Modelling demand and costs for palliative care services in England

A final report for Sue Ryder







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Executive Summary

The palliative care sector is facing rising demand for its services and there are growing concerns about the financial sustainability of the independent charitable sector. Financial pressure on the hospice sector was already increasing at the beginning of 2020, but the COVID-19 outbreak brought almost all fundraising activities to a halt, with a substantial loss in income for the hospice sector.

Sue Ryder has commissioned this research in response to the issue, which will explore the demand for palliative care services and the associated costs of service provision over the next ten years.

Palliative care services are provided to patients who are nearing the end of their lives to ensure that they can die comfortably, with dignity, and without pain. Research has shown that most people would prefer to die at home rather than in hospital, but hospital was still the most likely place of death in England in 2019 (although the number dying in hospital has been declining in recent years).

According to recent data, slightly less than 50% of all people dying in England receive palliative care and support (around 240,000 in 2018/19). Existing estimates suggest that many more individuals could benefit from receiving palliative care - up to around 215,000 additional people (455,000 in total), based on 2018/19 mortality figures and estimates that up to 90% of all people dying in England may have palliative care needs.

Costs of service provision for specialist palliative care services provided by the charitable sector have typically been funded with a combination of fundraising activities (donations, revenues from charity shops, events) and statutory funding via the NHS, which covered around 37% of total charity expenditure on palliative care services in recent years. Even before the impact of COVID-19, there were increased concerns over the ability of the charitable sector to continue to raise the required funds to meet current and future demand. These have increased further due to rising pressure on services and a drastic reduction in fundraising activities due to the COVID-19 crisis.

In this report we have projected future **demand and costs for providing specialist palliative care services over the next decade** (from 2021/22 to 2030/31). The projections do not take into account the COVID-19 effect and any emergency funding provided by the government to face the crisis.

When constructing demand projections, we have assumed that the number of people in receipt of palliative care will evolve in line with recent historical trends (at a positive but declining rate), predicting that numbers will rise from 240,000 in 2018/19 to 379,000 in 2030/31, corresponding to two thirds of total deaths by the end of the decade.

The growing demand projections were analysed alongside cost estimates to provide projections for expenditure on palliative care services under different funding scenarios, outlined below:

Table 1 Description of different cost scenarios – average annual cost over next ten years

		Share of total costs covered by	Total cost of palliative care	Average level of statutory
Name	Description	statutory funding	services (pa)	funding (pa)
Baseline	Baseline – funding arrangements as in recent years	37% of palliative care costs	£947m	£350m
Scenario 1	Statutory funding covers all clinical costs, plus a small contribution to other non-clinical costs	70% of palliative	£947m	£663m
Scenario 2	Full statutory funding - all independent sector palliative care costs covered by the NHS	100% of palliative care costs	£947m	£947m
Scenario 3	Palliative care is no longer provided by the independent sector - all palliative care services are provided by the NHS	100% of palliative care costs funded by the NHS	£834m	£834m

Note: Costs presented are in 2020 prices (adjusted for expected inflation but not discounted) over the period 2021/22-2030/31 (annual average in £million). Figures refer to the 'Increasing demand' scenario. 'Increasing demand': proportion receiving services increases over time as a share of total deaths but at a declining rate. In the baseline scenario, scenario 1 and scenario 2, the independent sector provides palliative care services as in the existing situation, with varying levels of statutory funding. In scenario 3 the independent sector no longer provides palliative care services, which are directly provided by the NHS.

Source: London Economics projections

The main findings and assumptions used in the analysis are presented in the box below. All figures are in 2020 prices and calculated as an average over the next decade.

Key findings

- The number of patients in receipt of palliative care services is projected to increase from 240,000 in 2018/19 to 379,000 by 2030/31 (rising from 47% to 66% of total deaths) reflecting recent trends in demand;
- The baseline scenario is modelled on recent levels of statutory funding across the sector (37% of palliative care costs) the cost of providing palliative care services is estimated at an average of £947M per year, receiving statutory funding of around £350M per year;
- Statutory funding under Scenario 1 would rise to £663M per year, with additional costs for the government of £313M per year, compared to the baseline scenario. This scenario would see the statutory funding contribution rising from 37% to 70% of palliative care costs, but it would ensure that palliative care service provision is not affected by the prolonged effect of COVID-19 or other future shocks affecting the capacity of the independent hospice sector to raise funds;
- In Scenario 2 we have assumed that the charitable sector is no longer able to raise any funds and the gap is filled by statutory funding. The additional statutory funding required to plug this gap and continue independent palliative care services under the existing system is estimated at £597M per year on average;
- Scenario 3 assumes that the independent hospice sector collapses due to lack of funding and, as a result, the NHS would directly provide specialist palliative care to the people who need it. When modelling this scenario we have notionally assumed that the NHS would be able to meet the additional demand for palliative care services although this is unlikely to be the case in practice. The cost for the NHS to provide directly these services was estimated at £834M per year (an additional expenditure of £484M per year compared to the baseline scenario).

However, when comparing Scenario 3 with the other scenarios (modelled under the existing care provision arrangements), it should be noted that if someone is in an NHS hospital rather than a hospice receiving palliative care they are less likely to receive the holistic support that people in hospice care receive as the focus would be on pain and symptom management. Also, the care and support provided to families and others, particularly around bereavement, would largely no longer exist.

1 Introduction

Palliative care is the care and support given to individuals with advanced, progressive, and/or incurable conditions such as cancer, heart failure and lung disease. Palliative care aims to provide these individuals and their families with the best possible quality of life in their given circumstances by managing pain and other symptoms in the last weeks, months or years of their lives (palliative care is available at any point during a life shortening illness, so it does not necessarily coincide with end-of-life care). It can also include giving practical and emotional support to patients and those close to them. Palliative care can be provided in various settings including at home, in a hospice or hospital depending on patients' needs and preferences.

Specialist palliative care services are provided by clinicians with specific skills and experience to assess and manage complex needs and improve quality of life, and are able to support both the patient and their families. Specialist palliative care professionals are also able to liaise directly with GPs, nurses and other professionals treating the patient. General or non-specialist palliative care is provided to patients with a terminal illness by professionals with general competencies and skills, but not specific competencies on providing care and support for end-of-life patients who have complex needs as a result of their terminal illness.

Specialist palliative care services in the United Kingdom are provided by charities in the independent sector, with two large national providers, Sue Ryder and Marie Curie and around 200 small charitable providers (the 'hospice' sector)¹. Specialist palliative care services are generally provided in Inpatient Units (IPU) where patients are admitted and receive a range of care and support services, or through community-based services, either in the patient's own home (Hospice at Home and/or clinical specialist nurse service) or in the hospice itself (day care and outpatients). Palliative care may also be provided by NHS healthcare professionals. In this research we focused on specialist palliative care services provided by the independent charitable sector.

