

Children and Young People Continuing Care Policy

July 2022 - July 2024

CONTROL RECORD			
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			Sponsor Director of Nursing
			Team Quality (Commissioning)
Title	Children and Young People Continuing Care Policy		
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1. Introduction

- 1.1 This policy applies to the NHS Nottingham and Nottinghamshire Integrated Care Board, hereafter referred to as 'the ICB'.
- 1.2 In March 2010, the Department of Health published the 'National Framework for Children and Young People's Continuing Care' (National Framework). This was revised in 2016 to allow for:
 - The new commissioning structures introduced by the Health and Social Care Act in 2012;
 - The new integrated approach to the commissioning of services for children with SEND which the Children and Families Act 2014 has introduced; and
 - The changes to adult social care introduced by the Care Act 2014.
- 1.3 The National Framework sets out guidance for the process for assessment and agreement of eligibility for children's Continuing Care.
- 1.4 Good care for children with profound multiple disabilities or chronic severe illness generally involves input from all statutory agencies: Health, Local Authority Support and Education. Its provision depends on timely, comprehensive interagency assessment and co-ordination of services for this small but highly complex group.
- 1.5 This document describes the local approach by which children and young people with complex health needs are assessed using the principles established in the National Framework. It supports partnership working between Nottingham and Nottinghamshire Integrated Care Board (ICB), Nottingham City Council and Nottinghamshire County Council.
- 1.6 The policy has been developed in partnership with Nottingham City Council and Nottinghamshire County Council Children's Services.

2. Purpose

- 2.1 The purpose of this policy and appendices is to establish the commissioners' responsibilities in meeting the continuing care needs of children and young people, and to clarify the mandated elements of the process for assessment and eligibility of children and young people who may have Continuing Care needs.

3. Scope

- 3.1 This policy applies to children and young people from 0-17 years (up to their eighteenth birthday) with complex health needs. They may have one or a combination of the following:
 - Physical disability;
 - Mental health needs;
 - Learning disability/needs;
 - End of life needs.

- 3.2 The above mentioned may require additional support that is not available through universal, targeted or specialist services. They must be registered with a Nottingham or Nottinghamshire GP or have been so registered at the point that they became a looked after child.
- 3.3 This policy does not consider aftercare services as defined in Section 117 of the Mental Health Act 1983. Needs related to this should be given separate consideration under the Section 117 After-Care Local Policy.

4. Definitions

Term	Definition
The words “child” and “children”	Mean children or young people up until their 18th birthday.
The word “parent”	Means the person or people who hold parental responsibility. This includes corporate parents.
Continuing Care for children and young people	Is as defined in the National Framework i.e. ‘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.’
A Continuing Care package	Is a personalised commissioned service which can include care or equipment but does not include treatment. It can include contributions funded and commissioned by any of the statutory agencies.
End of life care	Refers to a child or young person whose condition is rapidly deteriorating and characterised by an increasing level of dependency and where a lifespan is thought to be days or weeks.
The Decision Support Tool (DST)	Brings assessment information together and presents it in a concise, consistent way. It is designed to help ensure that all relevant needs are assessed and captured to inform local decisions about the care needed and originates from the National Framework.
NHS Continuing Healthcare (CHC)	Is for children with long-term complex health needs who are assessed as eligible for care arranged and funded solely by the NHS.
A Care and Support Plan (CASP)	Is a tool used for personalised commissioning of NHS services for children. It identifies aspirations, health needs and outcomes of the child and defines a costed plan for

Term	Definition
	delivery of the child’s personalised service which enables review and audit.
Formal carers	Are those people who are employed or paid to provide care and undertake healthcare tasks. Informal carers are not paid and are more likely to be relatives and friends of the child.
The “Commissioner”	Refers to the ICB or Local Authority responsible for arranging the child’s care.
Local Authority Support	Is a term used in this document to encompass social care, short breaks and carer support including care for children who are looked after.

5. Responsibilities

- 5.1 Parents have the primary responsibility for the care of their child with statutory agencies supporting them to meet the child’s identified outcomes. Continuing Care assesses and supports delivery of identified health outcomes for the child. It is essential that families do not rely on NHS Continuing Care support to fulfill their primary caring responsibilities for a child (e.g. to allow them to go out to work). The NHS commissioner contribution to a Continuing Care package only provides support for the individual child with complex needs and is not intended to support the siblings or wider family.
- 5.2 Each child may require services commissioned by the NHS or Local Authority. Each agency is responsible for commissioning (either directly or by delegation) and funding their own contributions, in line with their statutory functions. All agencies must work together to provide seamless care for a child and their family and ensure that there is no untoward delay in service provision as a result of funding decisions between agencies. The Local Authority will remain responsible for assessing and meeting Local Authority support and education needs.
- 5.3 Agencies working together and in partnership with the child and parent should bring together a single set of outcomes. The arrangements for children with special educational needs or disability (SEND) provides a framework for outcomes-focused joint assessments (Education, Health and Care Plan, [EHCP]) involving different partners across Education, Health and Local Authority Support. There may be common elements to both the Continuing Care assessment and the EHCP and where appropriate the single set of outcomes identified within the EHCP may be duplicated or further detailed within the CASP.
- 5.4 “All professionals working directly with children and young people should ensure that safeguarding and promoting their welfare forms an integral part of all elements of the care they offer” (Working Together, 2018). Staff must comply with their organisation’s safeguarding policies and procedures.

- 5.5 The Children and Young People's Continuing Care service (CCCS) is a service commissioned by the ICB to undertake the assessment of health needs and eligibility for Continuing Care. It also has responsibility for coordinating the commissioning of services and, through case management, review and monitor changes in needs and achievement of health outcomes.
- 5.6 All parties have a responsibility to recognise and respond with appropriate review of needs and service planning in a timely manner when the needs of a child change unexpectedly.

6. Continuing Care Process

One Point of Contact

- 6.1 All enquiries relating to children with complex needs, or Continuing Care needs, or referrals for Continuing Care assessment will be directed to the CCCS who will act as the one point of contact.

