National Institute for Health and Care Excellence

Final version

End of life care for infants, children and young people with life-limiting conditions: planning and management

Appendix K

NICE guideline NG61

Health Economics

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Final

Developed by the National Guideline Alliance, hosted by the Royal College of Obstetricians and Gynaecologists

Contents

Appendix K: Health economics

As with all NICE guidelines, the Committee for this guideline aimed to produce recommendations on the best available evidence of clinical and cost effectiveness using established NICE methods. However, there are myriad problems in undertaking research in children and young people with life-limiting conditions, which means that clinical effectiveness evidence can be lacking.

Even if clinical effectiveness evidence was available, economic evaluation in the context of palliative and end of life care can be challenging. The scope for this guideline recognised that the use of quality-adjusted life years (QALYs), NICE's preferred measure for economic evaluation, is difficult in the context of end of life care for infants, children and young people. The problems include the difficulties of eliciting health state utilities in this population, the often limited duration of life, which means that any QALY gains will typically be very small, and ethical issues around using conventional NICE cost effectiveness decision rules. NICE's Social Value Judgements makes it clear that cost effectiveness is not the sole criterion for making decisions, and for the reasons mentioned above this is especially the case for this guideline.

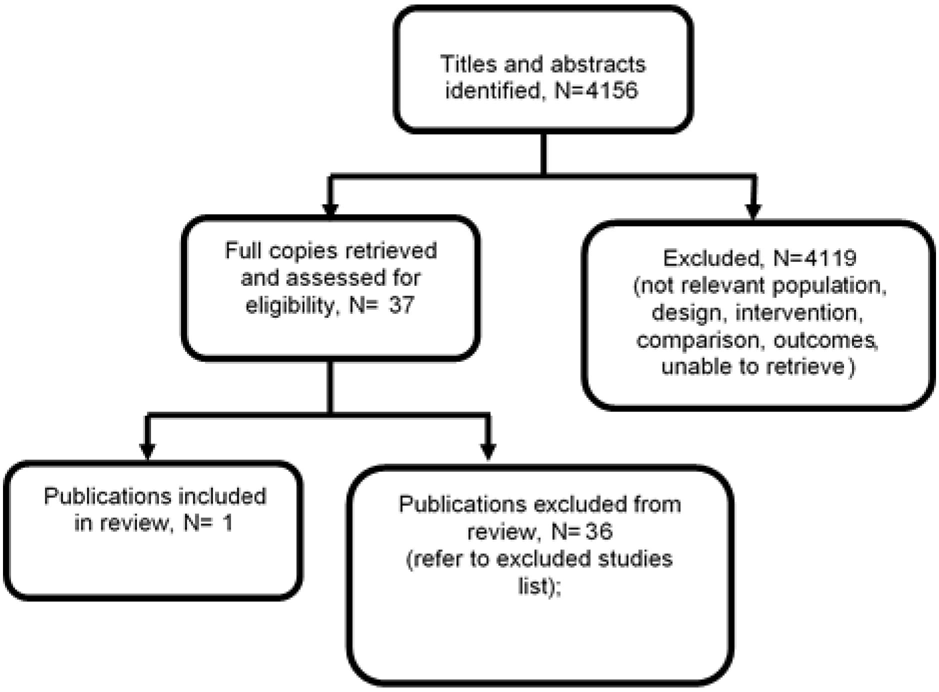
This section of the guideline describes the systematic literature review that was undertaken to elicit the best available published health economic evidence, relevant to the scope, on end of life care in infants, children and young people. This section also describes 2 costing models which were developed in order to support the Guideline Committee in making recommendations on aspects of service delivery.

K.1 Literature review

A global search for health economic evidence covering the complete guideline was undertaken. Double 'sifting' was undertaken on the initial literature search, with the second sifter reviewing a random sample of 5% of studies. Mismatches were discussed and discrepancies were the result of second sifter being more inclusive prior to detailed discussion.

The initial search and subsequent re-run identified 4,156 articles. After reviewing titles and abstracts, 37 papers were obtained. For the purposes of inclusion in this guideline, quality appraisal using a health economic quality appraisal checklist was not applied too rigidly. This was because we anticipated that there would be a limited number of studies and we did not want to miss studies that could inform any modelling. Nevertheless, 36 studies were excluded because they contained very little information on resource use or costs, did not consider the right population for this guideline or did not relate sufficiently well to the guideline scope. Most of the excluded studies were from a non-UK setting and were unlikely to be generalisable to a UK setting, although this criterion was not used alone as the basis for exclusion. A flow diagram of article selection is shown in Figure 1.

Figure 1: Flow diagram of health economic article selection for review



K.1.1 24/7 community nursing and telephone support

A single study which described an epidemiological and economic exemplar for North Wales to estimate the number of children aged under 19 years with a life-limiting condition and to cost end of life care at home, and with access to 24 hour support was included (Noyes 2013).

K.1.1.1 Quality appraisal

Strictly speaking, this study is not an economic evaluation as it does not explicitly compare alternative courses of action even in terms of their costs. The study reports estimates of the “additional” cost of providing 1 week of end of life care at home with 24 hour support. This might be interpreted as being the costs over and above current provision. However, the costing does not include any substitution of existing provision which would be likely when instituting a new service of this type. Also, the issue of current service provision is not discussed, so it seems unlikely that the “additional” costs are meant to reflect the incremental costs when compared with current practice.

Even though mainly descriptive, the study population and the costing undertaken were highly relevant to the guideline, addressing a very specific topic and review question. It was also a relatively recent study and set in the UK’s NHS, so likely to be generalisable to settings which would be covered by this NICE guideline. Costs are considered from an NHS perspective and discounting was not applied as there were no future costs to consider.

The paper proved helpful in developing the costing model produced for this guideline, even though a detailed rationale for the recommended staffing levels on which their costs were based were not provided in the study.

K.1.1.2 Summary of findings

The authors noted that estimating the number of children needing paediatric palliative care is problematic. One reason they put forward for this is the fact that palliative care is governed by the needs of the individual child, young person and family, and not by organ system. The requirement for palliative care will be determined by a whole range of symptoms and traits of the individual child, the assessment of which is subjective, whereas services for 'heart failure', for example, could be determined by a quantitative measure applied to that one organ system (New York Heart Association criteria). They also commented that because key terms are not agreed by providers, this can also make it difficult to determine the number of children needing palliative care, as in addition to services at and around the end of life, there may also be a need for services earlier in the trajectory of a life-limiting condition.

The report estimates that approximately 2,300 children and young people 0 to 19 years have a life-limiting condition in North Wales (population 680,000) and that approximately 500 of those would access inpatient treatment each year. Through a modelling process, they estimated that 24 children, young people and their families would need end of life care and bereavement support per annum. The authors note that this estimate is similar to what is shown by death certificate data, with around 25 deaths per annum in children with a life-limiting condition between 2002 and 2006.

It is estimated that the total cost of paediatric palliative care is approximately £5.5 million per year, which is provided by a mix of hospitals, hospices, and community and specialist nurse teams. The authors suggest that about half these costs are covered by the NHS, with charities providing the remaining funding. The author's argued that services in North Wales did not have all the key elements required for a children's palliative care network. In particular they pointed to the lack of:

- specialist consultants in children's palliative care
- a universal community nursing service, provision of end of life care at home and access to 24/7 support and advice.

In terms of costing these identified gaps in the palliative care network, the authors focused on a children's community nursing service which would facilitate the option for end of life care provided at home and access to 24/7 support. The authors took clinical advice from within their writing team to estimate the staffing that would be required to deliver such a service, assuming 1 week of 24/7 end of life care at home. In their North Wales locality, they estimate that it would cost an additional £336,000 per year to provide this service for 1 week to 24 children. This amounts to £14,000 per child per week.

The authors acknowledge that the duration of end of life care is variable on an individual basis, poorly researched and not consistently reported. The 1 week duration was an estimate based on their clinical experience, but they estimated that the costs would rise to £536,500 if a longer duration was assumed.

K.2 A cost analysis of providing a 24/7 community nursing and telephone support service

The economic model related to the following review question:

What is the effectiveness of 24/7 specialist telephone healthcare professional support (or parents/carers support), 24/7 community nursing support, and the combination of the two for the needs of infants, children and young people with life-limiting conditions, and for the needs of their family members and carers (as appropriate) during this time and after death as part of service delivery?

K.2.1 Introduction

The aim of the economic analysis was to consider the resource impact of providing a service of 24/7 community nursing and telephone support as an alternative to hospitalisation.

K.2.2 Methods

K.2.2.1 Conceptual map

A conceptual map is used to present a visual representation of a system in order to define the key issues or components of a system. In the context of this guideline it was used to inform the key data requirements for this service delivery model. The conceptual map that was developed in consultation with the Guideline Committee is shown in Figure 2.

In order to calculate the costs of providing a 24/7 community nursing/telephone service it is important to know the numbers of infants, children and young people who could be anticipated to use such a service. It was thought that having data on the following would provide a reasonable estimate of the number of children and young people who could potentially use such services.

i. Population ('region') for commissioning service

   Due to the relatively small number of infants, children and young people with life-limiting conditions, it is generally recognised that the optimal population size for commissioning paediatric palliative care services has to be much larger than the populations typically covered by clinical commission groups.

ii. Infants, children and young people with a life-limiting condition

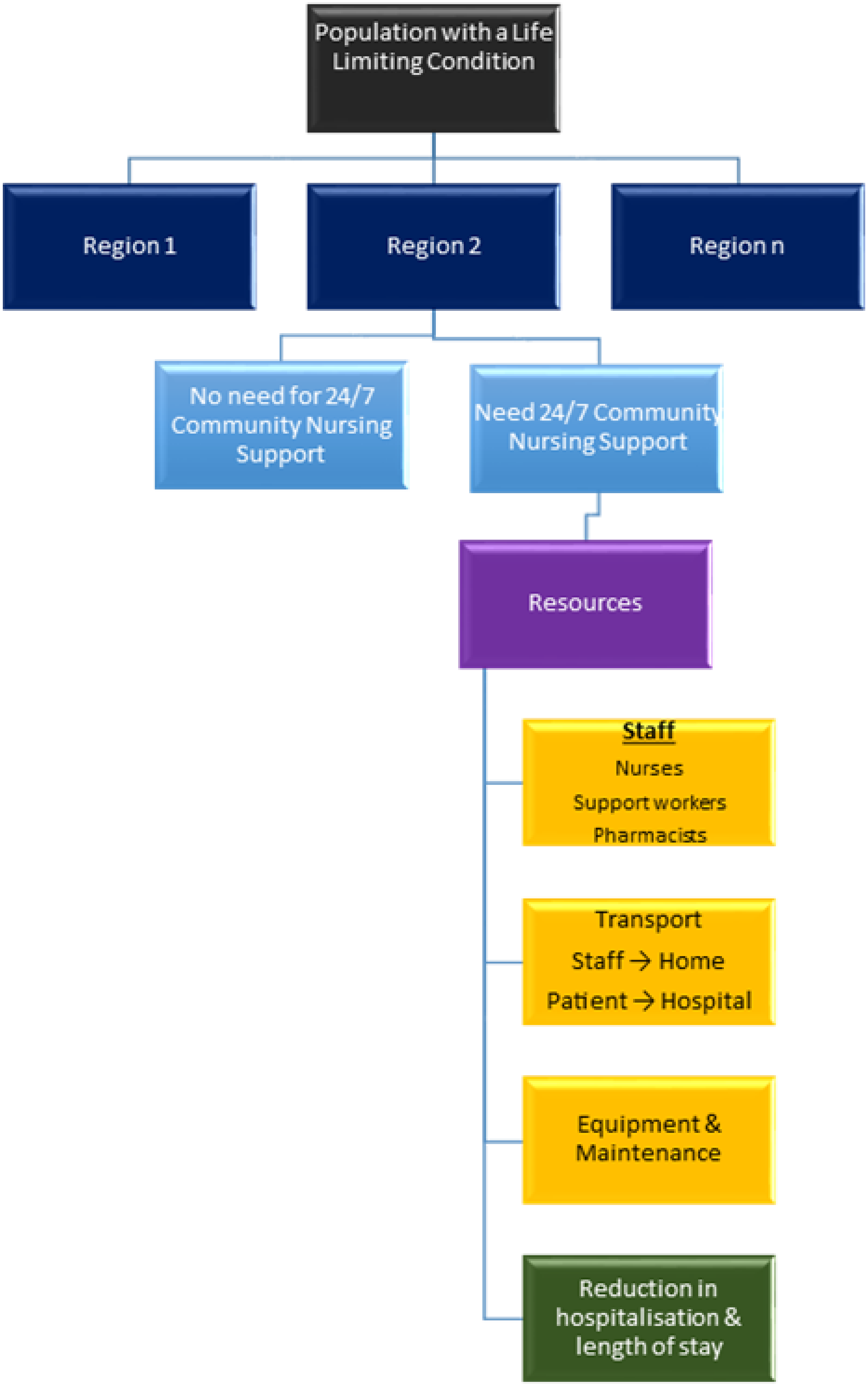
   This relates to the population covered by this clinical guideline. Prevalence data could be used to provide an estimate of the numbers of infants, children and young people with a life-limiting condition within a given 'region'.

iii. Subset of population of infants, children and young people with a life-limiting condition who would be eligible for 24/7 community nursing/telephone support

   It is assumed that the 24/7 community nursing/telephone service is specifically for 'end of life' care and not for the longer term management of the underlying life-limiting condition. Therefore, this service pertains to only a subset of the guideline population of infants, children and young people with life-limiting conditions (up to age 18). To reach an estimate of the total number of service users it is necessary to determine the proportion of infants, children and young people with a life-limiting condition who would be suitable for such a service within a given timeframe (for example 1 year).

Having estimated the number of children for whom a 24/7 community nursing/telephone support service could be suitable, it is then necessary to define the resource 'ingredients' that would be required to provide such a service to that number of children. In addition to staffing and equipment, this would include travel costs associated with home visits and ambulance transportation. Finally, it is important to include offsetting reductions in hospital resource use arising from the provision of such a service, recognising that there may be occasions when infants, children and young people need to be admitted to hospital.

Figure 2: 24/7 nursing and telephone support conceptual map

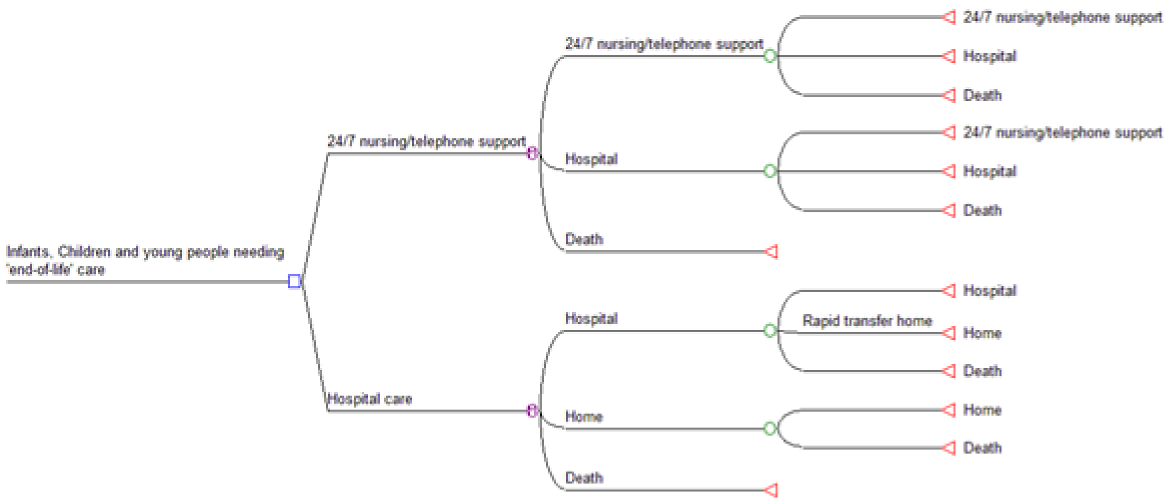


K.2.2.2 Modelling approach

A service delivery model was developed using Microsoft Excel® in order to compare the costs of providing a 24/7 community nursing/telephone support service with an alternative of hospital care. It was not possible to undertake cost effectiveness analysis because a systematic review undertaken for this guideline found no clinical evidence for the effectiveness of 24/7 community nursing support or the combination of 24/7 specialist telephone advice and 24/7 community nursing support.

The model utilises a "what-if" approach, which allows model inputs to be varied in order to explore the cost implications of different service configurations. A schematic of the model is shown in Figure 3 below.

Figure 3: Model schematic



K.2.3 Model inputs

K.2.3.1 Demographics

The model population is infants, children and young people approaching the end of life and requiring end of life care and therefore is a subset of the guideline population, namely all infants, children and young people with a life-limiting condition. It is anticipated that this service would only be available when children and young people are likely to die within hours or days.

The various demographic input variables are shown in Table 1.

Table 1: Demographic inputs

Variable	Value	Source
Population of region providing 24/7 support	1,500,000	Varied as part of "what-if" analysis
Proportion of population that are children	0.225	ONS (2016) [a]
Proportion of children with a life-limiting condition	0.0032	Fraser et al. (2012) [b]
Proportion of children needing palliative care	0.0015	Lowson et al. (2007) [c]
Proportion using palliative care who die per year	0.10	Lowson et al. (2007) [c]
Mean duration of 24/7 nursing support (days)	21	Varied as part of "what-if" analysis

(a) Population of England 54,316,618 of which 12,247,454 aged 0-18 years (http://www.ons.gov.uk/ons/taxonomy/index.html?nscl=Population#tab-data-tables – accessed 25 February 2016)

(b) L Fraser et al. Rising National Prevalence of Life-Limiting Conditions in Children in England, Pediatrics 2012;129:1-7 (www.pediatrics.org/cgi/doi/10.1542/peds.2011-2846).

(c) Lowson K, Lowson P, Duffy S: Independent review of the palliative care for children and young people: economic study (final report). Department of Health Independent Review team: York Health Economics Consortium; 2007.

K.2.3.2 Staffing level

The composition of the staff that would be needed to provide a 24/7 community nursing and telephone support was agreed with the Guideline Committee. The model allows the user to define the staffing level in 1 of 3 ways:

i. Fixed

   This would specify for a given region the number of whole time equivalent (WTE) staff who would be needed to provide a 24/7 community nursing and telephone support service.

ii. Staffing level as a function of the number of children who would use the service per annum

   Under this setting the number of WTE staff per child is specified. So, for example, in a published cost exemplar (Noyes 2013) there were 5.5 WTE community nurses for a service expected to be used by an estimated 24 children. This would amount to 1 WTE community nurse per 4.4 children. Specifying staffing levels using this method means that any changes in model inputs which affects the number of children who this service would cover (for example the size of the region providing service) will lead to a change in the staffing level.

iii. Staffing level as a function of the total number of children's 'end of life care days' per annum[a]

   Under this setting the number of WTE staff per total number of 'care days' per annum is specified. So, for example, in a published cost exemplar (Noyes 2013) there were 5.5 WTE community nurses for a service expected to be used by an estimated 24 children and young people for an assumed period of 7 days, giving a total of 168 'care days' per annum. This would amount to 1 WTE community nurse per 31 'care days'. Specifying staffing levels using this method means that any change in model inputs which affects the number of children who would use the service or the mean duration of service use per child will lead to a change in the staffing level.

Figure 4 shows the user form which allows the model user to determine how the staffing level is to be specified.

[a] The model has inputs which give the number of children and young people who would be using a 24/7 community nursing and telephone support service. Another input then gives the mean duration that any individual or child might be expected to use such a service within the context that It is anticipated that this service would only be available when children and young people are likely to die within hours or days. Therefore, the total number of 'care days' is the total number of children and young people using the service per year multiplied by the mean duration of days. It gives the aggregate number of days of 24/7 community nursing and telephone support that are provided across all children and young people per year.

Figure 4: User form to select approach to defining staff levels

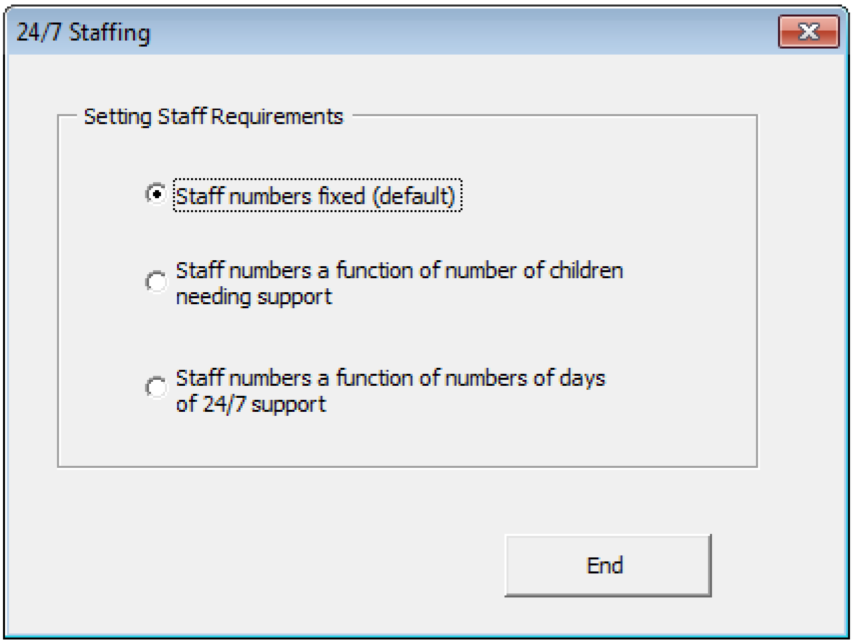


Table 2 shows the default values for the levels of staffing according to the method used to define staff levels. These values were based on those in the published study (Noyes 2013) and the views of the Committee.

Table 2: Staffing level

Staff	Fixed (whole time equivalent [WTE])	Children per WTE	Days per WTE
Children's community nurse	5.50	5	100
Children's specialist palliative care nurse	1.00	25	500
Medical equipment technician	0.20	100	2,000
Clinical psychologist	0.50	50	1,000
IT support specialist	0.10	250	5,000
Administrator	0.50	50	1,000
Consultant community paediatrician	0.05	500	10,000

The annual WTE costs for these staff are given in Table 3.

Table 3: Staff WTE annual costs

Staff	WTE annual cost	Source
Children's community nurse	£39,000	PSSRU 2015
Children's specialist palliative care nurse	£48,000	PSSRU 2015
Medical equipment technician	£39,000	PSSRU 2015
Clinical psychologist	£48,000	PSSRU 2015
IT support specialist	£48,000	PSSRU 2015
Administrator	£29,000	PSSRU 2015
Consultant community paediatrician	£110,000	PSSRU 2015

K.2.3.3 Staffing for 24/7 telephone support service

The model allows the staffing resources for 24/7 telephone support to be captured in 1 of 2 ways.

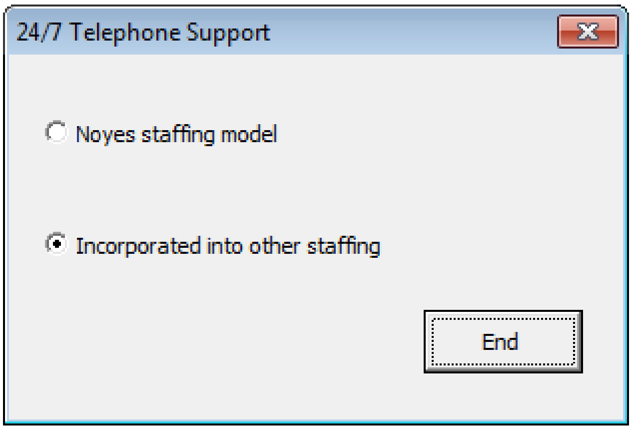
i. The Noyes approach

   This involves detailing the number of nurses, their grade and the number of hours they would each work per annum on providing 24/7 telephone support. It is assumed that each WTE nurse works 1,590 hours per year and this can then be combined with the staff WTE annual cost to estimate the staffing costs of providing this support.

ii. Including staffing levels for provision of a 24/7 telephone service within the staffing resource indicated in Table 2.

