
What's important to me.

A Review of Choice in End of Life Care

ANNEX B: Modelling Choice in End of Life Care



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Annex B of What's important to me: A Review of Choice in End of Life Care

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Modelling Choice in End of Life Care

Introduction

1. This annex sets out how the costs and benefits of introducing greater choice into end of life care have been estimated. It describes the person-centred model of care that has been created, including its methodology, results and limitations.
2. There are a range of existing models and case studies of the effects of introducing greater choice into end of life care. These include models by the National End of Life Care Intelligence Network and the Nuffield Trust and case studies from areas including the Midhurst Real Choice Project. More details of a selection of these are available in Appendix A. While these studies and models provide valuable information on a range of the effects, none of them comprehensively estimate or evaluate the effects across the whole health and social care system. As a result, a new model has been created that incorporates this intelligence more comprehensively.
3. This model has been built with extensive input from members of the Review's Programme Board to ensure as many services as possible are included, that a variety of providers (the NHS, social care, and the voluntary sector) and their respective contributions are incorporated, and that service usage is realistic and representative. For more information, see Appendix B.
4. There are limitations to the model. Data on some services is not available, so the model relies on a number of assumptions that have been tested in sensitivity analysis. In particular, there is limited evidence on the extent to which greater availability of end of life services in the community will lead to people choosing to spend their last weeks and months in their own home, care home or hospice instead of a hospital.

Methodology

5. This model follows a bottom-up approach, estimating the services used by an average person at the end of life. This covers a range of services including NHS acute and community costs; specialist palliative care staffing; hospice inpatient costs; and social care costs including care home fees, domiciliary home care, telecare, and equipment and adaptation costs.
6. The type of services and the quantity required per person are predominantly derived from expert opinion. Unit costs for each of these services have mostly been derived from national, publicly available, data sources. Detailed information on these services is provided in Appendix B.

7. It is difficult to directly assess the impact of increased choice. As a proxy for this, the model instead investigates the cost of providing more comprehensive services in the community. It then investigates three different scenarios for how individuals may respond to this, estimating the impact of greater proportions choosing to die outside of hospital.

Care Options

8. The model evaluates the cost of three possible options, which relate to increasing provision of end of life care services. These three options are:

1. What is available across the country now (i.e. the baseline).
2. Increased service availability that would enable choice and improve access.
3. Further increased availability and additional services that would enable choice and improve access.

9. Option 1 reflects the types of services currently available. While there is known to be significant variation in service availability across England, option 1 aims to reflect the average across the country, derived from expert opinion. It is possible that this may overestimate current national levels of provision. Therefore, incremental costs of options 2 and 3 (over and above option 1) may be underestimated.

10. In moving from option 1 to option 2, usage of community services, such as district nursing and allied health professionals (occupational therapists, physiotherapists, dieticians, pharmacists) and specialist palliative care teams increase per person. Evidence from the Nuffield Trust¹ shows that increasing community provision and more widespread provision of 24/7 specialist care leads to fewer hospital admissions and A&E visits per person.

11. Option 3 is more aspirational and builds on option 2. It incorporates additional, more innovative methods of care such as telehealth. It also includes a further increase in usage of the previously mentioned services to ensure individuals can have their choices met. For more details on what is included on average in each care option and approximate incremental increases between the three, see Appendix B.

Effect of Care Options on Behaviour

12. There is currently limited evidence on the behavioural impact of increasing the provision of

¹ Exploring the cost of care at the end of life; Georghiou, T and Bardsley, M; The Nuffield Trust, September 2014; http://www.nuffieldtrust.org.uk/sites/files/nuffield/publication/end_of_life.pdf

end of life care in the community. It is likely that more people will take up the option of out-of-hospital care as it becomes more available and prominent. However, it is not known with any certainty how much this is likely to happen.

13. In England, currently nearly half of all people die in hospital. A further six percent die in a hospice inpatient bed, while the remainder die in either their own homes or a care home², with a roughly even split between the two.

14. For all scenarios in the model, it is estimated that approximately 75% of people will have some need for End of Life Care^{3, 4}. This is based on previous evidence that suggests approximately one in four deaths are unexpected. The model assumes that the place of death of the 75% of people where death was not unexpected is similar to the place of death of all individuals.

15. The National Audit Office reported⁵ that, from a detailed examination of patient records in Sheffield PCT, “40 percent of patients who died in hospital in October 2007 did not have medical needs which required them to be treated in hospital, and nearly a quarter of these had been in hospital for over a month”. As community services are strengthened, it is therefore expected that fewer people will choose to die in hospital.

16. Many people would like the opportunity to die in a hospice instead of a hospital or their usual place of residence⁶. Therefore, the model assumes that increased choice is likely to lead to greater proportions of people choosing to die in a hospice.

17. The model investigates three different scenarios where differing proportions of people die in hospital, in a hospice inpatient bed, home or care home. These three scenarios are:

- a. No change in where people die based on the latest available death registration data.
- b. More people die in their usual place of residence (home or care home) or in a hospice inpatient bed. In this scenario, deaths in hospital decrease by 20% and are redistributed to hospices (an increase of 25% compared to scenario (a) and to the usual place of residence, proportionally, according to available death registration data.

² Death Registered in England and Wales, 2013, ONS

<http://www.ons.gov.uk/ons/rel/vsob1/death-reg-sum-tables/2013/sb-deaths-first-release--2013.html>

³ Predicting Death: Estimating the Proportion of Deaths that are 'Unexpected' National End of Life Care Intelligence Network; http://www.endoflifecare-intelligence.org.uk/resources/publications/predicting_death

⁴ How many people need palliative care?: A study developing and comparing methods for population-based estimates; Murtagh, F. E., Bausewein, C., Verne, J., Groeneveld, E. I., Kaloki, Y. E. & Higginson, I. J. Jan 2014 In : Palliative Medicine. 28, 1, p. 49-58

⁵ National Audit Office 2008 End of Life Care <http://www.nao.org.uk/wp-content/uploads/2008/11/07081043.pdf>

