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Issues facing commissioners of end-of-life care



Key points

- The diverse needs of people nearing the end of life mean that commissioners need to develop approaches to commissioning integrated and personalised care. There are a number of challenges to effective commissioning of end-of-life care, including defining what constitutes end of life, calculating the associated costs, and defining appropriate outcomes.
- The integration of services is hindered both by the way that end-of-life care is currently funded and by the contracting mechanisms at local level. Financial incentives that encourage hospital activity work against the ambition of supporting patients in the community, and block contracts limit patient choice and discourage integration across providers.
- Commissioners should contract for a pathway or package of care in order to encourage providers to work together to deliver a more streamlined service. However, packages should be structured so that they can cater for a range of individual needs and preferences.
- Commissioning for outcomes can promote the integration of services. However, comparable and transparent data are vital to allow assessment of whether these outcomes have been achieved in practice. Information technology systems and shared data sources will be required to make this a reality.
- Pooled budgets offer the most concrete approach for encouraging integration across providers, although they are complex to develop and sustain. Commissioners should start small in their approaches to using pooled budgets, and focus on areas where the relationships, common pathways and data exist to support such a model.
- Personal budgets offer the opportunity for people at the end of life to commission integrated and personalised care that meets their needs. However, personal budgets are likely to be more appropriate for people who have prior experience of them, and end-of-life care may not be the time to introduce them.

Introduction

The coalition government has proposed a new structure for commissioning, under which primary care trusts (PCTs) will be abolished in 2013 and be replaced by clinical commissioning groups. These groups will have responsibility for managing NHS resources and commissioning services for local populations (Department of Health 2010b).

Clinical commissioning groups will comprise GP practices, other health professionals and lay representatives. They will be held to account by an independent NHS Commissioning Board, which will distribute NHS resources as well as commission primary medical services and national and specialist services. GPs and other clinical professionals will play a key role in the new structure, ensuring care is co-ordinated and commissioned appropriately to meet the needs of the local population. In addition, the new system will allow services to be supplied by 'any qualified provider', placing greater emphasis on choice and competition and giving patients access to more personalised care (Department of Health 2011). These changes are likely to have an impact on how end-of-life care is commissioned in the future.

The King's Fund recently published its 10 priorities for commissioners in the changing health care system (Imison *et al* 2011). Among them was the need to focus on the delivery of high-quality end-of-life care, central to which should be the integration and co-ordination of provision across the care pathway.

Clinical commissioning groups, especially GPs, might be well placed to manage the care of their local populations, but they will need additional knowledge and support to commission and administer care packages that are specifically for patients at the end of their lives.

End-of-life care services are typically funded and delivered by a mix of providers from the health (NHS), social (local authority) and voluntary sectors (such as Marie Curie and hospices), as well as by independent agencies and through individual means (informal or family carers). Very little is known about the composition of health and social care needs of this population (National Audit Office 2008) or about the associated cost and resource implications for the sector as a whole (Hughes-Hallett *et al* 2011). However, we do know that there is immense pressure on PCTs and local authority budgets to meet the increasingly complex care needs associated with an ageing population, and that the current system of funding and commissioning end-of-life care is inadequate for meeting patients' care needs and preferences.

In order to satisfy the diverse need of individuals at the end of life, as well as those of their families, care can involve a wide range of services, spanning multiple sectors and settings (Department of Health 2008). The significant variability in co-ordination between services can result in end-of-life care being disjointed and ineffective, which is often a cause of distress (Department of Health 2008; Hughes-Hallett *et al* 2011), and this fragmentation of care can make the transition from one provider to another particularly difficult (National Audit Office 2008; National Council for Palliative Care 2010a).

The coalition government is increasingly highlighting the value of integration across providers, and this is especially vital for ensuring high-quality end-of-life care.

The establishment of these commissioning groups is intended to allow wider professional involvement in service configuration and commissioning – including GP practices and other local health professionals and the public. Health and wellbeing boards will be involved in the development of local commissioning plans and have a role in the integration of the commissioning and provision of health, social care and public health services. The overarching emphasis of these commissioning groups is that they are to be clinically led, with those most in touch with patients at the centre of decision-making and resource allocation.

In the new commissioning environment, the NHS Commissioning Board will hold clinical commissioning groups to account for achieving quality outcomes. However, it is essential that processes are put in place to ensure that quality markers can be routinely monitored, embedded into contracts, and used in local policies, for example, the development of the Commissioning for Quality and Innovation (CQUIN) payment framework to promote quality improvement (Addicott and Ross 2010). The NHS Commissioning Board will support the new commissioning approach through the development of tariffs, helping commissioners to establish contracts and ensuring that these contracts act as a mechanism for guaranteeing that standards and outcome measures are met.

The National Council for Palliative Care (Sam *et al* 2011) recently recommended that all clinical commissioning groups should involve a dedicated end-of-life care lead. Given the growing complexity of and demands on end-of-life care services, commissioning in this area is likely to be one of the more challenging tasks facing the commissioning groups. It is therefore vital that commissioners are aware of and understand the options they have for funding end-of-life care at a local level, and that providers have the capacity to innovate within these frameworks. The personalisation of care and the integration of services must be seen as fundamental in order to ensure that patients and their carers have greater control over the management of their care.

However, further evidence is required about what is known to work in the commissioning and provision of end-of-life care. This paper seeks to address this evidence gap – highlighting current barriers in funding and commissioning as well as opportunities within the system to use commissioning as a lever for meeting the challenges outlined by the coalition government. We provide a synthesis of and narrative on the issues facing commissioners of end-of-life care and, with the support of primary data (interviews with 28 commissioners, managers and clinicians in end-of-life care), we then focus on three major priorities in the coalition government's approach to organising and commissioning health care: integration, clinically led commissioning and personalisation of care. We consider these issues in relation to end-of-life care and add some early reflections from those currently commissioning care.

Why is end-of-life care important for commissioners?

Demographic changes affecting the provision of end-of-life care

As a result of the United Kingdom's ageing population, the number of deaths per year is expected to rise by 17 per cent between 2012 and 2030. In addition, many more people will be dying at an older age and will therefore be likely to have more complex needs and multiple co-morbidities as they near the end of their lives. These demographic changes will undoubtedly have a significant impact on the level and intensity of provision that is necessary and will require change in the way that services are commissioned (Gomes and Higginson 2008).

