A time and a place
What people want at the end of life
This report was prepared by Claudia Wood and Jo Salter of Demos

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## Key findings*

### What do people want at the end of life?

<table>
<thead>
<tr>
<th>Percentage</th>
<th>Description</th>
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<tbody>
<tr>
<td>78%</td>
<td>Being free from pain and discomfort</td>
</tr>
<tr>
<td>71%</td>
<td>Being surrounded by loved ones</td>
</tr>
<tr>
<td>53%</td>
<td>Having privacy and dignity</td>
</tr>
<tr>
<td>45%</td>
<td>Being in familiar surroundings and being in a calm and peaceful atmosphere</td>
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### Home

<table>
<thead>
<tr>
<th>Percentage</th>
<th>Description</th>
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</thead>
<tbody>
<tr>
<td>63%</td>
<td>Of people want to die at home</td>
</tr>
<tr>
<td>78%</td>
<td>Of people said that their main priority at the end of life was being pain free</td>
</tr>
<tr>
<td>27%</td>
<td>Only felt that home was a place where they would be free from pain during their final days</td>
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### Where do people want to be cared for at the end of their life?

<table>
<thead>
<tr>
<th>Last year of life</th>
<th>Last weeks of life</th>
<th>Last days of life</th>
</tr>
</thead>
<tbody>
<tr>
<td>Home</td>
<td>Hospice</td>
<td>Home</td>
</tr>
<tr>
<td>85%</td>
<td>11%</td>
<td>44%</td>
</tr>
<tr>
<td>67%</td>
<td>30%</td>
<td>55%</td>
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The differences in perceptions among those with and without first hand knowledge of hospices is significant. More people want to die in a hospice the closer they get to death. This shift is most dramatic for those who already have experience of hospice care.

*Findings taken from polling conducted by Demos*
My mother, Yvonne Johnston, aged 85, wrote in her diary in October last year ‘From believing my luck had run out, to regaining my peace of mind – Clare took me to meet Elise (hospice manager) at the Sue Ryder Hospice, such a professional place, and Elise herself warm, sympathetic, sweet and straight-forward – she and Clare have lifted the load from my shoulders’.

If my Mum were here today I feel sure she would say how beautiful her death was; it was everything the staff at Sue Ryder had promised her it would be, and more. The relief in her diary entry was heartfelt. Mum was diagnosed with pancreatic cancer in September 2012. The news simply terrified her, she shook visibly for over a month. She made the informed and brave decision not to have treatment. On diagnosis the consultant advised her to find a Macmillan nurse; she was an old woman, in total shock, and didn’t know where to turn. Essentially from then on in she seemed almost to fall out of the loop of NHS care. Her doctor visited her on only a few occasions. Luckily a close friend worked at Sue Ryder, we arranged an appointment, and because of the nature of her illness they took her under their care. We were fortunate, others perhaps experience difficulties in being assessed. From then on in Sue Ryder became my mother’s lifeline; other services, without prejudice, simply failed her.

Her cancer took hold very quickly, and she deteriorated rapidly. We were simply not prepared for what would happen. Mum had to have an overnight stay in hospital for a blood transfusion, which turned out to be a traumatic experience. She woke in the night to find a nurse going through her handbag, another forgetting how much blood she had been given, and a doctor getting cross with her when she complained. As a result she put in her end of life plan that she would rather just die than go back to hospital.

Mum really wanted to enjoy the comforts and security of her home during this difficult time. Our lives were spent sorting out pill boxes, buying food, caring for her and making appointments. Having had no experience of end of life care this was a challenge in itself, but both myself and my mother had advice, support and real friendship from our Sue Ryder nurse. On one occasion Mum coughed up blood, which was truly terrifying. We thought she was going to die literally then. Luckily she was referred to the hospice, where she stayed for two weeks, and was discharged home feeling a different person.

Mum was terrified of dying. This was a real worry to me. In the beginning she wanted to be treated at home. However having stayed at the hospice, and being staggered at the quality of care she received, she learnt not to be frightened. Most importantly she felt safe for the first time since her diagnosis. At home she had begun to feel out of control. I can’t imagine how we would have coped without the almost daily advice of the Sue Ryder community nurse, particularly with the medication. By the nature of the disease, the symptoms changed constantly, to a point where daily, or even hourly changes to the medication were necessary. This was a huge problem, and a real worry for us.

By December Mum’s symptoms worsened, and it became evident that she needed to be re-admitted. She was delighted to return to Nettlebed; it felt like home. Luckily there was a bed available for her, and she chose to spend her last days in the hospice, where she felt confident and happy.

It is very clear to me now that the system does not work for everyone. My mother was left unsupported at the most frightening time of her life. She didn’t know which way to turn, and neither did we. We had no idea what choices were available to us. We are lucky enough to live close to a Sue Ryder hospice. Sadly I’m left with the conviction that the NHS cannot always provide an acceptable standard of care for the terminally ill.

Mum died, with great dignity, at Nettlebed Hospice on 19th December 2012. She was cared for in a way she simply thought did not exist in the world today. She was fortunate enough to be given the choice to die in a hospice. We were the lucky ones; but I cannot help but wonder what happens to those who are not so fortunate.

Clare Sherriff
July 2013
Clare and Yvonne’s story is one of chance. It should have been one of choice.

With no experience or knowledge of end of life care Yvonne chose to be cared for at home, surrounded by home comforts, but in the end chose to spend her final days in a hospice where she felt safe and secure. Her decision making process was influenced at key points, by her experience in different settings, alongside her priorities for quality of life. This research explores these issues and starts to provide us with a greater understanding about what choices people make and when. We have become concerned that for policy and decision-makers, achieving personalisation at the end of life is being measured against where, not how individuals die.

Without a clear understanding of what people really want when it comes to care at the end of their life, we can’t determine whether or not existing support meets their needs.

At Sue Ryder we start with the individual. This means finding out each person’s needs and preferences, goals and aspirations to determine how we can provide care that is tailored to their needs. Delivering personalisation at the end of life is no different. We were therefore keen to work with Demos to unpick the relationship between location and outcomes in end of life care.

This research starts by investigating the elements of end of life care that are important to individuals to ensure we have a better understanding of what qualifies a good death.

The report demonstrates peoples’ perceptions about end of life care, and compares this to the reality.

We explore the outcomes that individuals want to achieve and how these can be achieved in all settings, at home, in hospitals, hospices and residential care centres.

We recently worked with Demos to launch Ways and Means which explored the barriers that prevent people from being able to make choices about their end of life care. This second report builds on this by setting out the decisions individuals make and what influences them. By unpicking the elements of end of life care we can begin to have a better understanding of what people really want and develop services that better respond to their needs. This report, alongside Ways and Means launches Sue Ryder’s Dying Isn’t Working campaign.

As Clare’s moving story above demonstrates, the system, as it stands, isn’t working. It shows that dignified and quality care is still not up to standard across all settings, care is not coordinated, and individuals and their families remain unsupported at the most life changing and emotionally challenging time.

We want to work towards improving each individual’s experience of end of life care by making it a national and local priority. We will be seeking to reposition the policy debate on end of life care so that individuals receive a personalised and quality service no matter where they are cared for.

Paul Woodward
Chief Executive,
Sue Ryder
End of life care policy and practice has, for some years, focused on ensuring people die in their preferred place of death and usually at home. But this focus on where people die — rather than what they want at the end of life — has inhibited personalisation and informed choice for patients and their families. It has led to a lack of proper scrutiny of the experience of dying at home and left other settings neglected when it comes to developing them as good places for people to die. Moreover, it sits uncomfortably with the wider shift towards achieving outcomes across health and social care, and is no longer sustainable in the face of demographic change.

And yet, it is understandable. The popular preference for dying at home — the least resource intensive form of support — creates a convenient alignment, where reducing healthcare costs can be achieved while supporting peoples’ preferences. It means there is little incentive to question why exactly it is that people say they want to die at home. If this synergy had not existed — and the majority of people had expressed a wish to die in hospital, for example — it is likely that more attention would have been paid before now to why this preference was expressed, and how best practice from hospital settings could be replicated in lower-cost settings.

As such, we know many people want to die at home — but we know very little about why.

In this report, for the first time Sue Ryder seeks to answer this question. It unpicks the relationship between people’s preferred place of death and the outcomes people value at the end of life. We identify what outcomes people prioritise at the end of life, how they associate these with different places of death (hospice, hospital, care home and their own home) and whether first-hand experience of these locations changes peoples’ perceptions of what care they can offer.

Sue Ryder believes end of life care should focus, first and foremost, on ensuring people have a personalised experience at the end of life, and a credible, informed choice regarding the services they use. But without knowing what people actually want, this is impossible for policy makers and practitioners to deliver. So, in partnership with Demos, Sue Ryder sought to gain a better understanding of the outcomes people value at the end of life — through a combination of a survey of members of the public, consultation with experts and practitioners in end of life care, and a focus group with bereaved relatives to explore their different experiences.

The findings presented in this report are enlightening and challenging both for policy and practice.

People’s first priority for the end of life is to be free from pain and discomfort (78% of respondents said this would be important to them), followed by being surrounded by their loved ones (71%), having privacy and dignity (53%), and being in familiar surroundings and being in a calm and peaceful atmosphere (both 45%).

However, the extent to which people associated such outcomes with home, hospital, hospices and residential or nursing homes is extremely interesting. Our findings suggest that — unsurprisingly — many of the medical aspects of care (pain relief, trained carers, emergency medical support) are associated with hospital and to a lesser extent care home settings, while dying at home is closely associated with the personal aspects of care (e.g. having relatives around you, being surrounded by your things and being in familiar surroundings).

However — crucially — while dying without pain and discomfort is a top priority for 78% of those surveyed, only 27% felt that home was a place where they would be free from pain during their final days. Dying at home is most closely associated with the next three of people’s priorities for end of life — suggesting that people are willing to sacrifice their first preference (pain relief), in order to satisfy more of their preferences overall by opting to die at home.

The importance of these findings cannot be overstated. Many professionals consulted during this research assumed that the public were ill-informed about the lack of pain relief when dying at home, and if they knew of the problems commonly encountered in accessing medication at home then fewer would opt for a home death. Our findings suggest this is not the case. In fact, the popularity regarding dying at home is not from a lack of understanding — rather a trade-off where people choose to make compromises and sacrifice some aspects of good quality care.

At the same time, the poor knowledge of hospice care is clear. Comparing hospices with each of the other three locations, it appears they occupy a space between the home and the hospital — balancing medical and personal, but lacking the advantages of either. And yet, when attributing scores to people’s priorities for the end of life, we found that dying at home results in a score of 42 — the highest of all four locations — but hospices come a very close second with 39. Hospitals and residential homes both score 25. It seems, in fact, that hospices are better at delivering the outcomes that people value than is currently recognised by the general public.
The findings here suggest that to state that most people ‘want to die at home’ is an unhelpful generalisation, as it prevents us from identifying ‘when’ people want these things. At the moment of death, perhaps people do want to be at home. But what about the days, weeks or years that precede it? Peoples’ preferences appear to change very significantly over this longer time period. No previous research has yet fully explored how people’s preferences might change over time, and this omission (which our research begins to address) has significant implications for end of life policy and practice.

More people want to die in a hospice the closer they get to death – rising from 4% to 17% to 28% in the final year, months and days before death respectively. At the same time, fewer people want to die at home – from 91% to 75% to 63% over the same period. However, this shift is most dramatic for those with experience of hospice care.

11% of people with experience of hospice care say they would like their last year there, while 30% would want to spend their last weeks there. Most importantly, at the very end (last days) of life, hospice becomes the preferred place to be for those with experience of hospices: 44% say they want their last days at home, and 55% in a hospice.

Most striking, however, was how people’s views of hospice care relative to care at home changed when asked about the final year, weeks and days before death. It is important to consider end of life care as a journey, and people will want and need different services, delivered in different locations, depending on how their needs change over time.

This was corroborated by analysis comparing how people’s perceptions of dying in different locations compared between those with and without first-hand experience of end of life care. It showed that:

- Care homes, by those with experience of friends or family dying there, are viewed as worse in medical care than expected and better in personal support, but still not as good on these fronts as dying at home or in a hospice.
- Those with experience of relatives dying in hospitals report the medical support is not as good as expected, while personal support is poor, but as expected.
- Dying at home is broadly as expected or slightly worse than expected among those with experience of this.
- Hospices, on the other hand, displayed some of the biggest differences in perceptions between those with and without experience of them, with some aspects more positive, and some more negative, than expected.

Where would you like to be? People with hospice experience.
Person-centred practice in end of life care is placed front and centre in new CCG indicators, and Health and Wellbeing Board strategies, with more obvious links to the NICE Quality Standard for End of Life Care (in particular statement 5 – that People approaching the end of life are offered timely personalised support for their social, practical and emotional needs, which is appropriate to their preferences, and maximises independence and social participation for as long as possible).1

The new CCG indicator regarding preferred place of care is broadened to something which leads on outcomes, not location – for example: the proportion of people who have been able to express their wishes for the end of life (e.g. through Advance Care Plans) and the proportion of people who have had their wishes for end of life met.

Local authorities’ duty to provide information regarding care services (as laid out in the Care Bill 2013) must include the full array of end of life care options, focusing on promoting informed choice based on the outcomes people want to achieve and not assuming that people only need to learn how to secure a home death. However, we must also recognise that there will always be families in circumstances (sudden, unexpected choices following a stroke or heart attack) which do not allow for the time to plan and make decisions about their care. For this reason, improving quality across all care settings is a must. No care setting is perfect – home, hospices, hospital and care home all have weaknesses – but all can do more to ensure that no matter where a person dies, the experience will deliver as much as possible on the outcomes people value at the end of life.

Recommendations to achieve this include:

1. An increase in the commissioning of floating ‘hospice at home’ support so that more people can access high quality palliative care and professional and medical support in a home setting – particularly pain and symptom-relieving medication.

2. Hospices offering a variation of the ‘hospice at home’

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scheme for care homes. This would provide care workers with important hands-on training and advice regarding palliative care, and give care home residents access to specialist support — reducing the risk of hospitalisation.

6. Specific support for informal carers of those nearing the end of life. This should be in the form of out of hours support and access to a single coordinated source of advice, such as the Sue Ryder Partnership for Excellence in Palliative Support (PEPS) scheme, as well as training in the practicalities of end of life care and ways to cope, to reduce carers feeling overburdened.