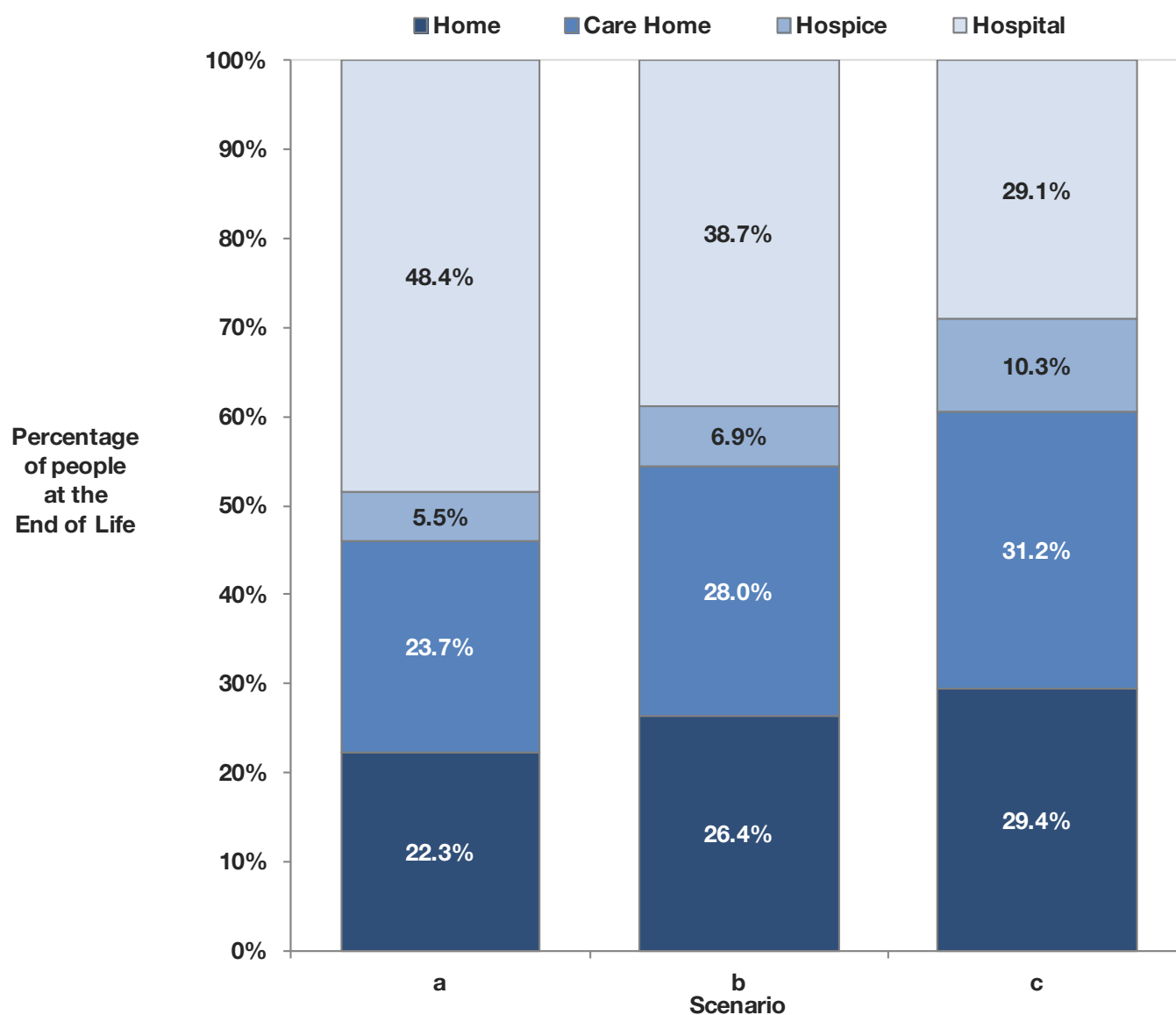
⁶ The impact of advance care planning of place of death, a hospice retrospective cohort study Abel J, Pring A, Rich A et al BMJ Support Palliat Care doi:10.1136/bmjspcare-2012-000327

www.spcare.bmj.com/content/early/2013/03/14/bmjspcare-2012-000327.full#T4

c. As scenario (b) but with an even greater proportion of people dying in their usual place of residence or in a hospice. As a result there is a reduction in deaths in hospital by 40% compared to scenario (a). These deaths are then redistributed to the individual's usual place of residence, proportionally according to ONS death registrations, or into hospices (an increase of 85% compared to scenario (a)).

18. The model has been run under these three care options and using these three scenarios. The different total proportions of people in each care setting for each of the three scenarios can be seen in Figure 1. These proportions do not change across the three care options.

Figure 1: Changes in the numbers of people in each care setting by scenario, reflecting the changes in people's choice.

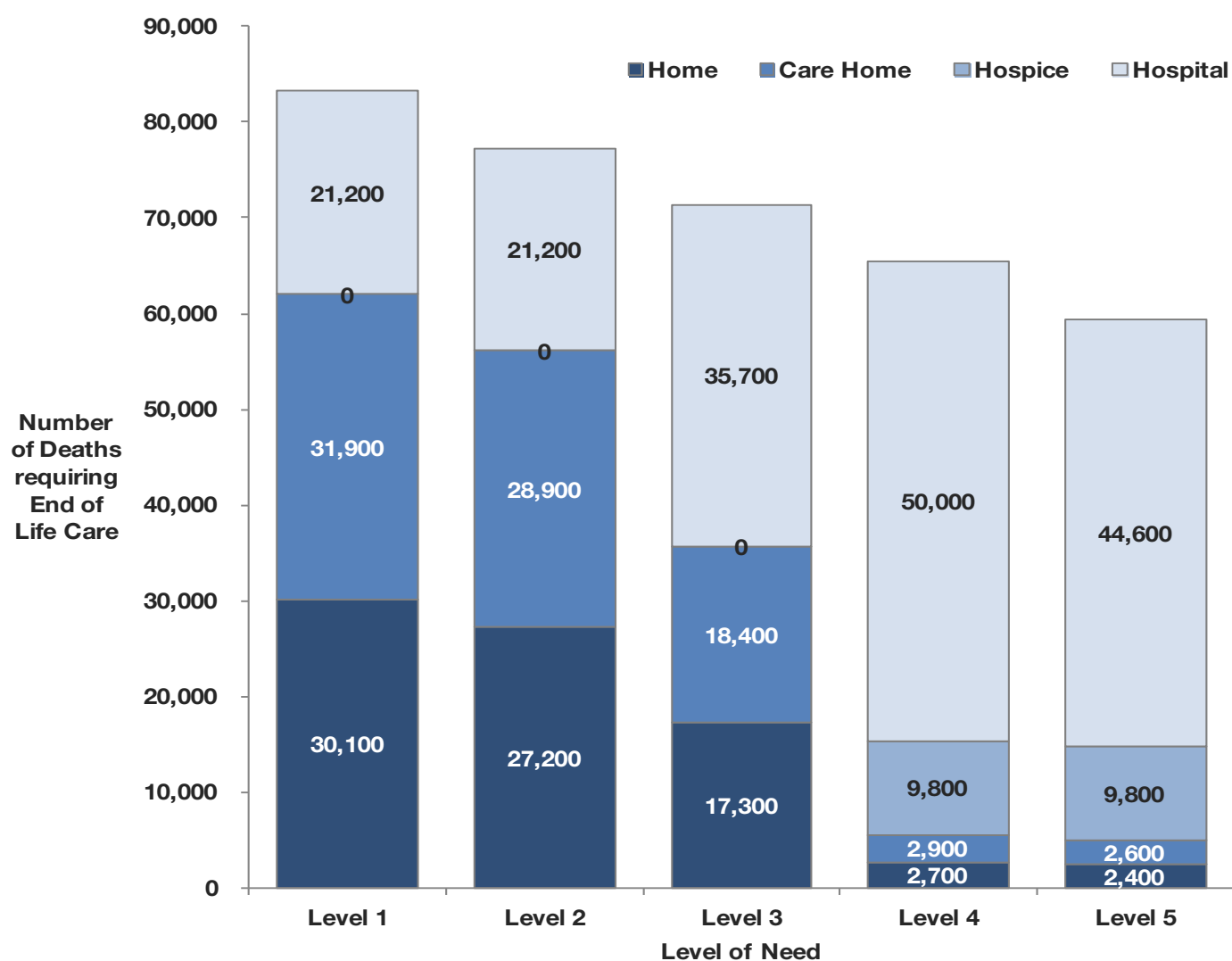


Levels of Need

19. In order to reflect the different service usage of those at the end of their lives, individuals are categorised into five different levels of need. As an individual's level of need increases, the complexity of their condition increases as well and, as a result so will their type and level of service usage. For more details on the levels of need, see Appendix C.