As well as taking account of the pressures of an ageing population that is living longer with increasingly complex disease and co-morbidities, the provision of end-of-life care must also address the full range of conditions and diseases that people experience. Historically, end-of-life care has been associated with those suffering from cancer, but future provision must also cater for the full range of other conditions that can be present at the end of life, such as long-term illnesses (for example, respiratory, cardiac and neurological diseases) or diseases associated with older age such as dementia (Department of Health 2008; Connolly *et al* 2010).

Alongside these demographic pressures, the current financial crisis is also likely to have an impact on the provision of end-of-life care. The NHS is now committed to making productivity savings of up to £20 billion by 2014, but in doing so must achieve better

value for money rather than simply reducing spending, staff and services, which could have a detrimental effect on quality (Appleby *et al* 2010). Commissioners and providers of end-of-life care will therefore need to work more intelligently and efficiently if they are to ensure that the increasing care requirements of a growing number of patients nearing the end of life can be fulfilled with the same or fewer resources.

The government's end-of-life care strategy

The government's end-of-life care strategy set out the intention of developing a system to give access to high-quality care for everyone at the end of life in all settings (Department of Health 2008). Specifically, the strategy intended to establish end-of-life care as a local commissioning priority and emphasised the need for a strategic approach. It outlined the importance of integration and co-ordination across all sectors and the involvement of all relevant providers in the commissioning process.

Enabling people to die in the place of their choice has been a primary concern of recent health policy (Department of Health 2003). Research shows that people are still largely unable to die in their preferred location, with between 56 per cent and 74 per cent of people wishing to die at home, but only 35 per cent actually dying there or in a care home (National Audit Office 2008). In one PCT area, 40 per cent of the patients who had died in hospital had no medical need to be there.

Comprehensive data available about the costs of end-of-life care are limited, but the National Audit Office (2008) estimated that, for cancer patients alone, £104 million could be saved (or redistributed) by reducing emergency admissions to hospital by 10 per cent and reducing the length of stay by three days. If these figures are extrapolated across the range of other conditions that people have at the end of life, the cost savings could be significant. These resources could then be redistributed so as to meet patients' care preferences more effectively and deliver a more streamlined service.

By delivering more care outside the acute setting, and reducing the number of deaths in hospital by a projected 60,000 per year by 2021, the Palliative Care Funding Review estimated that savings of approximately £180 million per year could be made (Hughes-Hallett *et al* 2011).

Incentivising and measuring quality in end-of-life care

There are several monitoring and incentive programmes aimed at improving the quality of care, including that at the end of life. The Quality and Outcomes Framework (QOF) was introduced in 2004 to reward general practices for meeting specific indicators in a number of different areas, including end-of-life care. Practices receive points for meeting these indicators, which are then translated into financial rewards. Similarly, the world class commissioning (WCC) programme set out core competencies for PCT commissioners to achieve.

More recently, the Department of Health published the NHS Outcomes Framework, which details the outcomes and corresponding indicators by which the NHS Commissioning Board will be held to account as part of its mandate (Department of Health 2010c). The Secretary of State will use this framework across five domains, which will then be tested through impact indicators. The fourth domain, 'Ensuring that people have a positive experience of care', includes the improvement indicator 'improving the experience of care for people at the end of their lives', which is to be developed through surveys of bereaved relatives (Department of Health 2010c, p 24).

Policies such as the WCC programme, the QOF, the NHS Outcomes Framework, the Quality, Innovation, Productivity and Prevention (QIPP) programme and CQUIN are all intended to promote high-quality end-of-life care and cost savings at a time of

considerable economic uncertainty. There is some evidence of savings and improvements in areas that have been prioritised by commissioners (House of Commons Health Committee 2011), and end-of-life care certainly appears to have become a higher priority for PCTs (Health Mandate 2009). However, practical tools for improving end-of-life care are still in development, and it is therefore difficult to predict the full implications of these policies on the provision and quality of care.

How is end-of-life care currently commissioned?

The second annual report of the government's end-of-life care strategy furthered the commissioning agenda by stating: 'Commissioning is the single key mechanism for making sure that the right services are available to meet local need, and that they are sensitive to the needs of those approaching the end of life regardless of their condition' (Department of Health 2010a, p 68).

Broader systems of funding, as well as contracting at a local level, have a significant impact on how end-of-life care is delivered in practice.

Funding for end-of-life care

The Palliative Care Funding Review recently recommended a system of funding end-of-life care that is fair and transparent, delivers outcomes for patients, and provides value for money (Hughes-Hallett *et al* 2010). Health and social care funding systems should also be integrated with other sources of individual funding, such as carers' allowance.

It can often be difficult to ascertain which of a patient's needs are medical (and therefore paid for by NHS continuing care funding), and which are social (and therefore covered by local authority or personal funding). This has implications for identifying which is the most appropriate funding source for individual patients, as their needs might span both health and social care (National Audit Office 2008; Hughes-Hallett *et al* 2011). There might be very little, if any, integration of funding, except, for example, where pooled budgets are being used. Alternatively, it has recently been reported that two PCTs (Rotherham and Berkshire West) have outsourced their entire end-of-life care service to a voluntary sector provider (Bawden 2011).

The coalition government recognised that the current system of social care funding, in particular, was inadequate for meeting individual needs and, in July 2010, set up the Commission on Funding of Care and Support to consider how to implement a fairer and more sustainable system. Chaired by Andrew Dilnot, the commission published its report in July 2011 (Commission on Funding of Care and Support 2011), recommending a cap on the amount of money that individuals are expected to contribute to their care over their lifetime, and the introduction of a more co-ordinated system in which social care works alongside health care, housing and benefit arrangements.

Different funding streams and variations in their accessibility have led to an unco-ordinated and fragmented system. It is imperative that these services are better co-ordinated to ensure that patients do not suffer.

Types of contracts

Previous analyses in this field demonstrate that a strategic commissioning approach that emphasises the achievement of outcomes can be supported by using 'sharper contracts'. The main barriers to building outcomes into contracts are considered to be technical in nature, relating to the identification of appropriate outcomes and the subsequent availability of data (Flynn *et al* 1997).

