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Support at the end of life

The role of hospice services across the UK

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nuffieldtrust

In association with

hospiceUK

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Key messages

The Covid-19 pandemic has caused major disruption across health and care services, including care for people at the end of life. In addition, there has been a significant shift in where people die, with more than 105,000 extra deaths at home in the UK over the first two years of the pandemic. The reasons for this are not fully understood, but have profound implications for the experience of people dying and their families and carers, and for the type and quality of care they receive.

Hospices play an important role in providing care at the end of life, supporting people and their families, and others who are affected. Only a small proportion of people die in a hospice – under 5% of the 650,000 people who died in 2021. Our findings demonstrate the huge role that hospices play in supporting a much wider group of people at the end of life and their families:

- In 2020/21, hospices supported an estimated 300,000 people in the UK, including people at the end of life, families, carers and bereaved relatives.

- During the pandemic there has been a shift in where and how services are provided, with more care delivered at home. In 2020/21, there were almost a million ‘hospice at home’ contacts. In contrast, day services and outpatient settings saw a decline in the number of contacts and people seen, and fewer people were inpatients.

- In addition, the complexity of patients’ needs may have increased, with patients receiving inpatient care having more contacts each, and contacts per person for bereavement services also increasing.

- In 2020/21, more than 120,000 community support contacts were delivered virtually, along with virtual welfare, bereavement and therapy services. Hospices switched to providing services remotely, to respond to concern from patients about attending appointments and to reduce the risk of Covid-19 infection.

- Hospices also reported changing their delivery in response to Covid-19 in other ways, for example introducing multidisciplinary teams to address workforce gaps, but they were not always able to capture information about new service models in their survey responses.

- In 2020/21, there was a drop in the number of people who hospices supported but this was small, particularly when compared to the significant falls in activity across other health services during the pandemic.

The data collection issues and challenges we experienced in carrying out this research limit our findings. Not all hospices responded to the survey, and data were incomplete, as many hospices do not routinely capture information about patients, including ethnicity and other protected characteristics. The challenges that hospices faced in responding included a lack of standard definitions for hospice activity, limited resources for data collection or analysis, and difficulties extracting data from information technology (IT) systems.

More consistent and better-quality data on what hospices do, who they support and how, is vital to enable hospices to improve their services and demonstrate their value, as well as enable health systems to understand local needs, address unmet needs and provide the most appropriate care for the population. In this report we make specific **recommendations** for improving data collection across the hospice sector, which will require a strategic approach at national levels, as well as local action.

New service models that hospices have developed over the past two years, along with closer working between organisations at a local level, could provide the basis for improving care at the end of life, and deliver services within communities rather than acute care settings. Wales and Scotland are developing end of life care strategies, while in England, newly established integrated care systems could improve collaboration and the planning of services to ensure equal access to specialist services.

This is more urgent than ever, given the impact of the pandemic on how and where care is provided and where people are dying. The NHS needs to better understand the needs of people at the end of life, particularly those who are at home, and ensure adequate community capacity and support. It also needs to make sure that new service models that have been developed in response to Covid-19 are responsive to the needs of people dying and their families and loved ones.

1 Introduction

This report addresses a significant gap in our understanding of the services that the hospice sector provides across the UK, including how the Covid-19 pandemic has impacted services.

The pandemic has seen major disruption to services across health and social care, along with a huge shift in where patients are dying, with both significantly impacting on end of life care. However, data from hospices is not routinely collected, and the last reported data are from a survey in 2016/17.[1]

In this report, we provide information on hospices' service provision for the years 2018/19, 2019/20 and 2020/21. The data draw on a nationwide survey of hospices, conducted by Hospice UK. The findings from the report illuminate the impact of Covid-19 on services that the hospice sector provides, and the people who hospice services support.

An introduction to hospices and palliative care in the UK

Hospices provide palliative care to people with a life-limiting or terminal condition, which aims to improve their quality of life and wellbeing. It can be provided in a person's home, in hospital or at another community setting. Hospice care includes support for physical needs, such as pain management and stabilising the person's condition, as well as emotional and spiritual needs. Importantly, hospices provide care at different stages of a person's illness, not just at the end of life.[2]

In addition to adults, hospices also play a vital role supporting children and young people who have been diagnosed with a life-limiting condition and their families. There are hospices that are dedicated to the care of children and young people, a number of hospices that provide care for both children and adults, and hospices just for adults.

The majority of hospices are independent charities and receive their funding through a combination of NHS and charitable donations. There are two national hospice providers – Marie Curie and Sue Ryder – as well as multiple local hospices.

The range of services that hospices provide extends from clinically led inpatient or hospital-at-home care, through to befriending and visiting services, which volunteers deliver. Care for families and carers, including bereavement support, is a key part of hospices' work.

While only a small proportion of deaths occur in a hospice bed (23,825 deaths, representing 4.5% of deaths, in England in 2021), we estimate that more than 300,000 people received care from hospices in the UK in 2020/21. This is a significant number against a backdrop of more than 650,000 deaths in the UK in 2021.[3]

How we carried out the analysis

Together with Hospice UK, the Nuffield Trust designed an online survey to collect aggregate data on hospice activity over three years from 2018/19 to 2020/21. We asked for details of where care was provided, the types and volume of care and, for 2020/21, for what kinds of people (in terms of demographics, needs and preferences). The survey questions, which are listed in Annex 1, covered topics that had been included in previous data collections, as well as new topics, including digital and remote contacts.[4,5,6] Hospice UK sent the survey to its members in Autumn 2021 (its membership covers all hospices in the UK).[*] A reference document of definitions was included in an attempt to harmonise responses across hospices (see Annex 2). We received replies from 127 Hospice UK members, which equates to a response rate of 62%.[†] Further details on the response rate by selected characteristics can be

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[*] There are a number of palliative care services within NHS organisations that come in various forms, including several hospices within the NHS. This report does not cover these.

[†] For this report we have counted the nine Marie Curie and seven Sue Ryder hospices separately, rather than as two organisations, as they are based across the four countries of the UK, they provide different services by site, and we did not receive data for all sites.

found in Annex 2 and detail on comparisons with other data can be found in Annex 3.

In January 2022, we held a workshop with Hospice UK and representatives from a range of hospices, to share our emerging findings, discuss challenges with data collection and potential solutions, and identify broader implications for end of life care services. Throughout the project we engaged with stakeholders from national organisations with a remit relating to community and end of life care data to understand current priorities for improving information collection from hospices.

2 Context

Impact of Covid-19

The Covid-19 pandemic has seen a huge shift in where patients are dying, with a third more people dying at home than before the pandemic.

Across the UK, more than 105,000 additional people died in private homes in the first two years of the pandemic (see Annex 4). We do not know how many people who died at home received care from hospice services, but the number of people dying in a hospice inpatient bed was lower during the pandemic than before it. For example, in England during the first two years of the pandemic, more than 11,000 fewer deaths occurred in a hospice than the five-year average in England.[7] The situation is similar in Scotland, Wales and Northern Ireland.

It is not exactly clear why this shift has taken place. Covid-19 has largely not been a direct cause of increased deaths at home, for which the leading causes are heart disease, cancers and dementia.[10] Patient and family decisions may have been an important driver, following visiting restrictions across hospitals, hospices and care homes, as well as concern about the risk of Covid-19 infection.[11] Pressure on health and care services may also be a factor.

The shift towards more people dying at home since the pandemic hit has rapidly accelerated a pre-pandemic trend, and the numbers of people dying at home have already reached the earlier estimates predicted for 2030.[12]

The direct impacts of Covid-19 on health and care services are well documented – with Covid-19 patients occupying around 30% of hospital beds in the UK in the peak of the second wave of the virus in January 2021.[13] Non-Covid care has also been significantly impacted. In March 2020, non-Covid services were reduced to protect capacity for Covid-19 patients, patient stayed away from services – both hospitals and primary care – and the number of referrals from GPs to specialist care fell. Subsequently, the

NHS has struggled to deal with the combined effects of Covid-19, recovering lost activity, very high demand for urgent care[14] and delivering the Covid-19 vaccination programme.[15] Covid-19 has also impacted NHS community services, which responded by delivering more services remotely, via digital routes or the telephone.[16]

The Covid-19 pandemic has had a significant impact on end of life care, including the ability of organisations such as hospices to provide services, as well as the experience of people at the end of life and their families. The CovPall Study, led by King's College London, was launched in 2020 to understand more about how specialist palliative care services (including hospices) have responded to the pandemic. This has highlighted (among other things) a shift in where services are provided, with a greater focus on community care, increased use of remote communication both with patients and between services, and greater use of technology.[15]

In recognition of the potential impact of the pandemic on charitable donations, as well as the need to adapt services, additional funding has been provided to hospices across the UK during the pandemic.[16]

The combined impact of disruption to end of life services, at the same time as more people have been dying at home, raises significant questions about the quality of end of life care. Surveys have found that most people express a preference to die at home,[17] although when the circumstance of being close to death arises, the situation is often complex, and dependent on individual, family and service factors.[18] There is, however, consensus that emergency hospital admission at the end of life is often not the best outcome for patients and there has long been a focus at a national policy level to encourage end of life care planning, and to enable more people to die in their place of choice.[19] Before the pandemic there were concerns about access to high-quality palliative care at home or elsewhere.[20] While the pandemic may have accelerated a trend for more people to die at home, in line with recent policy, it is unclear whether the experience of dying at home during the pandemic has been a positive and dignified one and whether services have been able to respond appropriately and adapt to changing patterns in place of death.[21]

Hospice care across the UK

How services are provided and funded varies across the UK. More consistent and better-quality data on what hospices do, who they support and how, will be vital for understanding how to provide the most appropriate care. This includes where care is provided, who would benefit from these services and how to respond to unmet need.

