Together for Short Lives' report to NHS England:

A national overview of the readiness of the children's palliative care sector to implement the NICE End of Life Care for Infants, Children and Young People: Planning and Management Guideline.

December 2017

Introduction

1. Together for Short Lives has developed this report with the support of NHS England, to provide a baseline of the current position of the children's palliative care sector in providing high quality, equitable palliative and end of life care based on the NICE Guideline on ***End of Life Care for Infants, Children and Young People: Planning and Management*** (2016) (https://www.nice.org./guidance/ng61)*.* The data was collected from the chairs, or their representative, of the regional children's palliative care networks and was then collated and analysed against the NICE guideline.

   The results showed a mixed level of achievement reflecting the wide variation that exists across each of the networks. To achieve a high, consistent, level of care in every region, we would recommend the following four key actions (see Next Steps and Recommendations for fuller description):

   - an exercise to benchmark networks against each other, to show high performing areas who can share their local solutions with those that have yet to find solutions;
   - a review of the provision of end of life care by children's community services which is available 24-hours a day, 7-days a week;
   - a review of the provision of level 4 paediatric palliative care consultants[1] for all regions;
   - identify sustainable funding of coordinators[2] for each regional network to support and enable networks to engage with all services across their region to provide high standard care to all;

   If we are to build on the opportunities offered by the NICE guidelines and the Government's Choice Commitment then the regional palliative care networks in England have a key role to play. Adequately supported, they can improve and develop services through strong strategic leadership, facilitating the sharing of good practice and building learning.

   Jane Houghton, Autumn 2017

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[1] Level 4: a consultant paediatrician in PPM, or a small number of children's hospice medical leaders (mainly leaders in sub-specialty formation and development, and with roles beyond their local hospice), and who have a substantive role in children's palliative medicine. Manage uncommon symptoms; understand principles in order to develop a logical approach even where there is no evidence basis. Considerable emphasis on leading and developing services within and beyond the local hospice, and on supporting and teaching other professionals involved with children with life-limiting conditions who are not trained in palliative medicine .(APPM/RCPCH, 2015)

[2] Of particular importance is how the network coordinators successfully engaged stakeholders within their region and encouraged partnership working thereby creating unified networks able to successfully deliver specific projectsEvaluating the role and perceived impact of four regional Paediatric Diabetes Network Coordinators: The key findings. NHS Diabetes, 2013)

Contents

Background

2. This report has been prepared by Together for Short Lives to provide a national overview of the readiness of the children's palliative care sector to implement the NICE guidelines.

3. The findings within this report will enable the networks to develop solutions to common challenges, develop network improvement plans and build connections between high performing areas and those that have yet to implement best practice, through benchmarking, a summit, and a compendium of local solutions

4. The NICE guideline aims to improve the planning and management of end of life and palliative care[3] for infants, children and young people (aged 0–17 years) with life-limiting and life-threatening conditions. It aims to involve children, young people and their families in decisions about their care, and improve the support that is available to them throughout their lives. The associated **Quality Standard** (2017) (https://www.nice.org.uk/guidance/qs160), for this guideline, describes six high-priority areas for quality improvement in a defined care or service area.

5. The NICE guideline and the quality standard, if implemented, will improve the overall quality of children's palliative care across the country and to ensure that services meet the growing needs of children and families who require palliative care, wherever they live. Together for Short Lives therefore believes that the successful implementation of the guidance is a key tool to meet the growing needs of this most vulnerable population.

6. The successful implementation, of the guideline and the quality standard, is also key to achieving the **Government's Choice Commitment (2016)** which explicitly states: "To support high quality personalised care for children and young people, commissioners and providers of services must prioritise children's palliative care in their strategic planning so that services can work together seamlessly and advance care planning can be shared and acted upon." (https://www.gov.uk/government/publications/choice-in-end-of-life-care-government-response). The establishment of Managed Clinical Networks, as recommended in the NICE guidance, can be a key mechanism for achieving this commitment.

7. Together for Short Lives is currently producing a report, 'Commissioning children's palliative care in England: 2017 edition' (extract contained in appendix 6), which sets out the findings of a series of freedom of information requests that Together for Short Lives issued to each clinical commissioning group (CCG) in June 2017. The Together for Short Lives report includes responses from CCGs about whether they were implementing the NICE guideline and the Governments Choice Commitment. We have included this in the report as it helps provides context for this work in the wider commissioning environment.

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[3] Children's palliative care is defined as an active and total approach to care, from the point of diagnosis or recognition, throughout the child's life, death and beyond. It embraces physical, emotional, social and spiritual elements and focuses on the enhancement of quality of life for the child/young person and support for the family. It includes the management of distressing symptoms, provision of short breaks and care through death and bereavement." (Together for Short Lives 2013)

Method

8. The data was collected through a telephone survey with the chairs (or their representative) of all the 11 regional children's palliative care networks[4] in England (appendix 1), using a series of 20 questions (appendix 2). Questions 1 to 19 were based on the NICE guideline baseline assessment (https://www.nice.org.uk/guidance/ng61/resources). Question 20 was included because the Paediatric Palliative Care Sub Group of the Specialised Commissioning Clinical Reference Group is reviewing the commissioning of children's palliative care and is interested in seeing the results of this review and to find out whether key aspects, of the NHS England Specialised Commissioning specification E03/S/h Paediatric Medicine Palliative Care, are being delivered (https://www.england.nhs.uk/wp-content/uploads/2013/06/e03-paedi-med--pall.pdf).The data answers questions about the key aspects generally, but specifically the amount of cover provided by medical consultants working at Paediatric Palliative Care Competency Level 4, across the country .

9. Interviewees were asked to rate the frequency of their region's overall delivery of each of the 19 areas of good practice that relate to the NICE baseline assessment and the questions about specialised commissioning on the following scale:

Always	Usually	Sometimes	Rarely	Never
91-100% of the time	61 – 90% of the time	41-60% of the time	11-40% of the time	1 – 10% of the time

Results

10. The results should be viewed as a snapshot and are not representative of all practice in England. The results do, however, provide a national overview of the readiness of the children's palliative care sector and the NHS to implement the NICE Guideline on *End of Life Care for Infants, Children and Young People* (2016), in order to ensure the quality of palliative and end of life care of children and young people in England.

11. The list of responses of each network, are included at Appendix 3, and for each question at Appendix 4 and 5.

Analysis of results

12. The level to which services are able to meet the recommendations within the NICE Guidelines were categorised as follows:

- Category 1. High level of achievement: most areas are already implementing the NICE guideline (responses in the main 'always' and 'usually')
- Category 2. Variable levels of achievement: some areas are delivering; others are not

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[4] linked groups of health professionals and organisations from primary, secondary and tertiary care, and social services and other services working together in a coordinated manner with clear governance and accountability arrangements". There are regional or sub regional children's palliative care networks in all English regions except across Surrey and Sussex

yet delivering a service against the guideline (responses in the main 'usually' and 'sometimes')

- Category 3. Low level of achievement; most areas are not yet implementing the NICE guideline (responses in the main 'sometimes', 'rarely' or 'never').

The graded results of each question are as follows:

13. CATEGORY 1:
The following areas of practice are identified as at a high level of achievement with the majority of areas already implementing the NICE guideline:

Q1. Communication between professionals/parents: Professionals think about how best to communicate with each child or young person and their parents or carers.

Q8. Multi-disciplinary team Children and young people with life-limiting conditions are cared for by a multi-disciplinary team.

Q13 End of life care: Every child approaching end of life has 24-hour access to paediatric nursing care, at least sometimes or usually.
Q15 Rapid transfer: There is a rapid transfer process for children and young people with life-limiting conditions to allow urgent transfer to the preferred place of care.

Q17 Care after death: the practical arrangements that will be needed after the death of their child are discussed with parents/carers.

Q18 Staff support: Professionals have access to ongoing support and supervision, including care assistants.

Q20 d) Specialist paediatric palliative care team: The MCN or children's palliative care network provides the full range of specialist paediatric palliative care interventions including use of alternative opioids.

Q20 e) Specialist paediatric palliative care team: The MCN or children's palliative care network are able to treat all children and young people, regardless of their age.

14. CATEGORY 2:
The following areas of practice are identified as at variable levels of achievement with some areas delivering and others not yet delivering a service against the guideline:

Q2. Communication between professionals: Services within all relevant agencies engage in planning for the specific needs of the child/young person.

Q3. Information available: Children, young people and their families have easy access to information about their condition and services available to them.

Q4. Advance care plans. Each child or young person and their family has an Advance Care Plan or equivalent

Q5 Emotional/psychological support is available for children and young people with a life-limiting condition.

Q6 Religious/spiritual support is available is available for children and young people with a life-limiting condition

Q9 Family support: Care plans address the care and support needs of all immediate family members.

Q10 Organ and tissue donation: Processes are in place for families to discuss their preferences for organ and tissue donation.

Q11 Recognition that a child is likely to die: professionals are able to recognise when a child is likely to die within the next few days.

Q12 EOL care: Every child and family have an end of life plan when appropriate.

Q19 Bereavement support: Parents or carers are offered bereavement support when their child is nearing the end of their life and after their death. There are some gaps, with long waiting lists in some areas for bereavement support.

15. CATEGORY 3:
The following areas of practice are identified as at a low level of achievement with most areas are not yet implementing the NICE guideline.

Q7 Symptom management: Staff have 24/7 access to specialist advice on complex symptom management in children and young people.
Q14 End of life care: The carers of children approaching the end of life have 24-hour access to advice from a consultant in paediatric palliative care.

Q16 Care at home: Every child has access to a 24-hour multi-disciplinary children's palliative care team for care within the home.

Q20a) Specialist paediatric palliative care team: Service delivery by a consultant-led multi-professional specialist palliative care team across the network/MCN.

Q20b) Specialist paediatric palliative care team: Clinical leadership role in planning delivery and evaluation of children's palliative care services across a network/ MCN.

Q20c) Specialist paediatric palliative care team: Care led by a medical consultant working at Paediatric Palliative Care Competency Level 4.

Conclusion

16. The survey provides a snapshot of the relative implementation of NICE *End of Life Care for Infants, Children and Young People: Planning and Management Guideline* (2016), in different regions of the country. It also provides a good reference for the Government's Choice Commitment.

17. The results demonstrate that the quality of palliative and end of life care is high in some respects, as infants, children and young people with a life-limiting condition usually have coordinated care, provided by a multidisciplinary team. However, this team is often not a specialist palliative care team with a level 4 consultant, but led by a level 3 consultant with an interest in paediatric palliative care[5]. These teams are able to provide all alternative opioids needed.

18. Professionals say that they consider how best to communicate with parents, including

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[5] Level 3: a paediatrician (consultant or Staff or Associate Specialist (SAS) doctor) who has developed a special interest in PPM, an established children's hospice doctor or GP with Special Interest (GPWSI) in paediatric palliative care. Likely to have a relevant postgraduate qualification such as the Cardiff Diploma in Palliative Medicine (paediatrics) (APPM/RCPCH,2015)

care after death and have processes in place if the family wish to have a rapid transfer to their preferred place of death at end of life.

19. There is support in place for professionals if they wish to accept it.

20. Most parents or carers of infants, children and young people approaching the end of life and after their death, are offered support for grief and loss, but there is a need to reduce waiting lists and the variable availability of services[6]

21. Although many families are involved in developing an advance care plan and end of life plans, more work needs to be done to ensure every family across England has those opportunities, regardless of their diagnosis or place of care as well as ensuring all families consistently have the opportunity to discuss organ donation.

22. More families need to be given the information and opportunity to access commissioned emotional, psychological, religious and spiritual support. This kind of family support should be included in care plans.

23. There is a shortage of children's community nursing (CCN) services and this survey highlights that there is also a shortage of services commissioned to provide 24hr end of life care[7], thereby denying families the choice of care at home. This, combined with the finding that half the networks do not consistently have a level 4 paediatric palliative care consultant means that many children requiring palliative care are denied that level of support, including advice on symptom management.

Next steps & Recommendations

24. We will share benchmarking information with each network/sub-regional network to support local conversations for prioritising activity with the chairs of the networks. We will provide an opportunity to discuss the implications at a proposed summit in February 2018 at which we will explore best practice, where teams are working well and identify some of the common challenges. We would welcome NHS England's involvement in that summit.

25. We would like to explore opportunities to work with NHS England, Department of Health and Health Education England, to support networks to:
    - Develop solutions to common challenges (Category 3)
    - Develop network improvement plans (Categories 2 and 3)
    - Build connections between high performing areas and those that have yet to implement local solutions – through buddying, mentoring and training (Category 2).

26. The networks need to continue to benchmark against each other and to exchange local solutions through a central focus group or network of networks. NHS England may consider the funding of a part time central role to focus on helping to support networks across the country.

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[6] It is vital to offer bereavement care to anyone who has lost a child, however care offered to parents is worryingly inconsistent. Together for Short Lives (2017)

[7] a number of locations in the UK still have no CCN service provision. Furthermore, very few of the existing CCN services are able to offer the 24/7 service that is especially critical for end of life care. (The Future for Children's Community Nursing: Challenges and Opportunities. RCN, 2014)

27. NHS Diabetes (2013) have shown the impact of the role of a network coordinator [8]. Together for Short Lives will follow, with interest, and share the progress of those networks that are developing new coordinator roles, as part of their efforts to become Managed Clinical Networks (MCN). Together for Short Lives could work to help provide oversight of these coordinator roles.