20. Individuals are assumed to die in different settings, depending on their level of need. The total numbers of people allocated to each setting, irrespective of need, is based on ONS death registration data². It is assumed that those with higher need are more likely to have died in hospital or a hospice. Those with lower need levels are more likely to receive their care in their usual place of residence. Figure 2 demonstrates how the numbers of people dying in scenario (a) change by setting and by level of need. Level 1 represents the lowest need and Level 5 is those with the greatest need.

Figure 2: Numbers of people, rounded to the nearest 100, dying per year modelled by level of need and by care setting for scenario (a).



Time Period

21. The model investigates costs in the last three months of life – the point, on average, at which an individual is likely to be offered the opportunity to be included in an Electronic Palliative Care Coordination System (EPaCCS). Over three months, an individual's level of need will change. This is implicitly included within the model by capturing a snapshot at a point in time and assuming that, while individuals will increase in need as they approach death, additional new people will enter the end of life cohort with a lower level of need. Therefore, the average at any one point in time remains roughly constant.

22. In its assumptions about the proportion of people in each level of need, the model implicitly assumes that the average individual will spend around 21 days with around level 1 need, and fewer days in higher levels, down to 15 days at around level 5 need.

Calculating Impact to the Wider Economy

23. The End of Life Care sector is highly complex with a variety of sources of providers and income streams including a substantial contribution from the charitable sector. Social care is a key component of the care a person receives in their last months and a large proportion of people will fund themselves. Some self-funders may be eligible for NHS Continuing Healthcare under a fast track arrangement. However, insufficient data are available for a breakdown of this information.

24. In order to reflect these contributions from outside the Government, the model distinguishes where the costs fall. In the case of self-funders, the analysis has been provided by the Department of Health based on three sources, the Community Care Statistics, Social services activity for England, and Personal social services: Expenditure and unit costs for England. This same work has also been used as the basis for calculating the breakdown between residential care with and without nursing. The charity sector's relative contribution has been calculated using the annual Hospice UK accounts⁷.

Results

Current Situation

25. Based on the above assumptions, the model estimates that the current expenditure on

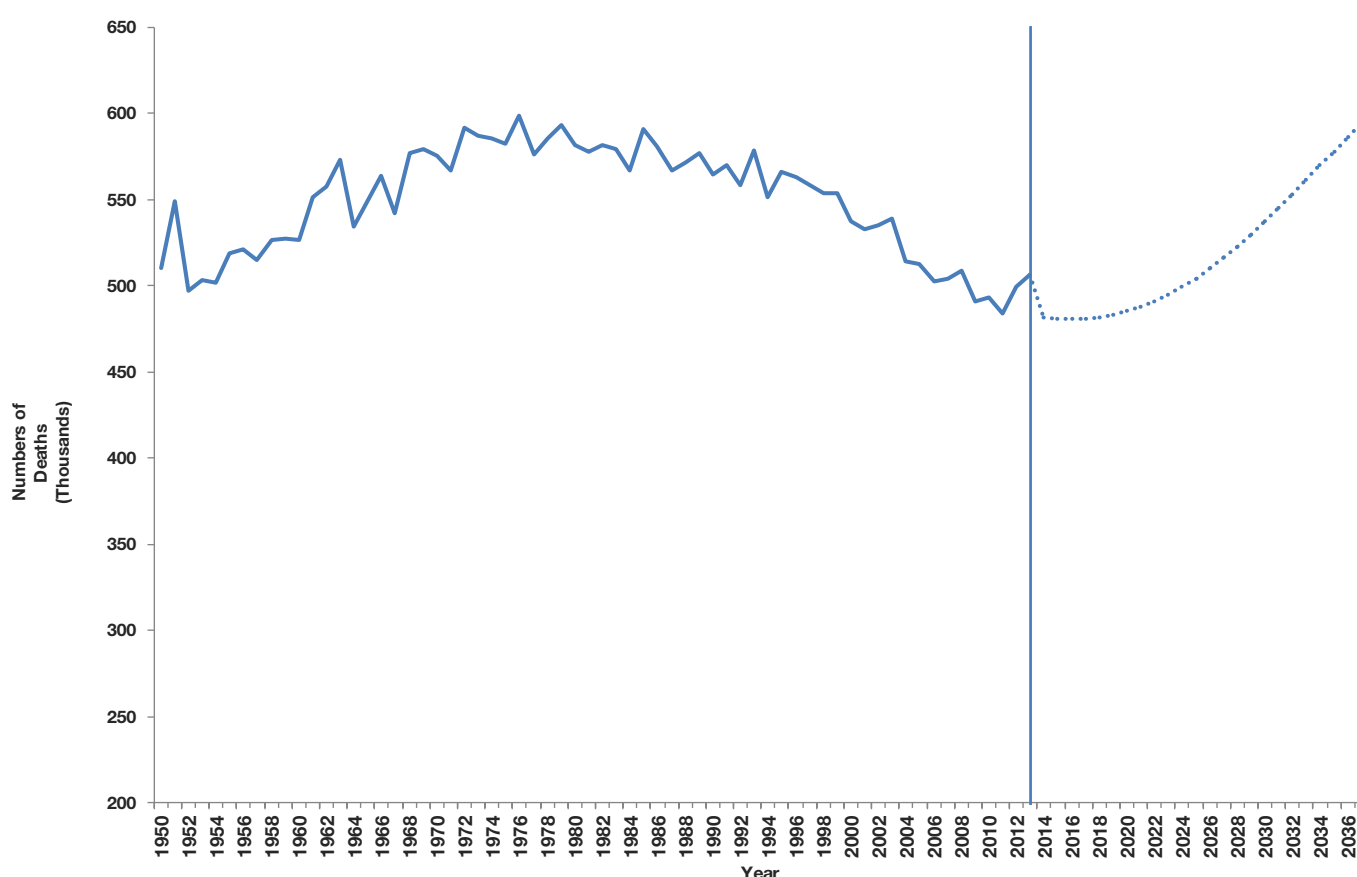
⁷ Analysis of the accounts of UK independent voluntary hospices for the year ended 31 March 2013, Hospice UK October 2014

end of life care funded by the exchequer is approximately £3.3bn per year. £2.9bn of this is NHS funding, while around £0.4bn is funded by local authorities in social care.