Figure 5 shows the user form which allows the user to choose how the staffing levels for the provision of 24/7 television support is to be incorporated.

Figure 5: User form to select how 24/7 telephone staff levels are incorporated



For the results presented in this analysis the Noyes approach was adopted, with the default staffing inputs for that approach shown in Table 4.

Table 4: Staffing levels for 24/7 telephone support

Variable	Value	Source
Number of nurses [a]	15	Noyes 2013
Hours worked by each nurse per annum	100	Noyes 2013

(a) The model also allows the user to determine whether the nursing staff input is at band 6 or band 7 (default)

K.2.3.4 Visit inputs

As part of the provision of 24/7 community nursing support, it will sometimes be necessary for nurses to make home visits, which incurs opportunity costs both in terms of fuel and mode of transport. There is also an opportunity cost of a nurse's time in making a visit, but this is captured within the model by the WTE staffing levels.

As with staffing levels, the number of visits for a given region per year can either be incorporated as a fixed amount independent of changes in other model inputs, or made a function of the number of children using the service per year or, perhaps most intuitively, as a function of the number of 'care days' per year. Figure 6 shows the user form which allows the method of determining the total number of visits to be incorporated into the cost analysis.

Figure 6: User form to determine how the number of visits are to be incorporated into the model and how those visits are to be costed

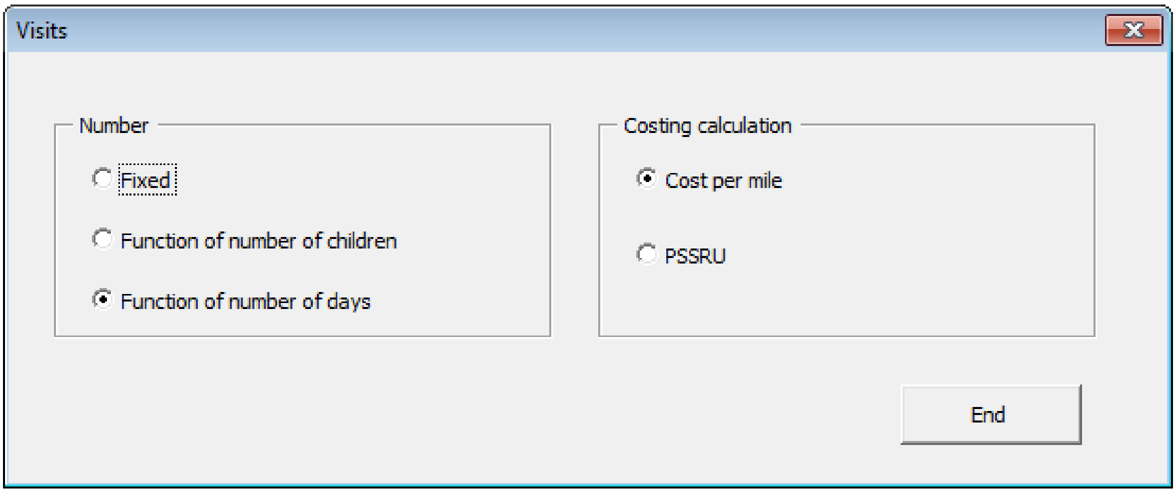


Table 5 shows the default values used for each of the alternative methods of determining the number of visits per year.

Table 5: Variables used to determine number of visits

Variable	Value	Source
Fixed visits	1,000	Guideline Committee (GC) estimate
Visits per child	20	GC estimate
Visit per day	1	GC estimate
Distance per visit (miles)	80	Varied as part of “what-if” analysis

K.2.3.5 Visit costs

The model allows the cost per visit to be incorporated in 1 of 2 ways.

i. Distance travelled and cost per mile rate

In this approach the model uses the mean trip distance for the region and then multiplies that by a mileage allowance which covers fuel and depreciation costs. This approach can be used to explore how the geographical spread of a region would influence the costs of a service because rural areas would typically involve longer mean travel distances.

ii. Using a Personal Social Services Research Unit (PSSRU) estimate

The alternative uses a published source (PSSRU 2015) for a visit. The costing was based on the costing of a hospice Rapid Response Service (RRS) introduced by Pilgrims Hospices in East Kent in 2010. This service involves the provision of intense care at times of crisis in order to help avoid admission to hospice or hospital. As part of the service a team responds rapidly 24/7 to crises in patients’ own homes. Travel was a part of that service and a cost per visit is provided.

Figure 6 depicts the user form used to select what method of costing visits is to be used. Table 6 shows the unit costs associated with the different approaches to costing a visit. The estimation of the cost per visit is used together with the number of visits to determine the overall costs associated with visiting patients in order to provide 24/7 community nursing support.

Table 6: Unit costs of visit to patients' homes

Approach	Value	Source
Fixed	£12.10	PSSRU 2015
Cost per mile [a]	£0.56	NHS Employers

(a) Based on using a car with an annual mileage of less than 3,500 miles (http://www.nhsemployers.org/your-workforce/pay-and-reward/nhs-terms-and-conditions/nhs-terms-and-conditions-of-service-handbook/mileage-allowances - accessed 26 February 2016)

K.2.3.6 Hospital costs

It is assumed that the alternative to 24/7 community nursing support at home would be hospital care which would carry its own opportunity cost. In addition, the model allows for the possibility that it may be necessary for an infant, child or young person receiving 24/7 community nursing support to be admitted to hospital, which is assumed to incur the cost of an ambulance transfer. The model inputs that are used to estimate hospital costs are shown in Table 7. They include a variable to estimate the proportion of those receiving a 24/7 community nursing support service who would be hospitalised and a variable to estimate the numbers of days of hospital care that would be required from such hospitalisation. For example, the numbers in Table 7 mean that it is assumed in the model that 10% of children and young people using a 24/7 community nursing and telephone support would require hospitalisation at some point and that their hospital length of stay would be 50% of the mean duration that the model assumes for children and young people using a 24/7 community nursing and telephone support.

Table 7: Model inputs for hospitalisation

Variable	Value	Source
Cost of hospital stay (per day) [a]	£965	NHS Reference Costs 2014-15
Cost of ambulance transfer [b]	£233	NHS Reference Costs 2014-15
Proportion of children requiring hospitalisation	0.10	Guideline Committee (GC) estimate
Hospital stay (proportion of days 24/7 support)	0.50	GC estimate

(a) Service description Daycase and Regular Day/Night; Currency code SD02B, Currency description: Inpatient Specialist Palliative Care, 18 years and under
(b) Currency code ASS02, Currency description: See, treat & convey

K.2.3.7 Overheads

The overheads can be allocated either as a fixed sum or as a proportion of staff costs. Figure 7 shows the user form that is used to select how overheads are incorporated and Table 8 shows the default value for these two approaches.

Figure 7: User form to select method of incorporating overheads

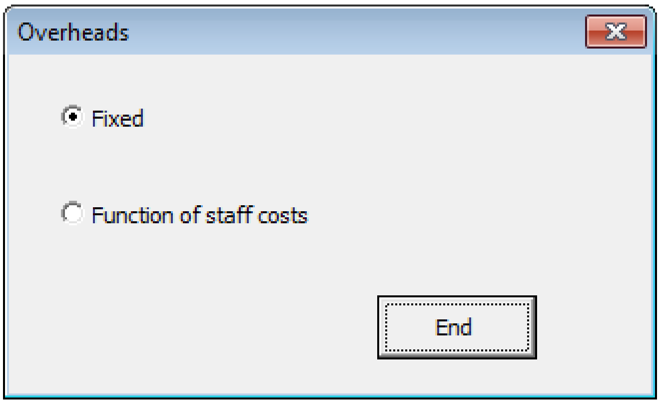


Table 8: Model inputs for overhead costs

Variable	Value	Source
Overhead costs (fixed)	£5,000	Varied as part of a “what-if” analysis
Overheads as a proportion of salary costs	0.06	Varied as part of a “what-if” analysis

K.2.4 Results

Table 9, Table 10 and Figure 8 show the results using the model’s default values with the number of visits being a function of the number of 24/7 ‘care days’, visit costs based on the cost per mile, 24/7 telephone support based on the Noyes model, overheads being a function of staff costs and staffing levels fixed.

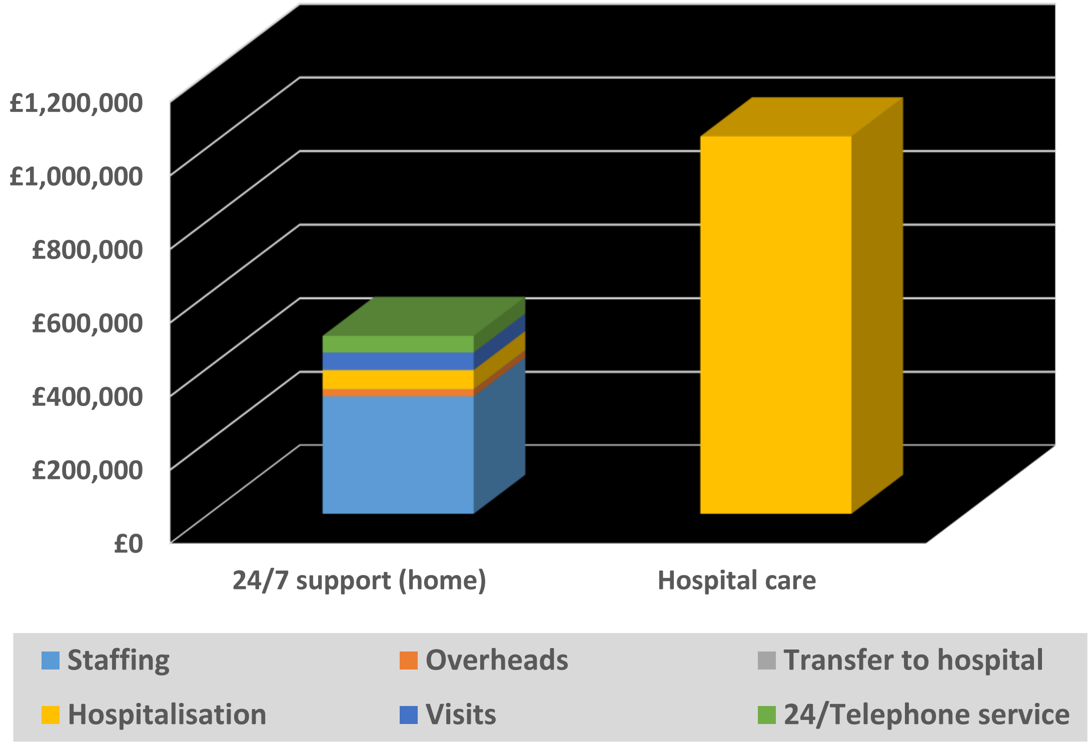
Table 9: Population demographic for this analysis

Variable	Value
Number of children in region	337,500
Number of children with a life-limiting condition	1,080
Number of children needing palliative care per year	506
Number of children eligible for 24/7 nursing support per year	51
Total 24/7 nursing support ‘care days’	1,063

Table 10: Cost comparison of 24/7 nursing/telephone support compared with hospitalisation using the model’s default values

Cost category	Total cost per region		Cost per child	
	24/7	Hospital care	24/7	Hospital care
Staffing	£319,100	-	£6,303	-
Overheads	£19,146	-	£378	-
Transfer to hospital	£1,180	-	£23	-
Hospitalisation	£51,296	£1,025,916	£1,013	£20,265
Visits	£47,628	-	£941	-
24/7 Telephone	£45,283	-	£894	-
Total	**£438,632**	**£1,025,916**	**£9,553**	**£20,625**

Figure 8: Graphical representation of costs of 24//7 nursing/telephone support compared with hospitalisation using the model's default values



Source: Cost model developed for this guideline

The results presented above with the model's default values suggests that a 24/7 community nursing and telephone support service costs almost £600,000 less than the alternative where the child or young person is in a hospital setting. In this case the additional costs of providing 24/7 community nursing telephone support are more than completely offset by reduced costs from hospitalisation.

Table 11 gives the net costs of a 24/7 service relative to the hospital alternative when using different model option settings. They all show the 24/7 service to be cost saving, although that is unsurprising as the defaults for the different options are generally set to give similar resource use for the default population. However, staffing levels are lower when using the fixed staffing model option.

Table 11: Net costs of a 24/7 service per child when using alternative model options

Service	Staffing fixed	Staffing function of children	Staffing function of 'care days'
Telephone support based on Noyes model [a]	-£11,072	-£4,607	-£3,968
Telephone support incorporated into other staffing	-£11,606	-£5,502	-£4,683
Fixed visits	-£10,768	-£4,663	-£4,024
Visits a function of children	-£10,757	-£4,652	-£4,013
Overheads fixed	-£10,991	-£5,232	-£4,625

(a) Model defaults are based on this model setting when not explicitly altered in this table

K.2.4.1 Sensitivity analysis

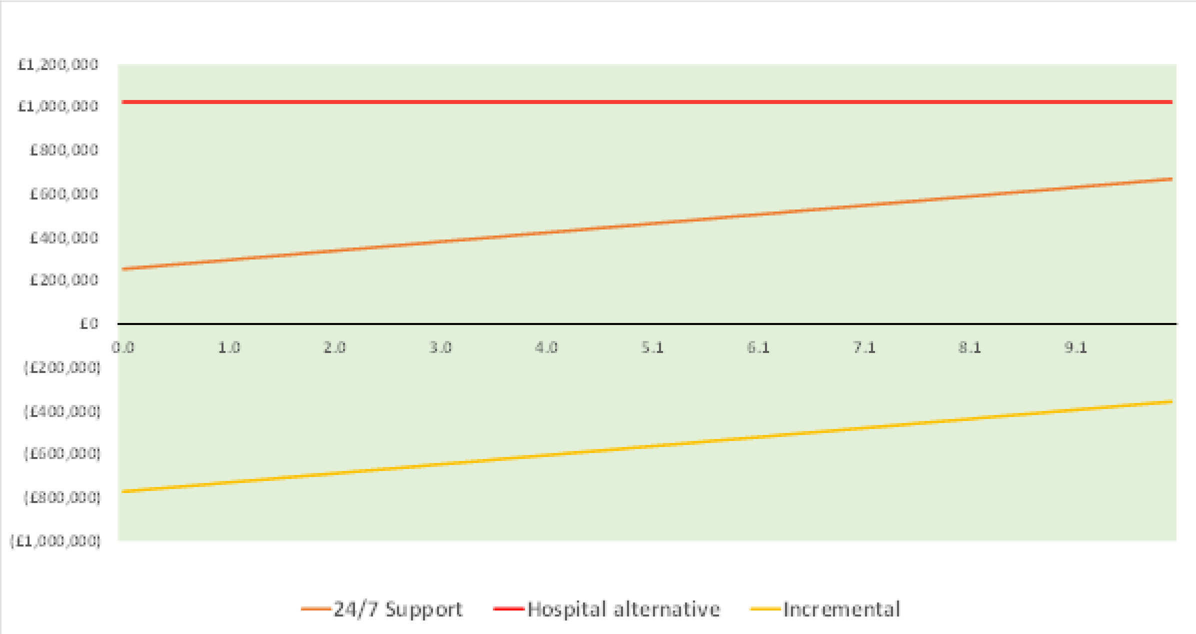
A number of one-way and two-way sensitivity analyses reported below were undertaken to assess the impact of alternative service configurations and inputs. The one-way sensitivity analysis graphs show both the costs of 24/7 community nursing and telephone support and the costs of the hospital alternative. They also show the incremental costs of 24/7 community nursing support relative to hospitalisation. In cases where a 24/7 service is cost saving, then the incremental cost line lies below the horizontal axis.

Varying the number of whole time equivalent community nurses used to provide the service

In this analysis all other model inputs are as per their default value used in section K.2.3. The results of this analysis are shown in Figure 9.

This sensitivity analysis shows that as the staffing input (community nurses in this case) to provide 24/7 nursing and telephone support is increased, the costs of 24/7 provision increase; however, 24/7 nursing and telephone support remains markedly cheaper even if the service utilises 10 WTE community nurses. Cost neutrality is achieved with 18.6 WTE community nurses.

Figure 9: Graph showing the costs of a 24/7 nursing and telephone support service varying the number of whole time equivalent community nurses



Source: Cost model developed for this guideline

Varying the number of whole time equivalent community nurses per number of days of care

In this one-way sensitivity analysis the number of WTE community nurses per number of days of care is varied between 1 WTE for every 10 'care days' and 1 WTE for every 1,200 'care days' of care. Figure 10 shows the point or threshold at which a 24/7 community nursing and telephone support service would become cheaper when maintaining all other model inputs at their default level. In this analysis it was found that the 24/7 community nursing and telephone support service would be less expensive as long as each WTE equivalent nurse accounted for 70 'care days' or more, as shown in Figure 10.

In the default analysis there was approximately 1 WTE for every 193 ‘care days’:

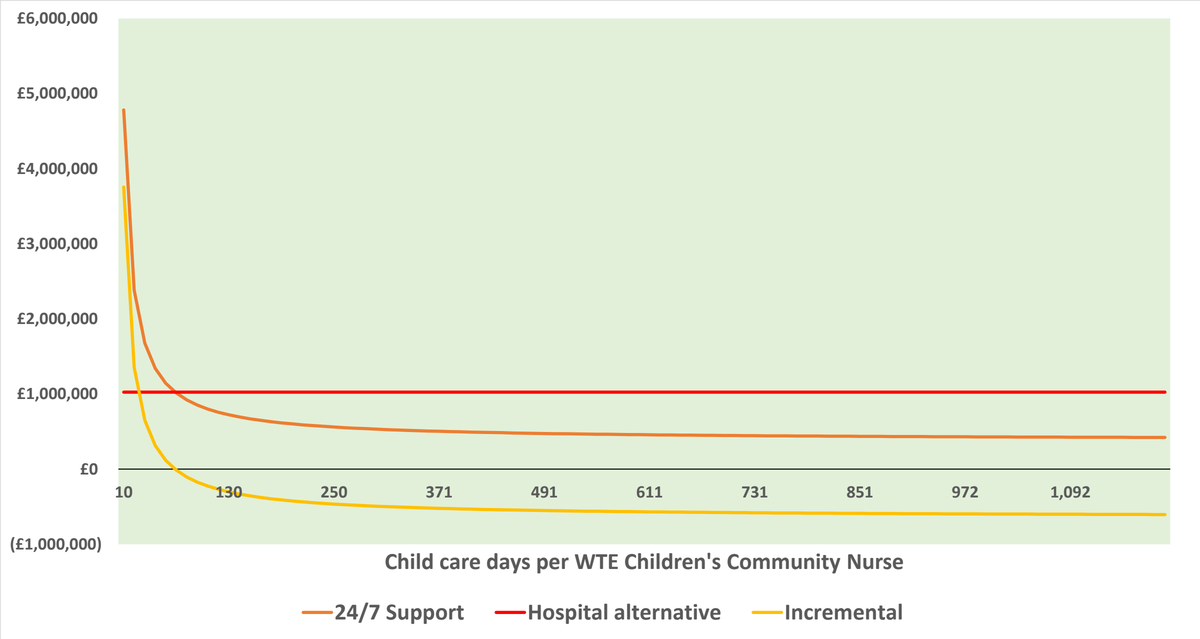
5.5 WTE nurses

21×50.6=1,063 ‘care days’ (duration × children using 24/7 service)

1,063÷5.5=193 ‘care days’ per WTE community nurse

In the Noyes paper there were 5.5 WTE community nurses for 168 ‘care days’, or 1 WTE for every 31 days of care.

Figure 10: Graph to show the costs of a 24/7 nursing and telephone support service varying the number of whole time equivalent community nurses per number of days of care



Source: Cost model developed for this guideline

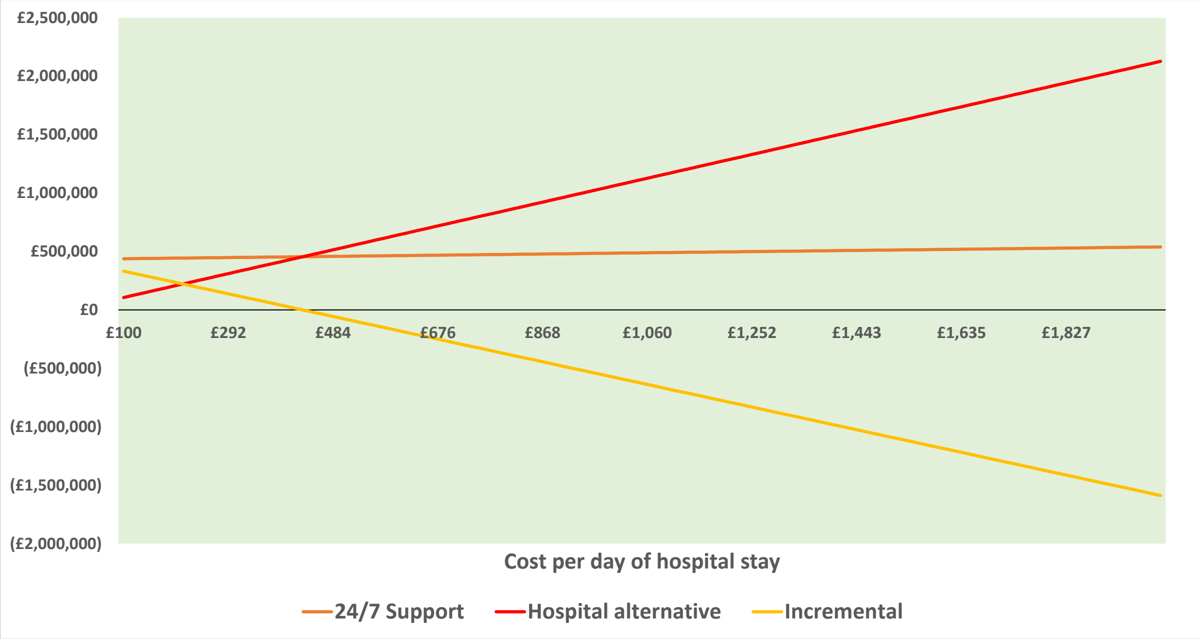
This graph shows that the cost advantage of 24/7 services increases as community nursing staffing for this service is decreased, with each WTE community nurse being responsible for more ‘care days’.

Varying the cost of a hospital stay

This sensitivity analysis, illustrated in Figure 11, suggests that a 24/7 community nursing and telephone support service would be cheaper than a hospital alternative as long as the cost of a hospital bed was more than £428 per day, holding other model inputs constant at their default value. The cost advantages of 24/7 provision increase the higher the costs of the hospital alternative.

This is because only a proportion of every £1 increase in the costs of a hospital stay are incurred in a rapid 24/7 service where only a proportion of children and young people require hospitalisation and for only a proportion of the time. Conversely, all the increase in the costs of a hospital bed are incurred in the hospital alternative to 24/7 support.

