NICE National Institute for Health and Care Excellence

Putting NICE guidance into practice

Resource impact report:
End of life care for infants, children and young people with life-limiting conditions: planning and management (NG61)

Published: December 2016

Summary

This report looks at the resource impact of implementing NICE's guideline on end of life care for infants, children and young people with life-limiting conditions in England.

This report focuses on the recommendations that we think will have the greatest resource impact nationally, and will need the most additional resources to implement or potentially generate the biggest release of resources. They are:

- rapid transfer arrangements – cost per transfer £1,100 to £2,700 [recommendation 1.5.8]
- care at home – cost to be assessed locally [recommendation 1.5.9].

Implementing NICE's guideline may result in the following benefits and resources released from more children and young people being able receive end of life care in a place of their choice and less services being delivered in an acute setting.

NICE has illustrated the estimated potential resource impact of providing services for a population of 1.5 million. It is anticipated that some of these costs will be met from using existing resources differently. The resources released are unlikely to be cash releasing

Table 1 Potential resource impact of providing end of life care for infants, children and young people using illustrative costs and benefits for a population of 1.5 million

Description	£000s
Illustrative costs:	
Rapid transfer arrangements	53
Day and night care at home (see appendix A)	381
Total illustrative costs	**434**
Illustrative resources released:	
Reductions in critical care bed days	-1,037
Unplanned admissions	-98
Total illustrative resources released	**-1,135**
Potential resource impact	**-701**

Commissioners and providers should decide together whether the resources released are cash releasing or help manage demand for paediatric critical care beds.

Palliative care services for children and young people are commissioned at regional level by neighbouring clinical commissioning groups. Specialised services (such as services for children and young people with severe congenital heart disease or cerebral palsy, or for children and young people who are technology dependent) are commissioned by NHS England. Providers are NHS hospital trusts, community providers and voluntary sector providers (including hospices).

1 Introduction

1.1 The guideline offers best practice advice on end of life care for infants, children and young people with life-limiting conditions.

1.2 This report discusses the resource impact of implementing our guideline on end of life care for infants, children and young people in England. It aims to help organisations plan for the financial implications of implementing this NICE guideline.

1.3 We encourage organisations to evaluate their own practices against the recommendations in the NICE guideline and assess costs and savings locally. Organisations can input estimates into the local resource impact template to reflect local practice and estimate the impact of implementing the guideline.

1.4 Clinical commissioning groups commission paediatric end of life care services. Because the population for these services is small, this is generally done together with neighbouring clinical commissioning groups. In future these services may be delivered on Sustainability and Transformation Plan footprint through collaborative commissioning.

1.5 Specialised paediatric palliative care includes services that manage complex symptoms and prescribe unlicensed medicines. These are commissioned directly by NHS England.

1.6 NHS hospital trusts, community providers and the voluntary sector (including children's hospices) all provide paediatric palliative care.

2 Background

2.1 Around 15 per 10,000 children and young people need palliative care services each year (Noyes et al. 2013). If applied to everyone in England under 18 years old, this equates to around 17,400 children and young people. For a regional population (as assumed

in the modelling) of 1.5 million, this equates to around 480 children and young people.

2.2 End of life care combines a broad range of health and other care services, including hospitals, hospices, primary care and community professionals, ambulance services, dedicated palliative care teams, and other support providers. Services span the public sector and charities. Because of this, good communication, care coordination, and effective networking are essential.

2.3 The guideline covers the physical, emotional, social and spiritual elements of end of life care, and focuses on improving the child's or young person's quality of life and supporting their family.

3 Assumptions made

3.1 Table 2 shows the overall assumptions made in the local template. This allows users to estimate the number of children and young people who may use day and night care at home and rapid transfer services.

3.2 It is assumed that this guideline will lead to more care being provided at home.

3.3 With more services being provided at home, it is assumed that the demand for paediatric critical care beds will reduce.

