

Operational Policy for Children's Continuing Care.

Health, Better Care, Better Value

October 2016

Document Control Sheet

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Equality and Diversity Impact Assessment

In reviewing this document, as a minimum, the following questions were considered following a 4 stage staff consultation process as outlined in the CCG policy document.

- Are the aims of this document clear?
- Are responsibilities clearly identified?
- Has the document been reviewed to ascertain any potential discrimination?
- Are there any specific groups impacted upon?
- Is this impact positive or negative?
- Could any impact constitute unlawful discrimination?
- Are communication proposals adequate?
- Does training need to be given? If so is this planned?

Adverse impact has been considered for age, disability, sex, gender reassignment, marriage/civil partnership, pregnancy/maternity, race/ethnic origin, religion/belief and sexual orientation.

The CCG seeks to ensure its Policy Infrastructure complies with statute and best practice in relation to Equality and Diversity. Impact assessment is carried out on the policy infrastructure and a copy of the assessment records are available from the Governance Manager at the CCG who can be contacted via the contact email address on the external website. CCG staff can contact the manager direct on the governance email address provided in staff email updates.

Consultation

A small number of policy documents are required by statute to be put through a consultation process. The CCG has developed a policy infrastructure in line with statute and best guidance to ensure the appropriate consultation process is followed.

Where policies relate to key service areas and require system/service consultation the CCG will use a variety of mechanisms to secure feedback which may include surveys, focus groups, review by key specialists.

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1.0 Introduction

1.1 Background

1.1.2 The Department of Health published its revised National Framework for Continuing Care Needs of Children and Young People in February 2016 (see Appendix A), setting out renewed guidance with a particular emphasis on the new SEND reforms for partners in Health, Education and Social Care. This document aims to clarify the respective roles and responsibilities of those services and to provide an objective, transparent process that will deliver timely and consistent decisions regarding the funding of care packages for children and young people who have specific health needs that meet the NHS Continuing Care criteria.

1.1.2 The Continuing Care for Children and Young people policy and process covers children from birth up to the age of 18. Post 18 years of age, the National Framework for NHS Continuing Healthcare and NHS-funded Nursing Care (Revised 2012) applies and uses different criteria (see Appendix I).

1.1.3 The National Framework for Continuing Care Needs of Children and Young People in February 2016 does not give guidance on the content or funding of the actual package of Continuing Care. Local children's and young people's Continuing Care decision-making should be based on the assessed needs of the individual child or young person. The application of the National children's Continuing Care Framework will ensure that:

- a) Children, young people and their families are actively engaged in the Continuing Care process;
- b) The Continuing Care process is co-ordinated and consistent between organisations; and
- c) Health, education and social care practitioners, including those working in the independent and third sectors, and the public understand the Continuing Care process.

1.1.4 In October 2013, the government announced that from 1st October 2014 that anyone eligible for NHS Continuing Healthcare and Continuing Care for children benefit from the 'right to have' a personal health budget. See Appendix B

1.2 Definition

1.2.1 The definition of a children and young people Continuing Care package is set out in the National Framework for Children and Young People's Continuing Care:

"A Continuing Care package will be required when a child or young person has needs arising from disability, accident or illness that cannot be met by existing universal or specialist services alone. Continuing Care does not cover children and young people with care needs that may be met appropriately through existing universal or specialist health services. In this instance, their needs should be addressed using a case management approach."

1.2.2 The framework goes on to clarify that Continuing Care is different for children and for adults:

“Continuing Care is organised differently for children and young people than for adults. Continuing Care for adults is governed by the National Framework for NHS Continuing Healthcare and NHS-funded Nursing Care. That framework gives guidance on putting in place complete packages of care where an adult has been assessed as having a primary health need. It means that the provision of all their resulting care needs, whether at home or in a care home, is the responsibility of the NHS

1.2.3 It further delineates the special nature of childhood and youth and the importance of recognising the context in which they live their lives:

“Childhood and youth is a period of rapidly changing physical, intellectual and emotional maturation alongside social and educational development. All children of compulsory school age (5 to 16) should receive suitable education, either by regular attendance at school or through other arrangements. There may also be social care needs. Most care for children and young people is provided by families at home, and maintaining relationships between the child or young person, their family and other carers, and professionals, is a particularly important aspect.

