

## London Children's Palliative Care Network audit 2020

### 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<sup>[1]</sup>.

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)
Kaleidoscope Team, Central London Community Healthcare	London Boroughs -Westminster, Hammersmith and Fulham and Kensington and Chelsea. Central London, Hammersmith and Fulham and West London CCG's	NHS funded
The SPACE team	South West London CCGs	NHS funded
Diana Children's Community Palliative Care Team, East London NHS Foundation Trust (nursing, psychology and play specialist MDT)	London Borough of Newham	NHS funded
Royal Marsden Palliative care team	South Thames, Kent, Surrey Sussex	NHS funded
Life Force	Camden, Haringey, Islington	NHS funded
Noah's Ark Children's Hospice	Barnet, Enfield, Camden, Haringey, Islington, Hertsmere (In response to the pandemic, Noah's Ark will consider referrals from outside our catchment area on a case-by-case basis)	NHS Funded, Local Authority, Charitable
Richard House Children's Hospice (RHCH)	Newham, Barking and Dagenham, City&Hackney, Tower Hamlets, Waltham Forest, Redbridge, Havering	NHS funded

<sup>[1]</sup> 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>

Shooting Star Children's Hospices	Brent, Ealing, Harrow, Hounslow, Hillingdon, Kensington and Chelsea, Hammersmith and Fulham, Westminster, Richmond, Merton, Sutton, Kingston, Croydon, Wandsworth	Charity, Local Authority and NHS funded.
Haven House Children's hospice	Waltham Forest, Redbridge, Havering, Barking & Dagenham, West Essex, Enfield (If referred to the Specialist Children's palliative care team at GOSH)	NHS & Charity funded
Evelina London children's hospital Palliative Care Team	London boroughs, Kent, Surrey, Sussex plus any child known to the ELCH network	NHS Funded
Louis Dundas Palliative Care Team Great Ormond Street London	London Boroughs and The South East. Essex any CYP referred by GOSH specialist teams	NHS Funded
Demelza Children's Hospice	Bexley, Bromley, Croydon, Greenwich, Lambeth, Lewisham, Southwark	Charitable, Local Authority and NHS funded.

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.

<b>Name of individual professional, team or provider organisation</b>	<b>Geographical areas where this standard is being met</b>	<b>How this work is being funded (NHS, local authority or charitable)</b>
Royal Marsden Palliative care team	South Thames	Charity funded
The SPACE team	South West London	NHS funded
Diana Children's Community Palliative Care Team, Psychology and Play specialist Service within this team	London Borough of Newham	NHS funded
Kaleidoscope Team and Children's Community Nursing Team, Central London Community Healthcare	Westminster, Kensington and Chelsea and Hammersmith and Fulham. Central London, Hammersmith and Fulham and West London CCG's	NHS funded
Life Force	Camden, Haringey & Islington	NHS funded - provided by our psychologists and youth worker.
Noah's Ark Children's Hospice	Barnet, Enfield, Camden, Haringey, Islington, Hertsmere (In response to the pandemic, Noah's Ark will consider referrals from outside our catchment area on a case-by-case basis)	NHS Funded, Local Authority, Charitable
RHCH	Newham, Tower Hamlets, City & Hackney, Redbridge, Havering, Barking and Dagenham	NHS funded
Shooting Star Children's Hospices	Brent, Ealing, Harrow, Hounslow, Hillingdon, Kensington and Chelsea, Hammersmith and Fulham, Westminster, Richmond, Merton, Sutton, Kingston, Croydon, Wandsworth	Charity, Local Authority and NHS funded.
Haven House Children's hospice	Waltham Forest Redbridge Havering Barking & Dagenham West Essex Enfield	Charity & NHS funded
Evelina London Children's hospital Paediatric Palliative Care Team	London boroughs, Kent, Surrey, Sussex plus any child known to the ELCH network	NHS Funded

Louis Dundas palliative care team and Bereavement manager 1.0wte Great Ormond Street	London Boroughs and South East. Essex and CYP referred by GOSH specialised teams	NHS funded
Demelza Children's Hospice	Bexley, Bromley, Croydon, Greenwich, Lambeth, Lewisham, Southwark	Charitable.

3. Children and young people approaching the end of life and being cared for at home have access to both children's nursing care<sup>[2]</sup> and advice from a consultant in paediatric palliative care<sup>[3]</sup> during normal working hours.

