

24/7 access to children's palliative care in England



Key standards for seriously ill children and their families and how they are met round the clock.

May 2022



A report by Together for Short Lives.

#EVERYDAYEVERYNIGHT

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Foreword

Hearing the news that your child has a life-limiting condition and is going to die young is a parent's worst nightmare. These children often have very complex and unpredictable needs. Families have to provide highly skilled, clinical care to their child at home, throughout the day and night, all the while coming to terms with the knowledge that their child will die before them. They do so with very little sleep, while also having to meet the needs of their other children.

These families are supported by brilliant services and professionals, in hospitals, voluntary sector settings such as children's hospices and at home. But many of these services at breaking point, neither commissioned nor consistently funded by NHS and local authorities.

The government and NHS England (NHSE) have made some welcome progress in recent years:

- The Health and Care Act 2022 includes a duty on integrated care boards (ICBs) to commission palliative care as they consider appropriate for meeting the reasonable requirements of the people for whom they are responsible.
- The NHS Long Term Plan commits NHSE to match up to £7million of clinical commissioning group (CCG) funding for children's palliative care by 2023/24.
- NHSE is increasing the Children's Hospice Grant to £25million by 2023/24 and ringfence this money specifically for children's hospices.
- NHSE is funding a dedicated children and young people's palliative care lead in each of the seven strategic clinical network (SCN) regions in England.
- In April 2020, the government's Emergency Coronavirus Fund for charities included a commitment of £200million for hospices, including children's hospices. This was followed by an additional £125million until March 2021 to secure additional hospice capacity and up to £148million for the period December 2021-March 2022 to secure and increase NHS capacity to enable hospital discharge.

Together for Short Lives has examined the extent to which the National Institute for Health and Clinical Excellence's (NICE) children's palliative care standards are being met across England. We wanted to provide information that the NHS and other decision makers could use to better plan, fund and fill the gaps in children's palliative care across the country.

Worryingly, we have found the extent to which seriously ill children and their families can access palliative care services which achieve the NICE standards depends on where they live. We are particularly concerned about children and families' access to end of life care at home, 24 hours a day, seven days a week, provided by professionals who have access to specialist advice to help them meet complex needs. We have identified a series of barriers, including a £2.3million annual funding gap in education and training and a £301million annual funding gap for services. These all need to be overcome to help make sure seriously ill children and their families can access the palliative care they need.

We have also identified a number of recommended policy actions that we urge the government, NHSE and others to take to overcome these barriers. If these actions are not taken now, more seriously ill children and their families will be unable to make meaningful care choices, particularly at end of life, as the number of cases of life-limiting and life-

threatening conditions in children increases. ICBs will not be able to meet their new legal duty. And the NHS will waste money unnecessarily.

Seriously ill children do not have time to wait. We welcome the Prime Minister's determination to level up the country for everyone, including disabled people. To build back better and fairer for all from the COVID-19 pandemic, his government must bring about sustainable, 24/7 children's palliative care for seriously ill children, for whom time is short.

Andy Fletcher
Chief Executive
Together for Short Lives

Executive Summary

- The UK Government, NHS England and NHS Improvement (NHSE/I) and the National Institute for Health and Care Excellence (NICE) have published a number of clear policies which provide an imperative for providing palliative care to seriously ill children and their families. These are clear that:
 - children and young people with a life-limiting condition and their parents or carers should have the opportunity to develop an advance care plan
 - children with a life-limiting condition should have a named professional who leads and coordinates their care
 - children with a life-limiting condition and their parents or carers should be given information about emotional and psychological support, including how to access it
 - children with a life-limiting condition should be cared for by a multidisciplinary team that includes members of the specialist paediatric palliative care team
 - parents or carers of children approaching the end of life should be offered support for grief and loss when their child is nearing the end of their life and after their death
 - children approaching the end of life and being cared for at home should have 24-hour access to both children's nursing care and advice from a consultant in paediatric palliative care.
- Worryingly, our mapping work, carried out in 2021, found that the extent to which seriously ill children and their families can access services which achieve these standards is very patchy and depends on where they live. Of particular concern is children and families' access to **end of life care at home, 24 hours a day, seven days a week**, provided by nurses and supported by advice from consultant paediatricians who have completed sub-specialty training in paediatric palliative medicine (also known as GRID training). While this standard is met in just over half (54%) of local authority areas in England during normal working hours, it is not being met four fifths (81%) of local authority areas 24/7. **This means that the 24/7 standard is not being met in nearly four fifths (79%) of integrated care system (ICS) areas.** It is only being met fully in three ICS areas (7%). It is being partially met in six (14%) ICS areas.
- There is inconsistency between what is commissioned and what is provided. Just a third (33%) of NHS clinical commissioning groups (CCGs) in England have a service specification which states that infants, children and young people approaching the end of life and being cared for at home should have 24-hour access to both children's nursing care and advice from GRID-trained specialist paediatric palliative medicine consultants.
- This means that CCGs in just under a fifth (19%) of ICS areas have a specification which says that children approaching the end of life should have access to 24-hour palliative support at home. The standard is partially commissioned by CCGs in just over a fifth (21%) of ICS areas – and not at all in nearly half (45%) of ICS areas.
- Our mapping shows that, in some areas, standards are being met without commissioned service specifications being in place. This suggests that the costs of some clinical children's palliative care services – particularly some specialist services provided by NHS acute trusts – are being absorbed by the NHS trusts themselves or funded from charitable sources without being fully reimbursed by CCGs.

- Where it is available, children's end of life care at home is provided by children's nurses as part of NHS community children's nursing (CCN) teams, hospice at home teams, hospital outreach teams or a combination. Nurse consultants, clinical nurse specialists and/or children and young people's oncology outreach and symptom care nurse specialists (CYPOONS) have the skills and experience to manage a range of symptoms, including prescribing where needed. In many cases, the medical support provided by consultant paediatricians, including those who have completed special interest (SPIN) training in paediatric palliative care, is sufficient to manage these symptoms.
- However, it is important that nurses and paediatricians providing children's end of life care in family homes in every part of England have access to advice from GRID-trained specialist paediatric palliative medicine consultants. This should be organised using a hub and spoke network model in each region. They have the skills and experience to meet the most complex palliative care needs, either directly or remotely through advice provided to other paediatricians. This is the level of care is set out in guidance and quality standards published by NICE.
- The lack of access to 24/7 community children's nursing and/or GRID-trained specialist paediatric palliative medicine consultants that we have found means that too many seriously ill children and their families do not have choice and control over how, when and where they receive palliative care. Too many are unable to access end of life care at home if that is what they choose. This is a serious health inequality. When families wish to be cared for at home – and it is in the best interests of the child to be there – keeping them in hospital because of a failure to invest in community-based children's palliative care represents an ineffective use of NHS resources.
- As was the case when the APPG published its 'End of Life Care: Strengthening Choice' report in 2018¹, we believe that key barriers preventing end of life care and wider symptom management for seriously ill children and their families being sustainably planned, funded and provided are:

Workforce

- In the short term, there are currently too few nurses, paediatricians and other professionals with the skills and experience to provide children's palliative care in hospitals, children's hospices and in the community.
- If safe staffing levels recommended by the Royal College of Nursing (RCN) were being adhered to, 5,500 CCNs would be working in England. Yet there are only 713 community children's nurses employed by the NHS in England. There are only 18 GRID-trained specialist paediatric palliative medicine (PPM) consultants in the UK, when the Royal College of Paediatrics and Child Health (RCPCH) estimates that 40-60 are needed. In 2022, the average vacancy rate for non-medical care and support roles (including nurses) equivalent to Agenda for Change bands 2-9 for children's hospices charities in England is 18.4%.
- We estimate that there are 10 sites across the UK that could provide GRID and special interest (SPIN) training in PPM to consultant paediatricians – and there are many who wish to undertake this training. However, only one whole time equivalent (WTE) GRID training place is being funded in the UK in 2022. **We estimate that there is a funding**

¹ All-Party Parliamentary Group for Children Who Need Palliative Care. 2018. End of life care: strengthening choice. Available to download from: www.togetherforshortlives.org.uk/appg

gap of £2.26million in investment in GRID and SPIN training – in addition to other funding gaps in educating and training other professionals, including children's nurses.

Funding

- Positive progress has been made in recent years, including NHSE/I's decision to ringfence and increase the Children's Hospice Grant to £25million by 2023/24 – and the commitment in the Long Term Plan to match fund CCG children's palliative care funding by up to £7million a year by 2023/24.
- Despite this we estimate that the NHS should spend approximately £385million every year to meet the NICE children's palliative care standards. Yet it will be spending only £84million every year on children's palliative care by 2023/24. **We therefore estimate that there will be a £301million gap in NHS spending on children's palliative care in 2023/24.**

Accountability

- We welcome the legal duty on integrated care boards (ICBs) in the Health and Care Act 2022 to commission palliative care as they consider appropriate for meeting the reasonable requirements of the people for whom they are responsible.
- However, we have specific concerns about the extent to which the government and NHSE/I will hold ICBs to account for the way in which they commission children's palliative care.

The action we recommend

- Whether or not seriously ill children and their families can access the palliative care they need at home, out of hours and at weekends should never depend on where they live. It cannot be right that the costs of some children's palliative care services – particularly some specialist services provided by NHS acute trusts – are being absorbed by the NHS trusts themselves or funded from charitable sources without being fully reimbursed by CCGs. We therefore call for the following, urgent action:
 1. **The government should make sure that, using NHSE/I's children's palliative care service specification, NHSE/I and Health Education England (HEE) work with stakeholders to develop a plan to use the existing children's palliative care workforce as effectively as possible, which includes organising services into NHS-commissioned children's palliative care operational delivery networks (ODNs).**
 2. **When the government settles the health workforce education and training budget with the NHS, it should include funding to expand the children's palliative care workforce. This should include an aspiration to increase spending on specialist paediatric palliative medicine GRID and SPIN training to £2.26million per year, proportionate to an expansion in the overall medical education and training budget. Ministers should also make sure that the additional 50,000 nurses that the government has committed to by the end of this parliament includes children's nurses with the skills and experience to provide palliative care to children in hospitals, children's hospices and at home.**

- 3. As the government increases NHS funding by a total of £10.8billion in the period to 2024/25², it should make sure that the NHS invests an additional £301million in children's palliative care in England every year to meet the funding gap for services. This NHS should also maintain existing funding streams for the long term, including children's palliative care match funding and the Children's Hospice Grant.**
 - 4. We call on the Secretary of State for Health and Social Care to use their new powers in the Health and Care Act 2022 to direct NHSE/I to make sure that all seriously ill children in England and their families should be able to choose to receive palliative care at home, 24 hours a day, seven days a week, if it is in their best interests. This should build on the legal duty on integrated care boards (ICBs) in the Health and Care Act to commission palliative care as they consider appropriate for meeting the reasonable requirements of the people for whom they are responsible.**
 - 5. Integrated care partnerships (ICPs) should take our findings into account as they determine the health and healthcare needs of their population. Integrated care boards (ICBs) should commission children's palliative care services in a way which meets the NICE standards. NHSE/I should regularly monitor the extent to which ICPs and ICBs do this through the new strategic clinical networks (SCNs) – and hold them to account if they fail to do so.**
- If these actions are not taken now, more seriously ill children and their families will be denied choice and control over their palliative care, particularly at end of life, as the number of cases of life-limiting and life-threatening conditions in children increases. The NHS will also waste money unnecessarily: NICE have already calculated that by implementing its guidance in full, valuable non-cash savings could be generated for the NHS, created by fewer unplanned, emergency admissions to hospital among seriously ill children, some of whom may prefer to access palliative care at home.

² HM Treasury. Autumn Budget and Spending Review 2021: documents. Available to download at: <https://www.gov.uk/government/publications/autumn-budget-and-spending-review-2021-documents>

1. About Together for Short Lives

- 1.1 Together for Short Lives is the UK charity for children's palliative care. We are here to support and empower families caring for seriously ill children, and to build a strong and sustainable children's palliative care sector. We support all the professionals and children's palliative care services that deliver lifeline care. We have over 1,000 members, including children hospices, voluntary sector organisations and statutory service providers.

Best practice case study: George Young

George was born with an extremely rare condition called Batten Disease variant CLN8. This causes vision loss, seizures, learning difficulties, loss of speech and motor skills and early onset dementia.

In October 2016, when George was three years' old, he had seizures at nursery. A specialist diagnosed him with epilepsy. However, after displaying other symptoms which concerned doctors, George was given a series of tests. In February 2017, these confirmed that George had Batten Disease.

Within a month of his diagnosis, George was referred to the NHS South Warwickshire Foundation Trust community children's nursing (CCN) team. His mother Claire says: "The team were amazing. We would not have got through George's journey without them. They held our hand and helped us to understand what was to come."

George began having seizures regularly and suddenly became unable to climb the stairs – something he had been able to do easily before. Instead of walking all the time he began crawling. By the end of 2017, he needed a frame to walk.

Over the next year George's condition continued to deteriorate to the point where the few words he could say were gone. He also lost the ability to stand or walk and had to rely on a wheelchair.

George was moved to a special school, which he attended four times a week, and was given regular physiotherapy, speech therapy and palliative care.

George had to have a feeding tube fitted because he could no longer chew his food properly. We went blind and began to have up to 30 seizures a day. He suffered from dystonia, causing stiffness and pain in his body.

By 2019, George was approaching the end of his life. "We wanted George to receive end of life care at home" says Claire. "The CCN team helped us to make an end of life plan and supported us to give George the palliative care he needed. They showed me how to carry out complex clinical tasks, like changing tubes and administering medicines. They taught me to be a chemist."

George died in June 2019, two weeks before his sixth birthday. "We had no idea how much time we would have with George and the final weeks of his life were traumatic" says Claire. "But with the CCN team's support, we were able to make choices and to control his symptoms. They were at the house when we needed them, day or night, and were at the end of the phone. George was able to die at home, and they gave me time to be with him, which was precious."

"The care the CCN provided to us was immaculate."

2. Why we have carried out this mapping project – and how we did it

2.1 This project set out to understand the extent to which the NICE children's palliative care standards are being met across the UK. This report aims to enable:

- Families caring for seriously ill children to make informed choices about the children's palliative care they decide to access.
- The UK Government, NHSE/I, and other decision makers to better plan, fund and fill the gaps in children's palliative care provision across the country.

2.2 A number of national standards apply to palliative and end of life care for children and young people in England. These standards outline what key standards of health and care should be being met for children with life-limiting conditions and their families and can be used as measure for what care is currently available across the country. These national standards include:

- **NICE Guidance NG 61:** End of life care for infants, children and young people with life-limiting conditions: planning and management.
<https://www.nice.org.uk/guidance/ng61>
- **NICE Quality Standard QS 160:** 2017. End of life care for infants, children and young people – NICE quality standard [QS160].
<https://www.nice.org.uk/guidance/qs160>
- **Department of Health.** 2016. 'Our Commitment to you for end of life care: The Government Response to the Review of Choice'. <http://bit.ly/2oOUsfj>
- **NICE guideline NG43:** 2016. Transition from children to adults' services for young people using health or social care services. <https://www.nice.org.uk/guidance/ng43>
- **NICE Quality standard QS140:** 2016. Transition from children to adults' services.
<https://www.nice.org.uk/guidance/qs140>

2.3 In particular, the National Institute of Health and Care Excellence's (NICE) Quality Standard for End of life care for infants, children and young people [QS160], published in 2017, outlines well measure for health and care for children with life-limiting conditions. Each NICE Quality Standard sets out priority areas for quality improvement in health and social care. This quality standard expected to contribute to improvements in the following outcomes:

- health-related quality of life for parents, siblings and carers of infants, children and young people having end of life care
- experience of end of life care for infants, children and young people, and their families and carers.

2.4 The NICE Quality Standard outlines six quality statements which enable the identification of gaps and the measuring of the quality of care. These quality statements include:

- i. [Statement 1](#) Infants, children and young people with a life-limiting condition and their parents or carers are involved in developing an advance care plan.

- ii. [Statement 2](#) Infants, children and young people with a life-limiting condition have a named medical specialist who leads and coordinates their care.
- iii. [Statement 3](#) Infants, children and young people with a life-limiting condition and their parents or carers are given information about emotional and psychological support, including how to access it.
- iv. [Statement 4](#) Infants, children and young people with a life-limiting condition are cared for by a multidisciplinary team that includes members of the specialist paediatric palliative care team.
- v. [Statement 5](#) Parents or carers of infants, children and young people approaching the end of life are offered support for grief and loss when their child is nearing the end of their life and after their death.
- vi. [Statement 6](#) Infants, children and young people approaching the end of life and being cared for at home have 24-hour access to both children's nursing care and advice from a consultant in paediatric palliative care.

2.5 These statements are used as a measure of what children with life-limiting conditions and their families should be able to access across the country – forming the basis of the data collection. These measures are also expanded upon to include a more nuanced picture of what is available – including some of measures included in other national standards. In addition to these national standards, this mapping project also draws from the draft service specification from NHSE/I published in 2020.

2.6 Data collection for this project consisted of using these national standards to put questions to:

- i. **CCGs** - organisations with responsibility for commissioning care locally across the country. CCGs are responsible for planning and funding services through specifications. A draft service specification for children's palliative care has been made available since 2020. Data from CCGs determines what is planned and funded locally across England.
- ii. **Children's palliative care networks in England** - interdisciplinary structured groups representing providers and sometimes users and commissioners of services over a defined geographical area, drawn together with the common aim of sharing best practice, co-ordinating, strengthening and developing services for children and young people life-limiting conditions.³ Data from Networks determines whether key standards of health and care are being met on a regional basis. The networks cover the following geographical footprints:
 - East of England
 - East Midlands
 - London
 - Kent and Medway
 - Northern (North East, including North Cumbria)

³ https://www.togetherforshortlives.org.uk/wp-content/uploads/2019/06/ProRes_Setting-up-a-MCN-in-CPC-December-2017.pdf

- North West (Cheshire and Merseyside, Greater Manchester and Lancashire & South Cumbria)
- South West
- South West London and Surrey
- Thames Valley (Berkshire, Buckinghamshire, Oxfordshire and North East Wiltshire)
- Wessex (Sussex, Hampshire, Berkshire and Isle of Wight)
- West Midlands.

- iii. **Children's palliative care provider organisations in England** – both voluntary and Statutory services across England. Data from organisations shows what is available to children and families locally across England.

2.7 Requests were issued to each group of organisations seeking to measure a different element or angle of the national standards of children's palliative care. The requests that were submitted include:

- i. **Freedom of information (FOI) requests** were issued to CCGs asking if they have a children's palliative care service specification – and if these specify that the quality standards in NICE Quality Standard QS 160 (End of life care for infants, children and young people) should be met. These requests were made jointly with the All-Party Parliamentary Group (APPG) for Children Who Need Palliative Care. Our FOI request is set out in Appendix One.
- ii. **An online form** was issued to Children's Palliative Care Networks in England. This data requests asked where in regions key standards of children's palliative care are being met in the community – by the NHS, the voluntary sector or a combination of both. The request of networks is set out in Appendix Two.
- iii. **An online survey** was issued to children's palliative care services in England. This online survey of organisations providing children's palliative care, including NHS trusts and voluntary sector organisations, asked providers about the extent to which different elements of children's palliative care are available to children and families. We have asked what services are available, where they are provided, when they are provided and who they are provided by. Our questionnaire is attached with this report.

