

SERVICE SPECIFICATION

Service Specification Number	06_CEOL_0009
Care Pathway/Service	Palliative Care Services for Children and Young People Julia's House
Commissioner Lead	Service Improvement Manager for Children & Young People – NHS Dorset
Provider Lead	Director of Finance – Julia's House Children's Hospice Trust
Period	1 April 2013 to 31 March 2014
Date of Review	

Please note: Throughout this specification the term "Children's Hospice" includes both those services provided in a residential setting specifically for that purpose as well as palliative care services provided in the child's own home/community.

Key Service Outcomes

- Children and young people with palliative care needs and their families will have their emotional and physical challenges mitigated by the care and support they receive by the services delivered by the hospice
- Families and children report that their social, cultural, spiritual, physical and emotional needs of the child/young person and their family are met.
- It can be demonstrated that child/young person is pain free or pain is minimised as far as possible
- Child and family can demonstrate that they are supported to improve the quality of their lives through access to specialist clinical and psychological expertise, either for regular interventions, in an emergency or for respite care
- Parents and children report they are well informed about their conditions and the support/services available both within the hospice and within their own local area
- Parents and siblings experience a positive experience in the last days/hours of their child's (sister or brother's) life through the provision of timely interventions and support,
- The child and family will expect clear links and regular information exchange to be made with the named professional(key worker) in child's local community
- Choice of place of death

1. Purpose

1.1 Aims

The children's hospice will aim to offer high quality care and support to children and young people with life limited or life threatening illnesses, who are registered with a GP within the catchment area for the Clinical Commissioning Group (CCG). The hospice will provide a range of services which should include short breaks, emergency and end of life care, either within the hospice premises or within the child's home which will include various leisure and therapeutic activities and facilities to help children be comfortable. The provider will work in the context of the wider network of services and support commissioned and provided by the CCG and other partners for these children and families.

Care definitions

- Group 1 – Life-threatening conditions for which curative treatment may be feasible but can fail (cancer, irreversible organ failures)
- Group 2 – Conditions with long periods of intensive treatment aimed at prolonging life and allowing participation in normal childhood activities, but premature death possible. (cystic fibrosis, muscular dystrophy)
- Group 3 – Progressive conditions without curative treatment options, where treatment is exclusively palliative and may commonly extend over many years. (Batten's disease, mucopolysaccharidosis)
- Group 4 – Conditions with severe neurological disability which may cause weakness and susceptibility to health complications, and may deteriorate unpredictably, but are not usually considered progressive. (severe multiple disabilities, such as following brain or spinal cord injuries)

ACT and RCPCH (1997)

1.2 Evidence Base

The well researched government paper *Better Care Better Lives* (Department of Health, 2008) recognises the specialist skills and expertise of the voluntary sector, particularly children's hospices, in palliative care and end-of-life care. Local partners should work with hospices to identify the most appropriate ways to provide and deliver this support for children and their families. The document also recognises the needs of families in being able to access the specialist short breaks they need, whether at home, in a children's hospice or other voluntary sector provider, or in the community. This service specification is based on a funding agreement that has been reached between this Clinical Commissioning Group (CCG) and this Provider (as identified within this contract) who will have available a menu of services for children with palliative care needs who are eligible, based on the threshold criteria.

1.2.1. National Policy

- The National Service Framework for Children Young People & Maternity services (2004) Children Act (2004)
- *Every Child Matters* - Change for Children programme 2004
- Standards for Better Health (2004)
- Our Choice, Our Care, Our Say (2006)
- Aiming High for Disabled Children (2007 DCSF.DH)
- The Children's Plan (Department of Children, Schools and Families, 2007)
- Darzi review (October 2007)
- Better Care Better Lives (DH 2008)
- World Class Commissioning. (DH 2008)
- Healthy Lives, Brighter Futures (DCSF, DH 2009)
- Transforming Community Services (DH 2009)
- The Operating Framework for the NHS 2010-11
- Working together to safeguard children (HM Government 2010)
- National Framework for Children and Young People's Continuing Care (DH 2010)

1.2.2. National Standards

The services provided will be subject to inspection by the Care Quality Commission

