**National Institute for Health Research**

**Service Delivery and Organisation Programme**

# Coordination of care for people at risk of dying in the next 12 months: a multi-site prospective study and consensus seeking exercise

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# Glossary of terms/abbreviations

**Abbreviations**

A&E Accident and Emergency

ACP Advance care planning

CAA Combined Assessment Area

CCRP COMPASS Collaborative Consumer Research Panel

COPD Chronic Obstructive Pulmonary Disease

CSRI Client Service Receipt Inventory

DNACPR – Do not attempt Cardiopulmonary Resuscitation

DOH Department of Health

ECOG Eastern Cooperative Oncology Group

EPCS Electronic Palliative Care Summary

EPR Electronic Patient Record

ERDG Edinburgh Research Discussion Group

GSF Gold Standards Framework

KCH King’s College Hospital

KLSG King’s College London Lung Support Group

IHD Ischemic Heart Disease

ILC Interstitial Lung Clinic

LCC Lung Cancer Clinic

LCNS Lung Cancer Nurse Specialist

LCP Liverpool Care Pathway

LNS Lead Nurse Specialist

MCN Managed clinical network

MDT Multi-disciplinary team

NICE The National Institute for Health and Clinical Excellence

PIG Prognostic Indicator Guide

PPI Public and patient involvement

SDO National Institute for Health Research Service Development Organisation

| | |
|---|---|
| SDS | Service Development Statement |
| SEA | Significant Event Analysis |
| SPICT | Supportive and palliative care indicator tool (see below) |
| UI | User involvement |
| UWUG | The University of Warwick User Group |
| WHO | World Health Organisation |

**Terms**

**Approaching the end of life:** the stage when patients may be considered for end-of-life or palliative care.

**Carers:** relatives and informal carers. Professional carers will be termed professional carers.

**End of life:** a term that is used to signify a period of weeks, months or years which patients may have from diagnosis of a life-threatening progressive illness to death.

**End-of-life care:** the care of patients in their last weeks, months or years when death is not unexpected.

**Generalists:** used in this report to refer to hospital and community based doctors and nurses who are not specialists in palliative care.

**Generalist palliative care:** palliative care provided by **generalists**.

**Generalist palliative care settings:** primary care, hospital inpatient and outpatient care (except for any specialist palliative care), care homes, nursing homes.

**Informal (Family) carer**: as per the Carer's Trust definition (http://www.carers.org/what-carer) we use this term to refer to a carer "who provides unpaid support to family or friends who could not manage without this help." We use the term "informal carer" synonymously with term "family carer."

**Keyworker:** health or social care professional with responsibility for organising the care of a particular patient.

**Palliative care approach:** an approach that generalist health and social care providers can adopt whereby they consider all dimensions of the patient experience and plan holistic care for the future as well as the present.

**Primary palliative care:** the practice of palliative care in primary care by general practitioners and community nurses.

**Service Development Statement:** a brief statement of a development that should improve coordination for people approaching the end of life.

**Specialist palliative care:** the provision of services whose core activity is limited to the provision of palliative care. The main role of specialist palliative care is to manage patients with complex and demanding care needs, while supporting and training generalist palliative care providers.

**Supportive and palliative care indicator tool (SPICT).** The SPICT is a clinical tool initially developed following a literature review of key clinical indicators suggesting advanced illness.(1) It is increasingly being used throughout the UK as an alternative to the Prognostic Indicator Guide of the GSF to identify patients with advanced, progressive, incurable conditions or who are at risk of dying of a sudden acute deterioration who may have unmet supportive or palliative care needs. Patients identified using the SPICT, and their families, should be considered for holistic needs assessment and care planning. See Annex 2 for a copy of the version used during the project or for further details and the most up to date version www.palliativecareguidelines.scot.nhs.uk/careplanning/spict.asp

**Surprise question:** name for a question that can be used to test clinical intuition about whether a patient is approaching end of life. "Would I be surprised if this patient died in the next 6-12 months?"

**Terminal care:** a term previously used for care in the last days or week of life, sometimes referred to as "care in the dying phase".

**Transition in care:** a change in setting or place of care, or a change in focus of care from being largely curative to being more supportive and palliative.

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**Contributions of authors**

Bruce Mason was involved in the conception and design of this study, data generation, analysis and interpretation, drafting and revising the report, and final approval of the version to be published. Veronica Nanton and Eleni Epiphaniou were also involved in data generation, analysis and interpretation, drafting and revising the report and final approval of the version to be published. Anne Donaldson, as management fellow, was involved in data generation, analysis and interpretation, drafting and revising the report and final approval of the version to be published.

Dan Munday, Irene Higginson, Kirsty Boyd, Jeremy Dale, Marilyn Kendall and Cathy Shipman were involved in the conception and design of this study, data analysis and interpretation, drafting and revision of the report, and final approval of the version to be published. Barbara Daveson, Eleni Epiphaniou, Richard Harding, and Irene Higginson were also involved in data generation analysis and interpretation, drafting and revising the report and final approval of the version to be published.

Allison Worth and Stephen Barclay were involved in the conception and design of this study, revising of the report, and final approval of the version to be published.

Scott Murray managed the overall project and was involved in the conception and design of this study, data analysis and interpretation, drafting and revising of the report, and final approval of the version to be published.

# *Executive Summary*

## Background

The National Audit Office in November 2008 confirmed that most end-of-life care in the UK occurs in a generalist rather than a specialist palliative care setting. People generally spend most of their last year of life at home being cared for by family, family doctors, community nurses, voluntary sector services and as outpatients by hospital clinicians. Coordination of care is considered vital for good quality, reliable care, but is often found wanting.(2-5) Lack of coordination is considered a frequent reason for poor quality care and increased burden on family carers. This study addresses coordination of care for people approaching the end on life by professionals who are not specialists in palliative care.

## Aims

- To understand the processes by which end-of-life care is coordinated and managed in settings other than in specialist palliative care.
- To identify best practice in care coordination and optimum outcomes for patients and their carers
- To inform service and policy development so that access to and coordination of high quality of end-of-life care can become more reliable and equitable in all settings.

## Methods

This was a multi-method, multi-site study structured into three phases, incorporating a review of literature and service user consultation, an empirical study using an organisational ethnographic approach in three case studies and thirdly, consensus-building methods.

**Phase 1:** narrative literature review on coordination of care and best outcomes; service user consultation on coordination of care and outcomes of care.

**Phase 2:** case studies in three generalist settings, each incorporating ethnographic observation, serial interviews and a significant event analysis. The settings were an acute receiving unit in Edinburgh, a primary care team in the Midlands and a respiratory clinic in London. After ethnographic observations of each setting, around 20 patients associated with each setting were identified and tracked for nine months. Qualitative interviews were conducted with patients, family members and service providers and service usage data was collected at the same time. Issues arising from the fieldwork were then presented back to staff at each setting in a Significant Event Analysis. This enabled us to explore key issues around coordination of care.

**Phase 3:** analysis of the data from previous phases enabled us to identify key components of effective coordination of end-of-life care. These were tested for validity, priority and potential for implementation by using consensus building methods, incorporating a national Delphi survey with key stakeholders and then three workshops to prioritise service recommendations. Service users continued to meet throughout the project to help ground the analysis of these data.

# Results

The narrative literature review examined over 1,500 potential matches for developments in coordination in end-of-life care. Fifty seven articles were considered relevant to inform the scope and models of generalist end-of-life care. There was no consensus around the definition of coordination but activities such as communication, information sharing and collaboration were associated. Nor were there any metrics to enable measuring a change in coordination nor how changes in coordination might impact patient outcomes. Our service user groups asserted that lack of coordination was a common harmful event and supported the literature and current policies that called for greater coordination. Some, but not all studies showed positive effects using structures such as keyworkers, shared care, frameworks and collaboratives, and we used these categories to consider the various roles and modes of coordination we identified.

In the case studies, the ethnographic observations highlighted that patients possibly in their last year of life were not uncommon in general settings and often unidentified as possibly being in their last year of life. In two of the case studies (Edinburgh and Warwick), most generalists encountered seemed to equate palliative care with the last weeks of life or “terminal care”. Consequently generalists in these settings did not try to identify patients with non-malignant advanced diseases for an early palliative care approach and hence for additional coordination. In the London setting, generalist professionals associated with the respiratory clinic had a more progressive understanding of the palliative care approach, with a long-established link with a palliative care research institute. The picture was more mixed for other generalists in London.

Dealing with acute events and managing multiple chronic illnesses left little time for wider considerations. Fewer than 10 of the 56 patients whom we identified as having palliative care needs according to current policy criteria had been identified as such, and those identified nearly all had cancer. Holistic needs assessment and future planning were rarely performed. Coordination was hampered by significant barriers to communication and information sharing both within and especially across settings, typically at emergency hospital admission or discharge, when many patients expected a visit from their GP which did not materialise. Changes in practices to promote efficiencies, such as District Nurses being geographically zoned rather than practice-attached, often promoted efficiency but were perceived as hindering coordination and continuity of care. Coordination was facilitated if a well-resourced keyworker was present with good communication channels to other professionals. Generally, only patients with cancer or certain other long term conditions such as diabetes, had access to such a keyworker, while many patients with multimorbidity had little coordination.

Patient interviews revealed the importance of informal carers in coordinating care but many carers felt undervalued and there was little evidence of formal recognition of this by local health professionals. Patients with multi-morbidities fell through several gaps in services and lacked awareness of how to access additional support. Most patients did not regard themselves as having palliative care needs; they focused on living in the present and self-managing wherever possible.

The Significant Event Analyses showed the professionals were generally aware of difficulties in communicating across settings (such as across primary and secondary care) and of difficulties in identifying palliative care needs.

Informed by the results of the literature review, recommendations from the service user groups and the findings from the case studies, we created 20 “service development statements” (SDSs). These were derived from examining examples of poor or good coordination in the case studies and successful interventions discovered in the narrative review. The SDSs covered elements of clinical good practice (identification, assessment, planning) components associated with increased coordination (information sharing, communication, collaboration) and potential roles (informal carers, keyworkers).

The consensus seeking phase consisted of a Delphi study of 50 professionals followed by three regional workshops with a total of 62 participants. This process identified five SDSs that were consistently seen as most important from which we are able to suggest the components of a model.

A successful model to promote coordination for people approaching the end of life has first to *identify* the relevant people as they approach end of life, *assess* their needs holistically and then *plan* their care. However excellent communication, collaborative working and relevant specific personal information are also necessary for a satisfactory patient experience. Two processes in this were seen by professionals as most important: the need for holistic assessments of all patients approaching end of life and improved methods of information sharing among service providers, such as through the use of a single register.

The results support and can help operationalize recent quality standards issued by NICE in end-of-life care, specifically the importance of identification and the role of coordination. Professional feedback from the workshops indicate, however, that structural reorganisations tend to reduce clinician focus on patient-centred care while causing distress and uncertainty among patients and carers. In particular, the role of informal carers in coordination and the impact on them acting as coordinators appears to lack consideration.

## Conclusions

Presently there are no sound metrics for measuring improvements in coordination nor for measuring the impact of such changes on patient outcomes. It appears that reorganisations to promote efficiency may inadvertently reduce coordination. Further qualitative modelling of coordination is required to ensure that future potential interventions can be shown to be capable of meeting their aims.

Any model of care to improve coordination for people approaching end of life must first ensure that such patients are identified as such so that they can then be assessed and their care planned. This is not necessarily identifying them for referral to specialist palliative care, but for the extra coordination, communication and support that a generalist would initiate when deciding to transition into the palliative care approach with a person with advanced progressive illness. This is a traditional clinical model which is uniformly supported in principle, but found difficult in practice. Likewise, any model of care will need to include developments around these three other aspects: collaboration, communication and information. This research highlights some specific service developments that can be built into a comprehensive model, or strengthen existing models, to improve coordination for all people at risk of dying in the next 12 months. We specifically highlight the importance of identifying more people with non-malignant disease and multimorbidity, so that their care can be coordinated.

We suggest the following recommendations for future research.

1. Development of valid and reliable means for increasing the consistency of health professionals, and the ability of patients and carers, to self-identify supportive and palliative care needs.
2. Intervention study of how patients approaching the end of life can best be identified in a systematic fashion. What are the roles of patients, carers, and primary and secondary care?
3. Development of tools to measure coordination and thereby its impact on patient outcomes.
4. Intervention study to scope the content, desirability and practicality of a holistic assessment focused on additional needs.
5. National intervention studies to promote identification, assessing and planning as an integrated model for generalist end of life care, enhancing information sharing, communication and collaboration among multiple agencies.

# The Report

# 1 Introduction

Good generalist care for patients at the end of life and their families is recognised as an essential component of high quality, equitable care, but is often found wanting. Improving coordination of care is one of the core elements of all UK national end-of-life care Strategies. Thus it was timely to examine how well generalist services coordinated the care of people with advanced progressive illnesses. This would provide evidence to inform and support end-of-life service development in a time of substantial change.

## *1.1 Background*

The National Audit Office in November 2008 confirmed that most end-of-life care in the UK occurs in a generalist rather than a specialist palliative care setting. (6) People generally spend most of their last year of life at home being cared for by family, family doctors, community nurses, voluntary sector services and as outpatients by hospital clinicians.(2-5) Hospital admissions are common in the last year of life with most people experiencing two emergency admissions in the last year of life while a small subgroup experiences 10 or more such admissions.(7) Although there is an increasing trend for people to die in their usual place of residence(7) it is still the case that most people die in institutions such as hospitals, nursing homes, and increasingly in care homes where, again, generalists provide most care. Only around 20% of people die in their own homes and(8), generally, the older the patient the less likely this is to happen. (7) Lack of coordination is considered a frequent reason for poor quality care and increased burden on family carers. The breakdown of social support at home is a common cause of emergency hospital admission, and is more common when coordination is poor.

The need for palliative care for people with cancer and other long term conditions is well established in policy terms, but service responses remain inadequate. (9, 10) Conditions such as heart failure, chronic obstructive pulmonary disease (COPD), dementia and frailty cause a substantial proportion of deaths and yet the needs of patients and families are often less well addressed than those of people affected by cancer.

Coordination of care for those with multimorbidity may be particularly fragmented. (11) Mercer notes an “inverse care” law where people with multimorbidity are also more likely to be from socially deprived areas and thus in need of more services yet routinely receive less coordinated care.(12) There is currently little evidence of effective transition from a chronic disease management model for high needs users to a supportive and palliative care approach. “Prognostic paralysis” has been described where clinicians are wary of transitioning into a palliative care phase due to prognostic uncertainty. A a lack of coordination at practice and policy levels is also described. (13)

End-of-life care, particularly for those with non-malignant conditions and dementia, is marked by uncertainty. Recognition of the need for palliative care, how symptoms should be assessed and managed, decisions about the cessation of, or continuation of treatments, and issues about the place where the person should be cared for are all complex.(14) The study was designed to advance understanding of these contextual complexities in end-of-life care delivery and how they can be overcome.

## *1.2 Policy context*

### 1.2.1 Original policy context

When this project was designed, generalist end-of-life care had recently become a major focus of health policy in the United Kingdom. (15-17) In July 2008, the Department of Health (DOH) published an end-of-life care Strategy to "bring about a step change in access to high quality care for all people approaching the end of life" in all care settings. This was to be achieved using a whole systems and care pathway approach. Key elements of the end-of-life care pathway identified for action were:(10)

- Step 1 Discussions as the end of life approaches
- Step 2 Assessment, care planning and review
- **Step 3 Coordination of care for individual patients**
- Step 4 Delivery of high quality services
- Step 5 Care in the last days of life; and
- Step 6 Care after death

Effective coordination of care was seen as requiring services responsive to changing need; coordination between multiple agencies and settings; coordination within individual care settings, within institutions and across organisational boundaries; strategic coordination; all underpinned by support and information for patients and families.(18)

The End of Life Strategy highlighted the value of various methods of improving coordination of care, including the Gold Standards Framework (GSF), rapid response teams, coordinating centres, and supported discharge schemes, particularly those embodied in the Marie Curie Cancer Care Delivering Choice pilots. E-health and technological advances also offered new opportunities for better care coordination. Many innovative and potentially valuable schemes were available only in small locality areas and funded for a limited period. There is a need for more equitable, sustainable models, which necessitates a central role for generalist care.

At the start of this project, in England Primary Care Trusts were developing responses to the End of Life Strategy. In Scotland, Health Boards were developing their actions to implement the Scottish End of Life plan, "Living and dying well." (19) Consequently, this study has illuminated the processes, barriers and facilitators to service development as local and national services were formulating strategies and implementing change. We were thus able to capture pertinent information regarding service developments in different contexts and so strengthen the study.

The study emphasised key SDO themes in service design and delivery, particularly in understanding the processes of care coordination and the patient, family and staff-centred outcomes. SDO also highlights the importance of patient and family experience in shaping service development. This project set out to produce experiential evidence and suggestions from patients nearing the end of their lives and their relatives how health services could be better coordinated and delivered. It also sought to suggest processes and outcomes that are important to users and which are feasible and acceptable to staff. By involving NHS clinicians and managers as collaborators in this project, and specifically by the appointment of a Management Fellow we sought to help build ongoing capacity within the NHS to carry out health services research and quality improvement cycles.

### 1.2.2 Changes in context: policy and guidance

Throughout the UK, the Gold Standards Framework (GSF) has continued to be disseminated in practices and nursing homes, with a more comprehensive package "Going for Gold" now being embraced by an increasing number.(20) In England end of life locality registers have been piloted in eight sites which has brought increased integration of primary and secondary care and ambulance and out-of-hours services and greater numbers on these registers. In Scotland the electronic palliative care summary is in 2012 used in most general practices, although less than 20% of non-malignant patients are registered when they die. It allows automatic daily updates of information to be sent from GP records to a central store with the patient's consent. (21)

A rapid progression of national guidance and policy documents has been published while this study was taking place. Developments include:

1. Commissioning end-of-life care: ACT and EARLY. This publication supports and gives advice to commissioners to ensure that end-of-life care is a top priority and is based around the acronym ACT & EARLY. Many recommendations highlight coordination and communication.(22)

2. The National Institute for Health and Clinical Excellence end-of-life care for Adults Quality Standard. This document provides concise quality statements and measures with definitions of high quality care. This includes number 8 "*People approaching the end of life receive consistent care that is coordinated effectively across all relevant settings and services at any time of day or night and delivered by practitioners who are aware of the person's current medical conditions, care plan and preferences."* Specific measures of structures, process and outcomes are given, such as the proportion of people approaching the end of life who receive care that is coordinated effectively across all relevant health and social care organisations. (23)

3. Holistic common assessment of supportive and palliative care needs for adults requiring end-of-life care. This paper gives guidance for completion of a holistic common assessment for end of life patients to ensure that their care needs are met. It specifically states that meeting these needs require effective care coordination across boundaries. (24)

4. Improving care for people with long term conditions: information sheets. These assist with the implementation of personalised care planning for people with long term conditions and are potentially very relevant to end-of-life care. (25)

5. Quest for quality: an inquiry into the quality of healthcare support for older people in care homes. This document suggests that coordinated teams should work together built on primary care and supported by a range of specialists. (26)

6. Quality standards for the care of older people with urgent and emergency care setting needs. This describes the standards of care for older people during the first 24 hours or urgent care episodes. (27)

7. Integrated care for patients and populations: Improving outcomes by working together. This King's Fund and Nuffield Trust Report

states that integrated care is essential to meet the needs of the ageing population and sets out priorities for the future. (28)

Recent projects, policy documents and practice guidelines have thus continued to call for coordination and collaboration in many patient groups relevant to end of life care, and we now look to our primary research with patients, family carers and health professionals to gain evidence to further develop health policies and services.

# 2 Aims

This study aimed:

To understand the processes by which end-of-life care is coordinated and managed in generalist care settings.

To identify best practice in care coordination and optimum outcomes for patients and their families.

To inform service and policy development so that access to and coordination of high quality of end-of-life care can become more reliable and equitable.

## *2.1 Objectives*

Identify current models of collaborative working at the end of life in primary and secondary care settings.

Identify best practice and optimum outcomes for patients, families and services, focussing on coordination of care.

Identify the factors contributing to gaps in identification of end-of-life care need, provision of care and coordination of care at patient/family carer, organisational and strategic levels.

Develop and propose models which could lead to more effective coordination of end-of-life care.

Establish consensus among stakeholder groups on the best models of service provision to improve collaborative working in end-of-life care within and between different settings and for different conditions.

# 3 Methods

## *3.1 Design*

This was a three-phase study lasting 27 months, with Phase 1 as the set-up phase, Phase 2 employing ethnographic case studies to examine practice in detail, and Phase 3 seeking consensus on best models. Thus the specific findings from each case study informed the development of a national consensus. The study shifted from the ‘micro’ level of the case studies which identified patient and service-relevant data on coordination of care within and between a range of generalist settings and teams to the ‘macro’ level of seeking national clinical and management consensus. This way we were able to ensure that this study addressed patients and carer perspectives as well as those of health and social care professionals. Figure 1 below gives an overview of how the different elements interacted during the project.

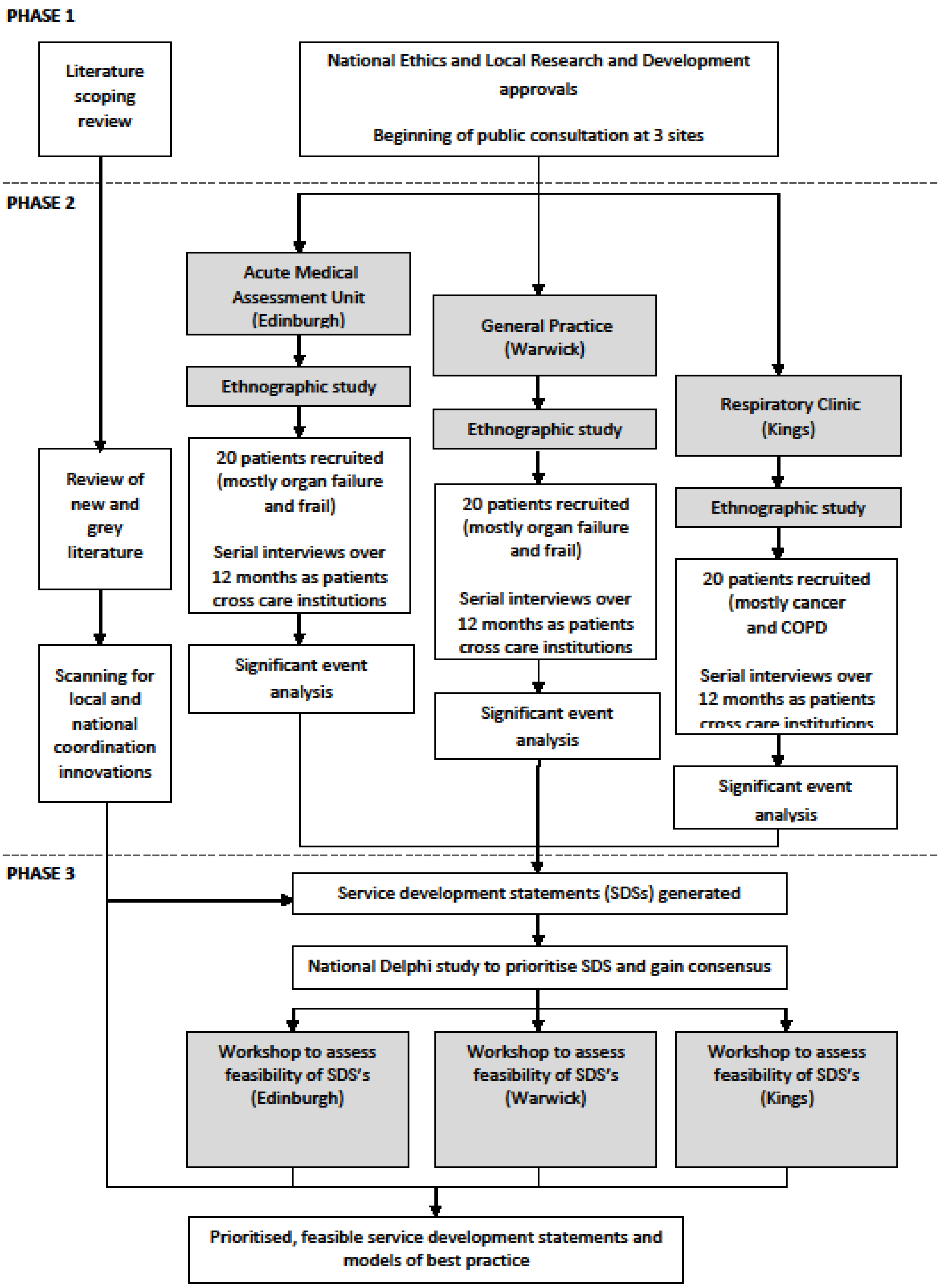

**Figure 1. Project flowchart**

This study used ethnographic methods to investigate the practices involved in delivering end-of-life care. We undertook three ethnographic case studies in different healthcare and geographical settings. Ethnography encompasses a wide range of techniques that include both qualitative and quantitative methods.(29, 30) The overriding framework is a commitment to the first-hand experience and exploration of a particular social or cultural setting, and this commitment provides a particularly appropriate set of tools for the description and interpretation of complex process from multiple perspectives. (31) Ethnography is particularly useful in understanding the organisation of healthcare.(30)

Ethnography as a methodology centres around sustained, systematic interactions between a researcher and participants within one or more settings. It draws upon both qualitative methods (such as observation, interviewing, document analysis and fieldwork journals) and quantitative methods (such as questionnaires, and relationship mapping) to enable sophisticated and powerful interpretations of complex data.

Ethnography has been successfully applied as a method of research in healthcare settings both in its own right and as a technique for evaluating prior research. For example, an ethnographic study of terminal care in hospices captured important elements of patient experience that had been missed by an earlier randomised clinical trial which appeared to show no significant difference in the experiences of patients in hospices as opposed to hospital wards.(32) An ethnography of haematologists at work uncovered how expert reasoning emerged from the conversations among clinicians in a manner that had significant implications for clinical decision making processes.(33) Similarly an ethnographic study of information sharing between doctors and nurses helped explain why the introduction of electronic patient records in a hospital was perceived to have been a failure.(34)

The research brief for this proposal with its stress on the need to consider holistically the many interrelations between generalist services in people approaching the end of life in the community as well as considering the views of multiple perspectives made ethnographic methods a natural fit. Although ethnography originated as a tool for studying single locales it has become increasingly used in the study of complex, multi-sited activities. Thus it has been applied to studying the flow of information around the trial of a nanny accused of murdering a young girl, (35) the connections between multiple sites, (36) and working practices across multiple media. (37)

Similarly, ethnography has been deployed as an effective means for uncovering and representing perspectives that may otherwise have gone unheard. (38) The Protean nature of ethnography combined with its 'close to the ground' nature makes it an ideal method for a study of service organisation that elicits and interprets the lived experience of those involved in delivering and receiving end-of-life care as it is actually experienced.

In each case a 'micro-ethnography' was conducted at each setting, enabling the researcher to undertake a short, focused period of observation. Such an approach allows the researcher to focus on the "local and situated ecology obtaining among participants in face-to-face interactional engagements, constituting societal and historical experience."(39) Micro-ethnographic case studies have been used to great effect in health services research(40) educational settings (39) and control rooms (41) among many others.[1]

Through recruiting participants via their attendance at the sites for longitudinal interviews over a period of 6-9 months and maintaining presence at the sites for the project duration we were able to construct an ethnographic frame around the research allowing us to take full advantage of the range of ethnographic techniques and methods to explore both qualitative and quantitative data. Through close and detailed interactions with health providers, patients and their carers, we sought to map out the links and the breakages in the network of care for people with advanced progressive illnesses as they were seen and experienced by those who are actually involved. Therefore, we are confident that the inferences drawn are generalisable to palliative care in the community more widely.

## *3.2 Plan of Investigation*

Phase 1: setting up access; ethics and Research & Development approval; engaging with service users to define optimum outcomes.

Phase 2: three in-depth prospective case studies in England and Scotland, focusing on the process of care coordination in a range of generalist care settings.

Phase 3: employing a national e-Delphi survey and three workshops to seek consensus on findings from Phases 1 and 2.

**Table 1. Project timetable summary**

| | |
|---|---|
| Months 0-6 | Focussed literature review |

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[1] It should be noted that we are not referring to the recording of detailed interactional behaviours which is commonly referred to as 'microethnography' – the terminological confusion is regrettable.

| | |
|---|---|
| | Consultation with service users |
| | Ethics and R&D approvals |
| | Set up access to sites for Phase 2 case studies |
| | |
| Months 7-18 | Case studies |
| | Tracking patients |
| | ongoing user involvement |
| | case study data analysis |
| | ongoing literature and policy review |
| | |
| Months 19-27 | Case study integration |
| | Development of service development statements |
| | Final literature and policy review |
| | National electronic Delphi survey |
| | Workshops with key stakeholders |
| | Final report |

## *3.3 Phase 1: Set-up*

### 3.3.1 Focussed international literature review

This consisted of a narrative review of generalist palliative care and other relevant literature to establish whether the elements of good coordination of care have been identified; the strength of evidence underpinning best practice; identification of outcomes and how these are measured; and whether and how costs of best practice models have been determined. A focus on recent developments was maintained. The initial search was supplemented by "alerts" set up to flag new publications in the area and a revised search was conducted during Phase 3.

### 3.3.2 Engaging service users

Service user groups were consulted at all three sites as well as input from an email group of service users run by the COMPASS Collaborative. In Phase 1 the Scottish group facilitated initial approvals and design details, and the other service user groups were engaged throughout the rest of the project. These groups advised us about what they considered to be examples of good and poor coordination of care from their experiences. They were then consulted throughout the study for their perspectives on emerging findings so that user views were embedded in the project. Defining and conceptualising effective coordination of care from the service user perspective was therefore ongoing through the research study. Appendix 2 provides a full account of the process.

## 3.4 Phase 2: Case studies

### 3.4.1 Overview

In phase 2 we investigated and described the complexity of end-of-life care through in-depth case studies of three typical generalist settings in primary and secondary care using ethnographic methods. In each setting, patient, carer, staff and management perspectives were gathered through a mixture of observation, formal and informal interviews, and document analysis. The aim was to identify 20 patients at each site and track them over time as they encountered a range of services across various settings and sectors.

### 3.4.2 Settings

A total of three in-depth case studies were conducted in Edinburgh, the Midlands and London. The settings were selected to sample different types of generalist services, different populations and different patterns of collaborative working. Each encompassed patients with cancer and other long-term conditions:

- A combined assessment unit (CAA) and medical ward [Edinburgh]
- An urban primary care team (multi-ethnic area) with involvement with care homes [Midlands]
- A respiratory outpatient clinic, dealing with malignant and non-malignant conditions [London]

We sought to gain information on coordination of care within and between settings.

### 3.4.3 Data generation - Phase 2

Data gathered in each case study consisted of qualitative and quantitative information. The methods used and data gathered were selected to ensure that we could be sure of the validity of the findings. We explored several primary sources.

*Documents*. This included review of printed documents (for example policies, minutes, audits, ward annual workload data), case notes, care plans, palliative care registers and online resources such as websites.

*Observation in care settings*. In each site, the researcher spent four to eight weeks in daily observation in the care setting. The researcher observed routines, team meetings, staff interactions with patients, ward rounds, and handovers in order to examine both organisational structures (staff, skills, resources, management) and processes (roles, relationships, teamwork, communication, mechanisms, information systems, conflicting demands, leadership).

*Interviews with staff.* This concerned their practice in relation to patients with advanced progressive illnesses, incorporating awareness and knowledge of palliative care, how/if patients were identified as needing palliative care, assessment and referral processes, care planning, responsibilities and key collaborations. The focus was on barriers and facilitators to coordination of care, and how staff think patients could be better identified for care, and have their care coordinated across settings. There were variations between settings.

At the Midlands site, most interaction with staff took place informally while the researcher was shadowing or sitting in on surgeries or clinics. This method allowed the clinician to continue with their work and gave the opportunity for the researcher to ask questions relevant to a particular activity or patient as it took place. In both the Edinburgh and London sites, formal interviews with staff members took place throughout and after the observational period rather than being performed on a baseline.

In London, professionals from the respiratory department were approached by the researcher and asked whether they would like to be interviewed for the project. In Edinburgh, professionals working at the site were approached by the researcher for interviews to answer questions the researcher couldn't address through observations given the multi-faceted nature of the site. These interviews included the pharmacist most commonly working on the site, a consultant who had recently started a new intervention in assessing the needs of elderly patients as they entered the assessment unit and four members of the hospital's specialist palliative care team.

*Identification of patients at risk of dying in the next 12 months for serial interviews*. Patients with palliative care needs due to conditions such as cancer, heart failure, COPD, and frailty were identified by the researcher, whether or not such patients were being recognised as being eligible for a palliative care approach in the clinical care they were receiving. In primary care this included patients on the practice palliative care register, and others especially with non-malignant illnesses, and including some patients in care homes. In secondary care settings, this required case finding in collaboration with staff, inviting them to identify patients using a new tool the researchers had develop, the Supportive and Palliative Care Indicator Tool (SPICT) – see Annex 2 for a copy of the version used. (1) We excluded patients with moderate or severe dementia. A sampling grid was drawn up by the research team and can be found in Annex3. This allowed us to recruit a group of around 60 patients across the three sites which reflected the demographic profile of patients in their last 12 months of life. We have already described the development of this instrument in detail in an article we wrote in the BMJ(38)

*Patient serial interviews*. A total of 60 patients plus associated carers were purposively selected to include a range of conditions and ages at each site. These patients were 'tracked' for six to nine months each as they encountered different services and care settings such as out-of-hours, hospital admissions, hospital clinics, community care and specialist palliative care. The researcher conducted up to three interviews (T1, T2 and T3) with each patient (and carer as a dyad where present). The first interview was conducted shortly after recruitment and the second and third at three-monthly interviews. Declining health meant considerable attrition was factored in, and interviews were sometimes delayed due to an exacerbation of illness.

At each T1 interview, patients' written consent was sought and participants were reminded about their right to withdraw from the study at any time without providing any reason or their care being affected. If the carer was present during the interview then they were invited to interrupt at any time they thought was necessary to share their experiences as well. After discussion at steering group meetings it was agreed that concurrent interviews with patients and carers would not cause any harm or discomfort to the patient or the carer because the interview focused on their experiences of how professionals coordinated the patient's care and not their experiences around their role as patients or carers.

The first part of T1 interviews mainly explored the patients' pathway of diagnosis and prognosis, recent experiences and identified their main source of support and professional care and looked at their needs and main sources of information. The second part focused on the coordination of care and sought to explore whether professionals were updated about their condition, shared information with the patients and patients were able to understand this. This part also explored the coordination of care when moving between sites, or after being discharged from the outpatient clinic. See annex 4 for interview guide

The subsequent T2 and T3 interviews were conducted approximately every eight weeks always depending on the patient's availability and ability. The aim was to follow-up important issues, which were raised during the previous interviews and discuss any new matters important for the patient.

*Service usage inventory.* Usage by these patients in the three months preceding each interview was recorded using the Client Service Receipt Inventory (CSRI) to complement the qualitative data.

The CSRI is a comprehensive inventory with which cost-related data can be collected that has been used in more than 200 economic studies in a variety of subjects.(42).

After the completion of each interview, patients or carers completed a copy of the form that had been modified for the study. The form consisted of four main sections. The first section used the ECOG performance status(43) tool to measure the participant's performance from "0" (full activity) to "4" (completely disabled). The following three sections summarised the participant's use of secondary services and community services over the previous three months. The final section summarised routine help from informal carers. This data was used to complement the qualitative data from interviews and observations. See annex 5 for the modified CSRI we used.

*Significant event analyses* (SEA). A meeting was held with clinicians in each of the three settings to discuss and reflect on coordination of care in five incidents related to the setting. This facilitated a team approach to analysing coordination of care, and permitted focussed exploration of particularly illuminating cases.

*Context analysis*. In each setting, the local, regional and national strategic context was examined. In England this included Primary Care Trusts and Strategic Health Authorities, and in Scotland Managed Clinical Networks (MCNs).

Reflexivity was a significant element of the ethnographic work. Each researcher had a different level of experience in palliative care research. One researcher had previous clinical experience. None had any pre-existing knowledge of the research site. This varied orientation of the researchers to the subject matter and locations enabled the researchers to query each other's emerging perspective. As with Hammersley and Atkinson, we regard the researcher as embedded within social, historical and intellectual traditions that "implies the unavoidable implication of the observer in what he or she observes." (29) Through using multiple researchers at multiple sites, it was possible to illuminate the presumptions of the researcher without falling prey to "self-absorption."

### 3.4.4 Data Analysis - Phase 2

This was ongoing throughout the case studies. As the case studies drew to a close, the three researchers collaborated to share the locally emerging themes in order to triangulate their findings. In each research centre, a similar process was followed.

**Observational data**

The observation data emerged from shadowing, on-site informal conversations with clinicians and from observing individual consultations. Field notes represent the researcher's observations and experiences and were written up by the researcher immediately after leaving the research site each day.

The notes include descriptions of staff interactions with service users and other clinicians, informal discussions between the researcher and the clinicians, routines, team meetings, ward rounds (where present), processes, non-verbal behaviours. They also have a reflective character as the notes consist of the researcher's thoughts, explanations, questions, and sometimes emotions. Field notes supported the researcher's memory in recalling certain events from the field and helped to explain and understand events from the interviews.

Field note analysis aided code and thematic identifications and development and the retention of contextual information to aid the interpretation for the data in order to help tell a story about the observed clinical settings. Initially, narrative logs were chronologically ordered to help the reading of the data. Then the researcher read and re-read all field notes, which recorded the observations evolved over time, and looked for patterns in the data using the research question to focus analysis. Line-by-line coding of the notes was applied for data analysis to generate various codes. The researcher identified themes by combining, eliminating or subdividing initial codes and then themes were grouped accordingly. Themes and subthemes were finally developed from the analysis.

