

## Advance Care Plan for a Child or Young Person (This form will be printed in lilac)

This document is a tool for discussing and communicating the wishes of a child / parent(s) or young person. It is particularly useful in an emergency, when the individual cannot give informed consent for themselves and / or next of kin / parent(s) cannot be contacted.

<b>Name:</b> .....	<b>Date of Birth:</b> ...../...../.....
<b>Known as:</b>	<b>Hospital Number:</b>
<b>First Language:</b>	<b>NHS Number:</b>
<b>Home Address:</b>	
	<b>Postcode:</b>
<b>Telephone Number:</b>	

**NB: If the child or young person becomes unwell and needs an ambulance, inform ambulance control that the child has an Advance Care Plan. Ambulance Control will have an electronic copy of the ACP flagged under the child's *home address* and *postcode*. Don't forget to give ambulance control the child or young person's *current location* as well, if they are away from home.**

Name of person/people with parental responsibility (and address if different from above):

.....

Emergency contact number for person with parental responsibility: .....

Other emergency contact numbers:.....

Other key people (e.g. family and friends) .....

Name.....Relationship.....Tel.....

Name.....Relationship.....Tel.....

Primary diagnosis and background summary:

--

Advance care plan for use in:							
<input type="checkbox"/>	Home	<input type="checkbox"/>	School	<input type="checkbox"/>	Hospital	<input type="checkbox"/>	Hospice
Other please state:							

**Date Plan Initiated**...../...../.....

**Date Review is due**...../...../.....

Date reviewed/amended:	Name & title of lead reviewer	Next review due

## Advance Care Plan: Management of cardio-respiratory arrest

Name: .....

Date of Birth: ...../...../.....

Regardless of the patient's resuscitation status, the following immediately reversible causes should be treated: **choking, anaphylaxis, blocked tracheostomy tube, other** (*please state*):

### RESUSCITATION STATUS

Resuscitation status has not been discussed – **attempt full resuscitation**

Resuscitation status has been discussed and the following has been agreed:

### Clearly delete actions not required

For full resuscitation	<b>Attempt resuscitation with modifications below:</b>	<b>Do not attempt cardiopulmonary resuscitation DNACPR</b>
Attempt resuscitation as per standard RC(UK) guidelines	<b>Patient-specific modifications to standard resuscitation guidelines</b>  AIRWAY:  BREATHING:  CIRCULATION:  DRUGS:  OTHER:  PICU/HDU:	Patient-specific supportive care is documented on pages 3 and 4     In the event of sudden death 24 hour emergency number for doctor who knows the child:  .....

### Ambulance directive: (eg transfer to home/ward/Emergency Department /hospice)

.....

Reason(s) for decision

Senior Clinician Signature ..... Name ..... GMC No.....

Date Initiated ...../.. .../.....

Review Date (see page 1)

## Advance Care Plan: Intercurrent illness / acute deterioration

Name: .....		Date of Birth: ...../...../.....	
Main Diagnoses:		Known Allergies:	
Signs / Symptoms to expect			

In the event of a likely *reversible* cause for acute life-threatening deterioration such as choking, tracheostomy blockage or anaphylaxis please intervene and treat actively. Please also treat the following possible problems actively e.g. bleeding (please state):

If a cardiac or respiratory arrest is not specifically anticipated, decisions about resuscitation would normally be made on a 'best interests' basis at the time of such an event. Unless a separate resuscitation section has been completed, the presumption would normally be for attempted resuscitation initially unless this seemed futile, unlikely to be successful, not in best interests, or otherwise directed.

### ***In the event of acute deterioration:***

(Clearly delete all options NOT required. Add comments to clarify wishes):

- Support transfer to preferred place of care if possible (*specify*):.....  
.....
- Maintain comfort and symptom management, and support child / young person and family
- Clear upper airway
- Face mask oxygen if available
- Bag and mask ventilation
- Emergency transfer to hospital if doctor considers appropriate in the specific situation
- Intravenous access or intraosseous access
- Consider nasogastric feeding tube (*insertion or removal*)
- Non-invasive ventilation
- Intubation
- Consider stopping feeds
- Consider stopping fluids
- Other; please state.....  
.....

**Advance Care Plan: Intercurrent illness/acute deterioration** *continued*

Name: .....

Date of Birth: ...../...../.....

***Specific treatment plans if indicated***

**Management of seizures**

Description of usual seizure pattern / types: .....

Rescue medication: (drug name, dose and route)

First line	after.....mins
Second line	after further .... .mins
Third line	after further .... .mins

Call 999 for emergency transfer to hospital?  Yes  No (√)

If yes, at what stage?.....

Other instructions for seizures:.....

**Management of infection** *(prompt, check for known allergies recorded p3)*

Preferred antibiotic or regime for recurrent infections – drug dose, route, duration:

.....

Intravenous antibiotics will normally require transfer to hospital for investigation and initiation of treatment.

Other instructions/comments regarding infection-related symptoms e.g. nebulisers, steroids.

.....