Across the UK, hospices face a number of shared challenges. These include the need for adequate and sustainable funding, the need to address inequalities in access to hospice care, and staff shortages and burnout. But the specific policy context in each of the four UK countries is also relevant. Taken together, they demonstrate that now is a significant time to highlight the vital role that hospices play in providing end of life care, and the importance of accurate data in demonstrating this.

In May 2021, the National Palliative & End of Life Care Partnership in England published the refreshed *Ambitions for Palliative and End of Life Care* framework, which includes six ambitions describing what good palliative and end of life care looks like.[22] *The NHS Long Term Plan* includes a commitment to improved personalised care at the end of life[23] and the Ambitions framework is considered important to achieving this.

NHS England and NHS Improvement are also developing guidance to support the commissioning of both specialist and generalist palliative care services, through updated service specifications for specialist and generalist palliative care and palliative care currencies. Currencies attempt to define community activity on a pathway basis, rather than as a single intervention, and can help to improve transparency around palliative services and their cost.[24] More widely, the development of integrated care systems is an important opportunity for organisations, including hospices, to work collaboratively to provide services that meet the needs of their local population. An amendment to the Health and Care Act 2022 establishes palliative care as a core service that integrated care systems have a duty to provide equitably.[25]

Scotland's *Strategic Framework for Action on Palliative and End of Life Care* included a vision for everyone who needed palliative care to have access to it by 2021, as well as a commitment to improved data collection and analysis.[26] The Scottish government has also committed to developing a new palliative and end of life care strategy.[27] The proposal for a National Care Service is also likely to have implications for hospice care in Scotland.[28]

In Wales, the *Palliative and End of Life Care Delivery Plan* sets out seven themes to improve care for people at the end of life, recognising the importance of hospice services.[29] The Welsh government also announced additional funding to support the provision of end of life care in 2021.[30] Phase 1 of an end of life care review has led to an additional £2.2 million for core funding for hospices (including £888,000 for the two children's hospices in Wales), and phase 2, with a commitment to create a new national programme for palliative and end of life care, was expected to begin in April 2022.[31] Hospices have discretion about how to use this funding.

At present, Northern Ireland does not have an overarching palliative and end of life care strategy, with the most recent document published in 2010.[32] However, there is a strategy for children's palliative care covering the period from 2016 to 2026. Organisations including Hospice UK called for this to be renewed in the lead-up to Northern Ireland Assembly elections, which took place in May 2022.

3 Findings

People receiving services from hospices

Hospices support people at the end of life and also their families and carers, including bereaved relatives. In 2020/21, hospices reported providing services to 204,214 people (n = 125).‡ We estimate that this could equate to just over 300,000 people when non-response is considered.§ The year 2020/21 was an unusual one; for hospices that responded to this question for both 2019/20 and 2020/21 (n = 122), we see that the reported number of people using hospice services was lower in 2020/21 at 200,772 compared to 208,912 in 2019/20.

There is huge variation in how hospice services are organised, in what settings and what services are provided. In 2020/21, across the different settings (see Table 1 for definitions) where services are provided, the highest numbers of individuals were reported accessing services through 'hospice at home' and the lowest through hospital outreach (see Figure 1). Hospices reported more than 75,000 people accessing services through hospice at home, which we estimate could equate to almost 118,000 when non-response is considered.

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‡ The number of hospices that responded to each question varied; 'n = ' indicates the number that responded to the given question.

§ Details of our estimation method are given in Annex 5.

Table 1: Definitions of settings listed in the survey

Setting	Definition
Inpatient	A patient admitted to a hospice bed.
Outpatient	A patient attending a clinical appointment for assessment or treatment.
Day services/day care	Care to help people to live as actively and independently as possible, from clinical, wellbeing and emotional support, to creative and social activities, and including support provided to family members and informal carers.
Hospice at home/ domiciliary care/care at home	Direct care provision or wider support provided in the person’s home (including advice and support provided remotely, digitally or by telephone) that is delivered by a professional.
Outreach into hospital	Direct care provision or support/advice provided for patients in an acute or community hospital bed.
Other community	Any other services provided in the community, including support from volunteers or local community groups.
Any other	Services supporting people, families and carers that are not captured by the options above.

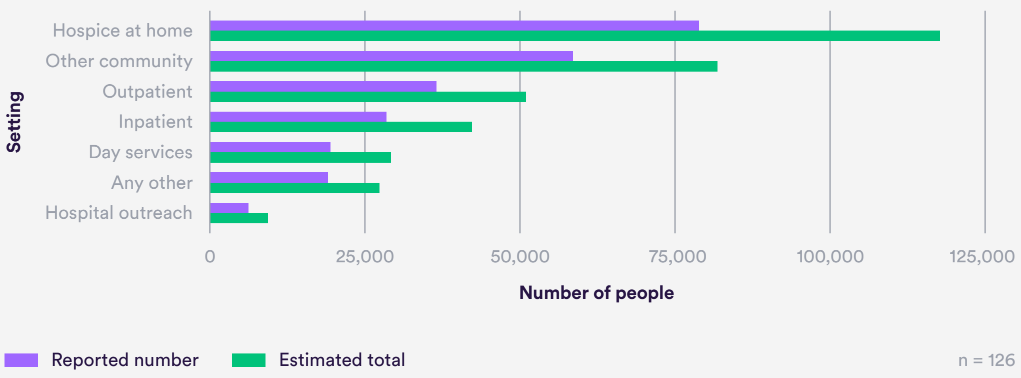
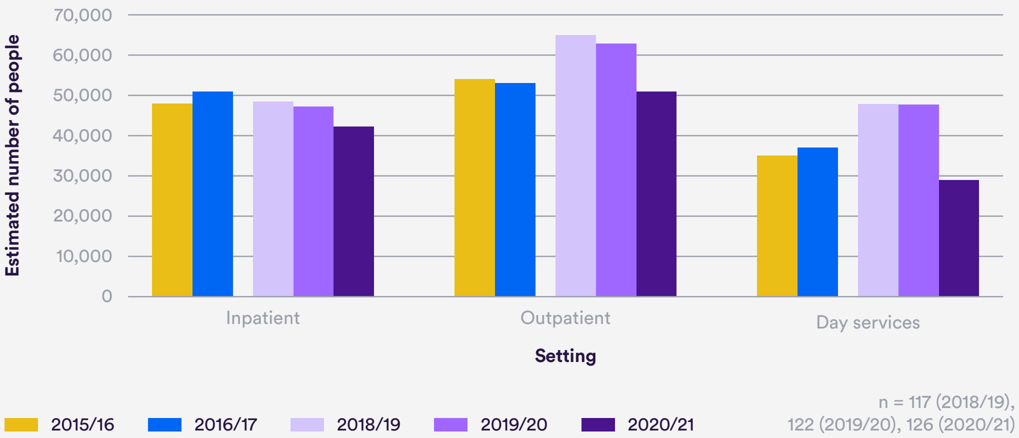


Figure 1: People using hospice services in 2020/21 by setting, number reported and estimated total

For the settings where there is comparable information available from previous Hospice UK reports – on inpatient, outpatient and day services – we see that the estimated numbers of inpatients remained relatively constant between 2015/16 and 2019/20 (see Figure 2). For outpatient and day services, we estimated higher numbers of people using hospice services in 2018/19 and 2019/20 than in previous years. There was a drop in the number of people using all three types of services between 2019/20 and 2020/21, which likely reflects the impact of Covid-19 on service provision. The drop was most noticeable for day services.

Figure 2: Estimated number of people using hospice services by setting, 2015/16 to 2020/21



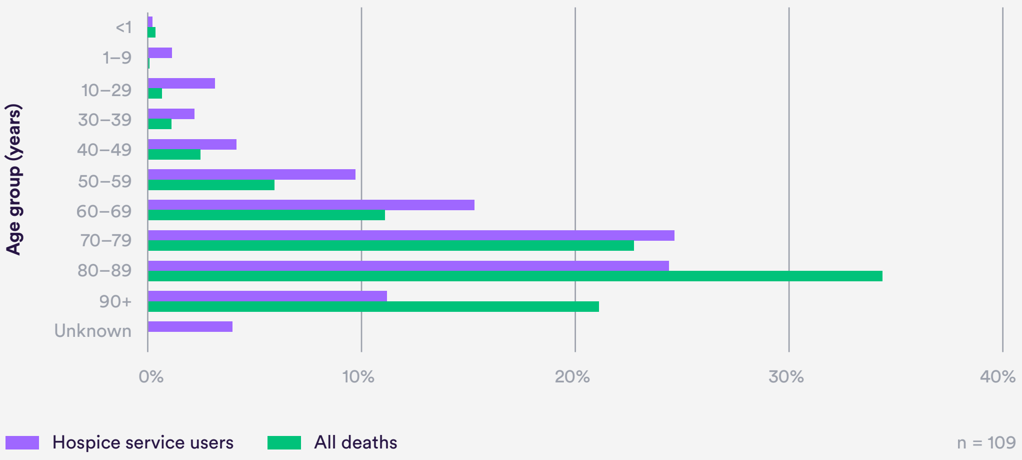
n = 117 (2018/19), 122 (2019/20), 126 (2020/21)

Note: No data were collected for 2017/18.

Sources: Hospice UK (2016) *Hospice Care in the UK 2016*. Hospice UK. Accessed 14 April 2022. Hospice UK (2017) *Hospice Care in the UK 2017*, Hospice UK. Accessed 14 April 2022.

