

Research paper

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# End-of-life care



An Inquiry into the Quality of General Practice in England

# **End-of-life care**

Rachael Addicott

**This paper was commissioned by The King's Fund to inform the Inquiry panel.**

**The views expressed are those of the authors and not of the panel.**

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## About the author

Rachael Addicott has been a Senior Research Fellow at The King's Fund for the last three years, having previously been a Lecturer in Public Sector Management at Royal Holloway University of London. Rachael has an interest in organisational change and models of governance and accountability in the public sector, and works on a number of projects in these areas. She also leads on end-of-life care research for The King's Fund. Rachael has a PhD in health service management from Imperial College London.

## Introduction

Recent government guidance (Department of Health 2008a, NICE 2004) has raised the profile of end-of-life-care (EOLC). However, historically care has been poorly organised, with large gaps in provision depending on geography and diagnosis. Some of these gaps are a result of confusion over roles and responsibilities, and a reluctance or lack of confidence among health and social care professionals in providing this care and engaging with patients and carers in a meaningful way at the end of life.

This report forms part of the wider inquiry into the quality of general practice in England commissioned by The King's Fund, focusing specifically on the quality of end-of-life care (EOLC). This report discusses:

- the role of general practice in EOLC
- what high-quality EOLC in general practice might look like
- how this might be measured.

EOLC has received significant policy attention over the last several years – most recently with the publication of the *End of Life Care Strategy* (Department of Health 2008a) and the 2009 strategy document from the Royal College of General Practitioners. Much of the focus of this discourse has been on patient choice and shifting care into the community. Clearly, this represents a more significant EOLC role for GPs, and for community care providers more generally. From the literature review and case study research, it is evident that GPs also consider themselves to have a significant and continuing role to play in the delivery and organisation of EOLC.

The discussion and findings presented in this report are based on a literature review of existing research and empirical findings from case studies of two general practices. These practices were chosen through discussion with several national primary care stakeholders to represent illustrative cases of high and low performance in relation to the planning and delivery of EOLC in general practice. They provide illustrative evidence to support findings from the literature review, and offer contrasting case examples. We sought research findings that identified the challenges to providing good quality EOLC in general practice, as well as illustrative and comparative examples of good practice.

This report highlights the role of GPs and general practice in the delivery and organisation of EOLC. While EOLC is managed by a variety of health and social care professionals, GPs continue to play an important role in co-ordinating patient care, in providing support to patients and carers, addressing the practicalities of prescribing and verifying death, and managing follow-up and bereavement care.

Although the findings of this report highlight clear and concise characteristics that are considered significant for improving the quality of EOLC, they revealed less agreement on how such quality might be measured in practice. Existing guidance (Department of Health 2008a) and quality markers (Department of Health 2009) focus heavily on indicators related to structure and process. Outcome measures, and indicators of quality, are difficult to define because traditional health outcome indicators (such as mortality or morbidity) are inappropriate and ineffectual in EOLC.

# 1 Background

This report discusses:

- the role of general practice in end-of-life care (EOLC)
- what high-quality EOLC in general practice might look like
- how it might be measured.

The discussion and findings presented in this report are based on a review of existing research and literature, and empirical findings from case studies of two general practices.

This report forms part of the wider inquiry into the quality of general practice in England commissioned by The King's Fund, focusing specifically on the quality of end-of-life care (EOLC). To coincide with the Department of Health's (2008a) *End of Life Care Strategy* and the National Council for Palliative Care (2006) definition, EOLC is not considered to be care that takes place at a specific period of time preceding death, but rather a reflection of the care and support needs of patients and carers. As such, it is considered to encompass the care and support provided for patients and their carers regardless of diagnosis, and regardless of the estimated period of time before death.

The report focuses on the role of general practice, and general practitioners (GPs), in providing and organising this care and support. The Royal College of General Practitioners (2009) considers EOLC to be the core business of general practice. As such, its paper *The RCGP End of Life Care Strategy Document* seeks to respond to and prepare for the predicted increases in demand for EOLC services. The curriculum statement from the Royal College of General Practitioners (Royal College of General Practitioners 2007) suggests that GP trainees have a role in prevention and diagnosis right through to terminal care. This role requires confidence in handling common distressing symptoms and an appreciation of the psychosocial factors that are important in end-of-life care.

Recent government guidance (Department of Health 2008a, NICE 2004) has raised the profile of EOLC, but historically care has been poorly organised, with large gaps in provision depending on geography and diagnosis. Some of these gaps are a result of confusion around roles and responsibilities in the delivery of EOLC, and a reluctance or lack of confidence among health and social care professionals in providing this care and in engaging with patients and carers in a meaningful way at the end of life (King's Fund 2009).

This report highlights the role of general practice and GPs in EOLC, and asks what high-quality EOLC in general practice might entail and how this might be measured. One of the main organisational issues in EOLC in primary care is that of maintaining a dynamic database of patients with EOLC needs and capturing their care preferences. There are various tools available for managing this process, and this report examines the use and application of one of these tools: the Gold Standards Framework.

The report is based on a literature review and illustrative case studies of two general practices. This methodology is described in more detail in the following section.

## 2 Methodology

The discussion and findings presented in this report are based on a literature review of existing research and empirical findings from case studies of two general practices.

We conducted a literature review through a search of the following databases: the Applied Social Sciences Index and Abstracts, the Health Management Information Consortium, the Social Care Institute of Excellence, PubMed, the Gold Standards Framework and King's Fund databases. Various combinations of the following search terms were used to narrow the search results:

- general practitioner, primary care, nurse
- end of life, end-of-life care, palliative care
- patient register
- palliative care register
- Gold Standards Framework, barriers to implementation
- advanced care planning
- adoption of new innovations, adoption of new practice, organisational behaviour.

After reviewing the literature generated by these searches, we used a snowball approach to yield further relevant references. We then conducted a manual search of the bibliographies of the retrieved articles to generate further references. In some instances, these reviews led to further manual searches, resulting in a snowball reviewing approach. Findings were limited to articles published between 1999 and 2009, with the exception of one highly cited reference.

Following an initial scan of abstracts, we reviewed 75 articles. These articles reflected a variety of research designs and methodologies. Many of the reviewed papers presented research that was not systematic, so the literature reviewed here represents a combination of qualitative and quantitative research studies. The reviewed literature was largely published in the UK, but it includes some sources from Canada, the United States, the Netherlands and Australia.

In addition to the literature review, the report draws on findings from two case studies of general practices in south-east England. We sought to identify general practices at differing degrees of engagement in EOLC. The intention was to work with one practice that was considered to be more proactive and innovative in its management of patients nearing the end of life, and another that was less advanced in EOLC.

We identified these practices through discussion with several national primary care stakeholders to represent illustrative cases of high and low performance in relation to the planning and delivery of EOLC, particularly characterised by their use of an EOLC register. These national stakeholders who were consulted were involved in development and training of end-of-life care registers, and had a working knowledge of various practices performance. One general practice was quite large, and regarded by expert stakeholders as a high

performer. The second general practice was mid-sized, and was considered less advanced in the organisation and delivery of EOLC.

Case study research is appropriate for studying complex phenomena, such as the roles and responsibilities studied in this context, and is considered more powerful than other methods (such as randomised controlled trials) in revealing the complexities of an organisation, and relationships across stakeholders (Yin 1994). Although the limited scope and representativeness of the case study research does not provide opportunity for statistical or theoretical generalisation, it does provide illustrative evidence to support findings from the literature review, and provides vignette examples of what good quality EOLC in general practice might look like.

From the two contrasting case examples, we sought research findings that identified challenges to providing good quality EOLC in general practice, as well as illustrative and comparative examples of good practice. We also combined the findings from the case studies with the literature review, to provide a robust analysis of this complex contextual area, from different perspectives.

Across the two case study sites, we conducted interviews with eight GPs, one practice nurse and two district nurses (n=11). Semi-structured interviews (of approximately 45 minutes each) took place during July and August 2009. In keeping with the broader objectives of the GP Inquiry, these were focused on determining the nature and mechanics of EOLC delivered by the general practice or GP, including the use of existing tools and registers, the interviewees' views and experiences with the delivery of this care, and their broader perspectives on what an ideal version of EOLC would look like and how it might be measured.