1.2.4 The implication for and expectations of health and local government services is made clear in the Framework

“Children and young people’s Continuing Care needs are best addressed holistically by all the agencies that are involved in providing them with public services or care: predominantly health, social care and education. It is likely that a Continuing Care package will include a range of services commissioned by, CCG’s, LA Local Authority children’s services and sometimes others.”

1.2.5 Section 16 of the National Framework 2016 states that unless there is a good reason for this not to happen, Continuing Care should be part of a wider package of care, agreed and delivered by collaboration between health, education and social care.

1.2.6 Section 22 of the National Framework 2016 states that CCGs and local authorities must work together to consider how the Education Health Care plan assessment and the Continuing Care assessment can be brought together.

1.2.7 The policy and pathway that is set out in the following paragraphs provides the relevant agencies in the Great Yarmouth and Waveney area with robust arrangements for meeting the challenges described in the National Framework.

1.2.8 The key trigger for entry to the children’s Continuing Care pathway is the recognition that the child or young person in question has complex health needs above and beyond the level that universal and specialist health services are currently commissioned to meet and may be eligible for Continuing Care. The level and nature of local health commissioning varies across the country and it is important therefore to recognise that there is no standard set of universal and specialist health services.

1.3 Purpose of the Policy

1.3.1 The operational policy aims to:

- a) Set out a children's Continuing Care process for the Great Yarmouth and Waveney and social care economy that follows the principles and approach of the National Framework 2016 but also makes sense in the local context and:
- b) Ensures a joint, consistent and transparent approach to assessing care needs and commissioning and providing services in the light of those needs;
- c) Provide local practitioners with the knowledge and tools to follow the process;
- d) Set out transition arrangements from child to adult services in relation to Continuing Care arrangements;
- e) Clarify the remit, membership and working practices of the Children's Continuing Care Panel;
- f) Clarify funding responsibilities
- g) Set out an appeals process;
- h) Set out a robust process for resolving disputes between agencies.

1.4 Process Outline and Pathway

1.4.1 A paediatric trained Registered Nurse and/or Learning Disabilities Continuing Healthcare Nurse, depending on the need of the young person will take the role of Children's Continuing Care Assessor. They will work closely with the lead professional for the child, coordinate the multi-agency assessment process, liaise with the child and family to ensure their views and preferences are taken into account and present recommendations for a care package to the Continuing Care panel.

1.4.2 The Decision Support Tool (DST) (see Appendix E) as set out in the National Framework will be used to assess against the 10 Care Domains alongside other assessments that have been undertaken within Health, Social Care and Education and with the input of the family to form an holistic picture of the child and their family's needs. The analysis of these assessments and discussions with the family will identify the care needs and recommendations as to how these needs may be addressed will be formulated to present at the Continuing Care panel.

1.4.3 The Children's Continuing Care Panel will be held monthly (see Appendix H for terms of reference)

1.4.4 The aim is to complete the process from referral to written confirmation of panel decision and a costed care package within 6 weeks. A fast track will be followed for urgent cases

1.4.5 The Health Assessor will take the lead in arranging reviews. The first review will be 3 months and thereafter annually unless circumstances indicate the need for an earlier review.

1.4.6 Great Yarmouth and Waveney CCG (GYWCCG) is accountable for the process, therefore if the young person or their parents or carers wish to pursue concerns about the Continuing Care process or the decision itself, the matter will be dealt through the Great Yarmouth and Waveney's CCG complaints procedure.

1.5 The Eligibility Criteria

1.5.1 The National Framework includes a Decision Support Tool (DST) to ensure consistent and comprehensive consideration of an individual's needs over 10 care

domains. This is completed by the health assessor, taking into account all relevant assessments, and the views of the child or young person and parents/ carers.

1.5.2 The National Framework suggests that needs of 3 highs, **or** 1 severe **or** 1 priority across the DST care domains are indicative of eligibility for Continuing Care. However, this is not meant to be prescriptive or restrictive. This threshold will be used as a guide and applied with some flexibility, looking at the complexity and intensity of needs across all the care domains and the interactions between needs in different care domains.