3.4 Resources released may not be cash releasing as paediatric critical care beds are unlikely to close.

3.5 Average costs associated with paediatric critical care beds vary from £849 to £4,824 per day (NHS reference costs 2014/15; see appendix B).

Table 2 Estimated the number of infants, children and young people who may use end of life services each year for a population 1.5 million people.

Description	Percentage	Number of infants, children and young people
Population		1,500,000
Proportion of Infants, children and young people under 18 years old[a]	21.35%	320,000
Proportion of Infants, children and young people who need palliative care services per year[b]	0.15%	480
Proportion of Infants, children and young people who die per year and need day and night nursing support as they are approaching the end of life[b]	10%	50

[a] Office for National statistics (2014) Mid-year population estimates available from: Clinical Commissioning Group Mid-Year Population Estimates - Office for National Statistics

[b] Noyes J et al. (2013) Evidence-based planning and costing palliative care services for children: novel multi-method epidemiological and economic exemplar. BMC Palliative Care 12:18

4 Recommendations with potential resource impact

4.1 *Rapid transfer arrangements*

4.1.1 In collaboration with local hospitals, hospices, and community, primary care and ambulance services, ensure there is a rapid transfer service process for children and young people with life-limiting conditions to allow urgent transfer to the preferred place of death (for example from the intensive care unit to their home, or to a children's hospice). See recommendations 1.3.15 to 1.3.19 for the planning and practical arrangements of this transfer [recommendation 1.5.8].

Background

4.1.2 Demand for this service is increasing steadily as more families become aware of it and how it could help them. There is likely to be a resource impact, for example from the increased number of

ambulances needed to provide the service and rapidly transfer people at short notice, the additional staff needed during transfers, and the impact on ward functioning during staff absence.

Assumptions made

4.1.3 Table 3 estimates that 50% of children and young people need rapid transfer services to their preferred place of death. This can be amended locally in the template.

Table 3 Estimated number of infants, children and young people who need rapid transfer services per year for a population of 1.5 million

Description	Percentage	Number of infants, children and young people
Proportion of Infants, children and young people who need palliative care services per year (see table 2)	0.15%	480
Proportion of Infants, children and young people who die per year and need day and night nursing support as they are approaching the end of life (see table 2)	10%	50
Proportion of Infants, children and young people families who want their child to die at home [(a)]	80%	40
Proportion of Infants, children and young people who need rapid transfer to their preferred place of death[(b)]	50%	20

(a) Noyes J et al. (2013) Evidence-based planning and costing palliative care services for children: novel multi-method epidemiological and economic exemplar. BMC Palliative Care 12:18

(b) NICE Full guideline – health economics

Costs

4.1.4 Table 4 shows the costs of neonatal critical care and paediatric critical care transportation. These are consistent with the NICE full guideline economic modelling – see table 18 (p44–45) in Appendix K.

Table 4 Rapid transfer service cost per transfer

Description	£
Infants who need neonatal critical care transportation	1,101
Children and young people who need paediatric critical care transportation	2,657
Source: NHS reference costs 2014/15	

4.1.5 The number of infants, children and young people needing rapid transfer should be estimated at a local level. The resource impact template allows users to enter local estimates.

4.1.6 As an example, for 20 children and young who require rapid transfer services per year the estimated cost is £53,000.

Benefits and savings

4.1.7 Implementing this recommendation may lead to redirection of NHS resources by allowing children and young people to die in their preferred place. It is unlikely that the resources released will be cash releasing. The resource impact template allows the impact to be estimated locally.

4.2 *Care at home (day and night)*

For children and young people with life-limiting conditions who are approaching the end of life and are being cared for at home, services should provide (when needed):

- advice from a consultant in paediatric palliative care (for example by telephone) at any time (day and night)
- paediatric nursing care at any time (day and night)
- home visits by a healthcare professional from the specialist paediatric palliative care team (see recommendation 1.5.4), for example for symptom management
- practical support and equipment for interventions including oxygen, enteral nutrition, and subcutaneous and intravenous therapies

- anticipatory prescribing for children and young people who are likely to develop symptoms.