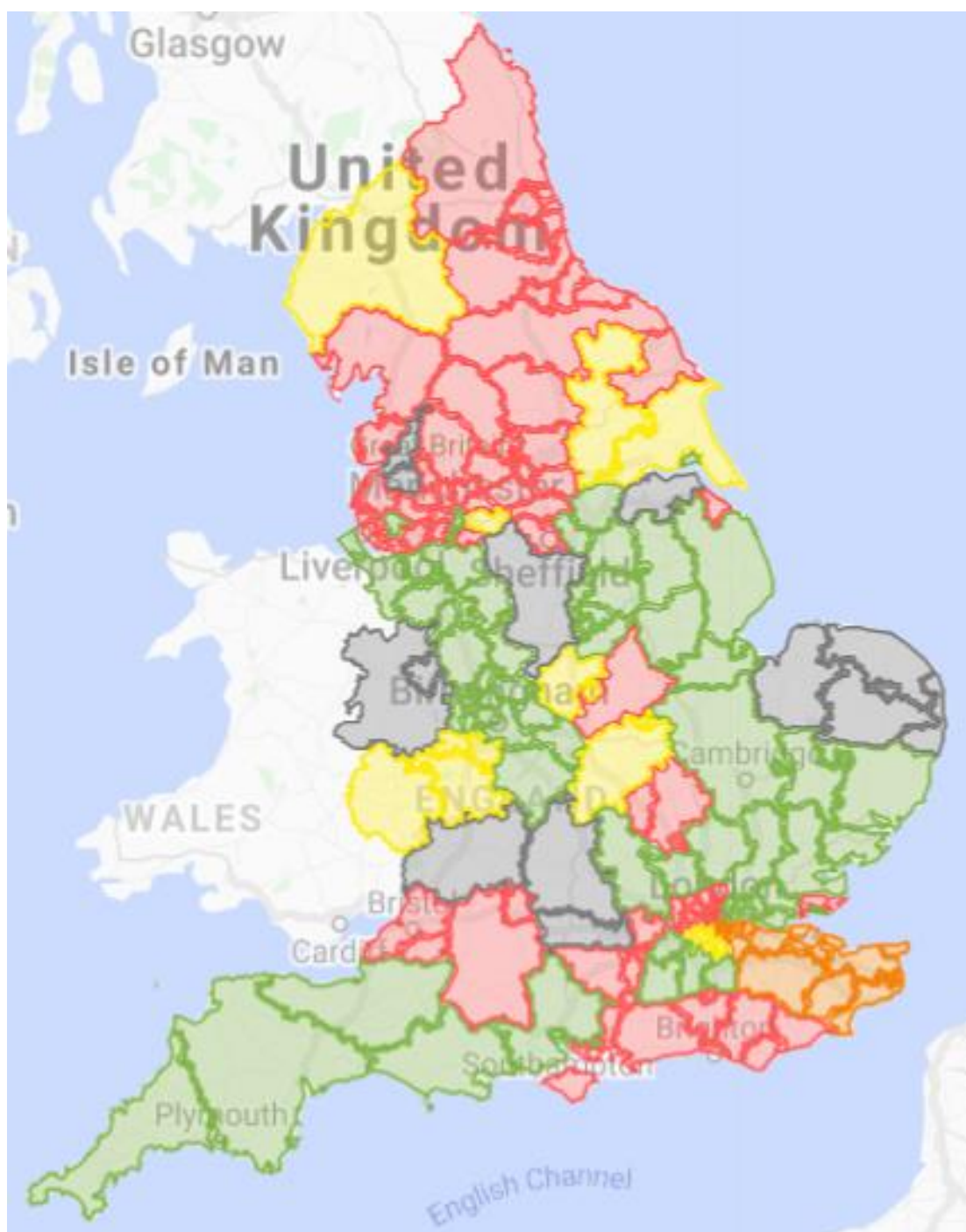
3. What we have found

- 3.1. Data for this report was gathered from February – August 2021. All children's palliative care networks and all CCGs responded the request for data. In addition, all data collected from Children's Palliative Care Networks across the country has been moderated by the Association for Paediatric Palliative Medicine (APPM). This section sets out the findings from each strand of the mapping.
- 3.2. It is important to note that there has been no mechanism by which it is possible to ensure that definitions are applied universally. Neither has it been possible to moderate to understand whether, if a standard has been reported as being met, it is available to all families. Equally, it has not been possible to moderate to understand whether, if a standard has been reported as not being met, if it is available to some families in that area. It is also important to note that Together for Short Lives asked networks not to map areas where services which are provided on the basis of good will by professionals, outside of the scope of their role. For example, we asked them to include out of hours services which are provided because professionals are contracted and/or paid overtime to provide them – but not those where professionals are delivering out of hours services free of charge as gestures of good will.

NHS CCGs – freedom of information requests

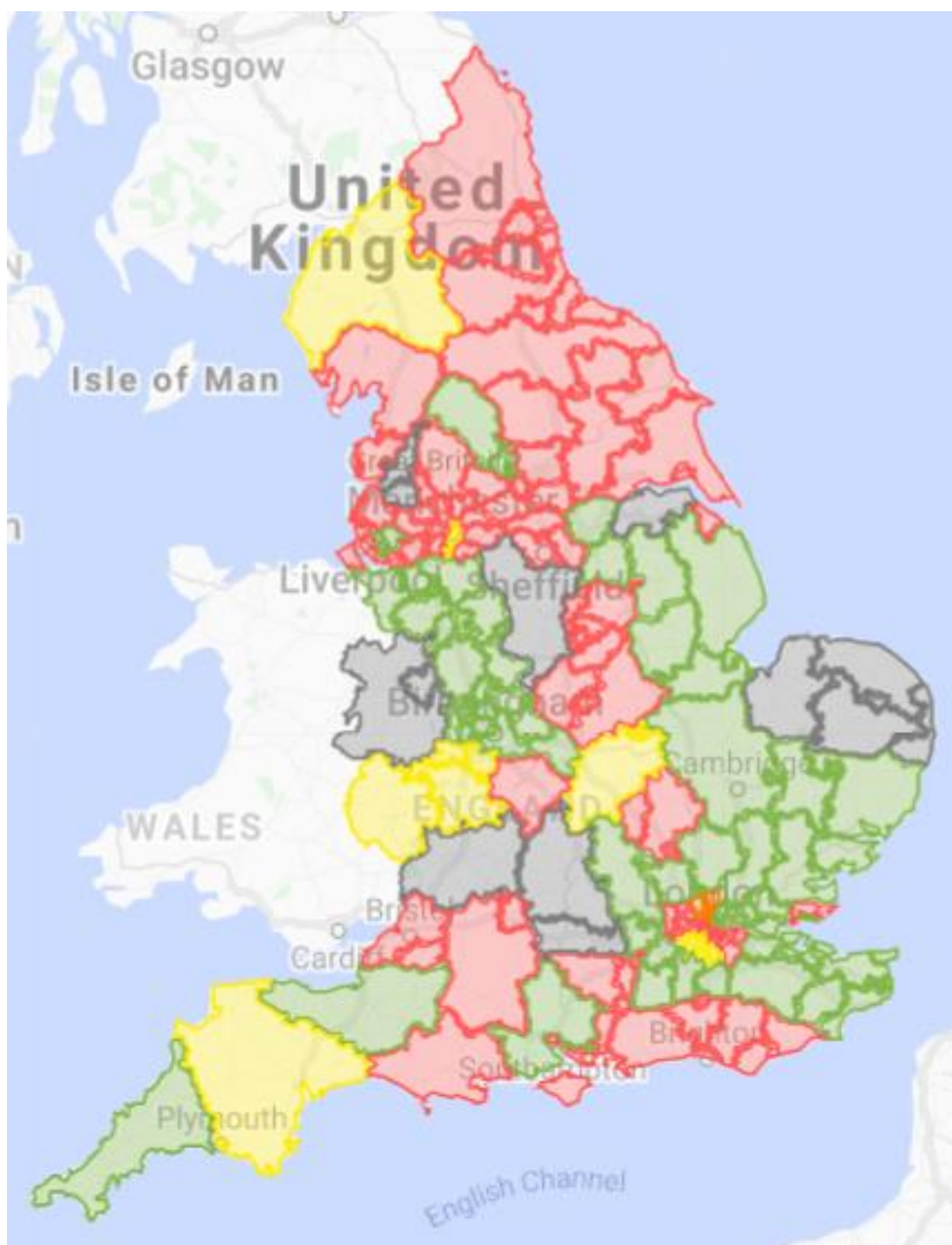
- 3.3. We issued our FOI requests on 15 February 2021. All 135 CCGs that existed at the time responded to our request (100%). The following pages set out what their responses told us. [You can download and access a full analysis of each CCG's response here.](#)
- 3.4. Where we have included images of the digital maps we have created, we have shaded CCG areas in different areas according to whether or not a particular standard is reflected in CCGs' service specifications. A key is available at the base of each map.

37% of CCGs in England have a service specification which states that infants, children and young people with a life-limiting condition and their parents or carers should be given information about emotional and psychological support, including how to access it.



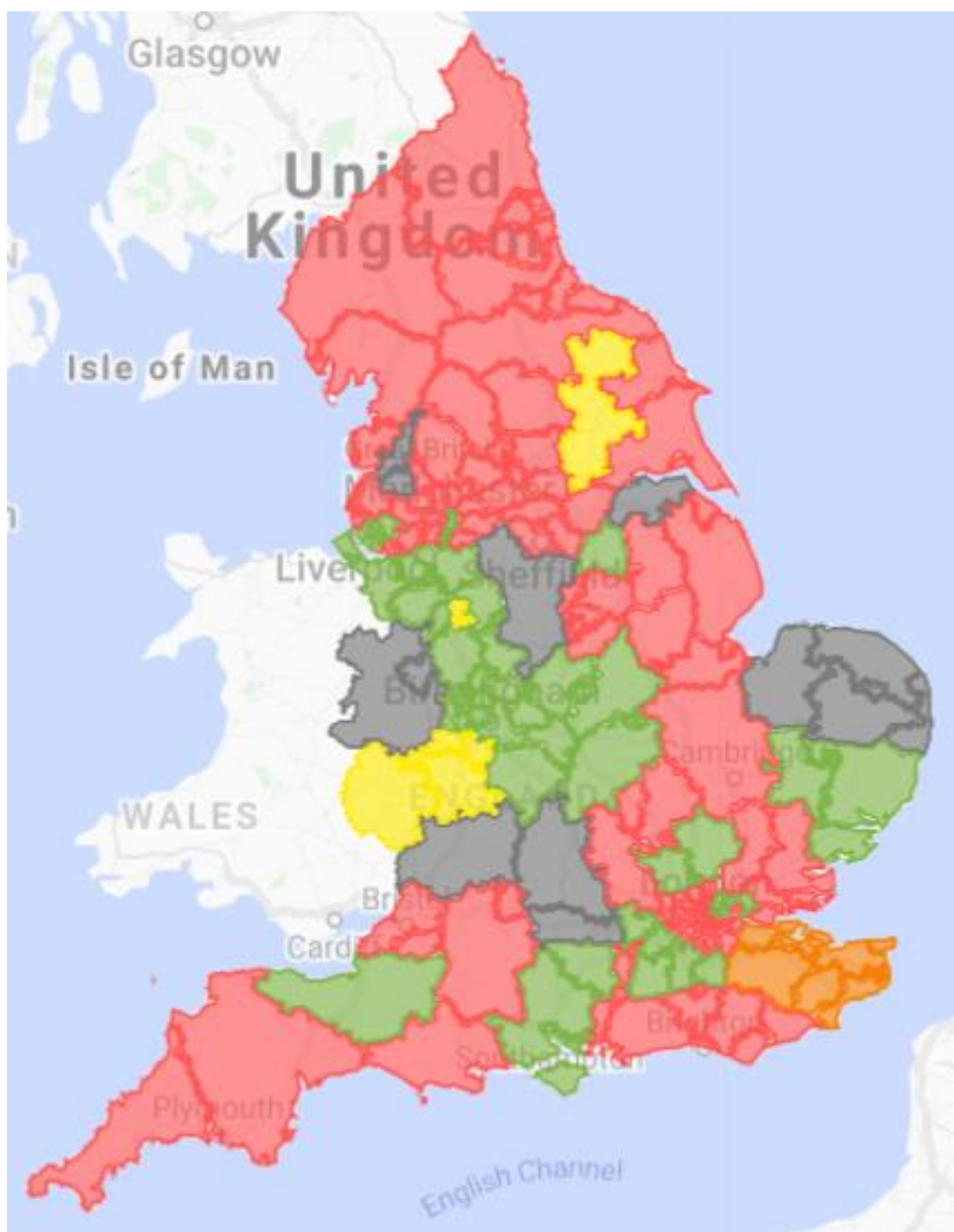
- Green: Yes, statement being met.
- Red: No, statement not being met.
- Yellow: Maybe, statement possibly met.
- Orange: Partially, statement partially met.
- Grey: Specification currently in development.

33% of CCGs in England have a service specification which states that infants, children and young people with a life-limiting condition should be cared for by a multidisciplinary team that includes members of the specialist paediatric palliative care team.



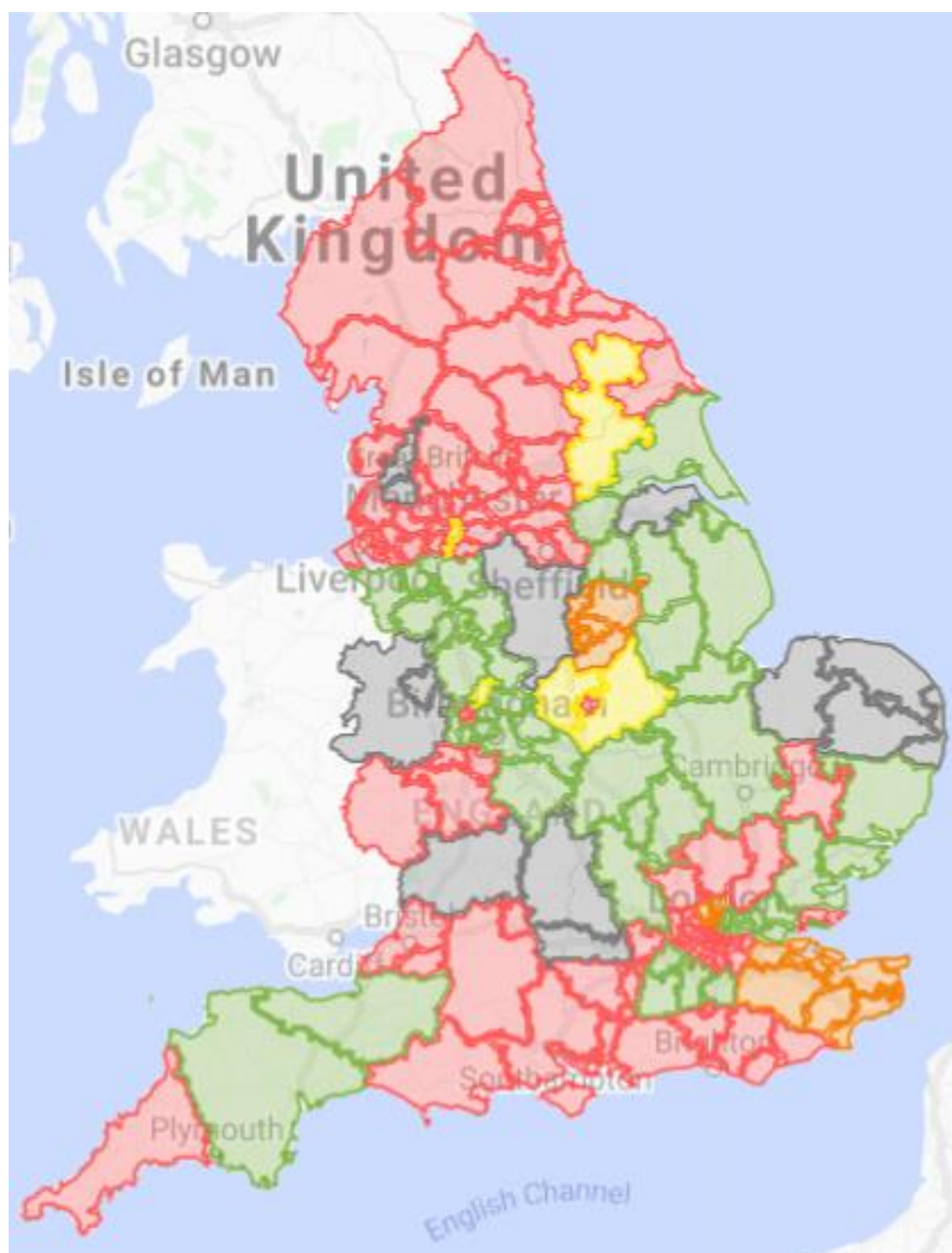
- Green: Yes, statement being met.
- Red: No, statement not being met.
- Yellow: Maybe, statement possibly met.
- Orange: Partially, statement partially met.
- Grey: Specification currently in development.

33% of CCGs in England have a service specification which states that infants, children and young people approaching the end of life and being cared for at home should have 24-hour access to both children's nursing care and advice from a consultant in paediatric palliative care.



- Green: Yes, statement being met.
- Red: No, statement not being met.
- Yellow: Maybe, statement possibly met.
- Orange: Partially, statement partially met.
- Grey: Specification currently in development.

33% of CCGs in England have a service specification which states that infants, children and young people with a life-limiting condition and their families should have access regular short breaks for respite.



- Green: Yes, statement being met.
- Red: No, statement not being met.
- Yellow: Maybe, statement possibly met.
- Orange: Partially, statement partially met.
- Grey: Specification currently in development.

3.5. We also found the following from our FOI request:

- 52% of CCGs in England have service specifications which cover children's palliative care, or elements of children's palliative care.
- 36% of CCGs in England have a service specification which states that infants, children and young people with a life-limiting condition and their parents or carers should have opportunities to be involved in developing an advance care plan.
- 27% of CCGs in England have a service specification which states that infants, children and young people with a life-limiting condition should have a named medical specialist who leads and coordinates their care.
- 40% of CCGs in England have a service specification which states that parents or carers of infants, children and young people approaching the end of life should be offered support for grief and loss when their child is nearing the end of their life.

3.6. Outside of the specific questions which were put to CCGs on the FOI requests, some other common responses were noted:

- Of the CCGs which did not have a service specification covering children's palliative care, eight responded saying that one was in development.
- Four CCGs incorrectly stated that NHSE/I were responsible for commissioning services to meet the standards we asked about in the FOIs.

Best practice case study: Service specification for Coventry and Warwickshire Children's Community Nursing and Complex Children's Nursing Services

Part of the CCG's response to our FOI request

"The primary purpose of the service is to provide a community-based nursing service to children and young people across Coventry who have specialised complex nursing needs in order to enable them to achieve their optimum health and reduce the impact of any illness on their health and well-being."

"Our vision is that "Every child and young person, including those who are vulnerable and disadvantaged, has the greatest possible opportunity to physically be the best they can be"."

"Realising this vision will mean healthier, happier children and young people who are ready to take advantage of positive opportunities and able to reach their full physical potential, regardless of their original health status or home background."

"The vision of the children's community nursing (CCN) and complex children's nursing services is that every child and young person with a life-limiting or life-threatening condition will have equitable access to high-quality, family-centred, sustainable nursing care and support, with services provided in a setting of choice, according to the child and family's wishes."

"The primary aim of the service is to:

- Achieve the best possible health and well-being outcomes for all children and young people with complex nursing needs.
- Deliver care in collaboration with the child, young person, family, carers and professional colleagues.
- Effectively meet complex nursing needs of children and young people to support them remaining at home with their families or to achieve smooth discharge from hospital."

