

National Institute for Health Research
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Variations in out of hours end of life care provision across primary care organisations in England and Scotland

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Glossary of terms/abbreviations

ACP	Advance care planning
A&E	Accident and emergency
CHP	Community Health partnership
DN	District nurse
DNAR	Do not attempt resuscitation
DNACPR	Do not attempt cardiopulmonary resuscitation
EoL	End of life
EoLC	End of life care
ePCS	Electronic palliative care summary
GMS	General medical services
GP	General Practitioner
GSF	Gold Standard Framework
HB	Health Board
KPI	Key performance indicators
LA	Local authority
MDT	Multi-disciplinary team
NHS	National Health Service
NICE	National Institute for Health and Clinical Excellence
NRES	National Research Ethics Service
OoH	Out of hours
PCO	Primary care organisation
PCT	Primary care trust
PPoD	Preferred place of death
PPoC	Preferred place of care
RR	Rapid Response
SHA	Strategic Health Authority
SPA	Single point of access
SPC	Specialist palliative care

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The views expressed in this report are those of the authors and not necessarily of the Department of Health.

Executive Summary

Background

Timely access to high quality appropriate end of life care in the out of hours period has been reported to be a key factor in enabling patients at the end of life to be able to remain at home, if this is their wish. Deficiencies in out of hours end of life care have long been recognised. Most out of hours end of life care is provided by generalists: health care professionals who, although often expert in their own field, have not had specialist palliative care training. Research into generalist out of hours end of life care is limited. A scoping report on generalist end of life care funded by the National Institute of Health Service Delivery and Organisation programme concluded that research is needed 'to define and evaluate models of generalist out of hours care at the end of life within a systems approach, taking account of different providers ...' Before research into this can take place, however, more information is needed about how this care is currently provided, about variations in service provision, and whether identifiable models of service provision exist from a systems perspective.

Aims

To establish how generalist out of hours end of life care is provided in the community; to explore variations in provision, including evidence for distinct models of care; to investigate views of commissioners and senior managers, in order to help inform commissioning decisions, and the direction of further research.

Methods

1. A qualitative telephone interview study with senior managers in Strategic Health Authorities in England and Health Boards in Scotland responsible for end of life or out of hours care which explored participants' views of service provision, its strengths and weaknesses.
2. A telephone interview survey of key informants knowledgeable about commissioning or providing out of hours end of life care in Primary Care Organisations in England and Scotland. 50% of Primary Care Organisations in England and Scotland were sampled. Questions about the provision of out of hours end of life care services were coded and

- analysed numerically, and views on service provision, its strengths and weaknesses were analysed using qualitative methods.
3. An Expert Panel who discussed service delivery variations within these data, considered whether there were emerging care models, discussed 'good' out of hours end of life care characteristics, and began to develop theoretical propositions about out of hours end of life care.
 4. A 'Virtual' User Panel which obtained views about preferences for, and experiences of, out of hours end of life care.

Results

Senior managers from 30% of Strategic Health Authorities/Health Boards participated in interviews (n=13). Response rate for the Primary Care Organisation survey was 42.8% (51 of 119 sampled Primary Care Organisations). Participating Primary Care Organisations in England probably had larger populations and GP practices than all Primary Care Organisations. 5/51 Primary Care Organisations were excluded from qualitative analysis because of inadequate data.

20 'experts' in end of life or out of hours care were approached to participate in the Expert Panel: 14 agreed and 6 participated on the day. Professional roles included Strategic Health Authority Executive Nurse, Palliative Care Consultant, GP and GP commissioner, PCT Director of Commissioning, Lead Advisers for two national palliative care organisations, Technical Officer and GP out of hours database provider (one member had dual roles). Project team representation contributed expertise in out of hours and urgent care, primary palliative care, and an expert commissioning perspective. As planned, six service users participated in the 'Virtual' User Panel: two each with cancer, organ failure and with frailty.

The research has two main findings. Firstly, the importance of considering out of hours end of life care as a complex system which includes aspects of 'in hours' generalist end of life provision as well out of hours GP, urgent care, nursing and social care, and specialist care services. Secondly, that there is considerable variation amongst Primary Care Organisations in England and Scotland in both the type and level of provision of generalist end of life out of hours services and the use of mechanisms to facilitate end of life care.

Out of hours end of life care as a complex system

The study findings demonstrate that out of hours medical care is just one component, albeit an important one, of the out of hours services needed by EoL patients at home. This contrasts with previous research, which has focused on out of hours GP provision. They also illustrate the importance of viewing out of hours end of life care as a complex system. Data show, for

example, how perceived deficiencies within one part of the system may be addressed by service innovations elsewhere, and how problems at one point in the system have implications elsewhere.

These results also show the extent to which good out of hours end of life care depends on actions within working hours. Good OoH EoL care cannot be separated from care within hours, and in-hours care must be seen as part of the out of hours end of life care system.

Variations in extent and type of service provision

All Primary Care Organisations reported that practices in their Primary Care Organisation had a system to notify out of hours GPs about end of life patients. 62% used fax/email and 38%, an electronic system. In only 18% of Primary Care Organisations did GP practices and out of hours organisations share the same electronic system, although a further 22% planned to do so. Respondents' comments indicate that these figures represent the best picture within Primary Care Organisations. Not all practices used these systems regularly if at all; there were difficulties in getting information updated; and there were wide variations in how much information was shared, from name only through to full care plans, PPOC and DNAR. Less than half of ambulance services were able to access information on end of life patients. Respondents in several Strategic Health Authorities and Primary Care Organisations discussed implementation of an electronic palliative care register, and reported varied experiences.

Patients wanted the out of hours organisation to know about them to ensure informational continuity but, importantly, they wanted the out of hours system to work differently for them. They did not want to have repeat their information to different people, and found this difficult; they wanted prioritisation at triage and to be contacted by the clinician within a reasonable, specified, period. Some Primary Care Organisations did things differently in this respect, but no evaluations on the impact of different mechanisms were reported.

49% of responding Primary Care Organisations reported that District Nurses were available 24/7 consistently across the Primary Care Organisation, and the remaining 49% reported either partial provision 24/7 (for example at weekends or up to 10pm weekdays) or varying provision across the Primary Care Organisation. No previous studies have looked at the prevalence of nursing and personal care services other than 24/7 community nursing services. These findings suggest considerable innovation in provision, and uncertainty, particularly in rural areas, about the feasibility of 24 hour district nurse services.

The Expert Panel agreed on five characteristics of 'good' out of hours end of life care. Only one in eight Primary Care Organisations had all five characteristics, with two fifths having four out of the five.

Conclusions

Implications for healthcare

Significant variations in out of hours end of life care, both between and within Primary Care Organisations, demonstrate that progress is still needed to ensure all end of life patients and families receive high quality out of hours care.

The evidence in this research suggests that the first two steps of the Department of Health end of life care pathway (i.e. Discussions as end of life approaches, and assessment, care planning and review) should be regarded as integral parts of out of hours end of life care, even though these steps usually take place during normal working hours.

There is variation both between and within PCTs in what information on end of life patients is notified to out of hours GP services, in the proportion of this which happens in 'real time' and, if not, how often it is updated. There is also variation between out of hours providers in what happens as a consequence of this information. This evidence suggests that the wishes of EoL patients and their families would be better met if more Primary Care Organisations met the standards of the best and improved their out of hours end of life care informational continuity.

Commissioners in this research were concerned about the impact of ambulance services through unscheduled admissions in EoL care. These services currently have poor access to information. It is unclear whether improved information would impact positively on patient experience, but this seems likely.

The evidence suggests uncertainty amongst NHS senior managers and commissioners about the feasibility of providing 24 hour District Nurse care, accompanied by a range of models for meeting patient's nursing and personal care needs, and family respite needs, at night. Debate is therefore needed about available models and their perceived strengths, weaknesses and costs, in order to ensure that all end of life care patients receive appropriate care at home and avoid unwanted hospital admissions.

Recommendations for research

Research is needed into the

- 1) the most effective, efficient and acceptable models of providing care to meet end of life patients nursing and personal care needs out of hours, taking into account the impact on the whole out of hours end of life system.
- 2) the most effective, efficient and acceptable strategies to provide continuity out of hours for end of life patients and their families.

- 3) generalist out of hours end of life care as complex systems, including patient notification and advance care planning in normal working hours, from the perspectives of patients, families, staff and organisations; to explain the antecedents, impacts and consequences of differing OoH configurations in this context.
- 4) the most effective and efficient strategies to avoid unwanted hospital admissions following ambulance call-out for EoL patients who want to remain at home, and to ensure rapid hospital discharge when admission is unavoidable.
- 5) the costs of maintaining end of life at home out of hours compared to admitting them to hospital.
- 6) the most effective and efficient ways of providing education and training in end of life care for generalist staff working in out of hours services.

The Report

1 Introduction

1.1 Overview

In this report, the findings are presented of a research project funded by the National Institute of Health Service Delivery and Organisation research programmeⁱ to address a recommendation for further research made in an earlier scoping exercise on generalist services for adults at the end of life (EoL)¹. This made four recommendations for further research, based on a comparison of key research themes emerging from a consultation exercise with key issues from a literature scoping review. The second of these called for 'primary research to define and evaluate models of provision of generalist out of hours (OoH) care at the EoL within a systems approach, taking account of different providers'. The research would assess how service configurations work in different geographical areas, identifying factors that lead to improved patient care as well as factors that prevent optimum care. Models of good practice would be tested in other geographical areas and under different conditions'.

Before such research can take place into the consequences of variations in OoH EoL care, however, more information is needed about how this care is now provided and, in particular, what currently is the variation in service provision, and whether there is indeed evidence of identifiable models of service provision from a whole systems perspective. This will inform the choice of service configurations, types and/or models for inclusion in future evaluations of generalist OoH EoL care. This is also true of the opinions of those currently commissioning this care, of experts in EoL care, and of service users. In addition, in an area currently lacking robust evidence, the experiences of commissioners and experts familiar with the complexities of OoH EoL care, as well as their views of factors that enhance or inhibit high quality patient care, will begin to address the need for information to help guide commissioning decisions by clinical commissioning groups.

The research reported here therefore aimed to address the lack of information on the variation in availability, organisation and delivery of generalist OoH EoL care, and to supplement this with the views of those commissioning this care, as well as that of experts and of service users, in order to inform future research studies in this area and to provide guidance to commissioners in an under-researched area.

ⁱ Now Health Services and Delivery Research

Chapter 1 contains background information and literature. It begins with an introduction to the Department of Health's EoL Strategy, which provides an important conceptual model and organising template throughout the report, and continues with a discussion of the current emphasis on increasing home deaths (or reducing hospital admissions), an important motivating factor for improving EoL OoH care. Palliative care in the community is then described and discussed, primarily to provide context for OoH care, the focus of this report, but also to give background information on palliative care for those unfamiliar with it. The chapter then turns to OoH care itself, first in general and then the literature on OoH care in EoL care is reviewed. The chapter concludes with the study aims and objectives. The project's methods are described in Chapter 2, first for a qualitative interview survey of senior managers and secondly for telephone interviews with key informants from primary care organisations (PCOs). The methods of an Expert Panel and a 'Virtual' User Group are then described. The research results are then presented in three chapters. Again, those for the qualitative interview survey of senior managers are presented first (Chapter 3). Those for the PCO interview study are presented in Chapter 4 in three sections: response rate and bias; numerical analysis; and then qualitative findings. Findings from the Expert Panel and 'Virtual' User Panel are presented in Chapter 5. The implications of the results for health care and recommendations for research are presented in Chapter 6, the Discussion.

1.2 Background

1.2.1 End of Life Strategy

In 2008, the Department of Health launched England's first EoL Strategy, intended to promote high quality care for all adults at the EoL, regardless of cause or setting^{ii,2}. A central component of the Strategy was the development of the EoL Care pathway, for use both when commissioning services and for the delivery of integrated care for individuals. This recognised that, rather than focusing on improvement to individual services, a whole systems approach to quality improvement was needed, with emphasis first on the need to identify people approaching the EoL and initiating discussion with them about EoL preferences, then on regular care planning to address their needs and preferences, and thirdly on the coordination of care between the multitude of different services involved in

ⁱⁱ In the Strategy, the Department of Health used the following working definition of EoL care: '... care that helps all those with advanced progressive, incurable illness to live as well as possible until they die. It enables the supportive and palliative care needs of both patient and family to be identified and met throughout the last phase of life and into bereavement. It includes management of pain and other symptoms and provision of psychological, social, spiritual and practical support' (Department of Health, page 47). Importantly, this definition puts no time limit on EoL care: it does not equate it solely with the last weeks of life, but recognises that for some patients and their families this period may last months or even years.

addressing these needs from National Health Service (NHS) and social services, and voluntary sector. Since the launch of the Strategy, the EoL Care Programme has worked together with the Department of Health, commissioners, providers and national charities to begin to make this pathway a reality and to improve care for patients and families³.

1.2.2 Place of death

A strong factor in the motivation both for the original Strategy and for its implementation is the perception that more patients are currently dying in hospital than either wish to or need to^{2,4}. In many developed countries the proportion of home deaths has decreased in previous decades, with the number of home deaths in England and Wales reducing by nearly half between 1974 and 2003⁵. Surveys investigating preferences for place of death amongst cancer patients and members of the general public have consistently shown a majority in favour of dying at home, in a biographically meaningful context^{6,7} amongst familiar surroundings and with loved ones present⁴. The evidence for preferences amongst people who die with organ failure or from frailty is more limited, but again supports home death as the majority preference. Some contradictory evidence exists for older people who may not want to die alone or to be a burden to families, but here the preference is for hospice, not hospital death^{4,8}. These surveys have been criticised for failing to capture the complexities of and fluctuations in peoples' preferences for place of death⁹. Despite this, there is little doubt that as the majority of people die in hospital, more people do so currently than would chose to do so⁴. This is contrary to the notion of patient choice which is of central importance to both the EoL Strategy² and to the historical development of hospice and palliative care¹⁰, as well as being out of line with the professed importance in current UK health policy of increasing opportunities for individuals to exercise choice about their health and healthcare¹¹. Statistical projections in 2008 suggested that the home death rate might fall further to an estimated 1 in 10 deaths by 2030¹², emphasising the importance of addressing factors which hinder patient choice about place of care and death at the EoL. These projections are challenged by recent time-series analyses which have shown a small increase in home deaths in England and Wales between 2004 and 2010 from 18.3% to 20.8%⁵. Nevertheless, there is still a considerable way to go before the proportion who die at home begins to match the proportion who apparently express a wish to do so or, indeed, the British home death rate begins to approach that found in Belgium, Italy or the Netherlands¹³.

Avoidable hospital admissions at the EoL are of concern not only because they prevent many patients from dying in their place of choice, but also because of their perceived impact on NHS resources. A National Audit Office report on EoL care in 2008, which included detailed analysis of costs associated with EoL in one primary care trust (PCT), reported that '£104 million could be redistributed to meet people's preference of place of death by reducing emergency hospital admissions by 10% and average length of

stay by three days'. They concluded that "there is scope for PCTs to improve services in all settings by deploying existing and future resources more effectively in supporting people in their preferred place of care"¹⁴. The King's Fund has recently drawn attention to the importance of reducing the lengths of stay for patients admitted as emergencies to hospital beds, if the NHS is to find the £20 billion in productivity improvements it needs by 2015 to maintain quality and avoid significant service cuts in the face of the 2010 Spending Review¹⁵. They report that reducing stays of over two weeks would be particularly cost-effective, and that patients particularly likely to stay (much) longer than this include older patients, those with dementia and delirium, with stroke, hip fractures, pneumonia and urinary disorders. The authors recognise the importance of other services, particularly social and community care, being in place if cost-savings are to be realised. Although The King's Fund does not explicitly mention palliative or EoL care, it is likely that some – if not many – of these patients fulfil criteria for EoL care. The importance of close collaboration between hospitals, primary care, community and social care is a familiar theme in the debate on reducing hospital deaths in EoL care.

1.2.3 Palliative care in the community

People with advanced, progressive incurable disease can experience distressing symptoms, increasing physical dependency, social isolation and psychological despair as their illness progresses^{16,17,18,19}. Their familiesⁱⁱⁱ are also affected, both by the emotional impact of watching the patient deteriorate and anticipating their own bereavement on the one hand²⁰, and by the physical and emotional stresses of caring for the patient on the other^{21,22}.

Family caregivers play an essential role in supporting people at the EoL in the community, and it has been estimated that about 500,000 people in the UK currently do this²². Many wish to provide care, see it as an extension of usual family relationships, and report experiencing positive benefits from the experience. Others, or indeed the same caregivers given the ambivalence many describe, report experiencing considerable burden and stress, feeling they have no option other than to take on the role of carer, and receiving little professional support^{21,22}.

Specialised care for these patients and their families first developed in the 1960s, initially in the UK by (the later) Dame Cicely Saunders who founded St Christopher's Hospice, Sydenham in 1967. What has become known as palliative care has been characterised from its beginning by its multi-professional approach; its attention (at least in theory) to physical, psychological, social and spiritual distress, conceptualised by Dame Cicely

ⁱⁱⁱ The term 'families' is used here to refer to those important to the patient. It includes friends and partners, as well as spouses and birth families

Saunders as 'total pain'²³; its recognition of the importance of family members; and by its insistence that 'there is always something that can be done' for patients previously often ignored by the health care system²⁴. Initially only provided in in-patient units, the importance to patients of being at home was quickly recognised and teams of home care nurses established²⁵. Although in the early years these nurses provided 'hands on' care, they now have specialist qualifications in palliative care and act in an advisory role to the primary health care team, providing education, advice and support, as well as offering specialist knowledge and advice to patients and families^{iv}. Specialist community palliative care teams may also include doctors^v, social workers, physiotherapists, occupational therapists, dieticians, pharmacists, and practitioners of complementary therapies. There are now 189 teams in the UK, 56% of which are managed by the NHS²⁶. The proportion and number of people seen by these teams who have a diagnosis other than cancer has increased from 5% in 1999/2000 to 10% in 2009/2010. These specialist palliative care (SPC) teams work in an advisory capacity: general practitioners (GPs) and district (community) nurses are central to community palliative care, as they deliver most of the care needed in the home, as well as being the source of important links to specialist services.

1.2.4 Generalist palliative care

GPs and district nurses (DN) are generalists in palliative care. In common with many health professionals working in hospitals and other settings, such as care homes, they have not chosen to specialise in palliative care, to gain an appropriate qualification and to work predominately or exclusively in palliative care. Nevertheless, they do provide palliative care as part of their role, and are therefore expected to be able to assess patient and family needs, to meet these competently within the limits of their knowledge and skills in palliative care, and to know when to seek expert advice or to refer to SPC²⁷. Many GPs in the UK and elsewhere view palliative and EoL care as an important part of their role, value their involvement in it²⁸ and find it rewarding²⁹. A survey of London GPs found that most did not see it as primarily the work of the DN, although this was more likely amongst single handed GPs³⁰, who had also been found in a previous study to be more likely to want to hand patients over entirely to specialist palliative care services, rather than to use them as a resource (the most popular option), to work together as an extended team, or to seldom use them³¹. The high value placed by many GPs on palliative care may explain the continuing, and sometimes heated, debate between primary and specialist palliative care as to whether the latter adds anything to the quality of palliative care

^{iv} Often known as Macmillan nurses because of the charity's extensive role in pump priming these posts

^v Palliative Medicine was first recognised as a medical specialty in the UK in 1987

in the community³², and calling for the expertise of GPs to be recognised, supported and extended^{33,34}.

District nurses have been described as the 'lynchpin' of palliative care in the community, promoting physical and emotional support³⁵, as well as increasingly taking on the role of patient assessor and care coordinator³⁶. Along with GPs, they also value their role in EoL care, reporting it to be challenging but an essential and satisfying aspect of their role³⁷. An analysis of community nursing workload by the Audit Commission estimated that one in 12 patients was receiving EoL care. Nurses working in London reported that providing this care was unpredictable and time-consuming, particularly in the context of staff shortages and a lack of time. They experienced a tension between the demanding and emotionally intense palliative care work and their more routine cases, which meant that although this work was rewarding it took its toll on their emotions, particularly if they lacked managerial support³⁸. 'Knowing the patient' and his or her family was of fundamental importance to them in providing quality EoL care³⁹.

Although caring for patients at the EoL can be both rewarding and time-consuming for both GPs and DNs, and people spend around 90% of their last year of life at home, it is not necessarily a regular or major component of their work, particularly for GPs. It has been estimated that of the 1881 patients on the list of the 'average' GP, 20 will die each year: 15 from diagnoses other than cancer of whom 6 will die under the care of the GP, and 5 from cancer, of whom 2 will be in their GP's care⁴⁰. This can make it difficult to maintain or extend skills, and means that, as explored above, these patients have to be cared for in the midst of 'normal' business, with competing demands on practitioners' time. One consequence of this is that GPs, particularly those working in single handed practices, have relatively limited knowledge of the community and SPC nursing in their area²⁸. There is increasing recognition of the need for all health professionals to receive education in palliative care as part of their initial training: as this is a comparatively recent development many doctors and nurses already in practice have received limited pre-qualification training. This was recognised by the Department of Health in 2001 when it invested in a three year education and support programme in the principles and practice of palliative care for DN teams, found by an independent evaluation to have probably led nationally to an increased level of confidence in palliative care competence and knowledge: the long-term effects and sustainability of the programme are unknown⁴¹. Barriers to multi-professional working, such as working for different organisations, in different places and without regular methods of communication, can also make it difficult to provide good EoL in primary care.

In 2000, Professor Keri Thomas, a GP with a special interest in palliative care, developed a framework for organising and delivering EoL care in

primary care in order to address these problems. In 2009 the 'Gold Standards Framework' was being used to at least some degree by 90% of general practices and community teams in the UK⁴². It provides a stepwise approach to the implementation within the practice of what are called the '7 Cs': communication, co-ordination, control of symptoms, continuity, continued learning, carer support and care of the dying. Implementation is supported by guidance documents, workshops, tools, a website, a National GSF team, and PCT GSF facilitators. The framework was rapidly adopted, helped by the fact that it has been endorsed nationally as a model of good practice⁴³; and because obtaining what is now known as the Foundation Level of GSF^{vi} has been incorporated into the Quality and Outcome Framework (QoF) part of the General Medical Services (GMS) Contract for GPs⁴⁴. A critical review in 2010 of its impact since introduction in 2001 found methodological limitations in the fifteen studies it identified. Nevertheless, it concluded that there was consistent evidence that the GSF can improve general practice processes, co-working and the quality of palliative care. It noted, however, that there was variable implementation across practices and little understanding of what factors influenced this. There was also little evidence of the extent to which practices adopted the framework in the long-term, of the direct impact on patients and families, and of what factors promote or hinder long-term success^{44,45}. It is difficult to over-estimate the impact of the GSF on palliative care in primary care in the UK, particularly in combination with other initiatives such as GP facilitators, who provide a bridge between primary and specialist palliative care⁴⁶.

1.2.5 Out of hours care

One of the seven areas the GSF draws attention to is the need to improve continuity, particularly OoH. The OoH period covers from 18.30 through to 08.00 on weekdays, at weekends from Friday 18.30 to Monday 08.00, and on bank and public holidays (from 18.30 on the last working day to 08.00 on the first working day following the holiday). Traditionally, medical care OoH was provided by the patient's own GP, substituted over time by an increasing use of deputising GP services and the development of GP cooperatives. Many GPs continued to provide their own OoH care for patients at the EoL, recognising the importance of 'knowing the patient'³⁹ and of continuity of care. In a nationally representative survey of GPs and DNs in 1999, 71% of GPs used GP co-operatives, 19% practice-based arrangements, and 5% deputising services; three-quarters at least sometimes provided their own OoH palliative care⁴⁷. A recent survey in the Netherlands showed the personal availability of one's own GP OoH was still

^{vi} Communication (maintaining a supportive care register to record, plan and monitor care; hold regular primary health care team meetings to discuss patients on register; plan care and review practice) and Coordination (primary health care team have a nominated coordinator for palliative care)

considered by GPs to be important to ensure personal continuity, with 86% of those responding willing to provide OoH care personally for their own EoL care patients⁴⁸. In the UK the escalating use of the OoH service in the context of high workloads, increasing desire for separation of work and private life; concern over GP reimbursement; and a shortage of GPs led to increasing reluctance by GPs to continue to provide OoH care⁴⁹. The Carson Review in 2000 also raised questions about the quality, safety and effectiveness of existing OoH systems⁵⁰. Changes in the General Practitioner Contract in 2004 gave GPs for the first time the option of opting out of their 24-hour responsibility for providing care to patients, and gave PCTs (NHS Unified Boards in Scotland) responsibility for commissioning OoH care for their communities: only 3% of GPs intended to still provide OoH services⁴⁹.

The OoH context has been the locus of considerable and rapid change, as PCTs have worked to ensure patients are provided with a service that meets the national OoH Care Quality Requirements, first published in 2004 and amended in 2006⁵¹. Varying models have emerged such that one PCT may commission services on behalf of another, may have contracts with a single provider, or with a number of providers forming a network of provision. Not only have commissioning arrangements varied, but different areas have used different types of staff and organisations to provide care⁵². The policy emphasis is shifting away from focusing solely on the traditional OoH period to more emphasis on having better systems in place for meeting patients' need for unscheduled care, whenever these needs arise. This means that traditional demarcations between 'out-of-hours and 'in-hours' providers are becoming blurred, with those organisations which previously only worked in the OoH period (such as GP cooperatives) working closely with other services that provide an extended hours day time service (such as NHS walk-in centres and minor injuries units) and organisations that provide first contact care 24 hours a day, such as emergency departments, ambulance services, and nurse-led triage and advice lines (NHS Direct in England and Wales, NHS 24 in Scotland). Of nine different organisational models for OoH care identified in a literature review forming part of an international comparison of the strengths and weaknesses of models, all but one are found in the UK, albeit to varying degrees⁴⁸. These included individual general family practice, rota groups, GP cooperatives, primary care centres, deputising services, minor injury centres or walk in centres, telephone triage and advice services, hospital emergency services, and primary OoH care integrated in the hospital.

A 2006 National Audit Office report concluded that not all providers were meeting the OoH Care Quality requirements, and raised particular concerns about the speed of response³. A review in England in 2008¹⁴ showed that many people still experience problems contacting or seeing a GP OoH and that services are not always meeting the needs of patients with long term and or complex needs, particularly vulnerable patients, who are not always treated with dignity and respect (p5). A review in 2006 on publications

about OoH care since the implementation of the new GMS in 2004 reported that palliative care was one service that was particularly in danger of being neglected as OoH services were reorganised, but this conclusion was based on very limited data⁴⁹. There is little other systematically collected evidence about the impact of these changes on vulnerable patients such as those at the EoL. Of course, these changes themselves are now subject to further development following publication of the 2010 White Paper with its proposed abolition of PCTs in England and transfer of commissioning responsibilities to the new clinical commissioning consortia.

OoH care is not restricted to medical care: help with nursing and personal care are also needed by patients and their families in the OoH period, both in an emergency and as part of the patient's planned care. The availability of 'twilight' (evening) and night community nursing service varies across the UK. This will be discussed below, in specific relation to the provision of EoL care OoH.

1.2.6 End of Life care in the out of hours period

Timely access to high quality appropriate EoL care in the OoH period has repeatedly been reported as being a key factor in patients being able to remain at home, if this is their wish^{2,14,53}. The EoL Care strategy states that 'it is clear there are special problems in respect of those requiring EoL care in the community being able to access urgent care, including medicines, outside 'normal' NHS hours. There is inequality of access and widespread difficulty in accessing a full range of services, often resulting in delays in providing appropriate care'². (4.21). Symptom control is a frequent reason for calls to a GP OoH service. An analysis in The Netherlands of 722 consultations for 388 palliative care patients showed that 23% were for pain, 22% for respiratory symptoms, 19% for anxiety, restlessness or confusion, 11% for queries about medication, 8% for gastrointestinal symptoms, 4% for organisational problems, 2% for psychosocial problems, and 12% for other problems⁵⁴. In a setting where visits to an emergency department substitute for GP OoH services in the UK, a retrospective analysis of administrative databases found that the most common reasons for visits to emergency rooms in the last two weeks of life in over 31,000 cancer patients were abdominal pain, lung cancer, breathlessness, pneumonia, malaise and fatigue, and pleural infusion⁵⁵.

In systems such as the UK, good OoH care is needed to avoid visits wherever possible to emergency rooms/accident and emergency by patients at the EoL because this is the route to hospital admission which may be unwanted or unwarranted⁵⁶. Bailey, Murphy and Porock⁵³ have demonstrated that EoL care in these settings can often be poor for patients on what they identify as the 'subtacular' EoL trajectory, in comparison with the 'spectacular' trajectory of deaths from trauma or acute events which receive instant attention and focus. Patients and families may call '999' when faced with uncontrolled symptoms, when families feel that they

cannot continue to cope, and/or when care arrangements break down. OoH doctors may also call for an ambulance, particularly when they have no information on the patient and when they are under time pressure. Access to do not attempt resuscitation (DNAR) orders compatible with ambulance service protocols⁵⁷ together with training in the legal aspects of EoL decision making in emergency situations is needed for ambulance services and paramedics if they are to be enabled to play a positive role in enabling patients to remain at home⁵⁸.

Deficiencies in EoL OoH care have long been recognised^{53,59}. The lack of OoH support has recently been identified as a particular problem for nursing homes wanting to improve their EoL care⁶⁰. An interview study in Scotland with patients with advanced cancer and their carers who had used OoH services reported that respondents had difficulty deciding when to call OoH services due to concern about the legitimacy of their needs, the lack of continuity of care, and the nature of the services available⁶¹. A smaller subsequent Scottish study again found that patients were reluctant to use OoH services, and in particular found it a 'rigmarole' to have to do through the telephone triage process, sometimes putting off calling until their practice was next open despite potential harm from the delay⁶².