28. In addition to providing a resource “Setting up a Managed Clinical Network in Children’s Palliative Care” to inform local services and networks as they explore this option for developing services Together for Short Lives is working directly with regional networks who are interested in such developments.

29. We will share new ways of developing the commissioning of services, especially of children’s community nursing and Level 4 paediatric palliative care consultants.

30. We are interested in working with NHS England to use this audit to help inform engagement with STPs. Many of the STP plans do not currently address children’s palliative care or end of life care. The audit can serve as a useful tool to inform STP thinking and improve understanding of the health needs of children and families in their area and the services that are there to support them.

31. We recommend that a complementary study of family and children’s experiences is undertaken to provide evidence and insight from a service user perspective.

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[8] Network coordinator is pivotal to the effective functioning of the networks. Retaining this role will help maintain the momentum of the regional and national networks to help drive towards achievement of the vision of the national network – to reduce variation of care and deliver better outcomes for children and young people with diabetes, their families and carers, no matter where they live in England. (Evaluating the role and perceived impact of four regional Paediatric Diabetes Network Coordinators: The key findings. NHS Diabetes, 2013)

Appendix 1

English Regional Children's Palliative Care Networks.

(information from South East Coast was provided by Kent and Medway network)

Appendix 2

NICE Guidelines for CPC service data collection questions

For each question we are seeking a response of Always; Usually; Sometimes; Rarely; Never.
Frequency: Never 1 - 10%   Rarely 11 – 40% Sometimes 41 - 60 Usually 61-90% and Always is 91-100% of the time

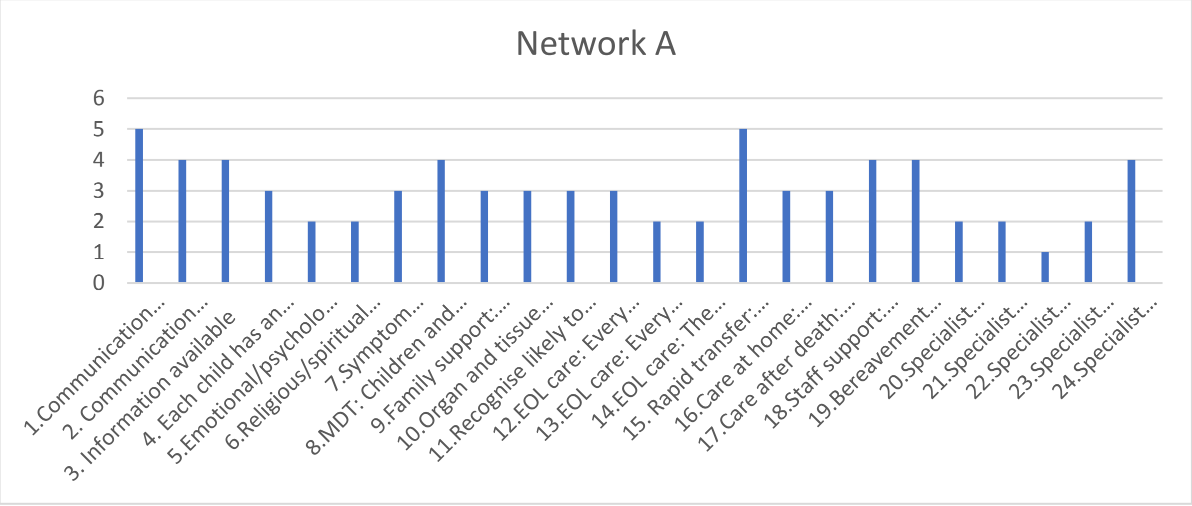
	Statement	Always	Usually	Sometimes	Rarely	Never
1	**Communication between professionals/parents**: Professionals think about how best to communicate with each child or young person and their parents or carers					
2	**Communication between professionals**: services within all relevant agencies engage in planning for the specific needs of the child/young person					
3	**Information available**: Children, young people and their families have easy access to information about their condition and services available to them					
4	**Advance care plans**: Each child or young person and their family has an Advance Care Plan or equivalent					
5	**Emotional/psychological support** is available for children and young people with a life-limiting condition.					
6	**Religious/spiritual support** is available for children and young people with a life-limiting condition.					
7	**Symptom management**: Staff have 24/7 access to specialist advice on complex symptom management in children and young people					
8	**MDT**: Children and young people with life-limiting conditions are cared for by a defined* multi-disciplinary team					

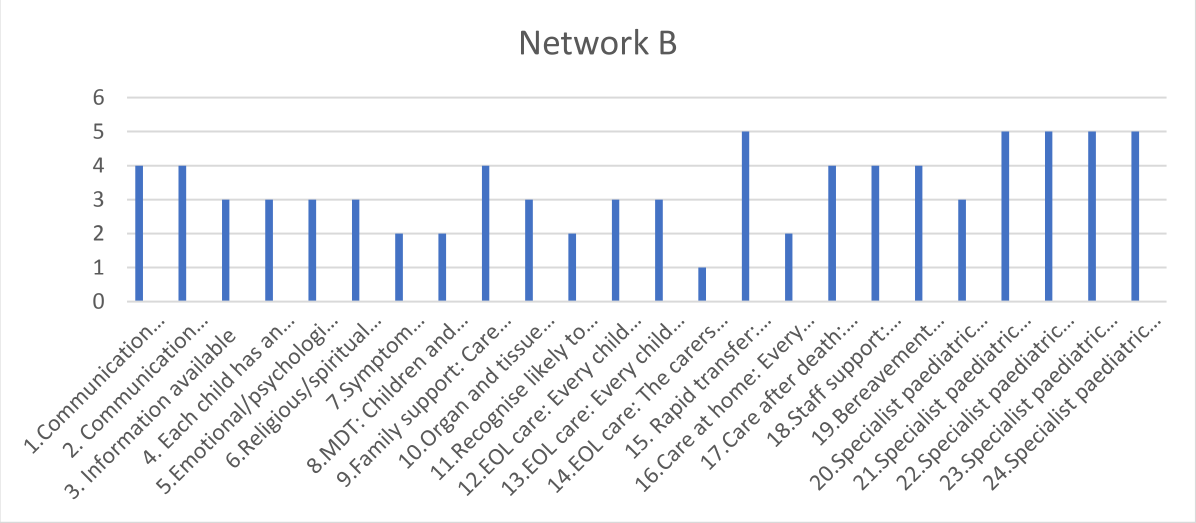
9	**Family support:** Care plans address the care and support needs of all immediate family members					
10	**Organ and tissue donation:** Processes are in place for families to discuss their preferences for organ and tissue donation					
11	**Recognise likely to die:** professionals are able to recognise when a child is likely to die within the next few days					
12	**EOL care:** Every child and family has an end of life plan when appropriate					
13	**EOL care:** Every child approaching the end of life has 24-hour access to paediatric nursing care					
14	**EOL care:** The carers of children approaching the end of life have 24-hour access to advice from a consultant in paediatric palliative care.					
15	**Rapid transfer:** There is a rapid transfer process for children and young people with life-limiting conditions to allow urgent transfer to the preferred place of care					
16	**Care at home:** Every child has access to a 24-hour multi-disciplinary children's palliative care team for care within the home					
17	**Care after death:** the practical arrangements that will be needed after the death of their child are discussed with parents/carers					
18	**Staff support:** Professionals have access to ongoing support and supervision.					
19	**Bereavement support:** Parents or carers are offered bereavement support when their child is nearing the end of their life and after their death.					

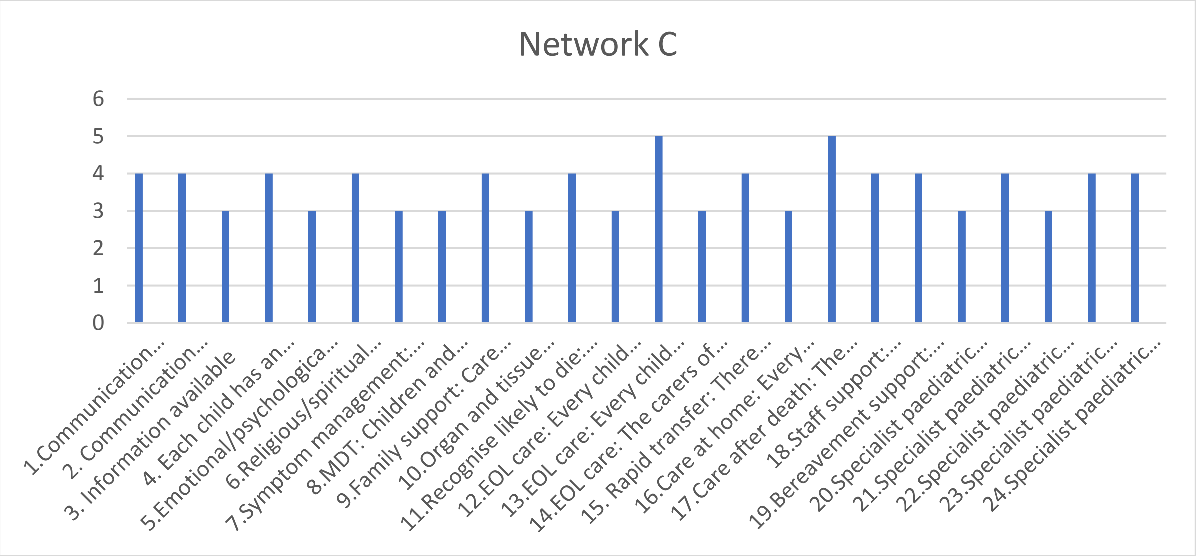
20	Specialist paediatric palliative care team:					
A	Service delivery by a consultant-led multi-professional specialist palliative care team across the network/MCN					
B	Clinical leadership role in planning delivery and evaluation of children’s palliative care services across a network/ managed clinical network					
C	Care led by a medical consultant working at Paediatric Palliative Care Competency Level 4					
D	MCN/network provides the full range of specialist paediatric palliative care interventions including use of alternative opioids					
E	MCN/network able to treat all children and young people, regardless of their age					

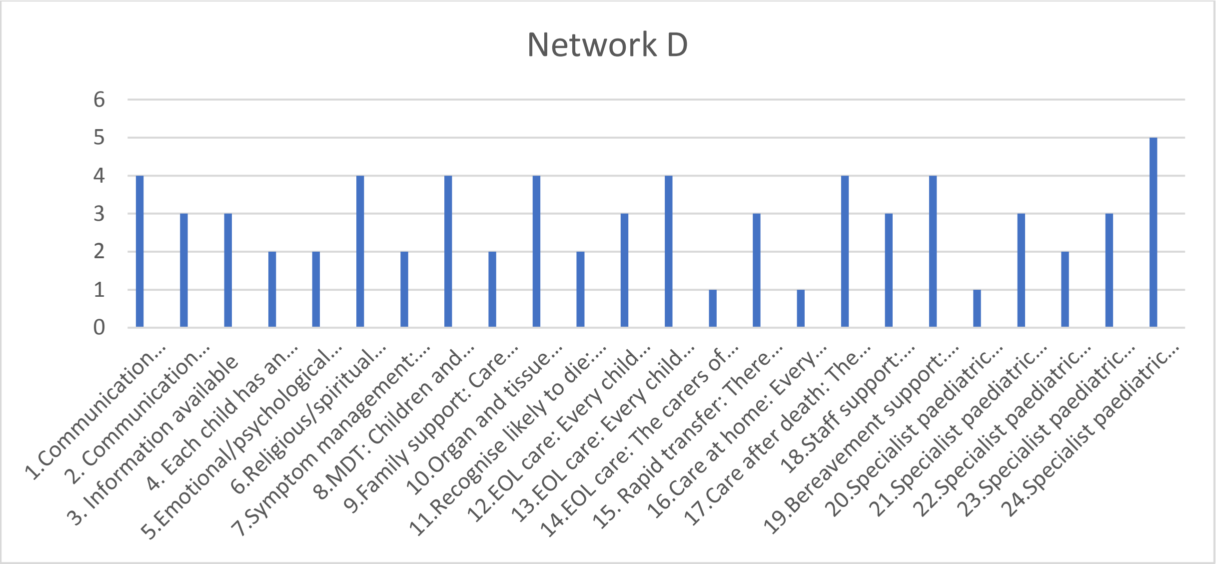
Appendix 3

<u>Network Responses</u> (5 = always, 4 = usually, 3 = sometimes, 2= rarely, 1= never)





