" People's final journey must be one of their choosing..."

WAYS AND MEANS

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DEM☺S

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Foreword

It's said that there are two certainties in life – death and taxes. At some point we will all need end of life care, and yet we know that many people do not experience a 'good death'. At Sue Ryder countless relatives tell us that it was only when their loved ones came to our hospices at the very final stages of their lives that they felt that they received the personalised care that they wanted. Why is it that despite considerable efforts being made to improve the standard of end of life care across the UK dying isn't working? This report marks the start of our new campaign, which will seek to answer this question.

In 2011 we supported the publication of Tailor Made by Demos. This explored the importance of personalisation in all aspects of care, and the difficulties that there can be in ensuring that care is personalised in all settings. In this new report we explore some of the challenges and barriers that prevent people from being able to make choices about the kind of end of life care that they receive.

This research highlights the following key messages:

1 Many best practice tools and processes have been established for end of life care, but they're not always being used effectively, resulting in patchy patient experience which too often falls short of what it should be.
2 More people are dying with multiple, complex, non-cancer conditions. However, the evidence suggests that their experience suffers the most from poor practice.
3 There are several inequalities in end of life care. Crucially, the manner in which people enter the care system has a direct impact on the subsequent quality of their experience.
4 Too often, patient choice is not prevalent and consequently care is not personalised.

End of life care has seen significant innovation in recent years. Numerous programmes, tools and processes have been established in an effort to establish best practice. However, tools and processes cannot be used in isolation. Professionals must be trained to use them in conjunction with each other in

order to create an integrated and comprehensive approach to end of life care. This holistic approach is the key to ensuring that care is personalised. This report identifies that healthcare professionals are not always equipped to translate innovation into consistently good patient experience. Our own experiences tell us that communication between professionals and patients is key to achieving truly personalised care. Unfortunately it appears that many healthcare professionals still don't feel comfortable having difficult and sometimes complex conversations with their patients.

At Sue Ryder we approach care from the perspective of the individual receiving it. We are passionate about providing the care that people want. We don't just ask professionals for their expertise, we also ask the people we care for and their families how they would like to be cared for and supported. This report seeks to reflect this approach. We believe that widespread adoption of the right tools and processes, when fully integrated with the right training of healthcare professionals, would enable everyone to have a good death. We believe anything less is not good enough. We hope this report will start the conversation about how to make a good death a reality for everyone.

Paul Woodward
CEO, Sue Ryder

Glossary

A&E	Accident and Emergency
ASCOF	Adult Social Care Outcomes Framework
BME	black and minority ethnic
CCG	clinical commissioning group
CEO	chief executive officer
CHC	continuing health care
COPD	chronic obstructive pulmonary disease
DNACPR	Do Not Attempt Cardio-Pulmonary Resuscitation
DTU	day therapy unit
EPaCCS	electronic palliative care coordination system
GP	general practitioner
GSF	Gold Standards Framework
HWB	health and wellbeing board
JSNA	joint strategic needs assessment
LCP	Liverpool Care Pathway
MND	motor neurone disease
NEoLCP	National End of Life Care Programme
NICE	National Institute for Clinical Excellence
PEPS	Partnership for Excellence in Palliative Support
PPC	Preferred Priorities for Care
QOF	Quality Outcomes Framework

Executive summary

The problem with dying

To say that death and dying is a universal experience is stating the obvious. Yet that does not mean we are adept as a society in conceptualising the process. Part of this is, no doubt, because of our sensitivities and reluctance to truly unpick what dying entails, but a bigger issue is that the 'end of life', as an idea, is inherently challenging. There is rarely an objective 'moment' at which point the end of someone's life can be predicted with certainty. Even with terminal illnesses, with a clear prognosis (such as cancer), treatment may still be ongoing until the very last stages – practitioners and patients alike often (and rightly) see death as something that can be avoided for as long as possible. But everyone reacts differently, with different levels of acceptance for when to carry on and when to stop and prepare for death. There is no correct moment for this. A patient's consultant may well be planning another round of chemotherapy while their GP raises the issue of where one wants to die. This is unwieldy, uncomfortable perhaps, but somewhat inevitable. Because how we want to die is an inherently personal and subjective issue. Practitioners may not agree with their patients – or indeed with other practitioners – regarding the 'when' or the 'how' of preparing for death. There are no right answers.

This lack of certainty and objectivity about dying is deeply problematic when it comes to trying to plan or support people who are nearing the end of their life. Simply identifying who that population is can be a challenge. And this cannot be fixed overnight or with a simple policy solution. But there are two things we must do.

First, we must think hard about the process we create to help people. End of life care cannot be conceptualised as a neat, textbook element of health and social care, delineated into

stages for the purposes of service commissioning and provision. The reality is complex, sometimes chaotic, and always unique to each individual. If policy makers realise this, then we will not try to fit people neatly into a process conceived of in the abstract, but start developing support which begins with people's personal experiences and ask: what would improve that? Flexibility, responsiveness to change and cultures of care suddenly become more important, while achieving the perfect organisational structure less so.

Second, we must find out what people actually want. This may sound simple enough, but too often people make assumptions about a 'good death', conflating it with where people die.[1]

This report is the first of two developed by Demos for Sue Ryder, and addresses the first of these issues. It explores the quality of the patient experience of end of life care, conceived of as a journey through different services, and the sorts of things that can be done to improve this from the patient's perspective. In some cases this is an issue of learning from, implementing and standardising existing good practice, and in other instances there is the necessity for a more radical cultural shift around personalisation and choice.

The second report, launched shortly after this one, tackles the second issue regarding what people want as distinct from their place of death. The two ought to be read in tandem – first, conceptualising the problem from the lens of the individual, and second, driving to the heart of the issue – what do people *actually want*?

Service journeys

The issue of poor service journeys is central to the quality of end of life care, because end of life care, by its very nature, is an experience over time and location – a journey through different fields of health and social care, from home to hospital to hospice and back again. It can last days, months or years. The NHS End of Life Pathway lays out this journey in a linear fashion, as a guide for care providers and commissioners.

However, we conceptualise the journey firmly from the perspective of the individual and their family.

We place personalisation at the heart of this analysis, recognising that everyone's journey will be different, and should be flexible according not only to their disease or stage of illness, but their personal preferences and wishes. With demographic change comes an increase in the number of people dying of complex, multiple conditions – ensuring we can diagnose and support these people in a more flexible way will be critical if our end of life care is to be fit for purpose in the future.

Thinking in this way leads us to recognise that an ideal journey need not be linear, but perhaps circular, following the individual rather than placing them in distinct 'stages'. It will also include softer outcomes beyond structures and process, including the quality of transition from one service, setting or funding stream to another, the opportunities for choice and control, the coherence of communications and sense of empowerment, and so on.

A good service journey is typified by early and ongoing, seamless support. It can only be achieved through a high level of personalisation. Poor service journeys, on the other hand, are disrupted, delayed and prevent patients and their families from having choice and control over the end of life. Such journeys drive up health and care costs and lead to worse outcomes for patients. Through speaking to experts, practitioners and service users, and reviewing existing evidence, we have been able to identify seven key drivers of poor service journeys:

· delayed identification of the dying phase
· gaps in discussing, recording and acting on end of life preferences
· difficulties in triggering appropriate care after diagnosis
· perverse incentives in the assessment of eligibility for support
· problematic or delayed discharge into the community
· multiple and incompatible funding streams
· patchy support for carers in the community.

We collaborated with a range of experts from all areas of end of life care to create two 'typical' service journeys, which highlighted the impact of the above.

Box 1 **Typical journey A**
'A' is an older woman with multiple conditions (eg chronic obstructive pulmonary disease (COPD), diabetes and heart failure). A undergoes several separate incidences of assessment for these different conditions. She then moves cyclically through periods of decline and crisis, some of which lead to her hospitalisation. Finally, one of these events results in her death in hospital.

Box 2 **Typical journey B**
'B' is a social care user, living at home. Like A, B experiences a number of crises, which result in emergency hospital admissions. Eventually he receives a diagnosis of a life-limiting condition, and a prognosis of less than 12 months. He is then discharged. While he is being cared for at home, a crisis occurs; there is a sudden deterioration in his condition. B's family suddenly experience 'panic' about their ability to cope, and this results in an emergency hospital admission. In the worst case scenario, B does not reach a ward but dies in A&E.

These two service journeys show how they are typically beset by either a lack of coordination or a lack of professional communication and support for carers. However, and perhaps more importantly, this information led us to a further level of understanding: there are clear inequalities in the experience of service journeys, and in many cases these are a result of a person's 'starting point' on their journey. 'Starting points' often dictate the type of journey a person has, and where they die. Inequalities in starting points, therefore, had a fundamental impact on the overall experience of a person's end of life. These inequalities may be dictated by the type and timeliness of a patient's diagnosis (with clear indications of a two-tier system between cancer and non-cancer diagnoses), by the services they already use (eg whether they are existing social care users, and which

professionals they have contact with), or by ethnicity, location or other demographic factors. With this in mind, we asked a range of experts to revisit the 'typical' service journeys above and consider how these might be turned into 'ideal' patient experiences through addressing common sources of disruption and reducing inequalities dictated by patients' starting points.

Box 3 **Ideal journey A**
'A' is an older woman with multiple conditions (eg COPD, diabetes and heart failure).

- *A's GP uses a long-term conditions register, thanks to greater awareness of how to balance multiple diagnostic indicators (through training or awareness raising such as Find Your 1%).*
- *As a result, A is flagged on the GP's Gold Standards Framework (GSF) and/or an electronic palliative care coordination system (EPaCCS). This is the trigger for a discussion about her eventual end of life preferences, which are duly recorded on the EPaCCS.*
- *Through her GP, A and her family access education on how to manage her health, reducing the likelihood of her suffering an avoidable crisis.*
- *Instead of receiving separate assessments for her multiple conditions she has a single, whole-person assessment involving a multidisciplinary team.*
- *She is also encouraged to use so-called 'What if' planning, whereby she formulates contingency plans for her care in case of declining health. This may also result in fewer hospital admissions for A.*

A may nonetheless move cyclically through periods of decline and crisis, some of which may still lead to her hospitalisation.

- *One of these episodes should trigger a referral to a geriatrician, who should form part of her care team from then on.*

Because A's wishes have been recorded and made available to others involved in her care, she is able either to stay out of hospital or to be discharged quickly from the hospital to her

preferred place of care. A dies in the location of her choice, according to her expressed preferences.

Box 4   **Ideal journey B**
'B' is a social care user, living at home. Like A, B experiences a number of health crises, which result in emergency hospital admissions.

· *B's GP is kept informed of these admissions by means of an electronic register shared between primary and secondary care (and other agencies).*

Eventually B receives a diagnosis of a life-limiting condition through a hospital consultant, and a prognosis of less than 12 months. The diagnosis is the trigger for a number of actions:

· *B's GP is informed of his diagnosis, and places him on an end of life care register (GSF).*
· *B is referred to specialist palliative care social workers, among whose roles is the provision of information, advice and support to B's family.*
· *B receives coordinated care through a scheme such as Partnership for Excellence in Palliative Support or Coordinate My Care. This includes access to 24/7 support for him and his family.*
· *B's family receive advice and education on how to care for him at home.*
· *Advanced care planning is initiated by the diagnosing clinician. B's preferences, including his wish to die at home, are documented in his discharge summary on leaving hospital and communicated to his GP. These plans are sufficiently flexible to accommodate any change in B's preferences over time.*
· *In addition to his preferences, B's needs are also assessed at this stage – in particular for equipment to support his care at home, and input from community nurses. Equipment might be sourced from a hospice equipment bank, or overseen by a named coordinator (eg an occupational therapist), or both.*
· *B's care may be coordinated by a community nurse.*

With adequate support (including out-of-hours support) available, and better training in what challenges to expect, B's family is better equipped to deal with any crisis in his condition. An emergency hospital admission is thereby avoided, and B dies at home.

There are clear recurring themes across journeys A and B. The ideal journey incorporates advanced care planning that is proactive, flexible and patient-centred, and coordinated care facilitated by an effective electronic records system. Expanding on these themes, we grouped potential improvements to service journeys under the following broad headings:

· societal and cultural factors:
    – awareness raising
· workforce:
    – system capacity and practitioner mix
    – practitioner training and practitioner support
    – 'relational' aspects of care
· delivery:
    – care coordination
    – flexibility
· personalisation:
    – person-centredness and patient-held records
    – greater involvement of families and informal carers
· policy:
    – health and social care integration
    – commissioning
    – funding.

From the range of improvements that could be made, we distilled eight specific recommendations which we felt, taken together, would ensure everyone's end of life journey was of better quality – smoother, more coordinated, and offering greater opportunities for choice and control:

1 Adopt free social care at the end of life as soon as possible.
2 Make electronic records systems standard practice with

automated prompts, suggesting GPs initiate certain aspects of end of life care (eg advanced care planning, referral to specialist palliative care nurses) at an appropriate time, according to standardised and automated 'triggers' linked to the GSF.

3   In each clinical commissioning group (CCG), designate at least one specialist in dementia and end of life care, and specialists in other conditions as identified by each area's joint strategic needs assessment (JSNA), as 'primary care end of life links'. GPs can call on these 'link' practitioners to assist them with diagnosing patients in need of end of life care.

4   Make training in holding discussions about the end of life a core part of the medical and nursing undergraduate curricula.

5   Integrate end of life care teams, bringing existing health, care and community services together to work in a coordinated way around each person on the end of life register.

6   Give top priority to investment in care coordination – through care coordinators, EPaCCS and Partnership for Excellence in Palliative Support (PEPS), with patient-held records at its heart.

7   CCGs should commission specific training in end of life care for families and carers of those at the end of life, to help carers cope, and to promote greater choice and control over care.

8   Include support for informal carers' wellbeing in commissioning of end of life care services, as part of local authorities' new duty to promote the wellbeing of carers. This should incorporate availability of 24/7 end of life support, as well as access to a range of types of support after death and in the longer term.

Fortunately, the integration of health and care and free social care at the end of life have already been identified by the Coalition Government as priorities and Demos hopes these will be implemented with the urgency they warrant. This report presents recommendations on how this agenda could be implemented. The timing – of substantial policy reform married with demographic change and straightened resources – could not be more opportune for the implementation of our other recommendations, based as they are on evidence of good practice, in line with the overarching themes of personalisation in health and care, and with the potential to save significant resources by reducing the costliest, poor quality outcomes (such as hospitalisation).

Underpinning all of the changes to process and funding we recommend is a shift in cultures and communication regarding end of life care. Running through our research with experts, practitioners and service users was a perception that staff across health and care – from GPs to consultants and home carers – are ill equipped to discuss end of life issues, for various reasons, including underrepresentation of end of life care issues in basic generalist training, and an infrastructure that promotes risk averseness and fails adequately to support practitioners. The National End of Life Care Programme has made progress in embedding awareness of end of life care as a universal responsibility among healthcare workers, with GPs often best placed to help patients express their wishes, make choices and take control over their service journeys. However, this has not always translated into action by practitioners. This leads to uncertainty, disruption, delay, lack of choice and overall poorer outcomes for people at the end of life and their families. In this respect, other settings for health and social care can learn from staff approaches in hospices, where service users and their families consistently report feeling well informed and regularly consulted about their care, making for a more personalised experience than they might have elsewhere.

With demographic change, larger numbers of people will be dying each year over the next 20 years, and more of these will have multiple conditions and less predictable end of life trajectories. The uncertainty and subjectivity of defining and planning the end of life, described at the beginning of this summary, will only become worse, so the need for health and care staff to be more adept at diagnosing and supporting people at the end of life – in a fundamentally more flexible way – will only become more pressing. These changes also present a challenge: to meet the level of increased demand within existing resource constraints, and to do this through a period

of significant disruption to existing health and care structures ushered in by the Health and Care Act and Care Bill. We believe that the prospect of improved end of life care should be treated with cautious optimism: the circumstances are right across policy and practice for a more personalised, empowering conceptualisation of an end of life care journey. This report sets out how this can be achieved.

1 Background to the report

Health and social care are in the midst of root and branch reform. Local health structures have been drastically reorganised as a result of the Health and Social Care Act 2012, while the new vision for care set out in the Care Bill is poised to reshape our outdated and unwieldy legislative and operational frameworks into a system fit to meet growing demand. The changes it proposes are designed to improve the quality of health and social care through the principles of greater local accountability, widespread personalisation of services, and support for those using health and care, and their carers and families, in a more holistic and integrated way. It is an ambitious undertaking but one which, if successful, will see people's experiences of these two interrelated services drastically improve.

