Foreword

In 2017 we mark the 50th anniversary of the modern hospice movement. Over that time hospice care has transformed the way we live until we die, our attitudes to death and bereavement, and supported millions of people and their families in their physical, emotional and spiritual needs at their time of greatest need.

As we look forward to the next 50 years it is timely to take stock. Are we reaching everyone who could benefit from hospice care? How do people want to receive care? What are the needs of their carers, loved ones and communities?

In assessing the current available evidence about hospice care, we can see that hospices achieve a great deal, have adapted their care to respond to the changing needs of the population, and driven better end of life care in hospitals, care homes and people’s own homes. But there is so much that we do not know or have not measured.

The hospice movement needs to know more about itself, and shout about what it does. While we can count the number of people accessing the services hospices provide, we cannot yet count the number of carers we support, or demonstrate how hospice support into settings such as care homes improves experiences of end of life.

This brief report is a starting point. It is the first step in a journey to understanding the full depth and breadth of hospice care, and its essential role in the lives of people in the UK. As we develop the future strategy for the hospice movement together with our members, improving evidence and data to be able to tell our story in ever more impactful ways will be a priority for Hospice UK.

Tracey Bleakley
Chief Executive, Hospice UK

What is hospice care

Hospice care seeks to improve the experience of people living with terminal and life-shortening conditions, and helps people to live as well as they can, to the end of their lives. It understands that a person’s physical, emotional, spiritual and social needs are of equal importance, and supports carers, family members and friends – through a loved one’s care, during bereavement and into remembrance.

Even at the end of our lives we have hopes and aspirations. We want to be where we feel most comfortable, do what brings us joy, and have those we love by our side. We want to be, despite everything, ourselves.

Hospice care is defined by its work to fulfil such hopes, and it is the mission of hospice care to improve people’s experience of death, dying and bereavement. It has developed over the last 50 years to provide care and support to more people, in many different settings – in hospice beds, at home, in care homes and in hospitals – and for ever more complex needs.
Introduction

In this report, we set out the vital contribution that hospices in the UK make to supporting people with terminal and life-shortening conditions. To understand more fully the scope, scale and opportunities for hospice care in the UK in 2016, we have undertaken analysis of the hospice responses to the Minimum Data Set (MDS) for Specialist Palliative Care Services. The MDS is produced annually in partnership between Public Health England, the National Council for Palliative Care and Hospice UK, and covers England, Wales and Northern Ireland. When combined with our own data on hospice care in Scotland, this analysis allows us to postulate the extent of care provided by hospices in the UK, and to understand some of the challenges faced and potential solutions. We present these findings here, alongside key contextual information, as a snapshot of hospice care in the UK.

Hospice care in the UK is predominantly provided by charitable hospices that rely on the generous support of the local communities that they serve. Hospice UK works with all these hospices, and a number of NHS hospices. In this document, when we talk about the scope and scale of the care provided by hospices, we mean the care provided by our members. There is no reliable data source on the scale of specialist end of life care in the NHS across the UK. More detailed explanation of the methodology and limits of the MDS data can be found in the methodology at the end of this document.

In 2015-16 charitable hospices in the UK provided expert end of life care to an estimated 200,000 people; this potentially represents around 44 per cent of all people likely to need expert end of life care. In addition, hospices also provided bereavement support for 41,000 people, and reached many more people indirectly or informally through support for families and carers.

There are multiple entry points to hospice care. Depending on a person’s individual need and circumstances they might, for example, have a period in inpatient care, followed by outpatient care, and care in their home. Another person might use day hospice and inpatient care, and yet another might only have contact with community-based hospice care. The MDS does not allow us to identify where individual people have used more than one service. We have attempted to identify unique individuals in each of the clinical services by counting only those records which indicated that the patient had been discharged from the service. While this methodology likely minimises some double counting, we know there is overlap of individuals between services; however, the sum of these categories allows us to illustrate the scale of care provided by hospice care across its broad range of services.