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12.EOL care: Every child...
13.EOL care: Every child...
14.EOL care: The carers of...
15. Rapid transfer: There...
16.Care at home: Every...
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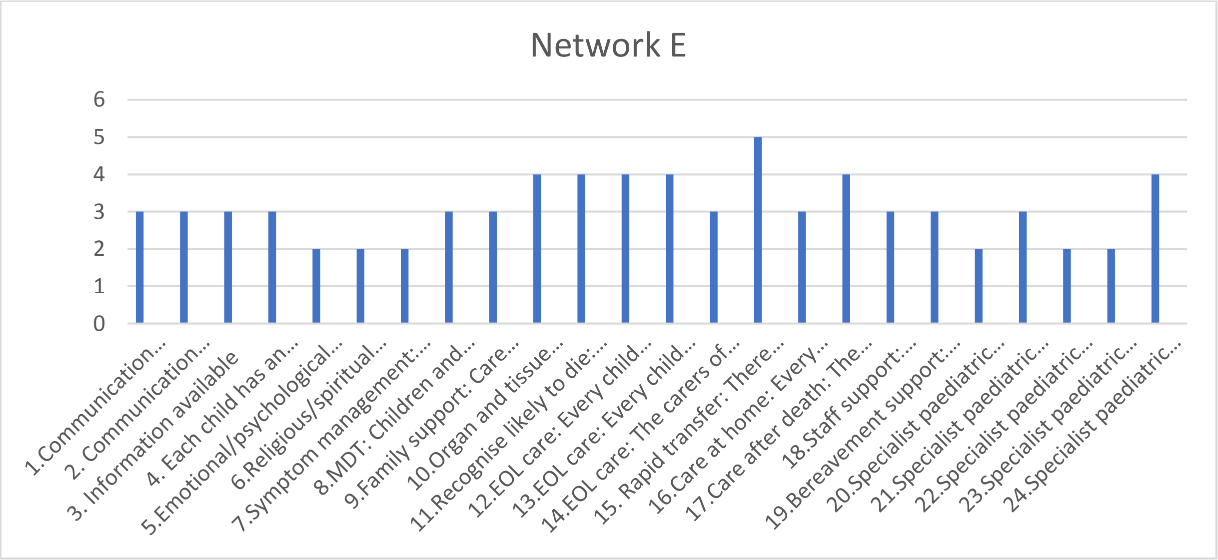
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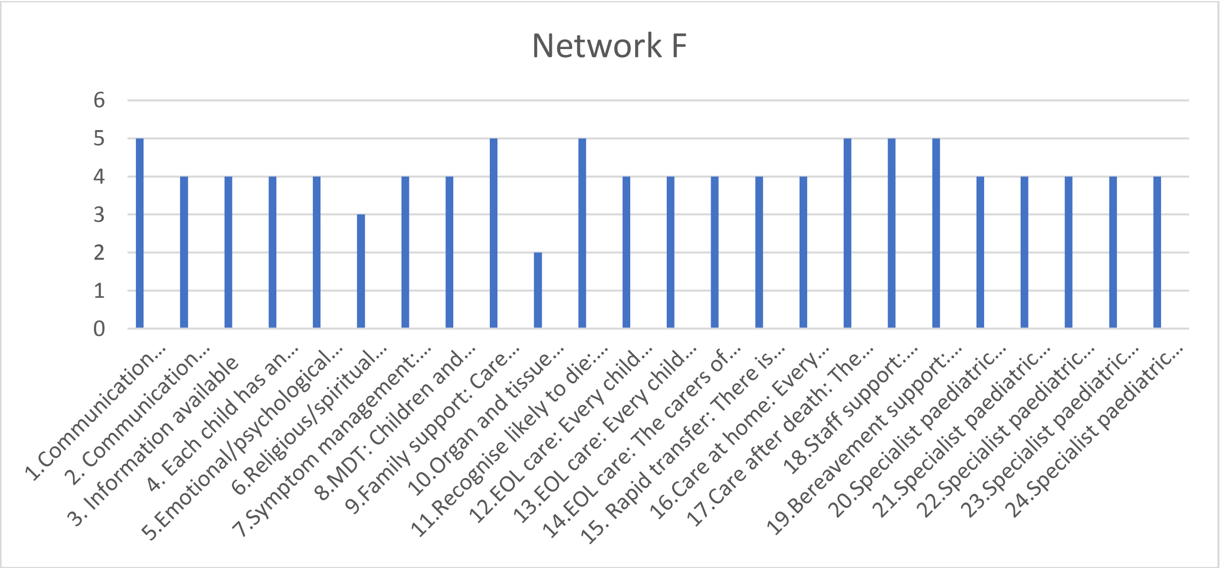
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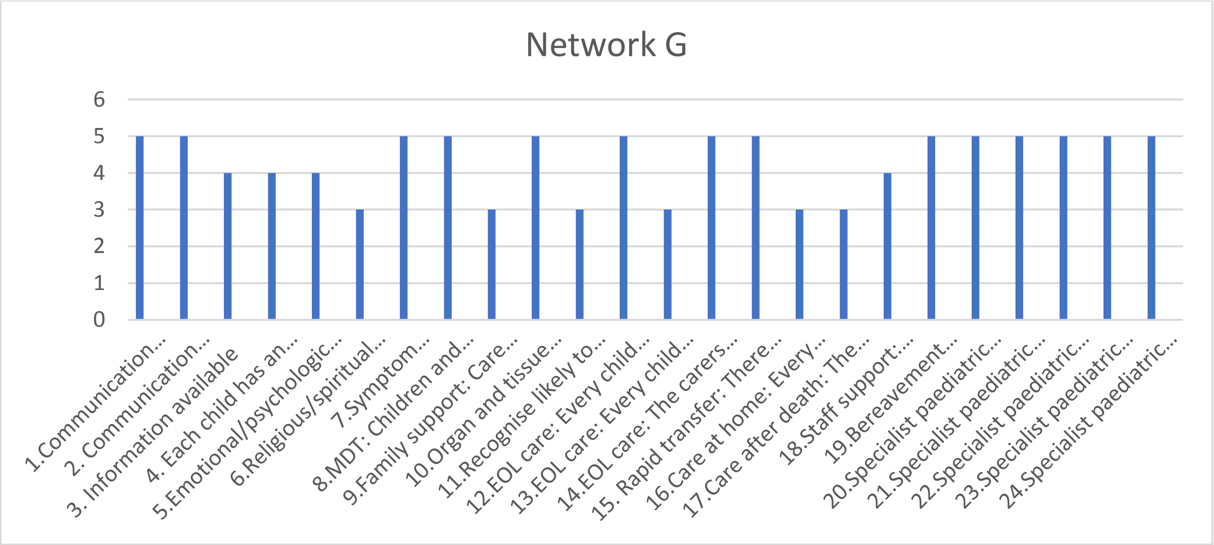
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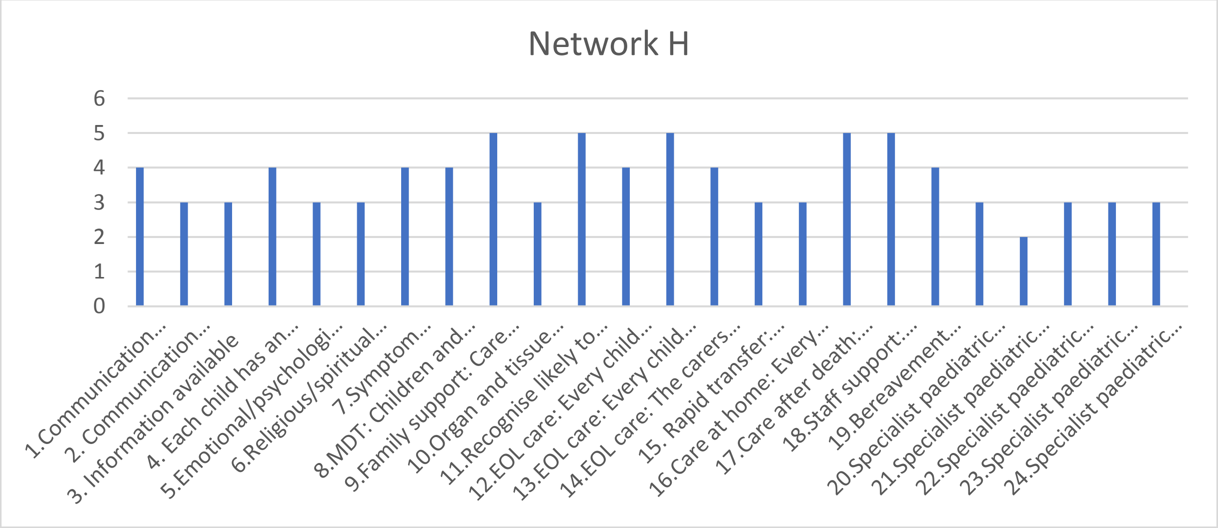
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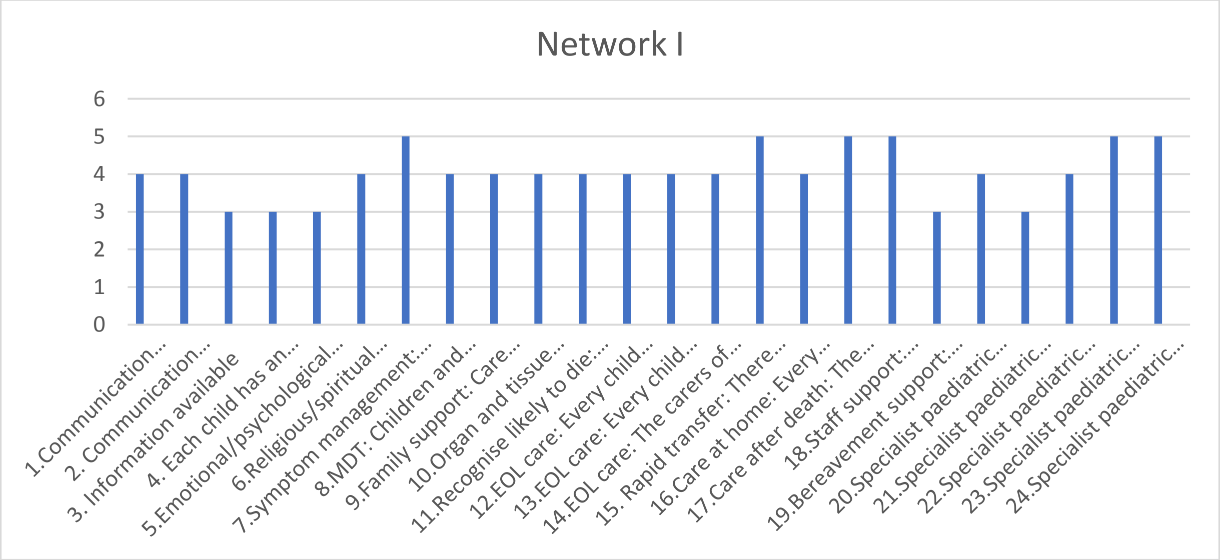
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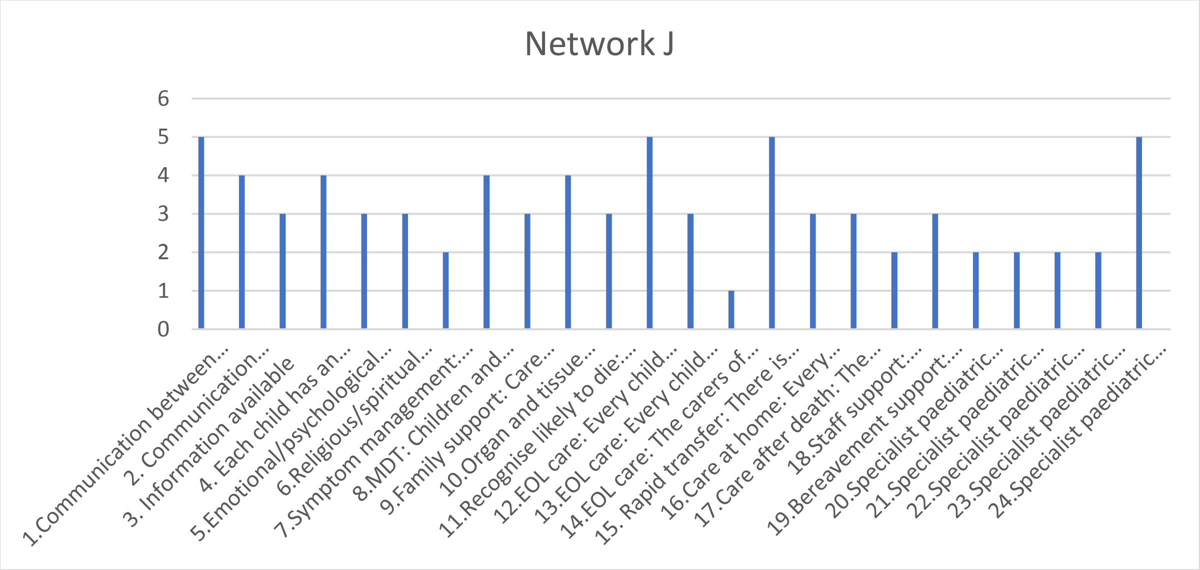
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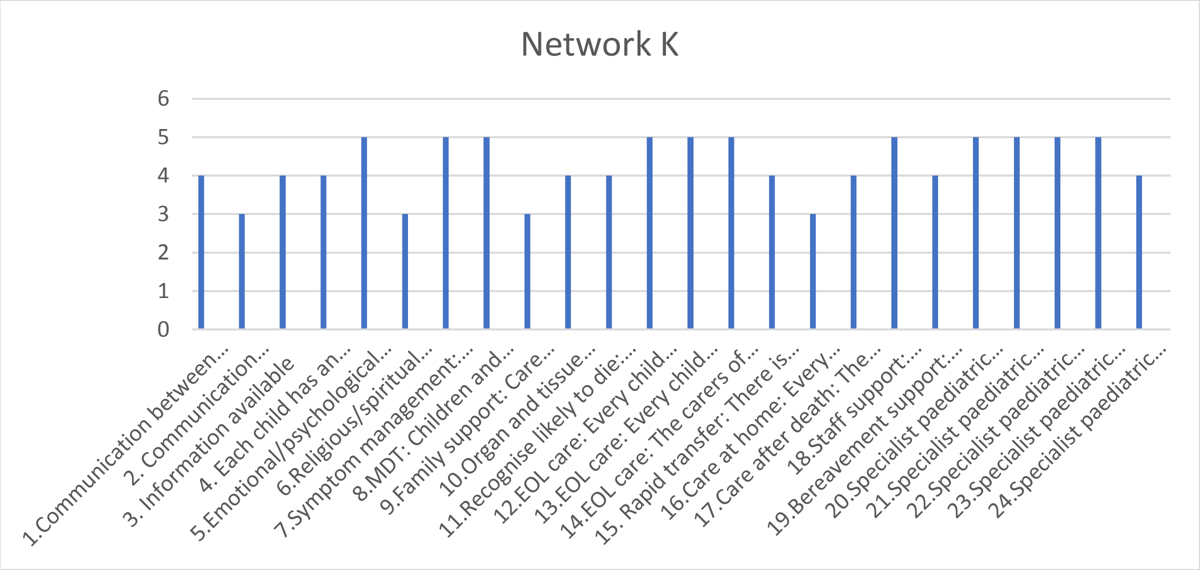
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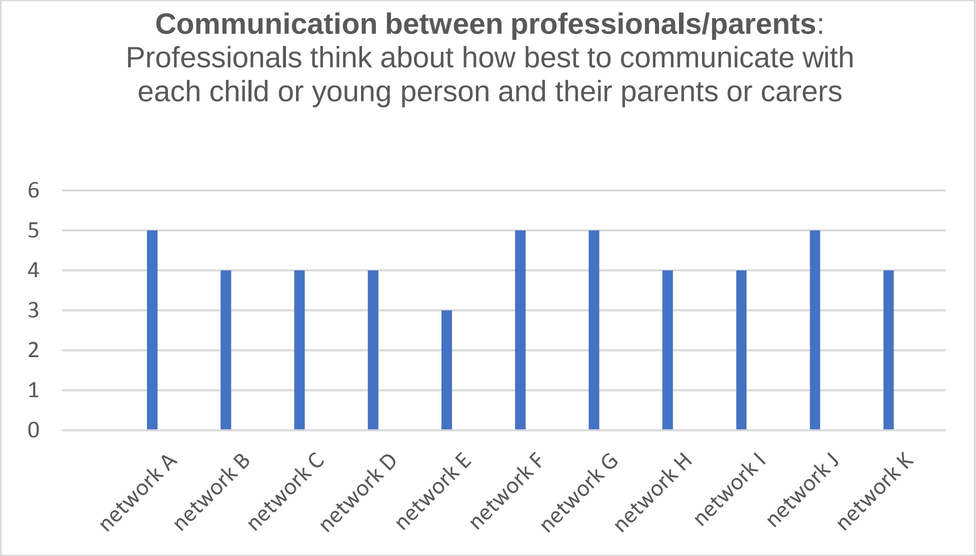
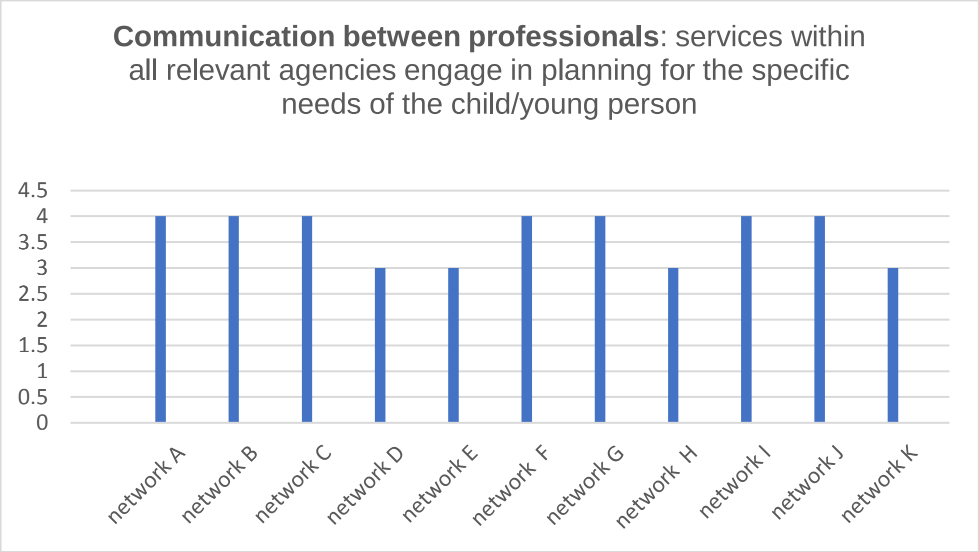
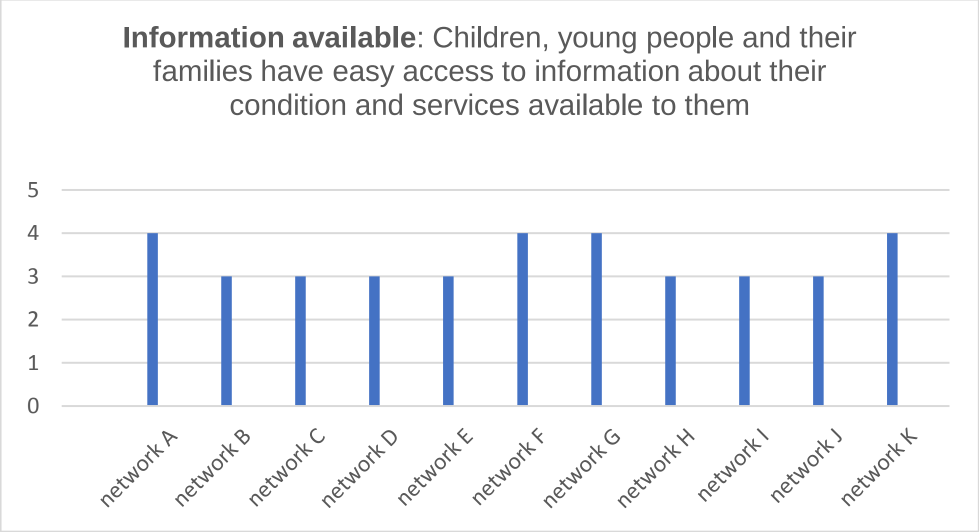
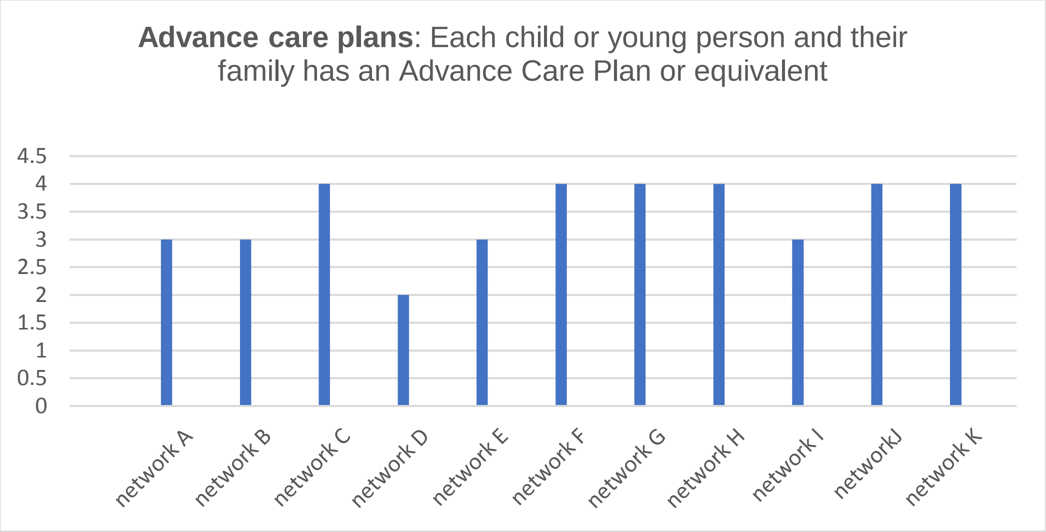
Appendix 4 Network Responses to Questions