Along with the overall numbers of people accessing hospice services, we also wanted to look at the characteristics of those using these services. For 2020/21, hospices reported that 53% of people using their services were female, 43% were male and 4% had an unknown gender (n = 115, people = 178,867). More than 60% of people using hospice services were over the age of 70. However, the age distribution was actually skewed towards younger ages when compared to all deaths in the UK, with 36% of hospice service users being under the age of 70 compared to 22% of all deaths (see Figure 3). This aligns with the age distribution of deaths reported by location for England and Wales, with the age of people dying in a hospice being younger than the age of those dying in care homes, hospitals and at home.¶

Figure 3: Age distribution of people using hospice services and UK deaths (in all locations)



Sources: National Records Scotland (2019) *Vital Events Reference Tables 2020 (Table 5.02)*. Accessed 27 April 2022. Northern Ireland Statistics and Records Office (2020) *Death Statistics – Deaths by Age 1955–2020*. Accessed 27 April 2022. Office for National Statistics (2020) *Deaths Registered in England and Wales, 2020 (Tables 4 and 5)*. Accessed 27 April 2022.

More than 60% of reported hospice service users were from a white ethnic background, while 10% were from a non-white one (n = 105, people = 164,342). Almost 30% of people's ethnicity was reported as unknown, which makes it difficult to ascertain whether hospices are serving a representative group of people compared to the population.

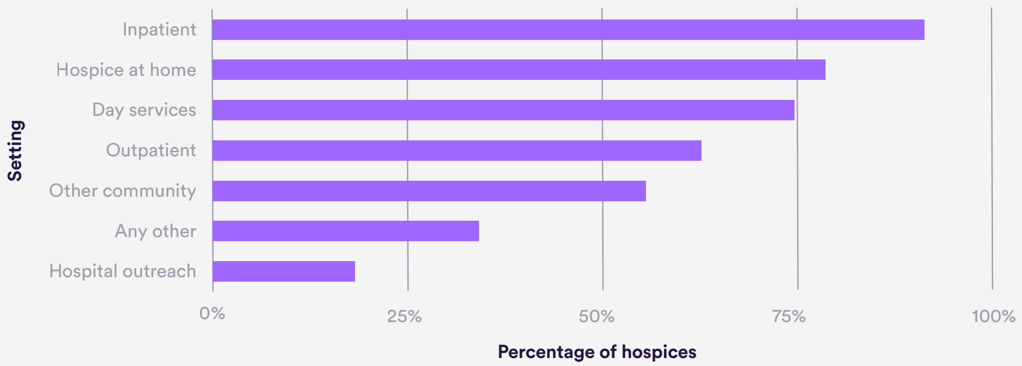
In terms of the needs of hospice service users, more than 50% of their diagnoses were reported as cancer (n = 97). Again, a high proportion of unknown diagnoses (20%) limits what conclusions can be drawn. The reporting of unknown characteristics or a low response to the question were also an issue when looking at the other characteristics that we asked about, including religion, sexual identity, living arrangements, functional ability to complete activities of daily living and advance care plans.

¶ Office for National Statistics (2021) 'Deaths registered in England and Wales: 2020' (Table 10). Equivalent data are not available for Scotland and Northern Ireland.

Settings of care and services provided

As there is huge variation in the organisation of hospice services, we wanted to gain an understanding of where and what hospice services are provided. More than half of the hospices reported providing care in all of the settings we asked about, with the exception of hospital outreach and ‘any other’ settings (see Figure 4). Hospice inpatient care was by far the most commonly reported setting across hospices, with more than 90% stating they provided services in this setting.

Figure 4: Percentage of hospices reporting providing services by setting in 2020/21



n = 126

Within these settings (or virtually), a bereavement service was the most commonly reported service (90%) and education for the general public was the least common, with just 10% of hospices stating they provided this service (see Figure 5; and also Table 2 for definitions of the different types of services provided).

Figure 5: Percentage of hospices reporting providing each service in 2020/21

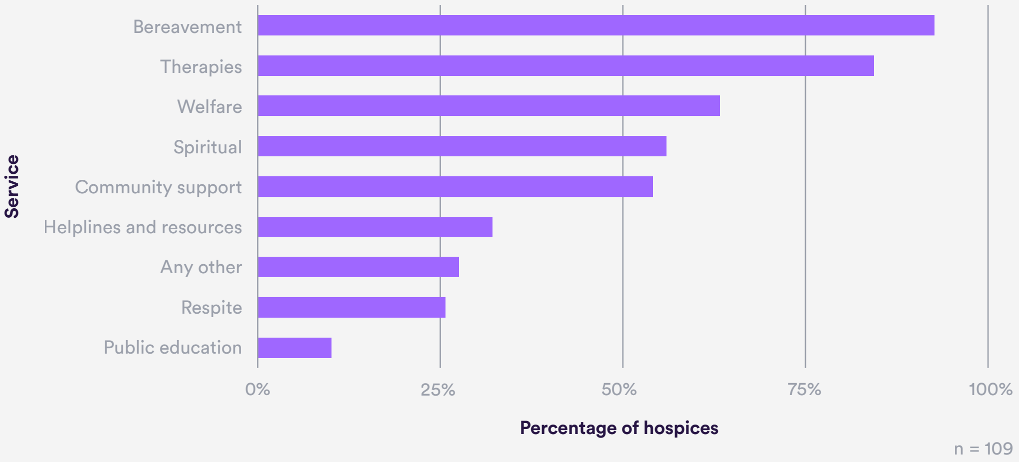
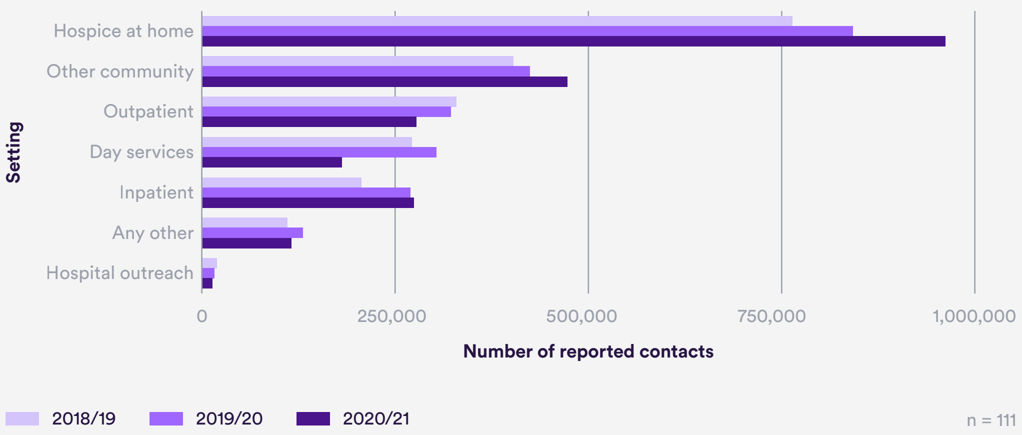


Table 2: Definitions of the services listed in the survey

Service	Definition
Therapies	Care to help people to live as actively and independently as possible, including through the reduction of pain or distress. Services may include outpatient clinical, psychological, emotional or wellbeing support, along with therapies that volunteers deliver such as complementary therapies, art therapies, counselling and rehabilitation.
Spiritual care	Spiritual care, covering all settings where this is recorded.
Respite care	Short-term care to provide carers with a break, support or for treatment.
Bereavement	Services provided to members of the person's family or informal carers.
Welfare and social work	Support with financial and other needs, including benefits.
Community support services	Other community services including support from volunteers or delivered for, or with, local community groups that might support people who are disadvantaged.
Helplines, information or resources	General information and advice not covered above, which are provided to members of the public.
Education for the general public	Education, training and learning for members of the public, in support of end of life care provision and/or around what the hospice does.
Other	Services supporting people at the end of life, their families and carers that are not captured by the options above.

The amount of care delivered in these settings and across the different service types varied over time. Some of this variation reflects improvements in recording. We measured the amount of care in contacts, which are any touch points people have with the service, for example, an admission to a hospice inpatient bed would be one contact and each hospice at home visit would also count as a contact. Hospice at home was the setting with the highest number of contacts in all years, with almost a million contacts in 2020/21 (see Figure 6). Hospital outreach meanwhile consistently had the fewest number of contacts across all years.

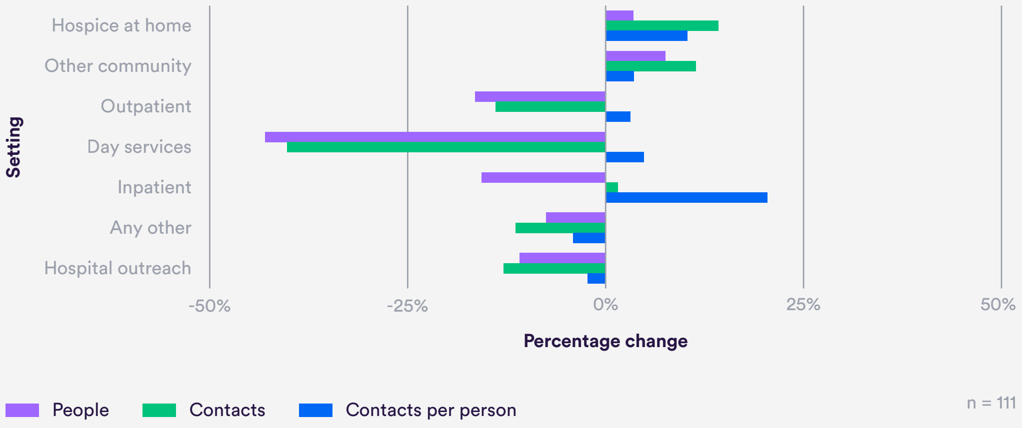
Figure 6: Number of reported contacts by setting and year



The biggest changes in contact numbers occurred between 2019/20 and 2020/21, likely due to the impact of the Covid-19 pandemic. For hospice at home and community support services, the number of contacts per person increased.** This was a result of a slightly larger increase in the number of contacts relative to the increase in the number of people (see Figure 7). The inpatient setting had the largest increase in contacts per person; there was a small increase in admissions (contacts) but the number of people admitted declined. Day services, outpatients, hospital outreach and 'any other' setting all saw declines in both contacts and people seen.