Hospice care is provided by multidisciplinary teams – made up of nurses, doctors, social workers, physiotherapists, occupational therapists, counsellors, chaplains, complementary therapists, volunteers, and
more – working together to support individuals and their loved ones. Hospices are unique among charitable providers of healthcare because they contribute so significantly to the health economy. Last year, hospices in the UK spent £868 million on caring for people, their carers and families.

Hospice care goes far beyond inpatient beds – 80 per cent of clinical care is through community-based/at home care, day hospice or outpatient hospice care (see Figure 1).

Figure 1: Proportions of people supported through the main hospice service types (adults’ hospices)
Hospice care in the UK 2015-16: Key statistics

- 200,000 people accessed direct support from hospices
- 44% of those who might benefit from expert end of life care currently receive some form of support from hospices
- 48,000 people accessed inpatient hospice care
- 2,760 beds in inpatient hospices
- 16,000 people seen in hospital settings by hospice services
- 32% of people returned home after a spell of care in an inpatient hospice
- 796,000 overnight stays in inpatient hospices
Please see the methodology at the end of this document for details of these calculations.


159,000 people were seen by community care (home care and hospice at home)

948,000 community/home visits were made by charitable hospices

35,000 people were seen in day hospice

41,000 people used bereavement support provided by hospices

54,000 people were seen in outpatient hospice

£868 million was spent by charitable hospices on providing services 2014-15*

£2.7 million Needs to be fundraised by charitable hospices every day*

33% The statutory contribution to the costs of running charitable adults’ hospices*

17% The statutory contribution to the costs of running charitable children’s hospices*
Death and dying in the UK

Anyone with a condition that is terminal or life-shortening could benefit from hospice care and support. In 2015, just over 600,000 people died in the UK; of these, experts estimate 75.5 per cent of all deaths, or 455,000 people, will have had a ‘predictable death’ in that their death was not sudden and their health was known to be poor.4

The final report of the Palliative Care Funding Review also proposes that 75 per cent of all deaths should be considered ‘expected’. Applying the formula set out in the final report of the Review, which looked at England only, to UK-wide figures, we conclude that there are potentially 100,000 people who have an unmet need for expert end of life care across the UK – someone in five of all predictable deaths.5 While much end of life care is successfully delivered by generalists, such as GPs and nurses, there are times when specialist care is needed. (See figure 2)

‘Unmet need’ means many things. It can mean that a person has complex pain issues which might benefit from the specialist skills of a consultant but no referral is made. It can mean that without being supported to understand the processes of end of life, a family calls an ambulance for a person experiencing breathlessness, leading to them then dying in a busy accident and emergency department instead of peacefully at home. It could mean a person dies sooner than they might because needs like nutrition and mobility were not given the priority required.

As we are all living longer we have increasingly complex needs at the end of life.6 At the same time, social change means that people are more likely to live alone in older age, and families are increasingly likely to have greater geographic spread – it is more likely that children are further away than in previous generations.

The number of people with a need for expert end of life care is also likely to increase, as the number of people dying each year is projected to rise over the next 25 years. This changing demographic means that there will be more people living and dying with multiple conditions with less local family support. All this will change the end of life journey for large numbers of people, and presents a clinical challenge too, as it becomes increasingly difficult to identify the ‘dying phase’.

People with a cancer diagnosis are currently overrepresented in hospice care referrals. Charitable hospices estimated that the vast majority of the referrals they received in 2015-16 were for people with cancer (see figures 3 and 4). Hospices report that referrals for people with a non-cancer diagnosis are slowly increasing, but cancer remains the primary diagnosis in most people they see.