4.3 Days/Hours of operation

"CCN Team:

The service core hours of operation will be Monday to Friday between 8.30am and 5.30pm
The CCN team will also offer a 24 hour/7 days a week telephone information and advice service
The CCN team will also provide 24/7 support to children & their families at the End of Life stage

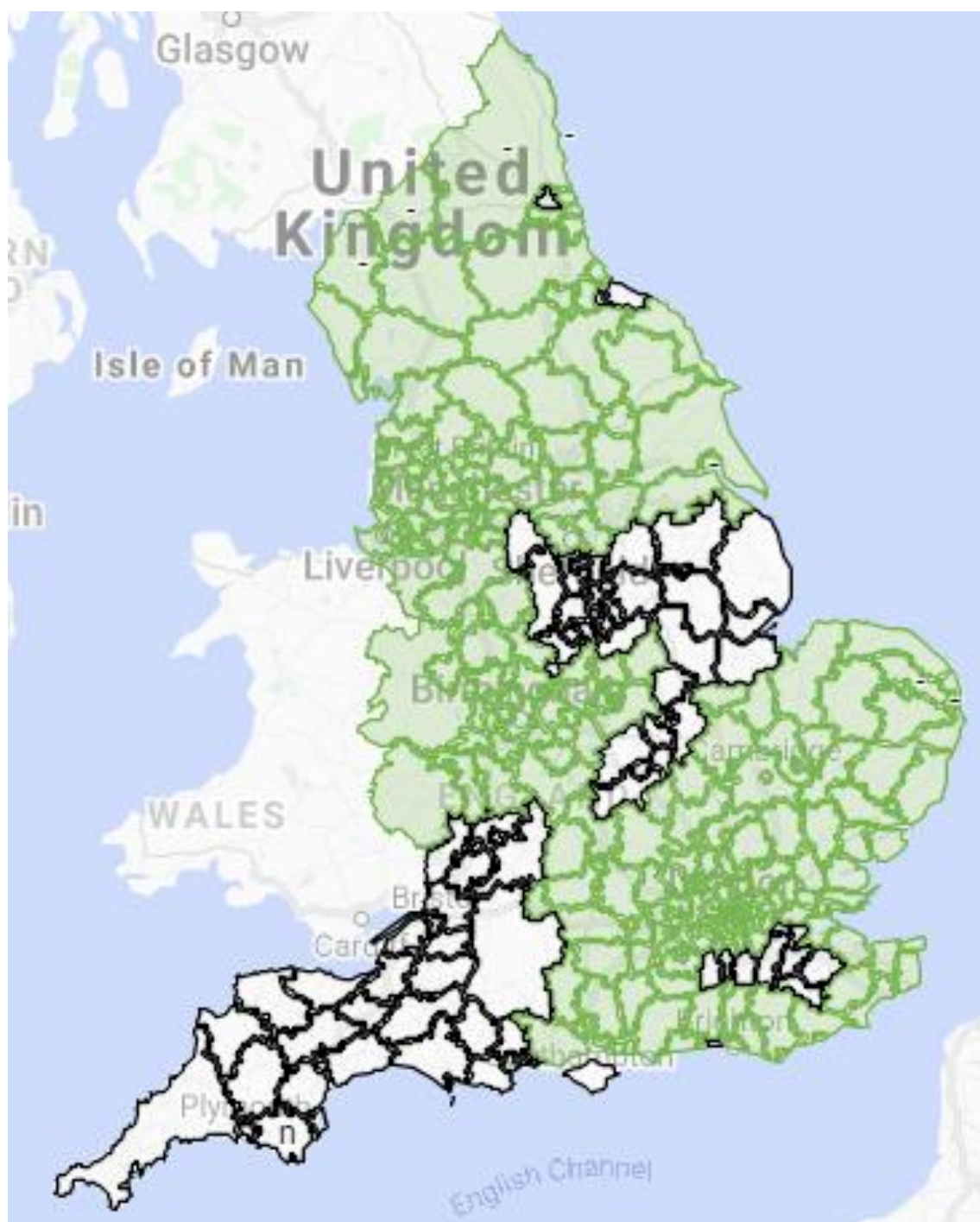
The Children's Continuing Health Care Team will provide nursing care to meet the assessed needs of the children and young people for whom Continuing care packages have been agreed. This may be less than 24 hours/7 days a week."

Children's palliative care network mapping

- 3.7. Following a successful pilot of this data collection with the Thames Valley Children's Palliative Care Network in December 2020, this request was issued to all networks in England in March 2021. The request was not directly prescriptive with how networks should categorise their response data to each question, however, this was generally done via local authority areas. Therefore, this data is presented via the number of local authority areas which meet each standard.
- 3.8. In each of the following maps, the areas shaded green represent the local authority areas where the standard specified is being met.

Access to palliative care at home provided by a multidisciplinary team that includes members of the specialist paediatric palliative care team

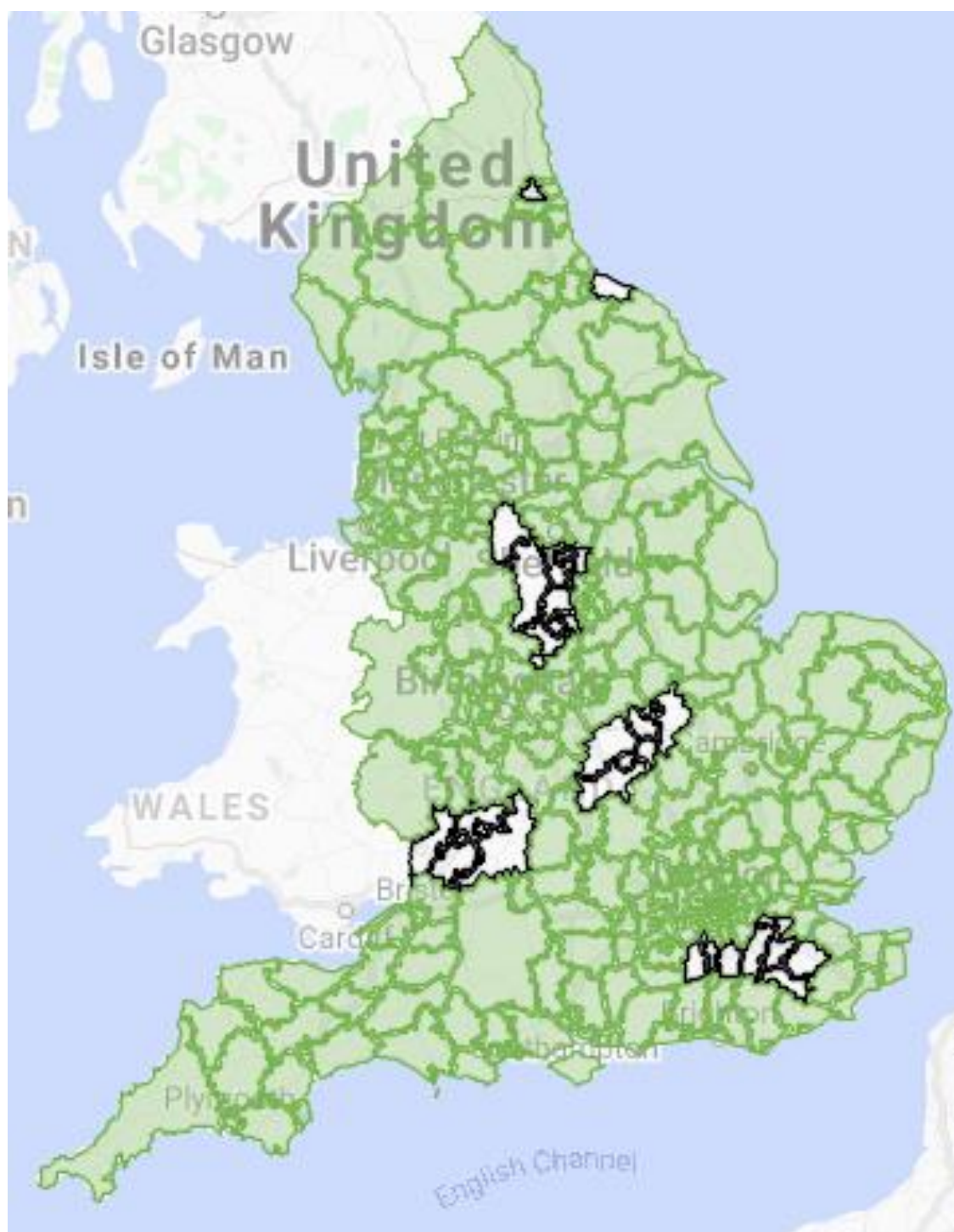
3.9 75% of local authority areas in England meet the standard that infants, children and young people with a life-limiting condition can access palliative care at home provided by a multidisciplinary team that includes members of the specialist paediatric palliative care team [1].



[1] This is defined in NICE guideline [NG61] 'End of life care for infants, children and young people with life-limiting conditions: planning and management': <https://www.nice.org.uk/guidance/ng61/chapter/recommendations#multidisciplinary-team>

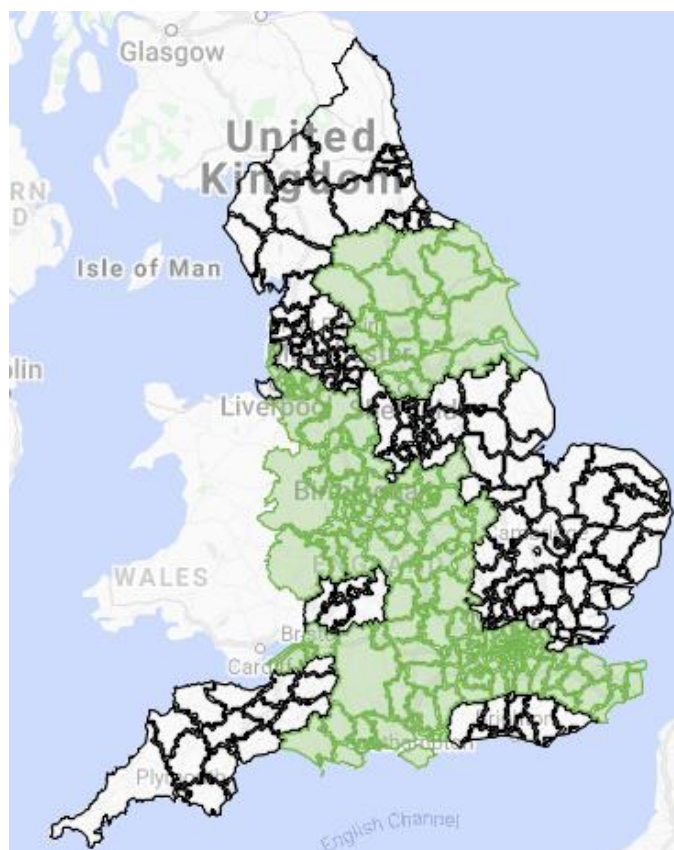
Support for grief and loss at home when a child is nearing the end of their life and after their death

- 3.10 90% of local authority areas in England meet the standard that parents or carers of infants, children and young people approaching the end of life can access support for grief and loss at home when their child is nearing the end of their life and after their death.



Children and young people approaching the end of life and being cared for at home have access to both children's nursing care and advice from a consultant in paediatric palliative care during normal working hours

3.11 54% of local authority areas in England meet the standard that children and young people approaching the end of life and being cared for at home have access to both children's nursing care [2] and advice from a consultant in paediatric palliative care⁴[3] during normal working hours.



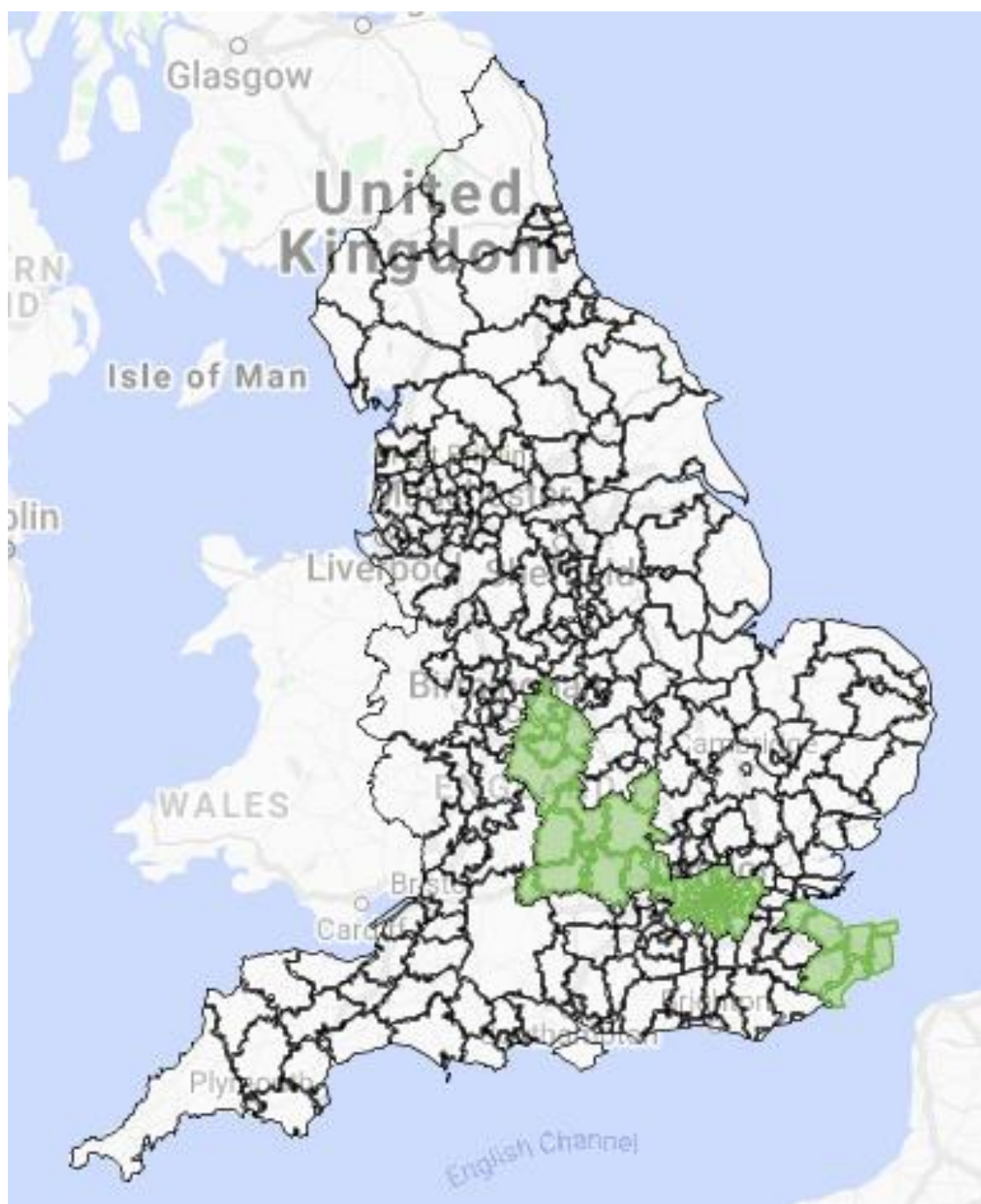
^[2] We would like to capture those areas where registered nurses can provide both core and specialist children's palliative care in the community, to children with a range of medical complexity. We acknowledge that, where this is provided, it is done so by nurses with different roles, employed by the NHS and/or the voluntary sector. This will include specialist children's palliative care nurses providing care directly, or providing advice to other nurses providing direct care.

^[3] NHS England and NHS Improvement state that specialist children's palliative care teams should be led by specialist medical consultants. These GRID-trained specialist consultants are vital because they:

- have specialist expertise in managing life-threatening illness and life-limiting conditions across the paediatric spectrum
- the ability to manage the full range of symptoms experienced as disease and illness progresses
- lead and develop services within their region
- enable, support, teach and train other health care professionals.

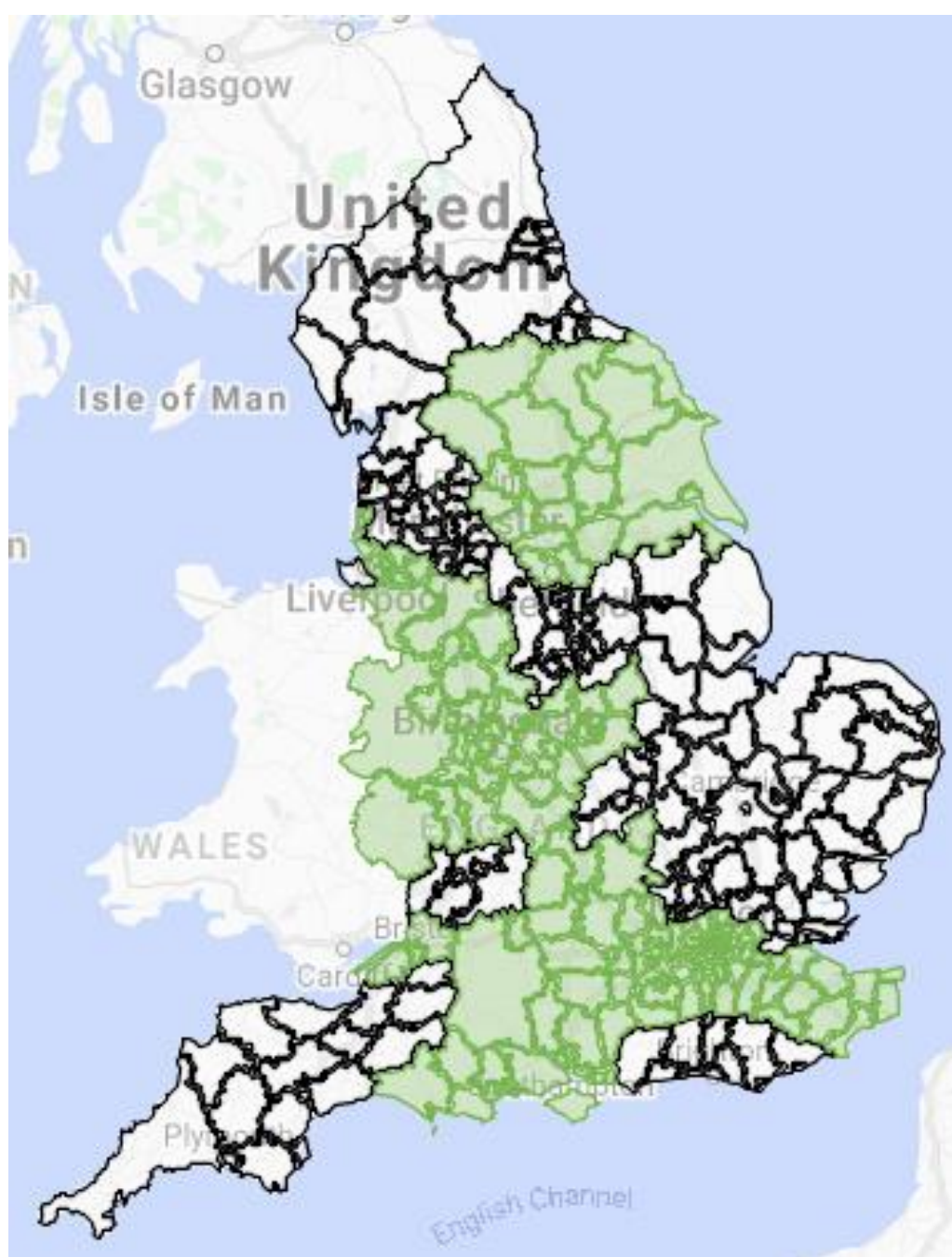
Children and young people approaching the end of life and being cared for at home have access to both children's nursing care and advice from a consultant in paediatric palliative care 24 hours a day, seven days a week

3.12 19% of local authority areas in England meet the standard that children and young people approaching the end of life and being cared for at home have access to both children's nursing care and advice from a consultant in paediatric palliative care 24 hours a day, seven days a week.



