NHS
Herefordshire and Worcestershire
Health and Care
NHS Trust

Children's Collaborative Advance Care Plan Policy

Working Together for Outstanding Care

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Summary of Key Points

- This policy considers the use of The Child and Young Person's Advance Care Plan (CYPACP) pro-forma as a holistic, framework for both discussing and documenting the agreed wishes of a child or young person and his or her parents/family, when the child or young person has or develops potentially life-threatening complications of his or her condition or chronic illness.
- It sets out an agreed plan of care to be followed when a child or young person's condition deteriorates.
- The CYPACP was revised in 2019 to incorporate the principles of ReSPECT (Recommended Summary Plan for Emergency Care and Treatment).
- It is designed for use in all environments that the child encounters: home, hospital, school, hospice, respite care, and for use by the ambulance service.
- The CYPACP can be used as a resuscitation plan and as an end-of-life care plan.
- It remains valid when parent(s) or next of kin cannot be contacted.
- It includes guidance on legislation to be considered in making such difficult decisions and additional resources that may help in decision making.
- The policy also addresses the legal considerations to be made and how this may differ in various age groups.
- Guidance on when it may not be appropriate to use a CYPACP, is also discussed

Document Type	Clinical Policy
Unique Identifier	CL206
Document Author	Debbie Bolt. Children's Practice Facilitator
Target Audience	Community Paediatricians and Community Children's Nurses (Orchard Service) employed by Herefordshire and Worcestershire Health and Care NHS Trust, inclusive of Student Nurses and Trainee Nursing Associates. This guideline is also relevant to all Health Care Professionals involved in the care of a child with an Advance Care Plan (ACP)
Responsible Group	Clinical Policies Group
Date Ratified	05/07/2023
Expiry Date	05/07/2026

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Version History

Version	Circulation date	Job title of person(s) or name of group circulated to	Brief summary of change
4	16.1.23	Community Children's Nurse Team Leads	No comments received
		Clinical Lead for Children's Nursing	No comments received
		Special School Nurse Team Lead	No comments received
		Home Support Team Lead	No comments received
	14.2.23	Deputy Head of Education & Clinical Development	No comments received
		Safeguarding Services Manager	Reference to Electronic Alerts Policy in section 8.8
		Audit, Research & Clinical Effectiveness Manager	No comments received
		Professional Lead for Allied Health Professions	Addition to 6.1.6 - support available from Trust Legal Services
		Professional Lead for Nursing	No comments received
		Chief Pharmacist	No comments received
		Deputy Chief Pharmacist	No comments received
		Nurse Consultant Infection Prevention & Control	No comments received
		Preceptorship & Practice Facilitator	Update MCA to 2019
		Head of Technical Estates	No comments received
		Head of Quality Governance	No comments received

Version	Circulation date	Job title of person(s) or name of group circulated to	Brief summary of change
		Head of Equality, Diversity and Inclusion	Additions to Equality Analysis
		All SDU Leads	No comments received
		Trust Medical Director	No comments received
		Director of Nursing & Quality	No comments received
		Deputy Directors of Nursing	No comments received
		All Quality Leads	No comments received
5	13.4.23	Virtual approval	No amendments

NHS
Herefordshire and Worcestershire
Health and Care
NHS Trust

Child and
Young Person's
Advance Care Plan
Collaborative

Policy

Child and Young Person's Advance Care Plan

A unified collaborative approach

This document is intended as a template for local policy for centres using the Child and Young Person's ACP (CYPACP) forms (Version 4). Please also refer to the national policy for the ReSPECT form.

In the interests of safety, portability and clarity please ensure that any deviations from the content of the template, will not have the potential to result in an unintended interpretation of the plan.

The legislation, guidance and hyperlinks are up to date at the time or writing but it is the responsibility of the user to check that the most recent legislation is being adhered to. This information can be found on the website.
http://www.cypacp.uk/

http://www.respectprocess.org.uk

1. Introduction

The Child and Young Person's Advance Care Plan Collaborative have developed this policy for use with Version 4 of the Child and Young Person's Advance Care Plan (CYPACP). Version 2 of the policy also follows the publication of the National Institute for Health and Care Excellence (NICE) guidelines and quality standards on end-of-life care for infants, children and young people with life limiting conditions. It builds on the work of the South-Central Group for Advance Care Planning. The collaborative is a voluntary group of NHS and private sector organisations concerned with delivering the best possible care for children with potentially shortened lives. Members span across much of England.
This template policy is intended for incorporation into local policies in order to deliver a unified approach to the care of the children and young people it concerns. The policy is designed to be compliant with the NICE guidelines on end-of-life care for infants, children, and young people with life-limiting conditions, (NG61 2016) and to adhere to the quality standard (qs160 2017). The template remains valid until its review. It will be reviewed at three-to-five-year intervals. Details of the timing of the next review, including information on how to submit suggestions for refinement can be found on the collaborative website.

This policy is supported by a package which consists of:

- A Child and Young Person's Advance Care Plan (CYPACP) pro-forma http://cypacp.uk/document-downloads/care-plan/
- A Guide (This accompanies the pro-forma and is designed to provide the user with practical advice in how to fill out the CYPACP). http://cypacp.uk/document-downloads/document-guidelines/
- A website that includes supporting information and a discussion forum to support education and development of the plan: http://cypacp.uk/
- An information leaflet for parents and carers about Advance Care Plans http://cypacp.uk/wp-content/uploads/2017/01/CYPACP-Parent-Info-Final-v1.3.pdf
- An information leaflet for young people about Advance Care Plans http://cypacp.uk/wp-content/uploads/2017/01/CYPACP-Young-Person-Guide-Final-v1.3.pdf

The Child and Young Person's Advance Care Plan (CYPACP) pro-forma is designed to be a holistic, summary document that facilitates the clear and concise communication of the wishes of children or young people (and their families), who have chronic and life-limiting conditions:

- It sets out an agreed plan of care to be followed when a child or young person's condition deteriorates.
- It provides a framework for both discussing and documenting the agreed wishes of a child or young person and his or her parents, when the child or young person develops potentially life-threatening complications of his or her condition.
- It is designed for use in all environments that the child encounters: home, hospital, school, hospice, respite care, and for use by the ambulance service.
- The CYPACP can be used as a resuscitation plan and as an end-of-life care plan.
- It remains valid when parent(s) or next of kin cannot be contacted.
- It incorporates the ReSPECT form (Recommended Summary Plan for Emergency Care and Treatment) as a summary for those geographical areas where ReSPECT has been adopted. A version with an original style page for the management of cardiopulmonary arrest is still available for areas that have not transitioned over to ReSPECT (Legacy Version).