End of life care, as a complex blend of health and care services delivered to support people approaching the end of life, is significantly affected by these dual reform agendas. Yet – as a result of its unique nature – the way in which it can be improved differs from other forms of health and care support and requires specific attention. The outcomes for those needing end of life care, and the measures of success and quality, differ from the indicators used to judge other forms of support. Measures of mortality and morbidity cede to other indicators of quality, such as the satisfaction of patients and their relatives or carers. Nonetheless, many of the key concepts driving improvement in health and social care remain the same. Chief among these is personalisation.

Personalisation – informed choice and control over the services one receives – has been the cornerstone of health and care innovation for many years. But the reach of personalisation has not fully extended to end of life care, which can often be characterised by a lack of choice and – at worst – an impersonal

and institutional experience. In 2011, with the support of Sue Ryder, Demos explored the challenges for achieving personalisation in contexts where the usual personalisation tools – personal budgets – were more difficult to implement. This included end of life care.[2]

We found that high quality, person-centred services could be – and are being – delivered at the end of life without the need for specific structures that give people direct control. Good practice was concentrated particularly in hospices, with their long history of delivering holistic palliative care and building individual relationships with the dying and their families. More broadly, we found that since end of life care sits on the fault line between health and social care, a vital element of successful personalisation at the end of life is the integration of these two systems, complemented by 'softer' tools of personalisation, such as appropriate staff cultures. We concluded that, as it is not necessarily appropriate for patients to take financial control of their end of life care (eg through personal budgets), much more thought needs to be put into service design and integration to achieve the same personalised ends.[3]

With this in mind, Demos and Sue Ryder wanted to explore in greater depth how a broader understanding of quality, including improved person-centred support, might be achieved at the end of life against a backdrop of rapidly changing health and social care structures.

It is clear, however, that to assess the quality of a person's end of life care, and to develop ways of improving their experiences of this, one must consider how each person and their family arrived at the point where they required this care. End of life care is not a 'snapshot', but rather the culmination of a journey, which may have involved many different health and care related services. If we were to consider just one stage, or one theme, in isolation, we would lose the sense of overview needed to judge how personalised a person's end of life experience is, across services and over time. Getting people's service journeys to and through end of life care right is the central focus of this report.

Of course, not everyone's starting point on the end of life care journey is the same. There is variation according to a Background to the report patient's condition (or conditions), the support they already receive and where they receive it, and even where they live. Through our research, we conclude that variations on these starting points are critical in dictating the quality of people's journeys and can strongly influence where people die. This report therefore considers how we can equalise access to high quality, personalised care even where people's starting points are inevitably different. This represents a significant challenge, as some variation is unavoidable; there will always be people for whom diagnosis happens very late, and we can never expect everyone to have the same resources (whether money, suitable housing, or informal care from relatives). The system in which end of life care is delivered has to be robust enough to offer a 'personalised approach to personalisation' – one that accommodates these differences. In the following chapters, we seek to identify the drivers of smooth service journeys and consider how these can be exported to other patient groups and other models of delivery.

To address this issue, Demos has carried out research exploring the current types of service journeys to the end of life being experienced, the common points of disruption and delay, which groups are most likely to experience these and how service journeys might be improved, in particular through the intuitive joining up of services. It complements a second piece of work by Demos and Sue Ryder, to be published in July 2013, which examines in greater detail the factors governing individuals' choices at the end of life, specifically their preferred place of death.[4] Overall, our concern is with how to deliver end of life services that meet individuals' expectations and respect their needs for safety, dignity and choice in dying.

We have found that people needing end of life support pass through the health and care systems at different stages, and this experience is often confused and disjointed – undermining the potential for person-centered support particularly in those vital final weeks and days when high quality, integrated care is paramount. While there are

several instances of good practice, the alignment of different sources of support at the end of life is harder than it should be, leaving too many people and their families with poor end of life experiences. Demos has taken this problem to a wide array of experts from different fields related to end of life care to gather constructive suggestions on how people's experiences might be improved. This report discusses the difficulties identified with service journeys at the end of life and presents recommendations on how these might be addressed.

Definition of terms
Service journeys
The term 'service journeys' in this report refers to the combination and succession of services being used by those requiring end of life care in the years, months and days before death. Journeys are likely to span across and between health and social care, palliative care and other support services as time goes on. Chapter 1 sets out the difference between the service journey and a related concept, the 'care pathway'.

An ideal journey begins with timely diagnosis, is characterised by an integrated and person-centred package of support, and concludes with a well-supported death in the location of the person's choice.

End of life care
End of life care refers to the support services used by people approaching the end of life, which can include a variety of different health and social care services, as well as alternative therapies and support for the families of those approaching the end of life. One form of end of life support is palliative care (see below). The General Medical Council considers that patients are approaching the end of life when they are likely to die within the next 12 months; however, end of life care can last days, months or several years.[5] Indeed, for those with terminal conditions, end of life support and planning can begin with diagnosis. As we explain in more detail

below, the definition of 'end of life care' is shifting to accommodate the effects of medical and technological advances and demographic change.

Palliative care
Palliative care is an holistic approach to pain relief and support, which can be used for people with serious illnesses, but is often a form of end of life support. It is usually delivered by a multidisciplinary team, reflecting the concern with physical, emotional and spiritual needs of the individual and their family to improve overall wellbeing. It is most often true that palliative care begins where 'curative' treatment leaves off, but this is not always the case; a cancer patient may begin to use hospice outpatient services while still undergoing chemotherapy, for example. In the UK, the boundary is more fluid than in other countries such as the US, where patients may only become eligible to receive palliative care when they have ceased curative treatment.[6]

Methodology
To address the question of end of life journeys, Demos hosted focus groups with end of life care service users to hear first-hand accounts of transitions between and within the health and care services as people approach the end of life. We hosted discussion groups at the day therapy units of two Sue Ryder hospices – Wheatfields, Leeds, and Manorlands, Keighley.

We also carried out semi-structured interviews with six members of frontline staff in these hospices, to hear their perceptions of service integration and their attempts to smooth people's transitions across services.

Demos also interviewed several academic experts, commissioners, policy makers and practitioners (listed in appendix 1) to help us identify 'weak links' – common points of delay and disruption within service journeys that contribute to poor outcomes for service users, as well as insights about good practice in the UK and further afield.

These findings – from experts, frontline staff, and people using services, combined with our own review of the existing literature – were presented at a half-day workshop where stakeholders from different fields were brought together to consider our findings and help us develop our thinking on what an ideal integrated service journey might be like, and the changes necessary to achieve this. The attendees at this workshop are listed in appendix 2.

This report presents these findings, first by describing the changing policy context in which this research is situated, and then setting out the barriers to integrated service journeys at the end of life. We then consider the associated question of who is most at risk of poor or disjointed service journeys as a result of inequalities in 'starting points', before discussing how service journeys might be improved and inequalities of access reduced, referring to examples of good practice we have encountered during this project. Finally, we bring this together in a series of recommendations related to policy and practice, which we believe would help achieve better quality and more personalised end of life service journeys for greater numbers of people.

A note on the end of life policy context

End of life care has been much discussed in recent years – both as part of wider health and social care related reforms and as a distinct policy area in need of improvement. Therefore the context in which this research is set is still changing – with some reforms imminent and others being debated and consulted upon. In this section, we will briefly review the backdrop against which reform of end of life care is taking place. A more detailed outline of recent policy developments can be found in appendix 3; here we highlight those developments singled out by experts we consulted as being particularly opportune or challenging for end of life care.

One of the most recent changes has been the end of the National End of Life Care Programme (NEoLCP), set up in 2004 to promote and disseminate best practice in end of life care, which came to an end in April 2013. Some of its functions are now split between various bodies including NHS England and NHS Improving Quality.7 Both the programme and the accompanying end of life care strategy were seen by our expert interviewees as a 'positive step', which had helped raise the profile of end of life care across disciplines – particularly in social work. However, some we spoke to were uncertain about whether the drive to improve end of life care would retain its momentum post-NEoLCP: 'Choice was on the political agenda at one time, though less so now, but it is used euphemistically… to mean care at home.'

Of greater importance perhaps was the Palliative Care Funding Review (2011), which mooted the possibility of providing free social care at the end of life.8 The experts we consulted consistently identified this as a vital change, which would create immediate and significant improvements to the experience of service journeys for patients and the quality of outcomes.

On a more micro level, clinicians in primary and secondary care are also now equipped with a battery of frameworks and tools with an end of life care focus: the GSF, Preferred Priorities for Care (PPC) and the Liverpool Care Pathway (LCP). These are almost universally welcomed by experts as having the potential to improve patient outcomes, but their implementation has hitherto been variable, and inhibited by lack of standardisation, lack of support by practitioners and poor communication with patients and relatives.

Beyond the realm of end of life care, changes in health and care policy more generally will have significant implications. For example, as a result of the Health and Social Care Act 2012, CCGs and health and wellbeing boards (HWBs) have now assumed their statutory powers, with implications for how local priorities are identified, and local services commissioned and delivered. 'Improving the experience of care for people at the end of their lives' is now specified as an area for improvement in the Government's mandate to the NHS Commissioning Board and in the NHS Quality Outcomes Framework (QOF) (under the fourth priority area, 'Ensuring that people have a positive experience

of care'). The Department of Health has also stated its intention to consider end of life care in relation to the Adult Social Care Outcomes Framework (ASCOF). The QOF sets out the indicators against which the Government and the public can hold NHS commissioners to account, so the inclusion of end of life care is vital to cementing it as a priority and to driving up quality.

The Care Bill, which at the time of writing (June 2013) has just been through its second reading in the Lords, is designed to rationalise the UK's overly complex and out of date social care legislation and fit it for current and continued demand. Central to the Bill is the introduction of a new, local duty to promote wellbeing. The details of the Bill stand to affect end of life care in a number of ways. It reiterated government support for free social care at the end of life, and placed carers on a par with those they care for in their entitlement to support. They also stand to benefit from new duties on local authorities to provide information about available sources of support. Finally, the proposals should improve service journeys for those moving from one local authority to another, as local authorities will have a duty to continue a transitioning patient's previous care arrangements until a new package has been put in place.

Most recently, and most promisingly, the Department of Health's announcement of its intention to 'make joined-up and coordinated health and care the norm by 2018' could be a real breakthrough for end of life care in particular, sitting as it does on the interface between these two service areas. A number of 'pioneer' projects will be set up within a few months, with further pilots promised in every part of the country by 2015. Indicators based on patient experience to measure the effectiveness of efforts at integration will also be developed this year.[9]

It is clear, just from this brief overview of the most significant changes, that end of life care is buffeted by several ongoing agendas – health, social and palliative care are in a state of flux, with structures and funding streams being reshaped. Furthermore, this is all taking place against a backdrop of demographic change and medical and technological advances, which necessitates a broadening of the definition of 'end of life care'. By 2018, over 50 per cent more people in England will be living with three or more long-term – and in many cases lifelimiting – conditions than in 2008,[10] and our improved ability to manage conditions such as cancer and HIV means that the boundary between 'terminal' and 'chronic' conditions will become increasingly blurred.[11]

This combination of demographic change and policy shift creates an opportune moment to review current practice afresh, consider the likely impact of emerging changes, and identify what may have been overlooked and ought to be considered as part of this wider shake up.

Why are service journeys important?

The journeys taken by individuals from the time they are advised that they are going to die to the time of their death are extremely variable. In the words of one of our expert interviewees, service journeys are 'smooth for some, problematic for many'. Precisely what support people will need, and at what point, varies according to a number of factors, both personal and diseaserelated. What can be said with more certainty is that people and their families will need input from a variety of sources during the journey, and that the composition of this support is likely to shift. The NHS end of life care pathway is one of eight clinical pathways established by NHS England to set out what that support might look like, introducing an element of standardisation into the planning, commissioning and delivery of local services, specifying what kind of support must be offered and at what stage (figure 1).

While Demos also considers the whole journey in this report – from diagnosis to death – the approach we take is quite different from the pathway outlined above. This pathway was developed from a provider and commissioner perspective, whereas we consider the journey firmly from the perspective of the individual and their family. We place personalisation at the heart of this analysis, recognising that everyone's journey will be different, and should be flexible, depending not only on

their disease or stage of illness, but also their personal preferences and wishes. An ideal journey need not be linear, but perhaps circular, following the individual rather than placing them in distinct 'stages'. Of course, a 'good' service journey will incorporate more of the elements of the care pathway outlined above than will a 'bad' one, but it will also include softer outcomes – the quality of transition from one service, setting or funding stream to another, the opportunities for choice and control, the coherence of communications and sense of empowerment, and so on.

Figure 1   **NHS end of life care pathway**[12]
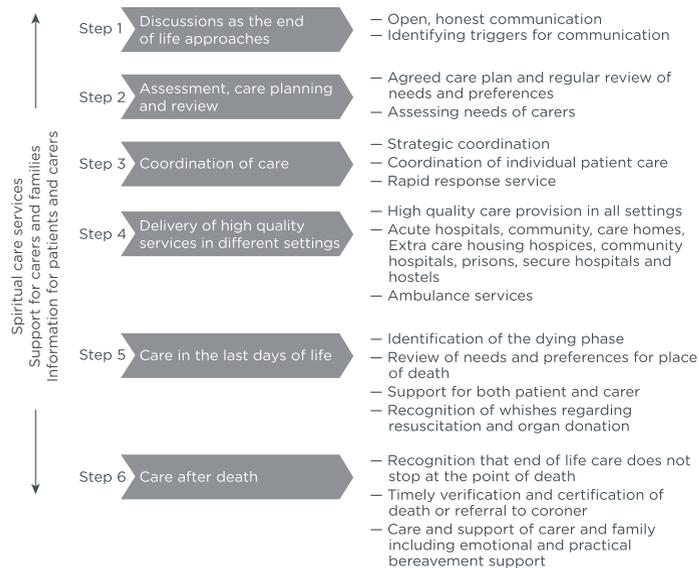
Why is it important to look beyond the pathway above, to consider the quality of journey from the individual's perspective? First and foremost, poor service journeys are expensive. Breakdowns in patient journeys are often symptomatic of wider, systemic problems – for example the lack of integration between health and social care, and the complex arrangements and perverse incentives that promote cost-shunting between services and locations. The results can trigger rising costs across the board. Unwarranted emergency hospital admissions, perhaps the Background to the report most visible symptom of poor service journeys, are also the most costly. With an average cost of £6,336 per person, emergency inpatient admissions comprise 46.6 per cent of all costs, and 71.1 per cent of hospital costs, at the end of life.[13] In total, adult hospital admissions in the last year of life cost the NHS an estimated £1.3 billion. In perspective, that is just over three times the estimated total cost (£411 million) of providing core and specialist palliative care.[14] Each death in hospital is estimated to cost £3,000,[15] and is usually something individuals and their families want to avoid. This is now even more pressing, given recent concerns regarding the pressures on A&E services and the financial sustainability of acute care, prompting Professor Sir Bruce Keogh, medical director of the NHS in England, to lead a review of the model of urgent and emergency services.[16]

Hospital deaths are also associated with a range of poorer outcomes, and approximately half of all complaints to NHS hospitals relate to end of life care.[17] Poor journeys also militate against early intervention – late diagnosis or delayed planning invariably generates greater costs, as more significant levels of support are required, or emergency moves from location to location, to support needs with little forewarning.

Second, and perhaps more importantly, poor service journeys act as a vehicle for a plethora of poor outcomes. Poor journeys result in reduced choice over what support is delivered at the end of life, where, and by whom. Disruptions or delays make planning harder to achieve, leaving no time for the communication of preferences and a pervading sense

among patients and their families of 'being done to' rather than taking control of something which is personal and unique to each individual. Too often, this leads to individuals' needs – medical (pain relief and symptom management) and personal (dignity and privacy) – not being met. Arbitrary variations in service journeys also increase inequalities, disadvantaging one group of patients relative to another: for example, our research revealed 'patchiness' and a lack of standardisation in the use of tools to record preferences (such as PPC), leading to the level of personalisation any one patient receives being contingent on geographical location and practitioner competence.

Overall, therefore, poor service journeys (and by this we mean where support is not coordinated, transitions between services are disjointed and communication – either between practitioners or between practitioner and patient – is poor) militate against early intervention, drive up costs, limit patient choice, inhibit personalisation and increase inequality and unfairness.

Considering the journey just from a commissioning and service provision perspective will not get to the heart of these problems – they look only to processes and structures, without considering culture, communication and person-centred approaches which really make a difference to the quality of experience for those nearing the end of life and their families. It is for this reason Demos has re-conceptualised the 'pathway' – a top-down clinical guideline – into the 'journey' – an experience unique to each person and their family from diagnosis to death. The problems identified in the next chapter are those which drive poor experiences as described by patients, carers and practitioners with first-hand insight into this issue, and the solutions in the chapter which follows are targeted at tackling those problems from the bottom up – putting each patient at the heart of their journey.