Key facts:

- In 2015 cancer caused 28 per cent of deaths, and circulatory diseases (heart disease and strokes) caused 26 per cent of deaths;7 but cancer was the primary diagnosis in the majority of referrals to hospice care.
- Too many people who would benefit from hospice care are not being identified, assessed or referred.
- People with a non-cancer diagnosis tend to be referred to hospice care in fewer numbers and later than those with a cancer diagnosis.8
Figure 2: Comparison of indicators and estimates of need for expert end of life care

Deaths UK (2015)
‘Predictable’ deaths
Number of people accessing hospice services
Number of people not seen in palliative care at end of life
Number of those not seen who may need expert end of life care

Figure 3: Proportions of people seen in community-based hospice care by cancer/non-cancer diagnosis

Cancer
Non-cancer
2009
2016
ONS, causes of death 2015

Figure 4: Proportions of people seen in inpatient hospice care by cancer/non-cancer diagnosis

Cancer
Non-cancer
2009
2016
ONS, causes of death 2015
The majority of hospice care in the UK is delivered in a wide variety of settings by charitable hospices. As an indicator of the reach of hospice care, the map below shows the inpatient settings and community team bases of those providers who are members of Hospice UK. This includes all charitable providers of hospice care and 24 NHS providers.
Hospices currently provide support to just over four in 10 (44 per cent) people who it is estimated could benefit from expert end of life care in the UK, and another 41,000 receive bereavement care through a hospice service.

Hospices also provide a wide range of less formal support to the loved ones of the people they care for, such as casual drop-in sessions, wellbeing sessions, remembrance gatherings, and the day-to-day support of friends and family. Most of this activity is not currently counted at a national level, but hospices estimate that for every person for whom they provide direct care, two others are supported informally.

Figure 5: Estimated numbers of people cared for in each of the five main clinical service types (adult hospice care)
Community and hospice at home

People do not have to go to a hospice building to receive hospice care. Most people want to die in their own homes.9

“Before James died my two adult children came home and were most anxious that enough was enough and dad had to be taken into hospital or hospice. That wasn’t his wish, that wasn’t the way he wanted to end his life. He wanted to be at home and so the hospice at home team made that possible for us, but also helped me explain to the children that we could all manage this together as a team [...] and we were all engaged in this effort to make it as good a death as possible.”
– Mrs E.G

People who receive care at home are more likely to be able to die at home.10 This depends on a number of factors including personal preferences, family/carer capacity and importantly, support from expert services.

Key facts:
• 159,000 people were seen by community-based hospice care services (home care and hospice at home).
• 948,000 community/home visits were made by charitable hospices.
• The average length of care in community-based hospice care services is 91 days, but around one-third of people receive care for less than two weeks.

Inpatient hospice care

Some people have complex symptoms that cannot be controlled at home, or may not have people around them who can support them at home. In these instances, care in an inpatient hospice bed may be appropriate.

Hospice inpatient beds help people to manage pain and other symptoms, and provide respite for carers. For almost one-third (32 per cent) of people who are admitted, a period in a hospice inpatient bed is brief and they return home.

Key facts:
• Hospice UK members provide 2,760 inpatient hospice beds in the UK.
• 48,000 people accessed inpatient hospice care in 2015-16.
• 32 per cent of people returned home after a period of care in an inpatient hospice bed.
• Hospices provided 796,000 nights of care in 2015-16.
• Inpatient hospice care makes up 15 per cent of the clinical care provided by hospices.
• The average length of stay in an inpatient hospice is 15 days, but 25 per cent of stays are less than five days.
“I really hadn’t wanted to leave my home. I’d been sleeping in a specially-adapted bed in the sitting room of our cottage. My husband had given up his job to look after me and I was really anxious about handing over my care. Following a risky but successful operation, the pain in my legs became intolerable, I couldn’t walk and emotionally and physically, my husband was exhausted.

“I came to the hospice for pain management, symptom control and respite care and initially I wasn’t with it at all. I was tearful, anxious and on a cocktail of nine painkillers, which weren’t working and were making my breathing erratic. The care helped calm and reassure me, enabling me to start processing what I knew and understand more about what was going on in my body. The hospice also helped me stop worrying about my husband and two sons.

