

## **Response 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, STP 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 team

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)
CCN teams in Midlands Partnership Foundation Trust (MPFT), Medical cover from Dr Thompson and Dr Roe University Hospitals North Midlands (UHNM). Lack of specialist pharmacist service	North Staffordshire	NHS 2 PA's/ week
CCN teams in MPFT, BCH, One consultant Dr Liang, UHNM: Dr Thompson and Dr Roe, If New Cross, no identified consultant for palliative care	West Staffordshire	NHS 2 PA's/ week
CCN teams if BCH, One consultant Dr Liang, <b>If Burton and Derby no</b> <b>identified consultant for palliative</b> <b>care</b>	East Staffordshire	NHS
Birmingham Women's and Children's Hospital NHS Trust Palliative and Bereavement Team- Consultant support of local community nursing team	West Midlands (if patient already known to BWCH)	NHS from 1/4/21 (previous 3 years charity funded post)
Acorns Hospice	West Midlands and Gloucestershire	Charitable With 35% contribution (total) from CCG's
Dudley- Nil available	n/a	n/a
Shropshire Community Health Trust	Shropshire and T&W	NHS
SCHT Paediatricians	Shropshire and T&W	NHS

SCHT Community Children's Nursing service	Shropshire and T&W	NHS
Hope House Hospice	Shropshire and T&W	Charity

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)
MPFT provision by psychologist/ If oncology Hospital psychologist	North/ South (parts of Cannock) Staffordshire- Must have oncology diagnosis	NHS/charity
Hospice counsellor available	(not diagnosis limited)	
If oncology Hospital psychologist Hospice counsellor available	West Staffordshire Must have oncology diagnosis	NHS/charity
If oncology Hospital psychologist Hospice counsellor available	East Staffordshire Must have oncology diagnosis	NHS/charity
Birmingham Women's and Children's Hospital NHS Trust Palliative and Bereavement Team- Consultant support of local community nursing team	West Midlands (patient already known to BWCH). Family support worker- support only available in hospital. Can do remote support at home	Consultant: NHS from 1/4/21 previous 3 years charity funded post Family support worker: NHS
Acorns Hospice	West Midlands and Gloucestershire	Charitable with contribution from CCG's
Dudley Integrated Community Children's Nursing team Mon-Fri 08.00-16.00	Dudley	NHS- 3 WTE band 6 1 wte band 5 and 1.2 wte band 3. I am band 7 and team lead the ccn and special schools
The Donna Louise/ Dougie Mac Hospice	Stoke and Staffordshire	Charity
Hope House Hospice	Shropshire and T&W	Charity
SCHT Paediatric Psychology Service	Shropshire and T&W	NHS

3) 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 house.

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)
CCN teams in Midlands Partnership Foundation Trust (MPFT) 3.8 wte, Medical cover from Dr Thompson and Dr Roe University Hospitals North Midlands (UHNM)	North Staffordshire	NHS- 2 PA's total/ week- 1 PA per Consultant
CCN teams in MPFT (8wte), BCH if known to them, One consultant Dr Liang, If UHNM: Dr Thompson and Dr Roe, <b>None for New Cross/Walsall</b> <b>Manor CYP would use there</b> <b>general consultant</b>	West Staffordshire	NHS 2 PA's (Stoke and Staffordshire)- 1 PA per Consultant 8 WTE nursing
CCN teams in MPFT (7.2 WTE), BCH if known to them, One consultant Dr Liang, If UHNM: Dr Thompson and Dr Roe, <b>None for Burton and Derby CYP,</b> would use there general paediatric consultant	East Staffordshire	NHS
Birmingham Women's and Children's Hospital NHS Trust Palliative and Bereavement Team- Consultant support of local community nursing team	West Midlands (if patient already known to BWCH) Consultant and Senior Palliative nurse ( non medical prescriber) support of local community nursing team by phone	Consultant role: NHS from 1/4/2021. Joint post with Birmingham Community healthcare Trust. 5 sessions community 5 hospital based.1 wte Senior palliative nurse: NHS 1 wte
Acorns working with CCN's on a planned basis Dudley Integrated Community Children's Nursing team Mon-Fri 08.00-16.00 (no syringe drivers)	West Midlands and Gloucestershire Dudley	Charitable (From July 2021) Nhs- 3 WTE band 6 1 wte band 5 and 1.2 wte band 3. I am band 7 and team lead the ccn and special schools
SCHT Dr Buch SCHT CCN Service	T &W, Shropshire Shropshire and T&W	NHS NHS