2 Problems driving poor service journeys

In this chapter, we explore the particular weaknesses in current structures, processes and cultures which create poor service journeys. The following 'typical' journeys, constructed with the help of assembled experts at our end of life care workshop, illustrate how these problems lead to poor outcomes.

Box 5 **Typical journey A**
'A' is an older woman with multiple conditions (eg COPD, diabetes and heart failure). A undergoes several separate incidences of assessment for these different conditions. She then moves cyclically through periods of decline and crisis, some of which lead to her hospitalisation. Finally, one of these events results in her death in hospital.

Box 6 **Typical journey B**
'B' is a social care user, living at home. Like A, B experiences a number of crises, which result in emergency hospital admissions. Eventually he receives a diagnosis of a life-limiting condition, and a prognosis of less than 12 months. He is then discharged. While he is being cared for at home, a crisis occurs; there is a sudden deterioration in his condition. B's family suddenly experience 'panic' about their ability to cope, and this results in an emergency hospital admission. In this worst case scenario, B does not reach a ward but dies in A&E.

The two 'typical' journeys both result in hospital deaths. The most recent available figures show that more than half of deaths – 55–57 per cent – occur in hospital,[18] and it is estimated that £1.3 billion is spent by the NHS each year on hospital admissions at the end of life. As yet, there are no data to determine the effect of the drive to increase deaths at

home at a national level, although many local initiatives have shown positive results.[19] The fact that experts at our workshop chose to portray journeys ending in hospital deaths may therefore either demonstrate a perception that hospitals deaths are (still) 'the norm', or simply flag hospital deaths as a common occurrence in need of further change. The experts outlining B's journey considered placing B's death either in A&E or en route, in the ambulance. This chimes with an observation by one of our expert interviewees that although there were fewer than in the past, deaths in A&E still occurred 'far too often'.

Journeys A and B also illustrate a phenomenon – to be explored further in chapter 3 – whereby a patient's 'starting point' in their end of life journey (eg the time and type of diagnosis they receive, their referral route, the support they are already receiving at the point of diagnosis) influences the rest of their service journey. Because A's starting point is that she suffers from multiple conditions, there is no 'ownership' or coordination of her care by professionals. Journey A is subsequently characterised by a lack of central cohesion or coordination; it is fragmented along the lines of her different health conditions. No care planning takes place, no terminal diagnosis is given, and A and her family have no opportunity to express their preferences or make choices about care. Unsurprisingly, A's journey then ends with no support in place to assist her and her family's needs.

B, on the other hand, has the starting point of being a social care user, and he continues to be so rather than be provided with health care or other specialist support. This is a common pattern: two-thirds of social care users in the last 12 months of life are existing users.[20] B receives his terminal diagnosis earlier than A, so advanced care planning is initiated at an earlier stage, and his preferences are – at least initially – respected. Nonetheless, this does not prevent a crisis because his informal carers, given little support or preparation specific to end of life care, find they cannot cope. Care planning and discharge planning have both taken place, but as a result of Problems driving poor service

journeys failure of communication and support for the family and carers in the home setting this journey unravels.

Experts felt that these two journeys are typical of the experiences faced by many people and families, even though each person's journey is unique. They also capture a number of specific processes and transitions which can lead to poor outcomes:

· delayed identification of the dying phase
· gaps in discussing, recording and acting on end of life preferences
· difficulties in triggering appropriate care after diagnosis
· perverse incentives in the assessment of eligibility for support
· problematic or delayed discharge into the community
· multiple and incompatible funding streams
· patchy support for carers in the community.

We consider these in more detail below.

Specific areas of weakness in service journeys
Initial diagnosis
Being able to 'diagnose dying' effectively is vital to a good end of life care journey. If such a diagnosis is made too late, there may not be enough time to discuss preferences, put plans in place and ensure relatives are prepared. If a person's death is diagnosed, but the appropriate referrals and actions are not triggered, then people can be left struggling to cope, with questions unanswered. Unfortunately, both these situations occur fairly frequently. Many professionals and GPs in particular lack the confidence to 'diagnose' dying, either because of the difficulty of identifying this for some groups and conditions (eg the frail elderly, those with dementia, those with a number of comorbidities), or simply because they are unwilling to initiate a sensitive discussion with the patient. Some do not make appropriate referrals because they are uncertain about what action should be taken next.

One delegate at our expert workshop with a clinical background ascribed this reluctance to diagnose dying to clinical culture; medics are taught to provide information where they are certain rather than to speculate, and are therefore resistant to communicating where a diagnosis, prognosis or a course of action is uncertain – unfortunately, the very nature of end of life means this is often the case. As one Sue Ryder hospice user with Motor Neurone Disease (MND) explained:

When you get told you've got a disease or a terminal illness the first thing you want to say is 'when?' How long have I got to live? You want to know whether to cram it all in and get as much in as you can or take your time and enjoy every day. And basically the words were 'it could be 8 months, it could be 2 years'. We're just past 5 years and I think I've still got a little bit left in the tank. You've got to be positive with these things.

This can be contrasted with cancer diagnosis – indicators are well developed so identifying terminal illness is easier, and prognoses are often accurate and can be communicated with some certainty. There is also a clear course of action to take – referral to a cancer support nurse. Unsurprisingly, cancer patients often find they have an earlier diagnosis, and a clearer course of action established, than non-cancer patients (an inequality we explore further in the next chapter).

Discussing, recording and acting on end of life preferences
Delivering choice and achieving personalisation in end of life care is dependent on robust and proactive systems for communicating information to patients (enabling informed choice), eliciting preferences and recording them in a way that is communicable to all those with whom the patient comes into contact. A breakdown in any one of these areas makes its impact felt in a poor quality and impersonal experience.

A substantial body of evidence suggests that people are open to having a conversation about the end of life with their physician,[21] and research by Dying Matters showed that, after friends and family, individuals would prefer to discuss their preferences with their GP. However, as outlined above, GPs often struggle with communicating about dying. The same unease that makes them reticent about 'diagnosing dying' also inhibits them from discussing end of life planning and preferences openly. Some 35 per cent of GPs reported never having initiated an end of life care conversation with one of their patients.[22]

At present, medical students receive training in end of life care that has a clinical focus, as well as training in holding difficult discussions (but it does not look specifically at end of life issues). Nurses are not trained specifically in communication about end of life care, though there is an optional, post-qualified module. Although many practitioners rate their confidence in holding such discussions highly, according to the Royal College of Physicians, data from complaints and audits 'would suggest that the self-reported confidence of physicians is sometimes misplaced or that physicians are not putting their skills into practice'.[23] The same survey found that only a third of physician respondents had attended a learning event on end of life in the past five years.[24]

Poor recording of preferences cannot simply be put down to communication difficulties among generalists. Tools designed to record preferences such as the PPC form are shown to have a positive impact in achieving death in the preferred place of care,[25] but still relatively few patients are being offered the chance to complete a PPC form. This was confirmed by our research with hospice service users, most of whom had discussed their preferences for the end of life with family members alone rather than professionals. Most were therefore unsure whether or how these had been officially recorded. Even if such tools are used and preferences are recorded, there remain difficulties in ensuring these are carried out, particularly where patients are cared for at home. A common example of this is where Do Not Attempt Cardio-Pulmonary Resuscitation (DNACPR) orders may either not be known to ambulance services or out-of-hours GPs, or not be recognised by them.[26]

Triggering appropriate care following a diagnosis

The evidence we reviewed through this research suggests that tools designed to help GPs to put care in place for those diagnosed as dying, such as the GSF and end of life registers, are often applied inconsistently, or else not maintained at all. For example, activities relating to the GSF also tend to be ad hoc – attendance of different professionals at GSF meetings varies from one area to another. Some GPs may place people with a terminal diagnosis of any length on a locality register, while others will include only those with a prognosis of 12 months or less. Hospice staff we interviewed reported that an estimated 10–30 per cent of the patients attending the hospice's day therapy unit (DTU) were not on a register at all.

Equally, there is a lack of consensus about what action should be triggered by placement of a patient on the register. We heard that it is common for GPs not to refer to specialist palliative care at this stage. Hospices reported that referrals from GPs were more likely than those from other practitioners to come too late, and to be lacking in patient information, resulting in a knock-on effect on the hospice's ability to put in place appropriate care. A significant proportion of referrals to the DTU came too late, with patients by that stage being too ill to attend as outpatients. This can lead to an inefficient use of resources, with inappropriate referrals inhibiting access to already scarce DTU places for other patients who would benefit. Data collected by NHS Bedfordshire and Sue Ryder as part of the evaluation of their PEPS programme confirmed the need for GPs to be more proactive in making end of life care referrals – with just 1 per cent of referrals to the PEPS care coordination centre coming from GPs. One Sue Ryder hospice user explained the difficulties in getting the right treatment set up after diagnosis: Problems driving poor service journeys

Before I came to Sue Ryder, it took some time to find out what was wrong with me. I was then told there was no cure. I seemed to go from pillar to post to get the right treatment to manage my symptoms. I ended up having blood transfusions at the hospital every two weeks for three years. I felt so weak and I couldn't even hang out the washing.

Locality registers are rendered still less effective for not being shared with adult social care teams. SystmOne Palliative, a clinical software system aimed at achieving the 'one patient, one record' model to allow sharing of patient data between NHS hospitals, GPs and voluntary hospices,[27] is used by over 5,000 NHS services, suggesting a significant level of information sharing takes place. Nonetheless, hospice staff we spoke to were still having to spend a long time processing referrals when these came from referrers who were not on SystmOne – they felt that a problem of divergent systems was the main difficulty they faced, rather than an unwillingness to share data.

Assessing eligibility

Currently, new social care users have to undergo both a means test and an assessment of need, and for those at the end of life this is likely to be followed up with additional assessments for eligibility for free care through NHS continuing health care (CHC). Multiple assessments can be distressing for patients and their families adjusting to the news of a diagnosis, and can undermine confidence that they are receiving joined-up care. They can also be administratively burdensome and unacceptably time-consuming at a point when time may be of the essence. The assessment of eligibility for CHC has been singled out as a particular source of delay.[28]

CHC requires assessment by a multidisciplinary team, reviewed by a decision-making panel which sits infrequently. As there is a considerable, and understandable, financial incentive for local authorities to increase the flow of care users onto the CHC, supported by NHS budgets, practitioners reported to us a tendency in some areas for local authorities to refer speculatively to the CHC assessment process. While many of those referred would be ineligible, all are assessed, and this attempt at costshunting slows the process for those in need of rapid CHC support. Many attendees at our seminar also felt that CHC eligibility criteria were discriminatory. This problem has been picked up by a number of organisations representing different patient groups – for example the

Alzheimer's Society.[29] The prioritisation of health needs over social care needs in CHC means that dying people with long-standing or acute social care needs can be disadvantaged, or find the CHC assessment is even slower as they must appeal or provide additional evidence to help their claim.

In July 2009 the Fast Track Pathway was introduced, designed to help patients nearing the end of life to access CHC more quickly,[30] but our research suggests that its implementation has not solved the problems of delayed and inequitable access to CHC. Experts reported that practitioners tended to feel that all their patients would benefit from the fast track as opposed to waiting for the longer CHC process, so that the new tool had simply become the norm for all applications.

Many felt that the only suitable replacement for the failed fast track would be a distinct end of life care system, which guaranteed immediate support and had a policy of acting first and worrying about the finances later. However, it is important to note that the ideal scenario among all those we consulted as part of this research was one in which needs assessment was redundant because social care at the end of life was free at the point of entry.

Delayed discharge into the community

For those nearing the end of life, a stay in hospital can often become a permanent move. In most cases, this situation is avoidable, and is only rarely necessitated by the individual's health needs, and still less by their preferences. Rather, the situation arises because there are delays in putting together an appropriate care package to move patients back into the community – to hospice or residential care, or back home.

According to our expert interviewees, a common cause of delay in assembling community care packages is the sourcing of appropriate equipment. Sometimes equipment is simply not available or takes weeks to arrive, removing the opportunity for care at home. In a survey of primary care trusts, only 54 per cent reported having timely access to equipment such as hospital beds and commodes outside normal working hours.[31] This was reported to be a particular problem in Greater London, where St Christopher's Hospice has resorted to funding and administering its own bank of equipment, to meet the shortfall in the local authority stock, facilitating rapid discharge from hospital. Seminar delegates were aware of other such instances of the voluntary sector 'stepping in' – uncommissioned – to fill gaps in local authority provision. This raised broader questions about the role of the voluntary sector; many were uncomfortable that the line between its remit and that of statutory services was becoming blurred.

We heard anecdotal evidence of delays in equipment procurement caused by unacceptable levels of bureaucracy – for example a woman who was without a commode for several weeks, pending the next meeting of a local authority committee with the power to sign off its purchase as an 'extraordinary expenditure'. It remains unclear whether problems procuring equipment are due to budget constraints, inadequate processes, or both. In either case there is a need for robust scoping of local need, as well as forecasting of future needs as increasing numbers of people choose to die at home and need equipment. Responsibility for these activities rests with HWBs in compiling a JSNA, as well as with CCGs in taking due account of this intelligence in their commissioning decisions.

Community care packages are made still more difficult to put together when they require coordination across geographical areas – when patients are moving to be near family, for example. Hospital trusts may serve multiple administrative areas, without standardised forms across all of them. Transferring funding and care packages from one strategic health authority to another is also highly problematic. This ought to be improved under the provisions of the Care Bill, which requires local authorities to continue a transitioning patient's previous care arrangements until a new package has been put in place.[32]

Multiple and incompatible funding streams

While end of life care may not be chronically under-resourced like other areas of care, many felt the range of funding streams

operating within end of life care was incoherent and could often provoke a range of negative consequences. The coexistence of means-tested social care, non-means-tested social care (provided through CHC) and free health care, palliative tariffs, personal budgets and soon 'care accounts' is a significant and growing source of confusion for those navigating end of life care. It is likely to complicate people's understanding and expectations, and make it unclear where responsibility for support lies.

A second negative outcome, as discussed above, is that the existence of two or more competing budgets in the mix of funding streams increases the risk of cost-shunting between health and social care teams, where practitioners might be encouraged to move people around the system rather than take responsibility for their care – only adding to delay and complexity of transitions between services. One expert we spoke to believed that the system had lost its focus on need and become more of a question of 'managing the entry points into different budgets'.

Another negative consequence of separate funding streams is that this could often dictate the type of care available, inhibiting people's choice. For example, a significant proportion of those using end of life care will have had ongoing social care needs for at least a year before their death.[33] But those who move onto CHC may not be entitled to maintain the same social care arrangements when these become NHS-funded. For example, if the NHS does not usually contract the care home where someone is already accommodated, it may require an individual to move to a home where it does fund beds. The same might apply with domiciliary care agencies, leading to people losing carers they may have become accustomed to over many years. Choice of care home may be further restricted for those on CHC, with reports last year suggesting that some care homes in London were refusing to accept CHC patients where they deemed levels of funding set by the regional strategic health authority to be too low.[34]

Another problem identified was the funding distribution *within* the health system: it was felt that the desired shift to primary and community end of life care would not be achieved so long as resources remain tied into secondary care, but, as one expert told us, it would be 'politically almost impossible' to take funding out of the secondary system (given high profile instances of hospital closures and exposed failures in care) to fund primary and community support.

Patchy support in the community

It is well acknowledged that relatives caring for someone at home might experience 'panic' and feel unable to cope with a sudden change or deterioration in condition. This is a major driver of unnecessary hospital admissions, but ought to be largely avoidable if adequate support is provided. However, there is a widespread shortage of out-of-hours services, including for home visits and giving telephone support.[35] Despite frequent acknowledgement that more needs to be done to help informal carers, little action was forthcoming, and families are not being educated about the needs of dying people, nor given advice on how to cope and use the (albeit patchy) support that was available.

We also found widespread concern over the lack of support and training for professionals caring for patients nearing the end of life at home or in care homes. For example, care providers (particularly in a care home setting) may not have adequate training to detect signs of deterioration that warrant medical attention. In other circumstances, where decline can reasonably be expected, home carers may find this difficult to accept; they may feel that they are 'doing something wrong' if they ignore a patient's worsening condition, but may be unsure with whom they should raise concerns. This could lead – again – to unnecessary hospitalisation, or a lack of appropriate end of life support being put in place. Some of the pilot sites run by the NEoLCP focused on educating social workers in end of life care, with positive reported outcomes, but our research with experts revealed a perception that the learning from these localised initiatives had not translated into general social care practice.