The interviews were transcribed and anonymised, and analyses on this collected data were undertaken to reveal common themes, which were used to develop the discussion presented here and to support the findings from the literature review.

From the initial literature review, this report considers first the role of general practice in EOLC, and then asks what high-quality care might entail. In many instances it is difficult to make this differentiation, so the discussion focuses primarily on the second issue – what high-quality care might (or should) look like – with examples from the literature regarding how general practices are known to be performing in these areas. Following this discussion, it presents findings from the case studies to support the literature, and to provide examples of good practice and highlight challenges to providing high-quality EOLC in general practice.



### 3 Literature review: the policy context

This section provides an overview of the role of general practice in EOLC, primarily concentrating on the direction of government guidance. Much of this guidance pertains to the delivery and organisation of EOLC more widely across the health sector, and sometimes the social care sector. However, the discussion of this guidance focuses more generally on highlighting current policy direction, the growing profile of EOLC, and how this shift in emphasis applies to general practice.

Literature suggests that GPs play a vital role in the delivery of EOLC – particularly in assuming overall responsibility for direct patient care, and for ensuring co-ordination and communication with other health care providers involved with the patient (Mitchell 2002, Thomas 2003, Murray *et al* 2004, Forrest and Barclay 2007, NICE 2004). There is limited research regarding patient and carer satisfaction with EOLC and general practice, but available findings do suggest that bereaved carers have generally reported feeling satisfied with the EOLC provided by their GP (Hanratty 2000).

Nevertheless, despite occupying a key role in the delivery of a very important aspect of care, EOLC represents a relatively small component of the workload of most general practices and consequently presents a challenge for GPs to stay abreast of the latest policy and practice developments in the field. This may be further exacerbated by the reported inadequacy of current training, including a lack of case-based learning approaches in EOLC for general practice (Mitchell 2002, Mitchell *et al* 2004, Higginson 2005, Shipman *et al* 2008).

Perhaps consequently, a 36-year systematic review revealed that many GPs feel ill-prepared and lack confidence in EOLC, despite being considered vital players in its delivery, and despite the fact that they themselves value this part of their work. GPs reported feeling particularly challenged when it came to managing patients' and carers' psychological needs at the end of life, although more experienced GPs reported this as being less problematic. Some were also troubled by the challenges of managing pain and other symptoms, although the degree of concern was shown to fall over time (Mitchell 2002). These findings suggest that in the absence of adequate training for GPs, experience is considered to be the most reliable indicator of confidence and skill in the delivery of EOLC.

On this basis, it is evident that GPs – and general practices, more widely – do have a key role to play in organising and delivering EOLC. However, there may be some confusion about the specific nature of the care that is provided, and limited resources to ensure that GPs and other primary care providers feel supported and confident in performing this role. Nevertheless, recent government guidance goes some way in attempting to alleviate these concerns and to provide a systematic foundation for care delivery and organisation.

#### *Quality in end-of-life care*

There is considerable government guidance available to health and social care providers, including GPs, on how best to deliver EOLC. The National Institute for Health and Clinical Excellence (NICE) practice guidelines for

cancer and EOLC have been in place since 2004, and the Department of Health's (2008a) *End of Life Care Strategy* offers a detailed care pathway. In addition to these, the Royal College of General Practitioners has developed an EOLC strategy, and practitioners can also consult the Liverpool Care Pathway (LCP) and the Gold Standards Framework (GSF) as pathway tools for the delivery of EOLC. The Appendix provides an overview of each of these guidance documents. The GSF, as a guidance tool for monitoring patients who are nearing the end of their life, is discussed in more detail throughout the report.

The publication of the *End of Life Care Strategy* (Department of Health 2008a) has radically raised the profile of EOLC in England, signalling the need for development in the planning and delivery of EOLC, to ensure that individuals are able to exercise genuine choice in where they are cared for and die. The strategy builds on a range of existing evidence, including policy documents and national standards, and is clearly aligned with the quality agenda that is highlighted particularly in *High Quality Care for All: The NHS next stage review* (Darzi 2008), and the World Class Commissioning vision (Department of Health 2008b). Similarly, the growing emphasis on place of care preferences in EOLC has developed alongside wider emphasis on patient choice.

The paper *Building on the Best: Choice, responsiveness and equity in the NHS* (Department of Health 2003) set the policy agenda for the introduction of greater patient choice. This paper established objectives to develop more responsive services, to offer patients real choices, and – in delivering that – to ensure optimum use of capacity. The paper outlined six priority areas in which to increase patient choice, one of which was EOLC, and expressed a government commitment to offer all patients equal access to specialist palliative care services, regardless of their diagnosis, so that they could choose to die at home should they so wish.

More recently, the White Paper *Our Health Our Care Our Say* (Department of Health 2006) furthered this commitment to choice in EOLC, with pledges to double funding for EOLC, to establish EOLC networks in order to improve service co-ordination, and to implement the national roll-out of EOLC tools such as the GSF and the LCP. More broadly, *Our Health Our Care Our Say* was significant in signalling a government commitment to move from an acute to a community model of health care, with delivery of services closer to people's homes.

Developments in EOLC policy are aligned with this agenda – in particular, moves to establish community services that enable people to exercise genuine choice in EOLC and to ensure that they are supported to be cared for at home should they so wish. This shift clearly has implications for general practice.

The development of EOLC policy has largely been driven by the issue of patient preference, both at local and national levels. Research suggests that two-thirds of individuals would prefer to die at home, while in reality only about one-third achieve this (Higginson 2003). Aware of this variance, much policy and literature has sought to ensure that EOLC services are appropriately configured and delivered, to ensure that a greater number of people can be cared for in the place of their choice (which is often assumed to be home).

Recent policy has attempted to identify gaps in existing service provision, and to make recommendations on how services should be developed to better meet individual's preferences. This guidance tends to share the aim of being responsive to the unique needs of individual patients and their families, whether in the community, hospital, care home or other setting. Although

much of the focus of EOLC continues to be on the organisation and delivery of care for patients with cancer, government directives and strategies apply to all patients regardless of diagnosis (Murray *et al* 2004), recognising the need for high-quality and organised end-of-life care.

### *Equitable access to end-of-life care*

There is general recognition across service providers of the value of the guidance mentioned above. However, there are calls for more explicit acknowledgement that many people will require EOLC for extended periods of time. In particular, the frail elderly and those with long-term conditions will require care and support over a long timeframe, and may require different types of support from those with cancer.

Patients with cancer tend to experience a gradual decline in their condition, while those with non-malignant diseases tend to follow a less predictable disease trajectory characterised by a series of peaks and troughs: acute exacerbations, which often require medical intervention and hospitalisation, followed by periods of relative stability. An individual may die in any one of these dips in their condition, or may progress to a period of stability. Consequently, it can be difficult for clinicians to assess when a patient is approaching the end of life – deterioration in condition may simply be another acute exacerbation from which an individual may recover (Murray *et al* 2005, Dy and Lynn 2007).

Previous research (King's Fund 2009) suggests that there are several interrelated reasons why access to EOLC is more difficult for patients with a non-malignant diagnosis. There are fundamental differences in disease trajectories that make prognosis for non-cancer patients more difficult. There is limited interaction between specialist and generalist teams, and knowledge and experience regarding prognostic indicators is not routinely shared. In particular, generalist staff have difficulty identifying when patients with a non-cancer diagnosis would be regarded as in need of EOLC and support. As such, access to EOLC services is offered comparatively late in the patient journey.

Recognising these trajectories allows GPs and others charged with designing and delivering end-of-life programmes to plan, organise and deliver services more effectively, and to provide appropriate training to health care workers (Dy and Lynn 2007). A shift of this nature might also allow for a more balanced allocation of resources and focus across different trajectories, and might address what some see as a current imbalance, where the needs of patients with cancer are prioritised over the needs of others (National Audit Office 2008, Department of Health 2008a, Higginson 2005). However, the literature offers little suggestion as to how this might be achieved.