District and SPC care nurses recently reported that difficulties with OoH services, particularly with the prescribing of appropriate medication, and with OoH GPs lacking access to medical records, were important barriers to patients being able to remain at home. The authors note that lack of familiarity with the patient is a particular problem as 'knowing the patient' is recognised to be vital in palliative care^{39,63}. Scottish health professionals interviewed alongside patients with advanced cancer⁶¹ had concerns about how to provide good palliative care within the constraints of a generic service designed for acute illness problems, and which did not take into account the complex needs associated with EoL care. In particular, they thought it did not recognise the importance of continuity of care, or place sufficient attention on ensuring informational and managerial continuity when personal continuity was unlikely: the move away from personal on-call is good for GPs but not for palliative care patients because of the loss of continuity. They also reported problems accessing other health and social services^{61,64}. Richards et al⁶¹ found that the time taken to triage cancer and palliative care patients increased in a one year period after the 2004 GMS contract implementation compared to a similar period before, and the number of calls where a special message was passed from the on-call team to the GP decreased. However there were no differences in hospital admissions or home visits.

The EoL Care Strategy indicated a number of ways in which OoH care could be improved. This included ensuring that all OoH service providers have access to up to date information on patients with palliative care needs; prioritisation of phone calls from these patients; improved emergency and planned access to medication; clarity about access to telephone advice

lines; and improved education in EoL care for OoH providers. The transfer of information to those providing OoH care to ensure continuity of care was one of the recommendations of a 2001 Macmillan report on OoH palliative care in the community⁵³. Lately the need for new GP commissioners to implement '... local systems' to share information across health and social providers, particularly OoH services' (pg. 3) has emerged as one of the recommendations of a joint National Council for Palliative Care and Macmillan Cancer Support report on OoH EoL care²⁶.

An analysis of the use of information handover systems for palliative care patients in four OoH cooperatives in 2002 found that 2.1% of the total calls to the services were from palliative care patients. Handover forms were used for between 1.2% and 32.5% of these patients: indicating these systems were clearly underutilised at this point³¹. A similar analysis in The Netherlands found transfer of information had taken place for only one in five palliative care patients contacting the OoH service, and only half of these contained an anticipatory EoL plan⁵⁴. GPs were interviewed about barriers and facilitators to the transfer of information: all saw continuity of care as important, but some doubted that transfer of information was relevant for the quality of care and did not see the need for transfer notes, with one saying "patients and families often tell their stories in an excellent way" (pg. 284).

One reason for not completing the forms was that death was not thought to be imminent⁵⁴. A recent Scottish study also found that forms were often completed too late, with many GPs only completing them if they thought an OoH call was likely⁶². There were issues with remembering to update them as the patient's condition changed, and the forms were also felt by those GPs who worked in the OoH services to contain too little information⁶². The authors recommend the introduction of an enhanced special note for palliative care patients, to be completed and transmitted electronically and with an automatic review date. They also suggest that the form should be completed as early as possible, and suggest doing so when the DS1500 form is completed, (a specific benefit for palliative care patients which requires the completing doctor to give an estimate of prognosis of six months or less).

Improving the information available in this way might help to alleviate the anxieties of OoH doctors called to EoL care patients. A small qualitative study of GPs working shifts in an OoH service since the GMS changes reported that a lack of familiarity with the patient was stressful for these doctors who felt isolated within the system, especially when they had no information on the patient, and no knowledge of who to call for advice. They were not confident in their palliative care knowledge and expressed a wish for educational opportunities. The doctors experienced a conflict between on the one hand, the need for speed and efficiency, and on the other the needs of their palliative care patients. It was difficult for them to reconcile the ethos of OoH care, an acute fast paced service, with that of palliative

medicine, which required time and listening skills^{38,65,66}. Burt et al⁶⁴ reported a similar finding in relation to DNS.

The 2004 National Institute for Health and Clinical Excellence (NICE) supportive and palliative care guidelines, recommended that the services available in PCTs should include 24 hours, 7 days a week availability of nursing services⁶⁷. However, community nursing was reported to be available to all patients 24/7 in around 53% of PCTs in 2006-7. The EoL Strategy (2008) viewed the lack of 24/7 nursing and personal care services in some parts of the community as a particular problem, and encouraged the development of rapid response services where full 24/7 nursing services were not yet available⁶⁸. A Freedom of Information request in 2010 to all PCTs in England by Macmillan Cancer Support resulted in replies from 84% of PCTs. Somewhat unusually, their definition of community nursing included SPC nurses, health care assistants and professions allied to medicine, as well as DN team members (page 6). They reported that community nursing was available 24/7 in 56% of PCTs, but 16% of responding PCTs neither provided this service to all palliative care patients nor intended to improve their service. Provision was more widespread in predominately urban compared to predominately rural areas. Following this survey, a recent joint meeting report on OoH EoL care from the National Council for Palliative Care and Macmillan Cancer Support concluded that 24-hour care and nursing is a necessity²⁷.

1.3 Conclusion

As the preceding section has shown, empirical research into OoH EoL care is limited. There is little or no substantive evidence to support what appear to be 'taken for granted facts': that, for example, improving OoH care will reduce hospital admissions and therefore reduce health service costs; that 24/7 community nursing is a necessity in every PCO; that handing over information about palliative care patients at the EoL to OoH services is efficient and effective; and that electronic systems will solve the problems of information transfer. This supports the findings on EoL generalist OoH care of the initial SDO scoping report¹. Such a lack of evidence, has not, of course, been unusual in the history of palliative care. Few, if any, studies have attempted to look at this area of health care as a complex system, in which a range of services from different organisations and with different goals, ways of operating and methods of communicating need to work together for the benefit of patient and family. Moreover, there is no one agreed way in which to provide these services and therefore each local health system is its own complex system in this regard. The fact that OoH EoL is a complex system and needs to be considered as such becomes even more apparent when changes over the past eight years since the 2004 GMS contract change in the provision of OoH care itself are considered.

A result of the continuing changes to the NHS OoH emergency and urgent care system is that patients and carers requiring EoL OoH care are at the

centre of complex OoH care systems, bringing together NHS emergency and urgent care services, planned (and unplanned) nursing and personal care services, and (in some cases) specialist palliative care services; any or all of which may have experienced or be experiencing change and which are likely to vary from provision elsewhere in the country^{14,36}. Evidence of the consequences for patients, carers, staff and the health system of such variation in the availability, organisation and delivery of OoH EoL care is limited, as indeed is evidence of what types of OoH care are needed at the EoL and by whom. Without such evidence commissioners lack the information they need to make knowledgeable decisions about the provision of quality OoH EoL care, informed by patient and carer experience.

As argued in the Introduction to this chapter, before research takes place into the consequences of variations in OoH EoL care, however, more information is needed about how this care is now provided and, in particular, what currently is the variation in service provision, and whether there are identifiable models of service provision from a whole systems perspective. This will inform the choice of service configurations, types and/or models for inclusion in future evaluations of generalist OoH EoL care². This is also true of the opinions of those currently commissioning this care, of experts in EoL care, and of service users. In addition, in an area currently lacking robust evidence, the experiences of commissioners and experts familiar with the complexities of OoH EoL care, and their views of factors which enhance or inhibit high quality patient care, will begin to address the need for information to help guide commissioning decisions by clinical commissioning groups.

This research therefore aimed to address the lack of information on the variation in availability, organisation and delivery of OoH EoL care, and to supplement this with the views of those commissioning this care, as well as those of experts and of service users, in order to inform future research studies in this area and to provide guidance to commissioners in an under-researched field.

1.4 Aims

To establish how generalist OoH EoL care is currently provided in the community; to explore variations in provision, including evidence for distinct modes of care; and to investigate current views of service provision of commissioners and senior managers, in order to help inform commissioning decisions, and the direction of further research

Objectives:

1. to interview senior managers at Strategic Health Authority (SHA) level, responsible for generalist EoL/OoH, about current generalist OoH EoL service provision, its strengths and weaknesses.
2. to conduct an interview survey of generalist OoH EoL care provision in primary care organisations in order to:

- a. establish how generalist OoH care is currently provided for people at the EoL in England and Scotland.
 - b. identify variations in generalist OoH EoL care provision (including in information transfer systems).
 - c. explore whether variations in provision can be grouped into distinct models of OoH provision and, if so, how.
 - d. identify the views of current commissioners of generalist OoH EoL care about current service provision, its strengths and weaknesses
 - e. organise data obtained on generalist OoH EoL care service provision graphically to inform discussions of Expert Panel
3. to hold an Expert Panel to discuss variations data; to consider emerging care models within the data (if any); to discuss characteristics of 'good' generalist OoH EoL care, and to begin to develop theoretical propositions about predictors of quality OoH EoL care.
 4. to obtain the views of service users about their preferences for, and experiences of EoL OoH care, in a 'Virtual' User Panel.
 5. to synthesise learning from the study for policy makers, commissioners, providers of OoH EoL care, patient representatives, practitioners and researchers.

2 Methods

2.1 Overview

Four studies were conducted. These differ in size and scope, but all contribute to addressing the research aim and objectives.

- A qualitative telephone interview study with senior managers in Strategic Health Authorities (SHAs) in England and Health Boards (HBs) in Scotland responsible for EoL or OoH care which addressed objective 1 by exploring participants' views of current EoL OoH service provision and its strengths and weaknesses.
- A telephone interview survey of key informants involved in the commissioning or providing EoL OoH care in primary care organisations in England and Scotland. Respondents in this PCO telephone survey answered questions about the provision of OoH EoL care services within their PCO, as well as giving their views on current service provision, its strengths and weaknesses. Data from these interviews are used to address objectives 2a to 2d. Following initial analysis and graphical representation (objective 2e) these data were presented to an Expert Panel.

- The convening of an Expert Panel, who discussed variations in service delivery within these data, considered whether there were emerging care models, discussed characteristics of 'good' EoL OoH care, and began to develop theoretical propositions about quality OoH EoL care (objective 3).
- User views were incorporated into the study by means of a 'Virtual' User Panel which sought to obtain the views of service users about their preferences for, and experiences of EoL OoH care (objective 4).

The research was originally intended as the first phase of a two phase study. Its design was influenced by the need to generate data to inform the selection of case study sites for Phase II, which was intended to evaluate innovative models of generalist OoH EoL care from a systems approach to identify factors that promote or inhibit care. The research has not proceeded beyond Phase I, largely because of the challenges experienced by the research team in conducting these studies in the NHS across commissioner/provider boundaries and at the interface of community health/ social services/ SPC/ emergency services/acute care services at a time of great organisational change in the NHS⁶⁹. It is, however, necessary to situate this research within its original context as the first phase of a two phase study to understand some design decisions.

2.2 Ethical approval

The SHA interview study, the PCO interview survey, Expert Panel and 'Virtual' Users Panel were submitted for consideration to the National Research Ethics Service (NRES) and Isle of Wight, Portsmouth and SE Hants Research Ethics Committee in September 2010. Confirmation was received that these were considered to be service evaluations. Ethical approval was therefore not necessary to conduct these studies. Written confirmation of this was obtained from NRES on 12 October 2010 and from Isle of Wight, Portsmouth and SE Hants Research Ethics Committee on 21 October 2010.

2.3 SHA interview study

2.3.1 Objectives

This study addressed the first research objective: to interview senior managers at SHA level, responsible for EoL/OoH, about current OoH EoL service provision, its strengths and weaknesses, including information on service innovations and methods of performance monitoring. In order to place findings in context, respondents were also asked about their views of the impact of forthcoming NHS changes on OoH EoL care.

2.3.2 Study Design

Qualitative semi-structured, one-to-one telephone interviews with senior managers responsible for OoH and/or EoL care in SHA or Health Boards (HB).

2.3.3 Sampling strategy and recruitment of participants

Sampling strategy

In order to gain a comprehensive strategic view of EoL OoH care, all senior manager leads for both OoH and EoL care in the 10 SHAs in England and 14 HB in Scotland were included in the study.

Recruitment of participants

Senior managers were invited to participate in the study during the period December 2010 to mid-March 2011. Potential participants were initially identified by contacting the SHA/HB directly. Additional strategies were then employed to increase recruitment.

In England, the Assistant Director of the National EoL Care Programme forwarded the invitation email to all SHA senior managers responsible for EoL care, to ask them to consider participating in the study. In Scotland, the Head of Planning and Performance for NHS 24 was contacted to identify senior managers in HBs responsible for Urgent care. In addition, the Chair for the National Operations Group for Medical Services forwarded the invitation email to all urgent care managers. The National Clinical Lead for Palliative Care in the Scottish Government, Richard Dimelow at the Directorate of Healthcare Policy and Strategy, Scottish Government (involved in the national action plan for palliative and EoL), as well as the Aberdeen and National Clinical Lead Palliative Care eHealth forwarded the invitation email to all lead EoL managers in each HB.

At the time of recruitment, 21 senior managers responsible for EoL care (9 in England; 12 in Scotland) and 22 senior managers responsible for OoH care (8 in England; 14 in Scotland) were in post, giving a sampling frame of 43.

Potential participants were sent a letter of introduction, participant information sheet, the interview guide and consent form by email inviting them to participate. Two reminders were sent.

2.3.4 Interview conduct

Informed written consent was obtained prior to interview, usually via email. The telephone interview, conducted by Sarah Brien (SB), was guided by an interview guide (Appendix 1). This ensured respondents were asked about their responsibilities for OoH EoL care and strategic priorities; how OoH EoL care was monitored; their perceptions of current service provision – what worked and what did not, and what could be improved without additional

financial cost. To inform Phase II sampling, respondents were also asked for examples of innovative services within the SHA/HB. To place the study in context at a time of change within the NHS they were also asked their views of the likely impact of the forthcoming NHS changes on EoL OoH care.

Interviews were digitally recorded. One participant did not give written permission for this, so summary notes were prepared instead.

2.3.5 Data Analysis

All digitally recorded interviews were transcribed verbatim; anonymity was ensured during this process by the removal of any identifiable information relating to either the SHA/HB and the participant. All transcripts (or summary notes, where the interview was not audio recorded) were imported into Atlas.ti v5.2 for coding to facilitate thematic analysis.

Thematic analysis^{70, 71} permitted a detailed exploration of key ideas present in the data. Braun and Clarke's (2006) phases of thematic analysis guided the systematic sifting of the data (Appendix 2). The analytical procedure was undertaken as follows. To aid familiarisation of the data, all audio tapes were listened to by SB, and summaries of the interviews were prepared and read. Line by line open coding was undertaken on all transcripts/summary notes from the interviews. A total of 61 emergent codes were identified and clustered in an iterative process using mind-mapping and the constant comparative approach^{71,72,73} and a thematic framework derived. The initial themes were then reviewed and refined, guided by data as analysis progressed. Particular attention was paid to negative case analyses (i.e. seeking out disconfirming examples in the data set) to ensure that all views were represented. Additional themes were added where necessary. These were checked against earlier interviews, according to the procedures of constant comparative analysis, to derive the final thematic framework.

Meetings between the analysis team (SB and CMcD) ensured a reflexive approach during data analysis and interpretation to manage potential bias and ensure rigour. The team cross checked coding strategies and interpretation to ensure that coding was consistent and all points were included. Coding strategies were cross checked independently; the team reviewed and revised the emerging themes. This iterative process was aided by discussion and reflective feedback to identify biases, overstatements and discrepancies in the analytical and interpretative phases ensuring the final thematic framework was fully supported by the data. An audit trail was reported to ensure clear articulation of all aspects of data collection and analysis.

2.4 PCO Interview Survey

2.4.1 Objectives

This interview survey, which produced both numerical and qualitative data, addressed objectives 2 (Section 2). It is the source of data on how generalist OoH EoL care is currently provided (objective 2a), the variation in its provision (2b), on whether there are distinct models of OoH EoL care provision (2c); on the views of commissioners of generalist OoH EoL care services of the strengths and weaknesses of these services (2e); and provides the data presented to the Expert Panel (2d).

2.4.2 Study Design

A telephone interview survey of Primary Care Organisations (PCOs) in England and Scotland using semi-structured, one-to-one telephone interview or email-conducted 'interviews' with key informants, familiar with OoH care for EoL patients. First, questions relating to current OoH EoL care service provision were asked, and later coded and analysed using numerical research methods (PCO survey: numerical data). Next, questions about respondents' perceptions of these services, their strengths and weaknesses were asked. Responses to these questions were analysed using qualitative research methods (PCO survey: qualitative data). Methods of organising these data visually were explored in order to present them to an Expert Panel.

2.4.3 Recruitment of Primary Care Organisations

Sample size

It had originally been planned to recruit participants from all PCOs in England and Scotland in this survey and to have therefore, a census of PCOs. However, the changes in personnel within PCTs as a result of the NHS re-organisation resulting from the 2010 White Paper were already taking effect in the data collection period and could only increase as time progressed. This meant that PCTs were often unclear who had responsibility for OoH services or EoL care, and remaining staff felt too busy to participate in research. A decision therefore needed to be made between continuing to aim at a complete census of PCTs but risking a very low response rate given the time frame of the study and the amount of time which needed to be expended on each PCT to identify and then recruit suitable participants, or to reduce the sample size and to concentrate resources on getting a better response rate in order to reduce response bias and increase the representativeness of the attained sample. It was therefore decided that the latter was the better scientific strategy, given the evidence of the difficulties in identifying the targets in each PCO, in then contacting them, and in then obtaining an interview on the one hand, and the study's time

constraints on the other. The research team's experience in recruiting participants for the SHA interview study supported this conclusion.

It was therefore planned to sample 50% of all PCOs in England and Scotland. In England, there are 152 PCTs located in the 10 SHAs. In Scotland, there are 34 community health partnerships (CHPs) within the 14 HBs. In order to sample 50% of all PCOs across England and Scotland, the minimum sample required was therefore 93 (i.e. 50% of the 152 PCTs + 50% of the 34 CHPs).

Sampling approach

Ideally, the 50% sample would have been selected at random from among the total population of PCTs and CHPs, probably stratifying the PCOs by country and SHA, in order to ensure that each PCO had an equal, non-zero, and calculable chance of being sampled, a fundamental prerequisite of random sampling in survey research⁷⁴. At this stage, however, the research team's choices were constrained by the requirements of the planned Phase II of the research. The research proposal stated that the Phase II case studies would take place in the SHAs of the grant holders to allow their active engagement, and that the case studies would be chosen on the basis of information gathered in the PCO interview study. Therefore, rather than using random sampling methods to draw the sample, the requirements of the planned Phase II meant that all PCOs were approached within the SHA (4) and Health Board (1) in the geographical locality of the Chief Investigator (JAH) and four co-applicants (CS, VL, CT, DH). A total of 62 PCOs were contacted in these SHAs/HBs; 61 from England and one from Scotland.

A further eleven PCOs located in three SHAs in England had been approached when seeking to obtain EoL documents (Appendix 3). As appropriate contacts had already been identified in these PCOs they were also invited to take part in the PCO interview study.

Stratified random sampling was then used to identify the remaining sample. PCOs were randomly selected in a further two SHAs in England (25 PCTs) and six Health Boards (12 CHPs). A random number generator was used in Excel to select both the SHAs/CHPs and then a further 38 PCOs. This gave a total sample size of 110, compared with 93 needed for a 50% sample.

As interviewing approached completion it was clear that the initial sampling strategy, a result of the Phase II design and a lower than expected response rate, was resulting in a lack of geographical spread in the sample. Following discussion with SDO, it was therefore agreed to employ purposive sampling after the main period of data collection to increase the geographical spread of the achieved sample, and to increase the response rate. These interviews were planned in the lead up to Phase II. A total of 10 PCOs in England (seven new PCOs and three re-invitations) and two PCOs in Scotland were identified to improve both response and geographical spread. As the three re-invited PCOs were already in the sampling frame,

nine new PCOs were added to the sampling frame in this follow up recruitment phase (seven in England and two in Scotland).

The final sampling frame therefore consisted of 119 PCOs: 110 PCOs in the original sampling frame (97 from England and 13 from Scotland); and an additional 9 PCOs (7 from England and 2 from Scotland).

2.4.4 Recruitment of key informants in PCOs

Interviews were sought within each sampled PCO with at least one individual who was knowledgeable about OoH EoL care service provision and/or commissioning in that PCO. Key informants were identified through a combination of approaches. Initially, respondents interviewed in the SHA interview study were asked to identify appropriate individuals in PCOs within their SHA/HB. Snowball sampling was then employed by asking these individuals to identify informants in other PCOs within their SHA/HB. Each PCO was also contacted directly to identify appropriate informants. However, in the context of impending organizational changes in commissioning within the NHS and associated staff movements, the most effective way of identifying the appropriate key informants was found to be contacting the Directors of Commissioning in the PCOs directly and asking them to forward the team's request for participation to the most relevant personnel. It still remained difficult to find individuals who were familiar specifically with OoH care for EoL patients. Everyone who consented to an interview was therefore asked to provide contact details for their colleagues in either the OoH services or EoL services as appropriate. More than one interview was therefore conducted in some PCOs. Finally, at the team's request, the Assistant Director of the NHS National EoL Programme contacted all EoL senior managers within SHAs in England to ask for their assistance in participating in this study. The senior managers were asked to forward the study invitation letters to the PCOs within their organisations. Therefore in each PCO, a variety of recruitment approaches were used to target a range of people to ensure that every effort was made to obtain the relevant information to meet the study aims. Data were collected on number of contacts made to find the key informant, background of the respondent (commissioning lead, OoH lead, EoL lead), response rate and response bias.

2.4.5 Study Procedures

Recruitment

Recruitment took place during the period December 2010 to May 2011. Potential participants were emailed a letter of introduction, participant information sheet and consent form inviting them to participate in the study. The interview guide was also included. Reminders were sent (by telephone or email) if no response was received in three weeks.

The follow up recruitment phase of the study took place between August and October 2011. For PCOs that had not been sampled before, the procedures outlined above were followed. PCOs that had been in the original sample but had not responded were contacted by telephone by the research project's Management Fellow, as they had been selected at least in part due to her personal contacts in PCOs.

Telephone interview

Participants who agreed to participate were asked to return their written informed consent form prior to the interview. A semi-structured interview was conducted, using an interview guide to ensure issues of interest were covered in each interview. This included more structured questions at the beginning about the provision of specific OoH services, as well as more open questions towards the end about the informant's views on the provision of these services. The former are analysed below in PCO interviews: numerical analysis and the latter in PCO interviews: qualitative analysis. The interview guide is presented in Appendix 4.

All interviews were audio-taped, using a digital voice recorder. Interviews ranged from 19 to 74 minutes, and were on average about 48 minutes long. Interviews were not transcribed verbatim; instead summary notes were prepared by the interviewer for each PCO soon after the interview was completed. The data analysis was conducted using the summary notes, augmented by listening to the audio recordings as appropriate.

Email response

Informants in PCOs who were not able to conduct a telephone interview (often due to lack of time) were sent the questions in the interview guide and asked, if possible, to email their responses back to the researcher. This had the advantage of enabling respondents to research information they did not know, and to complete the questions in sections when time was very limited. Email responses were not necessarily therefore inferior to interview data, especially for the PCO interview study: numerical analysis. As in interviews, respondents were asked for contact details of colleagues who might be able to provide additional data.

Where possible, relevant documents were also sought to supplement email and interview data from the informants. These included PCO EoL care strategy documents and needs assessments, Marie Curie Cancer Care 'Delivering Choice' programme documentation, and information for patients and carers on local palliative care services.

2.4.6 Data analysis – PCO interview study: numerical analysis

Data coding

Data were derived from the PCO interview study for both numerical and qualitative analysis. As indicated above, the former focused on service

delivery and the latter on informants' perspectives on OoH EoL care. Data coders (SB/HE/PC) used the summary notes of each interview to retrospectively code data for numerical analysis. Information recorded in the summary notes included, where available, name of service, hours of operation and provider. The coding matrix was predominately determined by the content of the interview guide, which itself had been designed by the research team on the basis of a review of the literature and knowledge of the field. Additional services were added to the coding matrix following initial reading of the summary notes. A limitation of this approach is that services that were not specifically included on the interview guide are likely to be under-reported. Data coders met to agree definitions.

Table 1 links the interview guide questions with the list of variables in the coding matrix. These variables were used in the numerical analysis. Table 1 shows the relationship between questions in Section C of the interview guide (Appendix 4), the topic covered and the numerical variables in the coding matrix which were derived from these questions. Where available, information was also added to the coding matrix from documents such as EoL care strategies obtained from respondents.

Table 1. **PCO Interview numerical analysis: relationship between questions in Section C of interview guide, and variables in coding matrix**

Relevant interview guide question no.	Topic	Coding matrix
1.a)	GP OoH services and their management	GP OoH services GP identification of EoL patients GP OoH notification system GP and other OoH services share electronic notification Emergency services knows OoH status OoH services enter information to/use electronic notification
1.b)	District nursing services OoH	District nurse Community matron Generalist palliative care team Generalist-led Hospice at Home
1.c)	Specialist palliative care services OoH	Community specialist palliative care nursing Community palliative care matron Planned/emergency night sitting (for example Marie Curie) Community palliative care support teams Dedicated end of life Rapid Response Hospice at Home 24hrs palliative care admission
1.d) & 1.f)	Night sitting services other than Marie Curie	Planned night sitting Emergency night sitting
1.e)	Rapid response team	Rapid Response Generic crisis response team Emergency care practitioners
1.g)	Other services not mentioned above	Palliative care coordination service Advice Lines -Telephone advice line for Patients -Telephone advice line for health professionals -EOL diversion bed schemes Marie Curie Delivering Choice programme Care home team Integrated Health and Social Care team
1.j)	Medication access OoH	Medication Access – emergency & planned
1.k)	Access to equipment OoH	Equipment Access – emergency & planned
1.l)	Communicating a patient is EoL and their wishes between OoH services	Systems for coordination of services

Numerical variables

The Department of Health's EoL Care Pathway was used as a framework for grouping the variables in a way which related them to key steps relevant to the delivery of high quality OoH EoL care services.

Four of the six steps in the End of Life Care Pathway have particular relevance for OoH EoL care. These are presented in Table 2, together with adaptations demonstrating their particular relevance to this situation, and definitions of what the successful application of the OoH EoL Care Pathway would look like at each stage. This framework is used to organise and present the numerical detail.

Table 3 lists the variables used in the numerical analysis presented in this report, indicates their relationship with the End of Life Care Pathway as well as defining each variable in detail.

Table 2. The NHS EoL Care Pathway and care pathway relevant to Out of Hours care

Step	EOLC pathway	Care pathway relevant to OoH	Definition
1	Discussions as end of life approaches	Identification of EoL patients for OoH services	Mechanisms available to GP practices and OoH providers which identify people known to be at the end of life
2	Assessment and care planning	Mechanisms for care planning OoH	Mechanisms to enable effective forward planning through the transfer of patient specific information to all OoH providers about care plans for EoL patients; anticipatory planning including planned medication and equipment needs
3	Co-ordination of care	Co-ordination of care OoH	Mechanisms to support the co-ordination of the many and varied generalist and dedicated OoH services
4	Service delivery	Service delivery OoH	Access to services for EoL patients and carers during the OoH period

In addition to the variables listed in Table 3, the coding matrix including a number of other variables which are not included in analyses because they were mentioned by fewer than one in ten PCOs. These include Community Matrons; generalist palliative care teams; a community palliative care support team, community palliative care matrons; generalist patient and professional telephone advice lines; EoL diversion beds, and dedicated EoL emergency night sitting services.

Table 3. **Description of numerical variables derived from PCO interviews**

OoH EoL Care Pathway	Numerical Variable	Description
<i>STEP 1: Identification of EoL people for OoH:</i>	GP identification of EoL patients	Describes whether across the PCO there are systems in place in general practices to identify EoL patients and to record this on supportive or palliative care registers. Ideally this would include both EoL patients with a diagnosis of cancer and non-cancer diagnoses.
<i>STEP 2: Care planning OoH:</i>	1) GP OoH notification 2) GP/OoH share electronic notification 3) OoH services enter information to/use electronic notification 4) Emergency services knows OoH status 5) Medication Access – planned 6) Medication Access – emergency 7) Equipment Access – emergency	1) At least some general practices in PCO transfer information on EoL patients to the PCOs' OoH providers, by fax/email or electronic system (if varies, electronic scored). 2) At least some GP practices and OoH services in the PCO share the same electronic system, thus facilitating communication about EoL care patients. 3) OoH services in the PCO use an electronic system. 4) In some PCOs ambulance and other emergency response services are able to access information about EoL patients, either through the OoH care system, through records in the patient's home or through a 'message in a bottle'. This variable records whether such a system exists at all in the PCO. 5) Describes arrangements in place to access medication for the EoL patient's planned needs during the OoH period; both in terms of the existence of mechanisms and, if so, whether medication is stored at the patient's home (i.e. best practice). 6) Records arrangements for access to emergency medication for unplanned needs during the OoH period. Examples of such arrangements include access to medication via OoH GP, nurse prescriber, acute services, community hospitals or late night pharmacies. 7) Refers to small items of equipment (for example pressure mattresses, syringe drivers) available OoH via a generic service which is available to EoL patients.