Impact of doing nothing

26. The number of deaths is forecast to rise by 0.7% per year on average over the next two decades. Therefore by 2035/36, there will be around 552,000 deaths, 15.4% higher than those registered in 2013. Assuming the proportion of unexpected and sudden deaths remains constant; there will be over 415,000 people with palliative care needs in a given year in England. For graphical purposes, Figure 3 illustrates this comparison with a recent decline in numbers of deaths in England and Wales over the past 60 years.

Figure 3: Numbers of Deaths (thousands) in England and Wales from 1950 to 2037. The solid line indicates the numbers of deaths registered in a given year according to ONS publications. The dotted line shows the ONS principle projection, based on 2012 data, for deaths up to the year 2037.



27. With this increase in the end of life population and no change in services, NHS spending would increase by £470m to £3.4bn a year in 2035-2036. Social care spend by local authorities would increase by £70m to £430m a year by 2035/36. Total expenditure from across the economy, including social care, charitable and self-funding spend would increase to £4.5bn a year. The discounted⁸ total costs of this would be approximately £2.3bn.

28. Over the past few years, the proportion of deaths occurring in hospitals has been decreasing. In this model, it has been assumed that this proportion remains constant and would not continue to decrease without any further intervention. If this is not the case and fewer people continue to die in hospital without any further intervention, the incremental effects of increasing choice therefore would be smaller.

Incremental Costs

29. The incremental costs of each option and scenario are presented in Table 1. These show the net incremental costs for each option and scenario compared to option 1 scenario (a), the estimated current position.

30. Moving from option 1 to option 2, more services are made available that enable people to die in a place and manner of their choosing. This is likely to lead to more people choosing to die in their usual place of residence or a hospice inpatient bed i.e. a move from scenario (a) to scenarios (b) and (c). However, the extent of this is not known. Table 1 shows the net incremental costs to the Exchequer of each option and scenario over and above the current situation i.e. option 1 scenario (a). Values have been rounded to the nearest £10m in order to reflect the uncertainty around these estimates.

Table 1: Annual incremental costs (£m), to the nearest £10m, for each of the Options for Care and Scenarios – note: totals may not sum due to rounding

| Incremental Cost (£m*) | Scenario a | Scenario b | Scenario c |
|------------------------|-------------|-------------|-------------|
| Option 1 | | | |
| (Total) | £0 | £40 | £100 |
| NHS spend | £0 | -£30 | -£20 |
| Social Care Spend | £0 | £70 | £120 |
| Option 2 | | | |
| (Total) | £50 | £130 | £200 |
| NHS Spend | £30 | £30 | £50 |
| Social Care Spend | £20 | £100 | £150 |
| Option 3 | | | |
| (Total) | £610 | £730 | £830 |
| NHS Spend | £560 | £580 | £610 |
| Social Care Spend | £60 | £150 | £220 |

⁸ Discounting is a way to adjust future costs (and benefits) to today's equivalent costs (called the 'present value'), taking into account societal preference for earlier realisation of consumption benefits and deferred incursion of costs. Financial costs and benefits are discounted at 3.5% per year as set out in the Green Book, by HM Treasury.

31. By expanding the capacity of community provision, we expect more people will choose to die in their usual place of residence or a hospice inpatient bed. While it is unlikely that all those who can move out of hospital will do so, it is likely that some will. Therefore we assume that option 2 is likely to lead to scenario (b). The total net incremental cost under 2(b) across both health and social care is £130m per year (NHS spending of £30m, social care spending of £100m).

32. By providing substantially more capacity for care in the community, we expect more people will choose to die outside of a hospital. We expect that with the range and availability of services provided under option 3, this will enable even more people to receive care in their usual place of residence and hence enable scenario (c). The net incremental cost of option 3 under scenario (c), i.e. providing enablers of choice and new services, compared to option 1, leads to a total net increase in spending of £830m per year (NHS spending of £610m, social care spending of £220m).

Community Investment and Acute Savings

33. The main savings of improving choice and enabling more people to move to the community would be through reduced unplanned emergency admissions, decreased length of stay, and A&E visits. These savings are included in the figures above. Table 2 provides greater detail on the split of the costs and savings in different sectors of the NHS. It shows that there are savings in the acute sector but that these are outweighed by additional costs in the community sector. It is likely that, in order to realise these savings in an acute setting, hospital beds would need to be closed.

Table 2: Incremental changes in cost (£m) across care options and choice scenarios, rounded to the nearest £10m, focusing on acute and community NHS services.

| Incremental Cost (£m*) | Scenario a | Scenario b | Scenario c |
|------------------------|------------|------------|------------|
| Option 1 | | | |
| Acute | £0 | -£160 | -£330 |
| Community | £0 | £140 | £310 |
| Option 2 | | | |
| Acute | -£160 | -£370 | -£580 |
| Community | £190 | £400 | £640 |
| Option 3 | | | |
| Acute | -£110 | -£410 | -£720 |
| Community | £660 | £990 | £1,330 |

34. If providing option 2 of expanded care enables more people to die in their usual place of residence as would be expected, i.e. under scenario (b), the total incremental savings to the acute sector would be £370m per year, while £400m per year would need to be invested into community provision. This would lead to a net incremental cost to the NHS of £30m per year.

Impact of model for Full Time Equivalent Staffing Costs

35. There would need to be a substantial increase in full time equivalent (FTE) staff under option 2, scenario (b), i.e. more people choosing to die in their usual place of residence. The largest increase would be needed in specialist palliative care nursing provision with 1,000 additional nurses required to enable greater choice. A further 530 more community district nurses and 490 more healthcare assistants would be needed to enable this move care out of the acute sector. For an average Clinical Commissioning Group, this would relate to an extra 5 specialist nurses, an extra 3 district nurses, an extra 2 healthcare assistants and a further 2 social care home workers. These increases in staff numbers assume that current workforce levels are maintained.

Investment from the Wider Economy – self-funders and the voluntary sector

36. The end of life care landscape is complex and characterised by a multitude of providers of care, and several sources of funding. In particular, the hospice sector raises almost £735m annually in charitable donations, supplemented by a further £260m of statutory income. This helps fund their expenditure on care providing functions, which is currently approximately £700m⁷.

37. Self-funders are another key part of funding care at the end of life. Large proportions of those in the last year of life are care home residents or have care needs in their own homes. We have assumed that, on average, 49.4% are self-funders depending on the type of care received. This is based on the percent of over 65s in general who are self-funders from Department of Health analyses, based on the Community Care Statistics, Social services activity for England, and Personal social services: Expenditure and unit costs for England.

38. Table 3 shows the incremental changes in expenditure for each sector – the NHS, charitable sector, Local Authority funded social care, and self-funders – from each option and scenario compared to the situation now, option 1, scenario (a).

