to provide care plans for all of the discrete activities which the HPCAs need to perform – everything from detailing when a patient needs to be given a meal, to how they should be moved or turned. From the perspective of the HPCAs, these care plans are essential because they spell out exactly what it is that the patient requires – particularly in terms of the more medical and technical issues which the HPCA may be unfamiliar with.

‘Yes, the care plans do work. And you’ve got... it’s really good, because sometimes if we’re doing something different, like a hoist, we’d just ring up and say can we have a moving and handling for the hoist, and they put in a care plan. Not all the care plans are put in straight away - because it’s like pressure sores might develop, or then we might have to start doing the medication, so all that has to go in’

(Respondent: GW-CAP-21-10 – HPCA)

Similarly, when asked to rate the effective use of care plans on a scale of 1 to 5 (with 1 being *highly efficient*, and 5 being *not efficient*), of the DNs who responded to our survey (n=14), 6 gave a score of 3, indicating that they saw the system was acceptable; 6 DNs gave a slightly higher score of 2, and the remaining 2 gave a score of 1, indicating that they saw the system as *highly efficient*.

Where a slight misalignment was reported, however, is in the level of detail and number of care plans that HPCAs appeared to require:

‘What I have found quite difficult to get my head round, is the prescriptive nature of the care plans that they [HPCAs] like. I mean, really, we’ve got this gentleman at the moment who is having personal care, and I kid you not he’s got 25 care plans, all for different things. You know, and you go in and it’s just almost impossible, because they want care plans for every tablet that he takes – even though it’s in a community pack – a care plan for his catheter, a care plan for his pressure areas, moving and handling assessment, care plan for moving and handling assessment, care plan for personal care, care plan for mouth care. . . care plan for his meals... And it’s almost like, you know, where’s common sense here, you know. And it is dangerous, because now there are so many care plans, when you’re trying to look for something that is important you know.’

(Respondent: DN5-16-10 – District Nurse)

Because HPCAs are essentially non-medical personnel, and their level of autonomy is much lower than that of the DNs or other healthcare professionals involved in a patient’s care, it could be that the kind of over reliance on care plans which this respondent alludes to will lessen as the HPCAs become more familiar with procedures and processes. However, it should also be noted that the wish to perform their tasks ‘by the book’ is perhaps a reflection of good practice on their part, and it may be counterproductive to downplay the importance of accurate care plans, even if they occasionally appear superfluous to more experienced professionals.

3.11 Impact on patients and families

As with other palliative care interventions designed to improve the quality of care of people as they enter the very final stages of the dying process, it is not always possible or appropriate to interview patients themselves about the care they are receiving.

However, as with the CHESSE evaluation, we were able to talk to a range of carers and family members who had directly experienced the CAPCCS service. Because of the close day to day involvement that these individuals had with the dying patient, and their experiences of caring for them both before and during the involvement of CAPCCS, they are extremely well placed to comment on the way the service actually works. And as one of the aims of CAPCCS is to provide support for the carer as well as the patient, their perspective is doubly valuable.

3.11.1 *Qualities of the Health and Personal Care Assistants*

Overall, it was very difficult to find carers who had any significant criticisms of CAPCCS in general, or HPCAs in particular. In fact, the vast majority of reports we obtained unreservedly praised the service, and focused on the professional qualities of the HPCAs who provided care. The following interview extracts give a flavour of the impact that the involvement of these individuals had on carers:

'I mean [you're] totally yourself with them. . . even when - the day she was dying when they came, they were still very respectful, one of them did say, 'Goodbye [patient name].' I think she knew she wouldn't see her the next morning. But they stroked her head and they both used to lean down and give her a kiss. They were just out of this world... they were fantastic.

(Respondent: BC-CAP-25-11 – bereaved carer)

'They were just... I don't know, they were so pleasant, so nice; they just made it better, if you can say that, for us you know. Instead of it just being all down and that, you know when they came it wasn't all [morbid]. . . you know. They were so nice, they really were, every one of them. They just made it so... a pleasant thing out of an awful thing if you know what I mean.

(Respondent: BC-CAP-23-10 – bereaved carer)

The particularly good personal qualities of the HPCA were a reoccurring theme in the stakeholder interviews we conducted. One Community Nurse Specialist, for example, noted that in the homes she had visited while CAPCCS personnel were working, the relationship with the patients and carers was ' . . . just fabulous'. Other stakeholders reported the adaptable and sensitive way in which HPCAs were able to integrate

themselves into the home environment, and how their approach was a subtle mix of efficiency and compassion.

‘And it was the tenderness they showed her. They always went out and gave her a kiss, ‘See you tomorrow [patient name].’ And it was... it was just remarkable. I mean you know knowing they were going to other places, doing the same thing, you really felt you were the only people that mattered to them.

(Respondent: BC(H)-25-11 – bereaved carer)

It appears that one of the key reasons why there was such an apparent ‘fit’ between the HPCAs and the carers, patients and professionals that they worked with was that a very high degree of careful selection was carried out during the recruitment process for HPCA posts. It is widely acknowledged that working in this particular area of healthcare requires people who have a particular attitude and personal approach – aside from any specialised training or experience they may also bring. Many of the HPCAs we were able to talk to, for example, perceived what they did in terms of a vocation rather than a ‘job’, and acknowledged that it was a field that relatively few people would actively choose to work in. Further, as the following extract illustrates, there was even a sense in which the task of helping someone to through the final stage of their life was seen as something that went well beyond the routine processes of healthcare:

I know it might sound a little bit... but it’s such... I don’t know, I suppose it’s like a privilege to be able to go out to people. You know for the end of their life that you’re giving them the care and they’re able to stay in their own homes. They’ve got that choice, which is really... I think it’s something that you... I don’t class this as just a job. It’s something you’ve got to want to do. It’s not for everybody.

(Respondent: GW-CAP-21-10 – CAPCCS HPCA)

Another feature of the CAPCCS operatives’ ethos which was mentioned by several respondents was the attention to detail that they displayed when dealing with patients, or more importantly, their awareness of the details that had the greatest impact on quality of care and their willingness to act on them:

‘My husband said to me that he had never felt so comfortable and well cared for as he did then. Some of that would be down to the pain patch, and some to the profiling bed and air mattress, but most of it was because of the expert care he received from the CAPCCS team who went to great lengths to ensure that he was comfortable. One of the things he particularly hated was to have a fold or crease under him in his pyjamas, and everyone very quickly was aware of this and took enormous care to make sure there were no creases anywhere. I think this is typical of the detailed and personal attention which was such a feature of the care he received.’

(Respondent: BC-EM-12-11 – bereaved carer)

This attention to detail, and a flexibility to act on anything (within reason) that might make things better for both the patient and the carer was also noted by healthcare professionals. It is significant too, perhaps, that in this context comparisons were often made with the care provided by some agency staff - particularly those who attended infrequently, or were perceived as not attempting to build a rapport with the carer or patient:

‘I’ve been in to patients’ homes during their last hours of life, after CAPCCS have been in and turned them, and changed them, and so on, and they look so well cared for. I’ve been in a patient’s home where agency have been in, or homecare have been in, you know and they may be turned, but they’re not quite over on their side, or they may be turned but they haven’t flattened their hair down or, you know, the pillow was a bit skew-wiff, and you know and how patients look when they’re dying is... you know because relatives often choose that time to go and have a cup of tea, or go and have a fag in the back garden or whatever. And if they come in and look at the patient and they look well cared for, and the pillow is straight, and their hair’s been cut, you know it’s that detail that... well that goes with patient’s relatives into bereavement really. You know it’s that level of detail that people remember. And that’s what... the feedback we get about the CAPCCS team is, is their sort of level of detail, and nothing’s too much trouble.

