Scoping exercise on generalist services for adults at the end of life: research, knowledge, policy and future research needs

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Report 1: Overview and recommendations for future research in generalist end of life care

Report for the National Co-ordinating Centre for NHS Service Delivery and Organisation R & D (NCCSDO)

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Executive summary

Aims

This report presents recommendations for future research to be commissioned by the SDO on generalist end of life care for adults.

The aims and objectives were to define what was meant and understood by generalist end of life care; to map the existing knowledge base; to identify methodological and ethical issues; to consult with national and local stakeholders and to determine the extent to which existing knowledge and research mapped against priority issues identified by stakeholders.

Methods

A scoping exercise was undertaken to determine end of life care research priorities. This included a literature review and a consultation with key informants who were associated with care at the end of life.

The literature review was of recent publications and reviews. It included an assessment of the number, type of studies undertaken and position in the hierarchy of evidence.

The consultation exercise was undertaken in four different UK geographical localities: London, Cambridgeshire and the East of England, Warwickshire and Scotland. A separate consultation exercise was carried out with key informants of national organisations in England. A modified form of the nominal group technique was used to identify the range of views and develop a broad consensus on key priorities for future research.

The priority research subjects from the consultation were compared with the results of the literature review, and four broad research themes were developed.

Results

What is meant and understood by generalist end of life care?

The literature review found generalist end of life care to be a broad and diffuse concept, which was used more in discussion amongst academics than amongst practitioners and literature based on research.

Participants in the consultation held varying perceptions of 'generalists'. For some this was linked to primary rather than secondary care. Variations were also found in the definition of end of life care. For some this was the last few days of life but for others it was an overarching phase which also included palliative and terminal care.

Our definition of generalist care for the purposes of this scoping exercise referred to care provided by practitioners whose working remit was not exclusively concerned with specialist palliative care. This definition did include specialists in other clinical areas. By 'end of life care' we mean care provided within the last year/s of life to anyone with any advanced progressive disease likely to shorten their life.

To map the existing knowledge base

The literature review found generalist care at the end of life to be an area of disparate research activity defined more by the academic community than by practitioners or patients. The extent of published studies was limited and this tended to be concentrated at the lower level of the hierarchy of evidence. Little secondary research was identified. Service development and innovation in this area typically comprised complex interventions which are methodologically and ethically challenging to undertake.

Most research was concerned with understanding what was going on (experiences of and issues with care provision), less concerned with finding solutions to problems and very little with testing or evaluating interventions.

The majority of studies on generalist care at the end of life were concerned with service delivery organisational issues and health professionals' experiences. Less were concerned with patients' experiences and only three with carers' experiences. Half of the studies were set in community settings and very few set in hospital.

To identify methodological and ethical issues

The difficulty of undertaking research with patients and carers at the end of life was raised in the consultation together with problems of knowing the best time to engage with users.

Demonstrating effectiveness was considered to be a methodological problem in the consultation as was implementing the traditional methods for complex interventions. From the literature review, flexibility was felt to be important in undertaking research, gaining a good understanding of the context of an intervention in order to see how it might apply elsewhere, and the use of mixed methods.

Consultation with national and local stakeholders

Two hundred and ten participants were involved in the consultation events in London, Cambridgeshire, Warwickshire and Scotland and with the representatives of English national organisations. There was enthusiastic participation and a range of generalist end of life care research subjects were identified.

Between 13 and 18 research subjects were identified at each consultation. The priority subjects were aggregated and ordered into two key themes with two major cross-cutting themes. The first key theme was 'models of care' which included out of hours care, generalist provision, care for patients suffering from non malignant disease and access to care. The second key theme was 'place of care', including the home, hospital and care home.

Patient and carer experience was identified as a major cross-cutting theme that should be an important component of all research commissioned on generalist end of life care.

Resource and health economic evaluation was the second cross-cutting theme which should be an important component of research.

Determining the extent to which existing knowledge and research mapped against priority issues identified by stakeholders

A comparison of the key research themes arising from the consultation and key issues emerging from the literature review led to the following recommendations for future research:

Recommendation 1

Primary research to define and evaluate models of collaborative working in primary and secondary end of life care. This research would employ a systems approach whereby the different forms of organisation (for example General Practitioners (GPs) and District Nurses (DNs) working collaboratively in the community, or medical and nursing teams in hospital settings) were investigated within the context of collaboration or shared care with specialist palliative care and social services. Studies should identify current models of organisation, establish how well they work, identify best practice and define models that lead to optimum outcomes for patients, families and services, as well as factors associated with gaps in provision. Studies should investigate and/or test models of care from the perspective of patients and carers as well as from that of health care professionals and ideally consider costs.

Recommendation 2

Primary research to define and evaluate models of provision of generalist out of hours care at the end of life within a systems approach, taking account of different providers (for example GP out of hours' organisations, DN services, ambulance services, pharmacists, social services, specialist palliative care). The research would assess how service configurations work in different geographical areas, identifying factors that lead to improved patient care including for example information transfer, appropriateness of response, availability of drugs, good channels of communication between providers, clear role remits and good collaborative working as well as factors that prevent optimum care. Models of good practice would be tested in other geographical areas and under different conditions. The experiences and preferences of patients and carers should form a major component of the assessment of the impact of the care models and the costs of different models should be considered.

Recommendation 3

A systematic literature review (including grey literature) of place of care and place of death of people dying from non malignant disease. This would identify factors affecting transitions of care as well as place of death for people dying from a number of non malignant diseases such as COPD, heart failure, stroke, dementia and neurological conditions.

Recommendation 4

Primary research to define and evaluate models/organisation of care of the dying in different settings including A&E; to assess the impact of different forms of care, together with an assessment of the additional impact of, for example, the Liverpool Care Pathway and the hospital palliative care team. This research should be undertaken from patient/carer and professional perspectives and focus particularly on the experience of patients dying from non malignant disease. More research should be undertaken on how preferences are formed and develop over time.

Chapter 1 Introduction

This report presents recommendations for future research to be commissioned by the SDO arising from a scoping exercise to determine priorities for improving generalist end of life care for adults. The scoping exercise comprised a literature view and consultation exercise with providers, commissioners, policy makers and users and academics associated with end of life care services. Both documents can be found in separate accompanying reports.

Most end of life care is provided by generalists. By 'generalists' we mean practitioners whose working remit is not exclusively concerned with specialist palliative care. This includes those working within primary, secondary, tertiary care, social care and the voluntary sector, and includes many who are specialists in their own sphere of expertise. Where working remits also include care of those with chronic, acute or minor illnesses, these are defined as 'generalist' for the purposes of this scoping review. By end of life care we mean care provided within the last year/s of life to anyone with any advanced progressive disease which is likely to shorten their life.

Chapter 2 Background

Most care at the end of life is provided in a generalist setting: the home, a care or nursing home or hospital. Practitioners in primary and secondary care provide most care together with colleagues from social care and specialist palliative care (largely for cancer patients). The significance of generalist care has been recognised through the NHS End of Life Care Programme which has provided support and opportunities to increase skills to generalists (http://eolc.co.uk/eolc). Models of care such as the GSF, LCP and PPC have been prominent in this respect, as has the education and support programme for District and community nurses in the principles and practice of palliative care. The patient choice agenda has also been a key motivating factor in service development to enable choice of type and place of care at the end of life. However, much less is known about generalist end of life care than about specialist palliative care service provision. Much less is also know about the care of patients suffering from non malignant disease at the end of life as much research has been focused on the care of cancer patients. The SDO therefore commissioned a scoping exercise to identify key research priorities that would inform future research funding.

Chapter 3 Aims and objectives

The aim of this scoping exercise was to map current research, knowledge and policy on generalist services for adults at the end of life to identify specific topics for research to inform future commissioning by the SDO programme.

The objectives were to:

- To define what is meant and understood by the term generalist services for people at the end of life
- To map the existing knowledge base and policy context, including recent publications, and information on work in progress (where available or anticipated); to appraise a wider range of published and unpublished grey literature than undertaken previously, including qualitative as well as quantitative research, and extend previous reviews to include non cancer patients, policy issues and material on best practice.
- To identify the methodological and ethical issues encountered in conducting the research and successful approaches to research in this field
- To consult with national and local stakeholders (including statutory and voluntary organisations) about the current policy and most pressing research questions concerning the delivery and organisation of generalist services for end of life care
- To determine the extent that existing knowledge and current/planned research maps against the priority areas raised by stakeholders in order to identify gaps and future priorities for research

Chapter 4 Methods

This scoping exercise comprised two components of work. Firstly a literature review identified the scope and quantity of research undertaken more recently on generalist services for adults at the end of life, building on previous systematic reviews. Secondly, a consultation exercise was undertaken in different geographical areas of England and in Scotland. The aim of the consultation exercise has been to identify research priorities from the perspectives of practitioners and commissioners within statutory and voluntary organisations and from users. Full details of the methods and results are available in the attached reports on both the literature review and the consultation.