OoH EoL Care Pathway	Numerical Variable	Description
<i>STEP 3: Co-ordination of care OoH:</i>	Overall coordination	Describes whether care is formally co-ordinated during the OoH period. This may or may not be designed specifically to meet the needs of EoL patients and includes activities/services such as 'single point of access', 'generic coordination centre', dedicated EoL coordination centres, 'call team' to coordinate hospital at home and night sitting services and '24/7 crisis response team'.
<i>STEP 4: Service delivery OoH – Primary care</i>	<p>1) GP OoH</p> <p>2) District nursing</p> <p>3) Specialist palliative care community nursing/team</p> <p>4) Hospice at Home</p> <p>5) Rapid Response</p> <p>6) Patients Telephone Advice Line – dedicated</p> <p>7) Professional Telephone advice line - dedicated'</p>	<p>1) Provision of an OoH GP service; examples include practice-based GP cooperatives, deputising services or primary care centres.</p> <p>2) Generalist community-based service that usually provides core nursing care to all patients during OoH, not just EoL patients.</p> <p>3) Services provided by nurses with specialist training in palliative care. This may be organised as part of the specialist palliative care community clinical team, Macmillan nursing team, or hospice community nursing team.</p> <p>4) Hospice at home services labelled as such by commissioners and/or providers. These are provided by a specialist and/or dedicated palliative care team based in the community (primary care, local authority and/or voluntary sector).</p> <p>5) A team whose role is to provide immediate care and to coordinate generalist, specialist and acute services to prevent hospital admission and/or enable rapid discharge home. These services were not specific to EOLC: some dedicated RR services were available but too few to include.</p> <p>6) OoH telephone-based advice dedicated for EoL patients and manned by specialists based in acute or hospice based settings. Telephone advice lines were available for both health professionals ('Professional Telephone Advice'), and for EoL patients and their families ('Patient Telephone advice').</p> <p>7) OoH telephone-based advice dedicated for healthcare professionals and manned by specialists based in acute or hospice based settings.</p>

OoH EoL Care Pathway	Numerical Variable	Description
	8) 24hr Palliative Care Admission	8) The availability of inpatient admission during the OoH period for EoL patients to units (usually hospice beds or sometimes specialist hospital beds) which specialise in palliative care.
	9) Night Sitting Planned – generalist	9) Planned night sitting OoH support for carers of EoL patients from generalist services, for example Crossroads sitting, sitting via the district nursing service or local authority.
	10) Night Sitting Planned – dedicated	10) Planned night sitting from services dedicated to palliative care patients, for example Marie Curie and Sue Ryder night sitting, palliative care night sitting.
	11) Night Sitting Emergency – generalist	11) Emergency night sitting services.

All service delivery variables (Step 4 in Table 3) are coded according to the hours the service is available during the OoH period and the consistency of provision across the PCO. So, for example, the variable 'GP OoH' describes provision of an OoH GP service. Eight categories are used to classify the extent of OoH coverage:

1 = consistent 24/7 cover across the PCO (i.e. data coders judged cover was provided over all OoH period for most of the PCO geographical area),

2 = partial OoH cover consistent across PCO (i.e. data coders judged a substantive part of OoH period was covered (usually late evening, 22:00 hours onwards and weekend day cover consistently across PCO),

3 = limited OoH cover consistently across the PCO (i.e. restricted to a few hours over usual hours, such as up to 22:00 on weekdays),

4 = variations in OoH across the PCO (i.e. different cover in different parts of the PCO),

5= service available OoH but hours unknown,

6= unavailable for any period;

7= unavailable only during OoH period; and

8= 'unknown'.

Analysis of provision of OoH nursing and personal care

The coding matrix enabled services to be differentiated on the basis of service provider; whether the service was generalist, dedicated to EoLC or specialist in EoLC, and the main function. This served the main purpose of the numerical analysis, but did not permit analysis of what

services PCOs provided OoH to meet EoL patients nursing and personal care needs, regardless of provider.

An additional abstraction and coding exercise was therefore undertaken to establish whether in each PCO the following services were provided, regardless of the name given to the service by the respondent:

a. Hospice at Home/augmented home care: includes all services identified as being hospice at home services, plus services with different names that served the same purpose of enabling patients at the EoL to remain at home and avoid hospital admission by providing intensive support with nursing and personal care, usually for limited periods.

b. Night sitting services: includes all night sitting services, regardless of provider or funder, or whether dedicated to EoL care or not. This therefore includes night sitters provided by social services, health services and voluntary services, including Marie Curie Cancer Care.

c. Rapid response services: includes all services that include at least a component whose function was to respond rapidly to prevent or avert a crisis at the home of an EoL patient, regardless of provider or funder. This includes both generic services and those dedicated to EoL care, as well as the full range of services from those staffed entirely by health care assistants to those teams comprising medical, nursing and HCA members.

Coding in each case is restricted to whether the service is available in at least part of the PCO or not and, if so, who the providers of the service are.

Analysis

Assessment of non-response bias was made using sources of routine national statistics reported at PCO level (as shown in Table 6). As these differed by country they are correspondingly presented and interpreted separately. In England routinely available data included: organisational characteristics of PCOs (population size, number of general practices in a PCO and average list size); socio-demographic information (percentage of a PCO's population classed as 'income deprived') and health outcomes (percentage of population who die at home and percentage of cancer patient deaths at home). In Scotland routine data are available for organisational characteristics and socio-demographic characteristics but not for outcomes.

Assessment was made by considering the differences between the percentage distributions of each variable across all PCOs and survey respondents in each country separately. Chi-square tests of association were investigated for the data from England but due to the small numbers present in the data the same could not be done for Scotland.

The numerical data were entered into an Excel spread sheet, checked for errors and edited accordingly. They were then analysed using Excel and Statistical Package for the Social Sciences (SPSS) as appropriate.

2.4.7 Data Analysis – PCO interview study: qualitative analysis

This focused on exploration of data generated in response to questions in the latter part of the interview guide, although relevant data from earlier in the interview was also included. Thematic analysis was used, following the same analytical procedure as that used in analysing the SHA interviews (Section 2.3.5). In this case, initial analysis was conducted on data summaries from 11 interviews, and the 39 emergent codes identified and clustered before overarching themes were identified from these code clusters. Based on these initial codes and themes, the full data body was then coded and a final thematic framework derived. The initial themes were then reviewed and refined by the research team (CMcD, SB and GL), guided by data as analysis progressed. The same reflexive approach to managing potential biases in the data and ensuring rigour (i.e. cross checking coding strategies, thematic framework, negative case analysis, audit trail) were carried out as previously described (Section 2.3.5).

2.5 The Expert Panel

2.5.1 Objectives

This addressed the third study objective i.e. 'to hold an Expert Panel to discuss variations data; to consider emerging care models within the data (if any); to discuss characteristics of 'good' generalist OoH EoL care, and to begin to develop theoretical propositions about predictors of quality OoH EoL care'.

2.5.2 Recruitment of Panel Members

The aim of the recruitment process was to secure a cross section of experts working in the fields of EoL and/or OoH care from clinical, academic, policy, provider and commissioner backgrounds. Three approaches were adopted to recruit panel members:

1. Using the professional networks of members of the research team to invite key individuals with a professional interest in EoL care or OoH services.
2. Inviting representation from recognised statutory and voluntary sector bodies and organisations that influence the EoL agenda at a national level

3. Inviting individuals who have played a key role in the development of the national strategy for EoL care in the NHS or are instrumental in its delivery, including researchers.

Approaches were made as a result to the following organisations: the National EoL Care Programme; Department of Health Urgent Care Team; Marie Curie Palliative Care Institute; Marie Curie Cancer Care; National Council for Palliative Care; National Gold Standard Framework Centre; International Observatory on EoL Care; and The Queen's Nursing Institute. In addition, invitations were extended to the Rural Medicines Working Group, NHS OoH Providers (BriSDoc, Harmoni, G-MED OoH Service); Macmillan Cancer Support GP Advisors, a consultant in palliative medicine; a GP OoH Database Provider, a clinical director of an ambulance trust; a GP Commissioner, NHS Management Representatives, nursing researchers with an interest in EoL, and palliative and primary care researchers.

In total, 20 people received a letter of invitation from the Dean of the Faculty of Health Sciences at the University of Southampton to join the Expert Panel. Of these, 14 agreed to take part either through direct participation in the panel meeting or via virtual membership. The Expert Panel met in mid-July 2011. All fourteen members were scheduled to attend: unfortunately, eight gave their apologies at the last moment. It was necessary to proceed with the meeting despite the number of apologies received because of the timetable of the planned Phase II: case studies needed to be selected in order for Research Ethics and research governance permissions to be obtained in time for fieldwork to commence in January 2012.

The following professional roles were represented at the Expert Panel meeting, with one member having two roles: SHA executive nurse; palliative care consultant; GP and GP commissioner; PCT director of commissioning; lead advisers and officers of the National Council of Palliative Care, and of Marie Curie Cancer Care; technical officer, and GP OoH database provider.

The panel meeting was chaired by Professor Lattimer, who provided academic expertise in OoH and urgent care to the meeting, compensating to some extent for the fact that apologies had been received from a clinical director for an ambulance trust, and from a general manager of a GP OoH service. Professor Todd was also present at the meeting, bringing his expertise in primary palliative care, which was particularly welcome as apologies had been received from four palliative care academics, two of whom had particular experience in primary palliative care. Helen England, the SDO Management Fellow attached to the research study, joined the panel to provide an expert commissioning perspective.

2.5.3 Expert Panel Process and Exploration of the Data

In order to meet the objectives for the Expert Panel, findings from the PCO Interview Study: numerical data needed to be presented to them in a way that facilitated the process of identifying patterns in the data, and rapidly being able to make sense of OoH EoL service provision across participating PCOs. Data collection was finished at the end of May, allowing approximately four weeks for this process before the results needed to be sent to Expert Panel members. This took place before the main process of data coding described above.

Following a workshop to discuss the most appropriate way to analyse and present the data, the research team agreed a summary form, known as the 'traffic light form' (Appendix 5), to summarise the interview data from each participant PCO. In order to present the data to the Expert Panel in a succinct and visually intuitive manner, the research team decided to use the DH EOLC pathway as a guide for organising the information (this process was further refined in the main process of data coding (Section 2.4.6): this focused attention on mechanisms for identifying patients at the EoL, and on advance care planning, as well as on service delivery in EoL care²).

The following categories were therefore included on the summary form: identification of EoL patients; GP service; nurse led services; hospice/SPC services; acute care; access to medication and equipment; Advanced Care Plans; use of other EoL tools; coordination of care; managing end stage care; and staff training.

Each category was allocated an indicative score using a traffic light system of red, amber or green to assess the extent to which each component was available or established within the OoH period in the PCO: appropriate codes were used for missing information. A score of green indicated a service or function was routinely available in the OoH period, a score of amber indicated that a service was partially available and a red score that its availability was limited or that it was not available at all OoH.

The researchers who conducted interviews (Sarah Brien, Phil Cotterell and Helen England) prepared a summary 'traffic light' form for each PCO they interviewed using the summary interview notes as their data source, and scored each component using the traffic light system. In order to minimise bias and ensure consistency, each PCO was also independently scored by another member of the research team. Where differences between scores were identified, the two raters reviewed the data and agreed a final score by consensus.

Expert Panel members were each sent eight 'traffic light' summaries to review before the Expert Panel meeting, half of which were allocated individually and half of which were common to all panel members.

2.6 The 'Virtual' Users Panel

2.6.1 Objective

This addressed the research project's fourth objective: 'to obtain the views of service users about their preferences for, and experiences of, EoL OoH care, in a 'virtual' User Panel.

The possibility of including service users in the Expert Panel was discussed. However, the research team's previous experience in involving service users in EoL research indicated that it is usually preferable to interview seriously ill patients in their own homes, rather than expecting them to attend a planned meeting. This facilitates their participation as they are able to control the date and time of the interview, to be in comfortable surroundings, and take whatever steps they need to maximise their physical comfort⁸. The 'Virtual' Users Panel was therefore intended to be viewed as an essential element of the Expert Panel: a way of ensuring users' perspectives were incorporated into the research team's deliberations about variations in OoH EoL care; it was not intended to be a full-scale research study investigating users' experiences of this care^{vii}

2.6.2 Recruitment

In order to gain insights into differing experiences of accessing OoH EoL care it was planned to recruit two service users whose EoL experiences might be expected to be conforming to one of each of three theoretical EoL trajectories: the cancer trajectory, the organ failure trajectory, and the frailty trajectory⁷⁵: a total sample of six. Within the limits of this sample size, it was also planned to recruit users of different ages to the sample.

Local hospices on the south coast were contacted to identify service users with advanced cancer and users of a range of palliative care services. Hospice staff was given a brief information sheet describing the aims and the conduct of the 'Virtual' User Panel, and used this to discuss the study with potential users. If the service user was interested, and gave their permission, their contact details were given to the researcher for follow up.

Networks available to members of the research team were also utilised to identify frail elderly people and people with organ failure. Again, a brief information sheet was given to these colleagues to identify potential interested service users; service users who were interested in

^{vii} An interview study of EoL patients' experiences of using OoH care was included as part of the planned Phase 2 of this study. The literature review in this report demonstrates the lack of evidence in this area.

taking part, provided contact details for the researcher to contact them and discuss participation further.

2.6.3 Convening the 'Virtual' User Panel

As discussed above, it was not feasible to invite the service users to a joint meeting given their health condition and the fact that users were recruited from different geographical locations. Instead the researcher (PC) interviewed each person in their own home.

Once potential users were identified, the researcher (PP) telephoned potential users to explain the purposes of the user group and if they were willing to consider this; an information sheet was then sent to them. The researcher re-contacted the potential users and with their consent, arranged a date for the informal interview. All interviews were conducted at the service users' homes during June to July 2011. Written consent was obtained prior to the start of the informal interview. An interview guide was used to guide the interview (Appendix 6). This guide addressed seven questions covering three topics: their experience of accessing and using OoH EoL care, their preferences for OoH care and what matters to them, and what they would like to happen if they needed help in the OoH period. Interviews were digitally recorded if written consent was given by the participant.

2.6.4 Analysis

The aim of data collection was not to conduct an in-depth qualitative exploration of users' views but rather to identify key issues relating to their experiences of, and preferences for OoH EoL care. Therefore detailed qualitative analysis was not conducted on the interview data. Instead, narrative summaries were prepared for each service user by the researcher, from the digital recording. Anonymity was ensured during the preparation of the summaries by the removal of any identifiable information relating to the participant and the use of pseudonyms. Simple thematic analysis was then conducted to identify a list of the key issues emerging from each of the seven questions addressed in the interviews, and verbatim quotations were identified to illustrate key points emerging from the data.

3 RESULTS I : SHA interview study

3.1 Overview

As reported in Section 1.5, this study addressed the first of the project's objectives: to interview senior managers at Strategic Health Authority (SHA) and Health Board (HB) level, responsible for EoL/OoH, about current OoH EoL service provision, its strengths and weaknesses. Before presenting these findings, the response rate for the study and the participants' characteristics are described.

3.2 Response rate

A total of 43 senior managers were contacted, 25 (58%) responded and 13 (30%) agreed to participate (Table 4). A larger proportion of EoL leads (43%) than OoH leads (18%) took part in an interview. On average 3.8 contacts were made to identify each of the 43 senior managers within the SHA or HB.

Participants who agreed to take part represented eleven different regions across England and Scotland (five HB and six SHAs). Two regions were represented by both the OoH and EoL lead; in one of these regions, a joint interview was conducted with both leads.

On average, interviews lasted 39 minutes (range 18–54 minutes). One interviewee was unwilling for the interview to be recorded. In addition, the digital recording failed on a further interview. Therefore summary notes were prepared for these two interviews and these summaries were used as the data source for analysis.

Table 4. **Response rates for SHA Interview Study**

	Responsibility for	Senior managers in SHAs/HBs (N)	Responded (N,%)	Agreed and interview conducted (N,%)	Declined interview (N,%)
England	EoL	9	9 (100%)	4 (44%)	5 (56%)
	OoH	8	5 (63%)	3 (37%)	2 (25%)
Scotland	EoL	12	6 (50%)	5 (42%)	1 (8%)
	OoH	14	5 (36%)	1 (7%)	4 (29%)
Total	EoL	21	15 (71%)	9 (43%)	6 (28%)
	OoH	22	10 (45%)	4 (18%)	6 (27%)
Overall total		43 (100%)	25 (58%)	13 (30%)	12 (28%)

3.3 Roles, responsibilities and priorities

3.3.1 Participants' role and responsibilities

Participants were asked to report their role and their responsibilities for OoH and/or EoL care to provide context for the findings reported in subsequent themes. These are described in detail in Appendix 7.

Of the nine EoL leads interviewed, four represented SHAs in England and five HBs in Scotland. Of these, only three participants had roles only focused on EoL care; the others had remits covering additional portfolios. Only one participant had a remit that specifically related to OoH provision in respect of EoL care. Of the four OoH leads interviewed, three represented SHAs and one a HB in Scotland. The participants had some, if not all their role specifically dedicated to generic OoH care and this included some limited remit for EoL OoH care.

3.3.2 Strategic priorities in respect of OoH EoL care

Participants were asked to describe specific strategic aims relating to OoH and/or EoL care, again to provide context for the rest of the interview. Key strategic priorities identified by EoL participants are described in Appendix 8. These focussed on supporting PCTs to develop the DH EoL Pathway and co-ordinating its implementation, ensuring patients could remain at home if it is their PPOD, actions to facilitate steps 1, 2 and 4 of the Pathway and monitoring performance.

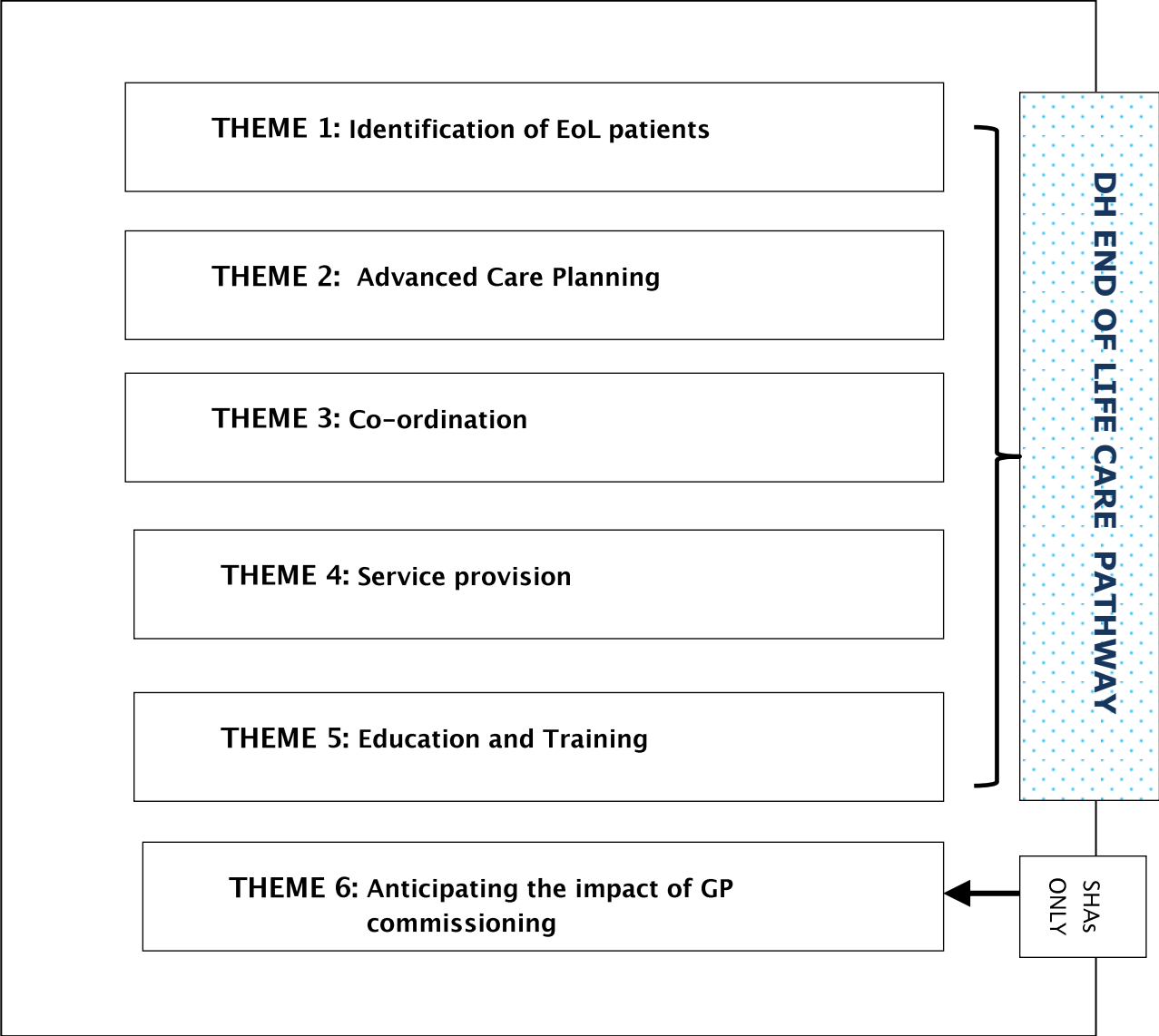
Key priorities identified by OoH participants are described in Appendix 9. These related to the implementation of the EoL Pathway overall and in relation to specific steps, but additionally included strategic priorities relating to monitoring OoH and/or EoL care and managing the introduction of GP commissioning. Generally most strategic priorities indirectly related to OoH EoL care, with only three participants identifying priorities specifically relating to access to services 24/7.

Priorities relating to monitoring performance of services as well as specific outcomes (for example reduction in hospital death rates) were also reported for OoH and/or EoL care. These will be discussed in detail later. Notably, performance monitoring, specifically for OoH EoL, was generally limited, with only a few participants reporting systems specifically dedicated to monitor OoH EoL services. Generally monitoring was undertaken at PCO level, although some regions were jointly involved in some aspects of monitoring. Where OoH EoL care performance was monitored, most considered this was not thorough. Those who did monitor OoH EoL, were characteristically small SHA/HBs; the small population and area of these SHA/HBs made this specific monitoring feasible.

3.4 Findings – thematic analysis

Six themes were identified, as shown in Figure 1. These relate to participants’ views of current OoH EoL service provision in their SHA/HB, and of its strengths and weaknesses. The data mapped onto Steps 1 to 5 of the EoL care pathway, and therefore this is used as a framework to report these data. The final theme, theme 6, reports the perceptions of participants in England on the anticipated impact of GP commissioning on OoH EoL provision within their SHA. Quotes to illustrate these themes are referenced in the text. The anonymity of the SHA and participant was ensured when reporting these data. Senior Managers with responsibility for EoL are coded SM,EoL and those responsible of OoH are coded SM,OoH. Each participant is given a unique code number.

Figure 1. Diagrammatic representation of themes identified in SHA Interview Study.



3.4.1 Theme 1: Identification of EoL patients

Participants described strengths relating to three specific areas concerning the identification of EoL patients as described below. It is notable that no regions had any specific remit to monitor this step of the pathway.

Identification of non-cancer EoL patients

The ability to identify EoL patients, including those with a non-cancer diagnosis, is essential to facilitate appropriate patient care both in and out of hours. One SHA reported that this as a key priority and another SHA explained this was an area that their region had focussed on in recent years. This latter participant reported significant advances in developing systems to enable identification, and therefore subsequent care, of patients with non-cancer diagnosis.

I think that we have arranged for a better standard of care and understanding around people with, for example, chronic obstructive pulmonary disease, who are reaching the situation where their care should be palliative rather than curative and the expertise in the specialist palliative care team in dealing with people who have a non-cancer diagnosis has definitely improved. I think to be fair it was probably, if you go back two to three years, it was one of our biggest weaknesses and I think we have done a fair amount. (SM,EoL;8)

Developing tools to enable the early identification of EoL patients

Identifying when a patient is at the EoL is often challenging especially where the prognosis is uncertain as is usually the case with diagnoses other than cancer. One participant described how they were developing a palliative care plan to address this which enabled patients with chronic progressive illnesses to be automatically linked to the GSF, even if at the time of planning, it was not clinically possible to define them as being at the EoL.

The Liverpool Care pathway is recommended by the Scottish government but as to what is meant by EoL is nebulous, [so] this isn't always used. So we have developed this plan which is on their systems so when someone is diagnosed with an illness this would automatically open up the Gold Standards Framework and patients would be assessed and scored, the OoH alerts notified and information would be automatically populated into the patient records. So it follows the patients along their illness. Therefore it doesn't matter if we don't know how long patient is near death because it will advise the GP/OoH provider etc about what to do based on the patients individuals needs rom point of diagnosis to EoL and has links to advice and protocols etc. It has been piloted on the [name of] software with GPs in [name of region] and will be implemented on the other electronic systems. (SM,EoL;9)

This plan was accessible to providers during the OoH period so that when a patient required care during this period, the provider could access their care plans along with the predicted trajectory of their illness and thus be alerted to the appropriate care required at that time depending on the patient's current health status.

Electronic communication systems to enable identification of EoL patients across OoH sectors

Electronically based mechanisms that enabled or improved how EoL patients in the OoH period were identified were described as strengths. These included:

Developing a locality register or expanding its accessibility.

Establishing locality or EoL registers, which record key information about a person nearing the EoL and are accessible round-the-clock by a range of services involved in the individual's care, was in progress. In England, all PCTs needed to have a register in place by March 2012. The registers were viewed as an important way to both reduce inappropriate hospital admissions as well as enabling people to die in their preferred place of death (PPoD). Some regions were at pilot stage, others had rolled out the register and some were "upgrading" the register by, for example, linking it to a single point of access.

Developing flagging systems to alert ambulance crew to reduce inappropriate hospital admissions.

Electronic flagging systems to alert ambulance crews of a patient's EoL status (and possibly enabling access to their care plans) aim to reduce inappropriate hospital admission rates. Several regions were developing these systems. Participants considered this approach so successful that they had plans to extend it. For example, one SHA which had piloted this in one PCT within their region was planning to roll out the alert system region wide as they considered it had such a high impact at low cost.

This ambulance [pilot alert] service ... they have done some tweaks to their system and it has cost £5000 ... and could be available across the [region]. So it is not exactly cost nothing, but next to nothing ... but it has quite a bit impact.
(SM,OoH;4)

Another region, which had already rolled out the ambulance alert system region wide, was also planning to extend the system into the acute sector, so A&E could also identify an EoL patient's status and manage their care accordingly.

Improving EoL identification between OoH providers

Five SHA/HBs were developing or implementing electronic systems to improve access to patient information between OoH providers to

improve patient management. This included linking GP 'in hours' systems to GP OoH systems, and also 'in hours' community nursing to OoH nursing systems allowing access to care plans across the 24/7 period. In Scotland, the electronic palliative care summary (ePCS) was in various stages of being rolled out enabling access to patients' care plans across OoH providers (including A&E, the ambulance service, Macmillan nurses and hospices).

3.4.2 Theme 2. Advance Care Planning

The role of effective forward planning in EoL care emerged as a strong theme, with Advance Care Planning (ACP) being widely regarded as an important strategy to enable a smoother and more integrated approach to end of care both in and OoH.

I think the key [to good EoL care] is good anticipation of what might happen OoH and having a plan. (SM,EoL;12)

Focussing on 'in hours' care was considered an important part of enabling good OoH provision; one participant argued that an OoH request from an EoL patient should be considered as a 'significant event' because care should be anticipated and planned for.

The other thing is, continuing the policy which the palliative care specialist preaches to everyone about emergencies are predictable and if not avoidable then manageable. ... So the more you work during the day the less you need to deliver in OoH. ... We need to continue to work on that, and almost consider [that] if someone phones OoH was that a significant event because we could we have done something about it to face the problem before. (SM,EoL;8)

Strategic priorities relating to ACP included ensuring the implementation and/or audit of ACP; the roll out of DNAR/ do not attempt cardiac pulmonary resuscitation (DNACPR) and other ACP tools, as well as monitoring preferred place of death (PPoD) as a key performance indicator (KPI). These priorities are reflected in the two main areas that participants reflected on in respect of ACP: monitoring its performance of ACP and perceptions of progress with its implementation.

Monitoring performance of ACP

Five of the regions reported monitoring performance in relation to different aspects of ACP. This included the implementation of ACP and KPIs. The process of monitoring was at different stages of implementation.

Monitoring implementation of ACP

Only one HB reported monitoring the number of electronic palliative care summaries (ePCS) and ACPs in their region. Another participant described how their HB was monitoring DNAR case reviews, comparing

CPR attempts and DNARs documentation on a patient by patient case to identify any cases where patients' wishes were not met. This participant explained that he was able to be directly involved in this level of monitoring because the HB had a small population of EoL patients.

Monitoring key performance indicators

PPoD was the only KPI being specifically monitored by a number of regions. Two SHAs had strategic aims to improve PPoD rates and to ensure they were being monitored at PCO level. Monitoring PPoD was being implemented in different ways and was at various stages of progress. Electronic systems to directly monitor PPoD were being used and regions were at various stages of implementing them. One SHA, who had a target to reduce hospital deaths by 10%, was in the planning stage yet two other SHAs already had electronic web-based systems in place to determine the patient's place of death in relation to their PPoD. One SHA was "self-sufficient" and has now been taken on by the National End of Life Care Intelligence Network. The other had systems in place managed at PCT level, with the SHA having a quality assurance role. A more indirect approach to monitoring PPoD was described in one HB where PPoD was being monitored by comparing place of death to the receipt of a 'just in case boxes', which are distributed to patients very near the EoL who wished to die at home. Monitoring place of death in these patients therefore gave an indication of how effective the region was in achieving PPoD.

We audit what happens ... to a patient once an EoL box has gone out. So are they admitted or aren't they admitted? But that is very much EoL, [the] last few days. The usual sort of performance monitoring about the number of patients who die at home versus the number of patients who die in hospital, that is a figure we keep an eye on. (SM,EoL;12)

Perceptions of progress in implementation of ACP

Three specific areas relating to perceptions of implementation of ACP were discussed.

Tools used in ACP.