Historically, the provision of specialist palliative care services by the independent sector has been partially funded by the NHS (with a share ranging between less than a fifth to two fifths of total expenditure) with the rest of the funds raised from donations, fundraising activities, charity shops etc. Information gathered from Hospice UK (the national hospice membership charity) showed that, even before the start of the COVID-19 outbreak, around 90% of surveyed hospices reported a lack of resources to meet increasing demand for services, and one fifth were thought to be at risk of imminent closure due to extreme financial difficulties².

Fundraising activities have been severely hit by the COVID-19 crisis with significant financial implications (at least in the short term) for charities providing palliative care services. In fact, Sue Ryder reported a fall in retail income of around 65% between April and December 2020 compared to the same period in the previous year³. By October 2020 about two thirds of hospices in England were reported to have started planning for redundancies.

The government provided emergency funding for the hospice sector in 2020 to cope with the COVID-19 crisis (around £200 million) and a second round of funding has been announced for the winter period (up to £125 million). However, these measures are ad-hoc and not designed to address the

¹ See Hospice UK (2019). Hospice Accounts. Available at https://www.hospiceuk.org/what-we-offer/hospice-finance/benchmarking

² Information gathered from Hospice UK in 2019 and reported by Sue Ryder

³ Information supplied by Sue Ryder

longer-term financial sustainability of the palliative care sector; also they may not fully cover the shortfall in income due to the COVID-19 crisis.

Sue Ryder, one of the largest charities providing palliative care services in England, asked London Economics to project demand for palliative care services and the associated costs of service provision over the next 10 years. Key research aims of the analysis are:

- To provide an estimate on future demand for palliative care services in England from 2020/21 to 2030/31;
- To estimate the total costs of service provision for the independent palliative care sector over the same horizon under a 'business as usual' assumption (baseline scenario);
- In the baseline scenario, to estimate the cost for the government assuming that the statutory funding will stay at similar levels observed in recent years (around 37% of total expenditure on palliative care services in England);
- To estimate the cost to government if clinical costs are covered by the NHS, amounting to 70% of total palliative care costs, while the hospice sector raises funds to cover the other costs this is defined as 'scenario 1';
- To estimate the cost for the government if the charitable sector is no longer able to raise any funds and the NHS needs to cover 100% of overall costs of palliative care service provision, assuming that palliative care services are provided as usual ('scenario 2');
- To provide an alternative scenario ('scenario 3') where independent palliative care services are no longer provided by the independent sector and the NHS provides directly all palliative care services. This alternative scenario was modelled under the assumption that the NHS would have enough capacity to meet the additional demand, however that is unlikely to happen in practice.

For the purposes of the analysis, we have assumed throughout the report that the supply of services is able to accommodate demand (however, that may not be the case) and only considered direct costs of healthcare services provided by the NHS, excluding the cost of any informal care provision and also any social care costs⁴.

In the next section we present a brief review of the relevant literature, while in section 3 we discuss demand projections and in section 4 we present the estimated costs of service provision in the different scenarios.

Potential COVID-19 implications

Although the COVID-19 crisis may be having a significant effect on demand for palliative care services, either directly or indirectly as people delay seeking medical advice or healthcare services are interrupted, we are not aware of any existing data or research providing an assessment of the impact of COVID-19 on palliative care services. Our analysis covers a 10-year horizon and all of the historical demand and cost data used in the analysis refer to the pre COVID-19 period. All this means that we have not made any adjustment for the impact of COVID-19 on demand for palliative care services in our modelling, but it should be noted that such an effect is likely to exist and become visible in the near future.

⁴ Social care costs are borne by local authorities or patients (depending on their income and asset levels)

2 Brief review of literature on specialist palliative care

Demand for palliative care services

Existing literature suggested that demand for palliative care may be higher than the current supply of palliative services. Murtagh et al (2014) estimate the number of total patients with palliative care needs in England based on mortality data from 2006-2008. They find that between 63% and 82% of all patients who die, die from conditions associated with needing specialist palliative care. In 2006-2008 the authors estimate that between 100,000 and 242,000 individuals were receiving palliative care annually, while the number of individuals who could benefit from such care was between 298,000 and 387,000. This suggests that there are a substantial number of patients who are currently being excluded from the palliative care sector. In 2016 Marie Curie, a charity which also provides palliative care, replicated the methodology used by Murtagh et al (2014) using data from 2012-2014. They found that the number of deaths of patients in England with palliative care needs increased from between 63%—82% to between 74%-90% of all patients.

The literature suggests that the demand for palliative care will continue to increase due to population growth and a rise in the proportion of individuals who die of illnesses associated with needing palliative care. Etkind et al (2017) estimate the number of individuals who will need specialist palliative care by 2040. The authors find that based on mortality statistics and population projections for England and Wales, annual deaths will rise by 25.4% by 2040. Based on the annual increase in deaths from chronic, progressive illnesses such as dementia, cancer and organ failure over the period from 2006-2014, the number of individuals who will need palliative care will increase by 42.4%. Therefore, when projecting need for 2031/31, the increased demand projection is more likely than constant demand.

Cost of care at the end of life

The care for patients with chronic diseases accounts for a substantial proportion of NHS costs. In an analysis of national hospital data from 2005/06 Hatziandreou, Archontakis and Daly (2008) found that only 5% of hospital patients accounted for almost 50% of all inpatient bed days. It is estimated that in England and Wales 35% of deaths are caused by circulatory disease, 27% by cancer, and 14% by respiratory disease (Hatziandreou, Archontakis and Daly, 2008). Although most individuals express a preference for dying and being cared for at home almost half of all deaths, 46%, occur in hospital (ONS, 2019) and 90% of people spend time in hospital in the last year of life (Public Health England, 2017).

Gardiner, Ward, Gott and Ingleton (2014) examine data from two large hospitals in the UK to determine the extent of potentially avoidable hospital admissions among patients in their last year of life. They find that 7.2% of all hospital admissions could have been avoided by dealing with them in nursing homes, in patients' homes or hospices. Abdel, Rich, Griffin and Purdy (2009) used a similar methodology and found that at least 20% of their sample could have clearly stayed at home, and a further 13% probably could have stayed at home if palliative care services were available. In addition, the authors found that almost one-third of all hospital deaths could have occurred at home if end of life services were in place. This finding is similar to a report written by The Balance of Care Group (2008) which found that around 40% of deaths that occurred in hospitals could have occurred in patients' homes if the right care and support had been put in place.