All services will be required to meet the following:

- Care Quality Commission Core Standards and performance indicators
- NSF Standards for disabled and ill children
- Relevant NICE guidelines

- Children Act (2004) section 11 and other safeguarding legislation
- PEAT (patient environment assessment tool)
- All service provision should be delivered in an appropriate, safe, child/young people centred environment, which promotes effective care and optimises health outcomes
- Essence of Care –Privacy and dignity
- “You’re Welcome”

1.2.3. Local Standards –
for the area in which the hospice provides services

Local Safeguarding procedures

Local Area Agreement

Local applicable Clinical Commissioning Group or multi-agency policies and procedures

CYPP

1.3 General Overview

The provider is expected to provide holistic, family centred care in either a residential establishment or within a child’s own home. It is anticipated that the model of delivery will be as non-medicalised as possible within the parameters of the child’s medical and nursing needs.

The provider will also make available specialist expertise and advice to children’s community nursing teams and paediatric teams within the child’s local area.

1.4 Objectives

To enter and build a collaborative relationship with this/these Clinical Commissioning Group(s) which will enable care to be available to local children with palliative care needs who are eligible for care in line with the local eligibility criteria and the identified level of need set out in the Decision Support Tool from the national Framework for Continuing Care for Children and Young People (DH 2010).

The service will provide for these patients high quality:

- End of life care and support
- Short breaks care and support
- Emergency/crisis support
- Associated care such as bereavement and sibling support, symptom control, the provision of therapies including play and social activities, and advisory support to families.

This would be agreed with Clinical Commissioning Group commissioners as part of a care package for each patient.

2. Scope

2.1 Service Description

The services offered by the provider will be available to children and young people with life-limiting or life-threatening conditions and their families as outlined in Section 1.

2.2 Accessibility/acceptability

The service can be accessed by children from the age of 0-18 years registered with a local GP. Referrals to the provider will be subject to approval by the Clinical Commissioning Group commissioners. See section 4.

2.3 Whole System Relationships

The Provider will work collaboratively with NHS commissioners and providers to ensure that referrals of locally eligible children go through the agreed referral pathway as outlined in section 3 and 4.

2.4 Interdependencies

The provider will link with all relevant NHS, social care and independent providers in and out of the

Local Authority as required ensuring continuity of care for children and their families.

2.5 Relevant Clinical Networks

All providers will continue to be invited and encouraged to attend the South West Children's Palliative Care Commissioner forums.

3. Service Delivery

The provision of services for children and young people with palliative care needs provided by the hospice may be delivered in different ways through the provision of a menu of services designed to enable the delivery of specialised individual packages of care, tailored to an individual child. Hospices have always aspired to the highest standards for this group of children and this specification is supportive of that trend continuing, with clear and transparent requirements that enables demonstration of their high quality work.

3.1 Service Model

The services offered by the Provider will be available to children and young people with life-limiting or life-threatening conditions and their families. This service model is based on the guidelines for best practice by Children's Hospice UK 2008.

3.1.1. Environment

Where residential accommodation is available the provider will provide a safe homely appropriate environment which enables privacy, relaxation and enjoyment but with the provision of specialist equipment such as hoists, soft play, sensory equipment and communication aids to support the care offered, where required. An appropriately furnished area for young people/older service users, facilities for siblings and other family members and a range of leisure activities may also be made available.

3.1.2.Care

The care offered will aim to meet the social, cultural, spiritual, physical and emotional needs of the child/young person and their family. The team will endeavour to meet the needs of families from all cultural and ethnic backgrounds taking into account the customs, values and spiritual beliefs of the child and his/her family. The confidentiality, privacy and choice of the child/young person will be respected. The team will promote welfare and protection for children/young people (Children Act 1989) and may provide advocacy where needed. (New Children Act 2004 and National Service Framework for Children, Young People and Maternity Services 2004). The care given will be guided by the wishes of the individual child/young person and their family, whether in the children's hospice or in the community. Care will be provided in partnership with the child and family in a spirit which acknowledges their right to confidentiality and choice, recognises the child's individual needs, whilst preserving dignity, within available resources.