2.0 Identification, Assessment and Recommendation Phase

2.1 Identification and Referral

2.1.1 Children and young people needing Continuing Care assessment will in many cases already be well known to local services. Most will be known to children's health services. Some children who have disabilities may have a social worker and regular multi-disciplinary meetings. Some will be identified due to increasing needs or changes in family circumstances and will require re-assessments.

2.1.2 A child or young person should be considered for Continuing Care assessment when it is recognised that they have health, needs that cannot be met by mainstream services alone. This may be in conjunction with Social care and/or education needs. The referral process should be led by the lead professional for the child or young person. If there is no lead professional, then the process may be led by any health, social care or education professional working with the child or young person.

2.1.3 The Administrator will log the referral, including the date of receipt, in order to support planning and scheduling of cases coming to continuing health care panel and in monitoring timescales for completion of the process.

2.1.4 The case will then be allocated to a Nurse Assessor. The Assessor will check the completeness of the information provided, including the range of universal and specialist health services currently being provided and seek further information from the referrer if necessary. The Assessor will also meet the child and family/carer, introduce them and explain the process (although this may not always be possible if the child is Looked After).

2.1.5 In these circumstances the Assessor will seek guidance from the child's social worker about the appropriateness of engaging the parents. In the light of the information provided using the pre-assessment checklist documentation if the assessor does not clinically deem the likelihood, of meeting the threshold for Continuing Care. Such referrals will be forwarded onto the appropriate pathway following discussion and agreement with the referrer.

2.1.6 These other pathways include:

- a) Self-referral to universal or targeted services
- b) Referral to Children with Disabilities team for social care needs
- c) Application being made to the Local Authority resource Allocation Panel for partnership services including short breaks
- d) Referral to the relevant health service for health need.

2.2 Assessment

2.2.1 For all appropriate Continuing Care referrals, the health assessor will lead the process for completing the assessment section (Appendix E)

2.2.2 This will require obtaining and collating health, social and education reports and assessments, as appropriate.

2.2.3 Health assessment – this will be led by the health assessor. The decision support tool should be used. If the child or young person is already known to another health professional, it may be appropriate for the health assessor to ask that person to complete a health assessment. In other cases the health assessor should complete the health assessment. In addition to specific health factors, the health assessment also includes the preferences and view of the child or young person and their family and social factors

2.2.4 The assessor should contact other health professionals involved with the child or young person such as paediatricians, therapists and specialist nurses to obtain any existing reports and assessments of relevance to the Continuing Care process.

2.2.5 Educational assessment, including where available the Statement of Educational Need (SEN) /educational health and care plans (EHCP) should be requested if Continuing Care is being considered to support a child with complex health needs in school.

2.2.6 The assessment covers the four areas in line with the National Framework. However, the aim is not to unnecessarily duplicate information and to streamline the process as far as possible.

Area 1 – preferences and view of child or young person and their family – this can be a summary of information provided in the health or social care assessments, cross referenced to the relevant assessments.

Area 2 – holistic assessment – a summary of the overall family situation and needs, referencing the assessments and reports that give the details

Area 3 – needs and risks. Again a summary with cross-referencing to the relevant reports and assessments for the specific evidence

Area 4 - is the Decision Support Tool for completion and scoring.

2.3 Recommendation

2.3.1 For children and young people assessed as having Continuing Care needs then recommendations for community support packages should take account of local criteria for access to services and thresholds for the level of service provision for example the number of nights per month for residential overnight breaks.

2.3.2 All cases will then go forward to the continuing health care panel for agreement decision regarding whether Continuing Care thresholds are met and any package of care being proposed

2.3.4 For cases not passing the Continuing Care threshold, the meeting should still make recommendations and then refer on to ensure a smooth transition through the pathways. Depending on the needs and the recommendations made, onward referral would be to:

- a) Universal or targeted services accessed via self-referral
- b) Partnership services including short breaks
- c) Intake and Assessment / Children with Disabilities team
- d) Relevant mainstream health service.

2.4 Decision making-phase

2.4.1 Decisions regarding eligibility is are based on the Framework for Continuing Care. The decision is made at the panel and based on the National Framework for Children and Young People's Continuing Care.

2.4.2 Cases will be presented to the Continuing Care Panel. The Panel should have copies of the completed DST and the recommendations for care options, together with all the reports and assessments used.