PCTs are likely to have many contracts of varying terms and conditions with different providers, each contributing a part of the total provision of end-of-life care. It is evident that short-term contracts with a host of different providers do not allow commissioners to encourage service quality and collaboration through incentives and prevent providers from developing or planning future services: they have only a limited time for building capacity, strategic planning or developing relationships with other providers across a sector (National Audit Office 2008; Hughes-Hallett *et al* 2010).

Table 1 outlines the different contract arrangements that can be used to purchase end-of-life care services and considers the advantages and disadvantages of each with regard to the integration of services and provision of patient-centred care. These contract types are in use in the local areas that contributed to this research, and are also described in the literature (for example, Duran *et al* 2005).

Table 1 Advantages and disadvantages of different types of contracts

Contract type	Advantages	Disadvantages
Block contract: providers receive a flat rate to care for a specific patient population regardless of the amount of care actually provided	<ul style="list-style-type: none"> As this contract type is based on fixed payments and does not pay for activity, it might provide better value for money if more activity is provided than was anticipated More certainty for providers Potentially greater sustainability for small or specialist enterprises 	<ul style="list-style-type: none"> Inhibits the provision of care on a case-by-case basis to meet individual needs Leads to a lack of individual choice for quality, patient-centred care in the community Often inflexible and does not allow funds to be released or redirected to other services, or for their use in personal health budgets Might discourage the provider market from innovation and delivering services in an integrated way
Cost-per-case contract: used when there is a set cost for each specific episode of treatment or care, the number of episodes of which might be pre-defined	<ul style="list-style-type: none"> Potentially useful to allow the release of funds for other services (eg, if hospital admissions are reduced, funds could be redirected into community-based services) More flexible and patient-centred way of contracting services, as commissioners have the ability to choose the services that are most suited to individual needs rather than the services that have traditionally been provided Stimulates choice and competition 	<ul style="list-style-type: none"> Could encourage providers to over-deliver services, which could incur higher costs than anticipated for commissioners More difficult for commissioners to plan care Limited value for money through economies of scale Voluntary-sector organisations could find the approach problematic, as they might not be able to guarantee a minimum income because of being paid in arrears Does not promote integrated care
Cost and volume contract: includes payments for a defined volume of activity, with any additional activity paid for on a cost-per-case basis (Duran <i>et al</i> 2005)	<ul style="list-style-type: none"> Ability to provide individualised services Benefits of economies of scale 	<ul style="list-style-type: none"> Could encourage providers to increase activity at lower costs, which might impede the quality of the activity Does not promote integrated care
Risk-sharing contract or pathway tariffs: health and social care professionals work together to take on a capitated risk-bearing budget to deliver services to a defined population	<ul style="list-style-type: none"> Aligned financial incentives Supports providers to work collaboratively 	<ul style="list-style-type: none"> Provider failure could destabilise a system of care

In addition to the types of contracts outlined in Table 1, the CQUIN payment framework provides commissioners with a way of rewarding good-quality patient care by means of financial payments for the achievement of specific measures (Department of Health 2010d). Commissioners can link a proportion of providers' remuneration to attainment of locally derived quality-improvement goals.

The more flexible use of contracts, such as the disaggregation of block contracts, should be promoted so as to allow more personalised care and to encourage providers to deliver services in more innovative and flexible ways. Through contracts, commissioners have the power to influence local providers to work together to bid for and subsequently deliver care.

Where possible, commissioners should be encouraged to seek contracts with consortia of providers rather than single organisations. This acts as a formal lever to ensure that local providers work together to bid for contracts, plan services and deliver care. An emphasis on ambitious (but realistic) local outcomes in these contracts will require providers to work together to achieve these goals. Commissioners can thus use contracts as a way of ensuring that integrated approaches to bidding for and delivering care become the default option.

Focusing contracts on outcome measures (rather than structures or processes) means that providers are more likely to be motivated to work collaboratively in order to meet these outcomes. If commissioners are strategic in setting aspirational outcomes that are most sensibly and effectively met by collaborative working, they are more likely to encourage integrated care through commissioning – rather than forcing it unnaturally on to existing relationships and ways of working.

Difficulties of commissioning end-of-life care

Defining end of life

The available research on disease trajectories suggests that identifying the point when a patient is nearing the end of life may be relatively more straightforward in those with a diagnosis of cancer than in those with other diseases, such as organ failure, dementia or frailty in old age.

Patients with cancer tend to experience a more clearly identifiable gradual decline in their condition, whereas patients with non-malignant disease predominantly follow a less predictable disease trajectory characterised by a series of peaks and troughs (Murray and Sheikh 2008). These variations in disease trajectory and complexity further demonstrate the need to establish a system of commissioning and provision that is integrated but is also structured to cater for individual needs and preferences, and flexible enough to cope with how they might change over time.

If professionals feel unable to make (and communicate) a confident prognosis about when a patient is nearing the end of life, they may also not make onward referrals to the appropriate services, particularly when there are concerns about the consequent resource and cost implications. The combination of these two barriers (prognosis and referral) can have serious knock-on effects for the planning and co-ordination of care. Without identification of the end-of-life phase, there can be no discussion with patients about their care preferences.

Calculating costs

There have been some attempts to quantify the cost of end-of-life care for certain conditions and time periods. The provision of health and social care during the last 12 months of life is estimated to cost the United Kingdom some £1.8 billion for people with cancer (National Audit Office 2008), approximately £553 million for those with heart and

respiratory failure (Hatzian greu *et al* 2008), and £198,459 for each patient with motor neurone disease (Motor Neurone Disease Association 2008).

It is important to note that these estimates do not include the care provided by informal carers. It has been estimated that replacing all informal care in the United Kingdom with professional care would cost £71 billion per year; professional care in place of 12 months of informal care for one patient with motor neurone disease alone has been estimated to cost £101,000 (Buckner and Yeandle 2007).