Participants made reference to various tools to enable ACP such as the ePCS in Scotland (see above), and the tool described above to aid the early identification of EoL patients and therefore make EoL patients care plans accessible early on. Participants in England described how the roll out of DNAR policy was being delayed due to issues with consent for sharing patient information.

There have been a number of conversations that are going on nationally about a do not resuscitate policy - whether or not and how much you can put it on the summary care record of shared case notes. This is, I think there have been some problems with this nationally so we have not gone very far with it locally because of different issues that it raises about how to share the summary care records

hence the do not resuscitate policy within it. I think it has been a national information hurdle as much as anything else. (SM,OoH;4)

Participants in Scotland did not report this problem.

Perceptions of ACP roll out.

Improving the roll out of ACP was generally considered an area still to be addressed.

I am still not convinced that we have got our advance care planning to everybody who needs it. ... It is understood all palliative care leads have training within that but the bit that is less clear is how well it is rolled out. Yes if you look at an average population, how many people who could benefit from it actually receive it? I think this is where we all ... could make some improvement. (SM,OoH;4)

Some participants called for more rigorous monitoring to ensure GP practices sign up to GSF and ensure they keep their records up to date. One way to improve ACP was to ensure that 'early conversations' were undertaken, or improved upon, in order to find out patient's wishes.

I think the other thing is about everyone feeling confident to have that discussion early with the patient about what their wishes would be. Whilst it is working well in some areas, not in all, I think there is still room for improvement on that one. (SM,EoL;6)

This was seen as a way to improve ACP without significant financial investment.

Interviewer: do you think OoH EoL care could be improved without necessarily costing much more money, and if so how?

Participant: Oh yes. Advance care planning, for example, ... I think a simple advance care plan with an understanding of patient's wishes and aspirations, preferences would go an awful long way. ... Those conversations are so difficult. Finding out a patient's preference, finding out what they would like to do. ... You need training. (SM,OoH;4)

ACP in care homes

Ways to improve ACP in care homes were described. One scheme was described where a nurse had been employed to both identify the wishes and preferences of EoL patients living in care homes, and then to train nurses in implementing and updating ACP. This approach was considered to have a significant impact on reducing inappropriate hospital admissions in for these EoL patients.

We have a process of a nurse going to interview the patient and relatives throughout all our care homes to establish a anticipatory care plan. ... The other role of that nurse was to train nursing home staff to actually undertake that and update it in a regular basis. I am not saying it is perfect but I do note that the number of completely inappropriate admissions has gone down. ... I think the approach of going round all care homes and having the difficult conversations

about what would be a ceiling of care, and what the patient and relatives would expect in the event of deterioration, is probably the most innovative step that we have taken around here. It is not original but it does seem to have made a significant difference. (SM,EoL;8)

3.4.3 Theme 3: Coordination of EoL care

Nine participants commented on issues relating to the coordination of EoL care in their region. Of these, only one SHA had a strategic aim specifically relating to this, which was to develop a generic single point of access (SPA). They described systems currently in place to enable or improve coordination of care. Generally, none of the participants considered this aspect of the Department of Health End of Life Care pathway was working particularly well in their region, but provided suggestions on how to improve coordination as well as giving examples of innovation. No systems to monitor coordination were reported by any participants. Most participants considered coordination could be improved without significant financial impact and indeed that investing in improvements may be cost-effective and/or would improve the quality of OoH EoL care.

Integration of care OoH, [could be improved] however that be done. Whether it be a lead provider model or whether it be more closely specifying that links are made between the various providers in that period. ... That by greater coordination all of these responses, that either savings could be made or a better quality of service could be provided within the existing services. (SM,OoH;1)

Participants described various existing models of coordination. Formal models of coordination were reported in a few regions. Only one region reported having dedicated EoL coordination centres which, although initially available 'in hours', were thought to have been beneficial for EoL patients during the OoH period. Single Points of Access (SPA) were however more common and either in the process of development or available or being expanded. Having a SPA was seen as a way to avoid duplicity of services, to streamline care provision as well as identify gaps in provision during the OoH period. One region, in the process of developing a SPA reflected it would enable commissioners to make better informed decisions about provision of EoL services.

We are hoping that through the development of single points of access and the development of a directory of services, we will uncover some of the gaps and the variances within the out of hour's provision. And then commissioners can take a much more informed and intelligent decision about [service provision] ... that they actually weren't aware of ... and that is borne out in all of the national pilots. (SM,OoH;3)

Another participant considered having an up to date register of service provision would ensure services remain available if boundaries change as a result of the shift to GP commissioning.

One participant also explained how they were planning to link the EoL care register, which they were currently piloting in their region, with the SPA to ensure an improved response for EoL patients and their carers both in and OoH. This particular SHA reported significant challenges in providing OoH care generally, as the region was characterised by single GP practices. This development would, if successful, enable improved coordination of care.

A number of other approaches to coordinating care were also reported that were not specific for EoL patients but were seen as being beneficial. These included:

- multi-disciplinarian teams (MDTs) including virtual wards which although these were generally 'in hours' were perceived to have a positive impact on the OoH period;
- systems to enable coordination between specific sectors during the OoH period, which were seen as having potential to reduce admissions for EoL patients. This included, for example, coordinating responses between ambulance and community nursing teams or between the ambulance service and GP OoH;
- a planned review service provided by GP OoH service enabling GPs to anticipate the care needs of any patient, including EoL patients, during the OoH period;
- and the introduction of the generic '111' number. One participant described how their region was planning to link EoL coordination centres to the '111' number as a cost neutral way to improve the coordination of OoH EoL care.

I think you would want the EoL coordination centre feeding into that [the 111] system and then they could all work together wonderfully. ... It will cost a bit up front but it is supposed to be cost neutral, or as efficient in about three years' time, because it means you don't have lots of people providing answering the telephone providing the service. (SM,EoL;7)

3.4.4 Theme 4: Service provision

This theme was discussed at some length by participants. Improving service provision was identified as a strategic priority in six regions, but all participants considered this an area for improvement. Most participants did not have detailed knowledge of specific services in their region, apart from one participant who was also a palliative care clinician, but instead were more familiar with developments in their region and provided examples of these as described below.

Challenges with providing 24/7 EoL care

Providing seamless 24/7 care for EoL patients was considered an ideal but a challenge. Most participants considered this was an area for improvement either by introducing new services not currently available (for example, rapid response or hospice at home) or by expanding current provision (for example, night sitting services) in order to meet the needs of their population.

Participants focussed on three specific areas they considered important to improve 24/7 cover. This include the provision of 24/7 access to DN and better integration between health and social care. One participant considered poor integration was attributable to staff and patients' lack of awareness of services available in their region.

I think that the health and social care teams working together 24/7 is not working as well ... I think that comes back to whoever is on the phone having the right knowledge in front of them, knowing what is going to be and picking out what is best ... for the patient. So it is about the awareness and understanding of the very services that could support that patient. (SM,EoL;6)

Managing carer breakdown to ensure patients were not admitted into hospital unnecessarily was also another issue that needed to be addressed. One participant considered that providing a night sitting service would help the carer and circumvent unnecessary hospital admissions.

a lot of the feedback that we got from the input of the district nurses OoH could have been avoided by the commissioning of a very low cost sitting service where people have the confidence of having someone with them in the night. (SM,OoH;1)

Several factors were identified as challenging to improving 24/7 care provision. These included the cost implications of being able to enable EoL patients to die at home. The SHA/HB had to ensure that service delivery was financially sustainable but remained of high quality.

It is making people think that we can't put in 'x' amount of thousand to a service every year. That has to stop. It is how does that service do things differently in order to continue getting good care to patients and also improve the care to patients? Because some deliver really good care to patients. It is how we continue to do that or improve the care that they receive but making sure that we can do that in a reduced cost way. It is about doing what we do for less basically. (SM,EoL;6)

Identifying these costs was a challenge, and no participants reported having yet calculated these fully despite recommendations in the 2008 Darzi report commending increased rates of home deaths.

We need evidence that the changes will make savings. They haven't worked this out yet, for example, caring for people at home not in hospital. Would this save money on hospital beds, diagnostic tests and meet patient wishes? The recent

Darzi report reported that the strategy should be to shift patients from acute to home deaths and the milestones should be reduced bed occupancy and value. (SM,EoL;11)

None of the regions in this study had yet identified calculating these costs as a strategic priority. Conversely, as one participant explained, the lack of progress in calculating costs had hindered their region from making firm strategic plans to address increasing rates of home deaths.

The point is, [enabling EoL patients to remain and die at home] may be a preference but it may end up being more expensive, and the demand on the services and what would the likely demand be? How can that demand be met? I don't think we have reached that level of sophistication [in identifying these costs] at the moment in order for us to get where we need to be in terms of some of the strategic plan. (SM,OoH;4)

The complexities of managing the workforce was another challenge in 24/7 provision. Differences across individual PCTs' strategies made it difficult to ensure a region had consistent service provision. In addition, regions that were large, diverse and/or rural posed a problem in terms of managing the number and type of workforce needed. For example, one SHA which covered a mainly large urban area of single handed GP practices had difficulties ensuring standardised OoH cover and as such had high rates of inappropriate hospital admissions for EoL patients.

One of the things we do know is we have got a problem with [EoL] patients ... attending A&E ... within the final days of life. So we do know that is a particular problem across [name of SHA] just by the numbers of unscheduled emergency admissions. (SM,EoL;2)

In addition, restrictions on OoH staff contracts were stopping staff from being able to provide care, even if they have the necessary skills, because their contract only enabled them to undertake specific duties.

However despite these challenges, two innovative approaches were being piloted to improve 24/7 care. Mobile technology was being used to manage OoH provision in rural areas. For example, one HB was piloting a scheme whereby EoL patients were given a mobile phone enabling them to access staff during the day and a mobile application for pain management. Another scheme was filling in the gaps in 24/7 care in rural areas using Marie Curie nurses.

We have another initiative on-going at the moment working with the community health partnerships to put in place on call Marie Curie nurses [to fill] the gaps in some parts of the rural areas. Because of the nature of OoH nursing in [name of HB] there are significant issues having on call nurses. And these are staff government issues where staff are reluctant to be on call [and] working all day and then on call and being called out at night and then working next day again. But what we are trying to set up is three mobile vehicles staffed very similar to our OoH cars, but with a nursing team in partnership with Marie Curie and these would be on duty nurses working night shifts. ... That would be their only job.

Working in partnership with the OoH service and the CHP daytime nurses.
(SM,OoH;10)

Too many hospital admissions

Inappropriate hospital admissions at the EoL were considered a common problem amongst participants.

I still think we take too many people to hospital when they don't want to go.
(SM,OoH;4)

One SHA in particular was focussing on identifying alternative options to avoid A&E admissions for EoL patients as a strategic priority.

Additionally, improving the rapid discharge of EoL patients from hospital to home/hospice was also highlighted as a challenge. One participant considered that this would not require significant financial investment yet would have significant benefit for EoL patients.

Improve discharge planning. This is obvious - it would cost money but would decrease hospital costs. (SM,EoL;11)

One SHA had invested in a palliative care ambulance to specifically address this and had provided additional training for the ambulance crew to manage patients at the very end of life.

'Access to OoH care is a lottery'

Variations in access to social care OoH and apparent bias towards cancer patients were two areas highlighted as creating inequality in access to OoH care for EoL patients. Access to social care packages was a problem in some regions due to variations in the eligibility criteria for EoL patients and was perceived as resulting in a 'lottery' style of care provision. In one HB, for example, the local authority provided care packages only for patients who had conditions where some degree of improvement was possible, thus EoL patients were excluded. Yet in another HB, the eligibility criteria had been extended so EoL patients could access social care packages.

Inequality of access for non-cancer patients was reported.

During the OOH period, cancer patients are 10 times more likely to get support than non-cancer. This is partly historical (as specialist palliative care services set up for cancer) and takes time to address. I am trying to focus hospices onto non-cancer to raise their activity in treating non cancer patients from 3% to 7% but it's slow. (SM,EoL;11)

Two participants in HBs in Scotland were making good progress in addressing this issue. One participant, who was also a clinician, described how they were actively seeking to identify non-cancer patients early on in their palliative care phase during ward rounds and then setting up appropriate care plans.

Certainly through a lot of the work that we have been doing through the long term conditions collaborative in [region of HB], we have been trying to make that link between patients with a life limited long term condition and entry [into] a palliative care phase ... I go round the acute wards at 4 o'clock every day myself or one of my colleagues, and we trawl for patients we look for palliative care patients. ... So we are now actively looking for patients non-cancer non-malignant patients that we can intervene earlier and maybe get some of the benefits that the cancer patients get. It is not always easy, all the issues of prognosis, prognostication in these groups of patients is quite tricky but actually what we are finding is if we intervene earlier we can manage to keep the patients at home for longer. (SM,EoL;8)

As this HB covered a small geographical area, this personal approach was feasible.

Managing the balance between quality and cost

Several issues regarding the procurement of OoH EoL services were highlighted. The main issue was the perceived tension between the drive to reduce costs while maintaining high quality care provision. This was reported to have created conflict between different stakeholders involved in providing OoH EoL care, hindering effective partnership working because essentially while the stakeholders were trying to provide good quality joined up care, they were also a business. This tension both between and within the different sectors involved in this care, was thus considered to impact negatively on the overall care pathway.

Managing this balance was reported to have had negative repercussions for OoH EoL service provision. One participant described a situation where the quality of service had been compromised because local commissioners had used the cheapest providers. The provider had not employed local staff which had created a poor service and the provider had failed.

Within a year ... the provider [was] struggling financially. ... It was just an over aggressive tender process where perhaps priority wasn't fully aligned with quality and the skill-mix and the management of the future provider. So within a year ... that provider has now failed and we having to go through the procurement phase [again]. (SM,OoH;1)

As a result, this SHA was only considering contracting those providers employing local staff even though it could be more costly; to be assured of consistent and effective service provision.

I think it has been that drive to make savings by procurement processors elsewhere that has led to providers potentially coming from outside the patch. [I] feel the processors that haven't put enough weighting on local connections ... we are looking to [employ] local staff at the expense of a cheaper contract. That has led to some of the problems that we have in the country, [it] hasn't emphasised that local connection enough in my opinion. ... What works really well are those

providers that have been able to hang on to a core group of local GPs who used ... to be responsible for the OoH care when they were running their own OoH practice ... and as new providers have been commissioned, that core group of staff have mainly stayed and transferred or been part of the new provider. And where you have ... got the active engagement of local clinicians as providers of the OoH service ... it is a strong and robust response ... where there hasn't been the engagement with local GPs, where it may be a provider which comes from out of the area with very little attachment to that area, and the GPs withdraw their labour essentially don't want to work for that particular provider ... and that has then resulted in the problems ... whereby people then went to locum agencies providers ... or perhaps potentially going aboard and that's where the quality drops ... In this region, almost, in fact all of the providers have been able to hold on to that core group of local GPs ... and that is one measure of success. (SM,OoH;1)

Inconsistency in the procurement process was also highlighted. One participant reflected that although the process of procurement could work well at times, this was not always the case and they perceived that services were commissioned that did not necessarily reflect value for money.

Contracting is not straightforward and it needs to be adapted locally depending on what services are out there and what you want to commission for your population need.. ... There are different approaches to it. I am not sure that from the procurement processes that are used right the way across [the region], or the framework [used, that] we get absolute value for money. There is best practice examples but I am not sure everyone follows those ... there is an issue around procurement and how do people do that and are they competent to do it, do they get the best out of that that they should do when they commission services or set up a contract. (SM,EoL;6)

No suggestions as to how this could be improved were provided by participants, essentially because cost was the rate limiting factor and regions needed to provide high quality but financially sustainable EoL provision, both in and OoH hours within a climate of reducing or reduced funding.

Monitoring service provision

Systems were in place to monitor both EoL and OoH performance as described. Examples of monitoring the performance of EoL service provision included annual audits of both in and out of hours care provided by SPC providers, and weekly case note reviews of patients on the EoL register. This latter example was feasible because the HB was small with few EoL patients. Monitoring OoH performance was generally conducted at PCO level and reported back to the SHA/HB, using the key performance indicators (KPI) for OoH, i.e. four hour wait in A&E and general activity. One participant recognised this level of OoH monitoring was limited but was not sure what else to monitor, given that they were aware a lot of care was informal. In some regions, performance of OoH

clinical staff were also being monitored: for example the performance of GPs and nurse practitioners, and a scheme aiming to assess both the quality of GP OoH consultations and “significant OoH events” was also being piloted.

In terms of monitoring the quality of care, we have a clinical lead for the GP OoH service, he will randomly select case notes on the screen of consultations that are carried out [during] the OoH, going through them. ... In the last year we had three interviews with doctors where we felt that they had not provided the best possible care. We also have a significant events system ... which forces us to make sure that each significant event has been raised is appropriately investigated and addressed. (SM,EoL;8)

3.4.5 Theme 5: Education and Training

Training in EoL care was not identified as a strategic priority in any of the participating regions and no systems to monitor training/education were reported. The eight participants who discussed this issue were committed to ensuring adequate training was available. As one participant, who was also a palliative care clinician, described, providing education was necessary to reduce crisis management.

I think the more education we do then the less crisis management we do. (SM,EoL;12)

Participants focussed on two areas: training for care home staff and training for other staff.

Educating care home staff

Four participants described how the roll out of GSF training for care homes had been overwhelmingly positive, and a successful approach to reducing inappropriate A&E admissions for patients in care and residential homes.

I particularly know about a PCT that had a very high transfer of patients coming in for just a few days, or even in just for the final few hours of life and spending that time in an A&E. ... The PCT wanted to address this as a particular issue, as the [admissions] were coming mainly predominately from nursing or care homes. So the PCT set out ... an education programme working with all of their providers of continuing care and residential homes and ... gave them contact numbers and support and future contact. When, if and the type of symptoms to expect. ... They experienced something like an 87% drop, in that PCT, of patients being admitted ... in an ambulance to A&E. (SM,EoL;2)

Specific aspects of GSF training in care homes were also seen as particularly valuable. Training care home staff in ‘early conversations’ in order to identify patient wishes and preferences, was perceived to have

had a significant impact in one SHA. Increased awareness of local service provision also enabled care home staff to access the right help or advice when following ACPs.

Educating other staff

Projects dedicated to providing EoL training for specific clinicians such as GPs and nurses were reported. A scheme where a nurse was training GPs to use GSF tools in allocated care homes was proving successful in enabling care home patients to die at their place of choice.

One ... nurse [is] carrying out a research project with the care homes in [name of town] and what she is doing is introducing the tools ... putting instructors with our GP colleagues. So a GP practice will be aligned to the care home, and the tools will be introduced. ... What we are finding is that those patients who said that they wished to die in the care home are being enabled to stay there rather than being admitted last minute into the hospice or indeed into the teaching hospital. ... Only ... one year into the project ... but I think the education is certainly paying off. (SM,EoL;13)

Another education project was described whereby all clinical staff working OoH were given handbag sized copies of palliative care guidelines to ensure they had access when at patients' homes.

The other thing that we have developed ... is the palliative care guidelines ... [and] we have distributed hard copies ... handbag sized copies for the GPs and the district nurses and all the other [OoH staff] ... if you are just in a patient's home you can't access [the internet to access them] ... you have at least got access to this. (SM,EoL;13)

3.4.6 Theme 6: Anticipating the impact of GP commissioning

All eight participants from the seven SHAs who were asked to comment on this issue reflected mixed feeling and uncertainty about the process of change to GP commissioning and the potential impact on patient care.

I think [my concerns] it is just how it works. A lot of these things you don't know what the mechanisms are going to be. And whether GPs will need to join together in a consortium ... and you will need some strategic planning for a lot of these things as well as local [planning]. It depends on the size of your consortium. There is a lot of uncertainties and nervousness about it but actually for this area it might be quite reasonable. (SM,EoL;7)

Participants reflected how SHAs were taking steps to help commissioners manage the period of flux and transition, by enabling PCTs to become more independent of their SHA, a necessary process as SHAs were being dissolved.

Also, that we leave the systems in good order so that the systems are actually about working together independent of the SHA. So we are trying very much to

create an environment that doesn't depend on us to say yes or no to them [the PCTs]. And that is harder to do because it is slower and also sometimes it feels a bit passive because actually you just want to say to people "just do it". But what it does it continues the dependency model which is absolutely contrary to what we are trying to develop. (SM,OoH;3)

Yet for some normally proactive SHAs, letting go of control to create a culture of independence amongst PCTs was challenging.

We tried to be proactive ... I mean the point is that you want to [be proactive in helping the PCTs manage this transition] but there comes a time when you have got to let people get on and do ... So we hope we have planned for the unforeseen. It is always very hard, sometimes. (SM,OoH;4)

Three specific areas relating to both the transition period as well as the change to GP commissioning, were discussed by participants.

GPs as commissioners

Participants had mixed views regarding the role of GPs as commissioners. Having GPs as the commissioners responsible for commissioning OoH EoL care was seen, on the one hand, as positive. Being the clinicians responsible for their patients' care, GPs were thought to fully understand the needs of EoL patients and therefore would know what services need to be commissioned especially with regard to the OoH period.

I think that commissioning moving to the GP is ... the right way to go, I think, because they are so key in determining what the patient requires, what stage they are at the end of their life. They are absolutely key in that ... they are the lead clinician in charge of that patient's care. So I think the impending changes have some positives around that as to who is doing it. (SM,EoL;6)

Additionally they were thought to be well placed to ensure the quality and monitoring of these services provided.

I mean it in some ways you would think this [i.e. OoH EoL] is probably a service that is quite actable, then isn't it? Because it is at the right level, it is local and their patients, they know them in hours and they may often be the same person in OoH. And so they can be responsive to what their patients need and they can see what is going on in terms of monitoring the service for quality. So in some ways it could be good. (SM,EoL;7)

Additionally, participants thought GPs clearly knowing their patients' needs would have the advantage over previous commissioners, and that they would be able to learn from previous commissioning errors, make better informed decisions for future OoH EoL care provision and ensure services were not provided solely for historical reasons.

If their GPs are made much more aware of and exposed to some of the poor quality inefficiencies, as a result of commissioning decisions or passive commissioning decisions, or provider response to those commissioning decisions,

then potentially GP consortia locally can really make a much more informed decision around the services that they commission. And then the monitoring of those services and the impact on patients ... so potentially this could really be a good thing for patients at the EoL, particularly around the OoH provision. (SM,EoL;2)

However, concerns were also raised. GPs were not commissioners and they would not have the necessary skills and knowledge or the capacity to take on this role.

They are not commissioners, they are clinicians. So I think that is going to be a challenge. (SM,EoL;6)

Have they got the capacity ... and the capability of understanding all of the issues around commissioning, as well as understanding the outputs of both provision and commissioning? (SM,EoL;2)

GP commissioners would need support and an infrastructure set up in order to be effective in their role, given the breadth of work that PCTs are involved in with regard to commissioning and its management.

I think that [the GP] who is doing it will need lots of support and infrastructures around that, to support them in making that right decision and commissioning the right services. Because if I think of the role of PCTs at the moment, that is huge on them; commissioning, right services monitoring, contracts, terminating, starting up new contracts, looking at population need. So I think the GP is going to need a lot of support skills in addition to their lead role in commissioning. (SM,EoL;6)

The change to GP commissioning

Loss of commissioning skills

With the change to GP commissioning and current commissioners leaving posts, participants' main concern related to the loss of commissioning skills and knowledge both generically, but also specifically related to commissioning EoL OoH care.

In general, my only problem I think, moving from the structure we've got at the moment to the new structure is that the reason we have progressed so much, [is] that we've got a strong EoL Care Team ... in the SHA, and then we've got EoL Care Leads in each PCT Team, and of course all of that's going ... So my main concern will be that all the work that's gone to date, it's lost, because all the people leave, and then GPs have to start again. (SM,EoL;6)

It was deemed essential that some mechanisms were put in place to pass the knowledge from current commissioners to the GP commissioners.

I think it is that context of working with commissioners to ensure that as much as possible the lessons have been learned and they are understood and shared across whichever organisations are going to carry the responsibility for it. And it would be very easy to say "well it is not going to be our problem but actually most

of us who work here have worked in a system that [we] inherited". Because it is only five years ago since we did this previously ... we have got a lot of experience in what could get lost and could go wrong. So we were very, very clear that we want to ensure that the new commissioning consortia have all that information and have access to that. (SM,OoH;3)

One participant described how they were addressing this by setting up a stand-alone EoL care hub which would include EoL care leads from the PCT, local authority as well as providers, to ensure that the knowledge and skills remain intact and accessible. However for some SHAs, addressing this loss of commissioning knowledge and skills was proving more problematic as identifying the key staff responsible for OoH and/or EoL commissioning was challenging with staff leaving posts.

The prioritisation of EoL care by commissioners

The impact of the change on OoH EoL care provision was seen as dependent on how EoL care was prioritised by future GP commissioners. Again participants reported mixed feelings. Those who were generally positive about the change thought EoL care would remain a priority firstly, because as EoL care will continue to be included in the KPI in the next NHS Operating Framework, it would remain on the GP commissioners' agenda, and secondly, their perception that GP commissioners, as clinicians responsible for EoL patients' care both in and out of hours, would consider OoH EoL care provision a priority both in terms of service requirements but also in monitoring the quality of service provision.

Monitoring performance during and after the transition

Concerns about the quality of service provision both during and after the transfer to GP commissioning were raised. Some were concerned that the quality may be compromised with potentially increased competition from providers, and an aggressive procurement process. One participant in particular described how their SHA was taking a very active role in monitoring performance (for example patient experiences, levels of complaints) both during and after the transition to ensure continuity of services was a key priority and had contingency plans in place once the transfer had occurred.

We have made sure that all the staff that are transferring maintain the continuity. We have done a number of workshops now where with the receiving Trust. We have gone through due diligence with the governance so we have shared with them what is happening. We have shared with the issues over the past two years - it was quite comprehensive. I couldn't fault it. I don't know whether it will continue that way but what they have done they have spent time making sure that this continuity would be retained that people had the same roles. (SM,OoH;4)

Possible benefits resulting from the change to GP commissioning

While participants were hopeful that the change would not affect patient care, it was notable that they were quite reticent in their comments. Participants suggested EoL OoH service provision could potentially improve for three reasons. Firstly, that the choice of services may increase as providers review their current provision and consider expanding their role to become competitors in the market for EoL and/or OoH care services.

I think there will be a variety of services that they can commission from so for example, widening that market, social enterprise ... different services saying "oh we could do that, we could deliver that", which I think a lot of charities voluntary sector are doing at the moment, hospices, are really expanding their role. So you know what can they provide OoH could there be an advice line? I think everyone is looking at how do we do this differently, so we make sure we are attractive service and we are value for money and we deliver good quality care to the patients. So I think lots of people are looking at their core business at the moment and how would that be different. (SM,EoL;6)

Secondly, that the personalisation agenda would become a driver to encourage good partnership working between stakeholders and thus improve current provision as patients would become more involved in making choices about their care preferences.

I think what needs to change is, what does it look like and who needs to know what is out there in their work so they can advise the patient appropriately. How else do I see it changing? I think information to patients is going to be far greater and look very different, and clinical information based on outcomes of care. So they can start to say ok this is my choice and I want to be cared for in this place, and then when I die I want to be cared for either in this place or at home. So I think that that choice element based on clinical outcome information will be crucial for the patient, and they will put their money where their mouth is a bit more. So their involvement, I think, and the personalisation agenda for me is huge - as in it will be, we need to really, really think about the future. How we personalise the care that patients actually receive, and the plan of care that patients are going to receive. ... So I think it is going to be a lot more of a partnership work. (SM,EoL;6)

Finally, some participants were hopeful of improved integration of OoH services for EoL patients, with GP making commissioning decisions based on patients' needs. For example, one participant expected improvements specifically in respect of OoH provision in primary care.

It depends. You could see a greater integration of services. You could see the commissioning of a specific care pathway and greater integration of primary care with OoH primary care, which is essentially what we are talking about. So there are these that could well be delivered through GP commissioning. And what the GPs of this region are active workers OoH and they know the systems, [so] it may well be they may seek to improve ... coordination, so yes there may well be improved [care]. (SM,OoH;1)

Another considered that health and social care would need to integrate more effectively, to ensure more streamlined OoH EoL service provision.

I think there is going to be far more working together of health and social care in real partnership terms I don't know quite what that will look like and that throws up all sorts of issues of course but I think in order to deliver good and effective EoL care health and social care have got to do it right from the beginning. Training together, delivering together evaluating together. I just think it has got to be so much a real partnership approach to someone who is nearing the end of their lives. (SM,EoL;6)

4 RESULTS II: PCO INTERVIEW STUDY

4.1 Numerical analysis

These findings are reported in three sections. In the first, the response rate and response bias are reported. Next, the range of services provided during the OoH period in the PCOs are presented and details given on the levels and variations in availability of service provision across PCOs, (Section 2.4.6). Finally, given the current importance given to 24/7 nursing in OoH ^{26,66} the availability of services across PCOs to meet EoL patients' nursing and personal care needs OoH is described.

4.1.1 Response rate and response bias

Response rate

Table 5 reports the response rate for the PCO interview study, as well as data on selected background characteristics of PCO survey respondents. On average, the research team had 2.36 contacts with each PCO before an appropriate person to interview was identified to request their participation in the survey (260/110; range 1-5). The overall response rate was 42.8%, with 51 of the 119 PCOs approached participating in the study. The response rate from English PCOs was higher than from Scottish HBs (44.2% versus 33.3%). Forty four PCOs took part in a telephone interview (39 in England and five in Scotland) and seven responded by email (all English PCOs). Email responses were brief and further information to supplement this data was sought where available, from strategy documents and internet searches. 118 interviews were conducted within these 51 PCOs. The roles of respondents are shown in Table 5; the majority were commissioners responsible for EoL care. Where more than one interview was conducted within a PCO, the coding matrix for that PCO was completed using data from all PCO interviews.