Referral

- 6.2 Referral to the CCCS for Continuing Care assessment will be made when a need has been identified that cannot be met through universal, targeted or specialist services and where needs are such that they can only be met through a package of Continuing Care. Consent from a young person or parent must be obtained to refer to Continuing Care, including consent for referral to Local Authority Support so that a joint assessment can be carried out.
- 6.3 It is the referrer's responsibility to promptly identify the child and young person's outstanding health needs and suggest a desired health outcome which cannot be met by existing services in order to ensure that there is not a delay in providing support. The referrer will usually be a regulated professional employed by the NHS or Local Authority.
- 6.4 Unmet health needs and outcomes may be identified through an Early Help Assessment or other robust assessment from a registered health Local Authority Support or education professional. The relevant element of this assessment should be appended to the Continuing Care referral.
- 6.5 Referrals should be made on the appropriate referral form (**see Appendix A**). All the additional information identified within the form as needed to support the referral should accompany it. Referrals will not be accepted unless all the required information is present.
- 6.6 Cases who are being 'fast tracked' for end of life care are not required to have a full assessment. In these cases a Fast Track Form (see **Appendix B**) must be completed and signed and sent to CCCS.
- 6.7 Receipt of Continuing Care referrals will be recorded and acknowledged by the CCCS within one working day. The CCCS will pre-assess or 'checklist' the referral

information. Where information is incomplete the referrer will be contacted and advised without delay and a plan agreed for any further information retrieval.

- 6.8 Where a referral clearly does not identify Continuing Care needs the reasons will be fully documented and the referrer notified and signposted to other services.
- 6.9 Some children with complex needs do not demonstrate eligibility for continuing care and may even be declined before full assessment. Challenges to these decisions should follow the continuing care appeals procedure or Inter Agency dispute procedure as appended. The rationale for a decision to proceed to a full assessment should be documented and shared with the referrer, child and parent.

Assessment

- 6.10 Informed consent for assessment and sharing of information from a child or parent should always be gained prior to commencing an assessment. If a child or parent does not consent to an assessment of eligibility for Continuing Care it should be confirmed and recorded that they have understood the potential effects of their decision.
- 6.11 The child and parent's understanding of Continuing Care should be supported with accessible information and the opportunity to ask questions of the CCCS. Their understanding should include their responsibilities as identified in Section 5 and that review may demonstrate that needs no longer require Continuing Care support. They should also understand that diagnosis of a disease or a particular condition is not in itself a determinant of a need for Continuing Care.
- 6.12 Once the referral has been accepted, if there is not an allocated Local Authority worker, the Nurse Assessor will ensure the Local Authority Children's Service is aware of the referral and has the opportunity to contribute.
- 6.13 The Continuing Care assessment and decision-making process should be completed within 30 working days of referral.
- 6.14 The family should be given a clear timetable with regular updates. If more time is required to undertake this process, the referring party and the family will be informed of this extension, the reasons why and the proposed date of completion.
- 6.15 The CCCS will ensure that the child or young person and their family understand the Continuing Care process, and receive accessible advice and information in a timely and clear manner.
- 6.16 The assessment will involve a clear, reasoned evidence base from a range of professionals working directly with the child that takes account of the child's particular health needs in a holistic context and embraces the principles of personalisation. This may include completion of a 72 hour diary of care by those currently delivering care.
- 6.17 The assessment must be child centred and include what outcomes the child wishes to achieve and how services including health, might support delivery of them. The

assessment must also identify other elements of support that the child receives. Some of this information may already have been gathered by other professionals and where possible duplication of interrogation of child and parent can be avoided.

6.18 The following should be considered as part of the assessment:

- The voice of the child;
- Other assessments and reports of the child's needs including health reports and records, child and family assessments, early help assessments, education reports and EHCP;
- Identified health outcomes and preferences of the child and parent and how these outcomes might be met;
- Risk assessments;
- Decision Support Tool;
- Current evidence-based practice e.g. NICE guidance.

6.19 The lead assessor will have as a minimum expertise in:

- National Framework for Children and Young People's Continuing Care;
- Child development;
- Assessing children;
- Working with children and parents;
- Health assessment;
- Access to specialist knowledge and expertise in Children's mental health

and will have:

- Well-developed leadership qualities including listening skills;
- An understanding of local health and social care commissioning;
- Child safeguarding skills and competencies to Level 3.

6.20 Where the views of the child are different from those of their parent, these will be reflected in the DST and the benefits of advocacy will be considered.

6.21 The outcome of the Continuing Care assessment is a recommendation with rationale from the CCCS assessor to the Children's Continuing Care Panel (CCCP) as to whether the child is eligible for Continuing Care Services.

6.22 Once the Continuing Care assessment and, if required, the Local Authority Support assessments have been completed the CCCS assessor and the Local Authority Worker will discuss the findings of the assessment and work to resolve any gaps or conflict before sharing and explaining the DST and final recommendation to the child and parent for inclusion of their comment. This explanation should give realistic expectations to the child and parent about how decision makers might reject the recommendation.

6.23 Exceptionally, information may be withheld from a child or parent if professionals consider that it would be likely to cause significant harm to the physical or mental

health or condition of the child or would otherwise not be in their best interests. Professionals should consider seeking advice in these circumstances e.g. from the Caldicott Guardian and should document their decisions.

Decision-Making

- 6.24 NHS Continuing Care should be part of a wider package of care agreed and delivered by collaboration between Health, Education and Local Authority Support and therefore decisions are made by the ICB in consultation with Education and Local Authority representatives.
- 6.25 The final decision regarding whether a child is eligible for Continuing Care will be made at the CCCP. Terms of reference for the CCCP including who must be part of the decision and how it is recorded can be found in **Appendix C**.
- 6.26 Decisions must be demonstrably fair, equitable and impartial: other professionals, legal representatives or parents are therefore not able to attend panel with the exception of observation for training purposes.
- 6.27 Continuing Care eligibility is determined by the presenting health needs, their level of complexity, and whether existing services can meet the identified outcomes. The nature of the health need can be varied or multiple e.g. physical health, mental health, disability. The DST, including child and parent comment, will be used to support decision-making.
- 6.28 In accordance with the National Framework Decision Support Tool, a child is likely to have continuing care needs if assessed as having a severe or priority need in at least one domain of care, or a high need in at least three domains of care within the DST.
- 6.29 The CCCP members will not make decisions on how care is to be provided until Continuing Care need and eligibility is confirmed.
- 6.30 The Panel decision will be one of the following options:
- **Continuing Care need determined (eligible)** which requires a package of care/support;
 - **Continuing Care need not determined (not eligible)**, and no additional package of care/support is required from NHS Continuing Care;
 - **Continuing Care need not determined – well managed need** CCCP agree that the evidence (specialist assessment/review, behavioural plans, and planned outcomes) demonstrate a well-managed need. Joint arrangements will continue until further review shows the provision and support required has reduced enough to consider transfer to a setting 'less intensive/complex' or health and behavioural support has reduced to a level to warrant less support within placement
- 6.31 A Continuing Care decision will include agreement as to which commissioner (i.e. ICB or Local Authority) has responsibility for commissioning the different elements

of the care package to meet the identified outcomes. This will be recorded in the CASP.