**Instructions for emergency care in other specific circumstances:**

*(Document here regimes specific to this child/young person, for example for management of metabolic disturbance etc).*

**Additional Comments:**

## Advance Care Plan: Wishes

Name: .....

Date of Birth: ...../...../.....

(please continue on p7- free text for communications and discussions if insufficient space for responses)

<b>WISHES DURING LIFE</b>
<p><b>Child's / Young Person's wishes</b> e.g. Place of care, symptom management, people to be involved (professional/non-professional), activities to be continued (spiritual and cultural).</p>
<p><b>Family wishes</b> e.g. Where you want to be as a family, who you would like to be involved (e.g. medical, spiritual or cultural backgrounds).</p>
<p><b>Others wishes</b> (e.g. school friends, siblings)</p>
<b>WISHES AROUND THE END OF LIFE</b>
<p><b>Preferred place of care of child /young person</b></p>
<p><b>Funeral preferences</b></p> <p style="font-size: small; margin-top: 10px;">Seek detailed information or further advice if needed</p>
<p><b>Spiritual and cultural wishes</b></p>
<p><b>Other child/ young person &amp; family wishes, e.g. what happens to possessions?</b></p>
<p><b>Organ &amp; tissue donation</b></p>

**This page discussed by:**

Child /Young Person / Parent / Carer  
Professional (full name and job title)

**Date:**...../...../.....



## Advance Care Plan

### Who has agreed and supports the plan?

Name: .....

Date of Birth: ...../...../.....

#### Senior Clinician e.g. Paediatric Consultant – I support this care plan

Name: .....Signature.....GMC No.....Date... /... /20...

#### Child / Young person – I have discussed and support this care plan (optional)

Name: .....Signature..... Date.../...../20...

#### Parent/Guardian – We / I have discussed and support this care plan

Name: .....Signature..... Date.../.../20...

#### Other e.g. CCN – I have discussed and support this care plan

Name: .....Signature..... Date.../.../20...

#### Other e.g. GP – I have discussed and support this care plan

Name: .....Signature.....GMC No.....Date.../.../20...

#### Other e.g. Hospice doctor – I have discussed and support this care plan

Name: .....Signature.....GMC No.....Date.../.../ 20.....

**Other people informed:** see circulation list

#### **Clinicians have a duty to act in a patient's best interests at all times.**

If a parent or legal guardian is present at the time of their child's collapse, they may wish to deviate from the previously agreed Advance Care Plan and under these circumstances their wishes should be respected, provided they are thought to be in the best interests of the child/ young person. The child/young person or parents /guardian can change their mind about any of the preferences on the care plan at any time.

### ***Communications and discussions***

Name: .....

Date of Birth: ...../...../.....

**Name and contact details**

**ACP Co-ordinator –  
responsible for distributing  
this Advance Care Plan.**

--

**A copy of this ACP is held by:**

- Parents/guardians
- General practitioner
- Paediatrician (Community)
- Paediatrician
- Hospital (e.g. open access ward)
- Hospice (please provide the name of the hospice)
- Community Nurses (CCN)
- CCN Specialist Nurses/School Nurse
- GP Out of Hours Service
- Ambulance Control/Rapid Response Team
- Emergency Dept
- School-Head Teacher (with consent to share with school staff)
- Other e.g. Social Care, Short break care provider
- Other e.g. CDOP, Police, Coroner
- Other