“The whole medical team worked so hard to come up with a solution to stop my pain, trying me on different combinations and doses of drugs to make me more comfortable. I’ll never forget the feeling of waking up after sleeping through the night – pain-free – for the first time in months.

“Once my pain was under control, I started having massages to help me relax. I took part in workshops, which really helped lift my spirits, and I started physiotherapy to give me the confidence and determination to start getting back on my feet. Mentally, that was a really important breakthrough for me. The hospice pampered me and made me feel special but the biggest thing they gave me was my independence and the confidence to know I could go home.”

– Ms C.F

Day hospice and outpatient clinics

Day hospice and outpatient care give people the opportunity to spend time in a hospice and use the majority of services available, without being admitted as an inpatient. This allows people to get the care and support they need while living at home. The care and support offered may include medical and nursing care, rehabilitation services, counselling, art and music therapy, massage, meditation, complementary therapies such as aromatherapy, as well as hairdressing in fully equipped on-site salons.

There is a focus on advance care planning, preparing for the future, remembering the past and a growing philosophy of encouraging self management and independence. Family meetings are frequent, with a specific focus on how to support the main carers both emotionally and practically.

Being able to access hospice care through day and outpatient services means people can get care, advice, support and company in a way that works for them. Day and outpatient services cover a wide range of services attending to people’s physical, psychological, emotional and social needs.

Key facts:

• 35,000 people were seen in day hospice services.

• 54,000 people were seen in outpatient clinics provided by hospices.

• Outpatient and day hospice make up 29 per cent of the clinical care that hospices provide.
Bereavement care

We will all experience bereavement. Grief and loss are normal experiences and the hospice movement has always considered the care and support of people affected by bereavement to be a key part of their role.

Without the right care and support, bereavement has the potential to lead to a number of poor outcomes across health, income and employment. Hospices help to mitigate negative outcomes of loss by offering support – both before and after a death – to help people manage what can be a hugely painful and isolating experience. Such support may be through formal engagement with a professional therapist, group sessions, or more general social support and information.

Key facts:

- Hospices provided formal bereavement support to more than 41,000 people in 2015-16.
- Bereavement support represents 12 per cent of all the people who received direct support from a hospice.

Supporting care in other settings

Despite our best efforts, not everyone will have the chance to decide where they will be when they die, or ‘home’ may turn out to be somewhere unexpected, so it is important that hospices take their care to wherever people may be. As a result, many hospices provide support to people, clinicians and staff in other care settings such as acute hospitals and care homes. Telephone-based support, for people and clinicians, is extremely important. Being able to call a hospice for immediate expert advice on medications, pain relief, breathlessness and/or a difficult decision can mean the difference between staying at home or an unnecessary admission to hospital.

Around half of all deaths currently occur in hospital, and many of these will be expected following a period of illness. Hospices have a lot to offer hospitals in improving end of life care, and many work directly with hospitals to provide this support. In 2015-16, hospice staff reached 16,000 people in hospital at the end of life.

Much of the support offered into other settings is currently unquantified. We know that hospices are increasingly working with care homes in their communities, supporting GPs, community hospitals and more, but there is very limited data on the numbers of people they reach.

One of the big challenges for extending the reach of hospice care is addressing the needs of people in dispersed or rural communities. Project ECHO (Extension for Community Healthcare Outcomes) uses video conferencing technology to support and train healthcare providers remotely. This means that community-based ‘generalists’ can improve their skills working with specialists in the field. The ECHO project in Northern Ireland provided weekly two hour sessions of teaching and case-based discussions facilitated by hospice staff, linking with nine teams of community nurses. An evaluation of the project found that 70 per cent of nurses involved said the technology used in ECHO had given them access to education that would have been hard to access due to geography, 96 per cent recorded gains in learning, and 90 per cent felt that ECHO had improved the care they provided for patients.
Hospice care for babies, children and young people

Babies, children and young people living with life-shortening or terminal conditions require specialist support, both medical and social. The needs of these children and their families can be highly complex and long-term – hospice care might support a family over a number of years, and across many settings. This means bringing together education, health, and social care in meeting the child and family’s needs.