- 6.32 A decision about eligibility should be made and communicated to the child and parent within 30 working days of referral. The proposed date of decision-making and any revision of this date must be advised to referrer, child and parent by the CCCS and a rationale and new timescale provided. CCCS will also advise the referrer, child and parent of the decision and rationale verbally and in writing within 5 days of it being made. This advice should also include information about how to complain or appeal and, where eligible, how to contact their allocated CCCS case manager.
- 6.33 Decisions will be reported via panel members to their respective agencies and through their appropriate governance route. Local authority representatives will follow the local authority internal process to seek approval for any Local Authority and educational care elements of the proposed package.
- 6.34 Decisions made outside of the panel will be brought to the next available panel for ratification e.g. fast track.
- 6.35 In cases which have not been fast tracked but where waiting for decision making through the usual process could cause significant harm, the CCCS Case Manager can consider if a child or young person meets eligibility for Continuing Care services and ask the ICB for an 'Out of panel' decision. These decisions should then be presented at the next CCCP for ratification.

Implementation

- 6.36 The assessments as presented to panel should be used to inform a CASP developed with the child and parent and approved by the ICB within 3 months of the eligibility decision
- 6.37 After eligibility is agreed and until the CASP is approved, it may be necessary to reduce risk and meet needs by commissioning services on an interim basis. This will be coordinated by the CCCS case manager who will identify and manage risk in partnership with child, parent, MDT members and the commissioners.

Appeals

- 6.38 The ICB will be the first point of contact for an appeal relating to a Continuing Care decision.
- 6.39 The ICB will request the CCCS to work with the appellant to try and resolve the matter to the appellant's satisfaction at the time or within a very short period through local resolution.
- 6.40 Where a referral for assessment has been declined and the rationale is not agreed by the referrer, the case will be escalated for consideration to the ICB who in

exceptional circumstances may request assessment even though it looks unlikely that the threshold will be met.

- 6.41 Any appeal should be made in writing, by the child or parent to the ICB within 3 months of the panel decision.
- 6.42 The local inter-agency dispute process is described at **Appendix D** and the appeals procedure can be found at **Appendix E**.
- 6.43 Complaints including their escalation to the relevant Ombudsman, should follow the complaints procedure of the relevant organisation e.g. Nottingham and Nottinghamshire ICB, Nottingham CityCare Partnership, Nottingham City Council, Nottinghamshire Healthcare Trust, Education.

Review and Reassessment

- 6.44 Eligibility for Continuing Care is reviewed within the first 3 months and then annually or when there has been a significant change in the child's health need. The child or parent can request a review at any time.
- 6.45 All children with Continuing Care packages will be allocated a CCCS case manager who will proactively identify changes in the child's needs and initiate reviews.
- 6.46 As a minimum, reviews will identify current health needs and whether the outcomes in the child's CASP are being achieved: if not, timely corrective action must be demonstrated.
- 6.47 Where the review includes an assessment of eligibility, the same process will apply for assessment, recommendation and decision making as is described for initial assessment.
- 6.48 Children who are receiving care through the fast track process should be reviewed to ensure needs are being met after a maximum of 2 weeks and begin full assessment for eligibility after eight weeks. If the Case Manager deems this clinically inappropriate, a review of health needs and outcomes should be undertaken and presented to the CCCP for consideration in the same time frame.
- 6.49 All reviews will recognise the voices of child and parent and will involve the Local Authority and education representatives. Where possible they will be undertaken as part of an existing MDT forum e.g. EHCP review or Child in need meeting.
- 6.50 As part of each review the CASP, will be updated and submitted to the ICB for approval prior to implementation. Where a delay may result in unmet need, the Case Manager will escalate to the ICB for an out of panel decision making.
- 6.51 Where health needs have changed and the recommendation is that universal, targeted and specialist services can meet the child's needs, a Continuing Care discharge or transition plan should be discussed with the child and parent and presented to the CCCP with the Case Manager's recommendation. The child/young person's EHCP should also be amended to reflect any changes in

subsequent issue of the reviewed plan. The child and parent will be offered support throughout the transition.

Transition

- 6.52 The aim of providing Continuing Care should be to support the move from dependence to independence, with children being enabled to manage their condition themselves or with the support of their parent, informal network and universal, targeted or specialist services .
- 6.53 Every child with a Continuing Care package who is approaching adulthood should have a multi-agency plan for transition. This process is led by the CCCS Case Manager, with the active involvement of the CHC Case manager and the Local Authority.
- 6.54 The CCCS will identify the need for transition at the 14th birthday and notify the adult Continuing Healthcare service.
- 6.55 The CCCS will refer the young person for formal screening by Adult Continuing Healthcare services at their 16th birthday. A Liberty Protection Safeguarding (or Deprivation of Liberty Safeguarding) referral will also be considered by the CCCS case manager and the decision recorded at this point.
- 6.56 Within one month of the child's 17th birthday a Continuing Care meeting will be arranged by the CCCS case manager with representatives from the Transitions Team, Local Authority Support and NHS Continuing Healthcare in attendance. A transition action plan will be commenced.
- 6.57 NHS Continuing Healthcare should have decided, in principle, whether the child will be eligible for NHS Continuing Healthcare at least 6 months before their 18th birthday. Changes in contracts and alterations to packages of care must be commissioned and ready for the 18th birthday. The final date for the transition of Continuing Care arrangements for all children will be their 18th birthday.
- 6.58 Equipment purchased specifically for the child will, where suitable, remain with them for use as an adult.