It is evident that any lack of confidence or experience in organising and delivering care for patients at the end of life is most pronounced for patients with non-malignant conditions. Government guidance further entrenches processes and outcomes for patients with cancer, while there is limited recognition of the different care needs of those with non-malignant conditions.

However, recent guidance offers some suggested mechanisms for general practice to more effectively identify, monitor and manage patients at the end of life, regardless of diagnosis. Some such elements of this guidance carry compliance incentives – in particular, the recommendation that general practices should hold a register of patients who are nearing the end of their

life. These compliance incentives are built into the Quality and Outcomes Framework (see below/opposite/overleaf).

### *Incentives for performance*

#### **The Quality and Outcomes Framework**

The Quality and Outcomes Framework (QOF, Health and Social Care Information Centre 2008) is an incentive system that was introduced as part of the general medical services contract in 2004 and that recognises and rewards individual general practices for meeting various indicators of quality care, in a wide variety of practice areas. When GPs reach certain predefined performance thresholds (through clinical or organisational processes, patient experience and additional services), this is recognised through a points structure. At the end of each year the points are calculated, and practices receive a relative payment. At present, participation in the QOF is voluntary.

QOF points are now available to practices performing two specified EOLC functions:

- **PC1** – the practice has a complete register available of all patients in need of palliative care or support
- **PC2** – the practice has regular (at least three-monthly) multidisciplinary case review meetings where all patients on the palliative care register are discussed.

These act as an incentive for general practices to develop and use such registers of patients with EOLC needs. The case study findings also provide further discussion regarding EOLC registers – in particular, using the GSF as a means for collecting and acting on information collected.

#### **The Gold Standards Framework**

The Gold Standards Framework (GSF) intends to provide a systematic and consistent approach to the delivery and organisation of high-quality EOLC in general practice and care homes. The GSF has five goals, to provide for patients with any final illness with:

- consistent high-quality care
- alignment with patients' preferences
- pre-planning and anticipation of needs
- improved staff confidence and teamwork
- more home based, less hospital-based care.

As with many other components of high-quality EOLC, the implementation of the GSF relies heavily on strong communication between patients and general practices. The GSF is implemented via three key processes:

- identifying patients in need of EOLC
- assessing their needs
- planning and co-ordinating the delivery of this care.

At its most basic use, the GSF acts as a repository list of patients nearing the end of life. However, in a more sophisticated way it can be used to prompt

greater communication and care planning around EOLC needs. Clearly, the principles of the GSF offer a potential mechanism for meeting the EOLC indicators of QOF. Consequently, as will be discussed below, there is a heavy reliance on processes – particularly processes of co-ordination and practice organisation – in executing the Framework.

Approximately 90 per cent of general practices in England have a register of patients, and 60 per cent have adopted the use of a register at a more sophisticated level, to act as a lever for care planning (see the GSF website at: [www.goldstandardsframework.nhs.uk](http://www.goldstandardsframework.nhs.uk)). To date, evaluations have been largely positive while also consistently noting some drawbacks (Munday and Dale 2007). Acknowledged positive aspects (Walshe *et al* 2008, Thomas and Nobel 2007, Mahmood-Yousuf *et al* 2008 and King *et al* 2005) include:

- enhanced cross-discipline communication and teamwork, including higher quality relationships among colleagues
- shared philosophies of care across providers
- better patient information sharing
- more formalised processes to reduce the chance that patients might be overlooked, such as regular multidisciplinary team meetings.

However, a number of downsides of the GSF have also been cited (Mahmood-Yousuf *et al* 2008, King *et al* 2005), including:

- an increased paperwork burden with the use of lists, tick boxes (which were sometimes seen as impersonal) and evaluation
- increased demands on GP time arising from the need for regular meetings
- a focus on process at the potential cost of a patient-centred approach
- the risk that a high level of variation in implementation of the the GSF, which can make it challenging for practices to directly attribute improvements.

A sufficient level of financial and other resources are seen as vital to support the broad, effective and long-term implementation of the GSF – particularly in relation to proactive management of the database and the resources required to co-ordinate and conduct the associated multidisciplinary team meetings (McClelland *et al* 2008, Munday *et al* 2007a, Munday and Dale 2007). A Canadian project in which participants were tasked with designing the ideal EOLC system resulted in a model that contained almost all elements of the GSF. Participants in this project also noted the potential problems with such a model in the absence of adequate resources – particularly for out-of-hours care and nursing coverage (Brazil *et al* 2007).

Within the academic literature there is a clear focus on examining the GSF's impact in terms of administration and processes rather than its subsequent effect on patient outcomes. The National Audit Office (2008) examined whether the GSF resulted in improved delivery of EOLC, and concluded that further research is required before any conclusions could be drawn. However, it did note that the limited research undertaken to date points to fewer unanticipated hospital admissions, and increased likelihood of individuals dying where they choose.

The GSF has seen considerable uptake by general practices within the

UK. However, the ensuing scrutiny and evaluations have focused largely on whether it has led to improvements in various organisational and communications processes within general practice, rather than on whether patients nearing the end of their lives are receiving higher quality care. (These findings are discussed in more detail in the following section.) Consequently, the findings of these studies, while useful, are clearly limited.

In summary, EOLC has received significant policy attention over the last several years – most recently with the publication of the *End of Life Care Strategy* (Department of Health 2008a) and the strategy document from the Royal College of General Practitioners (2009). Much of the focus of this strategy has been on patient choice and shifting care into the community. This clearly represents a more significant role for GPs in EOLC, and community care providers more generally. GPs see that they have an important role in EOLC, but so far it represents a small part of their workload, and consequently GPs have expressed some anxieties regarding competencies in this area. Further, there is little evidence documenting patient and carer experiences of EOLC within general practice.

These issues and policy documents are raising the profile of EOLC in the UK, and providers and commissioners are now tasked with implementing the recommendations within these strategies.

It is evident that general practices in England are able to call upon a significant body of research and advice to support their work in caring for patients who are nearing the end of life. The next section provides an overview of what high-quality EOLC in general practice should look like, according to the recent literature, examining the key themes and features of this care, as they were found to emerge in current literature on the subject.



## 4 High-quality end-of-life care in general practice

This section presents the main themes that emerged from a review of the literature published since 1999 on factors considered to be significant in the organisation and delivery of high-quality EOLC in general practice:

- co-ordination of care
- continuity of GP care
- communication with patients and carers
- bereavement care.

In this section each of these themes is considered in turn. In the following section we then consider how these, and other emerging themes, are represented in the case study findings.

### *Theme 1: Co-ordination of care*

#### **Interprofessional communication and organisation structures**

The importance of multidisciplinary teamwork and communication features prominently in a range of guidance, and is cited frequently both by patients and medical professionals as an central component in the delivery of high-quality EOLC (Mahmood-Yousuf *et al* 2008, Department of Health 2008a, Borgsteede 2006, Patrick *et al* 2003). Such communication across professional groups and organisational structures will also go some way towards meeting the current concerns regarding the provision of out-of-hours care, as described above.

Much of the literature on interprofessional and inter-organisational communication relating to EOLC focuses on communication and implementation of the GSF (see Section 3). Perhaps unsurprisingly, general practices that are strong on communication and co-ordination are generally more positive about their experience of implementing the GSF than are those that place less importance on communication. Internal practice communication and co-ordination were most consistently seen within practices that had adopted the GSF (Mahmood-Yousuf *et al* 2008, Shipman *et al* 2008, Munday *et al* 2007a, Thomas 2007, King *et al* 2005, Dale *et al* 2009).

Tools such as the GSF go some way to compensate for weaker organisational practices by formalising and standardising cross-discipline communication and work practices that may otherwise be ad hoc and inconsistent (Thomas and Nobel 2007, Mahmood-Yousuf *et al* 2008, King *et al* 2005). This is achieved through activities such as implementing formal EOLC registers and holding regular multidisciplinary meetings. However, Walshe *et al* (2008) found that the GSF was more likely to have a positive influence on professional communication and processes but had limited evidence of impact on patient care and outcomes.