Background

4.2.1 The recommendation specifies that children and young people should have paediatric nursing whenever they need it (day and night). The cost will vary based on individual need, and implementation will depend on the resources and staff available. As care is individually based, a standard staffing model could not be given. An example of a staffing and cost structure is provided in appendix A.

Assumptions made

4.2.2 To assist with local calculations, the staffing configuration outlined in the health economics section of the guideline has been used to structure the 'assumptions input' sheet of the template (see appendix A). This is based on an economic exemplar staffing model for children and young people's end of life care services covering North Wales (Noyes et al. 2013), and on expert opinion.

4.2.3 Based on expert opinion, the staffing structure in the model provides end of life care to around 50 children in a population of 1.5 million (see appendix A). The health economics model assumes the average period of day and night care at home per child is 21 days. This equates to around 1,050 days for 50 children.

4.2.4 Some children and young people may need continuous tracheal ventilation when they are approaching the end of life. It is estimated that the average period of continuous tracheal ventilation is 1 week, and expert opinion suggests that around 5% of children and young people will need continuous tracheal ventilation. Table 5 shows the number of support days that may be needed to provide ventilation support for a child or young person at home.

Table 5 Estimated number of infants, children and young people per year who need continuous tracheal ventilation in the home for a population of 1.5 million

Description	Percentage	Number of infants, children and young people
Proportion of Infants, children and young people who need palliative care services per year (see table 2)	0.15%	480
Proportion of Infants, children and young people who die per year and need day and night nursing support as they are approaching the end of life (see table 2)	10%	50
Proportion of Infants, children and young people families who want their child to die at home (see table 2)	80%	40
Proportion of Infants, children and young people who need continuous tracheal ventilation[a]	5%	2
(a) Estimate based on expert opinion.		

4.2.5 Based on the number of children and young people who need continuous tracheal ventilation (see table 5) and the average time this lasts, 14 days of support per year are needed in the home (2 children/young people x 7 days).

Costs

4.2.6 Current practice is likely to vary, as commissioner and provider services cover different populations, services have evolved according to regional circumstances, and different services have different levels of access to voluntary sector or community services.

4.2.7 The 'resource impact template' page of the tool allows users to enter their own current cost estimate. The template then calculates any additional costs from the local staffing structure entered in the 'assumptions input' sheet.

4.2.8 Organisations should use the template to estimate the local resource impact of implementing the recommendation.

Potential resources released

4.2.9 Providing more care at home may reduce the demand for paediatric critical care beds.

4.2.10 The unit cost of a paediatric critical care bed ranges from £849 (code XB09Z) to £4,824 (code XB01Z) per day (NHS reference costs 2014–2015). The wide range in costs reflects the differences in the level of care needed.

4.2.11 The cost per day of basic paediatric critical care is £988 (NHS reference costs 2014/15 XB07Z). For around 1,050 support days (see 4.2.3 above) this gives a non-cash releasing resources of £1.04 million.

4.2.12 For children and young people who are approaching the end of life, providing continuous tracheal ventilation may release hospital resources. The estimated cost in a hospital is £1,924 per day. Commissioners should estimate the cost of providing this at home at a local level.

4.2.13 Implementing the guideline may reduce unplanned admissions to hospital. The cost per day of a paediatric critical care bed (level 3 advanced critical care) is £1,967 (code XB03Z; NHS reference costs 2014/15). For 50 children who choose to die at home, this would be a non-cash-releasing resource of around £98,000.

Benefits and savings

4.2.14 Providing care at home for children and young people who are approaching the end of life may reduce unplanned admissions to hospitals and the demand for paediatric critical care beds.

4.2.15 An effectively commissioned and delivered service for day and night care at home (including a 24/7 telephone service) can reduce costs by helping children and young people to be discharged early from acute care settings at the end of life.

4.2.16 Offering a choice of care settings to children and young people allows them and their families to receive care according to their needs and wishes.

4.2.17 Although resources released are unlikely to be cash releasing, the demand for paediatric critical care beds will reduce and they will be available for other children and young people who need them.