4.1 Methods for the literature review

4.1.1 Search strategy

The search strategy included identification of existing systematic and relevant reviews, electronic database searches, and hand-searching for grey literature, of key journals and of reference lists, as detailed below. This included some very major reviews (e.g. those for the NICE guidance on supportive and palliative care, UK(Gysels & Higginson, 2004), the AHRQ systematic review(Lorenz *et al*, 2004), the review of psychosocial support(Shipman *et al*, 2002), a review of primary palliative care for cancer patients (Burt *et al*, 2004), the WORD (Welsh Office) review on models of palliative care (Snooks *et al*, 2006), related reviews from scoping exercises and documents containing evidence, which were written for use in policy.

In view of the number of major systematic reviews, and the policy developments in recent years, we concentrated on the most recent reviews and original studies. We searched MEDLINE, EMBASE, CINAHL, PsycLIT, ASSIA, HMIC, Cochrane Databases, CANCERLIT, databases held at the King’s Fund and collections of specialist literature held by the project applicants for the last 5 years for original studies relevant to generalist palliative and end of life care. We developed search terms to retrieve all relevant literature (see Report 2).

4.1.2 Inclusion/exclusion criteria

Studies were assessed for inclusion on the basis of relevance and design. To be included, a study or review must have addressed generalist end of life or palliative care and/or include patients receiving care in a generalist setting (home, care or nursing home, hospital) including some care from generalists. We included a broad range of study designs (quantitative and qualitative), systematic reviews, reviews and consensus opinion papers but not individual opinions or single patient case reports. Studies were excluded on specific methods of treatment or drugs, concerned with children, critical illness and euthanasia or physician assisted suicide. Given the focus on British healthcare, non-English language publications were excluded (most literature is written in English).

There was no time limit applied to research integration studies identified as relevant. The individual studies, however, were limited to a sample of studies which had appeared in the time period between 2004-2006, as a number of important reviews synthesising the evidence on end of life care had appeared in 2004. We did not grade individual studies in detail, but the systematic reviews were graded for methodological quality using a standard grading scale with criteria developed by Russell *et al* (1998).

4.1.3 Data extraction and Analysis

Systematic Reviews

Recent research integration studies in this field were read, reviewed and categorised according to type of review, its function, the topics addressed and the type of evidence included.

Individual Studies

Data were extracted into tables documenting the reference number – for easy retrieval in the bibliography – study population, type or method of study, country of origin, and theme, sub-theme and primary focus of the study. A separate table documented the main findings or statements of the paper. Because of time constraints and the nature of the scoping exercise this information was based on abstracts and summaries rather than the full paper. If the abstract lacked detail or was ambiguous, the full paper was read and investigated.

The evidence was analysed according to the information it provided on groups of participants targeted by the studies, themes featuring in the reviewed sample, type of data collected, settings where studies were carried out, type and design of the references, and purpose with which the studies were conducted.

4.2 Methods for the consultation

The consultation took place at a national level across England, with representatives of national organisations, and at a local level with providers, commissioners and users of services across London, Cambridgeshire and East of England and Warwickshire. In Scotland both national organisations and a range of providers and users across the country were included. The aims of the consultation were:

- to explore what is understood by generalist end of life and palliative care, and what constitutes effectiveness and cost-effectiveness in this context
- to explore what are the clinical, IT, skill mix, educational and workforce issues that are faced in providing end of life (including out of hours) care
- to explore what research they would find useful, either in their own context of work or that of the groups with whom they work, and their priorities for such research
- to identify information, knowledge, models of care and practice already developed, to identify areas of potential good practice and to supplement the findings of the literature review.

4.2.1 The Nominal Group Technique

The Nominal Group Technique was used in a modified form to develop a consensus from the consultations. The method involves seeking views, discussing and clarifying issues and then voting on priorities (Jones and Hunter, 1995). The following are the steps followed in each of the five consultations:

Drawing up list of key informants

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Selecting a sample and interviewing or sending questionnaires

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Categorising responses into key research themes

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Holding consultation meetings – to discuss, clarify and prioritise responses

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Each consultation compiling a short report

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Reports including priorities for research aggregated

4.2.2 The Consultation of representatives from English national organisations

Relevant national stakeholders were identified from five main groups:

1. National Policy / Commissioners, including the Cancer Policy Team and other relevant policy officers at the Department of Health, and key representatives from the NSFs, SHAs.
2. Primary care professional views were sought from the Royal College of General Practitioners and the Royal College of Nursing, the NHS Confederation and other national organisations.
3. Representatives from user organisations were contacted, including Age Concern, Cancer Black Care, Long Term Medical Conditions Alliance, the MS Society and the Parkinson's Disease Society
4. Representatives from Specialist Palliative Care Services, including National Hospice and other charitable organisations.
5. Academic departments known to undertake work on end of life care were contacted from both within and without the 2 NCRI SuPac collaboratives and across Palliative Care, Nursing, Primary Care and other Departments.

A list of potential participants was drawn up for selection on a purposive basis to gain wide representation from between and within the above four categories.

4.2.3 Different geographical consultations

The consultations in different geographical areas took place in London, Cambridge and the East of England, Warwickshire and Scotland to gain a spread of opinion informed by different geographical and socio-economic contexts. Consultation was facilitated by research co-applicants based within these localities. Within each of the English regional and Scottish national consultations the aim was to select 30 key informants from among the following groups of practitioners, commissioners and users:

- Commissioning Stakeholders [SHAs, PCTs, Social Services, Acute Trusts in England: the Scottish Executive, Health Boards, PCTs and CHPs in Scotland]
- Generalist Service Stakeholders [Local GPSIs, DNs, CNSs, GPs, acute trust clinicians, care homes, social services]
- Local patient / carer groups (e.g. carer groups, local branches of user-led organisations, and other user forums, including local service groups).
- Specialist Service Stakeholders [Hospices, Specialist Palliative Care, Cancer Networks, Cancer UK, NSFs, Specialist user groups, clinical nurse specialists]

Participants were again selected on a purposive basis from amongst the above categories of informants, and further contacts gained by their recommendation.

4.2.4 Data collection and analysis

The views of participants were sought using a short semi-structured questionnaire that was standardised for all 5 consultations. This was developed collaboratively with the different research teams, project advisory group and grant collaborators, and piloted within King's College London. Further questionnaires were developed for completion by email, for voluntary groups and for users. Full details can be found in Report 3.

A thematic analysis was undertaken on responses made to each consultation to identify key research themes. We sought to identify suggestions for research and code these suggestions into main themes. Many practitioners were unused to research. While all were able to identify problems and good practice, some found difficulty in converting these issues into research questions. It was thought important not to minimise the views of those who deliver services, and so where strong issues were identified but robust research questions lacking, the research team help practitioners to formulate how these might be translated into areas of research.

The nominal group technique enables the development of a consensus about research priorities by bringing people together to discuss, clarify and vote. All key informants who had provided information either through an interview or email questionnaire were invited to attend one of the consultation meetings. These were held in Cambridge, Coventry, Edinburgh and two in London (for the regional and English national meetings). These meetings provided an opportunity for developing and voting on the key themes. Those unable to attend meetings were offered the opportunity of postal or email voting.

4.3 Integration of literature review and consultation, and outputs

The key priorities for research identified in the consultation exercise were compared with findings from the literature review. The table of comparison can be seen in Appendix 1. Comparison also took account of known existing research in order to identify recommendations for future work.

Chapter 5 Results

5.1 What is meant and understood by the term generalist services for people at the end of life

The review of literature found generalist end of life care to be a broad and diffuse concept which does not feature in much of the literature identified. Generalist palliative care is a term that is primarily used in academic discourse among researchers with an interest in palliative care. It suddenly gained in importance as a result of the establishment of the NHS End of Life Programme (NHS, 2006) which carried the vision outlined in the White Paper 'Our Health, Our Care, Our Say' (Department of Health, 2006), towards health care in the community and support for patients to die in their place of choice, which is most often the patient's home. These policy developments are now taking place on the territory of generalist palliative care. Delineating this area is not an easy task as there is not an agreed understanding of what generalist palliative care stands for exactly. The concept is often defined in negative terms, as the type of palliative care not provided by specialist teams, which leaves a very wide field of enquiry.