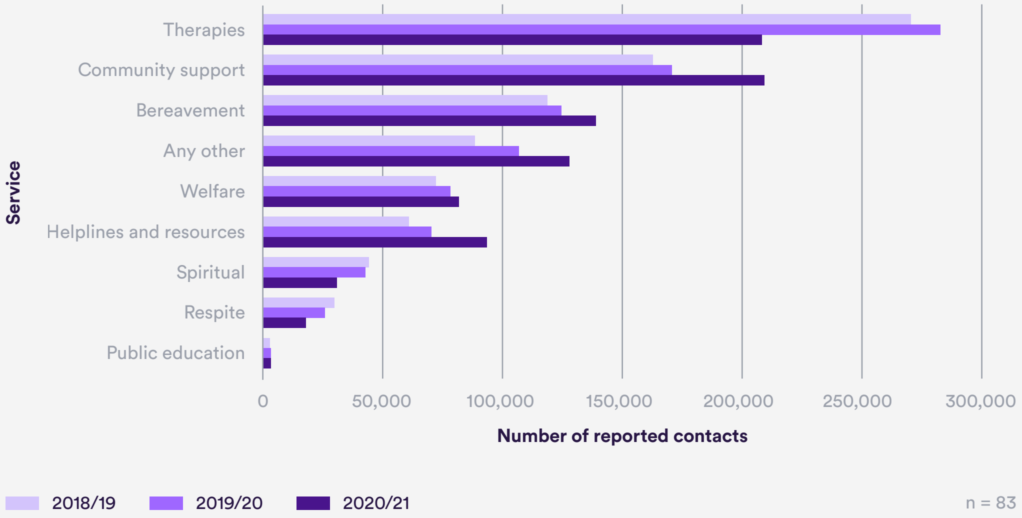
** Time series charts of contacts per person by setting and service are available in Annex 6.

Figure 7: Percentage change in reported people, contacts and contacts per person between 2019/20 and 2020/21 by setting



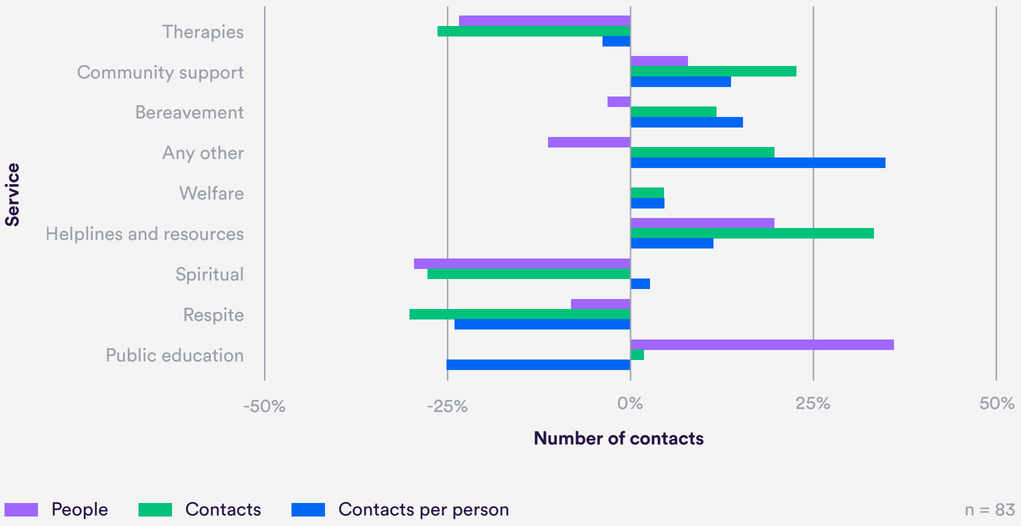
Across the services that hospices provided, therapies had the highest number of contacts in earlier years, but there was a large decline in 2020/21 (see Figure 8). There were increases in contacts for community support, bereavement, welfare and helpline and resource services in 2020/21 compared to the previous years. Contacts for 'any other' services were also 20% higher in 2020/21 compared to 2019/20, which may reflect new services being developed in response to Covid-19, which could not be categorised using existing codes. For example, some services reported switching to multidisciplinary teams in order to pool capacity for delivery during Covid-19 waves.

Figure 8: Number of reported contacts by service and year



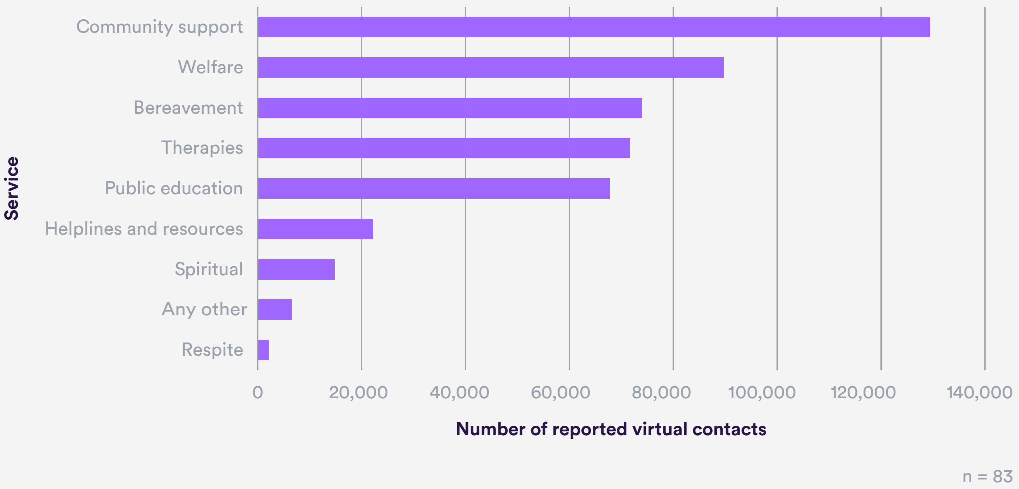
Along with the large decline in therapy contacts between 2019/20 and 2020/21, there was also a large decline in the number of people seen (see Figure 9). Meanwhile, an increase in community support contacts was mirrored by an increase in the number of people seen. This means that there was very little change in contacts per person between the two years for these two service types. For respite and public education there were large decreases in contacts per person. For public education there was a large increase in the number of people reported as accessing the service but not an equivalent increase in contacts. This may reflect better data collection, a more efficient service as people get what they need with fewer contacts, or more demand for this service in 2020/21 without an equivalent increase in resources to provide people with the same number of contacts that they would have received in 2019/20.

Figure 9: Percentage change in reported people, contacts and contacts per person between 2019/20 and 2020/21 by service



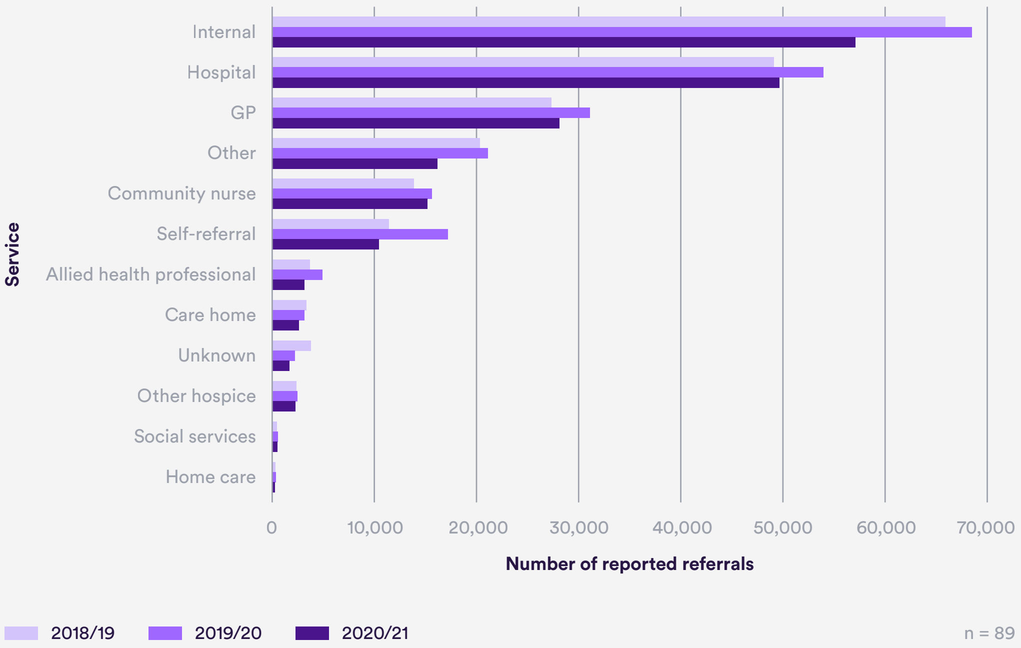
We also asked hospices about their virtual contacts. These were rarely reported in previous years, but in 2020/21 this type of contact was used across a variety of services. Community support was the most common service to have virtual contacts, with more than 120,000 reported contacts (see Figure 10). Virtual contacts were much less commonly reported for respite, which likely reflects that this type of service is less suitable for a virtual contact.

Figure 10: Number of reported virtual contacts reported for each service in 2020/21



People were referred to hospice services from a variety of different sources (see Figure 11). Referrals between different internal hospice services were common but referrals from hospitals were also commonly recorded. Overall referrals to hospice services were lower in 2020/21 than in previous years, which was reflected to varying degrees across all referral sources.