(Respondent: COM1-CAP-30-9 – Community Nurse Specialist)

3.11.2 The facilitation of dying at home

A key objective of the CAPCCS service is to increase choice at end of life, and support individuals if they wish to remain within their home environment. There is some evidence that this is taking place. One Community Nurse Specialist attached to a local hospice said that she could see a definite shift in people being able to stay at home to die, and that along with the District Nursing Framework, which put the District Nurse back in charge of end of life care, she was ‘blooming confident’ that this was because of the input that the CAPCCS team had been able to put into peoples’ homes. She also emphasised that she thought it had been very much better for the District Nursing service to be able to access a resource such as CAPCCS, rather than having to utilise Social Services or agency workers, and thus reduce the likelihood of involving inexperienced staff.

3.11.3 *Help for carers*

It was also clear from carers that many would not have been able to continue the caring process at home had it not been for the support provided by the CAPCSS team. Practical issues, such as being able to turn the patient, or wash and change them were cited as developing into major difficulties – particularly if the person became moribund and was unable to do anything without help. As end of life approached, these problems could be compounded by other care needs such as complicated medication routines, and the need to be ‘on duty’ 24 hours a day.

‘[providing care] was impossible. We couldn’t have done. I could have washed her arms and her feet and legs, but I couldn’t have turned her over. And I couldn’t have changed her nightie while she was lying... as I say I couldn’t even get her out of bed to go on the commode in the end. No, without them it would have had to be hospital. I couldn’t have managed.’

(Respondent: BC-CAP-25-11 – bereaved carer)

‘[looking after the patient at home] was so much more personal than being shot off to hospital. I mean alright we’d have been visiting and all the rest of it, but however you try and make it – I’ve never been in a hospice so I don’t know – but in hospital it’s impersonal. It has to be because it’s a working institution. And it’s... I mean everything happened here, everything was in a nice homely environment, and it made all the difference.’

(Respondent: BC(H)-25-11 – bereaved carer)

Recognition of the support that the CAPCSS team had provided to carers was also reportedly acknowledged by patients. According to one bereaved carer, just before he died a patient mentioned how he had been enormously relieved that so much of the burden of caring had been taken from his wife’s shoulders, and that they were getting so much expert help. Another bereaved carer we were able to interview related how she had struggled alone for some months with the care of her husband, and that following the unexpected ‘arrival of the cavalry’ (i.e. the CAPCSS team) it took her a few days to realise that their involvement meant that she could actually now take a little time for herself:

‘As I say we never had a minute’s aggro with any of them – nothing. And anything I wanted... if they were washing him in there, and I’d say to them – because I wasn’t supposed to leave him you know – and I’d say to them ‘do you mind you know when you’re washing him, can I just slip round to the shop?’ And they’d go yes, one of us will wait while you come back. And I’d just slip round to the shop. And if they’d finished when I came back one of them would be still here with him. And they’d either made him a cup of tea or something while I come back you know. Yes, they’d do anything for him, yes.’

(Respondent: CAP-CAR-23-10 – bereaved carer)

3.11.4 Possible improvements

When patients and carers were asked what they would like to see done to improve the CAPCCS service, only two relatively minor issues emerged. Both of these related more to the wellbeing of the HPCAs rather than any problem with the quality of care provided. The first issue concerned the way in which HPCAs are required to break off all contact with a family as soon as the patient has died. Often, if CAPCCS has only been involved for a short space of time this is not really an issue, but for cases where care has been provided for longer periods it is normal practice for the office to send a generic, non-religious bereavement card to the carer. HPCAs are not allowed to attend funerals and so forth, and while the bereaved carers we spoke to fully appreciated that this arrangement is required in order to facilitate a cut off point (for both the carer and the HPCAs), several of them said they would have liked to have been able to see their HPCAs again. This demonstrates, perhaps, how highly carers value the relationships they develop with their HPCAs.

The second issue related to the way in which visits are arranged, or more specifically, the amount of time that HPCA have to spend travelling between patients. Some respondents thought that the travel involved put a big strain on the HPCAs, and the system of allocating visits could be made more efficient (i.e. patients who were relatively close could be visited by the same HPCA).

The issue of inefficient use of travelling time was also raised by one of the senior managers at Leeds PCT. Again, however, it was acknowledged that with the small number of HPCAs currently available, and the large geographical area they needed to cover, this might be a difficult issue to address. Similarly, the CAPCCS administrators who allocate patients to the HPCAs reported that they are aware of this issue and already try to allocate work as efficiently as they can within the limitations they have.

3.12 Workforce implications

3.12.1 *Is there a workforce available?*

It might be expected that the physical and psychological demands of working as a HPCA in end of life care are not likely to make it a popular career choice. However, it appears that there are in fact a large number of people who are interested in doing this type of work. At the level of initial recruitment at least, there have reportedly been very high response rates to advertising campaigns in the local press. However, as one of the Senior Nurses in charge of administering CAPCCS noted, of the large number of people who might apply to an advertisement, the individuals who are actually suitable is relatively small. This stems partly from misconceptions about what the role really entails, and partly because even individuals who have all the necessary practical abilities might not have the particular mix of psychological and attitudinal strengths that are essential in the role. Because of this, the interview and selection process for HPCA is very rigorous:

‘I mean obviously when we’re interviewing we’ve got certain criteria we’re going through. It’s a *very* different job. It’s not just a care worker/support worker. It’s end of life - dying patients you know. And obviously the questions that we’re asking are around that and the scenarios that we give. They could be walking in and somebody has died, somebody is about to die as they’re there. And people have got to realise what they are going to be doing out there. It’s very different, very... people have to want to do that.’

(Respondent: SH-CAP-21-10 – CAPCCS Senior Nurse)

Potential HPCAs are also encouraged to visit the CAPCCS offices so that staff can talk informally with them, explain exactly what it is that they will be getting involved with, and ensure that this is a role they are really prepared to do. It was commented on by several of the DNs and other stakeholders we interviewed that CAPCCS does appear to have been able to recruit people who are very empathetic and well suited to the role. One DN, for example, noted that the HPCAs seem to be ‘...able to make relationships with poorly people very readily’.

Once accepted as a HPCA, the training and induction programme is described as ‘robust’ by senior CAPCCS staff, and lasts at least a month. A key part of the training involves shadowing other HPCAs, going out with District Nurses, spending time at hospices, and receiving more formal instruction on aspects of end of life care. It was

also regarded as important that HPCAs get a ‘feel of what the community’s about – how the community works’, and neophytes even spend time with a funeral director and other agencies that become involved once a patient dies so that they know the processes and procedures that carers are likely to be faced with.

3.12.2 The mix of skills

In terms of whether or not there is a workforce available to fill the needs of a continuing and expanded CAPCCS programme in the Leeds area, it would seem that there is. None of the administrative, management or commissioning stakeholders we interviewed appeared to think this would be a significant issue. However, as outlined already, it may be that the careful selection of individuals with the right mix of skills, psychological disposition and attitude will continue to be a time consuming process.