### Qualitative interviews

All qualitative interviews (whether with patients or professionals) were transcribed verbatim. Initially, each individual transcript was read several times to ensure familiarity and was then imported into NVIVO 9 software for thematic analysis.(44) All identifying information was removed and unique code numbers were allocated to participants. Line-by-line coding of the transcripts was applied for data analysis. For each individual interview, the local researcher identified codes and grouped them accordingly into themes. This procedure was followed every time a new transcript was analysed. The codes were then connected and grouped under a general heading. Instances for each topic were coded from the transcripts. Themes and sub-themes were finally developed for each transcript. These themes and sub-themes were then checked to ensure that the findings were logically represented within the data contained in the transcripts.

An understanding of data patterning was developed based on the confirmatory and deviant cases with a random sample of transcripts being reviewed by other members of the team. The resulting coding frame was re-examined to ensure that each code identified substantive and autonomous themes. For comparison between sites, the themes of information, communication, expectations and role were agreed to be analysed for each site, for the patients' interviews.

**Integration**

Data analysis of the case studies in phase 2 was in stages. Firstly, each data set was analysed separately, using thematic content analysis. This was ongoing, to allow emerging themes to be fed into continuing data collection. Data was then integrated for each site in a within-case analysis. Cross-case analysis was then conducted to triangulate the data and produce an integrated, multi-level understanding of coordination of care across settings and in different contexts. This was co-ordinated by the lead researcher who also did all the filedwork in Edinburgh……. The research team utilised their considerable experience in the analysis of such longitudinal qualitative and quantitative data. (45)

### 3.4.5 User Involvement in Phase 2

One of the project team (MK) was responsible for user involvement across the project as a whole with the researchers at each site taking responsibility for the local groups. In Edinburgh, Anne Donaldson, and Bruce Mason fed back emerging findings regularly to the user groups, promoting frequent dialogue between the user group and the project team. Similar groups facilitated by the University of Warwick and at King's College met to contribute in a similar way.

## *3.5 Phase 3: Seeking consensus*

In this phase, analysis of case study data and data on outcomes took place with reference to developing policy, to produce service development statements to promote best practice in care coordination. The following tasks were conducted:

### 3.5.1 National e-Delphi survey

The service development statements were tested for generalisability and validity via a national 2-round e-Delphi survey. (46) We identified the key elements of the models and formulated a list of service development statements for distribution to 50 key informants in England. These were purposively selected from policy makers, Clinical Leads for end-of-life care, clinicians, and national user representative groups. Respondents were asked to score the statements on a 5-point scale ranging from 'very important' to 'irrelevant'. A second Delphi round allowed participants to consider all the scores from round 1. Consensus was attained for those aspects where there was 80% or greater agreement that the item was very important or important after the second round.

The Delphi study data was analysed using the survey software (Bristol Online Surveys) and Excel to calculate the median score and the percentage agreement for each item. These values were incorporated into the second round questionnaire and panel members asked to re-score each item with knowledge of what other panel members scored in round 1. The analysis was then repeated to calculate the final agreement on each item.

### 3.5.2 Regional Workshops

The findings from the Delphi study, with illustrations from the case studies, were discussed at three regional workshops with approximately 20 key stakeholders at each, to determine how the favoured service development statements from the Delphi could be implemented. Participants were purposively selected from among the Strategic Health Authority and Primary Care Trust/Acute Trust Clinical Leads for end-of-life care to ensure a wide range of professionals and service types were represented. The workshop facilitators utilised nominal group technique (47) to enable service priorities to be identified and prioritised.

Descriptive statistics from the workshops were collected and analysed in Excel. Qualitative data were excerpted from the score sheets and summarised from the recordings and entered into Microsoft Word where they were read to check against the quantitative data. Summative transcripts were made of the recordings of the open discussion and read for emerging themes. Thus as well as the emergent consensus achieved through using the technique, it was possible to include the qualitative and quantitative data generated in the overall project dataset.

Workforce training and development needs were identified through consultation on the models with staff in the case study sites, the project advisory group and the workshops.

### 3.5.3 User Involvement – Phase 3

In the last phase service user groups contributed in responding to the Delphi and workshop results and in the interpretation of the findings.

## 3.6 Ethical considerations

The research conducted within the project was conducted within well-established research parameters. To ensure that everyone at the research sites had access to information about the project and could easily identify the researcher, a laminated project poster and leaflets were placed in the relevant public area. In addition to this, for patients attending a consultation with a member of the staff who at that time was observed by the researcher the receptionist initially informed the patient about the physician being observed when the patient signed in for the appointment. The receptionist also provided the patient with documents about the project. Before the consultation, the physician asked the patient whether they would consent to have the researcher present at the consultation. If yes, this was considered a verbal consent and the researcher was called in, otherwise the researcher was not invited into the consultation room.

Patients and their carers were informed about their right to refuse to be observed and also their right to withdraw from the project even after they provided their consent. The researcher highlighted that their refusal would not have an impact on the care they received from the healthcare services.

The length of observation within consultations was determined by the patient or the carer. This resulted in partial observation of consultations in one instance.

The workplace ethnography challenged us to find ways of gaining and maintaining informed consent among staff and service users at each of the three sites, and preserving the confidentiality of people at those sites while conducting the detailed research required to meet our research aims.  After consulting previous research, service users, staff and managers at each site, the Caldicott Guardian and drawing on the team's prior experience of conducting workplace ethnographies we developed an assent model of consent. The assent model required us to ensure that everyone at the site had access to information about the project, could clearly identify the researcher and, most importantly, that the researcher remained active in maintaining a sense of awareness about whether their presence was causing discomfort, invading privacy or at risk of breaching confidentiality. Through performing this properly we ensured "assent" to research: i.e. that no one objected to the researchers' presence and everyone had some warning of their purpose and presence.

To achieve this we undertook several procedures at each site.

- We provided A4-sized laminated posters about the project for each site to be displayed in both staff and public areas.
- Provided paper copies of the same posters in easily accessible areas at each site.
- Ensure that the researcher at each site wore a badge which clearly identified them as a researcher and, also, dressed in such a way that it was unlikely that they would be mis-identified as a member of staff by any public present.
- Each researcher periodically reminded staff of the researcher's role.
- No member of the public was approach without pre-arranged consent.
- If present while care is being provided, we ensured that all participants could easily withdraw assent.
- Applied "Caldicott Guardian Principles"(48) to observation and note taking, which is to say that no notes of observations containing patient identifiable material were taken unless it was deemed vital to the research.
- Implemented a procedure to inform the researcher's response if they observe criminal, abusive or negligent activities during research.

These procedures rarely inhibited research, indeed they often facilitated it. For example, the use of posters featuring a photograph of the researcher appeared to generate interest among the staff and facilitated initial conversations with staff. Conversely there was no evidence that any service users attending the site had noticed or paid any attention to the posters, implying that there was no effect on the project but also raising the issue of how effective there were for the intended purpose. There was also some feedback from the researchers that the increasingly detailed consent forms were becoming more burdensome to participants at interviews.

It should also be noted that the ethical issues faced by service providers in this field constitute a major challenge, especially if electronic records are proposed as a means to facilitate coordination.(49, 50) It is in general, a risk that coordination with its requirements for greater sharing of personal information is seen as antithetical to ethical standpoints around privacy and ownership of data.

# 4 Literature review

Our aim was to define and categorise models of coordination and collaboration in generalist end-of-life care; to determine the effect of such models of coordination on patient and carer outcomes; and to determine best practice in coordination and collaboration.

An initial scoping exercise identified little focused literature, requiring us to cast the net quite widely in order to draw together disparate studies. Thus a narrative review was appropriate due to the nature and extent of the data related to coordination and collaboration identified within our initial scoping exercise. Narrative reviews have been considered appropriate for "surveys of the state of knowledge on a particular topic,"(51) and particularly valuable "as a means of pulling together what is known about a particular phenomenon." (ibid). Although such a review does not generally present details of the search strategy and results, we have done so here in order to provide an evidential base. A quality appraisal, as routinely performed for a systematic review has not been included here as it would not be appropriate to the method.

We thus set out to establish whether the elements of good coordination of care have been identified; assess the strength of evidence underpinning best practice; identify outcomes and how these are measured; and establish whether and how costs of best practice models have been determined. The focus was on recent developments from 2005 onwards but some landmark studies prior to this date were also inspected.

## *4.1 Methods*

The narrative literature review involved three steps. First, a literature scoping exercise was conducted in order to identify and categorise models of coordination and collaboration. Step two involved further investigation of each model category to determine its key components. This step involved extraction of the following information:

- patient and professional groups involved and relationships between these groups.
- whether the groups involved were specialists or generalists in palliative care.
- organisational structures (where they existed).
- modes of communication used.

Finally a search strategy encompassing key words, phrases and concepts uncovered in this preliminary stage was developed.

### Search strategy

In order to capture research advances and developments throughout the period of the project, electronic searches of PUBMED (2005 to present) and ISI Web of Science (2005 to present) were conducted twice: in March 2010 and in October 2011. These were supplemented by hand searches of leading journals in palliative care. Table 1 lists the number of matches for each strategy.

The search strategy involved five steps:

1. A keyword search for the stems "coordinat-" or "collaborat-" in the context of the stem "palliat-" or the phrase "terminal care" was conducted.
2. This search was conducted in PUBMED and ISI Web of Knowledge. An additional search on Web of Knowledge for "generalist healthcare" and "palliative" was also conducted at this time.
3. Third, a PUBMED MeSH[2] terms search for the categories "palliative care admin and organisation" and "terminal care admin and organisation" was completed.
4. A search for the MeSH terms "Cooperative Behavior" in the context of ("Community Networks," "Community Networks/organization and administration"[Mesh] or "Community Networks/standards") was conducted.
5. Hand searches of palliative care journals over the period 2008-2010 were conducted to determine whether there were any potential matches that had not been previously identified.

Finally, two articles out-with these dates (52, 53) were included due to their perceived importance after consultation with the wider steering group.

The second search in October 2011 used the same criteria but only for publications with a publication date after the original search.

**Table 2. Search strategy**

| Search | Criteria | Source | Matches (March 2010) |
|---|---|---|---|
| 1 | (((coordinat*[Text Word]) OR collaborat*[Text Word])) AND (((palliat*[Text Word]) OR "End of Life"[Text Word]) OR terminal care[Text Word]) | PUBMED | 1063 |
| 2 | (((coordinat*[Text Word]) OR collaborat*[Text Word])) AND (((palliat*[Text Word]) OR "End of Life"[Text Word]) OR terminal care[Text Word]) | ISI Web of Knowledge | 760 |
| 3 | ("Generalist healthcare" AND | ISI Web of | 20 |

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[2] " Medical Subject Headings" – controlled vocabulary.

| | | | |
|---|---|---|---|
| | “palliative”) NOT Search 2 | Knowledge | |
| 4 | MeSH terms search for “palliative care admin and organisation” AND “terminal care admin and organisation” | PUBMED | |
| 5 | MeSH terms: "Cooperative Behavior"[Mesh] AND ("Community Networks"[Mesh] OR ("Community Networks/organization and administration"[Mesh] OR "Community Networks/standards"[Mesh])) | PUBMED | |
| 6 | Hand search | Various | |

**Inclusion and exclusion criteria**

- Only papers published in English were included.
- Only developments from “high income” countries (as defined by the World Health Organisation)[3] were included.
- Developments in paediatric palliative care were excluded.
- We included research articles and reviews written in English or with English language abstracts, but excluded editorials and letters.

Articles regarding palliative care provided by non-high income countries were excluded as the healthcare infrastructure within these countries varied dramatically from the healthcare system in the UK. The value of including these studies was therefore questionable. Articles for paediatric palliative care were excluded as the focus of this project was primarily on provision of care to adults.

After combining all searches we identified a total of 1,672 unique matches. These titles were then reviewed against the exclusion criteria above, leaving 238 matches. The abstracts for these articles were reviewed and only those that indicated that coordination or collaboration featured were included, leaving 79 matches. A re-read of abstracts and/or the article itself was then conducted to filter out articles that did not significantly feature an interest in coordination or collaboration leaving 50 articles that were then read in depth (see Table 3 below). The researcher consulted with SM and AD where there were cases of uncertainty in which items to include.

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[3] http://data.worldbank.org/about/country-classifications

**Table 3. Search results March 2010**

| Stage | Matches remaining |
|---|---|
| Total unique matches | 1672 |
| After reviewing titles | 238 |
| After reviewing abstracts | 75 |
| After re-reading of abstracts and scanning of articles: articles where coordination/collaboration were significant elements of the research | 47 |

### On-going and final search

For the purposes of the project we then set up search alerts which were monitored for new publications matching the criteria. Towards the project end (October 2011) a final search was conducted. The final search corpus is listed in Table 4 below.

**Table 4. Consolidated search results**

| Stage | Matches remaining |
|---|---|
| Total unique matches | 1672+799=2471 |
| After reviewing titles | 238+85=323 |
| After reviewing abstracts | 75+24=99 |
| After re-reading of abstracts and scanning of articles: articles where coordination/collaboration were significant elements of the research | 47+10=57 |

## 4.2 Results

The findings from the scoping exercise showed that there is no clear consensus regarding the definition or model of coordination and collaboration within the context of generalist end-of-life care. Despite this finding the search showed conceptual distinction between the two constructs of coordination and collaboration. Namely, coordination was treated as a structural issue while collaboration was treated as a behavioural one. Despite conceptual differences both constructs involved communication.(54-57)

Given the lack of clarity of usage in healthcare, we decided for this review to draw on definitions from organisational research in order to meet the project's remit of investigating the organisation of services.

***Collaboration:*** *"the process of facilitating and operating in multi-organisational arrangements to solve problems that cannot be solved, or solved easily, by single organisations*."(58)

***Coordination:*** *"exchanging information and altering activities for mutual benefit and to achieve a common purpose."*(59)

**Four categories or dimensions of coordination** emerged from step two of the review, and each paper was considered in each of these four categories to understand the organisation of the intervention, the specific roles involved, the modes of communication used and how generalists were involved. These categories, with sub-headings were:

1. Organisational developments (ORG)
    a. The use of "nominated coordinators" or keyworkers.
    b. Shared care or Partnerships
    c. Integrated Care Pathways (e.g. LCP)
    d. Networks. (e.g. managed clinical networks)
    e. Frameworks (e.g. Gold Standards Framework - GSF)
    f. Programmes (e.g. Ontario PCIP)
    g. Collaboratives (e.g. Quality improvement, The New York Palliative Care Collaborative)
    h. Targets and incentives
    i. Guides/checklists/pro-formas
    j. Training/education
2. Roles & relationships (ROLE)
    a. Healthcare Professional (HCP) to other HCPs, both within and between teams.
    b. HCP to patients or informal carers.
    c. HCPs and non-healthcare professionals such as lawyers, social workers, housing officers and so on.
    d. HCPs and advocacy groups such as charity organisations.
3. Modes of communication (MODE)
    a. Direct synchronous: 3a
    b. Mediated synchronous: 3b
    c. Direct asynchronous: n/a
    d. Mediated asynchronous: 3c
4. Generalist or specialist activities (GEN)
    a. Generalist to Generalist: generalist (4a)
    b. Generalist to specialist: generalist versus specialist (4b)
    c. All: all (4c)

Sixty articles were included in this review: 40 research, audit or evaluation; 13 reviews and seven related studies. They covered work conducted in the UK, US, Canada, Australia, the Netherlands and Belgium. The original studies comprised pilot and feasibility studies, RCTs, surveys, record reviews, case studies of networks and qualitative studies and focus groups. Measurement items were varied and included patient satisfaction, symptom control, service usage data including use of emergency visits to hospital, inpatient days, use of hospital beds in the last three months, feedback from professionals, carer burden, costs, and compliance with standards.

“Community matrons” and heart failure and COPD nurse specialists were the most commonly involved professionals within these papers. Other studies involved GPs or hospital staff, including surgeons, oncologists and ICU teams. Patient groups who could be identified as being involved included all with advanced illnesses (12), cancer (10), heart failure (5), the elderly (3) and others including COPD, patients in intensive care, terminally ill patients with cancer and trauma patients.

Organisational elements identified included the use of keyworkers (9), shared care or partnerships (5), frameworks such as the Gold Standards Framework (3), integrated care pathways (2), networks (2), programmes (2) and other collaborative and organisational developments. With respect to roles and relationships around half of the studies focussed on the relationship between healthcare professionals, some within and others between teams. Fourteen included relationships to increase coordination between professionals and patients or their informal carers. A few increased coordination with non-healthcare professionals such as social workers, housing officers or advocacy groups. Most of the studies related to improving face-to-face communication although some focused on the improvement of mediated synchronous communication (e.g. use of telephones or computer networks) and also a number were mediated asynchronous (creation of plans or frameworks or record sharing).

We found 33 studies aiming to improve generalist to generalist communication (for instance primary care and oncology or the promotion of the GSF in a practice) although some of them were mediated by specialist palliative care. We also found a number of examples where specialist palliative care worked with generalist care to improve generalist palliative care such as in case-conferencing, with heart failure specialist nurses, and with specific wards in hospitals.

This information is summarised in tables 5-7 below.

**Table 5. Primary research, audit and evaluation**

| Author and year of publication | Type of study/ audit | Study outcomes (where given) | Professional groups | Patient groups | ORG | ROLE | MODE | GEN |
|---|---|---|---|---|---|---|---|---|
| Addington-Hall 1992(52) | RCT | Presence and severity of physical symptoms, Satisfaction with services, carers problems | Nurse coordinators | cancer | 1a | 2b | 3a | 4a |
| Aiken 2006(60) | RCT | Physical/mental functioning (measured by the SF-36TM), ED visits | Nurse case managers | COPD, CHF | 1a | 2b | 3a | 4a |
| Bellamy 2006(61) | Evaluation | Use of case review process as a proactive learning tool leads to evidence of improved communication in multiprofessional teamwork. | Hospice and community teams | Hospice clients | N/A | 2a | N/A | 4a; 4b |
| Boyd 2009(62) | Qualitative | Participants confirmed the value of a key health professional coordinating care. | All associated with heart failure. | Advanced Heart failure | 1a | N/A | N/A | 4a; 4b |
| Brazil 2009(63) | Survey | Statement relating to coordination, i.e., "Information sharing within organization addresses patient needs". | Program Administrators | Cancer | 1f | 2a | all | 4a |

| **Author and year of publication** | **Type of study/ audit** | **Study outcomes (where given)** | **Professional groups** | **Patient groups** | **ORG** | **ROLE** | **MODE** | **GEN** |
|---|---|---|---|---|---|---|---|---|
| Burnod 2011(64) | Evaluation | Whether a patient's wishes were respected | emergency HCP; palliative care network professionals | all | 1d | 2a | 3c | 4b |
| Dale 2009(65) | Survey | 35 organisational and clinical processes; self-rated assessments of quality | General practice staff: GPs with an interest in palliative care, District Nurses, palliative care nurses | N/A | 1a; 1e | 2a | 3a | 4a |
| Daley 2006(66) | Audit | Service data, e.g .Referral demographics, number. of patients attending support group. Qualitative data also collected on benefits of the support group. | Community based heart failure nurse specialists and staff from specialist palliative care services | Heart failure | 1a; 1g | 2b | 3a | 4b |
| Dudgeon 2007(67) | Report | A regional network of organisations created a quality improvement project, which disseminated common symptom assessment tools, collaborative care plans, and evidence-based guidelines across the continuum of care. Resulted in better documentation of palliative care needs | All involved in local care area. | Cancer | 1b; 1f | 2a | 3a | 4a; 4b |

| **Author and year of publication** | **Type of study/ audit** | **Study outcomes (where given)** | **Professional groups** | **Patient groups** | **ORG** | **ROLE** | **MODE** | **GEN** |
|---|---|---|---|---|---|---|---|---|
| Dudgeon 2008(68) | Evaluation | Implementation of common assessment tools, collaborative care plans, and symptom management guidelines across health sectors within Quality Improvement programme can result in some increased documentation of symptoms and efficiencies in care. | All associated with local care area | All | 1b; 1f | 2a | 3a | 4a; 4b |
| Dudgeon 2009(69) | Evaluation: Intervention | Feedback from healthcare professionals - focus groups and survey data collected to capture feedback | Health professionals providing direct care | Cancer | 1b;1f | 2a | 3a | 4a; 4b |
| Engelhardt 2006(70) | RCT | Satisfaction with care communication; advance planning; consistency of care; healthcare costs. | Care Coordinator | All | 1a; 1f | 2b | 3a | 4a; 4b |
| Goodridge 2010(71) | Review | No. of written medical orders; documentation of care plan discussions | Not specified | All | NA | 2a | all | 4a |
| Gould 2007(72) | Intervention | apply quality improvement methodology to palliative care services. Substantial improvements were noted in most of the team projects (advance care planning, pain, family support, coordination of care), | Healthcare providers in NY city. | All | 1g; 1d; 1f | 2a | all | 4a; 4b |

| Author and year of publication | Type of study/ audit | Study outcomes (where given) | Professional groups | Patient groups | ORG | ROLE | MODE | GEN |
|---|---|---|---|---|---|---|---|---|
| Groot 2005(54) | Qualitative | Significant barriers to palliative care in the community related to theorganization of care and compartmentalization in healthcare. | GPs | All | NA | 2a | all | 4a |
| Groot 2007(55) | Survey | Communication; organisation and coordination of care; knowledge and expertise; integrated care; time for relatives. | GPs | All | NA | 2a | all | 4a |
| Hall 2007(73) | Pilot Intervention | Perceived continuity of care; inter-professional collaboration; physician time on floor | Palliative care team in hospital palliative care unit. Nurses, physicians. | All | 1b | 2a | 3a | 4b |
| Hannon 2011(74) | Qualitative | Evaluation of a financial incentive to add patients to practice palliative care register. The indicator was not deemed appropriate by professionals involved for incentivization due to concerns about incentivizing an isolated, single issue within a multi-faceted, multi-disciplinary and complex topic | GPs; community nurses; practice managers; IT experts | all | 1h | na | na | 4a |
| Kaasalainen 2011(75) | Survey | job satisfaction | Community nurses | all | na | 2a | na | 4a |

| Author and year of publication | Type of study/ audit | Study outcomes (where given) | Professional groups | Patient groups | ORG | ROLE | MODE | GEN |
|---|---|---|---|---|---|---|---|---|
| King 2010(76) | Qualitative | District nurses (DN) saw themselves as having a pivotal role, often coordinating other services. community matrons agreed with the importance of the DN role, but had doubts about whether DNs had the capacity or skills to provide genuine case management. | District nurses and community matrons | All patients admitted | NA | 2a | NA | 4a |
| Lawson 2009(56) | Audit | Emergency Department (ED) visits | | All | | | no data | 4b |
| Machare 2009(77) | Feasibility study | No. of patients taking part; no. of MDTMs held. | ICU staff | Patients requiring ventilation for five or more days in an ICU. | | 2a, 2b | 3a | 4a |
| Main 2006(78) | Pilot study | Improving documentation; reducing variability in identifying and supporting patients | Generalists | Elderly | 1c | 2a | 3c | 4a |

| **Author and year of publication** | **Type of study/ audit** | **Study outcomes (where given)** | **Professional groups** | **Patient groups** | **ORG** | **ROLE** | **MODE** | **GEN** |
|---|---|---|---|---|---|---|---|---|
| Marshall 2008(79) | Intervention | To implement a model of shared care to enhance family physicians' ability to deliver palliative home-care in the community. Participants reported improved communication, effective interprofessional collaboration, and the capacity to deliver palliative home-care. | GPs, specialist palliative care team. | All patients accessing services | 1b | 2b | 3a | 4a |
| Michiels 2007(80) | Qualitative longitudinal | Patients identified barriers to continuity primary end-of-life care such as lack of informational continuity, time and of GPs' initiative. | GPs | Terminal cancer | NA | 2b | 3a | 4a |
| Morin 2007(81) | Qualitative | A case study of the local implementation of an integrated network in palliative care. Important effects included improved interdisciplinary collaboration, and more efficient circulation of information between care settings, | All involved in the network | All | 1d | 2b | all | 4a; 4b |

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| Author and year of publication | Type of study/ audit | Study outcomes (where given) | Professional groups | Patient groups | ORG | ROLE | MODE | GEN |
|---|---|---|---|---|---|---|---|---|
| Mosenthal 2008(82) | Intervention | DNR orders - when introduced; withdrawal of life support; ICU length of stay. | ICU physicians | Trauma patients admitted to ICU | 1e | 2b | 3a | 4a |
| Penrod 2007(83) | Intervention | Number of patients who received consults | PC Director, PC Coordinator | Veterans | 1a | 2a | 3c? | n/a |
| Ray 2006(84) | Intervention | Implementation of educational, environmental, clinical, and communication interventions designed to maximize indicators of improved palliative care in a community hospital intensive care unit (ICU). Intervention changed the daily nature of discourse in the intensive care unit among staff and between the staff, patients, and families. | ICU staff | All attending ICU | 1a | 2a; 2b | 3a | 4a |
| Strachan 2009(57) | Survey | Patient rated 'Importance' of and 'satisfaction with' various aspects of end-of-life care. | NA | 0 |  | 2a; 2b | 3a; 3b | 4a |

| **Author and year of publication** | **Type of study/ audit** | **Study outcomes (where given)** | **Professional groups** | **Patient groups** | **ORG** | **ROLE** | **MODE** | **GEN** |
|---|---|---|---|---|---|---|---|---|
| Tilden 2009(85) | Qualitative | Grounded theory approach used to identify salient themes | Surgeons | Trauma patients | NA | 2a | 3a | 4a |
| Treece 2006(86) | intervention | Description of a multifaceted, nurse-focused, quality improvement intervention based on self-efficacy theory applied to changing clinician behaviour in ICU. No outcomes reported. | Nurses, physicians | ICU patients | 1a | 2a | 3a | 4a; 4b |
| Twaddle 2007(87) | Review | Compliance with 11 key performance measures derived from practice standards. | Hospital staff | All | NA | NA | NA | 4a |
| de Vogel-Voogt 2007(88) | Qualitative | Problems in end-of-life care included communication, difficulties in coordination. Comprehensive and interdisciplinary end-of-life care may address patients' needs, but it is a challenge to optimal communication among disciplines and between caregivers and the patient. | GPs | 128 patients with incurable cancer. | NA | 2a, 2b | NA | 4a |

| **Author and year of publication** | **Type of study/ audit** | **Study outcomes (where given)** | **Professional groups** | **Patient groups** | **ORG** | **ROLE** | **MODE** | **GEN** |
|---|---|---|---|---|---|---|---|---|
| Walsh 2010(89) | Qualitative | Semi-structured individual interviews and focus groups identified barriers to cancer care coordination. These included recognising health professional roles and responsibilities, implementing comprehensive multidisciplinary team meetings, transitioning of care: falling through the cracks, inadequate communication between specialist and primary care, inequitable access to health services and managing scarce resources. | Health professionals involved in providing cancer care. | Cancer | NA | NA | NA | 4a |
| Woodhouse 2009(90) | Qualitative | Confusion around role, skills, communication, care planning and coordination of care within a shared care model are creating barriers to effective sharing of care. | Nurses in a rural setting. | All | 1b | 2a | NA | 4a |

| Author and year of publication | Type of study/ audit | Study outcomes (where given) | Professional groups | Patient groups | ORG | ROLE | MODE | GEN |
|---|---|---|---|---|---|---|---|---|
| Wotton 2005(91) | Qualitative | Registered nurses' (RNs') perceptions of factors influencing care for patients in the palliative phase of end-stage heart failure (ESHF). According to participants, the care of patients with ESHF is dominated by a focus on symptom management with a perceived deficit in other aspects of palliative management. Key mitigating factors against quality palliative care for this population included the difficulty in recognising ESHF and reluctance by physicians to negotiate end-of-life decisions. | Nurses in an acute setting | All | No data | No data | no data | 4a |

**Table 6. List of reviews**

| Author | Results / discussion | Professionals | patients | GEN |
|---|---|---|---|---|
| Bomba 2011(92) | Recommendations are made for research on education and training of social workers, and investigation of the role and influence of systems in shaping social work involvement in end-of-life and palliative care. | Social workers | all | 4a |
| Chan 2010(93) | Cochrane Review of end of life pathways. 920 potentially relevant titles, but no studies met criteria for inclusion in the review. Authors' conclusions Without further available evidence, recommendations for the use of end-of-life pathways in caring for the dying cannot be made. |  | All | 4c |
| Devlin 2009(94) | Review of role of home-care workers in caring for patients at home. Negative aspects of the role including lack of continuity of care and poor quality of communication with other services were identified. | Home-care workers | All | 4a |
| Dy 2008(95) | Eight of 13 studies concerning collaboration and consultation interventions showed a significant effect on satisfaction. Conclusion that different types of palliative care interventions can improve satisfaction, but it is often not included as an outcome. | Not specified | All | 4c |
| Han 2010(96) | Lack of data on the extent to which end-of-life care is coordinated between oncology and primary care physicians. Preliminary evidence suggests that coordinated care improves health outcomes. | NA | All | 4c |
| Heffner 2011(97) | Patients with COPD benefit from better integration of palliative and disease-specific care throughout the course of their disease from diagnosis to death. Pulmonary rehabilitation may provide a platform for coordinating integrated care. | Respiratory specialists; pall care specialists | COPD | 4a; 4b |

| Author | Results / discussion | Professionals | patients | GEN |
|---|---|---|---|---|
| Lawson 2007(98) | Social workers' role varies due to differences in organisation of the care team in hospital as opposed to home and hospice settings. Coordination is led by either a consultant in hospital but possibly by a nurse or palliative care specialist in home/hospice settings; patients may experience this as lack of continuity. | Social workers | All | 4a |
| Lorenz 2008(99) | Strong evidence supports multicomponent interventions to improve continuity in heart failure. Moderate evidence supports advance care planning led by skilled facilitators who engage key decision makers. Many critical issues lack high-quality evidence. | NA | All | 4c |
| Masso 2009(100) | The importance of a common clinical information system. Coordination required specific person designated to coordinate - usually a nurse. | GPS and other community based health providers | All | 4a |
| Mularski 2007(101) | The most robust measures identified were in the care of symptoms, quality of life, and satisfaction. Significant gaps existed in continuity of care, advance care planning, spirituality and caregiver well-being. Conclusion that most measures have not undergone rigorous development and testing. | NA | All | 4a |
| Reynolds 2010(102) | The framework's successful implementation can improve staff confidence and team work, enabling them to deliver more effective home based care, aligned with patient and carer preferences, to achieve the best quality of life, death and bereavement. | GPs; nurses | all | 4a |
| Widera 2009(103) | Findings demonstrate that institution of a comprehensive care plan at discharge reduces the high rates of readmissions and death seen inpatients with heart failure. | Hospital staff | Heart failure | 4a |
| Wilson 2008(104) | 4 essential components for a best practice integrated EOL care model for Canada were identified: (a) universality; (b) care coordination; (c) assured access to a broad range of basic and advanced EOL services and (d) EOL care provision regardless of setting. | NA | All | n/a |

**Table 7. Related studies**

| Study | Type | Results/discussion | Professionals | patients | GEN |
|---|---|---|---|---|---|
| Alsop 2010(105) | Service development | Development of a guide to enhance collaborative working: | Palliative care nurse specialists and community matrons | Non-cancer | 4a; 4b |
| Bainbridge 2010(106) | theoretical | Realizing palliative patients' needs for complex packages of treatment and social support, in a seamless, cost-effective manner, are major drivers of the impetus for network-integrated care. | all professionals who might be involved in a palliative care network. | palliative; all | 4c |
| Davidson 2010(107) | review | Patients with symptomatic chronic heart failure should be managed in collaboration with a multidisciplinary heart failure program. | Heart failure specialists; generalists | Heart failure | 4a; 4b |
| Dobrof 2011(108) | description | Description of The Collaborative for Palliative Care in Westchester County, New York. | All professionals | all palliative | 4b |
| Mularski 2006(109) | consensus process | A consensus group proposed 18 quality measures to assess the quality of palliative care for the ill and injured. | n/a | All | n/a |
| Schneider 2010(110) | Modified Delphi | Six targets for public health initiatives to improve palliative care in Germany included: (2) Co-ordinating healthcare for people in the last phase of life; (3) Establishing cooperation among healthcare professionals and disciplines; | Experts in public health and palliative care | All | 4a; 4b |

| Study | Type | Results/discussion | Professionals | patients | GEN |
|---|---|---|---|---|---|
| Weissman 2010(111) | review | Review of a checklist approach by a consensus panel. Implementing a checklist approach to screening patients for unmet palliative care needs by hospital staff engaged in day-to-day patient care can identify a majority of such needs, | No information | n/a | 4a |

**Four categories of overlapping interventions designed to enhance coordination were identified:**

1. the use of keyworkers or nominated coordinators;
2. shared care or collaborative models;
3. integrated care pathways;
4. and a group comprising various organisational and regional structures such as networks, frameworks, programmes and collaboratives.

These identified categories aid the description of healthcare provision models that are currently used in the provision of palliative care by generalists.

**Keyworkers or nominated coordinators.** The most commonly reported organisational interventions identified were the establishment of nominated coordinators. Coordinators are an example of keyworkers including for example case managers , 'ambassadors,' 'champions' and others whose job it is to either ensure that professionals work together or that patients have a professional who is their point of contact with the health system. In many cases coordinators perform both roles.

In one such example community palliative care nurse specialists encouraged collaboration between heart failure specialist nurses in the community with specialist palliative care.(112) The author argued that communication both between and within teams is the key to efficient collaboration and this was meant to help achieve this. A similar approach was reported by Daley et al although the heart failure specialist nurses remained as 'keyworkers' and a patient support group was initiated.(66) King et al explored the role of community matrons as coordinators and their relationship with District Nurses.(76) The results were ambivalent with workers in both roles unsure about the value of the other. Typical also was a study by Han et al in which coordination between oncologists and primary care physicians was assessed as follows: "preliminary evidence suggests that coordinated care improves health outcomes. However, more work needs to be done to corroborate these findings, and many unanswered questions remain."(113) Although the authors take great care to rigorously define terms such as "end of life" and "oncologist" they do not define coordination.

Many interventions used coordinators as part of general reorganisation. Engelhardt et al reported a randomised trial in which participants were assigned to a coordinator. The participants who were assigned reported greater satisfaction with care and communication, were more likely to complete or revise an advance directive and there was no change in mortality.(70)

**Shared care or collaborative models.** Interventions which did not appear to use a specific coordinator often drew on a shared care or collaborative model. For example a *health collaboration model* to describe the interactions between pharmacists, patients and patients' prior experiences with a particular drug.(114) This covered collaboration between HCPs and between HCPs and patients/carers. Other examples include shared care with social workers. Marshall et al (79) report a shared care model where an inter-professional palliative care team worked with physicians at three primary care practices. The physicians appear to have appreciated the intervention but there was no indication of improved patient outcomes.

The most common method of collaboration was the use of team meetings and case reviews. (77, 115) Bellamy et al (61) claimed that the "case review process was a proactive learning tool has shown evidence of improved communication and challenged thinking in relation to changing practice." Groot et al's investigation of obstacles to palliative care in the community found that GPs who participated in case reviews perceived fewer barriers to the provision of palliative care.(55) Masso reported that case reviews were a commonly used technique for improving the provision of palliative care in rural communities but noted that "the terms 'integration' and 'coordination' were used frequently but without clear definitions" meaning that it was not possible to analyse the role such reviews played.(100) Machare et al reported on an experiment with a "multi-disciplinary family meeting program" to enhance discussions between professionals and family members of patients requiring mechanical ventilation in ICU and claimed that they improved communication and understanding between patients' family and the treating team.(77) Collaboration between physicians and nurses may lead to greater continuity of care.(73) A common group of collaborative interventions featured attempts to incorporate a specialist palliative care team member(s)in particular settings such as hospitals in general, or at cardiology or respiratory, dementia or renal clinics or to attend practice MDT meetings or ICU.

**Integrated Care Pathways**.(ICPs) The above attempts at coordination or collaboration focus on synchronous, usually face-to-face techniques through the use of either a keyworker who manages the coordination/collaboration or through meetings between teams, sometimes including patients and families. There is however a different strand of approach, one in which the coordination comes from following a particular process over time. Such interventions are generally known as pathways, for example the Liverpool Care Pathway. A Cochrane review by Chan & Webster claimed "there is insufficient data at present to make recommendations regarding the use of such end-of-life care pathways for the dying."(93) However Cochrane reviews focus on randomised controlled trials, a method little used in end of life studies.

ICP are assumed to lead to greater coordination and require collaboration but there is little evidence that ties increased coordination and collaboration to outcomes.(78, 116-119) For example, Main et al report on the development of an ICP for all patients with advanced life-limiting illness but went no further than claiming that it is 'believed' that the pathway may reduce variation in standards of care for people in their last year of life.(78) There may be a counter-argument that pathways with their 'production line mentality' may decrease direct collaboration as each specialist focuses on their tasks within the pathway, although no study was found which explores this hypothesis. See Alsop, however, as one possible contradiction to this hypothesis.(105)

Interventions that focus on action at a certain trigger point can be seen as broadly similar to aspects of pathways. Within the literature there is some evidence for interventions triggered by discharge from hospital. For example Brody et al report that "Patients receiving an inpatient Palliative Care Team consultation are more likely to receive follow-up services upon discharge from the hospital. These services likely contribute to better quality of care and financial benefits, and warrants further study, especially considering the current focus on healthcare efficiency and quality," (120) Widera et al examine the potential for palliative care assessments at hospitalization for heart failure and claim that it would positively impact on health and quality of life.(103)

In primary care the identification of trigger points to commence care frameworks is being increasingly stressed to address the under-recognition of patients for palliative care, but no trials of this approach in primary care were found.