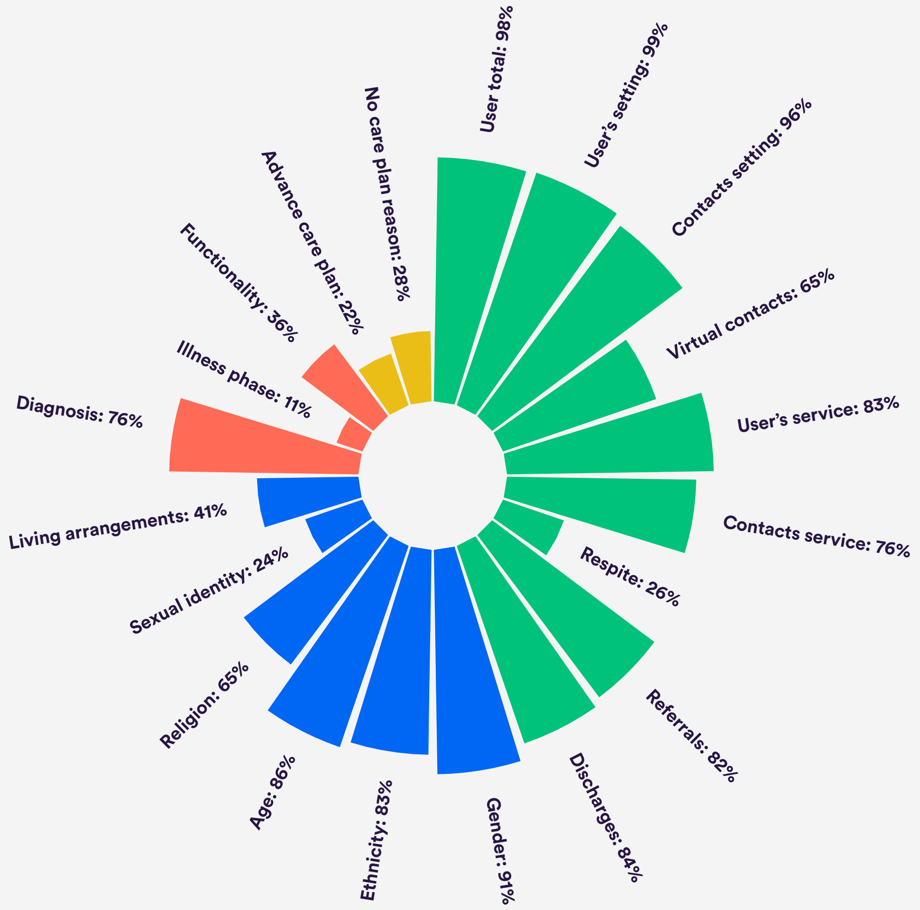
Figure 11: Number of reported referrals by source and year



What information were hospices able to provide, and what were the challenges?

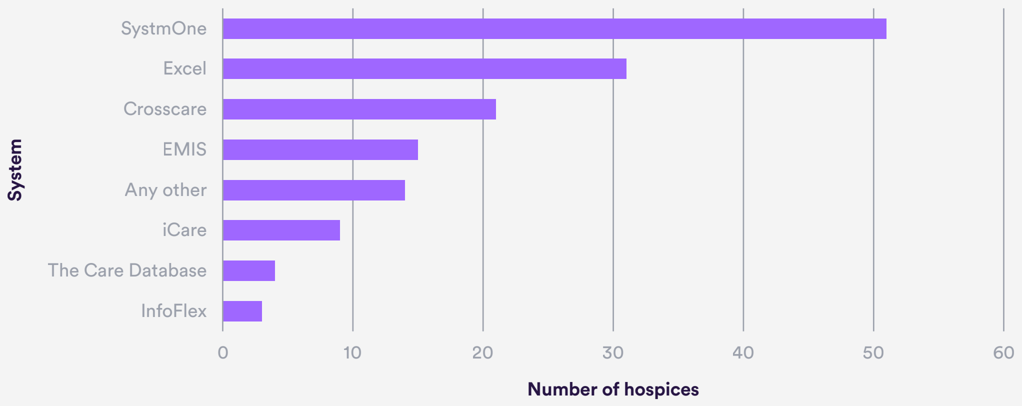
There was variation in what questions from the survey hospices could provide information for (see Figure 12). We received a good response for questions relating to overall activity, such as numbers of users and contacts with hospices, as well as those on basic demographics such as age and gender. Questions that hospices were less likely to have answered included those related to contacts with respite care, sexual identity, illness phase, functionality and advance care plans.

Figure 12: Percentage of hospices that responded to each question



The systems that hospices used to record care will have influenced the kinds of information they were able to record and how accessible it was for reporting. Some of the commonly used systems, such as SystmOne and Crosscare, are designed for individual record management, although not necessarily hospice records (see Figure 13). Meanwhile, Excel, which was the second most commonly reported data system, is not set up for individual record management and reporting.

Figure 13: Data systems that hospices used



Note: Hospices could report using more than one system.

In their comments, hospices described challenges with providing data, from which a number of common themes emerged (see Table 3).

Table 3: Examples of the most common challenges with data collection

Challenge	Number of hospices	Examples
Information is held within records but not collated, or an inability to extract the data in the format requested	45	The categories used, for example to describe services or age bands, are different from those requested. Data are not held in a way which is easily reportable, for example they are held separately within each service, or in different ways across the organisation. They are unable to report data as the information is recorded in free text, or only in paper records (for example advance care plans).
Data are not collected or are incomplete	34	Data items are not collected – particularly demographic data and data on living conditions. Improvements in data collection are ongoing, so data for earlier time periods are incomplete or only cover part of a year. The Covid-19 pandemic has had an impact, for example there were changes to service provision that were not fully captured in the data, or the capacity for data collection impacted data quality.
Issues relating to the IT system	22	Changes to IT systems in the period covered meant that some data could only be extracted for part of the period. There were difficulties with extracting data due to limitations with the system or how the data were entered. The switch from Read codes to the SNOMED system for recording clinical data has had an impact.
Data are recorded only for palliative care patients	19	Hospices varied in whether they reported on palliative care patients only, or all people who had received their services. In the latter case, they often did not capture demographic data, for example on people receiving bereavement support, and some fields such as diagnosis were not applicable.

Our workshop with Hospice UK and hospices reinforced the challenges with data collection from hospices. Participants at the workshop also noted that they received multiple requests for information from different sources, often with similar but different definitions. And while hospices often faced the same challenges and resource constraints, there was a lack of peer support for hospices to help each other and develop consistent standards. Participants also felt that sometimes staff did not feel comfortable collecting potentially sensitive information from service users.

The feedback from hospices about providing data reflects broader underlying challenges:

- There is no standard dataset used across the hospice sector. But even where hospices are collecting and using data internally, it may not be possible for them to contribute to a central data collection system if such a system did exist.

- The implementation of IT systems within hospices varies, from those relying largely on paper records, to those using established clinical systems. However, capability to extract useful data from systems is often limited, and will be challenging if systems have not been set up to support data collection and reporting, or configured to support data capture across the hospice's services.

- Important data items, such as care plans, are often only held in paper notes. Even where an IT system is used, data may only be in free text and therefore difficult to extract.

We have little information on the types of systems that smaller hospices used due to their low response rate. Smaller organisations are less likely to have these kinds of systems in place, which may have contributed to the low response.

A number of hospices reported that they were working on improved data collection, or had recently switched clinical systems. There is therefore an opportunity to improve data collection across the whole sector, but it will require a coordinated programme to agree common definitions and standards, engage with clinical system suppliers, and support hospices with implementation and developing the capability for using the data. It is likely that hospices, particularly small ones, will need support to manage information governance issues, such as how to record, handle and share patient information appropriately.

Variation across the UK

Across the four UK countries, Northern Ireland had the highest response rate to the survey – 75% – although from a relatively small number of hospices – followed by England (63%), Scotland (60%) and Wales (with the lowest response rate of 42%) (see Table 4). After accounting for non-response, Northern Ireland had the highest number of people accessing hospice services relative to its population size and Scotland had the lowest number.

Table 4: Response rate, and reported and estimated number of people accessing hospice services by UK country for 2020/21

	England	Northern Ireland	Scotland	Wales
Responded	110 (63%)	3 (75%)	9 (60%)	5 (42%)
Reported number of people accessing services	181,975	8,558	9,375	4,306
Reported number of people accessing services per 100,000 population	322	451	172	136
Estimated number of people accessing services	266,141	9,620	16,302	11,569
Estimated number of people accessing services per 100,000 population	471	508	298	365

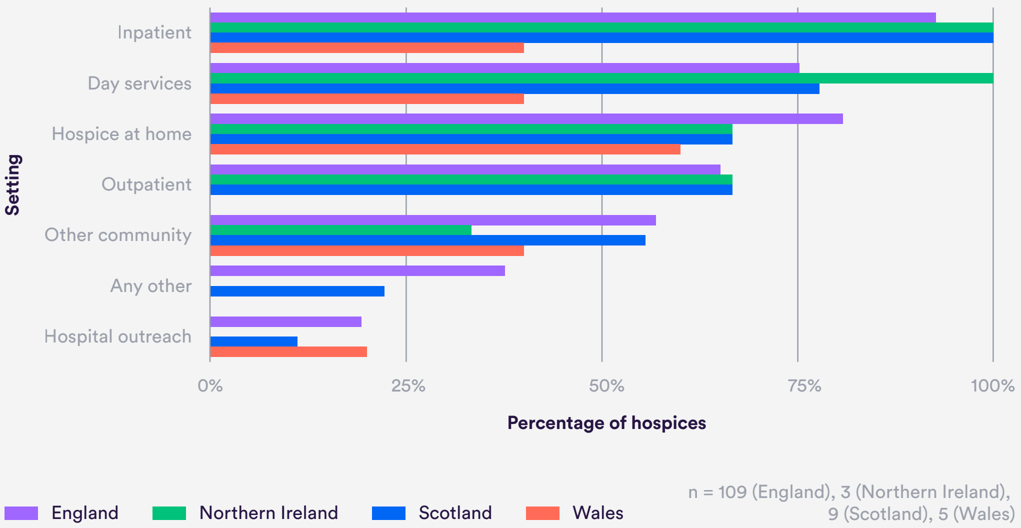
The types of services hospices provided, and the settings in which they reported providing them, differed across the UK in 2020/21 (see Figures 14 and 15). Nearly all hospices in England, Northern Ireland and Scotland reported providing inpatient care, whereas only two of the five that responded from

Wales did. None of the Welsh hospices reported providing outpatient care and none of the Northern Irish hospices reported hospital outreach.