7. Improved end of life training for care workers in residential care. Due to staff turnover and an environment which may not be conducive to professional development this may be hard to achieve. CPD end of life care training is already available for experienced care workers, but such training should be available earlier on, in entry levels.

8. Care homes and hospices developing working partnerships which enable care home residents to be referred to day-services in hospices, so they can visit to receive specialist condition management and other support while still living in their care home.

9. Hospices outreach to the local community and health and care staff. This may include offering hospice at home services (as mentioned above), and day-services, so that those at the end of life actually get to see, first hand, what hospice care involves and increase a sense of familiarity earlier on in their care journey. Hospices should also consider ‘opening up’ to the community. Many hospices have gardens and meeting spaces which could be used by the wider community when free, to help raise awareness of the services hospices provide, break down barriers in perceptions.

10. Care homes should also open up to the community. Many care homes have unused spaces which community groups could utilise without disrupting the residents. The idea here again would be to make care homes less unfamiliar to the wider public, so people understood the type of support they offer and break down misperceptions, helping them to make informed choices.

11. Hospices should develop opportunities (and promote these within the community) for peer support — not just for carers and bereaved, but for those at the end of life — and schemes which enable people both to become more familiar with hospices (e.g. through day services) and to personalise their surroundings, assuaging concerns regarding hospices being unfamiliar environments.

12. Innovations such as the King’s Fund Enhancing the Healing Environment work on Environments for Care at the End of Life (ECEL), which looks at the physical design of palliative care suites, facilities for visitors and outdoor spaces in hospitals become standard practice.

13. Training for hospital staff at all levels in communicating about the end of life and delivering care holistically for this group — rather than just within the bounds of clinical practice — ought to be a core part of medical and nursing undergraduate curricula, while health trusts should explore opportunities for rotations and shadowing in hospices for staff most in contact with older patients and those with terminal illness.

Concluding thoughts

Personalisation at the end of life is harder to achieve than in many other care settings. Events can unfold rapidly, leaving traditional mechanisms for personalisation — such as personal budgets and coproduced care plans — redundant. In their place, providers and commissioners must strive for a culture of personalisation which puts individuals and their families at the heart of services. To achieve this, we must really get to the heart of what people want and value at the end of life. But our reliance on dying at home being universally popular has led us to conflate quality with place, inhibiting our understanding and thwarting attempts to truly personalise end of life care.

Through this research, Sue Ryder seeks to change this, by moving the debate on from the where to the what. The implications for policy and practice are significant and challenging, but it is a challenge we must take head on if end of life care is to keep up with both demographic change and with the wider move to personalisation in health and social care more generally.

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3 The King’s Fund, Environments for care at end of life. The King’s Fund’s Enhancing the Healing Environment Programme 2008-2010, London: The King’s Fund, 2011
There has been a considerable amount of research regarding the public’s views when it comes to where people want to die. We know that the majority of people want to die at home, when about 60% actually die in hospital. Only 8% (according to polling carried out for this project) want to die in hospital, and very few people consider hospice care as an alternative. The hospital system is already under pressure from the cost of caring for an ageing population, and projections based on current trends in place of death predict that it will come under extra strain in the future, with demand for end of life care in hospitals increasing by 20% by 2030.

In this context, the popularity of home death among the general public is fortuitous, and policy and practice in end of life care is now heavily focused on enabling more people to die at home through better community-based services.

This coming together of public inclination and financial necessity means that there has been little reason to dissect why exactly people say they want to die at home — what images and ideas home conjures up — or to use these characteristics as the basis for providing quality end of life care, rather than place itself. If somebody says that they would like to die in their own home, and then go on to die in their own home, then this is classed as a good death, regardless of what it was actually like for that person to die at home. Across the sector, ‘where’ has become as proxy for ‘how’.

But it is vital to decouple the two. As we explore in the following chapter, the focus on location rather than outcome is wildly out of step with the rest of government health and social care policy, but more importantly, it stifles incentives to improve care across all locations. In doing so, it inhibits choice and, ultimately, personalisation at the end of life. It is only by moving from the ‘where’ to the ‘what’ will we be able to help everyone achieve a good death, regardless of where they die.

In 2011, Sue Ryder worked with Demos to identify end of life care as an area where the conventional tools of personalisation — such as personal budgets — may not be appropriate. Sue Ryder (and other providers of hospice care) wants to improve the personalisation of our offer — delivering greater informed choice and control — in end of life care services. But without understanding the type of death that people want — beyond just where they want it to take place — there is a risk of making assumptions about what is important to people in their final months, weeks and days of life, and failing to accommodate personal choices and preferences accordingly. Previous Demos research on personalisation concluded that hospices have a strong culture of personalisation, and that person-centred holistic support is an integral part of their approach. In end of life care more generally, though — and particularly at a policy level — personalisation has not gone much further than place of death. It is to fill this gap in our knowledge that Sue Ryder embarked on this piece of research, by working again with Demos to help us look beyond what we know — and what we think we know — about preferred place of death.

Methodology

There were three phases to this piece of research. The first involved in-depth interviews with five experts in the fields of palliative and end of life care, to get a sense of how, in their professional opinion, place and preference are currently shaping services for people approaching the end of life, the appropriateness of this, and the capacity of different care settings to deliver peoples’ preferences.

The second phase involved commissioning a survey of 2,038 members of the public, in which people were asked to prioritise aspects associated with a good death (things like being free from pain, being surrounded by loved ones, and having dignity and respect) the things that would be important to them personally during their final days of life. To understand how these preferences map on to different locations, people were then asked how well they felt the same list of features were delivered across four different end of life care settings — home, hospital, hospice and nursing or residential care home. The resulting analysis was able to compare peoples’ answers to each of these questions in relation to their previous experience of spending time with a family member or friend during their final days of life, and where this occurred.

Finally, a focus group was hosted, with nine bereaved relatives of people who had died in different locations (in hospital, in a hospice, or at home), to explore how their expectations of dying in different places — both positive and negative — were met, and where the reality differed from their expectations.

*C Wood, Tailor Made, London: Demos, 2011*
No place like home?

The Government drive to increase the number of people able to die at home began in 2008, when Gomes and Higginson at the Cicely Saunders Institute published research projecting that demand for palliative and end of life care in institutions such as hospitals and hospices would far outpace supply by 2030. Later that year, in July, the Labour Government published the first National End of Life Care Strategy – up until this point, there had been no comprehensive framework for national improvements to end of life care across health and social care services. The foreword to the Strategy, by the then Secretary of State for Health Alan Johnson MP, points out that “most people would prefer to die at home. In practice, only a minority manage to do so.” 6

In the intervening years, a flurry of research has appeared focusing on the importance of meeting people’s wishes regarding their preferred place of death (including the 2010 Demos report Dying for Change). 7

In 2013, the focus on place of death is well established, and reflected in local Health and Wellbeing Boards’ joint health and wellbeing strategies. Where strategies contain a target for improving end of life care, these targets are concerned almost exclusively with ‘where’ people die in the future, rather than ‘how’. Their aim is either to increase deaths at home or in ‘preferred place of care’. This is reflected in the proposed new end of life indicators for Clinical Commissioning Groups (CCGs) in 2014-15. The new ELC05 indicator states that CCGs should monitor “People who have stated their preferred place of death, the proportion who died in their preferred place of death”. 8 No mention is made of the level of personalisation here – what if only 1% of people were given the opportunity to state their preferred place of death? And what about the opportunity to have other preferences met?

The assumption behind much of this is that ‘place’ of death is an adequate proxy for ‘type’ of death – that if people die in the right place, they will also automatically experience a better death, thereby rendering unnecessary the monitoring of the delivery of outcomes. The language of many of these reports uses location and quality of death almost interchangeably.

For example, the National Institute for Health and Care Excellence (NICE) quality standard for end of life care sets out markers for high quality end of life care across 16 areas, ranging from assessment and co-ordination to workforce training and providing holistic support to dying people and their families. Although the quality standard aims to improve patient experience at the end of life ‘regardless of the underlying condition or setting’, impact on place of death features among the outcomes, in the following ways:

- “The care that people approaching the end of life receive is aligned to their needs and preferences
- Increased length of time spent in preferred place of care during the last year of life
- Reduction in unscheduled care hospital admissions leading to death in hospital (where death in hospital is against their stated preference)
- Reduction in deaths in inappropriate places such as on a trolley in hospital or in transit in an ambulance” 9

There is an assumption here that place and outcome are the same thing – that being in your preferred place of death guarantees good quality care, while being somewhere you didn’t wish to be automatically means poor care. As we explain in the following chapters, those with first-hand experience of end of life care reported that this is not always the case.

But it is not simply an instinct to meet popular demand that has driven policies to enable people to die in their preferred place of death.

When asked, most people express a wish to die at home. Successive surveys of the public over many years have found that around two thirds of people – across age, gender, geographical and social difference – would choose to die at home. The latest of these surveys, carried out for this report, found that 63% of people wanted to spend their final days at home – a statistic that has barely changed from a similar survey Demos carried out in 2010, which found that 66% of people wanted to die at home. 10 Numerous other surveys have produced similar results – the public’s wish to die at home is an enduring one that shows little sign of changing.

This – from the Government’s perspective – is highly fortuitous. Because demographic change will soon mean that helping the burgeoning numbers of people dying each year to die at home is the only financially sustainable way forward.

According to the 2008 paper by Gomes and Higginson, the total number of deaths per year is predicted to increase to almost 590,000 per year by 2030 (a 16.5% increase on 2012 levels), when...
the annual number of deaths will begin to outnumber births.

In 2030 people will also be more likely to be dying in advanced old age – when they will have accumulated more long-term conditions. Gomes and Higginson predict that by 2030, 87% of deaths will be among people aged 65 and over, and 44% of deaths will be among people aged 85 and over.14

Their paper also looked at trends in place of death between 1974 and 2003, showing that over this time period, the proportion of home deaths fell from 31% to 18% of all deaths. This was accompanied by an increase in the proportion of deaths occurring in hospital – in the 5 years between 1999 and 2003, the only place in which the number of deaths increased in proportion to other locations was in NHS hospitals.12

If these trends were to continue – and accounting for changes in age and gender distribution – by 2030, the number of people dying at home will have fallen by 42%, so that only 9.6% of deaths will occur at home. At the same time, deaths in institutions (classified at hospitals, hospices and residential care or nursing homes) will increase by just over 20% – with most of this increase (19%) being accounted for by NHS hospitals.

This presents a huge problem because of the high cost of providing end of life care in hospitals. Marie Curie recently carried out research contrasting the cost of end of life care in hospitals and at home, using community-based services, such as District Nursing and community specialist palliative care nursing. This found that a day of community care at the end of life costs £145, compared to £425 for a day of specialist palliative inpatient care in hospital – a difference of £280 a day.13 No comparable data exists for hospices – though figures obtained through Sue Ryder estimate that it costs around £5,500 per day to run a hospice’s inpatient care services, obtained through Sue Ryder estimate that it costs around £5,500 per day to run a hospice’s inpatient care services, obtained through Sue Ryder estimate that it costs around £5,500 per day to run a hospice’s inpatient care services, obtained through Sue Ryder estimate that it costs around £5,500 per day to run a hospice’s inpatient care services.

This lack of examination of what it is about death at home that makes it such a popular choice – and perhaps an assumption that it is something indefinable, subjective and therefore not possible to replicate in other (possibly lower-cost) settings. This convenient alignment, where reducing healthcare costs can be achieved while supporting peoples’ preferences for place of death, means there has been little incentive to question why exactly it is that people say they want to die at home. If this synergy had not existed – and the majority of people had expressed a wish to die in hospital, for example – it is likely that more attention would have been paid before now to why this preference was expressed, and how best practice from hospitals could be replicated in other (possibly lower-cost) settings.

Dr Mary Turner from the International Observatory on End of Life Care, who was consulted during this research, commented:

“It isn’t really about choice, although we’re supposed to have this choice agenda – it is also about saving money. If people opted to die in hospital, that would cause problems, and there is an incentive there to push costs onto the relatives by having people cared for at home.”

In addition, there is still a significant level of unmet need for palliative care. Research commissioned by the Palliative Care Funding Review estimated that between 92,500 and 142,500 people each year who need palliative care are not receiving any.16 If the Government is to meet current and future need for end of life care, without costs spiralling out of control, it is clear that future growth in demand cannot be met through hospital care – and the cheapest alternative is care at home. Fortunately, it is also the most popular.
Government initiatives to increase home deaths

Up until the early 2000s, there was no framework for the systematic improvement of end of life care across the country, and as a result, the quality of care was extremely variable. The first National End of Life Care Programme (NEOLCP) was launched in 2004 with the aim of raising the profile of end of life care within the health and social care systems, and identifying and spreading best practice. Between 2004 and 2013, the programme contributed to the development and implementation of several key tools for end of life care including the Gold Standards Framework, Liverpool Care Pathway for the Dying Patient and Preferred Priorities for Care.

Part of the NEOLCP’s remit was to support people to die in their preferred place – understood to mean home for the majority of people. Recent research by the Cicely Saunders Institute showed that since 2005, the proportion of home deaths has increased, while the proportion of hospital deaths has declined, which the Institute attributes to the success of the NEOLCP.17

Since 2008 (up until its closure in 2013), the NEOLCP has also been responsible for helping to enact the Department of Health’s National End of Life Care Strategy, which was published that year. The Strategy – developed through consultation with stakeholder groups – recommends a care pathway approach, ensuring that care is integrated throughout the final months, weeks and days of life, and after death.

There are several recurring themes throughout the Strategy:

- Meeting peoples’ needs and preferences at the end of life
- Co-ordination of care and support
- Rapid 24/7 access to care and support
- Support for relatives who may also be acting as carers, both before and after death
- Workforce development, education and training
- Raising the profile of end of life care, and changing public attitudes towards death and dying

The Strategy acknowledges the importance of improving care for all people approaching the end of life, regardless of where they die, and yet certain of the actions recommended by the Strategy would particularly serve to improve and enable home deaths – things like lack of access to 24/7 support, and inadequate support for carers, will have the most impact on people dying at home, as opposed to in an institutional setting, such as a care home or hospice. The Strategy document also notes the diverse range of professionals involved in caring for somebody in their own home as they are dying, and so care co-ordination may also be especially pertinent for people dying at home.

At a local level, many of the newly operational Health and Wellbeing Boards have also adopted death at home as an indicator of success in end of life care. Each Board has been required to produce a Joint Strategic Needs Assessment (JSNA) for their area, and develop a joint health and wellbeing strategy to meet these needs.