It is important to note that this policy and plan are intended to support and enhance the delivery of the best possible care to the child or young person and their family. If the structure provides a barrier to this goal, it should not be used. Should this situation occur, an anonymised summary of the problem should be submitted to the working group in order that the circumstance can be considered in future revisions. The group can be contacted through the website http://cypacp.uk/.

2. Definitions

2.1 **A Child and Young Person's Advance Care Plan (CYPACP)** is a document that records the advance wishes of a child or young person and/or those with parental responsibility for them. A different Advance Care Plan should normally be used in adults. **For the purposes of this document where "Advance Care Plan" or ACP is written, it should be read as referring to the "Child and Young Person's Advance Care Plan (CYPACP)".** A CYPACP will include whether the cardiopulmonary resuscitation status has been discussed, and the outcome of that discussion should a cardiorespiratory arrest occur.

2.2 **Cardiorespiratory Arrest** is specifically the cessation of breathing and loss of cardiac output. This definition is strict and should not be extrapolated to include any other circumstances. The terminology Cardiopulmonary Arrest is also used in some documents. In children a particular arrest is sometimes documented as a respiratory arrest where there is still cardiac output but cessation of breathing or as a cardiac arrest where there is cessation of breathing and loss of cardiac output. A respiratory arrest is much more common in children than in adults.

2.3 **Cardiopulmonary Resuscitation (CPR):** Interventions delivered with the intention of restarting the heart and breathing. These will include chest compressions and manual ventilation via mouth, bag and mask or endotracheal tube, and may include attempted defibrillation and the administration of drugs.

2.4 **Do Not Attempt Cardio Pulmonary Resuscitation (DNACPR)** refers to a specific, agreed decision to refrain from making efforts to restart breathing and/or the heart following a cardiorespiratory arrest.

2.5 **Valid DNACPR:** A DNACPR is only valid if the form is appropriately completed and is signed and dated.

2.6 **Local Lead Clinician for Advance Care Planning:** Acts as the primary link between members of his or her organisation and the Child and Young Person's ACP Collaborative.

Within Worcestershire there is no designated Lead Clinician for Advance Care Planning. Individual Paediatricians take responsibility for those children for whom they hold clinical responsibility.

2.7 **CYPACP Co-ordinator:** is responsible for ensuring that all CYPACPs in his or her area are appropriately completed, regularly reviewed and that all relevant parties have the most recent copy of the CYPACP. Ideally each area should appoint and fund a CYPACP co-ordinator. This role is usually undertaken by a senior clinician, an advanced nurse practitioner or a consultant nurse. If an area does not have such a post, an individual nurse or key worker can act as a CYPACP co-ordinator for individual children on their caseload.

Within Herefordshire and Worcestershire Health and Care NHS Trust this role is covered by the Community Children's Nurses (Orchard Service) Team Leaders.

2.8 **Child Death Overview Panel (CDOP):** This group monitors and reviews the deaths of all children.

2.9 **Rapid Response team:** When there is a Sudden and Unexpected Death in Childhood, (SUDIC/SUDC) a Rapid Response occurs. Police and Health work together to understand why the death occurred at that time. If the death of a child with a CYPACP occurs at an unexpected time, a rapid response may be triggered.

2.10 **Adult:** A person aged 18 years or over.

2.11 **Young Person:** A person aged 16 or 17. Anyone under this age is regarded as a baby, infant or child.

For the purposes of this document when the word 'child' is used it should be read as 'baby, infant, child or young person'

3. Policy Statement

The CYPACP is underpinned by the following assumptions:

3.1 All children are presumed to be for attempted CPR unless a valid Do Not Attempt Cardio Pulmonary Resuscitation (DNACPR) decision has been made.

3.2 All DNACPR decisions are based on current legislation and guidance.

3.3 Standardised documentation for the Child and Young Person's Advance Care Plan should be used wherever possible. http://cypacp.uk/document-downloads/care-plan/

3.4 The existence of a CYPACP for a child will be communicated to all affected members of the child's multidisciplinary team and to all relevant settings.

3.5 The CYPACP process is measured, monitored and evaluated in the context of a robust governance framework

3.6 All staff facilitating and documenting a CYPACP will ensure they are familiar and up to date with both this policy and national legislation covering this area.

3.7 Training will be available to enable staff to meet the requirements of this policy.

4. Purpose

4.1 This policy provides guidance for staff responsible for providing or organising health care for children within the collaborating organisations. The guide is designed more as a practical tool to help the user fill in the CYPACP.

5. Scope

5.1 This policy applies to all the multidisciplinary healthcare team involved in children's care across the range of care settings within the collaborating organisations.

5.2 This policy also applies to Student Nurses and Trainee Nursing Associates, under the supervision of a Registered Nurse or other Registered Health and Social Care professional.

5.3 This policy is appropriate for all children up to 18 years of age. Once initiated the CYPACP may be extended beyond the 18th birthday, with discretion, for young adults within the special education or hospice environment.

6. Key Legislation and Guidance

6.1.1 Legislation

Clinicians using the CYPACP should be familiar and act in compliance with the following legislation: (http://www.opsi.gov.uk/acts)

6.1.1 *Children Act* (1989 and 2004)

Clinicians are expected to understand how the Act works in practice. The key consideration is to make decisions consistent with the best interests of the child.