--

--

--

--

--

--

--

--

--

--

--

--

--

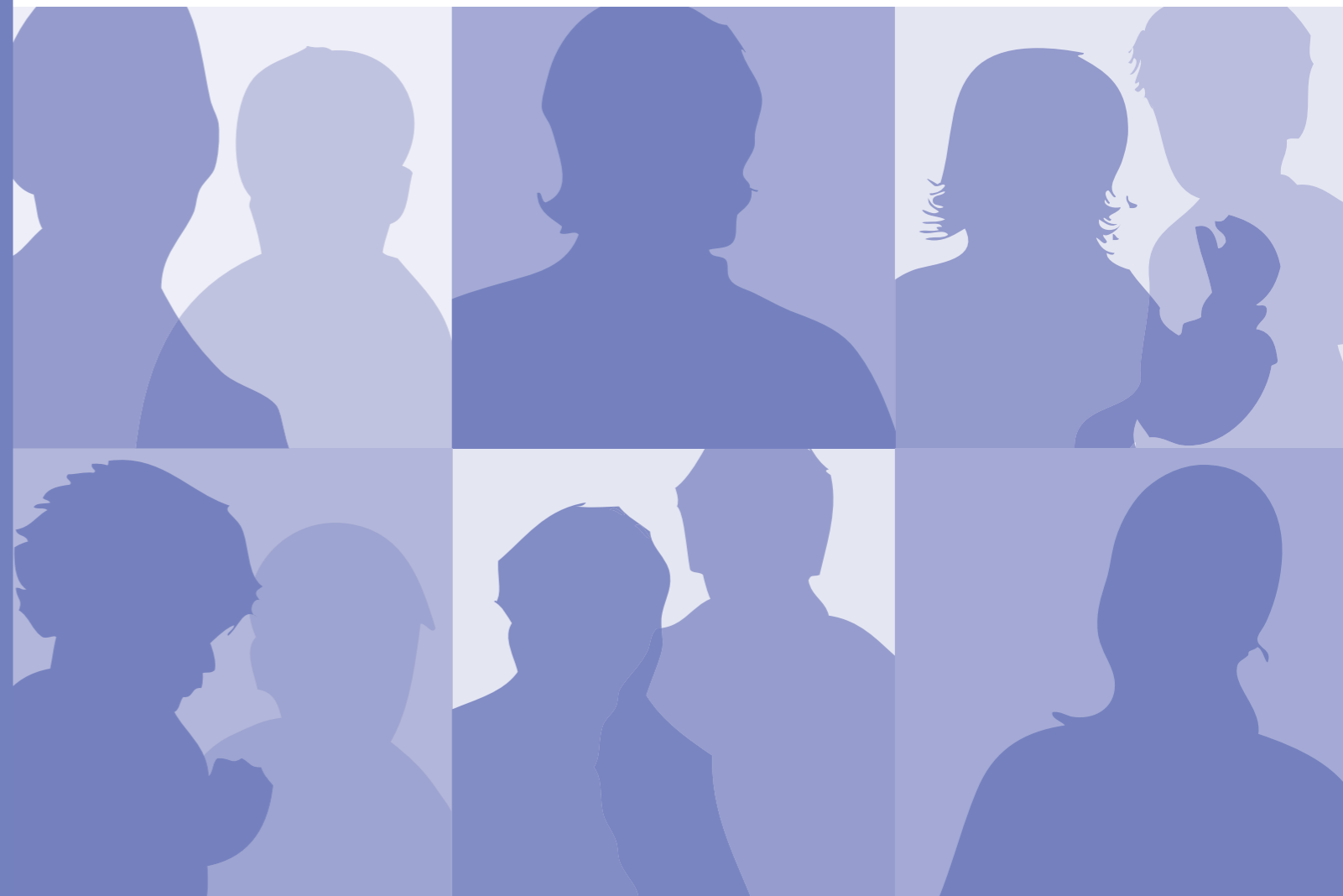
--

--



## Guide to using the Child and Young Person's Advance Care Plan

This guide is for professionals who may be involved  
in developing an Advance Care Plan for a child or  
young person in their care



**Contents**

Page	Content
3	Definitions and Terminology
4	Introduction
4	Legislation
4	Guidance
5	What is an Advance Care Plan (ACP)?
5	Who should initiate an Advance Care Plan?
6	What a Do Not Attempt Cardiopulmonary Resuscitation (DNACPR) decision means
6	How to complete the Advance Care Plan forms
11	Key points
12	Review process
12	Cancellation of a DNACPR decision
12	Exclusions from and suspension of DNACPR decisions
12	Ethical and legal background
15	Further Reading and Resources
15	South Central Child and Young Person’s Advance Care Plan Working Group
15	Contributors

**Definitions and Terminology**

**Child and Young Persons Advance Care Plan (ACP):** a document that records the advance wishes of a child or young person and/or those with parental responsibility for them. A different ACP can be used in adults. An ACP will include whether the child’s resuscitation status has been discussed, and the outcome of that discussion.

**Cardiopulmonary Arrest:** is the cessation of breathing and loss of cardiac output.

**Cardiopulmonary Resuscitation (CPR):** Interventions delivered with the intention of restarting the heart and breathing. These will include chest compressions and ventilations and may include attempted defibrillation and the administration of drugs.

**Do Not Attempt Cardiopulmonary Resuscitation (DNACPR):** refers to not making efforts to restart breathing and/or the heart following a cardiopulmonary arrest.

**Valid DNACPR:** A DNACPR is only valid if it is signed and dated.

**Local Lead Clinician for Advance Care Planning:** Acts as the primary link between members of his or her organisation and the South Central Strategic Health Authority (SCSHA) Child and Young Person’s ACP Working Party.

**ACP Co-ordinator:** is responsible for ensuring that all ACPs in his or her area are appropriately completed, regularly reviewed and that all relevant parties have the most recent copy of the ACP. This role can be undertaken by a senior clinician, an advanced nurse practitioner or consultant nurse.

**Child Death Overview Panel (CDOP):** This group monitors and reviews the deaths of all children, and a rapid response team is activated to initiate a review within a designated time frame each time that a death occurs.