Allocation of Resources

- 6.59 Children who have been agreed to have needs eligible for Continuing Care will be offered personalised health support to meet the outcomes agreed in the CASP. This will be achieved through the allocation of a personal health budget (PHB). Detail of the different types of PHB and how these should be chosen and implemented are within the ICB PHB policy. When deciding which type of PHB is appropriate, the Case Manager must consider:
- How continuing care integrates with SEND provision, and existing universal and specialist providers;
 - Sustainability and long-term outcomes (see below for transition);

- A multi-professional approach, rather than one which focuses on venues of care;
- The child or young person's home as the focus of care. When home care options have been fully considered and ruled out on care, risk or capacity grounds and/or family choice, then residential care should be considered to support home care or to replace it;
- Out of hours support and emergency escalation;
- Staff competency and training of parents, staff and foster carers (including training costs).

- 6.60 Continuing Care may fund supply and maintenance of equipment that is not available from anywhere else e.g. through existing equipment suppliers if it will help to meet health needs and outcomes identified and assessed by the CCCS. This will be detailed and costed in the CASP and included in the PHB.
- 6.61 The Continuing Care PHB is discreet from the Personal Budget that is possible as part of funding a child's EHCP outcomes. The outcomes in the Child's CASP may duplicate or support or complement the outcomes identified in the EHCP.
- 6.62 The number of hours of health care within a Continuing Care package is informed by the child's assessed health need and allocated using the 'criteria for allocation of health support' (see **Appendix F**). This is a needs led allocation tool and is used as a guide. Its purposes are to be transparent so families understand how packages of care are allocated and to provide equity to all children receiving Continuing Care. It is based on the needs of the child and does not recognise the need for carer support e.g. for single parents, parents during pregnancy and childbirth or for the needs of siblings which may be considered in a local authority assessment. The guide does not include support needed to access education which should be assessed on an individual basis identifying unmet needs from the Schools Individual Health Care Plan following exhaustion of the graduated response.
- 6.63 It is important that parents maintain their competencies for caring for their child as in the event of cancellation of support due to unforeseen circumstances and despite all efforts to provide alternative support, the expectation is that parents will continue to provide the child's care. For this reason the commissioner will not routinely commission a package of care which provides care for 7 nights each week (see **Appendix H**)
- 6.64 The CASP will include assessment of outstanding risks and will include individual contingency planning which may be funded.
- 6.65 Where a child is admitted to hospital, their usual package of care may, with prior hospital agreement, continue and homecare staff can support in the acute setting for continuity purposes. The responsibility for the care and treatment of the child will remain with hospital staff.
- 6.66 Every effort will be made to commission services to meet the child's assessed need, however in exceptional circumstances some families may regrettably receive

a reduced or no service for a short period. Where a provider is unable to cover the agreed and scheduled shifts, e.g. due to employee ill health, flexibility to replace those hours by agreement with the child and young person or their family within the same invoice period is accepted by the ICB. In these circumstances the CCCS will undertake risk assessment and management followed by sourcing other providers to see if alternative support can be identified (see **Appendix I**). Parents should be made aware of this as part of contingency planning within the CASP.

- 6.67 Provision of transport to and from school is the responsibility of the Local Authority Education Department. However the ICB may support with funding training for escorts to support a child or young person with their assessed health needs.
- 6.68 There may be individual exceptional circumstances where more resources are made available by the ICB. Examples of exceptional circumstances might include:
- agreeing an incremental increase in a package of care during transitions to adult services, so that the final care package matches that of adult services, or
 - where a child has exceptionally high medical and nursing needs, which requires intense, frequent interventions overnight, e.g. responding to frequent apnoea.
- 6.69 Any exceptional circumstances must be presented to the ICB for decision making and accompanied by a risk assessment which includes impact on child and parent and demonstrates no other possible mitigation, in line with the ICB policy: Continuing Care (Adults and Children) Commissioning Policy.

7. Agency Provision

- 7.1 The ICB has contracts with a number of children's homecare providers under a procurement framework which sets out the expected core requirements. Other homecare providers contracted outside the framework are also expected to meet these requirements with appropriate due diligence being undertaken by CCCS.

8. Consent and Voice of the Child

- 8.1 The Mental Capacity Act applies to those over the age of 16. The Children Act 1989 and 2004 is the legislative framework for decision making for those under the age of 16.
- 8.2 People aged 16 or over are entitled to consent to their own treatment. This can only be overruled in exceptional circumstances.
- 8.3 Like adults, young people (aged 16 or 17) are presumed to have sufficient capacity to decide on their own medical treatment, unless there's significant evidence to suggest otherwise.

- 8.4 Children under the age of 16 can consent to their own treatment if they're believed to have enough intelligence, competence and understanding to fully appreciate what's involved in their treatment. This is known as being Gillick competent. Otherwise, someone with parental responsibility can consent for them.
- 8.5 These principles are also applied to involvement in the continuing care process and wherever possible, even if they are not competent to give full consent, the voice of every child should be sought regarding their needs and care preferences.

9. Information Requirements

- 9.1 In addition to written information about Continuing Care (see **Appendix G**) information sessions about Continuing Care may be requested from CCCS for all relevant staff working across NHS Community and Acute providers and Local Authorities.

10. Clinical Governance

- 10.1 Health care tasks are regulated and require delegation from a health care professional to formal carers. All delegated health care tasks must be identified in the CASP and the appropriate delegation procedure followed and recorded as described in the PHB Guidance Policy. This means that all formal carers will need to undertake training and competency assessment in relation to each delegated health care task for each child. Where a notional PHB is in place, the provider organisation holds clinical accountability for all delegated tasks.

11. Equality and Diversity Statement

- 11.1 Nottingham and Nottinghamshire ICB pays due regard to the requirements of the Public Sector Equality Duty (PSED) of the Equality Act 2010 in policy development and implementation as a commissioner and provider of services as well as an employer.
- 11.2 The ICB is committed to ensuring that the way we provide services to the public and the experiences of our staff does not discriminate against any individuals or groups on the basis of their age, disability, gender identity (trans, non-binary), marriage or civil partnership status, pregnancy or maternity, race, religion or belief, gender or sexual orientation.
- 11.3 We are committed to ensuring that our activities also consider the disadvantages that some people in our diverse population experience when accessing health services. Such disadvantaged groups include people experiencing economic and social deprivation, carers, refugees and asylum seekers, people who are homeless, workers in stigmatised occupations, people who are geographically isolated, gypsies, roma and travellers.

- 11.4 As an employer, we are committed to promoting equality of opportunity in recruitment, training and career progression and to valuing and increasing diversity within our workforce.
- 11.5 To help ensure that these commitments are embedded in our day-to-day working practices, an Equality Impact Assessment has been completed for, and is attached to, this policy.