Children’s hospice care also nurtures children through their developmental milestones and supports experiencing the world through play and social interaction with their peers.

As more and more young people with complex health needs are able to live well for much longer, there is also a growing need for services which support the transition into adulthood.

Neonatal care is also important to children’s hospices, with many providing comforting and safe spaces for families to spend valuable time with their baby and to begin the grieving process at their own pace. This can mean the transfer of a family away from a bustling hospital environment, either before or after the death of the child.

Most children’s hospice care is provided through specialist children’s hospices, but some hospices provide care for both adults and children. Among Hospice UK members, there are 25 specialist children's hospice care providers, and 13 that provide care to adults and children. Approximately 49,000 children in the UK are estimated to be living with a life-shortening or terminal condition, plus almost 100,000 parents, as well as siblings and extended family.14

Key facts:
- 49,000 children in the UK estimated to be living with a life-shortening or terminal condition.
- 17 per cent – the statutory contribution to the cost of running a children’s hospice.
- 25 specialist children’s hospice care providers, and 13 that provide care to adults and children, are members of Hospice UK.

Zahra was born prematurely and was diagnosed with a life-threatening condition shortly after birth. Zahra’s parents and the neonatal team agreed she had palliative care needs and a referral was made to hospice care. The team, made up of children's hospice and neonatal staff working together, cared for Zahra and her family. This care included supporting conversations about end of life choices, and life beyond.

Hospice care enabled Zahra’s family to take her home to die when it was clear neonatal intensive care was no longer in her best interests. Collaborative working provided the opportunity for enhanced end of life care and support. Zahra was brought home to spend the last hours of her short life in the loving care of her family, in her own home for the first and last time.

“When we knew our baby was going to die it was important she had a ‘good death’. Taking her home allowed this to happen.” – Zahra’s mum
Research and education

Research and education have been fundamental pillars of the hospice movement since its inception almost 50 years ago. Hospices need an evidence base for the care and support they provide, as well as testing and improving the interventions that improve people’s outcomes. This is often research that would not happen anywhere else in the health system.

A commitment to research drives a culture of learning, which in turn is disseminated through wide-ranging educational work. Hospices deliver education intra- and inter-hospice, and widely into other health and social care settings. They are often the main providers of education on end of life issues.

Volunteering

Volunteers are integral to hospice care and have been at the centre of the hospice movement since it began. Hospices could not deliver the quality of care they do without their volunteer workforce. People give their time to hospices across a wide range of roles. Volunteering, whether it is in a hospice shop, or on an inpatient ward, not only saves significant sums of money, it also makes a real difference to the people using hospice care through friendship, ‘ordinary’ interactions, and the sharing of diverse skills and experiences.

Volunteer roles in hospice care vary widely, evolving within a hospice depending on where there is greatest need and what particular skills volunteers can offer. Volunteers undertake administrative tasks, driving roles, running receptions and cafes, being on the inpatient unit, running classes, to name a few. What can seem like a small task – like changing the flowers in a hospice room, providing a haircut, or helping someone attend day hospice – can mean a lot.

Hospices are looking at how they can expand the contributions made by volunteers. Many hospices are now looking beyond traditional volunteering to maximise both the impact for the people who use hospice care and the experience of the volunteers themselves.

Living with, or caring for someone with a life-shortening or terminal condition can be an isolating experience which compounds the effects of illness. To address this, a number of hospices have developed ‘compassionate neighbour’ programmes to support people and carers. A hospice in east London provides free, community-led support for anyone living with or caring for a person with a serious, long-term or terminal illness, or a person who is frail and/or isolated.