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

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

**For the purposes of this document, when the word child is used it can be read as child/young person.**

**Introduction**

This document was written by the Child and Young Person's South Central Advance Care Plan Working Group with a launch date of 18th March 2010. This group is a subgroup of the NHS SC eolc (National Health Service South Central end of life care) programme board. It is designed for health care professionals who are considering an Advance Care Plan for a child in their care. This booklet is part of a package that consists of:

- A policy on the Advance Care Plan: [www.southcentral.nhs.uk](http://www.southcentral.nhs.uk)
- An Advance Care Plan pro forma
- A guide to using the Advance Care Plan
- An information leaflet for parents
- An information leaflet for young people

**Legislation** [www.opsi.gov.uk/acts](http://www.opsi.gov.uk/acts)

Children Act 1989 & 2004

Adoption and Children Act 2002

Mental Capacity Act 2005 and 2007

Working together to Safeguard Children 2006

Human Rights Act 1998

Coroners Act 1988

**Guidance**

1. European Resuscitation Guidelines. [www.resus.org.uk/siteindx.htm](http://www.resus.org.uk/siteindx.htm)
2. Advanced Paediatric Life Support Guidelines. [www.alsg.org/en/?q=en/apls](http://www.alsg.org/en/?q=en/apls)
3. Decisions relating to Cardiopulmonary Resuscitation. A Statement from the BMA and RCN in association with the Resuscitation Council (UK) 2007. [www.bma.org.uk/ethics/cardiopulmonary\\_resuscitation/CPRDecisions07.jsp](http://www.bma.org.uk/ethics/cardiopulmonary_resuscitation/CPRDecisions07.jsp)
4. Royal College of Paediatrics and Child Health (1997, 2004) Withholding or Withdrawing Life Sustaining Treatment in Children: A Framework for Practice. [www.rcpch.ac.uk/Publications/Publications-list-by-title#W](http://www.rcpch.ac.uk/Publications/Publications-list-by-title#W)
5. BMA (2006) Parental Responsibility: Guidance from the British Medical Association. [www.bma.org.uk/ethics/consent\\_and\\_capacity/Parental.jsp](http://www.bma.org.uk/ethics/consent_and_capacity/Parental.jsp)
6. General Medical Council (2007) 0-18 years: guidance for all doctors. [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)
7. DNAR decisions in the Peri-operative Period; Association of Anaesthetists of Great Britain and Ireland May 2009. [www.aagbi.org/publications/guidelines/docs/dnar\\_09.pdf](http://www.aagbi.org/publications/guidelines/docs/dnar_09.pdf)
8. Withholding and withdrawing life-prolonging medical treatment 3rd Edition BMA 2007. [www.bma.org.uk/ethics/end\\_life\\_issues/Withholdingwithdrawing.jsp](http://www.bma.org.uk/ethics/end_life_issues/Withholdingwithdrawing.jsp)

**1. What is an Advance Care Plan?**

An ACP is designed to communicate the health-care wishes of children who have chronic and life-limiting conditions. It sets out an agreed plan of care to be followed when a child's condition deteriorates. It provides a framework for both discussing and documenting the agreed wishes of a child and his or her parents, when the child develops potentially life-threatening complications associated with 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. This ACP can be used as a resuscitation plan or as an end-of-life care plan. It remains valid when parent(s) or next of kin cannot be contacted.

**2. Who should initiate an Advance Care Plan?**

This is usually a senior clinician who knows the child and his or her family well. It is important that all possible treatment options for the child's condition are considered in terms of benefit to the child. It is good practice to involve all key members of the multidisciplinary team in the process, including the general practitioner. The process may involve several different discussions over a period of time as it is essential that all concerned in the decision-making process be allowed enough time for information to be given and understood, to ask questions and to express their opinion. There are information leaflets for families and for young people about advance care planning included in this pack. Further leaflets may be ordered from [www.nhscreative.org](http://www.nhscreative.org). Additional resources for staff are listed at the back of this booklet.

A suggested approach to initiating a plan is shown below.

Step	Action	By
1	Assessment of the child's clinical situation. Has there been a recent change in the prognosis or clinical condition as a result of either a sudden or gradual deterioration?	Any professional involved with the child's care.
2	Discussion with all health care professionals involved with the child whether to prepare to develop an ACP. Consideration as to whether it is appropriate to discuss the DNACPR section of the plan.	Senior clinician.
3	Discussion with parents/ legal guardian and child (if appropriate), and other significant family members regarding the need for an ACP.	Senior clinician.
4	When writing the ACP with the parents/guardians allow 1 – 2 hours, and possibly undertake this in the home setting. The amount of input into this process by the child depends on their capacity for this decision (see section on ethical and legal background).	Senior children's community nurse (CCN) / Palliative care specialist nurse or senior clinician.
5	ACP is completed, dated and signed by parents/ legal guardian, clinician and/or specialist nurse.	Senior specialist nurse and/or senior clinician.
6	Set review date for ACP. The maximum time before review should be no more than 12 months.	Senior clinician.
7	Ensure that all care settings that the child attends have copies of the plan, and receive updated copies as appropriate.	Local ACP co-ordinator.

It is the responsibility of the local ACP leads to ensure that the senior clinicians and specialist nurses have the appropriate knowledge and skills to complete an ACP.