The National Council for Palliative Care surveyed the 152 Health and Wellbeing Boards that existed in shadow form in 2012 to review the extent to which end of life care featured in these. Of the 83 boards with a published strategy or draft strategy, 38 – just under half – contain an explicit reference to end of life care.18 Looking in more detail at what aims and outcomes these 38 Boards are using in their local strategies for end of life care, we found that while eleven talk about increasing the number of people being cared for and dying in their preferred location, nine specifically aim to increase number of deaths at home (or ‘usual place of residence’ – which could mean a care home for some people). Some of the indicators used to measure this are extremely specific – for example, one strategy aims to ‘increase the proportion of people who die at home from 19.7% in 2008-10 to 23% by 2015’.19

Outside of Government, charities working in end of life care have been campaigning to increase the number of home deaths. Since 2004, Marie Curie Cancer Care has campaigned for people to have the right to die in the place of their choosing.20 In one report from 2012, the charity states that they campaign “to ensure that more people are able to be cared for and die at home”, saying that:

“We do so because we know that most people would choose to die at home if they were terminally ill (63 %) and because it makes good economic sense. Our estimates suggest that reducing hospital stays for 30,000 patients by just four days could potentially save the NHS £34 million per year.”21

19 Draft Health and Wellbeing Strategy for one Health and Wellbeing Board in north west England
Since the recommendation that all social care at the end of life should be free at point of use – a highly publicised recommendation of the Palliative Care Funding Review, and also endorsed by the Dilnot Commission – free social care has formed a focal point for many campaigns. Many also see this as an important tool in improving the numbers of deaths at home, with readily available care and support being a means to an end when it comes to home deaths.

Outcomes and place – the how and the where

The above examples from recent policy and campaigning work show how place is being used as a proxy for good care. Tessa Ing, formerly Head of End of Life Care at the Department of Health, interviewed for this research, acknowledged that:

“We’re using place as a proxy for quality, but we know that there’s a gap there.”

Similarly, Heather Richardson from Help the Hospices commented:

“Definitely the focus is where, and I think it’s a smokescreen for the harder job of thinking about how people want to die and how we can achieve that.”

This lack of thinking about how people want to die means that, despite the amount of emphasis placed on ‘meeting peoples’ preferences’ for the end of life, there is very little comprehensive evidence about what these preferences actually are. Some things are consistently mentioned as features of what it means to die well – such as having friends and family close by, being in a peaceful place, and having your dignity preserved, but this is based primarily on anecdotal evidence – more importantly, these preferences have not been linked to preference for place of death, allowing the assumption that most aspects of a good death can be delivered in a home setting to prevail, without subjecting it to any real scrutiny.

Why is it important to move from where to how?

There are two reasons why shaping future of end of life care around place rather than outcome should be discouraged. The first is that it is anathema to the rest of the health and social care system, and the second is that it leads to the prioritisation of certain locations over others, undermining proper development of quality care in all settings, and compounding the belief among the general public that it is impossible to have a good death anywhere other than at home – despite the fact that for certain groups, such as the extremely elderly and infirm, a home death may not be a realistic option.

Outcomes in health and social care

Making place an outcome in and of itself is distinctly at odds with the rest of the health and social care system, which has focused increasingly on promoting the outcomes people hope to achieve, rather than being bound by particular types of services or service setting. There is now, for example, an Outcomes Framework for the NHS,\(^22\) public health and adult social care.

The launch of these three Outcomes Frameworks between 2011 and 2012 marked a step-change away from national measures that focus on processes or services, and towards measures of the outcomes that people achieve, and their experiences of care.\(^23\)


NHS Outcomes Framework, 2013/14

The NHS Outcomes Framework for 2013/14 (now in its third successive year) builds on the Coalition Government’s efforts to move the NHS away from measuring process targets to measuring health outcomes. The framework looks for new ways to get a national picture of NHS performance and build a structure by which the NHS can be held to account.

The outcome indicators for the NHS are grouped into five broad domains with defined indicators as their focus:

1. Preventing people from dying prematurely focussing on potential years of life lost from causes amenable to healthcare indicators, cancer survival with one- and five-year survival rate indicators for all cancers and for specific types of cancer, and indicators relating to premature deaths among people with learning disabilities.

2. Enhancing quality of life for people with long-term conditions focussing on health-related quality of life indicators for people with long-term conditions, dementia treatment, including early diagnosis indicators, time in hospital indicators, and measures of how supported people feel to manage their condition.

3. Helping people to recover from episodes of ill health or following injury focussing on mental health with indicators for access to psychological therapies, patient reported outcome measures using indicators from post-elective surgery recovery, and emergency admissions, including avoidable hospital admissions, and readmission rates.

4. Ensuring that people have a positive experience of care focussing on patient experience feedback for all forms of primary care and hospital care, the friends and family test as an indicator of whether patients would recommend the services they used to others, and access – with data on the hours and availability of services.

5. Treating and caring for people in a safe environment, and protecting them from avoidable harm focussing on patient safety using data for reported safety incidents, hospital deaths attributable to problems in care and reducing avoidable harm using indicators on hospital related venous thromboembolism and hospital related infection such as MRSA and C. difficile.
In social care, the recent White Paper and Draft Bill spoke exclusively about a system created to support the outcomes valued by older and disabled people. While there has been a move towards greater care in the community (and for many, this has meant living in their own homes or supported housing instead of in residential care), this has clearly been outcomes- rather than location-led: greater choice and control, independence and empowerment are proven (and not just assumed) to be associated with care in the home. These concepts are at the heart of social care and health reform and, as such, care at home is seen as an important vehicle through which these aims can be achieved. However, care at home is not seen as an end in and of itself, and much has been done both to promote the quality of home care around the outcomes outlined above, as well as to improve the quality of care in other settings.

With these frameworks acting as a precedent, for the Government to present a coherent vision of the future of health and social care, end of life care needs to be aligned to wider conversations about outcomes. The use of place of death as an indicator of quality of care in end of life services is an anomaly among wider care services.

Prioritising different locations
Maintaining the emphasis on location over outcomes also presents practical difficulties in delivering high quality end of life care in the future. The same demographic changes that will see increasing demand on hospital services over the next decades also mean that people are no longer living and dying at home in the same way that they were 20 or 30 years ago. Increased longevity means that the very elderly population (aged 85 and above) is increasing rapidly, and Gomes and Higginson concluded that by 2030, the majority of deaths will be among the demographic groups for whom a home death is least likely to happen – namely the very elderly, who may be living for many years in a residential setting before death, and women, who are more likely to be widowed and living alone in old age, perhaps living far from their children (and therefore less likely to be supported at home at the end of life). Another piece of research recently commissioned by Sue Ryder from Demos similarly identified people suffering from dementia (also generally among the elderly) as those especially unlikely to be able to die at home, given the chances of them being in residential care before death.

When faced with this reality of an ageing society, it is clear that in the future, larger numbers of people will not be able to die at home – for many, this will be because ‘home’ is actually a residential or nursing care setting, while for others it will be because there is not adequate family support to make this viable.

Of course, the widespread wish to die at home is too rarely met, and more should be done to help people fulfil this. But by making home death the benchmark for good quality end of life care, and focusing on developing and expanding services that particularly target people dying at home (such as out-of-hours support for patients and their carers), there is a risk of neglecting the standard of care in settings other than home. This is particularly the case for hospitals and care homes, where (even with a significant increase in home deaths), some people will need (or want) to die.

The problem should not be that people are dying in the wrong place, but that they are dying in the wrong way. Rather than simply moving people from hospital to home, we should be doing more to ensure that all locations where people die provide good quality care, so that wherever somebody spends their final days, they are ensured a good death. Doing this would serve to lower the stakes of dying in the purported ‘wrong place’, as no place would fall far short in providing the type of experience that people would like at the very end of life.

To be able to move from ‘where’ to ‘how’ we, as a society, want and expect to die, we need to know more detail about peoples’ preferences towards the end of life, and how end of life care – regardless of location – can fulfil these preferences. This means looking beyond people’s preferences regarding ‘where’ they want to die and considering which outcomes at the end of life they value, and which outcomes they associate with different locations. We know many people want to die at home – but we know very little about why.

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24 B Gomes and I Higginson, 2008
25 A Paget and C Wood, 2013
In the previous chapter, we explored how a continued policy focus on *where* rather than *how* people die and what they value has led to a drive to encourage people to die at home – a cost-effective and popular choice – without exploring further whether this is of high quality. This leaves other settings neglected when it comes to developing them as good places for people to die, and seems incongruous when considered alongside wider health and care reform which is focusing more and more on the achievement of outcomes, blind to types (or locations) of service.

In this chapter, we attempt to fill the gap in current understanding regarding what people want when it comes to end of life care, and how this relates to place of death. We seek to unpick what people mean when they say they want to die at home – is this a proxy for a set of outcomes they want to achieve, and if so, what are these?

**What is important at the end of life?**

A survey of the UK public was commissioned for this research, asking people about their preferences for the end of their life, and the extent to which they perceive different locations to meet these preferences (for a full list of the questions we asked, see the appendix to this report). We first asked a hypothetical question about peoples’ priorities in the final days of their life, assuming that they were diagnosed with a terminal illness, and so likely to be receiving palliative care (i.e. not a sudden death).

The responses we received show that being free from pain and discomfort (78% of respondents said this would be important to them), and being surrounded by your loved ones (71%) were the top two priorities across all age groups and other demographic factors (small differences were found, as we explain further below). This was followed by having privacy and dignity (53%), being in familiar surroundings and being in a calm and peaceful atmosphere (both 45%).

### Which of the following would be most important to you regarding how you spend your final days?

- Being pain free/having condition managed
- Surrounded by your loved ones
- Having privacy and dignity
- In familiar surroundings
- Being in a calm and peaceful atmosphere
- Surrounded by your personal things and/or your pets
- Trained carers nearby to help you and your family
- Access to professionals for last-minute concerns
- Having religious, cultural or spiritual needs met
- Having other people around going through the same thing

0% 10% 20% 30% 40% 50% 60% 70% 80% 90%
We grouped this list of preferences for the end of life under four headings – medical, personal, environmental and practical – to help us understand how people are prioritizing some elements of care over others.

Breaking peoples’ responses down in this way shows that people are much more concerned with personal and environmental factors than medical ones. Aside from medicines being administered, peoples’ top priorities for the end of life included very little involvement from medical or care professionals – only 24% of people selected having trained carers nearby as something that would be important to them, and only 16% selected professional medical support on standby for emergencies. People clearly want as ‘un-medicalised’ a death as possible – but they still want to be free from pain. This is perhaps because pain is viewed as a quality of life issue, rather than a medical one. In our focus group with bereaved relatives, this was described more generally as a desire to be ‘comfortable’, rather than in clinical terms.

| Medical          | • Being pain free/having your condition managed with medication  
                  | • Professional medical support on standby for emergencies  
                  | • Trained carers nearby to help you and your family |
|------------------|----------------------------------------------------------|
| Environmental    | • In familiar surroundings  
                  | • Being in a calm and peaceful atmosphere  
                  | • Feeling in control of your environment and what support you get |
| Personal         | • Surrounded by your loved ones  
                  | • Surrounded by your personal things and/or your pets  
                  | • Having your religious, cultural or spiritual needs met (e.g. having a priest with you)  
                  | • Having privacy and dignity  
                  | • Having other people around going through the same thing, to talk to and provide support |
| Practical        | • Access to professionals for last-minute concerns about your family or legal affairs |

Chapter 2
People we spoke to in our focus groups, like the survey findings, emphasised personal and environmental factors as being the most important aspects of quality end of life care. The two things that bereavement support group members unanimously said their dying relatives had wanted were comfort and dignity. Other things that people associated with good care (generally in a hospice setting) were compassion, a calm atmosphere, feeling cared about, having some of the stress and responsibility of caring offloaded, quick and efficient support, friendship and professionalism. These are overwhelmingly personal factors that relate to how dying people, and their carers, are treated as individuals.

Priorities at the end of life according to age and social group
The results of our polling show that preferences vary according to age and are also dependent, to some extent, on socio-economic status. Those aged 18-24 were more likely than average to say that they would like to die surrounded by loved ones, in familiar surroundings, in a calm and peaceful environment and surrounded by personal possessions. In contrast, people aged over 65 were a lot more likely than average to say that they wanted to be free from pain in their final days (90% said this was important), and have trained carers nearby. Using the framework above, this suggests a shift in concern from more personal and environmental factors among younger people to an appreciation of medical support, perhaps as the realities of ageing and illness begin to kick in.

A further implication of this is that the profile of a home death (as we will go on to show) is much more aligned with the preferences of younger age groups than older ones. This is also reflected in responses to our question about what would be important to them as they approach the end of life. People working in skilled manual occupations, unlike people of all other social grades, value being surrounded by loved ones above being free from pain (74% said that being surrounded by their loved ones was important compared to 71% who said that being pain-free was important). And yet, these different preferences did not translate into statistically significant differences related to place of death – an issue we explore further below.

One final factor that helps determine what outcomes different people use to define ‘a good death’ is their previous experience of end of life care. For example, people who had spent time with a friend or relative in the days leading up to their death in hospital were more likely to say that privacy and dignity were important to them personally, while people who had experience of a loved one’s death at home were more likely to say that being in familiar surroundings was important. This suggests that experiences – both positive and negative – of end of life care may influence peoples’ priorities for their own death. People with no experience of any location were much less concerned with being pain-free, and more concerned with things like being able to put their affairs in order and having other people around them – both friends and family, and other people who are going through the same thing.

Living well or dying well?
From our polling evidence, people seemingly have a clear idea of what is important to them as they are dying, but the reality of dying with a terminal illness does not always allow for the same level of reflection and detachment. It is one thing to ask a representative sample of the public – out of context – what things would be important to them at the end of their life, when this is still many years away. It is very different to suddenly be faced with your death – or the death of someone close to you – and to try to think clearly and rationally about the features that will best help you to die in the way that you want to.

Heather Richardson, the National Clinical Lead for Help the Hospices, acknowledged that surveys of the public, and even asking people to record their preferred place of care, ask people at a stage when they are still healthy and, in doing so, risk conflating ‘living’ well with ‘dying’ well. It is to be expected that we associate home with a good life, but this is not necessarily the same thing as a good death.26 When asked at an early stage, people are more likely to be making a statement about home than making a statement about dying.