<b>Name of individual professional, team or provider organisation</b>	<b>Geographical areas where this standard is being met</b>	<b>How this work is being funded (NHS, local authority or charitable)</b>
The SPACE team	South West London CCGs	NHS Funded
Diana Children's Community Palliative Care Team Specialist Nurses	London Borough of Newham	NHS funded NB the consultant support if via Tertiary Centres, accessed as required
Royal Marsden Palliative care team	South Thames	NHS funded
Kaleidoscope Team and Childrens Community Nursing Team, Central London Community Healthcare	London Boroughs - Westminster, Kensington and Chelsea and Hammersmith and Fulham. Central London, Hammersmith and Fulham and West London CCG's	NHS Funding No consultant within the team but Specialist Consultant from Tertiary Centres, accessed as required.
Life Force	Camden Haringey & Islington	NHS (we have SLA with GOS palliative care providing us with Consultant hours)
Noah's Ark Children's Hospice	Barnet, Enfield, Camden, Haringey, Islington, Hertsmere	Medical Director Cover (Paediatric Consultants).

<sup>[2]</sup> 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.

<sup>[3]</sup> 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.

	(In response to the pandemic, oah's Ark will consider referrals from outside our catchment area on a case-by-case basis)	Paediatric Consultants (Barnet Hospital SLA). Referred babies, children and young people who are referred under their own Medical Team.
RHCH	Newham, Barking and dagenham, City and Hackney, Tower Hamlets, Redbridge, Havering	NHS funded, working with referring consultant
Shooting Star Children's Hospices	Brent, Ealing, Harrow, Hounslow, Hillingdon, Kensington and Chelsea, Hammersmith and Fulham, Westminster, Richmond, Merton, Sutton, Kingston, Croydon, Wandsworth	Charity, Local Authority and NHS funded.
Haven House Children's hospice	Waltham Forest Redbridge Havering Barking & Dagenham West Essex Enfield	NHS & Charity
Evelina London Children's hospital Paediatric Palliative Care Team	London boroughs, Kent, Surrey, Sussex plus any child known to the ELCH network	NHS Funded
Louis Dundas Palliative Care team GOSH	London Boroughs and South East. Essex and CYP referred by GOSH specialised teams	NHS funded
Demelza Children's Hospice	Bexley, Bromley, Croydon, Greenwich, Lambeth, Lewisham, Southwark	Charitable and NHS funded.

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.

<b>Name of individual professional, team or provider organisation</b>	<b>Geographical areas where this standard is being met</b>	<b>How this work is being funded (NHS, local authority or charitable)</b>
Kaleidoscope Team and Childrens community nursing team (Medical support from GOSH Palliative care team) Central London Community Healthcare	London Boroughs -Westminster, Kensington and Chelsea, Hammersmith and Fulham. Central London, West London and Hammersmith and Fulham CCG's	NHS funded. Nurse led visiting service is available. No consultant within the trust but Specialist Consultant from Tertiary centres accessed as required.
Life Force	Camden, Haringey & Islington	We work with individual community children's nursing teams in each

		area to cover a 7 day a week service. If parents are wanting overnight care this is commissioned on an individual basis. We have a SLA with GOS Louis Dundas Centre which provides 24 hour telephone support to the families. All NHS funded
Noah's Ark Children's Hospice	Barnet, Enfield, Camden, Haringey, Islington, Hertsmere (In response to the pandemic, Noah's Ark will consider referrals from outside our catchment area on a case-by-case basis)	Charity Funded through Noah's Ark Medical Directors (Paediatric Consultants). Paediatric Consultants (Barnet Hospital SLA). Referred babies, children and young people who are referred under their own Medical Team.
RHCH	Newham, tower Hamlets, Barking and Dagenham, City and Hackney, Redbridge, Havering	NHS funded. Gosh Palliative care team for advice
Shooting Star Children's Hospices	Brent, Ealing, Harrow, Hounslow, Hillingdon, Kensington and Chelsea, Hammersmith and Fulham, Westminster, Richmond, Merton, Sutton, Kingston, Croydon, Wandsworth	Charity, Local Authority and NHS funded.
Haven House Children's hospice	Waltham Forest Redbridge Havering Barking & Dagenham West Essex Enfield	NHS & Charity
Diana Children's Community Palliative Care Team	London Borough of Newham	NHS Funded Nursing on call service 24/7 for children at EoL, individually commissioned packages of agency nursing care for EoL at home, consultant on call support 24/7 via tertiary services
Evelina London Children's hospital Paediatric Palliative Care Team	London boroughs, Kent, Surrey, Sussex plus any child known to the ELCH network	NHS Funded
Louis Dundas Palliative care team GOSH	London Boroughs and South East. Essex, CYP referred by GOSH specialist teams	NHS funded

Demelza Children's Hospice	Bexley, Bromley, Croydon, Greenwich, Lambeth, Lewisham, Southwark	Charitable and NHS funded.
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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.