A recent evaluation of the implementation of the GSF for patients with dementia also highlighted the value of strong communication between GPs and other health care professionals. The evaluation concluded that good communication can help respond to the preferences of a patient with dementia who is dying (when these preferences are known), enhances out-of-hours care by formalising the use of handover reporting forms, and

increases the confidence of other primary care providers involved in the delivery of EOLC and decision-making. The support of GP leaders for the GSF was key in enhancing this confidence and fostering open communication among health care team members (McClelland *et al* 2008).

The QOF encourages the co-ordination of multidisciplinary meetings, as a forum to discuss the care of patients who are nearing the end of their life. Reviews of the GSF and other end-of-life registers consistently reveal that general practices with strong teamwork and communication skills tend to be associated with the overall delivery of high-quality EOLC (Shipman *et al* 2008, Mitchell 2002, Curtis *et al* 2001).

For example, the importance of cross-functional communication and organisation (along with the problems which arise when such systems falter) was highlighted in a study of EOLC in advanced dementia patients. Carers reported wanting more information on the disease, its treatment and how best to plan ahead. At the same time, GPs reported relying on secondary care to provide this information, while expressing the (justifiable) concern that carers were inadequately informed. The study concluded that if these sorts of shortcomings in organisational communication practices were addressed, and better education and information provided to patients and carers, this could result in increased quality of EOLC for patients with dementia and better bereavement outcomes for carers and relatives (Sampson *et al* 2008).

It is evident that the introduction of the GSF has gone some way to formalising and standardising communication and processes. However, less is known about its impact on patient outcomes or experiences. The existence of an EOLC register in itself will not improve patient care or outcomes, so it is vital that general practices work to act on the information that they are collecting for care planning – both for their individual patients and across their populations.

As well as discussing interprofessional communication, the Sampson *et al* (2008) study particularly draws attention to two other important themes that emerged from the EOLC literature: the importance of good communication with patients and their families, and issues surrounding bereavement care for family and carers. These are addressed later in the section.

## *Theme 2: Continuity of GP care*

### **Out-of-hours care**

Although most GPs are satisfied with the quality of the out-of-hours general primary care delivered (Shipman *et al* 2000), many believe that the availability (or quantity) of out-of-hours care for patients nearing the end of life is often inadequate (Thomas 2003, Murray *et al* 2004, Shipman *et al* 2008). Further, research findings suggest that patients and carers are less positive about the care that they receive from out-of-hours services than from their GPs (Worth *et al* 2006). Following recent failings in out-of-hours care, such as the death of a patient being treated by a locum GP, the Department of Health (Colin-Thome and Field 2010) have published a review of the current system of out-of-hours care. It recommends that commissioners promote greater integration of out-of-hours primary care services, and that more attention is given to ensuring that patients are aware of the out-of-hours services that are available to them.



Patients consider good out-of-hours care to be important, and ideally they prefer to receive it from their regular GPs (Borgsteede *et al* 2006). Historically this care has been delivered by an extended primary care team rather than an individual practitioner, but recent reorganisations (including separation of provider services and other factors) have fractured this multidisciplinary team, threatening the capacity of a more personalised model of care in out-of-hours periods. Recent reorganisation initiatives flow from a general uploading of responsibility from GPs to local primary care trusts, the establishment of a centralised, single point-of-access 24-hour triaging service and, perhaps most importantly, the co-operation of general practices, which now often use deputised GPs to provide out-of-hours care (Worth *et al* 2006).

All this means that patients are less likely to receive consistent out-of-hours care. Seamless and continuous provision was identified as a key feature of high-quality primary care, so efforts should be made to ensure that patients are able to expect the same level of care regardless of the time of day, or day of the week. It remains to be seen whether newer initiatives (such as polyclinics, polysystems, integrated care organisations and social enterprises) can reverse this unhelpful disconnection and reinvent the primary care team, with its ability to provide more integrated care across out-of-hours periods.

Out-of-hours services are responsible for covering approximately 75 per cent of the hours in the week, and although many practices rely on out-of-hours GP services, the GPs providing the service may be inadequately informed of the specific needs of patients nearing the end of life, often being better equipped to deal with acute emergencies (Shipman *et al* 2008, Murray *et al* 2004, Mitchell 2002). This finding is supported by evidence from the case studies conducted as part of this project.

### *Theme 3: Communication with patients and carers*

Although not always specific to GPs and general practice, a number of studies demonstrate the importance of communication with patients nearing the end of life and their carers (Wright *et al* 2008, Murray *et al* 2008, Kendall *et al* 2006).

Patients and their carers particularly valued proactive communication from the point of first diagnosis (Murray *et al* 2008, Kendall *et al* 2006). A US randomised study followed patients in a formal EOLC programme and measured satisfaction with patient care, the presence of advance directives (such as advance decisions to refuse treatment), and patient and carer experience with the health care system. Researchers concluded that ensuring strong and dynamic communication was advantageous to both patients and their carers (Englehardt *et al* 2006).

Open discussions about EOLC were also seen to significantly help carers manage their bereavement. Those who had experienced open discussion demonstrated better outcomes, including self-reporting of less distress (Wright *et al* 2008). However, other research has found that end-of-life discussions that focus on planning offer questionable benefits – largely because patients are often not truly engaged in the discussions or lack sufficient knowledge to make informed decisions (Saraiya *et al* 2008).

These seemingly contradictory findings may reflect an ambivalence or resistance among clinicians to be the bearers of 'bad news', and to have discussions in which they must communicate prognoses (Cherlin *et al* 2005,

Wright *et al* 2008). The findings may also illustrate the challenges that such complex and difficult discussions sometimes cause for clinicians, as research found that approximately 20 per cent of clinicians find delivering bad news to patients stressful, and for 42 per cent of this group, this stress can last for three or more days (Ptacek *et al* 2001).

These findings might reflect GPs' lack of confidence in delivering and organising end-of-life care, discussed earlier, which is specifically exhibited in terms of the extent of discomfort a GP feels when having potentially difficult conversations with patients and carers. These limitations have implications for the effectiveness with which GPs communicate with patients and carers about prognoses, care needs and options about place of care and death – potentially leading to gaps in service provision for this group of patients. As such, it is important that GPs are supported to increase their confidence and skills in delivering and organising EOLC, and in communicating openly with patients and carers about EOLC.

### **Preferred place of death**

End-of-life discussions such as those examined above often involve determining a patient's preferred place of death, and represent another instance in which communication skills and strategies between patients, their carers and GPs are important. Related to this is the need for GPs to remain up to date on patients' preferred place of death. This choice is dynamic, and often changes over time as the patient moves nearer to death (NICE 2004, Munday *et al* 2007b).

A major Department of Health (2008a) review found that most people, if given a choice, would prefer to be cared for and die at home. Offering patients choice in place of death is also highlighted within NICE guidance (2004), the GSF and the *End of Life Care Strategy* (Department of Health 2008a). The medical community is committed to assisting patients to die where they wish, when reasonably and ethically possible (Munday *et al* 2007b, Murray *et al* 2004), and research has found that patients who state a preference for dying outside of hospital are more likely to do so (Levy *et al* 2008, Swindlehurst *et al* 2006).

Nonetheless, the National Audit Office (2005) has noted a significant discrepancy between preferred and actual place of death – an observation that was confirmed by a large government study, which concluded that currently only about one-quarter of the population realise this preference, with the vast majority dying either in hospital or other facilities, including care homes (Department of Health 2008a, Office for National Statistics 2006). This figure can be contrasted with data from the Netherlands, for example, where 60 per cent of patients with non-acute illness die at home (Borgsteede *et al* 2006). However, a small, regional study in the UK concluded that the GSF and other initiatives have the desired impact of increasing the numbers of patients who do die at home, with 44–71 per cent of patients in the regional areas studied now dying at home (Swindlehurst *et al* 2006).

It should be acknowledged that individuals may change their minds about where they would wish to die depending on circumstances, or depending on whether they are making the decision when they are healthy and well, or nearing the end of life. As such, these decisions should be considered dynamic and a combination of processes used for monitoring patient preferences.

This discussion has highlighted how GPs and general practices may effectively deliver high-quality EOLC to patients and their carers. However, there is also a role for GPs in bereavement support.