The government's end-of-life care strategy stated 'it is difficult, if not impossible, to calculate the cost of end of life care in this country' (Department of Health 2008, p 15), although it did estimate that cost to be in the billions of pounds. The difficulty of calculating the sums involved arises partly because of the problem of defining what comprises end-of-life care (versus more interventionist care) and when this care starts, particularly given the complex disease trajectories of many long-term conditions (Addicott and Dewar 2008; Department of Health 2008; Hughes-Hallett *et al* 2010), and partly because of the multiple services involved in the delivery of end-of-life care (for example, the health, social care, voluntary and independent sectors, all with differing sources of funding and differing costs depending on specific local contracts (National Audit Office 2008)).

Defining outcomes

The King's Fund summit on end-of-life care (Addicott and Ashton 2010) highlighted 10 critical actions for implementing the national end-of-life care strategy (Department of Health 2008), including a need to commission for outcomes rather than activity. This would require a multi-layered approach to commissioning end-of-life care (from regional to local level), in which commissioners and providers worked together to provide high-quality services with the funding available. The key challenge for commissioners will be to specify the actual outcomes expected and the funding available and to empower providers to develop innovative solutions within this framework.

Traditional measures such as morbidity and mortality do not apply in the same way in the context of end-of-life care. It is the qualitative experience of care, particularly whether the care provided has met the patient's needs and preferences, that is more applicable (Addicott 2010). It is important that these local-level outcome measures are based on national outcome measures, such as use of the Gold Standards Framework (2011) and establishing whether individuals' preferred place of care and death was achieved.

Current issues in end-of-life care commissioning policy

Tariffs

The complex nature of end-of-life care has meant that there is no national tariff or fixed payment to the acute sector for end-of-life care activities (Hughes-Hallett *et al* 2010). Because of this, patients who are in hospital as they come to the end of their lives are allocated to more interventionist health resource groups for receiving treatment or requiring tests. This means that payments are not necessarily appropriate to the service delivered, and there is limited knowledge of how many patients receive end-of-life care in hospital with no actual specialist intervention.

Any tariff developed should not give hospitals a greater incentive to provide potentially unnecessary care for people at the end of their lives. If hospitals receive direct payments for delivering end-of-life care, patients might end up staying in hospital when there is no particular medical need for them to be there, potentially going against their wishes to be cared for in the community.

Many commissioners have found the gaming around these perverse incentives frustrating to manage as they contradict the ambition of providing more choice for people, most of whom would choose to be cared for in their own homes at the end of their lives. Current perverse financial incentives need to be addressed to encourage care to move from hospitals into the community.

In 2010, the Secretary of State commissioned a review of palliative care funding for children and adults in England (Hughes-Hallett *et al* 2011), which was tasked with establishing a per-patient funding mechanism for end-of-life care. The review recommended a more flexible and individualised approach to funding (based on complexity and need) and the establishment of a tariff model in which funding would follow the patient. The report proposed the development of 25 classes of need (for adults and children) that would each be linked with a tariff. Allocation of these tariffs would be subject to constant review, based on the complexity and level of need of each patient. The review estimated that the model would, in itself, be cost neutral.

There are currently no tariffs or fixed prices for the provision of community services, as a consequence of which the amount paid by PCTs for the provision of care outside hospitals varies hugely. The Palliative Care Funding Review recommended that the tariff in its proposed per-patient funding system apply to the package of care, across providers (Hughes-Hallett *et al* 2011). This is similar to recommendations for changes to the funding of mental health care, an area with comparable issues as care is delivered by both mental and physical health care providers, resulting in problems at the boundaries of provision. Naylor and Bell (2010) recommended the establishment of a payment system for mental health that is focused on whole packages of care rather than on discrete episodes of treatment.

Care pathways

Commissioning end-of-life care across a pathway, or across providers, might promote integration between services. In addition, the involvement of relevant stakeholders – the public, patients and carers – is essential. Clinical commissioning groups will have a key role in ensuring that commissioned care meets the needs of local populations. To work effectively, commissioners need to be aware of the context in which commissioning takes place and the challenges relating to different areas of care, such as that provided at the end of life.

End-of-life care needs to be developed as an integrated health and social care service drawing on many different sectors, including specialist palliative care, psychiatric services for patients with dementia, community matrons and social support for patients with long-term conditions, as well as GPs. Without needs assessment at an individual or population level, the reality is that many patients in need rarely receive any health and social care support. It is also important that any support that is available be disease- rather than need-dependent.

Shifting money from the acute sector would be challenging, and the right incentives and financial systems would need to be in place to enable the money to follow patients, but this kind of formalised care-pathway approach would help to improve funding for end-of-life care in the community, avoid unnecessary admissions to hospital and promote an integrated approach to care. However, in order to establish a tariff for a pathway or package of care, more information is required about the actual costs of care across sectors.

As part of its end-of-life care strategy, the Department of Health (2008) outlined a whole-systems care-pathway approach for the commissioning and delivery of integrated care. This pathway was set out in six steps, from the first discussions about end of life and assessment of need to the co-ordination of care across multiple settings and care

after death. The benefits of this approach were further demonstrated by the Marie Curie Delivering Choice Programme (Addicott and Ross 2010).

Commissioners and providers increasingly recognise that the provision of end-of-life care requires a multitude of stakeholders working together to offer a streamlined package. In 2004, the then National Institute for Clinical Excellence (NICE; renamed the National Institute for Health and Clinical Excellence on 1 April 2005) issued guidance on improving supportive and palliative care for adults with cancer (National Institute for Clinical Excellence 2004). It said that studies had consistently shown that patients expect their care to be: high-quality and well co-ordinated as they approached the end of life; individualised; and provided through to death, along with bereavement support for their relatives after their death. The NICE guidance recommended that end-of-life care was best provided through a partnership approach in which agencies worked together to deliver seamless care.

Lead-provider model

Other research has also emphasised clinical input in commissioning through a lead-contractor model (Ham *et al* 2011). This research highlighted the impact that contracting has in encouraging providers to change their behaviour and suggested that a single organisational provider could co-ordinate and be accountable for pathways or packages of care that are actually delivered by consortia of providers.

The lead-contractor model was successful in most clinical areas, but Ham *et al* (in press) found it to be unsuccessful in the end-of-life care case that they examined. They concluded that it was the difficult economic conditions facing the PCT at the time, in conjunction with the start-up costs of a new lead-contractor model, that led to its abandonment. They concluded that commissioners should start small when considering alternative approaches to commissioning such as this and focus on areas where there is a commonly shared care pathway and cross-sector data on costs and outcomes of care are available.