DNs who responded to our survey suggested a number of key skills which they thought HPCAs needed to have. These included:

- Good communication and interpersonal skills.
- Empathy, discretion, and a caring nature.
- Basic nursing skills.
- Personal care skills (i.e. hygiene, catheter care etc.)
- Moving and handling training.
- Knowledge of medication.
- Previous knowledge of caring for people with long term conditions and an awareness of end of life issues.

71 % (n=10) of DNs who responded (n=14) thought that the current post holders had the right mix of skills required.

3.12.3 The ‘generic worker’ model

Overall, it appears that the ‘generic worker’ model was considered to be the most effective way of supplying the type of care that the CAPCCS service aims to provide. Certainly, none of our stakeholders were able to suggest a model that might provide a better ‘fit’ with requirements. Similarly, in our DN survey, 13 out of the 14 who responded said they considered that HPCAs helped to maximise support for patients and families. It also generally acknowledged that without this form of targeted, yet

versatile, intervention, far fewer people would be able to die at home – particularly those who have little or no family or carer support.

3.12.4 Training and support requirements

In general, the current level of training and support available to HPCA staff appears to be very well suited to the tasks they were required to perform, and set at an appropriate level. One Community Nurse Specialist who had worked closely with HPCAs commented:

‘I think they’ve been really good – professional, well trained, well supported. I think it’s very clear that they’ve... you know the girls have got support back, and had reflection. And they haven’t got the turnover problems that other organisations [have]. And that’s a lot to do with training and support back at base. Because recognising, you know, that they are providing a lot of intense support at the end of life for a few days or whatever, and then the patient had died you know. And it’s quite a big emotional impact, especially on people that have perhaps not worked in that field before.

(Respondent: COM2-CAP-08-10 – Community Nurse Specialist)

Significantly, as alluded to in the extract above, although many HPCAs do have a background in nursing or healthcare, this type of experience is not necessarily a prerequisite for the job. Several of the current CAPCCS team, for example, had had little or no professional experience in healthcare prior to their involvement with the service. So considering the positive feedback received from many healthcare professionals and carers, this is perhaps a good indication of the effectiveness of the training that they receive. Another hospice based Community Nurse Specialist commented that:

‘They’ve had an excellent package of training. You know I think we’ve thought about that a lot, and I think most of them have been here [to a local hospice], because some of them were working in a bank or a shop the day before! So I think most of them have been on placements here on the inpatient unit. And we’ve been involved with quite a lot of the teaching, so I think they’ve had a good induction from what I can see.’

(Respondent: COM1-CAP-3-09 – Community Nurse Specialist)

In terms of what further training might be considered in the future, it was suggested that perhaps a little more emphasis on medically related skills might be considered –

particularly in relation to the ability to give medication. Similarly, it was suggested that any training which would reduce the need for HPCAs to require such detailed care plans would be useful.

3.13 *Summary and recommendations (CAPCCS)*

- Overall, the CAPCCS programme does appear to have had a significant positive impact on the way end of life care is delivered to patients who choose to die in their own home (or care home). The CAPCCS service as a whole is very popular with carers and DNs, and the personal approach and good communication skills of the HPCAs were particularly noted.
- The method of referring patients to CAPCCS appears to be satisfactory in terms of the way it is integrated into existing computerised systems (i.e. RIO). There were some concerns expressed about the speed at which the system could be updated in the light of fast changing patient conditions. However, these were not regarded as particularly significant due to the close telephone contact that DNs usually maintained with HPCAs.
- Referral pathway issues were raised by some stakeholders. In particular, it was suggested that opening up referral access to groups of healthcare professionals other than DNs would be advantageous. However, much of the success of the pilot programme has been due to the simple and straightforward way in which the service has been meshed with the particular organisational needs of the DN service. This has allowed the activities of the programme to be relatively streamlined and focused, with lines of accountability and the demarcation of roles clearly stated. While it may be that opening up the referral pathway is a valid proposition, at present the relatively limited resources available to CAPCCS would make this difficult.
- Communication between DNs (i.e. case holders) and HPCAs is reportedly very good, with a degree of mutual respect on both sides – HPCAs deferring to the

DNs whenever necessary, and DN's voicing few complaints about the abilities and professionalism of the HPCAs.

- Some higher level inter-agency communication issues have been raised. These relate mainly to contacts between CAPCCS administrators and joint care managers. It has been suggested that systems and procedures for withdrawing CAPCCS services from patients - in cases where a patient's condition has improved and they are no longer regarded as 'fast track' - need to be reviewed so that relevant personnel are always informed before HPCAs are pulled out.
- Similarly, it appears that although CAPCCS is designed to work closely with DN services on the ground, there needs to be closer synchronisation of lead-out times with other agencies so that withdrawal of CAPCCS dovetails with the provision of alternative care arrangements.
- The organisation and implementation of care plans works well from the perspective of HPCAs. Similarly, most DN's regarded the system as adequate. However, an issue of concern to some DN's was the number of different care plans that HPCAs need for a given patient, and the level of detailed instruction that they appear to require. The implementation of 'generic' care plans for commonly used interventions (such as the use of lifting hoists) could be a means of reducing the administrative burden on DN's.
- In general, the current level of training and support available to HPCAs appears to be well suited to the tasks they are asked to perform. Further training might focus on more 'medical' issues, such as the giving of medication.
- The selection and training of HPCAs is regarded as a crucial element in the success of CAPCCS. The level of attention given to making sure that applicants for HPCA posts have the right mix of social and communication skills for end of life care - along with the routine caring skills that are required - has meant that the current team of HPCAs are seen as extremely professional and effective. If CAPCCS is developed further, it is crucial that this element of the service is not neglected.

- It appears that the ‘generic worker’ model is likely to be the most effective way of supplying the type of care that the CAPCCS service provides. Certainly, none of our respondents were able to suggest a model that might be more suitable. It was generally acknowledged that without this form of targeted, yet versatile, intervention, far fewer people would be able to die at home – particularly those who have little or no family or carer support.

4 DISCUSSION

There is currently much discussion around the palliative care needs of older people (Gott 2008), and this is placing care homes in the spotlight as a significant place of care and death at the end of life (Hewinson *et al.* 2008; Ingleton and Froggatt in press). Only in recent years has research specifically investigated the quality of dying and management of death in care home settings (Katz and Peace 2003; Seymour *et al.* 2005; Froggatt and Payne 2006). Studies and reports in the UK have consistently observed the poor quality of dying in care home settings and more recently have identified the urgency of improving terminal care in these settings and set targets for doing so (Owen & NCHRDF 2006).

4.1 CHESS

CHESS is one in the small but growing number of service improvement initiatives which aim to support care homes in the delivery of palliative care to their residents, and improve the residents and family experience of care delivery during the last 6-12 months of life.

In attempting to work within this often challenging arena (Katz 2008), the CHESS initiative does appear to have met with a degree of success. Although there are a number of statutory requirements for the organisation and operation of care homes, this care setting has been notoriously difficult to influence in terms of general residential care improvements. This may be due in some part to a number of factors: it's largely independent and fragmentary nature, the way in which professional networks between homes have not always been fully developed, and the significantly high turnover of staff that these particular organisations are often faced with (Sidell *et al.* 1997). Similarly, care home work has not traditionally been seen as particularly high status among health professionals and other workers, and this has also impacted on the continuity of any training initiatives which have been attempted (Nolan *et al.* 2008).