3.1.3.Support

Appropriate support will be made available to meet the needs of the family members and those closely involved with the child/young person and family. The provider should aim to develop facilities and services which are flexible enough to meet the support needs of all family members. Particular and appropriate facilities and care should be provided for the child/young person's siblings staying in the hospice. A named member of the team (key worker) should be responsible for maintaining contact with a family in order that support continues when a child is at home between visits. The frequency of this contact will depend upon the needs of individual families.

3.1.4.Symptom Control

Symptom control will aim to promote comfort and enhance quality of life. Collaboration with paediatricians, paediatric palliative care consultants, GPs, specialist nurses and other professionals will ensure that every effort is made to control distressing symptoms and provide choices of management. The child/young person should be involved in all decisions relating to care, and consent for any invasive procedures should be obtained. Symptom control requires frequent evaluation in order for it to be effective. Forward planning which anticipates a change in need is often required to facilitate effective medicines management within the hospice and community settings. Advanced Care Plans

should be discussed and documented. All care, whether conventional or complementary, will be given by staff with appropriate knowledge and experience, aimed at enhancing quality of life for the child and his or her family. Julia's House will work with the paediatric team to support symptom control.

3.1.5. End of life care

An End of Life Care Plan should be developed as early as possible with the child and family, in line with the ACT Care Pathway. If Julia's House does not anticipate being able to provide the resource to support end of life within the Hospice, that needs to be discussed with commissioners at the earliest opportunity, to enable alternative arrangements to be made in a timely manner, minimising distress and disruption to the child and his / her family and enabling relationships with trusted professionals to be maintained. Care will be continued during the terminal phase of a child's illness and following death if it is the choice of the child/young person or family. The spiritual care offered to the child and family at this stage will be appropriate to their individual wishes. When death occurs within the children's hospice there should be facilities for the child's body to remain there until the funeral if this is the family's wish. The family can then spend as much time with their child after death as is helpful. Unless the service offered is "hospice care at home". Accommodation should be available for the family to remain at the children's hospice during this time. A team member must be available to give support and information to the family as well as practical help if desired with organising the funeral and any other issues relating to the death. Sensitive, emotional support is essential for all close members of the family and the other children and families in the children's hospice at the time. Julia's House aim to support each child and young person with end of life support. The hospice considers each child and their ability to meet the support needs on a case by case basis.

3.1.6. Bereavement

After death, bereavement care will be available to the family with support being an integral part of that care, respectful of cultural and religious needs.

Staff working with bereaved families must have access to supervision/support.

Staff will have appropriate skills and experience and work closely with other agencies who may offer support in the family's own locality.

3.2 Pathways

The provider will deliver children's palliative care in accordance with the "ACT Integrated Multiagency Care Pathway for Palliative Care for Children (2004)". This pathway has been agreed as the most appropriate model for NHS palliative care delivery.

4. Other

4.1 Geographic coverage/boundaries

The funding agreement for this service specification covers all children who reside in Bournemouth, Dorset and Poole and who are registered with a Bournemouth, Dorset or Poole GP.

4.2 Location(s) of Service Delivery

Children's Hospice Trust

Julia's House
135 Springdale Road
Broadstone
Dorset. BH18 9BP

Tel 01202 389837

4.3 Days/Hours of operation for Julia's House

- a) Residential - 24 hours variable on demand – refer to Statement of Purpose
- b) Community – variable 0800 – 2400, Monday – Sunday

- Letter of agreement between Provider and service users @Julia's House-

Dear Parent

We are very pleased to provide details of prospective session dates for the **whole year of 2013/14** at Julia's House. The times of these sessions are from **10am to 4pm**. You will be given a booking in/arrival time which may be slightly earlier or later than this. You are still welcome to collect your child earlier than 4pm if you wish to do so.

Please take the time to read this letter even if you regularly bring your child into Julia's House, as we have made significant changes to our allocation of hours process to commence 1st January 2013.