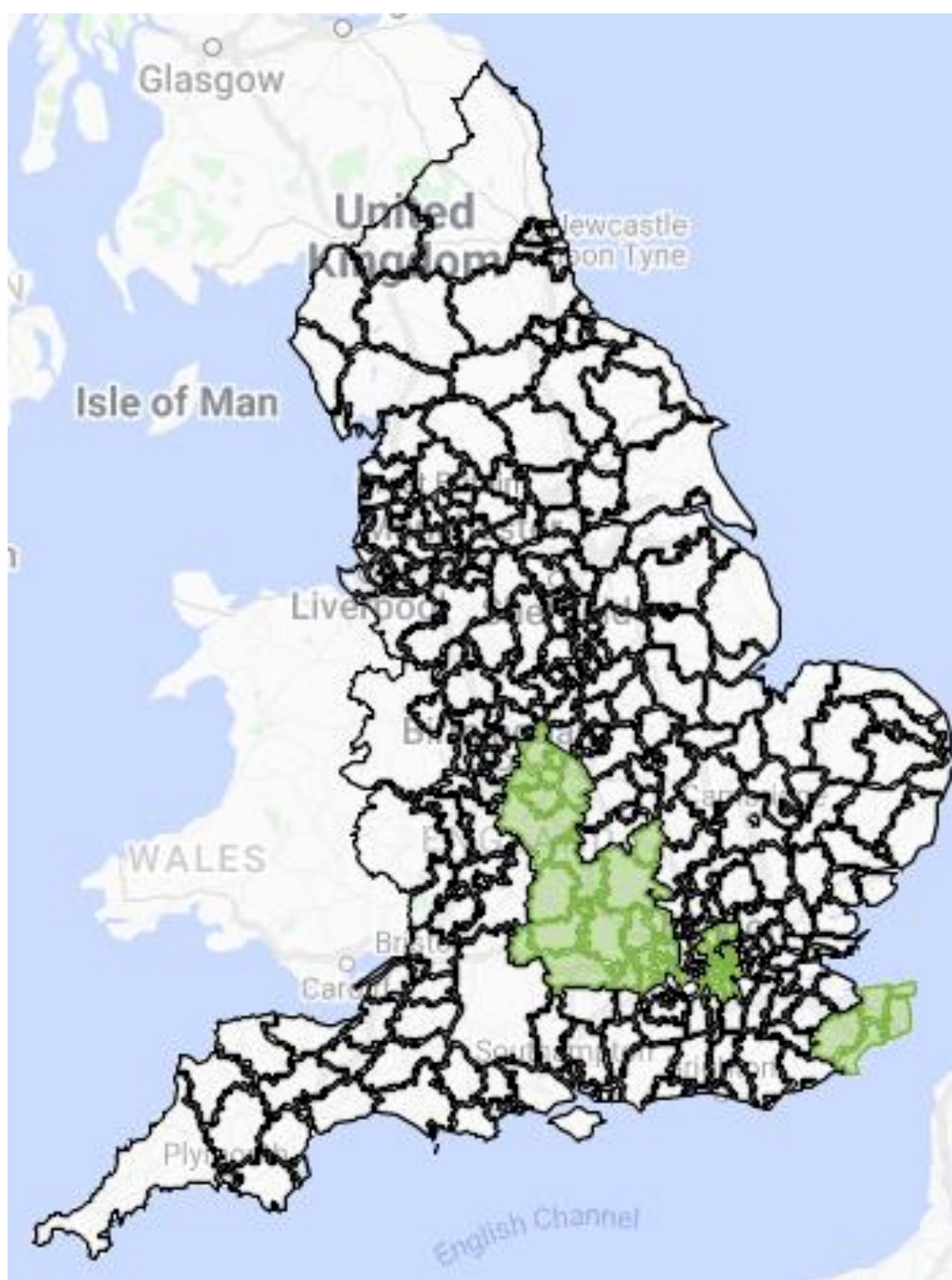
Children and young people with a life-limiting condition and being cared for at home have access to both children's nursing care and advice from a consultant in paediatric palliative care to manage their symptoms (not including end of life care) during normal working hours

- 3.13 52% of local authority areas in England meet the standard that children and young people with a life-limiting condition and being cared for at home have access to both children's nursing care and advice from a consultant in paediatric palliative care to manage their symptoms (not including end of life care) during normal working hours.



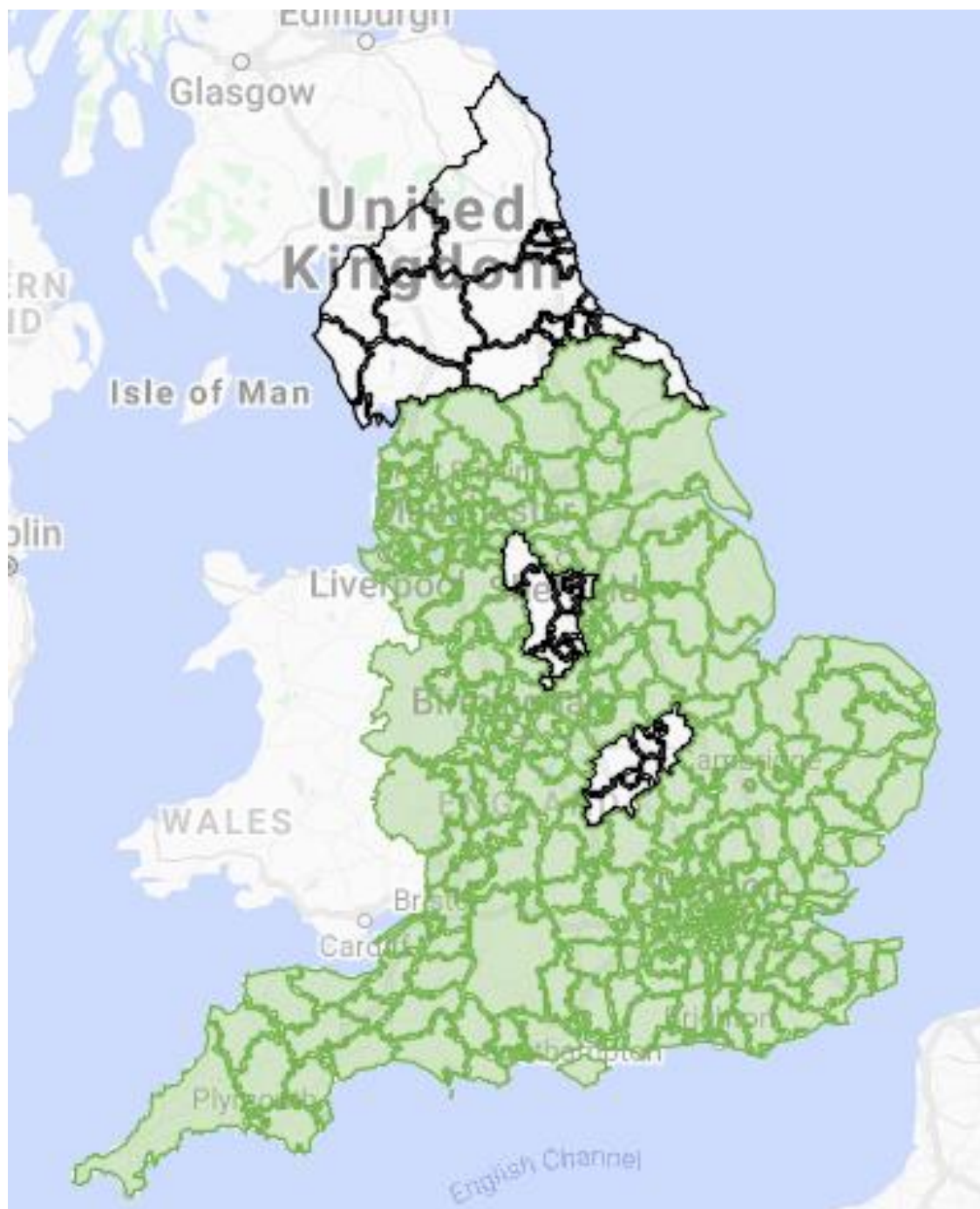
Children and young people with a life-limiting condition and being cared for at home have access to both children's nursing care and advice from a consultant in paediatric palliative care to manage their symptoms (not including end of life care), 24 hours a day, seven days a week

3.14 15% of local authority areas in England meet the standard that children and young people with a life-limiting condition and being cared for at home have access to both children's nursing care and advice from a consultant in paediatric palliative care to manage their symptoms (not including end of life care), 24 hours a day, seven days a week.



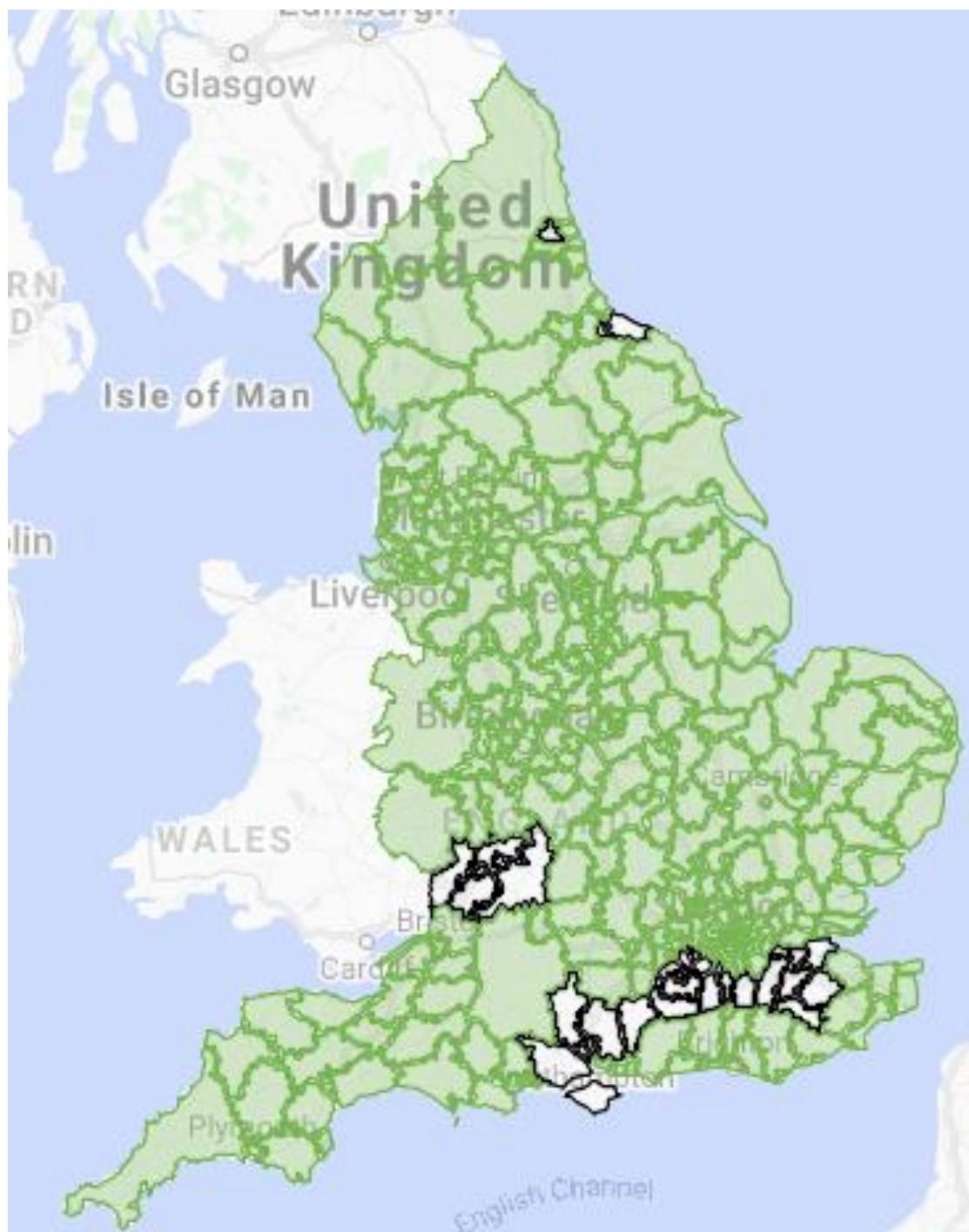
Infants, children and young people with a life-limiting condition and their parents or carers can access emotional and psychological support at home

3.15 89% of local authority areas in England meet the standard that infants, children and young people with a life-limiting condition and their parents or carers can access emotional and psychological support at home.



Infants, children and young people with a life-limiting condition and their families can access regular short breaks for respite at home should they wish.

3.16 89% of local authority areas in England meet the standard that infants, children and young people with a life-limiting condition and their families can access regular short breaks for respite at home should they wish^[8].



^[8] Short breaks may take place in the child's home or in a setting outside of the home such as a long-term care facility or hospice. It may include overnight breaks, or breaks lasting only a few hours.

3.17 There are a number of local areas in England in which children's palliative care is being commissioned and provided in ways which meet key standards for seriously ill children and families. However, this is a postcode lottery. The extent to which seriously ill children and their families can access the palliative care they need, when and where they need it, particularly out of hours and at weekends, depends on where they live. This represents a serious health inequality. We have also found that, in some areas, key children's palliative care standards are being met despite the fact that they are not being specified by local CCGs.

3.18 The results from the children's palliative care networks illustrate the significant gap in what is available during normal working hours, and what is available 24 hours a day, seven days a week. Looking specifically at those standards, we know that:

- Children and young people approaching the end of life and being cared for at home have access to both children's nursing care and advice from a consultant in paediatric palliative care...
 - ...during normal working hours: **this standard is not met in just under half (46%) of local authority areas** (151 LAs not meeting standard / 327 total LA areas with data collected/available)
 - 24 hours a day, seven days a week: **this standard is not met in four out of five (81%) local authority areas** (266 LAs not meeting standard / 327 total LA areas with data collected/available)
- Children and young people with a life-limiting condition and being cared for at home have access to both children's nursing care and advice from a consultant in paediatric palliative care to manage their symptoms (not including end of life care)...
 - ...during normal working hours: **this standard is not met in 48% of local authority areas** (158 LAs not meeting standard / 327 total LA areas with data collected/available)
 - 24 hours a day, seven days a week: **this standard is not met in 85% of local authority areas** (277 LAs not meeting standard / 327 total LA areas with data collected/available)

3.19 In addition, only 33% of CCGs in England have a service specification which aims to meet this standard at end of life. This states that children approaching the end of life and being cared for at home should have 24-hour access to both children's nursing care and advice from a consultant in paediatric palliative care. Even more starkly, **only in 3% of local authority areas (11) is 24-hour care from a children's nursing team and consultant in paediatric palliative medicine planned and funded by CCGs and available to seriously ill children at end of life.**

3.20 All of the data collected is incorporated in eight interactive Google Maps. These maps, categorised by statements from the request to children's palliative care networks, allow users to compare:

- where the standards are being met across the country by local authority footprint
- the number of children and children and young people aged 0-24 with life-limiting conditions per ICS area

- the prevalence of life-limiting and life-threatening conditions per 10,000 children and young people aged 0-24 per ICS area^{5 6}
- whether local CCGs plan and fund services to meet that standard (only available on maps 1, 4, 8 and 8)
- where inpatient children's palliative care services are located
- where Westminster parliamentary constituencies are located.

3.21 The interactive maps can be accessed by clicking the link next to the corresponding standard:

- i. Infants, children and young people with a life-limiting condition can access palliative care at home provided by a multidisciplinary team that includes members of the specialist paediatric palliative care team.
<https://www.google.com/maps/d/u/0/edit?mid=1ECQdc8Sj61FYKwRXHfxyKHJ7z9tAkRbj&usp=sharing>
- ii. Parents or carers of infants, children and young people approaching the end of life can access support for grief and loss at home when their child is nearing the end of their life and after their death.
https://www.google.com/maps/d/u/0/edit?mid=1cDT_W-EdolEmR_2_iPrTREAtqERCmF2J&usp=sharing
- iii. Children and young people approaching the end of life and being cared for at home have access to both children's nursing care and advice from a consultant in paediatric palliative care during normal working hours.
https://www.google.com/maps/d/u/0/edit?mid=17jUgfvq2zss60Do_g57vaWCFufp1WS8n&usp=sharing
- iv. Children and young people approaching the end of life and being cared for at home have access to both children's nursing care and advice from a consultant in paediatric palliative care 24 hours a day, seven days a week.
https://www.google.com/maps/d/u/0/edit?mid=1DIh4yGad28LkZ5Kp2Qf_VA_cQ9hhV2q&usp=sharing
- v. Children and young people with a life-limiting condition and being cared for at home have access to both children's nursing care and advice from a consultant in paediatric palliative care to manage their symptoms (not including end of life care) during normal working hours.
https://www.google.com/maps/d/u/0/edit?mid=1NCFWKBTAENFMDpXR_nFyl8PaorV_hvL&usp=sharing
- vi. Children and young people with a life-limiting condition and being cared for at home have access to both children's nursing care and advice from a consultant in paediatric palliative care to manage their symptoms (not including end of life care), 24 hours a

⁵ Fraser LK, Gibson-Smith D, Jarvis S, Norman P, Parslow RC. 2020. 'Make Every Child Count: Estimating current and future prevalence of children and young people with life-limiting conditions in the United Kingdom.' Available to download from: <https://www.togetherforshortlives.org.uk/resource/make-every-child-count/>

⁶ Fraser LK, Gibson-Smith D, Jarvis S, Norman P. 2021. 'Making Every Young Person Count: Estimating current and future prevalence of young people with life-limiting conditions in England.' Available to download from: <https://www.togetherforshortlives.org.uk/resource/making-every-young-adult-count/>

day, seven days a week.

https://www.google.com/maps/d/u/0/edit?mid=1nVUb1w7RK_iz8pz29Wfm4M4YDsgS-UhMI&usp=sharing

- vii. Infants, children and young people with a life-limiting condition and their parents or carers can access emotional and psychological support at home.
<https://www.google.com/maps/d/u/0/edit?mid=1IC-oXVBQVBkjWzNSnE9NOzHIKI6S-Xho&usp=sharing>
- viii. Infants, children and young people with a life-limiting condition and their families can access regular short breaks for respite at home should they wish.
<https://www.google.com/maps/d/u/0/edit?mid=1wR3IJZt5DhAH7zRmWsGz-yuAvbksCfKM&usp=sharing>

3.22 The maps incorporate data from then 2020 Making Every Child Count study⁷, displaying levels of cases and of prevalence of children with life-limiting. The maps to show where the highest levels of unmet need are across the country – contrasting need with where services are available and commissioned. For each map, the information described in paragraph 3.21 can be accessed by switching the layers on and off using the buttons on the left hand side of the screen.

3.23 The forms submitted by each children's palliative care network in England, on which this mapping is based, are also available to view here:

- [East of England](#)
- [East Midlands](#)
- [London](#)
- [Kent and Medway](#)
- [Northern \(North East, including north Cumbria\)](#)
- [North West \(Cheshire and Merseyside, Greater Manchester and Lancashire & South Cumbria\)](#)
- [South West](#)
- [Thames Valley \(Berkshire, Buckinghamshire, Oxfordshire and North East Wiltshire\)](#)
- [Wessex \(Sussex, Hampshire, Berkshire and Isle of Wight\)](#)
- [West Midlands](#)
- [Yorkshire and Humber.](#)

⁷ <https://www.togetherforshortlives.org.uk/resource/make-every-child-count/>

Best practice case study: Ted Ellard

Ted was born three months prematurely in May 2017 weighing just 1lb 9.5oz. He wasn't breathing when he was born and was taken straight to the neonatal intensive care unit (NICU). Ted had chronic lung disease and spent the next four months in NICU and was finally discharged home on permanent oxygen in September 2017.

At nearly eight months old, following another hospital admission, Ted was diagnosed with a rare, incurable heart condition called pulmonary vein stenosis. This causes veins going to the heart to narrow and eventually close.

Ted was referred to the NHS South Warwickshire Foundation Trust children's palliative care team immediately after his diagnosis. "The team attended meetings with us to help assure the hospital professionals that his needs could be met at home" says Ted's mother Natalie. "They developed an advance care plan with us and ensured that we were able to do everything we needed to do for Ted at home. This meant that we got to spend as much time as possible at home as a family between hospital stays. This time at home meant we got to make such amazing memories with Ted, we took him on so many days out and weekends away, memories we wouldn't have been able to make inside a hospital room. Being able to do that made all the difference in the world, it totally changed the quality of Ted's life and meant we could make the most of the short precious time we got to spend with him. When we got home, the children's palliative care team came round regularly to check on Ted and to support us."