6.1.2 *Adoption and Children Act* (2002) (2006) addendum 2014

Clinicians are expected to understand who has parental responsibility to consent to treatment in a child

6.1.3 *Mental Capacity Act* (2019)

Applicable to 16 and 17 year old patients and adults (see point 7.2)

The Mental Capacity Act (MCA) 2019 is specific to a particular decision being considered: so a person may lack capacity for a DNACPR decision but have capacity for another e.g. preferred place of care. Clinicians facilitating a CYPACP for 16 and 17 year old young people must be familiar with, and fully comply with the MCA.

6.1.4 *Working Together to Safeguard Children* (2006 and 2013) revisions Jan 2018

This details the responsibilities to report child deaths to the Child Death Overview Panel (CDOP) and the role of the local Rapid Response Team.

http://www.workingtogetheronline.co.uk/chapters/chapter_five.html

6.1.5 *Human Rights Act* (1998)

The following sections of the Act are relevant to this policy:

- Failure to provide CPR could be a breach of the individual’s right to life (article 2)
- To be free from inhumane or degrading treatment (article 3)
- Respect for privacy and family life (article 8)

- Freedom of expression, which includes the right to hold opinions and receive information (article 10)
- To be free from discriminatory practices in respect to those rights (article 14)

6.1.6 *Coroners Act* (1988) new guidance updated 2012
Clinicians are expected to know the circumstances when a death must be discussed with the District Coroner.
https://www.gov.uk/government/publications/update-for-coroners-on-death-certification-reforms
Where coroners are involved, the Trust Legal Team will support staff.

6.1.7 NICE guidance for end-of-life care for infants, children and young people with life limiting conditions NG61, 2016 and QS160

6.2 Guidance

Additional guidance may be drawn from the following sources:

6.2.1 End of life care for infants, children and young people with life limiting conditions: planning and management. (NG61 2016)
http://www.nice.org.uk/guidance/ng61

6.2.2 End of life care for infants, children, and young people NICE quality standards 160 (2017) Standard http://www.nice.org.uk/guidance/qs160

6.2.3 Resuscitation Council (UK) Guidelines
2021 Resuscitation Guidelines | Resuscitation Council UK

6.2.4 Advanced Paediatric Life Support Group Guidelines
http://www.alsg.org/uk/apls

6.2.5 Royal College of Paediatrics and Child Health (2015) Making decisions to limit treatment in life-limiting and life-threatening conditions in children: A Framework for Practice.
http://adc.bmj.com/content/100/Suppl_2/s1.full.pdf+html

6.2.6 Resuscitation Council (UK) CPR Decisions, DNACPR and ReSPECT
https://www.resus.org.uk/public-resource/cpr-decisions-and-dnacpr

6.2.7 Decisions relating to Cardiopulmonary Resuscitation (3rd edition 1st revision) Guidance from the British Medical Association (BMA), the Resuscitation Council (UK), and the Royal College of Nursing (previously known as the “Joint Statement”) 2016
https://www.resus.org.uk/library/publications/publication-decisions-relating-cardiopulmonary

6.2.8 BMA (2006) Parental Responsibility: Guidance from the BMA.
https://www.bma.org.uk/advice/employment/ethics/children-and-young-people/parental-responsibility

6.2.9 General Medical Council (2007) 0-18 years: guidance for all doctors https://www.gmc-uk.org/ethical-guidance/ethical-guidance-for-doctors/0-18-years

6.2.10 DNAR decisions in the Perioperative Period; Association of Anaesthetists of Great Britain and Ireland May 2009

6.2.11 Reconsideration of ACP for surgery or procedures, Great Ormond Street (GOS) protocol http://www.togetherforshortlives.org.uk/assets/0000/8555/Great_Ormond_St_policy_required_reconsideration.pdf

6.2.12 General Medical Council (2010) Treatment and Care towards the end of life: good practice in decision making. https://www.gmc-uk.org/-/media/documents/Treatment_and_care_towards_the_end_of_life___English_1015.pdf_48902105.pdf

7. Legal Considerations across the age range

This section is currently being updated and will feature as a separate section on the website. It will include advice on transition to adult services.

7.1 Children (under 16 years of age)

7.1.1 For these children the MCA can only provide decisions, through the Court of Protection (a body that the MCA creates) about property and finance relating to children in certain circumstances. However, it has no role in resuscitation decisions.

- Those with ‘parental responsibility’ for the child make decisions on the child’s behalf. This ‘parental responsibility’ bestows on parents the responsibility of making decisions for, and acting in the *best interests of the child*, until he or she is old enough to make their own decisions.
- Parents hand over the responsibility for making decisions to their child when a child is old enough to make his or her own decisions affecting their care and ultimately their life. As a child develops and matures so will his or her understanding of their illness or disability. They will come to understand their condition, the reasons for their treatment, and the consequences of not having that treatment. This maturity or competence has been referred to as ‘Gillick’ (or Fraser) competence. Such competence is both time and decision specific and may not apply when a child wishes to refuse lifesaving interventions and their parents disagree.

- The child who understands the nature of his or her illness and the likely outcomes of treatment options should be involved where possible in the decision-making process.

7.1.1 The child's family and health care team must decide whether the child is competent to make his or her own decisions relating to resuscitation, and to what degree they will be involved in the discussions. Over the last decade the Courts have been consulted several times regarding children who have made 'competent' decisions that were at odds with the wishes of their health care professionals and/or those with parental responsibility for them. The current position in Common law is that a 'child' under 18 can consent to treatment, but if they refuse treatment then those with parental responsibility for them can override that decision, but it would be wise to seek legal advice case by case in such circumstances.

7.1.2 The Consultant in charge of the child's care has final responsibility for resuscitation decisions. There is no legal obligation on the doctor to provide any medical treatment if it is not in the best interests of the patient.