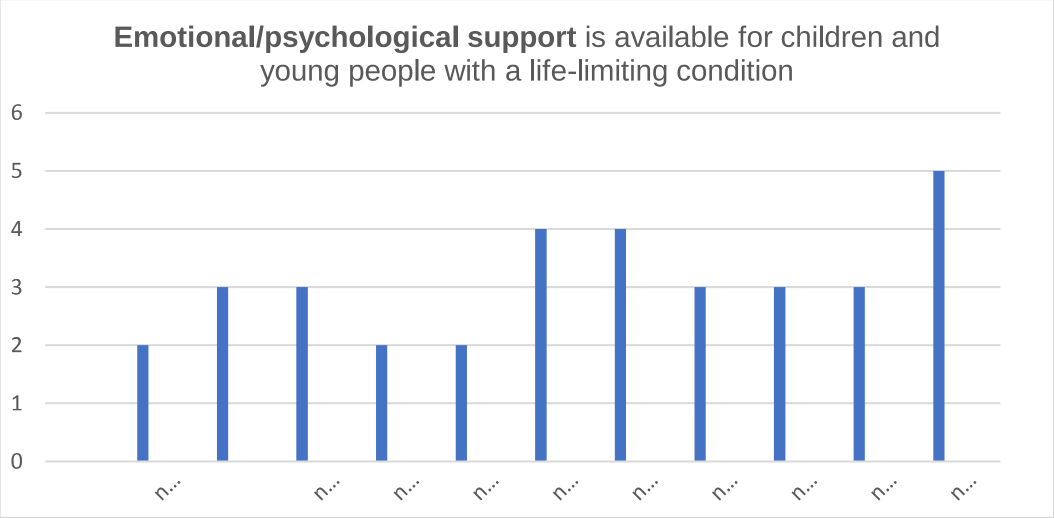
Scoring :- 1=never, 2= rarely, 3= sometimes, 4= usually, 5= always.

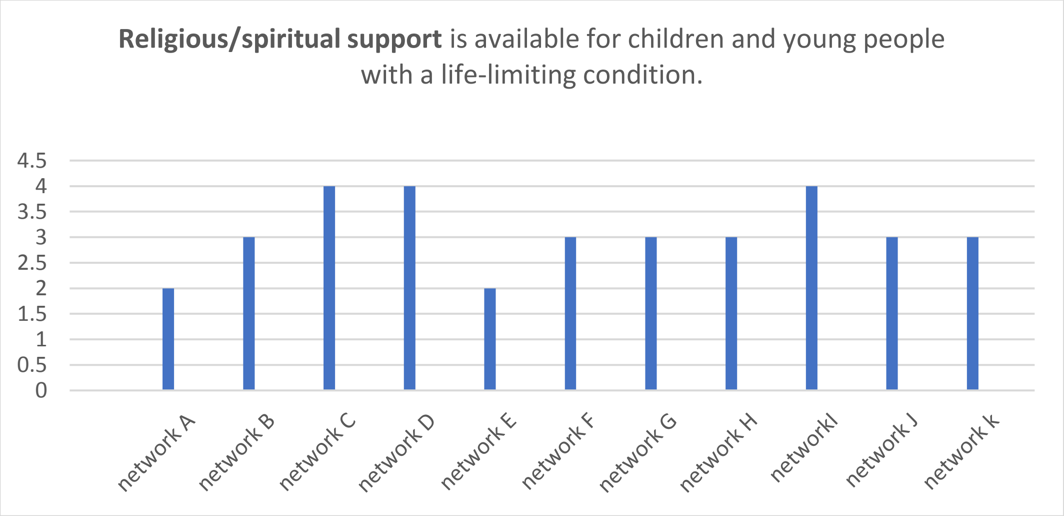

Communication between professionals/parents: Professionals think about how best to communicate with each child or young person and their parents or carers

