

## National Policy

### Child & Young Person’s Advance Care Plan Policy

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Purpose of Agreement	This policy is a review of the existing South Central Advance Care plan policy and has been reviewed and updated by the National Child and young person collaborative
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Include details of when the document was last reviewed:

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2	April 2020	S Clark	Expiry date extended to March 2021 in light of Covid-19 National Emergency	Policy rapid review
3	December 2020	S Clark	Policy converted over to new template; no amends made to content of policy, following National Policy	

## SUMMARY OF POLICY

This document was developed from a South Central policy by a working group for the Child and Young Person's Advance Care Plan Collaborative. The collaborative is a voluntary group of NHS & private sector organisations concerned with delivering the best possible care for children with potentially shortened lives. Members span across much of the West 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 template remains valid until its review. It will be reviewed initially at three yearly 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.

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 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 [www.cypacp.nhs.uk](http://www.cypacp.nhs.uk).

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## Child and Family Person's Advance Care Plan Policy

### 1. Introduction

This document was developed from a South Central policy by a working group for the Child and Young Person's Advance Care Plan Collaborative. The collaborative is a voluntary group of NHS & private sector organisations concerned with delivering the best possible care for children with potentially shortened lives. Members span across much of the West 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 template remains valid until its review. It will be reviewed initially at three yearly 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 & Young Person's Advance Care Plan pro-forma (**Appendix 1**)
- A Guide (This accompanies the pro-forma and is designed to provide the user with practical advice in how to fill out the CYPACP).
- A website that includes supporting information and a discussion forum to support education and development of the plan: <http://www.cypacp.nhs.uk/>
- An information leaflet for parents and carers about Advance Care Plans (**Appendix 2**)
- An information leaflet for young people about Advance Care Plans (**Appendix 3**)

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 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 [www.cypacp.nhs.uk](http://www.cypacp.nhs.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 & Young Person's ACP Collaborative.
- 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.
- 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 or 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 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 where ever possible. **(See appendix 1)**
- 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.
- 3.6 Training will be available to enable staff to meet the requirements of this policy.

### **4. Purpose**

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

## 6. Key Legislation & Guidance

### 6.1 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 & 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 (2005)

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

The Mental Capacity Act (MCA) 2005 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 & 2013) revisions Jan 2015

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](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.

<http://www.medicalprotection.org/uk/resources/factsheets/england/england-factsheets/uk-eng-reporting-deaths-to-the-coroner>

<https://www.gov.uk/government/publications/update-for-coroners-on-death-certification-reforms>

#### 6.1.7 Equality Impact Assessment (See Appendix 5)



- 6.2 Guidance, additional guidance may be drawn from the following sources:
- 6.2.1 Resuscitation Council (UK) Guidelines <http://www.resus.org.uk/pages/Guid.htm>
  - 6.2.2 Advanced Paediatric Life Support Group Guidelines <http://www.alsg.org/uk/apls>
  - 6.2.3 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](http://adc.bmj.com/content/100/Suppl_2/s1.full.pdf+html)
  - 6.2.4 Resuscitation Council (UK) Recommended standards for recording "Do not attempt resuscitation" (DNAR) decisions (2009) <http://www.resus.org.uk/siteindx.htm>
  - 6.2.5 Decisions relating to Cardiopulmonary Resuscitation (3<sup>rd</sup> edition) 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/pages/dnacpr.htm>
  - 6.2.6 BMA (2006) Parental Responsibility: Guidance from the BMA. <http://bma.org.uk/practical-support-at-work/ethics/children>
  - 6.2.7 General Medical Council (2007) 0-18 years: guidance for all doctors [http://www.gmc-uk.org/publications/standards\\_guidance\\_for\\_doctors.asp#0-18](http://www.gmc-uk.org/publications/standards_guidance_for_doctors.asp#0-18)
  - 6.2.8 DNAR decisions in the Perioperative Period; Association of Anaesthetists of Great Britain and Ireland May 2009 [http://www.aagbi.org/sites/default/files/dnar\\_09\\_0.pdf](http://www.aagbi.org/sites/default/files/dnar_09_0.pdf)
  - 6.2.9 Reconsideration of ACP for surgery or procedures, GOS protocol [http://www.togetherforshortlives.org.uk/assets/0000/8555/Great\\_Ormond\\_St\\_policy\\_required\\_reconsideration.pdf](http://www.togetherforshortlives.org.uk/assets/0000/8555/Great_Ormond_St_policy_required_reconsideration.pdf)
  - 6.2.10 General Medical Council (2010) Treatment and Care towards the end of life: good practice in decision making. [http://www.gmc-uk.org/static/documents/content/Treatment\\_and\\_care\\_towards\\_the\\_end\\_of\\_life\\_-\\_English\\_0914.pdf](http://www.gmc-uk.org/static/documents/content/Treatment_and_care_towards_the_end_of_life_-_English_0914.pdf)

## 7. Legal Considerations

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.

7.1.2 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.