Changes of allocation of hours

Following family feedback and a review of our allocation process the new allocation for **ALL** children will be as follows:

104 hours of community support per year

AND

12 hospice sessions per year OR an additional 96 hours of community support

Each hospice day care booking = 1 session
Each hospice overnight weekend = 6 sessions

You may use your hospice sessions at any of the times you are offered for your child's group on a first come first served basis.

If you choose to use only part of your hospice allocation please note that each hospice session is equivalent to 8 hours of community care and that community care must be spread throughout the 12 months of the year.

In individually assessed specific packages additional hours may be allocated for a fixed period of time.

If you wish to discuss any aspect of this new allocation please contact your named nurse or Ali or Karen (at the Arena office 01202 607400)

Complete the attached form indicating your requirements.

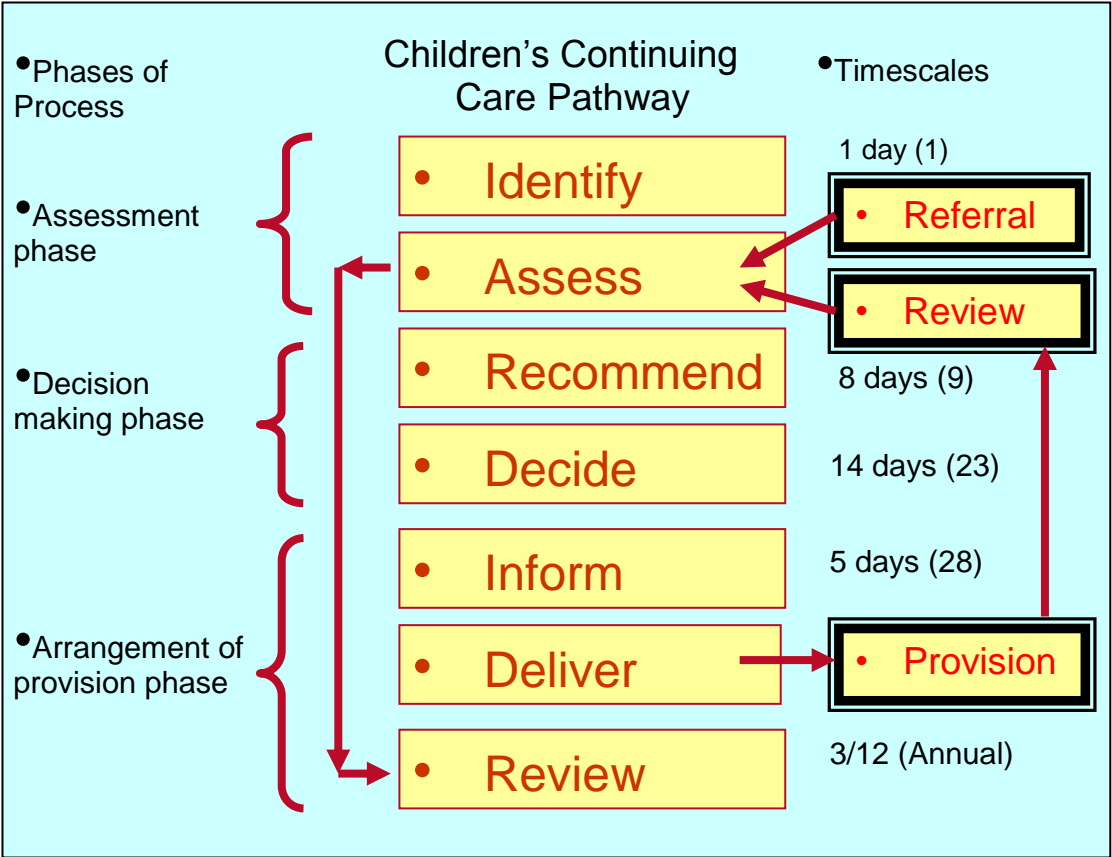
Please note that your request does not guarantee session as they will be allocated on a first come first served basis.

4.4 Referral criteria & sources

A consultant paediatrician or children's community nursing team manager or other healthcare professional will need to make a referral where a funding contribution from the Clinical Commissioning Group is expected. Please refer to the operational protocol.