<b>Name of individual professional, team or provider organisation</b>	<b>Geographical areas where this standard is being met</b>	<b>How this work is being funded (NHS, local authority or charitable)</b>
The SPACE team	South West London CCGs	NHS Funded
Royal Marsden Palliative care team	South Thames	NHS funded
Kaleidoscope team and Childrens community Nursing team. 7 day a week service (medical support from GOSH). Central London Community Healthcare Trust	London Boroughs- Westminster, Kensington and Chelsea and Hammersmith and Fulham. West London, central London and Hammersmith and Fulham CCGs	NHS funded
Life Force	Camden Haringey & Islington	NHS funded
Noah's Ark Children's Hospice	Barnet, Enfield, Camden, Haringey, Islington, Hertsmere (In response to the pandemic, Noah's Ark will consider referrals from outside our catchment area on a case-by-case basis)	Charity Funded through Noah's Ark Medical Directors (Paediatric Consultants). Paediatric Consultants (Barnet Hospital SLA). Referred babies, children and young people who are referred under their own Medical Team.
RHCH	Newham, Tower Hamlets, Barking and Dagenham, City and Hackney, Havering, Redbridge	NHS funded
Shooting Star Children's Hospices	Brent, Ealing, Harrow, Hounslow, Hillingdon, Kensington and Chelsea, Hammersmith and Fulham, Westminster, Richmond, Merton, Sutton, Kingston, Croydon, Wandsworth	Charity, Local Authority and NHS funded.
Haven House Children's hospice	Waltham Forest Redbridge Havering Barking & Dagenham West Essex Enfield	NHS & Charity funding  (Requires a referral to Specialist Palliative care team for consultant support)
Diana Children's Community Palliative Care Team	London Borough of Newham	NHS Funded Consultant support is via tertiary centres

Evelina London Children's hospital Paediatric Palliative Care Team	London boroughs, Kent, Surrey, Sussex plus any child known to the ELCH network	NHS Funded
Louis Dundas Palliative care team GOSH	London Boroughs, South East England. Essex. CYP referred by specialist teams at GOSH.	NHS funded
Demelza Children's Hospice	Bexley, Bromley, Croydon, Greenwich, Lambeth, Lewisham, Southwark	Charitable and NHS funded.

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.

<b>Name of individual professional, team or provider organisation</b>	<b>Geographical areas where this standard is being met</b>	<b>How this work is being funded (NHS, local authority or charitable)</b>
The SPACE team	South West London CCGs	NHS Funded
Royal Marsden Palliative care team	South Thames	NHS funded
Kaleidoscope Team and Childrens community Nursing Team, 7 day a week service. Central London Community Healthcare	Westminster, Kensington and Chelsea and Hammersmith and Fulham	NHS Funded.
Life Force	Camden Haringey & Islington	Have SLA with GOS Louis Dundas which provides 24 telephone support allow parents to manage their symptoms. We work with local CCN teams to provide support 7 days a week 8 – 6pm. If parents want care overnight this is commissioned individually and agency sought.
Noah's Ark Children's Hospice	Barnet, Enfield, Camden, Haringey, Islington, Hertsmere (In response to the pandemic, Noah's Ark will consider referrals from outside our catchment area on a case-by-case basis)	Charity Funded through Noah's Ark Medical Directors (Paediatric Consultants). Paediatric Consultants (Barnet Hospital SLA). Referred babies, children and young people who are referred under their own Medical Team.
RHCH	Newham, Tower Hamlets, Barking and Dagenham, City and Hackney, Redbridge, Havering	NHS funded



Shooting Star Children's Hospices	Brent, Ealing, Harrow, Hounslow, Hillingdon, Kensington and Chelsea, Hammersmith and Fulham, Westminster, Richmond, Merton, Sutton, Kingston, Croydon, Wandsworth	Charity, Local Authority and NHS funded.
Haven House Children's hospice	Waltham Forest Redbridge Havering Barking & Dagenham West Essex Enfield (consultant support only if referred to specialist palliative care team)	NHS/Charity funded
Evelina London Children's hospital Paediatric Palliative Care Team	London boroughs, Kent, Surrey, Sussex plus any child known to the ELCH network	NHS Funded
Louis Dundas palliative care team GOSH	London Boroughs South East England. Essex. CYP referred by GOSH specialist teams	NHS funded
Demelza Children's Hospice	Bexley, Bromley, Croydon, Greenwich, Lambeth, Lewisham, Southwark	Charitable and NHS funded.