7.2 Young Persons (16 and 17 year olds)

7.2.1 Although applicable to young people in many respects, the MCA does not permit 16 and 17 year olds to make arrangements to enable them, once incapacitated, to refuse lifesaving treatment. Thus, there is no provision for them to appoint Lasting Powers of Attorney, or to make an Advance Decision to Refuse Treatment (ADRT)

7.2.2 There is a presumption that 16 and 17 year olds have the capacity to make decisions for themselves. Young people of this age can consent to treatment and may be able to refuse treatment in some circumstances. Legal advice may be required in this situation.

7.2.3 If a 16 or 17-year-old is thought to lack capacity for a specific decision, then consultation must take place with those with parental capacity under the normal arrangements under the Children's Act.

7.2.4 For 16 or 17-year-olds the main effect of the MCA is to consolidate into Parliamentary law (statute) the common law that has for many years accumulated, with respect to how 16 and 17 year olds who lack capacity, have decisions made about them.

The MCA runs 'parallel' with the Children Act 1989 (CA), and the two statutes are drawn up in such a way as to co-exist, rather than provide contradictory advice. There will be times when it is not clear whether a clinical problem should be approached via the CA, and thus through the Family Courts, or the MCA, and thus the Court of Protection. Sometimes the distinction may be rather fine.

7.3 Adults (18 years and older)

7.3.1 The legal definition of an adult is anyone of 18 years or over.

Anyone of 18 years of age or above can make his or her own decisions about consenting to or refusing treatment. He or she can also make a legally binding ‘Advance Decision’ about these issues. An ACP should not be used for this purpose.

7.3.2 In the majority of circumstances, the Child and Young Person’s Advance Care Plan should not therefore be initiated after the 18th birthday and the adult form should be used. However, if the form is already being used it may be better for the individual and their family to continue with the Child and Young Person’s Advance Care Plan beyond the 18th birthday. There may also be occasions where it is appropriate to use this form for adults still under paediatric services or within the hospice environment.

7.3.3 MCA provides a test of capacity. A person lacks capacity if they have an impairment or disturbance that affects the way their mind or brain works and the impairment or disturbance means that they are unable to make a specific decision at the time it needs to be made. This two-stage test should therefore be used if a clinician has cause to believe that the person lacks capacity. A person is deemed to be ‘unable to make a decision’ if they cannot:

- understand information relating to the decision that has to be made
- retain that information in their mind
- use or weigh that information as part of the decision-making process, or
- communicate their decision.

7.3.4 If an adult is found to lack capacity, then the decision is made on best interests. The only person who determines best interests (i.e., decides what the best interests of the person are) is the decision maker. The decision maker is usually the clinician in charge, otherwise the Court of Protection, its deputy, or someone with Lasting Power of Attorney. Everyone else including parents or Independent Mental Capacity Advocates, are not legally able to determine best interests; they merely support the decision maker by, amongst other means, providing the information to allow the decision to be made

7.3.5 The MCA provides clarification on decision making in adults.

8 Roles and Responsibilities

8.1 The Chief Executive of each collaborating centre is responsible to ensure that:

- The local version of this policy adheres to statutory requirements and professional guidance.
- Their organisation supports the unified policy development and the implementation within other organisations
- The policy is monitored and reviewed

8.2 National Health Service (NHS) Commissioners must ensure that commissioned services provide funding to ensure implementation and adherence to the policy and procedure and to ensure staff training. They must resource/enable funding of an ACP Co-ordinator or ensure the inclusion of this role into the job plan of an existing post.

8.3 Chief Executives of all provider organisations must ensure that provider services:

- Implement and adhere to the policy and procedure
- Procure and/or provide legal support when required
- Resource/enable funding of an ACP Co-ordinator or identify the inclusion of this role into the job plan of an existing post
- Resource/enable training for staff

8.4 Directors or Managers who are responsible for the delivery of care must ensure that where the policy is implemented:

- That staff are aware of the policy and how to access it
- Staff understand the importance of issues regarding DNACPR/ACPs
- Staff are trained and updated in managing DNACPR/ACPs
- Sufficient supporting materials are available for staff and for families
- The policy is audited

8.5 Local Lead Clinician for CYPACPs is responsible for:

- Disseminating information about the ACP package to all staff in their area who are affected by it.
- Feeding back queries about the contents and application of the package to the Collaborative Working Party on behalf of the staff in their domain.
- Acting as a resource and support for clinicians.

8.6 Senior clinicians take ultimate responsibility for the completion of a CYPACP for a child in their care. They will ensure that:

- All ‘interested parties’ are involved in the initial discussions about the possibility of an ACP for a particular child.
- Information about all possible treatment options for the child, and their implications, are available to the group while discussing Advance Care Planning.
- The group discuss whether it would be appropriate to raise the issue of DNACPR with the child and his or her family.
- Decisions are appropriately documented, disseminated and reviewed.

8.7 CYPACP Co-ordinator is responsible for ensuring that all CYPACPs in their area are appropriately completed, regularly reviewed and that all relevant parties have the most recent copy of the CYPACP.

8.8 HWHCT staff who implement or are involved in the care of a child with a CYPACP should ensure that an appropriate electronic alert is completed on Carenotes. The CYPACP should be held within the correspondence section of Carenotes and an appropriate clinical entry made. Alerts should be time limited and reviewed regularly.

Further information can be found in HWHCT Electronic Alerts Policy – CL-248
https://intranet.hwhct.nhs.uk/clinical-policies?media_item=2964&media_type=10#file-viewer

A CYPACP would usually be reviewed annually, as a minimum; an electronic alert must always be reviewed at the young person's 18th birthday, and appropriate arrangements made where appropriate for transfer of care and completion of appropriate documentation.