There were considerable variations in definition of end of life care and its relationship to palliative and terminal care emerging from the consultation. For some, end of life care was similar to terminal care and comprised care within the last few days or weeks of life undertaken under the broad overarching approach of palliative care. For others end of life care preceded terminal care and for some comprised up to the last year of life encompassing palliative and terminal care. It should be noted however, that terminal care itself also had varied definitions. For many, end of life care comprised a phase when it was clear that a patient was going to die and reflected a change in emphasis from curative to supportive and palliative care for patient and family. All of these definitions appear to be based on a 'prognosis' or time period, rather than specific patient/family needs or circumstances.

The consultation also revealed variations in perceptions of the role of generalists and of the applicability and suitability of the term. Some informants, particularly in primary care, were quick to identify themselves in the role of generalist but did not necessarily identify hospital colleagues as generalists. Generalists were considered to deal with all conditions on a day to day basis including long term and acute care such as GPs, DNs and Geriatricians although all three could also be seen as specialists in their own field. Generalists could also include all those working in health and social care in acute and rehabilitation settings, in continuing care, nursing home and residential care. The role of the generalist was seen to include co-ordination of care, being a key worker and gatekeeper and referrer to other, particularly specialist palliative care services. There was a suggestion that the role of the generalist was changing within primary care. In the past many would have known their GP. Although this was felt to be true in some settings, it was felt by some that increasingly people did not have a relationship with a particular doctor. The theme of the disengaged generalist, who was less involved in end of life care, was identified within the Cambridge consultation and also in Scotland. While our brief was to understand perceptions of care provided by practitioners other than specialist palliative care professionals, the importance of recognising the role of hospital specialisms was also frequently reiterated.

5.2 Mapping the existing knowledge base: summary of results from literature review

The review presented a broad overview of the current literature that addresses issues in generalist care at the end of life. Searching for issues that are central to an area that is not well delineated is challenging. For the identification of secondary research we only found one unpublished thesis on palliative care in primary care that brought together some essential components on which to build a framework for capturing generalist care at the end of life (Department of Health, 2006). The other secondary research presented focused in different ways on discrete areas that are part of this field, to constitute a broad overview of what generalist care represents. We targeted the most recent studies that provided a synthesis of the available evidence covering documents that were written for different purposes, on a wide variety of topics, and applying diverse methodologies of synthesis. As this scoping exercise was largely to identify research priorities to be used in the current policy context we restricted ourselves to the reviews that had general relevance to generalist care. We excluded reviews that investigated issues unique to specific countries. Reviews on symptoms or conditions that were common in advanced disease were included. For the individual studies, issues pertaining to specific countries were also included.

Generalist care at the end of life typically requires complex interventions and many of the themes are inter-linked and cannot be considered in isolation. It became apparent from the mapping of the evidence that generalist palliative care is a multidimensional concept involving a variety of conditions, settings, carers, services, states of being, values and priorities and interactions with specialist palliative care.

Two systematic reviews were included that provided negative evidence, one was on access to specialist palliative care, which identified the types of patients that are usually excluded from specialist palliative care and thus tend to receive the care from generalist providers (Barclay, 2005). The other negative evidence came from a systematic review on specialist palliative care teams, showing the gaps in knowledge on the functioning and ways of operating with different combinations of roles and skills (Higginson *et al*, 2000). The integration studies were often exploratory, concluding that there was a dearth of evidence on the research topic.

The results focusing on patient groups in the individual studies showed that most of the studies reported to target a 'general' group with palliative care needs. We assumed that this was a mixed diagnostic group. Some illnesses with definite palliative care needs, such as neurological conditions, were not identified by the searches for individual studies.

The data were collected mostly on service delivery organisational issues. Where studies focused on views and experiences, data primarily collected from health professionals and patients' perspectives were less well represented. The evidence on carers was scant. To ensure that meaningful definitions and criteria are developed and applied, patient and carer's trajectories and interactions with care need to be understood. The studies collected their data mostly from the community in general without specifying the exact places in the abstracts. Where the setting was specified most of the studies focused on home care.

What the distribution of designs across this research field means becomes clearer when examining the studies' purpose. We could discriminate three levels of what the enquiry wanted to achieve. From this, we found that the great majority of studies investigated 'what is going on' in generalist care at the end of life. Studies were less often directed to finding solutions to problems: ie 'what needs to be done'. Only a few studies were conducted with the purpose of testing or evaluating interventions: 'let's try this or see if this works'.

Restructuring of funding, organisation and delivery of health services is almost continuous in the UK's NHS. Reforms in policy happen rapidly and much research is often only available when it eventually gets published. We found some very useful syntheses of the literature directly placed in the context of current policy. However, policy analyses become quickly outdated as health services are constantly evolving and are in need of ongoing evaluation. Within the evidence identified, we could see that studies are now starting to appear that address some of the key foci in current policy. The results of the Department of Health (DH) three-year education and support programme for District and community nurses (DNs) in the principles and practice of palliative care have been published and are available on the DH website (www.dh.gov.uk). The use and functioning of the tools, which have been promoted nationally have been studied by small research projects awaiting the results of the ongoing larger research programme on the GSF, carried out by the University of Warwick. The systematic review on home death included in this scoping study was based on 58 studies. However, much more needs to be done in this area as this review showed the lack of evidence on the quality of home deaths, problems with transitions in care and the need for expansion of the model developed in this review in the light of new evidence (Gomes & Higginson, 2006).

Other places of care in the community are now being studied. These include community hospitals and nursing and residential homes and the needs they have for support to realise good quality palliative care in these settings. Out-of-hours-care is one of the mechanisms to attain this goal and this is now recognised in the literature that shows a number of studies documenting obstacles and solutions to problems that were developed locally. The workforce needed to fulfil the aim of good quality care in the community featured over different categories and was directed mainly to nurses with a variety of backgrounds and specialities, to GPs, and more sporadically to the informal carer and the social worker. The confusion of roles and ways of co-operating across professions appears as an issue in this material.

Studies of the media and the messages they send to the general public on the end of life were absent. Yet this is an important source of information on community perceptions and attitudes, and an important resource for raising awareness about the end of life, especially given the need for well-informed and actively involved patients and informal carers.

Clear gaps were found regarding certain topics such as under-served populations, no work on ethnic minorities was identified, neither was anything found on groups such as prisoners. Studies on bereavement were also lacking. Mental health at the end of life was poorly represented. The systematic reviews on depression found very few studies and identified the area of mental issues in advanced disease such as anxiety or depression as little researched and receiving little attention from services (Hotopf *et al*, 2002; Ly *et al*, 2002)). Also the systematic review on advanced dementia identified very few empirical studies on this topic (Sampson & Ritchie, 2005). No individual studies on technological developments were found, which is important because these may support community-based services.

The time in which the mapping of the literature had to be undertaken limited the findings of this study. This scoping exercise should be considered as a first step. We do not claim that we have provided a comprehensive overview of all research activity in this area but rather worked with a sample. Seeing the broad search strategies we worked with, we believe that this is reasonably representative of the field. The conclusions of this scoping exercise are constrained by the limitations of the original primary studies. The analysis is largely based on the work of one reviewer. In instances of doubt, members of the expert panel were consulted to verify approaches or interpretations, but there was no detailed second coding.

From our review of research integration studies and scoping of the individual studies (between 2004-2006) we conclude that:

- Generalist care at the end of life is a vast area with much disparate research activity but little systematic initiative to achieve understanding of the meaning of this term.
- Considering the scope of the field there are relatively few secondary analyses such as systematic reviews.
- Published studies are concentrated at the lower level of the hierarchy of evidence.
- This field typically contains complex interventions and conducting these is methodologically and ethically challenging. There were few of the 'let's try this' evaluation studies and the evidence base for practice is scant.
- Evidence related to current policy developments and its key foci are sparse.
- Areas that have been covered most frequently include health professionals' roles, services (aspects of out-of-hours care and community care), 'models' of good practice, quality of generalist care in practice, place of care with the greatest concern for home care, and education for generalists.
- There is still less work beyond cancer.