Hospital costs are the largest cost element of end-of-life care, predominantly due to a high rate of emergency hospital admissions. On average, total hospital care costs around £4,500 per person in

the last three months of life (Georghiou and Bardsley, 2014). Chitnis, Georghiou, Stevenson and Bardsley (2012) find that patients who had access to Marie Curie Nursing Services were significantly more likely to die at home than patients who did not have access (76.7% versus 34.9%). These patients were also less likely to use all forms of hospital care, which resulted in an average savings of £1,140 per person over the 2-year study. The net savings for cancer patients was estimated to be slightly higher at £1,475 per patient.

Gade et al. (2008) analyse the results from a randomised controlled trial with over 500 patients with life-limiting diseases in the United States. Patients in the intervention group received specialist palliative care services, while the control group received usual hospital care. Because patients in the intervention group had access to support from palliative care specialists, they had fewer emergency calls and intensive care admissions resulting in lower total health care costs of around 23%⁵ per person.

Wellbeing impact of specialist palliative care

Specialist palliative care has an additional advantage over hospital care as it can offer a higher quality of life in the final period of patients' lives and provides greater satisfaction with care (Gade et al, 2008). Addington-Hall and O'Callaghan (2009) surveyed the bereaved relatives of cancer patients who had received treatment in both hospitals and hospices in the last three months of their lives. Although their study was limited by a small sample (n=40), the authors found statistically significantly higher ratings for hospices in almost all wellbeing variables measured. These variables include pain control, communication with patients and families and overall better medical, personal and nursing care. Bereaved relatives also reported that hospice staff treated the patient with more dignity. Higginson and Evans (2010) also found higher overall levels of wellbeing in their review of evidence on specialist palliative care in different settings, and Gaertner et al. (2017) found that specialist palliative care is associated with an increase in quality of life compared with standard care. The impact of palliative care on quality of life is especially pronounced for cancer patients, and patients who receive care early on in their illness (Gaertner et al, 2017).

Wellbeing impacts are clearly difficult to quantify precisely and often are based on studies relying on relatively small sample sizes. However, existing evidence points to a greater quality of life for patients in receipt of palliative care services. As part of the quantitative analysis, we have not quantified explicitly these additional wellbeing costs, but when assessing the cost of the different scenarios it should be considered that there are additional non-monetary costs associated with the removal of palliative care services.

⁵ In absolute terms, the lower costs were estimated at \$4,885 (circa £3,000) per person in 2002/03 prices

3 Demand projections for specialist palliative care in England

In order to estimate existing and future demand for palliative care services we used the **following** data sources:

- Number in need of palliative care services: the number of patients in need of palliative care/support, as recorded on General Practice disease registers, irrespective of age (source Quality and Outcomes Framework (QOF), NHS Digital, provided by Public Health England).⁶ The series currently covers the period from 2009/10 to 2018/19 and refers to England;
- Number of people receiving palliative care support and volume of services provided in the United Kingdom during 2016/17 published by Hospice UK;^{7,8}
- Number of deaths (historical and projected) from the Office for National Statistics.⁹

Neither data series with information on demand is ideal for the analysis as the Public Health England series records the number of patients in need of palliative care services according to GP assessment, but not actual service provision. Also, the number on the register increased from 75,000 to 240,000 in a decade, probably reflecting both an increase in demand, but also improvements in the data quality over time.

The Hospice UK data captures service provision but has not been updated since 2016/17. As it relies on collection of data from hospices themselves, it does not provide a consistent series over time¹⁰ and has some potential data quality issues¹¹. The data covers the whole of the UK and focusses on adults only.

As a result, a comparison of the two data sources is problematic: however, data for 2016/17 from PHE estimated 215,000 people on the general practice disease register (all ages, England only) compared to an estimate of 212,000 (UK wide but adults only) from Hospice UK in the same year.

In the model we proxied demand using the Public Health England series as it is available over the last 10 years and England-specific, while data from Hospice UK data was used when looking at the different services provided.

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⁶ Public Health England (2019). Palliative and End of Life Care Profiles. [Data Repository] Available from <a href="https://fingertips.phe.org.uk/end-of-life#page/3/gid/1938133060/pat/15/par/E92000001/ati/154/are/E38000004/iid/294/age/1/sex/4/cid/4/page-options/ovw-do-ocar-do

⁷ Hospice UK (2017). Hospice Care in the UK 2017: From numbers to insights. Retrieved from https://www.hospiceuk.org/docs/default-source/Policy-and-Campaigns/briefings-and-consultations-documents-and-files/hospiceuk hospice-care-in-uk 2017.pdf?sfvrsn=2">https://www.hospiceuk.org/docs/default-source/Policy-and-Campaigns/briefings-and-consultations-documents-and-files/hospiceuk hospiceuk hospice-care-in-uk 2017.pdf?sfvrsn=2">https://www.hospiceuk.org/docs/default-source/Policy-and-Campaigns/briefings-and-consultations-documents-and-files/hospiceuk hospiceuk hospice-care-in-uk 2017.pdf?sfvrsn=2">https://www.hospiceuk.org/docs/default-source/Policy-and-Campaigns/briefings-and-consultations-documents-and-files/hospiceuk hospiceuk hospice

⁸ Hospice UK (2015). Minimum Data Set (MDS) for the years 2014-2015. [Data file]

⁹ Office for National Statistics (ONS) (2019). Mortality statistics – underlying cause, sex and age. [Data Repository]. Available from https://www.nomisweb.co.uk/datasets/mortsa

¹⁰ Hospice UK used to collect and publish data from hospices in the Minimum Data Set (MDS) for Specialist Palliative Care Services series, but that data collection has been discontinued after 2015/16 due to data quality issues.

¹¹ Data is extrapolated due to non-response and a figure for unique patients is calculated from the volume of service provision using an adjustment factor between 65%-70% (to account for double counting).

When estimating demand projections, we use two different methods, to reflect the uncertainty on existing and future demand for palliative care services:

- The first method ('increasing demand') assumes that demand will rise over the next decade as a proportion of deaths, but at a decreasing rate, reflecting recent trends¹² (the ratio demand/deaths is projected to rise from 47.4% in 2018/19 to more than 66% in 2030/31);
- The second method ('constant demand') assumes that the demand for palliative care services will stay constant as a proportion of deaths in the next decade at the 2018/19 level (47.4% of total deaths);
- These estimates compare to a 75% 'minimal' estimate for population-based need for palliative care services estimated in the literature¹³ (based on cause of death), i.e. the proportion of the population which may potentially benefit from palliative care services;
- Below we present the projected demand for palliative care services as number of patients (Figure 1) and as a proportion of total deaths (Figure 2). The demand for palliative care services is projected to rise from 245,000 in 2021/22 to 271,000 in 2030/31 in the 'constant demand' scenario and to 379,000 (in 2030/31) in the 'increasing demand' scenario.