**Various organisational and regional structures**. Networks,(67, 68, 81) collaboratives,(72) frameworks,(62, 65) and integrated services (56) are variously described though without a consistent nomenclature. All of the examples identified suggested that the structure chosen would increase coordination though evidence for whether this actually happened or what outcomes might have been facilitated by the increased coordination is weak. It should be noted that frameworks and programmes can be regarded as broadly similar in that they both consist of a series of processes that are meant to be undertaken by currently existing organisations. So for example the GSF is a series of processes that are meant to be followed by currently existing health service providers.

A particularly widespread example of a programme-based approach is the Gold Standards Framework (GSF) now used in most general practices in the UK and increasingly being adopted internationally. The GSF programme includes the use of coordinators to better organise and champion end-of-life care in each primary care practice and regards coordination of patient care as one of its aims. Dale et al (65) report on this and note that "aspects of process related to coordination and communication showed the greatest change." However it was again not possible to ascertain the role this played in the “substantial improvements in process and quality of palliative care” that are reported. This approach has been modified for nursing care homes (GSFCH) where a decrease of around 50% of inappropriate admissions to hospitals is claimed.(121) The introduction of advance care planning is central in the GSF and is advocated by various national policies, but is little documented in UK primary care. A practice-based educational intervention to promote ACP in practice in Scotland had little effect as primary care teams found it difficult to raise this subject with patients.(122)

Lawson et al report on an integrated model of palliative care services in Halifax, Nova Scotia(56) and suggest that “There is some evidence to suggest the introduction of the integrated service model has resulted in a decline in [Emergency Department] visits among PCS patients,” however they caution over whether the results will persist.

An evaluation of the Palliative Care Integration Project in Ontario, Canada, which was an attempt at creating an integrated set of networks, revealed a decrease in emergency admissions and deaths in acute care and an increase in documentation of symptoms which may be due to changes in coordination.(69) In general, emergency admissions have been one of the few outcomes to be referenced in different projects, giving it some weight as a possible outcome measure. (56) However as Lorenz notes in a systematic review of evidence about interventions to improve palliative and end-of-life care “many critical issues lack high-quality evidence.”(99)

## *4.3 Discussion*

A considerable body of literature was identified and reviewed but little to no literature assessed any ‘increase’ in coordination or provide a rationale for how this would lead to the desired outcomes.(55, 100) Instead an a-priori assumption that increasing coordination or collaboration would lead to improved quality or delivery of care was evident. Most studies reported that efforts to improve coordination improved outcomes such as physical functioning, increased communication, increased continuity of care and the increased documentation of various processes including advance care planning. The Cochrane Review showed no evidence that end of life pathways improved coordination but found that a care coordinator or care worker often had a positive effect on coordination. In general, though, it was unclear what the strength of effect or mechanism for causality was.

The review papers are largely unclear about how improvements have been measured. Lack of coordination and/or collaboration is routinely identified as a barrier to good palliative care. For example the National Institute for Health and Clinical Excellence (NICE) manual, *Improving Supportive and Palliative Care for Adults with Cancer* states “Assuring that care is well coordinated at strategic and operational levels will lead to improved quality of life for patients and higher satisfaction with services”(123) (p36). There is though little attempt to theorise or describe what constitutes successful coordination or collaboration. For example, Gysels & Higginson identified thirteen studies of interventions to improve the organisation of services for patients who were terminally ill compared with the usual care but it is difficult to differentiate between organisational changes in general and changes to coordination or collaboration in particular.(53)

Addington-Hall et al show that an attempt to improve coordination appeared to have no great effect on outcomes,(52) but some of the secondary effects were seen as gold standard evidence for the benefits of increased coordination by the Department of Health in the UK.(124) Conversely Aiken et al show distinct positive effects (60) while Engelhardt et al found greater patient satisfaction in a program that aimed to coordinate care more effectively (70).  Internal coordination and collaboration processes appear to have increased greatly with GSF but external collaboration (e.g. meetings between practice team members and outside agencies) showed less increase. Dudgeon et al argue that a regional quality improvement programme which directed various currently existing resources and organisations improved coordination and integration again without providing any way of measuring this improved coordination and integration.(69) However, as Han et al stated in discussing coordinating end-of-life care among oncologists "preliminary evidence suggested that coordinated care improves health outcomes. However, more work needs to be done to corroborate these findings, and many unanswered questions remain."(113)

## *4.4 Conclusions*

The lack of metrics to directly measure coordination or collaboration mean it is not generally possible to determine whether a particular intervention actually increased coordination or collaboration. Whilst indirect measures such as rates of hospital admission or deaths in preferred place might be appropriate, it is unclear how they causally relate to coordination and collaboration. Without robust and valid measurement, it is impossible to confirm a causal link between improvements in coordination or collaboration gained and health outcomes measured in the literature. We have defined and categorised models of coordination and collaboration in generalist end-of-life care, and reviewed the outcomes that have been measured in such studies. It may be useful to agree a set of measurable proxy outcomes resulting from coordination of care. There is enough evidence and expert support to justify further studies of increasing coordination while carefully assessing the degree of increased coordination and other outcomes.

# 5 Edinburgh case study

## 5.1 Setting

The setting is a large, urban teaching hospital with one of the busiest Accident and Emergency departments in Scotland. A&E is integrated with a "combined medical and surgical assessment area" (CAA) where patients can be assessed and treated for up to 24 hours. The focus of this case study was the management of patients with palliative care needs (whether formally identified by a health professional or not) in the CAA and thereafter in the community.

### 5.1.1 Site negotiations

One of the research team, a consultant in palliative medicine at the hospital, was able to approach the clinical lead and senior nurse. The appointment of a nurse manager who had worked at the unit previously as the project management fellow aided access to the site and communication with staff.

### 5.1.2 Ethics

As at all sites, project posters and flyers were displayed but the large number of staff (around 150) working directly in the CAA as well as many staff passing through made it impossible for the researcher to consent them individually. We estimated that around 2,000 patients and their relatives or friends would visit the CAA during the ethnographic work. The speed and intensity of the care and the stressful nature of an unplanned hospital admission with an acute illness necessitated that the researcher be aware of the need to balance being unobtrusive enough to avoid potential disturbances to care delivery while remaining visible enough to be easily accessible. This balance was achieved with the researcher quickly becoming well known and accepted by the key staff.

## 5.2 Methods

An initial familiarisation period led into a series of specific ethnographic observation techniques. Once the observations had concluded, the researcher sought to recruit patients who were in the CAA or had received care there and moved onto a ward. The researcher maintained informal contact with the staff until the interviews were complete and a Significant Event Analysis (SEA) could be held.

### 5.2.1 Ethnographic observations

The ward is a complex physical space with six bays, four side rooms and many staff rooms so observing the entire ward at once was not possible. Initial observation consisted of spending a half-day in each major location in order to familiarise the researcher with the activities: "stationing."

Once familiar, fieldwork focused on shadowing (in order to understand how staff moved around the unit and observations of routines such as ward rounds and shift hand-overs. Most interactions with staff were through informal questions rather than formal interviews. The rapid pace of activity at the site meant that formal interviews would be interrupted or too disruptive. A small number of staff in different roles participated in recorded interviews throughout the project focusing on the organisation of their work, communication with colleagues and professionals in different settings and their perceptions of coordination in general and specifically in relation to palliative care.

### 5.2.2 Serial interviews

Patients were recruited in two ways.

1. After the period of ethnographic observation, the researcher remained on the ward and asked appropriate staff to identify potential participants. First the staff member was asked the "surprise question" ("would you be surprised if this patient died within the next 12 months?") about any patients he or she had "seen today." If any patients were mentioned then further details were requested as to why. For example, the researcher would attempt to clarify if there was there a particular health condition that triggered the answer, issues around age or frailty or social context or issues around multiple recent admissions. These were based on criteria developed in the SPICT tool. As the researcher was not a clinician, he occasionally checked these matches with the management fellow (a nurse manager) for clinical input. Provided the patient appeared to match the criteria and represented a current gap on the sampling grid (see annex 4), the researcher then contacted the nurse on the ward with the most direct knowledge of the patient, ascertained the patient's current condition, checked whether the patient was a valid potential participant and, if appropriate, asked the nurse to contact the patient about their willingness to be approached to participate.
2. Recruitment through CAA was time-consuming and frequently ineffective due to rapid throughput of patients so a second approach was developed. The management fellow arranged for the researcher to make daily contact with the charge nurses on those wards where eligible patients from CAA are likely to be admitted. These senior nurses helped to identify and approach potential interviewees in the same way as in CAA.

## 5.3 Results

### 5.3.1 Ethnographic observations

Stress, speed and complexity were the three dominating factors. For 24 hours a day, seven days a week, 52 weeks a year, patients arrive in an endless array of distress. Some dying, angry, confused, resigned, each with their own story. Admissions ranged from the completely idiosyncratic, such as man who had swallowed someone else's false teeth, to the many frail, elderly people who had fallen or become confused and now lay unsure of how they had arrived. The complexity and speed of activity made it a bewildering and somewhat intimidating environment for researcher and patient alike.

Trying to piece together the varied observations was challenging because the structure of the unit and its continual operations made it hard to gain an overview. With time, though, repeated concerns, activities and events emerged, making it possible to inventory issues pertinent to coordination and collaboration as expressed by staff or observed in action.

The unit's events contained both imposed and emergent routines. Imposed routines included the morning and afternoon ward rounds, the charge nurse meeting, ward manager nurse meeting and a myriad of other meetings for the various staff members. These activities structured the day and dictated the flow of patients into, out from and around the unit. All of them however were dictated by a single dominant imperative: "the flow." Staff constantly referred to "the flow" as meaning the throughput of patients. Their activities were based around finding space in the area to accept new patients, complete assessments and finding the quickest, most effective ways to get the patient moved on. Ideally it would be a seamless set of activities In practice, like the metaphor it suggests, there were dams, backwaters, white-water rapids, floods and droughts.

For example, the ward rounds focused on one primary subject: does the patient need admission or can they be discharged. The answer to that question was based on a mix of information:

- the patient's present condition;
- the patient's previous medical history and home life;
- the availability of beds elsewhere in the hospital (or associated hospital).

The level of information about the patient's present condition, i.e. the acute reason for them attending the hospital as an emergency, depended on which assessments had been completed. Information about the patient's previous medical history and situation at home (i.e. if discharged could the patient function at home) depended on how effectively the admitting junior doctor had accessed patient records, the presence of an admission letter from the GP and whether the patient had been able to answer questions. After each ward round, patient information was presented on white boards while the duty consultant took triage decisions and nominated each patient for discharge home, admission to hospital or to wait for the results of assessments. Although some patients were discharged or admitted on an ad-hoc basis, for most patients it was the ward round that decided their destination. This meant that the rest of the staff built their jobs around these twice daily, decision making points.

### Staff interviews

The ethnographic observations informed the choice of subjects for further exploration in the staff interviews and the serial interviews with patients.

The primary focus of the staff on the ward was internal; the staff worked mainly with the patient in front of them in a reactive manner. What assessments needed doing? Which was the best bed? What was the discharge plan? A common description of their activity that staff gave me was that of "detective work." As one pharmacist said, *"in my next life I'm going to be a private investigator."* Staff routinely considered themselves to have a partial understanding of a patient's condition and circumstances and lacked easy access to information about it. Therefore they worked reactively with what they knew and attempted to deduce the rest through professional expertise and, where possible, making phone calls.

### Flow driven

During the fieldwork, A&E was required to treat 98% of attendees within four hours. Those who cannot go home are sent to CAA. If there are no free beds in CAA, patients from A&E cannot leave. The bed flow manager of the day must therefore continually free up beds. This requires an average of four patients leaving CAA every hour. Those who can't go home have to be admitted to a ward which, of course, requires free beds on that ward.

If the flow stops, the system breaks.

The bed manager spends the day with two mobile phones, a clip board, several pencils and two erasers. For the day, he or she continually visits each bay in the ward checking the progress of current patients, chivvying staff to move people on, attends the ward rounds and advocates for patients to go home, calls the central flow managers at the hospital for updates on free beds, calls charge nurses on the wards that most commonly receive patients to see if any beds might have just become free or might be free soon. The next day, a different staff member from a group of about 4-6 bed managers will take it up. For all the stresses involved some (though not all) of the bed managers actively enjoyed the challenge and took pride in managing such a demanding but key role.

During my fieldwork I saw days where the system became badly congested, like a traffic jam on the motorway, for no reason other than under capacity to deal with the flow. At the end of one averagely busy day, a nurse said to me *"there's not a single nurse who goes home at the end of the day* *feeling that they have done a good job."* It was not a sentiment that was completely shared but it did shed a light on the demands faced by the staff.

**Identifying palliative care needs**

The speed and structure of the work meant that palliative care needs were not identified unless a patient was considered to be terminally ill and approaching the last days or hours of life. Such patients were described as needing "TLC" - tender loving care. If there were considered to be complicating factors then the specialist palliative care team would be contacted. Otherwise the main decision was whether the patient was well enough to be moved to another ward or not. If not, the aim was to keep the patient in one of the four side wards and provide end-of-life care there.

Talking informally with staff it was plain that palliative care was considered as simply another speciality, performed by members of another team. One nurse gave me a text-book answer about providing supportive care for all the needs of a person in the "last year or two of life" but for most, palliative care was about treating pain and cardiopulmonary resuscitation status.

Clearly there are significant issues about how supportive and palliative care needs might be identified and assessed in this context. Patients in the unit are constantly assessed by a variety of specialists, quizzed by junior doctors, and tested by nursing staff. Information coming into the unit is fragmentary and often inconsistent and in the vast majority of cases the patient is not known to the staff. Adding yet more information gathering or asking for more assessments seemed likely, with good reason, to be resisted. The hospital's specialist palliative care team considered that CAA staff were not readily able to take on more tasks relating to palliative care.

Attempting to identify or assess palliative care needs beyond TLC risks disrupting the flow at CAA. Care provision was inward focused, proactive and oriented around transition as quickly as possible through the unit. Yet staff were able to engage with basic palliative care identification when asked the "surprise question" and often seemed able to identify research candidates quite effectively, implying that the potential for identification and assessment does exist. In particular, some patients who had had multiple recent admissions were clearly known to some of the staff.

### 5.3.2 Serial Interviews

Forty patients consented to take part in the project but 50% were not able to take part in a first interview for a variety of reasons, such as dying or becoming too ill, chaotic home conditions, readmission to hospital, changing their mind or simply not responding to contact once home. Of the 20 who did not take part, a survey of death records showed that nine had died by the end of the interview process. One possible implication is that the patients who took part may have been less unwell than those who agreed but then didn't take part. Everyone who provided confirmed consent was given a number (1-40) but Table 8 below only summarises those who took part in at least one interview.

All the interviewees in this case study had recently had an upsetting and worrying experience or were still in the midst of one at the time of their initial interview. This meant that the longitudinal 'trajectory' of these patients had been disrupted by a crisis and then evolved from that event.

Table 8 below details the 20 participants. Ten were male, ten female; their average age was 74 (with a range of 56-87), and 12 lived with carers. We obtained a sample that broadly reflected the frequency of the long term conditions presenting to CAA, but excluded patients with moderate or severe dementia. Illness trajectories sampled included 11 with organ failure, nine frailty and two cancer trajectory; most had multimorbidity. Most presented to CAA due to collapse, confusion, fall, or shortness of breath. In total 46 patients and 28 carer interviews were completed. Most carer interviewers were performed with the patient present.

**Table 8. Serial Interview participants**

| ID | Age | Sex | Presenting comp | Main Conditions | Traj | Pat# | Carer | Car# | Status |
|---|---|---|---|---|---|---|---|---|---|
| E1 | 82 | M | Chest infection | COPD; heart failure, renal failure | OF | 1 | No | - | Dead |
| E2 | 76 | F | Chest infection | Heart failure, renal failure, diabetes | OF | 1 | E102 | 2 | Dead |
| E4 | 85 | M | Chest pain, SOB | Heart failure, Ischemic heart disease , mild dementia | OF | 3 | E104 | 3 | Alive |
| E5 | 86 | F | SOB | Pulmonary fibrosis, IHD, Paget's disease, hypothyroidism | OF, Frail | 2 | No | - | Dead |
| E6 | 66 | F | Collapse, UTI | Liver failure, diabetes, IHD | OF | 3 | No | - | Alive |
| E8 | 56 | F | Collapse, confusion | Neurological illness, polio, COPD, epilepsy | OF | 3 | No | - | Alive |
| E13 | 89 | F | Collapse | Unresponsive episodes, atrial fibrillation, hypertension, aortic stenosis | Frail | 3 | E113 | 3 | Alive |
| E15 | 58 | M | Mass abdomen | Pancreatic cancer | Cancer | 1 | E115 | 1 | Dead |
| E17 | 75 | F | Collapse, anaemia | Diabetes, hypertension | OF | 2 | No | - | Dead |
| E20 | 75 | F | SOB | Iischemic heart disease | OF | 3 | No | - | Alive |
| E25 | 70 | F | UTI | Multiple sclerosis | Frail | 2 | E125 | 2 | Alive |
| E26 | 71 | F | Chest pain, SOB | Parkinson’s disease, asthma | Frail | 3 | E126 | 3 | Alive |
| E27 | 68 | M | Falls, confusion | Alcoholism, prostate cancer, peripheral vascular disease | Frail | 3 | No | - | Alive |
| E28 | 87 | M | Collapse | Prostate cancer, renal failure, diverticular disease, mild dementia | Frail | 3 | E128,<br>E141 | 4 | Alive |
| E32 | 75 | M | Decreased mobility, dizziness | Mitral valve disease, | OF | 1 | No | - | Dead |
| E33 | 71 | M | Decreased mobility | Hypertension, atrial fibrillation, heart failure | OF | 3 | E133 | 2 | Alive |
| E34 | 85 | M | Fall | Hypertension, motor neurone disease, arthritis | Frail | 1 | No | - | Alive |
| E37 | 69 | M | Chest pain | peripheral vascular disease, Ischemic heart disease | OF | 3 | E137 | 2 | Alive |
| E39 | 60 | M | Fatigue | Multiple sclerosis | Frail | 3 | E139 | 2 | Alive |
| E40 | 87 | F | Falls | Renal failure, metastatic melanoma | Cancer, Frail | 1 | E140 | 1 | Dead |

Column headings: Presenting comp (presenting complaint at CAA), Traj (trajectories represented), Pat# (number of patient interviews), Carer (ID of carer(s) if present), Car# (number of interviews that carer participated in), status (whether the patients was alive or dead at the conclusion of the case study).

Abbreviations: OF – Organ Failure; SOB – shortness of breath; UTI – urinary tract infection

### Serial Interview themes

The themes emerging from the interviews are summarised in Table 9 below.

**Table 9. Themes from the serial interviews – Edinburgh**

| |
|---|
| **Information:** information participants received about their illness. |
| **Communication**: how patients and carers perceived communication between and within settings. |
| **Expectations**: of patients and carers in regard to the services they received, the care they received and treatment. |
| **Role:** the *carer's role;* the role of the *keyworker*, (professional who is the main coordinator for the patient's care) and other professionals perceived as important by patients/carers. |
| **Experiences**: of noticeably good or poor care from the perspective of a patient, carer or professional and **explanations** why this may have occurred. |

### Theme – Information

Participants reported lack of information about their condition(s), care planning and the role of palliative care.

With the exception of those who had cancer as a primary or secondary diagnosis or those who had a single, dominant condition, patients and carers were unsure about diagnosis, prognosis and treatments. Although patients and carers often had information about particular conditions, they generally did not appear to have a clear idea of the interplay of these, the relative effects of them or any concept that they might be receiving (or could be receiving) additional supportive care. On the whole, participants seemed to believe the multiple conditions that befell them were a consequence of getting older or simply being "unlucky."

Where information was shared successfully, the common factor seemed to be that the patient had a single condition (cancer or diabetes) with several services cooperating to manage information about management. *"I got in touch with the GP, with the diabetic nurse. They said that on the form, that if you were worried about your insulin at all get in touch, and they gave me a number in case I wanted to contact them. And then when I went in everything was explained to me." (E6 T1)*[4]

There was no indication of any systematic future care planning apart from two cases. One participant (E26) had a DNACPR form although it was 'lost' for the whole interview period. Another, the carer for E40, had had several conversations with the patient's GP about his mother's supportive and palliative care needs but the patient had already spent time in a hospice and was well known to palliative care specialists. *"I think the GP and [the hospice], had a*

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[4] Quotes are identified throughout the report by participant code and, in the cases of serial interviews, by the "T" number of the interview. E.g. the quote above is from patient E6 and happened at the first interview (T1).

*very good awareness of the case and were putting in place lots of things, and were speaking to mum about lots of decisions that would have to be made. Mum decided that there would be on her notes, do not resuscitate."* (E140, T1)

There were several reasons given for lack of planning, often focusing on it seeming inappropriate, unnecessary or the GP being too busy. "*I am quite happy to just float along as we are doing now. I remember a time when you could go to a doctor and talk to him and you know, just give him your worries and what did he think? Can't do that now because they haven't got time."* (E13 T2)

Without information about options or communication with professionals, patients and carers made their own plans:

*Carer: Absolutely nothing, nobody has said anything to me about future care.*

*Patient: But we'll know, let's face it we carry on ourselves. You see I'm of the type of person that if you get awful ill and you can't manage. … I'm for Margo MacDonald, euthanasia. (E2 & E102, T1)*

One patient described feeling "daunted" by "sorting out files,"(E13) but many refused to engage with the prospect, "N*obody has ever said anything to me about [it] and I've never broached the subject cause I think like I'd rather be positive. I think 'I'm not going to get worse'.*" (E6 T1)

There was no indication that any of the participants possessed any information about palliative care (except for E40) whether generalist or specialist. No patient or carer brought up the term and there was no suggestion that it was known or considered to be relevant to them. On the few occasions the researcher felt it appropriate to introduce the term, knowledge about it was restricted to meaning that 'there was no cure.' In the following quote, a patient with advanced Parkinson's disease responds along with her carer.

*Carer: Well, I don't think there is a cure, let's put it that way. It is just trying to keep things at a level.*

*Patient: Palliative. There is no cure, so.*

*Carer: Well, they might come across something one of these days.*

*Patient: No. I don't know how much time I have got left. (E26, E126 T1)*

### Theme - Communication

Where information was available after a patient moved between care settings, such as a hospital discharge letter, it was often hard to decipher. "[*The GP] couldn't … read it and make it out either. He just sat and studied it." (E6 T1)* At the same time, participants assumed that their information was available to all parties concerned with their care, leading to confusion when professionals did not seem to have access to the facts on arrival in hospital. "*I had gone through them all before. What happens to that information? Who gets it? Why do you have to repeat it over and over again? There's no sort of, coordination at all. At least I don't think there is." (E13 T1)*

Communication can be seen as a proxy for coordination of care and planning. Communication outside of a normal consultation, was highly regarded. In the following case, a hospital admission had been avoided by a quick change of medication by the GP who then phoned to ensure that the prescription had been collected. *"[The GP] phoned, he said he would phone Boots to get a prescription in, and he phoned me at night to ask me if I had got the prescription alright. And the next day, in the middle of the day, he phoned to ask how [Patient name] was, which I was very impressed with, cos that doesn't happen very often. (E114 T2)*

There was also a widespread belief that GPs would rather talk on the phone than meet face-to-face, leading patients to be unsure about when to contact them for 'important' matters. "*Even when you make an appointment, they would rather just speak to you on a phone. Please don't make an appointment unless it is absolutely necessary. Well, what do you know is absolutely necessary?" (E20 T2) Another carer described it as care by "remote control." "So that is the only contact. No follow up, nothing. But it feels everything is by remote control. It is not as joined up as it should be. (E113 T1)*

It was not uncommon for both professionals and patients/carers to express a desire not to communicate. Professionals, especially GPs, believed that it was often better to avoid upset while participants and carers didn't want to 'bother' someone or simply didn't see it as an option. For example, the GP for patient E1 explained that "*I think our involvement has been quite peripheral. But if he, you know, if he has got a problem or he needs us, he uses us. But if he doesn't need us, then he doesn't bother us. That seems to be the way he wants it to be.*" (E303)

Communication that did occur seemed to be reactive and driven by events. In one case, a carer was told shortly before his wife died with renal failure and heart failure that she had been at risk of dying for over a year.

*Participant: [Her death] was totally unexpected. Dr XXX did say to me, just after Christmas when he had been up…. And going outside, he says, "she is on a knife edge, I hope you are prepared. It could happen anytime. I'd say, for the past year and a half." (E102 T2)*

### Theme - Expectation

The nature of this case study was that most participants were interviewed after a recent discharge from an emergency admission into hospital. Without fail, they expected that they would be contacted by their GP and were disturbed when, usually, this did not happen.

*Patient: But what happened was they sent a letter home, now nobody came up the first day. And well I would have thought that a doctor would be up right away, but no he (carer) had to phone. And he (GP) had a letter for it, but I think maybe they expected me to go down but I couldn't. He says 'you've been a very ill lady reading the letter.. But nobody else, nobody's been now. (E2 T1)*

There was some evidence of successful coordination, but such coordination was not noticed explicitly by participants because it was expected to be the norm.

*Carer: The GP's been in. She came in 2 days after he got discharged from hospital. You get a discharge letter from the hospital and you hand it in to your GP. And [the hospital] must have put on it for the GP to call in, because I had phoned to make an appointment and the receptionist said an appointment was already made for the doctor to come in. (E137 T2)*

**Theme - Role**

*Coordination managed by patient/carer*

Where a carer could be identified it was often clear that the carer took a major role in trying to navigate and coordinate the system for the patient. Where the patient had no such carer their daily life was more chaotic. One carer says:

*Eventually I phoned and made an appointment, because I wanted his blood checked to just to make sure that everything was alright. Because I had been told that the pills that he is on, sometimes, it can cause kidney problems. (E114 T2)*

Conversely, the presence of a carer could contribute to a lack of communication with health professionals. This carer, talking with the patient present, said, "*Carer: I personally don't want anybody to come in because we cope ourselves and the way we cope is because we co-operate with one another you know. The way I look at it is it's for better or worse isn't it?" (E102 T1)*

*Coordination managed by professional*

It was relatively rare to identify a professional who described themselves as a coordinator. One example was the GP of E32 (M 75) who appeared to have made additional house calls due to the patient lacking support. One practice (for patient E5, F 86) had a "vulnerable" list which meant that the patient received a house call once per month. The patient seemed to have no idea that this was unusual.

It was notable that patients often experienced changes in practice organisation as decreasing continuity and coordination. The impact of health service organisational change on patients and carers is probably under appreciated.

*Carer: There is no consistency in terms of seeing the same doctor all the time. And when you reach mum's stage of health and age, you don't want to have to keep repeating over and over So many changes, so many different doctors…. Each of them very considerate, but clearly clueless about the uniqueness of the patients. And the whole business of having to re-educate and re-inform each time you go in. (E113, T1)*

For one patient, a social worker played a key role.

*Patient: It was the social worker…. Initially, he didn't know what was involved, when he gave me his first care plan. I had to call him in and put him right sometimes. And after that he got in touch with the District Nurses and things like that. (E33, T2)*

*Role of home-care providers*

Home-care workers featured strongly, both positively and negatively, in the interviews. The CSRI data shows that the most common interaction with care services was with these social carers. The service was problematic in that it seemed to represent loss of autonomy of patients. When a degree of relational continuity (125, 126) was achieved it was valued highly but the perception was often of an unreliable and inconsistent service.

*Patient: I know it is difficult to get [home-care workers], because they are in very short supply. I have heard of people having to wait for quite a while for help. Some lady had to phone up wondering why the help hadn't come, and apparently the help wasn't well, and there was nobody else. So she just had to do without. (E14 T2)*

**Theme - Experience**

Experiences of noticeably good or bad care influenced subsequent patient/carer responses. Several patients expressed a wish not to go to a particular hospital or ward due to prior bad experience so they might hesitate to contact a professional if there was a risk of re-admission. There was a general perception of secondary care being noisy, disturbing and staff being too busy to perform their jobs properly. There were many accounts of perceived lack of care concerning alterations to life-threatening medication. A second major element was a perception of changes in primary care meaning that there is no "personal" GP leading to lack of a caring relationship. Conversely, some patients/carers differentiated older GPs who were hard to approach with younger new GPs who were more forthcoming.

*Patient: She's a breath of fresh air, as well. I mean, she was down, phoned her up about the hand and she was down within 2 hours. (E37 T2)*

Participants' **explanations** why particular experiences (whether directly experienced or reported) may have occurred informed their attempts to navigate the system and participate in the successful coordination of their care.

**Ageism** was a frequent explanation for lack of communication or attention. Patients and carers sometimes expressed the view that staff treat older patients poorly because they are old and not as important as young patients. Although this may not be accurate, the perception of it influenced patient/carer actions.

*Patient: "You know, when you turn 70, they forget you're alive. I find now when you go in, if you're old, they haven't got the same time for you. A friend of ours was saying, "there's nothing wrong with our brains although our bodies are breaking up." (E20 T3)*

**Lack of resources** was the most frequent explanation for failure of hospital care. A frequent expression was that the "nurses are great" but they don't have time to do their job properly. This was a huge deterrent to patients and carers who expressed profound distress about the possibility of going back into hospital. The daughter of patient E28 described several distressing events from admissions to a particular hospital. "*My dad hates [hospital 1]. And if there is any question of my dad has to go to hospital, he always asks for [hospital 2] …,* *but I know it is lack of resources. I do think there is a lot of [nurses] do, really do a good job. (E28 T1)*

### Summary

These interviews taken as a whole, illustrate patients and carers who though often capable of proactively coordinating with the health service rarely do so. Patients and carers evidenced little knowledge of palliative care beyond a rudimentary understanding of it as representing care when no cure is possible. In this light, it seems many of them take the rational response to fall back onto their own resources in order to conserve a sense of autonomy and dignity. Such an approach actively mitigates against successful coordination between patients, carers and health professionals. A lack of planning means that when the inevitable crisis occurs there is little to be done but call the ambulance and hope for the best.

## 5.3.3 Client Services Receipt Inventory Data

A CSRI form, tracking service usage over the previous three months was filled in after each interview where possible.(annex 5) A total of 43 CSRI forms were completed by 19 of the 20 participants. There was no obvious pattern of physical decline identified using the ECOG scoring.

**Secondary care.** All participants at T1 had recently attended the acute admissions unit so there were 24 instances of hospital admissions in the three months before T1. There were no reported A&E admissions in the three months before T2, however five of the participants who had completed a T1 CSRI had either withdrawn or died and three spent the entire period between T1 and T2 in hospital, accounting for 270 of the 313 days of hospitalisation reported at T2. Secondary care services started to increase again in T3. At T2, all of the hospital admissions were reported by just four of the 14 respondents while at T3, seven of the 12 participants had been hospitalised at least once in the preceding three months. This pattern may indicate that after discharge from home, most participants were able to avoid readmission for 3-4 months but after that point readmissions became more frequent.

**Table 10. Secondary care usage in previous 3 months**

| Secondary care | T1 (n=17) | T2 (n=14) | T3 (n=12) | Total |
|---|---|---|---|---|
| 1. Hospital admissions | 24 | 5 | 14 | 43 |
| Total days in hospital | 596 | 313 | 178 | 1087 |
| 2. Outpatient visits | 14 | 13 | 20 | 47 |
| 3. Day visits | 6 | 5 | 6 | 17 |
| 4. A&E visits | 19 | 0 | 4 | 23 |
| 5. Emergency Ambulance calls | 18 | 0 | 3 | 21 |

**Primary care.** Involvement by the primary care team showed a pattern of decreasing input from the GP and increasing input from the nursing team over time. This may be showing the impact of a discharge from hospital where initial input comes from GPs and then nursing staff gradually take over. No one reported any interactions with a palliative care nurse of any type. Two participants mentioned such nurses but in both cases the last visit had been more than 3 months before T1.

**Table 11. Community service usage - Edinburgh**

| Community Services | T1 (n=17) | T2 (n=14) | T3 (n=12) | Total |
|---|---|---|---|---|
| GP at Practice | 12 | 16 | 5 | 33 |
| GP at Home | 34 | 17 | 13 | 64 |
| GP on Phone | 25 | 12 | 6 | 43 |
| NHS24 | 10 | 3 | 4 | 17 |
| Practice Nurse | 4 | 10 | 47 | 61 |
| District Nurse | 58 | 106 | 119 | 283 |
| Palliative Care Nurse | 0 | 0 | 0 | 0 |
| Lung Special Nurse | 0 | 0 | 0 | 0 |
| Other | 7 | 3 | 13 | 23 |

**Social care.** The one indication of increasing episodes of care came for social service carers. In total, 3545 incidences were recorded during the project. Each incident refers to one visit by one worker so if two workers visit three times per day then that would be 6 incidences. The numbers represent the total number of visits per day multiplied by 90 (3*30 days) if the visits were reported as happening "every day" then pro-rated if the input had changed during the time. The totals are given in Table 12 below.

**Table 12. Home Help visits**

| Time | T1 | T2 | T3 |
|---|---|---|---|
| Number of Patients living at home and receiving home help | 4 of 14 | 5 of 13 | 6 of 11 |
| Total Visits | 720 | 797 | 2028 |

The increase at T3 is largely represented by two patients both receiving 720 incidences of care over the period: which is to say 2 workers visiting 4 times per day. One patient, (E25) with MS had a significant increase between T2 and T3. The other was completely bedbound with spinal cord compression and was discharged home a few days before T2. One measure is to look at the number of patients who spent some time at home during any period and received social help while at home. As can be seen, there was a general increase in the number of patients from 4 of 14 at T1 to 6 of 11.

**Family carers.** Sixteen of the participants had a family carer either living-in or present for several hours per day. These were spouse 7, child 7, parent1, and friend 1.

These numbers do not capture the complexity uncovered in the interviews. In practice most patients had some sort of network of support consisting of various family members, friends and often neighbours. Four participants, (E8, E17, E27 and E32) had no identifiable support and two died during the project; E8 acted as a carer for her older, frail spouse while E27 had a very loose circle of friends with whom he socialised at the pub.

Assessing the workload for carers was problematic. Where a live-in carer was present, they regarded themselves as always "on duty" and often had minimal help from other family members. Where there was no live-in carer, family members often divided up care responsibilities between several people. The presence of home help seems to have mitigated the physical exhaustion reported by live-in carers but a common irritation was the lack of any help with the housework.

### 5.3.4 Significant Event Analysis

The event was held at the research site (CAA) on 2/9/2011 in the format outlined earlier. Issues highlighted included the patients' frequent expectation for contact from the GP after hospital discharge, but the common failure of this to happen unless the patients had a specific physical need such as removal of sutures or dressing of a wound. Hospital staff explained they felt unable to instruct or even advise GP to visit even if they thought it would be in the patient's best interest, as the GP may not appreciate such instruction. This issue of coordinating with primary care professionals who wish to preserve professional autonomy had no apparent solution.

## *5.4 Discussion*

The CAA functions to give emergency care and speedily triage and dispatch people with acute medical or surgical conditions and had little time to consider wider issues. There was little realisation that such patients who might be in the last year of life had additional needs that might be addressed during their care.

There was lack of coordination at admission, especially out-of-hours. Patients and carers routinely described the process as noisy, stressful and confusing though there were many examples given of good communication and evidence of caring. Discharge back into the community was particularly fraught with plentiful evidence of communication between primary and hospital care being unreliable and sometimes delayed.

By its nature, the care setting is not configured to take a longer time view of patients who may be in their last year of life. If the system were re-designed to give staff more time this would help but such a re-design would have a significant impact on throughput from A&E.

Care planning for multi-dimensional needs plus better communication with emergency services might prevent many admissions from people approaching end of life. Currently there is little evidence of care planning in the community, possibly due to lack of identification of such patients in the first place. Better identification allied to care planning may reduce admissions which would have the benefit of both reducing the time pressures at the unit and possibly allowing the spending of more time with those who are admitted.

The hospital was considered as a busy impersonal place, often best avoided according to previous experiences and stories. Each admission and discharge cycle tended to disrupt care patterns, often resulted in confusing changes in medication and tended to intensify carer stress.

In the community, GPs and nurses tended to be too busy to speak about planning, and some people did not wish to communicate to avoid losing control. Those patients who had a live-in carer appeared to have a better quality of life but the carer's ability to help coordinate the patient's care seemed little recognised.

Of the 20 patients who participated, only one was identified as having palliative care needs yet all were recruited as potentially approaching the end of life. Attempting to coordinate services for such patients will remain problematic if such patients cannot be reliably and systematically identified, or if they see no reason to self identify.

# 6 Midlands case study

## *6.1 Setting*

The setting is a large primary care practice with a patient list of over 11,000. It is situated on the north side of a city of over 300,000 inhabitants in the English Midlands. The practice boundaries extend over multi-ethnic urban areas and rural locations within which there are some ex-coal mining villages with a predominantly white, elderly population.

The practice has five partners and three salaried doctors, three practice nurses, a healthcare assistant and seventeen administrative, clerical and reception staff, many of whom are part time. It is a training practice and therefore has a constant turnover of trainee GPs and medical students. None of the partners had a special expertise in palliative care e.g. as a Macmillan GP facilitator or with post-graduate training in palliative care. The practice had come into GSF following its attempts to address its Quality Outcomes Framework (QOF) goals and not as an earlier adopter of the Gold Standards Framework (GSF) in the pre-QOF phases of GSF. One partner, as happens in most practices in the UK had developed a particular interest in palliative care and convened the palliative care meeting, and was the defined GSF lead GP whilst the other partners had a variable degree of interest in the issue and a variable degree of experience and expertise.

The practice has its main site in a purpose built building, opened in 2006 as a Local Improvement Finance Trust project. The practice shares its main premises with another practice of a similar size and has two smaller branch surgeries, one two and the other four miles from the main surgery. The branch surgeries serve the villages on the north side of the practice offering a more limited service, with doctors taking turns for one or two sessions a week each. It also provides medical cover for 16 nursing and care homes.