Figure 2 shows the geographical distribution of respondents; this figure will not be published elsewhere to protect the anonymity of PCOs taking part in the survey.

Figure 2. Geographical distribution of PCOs participating in survey

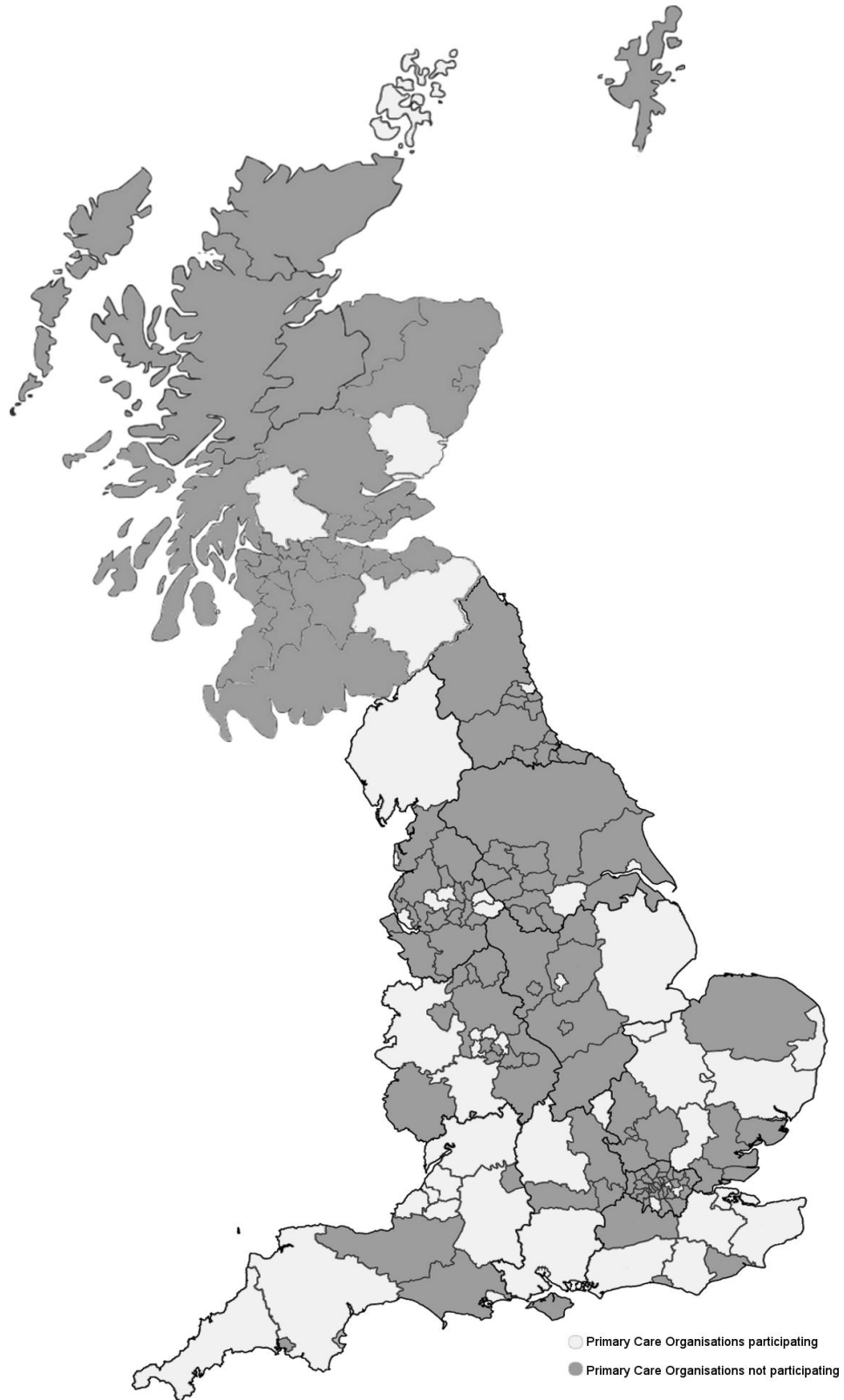


Table 5. **PCO interview study response**

	England	Scotland	Total
Initial sample PCOs identified	97	13	110
Number contacts ¹ made with PCOs prior to survey interviews	228	32	260
Number of PCOs with at least one interview:			
• Telephone interview	32	5	37
• Email	7	0	7
Total responses (%)	39 (40.2%)	5 (38.5%)	44 (40.4%)
Total number of interviews conducted with respondents in all participating PCOs	112	6	118
Respondents' backgrounds ² :			
• EoL lead commissioners	43	2	45
• OoH lead commissioners	19	1	20
• Other commissioners	32	0	32
• Others ²	18	3	21
Follow up recruitment phase	7 new invitations (3 re-invitations)	2	9 new invitations (3 re-invitations_
Respondents:			
• Telephone interview	4 new invitations (3 re-invitations)	0	4 new invitations (3 re-invitations)
Respondents backgrounds:			
• EoL lead commissioners	7	-	7
Grand total PCOs (%)	46 / 104 (44.2%)	5 / 15 (33.3%)	51 / 119 (42.8%)

Notes:

1 = Contacts were email or telephone to identify the lead individual and seek participation

2 = Others' were providers of EoL or OoH services, or Directors of a service such as Nursing or Palliative Care.

Table 6. **Selected characteristics of populations served by PCOs in England and Scotland: comparison of all PCOs with study respondents**

England	All PCOs (N=151)	Study respondents (N=46)	P (Chi ²)
Population of PCO: <i>Up to 200,000</i> <i>>200,000 - 400,000</i> <i>>400,000 - 600,000</i> <i>> 600,000</i>	19.2% 55.0% 15.2% 10.6%	8.7% 52.2% 21.7% 17.3%	<i>p</i> = 0.035* (8.62)
No GP practices in PCO: <i>Up to 30</i> <i>>30-70</i> <i>>70</i>	18.5% 58.9% 22.5%	21.7% 47.8% 31.4%	<i>p</i> = 0.166 (3.59)
Average list size in PCO: <i>Up to 6,000 patients</i> <i>6,000-8,000 patients</i> <i>> 8,000 patients</i>	39.1% 43.0% 17.9%	30.4% 41.3% 28.3%	<i>p</i> = 0.071 (5.29)
% population 'income deprived': <i>Up to 10.0%</i> <i>10.0-17.5%</i> <i>> 17.5%</i>	16.6% 49.7% 33.8%	23.9% 47.8% 28.3%	<i>p</i> = 0.507 (0.44)
% population who died at home, 2007-09: <i>Up to 18% of all deaths</i> <i>>18 -20% of all deaths</i> <i>>20 - 22% of all deaths</i> <i>>22% of all deaths</i>	15.2% 41.1% 33.8% 10.0%	13.0% 37.0% 30.4% 19.6%	<i>p</i> = 0.262 (2.80)
% cancer patient deaths at home, 2007-09: <i>Up to 0.25% cancer deaths</i> <i>>0.25% cancer deaths</i>	47.7% 52.4%	39.1% 60.9%	<i>p</i> = 0.374 (0.79)
Scotland	All PCOs (N=14)	Study respondents (N=5)	
Population of PCO: <i>up to 70,000</i> <i>70-100,000</i> <i>100-130,000</i> <i>more than 130,000</i>	13% 29% 16% 42%	20% 20% 40% 20%	n.a
No GP practices in PCO: <i>up to 15</i> <i>15-20</i> <i>20-25</i> <i>more than 25</i>	16% 29% 16% 40%	20% 20% 40% 20%	n.a
Average list size in PCO: <i>up to 4,500</i> <i>4,500-5,500</i> <i>more than 5,500</i>	29% 29% 42%	40% 40% 20%	n.a
% Population income deprived: <i>up to 11.0%</i> <i>11.0-15.0%</i> <i>more than 15.0%</i>	18% 45% 37%	20% 60% 20%	n.a

Sources: <http://www.ic.nhs.uk/statistics-and-data-collections/workforce/nhs-staff-numbers/nhs-staff-2000--2010-general-practice> [Accessed 28 Sept 11], <http://www.communities.gov.uk/publications/corporate/statistics/indices2010> [Accessed 23 Sept 11], http://www.ncin.org.uk/cancer_information_tools/eatlas/pct/atlas.html?select=Eav&indicator=i0 [Accessed 16 Dec 11], <http://www.scotpho.org.uk/profiles/> [Accessed 29 Sept 11] and www.isdscotland.org [Accessed 29 Sept 11].

Response bias

From Table 6 it can be seen that the sample of PCOs from England comprises similar characteristics to those of all PCOs in England with the exception of a slightly better response rate from larger PCOs (17% v 10%) and possibly PCOs with larger practices (31% v 22%). Therefore one cautious interpretation is that the study PCOs appears to be broadly representative of all PCOs in terms of the indicators presented, including outcomes (i.e. the % population who die at home and the % of cancer deaths at home). Chi-square tests can only demonstrate an association between variables and are dependent on the way the test is set up.

It is more difficult to place an overall interpretation on response bias for the Scottish data as here the numbers were small on all counts.

4.1.2 OoH service provision in participating PCOs

Steps 1 to 3: Identification, care planning and coordination

Data regarding OoH service provision and variation during the OoH period are reported in Tables 7, 8, 9 and 10. Table 7 presents findings on variables relating to the first three steps in the Department of Health EoL care pathway - 'Identification', 'Care planning' and 'Coordination of care' (see Table 2). Most PCOs reported that GP practices in their PCOs used systems to identify patients at the EoL: two thirds thought these systems were inclusive of all relevant diagnoses and most practices regularly updated their records. A fifth were more critical of the systems in place in their PCOs, recognising that, for example, at least some of the practices focused on cancer, more patients should be being identified, and that registers were not updated regularly. When respondents who were unable to answer questions about these systems were excluded, 75% of PCOs reported that practices in their PCOs had inclusive and regularly updated systems.

Just over half of PCOs reported that local practices used fax or email to notify OoH services about patients at the EoL, and in 35% at least some practices used electronic systems to share information. However, in only 18% of PCOs did GP practices and OoH organisations share the same electronic systems, with a further 22% planning to do so in the foreseeable future. The ambulance service or paramedical workers were able to access at least some information about these patients in 47% of PCOs, with a further 24% of PCOs having plans to enable this: systems in PCOs included patient-held records and 'message in a bottle' schemes, as well as electronic access to records and care plans.

Almost all respondents reported that there were local arrangements for planned access to medication during the OoH period for EoL patients. In three fifths of PCOs there were mechanisms in place to enable medication to be stored in the patient's home. In terms of emergency access, a majority of PCOs (71%) reported emergency medication

access was consistently available 24/7 via a route other than GP OoH such as access to pharmacies in GP OoH centres, community or acute hospitals or via rapid response services. In terms of emergency access to equipment, most PCOs had some availability OoH with 43% having systems in place for 24/7 access; this was often via the DN. Two fifths of PCOs reported that there was some system available within the PCO to coordinate care for EoL patients.

Table 7. **Variation in reported availability of mechanisms supporting patient identification, care planning and co-ordination in participating PCOs (n=51)**

EoL Care Strategy's Care Pathway	Variable	Level of availability	Frequency (%)
Step 1	GP identification of EoL patients	1. Yes identification in place for all diagnoses & most practices update register regularly	34 (66%)
		2. Partial identification available but not inclusive of all diagnoses or standard across practices	10 (20%)
		3. Limited identification of EoL patients	1 (2%)
		4. No identification system in place	0 (0%)
		5. Unknown	6 (12%)
Step 2	GP/OoH share electronic notification	1. Yes	9 (18%)
		2. No	24 (47%)
		3. Planned	11 (22%)
		4. Not recorded	6 (12%)
		5. Unknown	1 (2%)
	GP OoH notification	1. Fax or email system across some providers	29 (56%)
		2. Electronic system across some providers	18 (35%)
		3. No formal system	0 (0%)
		4. Not recorded	4 (8%)
		5. Unknown	0 (0%)
	Emergency services knows OoH status	1. Yes	24 (47%)
		2. No	10 (20%)
		3. Planned	7 (24%)
		4. Not recorded	10 (20%)
		5. Unknown	0 (0%)
	OoH enter information to/use electronic notification	1. Yes	28 (55%)
		2. No	1 (2%)
		3. Planned	6 (12%)
		4. Not recorded	15 (29%)
		5. Unknown	1 (2%)
	Medication Access – planned	1. Mechanisms in place and medication stored in patient home across most providers	31 (61%)
		2. Mechanisms in place but NOT stored in patient home	5 (10%)
		3. No mechanism apart from GP OOH	0 (0%)
		4. Variations in mechanisms across some providers	12 (23%)
		5. Unknown	3 (6%)
	Medication Access – emergency	1. Consistent mechanisms in place during OoH across most providers	36 (71%)
		2. Mechanisms for partial OoH period	6 (12%)
		3. Mechanisms in place for limited OoH	0 (0%)
		4. Other variations	6 (12%)
		5. No emergency access OoH	1 (2%)
		6. Unknown	1 (2%)
	Equipment Access – emergency	1. Consistent mechanisms in place during OoH across most providers	22 (43%)
		2. Mechanisms for partial OoH	10 (20%)
		3. Mechanisms for limited OoH	4 (8%)
		4. Other variations	10 (20%)
		5. No emergency access OoH	3 (6%)
		6. Unknown	2 (4%)
Step 3	Systems for coordination	1. Yes, in place 2. No, not in place 3. Unknown	21 (41%) 25 (49%) 5 (10%)

Step 4. Service Delivery Out of hours

Tables 8, 9 and 10 present findings on the reported availability of OoH services for patients at the EoL in participating PCOs in different

settings. Table 8 reports on primary care services; Table 9 on other services and Table 10 on services to support family carers.

Table 8. Variation in reported availability of primary care services delivering OoH care to EoL patients, N=51

Level of availability	GP OoH	District Nursing	Specialist Palliative Care community nurse /team	Rapid Response
24/7 cover evenly across PCO	48 (94%)	25 (49%)	2 (4%)	9 (18%)
Partial OoH cover across PCO	1 (2%)	16 (31%)	5 (10%)	12 (23%)
Limited OOH cover across PCO	0 (0%)	2 (4%)	14 (27%)	0 (0%)
Varied OoH cover across PCO	0 (0%)	6 (12%)	0 (0%)	2 (4%)
Available but OoH coverage unknown	0 (0%)	1 (2%)	1 (2%)	3 (6%)
Unavailable any period	0 (0%)	1 (2%)	0 (0%)	23 (45%)
Unavailable OoH period	0 (0%)	0 (0%)	17 (33%)	1 (2%)
Unknown	2 (4%)	0 (0%)	12(24%)	1 (2%)
Total	51 (100%)	51 (100%)	51 (100%)	51 (100%)

Table 8 shows the range of primary care services reported to be available during the OoH period across PCOs. GP OoH and district nursing were available 24/7 in approximately half or more of the PCO sample: when respondents who did not know about these services were excluded, these services were available 24/7 in 98% and 49% respectively. A further 47% of PCOs reported partial or limited OoH availability of district nursing in their PCO, or that it varied across the PCO. Rapid response services were reported to be less widely available with 18% of PCOs reported to have these services available 24/7, 27% reported to have partial, or varied provision, and 45% reported to have no provision during the OoH period. SPC nurse/teams were reported to be most limited in their availability OoH, with 37% of PCOs reporting limited or partial OoH provision, and 33% of PCOs reporting that the service was not available OoH: when respondents who did not know about the availability of this service were excluded, this service was available 24/7 in only 5% of PCOs.

Table 9. **Variation in reported availability of other services delivering OoH care to EoL patients in participating PCOs (n=51)**

Reported availability	Hospice at Home	Patient Telephone advice	Professional Telephone advice	24hrs Palliative Care Admission
1.24/7 cover across PCO	12 (23%)	27 (53%)	33 (65%)	12 (23%)
2.Partial OoH cover across PCO ¹	6 (12%)	1 (2%)	3 (6%)	8 (16%)
3.Limited OoH cover across PCO ²	0 (0%)	0 (0%)	0 (0%)	1 (2%)
4.Varied OoH cover across PCO	2 (4%)	2 (4%)	0 (0%)	1 (2%)
5.Available but OoH coverage unknown	5 (10%)	2 (4%)	2 (4%)	8 (16%)
6.Unavailable 24/7	21 (41%)	13 (25%)	5 (10%)	3 (6%)
7.Unavailable OoH period	1 (2%)	1 (2%)	1 (2%)	2 (4%)
Unknown	4 (8%)	5 (10%)	7 (14%)	16 (31%)
Total	51 (100%)	51 (100%)	51 (100%)	51 (100%)

Table 9 presents the reported availability across participating PCOs of hospice at home services, patient telephone advice OoH, professional telephone advice OoH, and 24-hour palliative care admissions. Patient telephone advice and professional telephone advice were available 24/7 in half or more of the PCO sample: when respondents who did not know were excluded, these services were reported to be available 24/7 in 59% and 61% of PCOs respectively. In contrast, hospice at home was reported to be available 24/7 in 25% of PCOs and 24-hour palliative care admission in 34%, excluding PCOs where respondents did not know about these services.

Table 10 shows the range of night sitting services reported to be available during the OoH period across PCOs, to support family carers. Excluding PCOs where respondents did not know about availability, planned night sitting services provided by generalists available for all patients including EoL patients were reported to be available 24/7 evenly across the PCO in 29% of PCOs, and to have more varied availability in terms of times or geographical eligibility or both, in a further 56%. Planned night sitting services specifically dedicated to EoL

patients were reported to be available 24/7 in 16% of PCOs, with more varied availability in a further 53% of PCOs. Emergency night sitting services were reported to be available 24/7 in 6% of PCOs with more varied availability in a further 36% of PCOs.

Table 10. **Variation in reported availability of night sitting services to support family carers in participating PCOs (n=51)**

Reported availability	Night Sitting Planned (generalist)	Night Sitting Planned (dedicated) ^{viii}	Night sitting Emergency (generalist)
24/7 cover across PCO	12 (23%)	8 (16%)	3 (6%)
Partial OoH cover across PCO	16 (31%)	20 (39%)	8 (16%)
Limited OoH cover across PCO	0 (0%)	0 (0%)	0 (0%)
Varied OoH cover across PCO	2 (4%)	4 (8%)	0 (0%)
Available but OoH coverage unknown	5 (10%)	3 (6%)	10 (20%)
Unavailable any period	6 (12%)	16 (31%)	3 (6%)
Unavailable OoH period	0 (0%)	0 (0%)	0 (0%)
Unknown	10 (20%)	0 (0%)	27 (52%)
Total	51 (100%)	51 (100%)	51 (100%)

Services provided by less than one in five PCOs.

Some services were rarely provided and have not been included in the previous tables. These rarer services are shown in Table 11.

^{viii} Dedicated services are provided exclusively for palliative and EoL care patients, but are not necessarily staffed by health professionals whose focus of work is in this field and who have a specialist qualification in palliative care: they do not, therefore, necessarily meet the criteria for SPC services

Table 11. **Services reported to be available in less than one in five PCOs.**

OoH service reported to be available to EoL patients in < 20% of PCOs (n=51)	Frequency (%)
<i>Generalist services:</i>	
Community Matron – generalist	6 (12%)
Community Palliative Care Matron	1 (2%)
Community Palliative Care Team/support Team	8 (16%)
Hospital at Home	3 (6%)
Dedicated EoL Rapid Response	5 (10%)
Patient Telephone Advice (generalist provider)	2 (4%)
Professional Telephone Advice (generalist provider)	4 (8%)
EoL diversion beds	5 (10%)
<i>Specialist services:</i>	
Dedicated EoL Rapid Response	6 (12%)
Night Sitting – emergency (specialist)	2 (4%)

N

Notes: *Responses do not include missing data.

Analysis of provision of OoH nursing and personal care variables

As described in the Methods (Section 2.4.6), in order to understand better the nature of nursing and personal care provided to patients at the EoL in each PCO, an additional abstraction and coding exercise was undertaken to establish whether five key services were provided in each PCO, regardless of the name used by the service, whether the service was dedicated for EoL patients or available to a wider sector of the population. For example, we combined rapid response services provided by generalist services (Table 8) with those dedicated for EoL (Table 11), as well as services which had a different label but where rapid response was a clear component.

Table 12 shows the reported availability of district nursing; community SPC nurses/teams; hospice at home/augmented home care services; night sitting/respice care services; and rapid response services. No attempt has been made to judge the extent to which each service is available OoH in each PCO: each service is coded as available or not. The provider is also listed.

Table 12. **Reported availability in PCOs of OoH nursing and personal care variables (n=51)**

	District nursing	Specialist palliative care nurse /team	Hospice at Home/augmented home care	Night sitting / respite care	Rapid response*
Availability:					
Available	50 (98%)	22 (43%)	34 (66%)	50 (98%)	33 (65%)
Not available	1 (2%)	17 (33%)	15 (29%)	0 (0%)	15 (29%)
Unknown	0 (0%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)
Not recorded	0 (0%)	12 (24%)	2 (4%)	1 (2%)	3 (6%)
<i>Total</i>	51 (100%)	51 (100%)	51 (100%)	51 (100%)	51 (100%)
Provider:					
NHS	50 (100%)	5 (23%)	7 (20%)	2 (4%)	23 (70%)
Independent	0 (0%)	12 (55%)	18 (53%)	35 (70%)	4 (12%)
NHS & Independent	0 (0%)	1 (4%)	8 (24%)	9 (18%)	1 (3%)
Social services	0 (0%)	0 (0%)	1 (3%)	3 (6%)	1 (3%)
NHS & Social services	0 (0%)	0 (0%)	0 (0%)	1 (2%)	2 (6%)
Provider not recorded	0 (0%)	4 (18%)	0 (0%)	0 (0%)	2 (6%)
<i>Total</i>	50 (100%)	22 (100%)	34 (100%)	50 (100%)	33 (100%)

Note: * this is broader definition of rapid response including all generic and dedicated services as described in Methods.

It can be seen from Table 12 that almost all PCOs provide district nursing and night sitting/respite services to meet EoL patients' OoH nursing and personal care needs. As has already been shown, the extent to which these services were available throughout the night and across PCO 'patches' was variable, and these figures therefore represent the 'best' situation (Tables 8 and 10). Hospice at home/augmented home care services were each available to two-thirds of PCOs, while Specialist Palliative Care nurses had some OoH availability in two-fifths of PCOs. Table 12 also shows the significance of the role played by the independent / voluntary sector in providing these services. They were reported to provide more than half of Specialist Palliative Care, hospice at home and night sitting services. Providers were usually independent hospices, Marie Curie Cancer Care, Cross Roads or local charities. In contrast, this sector provided only a third of rapid response services.

Table 13. **Comparison of OoH service provision by provision of district nursing service out of hours, (n= 50)**

	District nursing = '1' (i.e. available 24/7 across PCO)				District nursing = '2', '3', '4' or '5' (i.e. some OOH provision but less than full coverage)			
	availability of service				availability of service			
	24/7 cover	Some OOH cover	No OOH cover	Not known ^b	24/7 cover	Some OOH cover	No OOH cover	Not known ^b
Specialist palliative care nurse/team	2 (8%)	9 (36%)	14 (56%)	(0)	0 (0%)	11 (44%)	14 (56%)	(0)
Hospice at Home	7 (28%)	12 (48%)	6 (24%)	(0)	5 (23%)	9 (41%)	8 (36%)	(3)
Patient Telephone advice	9 (36%)	11 (44%)	5 (20%)	(0)	17 (74%)	2 (9%)	4 (17%)	(2)
Professional Telephone advice	15 (60%)	5 (20%)	5 (20%)	(0)	17 (81%)	2 (10%)	2 (10%)	(4)
24hrs Palliative Care Admission	6 (24%)	7 (28%)	12 (48%)	(0)	6 (35%)	9 (53%)	2 (12%)	(8)
Night Sitting Planned (generalist)	8 (33%)	11 (46%)	5 (21%)	(1)	4 (22%)	12 (67%)	2 (11%)	(7)
Night Sitting Planned (dedicated)	5 (21%)	18 (75%)	1 (4%)	(1)	3 (12%)	16 (64%)	6 (24%)	(0)
Night sitting Emergency (generalist)	2 (25.0%)	5 (62.5%)	1 (12.5%)	18	1 (6.2%)	13 (81.3%)	2 (12.5%)	9
Rapid response	3 (12%)	19 (76%)	3 (12%)	(0)	6 (24%)	6 (24%)	13 (52%)	(0)

Notes:

^a Information missing in one PCO

^b Percentages excluded 'not known's

The Department of Health EoL Strategy in 2008 recommended that PCOs without 24-hour district nursing should provide rapid response services as an alternative interim measure. Table 13 therefore explores how the provision of OoH EoL services differed between those PCOs with 24-hour district nursing and those without. Statistical analysis was not employed because of small numbers and attention is only drawn to differences of 20% or more.

Excluding PCOs in whom provision was not known, PCOs without 24 hour district nursing were more likely to have both patient and professional telephone advice available 24/7 (74% versus 36%; 81% versus 60%), as well as 24 hour palliative care admissions available in at least part of the PCO (88% versus 52%) and planned generalist night sitting services (90% versus 79%). In contrast, PCOs reported to have 24 hour district nursing were more likely to report having: hospice at home services available in at least part of their PCOs (76% versus 56%) planned night sitting services dedicated for EoL patients (96% v 76%) and rapid response services (88% versus 48%). PCOs without 24 hour district nursing were more likely to report that they did not know about provision in 6 of the 9 variables in this table.

4.2 Qualitative Analysis

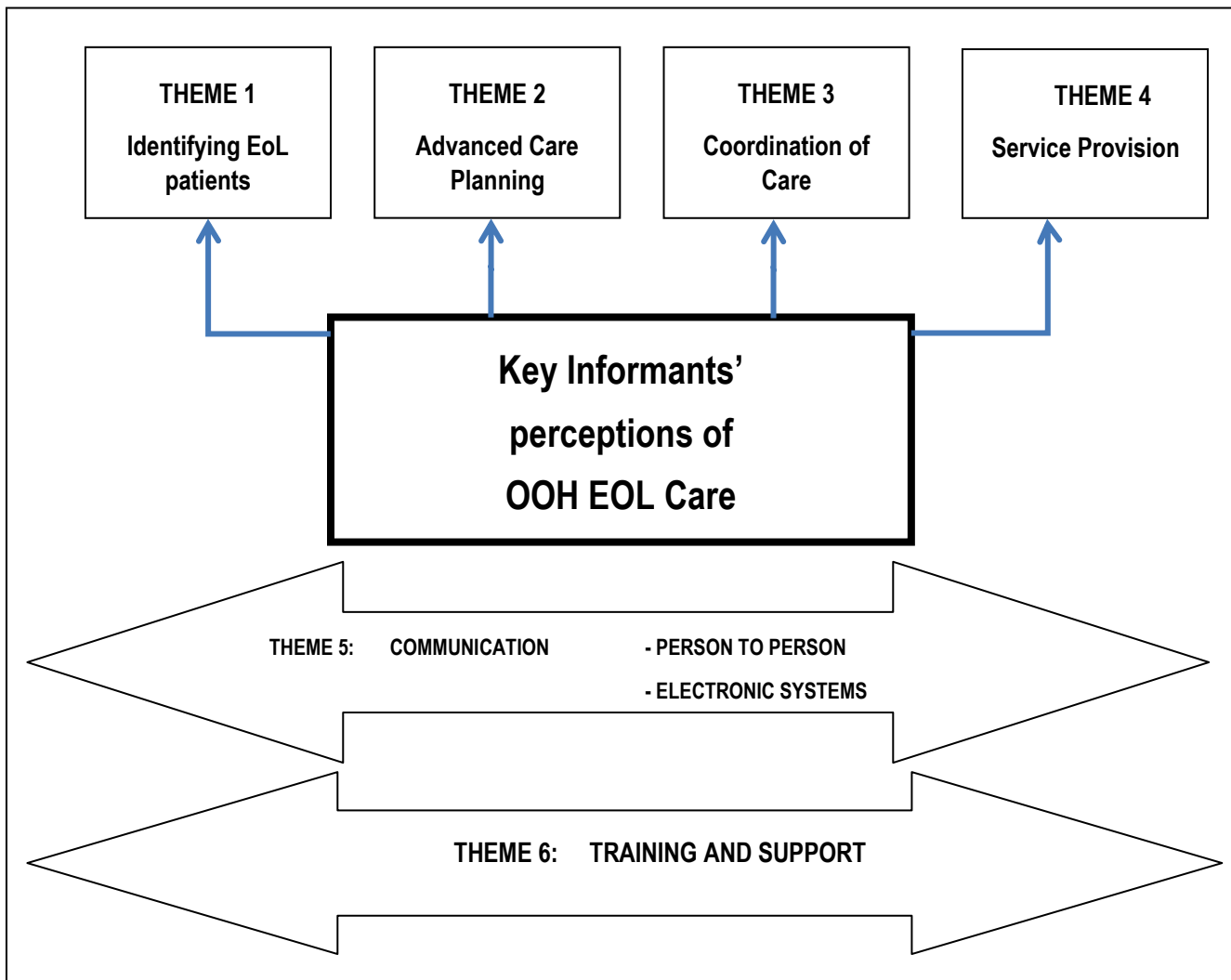
Of the 51 PCOs taking part, participants representing 44 PCOs took part in a telephone interview and participants from seven PCOs responded by email. Six of the email responses contained little or no information pertaining to this component of the PCO interview study. The qualitative analysis is therefore based on data obtained from interviews with participants from the 45 PCOs who provided adequate data.