Although the practitioners Demos spoke to reported recent improvements, there are also still problems with GPs not prescribing sufficient symptom-relieving medication for those dying at home, partly as a consequence of the Shipman Inquiry,36 which manifested in an unwillingness to increase or withdraw medication in response to changing symptoms. The inquiry also led to stricter regulations surrounding controlled drugs being introduced in 2004.[37] In the past, these have been linked to a rise in hospital admissions at the end of life, due to increased reluctance among practitioners to carry, prescribe and administer drugs essential to pain relief (eg diamorphine) in the community.[38] A second problem associated with access to pain relief is the makeup and qualifications of the workforce, with only a relatively small number of community professionals qualified to prescribe. Sue Ryder has sought to remedy this, pledging in its strategy that all its community nurse specialists will have prescribing powers by 2018.

Finally, a lack of generalist training in administering medication – in particular in the use of syringe drivers (an alternative to oral administration of pain relief, anti-emetics, sedatives and other symptom-relieving drugs, over up to 24 hours) means that again, those nearing the end of life often find themselves hospitalised unnecessarily when community carers find they cannot cope. Experts we spoke to told us that such equipment varies from one area to another, exacerbating the problem of unfamiliarity when community professionals move locations.

Overview

These seven problematic areas all risk undermining the quality of people's end of life care service journeys. Combined, they create the poorly coordinated, poorly supported 'typical journeys' described at the beginning of this chapter. But perhaps more interesting is that when these problems are considered in the form of a journey, setting off on the wrong foot (eg because of a Problems driving poor service journeys delayed diagnosis or lack of planning) is liable to render the whole journey that follows (and end point) sub-standard. In other words, where someone begins their service journey can often create a domino effect of good or poor outcomes. It is clear, therefore, that to improve service journeys across the board, one must ensure that everyone's 'starting point' promotes positive outcomes. This is currently far from the case. The next chapter explores the deep inequalities that exist between the 'starting points' of different groups, which set them on course for good or poor service journeys as a result.

3 Inequalities

Variation in service journeys – reflecting people's needs and preferences – is the mark of personalisation: each end of life journey ought to reflect each individual's and their family's choices. But arbitrary and unchosen differences – based on personal circumstances, condition(s), age, location or ethnicity – often work counter to personalisation, as people's experiences are defined by these factors, rather than by what they actually want. In this section, we present some of the inequalities in care service journeys identified through our research, which inhibit personalisation and generate poor outcomes.

Cancer and non-cancer diagnoses

Both our desk research and field work with experts and practitioners pointed to a significant inequality between those with a cancer and non-cancer diagnosis, for example the frail elderly, those with respiratory disease or heart failure, and those with degenerative conditions such as MND. This is generally attributed to two factors. First, these conditions often have a less predictable disease trajectory than cancer; they often involve peaks and troughs rather than a steady decline, making prognosis more uncertain. Second (with the exception of the frail elderly), these conditions are generally scarce on GPs' patient rolls, so practitioners are less experienced in recognising the relevant diagnostic indicators specific to that condition. As a result, a non-cancer diagnosis of dying can often occur later, or indeed not at all – so people do not receive the level of support, advice and help with planning they might have received if they had been placed on a local end of life register in a more timely fashion.

Beyond the issue of diagnosis, the disadvantage of noncancer sufferers relative to cancer sufferers continues. Although many more people die of, and with, a mixture of conditions such as diabetes, arthritis, frail old age, lung disease and heart disease, cancer – which accounts for just over 27 per cent of deaths – still accounts for the largest proportion of specialist palliative care services.[39] As one of our expert interviewees cautioned, 'Specialist providers need to engage with the non-cancer agenda.' That said, there are several examples of good practice by hospices in widening access to services for people with noncancer diagnoses. This can be accomplished through forging links with specialist consultants (eg neurologists), or through outreach-style initiatives which 'expose' people to the hospice's services at an earlier stage of their illness. An example of the latter is the Heart Failure Support Group at Sue Ryder Wheatfields.

Box 7   **Wheatfields Heart Failure Support Group**
Sue Ryder's Wheatfields hospice has taken steps to increase awareness of and access to the hospice's services for groups with non-cancer conditions. The Heart Failure Support Group, which meets monthly, is for anyone with heart failure who has been seen by a heart failure nurse. Its aim is to provide infor-mation, advice and support to patients and their carers who may not have adequate resources locally. As well as a valuable opportunity to share experiences, the hospice runs education sessions on topics such as healthy eating and nutrition, per-sonal safety, and managing anxiety. Group members also ben-efit from chair-based exercise sessions and the presence of a heart failure nurse.

Inequality of access to specialist palliative care is not confined to hospice inpatients; it applies similarly to community provision. In our research with users of the DTU, the majority of whom had cancer, we found that many had been referred to the outpatient service by specialist nurses – either Macmillan nurses or (for those with COPD, and to a lesser extent) respiratory nurses. This suggests that boosting

hospice access for other groups might involve establishing an equivalent point of contact to a Macmillan nurse for other conditions, to boost referrals.

The situation is summed up well by this quote – taken from previous Demos research – by the daughter of a man who died of heart failure, aged 82, but who was diagnosed with lung cancer shortly before he died:

It seems like you can have everything if you have cancer. Because he was diagnosed with lung cancer, he could have everything, night sitter, Macmillan nurses. It seems so unfair. He couldn't walk before and we had to manage with him at home.[40]

A disproportionate focus on cancer in end of life care risks having a cyclical effect: shaping both public expectations (eg what sort of people we believe hospices are 'there for') and practitioner expertise, so that cancer sufferers remain the most likely to access many specialist palliative care services. Hospices can potentially play a large part in addressing this imbalance, through outreach into secondary care services for other specific conditions (see below), and outreach from specialist palliative care into primary care to increase GPs' awareness and drive up referrals for people with non-cancer diagnoses.

Access to funding

As outlined above, the 'high stakes' needs and means assessments for health and care is a source of considerable delay and confusion within people's end of life care journeys. But it also creates significant inequalities: the CHC system (with eligibility criteria that require an applicant's primary need be health related) penalises those whose end of life conditions may require substantial personal care needs, and makes it harder for those who do have a primary health need to prove it if they have significant previous social care needs. This is often the case for people with long-term conditions such as MND, who often require substantial social care

support towards the end of life – the burden of proving valid health needs creates difficulties.[41] The same applies to people who live in their own home or a care home as opposed to a nursing home, as it is often assumed that their health needs are not significant enough to warrant NHSfunded care and by extension CHC.[42]

Those who are ineligible for CHC are subject to the standard social care means test, and are required to fund their own care if they have assets exceeding the relatively modest £23,250 threshold (rising to £118,000 for residential care in 2016). Across the health and care systems, then, there is potential for stark inequality. One individual eligible for CHC with substantial assets can receive social care for free at the end of life if they have a CHC-eligible health need, while a second individual with exactly the same social care needs, if deemed ineligible for CHC, would have to pay for the entire costs of their care even if they have modest savings.

With its primary purpose to distinguish between health or social care need, it is clear that CHC is not an appropriate tool to establish the level of end of life care needs, which are often a complex and changing blend of the two. It is only used in the absence of more appropriate criteria, which ought not to distinguish between these two forms of care, but rather to determine whether that person requires any and all end of life care support. There is then a compelling case – both ethical and practical – for making end of life care support entirely free, as we outline in chapter 5.

Recording of preferences

There are groups for whom the recording of end of life preferences is a challenge. For example, those with dementia or other mental capacity issues, learning disabilities or cognitive impairment often find they are unable to have their voices heard when it comes to important decisions regarding resuscitation or medication at the end of life. Diagnosis of dying among those with degenerative conditions involving diminishing capacity often comes too late for consultation

with the patient to take place, while doctors may have poor awareness of the law surrounding mental capacity, exacerbating the issue.

However it is not just those with capacity issues who find they lose out on having choice and control over their deaths. Groups with whom doctors might find it particularly difficult to hold end of life conversations – for example, younger people and children – may lose out on an opportunity for timely discussion of their preferences because of practitioner discomfort.

General vulnerabilities

There is a wide range of groups with existing vulnerabilities – spanning people with learning disabilities, those who live alone, homeless people and the prison population – who are at risk of disrupted service journeys and poorer eventual outcomes. Members of any such group need (as we all do) to be recognised and accommodated as eventual users of end of life care. This is in part the task of HWBs, which must be alert to current and future local demand for end of life care from vulnerable groups when compiling their local JSNAs. Beyond commissioning, vulnerable groups must be taken into account in the delivery and design of services. Different vulnerabilities impact on the service journey in different ways, necessitating solutions that are targeted at different groups. By way of illustration, we consider some of the particular challenges affecting three of the more common vulnerable minority groups: those with dementia, those with a learning disability, and black and minority ethnic groups

Dementia

Although deaths from dementia account for only between 3 per cent and 7 per cent of all deaths, one in three people aged over 65 die with some form of the condition.[43] Many members of this group go unrecognised; approximately 57 per cent never receive a formal diagnosis.[44]

People with dementia are seen as disadvantaged by a double stigma surrounding both death and the condition itself, and so are even less likely than the general population to be given the opportunity to discuss their end of life needs. In addition to the problem of diagnosing dying before consultation is no longer possible (see above), the uncertain course of dementia, coupled with this diminishing mental capacity, makes advanced care planning difficult. Particularly in the latter stages, patients may find it difficult to communicate their needs, which impacts on their chances of experiencing a pain-free death. The emotional and spiritual concerns are 'disproportionately neglected' in this population,[45] and a large majority of this group (63 per cent) currently die in care homes, because their care needs may have become too significant for care at home before they are diagnosed as having end of life care needs. People with dementia are over-represented in hospital deaths, in part because they are more likely to be in a care home before death (with care home staff often unable to cope with end of life care and therefore calling for emergency admissions). Nearly one in three (30 per cent) of people with dementia die in hospital, and just 6 per cent in their own home.[46] They are extremely underrepresented as recipients of hospice services – something that Hull and East Riding council sought to address with an innovative integrated pathway design.[47]

Box 8 **Dementia integrated end of life pathway in Hull and East Riding of Yorkshire**

Following identification of poor quality end of life care for people with dementia, Hull and East Riding set up a multidisciplinary taskforce comprising health, social care, voluntary sector and academic stakeholders. They mapped out an ideal journey, and used this as a basis for developing an integrated care pathway, unifying input from social care, hospices, neurologists, psychiatrists, district nurses and GPs, with a key worker assigned to the patient from diagnosis. One of the most significant barriers identified was a lack of awareness between care workers and mental health and dementia specialists of each other's roles. This was addressed by 'swap-shop' training. Hull and East Riding have plans to assess the outcomes of the pilot in greater detail, but there is already evidence that integrated working has resulted in spontaneous collaboration between dementia and end of life care – for example in reach between Dove House Hospice and a psychiatric unit, and Admiral Nurse team advising Dove House Hospice on the care and accommodation of their dementia patients.

Learning disability

On average, each GP surgery in England has 50 people with learning disabilities on its register. This number is set to rise, as the incidence of learning disability in the population increases by 1.1 per cent year on year.[48] Still more rapid is the rising demand for end of life care in this group, who for the first time are beginning to survive into old age; the number of people aged over 60 with a learning disability is projected to rise by 36 per cent between 2001 and 2021.[49]

People with a learning disability face several challenges related to end of life care. First, there is a problem of expressing and recording of preferences. As outlined above, medical staff without a proper grasp of mental capacity guidelines may not consult and give decision-making opportunities to those with a learning disability. On top of a general reticence in holding end of life discussions, and a limited understanding of mental capacity, practitioners may also lack the skills to connect with communication-impaired patients, and may doubt whether doing so is in the patient's best interests. NEoLCP guidance cautions that people with a learning disability may – either through lack of experience, or as a consequence of their impairment – find it difficult to make choices, and require more information and time to do so.

Second, people with a learning disability can be difficult to diagnose as dying. They are at an increased risk of a number of chronic conditions (eg obesity, with implications for heart

disease and diabetes; specific long-term illness or physical disability; epilepsy; visual or hearing impairment; mental ill health, including dementia; and respiratory disease). Therefore, they are highly unlikely to reach the end of life without a number of comorbidities. As we have seen, those with multiple conditions are likely to experience a delayed and uncoordinated service journey, due to difficulties with diagnosis of dying and coordinating multiple condition-led interventions into an end of life care package.

Third, older adults with a learning disability already suffer from a lack of 'ownership' of their care, falling through the gap between learning disability teams and older people's teams. Individuals can no longer attend day centres when they turn 60, but this is often too young for older people's services to assume responsibility. This has important ramifications for identification of end of life care needs and access to the relevant services, particularly as people with a learning disability tend to experience those needs some five to ten years earlier than the general population.[50]

Finally, experts we spoke to highlighted the need for specific consideration of carers for people with a learning disability. Carers for adults with a learning disability – often their parents – may themselves be entering late old age. When caring for a dying individual at home, they may therefore be particularly susceptible to the crises which are a major cause of unnecessary hospital admissions. In addition, older carers are frequently more distant from services, having spent many years caring for a person (eg a son or daughter with a learning disability) with no, or minimal, support. Unsurprisingly, a recent informal survey of a specialist cancer hospice identified only one person with a known learning disability across all its services.[51] Community end of life care support services may have to expend particular, targeted effort on engaging and reaching out to these carers.

Black and minority ethnic groups
End of life outcomes for ethnic minorities show a significant difference from the White British population. Members of black and minority ethnic (BME) groups are much more likely than the majority to die in hospital and much less likely to access hospice services.[52] Similar inequalities are apparent in advanced care planning: a study focusing specifically on cancer patients found that 37 per cent of deceased patients of Black Caribbean origin and 44 per cent of their family or caregivers had reported being given sufficient choice over location of death, compared with 55 per cent of White British patients and 71 per cent of their families or caregivers.[53] White British patients were also found to be more likely to recognise the term 'palliative care', and to understand the role of Macmillan nurses.[54]

The Department of Health's project Stories that Matter found that many older BME people did not feel listened to or taken seriously, and identified a need for more advocacy and information about services. Interviewees from the project described feeling 'stuck' in 'mystifying' health and social care systems. On the provider side, health and social care professionals reported feelings of fear and anxiety about catering for BME groups, compounded by an awareness of institutional racism, lack of knowledge about cultural and religious beliefs and values, language barriers, and inadequacies in the provision and use of advocates and interpreters. BME immigrants to the UK in particular may have low expectations, as well as limited awareness, of the services available to them.

Finally, one expert interviewee cautioned against making assumptions about the availability of informal care for BME individuals at the end of life; the offer of support should be equal to all, not affected by stereotypes of families willing to 'rally round'. High levels of hospital deaths in these communities are likely to be in part driven by assumptions on the part of professionals that some minority groups are more capable and willing to provide care at home. St Joseph's Hospice in East London, where there is a large Bangladeshi population, carried out a consultation to determine how they could work with the community to reduce the identified high proportion of hospital deaths. The response they received was a desire for training for informal carers in what to expect in

the final stages of life – suggesting that carers' inability to cope was a key issue in hospitalisation.

Box 9   **Sue Ryder Manorlands Apprenticeship Scheme**

Sue Ryder's Manorlands Hospice is situated a few miles outside Bradford, a city with the second highest BME population of any district outside London.[55] *However, the makeup of the general population is not reflected in the profile of hospice users; in 2008 just four of the 404 referrals to the hospice were from ethnic minorities. In response, in 2009 Sue Ryder launched a BME programme incorporating an apprenticeship scheme and a series of awareness-raising events (including Health MOT clinics and Q&A sessions in local community centres). Young unemployed people from the South Asian community in West Yorkshire were recruited to the apprenticeship scheme. Apprentices completed four placements over the course of a year in different services run by the hospice, resulting in an NVQ Level 2 qualification in health and social care. They also assisted in running the awareness-raising events.*

Between 2009 and 2012, the number of referrals to the hospice for local BME people rose to 33. Some 840 local people from BME groups either attended an event or visited the hospice.

One service user said, I was in two minds about coming to the hospice, and did not feel comfortable about it. I was originally with the community nursing team and then they let me come here for a visit to see how things for myself. Seeing other people who shared my cultural identity made me feel reassured. I have now been coming to Manorlands for a few months. The staff are very professional.