Table 3: The estimated incremental costs (£m), to the nearest £10m, to the economy by sector – note: totals may not sum due to rounding

| Cost (£m*) | Scenario a | Scenario b | Scenario c |
|--------------------|-------------|-------------|---------------|
| Option 1 | | | |
| (Total) | £0 | £180 | £410 |
| NHS spend | £0 | -£30 | -£20 |
| Charity Spend | £0 | £50 | £170 |
| Social Care Spend | £0 | £70 | £120 |
| Self-funding Spend | £0 | £80 | £150 |
| Option 2 | | | |
| (Total) | £100 | £320 | £580 |
| NHS spend | £30 | £30 | £50 |
| Charity Spend | £0 | £50 | £170 |
| Social Care Spend | £20 | £100 | £150 |
| Self-funding Spend | £50 | £150 | £210 |
| Option 3 | | | |
| (Total) | £710 | £970 | £1,260 |
| NHS spend | £560 | £580 | £610 |
| Charity Spend | £0 | £50 | £170 |
| Social Care Spend | £60 | £150 | £220 |
| Self-funding Spend | £90 | £190 | £270 |

39. If providing option 2 of expanded care enables more people to die in their usual place of residence, as is expected, i.e. under scenario (b), the total incremental costs across all sectors would be £320m (£30m of NHS spending, £50m of charity spend, £100m of social care spending, and £150m of self-funding spending).

Sensitivity Analysis

40. The impacts of increasing choice in end of life care are highly uncertain. In part, this has been reflected by the scenario analysis above, however, further sensitivity analysis has been performed.

41. The above analysis relies on a number of assumptions. Sensitivity analysis investigates the impact of variation in these assumptions on the key results. It assesses the effect on the net incremental cost of option 2 scenario (b) over and above option 1 scenario (a). The assumptions tested are:

- a. A 10% increase or decrease in unit costs
- b. Variation in the proportion of deaths per year with end of life care needs
- c. Choice scenarios (as described above)
- d. Distribution of the level of need of the end of life care population

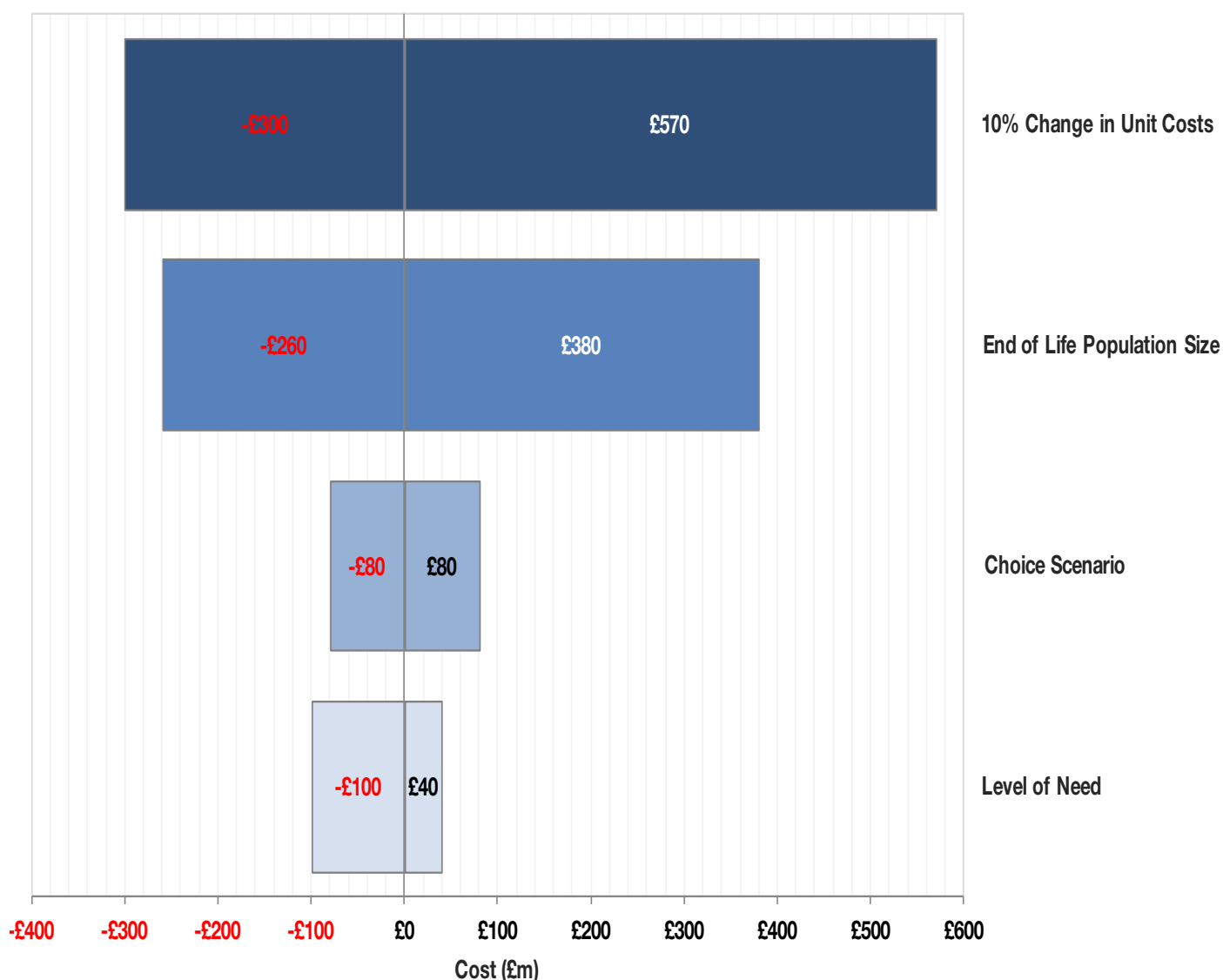
42. As staff costs account for the majority of the total costs, the effect of either increasing or decreasing unit costs by 10% have been modelled. This could reflect a 10% change in cost, a 10% change in time required, or some combination of the two. This has the effect of either increasing the incremental cost by £570m or reducing it by £300m. As a result, the incremental cost of option 2 scenario (b) over option 1 scenario (a) may range between £700m and -£170m (i.e. a net saving) per year.

43. By using the maximum and minimum proportions of people with potential end of life care needs⁴, the total numbers of people either increases or decreases by approximately 8.5% (see paragraph 14). This substantial variation in the numbers of people leads to a large range from -£260m to £380m around the central estimate of the total incremental cost of moving from option 1 scenario (a) to option 2 scenario (b) (£130m) (Figure, below). As a result, the incremental cost of option 2 scenario (b) over option 1 scenario (a) may range between -£130m (i.e. a net saving) and £510m (a net cost) per year.

44. The variation across the three scenarios (a), (b), and (c) have been included in this sensitivity analysis as well. As can be seen from Table 1 and Figure 4 this ranges from -£80m to £80m around the central estimate of incremental cost. As a result, the incremental cost of option 2 scenario (b) over 1(a) may range between £50m and £210m per year.

45. The central estimate for the proportion of people in each level of need is based on expert opinion (see above). A series of variations on this have been created including a greater proportion of people with level 1 need compared to level 5 need (either through a steeper slope or exponential gradient) and a smaller proportion with level 5 need, and an even distribution across all settings and levels of need. The maximum and minimum differences have then been used to develop the range seen in Figure. This leads to a relatively small variation from -£100m to £40m around the central estimate. As a result, the incremental cost of option 2 scenario (b) over option 1 scenario (a) may range between £30m and £170m per year.