Pooled budgets and other mechanisms for contracting consortia of providers should be supported through commissioning where possible. Until providers have developed the competencies to lead these consortia, commissioners should take an active role in ensuring that the model actually supports a pathway approach to organising and delivering care in practice. The establishment of a lead-contractor model should not be a distraction from the overarching ambition of providing more integrated, more patient-centred care.

Individualised approach

It is evident that end-of-life care is not a linear process but requires a flexible and co-ordinated approach to its commissioning and delivery that is able to take account of variations in and between disease trajectories and individual patients. As such, packages of care need to be individually tailored to the changing needs and preferences of patients. A care-pathway model might be too prescriptive and inflexible unless providers work together to provide the necessary individualisation and flexibility of approach, and the commissioning of this care must reflect this requirement.

As people approach the end of their lives, they might require a wide variety of both health and social care services, spanning a range of providers across many sectors (Department of Health 2008). There is currently considerable variability in co-ordination between these services, which can lead to care that is fragmented and ineffective, often making the transition from one provider to another particularly difficult (National Audit Office 2008; National Council for Palliative Care 2010b).

Commissioners in future need to provide services that are flexible and responsive to variations in the end-of-life care needs of individuals, their carers and their families. This might require greater reliance on new entrants to the market, such as those from the voluntary or private sectors, alongside those already in regular use, such as hospices. The configuration of this provision – and how personalisation, integration and outcomes are assured in that process – will be the job of commissioners.

Alternative approaches to commissioning end-of-life care

The coalition government has continued to emphasise personalisation of care (and patient choice), clinically led commissioning and integration of care. In the following section, we consider these themes in relation to end-of-life care.

We draw on the available literature, as well as on interviews with 28 commissioners, managers and clinicians who are beginning to use alternative approaches to commissioning end-of-life care. Many examples of such approaches are at this stage largely theoretical. As they have not been fully implemented, this section considers how commissioners see these issues emerging over time, along with some of their early reflections, which should assist clinical commissioning groups as they develop some of these commissioning priorities across the country.

Personalisation of care

The coalition government has emphasised choice and competition as being at the heart of its reform programme: all individuals should have choice and control over their care and treatment, and choice of any qualified provider, wherever relevant. Building on the aspirations of the previous government, it is hoped that this choice and control will allow a more personalised approach that is better able to meet the care needs of the individual.

Example of personalisation: personal health budgets

In the drive to increase personalisation and choice in the health service, personal health budget pilots were introduced in 2009 by the previous government (Department of Health 2009). By means of a notional budget, a budget held by a third party or direct payments, personal health budgets give patients greater control over deciding on the most appropriate care for their individual needs.

This personalised approach had the additional aim of encouraging more holistic care by promoting continuity over time and emphasising patient experience. Personal budgets have been shown to be effective in social care, increasing patients' sense of control and quality of life (Glendinning *et al* 2008; Alakeson 2010), which makes a positive case for their use in health care.

Personal health budgets do have the potential to stimulate greater patient choice, which is particularly important in this context where patients might need to access a number of different services, and there are difficulties defining whether individual needs are health or social. Personal health budgets have the potential to reduce the divisions between services and sectors – the patients' needs become paramount, making the care focused on outcomes rather than being based around each specific service (Alakeson 2010). In turn, it might be possible for a number of agencies to provide the care necessary to achieve those outcomes. In cases in which individuals require care from multiple services spanning different sectors, personal health budgets could thus be a way to simplify the process (Department of Health 2009).

Personal health budgets have been described as a way of creating 'a new opportunity to improve efficiency at the boundary between health and social care' (Alakeson 2010, p 17). Evidence from the initial pilots of direct payments for health care indicates that allowing

individuals to continue to use the same direct payment mechanism when they move from the social care to the health care sector promotes continuity of care and – as described by one interviewee – ‘a seamless transition’. Direct payments allow individuals to employ the same carers whether they are in the social care or health care system.

What do we know so far?

Because they are still in the pilot stage, only a very limited number of individuals are currently using personal health budgets fully, particularly for end-of-life care. The evidence on their success is patchy so far, although the NHS Future Forum recently recommend a ‘stronger push to offer personal health budgets where these are appropriate’ (Field 2011, p 24). This, along with an ongoing government commitment, means it is likely that they will continue to be offered in some form.

It does offer some people a way to have the care that they want at the end of their life and which they couldn't previously have.

(Manager 6)

The use of personal budgets might prove to be beneficial as they encourage self-management and a personalised approach (National End of Life Care Programme 2010), but their introduction and use in end-of-life care has raised concerns. Personal budgets could cause additional stress to individuals at what is already a potentially difficult time (Hughes-Hallett *et al* 2010; National Council for Palliative Care 2010b). Furthermore, those most in need of end-of-life care are often unable to choose for themselves (because of a loss of capacity), might have few resources with which to exert control, and often do not recognise that they are approaching the end of life.

Although personal health budgets provide some individuals with an increased sense of control, additional decision-making and responsibility for care planning at this point in a disease trajectory could be burdensome. Furthermore, there is concern that the use of personal health budgets might require patients to play a large role in co-ordinating the services themselves, rather than the service providers having the responsibility of communicating with each other to organise the care. This could lead to isolated and disjointed services with no provider integration at all.

The use of a centralised hub to co-ordinate end-of-life care in this manner has been found to inhibit direct integration among local services (The King's Fund 2009). Centralised care co-ordinators took such an active role in arranging whole packages of care that the providers had limited formal reasons to communicate among themselves, and many of the corresponding informal channels of communication therefore ceased to exist. Where the patient (or another centralised co-ordinator) is responsible for managing the allocation of care across a range of providers, direct communication between these services could be more limited. It is therefore imperative that such co-ordination continues to promote open and transparent communication across the range of providers.

We would want to caution against the introduction of personal health budgets at the end of life. Instead, they may be more valuable if continued (if appropriate) for patients using this approach already, such as throughout a long-term condition. It is important that these personalised approaches to increasing patient choice do not create an extra and unnecessary burden on patients at a very difficult time in their lives. An emphasis on care planning at an individual and population level, and ensuring equitable access to quality services, might be of greater value to patients at the end of life than the traditional focus on choice and control.