Prior service use

Another important driver of inequalities in end of life care journeys is in the services being used in the run up to diagnosis. For example, cancer patients account for the vast majority of users of hospice inpatient services, while figures show that people already receiving (local authority funded or self-funded) social care when they enter their palliative phase continue down a social care pathway, with less input from health or hospice services,[56] and so are far less likely to use hospices. Care home residents are particularly disadvantaged, experiencing the highest number of hospital admissions in the final year of life, as well as being the least likely to die in a hospice.[57] People with dementia are more likely than other groups to spend their last months in residential care, and it remains extremely common for them to be transferred to hospital immediately prior to death.[58]

As one practitioner explained to us, 'social care hasn't yet caught up with the fact that most people's first entry point into care for the dying is social care', suggesting that difficulties in accessing hospice care for those with longer term social care needs could be down to poor rates of referral from social care staff. Complexity (and therefore perhaps delay) of diagnosing dying is also likely to play a part, as is residential care staff lacking the expertise – or perhaps the time and capacity – to detect deterioration and initiate support at an early enough stage, or to poor awareness on their part of what action to take. Informal or professional carer inexperience with end of life care for those with social care needs may also lead to increased rates of hospitalisation.

Other inequalities exist for those in the health system. Experts reported to us that, in their experience, individuals who had been admitted to hospital were less likely to be accepted by a hospice if referred. This was attributed to the criteria hospices apply to manage their oversubscription: since people in hospital are perceived to be in a safe place (with access to pain relief and symptom management), they are considered less of a priority for hospice admission than those coming from other care settings.

It was also reported to us that the ongoing smoothness of the patient journey was to some extent dependent on the care setting. In a hospice, for example, referrals are reportedly easier and more patient-centred, with several referrals made at the same time and with the same assessment of need, whereas those referred by a GP may have to have multiple hospital appointments. D, whose wife died from

MND and was cared for in a Sue Ryder hospice, said,

They [Sue Ryder hospice staff] work together and liaise with everyone – patients, relatives and GPs – to make sure the care is coordinated and tailored to meet the individual's needs. They really go that extra mile.

Finally, the variability between settings extends to the experience of relatives and carers, who are much more likely to be offered bereavement counselling in a hospital or hospice, which often provides this on-site, than if their relative had died at home or in residential care.[59]

Geographical variability

In this chapter we have identified several drivers of inequalities in people's service journeys towards the end of life. These are all associated with people's 'starting points' on their journeys – eg their pre-existing conditions, service use, ethnicity, age. But all of these are also set within a context of geographical variation in what services are available in a particular area. As discussed in chapter 2, some areas are under-resourced in specialist equipment available for use in the community (anecdotally a particular problem in central London). Similarly, the quality and availability of hospice at home care, out-of-hours services and specialist palliative care are all highly dependent on local commissioning arrangements. Local authorities also differ in the forms of means-tested social care they provide.

Variability extends to practice and even practitioner level. Experts informed us that use of end of life registers currently was not standardised, with GPs differing not only in the thoroughness with which they use them but also in the coding employed; for example 'red', 'amber' and 'green' on the GSF is not used uniformly by all practitioners. It seems, then, that people's end of life care service journey is likely to be affected by a variety of different arbitrary factors, undermining the level of choice and control available and

therefore the quality of outcomes achieved. It is clear that to improve people's service journeys across the board, we must equalise these inequalities, enabling all groups – regardless of condition, location, and so on – to access the same level of personalised, high quality journey towards end of life. The next chapter explores what this journey might look like.

4 Creating a better service journey

Previous chapters have explored the problems with end of life service journeys as they are currently experienced, looking at the most common points of breakdown and delay, and the disadvantages some groups face. This chapter draws on the existing evidence base, expert opinion, and the insights of practitioners and service users to offer some solutions. We revisit the 'typical' service journeys set out in chapter 2 and consider how these might be improved. We consider the improvements to be made under the following broad headings: societal and cultural factors, workforce, delivery, personalisation and policy.

'Ideal' service journeys

We asked the attendees at our half-day workshop to indicate the changes necessary to turn their 'typical' service journeys (see chapter 2) into 'ideal' ones.

The ideal journey was conceptualised in more than one way. One group of delegates felt that the existing NHS end of life care pathway (see chapter 1) provided a solid foundation for practitioners to guide people from diagnosis to death; they felt that any changes to specific patient journeys should be made within this existing framework. At the other end of the spectrum, a second group dismissed the notion of there being a linear experience and depicted the service journey as a series of concentric circles, with the patient moving outwards over time from a central point of uncertainty towards greater reassurance. This journey is mediated by communication, which is more effective the more it is tailored to people's personal circumstances, condition and so on.

After distilling the key messages from each of the journeys the groups designed for us, we concluded that the 'typical' journeys of patients A and B discussed in chapter 3 could be improved in the following ways.

Box 10 **Ideal journey A**

A is an older woman with multiple conditions (eg COPD, diabetes and heart failure).

· *A's GP uses a long-term conditions register, thanks to greater awareness of how to balance multiple diagnostic indicators (through training or awareness raising such as Find Your 1%).*
· *As a result, A is flagged on the GP's GSF and/or an EPaCCS. This is the trigger for a discussion about her eventual end of life preferences, which are duly recorded on the EPaCCS.*
· *Through her GP, A and her family access education on how to manage her health, reducing the likelihood of her suffering an avoidable crisis.*
· *Instead of receiving separate assessments for her multiple conditions she has a single, whole-person assessment involving a multidisciplinary team.*
· *She is also encouraged to use so-called 'What if' planning, whereby she formulates contingency plans for her care in case of declining health. This may also result in fewer hospital admissions for A.*

A may nonetheless move cyclically through periods of decline and crisis, some of which may still lead to her hospitalisation.

· *One of these episodes should trigger a referral to a geriatrician, who should form part of her care team from then on.*

Because A's wishes have been recorded and made available to others involved in her care, she is able either to stay out of hospital or to be discharged quickly from the hospital to her preferred place of care. A dies in the location of her choice, according to her expressed preferences.

Box 11 **Ideal journey B**

B is a social care user, living at home. Like A, B experiences a number of health crises, which result in emergency hospital admissions.

· *B's GP is kept informed of these admissions by means of an electronic register shared between primary and secondary care (and other agencies).*

Eventually B receives a diagnosis of a life-limiting condition through a hospital consultant, and a prognosis of less than 12 months. The diagnosis is the trigger for a number of actions:

· *B's GP is informed of his diagnosis, and places him on an end of life care register (GSF).*
· *B is referred to specialist palliative care social workers, among whose roles is the provision of information, advice and support to B's family.*
· *B receives coordinated care through a scheme such as PEPS or Co-ordinate My Care. This includes access to 24/7 support for him and his family.*
· *B's family receive advice and education on how to care for him at home.*
· *Advanced care planning is initiated by the diagnosing clinician. B's preferences, including his wish to die at home, are documented in his discharge summary on leaving hospital and communicated to his GP. These plans are sufficiently flexible to accommodate any change in B's preferences over time.*
· *In addition to his preferences, B's needs are also assessed at this stage – in particular for equipment to support his care at home, and input from community nurses. Equipment might be sourced from a hospice equipment bank, and/or overseen by a named coordinator (eg an occupational therapist).*
· *B's care may be coordinated by a community nurse.*

With adequate support (including out of hours) available, and better training in what challenges to expect, B's family is better equipped to deal with any crisis in his condition. An emergency hospital admission is thereby avoided, and B dies at home.

When presenting the two 'typical' service journeys in chapter 2, it was clear that these captured many elements which worked together to create a negative experience for A and B. The same is true of the two ideal journeys outlined above – while concise, these two journeys contain many elements which need to come together to create positive experiences for A and B and their families. In the following section we break down these journeys into their component elements.

Societal and cultural factors
Awareness raising
A and B's experiences might have been improved if they or their families were better informed about how to access information and support related to end of life. This can be difficult, however, given the level of discomfort many people have about this issue. The importance of overcoming the taboo surrounding death and increasing awareness of end of life care (the choices to be made, and the service options available) should not be downplayed. These activities – exemplified by the work of Dying Matters – underlie the 'informed choice' that is a prerequisite for personalisation when it comes to end of life care. An expert interviewee commented, 'As a society we need to get much better at preparing and planning for death. Because of the way our health system is structured, everything falls to acute services.'

It is notoriously hard to measure the effectiveness of awareness-raising activities,60 but our research did reveal a prevailing scepticism about the progress made in stimulating public discussion of dying. Some attendees at our half-day workshop thought that the end of life lobby ought to 'think bigger' – perhaps aspiring to the scale of publicity given to

Creating a better service journey encourage blood and organ donation. Certainly people seem to be more willing to discuss decisions about what happens after their death (eg relating to inheritance, organ donation, and whether they want to be cremated or buried) than those decisions that affect the months, weeks and days leading up to death. Others were supportive of suggestions that ageing, death and bereavement ought to feature on the school curriculum. However, while there was consensus that the public is ill-informed about the end of life, some experts questioned the extent to which raising public awareness should be a priority for action relative to investment in professional training in this matter.

This is because perhaps the most important components of informed choice is *who* you tell and *how* it is recorded. Otherwise the outcome – the achievement of that choice – may not happen. The role of the professional in being involved in conversations is, therefore, crucial. Several of the hospice service users to whom we spoke reported having discussed their end of life preferences with their family, but far fewer were able to recall having discussed them with a health or social care professional, nor whether they had been recorded. Public preparedness to talk about death and dying can achieve little if professionals are reticent to broach these issues. Yet there is ample evidence of this reticence – an uncommunicative professional culture, and a lack of competence and confidence to hold end of life discussions (see chapter 2).

In the current economic climate, we feel, on balance, that it should not be a priority to fund initiatives focused solely on awareness raising of the public, but that both public and professionals need encouragement to communicate and that the onus must be on the professional – rather than with the individual coping with the news of a terminal diagnosis – to broach the subject and to elicit and record people's preferences.

Workforce

System capacity and practitioner mix

Those we spoke to raised concerns about the size and distribution of the end of life care workforce. The availability of home visits by GPs and district nurses is diminishing, while experts warned of a crisis in recruitment of clinical nurse specialists. These factors could substantially reduce the ability of end of life services to weather the coming demographic storm. Interviewees stressed the importance of maintaining a large enough pool of clinical nurse specialists, as well as advocating increased access to gerontologists – specialists in ageing who are, elsewhere in the EU, as likely to be involved in older people's care as paediatricians are in children's care. One expert interviewee commented:

If we are going to develop community services… I think we need to start looking at the divide between primary and secondary health care services and have much more secondary care expertise available in the community rather than in hospitals. Once you start to move a significant number of people out of a hospital setting, who still need specialist input, that doesn't really work unless the specialist input goes with them… Rather than this group of people that we are talking about having to go to hospital to access the specialisms, the specialisms need to come out into the community in order to provide a much more patient-centric service and a much more efficient cost-effective service.

System capacity is absolutely integral to personalisation; before offering patients choice, policy makers' first task should be to ensure that there are good quality and credible options to choose between.

Practitioner training and practitioner support

Given the inadequacy of end of life discussions and the low profile of end of life discussions in practitioners' training (see chapter 2), there have been many calls for end of life care to feature more heavily on the medical and undergraduate nursing curricula.[61] A relevant question here is what balance we should aim for between revising generalists' training and creating more end of life specialists. We contend that the scale of demographic change, and the scale of our unpreparedness for it, is certainly enough to justify both, but we feel that improved generalist training in end of life care is the more critical move given the crucial role GPs have as most people's most common and consistent point of contact with health services, and as the main gatekeepers of locality registers and the GSF. Therefore GPs are best placed to hold discussions about end of life care with their patients. In the words of one of our expert interviewees, 'The GP sits at the heart of the majority of end of life communication.' GPs are also the professionals with whom most people want to hold these discussions.[62]

As a result of the strategic shift from secondary to primary care (which is itself motivated by demographic change), the GP will more than ever be the first point of contact in the end of life service journey. This applies particularly to groups who are more vulnerable to poor outcomes (eg those with a non-cancer diagnosis, as people with cancer are more likely to make the transition to end of life care at the end of a period of active treatment and therefore from secondary rather than primary care).

Those to whom we spoke were concerned that doctors should be better trained, and receive better support, in communicating and 'diagnosing death' (identifying that someone is an appropriate candidate for end of life care). As outlined in the previous chapter, some patient groups are much more likely to be identified as needing end of life care than others. Groups at risk in this way include those with degenerative neurological conditions such as MND, those with multiple conditions, non-cancer diagnoses generally, and the frail elderly (all groups, through demographic change, are on the rise). GPs would certainly benefit from having access to the best information available on diagnostic indicators in different conditions.[63] Those we spoke to put 'frailty' as a priority in this regard.

Find Your 1%

This campaign, run by Dying Matters and the NEoLCP, takes as its basis the statistic that 1 per cent of the population dies every year. It encourages GPs to attempt to identify those of their patients likely to die in the following 12 months.

GPs receive a resource pack containing practical advice on the discussion, planning, management and coordination of end of life care. The resources supplied include details of the general and specific indicators of deteriorating health, a prompt to use the 'surprise question' ('Would you be surprised if this patient were to die in the next 6–12 months?'), and phrases for use in a consultation with a patient about the end of life.

The idea of including communication about death and dying in the generalist training curricula was not the only suggestion for improving skills. Speaking about the future of hospice services, Barbara Monroe (CEO of St Christopher's Hospice) has envisioned an expanding role for hospices in 'cascading' their end of life expertise into the healthcare workforce.[64] This can be a valuable resource for primary and secondary care, as it allows for ongoing professional development and awareness raising beyond any initial training they might have. Hospices also train care workers – an extremely important role given that those living in care homes are less likely to be referred to hospices and more likely to die in hospital.[65] Education of care staff (residential and domiciliary) is also particularly important and harder to achieve because of a combination of high turnover, a lack of regulation, and working patterns and remuneration that do not incentivise – or at worst do not permit – staff to access training. Attendees at our seminar felt that extra guidance should be available to this wider group of practitioners likely to come into contact with someone at the end of life – including domiciliary care workers, extra care housing staff, and housing support workers. The training of Sue Ryder's domiciliary care workers in Stirling in end of life care and the course offered by Tees Valley Partners[66] are the limited examples of good practice we found in this regard. Seminar

attendees were also enthusiastic about the potential for new technology (including remote access) to support and up-skill practitioners in identifying and communicating end of life care needs. Electronic systems could facilitate information sharing and providing access to better Creating a better service journey information and dissemination of best practice, thereby improving specialist knowledge in primary care without the costs associated with creating new specialists. Moreover, they could have an application in improving decision making and removing professional uncertainty by triggering specific interventions if certain care criteria are met. For example, we were informed of high levels of professional anxiety about amending and withdrawing medication in the end of life population – in large part a legacy of the Shipman case – and it was suggested that doctors would benefit from specific automated 'trigger points' to help prompt these actions to remove (but obviously not replace) some level of professional discretion, which could leave them open to charges of over-medication or inappropriate withdrawal of medication, for example.

Such tools are not a magic bullet, and new systems or procedures to assist practitioners must also include training, as outlined above, regarding communicating with people and their families about dying and planning for death.

The LCP tool is a prime example of a failure to support practitioners to communicate. Our research with experts revealed high levels of confidence in the Pathway's ability to deliver positive outcomes for patients at the end of life – an insight further supported by the finding from a survey by the British Medical Journal that 89 per cent of doctors would choose the LCP for their own care.[67] However, 74 per cent of respondents to the same survey believed that the criticism attracted by the Pathway had led to a decrease in its use, with 84 per cent reporting that staff were apprehensive about complaints from relatives.[68] There was widespread consensus among those we consulted that the LCP remained a valuable tool, with the controversy surrounding it a function of poor communication between practitioners and patients and

families about its purpose, further compounded by hyperbolic media coverage. The lesson to be drawn from the experience of LCP is that it is insufficient to provide practitioners with tools without ongoing support in how to implement them, and – crucially – how to involve patients and (where appropriate) their families in their use. The Royal College of Physicians summarises the problem thus: 'The introduction of tools without... support may lead to a 'tick-box' approach, which is counterproductive and should be discouraged.'[69]

Relational aspects of care

Academic research, such as the ongoing work at the International Observatory for End of Life Care at Lancaster University, has consistently shown that it is the so-called 'relational' aspects of care – those relating to the relationship developed between practitioner and patient – that are most valued by individuals and their families.[70] These sources and our anecdotal evidence from current patients and frontline staff are united in their appreciation of staff who were considered to have gone 'above and beyond' in delivering care, and who had fostered a strong personal understanding of each patient's specific needs and preferences. The relational aspects of care are not only important in improving people's experiences in and of themselves – they can also prevent problems from occurring, as where staff are trusted and know their patients well, communication is easier, and this promotes timely detection of potential problems. This also impacts on the level of choice and control over the care received, as there is more likely to be the time, will and means to record and act on patients' preferences.

This relies on staff having an ongoing and consistent relationship with those they care for – something previous Demos research identified as crucial in supporting personalisation, particularly for those with high support needs.[71] An attendee at our seminar lamented the loss of 'a degree of professionalism' whereby healthcare staff had 'a sense of ongoing responsibility for patients' – something she felt was inhibited by the current system of multiple funding streams

and handovers to different health and social care teams. The role of a 'care coordinator' (see below) could replicate this consistency or relationship and in-depth knowledge in the absence of a single health or care professional.