Despite numerous heart surgeries, spells in hospital and initial signs of recovery, Ted's condition deteriorated. As it became clearer that he was nearing the end of his life, the children's palliative care team helped Natalie and Kev to meet Ted's complex palliative care needs at home.

"When we decided it was time for Ted to be at home following his final admission to hospital" says Natalie, "we informed the children's palliative care and within eight hours they had set up the equipment Ted needed at home including a high flow machine to help him breathe, had the medication he required ordered and prescribed and we were taken home by ambulance and met by the team and all our family."

"We arrived home on a Thursday evening and the children's palliative care team were there until around midnight that night to support us."

"We had a wonderful couple of nights with lots of visitors, one being a pony which Ted loved and had a sit on. On the Saturday morning we could see that we didn't have long left with Ted so we called the team to start making arrangements. They came straight out to us and sorted out any medication that we would need to manage Ted's symptoms and explained to us what would happen. They then left to give us time as a family and to say our goodbyes. We called them back at 10pm that night to be with us at the end. Ted passed away in our arms at home in June 2018, 16 days after his 1st birthday.

In the following days, the children's palliative care team helped Natalie and Kev in their grief for Ted as they made plans for his funeral. The team also arranged a cold cot for Ted so that the family could stay at home together for a couple of days and then arrangements were made for them to stay at their local children's hospice, Zoe's Place in Coventry. They then spent their last night at home together before the funeral. The team showed their support further by attending Ted's funeral.

"We always knew that we wanted to say our goodbyes to Ted at home where he belonged and not in a hospital room, this was very important to us and the team and the hospital were aware of this. We would however never have managed to get Ted home with the additional support he required if it wasn't for the amazing care and extra support we received from the team. This extra time at home was amazing and something we will be forever grateful for. We made such special memories at home that weekend and words cannot describe how much it meant to us and what a difference it made for us all. It really helped us at the hardest time of our lives and it gave us the privacy we all deserve."

Local areas demonstrating best practice in meeting standards

3.24 Table 1 lists all the ICS where children's palliative care standards are being met.

Table 1

Local authority	Standards met	Annual prevalence of life-limiting conditions per 10,000
Warwickshire	<ul style="list-style-type: none">• All standards met	60
Buckinghamshire	<ul style="list-style-type: none">• All standards met	58
North London Central	<ul style="list-style-type: none">• All standards met	68
North West London	<ul style="list-style-type: none">• All standards met	72
North East London	<ul style="list-style-type: none">• All standards met	72
South West London	<ul style="list-style-type: none">• All standards met	70
South East London	<ul style="list-style-type: none">• All standards met	69

The areas of with the greatest challenges in meeting standards

3.25 Table 2 shows the ICS areas where there is the least available care. This includes all ICS areas where 2 or fewer key standards of children's palliative care are being met.

Table 2

Local authority	Standards met	Annual prevalence of life-limiting conditions per 10,000
Gloucestershire	<ul style="list-style-type: none">• Standard 7	64
Derbyshire	<ul style="list-style-type: none">• Standard 8	61
Northamptonshire	<ul style="list-style-type: none">• Standard 3• Standard 8	67

3.26 Table 1 and Table 2 illustrate how patchy service provision is across England. Outside of London, there is little consistency on whether children with life-limiting conditions can access care that meets NICE standards. For example, in Buckinghamshire all the NICE children's palliative care standards are being met. However, over the local authority boundary in Northamptonshire, six standards are not being met, including access to care 24 hours a day.

3.27 Table 3 compares ICS areas in England in terms of the extent to which 24/7 end of life care is provided and/or commissioned, 365 days a year. It also shows the number of cases of life-limiting and life-threatening conditions in children and young people aged 0-24 in each ICS area, in addition to the prevalence of life-limiting and life-threatening conditions per 10,000 children and young people aged 0-24 in each ICS area.

Table 3

ICS	Number of cases of life-limiting and life-threatening conditions (LLCs and LTCs) among children and young people aged 0-24 in England	Rank by cases	Total population of children and young people 0-24	Prevalence of LLCs and LTCs per 10,000 children and young people in England aged 0-24 years old	Provided : Child with LLCs and LTCs cared for at home have access to children's nursing and consultant for end of life care 24/7	Commissioned: Child with LLCs and LTCs cared for at home has access to children's nursing and consultant for end of life care 24/7	Rank by prevalence
Greater Manchester Health & Social Care Partnership	6241	1	873958	71.4	No	Partially: only in Manchester CCG	8
Cumbria and NE	6019	2	880871	68.3	No	No	14
West Yorkshire Health & Care Partnership	5318	3	763423	69.7	No	No	9
Cheshire and Merseyside	4856	4	721332	67.3	No	Partially	17
North West London Health & Care Partnership	4068	5	568841	71.5	Yes	No	7
North East London Health & Care Partnership	4006	6	554599	72.2	Yes	Partially: not in Barking and Dagenham CCG	5
Healthier Lancashire and South Cumbria	3437	7	502922	68.3	No	No	13
Our Healthier South East London	3400	8	490600	69.3	Yes	No	11
Hampshire and the Isle of Wight	3373	9	523136	64.5	No	Partially	21

Kent and Medway	3301	10	517431	63.8	Partially	Spec in development	23
South Yorkshire and Bassetlaw	3270	11	454676	71.9	No	Partially: only in Bassetlaw	6
The Black Country and West Birmingham	3104	12	410934	75.5	No	Yes	2
Sussex Health and Care Partnership	2980	13	442427	67.4	No	Partially	16
Buckinghamshire, Oxfordshire and Berkshire West	2945	14	505501	58.3	Partially	No	36
Birmingham and Solihull	2871	15	386491	74.3	No	Yes	3
South West London Health & Care Partnership	2860	16	411342	69.5	Yes	No	10
Humber Coast and Vale	2755	17	492490	55.9	No	No	39
North London Partners in Health& Care	2719	18	399457	68.1	Yes	No	15
Hertfordshire and West Essex	2552	19	417811	61.1	No	Partially	31
Bedfordshire , Luton and Milton Keynes	2101	20	278001	75.6	Partially: only in Milton Keynes	No	1
Mid and South Essex	2079	21	335057	62.0	No	No	27
Devon	2075	22	329179	63.0	No	No	25
Staffordshire & Stoke on Trent	2027	23	316909	64.0	No	Yes	22
Nottingham and Nottinghamshire Health and Care	1926	24	311302	61.9	No	No	28
Bristol, North Somerset and South	1859	25	285263	65.2	No	No	20

Gloucestershire							
Joined Up Care Derbyshire	1746	26	284652	61.3	No	Spec in development	30
Surrey Heartlands Health & Care Partnership	1744	27	288602	60.4	No	Partially	32
Leicester, Leicestershire and Rutland	1739	28	322329	54.0	No	Yes	42
Coventry and Warwickshire	1596	29	266058	60.0	Yes	Yes	34
Suffolk and North East Essex	1553	30	267857	58.0	No	Yes	37
Cambridgeshire and Peterborough	1540	31	255934	60.2	No	No	33
Norfolk and Waveney Health & Care Partnership	1477	32	270388	54.6	No	Spec in development	41
Bath and North East Somerset, Swindon and Wiltshire	1456	33	258463	56.3	No	No	38
Northamptonshire	1373	34	206193	66.6	No	Yes	18
Frimley Health & Care	1297	35	221132	58.7	No	Partially	35
Herefordshire and Worcestershire	1257	36	203879	61.7	No	Possibly	29
Dorset	1251	37	200486	62.4	No	No	26
Lincolnshire	1113	38	199737	55.7	No	No	40
Gloucestershire	1105	39	173823	63.6	No	Spec in development	24
Cornwall and the Isles of Scilly Health & Social Care Partnership	1076	40	147483	73.0	No	No	4

Somerset	1011	41	147617	68.5	No	Yes	12
Shropshire and Telford and Wrekin	881	42	134598	65.5	No	Spec in development	19
TOTAL	105357		16023184				

3.28 What Table 3 shows is that, despite some ICS areas having a high number of cases of life-limiting and life-threatening conditions among children, there are high levels of unmet need in terms of access to end of life care at home.

3.29 Table 3 also shows that, outside of London, 24/7 end of life care at home is only accessible to children in Coventry and Warwickshire and parts of Buckinghamshire, Oxfordshire, Wiltshire, and Kent. The 24/7 standard is not being met in 33 (79%) integrated care system (ICS) areas. It is only being met fully in three ICS areas (7%). It is being partially met in six (14%) ICS areas.

3.30 Of these, only in Coventry and Warwickshire ICS and parts of North East London ICS is this standard of care both commissioned and provided. CCGs in eight (19%) ICS areas have a specification which says that children approaching the end of life should have access to 24-hour palliative support at home. The standard is partially commissioned by CCGs in nine (21%) ICS areas – and not at all in 19 (45%) ICS areas. CCGs have specifications in development in 5 (12%) of ICS areas.

What our findings mean for seriously ill children and their families

3.31 We have found worrying disparities in the standards of palliative care that seriously ill children and their families experience – and, in particular, in the symptom management and end of life care that they can access out of hours at weekends. However, it is important to emphasise that this exercise has mapped the care and support that is available to children and families, rather than their experiences of that care. Together for Short Lives has commissioned separate research to examine the latter. Experiences of individual children and families will vary from area to area according to the number and complexity of their needs, their conditions and according to the way services are delivered.

3.32 Where it is available, children's end of life care at home is provided by children's nurses as part of NHS community children's nursing (CCN) teams, hospice at home teams, hospital outreach teams or a combination. Nurse consultants, clinical nurse specialists and/or children and young people's oncology outreach and symptom care nurse specialists (CYPOONS) have the skills and experience to manage a range of symptoms, including prescribing where needed. In some areas, there are sufficient nurses for rotas to provide 24/7 support to these children, through NHS or voluntary sector teams, or a combination of both. In some areas, paediatric oncology services will meet the palliative care needs of children with cancer.

3.33 In terms of medical support, not all children will need access to GRID-trained specialist children's palliative care consultants either directly or indirectly (for example, through medical advice provided remotely to the paediatricians caring for them). Some children will only need access to community nursing and a consultant paediatrician.

3.34 In more complex cases, some children's needs can be met by consultant paediatricians who have completed special interest (SPIN) training in children's palliative

care. In a number of the areas which we highlight as not meeting standards three, four, five and six, seriously ill children and young people can choose to access a high standard of end of life care or other forms of complex symptom management at home from these consultants.

3.35 From the information we have received from networks, it is clear that the medical and nursing support available to seriously ill children and families at home varies from place to place, below the level of SCNs and ICSs. The forms which network have submitted, which we link to in paragraph 3.23, show this placed-based detail. We recommend that politicians and officials view both in conjunction to understand the variations within ICS areas – and to understand how much action is needed, in terms of further developing medical or nursing support, to meet the standards.

3.36 Despite this, we strongly believe that nurses and paediatricians providing children's end of life care in family homes in every part of England should have access to advice from GRID-trained specialist paediatric palliative medicine consultants. They have the skills and experience to meet the most complex palliative care needs, either directly or remotely through advice provided to other paediatricians. This is the level of care set out in guidance and quality standards published by NICE. It should be organised on a networked hub and spoke model in every region. GRID-trained specialist consultants are vital because they:

- have specialist expertise in managing life-threatening illness and life-limiting conditions across the paediatric spectrum
- the ability to manage the full range of symptoms experienced as disease and illness progresses
- lead and develop services within their region
- enable, support, teach and train other health care professionals.

3.37 It is, therefore, particularly concerning that in the following ICS areas, which have relatively high caseloads of life-limiting and life-threatening conditions among children, 24/7 access to these consultants is not available.

- Greater Manchester
- Cumbria and the North East
- Cheshire and Merseyside
- Lancashire and South Cumbria
- Hampshire and the Isle of Wight
- South Yorkshire and Bassetlaw
- The Black Country and West Birmingham.

3.38 It should be noted that, despite the fact that access to GRID-trained specialist consultants is a standard which is met much more widely during normal working hours (as we set out in paragraph 3.11), it is concerning that even this is not being met for

children with life-limiting conditions in the following ICS areas. These may also be regarded as urgent priorities for action:

- Greater Manchester
- Cumbria and the North East
- Lancashire and South Cumbria
- Sussex
- Devon
- Nottingham and Nottinghamshire Health and Care
- Joined Up Care Derbyshire
- Lincolnshire
- Gloucestershire
- Cornwall and the Isles of Scilly
- Somerset.

3.39 It is important to note that, when we conducted our mapping in 2021, East of England did not have access to specialist GRID-trained children's palliative care consultants at any time. However, as a result of securing recurring funding from NHSE/I Specialised Commissioning, a new regional specialist palliative and end of life care team has been established in East of England. This currently includes 1.2 WTE palliative and end of life care consultants, specialist nurses, a clinical psychologist/family therapist and a specialist pharmacist. [An updated version of the East of England children's palliative care network form submitted to us in May 2022 is available here.](#) We were unable to reflect this in our mapping in time to collate, analyse and present the information in our digital maps, but will ensure that we do so if and when we repeat our mapping exercise.

3.40 Through our mapping, we have found that other NICE children's palliative care standards are being met for children and young people at home in the majority of places in England. While this is very encouraging, again the individual experiences of families will vary according to the nature and complexity of their needs. Whether or not these standards are achieved depend on families having access to sufficient children's palliative care professionals with the skills and experience to provide short breaks for seriously ill children in their homes.

Children's palliative care services in England: online survey

3.41 Children's palliative care provider organisations have responded to our survey from December 2020 onwards. Our response rate has been as follows:

- 32 of the UK's 37 children's hospice organisations responded to our survey (86%).
- 19 of England's 217 NHS trusts responded (9%).
- Two of the seven local health boards in Wales responded (29%).

- No NHS boards in Scotland have responded.
- No health and social care trusts in Northern Ireland have responded.
- 13 of Together for Short Lives' non-hospice voluntary sector members have responded.

3.42 The data collected will be used alongside the data from CCGs and Children's Palliative Care Networks in updating the Together for Short Lives Service Directory which is available here: <https://www2.togetherforshortlives.org.uk/portal/public/volunteer/>

Children's hospices

3.43 There are 83 different types of service provided across these children's hospices (please see Appendix Three for full list).

3.44 Location:

- 25 hospices provide care both in a hospice, and at home (78%).
- Four provide hospice-at home support only (13%)
- 4 provide support only through a hospice (13%).

3.45 End of life care:

- 30 (94%) of children's hospices provide end of life care.
- 24 (75% of all children's hospice organisations) provide end of life care in the community. Of these:
 - 19 (59%) provide this 24 hours a day, seven days a week, every day of the year
 - Three (9%) provide this outside of normal working hours, but not 24/7
 - Two (9%) provide it during normal working hours (8am-6:30pm, Monday-Friday, excluding bank holidays).
- 26 (81%) of children's hospices organisations provide end of life care as an inpatient service at a children's hospice. Of these:
 - 24 (75%) provide this 24 hours a day, seven days a week, every day of the year
 - One (3%) provide this outside of normal working hours, but not 24/7
 - One (3%) provide it during normal working hours (8am-6:30pm, Monday-Friday, excluding bank holidays).

3.46 28 (88%) offer symptom and pain management; nursing care in house is also provided by 28 (88%) of hospices, and 25 (78%) also provide this care at home.

3.47 Over half (53%) of children's hospices are able to provide the highest level of ventilation support for seriously ill children (Level 3 for children with a priority level of need, who are unable to breathe independently and for whom disconnection would be fatal). 14 (44%) are able to provide this 24 hours a day, seven days a week, every day of the year. 1 (3%) provides this outside of normal working hours, but not 24/7. Two (6%) provide this during normal working hours only.

3.48 Over half (18, 56%) of children's hospices are able to provide total parenteral nutrition (TPN). 14 (44%) can provide this 24 hours a day, seven days a week, every day of the year.

- 3.49 Just under one half (15, 47%) can provide essential continuous intravenous or subcutaneous therapies (not nutrition). All of these can provide this service 24 hours a day, seven days a week, every day of the year.
- 3.50 88% provide advance care planning (key means of improving care for people nearing the end of life, enabling better planning and provision of care to help people live well and die well in the place and the manner of their choosing).
- Short break care: 59% of hospices offer in a patient's home; 88% provide on an inpatient basis.
 - 17 hospices (52%) provide virtual support services (for example, a helpline or webchat).
 - 9% provide neonatal or paediatric intensive care support.
 - 94% provide emotional and/or psychological care and support, and family support services.
 - 97% provide bereavement support
 - 88% hold memorial days.
 - 94% provide fun days and activities for children and families.
 - 88% provide specialised support services for siblings.
 - 84% support children and families with the transition to adult services.
 - 66% offer complementary therapies and play therapy, and 44% offer art therapy; 63% provide hydrotherapy.
 - 81% run parents' groups; 56% run fathers' groups, and 56% offer mothers' groups; 44% offer parent and toddler groups, and 38% run grandparents' groups.

Non-hospice voluntary sector children's palliative care providers

- 3.51 A total of 13 non-hospice voluntary sector (VCS) children's palliative care providers responded to our survey. Their charitable objectives vary and are set out in the table below:

What type of organisation are you? Please pick one	Tally	%
Condition-specific charity	5	38%
A bereavement support service	1	8%
A voluntary sector provider of social palliative care to children	3	23%
An equipment/aids provider	1	8%
A dream/wish-granting organisation	1	8%
Psycho-social service provider	1	8%
Did not answer	1	8%
Total	13	100%

3.52 Eight (62%) of these organisations operate across the UK. Two (15%) operate on a national or regional basis and three (23%) on a local basis.

3.53 A full list of the services that these organisations provide is set out in Appendix Four. The most commonly provided services by these organisations are:

- Family support services: 10 (77%)
- Bereavement support after a child has died: 9 (69%)
- Bereavement: one-to-one support: 9 (69%)
- Bereavement support before a child has died: 8 (62%)
- Siblings work after a child has died: 8 (62%)
- Siblings work before a child has died: 8 (62%)
- Emotional and/or psychological care and support: 7 (54%)
- Fun days/activities: 7 (54%)
- Parents' groups: 7 (54%)
- Practical support: 7 (54%).

NHS trusts

3.54 Our low response rate from NHS trusts has meant that our sample is too small to analyse. Despite this, NHS-provided children's palliative care teams and professionals have contributed to our network mapping. The regional response forms that we link to in paragraph 3.23 show the services that they are providing in local areas. Specialist children's palliative care is provided at a number of NHS hospital sites, with some included outreach support in the community and to children's hospices. Children's palliative care is also provided by community teams.

Best practice case study: Isabelle

“When Isabelle was unwell and eventually diagnosed with Zellweger Syndrome we felt totally alone. But when we met the NHS Children’s Palliative Care team, everything changed. We were determined to care for Isabelle at home and they helped make this possible.

“Isabelle would have a lot of seizures overnight and cried a lot. Nothing would help settle her. Sometimes we felt inadequate and sometimes things were very hard. The team offered us respite and a break from 24/7 caring, allowing us to rest and catch up on sleep. We became very comfortable having them in our home, they became like friends. They took all the strain away and made sure that we could make the most of the time we had with Isabelle. They made sure that we felt in control at all times. As well as twice-weekly respite breaks, they helped with equipment and prescriptions, which took a great weight off our minds.

“We took Isabelle on holiday a couple of times and the team always supported us by contacting the local hospital for us to ensure they were aware we would be in the area. This gave us peace of mind when taking Isabelle away.

“Isabelle deteriorated very quickly. We called their on-call number immediately for support, and they were there instantly. We trusted our consultant completely. She took control of the whole situation. She made sure that Isabelle’s death was the best it could be.

“When Isabelle died in June 2019, the care didn’t stop. We had a lot of questions, which they happily answered, which helped us to look forward and not back. The team always advocated for Isabelle to ensure she received the best possible care. We will never be able to truly thank them for all they did.”