Although only implemented in a small proportion of eligible care homes in a single Northern UK city, what CHESS does appear to have shown is that the training approach which underpins the programme is an effective starting point from which to

make inroads into improving care in this setting. The education and training of staff within care homes are often suggested as a way of raising standards and ensuring a motivated and stable workforce and has long been seen as an important means of ensuring change with respect to end-of-life care in care homes (Froggatt *et al.* 2006). Care home staff do tend to be marginalised when it comes to receiving education as they are often excluded from the consortia of education that is provided to their NHS counterparts. For those homes participating in the CHESSE scheme, there was perceived to be a positive impact on the care of residents in relation to end of life care, and lessons learned during the planning and implementation of the programme are likely to be relevant to other regions, should they wish to use this particular training and development model. However, it should be noted that concerns have been raised over the effectiveness of recruiting homes on a voluntary basis, as it is evident that, in this pilot at least, participating homes have tended to be ones that already display a reasonably good awareness and infrastructure relating to end of life care.

In terms of specific issues which can be taken from the initiative, there are three main points that can be highlighted. Firstly, the formalisation of procedures and protocols across different care homes has reportedly made a big impact on the way in which end of life care is organised. While effective administrative frameworks were already in place in the majority of participating homes, these had largely been developed independently, with little compatibility between homes, and little direct connection to NHS systems. While, on one level this was not a problem, on another, the introduction of comprehensive standardisation has resulted in greater information flow between homes and outside healthcare agencies, such as ‘out of hours’ services. Having a specific and comprehensive protocol at any given stage in the end of life trajectory (an advance care plan, for example) has similarly clarified what has previously been a particular area of inconsistency.

A second issue which requires comment relates to the way in which the CHESSE initiative was introduced, or more specifically, the way in which some opportunities to learn from and integrate with existing palliative care services were either missed or not fully exploited. While MCCC conducted ground work and scoping exercises in the region before developing their CHESSE training programme, it is also evident that in some respects (notably the use of large ‘workshop’ events rather than care home

delivered training) their final approach did not entirely take on board the preferences of potential participants. Similarly, the slight alienation commented on by some groups of healthcare professional who were already reported as providing excellent palliative care training in care homes (i.e. the palliative care teams based at the two main city hospices) could have been avoided had slightly more account been taken of the working realities and organisational idiosyncrasies of the region.

Finally, in terms of whether or not the CHES initiative can be further developed and possibly adapted for use in other regions, the programme does appear to have a lot to commend it. Taking aside the issue of limited funding and the difficulties of encouraging homes which are currently underperforming to become involved, it may be that the CHES model can be adapted to become a much more targeted entity – possibly evolving into a service that concentrates on proactive outreach strategies alongside the more formalised (and relatively expensive) training programme that currently forms the mainstay of the initiative.

A significant issue here, then, is the sustainability of the programme, and particularly the issue of how best to maintain momentum and continuity of knowledge in an area that is beset with high staff turnover. It is, after all a key tenet of CHES that skills and knowledge are actively maintained by being ‘championed’ by particular individuals. If these key individuals choose to leave, it is likely that a degree of momentum will be lost and may not be regained. Participation in CHES has had a very positive effect on many care home staff in terms of their confidence and professional self image, but whether or not this boost to self-esteem is sufficient to encourage a significant number of them to remain in this sector is unknown.

4.2 CAPCCS

In the wake of recent government policy (DoH 2008), service improvement initiatives designed to facilitate end of life care in the community are attracting more attention. The CAPCCS programme was largely based on services that already existed in Leeds – the North West District Nursing Relief Team, and the East Leeds Integrated Palliative Care Service (ELIPCS). However, these services were previously limited to

discrete regions of the city, and a major aim of CAPCCS has been to provide city wide cover.

Based on the provision of dedicated health and personal care assistants, it can be said that CAPCCS has proven to be a successful intervention. It has been very popular with users (i.e. carers of people who have chosen to die at home), and has similarly been praised by the District Nurses who have benefited from the support it has been perceived to provide.

CAPCCS also appears to have been integrated effectively into the various administrative networks which comprise the regional referral system, although it was suggested by a number of healthcare professionals allied to the District Nursing Service that the referral system might be usefully expanded to include healthcare professionals in other relevant sectors. While this might be desirable, it is acknowledged that the current 'District Nurse only' system has enabled CAPCCS to maintain a relatively streamlined and efficient service – particularly when it is considered that at this initial stage of development CAPCCS staffing levels are quite low (currently 16 HPC assistants and a small administrative staff). With current arrangements it would probably be counter-productive to open the referral pathway up too far, as this would inevitably put a strain on administrative and organisational systems. It would perhaps also introduce inconsistencies into the chain of information and case control which is currently very straightforward.

While communication between District Nursing Services and CAPCCS was reportedly very good, one area of concern related to higher level inter-agency communication. Specifically, it was suggested by a number of senior level administrators in the local PCT that systems and procedures for the withdrawing of CAPCCS services could be streamlined, and that communication at higher levels needs to be formalised to ensure that lead-out times and withdrawal of cover are synchronised. It would appear that this issue needs to be addressed with some urgency as continued misalignment in this area could threaten to undermine the very positive image that CAPCCS has managed to cultivate among health professionals and users in the field. Similar communication difficulties have been reported in other studies (Walshe *et al.* 2008; Walshe *et. al* 2008a).

Overall, despite the reservations described above, the various elements of previously existing services that were appropriated into CAPCCS appear to have been integrated into a well run and valued service. This is particularly notable given the limitations of staffing that currently pertain. Likewise, in common with other studies (c.f. Goodman *et al.* 2003), it could also be said that the high degree of attention given to the recruitment and training of dedicated health and palliative care assistants has definitely paid dividends.

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Appendix 1 – The care home ‘champions’ survey.



Evaluation questionnaire about the Marie Curie Delivering Choice Programme initiative *Care Homes End of Life Supportive Services (CHESS)*

Dear ****CHAMPION NAME****

This questionnaire is being sent to all care home staff currently acting as nominated champions for the Marie Curie CHESS programme in Leeds. The survey forms part of a wider independent evaluation of the Marie Curie ‘Delivering Choice Programme’ which is based at Lancaster University.

We are interested in your views about the way the CHESS programme has been implemented in the care home where you work. We would also like your opinions on how it could be improved, and any other suggestions you may have about its future development.

This evaluation is independent of any questionnaire distributed by Marie Curie, and has full ethical approval. Your answers will be treated in the strictest confidence and you will not be identified in any reports associated with this evaluation.

The questionnaire should take approximately ten minutes to complete. **Please return it in the enclosed prepaid envelope by 31st Aug 2008.**

If you have any questions about the questionnaire or the study please contact:

Dr. John Chatwin

Research Fellow
Institute for health Research
Lancaster University
Lancaster
LA1 4YW

Tel 01133 431374 (Leeds office)
Email: j.chatwin@lancaster.ac.uk

Many thanks for your help!

Evaluation questionnaire about the Marie Curie Delivering Choice Programme initiative *Care Homes End of Life Supportive Services (CHESS)*

1. The care home where you work.

In this first section we would like to ask a few questions about your job, and the care home where you work.

a) What is your job title.....

b) How long have you worked in your present job?

c) What are your main responsibilities?
.....
.....
.....

c) What type of care home do you work in? (i.e. nursing home / residential home)
.....

d) What type of client does your care home mostly cater for (i.e. old age / dementia / physical disability etc.)

e) How many beds does it have?

f) How many rooms does it have?