Figure 4: Sensitivity Analysis of the key variables on the incremental cost of implementing option 2 scenario (b)



Limitations

46. The model currently does not include the cost of education and training of both current and additional professionals needed to provide these services. This is in part due to lack of data. This will lead to an underestimate of the cost of doing nothing (option 1) and of the incremental costs of options 2 and 3.

47. The projected 25 percent increase in deaths in hospice from option 1 to option 2 would require an increase in hospice bed capacity. This cost has not been included in the model. This potential cost may be mitigated by hospices providing their services to people in their own home or care home ('hospice-at-home'), in which case these deaths would be categorised as deaths in community settings. This could lead to an underestimate of the costs to the charitable sector and the NHS in options 2 and 3.

48. The estimates for the savings to acute trusts in the NHS are based on a study on the provision of a specialist palliative care nursing service¹. As this model assumes wider provision of services in the community, it is possible that there will be further savings to the acute sector, which are currently not captured in the model. However this data is unavailable at this time.

49. Under scenario (a), it is assumed that there are no social care costs for people who currently die in hospitals. This is unlikely to be the case and some individuals may already be residents in a care home. Unfortunately, data on this was unavailable at the time of writing. This assumption is likely to underestimate the social care costs of scenario (a), therefore the incremental social care costs of scenarios (b) and (c) are likely to be an overestimate.

50. Some assumptions have been made around the ONS death registration statistics due to the lack of other available data. Ideally, modelling the care service usage in the last 90 days of life would revolve around care setting rather than place of death but death registration statistics have been used as an approximation, as there are no correspondingly comprehensive data on place of care. The proportion of people with end of life care needs in the run up to their death has also been assumed to hold constant across care settings, with no bias for a particular setting for a sudden or unexpected death.

51. Previous evidence^{1,9}, has suggested that cost of end of life care is dependent on an individual's condition or diagnosis. Georghiou and Bardsley¹ found that those with a cancer diagnosis on average cost substantially more than those with no cancer diagnosis. For example, the hospital care costs for three months for someone with a cancer diagnosis were £5,890 compared with £3,785 for someone with no cancer diagnosis. To ensure that all conditions are reflected in this analysis, the level of need variable has been included in an attempt to reflect the varying service usage, irrespective of diagnosis. The Nuffield Trust studies also suggest there are potentially larger hospital savings for non-cancer diagnoses, which account for approximately 70% of all deaths. If this is the case, the acute savings of options 2 and 3 may be underestimates.

52. Other aspects of end of life care that have not been included in the model are bereavement services and chaplaincy costs. This is due to the potential for extremely wide variation of personal choice in the usage of these services. The Palliative Care Funding Review pilot data suggest that less than 0.3% of people use hospital chaplaincy services in a hospital setting. Nevertheless they may still be important to ensure individuals' spiritual needs are taken into account in the last days of life. Assuming a constant level of expected deaths, the incremental costs of these services would not be expected to change significantly.

⁹ Evaluation of the Midhurst Real Choice Project, Macmillan Cancer Support London and South East Region, May 2011 <http://www.macmillan.org.uk/Documents/AboutUs/Research/Researchandevaluationreports/Midhurst-Evaluation-FINAL-economic-report.pdf>

53. Visits to Accident and Emergency departments have been included in this model but the cost of the individual's arrival by ambulance has not. If admissions can be prevented through enhanced community care and enabling people's choices, there may be a decrease in ambulance callouts for those at the end of life, thus resulting in either a cost saving or freeing up ambulances for other urgent and emergency care. It is possible that this leads to an underestimate of the savings in options 2 and 3.

54. As the model is built in a bottom-up manner, it is possible that there may be additional services that have not been included in it. The model has been reviewed by a range of experts so the effects of this are expected to be small, particularly on incremental costs.

55. Earlier recognition that someone is progressing towards the end of life may improve the chances of an individual attaining their choices. As the model captures the last 90 days of life, it is possible that moving to options 2 or 3 will facilitate earlier recognition of a terminal prognosis and may in itself affect costs of care. The model cannot predict this impact, beyond what is available through changing scenarios from (a) to (b) to (c). This could lead to a shift of people out of the higher need levels into the lower ones. To reflect this, the numbers of people in each level of need has been altered to show the potential effects on costs, as discussed in the sensitivity analysis (see paragraph 45).

Discussion

56. This model has estimated the current cost of end of life care in the last three months of life using accredited sources with extensive expert opinion to replicate an average service an individual may be able to access. It has also estimated the incremental cost of increasing community provision and enabling more people to choose to die in their usual place of residence or a hospice.

57. By using the three options for care and three scenarios for choice to reflect the variation in service usage, a variety of possibilities have been costed and compared to the current situation. Providing increased community provision and more specialist palliative care outside of the acute sector will enable people's place of care to shift from hospital into a place of their choosing and this model estimates what the implications for the NHS, local authorities, charity sector and self-funders might be.

58. Moving from option 1 scenario (a) (i.e. the situation now) to option 2 scenario (b) would require some investment in the system. Approximately £320m from the wider economy would be required for the implementation of option 2 scenario (b). £400m investment would be needed into NHS community services to achieve £370m savings in the acute sector - £30m net spend in the NHS. A further £100m investment into local authority social care would also be needed.

59. This model has assumed that it is possible to instantaneously increase provision in community services and have a similarly rapid effect on individuals' behaviour. In reality, it will take a number of years to reach this situation. Therefore, the above estimates should be treated as a plausible steady state after a number of years.

Appendix A: Other Community Models of End of Life Care

60. Many studies have investigated the impact of community-based specialist palliative care, the potential resulting savings for hospitals and whether patient choice for place of death is achieved¹⁰.

Midhurst Macmillan Specialist Palliative Care Service (Real Choice Project)

61. One example of this is the Midhurst Macmillan Specialist Palliative Care Service¹¹ that was set up in response to the closure of the King Ed VII Hospital in Eastbourne, West Sussex in 2006. This service includes a comprehensive team with integrated consultants for the individual, a central hub for staff and volunteers and that can act as a local venue for appropriate treatments, such as blood transfusions.

62. The aim of the Midhurst model aimed to:

- a. Put in place a sustainable affordable specialist palliative care service for the population.
- b. Ensure that personal choice is maximised by providing as much treatment and support in the home/community setting as possible.
- c. Reduce acute hospital interventions and inpatient hospice stays.
- d. Achieve closer working between the NHS, voluntary, charitable and private sectors.
- e. Increase compliance with NICE guidelines.

63. The evaluation of this project presented a largely quantitative retrospective analysis of Hospital Episode Statistics data, supplied by the participating PCTs. Comparisons were performed on healthcare usage of people i) using the Midhurst model, ii) using a local hospice and iii) not known to have used a specialist palliative care service. Inpatient, outpatient and A&E usage was contrasted across the three groups. This study reviewed the impact of 'when' a

¹⁰ Effectiveness and cost-effectiveness of home palliative care services for adults with advanced illness and their caregivers (Review) (Gomes, Calanzani, Curiale, McCrone and Higginson, The Cochrane Collaboration, 2013) <http://onlinelibrary.wiley.com/doi/10.1002/14651858.CD007760.pub2/pdf>

¹¹ Evaluation of the Midhurst Real Choice Project, Macmillan Cancer Support London and South East Region, May 2011 <http://www.macmillan.org.uk/Documents/AboutUs/Research/Researchandevaluationreports/Midhurst-Evaluation-FINAL-economic-report.pdf>

patient was referred to the service, either a) before any inpatient stay, b) after 1 inpatient stay or c) after 2 or more inpatient stays.