Figure 11: Graph to show the costs of a 24/7 nursing and telephone support service varying the cost of a hospital bed-day

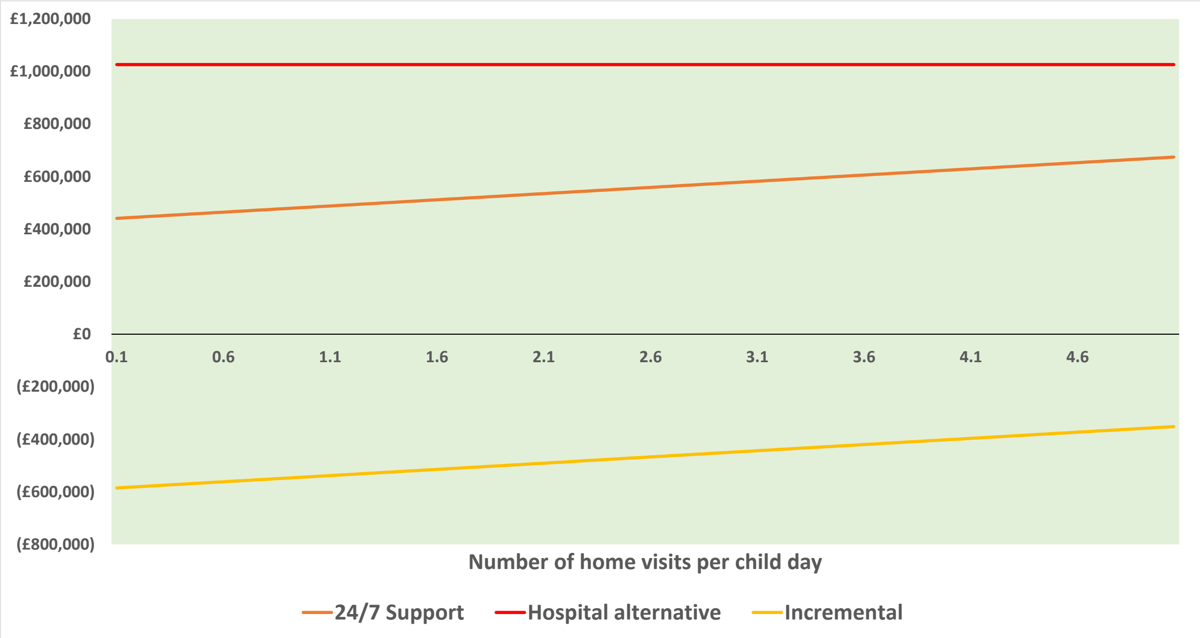


Source: Cost model developed for this guideline

Varying the number of visits per day per child supported by 24/7 community nursing support service

This sensitivity analysis, shown in Figure 12, shows how the costs of a 24/7 service change when the assumption about the number of visits per child per day are changed.

Figure 12: Graph to show the costs of a 24/7 nursing and telephone support service varying the number of home visits per child per day



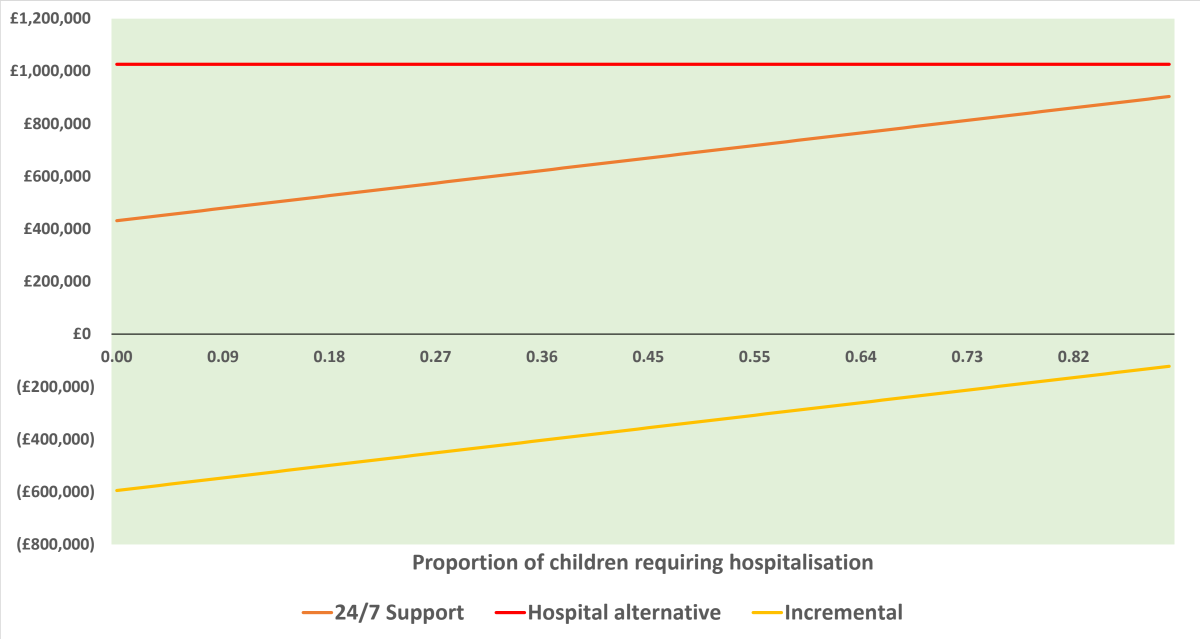
Source: Cost model developed for this guideline

Although this analysis shows that the costs of 24/7 provision increase as the number of home visits per 'child day' needed to provide this service increases, the overall cost impact of increasing visits is limited. Equivalence in costs is achieved at 12.4 home visits per child per day, holding other model values constant at their default value.

Varying the proportion of children using 24/7 community nursing support who require hospitalisation

Figure 13 depicts a sensitivity analysis where the proportion of children and young people, (who are users of a 24/7 support service) requiring hospitalisation is varied. This analysis shows that the lower the rates of hospitalisation with 24/7 provision, the greater the cost saving achieved with a 24/7 service. Even if all children are assumed to require hospitalisation, a 24/7 support service still offers a small cost saving when other model inputs are held constant at their default value. This is because it is assumed that hospitalisation will only be for a proportion of the time covered by the period of a 24/7 service.

Figure 13: Graph to show the costs of a 24/7 nursing and telephone support service varying the proportion of children using 24/7 community nursing support who require hospitalisation



Source: Cost model developed for this guideline

Varying the mean distance per visit

This sensitivity analysis shows the impact of the mean distance per visit on the costs of a 24/7 community nursing and telephone support service (see Figure 14).

A one-way sensitivity varying the cost per mile produces a similar result as both increase the cost per visit. However, these analyses show that the total costs of a 24/7 community nursing and telephone support service are not particularly sensitive to the travel costs per visit when maintaining the other model inputs, including staffing levels, constant at their default value. The mean distance per visit would need to reach 991 miles before cost neutrality was achieved. However, it is important to remember this is based on a default model option set to fixed staffing and therefore independent of the visit distance.

Figure 14: Graph to show the costs of a 24/7 nursing and telephone support service varying the mean distance per visit

Source: Cost model developed for this guideline

Varying the size of the region covered by the 24/7 community nursing and telephone support service

Figure 15 depicts a one-way sensitivity analysis where the population size is varied. This suggests that for populations larger than 600,000, a 24/7 community nursing and telephone support service is cheaper than the hospital alternative. This 'threshold' result is based on other model inputs, including staffing levels, being held constant at their default level.

Figure 15: Graph to show the costs of a 24/7 nursing and telephone support service varying the population of the region covered by the service

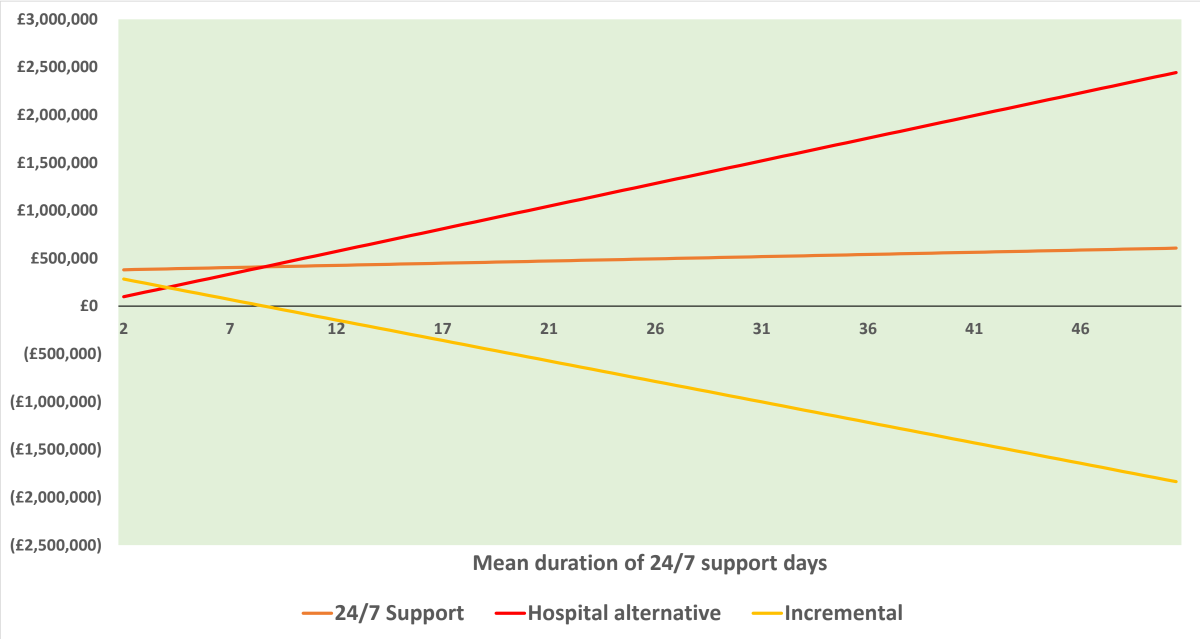
Source: Cost model developed for this guideline

Varying the mean duration of use of 24/7 community nursing and telephone support service by individual child or young person

This one-way sensitivity analysis, illustrated in Figure 16, explores the impact of the mean duration of 24/7 nursing support on the cost of a 24/7 service and the hospital alternative when duration is varied between 2 and 50 days. The cost of a 24/7 community nursing and telephone support service only increases relatively slowly with increased duration. This is because staff costs, the costs of 24/7 telephone support and overheads (a function of staffing) are all independent of duration in this analysis. The cost of 24/7 community nursing and telephone support does increase, however, with increasing duration, because duration is a determinant of both hospitalisation and visit cost for a 24/7 service. However, the hospitalisation cost for 24/7 service rises at a slower rate than the hospital alternative. This is because only a proportion of children and young people using a 24/7 service require hospitalisation and, in these children, this only accounts for a proportion of the time period covered by the analysis. As Figure 16 shows, 24/7 community nursing and telephone support is cheaper than the equivalent hospital costs when duration of service use exceeds 9 days.

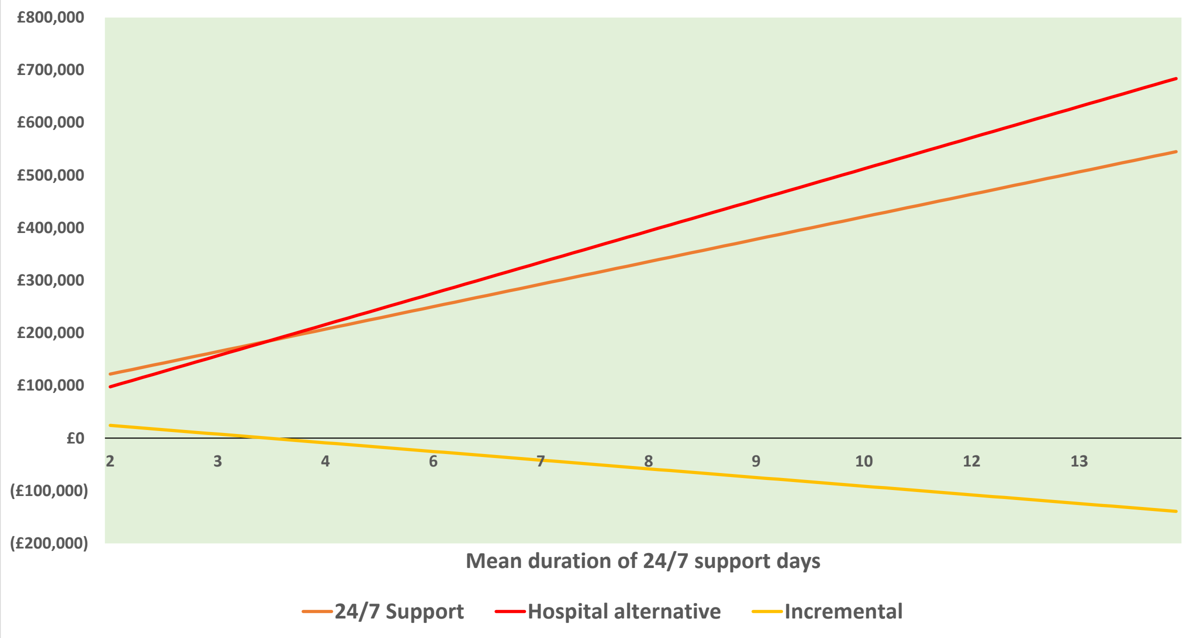
In Figure 17, where staffing is a function of the number of days of child care, then as long as the mean duration of a 24/7 community nursing and telephone support service is longer than 4 days, such a service is cheaper than the hospital alternative.

Figure 16: Graph to show the costs of a 24/7 nursing and telephone support service varying the mean duration of the use of the service (staffing level fixed)



Source: Cost model developed for this guideline

Figure 17: Graph to show the costs of a 24/7 nursing and telephone support service varying the mean duration of the use of the service (staffing level a function of days of child care)



Source: Cost model developed for this guideline

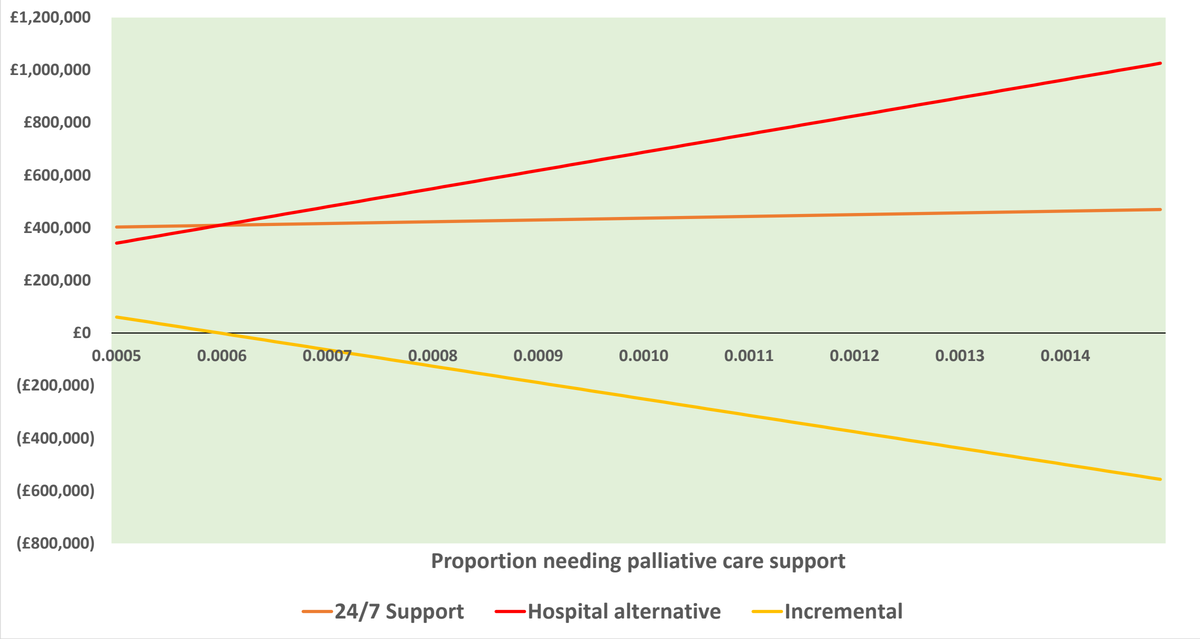
Varying the proportion of children needing palliative care

Figure 18 displays a one-way sensitivity analysis where a 24/7 community nursing and telephone support service is cheaper than the hospital alternative as long as the proportion of children and young people needing palliative care in a region of 1.5 million people (model default) is 6 per 10,000 or more and the staffing level is fixed.

Figure 19 shows that an increasing proportion of children needing palliative care leads to increased savings even when the staffing level is made a function of the number of 'care days', which increases with the size of the palliative care population. However, it should be noted that this is based on the staffing levels per 'care day' suggested in Table 2.

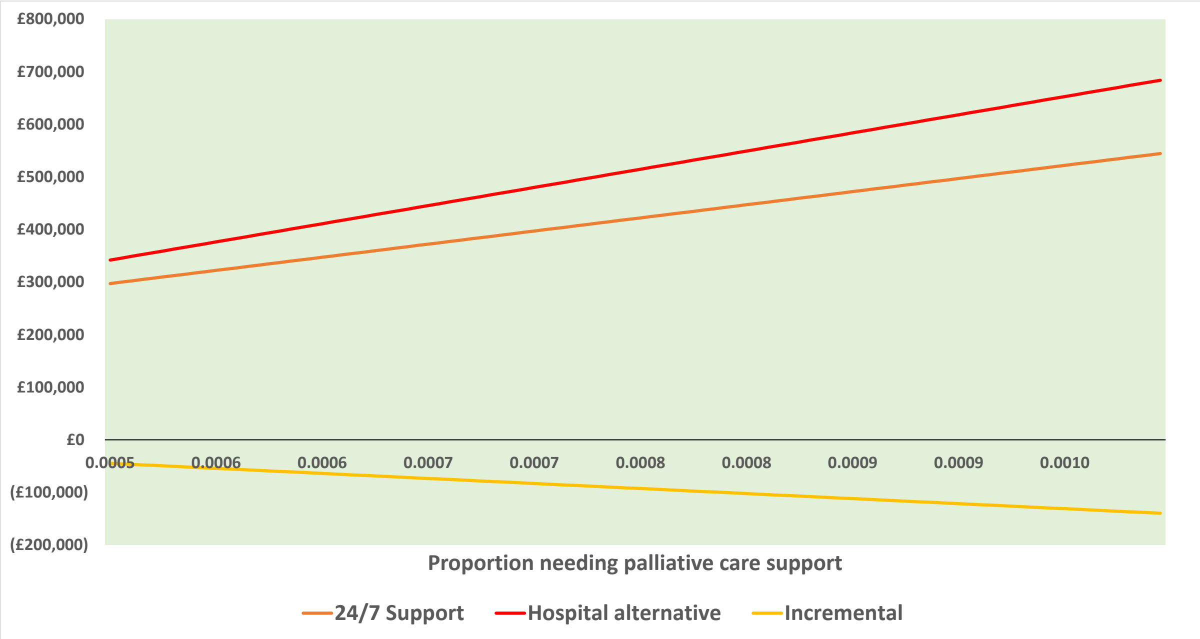
However, if the staffing configuration assumed more WTE staff were required per 'care day' than suggested in the default, then the costs of a 24/7 community nursing and telephone support service could increase with an increasing proportion of children needing palliative care. Figure 20 shows the relationship when it is assumed that 1 WTE community nurse is needed per every 50 child days of 24/7 community nursing and telephone support (compared with the default which is 1 WTE community nurse needed per every 100 child days of 24/7 community nursing and telephone support). A threshold analysis suggested that at 1 WTE community nurse for every 59 child 'care days' of 24/7 community nursing and telephone support, the proportion of children needing palliative care would be cost neutral with respect to a 24/7 service or the hospital alternative (see Figure 21).

Figure 18: Graph to show the costs of a 24/7 nursing and telephone support service varying the proportion of children needing palliative care (staffing fixed)



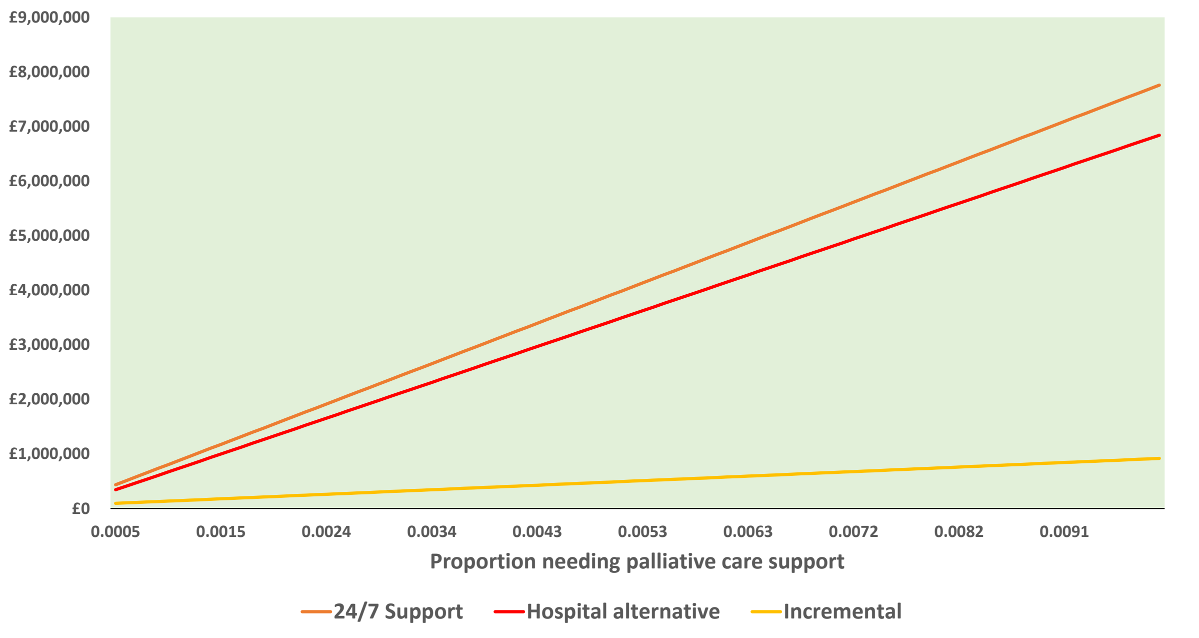
Source: Cost model developed for this guideline

Figure 19: Graph to show the costs of a 24/7 nursing and telephone support service varying the proportion of children needing palliative care (staffing a function of days of child care)



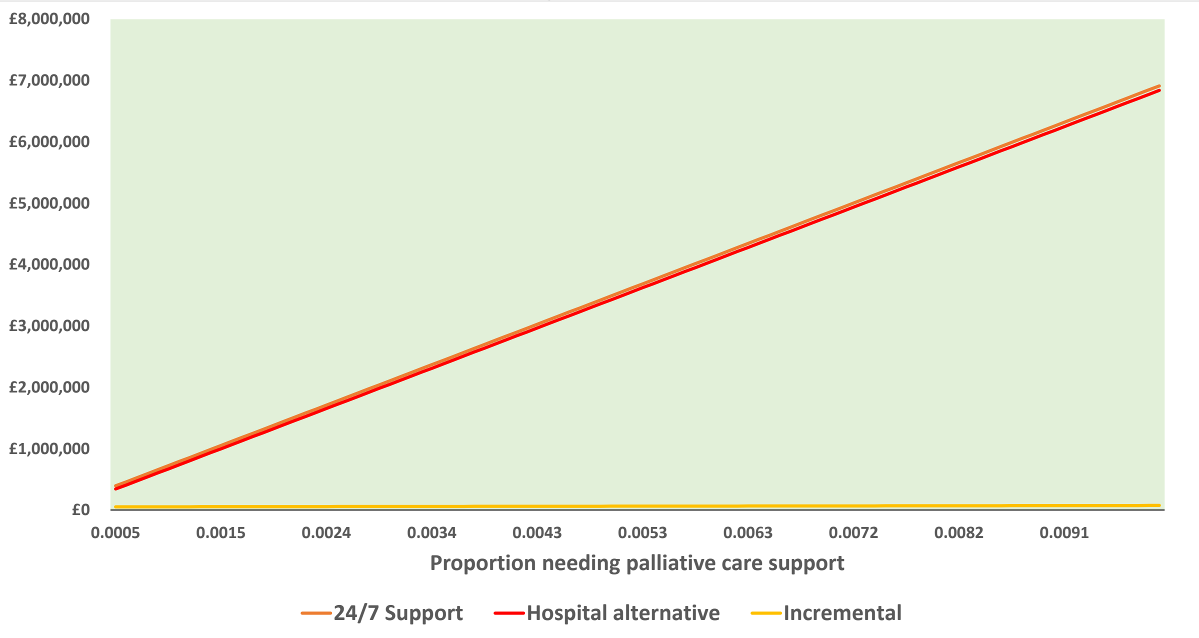
Source: Cost model developed for this guideline