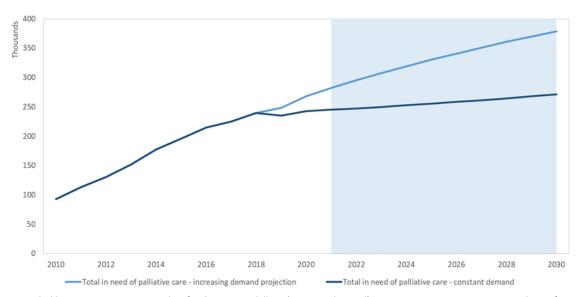


Figure 1 Demand projections, overall (2021/22 to 2030/31)

Note: Light blue area is projection window for the cost modelling. 'Constant demand': proportion receiving services as a share of total deaths stays constant over time (rising in line with deaths) at 2018/19 levels. 'Increasing demand': proportion receiving services increases over time as a share of total deaths but a declining rate.

Source London Economics projections based on ONS and Public Health England data

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¹² In order to project forward we calculated the historical three-year rolling average in the growth rate of the ratio demand/deaths and then computed the decay in the growth rate between consecutive years. The median decay in growth rates (around 86.8%) was used in the projections, meaning that the growth rate in the ratio in each year was assumed to be 86.8% of the growth rate observed or projected in the previous year.

¹³ See Marie Curie (2016) and Etkind et al (2017)

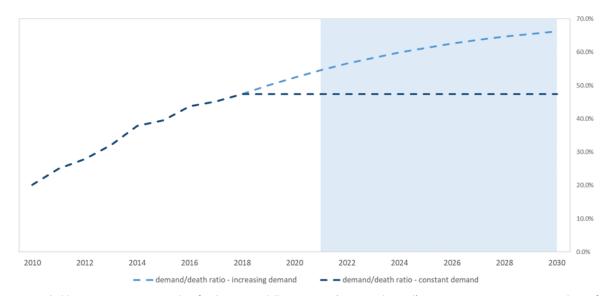


Figure 2 Demand for palliative care services as a share of total deaths (2021/22 to 2030/31)

Note: Light blue area is projection window for the cost modelling exercise. 'Constant demand': proportion receiving services as share of total deaths stays constant over time (rising in line with deaths) at 2018/19 levels. 'Increasing demand': proportion receiving services increases over time as a share of total deaths but a declining rate.

 $Source\ London\ Economics\ projections\ based\ on\ ONS\ and\ Public\ Health\ England\ data$

Key findings

- Demand for palliative care services is projected to rise from 245,000 in 2021/22 to 379,000 in 2030/31 assuming a steeper increase in demand (the most likely case) and to 271,000 in 2030/31 assuming a flatter increase in demand;
- These figures on number of patients correspond respectively to 47% and 66% of total projected deaths in 2030/31;
- Even the upper estimate is still below demand levels estimated in the literature and presented in section 2 (74%-90%), meaning that under both scenarios there will still be levels of unmet need. If this need was to be met, there would need to be greater levels of investment in palliative care services that those outlined in the scenarios in this report.

4 Costs of providing specialist palliative care in England

4.1 Baseline projections

In order to model the cost of providing specialist palliative care in England under the different scenarios we used information from hospice accounts (published by Hospice UK) and combined data on overall costs for palliative care services with the demand projections presented in the previous section. Total projected cost of palliative care service provision over time was generated as the number of people receiving palliative care services, multiplied by cost per person over time. Below we present the data used in the modelling and the assumptions used to generate total projected expenditure for the palliative care sector over the next decade.

- Income and expenditure data for the specialist palliative care sector: charity expenditure on palliative care services (excluding other expenditure, e.g. cost of fundraising activities) and the amount of statutory funding, from Hospice UK accounts publications (covering the financial years 2011/12 to 2017/18)¹⁴;
- Total charity expenditure in the UK was reported to be £969M in 2017/18. No breakdown by home nation or region is provided, so we allocated expenditure to England based on the English share of number of deaths in 2018 (82.1%), resulting in an estimated charity expenditure on palliative care services in England of £796M during 2017/18;
- Statutory funding covered around 37% of charity expenditure in the period considered (median across all available years)¹⁵;
- Nominal costs were deflated using actual or forecasted CPI to generate a constant price series (in 2020 prices);
- When computing the Net Present Value (NPV) of future costs we applied a 3.5% discount rate as in the Green Book.

In the baseline projections we assumed that cost per patient (defined as total expenditure divided by number of people in need of palliative care services) will stay constant in real terms (i.e. increase in line with inflation) in the 'constant demand' scenario, while in the 'increasing demand' scenario costs per patient are projected to decline in line with recent trends¹⁶. The combination of a rising demand and declining cost per person in the 'increasing demand' scenario results in a similar projected total expenditure under the two scenarios (as cost per person are kept constant in real terms in the 'constant demand' scenario, while declining in the 'increasing demand' scenario).

Costs of service provision may vary significantly across different types of services. High costs are associated with services provided in inpatient units (hospice settings providing accommodation as

¹⁴ Hospice UK (2019). Hospice Accounts. Available at https://www.hospiceuk.org/what-we-offer/hospice-finance/benchmarking

¹⁵ Based on Figure 1 of the Hospice Accounts reports, which refers to all charitable hospices, including the two national charities (Sue Ryder and Marie Curie) and covering financial years 2011/12 to 2017/18.

¹⁶ Trends in cost per patient may be declining due to a combination of available resources rising slower than demand and service provision shifting to less expensive services in terms of charity expenditure (e.g. hospice at home compared to inpatient units);

well as palliative care services) and lower costs (in terms of charity expenditure) are associated with services provided at home or in community settings (outpatients and day care).

However, there is no consistent information available over time on trends in demand or associated costs for each type of service. Consequently, we modelled demand and cost projections at the aggregate level, looking at total demand for palliative care services and the average cost per patient across all services¹⁷.

The cost projections are presented in Figure 3 and are very similar under the 'constant' and 'increasing' demand projections with total charity expenditure costs projected to rise in the 'increasing' demand scenario from £910M to £960M (in 2020 prices) between 2021/22 and 2030/31 (last year of the projections). The share per annum of the total costs met by statutory funding is assumed to remain at 37% of overall expenditure and is projected to rise from £340M to £360M in 2020 prices between 2021/22 and 2030/31 (in the 'increasing' demand scenario). For the purposes of the scenarios described in sections 4.2, 4.3 and 4.4 we use the 'increasing demand' projections.