8.9 Clinical staff delivering care must:

- Adhere to the policy and procedure
- Notify line manager of any training needs
- Check the validity of any decision – that it is in date and signed.
- Notify other services of the existence of the DNACPR/CYPACP on the transfer of a child
- Participate in the audit process
- Be aware of local procedures for storing and accessing ACP information.

8.10 Commissioners and commissioned services, for example pharmacists and dentists, should be aware of this policy and consider its implications when commissioning or providing services.

8.11 The Ambulance service staff will:

- Adhere to the policy and procedure
- Notify line manager of any training needs
- Ensure they are aware of the existence of a DNACPR/CYPACP via the individual / relatives or the health care professional requesting assistance
- Check the validity of any decision – that it is in date and signed.
- Participate in the audit process
- Be aware of local procedures for storing and accessing ACP information

8.12 Hospices will adhere to the policy and procedure, and will ensure that:

- Information regarding a DNACPR/CYPACP is included in pre-admission documentation.

- All DNACPR/CYPACP are effectively cascaded to staff.
- Individual staff will:
  - Notify line manager of any training needs
  - Ensure they are aware of the existence of any DNACPR/CYPACP's for patients in their care.
  - Check the validity of any decision– that it is in date and signed.
  - Participate in the audit process
  - Be aware of local procedures for storing and accessing ACP information

8.13 Schools have a responsibility to ensure that:

- The CYPACP is available and followed.
- In an acute event, an ambulance is called and the presence of the CYPACP highlighted to ambulance staff (follow protocol including giving home postcode).
- In an acute event, parents are immediately contacted by phone.

9 Process

The guide to using the CYPACP should be used when initiating an ACP http://cypacp.uk/document-downloads/document-guidelines/

It provides guidance on the overall process.

Guidance for using the ReSPECT form should be sourced from the national website https://www.respectprocess.org.uk/

10 Do Not Attempt Cardiopulmonary Resuscitation

10.1 Whatever the prognosis and advance directives that may be in place, the child's comfort should always be a primary consideration. Every attempt should be made to minimise distress and to fulfil the child and the families' wishes wherever possible.

10.2 Notwithstanding the above, a child with a valid DNACPR decision in place should not have any attempt made to resuscitate them in the event of a life-threatening change in his or her clinical condition (excluding reversible causes such as choking or anaphylaxis, or causes specific to the individual child specified in the CYPACP).

10.3 In hospital a clinical emergency (crash/2222) call will not usually be made, and no active interventions will be made to assist the child's failing respiratory or circulatory function including compressions and ventilation.

10.4 If an ambulance is called, then Ambulance Control must be told about the existence of a CYPACP.

10.5 A DNACPR decision specifically directs the omission of CPR, it does not mean withdrawal of care.

10.6 *All children are for attempted resuscitation unless there is a valid DNACPR decision in place. If there is any doubt about the validity of a DNACPR decision, then resuscitation should be initiated.*

10.7 **A valid DNACPR decision:**

- Reflects the agreed wishes of the child (where appropriate), those with parental responsibility for the child, and the health care professionals caring for the child.
- Is clearly recorded in the DNACPR section of the ACP.
- Falls within the time period specified on the form.

10.8 If the death is anticipated in the community, the GP should be called.

11 Guidance on when the CYPACP may not apply

The CYPACP will only apply to situations described within the care plan and when it is signed by the child's lead clinician. There is an opportunity on the pro-forma for both the child (if they have capacity) and their parent to endorse the plan, where dictated by local policy or considered appropriate. This does not include the DNACPR form which is validated by the signature of a senior clinician and can be found in the ReSPECT form section 4 or on the final page of the CYPACP.

11.2 The CYPACP should not usually be used for the first time in an adult of 18 years or over. There may be some young adults in which this form was initiated before their 18th birthday. If the young adult is deemed competent and has signed the form, it will remain valid, and a parental signature is not required.

11.3 In all circumstances not covered by the CYPACP and or ReSPECT form it must be assumed that the child should have full resuscitation measures in the event of deterioration or collapse. Clinicians retain the right to not resuscitate or to stop resuscitation if they believe it is futile.

11.4 A valid CYPACP should be followed even when the parent or legal guardian is NOT present at the time of the child's acute deterioration or collapse.

11.5 If a parent or legal guardian is present at the time of his or her child's collapse, and they wish to deviate from the previously agreed ACP, then their wishes should be respected provided they are thought to be in the best interests of the child.

For further guidance on how to complete the Child and Young Person's Advance Care Plan, please see Staff Guidance leaflet available at:
http://cypacp.uk/document-downloads/document-guidelines/

12 Review

There is no fixed expiry time on a CYPACP, although this may be dictated by local procedures. Normally the review date would be specified by the senior clinician completing the form. It should be reviewed regularly. Review meetings need to be organised well ahead of time to ensure there is always a current valid plan.

13 Situations where there is lack of agreement

Where the clinical decision is challenged and agreement cannot be reached, a second opinion should be sought. Mediation should be considered. If there remains disagreement, legal advice must be sought in a timely fashion.

14 Cancellation of a DNACPR Decision

If a decision is made to cancel or revoke the CYPACP or DNACPR decision the plan should be crossed through with 2 diagonal lines in dark ball-point ink and the word **'CANCELLED'** written clearly between them, dated and signed by the senior clinician. The reasons for this change should be clearly documented in the child's clinical notes. The appropriate Electronic Alert on Carenotes must also reflect the cancelation of a CYPACP or DNACPR.

15 Exclusions form and suspension of DNADPR decision

15.1 A DNACPR decision does not include immediately remediable and acutely life-threatening clinical emergencies such as choking or anaphylaxis.

Appropriate emergency interventions, including CPR should be attempted in such circumstances.

15.2 A valid DNACPR decision may be temporarily suspended, for example around the time of specific interventions such as anaesthesia or surgery that have an associated increased risk of cardiopulmonary arrest. If such procedures are planned, then the CYPACP should be reviewed and whatever decision is made should be documented and communicated accordingly. This documentation should clearly specify the beginning and end date of the suspension (*cross reference policy* ***6.2.9 page13***).