Other considerations

4.2.18 The costs of emotional and psychological support from a clinical psychology professional and counsellor are included in the example staffing structure in the resource impact template. However, the recommended level of support is likely to be beyond what is available in most areas. The resource impact needs to be assessed locally.

4.2.19 The Guideline Committee stated that there may be some costs associated with parenteral drug administration at home. The number of children and young people who may need parenteral drug administration while approaching the end of life and receiving day and night care at home [recommendation 1.5.11] could not be estimated. This is likely to depend on a number of variables, so the template allows users to make local assumptions.

4.2.20 The resource impact template can be adapted to reflect local estimates and populations. This would allow for in area variations in the proportion of the population aged under 18 years old.

5 Implications for commissioners

5.1 The programme budgeting code for inpatient specialist palliative care for people aged 18 years and under is 02X. The incident classification code for ambulance services for Transfer/Interfacility/Palliative care is 23X.

5.2 There is currently no payment tariff for paediatric end of life care. Local commissioners provide some funding to voluntary sector providers such as hospices. Providers receive some funding from NHS England, but this funding is matched or exceeded by charitable donations and charities also contribute to running services. This presents challenges for the sustainability of services.

5.3 The NHS standard contract for paediatric medicine: palliative care states that specialist paeditric palliative care services are most sustainable and cost effective when they are planned and commissioned across total populations of 1 to 1.5 million.

5.4 The relatively small number of children and young people with life-limiting conditions means that clinical commissioning groups and local authorities struggle to create economies of scale to commission paediatric palliative care effectively. Any local authority contribution is likely to be limited to respite care.

5.5 The current cost of services could not be estimated due to wide variations in services provided. After taking into account the cost of services currently available, iit is estimated that implementing the guidance is unlikely to have a significant resource impact.

Appendix A. Example of service structure and staffing costs used in the local template

Expenditure Heading	Pay Band	WTE	£'000
Consultant community paediatrician	Consultant	0.05	4,900
Children's community nurses (trained in palliative care)	6	5.50	207,700
Children's specialist palliative care nurse (providing on call support)	7	1.00	45,300
Doctor/GP (level 3)	MC46-03	1.00	56,600
Medical equipment technician	6	0.20	7,600
Clinical psychologist	7	0.50	22,700
Occupational therapist	5	0.50	16,600
IT support specialist	7	0.10	4,500
Administrator support	5	0.50	15,300
Total estimated resource impact		**9.35**	**381,200**

Appendix B – Table of 2014/15 reference costs for paediatric critical care beds

Description	Code	2014/15 cost per day £
Paediatric critical care - advanced level 1	XB05Z	4,824
Paediatric critical care - advanced level 2	XB04Z	1,783
Paediatric critical care - advanced level 3	XB03Z	1,967
Paediatric critical care - advanced level 4	XB02Z	1,924
Paediatric critical care - advanced level 5	XB01Z	1,662
Paediatric critical care – Intermediate	XB06Z	1,297
Paediatric critical care – basic critical care	XB07Z	988
Paediatric critical care – enhanced care	XB097	849

About this resource impact report

This resource impact report accompanies the NICE guideline on end of life care in infants, children and young people with life-limiting conditions and should be read in conjunction with it. See terms and conditions on the NICE website.

This report is written in the following context

This report represents the view of NICE, which was arrived at after careful consideration of the available data and through consulting healthcare professionals. The report is an implementation tool and focuses on the recommendations that were considered to have a significant impact on national resource use.

Assumptions used in the report are based on assessment of the national average. Local practice may be different from this, and the impact should be estimated locally.

Implementation of the guidance is the responsibility of local commissioners and providers. Commissioners and providers are reminded that it is their responsibility to implement the guidance, in their local context, in light of their duties to have due regard to the need to eliminate unlawful discrimination, advance equality of opportunity and foster good relations. Nothing in this resource impact product should be interpreted in a way that would be inconsistent with compliance with those duties.