### *Theme 4: Bereavement care*

Despite a dearth of research on bereavement care, there is some agreement in the literature that after a patient's life has ended, GP support for bereaved carers is a vital part of delivering good-quality and continuing EOLC (Department of Health 2008a, Mitchell 2002, Saunderson and Ridsdale 1999, Teno *et al* 2001, Steinhauser *et al* 2000). This is further underscored by research demonstrating that bereaved carers are at increased risk of various morbidities and even death (Relf *et al* 2008, Saunderson and Ridsdale 1999).

Nonetheless, research from both the UK and Canada reveals dissatisfaction among bereaved carers with the support they received from their GP (Sisler *et al* 2004, Main 2000). GPs themselves are divided as to whether bereavement care should be offered proactively (to all), or reactively (only to those relatives who request support). Perhaps unsurprisingly, practices that self-identify as having a special interest in EOLC are more inclined to offer proactive support (Harris and Kendrick 1998).

### *Summary*

This section of the report has highlighted a number of important and interrelated issues that are considered vital for ensuring quality in the delivery of EOLC in general practice. The literature reviewed in this section suggests that the following components are key in the provision and organisation of quality EOLC in general practice:

- co-ordination of care and strong organisational systems or structures (including interprofessional communication)
- continuity of GP care – particularly during out-of-hours periods
- communication with patients and carers, including around aims to meet preferences for place of care and death
- appropriate bereavement care.

The provision of out-of-hours care, in particular, has received significant media and political attention over recent months. This is especially topical for the provision of EOLC, where efforts are being made to shift more care into the community setting. This area of provision is likely to receive greater attention over the coming period – particularly following the recent Department of Health review into the matter (Colin-Thome and Field 2010).

The GSF and other EOLC tools have shown a positive impact in formalising and standardising the management of patients at the end of life. However, while EOLC tools have had some impact on the capacity to monitor patient preferences, they have as yet demonstrated very little direct impact on patient care or outcomes, or care planning at a patient or population level.

The next section explores these issues and level of quality of care in the context of case studies of two general practices. The case studies also yielded further issues that GPs and other general practice care providers considered to be pivotal to the provision of quality EOLC – particularly the value of organisational leadership and continuity of GP care. The discussion of the

case study findings is followed by a review of the literature and case study findings relating to the question of how to measure the quality of EOLC in general practice.

## 5 Case study examples

As part of the research, we conducted two case studies of general practices in south-east England. As described in Section 2, we chose these practices as examples of high and low performance in the planning and delivery of EOLC, following discussions with several national primary care stakeholders.

### *Two case studies*

One of the general practices that participated in this study (case study site 1) was quite large, and expert stakeholders considered it to be a high performer. This practice consisted of 14 GP partners, who employed approximately 90 members of staff. The practice cared for approximately 27,500 patients.

The second general practice (case study site 2) was mid-sized, and expert stakeholders considered it to be less advanced in the organisation and delivery of EOLC. This practice cares for approximately 12,000 patients but had far fewer members of staff. From these contrasting case examples, we sought research findings that clarified the perceived role of GPs and general practice in EOLC and identified challenges to the provision of good quality EOLC, as well as offering illustrative and comparative examples of good practice. The key points are presented within each of the four themes highlighted in the previous section.

### *Theme 1: Co-ordination of care*

#### **The role of the GP**

All of the GPs who participated in this research reported that at the time of being interviewed they had approximately five patients with EOLC needs under their care. Within a large overall caseload, the number of EOLC patients with whom they interacted was relatively small.

There was general agreement that there are many different health and social care professionals involved in patient care at the end of life, with many patients being managed within a disease speciality or by a specialist palliative care team. As such, there was some variation in the importance to which each GP attached his or her own role in this process. Respondents tended to indicate that if there was an effective specialist palliative care team caring for the patient, or good local hospice provision, then their level of involvement in care planning and delivery was less. However, the primary GP role that was discussed was that of oversight and co-ordination of care for patients nearing the end of life:

*I think our role is really about responsibility for making sure that everything's fitting together in the jigsaw provision of that care.*

(GP 3, case study site 1)

While GP respondents largely saw their role as to co-ordinate EOLC, the district nurse was considered to be the key provider of direct patient care – primarily for patients being cared for in the community. Much direct care is provided by district nurses, while GPs are responsible for overseeing this care delivery, prescribing medication as necessary, managing pain and other symptoms, and providing social and psychological support for patients and carers.

### Leadership

In comparing the performance of the two case study sites, it was clear that the reportedly more effectively performing practice (case study site 1) exhibited much stronger internal leadership in relation to EOLC. This practice employed a GP with a special interest in EOLC who led on co-ordinating multidisciplinary team meetings as part of the GSF, and provided education and support for other GPs and members of practice staff in the organisation and delivery of EOLC. Conversely, case study site 2 demonstrated minimal leadership, with an ambivalence or reluctance among the GPs in the practice to assume responsibility for providing or organising EOLC.

Although there was mention of leadership in the literature that was reviewed for this report, it was not emphasised strongly. In contrast, the case study findings highlighted leadership as a significant issue. This is a key finding from the empirical data collection in this report. The positive impact of strong leadership was particularly noted as an example of good practice in case study site 1. Poor leadership in case study site 2 was linked to the GSF being abandoned.

Although the findings presented here indicate that leadership was an important factor in engaging other GPs and practice staff in organising and delivering EOLC, some GPs who were interviewed expressed a lack of confidence in their ability to manage patients at the end of life, and to communicate with patients and their carers regarding prognoses and care options:

*I absolutely dreaded it as a registrar. I remember being sent up to a man who was dying of prostate cancer and I actually shook in the car going up.*

(GP 2, case study site 1)

This lack of confidence is likely to be linked to the assertion by the GPs interviewed that EOLC does not constitute a significant component of their day-to-day role. As such, through unfamiliarity with the process and limited experience, the GPs who were interviewed may be less comfortable and confident engaging with patients and their carers at the end of life. The GP with a special interest in EOLC in case study site 1 reported engaging in such communication more frequently than colleagues and, as such, reported greater confidence with the process, even describing it as 'rewarding'.

These findings support assertions in the literature that many GPs feel ill prepared and lacking in confidence when delivering EOLC. GPs reported feeling particularly challenged when it came to managing patients' and carers' psychological needs at the end of life – although more experienced GPs report this as being less problematic than their less experienced colleagues (Mitchell 2002).

### Use of end-of-life care tools

The earlier sections of this report described the GSF – a tool that intends to capture (in order to act on) patient-level data, and to guide the delivery and organisation of EOLC. Those who were interviewed were asked about their use of EOLC tools – particularly the GSF.

As explained in Section 3, GP practices can gain QOF points as a result of collecting data on two indicators for patients who are nearing the end of life – first, whether the practice has a register of patients with EOLC needs, and second, whether the practice has regular multidisciplinary meetings where all patients on the EOLC register are discussed. Because of this incentive, both

GP practices were somewhat invested in maintaining an EOLC register.

Initially, both sites had started to use the GSF. However, their eventual experiences were considerably different. Under the leadership of the GP with a special interest, case study site 1 had fully implemented the GSF, and was using it to capture data on the number of patients who were considered to have EOLC needs. This site also held regular multidisciplinary meetings to discuss the care of patients on the register.

Case study site 2, on the other hand, had initially begun to use the GSF in its practice, but the funding for leading on and managing the use of the tool was withdrawn, and staff no longer felt able to continue participating. The site continued to maintain a register of patients who were nearing the end of life, but some described use of this register as 'ad hoc'. The site had stopped holding regular meetings to discuss these patients due to time and resource constraints:

*One of the problems is that we're so busy, and it was another lunchtime meeting. Obviously its value is self evident, to talk about all the patients at any one time who are receiving end-of-life care. I do accept that. It's just that we're all so heavily busy, it doesn't seem to work that well.*

(GP 11, case study site 2)

GPs in case study site 2 could clearly appreciate the benefit of maintaining an EOLC register, and of holding regular meetings to discuss the patients on their register, but had not prioritised these activities within their busy caseloads since the participation funding had been withdrawn. Nevertheless, the site did continue to maintain the ad hoc register, and as such continued to collect some of the QOF points associated with this indicator:

*I hope GPs still see [end of life care] as core work, and I think it is work that people enjoy. But I think its priority has gone down since QOF, which is very sad. We shouldn't be doing it just because we get money for it.*

(GP 1, case study site 1)

Patients in general practices that are not using the GSF may be more likely to fall through the gaps so that their EOLC needs are not recognised. However, it should be noted that although case study site 2 had not engaged fully with formal EOLC tools and registers, and was not fully complying with the QOF indicators on EOLC, there was no indication that the quality of EOLC provided within this practice was compromised. While EOLC might be organised and delivered more systematically under the direction of the GSF or another EOLC tool, it is not obvious from these case study findings that patients experience a higher standard of care, or better outcomes, simply because their GP practice uses the GSF.