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26 Demos interview with Heather Richardson, the National Clinical Lead for Help the Hospices
In the experience of the people who attended our focus group, all of whom had lost a close family member, the whole process of thinking about preferences, and weighing up pros and cons, can be squeezed into a very short timeframe — often months, weeks or even days. We heard many stories where a person’s condition had deteriorated very rapidly, and where their relatives and carers were left trying to gather information and make decisions in very painful and confusing circumstances. One woman described this disorientation in the following way:

“When you’re losing loved ones, it’s very, very difficult and frustrating, and it makes you... you don’t know what day it is, you don’t know where you are.”

This is often exacerbated by a profound lack of confidence that wishes and preferences will be respected, resulting in a feeling that is pointless to even entertain a preference. One woman described her experience in hospital as being ‘railroaded’:

“The whole experience of going into hospital is one of being railroaded into the course of action that they are going to take, no matter what you say.”

Another said:

“You don’t have a preference if you don’t have any control over it.”

Feeling like your wishes are not being respected can be a poor outcome in itself. Karen Weatherill, from the Long Term Conditions and End of Life Team at NHS West Essex said that, in her view, one of the things that is most important to people approaching the end of life is that “people actually get their wishes” — or even just that an effort is made to grant these wishes, even if it does not end up being possible to do so. This pessimism is not limited to service users. We asked Heather Richardson, the National Clinical Lead for Help the Hospices, about whether peoples’ preferences tended to dictate where they would end their life, and her response was

“As a general rule, people feel they have little choice. In reality, they have even less.”

Dr Mary Turner, from the International Observatory on End of Life Care, agreed that in many cases, practicalities play a more significant role in determining place of death than preferences.

Preferencem and place

To understand whether people themselves prioritise where or how they would like to die, we need to look at how people currently perceive the various settings for end of life care — home, hospital, hospices and residential or nursing homes. We know that around two thirds of people wish to spend their final days at home — in our own polling for this report, 63% of people said that this would be their preferred place of care in their final days, while 28% wish to die in a hospice, 8% in a hospital, and only 1% want to die in a care home. But what is it about the type of death associated with each of these different places that prompts this choice?
What outcomes do people associate with different locations?
The table below presents the findings from our polling, where we asked members of the public to select which outcomes they associated with dying in each of four locations – at home, in a hospital, in a hospice, and in a residential or nursing home. It suggests that – unsurprisingly – many of the medical aspects of care (pain relief, trained carers, emergency medical support) are associated with hospital and to a lesser extent care home settings. Home scores highly in all environmental and personal aspects. Hospices, on the other hand, occupy a space between the home and the hospital – part personal, part medical – but not seen as excelling in any one field. They come top in offering a ‘calm and peaceful atmosphere’ – but in this respect they are only two percentage points ahead of the home, which is not significant in this sample, given the confidence interval. In the following sections, we consider each location in turn.

<table>
<thead>
<tr>
<th>Outcomes</th>
<th>At home</th>
<th>In hospital</th>
<th>In a hospice</th>
<th>In a residential or nursing home</th>
</tr>
</thead>
<tbody>
<tr>
<td>Being pain free/condition managed with medication</td>
<td>27%</td>
<td>87%</td>
<td>75%</td>
<td>54%</td>
</tr>
<tr>
<td>Surrounded by your loved ones</td>
<td>83%</td>
<td>18%</td>
<td>37%</td>
<td>25%</td>
</tr>
<tr>
<td>Professional medical support on standby for emergencies</td>
<td>8%</td>
<td>88%</td>
<td>55%</td>
<td>56%</td>
</tr>
<tr>
<td>In familiar surroundings</td>
<td>83%</td>
<td>6%</td>
<td>8%</td>
<td>23%</td>
</tr>
<tr>
<td>Trained carers nearby to help you and your family</td>
<td>12%</td>
<td>70%</td>
<td>69%</td>
<td>76%</td>
</tr>
<tr>
<td>Being in a calm and peaceful atmosphere</td>
<td>50%</td>
<td>10%</td>
<td>52%</td>
<td>25%</td>
</tr>
<tr>
<td>Access to professionals for last-minute concerns</td>
<td>3%</td>
<td>32%</td>
<td>19%</td>
<td>27%</td>
</tr>
<tr>
<td>Surrounded by your personal things and/or your pets</td>
<td>60%</td>
<td>4%</td>
<td>6%</td>
<td>23%</td>
</tr>
<tr>
<td>Having your religious, cultural or spiritual needs met</td>
<td>4%</td>
<td>10%</td>
<td>10%</td>
<td>12%</td>
</tr>
<tr>
<td>Feeling in control of your environment and support you get</td>
<td>22%</td>
<td>7%</td>
<td>8%</td>
<td>10%</td>
</tr>
<tr>
<td>Having privacy and dignity</td>
<td>46%</td>
<td>11%</td>
<td>29%</td>
<td>18%</td>
</tr>
</tbody>
</table>

\[\text{With 95\% confidence level we calculate the margin of error to be } \pm 2.17\]
Home

Characteristics most associated with home

Surrounded by your loved ones

In familiar surroundings

Surrounded by your personal things and/or your pets

Being in a calm and peaceful atmosphere

Having privacy and dignity

Being pain free/having condition managed

Feeling in control of your environment

Trained carers nearby to help you and your family

Professional medical support on standby

Having religious, cultural or spiritual needs met

Access to professionals for last-minute concerns

Having other people around going through the same thing

0% 10% 20% 30% 40% 50% 60% 70% 80% 90%

The characteristics most commonly associated with home are:

- Surrounded by your loved ones (83%)
- In familiar surroundings (83%)
- Surrounded by your personal things and/or your pets (60%)
- Being in a calm and peaceful atmosphere (50%)
- Having privacy and dignity (46%)

Home is a place that is associated with meeting peoples’ personal and environmental needs; it is a place where they can spend time with the people they love, a place that is familiar, peaceful and humanising – literally a place where they feel ‘at home’.

At the opposite end of the scale, home was least commonly associated with having other people around going through the same thing and access to professionals for setting your affairs in order. Both of these things highlight the potential for isolation and disconnection at the end of life – not necessarily from medical professionals, but from the people who may be most able to make somebody feel supported and prepared for death, psychologically and emotionally.

Access to professional medical support also ranks very low – and experience makes very little difference to this perception. This is possibly connected to the difficulty of accessing out-of-hours support from GPs. Out-of-hours support has come under scrutiny recently from the Health Secretary Jeremy Hunt, who claimed in April that poor out-of-hours GP services result in 4 million extra people being admitted to hospital each year.28

The most interesting finding from this data is that - in spite of pain relief being a top priority for 78% of those surveyed, only 27% felt that home was a place where they would be free from pain during their final days.

On the other hand, home meets all of the rest of the requirements for a good death – peoples’ next four priorities below pain relief are all things that people associated strongly with dying at home. This suggests that people are willing to sacrifice their first preference (pain relief), in order to satisfy more of their preferences overall.

This is not a compromise that people ought to have to make – and the lack of access to pain and symptom relieving medication in the community is already a source of concern among medical professionals, with issues including GPs prescribing insufficient medication and lack of generalist training among community practitioners in administering medication and using equipment for this task.29

29 A Paget and C Wood, 2013
In contrast to home, hospital is at the other end of the spectrum: a setting that neglects personal and environmental needs, in return for excelling in medical and practical support. Hospital was least associated with being in familiar surroundings and being surrounded by personal things. People also had a lot of actively negative associations with hospital. Many people listed ‘other’ associations in the survey, and used their own terms such as neglect, impersonal, noisy, chaotic, stressful environment, death and uncaring staff.

Nonetheless, hospitals are associated more than any other place with access to pain and symptom relieving medication. As outlined above, pain relief is the public’s top priority overall, but on its own clearly does not outweigh the combination of peoples’ other top preferences: being in familiar surroundings, being surrounded by loved ones and having privacy and dignity – all of which are associated with dying at home, but hospitals fall far short on. It was expressed strongly in our focus group with bereaved relatives that many of the features that allow people to retain their individuality and personalisation in care up until, and beyond, their death are notably absent from a hospital setting. As one woman, whose husband had died in a hospital, explained:

“They take a lot of decisions out of your hands... My husband went downhill quite suddenly, and it just all went to pot really, they couldn’t give a toss really what he wanted at the end. It was all ‘what they could manage to do’, there was no respecting somebody’s last wishes.”

While another, whose relative died in hospital, added:

“The doctors ought to listen and not be dismissive, and certainly they were indifferent to anything that was said to them... It was a wafting of the hand: ‘oh, what do you expect?’”
Chapter 2

Hospice
Characteristics most associated with hospice

- Being pain free/having condition managed
- Trained carers nearby to help you and your family
- Professional medical support on standby
- Being in a calm and peaceful atmosphere
- Surrounded by your loved ones
- Having other people around going through the same thing
- Having privacy and dignity
- Access to professionals for last-minute concerns
- Having religious, cultural or spiritual needs met
- In familiar surroundings
- Feeling in control of your environment
- Surrounded by your personal things and/or your pets

The characteristics most commonly associated with hospices are:

- Being pain free/having condition managed (75%)
- Trained carers nearby to help you and your family (69%)
- Professional medical support on standby (55%)
- Being in a calm and peaceful atmosphere (52%)
- Surrounded by your loved ones (37%)

Hospices are least associated with being in familiar surroundings, surrounded by personal things, and feeling in control – suggesting that many people still view hospices as quite alien environments. They are recognised as being places where pain and symptoms can be managed, no doubt due to associations of hospices with palliative care, but similarly to hospitals, they perform less well on peoples’ subsequent preferences – although 37% of people said that a hospice was a place where they could be surrounded by loved ones, this is much less a feature of hospices than of home. Only 8% of people said they associate hospices with being in familiar surroundings, fewer than said the same about residential care.

Overall, comparing hospices with each of the other three locations, it appears most similar to a residential home, and least similar to home. More precisely, hospices appear to be viewed as a ‘halfway house’ between home and hospital, balancing medical and personal, but lacking the advantages of either. Hospices are viewed as less ‘homely’ and familiar than home, but with less professional support available than in hospitals or residential care. Hospices are equivalent to residential care for access to medical support, and fare marginally worse regarding ‘having trained carers nearby’ – a concerning misconception, given the high level of expertise concentrated in the hospice sector and the acknowledged lack of palliative training among residential care staff. This would suggest a low level of understanding regarding what hospices do, and what palliative care is – an issue we explore in further detail below.

This is a problem that is recognised in the hospice sector. Sue Ryder’s Head of Clinical Quality and Nurse Lead, Sue Hogston told researchers that:

“There is still a perception that hospices are places where people go to die. Better understanding and communication regarding the role of hospices in enabling choices – in what are often emotionally challenging circumstances – is crucial”

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30 The End of Life Care Strategy and the NHS End of Life Care Programme both emphasise the need to improve end of life care in care homes. The End of Life Care Strategy particularly notes that "significant numbers of residents are being transferred from care homes to acute hospitals in the last days, or weeks of life" (pp. 90-91). Inadequate staff training in how to care for people at the very end of life may explain why this is occurring.
Residential care or nursing home

Characteristics most associated with residential or nursing home

- Trained carers nearby to help you and your family
- Professional medical support on standby
- Being pain free/having condition managed
- Having other people around going through the same thing
- Access to professionals for last-minute concerns
- Surrounded by your loved ones
- Being in a calm and peaceful atmosphere
- Surrounded by your personal things and/or your pets
- In familiar surroundings
- Having privacy and dignity
- Having religious, cultural or spiritual needs met
- Feeling in control of your environment

The characteristics most commonly associated with residential care or nursing homes are:

- Trained carers nearby to help you and your family (76%)
- Professional medical support on standby (56%)
- Being pain free/having condition managed (54%)
- Having other people around going through the same thing (48%)
- Access to professionals for last-minute concerns (27%)

Residential and nursing homes were least associated with feeling in control of your environment and having your religious, cultural or spiritual needs met. Younger age groups (those aged 18-24) were slightly more likely to have positive associations with residential homes, associating them with feeling in control of your environment and support, and being surrounded by personal things, more so than older groups—perhaps because they have had less contact with them.

It is interesting to note that people have very similar associations with hospitals and residential homes—both are perceived as medical places, with lots of input from different professionals. Where both fall down is in creating a positive care environment—neither was associated with any of the environmental outcomes in our list, such as a calm and peaceful atmosphere, or feeling in control of your environment and the care you receive. Nonetheless, they are an (admittedly distant) second to home, when it comes to being in a familiar environment—suggesting an understanding on the part of the public that many people dying today are those already living in residential care and that is a familiar ‘home’ of sorts.
Allocating scores to different outcomes ranked in order of preference

How does each location measure up overall?

What is apparent is that no single location fulfils all peoples’ needs and preferences for the end of life – but some locations are better at fulfilling them than others. By allocating a score to each of the features that people associate with a good death (from 11 for highest ranked to 1 for lowest ranked), it is possible to calculate the overlap between what people say they want during their final days and how they perceive the ability of each location to deliver on this.

<table>
<thead>
<tr>
<th>Preference</th>
<th>Ranking</th>
</tr>
</thead>
<tbody>
<tr>
<td>Being pain free/condition managed with medication</td>
<td>11</td>
</tr>
<tr>
<td>Surrounded by loved ones</td>
<td>10</td>
</tr>
<tr>
<td>Privacy and dignity</td>
<td>9</td>
</tr>
<tr>
<td>Familiar surroundings/calm and peaceful atmosphere</td>
<td>8</td>
</tr>
<tr>
<td>Surrounded by personal things</td>
<td>7</td>
</tr>
<tr>
<td>Trained carers nearby</td>
<td>6</td>
</tr>
<tr>
<td>Feeling in control</td>
<td>5</td>
</tr>
<tr>
<td>Professional medical support</td>
<td>4</td>
</tr>
<tr>
<td>Access to professionals for last-minute concerns</td>
<td>3</td>
</tr>
<tr>
<td>Having religious, cultural or spiritual needs met</td>
<td>2</td>
</tr>
<tr>
<td>Having other people around you going through the same thing</td>
<td>1</td>
</tr>
</tbody>
</table>

Adding up the scores for the five features most commonly associated with home results in a total score of 42 – the highest of all four locations.

How does ‘dying at home’ score according to the rankings above?