Seven themes were identified. These are visualised in Figure 3. The first six themes relate to participants' perceptions of current OOH EoL service provision. The final theme reports participants' perceptions of the anticipated impact of GP commissioning on OOH EoL provision. Participants interviewed on behalf of PCTs in England were additionally asked to discuss this during the interview in order to gain insight into their perceptions of the proposed health reforms. Quotes to illustrate these themes are referenced in the text. To ensure anonymity of both key informant and PCO, quotations are identified using a code to represent the PCO.

4.2.1 Theme 1: Identification of EoL patients

Developing effective mechanisms for identifying EoL patients in primary care was perceived as central to providing good OoH EoL care. Many PCOs were using systems to identify EoL patients which currently had limited accessibility, such as paper based reporting, with information faxed to OoH services. Some respondents perceived this approach to be working reasonably well. However, others reported problems with paper based approaches, and noted that lack of informational continuity could hinder palliative care, for example when a hospice or ambulance service lacked access to a patient's information.

Figure 3. Diagrammatic representation of themes identified in PCO interviews



Participants noted that electronic EoL registers offered a means to address this issue. However, in most PCOs, electronic systems for identifying EoL patients used by different services varied in type and could not therefore be accessed across all EoL service providers, leading to informational discontinuity.

Every GP practice likes their own system, and you know, all our teams are based in GP practices so community care team 1 in [name of town] is not necessarily using the same system as community care team 2, because they are in two different GP surgeries; so it is challenging. (PC06)

The adoption of electronic registers which could be accessed by all EoL services during the OoH period was widely regarded as the route to address this problem. The system of this type cited most frequently by participants was the ADAstra system. Whilst interviewees noted that putting such systems into place involved considerable time, commitment and perseverance, the potential benefits to EoL care were also emphasised.

Slowly but surely implementing the EoL register, using the ADAstra system, but I stress slowly but surely ... I mean it's far from bedded down yet, because it is the most ambitious project ever ... All services can access that register ... Our huge piece of priority work is to get the register bedded down ... Use of that register will make an amazing difference. (PC011)

4.2.2 Theme 2: Advance Care Planning

The role of effective forward planning in EoL care emerged as a strong theme. Advance Care Planning (ACP) was widely regarded as an important strategy for enabling a smoother and more integrated approach to EoL care with enhanced consistency of care between in-hours and OoH provision.

Improvement means good forward planning. (PC044)

Key areas identified for improvement for ACP within their PCO related to more detailed and consistent advance planning for individual patients, including planned protocols of care and anticipatory prescribing/provision of palliative drugs. Participants noted that in situations where ACP had not been put in place or where plans had broken down, this could put considerable stress on patients, carers and health professionals. For example, one respondent cited an instance where lack of anticipatory prescribing had led to the patient's family having to make a 70 mile round trip in the middle of the night to get medication for the patient. Others reported instances of nurses having to make similar emergency journeys. Many PCOs had specific mechanisms in place to address this issue, such as 'just in case' boxes for palliative medication, and provision of palliative care equipment (e.g. syringe drivers) stored at locations which health professionals could

easily access OoH. Forward planning was perceived by many participants to be a priority area for improvement .

There are still too many surprises and more upstream planning is needed. (PCO3)

The Gold Standard Framework was widely perceived as a route towards improved anticipatory care.

We have about a 2/3 pick-up for GSF across our practices, and I think if they all actually did the Gold Standard Framework properly, then we would have much more anticipatory care than there currently is, so you would have less problems OoH. (PCO2)

Overall, respondents expressed strong support for the importance of ACP as a means of providing higher quality EoL care; albeit within a clinical setting where unexpected events could necessitate rapid changes to plans, and therefore forward planning required flexibility and could never fully anticipate every eventuality.

You can have the best plans in the world and they can all break down very, very quickly. (PCO10)

4.2.3 Theme 3: Coordination of EoL care

PCOs reported continuing challenges with integrating OoH care within the context of complex care networks involving diverse services and organisations.

Within our locality actually the providers we've got and the people that are leading those services are very good in terms of their individual knowledge and the way that they run their services, and also in terms of their willingness to engage. The problem that we're facing at the moment, that we've never really tackled, is getting these services to link in together. (PCO20)

Establishing a single point of access (SPA) for EoL patients was widely regarded as a valuable means of simplifying communication, co-ordinating care and avoiding duplication of provision between different services. Some PCOs already had SPAs in place, others did not, but regarded this as a priority for future improvement.

A key improvement would be to have a single point of contact for patients and families and a single mechanism for initiating a rapid response ... There are lots of services in [our PCT] but more integration is needed. (PCO3)

One of the problems in [name of PCO] is that we have duplication in what we have and what we do between our hospice provider and between our community nursing staff. So one of the core angles of my job is to pull these developments together, so you perhaps have a single point of access, but a method of being able to triage and facilitate that care that patient needs rapidly, without duplication. (PCO20)

Other strategies for addressing this issue included employing a dedicated health professional, for example a specialist nurse, to liaise between different services/ care providers and, as discussed in the previous theme, the use of electronic databases to facilitate informational continuity between services.

4.2.4 Theme 4: Service Provision

Whilst communication and co-ordination between service providers were widely perceived as priorities for improvement, the scope and content of service provision itself were raised as issues by some participants. Two specific aspects of service provision were highlighted.

Provision of 24/7 care

Given the variety of services, organisations and sectors involved in the 'jigsaw' of OoH EoL care, it is not surprising that the provision of 24/7 care was viewed as a continuing challenge. Notwithstanding, some PCOs reported that it was beginning to improve.

In the last year we made progress to committing 24/7 care; 18 months ago this wasn't the case and they didn't provide 24/7. So good it is acknowledged and moving there. Nothing [has] been audited yet though. (PCO11)

Other participants reported that more action was required and increased resources were essential to address the challenges of 24/7 service provision.

And I think our biggest other problem is the lack of 24 hour cover for district nurse services, and that will require money to address that ... I think that fits in across every aspect of community care, as well as EoL care, because if you don't have that consistency of cover, then nothing else can kind of be hung on it really. (PCO2)

Inequality of access of services

Equality of access was described as an important area for improvement.

We need to make sure services are equitable and standardised. (PCO16)

Key inequalities identified included geographical inequalities of access within the same PCO (for example due to old PCO boundaries) as well as inequalities of access between cancer patients and those with diagnoses other than cancer. Some participants highlighted the need to address this disparity.

Last 2 years [we have] focused on improving services for EoL, especially non-cancer; this was led by EoL clinicians and [the] PCT agreed to support 24/7 community care. [Our] Main priority is to improve non-cancer care. (PCO8)

Those who discussed this issue explained the reasons for inequality were a result of both poor communication from staff, with patients with diagnosis other than cancer not getting to hear about services that they

were eligible to access, and also resulted from inadequate identification of these patients as being at the EoL.

Care of non-cancer is not so good because of difficulty in identifying that they are palliative, so seen as treatable- but education should help. (PCO26)

Seven of the PCOs recruited in this study were identified during the numerical analysis to be proactive in addressing this issue, making this a priority for their PCO. The role of communication in effective care co-ordination was reiterated throughout the interviews, and is discussed in Theme 6.

4.2.5 Theme 5: Education and Training

Education and support, both for health professionals and carers emerged as a key factor in terms of ensuring quality service provision. Many respondents reported training initiatives which they felt were working well in their PCO, while others highlighted a need for improvement. In particular education and support for care home staff was highlighted. PCOs recognised the importance of addressing this.

Peer support is key. Would like to strengthen this to provide support to staff in care homes. (PCO11)

Those PCOs that had addressed educational support for care home staff described how effective they perceived it to be, reporting how care home staff keenly engaged with such training and implemented changes effectively.

Care homes, when they access training and information, they do brilliantly well. Staff are keen to learn and forward looking. (PCO44)

4.2.6 Theme 6: Communication

This theme was raised by participants as integral to every aspect of the care pathway, and the effectiveness of communication was seen as affecting the quality of care at all stages. Two aspects of communication were highlighted - direct person to person communication, and electronic systems.

Person to person communication

Participants noted that good communication was essential to the proper assessment and identification of the individual's needs. This could often involve a chain of communication from patient or carer, to one health professional, with information then conveyed on to a diverse range of other health professionals providing care. Where this communication chain broke down, or misunderstandings occurred, this could lead to situations where the patient's needs were misinterpreted, and the quality of care adversely affected. An example cited by one participant of this was that of an OoH triage system in which call handlers had been

trained to listen for specific 'trigger words' such as 'breathlessness' or 'gasping' when they listened to the caller, and to respond by automatically directing the patient towards hospital admission. This training had led to inappropriate admissions for some palliative patients, since, as the participant noted, these words described symptoms which could be 'normal' in a palliative care situation and thus did not indicate a need for admission.

An area particularly highlighted for improvement was communication between care homes and GPs. While some participants reported examples of good practice where GP practices and nursing homes had built close professional relationships with good communication, other participants noted more difficult situations. For example, situations were described where a single nursing home had patients registered with many different GP practices, so that staff had little opportunity to build strong channels of communication with any one GP practice. One participant described initiatives being taken to address this issue.

We're tackling it in different ways ... [we have a] care home task team ... [and an] adopt a care home project for GPs. ... Care homes patients could be registered with up to 15 different GP practices, so GPs never get to know that home well. If you have dedicated input for GP per care home, [the] register would be completed more rigorously. It would have a positive knock on effect both for GPs and for patients OOH. (PCO11)

Communication using electronic systems

As noted in Theme 1, communicating patients' EoL status and care plans across providers is vital to ensure patients receive appropriate treatment and are enabled to remain at home to die rather than be admitted to hospital if this is their preferred place of care and death. The implementation of accessible EoL registers was often seen as key to achieving this. Implementing integrated systems was thus seen as a key priority for the PCOs, especially where ambulance access to EoL patients' care plans was currently non-existent or inconsistent, which could lead to inappropriate hospital admissions. Where such systems were not in place, PCOs reported non-electronic methods of communicating this information and these included faxes from GPs to OoH services, or keeping patients' care plans in patients' homes for easy access by ambulance or other staff. However, as many participants noted, lapses in communication led to discontinuity of information which could result in inappropriate or unnecessary interventions for patients.

Not all GPs advise the OOHs services of a deteriorating patient. Patients are not identified as palliative and therefore inappropriate treatment and investigations are performed unnecessarily. This is mostly because GSF MDTs (Gold Standard Framework Multi-Disciplinary Teams) are not running as effectively as they might and that there is no register that can be accessed by all stakeholders. (PCO47)

Other communication issues highlighted included electronic registers/databases not being kept up to date, which was reported across many of the PCOs. Different geographical areas in the same PCO using different systems, as a result of old PCO boundaries, also posed further communicative complications.

4.2.7 Theme 7: Anticipating the impact of GP commissioning

Only participants representing PCOs in England were asked to express their views on the proposed change to GP commissioning, as these changes would not apply in Scotland.

Participants' comments related to two aspects of the organisational changes: the formation of PCO clusters and the creation of clinical commissioning groups resulting in GPs having more involvement in commissioning of services. The formation of PCO clusters was viewed positively by several participants; they reflected that this process provided the opportunity to review and monitor current service provision, which would highlight gaps and inefficiencies in services. Only one participant reported that service provision would not be affected in their new PCO cluster.

Some participants were optimistic about the change, reflecting that the change provided the opportunity to review current service provision and monitor existing service provision, which would highlight gaps and inefficiencies in services. Others also welcomed the opportunity to have more involvement of GPs in service provision. Increased GP support for EoL care was described as ultimately focusing more resources on EoL care provision. These PCT interviewees appeared to be confident that EoL care would remain a high priority in the new CCG structure. Not all participants however, were confident that EoL care would be considered a priority. Some participants were concerned services could be cut and/or the quality of OoH EoL services reduced because of a lack of consensus on which services to prioritise within the new NHS structures.

My biggest fear is that they will reduce the commissioning down so much, ... all these pieces of work take a huge amount of time and effort and energy to put in place. Anything that crosses over organisations needs a clear strategy across the pathway. (PCO10)

Some participants suggested that the tendering process might influence what OoH EoL services would be provided, and were concerned that this could lead to a reduction in service quality.

Other issues raised included a possible impact on the integration of services. Whilst one PCT described how the change would improve integration, others were concerned that services would become more fragmented. Potential reduction in service provision was also a significant concern for two reasons. One PCT feared a dedicated EoL coordinator post would be lost, and therefore EoL care would not be

prioritised as highly if EoL care was managed alongside other services. It was also suggested that changes to boundaries could result in inequality of access and poor coordination of services.

GP consortia go across county boundaries so that likely to be an issue. (PCO19)

Prioritising EOLC is a real issue. Potentially each cluster could prioritise different issues, so could lead to inconsistent services within a PCT, [and] so loose coordination. [This is a] real possibility if [there are] different systems with OoH [services]. If [they] don't have consistent cover then it will continue to be a problem. (PCO2)

Other participants voiced concerns that during the transitional phase of major organisation change, organisational disruption and uncertainty about the future could have a negative impact on the ability or confidence of organisations and services to plan for future service provision or to adopt initiatives to improve services. A particular concern was the effect of anticipated organisational changes on any initiatives which required cross-organisational collaboration.

My biggest fear is that they will reduce the commissioning down so much ... all these pieces of work take a huge amount of time and effort and energy to put in place. Anything that crosses over organisations needs a clear strategy across the pathway. (PCO10)

5 RESULTS III: Expert, and 'Virtual' User, Panels

5.1 Expert Panel

5.1.1 Overview

As outlined in Section 2.5.3 the research team summarised the PCO interview data for each PCO in a 'traffic light form', which showed how well the PCO was judged to be doing in terms of its mechanisms for identifying patients at the EoL, on advance care planning, and on service delivery on EoL care. Each panel member was sent eight 'traffic light' summaries to review before the Expert Panel meeting, half of which were allocated individually and half of which were common to other panel members.

Panel members used these data to inform their facilitated discussions on variations in EoL OoH service provision across England and Scotland, and to discuss whether there was evidence of emerging models of service delivery or organisation within the data. They also used the data to consider exemplar examples of innovation, a requirement of the planned Plan II study.

The facilitated discussion also included discussion on the following three issues:

- a. Contemporary issues in generalist OoH care for people at the EoL
- b. Key attributes required of a health system seeking to provide quality EoL care
- c. Priority areas in EoL care, particularly OoH, where innovation is especially required and therefore of significant interest. The features identified by the Panel in this respect were those thought to be less commonly embedded in health systems.

As part of their consideration of models of service organisation and delivery in OoH EoL care, the Panel considered what they would consider to be 'standard' or characteristic of a typical model. This was strongly influenced by emphasis placed on developing EoL care within the NHS in the preceding three years, and specifically by the DH EoL Care Pathway. The Panel considered that, for any system to be considered to be offering 'good' OoH EoL care, it should at least demonstrate these following five features:

- A system to identify EoL patients to the OoH GP service – by fax if not completely electronic

- A patient held record or care plan held in the patient's home
- Access to medicines that have been prescribed in anticipation, for example, a 'just in case' box
- Comprehensive day time cover from services and some availability of care in the twilight period
- An advice line for professionals working in the OoH period

It was agreed that there are a number of constraints that inhibit the delivery of excellent OoH EoL care but which are common in many health systems:

- A patient in crisis does not know whom to call
- Incomplete coverage or adoption of Advanced Care Planning
- Inadequate training of OoH responders
- Poor communication and continuity between services involved in caring for the patient
- Gaps in the availability of services in the OoH period
- Fragmented application of EoL tools such as the GSF, Liverpool Care of the Dying Pathway, or Preferred Place of Care tool
- Lack of timeliness of responses to unplanned or crisis events
- Lack of nurse-led verification of death

5.1.2 Prevalence of Expert Panel's characteristics of 'good' OoH EoL care in participating PCOs

In order to understand the quality of OOH EoL care from the perspective of the Expert Panel across participating PCOs, the prevalence of the five characteristics they identified as being the minimal requirement for 'good' OOH EoL care was estimated from the PCO interview survey: numerical data. How these characteristics were operationalized within the dataset is given in Table 14, together with the number and identification number of PCOs meeting each standard.

Although some individual components, in particular, systems for GPs to notify OoH services about EoL patients, were common, it is notable that the proportion of PCOs which had all of these characteristics was considerably lower (13%).

Table 14. **Prevalence of Expert Panel's characteristics of 'good' OoH EoL care in participating PCOs**

Expert Panel's component standards	Numerical variable, and codes used to indicate standard met	Frequency of PCOs attaining standard	PCO attaining standard
A system to identify EoL patients to the OoH GP service	GP OoH notification = '1' (i.e. system is fax or electronic)	47 (91%)	1, 2, 3, 4, 5, 6, 7, 9, 10, 11, 12, 13, 14, 15, 16, 17, 18, 19, 20, 21, 23, 24, 25, 26, 27, 28, 29, 30, 31, 32, 33, 34, 35, 38, 39, 40, 41, 42, 43, 44, 45, 46, 47, 48, 49, 50, 51
A patient held record or care plan held in the patient's home	Emergency services know OoH status = '1' (i.e. record/plan is available)	24 (47%)	1, 5, 6, 10, 12, 13, 15, 16, 17, 19, 21, 24, 26, 27, 29, 31, 34, 35, 38, 39, 40, 41, 45, 46
Access to medicines that have been prescribed in anticipation (for example 'just in case box')	Medication Access - planned = '1' (i.e. systems such as 'just in case' boxes available across PCO for whole OoH period)	31 (61%)	1, 2, 3, 4, 5, 6, 8, 10, 11, 14, 15, 17, 18, 19, 21, 24, 25, 26, 27, 28, 30, 35, 36, 38, 39, 40, 42, 43, 44, 45, 47
Advice line for professionals working in the OoH period	Professional Telephone advice = '1' (i.e. available across PCO for whole OoH period)	33 (65%)	1, 2, 4, 5, 7, 8, 9, 10, 11, 12, 13, 15, 16, 19, 23, 24, 25, 26, 27, 28, 30, 32, 33, 34, 35, 37, 38, 44, 45, 46, 47, 49, 51
Comprehensive day time cover from services and some availability of care in the twilight period	District nursing = '1' or '2' (i.e. service is available across the PCO for whole OOH period or partial to cover twilight hours)	41 (80%)	2, 3, 5, 6, 7, 8, 10, 11, 12, 13, 14, 16, 18, 19, 20, 21, 22, 23, 24, 25, 27, 28, 29, 30, 31, 33, 34, 36, 37, 38, 39, 40, 41, 42, 43, 44, 45, 47, 48, 49, 50
Meeting all 5 standards		7 (13%)	5, 10, 19, 24, 27, 38, 45
Meeting 4 of 5 standards		20 (39%)	1, 2, 6, 11, 12, 13, 15, 16, 21, 25, 26, 28, 30, 34, 35, 38, 39, 40, 44, 47

5.1.3 Innovation in OoH EoL care: Expert Panel's views

In addition to discussing the basic characteristics of 'good' OoH EoL care, the Expert Panel also discussed areas where innovation was particularly important, or might be indicative of a PCO which was succeeding in tackling some of the constraints it had identified to high quality OoH EoL care. This part of the Expert Panel's discussions was particularly pertinent to Phase II of this study, but is also relevant to the

aims of this research as it provides expert opinion relevant to both future commissioning decisions, and to the direction of future research. They, together with the remainder of the Expert Panel discussion, have contributed to the development of the research's theoretical propositions.

The five areas identified by the Panel were as follows:

1. Innovation in identifying EoL patients and ensuring that there is comprehensive information sharing in place to support identification across a range of relevant providers in and out of hours. This could be whole system adoption of a register or another mechanism.
2. Innovation in ambulance responses where there are established mechanisms for the ambulance service to support patients to remain in their usual place of residence.
3. Innovation or evidence of an unusually proactive approach to managing EoL care by the OoH GP provider. This may link to how the interface between these services and 'in hours' GP services is managed successfully. There may be very good specifications in place for GP roles in and out of hours in respect of EoL care.
4. Evidence of strong integration of care homes with the EoL system, for example the adoption of appropriate EoL tools such as advanced care planning and consideration of do not attempt to resuscitate protocols, in care home patients.
5. Innovation by specialist palliative care services where this improves system wide management of EoL care.

5.1.4 Example of Innovation

The SHA interview data and PCO interview survey: qualitative data were read systematically by SB and JAH to identify examples of innovation in the five areas identified by the Expert Panel. Innovations in other areas were also identified and reported. These included innovation in community nursing, co-ordination and education and training. These are presented along with innovations around the five areas highlighted by the Expert Panel. Examples in some areas duplicate information provided in quotes in previous chapters, but are brought together here to illustrate the innovations underway in this area of service organisation and delivery.

Innovations in OoH identification and information sharing

Identifying patients at the EoL with diagnoses other than cancer is often particularly challenging because of prognostic uncertainty. A palliative care plan was therefore developed in one Health Board to address this problem. This enabled patients with chronic progressive illnesses to be automatically linked to the GSF, even if at that time it was not clinically

possible to define them as being at the EoL. This plan was accessible to providers during the OoH period so that, if a patient required care during the OoH period, the provider could access their care plans along with the trajectory of their illness and thus be alerted to the appropriate care required at that point in time depending on the patients' current health status.

The Expert Panel regarded the current 'gold standard' approach to identifying EoL patients across sectors to be using electronic systems that were rolled out across the whole PCO using locality or EoL registers (England) or, in the case of Scotland, the electronic palliative care summaries (eCPS). Good examples were identified where the use of such registers enabled OoH providers to access information about EoL patients, because they are electronically accessible across the range of OoH providers, i.e. GP and community OoH services, ambulance, acute care, hospices, NHS 24 (Scotland); and they contain full care plans. Additionally such systems were audited regularly to improve the consistency of records by an EoL care facilitator or a Macmillan GP facilitator.

Where regions did not have electronic systems in place to enable identification of patients, paper based systems were employed. Good practice here was identified as faxing updates to the ambulance service daily, and ensuring that flagging EoL patients was a two-way process across sectors. Commonly, the GP practices were seen to be solely responsible for completing and communicating records to report EoL patients to the GP OoH service, ambulance and other providers. In some PCOs, it was notable that other services (such as SPC services in both the acute sector and hospice, as well as the GP OoH services) were reciprocating and they alerted GP practices about EoL patients on their "books".

Innovations in Ambulance Responses

The Expert Panel considered innovations in ambulance response where there are established mechanisms for the ambulance service to support patients to remain in their usual place of residence.

Electronic information systems often did not include ambulance and emergency services. A common approach to increase access to information and to attempt to avoid unwanted hospital admissions was the use of patient held records which ensured all pertinent information was accessible for any health care profession visiting the EoL patient's home. This approach relies on the professional asking the patient about the care plans or for the patient to tell them; this does not always work. Nevertheless, it was felt to be particularly important that the ambulance crew had some access to patient care plans when they were called out in an emergency so that they could quickly ascertain patient wishes. Flagging systems were reported that identified EoL status, DNAR and/or PPOC/PPOD, and, in addition, included a flag to confirm that patient-held

records are available at the patient's home for the crew to review, and, contact details of the patient's GP/DN if care plans were not at the patient's home. This enabled ambulance crew to speak to the patient's key worker before they made a decision to take the patient to A & E to reduce unwanted admissions.

Where there were limitations with electronic transfer of information, one particular innovation was reported frequently. The use of a "Message in a Bottle" system was seen as a cheap way of providing ambulance crew with some information about the patient. This is a crude version of patient-held notes. A green cross is placed on the patient's doorstep or a sticker is placed on the front door to tell the ambulance crew that a bottle is available in the patient's fridge which includes their care plans (including DNAR) and a list of their medication. This initiative has been funded by the Lions Club around the UK.

In addition to these innovations, to help ensure ambulance crews have at least some information on patients at the EoL, there are also examples of initiatives which can provide them with clinical advice on the patients, again with the aim of preventing unwanted admissions. These include, firstly, a clinical desk at the ambulance call centre. Clinical staff at the desk review ambulance calls in real time to see if another response is appropriate for EoL patients rather than admission to A & E. Secondly, there are systems whereby, when an ambulance is called to a patient, once the ambulance crew have assessed the patient, they call a dedicated phone number at the GP OoH service (who agree to respond promptly) to seek advice about admission if they consider it could be preventable. This service is not dedicated to EoL but is perceived to be a cost effective approach to reduce admissions.

There are also examples of schemes to facilitate the rapid discharge home of EoL patients who are admitted to hospital via A & E. For example, a pilot scheme to ensure a rapid discharge for EoL patients was set up in one PCO by coordination of the intermediate care team with the ambulance crew. If an ambulance crew brings an EoL patient into hospital but their PPOD is home, the intermediate care team will arrange for the patient to be taken back home by the ambulance crew within two hours and set up the appropriate nursing cover and equipment. In another PCO, they have provided a dedicated palliative care ambulance to return patients from hospital to their home/care home within a two-hour period. The ambulance crew are trained to care for EoL patients.

Innovations in GP OoH care

The Expert Panel considered PCOs should proactively seek approaches to manage EoL patients by the GP OoH provider. This may link to how the in and out of hours GP service is managed. A number of good examples to support this were identified.

Some PCOs prioritised EoL patient calls at triage. Although this was not available in most PCOs, who instead triaged patient calls on the basis of clinical need rather than clinical diagnosis, prioritising EoL patients was being achieved in several ways. For example: a direct and dedicated telephone number for EoL patients to contact which by passes the call handler and direct them to clinical staff within minutes regardless of their clinical problem. A "Green card system" was also used in one PCO, where patients/carers were given contact details for direct access to a clinician OoH to keep at home. An audit in one PCO identified that using a EoL dedicated direct line had been effective in reducing inappropriate hospital admissions. One PCO reported the innovative provision of a similar fast track number for care homes too again as a means to ensure a reduction in inappropriate hospital admissions.

Where a direct line was not in place, some PCOs reported prioritising EoL patients in different ways. The most common method was prioritisation by the call handler when identifying EoL patient status. The patient would receive a quick telephone response from the GP on call. In one PCO, the call handlers also had the ability to automatically book a home visit prior to passing the message to the GP to ensure a rapid response; and in some PCOs OoH DN's are given emergency nurse practitioner training to triage and pick up GP calls. Where PCOs did not specifically prioritise EoL patients at triage, to ensure that the patient or carer got the appropriate help, call handlers in some PCOs would ensure that the call went through to their key worker, if available, or if not to the most appropriate person.

Different models of GP OoH service provision were described which were thought to impact positively on EoL OoH care. Examples were given, for instance, of generic services which were thought to enable EoL patients to remain in their PPOC. These included GP units working in primary care units within A & E, which were thought to be able to ensure that EoL patients do not get admitted to hospital if their PPOC was at home; and GP-led wards based in community hospitals that enable EoL patients to be correctly assessed based on their care preferences.

A number of service developments were described which were designed to address EoL patient and family carers' nursing, personal care and support needs in the night, as well as their medical needs. These consisted of variously constituted multi-disciplinary teams with, for example, GPs (ideally local GPs who knew the patients and local systems), qualified and unqualified nursing and social care teams, and in some cases emergency care practitioners. The teams often had had specific training in EoL care, including call handlers. One example is a dedicated crisis response hospice rapid response service available via the GP OoH service. This pilot rapid response services is composed of a GP, palliative care nurse specialists, qualified and unqualified nurses, all based in the local hospice to give practical support where the OoH DN cannot help for both planned and unplanned needs. The team can

directly provide help or can coordinate help via other agencies. When an EoL patient calls up the GP OoH service, the GP or DN will call the crisis response team in the hospice to manage the patient's needs. The team will respond within a two hour period and will provide or coordinate urgent access medication or equipment, cover for the carer, etc. Similarly, another PCO has a dedicated rapid intervention service as part of the OoH service, staffed by a multi-disciplinarian team who provide and coordinate urgent medical and social care needs within 20 minutes and can provide care for up to six days. Another has a generalist palliative care team which coordinates the DN, social services and OoH GPs to ensure the patient has appropriate care set up. These services could also be geared specifically towards the needs of family carers within, for example, crisis response teams accessible via GP or DN OoH to send health care assistants (from social services or the voluntary sector) to deal with a carer in crisis providing personal care and support for carers until a care package is ready.

Innovations in OoH EoL care in care homes

The Expert Panel and research participants discussed particular problems with advanced care planning in care homes. This was felt to be a particular issue because patients in care homes are often covered by multiple GP practices and also because DNs may not do home visits to patients residing in care homes. Employing a dedicated GSF coordinator for care homes was one approach to help ensure this was addressed. Other approaches included an "Adopt a Care Home" project whereby a single GP practice was allocated to be responsible for one care home to ensure consistency and continuity of care; and projects whereby nurses are employed with a specific role to visit nursing homes to have the "early conversations" to identify patients' wishes so care plans can be developed. In one of the PCOs, the project also ensured that the same nurse could develop the care plans and then train the care home staff in how to implement the care plans. Finally, in one PCO, the EoL register was being rolled out to care homes to enable care home and OoH staff to identify a patients' care plan.

A further innovation commissioned by one PCO was the use of a care home for the provision of dedicated palliative care beds, to divert patients at the EoL from hospital admission. Patients could be transferred on referral from the community and hospital palliative care teams and the community matrons.

Innovations in specialist palliative care

The Expert Panel considered innovations by specialist palliative care services which improve the system-wide management of EoL patient, were important. Examples of innovation in this category have already been presented in the GP OoH category, with the description of a dedicated hospice crisis response service available via the GP OoH service. Specialist palliative care professionals and services were

integral parts of most of the services reported here, as well as being involved in planning and developing services at a strategic level. It is not surprising, however, given the focus of both the SHA and PCO interviews on generalist palliative care, that few other specific examples of innovation in specialist palliative care service provision are evident in the data.

Innovations in community nursing

Although innovations in community nursing were not identified as a particular focus, we identified several examples of innovation. There were examples where the DN team is replaced by a rapid response nursing team for the whole/part of the OoH period. Another example was where the 24/7 DN team is situated in different places during the OoH period. For example one OoH DN team is situated in a walk-in centre open until 23:00 and then switched to the nurses' base at the OoH hub after this time.