### 3. What a Do Not Attempt Cardiopulmonary Resuscitation (DNACPR) decision means

- 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 rapidly reversible causes such as choking or anaphylaxis, or causes specific to the individual child specified in the ACP).
- 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.
- if an ambulance is called then Ambulance Control must be told of the existence of an ACP.
- a DNACPR decision does NOT mean a withdrawal of care. Every attempt will continue to be made to make the child as comfortable as possible, and to fulfil the child's and the family's wishes.
- *all children are for attempted resuscitation unless there is a valid DNACPR decision in place. However, if a clinical decision is made that CPR is futile all attempts at resuscitation may be ceased. If there is any doubt about the validity of a DNACPR decision then resuscitation should be initiated.*

**"There are circumstances in which treatments that merely sustain 'life' neither restore health nor confer other benefit and hence are no longer in the child's best interests."** RCPCH(1997, 2004) Guidance 4.

- it is important to make it clear to families that if the most senior clinician present believes that resuscitation is unlikely to restart the heart or breathing then CPR would be futile and should not be continued.

#### 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, signed and dated in the DNACPR section of the ACP
- falls within the time period specified.

### 4. How to complete the Advance Care Plan forms

The ACP and any copies of it should be printed on **Lilac Paper** so that it stands out within the medical notes and is easily recognisable. The correct paper has the following specifications: manufacturer; NHS Supply Chain; Paper Copier A4 Fashion 80gsm, Colour; Lilac Papago FL2180 order no. WHO 391. The ACP given to families should be kept in a folder; cardboard folders designed for this purpose can be purchased from **NHS Creative** or alternatively families may want to purchase their own so that their child can personalise it.

Writing must be legible and completed using black ink or preferably typed. The name of the child should appear on every page. Once the document is completed it must be signed, both on the DNACPR page (page 2) and at the end of the document on page 7. Doctors are required to include their GMC number. The original care plan must stay with the child. Photocopies of the original should then be made for distribution. A copy of the child's drug prescription may be kept with the care plan.

#### Page 1: Basic demographic information.

- **Home address:** This is essential information used by ambulance control to identify whether an Advance Care Plan is in place. **The post code must be included in the address** as this is the key piece of information required by ambulance control.
- **Key people:** This information is provided by the family. The named key people (such as grandparents, other relatives or close friends) may be contacted in case of emergency.
- **Date of review:** This must be set and documented at the time of advance care planning by the clinician. If the date of review has expired, the plan will not stand as a legal document and the default position is that the child will be for attempted resuscitation. The maximum time for review is no more than 12 months. In setting this time frame the health care team will have to consider:
  - the nature of the child's condition or disability, and the likelihood of changes in prognosis or treatment options
  - the child's developing maturity (competence) and need for involvement in the discussion
  - whether there are any planned procedures or interventions that have the potential to precipitate a collapse, such as major surgery. In such circumstances the potential complications should be discussed, and an appropriate level of intervention (or non-intervention) agreed and documented. This may involve a temporary suspension of a DNACPR. The surgeon and anaesthetist must be consulted and kept informed of any decisions
  - families should be invited to take part in the review process but may choose not to if nothing has changed

Once the initial decision has been set, a senior doctor/nurse specialist in the child's team can undertake the review process. The child's senior clinician and the local ACP co-ordinator must be informed of any proposed changes to the initial plan.

#### Page 2: Management of cardiorespiratory arrest – the DNACPR form

Note: discussing a DNACPR decision is only justified if the child is at increased risk of cardiopulmonary arrest. It may not be necessary or appropriate to discuss this topic. If a decision is made not to discuss resuscitation status, please tick the appropriate box on page 2. Whatever decision is made the reasons should be documented in the relevant box at the bottom of page 2.

- after discussion it may be agreed that it is appropriate to attempt resuscitation, as per current Resuscitation Council UK (RCUK) guidelines. This must be documented
- attempted resuscitation may be agreed, with some patient-specific interventions. This may be appropriate for some children, for example those who already have non-invasive ventilation. Space is available on the form for documenting a specific resuscitation plan. All actions not requested/required should be documented or deleted clearly. If a mistake is made, this page should be filled in again so that it is clear to all parties the actions to be taken in the event of a cardiopulmonary arrest
- in making a DNACPR decision it is still assumed that all rapidly reversible causes of cardiorespiratory arrest (such as choking) are to be treated and this should be made clear to the parties involved in the decision making process
- reasons for DNACPR decision must be documented, according to The Royal College of Paediatrics and Child Health (RCPCH) guidance on 'Withholding or withdrawing of life sustaining treatment in children' (2004). Clinical staff who are involved in completing an ACP are advised to read the RCPCH document in full. [www.rcpch.ac.uk/Publications/Publications-list-by-title#W](http://www.rcpch.ac.uk/Publications/Publications-list-by-title#W)



- the document describes five circumstances (see below) where it may be ethical and legal to consider withholding or withdrawing of life sustaining medical treatment. The no chance, no purpose and unbearable situation are the most relevant areas when considering DNACPR so are quoted in full.