4.5 Referral pathway (route)

CHILDREN AND YOUNG PEOPLES CONTINUING CARE NATIONAL PATHWAY
(implemented locally October 2010)



National Framework for Children and Young People's Continuing Care Pathway
NHS Bournemouth Dorset and Poole Flowchart for Continuing Care Applications

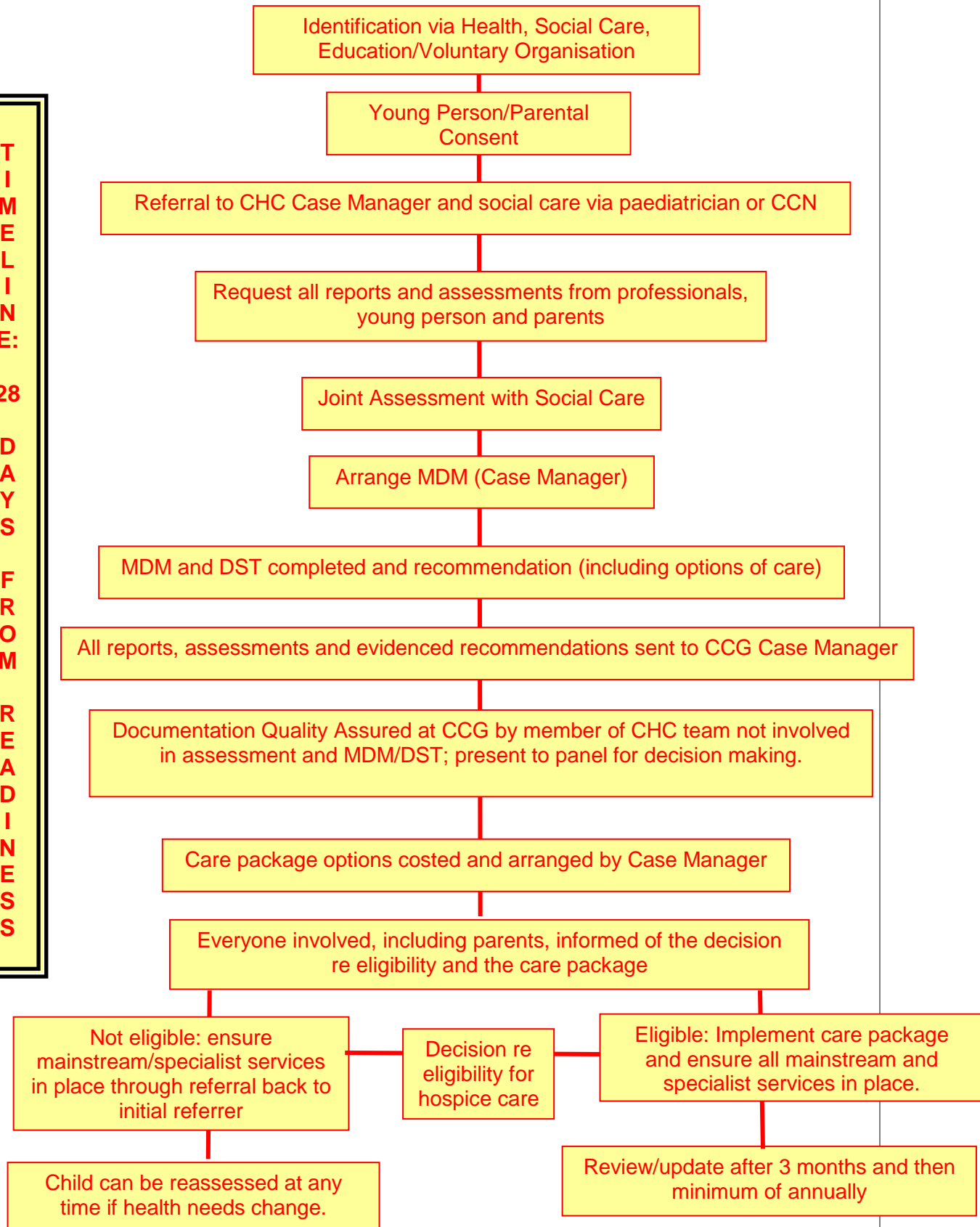
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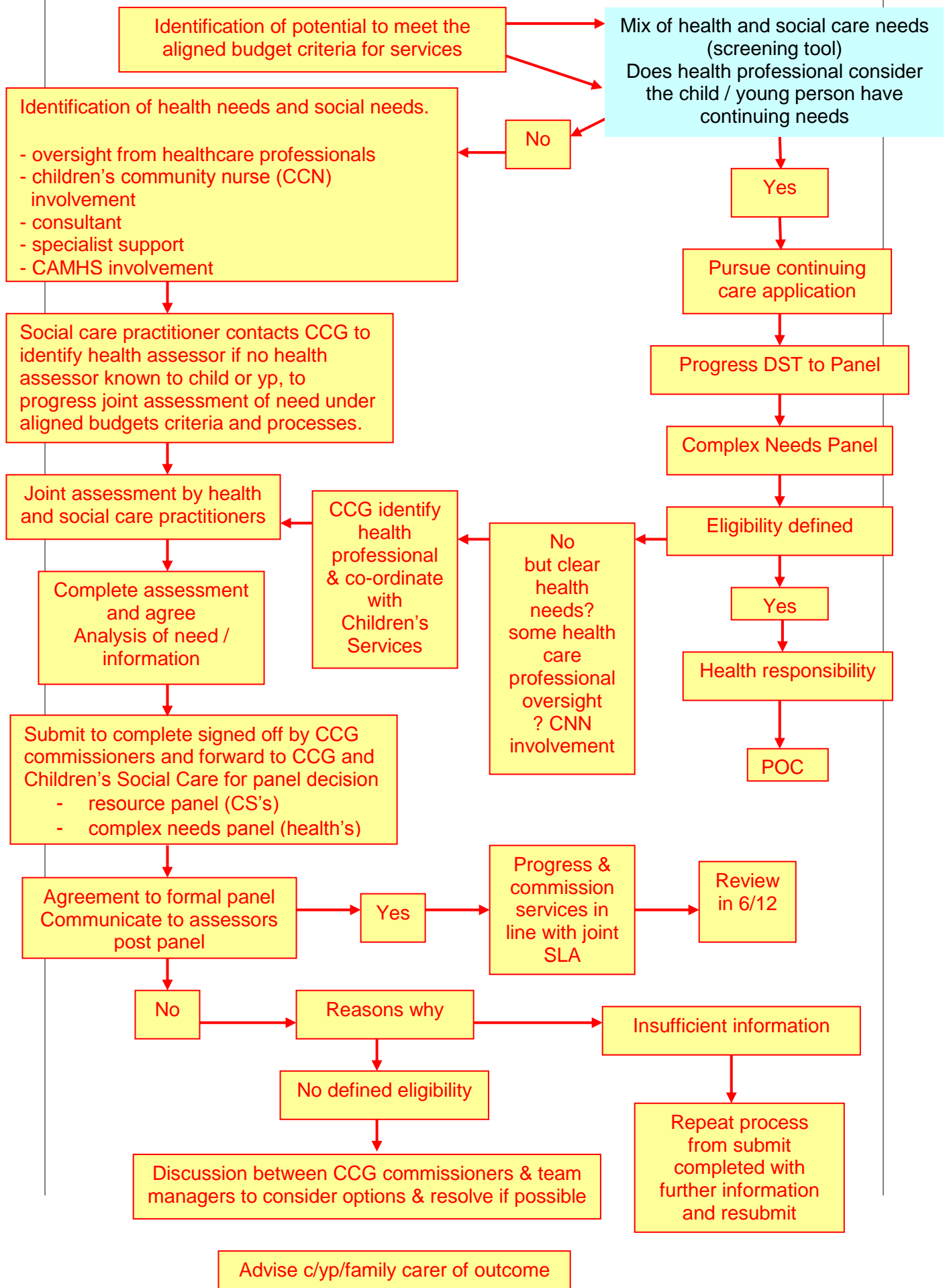
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ALIGNED BUDGETS CARE PATHWAY (Locally implemented March 2010)



4.6 Exclusion Criteria

Children who do not meet the care group definitions and children referred and admitted to any of the providers services without being subjected to the agreed referral pathway and panel process will not have funding agreed by the Clinical Commissioning Group.