5.3 To identify methodological and ethical challenges

Respondents to the consultation were asked if they were aware or concerned about any methodological or ethical issues in undertaking research with patients and carers at the end of life. A key concern was the difficulty of engaging with users at such a vulnerable time, and understanding the best time to speak to patients and relatives, particularly as not everyone wanted to talk about death. Other ethical concerns included the patient's capacity to make decisions and be involved in research activity when very ill. There were concerns about patient confidentiality and about participation in double blind trials. Gate keeping by professional staff was identified as an understandable but difficult methodological issue. Demonstrating effectiveness and measuring appropriate outcomes, for example in achieving a good death, was identified as problematic. The need to highlight end of life care as an important area for research and funding was also suggested which could be aided by improved dissemination of findings and implementation of research.

Most of the studies identified by the literature review were concentrated at the lower level of the hierarchy of evidence and there were only four RCTs. Most studies were conducted with qualitative research designs and based on interview material and survey research. These are research designs that are typically employed in areas that are relatively unexplored. This does not mean that no more of these types of studies are needed. This is a vast area of research and needs much more exploratory and pilot work for the generation of empirically-grounded and plausible hypotheses.

However, qualitative designs should not only be employed in the early stages of research projects but are very useful when carried out alongside experimental research to inform about processes and contextual issues. Generalist care at the end of life is a complex area and requires innovative designs, often employing mixed methods, to ensure both the acceptability of the intervention, as well as reliable outcomes of its evaluation. The four RCTs were high quality trials addressing service delivery models to translate into practice in generalist end of life care, and they were conducted with novel methodological approaches to address the common challenges of this type of research in a palliative care population (Abernethy *et al*, 2006; Gutheil & Heyman, 2005); Mitchell & Abernethy, 2005).

One model which is particularly suitable is the MRC Framework for the Design and Evaluation of Complex Interventions with phases of modelling through to preliminary evaluation, ultimately testing the intervention in a randomised controlled trial (Campbell *et al*, 2000). Where the conduct of RCTs is impossible or inappropriate due to practical or ethical obstacles in end of life research, well designed observational methods are valuable alternatives for the evaluation of the effectiveness of health services.(Black, 1996; McKee *et al*, 1999) New initiatives proposing more flexible development of the MRC framework for complex interventions appear promising. Preliminary suggestions have been made for the initial stepwise approach to be undertaken as a more iterative process.(Campbell *et al*, 2007) Greater account should also be taken of the context within which an intervention is taking place to enable an assessment of how transferable the model of care might be to other settings. However, such an approach will require funders to support these new designs, which initially may appear more costly, and will involve sustained programmes, rather than short projects of research. However, in the longer term cost benefits will be achieved, as the research will yield better results.

5.4 To consult with national and local stakeholders in England and Scotland

5.4.1 The consultations

The consultation was undertaken with a wide range of participants including practitioners, commissioners, policy makers, academics, users and the voluntary sector. It was less easy to engage professionals from policy backgrounds. While efforts were made to secure the participation of respondents from social care backgrounds, the majority of participants were from health services. Engaging the participation of users was also a key aim which was most successfully achieved in Scotland.

The areas included - London, Cambridgeshire and Warwickshire - are not representative of all geographical and socioeconomic locations in England but, given the limited resources and time available to the scoping exercise, do provide perspectives from inner city, more rural and urban locations. An opportunity to consult professionals in Newcastle was identified, but unfortunately this arose too close to the completion of the project and could not be taken up. The Scottish consultation was wide ranging involving participants from cities to the Scottish islands.

The modified Nominal Group Technique proved useful to generate consensus in each consultation. At the meeting the research priorities were revisited and those attending were able to add to existing themes and develop further themes after consideration. Those unable to attend and who voted by post or email were unable to participate in discussion and development of the themes. Not all participants returned their voting forms, and responses were lower in the London and English national consultations.

When the top six categories of each consultation were compared there were common themes but also some variation. Sufficient key themes were common to the top 6 categories of most consultations, however, to redress concerns about any change in ordering that might have resulted had more participants voted.

There was considerable enthusiasm amongst participants and concerns from amongst health and social care, statutory and voluntary groups and users that this was a vital area for health and social care. There were many subject areas identified as important in addition to the main priorities identified here (see Report 3).

5.4.2 The main research themes: results from the consultation

From prioritisation of the research themes generated within the consultation, our scoping found that the priorities for research in generalist end of life care should include:

1. Research into models of care: defining and evaluating different forms of organisation of service provision for:
    - out of hours care
    - different generalist models
    - services for non cancer patients and older people

   - access to care and inequalities in provision

2. Research into the patient and carer experience.
3. Research to understand more about factors affecting place of care and death, about the experience of dying, resource, support and care needs within
   - home
   - hospital
   - care homes
4. Resources and health economic implications

We suggest that the theme of patient and carer experience should be a key cross-cutting theme providing a main focus for research concerned with both service provision and place of care and death. The theme of resources and health economics should be a second cross-cutting theme to be taken into account with undertaking research within models of service provision and place of care and death.

<table>
<tr><td>Models of care: Service Provision
• Out of hours
• Generalist models
• Non cancer and older people
• Access and inequalities</td><td>Place of care and death
• Home
• Care home
• Hospital</td></tr>
<tr><td colspan="2">The patient/carer experience</td></tr>
<tr><td colspan="2">Resources and health economics</td></tr>
</table>

5.5 Priorities for future research

The top four broad themes for research generated from the consultation were compared with the results of the literature review (Appendix 1) and known ongoing research. Recommendations for future research were made on the basis of this comparison.

5.5.1 Service provision and models of care

This is the largest area of suggestions for research, and also the area within which most research has been undertaken although it is patchy and often of limited quality and scope. One of the suggestions arising from the literature review is that more needs to be understood, and interventions focused, on collaborative teamworking amongst generalists, such as clinicians and nurses. The primary health care team is the key provider of end of life care in the community, and hospital teams are key providers for people who die in hospital.

Recommendation 1

Primary research to define and evaluate models of primary and secondary collaborative working at the end of life. This would employ a systems approach whereby the different forms of organisation (for example of GPs and DNs working collaboratively in the community, or medical and nursing teams in hospital settings) are investigated within the context of collaboration or shared care with specialist palliative care and social services. Studies should identify current forms of organisation, establish how well they work, identify best practice and what models lead to optimum outcomes for patients, families and services, as well as factors leading to gaps in provision. Studies should investigate and/or test from the perspective of patients and carers as well as health care professionals and ideally consider costs to patients, carers and health and social care.

5.5.2 Out-of-hours care

We know some of the problems of out-of-hours care including factors relating to GP out-of-hours organisations, lack of 24 hour DN services, variability of specialist palliative care provision and some research on patient experience**.** Out-of-hours support is critical because it is when many usual services are not accessible, when patients are most likely to see people who do not know their history, and when inappropriate hospital admissions are most likely to occur.

Recommendation 2

Primary research to define and evaluate models of provision of generalist out of hours care at the end of life within a systems approach, taking account of different providers (for example GP out-of-hours organisations, DN services, ambulance services, pharmacists social services, specialist palliative care). The research would assess how service configurations work in different geographical areas, identifying factors that lead to improved patient care including for example information transfer, appropriateness of response, availability of drugs, good channels of communication between providers, clear role remits and good collaborative working as well as factors that prevent optimum care. Models of good practice would be tested in other geographical areas and under different conditions. The experiences and preferences of patients and carers should form a major component of the assessment of the impact of the care models and the costs of different models should be considered.

5.5.3 Non cancer and older people

There is a systematic literature review on factors affecting place of death for cancer patients. There is a need to look at factors affecting place of care and death of patients dying from non malignant disease, in order to inform the development of better models of service provision, i.e. for COPD and heart failure patients.

Recommendation 3

A systematic literature review (including grey literature) on place of care and place of death of people dying from non malignant disease. This would identify factors affecting transitions of care as well as place of death for people dying from a number of non malignant diseases such as COPD, heart failure, stroke and dementia.

5.5.4 Place of care and death

Key issues for research for participants in the consultation included assessing costs and resource needs related to place of care and death; assessing patient preferences; improving care in care homes and patient experiences, staff attitudes and identifying and evaluating models of care in hospital. Continuity of care, particularly concerning hospital discharge was also a key area for research. Some research is currently taking place in care homes, as well as an audit of care in hospital and research on admission.

Recommendation 4

Primary research to define and evaluate models/organisation of care of the dying in different settings including A&E; to assess the impact of different forms of care, together with an assessment of the additional impact of, for example, the Liverpool Care Pathway and the hospital palliative care team. This research should be undertaken from patient/carer and professional perspectives and focus particularly on the experience of patients dying from non malignant disease. More research should be undertaken on how preferences are formed and develop over time.