- the **no chance** situation: The child has such severe disease that life-sustaining treatment simply delays death without significant alleviation of suffering. Treatment to sustain life is inappropriate
- the **no purpose** situation: Although the patient may be able to survive with treatment, the degree of physical or mental impairment will be so great that it is unreasonable to expect them to bear it
- the **unbearable** situation: The child and/or family feel that in the face of progressive and irreversible illness further treatment is more than can be borne. They wish to have a particular treatment withdrawn or to refuse further treatment irrespective of the medical opinion that it maybe of some benefit
- permanent vegetative state
- brain stem death.

#### Good practice points

- the opinion of the child and parents in the unbearable situation is often shared by the clinicians. However there may be circumstances when a mentally competent child makes an informed decision that they do not wish to be resuscitated and they express this wish on an ongoing basis but this view is not shared by the parents and clinicians. The parents may also have divergent views. Legal advice should be sought in these circumstances
- the parents and child are not asked to sign the DNACPR section. It would place an unnecessary stress on families to feel that they have to bear any responsibility for a DNACPR decision
- if the date of review on the Advance Care Plan has passed without further discussion, the default position is that the child will be for full resuscitation, unless the parent or legal guardian is present to state their wishes. It is important to stress the need to all those involved in the decision, that the ACP should be reviewed regularly. The RCPCH suggest a maximum of six months between review dates. However, we have suggested a maximum of 12 months as this may be appropriate for some children with more stable conditions. Earlier review may be appropriate if the child's condition changes or at the request of the family or young person. Ask at review whether a change of school is occurring in the next year to ensure handover is given to the new head teacher.

#### Pages 3 and 4: Planning for inter-current illness / acute deterioration

- it is assumed that all reversible causes of acute deterioration will be treated. This should be made clear to all parties involved in the decision making process
- in the event of an acute deterioration of the child, select desired options and delete unwanted treatments
- seizures- the standard advanced paediatric life support (APLS) guidelines will be followed unless there are specific instructions from the patient's physician about the management of seizures. Please include names of drugs and dosages
- infection - antibiotic regimens should only be documented if there is a specific antibiotic regimen appropriate for the patient (e.g. patients with cystic fibrosis or malignancy). Otherwise the decision will be made by the attending physician

- feed and fluids – these are added as prompts for consideration, not necessarily decided in advance. In some circumstances, feed may be withdrawn but fluids continued. In others, particularly at end of life, both may be withdrawn. These are emotive issues and need to be considered, especially for children in the end of life phase, and for transfer between care settings. Assumptions may otherwise be made inappropriately by both parents and staff. In cases of disagreement or uncertainty, a second medical opinion, and/or ethical or legal advice may be required. (Withholding and withdrawing life-sustaining medical treatment 3rd Edition BMA 2007).

#### Page 5: Child / Young person / Family wishes during life and around the time of death

- these pages are to document any information that the parties involved in the decision making process wish to share with the professionals involved in their care
- no information is deemed too small or trivial to include
- whether or not organ donation is discussed is up to the individual clinician's discretion. There are 2 types of organ donation; beating heart and non- beating heart. Beating heart donation is only considered in a child who has confirmed brain stem death. Non-beating heart donation is usually only considered for children who have a death that is expected within a specific time period, e.g. withdrawal of care, and can be any organ. For most organs the child must be taken to theatre within 10 minutes of death for organ harvesting. Corneas and heart valves can be harvested up to 48 hours after death. Tissue donation may be possible even when organ donation is not feasible. For more information please contact your local transplant coordinator. You may also wish to provide local written information for the families about tissue and organ donation
- if the ACP includes a DNACPR order then the Child Death Overview Panel (CDOP) and the local rapid response team should be sent a copy of the plan. This is often done via the designated paediatrician for child deaths (DP). Please check local policy
- if a child is receiving palliative care and has a DNACPR order in place dies at home then the GP should be called. As with any other death, the GP will need to contact the coroner and the rapid response team if:
  - the cause of death appears to be related to a medical procedure, medical treatment or equipment failure
  - the cause of death appears to be related to drug use, overdose, alcohol or neglect
  - there are any suspicious circumstances or a history of violence
  - the cause of death appears to be suicide
  - the death is linked to an unnatural event or accident
  - the death is within 24 hours of surgery or anaesthesia or within 1 year of major surgery (Coroners Act 1988).
- when an expected death occurs and none of the above conditions apply then the GP can write the death certificate and the child may stay at home or be transported to the family's place of choice. The clinician then contacts the CDOP and the designated paediatrician. All child deaths are reviewed by the CDOP as a statutory obligation under "Working together to Safeguard Children" 2006. The child death review notification form should be completed within one working day and sent to the CDOP.

Good communication between all agencies minimises the distress for grieving families.

- if the body is being transported by car or ambulance then there should be an accompanying letter, on headed paper and signed by a doctor, stating that the child is dead.