2.4.3 The Panel should complete the meeting decision form recording decisions regarding eligibility for a Continuing Care package.

2.4.4 The Panel should identify the case manager and set a first review date. The case manager may be the social worker already working with the child or young person or a health professional from the service that will be providing all or some of the agreed community support package.

2.4.5 Following the decision, the head of children, young people and maternity services at GYWCCG should write to the child or young person and their family. The letter should:

- a) Explain what has been agreed, include a copy of the Decision Support Tool, and the name of the case manager overseeing implementation of the community support package, the next steps and likely time-frames for implementation;
- b) Explain the review process, noting that community support packages are not permanent and may change as needs change;
- c) Provide information should the recipient wish to complain about any aspect of the process or to appeal against the decision made.

2.5 Leadership and Accountability for the Continuing Care Process

2.5.1 GYWCCG is the lead and the accountable body for ensuring that children are assessed for their Continuing Care needs and for providing a package of care that meets those needs. The Continuing Care process and supporting arrangements will be led by the head of children young people and maternity services and the Director of Commissioning and Engagement. It will include the provision of administrative support.

2.5.2 The co-ordination role will be undertaken by the head of children, young people and maternity services. The work will include:

- a) Co-ordinating the assessment and recommendation process; ensuring that the package of care is arranged and reporting back to the panel in the event that there is delay or difficulty in putting the care into place;
- b) Overseeing the review process.
- c) Acting as a point of contact for new referrals.
- d) Informing families of outcomes of the Continuing Care panel.

2.5.3 The health assessment role will be undertaken by a lead paediatric nurse or professional with experience of children and young people with complex needs and expertise in health assessment. This may be a registered nurse in Learning Disability/ CAMHS, Community Children's Nurse. The work could include:

- a) Undertaking the health assessment as part of the Continuing Care assessment;
- b) Presenting the case to the Continuing Care panel.
- c) Attending the multi-agency meeting;
- d) Undertaking reviews.
- e) Co-ordinating the assessment and the recommendation process.

2.5.4 The Lead professional is responsible for

- a) Ensuring the sharing of relevant information
- b) Assessments with the consent of the service user (or their parent(s) / carer(s))
- c) Attending key multi agency meetings and the continuing health care panel with relevant information.
- d) Responsible for the co-ordination of transition from Children to Adult Services, inviting relevant stakeholders to appropriate meetings.

3. The Continuing Care Process and documentation

3.1 The referral form (Appendix D) to be completed

3.2 Consent form to be signed prior to assessment (see Appendix F)

3.3 Assessment completed using Decision support tool. (See Appendix E)

4.1 Arrangement of Provision Phase

4.1.1 Where a personalised budget has been declined or is not appropriate the children's Continuing Care nurse at GYWCCG will take the lead in arranging or commissioning the agreed community support package. Wherever possible, this will be through existing GYWCCG and Local Authority contracts with providers.

4.1.2 The children's Continuing Care nurse will be responsible for overseeing delivery of the community support package and will provide on-going case management.

4.1.3 The children's Continuing Care nurse will review the provision of care 3 months after commencement and yearly thereafter or when clinically appropriate.

4.1.4 If only minor changes to the package are indicated, then a full re-assessment need not be undertaken.

4.1.5 If the care needs have changed and/or the community support package is no longer fully appropriate or is not meeting the expressed needs of the family, then a full review is required and the case presented to the appropriate continuing health care panel.

4.2 Timescales

4.2.1 The pathway should aim for a decision to be given to the child or young person and their family within 6 weeks. However, given the complexity and variety of needs which a CCG may be assessing, there should be scope for flexibility – where it is not contrary to the

best interests of the child or young person. For example, if an assessment is being made pending a child's discharge from hospital which is not planned for several months, other assessments may be reasonably given priority. In cases of very complex needs, there may be a number of professionals involved. As outlined above, there may also be a need for a simultaneous social care assessment.

4.2.2 The health assessor will forward the completed documentation to the administrator five working days prior the panel. The Panel will meet every month and letters confirming decisions will be sent out within 5 working days of the panel

4.2.3 In order to support the timescale detailed the identification, assessment and recommendation stage needs to be completed within three to four weeks.