<table>
<thead>
<tr>
<th>Preference</th>
<th>Ranking</th>
</tr>
</thead>
<tbody>
<tr>
<td>Surrounded by loved ones</td>
<td>10</td>
</tr>
<tr>
<td>In familiar surroundings</td>
<td>8</td>
</tr>
<tr>
<td>Surrounded by personal things</td>
<td>7</td>
</tr>
<tr>
<td>Calm and peaceful</td>
<td>8</td>
</tr>
<tr>
<td>Having privacy and dignity</td>
<td>9</td>
</tr>
</tbody>
</table>

Performing a similar analysis for the three remaining locations results in a score of 39 for hospices, 25 for hospital and 25 for residential and nursing homes. What is clear from this is that hospitals and residential homes are perceived to be equally bad at delivering a good death, based on peoples’ top priorities for their care at the end of life, while hospices score only very slightly lower than home – suggesting that they are actually better at delivering the outcomes that people value most than is currently recognised by the general public. Moreover, the overall high score of hospices is driven by good or fair performance across all four aspects of care (medical, practical, personal, environmental), whereas the high score for home is a result of very strong performance in just the latter two of these.

This analysis paints a very different picture from the commonly held understanding of preferred place of death – with home way out in front, and the remaining locations a distant second, third and fourth. People say they value the kinds of things that hospices can deliver – almost equally with home – and yet when asked, far many more people express a wish to die at home than in a hospice.
How does ‘dying in a hospice’ score according to the rankings above?

<table>
<thead>
<tr>
<th>Ranking</th>
<th>Feature</th>
<th>Percentage</th>
<th>Score</th>
</tr>
</thead>
<tbody>
<tr>
<td>11</td>
<td>Being pain free</td>
<td>75%</td>
<td></td>
</tr>
<tr>
<td>6</td>
<td>Trained carers nearby</td>
<td>69%</td>
<td></td>
</tr>
<tr>
<td>4</td>
<td>Professional medical support</td>
<td>55%</td>
<td></td>
</tr>
<tr>
<td>8</td>
<td>Calm and peaceful</td>
<td>52%</td>
<td></td>
</tr>
<tr>
<td>10</td>
<td>Surrounded by loved ones</td>
<td>37%</td>
<td></td>
</tr>
<tr>
<td></td>
<td><strong>Point score</strong></td>
<td><strong>39</strong></td>
<td></td>
</tr>
</tbody>
</table>

How does ‘dying in hospital’ score according to the rankings above?

<table>
<thead>
<tr>
<th>Ranking</th>
<th>Feature</th>
<th>Percentage</th>
<th>Score</th>
</tr>
</thead>
<tbody>
<tr>
<td>11</td>
<td>Being pain free</td>
<td>75%</td>
<td></td>
</tr>
<tr>
<td>6</td>
<td>Trained carers nearby</td>
<td>69%</td>
<td></td>
</tr>
<tr>
<td>4</td>
<td>Professional medical support</td>
<td>55%</td>
<td></td>
</tr>
<tr>
<td>1</td>
<td>Other people going through</td>
<td>48%</td>
<td></td>
</tr>
<tr>
<td>3</td>
<td>Access to professionals</td>
<td>27%</td>
<td></td>
</tr>
<tr>
<td></td>
<td><strong>Point score</strong></td>
<td><strong>25</strong></td>
<td></td>
</tr>
</tbody>
</table>

How does ‘dying in a residential or nursing home’ score according to the rankings above?

<table>
<thead>
<tr>
<th>Ranking</th>
<th>Feature</th>
<th>Percentage</th>
<th>Score</th>
</tr>
</thead>
<tbody>
<tr>
<td>6</td>
<td>Trained carers nearby</td>
<td>75%</td>
<td></td>
</tr>
<tr>
<td>4</td>
<td>Professional medical</td>
<td>56%</td>
<td></td>
</tr>
<tr>
<td>11</td>
<td>Being pain free</td>
<td>54%</td>
<td></td>
</tr>
<tr>
<td>1</td>
<td>Other people going through</td>
<td>48%</td>
<td></td>
</tr>
<tr>
<td>3</td>
<td>Access to professionals</td>
<td>27%</td>
<td></td>
</tr>
<tr>
<td></td>
<td><strong>Point score</strong></td>
<td><strong>25</strong></td>
<td></td>
</tr>
</tbody>
</table>

Total score of five most commonly associated features of each location

<table>
<thead>
<tr>
<th>Location</th>
<th>Score</th>
</tr>
</thead>
<tbody>
<tr>
<td>Home</td>
<td>42</td>
</tr>
<tr>
<td>Hospice</td>
<td>39</td>
</tr>
<tr>
<td>Hospital</td>
<td>25</td>
</tr>
<tr>
<td>Residential or Nursing home</td>
<td>25</td>
</tr>
</tbody>
</table>
Perception versus reality
So far, we have explored the outcomes people value at the end of life, and their perceptions of how different outcomes are associated with different locations.

Interestingly, it seems the popularity of dying at home is not based on a misplaced belief that dying at home is perfect — indeed, it falls short on the public’s top priority: dying without pain. In this instance, evidence suggests the public’s perceptions are correct: the 2012 Department of Health’s VOICES (Views of Informal Carers for the Evaluation of Services) survey of bereaved relatives found that, when asked how well pain was relieved during the last 3 months of life, only 17% of respondents whose loved one had died at home responded ‘completely — all of the time’, compared to 62% whose relatives had died in a hospice, 45% in a care home and 36% in hospital.31

But to what extent is it true that public perceptions regarding different locations are accurate? It is possible that some of the conflicting opinions about hospices, outlined above, are driven by a poor understanding of their role. Which of the public’s perceptions are misplaced?

One way of answering this is to test the extent to which people’s perceptions about different locations are informed by their experience of these locations, or of end of life care more generally. This was achieved in two ways — through polling members of the public and contrasting the responses of those with and without first-hand experience of end of life care, and by speaking to a group of people who had recently lost loved ones, and were receiving bereavement support from a Sue Ryder hospice.

The polling evidence shows that a large proportion of people are able to draw on direct experience regarding end of life care. Two thirds of people (67%) said that they had a personal experience of being with someone during their final days of life. This, predictably, increases with age — from 40% of 18-24 year olds to 83% of those aged 65 and over. The most commonly experienced location was in hospital (39%), followed by at home (22%) in a residential home (12%), and in a hospice (9%). By way of comparison, the actual proportions of people dying in different locations are 60% in hospital, 18% at home, 17% in care homes, and 5% as hospice inpatients.32 The similarity between the proportion of deaths that occur at home, and people who say they have spent time with someone in the period leading up to their death at home, is a good indication that people are having their wish to have family and friends around them met at home. This is far less true of hospitals — despite 60% of deaths occurring there, only 39% of people in the sample had visited someone there during their final days — suggesting that dying surrounded by friends and family is less often achieved in hospital.

In the following sections, we explore the differences in opinion between those with and without first-hand experience of end of life care regarding each of the four locations (home, hospice, hospital, care home).

We use tables with green and red cells to illustrate the difference between opinion and experience. Green cells indicate factors that are more associated with a location by people who have experience of that location (or end of life care generally). Red cells indicate factors that are less associated with a location by people who have experience of that location (or end of life care generally). This means if a location is worse than expected, it will have more red cells; if it is better than expected, it will have more green cells. We only highlight differences that are greater than 2 percentage points (and are therefore statistically significant).

32 B Gomes and I Higginson, 2008
Opinion of dying at home

As can be seen from the table below, people with experience of a friend or relative dying at home were slightly less likely to associate aspects of a good death with dying at home. In other words, dying at home isn't as good as people expect. Adrienne Betteley, Palliative and End of Life Care Programme Manager at Macmillan told us:

“If people were better informed about the experience of dying at home, they might be less inclined to express a preference for it.”

Nonetheless, most of the differences between the opinions of those with and without experience of dying at home are fairly small – suggesting people are fairly well informed about this (and what it might entail), even if they have no experience of it. The fact that people (accurately) expect pain relief to be poor at home, and yet still choose it as their preferred place, suggests in fact that people do not choose a home death from a position of ignorance, but from a willingness to sacrifice this in order to achieve other outcomes they value – an issue we explore in further detail below.

An interesting difference between the opinions of those with and without experience of home death is regarding pain relief. As mentioned above, while pain relief is a top priority for people at the end of life, only 27% of people associate this with the most preferred place of death: home. Even fewer people with no experience of end of life care believe pain relief is deliverable in the home – 20%, and yet 36% of those who have experienced a friend or relative die at home associate pain relief with home death. While this is still very low, it does suggest pain relief at home is better than people imagine, not worse. This makes the popular choice of dying at home even more surprising.

However, the largest discrepancy of opinion in the data above was regarding having your pets and personal things around you at home, which 67% of people with no experience felt would be the case, compared to 54% who had actually had first hand experience. This may well be due to the fact that dying at home often necessitates equipment being brought in to facilitate care (e.g. hoists) or medical support (pain relief, oxygen etc), and suggests that people may not be able to properly envisage the reality of death.

<table>
<thead>
<tr>
<th>What factors do you associate with dying at home?</th>
<th>Total</th>
<th>No experience</th>
<th>Experience any</th>
<th>Experience home</th>
</tr>
</thead>
<tbody>
<tr>
<td>In familiar surroundings</td>
<td>83%</td>
<td>84%</td>
<td>83%</td>
<td>79%</td>
</tr>
<tr>
<td>Surrounded by your loved ones</td>
<td>83%</td>
<td>83%</td>
<td>83%</td>
<td>83%</td>
</tr>
<tr>
<td>Surrounded by your personal things and/or your pets</td>
<td>60%</td>
<td>67%</td>
<td>57%</td>
<td>54%</td>
</tr>
<tr>
<td>Being in a calm and peaceful atmosphere</td>
<td>50%</td>
<td>51%</td>
<td>50%</td>
<td>47%</td>
</tr>
<tr>
<td>Having privacy and dignity</td>
<td>46%</td>
<td>49%</td>
<td>45%</td>
<td>47%</td>
</tr>
<tr>
<td>Being pain free/ managed with medication</td>
<td>27%</td>
<td>20%</td>
<td>31%</td>
<td>36%</td>
</tr>
<tr>
<td>Feeling in control of your environment</td>
<td>22%</td>
<td>21%</td>
<td>22%</td>
<td>23%</td>
</tr>
<tr>
<td>Trained carers nearby to help you and your family</td>
<td>12%</td>
<td>11%</td>
<td>12%</td>
<td>12%</td>
</tr>
<tr>
<td>Professional medical support on standby</td>
<td>8%</td>
<td>6%</td>
<td>8%</td>
<td>9%</td>
</tr>
<tr>
<td>Having your religious, cultural or spiritual needs met</td>
<td>4%</td>
<td>3%</td>
<td>4%</td>
<td>4%</td>
</tr>
<tr>
<td>Access to professionals for last-minute concerns</td>
<td>3%</td>
<td>3%</td>
<td>3%</td>
<td>2%</td>
</tr>
<tr>
<td>Having other people around going through the same thing</td>
<td>2%</td>
<td>1%</td>
<td>2%</td>
<td>3%</td>
</tr>
</tbody>
</table>

Note: Above average: ▲ Under average ▼

33 Demos interview with Adrienne Betteley at Macmillan
When speaking to people who had first-hand experience of dying at home, this became clear. It also became clear why the polling suggested that those who had experience of dying at home were slightly less positive about it. We were told that dying at home creates complications and difficult experiences that no one anticipates. One woman in our focus group described how she had been caring for her husband, who had cancer, for five and a half years before he was admitted to hospital. He spent six weeks there before being discharged to a hospice, but he still wanted to die at home. After two weeks in the hospice, he was able to come home, where he stayed up until his death two weeks later. The things she remembered most about this experience were being surrounded by medical equipment (a bed, a commode, drip stands — ‘all the paraphernalia’, as she described it) — which was not collected for three weeks after her husband’s death; having nurses come in to sit with her husband so that she could sleep; and waiting six harrowing hours for the doctor and the undertaker to arrive after her husband finally passed away during the night.

These practical details — which in any other location would be dealt with swiftly, with support on hand — become highly traumatic when unfolding in one’s own bedroom or living room. They are also things that particularly affect the people who are left behind after somebody dies, often living on in the same house. Knowing this can make death at home seem less appealing for those concerned about their families – research with those very close to the end of life suggesting that fewer wanted to die at home, because they did not want to be a burden on, or leave difficult memories for, their family.34

Opinions of dying in a hospice

As the table below shows, the differences in opinion between those with and without experience of hospice care are larger (i.e. there are more coloured cells, indicating differences of more than 2 percentage points), suggesting hospices are a more misunderstood location. There are also a few more red cells, suggesting hospice experience was not as good as expected — although the positive (green) differences were quantitatively larger than the negative (red) ones.

People with experience of end of life care for a friend or relative in a hospice were less likely to say that being in a hospice means trained carers are on hand, less likely to say that there was medical support and much less likely to say that there was professional support available than people with non-hospice or no experience. However, they were much more likely to say hospices meant a calm and peaceful atmosphere and being surrounded by loved ones. Interestingly, dignity and privacy was better than expected, while peer support was lower — suggesting hospice care may be more individual than expected, and potentially underlining the need for more day care services in hospices, where people have an opportunity to talk to people in a similar situation to themselves.

In the previous section, we saw more people felt there were trained carers in residential homes than in hospices, which we felt may be a symptom of poor understanding of hospices, given their higher level of palliative care expertise compared to care homes. It is particularly interesting then that while 69% across the sample associate hospices with trained carers, slightly less with hospice experience do (64%), but (not displayed in the table above but in the raw data) a much larger proportion with experience of death in a residential home believe hospices to have trained carers on hand (76%). This suggests that, indeed, those with residential care experience recognise the greater level of end of life care expertise among the staff in the hospice sector.

34 C Leadbeater and J Garber, 2010
Lack of awareness was a common theme in our focus group, particularly around hospices. One man’s wife had previously worked in a hospice, and knew that this was where she wanted to die. Her husband felt that they were the exception rather than the rule, though, saying:

“I don’t think the majority of people know enough about hospices. Some people don’t even know very much about hospitals... Now a lot of people probably would have wanted to do the same [die in a hospice, as his wife did], if they had known what a hospice was.

I think many people think a hospice, it sounds a little bit like a hospital, it probably is a little bit like a hospital. So most people are misinformed — or not misinformed, they are just not informed at all.”