Figure 20: Graph to show the costs of a 24/7 nursing and telephone support service varying the proportion of children needing palliative care (staffing a function of days of child care – more resource intensive service configuration)



Source: Cost model developed for this guideline

Figure 21: Graph to show the costs of a 24/7 nursing and telephone support service varying the proportion of children needing palliative care (staffing a function of days of child care – cost neutral with respect to changes in the proportion of children needing palliative care)



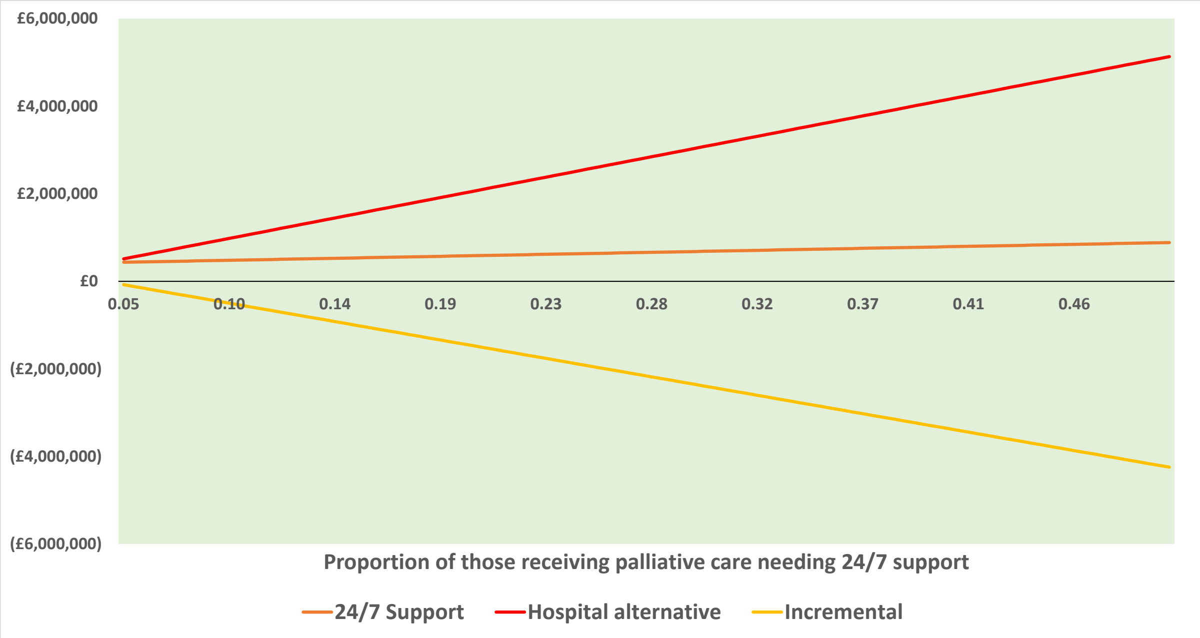
Source: Cost model developed for this guideline

Varying the proportion of children receiving palliative care who use a 24/7 community nursing and telephone support service

This one-way sensitivity analysis shows the relationship between the proportion of children receiving palliative care who additionally use a 24/7 community nursing support and telephone service and the costs of providing that service when compared with a hospital alternative. It is similar to the previous sensitivity analysis varying the proportion of children needing palliative care. This is because the number of children using a 24/7 community nursing and telephone support is determined as a proportion of the children and young people needing palliative care.

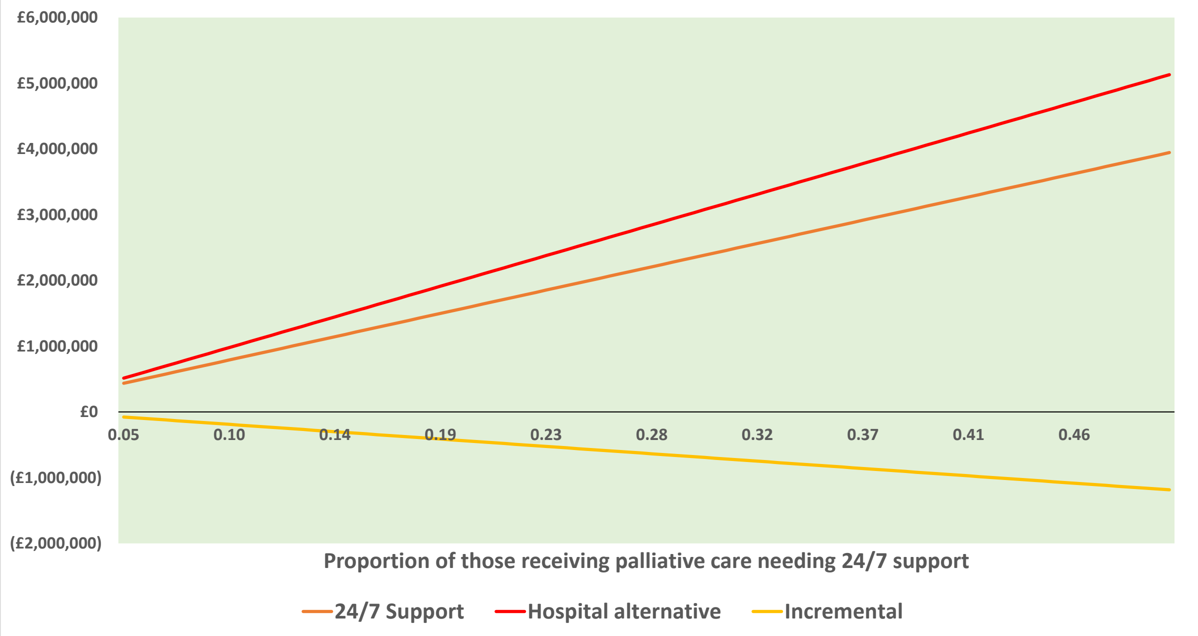
Figure 22 shows the relationship when staffing levels are fixed at their default value and Figure 23 shows the relationship when staffing levels are made a function of the number of 'care days' provided, which in turn is a function of the number of children and young people using such a service.

Figure 22: Graph to show the costs of a 24/7 nursing and telephone support service varying the proportion of those receiving palliative care needing 24/7 support (staffing fixed)



Source: Cost model developed for this guideline

Figure 23: Graph to show the costs of a 24/7 nursing and telephone support service varying the proportion of those receiving palliative care needing 24/7 support (staffing a function of days of child care)



Source: Cost model developed for this guideline

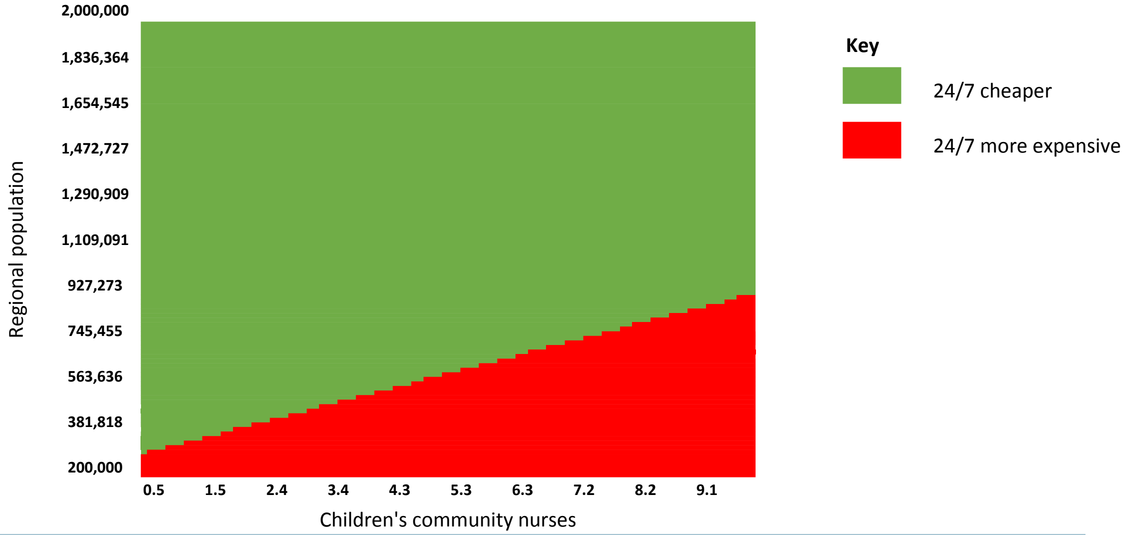
A number of two-way sensitivity analyses are presented below. In these analyses 2 model inputs are varied between a lower and upper range specified by the model user. In total, the sensitivity analysis uses 100 input values for each variable, bound by the specified lower and upper range, and evaluates the model for 10,000 (100 × 100) combinations of the 2 model inputs being varied. The results are illustrated graphically with combinations where a 24/7 service is cheaper than the hospital alternative marked as green and combinations where the 24/7 service is more expensive marked in red. The border between the green and red shaded areas denotes combinations of those 2 model input values that are where a 24/7 service would be cost neutral while holding all other model inputs constant at their default value.

Varying the number of children's community nurses and the size of the regional population

In this two-way sensitivity analysis both the size of regional population and the number of WTE children's community nurses are varied, keeping the other model inputs constant at their default level. The outputs of this analysis are shown in Figure 24 for when the staffing level is fixed. In this case this means that staffing is independent of the number of 'care days' (as the staffing level itself is varied as part of the sensitivity analysis). In other words, when the regional population (vertical or y-axis) is increased, the number of children who would use a 24/7 service rises, which means an increase in 'care days'. In this analysis the staffing levels do not change in response to this increase. However, for any given regional population (and its associated 'care days') on the y-axis, the results are assessed according to the variable children's community nurse staffing levels shown on the horizontal or x-axis.

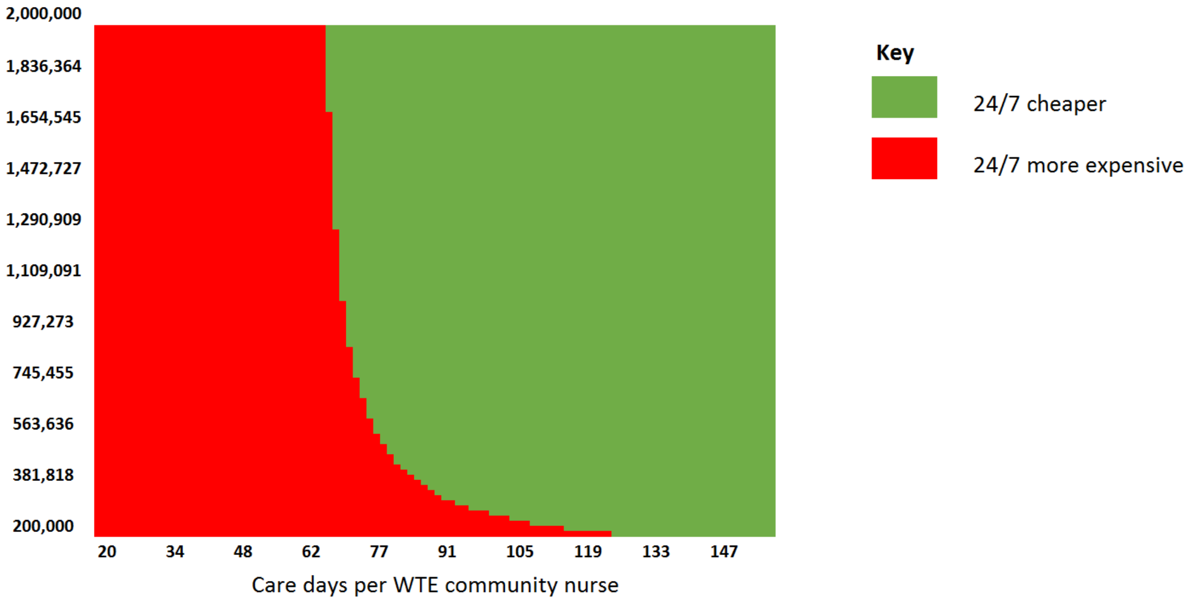
Figure 25 shows a similar relationship, but with staffing level a function of 'care days', which is a function of the size of the regional population. So for any increase in regional population, there will be an increase in the number of WTE community nurses, in addition to the changes in WTE represented along the x-axis (an increase in 'care days' per WTE community nurse represents a reduction in WTE community nurses).

Figure 24: Graph to show the cost thresholds for a 24/7 nursing and telephone support service varying the proportion of the size of the regional population covered by the service and the number of whole time equivalent children's community nurses (staffing level fixed)



Source: Cost model developed for this guideline

Figure 25: Graph to show the cost thresholds for a 24/7 nursing and telephone support service varying the proportion of the size of the regional population covered by the service and the number of whole time equivalent children's community nurses (staffing level a function of 'care days')

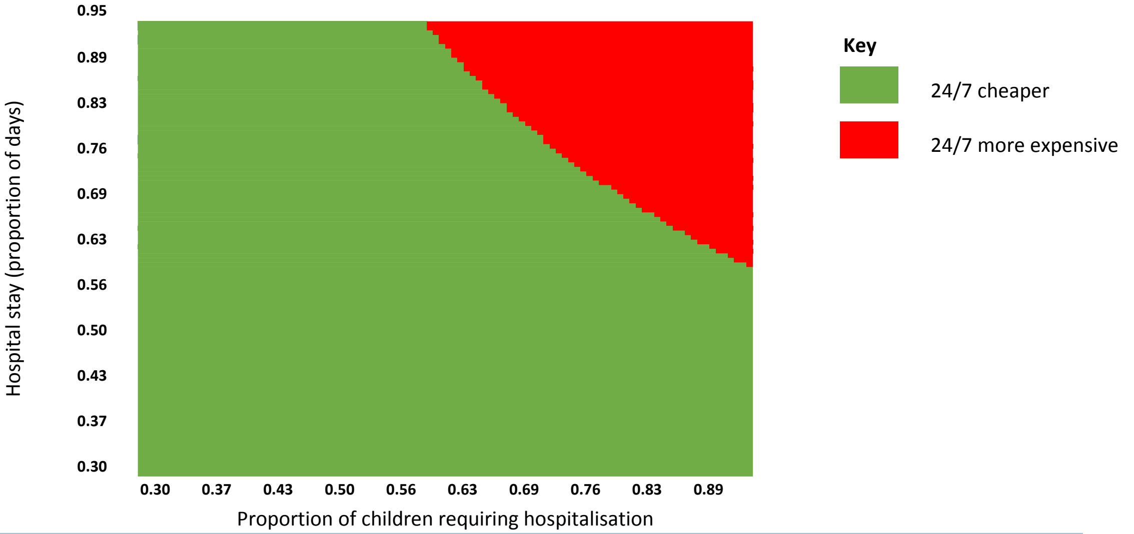


Source: Cost model developed for this guideline

Varying the proportion of children using a 24/7 service who require hospitalisation and the proportion of the mean duration that is spent in hospital

In this two-way sensitivity analysis, shown in Figure 26, both the proportion of children requiring hospitalisation and the proportion that hospital stay accounts for of the mean duration of 24/7 service use are varied.

Figure 26: Graph to show the cost thresholds for a 24/7 nursing and telephone support service varying the proportion of children requiring hospitalisation and the proportion of the mean duration of a 24/7 service accounted for by that hospital stay

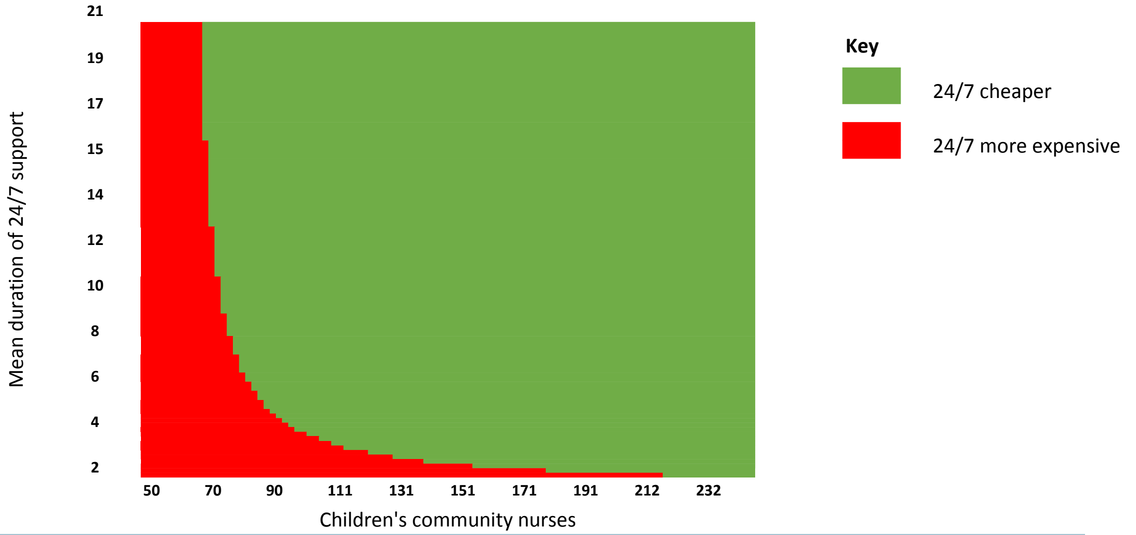


Source: Cost model developed for this guideline

Varying the days of child care per whole time equivalent children's community nurse and the mean duration of 24/7 support

In Figure 27 a two-way sensitivity analysis is depicted where the number of WTE children's community nurses per days of child care provided by 24/7 community nursing and telephone support, and the mean duration of that support, is varied. Although the actual number of WTE nurses per child care day is fixed by the iterations in the sensitivity analysis , the actual number of WTE nurses is also a function also of the mean duration as that determines the total number of 'care days'.

Figure 27: Graph to show the cost thresholds for a 24/7 nursing and telephone support service varying the days of child care per whole time equivalent children's community nurse and the mean duration of 24/7 support

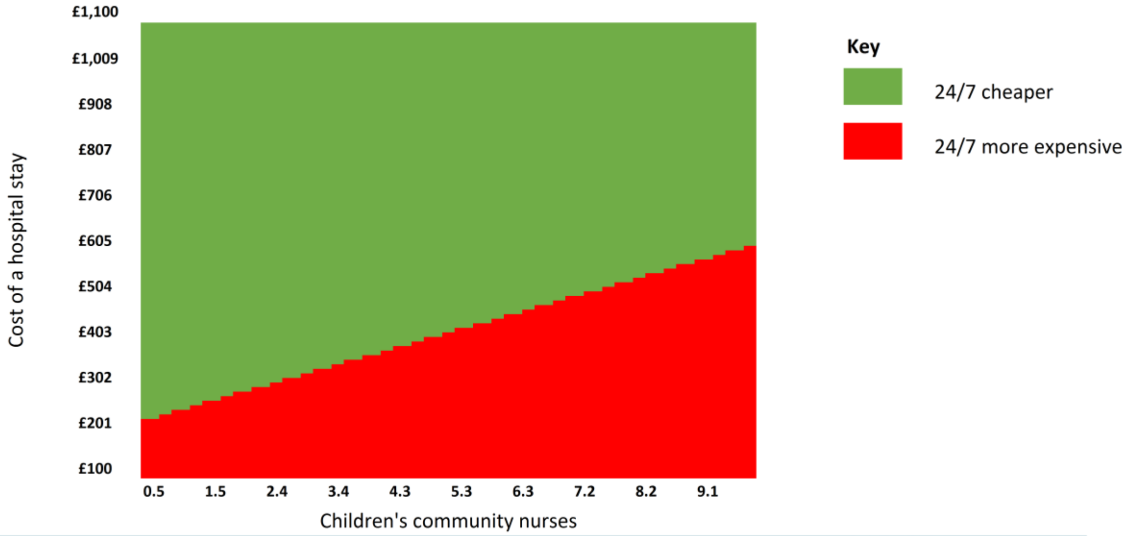


Source: Cost model developed for this guideline

Varying the number of WTE community nurses and the cost of a hospital stay

Figure 28 shows how the threshold for the cheaper service changes as the cost of a hospital stay and the number of WTE community nurses is varied. Increasing staffing levels for a 24/7 service imply that a higher cost of a hospital stay is necessary to achieve cost neutrality.

Figure 28: Graph to show the cost thresholds for a 24/7 nursing and telephone support service varying the cost of a hospital bed-day and the number of WTE children's community nurses

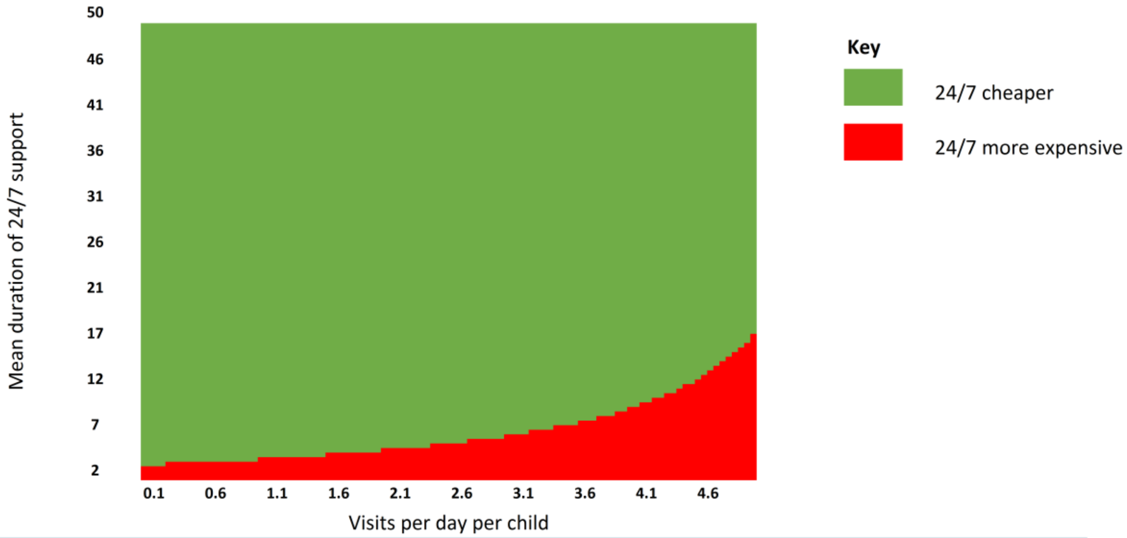


Source: Cost model developed for this guideline

Varying the number of visits per day and the mean duration of use of 24/7 community nursing and telephone support service

In this two-way sensitivity analysis, both the number of visits per day per child and the mean duration of a 24/7 community nursing and telephone support service were varied, with the results as illustrated in Figure 29. Increasing visits per day per child increases the cost of a 24/7 service. Conversely, because of the costs of hospitalisation, increasing the mean duration of 24/7 support reduces the net costs of 24/7 support relative to the hospital alternative.