Delivery
Care coordination

Even in a short end of life journey, where diagnosis has occurred relatively late, a patient may receive input from a totally different collection of practitioners and services by the end of their life, compared to the beginning. At particular risk is the ever-increasing group of people with multiple conditions. One expert interviewee referred to 'huge numbers of people with multiple chronic conditions who are seeing multiple members of multiple teams'. Schemes promoting care coordination (usually through records shared across services and sectors) provide an element of consistency in a journey characterised by shifts – sometimes rapid ones – between services and systems, and are therefore extremely important in improving people's care service journeys.

Electronic palliative care coordination systems (EPaCCS) (formerly known as locality registers) are one such system currently being rolled out.[72] While many of those we spoke to recognised the potential of EPaCCS to prevent and manage crises and achieve patients' care preferences, they were only cautiously supportive of a full rollout. Implementation of EPaCCS has reportedly been 'patchy' and, as mentioned above in connection with the LCP, all such tools – in order to be effective – require practitioners to be trained and guided in their use and communication.

Many of the experts we consulted felt that the centralised care coordination offered by EPaCCS would be more effective when complemented by a designated practitioner with responsibility for coordination – along the lines of a 'key worker' model in social care. Currently, whether an individual has someone on their care team with a coordinating role is largely condition-dependent; our research with hospice service

users confirmed this – it was most common for the hospice referral to have been made by a Macmillan nurse or respiratory nurse. Having a designated care coordinator for each patient would therefore help to address the diagnosis-driven inequalities outlined in chapter 3, but there is a question of who should fulfil this role. Creating a specific coordinator role could have significant cost implications, and care teams for different patients are very differently composed – how could consistency be assured? If – as we strongly recommend below – free social care at the end of life is introduced, then all patients will undergo a needs assessment to determine their social care package. It was suggested by some of those we spoke to that the assessor could take on a care coordination role alongside improved record-sharing solutions, although there is also a model that marries electronic records with an expert coordinator – PEPS.

Box 13   **Partnership for Excellence in Palliative Support**
The Partnership for Excellence in Palliative Support (PEPS) service is a 24-hour coordinated end of life care service led by Sue Ryder and NHS Bedfordshire. Although the service began as a one-year pilot, in January 2013, Sue Ryder secured funding to continue delivering it. PEPS uses a 'hub and spoke' model, whereby patients and their carers have a single point of contact – a 24/7 palliative care coordinating centre provided at Sue Ryder's St John's Hospice. Callers are directed to the most appropriate service across 15 different local partner organisations, including hospitals, local authorities, voluntary and community services, and the ambulance service. Services are coordinated using a shared electronic record system, to which all partners have access. In addition, all those registered with the service hold their own patient records, so their individual needs and preferences are easily communicable to all services with which they have contact.

Over the 12 months during which PEPS was piloted, 1,051 people signed up to the scheme, of whom 620 died. Most of these people (65 per cent) were able to die at home – but the advantages of the scheme extended beyond place of death. In

the last four months of life, people registered to PEPS had 30 per cent less emergency hospital admissions than before they were registered, and their length of stay in hospital was reduced by 30 per cent, at a reduction in cost of around £300 per admission. The service was also well received by other health professionals, with 90 per cent of GPs feeling that the phone helpline had made a difference, and 87 per cent feeling that it had improved coordination of care across Bedfordshire. The phone service was used by a variety of people – around 50 per cent of calls were from patients and their families or carers, with the remainder coming from medical and nursing staff. In total, 26 per cent of calls were made outside normal working hours (between 5pm and 11pm).

PEPS demonstrates the impact that support for carers can have on the patients whom they care for; reducing the burden on the carer reduces the likelihood that they will feel unable to cope, which is often the cause of avoidable hospital admissions. One practitioner told us, 'The difficulty, prior to PEPS, was accessing – for patients, for families, for carers – accessing the individual health professionals out there because they had so many phone numbers.'

Flexibility
The system as it currently stands is at odds with the lived experience of the end of life – the way that support is delivered tends to assume a linear progression of a patient's condition, and a steady increase in their levels of need, towards death.[73] In reality, need goes in both directions and people experience periods of recovery as well as deterioration. This is likely to become increasingly true as the boundary between 'terminal' and 'chronic' conditions shifts,[74] and we live longer with more multiple illnesses and disability. Those we spoke to felt strongly that greater flexibility should be built into the way that services are commissioned and delivered, as well as into funding arrangements, to take account of fluctuations in support requirements. Some experts thought this would, in theory, be facilitated by the implementation of the recommendations in the Palliative Care Funding Review, with

'stable' and 'unstable' phases accommodated in the tariff.[75] This would need to be supported by a wider recognition of the reality of end of life experience, so that everyone – from GPs to families and residential care workers – was aware that those needing end of life support might appear to undergo a period of 'recovery' as their symptoms changed.

Box 14 **The AMBER care bundle**

The AMBER care bundle is a tool developed by Guy's and St Thomas' NHS Foundation Trust to streamline and expedite the decision-making process for patients at the very end of life whose exact prognosis is uncertain.

A patient can be identified as suitable for the AMBER care bundle if they are deteriorating, clinically unstable, have limited 'reversibility' (likelihood of recovery), and are at risk of dying within the next two months. Following identification, a medical plan is agreed and documented within four hours, together with a contingency medical plan in the event of escalation of the patient's condition. Within 12 hours a discussion with the patient and their carers is held, where parties discuss uncertain recovery and treatment options, the patient's and carers' concerns or wishes, and preferred places of care.

Evidence suggests that the AMBER care bundle has improved decision making and communication and led to patients being treated with greater dignity and respect.

The experts we consulted on this matter felt that, although people's needs vary with their condition, and condition-related support is important, eligibility for support and services should ultimately not be condition-dependent and fixed, but determined by level of need and functioning, flexible and personalised. For example, seminar attendees supported the idea of advanced care planning that would incorporate contingencies for deterioration and recovery – so-called 'just in case' or 'what if' plans. Staff at a DTU run by Sue Ryder also supported this view. At present, the DTU is oversubscribed, necessitating careful management of not only the period for which people can attend (fixed at 12 weeks), but also referral criteria (the individual must be at a fairly advanced stage of their illness, although well enough to attend). Ideally, given sufficient resources, staff reported that they would be in favour of receiving people at a much wider range of stages in their disease – particularly very early on – to provide more flexible support.

Personalisation

Person-centredness and patient-held records

Those we spoke to identified a need for increased acknowledgement of the dying individual as the decision maker in his or her care, and as the centre of their journey. The current system was seen as too often being 'paternalistic' and 'riskaverse', particularly with regard to transitions from hospital to home and avoiding hospital admissions from home. Too many people do not have the opportunity to exercise choice and control, or be involved in decision making; making service journeys more personalised is an obvious way of improving people's overall experiences and providing more coherent and seamless support. Improved practitioner–patient communication, consistency in staff support and care coordination (all outlined above) are key tools in improving personalisation, but there also needs to be a cultural shift towards a more empowering, personalised and risk-managed approach to end of life care, which is hard to create without root and branch training and awareness raising in these concepts as we are already seeing in social care. Previous Demos research identified hospice care as particularly personalised in its approach, but end of life care in other settings remains less so because of the top-down, paternalistic attitudes which often accompany those caring for people who are dying.

Patient-held records are also a promising tool to encourage personalisation and coordination of care. One delegate at our seminar drew an analogy with patient-held records in maternity services – mothers-to-be have birth plans which they 'own'; they are flexible in case of complications or a change in preference, and are communicable across all practitioners involved. Perhaps the most common example of

patient-held records in end of life care is the PPC document. Although a national review by NEoLCP found that PPC documents were not used widely enough,[76] there is evidence that they have a positive impact on the proportion of deaths in the preferred place of care.[77] The PEPS model mentioned above combined three elements of coordination and personalisation – patient-held records, recordsharing systems linking different organisations together and an expert coordinator to oversee it.

Families and informal carers

The end of life journey is rarely experienced by an individual in a vacuum – more often than not, it is experienced by a circle of relatives and friends around that individual. To personalise an individual's journey therefore, professionals must also support the circle of people around them. A major cause of avoidable hospital admissions – and thereby of disrupted service journeys – for patients receiving end of life care in the community is their carers feeling unable to cope in a crisis (eg a sudden deterioration). Likewise, where patients see their carers becoming fatigued, it is common for them to change their preference from a home death to a death in a hospice, nursing home or hospital. Although the need for out-of-hours support has been acknowledged for a long time, provision still varies greatly from one area to another.[78] There should also be sufficient support (eg respite breaks) available to prevent carer fatigue[79] – but where it does occur, care plans need to be flexible to allow patients' 'contingent preferences' to be met (see above).

In supporting families and carers, we must also remember they are not passive observers – they too experience the service journey and must also be included in the decisions which affect them. Several experts we consulted felt relatives should be included on care teams, and referred to the successful Team Around the Child model in social care for children, which includes the child, family members, and practitioners from education, health and social care.[80] Formalising carers' involvement in this way would have the

added benefit of making them more visible than they are currently, and giving them a greater sense of involvement and control over a process that affects them. Experts also cautioned that giving carers a formal role should be handled carefully; families should be enabled and empowered to participate in the dying person's care as far as they wished, but should by no means be expected to step in and provide or organise care.

Policy

Health and social care integration

The integration of health and social care is a major lever for improving service journeys at the end of life. *Ready for Ageing?*, the recent report by the House of Lords Committee on Public Service and Demographic Change, highlighted this integration as key to increasing the robustness of our system to deal with increased demand in later life generally, and at the end of life.[81] Perhaps the greatest effect of this would be on reducing inequalities in end of life care; currently, the service journey of an existing social care user differs significantly from that of someone who accesses end of life care through the health system. The joint announcement in mid-May by the Secretary of State for Health and the Minister for Care and Support that the UK can expect to see a greater degree of health and social care integration by 2018 is particularly encouraging. Demos hopes that end of life care will be a specific focus for at least some of the 'pioneers' selected by the Department of Health, and that CCGs will be encouraged to invest in integration initiatives that touch specifically on end of life care.

Outcomes frameworks that link outcomes to incentives should incorporate both health and social care, ensuring that practitioners are incentivised to ensure quality of care that extends beyond their immediate remit. Part 3 of the ASCOF, 'Ensuring that people have a positive experience of care and support',[82] is the counterpart to part 4 of the NHS Outcomes Framework, 'Ensuring that people have a positive experience of care',[83] and one NHS Outcomes Framework measure (4.9), 'Improving people's experience of integrated care', is

referenced in the ASCOF. However, the ASCOF makes no specific reference to end of life care, nor a cross-reference to end of life care in the NHS Framework. This is something Demos would like to see revised in fulfilment of the Department of Health's commitment, stated in the ASCOF, to 'work to ensure that the framework best supports White Paper priorities, for example strengthened entitlements for carers, and the importance of the best quality end of life care'.[84]

We believe that getting health and social care working together is such a pressing issue, with such potential to bring about drastic change to the quality of end of life, that there is a strong case for integration within end of life teams (along the same lines as mental health teams) to precede any wholesale integration of health and social care (see recommendation 5 in chapter 5).

Commissioning

Several expert interviewees commented on the difficulty of defining outcomes in end of life care (as, strictly speaking, the primary patient outcome is death). It was suggested that commissioning should take account of 'wider social value', which could include improving information of available services, building community capacity to care for dying people, and considering outcomes for relatives and carers according to their wellbeing, employment and health. The present system was thought to focus excessively narrowly on reducing unwarranted hospital admissions.

Current innovations in commissioning, including the prime contractor model and co-commissioning, are promising.[85] However, the role of the third sector may not be clearly delineated; expert interviewees spoke of a troubling tendency on the part of commissioners to simply 'assume' that voluntary services, including hospices, would 'step in' regardless of whether they were formally commissioned. It was thought that this situation might worsen with the recent introduction of CCGs. Commissioners need to be alert to this, particularly in areas where hospices are meeting needs that are strictly statutory – such as in specialist palliative care at home,

and provision of equipment. Some smaller hospices are already at a disadvantage in the commissioning process – at least where they are in direct competition with private providers – as regulations governing charitable donations prevent them from offering a competitive service.

Funding

We have concluded that free social care at the end of life is nothing less than a necessity in addressing many of the problems set out in previous chapters – for example cost-shunting between the NHS and local authority, delayed discharge from hospital while assembling care packages, and loss of continuity of care when transitioning from self-funding to CHC. Most importantly, free social care at the end of life would transform the inequality of access and outcomes currently seen between those who enter end of life care by different routes – as self-funding or local authority funded recipients of social care, or as users of free at the point of access NHS services alone. Care at the end of life should be free regardless of condition, and it is deeply unfair that it is only free for those whose primary needs are deemed to fall within the responsibility of health rather than social care. Should free care be introduced, we would expect eligibility to be based on whether someone is placed on an end of life care register rather than through a financial gatekeeping eligibility assessment. However, if the current – unfair and complex – system continues then, at the very least, the existing fast-track system for continuing health care needs to be scrapped and a new regime put in its place, which puts all those on end of life care registers (which would be more people if diagnosis was improved) at the front of the CHC assessment queue. An expert interviewee commented:

The ideal situation is for someone to be managing that individual's care, just to be able to plot their needs both in terms of their health needs and their social care needs and then draw down the resources – whether the services or funding – from either or both of those bodies, so that the patients don't see a gap between the funding streams.

5   Recommendations

In the previous chapter, we distilled the themes which make up an 'ideal' end of life service journey:

· societal and cultural factors:
  – awareness raising
· workforce:
  – system capacity and practitioner mix
  – practitioner training and practitioner support
  – 'relational' aspects of care
· delivery:
  – care coordination
  – flexibility
· personalisation:
  – person-centredness and patient-held records
  – greater involvement of families and informal carers
· policy:
  – health and social care integration
  – commissioning
  – funding.

In this chapter, we develop these into specific, actionable recommendations for policy and practice.

1 Adopt free social care at the end of life as soon as possible
Demos strongly supports the provision of free social care at the end of life, as proposed by the Palliative Care Funding Review and campaigned for by a coalition of charities including Help the Hospices and Macmillan.86 It is clear – reviewing the variety of problems that currently beset service journeys – that free social care would be the single most important step in improving end of life care the Government could take to address the unacceptable inequalities between those with

'health' and 'care' needs that beset the current system. We found consensus among everyone we consulted during this research that this policy move was critically important and widely and warmly anticipated.

Nonetheless, some concerns were raised about the persistence of perverse financial incentives and cost-shunting being carried over into this new system. The funding for free social care will come from NHS budgets – so in theory the same problems with CHC referrals will replicate themselves here: GPs have a disincentive to place people on the register, while local authority teams have an incentive to place people on the register.

In reality, this is unlikely to be the case. First, GPs have a target to place people on the end of life care register as part of the drive to improve how GPs approach difficult end of life conversations with their patients. Second, there are unlikely to be mass referrals from the local authority under this system as has been seen in some areas with CHC assessments, because of the strength of the relationship between GP and patient for most of the UK population. This relationship – characterised by high levels of trust and a deep knowledge by the GP of their patients – is one of the most successful elements of the NHS. Because of the frequency of contact GPs have with their patients (particularly elderly patients) a lengthy assessment for end of life care eligibility (akin to CHC) will most likely be unnecessary, and referrals via the local authority or care teams to the GP or a consultant will be less frequent – GPs are more likely to pick up on end of life care needs early on (where this referral has not come through a consultant or specialist) rather than rely on local authorities to refer on to them. A wider backdrop of integration between health and care (described below) would nonetheless reduce any residual risk that practitioners were discouraged from diagnosing dying for financial reasons. Free social care at the end of life is no 'magic bullet' to resolve all of the problems we have identified during this research. With an area as complex as end of life care, no single policy move is enough.

Free social care will need to be supported by a range of other changes to process, practice, culture and communication – including efforts to make GPs more comfortable with their role as a key referral point for end of life care. We have identified some of the most important such changes below.

2 Create an electronic records system with on-screen GP prompts
This would prompt GPs to initiate certain aspects of end of life care (eg advanced care planning, referral to specialist palliative care nurses) at an appropriate time, according to standardised and automated on-screen prompts. This could be made compatible with the GSF colour coding, although we heard on several occasions from experts in different parts of the end of life care system that the GSF was not used consistently by GPs nor effectively in some areas. A new automated system – linking the GSF to everyday practice through on-screen prompts linked to patient records – could help improve and standardise the use of the GSF.