Shrewsbury and Telford Hospitals	Shropshire and T&W	NHS
Children's Oncology Team		

4) CYP approaching 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)
CCN teams in Midlands Partnership Foundation Trust (MPFT), Medical cover from Dr Thompson and Dr Roe University Hospitals North Midlands (UHNM)- 5 consultants ( 2 with paed pall care training and 3 with experience) support an out of hours rota which is only initiated when an end of life patient is identified,	North Staffordshire	NHS- 2.5 PA's
CCN teams in MPFT, BCH if known to them, One consultant Dr Liang, If UHNM: Dr Thompson and Dr Roe lead 5 consultant rota (2 with paed pall care training and 3 with experience) support an out of hours rota which is only initiated when an end of life patient is identified <b>None for New Cross/Walsall</b> <b>Manor CYP</b> (Dr Liang available in hours only)	West Staffordshire	NHS- 2.5 PA's
CCN teams in MPFT, BCH if known to them, One consultant Dr Liang, If UHNM: Dr Thompson and Dr Roe, None for Burton and Derby (Dr Liang available in hours only)	East Staffordshire	NHS
Birmingham Women's and Children's Hospital NHS Trust Palliative and Bereavement Team- Consultant support of local community nursing team (Dr Liang available in hours only)	No out of hours Consultant availability	
Acorns Hospice- Telephone support provided for the family when a known child at EoL is identified from the hospice and access to hospice 24/7 provided (Dr Liang available in hours only)	West Midlands and Gloucestershire	Charitable with contribution from CCG's
Dudley- NOT AVAILABLE The Donna Louise / DMH	n/a Stoke and Staffordshire	n/a Charity

Telephone support provided for the		
family when a known child at EoL is		
identified from the hospice and		
access to hospice 24/7 provided-		
This has been COVID impacted and		
is not currently available (hopefully		
will be back in place come July 2021		
SCHT CCN Service On-call service	Shropshire and T&W?	NHS
as required		

5) CYP 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 professional, team or provider organisation	Geographical areas where this standard is being met	How this work is being funded (NHS, local authority or charitable)
CCN teams in Midlands Partnership Foundation Trust (MPFT), Medical cover from Dr Thompson and Dr Roe University Hospitals North Midlands (UHNM), DLT	North Staffordshire	NHS 2 PA's (Stoke and Staffordshire)- 1 PA per Consultant
CCN teams in Midlands Partnership Foundation Trust (MPFT), Medical cover if UHNM CYP from Dr Thompson and Dr Roe University Hospitals North Midlands (UHNM), DLT BCH consultant Dr Liang <b>No specialist consultant at New</b> <b>Cross, Walsall manor</b>	West Staffordshire	NHS- 2 PA's (Stoke and Staffordshire)- 1 PA per Consultant Charity
CCN teams in Midlands Partnership Foundation Trust (MPFT), Medical cover if UHNM CYP from Dr Thompson and Dr Roe University Hospitals North Midlands (UHNM), DLT BCH consultant Dr Liang <b>No specialist consultant at,</b> <b>Burton or Derby</b>	East Staffordshire	NHS/Charity
Birmingham Women's and Children's Hospital NHS Trust Palliative and Bereavement Team- Consultant support of local community nursing team BCH consultant Dr Liang	West Midlands (if patient already known to BWCH) Consultant and Senior palliative nurse (non-prescriber) support of local Community Nursing team by phone. Consultant available to support at home in	Consultant role: NHS from 1/4/ 2021 previous 3 years charity funded post. Senior palliative nurse: NHS