The overall running of the practice is undertaken by the business manager and a patient services manager. The business manager is responsible for strategic management and overall timetabling including that of the clinical staff, whilst the patient services manager ensures that all sessions within the practice are covered.

The practice has taken an active role in a Practice Based Commissioning Group and more lately a Clinical Commissioning Group. This has given it access to a number of resources and services, including a Carers' Support Worker who attends the surgery once a month.

### 6.1.1 Site negotiations

Access to the setting was achieved through the local Primary Care Research Network (PCRN). The practice was research active having been a major recruiter for previous PCRN supported trials and already had good contact with members of the local study team. Following initial agreement to participate, the researcher attended a weekly clinical meeting, which was attended by all of the clinical staff (doctors and practice nurses), to explain the project, answer questions and address any concerns that members of staff had.

## *6.2 Methods*

### 6.2.1 Ethnographic observation

At the beginning of this phase of the study, the researcher spent three sessions (half days) observing the space and flow of patients and staff around the practice. This was carried out by stationing in the main reception area at the entrance to the practice, in a sub-waiting room on the ground floor along a corridor nearer the clinical rooms and in the staff coffee room upstairs. This was valuable in understanding the spatial and temporal context within which daily activities took place.

The researcher also spent two sessions in the upstairs telephone room where receptionists staff two telephone lines during office hours and operate the triage system for calls from patients. The triage system is the defining organisational aspect of the practice and is in itself of major significance in relation to palliative care.

Following this introductory phase the researcher spent an observational period spread over three months sitting in on telephone triage sessions, doctors surgeries and practice nurse sessions, shadowing GPs on home visits and visits to a care home and attending clinical meetings and fortnightly palliative care team meetings at the practice.

These activities were essential to the development of an understanding of the context in which patients with palliative care needs are managed. Since palliative care only forms a small part of the activity in the practice, the researcher spent considerable time observing other aspects of clinical care.

### 6.2.2 Serial interviews

First the researcher attended a practice clinical meeting and discussed the range of patients for inclusion according to a sampling grid (see annex 3) that had been developed for use in the study. Additionally, the researcher (RN) presented an explanation of the SPICT at a practice meeting. These two events led to the identification of a number of potential participants and it was agreed that more would be suggested to the researcher in due course. Initial progress was slow until the lead GP at the practice took responsibility for the process.

## *6.3 Results*

### 6.3.1 Ethnographic observations

The main surgery reception area is spacious, airy and modern and has an unhurried and relaxed atmosphere. The main waiting area is comfortable and there are notice boards and stands with health related information sheets and leaflets as well as magazine racks for patients use.

Seating is in rows facing the front in the main reception though in the sub waiting area some chairs face each other. All face-to-face clinical activity with patients takes place downstairs. The practice management is run from upstairs where there are a number of administrative offices.

Activity at the Medical Centre can be divided in to four broad and overlapping categories. Clinical consultation involving patient contact; clinical administration (e.g. signing prescriptions; interaction between healthcare professionals (formal and informal); and management of the practice.

Communication within the practice is undertaken through the practice computer system, internal telephone and face-to-face contact. Communication with secondary care takes place largely through letters with some telephone contact. In certain instances personal relationships facilitate communication. Telephone communication with Macmillan nurses works effectively and a close working relationship has developed. Communication with DNs was previously facilitated through the attachment of nursing teams to GP practices but is currently problematic due to the new geographical system. Although GPs are expected to use the centralised hub system for telephone contact this is agreed to be unworkable and direct telephone contact is arranged between the nurses and GPS.

## Ethos and culture

The approach to care observed in the practice endeavours to be ‘holistic’. Staff demonstrated interest in their patients’ overall well-being and expressed accepting and non-judgemental attitudes. Presenting symptoms or conditions were addressed within the context of family and social circumstances.

Many of the patients were well known to the staff and had been with the practice for many years. Two of the partners had themselves been with the practice for over 20 years and another for 13 years. This long association facilitated a general sense of continuity which was greatly valued by older patients. It also helped members of staff who were generally aware of family networks, resources and dynamics.

Doctors and practice nurses, in telephone or face-to-face consultations made an effort to take time with patients and were careful not to sound or appear rushed. Behind the public face it was clear that the doctors and nurses were extremely busy and at times highly pressured. There was, however, a great deal of informal cooperation and a willingness to lend a hand when one member of staff was seen as over-stretched.

## Palliative Care

The practice had adopted aspects of the GSF but not the whole framework. A member of the administrative staff acted as the GSF facilitator and one of the GP Partners took the clinical lead in palliative care, as is normal practice. There was no formalised process of identifying patients to be included on the register. This usually occurred as a result of information given in a hospital discharge summary or from a discussion between the lead GP and colleagues. There were only 15-20 patients (about 0.2%) on the list during the observational period. Most had a cancer diagnosis with co-morbidities and some had other advanced illnesses.

Palliative care meetings were held fortnightly chaired by the palliative care lead GP. At the beginning of the ethnographic observation, District Nurses from two teams covering different geographical locations attended, although some patients in the practice were under the care of a third district nursing team. A senior Macmillan Palliative Care Clinical Nurse Specialist also attended.

Each patient on the register was discussed at the meeting. The discussion was usually quite lengthy and decisions regarding drugs or other interventions were made. The advice of the Macmillan nurse was always accepted, with the DNs generally providing information on changes in the patient’s condition. Other doctors in the practice who knew the patient were called in to contribute to the discussion on an ad-hoc basis.

## Coordination – facilitators and barriers

All the practice doctors and in many instances, the practice nurses, were involved in the care of patients on the palliative care register. The organisation of the practice in terms of the triage system discouraged patients from seeing themselves as under the care of a single GP. When a patient or carer phoned they were put through to the duty doctor who would assess whether the call should be dealt with by telephone, attendance at the surgery or through a home visit. If an appointment was made it would be with one of the doctors who were holding surgeries that day or in the "book ahead" slots for doctors holding surgeries on subsequent days. House calls were allocated to the GPs available at the end of surgery sessions. All calls and consultations were recorded on the practice computer system. Thus all doctors had immediate access to relevant information.

The aim of the triage system was to improve care for all types of patients by increasing efficiency by coordination and providing immediate access by telephone to a doctor and same day appointments. Among our participants, however, the triage system was not unequivocally seen as an advantage or facilitator of coordination.

Close working relationships, physical proximity, weekly clinical meetings as well as the organisational structure contributed to coordination of care within the practice. The relationships that had developed with District Nurses, Macmillan nurses and with care homes both formally and informally were also major contributory factors.

The practice staff identified lack of communication with hospitals as a major barrier to coordination. Many patients had spent periods as inpatients or at specialist outpatient clinics. Practice staff could access the computer system of the local hospital in the city but there was no similar arrangement with a second local hospital serving the rural area. Computer access was regarded as useful by staff with regard to diagnostic and treatment information but was of little help with regard to coordination in relation to discharge. Discharge management by hospitals varied from well planned and coordinated with community services to almost completely unplanned. When patients were sent home without the involvement of hospital-based or community-based palliative care teams, GPs were often unaware that a patient had been sent home until the discharge summary arrived. There appeared to be little dialogue between secondary and primary care and few relationships had developed to ensure communication occurred. Boundaries appear to be rigidly maintained and there appeared to be a lack of mutual trust, cooperation and contact.

## Changes in the District Nursing Service

Two significant changes in the district nursing service occurred during the study period. During the fieldwork, a new system was adopted whereby DNs were to be contacted only through a centralised 'hub' rather than directly by telephone to the district nursing base. This change was discussed in the palliative care meeting and was seen as impractical for staff needing to communicate with

DNs. Mobile phone numbers were exchanged between some nurses and the GP in order to circumvent the system. Some District Nurses also indicated that they had given palliative care patients or carers a direct contact number as the potential difficulties of having to use the hub were readily apparent.

A second major change to the district nursing service was the introduction of geographical (locality-based) working. Previously District Nurses had been attached to GP practices with each practice linked to two or three district nursing teams. Under the new system, DNs were reorganised into large teams which were allocated a geographical area and were required to work with any of the practices that cared for patients within that area. This change had a major negative impact on the process of palliative care as GPs had no way of knowing initially which nursing team was relevant to the care of a particular patient. Whereas GSF meetings had initially been well attended by two of the district nursing teams, following the change to geographical working six teams needed to be invited to the meeting resulting in a sudden drop in attendance.

### 6.3.2 Serial Interviews

In total 16 patients and 8 associated carers were interviewed. The average age was 73 (range 41-92), 11 were male and 5 female. Participants were selected from the practice palliative care register with the assistance of the SPICT tool to encourage consideration of advanced non-malignant disease. We ecruited a sample with cancer, organ failure and frailty trajectories, and 75% had two or more significant illnesses. At the time of recruitment none of the patients had had a hospital admission within the previous month. All had spent time in hospital previously and two participants had been discharged from hospital into care 4-6 weeks prior to contact. See Table 13 below for a summary.

Eight of the patients lived at home with a partner. In each instance the partner had assumed the role of carer although in many cases they themselves were not in good health. Seven of the carers were women looking after husbands.

The caring role involved varying degrees of physical care, responsibility for meals, medication, making sure appointments were kept, coordination of services and vigilance regarding the patient’s condition. In all but one instance carers were looking after patients with a range of co-morbidities. Amounts of contact between couples and medical and support services varied and changed over time. In three instances carers from private care agencies came in to the home 2-4 times daily. In all instances patient care was shared between the GP practice and one or both of the local hospitals. District nurses were involved with seven patients and Macmillan nurses with two.

Three participants (one female, two males) lived by themselves at home. The two men were active coordinators of their own care. The care of the female participant was coordinated by her adult sons who were in daily contact. Only two of the participants living in nursing or care homes were able to take an active role of any form in the coordination of their care due to the stage of their illness.

**Table 13. Participant summary table - Midlands**

| ID | Age | Sex | Main Conditions | Trajectories | Pat# | Carer | Car# | Status |
|---|---|---|---|---|---|---|---|---|
| W1 | 67 | M | Diabetes, Charcot's arthropathy, cellulitis | OF, Frail | 3 | No | 0 | Alive |
| W2 | 79 | F | Diabetes, heart failure, osteoarthritis | OF, Frail | 3 | No | 0 | Alive |
| W3 | 79 | M | Renal failure, heart failure, ischaemic heart disease (IHD), hypertension, osteoarthritis | OF, Frail | 3 | W113 | 3 | Alive |
| W4 | 82 | F | Lung cancer, stroke, ischaemic heart disease | Cancer, Frail | 2 | W114 | 2 | Dead |
| W5 | 56 | M | Pulmonary fibrosis, cerebral aneurysm, hyperlipidaemia | OF | 2 | No | 0 | Dead |
| W6 | 82 | M | Renal failure, heart failure, anaemia, osteoarthritis | OF, Frail | 3 | W116 | 3 | Alive |
| W7 | 92 | M | Respiratory failure, heart failure, renal failure, osteoarthritis, blind (glaucoma) | OF, Frail | 3 | W117 | 3 | Alive |
| W8 | 80 | M | Prostate cancer, mild dementia, osteoarthritis | Cancer, Frail | 1 | W118 | 1 | Dead |
| W9 | 71 | M | Multiple sclerosis, osteoarthritis | Frail | 3 | No | 0 | Alive |
| W10 | 73 | M | Prostate cancer, mild dementia, hypertension | Cancer, Frail | 2 | W110 | 2 | Alive |
| W11 | 71 | F | Multiple sclerosis | Frail | 3 | No | 0 | Alive |
| W12 | 67 | M | Peripheral vascular disease, renal failure, COPD | OF, Frail | 3 | W112 | 3 | Alive |
| W14 | 41 | M | Metastatic melanoma | Cancer | 1 | W13 | 1 | Dead |
| W15 | 81 | F | COPD | OF, Frail | 1 | No | 0 | Alive |
| W16 | 58 | M | Multiple sclerosis | Frail | 2 | No | 0 | Alive |
| W17 | 90 | F | Stroke, osteoarthritis | Frail | 1 | No | 0 | Alive |

Column headings: Presenting (presenting complaint at CAA), Trajectories (trajectories represented), Pat# (number of patient interviews), Carer (ID of carer(s) if present), Car# (number of interviews that carer participated in), status (whether the patients was alive or dead at the conclusion of the case study).

The issue of coordination was explored in the interviews in terms of 'good care', or what has worked or what has not worked. The concept of coordination was not generally meaningful except when notably absent. Patients' and carers' perceptions related primarily to aspects of communication and information.

Carers and patients identified communication as a central element of care. This included communication between themselves and healthcare providers and between healthcare providers within and in different organisations. See Table 14 below.

**Table 14. Serial interview themes - Midlands**

| Theme | Subthemes |
|---|---|
| Communication between patients and healthcare providers | • Structure<br>• Process<br>• Behaviour: Information giving, listening<br>• The role of expectation |
| Communication between healthcare providers | • Effective/poor communication<br>• Patients as coordinators<br>• Communication and the practice palliative care register |
| Communication, uncertainty and time | • Patient explanations<br>• The future |

## Theme - Communication between patients and healthcare providers

Four subthemes were identified.

### Communication and Structure

A number of patients and carers perceived the triage system used by the GP practice as a barrier to communication. Some disliked being asked the nature of the problem by a receptionist and others disliked having to wait for a return call. "*… they will say 'oh the doctor will ring you back later'. Well I've been in for hours and hours and this could be when I ring at 10.30am. I now think if it's something I want to talk to him about, I'll ring about 10.30am/11am but they won't ring back until…. Well, one evening it was 6.30pm when he rang.*" (W116) This is in direct contrast to the rationale of the triage system as a means of facilitating communication by ensuring patients had access to a GP within an hour or two of contacting the surgery.

Others had difficulty with speaking to or seeing specific GPs. This was particularly evident with those who had built up a personal relationship. Others had become accustomed to the system and had learnt how to make it work for them. "*I know Dr X is on the phone on a Thursday so if I've got any quibbles I just phone up on a Thursday*."(W14)

The GP practice was proactive in communicating with patients regarding its services and changes in provision through its practice leaflet, website and patient forum but this was often not effective for patients with palliative care needs.  For instance a leaflet advertising a service for carers was posted on the wall of the reception area, but none of the carers who took part in interviews however were aware of the service. GPs acknowledged that they 'forgot' to mention the service to carers. The future of the service in the practice is uncertain at present due to lack of referrals.

The district nursing service was central to the care of the majority of the patients. Patients and carers experienced the change in accessing the district nursing service from telephoning the nurse directly to calling a "hub" as creating a barrier to communication. This change meant that an anxious carer might have to explain a worrying situation to several different people with whom there had been no previous contact before a decision would be made regarding the response.  "*Every time I ring, when I eventually get through because apparently it goes through ambulance or fire places, I think it's over in Birmingham, and then it has to come back here, but the clinic is only down the road. It's crazy, if I could lift him and get him down to the nurse…. But it doesn't work like that you see. You know, it's complicated now*." (W116)

### Communication and Process

Patients also identified processes as impeding communication and creating unnecessary stress. One patient (W1) had been attending a hospital outpatient department regularly and was on good terms with the staff. When he developed a new symptom, although apparently associated with the same underlying condition, and was referred by the GP back to the hospital, he was treated administratively as a new patient and asked to choose where he would like to be seen. Already anxious over the symptom, the patient was distressed at the thought of being seen somewhere unfamiliar and at having to 'start again'.

Others expressed frustration at the need to keep contacting a hospital department for information or appointments and the gate-keeping role apparently played by secretaries or administrative staff. "*I was chasing [the hospital] up and my nurse told me to phone Dr X's secretary and ask her to get in touch with [the hospital]. So I phoned her up once and she said 'yes, I'll phone you back.' And she never phoned me back that day. So the next day I phoned her up and she said 'Mr D can't you do that yourself?' and I said 'excuse me,* *I'm sitting here on benefits,' and she said 'I can't get through to Dr X.' So in the end I phoned myself and I got through within 10 seconds and I got through to this number, to Dr X*."(W5)

**Communication and Behaviour**

Communication by individual healthcare staff was experienced both negatively and positively. In one instance, a woman with heart failure was to undergo investigations for a pacemaker. She was both alarmed at the idea of the pacemaker and did not understand its relevance to her condition for which she had her own interpretation. "*Even though I keep saying there's nothing wrong with my heart. Well you would expect some pain or something, surely? I was tired and I still am a bit tired. But I'm getting old, you can't do what you did*." (W2)

One carer described her concern as a hospital bed arrived at her house without warning or explanation; an event which caused her to wonder if this was a sign that her husband was close to death.

Where problems of communication arose at the individual level, as well as not receiving information, patients or carers felt that no one would listen. One carer described her frustration and increasing desperation as she tried to explain her anxiety over her husband's symptoms, and her failure to convince anyone at the Out-of-hours Walk in Centre that her husband could not wait there any longer and his resulting eventual emergency admission via A&E. "*…in the end I took him to the walk in Centre on a Saturday morning. And I said to them 'if you can't see my husband more or less straight away I will have to take him to the hospital because he is not well enough to sit there'.*" (W118)

Another patient described his failed attempts to convey his fear of the scanner to hospital staff. "*And I said 'I can't do it' – I couldn't.. I was crying with frustration I was that embarrassed I couldn't go in it. But the doctors and nurses, they are all like, 'come on, you can do this'. They don't listen to you, they think I'm just there to make a scene*."(W14)

Good communication was seen as extremely important and enabling. One carer described how she had learnt to manage her husband's medication with the help of her District Nurse and to identify when his leg ulcers needed medical attention. Patients or carers who felt they could ring the surgery, a District Nurse or the ward in a hospital and that they would be heard and attended to described the reassurance and confidence this gave them.

### Communication and expectation

Communication was also important in relation to patient expectation. A re-occurring example of this related to expectations regarding follow-up after discharge from hospital. Patients and particularly carers, regardless of how well they were supported in a practical sense, expected some contact with the GP at hospital discharge. However, unless there was a particular reason for this to take place GPs did not visit or telephone routinely. From the GP perspective this follow-up role would be the District Nurse's. This mismatch of expectation caused carers to feel unsupported.

Although the level of care in the community was usually considered excellent by participants, evidence of *caring* was very important. One carer compared her experience with that of her father who had received curative treatment at the hospital and had been telephoned weekly by hospital staff once he had returned home. "*I compare it to Dad's experience and at the hospital, my Dad's consultant, a lovely gentleman, really nice, very straight talking. We were so appreciative that he was so straight talking. Dad's nurse now still rings him once a week but I don't hear from (my husband's) nurse. She has never rang me from the hospital, ever.… and I find that odd.*" (W13)

Similarly another patient with complex co-morbidities who attended hospital for dialysis three times weekly and who was in regular contact with clinical nurse specialists felt disappointed that the GP did not visit. The GP however viewed the patient as having his care managed by secondary care and therefore that unless a specific request was made to the practice, there was no need for her active involvement.

## Communication between healthcare providers

A lack of communication between hospital and primary care services and between hospitals was identified by a number patients and carers. Sometimes patients or carers felt it necessary to take on the coordinating role between hospitals, or between hospitals and the practice themselves, as these did not appear to 'talk to each other.' "*And she's dealing between the hospital and the surgery and half the time the surgery doesn't know what's happening so they have to inform them.*" (W12)

A young man with melanoma contrasted the effective communication between the Macmillan nurse and the GP practice with the relationship between the hospital and the practice in relation to prescriptions. "*She'll come in here and she'll write everything down and go back and see the doctor and get everything all finalised. … It's brilliant. But the relationship between the hospital and the* *practice, you know, as I say they give me medicines at the hospital but send no notice to the practice so it can't go on my notes*." (W14)

Difficulties over prescriptions were also apparent at hospital discharge. In one instance a carer who lived far from the hospital had to return by bus two days later and waited for several hours to collect medication. This episode was discussed with the GP and it became clear that the prescription could have been dispensed by the community pharmacy had the hospital contacted the practice.

The lack of communication between hospitals in some instances necessitated the patient or carer taking a coordinating and advocacy role. A patient with pulmonary fibrosis awaiting a lung transplant described his role by saying "*my young cousins in Scotland, they just told me to push it. They live in Scotland the National Health is going up there, and they said you have to push it. And since I've started pushing them I've got further and further*." (W5)

### Communication and the practice palliative care register

Despite the fact that all the patients who took part in the study fulfilled national criteria for being identified for a palliative care approach, less than half were on the practice palliative care register. Patients with advanced cancer at home or in care homes were almost always entered on to the register where they remained unless they became stable for long periods. Other patients who frequently suffered from multiple comorbidities were generally added to the register following an admission or other trigger point. For the patients who were on the register and therefore discussed at palliative care meetings it was apparent that good communication with a resulting impact on care was taking place. One patient in the terminal stages of his illness observed that the GP, Macmillan and DNs were exchanging information and how helpful it was that everyone was kept aware. For other patients where no formal mechanism or forum for identification of review was in place communication and coordination were more reliant on behavioural factors, interpersonal relationships and patients themselves or their carers.

## Communication, uncertainty and time

### Explanations

Lack of communication or lack of joined-up thinking between organisations were the prime reasons given by patients and carers for a poor experience. This was described by some as due to the increased use of technology and a decrease in the 'personal touch'. Individual organisations such as the private home-care providers were widely criticised for their inefficiency and bad management which was seen as resulting in a poor service for patients. Local reorganisations were also identified as causing particular problems. Individual healthcare professionals were, in general, highly regarded though several patients remarked on the poor quality of nursing they had received as hospital inpatients.

While there was no indication that patients or carers felt age to be a factor in the care they received a number of participants were clear that taking an active role or being willing to 'push' was necessary to achieve a particular outcome.

Most of the patients expressed appreciation and gratitude with respect to the clinical management of their conditions, although several patients living in care were critical regarding their overall level of attention.

**The future**

Few participants spontaneously mentioned the future.Two with cancer did discuss the future though the term 'palliative' was not used at any time. The younger patient suffering from melanoma had made his wishes regarding his place of death (which was not to be at home) clear to the Macmillan nurse. The older patient with lung cancer focussed more on family occasions she was determined to attend. She discussed her illness as little as possible to the point that the nurses described her as 'in denial.'

A number of carers expressed concerns over the future and how they would cope. These concerns related more to the challenge of symptoms and disabilities that would become increasingly difficult to manage rather than issues surrounding the place of death.

Concerns amongst patients with multiple morbidities whose health fluctuated or appeared to decline more gradually were largely focussed on maximising wellbeing through appropriate medication and care thus enabling them to take part in life as fully as possible. While patients occasionally admitted to being '*a bit down'* only the two most incapacitated patients found it hard to identify aspects of life that were enjoyable.

### 6.3.3 Client Services Receipt Inventory Data - Midlands

CSRI forms were completed with regard to the 11 patients living at home at the first interview, 9 patients in the second interview and 6 at the third interview. As with other case studies, there was no discernible pattern of physical decline. Only participant W004 showed a downward progression from an ECOG (43) score of 3 to 4 to death following T2. Two other participants with cancer declined rapidly from an ECOG of 3 at first interview and died shortly afterwards.

Table 15 below shows the usage of secondary care services. The number of outpatient appointments is striking and included the heart failure, respiratory, diabetic, renal and oncology clinics. Participants valued these appointments highly but transport was an issue because of parking costs and the unpredictability of the ambulance service. One patient attended for dialysis three times weekly. Other patients had attended between 1 and 3 times in the three month time period.

**Table 15. Secondary care usage**

| Secondary care | T1 (n=11) | T2 (n=10) | T3 (n=5) | Total |
|---|---|---|---|---|
| 1. Hospital admissions | 2 | 8 | 1 | 11 |
| Total days in hospital | 14 | 34 | 14 | 62 |
| 2. Outpatient visits | 50 | 46 | 43 | 139 |
| 4. A&E visits | 1 | 2 | 0 | 3 |
| 5. Emergency Ambulance calls | 0 | 5 | 1 | 6 |

The use of community service is shown in Table 16 below. The most notable feature is the limited amount of face-to-face contact with the GP compared to a high number of telephone consultations at each time point. Home visits were extremely rare: only four occurred during the study period.

District nurses played the largest part in the ongoing care of the majority of this patient group. Contacts varied between two patients who were visited almost weekly at time point one and those who were seen every few weeks for example in order to change a catheter bag. Use of services shows a decline over the period however this is accounted for by a decrease in the number of participants from 11 at T1 to 5 at T3. Use of services appeared to remain fairly stable amongst the remaining participants.

**Table 16. Use of community services**

| Community Services | T1 (n=11) | T2 (n=10) | T3 (n=5) | Total |
|---|---|---|---|---|
| GP at practice | 10 | 8 | 5 | 23 |
| GP at home | 5 | 3 | 0 | 8 |
| GP on phone | 45 | 34 | 18 | 97 |
| Practice nurse | 10 | 11 | 11 | 32 |
| District nurse | 39 | 29 | 22 | 90 |
| Macmillan nurse | 6 | 0 | 0 | 6 |

| | | | | |
|---|---|---|---|---|
| Lung nurse | 8 | 8 | 6 | 22 |
| Other | 11 | 11 | 9 | 31 |

Three participants received help from a private care agency. In two instances a carer attended twice daily at T1 and in one instance four times daily.  In the case of one patient who was hospitalised at T3 the amount of care was to be increased to four times daily upon discharge. The care given, involved washing, shaving, dressing the patient, getting them out of bed and in one instance assisting with feeding. These carers do not perform cleaning tasks and in six instances private cleaners were employed on a once weekly basis.

Seven of the participants had had some involvement with Social Services mainly with regard to the provision of aids and adaptations to the home. Only two participants were aware of having a social worker and one of these was visited at intervals as he and his wife lived in specially adapted accommodation. One participant who lived alone had a personal alarm to summon help in the event of a fall. This had been provided by a private firm but had been organised by the Social Services Department. One carer was also provided with an alarm between T2 and T3. She explained this as a way of ensuring her husband would be looked after should anything happen to her.

### 6.3.4 Significant Event Analysis (SEA)

The SEA workshop was attended by the lead GP, the palliative care coordinator (member of administrative staff), two District Nurses from the city, one District Nurse from the rural area, the Macmillan nurse who cares for all of this practice's palliative care patients with complex palliative care needs, and a palliative medicine specialist who supports the Macmillan nurse.

Four cases were discussed to explore issues found significant in the ethnographic study and serial interviews. These included:

1) Working with care homes and ensuring good governance and working relationships
2) Communication: patient to District Nurse/ healthcare professional, hospital to community and community to hospital
3) Need for ongoing continuity of care in the community
4) Identifying patients who have palliative care needs to ensure that they have appropriate care.

## 6.4 Discussion

In this setting, two recent organisational changes to promote overall practice efficiency hindered communication and coordination in this patient group. The practice triage system introduced to manage

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patient demand encouraged telephone contact and has resulted in limiting face-to-face contacts in this group of patients as well as in less needy patients. GPs see this as an efficient use of time. Patients have commented on a perceived decline in personal contact and care but in general have acknowledged the rationale for this change. Secondly, District Nurses previously aligned and members of practice teams were given specific geographic work areas. This again promoted efficiency at a cost of decreasing opportunities for collaboration between professionals and an unfortunate immediate fracturing of some professional and patient relationships.

The palliative care register fulfilled an important function in maintaining the visibility of these patients. Less visible were equally needy patients not on the register. Generally these were patients with non-cancer chronic disease, frailty or multiple comorbidities who were not perceived as close to the end of life. The communication necessary to ensure good care for these patients was less formalised and was dependent on a combination of working relationships amongst healthcare professionals and the active involvement of carers or patients themselves. As the carers as well as the patients were frequently frail, with their own healthcare needs, the burden of needing to take on a major coordination role themselves was very high.

As seen in Edinburgh, coordination at hospital admission and discharge, and between professionals generally was not reliably good.

# 7 London case study

## *7.1 Setting*

The setting is one of London's busiest teaching hospitals that serve primarily the most deprived boroughs in England with life expectancies for men and women remaining worse than the England average. The hospital has extensive links with an academic palliative care department built through participation in multiple research projects. Members of the department participate in clinical practice through various means such as participation in some of the multi-disciplinary meetings discussed below. During the lifetime of the case study, a new institute of palliative care opened on site providing further expansion of both palliative care and rehabilitation, and enabling the co-location of academic and clinical teams.

### 7.1.1 Site negotiations

This London site conducted research with the Department of Respiratory Medicine at King's College Hospital (KCH). The Department comprises a director of clinical strategy, consultants, registrars, senior and lead nurse specialists (LNS) that treat and provide care for people with various chest conditions including asthma, asbestosis, TB, lung cancer, COPD and interstitial lung disease. A comprehensive range of services is provided including lung screening, bronchoscopy and outpatient clinics.

Site negotiations with the Department were brokered through an advisory group member of the research team who was also a Department clinical member. During negotiations, the project's aims, plans and methods were introduced and it was agreed that a key professional from each clinic would liaise with the researcher and facilitate access to documents, staff, patients and families.

## *7.2 Methods*

### 7.2.1 Ethnographic observation

Observational ethnographic data were collected from multidisciplinary team meetings (MDTs) and three outpatient clinics: the lung cancer (LCC), the respiratory medicine clinic (chest clinic), and the interstitial lung clinics (ILC).

### Multidisciplinary Team Meetings

Observational data were collected from 16 hour-long MDTs chaired by the Lung Cancer Lead Consultant which a respiratory consultant, LNS, surgeons, oncologists, radiologists and registrars attended. A standard meeting format was observed: 1) brief patient description; 2) a review of the scans to highlight if cancer was suspected followed by a discussion of the future investigations and diagnosis. Patients were reviewed until accurate outcomes emerged from the investigations. MDT discussion was recorded by a clinician in the Electronic Patient Record (EPR) that holds patient data electronically and can be accessed by all clinicians from various departments across King's Health Partner Hospitals. The EPR is used to request tests, receive results electronically, update the medical record, and review patient care. The EPR is complemented by Medinet, the speciality's online patient record designed to support the Department's multidisciplinary working. Medinet contains more respiratory illness specific information.

## The Respiratory Outpatient Clinics

Over 11 weeks three respiratory outpatient clinics were observed: the LCC (Monday afternoon), the chest clinic (Tuesday morning) and the ILC (Wednesday afternoon). Generally patients reported to the reception and waited to be called by the clinician (consultant/ registrar/nurse specialist). Clinicians in all clinics used the EPR or Medinet.

### The Lung Cancer Clinic

Annually the LCC services approximately 1,400 patients comprising 140 new referrals from hospital consultants (65%) and GPs (35%).

The LCC was usually staffed by lung clinical nurse specialists (LCNS), respiratory consultants, cardiothoracic consultant, consultant in palliative care and oncologists. The LCNS is a registered nurse and has completed a palliative care degree.

All patients with, or suspected to have, lung cancer have access to a nurse specialist in lung cancer via this clinic. Observational data indicated that the LCNS was more likely to see patients with a confirmed or suspected lung cancer diagnosis. To some, especially those who lived alone, the LCNS suggested a referral to a community palliative care team. During every observational encounter the LCNS instigated referral for these patients to the community care or the Macmillan service in order to enable some support in the community and to have *'eyes out in the community'.*

The consultants' caseload also involved providing services to patients whose scan indicated no cancer or who had other lung-related problems. Consultants played a central role in the diagnosis and treatment pathway of the patient while the LCNS was more likely to follow the patient from the diagnosis, as she was viewed as being responsible for breaking bad news, through the treatment programme and until discharge or the patient's death. During ward round shadowing of the LCNS it was shown that the LCNS aimed to *"return some of their lost control"* by updating the patients about their condition (LCNS comment).

### Chest Clinic

Annually approximately 105 new patients visited the chest clinic, 80 patients were followed-up, 48 were non-attendees and 36 patients walked into the clinic.

Patients were seen either by the consultant or nurse specialist. The nurse indicated that consultants were more likely to prescribe medication, order tests and mainly concentrate on diagnosis and treatment, while nurse specialists were more likely to monitor and review the patients, educate patients about medication or provide information about illness, and manage the illness and symptoms.

Nurses also attended inpatient wards and reviewed the hand-over sheet to see if patients with respiratory problems were admitted. If patients with respiratory problems were admitted, then the nurses consulted the EPR and Medinet for an update. They then visited the patients for an assessment, entered recommendations in the EPR or liaised with ward consultants or physiotherapists.

During shadowing of a nurse specialist, the handover sheets were reviewed to check whether a patient with respiratory problems was admitted to the ward, and the nurse liaised with consultants, pharmacists, occupational therapists, and psychotherapists regarding medication, treatment plans, or discharge. They then updated the EPR with the interactions and the decisions made.

**Interstitial Lung Clinic**

Annually the ILC clinic sees approximately 750 patients. GPs refer 35% and 65% of patients are referred by consultants.

Observational data showed that the process of service access was similar to both the lung and chest clinic. Communication occurred between the consultant and the registrar mainly when the latter came in the room for advice or a second opinion.

Communication between the consultant and the receptionist occurred to aid coordination when clarification of the referrals or notes was required. The timing of coordination of care also varied in relation to the immediacy of patient need.

## 7.3 Results

### 7.3.1 Ethnographic Observation

Two themes emerged from the observational data which were explored further within the serial interviews (see Table 17 below).

**Table 17. Themes from observational data**

| |
|---|
| Coordination: comprises communication, barriers and markers to identify patients with palliative care needs |
| Role: role of different clinicians in the patient’s care |

### Coordination

Coordination describes how clinicians coordinated the patient’s care, how they communicated and what barriers were experienced in

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coordinating and communicating about patient care. A number of markers which professionals used to identify patients with palliative care needs emerged in the findings. This theme comprised three subthemes: mode of coordination, barriers in coordination, and markers.

The modes of coordination comprised EPRs, letters, phone calls and personal contacts. Barriers in coordination emerged as impeding good coordination and thus continuity of patient care. Two barriers were identified: 1) relating to information and 2) obstacles to coordination across settings. Insufficient information or increased information, but unrelated to all specialties, impeded clinicians from being able to respond in a clinically optimal manner and hindered the coordination of care. This in turn may have a negative influence on continuity of care. Obstacles in coordinating the patient's care between two settings, for instance between the hospital and the GP practice were also identified. Data showed that clinicians used markers to identify patients with palliative care needs, specifically: specific symptoms, frailty, metastases, living alone, and need for support.

### Differences in roles

From the data, differences in roles between the lung nurse specialists (LNS), the LCNS, and consultants were identified. In essence the LNS monitored and reviewed the patient, provided advice and education, helped manage illness and symptoms, and was integral to discharge planning. The LCNS shared bad news with patients, discussed treatment options, ensured symptom control, psychological and financial support and referred to specialist palliative care. The LCNS followed the patient along the illness trajectory. The LCNS explored patient's needs, worries, and experiences. Consultants were involved in the diagnosis and treatment of the illness. For example, during the MDT, the consultants discussed with the radiologist the different scans and decided whether the patient had cancer. Then they discussed treatment options with surgeons and oncologists. Consultants discussed results from tests and informed patients in not having cancer.

## 7.3.2 Serial Interviews

### Participant information

Fifty seven patients were initially identified. Thirty five patients were approached to inform them about the project. Among them fifteen declined participation. Some of the reasons for their decline were: '*too much at the moment', 'not much to say', 'I only got chesty pains'*. Twenty two patients were not approached because they either lived in another county had hearing problems, were just diagnosed, or they were breathless due to increased weight and not due to lung problems. Twenty patients were interviewed for time one (T1) interviews (Table five).

Twenty patients with respiratory problems (Table 18 below) were recruited from the three outpatient clinics for serial interviews. In total 43 interviews were completed. Of those, 29 were with just the patient present and 14 were joint interviews with both the patient and one or more carers present. A total of 20 patients (13M, 7F) and seven carers took part in the interviews. At the conclusion of the case study five participants had died.

**Participant summary**

- Average age 67: range 46-90
- Trajectories represented
    - Organ failure 13; Frailty 2; Cancer 12
- Main conditions
    - Cancer 13 (12 lung, 1 breast)
    - Organ Failure 16 (Heart failure=1, COPD=9, IHD=2, Emphysema/pulmonary/fibrosis/embolism/asbestosis/asthma=6)
    - Frailty 2

**Table 18. Patient characteristics - London**

| ID | Age | Sex | Main Conditions | Trajectories | Pat# | Carer | Car# | Status |
|---|---|---|---|---|---|---|---|---|
| K1 | 61 | F | Lung cancer, metastatic to adrenal glands | Cancer | 3 | K101 | 3 | Alive |
| K2 | 68 | M | Lung cancer, emphysema | Cancer, OF | 3 | K102 | 1 | Alive |
| K3 | 76 | M | Lung cancer, Asbestosis | Cancer | 3 | No | | Alive |
| K4 | 82 | M | Lung cancer with leg metastasis, ischemic heart disease (IHD) | Cancer, OF, Frail | 1 | No | | Dead |
| K5 | 54 | M | Lung cancer with bone metastasis | Cancer | 3 | K103 | 3 | Dead |
| K6 | 78 | M | Pulmonary fibrosis, IHD, emphysema, | OF | 2 | K104 | 1 | Alive |
| K7 | 55 | F | Pulmonary embolism, dermatomyositis, breast cancer, hypothyroidism, | OF | 2 | No | | Alive |
| K8 | 70 | M | COPD | OF | 3 | K105 | 3 | Alive |
| K9 | 90 | F | Lung cancer, COPD, osteoporosis | Cancer, OF, Frail | 2 | No | | Dead |
| K10 | 72 | M | COPD, emphysema | OF | 3 | No | | Alive |
| K11 | 59 | M | Lung cancer, with stomach, throat and bone metastasis | Cancer | 1 | K106 | 1 | Dead |
| K12 | 65 | M | Lung Cancer | Cancer | 3 | No | | Alive |
| K13 | 69 | M | Lung cancer , COPD, emphysema | Cancer, OF | 2 | No | | Dead |
| K14 | 63 | M | COPD | OF | 3 | K107 | 1 | Alive |
| K15 | 66 | F | COPD | OF | 2 | No | | Alive |
| K16 | 52 | F | COPD | OF | 1 | No | | Alive |
| K17 | 46 | M | Lung cancer (small cell) with brain metastasis | Cancer | 2 | No | | Alive |
| K18 | 64 | F | Lung cancer, diabetes, hyperthyroidism | Cancer | 1 | No | | Alive |
| K19 | 74 | F | COPD | OF | 1 | No | | Alive |
| K20 | 79 | M | Lung cancer, COPD, asthma, heart failure, | Cancer, OF | 2 | No | | Alive |

Column headings: Trajectories (trajectories represented), Pat# (number of patient interviews), Carer (ID of carer(s) if present), Car# (number of interviews that carer participated in), status (whether the patients was alive or dead at the conclusion of the case study).