Figure 29: Graph to show the cost thresholds for a 24/7 nursing and telephone support service varying the mean duration of a 24/7 support service and the mean number of visits per day per child

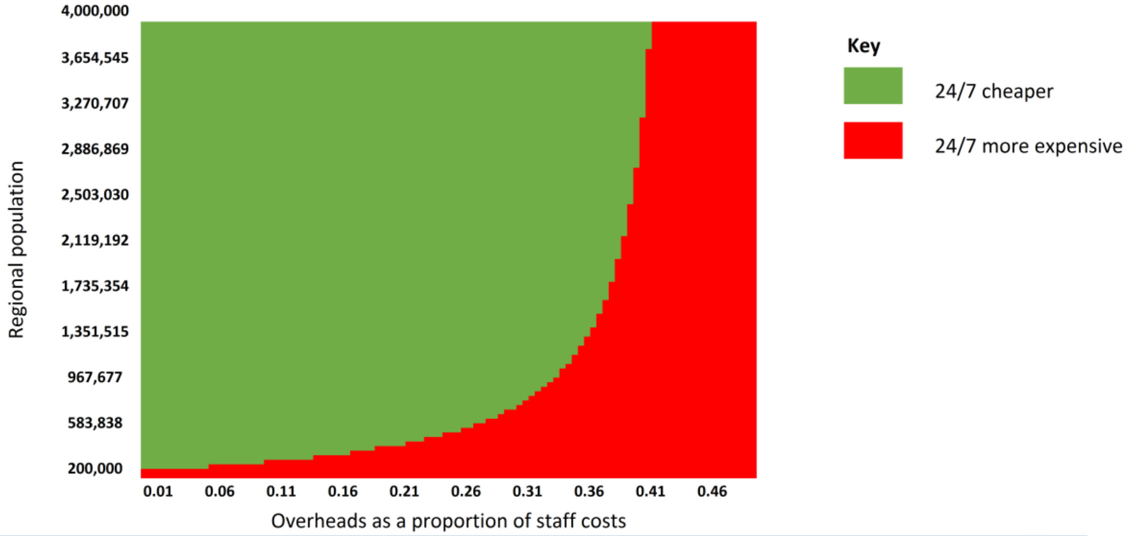


Source: Cost model developed for this guideline

Varying the overheads as a proportion of staff costs and the size of the regional population

Figure 30 shows the results of a 2-way sensitivity analysis where the size of the regional population covered by a 24/7 support service is varied together with the overhead cost, estimated as a proportion of staff costs. For any level of overhead cost, a larger regional population will be relatively more cost effective because staffing and overheads costs associated with 24/7 are independent of population, while the costs of the hospital alternative are not.

Figure 30: Graph to show the cost thresholds for a 24/7 nursing and telephone support service varying the overheads as a proportion of staff costs and the size of the regional population



Source: Cost model developed for this guideline

K.2.4.2 Discussion

No clinical evidence was found in the review with respect to the effectiveness of 24/7 community nursing support and 24/7 specialist telephone advice for children and young people receiving home care and approaching the end of life. This is not surprising, given the context in which such services would be provided. However, 24/7 services facilitate home care should it be wished for and therefore it is reasonable to infer that, in those children and young people who would like to be cared for at home when they are approaching the end of life, 24/7 services do provide net benefits. However, NHS resources are scarce and patient preferences alone are not a sufficient justification for the provision of a tax funded service.

Notwithstanding this, publicly funded bodies have indicated support for 24/7 services. In the End of Life Care strategy (Department of Health 2008) it was stated that “PCTs and LAs will wish to consider how to ensure that medical, nursing and personal care and carers’ support services can be made available in the community 24/7” and “that provision of 24/7 services can avoid unnecessary emergency admissions to hospital and can enable more people at the end of their life to live and die in the place of their choice”. An independent report (Palliative Care Funding Review 2011) recommended that “Community services should be built up, to provide 24/7 access to community care across the country. Availability of 24/7 care in the community is crucial to enable people to be cared for at home if they wish to do so.”

There are approximately 39,000 children or young people in England with a life-limiting condition. Of these, it is estimated that 18,000 per year would be receiving some form of palliative care. The Guideline Committee agreed that the provision of 24/7 community nursing support and 24/7 specialist telephone specialist advice would predominantly be for a service for children and young people who are approaching the end of life and having home care. Using a published estimate (Lowson 2007) which suggested that approximately 10% of children and young people in receipt of palliative care would die per year, then around 1,800 children and young people might be expected to make some use of a 24/7 community nursing support and 24/7 specialist telephone specialist advice during the course of the year. This might be considered an ‘upper bound’ estimate of the number of service users, as not all children and young people with a life-limiting condition will be receiving home care at the time of death. It is important to note that the duration for which a child or young person would use these services is anticipated to be relatively short; typically a few days or weeks. These numbers represent a very small population from a commissioning perspective, which will tend to limit the resource impact of recommendations on such a service.

It was in this context of an absence of published evidence and limited information on actual service configuration that a "what-if" costing model was developed, to allow different service configurations to be assessed in terms of their cost.

Notwithstanding the relatively small numbers of users of any 24/7 community nursing and telephone support service, the model provides some support for the possibility that these services have the potential to be cost saving when compared with a hospitalisation alternative. The result using the model's defaults suggests that a 24/7 service would save approximately £11,000 per child using that service.

The provision of a 24/7 service clearly has opportunity costs associated with it, but it substitutes care in a hospital setting for care in a predominantly home setting, and therefore there are off-setting savings from reduced hospitalisation. Some of the costs of treatment will be the same irrespective of setting and the Guideline Committee thought that, for example, the 0.5 WTE clinical psychologist included in the default model might fall into that category. However, it was retained in the model to be consistent with a published cost exemplar (Noyes 2013) and because it represented a relatively small proportion of staff costs with a limited impact on total costs.

A 24/7 service will be cheaper than a hospital service if the costs of that service are more than offset by savings from reduced hospitalisation. The "what-if" model suggests that there are service configurations where such off-setting savings would be realised, but it also shows that more resource-intensive 24/7 services may increase costs when compared with a hospital alternative.

This impact of service configuration on costs is explored through a number of one-way and two-way sensitivity analyses. Many of these analyses are described as "what-if" analyses as there is little or no data or Committee consensus on which to base a plausible range for model inputs. In the one-way sensitivity analyses, a single model input is varied while other model inputs are held constant, usually at their default value. Two-way sensitivity analyses are similar, but 2 model inputs are varied and analyses are automated in Excel® in order to evaluate 10,000 (100 × 100) combinations of these 2 variables between a pre-defined lower and upper range. The approach can give useful insights to the overall uncertainty in model results and also an understanding of what the key model inputs are in driving those results. However, it is important to appreciate the limitations of that approach. Key among the limitations is that the uncertainty extends across multiple model inputs and not just one or two. For example, a one-way sensitivity analysis may give the threshold for the cost of a hospital bed-day at which a 24/7 service becomes cheaper than the alternative and that threshold value may be well below the plausible value of the cost of a hospital bed-day. This may give added confidence that a 24/7 service would generate cost savings when compared with an alternative hospital service. However, it needs to be remembered that for a different set of model inputs (for example increased staffing levels) that threshold value for the cost of a bed-day may be much higher.

Unsurprisingly, the sensitivity analyses suggest that the number of children's community nurses providing a 24/7 support service is an important determinant of the cost of a 24/7 service (see the sensitivity analysis varying the number of WTE community nurses per number of days of care). Staff costs are the most important determinant of the costs of providing such a service and children's community nurses would seem to be, in numerical terms, the most important healthcare professionals in delivering such a service. The more healthcare professionals are involved in providing a 24/7 community nursing and telephone support service, the more costly that service becomes relative to the hospital alternative. Increasing the number of home visits that are needed as part of 24/7 service also increases the costs of a 24/7 service relative to hospital alternative. Figure 12 suggests that this is a relatively small effect, but it should be acknowledged that that this analysis does not change the staffing levels in response to changes in the number of visits, which means that the impact of increasing visits on the costs of 24/7 support is likely to be underestimated. A limitation of a number of the presented sensitivity analyses is that they assume that staffing levels are unchanged with respect to the input being varied, when in reality they would often be expected to be functionally related to that input (such as population size)

Conversely, as the sensitivity analysis varying the cost of a hospital bed shows, the greater the cost of a hospital bed-day which could be substituted by 24/7 support at home, the greater the potential for the 24/7 service to generate cost savings relative to a hospital alternative. The threshold value for this is well below the default model input. The Guideline Committee thought that it would be reasonable to assume that children and young people not receiving 24/7 support at home would otherwise be in a paediatric intensive care unit (PICU) or high dependency unit (HDU) bed for at least some period of their end of life care.

As indicated in Figure 13, the cost of 24/7 support increases as the proportion of children using a 24/7 service requiring hospitalisation increases. Again, this is an intuitive result and reflects that the higher this proportion is, the less well 24/7 support at home is able to substitute for hospital care.

Figure 14 indicates that the mean distance per visit has a relatively trivial impact on total costs even when varied between 5 and 200 miles. However, this assumes that the journey time is captured in the fixed staffing levels, when in practice, the longer the travelling time, the greater the number of staff that will be needed in order to provide a service. This may be a particular issue in rural locations where in order to cover a sufficiently large population, journey times may be considerable.

There are likely to be economies of scale in providing 24/7 support services. At the most basic level there may be insufficient children to occupy staff in relatively small populations. That may be partly addressed by using only a small part of each member of staff’s time to provide 24/7 support, but that may come at the expense of less specialisation and expertise. Figure 15 illustrates this potential economy of scale from increased population coverage, but an important caveat in interpreting this is that staffing levels in practice are not likely to be entirely independent of the number of children using the 24/7 service.

In the model’s default, the longer the mean duration of 24/7 support, the greater the cost advantage of 24/7 support over a hospital alternative. This is because of the substantial increases in hospitalisation cost with increased duration. The impact of this variable is considered in Figure 16 and Figure 17. In the former, staffing levels in the 24/7 support service are assumed to be fixed. Unsurprisingly, this has a far greater impact on the relative costs of hospitalisation. However, Figure 17 uses the model option in which staffing levels are a function of the number of days of child care support, which increases with mean duration. In the analysis presented this still shows that increased mean duration increases the cost advantage of 24/7 support, albeit to a lesser extent, but that is an artefact of the “what-if” level that staffing is increased in response to increased days of support.

The sensitivity analysis varying the proportion of children needing palliative care is analogous to changes in the regional population, as changes to the proportion of children requiring palliative care impacts on costs by changing the number of users of a 24/7 service, in the same way that changing the population covered by a 24/7 service would. The sensitivity analyses addresses how the cost impact is affected by “what-if” assumptions about changes to staffing levels as a result of changes in the number of children that would be suitable for a 24/7 community nursing and telephone support service.

The two-way sensitivity analyses indicate the thresholds for cost neutrality across a range of input values for 2 variables. The threshold value is the point at which the 24/7 service goes from being the cheaper alternative to the more expensive (and vice versa).

The sensitivity analysis varying the number of children's community nurses and the size of the regional population considers what staffing levels (children's community nurses) are consistent with a 24/7 service being cheaper than the alternative hospital service. Figure 25 suggests that more staff (less 'care days' per WTE staff) is consistent with cost neutrality as the size of the regional population increases, although the precise relationship also reflects the other inputs that are being kept constant. This is because the costs of the hospital alternative increase in proportion with increases in the regional population, whereas the costs of a 24/7 service increases less than proportionately with increases in the regional population because the costs of providing 24/7 telephone support are assumed to be independent of population size in this analysis.

Figure 26 provides the cost neutrality thresholds for 2 inputs that could be used as a proxy for the effectiveness of 24/7 support. Both these inputs are concerned with determining the number of days that will be spent in hospital even when someone is a user of the 24/7 community nursing and telephone support service. However, this two-way sensitivity analysis suggests that the proportion of children requiring hospitalisation and the hospital stay as a proportion of mean duration would both have to be considerably higher than their default values before a 24/7 service became more expensive than the alternative.

In Figure 28 the two-way sensitivity analysis shows cost neutrality thresholds for the cost of a hospital stay and number of WTE children's community nurses. The former impacts more on the cost of the hospital alternative and the latter on the cost of a 24/7 service. Therefore, it is intuitive that the cost neutrality threshold exhibits this relationship – the more expensive a hospital stay, the more staff a 24/7 service can have and still maintain cost neutrality.

'Real world' 24/7 community nursing and telephone support

The model utilised a "what-if" approach to assess the cost implications of providing a 24/7 community nursing and telephone support with different service configurations and assumptions. Our understanding is that there is variation in practice with regard to the provision of 24/7 services in end of life care which lends credence to the "what-if" approach. For example, albeit not restricted to a paediatric population, a report suggested that that 24/7 community nursing to patients in their homes was provided by just over half of primary care trusts (PCTs) in 2006-07 (National Audit Office 2008). A Macmillan Freedom of Information request 3 years later found that 24/7 support was still only available for end of life patients in 56% of PCTs (Macmillan 2010). A slightly later report noted that the "the absence of sufficient provision of 24/7 community services is stark" (Palliative Care Funding Review 2011).

Nevertheless, considerable uncertainty pervades the 24/7 costing model and therefore it is useful to compare or benchmark its findings against operational 24/7 community nursing support services. Through a member of the Guideline Committee we were able to obtain some details on a 24/7 community nursing and telephone support service provided by East Anglia's Children's Palliative Care Managed Clinical Network (MCN) and hosted by East Anglia's Children's Hospices (EACH). The objectives of this "Specialist Medical Advice at All Times" service include "providing access to specialist medical advice is available at any time of the day or night 365 days a year".

The population covered by this service is approximately 3 million, with just over 700,000 children (see Table 12) and representing an area covered by 11 clinical commissioning groups (CCGs). It has been recognised that the commissioning arrangements for paediatric palliative care need to be considerably larger than the size covered by CCGs because of the relatively small numbers of children involved (Palliative Care Funding Review 2011). This report recommended populations of approximately 1.5 million for commissioning paediatric palliative care services.

Table 12: The population served by the Symptom Management Nursing Team [a]

Category	Peterborough UA	Cambridgeshire	North & West Essex	Norfolk	Suffolk	Total
Child (0-19 years)	50,964	147,760	150,220	187,497	167,094	703,535

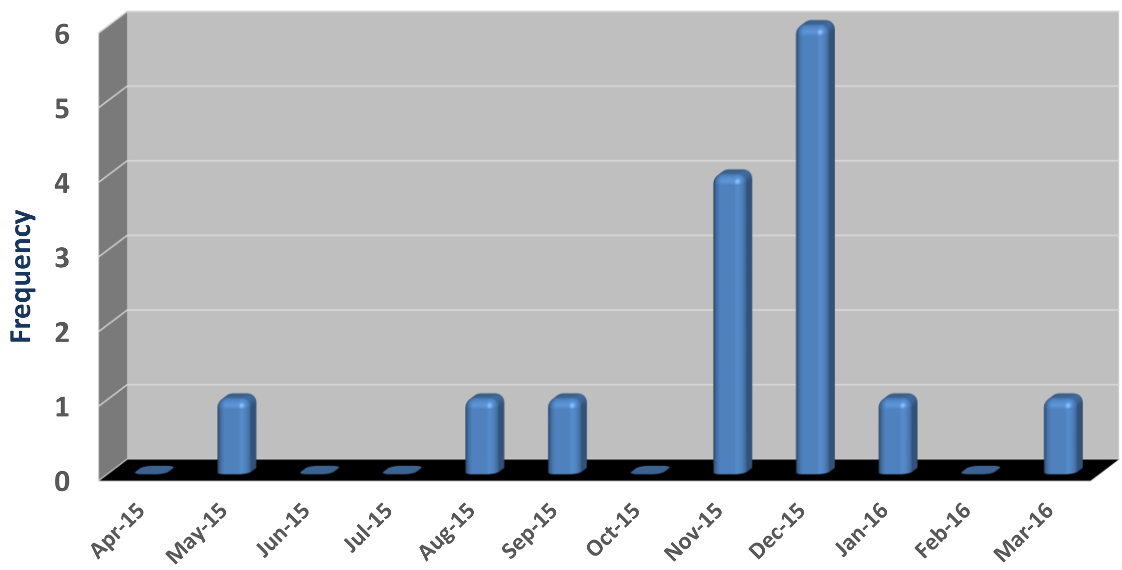
(a) Population estimates by age in England, mid-2014 (ONS, 2015) (http://www.ons.gov.uk/peoplepopulationandcommunity/populationandmigration/populationestimates/datasets/populationestimatesforukenglandandwalesscotlandandnorthernireland) – Data compiled by Linda Maynard and Caroline Cannon (EACH)

An out-of-hours on-call telephone service is provided as part of 'Specialist Medical Advice at All Times'. This service offers telephone advice to the EACH team of clinical nurse specialists between 6pm and 8am, Monday to Friday, and over the full 24-hour period at weekends and bank holidays. The service is operated with a rota of 4 consultant paediatricians and 1 nurse consultant. One of the paediatricians works 0.5 WTE, and is solely engaged in children's palliative care work. The other 3 paediatricians are based in district general hospitals (DGHs) or the community. They have an interest in palliative care and additional qualifications in children's palliative care and are based in DGHs or the community within the region. Children's palliative care represents a very small minority of their overall work. The nurse consultant is employed full time by EACH. The East Anglia's Children Palliative Care Managed Clinical Network provides funding for the service based on a 1% supplement of the basic salary of the specialist consultants.

The total cost of the MCN specialist on-call telephone service for 2015/16 was £4,150. Even if there were some element of cross-subsidisation in the provision of this service from other NHS services, this cost is markedly less than the £45,000 estimated by the cost model for the provision of such a service, despite the fact that a much smaller population is being served in the model.

Figure 31 shows the number of calls made from the symptom management team to the specialist on-call rota for a calendar year as part of the 'Specialist Medical Advice at All Times' service.

Figure 31: Calls from symptom management team to the specialist on-call by month 2015/16



Source: EACH (data supplied by Linda Maynard and Caroline Cannon)

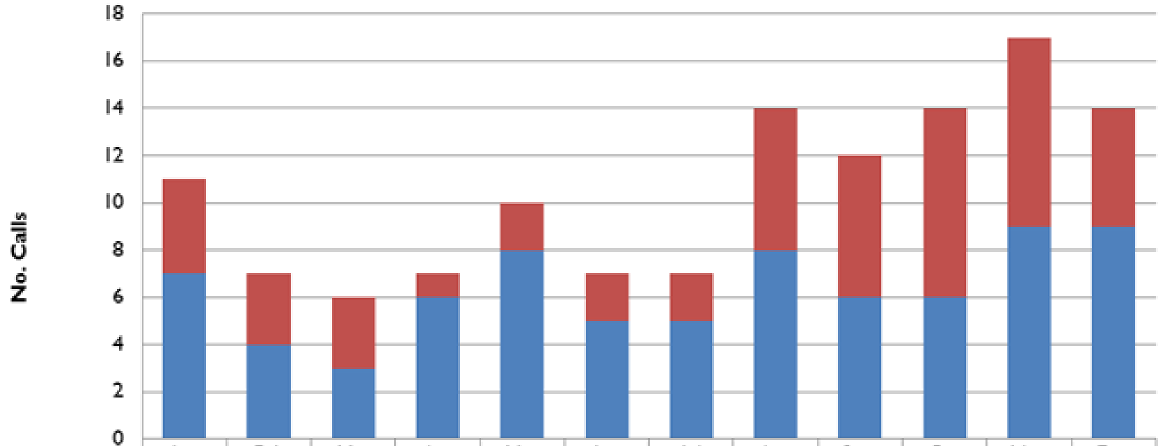
The Symptom Management Nursing Team comprises:

- Band 7 WTE nurses = 8
- Band 8 WTE nurses = 1
- Band 9 WTE nurses = 1

The WTE Band 7 team budget for 2015/16 was £554,000 (including National Insurance and pension contributions). On average, 6 Band 7 nurses participated in the out of hours on-call rota during 2015/16. The fixed cost of having a Band 7 nurse on standby out of hours every year is £45 per 24 hours, which is £16,425 per year. In addition, the on-call symptom management team recorded 295.75 hours of overtime associated with work delivered while on call during 2015-16. These hours were paid at 'time plus 30%'. The staffing levels and costs reported here seem to be of a similar order of magnitude to those reported in the cost model default results on a per capita basis.

Figure 32 and Figure 33 provide further information on the use of the service provided by East Anglia's Children's Paediatric Palliative Care Managed Clinical Network.

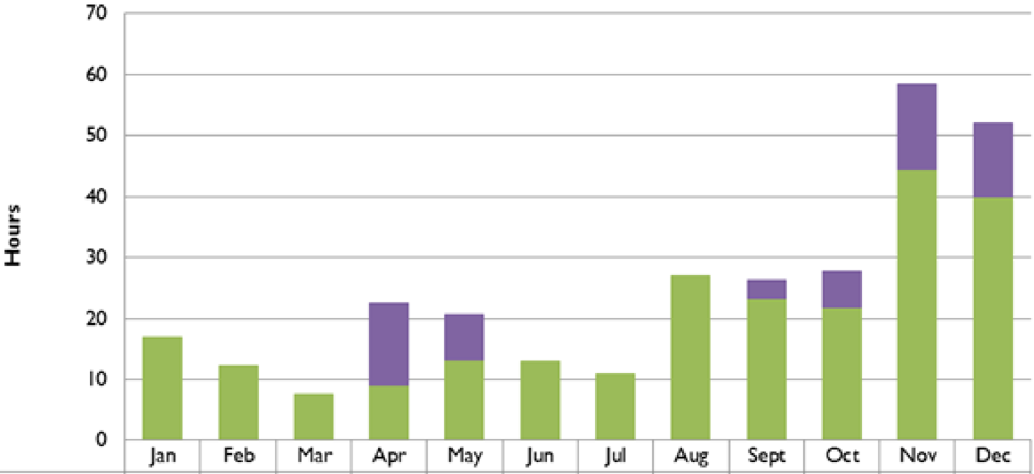
Figure 32: Out of hours calls made to EACH Symptom Management Team (2015)



	Jan	Feb	Mar	Apr	May	Jun	Jul	Aug	Sept	Oct	Nov	Dec
Week Day Calls	4	3	3	1	2	2	2	6	6	8	8	5
Weekend Calls	7	4	3	6	8	5	5	8	6	6	9	9

Source: EACH (data supplied by Linda Maynard and Caroline Cannon)

Figure 33: Hours spent by nurse specialist responding to out-of-hours calls (2015)



	Jan	Feb	Mar	Apr	May	Jun	Jul	Aug	Sept	Oct	Nov	Dec
Visit by CNS	0	0	0	13.5	7.5	0	0	0	3	6	14	12
Telephone Response by CNS	17	12.25	7.5	9	13.25	13	11	27	23.25	21.75	44.5	40

Source: EACH (data supplied by Linda Maynard and Caroline Cannon)

A number of Committee members commented that the volume of calls and staff input seemed on the low side compared with their own experience with similar services and therefore more resource intensive service configurations might be needed to operate 24/7 community nursing and telephone support services elsewhere.

By way of contrast, a conference abstract (Sheridan 2008) reported on the use of an established tertiary centre service over 1 week in order to estimate the likely demand for a 24-hour specialist palliative care telephone support service. In total, 276 calls were received and 233 calls were made. A total of 72 hours was spent on the telephone. Some 96 calls (19%) were made out of office hours, with a majority of calls about children and young people with malignant disease. Nearly one-fifth of calls required immediate action, 9% of calls required changes to medication and 9% resulted in an unplanned home visit by a member of the specialist team. The authors estimated that the amount of time spent on the telephone amounted to almost 2 WTE posts and as such this would be a more expensive telephone support service to run than that outlined by EACH. Nevertheless, these data were estimated from a tertiary centre service with a broader remit, rather than an actual 24/7 telephone support service for the population covered in this guideline. Furthermore, the timeframe for this data collection was very short and therefore there is considerable uncertainty about whether the observed call volumes would be representative of an actual service.