What these findings also suggest is that hospice care is substantively different from — and cannot necessarily be compared to — end of life care in other settings. People with experience of hospice care in particular have very different views of this to people with experience of end of life care more generally. Looking at the hospice table above, it is clear that there are three separate views — those with no experience of end of life care, those with experience in all other locations, and those with experience of hospice care. The tables for the other three settings, on the other hand, only demonstrate two distinct views — those with and without experience. The views of those with experience of hospital, care home and home death are not distinct from the views of those with experience generally, suggesting that hospice experience is unique and cannot be anticipated by experiencing other settings.

<table>
<thead>
<tr>
<th>What factors do you associate with dying in a hospice?</th>
<th>Total</th>
<th>No experience</th>
<th>Experience any</th>
<th>Experience hospice</th>
</tr>
</thead>
<tbody>
<tr>
<td>Trained carers nearby to help you and your family</td>
<td>69%</td>
<td>73%</td>
<td>67%</td>
<td>64%</td>
</tr>
<tr>
<td>Being pain free/managed with medication</td>
<td>75%</td>
<td>72%</td>
<td>77%</td>
<td>78%</td>
</tr>
<tr>
<td>Professional medical support on standby</td>
<td>55%</td>
<td>57%</td>
<td>55%</td>
<td>53%</td>
</tr>
<tr>
<td>Being in a calm and peaceful atmosphere</td>
<td>52%</td>
<td>47%</td>
<td>55%</td>
<td>71%</td>
</tr>
<tr>
<td>Having other people around going through same thing</td>
<td>33%</td>
<td>38%</td>
<td>30%</td>
<td>21%</td>
</tr>
<tr>
<td>Surrounded by your loved ones</td>
<td>37%</td>
<td>33%</td>
<td>38%</td>
<td>45%</td>
</tr>
<tr>
<td>Having privacy and dignity</td>
<td>29%</td>
<td>24%</td>
<td>31%</td>
<td>35%</td>
</tr>
<tr>
<td>Access to professionals for last-minute concerns</td>
<td>19%</td>
<td>22%</td>
<td>17%</td>
<td>12%</td>
</tr>
<tr>
<td>Having your religious, cultural or spiritual needs met</td>
<td>10%</td>
<td>10%</td>
<td>9%</td>
<td>9%</td>
</tr>
<tr>
<td>Feeling in control of your environment and support you get</td>
<td>8%</td>
<td>9%</td>
<td>8%</td>
<td>6%</td>
</tr>
<tr>
<td>In familiar surroundings</td>
<td>8%</td>
<td>8%</td>
<td>7%</td>
<td>2%</td>
</tr>
<tr>
<td>Surrounded by your personal things and/or your pets</td>
<td>6%</td>
<td>6%</td>
<td>6%</td>
<td>3%</td>
</tr>
</tbody>
</table>

Above average | Under average
Opinions of dying in hospital
On the whole, differences in opinion between people with and without experience of hospital end of life care were smaller than for hospices and care homes, but larger than for home. This suggests hospitals are the better understood (no doubt as most people have been to hospital during the course of their life, and can envisage what end of life would entail there.) Nonetheless, the larger differences in opinion consistently weighed against hospital – suggesting opinions of dying in hospital are worse amongst those with direct experience of it.

People with experience of end of life care for a friend or relative in a hospital were less likely to say that hospitals give you access to professional medical support or provide you with trained carers on standby than people with no experience at all of end of life care. The biggest difference was around peer support – 61% of people with no experience said that they would expect there to be other people around to share their experience and offer support, but only 52% of people who had experienced hospital care felt that this was the case, suggesting hospital setting are more isolating than expected (but less isolating than all other locations). On the positive side, those with experience were more likely to say that hospitals mean being surrounded by loved ones (but this was still lower than all other locations).

In the absence of experience, peoples’ expectations of hospital’s ability to deliver the things that matter to them (with the important exception of pain relief) – the calm, dignified, loving death that people say they would like – are extremely low. These are confirmed with experience. If anything, from the figures above, people are more disappointed by the medical side of the hospital experience, not the poor performance on the personal and environmental side – which are about as expected.

In our focus group, people differentiated between hospital care in general – which several of them had encountered while caring for other people – and hospital care ‘at the end of life.’ The woman in the group whose husband had died at home had been in and out of hospital with him for appointments and short stays over the five and a half year course of his illness, and said:

“After five and a half years, you get to know people almost as friends – the oncologists and everyone.”

<table>
<thead>
<tr>
<th>What factors do you associate with dying in hospital?</th>
<th>Total</th>
<th>No experience</th>
<th>Experience any</th>
<th>Experience hospital</th>
</tr>
</thead>
<tbody>
<tr>
<td>Professional medical support on standby for emergencies</td>
<td>88%</td>
<td>91%</td>
<td>86%</td>
<td>87%</td>
</tr>
<tr>
<td>Being pain free/condition managed with medication</td>
<td>87%</td>
<td>87%</td>
<td>87%</td>
<td>88%</td>
</tr>
<tr>
<td>Trained carers nearby to help you and your family</td>
<td>70%</td>
<td>72%</td>
<td>69%</td>
<td>68%</td>
</tr>
<tr>
<td>Having other people around going through same thing</td>
<td>56%</td>
<td>61%</td>
<td>54%</td>
<td>52%</td>
</tr>
<tr>
<td>Access to professionals for last-minute concerns</td>
<td>32%</td>
<td>36%</td>
<td>30%</td>
<td>30%</td>
</tr>
<tr>
<td>Surrounded by your loved ones</td>
<td>18%</td>
<td>14%</td>
<td>20%</td>
<td>20%</td>
</tr>
<tr>
<td>Being in a calm and peaceful atmosphere</td>
<td>10%</td>
<td>9%</td>
<td>10%</td>
<td>10%</td>
</tr>
<tr>
<td>Having privacy and dignity</td>
<td>11%</td>
<td>9%</td>
<td>11%</td>
<td>12%</td>
</tr>
<tr>
<td>Having your religious, cultural or spiritual needs met</td>
<td>10%</td>
<td>7%</td>
<td>12%</td>
<td>11%</td>
</tr>
<tr>
<td>Feeling in control of your environment and support you get</td>
<td>7%</td>
<td>6%</td>
<td>7%</td>
<td>7%</td>
</tr>
<tr>
<td>In familiar surroundings</td>
<td>6%</td>
<td>4%</td>
<td>6%</td>
<td>6%</td>
</tr>
<tr>
<td>Surrounded by your personal things and/or your pets</td>
<td>4%</td>
<td>3%</td>
<td>4%</td>
<td>4%</td>
</tr>
</tbody>
</table>

Above average | Under average
She felt that her husband had received better care because of this, saying that he was ‘never on his own’. Other members of the group agreed that having a friendly experience and a ‘human touch’ in hospitals could make these exemplary places for care — but not for death. Among group members, experience of hospital was based on dying in an acute general ward, which influenced peoples’ views of hospitals as places to die.

Perhaps this is because, as Adrienne Betteley of Macmillan explained, there is “confusion between treatment and palliative care.” Hospitals, particularly, are places that exist, in the public mind, to ‘make people feel better’. National Audit Office figures show that 40% of people who die in hospital do not have treatable conditions, but this means that the remaining 60% of hospital deaths are among people who have been admitted for treatment, but then die in hospital. Perhaps peoples’ low expectations around hospitals can be explained by the fact that they expect treatment (i.e. cure) rather than palliative care, and so death is perceived as a failure of care, in a way that it is not in other settings.

Opinions of dying in a residential or nursing home
As with hospices, the differences between people’s opinions with and without experience of care homes in several areas was relatively significant, suggesting respondents had little knowledge of end of life care in residential settings, no doubt due to the fact that few people come into contact with them.

Several indicators scored more highly among those with experience compared to those with no experience. However, looking at the percentages, it is clear that care homes invariably started from a low base — the green cells here indicate better than expected performance, not good performance per se. Expectations on many areas were fairly poor, and proven only slightly better through first-hand experience.

People with experience of end of life care for a friend or relative in a residential home were less likely to say that dying in a home meant access to professional medical support and being in familiar surroundings, but more likely to say it is pain free, that you are surrounded by loved ones and that you have dignity. This suggests expectations of a more medical experience were proved wrong (as outlined above, opinions of hospitals and care homes were fairly similar), while more personal and environmental factors were stronger than expected (as already noted, from a low base).

<table>
<thead>
<tr>
<th>What factors do you associate with dying in a residential or nursing home?</th>
<th>Total</th>
<th>No experience</th>
<th>Experience any</th>
<th>Experience R/N home</th>
</tr>
</thead>
<tbody>
<tr>
<td>Trained carers nearby to help you and your family</td>
<td>69%</td>
<td>73%</td>
<td>67%</td>
<td>64%</td>
</tr>
<tr>
<td>Professional medical support on standby for emergencies</td>
<td>75%</td>
<td>72%</td>
<td>77%</td>
<td>78%</td>
</tr>
<tr>
<td>Having other people around going through the same thing</td>
<td>55%</td>
<td>57%</td>
<td>55%</td>
<td>53%</td>
</tr>
<tr>
<td>Being pain free/condition managed with medication</td>
<td>52%</td>
<td>47%</td>
<td>55%</td>
<td>71%</td>
</tr>
<tr>
<td>Access to professionals for last-minute concerns</td>
<td>33%</td>
<td>38%</td>
<td>30%</td>
<td>21%</td>
</tr>
<tr>
<td>Being in a calm and peaceful atmosphere</td>
<td>37%</td>
<td>33%</td>
<td>38%</td>
<td>45%</td>
</tr>
<tr>
<td>In familiar surroundings</td>
<td>29%</td>
<td>24%</td>
<td>31%</td>
<td>35%</td>
</tr>
<tr>
<td>Surrounded by your loved ones</td>
<td>19%</td>
<td>22%</td>
<td>17%</td>
<td>12%</td>
</tr>
<tr>
<td>Surrounded by your personal things and/or your pets</td>
<td>10%</td>
<td>10%</td>
<td>9%</td>
<td>9%</td>
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<tr>
<td>Having privacy and dignity</td>
<td>8%</td>
<td>9%</td>
<td>8%</td>
<td>6%</td>
</tr>
<tr>
<td>Feeling in control of your environment and support you get</td>
<td>8%</td>
<td>8%</td>
<td>7%</td>
<td>2%</td>
</tr>
<tr>
<td>Having your religious, cultural or spiritual needs met</td>
<td>6%</td>
<td>6%</td>
<td>6%</td>
<td>3%</td>
</tr>
</tbody>
</table>

35 Demos interview with Adrienne Betteley
What have we seen?
In this chapter we have identified what people value at the end of life – being pain free, surrounded by loved ones, and having dignity and privacy in familiar surroundings. Three of four of these are, unsurprisingly, associated with dying at home. People’s top priority – being pain free – is recognised as something home care cannot deliver as well as other locations, but nonetheless, dying at home is the most popular choice. This suggests people are sacrificing the achievement of their top priority for the combined achievement of several of their other priorities. It is clear people feel that medical and practical forms of support are better in hospitals and care homes, while personal and environmental support are better in the home. Hospices occupy a position between the two, scoring well across all four domains but excelling in no one factor in particular. Taken overall, hospices score only slightly lower than dying at home when it comes to delivering the outcomes for end of life care people value – which is surprising given that hospices, hospitals and care homes are distant seconds to dying at home when people express their preferences for place of death alone.

We also explored how first-hand experience affects opinions of dying in different locations. Care homes, by those with experience of friends or family dying there, are viewed as performing more poorly across medical domains and more strongly in personal domains, but still not as good on these fronts as dying at home or hospice. Those with experience in hospitals feel their performance regarding medical support is not as good as is perceived; personal support is poor, but as expected. Dying at home is broadly as expected, with only very slightly worse views across domains among those having witnessed people die at home. Hospices show slightly better than expected environmental and personal support, and slightly worse than expected medical support. Both hospice and care homes had more areas of difference between those with and without experience, suggesting they were the least well understood of the four locations.
What does this mean for the delivery of end of life care?

End of life as a service journey

End of life is not a ‘snapshot’ experience. It can last days, weeks, months or years, and people will need different services, delivered in different locations, depending on how their needs change over time. Somebody who is dying – and their family – are therefore likely to have experience of care in multiple locations, simultaneously or sequentially. They may be attending appointments in hospital while also receiving care at home, or being discharged from hospital into a care home or hospice.

This allows people to compare and contrast different locations – something that we witnessed in our focus group and which seemed to amplify both positives and negatives – after a poor experience of hospital care, one woman described arriving at the hospice with her husband as ‘like walking into heaven’. Heather Richardson, the National Clinical Lead for Help the Hospices, who also works part-time as an advisor to St Joseph’s Hospice in London says she is always surprised at how few complaints the hospice receives, and attributes this to comparisons with a previous poor experience in hospital.

Perhaps more importantly, it also enables people to make more nuanced choices about where they might like to receive end of life care over different periods of time. To state that most people ‘want to die at home’ without exploring what people actually want when it comes to end of life care prevents us from pinpointing ‘when’ people want these things. If people’s preferences change over time, then it is vital that these are explored in order to make end of life care alert to them and able to respond flexibly.

Our survey asked people to differentiate between where they wanted to be in the last year, weeks and days of life. The findings are striking. While the popularity of residential and hospital care remain consistent (and low) over time, it is clear that fewer people want to be at home the closer they are to death, and more people want to be in a hospice. The proportion of people opting for hospice care rises from 4% to 17% to 28% in the final year, weeks and days before death respectively. The proportion of people opting for dying at home falls from 91% to 75% to 63% over the same time frame.

These findings could suggest that peoples’ priorities change over the course of their end of life journey, or alternatively, that their understanding of where these might be best catered for changes. Members of the bereavement support group we spoke to did not feel that the things that were important to their loved ones had changed significantly over the course of their illness, but that external factors could have influenced how these factors were weighed up against each other. For example, the preference for pain relief might become more or less important depending on the course of the person’s illness, as might the emphasis placed on privacy and dignity.

The prospect of dying without support can prompt people to opt out of home care at the last minute, as Adrienne Betteley from Macmillan explained:

Where would you like to be? Home vs. hospice

![](chart.png)

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37 A Paget and C Wood, 2013
“People are consistent in their wishes, but they do panic – and family members especially.”