GPs are the first link in the chain of the end of life journey for a large number of people. The delay created by problems at the outset (eg untimely diagnosis, failure to refer to specialists) affects the quality of the whole patient journey through end of life care. By the same token, early diagnosis and establishing links with a range of sources of support early on could lead to significant gains in the quality and coordination of service journeys.

The proposed electronic records system, building on existing electronic health record software, should draw on the learning from the GSF regarding diagnosis and prognosis of a wide range of conditions in order that the suggested 'triggers', generating on-screen prompts, are tailored to different medical needs. The design of the system could borrow from other emerging innovations, such as the newly announced cancer database. This service combines historic data with ongoing data collection on some 350,000 cancers to inform practice. It permits both the delivery of highly personalised care, and the monitoring of unequal performance.[87] However, technology is never a substitute for

practitioner expertise, and it is not our intention to make such a substitution here; when a patient reaches a 'trigger point', the referral does not occur automatically – the system suggests it to the GP, who can choose whether to action it. The aim is to increase GPs' confidence and reduce the uncertainty associated with professional discretion, while also maintaining it. Implementation of an electronic records system would also increase GP access to specialist expertise (in the form of an automated suggestion) without an unnecessary overburdening of specialists themselves. In cases of uncertainty, GPs can draw on the expertise of 'link' specialists as outlined in recommendation 3.

Similar variants of such systems already exist, such as SystmOne in Airedale (which allows clinicians across the region to access and share patient records),88 and PROG-RES, which creates automated on-screen prompts for GPs to collect data.[89] These existing models could be adapted specifically to support GPs in making end of life care decisions.

3 Create end of life 'link' specialists in each CCG.
In each CCG, at least one specialist in dementia, and specialists in other conditions as identified by each area's JSNA, should be designated as 'primary care end of life links'. GPs can call on these 'link' practitioners to assist them with diagnosing patients in need of end of life care. These specialists could be the existing clinical nurse specialists if expert in the relevant condition and end of life care, or secondary care consultants given designated 'link' status, which entails a responsibility to support GPs in diagnosis and prognosis for more complex contexts.

This recommendation complements the electronic system outlined in recommendation 2, and has the same aim – to assist GPs in 'diagnosing dying' in conditions with more complex diagnostic indicators. This would help reduce condition-led inequalities and promote timelier support, recognising that with increased responsibility on the part of GPs for making timelier diagnoses and

initiating conversations comes a need for greater levels of external support.

Health and wellbeing boards play a crucial role in assuring the effective implementation of this recommendation; the mix and number of 'link' practitioners made available in each area (or rather, given link responsibility from within the existing local pool of specialists) should be determined according to local need – as set out in the JSNA. Our research suggests JSNAs are not well attuned to local end of life care needs – this is clearly an area which needs to be examined by HWBs in order to improve commissioning of end of life care services and the support services for carers and practitioners alike.

4 Make training in communicating about end of life a core part of medical and nursing undergraduate curricula
Both generalists and those who are not end of life specialists – who nonetheless come into contact with patients receiving end of life care (eg cardiologists, neurologists) – need to have had specific instruction in how to initiate discussions about the end of life. At the moment, it is clear that many professionals across the health and care fields are uncomfortable when talking about dying or planning for death. Experts we consulted suggested that, apart from the obvious sensitivity of the subject, the very nature of conversations about dying sat uncomfortably with clinical practice. Planning for dying implied a clinician's failure to 'treat and cure', while also generating high levels of uncertainty – clinical training tended to weigh against communicating facts until and unless they were certain, whereas for most people with a terminal illness, predicting the how and the when can never be done with precise certainty. The temptation to communicate less rather than more in such situations is pervasive.

With this in mind, it's clear that encouraging public destigmatisation of death and dying is not enough – professionals must be given specific training about how to communicate uncertainty and talk about planning for death in confidence. The onus on initiating conversations about care planning, support needs and the uncertainty associated with

some diagnoses must lie with professionals – without it, conversations about planning can be put off indefinitely, leading to poor outcomes and no choice or control later down the line; people and their families remain ill-informed, which can lead to difficult situations. For example, the experts we consulted were convinced that the recent criticisms of the LCP could have been avoided if the tool – which is sound – was used as it was intended: with full and open communication with the patient and their family early on about the Pathway and the options open to them. Clinical reticence to broach difficult subjects has a significant impact on the wellbeing of patients and their families in such cases.

We therefore fully support the past recommendations made by Help the Hospices[90] and the Royal College of Physicians[91] among many others who call for specific training in communicating about end of life, and feel that the lack of progress in making this standard practice cannot be supported any longer. The Dying Matters Coalition has pioneered resources for GPs to help initiate conversations, and has piloted hands-on support to great effect.[92] Such evidence – combined with demographic change, which will lead to an increase in the number of deaths each year – makes this a priority for inclusion in any review of the undergraduate curriculum.

5 Introduce integrated end of life care teams as part of the wider move to integration by 2018

The integration of health and social care has been an objective of successive governments for at least the last 20 years, but only very recently has the Government announced its intention to make an integrated health and care system a reality by 2018.[93]

End of life care is one of a few areas which operates on the interface between health and social care. Poor integration, leading to delayed transfers, changing in support teams, cost-shunting and so on, is one of the main drivers of substandard patient journeys. Therefore, if this latest pledge to integrate proves successful, the consequences will be revolutionary for the delivery of quality end of life care.

Therefore, we would like to see some of the ten pioneer sites invited to bid for support from the Department of Health to develop large-scale experiments in integration[94] to focus on end of life care. Achieving integration in this area would lead to some of the greatest gains in cost efficiency, patient outcomes and satisfaction, while also thoroughly test the new flexibilities awarded to the sites. Moreover, pioneer sites would not need to start from scratch – as mentioned above, Hull's multidisciplinary working to support end of life care for people with dementia[95] and Sue Ryder's PEPS both represent models of integration that could be learnt from. Most local authorities are already familiar with community mental health teams, which bring together health, social care and voluntary providers, often through a single referral pathway. A similar approach could be adopted for end of life care, where those placed on local end of life registers are referred to a team of existing staff across social and health care at the end of life, condition-specific and palliative specialists, as well as local hospice teams for community-based support. This team would share information and coordinate the management of local cases. Guidance on these models also exists within the GSF and the wider push for integration could be a good opportunity to make this vision (or the models pioneered by PEPS) a reality across the country.

6 Invest in (technological and human) care coordination

During our research coordination of end of life care journeys (even if care and health were integrated) was consistently identified as an area in need of radical improvement. Many felt a lack of guidance for people to navigate their journey was key to many poor outcomes, compounded by poor information sharing between teams creating clumsy handovers between different care teams or locations. They argued that at no other point would people and their families be so vulnerable and in need of seamless and coordinated services, to make their experience as least challenging as possible.

Several options were discussed by the experts and practitioners we consulted for improved coordination. An

immediate and relatively low-cost step would be to ensure end of life care users hold their own records – including their end of life preferences. Following the success of this practice in maternity care, several experts in the field felt that if patients owned records there would be significant gains in coordination, as records followed the patient wherever they found themselves (be that in an ambulance, A&E, or a hospice).

However, it was felt that this would only be fully effective if combined with some form of central electronic record system – as we outline in recommendation 2. In this regard, SystmOne in Ayrshire is a promising model, as is EPaCCS[96]– when practitioners are well supported in its implementation – to improve coordination of services in a local area through an electronic patient register.

Nonetheless, technology used in isolation will not coordinate end of life care. The idea of an active coordinator, responsible for bringing services together for each person's journey, was compelling for many experts, practitioners and patients we consulted. For example, the service users we spoke to identified their Macmillan nurse as a vital source of advice and coordination, navigating them through a complex system of assessment and eligibility. Several end of life care experts understandably feel this type of consistent support should be available to those with non-cancer diagnosis too. Some referred to ad hoc local examples of MND end of life specialists, for example, but these were acknowledged as patchy and disease specific. A more universal suggestion was the use of social workers who – if free social care at the end of life was implemented – would be carrying out end of life care needs assessments and putting together care plans. Taking on the role of navigator, coordinator and facilitator of this care plan would not be a radical departure for social workers who, because of the advent of personal budgets, are increasingly taking on this case management role.

A promising model, which marries technological coordination and human expertise, is PEPS, the joint initiative between Sue Ryder and NHS Bedfordshire described in chapter 4. This combines an electronic records system and patient-held records with active care coordination by experts in a 24/7 palliative care centre. This acts as a one-stop shop for people with end of life care needs, who can access round the clock support via one phone number to 15 separate services across the area.

We therefore recommend – as an immediate step – that patients at the end of life and/or their families are given the opportunity to hold their own records. In the shorter term, ensuring social workers have a remit to coordinate the care packages for those receiving free social care at the end of life with their health and other counterparts would be a relatively low cost but immediate improvement, particularly for those without the support of specialist (often cancer) nurses.

Further to these two steps, we recommend that local commissioners look closely at EPaCCS, PEPS and dedicated care coordinators and consider the cost-benefit of implementing them. The PEPS is an example of holistic care coordination underpinned by an electronic register (like an EPaCCS). While it requires a greater resource commitment than an EPaCCS alone, its combination of expert coordination and patient-held records is likely to prove effective. For those areas whose JSNAs identify a growing end of life care priority in the population, PEPS could prove a real cost saver in reduced hospital admissions and meeting targets to ensure more people die at home.

7 Commission specific training for families and carers
We believe upskilling families and carers in the practicalities of end of life care, the options available to them, and how to cope and access help when required would improve people's ability to die at home (where preferred); reduce the likelihood of carers becoming overwhelmed, leading to unnecessary hospital admissions; and improve levels of informed choice and control for patient and family. Some groups (eg minority ethnic groups or those with English as a second language) which have a higher than average number of poor end of life outcomes, eg high numbers of hospital deaths, would particularly benefit.

Commissioning such services may increasingly fall within local authorities' remit, give the Care Bill places new duties on local authorities to assess and meet the support needs of informal carers; however, in some areas funding for carer support services may still be channelled through the CCG and in such instances the responsibility would lie with them. Such sessions could be hosted by the third sector (including hospices). Encouraging third sector organisations to provide such training in a formal commissioning framework gives them a defined role within the commissioning structure, avoiding the problem whereby commissioners assume 'free' voluntary sector support.

8 Include support for informal carers before and after death in commissioning of end of life care services.
How outcomes are conceptualised in end of life care needs to be broadened, and many argue that it should be broadened to incorporate carers' outcomes. The availability and quality of carer support makes a significant difference to the journey and outcomes of a patient at the end of life, but the wellbeing of the carer must also be considered an important aim in itself. Carers' physical and mental health, their employment and (for young carers) their education may all be adversely affected in the long term by the burden of caring. The amount of NHS and social care money saved by informal carers, and their pivotal role in making death at home possible, more than justify the expenditure on increased and ongoing support for carers.

We recommend, therefore, that while caring for a dying person, carers should receive 24/7 advice and practical support (perhaps through PEPS or another such service) and training on the practicalities of end of life care and coping strategies (as outlined in recommendation 7). During this time and thereafter they should have access to – and be actively directed to – bereavement counselling, talking therapies, housing and legal advice, career support and (for young carers) education support. Such services should be commissioned (most likely from the third sector) under the aegis of end of life care, with carers eligible for a fixed period (at least 12 months) after the death of the individual they were caring for.

We see this as an extension of step 6 in the NHS end of life care pathway, 'Care after death', but it is also clearly in line with the proposals outlined in the Care Bill, which gives carers for the first time the right to have their needs assessed and supported. While the focus remains on supporting carers during their caring duties, many carers will inevitably be providing care up until the point of death. After death support is an important aspect of carer support, but remains under-developed.

A holistic journey – overview of recommendations
These eight recommendations come together to create a service journey that addresses the variety of problems related to delay and disruption, and inequality of access, as outlined in chapters 2 and 3 of this report. The way in which they interact and mutually reinforce improved end of life outcomes can best be illustrated through the diagram shown in figure 2.

Figure 2 **How the eight recommendations interact and reinforce improved end of life outcomes**
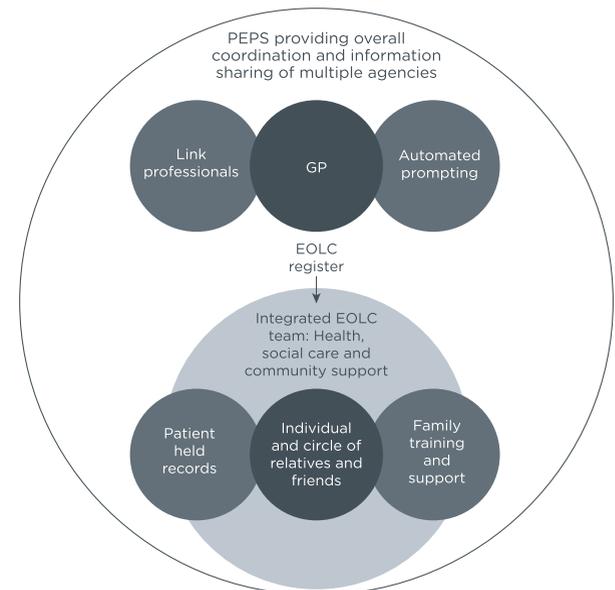
Figure 2 shows how a journey can be conceptualised in a non-linear fashion, with the individual and family at the heart, and support structures and information flows placed around them, rather than them passively travelling through different stages. This shows a journey whereby an integrated package of end of life care, including free social care (recommendation 1) is triggered by the placement on an end of life care register by a GP or secondary care consultant, removing the need for a new 'fast track' to CHC-type services. This GP-held register is the gateway for being given end of life care support, but the decision to be placed on this register is now supported by improved training to help GPs diagnose dying and have difficult conversations about end of life planning (recommendation 4) and a network of 'link' specialists (recommendation 3) and electronic patient records (such as EPaCCS) with automatic triggers designed by condition and end of life specialists (recommendations 2 and 6). Both of these help ensure general practitioners are better supported in making timely diagnoses and referrals to the register.

The referral to a free social care package leads to a needs assessment by a social worker, part of the integrated end of life care team (recommendation 5). They develop an integrated care package and could perhaps act as a care coordinator for the patient (recommendation 6). They also refer family and carers to training and support services (recommendations 7 and 8), and perhaps round the clock advice from PEPS (recommendation 6). The package is underpinned by the patients holding their own records, facilitated by EPaCCS, and given overall coordination by PEPS (recommendation 6). Together, they create the personalised, integrated, high quality journey we envisaged in chapter 4, which is accessible to everyone (not just those with a cancer diagnosis, or eligible for CHC etc).

6 Concluding thoughts — the case for cautious optimism

At the outset, we explained how the 'end of life', as an idea, is inherently challenging. There is rarely an objective moment at which point the end of someone's life can be predicted with certainty, and this is a deeply personal and subjective judgement to make. Practitioners may not agree with their patients – or indeed with other practitioners – about the 'when' or the 'how' of preparing for death, and there are no right answers.

This lack of certainty and objectivity regarding dying is deeply problematic when it comes to trying to plan or support people who are nearing the end of their life, and this cannot be remedied with a simple policy solution. The first step to unpicking this issue must surely be to recognise that end of life care, as a process, cannot be 'perfected' through organisational structures or commissioning guidance, but it can be improved to make the experience – as a personal journey – better for everyone. This may – still – involve some processes and structures, but will also involve cultures of personalisation and the quality of communication.

Fundamentally, it hinges on how we view end of life care. And we must view it from the bottom up.

This report is the first of two developed by Demos for Sue Ryder, and has sought to reconceptualise a process influenced heavily by top-down policy agendas into something less precise, but more real. It considers the service journey as a lens through which we can consider the provision in end of life care holistically (covering health, social care and other support services, and over time) and from an individual's perspective (people's experience of the end of life is very much of a journey – defined not by set 'stages' or 'service requirements' but by changing levels of need and preferences for support.) We see this approach as distinct from research which has gone before,

and also from the NHS End of Life Pathway, which guides the commissioning and provision of services in a linear fashion towards death. Such a top-down conceptualisation risks focusing on process and structure, while overlooking the importance of empowerment, choice and control, positive culture and communication, and other soft outcomes which people and their families value.

Through speaking to experts, practitioners and service users, and reviewing existing evidence, we were able to identify a number of delays and disruptions to service journeys as perceived by the people experiencing it first hand. This included the poor coordination often exacerbated by cost-shunting, practitioners' reticence to discuss preferences and plan ahead, and a pervading sense of people finding themselves being 'done to' rather than having choice and control over the services they receive at the end of life. We developed two 'typical' journeys to illustrate the problems of coordination and communication, but this led us to a further understanding – that where individuals 'start' their journey influences the subsequent quality of that journey, and can often dictate their end point (dying in different settings and with different levels of support). The recommendations we distil from the solutions we have investigated therefore consider in particular how inequalities relating to people's 'starting points' can be reduced. These inequalities included the type and timeliness of diagnosis made (with a clear two-tier system emerging between cancer and noncancer diagnosis); the services being used before starting the journey (starting in a care home or with different professional referrals had considerable influence on people's journeys); and belonging to particular groups (such as those with cognitive impairments or from BME groups).