64. There were a variety of benefits found in the study. Both the Midhurst model Hospice care models reduced the number of deaths occurring in a hospital setting with potential cost saving implications. However, earlier identification also led to individuals being on the Midhurst service for long periods of time.

65. While the Midhurst study identifies the potential for improving choice and increasing community, rather than hospital deaths, it has a few limitations that mean it does not cover the whole picture of end of life care. The majority of people in the Midhurst cohort have cancer diagnoses, with a maximum of 24% of its population having non-cancer diagnoses. This is unrepresentative of the end of life population where cancer accounted for 29% of all deaths registered in England and Wales in 2013². It also does not take into account any impacts on local authority funded social care.

Marie Curie Nursing Service – The Nuffield Trust

66. Another example of a specialist palliative care nursing service is the Marie Curie Nursing Service (MCNS), evaluated by the Nuffield Trust in November 2012¹². MCNS provide a number of different models of care, from planned, advanced booking overnight nursing care to rapid response urgent support for a crisis occurring out-of-hours. It also provides emotional support, discharge support to get people home from hospital, and integrated health and social care.

67. The Nuffield study investigated the economic impact of MCNS on place of death and level of hospital care for an end of life cohort. They found that those in receipt of MCNS were less likely to use all forms of hospital care, were significantly more likely to die at home than in hospital, and had less planned and unplanned hospital care, compared to the control cohort.

68. The MCNS study also investigated a variety of sub-groups and found that the service had a greater impact for those with non-cancer diagnoses (23% of the cohort) than those with a history of cancer (77%), with even fewer admissions and greater potential savings.

69. The MCNS discussed here has been used in the model as an additional service in care option 2 and the costing data has been used to inform reductions in hospital costs. It is possible that greater savings are possible under the general demographics of the end of life population, where 71% of people do not die from cancer.

¹² The Impact of the Marie Curie Nursing Service on Place of Death and Hospital Use at the End of Life, The Nuffield Trust, Chitnis et al. November 2012; http://www.nuffieldtrust.org.uk/sites/files/nuffield/marie_curie_full_report_final.pdf

70. The MCNS also does not include the cost of other services such as allied health professionals (occupational therapists, physiotherapists, dieticians) or the potential impact of increased choice on hospice care, both inpatients and day hospice services. As a result, it does not provide the full picture of end of life care for an individual.

Impact of Social Care on Hospital Costs – The Nuffield Trust

71. In October 2012, the Nuffield Trust released a paper investigating the patterns of both health and social care in the last year of the end of life phase¹³. It is one of the few papers that examine the impact on social care. The Nuffield Trust investigated health and social care usage of nearly 75,000 people across 7 sites.

72. They found considerable variation in the use of social care at the end of life between local authorities and that many more people use hospital care in the last year of life than social care (90% versus 29% respectively). Those with the highest social care costs were found to have relatively low average hospital costs, supporting the idea that those in residential care settings tend to lead to less hospital care usage than those in intensive home care settings.

73. This study provides more of a baseline understanding of the patterns of social care at the time of publication, rather than how choice may affect its usage. One key finding is that, per user, using only social care costs over three times as much as solely hospital care but the differences in the proportions of people using these services leads to much greater costs.

74. While this study investigates the implications for hospital and social care, it does not look into the wider picture of end of life care, including allied health professionals, the implications for community health care, and impacts on hospices.

75. None of these services calculate the cost of providing less specialised community-based services, such as GP practices and 'out-of-hours' provision or district nursing, which are potentially a vital part of a holistic end of life care package. As a result, none provide a comprehensive view of the current or possible community services at end of life care.

¹³ Understanding Patterns of Health and Social Care at the End of Life, The Nuffield Trust, Bardsley et al. October 2012
http://www.nuffieldtrust.org.uk/sites/files/nuffield/121016_understanding_patterns_of_health_and_social_care_full_report_final.pdf

Appendix B: Services included in each option

76. The following table presents approximate usage of services for each option, for the whole cohort. Precise unit costs will be dependent the level of need and care setting; averages are used here.

77. These levels are based on expert opinion from member of the Choice Review Programme Board and include representatives from primary care, the Royal College of Nursing, the Association for Palliative Medicine of Great Britain and Ireland, NHS England, Public Health England and the National Care Forum.

| Services | Option 1 | Option 2 | Option 3 |
|---|---|---|---|
| NHS Staffing | | | |
| Cost of District Nurse incl. travel ¹⁴ | Ranges from short daily visits for those with high needs, once a fortnight for moderate needs to one or two visits over the time period for low need individuals. | Approx. increase of 50% of DN time compared to Option 1. | Approx. tripling the amount of DN time compared to Option 1. |
| Band 6 and 7 Specialist Nurses ¹⁴ | Depends on setting – more frequent in hospital/ hospice Ranges from one hour a month for low need to daily hourly visits for those with high needs. Assumed time split evenly between band 6 and band 7 nurses. | Approx. increase of 30% of patient-contact time compared to Option 1. | Approx. doubling of specialist nurse time compared to Option 1. |
| Specialist Palliative Care Consultant ¹⁴ | Ranges in contact hours from once a month to daily depending on setting/ level of need. Time is split between in-person and on the phone providing support. | Approx. 10% increase on Option 1. | Approx. 90% increase on Option 1. |

¹⁴ Unit Costs of Health and Social Care, 2013; <http://www.pssru.ac.uk/project-pages/unit-costs/2013/>

| Services | Option 1 | Option 2 | Option 3 |
|---|--|--|--|
| Allied Health Professionals incl. Occupational therapist (OT), physiotherapist, and dietician ¹⁴ | Ranging from an hour in three months to one hour per month depending on setting and need. Physiotherapists and OTs set together as they have the same unit costs. Dietician has less frequent contact. | 25% increase compared to Option 1 for Physiotherapists / OTs / dieticians. | Doubling of all these professionals time compared to Option 1. |
| Community or Hospital Pharmacist ¹⁴ | Assumes approx. 15 minutes per week per person | Increase of 50% of pharmacist's time from Option 1. | Doubling of pharmacist's time from Option 1. |
| GP consultations ¹ | Assumes an average number of consultations (4.6) in a three month period. | Approximately 2% increase in GP consultations. | Takes into account extra GP consultations that would occur (approx. 4% increase) |
| Out of Hours or On-Call GP ¹⁵ | Range of call outs over a three month period, from once a month to once a fortnight | Assumes more call outs. Increase of approx. 10% on Option 1. | Again, more call outs up to an hour a week. Approx. increase of 20% from Option 1. |
| Care Assistants in Health and Social Care (depending on setting) ¹⁴ | Assume to range from half an hour twice a week to two hours per day, depending on setting and level of need. | Increase in time of approx. 25% on Option 1. | Increase of approx. 50% compared to Option 1. |