16 Monitoring Implementation

16.1 Collaborating organisations should monitor and evaluate compliance with this policy through audit and data collection. See Appendix 1 for a model audit form to be completed for an agreed sample of CYPACP forms.

16.2 All organisations must have clear governance arrangements in place which indicate individuals and committees who are responsible for the governance of this policy at a local level.

This includes:

- Data collection
- Ensuring that approved documentation is implemented
- Managing risk
- Sharing good practice
- Monitoring of incident reports and complaints regarding the CYPACP, ReSPECT and DNACPR process.
- Developing action plans and ensuring that they are completed

16.3 Frequency and information.

- Compliance with the policy should be audited annually
- Local leads will decide the number of CYPACPs to be examined.

16.4 Information from audit will be used for future planning, identification of training needs and for the policy review.

16.5 It may also be useful to audit and review how the CYPACPs are used:

- how many children have a CYPACP
- whether it was used in practice

- how many children who have died had a CYPACP
- location of death for children with and without a CYPACP

Within Herefordshire and Worcestershire Health and Care NHS Trust the above points will fall within the remit of the Children's Palliative Care Coordinator, which is covered by the Community Children's Nurses (Orchard Service) Team Leaders.

Monitoring incident reports and complaints will be covered by the Quality Lead for Children, Young People and Families and Specialist Primary Care SDU.

17 Training and competencies

17.1 All nursing and medical staff who regularly/routinely care for a children/young people with life limiting/life threatening conditions, as part of their role, should ensure they are sufficiently equipped with the skills to complete a CYPACP with a family, where this becomes necessary

17.2 For Community Children's Nurses (Orchard Service) this will be supported by their Team Leaders, who will work alongside their staff, where there is a need for a CYPACP to be completed.

17.3 Advance Communication Skills training will be offered to all Community Children's Nurses (Orchard Service) as a means of addressing this requirement. This will be included as part of their annual training plan.

17.4 Training and education is also provided through the website associated with this document http://cypacp.uk/education-training/. This includes training events as well as education documents.

17.5 All staff should notify their manager of their training needs as part of the SADR process, in order that plans can be put in place to meet these needs.

18 References

- Adoption and Children Act (2002) http://www.legislation.gov.uk/ukpga/2002/38/contents
- Adoption and Children Act (2006) http://www.legislation.gov.uk/ukpga/2006/20/contents
- Adoption and Children Act (2014) http://www.legislation.gov.uk/ukpga/2014/6/contents/enacted
- Advanced Paediatric Life Support Group Guidelines http://www.alsg.org/uk/apls
- Association of Anaesthetists of Great Britain and Ireland May 2009, DNAR decisions in the Perioperative Period

- British Medical Association (2008) https://www.bma.org.uk/advice/employment/ethics/children-and-young-people/parental-responsibility
- Children Act (1989) http://www.legislation.gov.uk/ukpga/1989/41/contents
- Children Act (2004) http://www.legislation.gov.uk/ukpga/2004/31/contents
- Children and Young Person’s Advance Care Plan Collaborative (2019) http://cypacp.uk/
- Coroners Act (1988) updated 2012 http://www.legislation.gov.uk/ukpga/1988/13/contents
- Decisions relating to Cardiopulmonary Resuscitation (3rd edition 1st revision) Guidance from the British Medical Association (BMA), the Resuscitation Council (UK), and the Royal College of Nursing (previously known as the “Joint Statement”) Oct 2014 https://www.resus.org.uk/dnacpr/decisions-relating-to-cpr/
- General Medical Council (2007) 0-18 years: guidance for all doctors https://www.gmc-uk.org/ethical-guidance/ethical-guidance-for-doctors/0-18-years
- General Medical Council (2010) Treatment and Care towards the end of life: good practice in decision making https://www.gmc-uk.org/-/media/documents/Treatment_and_care_towards_the_end_of_life___English_1015.pdf_48902105.pdf
- Great Ormond Street Hospital (2019) Policy – Required Consideration https://www.togetherforshortlives.org.uk/resource/great-ormond-street-hospital-policy-required-reconsideration/
- Human Rights Act (1998) http://www.legislation.gov.uk/ukpga/1998/42/contents
- Mental Capacity Act (2019) https://www.legislation.gov.uk/ukpga/2019/18/enacted
- NSPCC (2018) A child's legal rights, Gillick competency and Fraser guidelines https://www.nspcc.org.uk/preventing-abuse/child-protection-system/legal-definition-child-rights-law/gillick-competency-fraser-guidelines/
- National Institute for Health and Care Excellence (NICE) 2016, update 2019. End of Life Care for Infants, Children and Young People with Life Limiting Conditions: planning and management – NG61. https://www.nice.org.uk/guidance/ng61
- National Institute for Health and Care Excellence (NICE) 2017. End of life care for infants, children and young people, Quality Standard QS160. https://www.nice.org.uk/guidance/qs160
- ReSPECT (2019) Resuscitation Council. https://www.resus.org.uk/respect/
- Resuscitation Council (2019) 2021 Resuscitation Guidelines | Resuscitation Council UK

- Resuscitation Council (UK) CPR Decisions, DNACPR and ReSPECT https://www.resus.org.uk/public-resource/cpr-decisions-and-dnacpr
- Royal College of Paediatrics and Child Health (2015) Making decisions to limit treatment in life-limiting and life-threatening conditions in children: A Framework for Practice. http://adc.bmj.com/content/100/Suppl_2/s1.full.pdf+html
- Working Together to Safeguard Children (2006, 2013, 2015, 2018) HM Government https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/779401/Working_Together_to_Safeguard-Children.pdf