**Good practice points**

- if an expected death is anticipated out of hours, it is good practice to contact the emergency response team during office hours to inform them that the death is expected. The ambulance crew must transport all children to the Emergency Department if the death is considered unexpected, suspicious or where there is lack of clarity
- contacting the coroner during working hours before an anticipated death is also useful as discussion may be had as to what to write on the death certificate and under which circumstances a death may be considered expected. The Emergency Department has a list of the coroner's officer on-call details and contact numbers
- some deaths are sudden but not unexpected (the mode of death is predictable but the timing cannot be anticipated). The requirement is for the rapid response team and coroner to be contacted but careful advance planning including providing a 24 hour contact number for the hospice doctor or CCN can aid rapid stand down of the response team minimising distress for the families
- in Oxfordshire there is a proposal to have a CCN on the rapid response team
- there is space at the bottom of pages 6 and 7 to add further details of specific wishes if the need arises.

**Page 6: Decision making**

- it is important to tick all the boxes that apply to the decision-making process
- the questions on page 6 are intended as prompts for discussion and can be used or omitted as appropriate for each individual. Please use the space below the questions for recording of the discussion
- informing the ambulance service: If the DNACPR form has been completed on page 2 of the ACP this will be recorded electronically at ambulance control and with the Out of Hours (OOH) service. It is important to stress that the person calling an ambulance must give the child's home address (including the post code) as well as their current location. This will then flag up with the ambulance service that the child has a current DNACPR form and/or an ACP. The family should be advised to have the child's ACP ready for the ambulance personnel to refer to when they arrive.

**Pages 7 and 8: Agreement and support for the plan**

- it is important that all those involved in making the decisions in the ACP are signatories
- the health care team should ideally be in agreement about the proposed plan. Unanimity for the final decision is not required, but it is clearly beneficial for all if consensus is obtained. The consultant/senior clinician in charge of the child's care has final responsibility for the decision. An ACP should only be made with the agreement of the parents/ carers, and the child where appropriate. If the family do not agree with the plan proposed by the professional carers, then a second opinion should be offered. If consent is still not forthcoming and the clinician in charge wishes to proceed with the ACP then legal advice should be sought. The nature of all discussions, concerns and referrals should be documented in the patient notes

- there will be a locally appointed co-ordinator in your area designated to distribute the ACP document to appropriate professionals. Please discuss with the child (where appropriate) and his or her family to whom they would like the document distributed. The ACP co-ordinator's details should be listed on page 8 of the ACP
- copies of the ACP should be made onto **lilac paper**

- Child's school. the head teacher must be informed at the earliest stage possible that the ACP process is beginning. Later, the implications need to be discussed with the head teacher and relevant staff before the ACP is signed off. Consideration should be given to the process of timely communication with the new head teacher if a child changes school

**Good practice points**

- It is good practice for the GP and/or hospice doctor to sign the ACP as they will often be asked to write the death certificate.
- Schools should be encouraged to work with paediatric community paediatricians to develop policies regarding the use of ACPs in schools.

**5. Key points**

- 5.1 The ACP will only apply to situations described within the care plan and is valid when it is current (before the review date), dated and signed by the child's parent or legal guardian (see section on ethical and legal background on pages 12-14 of this guide). If the child has capacity for the decision, their signature may also appear on the form, although this is optional.
- 5.2 The Child and Young Person's ACP should not usually be used for the first time in an adult. There may be some young adults in which this form was initiated before their 18th birthday. If the adult is deemed competent they must sign the form for it to remain valid and a parental signature is no longer required. Advice should be sought from the local adult lead for DNACPR. It may be useful to consider legal advice.
- 5.3 A valid ACP should be followed even when the parent or legal guardian is NOT present at the time of the child's acute deterioration or collapse. Phone contact should be made immediately with the parent or legal guardian to inform them of their child's deterioration and that the ACP will be followed.
- 5.4 If a parent or legal guardian is present at the time of their child's collapse, they may wish to deviate from the previously agreed ACP and under these circumstances their wishes should be respected, provided they are thought to be in the best interests of the child. This should be made clear to families at the time of writing the ACP.
- 5.5 The ACP must have a named health care professional who is responsible for keeping the plan up-to-date. The local co-ordinator will be listed on page 8 of the ACP. They will hold a list of relevant organisations and named responsible persons in each area where a copy is held e.g. school, emergency department, paediatric ward, GP Surgery, hospice and ambulance department. There should be a designated alternative contact in each area to avoid problems of whom to contact when a member of staff is on leave
- 5.6 School liaison see above.

## 6. Review Process

The ACP should be reviewed regularly. Review meetings need to be organised in good time to ensure there is always a current valid plan. The local ACP co-ordinator is responsible for distributing the latest version of the ACP. It is vital that every contact documented on page 8 of the ACP receives the updated version. If you do not have a current valid ACP for a child you should contact the local ACP co-ordinator.

## 7. Cancellation of a DNACPR Decision

In rare circumstances a decision may be made to cancel or revoke the ACP or DNACPR decision in an emergency situation. The whole ACP or DNACPR should be crossed through with 2 diagonal lines in black ball-point ink and the word **"CANCELLED"** written clearly between them, dated and signed by the senior clinician, and the reasons clearly documented. It is the responsibility of the ACP co-ordinator to inform all parties and to arrange an urgent review so that a new ACP can be completed.