In NPV terms, the total cost of providing palliative care services is projected to be around £7,860M between 2021 and 2031, with statutory funding covering about £2,900M. This corresponds to a total average expenditure of £947M and average statutory funding of £350M per annum (in 2020 prices).

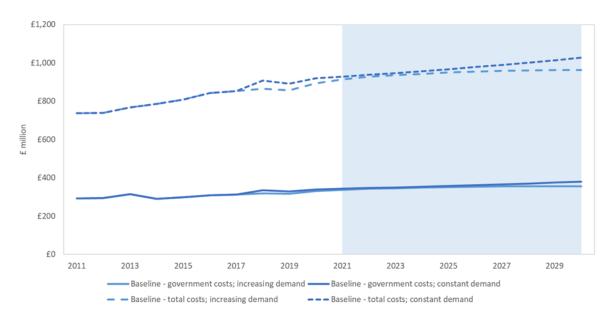


Figure 3 Cost projections – baseline scenario, 2020 prices

Note: Light blue area is projection window for the cost modelling exercise. 'Constant demand': proportion receiving services as share of total deaths stays constant over time (rising in line with deaths) at 2018/19 levels. 'Increasing demand': proportion receiving services increases over time as a share of total deaths but a declining rate. Statutory contribution set at 37% of overall expenditure in line with recent years.

Source London Economics projections based on ONS, PHE, Hospice UK and OBR data

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¹⁷ However, it should be noted that demand is split into different components when estimating the cost of alternative scenario in section 4.4.

4.2 Scenario 1

Under scenario 1 we assumed that all clinical costs are funded by the NHS (covering costs for doctors, nurses and clinical administrative staff), with a small contribution towards other costs (palliative management teams, catering, maintenance, domestic staff, therapy teams, family support teams, marketing, finance, IT and other costs relating to supplies and operating costs). and the shortfall covered by hospice fundraising This would equate to statutory funding to cover 70% of all costs, while the remaining 30% is paid for by hospice driven income.

Under this scenario, the total NPV cost for the public purse over the next decade is estimated to be around £5,500M, compared to £2,900M over the same period in the baseline scenario (which equates to an additional £2,600M over the period). The average statutory funding contribution over the decade would be £663M per annum (in 2020 prices) in scenario 1, with an additional £313M per annum in statutory funding compared to the baseline scenario (statutory funding is £350M per annum under the baseline projections). All reported figures refer to the 'increasing demand' scenario but are similar in the 'constant demand' scenario.

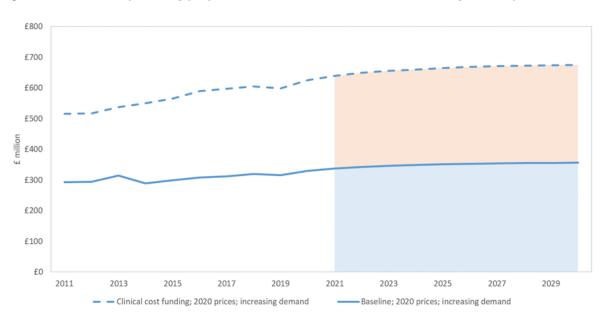


Figure 4 Statutory funding projections – scenario 1 ('clinical cost funding'), 2020 prices

Note: Light blue area identifies cost for the NHS in the baseline scenario. Light orange area identifies the additional costs for the statutory sector to fund all clinical costs. 'Increasing demand': proportion receiving services increases over time as a share of total deaths but a declining rate. Statutory contribution set at 37% of overall expenditure in baseline and 70% in the 'clinical cost funding' scenario.

Source London Economics projections based on ONS, PHE, Hospice UK and OBR data

4.3 Scenario 2

In the second scenario we have assumed that the hospice sector is no longer able to raise any of the necessary funds to fill in the gap between statutory contributions and charity expenditure and all costs (100% compared to 37% in the baseline and 70% in scenario 1) have to be borne by the statutory sector. The resulting total costs for the statutory sector over the decade are £7,860 (NPV) corresponding to an average of £947 per annum (2020 prices). Additional statutory costs over the decade are £4,960M (NPV), corresponding to an additional £597M per year on average (2020 prices).

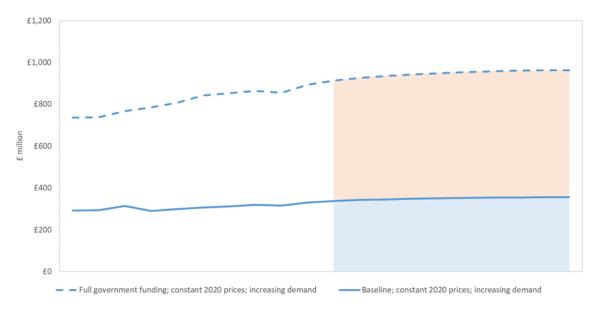


Figure 5 Statutory funding projections – scenario 2 ('full statutory funding'), 2020 prices

Note: Light blue area identifies statutory funding requirement in the baseline scenario. Light orange area identifies the additional statutory funding required to fund all costs of the hospice sector. 'Increasing demand': proportion receiving services increases over time as a share of total deaths but a declining rate. Statutory contribution set at 37% of overall expenditure in baseline and 100% in the 'full statutory funding' scenario.

Source London Economics projections based on ONS, PHE, Hospice UK and OBR data

4.4 Scenario 3 (alternative scenario)

All the scenarios discussed so far assume that palliative care services will continue to be provided as under the current arrangements, while in this section we present an 'alternative scenario' constructed assuming that palliative care services are no longer provided by the independent charitable sector, and the NHS needs to increase the direct provision of palliative care services to meet the additional demand. We have notionally assumed that the NHS would be able to cope with the additional demand, but that is unlikely to be the case in practice.

A different approach has been taken to modelling this scenario – the demand for palliative care has been classified into three different groups, based on the expected type of needs and palliative care service provision. When comparing Scenario 3 with the other scenarios (modelled under the existing care provision arrangements), it should be noted that if someone is in a hospital rather than a hospice receiving palliative care they are less likely to receive the holistic support that people in hospice care receive as the focus would be on pain and symptom management. Also, the care and support provided to families and others, particularly around bereavement, would largely no longer exist.

Below we present the assumptions used, how we estimated the size of each group and how we modelled the costs in this scenario.

Total costs for the alternative scenario are presented in Figure 6 and they are **projected to increase** from £718M to £937M between 2021/22 and 2030/31. This would be an additional cost of £4,000M (NPV) to the NHS in the 10-year period considered. The average annual total statutory funding required (direct costs for the NHS system) would be £834M with additional cost (compared to the baseline) of around £484M per annum over the decade.