Due to the low response rate from Welsh hospices, we also looked at a previous Hospice UK data collection for 2018/19 with complete responses.[33] Half of hospices reported providing inpatient care and only three reported providing care in an outpatient setting. Two of these three responded to the present survey but did not report providing care in an outpatient setting in 2020/21.

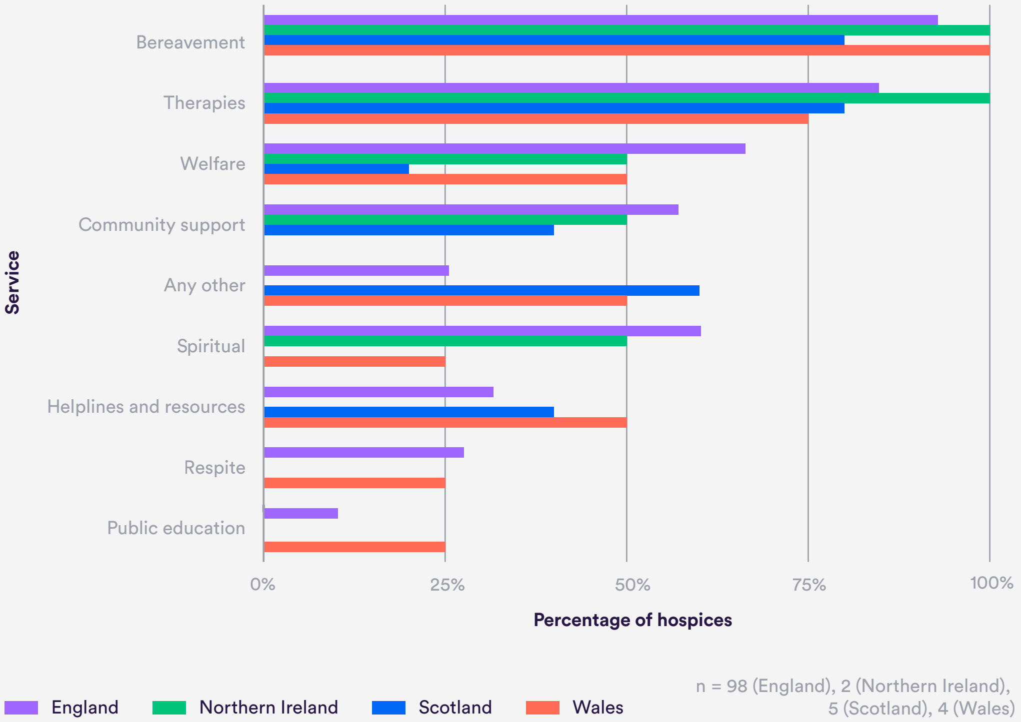
Bereavement and therapy services were reported in all four countries, whereas the other services listed were less consistently reported. Only English and Welsh hospices reported providing respite and public education services. Northern Irish hospices did not report providing helplines or resources and Welsh hospices did not report providing community support services. Further details on activity by setting and service for each UK country are available in Annex 7.

Figure 14: Percentage of hospices providing care by setting and UK country in 2020/21



n = 109 (England), 3 (Northern Ireland), 9 (Scotland), 5 (Wales)

Figure 15: Percentage of hospices providing care by service and UK country in 2020/21



n = 98 (England), 2 (Northern Ireland), 5 (Scotland), 4 (Wales)

4 Discussion and recommendations

This report provides an up-to-date picture of activity across the hospice sector in the UK, and the sector's response to the Covid-19 pandemic. In this section we discuss our findings, along with insights from the survey about the challenges hospices face in collecting information. We also make recommendations for how to improve the situation.

Implications for care and services at the end of life

Although only a small proportion of people in the UK – under 5% – die in hospices, our findings demonstrate the huge role hospices play in supporting a much wider group of patients and families at the end of life.

We found that the Covid-19 pandemic has caused a shift in how care is provided. In 2020/21, more care was provided in the community and through hospice at home, and less care in hospice buildings, such as day services. Overall, the number of people who hospices provide services to declined slightly in 2020/21. These findings are consistent with other studies.[34]

For some services and settings, we found reductions in the number of people care was available for. This could indicate greater need among those individuals who did access care. This is consistent with a survey of primary care providers, which reported an increase in the number of patients choosing to remain at home (rather than be admitted to hospital), and an increase in the complexity of patients who were being cared for at home.[35]

We also found evidence that the range of services that hospices provide increased in 2020/21. Contacts for 'any other' services increased, which may reflect new services being developed in response to Covid-19, and virtual contacts were also reported across a wide range of services in 2020/21 for the first time.

Hospice services have responded to the pandemic by providing more care remotely, and delivering more services in patients' homes, rather than on hospice premises. In many cases, these changes have been built on developments in service provision that were already taking place before the pandemic. Some evidence suggests that the changes services have made due to the pandemic were things that they had wanted to do before, but had not been able to.[36]

Information from the survey provides a national picture of the range of services hospices provide, but our data are incomplete. Not all hospices responded to the survey, and those that did were not able to provide all the information requested. These gaps in understanding hinder the effective development of end of life care services.

As outlined earlier, this is an important time for end of life care services across all four countries of the UK, and the hospice sector has an important role to play in these developments. Information on what hospices do and who they care for is essential for hospices to be able to contribute effectively to these discussions, and ensure that their services are designed to meet the needs of the populations they serve. In particular, the shift in place of death that has occurred during the pandemic makes it increasingly urgent for integrated care systems in England, and commissioners in Scotland, Wales and Northern Ireland, to understand local need and capacity for end of life care, across both specialist services and generalist community services.

New service models that hospices have developed over the past two years, along with closer working between organisations at a local level, could provide the basis for improving care at the end of life, and deliver services within communities rather than acute care settings. But, at the same time, it is important to recognise that these changes have taken place within a context of immense resource pressure, and are likely to have had a significant impact on staff wellbeing. Further research to understand the *sustainability* of these changes has been noted as key,[37] as well as a better understanding of whether public attitudes about and expectations of end of life care have changed.

Improving information about the hospice sector

Information on hospice activity is essential to understanding the role hospices play in providing care to people across the UK, including who is accessing their support. This can help to inform both the commissioning and provision of palliative care services. But it is also important for hospices themselves to understand how they can most effectively support the people in their local area, and highlight the significant contribution they make to providing palliative care.

The survey for this research has highlighted significant gaps in the data that hospices were able to provide. Only a sample of the hospices in the UK were able to respond, with smaller hospices, children's hospices and Welsh hospices less well represented in the survey.

Along with variation in the overall response rate, there was also variation in the questions that hospices were able to answer. Critically, hospices often do not collect data about the characteristics of the people they support, which poses a significant challenge to ensuring equal access to hospice services. There are long-standing concerns that hospices are less accessible to some communities and groups,[38] but we were not able to explore this in our analysis because of the limited data that hospices were able to provide. Hospices do not necessarily collect demographic information for contacts with services such as bereavement services. Any future data collections need to consider how best to capture the breadth of activity that hospices undertake beyond that for their palliative care patients.

Hospices report systemic challenges in collecting data, including capacity and resource constraints, and a lack of agreed definitions and standards for hospital activity. These exacerbate the challenges of responding to data requests from local and national stakeholders.

The Covid-19 pandemic has impacted on activity but it will have also impacted on other aspects of hospice data. There has been a big focus on data as a result of the pandemic and this may have led to changes in data collection. Hospices may have also been more aware of the need to record certain types of activity, such as virtual contacts.

A number of initiatives are already under way to improve this situation, at both national and regional levels. However, there is a lack of coordination between organisations working to improve data from hospices. There is a particular need for organisations to align data collection requirements and standards, and to ensure that smaller hospices are engaged and supported.

Recommendations for improving information about hospice services

Improving information about hospice services across each of the four UK countries requires a strategic approach and action to address current challenges. National policy organisations, commissioners, hospices and information system suppliers all have a key role to play in this. Specific areas for action include the following:

- Consistent standards for collecting and reporting data, and for describing the range of services that hospices provide and the people receiving care, need to be developed. This must be led centrally but with strong engagement from the hospice sector and information system suppliers.

- There needs to be clarification on how data about hospice activity aligns with data collections from NHS services, and data collections from hospices that are required for different purposes or systems, including national and local requirements, need to be streamlined.

- For end of life care to engage with hospices, including small providers, and the hospice workforce to establish the case for improved data collection and collaboration across the sector to achieve this, national stakeholders need a consistent approach.

- Organisations commissioning services and hospice providers need to recognise that greater investment in information infrastructure for hospices is required, including staff skills, from data collection through to analysis and reporting.

- Avenues for hospices to support each other with data collection processes and share best practice need to be established. For example, Hospice UK could support the sector by providing a forum for hospices to network and share learning and expertise in the use of information, and engaging with national organisations with a remit for data, information, commissioning and policy.

- The hospice sector needs to be supported to recognise the benefits that could be accrued from improving data collection, including monitoring and developing services, improving access and equity, and demonstrating benefit.