4. The barriers to 24/7 access to children's palliative care in England – and the action we recommend

4.1 We have identified three policy barriers which explain why seriously ill children in England and their families are unable to access children's palliative care which meets the NICE standards of quality – including symptom management and end of life care at home, 24 hours a day, seven days a week.

4.2 We ask government ministers and officials, working with partners including NHSE/I and Health Education England (HEE), to work with us to overcome the following issues:

Workforce

4.3 There are too few professionals with the skills and experience needed to provide children's palliative care in hospitals, children's hospices and in the community. In 2019, Together for Short Lives found that:

- **There are too few community children's nurses (CCNs) employed by the NHS:** CCNs provide the bedrock of children's palliative care. If safe staffing levels recommended by the Royal College of Nursing (RCN) were being adhered to, 5,500 CCNs would be working in England. Yet there are only 713 community children's nurses employed by the NHS in England. While other NHS nurses do provide community-based care to children, this is an indicator of the shortages in this crucial part of the sector.
- **There are too few specialist children's palliative care consultants:** The Royal College of Paediatrics and Child Health (RCPCH) estimates that 40-60 specialist children's palliative care consultants are needed in the UK. Worryingly, there are currently only 18 in England. This suggests a significant deficit of 22-42 consultants.
- **The growing vacancy rate in the non-medical care and support vacancy rate in children's hospice charities is higher than in the NHS – and posts are increasingly difficult to fill:** In 2022, the average vacancy rate for roles equivalent to Agenda for Change bands 2-9 inclusive (including nurses) for children's hospices charities in England is 18.4%. The average vacancy rate for roles equivalent to Agenda for Change bands 5-9 inclusive (which we have historical data for) is 18.6%, compared to 12.2% in 2019, 11% in 2016 and 10% in 2015. The NHS nursing vacancy rate in quarter three of 2021/22 was 10.5%⁸, which is also worryingly high. Two thirds (67%) of vacant posts in children's hospices were proving hard to fill (vacant for three months or more), which is unchanged from 2019. 65% reported that posts were hard to fill in 2016 and 57% in 2015. Just under a quarter (24%) of posts had been vacant for over 12 months, compared to 25% in 2019.
- **There are too few skilled professionals to fill vacant posts in children's hospices:** 92% of children's hospices cite an overall lack of professionals as a significant or very significant factor in the vacancy rates they are experiencing, compared to just over a half (58%) in 2019.

⁸ Nuffield Trust. 2022. Vacancy rates for nurses and doctors. Available to download from: <https://www.nuffieldtrust.org.uk/chart/vacancy-rate>

- **There are shortages among other health and care professionals who support seriously ill children and their families:** in England in 2021, the overall vacancy rate for children and family social workers in England was 17%⁹.

- 4.4 Specific skills are needed when speaking to children and families about the choices available to them and developing advance care plans with them; there is no shortage in the number of people who have the desire to provide the complex palliative care and support that children need. However, there is a dearth of education and training places and shortages in children's nurses and children's palliative care consultants are particularly acute.
- 4.5 We are concerned by the low number of national GRID training posts available for paediatric palliative medicine consultants. There is currently one whole time equivalent (WTE) GRID post in the UK for 2022; because it takes two years for existing paediatric consultants to complete GRID training only one whole time specialist consultant is being produced every two years. This is not enough to fill the existing number of consultant posts available in the UK.
- 4.6 Opportunities for general paediatricians to undertake special interest (SPIN) training in children's palliative care is also compromised by a lack of training posts. This is despite considerable interest to develop capability in this field. This is being caused by the lack of paediatric palliative medicine consultants and a dearth of funding for these posts from HEE.
- 4.7 This paucity of speciality palliative medicine consultants means that it is particularly challenging for NHS trusts to provide and maintain specialist children's palliative care services within their organisations.
- 4.8 We estimate that a total of 10 GRID training posts and 12 SPIN training posts for consultant paediatricians could be provided by the existing specialist paediatric palliative medicine consultant workforce – if funding was available from HEE. We estimate that each training place would cost £113,000 per year; we have calculated this based on the cost of the time of the specialist consultants and senior nurses who would need to provide the training, in addition to the salary cost of the consultant undertaking the training. These posts would cost a total of £2.48million per year to fund. However, we estimate that only £226,226 is being spent every year on providing GRID and SPIN training to consultant paediatricians, which leaves an **annual funding gap of £2.26million**.
- 4.9 We support the call from RCPCH that, to meet the challenges of making sure that there enough professionals who have the skills and experience to meet the needs and wishes of children and families, the existing workforce should be mapped to establish a baseline and service delivery assessed against required standards.
- 4.10 We welcome the work of 'Managing Complexity in Children's Healthcare: A Partnership for Change'¹⁰, a group of individuals and organisations committed to working together and sharing good practice and resources. This collaborative aims to improve the healthcare of children with medical complexity and their families – and provide support and educational materials for the professionals looking after them.

⁹ HM Government. 2022. Children's social work workforce. Available to download from: <https://explore-education-statistics.service.gov.uk/find-statistics/children-s-social-work-workforce>

¹⁰ Managing Complexity in Children's Healthcare: A Partnership for Change. 2019. <https://collaborative.whitefuse.net/>

- 4.11 We also welcome the Children's Palliative Care Education and Training UK and Ireland Action Group's Education Standard Framework¹¹. This supports provides a sustainable, standardised approach to educating and training children's palliative care professionals in the UK. We ask NHSE/I, HEE and the Council of Deans of Health to work with us to make sure that this approach becomes embedded in education and training for all children's palliative care professionals in England.
- 4.12 We recognise that the workforce challenges which limit the extent to which seriously ill children have access to 24/7 palliative care are part of wider shortages in the healthcare workforce in England. We acknowledge that the government has committed to an additional 50,000 nurses by the end of this parliament, in addition to five new medical schools. We also accept that specialist children's palliative care education and training places for health professionals, such as GRID and SPIN training, can only be expanded at a rate which is proportionate to an expansion to education and training for professionals in other areas of healthcare.
- 4.13 To overcome the children's palliative care workforce challenge, we call for action from the following organisations:

The government

- 4.14 The government should make sure that, using NHSE/I's children's palliative care service specification, NHSE/I and HEE work with stakeholders to develop a plan to use the existing children's palliative care workforce as effectively as possible. This should include organising services into NHS-commissioned children's palliative care operational delivery networks (ODNs), as is the case for neonatal critical care¹².
- 4.15 When the government settles the health workforce education and training budget with the NHS, it should include funding to expand the children's palliative care workforce. This should include an aspiration to increase spending on specialist paediatric palliative medicine GRID and SPIN training to £2.26million per year, proportionate to an expansion in the overall medical education and training budget. Ministers should also make sure that the additional 50,000 nurses that the government has committed to by the end of this parliament includes children's nurses with the skills and experience to provide palliative care to children in hospitals, children's hospices and at home.
- 4.16 We join other bodies including the Royal College of Nursing in asking that the government:
- introduces accountability for provision of workforce in legislation in England
 - acts to increase the supply of registered nurses
 - removes financial barriers to international health professional recruitment throughout the UK.

¹¹ Children's Palliative Care Education and Training UK and Ireland Action Group. 2020. Education Standard Framework.

Available to download from: <http://www.icpcn.org/wp-content/uploads/2020/10/CPCET-Education-Standard-Framework.pdf>

¹² NHS England. 2021. Operational Delivery Networks. Available to download from: <https://www.england.nhs.uk/ourwork/part-rel/odn/>

HEE (and then NHSE/I following the merger with HEE in July 2022)

- 4.17 Urgently assess the gaps in the children's palliative care workforce across the range of professions who care for seriously ill children, across hospitals, children's hospices and community services.
- 4.18 Assess the demand for nurses from children's hospice organisations and the independent sector and include it in their planning models.
- 4.19 Develop a core skills education and training framework for children's palliative care; this could help employers to identify key skills for roles and teams, conduct training needs analysis and plan, design and commission appropriate levels of and systems for training. This could also ensure robust peer review systems can be established.
- 4.20 Focus specifically on outlining career pathways and providing guidance for delivering outcomes-led education for children's palliative care nurses.
- 4.21 Fund NHS trusts to create more specialist medical training posts. This would help to make sure that paediatric palliative medicine GRID and SPIN training can take place.

Education providers

- 4.22 Education providers should make sure that children's palliative care is embedded in undergraduate and postgraduate medical and nursing courses; we note that children's palliative care should be embedded in nursing courses in a way that is consistent with existing regulations¹³.
- 4.23 If it is found that there are too few children's nurses likely to fill posts across all types of healthcare provider, for example, universities should increase the number of places they offer to undergraduates.

ICs

- 4.24 We believe that, in carrying out their people function¹⁴, ICs should develop actions plans to make sure seriously ill children and their families are well supported by children's palliative care professionals. The NHS Long Term Plan states that children's palliative care is a priority. Statutory, voluntary and independent sector providers will all be crucial in making sure that seriously ill children are able to access the palliative care they need. On this basis, it is vital that ICs secure sustainable children's palliative care workforces across all of these sectors.

¹³ Nursing and Midwifery Council. 2019. Standards. Available to download from: <https://www.nmc.org.uk/standards/>

¹⁴ NHSE/I. 2021. Building strong integrated care systems everywhere: guidance on the IC people function. Available to download from: https://www.england.nhs.uk/wp-content/uploads/2021/06/B0662_Building-strong-integrated-care-systems-everywhere-guidance-on-the-IC-people-function-August-2021.pdf

Best practice case study: Charles

“Charles was 11 when we received the devastating news that he had a terminal brain tumour. He was given a 10% chance of survival in the first year and 1% for any further years. We knew that time would be very short.

“We cared for Charles at home, where he loved to be. But this wouldn’t have been possible without the support of our local NHS Children’s Palliative Care Team. They were always there, whenever we needed them.

“As well as practical support (for example fitting a stair robot so Charles could sleep in his own room upstairs or helping with a hospital bed), they provided us with a tremendous amount of emotional support. Sometimes they would be at ours until past midnight, and we would talk on the doorstep. They helped me to prepare for Charles’ questions about whether we could cure his cancer because I didn’t know how to tell him he wouldn’t get better.

“Before he died, he was in hospital for a short spell but was finding it so hard to relax and sleep there, he was desperate to get home. The Children’s Palliative Care Team made this all possible. He arrived home and slept peacefully again. Charles died that night, in the comfort of his own bed.

“In all honesty I don’t know how we would have coped throughout Charles’ illness without their support. They were a lifeline, and I always knew they were there if we needed them. Any time, day or night. They were there.”

Funding

4.25 Funding is one of the most significant barriers to 24/7 children's palliative care being provided at home in every part of England. Based on the specialist and core professionals that NICE state should comprise children's palliative care multidisciplinary teams – and the population that needs access to them – we estimate that the NHS should spend approximately £385million every year to meet this standard¹⁵.

4.26 There have been positive developments in NHS funding for children's palliative care services in recent years. In July 2019, NHSE/I decided to increase the Children's Hospice Grant to £25million by 2023/24 and ringfence this money specifically for children's hospices. Through the hospice at home services they provide, often in collaboration with NHS community teams, children's hospices can play an important role in making sure 24/7 palliative care is available to children who need it. The planned Children's Hospice Grant amounts during this period are:

- 2020/21: £15million
- 2021/22: £17million
- 2022/23: £21million
- 2023/24: £25million.

4.27 In addition, the NHS Long Term Plan commits NHSE/I to match up to £7million of CCG funding for children's palliative care, including children's hospice services, by 2023/24. The money is available to NHS and voluntary sector providers and is already being used to fund some new and existing specialist children's palliative care services. The funding amounts during this period are:

- 2020/21: £2million
- 2021/22: £3million
- 2022/23: £5million
- 2023/24: £7million.

4.28 In 2022/23, NHSE/I is funding a dedicated children and young people's palliative care lead in each of the seven palliative and end of life care strategic clinical network (SCN) regions in England.

4.29 In April 2020, the government's Emergency Coronavirus Fund for charities included a commitment of £200million for hospices, including children's hospices. In November 2020, the government announced that it would provide an additional £205million of support for the NHS for the winter 2020/21. This included up to £125million to secure additional hospice capacity and up to £148million for the period December 2021-March 2022 to secure and increase NHS capacity to enable hospital discharge.

4.30 Despite this progress – and the money which we estimate that the NHS is also spending on funding specialist paediatric palliative medicine consultants, community

¹⁵ Please see Appendix Three for a detailed explanation of how we have derived this figure.

children's nurses and (through individual CCGs) children's hospices – we still approximate that the NHS will be spending only £84million every year on children's palliative care by 2023/24¹⁶. **We therefore estimate that there will be a £301million gap in NHS spending on children's palliative care in 2023/24.**

- 4.31 Our mapping shows that, in some areas, standards are being met without commissioned service specifications being in place. This suggests that the costs of some children's palliative care services – particularly some specialist services provided by NHS acute trusts – are being absorbed by the NHS trusts themselves or funded from charitable sources without being fully reimbursed by CCGs.
- 4.32 It is not right that in some areas, the sustainability of core and specialist care for seriously ill children and their families depends on the generosity of individual donors, sales made in charity shops and the success of fundraising events. **ICBs should have access to the financial resources to meet their legal duty to commission palliative care for children and young people.** [In 2016, NICE published a resource impact template alongside the guideline on end of life care for infants, children and young people.](#) This tool allows local areas to input their population data and it calculates the overall cost and savings of implementing the new guidelines. Using the total population of children in England, NICE calculate that by **investing £12.7million** in implementing the guidance, **non-cash savings worth £34.7million** would be released back into the NHS in England¹⁷
- 4.33 We are also concerned that NHSE/I has only committed to the Children's Hospice Grant until the end of 2023/24. The grant remains vital to the sustainability of children's hospices. It underpins their ability to work with their statutory sector partners to ensure that seriously ill children can exercise choice over how and where they receive palliative care.
- 4.34 As the government increases NHS funding by a total of £10.8billion in the period to 2024/25¹⁸, we believe the NHS should fund the lifeline 24/7 palliative care they need regardless of whether it is provided in hospitals, at home and in children's hospices:
- **We call on the government to ensure that the NHS invests an additional £301million in children's palliative in England every year to meet the gap.**
 - **We call on the government to ensure that NHSE/I maintains existing children's palliative care funding streams for the long term as a priority, beyond 2023/24, including match funding and the Children's Hospice Grant.**
 - **We call on NHSE/I to model for each ICB how much it should be spending on children's palliative care – and then hold them to account for the extent to which they spend money for this purpose.**

¹⁶ Please see Appendix Four for a detailed explanation of how we have derived this figure.

¹⁷ The National Institute for Health and Care Excellence. 2016. End of life care for infants, children and young people with life-limiting conditions: planning and management - NICE guideline [NG61]. Available to download from: <http://bit.ly/2ODg2hY>

¹⁸ HM Treasury. Autumn Budget and Spending Review 2021: documents. Available to download at: <https://www.gov.uk/government/publications/autumn-budget-and-spending-review-2021-documents>

Leadership and accountability

4.35 We welcome the clear policy imperative for 24/7 children's palliative care at home set out in:

- the legal duty on integrated care boards (ICBs) in the Health and Care Act 2022 to commission palliative care as they consider appropriate for meeting the reasonable requirements of the people for whom they are responsible
- the government's end of life care choice commitment¹⁹: this applies to people of all ages, and states that whether a dying person is being cared for at home, in a hospital, a care home or in a hospice, they have the right to expect that their pain will be managed actively at all times, whether at day or at night
- the National Institute for Health and Care Excellence (NICE) guideline²⁰ and quality standard on end of life care for children²¹
- the NHS Long Term Plan²², which on paragraph 3.41 states that children's palliative and end of life care is an important priority for the NHS
- the Ambitions for Palliative and End of Life Care Framework²³
- NHSE/I's Palliative and End of Life Care Delivery Plan²⁴
- NHSE/I's Palliative and End of Life Care Strategic Clinical Networks Operating Framework 2022 – 23.

4.36 Together for Short Lives supports NHSE/I's palliative and end of life care programme. The programme has the potential to realise the Long Term Plan commitment improve the extent to which children and families can access palliative care when and where they need it. The programme aims to:

- improve access, so that people are offered and able to access the palliative care services they need in a timely manner
- improve quality, so that palliative care is safe, personalised and high quality
- improve sustainability, so that palliative care is sustainably commissioned, funded and delivered.

4.37 The programme has already worked with Together for Short Lives and others to produce the following helpful resources:

- a service specification for children's palliative care

19 Department of Health. 2016. 'Our Commitment to you for end of life care: The Government Response to the Review of Choice'. Available to download from: <http://bit.ly/2oOU5fj>

20 The National Institute for Health and Care Excellence. 2016. End of life care for infants, children and young people with life-limiting conditions: planning and management - NICE guideline [NG61]. Available to download from: <http://bit.ly/2ODg2hY>

21 The National Institute for Health and Care Excellence. 2017. End of life care for infants, children and young people – NICE quality standard [QS160]. Available to download from: <http://bit.ly/2M6BHx3>

22 NHS Long Term Plan. 2019. Available to download from: <https://www.longtermplan.nhs.uk/wp-content/uploads/2019/08/nhs-long-term-plan-version-1.2.pdf>

23 Ambitions for Palliative and End of Life Care. 2020. Available to download from: <https://bit.ly/3CVIeH5>

24 FutureNHS. 2021. NHSE/I consultation on universal principles for advance care planning. Available to download from: https://future.nhs.uk/EOLC_Practitioners/view?objectId=113057285

- a palliative care commissioning and investment framework
- palliative care contracting guidance and methodologies.

4.38 These are available for commissioners and providers to download and use from the FutureNHS Platform²⁵.

4.39 We believe that NHSE/I's work to develop regional palliative care strategic clinical networks (SCNs) also provides an important opportunity to improve the way in which England-wide guidelines, standards and best practice examples are shared with ICSs. We welcome NHSE/I's decision to fund a dedicated children and young people's palliative care lead in each of the seven strategic clinical network (SCN) regions in England.

4.40 However, as was the case when the APPG published its 'End of Life Care: Strengthening Choice'²⁶ report in 2018, Together for Short Lives is concerned about the extent to which the government and NHSE/I holds ICSs and CCGs to account for the way in which they commission children's palliative care. We believe that this is, in part, contributing to the postcode lottery in the way in which it is planned, funded and provided. Whether or not seriously ill children and their families can access the palliative care they need at home, out of hours and at weekends should never depend on where they live.

4.41 Therefore, at national level:

- **We call on the Secretary of State for Health and Social Care to use their new powers in the Health and Care Act to direct NHSE to make sure that all seriously ill children in England and their families should be able to receive palliative care at home, 24 hours a day, seven days a week. This should build on the legal duty on integrated care boards (ICBs) in the Health and Care Act to commission palliative care as they consider appropriate for meeting the reasonable requirements of the people for whom they are responsible.**
- **We call for the government's mandate to NHSE/I to specify that services must be provided to achieve this vital standard.**
- **We call on NHSE/I to regularly monitor the extent to which ICBs are commissioning this care through the new SCNs – and hold them to account if they fail to do so.**

4.42 At local level:

- **We call on health and wellbeing boards to make sure that the 24/7 palliative care needed by seriously ill children is included within their joint strategic needs assessments; the JSNA should consider the most recent data on the**

²⁵ https://future.nhs.uk/EOLC_Practitioners/group/home

²⁶ All-Party Parliamentary Group (APPG) for Children Who Need Palliative Care. 2018. End of life care: strengthening choice. Available to download from: https://www.togetherforshortlives.org.uk/wp-content/uploads/2018/10/Pol_Res_181019_APPG_Children_Who_Need_Palliative_Care_inquiry_report.pdf

number and prevalence of children and young people with life-limiting or life-threatening conditions^{27 28}.