What a patient chooses and what a patient actually needs aren't always the same thing particularly when we're talking about end of life care and the complexity that exists with some palliative care.

(Commissioner 5)

Commissioners of end-of-life care reported low engagement with personal health budgets and considerable reluctance about their use, which could affect how they are promoted to patients, and the support they are subsequently offered to help them manage their own budget. Some interviewees suggested that this reluctance might stem from professionals being keen to protect their services by maintaining current demand for them, out of concern that if patients are given greater choice they might choose to use a different service.

Relevant lessons for commissioners

Introducing personal health budgets for patients nearing the end of life presents a number of challenges. In particular, we would caution against their being given to patients at the point at which they are nearing the end of life. Rather, patients should be supported to use personal health budgets throughout their illness as appropriate. Brokers or care co-ordinators could assist in this process – particularly during transition periods, when complexity or care needs change. However, these brokers should also be tasked with ensuring the continuation of communication across the range of providers, thus reducing the pressure on patients to be the hub of the co-ordination process.

Clinically led commissioning

A significant element of the coalition government's health reforms is the introduction of clinical commissioning groups, giving decision-making about the organisation of care at a local level to GPs and other health care professionals. Clinically led commissioning has been tried in the NHS before, of course, with GP fundholding in the 1990s and practice-based commissioning in the mid-2000s.

Example of the clinically led approach: practice-based commissioning

Practice-based commissioning was introduced in 2005 to give GPs and other professionals working in primary care the opportunity to make commissioning decisions about the care needs of their local populations. The responsibility for funding remained with the PCTs, however, as GPs were given only virtual budgets. The policy aimed to improve the use of resources and to lead to better patient care, as GPs were seen as being best placed to make decisions about their local populations (Department of Health 2006a; Curry *et al* 2008).

Despite concerns and evidence that practice-based commissioning has been less successful than was hoped (Curry *et al* 2008), there have been continuing efforts to promote its use, particularly in clinical areas such as end-of-life care. We found some examples where practice-based commissioning has been fundamental in engaging GPs in strategic planning around end-of-life care – something that has proved to be a challenge in the past (Addicott 2010). Given the current emphasis on commissioning care at a practice level (Department of Health 2011), it is clear that GPs will continue to be involved in decision-making in this area.

What do we know so far?

Research by The King's Fund found that practice-based commissioning had had only a minimal impact on the efficient use of resources or the quality of care for patients (Curry *et al* 2008). However, it had had some positive effects on communication and collaborative working, and so might provide an effective mechanism for promoting greater integration in the delivery of end-of-life care in future.

Echoing this finding, the commissioners we spoke to identified examples of how practice-based commissioning had encouraged a range of professionals to work together to plan and deliver care, specifically at the end of life. The health economies that were using

practice-based commissioning reinforced the opportunities that it offered to promote greater integrated working across providers and the ability to develop services across a sector (for example, rapid response services and link nurses).

The main challenge is making sure all the services work very closely together and have a real commitment to the patient pathway rather than their own individual service.

(Manager 11)

However, successes in practice-based commissioning were reliant on a GP commitment to lead and take a particular interest in end-of-life care, and engaging GPs in this manner had been difficult, our research showed. One of the health economies we studied had identified three local GPs to take a lead in end-of-life care. The success of the model relied on having a dedicated programme lead whose responsibility it was to co-ordinate the commissioning strategy across practices. This co-ordination role was challenging, however, with the person fulfilling it frequently being perceived as an 'outsider'.

Commissioners also expressed concerns that the encouragement of practice-based commissioning had had a detrimental effect on existing clinical networks. Efforts had been concentrated on developing GP-led commissioning strategies across a locality, as a consequence of which longer-standing relationships and knowledge sharing had suffered.

One of my concerns is how we move from the local success that we've had through practice based commissioning... to maintain that momentum through the transition to GP commissioning alongside all of the changes to the PCT and everything else that's going on at the moment.

(Medical 8)

Relevant lessons for commissioners

Variations on practice-based commissioning are being encouraged through clinical commissioning groups, and GPs will need to have the necessary competencies to manage and commission care for patients at the end of life. The National Council for Palliative Care (Sam *et al* 2011) recommends the appointment of a clinician within each commissioning group to lead on end-of-life care planning.

Such an approach would ensure that the complex issues surrounding the delivery of high-quality and personalised end-of-life care are not lost in the broader commissioning picture. Commissioning groups, and any lead-commissioner model that is established, should work closely with existing formal and informal end-of-life care networks to avoid damaging existing relationships and patterns of communication.

Health and social care integration

Following the listening exercise, the government's response to the NHS Future Forum report was to give stronger emphasis to integration, both between the range of professionals to be involved in clinical commissioning groups and also across the services that they will be commissioning. The Department of Health said 'clinical commissioning groups will have a duty to promote integrated health and social care around the needs of service users' (Department of Health 2011, p 20).

Monitor was originally intended to promote competition across health care providers but, following the government's revision of its reform programme, this has shifted to place a greater emphasis on promotion of both integration and competition where it is appropriate and in the interests of patients. Integration can already be seen in practice through the early use of pooled budgets.

Example of health and social care integration: pooled budgets

The use of streamlined or pooled budgets to improve joint commissioning and promote closer partnership working between health and social care organisations was proposed by the Department of Health in its 2006 White Paper (Department of Health 2006b). Pooled budgets were one of a number of flexibilities set out in the subsequent Health Act 2006 to enable health and social care organisations to work in an integrated way, providing joint services to meet local need and remove any duplication in provision. However, as a proportion of total health and social care expenditure in 2007/8, joint financing represented only approximately 3.4 per cent (Goldman 2010).

The integration of budgets has particularly facilitated the bringing together of frontline health and social care teams to improve the co-ordination and delivery of care (Curry and Ham 2010). Pooled budgets have enabled care to be provided rapidly as there is no need for time-consuming referrals across sectors or checking where the money is to be sourced from, and this has especially benefited those at the end of life, when speed of delivery of care is often particularly important.

What do we know so far?