Annex 1: Survey questions

Patient activity (2018/19–2020/21)

1 Total number of patients to whom you provided care across all services that you record.

2 How many patients used services in the following settings (including virtually)?

3 How many times did patients access services in the following settings (including virtually)?

4 How many times did patients access the following services virtually?

5 How many patients have accessed the following services (in any setting)?

6 How many times did patients access the following services (in any setting)?

7 Respite care – number of contacts (where recorded).

8 Referrals – how many referrals were accepted as patients from the following sources?

9 For all inpatient discharges, where were the patients discharged to?

Your patients (2020/21)

10 Gender

11 Ethnicity

12 Age

13 Religious affiliation

14 Sexual identity

15 Living arrangements

Patient needs (2020/21)

16 Primary diagnosis upon entry to service

17 Phase of illness upon entry to service

18 Functionality of patients upon entry to service (Australia-modified Karnofsky Performance Status [AKPS] scale)

Patient preferences (2020/21)

19 a. Advance care planning – how many inpatients have/had a documented plan?
b. Advance care planning – how many other patients (including hospice at home patients and outpatients) have/had a documented plan?

20 For those without an advanced care plan, what is the reason?

Annex 2: Survey response rate

Only 33% (eight) of the children's hospices returned the survey, while 63% (104) of the adult hospices and 94% (15) of the combined adult and children's hospices did. There was a relatively low response from hospices with an expenditure of less than £1 million in 2020/21 (see Table 5).

Table 5: number and percentage of hospices responding by hospice expenditure

Expenditure	Responded	Total	Response rate
< £1 million	2	21	10%
£1 million to < £3 million	18	34	53%
£3 million to < £5 million	34	50	68%
£5 million to < £10 million	42	63	67%
£10 million to < £20 million	17	21	81%
£20 million to < £30 million	5	7	71%
£30 million to < £40 million	0	0	0%
£40 million to < £50 million	9	9	100%
Total	**127**	**205**	**62%**

Note: Separate surveys were sent to each of the nine Marie Curie and seven Sue Ryder local sites, rather than treating Marie Curie and Sue Ryder as two organisations.

Annex 3: Comparisons with other data

For some questions, we compared values to data that Hospice UK had previously collected and reported on. This was only possible for certain questions as the definitions we used for services and settings had been updated and, therefore, did not always align to previous Hospice UK work.

We compared the survey data we collected to other published data sources, for example the number of deaths per age group reported by the national statistical bodies: National Records Scotland, Northern Ireland Statistics and Records Office and Office for National Statistics.

We also looked at how hospice activity was recorded in national patient datasets, including Hospital Episode Statistics (HES) and the Community Services Data Set (CSDS). Hospice activity was rarely separated from the hospitals they were located in and therefore limited conclusions could be drawn from HES, and the CSDS has only recently started recording care provided at a small number of hospices. We have therefore not included any further analysis of this.

Annex 4: Change in place of death across the UK during the pandemic

Table 6: Number of registered deaths in the UK by place of death compared to the 5-year average, week 11 2020 to week 10 2022

		Home	Hospital	Care home	Other
England and Wales	Actual	342,723	520,758	255,565	82,758
	5-year average	251,892	499,630	234,347	84,576
	Excess	90,831	21,128	21,218	-1,818
Scotland	Actual	42,518	57,420	28,138	566
	5-year average	31,00	57,579	27,209	506
	Excess	11,200	-153	1,062	54
Northern Ireland	Actual	11,820	15,736	6,427	1,753
	5-year average	8,983	15,053	6,259	1,906
	Excess	2,837	683	168	-153
UK	Actual	397,061	593,914	290,130	85,077
	5-year average	291,875	572,262	267,815	86,988
	Excess	105,186	21,652	22,315	-1,911

Nuffield Trust analysis of published data.

Note: 5-year average based on 2015 to 2019. Hospice included under 'Other' with the exception of Scotland where it is included under 'Care home'.

Sources: Office for National Statistics (2022) 'Deaths registered weekly in England and Wales, provisional'. Accessed 15 April 2022. National Records of Scotland (2022) 'Deaths involving coronavirus (COVID-19) in Scotland'. Accessed 15 April 2022. Northern Ireland Statistics and Research Agency (2022) 'Weekly deaths – week ending 25 March 2022'. Accessed 15 April 2022. Northern Ireland Statistics and Research Agency (2022) 'Excess mortality & Covid-19 related deaths – December 2021'. Accessed 15 April 2022.

Annex 5: Estimation method

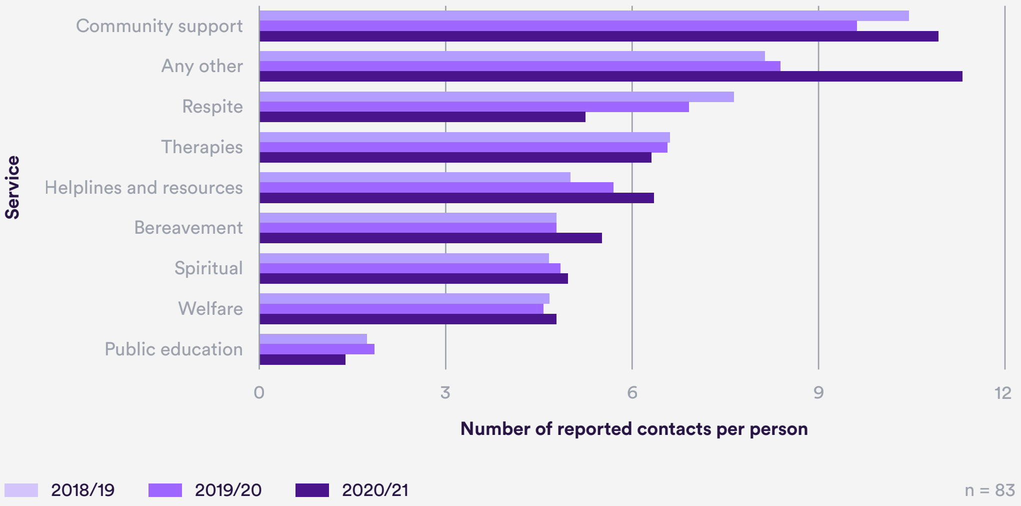
To gain an understanding of the total amount of care that the hospice sector provides, we estimated national activity, allowing for hospices that did not respond to the survey. To do this, we used hospice expenditure data provided by Hospice UK to calculate the average number of people using hospice services for every expenditure band (among the hospices that responded). We multiplied these averages by the number of hospices from each expenditure band that did not respond (either to the survey or to the individual questions within the survey), to get an estimated number of people. We then combined this with the numbers of people who were reported in the survey as using hospice services to get a total number of hospice service users.

Annex 6: Contacts per person

Figure 16: Number of reported contacts by setting and year

n = 111

Figure 17: Number of reported contacts by service and year



n = 83

Annex 7: Country-specific activity

England

Figure 18: Number of reported contacts by setting and year for England

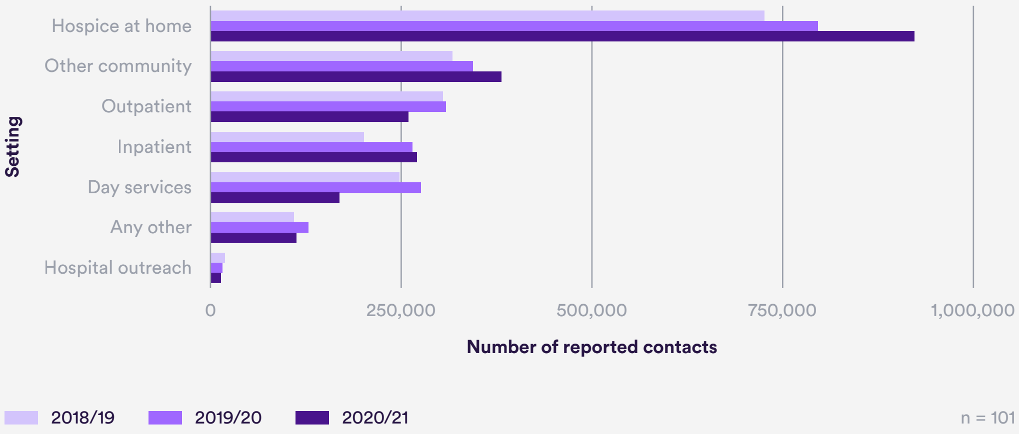


Figure 19: Number of reported contacts by service and year for England

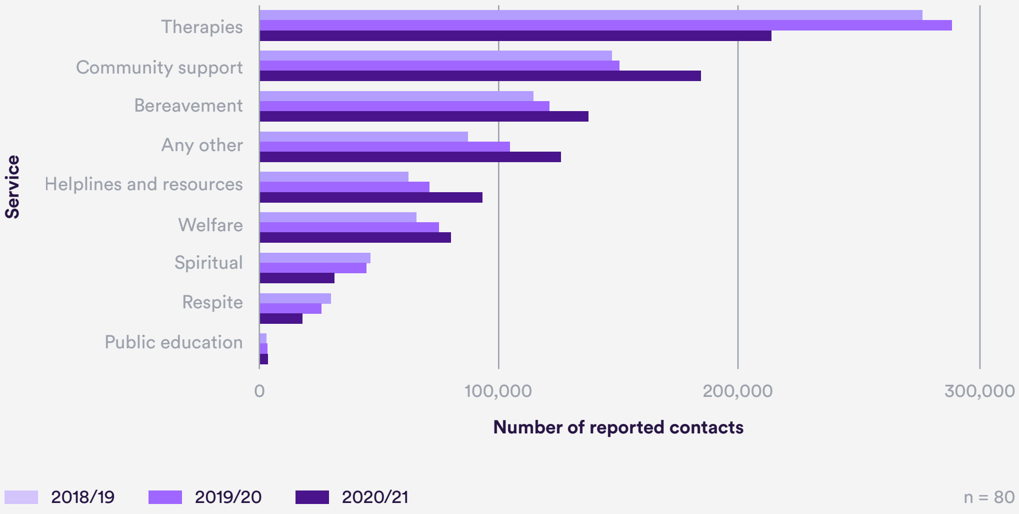


Figure 20: People using hospice services in 2020/21 by NHS England region: reported number of people and estimated total number of people per 100,000 population