Most participants were retired and seven participants had their main carer involved in the interview; 15 participants completed T2 interviews. Among the patients who did not complete the T2 interview, two had died and it was difficult for the researcher to locate the remaining three. Seven completed T3 interviews. Of those who did not, one patient had died, two patients did not think they had anything more to add and one patient was unable to be contacted again due to changed and missing contact details. In addition, seven carers were interviewed (see Table 19 below).

**Table 19. Carer interviews - London**

| Carer | Patient code | Relationship to patient | Gender |
|---|---|---|---|
| K101 | K1 (Lung cancer) | Son | M |
| K102 | K2 (Lung cancer) | Domestic partner | F |
| K103 | K5 (Lung cancer) | Daughter | F |
| K104 | K6 (COPD) | Wife | F |
| K105 | K8 (COPD) | Wife | F |
| K106 | K1(Lung cancer) | Domestic partner | F |
| K107 | K13 (Lung cancer) | Domestic partner | F |

## Serial interview themes

Six themes emerged from the patient and carer data (Table 20 below).

**Table 20. Serial interview themes**

| |
|---|
| **Communication**: variable perceptions of communication between primary and secondary care, within primary and secondary care, and modes of communication across and within primary and secondary care |
| **Experiences**: responsiveness of professionals to patient and carer need influences coordination, the timing of care, engagement with services and care satisfaction within and across primary and secondary care |
| **Expectations** for coordinated care: met and unmet |
| **Role**: carers help coordinate care within primary care and the main patient care coordinator, the professional keyworker, helps coordinate care within primary and secondary care and across care sectors. Clinicians supplement this process through information provision but their workload sometimes hinders their capacity to help coordinate care |
| **Timescale**: variable experiences of the time involved in care coordination and care delivery |
| **Information**: information provision is key to coordination of care and the sharing of the information is instigated in various ways including being prompted |

| by the patient |
|---|

## Communication

Variable experiences of communication *between* secondary and primary care and also within settings emerged. Patients and carers explained that good coordination between settings required enhanced communication aiming to achieve continuity across settings. Delays or gaps in communication jeopardised continuity of care. Examples of these gaps between primary and secondary care were evident, for example in relation to medication *"There's a lot of medication that I'm taking, that's been changed since, that I hadn't gone back to the GP. They say they're sending it back but it never seems to come. I go down there a week later and they don't (the GP) know anything about it… I'm going like an idiot to the doctor, telling me about, he doesn't believe me that I am taking sixteen a day now"* (K11).

Patients speculated as to why coordination at hospital discharge planning failed: *"Or I might get out and I feel very ill and I might want to see the GP straight away and my daughter will ring the GP to say "Will you come and see my father?" And they say "But he's not here, he's in King's College Hospital"… Don't know what goes wrong on those sort of things but we keep getting this GP being left out on a limb, ……., they've probably got all the information but the GP's too blasted lazy to look in their files, you know, got a pile like that in their files"* (K4).

Communication gaps *within* primary and secondary care were also identified in relation to diagnosis, treatment and medication supply with these lung cancer patients.

"*But he (the Dr at X hospital) said it's not cancerous, according to the letters, you know. But then when I was in, actually in X hospital as a patient, this doctor came along to me and he said 'You've got cancer of the lungs' and I thought 'oh, I can't believe it'… and yet, here, here was this lung specialist, you know, and I don't know whether I've got cancer or whether I haven't cause so many people have told me different things"* *(*K3).

*"When I was in the other ward I was getting physio twice a day. Now suddenly, when I came up here, I never had any physio….Why, what's gone wrong? it should've got the information, communication over to say, well look, we've done with him, he's gone to X Ward. But I think that didn't happen. Somehow or other there was a gap there, but anyway, they're here now"* (K4).

One carer discusses medication provision involving GPs and chemists *"I've been in there times crying because I've phoned up and pre-ordered something and he's been in pain and I've come down and then they're like, like really, really flippant"* (carer K103).

A number of communication modes to aid coordination across and within primary and secondary care were identified, including letters, faxes, phones and electronic means. Receiving letters were signs of not being forgotten, a sign that their care was being coordinated, as a means of gaining information "*Well I get, I get a, me GP gets a letter and I get a letter. It's like explaining to you*" (K11).

Patients viewed the EPR as a means to aid coordination even though they had no explicit direct access to the file themselves "*Now there you get put on computer and they're automatically there in Hospital X. So anything he writes about me goes on the computer. Dr X will write up notes about me, that goes into the computer; it's available to whoever's got access to the computer and, as far as I know, they all coordinate*."(K10)

## Experiences

Professionals with responsive behaviours were considered more likely to listen to patients' needs and feelings, to respect them and provide clear and concise information based on the patient's level of understanding "*Yes, I think she knows everything about me now, I explain sit down and have a good talk. I tell her my feelings, tell her how I feel*" (K2). Responsive staff were viewed as reinforcing patient-oriented care coordination which can lead to service users being grateful and satisfied with the services received. Non-responsiveness was described as leading to feelings of being disempowered, unwillingness to cooperate and attempting to 'work around' the service or questioning the value of the service "*So they send someone round to pull a duvet up in the morning, and they send someone round at twelve o'clock to take a, a micro dinner out of my freezer and put it in there, you know, in the microwave, and I can't understand that, you know. That's absolutely useless isn't it?*" (K3).

## Expectations

Patients' often had expectations about their coordination of care, which were sometimes not met. "*I was disappointed with [staff]...you'd have thought she knew what she was coming for. You would have thought she'd have got the dressings so that when she arrived here she could do me leg, but it didn't happen*." (K3) Others received coordinated care at a level better than they expected "*You know, like you go into a different hospital you think oh I'll have to explain…all these things, they'll be asking me all these different questions...no, it was not like that at all*." (carer K106).

## Role

**Carers** helped to coordinate care within primary care including, for example, in relation to medication and social services.

*'Yes, and I, in terms of ordering like repeat prescriptions and medications, I deal with it, I go in and deal with it'* (carer K104).

*'I've had to constantly say "'Please can you try and sort this?' I was worried that my mum's diet wasn't right, so can we now introduce Meals on Wheels?'* (carer K101).

In addition carers offered physical support to patients *'I will help him in and out of the bath and, he doesn't, you know, I, he fell down a few times the other day and I picked him up'* (carer K107).

The LCNS keyworker if present was usually viewed as the main coordinator of the patient's care, promoting continuity and ensuring patients and carers knew who to access for information and advice. This was sometimes achieved through regular phone contact *"I can ring her up and she could ring me up, you know, she rings me up now and again and asks me "How are you getting on?" and everything else, you know. But, you know, she's good as gold"* (K12).

*"…over Christmas it's a real fear of...are we going to have to have him suffering again for two weeks, she didn't, she sorted it, sent a request through to the chemist…I went and picked up a prescription, and everything was fine"*(carer K104).

The doctor's role was important in providing clear information *"She gives me the information; she's the only one who gives me any information. She's kind of straightforward with things. I know what she's talking about"* (P011).

But the doctor's workload was sometimes perceived by patients to hinder their capacity to help coordinate care "*I think she wants to be, and she tries to be, but I don't think she can be, because of the workload, the workload that they've got on top of them*" (carer K101).

## Timescale

Patients who perceived an inappropriate delay had occurred often presumed a lack of coordination "*I'm not looking for blame but what I am, what I am saying is the timescale between the actual issue arising, the problem, and making a diagnostic report of the outcome is too long*" (carer K101).

For others the timescale was short and efficient "*Yes, when I go into Hospital X they might turn round and say 'You need x-rays.' And they don't muck about, you know, so say if I had a clinic tomorrow, my x-ray would be tomorrow morning before I saw the doctor.*" (K16). Regular updates and clear consistent messages aided perceptions of good coordination.

## Information

Despite information throughout the entire care pathway being viewed as an integral component of the coordination of care the instigation of the sharing of information varied. Information provision was sometimes prompted by patients, or at other times offered freely by clinicians as in these two patients with COPD and emphysema *'Yes. If I don't, I ask. I mean last time I went, I asked them questions about my prognosis and Dr X, he gave me a prognosis. I mean I'm seventy-two so I said, you know "What, what are my, what's my future?" So he, he, he did a quick calculation on the computer and gave me a prognosis'* (K10).

*"...she's very nice, she was the first one that told me how me condition was and it was not curable. It's the first time I found out about that, and then she enlightened me the outcome of me situation"* (K6).

### 7.3.3 Client Services Receipt Inventory Data

All 20 patients completed a CSRI at T1, 15 at T2 and seven at T3.

Twelve (60%) patients named a person as their main carer who for the majority of participants was their son or daughter. Unlike the Edinburgh and Midlands report, the ECOG performance scale showed that for most cancer patients there was gradual health deterioration while patients with COPD seemed to remain stable across time. See Table 21 below.

**Table 21. CSRI completions and ECOG score**

| ID | Main condition | T1 (n=20) | T2 (n=14) | T3 (n=8) |
|---|---|---|---|---|
| K1 | Lung cancer | 0 | 0 | 0 |
| K2 | Lung cancer | 1 | 2 | 2 |
| K3 | Adenocarcinoma | 1 | 1 | 1 |
| K4 | Lung cancer | 3 | dead | |
| K5 | Lung cancer | 2 | No data | 2 |
| K6 | Idiopathic pulmonary fibrosis | 3 | 3 | withdrawn |
| K7 | Dermatomyositis | 3 | 2 | withdrawn |
| K8 | COPD | 2 | 2 | 2 |
| K9 | Lung cancer | 1 | 3 | dead |
| K10 | Emphysema, COPD | 2 | 3 | 2 |
| K11 | Lung cancer | 3 | dead | |
| K12 | Lung cancer | 2 | 0 | 0 |
| K13 | COPD, emphysema, Lung cancer | 1 | 3 | dead |
| K14 | COPD | 2 | 0 | 1 |
| K15 | COPD | 2 | 2 | withdrawn |
| K16 | COPD | 2 | withdrawn | |
| K17 | Lung cancer (small cell) | 2 | 2 | withdrawn |

| | | | | |
|---|---|---|---|---|
| K18 | Lung cancer | 2 | withdrawn | |
| K19 | COPD | 1 | withdrawn | |
| K20 | COPD, Lung Cancer | 1 | 2 | withdrawn |

Based on the longitudinal data, cancer patients were more likely to receive palliative care services in comparison to COPD patients who were more likely to self-manage while also accessing pulmonary rehabilitation. Tables 22-24 summarise usage of services for these patients.

**Table 22. Community services usage**

| Community services | T1 (n=20) | T2 (n=14) | T3 (n=8) | Total |
|---|---|---|---|---|
| GP at practice | 62 | 29 | 11 | 102 |
| GP at home | 16 | 3 | 0 | 19 |
| GP on phone | 100 | 2 | 1 | 103 |
| District nurse | 0 | 1 | 2 | 3 |
| Palliative care nurse | 18 | 9 | 12 | 39 |
| Lung nurse | 6 | 0 | 0 | 6 |
| Other | 22 | 14 | 4 | 40 |

**Table 23. Secondary care usage**

| Secondary care | T1 (n=20) | T2 (n=14) | T3 (n=8) | Total |
|---|---|---|---|---|
| 1. Hospital admissions | 6 | 1 | 2 | 9 |
| Total days in hospital | 141 | 14 | 2 | 157 |
| 2. Outpatient visits | 81 | 72 | 14 | 167 |
| 3. Day visits | 1 | 11 | 10 | 22 |
| 4. A&E visits | 10 | 3 | 2 | 15 |
| 5. Emergency Ambulance calls | 5 | 2 | 2 | 9 |

**Table 24. Home Help / meals on wheels visits**

| Time | T1 (n=20) | T2 (n=14) | T3 (n=8) |
|---|---|---|---|
| Number of Patients living at home and receiving home help (HH) or Meals on Wheels (MW) | 1 MW | 1 MW, 1 HH | 1 MW |
| Total Visits | 90 | 111 | 90 |

### 7.3.4 Interviews with clinicians

## Professionals on site

Seven clinicians were interviewed for the project.

**Table 25. Clinician interviews**

| Code | Staff | Current setting | Sex |
|---|---|---|---|
| K300 | Palliative nurse | Community | F |
| K205 | Consultant chest physician and general physician and clinical lead | Hospital | M |
| K201 | Respiratory nurse specialist | Secondary care | F |
| K202 | Lead respiratory nurse specialist | Secondary care | F |
| K203 | Nurse specialist | Secondary care | F |
| K204 | Lung cancer nurse specialist and palliative care nurse | Secondary care | F |
| K206 | Consultant chest physician and holder of lead clinical position | Secondary care | M |

## Qualitative results

Three themes emerged from the clinician data: coordination elements, identification, and roles.

#### Coordination

The quality of coordination can be dependent upon electronic access to information within and across primary and secondary care, a keyworker to coordinate care, and good working relationships. Outcomes of good coordination include minimal negative impact on patients, a peaceful death and grateful patients. COPD patients were difficult to identify for palliative care.

Good coordination involved easily accessible information for each specialty, a specialty specific electronic patient record *'So that I could be writing something, putting it in the notes here now and it's visible on the other side of the hospital, or at home or wherever, immediately. So what we need in specialities is ways of drawing information that suits us. So I may want to see the x-ray report, the histopathology report, the lung function, some nursing notes, for a patient with lung cancer'* (K205).

Access to a keyworker also reinforced coordination between professionals *'…It's really helpful to have our specialist nurses because they are sitting there looking after the patient, and that's, that's their role, so they coordinate things quite well, or very well I would say'* (K205).

Collaboration was also identified as an element required for coordination *'... in order to coordinate you've got to collaborate*'(K206).

Having good relationships with other clinicians and working in harmony aided coordination *'... it's crucial and (I) try very hard to make sure that I have good relationships with people like the GPs and the District Nurses and anybody else everyone ends up making different decisions if you don't work in harmony'* (K206).

One of the barriers to coordination across primary and secondary care was the lack of an integrated electronic patient record *'If we were all integrated and could see what, ….what we've been doing at X Hospital...but I could also see they went to see their GP last Thursday and it was about a cough... And the GP can see what we're doing. Enormous benefit…'* (K207).

Also, time was an important barrier and more specifically clinicians' lack of time to be *'on the ball'* about patients *'I think doctors in particular don't have as much time as one would, one would like'* (K202).

Outcomes of good coordination include minimal negative impact on patients '*Like the patient might need chemotherapy and radiotherapy and a CT scan, and coordinating is about trying to do that in the most efficient manner for the patient…Trying to make sure the patient doesn't have to come up three days running if they could have everything done on one day…*' (K205).

## Identification as having palliative care needs

Clinicians used diagnostic, symptom, treatment, trajectory and social support markers to identify patients with palliative care needs. Identification of these patients aids care coordination but identifying when COPD patients require palliative care was difficult due to the nature of the condition and the absence of open discussion about the trajectory of the illness and therefore also the need for palliative care in the future. Clinicians generally considered that because patients with COPD tend to fluctuate with periods of acute exacerbations and then recover it is difficult to predict when they will need palliative care *'The COPD is a disease that is in and out. One minute the patient is well, they are treated and out. It is difficult condition, in not like cancer…"* (K201).

Clinicians thought that the difficulty in identifying the COPD patients with palliative care needs may be due to the patient or GP *"The COPD patients... I think some of that is that they're so used to the, the whole thing around going to a respiratory clinic, being admitted, treated for a chest infection and thinking OK, I'm feeling better now, I don't need palliative care. GPs are sometimes not always happy to refer…partly because of the fact that they will be very ill then get better, and that makes them feel uncomfortable…"* (GP, K206).

## Roles

A cohesive approach to care coordination between primary and secondary care was absent where the coordination of patient care was dependent upon professional background *"Patients move from my care to treating physicians and they don't, they're not necessary at X hospital so they go into X Hospital for chemotherapy, X hospital for radiotherapy, they either have surgery with the thoracic surgeons at X hospital..."* (C207), the placement of the professional and the remit of individual professionals *"…Or they are already referred on to go to a hospice at that point and therefore we withdraw…"* (C203).

The LCNS role involved coordinating the care of the patient with the GP, with hospices and with other hospitals *"They do all sorts of nice things for them when they're in hospital, they often make sure the communication gets to the GP, they often make sure the communication is working well with Hospital X and Hospital X, they talk to the hospices"* (C205). The LCNS coordinates the care with home-care teams *"I would normally speak to one of the nurse specialists and they would talk to the hospice or the Macmillan home-care team"* (C205) and to know the patient's values, needs *'And the whole point of the key person is knowing the patient, knowing the family and knowing the patient's values and wishes'* (C204).

The consultant's role was central to diagnose, treat and refer for further treatment *'So my coordination with other colleagues for lung cancer patients for example is, it is limited. I think that's because I'm involved mostly in the diagnostic phase of the patient's pathway. So my role is to establish referral and put patients in touch with appropriate physicians'* (C207).

While the community nurse specialist focuses on coordinating the patient's care in the community ' *Well actually the palliative care team to ensure, in their own house, that they are safe, and they are supported, haven't' got any worries, that there is symptom control. So there you would then do the coordination of care and this would be the community coordination. So they have Social Services? Is that something they need at home…?'* (C204). Their role also involves efforts to build or rebuild relationships between professionals with the aim to improve coordination and thus patient care *'I have pestered now have regular meetings going on where it's been about rebuilding relationships with the GPs, the District Nurses. Because the relationship with myself has never been bad, but I've felt that I've been kind of, that they'll say to me "Oh I'm not going to bother asking the District Nurses, can you do this?" And you say "Well hang on a minute, they're responsible, they need to be involved in this"'* (C206).

### 7.3.5 Significant event analysis (SEA)

The SEA was conducted with staff from the Department to explore their reflections on specific cases, identify barriers to good coordination, the facilitators for good coordination and ways to improve coordination. Five cases were reviewed in the SEA  and the data gathered within the SEA mainly confirmed the analysis of the serial interview data. The SEA discussion enabled further context for the data to be gathered, explored and subsequently examined. The SEA provided an opportunity for the Department professionals to reflect upon coordination of care and to review their work in regard to this construct. They reported that data from patient surveys suggests that it is very important for patients to have someone there when they receive the cancer diagnosis, someone who has the time and skills to provide support.

### *7.4 Discussion*

The findings from the London data highlight the continuing and important role of information provision and communication within primary and secondary care and across these two care sectors. The patient and carer data indicate the importance for patients to have information provision shaped around their needs, values and current understandings of their care. Patient and carer data showed that they do evaluate the responsiveness of individual professions and this in turn shapes the way that they coordinate their efforts with care providers. Regular updates and an absence of mixed messages aid patient and carer perceptions of good coordination.

Staff identified key elements required for good coordination within and across primary and secondary care. This includes access to electronic information within and across primary and secondary care, a keyworker to coordinate care, and good working relationships. Staff identified that collaboration is key to care coordination and outcomes of good coordination were mostly described in terms of patient outcomes, specifically: minimal negative impact on patients, a peaceful patient death and grateful patients.

# 8 Case study synthesis

Through an iterative process of consultation and theme development, the project teams in each area collaborated to share data and findings. The findings were used to inform the choice of service development statements to be tested in the consensus seeking phase of the project. Integrating the findings consisted of a process of sharing initial themes emerging from the local case studies and consulting with colleagues to see which could be combined into common themes in each setting and which though not common, were significant in at least one setting. Each theme was further divided into sub-themes to better reflect the focus of each setting. The focus here is on the data around the serial interview participants.

## 8.1 Serial interview participants

In total, we recruited 56 patients and 25 carers and followed them through serial interviews (125 with patients, 56 with carers) to understand their experiences and opinions about coordination. See Table 26 below. They had 63 hospital admissions, 353 clinic attendances, 39 day visits, 31 A&E attendances and 36 emergency ambulance calls to reflect on. This cohort also had 376 District Nurse visits, 91 GP visits and 243 telephone calls with a GP.

In total the group completed CSRIs that covered 110 periods of three months in this diverse group of people approaching the end of life, which relates to 27.5 years of patient care.

Table 26. **Summary of all patients for serial interviews**

| ID | Age | Sex | Main Conditions | MM | Traj | Int # | Carer | Car# | Status |
|---|---|---|---|---|---|---|---|---|---|
| E1 | 82 | M | COPD; heart failure, renal failure | 3 | OF | 1 | No | - | Dead |
| E2 | 76 | F | Heart failure, renal failure, diabetes | 3 | OF | 1 | E102 | 2 | Dead |
| E4 | 85 | M | Heart failure, ischemic heart disease (IHD), mild dementia | 3 | OF | 3 | E104 | 3 | Alive |
| E5 | 86 | F | Pulmonary fibrosis, IHD, Paget's disease, hypothyroidism | 4 | OF, Frail | 2 | No | - | Dead |
| E6 | 66 | F | Liver failure, diabetes, IHD | 3 | OF | 3 | No | - | Alive |
| E8 | 56 | F | Neurological illness, polio, COPD, epilepsy | 4 | OF | 3 | No | - | Alive |
| E13 | 89 | F | Unresponsive episodes, atrial fibrillation, hypertension, | 3 | Frail | 3 | E113 | 3 | Alive |
| E15 | 58 | M | Pancreatic cancer | 1 | Cancer | 1 | Yes | 1 | Dead |
| E17 | 75 | F | Diabetes, hypertension | 2 | OF | 2 | No | - | Dead |
| E20 | 75 | F | IHD | 1 | OF | 3 | No | - | Alive |
| E25 | 70 | F | Multiple sclerosis | 1 | Frail | 2 | E125 | 2 | Alive |
| E26 | 71 | F | Parkinson’s disease, asthma | 2 | Frail | 3 | E126 | 3 | Alive |
| E27 | 68 | M | Alcoholism, prostate cancer, peripheral vascular disease | 3 | Frail | 3 | No | - | Alive |
| E28 | 87 | M | Renal failure, diverticular disease, mild dementia, prostate cancer, | 4 | Frail | 3 | E128, E141 | 4 | Alive |
| E32 | 75 | M | Mitral valve disease, | 1 | OF | 1 | No | - | Dead |
| E33 | 71 | M | Hypertension, atrial fibrillation, heart failure | 3 | OF | 3 | E133 | 2 | Alive |
| E34 | 85 | M | Hypertension, motor neurone disease, arthritis | 3 | Frail | 1 | No | - | Alive |
| E37 | 69 | M | peripheral vascular disease, IHD | 2 | OF | 3 | E137 | 2 | Alive |
| E39 | 60 | M | Multiple sclerosis | 1 | Frail | 3 | E139 | 2 | Alive |
| E40 | 87 | F | Renal failure, metastatic melanoma | 2 | Cancer, Frail | 1 | E140 | 1 | Dead |
| W1 | 67 | M | Diabetes, Charcot’s arthropathy, cellulitis | 3 | OF, Frail | 3 | No | - | Alive |
| W2 | 79 | F | Diabetes, heart failure, osteoarthritis | 3 | OF, Frail | 3 | No | - | Alive |
| W3 | 79 | M | Renal failure, heart failure, ischaemic heart disease (IHD), hypertension , osteoarthritis | 5 | OF, Frail | 3 | W113 | 3 | Alive |
| W4 | 82 | F | Lung cancer, stroke, ischaemic heart disease | 3 | Cancer, Frail | 2 | W114 | 2 | Dead |
| W5 | 56 | M | Pulmonary fibrosis, cerebral aneurysm, hyperlipidaemia | 3 | OF | 2 | No | - | Dead |
| W6 | 82 | M | Renal failure, heart failure, anaemia, osteoarthritis | 4 | OF, Frail | 3 | W116 | 3 | Alive |
| W7 | 92 | M | Respiratory failure, heart failure, renal failure, osteoarthritis, blind (glaucoma) | 5 | OF, Frail | 3 | W117 | 3 | Alive |

| ID | Age | Sex | Main Conditions | MM | Traj | Int # | Carer | Car# | Status |
|---|---|---|---|---|---|---|---|---|---|
| W8 | 80 | M | Prostate cancer, mild dementia, osteoarthritis | 3 | Cancer, Frail | 1 | W118 | 1 | Dead |
| W9 | 71 | M | Multiple sclerosis, osteoarthritis | 2 | Frail | 3 | No | - | Alive |
| W10 | 73 | M | Prostate cancer, mild dementia, hypertension | 3 | Cancer, Frail | 2 | W110 | 2 | Alive |
| W11 | 71 | F | Multiple sclerosis | 1 | Frail | 3 | No | - | Alive |
| W12 | 67 | M | Peripheral vascular disease, renal failure, COPD | 3 | OF, Frail | 3 | W112 | 3 | Alive |
| W14 | 41 | M | Metastatic melanoma | 1 | Cancer | 1 | Yes | 1 | Dead |
| W15 | 81 | F | COPD | 1 | OF, Frail | 1 | No | - | Alive |
| W16 | 58 | M | Multiple sclerosis | 1 | Frail | 2 | No | - | Alive |
| W17 | 90 | F | Stroke, osteoarthritis | 2 | Frail | 1 | No | - | Alive |
| K1 | 61 | F | Lung cancer, metastatic to adrenal glands | 1 | Cancer | 3 | K101 | 3 | Alive |
| K2 | 68 | M | Lung cancer, emphysema | 2 | Cancer, OF | 3 | K102 | 1 | Alive |
| K3 | 76 | M | Lung cancer, Asbestosis | 2 | Cancer | 3 | No |  | Alive |
| K4 | 82 | M | Lung cancer with leg metastasis, ischemic heart disease (IHD) | 2 | Cancer, OF, Frail | 1 | No | - | Dead |
| K5 | 54 | M | Lung cancer with bone metastasis | 1 | Cancer | 3 | K103 | 3 | Dead |
| K6 | 78 | M | Pulmonary fibrosis, IHD, emphysema, | 3 | OF | 2 | K104 | 1 | Alive |
| K7 | 55 | F | Pulmonary embolism, dermatomyositis, breast Cancer, hypothyroidism | 4 | OF | 2 | No | - | Alive |
| K8 | 70 | M | COPD | 1 | OF | 3 | K105 | 3 | Alive |
| K9 | 90 | F | Lung cancer, COPD, osteoporosis | 3 | Cancer, OF, Frail | 2 | No | - | Dead |
| K10 | 72 | M | COPD, emphysema | 2 | OF | 3 | No | - | Alive |
| K11 | 59 | M | Lung cancer, with stomach, throat and bone metastasis | 1 | Cancer | 1 | K106 | 1 | Dead |
| K12 | 65 | M | Lung Cancer | 1 | Cancer | 3 | No | - | Alive |
| K13 | 69 | M | Lung cancer , COPD, emphysema | 3 | Cancer, OF | 2 | K107 | 1 | Dead |
| K14 | 63 | M | COPD | 1 | OF | 3 | No | - | Alive |
| K15 | 66 | F | COPD | 1 | OF | 2 | No | - | Alive |
| K16 | 52 | F | COPD | 1 | OF | 1 | No | - | Alive |
| K17 | 46 | M | Lung cancer (small cell) with brain metastasis | 1 | Cancer | 2 | No | - | Alive |
| K18 | 64 | F | Lung cancer, diabetes, hyperthyroidism | 3 | Cancer | 1 | No | - | Alive |
| K19 | 74 | F | COPD | 1 | OF | 1 | No | - | Alive |
| K20 | 79 | M | Lung cancer, COPD, asthma, heart failure | 4 | Cancer, OF | 2 | No | - | Alive |

Column headings: MM – number of morbidities, Traj (trajectories represented), Int# (number of patient interviews), Carer (ID of carer(s) if present), Car# (number of interviews that carer participated in), status (whether the patients was alive or dead at the conclusion of the case study).

| **OVERALL TOTALS** | | | |
|---|---|---|---|
| Demographics | Long term conditions | Trajectories | Deaths |
| • Total participants 56<br>• Male 34, Female 22<br>• Average age 71.5; range 41-90 | • cancer=20, (lung 13, prostate 4, melanoma 2, pancreas 1)<br>• OF 45 (Heart failure=9, renal failure=7, COPD=13, Emphysema/pulmonary fibrosis/embolism/asbestosis/asthma=9, IHD=7)<br>• frailty 24 (Dementia=4, hypertension=8, neurological=7, diabetes=5,) | • 32-OF<br>• 23-Frail<br>• 18-Cancer | 16 |

Multimorbidity

- Number of patients with multimorbidity: 37
- Percentage of patients with multimorbidity 66.1%
- Average number of morbidities (all patients): 2.3
- Modal number of morbidities (all patients): 3
- average number of morbidities (patients with multimorbidity): 3.0
- average age (patients with multimorbidity) 75.8
- Deceased with multimorbidity 11
- Percentage deceased (all patients) 28.6%
- Percentage deceased (patients with multimorbidity) 29.8%
- Average age deceased patients: 72.0
- Average age deceased patients with multimorbidity: 78.6
- Average age deceased without multimorbidity 57.4

## 8.2 Combined CSRI data

The CSRI data allowed us to collate service usage patterns and measure physical mobility for each participant. The data provides some indication of the speed of final decline for cancer patients. Table 27 below shows average ECOG scores at each interview with number of completed ECOGs in brackets next to it.[5] Eighteen participants had a primary diagnosis of cancer at T1 (17 completed CSRIs). The number of completed CSRIs by patients with a primary diagnosis of cancer shows a severe drop off compared to non-cancer. As non-completion usually occurred due to either death or increasing illness causing a participant to withdraw, the comparison with non-cancer shows the relative speed of decline.[6] The seemingly anomalous increase in mobility at T3 for cancer patients should be understood as indicating that only those patients who were highly physically functioning at the start of the case study had survived to T3.

**Table 27. Cancer vs. non-cancer ECOG scores**

| Condition | T1 ECOG | T2 ECOG | T3 ECOG |
|---|---|---|---|
| Cancer | 1.76 (17) | 1.80 (10) | 1.00 (5) |
| Non-cancer | 2.45 (31) | 2.42 (26) | 2.57 (21) |
| All | 2.21 (48) | 2.25 (36) | 2.27 (26) |

The usage of both community and secondary services varied widely from setting to setting. The London data indicated that a patient with a malignant condition was more likely to be identified and offered palliative support than those with other main conditions. In the Edinburgh data, the amount of specialist palliative support experienced by serial interview participants in the community was close to nil and there was little evidence of generalist palliative care provision: where it occurred it appeared to be due to the initiative of either a particular clinician or a practice wide initiative. In the Midlands settings there was evidence of the impact of specialist palliative nurses in the community. The ethnographic observations at the Midlands site indicate that the practice was diligent in discussing and monitoring patients in the community who had been identified as having palliative care support needs.

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[5] An ECOG score of “0” shows full mobility and one of “4” shows complete lack of mobility.

[6] The T3 cancer column shows that those with a cancer diagnosis who were still well enough to participate were generally fairly highly functioning 6 months after initial recruitment.

Community services when averaged across sites showed a possible reduction in GP contact and increase in nurse contact over time.

**Table 28. Community service usage – all sites**

| Community Services | T1 (n=48) | T2 (n=36) | T3 (n=26) | Total |
|---|---|---|---|---|
| GP at Practice | 84 | 53 | 21 | 158 |
| GP at home | 55 | 23 | 13 | 91 |
| GP on Phone | 170 | 48 | 25 | 243 |
| NHS24[7] | 10 | 3 | 4 | 17 |
| Practice Nurse[8] | 14 | 21 | 58 | 93 |
| District Nurse | 97 | 136 | 143 | 376 |
| Palliative care Nurse | 24 | 9 | 12 | 45 |
| Lung Specialist Nurse | 14 | 8 | 6 | 28 |
| Other | 40 | 28 | 26 | 94 |

Secondary care usage (Table 29 below) gives an insight into the scale of services used by the participants over the different case studies. The nature of the Edinburgh case study which recruited patients based on a recent unplanned admission to a hospital explains why hospital admissions at T1 is seemingly higher per-capita than T2 or T3. Examining just the London and Warwick data indicates a higher usage of services per-capita over time.

**Table 29. Secondary care usage – all sites**

| Secondary care usage | T1 (n=48) | T2 (n=36) | T3 (n=26) | total |
|---|---|---|---|---|
| 1. Hospital admissions | 32 | 14 | 17 | 63 |
| 1a. Total days in hospital | 751 | 361 | 194 | 1306 |
| 2. Outpatient visits | 145 | 131 | 77 | 353 |
| 3. Day visits[9] | 7 | 16 | 16 | 39 |

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[7] Only includes data from the Edinburgh case study

[8] Does not include data from the London study.

| Secondary care usage | T1 (n=48) | T2 (n=36) | T3 (n=26) | total |
|---|---|---|---|---|
| 4. A&E visits | 30 | 5 | 6 | 41 |
| 5. Emergency Ambulance calls | 23 | 7 | 6 | 36 |

The amount of help given by relatives proved extremely difficult to quantify. Carers felt that they spent all their time caring regardless of how much physical activity they were undertaking. While the major stresses centred on aspects of physical care and ensuring medication was administered correctly, carers felt constantly on duty due to a continued need for vigilance regarding their partner's health.

Although this project is not able to provide accurate costings, the CSRI data does indicate a general increase in services over time for patients with most conditions but also seems to show a decrease in GP involvement balanced by increase in nurse involvement. The different patterns in service usage (for example the high amount of home help in the Edinburgh case study) may reflect a mixture of the different organisations and the cohort of participants in each study.

## *8.3 Combined serial interview themes*

Through an iterative process of work-shopping and teleconferencing between the local research teams, five common themes across all research settings were identified and are summarised in Table 30 below.

**Table 30. Common themes from the serial interviews**

| Themes | Subthemes |
|---|---|
| **Information:** The information participants received over time about their illness. | • for diagnosis<br>• for prognosis<br>• for treatment<br>• for treatment outcomes<br>• about future care<br>• about palliative care<br>• about resources and assistance |
| **Communication**: how patients and carers **perceived** communication between and within settings between professionals. | • between settings (secondary and primary care)<br>• within settings between professionals and patients/carers<br>• Mode of communication |
| **Experiences**: of noticeably good or poor coordination. | • Patient/carer experiences<br>• Professional experiences<br>• Explanations |

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[9] This row does not include data from the Midlands case study.

| | |
|---|---|
| | • Uncertainty<br>• Timescale and delays |
| **Expectations:** | • Patient/carer expectation of:<br>o Services received<br>o Care received<br>• Professional expectations |
| **Role** focuses on the *carer's role*, the role of the *keyworker*, (professional who is the main coordinator for the patient's care) and other professionals perceived as important by patients/carers | • Carer role<br>• Other professional role<br>• Keyworker role |

The themes were applied both synchronically and diachronically (i.e. longitudinally) to the data. Thus changes could be shown by differences between interviews (e.g. more or less access to information, increase in ability to navigate the system) as well as the accumulation of experiences. As an example of the latter, the subtheme of uncertainty was a key means for understanding how repeated experiences increased knowledge of the system but reorganisations decreased it. For example, the GP surgery in the Midlands case study used a telephone triage system. One carer very much disliked the triage system at the outset of the study and had been very reluctant to contact the surgery but, by the third interview had become used to the system and no longer hesitated to call when necessary. The carer described a corresponding increase in her confidence in coping. Another had learnt how to manage a number of her husband's problems with the help of the district nurse and at the same time was able to instruct the private carer as to how to undertake aspects of her role. Some patients were able over time to find ways of obtaining what they needed for themselves through developing personal contacts or strategies for dealing with systems-such as arranging ambulances.

## 8.4 Key issues in coordination

The aim of the fieldwork at the case studies was to evidence good practice in coordination and collaboration alongside evidence of failings in it. The themes of Information and Communication as perceived by patients/carers directly address events which are likely to be engendered by issues in coordination. Likewise, the discussion around Timescale in the London setting can be treated as a proxy for coordination. The theme of Role attempts to describe the actions of all involved who may collaborate with each other or need to coordinate their actions in some way. The two themes of experiences and expectations are used to describe what influences how participants (patients, carers, professionals) may act. For example, a carer with low expectations may decide that it is not worthwhile to initiate contact with a professional or may actively hide information if it is felt that there is a risk of being admitted to a location where they have had bad experiences. Likewise, professionals may decide not to offer support if they feel the system does not provide resources. Uncertainty and Explanation provide insights into behaviour.

Taken together with the literature review we derived some key moments and issues in coordination to inform the development of service development statements.

### 8.4.1 Transitions in care

Transitions between primary and secondary care in all the case studies demonstrated repeated failures of coordination. These can be inventoried as follows:

- Primary care to secondary care (especially emergency admissions)
    - lack of identification of palliative needs during process.
    - lack of information travelling with patient.
    - negative experiences reducing patient and carer willingness to collaborate with the health system.
- Secondary to primary
    - lack of an expected contact with GP after discharge. This was strongly stated.
    - disruption to home-care providers.
    - delays in discharge process.
    - disruptive medication changes.
    - it is of note that the Edinburgh case study shows a *psychological* dip immediately post discharge but often a *physical* recovery for a period of weeks or a few months afterwards.
- Reorganisation of care teams
    - this was evidenced in the Midlands study where the DN reorganisation seems to have massively increased uncertainty and reduced patient ability to coordinate with professionals.