4.3 Fast-Tracking (End of Life Care and Crisis Cases)

4.3.1 Children or young people who meet the criteria for children's palliative care nursing services and whose needs can be met should receive that service and do not need to go through the Continuing Care process.

4.3.2 If the case is too urgent to wait for the next Panel meeting, then the case should be presented to the CYWCCG commissioning lead for a decision.

5.1 Transition from child to adult services

5.1.1 A key aim is to ensure that a consistent package of support is provided during the years before and after the transition to adulthood. The nature of the package may change because the young person's needs or circumstances change. However, it should not change simply because of a move from children's to adult services or a move between organisations with commissioning or funding responsibilities. Where change is necessary, it should be carried out in a phased manner in full consultation with the young person. No services or funding should be withdrawn unless a full assessment has been carried out in respect of need for adult health and social care services, including funding responsibilities.

5.1.2 When a young person in receipt of Continuing Care reaches the age of 14, the case should be flagged by the transitions co-ordinator within the Local Authority and the GYWCCG lead to the adult continuing care team. However, it is possible that the transitions co-ordinator may not be aware of the involvement of the Continuing Care team and so it is good practice for the GYWCCG Continuing Care lead to flag the case with the Local Authority prior to the child's 14th birthday so that the Continuing Care co-ordinator is invited to participate in the Special Educational Needs (SEN) review at Year 11 and in subsequent reviews.

5.1.3 Every effort should be made by the joint agencies to ensure that any young person who may require ongoing services in adulthood and who may be deemed eligible for NHS continuing healthcare is identified early and included in the transitions pathway. This will include young people who may be in out of area placements, funded through specific resource streams.

5.1.4 The Continuing Care Co-ordinator GYWCCG will formally refer young person to Continuing Health Care team for screening at the age of transition by completing the NHS Continuing Healthcare Checklist 2009.

5.1.5 Where a child has not been eligible for Continuing Care within Children's Services or may not be known to the GYWCCG lead (usually because their needs have been met by universal or specialist provision) and it is thought that they may become eligible for Adult Services, the child's social worker or lead professional working with the child may make this referral to Adult Services in the same way as set out in 2.1 above.

5.1.6 The outcomes of the assessment and DST together with future care options will be presented by the co-ordinator to NHS GYWCCG Continuing Healthcare Panel (adults) for a decision.

5.1.7 Assessors should record written reasons for the decision and should sign and date the Checklist. Assessors should inform the individual and/or their representative of the decision, providing a clear explanation of the basis for the decision. The individual should be given a copy of the completed Checklist. The rationale contained within the completed Checklist should give enough detail for the individual and their representative to be able to understand why the decision was made. All completed checklist should be sent to the CCG for recording whether or not a full consideration for adult NHS Continuing Healthcare is required.

5.1.8 Once a decision has been made to undertake a full assessment for Adult NHS continuing healthcare eligibility GYWCCG has responsibility for coordinating the whole process until the decision about funding has been made and a care plan has been agreed. The CCG should identify an individual, or individuals, to carry out this coordination role. The coordinator may be a GYWCCG member of staff or may be from an external organisation by mutual agreement.

5.1.9 The assessment process will be undertaken as identified in The National Framework for NHS Continuing Healthcare and NHS-funded Nursing Care (Revised 2012) (See Appendix .

6.1 Continuing Care Panel (see terms of reference in Appendix H)

6.1.1 Continuing Care virtual Panel will operate for GYWCCG. It is the multi-agency forum with responsibility for making decisions regarding Continuing Care in relation to community support packages.

6.1.2 The Panel is responsible for:

- a) Ensuring that good practice has been followed in the Continuing Care process for each case;
- b) Reaching a decision on each case regarding Continuing Care need
- c) Informing the child or young person and their family as to the outcomes;
- d) Identifying an on-going case manager;
- e) Setting a first review date.

6.1.3 The membership of the Panel will include representatives from the Local Authority and GYWCCG and NHS provider representatives.

7.1 Funding of Continuing Care

7.1.1 When a child or young person is assessed as needing a package of Continuing Care (i.e. the Continuing Care thresholds is met and additional services are required to meet

need) GYWCCG will commission the agreed package of Health care either directly, or jointly with the appropriate Local Authority.