Volunteers aim to support people so that they can stay connected to their friends and the community; receive companionship, emotional support and a listening ear; and assist people to access important support services across the community. Programmes like ‘compassionate neighbours’ reflect the changing nature of volunteering in hospice care, and provide a glimpse of the kind of community-led responses which will be increasingly important in coming years.
Hospice care is provided at no charge to the people who use it. Adults’ and children’s hospices in the UK spend a combined £868 million per annum on providing care, and the majority of this is realised through fundraising. This is money the NHS does not have to find. Adults’ hospices in the UK receive on average just a third of their costs from the NHS. Children’s hospices are supported at a much lower level, receiving 17 per cent of the cost of providing care from the NHS. As such, charitable hospices are major funders and commissioners of care for people affected by terminal illness.

**Key facts:**
- Hospices in the UK spend a combined £868 million per annum on providing care.
- Hospices need to fundraise £2.7 million from their local communities every day.
- The statutory contribution to the costs of running adults’ charitable hospices is 33 per cent; and 17 per cent for children’s charitable hospices.
Hospice care in the UK is at a pivotal moment, driven by significant social and demographic change. With major government programmes and structural changes underway in each of the four nations of the UK, there is an extraordinary opportunity to build the right hospice care for the next 50 years.

Hospice UK is the national charity for hospice care. As a national hub we are able to offer national intelligence, experience and expertise in hospice care that is available to our members – the 220 hospices across the UK – as well as key decision makers and stakeholders at a national and local level. In considering the data highlighted in this report and our knowledge of the wider context within which hospice care operates, we believe that a radical change is needed to ensure expert care is available for everyone at the end of life, and propose the following as what is needed to achieve this:

**A community-driven and engaged response is vital**

The ageing population, funding and workforce pressures, and changing social demographics mean that the extension of community-based responses to end of life care needs will be essential. With strong community links and a developed volunteer base, hospices are well placed to support and facilitate new models of engagement at a local level. Hospices are committed to working with communities to do much more in supporting people at the end of life, from helping family and loved ones, to co-ordinating community-based volunteer responses such as ‘compassionate communities’/’compassionate neighbours’, Shared Lives, Casserole Club, and other similar initiatives.

**Death and dying must be a central feature of public health**

Death and dying are public health issues, but are not priorities in most strategies. Public health bodies at national and local levels have a vital role to play in encouraging more open and honest conversations about dying, death and bereavement. Public health responses to death and dying are about ensuring all aspects of the health and care environment work together and that community responses have the opportunity to flourish. They are about building resilient communities and strengthening the networks of support on which we all rely. Death and dying need to have greater priority in public health strategies across the country. This is particularly important in the context of an ageing society where more of us will live and die with increasingly complex needs and frailty.

**People need a seamless experience of care**

People and families affected by terminal and life-shortening conditions need help from multiple sources – across social and medical care – and across the public, private and voluntary sectors. Positive experiences of care at the end of life depend upon all of the sources to help and support working effectively together. Clinicians need information and support to understand more about the needs of people with terminal and life-shortening conditions and to make better use of the network of care available
through hospices. Social care that cannot be put in place quickly enough can leave people stranded in hospital beds when they may have no clinical need or wish to be there. Lack of appropriate and affordable community care can lead to inappropriate and distressing hospital admissions.

We need to do more to support families and carers

As our communities and needs change, there is no doubt that families, carers and informal care networks will be expected to do more to support people approaching the end of their lives, particularly if we are to be able to support more people at home. Families and carers are often the main providers of care for people at the end of life, but are often not recognised as such. We need to go further in the support that we provide to families, carers and local communities to be able to support people appropriately at the end of life.

We need better intelligence

We need to know a lot more about people’s needs at end of life, who accesses hospice support, and their experience of care. We simply do not know enough about the populations who use hospice care, and even less about those who do not access hospice or other high quality end of life care. Filling those gaps in our knowledge is critical to reducing the inequalities in care that we know exist.