5.5.5 Patient and carer experience

The patient and carer experience was a dominant research theme identified by participants. Because it is such an important and integral aspect of research, we have suggested that it forms a prominent cross-cutting theme across models of service provision and place of care.

Most of the literature on patient experience concerns that of cancer patients, and therefore there is a need to understand more about the experiences of patients suffering from non-malignant disease. For this reason we suggest the systematic literature review on factors affecting place of care and death, and research on dying in hospital for patients suffering from non malignant disease.

However, there is little research on the experience, support needs and interventions to better support carers during the end of life phase and into bereavement and this could comprise another recommendation.

5.5.6 Resources and health economics

This is an under-researched area and an important priority for participants in the consultation. Because of its importance we thought it would be appropriate to form a cross cutting theme linked to service provision and models of care. There are, however, huge unanswered questions that might suggest this should comprise a further recommendation. These questions concern what the real resource and financial costs of care at home, hospital and in care homes are to patients as well as professionals, together with what effect will/is current economic policy having on patient care (practice based commissioning and payment by results).

5.6 Limitations and conclusions

This scoping exercise comprised a review of recent literature and a consultation exercise in order to determine the priority areas for future research in generalist end of life care.

The literature review found generalist care at the end of life to be an area of disparate research activity defined more by the academic community than by practitioners. The extent of published studies was limited and this tended to be concentrated at the lower level of the hierarchy of evidence. Limitations of time and resources did shape the review, however, to focus on the amount and type of studies undertaken between 2004-2006, together with important systematic reviews. Little secondary research was identified. Service development and innovation in this area typically comprise complex interventions, which are methodologically and ethically challenging to undertake. However, most research was concerned with understanding 'what was going on', less concerned with finding solutions to problems and very few with testing or evaluating interventions. This needs to be addressed in future research and our investigation identified promising ways to achieve this.

The consultation was undertaken with a very wide range of practitioners, commissioners, policy makers, users and voluntary groups within different geographical locations in England and Scotland. While not representative of all geographical localities and population groups associated with end of life care, these provided perspectives from city, urban, rural areas in England and Scotland and user and different professional groups. Using a modified form of the nominal group technique, a consensus was developed on the key research themes that participants considered to be most important. These comprised models of service provision, principally concerning out of hours care, generalist provision and provision for patients with non malignant disease. Place of care and death was a second major theme. Patient and care experience was an important crossing cutting theme, relevant to the previous two areas, as was the theme of resources and health economics. The main themes were developed in consultation with the advisory group and grant collaborators. There was considerable enthusiasm from all participants and recognition that this was a vital area of health and social care and a very important area for research and development. All were delighted that the SDO had proposed work in this area.

When comparing the main themes with the results from the literature review we made recommendations for commissioning research on

- definition and evaluation/testing of models of primary and secondary collaborative working at the end of life
- definition and evaluation of different models of provision of generalist out of hours care within a systems approach
- a systematic literature review of place of care and place of death of people dying from non malignant disease
- definition and evaluation of different models/organisation of care of the dying in different hospital settings.

A major component of all research should be the patient and carer experience, which would be a cross-cutting theme, together with assessment of resource/health economic implications.

Some research on service developments within the above themes may typically comprise complex interventions, but we recommend flexibility in design and the use of qualitative as well as quantitative enquiry within a mixed methods approach to ensure that sufficient information is gained on the context of the service to enable consideration of its applicability elsewhere. This will require a longer term and strategic approach to research support.

References

Abernethy AP, Currow DC, Hunt R, *et al*. 2006. A pragmatic 2 x 2 x 2 factorial cluster randomized controlled trial of educational outreach visiting and case conferencing in palliative care - Methodology of the Palliative Care Trial. *Contemporary Clinical Trials* 27: 83-100.

Barclay S. 2005. *General Practitioner provision of palliative care in the United Kingdom*. University of Cambridge

Black N. 1996. Why do we need observation studies to evaluate the effectiveness of health care. *BMJ* 312:1215-1218.

Burt J, Shipman C, Addington-Hall J. 2004. *Cancer and palliative care within primary care: a review of the recent literature*. Commissioned by and produced for Macmillan Cancer Relief. Department of Palliative Care and Policy, King's College, London. London

Campbell M, Fitzpatrick R, Haines A, Kinmouth AL, Sandercock P, Spiegelhalter D, *et al*. 2000. Framework for design and evaluation of complex interventions to improve health. *BMJ* 321: 694-696

Campbell NC, Murray E, Darbyshire J, Emery J, Farmer A, Griffiths F, *et al*. 2007. Designing and evaluating complex interventions to improve health care. *BMJ* 334:455-459

Department of Health. 2006. *Our health, our care, our say: a new direction for community services*. Department of Health. UK.

Gomes B, Higginson IJ. 2006. Factors influencing death at home in terminally ill patients with cancer: systematic review. *BMJ* 332: 515-21.

Gutheil IA, Heyman JC. 2005. Communication between older people and their health care agents: results of an intervention. *Health Soc Work* 30:107-16.

Gysels M, Higginson IJ. 2004. *Improving Supportive and Palliative Care for Adults with Cancer: Research Evidence*. NICE. London. .

Higginson IJ, Finlay IG, Goodwin DM, *et al*. 2000. *The role of palliative care teams: Systematic review of their effectiveness and cost-effectiveness*. Report to Wales Office of Research and Development of the National Assembly of Wales. Cardiff.

Hotopf M, Chidgey J, Addington-Hall J, *et al*. 2002. Depression in advanced disease: a systematic review Part 1. Prevalence and case finding. *Palliative Medicine* 16: 81-97

Jones J, Hunter D. 1995. Qualitative research: consensus methods for medical and health services research. *BMJ* 311: 376-380.

Lorenz K, Lynn J, Morton SC, *et al*. 2004. End of Life Care and Outcomes. *Evid Rep Technol Assess (Summ)* 110: 1-6.

Ly KL, Chidgey J, Addington-Hall J, *et al*. 2002. Depression in palliative care: a systematic review. Part 2. Treatment. *Palliative Medicine* 16: 279-84.

McKee M, Britton A, Black N, McPherson K, Sanderson C, Bain C. 1999. Interpreting the evidence: choosing between randomised and non-randomised studies. *BMJ* 319: 312-315

Mitchell GK, Abernethy AP. 2005A comparison of methodologies from two longitudinal community-based randomized controlled trials of similar interventions in palliative care: What worked and what did not? *Journal of Palliative Medicine* 8: 1226-37.

National Health Service. 2006. *End of Life Care Programme*. National Health Service.

Russell L, Di Blasi Z, Lambert M, Russell D. 1998. Systematic reviews and meta-analyses: opportunities and threats. In: Templeton A, O'Brien P. (Editors). *Evidence-based fertility treatment*. RCOG Press. London

Sampson EL, Ritchie CW, Lai R, *et al*. 2005. A systematic review of the scientific evidence for the efficacy of a palliative care approach in advanced dementia. *International Psychogeriatrics* 17: 31-40.

Shipman C, Levenson R, Gillam S. 2002. Psychosocial Support for Dying People: What Can Primary Care Trusts Do? King's Fund. London.

Snooks H., Peconi J., and Porter A. 2006. An overview of the evidence concerning the effectiveness of services delivered jointly by health and social care providers and related workforce issues. Welsh Office for Research and Development in health and social care. Cardiff

Appendix

The appendix tabulates a comparison of the results of the literature review against key suggestions for research from the consultations, in order to identify recommendations for research to be made to the SDO

Research theme: Models of generalist provision

Research suggestions made in the consultations	We know the problems and much good practice - what are the barriers What is achievable without huge resource implications? **Models of care** Develop a consensus on models of care Evaluate different models of care – hospice at home, GPswSI, DN, telephone advice, leadership roles in hospital wards Supportive care – what should there be and what should it look like? How can the core principles underpinning spcs best extended to generalists What models of care work best for minority groups What is the patient experience of different models of care What models of care work well – e.g. GPswSI? What models of specialist palliative care do GPs prefer? **Organisation** How does EoLC integrate within generalist caseloads? What is the impact of changes in the organisation of DN teams? **EoLC tools** Do the end of life care tools provide better care, reduce costs, increase choice etc.? Provide EoLC beds in hospitals, the community, nursing homes and A&E **Case management** Is case management appropriate, who is the case manager? **The disengaged generalist** How to engage and educate the disengaged generalist **Primary/secondary interface** How to improve the interface of generalist and specialist? Hospitals What are the attitudes towards death and dying on hospital wards? What types of support help avoid unnecessary hospital admissions?