2. Your skills and experience.

a) Please think about the level of skills you possess and tick the box that applies to you:

Complete beginner	Novice	Quite Skilled	Competent	Expert	Other (specify)
Communication with patients	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Communication with relatives	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Communication with other members of staff at your care home	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Psychological support	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Bereavement support	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Spiritual support	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

The World Health Organisation defines palliative care as: ‘an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual’

b) What factors would you say contribute to the provision of good palliative care in the care home where you work?

c) Could you please describe any factors that prevent you or other members of the care home staff from delivering the best possible care to residents who are receiving palliative care?

3. This part of the questionnaire asks you to think about the CHESSE programme, and your involvement in it.

a) What made you want to volunteer to be a ‘champion’ for the CHESSE programme in your care home?

.....
.....
.....

b) Do you feel you have received enough support in your role as a champion from:

Marie Curie (i.e. local facilitators): **YES** **NO** **N/A**

Your care home management: **YES** **NO** **N/A**

Other staff at your care home: **YES** **NO** **N/A**

Outside health care agencies (i.e. GPs / district nurses / specialist palliative care nurses etc.)

YES **NO** **N/A**

c) If you have answered NO for any of the above, could you give more details please?

.....
.....
.....

d) In your opinion, has participating in CHESSE made a difference at the care home where you work?

YES

NO

Please say why you think it has or has not

.....

.....

.....

e) On a scale of 1 to 5, how strong would you say the commitment to CHESSE is from:
(Please tick)

		highly committed			not committed	
1	Your care home management	1	2	3	4	5
2	Other staff at your care home	1	2	3	4	5
3	Residents	1	2	3	4	5
4	Family and friends of residents	1	2	3	4	5
5	GPs (if applicable)	1	2	3	4	5
6	District nurses (if applicable)	1	2	3	4	5
6	Other (please specify)	1	2	3	4	5

Thinking specifically about the training that you received to help you organise and run CHESSE in your care home:

f) Were there any parts of the training that you found particularly helpful?
(please give details)

.....

.....

.....

.....

g) Were there any parts of the training that you found particularly difficult or challenging, or unhelpful?
(please give details)

.....

.....

.....

.....

h) What improvements or changes would you like to see in the way the training is offered?

(please give details)

.....
.....
.....
.....

i) From your experience as a champion, would you say that the way CHESS is delivered is efficient and effective?

YES NO Don't know

j) What improvements could be made?

.....
.....
.....
.....

k) Do you think that CHESS addresses all the areas that influence provision of palliative care in care homes?

YES NO Don't know

l) If not, which areas do you think need to be addressed?

(please give details)

.....
.....
.....
.....

m) In what ways has involvement in CHESS changed the way palliative care is offered in your care home?

.....
.....
.....
.....

n) Do you think that being part of the CHESSE programme enhances your care home's reputation – in particular with its residents and families?

YES NO Don't know

o) Can you say why / why not?

.....
.....

p) Prior to CHESSE, did your care home use any of the following care pathways?

Gold Standards Framework Liverpool Care Pathway

Preferred Place of Care Other (please identify)

Other

4. PERSONAL DETAILS

Finally, we would like to ask you a few questions about yourself.

a) Are you a registered nurse?

Yes No

If you are, which year did you register as a nurse?

Yr. _____

b) Do you have a specific qualification in palliative care?

Yes No

e.g. ENB 931, ENB 285, Diploma in Palliative Care

If yes, please describe: _____

c) Have you undertaken any courses relevant to palliative care in the last year? (For example: Communication Skills, Symptom control, use of equipment)

Yes No

If yes, please describe _____

4. COMMENTS

Please add any further comments you may have (continue over if necessary):

Thank you for taking the time to complete the survey!

This questionnaire is being sent to all the champions participating in CHESS. As part of our evaluation, we would also like to hold informal interviews with a selection of champions. This will allow us to explore how the programme is working in greater detail.

If you would be willing to talk to a researcher from the MCC independent evaluation , please fill in your contact details below and we will phone to arrange a time to see you. Interviews will only take around 30 minutes, and can be done in your own home, over the phone, or at a time and place convenient to you.

Yes, I would be willing to take part in a follow up interview, and would like a researcher to phone me to arrange a time. (Please tick)

Name:

Contact telephone number:

Email:

Please now return the questionnaire to the researcher in the envelope provided.

If you have any questions about the study please contact: Dr. John Chatwin. Institute for health Research, Bowland Tower East, Lancaster University, Bailrigg, Lancaster , LA1 4YW
Tel 01524 593309 (Leeds office: 0113 343 1374) Email: j.chatwin@lancaster.ac.uk

Appendix 2

'Champions' survey respondent sample characteristics

From the 33 participating homes canvassed, 19 champions returned a completed questionnaire, giving a response rate of 57%. Of these, 14 respondents (73%) described their normal role within the care home as either the *manager* or *deputy manager*; 2 (10%) were *qualified nurses*;¹ the remaining three described their roles as *team leader*, *NVQ assessor*, and *care supervisor*. (See table 2 below.)

Table 2: Normal working roles of 'champions' survey respondents

Champions' normal work role in care home (n=19)	Number of 'champions' in role
manager / deputy manager	n=14
Qualified Nurse	n=2
Care Team Leader	n=1
NVQ assessor	n=1
Care supervisor	n=1

Respondents reported being in their present posts for an average of ≈ 8 years, the actual length of employment ranging from 1 to 20 years. 4 described their home as purely nursing, 10 as residential, and 4 as nursing and residential. In terms of the types of resident that participating homes cared for, all 19 described their home as catering mainly for old age and related issues (i.e. dementia, Alzheimer's etc.). Three homes had facilities for caring for residents with physical disabilities, and one home also catered for residents with learning disabilities.

¹ It was not a requirement of participation in CHES that 'Champions' be qualified nurses, or have any previous medical training.

Appendix 3 - Data Collected in Leeds during May – November 2008

Evaluation Data	Anticipated recruitment / data	Details of participants and data collected	Final sample
Stakeholder interviews (CHES)	<p><i>Care home managers</i> n=10 (n=5 from participating homes n=5 from non-participating homes)</p> <p><i>'Champions'</i> n= 2-3</p> <p><i>CHES facilitators</i> n=2</p> <p>Health professionals from the community n=5-6</p>	<p>Interviews held n=6 Interviews held n=4</p> <p>Interviews held n=3</p> <p>Interviews held n=3</p> <p>Interviews held n=7</p>	<p>n=6 n=4 (n=10 total)</p> <p>n=3</p> <p>n=3</p> <p>n=7</p>
Postal survey – champions (CHES)	n=33	Returned n=19	n=19
Group observation-CHES training workshops	<p>1 workshop</p> <p>1 'cluster meeting' (CHES champions)</p>	<p>1 training workshop observed (n=>30 participants) Informal satellite interviews and observation conducted.</p> <p>1 cluster meeting attended – group observation and informal group interviews conducted (n=7 participants)</p>	<p>n=1</p> <p>n=1</p>
Interviews with bereaved carers (CHES)	n=3 from participating homes n=3 from non-participating homes	n=2 n=3 (including one written account)	n=3 n=3
Resident case studies (CHES)	n=2	n=2	n=2
Documentary material (CHES)	Any relevant documentary material was collected, i.e. reports, user feedback, workshop attendance figures etc.		
Survey - District Nurses (CAPCS)	n=30	Returned: n=14	n=14
Stakeholder interviews (CAPCS)	n=8-10	n=17	n=17
Bereaved carer/patient interviews (CAPCS)	n=6	n=6	n=6
Documentary material (CAPCS)	Any relevant documentary material was collected.		