12. Communication, Monitoring and Review

- 12.1 The ICB will establish effective arrangements for communicating the requirements of this policy on the internal Intranet site and Website, and will provide guidance and support to line management in relation to their responsibilities.
- 12.2 The policy will be audited as to the effectiveness of ensuring choice and equity in the delivery of NHS Continuing Healthcare or Children and Young Person's Continuing Care to individuals across the ICB.
- 12.3 This policy will be reviewed every three years, or if there are changes in national guidance on individual choice or NHS Continuing Healthcare or Children and Young Person's Continuing Care and will be approved by the ICB's Strategic Commissioning Committee.
- 12.4 An audit of cases will be undertaken every 6 months by the Head of Continuing Healthcare – this will check that the CHC process has been followed in terms of verification of decision, issue of decision letter to the patient and the commissioned care package is line with this policy and has been approved as per the ICB delegated limits. The audit findings will be presented to the Assistant Director of Quality and Personalisation who will communicate the findings to the Deputy Chief Nurse and ensure any corrective action is taken. The Deputy Chief Nurse may elect to report the audit to the Complex Care and Quality Assurance Panel which reports to the CHC Strategic Oversight Group.
- 12.5 Any individual who has queries regarding the content of the Policy, or has difficulty understanding how this relates to their role, should contact the ICB's Continuing Healthcare Team via email: nnicb-nn.chcteam@nhs.net

13. Staff Training

- 13.1 Awareness of this policy will be proactively undertaken throughout the ICB and ongoing support will be provided to individuals to enable them to discharge their responsibilities. The core training that all CHC staff will undertake in addition to mandatory training will be personalised care training including personal health budgets. The assessment teams will undertake CHC specific training including the NHSE CHC e-learning.

14. Interaction with other ICB Policies

14.1 This policy should be read in conjunction with the following ICB policies:

- Personal Health Budgets Policy;
- Continuing Healthcare, Children and Young People's Packages of Health and Social Care Policy;
- Section 117 After-Care Local Policy;
- Equality, Diversity and Inclusion Policy.

15. References

15.1 The following legislation and guidance has been taken into consideration in the development of this procedural document:

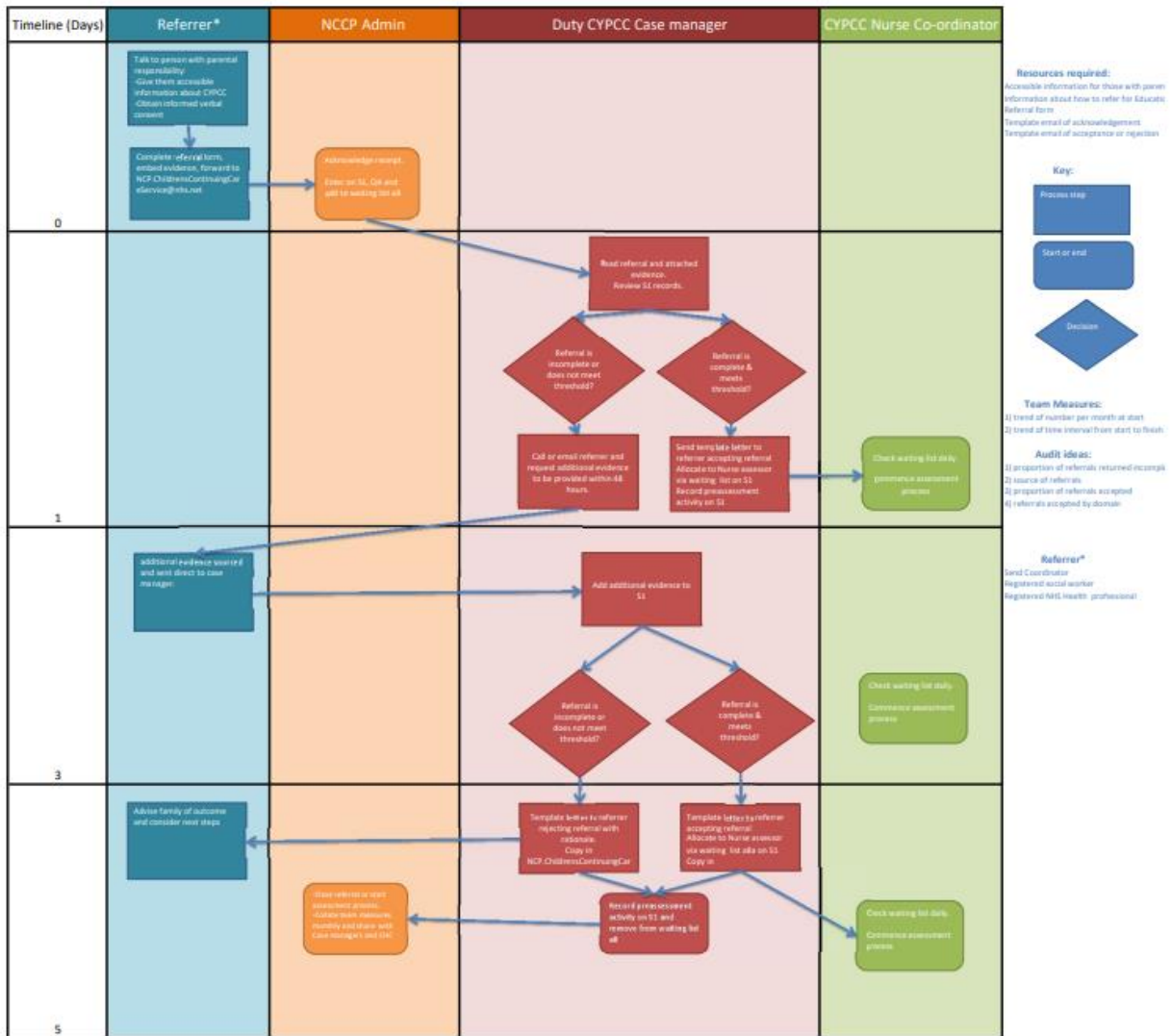
- NHS England (2016) National Framework for Children and Young People's Continuing Care. <https://www.gov.uk/government/publications/children-and-young-peoples-continuing-care-national-framework>
- Liberty Protection Safeguards <https://www.gov.uk/government/publications/liberty-protection-safeguards-factsheets/liberty-protection-safeguards-what-they-are>
- Mental Capacity Act <https://www.nhs.uk/conditions/social-care-and-support-guide/making-decisions-for-someone-else/mental-capacity-act/>
- Personal Health Budget [Policy for Dev and Mgmt of Policy Documents \(icb.nhs.uk\)](https://www.nhs.uk/conditions/social-care-and-support-guide/making-decisions-for-someone-else/mental-capacity-act/)
- Supporting pupils with medical conditions at school <https://www.gov.uk/government/publications/supporting-pupils-at-school-with-medical-conditions--3>