4.43 At system level, integrated care partnerships (ICPs) should:

- **Recognise that seriously ill children and their families need coordinated palliative care which is jointly commissioned by the NHS and local authority areas; ICPs should challenge partners to deliver the action required to implement the existing national children's palliative care policy framework.**
- **Develop strategies focused on addressing the needs and preferences of seriously ill children, young people and their families – and, in particular, include them in their integrated care strategies.**
- **Make sure they receive input from across the children's palliative care sector, including the statutory and voluntary sector, in addition to children and young people who need palliative care and their families.**

4.44 Also at system level, integrated care boards (ICBs) should:

- **Commission children's palliative care services in a way which is consistent with their new legal duty, the new service specification, commissioning and investment framework and contracting guidance and methodologies.**
- **Make sure that their plans to meet the healthcare needs of their populations include children's palliative care; in doing so, they should fill the gaps identified in our new maps.**
- **Allocate resources sufficient to make sure that children's palliative care services can achieve the NICE outcomes for seriously ill children and their families.**
- **Establish joint working arrangements between children's palliative care providers in acute, community and children's hospice settings and across the statutory and voluntary sectors.**
- **Make sure that their People Plans and People Promises include action to make sure that there are sufficient professionals with the skills and experience needed to provide palliative care to children, young people and families.**

²⁷ Fraser LK, Gibson-Smith D, Jarvis S, Norman P, Parslow RC. 2020. 'Make Every Child Count: Estimating current and future prevalence of children and young people with life-limiting conditions in the United Kingdom.' Available to download from: <https://www.togetherforshortlives.org.uk/resource/make-every-child-count/>

²⁸ Fraser LK, Gibson-Smith D, Jarvis S, Norman P. 2021. 'Making Every Young Person Count: Estimating current and future prevalence of young people with life-limiting conditions in England.' Available to download from: <https://www.togetherforshortlives.org.uk/resource/making-every-young-adult-count/>



Freedom of information request of NHS clinical commissioning groups (CCGs) in England

Dear Freedom of information officer

The questions below which we would like you to answer are designed to help me understand how you commission children's palliative care for children and young people with life-limiting and life-threatening conditions in your local area. In order to help you meet my request, I provide definitions to the terms I use in my questions below:

Children's palliative care

"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 or young person and support for the family. It includes the management of symptoms, provision of short breaks and care through death and bereavement."

Life-limiting and life-threatening conditions

"Life-limiting conditions are those for which there is no reasonable hope of cure and from which children will die. Some of these conditions cause slow deterioration over time rendering the child increasingly dependent on parents and carers.

Life-threatening conditions are those for which curative treatment may be feasible but can fail, such as cancer."

End of life care

"Care that helps all those with advanced, progressive, incurable illness, to live as well as possible until they die. It focuses on preparing for an anticipated death and managing the end stage of a terminal medical condition. This includes care during and around the time of death, and immediately afterwards. It enables the supportive and palliative care needs of both child/young person and the family to be identified and met throughout the last phase of life and into bereavement. It includes management of pain and other symptoms and provision of psychological, social, spiritual and practical support and support for the family into bereavement."

Please note that NHSE/I has created a draft Children's and Young People's Palliative and End of Life Care Service Specification. This is available for CCGs to access from the [FutureNHS Collaboration Platform](#)

The following national standards apply to palliative and end of life care for children and young people in England:

NICE Guidance NG 61: End of life care for infants, children and young people with life-limiting conditions: planning and management

<https://www.nice.org.uk/guidance/ng61>

NICE Quality Standard QS 160: 2017. End of life care for infants, children and young people – NICE quality standard [QS160].

<https://www.nice.org.uk/guidance/qs160>

Department of Health. 2016. 'Our Commitment to you for end of life care: The Government Response to the Review of Choice'.

<http://bit.ly/2oOU5fj>

NICE guideline NG43: 2016. Transition from children to adults' services for young people using health or social care services

<https://www.nice.org.uk/guidance/ng43>

NICE Quality standard QS140: 2016. Transition from children to adults' services

<https://www.nice.org.uk/guidance/qs140>

My questions

1. Do you have a children's palliative care service specification? (Yes/No). If so, please attach a copy to your response to this request.
2. Do you have a children's palliative care service specification which states that infants, children and young people with a life-limiting condition and their parents or carers should have opportunities to be involved in developing an advance care plan? (Yes/No)
3. Do you have a children's palliative care service specification which states that infants, children and young people with a life-limiting condition should have a named medical specialist who leads and coordinates their care? (Yes/No)
4. Do you have a children's palliative care service specification which states that infants, children and young people with a life-limiting condition and their parents or carers should be given information about emotional and psychological support, including how to access it? (Yes/No)
5. Do you have a children's palliative care service specification which states that infants, children and young people with a life-limiting condition should be cared for by a multidisciplinary team that includes members of the specialist paediatric palliative care team? (Yes/No)
6. Do you have a children's palliative care service specification which states that parents or carers of infants, children and young people approaching the end of life should be offered support for grief and loss when their child is nearing the end of their life and after their death? (Yes/No)
7. Do you have a children's palliative care service specification which states that infants, children and young people approaching the end of life and being cared for at home should have 24-hour access to both children's nursing care and advice from a consultant in paediatric palliative care? (Yes/No)
8. Do you have a children's palliative care service specification which states that infants, children and young people with a life-limiting condition and their families should have access regular short breaks for respite? (Yes/No)

For more information, please contact:

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Thank you in advance for your help.

Best wishes

Dr Caroline Johnson MP
Co-Chair
APPG for Children Who Need Palliative Care

Siobhain McDonagh MP
Co-Chair
APPG for Children Who Need Palliative Care

James Cooper
Head of Public Affairs and Policy
Together for Short Lives

Appendix two: sample network mapping information request form

For the standards we refer to in each of the following questions, please describe the geographical areas within your network region where they are being met. Please do this in a way which will make it as easy as possible for Together for Short Lives to draw these areas on our digital maps; for example, please reference ICS areas, CCG areas (all England), health and social care trust areas (Northern Ireland), NHS boards (Scotland), local health boards (Wales) or local authority areas (UK-wide). For each question, please also describe how those services are funded, which organisations provide them – and if they are only available to children with certain conditions (for example, children accessing oncology services). Please add in any further details if you would like to, for example how many whole time equivalent (WTE) staff involved in meeting these standards. There is no word limit on your answer – please use all the space you need. Please do add further lines to each table if needed.

1. Infants, children and young people with a life-limiting condition can access palliative care at home provided by a multidisciplinary team that includes members of the specialist paediatric palliative care team²⁹.

Name of individual professional, team or provider organisation	Geographical areas where this standard is being met	How this work is being funded (NHS, local authority or charitable)

2. Parents or carers of infants, children and young people approaching the end of life can access support for grief and loss at home when their child is nearing the end of their life and after their death.

Name of individual professional, team or provider organisation	Geographical areas where this standard is being met	How this work is being funded (NHS, local authority or charitable)

²⁹ This is defined in NICE guideline [NG61] 'End of life care for infants, children and young people with life-limiting conditions: planning and management': <https://www.nice.org.uk/guidance/ng61/chapter/recommendations#multidisciplinary-team>

3. Children and young people approaching the end of life and being cared for at home have access to both children's nursing care³⁰ and advice from a consultant in paediatric palliative care³¹ during normal working hours.

Name of individual professional, team or provider organisation	Geographical areas where this standard is being met	How this work is being Charityfunded (NHS, local authority or charitable)

4. Children and young people approaching the end of life and being cared for at home have access to both children's nursing care and advice from a consultant in paediatric palliative care 24 hours a day, seven days a week.

Name of individual professional, team or provider organisation	Geographical areas where this standard is being met	How this work is being funded (NHS, local authority or charitable)

5. Children and young people with a life-limiting condition and being cared for at home have access to both children's nursing care and advice from a consultant in paediatric palliative care to manage their symptoms (not including end of life care) during normal working hours.

Name of individual	Geographical areas where this	How this work is being
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³⁰ We would like to capture those areas where registered nurses can provide both core and specialist children's palliative care in the community, to children with a range of medical complexity. We acknowledge that, where this is provided, it is done so by nurses with different roles, employed by the NHS and/or the voluntary sector. This will include specialist children's palliative care nurses providing care directly, or providing advice to other nurses providing direct care.

³¹ NHS England and NHS Improvement state that specialist children's palliative care teams should be led by specialist medical consultants. These specialist consultants are vital because they:

- have specialist expertise in managing life-threatening illness and life-limiting conditions across the paediatric spectrum
- the ability to manage the full range of symptoms experienced as disease and illness progresses
- lead and develop services within their region
- enable, support, teach and train other health care professionals.

professional, team or provider organisation	standard is being met	funded (NHS, local authority or charitable)

6. Children and young people with a life-limiting condition and being cared for at home have access to both children's nursing care and advice from a consultant in paediatric palliative care to manage their symptoms (not including end of life care), 24 hours a day, seven days a week.

Name of individual professional, team or provider organisation	Geographical areas where this standard is being met	How this work is being funded (NHS, local authority or charitable)

7. Infants, children and young people with a life-limiting condition and their parents or carers can access emotional and psychological support at home.

Name of individual professional, team or provider organisation	Geographical areas where this standard is being met	How this work is being funded (NHS, local authority or charitable)

8. Infants, children and young people with a life-limiting condition and their families can access regular short breaks for respite at home should they wish³².

Name of individual professional, team or provider organisation	Geographical areas where this standard is being met	How this work is being funded (NHS, local authority or charitable)

³² Short breaks may take place in the child's home or in a setting outside of the home such as a long-term care facility or hospice. It may include overnight breaks, or breaks lasting only a few hours.

Please return your completed form to james.cooper@togetherforshortlives.org.uk and dan.steer@togetherforshortlives.org.uk

Appendix three: the services that children's hospice organisations in the UK provide

	Normal working hours (8am-6:30pm, Monday-Friday, excluding bank holidays)		Outside of normal working hours, but not 24/7 (please specify, including for eve, wkend and b hols)		24 hours a day, seven days a week, every day of the year		Limited access		Total of those that provide it		Do not provide	
Service	Tally	%	Tally	%	Tally	%	Tally	%	Tally	%	Tally	%
Emotional and/or psychological care and support	6	19%	3	9%	22	69%	0	0%	31	97%	1	3%
Family support services	15	47%	7	22%	9	28%	0	0%	31	97%	1	3%
Bereavement support after a child has died	9	28%	6	19%	16	50%	0	0%	31	97%	1	3%
Fun days/activities	11	34%	13	41%	6	19%	0	0%	30	94%	2	6%
Bereavement support before a child has died	10	31%	4	13%	16	50%	0	0%	30	94%	2	6%
Bereavement: one-to-one support	15	47%	5	16%	9	28%	0	0%	29	91%	3	9%
Keeping in touch calls (video or voice calls, for example)	12	38%	8	25%	9	28%	0	0%	29	91%	3	9%
Advance care planning	8	25%	4	13%	16	50%	0	0%	28	88%	4	13%

Care of body post death (for example, providing a cool room and family support)	2	6%	1	3%	26	81%	0	0%	29	91%	3	9%
Nursing care - in-house	3	9%	1	3%	24	75%	0	0%	28	88%	4	13%
Short break care in- patient	3	9%	4	13%	21	66%	0	0%	28	88%	4	13%
Symptom management, including pain	3	9%	2	6%	23	72%	0	0%	28	88%	4	13%
Telephone advice	4	13%	3	9%	22	69%	0	0%	29	91%	3	9%
Bereavement counselling	20	63%	4	13%	3	9%	0	0%	27	84%	5	16%
Care coordination/navigator/k eyworking	12	38%	6	19%	9	28%	0	0%	27	84%	5	16%
Memorial days	6	19%	20	63%	2	6%	0	0%	28	88%	4	13%
Parallel planning	8	25%	5	16%	14	44%	0	0%	27	84%	5	16%
Siblings work before a child has died	10	31%	12	38%	6	19%	0	0%	28	88%	4	13%
Siblings work after a child has died	12	38%	11	34%	4	13%	0	0%	27	84%	5	16%
Tracheostomy care	4	13%	2	6%	21	66%	0	0%	27	84%	5	16%

Transition to adult services - implementing a young person's transition plan, working together with other providers or agencies	15	47%	7	22%	5	16%	0	0%	27	84%	5	16%
End of life care in-patient	1	3%	1	3%	24	75%	0	0%	26	81%	6	19%
Nursing care - patient's home	6	19%	5	16%	14	44%	0	0%	25	78%	7	22%
Parents' groups	8	25%	15	47%	3	9%	0	0%	26	81%	6	19%
Support and information about post mortem and funeral planning	5	16%	5	16%	16	50%	0	0%	26	81%	6	19%
Transition to adult services - supporting young people to develop a transition plan	14	44%	7	22%	4	13%	0	0%	25	78%	7	22%
Bereavement drop-in sessions and/or groups	10	31%	12	38%	3	9%	0	0%	25	78%	7	22%
Day care	9	28%	9	28%	6	19%	0	0%	24	75%	8	25%
Emergency care - in house	3	9%	1	3%	21	66%	0	0%	25	78%	7	22%
Ventilation: Supportive ventilation (Level 1/High level of need - can be discontinued for up to 24 hours without clinical harm)	3	9%	1	3%	21	66%	0	0%	25	78%	7	22%
End of life care in the child's home or other community setting	2	6%	3	9%	19	59%	0	0%	24	75%	8	25%

Enteral Nutrition	3	9%	1	3%	20	63%	0	0%	24	75%	8	25%
Urinary catheter care and/or catheterization	4	13%	2	6%	18	56%	0	0%	24	75%	8	25%
Emergency care - patient's home	4	13%	5	16%	14	44%	0	0%	23	72%	9	28%
Music therapy	14	44%	6	19%	3	9%	0	0%	23	72%	9	28%
Oxygen therapy	3	9%	1	3%	19	59%	0	0%	23	72%	9	28%
Practical support	7	22%	8	25%	8	25%	0	0%	23	72%	9	28%
Spiritual support	6	19%	5	16%	12	38%	0	0%	23	72%	9	28%
Rapid transfers which allow urgent transfer to a child or family's preferred place	2	6%	4	13%	16	50%	0	0%	22	69%	10	31%
Step down care	2	6%	3	9%	17	53%	0	0%	22	69%	10	31%
Stoma care	4	13%	2	6%	16	50%	0	0%	22	69%	10	31%
Complementary therapies	11	34%	5	16%	4	13%	1	3%	21	66%	11	34%
Medical supervision - other doctors	3	9%	5	16%	13	41%	0	0%	21	66%	11	34%

Play therapy	7	22%	8	25%	6	19%	0	0%	21	66%	11	34%
Ventilation: Necessary ventilation (Level 2/Severe level of need - has respiratory drive and would survive accidental disconnection, but would be unwell)	3	9%	1	3%	17	53%	0	0%	21	66%	11	34%
Advocacy	9	28%	4	13%	6	19%	0	0%	19	59%	13	41%
Hydrotherapy	5	16%	10	31%	5	16%	0	0%	20	63%	12	38%
Short break care in patient's home	6	19%	7	22%	6	19%	0	0%	19	59%	13	41%
Fathers' groups	8	25%	9	28%	1	3%	0	0%	18	56%	14	44%
Finance/benefits advice	14	44%	3	9%	2	6%	0	0%	19	59%	13	41%
IV: Supportive intermittent intravenous/Subcutaneous therapies (not nutrition)	1	3%	0	0%	19	59%	0	0%	20	63%	12	38%
Medical supervision - led by specialist paediatric palliative medicine consultant(s)	3	9%	3	9%	12	38%	0	0%	18	56%	14	44%
Mothers' groups	6	19%	11	34%	1	3%	0	0%	18	56%	14	44%
Nutrition: Total Parenteral Nutrition	3	9%	1	3%	14	44%	0	0%	18	56%	14	44%

Physiotherapy	9	28%	6	19%	2	6%	0	0%	17	53%	15	47%
Ventilation: Essential ventilation (Level 3/Priority level of need - unable to breathe independently, disconnection would be fatal)	2	6%	1	3%	14	44%	0	0%	17	53%	15	47%
Monitoring technologies (e.g. blood sugar)	1	3%	1	3%	14	44%	0	0%	16	50%	16	50%
Research	15	47%	1	3%	0	0%	0	0%	16	50%	16	50%
IV: Essential continuous intravenous/Subcutaneous therapies (not nutrition)	0	0%	0	0%	15	47%	0	0%	15	47%	17	53%
Named medical specialist	2	6%	5	16%	8	25%	0	0%	15	47%	17	53%
Art therapy	10	31%	1	3%	3	9%	0	0%	14	44%	18	56%
Education and training for parents, carers and staff external to your organisation	12	38%	1	3%	2	6%	0	0%	15	47%	17	53%
Monitoring technology	1	3%	0	0%	13	41%	0	0%	14	44%	18	56%
Parent and toddler groups	8	25%	5	16%	1	3%	0	0%	14	44%	18	56%
Continuing care for children and young people	2	6%	1	3%	10	31%	0	0%	13	41%	19	59%

Pharmacy with expertise in children's palliative care	9	28%	1	3%	3	9%	0	0%	13	41%	19	59%
Grandparents' groups	3	9%	9	28%	0	0%	0	0%	12	38%	20	63%
Short break without clinical care	0	0%	2	6%	9	28%	0	0%	11	34%	21	66%
Social care	7	22%	3	9%	2	6%	0	0%	12	38%	20	63%
Transport	5	16%	5	16%	2	6%	0	0%	12	38%	20	63%
Bereavement weekends	0	0%	9	28%	1	3%	0	0%	10	31%	22	69%
Food parcels	6	19%	2	6%	1	3%	0	0%	9	28%	23	72%
Occupational therapy	6	19%	2	6%	1	3%	0	0%	9	28%	23	72%
Dream/wish-granting	6	19%	1	3%	1	3%	1	3%	9	28%	23	72%
Befriending	3	9%	2	6%	2	6%	0	0%	7	22%	25	78%
Hospital-based paediatric intensive care	2	6%	0	0%	1	3%	0	0%	3	9%	29	91%
Holidays	0	0%	2	6%	1	3%	0	0%	3	9%	29	91%

Wheelchairs: providing and maintaining	2	6%	1	3%	0	0%	0	0%	3	9%	29	91%
Hospital-based neonatal intensive care	1	3%	0	0%	1	3%	0	0%	2	6%	30	94%
Education for children and young people (for example, early years, school or further education)	2	6%	1	3%	0	0%	0	0%	3	9%	29	91%
Specialist paediatric oncology outreach nursing	1	3%	0	0%	1	3%	0	0%	2	6%	30	94%
Dialysis	0	0%	0	0%	1	3%	0	0%	1	3%	31	97%
Home adaptations	1	3%	0	0%	0	0%	0	0%	1	3%	31	97%
Dietetics	0	0%	0	0%	0	0%	0	0%	0	0%	32	100 %
Speech therapy	0	0%	0	0%	0	0%	0	0%	0	0%	32	100 %

Appendix four: the services that non-hospice voluntary sector children's palliative care organisations provide