Three of the local areas we studied in our research were in the process of pooling health and social care budgets, with the funds being managed by the local health commissioners to improve care for older people in the area. In one area, a strategic commissioning group with specific goals (for example, reducing the number of deaths in nursing homes) was set up to manage the joint budget, involving stakeholders from the PCT, acute sector, hospices, primary care and nursing homes. In another, a care trust was established formally to integrate health and social care services and finances. These funds were used to finance care irrespective of whether the need was for health or social care.

It's the only way forward, pooling budgets, it seems to me, I can't see how we can operate if we're not all working together, and that's across all budgets – health, social, secondary, primary. It's one patient, they need care the whole way and the budget should reflect that.

(Commissioner 2)

Managing a pooled budget for end-of-life care was considered to be particularly demanding 'because it goes across all the borders'. As already mentioned, the delivery of end-of-life care involves a multitude of providers, and engaging them all in a pooled budget arrangement offers challenges that might not be seen in clinical areas where there is less complexity. The commissioners involved in this research had experienced more success in pooling budgets (and establishing a programme budget) among different health care providers than they had among social care providers.

There are always tensions along the way obviously because some people have slightly different visions to others.

(Commissioner 2)

However, interviewees in one locality described how pooling budgets had proved particularly beneficial in end-of-life care, allowing them to provide a more responsive service for patients close to the end of life. Whereas in the past patients sometimes could not be discharged from hospital to die at home because of the time it took to arrange a package of care in the community (involving decisions about whether a patient's needs were for health or social care, identifying sources of funding, and then undertaking a needs assessment), commissioners commented that now, with pooled budgets, provision was seamless.

Some of the participants in our research felt that experiments with pooled budgets had also had the additional benefit of raising the profile of end-of-life care within the local

health economy, and that there was a new focus on delivering high-quality care across sectors, regardless of how and from where the money flowed.

However, there were also concerns that the introduction of clinical commissioning groups might add a level of complexity to the process that could result in the specific focus on end-of-life care being lost, possibly leading to a dilution of provision in this area.

Furthermore, some difficulties arise from the pooling of budgets for health and social care. At a system level, the limited uptake of pooled budgets could be due to a lack of knowledge about the processes and governance mechanisms relating to their implementation and use (Goldman 2010). If the government plans to promote these forms of integrated commissioning, it needs to ensure that there is support for commissioners who implement and use pooled budgets.

For instance, our research revealed a problem in one area with regard to the different proportions of funding that were derived from health and social care, which had caused some conflict between the organisations involved. In another local area, health care providers felt that they were financially 'propping up' the local authority's contribution. On the other hand, some interviewees pointed out that pooling budgets and integrating care actually alleviated some of the tensions around which organisation paid for what as the cost of care was balanced across the system, which was beneficial for patients.

Relevant lessons for commissioners

When integrating the management of pooled budgets, it is important for organisations to combine their information and audit systems so that outcomes can be monitored.

One of the ongoing challenges of this and the other approaches described is the difficulty of ascertaining its impact. Access to outcome and other baseline data is insufficient to track progress successfully. There is a lack of hard evidence linking the use of pooled budgets to the achievement of care outcomes (Goldman 2010), although there are some examples in practice and some anecdotal reports of positive experiences. Developing a sound evidence-base is crucial in order to encourage local organisations to consider using integrated finances and then to monitor its effectiveness. The integration and transparency of this information is also important for ensuring that governance is shared across organisations and for the documentation of the financial and clinical processes and outcomes.

Such evaluations should be built into pilots and other change initiatives from the beginning rather than retrospectively bolted on at the end of the pilot period, when the necessary baseline data might not be available. Formal alignment of information systems across sectors is imperative in order to collect the necessary information to identify the impact of joint commissioning.

The use of pooled budgets between the health and social care sectors has been limited in practice. From the current evidence, and also in principle, pooled budgets appear to promote integration between health and social care organisations and to enable more streamlined, more personalised care. However, it is worth noting that joint financing is not always appropriate for every area and is dependent on the context and historical relationships between stakeholders (Ham 2009). A lead-provider model could help to overcome some of the challenges experienced (*see* p 10 for further details).

Pooled budgets offer the most concrete approach for encouraging integration across providers, although they are complex to develop and sustain. Commissioners should start small in using pooled budgets and focus on areas where the relationships, common pathways and data exist to support such a model.

Elements of successful commissioning in end-of-life care

A whole-systems approach to commissioning end-of-life care, along a care pathway or across providers, could help to promote the integration of services and the personalisation of care. Receiving payment as part of a pathway or package of care will give providers an incentive to work collaboratively to provide a more streamlined and individualised service. This is likely to improve the communication of patients' needs among providers along the pathway, and to enable more seamless, higher-quality care to be provided. Clinicians might be best placed to lead this process.

Our literature search and the interviews we conducted with those currently commissioning end-of-life care revealed a number of common factors that could be considered critical for promoting a more integrated, personalised and clinically led approach to commissioning. We examine these below.

Shared vision and goals

It was evident from the commissioners we spoke to that a shared vision for end-of-life care was critical for encouraging commissioners and providers to work together. This needs to be further reinforced by means of formal goals or objectives that are strategically set to ensure that they are most easily met by collaborative working. It is essential to involve the relevant stakeholders – the public, patients and carers – if local needs are to be met.

Commissioners need to work closely with all these stakeholders, including members of the public, in order to develop and commission end-of-life care services that are appropriate for local populations. Using contractual mechanisms (particularly those based on outcome measures) to set appropriate objectives is more likely to encourage partnership working and allows commissioners to support providers in doing so.

Contractual levers

Building quality and outcomes into providers' contracts is an important method of encouraging them to innovate and offer high-calibre, personalised services. However, this requires a more strategic approach to contracting that builds considerably on standard contracts.

Currently, commissioners seem not to understand fully the complexities of end-of-life care or the magnitude of change in the patterns of and growth in patients' needs. It is vital for commissioners to be sufficiently informed and aware of what constitute appropriate outcomes in this area of care. Furthermore, commissioners will, in future, need to have been met.