	Training and support What are the skills training needs of generalists? How can we support excellence in generalists rather than foster dependence on specialists? **Improving access to care** How to improve the postcode lottery What models of care work best for minority groups? Exploring cultural differences between staff and patient and the impact this might make on patient and family experiences. Need to map current services, systems and use How can access be improved for minority groups, people in rural areas, frail older people and those in areas of greatest social deprivation? How can national policies support locally determined delivery of best practice? How to enable access of equipment when needed? Improving access out of hours Improving access to social care
Research identified from the literature review and gaps	**Systematic reviews** Review of joint working by health and social care providers – highlighted need to shift resource from hospitals to community/home Published evidence lacks rigour. Review of GP activity etc up to 2004(Barlcay, 2005) Barriers to access (Ahmed *et al*, 2004) Review of primary palliative care up to 2004 (Burt *et al*, 2004b) Review of interactive technologies and videotapes in cancer care (Gysel & Higginson, 2007) Patient held records (Gysels *et al*, 2006) **Research papers** *Nursing* Nurses role in community hospitals (Hamilton & McDowell, 2004) Input CNS in nursing homes (Ling, 2005) Community nurses role (Pieper & DAcher, 2004) Workload specialist nurse (Weber & Grohmann, 2004) DN function (Andrew & white, 2004) DN experience of care for dying at home (Dunne *et al*, 2005) DN care for cancer patients (Kennedy, 2005) DN working in LCP (Jones & Pooler, 2005) DN experience of working alongside HAH (Sullivan *et al*, 2005) DN Perceptions of availability of health and social services (Shipman *et al*, 2005)

	Education, support needs for DNs in the community (Shipman) *GPs* GP role, service knowledge, priorities (Burt *et al*, 2006) GP task perception (Groot *et al*, 2005) GP importance to palliative care (Steciwko *et al*, 2005) GP home visits (Aabom *et al*, 2006) *SW (Clausen et al, 2005)* SW – caregivers to dementia patients (Diwan *et al*, 2004) *Community* Obstacles to palliative care in the community (Goodman *et al*, 2005) Primary/secondary interface Intermediary care between nursing home and hospital (Plummer & Hearnshaw, 2006) Nursing outreach service in community hospitals (Sharp & Oldham, 2004) *Hospitals* Inpatient respite care (Payne *et al*, 2004) Hospital based palliative care teams (Demanelis *et al*, 2005) *EoL and other tools* Making Eol care principles operational through training etc hill *et al*, 2005) Evaluation GSF (King *et al*, 2005) Approach to implementation of care pathway for dying (Mirando *et al*, 2005) Basic care programme & approach to implementation (Rosenbaum *et al*, 2005) Feedback and views on care provided Life review intervention (Tueman & Parker, 2006) Symptom control management in breathlessness (Maher & Hemming, 2005) Perceptions good/bad death, home/hospital (Borbasi *et al*, 2005) **Current research includes** Evaluation of the end of life care tools Improving access to services for patients and families Evaluation of the Marie Curie ‘developing choice’ programme

	Gaps in the literature Identifying models of care in hospital particularly related to different specialisms Evaluation of models of supportive care Team working for GP and DN What models of care work best for minority groups Evaluation of models of care in both primary and secondary care

Research theme: Out of hours and emergency care

Research suggestions made in the consultations	**Assessment** Identifying the scale of the problem Identifying gaps in provision Identifying the quality of care How important is access to 24 hour specialist advice **Avoiding inappropriate admissions** How to avoid inappropriate admissions How to support carers How to develop crisis interventions **Improving information flow** How to improve information exchange between agencies Developments in A&E **Supporting DNR** How to support DNR decisions Evaluation of different models Evaluate the different models ooh within in hours context Training and support How to better support and train generalists Access to medication/just in case boxes
Research identified from the literature review and gaps	**What there is** Macmillan consultation/review of provision, gaps and models of good practice published in 2001 – highlighted inconsistencies in provision **Research papers** Hospice telephone service (Campbell *et al*, 2005) Handover systems in 4 co-ops (Burt *et al*, 2004a) Medical cover in community hospitals (Kerr *et al*, 2006) Carers experience (Grande *et al*, 2004) Patients, informal & prof carers experiences (Worth *et al*, 2006) Anticipatory prescribing to make ooh work (Amass & Allen, 2005) Levels of care and qualities of ooh care Referral DN to McM nursing (Aitken, 2006)

	Contribution of DNs & primary care services to care homes (Goodman *et al*, 2005) **Gaps** The experience of A&E Evaluation of different models of care out of hours Improving education and support to out of hours practitioners.

Research Theme: Non cancer and older people

Research suggestions made in the consultations	**Models of care** What models of care work at the end of life? Is there a single model sufficiently flexible to accommodate the complex needs of patients? What models are cost effective? What interventions are likely to be effective? **Identification** How and when to recognise palliative care needs; prognostic indicators Importance of looking at specific diseases; where are there registers; where are there gaps? **Communication** How to discuss EoLC with non cancer patients? **Preferences** Do non cancer patients want to be referred to spcs? **Collaboration** How can generalist/specialist and spcs best work together? **Specialist palliative care** What would be the impact of opening up referral of all long term conditions to spscs? What are the views of spcs teams?
Research identified from the literature review and gaps	**Systematic reviews** *Freeman: continuity* Little evidence on improved outcomes on discharge planning for older people Review of prediction of prognostication for older adults with non cancer Review (Gruenewald & White, 2006) on concerns of older people when approaching death Only literature on Cancer, older people COPD (6) , dementia, heart failure (2), chronic kidney disease, MS, younger people, carers *Research Papers* Non-cancer lack of palliative care (Jaul & Rosin, 2005)

	Communication of EoL choices for older people (Dobbins, 2004) Development of outcome measures for older people in nursing homes (Saliba *et al*, 2005) EoL planning for older people in community (Kahana *et al*, 2004) Comparison of EoL preferences of older people (Haydar *et al*, 2004) COPD patients in last year of life (Elkington *et al*, 2004) Components of good care for COPD patients **Current research** COPD palliative care needs of patients (Borgsteede *et al*, 2006) Impact of breathlessness (including cancer patients) Palliative care needs of patients with end stage renal failure (Ahmad) Palliative care needs of stroke patients Extending palliative care approaches in neurological care (Higginson) Palliative care for cardiac patients Evaluation of innovative hospice services for non-cancer patients **Gaps** Little evidence around care for dementia; need for development of prognostic indicators, predicting time of need for palliative care. Models of care for non cancer patients in primary and secondary care

Research theme: Place of care and death

Research suggestions made in the consultations	**Home** *Costs and resources* What are the full costs of keeping at patient at home What services are needed to provide effective EoL care Are sufficient resources allocated to all services? How do costs vary between home and hospital **Organisational responsibilities** Where do organizational responsibilities lie? **Preferences** What are patients preferences for place of care and death To what extent do carers want death at home and how can they be better supported How much information should patients/carers have to enable a choice of place of care: at what stage should this be given? Is communication of information a barrier to choice?