Inpatient Units (IPU)

Demand for care and support services in **Inpatient Unit (IPU)** settings represented almost **16%** of all services provided in 2016/17 according to Hospice UK data. The proportion was assumed to stay constant at 16% in the 'constant demand' scenario and projected to decline slightly (to around 14% by 2031) in the increasing demand scenario (as demand shifts to other services);

Using information provided by Hospice UK and Sue Ryder on median length of stay for IPU patients we estimated the cost for the NHS for the **last 14 days of life** of these patients in the alternative scenario. The **daily cost of service provision was set at £447** in 2019/20 (based on estimates from PSSRU¹⁸) and uprated using CPI forecasts;

The resulting cost in 2021/22 to provide NHS services for this group of patients (in the absence of palliative care services) is approximately £411M in the 'increasing demand' scenario.

Hospice at Home

For those currently receiving care and support at home (Hospice at Home) we looked at the number of patients and volume of services provided using information from Hospice UK¹⁹. Demand for these services represented 56% of all palliative care services in 2016/17 and the proportion was kept constant in the 'constant demand' scenario, while increased slightly over time (to 57% by 2031) in the 'increasing demand' scenario. The average number of visits across all patients was set at 5.95 using information from Hospice UK, while the cost per unit was drawn from the 'National Schedule of NHS Costs - Year 2018-19'²⁰ and set at £103 per care contact (figure uprated using CPI forecasts after 2018/19).

Total costs in 2021/22 for services provided to this group were estimated to be around £156M in the 'increasing demand' scenario.

Community settings

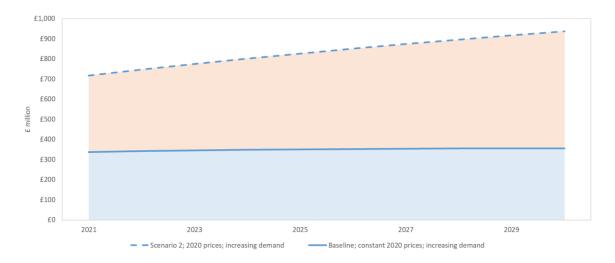
The remaining group of patients receive care and support in **community settings** (outpatients and day care) and account for 28% of services provided (rising to 29% by the end of the period in the 'increasing demand' scenario). Using information provided by Sue Ryder we estimated the number of visits and duration of each visit currently received by these patients.

Over the **6-month period** in which they receive services patients have on average 11 face to face contacts (with length between 30 minutes and one hour) and 28 telephone contacts (with length between 15 and 30 minutes) for a total of 15.5 hours of services provided.

These figures on services provided were combined with NHS unit costs for Specialist Palliative Care²¹ provided face to face (£103 per care contact, assumed to correspond to one hour) and non-face to face (£33 per care contact, assumed to correspond to 30 minutes) to generate overall costs for this group under the alternative scenario, estimated at £161M in 2021/22 (in the 'increasing demand' scenario).

Figure 6 Cost projections – alternative scenario compared to the baseline, 2020 prices

¹⁸ See the figure for 'Inpatient, specialist palliative care (adults only), average cost per bed day' reported in Curtis, Lesley A., Burns, Amanda (2020) Unit Costs of Health & Social Care 2020. Unit Costs of Health and Social Care. PSSRU, University of Kent.



Note: Light blue area under the solid line identifies statutory funding required for the baseline scenario. Light orange area identifies the additional costs over the baseline. 'Increasing demand': proportion receiving services increases over time as a share of total deaths but a declining rate. Statutory contribution set at 37% of overall expenditure in baseline. 'Scenario 2' assumes no provision of specialist palliative care services by the independent sector and increased demand for NHS specialist palliative care services. Constant 2020 prices *Source London Economics projections based on ONS, PHE, NHS, Sue Ryder, Hospice UK and OBR data*

4.5 Cost projections - summary findings

Below we present the key findings from the analysis and the various scenarios modelled. The baseline scenario and scenarios 1 and 2 are modelled based on the same assumptions and with the same overall cost of providing palliative care services, while scenario 3 (the 'alternative' scenario) is constructed based on the assumption that palliative care services are no longer provided by the independent care sector, but the NHS provides specialist palliative care to the people who need it.

Key findings

- The total cost (Net Present Value) of providing palliative care services in the 'increasing demand' scenario is estimated at £7,860M over the next decade, with the statutory funding of around £2,900M required in the baseline scenario;
- The difference between the statutory funding contribution and the cost of service provision has traditionally been covered by fundraising activities. However, there are increased concerns over the ability of the charitable sector to raise the required funds in the future to meet demand, due to increased pressure on services and a drastic reduction in fundraising activities due to the COVID-19 crisis. This could have a significant impact on services provided and on the wellbeing of patients and their families;

London Economics

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¹⁹ Hospice UK (2017). Hospice Care in the UK 2017: From numbers to insights. Retrieved from https://www.hospiceuk.org/docs/default-source/Policy-and-Campaigns/briefings-and-consultations-documents-and-files/hospiceuk hospice-care-in-uk 2017.pdf?sfvrsn=2">https://www.hospiceuk.org/docs/default-source/Policy-and-Campaigns/briefings-and-consultations-documents-and-files/hospiceuk hospice-care-in-uk 2017.pdf?sfvrsn=2">https://www.hospiceuk.org/docs/default-source/Policy-and-Campaigns/briefings-and-consultations-documents-and-files/hospiceuk hospice-care-in-uk 2017.pdf?sfvrsn=2">https://www.hospiceuk.org/docs/default-source/Policy-and-Campaigns/briefings-and-consultations-documents-and-files/hospiceuk hospice-care-in-uk 2017.pdf?sfvrsn=2">https://www.hospiceuk hospiceuk hospic

²⁰ https://www.england.nhs.uk/national-cost-collection/ code N21AF 'Specialist Nursing, Palliative/Respite Care, Adult, Face to face'

²¹ 'National Schedule of NHS Costs - Year 2018-19' codes N21AF 'Specialist Nursing, Palliative/Respite Care, Adult, Face to face' and N21AN 'Specialist Nursing, Palliative/Respite Care, Adult, Non face to face', see https://www.england.nhs.uk/national-cost-collection/

- In Scenario 1 we have assumed that statutory sources pay for clinical care costs (70% of the total) while the hospice sector raises funds for the remainder of costs. The additional statutory funding required for palliative care services is estimated at £2,600M over the next decade in NPV terms. This scenario would ensure the long-term financial viability of the hospice sector and that palliative care service provision is not affected by the prolonged repercussions of the COVID-19 crisis or similar shocks in the future.;
- In Scenario 2 we have assumed that the independent sector is no longer able to raise funds and the gap is filled by the public sector (100% of costs are covered by statutory funding). The additional statutory funding required for maintaining the operation of independent sector palliative care services is estimated at £4,960M over the next decade in NPV terms;
- we have constructed an alternative scenario (Scenario 3) which assumes that specialist palliative care services are no longer provided by the independent sector, but there is an increased provision of NHS specialist palliative care services to meet the additional demand²². The estimated cost of this option for the public purse is around £6,880M over the next decade, with an additional cost of almost £4,000M compared to the baseline scenario (all in NPV terms over the decade). People receiving NHS specialist palliative care services are less likely to receive the holistic support that people in hospice care receive as the focus would be on pain and symptom management. Also, the care and support provided to families and others, particularly around bereavement, would largely no longer exist.