There is evidence of successful coordination in both primary to secondary and secondary to primary admission but patients and carers generally only noticed experiences of poor care management. Some instances of successful coordination were as follows:

- Edinburgh case study. The hospital in the study generated a new discharge system where all discharge notes were recorded and orally processed using a speech recognition system. This seems to have facilitated the process and provided typed notes.
- Keyworker role. It is particularly noteworthy in the London serial interviews that patients with the Lung Cancer Nurse as a keyworker held the perception of well-managed care.
- Experience. The Midlands site shows that the surgery's telephone system once understood was seen as positive once participants had learned it.

### 8.4.2 Understanding of palliative care

In order to better coordinate supportive and palliative care both health professionals and service users need to understand its potential role and impact. Evidence from this research indicates that the understanding of palliative care was extremely variable. In cases where there were strong links with palliative care specialists, there was evidence of greater knowledge of the area. In other cases, individual clinicians might be strong champions of palliative care. Drawing from the findings it can be seen that:

- Palliative care provision is not 'normal' for generalists.
    - In primary care, some staff may become informal advocates for primary palliative care while others implicitly or explicitly 'opt-out' of it.
    - In primary care there is evidence of clinicians treating palliative care as an extension of the normal primary care role.
    - In secondary care, palliative care appears more likely to be perceived as a specialist discipline.
- Palliative care generally regarded as terminal care or as managing a final, swift decline by generalists without a special interest in palliative care.
    - Little evidence of patients being identified or assessed for palliative care other than managing terminal care.
    - In Edinburgh, where only one of the serial interviewees had a primary cancer diagnosis, none of the patients identified by the project for whom a GP could be contacted were on a palliative care register of any type. Nor were any discovered who had been added to the "electronic palliative care summary."
    - In Midlands and London, there was evidence of patients with a cancer diagnosis being added to a palliative care register such as a practice-based GSF register or equivalent.
- Patients and carers evidenced little understanding of palliative care unless previously admitted to a hospice. When asked directly, the answers suggested that palliative care was perceived as a withdrawal of treatment.

### 8.4.3 Identifying palliative support needs

With the exception of lung cancer patients in London, few of the patients had been identified as needing palliative support. The patients did not perceive themselves as needing or desiring palliative care support, although many regarded themselves as needing more support or care in general. It needs to be recognised that palliative care as used in this report is a professional construct and patients seek good care rather than being labelled as being in one group or another.

### 8.4.4 Planning future care

There was relatively little evidence that proactive planning for future care had been undertaken with the serial interview participants except for those with a single, dominant progressive life-limiting condition such as cancer with a poor prognosis, advanced multiple sclerosis or Parkinson's disease for example. There were some particular aspects of this that can be evidenced.

- Almost no evidence of patients or carers having expressed "a preferred priorities for care" or equivalent.

- No evidence of discussions about future care. It is notable that patients also indicated little desire to have such discussions.
- Some patients had a version of a "do not attempt resuscitation" form. Two known examples in Edinburgh  were due to a prior hospice admission and a patient with advanced Parkinson's disease.
- In the London data patients with cancer were more likely to have had such discussions than elsewhere.

### 8.4.5 Communication between professionals and service users

There was frequent evidence of a lack of communication between professionals and patients around issues pertaining to end-of-life care. This was often mitigated in cases where the patient had a keyworker.

- In Edinburgh there was evidence of non-communication on both sides as a strategy. There were examples of "not bothering" patients by primary care professionals and vice-versa.
- In Warwick the telephone contact system promoted efficiency for staff but initial contact with it by patients may have reduced patient desire to initiate contact.
- In London, patients with a malignant condition (primarily lung cancer in this study) had a noticeably different experience to those with non-malignant conditions.
- In general patients and carers expressed uncertainty about what is appropriate to communicate and therefore also 'not bothering' professionals.
- Patients expressed a perception that  consultations in primary care tended to be brief, possibly cursory and focused primarily on the immediate medical issues.
- There do seem to be some systems that promote communication. The electronic patient record in London and electronic palliative care summary in Edinburgh were noted in this regard. The latter, however, requires prior identification of the patient as having palliative care needs and thus was little in evidence during the fieldwork.
- Where communication  was perceived as successful by a patient or carer it was often the most highly regarded element of care. It may be a proxy for 'evidence of caring,' and also seems to engender trust and willingness to collaborate. It was particularly notable in the serial interviews that 'younger' clinicians were seen as much better communicators than 'traditional' clinicians.
- There were examples of where patients may have been put on local non-palliative registers (such as of "vulnerable" patients) leading to extra support. Patients often had no idea of this and perceived the increased support as normal.

### 8.4.6 Role of multiple morbidities

Although most patients and carers can provide an itemised list of health conditions, unless they had a dominant progressive illness, they seemed unsure about the implications. Many seemed to regard the multiple issues as simply a matter of "getting old."

- Coordinating multiple services appears to be extremely difficult leading to patients reporting positive experiences in some aspects of their healthcare but negatives in others.

### 8.4.7 Role of keyworker and long-term conditions

There is evidence in the London study that the patients with lung cancer had better coordinated care than those with non-malignant respiratory conditions. Patients with lung cancer had access to a lung cancer nurse specialist who provided dynamic, proactive and effective management of their healthcare needs. It was also noticeable that this nurse was a strong advocate and practitioner of providing early supportive and palliative care needs. Although this indicates a strong support for the role of a keyworker in coordinating supportive and palliative care, the data from other sites is more ambivalent.

- Particularly conditions appear to be well managed across all sites; cancer and diabetes in particular.
- There is relatively little sign of coordination by hospital specialists across specialities therefore patients with multiple morbidities experience patchy, uncoordinated care.
- DNs who may be seen as keyworkers only tend to attend a patient if there is a specific medical need such as dressing a wound or providing injections, this may be to manage their heavy caseload.

### 8.4.8 Summary

Taken together it seems that particular conditions are well managed for either historical reasons (substantial funding in cancer care for example) or because the condition is particularly amenable to short, intensive care (cancer) or can be controlled through a particular regime (diabetes).

Communication between providers and between providers and patients developed through structures and processes that facilitate contact, play an important role in effective coordination in palliative care. Communication between healthcare providers and patients/carers regarding the illness, treatment procedures and aspects of organisation of services play a major part in improving the experience of care. When appropriate structures are in place and the processes work well, the patient and their carer can experience well-coordinated care, where their needs are proactively managed and any change can be rapidly addressed.

## *8.5 Creating Service Development Statements (SDS)*

### 8.5.1 Method

The statements were designed by identifying the key issues emerging in developing and improving coordination of care for patients approaching end of life through the narrative literature review and the case studies summarised above.

First, each research team was asked to suggest key issues emerging from the case study and potential service developments deriving from it.

These suggestions were then integrated with the results of the literature review, consultation with service user groups and consultation with the steering groups. This resulted in a 'long list' of potential developments which was then circulated to the steering group.

Following feedback a short list of 20 SDS's was chosen. This was then shared with each centre who were asked to further refine it.

After discussion, the shortlist was revised and then categorised into seven sections and an iterative process of wording SDSs was undertaken and tested on local colleagues.

Each SDS was designed to cover a single change that could be implemented either at a strategy design level or as a single institutional change. Although there is no single definition of what constitutes a SDS, documents containing them that were examined by the research team revealed that they were generally short and declarative. The statements themselves were divided into two types: those that were associated with a specific setting or care provider and those that were seen as applying at a local policy level ("strategic"). The complete list can be seen in Table 31 below. Each SDS was given a number which will be used to identify it throughout this report. E.g. SDS#5 is number 5 in Table 31 below. Once finalised, these statements were used to create the e-Delphi survey.

As an example, the development of SDS 6 & 7 is given (see Table 31). At all sites, patient and carer interviews revealed that coordination often failed at hospital discharge. Our user groups confirmed this as a key issue needing addressed, so we discussed this at the significant event analysis meetings in Edinburgh and Warwick. Hospital doctors mentioned their reticence, from previous experience when told by GPs to mind their own business, to advise GPs to visit even if they thought this might be useful, unless there was a specific task to do. They helped formulate SDS#7. In Warwick it was noted that GP visits for all illnesses had been dropping nationally. Then we drafted SDS#6 and this was circulated with other candidate SDSs to the wider group for testing in the Delphi process. Similarly the literature review and the London data around specialist nurses led us to suggest SDS#4. Each patient has a named professional as a coordinator of their care (i.e. a 'keyworker').

**Table 31. Complete list of service develop statements**

| **In the Community** |
|---|
| 1. More patients with malignant and non-malignant diseases are identified and |

entered on a palliative care register.

2. Regular planned review by primary care teams of patients who ''may be'' approaching the end of life is undertaken for the purpose of being added to the practice palliative care register.

3. When a patient who ''may be'' approaching end of life has a care transition (e.g. discharge from hospital to the community) and as a result requires increased personal care they are considered for the practice palliative care register.

4. Each patient has a named professional as a coordinator of their care (i.e. a 'keyworker').

5. Each patient (and their informal carer) is offered personalised advice and information on how and when to seek help in an emergency, both in-hours and out-of-hours.

6. Following discharge from hospital, the primary care team contacts each patient who has been identified as approaching the end of life within two working days.

**Secondary care**

7. Where a hospital team has identified a patient as approaching the end of life they will suggest to the relevant primary care team on discharge that the patient is a candidate for the practice palliative care register.

**Care homes**

8. Everyone admitted to a care home is provided with the opportunity to have an advance care plan started.

**All Settings**

9. A patient-centred, holistic needs assessment is carried out when a patient is identified as approaching the end of life.

10. All patients are provided with the opportunity to develop an advance care plan. This may cover medical and non-medical issues as appropriate.

11. When a patient being in the last days of life is recognised in any setting, an integrated care plan such as the Liverpool Care Pathway is started.

**Informal Carers**

12. The main informal carers of patients who have been recognised as approaching the end of life are identified and recorded systematically.

13. Carers' needs are assessed for the purpose of being given support in accessing local services.

14. When a patient approaching the end of life has no informal carer, the need for additional support is considered.

**Home-care workers and providers**

15. Providers of personal care for people living at home who are approaching the end of life have procedures in place to ensure that these patients have at least one 'core' care-worker who visits the patient regularly and staff changes are minimised.

| |
|---|
| 16. Training is provided to enable professional home-care workers to assess patient (and carer) needs and identify gaps in services and resources. |
| **Strategic** |
| 17. Each area has measures in place to ensure effective collaboration between community healthcare (GPs, District Nurses, pharmacists and other allied health professionals) social services (social and personal care) and community/ hospice based palliative care specialists. |
| 18. Each local area has an "information strategy" to ensure that the information needs of patients and carers can be met. |
| 19. Whenever a service change occurs, patients and informal carers are fully informed, in advance if possible, and while a change is being made (e.g. change in a keyworker). |
| 20. Prompt and accurate communication between primary and secondary healthcare is maintained and out-of-hours services, home-care providers, informal carers and patients are included in this communication. |

# 9 E-Delphi survey

## *9.1 Methods*

In order to establish professional consensus on the most relevant service developments we used the Delphi technique. This is a method of reaching consensus on a particular research question and has been widely used in healthcare research.(46, 127) In general, a Delphi survey involves circulating a set of statements, assumptions, solutions or options to be anonymously scored by participants. Percentage agreements on the statements are then circulated to the participants who re-score them in a second round in the light of other participants’ responses.

We undertook this consensus-building work through the use of an online survey tool (Bristol Online Surveys),[10] allowing us to engage with a cohort of professionals from across the United Kingdom.

The intended cohort of 50 was purposively selected from policy makers, clinical leads for end-of-life care, clinicians, and national user representative groups.

**Inclusion criteria**

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[10] http://www.survey.bris.ac.uk/

- In-depth knowledge of current policies and/or practices in at least one of the three project areas.
- Experience gained as a policy maker, clinician, allied health professional or service user.

**Exclusion criteria**

- Associated with project (e.g. member of advisory group).
- Not based in the UK.

The aim was to recruit approximately 50% of the cohort from clinicians and the remainder to be a balance of the other three groups. Although the project focused on non-specialist palliative care, the Delphi aimed for a balance of specialist knowledge of end-of-life care and non-specialist knowledge.

**Scoring**

The participants were asked to score the importance of each statement for improving coordination on a five-point Likert scale ranging from 'very important' to 'irrelevant:'

- Very important
- Important
- Of Equivocal importance
- Unimportant
- Irrelevant

It should be noted that this scale was considered appropriate as it seemed unlikely that anyone would wish to give a negative opinion (as in, the proposed SDS would decrease coordination). However it was considered possible that participants might want to differentiate between developments that in their opinion would have no significant impact on coordination as opposed to those which would have no relevance to the subject. An option to leave free text comments was included. The questionnaire was piloted with six professionals and then revised before circulation.

In the first round, in addition to scoring the 20 Service Development Statements, the participants were asked to indicate their level of agreement with the statement:

*Improving the coordination of care will* **in itself** *lead to better patient and carer outcomes.*

This was added to the survey in an attempt to discover whether the general presumption in the literature surveyed that increasing coordination would improve patient outcomes.

Following round one, we calculated the median score and the percentage agreement for each item using the Bristol Online Surveys statistical tools.

In round two each participant who had completed round one was given a copy of their own scores, a summary of the group scores and asked to re-score the same 20 SDSs in the light of this information. The group scores were presented back to participants in round two in the form of "X% of respondents thought this development was important or very important. Of those, Y% thought it was very important." So for example, in SDS#1 the respondent learnt that "84% of respondents thought this development was important or very important. Of those, 65% thought it was very important."

In addition, following discussion with the steering group and in light of the high scoring in round one, participants were asked at the end of the survey to rank their top 5 SDSs in order of priority. This was thought to increase the chance of allowing us to discriminate more finely because the trial had shown that there was a high degree of importance attached to all the SDSs.

## 9.2 Results

### 9.2.1 Participation

A total of 99 potential participants who fulfilled the inclusion criteria were approached for recruitment. Of these, 60 people indicated a willingness to participate. These were divided into four categories: academic, clinical, managerial and service user depending on what the participant suggested was their main role. We then chose a sample of 50 and invited them to take part. Table 32 below gives a breakdown of the participants who took part in at least one round.

**Table 32. Delphi participation**

| Category | Agreed to take part | Completed round one | Completed round two |
|---|---|---|---|
| Academic | 11 | 9 | 9 |
| Clinical | 26 | 20 | 19 |
| Managerial | 11 | 10 | 10 |
| Service user | 4 | 4 | 3 |
| Total | 50 | 43 | 41 |

Note that the numbers who agreed to take part add up to 52 in total because two invitees withdrew quickly enough for us to invite replacements. This is a response rate of 86% for round 1 (43/50) and 95% for round 2 (41/43). There was a low uptake of invitations for the survey among service users we invited. Identifying service users who met the inclusion criteria was difficult and those we found were more likely than the other groups to decline the invitation: usually due to pressures of time.

### 9.2.2 Summary statistics

All SDS were rated as important or very important by 80%+ of respondents in both rounds: the generally agreed level for consensus. In round two there was a slight decrease in the standard deviation for 17 of the 20 SDSs, implying that there was an increase in consensus.

The question on coordination asked at the end of round 1 gained the following results using a standard five point agreement scale.

| 21. Improving the coordination of care will in itself lead to better patient and carer outcomes. | | |
|---|---|---|
| strongly disagree: | 9.3% | 4 |
| disagree: | 2.3% | 1 |
| neither agree nor disagree: | 9.3% | 4 |
| agree: | 44.2% | 19 |
| strongly agree: | 34.9% | 15 |

It does indicate that although there is a strong consensus for the statement (34 out of 43 agreed) that there was significant disagreement.

**Scoring SDSs**

Table 33 below shows the SDSs listed in order of most to least important after round two. Although all received a rating of important or very important by 80% plus of respondents, SDS#6 and #18 were the only ones to score less than 50% of very important. Conversely, just four had more than 80% of participants rating them as very important.

**Table 33. Service Development statement scores**

| | **Service development statement** | VI | Im |
|---|---|---|---|
| 1 | 5. Each patient (and their informal carer) is offered personalised advice and information on how and when to seek help in an emergency, both in-hours and out-of-hours. | 90% | 10% |
| 2 | 20. Prompt and accurate communication between primary and secondary healthcare is maintained and out-of-hours services, home-care providers, informal carers and patients are included in this communication. | 90% | 10% |
| 3 | 14. When a patient approaching the end of life has no informal carer, the need for additional support is considered. | 85% | 15% |
| 4 | 17. Each area has measures in place to ensure effective collaboration between community healthcare (GPs, District Nurses, pharmacists and other allied health professionals) social services (social and personal care) and community/ hospice based palliative care specialists. | 85% | 15% |
| 5 | 13. Carers' needs are assessed for the purpose of being given support in accessing local services. | 73% | 27% |
| 6 | 1. More patients with malignant and non-malignant diseases are identified and entered on a palliative care register. | 71% | 27% |
| 7 | 9. A patient-centred, holistic needs assessment is carried out when a patient is identified as approaching the end of life. | 71% | 24% |
| 8 | 12. The main informal carers of patients who have been recognised as approaching the end of life are identified and recorded systematically. | 68% | 29% |
| 9 | 2. Regular planned review by primary care teams of patients who ''may be'' approaching the end of life is undertaken for the purpose of being added to the practice palliative care register. | 59% | 41% |
| 10 | 7. Where a hospital team has identified a patient as approaching the end of life they will suggest to the relevant primary care team on discharge that the patient is a candidate for the practice palliative care register. | 59% | 39% |
| 11 | 10. All patients are provided with the opportunity to develop an advance care plan. This may cover medical and non-medical issues as appropriate. | 59% | 37% |
| 12 | 19. Whenever a service change occurs, patients and informal carers are fully informed, in advance if possible, and while a change is being made (e.g. change in a keyworker). | 51% | 41% |
| 13 | 3. When a patient who ''may be'' approaching end of life has a care transition (e.g. discharge from hospital to the community) and as a result requires increased personal care they are considered for the practice palliative care register. | 44% | 51% |
| 14 | 11. When a patient is recognised in any setting as being in the last days of life, an integrated care plan such as the Liverpool Care Pathway is started. | 54% | 37% |

| | **Service development statement** | VI | Im |
|---|---|---|---|
| 15 | 16. Training is provided to enable professional home-care workers* to assess patient (and carer) needs and identify gaps in services and resources. | 46% | 46% |
| 16 | 15. Providers of personal care for people living at home who are approaching the end of life have procedures in place to ensure that these patients have at least one 'core' care-worker who visits the patient regularly and staff changes are minimised. | 61% | 32% |
| 17 | 4. Each patient has a named professional as a coordinator of their care (i.e. a 'keyworker'). | 59% | 32% |
| 18 | 8. Everyone admitted to a care home is provided with the opportunity to have an advance care plan started. | 51% | 34% |
| 19 | 6. Following discharge from hospital, the primary care team contacts each patient who has been identified as approaching the end of life within two working days. | 41% | 49% |
| 20 | 18. Each local area has an "information strategy" to ensure that the information needs of patients and carers can be met. | 24% | 56% |

Key: column headers – VI (Very Important); Im (Important).

The top scoring development, #5 (personalised advice), was judged "*Absolutely critical to avoid unnecessary frustration and perhaps admissions*" by one clinician. Comments such as that from a clinician show that participants saw it as a form of contingency planning: "*contingency planning should be in place easy access to good out-of-hours advice/care which does not routinely send them to A & E is the crux of this*." Likewise a hospice manager wrote, "*Patients and carers need to know who to call and in what circumstances*" and another clinician stated that "*this is more than just practical, it involves discussing what an emergency is and is will form part of a care plan/advance care plan this is to prevent inappropriate admission to hospital and inappropriate medical interventions*."

When asked to rank their top five SDSs the results were different. To calculate the degree of importance, each SDS was given a score each time it was selected as one of the five most important, ranging from five points if listed as most important down to one point if listed as fifth most important. These scores were then totalled with the top five SDSs being listed in Table 34 below.

**Table 34. Top ranking SDSs**

| Rank | Score | SDS |
|---|---|---|
| 1st | 124 | #9. A patient-centred, holistic needs assessment is carried out when a patient is identified as approaching the end of life. |
| 2nd | 110 | #20. Prompt and accurate communication between primary and secondary healthcare is maintained and out-of-hours services, home-care providers, informal carers and patients are included in this communication. |
| 3rd | 97 | #5. Each patient (and their informal carer) is offered personalised advice and information on how and when to seek help in an emergency, both in-hours and out-of-hours. |
| 4th | 60 | #17. Each area has measures in place to ensure effective collaboration between community healthcare (GPs, District Nurses, pharmacists and other allied health professionals) social services (social and personal care) and community/ hospice based palliative care specialists. |
| 5th | 41 | #2. Regular planned review by primary care teams of patients who ''may be'' approaching the end of life is undertaken for the purpose of being added to the practice palliative care register. |

The top ranked development, #9 (patient-centred holistic needs assessment), drew mixed responses, with some participants indicating uncertainty about the SDS in the free text entry. "*This should be part of the overall ongoing assessment and review of care and treatment*" (Manager). "*All patients should get this so the question is rather poor*" (academic). " *But patient-centred holistic assessment should be routine anyway - so speaks a social worker!*" (social worker).

SDS #20 "Prompt and accurate communication" (the second placed SDS in both cases) drew comments demonstrating a belief in its importance but anxiety about what exactly it might entail and also the difficulty in implementing any such development. "*This is vital but proving very difficult to achieve*" (manager). "*I sometimes think that informal carers and patients don't want to be sent endless letters and phone calls - they just want a good service that is well coordinated with professionals who know what they are doing !!*" (clinician – hospice). "*But so hard to achieve...*" (clinician).

SDS #17 (collaboration between services) revealed some strong opinions that appeared to reflect the participants' own experiences. A social worker felt that their speciality was downplayed "*And in order for that to take place each service has to 'come to the table' on an equal footing*," (social worker) while others appeared keen to ensure that particular services were included. "*Though I still feel the hospital services should be included in this*." (Manager).] Another describes it as "*MDT working again. May also need to involve specialists in secondary/tertiary care*" (clinician).

## 9.3 Discussion

After reviewing the top ranking and scoring SDSs it was possible to divide them into six components of two different types:

- Identification, Assessment, Planning, and
- Collaboration, Communication, Information

Identification, Assessment and Planning are derived from a standard clinical model of palliative and supportive care as, for example encouraged in the GSF.[11] Information, collaboration and communication were derived from notions of component elements of coordination. Each SDS can be seen as featuring one or more of these elements. It appears that the top scoring and top ranking SDSs tended to feature a balance of components. This suggests that any model of care coordination for people in the last 12 months of life should feature each of these 6 elements as most locally appropriate.

**Table 35. Top scoring SDS's categorised**

| Service development statement | Category |
|---|---|
| 5. Each patient (and their informal carer) is offered personalised advice and information on how and when to | Planning;<br>Information |

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[11] http://www.goldstandardsframework.org.uk/

| | |
|---|---|
| seek help in an emergency, both in-hours and out-of-hours. | |
| 20. Prompt and accurate communication between primary and secondary healthcare is maintained and out-of-hours services, home-care providers, informal carers and patients are included in this communication. | Communication |
| 14. When a patient approaching the end of life has no informal carer, the need for additional support is considered. | Assessment |
| 17. Each area has measures in place to ensure effective collaboration between community healthcare (GPs, District Nurses, pharmacists and other allied health professionals) social services (social and personal care) and community/ hospice based palliative care specialists. | Collaboration |
| 13. Carers' needs are assessed for the purpose of being given support in accessing local services. | Assessment |

**Table 36. Top ranking SDS's categorised**

| **SDS** | **Category** |
|---|---|
| #9. A patient-centred, holistic needs assessment is carried out when a patient is identified as approaching the end of life. | Assessment |
| #20. Prompt and accurate communication between primary and secondary healthcare is maintained and out-of-hours services, home-care providers, informal carers and patients are included in this communication. | Communication |
| #5. Each patient (and their informal carer) is offered personalised advice and information on how and when to seek help in an emergency, both in-hours and out-of-hours. | Planning;<br>Information |
| #17. Each area has measures in place to ensure effective collaboration between community healthcare (GPs, District Nurses, pharmacists and other allied health professionals) social services (social and personal care) and community/ hospice based palliative care specialists. | Collaboration |
| #2. Regular planned review by primary care teams of patients who ''may be'' approaching the end of life is undertaken for the purpose of being added to the practice palliative care register. | Identification[12] |

It seems likely that the variation in ranking versus scoring is because participants realised that identification was an important element of the whole process. Whereas absolute scoring is performed without a context,

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[12] The word "planned" here refers to routine scheduling rather than "planning" as a component.

relative ranking forces participants to introspect about the developments as a whole, something they found difficult. "*Found prioritisation as pitched very hard and doubted relevance of my grading I'm afraid*." (clinician) "*These suggestions are all important - I cannot see that that anyone who has looked after patients with chronic complex disease would not grade them as important. How to achieve the aims is next question*." (clinician). "*You need all in place and all are integral/important to commissioning and delivering end-of-life care*." (manager).

As the ranking shows, there is a clear favourite development (#9 with a score of 124) then two others which rank significantly more highly than the rest. The presence of #5, #20 and #17, combined with the fact that these are three of the only four SDSs to score more than 80% as "Very Important" indicates that these are seen as significantly important in both absolute and relative terms. So although there is a consensus that all listed SDSs are important, there does also appear to be a clear consensus around a group of SDSs that are more important than the others. Where there is divergence is between scoring each SDS in isolation as opposed to ranking them in relation to each other. Our contention is that when ranking, the professionals attempted to judge the SDSs holistically rather than in isolation as when scoring. Identification which appears to be a "blind spot" when scoring thus became ranked more highly. Likewise, in the ranking a "comprehensive" assessment SDS (#9) appears to have replaced the more focused assessment needs found in SDS's #13 and #14.

Once analysed, these results were then presented at three workshops.

# 10 National Workshops

Workshops were held in Edinburgh, the Midlands and London within two weeks of each other in order that the results of each could inform the next. The aim was to attempt to achieve consensus on the priority ascribed to each suggested service development when assessed in terms of how achievable and effective they might be, and how they might be implemented in practice into a working model(s).

## *10.1 Methods*

After the presentation, the participants were sorted into four groups with a mixture of clinicians and academics in each. Each group was chaired by a member of the research team with another member or a volunteer to record the group's comments.

The group work consisted of five phases in each case.

1. Phase one: Each member privately scored each of the 20 service development statements based on their impact on coordination from 1 (lowest) to 10 (highest).
2. Each member then privately picked their top 5 most important statements and indicated an order from 1-5, where 1 was the most important and 5 the fifth most important.
3. Each participant was asked to provide a brief rationale why they picked their top statement.
4. Once all the private scoring was done, each group member informed the group of their personal top preference and, through a consensus seeking approach, the group was asked to pick one of the individual preferences as the group's choice for a top preference.
5. In the final round all the groups fed back their preferences to the room as a whole, at which point a discussion focusing on which of these preferences to prioritise and how to implement them was held.

There were two minor variations among the workshops. The private scoring in the London workshop used a scale of 1(highest) to 10 (lowest) rather than the other way around. Secondly, after a feedback session from the first workshop in Edinburgh, a final activity was added to step 5 in the workshop and all participants were asked to privately vote for a single preference from among those chosen by the groups as well as participate in whole-room consensus seeking.

## *10.2 Edinburgh workshop results*

### 10.2.1 Participation

A total of 54 professionals and service users were invited to the workshop. This led to 25 participants: 12 clinicians, 12 managers and one service user. Five project team members acted as facilitators. Three of the clinicians were palliative care specialists, the rest were non-specialists though all had a special interest in the subject. All worked within the South-central Scotland region.

### 10.2.2 Quantitative data - personal

Twenty five participants returned their score sheets. Two were rejected due to errors in completing the forms. Out of the 23 score sheets, only two participants scored any of the SDSs with a score of 3 or less. Table 37 below presents the statements in order of highest score to lowest. As can be seen, statement number 9 (holistic assessment) significantly outscored the others.

**Table 37. SDS's placed in scoring order - Edinburgh**

| Service Development statement | Score |
|---|---|

| | |
|---|---|
| 9. A patient-centred, holistic needs assessment is carried out when a patient is identified as approaching the end of life. | 9.52 |
| 8. Everyone admitted to a care home is provided with the opportunity to have an advance care plan started. | 9.13 |
| 20. Prompt and accurate communication between primary and secondary healthcare is maintained and out-of-hours services, home-care providers, informal carers and patients are included in this communication. | 9.04 |
| 5. Each patient (and their informal carer) is offered personalised advice and information on how and when to seek help in an emergency, both in-hours and out-of-hours. | 9.00 |
| 10. All patients are provided with the opportunity to develop an advance care plan. This may cover medical and non-medical issues as appropriate. | 8.87 |
| 17. Each area has measures in place to ensure effective collaboration between community healthcare (GPs, District Nurses, pharmacists and other allied health professionals) social services (social and personal care) and community/ hospice based palliative care specialists. | 8.83 |
| 11. When a patient is recognised in any setting as being in the last days of life, an integrated care plan such as the Liverpool Care Pathway is started. | 8.74 |
| 14. When a patient approaching the end of life has no informal carer, the need for additional support is considered. | 8.73 |
| 16. Training is provided to enable professional home-care workers* to assess patient (and carer) needs and identify gaps in services and resources. | 8.65 |
| 6. Following discharge from hospital, the primary care team contacts each patient who has been identified as approaching the end of life within two working days. | 8.61 |
| 15. Providers of personal care for people living at home who are approaching the end of life have procedures in place to ensure that these patients have at least one 'core' care-worker who visits the patient regularly and staff changes are minimised. | 8.43 |
| 13. Carers' needs are assessed for the purpose of being given support in accessing local services. | 8.22 |
| 4. Each patient has a named professional as a co-ordinator of their care (i.e. a 'key-worker'). | 8.04 |
| 7. Where a hospital team has identified a patient as approaching the end of life they will suggest to the relevant primary care team on discharge that the patient is a candidate for the practice palliative care register. | 7.91 |
| 19. Whenever a service change occurs, patients and informal carers are fully informed, in advance if possible, and while a change is being made (e.g. change in a key-worker). | 7.87 |
| 12. The main informal carers of patients who have been recognised as approaching the end of life are identified and recorded systematically. | 7.65 |
| 2. Regular planned review by primary care teams of patients who ''may be'' approaching the end of life is undertaken for the purpose of being added to the practice palliative care register. | 7.30 |
| 1. More patients with malignant and non-malignant diseases are identified and entered on a palliative care register. | 7.26 |

| | |
|---|---|
| 18. Each local area has an "information strategy" to ensure that the information needs of patients and carers can be met. | 7.17 |
| 3. When a patient who ''may be'' approaching end of life has a care transition (e.g. discharge from hospital to the community) and as a result requires increased personal care they are considered for the practice palliative care register. | 7.09 |

The results for the second task, (ranking the top 5 statements) are given in Table 38. All 25 participants completed the ranking though one participant had omitted one ranking and one had duplicated a ranking. The columns show how many times each statement was picked as one of the top 5 and a simply aggregate score based on awarding 5 points for being chosen as most important and 1 point for 5th most important.

**Table 38. Personal rankings in scoring order (highest to lowest)**

| Service Development Statement | Placing | | | | | |
|---|---|---|---|---|---|---|
| | 1 | 2 | 3 | 4 | 5 | Score |
| 9. A patient-centred, holistic needs assessment is carried out when a patient is identified as approaching the end of life. | 13 | 1 | 0 | 0 | 0 | 69 |
| 10. All patients are provided with the opportunity to develop an advance care plan. This may cover medical and non-medical issues as appropriate. | 4 | 5 | 0 | 3 | 3 | 49 |
| 5. Each patient (and their informal carer) is offered personalised advice and information on how and when to seek help in an emergency, both in-hours and out-of-hours. | 4 | 1 | 3 | 4 | 1 | 42 |
| 20. Prompt and accurate communication between primary and secondary healthcare is maintained and out-of-hours services, home-care providers, informal carers and patients are included in this communication. | 1 | 2 | 7 | 3 | 1 | 41 |
| 17. Each area has measures in place to ensure effective collaboration between community healthcare (GPs, District Nurses, pharmacists and other allied health professionals) social services (social and personal care) and community/ hospice based palliative | 0 | 3 | 4 | 3 | 3 | 33 |
| 13. Carers' needs are assessed for the purpose of being given support in accessing local services. | 0 | 0 | 4 | 1 | 2 | 16 |
| 16. Training is provided to enable professional home-care workers* to assess patient (and carer) needs and identify gaps in services and resources. | 0 | 2 | 0 | 2 | 4 | 16 |
| 8. Everyone admitted to a care home is provided with the opportunity to have an advance care plan started. | 1 | 2 | 1 | 0 | 0 | 16 |
| 4. Each patient has a named professional as a co-ordinator of their care (i.e. a 'key-worker'). | 0 | 3 | 1 | 0 | 0 | 15 |
| 11. When a patient is recognised in any setting as being in the last days of life, an integrated care plan such as the Liverpool Care Pathway is started. | 0 | 1 | 2 | 1 | 1 | 13 |

| | | | | | | |
|---|---|---|---|---|---|---|
| 14. When a patient approaching the end of life has no informal carer, the need for additional support is considered. | 0 | 1 | 1 | 2 | 2 | 13 |
| 15. Providers of personal care for people living at home who are approaching the end of life have procedures in place to ensure that these patients have at least one 'core' care-worker who visits the patient regularly and staff changes are minimised. | 0 | 1 | 0 | 4 | 0 | 12 |
| 6. Following discharge from hospital, the primary care team contacts each patient who has been identified as approaching the end of life within two working days. | 0 | 1 | 0 | 2 | 3 | 11 |
| 2. Regular planned review by primary care teams of patients who ''may be'' approaching the end of life is undertaken for the purpose of being added to the practice palliative care register. | 1 | 1 | 0 | 0 | 2 | 11 |
| 1. More patients with malignant and non-malignant diseases are identified and entered on a palliative care register. | 1 | 1 | 0 | 0 | 1 | 10 |
| 7. Where a hospital team has identified a patient as approaching the end of life they will suggest to the relevant primary care team on discharge that the patient is a candidate for the practice palliative care register. | 0 | 1 | 1 | 0 | 0 | 7 |
| 3. When a patient who ''may be'' approaching end of life has a care transition (e.g. discharge from hospital to the community) and as a result requires increased personal care they are considered for the practice palliative care register. | 0 | 0 | 0 | 0 | 1 | 1 |
| 12. The main informal carers of patients who have been recognised as approaching the end of life are identified and recorded systematically. | 0 | 0 | 0 | 0 | 0 | 0 |
| 18. Each local area has an "information strategy" to ensure that the information needs of patients and carers can be met. | 0 | 0 | 0 | 0 | 0 | 0 |
| 19. Whenever a service change occurs, patients and informal carers are fully informed, in advance if possible, and while a change is being made (e.g. change in a key-worker). | 0 | 0 | 0 | 0 | 0 | 0 |

It is notable that only seven statements are ranked as a top priority at least once, and that #9 (holistic assessment) ranks as top priority for 13 of the 25 responses with the next highest receiving only 4 top priority rankings. This shows, as with absolute scoring, a significant consensus around the priority given to this development.

### 10.2.3 Qualitative data

When assessing the popularity of #9, participants' responses indicated an underlying rationale regarding its importance, namely that #9 was viewed as the "*critical starting point*" (E46 - manager). It seems to have been treated as a combination of identification "*the only way of systematically* *identifying groups*." (E43 GP) and being foundational to planning, "*whole plan is dependent on an inclusive assessment*" (E11 manager). Two respondents mentioned patient-centred impact in passing "…*makes patient feel supported*" (E22 academic)and "*all people need to be assessed as a whole person*," (E32 manger). The primary focus however was on facilitating identification and planning.

It is noteworthy that the other two statements that were top choices for more than one person were #10 (advance care planning) and #5 (personal information plan). Both of these showed a common theme about helping professionals in "*understanding the patient's perspective*" (E35 clinician about #10) and "*involved patient and carers in decision making*," (E41 GP - about #10). Likewise, #5 was seen by one participant as something that "*puts the needs of the patient and their immediate support first*," (E27 manager).

### 10.2.4 Quantitative data - groups

Group #1 rated SDS#1 (palliative care register) as the most important SDS. This was after originally choosing SDS #9 (holistic assessment). It is notable that only one of the 6 group members had chosen #1 privately while 4 had chosen #9. This shows a significant impact of the conversation. Group #2 rated SDS #9 & #10 combined as the most important. Group #3 rated SDS #8 (ACP in care homes) as most important because it represented a "low-hanging fruit." Group #4 rated SDS #9 (holistic assessment) as most important.

In phase five conversation, a consensus emerged that SDS #9 was crucial but that without identification it was impossible. This appears to articulate the qualitative data that shows assessment being associated with identification.

## *10.3 Warwick Workshop*

### 10.3.1 Participation

Forty six professionals were invited to attend the Warwick workshop, drawn from health service managers at regional and local level, involved in service commissioning and provision. Clinicians invited included GPs, generalist and specialist community nurses, an occupational therapist and physiotherapist involved in community end of life care and hospital consultants in respiratory medicine, cardiology, geriatrics and palliative medicine. Twenty four participants attended the workshop representing all of the groups invited apart from consultant physicians (academic 1, clinicians 19, managers/commissioners 4). Twenty two of the participants filled in score sheets, one of them choosing to remain anonymous.

### 10.3.2 Quantitative data – personal

The 22 participants scored the 20 SDSs in the order shown in Table 39. In this case the absolute scoring and relative ranking (Table 40) were different. Scoring and ranking performed as per the Edinburgh workshop above.