	Support at home What physical and emotional support is given in people's homes? What stops a patient dying at home, what facilitates it? **EoLC tools** Do EoLC tools lead to improved services for patients and carers **Prognostic indicators** What prognostic indicators should trigger care packages? **Care home** **Assessment** Is basic care being provided? What is the level of need? How can EoLC be improved? What support do care homes need to prevent emergency admission? What is the understanding of palliative care in nursing homes? Can care homes cope with the complexities of EoLC - Why do patients in care homes get treated differently? **Skill mix and staffing** What skill mix is needed to deliver good EoLC? Is care better where DNs are involved? **Training** Training of staff: who does it and does it make a difference What support do staff need? **Culture** How do language, age and culture impact on care? Hospital **Patient experience** What is the patient experience in hospital? What effects do sudden admissions have? **Models of care** What the different ways the dying are cared for? What are the most effective ways to organize care? What models of specialist care would generalists prefer? Rigorous evaluation of different models. How best to coordinate care **Staff attitudes**

	What influences staff attitudes to the dying? What are the views of different hospital specialties? **Continuity of care** How to get people home more quickly to die at home? How can continuity of care be improved between hospitals and generalists (pathways?) How to develop inpatient and outpatient palliative care?
Research identified from the literature review and gaps	**Systematic reviews** Systematic review of cancer (Gomes) **Research papers** Home care – including study on nursing homes (Ling, 2005; Dunne *et al*, 2005; Goodman, *et al*, 2005; Albert *et al*, 2005; Allan *et al*, 2005; Appelin & Bertero, 2004; Goldschmidt *et al*, 2005) Community hospitals (Saliba *et al*, 2005; Hawker *et al*, 2006; Payne *et al*, 2004) General hospitals (Mirando *et al*, 2005; Jaul & Rosin, 2005) Residential Post acute setting (Hanson & Ersek, 2006) Trends in age and location of death (Ahmad & O'Mahony, 2005) Admissions to hospital (Hawley & Monk, 2004) Informal care and home death (Visser *et al*, 2004) **Ongoing research** National audit of care in hospital Why patients are admitted to hospital and care received Evaluation of EoLC tools including LCP and GSF Systematic review on preferences for place of care of non cancer patients Palliative care in care homes **Gaps** Gaps in knowledge of factors affecting choice and place – particularly for non cancer Patient experience of different models of hospital care Different forms of organisation and models of care in hospital Interventions in hospital to improve the care of the dying Improving continuity between secondary and primary care

Research theme: Patient and carer experience

Research suggestions made in the consultations	**Patient perspectives** What do patients want from care providers? How to generate patient and family trust in services? What do patients know about what they can access and expect? How to understand the journey. Understand the views of different patient groups What are patient experiences in different care settings – what are the gaps in our knowledge? How does patient experience vary by PCT or service model? What is the level of patient experience of care we are aiming for? Is there an effective method of monitoring patient feedback – particularly hard to reach **Service provision** What is realistic for NHS providers? How to generate informed care plans owned by patients and carers? What promotes dignity for patients and carers? **Communication** How do we communicate realistic expectations about access and effectiveness? How to improve access to advice and information
Research identified from the literature review and gaps	**Systematic reviews** None **Research papers** Measures of impact of care on outcomes for users. **Articles** *Patients views* Experience of home care by DNs (Appelin *et al*, 2004) Patient (heart failure, COPD, cancer) and GPs views on EoLC (Borgsteede, 2006) Views of patients, carers and GPs on EoLC (COPD) (Exley *et al*, 2005) End of life preferences in elder people with dementia and CHF (Haydar *et al*, 2004) COPD –(Elkingston *et al*, 2004) OOH care – advanced cancer patients and carers *Carers views* What valued from GP and DNs (Grande *et al*, 2004) Care at the end of life (Exley *et al*, 2005)

	Community hospitals (Hawker *et al*, 2006) Dementia in nursing home and home care; retrospective views of carers (Mitchell *et al*, 2004) Experience of ooh care and support services (King *et al*, 2004) **Ongoing research** Finding sensitive and effective ways to convey information about Eol issues to users/carers and the public Understanding more about palliative care for older adults at the end of life Psychosocial needs **Gaps** While services focus on carer's views of patient care, little recent work on carers needs and preferences. Literature review of the experience of end of life care – especially for non cancer patients How best to support carers Patient experience of user involvement.

Research theme: resources and health economics

Research identified from the literature review and gaps	**Costs** What are the full costs of keeping at patient at home? How do home and hospital costs compare? What are the costs of good clinical interventions? What is the different cost effectiveness of different models of care? How can we cost EoLC? **Resources** What actual material and social resources are needed at home and correlated to place of death? **Priorities** What are patients/public priorities on funding services? **Economic evaluation** Economic evaluation of informed choices at EoLC What can be done without huge resource implications? How much variation in spending between practices, PCTs and SHAs? **Practice based commissioning** Will PBC clusters shift resources to or aware from EoLC? Will PBC favour in-house multi-skilled nursing in GSF and bypass specialist palliative care services? **Funding responsibilities** Who should be funding which components of care (health/social)? Should the NHS fund voluntary care/hospices and what would be the implications of funding or not funding? Financial barriers What are the financial barriers to providing care? **Quality of data** How can we improve the quality of data? **Influence and impact of costs** What are the incentives for hospitals to improve EoLC? What are the relative costs of generalist and specialists? Does cost cutting damage quality? If resources were available, would minimum standards change?
Research identified from the literature review and gaps	**Systematic reviews** None **Research Papers** There is little research in this area. The review identified: – Time and cost of medical tasks for cancer in the community (Raphael

	al, 2005) – Expenditures for dementia patients at high risk of dying (Newcomer *et al*, 2005) – Comparison costs: home v hospital cancer care **Gaps** Widespread Particularly full costs and resource needs in different places of care Impact of current financial initiatives, eg PCB and PBR.

References for the appendix

Aabom B, Kragstrup J, Vondeling, H, Bakketeig, LS, Stovring H. 2006. Does persistent involvement by the GP improve palliative care at home for end-stage cancer patients? *Palliative Medicine* 20: 507-512.

Ahmad S, O'Mahony MS. 2005. Where older people die: A retrospective population-based study. *Monthly Journal of the Association of Physicians* 98: 865-870.

Ahmed, N, Bestall, JC, Ahmedzai, SH, Payne, SA, Clark D, Noble B. 2004. Systematic review of the problems and issues of accessing specialist palliative care by patients, carers and health and social care professionals. *Palliative Medicine* 18:: 525-542.

Aitken A. 2006. District nurses' triggers for referral of patients to the Macmillan nurse. *British Journal of Community Nursing* 11: 100.

Albert, SM, Simone B, Brassard A, Stern Y, Mayeux R. 2005. Medicaid home care services and survival in New York City, *Gerontologist* 45: 609-616.

Allan, DE, Stajduhar KI, Reid RC. 2005. The uses of provincial administrative health databases for research on palliative care: Insights from British Columbia, Canada, *BMC Palliative Care* vol 4: 2

Amass C, Allen M. 2005. How a 'just in case' approach can improve out-of-hours palliative care. *Pharmaceutical Journal* 275: 22-23.

Andrew J, Whyte F. 2004. The experiences of district nurses caring for people receiving palliative chemotherapy (including commentary by Aranda S). *International Journal of Palliative Nursing* 10: 110-112.

Appelin G, Bertero C. 2004. Patients' experiences of palliative care in the home: a phenomenological study of a Swedish sample. *Cancer Nursing* 27: 65-70.

Barclay S. 2005. *General Practitioner provision of palliative care in the United Kingdom*. Doctor of Medicine. University of Cambridge.

Borbasi S, Wotton, K, Redden M, Chapman, Y. 2005. Letting go: a qualitative study of acute care and community nurses' perceptions of a 'good' versus a 'bad' death. *Aust.Crit.Care* 18: 104-105.

Borgsteede SD, Graafland-Riedstra C, Deliens L, Francke AL, van Eijk JT, Willems DL. 2006. Good end-of-life care according to patients and their GPs. *Br.J.Gen.Pract.* 56: 20-26.

Burt J, Barclay S, Marshall N, Shipman C, Stimson A, Young J. 2004a. Continuity within primary palliative care: an audit of general practice out-of-hours co-operatives. *Journal of Public Health* 26: 275-276.

Burt J, Shipman C, Addington-Hall J. 2004b. *Cancer and palliative care within primary care: a review of the recent literature*. Department of Palliative Care and Policy. King's College, London. London.

Burt J, Shipman C, White P, Addington-Hall J. 2006. Roles, service knowledge and priorities in the provision of palliative care: A postal survey of London GPs. *Palliative Medicine* 20: 487-492.

Campbell C, Harper A, Elliker M. 2005. Introducing 'Palcall': an innovative out-of-hours telephone service led by hospice nurses. *International Journal of Palliative Nursing* 11: 586-590.

Clausen H, Kendall M, Murray S, Worth A , Boyd K, Benton F. 2005. Would Palliative Care Patients Benefit from Social Workers' Retaining the Traditional 'Casework' Role rather than Working as Care Managers? A Prospective Serial Qualitative Interview Study. *British Journal of Social Work* 35: 277-285.

Demanelis AR, Keresztury J, Emmett M, Moss AH. 2005. The development and outcomes of a statewide network of hospital-based palliative care teams. *Journal of Palliative Medicine* 8: 324-332.

Diwan S, Hougham GW, Sachs GA. 2004. Strain experienced by caregivers of dementia patients receiving palliative care: Findings from the Palliative Excellence in Alzheimer Care Efforts (PEACE) program *Journal of Palliative Medicine* 7: 797-807.