Underpinning all of our recommendations is a drive to improve professional cultures, competence, confidence and communication. Demos is convinced that these are at the heart of many people's poor experiences, and can and must be improved even while debates continue about funding responsibility and local structures. Staff across health and

care are simply not adequately trained and prepared to talk about end of life care and planning as openly as they should. This professional discomfort is a fundamental barrier to people taking greater control over the services they receive at end of life – through a misplaced sense of delicacy, professionals across the system are missing vital opportunities to help people express their wishes and make choices, and take control over their service journeys. This leads to uncertainty, disruption, delay and overall poorer outcomes for people at the end of life and their families.

Fortunately, of the eight recommendations we present, the integration of health and care and free social care at the end of life (perhaps the most urgent and critical steps that could radically improve end of life service journeys) have already been identified by the Coalition Government as priorities and Demos hopes these will be implemented with the urgency they warrant. Moreover, the opportunity to implement the other recommendations presented here has never been greater: they are aligned to ongoing reforms in health and social care (for example, the new duty to support informal carers proposed in the Care Bill); they build on existing good practice with proven results (such as electronic patient records and schemes such as PEPS); and they have the potential to save large amounts of money by reducing poor outcomes (the most significant of these being unnecessary hospitalisation).

Success is not guaranteed, and there remain significant challenges ahead. When speaking to experts about the range of reforms and changes facing end of life care (highlighted in chapter 1 and described in more detail in appendix 3) the prevailing mood was one of cautious optimism: on the one hand, the prospect of free care at the end of life and improved integration were a source of genuine hope, but the current situation, with its dangerous combination of large-scale structural change and straitened resources, remains without doubt particularly challenging. John Hughes, Group Medical Director of Sue Ryder, felt these immediate difficulties ought to be transitory:

The organisational change that is required, whether it's personal health budgets or whether it's joint commissioning of health and social care, is just beginning to start. Over the next two or three years hopefully some of these problems will begin to sort themselves out.

Nonetheless, there remained some longer term areas of concern. For example, some experts felt that cost-shunting between the NHS and local authorities would persist even if free social care at the end of life was introduced, as the funding would come from the health budget. This would increase incentives for local authorities to send people for assessment for end of life care eligibility, even if they were unlikely to be eligible, and thereby overloading the system (as was reported to us anecdotally regarding CHC assessments). One way of reducing this risk, we feel, is by ensuring GPs have a rigorous end of life care eligibility assessment support in the form of electronic prompts and link support (see above), rendering the 'grey area' often associated with CHC assessments smaller and less open to exploitation by speculative local authority referrals.

Another promising area – the introduction of HWBs to promote end of life care for the local population – was also viewed with caution. There was a perception that HWBs tended to be more concerned with 'traditional and more tangible public health issues' such as smoking and obesity than with end of life care. This is partly supported by a report by the National Council for Palliative Care, which found that a fortnight before assuming their statutory powers on 1 April 2013, only just over 50 per cent of (shadow) HWBs had identified end of life care as a priority.[97] A great deal was thought to depend on the composition of individual HWBs. Experts at our seminar suggested that the inclusion of a representative from a consortia of hospices, and/or a lay person with experience as a carer would improve the chances of end of life care being seen as a priority in JSNAs and day to day HWB operations. Practitioners' attitudes to CCGs were similar: confidence in CCGs was tempered by the recognition in the variability already seen between one CCG and another. For example, because much of the responsibility for the local commissioning structure is devolved, CCGs are free to choose whether to see end of life care as part of, or separate from, urgent care. The success of NHS Bedfordshire and Sue Ryder's PEPS scheme (see chapter 4) was partly attributed (by experts we spoke to) to the fact that it was commissioned under the umbrella of urgent care.

Finally, a few of the experts we spoke to saw the prevailing economic situation, and the need to save money across health and care, as a potentially positive stimulus – particularly in promoting greater integration and revisiting the balance in the workforce between generalists and specialists. However, some of the problems highlighted in chapter 2 can also be attributed to straitened resources – the tension between voluntary sector and statutory responsibilities, the attempt to shunt costs between health and social care, reductions in investment in community or preventative resources, and more generally an increase in 'uncooperativeness' between services – stemming from pressure to manage budgets strictly. Relatedly, the shift from secondary to primary care (while acknowledged as a way of improving outcomes and saving money) was feared as being harder to achieve as money would remain 'locked' in secondary care as each side tried to hang on to resources.

There remains, therefore, a mixed picture for the development of end of life care. It is buffeted by several care and health related reforms, economic realities and demographic pressures, some of which will facilitate, some undermine, improvements in quality. In such a challenging and changing environment it is all the more important to move forward with reforms to end of life care, which consider end of life as a subjective, personal journey, and are anchored by a 'first principle' – what do individuals and their families actually want? This report has addressed the changes needed to changing our understanding of the process, and should be read in tandem with a second report by Demos for Sue Ryder, to be published shortly, which answers the question 'what do people want?' in a more nuanced way than it has been answered before.

Appendix 1
List of expert interviewees

Nicky Bannister, Locality Project Manager, Bedfordshire CCG (formerly Commissioning Manager for Palliative and End of Life Care, NHS Bedfordshire)

Sophie Clark, Older People's Strategic Commissioner, Strategy and Commissioning Directorate, East Sussex County Council

Professor Margaret Holloway, Professor of Social Work, University of Hull, and Social Care Lead for the NEoLCP

Dr John Hughes, Group Medical Director, Sue Ryder

Professor Dame Barbara Monroe DBE, CEO, St Christopher's Hospice

Dr Sheila Payne, Director, International Observatory of End of Life Care, Lancaster University

Appendix 2
Attendees at the end of life service journey workshop

Simon Chapman, Director of Policy and Parliamentary Affairs, National Council for Palliative Care

Amanda Cheesley, Long Term Conditions Adviser, Royal College of Nursing

Phillida Cheetham, Researcher, Which?

Nicola Cole, Palliative Care Team, Frimley Park Hospital

Laura Cook, Policy Officer, Alzheimer's Society

Tom Cottam, Senior Policy Analyst, Macmillan Cancer Support

Jonathan Ellis, Director of Public Policy and Parliamentary Affairs, Help the Hospices

Baroness Ilora Finlay, Chair of the Wales Palliative Care Implementation Board

Dr Andy Fowell, Palliative Care Research Development Group (Thematic Lead, End of Life Care methodologies)

Alice Fuller, Campaigns and Development Manager, Motor Neurone Disease Association

Tom Gentry, Policy Adviser, Health Services, Age UK

Michelle Gillan, Senior Manager, Product Development, Mencap

Paul Healy, Senior Policy and Research Officer,
NHS Confederation

Davina Hehir, Director of Legal Strategy and Policy,
Dignity in Dying

Libby Hough, Project Development Manager,
Co-ordinate My Care

Revd Ruth Lambert, Senior Chaplain (Anglican),
Guy's and St Thomas' Hospital

Dr Liliana Risi, GP Clinical Lead, Cancer and Last Years
of Life, NHS Tower Hamlets

Deborah Rutter, Senior Research Analyst, Social Care
Institute for Excellence

Jason Suckley, Director of Fundraising and Marketing,
Sue Ryder

Karen Taylor OBE, Research Director, Deloitte UK Centre
for Health Solutions

Appendix 3
Further detail
on the policy
and practice context

The National End of Life Care Programme
(created 2004)

The National End of Life Care Programme (NEoLCP) was created to identify and reproduce best practice in the provision of end of life care, with a focus on the promotion of high quality, person-centred support and the aim of helping people to meet their preferences for preferred place of death. The NEoLCP oversaw the production of a range of publications, which emphasised the role social care professionals can play in supporting individuals and their carers with care planning at the end of life. The programme worked with health and social care staff, providers and commissioners, as well as third sector organisations across England. It also helped put into practice the End of Life Care Strategy and the quality standard for end of life care for adults of the National Institute for Clinical Excellence (NICE). The proportion of people dying at home and in hospices increased over the duration of the Programme.[98] The NEoLCP has now come to an end, and its functions have been split between various bodies including NHS England and NHS Improving Quality.[99]

The End of Life Care Strategy
(Department of Health, 2008)[100]

This document set out the Government's strategic vision for the development of end of life care. Its core aims include: delivering patient choice; raising the profile of end of life care within the NHS and, in particular, social care; improving care planning and coordination; and increasing support for carers

and the bereaved. As part of the strategy, the Department of Health committed to establishing the Dying Matters Coalition to raise the public profile of end of life care. Other calls to action included a major workforce development initiative, and the establishment of mechanisms 'to ensure that each person approaching the end of life receives coordinated care, in accordance with the care plan, across sectors and at all times of day and night', with particular emphasis placed on the provision of 24/7 services.

Supporting people to live and die well: a framework for social care at the end of life (Department of Health, 2010)[101]

This report, authored by the social care leads on the NEoLCP, set out ten key objectives and ten recommended actions aimed at achieving 'the full engagement of social care in end of life care'. This was acknowledged as crucial to the delivery of individualised, person-centred care, and – relatedly – to allowing more of the many people who wish to die at home to do so. The ten objectives centre on raising awareness of the role of social care in end of life care, facilitating the commissioning of integrated services, strengthening the palliative care social work specialism, disseminating good practice, building an evidence base and staff training and support. Eight sites across England received funding to trial implementation of the framework, each focusing on a subset of the ten objectives.

The NICE quality standard of end of life care for adults (2010)[102]

The NICE quality standard defines clinical best practice in end of life care. The aim of high quality care, as stipulated by the standard, should be to enhance quality of life for people with long-term conditions, and ensure that people have a positive experience of being treated and cared for in a safe environment. According to the standard, people approaching the end of life should be identified in a timely fashion and provided with

sensitive and accessible information. Those identified as in need of end of life care should be offered comprehensive and holistic Further detail on the policy and practice context assessments that are responsive to their changing needs and preferences, and should be given the opportunity to develop a personalised care plan. The quality standard makes clear that those in need of end of life care should always have their physical and psychological needs met safely, effectively and appropriately, and that these needs should be met in an holistic, coordinated, and personalised way.

The Palliative Care Funding Review (2011)[103]

This independent review begins from the premise that the inadequacy of the current funding system stems from the fact that the funding does not follow the patient. The Palliative Care Funding Review was tasked with developing a per-patient funding mechanism – a 'tariff' – to rectify this, with the ultimate aim of developing 'a funding system which incentivises good outcomes for patients, irrespective of both time and setting'.[104] Among the most important recommendations of the review are that:

· every CCG should appoint a lead provider to coordinate palliative care
· every CCG should hold an end of life locality register
· when a patient is put on the register, the NHS will meet all their needs (for health and social care) – in effect, social care should (like health) be free at the end of life.

The proposed tariff is due to be implemented from 2015.

The Health and Social Care Act 2012[105]

The Act addresses improved integration of health and social care services. GP-led CCGs and HWBs – both created by the Act – are presented as the driving force behind integration[106] and assumed their statutory powers in April 2013.

As part of the same set of reforms, the Coalition Government published a mandate to the NHS Commissioning Board, setting out the areas where it expects to see improvement between 2013 and 2015. The five key priority areas of the Mandate form the basis of the NHS Outcomes Framework, which further specifies the indicators of improvement in each domain. End of life care is covered in the fourth domain, 'Ensuring that people have a positive experience of care', where the relevant improvement area is 'Improving the experience of care for people at the end of their lives'. The indicator of improvement (4.6) is 'Bereaved carers' views on the quality of care in the last 3 months of life'.[107] The CCG outcomes indicator set is designed to hold CCGs to account for the quality of services and the health outcomes achieved through commissioning, although it does not specify thresholds that CCGs should aspire to meet. The indicators are informed by the national NHS Outcomes Framework. At present, there is no CCG measure for improving the experience of care for people at the end of their lives.[108]

The Care Bill of 2013
The Care Bill, which at the time of writing has just been through its second reading in the Lords, is designed to rationalise the UK's overly complex and out of date social care legislation and fit it for current and continued demand. Central to the Bill is the introduction of a new, local duty to promote wellbeing. The details of the Bill stand to affect end of life care in a number of ways. It reiterated government support for free social care at the end of life, and placed carers on a par with those they care for in their entitlement to support. The Bill places a duty on local authorities to provide information about available sources of support, as well as requiring them, when a patient is moving from area to another, to continue the previous care arrangements until a new package has been put in place. The Joint Scrutiny Committee report on draft care bill legislation (2013)[109] The Joint Scrutiny Committee expressed strong support for free social care at the end of life,

as recommended in the draft Care Bill, in the following terms:

People approaching the end of life and their families should not have to face this financial or emotional burden, nor be forced to go without the care that they desperately require… we agree that free social care at end of life has 'merit', and strongly endorse the case for its introduction at the earliest opportunity.[110]

Plans for integration of health and social care
In mid-May 2013, the Department of Health announced its intention to 'make joined-up and coordinated health and care the norm by 2018'. To inform its aims, the Department has worked with National Voices to develop an 'agreed definition of what people say good integrated care and support looks and feels like'. A number of 'pioneer' projects will be set up within a few months, with further pilots promised in every part of the country by 2015. Indicators based on patient experience to measure the effectiveness of efforts at integration will also be developed this year.[111]

Existing tools for end of life care practice
Over the past two decades, three tools have been developed to support the delivery of high quality end of life care in different contexts. As we discussed above, the effectiveness of these tools is not as well understood as it should be, and there has been some variability in their implementation. Notwithstanding these caveats, the experts we consulted saw them as generally well embedded in current practice, and as having the potential to be highly effective.

The Gold Standards Framework[112]
The Gold Standards Framework (GSF) was developed in 2001 with the aim of improving the quality and organisation of care in community settings within the final year of life. It provides a

mechanism for the systematic identification and recording of end of life care needs, and the continued coordination of end of life care provision. The GSF was rolled out to primary care, care homes and other end of life care-related areas in 2004.

Preferred Priorities for Care[113]
Developed in 2000 as part of the Palliative Care Education Programme, Preferred Priorities for Care (PPC) is a patient-held document in which individuals' wishes and preferences for their end of life care are recorded. In 2004 it was included in NICE Guidance on Supportive and Palliative Care for Adults with Cancer. PPC facilitates care planning by providing an impetus for professionals to initiate difficult discussions about end of life concerns. As PPC forms are standardised and patient-held, preferences are intended to be communicable to everyone who comes into contact with the patient, ensuring continuity of care. This can prevent inappropriate and unwanted interventions, as well as empower professionals to deliver individualised end of life care that is in line with the individual's preferences.

The Liverpool Care Pathway[114]
The Liverpool Care Pathway (LCP) was created in the late 1990s by the Royal Liverpool University Hospital in collaboration with Marie Curie, becoming part of the National Cancer Plan after 2000. In 2004 it was recommended in NICE guidance in Supportive and Palliative Care Strategy.

LCP is designed for use in secondary care settings, to support clinical judgement in the last hours or days of life. Its primary aim is to ensure as comfortable, peaceful and dignified a death as possible. Stages of the pathway include regular reviews of whether interventions (eg medication) or investigations (eg a blood test) are in the patient's interests, and whether or not it is advisable to continue artificial nutrition when a patient can no longer eat or drink. The patient's spiritual and religious needs are also considered. The

LCP is discussed further in chapter 4, where we consider how problems with its implementation have caused it to be presented as a source of controversy in the media.

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Death comes to us all, but this truism doesn't make it any easier to talk about. In health and social care, the understandable sensitivity around dying means that there are too few conversations between professionals and patients about patients' preferences, making it difficult to plan or support people who are nearing the end of their life. Instead, many receive care of varying quality, often characterised by delays, a lack of information and an insufficient say in their end of life 'journey'.

This report highlights several factors that contribute to these kinds of inequalities at the end of life. It reveals that the likelihood of what can be described as a 'good death' – one where the wishes of the patient and their family are met – can be significantly affected by where people live, their ethnicity and previous contact with social care. But the most critical factor is early diagnosis and timely initiation of support.

Ways and Means argues that tackling these inequalities requires placing an emphasis on training, communication and integration across health and social care. It recommends free social care at end of life be adopted as soon as possible, while ensuring that health and care professionals, who have a central role in providing well coordinated end of life care, are equipped and properly supported to talk about death. It concludes that a misplaced sense of delicacy must not prevent us from responding to people's needs.

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