Appendix A:

REFERRAL FORM



Referral to Children and Young People's Continuing Care for



Appendix B:

FAST TRACK PROCESS

1. Referrer makes a telephone call or sends an email to CCCS central admin.
2. Central Admin request adult fast track form (for demographic details only).
3. Central Admin register the child and referral on S1 and the appropriate financial database (e.g. iQA or Broadcare) as a fast track referral.
4. Central Admin send a written acceptance of referral.
5. Central Admin place the child on S1 children's fast track case load and advise Case Manager.
6. Case Manager Identifies requirements for care based on current and anticipated need.
7. Case Manager commissions services according to referrers health needs assessment, liaising with commissioner as soon as possible.
8. Central Admin complete an Individual Placement agreement.
9. After 2 weeks, Case Manager undertakes a review and presents to decision making panel before 8 weeks. If no services are in place the case is closed and a referral for Continuing Care is suggested to original referrer. If services are in place, the Case Manager should contact family and at week 8 a full Continuing Care assessment should be undertaken.

Appendix C:

DECISION PANEL TERMS OF REFERENCE

**Children and Young People's Continuing Care Panel
Terms of Reference**

To be inserted

Appendix D:

INTER-AGENCY DISPUTE PROCESS

To be inserted

Appendix E:

APPEALS PROCEDURE

To be inserted

Appendix F:

CONTINUING CARE GUIDANCE CRITERIA FOR ALLOCATION OF HEALTH SUPPORT

Level	Guidance Criteria Comments	Indicative hours per week
4a	Invasive 24 hour Ventilation 24 hour invasive ventilation can be increased up to 105 hour per week in school holidays for children who attend school.	24 hour Usual allocation Pre-school – Up to 95 School age – Up to 85 24 hour Enhanced allocation Up to 105
	Invasive Night time only	Night time Enhanced allocation up to 80 Usual allocation up to 70
4b	Non-invasive 24 hour Ventilation Non-invasive life supportive 24 hour ventilation can be allocated at level 4a dependent on a risk assessment.	24 hour Enhanced allocation up to 40 Usual allocation up to 30
	Non-invasive Night time only	Night time Enhanced allocation up to 30 Usual allocation up to 20
3	Fast track or End of Life Care Short term intensive allocation subject to review	Enhanced allocation - up to 60 Usual allocation - up to 50
2	Continuously unstable condition defined by nursing assessment and requiring nursing interventions to respond to: e.g. apnoea, irregular breathing, unstable airway, dropping heart rate, fluctuating O2 saturations despite O2.	Enhanced allocation - up to 50 Usual allocation - up to 40
1	Children who meet the continuing care criteria, whose condition remains largely unchanging, but who may have episodes of acute illness or instability, (e.g. chest infections managed by antibiotics, increased need for suction, episodes of increased fitting, short term increase in waking interventions) which may temporarily increase the need for delegated healthcare tasks. (delegated healthcare tasks as identified by the Continuing Care assessment)	Enhanced allocation - up to 30 Usual allocation - up to 20

CRITERIA FOR ENHANCED ALLOCATION - *If a child no longer meets the enhancement criteria, the usual allocation will apply and the hours reduced accordingly*

- High level health needs in a foster placement, as identified and evidenced by multidisciplinary meeting.
- Waking 4 or more times a night 5 nights a week for necessary delegated healthcare tasks, as identified by overnight assessment.
- Child not receiving regular schooling due to high level health needs and receiving home tuition or alternative provision at home confirmed by consultant letter. This does not apply for children who have elected to be home educated.
- Rapidly deteriorating condition as identified by consultant letter and nursing assessment.

Additional notes

- Indicative amounts of Health Care hours run from 0 up to the defined limit depending on assessed health need.
- Health support in school may be provided on exhaustion of the graduated response and is not included in the above figures
- The Indicative hours shown in this table represent the **total** amount of Health Care hours, irrespective of who provides the service.
- Hours are allocated for the assessed time period and cannot be “carried forward” or “banked” for use at a later time or beyond the provider invoice period
- The package of care must be shaped by the child’s needs not by what is offered by providers (e.g. shift lengths)

Developed from the original criteria with permission of Leeds CCG and with thanks to the author Caroline James, © 2005, revised 2011.

Appendix G:

INFORMATION FOR PROFESSIONALS (v5 Jan 2021)

Children's Continuing Care – An Overview for Health, Social Care and Education Professionals

The National Framework for Children and Young People's Continuing Care (DoH,2016)

<https://www.gov.uk/government/publications/children-and-young-peoples-continuing-care-national-framework> sets out the guidance for assessment and eligibility for this service. The appropriate care of children with profound multiple disabilities or chronic severe illness generally involves input from all statutory agencies: Health, Social Care and Education. High quality care for this small, but highly complex group of children depends on timely, comprehensive interagency assessment and co-ordination of services. The result is personalised commissioning of a bespoke service.

The continuing care assessment gathers information to provide a holistic picture of the needs of the child/young person in the family context to support partnership working. Continuing care eligibility is determined by the presenting health needs' complexity, intensity, and risk and whether existing services can meet the identified outcomes. Diagnosis of a disease or a particular condition is not in itself a determinant of a need for continuing care. Continuing care should be part of a wider package of care agreed and delivered by collaboration between Health, Education and Social Care, to meet identified outcomes.

Who may be eligible for continuing care?

Continuing care for children and young people is needed where a child or young person (17 or under) has complex health needs which may require additional health support, other than that which is routinely available from health services, and which is commissioned by the ICB or NHS England. It has been defined as:

'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.'