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

<b>Name of individual professional, team or provider organisation</b>	<b>Geographical areas where this standard is being met</b>	<b>How this work is being funded (NHS, local authority or charitable)</b>
Kaleidoscope Team, 7 days a week. Nursing and Play Specialist support. Central London Community Healthcare Trust	As above	NHS funded.
Life Force	Camden, Haringey & Islington	NHS funded. Support given by psychologists and youth worker within the team.
Noah's Ark Children's Hospice	Barnet, Enfield, Camden, Haringey, Islington, Hertsmere (In response to the pandemic, Noah's Ark will consider referrals from outside our catchment area on a case-by-case basis)	NHS Funded, Local Authority, Charitable
RHCH	Newham, Barking and Dagenham, City and Hackney, Redbridge, Tower Hamlets, Havering	Charitable
Shooting Star Children's Hospices	Brent, Ealing, Harrow, Hounslow, Hillingdon, Kensington and Chelsea, Hammersmith and Fulham, Westminster, Richmond, Merton, Sutton, Kingston, Croydon, Wandsworth	Charity, Local Authority and NHS funded.
Haven House Children's hospice	Waltham Forest Redbridge Havering Barking & Dagenham West Essex Enfield (current gap in counselling provision – recruiting resource in partnership with Richard House Children's hospice)	Charitable/match NHS funding
Diana Children's Community Palliative Care Team, Psychology and Play Specialist Service	London Borough of Newham	NHS Funded
Louis Dundas Palliative care team, Psychology, 1x family support worker and 0.2 wte social worker some play specialist support just started	London Boroughs and South East. CYP referred by GOSH specialist teams If CYP has been referred to hospice then sign post to those teams for emotional support	NHS funded

Demelza Children's Hospice	Bexley, Bromley, Croydon, Greenwich, Lambeth, Lewisham, Southwark	Charitable.
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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<sup>[8]</sup>.

<b>Name of individual professional, team or provider organisation</b>	<b>Geographical areas where this standard is being met</b>	<b>How this work is being funded (NHS, local authority or charitable)</b>
Kaleidoscope Team and CCN Team (continuing Care Healthcare Packages). Kaleidoscope care workers also provide respite in the home. Central London Community Healthcare	Westminster, Kensington and Chelsea and Hammersmith and Fulham. Central London, Hammersmith and Fulham and West London CCG's.	NHS funded
Life Force	Camden, Haringey & Islington	Provide sessions of respite 3.5 hours once or twice a week. If requesting more then referral made to continuing care and social care.
Noah's Ark Children's Hospice	Barnet, Enfield, Camden, Haringey, Islington, Hertsmere (In response to the pandemic, Noah's Ark will consider referrals from outside our catchment area on a case-by-case basis).	NHS Funded, Local Authority, Charitable
RHCH	Newham, Tower Hamlets, Barking and Dagenham, City and Hackney, Redbridge, Havering	NHS funded, LA
Shooting Star Children's Hospices	Brent, Ealing, Harrow, Hounslow, Hillingdon, Kensington and Chelsea, Hammersmith and Fulham, Westminster, Richmond, Merton, Sutton, Kingston, Croydon, Wandsworth	Charity, Local Authority and NHS funded.
Haven House Children's hospice	Waltham Forest Redbridge Havering Barking & Dagenham West Essex (limited nursing and HCSW resource (2.2WTE) which is diverted to urgent end of life referrals when required)	NHS/Charity funded

<sup>[8]</sup> 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.

Demelza Children's Hospice	Bexley, Bromley, Croydon, Greenwich, Lambeth, Lewisham, Southwark	Charitable and Local Authority funded.
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Please return your completed form to [james.cooper@togetherforshortlives.org.uk](mailto:james.cooper@togetherforshortlives.org.uk) and [dan.steer@togetherforshortlives.org.uk](mailto:dan.steer@togetherforshortlives.org.uk)