4.7 Response time and prioritisation

The provider will aim to respond to urgent referrals within two working days. If capacity prevents this then they will liaise with the referrer/lead professional and commissioner to prioritise while alternative provision (if appropriate) is sought elsewhere.

4.8 Discharge criteria and planning

The provider will develop a package of support with the child and family, and share this and its costing with the Commissioning Manager. Once agreed this will then be funded based on the funding agreement with the hospice. Any admissions of children that fall outside the agreed package of support will require authorisation by a commissioning manager in advance, unless as a result of urgent/end-of-life/crisis support.

It is recognised that packages of support may vary to that predicted and as a result, plans may need to be reviewed more regularly than quarterly. Similarly children/families may wish to be discharged at their choice and it will be the responsibility of the lead NHS professional and commissioners to find alternative provision if this is needed.

4.9 Self care and patient and carer information

The provider will be involved in the review and evaluation of care packages for children on their case load with other professionals, at each contact throughout the illness and at the request of the patient or carer.

When larger multiagency meetings are needed the provider is expected to be involved. These meetings will be to review packages of care. The date of the next review will be set and recorded.

Multiagency review of the care plan will include:

- The relevance and appropriateness of current care package
- The effectiveness of care plans
- Any newly identified needs
- Patient satisfaction with the care
- Modality and frequency of all therapies and support
- Activities of daily living/social care support
- Medication – how monitored/reviewed
- Pain plans
- Risk assessment procedures and crisis/urgent response

4.10 Service Delivery Information

Monitoring cycle is quarterly and this will include a 6 monthly review meeting as described in this specification. All quarterly or monthly reports submitted under this specification with the information specifically detailed within the activity returns in the grid. The activity data should be presented to the Clinical Commissioning Group commissioner for each trust who is party to the contract. Data submissions should be made within 6 working days of the period. Data reports should be presented in either Excel or Word programmes and provided electronically to the commissioners. The service provider is required to provide the following reports:

Type of Return	By when
i A quarterly confidential return as prescribed by the Clinical Commissioning Group	Quarterly aggregate figures Q1 by 31 st July; Q2 by 31 st October; Q3 by 31 st January; Q4 by 30 th April.

	(or on dates agreed locally to align with other performance requirements)	
ii A quarterly summarised narrative and statistical report on the Services provided by the service provider in a format to be agreed with the Clinical Commissioning Group	As above	
iii An annual report on the achievements of the Services, including the service provider own evaluation of the service and feedback from service users and results of any survey of the views of service users	Annually, by the 31 st July	

In addition, the Clinical Commissioning Group may reasonably request other information in order to comply with its own statutory or other obligations

Reporting requirements

MONTHLY Collated Data	QUARTERLY	ANNUAL (to include as a minimum)
Number of referrals <ul style="list-style-type: none"> source of referrals diagnostic groups thresholds number of children and young people who are referred for end of life care (residential or community services) or as receiving services as part of a wider package of care at end of life. 	A summary of monthly data	Aggregated monthly data
Number of referrals not accepted and reasons	Complaints and compliments received with action taken	Care plan audit
Discharges/Deaths	Copies of any quality assurance reports, to include audits and patient survey results	User engagement activity
Number of children receiving care at home		Indirect activity – e.g. staff training
Serious Untoward Events / adverse incidences (within 24hrs or next working day)	Number of active children – gender, age, ethnicity and belief (working towards the use of using NHS numbers by April 2012.)	Psychological supervision to staff

5. Quality Requirements

<i>Performance Indicator</i>	<i>Indicator</i>	<i>Threshold</i>	<i>Method of Measurement</i>	<i>Consequence of Breach</i>
Infection Control	Reducing and minimising the risk of serious infection.eg. MRSA bacteraemia and CDiff. Prevention and management of outbreaks.	All notifiable infections identified by the hospice to be reported to the relevant CCG within Nationally agreed timescales and then investigated.	Regular reporting/lab results.	Meetings with commissioner to formulate an agreed action plan to improve performance. Investigation and root cause analysis to be completed.