However, this shift could also be explained by the fact that people are considering the needs of family and carers, and their wish for a home death cedes to the wellbeing of their family who will have to cope with that experience and perhaps live on in that home. As such, an awareness of how dying at home can impact on family members and carers can influence someone’s preferred place of care, without changing their personal preferences, as Heather Richardson explains:

“Many patients feel increasingly unable to be at home, and their concern about being a burden to their family overrides their personal wishes.”

This may be part of the motivation for people opting out of home death at the very end of life, but we should also be aware that this shift occurs among those with and without experience of seeing a friend or relative die. If the theory that people’s preference moves away from a home death through concern for the burden on their family was correct, then one might expect to see a far larger shift away from home death for those with experience of death at home (as they are more aware of the potential burden placed on family members). In fact, this shift if the least marked, with 22% of those with experience of home death opting for hospice rather than home in the last days of life, compared to 28% on average across the whole group.

On the other hand, people with experience of death in residential care are particularly likely to choose hospice care, and also to choose this earlier in the process – 23% would like hospice in the final weeks, compared with 17% on average. Although 28% of the group on average say they would opt for a hospice in the last days, this goes up to 41% with residential home experience.

However, the shift is most dramatic for those with experience of hospice care, with more people opting for hospice care in the final weeks – even years – and not just days. 11% of people with experience of hospice care say they would like their last year there, compared to 4% with no hospice experience, while 30% would want to spend their last weeks there – compared to 17% of those with no hospice experience. This creates a direct reduction in preference for dying at home – 67% of people with hospice experience want to be at home in the last weeks of life, compared to 75% with no hospice experience. Most importantly, at the very end (last days) of life, hospice becomes the preferred place to be for those with experience of the care hospices offer – 55% of this group say they would opt for hospice care, compared to 44% opting for a home death.
Considering these findings in the light of the information gathered above regarding the features people associate with each location, it is clear that hospices are more associated with the unfamiliar, but are also recognized as delivering a pain free, dignified and calm experience – clear priorities for the very end of life. Home comforts, likely to be important for the weeks and months before death but less so at the point of death, explain why being at home becomes less important over time. It is likely to be the case that people with experience of hospices opt for hospice care earlier (in the final weeks or year) because they recognise that many ‘home comforts’ can be achieved in a hospice setting, and people often use them combined with spells back at home – or indeed attend as day patients.

Taken altogether, it is possible that the focus on boosting the numbers of those ‘dying at home’, without considering the time frame in which this preference is made, is denying proper choice to those people who want to have the longer term journey at home, but the last moments away from home. Having the flexibility to cater to this, perhaps very last minute, decision is a vital part of personalised and responsive end of life care – and having a grasp of the potential scale of this last-minute preference for hospice care is important to help prepare services for this eventuality.

Where would you like to be? People with hospice experience.
Informed choice?
Our findings suggest that people are not always well informed about the experience of dying in different service settings. People’s perceptions of different places of death, and what they offer, often depend on whether they have had experience of a friend or relative dying in those locations. Even people’s expectations of dying at home and in hospital places where one assumes the public could easily envisage receiving care, being ill or dying are not always accurate when compared with those who have first-hand experience.

This has significant implications for choice and personalisation in end of life care how can we expect people and their families to make choices and form preferences regarding location, if they do not know what that might entail in terms of the outcomes being delivered?

Experts interviewed in the course of this research confirmed that levels of awareness could have an effect on people’s stated preference for where they want to die, and many felt strongly that if better informed people would make different choices about where they died and with what support. In our polling, this was most apparent for hospices, where people were more likely to opt for that service for themselves if they had had experience of hospice care already. This was similarly confirmed in our focus group, where those whose relative had died in a hospice were extremely positive about it and recommended it as the best place to die but they also acknowledged that they would not have known this in advance. People also explained to us that information on end of life care that could help them to weigh up the pros and cons of different locations was very patchy perhaps driven by the overriding assumption that everyone wants to die at home, thereby rendering unnecessary the provision of information about other settings. Information received also depended a lot on who you happened to speak to.

Word of mouth and recommendations from friends were an important source of information, and it was felt that some professionals (district nurses, GPs, etc) were more helpful than others. People felt that this was really just a matter of luck, and phrases like ‘we were really lucky to have X nurse’ were common.

“The only person who could give me advice was my friend… If it hadn’t been for [her], I wouldn’t have known anything about what was available.”

In addition to poor awareness, and patchy information regarding options, the uncertainties surrounding death also work against people’s ability to make informed choices. How long somebody has to live, from point of diagnosis, is often an unknown variable, which makes it very difficult for patients and their families to plan ahead. Dr Mary Turner pointed out to us that it may be impossible for a GP to know whether they are asking somebody’s family to care for their relative for two weeks or two years. If, as our findings above suggest, peoples’ preferences change over time, and they may want to be cared for in different places depending on how close they are to death, then having some sense of where one is on the end of life journey is an important factor in enabling people to make choices about a move from hospice to home, or vice versa. Sue Ryder and Demos have recently considered in greater depth the issue of how GPs ought to communicate uncertainty and help people plan early on with contingencies, and recommended among other things – improvements in the use of record sharing and training to improve diagnosis, prognosis, and the communication of these.

36 A Paget and C Wood, 2013
Trade-offs
No place of death will offer everything a person needs or wants. The priority people place on personal and environmental outcomes, over and above medical and practical ones, does not mean these latter elements are not also important — and indeed, people’s top priority of being pain free — is a medical issue. In reality, people weigh up priorities and make a choice of ‘best fit’, trading off some outcomes in order to achieve others. This is most clearly the case when it comes to pain relief, which is weighed against other important factors such as being with family and in a familiar place — prompting many people to say they want to die at home even though they are aware poor pain relief may be the result.

Of course, compromise will always be a part of life, and one could argue that the trade-offs made when considering end of life care are no different to the ones made when picking a GP surgery, school, or new house. And yet it is different. The stakes are higher and choices are final. A choice of different services is important for people to select the right package for them, based on their and their families’ personal preferences. But no one should have to choose between pain relief and having ones family with them at such a time, nor between dignity and professional care. If we recognise that such ‘high stakes’ trade-offs — which fundamentally affect people’s wellbeing — are not acceptable, then this has significant implications for the quality improvements needed across all end of life care services and for making choice and personalisation a reality. True personalisation is being able to select a package of care that achieves the outcomes most valuable to you and your family, without being limited by access to services or funding. It should not involve having to choose between locations, each representing a pre-set combination of outcomes, only some of which you want, and which may not be well understood. Ensuring all end of life settings are able to be flexible enough to achieve — as far as possible — good quality care across all four domains (personal, environmental, medical and practical) according to people’s preferences must be the priority for end of life care reform. We explore what this would actually mean for different care settings in Chapter 3.

A non-choice?
Throughout this report, we have considered peoples’ priorities for end of life care and how they make those choices at different points. However, we recognise that this may be far from the reality of many people’s experiences of end of life. As we explained in the outset of this chapter, often individuals and their families do not have the time or the ability to properly weigh up different outcomes and make an informed choice about priorities. The findings of our survey — where we asked people not at the end of life to prioritise different outcomes, objectively, out of context and with time to give proper consideration to their answers, is a far cry from how many end of life choices are made. Indeed, our interviews with experts and focus group with bereaved relatives suggested that often, no choice was made at all, or if it was, it was made at a point of crisis or emotional stress and without all the facts to hand.

“I think you’re so confused at the time you don’t really [weigh up preferences], you just go with the flow.”

Heather Richardson, the National Clinical Lead for Help the Hospices, felt that a tendency to allow professionals to make all the decisions is particularly pronounced among older people, who are accustomed to being passive recipients of healthcare, rather than active users. As one older woman in our focus group told us:

“At that time, you don’t actually know that people will let you down. You believe what they [doctors] say, and you don’t follow it up, because what they say — you visualise that they are much cleverer than you, and know far more what they are talking about.”
There are two interrelated implications for end of life care here. The first is that in difficult or emotional circumstances, people may not have the time or be able to weigh up different outcomes and preferences and develop a bespoke care package. In such circumstances, thinking in terms of location (home, hospital etc) may be an easier task. In our focus group with bereaved relatives, the group had strong feelings about place of death (home or hospice, but definitely not hospital, and probably not a care home either), but when asked about their, or their loved ones’, preferences for how they died (in whatever location), people were more vague, using broad terms like ‘comfort’ and ‘dignity’. This may be a result of becoming accustomed to a system which articulates preferences in terms of location and never having been asked to think about distinct outcomes before. However, it was certainly also the case that people’s experience of end of life care for their relatives suggested that it was often not conducive to making rational, well-considered decisions. Ideally, everyone would have an end of life care journey conducive to choice and personalisation, with earlier diagnosis, good advance care planning, practitioners that support decision making and so on.

But in reality, there will always be families who the system lets down, or who have circumstances (sudden, unexpected choices following a stroke or heart attack) which do not allow for the time to plan and choose. It is critical therefore that all options — hospital, hospice, care home and one’s own home — are good quality. Each location must strive to ensure that they deliver on all four domains of care as far as possible, so that everyone has a more positive end of life experience regardless of location and regardless of whether they have been able to exercise choice.

In the following chapter, we explore how each location might work to improve the quality of its end of life offer.
Chapter 3
Conclusions and recommendations

This report has provided new insights – unpacking the what from the where in end of life care and exploring the dynamic between the two. We believe this is an important step forward in the debate regarding two parallel agendas: ‘a good death’ and dying at home. We have three conclusions to make in light of these insights.

Conclusion one:
We must define end of life care by what, not where

Being able to choose where one wants to die is important, and the majority of people do want to die at home. But the preoccupation with where people die as a proxy for quality is undermining the development of end of life care. It prevents proper scrutiny of dying at home and whether this experience could be improved, to deliver the type of care people actually want. It also means proper policy and practice development in other settings in neglected, as they are not viewed as desirable places to die in and of themselves. This overlooks the reality that the majority of people do not die at home, and even if home deaths were increased, it will always be the case that some people will not be able to – or will not choose to – die at home. The outcomes for these groups cannot be overlooked. Everyone is entitled to help achieving the outcomes they value, regardless of where they die.

The increased focus on ‘outcomes’ instead of ‘services’ across health and social care over the past few years has culminated in the Care Bill 2013. It is an important step in ending a regime of trying to fit people into services, and promoting a system where services are expected to fit around people and what they want to achieve. But this outcomes focus and personalisation has yet to be fully brought into end of life care – to do this, the sector must move away from using ‘location of death’ as the only outcome to strive for. Dying in the place of one’s choosing is important, but so too are other factors – such as dying without pain, in dignity, with family and so on. This research shows that we must not assume ‘preferred place’ automatically achieves all of these other outcomes simultaneously.

With this in mind, the proposed inclusion of ELC05 in new indicators for CCGs in 2014-15 (Of people who have stated their preferred place of death, the proportion who died in their preferred place of death) is not an adequate indicator to capture a good quality experience. We recommend:

• ELC05 is replaced with an indicator which puts personalisation at the heart of end of life care and leads on outcomes, not location – indicators should focus more on things like the proportion of people who have been able to express their wishes for the end of life (e.g. through Advance Care Plans) and the proportion of people who have had their wishes for end of life met.

• Health and Wellbeing Boards drop their targets to increase death at home or preferred place of care, and replace them with targets to improve personalisation of end of life care, defined by the achievement of outcomes people want at the end of life.

Conclusion two:
We must give people real choice

The sample for the survey discussed in this report was composed of people who are not terminally ill, and who had the time to reflect on their responses. It is a good start to a debate in which we decouple outcomes from location and the first step towards a more outcomes-based and personalised approach to end of life. Nonetheless, it cannot replace actually asking patients and their families what they want in the months, weeks and days before death.

Mary Turner from the International Observatory on End of Life Care points out that the views of carers and healthy people tend to be used when defining a good death, as most people who are dying do not take part in research. In her view, asking an ill population, as opposed to a healthy one, about their preferences at the end of life would show higher levels of concern for things like safety and security, symptom management, having professionals around and not being a burden on their family. This change towards the end of life is more to do with how different needs and preferences are prioritised, rather than things ceasing to be important – it is the conditions of the trade-off that change, not the preferences themselves. For example, Mary was part of the National Review Team for Preferred Place of Care, which in 2007 changed its name – and its emphasis – to Preferred Priorities for Care. During the initial rollout, people who were dying were attaching conditions to their preference for where they would like to spend their final days – saying, for example, “I would like to die at home, unless my family become unable to cope”.
We cannot, therefore, use the findings in this report to define a good death. But we can use it as evidence that enabling people to die in their preferred location is not enough to deliver a good experience for everyone at the end of life. This requires some of the aspects included in the new proposed ELC28 indicator for CCGs, such as information, communication and co-ordination of care, but also something more: an ingrained culture of personalisation which underpins these other factors. This culture is one which moves away from paternalism and gives opportunities for people to make real, informed decisions; one which manages not minimises risks; and one which empowers patients and their families to take control over their support. We recommend, therefore, that:

- Person-centred practice in end of life care is placed front and centre in new CCG indicators, and Health and Wellbeing Board strategies, with more obvious links to the NICE Quality Standard for End of Life Care (in particular statement 5 — that people approaching the end of life are offered timely personalised support for their social, practical and emotional needs, which is appropriate to their preferences, and maximises independence and social participation for as long as possible).

Conclusion three: We must achieve quality across all care settings

As we explain in Chapter 3, personalisation at the end of life will never be possible for everyone. The nature of sudden illness and death, and the emotional stress this entails, means there will always be some people who cannot or will not take control of their situation. It is for this reason that end of life care must improve across the board — so that everyone has a good experience, regardless of where they die.

To achieve this, and returning to the four domains we explore in Chapter 2, it is clear that the environmental and personal aspects of care needs to be brought into medical settings, and the medical and practical needs to be brought into personal settings. Each person requires a varying balance of these, based on personal preferences and priorities, but no location should present mutually exclusive choices (e.g. you can either have pain relief, or your family nearby).

Below we set out some recommendations for commissioners, policymakers and providers to improve quality of care in different sectors. The aim of these recommendations is to create a high quality experience across all four settings, and to better align the care that they provide with how people themselves say that they would like to die.

Pain relief and professional support

Although home is the favoured place of death for the majority of the public, people recognise that they are unlikely to have pain and symptoms managed effectively at home, or easy access to the practical or professional support that they might need to draw on. With this in mind, we recommend:

- An increase in the commissioning of floating “hospice at home” support so that more people can access high quality palliative care, and professional and medical support, in a home setting.