We need to know more about people’s experiences of care; proxy measures such as place of death or the Office of National Statistics’ National Survey of Bereaved People (VOICES) are helpful, but tell only a small part of the story. We need to actively seek out those who may be underrepresented in hospice care or whose care does not meet their needs.

Hospice UK is committed to supporting hospices to develop their intelligence, in particular ensuring that:

- data collection and analysis fully reflects the broad work of hospices
- good practice is shared and learned from
- the data that hospices report to the NHS can be accessed and analysed by hospices as needed.

The planning and delivery of sustainable, long-term services that meet the needs of local communities needs reliable funding

Governments across the four nations of the UK are doing a great deal of work to better understand the resource needs of end of life care. With statutory funding supporting only around a third of the costs of delivering hospice care, it is imperative that services are able to depend on this funding. The use of short-term contracts, spot purchasing and grants based on historical contributions rather than meaningful calculations impede planning for the future, service development and clinical innovation.
Methodology

The data presented in this report is primarily analysis of the Minimum Data Set (MDS) for Specialist Palliative Care Services, produced annually in partnership between Public Health England, the National Council for Palliative Care and Hospice UK. This data was provided to Hospice UK by the National Council for Palliative Care in July 2016. We have assessed only the data from services which identified as hospices. Further data has been used from Hospice UK’s 2016 research, “The role of hospice care in Scotland”\(^\text{16}\), to develop a UK-wide picture as the MDS covers only England, Wales and Northern Ireland.

The MDS is collected on an annual basis; however, it is not completed by every hospice, so it is necessary to cautiously extrapolate from the available data.

Key concerns and calculations are as follows:

- There is no definitive count of statutory services providing hospice care, thus all calculations and extrapolations are based on Hospice UK membership. The majority of the 220 members are independent charitable hospices, and there are approximately 25 members who are NHS services. We have used Hospice UK membership figures as a baseline for extrapolations noting, where possible, there are different totals by service type (for example, 176 provide inpatient care).

- The MDS only includes data for adult hospice services. It collects data across six different service types: inpatient services, day care (day hospice), community care (including home care and hospice at home), hospital support, bereavement support and outpatients. Hospices typically deliver more than one of these services, so simply adding together patient numbers across all hospices and all service types will lead to double counting.

- To estimate the number of people recorded in the MDS an attempt has been made to create mutually exclusive categories within the service types, counting only deaths and discharges from relevant services, and calculating unique patients based on those – see table on page 19.

- While this methodology minimises counting of individuals more than once as they use multiple services, it is not absolute, thus the sum of the estimated numbers of unique users of distinct service types should be treated with some caution.

- The MDS is not completed by every hospice so we need to extrapolate up to produce a national total.

- A total of 176 adult hospices are estimated to have inpatient units, based on Hospice UK’s dataset of members. This represents 83 per cent of all hospices. Applying this assumption to the MDS suggests a response rate of 65 per cent. This has been cross-checked using a similar calculation analysing day care services, which suggests a comparable response rate.

- The 65 per cent level is based on a multi-year analysis of MDS responses.

- The response rate in 2016 was approximately 70 per cent of all hospices.

- Extrapolating the patient figures up from the unique totals as detailed above based on a 65 per cent response rate produces a total figure of people accessing hospice clinical services of 207,969 plus 42,301 receiving bereavement support from hospices in 2015-16.
• Extrapolating the patient figures up from the unique totals as detailed above based on a 70 per cent response rate produces a total figure of people accessing hospice clinical services of 194,278 plus 39,486 receiving bereavement support from hospices in 2015-16.

• The mid-point between the 65 per cent and 70 per cent response rate extrapolations is a total of 201,594 people in clinical services and 40,894 in bereavement support.

• Thus, we state that approximately 200,000 people accessed hospice care services and 41,000 people accessed bereavement services in 2015-16.