Contract negotiations can be used to establish the shared vision and goals required, and strategic commissioners can build outcome measures into their contracts to ensure that providers have to work together to deliver streamlined care. The exact nature of these outcomes should be designated locally but be based on the NHS Outcomes Framework impact indicator 'improving the experience of care for people at the end of their lives' (Department of Health 2010c, p 24). Commissioners should build this into local service contracts.

It is vital that commissioning for quality and outcomes is achieved and that incentives for quality are embedded in contracts. There are several contractual levers available to commissioners who are using contracts as a mechanism for promoting integration and ensuring high-quality end-of-life care. These include:

- establishing long-term contracts to ensure stability in service delivery

- encouraging groups of providers as well as single organisations to bid for services
- identifying specific outcomes that the contractor must achieve within a given period
- including penalties and/or interim contractual reviews in instances where outcomes are not achieved.

The more flexible use of contracts that are centred on quality and outcomes is likely to allow more personalised care and enable providers to deliver services in more integrated and innovative ways. Contracts should build on the ambitions of existing quality measures such as CQUIN and QOF through a greater focus on outcome-based incentives in order to encourage this integration in a more transparent manner.

The CQUIN payment framework allows remuneration to be linked to locally derived goals embedded in local contracts. Based on national policy but tailored to meet local needs, these goals should be ambitious but realistic, and have been arrived at through co-ordinated discussions between commissioners and providers, with support and oversight from the strategic health authority.

Several of those interviewed for our research described CQUIN as a way of encouraging integrated working between multiple stakeholders, particularly for initiatives that involve the whole health economy, such as reducing admissions and managing complex discharge. Furthermore, using CQUIN measures in acute and community provider contracts could ensure good-quality care across the whole care pathway through an incentive-driven funding scheme.

A more flexible use of contracts, such as the disaggregation of block contracts, should be encouraged to develop more personalised care and support providers to deliver services in more innovative ways.

Appropriate and aligned funding mechanisms

To ensure commissioning is properly integrated using the methods discussed above, funding mechanisms should be sensibly aligned between health and social care.

As already mentioned, there have been some limitations to the use of pooled budgets in practice, particularly around their processes and governance mechanisms and a lack of evidence linking them to better health outcomes in complex areas like end-of-life care (Goldman 2010). Because of this, for integrated commissioning to be successful, organisations need to integrate and align their methods of individual assessment, co-ordination of care, data and communications processes and, in particular, the funding of care, so that the different sectors can work together effectively.

Single assessment in particular offers an opportunity for integrating care planning and funding across health and social care. This, in turn, will help to facilitate the effective monitoring and evaluation of these commissioning methods and funding mechanisms across the whole health system, particularly their impact on individual outcomes.

Clinical involvement

Our research highlighted the importance of clinical involvement (particularly GP input) at various stages of the commissioning process. The early and frequent engagement of stakeholders, along with effective leadership, are necessary to encourage integrated working through commissioning. The benefit of local-level knowledge is vital to the development of services that meet the needs of the local population.

Previous research by The King's Fund found that GPs consider themselves to play a fundamental part in the organisation and delivery of end-of-life care (Addicott 2010).

This is likely to expand as GPs take on a key role in commissioning and delivering end-of-life care in the future.

Our research showed that clinically led commissioning is thought to be important, but support from those with management experience – such as staff from the PCT with expertise in contracting and finance – is required to achieve it.

Commissioners as brokers for co-ordination

There is a clear need for a more co-ordinated approach to care, spanning all settings across the health economy. There is some evidence to suggest that improving the co-ordination of end-of-life care does not necessarily incur additional costs and can lead to increased quality (Addicott and Dewar 2008). The King's Fund recently recommended that commissioners adopt a multi-component approach in order to promote the co-ordination of care (Imison *et al* 2011, p 7). This includes a range of activities such as a joint approach to care planning and assessment, the sharing of clinical records across multidisciplinary teams and the role of the GP as a navigator or broker for patient care.

Not only do GPs and other clinical professionals play a central role in the co-ordination of care, but, in the new commissioning environment, they are also considered to be best placed to manage the care of their local populations. However, they will need knowledge and support to do so, particularly in areas such as end-of-life care, where needs can be complex and require different outcome measures and more inventive ways of collecting data (Addicott and Ross 2010).

Conclusions

This report proposes that the personalised, clinically led and integrated delivery of end-of-life care should be supported through alternative approaches to funding and commissioning. Current funding and commissioning mechanisms are inadequate for meeting the needs of patients as they near the end of life. More appropriate approaches can be encouraged by developing a tariff for a pathway or package of care (Hughes-Hallett *et al* 2011), with local commissioners specifying outcome measures and encouraging integration through service contracts.

There are, however, a number of fundamental challenges in adopting a comprehensive commissioning approach to end-of-life care. These include:

- defining a discrete episode of care
- ascertaining the cost of an episode or pathway
- developing quality markers that are applicable to – and measurable within – this particular context of care.

Work has also been undertaken to enable individuals to take more control over the health services they require, which is helping to promote empowerment but should be tailored around individual needs, particularly as it can be burdensome for some at the end of life.

Alongside patients and carers, clinicians (and particularly GPs) may be well placed to understand these individual needs and develop packages of care accordingly. Clinical commissioning groups demonstrate a recent attempt to involve clinicians in this way. Previous variations, such as practice-based commissioning, show that engaging GPs was difficult, and localities instead relied on programme leads or administrative support to manage the process.

The benefits of using commissioning to promote integration have been demonstrated, particularly through the early examples of joint budgets between health and social care. These need to be used to support more integrated delivery of end-of-life care.

Our research has identified a number of factors that are critical to the success of integrated working in end-of-life care, including:

- shared vision and goals
- contractual levers
- appropriate funding mechanisms
- clinical involvement
- commissioner or GP as broker for co-ordination.

With the introduction of clinical commissioning groups, GPs and other health care professionals have a key role in ensuring that care is co-ordinated and commissioned appropriately to meet local population needs. It is vital that they, and others involved in commissioning, are equipped with the relevant knowledge and skills to undertake the role, particularly given the increasing demand for services and pressures on finances.

Commissioners and providers will need to work more intelligently and efficiently, using alternative commissioning approaches to promote integration and the provision of care that is of high quality and meets the considerable variation in individual patient needs and preferences.

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