Hospice at home services are highly effective in boosting the number of people who can die at home (up to 74% from 28% in some cases). A national hospice at home service serving up to 90,000 people a year is estimated to cost £152 million, a small price to pay to reduce the £20 billion the NHS spends annually on providing end of life care in hospitals, in many cases unnecessarily and due to people looking after loved ones at home becoming overwhelmed.
Supporting carers

The burden on carers – both formal and informal – can undermine the experience of dying in care homes and at home respectively, and can often lead to emergency and unnecessary hospitalisation. We recommend:

- Specific support for informal carers of those nearing the end of life. This should be in the form of out of hours support and access to a single coordinated source of advice, such as the Sue Ryder Partnership for Excellence in Palliative Support (PEPS) scheme, as well as training in the practicalities of end of life care and ways to cope,\(^{43}\) to reduce carers feeling overburdened.

PEPS is based on electronic patient records, shared between practitioners and held by the individual. This would improve continuity of care and increase the chances of people staying in control of their care — improving end of life experiences across all care settings.

**LECKHAMPTON COURT HOSPICE**

Sue Ryder’s Leckhampton Court Hospice has been offering a hospice at home service to residents in Cheltenham, Gloucestershire who are approaching the end of life since 2008. Trained carers who receive tailored training from Sue Ryder provide practical, personal and psychological support to individuals and their family carers so that they can remain at home during their final weeks and days. Importantly, the hospice carers offer a quality visit, where they are not watching the clock. Each care package is tailored to the specific needs of the individual and their family, providing a safety net for patients at home, if they have any concerns or questions.

The hospice-at-home carers form an extension to the district nursing team who are on hand to help educate the hospice carers on a range of subjects relevant to families’ individual needs and circumstances such as massage techniques to help ease discomfort or to minimise the side effects of illness. Hospice carers do not administer medication, but receive specific training on the care needs of patients and support them to work towards meeting these needs. The service complements the work of other health and social care professionals, with the district nurse remaining the patient’s key contact and care co-ordinator.

The service is instrumental in helping people to avoid unnecessary hospital admissions. Without a hospice at home service individuals and their family carers are more likely to respond to a situation at home by calling a GP. An out-of-ours GP may not know the individual’s needs, nor how well they are supported, and so may be inclined to refer them to hospital. The hospice at home service continues to receive positive feedback from the district nursing team, and commissioners are also supporting the expansion of the service. Hospice at home has seen a year-on-year increase in individuals accessing the service. In 2012/13 each individual received, on average, the equivalent of just under 10 days of care, with the hospice overall delivering 6,000 hours of care.

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\(^{43}\) A Paget and C Wood, 2013
The difficulty for patients, for families, for carers — prior to PEPS — was accessing the individual health professionals accessing the individual health professionals out there because they had so many phone numbers.”

(Practitioner)

While supporting informal carers is important, getting end of life care right in residential care is vital due to demographic change. In the coming years, more very old people, and those with dementia, will be facing the end of life having lived for a while in a residential setting. For them, dying ‘at home’ will mean dying in their care home. The findings in this report suggest that while many of the personal aspects of end of life care were as good (or slightly better) than expected in a care home, the level of professional and care support was lacking. And emergency hospital admissions from care homes remain a problem, as residential care workers — like informal carers — can feel overwhelmed when caring for someone nearing the end of life. We therefore recommend:

- Improved end of life training for care workers in residential care. Due to staff turnover and an environment that may not be conducive to professional development, this may be hard to achieve. CPD end of life care training is already available for experienced care workers, but such training should be available earlier on, in entry levels.

Hospices could play a role here in providing more basic awareness-raising courses, opportunities for rotations or shadowing, building links between homes and hospices, and so on. We therefore also recommend:

- Hospices offering a variation of the ‘hospice at home’ scheme for care homes. This would provide care workers with important hands-on training and advice regarding palliative care, and give care home residents access to specialist support — reducing the risk of hospitalisation. CCGs have a role to play here by taking a more proactive approach to the commissioning of this type of training.

- Care homes and hospices developing working partnerships which enable care home residents to be referred to day services in hospices, so that they can visit to receive specialist condition management and other support while still living in their care home.

Informed choice

The survey findings in this report suggest that people are not very familiar with dying in care homes or in hospices, and many people have particular assumptions regarding the care delivered in these locations. Without better information regarding the pros and cons of hospices, hospitals, care homes and home deaths, then patients and their families cannot make a real choice regarding the service setting which best delivers the type of care they want. We recommend:

- An improved focus on personalisation and choice at the end of life — as recommended above — must entail improved information regarding different service options and the types of support on offer, rather than an overarching focus on dying at home.

Local authorities’ duty to provide information regarding care services (as laid out in the Care Bill 2013) should include the full array of end of life care options in the same way as they would about any other aspect of adult social care — that is, with a focus on promoting informed choice based on the outcomes people want to achieve.

In particular, direct experience of hospices leads people to feel more favourable about hospice care for themselves — suggesting that some people may be missing out on support that they would value if they were better informed. Few people will ever enter a hospice before the end of life (unlike hospitals) — hospices therefore have to work harder to improve people’s understanding early on. We therefore recommend:

- Hospices outreach to the local community and to health and care staff. This may include offering hospice at home...
services (as mentioned above), and day-services, so that those at the end of life actually get to see, first hand, what hospice care involves and increase a sense of familiarity earlier on in their care journey. Again, some of these (e.g. hospice at home) are things that CCGs can support through commissioning decisions, so that existing best practice can be replicated more widely.

- Hospices should also consider ‘opening up’ to the community. Many hospices have gardens and meeting spaces which could be used by the wider community when free, to host anything from play rehearsals to Scout meetings.

**Sue Ryder Wheatfields hospice – satellite clinics**

Sue Ryder Wheatfields hospice runs a satellite palliative care clinic out of a care home in South Leeds. The clinic was set up to reach out to and provide specialist palliative care services to people closer to their home. The clinic offers outpatient appointments with a specialist palliative care consultant and for complementary therapy, an opportunity for individuals to be assessed or reviewed by a clinical nurse specialist, a drop in facility for support, advice and complementary therapy and signposting to other services. The service increases access to specialist palliative care within the local community.

Some hospices are already pioneering in this area but, if this were more widely adopted, it would help raise awareness of the services hospices provide, break down barriers in perceptions that hospices are places ‘to die’, and give people a sense of familiarity with hospices which could help inform choice. In the face of reduced local authority funding, sparking closure of libraries, community centres and places traditionally used by local groups for meetings and rehearsals, hospices could become an important community resource.

- Care homes should also open up to the community. Many care homes have unused spaces which community groups could utilise without disrupting the residents.

The idea here again would be to make care homes less unfamiliar to the wider public, so that people understand the type of support they offer, and to break down misperceptions, helping people to make informed choices, meetings and Christmas fayres.

**Bringing the ‘familiar’ into alien settings**

People clearly value being in familiar settings, with their families, when it comes to end of life care – even if this means sacrificing medical care or pain relief. Settings that perform well in this latter respect, such as hospices and hospitals, must think carefully about how to cater to people’s desire for the familiar so that people do not have to make such sacrifices. For example, Sue Ryder have focused a lot of their work in this area on improving the experience of mealtimes in hospices, by catering to peoples’ choices. We recommend that:

- Hospices should develop opportunities (and promote these within the community) for peer support – not just for carers and bereaved, but for those at the end of life. They should also develop schemes which enable people both to become more familiar with hospices (e.g. through day services) and to personalise their surroundings”, assuaging concerns regarding hospices being unfamiliar environments.

A considerable amount of work needs to be done to improve the quality of end of life care in hospitals. Expectations of the care received there is low, and experience confirms this. While improvements in informal carer support, training among staff in care homes and support for GPs to diagnose dying more effectively should all help to drive down hospital admissions among those at the end of life, it is inevitable that many people will still die – and may in fact want to die – in hospital. Current policy efforts on this front seem to labouring under the assumption that end of life care in hospital can be eradicated, thereby removing the need to improve the hospital offer. As this is clearly not the case, we recommend that:

- Innovations such as the King’s Fund Enhancing the Healing Environment work on Environments for Care at the End of Life (ECEL), which looks at the physical design of palliative care suites, facilities for visitors and outdoor spaces in hospitals become standard practice.

- Training for hospital staff at all levels in communicating about the end of life and delivering care holistically for this group – rather than just within the bounds of clinical practice – ought to be a core part of medical and nursing undergraduate curricula. The GMCs review of the quality of medical training, reporting at the end of 2013 in response to the Francis Review, is an opportune time to consider whether medical training is responding to the demographic pressures which will see higher numbers of deaths in the coming years, particularly among those most at risk of hospitalisation (e.g. those with complex needs).

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45 A Paget and C Wood, 2013
46 The King’s Fund, Environments for care at end of life: The King’s Fund’s Enhancing the Healing Environment Programme 2008-2010, London: The King’s Fund, 2011
Health trusts should explore opportunities for rotations and shadowing in hospices for staff most in contact with older patients and those with terminal illness to help them learn the principles of high quality holistic support.

The Implementation of the Francis review recommendation that GPs should monitor the care of their patients with acute care needs in hospital should make specific mention of those at the end of life. GPs must be alerted when patients on their local end of life care registers are hospitalised to ensure care is coordinated and discharge to hospice or home is facilitated.

Environments for care at the end of life

With funding from the Department of Health, the King’s Fund have been running the Enhancing the Healing Environment programme since 2000. The aim of the programme is to enable local multidisciplinary teams (led by clinical staff) to work with service users in order to improve physical care environments in hospitals.

One strand of the programme has looked specifically at improving environments for care at the end of life (ECEL). Between 2006 and 2008, the King’s Fund piloted 25 projects across 19 NHS Trusts and one prison. Each project looked at improving one part of the end of life care environment, ranging from palliative care suites and day therapy units to bereavement and mortuary facilities. Of the 25 projects, 12 focused on improving palliative care facilities (as opposed to mortuary or viewing areas) – seven of which were spaces used exclusively or primarily by patients rather than relatives (one day care unit, five palliative care suites and one therapeutic garden).

The mix of patient- and relative-facing areas chosen reflects the fact that feedback on end of life care environments comes from bereaved relatives. Common complaints from relatives are that there are too few private spaces for visitors in hospitals, waiting in corridors and returning to the ward where a loved one has recently died can be very distressing, and viewing areas are frequently dingy and neglected.

A literature review carried out by the King’s Fund as part of the project identified some important elements that are valued by dying patients and their families, including home-like environments, on a domestic or human scale, natural light, soothing colours and artwork, gardens and outdoor spaces, and privacy – both for family members, and for the patient. All of these elements were incorporated into the 25 pilot projects.
Personalisation at the end of life is harder to achieve than in many other care settings. Events can unfold rapidly, leaving traditional mechanisms for personalisation — such as personal budgets and coproduced care plans — redundant. In their place, providers and commissioners must strive for a culture of personalisation that puts individuals and their families at the heart of services. To achieve this, we must really get to the heart of what people want and value at the end of life. But our reliance on dying at home being universally popular has led us to conflate quality with place, inhibiting our understanding and thwarting attempts to truly personalise end of life care.

Through this research Sue Ryder seeks to change this, by moving the debate on from the where to the what. The implications for policy and practice are significant and challenging, but it is a challenge we must tackle head-on if end of life care is to keep up with both demographic change and with the wider move to personalisation in health and social care more generally.
Appendix 1: Demos polling questions

These are the questions used in the polling carried out by Populous for this project. We received responses from 2,038 adults.

1. Do you have a personal experience of being with someone (e.g. a relative or friend) during the last days of their life? If so, where did they die?
   a. Yes – in hospital
   b. Yes – at home
   c. Yes – in a residential or nursing home
   d. Yes – in a hospice
   e. No
   f. Not say

2. If you had a terminal illness in later life, which of the following would be the most important to you regarding how you spend your final days? (Please pick your top 4 priorities)
   a. Being pain free/having your condition managed with medication
   b. Surrounded by your loved ones
   c. Having privacy and dignity
   d. In familiar surroundings
   e. Being in a calm and peaceful atmosphere
   f. Surrounded your personal things and/or your pets
   g. Trained carers nearby to help you and your family
   h. Feeling in control of your environment and what support you get
   i. Professional medical support on standby for emergencies
   j. Access to professionals for last minute concerns about your family or legal affairs
   k. Having your religious, cultural or spiritual needs met (e.g. having a priest with you)
   l. Having other people around you going through the same thing, to talk to and provide support
   m. Other

3. [Respondents are presented with the four responses they selected in the previous question] Of the four priorities you have chosen, are you able to rank them in importance (1 being the most important, 4 being the least important)?
   a. Being pain free/having your condition managed with medication
   b. Surrounded by your loved ones
   c. Having privacy and dignity
   d. In familiar surroundings
   e. Being in a calm and peaceful atmosphere
   f. Surrounded your personal things and/or your pets
   g. Trained carers nearby to help you and your family
   h. Feeling in control of your environment and what support you get
   i. Professional medical support on standby for emergencies
   j. Access to professionals for last minute concerns about your family or legal affairs
   k. Having your religious, cultural or spiritual needs met (e.g. having a priest with you)
   l. Having other people around you going through the same thing, to talk to and provide support
   m. Other

4. Thinking about where people spend their last days. Which characteristics do you most associate with the following places? [Respondents select four characteristics from the list in the previous questions]
   a. At home
   b. In hospital
   c. In a hospice
   d. In a residential or nursing home
5. Which characteristics do you least associate with the following places? [Respondents select four characteristics from the list in the previous questions]
   a. At home
   b. In hospital
   c. In a hospice
   d. In a residential or nursing home

6. If you were living with terminal illness, in which location would you like to be cared for during each of the final stages of your life?
   a. In the last year of your life [home/hospice/hospital/residential or nursing home]
   b. In the final weeks of your life [home/hospice/hospital/residential or nursing home]
   c. In the final days of your life [home/hospice/hospital/residential or nursing home]

7. If you were living with a terminal illness and needed help with activities of daily living such as cooking, doing the shopping, bathing and dressing yourself, would you be happy for your family members to carry out these tasks?
   a. Yes, I would be happy for them to do this
   b. Do not have any family who could do this for me
   c. No, I would not be happy for them to do this
   d. Don’t know

8. For those who would not be happy for family members to carry out these tasks, why not? [Free text question]
Sue Ryder would like to thank Claudia Wood and Jo Salter from Demos for preparing this report. We are grateful for their dedication and tireless commitment.

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