Meanwhile, although the GSF is evidently a useful tool for collecting data on patients who are nearing the end of life, there is very little evidence either from the literature or from these case studies that this data was being acted upon to directly improve patient outcomes.

### **Pre-emptive prescribing**

Patients who are nearing the end of life often need many different medications, and prescriptions and dosage can often change in order to manage symptoms effectively and quickly. In order to be able to respond to such changes (especially during out-of-hours periods), many GPs pre-emptively prescribe certain medications that patients can hold in their home



should they be required.

Some GPs expressed anxiety about this policy, as it may result in patients holding a large amount of medication in their home with limited direct supervision of its use. The GP would be held responsible for any error or misuse.

Despite these anxieties, the GPs who were interviewed felt that it was important that patients did have access to medications during out-of-hours periods, and all were willing to pre-emptively prescribe medication to this patient group. However, there was an acknowledgement that pre-emptive prescribing is a significant responsibility for GPs and that its practice required careful consideration. It was felt that the GP must be confident that patients and carers have been informed of what medications they have in their home and when to administer them:

*I think it's very important that patients have drugs at home, ready for whatever eventuality may be required. And, certainly, I think that's been a very useful step from the days when we used to just carry around a box in the boot of our car. [Today, we] actually have things ready and waiting – whichever doctor visits.*

(GP 3, case study site 1)

### Verification of death

With the increased emphasis on care and support for patients at the end of life taking place in the community, the procedures for verifying death are becoming progressively more significant. If a patient dies in the community, traditionally the GP will be called on to verify the death. In many cases, this process operates with minimal problems. However, if a GP has not consulted with the patient for a considerable time period (for example, more than two weeks), this can raise concerns. In such cases the GP is obliged to refer the death to the coroner – or at least to confer with the coroner's office about whether they support verification of the death by the GP.

In many instances the coroner will agree that the death was expected and no further action is necessary. However, it is evident that such interaction with the coroner may raise unnecessary anxieties for carers who have just been bereaved. As such, efforts are made to reduce occasions where deaths are referred to the coroner. Where possible, practices should have a system in place to ensure that a 'usual doctor' sees a patient during this end-of-life period. Since 2008, district nurses linked to case study site 1 have received the necessary training to verify deaths themselves. If patients are being managed at home towards the end of their life, they are likely to be interacting more frequently with their district nurses than their GP. As such, the system of verification of death by the district nurse is intended to reduce the number of deaths that are referred to the coroner unnecessarily.

The district nurses who were interviewed had as yet had little exposure to verifying deaths, so they expressed limited confidence with performing this procedure. However, they felt that with greater experience (and through shadowing GPs in performing this task) they would become more confident in verifying deaths:

*I did do one – my very first one. I was very, very anxious because, obviously, you get trained on how to check for responses and you can*



*verify the death. But then at the same time I'm glad that [the GP] was around and she was still able to come.*

(District nurse 2, case study site 1)

The district nurses who were interviewed reported that they would not verify a death if they had known a patient only for a short time period, and that it might be more appropriate for the GP to verify the death of a patient with whom they had a long-standing relationship. It was evident that while efforts had been made to reduce the burden on GPs of death verification, and to reduce the number of deaths referred to the coroner, GPs will continue to play – and, indeed, wish to play – a significant role in the verification of death.

### *Theme 2: Continuity of GP care*

Continuity of care was the subject of considerable discussion in the case study research. Continuity was linked to two particular issues – out-of-hours care and the provision of GP services in care homes.

The GPs who were interviewed considered their EOLC provision to be an extremely rewarding part of their job. These GPs had frequently cared for entire families over long time periods, and were dedicated to continuing providing that care through to the end of life.

Continuity of care was supported by GP practices, and was considered to be an important component in the provision of high-quality EOLC. Although district nurses were considered to play the key role in the practical provision of EOLC, GPs reported that patients still liked to maintain regular contact with their known GP as a consistent presence in the organisation of their care. As such, they felt it was important that continuity of GP services were available, through emergency cover and care planning. A key part of this continuity is 24-hour care, through provision of out-of-hours services.

GPs reported varied engagement with out-of-hours services, with one GP reporting a good relationship with out-of-hours care while all others reported either poor availability and poor quality of services, or having experienced a very limited relationship with out-of-hours providers. Respondents identified the majority of out-of-hours needs for patients at the end of life as being related to reassurance, support and basic social tasks, which do not necessarily require the skills of a GP, but may be provided by a nurse or health care assistant. However, some did report a gap in the provision of care to meet patient needs in these out-of-hours periods:

*[Out-of-hours care] is fine for the kids with the sore throats, but for end-of-life care I think that's the one area that deserves that little bit of extra attention and time.*

(GP 2, case study site 1)

*Although it's been great not having to get up at nights for us as a profession, I think it's a retrograde step for the patients.*

(GP 3, case study site 1)

Participants also expressed some concerns about continuity in the provision of GP services in care homes. Care homes typically work with a single GP, who will care for all of the residents in the care home. The GPs who were interviewed each reported that they had a designated care home that they visit, to provide care for those residents. It is clearly more efficient for GPs

to be responsible for the care of residents within a single care home, rather than continuing care for a caseload of patients across disparate care homes (particularly if they are conducting on-site visits). However, this would indicate that patients who move into a care home not covered by their known GP will be required to develop a relationship with another GP who is linked to that care home, which could potentially be distressing for people who could be close to the end of their life and highly vulnerable.

When asked whether they would make exceptions for particular patients as they entered care homes, the GPs interviewed showed some flexibility and variation. Some GPs reported that they would sometimes make a choice to continue seeing a patient in a care home, even if it was not their designated care home – particularly if they had a longstanding relationship with that patient and their family. Other GPs reported that they would no longer provide care for a patient if they entered a care home outside of their authority.

Some reported that where GPs did continue to provide care for patients across care homes, care home staff sometimes found this disruptive, but the majority view was that care home staff were grateful that GPs were willing to engage with their residents:

*Over the years I have had people who moved into a care home that have chosen to stay with me and then I've gone and disrupted the whole system of the care home by visiting an individual. The care homes don't really like it because it's not so easy for them. They can get everybody seen at once rather than being on the phone to the different GPs.*

(GP1, case study site 1)

*I think they [care home staff] are more than willing for anyone to look after them [residents] once the patient goes in and they want a doctor. So if I knew the patient, I think they would be 100 per cent happy with that.*

(GP 2, case study site 1)

Although there were opportunities to provide continuity of GP care for patients as they enter care homes, this was largely reliant on a willing and engaged GP, and a flexible care home. It was evident that with increased workloads and demands placed on GPs, their ability to offer this flexibility and visit patients at a range of care homes will diminish. As such, continuity of care for residents of care homes who are nearing the end of life is considered to be a significant gap in the provision of high-quality GP care.

### *Theme 3: Communication with patients and carers*

#### **Support for carers**

The GPs and other practice staff interviewed were adamant that informal carers played a significant role in supporting patients at the end of their life to remain in the community, and to avoid unnecessary hospital admissions. They considered patients living alone to be particularly vulnerable, and GPs reported that it is difficult to provide enough support to maintain their care in the community.

As such, GPs (and other health and social care providers) reported that they rely heavily on the support of informal carers to manage the care of patients at the end of their life. However, the provision of care by these informal carers carries a significant burden – especially for elderly carers who may have health and social care needs of their own.

The additional pressure of providing care and support for patients at the end of life is linked with elevated stress and other health care complaints among this group of informal carers. However, at a time when carers may feel that their own needs are secondary, their own anxieties and health care complaints may be more likely to remain unrecognised.