• The number of beds in inpatient hospice is the sum of the published bed numbers of 168 hospice providers who are Hospice UK members. Sources include hospice websites, annual reports, registrations with regulators.

• The number of bed days was calculated by multiplying the number of beds \( \times 365 \times 0.79 \). This is based on Hospice UK analysis (unpublished) of a sample of 110 inpatient units from our adults’ member hospices; bed occupancy is consistently between 78 per cent and 80 per cent in each of the last six quarters.

• The number of community visits was calculated by multiplying the estimated number of people seen in community care (159,297) by 5.95, being the average number of community visits per person in Scotland in 2014-2015. We have made the assumption that the number of visits per person will be similar in Scotland to the rest of the UK, based on the sample of 11,000 people receiving community care and hospice at home services.

• Some figures may not tally due to rounding.

### All users

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<th>Scaled from 70% response rate</th>
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<tr>
<td>Inpatient</td>
<td>32,266</td>
<td>49,381</td>
<td>46,094</td>
<td>47,738</td>
<td>21,863</td>
<td>33,460</td>
<td>31,233</td>
<td>32,347</td>
</tr>
<tr>
<td>Day hospice</td>
<td>23,878</td>
<td>36,544</td>
<td>34,111</td>
<td>35,328</td>
<td>15,897</td>
<td>24,329</td>
<td>22,710</td>
<td>23,520</td>
</tr>
<tr>
<td>Community based</td>
<td>107,669</td>
<td>164,780</td>
<td>153,813</td>
<td>159,297</td>
<td>57,677</td>
<td>88,271</td>
<td>82,396</td>
<td>85,334</td>
</tr>
<tr>
<td>Hospital support</td>
<td>11,067</td>
<td>16,937</td>
<td>15,810</td>
<td>16,374</td>
<td>4,108</td>
<td>6,287</td>
<td>5,869</td>
<td>6,078</td>
</tr>
<tr>
<td>Outpatient *</td>
<td>36,344</td>
<td>55,622</td>
<td>51,920</td>
<td>53,771</td>
<td>36,344</td>
<td>55,622</td>
<td>51,920</td>
<td>53,771</td>
</tr>
<tr>
<td>Bereavement care **</td>
<td>27,640</td>
<td>42,301</td>
<td>39,486</td>
<td>40,894</td>
<td>n/a</td>
<td>n/a</td>
<td>n/a</td>
<td>n/a</td>
</tr>
</tbody>
</table>

* Limitations of the MDS data mean that we cannot perform the same calculation on the outpatient data in order to estimate unique users as per other service types.

**As bereavement care is a singular service type, and thus it is unlikely that people would be counted in another service as well, a ‘unique user’ estimate was not required.
There is no definitive count of statutory services providing hospice care, thus all calculations and extrapolations are based on Hospice UK membership; there are 212 adults’ hospices and 27 children’s hospices who make up the 220 members (some members have more than one hospice). The majority of these members are independent charitable hospices, and there are approximately 25 members who are NHS services.


The paper states that between 69 – 82 per cent of all deaths in high-income countries could benefit from palliative care. For ease, we have used the midpoint (75.5 per cent) to broadly estimate how many people might benefit from palliative care in the UK each year, resulting in 455,096 (75.5% x 602,776 deaths), and the 207,969 people we have calculated as receiving hospice care are thus 46% of that group.

For example, an individual who used outpatient hospice care and community care may be counted as one person in each service, and thus two people in the final count, as each service provided care to a person. Thus we reflect the scale of care provided rather than absolute numbers of unique individuals.


11. The Hospice of St Francis see http://www.stfrancis.org.uk/support-us/testimonials/details/the-hospice-gave-me-back-my-life


14. Together for Short Lives see http://www.togetherforshortlives.org.uk/about/infographic_here_for_the_49_000

15. St Joseph’s Hospice see https://www.stjh.org.uk/neighbours


17. Ibid.