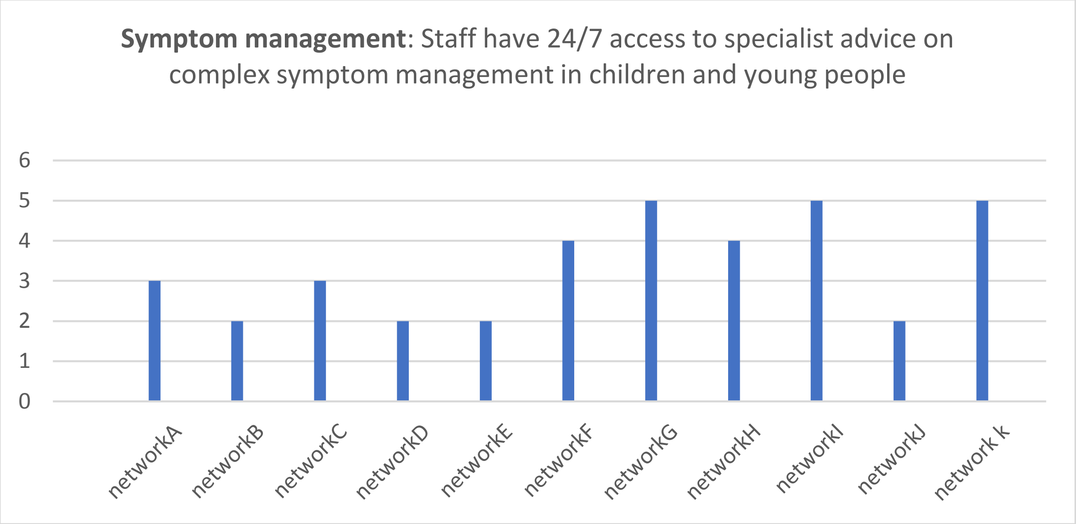

Communication between professionals: services within all relevant agencies engage in planning for the specific needs of the child/young person

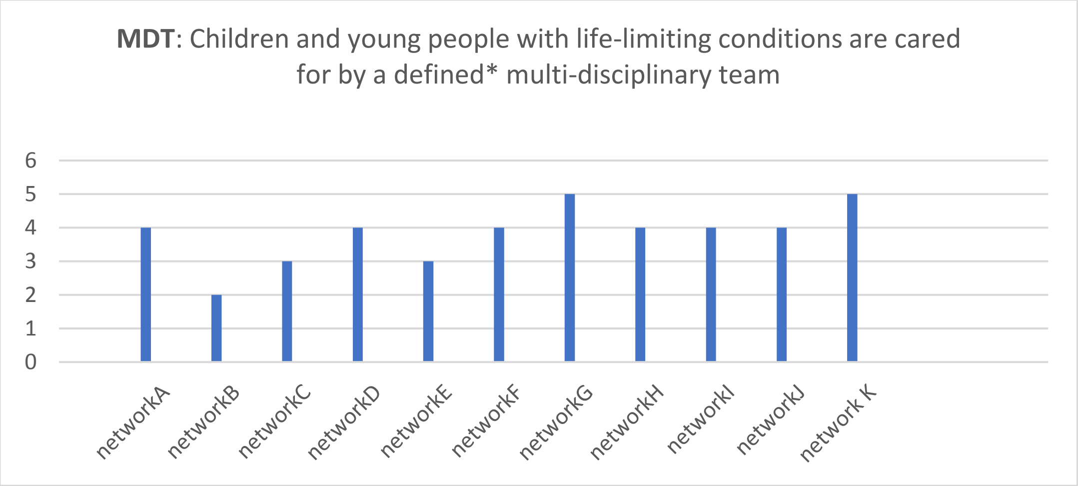

Information available: Children, young people and their families have easy access to information about their condition and services available to them

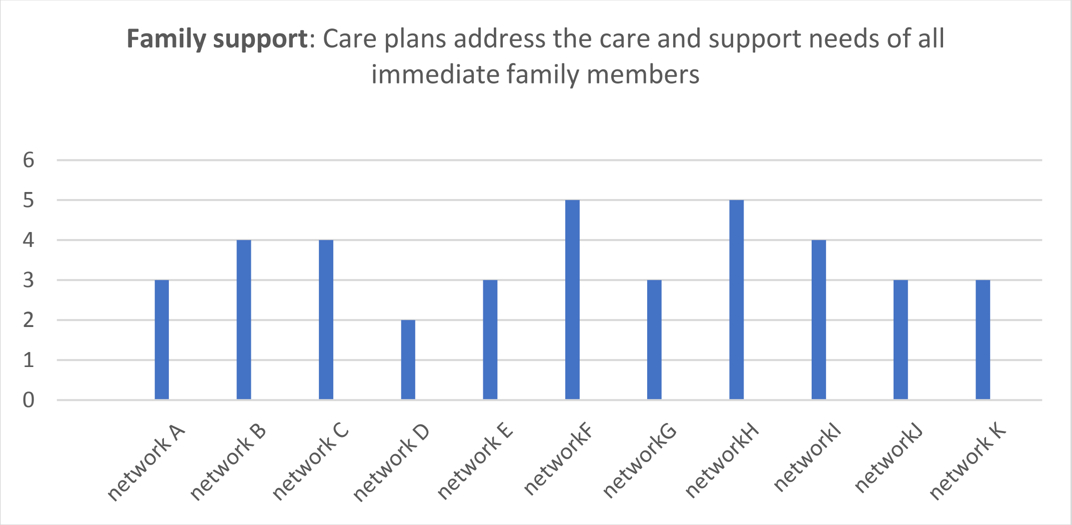

Advance care plans: Each child or young person and their family has an Advance Care Plan or equivalent

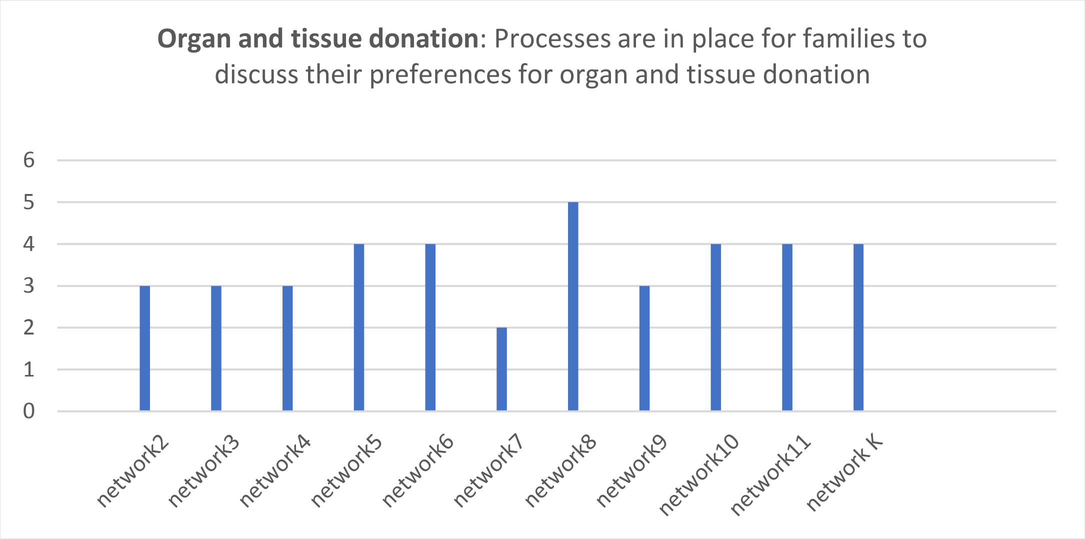

Emotional/psychological support is available for children and young people with a life-limiting condition


Religious/spiritual support is available for children and young people with a life-limiting condition.

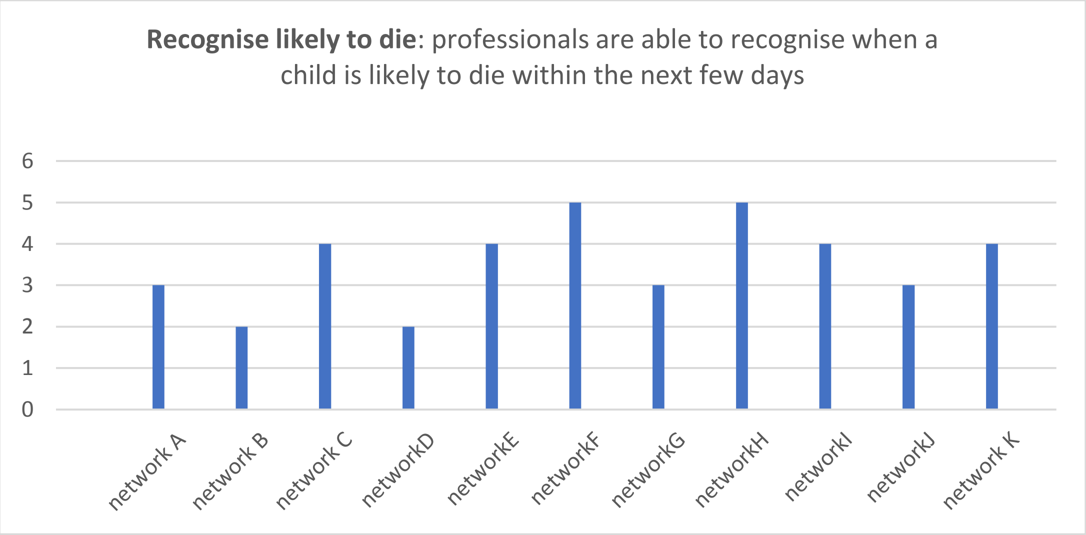

Symptom management: Staff have 24/7 access to specialist advice on complex symptom management in children and young people


MDT: Children and young people with life-limiting conditions are cared for by a defined* multi-disciplinary team

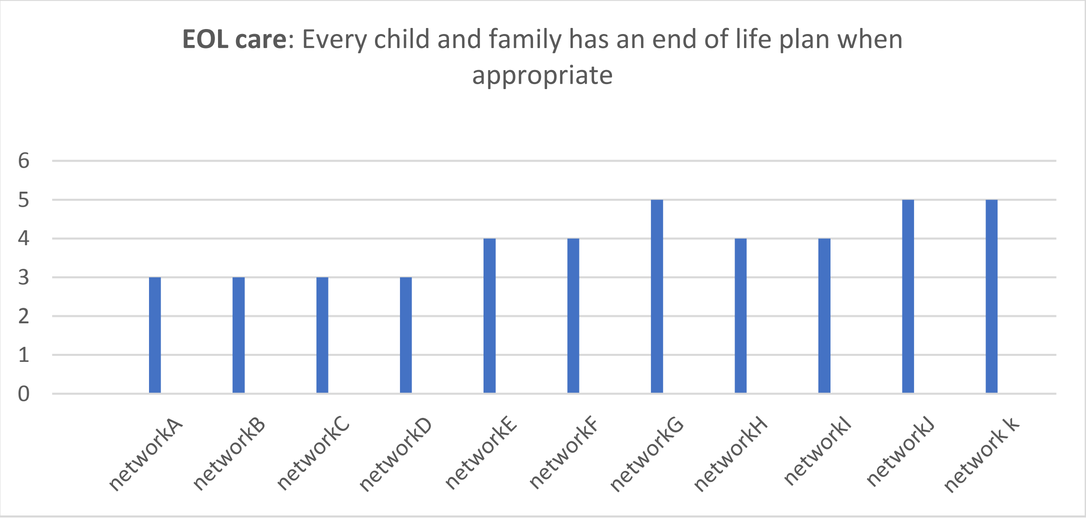

Family support: Care plans address the care and support needs of all immediate family members



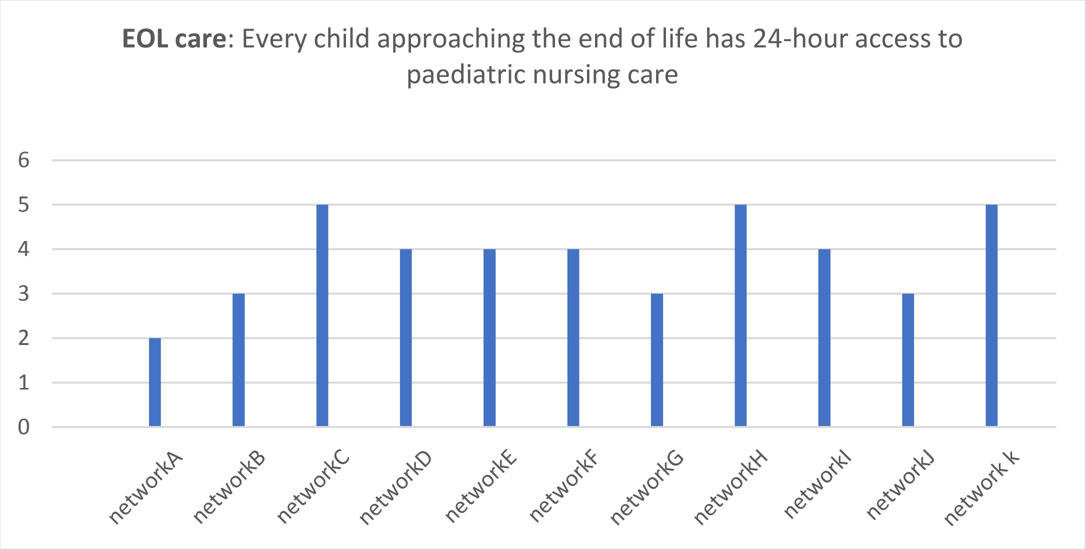
Organ and tissue donation: Processes are in place for families to discuss their preferences for organ and tissue donation