A number of innovations to provide or improve the management of 24/7 DN provision were identified which could impact positively on OoH care for EoL patients. Some PCOs that were not able to provide 24/7 DN cover aimed to provide some 24/7 service by covering gaps in DN care during the OoH period by employing Marie Curie nurses to ensure EoL patients can access 24/7 care. One PCO who was not currently providing 24/7 DN care conducted a six month pilot scheme in one region of their PCO to see the impact of providing such a service. They employed a trained and untrained nurse to provide night cover during the gap in DN cover OoH. The audit identified that although the service was not well used, they identified that the majority of patients contacting the night nursing team were EoL patients especially those with end stage chronic obstructive pulmonary disease (COPD). Providing the night nursing cover reduced hospital admissions by 40% and highlighted to the PCO that some night provision was necessary and they were considering providing an "on call" service to provide this cost-effectively. This pilot therefore highlighted an attempt by one PCO to improve 24/7 DN cover.

Ways to improve 24/7 cover from the DN OoH team for EoL patients included prioritising EoL patients in two ways. Firstly, by ensuring a quick response: DN OOH team would respond to all EoL patients within a short period (for example one hour) during the OoH period. Secondly, by providing a direct mobile telephone number for the EoL patient or carer to contact the DN during the OoH period. The DN would assess the situation and contact the GP if appropriate. Integrating clinical nurse specialists into the DN OoH team and working alongside them during the OoH period was another strategy adopted by some PCOs. These specialists focused on the care of patients with a non-cancer diagnosis for example heart failure, COPD, neurology. Although these

specialists were not specifically focused on EoL care, they provide specialist support for these patient groups at their EoL.

Other examples of good practice with regard to nursing care included a range of inter-disciplinary community based care teams aimed to support part of the OoH period which were led by the community nurse team. These teams could be generic or dedicated to EoL patients. Examples included teams consisting of qualified and unqualified nursing staff, occupational therapists and physiotherapists, who cover part of the OoH period led by the community nursing team supported by night sitting services from various providers overnight.

Innovations in co-ordination of care

This included dedicated palliative care coordination centres. Only four PCOs had such centres. The remit of the centres varied. For example, in a nurse-led centre, staff accessed and updated EoL registers, monitored key performance indicators, provided a 24/7 telephone advice line for professionals, dispatched nurses to patients, undertook ACP, organised packages of care and sourced equipment for patients. An audit of this centre showed that the service had reduced inappropriate hospital admissions and increased patients chance of dying at home. In other centres, their remit was more restrictive. Two centres were responsible for organising packages of care and sourcing equipment; and the remaining centre provided an information and contact point for both health professionals and patients.

Other formal approaches to coordinating care included single points of Access (SPA). The aim of these was to avoid hospital admission by coordinating appropriate care from a directory of services available both in and out of hours. Generally SPA are not specific to EoL patients but a recent audit in one PCO showed their SPA had saved 30 hospital admissions over 2 years for EoL patients. One SHA was developing an innovative approach to enable improved care for EoL packages by linking the EoL register to their SPA.

Innovations in education and training

Examples of good practice relating to the provision of training and education for staff involved in EoL care included: having a full time palliative care educator funded by the PCO to provide a range of dedicated EoL training across all sectors involved in care provision i.e. GP, community nursing, acute, care homes, hospices and other voluntary sectors and social care; provision of an annual conference dedicated in EoL care across sectors including training updates; providing cover for staff across all sectors to access training courses; and internal systems to review and monitor EoL care within sectors. One PCO for example reported training primary care staff in significant incident analysis in order for them to monitor and assess significant deaths/incidents to identify what worked well and what could or needs

to be changed. An alternative model to having a palliative care educator was seen in one PCO whereby an EoL education groups was formed involving representatives from each stakeholder who coordinate the education and training for providers across all sectors ensuring training is accessible and streamlined.

The provision of training did not necessarily ensure staff could access training courses and although some PCOs provide locum cover, this was not always feasible. One innovation around this was providing a handbag size copy of palliative care guidelines for all healthcare staff to carry with them when seeing EoL patients in their homes/care homes. This ensured that the professional always had access to the guidelines in areas where it was not possible to get internet access to access the guidelines online.

The provision of Advance Care Planning (ACP) was one consistent area PCOs were focussed on improving, ensuring nurses, GP and care home staff were trained to develop and employ the ACP tools. One PCO reported an innovative Macmillan funded project where a "road map" was developed to help train staff in ACP. Another PCO had developed a predictive modelling tool to specifically focus on ensuring EoL patients who are "at risk" have an ACP developed. Although examples of good practice regarding the provision of education packages in ACP training for care homes was noted, the lack of training for this sector was one area frequently highlighted as needing improvement. The Expert Panel highlighted this as one of their five areas to focus on. This area was specifically seen as a priority by PCOs and SHAs in order to reduce hospital admissions for patients from care homes. Several innovations were reported in relation to this: providing a dedicated EoL care implementation team to work with care homes to roll out ACP tools; training care home staff in having "early conversations" in order to prepare ACP for EoL patients; educating care home staff to ensure they are aware of local EoL services provided including support available OoH to enable them to access the right help at the right time; educating care home staff about when they need to contact the community nursing team, in order to avoid leaving it too late when crisis is reached and the ambulance crew are called. One PCO has devised a flowchart showing care home staff when to involve community nurses, and the care home staff are trained in using this. It has also provided verification of death training for nursing homes (and also community nurses) in order to avoid GPs having to visit during the night to confirm death so that certification can instead be done by the patient's GP in the morning.

5.2 'Virtual' User Panel

5.2.1 Participant characteristics

Six service users were interviewed in this study, two male and four females aged between 49 years to 96 years. Two users had cancer, two had organ failure and two were frail (Table 9). Four participants were recruited from networks available to the research team; the remaining two from local hospices.

5.2.2 Findings

Three main themes were identified from the interviews with participants in the virtual user panel. These related to (a) their experiences and barriers of using OoH services (b) their preferences for OoH care and (c) their "ideal" OoH service. This reflects the questions they were asked, unsurprisingly given the small numbers. Illustrative quotes are referenced in the text. Pseudonyms are used to ensure anonymity.

Table 15. **Participant characteristics of 'Virtual' Users Panel**

Pseudonym	Gender	Age	Details
Fred	Male	63	Lung cancer treated with radiotherapy. History of strokes–right hemiparesis and consequently difficulty walking. Prone to falling. Is an alcoholic and lives alone. Had several experiences of calling OoH services.
Mary	Female	49	COPD - requires oxygen 24/7. Lives with partner and one son. Had several experiences of calling OoH services.
Betty	Female	79	COPD. Has diabetes and lives alone. Had several experiences of calling OoH services.
Olive	Female	96	Diet controlled diabetes, hypothyroidism and difficulty walking. Lives alone. Had several experiences of calling OoH services.
Elizabeth	Female	93	Hypothyroidism. High blood pressure and unsteady on her legs. Vision is poor and registered as partially sighted. Had not previously called OoH services but had gained advice from community alarm staff. They had also called an ambulance for her on one occasion at a weekend.
John	Male	74	Lung cancer with bone metastases- chemo and DXT. In pain. Lives with partner. Lives close to a hospital and prefers to go to A & E OoHs, rather than calling OoH services.

Experiences and barriers of using OoH services

Participants described some of their experiences of using OoH services and, as a result of their experiences, barriers to accessing help via the services.

Participants' experiences of using OoH services

Participants reported a range of experiences of using OoH services. Reasons for contacting the OoH services related to seeking help for symptoms related to their EoL condition (for example extreme breathlessness, pain and anxiety) as well as those unrelated to their condition (for example needing help following a fall and fatigue related to hypothyroidism). They discussed examples of responses received as a result of their call to the OoH services. These included a visit from a GP in response to a call about breathlessness who called an ambulance to take the person to A & E; this particular participant did not want to go to hospital. Another participant explained that the GP who visited failed to resolve their problem concerning analgesic medication. However, not all participants would choose the GP OoH services as a first port of call. One participant explained how generally he would go straight to A & E because he felt reassured that he would have access to professionals who would understand the complexities of his specific treatment and problems.

Barriers associated with using the OoH service

Participants cited a number of barriers associated with accessing OoH services. Practical issues about contacting the service included difficulty being able to get through to the OoH service initially because there were several numbers to call.

Sometimes that can go over three phone calls because sometimes you'll ring up ... first of all you ring up your doctor and get the number, then you ring up and speak to a call handler who then decides who is going to ring you back. If you can't breathe and you're on your own you can't do that, you're struggling, fighting for breathe. Then you might get a nurse ring you back to triage you to see whether ... and then she'll say "Oh hang on, I'll get the doctor to call you back." Then that's three phone calls. If you've got an exacerbation of COPD you can't be doing that. (Mary)

Another issue raised was being understood.

I think sometimes they can't understand what you are saying (because you are so breathless)" (Mary)

As well as problems physically making a telephone call one frail participant had very poor eyesight which made it difficult to read and dial the OoH contact numbers.

Because I can't see very well, to get a phone number. (Elizabeth)

Participants highlighted several concerns about getting access to a health professional. One consistent issue was having to repeat information to call handlers about the problem they were phoning about.

Time delays in getting access to speak to a health professional were reported, as calls were being transferred from one person to another.

Hours they take to answer. It goes from one [person] to another. (Olive)

In addition, once they had talked a health professional, one participant reported frustration with not being given a time frame for when he would receive a home visit.

All I can remember is that no one could give me any idea of time. If someone had said someone will be with you probably in an hour or two, between one and two hours, I would have been happy with that. (Fred)

As a result, participants explained some of these factors would stop them from accessing the OoH services. For example, previous experiences of the time it takes to get through to the health professional.

I don't like to do it [call OoH services] unless I'm really ill but then I suppose I should do. With all the rigmarole by the time you get through to them, because I don't know the OoH doctors numbers so you have to ring your surgery and then somebody comes on and gives you a number. But when you're really poorly and you're in a bit of a panic as well ... (Mary)

Furthermore there were feelings that that they would not get the help they needed. Another reason cited for not contacting the services was that they would not want to put the OoH staff out, for example if they needed a home visit.

Preferences for OoH care

Preferences for provision of OoH care encompassed two main themes:

Ensuring quick and direct access to a health care profession

Participants would like to ensure that they were identifiable as being an EoL patient (for example via EoL register or special notes) when they called the OoH services.

That would be a great step forward. (Flagging OoH services) (John)

This respondent went onto request that the flagging system was extended to the ambulance and rapid response services too.

... there's nothing wrong with having the information, because even the rapid response have probably got a laptop or something like that haven't they? So if those sort of people have the information as well it would be roughly the same I suppose, the same idea. That would be quite acceptable as far as I'm concerned. The more people that know about me the merrier as far as I'm concerned. (John)

They would like to be prioritised at triage so that they were put directly through to the GP, or if not, to staff who knew them and their clinical history. To achieve this they would like OoH staff to have access to their medical record.

Someone that knows or can get hold of your case papers. Because naturally a doctor who doesn't know you he has got to ask you different things, by the time he asks you, you are breathless. (Betty)

This was expected to circumvent the common problem of being asked a lot of questions.

If you're feeling quite ill you don't need too many questions. (Fred)

or having to repeat their "story" to multiple staff. They also would like to receive help from staff who speak clear English.

Getting access to the appropriate care and support

Participants would like access in a timely manner, to a range of staff depending on their needs (for example nurses, specialist palliative care nurses, physiotherapists). They particularly highlighted access to night sitters. They also wanted access to medication and equipment OoH.

I don't want to go into hospital again, I certainly don't want to die in hospital ... there's going to be a time when I'll need a syringe driver and I need to know that will be available and I know that can be set up during the night if needed. (Mary)

A participant, who was elderly and frail, explained how she couldn't get out to access emergency drugs and needed someone to bring them to

her. Finally, participants wanted staff with a “good attitude” and one participant, an alcoholic, would like staff to be non-judgemental.

The Ideal OoH service

The ideal OoH services was described by participants as follows:

- that patients receive help in a timely fashion and are given a timeframe for visits and phone calls
- patients are treated by OoH staff with a positive and non-judgement attitude who communicate well and speak good English
- that they receive prioritisation at triage and are transferred directly to a GP
- that all OoH services have access to their clinical notes to ensure they know their clinical history; and thus ensuring the patient does not have to answer a lot of questions
- access to a range of staff appropriate for their clinical need
- access to medication and equipment OoH
- access to a local room for treatment or for overnight admission

6 Discussion

The aim of this research was to establish how OoH EoL care is provided in England and Scotland, to investigate the extent to which provision varied, and to explore models of service provision. This information is needed to inform the direction of further research as a necessary first step towards remedying the current dearth of evidence about the effectiveness and efficacy of service delivery in this area. In the absence of robust evidence, it will also enable those responsible for commissioning health and social care services for EoL patients to learn from the experiences of others who have had this role. This is particularly important given the current commissioning changes in the NHS, which bring the possibility of a loss of continuity of knowledge along with the possibility of new opportunities.

This research has two main findings. Firstly, the importance of considering OoH EoL care as a complex system which includes aspects of 'in hours' generalist EoL provision as well OoH GP, urgent care, nursing and social care, and specialist care services. Secondly, that there is considerable variation amongst PCOs in England and Scotland in both the type and level of provision of generalist EoL OoH services and the use of mechanisms to facilitate EoL care, and the implications for this finding.

6.1 *OoH EoL care as a complex system*

Previous research has considered OoH EoL care primarily as an issue for general practice, and one concerned particularly with the provision of medical care outside of normal surgery hours^{31,61,64,62,54, 65}. This is not surprising given the major changes in the provision of OoH medical care in westernised countries, including the UK, over the past two decades^{49,76,48}, which has resulted in the loss in personal continuity as GPs have ceased providing OoH care for their own patients. In contrast, this research has looked at generalist OoH EoL care as a whole. It is clear from the findings that OoH medical care is one component, albeit an important one, of the OoH services needed to sustain people at the EoL at home in the community.

The importance of the availability of other services during the OoH period has been recognised in policy documents. For example, there have been calls for every PCT to provide 24 hour DN services⁶⁷, whilst the DH EoL Strategy additionally request improved provision of both emergency and planned OoH access to medication, equipment and access to telephone advice for professionals². The GSF has expanded from its original focus on GPs and the primary care team (including practice nurses and often DNs too) to now include care homes as a new focus. Previous research studies have not, however, considered OoH EoL

care as a complex system, involving OoH GP, emergency response, nursing care, social care, care homes and community hospitals, and specialist palliative care services working together to address patient and family need and to prevent unwanted hospital admissions.

The findings of this research illustrate the importance of viewing OoH EoL care in this way. Data illustrates how perceived deficiencies within one part of the system may be met by service innovations elsewhere and how problems at one point in the system have implications elsewhere. OoH EoL care is therefore a complex system, where changes in one service are likely to have implications for other services. This needs to be taken into consideration in future research.

In addition, this research demonstrates the importance of seeing good OoH EoL care as being intimately interwoven with generalist EoL care provided within normal working hours. Good OoH EoL care depends on: the identification of the patient as being at the EoL and the recording of this on an appropriate register; advanced care planning, including discussions around care plans, and the transfer of this information to OoH providers; and on the co-ordination of care across providers.

The importance of GPs notifying the OoH providers responsible for their population about EoL patients has been recognised for more than ten years. It was, for example, one of the recommendations of the Macmillan Report on OoH care in 2001⁵³. This is now, however, seen as part of ACP i.e. Step 2 on the EOLC pathway². First, health professionals need to have timely conversations with patients who are approaching the EoL, and to seek their permission to enter them on an EoL register. GPs receive some incentive to do this, as it forms part of the Foundation level of the GSF, which has been incorporated into the Quality and Outcomes Framework (QoF) of the GPs' GMS Contract⁴⁴. The SHA respondents, PCT respondents and participants in the Expert Panel all recognised the importance of identifying a patient as being EoL to enable EoL OoH care. These research findings show that in addition to its importance in normal working hours, the identification of EoL patients and their entry (with their permission) in an appropriate register is an essential gateway to good EOL OoH care, allowing ACP to be instigated to identify patients' wishes and preferences for care as well as involving actions to anticipate care needs, such as notifying OoH EoL care providers. Both patient identification and ACP take place predominately within working hours. High quality OoH EoL cannot, therefore, be separated from care within hours, and in-hours care must be seen as part of the OoH EoL care system.

One major initiative in UK palliative care has adopted a whole systems approach to service redesign within PCTs, and is intended to be patient-centred, looking at all services required across 24 hours from NHS and social services, the voluntary and independent sectors. It therefore

includes, but is not restricted to, OoH services. Marie Curie Cancer Care 'Delivering Choice' Programme was initially trialled by the organisation in seven PCTs, with others using Marie Curie's toolkit. The first three projects were independently evaluated, with results suggesting that the programme increased the number of home deaths without increasing costs (KF report). Full participation in the programme involves three phases in which existing palliative care delivery is examined to identify barriers and understand local need, new service models are designed, and then piloted and evaluated over two years. Some PCOs in this research project were participating in the 'Delivering Choice' programme. The programme may provide a template for how PCOs might take a systems approach to their EoL OoH services, and work with stakeholders to plan service change.

6.2 Variations in type and level of provision of EoL OoH services

This research found considerable variation amongst PCOs in both the type and level of provision of generalist EoL OoH services and the use of mechanisms to facilitate EoL care.

Not surprisingly given the emphasis within general practice on supportive / palliative care registers, almost all PCO respondents reported that GP practices in their PCO used a system to identify EoL patients. Not all respondents were satisfied with the proportion of eligible patients identified, however, or with the number of practices with consistent robust systems. Both PCO and SHA respondents in particular recognised that people with severe, life-limiting illnesses other than cancer could be disadvantaged because of continued difficulties in judging prognosis beyond cancer. Some PCOs were trialling innovative methods to overcome this obstacle, for example, by relying on diagnosis rather than prognosis to trigger entry on a supportive care register. OoH care is likely to benefit from the continued efforts by, for example, the Department of Health EoL Programme, the GSF Programme and the Dying Matters Coalition to encourage health professionals and patients to have appropriate conversations about when it is time to join an EoL register, give health professionals the skills they need to be comfortable having these conversations, and address ways of including more patients with diagnoses other than cancer on these registers.

The identification of EoL patients was reported in the research to be beneficial to OoH EoL care because it allowed ACP and anticipatory planning, essential to good OoH EoL care, to be set up within normal working hours. The focus of this in previous research has been on the importance of, and systems for, keeping OoH medical services informed about EoL care patients in case an emergency call is received. This was an important element of anticipatory care in this research, but not the sole focus. Respondents also discussed the need to plan ahead in terms

of the medication that might be needed, and to ensure that this would be available. PCOs varied in the systems they have in place to meet predicted medication needs, ranging from 'just in case' boxes stored in the patient's home or GP OoH base, prescriptions from the GP OoH or nurse prescriber accessed by late night pharmacists or via the acute hospital. Some PCOs reported encountering legal difficulties with planned medications which seemed to have been overcome in other PCTs, whilst others reported having no systems in place to meet planned medication needs. A similar picture was reported with equipment needs. Respondents also discussed the importance of planning ahead for changes in physical deterioration, and for carer fatigue, and planning night sitting and nursing services accordingly. One respondent thought that almost all OoH EoL contacts represented a failure of anticipatory planning. Others thought that emergencies would always occur because of rapid changes in the patient's condition or because of the family carer's fatigue, and that services needed to be planned accordingly. Such differences in belief may help to explain some of the variations in service provision between PCOs.

Given the emphasis within primary care palliative care on ensuring informational continuity by, at the very least, ensuring that GP practices inform the OoH service about their EoL patients, it is encouraging that all PCOs reported that practices in their PCO had some sort of system to do this. 62% used paper based systems (fax or email) and 38% used some sort of electronic system. In only 18% of PCOs did GP practices and OoH organisations share the same electronic system, although a further 22% planned to do so in the future. In one in five PCOs, therefore, GP practices were sending information to OoH organisations electronically which then had to be entered again into the OoH organisations' own systems. Respondents' comments indicate that these figures represent the best picture within PCOs. Not all practices used these systems regularly if at all; there were difficulties in getting information updated, and there were wide variations in how much information was shared, from name only through to full care plans including, PPOC and DNAR. Less than half of ambulance services were able to access some information on EoL patients, at best via electronic flagging systems or if not through 'message in bottle' schemes or patient held records, with another quarter of PCOs planning to tackle this. A 2010 study in Scotland reported similar problems with patient identification and sharing of care plan OoH⁶².

Respondents in several HBs and PCOs discussed implementation of an electronic palliative care register (ePCR) to enable data sharing between GPs, OoH services, ambulance services, community nurses, specialist palliative care and acute services. At the time of the interview survey, these were expected to be implemented across Scotland in 2012. Respondents' views support those of an evaluation of a pilot implementation study, which found that a system which enabled

services from across the complex system of EoL OoH care to share information has the potential to increase collaboration and co-ordination, but that its value is ultimately dependent on the enthusiasm and commitment of the health professionals who input the data and use the system⁷⁷.

Sharing information alone may not be enough. Patients in this study and in previous research⁶² wanted those they contacted OoH to know about them to ensure informational continuity but, importantly, they wanted the OoH system to work differently for them. They did not want to have to repeat their information to several different people, and found this difficult. In addition, they wanted prioritisation at triage and to be contacted by the clinician within a reasonable, specified, period. This illustrates the tension the OoH doctors in Tambert and Nelson's research (2010) identified between the urgency and speed of OoHs medicine and the listening skills and time needed by EoL patients. Some PCOs did things differently in this respect, but no evaluations on the impact of different mechanisms are available.

In terms of service delivery, district (community) nurses have been described as central to OoH EoL care (for examples ⁶⁷) with a recent meeting report from the NCPC/Macmillan Cancer Support concluding that this service should be available 24/7 in all PCTs. Macmillan Cancer Support reported that a Freedom of Information request to PCTs in January 2010, with an 82% response rate, found that 56% of PCTs had 24/7 community nursing available to EoL patients⁷⁸. In the current research, 49% of responding PCOs reported that DN was available 24/7 consistently across the PCO, and the remaining 49% reported either partial provision 24/7 (for example at weekends or up to 9 or 10pm weekdays) or varying provision across the PCO. No previous studies have looked at the prevalence of nursing and personal care services other than 24/7 community nursing services; a lack of definition means that services such as these may be included within the MCS figures for community or DN.

There was uncertainty amongst SHA and PCO respondents in this study about the feasibility of providing 24/7 DN care in their PCOs. Several respondents discussed the difficulty of funding and staffing a night time service in rural areas where demand is limited, with one having recently terminated their night-time service and started an on-demand rapid response service in its place. MCS similarly noted that 24/7 community nurse services were more widespread in urban areas⁷⁸. Other respondents discussed whether a night time DN service was the most appropriate model, with alternative suggestions mainly including combinations of rapid response and night sitting services. The Department of Health EoL strategy suggests the use of rapid response services where 24/7 DN services are not (yet) feasible. This may have encouraged the growth of these services with at least two thirds of PCTs providing them in some form (although not necessarily dedicated to EoL

care), and others planning them. Somewhat unexpected, however, preliminary analyses suggested that both rapid response and hospice at home services were more likely to be provided in PCOs with 24/7 community nursing than in those without. Given low numbers, these may be chance findings. They may, however, suggest that some PCOs are particularly aware of and responsive to the needs of EoL patients and their families OoH, and/or that they have made preventing hospital admissions a high priority, and/or that the presence of 24 hour DN provides a strong, central structure on which to 'hang' other nursing and personal care services. The services which were more common in PCOs without 24 hour DN than in those with it, were access to 24/7 telephone advice for patients and professionals, and access to 24 hour admissions suggesting these PCOs placed more emphasis instead on responses to a need for expert advice and alternatives to home care in the absence of 24/7 DN.

The degree of variation and extent of innovation between PCOs (and between different areas of some PCOs) in the packages of service provision they employ to meet the nursing and personal care needs of EoL patients illustrate the lack of evidence in this area. Although it is often stated that 24/7 DN is a necessity, there is no evidence that this is the most effective and efficient model of service delivery (or, indeed, when it is) compared with alternative arrangements to meet patients' needs. Debate is therefore needed about appropriate models to meet patients' nursing and personal care needs at night and their perceived strengths, weaknesses and costs in order to ensure all EoL care patients receive appropriate care at home and avoid unwanted hospital admissions.

In providing five characteristics of 'good' OoH EoL care, the Expert Panel enabled a judgement to be made of the proportion of participating PCOs who met these standards, as operationalised by the research team. Only one in eight PCOs had all five characteristics, with two fifths having four out of the five. This demonstrates the progress still needing to be made before all patients and families at the EoL receive high quality responsive OoH care.

This may also be an issue of concern for the NHS itself, given many respondents saw the need to increase the proportion of people dying in their place of choice, to reduce unwanted hospital admissions and thereby to reduce NHS expenditure as an important motivator for improving OoH EoL care. Some reported uncertainty, however, about the cost implications of enabling patients at the EoL to remain at home. They acknowledged that they were unsure of the cost implications of supporting EoL patients to die at home given that the costs had not been worked out, as well as being unclear where the resources would come from to support improvements in community services. Nevertheless, the drive to reduce unwanted hospital admissions amongst this population is evident in innovations to provide alternatives

to admissions to A & E, to enable rapid discharge from hospital for patients on the EoL register who are admitted there via A & E, as well as in the range of innovative services to provide timely nursing and personal support to patients at home.

6.3 Models of service provision

In addition to establishing how OoH EoL care is currently provided and exploring variations in provision, this research also aimed to explore distinct models of care. The 2008 EoL Care Strategy and, in particular, the EoL care pathway² emerged as strong organising principles in both the SHA interviews, the PCO telephone interviews and in the discussion of the Expert Panel. This 'top down' approach appeared to dominate the way in which respondents presented strategy, commissioning and provision of services for patients at the EoL.

Based on the discussions of the Expert Panel, the research is able to distinguish a 'good' model of EoL OoH care in terms of service delivery from sub-optimal models. A good model, at a minimum, has a system to identify EoL patients to the OoH GP service, has a patient-held record or care plan held in the patient's home; provides access to medicines that have been prescribed in anticipation; provides comprehensive day time cover from health and social services and some availability of care in the twilight period; and provides an advice line for professionals working in the OoH period.

The research has not, however, been able to identify ways in which the organisation of EoL OoH care differs across participating PCOs. There are no clearly distinguishable models of service organisation visible in the data. This finding in itself is important, highlighting how variable the provision of OoH EoL care is. The possible impact of the Marie Curie Cancer Care 'Delivering Choice' Programme is discussed above. Small numbers meant the impact of the programme on OoH care could not be investigated in this research. PCOs choosing to be early adopters of this programme are, of course, likely to differ from other PCOs in any case with, for example, enthusiastic 'leaders' for EoL care within the PCO, a particular need to increase home death rates, or long-term relationships with the charity.

Further research is needed to explore what distinguishes PCOs in which 'good' OoH EoL care is provided from those in which it is not, and, in particular to learn whether particular models of service organisation and delivery best support high quality care and, if so, in what circumstances.

6.4 Theoretical propositions

Following data analysis and interpretation, and based on the Expert Panel's discussion and on existing literature, the research team have

developed five theoretical propositions about OoH EoL care to inform further debate and research on the subject.

- a. Good generalist OoH EoL care is likely to increase the likelihood of patients being able to die at home, if this is their wish.
- b. The quality of generalist OoH EoL care is significantly shaped by the quality of EoL Care within normal working hours, specifically the extent to which primary health care teams recognise patients as being at the EoL and engage in appropriate anticipatory planning.
- c. The expressed wishes of patients at the EoL and their families for personal and informational continuity are at odds with the function and working practices of services providing OoH medical care, and require specific strategies to overcome barriers. The most effective and efficient strategies to provide continuity remain to be determined.
- d. Generalist OoH EoL care involves medical, nursing (including extended practitioner roles), social, specialist palliative care and emergency services in complex systems of service delivery which vary across and between primary care organisations.
- e. Nursing care, both planned and unplanned, is central to generalist OoH EoL care. The most effective, efficient and acceptable models of providing this care are not known.

6.5 Strengths and weaknesses

The response rate for the SHA interview study was less than anticipated, resulting in these interviews representing a third of SHA/HBs. Recruitment was also an issue in the PCO interview survey, where the response rate was 42.8%. The sampling approach for the PCO interview study is also a weakness in terms of survey research, as it was initially influenced by the requirements of the planned Phase II study with the result that the drawn sample was not a random sample, but combined elements of convenience and random sampling.

Considerable effort was put into identifying suitable respondents within the sampled SHAs and PCOs and then into contacting them and seeking consent for an interview. This process began in both studies in December 2010, five months after the launch of the NHS White Paper in July 2010. During this period, commissioners and senior managers within SHAs responsible for EoL and OoH had already begun to leave PCTs in England, to change roles or to take on new responsibilities as others left. This made it challenging both to identify appropriate respondents and to secure interviews with those who remained. The PCO interview survey therefore has some degree of sampling bias, compounded by response bias due to the response rate. The

comparison of responding PCTs with published characteristics of all PCTs shows that large PCTs were probably more likely to respond, as were those with larger GP Practices. It is, of course, also likely that they differed on other characteristics, such as the commitment of the PCT to EoL care. Data on the prevalence of EoL OoH services within these PCOs is therefore likely to differ to some unspecified extent to that in all PCOs in England and Scotland. It can be hypothesised that PCOs with more enthusiasm about the subject matter participated, meaning that the data presented here may over-estimate the national picture. Comparisons between services are likely to be unaffected by this response bias.