7.1.2 If the Continuing Care threshold is not passed, or no additional services are required to meet assessed need, then it is expected that the child or young person's health needs would be met by existing services provided through existing pathways.

7.1.3 The National Framework for Children and Young People's Continuing Care ("the Framework") states 'All partners are responsible for funding their own contributions to the Continuing Care package in line with their statutory functions.'

GYWCCG, statutory responsibilities for providing health services are set out under the NHS Act 2006 (section 3)

8.1 Dispute Resolution

8.1.1 The Continuing Care Panel has responsibility for agreeing whether or not a child or young person has Continuing Care needs in the community. It is expected that in all but the most exceptional circumstances the Panel will be able to resolve any disputes regarding the scoring of the DST.

8.1.2 Should it be considered necessary, the Disputes panel may refer cases to an independent assessor (who would normally be a Children's Continuing Care lead from another area, with experience in providing independent assessments) Their recommendations will be considered by the disputes panel before a final decision is made.

8.1.2 If there is any dispute regarding funding etc. between statutory agencies such as health and social care a referral will be made to mediation and dispute service to resolve.

9.0 Appeals Process

If the child or young person or their family or carer wishes to pursue concerns about the Continuing Care process or about the decision itself, then the matter should be dealt with through GYWCCG complaints procedure.

10.0 Monitoring and audit.

An annual quality visit will be made by the Head of Children, young people and maternity services for all families in receipt of children's Continuing Care funding.

11.0 References.

DH (2000) *Framework for the Assessment of Children in Need and their Families*. London: The Stationery Office.

DfES and DH (2003) *Together from the Start – Practical guidance for professionals working with disabled children (birth to third birthday) and their families*. London: DfES and DH.

Carlin, J (2005) *Including Me: Managing complex health needs in schools and early years settings*. London: Council for Disabled Children and DfES. DH (2004) *National Service Framework for Children, Young People and Maternity Services*. London: DH HM Government (2006)

Joint Planning and Commissioning Framework for Children, Young People and Maternity Services. London: DfES and DH.

DH (2009) *Securing better health for children and young people through world class commissioning: A guide to support delivery of Healthy Lives, Brighter Futures: The strategy for children and young people's health.* London: DH.

DH (2016) National framework for children's continuing healthcare.