19 Associated Documentation

- Herefordshire and Worcestershire Health and Care NHS Trust's Consent Policy – CL- 189 (including Chaperone Responsibilities) https://intranet.hwhct.nhs.uk/clinical-policies?media_item=2953&media_type=10#file-viewer
- Herefordshire and Worcestershire Health and Care NHS Trust Clinical Record Keeping Guidelines - CL- 038 https://intranet.hwhct.nhs.uk/clinical-policies?media_item=2955&media_type=10#file-viewer
- Herefordshire and Worcestershire Health and Care NHS Trust Electronic Alert Policy - Covering Alerts for Safeguarding Patient Safety Staff Safety - Clinical - CL-248 https://intranet.hwhct.nhs.uk/clinical-policies?media_item=2964&media_type=10#file-viewer
- Herefordshire and Worcestershire Health and Care NHS Trust - A Guideline for Best Practice in Palliative Care for Babies Children and Young People Clinical - CL-030 https://intranet.hwhct.nhs.uk/clinical-policies?media_item=2931&media_type=10#file-viewer
- Herefordshire and Worcestershire Health and Care NHS Trust - Management of Children and Young People with Life Limiting/Life Threatening Conditions During Periods of Significant Health Changes Clinical - CL-224 https://intranet.hwhct.nhs.uk/clinical-policies?media_item=2928&media_type=10#file-viewer

- Herefordshire and Worcestershire Health and Care NHS Trust - Electronic Alerts Policy – CL-248 https://intranet.hwhct.nhs.uk/clinical-policies?media_item=2964&media_type=10#file-viewer

20 Appendices

Appendix 1 **CYPACP Model Audit Form**
(use in conjunction with quality standards NG160, Quality Standard 1)

Service……………………………………. Date………………………………………….

	Question	Yes	No	Comments
1	Is there a Child and Young Person's Advance Care Plan with evidence that there has been discussion between parents and/or carers and a senior clinician?			
2	Where applicable are there systems in place to allow this to be discussed with families prior to birth of their child?			
3	Has the decision been recorded on approved documentation?			
4	Has the decision been made by an appropriate clinician?			
5	Is the record clearly dated and signed in full?			
6	Are there clear patient identifiers?			
7	Are all fields of the records completed?			
8	Is there evidence that the best interests of the child have been considered?			
9	Is there evidence of discussions with the child or young person?			
10	Is there evidence that the multidisciplinary team are aware of the decision?			

11	Is there evidence that decisions are reviewed and documented?			
12	Is there evidence that copies of the ACP have been distributed to the individuals listed on the distribution page (p6)			

Comments:

Herefordshire and Worcestershire ICS - Equality Impact Assessment (EIA) Form

Please read EIA guidelines when completing this form

Section 1 - Name of Organisation (mark with an ‘X’ in the right-hand column)

Herefordshire & Worcestershire ICS	
Worcestershire Acute Hospitals NHS Trust	
Herefordshire & Worcestershire Health and Care NHS Trust	x
Herefordshire Council	
Worcestershire County Council	
Wye Valley NHS Trust	
Herefordshire & Worcestershire CCG	
Other (please state)	

Name of lead for activity	**Name**	**Job title**	**Email address**
Details of individual(s) completing this assessment, please include name, job title and email contact	Debbie Bolt	Children’s Practice Facilitator	debbie.bolt@nhs.net
	Louise Dargie	Clinical Lead for Children's Nursing	louisedargie@nhs.net
	Gail Jackson	Team Lead, Community Children’s Nurses, (Orchard Service) South Locality	gail.jackson3@nhs.net
Date assessment completed	20.12.22		

Section 2

Activity being assessed (e.g. policy/procedure, document, service redesign, policy, strategy etc.)	Children’s Collaborative Advance Care Plan Policy
What is/are the aim, purpose and/or intended outcomes of this activity?	To provide guidance on a framework for recording the wishes of children or young people (and their families), who have chronic and life-limiting conditions.

Who will be affected by the development & implementation of this activity? (Mark with an 'X' in the right-hand column)

Service user	x
Patient	x
Carers	x
Staff	x
Communities	
Other (please state)	

This is a… (Mark with an 'X' in the right-hand column)

Review of an existing activity	x
New activity	
Planning to withdraw or reduce a service, activity or presence?	

What information and evidence have you reviewed to help inform this assessment? (Please name sources, e.g. demographic information for patients / services / staff groups affected, complaints etc.	Review of relevant associated literature available. See reference list.
Summary of engagement or consultation undertaken (e.g. who and how have you engaged with, or why do you believe this is not required)	Consultation with relevant interested parties. See version history.
Summary of relevant findings	See version history. Updated references and electronic links.

Section 3

Please consider the potential impact of this activity (during development & implementation) on each of the equality groups outlined below. **Please tick one or more impact box below for each Equality Group and explain your rationale**. Please note it is possible for the potential impact to be both positive and negative within the same equality group and this should be recorded. Remember to consider the impact on e.g. staff, public, patients, carers etc. in these equality groups.

Equality Group	Potential positive impact	Potential neutral impact	Potential negative impact	Please explain your reasons for any potential positive, neutral or negative impact identified
Age	✓			This policy relates to Children and Young People from birth to 18 years of age. However, there is policy for adults that would be considered and discussed through transition and implemented in adult care. This policy is applicable to all settings a child may attend. It considers and encourages involvement of the child/young person where this is possible. It specifically references other processes relevant to children and young people, e.g. SUDIC. as well as relevant legislation
Disability	✓			Many children requiring Advance Are Plans will have disabilities which may be life limiting; this would be taken into consideration when developing an Advance Care Plan. All children and young people will be heard and their opinions regarding their wishes regarding life and death listened to. Appropriate support given to those with disabilities, to ensure this is recognised as far as is possible. Additional support would be offered to children/young people with sensory deficits, or who may be registered blind or deaf. Any instructions can be requested in Braille and the service has access to BSL interpreters should they be required. For those with receptive and/or expressive speech or language difficulties, communication tools should be considered and the involvement of someone who knows them well.