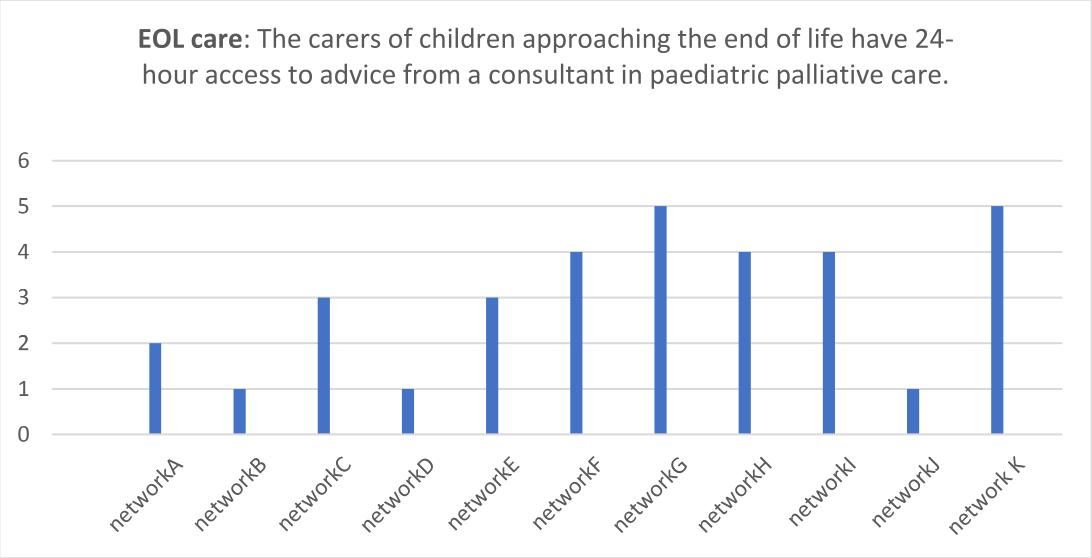


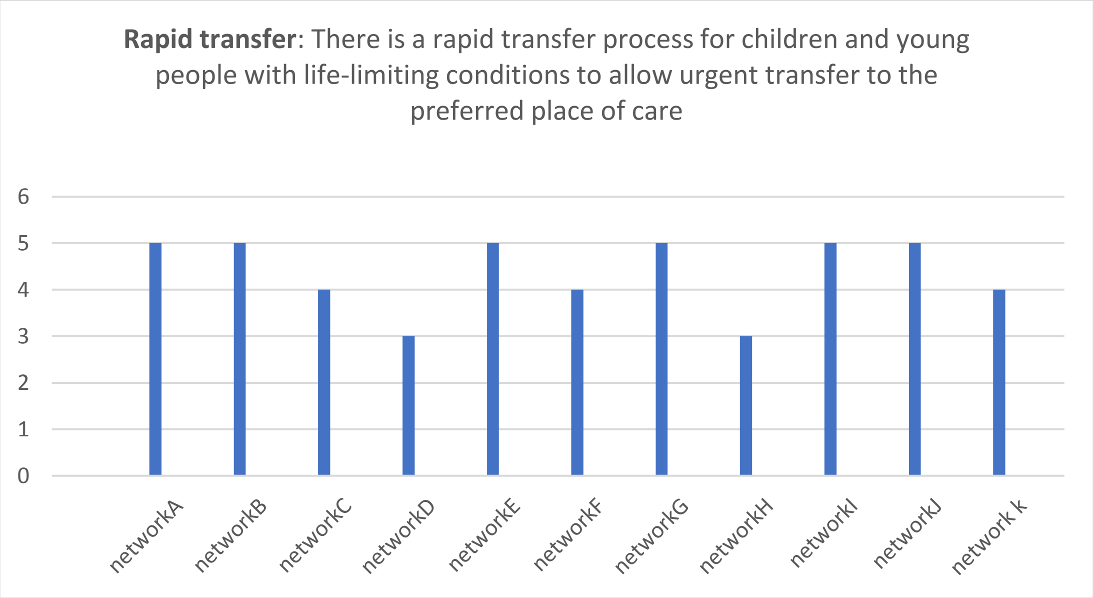
Recognise likely to die: professionals are able to recognise when a child is likely to die within the next few days

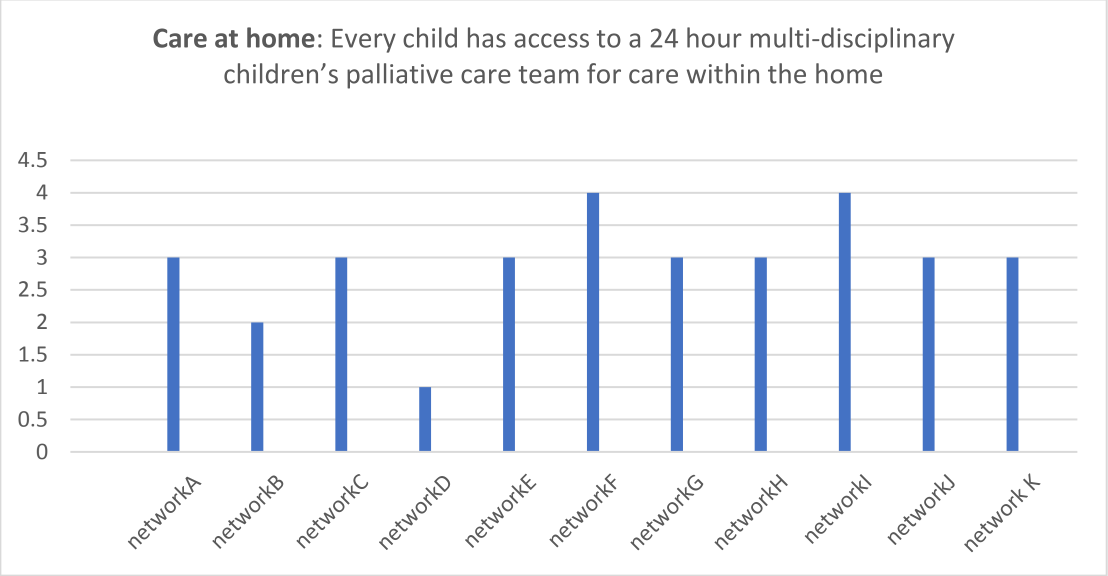


EOL care: Every child and family has an end of life plan when appropriate

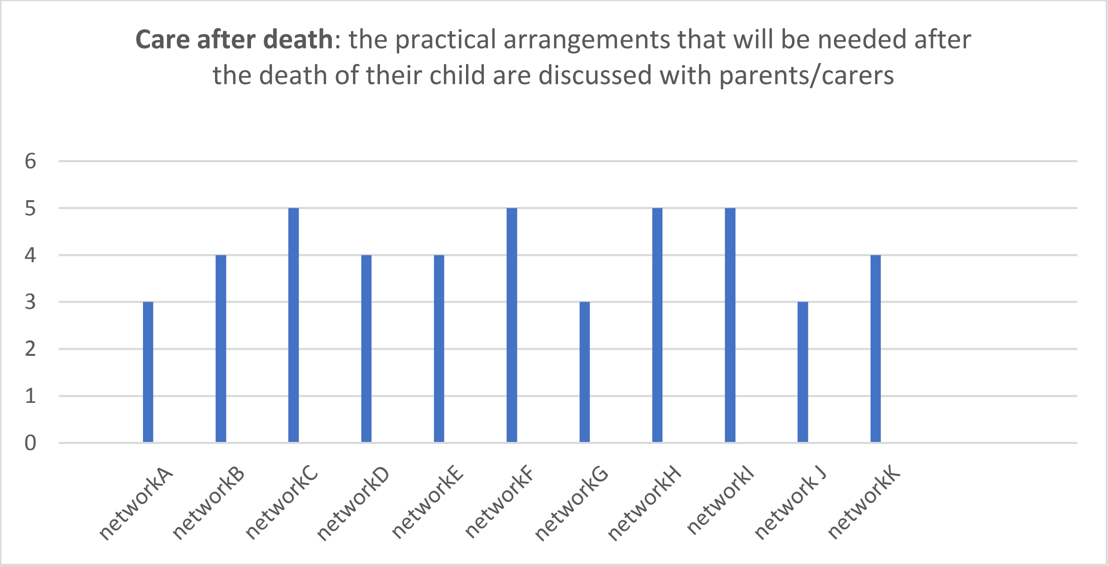

EOL care: Every child approaching the end of life has 24-hour access to paediatric nursing care


EOL care: The carers of children approaching the end of life have 24-hour access to advice from a consultant in paediatric palliative care.

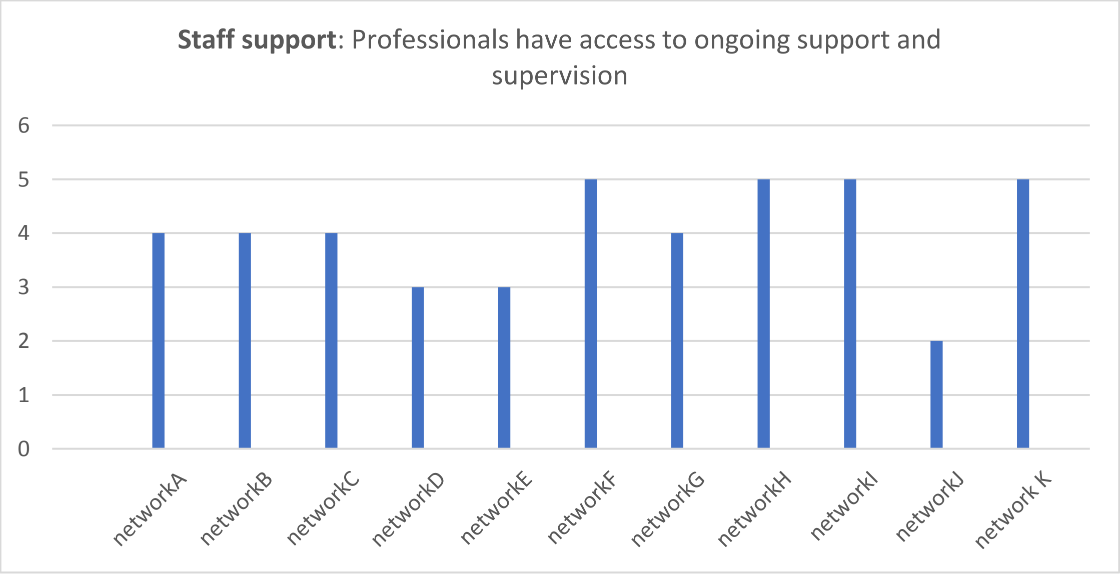

Rapid transfer: There is a rapid transfer process for children and young people with life-limiting conditions to allow urgent transfer to the preferred place of care



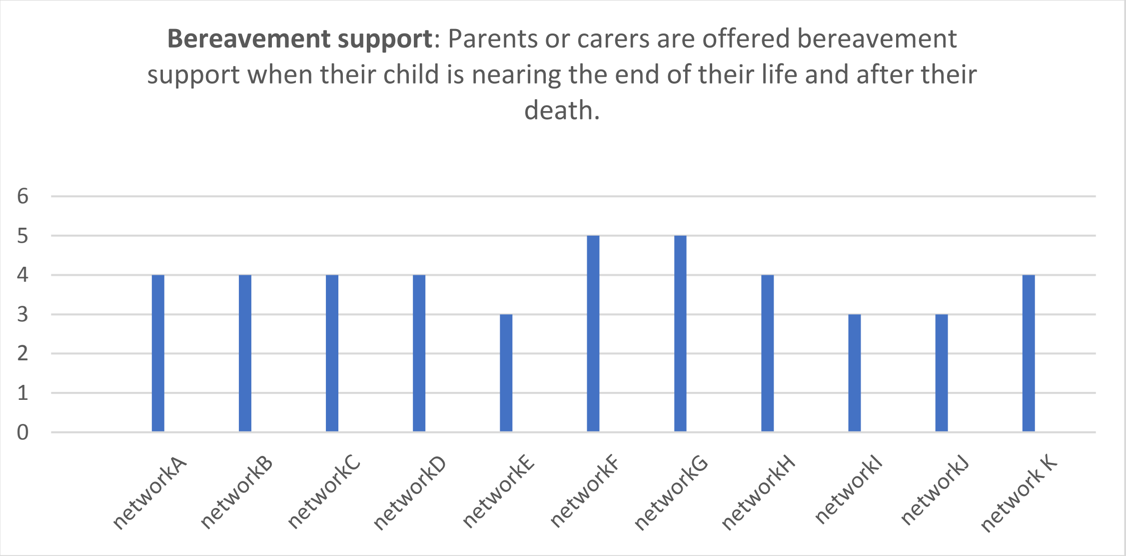
Care at home: Every child has access to a 24 hour multi-disciplinary children's palliative care team for care within the home