Finally, when the model inputs are set most closely to mimic a published cost exemplar for a 24/7 community nursing and telephone support service (Noyes 2013), the costs of the 24/7 service, which are similar in the model to those reported, are substantially above those of the hospital alternative (£398,000 compared with £148,000). In this published cost exemplar just 24 children used a 24/7 service and then only for a period of 7 days each a year (24×7=168 days). The number of WTE children's community nurses seems to be based on 1:1 care provided for 365 days and 24 hours. If a WTE nurse is assumed to work 1,590 hours per year:

$$365 \times 24 \div 1{,}590 = 5.5 \text{ WTE nurses}$$

However, as noted above, no actual 24/7 community nursing support would be required for 197 days of the year and therefore 5.5 WTE children's community support nurses may be a more resource intensive model than would actually be required to provide a 24/7 support service, especially as being on call is less resource intensive than round the clock one-to-one nursing. It also illustrates why there may be certain economies of scale in providing such services across a wider area where the number of children and young people accessing such a service would be greater.

K.2.4.3 Conclusion

This "what-if" costing hasn't definitively demonstrated that a 24/7 community nursing support and telephone service is cheaper than a hospital alternative. However, it does suggest that there may be service configurations of a 'real-world' 24/7 service which would be cost neutral or cost saving relative to a hospital alternative and therefore it provides some supportive evidence for the cost-effective provision of such services, which have been a policy objective for some time.

The small numbers of children and young people using such a service means that the overall resource impact of 24/7 community nursing and telephone support services is likely to be relatively limited. This small number of children also supports the idea that any 24/7 services need to cover a relatively large commissioning population. For example, even a population of 1.5 million people would only have approximately 50 children and young people per year using such a service, and it is expected that each of these 50 children would only be using the service for a very small proportion of the year.

On the other hand it is unlikely that a 'one size fits all' service would be appropriate and special consideration might have to be given in rural areas, especially where there may be logistical issues in organising home visits in a population large enough to warrant a service.

K.3 A cost analysis of a rapid transfer service for infants, children and young people with a life-limiting illness to their preferred place of care in their last days of life

The cost model relates to the following guideline review question:

What services have to be in place to make rapid transfer available to take infants, children and young people with a life-limiting illness to their preferred place of care in their last days of life as part of service delivery?

K.3.1 Introduction

The Department of Health's End of Life Care Strategy (2008) noted that the provision of high quality end of life care was not always fulfilled by the transport services provided at that time. It noted that people in hospital who wanted to be transferred home to die often experienced delays while waiting for an emergency vehicle to be made available.

The aim of the economic analysis was to compare the resource impact of providing a rapid transfer service to take infants, children and young people with a life-limiting illness to their preferred place of care in their last days of life with an alternative where such a transfer service was not provided.

K.3.2 Methods

Conceptual framework

A conceptual framework was developed to indicate the data that would be required in order to undertake a cost analysis of a rapid transfer service. The following possible data requirements were identified and discussed with the Guideline Committee:

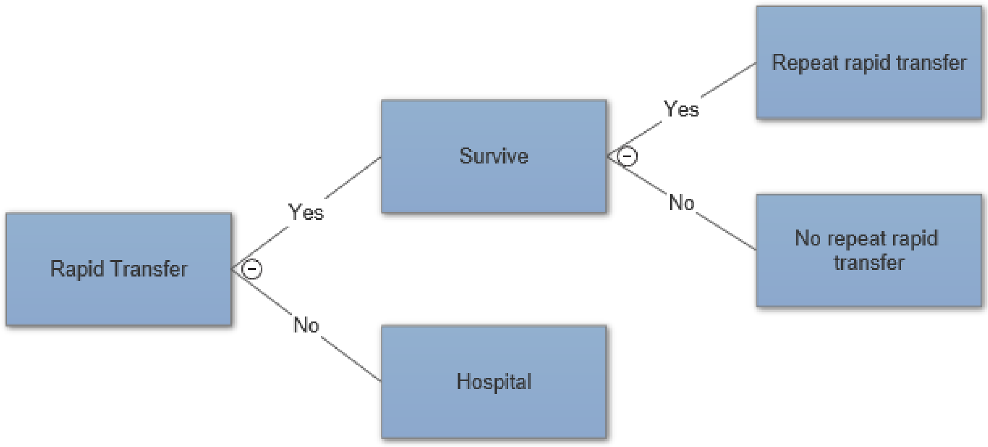
i. the population with a life-limiting condition
ii. the proportion of those with a life-limiting condition for whom rapid transfer to a preferred place of care in their last days of life would be in their best interests and an appropriate option in a given year
    a. does the proportion differ according to subgroup; for example neonates?
iii. potential barriers to achieving rapid transfer
    a. timescale to achieve transfer
    b. timeframe
    c. ‘out of hours’
    d. feasibility; for example home access
    e. paperwork
    f. including prescriptions/dispensing medications
iv. time to death/survival following rapid transfer
v. what has to be in place to facilitate rapid transfer:
    a. ambulance
    b. staff
    c. medications
    d. equipment
vi. resources to provide services at home following transfer:
    a. what nursing and palliative care might need to be provided and would this utilise a 24/7 nursing and telephone support service?
vii. potential savings arising from rapid transfer:
    a. release of neonatal/paediatric intensive care unit (NICU/PICU) or paediatric bed.

Modelling approach

A cost analysis was developed using Microsoft Excel® in order to compare the costs of providing rapid transfer to infants, children and young people with a life-limiting illness to their preferred place of care in their last days of life with costs of not providing a rapid transfer service. Costs were based on an NHS and personal social services perspective using a cost year of 2014/15. Probabilistic sensitivity analysis, as per the NICE reference case, was not undertaken as it was not possible to estimate meaningful distributions for many model inputs.

A decision tree of the cost model is shown in Figure 34.

Figure 34: Decision tree of costing model for rapid transfer to preferred place of death



K.3.3 Model inputs

K.3.3.1 Population

The population is those infants, children and young people who are likely to die within hours or days, are in a setting which is not their preferred place of death, and for whom rapid transfer would be clinically appropriate and logistically feasible. Therefore, this population is only a subset of the guideline population of infants, children and young people with a life-limiting condition.

Table 13 shows the total population of infants, children and young people in England in 2012. It was thought important to distinguish neonates in this population as they have higher mortality rates and are more likely be in a hospital setting. The precise numbers in Table 13 were rounded to the nearest 5,000 in the cost model.

Table 13: Population estimates by age in England, mid-2014 [a]

Age	Population	Source
<1 month [b]	55,349	ONS (2015)
1-12 months	608,834	ONS (2015)
1-4 years	2,766,774	ONS (2015)
5-9 years	3,272,365	ONS (2015)
10-14 years	2,973,055	ONS (2015)
15-19 years	3,230,954	ONS (2015)

(a) *MYE2: Population estimates by single year of age and sex for local authorities in the UK, mid-2014 (http://www.ons.gov.uk/peoplepopulationandcommunity/populationandmigration/populationestimates/datasets/populationestimatesforukenglandandwalesscotlandandnorthernireland - accessed 13 April 2016)*
(b) *The Office for National Statistics (ONS) estimates give the population of infants aged 0. Therefore, the population aged less than a month at any one time is assumed to be 1/12th of the ONS estimate of infants aged 0 (664,183 ÷ 12)*

A majority of the infants, children and young people who would utilise a rapid transfer service to preferred place of death would be expected to be in the last hours or days of life and therefore mortality rates are an important variable in determining the size of the population who could benefit from such a service. The mortality rates used in this cost model are shown in Table 14 and the data on which deaths in ages 1 to 19 years is based is shown in Figure 35.

Table 14: Mortality rates by age [a, b]

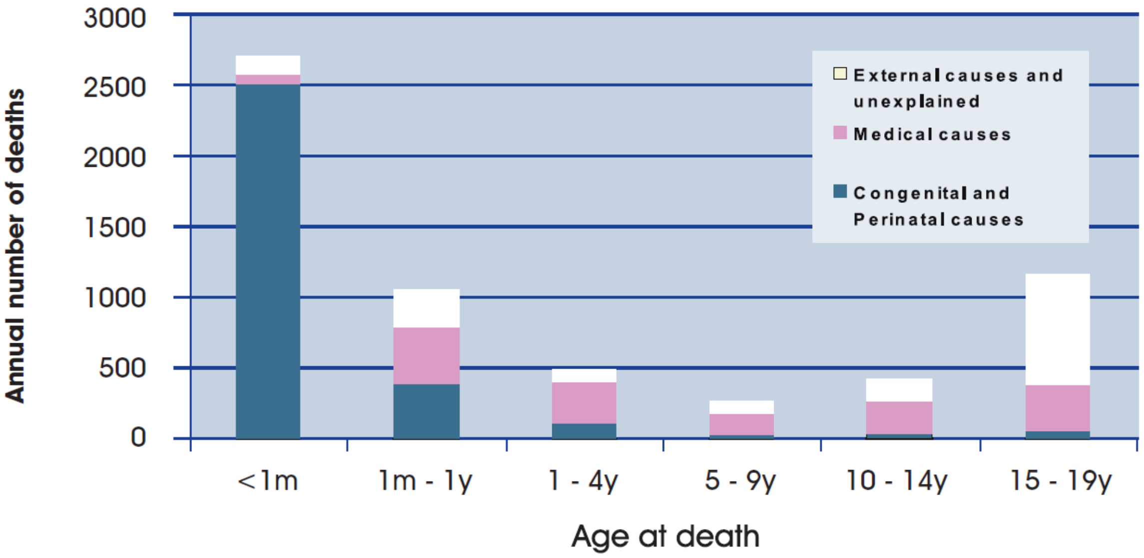
Age	Mortality rate	Source
<1 month [c]	0.00496	ONS (2015)
1-12 months [d]	0.00124	ONS (2015)
1-4 years [e]	0.00014	ONS (2007)
5-9 years [f]	0.00006	ONS (2007)
10-14 years [g]	0.00008	ONS (2007)
15-19 years	0.00012	ONS (2007)

(a) Birth cohort tables for infant deaths, England and Wales, 2012 (ONS, 2015) - http://webarchive.nationalarchives.gov.uk/20160105160709/http://www.ons.gov.uk/ons/publications/re-reference-tables.html?edition=tcm%3A77-348330 – accessed 13 April 2016
(b) Department for Children, Schools and Families – Information Sheet on "Patterns and causes of Child death": http://childdeath.ocbmedia.com/public_docs/Information%20Sheet%20-%20Patterns%20and%20causes%20of%20child%20death.pdf – accessed 13 April 2016. Source data: Office for National Statistics (2007a) Mortality Statistics: childhood, infant and perinatal, England and Wales, 2005. Series DH3 no.38 and Office for National Statistics (2007d) Review of the Registrar General on deaths in England and Wales: mortality cause, 2005. Series DH2 no.32
(c) Calculated as: (early neonatal deaths + neonatal deaths) ÷ Live births
(d) Calculated as: post neonatal deaths ÷ (Livebirths – early neonatal deaths – neonatal deaths)
(e) Approximately 400 deaths from medical, congenital and perinatal causes
(f) Approximately 200 deaths from medical, congenital and perinatal causes
(g) Approximately 250 deaths from medical, congenital and perinatal causes
(h) Approximately 400 deaths from medical, congenital and perinatal causes

The population given for children under 1 month in Table 13 is an estimate of the population at a single moment in time. Therefore, within a calendar year the number of children who fell into that category would be approximately 12 times that number and therefore total annual mortality in neonates is estimated as:

Neonatal deaths per year = Monthly neonatal population × mortality rate × 12

Figure 35: Annual deaths by age and cause



Source: Contains public sector information licensed under the Open Government Licence v3.0

The provision of rapid transfer to a preferred place of death will not be appropriate or necessary for all deaths. Some infants, children and young people will already be in their preferred place of death, which could be the hospital, in which case a transfer would not be necessary. For other children it may not be clinically appropriate to organise a rapid transfer and in other cases it may not be practically possible, perhaps because the home environment is not suitable. Therefore, it was necessary to incorporate a variable into the model which would quantify the proportion of infants, children and young people who die in which rapid transfer would be a clinically appropriate and practical option.

Table 15 indicates the default model values for the proportion of infant, child and young person deaths for which a rapid transfer to a preferred place of death could apply. In the absence of data on the number of rapid transfers, estimates were approved following discussion with the Guideline Committee. Owing to the uncertainty surrounding these estimates, the values were varied as part of a "what-if" sensitivity analysis.

Table 15: Proportion of deaths for which rapid transfer to the preferred place of death could be considered

Age	Proportion	Source
<1 month	0.80	Guideline Committee (GC) estimate
1-12 months	0.50	GC estimate
1-4 years	0.50	GC estimate
5-9 years	0.50	GC estimate
10-14 years	0.50	GC estimate
15-19 years	0.50	GC estimate

K.3.4 Resource use

K.3.4.1 Current place of care

The level of care and support required by the infant, child and young person in order to facilitate rapid transfer will vary and this has been proxied by assuming different costs for infants, children and young people transferred from critical care (paediatric intensive care unit, neonatal intensive care unit) and those transferred from a paediatric ward. To simplify the analysis, only transfers from hospital to home are considered, but transfers could also be from home to hospital and to and from a hospice setting.

The proportions of children being transferred for critical care or a paediatric ward for the various age categories are given in Table 16. Again, we were not able to find data to inform these values and default values were informed by the Guideline Committee.

Table 16: Place of care prior to transfer

Age	Paediatric ward proportion	Critical care proportion	Source
<1 month	0.00	1.00	Guideline Committee (GC) estimate
1-12 months	0.50	0.50	GC estimate
1-4 years	0.50	0.50	GC estimate
5-9 years	0.50	0.50	GC estimate
10-14 years	0.50	0.50	GC estimate
15-19 years	0.50	0.50	GC estimate

K.3.4.2 Costs

For infants, children and young people transferred from a critical care setting (NICU or PICU) it is assumed that the NHS Reference Cost for neonatal or paediatric critical care transportation would capture all the relevant costs involved in the transfer from an NHS and personal social services perspective.

For transfers from a paediatric ward the costs included the ambulance, estimated from NHS Reference Costs, staff time (which could be nurse and/or doctor) and return transport for staff accompanying the transfer. The costing model default assumes that 1 Band 6 nurse will accompany all transfers from a paediatric ward and that it will involve 5 hours of that nurse's time. A Guideline Committee member suggested that in her experience the time taken was typically 2 to 8 hours. In the default state the model assumes that no doctors accompany a rapid transfer from a paediatric ward, but this assumption can be relaxed in a sensitivity analysis.

It is assumed that a rapid transfer will avert 1 inpatient day, with the resulting saving determined by the place of care prior to transfer. Within that, the rapid transfer might facilitate a reduction in burdensome care.

Finally, it is assumed that a proportion of infants, children and young people will actually survive following their rapid transfer and that a proportion of these require a further rapid transfer to the preferred place of death in the future.

The unit costs used in the model are shown in Table 17 and Table 18. Additional model inputs relating to resource use are presented in Table 19.

Table 17: Staff unit costs

Staff	Cost per hour	Source
Band 6 nurse [a]	£51	Unit Costs of Health and Social Care 2015
Band 7 nurse [a]	£60	Unit Costs of Health and Social Care 2015
Doctor [b]	£72	Unit Costs of Health and Social Care 2015

(a) Cost per working hour including qualification costs
(b) Based on registrar working a 56 hour week and including qualification costs

Table 18: Transport and hospital costs

Variable	Unit cost	Source
Ambulance transfer [a]	£233	NHS Reference Costs 2014/15
Neonatal critical care transportation [b]	£1,101	NHS Reference Costs 2014/15
Paediatric critical care transportation [c]	£2,657	NHS Reference Costs 2014/15
Staff transportation/return trip [d]	£70	https://yourtaximeter.com/
Cost of PICU bed per day [e]	£1,967	NHS Reference Costs 2014/15
Cost of NICU bed per day [f]	£1,176	NHS Reference Costs 2014/15
Cost of paediatric ward bed per day [g]	£965	NHS Reference Costs 2014/15

(a) Currency code ASS02; Currency description: See and treat and convey
(b) Currency code XA06Z; Currency description: Neonatal critical care, Transportation
(c) Currency code XB08Z; Currency description: Paediatric critical care, Transportation
(d) Based on a taxi trip of 40 miles – website accessed 14 April 2016
(e) Currency code XB03Z; Currency description: Paediatric critical care, Advanced critical care 3
(f) Currency code XA01Z; Currency description: Neonatal critical care, Intensive care
(g) Service description Daycase and Regular Day/Night; Currency code SD02B; Currency description: Inpatient specialist palliative care, Same day, 18 years and under

Table 19: Miscellaneous resource model inputs

Variable	Value	Source
Inpatient days averted by transfer	1	Guideline Committee (GC) estimate
Proportion of transfers with nurse	1	GC estimate
Proportion of transfers with doctor	0	GC estimate
Survival rate following transfer	0.33	GC estimate
Repeat transfer in survivors	0.50	GC estimate
Health care professional time on transfer (hours)	5.0	GC estimate

K.3.5 Results

The results with the model's default values are given in Table 20, Table 21, Figure 36 and Figure 37 below. Table 20 gives the model's estimates of the number of infants, children and young people who would be transferred per year in the England with a rapid transfer service to the preferred location of death in place. Table 21 shows the estimated costs of providing such a service and Figure 36 and Figure 37 illustrate this graphically.

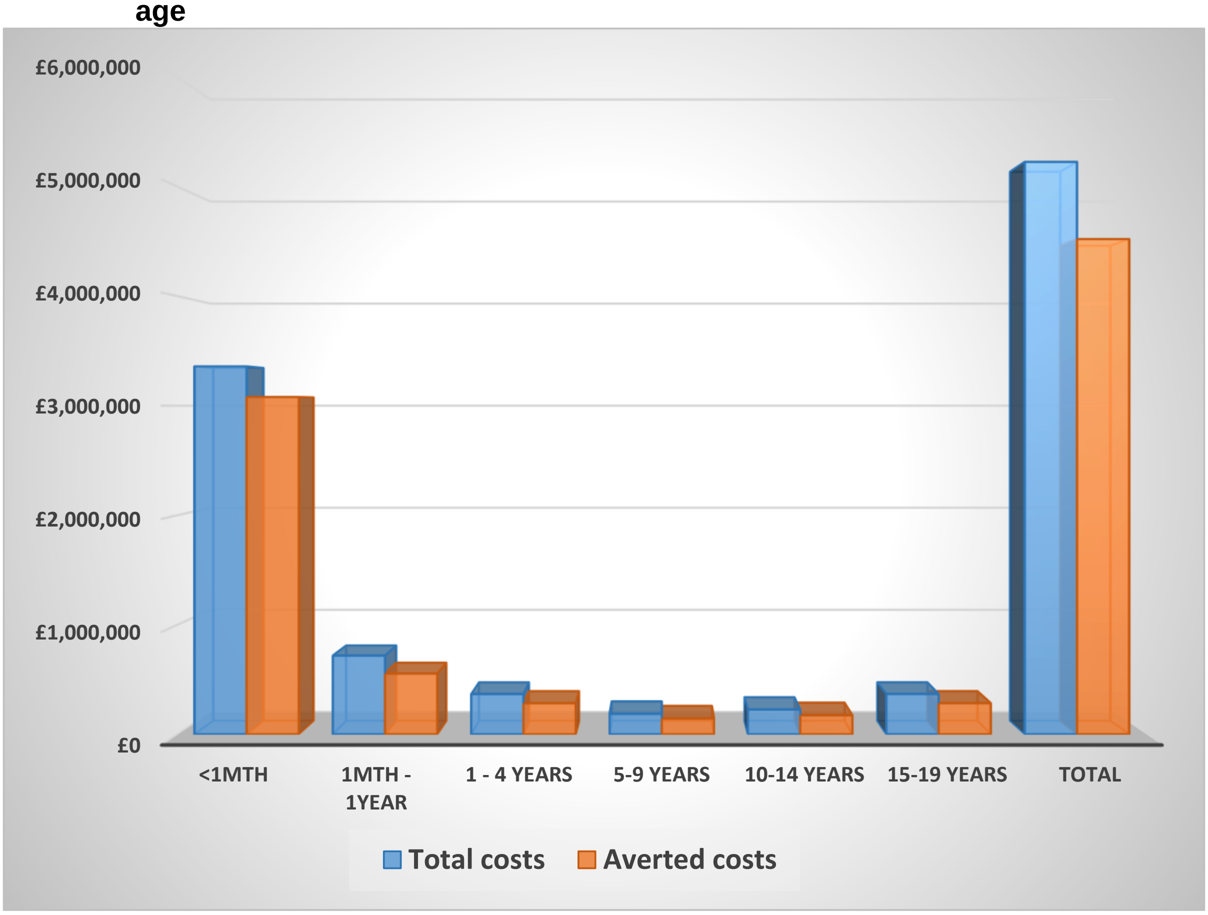
Table 20: Rapid transfers to preferred place of death by age (patient numbers)

Category	<1 month	1-12 months	1 -4 years	5-9 years	10-14 years	15-19 years	Total
Number transferred	2,619	378	194	98	119	194	**3,602**
Paediatric ward transfers	0	189	97	49	60	97	**491**
Critical care transfers	2,619	189	97	49	60	97	**3,110**
Repeat transfers	432	62	32	16	20	32	**594**

Table 21: Costs of rapid transfers to preferred place of death by age

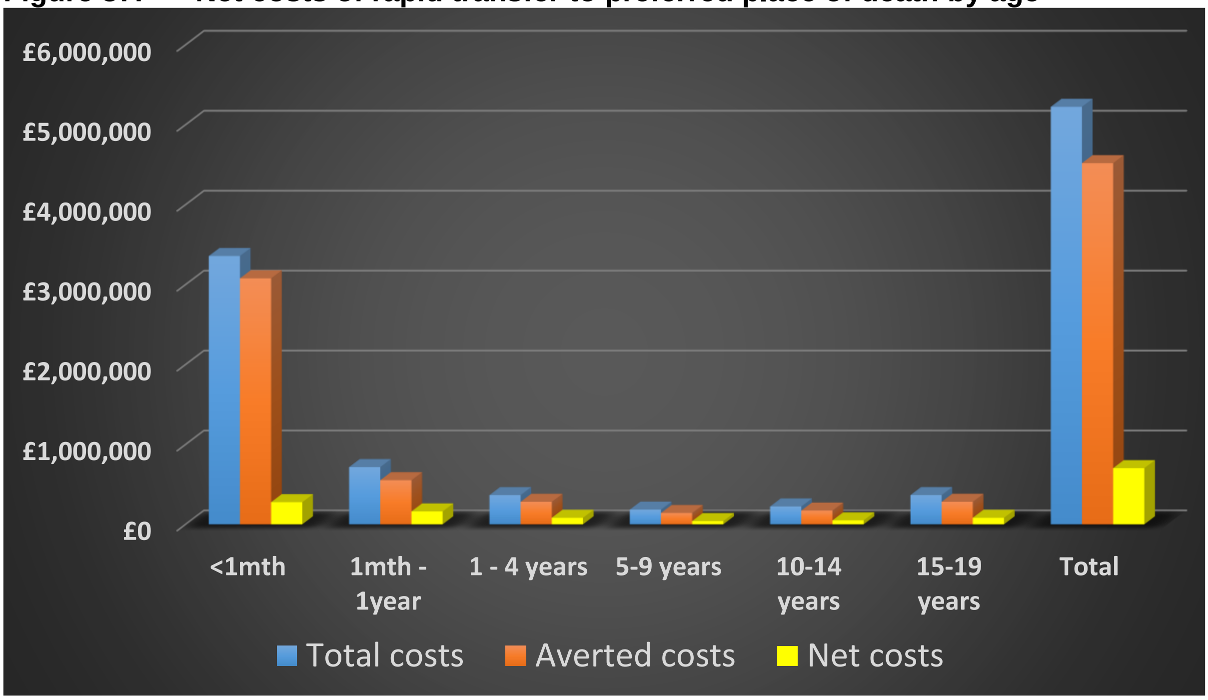
Category	<1 month	1-12 months	1 -4 years	5-9 years	10-14 years	15-19 years	Total
Paediatric transfers	£0	£114,027	£58,355	£29,622	£35,879	£58,431	£296,314
Critical care transfers	£2,883,387	£502,439	£257,131	£130,525	£158,092	£257,463	£4,189,037
Repeat transfers	£475,759	£101,717	£52,055	£26,424	£32,005	£52,123	£740,083
Total costs	£3,359,146	£718,183	£367,542	£186,572	£225,975	£368,017	£5,225,434
Averted costs	£3,079,803	£554,441	£283,744	£144,035	£174,454	£284,111	£4,520,588
Net costs	**£279,343**	**£163,742**	**£83,797**	**£42,537**	**£51,521**	**£83,906**	**£704,486**

Figure 36: Costs and averted costs of rapid transfer to preferred place of death by age



Source: Cost model developed for this guideline

Figure 37: Net costs of rapid transfer to preferred place of death by age



Source: Cost model developed for this guideline

These results show, with the model defaults, that a rapid transfer service costs more than the alternative where a rapid transfer service to the preferred place of death is not available. Table 21, Figure 36 and Figure 37 suggest this finding is consistent across different age groups.