**Table 39. SDS scoring – Warwick**

| SDS | Score |
|---|---|
| 17. Each area has measures in place to ensure effective collaboration between community healthcare (GPs, District Nurses, pharmacists and other allied health professionals) social services (social and personal care) and community/ hospice based palliative care specialists. | 9.41 |
| 5. Each patient (and their informal carer) is offered personalised advice and information on how and when to seek help in an emergency: both in-hours and out-of-hours. | 9.32 |
| 9. A patient-centred, holistic needs assessment is carried out when a patient is identified as approaching the end of life. | 9.09 |
| 20. Prompt and accurate communication between primary and secondary healthcare is maintained and out-of-hours services, home-care providers, informal carers and patients are included in this communication. | 8.91 |
| 14. When a patient approaching the end of life has no informal carer, the need for additional support is considered. | 8.77 |
| 15. Providers of personal care for people living at home who are approaching the end of life have procedures in place to ensure that these patients have at least one 'core' care-worker who visits the patient regularly and staff changes are minimised. | 8.50 |
| 13. Carers' needs are assessed for the purpose of being given support in accessing local services. | 8.32 |
| 19. Whenever a service change occurs, patients and informal carers are fully informed, in advance if possible, and while a change is being made (e.g. change in a key-worker). | 8.32 |
| 11. When a patient is recognised in any setting as being in the last days of life, an integrated care plan such as the Liverpool Care Pathway is started. | 8.27 |
| 16. Training is provided to enable professional home-care workers* to assess patient (and carer) needs and identify gaps in services and resources. | 8.23 |
| 6. Following discharge from hospital, the primary care team contacts each patient who has been identified as approaching the end of life within two working days. | 8.14 |
| 10. All patients are provided with the opportunity to develop an advance care plan. This may cover medical and non-medical issues as appropriate. | 8.14 |
| 7. Where a hospital team has identified a patient as approaching the end of life they will suggest to the relevant primary care team on discharge that the patient is a candidate for the practice palliative care register. | 8.05 |
| 12. The main informal carers of patients who have been recognised as approaching the end of life are identified and recorded systematically. | 8.00 |
| 4. Each patient has a named professional as a co-ordinator of their care (i.e. a 'key-worker'). | 7.91 |
| 8. Everyone admitted to a care home is provided with the opportunity to have an advance care plan started. | 7.86 |
| 18. Each local area has an "information strategy" to ensure that the information needs of patients and carers can be met. | 7.45 |
| 2. Regular planned review by primary care teams of patients who "may be" approaching the end of life is undertaken for the purpose of being added to the practice palliative care register. | 7.32 |
| 3. When a patient who "may be" approaching end of life has a care transition (e.g. discharge from hospital to the community) and as a result requires increased personal care they are considered for the practice palliative care register. | 7.18 |
| 1. More patients with malignant and non-malignant diseases are identified and entered on a palliative care register. | 7.00 |

**Table 40. Service development statement ranking – Warwick**

| SDS | 1 | 2 | 3 | 4 | 5 | Score |
|---|---|---|---|---|---|---|
| 9. A patient-centred, holistic needs assessment is carried out when a patient is identified as approaching the end of life. | 10 | 2 | 2 | 0 | 1 | 65 |
| 17. Each area has measures in place to ensure effective collaboration between community healthcare (GPs, District Nurses, pharmacists and other allied health professionals) social services (social and personal care) and community/ hospice based palliative | 6 | 3 | 2 | 3 | 1 | 55 |
| 20. Prompt and accurate communication between primary and secondary healthcare is maintained and out-of-hours services, home-care providers, informal carers and patients are included in this communication. | 1 | 3 | 4 | 4 | 3 | 40 |
| 5. Each patient (and their informal carer) is offered personalised advice and information on how and when to seek help in an emergency, both in-hours and out-of-hours. | 1 | 3 | 4 | 2 | 2 | 35 |
| 4. Each patient has a named professional as a co-ordinator of their care (i.e. a 'key-worker'). | 0 | 4 | 0 | 0 | 2 | 18 |
| 6. Following discharge from hospital, the primary care team contacts each patient who has been identified as approaching the end of life within two working days. | 1 | 1 | 2 | 1 | 0 | 17 |
| 10. All patients are provided with the opportunity to develop an advance care plan. This may cover medical and non-medical issues as appropriate. | 1 | 0 | 1 | 2 | 1 | 13 |
| 16. Training is provided to enable professional home-care workers* to assess patient (and carer) needs and identify gaps in services and resources. | 0 | 1 | 1 | 2 | 2 | 13 |
| 11. When a patient is recognised in any setting as being in the last days of life, an integrated care plan such as the Liverpool Care Pathway is started. | 0 | 1 | 1 | 1 | 3 | 12 |
| 15. Providers of personal care for people living at home who are approaching the end of life have procedures in place to ensure that these patients have at least one 'core' care-worker who visits the patient regularly and staff changes are minimised. | 0 | 1 | 1 | 2 | 1 | 12 |
| 14. When a patient approaching the end of life has no informal carer, the need for additional support is considered. | 0 | 0 | 2 | 2 | 1 | 11 |
| 7. Where a hospital team has identified a patient as approaching the end of life they will suggest to the relevant primary care team on discharge that the patient is a candidate for the practice palliative care register. | 0 | 1 | 2 | 0 | 0 | 10 |
| 1. More patients with malignant and non-malignant diseases are identified and entered on a palliative care register. | 1 | 0 | 0 | 1 | 1 | 8 |
| 18. Each local area has an "information strategy" to ensure that the information needs of patients and carers can be met. | 1 | 0 | 0 | 0 | 0 | 5 |
| 2. Regular planned review by primary care teams of patients who "may be" approaching the end of life is undertaken for the purpose of being added to the practice palliative care register. | 0 | 1 | 0 | 0 | 0 | 4 |
| 8. Everyone admitted to a care home is provided with the opportunity to have an advance care plan started. | 0 | 1 | 0 | 0 | 0 | 4 |
| 3. When a patient who "may be" approaching end of life has a care transition (e.g. discharge from hospital to the community) and as a result requires increased personal care they are considered for the practice palliative care register. | 0 | 0 | 0 | 0 | 2 | 2 |
| 12. The main informal carers of patients who have been recognised as approaching the end of life are identified and recorded systematically. | 0 | 0 | 0 | 0 | 2 | 2 |
| 13. Carers' needs are assessed for the purpose of being given support in accessing local services. | 0 | 0 | 0 | 1 | 0 | 2 |
| 19. Whenever a service change occurs, patients and informal carers are fully informed, in advance if possible, and while a change is being made (e.g. change in a key-worker). | 0 | 0 | 0 | 1 | 0 | 2 |

Compared to the Edinburgh workshop, there is less personal consensus for SDS#9 but it is still notable for its dominance. There is more of a dynamic interplay between the perception for the need for strategic organisation SDSs (#17 and #19) and patient-centred SDSs (#5 and #9) development.

### 10.3.3 Qualitative data – personal

The rationales given for the choice of which is the most important priority clustered around two following factors. Those who favoured SDS #9 focused on it being patient-centred and foundational to future care.

- "A*ssessment will then lead to communication/collaboration.*" (W4 clinician)
- "*I feel the needs of the patient comes first*." (W8 clinician)
- "E*ssential to ensure physical & psychological & social needs are met*." (W15 clinician)

This theme also turned up in some other priorities. For example, W1 (a GP) chose SDS #10 (Advance Care Planning) because "*the patient needs to be at the centre of this*."

The only other SDS to have more than 1 top ranking was #17. The focus on this case was to do with systematic change that "*would achieve greatest good for the majority*." (W9 clinician) Similarly, W19 (manager) stated that "*By ensuring a system wide strategic approach you can impact maximum change*." The perception is that current services are fragmented.

- "*I believe we have the personnel, skills and resources to provide excellent palliative care/end-of-life care. What prevents this happening is when the services are uncoordinated or uninformed*." (W10 anonymous)
- "*many different agencies involved in EOL care leading to the potential for confusion*." (W18 clinician)
- "*Needs to be a seamless service to ensure excellent EOL care.*" (W20 clinician)

A commissioner (W12) chose SDS #1 (identifying more patients for palliative care) as foundational to the system. "*Without identification no other element of the pathway can be delivered*."

### 10.3.4 Quantitative data – group

The four groups chose three different priorities between them. Group A chose SDS #9 (holistic assessment) as a "foundation for future care." Group B chose SDS #17 (collaboration between services) "things fall out of this area." Group C chose SDS #20 though noted that #9 was strongly favoured as well. Group D had struggled to reach a consensus, favouring both SDS #17 and #9.

Each participant was asked to privately note which of these statements they favoured. This was an innovation based on feedback after the Edinburgh workshop. The results were.

- SDS #9: 6 votes
- SDS #17: 10 votes
- SDS #20: 4 votes

This private preference was reflected in the room discussion where the consensus was for a focus on measures to enhance collaboration in the local area.

It is noteworthy then that the private results were changed through group discussion with a move from a focus on patient-centred assessment to a need to reorganise services.

## *10.4 London Workshop*

Forty three generalists and specialists in palliative care were invited to participate in the London workshop. Initially 13 invitees indicated their interest in attending the workshop. A week later, the researcher sent a reminder email after which 17 expressed an interest.

Thirteen participants attended the workshop: four clinicians were generalists and nine were specialists in palliative care. For the workshop participants were convened into three groups. They initially prioritised their 20 service development statements on a scale of 1-10 (1 being the most important and 10 being the least important) and then indicated their top 5 priorities.

The workshop was completed with a group feedback where participants shared their top priorities with the other groups and discussed their rationale for each of their top priorities. During this time, each group discussed their different top priorities with the aim of reaching a consensus for priority service developments. Participants also identified and discussed ways of implementing their prioritised service developments.

### 10.4.1 Quantitative data for service development statements

Among the 13 participants who attended the workshop, 12 returned their score sheets which referred to their priorities for service development. From the first scores participants scored the statements using scores 1 to 7. Only two participants scored two statements with 9, one participant scored one statement with 8 and another participant scored a statement with 10. For the majority of participants (82%) statement 20 (Mean = 1.27, SD = .647), ‘Prompt and accurate communication between primary and secondary healthcare is maintained and home-care providers, informal carers and patients are included in this Communication’ was most important and was followed by statement 5 (M = 1.54, SD = .891), ‘Each patient and carer is offered personalised advice and information on how and in what circumstances to seek help in an emergency, both in-hours and out-of-hours' and statement 9 (M = 1.75, SD = .866), 'A patient-centred, holistic needs-assessment is carried out when a patient is identified as approaching the end of life'.

**Table 41. Service development statement scoring - London**

| Service Development statement | Score |
|---|---|
| 20. Prompt and accurate communication between primary and secondary healthcare is maintained and out-of-hours services, home-care providers, informal carers and patients are included in this communication. | 1.27 |
| 5. Each patient (and their informal carer) is offered personalised advice and information on how and when to seek help in an emergency, both in-hours and out-of-hours. | 1.54 |
| 9. A patient-centred, holistic needs assessment is carried out when a patient is identified as approaching the end of life. | 1.75 |
| 1. More patients with malignant and non-malignant diseases are identified and entered on a palliative care register. | 1.83 |
| 10. All patients are provided with the opportunity to develop an advance care plan. This may cover medical and non-medical issues as appropriate. | 1.83 |
| 13. Carers' needs are assessed for the purpose of being given support in accessing local services. | 1.91 |
| 2. Regular planned review by primary care teams of patients who ''may be'' approaching the end of life is undertaken for the purpose of being added to the practice palliative care register. | 1.92 |
| 3. When a patient who ''may be'' approaching end of life has a care transition (e.g. discharge from hospital to the community) and as a result requires increased personal care they are considered for the practice palliative care register. | 2.00 |
| 17. Each area has measures in place to ensure effective collaboration between community healthcare (GPs, District Nurses, pharmacists and other allied health professionals) social services (social and personal care) and community/ hospice based palliative care specialists. | 2.17 |
| 14. When a patient approaching the end of life has no informal carer, the need for additional support is considered. | 2.25 |
| 7. Where a hospital team has identified a patient as approaching the end of life they will suggest to the relevant primary care team on discharge that the patient is a candidate for the practice palliative care register. | 2.33 |
| 8. Everyone admitted to a care home is provided with the opportunity to have an advance care plan started. | 2.33 |

| Service Development statement | Score |
|---|---|
| 4. Each patient has a named professional as a co-ordinator of their care (i.e. a 'key-worker'). | 2.36 |
| 15. Providers of personal care for people living at home who are approaching the end of life have procedures in place to ensure that these patients have at least one 'core' care-worker who visits the patient regularly and staff changes are minimised. | 2.58 |
| 11. When a patient is recognised in any setting as being in the last days of life, an integrated care plan such as the Liverpool Care Pathway is started. | 2.92 |

For the second scoring participants nominated their five most important statements by scoring them on a scale of 1 to 5 where 5 was the least important statement. Statement 20 had the highest priority and this was followed by statement 13 ‘Carers’ needs are assessed and they are given support in interacting with local services’, statement 2 ‘Proactive and regular reviewing in general practice of patients who may be approaching end of life is undertaken, and appropriate patients added to the practice palliative care register’, and statement 10 ‘All patients (approaching the end of life) are provided with the opportunity to develop a personal advance care plan. This may cover medical and non-medical issues as appropriate’. Statements 5 and 9 were important but further down the priority list for the participants.

### 10.4.2 Main issues emerging from workshop

The majority of participants considered which service developments were primary or subsumed into other ones. The discussion reached a consensus that for better collaboration and coordination of care a strategy is needed to improve identification of patients so that care can be proactive rather than reactive. Identification should be followed by the assessment of the patient’s holistic needs (social, psychological, physical, spiritual) leading to the development of plans (advance care planning not only in its narrow sense of Mental Capacity Act but preferably as an anticipatory care plan) for both the current situation and the future as well. Some indicated that, for a valid anticipatory care plan, clinicians needed to fully assess patient and carer needs.

Members of the group discussed patient needs’ assessment and emphasised its importance in developing healthcare plans. Some indicated that there are duplicating assessments from occupational therapists, DNs, social services etc. and suggested information sharing between professionals to save time and resources.

There was a discussion about the single assessment process and one of the participants used Northern Ireland as an example where professionals use a unified health and social care assessment, which can be completed by a nurse in ten minutes. Others indicated that this can be quite challenging especially in primary care as professionals continue to assess something new. There was a suggestion about patients self-completing the assessments although a recognition that all may not be able to do this.

Finally, the group highlighted that a prerequisite for improved collaboration and coordination of care for patients with advanced illness is to involve competent and trained professionals in the assessment and identification of patients, and professionals who are ready to learn from each other.

Participants also discussed that despite developing good strategies it is still difficult and challenging to deliver them on the ground. Some participants argued that the theoretical directions, arguments, and principles described in different strategies needed to be more realistic and more practical to make them more achievable.

### 10.4.3 Suggestions for implementation

Two main suggestions regarding the implementation of prioritised service developments emerged from the London workshop. The first recommendation related to identification in developing a single register which will be shared across settings and organisations. Multiple registers with different URLs across different geographical boundaries reduces possible patient benefits. An example was given of the London end of life care register called 'Coordinate My Care' in which GP, Ambulance, A&E services, palliative care and community nursing services and pharmacies who have an NHS connection are able to get onto the register. This register is currently being piloted in London and has some initial positive effects to the patient care.

The second suggestion focused on patient assessment. Some suggested asking patients to complete the assessment and have it ready before they are seen by the clinician. When patients highlight what is important to them clinicians can have a quicker view on what areas to focus on. The suggestion was to use this as an aid in assessment because on some occasions patients or carers are not able to self-complete the assessment due to language barriers or low educational attainment.

## *10.5 Discussion of the three workshops*

Each workshop focused on different areas. In Scotland, the holistic needs assessment (#9) appears to have been treated as a proxy for both identification and planning. Although this was also the dominant choice for Warwick, the qualitative data shows that it was seen as focusing on patient-centred care. Concern over processes such as identification and planning appears to have led to the secondary focus on structural changes in the area. As the local PCT (along with all other PCTs in England) was facing potential disbanding, it is likely that potential structural reorganisation had foregrounded the issue to the participants. Many, also, were drawn from community nurses who (as discussed in the case study) had recently been reorganised.

The London workshop also voiced a concern about structural reorganisation with SDS #20 (inter-service communication) showing the greatest support, followed by #5 (personal information) also receiving strong support. London PCTs potentially share the same fate as the Warwick one but it is likely that the presence of some participants involved in Coordinate My Care (128) led to a focus on communication and identification through a single register as opposed to Warwick where the concern was poor collaboration following reorganisations.

Despite the differences there is however a clear consensus around the set of important developments as seen in Table 42 below .

**Table 42. Workshop SDS preferences compared**

| Site | London | Warwick | Edinburgh |
|---|---|---|---|
| Developments | 20 | 20 | 10 |
| | 2 | 9 | 9 |
| | 10 | 17 | 1 |

The table indicates the top 3 SDS's for each workshop: for example they are numbers 2, 10 and 20 in London. The text of each SDS is repeated below. It can be seen that SDS's number 9, 10 and 20 were chosen in two workshops while 1, 2 and 17 were chosen in just one. No single SDS was chosen in all three workshops.

The SDSs featuring here are

1. More patients with malignant and non-malignant diseases are identified and entered on a palliative care register.

2. Regular planned review by primary care teams of patients who ''may be'' approaching the end of life is undertaken for the purpose of being added to the practice palliative care register.

9. A patient-centred, holistic needs assessment is carried out when a patient is identified as approaching the end of life.

10. All patients are provided with the opportunity to develop an advance care plan. This may cover medical and non-medical issues as appropriate.

17. Each area has measures in place to ensure effective collaboration between community healthcare (GPs, District Nurses, pharmacists and other allied health professionals) social services (social and personal care) and community/ hospice based palliative care specialists.

20. Prompt and accurate communication between primary and secondary healthcare is maintained and out-of-hours services, home-care providers, informal carers and patients

are included in this communication.

The room discussion in London seemed to indicate that SDS#2 was seen as a form of identification as was SDS#1 in Edinburgh. Concerns over pending structural organisations appear to feature strongly in the two English settings, particularly in the Warwick setting. In all cases, the conversation was clearly influenced by recent or pending structural reorganisations and recent local initiatives such as the electronic palliative care summary in Scotland and Coordinate my Care in London.

There were also some comments about the need for education though this was not addressed directly in the SDSs.

# 11 Discussion

## *11.1 Review of objectives*

This study had five objectives. The first was to ***identify current models of collaborative working at the end of life in primary and secondary care settings.*** Our literature review and subsequent fieldwork allowed us to understand the processes by which end of life care is co-ordinated and managed in generalist palliative care settings including initiatives such as keyworkers, shared care, integrated care pathways, networks, frameworks and collaboratives. However as most people approaching the end of life are not identified as such, initiatives developed in these areas do not reach most potential beneficiaries. Various relationships and modes of communication are involved in these initiatives from individual patient to national level. Where a patient has a single, dominant condition that is managed by a well-resourced keyworker, the keyworker appears to enhance collaboration.

The second objective, **to *identify best practice*** and optimal outcome for patients, families and services with respect to coordination of care was achieved by ethnographic observation in hospital, clinic and in general practice and through the serial interviews with 56 patients and associated carers as they crossed many care transitions, notably at hospital admission and discharge. Best practice and optimum outcomes were associated with continuity of care, staff displaying a caring attitude, good communication skills, stable healthcare systems generally and the presence of a system to identify, assess and plan care for people approaching the end of life.

The third objective to identify ***factors contributing to gaps*** in identification of end of life care, provision and coordination of care at patient/family care, organisational and strategic levels. It became apparent that most potential beneficiaries of palliative care were not being recognised as such either in hospital or the community. Lack of identification meant that subsequent dependent actions were not being undertaken and care, if given, was reactive. Very few of the patients and carers had self-identified as approaching the end of life. Many clinicians report waiting to start end-of-life care until the patient initiates a discussion about it, yet the evidence here shows that the majority of participants were either actively involved in strategies to avoid initiating such a discussion or, felt that such discussions were inappropriate or simply had no idea that they could initiate a discussion.

The fourth objective to ***develop and propose models*** was achieved through integrating the findings from the three different sites, with special attention being paid to the various transitions observed between settings and care in the community. By developing "service development statements" we identified key elements of potential models which could be brought together to form an integrated system. There is, however, a tension between clinicians' desire for better coordinated services and tolerance for reorganisation, with evidence showing that exposure to reorganisation can be distressing for service users and risks unintentionally reducing patient-centred care. This lack of identification highlights the need for a development in this area. However the current understanding of palliative care among generalist health and social care professionals alongside the 'lay' understanding of it, runs counter to interventions to improve early identification. Also, patients with the greatest needs for coordination among services are those for whom it is most demanding to establish coordination. One episode of failed coordination may be perceived as a global lack. Finally, little attention has been paid to the role of patients and carers in models of care delivery. This project has shown the importance of carers and patients in collaborating with professionals: an insight well known in mental healthcare and palliative care models, but less prominent in generalist care.

Finally, we set out to ***establish consensus*** among stakeholder groups on the best models of service provision to improve collaborative working in end-of-life care within and between different settings and for different conditions. This was achieved through the Delphi process followed by the workshops. Two factors emerged. The first was that without appropriate identification, assessment is impossible. For this reason it is noteworthy that although SDS#9 (holistic assessment) was the most popular individually scored development, in group conversation the focus tended to shift to reorganisation or other means of identification. The link between assessment and coordination is also somewhat tenuous at first glance but can be understood in terms of information sharing. As several quotes show, assessment is seen as a means to gather information about the patient's needs in order to be able to share them with relevant services. The consensus reached thus is somewhat nuanced.

## 11.2 Key components of an effective model

It became evident that a successful model to promote coordination for people approaching the end of life has first to ***identify*** relevant people as they approached end of life, ***assess*** their needs holistically and then ***plan*** their care, while having excellent **communication** between services, sharing **information** among all and working **collaboratively**. The configuration of the model would depend on the level at which it was functioning and the context, but various components had to be present to ensure that all the relevant patients and their carers could reliably benefit from coordinated care.

The research has given a clear message about what patients, professionals and managers throughout the UK consider would best improve coordination of people approaching the end of life.

Several barriers to implementing such a model exist.

- Palliative care is understood to mean 'no cure possible' by patients and carers and understood to mean 'terminal care' by generalists with no special training in palliative care. Thus there is no common frame to allow early identification. This is exacerbated by multiple morbidities; patients with such often seem to regard themselves as 'growing old' and lack an overall picture of how to manage their conditions and their combined prognosis.
- Radically different service organisations and priorities plus issues in professional autonomy make coordinating across primary care and secondary care in particular extremely difficult.
- Service reorganisations aimed at increasing efficiency may hamper informal communication mechanisms between key personnel.
- Service reorganisations also affect different types of continuity - particularly relational continuity (129) - and hamper the development of a "continuity friendly service" that would otherwise facilitate coordination.(126)
- Some general developments in primary care in particular are experienced as fragmented care by patients and carers who prize having access to a single, named GP.

There have also been some developments that may facilitate the development of a model.

- Information sharing services such as the electronic palliative care summary (Scotland), electronic patient record (England), and innovations such as Coordinate My Care with shared registers provide a resource that can facilitate collaborative working.
- Enhanced communication training for clinicians, which is experienced largely by patients as indicating 'being cared about' and therefore extremely highly valued, may be able to counteract the perception of fragmented care.

- The approach that patients and carers appear to have developed towards end-of-life issues rather than being seen as a 'negative' strategy of denial may be better understood in terms of dignity conserving practices. Initiatives that enhance patient/carer autonomy and ability to 'live for the present' may well be favourably received by patients and carers.
- Various initiatives for future planning with patient and carers, such as advance care planning, or anticipatory care planning

### 11.2.1 Service development statements related to six components

These statements developed and tested through this process can be categorised in terms of the six components listed above. Table 43 below illustrates how the highly-scored statements relate to the model components. To construct an appropriate model we suggest that leaders might work through these six categories of SDS in order (identification, assessment, planning, collaboration, communication and information) and chose to operationalize one or more SDS from each category to ensure that all aspects are in place for reliable coordination for people approaching the end of life.

**Table 43. Service Development statements and model components**

| **Identification** |
|---|
| 1. More patients with malignant and non-malignant diseases are identified and entered on a palliative care register. |
| 2. Regular planned review by primary care teams of patients who ''may be'' approaching the end of life is undertaken for the purpose of being added to the practice palliative care register. |
| 3. When a patient who ''may be'' approaching end of life has a care transition (e.g. discharge from hospital to the community) and as a result requires increased personal care they are considered for the practice palliative care register. |
| 7. Where a hospital team has identified a patient as approaching the end of life they will suggest to the relevant primary care team on discharge that the patient is a candidate for the practice palliative care register. |
| 12. The main informal carers of patients who have been recognised as approaching the end of life are identified and recorded systematically. |

**Assessment**

9. A patient-centred, holistic needs assessment is carried out when a patient is identified as approaching the end of life.

13. Carers' needs are assessed for the purpose of being given support in accessing local services.

14. When a patient approaching the end of life has no informal carer, the need for additional support is considered.

**Planning**

5. Each patient (and their informal carer) is offered personalised advice and information on how and when to seek help in an emergency, both in-hours and out-of-hours.

10. All patients are provided with the opportunity to develop an advance care plan. This may cover medical and non-medical issues as appropriate.

11. When a patient being in the last days of life is recognised in any setting, an integrated care plan such as the Liverpool Care Pathway is started.

8. Everyone admitted to a care home is provided with the opportunity to have an advance care plan started.

**Collaboration**

17. Each area has measures in place to ensure effective collaboration between community healthcare (GPs, DNs, pharmacists and other allied health professionals) social services (social and personal care) and community/ hospice based palliative care specialists.

4. Each patient has a named professional as a co-ordinator of their care (i.e. a 'key-worker').

**Communication**

20. Prompt and accurate communication between primary and secondary healthcare is maintained and out-of-hours services, home-care providers, informal carers and patients are included in this communication.

**Information**

19. Whenever a service change occurs, patients and informal carers are fully informed, in advance if possible, and while a change is being made (e.g. change in a keyworker).

## 11.3 Current policies, guidelines and initiative

This research study of patients approaching the end of life and their informal and professional carers gives an evidence base to support many of the recent pilot studies, policy initiatives and national guidance documents in this area and also adds particular insights. (See 11.4)

National intervention studies to promote identification, assessing and planning as an integrated package such as Coordinate My Care (128) are clearly supported by the evidence herein, although this specific intervention has yet to show if can deliver on identification. Likewise, the Marie Curie Cancer Care Delivering Choice Programme (130, 131) has demonstrated the effectiveness of establishing a central coordinating facility providing a single point of access through which all services can be coordinated. Improvements in coordination are desirable across the health system generally though initiatives to do so are often contentious and improvements hard to measure. In addition, as this study has shown, service reorganisations to improve coordination may in the short term decrease it.

Locality-wide registers or electronic palliative care coordination systems created for people approaching the end of life, so that they can receive priority care are also supported by the findings here. There were some indications that those of our interviewees who did not have a malignant condition but who we discovered were on some sort of register for extra support were likely to express more satisfaction with their care. Interviewees with a malignant condition were much more likely to be on register and generally seemed to regard their care as better managed. In itself, this appears to support findings such as that by The National Primary Care Snapshot Audit in End of Life Care (2009) where it is claimed that patients on a palliative care register receive better coordinated care.(132) However the small numbers involved and difficulties in being able to show causal links means that definite benefit is a weak finding.

In particular, NICE's End of Life Care for Adults Quality Standard starts with the importance of identification as its first standard, and states at standard number 8 "*People approaching the end of life receive consistent care that is co-ordinated effectively across all relevant settings and services at any time of day or night and delivered by practitioners who are aware of the person's current medical conditions, care plan and preferences.*" (23) Our research provides evidence to guide implementation of the NICE end of life guidelines in general, and most specifically to promote coordination. SDSs grouped under "identification" map directly onto NICE quality standard #1 – *"People approaching the end of life are identified in a timely way."* SDSs grouped under assessment and planning can be equated to NICE quality standard #3 *"People approaching the end of life are offered comprehensive holistic assessments in response to their changing needs and preferences, with the opportunity to discuss, develop and review a personalised care plan for current and future support and treatment*."

Providing a timely, effective and sensitive means for identification of palliative care need can be developed and that collaboration between services in terms of information sharing, routine communication and access to resources is achieved, this study found a strong consensus for the need to develop a holistic common assessment of supportive and palliative care needs for adults requiring end of life care. This study gives guidance for completion of a holistic common assessment for patients approaching the end of life to ensure that their care needs are met. It specifically indicates that meeting these needs requires effective care coordination across boundaries: not just between services but also between services and informal carers.

### 11.3.1 Relationship to studies of other high service user groups

It is useful to situate specific end of life initiatives in the wider context of what is already known about collaboration and co-ordination for high users of health and social care services. The Evercare approach to case management pilot in the UK found that the additional contacts and monitoring were highly valued by patients, but had no effect on total hospital admissions.(133) There was poor evidence of integration between primary and secondary care, and out of hours services were not focussed on caring at home. It was concluded that a more radical redesign was needed than simply case management.(125)

The King's fund concluded after reviewing such initiatives that improved primary care and continuity especially out of hours would decrease admission.(134) Challis et al found a failure to distinguish adequately between the type of support needed for a single condition from that required for multiple conditions, and specifically found little information guiding the transition between disease management and case management.(135) They also found inadequate evidence of effectiveness of key workers for people with complex needs.

Seeking specifically to avoid unplanned admissions in older people, Henderson suggests we should move from "a scattergun approach of large numbers of "boutique" pilot projects to focus on a smaller number of services that can be mainstreamed.(136) This approach can be seen in the likes of the electronic palliative care summary(21) and Coordinate My Care(128) where services are based in the community and help all those in need at risk of dying, and are not defined by a specific illness or age group.

Glasby suggests that despite a tendency to focus on structural 'solutions', evidence and experience points to a series of more important processes, approaches and concepts that might help to promote more effective inter-agency working—including a focus on outcomes, consideration of the depth and breadth of relationship required and the need to work together on different levels.(137)

## 11.4 What new emphasis do these findings bring?

1. There is an absolute imperative to first identify people approaching end of life so that their care can be better coordinated and so that clear preparations for emergencies can be made so that emergency transitions are minimised, especially out-of-hours. Although holistic assessment was prioritised over all key elements of coordination, it was presumed that the patient had been identified, as is the case of every patient referred to specialist palliative care. This may be why this first step of identification has not been prioritised sufficiently in most end of life initiatives to date. In 2011 only 30% of people who died had any record in their notes of any planning for this inevitable event.(138)
2. There is evidence that generalists can identify patients at risk of dying within the next 12 months when prompted by a researcher but that this was not routinely happening for patients with conditions other than cancer. The indication is that community nurses and GPs will need support and training to use tools such as the SPICT or the PIG of the Gold Standards Framework.
3. There is an emphasis on the need to enhance professional education about early palliative care and to ensure that any developments in providing palliative care support by generalists can be understood by service users in terms of increasing caring support that meets their goals, and gives them increased self-control rather than giving up hope for a cure and preparing to die. Enhanced coordination of services and priority access to services may well be a good starting point.
4. There is lack of evidence for the impact of increasing coordination on patient outcomes. This study promotes the idea of collaboration as an interpersonal behaviour or process that, if facilitated, can enhance coordination. Thus coordination can be treated as an outcome to measure in further research. Information sharing, ease of communication, perception of caring by patients, and decreases in delay and cancellation may well be items that indicate improved coordination.
5. There is a culture in generalist care to first deal with the presenting conditions and a perception among patients that the service no longer allows for a holistic interaction beyond the immediate concern. There is therefore a gap in service provision and patient expectation to enable all the WHO dimensions of palliative care that needs to be addressed.
6. An aging population, with multimorbidity being the rule rather than the exception (139) and quicker transit through all settings with less continuity of care has created a need for better coordination of care. Developments which attempt to address through efficiency and time management (such as a telephone triage system or 'hub' for doctor to nurse communication, or impersonal hospital referral systems) carry the

risk that they may reduce informal collaboration and therefore coordination unless this is specifically planned for.

7. The importance of the role of carers as informal coordinators within primary and secondary care was identified in this study. There is a need to recognise the role of carers as informal coordinators of care. This study has identified some of the inherent inequities within our healthcare system for those that do not have access to informal carers, and the reliance of the healthcare system on informal carers in relation to care coordination.
8. Most patients approaching the end of life have two or more long term conditions that clinicians are recommended to manage by using two or more disease-specific guidelines in parallel that each promote disease oriented rather than goal oriented care. However, despite progressive deterioration in function, these patients are infrequently recognised as actually approaching the end of life, and thus the importance of specifically coordinating their care is often overlooked. Crucially, patients and their carers are also not currently capable of or want to identify this need nor are they aware of the potential resources to support them. Liaison between policymakers responsible for long-term conditions and end of life care is indicated to better coordinate services, and might address the stigma of the term "palliative care" which hinders both professional and patient self-identification.

## 11.5 Strengths and limitations

This study provides a unique, longitudinal in-depth and multi-perspective view of the experience of delivering and receiving care by and from generalists as part of end of life care. The use of different settings and multiple methods provides a form of triangulation, increasing the validity, reliability and potential generalizability of the findings. The involvement of three research teams, each working within an agreed framework allowed us to synthesise diversity and examine commonality while maintaining a flexibility that allowed each team to focus on the emergent issues at their site.

The diversity of centres allowed us to sample a range of services and draw up sampling frames with a wide range of conditions to capture a wide range of participants. The many experiences, conditions and professionals encountered during the study provided very rich data. Naturally, handling such diversity was challenging and often time consuming when it came to correlating the emerging findings.

The iterative process whereby data from each source (the literature review, the case studies, user consultations) were fed into the next, through the synthesis, development of SDSs, testing in the Delphi and consensus seeking at the workshops ensured that the findings were conceptually driven, grounded in the evidence and tested against professional knowledge and regular user perspectives.

The scope of the project also allowed us to collect perspectives from generalists that are rarely accessed in palliative care research which has tended to focus more on specialist care. (140) When this is considered in conjunction with the ethnographic observations of generalists at work and interviews with patients and carers it can be seen that the project has successfully elicited perspectives that are not easily accessed.

The cooperation of three research teams, the employment of a management fellow and the systematic interaction with service user groups ensured that the research and findings have been assessed from a wide range of experiences throughout the project. The management fellow in particular, brought knowledge of clinical practice and organisation to the process as detailed in the next section.

Finally, we believe that this project has successfully illustrated the complexities of end-of-life care: whether as a professional health or social care worker or as a patient or as a carer of such a patient. It points to a fundamental paradox that the more complex a patient's needs are, the more coordination is required, yet the harder it is to accomplish.

Our limitations reflect the nature of qualitative research and the scale of this project. The focus is on an in-depth exploration of a small number of cases and, even with multiple teams, the breadth of data is relatively narrow. Furthermore, the variety of data sources occasionally caused difficult decisions as to which to explore in more depth and which to leave. It is both a strength and a limitation of the methodology that each team was able to prioritise research activities based on emergent findings but it did mean that some areas, notably the role of document analysis and context analysis, did not receive the attention that was originally planned.

It was surprisingly difficult to elicit GP perspectives outside of the Midlands case study. The researcher in the Edinburgh case study was able to interview GPs associated with half of the serial interview participants. The London case study found recruitment even more challenging. Although we were able to capture rich data about patient and carer perspectives of primary care teams, we were only able to capture about half of what we had expected directly from primary care clinicians.

We were unable to generate as much service user participation in the e-Delphi as we wished and structural factors around coordinating work at three sites in conjunction with delays in starting at one of the sites meant that service user group input was not as comprehensive as we hoped. In the light of our experiences, we would look to include service users from each research team on a steering group. The use of the CSRI to track quantitative data provided some useful insights into the participants' experiences but was problematic to administer. In order not to overburden participants with multiple visits, the questionnaire was administered after each interview by the researcher however this routinely added 15 minutes at least to the time required. Although the researchers were usually able to refer back to the interview just conducted (e.g. by asking question in the form of "you said you went back to hospital last month, was that the only time?") all of the researchers found that the process was time-consuming and risked tiring the participants. There was also a risk that the preceding interview was rushed. In addition there were issues in scheduling: serial interviews with people at risk of dying over the next 12 months can never be precisely scheduled due to changing personal, health and social issues meaning that interviews had variable amounts of time between them. Thus it became necessary to pro-rate information. Finally, for patients with high service input it was very hard to get a completely accurate record of services provided over a period of three months. It has to be surmised that the resources we had to devote to the CSRI data would have been better spent elsewhere.

An unexpected finding was the lack of reliable evidence for coordination in end-of-life care. Initial scoping had revealed that there was a large, in fact so large as to be unmanageable, body of literature on the subject, but the full scale review revealed that the notion was usually used informally. Without pre-existing tools for measuring the impact of developments on coordination and the subsequent lack of evidence for the impact of improvements on coordination it was not possible to fully assess 'models' of coordination in the fieldwork. The advantage of the methods used is that we were able to focus on likely proxies for coordination (information sharing, communication, perceptions of continuity, experiences and explanations for delay and poor care) in order to move us forward towards model building.

## *11.6 Role of the management fellow*

A particular strength of this project was the role of the management fellow (Anne Donaldson). An account of the fellowship is given in Appendix 1. The management fellowship has brought benefits to the research team, the parent NHS organisation and the management fellow.

The fellow's insights as a nurse manager in a "front door" capacity and links with secondary care in NHS Lothian facilitated the practicalities of the research, informed its development and critiqued its findings. Through publication of her experiences using a reflective diary the management fellow has evidenced that her immersion into research has enhanced the study greatly, developed her research skills and brought added value to her NHS employer through the promotion of innovation in the workplace based on her newly developed skills, knowledge and confidence. As a result, the management fellow is ideally placed to implement knowledge exchange and dissemination. She is now fully capable of facilitating further research projects that link research, academia and clinical practice.

The embedding of the fellow in the research project in particular allowed the research team to ensure that the research findings were grounded in actual experience and couched in terms that were easily understood by nonresearchers. Thus Anne acted as a bridge between the professionals at the settings facilitating a dialogue between the 'worlds' of research and practice.