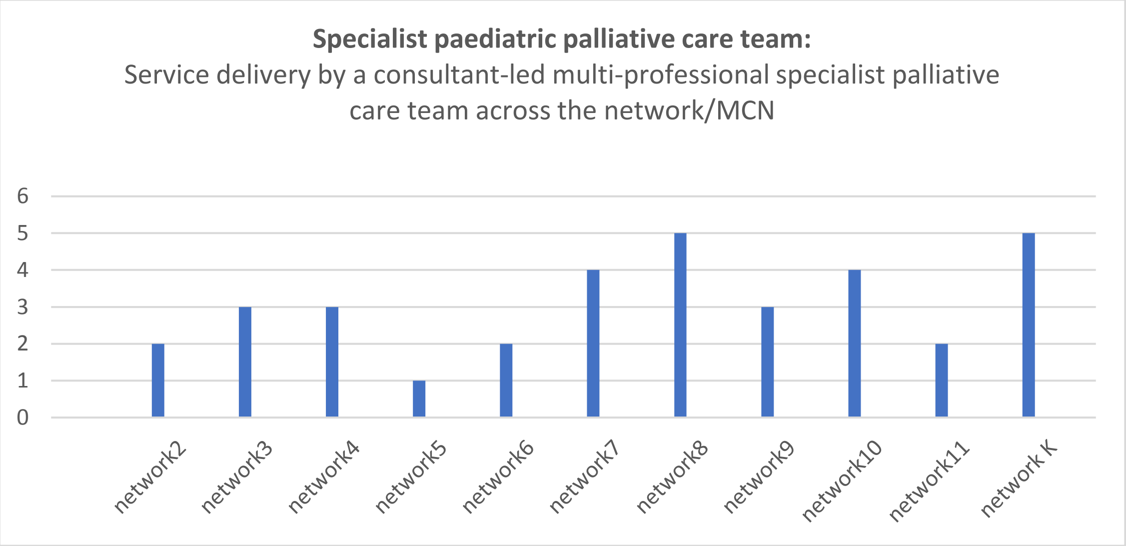


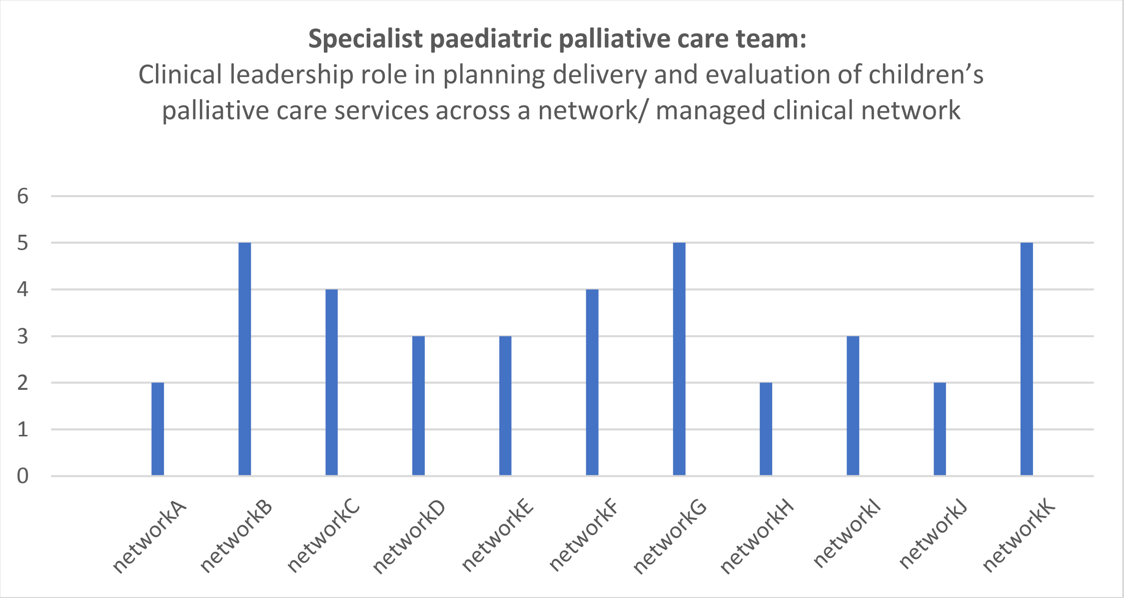
Care after death: the practical arrangements that will be needed after the death of their child are discussed with parents/carers

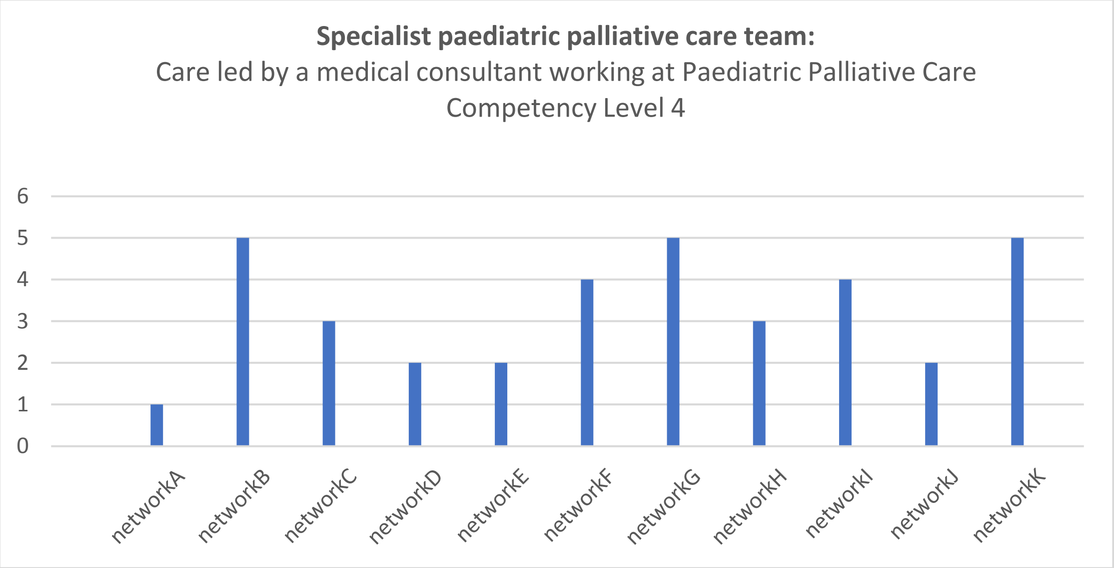


Staff support: Professionals have access to ongoing support and supervision

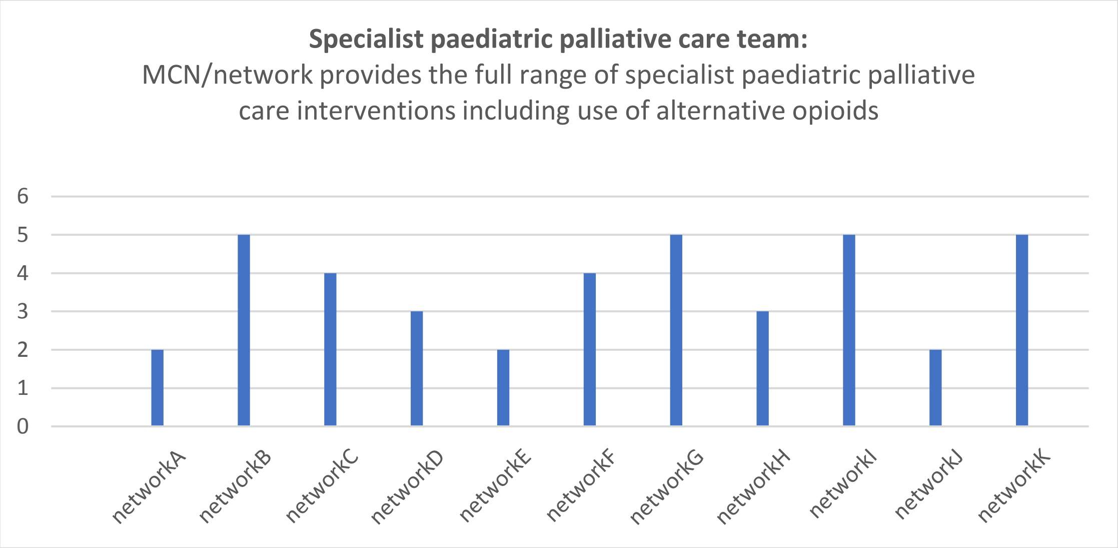

Bereavement support: Parents or carers are offered bereavement support when their child is nearing the end of their life and after their death.


Specialist paediatric palliative care team:
Service delivery by a consultant-led multi-professional specialist palliative care team across the network/MCN

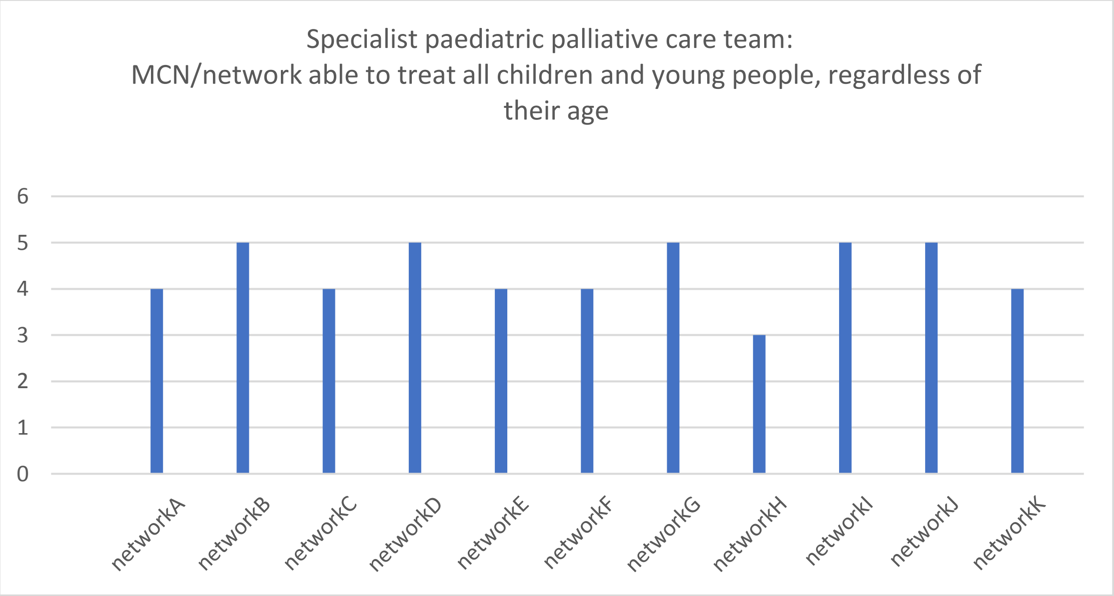

Specialist paediatric palliative care team:
Clinical leadership role in planning delivery and evaluation of children's palliative care services across a network/ managed clinical network



Specialist paediatric palliative care team:
Care led by a medical consultant working at Paediatric Palliative Care Competency Level 4



Specialist paediatric palliative care team:
MCN/network provides the full range of specialist paediatric palliative care interventions including use of alternative opioids



Specialist paediatric palliative care team:
MCN/network able to treat all children and young people, regardless of their age

Appendix 5

	Question	Results	Commentary
1	Communication between professionals/parents: Professionals think about how best to communicate with each child or young person and their parents or carers.	Always 4 Usually 6 Sometimes 1 Rarely 0 Never 0	One area thought this happens 'sometimes', ten areas said it 'usually' or 'always' happens.
2	Communication between professionals: Services within all relevant agencies engage in planning for the specific needs of the child/young person.	Always 0 Usually 8 Sometimes 3 Rarely 0 Never 0	All the networks thought they at least sometimes achieved this.
3	Information available: Information is available to children, young people and their families have easy access to information about their condition and services.	Always 0 Usually 4 Sometimes 7 Rarely 0 Never 0	Most of the networks thought the information was only sometimes available. Some mentioned having a service directory.
4	Advance care plans: Each child or young person and their family has an Advance Care Plan or equivalent.	Always 0 Usually 7 Sometimes 4 Rarely 0 Never 0	Several respondents said that there was a variance because not every family wants an ACP – it's an individual family's choice.
5	Emotional/psychological support Emotional / psychological support is available for children and young people with a life-limiting condition.	Always 1 Usually 3 Sometimes 5 Rarely 2 Never 0	Responses varied, with some saying how difficult it was to access psychology support and others saying that although it was always available information might not be shared or referrals might not be made.

6	Religious/spiritual support Religious/spiritual support is available for children and young people with a life-limiting condition.	Always 1 Usually 2 Sometimes 7 Rarely 1 Never 0	Most of the teams can ‘sometimes’ access religious or spiritual support for the children, but there was variation in the degree to which information about religious/spiritual support is passed on.
7	Symptom management: Staff have 24/7 access to specialist advice on complex symptom management in children and young people.	Always 3 Usually 2 Sometimes 2 Rarely 2 Never 2	The answers to this question were split 5 ways. There were several comments about how patchy symptom management advice is, depending on the specialist knowledge available in the area. Some areas always have access to advice when the child is at end of life, others only had this during office hours. A few areas are covered by an on-call rota. Some areas had a level 4 consultant, but they were not always available 365 days a year.
8	Multi-disciplinary team: Children and young people with life-limiting conditions are cared for by a defined multi-disciplinary team.	Always 3 Usually 5 Sometimes 2 Rarely 1 Never 0	Most networks reported that children are cared for by a defined multidisciplinary team.
9	Family support: Care plans address the care and support needs of all immediate family members.	Always 2 Usually 4 Sometimes 5 Rarely 0 Never 0	Most networks would ‘sometimes’ or ‘usually’ address the care needs of all family members, although there were some comments about this not being consistent.
10	Organ and tissue donation: Processes are in place for families to discuss their preferences for organ and tissue donation	Always 1 Usually 5	Most networks have a process in place but is dependent on the practitioner accessing it.