In retrospect, the decision to collect numerical data on service provision as part of semi-structured interview using an interview guide rather than a structured interview pro-forma has weaknesses. Although the guide ensured all respondents were asked about key services and about areas of service delivery, they were not asked specifically about all types of service. This will have led to under-reporting of some services. It also made data coding and analysis more time-consuming. At the onset of data collection, the full range of service provision was not clear, so use of a topic guide retained flexibility and allowed the interviewer to explore service provision in detail. The development of a more structured schedule after pilot interviews would, however, have had advantages.

A further weakness of the data is the disappointing attendance on the day at the Expert Panel meeting. The effect of this was moderated by the professional backgrounds and expertise of the members of the research team and the Panel members attending the meeting, which enabled a wide ranging and well-informed discussion. The agenda and timing of the meeting were determined in large part by the requirements of the planned Phase 2 study. It would have been run somewhat differently if from the outset it had been a freestanding meeting for the research reported here, and its timing would have been delayed to allow further data analysis and development of theoretical propositions so that the Panel could have played a more major role in shaping these. Nevertheless, the Panel were instrumental in determining the qualities of 'good' OoH EoL care, which have played a key role in discussion of this research, and in indicating where innovations in OoH EoL care are most needed.

A great strength of the research is that, for the first time in research into OoH EoL care, it has considered the whole system of OoH EoL care, rather than focusing primarily on the provision of OoH GP care. It has combined numerical data on the provision of services with the views of both senior managers at SHA level and PCO commissioners on the strengths and weaknesses of current service provision, and has captured examples of service innovation across the whole EoL OoH pathway. It has therefore identified areas of strong agreement – such as the fact

that the need to reduce hospital admissions is a strong motivator to improve OoH EoL services – as well as exposing a lack of agreement and evidence underlying statements presented as certain facts – such as all PCOs should provide 24 hour DN. It will therefore help inform commissioning decisions, as well as the direction of future research.

6.6 Conclusions

6.6.1 Implications for healthcare

The main implication for healthcare from the evidence presented in this report is that it indicates that there are significant variations in OoH EoL care, both between and within PCOs. This suggests that many PCOs have further progress to make before they can be said to be providing good OoH care for EoL patients in their population.

The evidence also suggests that those seeking to improve OoH EoL care should regard the first two steps of the Department of Health EoL care pathway (i.e. Discussions as EoL approaches, and assessment, care planning and review) as integral parts of the process, even though these steps usually take place during normal working hours. OoH care is likely to benefit from the continued efforts by, for example, the DH EoL Programme, the GSF Programme and the Dying Matters Coalition to encourage health professionals and patients to have appropriate conversations when it is time to join an EoL register, and to give health professionals the skills they need to be comfortable having these conversations.

The evidence from both SHA interviews, PCO interviews, and the Expert Panel discussion all indicate that the importance of patient prognosis in determining the timing of patient EoL discussions means that people with diagnoses other than cancer, including residents of care homes, are particularly likely to be excluded from OoH EoL care services from which they might benefit. This suggests the continued importance of ensuring EoL care services are made available beyond cancer. Examples of innovation reported here may suggest ways of overcoming the barriers to inclusion in OoH EoL care services.

There is considerable variation both between and within PCOs in what information on EoL patients is notified to OoH GP services, in the proportion of this which happens in 'real time' and, if not, how often it is updated. There is also variation between OoH providers in what happens as a consequence of this information. This evidence suggests that the wishes of EoL patients and their families would be better met if more PCOs met the standards of the best and improved their informational continuity in OoH EoL care.

Commissioners in this research were concerned about the impact of ambulance services through unscheduled admissions in EoL care. These

services currently have poor access to information. it is unclear whether improved information would input positively on patient experiences, but this seems likely.

A recent report from Macmillan Cancer Support⁷⁸ has echoed previous recommendations⁶⁷ in calling for all PCOs to provide 24 hour DN. The evidence presented here indicates that there is uncertainty amongst NHS senior managers and commissioners about the feasibility of providing 24/7 DN care accompanied by a range of models for meeting patient nursing and personal care needs, and family respite needs, at night. This suggests that debate is needed about available models, their perceived strengths, weaknesses and costs, in order to ensure that all EoL care patients receive appropriate nursing and personal care at home and avoid unwanted hospital admissions.

6.6.2 Recommendations for research

1. Research is needed into the most effective, efficient and acceptable models of providing care to meet EoL patients nursing and personal care needs OoH, taking into account the impact on the whole OoH EoL care system.
2. Research is needed into the most effective, efficient and acceptable strategies to provide continuity for EoL patients and their families who require OoH medical care.
3. Research is needed into generalist OoH EoL care as complex systems, including patient notification and advance care planning in normal working hours, from the perspectives of patients, families, staff and organisations, to explain the antecedents, impacts and consequences of differing OoH configurations in this context.
4. Research is needed into the most effective and efficient strategies to avoid unwanted hospital admissions following ambulance call-out for EoL patients who want to remain at home, and to ensure rapid hospital discharge when admission is unavoidable.
5. Research is needed to identify the costs of maintaining EoL patients at home OoH compared to admitting them to hospital.
6. Research is needed into the most effective and efficient ways of providing education and training in EoL care for generalist staff working in OoH services.

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Appendix 1

Interview Guide for Interviews with Senior Manager Leads Responsible for OoH and EoL in SHAs and HBs in England and Scotland

Introduction: check participant has received and read project information. Recap, answer questions as necessary. Talk through consent form, and gain permission to tape record. Ask participant to sign the consent form.

1. LEAD IN

'Thank you for agreeing to be interviewed as part of the study. In our discussion today, I would like us to focus on four aspects. First, I'd like to ask you about the commissioning arrangements for out-of-hours care locally and your role in this. Secondly, I would like to find out what in your view works and what doesn't with the current arrangements. Thirdly, what impact, if any, in your opinion will the impending changes in NHS organisation have on OoH care provision for patients at the end of their life? And finally I would like to ask for your help in identifying a key informant within each PCO in your area who would be aware of current provision of OoH care for patients at the end of their life'.

2. First, some questions about how out-of-hours care for EoL is commissioned

- a. Please could you tell me about your role (organisation) and any responsibility you have for OoH care for people at the end of their life?
- b. What services are available for these patients? We are particularly interested in identifying any innovative OoH services for this patient group. Are you aware of any pioneering services within your SHA and if so can you describe them to me?
- c. How is performance in the out-of-hours system monitored?
- d. In view of the impending NHS organisation, do you foresee any changes to current OoH EoL care provision? If so, what?

3. Secondly, some questions about your perspective on the current provision of OoH care for patients at the EoL.

Probe: integration of services, procurement of services

- a. What in your opinion works well and why?
- b. What in your opinion is not working well? And why?

c. How could services be improved given financial constraints?

4. What impact, if any, in your opinion will the impending changes in NHS organisation and commissioning influence OoH care provision for patients at the end of their life?
5. Finally, the next stage of our research is to identify and map provision within each Primary care trust/health board. I need to identify a key senior person within each PCO/Health Board that would really know this information. Please could you give the contact details of each key contact? Also if you hold details of up to date OoH EoL service provision within the PCOs in your authority please could you let us see this?

Appendix 2

Braun and Clarke's Phases of Thematic Analysis

Phase	Description of the process
1. Familiarizing yourself with your data:	Transcribing data (if necessary), reading and re-reading the data, noting down initial ideas.
2. Generating initial codes:	Coding interesting features of the data in a systemic fashion across the entire data set, collating data relevant to each code.
3. Searching for themes:	Collating codes into potential themes, gathering all data relevant to each potential theme.
4. Reviewing themes:	Checking if the themes work in relation to the coded extracts (Level 1) and the entire data set (Level 2), generating a thematic 'map' of the analysis.
5. Defining and naming themes:	Ongoing analysis to refine the specifics of each theme, and the overall story the analysis tells, generating clear definitions and names for each theme.
6. Producing the report:	The final opportunity for analysis. Selection of vivid, compelling extract examples, final analysis of selected extracts, relating back of the analysis to the research question and literature, producing a scholarly report of the analysis.

Appendix 3

Identifying and Reviewing Current Strategies for OoH Care at the EoL within all Primary Care Organisations in England and Health Boards in Scotland: Summary Report

Objective

To identify and review current strategies for OoH care at the EoL within all Primary Care Organisations in England and Scotland in order to inform data collection and interpretation in the PCO interviews.

Background

In England, the Department of Health commissioned baseline reviews of EoL care for each Primary Care Trust in 2007 to inform its EoL Care Strategy which was subsequently published in 2008. The reviews summarise services for adults with any advanced, progressive, incurable illness and in any setting (for example home, acute hospitals, care homes, extra housing, hospice, community hospitals, hostels for the homeless, prison or other institution). Local service provision was being audited in Scotland at the time of the research study.

Methods

Sampling strategy

We proposed to approach all PCOs in both England and Scotland. This entailed contacting all 152 PCTs in the ten SHAs in England and the 34 community health partnerships (CHPs) within the 14 Health Boards in Scotland.

Data collection

Data collection began in late October 2010 once confirmation that ethical approval for this exercise was not required. PCOs were contacted by telephone to identify who in the PCO were able to provide the strategy documents relating to the provision of EOL and OOH care. This usually entailed identifying and contacting both the EOL and the OOH managers in every PCO. Once the appropriate people were identified they were contacted by email to request that the following information be emailed or posted to the research team:

- In English PCTs, the EOL 2007 Baseline Review and any subsequent updated documents.
- In Scotland, any relevant strategy documents that detailed EOL and OOH care provision.

Finding the right people in PCOs in England to access the documents was very difficult and time-consuming, not least because as a

consequence of the proposed changes to GP commissioning, staff were leaving PCOs or their roles were changing. The response once people were identified was very poor. We therefore tried to find information on the internet ourselves.

It was decided to stop data collection in November 2010, after substantial effort, due to lack of response (see Results section).

Data analysis

It was planned to extract relevant data from strategy documents into an Access database to enable systematic collection and analysis of data. Because of the poor response rate no data analysis was undertaken.

Results

During the data collection period, 95 PCOs were contacted to request strategy documents. Strategy documents were returned from n= 3 PCOs; a 1% response rate. As stated above, finding the appropriate people was time consuming and difficult. Even when the appropriate person was identified and contacted, they were often reluctant to forward the documents until they had sought approval from Senior Managers, introducing further delay.

Conclusion

It was decided not to pursue this data collection exercise, given the imbalance between effort and reward: it was felt by the research team that it would be better to focus study resources on the SHA and PCO interviews. In addition, as interviews began, it became clear that strategies from at least three years before did not provide a good insight into current provision or strategy, given the focus on improving services in the light of the 2008 DH EoL strategy.

Appendix 4

Interview Guide For Key Informants within Primary Care Organisations (version 2 dated 21/2/11)

Introduction: check participant has received and read project information. Recap, answer questions as necessary. Talk through consent form, and gain permission to tape record. Ensure the consent form has been signed and sent.

A. LEAD IN

'Thank you for agreeing to be interviewed as part of the study. In our discussion today, I would like us to focus on three aspects. First, I'd like to ask you about both the provision and the commissioning arrangements for end of life out-of-hours care locally. Secondly, I would like to find out what in your view works and what doesn't with the current arrangements. Thirdly, what impact, if any, in your opinion will the impending changes in NHS organisation influence OoH care provision for patients at the end of their life?'

B. Before we start can you tell me a little about your PCO?

1. How many GP practices are there in your PCO?
2. What type of population and area does your PCO cover? *(is it city, rural or combination? Is it an affluent population, are there areas of high deprivation, is there a significantly older population etc ... as compared to other PCOs?)*
3. What is the history of your PCO? Has it evolved from a number of PCOs?
4. Is your PCO divided into localities and if so how many?
5. When will your PCO change to GP commissioning? Are you a Pathfinder PCO?

C. First, some questions about how out-of-hours care for EoL is commissioned

1. Which of the following OoH services do you currently have available? Please can you state what time periods during the OoH period they cover and if this service is 365 days/year?
 - a. GP OoH – is this managed by local GPs or locums or both?
 - Do GP OOH services have a way to identifying palliative care patients?
 - If so, are calls from them/their carer handled in a different way once received?

- Which organization does initial call handling (eg could be ambulance service) and who does initial clinical assessment.
- b. District nursing service?
- What service does this cover? Telephone, home visits, medication equipment?
 - Hours available? Does this service provide 24/7 cover?
 - How managed?
- c. Specialist Palliative Care services. These could include, for example, services provided by
- Local hospices (telephone advice lines for patients/professionals, OoH admissions, Hospice at Home, night sitting, clinical nurse specialists)
 - Marie Curie
 - Macmillan nurses.
 - Other telephone advice lines, for example through acute hospitals? NB for all telephone advice lines can you find out if the nurse can access senior input from a consultant in palliative medicine.

For each type of SPC service please explain

- Is this specific to cancer or for all EoL patients?
 - What service does this cover? Telephone, home visits, medication equipment?
 - Who is it staffed by?
 - Hours available?
 - How managed?
 - How do patients access this service? If they need to be referred who makes the referral – GP/DN or SPC team?
- d. Any other access to night sitters besides Marie Curie (for example local charities, Sue Ryder, Continuing Health Care funding via Social Services or NHS)
- How accessed by patients?
 - Is the capacity adequate for need?
 - Disease specific or equitable access for all EOL diagnosis
 - Staffed by whom? RGN/HCA i.e. is this purely sitting or can they provide additional health care support?
- e. Rapid response team
- f. Do social services provide any OOH care for palliative care patients/carers? For example, night sitting? Is this planned care only? Any cover for crisis situations?

- g. Any other services? Any pilot studies in place at the moment?
- h. Innovative services. Do you have any examples of pioneering services or pilot work that is being undertaken? If so, please could you provide details?
- i. Do you have any plans for developing new OoH services for patients at the EoL within the next 6 months? If so, what and when?
- j. Medication access OoH
- Can patients get access to medication OoH? If so how?
 - Is anticipatory prescribing used in PCO – is this also the case in care homes as well as patients' home?
 - What happens in an unanticipated crisis?
 - Do you have late night pharmacists? (Some PCOs have "100 hour pharmacists" i.e. open continuously for 100 hours.)
 - *Prompt:* Anticipatory prescribing –just in case boxes (in patients' homes or GP/community hospitals?); do GPs carry EoL drugs/ stocks in community/acute hospitals?
- k. Can patients get access to equipment OoH? For example if rapid hospital discharge or in unforeseen emergency
- If so how?
 - Do delivery team work any time during the OoH period
 - If not, where are equipment based (for example syringe drivers, mattresses, commodes etc)
- l. Communicating a patient is EoL and their wishes between OoH services
- How is information transferred between the different OoH services?
 - Which, if any, OoH services can identify if patient is EoL and what their care plans are for example DNAR/LCP/PPOC
 - Is this system electronic or paper/fax based ("special notes")
 - If electronic which OoH services can access this- ambulance, acute, GP/DN, hospices?
 - If there is no system at the moment, are there plans in the near future to link OoH services between GP, ambulance, nursing etc for EoL patients?
- m. EoL tools
- Which of the following EoL tools do you use across the PCO? For each of these confirm if they are used in care homes too:
- DNAR

- EOL register
- GSF – what % of GPs are signed up and what % of care/nursing homes
- Advanced Care Plan
- LCP
- Preferred place of care/death (PPOC/PPOD)

n. EOL training

- Is there training for staff in EOL care? If so, what does this involve, and which staff are trained? GP/DN/SPC/care homes/social services

Prompt for; are there any specific EOL facilitators: is training multi-disciplinary integrating specialists and generalists; what training is available for nursing/care homes – and has this started and at what level?

2. In addition, we would be really grateful to receive copies of any strategy documents your PCO has which would include details relating to OoH care for EOL patients. Would you be able to post (address below) or email this to me at s.brien@southampton.ac.uk?

D. Secondly, some questions about your perspective on the current provision of OoH care for patients at the EoL.

Probes: integration of services, duplication of services, procurement of services, use of local existing GPs or out of area GPs, IT communication systems, staff motivation, in/adequate in hours care provision for EOL, in/adequate 24/7 cover, lack of night sitting carer respite, provision biased towards cancer EoL?

- a. What in your opinion works well and why?
 - b. What in your opinion is not working well? And why?
 - c. How could services be improved given financial constraints?
- E.** What impact, if any, in your opinion will the impending changes in NHS organisation and commissioning have on OoH care provision for patients at the end of their life?

Traffic Light rating Criteria

RED (Non-existent/limited service)



ORANGE (In development/or partially implemented/partially available to population)



GREEN (Implemented/systematic/routinely used)




Not able to score



ID 1

- Population: 600,000
- No GP practices: 88
- Geography: Mix
- Number of Localities : 3

Appendix 5

	Description	Established service, new or in development	Period of Cover	Equality for all diagnosis	Dedicat ed EOL service	Generalist or specialist service	Sector NHS/Voluntary /Local authority
IDENTIFICATION Overall Rating for whole section RED Limited identification and sharing of records  ORANGE Partial identification and sharing of records GREEN Identification systems routinely used and records accessible by all stakeholders							
Identification of EOL patients across OoH period and services <u>Identification</u> <u>Access</u>	<u>Identifying EOL pts</u> GPs identify EOL patients and fax/email forms (Preferred place of care and DNAR) to GP OOH which are entered onto an electronic system (EMIS). System is "Hit and miss" at times. <u>Access</u> Records on EMIS can be accessed by GP, DN, ambulance. No information about access by acute and hospices. Piloting implementation of the Summary Care Record with some practices, which will enable such access to health care teams once in place. Also patients hold records at home. No prioritisation of EOL patients at triage	Established – identification and access	N/A	N/A	No	Generalist	Not know if mechanisms of identification and access to information occurs across sectors

Traffic Light rating Criteria

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ORANGE (In development/or partially implemented/partially available to population)



GREEN (Implemented/systematic/routinely used)



Not able to score



ID 1

- Population: 600,000
- No GP practices: 88
- Geography: Mix
- Number of Localities : 3

	Description	Established service, new or in development	Period of Cover	Equality for all diagnosis	Dedicated EOL service	Generalist or specialist service	Sector NHS/Voluntary /Local authority
OoH Service Available							
GP led Overall Score	<p>One provider who employs local and locum GPs.</p> <p>GPs communicate internally with GP OOH electronically about EOL patient.</p> <p>GPs identify EOL patients and fax/email forms (Preferred place of care and DNAR) to GP OOH which are entered onto an electronic system (EMIS) for access by GP, DN, ambulance. No information about access by acute and hospices.</p> <p>System is "Hit and miss" at times.</p>	Established	24/7	Yes	No	Generalist	NHS
Nurse led services Overall Score							
District Nursing	RGN and HCA available OOH across 2 of the 3 localities. One locality provides 24/7 care the other partial OOH cover (gap between 4pm -6pm). However this gap is being covered from April 2011. The other locality does not have OOH cover. Most of their work is for EOL patients	Established	24/7 cover in 2 of the 3 localities	Yes	no	Generalist	NHS
Containing Health care Fast track service	Dedicated PCT team providing carer and DN to give a full package of care (personal and nursing). Planned cover only via referral from DN/GP/hospital	Established	24/7	Yes	Yes	Generalist	NHS and Local Authority
Community Matron	Not available	N/A	N/A	N/A	N/A	N/A	N/A
Rapid Response/ Intermediate care	Not available	N/A	N/A	N/A	N/A	N/A	N/A
Nurse led services (ctd)							
Nursing and	Provide health and social	Established	24/7	Yes	No	Generalist	NHS and

Traffic Light rating Criteria

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Not able to score



ID 1

- Population: 600,000
- No GP practices: 88
- Geography: Mix
- Number of Localities : 3

	Description	Established service, new or in development	Period of Cover	Equality for all diagnosis	Dedicated EOL service	Generalist or specialist service	Sector NHS/Voluntary /Local authority
social care - Carer 24 hour response team	care at home by carers. Aim is to prevent hospital admissions and support early discharge. Provides planned and unplanned needs. Services: telephone advice, home visits, medication access and equipment (via DN or carers from the sub stores in the 3 localities). Staffed mainly by carers but some DN. Carers trained to support basic medical skills; more skilled work covered by DN Integrated with ambulance DN and GP and accessed via Single point of access						Local Authority
Patient telephone advice	Via nursing and social care team- see above	Established	24/7/	Yes	No	Generalist	NHS and Local Authority
Hospice Led Services Overall Score							
Marie Curie Hospice at Home (locality 1)	Sitting or nursing cover. Planned care only. Supported by RGN & HCA. Night cover only. Sparse availability; but increasing capacity from 2012. Mainly for cancer (80%). Via referral from DN Split funded NHS/Voluntary	Established	2200-0700	No Biased cancer (80%) and only in one locality	Yes	Generalists	NHS and Voluntary
Marie Curie Hospice at Home (locality 2)	Sitting or nursing cover. Planned care only. Supported by RGN & HCA. Night cover only. Sparse availability; increasing in 2012. Mainly for cancer (80%). Via DN referral. Mainly NHS funded.	Established	2200-0700	No Biased cancer (80%) and only in one locality	Yes	Generalists	NHS and Voluntary
Hospice at Home (locality 3)	Sitting or nursing cover. Planned care only; from 2013 unplanned cover. RGN & HCA. Night cover only. NB Inclusive of all diagnosis. Voluntary funded	Established	2200-0700	Yes	Yes	Generalists	Voluntary
Hospice Led Services (continued)							
Patient telephone advice	Based in 3 hospices in area. Not a specific phone line but via main hospice switchboard. Nurse and specialist medic available for advice.	Established	Yes	24/7	Yes	Specialist	Voluntary
Prof Telephone	Available but not details	Established	Yes	24/7	Yes	Specialist	Voluntary

Traffic Light rating Criteria

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GREEN (Implemented/systematic/routinely used)



Not able to score



ID 1

- Population: 600,000
- No GP practices: 88
- Geography: Mix
- Number of Localities : 3

	Description	Established service, new or in development	Period of Cover	Equality for all diagnosis	Dedicated EOL service	Generalist or specialist service	Sector NHS/Voluntary /Local authority
Advice Line							
Acute based services Overall Score							
Medication Access OoH	<p><u>Planned need</u> Anticipatory prescribing; just in case boxes stored at patients homes. some GPs don't use because of cost £25</p> <p><u>Unplanned need</u> Via GP/DN OOH. Both have access to Just in case medication. Carer 24 hour response team can also access medication. For other medication GP OOH prescription and medication accessed via late night pharmacists some of whom stock EOL drugs</p>	Established	N/A	Yes	Yes	Generalist	NHS
Planned							
Unplanned							
Equipment Access OOH	<p>Generally anticipated but simple small equipment stored in stores in localities that DN/HCA can access.</p> <p>No details provided about specific provision for rapid access for rapid discharge.</p>	Established	N/A	Yes	Yes	Generalist	NHS
Advance Care planning	<p>Not known</p> <p>No details provided</p>						
OTHER EOL TOOLS Overall Score							
GSF – GP GSF- care homes	Not known.						
LCP	Not known						
DNAR/ DNACPR	Standard practice in PCT	Established	N/A	N/A	N/A	N/A	NHS
PPoD	Not in place						
PpoC	Standard use in PCT	Established	N/A	N/A	N/A	N/A	NHS
CARE COORDINATION Overall Score							
Coordinating centre	Not available	N/A	N/A	N/A	N/A	N/A	N/A
Single point access	Available for each of the 3 localities	Established	24/7	Yes	No	Generalist and Specialist	NHS and Local authority
Virtual ward	Not available	N/A	N/A	N/A	N/A	N/A	N/A

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ID 1

- Population: 600,000
- No GP practices: 88
- Geography: Mix
- Number of Localities : 3

MANAGING END STAGE CARE <i>Overall Score</i>							
LCP	Not known						
Hospice at Home	Available but biased to cancer in 2 of 3 localities as well as limited availability.	Established	Night	Bias in 2 of 3 localities	Yes	Generalist	NHS
CHC Fast-track	Available – see above	New	N/A	Yes	Yes	Generalist	NHS
OOH Access to pall care bed	Not known						
	Description	Established service, new or in development	Period of Cover	Equality for all diagnosis	Dedicated EOL service	Generalist or specialist service	Sector
STAFF TRAINING <i>Overall Score</i>							
GSF coordinator	Not known						
GP EOL facilitator	Not known						
Advanced communication skills	Available except for care home staff but access for other staff unknown	Established	N/A	N/A	Yes	N/A	NHS/Voluntary/Local authority
Support for GPs to access	Available but accessibility for staff unknown	Established	N/A	N/A	Yes	N/A	NHS
Support for nurses to access	Available but accessibility for staff unknown	Established	N/A	N/A	Yes	N/A	NHS
Access to care home staff	Available but accessibility for staff unknown	Established	N/A	N/A	Yes	N/A	Local Authority
OTHER							
Marie Curie Delivering choices Programme	Undertaking at present Phase 1 from April 2011	New	N/A	N/A	N/A	N/A	N/A

Appendix 6

Topic Guide for Virtual Users Group

Introduction: check participant has received and read project information. Recap, answer questions as necessary. Talk through consent form, and gain permission to tape record. Ensure the consent form has been signed with a copy for the participant.

'Thank you for agreeing to talk with me as part of the study. In our discussion today, I would like us to focus on your experiences and priorities for out of hours care locally.

The out of hours period is evenings after 5.30pm, nights, weekends and bank holidays. Presently the way care is provided varies across the country in terms of what is available and when it is available. The purpose of this study is to identify the best way in which out-of-hours care can be provided for people with advanced disease and others who may need it, for example older people. To do this we need to talk to both patients (and/or their carers) and the staff who provide this care to find out their experiences of out-of-hours services locally.'

I'd like to find out what in your view is important, what works and what doesn't work so well at the moment.

1. Please tell me your experience(s) of contacting your local out-of-hours service?
(If no experience read case study example and carry on with questions).
2.
 - What is important for you about out-of-hours service?
 - Speed of access (direct line)
 - OoH staff aware of you and your medical condition
 - Access to health professionals (phone and/or visit)
 - Access to health professionals you know and who know you
 - Ability to access medication/equipment OoHs
 - Access to which particular health professionals – GPs, DNs, Macmillan nurses, Marie Curie/night sitters, hospice etc
3. What is unhelpful about your local out of hours service at the moment? Why?
4. How could the out-of-hours service be improved?
5. What may stop you from contacting the out of hours service?
6. What would need to be in place to help you contact the out-of-hours

service?

7. In an ideal world what would your local out of hours service look like?

Appendix 7

Responsibilities of Senior Manager EoL and OoH Leads in SHAs and HBs in England and Scotland

Participants' Responsibilities for End of Life and/or Out of Hours care

End of life Care

1. Strategic management for EoL and continuing care – commissioning and training
2. EoL lead for SHA - strategy role
3. Lead for EoL and Long term conditions - strategy role
4. Implementation programme manager for EoL, cancer and urgent care
5. Chair of Palliative Care Strategy group and EoL education lead
6. Medical Director responsible for EoL care + GP OoH services
7. Strategic management for cancer and palliative care
8. Lead for EoL to deliver EoL strategy
9. Manager for special services, mainly EoL

Out of Hours Care

1. Performance management of OoH services, includes support and developments of GPs as commissioners
2. Strategic commissioning and performance of OoH services
3. Associate Director for Primary and Community Care - main role to primarily support transforming community services agenda and the Foundation Trust pipeline
4. General manager for OoH services, and GP lead for delivery of OoH provision

Appendix 8

Key Strategic Priorities Identified by EoL Senior Manager Leads in SHAs and HBs in England and Scotland

- Overall EoL Pathway
 - Developing the EoL Pathway
 - Supporting PCTs to develop EoL Pathway
 - Coordinating implementation of EoL Pathway
 - To maintain the quality of services and ensure sustainability
 - To ensure patients can remain at home if that is their PPOD
 - Implementation of Standards for OoH EoL care
- Step 1 of EoL Pathway
 - E-palliative care summary
 - Focus on early identification of EoL patient
- Step 2 of EoL Pathway
 - Implement/Audit ACP
 - Roll out DNACPR or other tool
 - Monitoring PPOD
 - Instigating early ACP
- Step 4 of EoL Pathway
 - Access to services 24/7
 - Access to drugs and medication 24/7
 - Commissioning services
 - Adequate signposting of OoH EoL services
 - Clinical development, medical staff and behaviour in respect of EOL patients
- Step 5: EoL training
- Monitoring
 - PPOD
 - OoH EoL services via PCT
 - Reduce inappropriate hospital deaths
 - Achieving a 10% annual reduction in hospital deaths
 - Reduce inappropriate hospital admissions
 - Quality and efficiency management of OoH services
 - 10% annual reduction in emergency admissions to hospitals from nursing and care homes

Appendix 9

Key Strategic Priorities Identified by OoH Senior Manager Leads in SHAs and HBs in England and Scotland

EoL Pathway

- To follow national guidelines
- Supporting PCTs to develop EoL Pathway
- Develop standard treatment guidelines
- To ensure priorities of EOL care

Step 1 of EoL Pathway: Ensure good electronic communication of EoL status between sectors

Step 3 of EoL Pathway: Developing a Single Point of Access

Step 4 of EoL Pathway: Provision of services

- Providing alternative treatment options for EoL patients rather than A&E
- To ensure standard OoH services are available across whole SHA

Monitoring

- Addressing the Quality, Innovation, Productivity and Prevention (QIPP) End of Life Care work stream
- Quality and efficiency management of OoH services
- Continuity of care – monitoring complaints and patient experiences
- Outcomes
 - Implement/Audit ACP
 - Introduce and monitoring PPOD (including care homes)

GP commissioning

- Support the transforming community agenda
- Support the development of commissioning
- Managing the transfer to GP commissioning in respect of OoH care provision
- Increase the capacity for commissioning and manager services

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