	working hours	
Acorns Hospice- Outreach Nursing	West Midlands and	Charitable
Service Monday- Friday 9am - 5pm	Gloucestershire	
Dudley Integrated Community	Dudley	NHS
Children's Nursing team Mon-Fri		
08.00-16.		
The Donna Louise / DMH	Consultant sessions at	Charity / NHS
	the hospice/ Symptom	partnership
	management clinics	
SCHT Dr Buch Paediatrician	T &W, Shropshire	NHS
SCHT CCN Service	Shropshire and T&W	NHS

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)
MPFT CCN service currently only have 24 hour support to CYP if end of life. Access to symptom management from a consultant with paediatric palliative care experience is only available working hours and NOT 24 hours a day (unless EOL care) CCN provision is 0900-21:00 7 days a week In the north Staffordshire only. There are 2 / month enhanced symptom management clinics as well Patient known to the palliative service also have access to telephone support. This is provided by a nurse in an on call capacity working from home out of hours.	North/ South Staffordshire- standard NOT met	NHS
MPFT There is CCN support 7 days a week 0900-2100 and 0900-1700 BH	Standard not met in West as not 24/7	
MPFT CCN Service 7 days a week 0900-2000 weekdays and 0900- 15700 weekends and BH	Standard not met in East as not 24/7	
Birmingham Women's and Children's Hospital NHS Trust Palliative and Bereavement Team- Consultant support of local	No Out of hours Consultant availability	

community nursing team		
Acorns Hospice-	West Midlands and	Charitable with
Telephone advice from the hospice	Gloucestershire	contribution from
provided for identified children		CCG's
known to the hospice		
Dudley area- NOT AVAILABLE	n/a	n/a
The Donna Louise / DMH –	Staffordshire and Stoke	Charitable
Telephone advice available for		
identified children known to the		
hospice		
SCHT – no service	Shropshire and T&W	n/a

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)
MPFT CCN North have access to psychology session for CYP and parents	North Staffordshire	NHS/Charity
Donna Louise Hospice/Dougie Mac Hospice-	Stoke and Staffordshire	Charity
Birmingham Women's and Children's Hospital NHS Trust Palliative and Bereavement Team- Consultant support of local community nursing team	West Midlands (patient already known at BWCH) Family support Worker- support only available in hospital- can be remote to support at home Bereavement support by phone (at standardised time points)	Bereavement team- NHS Family support worker- NHS
UHNM- oncology patients only and those admitted to PICU	Stoke and Staffordshire	NHS
Acorns Hospice- Family Services provided by registered professionals providing psychosocial and pre and post bereavement support approx. 15 WTE across whole region .	West Midlands and Gloucestershire	Charitable and contributions from NHS CCG.
Dudley area- NOT AVAILABLE	n/a	n/a
SCHT	Shropshire and T&W	NHS

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 wish.

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)
MPFT CCN team have respite workers	North Staffordshire	NHS/Charity
MPFT CCN team have a respite worker(limited respite)	West Staffordshire	NHS/Charity
MPFT CCN team have respite workers	East Staffordshire	NHS/Charity
Donna Louise hospice- provision of respite markedly reduced due to COVID , but also financial difficulties	Stoke and Staffordshire	Charity Minimal NHS (5%)
Birmingham Women's and Children's Hospital NHS Trust Palliative and Bereavement Team- No provision	n/a	n/a
Acorns Hospices and Acorns outreach service	West Midlands and Gloucestershire	Charitable and contributions from NHS CCG.
		Paid for Beds can be funded by social care and or NHS based on a case by case basis
Dudley area- NOT AVAILABLE	n/a	n/a
Only a limited offer from CCN Service for the most complex	Shropshire and T&W	NHS
children with nursing needs		