7.1.3 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 & 17 year olds to make arrangements to enable them, once incapacitated, to refuse life saving 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 16/17 year old is thought to lack capacity for a decision and has a parent with them who can be consulted, they fall outside of the remit of the MCA 2005, since they are not unbefriended. The parents have a right to provide consent under the normal arrangements under the Children Act.

7.2.4 For 16/17 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 & 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 The 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 & 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 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.
- 8.9. Commissioners and commissioned services, for example pharmacists and dentists, should be aware of this policy and consider its implications when commissioning or providing services.

8.10 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

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

- Information regarding a DNACPR/ Child and Young Person's Advance Care Plan is included in pre-admission documentation.
- All DNACPR/ Advance Care Plans 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/ CYPACPs 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

8.12 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 ([www.cypacp.nhs.uk](http://www.cypacp.nhs.uk)) should be used when initiating an ACP. It provides guidance on the overall process as well as page-by page instruction on completing the documentation.

## 10. Do Not Attempt Cardiopulmonary Resuscitation (DNACPR)

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

- 11.1 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.
- 11.2 The CYPACP should not normally be 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 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: [www.cypacp.nhs.uk](http://www.cypacp.nhs.uk)

## 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. The local CYPACP co-ordinator is responsible for distributing the latest version of the CYPACP.

### 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.

It is the responsibility of the CYPACP Co-ordinator to inform all parties and to organise an urgent review so that a new CYPACP can be completed.

### 15. Exclusions from and suspension of DNACPR 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 page 9**).

### 16. Audit

- 16.1 Collaborating organisations should monitor and evaluate compliance with this policy through audit and data collection. See Appendix 3 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 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



## **Appendix 1**

### **Child and Young Person's Advance Care Plan**

Please refer to current document on website: [www.cypacp.nhs.uk](http://www.cypacp.nhs.uk)

## **Appendix 2**

### **Young Person's Information Leaflet**

Please refer to current document on website: [www.cypacp.nhs.uk](http://www.cypacp.nhs.uk)

## **Appendix 3**

### **Parents Information leaflet**

Please refer to current document on website: [www.cypacp.nhs.uk](http://www.cypacp.nhs.uk)

## Appendix 4

### CYPACP Model Audit Form

Service.....

Date.....

	Question	Yes	No	Comments
1	Is there a Child and Young Person's Advance Care Plan?			
2	Has the decision been recorded on approved documentation?			
3	Has the decision been made by an appropriate clinician?			
4	Is the record clearly dated and signed in full?			
5	Are there clear patient identifiers?			
6	Are all fields of the records completed?			
7	Is there evidence that the best interests of the child have been considered?			
8	Is there evidence of discussions with the child and/or their family?			
9	Is there evidence that the multidisciplinary team are aware of the decision?			
10	Is there evidence that decisions are reviewed and documented?			
11	Is the Child and Young Person's Advance Care Plan policy easily accessible to relevant staff?			
12	Is there evidence that copies of the ACP have been distributed to the individuals listed on the final page of the ACP			

Comments:

## Appendix 5

### Equality & Human Rights and MCA Impact Assessment

Step 1 - Scoping; identify the policies aims	Answer		
1. What are the main aims and objectives of the document?	This policy aims to deliver a unified approach to the care of the children and young people it concerns.		
2. Who will be affected by it?	All staff who are working with children and families to develop advanced care plans		
3. What are the existing performance indicators/measures for this? What are the outcomes you want to achieve?	n/a		
4. What information do you already have on the equality impact of this document?	None		
5. Are there demographic changes or trends locally to be considered?	n/a		
6. What other information do you need?	N/a		
Step 2 - Assessing the Impact; consider the data and research	Yes	No	Answer/Evidence
1. Could the document unlawfully against any group?		X	
2. Can any group benefit or be excluded?		X	
3. Can any group be denied fair & equal access to or treatment as a result of this document?		X	N/A
4. Can this actively promote good relations with and between different groups?		X	
5. Have you carried out any consultation internally/externally with relevant individual groups?	X		This has been developed through national collaboration with key groups across health organisations
6. Have you used a variety of different methods of consultation/involvement	X		Via email and face to face meetings
Mental Capacity Act implications		X	
7. Will this document require a decision to be made by or about a service user? (Refer to the Mental Capacity Act document for further information)	X		Children, young people & families will be making decisions about care
<a href="#">If there is no negative impact – end the Impact Assessment here</a>			
Step 3 - Recommendations and Action Plans	Answer		
1. Is the impact low, medium or high?			
2. What action/modification needs to be taken to minimise or eliminate the negative impact?			
3. Are there likely to be different outcomes with any modifications? Explain these?			
Step 4- Implementation, Monitoring and Review	Answer		
1. What are the implementation and monitoring arrangements, including timescales?			
2. Who within the Department/Team will be responsible for monitoring and regular review of the document?			
Step 5 - Publishing the Results	Answer		
How will the results of this assessment be published and where? (It is essential that there is documented evidence of why decisions were made).			