(National Framework, 2016)

Referral

Referral for continuing care assessment can be made when a registered health or social care or education professional has identified that a child's health needs may not be met through universal, targeted or specialist services and where needs are such that they may meet eligibility for a package of continuing care. Consent from a young person or the person with parental responsibility must be obtained before making a referral. Consent should also be obtained to share information for assessment purposes between NHS and Local Authority (Education and Social Care).

Referrers are asked to complete the Continuing Care checklist and to indicate current health needs that may be present and identify a health outcome that can only be met if assessed as eligible for continuing care funding. Needs may already have been recognised through an Early Help Assessment or through a social work assessment, Specialist Nurse Assessment including CAMHS, School Nurse report, medical information, Child and Family Assessment, Education, Health and Care plan (EHCP) or looked after child assessment in which case the referrer should include these assessments with the referral. The referral form for Notts and Nottinghamshire ICB can be obtained from and returned to NCP.ChildrensContinuingCareService@nhs.net.

Enquiries and requests for support completing the referral should also be made via this address. Referrals should be made via the children's community nursing team ChildrensCommunityNursing@nottshc.nhs.uk.

Who can make a referral?

- Any registered health professional
- Any registered social care professional
- Any special educational needs lead or coordinator.

The screening process:

Referrals (checklists) are recorded and acknowledged. The completed checklist is then reviewed by a Continuing Care Case Manager, if this demonstrates that the child's needs are close to or exceed the threshold for eligibility a nurse will be allocated to complete a full assessment. If the referral is incomplete or the child's needs are obviously lower than the threshold described in the National Framework for Children and Young People's Continuing Care, the referral will be returned to the referrer with a rationale and any comments or signposting for further support within 5 days of receipt.

The assessment process:

Each child has a nominated health assessor, a nurse, who coordinates the assessment and uses evidence based professional judgement in four areas to support a recommendation of eligibility. The four areas are:

1. The preferences of the child and their family
2. Holistic assessment of the child
3. Reports and risk assessments from the professionals in the child's multidisciplinary team
4. The completion of a decision support tool (DST). This is not a stand-alone tool and is designed to ensure that relevant needs are assessed, captured and described in a consistent way.

The assessor will usually coordinate a multidisciplinary team meeting and include the child or family in order to gather the relevant information. The referrer is often invited, and it should also include Social Care and, where relevant, education professionals.

The decision-making process:

In Nottingham and Nottinghamshire, the nominated health assessor will make a recommendation about the child or young person's eligibility for continuing care funding. This is reviewed by a multiagency panel led by the ICB and a decision is made whether or not to accept the recommendation. In Bassetlaw, all the information is reviewed by a panel who make a decision about eligibility. Families are given a clear written outcome with rationale and information about how to dispute the decision.

Provision of personalised services

Where eligibility is agreed, a package of continuing care is devised to meet the needs of the child. Where appropriate, families may be offered a **Personal Health Budget**. Construction of a Care and Support Plan (CASP) in partnership with the child and family enables the package of care to be personalised. Sometimes,

the Personal Health Budget is combined with a social care or EHCP personal budget to make an Integrated Personal Budget.

Personal Health Budgets can be

- Notional: where no money changes hands but the NHS organises the support
- Third Party: the money is held by a third party on the child's behalf. The third party organises the support and is the legal employer of care workers.
- Direct Payment: Money is paid to the person with parental responsibility who buys and manages services themselves.

Reviews

The child's needs are reviewed by the continuing care nurse assessor 3 months after a support package commences and then every 12 months. It is not unusual for a package of care to permanently reduce health needs and therefore it is possible that some children will be eligible for only a short time.

Fast track for end of life

A fast-track process for access to care and support is in place where a child has rapidly increasing needs in the days and weeks preceding end of life.

Enquiries should be made via:

NCP.ChildrensContinuingCareService@nhs.net

and in Bassetlaw:

ChildrensCommunityNursing@nottshc.nhs.uk

Does an HLN (High level needs) application for funding need to be completed before making a continuing care referral?

The criteria for eligibility for continuing care funding are that the child's health needs cannot be met through existing universal, or specialist commissioned health services.

Where a child is known to be in receipt of Children's Continuing Care Services and HLN funding, but unmet health needs or risks are identified please contact the Childrens Continuing Care service in Nottingham or Nottinghamshire, or the children's community nursing team in Bassetlaw and request a discussion with the child's Continuing Care case manager to consider the child's needs and Individual Health Care plan as described in:

https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/803956/supporting-pupils-at-school-with-medical-conditions.pdf

Appendix H:

CARERS ABSENT FROM PLANNED SHIFT: FURTHER GUIDANCE

This guidance has been developed to make clear who is responsible for providing care in the event of non-attendance of carers for planned and commissioned care delivery for children. This applies to the contracted care agency and to parents (or carers such as foster carers) / family / household members.

It is expected that care agencies deliver 100% of the commissioned care package. All Personal Health Budgets should have a contingency plan recorded in the care and support plan which is reflected in the commissioned care package and supports delivery of 100% of the commissioned care package. Where for unexpected reasons the agency is unable to deliver 100% then contact must be made with the Children's Continuing Care Service (CCCS) as soon as possible to advise of the situation, reasons, and to enable a risk assessment to be carried out. The risk assessment will consider whether a safeguarding referral and/or a referral to the CQC should be initiated and will be shared with the registered manager and the ICB and retained in SystemOne.

Where parental choice is cited as a reason for an unfilled shift, it must be clear that this is a genuine choice and a written record of the discussion, made by the agency, should be shared with CCCS who will make a recommendation to the ICB in relation to whether there is a need to fill the gaps in the package and the appropriate level of skill required. There may be times where a carer is the right person but none is available, and the family are unable to support. The ICB will consider a Registered General Nurse in this instance as set out below.

- Where between 80-99% of a commissioned care package is delivered as commissioned, it is considered reasonable for parents to provide the remaining care as part of parental responsibilities.
- Exceptionally, following assessment and identification of high levels of risk to the child or where less than 80% of a commissioned care package is delivered, the CCCS will share their risk assessment with and make a recommendation to the ICB to:
 - a) Fund a paediatric nurse at AQP framework rates to cover essential gaps or up to the 80% level of the package – this will be for a maximum period of 12 weeks where the unfilled shifts are in relation to a shortage of trained carers on the package and must be sourced and overseen by the agency (sub-contracted) – any on-going need beyond that period must be funded by the care agency as set out in the contract;
OR
 - b) Initiate direct payments to fund family members, to cover essential gaps or up to the 80% level – this must be in accordance with the PHB guidance (Employing a close family relative to provide care and support) and should be reviewed every 3 to 6 months.