	Normal working hours (8am-6:30pm, Monday-Friday, excluding bank holidays)		Outside of normal working hours, but not 24/7 (please specify, including for eve, wkend and b hols)		24 hours a day, seven days a week, every day of the year		Total of those that provide it		Do not provide	
	Tally	%	Tally	%	Tally	%	Tally	%	Tally	%
Family support services	5	38%	3	23%	2	15%	10	77%	3	23%
Bereavement support after a child has died	4	31%	3	23%	2	15%	9	69%	4	31%
Bereavement: one-to-one support	5	38%	3	23%	1	8%	9	69%	4	31%
Bereavement support before a child has died	3	23%	3	23%	2	15%	8	62%	5	38%
Siblings work after a child has died	4	31%	3	23%	1	8%	8	62%	5	38%
Siblings work before a child has died	4	31%	3	23%	1	8%	8	62%	5	38%
Emotional and/or psychological care and support	3	23%	2	15%	2	15%	7	54%	6	46%
Fun days/activities	2	15%	3	23%	2	15%	7	54%	6	46%
Parents' groups	3	23%	4	31%	0	0%	7	54%	6	46%
Practical support	4	31%	1	8%	2	15%	7	54%	6	46%
Advocacy	3	23%	1	8%	2	15%	6	46%	7	54%
Bereavement counselling	2	15%	2	15%	2	15%	6	46%	7	54%
Bereavement drop-in sessions and/or groups	3	23%	3	23%	0	0%	6	46%	7	54%
Parent and toddler groups	4	31%	2	15%	0	0%	6	46%	7	54%
Fathers' groups	2	15%	3	23%	0	0%	5	38%	8	62%
Finance/benefits advice	3	23%	1	8%	1	8%	5	38%	8	62%
Holidays	1	8%	2	15%	2	15%	5	38%	8	62%
Keeping in touch calls (video or voice calls, for example)	2	15%	3	23%	0	0%	5	38%	8	62%
Memorial days	3	23%	2	15%	0	0%	5	38%	8	62%
Mothers' groups	2	15%	3	23%	0	0%	5	38%	8	62%
Music therapy	3	23%	2	15%	0	0%	5	38%	8	62%
Play therapy	3	23%	2	15%	0	0%	5	38%	8	62%
Telephone advice	2	15%	1	8%	2	15%	5	38%	8	62%
Befriending	1	8%	1	8%	2	15%	4	31%	9	69%

Bereavement weekends	1	8%	2	15%	1	8%	4	31%	9	69%
Continuing care for children and young people	2	15%	1	8%	1	8%	4	31%	9	69%
Hydrotherapy	3	23%	1	8%	0	0%	4	31%	9	69%
Short break without clinical care	2	15%	0	0%	2	15%	4	31%	9	69%
Support and information about post mortem and funeral planning	1	8%	1	8%	2	15%	4	31%	9	69%
Advance care planning	0	0%	0	0%	3	23%	3	23%	10	77%
Art therapy	1	8%	2	15%	0	0%	3	23%	10	77%
Care coordination/navigator/keyworking	2	15%	0	0%	1	8%	3	23%	10	77%
Complementary therapies	1	8%	2	15%	0	0%	3	23%	10	77%
Dream/wish-granting	2	15%	0	0%	1	8%	3	23%	10	77%
Education for children and young people (for example, early years, school or further education)	3	23%	0	0%	0	0%	3	23%	10	77%
Education and training for parents, carers and staff external to your organisation	2	15%	1	8%	0	0%	3	23%	10	77%
End of life care in the child's home or other community setting	1	8%	1	8%	1	8%	3	23%	10	77%
Physiotherapy	3	23%	0	0%	0	0%	3	23%	10	77%
Short break care in-patient	0	0%	0	0%	3	23%	3	23%	10	77%
Social care	3	23%	0	0%	0	0%	3	23%	10	77%
Transition to adult services - supporting young people to develop a transition plan	1	8%	1	8%	1	8%	3	23%	10	77%
Transport	1	8%	2	15%	0	0%	3	23%	10	77%
End of life care in-patient	1	8%	0	0%	1	8%	2	15%	11	85%
Food parcels	1	8%	1	8%	0	0%	2	15%	11	85%
Grandparents' groups	2	15%	0	0%	0	0%	2	15%	11	85%
Monitoring technology	1	8%	0	0%	1	8%	2	15%	11	85%
Nursing care - in-house	0	0%	1	8%	1	8%	2	15%	11	85%
Occupational therapy	2	15%	0	0%	0	0%	2	15%	11	85%

Research	2	15%	0	0%	0	0%	2	15%	11	85%
Speech therapy	2	15%	0	0%	0	0%	2	15%	11	85%
Spiritual support	0	0%	1	8%	1	8%	2	15%	11	85%
Tracheostomy care	1	8%	0	0%	1	8%	2	15%	11	85%
Transition to adult services - implementing a young person's transition plan, working together with other providers or agencies	1	8%	1	8%	0	0%	2	15%	11	85%
Wheelchairs: providing and maintaining	1	8%	1	8%	0	0%	2	15%	11	85%
Care of body post death (for example, providing a cool room and family support)	0	0%	0	0%	1	8%	1	8%	12	92%
Day care	0	0%	0	0%	1	8%	1	8%	12	92%
Dietetics	0	0%	0	0%	1	8%	1	8%	12	92%
Emergency care - in house	0	0%	0	0%	1	8%	1	8%	12	92%
Enteral Nutrition	0	0%	0	0%	1	8%	1	8%	12	92%
IV: Essential continuous intravenous/Subcutaneous therapies (not nutrition)	0	0%	0	0%	1	8%	1	8%	12	92%
IV: Supportive intermittent intravenous/Subcutaneous therapies (not nutrition)	0	0%	0	0%	1	8%	1	8%	12	92%
Medical supervision - led by specialist paediatric palliative medicine consultant(s)	0	0%	0	0%	1	8%	1	8%	12	92%
Medical supervision - other doctors	0	0%	0	0%	1	8%	1	8%	12	92%
Monitoring technologies (e.g. blood sugar)	0	0%	0	0%	1	8%	1	8%	12	92%
Named medical specialist	0	0%	0	0%	1	8%	1	8%	12	92%
Nursing care - patient's home	0	0%	1	8%	0	0%	1	8%	12	92%
Nutrition: Total Parenteral Nutrition	0	0%	0	0%	1	8%	1	8%	12	92%
Oxygen therapy	0	0%	0	0%	1	8%	1	8%	12	92%
Parallel planning	0	0%	0	0%	1	8%	1	8%	12	92%

Pharmacy with expertise in children's palliative care	0	0%	0	0%	1	8%	1	8%	12	92%
Short break care in patient's home	1	8%	0	0%	0	0%	1	8%	12	92%
Step down care	0	0%	0	0%	1	8%	1	8%	12	92%
Stoma care	0	0%	0	0%	1	8%	1	8%	12	92%
Symptom management, including pain	0	0%	0	0%	1	8%	1	8%	12	92%
Urinary catheter care and/or catheterization	0	0%	0	0%	1	8%	1	8%	12	92%
Ventilation: Essential ventilation (Level 3/Priority level of need - unable to breathe independently, disconnection would be fatal)	0	0%	0	0%	1	8%	1	8%	12	92%
Ventilation: Necessary ventilation (Level 2/Severe level of need - has respiratory drive and would survive accidental disconnection, but would be unwell)	0	0%	0	0%	1	8%	1	8%	12	92%
Ventilation: Supportive ventilation (Level 1/High level of need - can be discontinued for up to 24 hours without clinical harm)	0	0%	0	0%	1	8%	1	8%	12	92%
Hospital-based paediatric intensive care	0	0%	0	0%	0	0%	0	0%	13	100%
Hospital-based neonatal intensive care	0	0%	0	0%	0	0%	0	0%	13	100%
Dialysis	0	0%	0	0%	0	0%	0	0%	13	100%
Emergency care - patient's home	0	0%	0	0%	0	0%	0	0%	13	100%
Home adaptations	0	0%	0	0%	0	0%	0	0%	13	100%
Specialist paediatric oncology outreach nursing	0	0%	0	0%	0	0%	0	0%	13	100%
Rapid transfers which allow urgent transfer to a child or family's preferred place	0	0%	0	0%	0	0%	0	0%	13	100%

Appendix five: an estimated cost of providing children's palliative care in England

Staff role	Specialist or core children's palliative care - or both	Number of WTE needed per children's palliative care network																		Total WTE	Cost (minimum)
		NHS pay band (if applicable)	Annual salary per person £																		
				East of England	East Midlands	London (North)	London (South West)	London (South East)	Kent and Medway	North East	North West	South Central North (Thames Valley)	South Central North (Sussex)	South Central South (Wessex)	South East (Surrey and Sussex)	West Midlands	Yorkshire and Humber				
Consultants in Paediatric Palliative Medicine (PPM)	Specialist	Threshold 8*	£ 120,273.17	6	6	2	2	2	3	6	6	3	3	6	6	6	60	£ 7,216,389.90			
Consultant paediatricians with a special interest in paediatric palliative medicine	Specialist	Threshold 8*	£ 120,273.17	6	6	2	2	2	3	6	6	3	3	6	6	6	60	£ 7,216,389.90			
Specialty registrars	Specialist		£ 53,077.00	3	3	2	2	2	3	3	2	2	2	3	3	3	35	£ 1,857,695.00			
NHS band 8 nurses (including nurse consultants and team leads)	Specialist	8(a)*	£ 66,523.75	6	6	3	3	3	4	6	6	4	4	4	6	6	67	£ 4,457,091.25			
NHS band 7 nurses (including clinical nurse specialists (CNSs) and children and young people's oncology outreach and symptom care nurse specialists (CYPOONS))	Specialist	7*	£ 57,298.75	6	6	3	3	3	4	6	6	4	4	4	6	6	67	£ 3,839,016.25			
Senior Specialist Pharmacists with expertise in paediatric palliative care	Specialist	8(b)*	£ 79,827.50	6	6	2	2	2	3	6	6	3	3	6	6	6	60	£ 4,789,650.00			
Practice educator	Specialist	6	£ 39,027.00	1	1	1	1	1	1	1	1	1	1	1	1	1	14	£ 546,378.00			
Experts in child/young person and family support who have expertise in providing psychosocial support in the context of palliative, end of life care and bereavement (for example in providing social, practical, emotional, psychological and spiritual support).	Specialist	4	£ 24,882.00	6	6	2	2	2	3	6	6	3	3	6	6	6	60	£ 1,492,920.00			
Community children's nurses and/or children's hospice at home nurses	Core	5-7*	£ 48,748.90															5080	£247,644,434.68		
Physiotherapists	Core	7	£ 45,839.00	6	6	2	2	2	3	6	6	3	3	6	6	6	60	£ 2,750,340.00			
Occupational therapists	Core	7	£ 45,839.00	6	6	2	2	2	3	6	6	3	3	6	6	6	60	£ 2,750,340.00			
Speech and language therapists	Core	6	£ 39,027.00	6	6	2	2	2	3	6	6	3	3	6	6	6	60	£ 2,341,620.00			
Dieticians	Core	6	£ 39,027.00	6	6	2	2	2	3	6	6	3	3	6	6	6	60	£ 2,341,620.00			
Social workers	Core	6	£ 39,027.00	6	6	2	2	2	3	6	6	3	3	6	6	6	60	£ 2,341,620.00			
Transition workers or transition service	Core	N/A	£ 20,000.00	6	6	2	2	2	3	6	6	3	3	6	6	6	60	£ 1,200,000.00			
Family support workers	Core	N/A	£ 35,000.00	6	6	2	2	2	3	6	6	3	3	6	6	6	60	£ 2,100,000.00			
Practitioners with recognised post graduate qualifications in psychological care with palliative care experience working at level 3 and 4	Core	4	£ 24,882.00	6	6	2	2	2	3	6	6	3	3	6	6	6	60	£ 1,492,920.00			
Practitioners with spiritual care experience at level 3 or 4	Core	4	£ 24,882.00	6	6	2	2	2	3	6	6	3	3	6	6	6	60	£ 1,492,920.00			
Practitioners providing family support in the context of bereavement	Core	N/A	£ 22,931.00	6	6	2	2	2	3	6	6	3	3	6	6	6	60	£ 1,375,860.00			
Children's hospice medical cover: specialist children's palliative care consultants	Both	Threshold 8*	£ 120,273.17																£ 13,116,159.15		
Children's hospice care staff: band 2 or equivalent	Both	2*	£ 24,897.50															204	£ 5,079,090.00		
Children's hospice care staff: band 3 or equivalent	Both	3*	£ 27,221.25															298	£ 8,122,821.00		
Children's hospice care staff: band 4 or equivalent	Both	4*	£ 31,102.50															177	£ 5,492,701.50		
Children's hospice care staff: band 5 or equivalent	Both	5*	£ 39,417.50															429	£ 16,894,340.50		
Children's hospice care staff: band 6 or equivalent	Both	6*	£ 48,783.75															375	£ 18,279,271.13		
Children's hospice care staff: band 7 or equivalent	Both	7*	£ 57,298.75															160	£ 9,184,989.63		
Children's hospice care staff: band 8 or equivalent	Both	8(a)*	£ 66,523.75															109	£ 7,277,698.25		
Children's hospice care staff: band 9 or equivalent	Both	9	£ 135,093.75															1	£ 175,621.88		
Administrative support	Both	4	£ 24,882.00	2	2	1	1	1	1	2	2	1	1	1	2	2	2	21	£ 522,522.00		
Managed clinical network co-ordinators	Both	N/A	£ 50,000.00	1	1	1	1	1	1	1	1	1	1	1	1	1	1	14	£ 700,000.00		
Data managers	Both	N/A	£ 43,772.00	1	1	1	1	1	1	1	1	1	1	1	1	1	1	14	£ 612,808.00		
TOTAL																		£384,705,228.01			
* Assumption made that 69% of professional time will be, on average, spent providing care outside of normal working hours, at weekends and on bank holidays																					

These estimates are based on the following assumptions:

Consultants in Paediatric Palliative Medicine (PPM)

1. We estimate that there are currently 18 specialist GRID-trained paediatric palliative medicine consultants in England and a very limited number of paediatric consultants who practice with an interest in palliative care. There are many regions in the UK with no access to paediatric palliative medicine specialists. Many single-handed consultants have no cover for leave or sickness and 'reprieve' from service requirement can be very challenging.
2. RCPCH have previously reported that paediatric palliative medicine specialists are very concerned about paediatricians taking on the 'lead' for palliative care services without having key capabilities and training in place. It states that a lack of access to fully trained specialists for advice and support is resulting in some unintended poor practice³³.
3. During the third oral evidence session of the APPG for Children Who Need Palliative Care inquiry into the extent to which the government's end of life care choice commitment was being met for children in England, Dr Simon Clark, Officer for Workforce Planning at RCPCH, made a conservative estimate that between 40-60 GRID-trained children's palliative care consultants were needed in the UK³⁴. This suggests a significant deficit of 25-45 consultants. We estimate that five full time equivalent specialist children's palliative care consultants are needed in every region to maintain a level of service 24 hours a day, seven days a week. This would be consistent with the standard of quality set out by NICE³⁵.
4. Separately, we also estimate that specialist GRID-trained children's palliative care consultants need to be available to provide medical support to children's hospices. This includes enough consultants to provide one four-hour period of programmed activity per week day at each children's hospice service in England, in addition to a rota resourced to make sure that, at any one time, day or night, there are three consultants available on call to provide 24/7 medical support to children's hospices within their region.

NHS community children's nurses (CCNs) and/or children's hospice at home nurses

5. The Royal College of Nursing (RCN) recommends that for an average-sized district, with a child population of 50,000, a minimum of 20 Whole Time Equivalent (WTE) community children's nurses are required to provide a holistic community children's nursing service³⁶. The Office of National Statistics estimates that there are 12,699,899 children aged 0-18 in England³⁷. If the RCN recommendation were to be met, this would require approximately 5,080 community children's nurses.

33 RCPCH. 2018. Written evidence to the APPG for Children Who Need Palliative Care. Available to download from: https://www.togetherforshortlives.org.uk/wp-content/uploads/2018/06/PolRes_RCPCH.pdf

34 The All-Party Parliamentary Group for Children Who Need Palliative Care. 2018.

Oral evidence: how the government is meeting its commitment to choice for babies, children and young people who need palliative care. Session 5: 7 March 2018. Available to download from: https://www.togetherforshortlives.org.uk/wp-content/uploads/2018/10/Pol_Res_Transcription_APPG_inquiry_session_five.pdf

35 The National Institute for Health and Care Excellence. 2017. End of life care for infants, children and young people – NICE quality standard [QS160]. Available to download from: <http://bit.ly/2M6BHx3>

36 RCN. 2014. The future for community children's nursing: challenges and opportunities. P.10. Available to download from: <http://bit.ly/1QgLhZb>.

37 Office for National Statistics. 2018. Population Estimates Analysis Tool. Available to download from: <http://bit.ly/2KhPnE5>

Children's hospice non-medical care and support workforce

6. Together for Short Lives carried out a survey of children's hospice organisations in April 2022. In the survey we asked about the vacancies in non-medical care and support roles currently being experienced by these organisations and how this was having an impact on the services they were able to provide.
7. The non-medical care and support workforce employed across all 34 children's hospice organisations was approximately 1431.0 WTE (extrapolated from responses of 27 hospices).
8. There were an estimated 323.0 WTE vacancies across the 34 children's hospice charities (extrapolated from responses of 27 hospices).
9. Using these figures, we estimate that 1754.0 WTE children's hospice nurses are needed in England:

	Number of WTE children's hospice non-medical care and support staff employed in England in 2022	Number of WTE children's hospice non-medical care and support staff vacancies in England in 2022	Total number of WTE children's hospice non-medical care and support staff needed (WTE employed + WTE posts vacant)
Band 2	155.4	48.6	204.0
Band 3	242.4	56.0	298.4
Band 4	158.9	17.7	176.6
Band 5	318.3	111.0	429.3
Band 6	317.6	57.1	374.7
Band 7	137.8	22.6	160.3
Band 8	100.6	8.8	109.4
Band 9	0.0	1.3	1.3
Total	1431.0	322.2	1754.0

Other professionals

10. In paragraphs 1.5.2 to 1.5.4 (inclusive) of its end of life care for infants, children and young people with life-limiting conditions guideline³⁸, NICE recommend that children and young people with life-limiting conditions should be cared for by a defined multidisciplinary team.

11. The guideline states that, depending on the needs of the child or young person, the multidisciplinary team may include:

- healthcare professionals from primary, secondary or tertiary services, including specialists in the child's underlying life-limiting condition, hospice professionals and members of the specialist palliative care team (see recommendation 1.5.4)
- social care practitioners
- education professionals
- chaplains
- allied health professionals (for example physiotherapists, occupational therapists, and psychological therapists).

12. The specialist paediatric palliative care team should include at a minimum:

- a paediatric palliative care consultant
- a nurse with expertise in paediatric palliative care
- a pharmacist with expertise in specialist paediatric palliative care
- experts in child and family support who have experience in end of life care (for example in providing social, practical, emotional, psychological and spiritual support).

38 The National Institute for Health and Care Excellence. 2016. End of life care for infants, children and young people with life-limiting conditions: planning and management - NICE guideline [NG61]. Available to download from: <http://bit.ly/2ODg2hY>

Appendix six: estimated spending on children's palliative care in England

Organisation	Item	Amount
NHS Integrated Care Systems	Community children's nurses (based on May 2021 workforce)	£27,826,251.00
NHSE/I	Children's Hospice Grant (by 2023/24)	£25,000,000.00
NHSE/I	Long Term Plan children's palliative care match funding (by 2023/24)	£7,000,000.00
NHS Integrated Care Systems	Long Term Plan children's palliative care match funding (by 2023/24)	£7,000,000.00
NHS Integrated Care Systems	Funding for children's hospices	£16,966,874.56
Total		£83,793,125.56

These estimates are based on the following assumptions:

- The mean charitable expenditure per children's hospice in England 2020/21 was £3,142,911.55.
- The mean CCG income per children's hospice in England 2020/21 was £499,025.72.
- The number of children's hospice organisations in England is 34.
- The number of WTE NHS community children's nurses employed in England in January 2022 was 713³⁹.
- The 2021/22 Agenda for Change pay rate for a band 6 nurse is £39,027⁴⁰.

39 NHS Digital. 2021. NHS Workforce Statistics – January 2022. Available to download from: <https://digital.nhs.uk/data-and-information/publications/statistical/nhs-workforce-statistics/january-2022>

40 NHS. 2021. Agenda for change - pay rates. Available to download from: <https://www.healthcareers.nhs.uk/working-health/working-nhs/nhs-pay-and-benefits/agenda-change-pay-rates/agenda-change-pay-rates>