Both GP practices raised concerns about the level of support they provide for informal carers, and felt that they were not particularly proactive in pre-empting the supportive needs of this group:

*We often see the carers come in as patients – stressed, having difficulties. That's sometimes how you hear of it. They're at the end of their tether, and you hear of it maybe a couple of weeks too late: when it's a crisis.*

(GP 7, case study site 1)

If the stresses, anxieties and health care needs of informal carers are not pre-emptively managed, their ability to provide support for those at the end of life will be diminished. This may place additional pressure on health and social care providers. There was no discussion of any practical support required by patients and carers, such as wills, funeral arrangements and preparation about 'what to expect'. Although current support was considered to be poor across the two practices, there was recognition that GPs and general practices do have a role in providing practical support for informal carers.

### *Theme 4: Bereavement care*

Neither GP practice had a formal policy of providing proactive follow-up support for bereaved carers. However, the majority of GPs who were interviewed considered this to be an important function of their role. Linked to the previous discussion around the supportive needs of informal carers, these and other emerging needs continue after the death of the patient, and the literature suggests that bereaved carers are themselves at greater risk of morbidity and death (Relf *et al* 2008, Saunderson and Ridsdale 1999). As such, GPs felt that they had a role to play in proactively managing these risks.

The GPs who were interviewed were aware that bereaved carers may subsequently experience their own health care needs, or may have emotional responses to the bereavement that require professional support. All of the GPs interviewed reported that they and/or the general practice send a sympathy card to the bereaved carer following the death, and encourage them to visit the practice to discuss any concerns they may have. The GPs reported that many of these bereaved carers do subsequently visit the practice.

In the majority of instances, the bereaved carer may be a patient of the same general practice, and a note would be made on their patient file to indicate that they were recently bereaved. This would then be taken into account should the bereaved carer present to the practice with health care needs.

### *Summary*

This section has provided evidence from case studies of two GP practices to support the earlier presentation of results from a literature review of the role and quality of GPs in the delivery and organisation of EOLC. The findings from these case studies largely reflect results of previous research studies. However, interviewees also emphasised several additional areas in which

they felt GPs played a significant role, and that they considered significant for the delivery and organisation of high-quality care.

In particular, interviewees emphasised that the GP role is to co-ordinate EOLC rather than providing direct patient care. This was particularly evident in case study site 1, where a large team, with effective leadership, enabled a co-ordinated approach. In a practical sense, the case study findings also yielded more discussion regarding the specifics of the GP role in EOLC – namely, in pre-emptive prescribing and verification of death.

The case study findings highlighted the importance placed on continuity of care – that GPs considered their role to follow through from communicating prognosis, co-ordination of care, prescribing, support for carers, verification of death, and bereavement support. Continuity of care and effective leadership were considered to be significant indicators of the quality of the GP role in EOLC. Leadership was an area of significant discussion that had not been particularly prevalent in the previous literature review. The role of a GP with a special interest in EOLC appeared to be particularly pertinent for encouraging the use of the GSF (and other EOLC tools), and for co-ordinating multidisciplinary meetings to discuss patient care planning. The following section considers the literature and empirical findings about how best to measure and monitor quality in this area.

## 6 Measuring and improving quality of end-of-life care

This section analyses the existing ways of measuring quality that have been considered throughout the report in the context of the four themes (co-ordination of care, continuity of care, communication with patients and carers, and bereavement care). The *End of Life Care Strategy* (Department of Health 2008a) observes that measurement is an important means of assisting with change and progress in the delivery of EOLC, but does not focus directly on the goal of using measurement to enhance the 'quality' of EOLC. It is evident that measuring quality or outcomes in EOLC is different from other areas of health care, in that reduced morbidity or mortality is not a realistic (or even desired) measure of outcome. Instead, it is the qualitative experience of care, and the extent to which services meet patient preferences and expectations, that are more reliable and relevant indicators of quality care.

### *Existing mechanisms for measuring quality*

Researchers have attempted to define and measure both quality of care at the end of life and the quality of dying and death, based on data generated from bereaved carers, with some input from health care professionals. The issues identified included:

- symptom control
- good communication between health care professionals, and with patients and carers
- feeling at peace with dying
- dying in the place of choice
- treating the whole person
- maintaining dignity
- providing support to carers both before and after the patient death (Patrick *et al* 2003, Patrick *et al* 2001, Curtis *et al* 2001, Teno *et al* 2001, Steihauser *et al* 2000).

### *Problems with existing mechanisms*

The literature notes the complexities in conducting prospective, controlled studies that require the input of dying patients (Mitchell 2002). It is difficult to collect direct data on, or with, this vulnerable patient group, and measures of traditional patient outcomes (such as mortality or morbidity) are not appropriate. In the absence of robust outcome measures, the list of issues presented [above/on the previous page] indicates that assessments of quality in end-of-life care tend to focus on process indicators, or qualitative judgments of the experiences or satisfaction of patients and carers.

Although collection of traditional patient outcome measures may not be appropriate, indicators from routinely gathered databases that have some bearing on the issue could be monitored (for instance, how many practices – adjusted for size – submit patient notes on out-of-hours databases). The system could usefully advocate for and incentivise improvement of these

measures, or could drill down to outliers to examine in more detail what gaps exist in provision or planning.

There are very few tools available to measure the provision or quality of EOLC. The Department of Health's recently published quality markers and measures for end-of-life care (Department of Health 2009) went some way to address this need. The quality markers are consistent with the whole-systems approach (namely, the end-of-life care pathway) outlined in the *End of Life Care Strategy* (Department of Health 2008a). The markers outline structures and processes of care that are most likely to yield good outcomes for individuals approaching the end of life and their carers. While not mandatory, they are designed to be of use to commissioners, performance managers and providers. For providers, such as GPs, the markers are intended to act as a guide to assess their progress in delivering improvements in EOLC.

The markers are designed to ensure that providers are able to provide end-of-life care that incorporates all elements of the pathway, by ensuring that they have the following in place:

- a strategic plan for end-of-life care, congruent with the PCT strategy
- mechanisms for identifying patients approaching the end of life
- mechanisms for assessing and recording individuals' needs and preferences in relation to end-of-life care
- training for staff involved in discussing end-of-life issues
- access to appropriate medication
- needs assessments for carers and relatives
- effective discharge processes to enable timely discharge.

Measures are assigned to the majority of quality markers. The measures included are predominantly output (as opposed to outcome) focused, and are essentially quantitative in nature. Some attention is given to the quality of EOLC provided. For example, a quality marker for acute hospitals is that they should provide quiet areas on wards for bereaved relatives. Another is that community hospitals should audit and review the quality of EOLC provision. However, the meaning and measurement of quality in this context is not clearly defined.

Given the attention given to quality of care and patient experience in the NHS Next Stage Review (Darzi 2008) and associated policy initiatives such as Commissioning for Quality and Improvement, at this stage it remains unclear how the proposed EOLC quality markers sit within the wider policy agenda.

The quality of EOLC is explored further in the National Audit Office report *End Of Life Care* (2008), which makes recommendations to the Department of Health emphasising the importance of evaluation of current improvement approaches – notably, the use of EOLC tools – to determine whether their use results directly in better quality care for patients. This would enable a more outcome-focused approach than the more quantitative measures included in the Department of Health's quality markers.

Quality is also an issue of significant emphasis in the NHS Next Stage Review (Darzi 2008), which provides a policy framework for the NHS in delivering high-quality care. The review recognises the need for greater dignity and

respect at the end of life. As part of the review all strategic health authorities have produced a vision document focusing on eight clinical pathways, one of which is EOLC.

Most of the suggested EOLC quality measures for use within general practice might be characterised as basic, including:

- the number of patients whose preferred place of death has been noted
- the number of patients whose carer has been recorded
- the proportion of deceased patients who were discussed during at least one multidisciplinary practice meeting during the last year of their lives
- whether a formal EOLC initiative (such as the GSF) has been adopted.