		Sometimes 4 Rarely 1 Never 0	When the process is offered, the take up is variable.
11	**Recognise a child is likely to die:** Professionals are able to recognise when a child is likely to die within the next few days.	Always 2 Usually 6 Sometimes 2 Rarely 1 Never 0	The answers to this question were mixed. One respondent commented that there was inconsistency in the ability to recognise that a child is soon likely to die.
12	**EOL care plan:** Every child and family has an end of life plan when appropriate.	Always 1 Usually 6 Sometimes 4 Rarely 0 Never 0	Most children will have an end of life care plan in place, but it can be inconsistent and dependent on who is leading the care. Sometimes the conversation happens but it is not documented.
13	**24-hour access to nursing for EOL care:** Every child approaching the end of life has 24-hour access to paediatric nursing care.	Always 4 Usually 2 Sometimes 4 Rarely 0 Never 0	1 network did not reply to this question. Although most children will have access to paediatric nursing care, there were concerns about whether this question related to community children's nurses or children's nurses in other settings. There are a few areas with no community children's nurses. Most areas cannot offer 24/7 CCN services. However, children's nurses were accessible via hospitals or hospices.
14	**24-hour access to a consultant for EOL care:** The carers of children approaching the end of life have 24-hour access to advice from a consultant in paediatric palliative care.	Always 2 Usually 3 Sometimes 2 Rarely 1 Never 3	This question drew a response of 'never' or 'rarely' from 4 networks. There was often due to having no level 4 consultant in the region. Even where consultant level advice was 'usually' or 'sometimes' available, it was from a level 3 consultant with an interest in CPC. There were some areas with one

			level 4 consultant, which means that covering 365 days a year is only provided on good will, with consultants often taking mobiles on holiday, even to Europe with them, to offer this advice and support. Only in very few areas is there a rota of more than 1 level 4 consultant.
15	Rapid transfer: There is a rapid transfer process for children and young people with life-limiting conditions to allow urgent transfer to the preferred place of care.	Always 5 Usually 4 Sometimes 1 Rarely 0 Never 1	Most areas have a process in place for rapid transfer, but it is not always put into practice. A few areas do not have a formal process but will arrange the transfer on an individual basis.
16	Care at home: Every child has access to a 24-hour multi-disciplinary children's palliative care team for care within the home.	Always 0 Usually 2 Sometimes 6 Rarely 1 Never 2	Most networks are 'rarely' or only 'sometimes' able to provide 24-hr care within the home across their region. Respondents mentioned a range of issues: the cuts being made to CCNs; the disparity in service levels for children with cancer and non-cancer conditions; that care at home is only available at end of life and that this can only be provided if the end of life phase is recognised; care at home is not commissioned separately so is provided within the core service; most CCN services don't have capacity to sustain 24/7 for any length of time and usually cannot provided it for more than 1 child at any one time (with a huge impact on core CCN services); even with funding for this in place services are reliant on managers agreeing that it can happen.
17	Care after death:	Always 4	Most parents/carers will be offered discussions about

	The practical arrangements that will be needed after the death of their child are discussed with parents/carers.	Usually 5 Sometimes 2 Rarely 0 Never 0	care after death and some teams have debriefs set up to review the advice given.
18	Staff support: Professionals have access to ongoing support and supervision.	Always 4 Usually 4 Sometimes 2 Rarely 1 Never 0	Most staff are given the option of ongoing support and supervision, if they choose to access it.
19	Bereavement support: Parents or carers are offered bereavement support when their child is nearing the end of their life and after their death.	Always 2 Usually 5 Sometimes 4 Rarely 0 Never 0	Although most parent/carers can usually access bereavement support, it is very variable, even within regions. It has been described as a postcode lottery with long waiting lists. Some CCN teams maintain links to bereavement services. There are gaps in bereavement support for carers such as care assistants.
20 a	**Specialist paediatric palliative care team:** Service is delivered by a consultant-led multi-professional specialist palliative care team across the network/MCN.	Always 2 Usually 2 Sometimes 3 Rarely 3 Never 1	This was a wide variation between areas with a level 4 CPC consultant and those without. Some of those without this reported that they never had access, or that parts of their region had services led by a level 3 consultant with an interest in CPC.
20b	**Specialist paediatric palliative care team:** There is a clinical leadership role in planning delivery and evaluation of children's palliative care services across a network/ managed clinical network.	Always 3 Usually 2 Sometimes 3 Rarely 3 Never 0	The responses to this question were on the whole more positive as the clinical leadership role was evident across the network. However, it was patchy across regions, and one respondent said the clinical leadership role in their region

			is funded by a charity and so is sustainable.
20c	**Specialist paediatric palliative care team:** Care is led by a medical consultant working at Paediatric Palliative Care Competency Level 4.	Always 3 Usually 2 Sometimes 3 Rarely 2 Never 1	These results are similar to those in 20a. There may be some confusion about what a level 4 consultant is and the whether they cover a whole or just part of a region. Also, in regions where there is only one level 4 consultant, they may not always be able to provide cover due to A/L etc.
20d	**Specialist paediatric palliative care team:** The MCN/network provides the full range of specialist paediatric palliative care interventions, including use of alternative opioids.	Always 3 Usually 4 Sometimes 1 Rarely 3 Never 0	In many areas this depends on whether there was a level 4 consultant to refer to, or a level 3 with considerable experience. There may be different provision for oncology.
20e	**Specialist paediatric palliative care team:** The MCN/network is able to treat all children and young people, regardless of their age.	Always 6 Usually 4 Sometimes 1 Rarely 0 Never 0	Most areas now cover neonates and children up to 19 years. There are issues in some areas about nursing care for 16-18yr olds, especially in the community because of the gap between the age criteria for commissioned CCN services and district nursing services.

Annex 6

Commissioning children's palliative care in England report

This annex is an excerpt from Together for Short Lives' 'Commissioning children's palliative care in England: 2017 edition' report. This report sets out the findings of a series of freedom of information requests that Together for Short Lives issued to each clinical commissioning group (CCG) in June 2017. The excerpt below sets out how CCGs responded when they were asked about whether they were implementing:

- 'Our Commitment to you for end of life care: The Government Response to the Review of Choice'

- the NICE clinical guideline on 'End of life care for infants, children and young people with life-limiting conditions.

The full report is available on the Together for Short Lives website.

Are CCGs implementing 'Our Commitment to you for end of life care: The Government Response to the Review of Choice' for children and young people with life-limiting and life-threatening conditions?

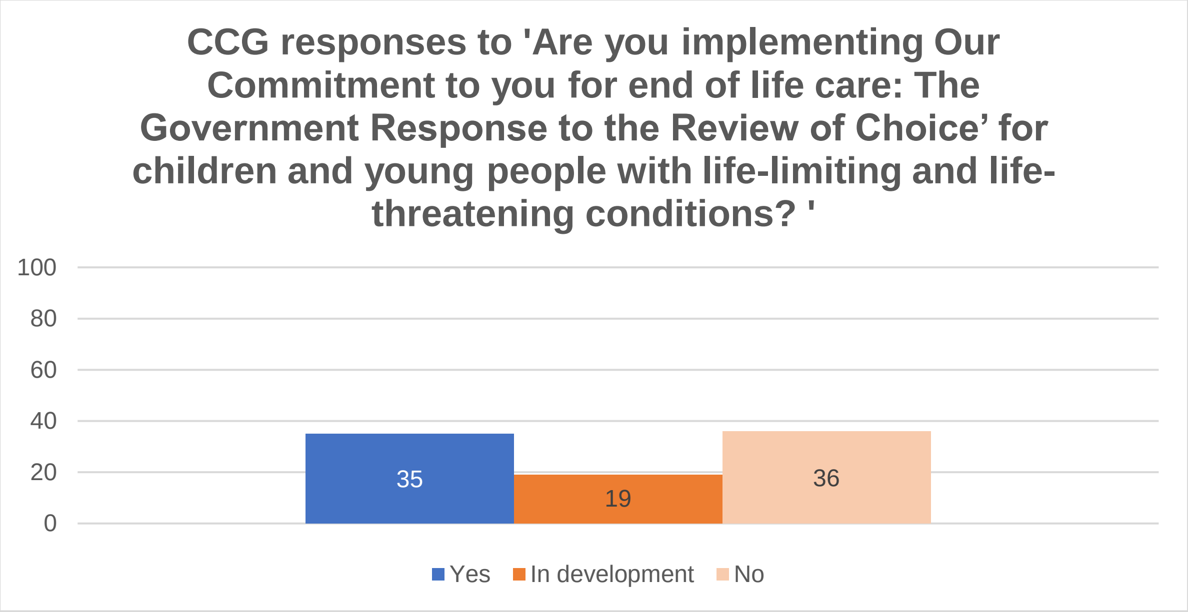
The government's response to the Choice Review states that:

'To support high quality personalised care for children and young people, commissioners and providers of services must prioritise children's palliative care in their strategic planning so that services can work together seamlessly and advance care planning can be shared and acted upon.

Commissioners should also consider how they can structure services that offer accessible, high quality respite and bereavement support for children and their families.'

Despite this, only a third (35%) of CCGs responded that they are implementing this guidance, while a further 19% stated that their plans to do so are in development.

This means that almost half (46%) of CCGs are failing to implement the government's end of life care choice commitment to children and have no plans to do so.



Are CCGs implementing the NICE clinical guideline 'End of life care for infants, children and young people with life-limiting conditions: planning and management'?

The NICE 'End of life care for infants, children and young people with life-limiting conditions' guideline states:

'Local commissioners and providers of healthcare have a responsibility to enable the guideline to be applied when individual professionals and people using services wish to use it.'[9]

Despite this, only three in ten (31%) CCGs state that they are currently implementing this guidance, while a further 27% responded that their plans to do so are in development.

Although many CCGs responded that it is down to individual providers of health and social care implement the guideline, this contradicts the government's position. In March 2017, Lord Carlile of Berriew submitted a written question in Parliament:

"To ask Her Majesty's Government what steps they will take to ensure that Clinical Commissioning Groups are accountable to NHS England for delivering a consistent level of children's palliative care across England."[10]

The minister's response to this was that:

"NHS England expects clinical commissioning groups to commission services in accordance with National Institute for Health and Care Excellence guideline End of life care for infants, children and young people with life-limiting conditions"

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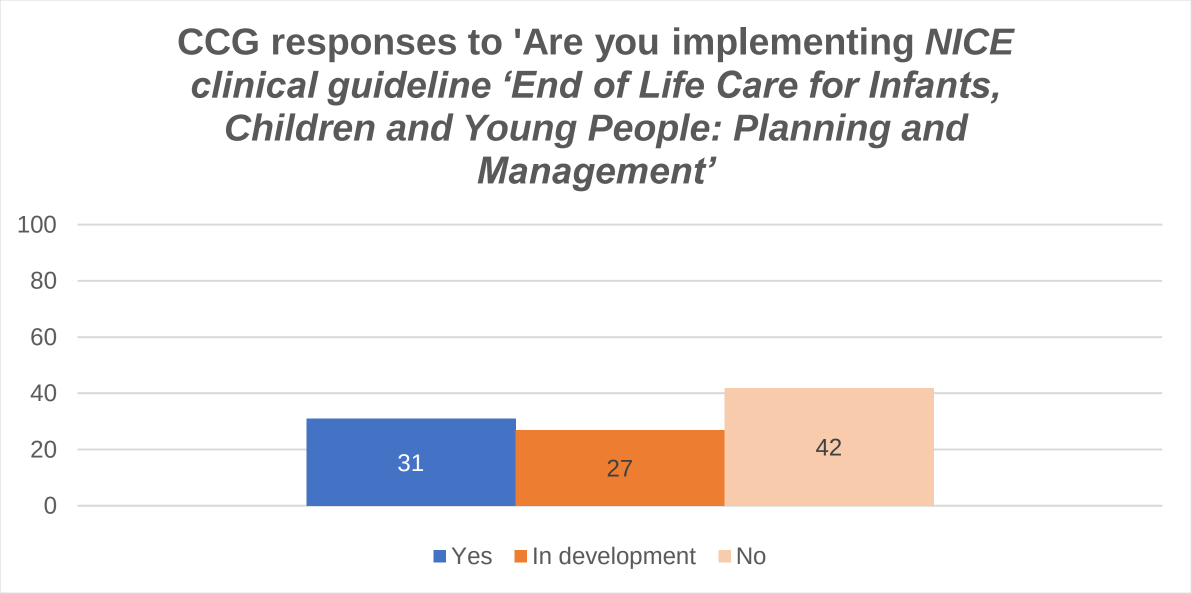
[9] NICE (2016). End of life care for infants, children and young people with life-limiting conditions: planning and management. Available at: http://bit.ly/2g9nIWA

[10] Hansard (2017). Oral Question HL6151 from Lord Carlile of Berriew. Asked on 16 March 2017. Available at: http://bit.ly/2xQvAtH


CCG responses to 'Are you implementing *NICE clinical guideline 'End of Life Care for Infants, Children and Young People: Planning and Management'*
100
80
60
40
20
0
31
27
42
Yes
In development
No