## *11.7 Dissemination and impact*

Presentations focusing on the literature review, methods and initial findings have already been made at national academic palliative care and primary care conferences in 2011 and 2012. Informal feedback about the necessity of first identifying patients so they might benefit from coordination has made that theme a central emphasis in the Scottish End of Life strategy review document in 2011 "Living and dying Well: Building on progress"(9), and in other national strategies such as Singapore's. Further abstracts have been accepted for the Royal College of General Practitioner and the Society of Academic Primary Care conferences in 2012, and the International Palliative Care Conference in Montreal (October 2012).

We plan to optimise outputs in high impact generalist and specialist journals. An overall paper covering the key findings of the study will be drafted in April for submission to a leading generalist medical journal: *The Lancet* or *BMJ*. Bruce Mason will be the lead author with input from the whole steering group. As well as the overall paper, key findings from each component of the study will be developed for publication in more detail by project sub-groups. These will consist of one article from each of the case studies, and articles focusing on the literature review, use of multiple methods in health service research, the Delphi and workshop findings. We have had some preliminary discussions about the feasibility of presenting several linked papers to a family of journals in order to publish simultaneously in different journals in the family: doing so may raise the impact of each paper. The provisional titles and writing teams are already assigned.

We will also ensure that each research setting has the results of the study to enable them to react appropriately locally. In addition, the Management Fellow has already begun to implement changes in her workplace based on her participation in this project, and has published in a management journal. (125) By maintaining links with the Primary Palliative Care Research Group at University of Edinburgh, she intends to facilitate an ongoing dialogue between research and practice.

# 12 Conclusions

Based on the results of our comprehensive study involving patients, carers and professionals, and our examination of the recent literature, developments and guidelines we now list implications for policy and healthcare, and recommendations for further research.

## 12.1 Implications for policy

Where there are systems for information sharing in place, such as the electronic palliative care summary in Scotland and shared registers via Coordinate My Care in London, there is evidence that professionals find these supportive and useful in coordinating healthcare delivery. Qualitative data from the workshops show that lack of such systems appears to lead professionals to feel as though they particularly struggle to provide well-managed care at the end of life.

Comparing results from the three workshops suggests that health and social care professionals who are affected by structural reorganisations may become less focused on patient-centred care during, before and after the implementation of the reorganisation. The literature review shows that reorganisations are often considered a route to increase coordination and facilitate collaboration. Thus, there is a clear implication that such reorganisations may diminish patient-centred care for a period. Reorganisation in itself seems unlikely to produce better coordination as coordination is also dependent upon resources (e.g., workload and time) and working relationships (e.g., relationships between District Nurses and GPs).

No clear metrics were found for measuring coordination thus there is no straightforward way to assess the impact of changes in coordination on patient outcomes. Without such metrics, it will be impossible to evaluate the effectiveness of any developments designed in whole or part to improve coordination or increase collaboration. Nor will it be possible to determine the causality of improved patient and/or carer outcomes.

It appears that presently there is little cognisance of how service developments and reorganisations affect and are understood by patients and carers. Service users appear to experience such changes as disruptive and unsettling, and this is exacerbated for people who may be approaching end of life and dealing with multiple encounters with different elements of the health and social care system. Some professionals appear to recognise this and thus ‘work around’ the changes.

There is thus a tension in this report between professionals’ desire for better integration of services and a reluctance to participate in future reorganisations. Service user fieldwork shows that examples of what are likely to be successful coordination between services (such as timely appointments) are not noticed but that problems that may be the result of poor coordination (such as delays) usually are noticed. Thus service developments which lead to improvements in management of the system may not be overtly perceived positively but should lead to improved experience and fewer complaints.

## *12.2 Implications for healthcare*

Improving identification, assessment and planning were all seen as vital elements for improving coordination yet it is likely that these are also seen as improvements in general. Thus there is a caveat that it is difficult to untangle professional perspectives on how to improve healthcare provision from specific methods for improving coordination. The mechanism for how improving these elements would improve coordination and how that improved coordination would lead to better patient outcomes remains a 'black box.' It is reasonable, however, to posit that there is a transmission mechanism. The Delphi results (Q21 in round 1) indicated that there was a strong professional consensus that improving coordination would improve patient outcomes. Likewise our qualitative data has shown that patients, carers and staff all suggest that patient outcomes will be impacted upon by good coordination. Thus, while it is plausible that improved coordination may impact positively on process measures, further qualitative modelling regarding the relationship between coordination and patient outcomes is required.

A patient-centred holistic assessment was the consensus for how to improve coordination, once the person was identified. The service developments that were prioritised by our participants are compatible with the NICE quality standards recently produced for end-of-life care in general,(23) which also highlight the necessity of identification, assessment and planning in the context of good communication and coordination.

Any model of care to improve coordination for people approaching end of life must first ensure that such patients are identified as such so that they can then be assessed and their care planned. This is not necessarily identifying them for referral to specialist palliative care, but for the extra coordination, communication and support that a generalist would initiate when deciding to transition into the palliative care approach with a person with advanced progressive illness.

The large number of interventions to improve coordination for people with advanced illness but not considered to be potentially dying reveals how remarkably similar interventions may be targeting specific illness groups or ages. Interventions that work across disease and age groupings are especially likely to be sustained in an end of life context and seem likely to reduce duplication of services and facilitate coordination generally.

To construct an appropriate model to promote coordination that might reach all people with advance progressive illnesses, planners might work through these six categories of SDS in order, from first identification, then assessment, then planning, collaboration, communication and information to ensure that due consideration is given to each component of the model. All components are necessary for reliable coordination for people approaching the end of life. At present the most pressing issue to address is the fact that less than one third of patients are being identified before they die.

In table 44 below we extract from Table 34 SDS that relate to identification which could, on the basis of this research, be considered for implementation to allow patients to be identified for a palliative care approach and greater coordination

**Table 44. SDS which might to be considered for implementation in the first stage in the developed model for coordination**

**Identification**

1. More patients with malignant and non-malignant diseases are identified and entered on a palliative care register.

2. Regular planned review by primary care teams of patients who ''may be'' approaching the end of life is undertaken for the purpose of being added to the practice palliative care register.

3. When a patient who ''may be'' approaching end of life has a care transition (e.g. discharge from hospital to the community) and as a result requires increased personal care they are considered for the practice palliative care register.

7. Where a hospital team has identified a patient as approaching the end of life they will suggest to the relevant primary care team on discharge that the patient is a candidate for the practice palliative care register.

12. The main informal carers of patients who have been recognised as approaching the end of life are identified and recorded systematically.

Where patients have access to a keyworker or are entered onto a register for additional support, there is evidence that they receive well-organised, managed and coordinated care. The impact is dependent on the condition, the resources available to the keyworker and the keyworker’s ability to collaborate through interpersonal networks with other health and social care providers. Currently, the barriers to identification of palliative care needs mean that access to a keyworker or being placed on a register tends to be associated with particular conditions (notably cancer) rather than need for supportive or palliative care. This project’s findings imply that increased identification and understanding of the potential for early supportive and palliative care will lead to better patient outcomes, extending palliative care beyond cancer, reducing inequalities in end of life care. In particular, there is evidence that patients experiencing multimorbidity may benefit from a keyworker competent to deal with multimorbidity rather than multiple keyworkers for different conditions. The relationship between high needs users of the health service, especially those with multimorbidity, and palliative care is complex when it comes to notions of ‘transitioning’ to palliative care and the impact on the patient of potential changes in keyworkers.

These findings also relate to the issue of frailty. Our serial in-depth longitudinal work over the last 10 years has helped document three typical trajectories of physical decline at the end of life which are acute, typically cancer, intermittent, typically organ failure and dwindling, typically physical frailty or dementia. Key data suggests that around 40% of people in the UK die having followed a frailty trajectory, 30% from organ failure and about 20% from acute, such as cancer. The other 20% relate to unexpected deaths. This study shows that frailty as a construct can be operationalized to identify patients at the end of life in primary care and also in secondary care. However the fact that this was done on the research study does not mean it can be carried out in the real world. A 2012 review on frailty in primary care highlights the fact that family physicians are ideally suited to incorporate the concept of frailty into their practice.(141) The authors suggest that tools to identify frailty are in the preliminary stages of development but would be very useful so that patients could be identified as being frail and then managed in a goal-orientated way to minimize iatrogenic illness.

The importance of the role of carers as informal coordinators within primary and secondary care was identified in this study. There is a need to recognise the role of carers as informal coordinators of care. This study has identified some of the inherent inequities within our healthcare system for those that do not have access to informal carers, and the reliance of the healthcare system on informal carers in relation to care coordination. Including patients and family as active participants in the collaboration may facilitate the stated need of some patients and carers for control, maintenance of autonomy, and dignity. Conversely, patients without such a carer are likely to need extra support.

This is a fast developing field with policies, guidelines and initiatives being undertaken across the United Kingdom and internationally. Changes in health and social service organisations among generalists allied to demographic changes around ageing and increasing survival with multiple progressive diseases means that the health service faces intense challenges in providing good quality, well-coordinated care. The challenge for public health is to systematically identify eligible patients and carers according to need rather than diagnosis so that their care can be coordinated to enable them to ensure that their priorities are acted upon.

## *12.3 Recommendations for future research*

1. Development of valid and reliable means for increasing the consistency of health professionals, and the ability of patients and carers, to self-identify supportive and palliative care needs.
2. Intervention study of how patients approaching the end of life can best be identified in a systematic fashion. What are the roles of patients, carers, and primary and secondary care?

3. Development of tools to measure coordination and thereby its impact on patient outcomes.
4. Intervention study to scope the content, desirability and practicality of a holistic assessment focused on additional needs.
5. Detailed qualitative modelling of potential service models.
6. National intervention studies to promote identification, assessing and planning as an integrated model for generalist end of life care, enhancing information sharing, communication and collaboration among multiple agencies.

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# Appendix 1 Management Fellowship Report

## *Executive Summary*

Undertaking a Management Fellowship has brought reciprocal benefits to the Research Team, the parent NHS organisation and the Management Fellow. Through publication of her experiences using a reflective diary the management fellow has evidenced that her immersion into research, has 1) enhanced the study greatly, 2) developed her skills in reviewing literature, project management, qualitative research and writing, and 3) brought added value to her NHS employer through the promotion of innovation in the workplace based on her newly developed skills, knowledge and confidence. As a result, the management fellow is ideally placed to implement knowledge exchange and dissemination. She is now fully capable of facilitating further research projects that link research, academia and clinical practice.

## *The Management fellow*

Anne Donaldson started a 50% secondment to the project as an SDO management fellow from month four onwards. She maintained her substantive post as Clinical Nurse Manager in a large Teaching Hospital alongside her SDO Fellowship role. This report outlines her initial aims and objectives, activities undertaken to meet these objectives and the personal learning and professional development that she has attributed to undertaking the fellowship role. Also identified in this report are Anne's knowledge mobilisation activities that she participated in during the project and her future plans to utilise her newly acquired skills in practice..

## *Management Fellowship*

### Objectives

1. To provide guidance and steering to the research team based on her own skill set as a clinical nurse manager.
2. To engage fully in the research project.
3. To document the issues involved in participating in research while maintaining a management role with her NHS employer.
4. To facilitate knowledge mobilisation.

These objectives were specified in more details as follows.

## Plan for engagement with the research project

The Fellowship holder will be an important and strategic member of the research team, and become a full member of the project's steering group.

## Proposed research engagement

The candidate will be engaged directly in the research process and contribute to all stages from reviewing the design in details, fieldwork, data analysis and reporting. In particular we will take the opportunity to extend the innovative ethnographic methods in the original proposal through having the candidate engage in "auto-ethnographic" research. (142, 143) Auto-ethnography is to ethnography what auto-biography is to biography, which is to say that the researcher participates in and analyses their own background. It is "research, writing, story and method that connect the autobiographical and personal to the cultural social, and political."(142) In this case, the candidate would take full-part in the ethnographic research as an "insider" into her occupational role and her insights could be cross-checked against the "outsider" perspectives of the other three researcher.

## Reflective diary

Simultaneously the candidate will undertake an auto-ethnographic account of her increasing understanding of the research project and her evolving understanding of the research methods through the systematic use of a research diary. This diary would be the data upon which training materials in gaining research skills for health service professionals would be created.

Through these two clearly defined activities, the candidate would bring both extra value to the research project through the reflective analysis of her own grounded experience as well as building research capacity in the NHS through her reflective participation in the application of innovative research methods to the study of service delivery and organisation of that service in the NHS.

It is intended, therefore, that the candidate would play a dialogical role throughout the research process. Her experience in practical, day-to-day management will inform and critique the researchers' analyses. At the same time, her exposure to the research is expected to inform and critique her understanding of her prior experience. This dialogue will inform more than just the fieldwork phase of the project: it will valuable in determining current best practice, analysing data, presenting findings and creating the final, consensus-seeking phase of the project.

Through the creation of this clearly defined dialogical role we will be able to facilitate the NHS-facing side of this project as the candidate will act as a bridge between professionals in the NHS and the team's researchers. This will ensure that NHS professionals' views are better understood among the research team and vice-versa, and links will be established which will benefit Lothian health (and individual units) and research team.

Finally, it is anticipated that the candidate would take responsibility for the adoption of innovative management research methodology into the project, specifically the utilisation of innovation, implementation and diffusion post the Darzi review (Department of Health 2008; NHS Confederation 2008).

### Engagement in local knowledge mobilisation activities

The fellow will help develop the local capacity and capabilities of the healthcare organisations contributing to the research in Edinburgh, Birmingham and London. While in post the fellow will stimulate management colleagues and clinicians to consider and review the role of research evidence in their daily practice, especially as they deal with patients with advanced illnesses who might benefit from a palliative care approach. She will formally be tasked within the organisation to act as a "research champion for integrating primary and secondary care in the seriously ill." She will use her pre-existing contacts to create and facilitate knowledge transfer activities such as local seminars journal clubs, and planned programmes for sharing research summaries. The central activity will be network building and the management of a series of research seminars that will present palliative care research in informal settings to health service professionals that will encourage the participants to discuss the matters at length with a particular focus on "what works" in context. Finally, the lead researcher (Mason) has extensive experience in the use and creation of "web2.0" services and will liaise with the fellow about the creation of such services as intranet wikis in order to facilitate research sharing.

The fellow will work in partnership with the SDO network to facilitate communication between research projects and will specifically seek out ongoing management research, and stimulate interest in, and engage in this, with academic and service colleagues.

As the project finishes, the candidate will focus on dissemination and planning further research and quality improvement activities. She will be well-placed to facilitate future research into generalist palliative care in specialist settings as well as being able to advise on research in NHS settings more generally.

## *Outcomes*

The proposed outcomes to the project are therefore

- Enhanced *communication* between NHS professionals and the project research.
- Creation of enduring *links* between the universities and NHS professionals in both Scotland and England ensuring a conduit for information not just between academia and the NHS but from the different experiences of NHS professionals in Scotland and England.

- Creation of training materials in research for NHS professionals based on a reflective fieldwork diary that will help *build research capacity* in the NHS.

## *Fellowship report*

### Activities

To achieve these project management fellows aims and objectives it was decided by Dr Bruce Mason, Professor Scott Murray and Anne to formulate a project activities framework. The aim of this framework was to identify key activities which would support the objectives agreed at the outset of the project.

When the fellowship commenced there were specific aims and objectives identified for Anne in the form of project activities to undertake, and these are summarised in Table 45 below.

**Table 45. Key Project Activities for Management Fellow**

| Timeline (Phase) | Project Activities | Fellowship holder's activities |
|---|---|---|
| Phase 1 | 1. International Literature review<br>2. Identifying "good outcomes" from patient and carer perspectives.<br>3. Confirm fieldwork sites for the Phase 2 case studies and gain ethical approval | • Training in qualitative and quantitative research methods.<br>• Training in literature review methods and participation in literature review with focus on management theory.<br>• Systematic maintenance of a research diary to continue throughout the project.<br>• Facilitation of user-group involvement.<br>• Facilitation of research site confirmation, training and experience in ethical approval applications. |
| Phase 2 | 1. Conduct ethnographic case studies in three sites including: participant-observation in situ, baseline | • Facilitate participant-observation at research sites and recruitment of participants for interviews. |

| | | |
|---|---|---|
| | and follow-up interviews with patients, carers and staff members, collecting quantitative data of service usage, completion of after-death analyses, and network analysis of local, regional and national operational structures.<br>2. Conduct interview data analysis using transcripts in NVivo.<br>3. Conduct statistical analysis of service usage.<br>4. Identification of barriers (system and individual) and facilitators to coordination of care; identification of outcomes from patient, carer and staff perspectives. Construction of model of service provision based on these findings. | Take lead on the analysis of the organisational contexts surrounding each research site.<br>• Manage and coordinate research at all sites.<br>• Collaborate in quantitative data collation<br>• Contribute to qualitative and quantitative data analysis.<br>• Critique and refine description of barriers and facilitators from the perspective of a service provider.<br>• Facilitate networking activities with the healthcare organisations involved to disseminate research insights. |
| Phase 3 | 1. Conduct 2-round e-Delphi survey of proposed model with 50 key informants in an attempt to gain consensus.<br>2. Dissemination of project findings at national workshops. | • Facilitate survey.<br>• Take lead in organising national workshops.<br>• Collaborate in presentations and publications of research findings.<br>• Engage in building research capacity within local healthcare organisations.<br>• Facilitate the creation of future research derived from this project. |

| | |
|---|---|
| Post - fellowship | The fellow would be expected to take responsibility for embedding the research findings into local NHS management practice, networking to spread the practice and collaborating with future research projects in order to continue building research capacity within the local health professional networks as a research champion. |

## ***Skills Development***

In order to achieve the aims and objectives of the project Anne's activities in the last 2 years have been numerous and varied.

Once these activities were identified Anne met with Dr Bruce Mason and Professor Scott Murray and a Management Fellow Learning Framework was developed by mapping learning objectives to planned activities. Once this was initiated it was regularly reviewed and adapted, through an iterative process, as the project progressed and Anne's role developed. The Management Fellows Learning Framework is attached see Table 46 below.

Each month Anne met with Dr Bruce Mason and Professor Scott Murray to agree specific objectives which mapped to the learning framework and the agreed project activities

The management fellowship has encompassed many areas; one of the first most important areas to develop was skills development.

This was commenced with ongoing training in qualitative research methods under the supervision of Dr Bruce Mason, this also consisted of relevant study sessions to develop and increase her research knowledge base and these included several one day courses provided by University of Edinburgh University. The formal workshops attended were on: 'How to write an abstract', 'How to construct a questionnaire', 'Identifying themes from participant interviews'

She has also undertaken a 1-day course provided by University of Edinburgh in literature searching with Medline in order to increase her skills and a 1 day workshop on 'Qualitative research'.

Other Developmental and training included: undertaking a workshop on delivering compassionate care.

An invaluable part of skills development entailed scheduling two meetings with Professor Jill Schofield (Somers Chair of Healthcare Management) , these meetings were fundamental in giving Anne a personal insight into the forthcoming research role and allowing Anne to develop an understanding of how to achieve and manage an ongoing balance between her Healthcare management and SDO research roles , and also how to bring maximum benefits to both NHS and the Research team. These meetings helped to outline strategies that could be used to manage her time effectively and produce the most positive outcomes.

Another important development opportunity that Anne had was to attend the COMPASS annual palliative care research day where she presented a poster and this was followed by attending the European Association of Palliative Care Conference which afforded a unique learning opportunity to increase her knowledge base on palliative care and the international research related to this specialist area.

Training in literature review methods was fundamental to undertaking this role. Some initial on-the-job training was provided by Bruce Mason and Scott Murray and this training was essential in allowing Anne to develop her skills to a level where she was able to assist by reviewing and inputting into a literature search paper which she will co-author produced by the research team. Anne also had the opportunity to complete her own 'Grey Literature review'.

## ***Research***

Anne continued with a 2 year systematic maintenance of an auto ethnographic research diary throughout the project under the supervision of Dr Bruce Mason and the CI, Prof Scott Murray. Anne received training in "auto-ethnography" and reflexivity to support her with this aspect of her fellowship role and iterative re-readings of her diary have led to the preliminary identification of emergent themes around language barriers; self /research/managerial development and knowledge awareness; and sharing.

Also other prominent themes emerged around the difficulty she initially faced changing her identity between researcher and manager, and how the research allowed her to develop her full managerial potential. Some more unusual themes became apparent around the significant use of mobile phones to manage patient flow.

She commenced and completed an article within the first year of her secondment and has also undertaken several reflective reviews of her diary. This culminated in her first published article where she was the lead author on an article reflecting her experiences in her first year which was published in *Nursing Management*. (144)

Anne also had the opportunity to observe a first, second and third stage qualitative interviews undertaken by Dr Bruce Mason and then was able to assist the team by reviewing transcripts and identifying emerging themes from these. Undertaking this in her central role has allowed her an invaluable insight from all sides of the research project: as user, researcher and NHS manager and offered her a unique opportunity to transform her new vision and understanding into improving service delivery in her parallel

NHS managerial role. She also has intimate knowledge of qualitative longitudinal research

Another important milestone event that Anne had was the opportunity to become involved in the ethical approval application and she was able to attend and observe the Ethics committee in action when the Dr Bruce Mason and Dr Alison Worth presented the final application for approval. This gave Anne some invaluable insight into the research process and allowed her to feel fully involved and integrated into the research team from an early stage of her secondment

Further research outputs have included a Poster Presentation for the COMPASS Collaborative Conference in Edinburgh (April 14-15, 2011) and also at the Primary Palliative Care Research Group presentation event

Anne managed and collated the initial long list of participants for the Delphi survey and also assisted with review of the questions set in this survey. She also helped review the 20 service Delivery statements which were produced as a result of this survey and was able then to observe these being launched at national workshops where experts then identified methods to put these Service Delivery statements into practice.

Anne took a full role in project steering group meetings, teleconferences and national workshops and also maintained contact with user-group involvement, regularly representing the research team when she attended user group meetings, she also helped with liaising with the Edinburgh research site, gained office space for the research team at the site and built a network of contacts and identified activities that would be beneficial to the research team.

The research team, including Anne, presented project information at the various training workshops and meetings that she identified as appropriate.

Anne attended the management fellowship evaluation workshop on 30th June 2011 where she participated in the SDO Management fellow evaluation project and was been interviewed by Professor Alison Bullock for this.

She has spent time with her local palliative care team and she has met with her managerial equivalent at St Christopher's Hospice and formed links with them for future service development within the acute hospital setting.

Other Management Fellow activities she has undertaken include attendance at the SDO Delivering Better Healthcare Services 2nd-3rd June2010 and attended and represented Professor Scott Murray at Lothian Palliative Care Managed Clinical Network meeting in August 2010

## *Management Fellow Learning from the Experience*

Through maintenance of personal diary it has been possible to map Anne's personal learning from the Management Fellowship.

Key learning outcomes have emerged at different stages of her secondment and are evidenced throughout her two year placement.

Initially Anne's learning was evidenced through her broadening knowledge base on the area of end of life care and research methods such as 'ethnography' and 'longitudinal qualitative', however other early learning can be identified through her identification of having to learn a new language, and her continual self-observation of how the research role initially highlights that her previous work experience has become narrower over the years, she also identifies early on how she often fails to let others take control and manage. Indeed this particular observation has led to her changing her own managerial practices and she is now able to see instant rewards of adapting her management style to benefit the team performance.

Another important learning for Anne was the realisation that she had become quite restricted in her career pathway choices, the fellowship had now shown her that she has been able to diversify successfully and that in the future she would be happy to apply for a job in a different area of healthcare, with her new found confidence in her abilities to undertake new roles.

Anne has personally learned a lot about the research process and is now able to identify how pivotal the research process is to her managerial role. She has also learned how research can be used to benefit the organisation she works for and she can utilise this through effective initiation and facilitation of knowledge mobilisation.

This experience has increased her self-awareness and how she is perceived by others. She is now more conscious of her professional interactions and how influential they can be dependent on the contextual background and the role of the person that she is interacting with.

Another invaluable learning experience has come from Anne's networking with her peer group of management fellows and this has afforded her a unique chance to share their expertise and collaborate with them to achieve shared aims.

## *Knowledge Mobilisation activities participated in during management fellowship*

Anne has undertaken several knowledge mobilisation activities during this secondment. These have been varied both in nature and target audience.

She has undertaken some of these as a member of the research team and also undertaken several autonomously, in particular as part of her managerial role.

Knowledge mobilisation activities she has undertaken with the research team include facilitating The Delphi survey, when 50 national and international experts in end of life care were given the opportunity to be the first people to review the newly developed Service Delivery Statements and offer their thoughts and valuable input, whilst also ranking these. The Delphi survey allowed these national and international strategy developers to share statements developed from the research emerging themes.

National workshops were another successful knowledge mobilisation output which Anne participated in. The target audience for this were both primary and secondary care healthcare professionals and user group representatives. The workshops required the invited participants to appraise 20 service delivery statements which were generated from the research findings and identify ways of implementing the most popular ones. These workshops raised great awareness amongst strategic key individuals who were chosen due to their ability to affect heath care delivery and had excellent professional networks allowing them to convey the research message far and wide.

Anne also contributed to the Significant Event analysis where the local research teams visited the individual research sites and shared information of 5 significant events which had emerged from their interviews with the recruited patients group and were relevant to the participating research areas.

Another method used to mobilise knowledge was through publication and Anne with assistance from Bruce and Scott wrote a reflective article on her experience of entering the world of research which was published in the Nursing Management Journal. (144)

Anne has also used local communication networks to disseminate knowledge from the research and this has included local Charge Nurse Meetings, Directorate meetings across Lothian and in her role as a local Quality Improvement Team Chair she is able to share information with key NHS individuals.

One of the effective ways that she has found useful to disseminate knowledge and increase research capacity within her parent organisation is through her Appraisal and Personal Development Plan meetings with individual Charge nurses and Specialist Nurses. During these meetings Anne is able to share her new knowledge with the individuals to help encourage them during their objective setting and facilitate relevant learning opportunities for them to meet their objectives ensuring that these are evidence based in nature.

Each area that Anne manages now has a knowledge mobilisation board where members of the clinical team take it in turn to share evidence based research findings which are relevant to their particular area. Anne is also able to use these areas top share knowledge that she has gained from her fellowship placement with her team.

Anne remained a key facilitator raising the profile of the research team and liaising with the Edinburgh research site, and her role was integral to ensuring effective knowledge mobilisation during this final phase of the project. She informed the project steering group on appropriate methods as they emerged from shared information sessions and resulting from her networking with her management fellow colleagues.

## *Future plans*

Anne plans to maintain links with the Primary Palliative Care Research Group and ideally this would consist of one day per fortnight secondment to them, continuing to participate and facilitate research and undertake knowledge mobilisation and exchange. This continuing link would allow ongoing integration and collaboration between Primary Palliative Care Group and NHS Lothian Acute Division. Another focus of this would be to develop ongoing relationships between healthcare professionals and research fieldwork teams

One of Anne's aims for the future is to facilitate a research project based at her NHS site, working in collaboration with the local palliative care team and Acute Medicine colleagues to introduce a simple tool at the front door assessment area, to identify deteriorating patients and alert their GP'S to this recent identification. This would allow Primary and secondary care to work in collaboration at identifying Patients with advancing illness and potential end of life needs and ideally trigger an holistic assessment and future planning to assist the patient and their carer to access appropriate healthcare support when required and potentially reduce 'Unscheduled Healthcare' attendances.

A further aim that Anne has on completion of her Management fellowship is to maintain collaborative working with peer group of Management Fellows. This includes a joint initiative from the Fellows to set up an Alumnus for knowledge exchange.

Further plans include:

- Using her current NHS networks to promote research and disseminate findings to improve patient care.
- Encourage NHS staff to undertake or participate in research projects.
- Continue and develop methods of knowledge dissemination in NHS settings
- To use current meeting structures such as local Charge Nurse Groups, Clinical Nurse Managers forum and individual Personal Development Plans to embed knowledge dissemination practices.
- To complete a second reflective article for publication and to co-author relevant publications derived from the SDO research work.

## *Summary*

Based on a review of the information available the Management fellowship placement has enhanced this SDO funded research project. Whilst the management fellow as an individual has developed professionally from undertaking this challenging role, it is essential to recognise that this placement has delivered reciprocal benefits both to the research team involved and to the manager's parent organisation. There are long term benefits to both organisations which must also be taken into account, however ultimately this role will benefit the patients overall as Anne continues with her knowledge mobilisation with an aim to improving healthcare pathway processes and healthcare delivery using relevant research based evidence.

**Table 46. Annex - Management Fellow Learning Framework**

| *Learning Objective* | *What/How* | *Where* | *When* |
|---|---|---|---|
| To develop broad understanding of qualitative and quantitative research methods. | Appropriate reading.<br>Attend qualitative research study day | UOE | Sept 2010 |
| To undertake training and experience in ethical approval applications | Attend ethics committee with Team | Deaconess House | April 2010 |
| Facilitate participant-observation at research sites and recruitment of participants for interviews. | Shadow Bruce in Fieldwork | RIE and participants' home | Aug 2010 |
| Training in literature review methods and participation in literature review with focus on management theory. | Literature review study day.<br>Own literature search completed and combined with Dr Bruce Mason | WTRFC | May 2010, June 2010 |
| Systematic maintenance of a research diary to continue throughout the project. | Regular updates of diary with quarterly reviews | EDIN UNIV | Jan 2010-Dec 2011 |
| Facilitation of user-group involvement | Attended user groups and maintain regular correspondence with key contacts | Dumfries | Continual |
| Take lead on the analysis of the organisational contexts surrounding local research site.<br>Manage and coordinate research participant data sheets at Edinburgh sites.<br>Collaborate in quantitative data collation | Duplicate files updated regularly on both sites | RIE | Oct 2010 |
| Contribute to qualitative and quantitative data | Identifying emerging themes from | U of E | Oct 2010- |

| | | | |
|---|---|---|---|
| analysis.<br>Critique and refine description of barriers and facilitators from the perspective of a service provider. | participant interviews | | Dec 2011 |
| Facilitate networking activities with the healthcare organisations involved to disseminate research insights. | Attended SDO conference Delivering Better Care<br>Assisted with preparation of 5 significant events.<br>Attended and facilitated at National workshops in Edinburgh and Warwick | Manchester<br>CAA<br>RIE | June 2010<br>Aug2011<br>Oct-Nov 2011 |
| To become competent in writing Abstracts | Abstract writing workshop | WTRFC | 3/2011 |
| To understand and develop questionnaires to allow assistance with facilitation of project | Questionnaire design workshop | WTRFC | 6/2010 |
| Take lead in organising national workshops. Dates confirmed and compilation of attendees. | National workshops dates arranged. | London<br>Warwick<br>Edinburgh | Oct /Nov<br>2011 |
| Collaborate in presentations and publications of research findings. | COMPASS poster presentation<br>Lisbon conference<br>Nursing Management article publication<br>Input into literature review for publication<br>Ongoing input into future publications derived from research project | Edinburgh<br>Lisbon | May-Dec 2011 |

| | | | |
|---|---|---|---|
| Engage in building research capacity within local healthcare organisations. | 1ARAU ‘speckled computer project<br>2 Entonox –implementation for Urology procedures<br>Future acute Medicine research project planned to identify Palliative care patients in front door setting. | NHS Lothian | 2011 |
| Facilitate the creation of future research derived from this project. | Meet with other researchers at U of E and disseminate projects | NHS<br>Lothian | ongoing |
| Undertake a piece of reflective writing for publication | Reflective piece completed | Nursing Management Journal | 3/2011 |
| Increase Palliative care knowledge and develop ongoing communication with key players | Attend MCN<br>Meet with managerial equivalent at St Columba's-completed<br>Maintain links with NHS Lothian Palliative care team.<br>Networking with research teams.<br>Network with peer SDO management fellows | Marie Curie<br>St Columba’s<br>Evelyn Howie<br>WGH/RIE<br>U of E, KCL, Warwick,<br>London | June 2010<br>Dec 20111<br>Ongoing |
| Attend EAPC Conference and network with key research players to increase understanding and contextual background of research roots. | Promotion of research and networking opportunities.<br>Knowledge base increased +++ Steering group and international field of expertise included in Ad Hoc meeting | Lisbon | May 2011 |

|  |  |  |  |
|---|---|---|---|
| To develop research project management skills by creating and managing eDelphi list and ensure circulation and feedback from all key stakeholders | Spread sheet drafted and circulated. Internet search undertaken and information feedback from steering group.<br>Iterative process to ensure final list is as appropriate field of experts as possible. | UOE | 6/2011 to 8/2011 |
| Research ‘Service delivery statements and feedback to team. | Search using Google, Medline and person resources | UOE | June 2011 |
| To facilitate modified nominal group technique discussions at national workshops | Act as either discussion facilitator or group scribe. | Warwick<br>Edinburgh | Oct /Nov<br>2011 |
| To ensure ongoing liaison with SDO and peer group of management fellows to enhance own learning and increase knowledge exchange | Attended and contributed at meetings and evaluation events.<br>Ongoing email contact with management fellows. | London<br>Edinburgh<br>London | 2010-11<br>To date |

# Appendix 2 User Involvement report

Patient and public involvement (PPI) has been a vital part of this study from original design through to dissemination and ideas for future research. Mareth Irvine, a member of the University of Edinburgh's ongoing Research Discussion Group (a PPI group), was a grant-holder on the study. As well as this, four different user groups contributed to give and work with patient perspectives.

1) The University of Edinburgh's Research Discussion Group (ERDG) worked with the research team throughout the study. Based in Dumfries, Scotland, the Group has been meeting three/four times a year since 2003. It currently has 8 lay members, with experience of cancer, COPD, diabetes and other long term conditions which helpfully meant it could experientially discuss issues about many conditions and co-morbidities.
2) The COMPASS Collaborative's Consumer Research Panel (CCRP) was consulted on specific issues arising from the study. CCRP was set up in 2009 and were experienced in contributing the patient perspective. With 16 members from across the UK, the panel has experience of a wide range of cancers and situations as well as a wealth of other skills. It operated via e-mail, through the Panel Chair, Peter Rainey, himself a cancer patient.
3) The University of Warwick User Group (UWUG). This group was set up specifically for this study. Its members consist of both patients and carers.
4) The Kings College London Lung Support Group. (KLSG) This group was formed specifically for the study out of members of previous user groups.

In phase 1, the various groups helped define the main issues and patient-centred outcomes, discussed how we could best conduct the ethnographic studies from a patient perspective and ensured that the study information sheets and interview questions were clear and relevant, which helped greatly with preparing for the ethics submission and success in obtaining ethical approval.

In phase 2 the groups worked with the research team to develop the emerging findings, and specifically the best use of Client Service Receipt Inventory. Mareth Irvine, as a steering group member also travelled to Edinburgh to consult on the best way to use service use groups as well as subsequently contributing to steering group discussion.

The lead researcher and the management fellow attended meetings of the Research Discussion Group on 6 occasions during this period and issues arising from the study were discussed at 10 meetings over two years. This frequent contact ensured that the priorities of service users as expressed through the group remained central to the research process.

In as much as it was possible, ERDG was asked to take an active role in assessing the research. For example, at the meeting in March 2011, emerging themes from the first round serial interviews were shared in advance with ERDG who were then asked to respond. One common theme was that patients who had been discharged from hospital were not receiving subsequent contact from the GP. The group was asked to explore this further and provided the following feedback.

*"User Group response was that [lack of contact from GP] was overwhelmingly the case and that the service from GPs 'was not what it used to be'. Several group members shared their own experiences of having to cope on their own following discharge and also this subject raised discussion around NHS 24. The group in general felt disinclined to phone NHS 24 and would rather attend A/E direct than phone and speak to 'someone in another part of the country.'*

This level of feedback from group members outside of the research setting helped us refine and further investigate the issue which was to become one of the key issues in coordination.

The Warwick User Group and the KLSG helped develop the team's understanding of the contexts and culture of care and relationships with healthcare professionals. Although the main ongoing consultation was with ERDG, the other user groups were able to address issues specific to the local teams. For example KLSG at a meeting in September 2011 helped validate the observed differences inpatient support between cancer patients for whom the Lung Cancer Nurse Specialist was a keyworker and non-cancer patients.

"*The communication between the Macmillan nurses, surgeons, lung consultants, GP and specialist nurse for lung cancer patients is brilliant* "first class care*", patients can't complain. Their appointment has never been cancelled, they were informed if the appointment was late and patients really appreciate that. On the contrary, COPD patients have to wait longer for their results and the absence of a specialist nurse make processes more complicated and experiences less positive. When patients are diagnosed with cancer they receive information about the disease, progression, medication, treatment etc. But for COPD patients this is not the same. Patients have to wait longer."*

In phase 3 members of the groups were active participants in the workshops and in the ongoing interpretation of the findings. All the groups re-iterated the importance they attached to this area of research and to the approach and methods adopted by the study.

As noted under the Strengths and Limitations of the main report, we did find that it would have improved the service user input to have had a service user take a more active role in each of the local research teams as well as the main project steering group. Although a service user was included in the main steering group, illness during the project plus lengthy travel times meant that it was hard for her to participate fully in meetings.

A process of critical reflection during the process of submitting and revising this report is being undertaken and we aim to consult with service user groups about more effective processes for future projects.

In summary, user views were embedded in the project from initial conception and throughout all phases. Defining and conceptualising effective coordination of care from the service user perspective continued throughout the study, and will support dissemination back to participants, as well as the normal reporting. In addition important lessons were learned about how best to work with user groups in research, which will be invaluable for future research.

# Annexes

The following documents are attached. The first is the final Gantt chart The second is the version of the SPICT used for the study. The third and fourth are the sampling grid and serial interview guide used at all sites. The final annex is the modification of the CSRI used for the study

Annex 1 - Gantt chart v7

Annex 2 – SPICT

Annex 3 - Patient recruitment sampling grid

Annex 4 – Serial interview guide

Annex 5 - Modification of the Client Service Receipt Inventory (CSRI) used in this study