Appendix I:

PARTNERSHIP PRINCIPLES – CHILDREN'S CONTINUING CARE PANEL (CCCP) DECISIONS

A child is likely to have continuing care needs if assessed as having a severe or priority need in at least one domain of care, or a high need in at least three domains of care within the DST.

Following completion of a DST at a Multi-Disciplinary Team Continuing Care assessment, whether as a review or new assessment following referral/checklist one of the following recommendations will be made to CCCP:

- a. **Eligible for Continuing Care** (or continued eligibility if a review)
- b. **Not eligible for Continuing Care** (or no longer eligible if a review)
- c. **Continuing Care need not determined due to well managed need** (applies to new assessments and reviews)
 - CCCP agrees that the evidence (specialist assessment/review, behavioural plans, and planned outcomes) demonstrate a well-managed need. Clinical needs have not changed but the presentation of needs in particular domains has improved due to those particular needs being 'well-managed'.
 - The presentation of needs in a particular domain(s) has reduced (in the case of a review) but it is believed that the reduction is a direct result of the package of care and support in place and should that package (or key aspects of it) be removed, the presentation of needs would increase. In the case of a new referral (e.g. child has had urgent admission to a secure or specialist setting) relevant evidence from the preceding 60 days should be taken into account to consider whether the current placement / service is reducing the presentation of needs because those needs are now 'well-managed'.
 - Joint arrangements will commence/continue, until further review provides clinical evidence that demonstrates needs have reduced to an extent that the package of care and support can be reduced.
 - This reduction in care and support package could be a reduction of the existing package (in a family setting or a residential placement) or a stepdown to a less intensive or less 'complex' setting.
 - No reduction or trial of reduced package can be done until clinical evidence demonstrates it is appropriate to do so.
 - If reduction of package begins, then close case management is required, with frequent joint health and social care reviews taking place - at least on a quarterly basis, with updates to CCCP as requested.
 - If this process of reducing a package of care in response to the progress of a child who is eligible due to well-managed need leads to a future recommendation of no longer eligible for Continuing Care, it is likely that CCCP will propose a phased withdrawal of care and support over an appropriate period of time (e.g. 3 months)

Appendix J: Equality Impact Assessment

Date of assessment:	June 2022			
For the policy, and its implementation, please answer the questions against each of the protected characteristic and inclusion health groups:	Has the risk of any potential adverse impact on people in this protected characteristic group been identified, such as barriers to access or inequality of opportunity?	If yes, are there any mechanisms already in place to mitigate the adverse impacts identified?	Are there any remaining adverse impacts that need to be addressed? If so, please state any mitigating actions planned.	Are there any positive impacts identified for people within this protected characteristic group? If yes, please briefly describe.
Age¹	no risk identified for children and young people within this protected characteristic	No impacts identified	N/A	This policy is specifically for age 0-17
Disability²	no risk identified for children and young people within this protected characteristic	No impacts identified	N/A	This policy is specifically for children and young people who meet the continuing care criteria

¹ A person belonging to a particular age (for example 32 year olds) or range of ages (for example 18 to 30 year olds).

² A person has a disability if she or he has a physical or mental impairment which has a substantial and long-term adverse effect on that person's ability to carry out normal day-to-day activities.

Date of assessment:	June 2022			
For the policy, and its implementation, please answer the questions against each of the protected characteristic and inclusion health groups:	Has the risk of any potential adverse impact on people in this protected characteristic group been identified, such as barriers to access or inequality of opportunity?	If yes, are there any mechanisms already in place to mitigate the adverse impacts identified?	Are there any remaining adverse impacts that need to be addressed? If so, please state any mitigating actions planned.	Are there any positive impacts identified for people within this protected characteristic group? If yes, please briefly describe.
Gender identity (trans, non-binary)³	no risk identified for children and young people within this protected characteristic	No impacts identified	N/A	None identified
Marriage or civil partnership status⁴	no risk identified for children and young people within this protected characteristic	No impacts identified	N/A	None identified
Pregnancy or maternity⁵	No risk identified for children and young people within this protected characteristic	No impacts identified	N/A	None identified
Race⁶	no risk identified for children and young people within this protected characteristic	No impacts identified	N/A	None identified

³ The process of transitioning from one gender to another.

⁴ Marriage is a union between a man and a woman or between a same-sex couple.

Same-sex couples can also have their relationships legally recognised as 'civil partnerships'.

⁵ Pregnancy is the condition of being pregnant or expecting a baby. Maternity refers to the period after the birth, and is linked to maternity leave in the employment context. In the non-work context, protection against maternity discrimination is for 26 weeks after giving birth, and this includes treating a woman unfavourably because she is breastfeeding.

⁶ Refers to the protected characteristic of race. It refers to a group of people defined by their race, colour, and nationality (including citizenship) ethnic or national origins.

Date of assessment:	June 2022			
For the policy, and its implementation, please answer the questions against each of the protected characteristic and inclusion health groups:	Has the risk of any potential adverse impact on people in this protected characteristic group been identified, such as barriers to access or inequality of opportunity?	If yes, are there any mechanisms already in place to mitigate the adverse impacts identified?	Are there any remaining adverse impacts that need to be addressed? If so, please state any mitigating actions planned.	Are there any positive impacts identified for people within this protected characteristic group? If yes, please briefly describe.
Religion or belief⁷	no risk identified for children and young people within this protected characteristic	No impacts identified	N/A	None identified
Gender⁸	no risk identified for children and young people within this protected characteristic	No impacts identified	N/A	None identified
Sexual orientation⁹	no risk identified for children and young people within this protected characteristic	No impacts identified	N/A	None identified
Carers¹⁰	no risk identified for children and young people within this protected characteristic	No impacts identified	N/A	None identified

⁷ Religion refers to any religion, including a lack of religion. Belief refers to any religious or philosophical belief and includes a lack of belief. Generally, a belief should affect your life choices or the way you live for it to be included in the definition.

⁸ A man or a woman.

⁹ Whether a person's sexual attraction is towards their own sex, the opposite sex, to both sexes or none. <https://www.equalityhumanrights.com/en/equality-act/protected-characteristics>

¹⁰ Individuals within the ICB which may have carer responsibilities.