¹⁵ Communications with NHS Lancaster North CCG

| Services | Option 1 | Option 2 | Option 3 |
|---|--|--|--|
| Specialist Palliative Care Nursing Service ¹ | Assumed unavailable | Costing for three month period of nursing service. | Same as Option 2. |
| Hospital Costs | | | |
| Hospital costs incl. A&E, emergency admissions, non-emergency admissions, out-patients, and laboratory and imaging tests ^{1, 16} | Average number of these per person over a given time period. Cost of lab and imaging tests constant | Decrease of 25% on Option 1 for all costs. Cost of lab and imaging tests constant | Decrease of 50% on Option 1 for all costs. Cost of lab and imaging tests constant |
| Other Health Costs | | | |
| Intermediate Care Facility ¹⁴ | Assumed unavailable | Includes a five day intensive service as an alternative to hospital care. | Assumed to be constant per person compared to Option 2. |
| Telehealth set up ¹⁴ | Assumed unavailable | Assumed unavailable. | Set up and running costs in usual place of residence included. |
| Telephone coordination hub ¹⁷ | Assumed unavailable | Assumed unavailable. | 24/7 helpline between 10pm and 8am 7 days a week |
| Hotline run by a Specialist Band 7 Nurse ¹⁸ | Assumed unavailable | Assumed unavailable. | Salary of one band 7 nurse who rings people to see how they are and follows their progress – not available out of working hours. |

¹⁶ Palliative Care Funding Review Data;

¹⁷ Communications with Sue Ryder

¹⁸ Communications with Specialist nurses from Oxford University Hospitals NHS Trust

| Services | Option 1 | Option 2 | Option 3 |
|--|---|--|---|
| Implementation of EPaCCS in Ambulances ¹⁹ | Assumed unavailable | Assumed unavailable. | Cost of developer's time per ambulance trust. |
| Hospice Costs | | | |
| Hospice Stay Costs ¹ | Assumed to be constant per person, based on 14 day stay. | Assumed to be constant per person, compared to Option 1. | Assumed to be constant per person, compared to Option 2. |
| 'Hospice-at-Home' ²⁰ | Average per patient – number of hours varies depending on need. | Assumed to be constant per person, compared to Option 1. | Assumed to be constant per person, compared to Option 2. |
| Day Hospice ²⁰ | Five and a half hour sessions, six times over the time period | Assumed to be constant per person, compared to Option 1. | Assumed to be constant per person, compared to Option 2. |
| Social Care | | | |
| Domiciliary care/ Home Care ¹⁴ | Range from one hour a week to ten hours a week | 25% increase between Options 1 and 2. | 50% increase between Options 1 and 3. |
| Cost of Equipment and Adaptation to place of residence ¹⁴ | Cost of three pieces of equipment to usual place of residence included. | Includes a multiplier to enable express delivery within 4hrs for higher need levels. | Includes a multiplier to enable out of hours delivery for higher need levels and within 4hrs for moderate need level. |
| Cost of Care Home Fees ¹⁴ | Assumed constant per person across care options. | Assumed constant per person across care options. | Assumed constant per person across care options. |

¹⁹ Communications with Weston Area Health NHS Trust

²⁰ Data for cost "per patient" received from St Peter's Hospice, Bristol.

Appendix C: Descriptions of Levels of Need

Level 1 – Very low to low need

78. These may be people with a mild physical or cognitive impairment that only need assessments or interventions on an urgent exacerbation. It is thought these won't happen too often and can be controlled by the district nurse and/or local GP with conversations with a Specialist Palliative Care (SPC) team member – either a consultant or band 6/7 nurse – over the phone. They have good level of personal and functional need control and so do not need any social home care. They may live alone in their own home, in a care home or in a communal assisted living location. It is possible that family carers fulfil a large proportion of their general needs. It is possible that, if they end up in hospital, their discharge may be delayed for a variety of reasons.

Level 2 – Low to moderate need

79. These patients may have slightly more severe physical and/or cognitive impairment. Again, assessment or intervention may only be required on an urgent exacerbation that can be controlled by the district nurse and/or local GP with conversations with the SPC team, or with an SPC nurse visiting the patient infrequently but regularly (e.g. once every six weeks). They may live at home (or in a care home or in assisted living accommodation) with a carer visiting once a week. Their level of social care need is likely to be too low to meet the assessment for Local authority (LA) payment. These people may be able to get themselves to outpatient clinics if required.

80. Both Levels 1 and 2 will need access to 24/7 pharmaceuticals, syringe drivers and to a coordination hotline for their care. Depending on individual circumstances, they may or may not need to have adaptations to their usual place of residence with extra equipment.

Level 3 – Moderate need

81. As the level of need increases, service usage inevitably increases. While people may still be able to remain in their own homes, they may require adaptations, more frequent visits by a district nurse or GP and more regular contact with the SPC team. If an exacerbation occurs, a member of the SPC team may be needed at the patient's location. If they are care home residents, after an exacerbation, they may need to enter a care home with nursing to account for their changing level of need. They may have more outpatient appointments or undergo extra hospital tests. Informal care given by family members may no longer be sufficient and

more formal social care may be required. Involvement with voluntary sector organisations is more likely and a Macmillan or Marie Curie nurse may provide some help to the family to enable them to get some respite.

Level 4 – High need

82. At this higher level of need, the patient may be in a deteriorating condition and have either high physical and/or cognitive impairment. It is possible they may enter this category of need after an incident or exacerbation. At this point they may need to be admitted to a hospice or indeed hospital where SPC teams can keep a close eye on the individual. After discharge, or if they remain in their usual place of residence, the intensiveness of community and social care is likely to increase, although this may be condition-dependent. Services such as ‘hospice-at-home’ or ‘rapid response’ services will help patients remain in their own residences while still having their needs supported. Contact with SPC teams is also likely to increase, whether this be in person or remotely via the phone using the DGN and/or local GP as an intermediary. They may have significant personal and functional needs that require input from professionals. Again they may receive nursing from a Macmillan or Marie Curie nurse.

Level 5 – Very high need

83. At the highest level of need, people will have very complex needs and require intensive observation and/or intervention, especially from SPC teams, in any location setting. If they are in their own residences, adaptations will be required and need to be maintained with clinical practitioners visiting the patient frequently, potentially daily if resource allows. Again, admission to a hospice or hospital is highly possible and, on discharge, individuals may need intensive services, such as ‘rapid response’ or ‘hospice-at-home’ to fill their requirements. A Macmillan or Marie Curie nursing service may enable a patient to avoid unnecessary emergency admissions (Nuffield 14) and so procuring a similar service for a CCG population may be helpful. With the advent of a National Choice Offer for End of Life Care, inventive solutions may be required to enable people to die in their place of choice. An example of this may be for complex procedures, such as lymphedema drainage, to be performed at home. SPC teams may need to be on-call with further back-ups in place (e.g. if a consultant is called out, there is a “second” consultant ready).