Northern Ireland

Figure 21: Number of reported contacts by setting and year for Northern Ireland

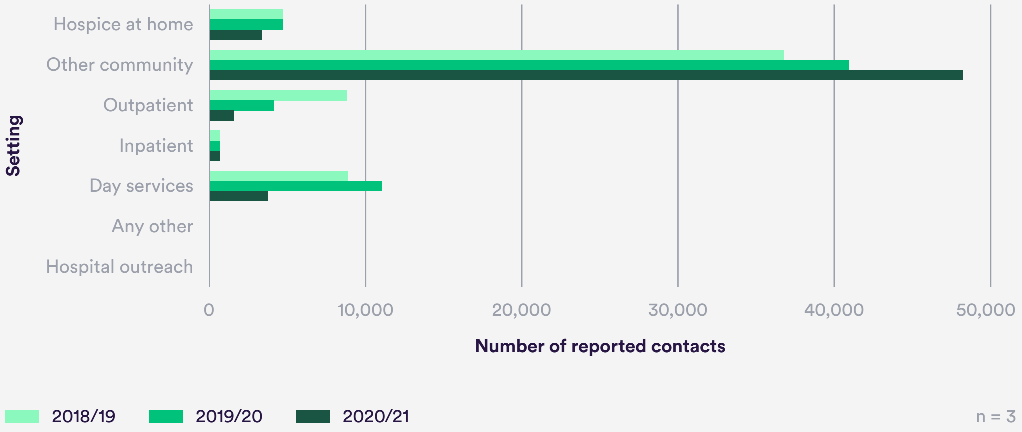
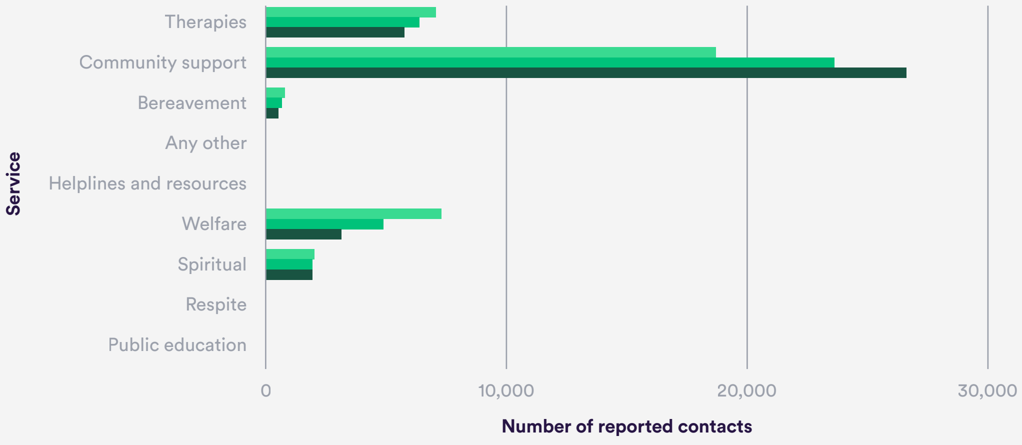
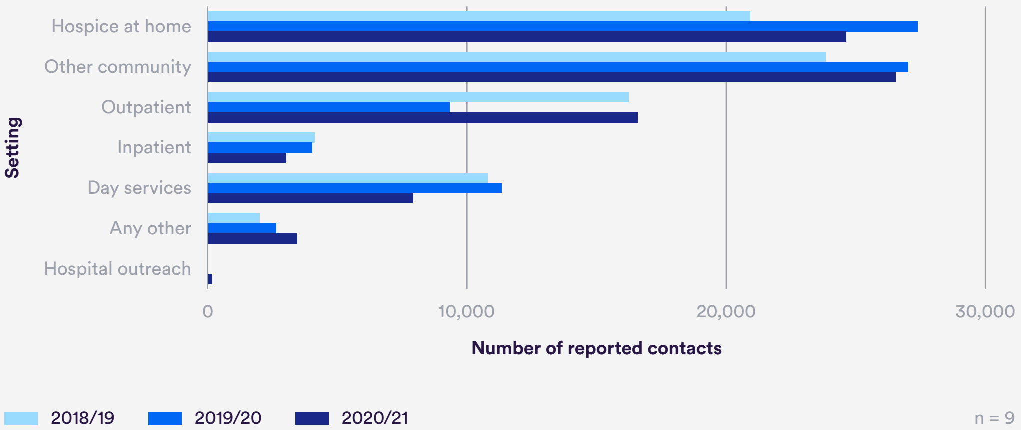


Figure 22: Number of reported contacts by service and year for Northern Ireland



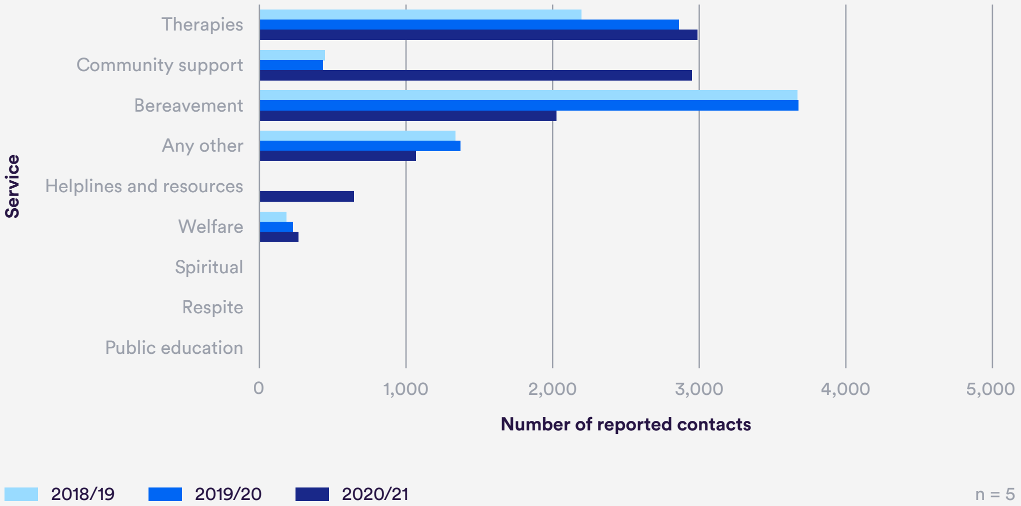
Scotland

Figure 23: Number of reported contacts by setting and year for Scotland



n = 9

Figure 24: Number of reported contacts by service and year for Scotland



n = 5

Wales

Figure 25: Number of reported contacts by setting and year for Wales

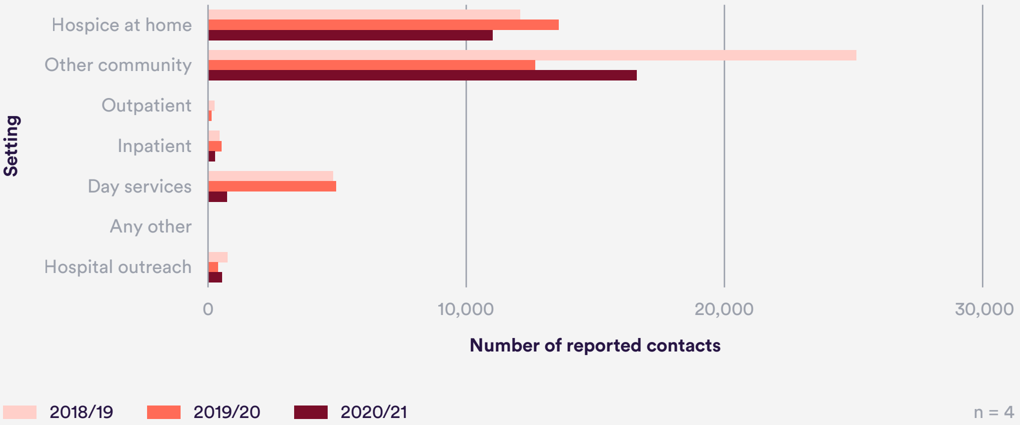
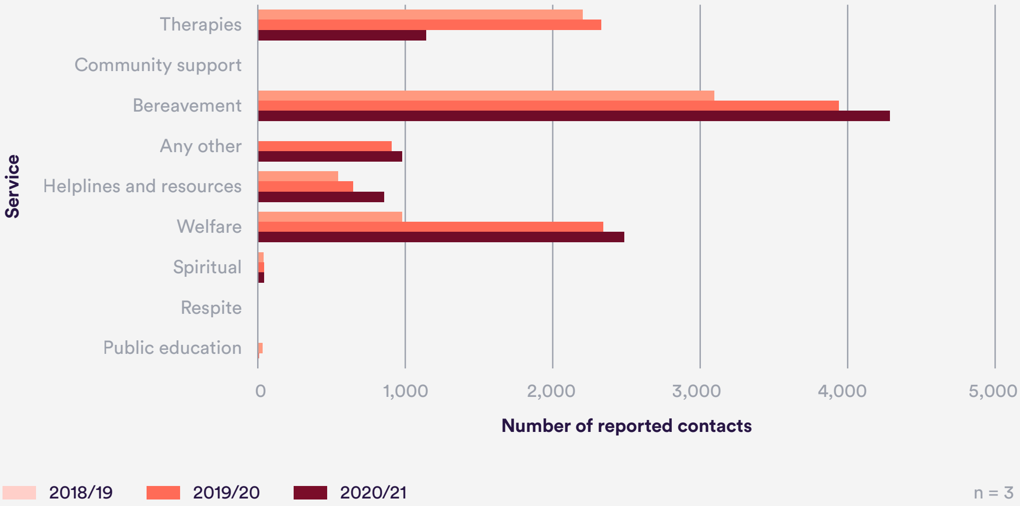


Figure 26: Number of reported contacts by service and year for Wales



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