Equality Group	Potential positive impact	Potential neutral impact	Potential negative impact	Please explain your reasons for any potential positive, neutral or negative impact identified
Gender Reassignment Gender Identity and Gender expression		✓		Gender reassignment would not impact on this policy Equitable care would be provided to all.
Marriage & Civil Partnerships		✓		If the young person was married or in a civil partnership their partners would be involved in the development of an advance care plan.
Pregnancy & Maternity		✓		This would be dealt with on an individual basis but would not prevent care delivery.
Race including Traveling Communities		✓		Race and cultural preferences would be taken into consideration and wishes included in the Advance Care Plan. Interpreting services would be accessed where necessary to ensure clear lines of communication are maintained throughout all discussions and end of life care.
Religion & Belief		✓		Religion, beliefs and cultural preferences would always be taken into consideration and included in detail in the Advance Care Plan. Relevant religious leaders would be contacted by the family ideally, or Community Children's Nurse, if this was the families wish.
Sex		✓		This policy would apply regardless of the gender of the child or young person.
Sexual Orientation		✓		This policy would apply irrespective of the child or young person's sexual orientation.
Other Vulnerable and Disadvantaged Groups (e.g. carers;		✓		Timing and location of discussions and care delivery

Equality Group	Potential positive impact	Potential neutral impact	Potential negative impact	Please explain your reasons for any potential positive, neutral or negative impact identified
care leavers; homeless; Social/Economic deprivation, travelling communities etc.)				would be taken into account particularly for working parents. Consideration would be given to children of travelling families, in order to deliver this care within their home setting wherever possible provided safe facilities were available
Health Inequalities (reduce inequalities between patients with respect to the ability to access health services, and (b) reduce inequalities between patients with respect to the outcomes achieved for them by the provision of health services. NHS Act 2006 (as amended)		✓		This service is accessible to all communities. It is highly unlikely that a child/young person would be homeless, at the end of their life; this would be a safeguarding issue and managed accordingly. Where a child/young person is from the armed forces community, or parents are serving in the armed forces, additional consideration would be given to minimise disruption to care wherever possible.

Section 4

What actions will you take to mitigate any potential negative impacts?

Risk identified	Actions required to reduce / eliminate negative impact	Who will lead on the action?	Timeframe

How will you monitor these actions?	
When will you review this EIA? (e.g. in a service redesign, this EIA should be revisited regularly throughout the design & implementation)	

Section 5 - Please read and agree to the following Equality Statement

1. Equality Statement

1.1. All public bodies have a statutory duty under the Equality Act 2010 to set out arrangements to assess and consult on how their policies and functions impact on the 9 protected characteristics: Age; Disability; Gender Reassignment; Marriage & Civil Partnership; Pregnancy & Maternity; Race; Religion & Belief; Sex; Sexual Orientation

1.2. Our Organisations will challenge discrimination, promote equality, respect human rights, and aims to design and implement services, policies and measures that meet the diverse needs of our service, and population, ensuring that none are placed at a disadvantage over others.

1.3. All staff are expected to deliver services and provide services and care in a manner which respects the individuality of service users, patients, carer's etc., and as such treat them and members of the workforce respectfully, paying due regard to the 9 protected characteristics.

1.4 Our organisations are expected to use the appropriate interpreting, translating or preferred method of communication for those who have language and/or other communication needs. Practitioners will need to assess that the implementation of the Children's Collaborative Advance Care Plan Policy is fair and equitable for all groups covered under the Equality Act 2010 and that they are implementing the Accessible Information Standard and have considered health inequalities.

1.5. Herefordshire and Worcestershire Health and Care NHS Trust must meet its statutory duty to reduce inequalities of access and outcomes, as set out in the NHS Act 2006 (as amended). As a result, the Herefordshire and Worcestershire Health and Care NHS Trust aims to design and implement policy documents that seek to reduce any inequalities that already arise or may arise from any new policy. Therefore, Herefordshire and Worcestershire Health and Care NHS Trust will consciously consider the extent to which any policy reduces inequalities of access and outcomes.

1.6. Any change to a service will require a conscious effort from the author(s) of that change to actively consider the impact that this will have on any Protected group(s) and act due diligently. Where an impact on any of the Equality groups is realised after the implementation of the Project/Service, the commissioners and or Providers, who are implementing the said Project and or service will seek to minimise such an impact and simultaneously carry out a full review.

Signature of person leading & or completing the EIA	Debbie Bolt
Date signed	20.12.22
Comments:	

Signature of person approving the EIA	Debbie Bolt
Date signed	20.12.22
Comments:	

Human Rights Consideration:

NHS organisations must ensure that none of their services, policies, strategies or procedures infringes on the human rights of patients or staff. You should analyse your document using the questions provided to determine the impact on human rights. Using human rights principles of fairness, respect, equality, dignity and autonomy as flags or areas to consider is often useful in identifying whether human rights are a concern.

Can you please answer the following Human Rights screening questions:

	Human Rights	**Yes/No**	**Please explain**
1	Will the policy/decision/service change or refusal to treat result in the death of a person?	No	
2	Will the service change/policy/decision lead to degrading or inhuman treatment?	No	
3	Will the service change/policy/decision limit a person’s liberty?	No	
4	Will the service change/policy/decision interfere with a person’s right to respect for private and family life?	No	
5	Will the service change/policy/decision result in unlawful discrimination?	No	
6	Will the service change/policy/decision limit a person's right to security?	No	
7	Will the service change/policy/decision breach the positive obligation to protect human rights?	No	
8	Will the service change/policy/decision limit a person's right to a fair trial (assessment, interview or investigation)?	No	

9	Will the service change/policy/decision interfere with a person's right to participate in life?	No	

If any Human Rights issues have been identified in this section, please get in touch with your Equality and Inclusion Lead who will advise further, and a full Human Rights Impact Assessment maybe required to be completed.