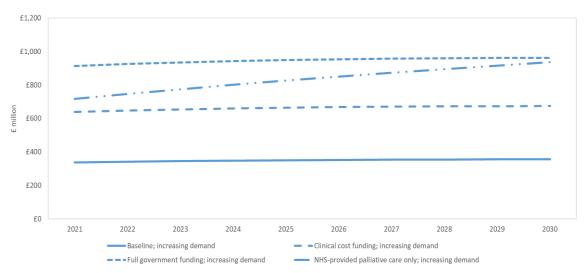


Figure 7 Cost projections summary for the 'increasing demand' scenario – 2020 prices

Note: 'Increasing demand': proportion receiving services increases over time as a share of total deaths but a declining rate. Statutory contribution set at 37% of overall expenditure in baseline, 70% in the 'clinical cost funding' scenario and 100% in the 'full statutory funding' scenario. 'NHS provided pallaitive care only' assumes no provision of specialist palliative care services by the hospice sector and increased demand for specialist palliatve care services provided by the NHS. Constant 2020 prices.

Source London Economics projections based on ONS, PHE, Hospice UK and OBR data

London Economics

²² When modelling this alternative scenario we have notionally assumed that the NHS has the capacity to meet the increased demand for specialist palliative care services; however, that is unlikely to be the case in practice.

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Annex 1 Tables

Clinical cost funding (scenario 1) and baseline

Table 2 Nominal (cash) costs for government funding of clinical costs and cost in the baseline; £ million

a) Increasing demand projection

	2021/22	2022/23	2023/24	2024/25	2025/26	2026/27	2027/28	2028/29	2029/30	2030/31
Cost of funding clinical costs	£648m	£670m	£691m	£710m	£729m	£748m	£766m	£783m	£801m	£817m
Baseline	£342m	£354m	£365m	£375m	£385m	£395m	£404m	£414m	£423m	£431m
Difference in costs	£306m	£316m	£326m	£335m	£344m	£353m	£362m	£370m	£378m	£386m
) Constant demand projection										
	2021/22	2022/23	2023/24	2024/25	2025/26	2026/27	2027/28	2028/29	2029/30	2030/31
Cost of funding clinical costs	£659m	£677m	£698m	£721m	£743m	£766m	£791m	£817m	£843m	£871m
Baseline	£348m	£357m	£369m	£380m	£392m	£405m	£418m	£431m	£445m	£460m
Difference in costs	£311m	£320m	£330m	£340m	£351m	£362m	£373m	£386m	£398m	£411m

Source: London Economics projections

Table 3 Costs for government funding of clinical costs and cost in the baseline; £ million in 2020 prices

a) Increasing demand projection

, , ,										
	2021/22	2022/23	2023/24	2024/25	2025/26	2026/27	2027/28	2028/29	2029/30	2030/31
Cost of funding clinical costs	£639m	£649m	£655m	£660m	£665m	£668m	£671m	£673m	£674m	£674m
Baseline	£337m	£343m	£346m	£348m	£351m	£353m	£354m	£355m	£356m	£356m
Difference in costs	£302m	£306m	£309m	£312m	£314m	£315m	£317m	£318m	£318m	£318m
o) Constant demand projection										
	2021/22	2022/23	2023/24	2024/25	2025/26	2026/27	2027/28	2028/29	2029/30	2030/31
Cost of funding clinical costs	£650m	£656m	£663m	£670m	£677m	£685m	£693m	£701m	£710m	£719m
Baseline	£343m	£346m	£350m	£353m	£357m	£361m	£366m	£370m	£375m	£379m
Difference in costs	£307m	£310m	£313m	£316m	£320m	£323m	£327m	£331m	£335m	£339m

Full government funding (scenario 2) and baseline

Table 4 Nominal (cash) costs for fully funding palliative care and cost for the government in the baseline; £ million

a) Increasing demand projection

	2021/22	2022/23	2023/24	2024/25	2025/26	2026/27	2027/28	2028/29	2029/30	2030/31
Cost of fully funding palliative care	£926m	£957m	£986m	£1,015m	£1,042m	£1,068m	£1,094m	£1,119m	£1,144m	£1,167m
Baseline	£342m	£354m	£365m	£375m	£385m	£395m	£404m	£414m	£423m	£431m
Difference in costs	£584m	£603m	£622m	£640m	£657m	£674m	£690m	£706m	£721m	£736m
b) Constant demand projection										
	2021/22	2022/23	2023/24	2024/25	2025/26	2026/27	2027/28	2028/29	2029/30	2030/31
Cost of fully funding palliative care	£941m	£967m	£998m	£1,029m	£1,061m	£1,095m	£1,130m	£1,167m	£1,205m	£1,244m
Baseline	£348m	£357m	£369m	£380m	£392m	£405m	£418m	£431m	£445m	£460m
Difference in costs	£593m	£610m	£629m	£649m	£669m	£690m	£712m	£736m	£760m	£785m

Source: London Economics projections

Table 5 Costs for fully funding palliative care and cost for the government in the baseline; £ million in 2020 prices

a) Increasing demand projection

	2021/22	2022/23	2023/24	2024/25	2025/26	2026/27	2027/28	2028/29	2029/30	2030/31
Cost of fully funding palliative care	£913m	£927m	£936m	£943m	£949m	£954m	£958m	£961m	£963m	£963m
Baseline	£337m	£343m	£346m	£348m	£351m	£353m	£354m	£355m	£356m	£356m
Difference in costs	£576m	£584m	£590m	£595m	£599m	£602m	£604m	£606m	£607m	£607m
b) Constant demand projection										
	2021/22	2022/23	2023/24	2024/25	2025/26	2026/27	2027/28	2028/29	2029/30	2030/31
Cost of fully funding palliative care	£928m	£937m	£947m	£957m	£967m	£978m	£990m	£1,002m	£1,014m	£1,027m
Baseline	£343m	£346m	£350m	£353m	£357m	£361m	£366m	£370m	£375m	£379m
Difference in costs	£585m	£591m	£597m	£603m	£610m	£617m	£624m	£632m	£639m	£647m