		The source of the infection should be identified.		
		Standard Hand Hygiene should be practiced. Compliance with the DH Hygiene Code 2006 and registration with the CQC.	Annual reporting with exceptional quarterly reporting for any incidents	
Service User Experience	Children, young people and families report satisfaction with services.	90% satisfaction at a minimum of 50% response rate.	Feedback from user's quantitative & qualitative assurance package e.g. "Are we getting it right?" (Children's Hospices UK)	" " "
Improving Service Users & Carers Experience	Parents or carers are actively involved in any substantial planned changes or development of new services.	90% of respondent service users or parents and/or carers agree.	Feedback from user's quantitative & qualitative assurance package e.g. "Are we getting it right?" (Children's Hospices UK)	" " "
	Parents /carer's feedback, complaints and compliments are listened to and acted upon.	100% Evaluation of complaints result in service changes that lead to improvements	Hospice has clear procedure for parents to complain to an independent body (e.g. CCG/CQC) <i>Quarterly report on complaints.</i>	
Reducing Inequalities	The service is available to all children eligible to access it.	Evidence of clear eligibility criteria and that they have been adhered to.	Analysis of referrals, refusals and activity by CCG/Postcode <i>Quarterly report.</i>	" " "
Reducing Barriers	The service is flexible and responsive to its users.	24 hour service available by agreement for inpatient care and telephone contact. 7 day a week access to outreach service provision.	Confirm facility open and available as outlined in specification, during required period. <i>Quarterly report</i>	" " "
		Notification of closure of any inpatient facility to commissioner within 48 hrs	<i>Quarterly report</i>	
	Requirement for translation	Interpreter/sign language services	Number of occasion's	

	and/or interpreting services.	will be available to 100% of patients who require them.	interpreters required and if not provided. <i>Quarterly report</i>	
Improving Productivity	Appropriate clinical skill mix to meet the needs of children with complex health needs.	100% of children and young people receive appropriately skilled care.	Demonstration of skill set of staff compliment and training programmes in monitoring reports. <i>Annual report</i>	“ “ “
Access	Adequate response time and prioritisation is required by all children eligible to receive care from hospice.	Hospice to respond to all urgent referrals within 2 working days. If capacity prevents this then hospice will liaise with referrer to help find alternative provision.	Referral and activity data. <i>Quarterly report</i>	“ “ “
		Consistent equality of access to all children meeting the threshold throughout the weeks/year	Annually, there is exchange of information re-patterns of service use and any other intelligence re: total service provision available to the child <i>Annual report</i>	
Personalised Care Planning	All children young people will have a personalised care plan, updated quarterly (minimum annually)	100% of children/ YP have received assessment leading to a personalised care plan.	Monitoring reports will demonstrate audit of care plans, minimum annually. <i>Annual report</i>	
	Children/ young people, where able are involved in developing their own care plans.	90% of respondent service users agree.	Evidence from annual monitoring report. <i>Quarterly report</i>	
End Of Life	The service is available to all children, young people and families who choose the hospice (residential services) or home (community	That children who express this choice can be supported by the hospice where possible	Evidence from quarterly and annual monitoring report. Quality meetings <i>Quarterly report</i>	“ “ “

	services) as their expressed choice of place of death and are able access this choice. See operational protocol.	See operational protocol		
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If required, relevant Quality Requirements from Section 3 Part 1 of Module B can be inserted here although these will apply to the Services even if not listed here.

6. Activity

6.1 Activity Plan / Activity Management Plan

The Provider will be required to provide quarterly activity reports which will be aligned with quarterly monitoring meetings.

An Activity Plan is required in relationship to the service; the parties acknowledge that the activity plan is essential to the effective operation of the services.

6.2 Capacity Review

If required, relevant parts of the Activity Plan and Capacity Review Criteria should be inserted here

7. Prices and Costs

7.1 Price

If required, relevant prices may be inserted below

Cost of care £27.90 per hour

Standard package of :

12 hospice sessions per annum	=	96 hours p.a.
2 hours community support per week	=	104 hours p.a.
TOTAL	=	200 hours p.a. per child