A review of the efficacy of the GSF (Munday *et al* 2007a) cautioned against measuring and subsequently rewarding processes (such as those covered by the QOF indicators and the measures contained in the Department of Health quality markers) while ignoring more finely tuned measures that can capture effective and essential organisational relationships. Even when more crude indicators are met, such as maintaining registers and holding meetings, the quality of the meetings held and the registers kept remains unknown, as does their potential impact on patient care.

Quality of care could be partially measured by considering the care plans and patient preferences documented in the GSF and ascertaining how closely these plans and preferences have been adhered to. However, due to the variety of care providers involved in end-of-life care, it could be difficult to attribute responsibility for preferences that were not followed.

### *Proposed mechanisms for measuring quality*

Clearly, the complex and highly emotional issues related to death and dying mean there are significant challenges associated with designing, and then measuring the quality of care for those nearing the end of life. The development of tools that are sufficiently nuanced and sophisticated to measure dynamic organisational and personal relationships, and sufficiently flexible and sensitive to use with patients, families and health care professionals, continue to challenge those involved.

Findings from the two case studies presented earlier indicate that GPs were resistant to highlighting indicators of quality in the delivery of EOLC. As distinct from other clinical areas, as we have already seen EOLC does not necessarily attempt to extend life, or to reduce deaths or morbidities, so such traditional quantifiable measures would not be appropriate:

*There are some things that are easy to measure if you look at structural things like place of death, symptom control – all those sort of things. But I think the whole holistic thing is actually much harder to measure. That's the art, rather than the science bit. And the science bit is fairly easy to measure, I think, but the art bit is much harder.*

(GP 3, case study site 1)

Much guidance has reverted to measures of quality that focus on structures and processes, with little recognition of outcomes or experiences. For instance, there is considerable discussion on the existence of EOLC tools or registers as an indicator of quality. However, this in itself does not indicate how the information collected through the register is being used to improve patient care.



Further, as GPs identified a key role in bereavement and follow-up care, and managing the health risks of bereaved carers, the benefits of such support may not become apparent for considerable periods of time. As such, the majority of GPs spoke of more qualitative, or experiential, indicators of quality that measured the experience of EOLC, and patient and/or carer satisfaction with the processes and care received.

There are many indicators relating to structures and processes that can be used to measure the quality of EOLC delivered by GPs and general practices. However, greater attention is required to provide measures of patient and carer outcomes and experiences of EOLC.



## 7 Conclusion and key lessons

Recent policy attention in EOLC has focused on patient choice and shifting care into the community – most recently with the publication of the *End of Life Care Strategy* (Department of Health 2008a) and Royal College of General Practitioners strategy document (2009). This shift in emphasis implies a significant role for GPs, and for community care providers more generally.

The research findings presented here demonstrate clearly that GPs consider themselves to have a significant and continuing role to play in delivering and organising EOLC. The provision of EOLC in the community is an example of the kind of communication and co-ordination required for any vulnerable patient (particularly, for example, in terms of out-of-hours care provision). As such, the approaches within EOLC should be co-ordinated with the provision of primary care more generally, to provide a new way for health care systems to function.

EOLC is managed by a variety of health and social care professionals, but GPs continue to play an important role in co-ordinating patient care, providing support to patients and carers, the practicalities of prescribing and verifying death, and in follow-up and bereavement care. Although EOLC does not form a significant component of a GP's workload, those GPs who participated in this research considered it to be a rewarding part of their role. However, there remained a number of areas of provision that continue to offer challenges for the delivery of EOLC in general practice – namely, out-of-hours care, monitoring and meeting patients' preferred place of care, and the confidence of GPs in communicating prognoses and care-planning discussions with patients.

The findings from the literature review and the case studies highlighted a number of factors considered significant in improving the provision and organisation of high-quality EOLC in general practice. These factors related particularly to the following themes, which are recommended to improve the quality of care:

- **Co-ordination of care** and communication across health and social care professionals
- **Continuity of GP care** – during changing patient conditions (for example, when entering a care home), and during out-of-hours periods
- **Communication with patients and carers** about the prognosis and care planning
- **Bereavement care** and minimising the health care risks of carers.

Leadership was an area of significant discussion in the case study findings that had not been particularly prevalent in the previous literature review. The role of a GP with a special interest in EOLC appeared to be particularly pertinent for encouraging the use of the GSF and other EOLC tools, and co-ordinating multidisciplinary meetings to discuss patient care planning.

Although the findings of this report highlight these characteristics that are considered significant for improving the quality of EOLC, there was less agreement around how such quality might be measured in practice. Existing guidance (Department of Health 2008a) and quality markers (Department of Health 2009) focus heavily on indicators linked to structures and processes. As we have seen, outcome measures are difficult to define because

traditional health outcome indicators such as mortality or morbidity are inappropriate and ineffectual in EOLC. The current policy emphasis in EOLC is on improving the experiences of patients and carers, and providing greater choice over how and where they are cared for at the end of life. As such, the main assertions in the reviewed literature and case studies support the assertion made here that more experiential measures are needed, to capture the qualitative interpretations of EOLC by patients and carers.

The ageing population (Gomes and Higginson 2008) and challenging financial context (Appleby *et al* 2009) demonstrate significant challenges for the organisation and delivery of EOLC across England. GPs and other health and social care providers will be expected to do more, with less resources. Alongside this challenge, there is a commitment to meeting patients' preferences about how and where they wish to be cared for at the end of life, and providing the resources to allow a greater proportion to receive care and die at home. These messages indicate that the delivery and organisation of EOLC will be a major priority for GPs and other health and social care providers in the community over the coming years.

The findings presented here demonstrate clearly the value of leadership and multidisciplinary team working as efficient and effective levers for the necessary care co-ordination and delivery. Such co-ordination and delivery is more difficult for smaller practices to achieve without the resources and workforce necessary to meet patient and carer needs. These findings build the case for a model that promotes greater collaboration across GPs and other primary care professionals – through networks or models of federated GP practices – to co-ordinate care that allows for, and offers, a co-ordinated pathway that is aware of and meets individual patient care preferences.

## Appendix: Glossary of key end-of-life guidance

### *End of Life Care Strategy*

[www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH\\_086277](http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_086277)

The government's *End of Life Care Strategy* (Department of Health 2008a), promoting high-quality care for all adults at the end of life. Its aim was to provide people approaching the end of life with more choice about where they would like to live and die. It addressed the needs of all adults with advanced, progressive illness and care given in all settings. The strategy was developed by an expert advisory board chaired by National Cancer Director Professor Mike Richards, and included key stakeholders from statutory health, social care, third sector organisations, professional and academic organisations. The strategy was informed and shaped by the work on end-of-life care undertaken by strategic health authorities for the NHS Next Stage Review (Darzi 2008).

### **Gold Standards Framework**

[www.goldstandardsframework.nhs.uk](http://www.goldstandardsframework.nhs.uk)

The Gold Standards Framework (GSF) is a systematic evidence-based approach to optimising the care for patients nearing the end of life delivered by generalist providers. It is concerned with helping people to live well until the end of life, and includes care in the final year of life for people with any end-stage illness. The GSF intends to help clinicians identify patients in the final years of life; assess their needs, symptoms and preferences; and plan care on that basis, enabling patients to live and die where they choose. GSF embodies an approach that centres on the needs of patients and their families, and that encourages interprofessional teams to work together.

### **Liverpool Care Pathway (LCP)**

[www.liv.ac.uk/mcpcil/liverpool-care-pathway](http://www.liv.ac.uk/mcpcil/liverpool-care-pathway)

The LCP is an outline of the care that a patient can expect in the final hours and days of life. It aims to guide health care professionals in continuing medical treatment, discontinuing treatment, and comfort measures during the final days and hours of life. The LCP is organised into sections that allow for continuous and consistent evaluation and care.

### **NICE guidance on supportive and palliative care for adults with cancer**

<http://guidance.nice.org.uk/CSGSP/Guidance/pdf/English>

This guidance (NICE 2004) seeks to define the service models needed to ensure that patients with cancer, their families and other carers receive support to help them cope with cancer and its treatment. The recommendations in the guidance concentrate on aspects of services that are likely to have significant impact on health outcomes. It considers the objectives of implementing the recommendations, alongside the resource implications.

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