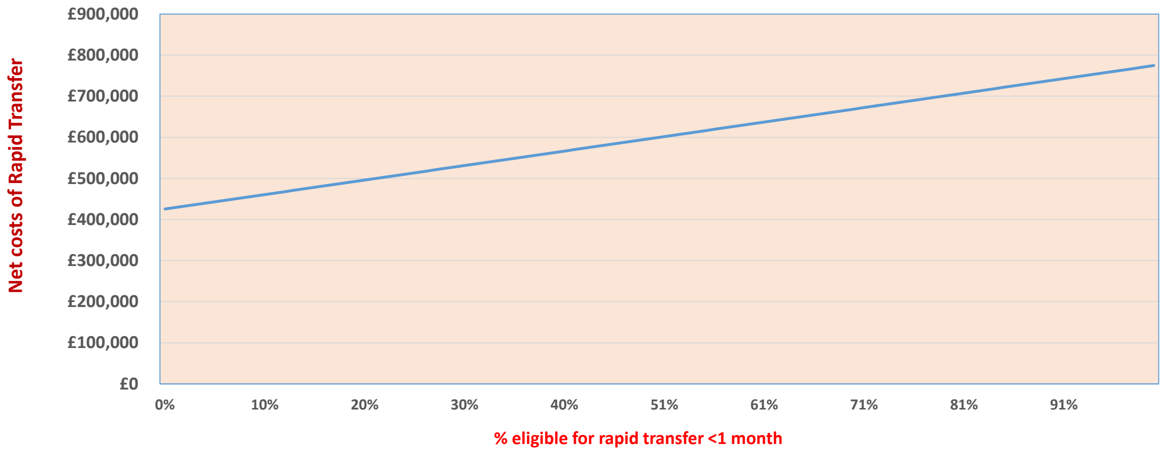
K.3.5.1 Sensitivity analysis

A number of one-way and two-way sensitivity analyses were undertaken to explore the impact different assumptions would have on the net costs of rapid transfer. In the some of the charts, axes refer to children being 'eligible' for rapid transfer. Rapid transfer may not always be wanted by the child, young person or their parents/carers. There may also be occasions when rapid transfer is not clinically appropriate or practical. The term 'eligible' here is shorthand for those children and young people for whom transfer to a preferred place of death is wanted, feasible and clinically appropriate.

Varying the proportion of children aged under 1 month who could be suitable for rapid transfer to the preferred place of death

In this sensitivity analysis, shown in Figure 38, the percentage of children aged under 1 month who could be suitable for rapid transfer to the preferred place of death is varied between 0% and 100%. It shows how the net costs of rapid transfer rise as the proportion of all neonates eligible for rapid transfer increases.

Figure 38: Graph to show net costs of rapid transfer service to preferred place of death varying the proportion of children aged under 1 month who could benefit from such a service

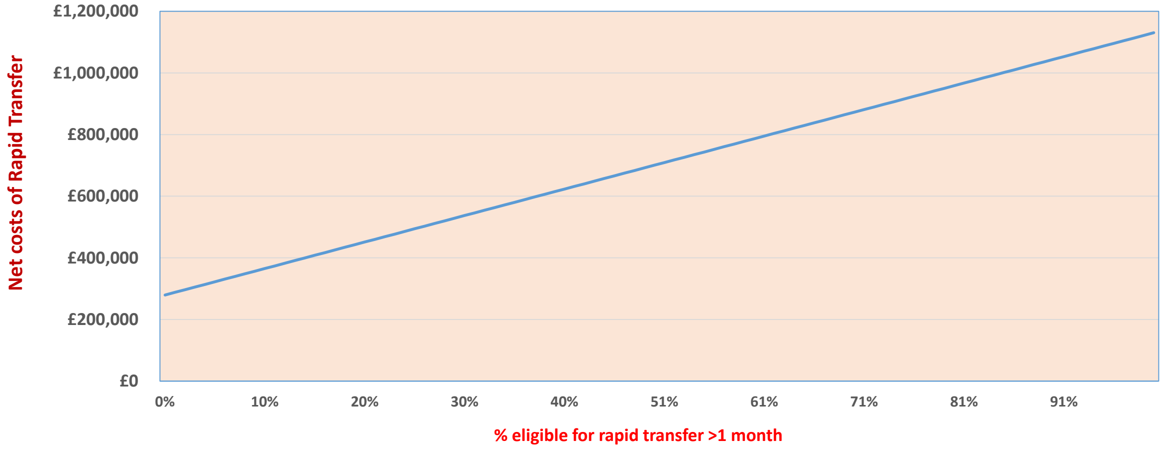


Source: Cost model developed for this guideline

Varying the proportion of children aged over 1 month who could be suitable for rapid transfer to the preferred place of death

Figure 39 depicts a sensitivity analysis where the percentage of children aged over 1 month who could be suitable for rapid transfer to the preferred place of death is varied between 0% and 100%. The higher the eligibility proportion in the relevant population, the higher the net costs of rapid transfer.

Figure 39: Graph to show net costs of rapid transfer service to preferred place of death varying the proportion of children aged over 1 month who could benefit from such a service

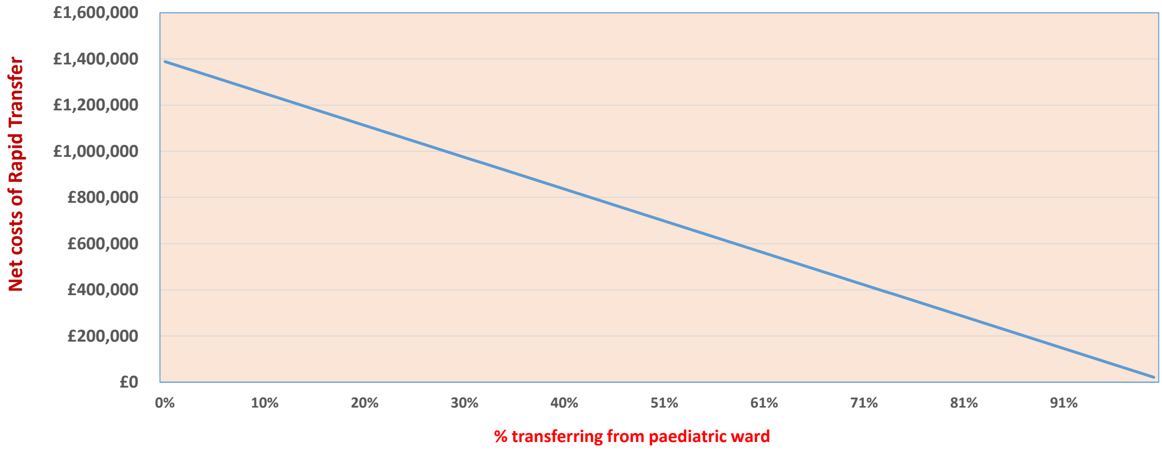


Source: Cost model developed for this guideline

Varying the proportion of children aged over 1 month whose setting at the point of rapid transfer is a paediatric ward

In this sensitivity analysis the proportion of children aged over 1 month who are transferred from a paediatric ward is varied between 0% and 100% (see Figure 40). The model assumes that those not transferred from a paediatric ward are transferred from a paediatric intensive care unit (PICU). Thus, as the paediatric ward proportion rises, the critical care proportion falls, and vice versa. Figure 40 shows that as the proportion of children transferring from a paediatric ward increases (with a corresponding reduction in children transferring from a critical care setting), the net costs of rapid transfer fall.

Figure 40: Graph to show net costs of rapid transfer service to preferred place of death varying the proportion of children transferred from a paediatric ward

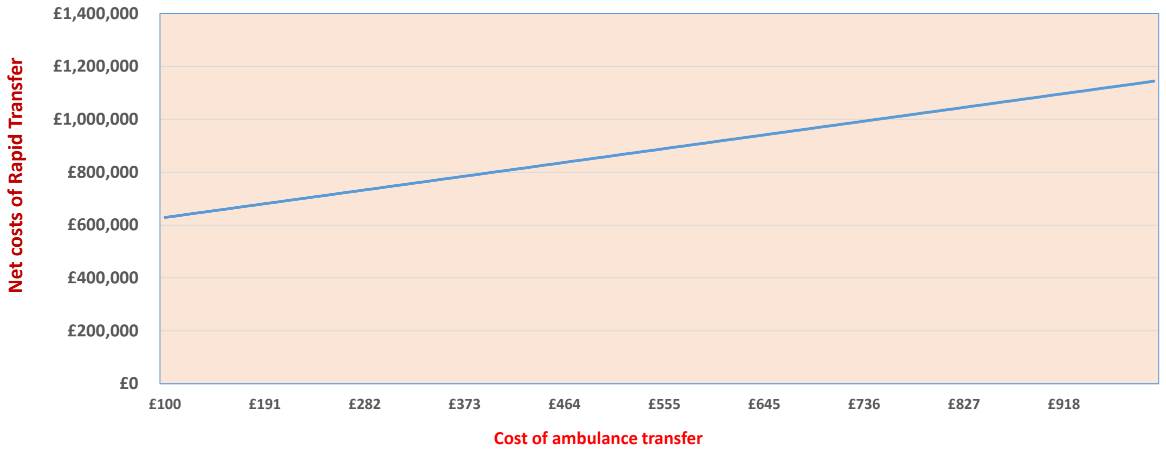


Source: Cost model developed for this guideline

Varying the cost of an ambulance transfer from a paediatric ward

In the sensitivity analysis shown in Figure 41 the cost of an ambulance transfer from a paediatric ward setting is varied between £100 and £1,000. This shows how the net costs of rapid transfer rise in response to increased costs of ambulance transfer.

Figure 41: Graph to show net costs of rapid transfer service to preferred place of death varying the cost of ambulance transfer (from a paediatric ward)

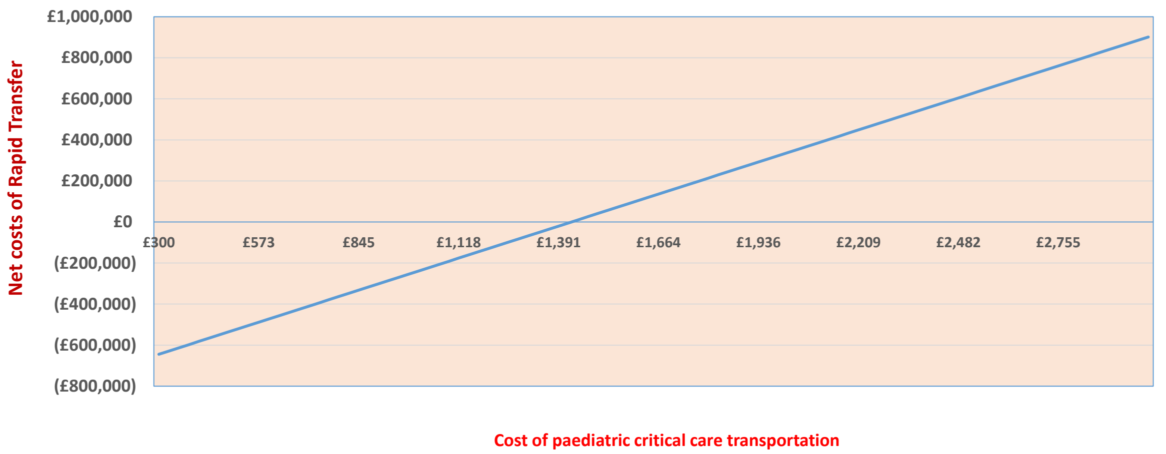


Source: Cost model developed for this guideline

Varying the cost of paediatric critical care transportation

In the sensitivity analysis presented in Figure 42 the costs of paediatric critical care transportation are varied to assess the impact of this on the net costs of a rapid transfer to the preferred place of death. This sensitivity analysis suggests the threshold for cost neutrality, holding all other inputs constant at their default level, for the cost of paediatric critical care transportation is £1,425. If the cost of paediatric critical care transportation falls below that then a rapid transfer service reduces costs compared with an alternative where such a service is not offered.

Figure 42: Graph to show net costs of rapid transfer service to preferred place of death varying the cost of paediatric critical care transportation

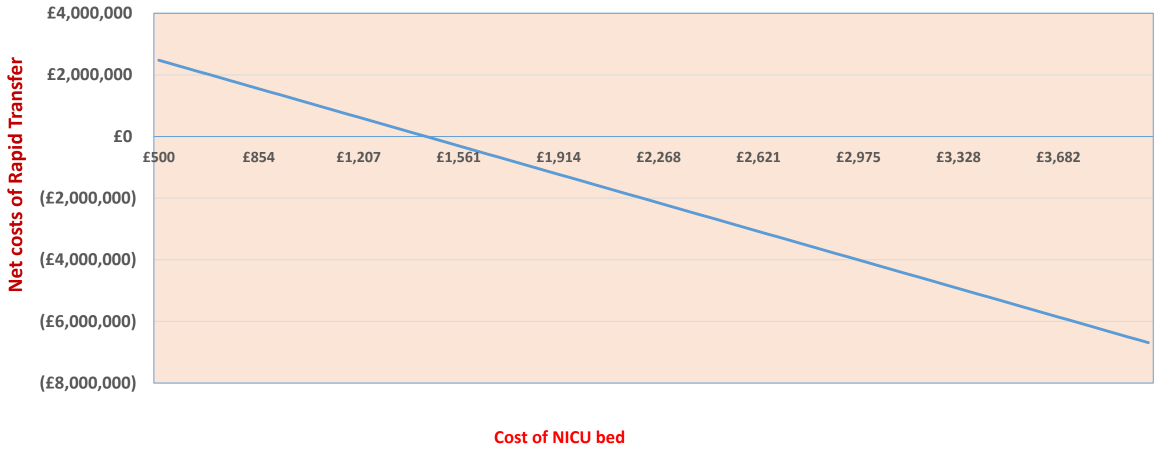


Source: Cost model developed for this guideline

Varying the cost of a neonatal intensive care unit (bed)

Figure 43 shows how the net costs of rapid transfer to a preferred place of death vary with changes in the cost of a NICU bed. This sensitivity analysis suggested that when the costs of a NICU bed exceed £1,450 then a rapid transfer service to the preferred place of death became cost saving.

Figure 43: Graph to show net costs of rapid transfer service to preferred place of death varying the cost of a NICU bed

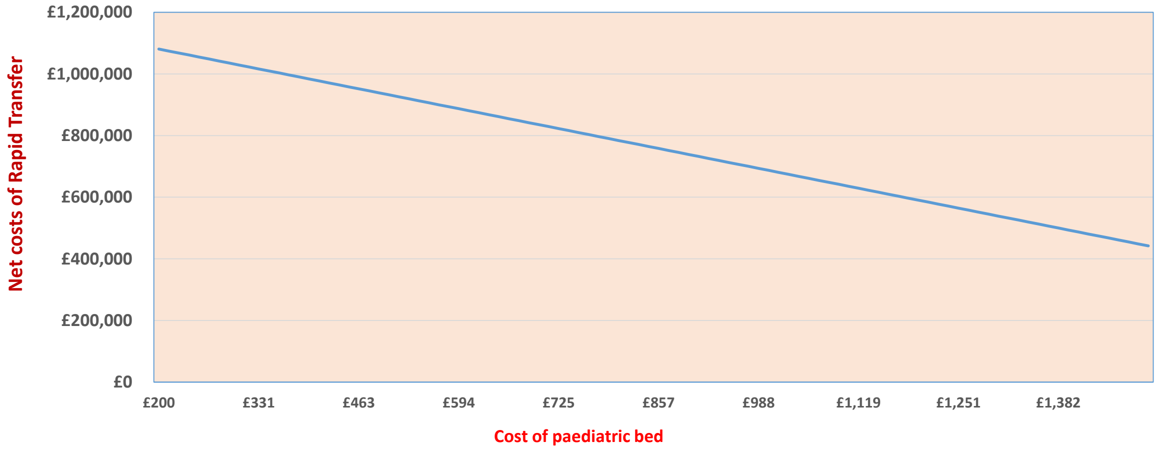


Source: Cost model developed for this guideline

Varying the cost of a paediatric ward bed

In Figure 44 the impact of the cost of a paediatric bed day on the net cost of a rapid transfer service to a preferred place of death is illustrated. Within the range of costs for a paediatric bed day shown, there was no value which produced a result where rapid transfer was cost saving.

Figure 44: Graph to show net costs of rapid transfer service to preferred place of death varying the cost of a paediatric bed

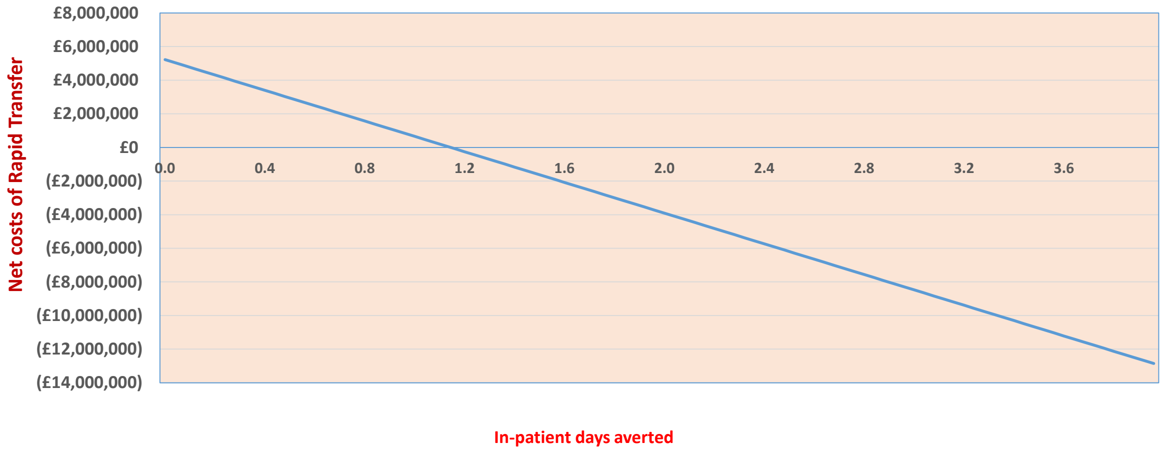


Source: Cost model developed for this guideline

Varying the number of inpatient days averted as a result of rapid transfer to a preferred place of death

In the sensitivity analysis depicted in Figure 45, rapid transfer becomes cost saving relative to an alternative where such a service is not available when 1.2 or more inpatient days are averted on average by a rapid transfer service.

Figure 45: Graph to show net costs of rapid transfer service to preferred place of death varying the number of inpatient days averted as a result of rapid transfer to a preferred place of death

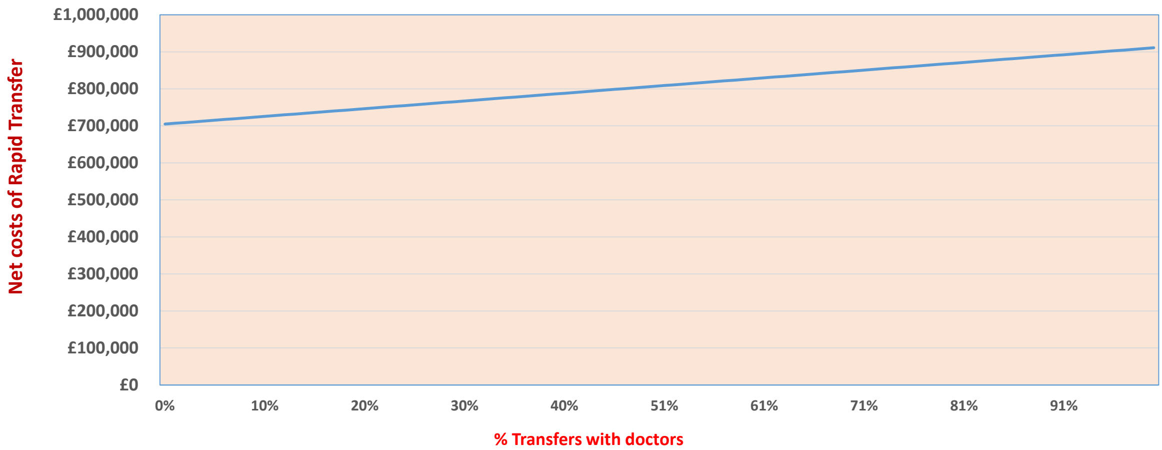


Source: Cost model developed for this guideline

Varying the proportion of transfers accompanied by a doctor

In this sensitivity analysis the proportion of transfers from non-critical settings which are accompanied by a doctor is varied between 0% and 100% (see Figure 46). It shows that increasing the proportion of transfers accompanied by a doctor increases the net costs of rapid transfer, but by a relatively small amount.

Figure 46: Graph to show net costs of rapid transfer service to preferred place of death varying the number of transfers from non-critical settings which are accompanied by a doctor

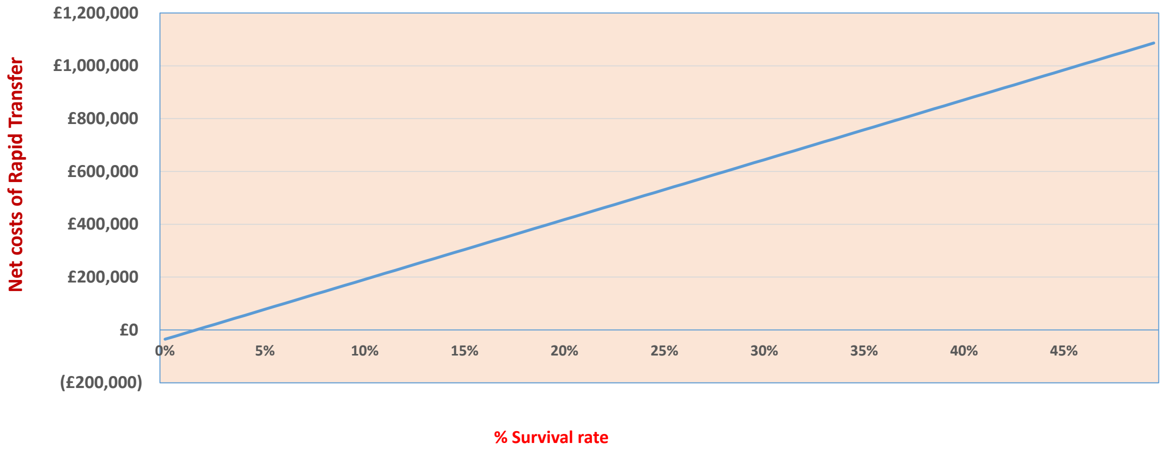


Source: Cost model developed for this guideline

Varying the survival rate of those transferred home

Not all children who accessed the rapid transfer service would die imminently following their rapid transfer. In this one-way sensitivity analysis this survival rate is varied between 0% and 50%. It can be seen from Figure 47 that below a survival rate of 1.5% a rapid transfer service would become cheaper than the alternative, holding all other model inputs constant at their default value.