Dobbins EH. 2004. *An analysis of the end-of-life choices of elderly patients and their healthcare providers at a community hospital in Tennessee*. The University of Tennessee.

Dunne K, Sullivan K, Kernohan G. 2005. Palliative care for patients with cancer: district nurses' experiences. *J.Adv.Nurs.* 50: 372-380.

Elkington H, White P, Addington-Hall J, Higgs R, Pettinari C. 2004. The last year of life of COPD: A qualitative study of symptoms and services *Respir.Med.* 98: 439-445.

Exley C, Field D, Jones L, Stokes T. 2005. Palliative care in the community for cancer and end-stage cardiorespiratory disease: The views of patients lay-carers and health care professionals *Palliative Medicine* 19: 76-83.

Goldschmidt D, Groenvold M, Johnsen AT, Stromgren AS, Krasnik A, Schmidt L. 2005. Cooperating with a palliative home-care team: expectations and evaluations of GPs and district nurses. *Palliative Medicine* 19: 241-250.

Goodman C, Robb N, Drennan V, Woolley R. 2005. Partnership working by default: district nurses and care home staff providing care for older people. *Health and Social Care in the Community* 13: 553-562.

Grande GE, Farquhar MC, Barclay SIG, Todd CJ. 2004. Valued aspects of primary palliative care: Content analysis of bereaved carers' descriptions *Br.J.Gen.Pract*. 54: 772-778.

Groot MM, Vernooij-Dassen MJF, Crul BJP, Grol RPT. 2005. General practitioners (GPs) and palliative care: perceived tasks and barriers in daily practice. *Palliative Medicine* 19: 111-118.

Gruenewald DA, White EJ. 2006. The illness experience of older adults near the end of life: a systematic review. *Anesthesiology Clinics* 24: 163-180.

Gysels M. Higginson I.J. 2007. Interactive technologies and videotapes for patient education in cancer care: a systematic review and meta-analysis of randomised trials. *Supportive Care in Cancer* 15: 7-20.

Gysels M. Richardson A, Higginson IJ. 2006. Does the patient-held record improve continuity and related outcomes in cancer care: a systematic review *Health Expectations.* In Press.

Hamilton F. McDowell J. 2004. Identifying the palliative care role of the nurse working in community hospitals: an exploratory study International *Journal of Palliative Nursing* 10: 426-434.

Hanson LC. Ersek M. 2006. Meeting palliative care needs in post-acute settings: to help them live until they die. *Journal of the American Medical Association* 295: 681-686.

Hawker S, Kerr C, Payne S, Seamark D, Davis C, Roberts H, Jarrett N, Roderick P, Smith H. 2006. End-of-life care in community hospitals: The perceptions of bereaved family members. *Palliative Medicine* 20: 541-547.

Hawley R, Monk A. 2004. Malignant mesothelioma: current practice and research directions *Collegian* 11: 22-26.

Haydar ZR, Lowe AJ, Kahveci KL, Weatherford W, Finucane T. 2004. Differences in end-of-life preferences between congestive heart failure and dementia in a medical house calls program. *J.Am.Geriatr.Soc.* 52: 736-740.

Hill TE, Ginsburg M, Citko J, Cadogan M. 2005. Improving end-of-life care in nursing facilities: the community state partnership to improve end-of-life care. *California Journal of Palliative Medicine* 8: 300-312.

Jaul E, Rosin A. 2005. Planning care for non-oncologic terminal illness in advanced age. *Israel Medical Association* 7: 5-8.

Jones J. Pooler J. 2005. District nursing and end-of-life care Cancer. *Nursing Practice* 9: 36-39.

Kahana B, Dan A, Kahana E, Kercher K. 2004. The personal and social context of planning for end-of-life care. *J.Am.Geriatr.Soc.* 52: 1163-1167.

Kennedy C. 2005. District nursing support for patients with cancer requiring palliative care. *British Journal of Community Nursing* 10: 566.

Kerr C, Hawker S, Payne S, Lloyd-Williams M, Seamark D. 2006. Out-of-hours medical cover in community hospitals: implications for palliative care. *International Journal of Palliative Nursing* 12: 75-80.

King N, Bell D, Thomas K. 2004. Family carers' experiences of out-of-hours community palliative care: a qualitative study. *International Journal of Palliative Nursing* 10: 76-83.

King N, Thomas K, Martin N, Bell D, Farrell S. 2005. 'Now nobody falls through the net': Practitioners' perspectives on the Gold Standards Framework for community palliative care. *Palliative Medicine* 19: 619-627.

Ling J. 2005. Palliative care in Irish nursing homes: the work of community clinical nurse specialists. *International Journal of Palliative Nursing* 11: 314-321.

Maher D, Hemming L. 2005. Palliative care for breathless patients in the community. *British Journal of Community Nursing* 10: 414-418.

Mirando S, Davies PD, Lipp A. 2005. Introducing an integrated care pathway for the last days of life. *Palliative Medicine* 19: 33-39.

Mitchell SL, Morris, JN, Park, PS, Fries BE. 2004. Terminal care for persons with advanced dementia in the nursing home and home care settings. *Journal of Palliative Medicine* 7: 808-816.

Newcomer RJ, Clay TH, Yaffe K, Covinsky KE. 2005. Mortality risk and prospective Medicare expenditures for persons with dementia. *J.Am.Geriatr.Soc.* 53: 2001-2006.

Payne S, Ingleton C, Scott G, Steele K, Nolan M. 2004a. A survey of the perspectives of specialist palliative care providers in the UK of inpatient respite. *Palliative Medicine.* 18: 692-697.

Payne S, Kerr C, Hawker S, Seamark D, Davis C, Roberts H, Jarrett N, Roderick P, Smith H. 2004b. Community hospitals: An under-recognized resource for palliative care. *Journal of the Royal Society of Medicine* 97: 428-431.

Pieper BB, DAcher JE. 2004. Looking backward toward our future: creating the nexus between community health nursing and palliative care. *Journal of the New York State Nurses Assoc.* 35: 20-24.

Plummer S, Hearnshaw C. 2006, Service evaluation. Reviewing a new model for delivering short-term specialist palliative care at home. *International Journal of Palliative Nursing* 12: 183-188.

Raphael R, Yves D, Giselle C, Magali M, Odile CM. 2005. Cancer treatment at home or in the hospital: what are the costs for French public health insurance? Findings of a comprehensive-cancer centre. *Health Policy* 72: 141-148.

Rosenbaum EH, Gautier H, Fobair P, Spiegel D. 2005. Initiating a community-based cancer supportive care program. *Community Oncology* 2: 73-77.

Saliba D, Solomon D, Rubenstein L, Young R, Schnelle J, Roth C, Wenger N. 2005. Feasibility of quality indicators for the management of geriatric syndromes in Nursing Home residents. *Journal of the American Medical Directors Association* 6: SUPPL. S49-S59.

Sharp J. Oldham J. 2004. Developing a palliative care outreach service *Nurs.Stand* 18: 33-37.

Shipman C, Addington-Hall J, Richardson A, Burt J, Ream E, Beynon T. 2005. Palliative care services in England: a survey of district nurses' views. *British Journal of Community Nursing* 10: 381-386.

Shipman C, Levenson R, Gillam S. 2002. *Psychosocial Support for Dying People: What Can Primary Care Trusts Do?* King's Fund. London.

Steciwko A, Kurpas D, Pirogowicz I. 2005. A family doctor significance in the palliative care. [Polish] *Onkologia Polska* 8: 181-185.

Sullivan KA. McLaughlin D, Hasson F. 2005. Exploring district nurses' experience of a hospice at home service. *International Journal of Palliative Nursing* 11: 458.

Trueman I. Parker J. 2006. Exploring community nurses' perceptions of life review in palliative care. *J.Clin.Nurs.* 15: 197-207.

Visser G, Klinkenberg M, van Groenou MIB, Willems DL, Knipscheer CPM, Deeg DJH. 2004. The end of life: Informal care for dying older people and its relationship to place of death. *Palliative Medicine* 18: 468-477.

Weber M. Grohmann L. 2004. Time expenditure in patient-related care provided by specialist palliative care nurses in a community hospice service. *Palliative Medicine* 18: 719-726.

Worth A, Boyd K, Kendall M, Heaney D, Macleod U, Cormie P, Hockley J, Murray S. 2006. Out-of-hours palliative care: A qualitative study of cancer patients carers and professionals. *British Journal of General Practice* 56: 6-13.

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