NHS specialist palliative care only (scenario 3) and baseline

Table 6 Nominal (cash) costs to government in baseline and under specialist palliative care provided by the NHS only; £ million

a) Increasing demand projection

	2021/22	2022/23	2023/24	2024/25	2025/26	2026/27	2027/28	2028/29	2029/30	2030/31
Cost to government in the baseline	£342m	£354m	£365m	£375m	£385m	£395m	£404m	£414m	£423m	£431m
Cost to government under NHS provision	£728m	£772m	£817m	£863m	£907m	£952m	£997m	£1043m	£1089m	£1135m
b) Constant demand projection										
	2021/22	2022/23	2023/24	2024/25	2025/26	2026/27	2027/28	2028/29	2029/30	2030/31
Cost to government in the baseline	£348m	£357m	£369m	£380m	£392m	£405m	£418m	£431m	£445m	£460m
Cost to government under NHS provision	£652m	£671m	£692m	£714m	£736m	£759m	£784m	£809m	£835m	£863m

Source: London Economics projections

Table 7 Costs to government in baseline and under specialist palliative care provided by the NHS only; £ million in 2020 prices

a) Increasing demand projection

	2021/22	2022/23	2023/24	2024/25	2025/26	2026/27	2027/28	2028/29	2029/30	2030/31
Cost to government in the baseline	£337m	£343m	£346m	£348m	£351m	£353m	£354m	£355m	£356m	£356m
Cost to government under NHS provision	£718m	£747m	£775m	£802m	£827m	£851m	£873m	£895m	£916m	£937m
b) Constant demand projection										
	2021/22	2022/23	2023/24	2024/25	2025/26	2026/27	2027/28	2028/29	2029/30	2030/31
Cost to government in the baseline	£343m	£346m	£350m	£353m	£357m	£361m	£366m	£370m	£375m	£379m
Cost to government under NHS provision	£643m	£650m	£656m	£663m	£671m	£678m	£686m	£695m	£703m	£712m

A1.1 Difference in total costs

Clinical cost funding (scenario 1)

Table 8 Costs to government for funding clinical costs in palliative care in Scenario 1 between 2021/22 and 2030/31; £ million

	Increasi	ng demand p	rojection	Constant demand projection				
	Baseline	Scenario 1	Difference	Baseline	Scenario 1	Difference		
In current prices	£3,887m	£7,363m	£3,476m	£4,005m	£7,587m	£3,582m		
In constant 2020 prices	£3,499m	£6,628m	£3,129m	£3,601m	£6,822m	£3,221m		
Net present value; 2020 prices	£2,905m	£5,503m	£2,598m	£2,985m	£5,656m	£2,670m		

Source: London Economics projections

Full government funding (scenario 2)

Table 9 Costs to government for fully funding palliative care in Scenario 2 between 2021/22 and 2030/31; £ million

	Increasi	ng demand p	rojection	Constant demand projection				
	Baseline	Scenario 2	Difference	Baseline	Scenario 2	Difference		
In current prices	£3,887m	£10,519m	£6,632m	£4,005m	£10,838m	£6,833m		
In constant 2020 prices	£3,499m	£9,468m	£5,969m	£3,601m	£9,746m	£6,145m		
Net present value; 2020 prices	£2,905m	£7,862m	£4,957m	£2,985m	£8,079m	£5,094m		

Source: London Economics projections

NHS specialist palliative care only (scenario 3)

Table 10 Cost to government for funding palliative care in Scenario 3 (NHS palliative care services only) between 2021/22 and 2030/31; £ million

	Increasi	ing demand p	rojection	Constant demand projection				
	Baseline	Alternative scenario	Difference	Baseline	Alternative scenario	Difference		
In current prices	£3,887m	£9,303m	£5,416m	£4,005m	£7,515m	£3,510m		
In constant 2020 prices	£3,499m	£8,342m	£4,843m	£3,601m	£6,758m	£3,157m		
Net present value; 2020 prices	£2,905m	£6,880m	£3,975m	£2,985m	£5,602m	£2,617m		

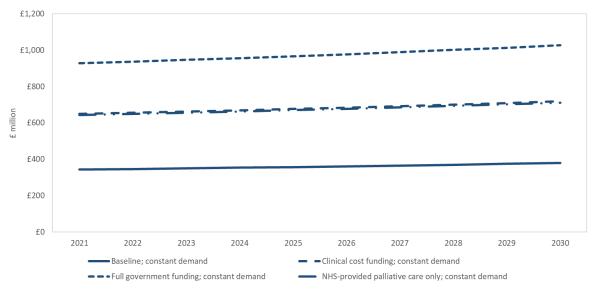
A1.2 Assumptions used in the alternative scenario

 Table 11
 Assumptions and sources used in the alternative scenario

Service	Unit cost	Type of cost	Length of time/Number of interactions	Source
IPU	£447	Cost per day	14 days (from Hospice UK/Sue Ryder)	'Inpatient, specialist palliative care (adults only), average cost per bed day' - Unit Costs of Health & Social Care 2020, PSSRU (2019/20)
Hospice at home	£103	Cost per face to face care contact	5.95 visits per year (average across all patients from Hospice UK 16/17)	N21AF 'Specialist Nursing, Palliative/Respite Care, Adult, Face to face' - National Schedule of NHS Costs (2018-19)
Community Nursing Services	£103	Cost per face to face care contact	Total of 6 hours of F2F contact over 6 months (Derived from information sent by Sue Ryder)	N21AF 'Specialist Nursing, Palliative/Respite Care, Adult, Face to face' - National Schedule of NHS Costs (2018-19)
	£33	Cost per non face to face care contact	Total of 9.5 hours of F2F contact over 6 months (Derived from information sent by Sue Ryder)	N21AN 'Specialist Nursing, Palliative/Respite Care, Adult, Non face to face' - National Schedule of NHS Costs (2018-19)

Annex 2 Cost projection summary in the 'constant' demand scenario

Figure 8 Cost projections summary for the 'constant demand' scenario – 2020 prices



Note: 'Constant demand': proportion receiving services as share of total death stays constant over time (rising in line with deaths) at 2018/19 levels. Government statutory contribution set at 37% of overall expenditure in baseline, 70% in the 'clinical cost funding' scenario and 100% in the 'full government funding' scenario. 'NHS provided pallaitive care only' assumes no provision of specialist palliative care services by the hospice sector and increased demand for specialist palliatve care services provided by the NHS. Constant 2020 prices.

Source London Economics projections based on ONS, PHE, Hospice UK and OBR data





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