2014 Childrens and Families Act.

Appendix A

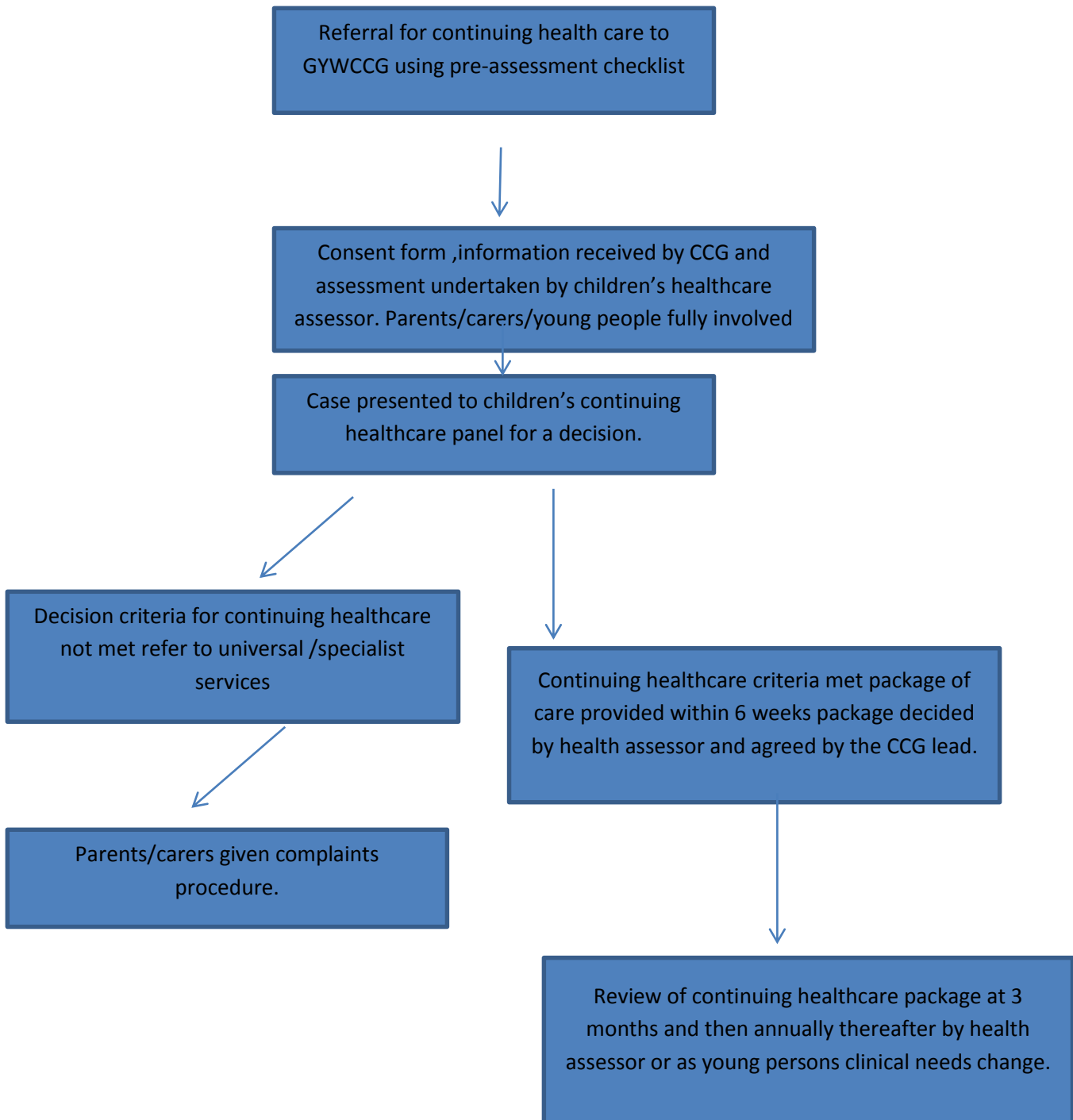
The National Framework for Continuing Care Needs of Children and Young People in February 2016 [here](#)

Appendix B

Guidance on the "Right to Have" a Personal Health Budget in Adult Continuing Health Care and Children and Young People's Continuing Care can be found [here](#).

Appendix C

Pathway for children's Continuing Care.



Appendix D

Children and young people's Continuing Care pre-assessment checklist

The Department of Health pre-assessment checklist can be found [here](#)

Appendix E

Decision Support Tool

The Department of Health Decision Support Tool can be found [here](#)

Appendix F

Consent Form



Consent Form for
Childrens CHC Asses

Appendix G

Risk Assessment



riskassessment2014
.docx

Appendix H

Children's Continuing Care Panel Terms of Reference



Great Yarmouth and Waveney Clinical Commissioning Group

HealthEast

Children's Continuing Care Panel Terms of Reference

Background and Role

The Children's Continuing Care Panel has been established in respect of children who have complex health needs over and above that which services are commissioned to support. The complex needs are determined by the following groupings;

- Continuing Care (CC) cases
- Palliative Care/End of Life (EOL) Cases

The panel is an eligibility decision making panel and does not determine the level of care needed or agree the costs of any care packages. The panel is also responsible for reviewing cases as outlined below.

Eligibility Criteria (follows National framework for children/young people's continuing Department Health 2016)

Key groups which are included in the category of complex medical needs may be seen as a combination of the following:

- Children with a degenerative or terminal condition with an increasing level of dependency, requiring medical and/or nursing supervision;
- Complex care needs that are characterised by the need for support and intervention by a Children's Community Nursing Team (CCN Team)/CAMHS LD teams;
- Technology-dependant conditions requiring specialist healthcare input, e.g. tracheostomy management, naso-gastric care, oxygen dependency, assisted ventilation, etc.;
- Have palliative or terminal care needs.

In addition the level of care required is such that:

- It is beyond that which can be met within existing mainstream medical services;
- Unless it can be provided, the child may need admission to hospital;
- The prescribed intervention/care can only be delivered by someone who has had specific medical training in order to carry it out, and is at a level such that the parent/carer cannot reasonably be expected to provide such care at all times.