Figure 47: Graph to show net costs of rapid transfer service to preferred place of death varying the survival rate of those transferred home

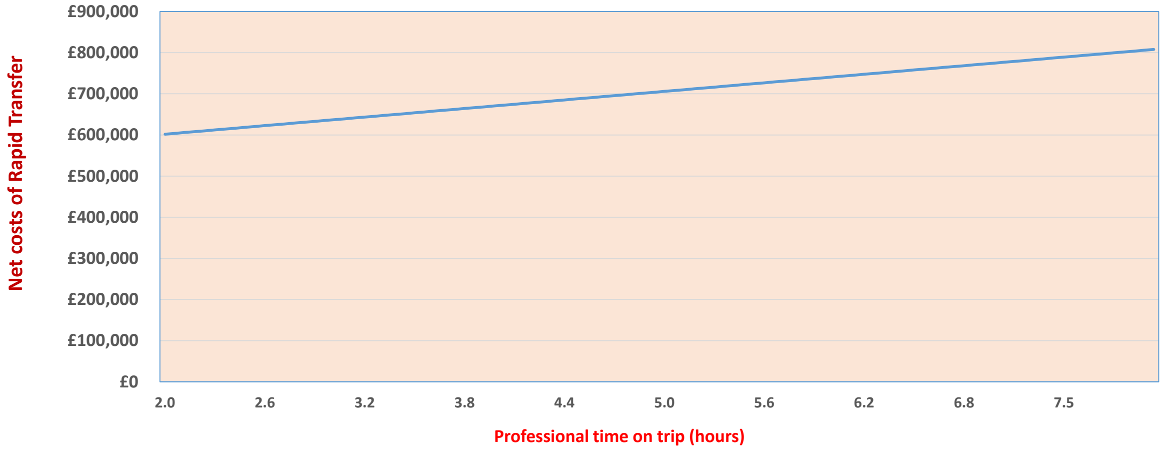


Source: Cost model developed for this guideline

Varying the time of the healthcare professional (doctor/nurse) involved in accompanying a transfer

In this analysis, which is illustrated in Figure 48, the time spent by the healthcare professional accompanying a rapid transfer is varied between 2 and 8 hours. As the time of the healthcare professional increases, there is a relatively small increase in the net costs of rapid transfer.

Figure 48: Graph to show net costs of rapid transfer service to preferred place of death varying the time of the healthcare professional (doctor/nurse) involved in accompanying a transfer

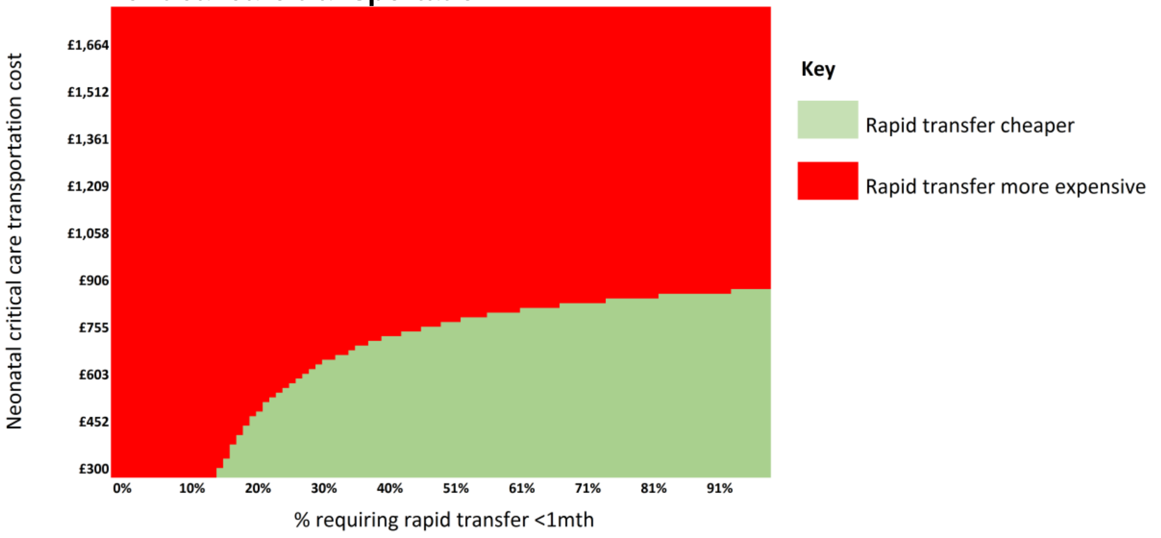


Source: Cost model developed for this guideline

Varying the cost of neonatal critical care transportation and the proportion of children aged under 1 month for whom a rapid transfer service could be of benefit

In this two-way sensitivity analysis both the cost of neonatal critical care transportation and the proportion of children aged under 1 month who could potentially use a rapid transfer service is varied and the relationship is shown in Figure 49. For a given input value of one of these variables, the graph shows the threshold for cost neutrality for the other model input, holding all model values constant at their default value.

Figure 49: Graph to show the impact on the net costs of a rapid transfer service to preferred place of death varying the proportion of children aged under 1 month who could benefit from such a service and the costs of neonatal critical care transportation

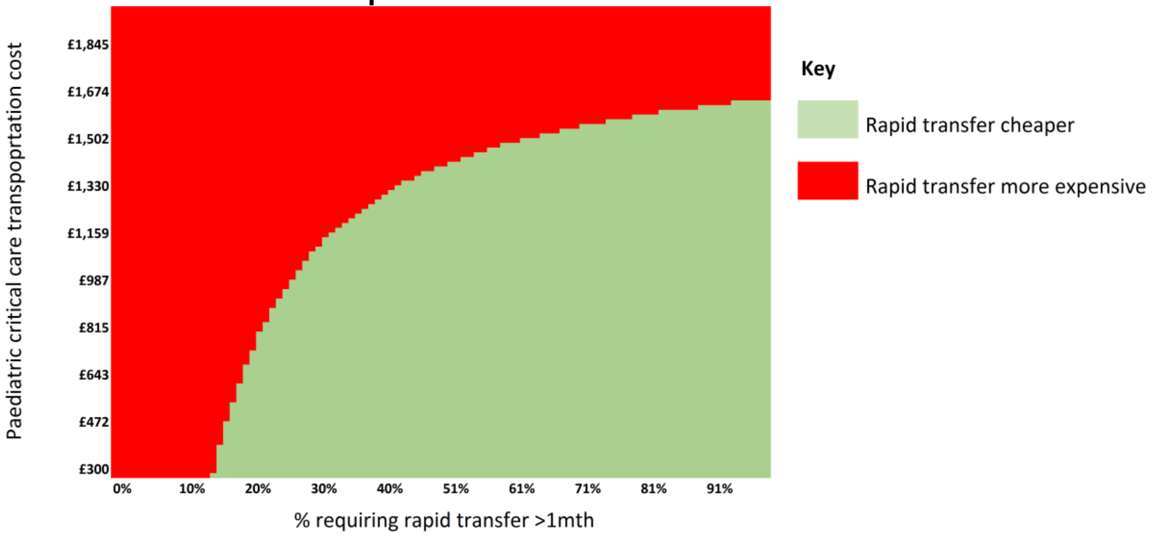


Source: Cost model developed for this guideline

Varying the cost of paediatric critical care transportation and the proportion of children aged over 1 month for whom a rapid transfer service could be of benefit

Figure 50 illustrates a two-way sensitivity analysis in which the proportion of children aged over 1 month and costs of paediatric critical care transportation are both varied.

Figure 50: Graph to show the impact on the net costs of a rapid transfer service to preferred place of death varying the proportion of children aged over 1 month who could benefit from such a service and the costs of paediatric critical care transportation

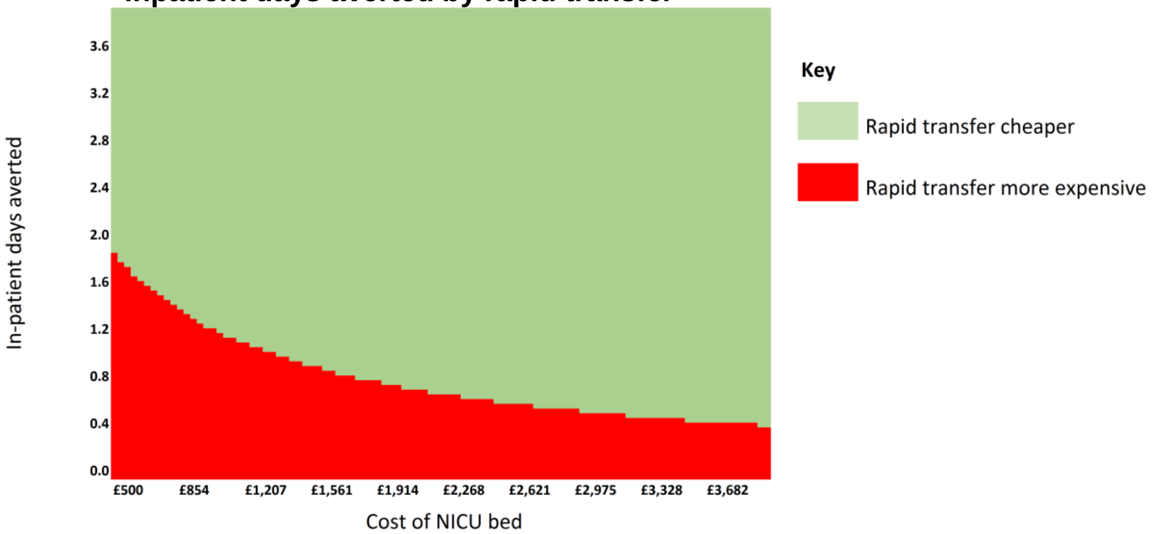


Source: Cost model developed for this guideline

Varying the cost of a NICU bed and the mean number of inpatient days averted by rapid transfer service to a preferred place of death

The impact of changing the assumptions about the number of inpatient days averted by rapid transfer and the cost of a NICU bed are explored in the sensitivity analysis illustrated in Figure 51.

Figure 51: Graph to show the impact on the net costs of a rapid transfer service to preferred place of death varying the costs of a NICU bed and the number of inpatient days averted by rapid transfer

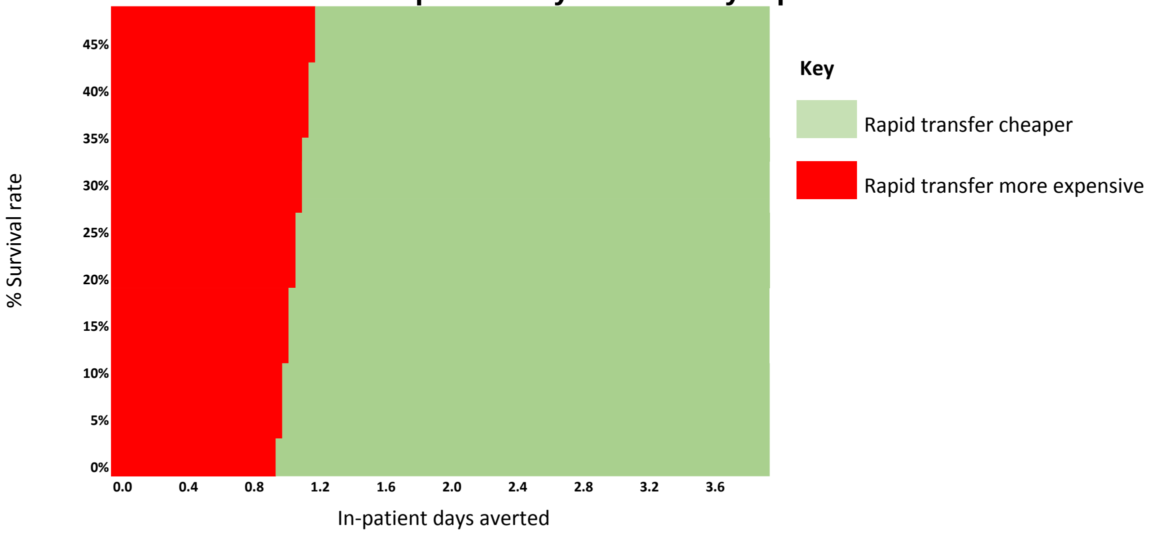


Source: Cost model developed for this guideline

Varying the survival rate and the mean number of inpatient days averted by rapid transfer service to a preferred place of death

In this final two-way sensitivity analysis the survival rate of those utilising a rapid transfer service is varied along with the number of inpatient days averted as a result of rapid transfer to a preferred place of death. The results are shown in Figure 52.

Figure 52: Graph to show the impact on the net costs of a rapid transfer service to preferred place of death varying the survival rate in those transferred home and the number of inpatient days averted by rapid transfer



Source: Cost model developed for this guideline

K.3.6 Discussion

The cost model results reported in section K.3.5 show that the net costs of a rapid transfer service would cost in the order of £700,000 across all of England when compared with an alternative where such a service was not available. There are costs associated with not transferring a child, but the analysis with the model defaults do not indicate that any savings are sufficient to more than offset the costs entailed in providing rapid transfer. However, the fact that a rapid transfer service may increase costs does not mean that such a service is not cost effective. Such a service can facilitate tangible, albeit difficult to quantify, benefits in terms of allowing a preferred place of death to be achieved. It may also expedite the withdrawal of burdensome treatment, saving some resources and furthering the best interests of the child or young person.

However, the magnitude and even the direction of the net costs of rapid transfer has considerable uncertainty which was explored in a number of sensitivity analyses. Not least, there is considerable uncertainty with regard to the number of children and young people who would use such a service, although 5,000 represents an upper bound estimate of the maximum use.

The sensitivity analyses which varied the proportion of children and young people who could be suitable for a rapid transfer service to a preferred place of death shows the impact the number of children using the service has on net costs. The net costs are an increasing function of the number of children because the default values of other model inputs (such as transportation costs and inpatient bed days) result in rapid transfer being more expensive than the alternative. Therefore, the greater the number of children and young people using the service, the greater the net cost.

The costs of ambulance transportation are considered in the one-way sensitivity analyses of ambulance transfer from a paediatric ward, paediatric critical care transportation cost, proportion of transfers accompanied by a doctor and health professionals' time spent accompanying transfers. Clearly, the net costs of rapid transfer increase when transportation costs increase but changes to the proportion of transfers accompanied by doctors or the time spent by doctors and nurses and doctors accompanying transfers has only a relatively small impact on total net costs. Net costs of rapid transfer are more sensitive to changes in the costs of paediatric critical care transportation, which accounts for a large proportion of the costs of a rapid transfer service to the preferred place of death (see Table 21). The sensitivity analysis suggests that a paediatric critical care transportation cost of £1,425 is the threshold for cost neutrality, holding other model inputs constant at their default level. Below this threshold paediatric critical care transportation cost, a rapid transfer service to the preferred place of death would produce net savings.

The sensitivity analysis varying the proportion of children aged over 1 month whose setting at the point of rapid transfer is a paediatric ward illustrates the impact of changing the proportion of children transferred from either a paediatric ward or PICU setting. There is considerable uncertainty about these proportions and the "what-if" analysis showed a considerable reduction as the paediatric ward proportion increased. This is because the model assumes that the costs of rapid transfer from a paediatric ward are considerably less than when transferring from a critical care hospital setting.

The net costs of rapid transfer to a preferred place of death are partly determined by the costs of the alternative, which in this model is estimated by the costs of hospitalisation which is calculated from the daily costs of a hospital bed and the mean number of inpatient days that would be averted by rapid transfer. Given the context of a rapid transfer service where death is expected to be imminent, it is not thought that rapid transfer would avert significant hospitalisation but timing of death is not predictable with certainty and therefore there is some uncertainty about the off-setting savings that a rapid transfer service would produce from reduced hospitalisation. One-way sensitivity analyses on the costs of a neonatal intensive care unit bed, a paediatric ward bed and inpatient days averted explore the impact of varying the costs of hospitalisation. Naturally, as costs of hospitalisation are increased, the net costs of a rapid transfer fall, and this is shown in Figure 43, Figure 44 and Figure 45. If the cost of a NICU bed was more than £1,450, a figure only slightly higher than the upper quartile range cited in 2014/15 NHS Reference Costs, then a rapid transfer service would produce net savings. Net costs are particularly sensitive to changes in the number of inpatient bed days averted. If the mean inpatient days averted by a rapid transfer service was 1.15 days (instead of the default of 1 day) then, holding other model inputs constant, a rapid transfer service would be cost saving.

Not all children and young people having a rapid transfer to the preferred place of death would die in the time expected and therefore such patients may incur further rapid transfer costs (and hospital costs at a later date). Although Figure 47 shows a threshold survival rate at which a rapid transfer service becomes cost saving, the Guideline Committee was confident that the model default survival rate of 33% was a good estimate and this value is well in excess of the survival rate needed for cost neutrality. In the model, an increasing survival rate increases the costs of rapid transfer because the model assumes that a proportion of those surviving their initial transfer will go on to have a subsequent rapid transfer at a later date.

Two-way sensitivity analyses varying the costs of critical care transportation and the proportion of children and young people who could benefit from a rapid transfer service address the joint impact of the number of children and young people using a rapid transfer service and the costs of critical care transportation. This is done separately for children aged under 1 month and for children and young people older than 1 month. Both analyses give a similar general pattern (see Figure 49 and Figure 50). The results shown in Figure 49 can be explained as follows. When it assumed that a rapid transfer service will only be appropriate and feasible for a small proportion of neonates who die, then the net costs of rapid transfer are driven overwhelmingly by children and young people aged 1 month and older. However, as the numbers of children aged under 1 month increases, then this population becomes relatively more important in determining the overall net costs of a rapid transfer service to a preferred place of death. Furthermore, when neonatal critical care transportation costs are below a certain level, the costs of rapid transfer (including neonatal transportation costs) are more than offset in this subset of the population by reduced hospitalisation costs.

A two-way sensitivity analysis varying the cost of a NICU bed and the number of inpatient days averted is presented. Both of these model inputs are important determinants of the cost of the alternative to a rapid transfer service. For any given cost of a NICU bed, a greater number of inpatient days averted implies a greater reduction in the net costs of a rapid transfer service. The higher the cost of a NICU bed, the less number of averted inpatient days are needed to offset this cost of hospitalisation and this inverse relationship is clear in Figure 51.

The final two-way sensitivity analysis described in section K.3.5.1 considers the trade-off between survival rate and inpatient days averted. As noted above in a one-way sensitivity analysis, the higher the survival rate, the higher the net costs of a rapid transfer service. Conversely, the greater the inpatient days averted by a rapid transfer service, the lower the net costs of rapid transfer. The inverse relationship between these 2 model inputs is shown in Figure 52.

There are a number of limitations with the approach described above and important caveats to consider when interpreting this data. First, a base-case analysis based on model defaults, one-way and two-way sensitivity analyses underplays the importance of uncertainty across multiple model inputs. Analyses of this type hold all other inputs at a constant level but a different sensitivity analysis output would result from changes in these other model inputs. Second, there was huge uncertainty with respect to some model inputs, including those which had an important impact on the net costs of a rapid transfer service. The proportion of dying children who would access such a service was essentially undertaken as a “what-if” analysis, given a lack of data and Committee uncertainty. Similarly, the number of inpatient days that would be averted by such a service was also very uncertain, which is important as sensitivity analysis suggested that net costs were sensitive to very small changes in this input. Finally, this evaluation considers only the cost side of the equation and not any non-financial benefits that might arise from a rapid transfer service. If it is assumed that a rapid transfer service to a preferred place of death when wanted by children, young people and their parents is a ‘good thing’ with positive net benefits, then cost effectiveness would be established when a rapid transfer service was shown to produce net savings. Although the analyses presented here don’t rule out the possibility that a rapid transfer service could be cost effective relative to the alternative, they don’t provide strong evidence that such a service would necessarily be cost neutral or cost saving. In the event that a rapid transfer service increases costs, then it can still be considered cost effective if the benefits achieved as a result of increased costs are considered to be good value for money. However, there is insufficient data and information to quantify the benefits of a rapid transfer service and the value currently placed on them.

The model does highlight that the number of children and young people who would be using such a rapid transfer service to a preferred place of death would be relatively small. Therefore, a rapid transfer service is unlikely to impose large costs on NHS budgets. Furthermore, the Committee’s view was that such services were largely current practice, although resource constraints sometimes mean the service cannot be accessed at all times. For example, the ambulance service may at times have to prioritise life-saving calls and the Committee accepted that this was reasonable.

K.3.7 Conclusion

The number of children and young people who would use a rapid transfer service in any given year will be quite small. Although there is considerable uncertainty with regard to the actual number, the children and young people who die each year from medical, congenital and perinatal causes provides an upper bound estimate. From the information given in Table 13 and Table 14, this upper bound estimate would be approximately 5,000 children and young people, a majority of whom would be neonates. The actual numbers would be lower than this upper bound estimate for a variety of reasons. For example, some children and young people would already be in their preferred place of death and some children, young people and parents/carers may not wish to transfer. Death is unpredictable and sometimes it will occur earlier than expected and before rapid transfer can be arranged, and sometimes it will not be practical, feasible or clinically appropriate to transfer.

As the numbers that use such a service would be small, the cost impact of a rapid transfer service to the preferred place of death would be fairly limited. Furthermore, although there is some variation in provision and differing local arrangements, the Committee members were of the opinion that rapid transfer to the preferred place of death is current practice in most of England.

There is too much uncertainty to determine whether a rapid transfer service to the preferred place of death would increase costs relative to the alternative where no such rapid transfer service was offered. The model's default results suggested that a rapid transfer service might lead to an increase in costs to the NHS of £700,000 across the whole of England. Many of the sensitivity analyses also suggested that a rapid transfer service would incur additional costs, although there were scenarios where rapid transfer generated net savings. It is very difficult to capture in the model (although it can be proxied through inpatient days averted) but rapid transfer may help expedite the withdrawal of burdensome treatment in some cases, saving some NHS costs and generating a welfare gain for the child or young person. These potential welfare gains are reflected in policy documents that have sought to promote opportunities to die in their preferred setting.

Even if rapid transfer does lead to a net increase in costs to the NHS, this does not mean that such a service is not cost effective as there are potential welfare gains for children, young people, parents and carers from the provision of such services. The quality-adjusted life year (QALY) is not an appropriate measure to assess the value of this welfare gain given the imminence of death, although it is worth noting for benchmarking purposes that a service costing £700,000 would be valued at between 23 and 35 QALYs (or 0.006 QALYs per child or young person using a rapid transfer service) using a £20,000 to £30,000 willingness to pay threshold.

In summary, the costs of a rapid transfer service are likely to be relatively small, there are real (though difficult to quantify) benefits to patients and carers from such a service, and by and large it can be considered to be current practice in England. This model does not provide strong evidence as to the cost effectiveness of such a service, but recommendations for such services are justifiable given wider Department of Health objectives and that very little uplift in cost is expected to result from such recommendations, given that such services are largely already established.