Appendix 4 – Evaluation project timeline

May 08	June	July	Aug	Sept	Oct	Nov	Dec	Jan 09
Set up								
	Pilot work	Data collection (CHESS)						
				Data collection (CAPCCS)				
					Analysis			
							Final report	

Appendix 5 – The District Nurse Survey (CAPCCS)



Evaluation questionnaire about the Marie Curie Delivering Choice Programme: *Complex and Palliative Continuing Care Service (CAPCCS)*

Dear >>DISTRICT NURSE NAME<<

This questionnaire is being sent to all District Nurses who have been involved with, or used, the Marie Curie *Complex and Palliative Continuing Care Service (CAPCCS)* in the Leeds area. It is part of an independent evaluation of the Marie Curie ‘Delivering Choice Programme’ which is being undertaken at the Institute for Health Research, Lancaster University.

We are interested in your views about the way that CAPCCS has been implemented and run. We would also like your opinions on how it could be improved, and any other suggestions you may have about its future development. At the end of the survey there are also some general questions about your experience of palliative care.

This evaluation is independent of any questionnaire distributed by Marie Curie, and has full ethical approval. Your answers will be treated in the strictest confidence and you will not be identified in any reports associated with this evaluation.

The questionnaire should take approximately ten minutes to complete.
Please return it in the enclosed prepaid envelope by 30th September 2008.

If you run out of space answering any of the questions, please feel free to continue on a separate sheet, and if you have any questions about study please contact:

Dr. John Chatwin

Research Fellow
Institute for Health Research
Lancaster University
Lancaster
LA1 4YW

Tel 0113431374 (Leeds office)
Email: j.chatwin@leeds.ac.uk

Many thanks for your help!



Evaluation questionnaire about the Marie Curie Delivering Choice Programme: *Complex and Palliative Continuing Care Service (CAPCCS)*

1. PERSONAL DETAILS

Firstly, we would like to ask you a few questions about yourself.

a) In which year did you register as a first level nurse?

b) In which year did you gain your Community Nursing qualification?

c) Do you have a specific qualification in palliative care?

Yes No

e.g. ENB 931, ENB 285, Diploma in Palliative Care

If yes, please describe:

d) Have you undertaken any courses relevant to palliative care in the last year? (For example: Communication Skills, Symptom control, use of equipment)

Yes No

If yes, please describe:

e) We are aware that some types of training course are easier to fit in around your work than others. Hypothetically, if you were offered training on an aspect of palliative care, which length of course would appeal most to you?

1 week +
type)

1 morning / afternoon

Other (please say which

3 days

correspondence course

1 day

internet based learning

2. This part of the questionnaire asks you to think about the *Complex and Palliative Continuing Care Service (CAPCCS)* and your experience of using it.

a) In your view, is the referral system effective?

Yes

No

Don't know

b) If not, could you say why not, and perhaps give an example from your own experience?

c) Have you experienced any problems or difficulties using CAPCCS.

Yes

No

d) If you have, could you say what they were?

e) Do you think that adopting CAPCCS has enabled you to use your time more efficiently?

Yes No Don't know

f) If not, could you say why not, and what changes might make it more efficient?

g) How efficient do you think the CAPCCS service is in terms of:

		highly efficient			not efficient	
1	Access by health professionals	1	2	3	4	5
2	Referral and delivery	1	2	3	4	5
3	Information flow between professionals	1	2	3	4	5
4	Effective use of established care plans	1	2	3	4	5
5	Flexibility of service	1	2	3	4	5

h) In your experience, has CAPCCS been effective in reducing the number of different healthcare professionals entering patients' homes?

Yes No Don't know

i) Do you think that CAPCCS has been effective in enabling more people to die at home? (Please give an example if possible.)

Yes No Don't know

j) In your experience, has CAPCCS prevented inappropriate admissions to hospital? (Please give an example if possible.)

Yes No Don't know

k) Do you think that the use of CAPCCS Community Healthcare Assistants contributes to maximising support for patients and families?

Yes No Don't know

l) If not, could you say why, and what approach you think would be better?

m) What mix of skills do you think it is important for a Health and Personal Care Assistant to have?

n) In your experience, do you think the current CAPCCS post holders have this mix of skills?

Yes No Don't know

o) Thinking generally about the CAPCCS programme, where do you think improvements could be made?

3. PALLIATIVE CARE IN YOUR PRACTICE

In this section we would like you to think about what helps or hinders you in the care of patients with palliative care needs and their families.

a) What factors contribute to the provision of good palliative care in your practice?

b) Could you please describe any factors that prevent you from delivering the best possible care to your patients who are receiving palliative care?

c) What do you perceive to be the top three priorities to improve palliative care provision in your practice?

1.
2.
3.

d) Do you feel confident in the palliative care you deliver?

Please think about the level of skills you possess and tick the box that applies to you:

	Complete beginner	Novice	Competent	Quite skilled	Expert
Communication with patients	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Communication with relatives	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Communication with other team members, and the wider team	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Psychological support	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Bereavement support	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Support for carers	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Spiritual support	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Use of equipment (e.g. syringe drivers)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Pain relief	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Other Symptom control	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

4. COMMENTS

Please add any further comments you may have (please continue on a separate sheet if necessary):

This questionnaire is being sent to all District Nurses in the Leeds area who are involved with the *Complex and Palliative Continuing Care Service* (CAPCCS). As part of our evaluation, we would also like to talk to a selection of respondents. This will allow us to explore how the programme is working in greater detail.

If you would be willing to talk to a researcher from the MCCC independent evaluation, please fill in your contact details below and we will phone to arrange a time to see you. Interviews will only take around 30 minutes, and can be done over the phone, or at a time and place convenient to you.

Yes, I would be willing to take part in a follow up interview, and would like a researcher to phone me to arrange a time. I understand that not everyone will be interviewed. (Please tick)

Name:

Contact telephone number:

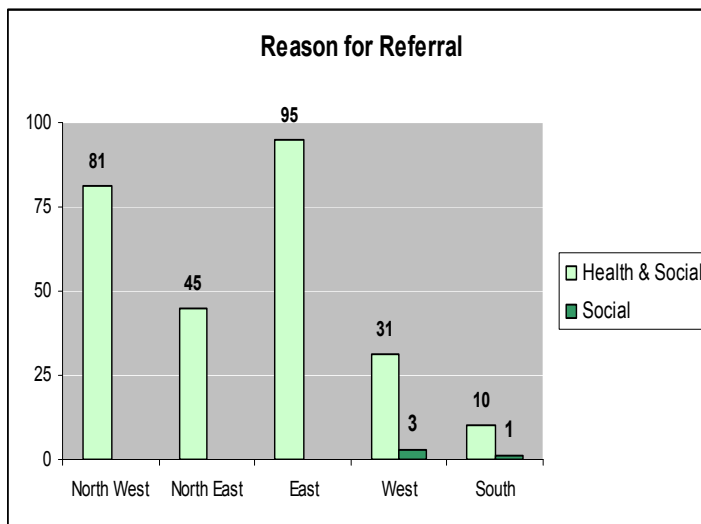
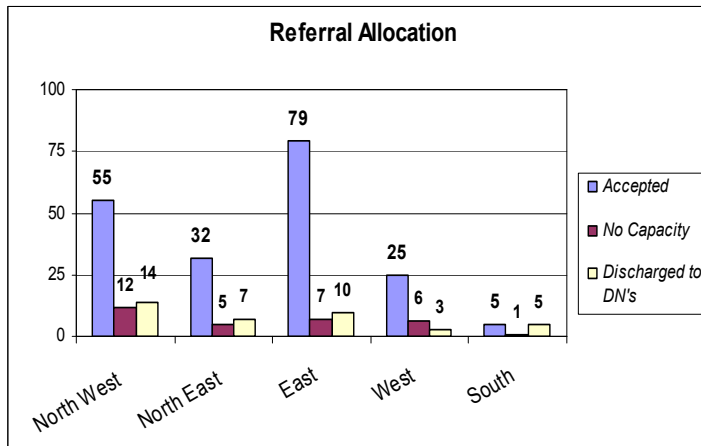
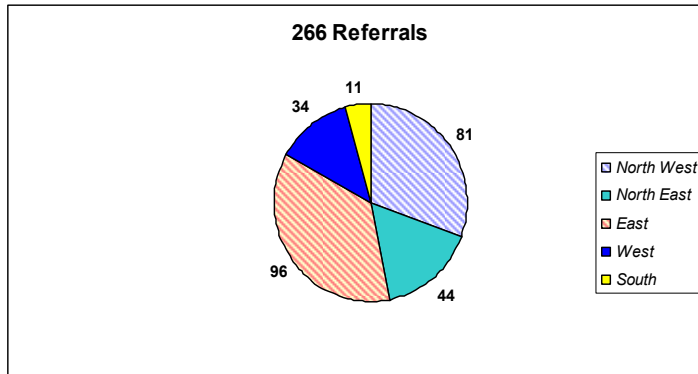
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If you have any questions about the study please contact: Dr. John Chatwin. Institute for Health Research, Bowland Tower East, Lancaster University, Bailrigg, Lancaster , LA1 4YW
Tel 01524 593309 (Leeds office: 0113 343 1374)
Email: j.chatwin@leeds.ac.uk

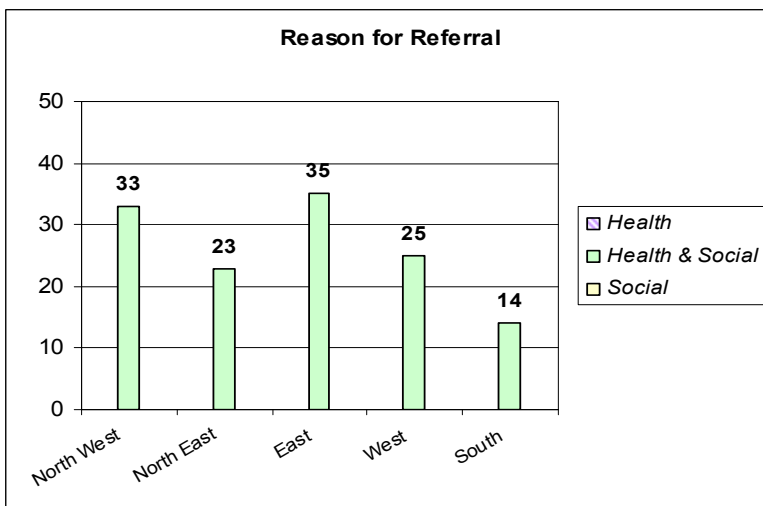
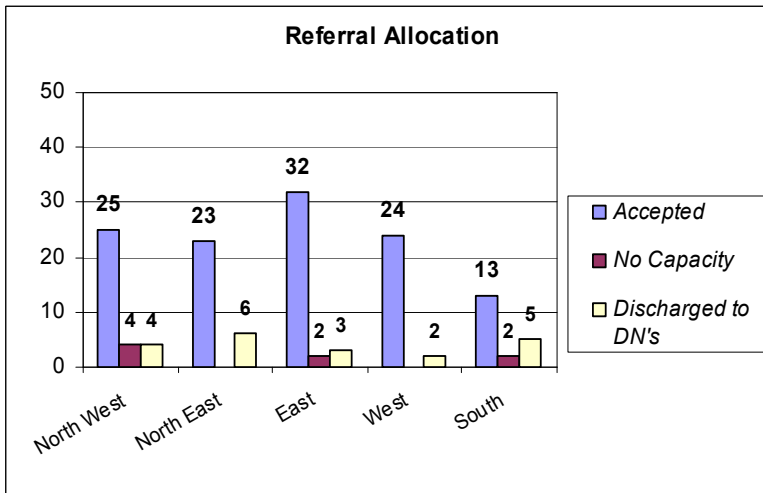
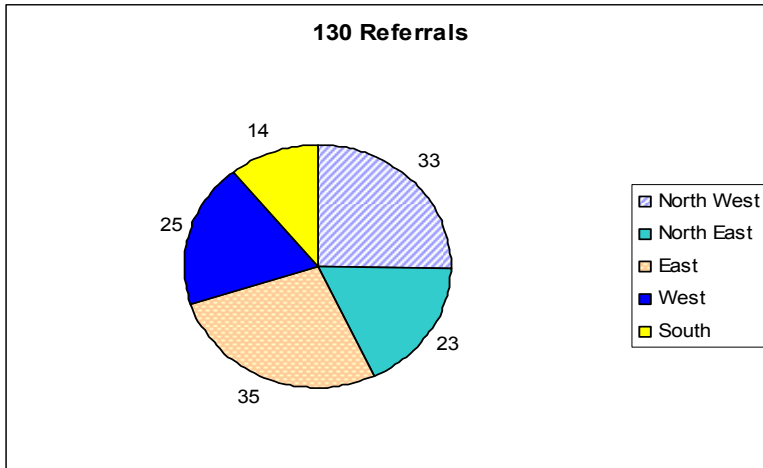