The National Framework includes a Decision Support Tool (DST) to ensure consistent and comprehensive consideration of an individual's needs over 10 care domains. This is completed by the health assessor, taking into account all relevant assessments, and the views of the child or young person and parents/ carers.

The National Framework suggests that needs of 3 highs, or 1 severe or 1 priority across the DST care domains are indicative of eligibility for Continuing Care. However, this is not meant to be prescriptive or restrictive. This threshold will be used as a guide and applied with some flexibility, looking at the complexity and intensity of needs across all the care domains and the interactions between needs in different care domains.

Chair: Retained GP

Membership

The panel membership will ensure expertise across a range of disciplines and cross county locations to inform the decision making process. Members will be at a sufficiently senior and experienced level. Members will be expected to act independently of any commercial considerations. The membership will include the following:

- CCG Lead
- Retained GP/Community paediatrician.
- Senior Children's community Nurse
- Paediatric Physiotherapist
- Senior LD/CAMHS manager.
- Social Worker from Norfolk county council (NCC) and Suffolk county council (SCC) Children with Disabilities service
- EACH Service Manager
- Designated Clinical Officer.

Responsibilities

- To consider new applications for Continuing Care and decide on eligibility
- To consider, palliative and rehabilitation cases where specific needs are not met by mainstream services and to advise on clinical appropriateness of proposed interventions and packages of care
- To Head of Children young people and maternity services will ensure that individual case managers review all new cases after three months of eligibility and that all cases at least annually or as needs change.
- An annual quality visit will be undertaken by the Head of Children and young people services on each individual care package where young people are eligible for Continuing Care funding.
- To maintain an overview of the working of this pathway and make recommendations to the relevant bodies to ensure its effective implementation
- To identify patterns of needs and service gaps to inform strategic and operational commissioning
- To ensure that the panel has in place agreed Terms of Reference, robust governance processes and clear requirements relating to the quality of care information presented with supporting standardised paper work

- The panel will effectively communicate its roles and responsibilities to Commissioners, strategic partners and where appropriate children and their families. This will ensure that clear information is available to families on Children's CC and the process in place for assessment and agreement of care packages.

Governance

- The children's community nursing staff are responsible for ensuring that all CC cases to be presented are appropriate and that all supporting documentation is completed to the required standard and consent obtained from parents. The pre-assessment form to be completed prior to assessment.
- Parents/young people will be given an information leaflet explaining CC process.
- If CHC criteria met package of care will be agreed with the CCG lead and information recorded on broadcare.

Frequency of Meetings

There will be a monthly Continuing Care panel.

Quoracy of the panel

For the panel to be quorate the following must be in attendance.

- Senior Children's community Nurse
- Paediatric Physiotherapist
- Senior LD/CAMHS nurse/clinical psychology
- Social Worker from either Norfolk county council (NCC) and Suffolk county council (SCC) Children with Disabilities service
- Retained GP/Community Paediatrician

Administration

To be provided by administrative support from the CCG.

Reporting

Child Health & Maternity programme Board and Clinical Executive Committee.

Recording and storage of records of decisions

GYWCCG will be responsible for the recording and storage of papers relating to all Panel decisions.

Confidentiality is the responsibility of all panel members and should be maintained at all times. If there is any conflict of interest this should be declared by panel members.

Executive Action

Where an urgent decision is required due to high levels of risk to a child with complex medical needs the GYWCCG lead may agree an interim package of support for a short period of time, usually up to the next formal panel date.

Complaints and Appeals

Complaints

Applicants who are not happy with the decision or operation of the panel in their case should initially be requested to discuss their concerns with the case manager. The case manager will seek a local resolution of their concerns.

At any time applicants have recourse to the GYWCCG formal complaints Procedure.

Appeals

In circumstances where the applicant wishes to appeal against a decision of the panel and this cannot be resolved by local resolution through the care manager they have a right to request an appeal.

Appeal will be to the Public Health GYWCCG lead and Director of Quality and Safety who will review the decision of the panel and if necessary convene an appeals panel.

These terms of reference will be subject to review annually

Appendix I

Children's Continuing Care Panel Leaflet



Children and
young people's con

Appendix J

National Framework for NHS Continuing Healthcare and NHS-funded Nursing Care (Revised 2012) can be found [here](#)

Appendix K

The policy for long term Ventilated Children in the community can be found [here](#)