Appendix 6

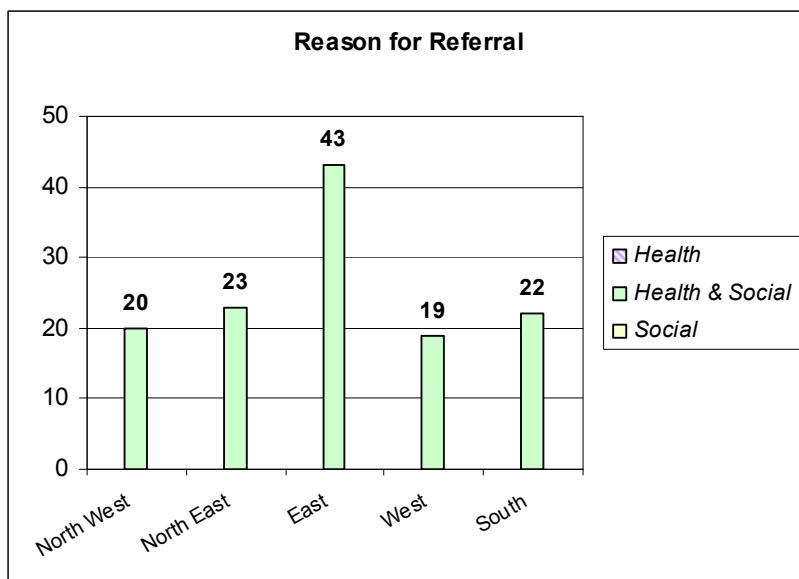
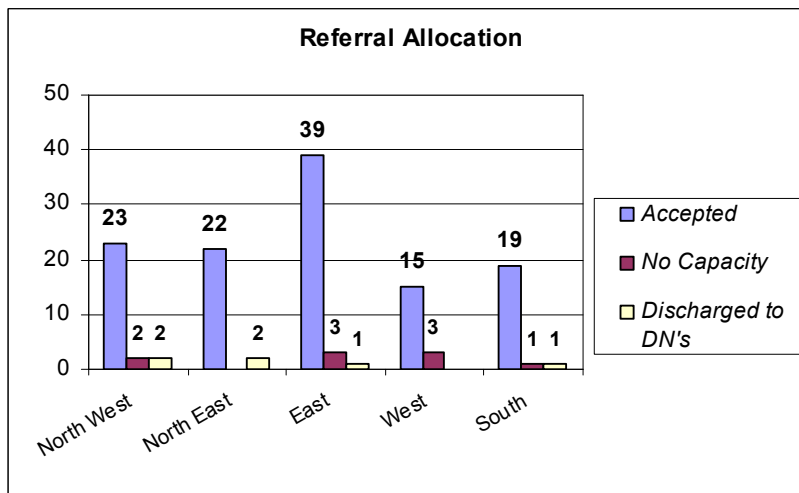
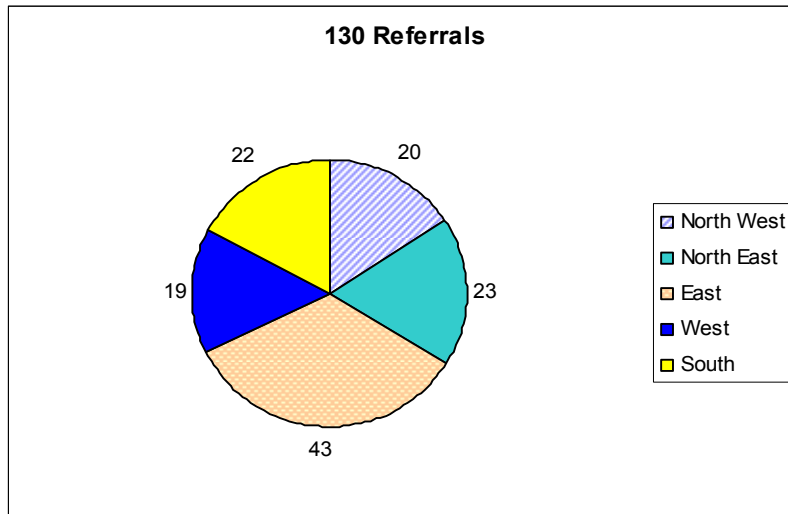
CAPCCS referrals between 28th January and 31st August 2008 (source: CAPCCS)



CAPCCS referrals between 1st September and 30th November 2008 (source: CAPCCS)

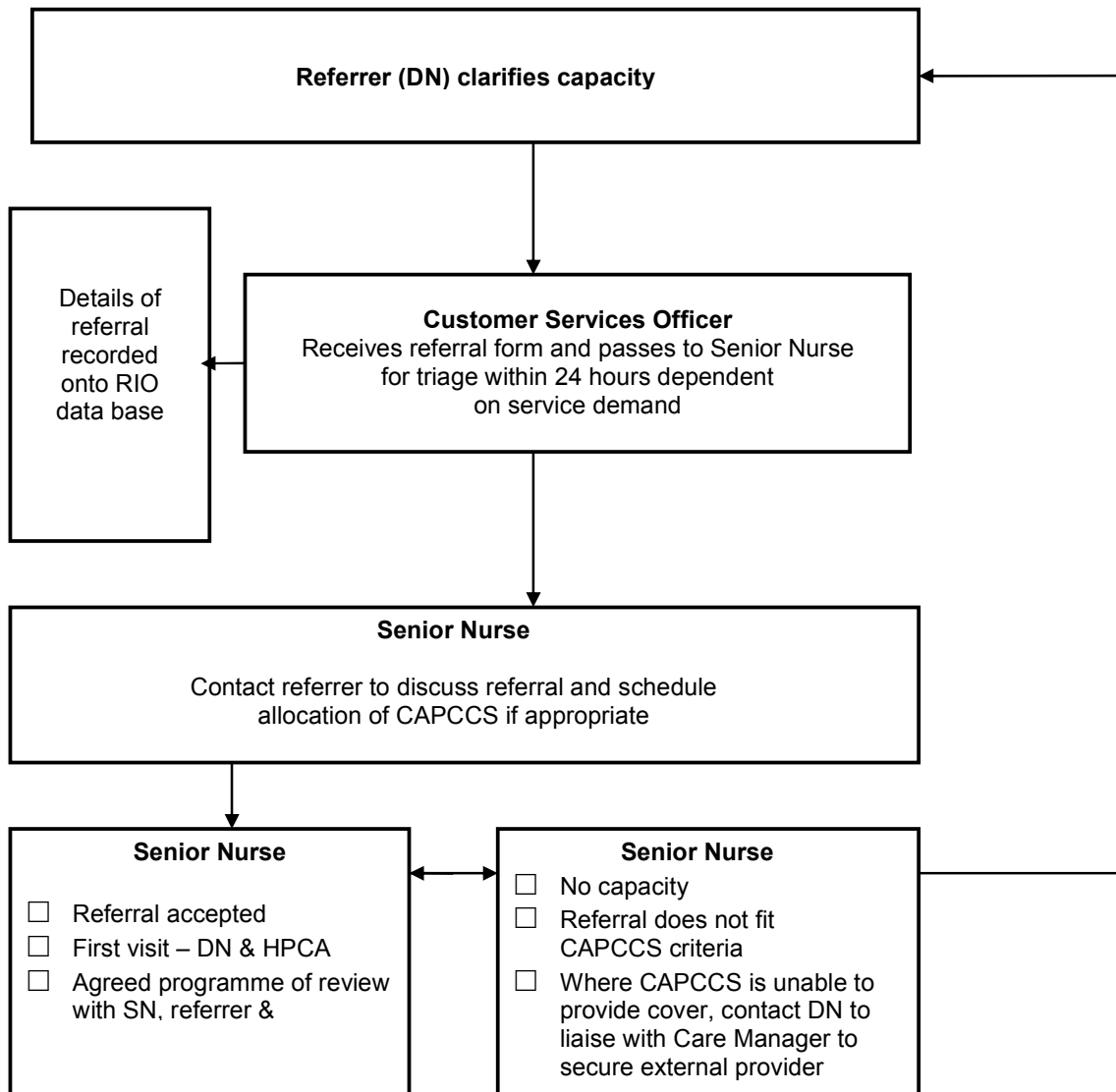


CAPCCS referrals between 1st December and 28th February 2008 (source: CAPCCS)



Appendix 7

CAPCCS referral pathway (End of life continuing care patients)



Appendix 8

CAPCCS referral pathway (highly complex care)