## 8. Exclusions from and suspension of DNACPR decisions

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

Appropriate emergency interventions, including CPR should be attempted. 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 ACP should be reviewed and whatever decision is made should be documented and communicated accordingly. The surgeon performing the procedure and the anaesthetist should be included in the decision making. This documentation should clearly specify the beginning and end date of the suspension.

## 9. Ethical and legal background

This section gives some of the ethical and legal background to help staff determine who has the legal and ethical rights to make decisions about health care and treatment in children and young adults.

### 18 year olds and older (terminology for this age group is adult)

- 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/she can also make a legally binding 'Advance Decision' about these issues. The ACP should not be used for this purpose
- in the majority of circumstances a Child and Young Person's ACP should not 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 his or her family to continue with the ACP beyond the 18th birthday. There may also be occasions where it is appropriate to use the ACP for adults still under paediatric services or within the hospice environment
- 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
- the MCA provides a test for 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.
- this test is simply a summary of the tests of capacity that have been used for the last 20 years, and does not represent new information. The MCA does not change the decision maker
  - if an adult is found to lack capacity then the decision is made on best interests. The only person who determines 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.
  - the adult DNACPR document and the MCA provide clarification on decision making in adults.

### 16 and 17 year olds (terminology for this age group is young person)

- 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 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
- 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
- the key consideration is to make decisions consistent with the best interests of the young person
- 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 (CA) 1989
- 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 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.

### For persons under 16 years of age (terminology for this age group is child)

- 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 (CA 1989). 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. Since the CA came into force there have been some amendments to the automatic



bestowing of parental responsibility, and this differs in different parts of the United Kingdom. The current position in England is that:

- in relation to children born before 1 December 2003, if the parents have never been married, only the mother automatically has parental responsibility. The father may acquire it in various ways, including by entering into a parental responsibility agreement with the mother, or through a parental responsibility order made by a court
  - for children born after 1st December 2003, both parents have parental responsibility if they are registered on the child's birth certificate. This applies irrespective of whether the parents are married or not
  - if special guardianship is held then birth parents retain parental responsibility and must be contacted in 'exceptional circumstances'
  - if both parents have parental responsibility, neither lose it if they divorce, and responsibility endures if the child is in care or custody. It can, however, be restricted by court order and it is lost if the child is adopted
  - the child's step-parent can share parental responsibility with the child's divorced parents, if all are in agreement
  - where the child has been formally adopted, the adoptive parents are the child's legal parents and automatically acquire parental responsibility
  - where the child has been born as a result of assisted reproduction, there are rules under the Human Fertilisation and Embryology Act 1990 that determine the child's legal parentage
  - a person other than a child's biological parents can acquire parental responsibility by being appointed as the child's guardian or by having a residence order made in his or her favour, in which case parental responsibility lasts for the duration of the order
  - a local authority acquires parental responsibility (shared with the parents) while the child is the subject of a care or supervision order
  - when do parents hand over the responsibility for making decisions to their child? In practical terms, when is a child 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' competence
- the child who understands the nature of their illness and the likely outcomes of treatment options should be involved where possible in the decision-making process
  - 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 the Common law is that a 'child' under 18 can consent to treatment, but if he/she refuses treatment then those with parental responsibility for them can override that decision. It would be wise to seek legal advice case by case in such circumstances
  - 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.

**Further reading and resources**

1. **Discussing future care with patients** (v12) Regnard C, Randall F, Matthews D, Gibson L 2008 (from A Guide to Symptom Relief in Palliative Care, 6th ed. Oxford: Radcliffe Press). [www.endoflifecare.nhs.uk/eolclindex.htm](http://www.endoflifecare.nhs.uk/eolclindex.htm)
2. **Making a CPR decision** v46 Adapted from: 2007 BMA/RC/RCN Guidelines and Regnard C and Randall F. Clinical Medicine, 2005; 5: 354-60.
3. **Children's Hospice Southwest 'Colours of Life'** 2009. [www.act.org.uk](http://www.act.org.uk)

**South Central Child and Young Person's Working Group for the Advance Care Plan**

**Chairperson**

Dr Serena Cottrell, *Consultant Paediatrician/Paediatric Intensive Care, Southampton Universities Hospitals Trust (SUHT).*

**Core Working Group**

Angela Anderson, *Service Manager-Children; Children's Management, St James Hospital, Portsmouth.*

Dr Charlotte Bennett, *Consultant Neonatologist, Oxford Radcliffe Hospitals (ORH) NHS Trust.*

Lesley Coles, *Senior Paediatric Nurse, Portsmouth Hospitals (PH) NHS Trust.*

Rachel Houltram, *Naomi House, Hospice Director of Care, Hampshire.*

Dr Jeremy Hull, *Consultant Respiratory Paediatrician ORH NHS Trust.*

Helen Jordan, *CCN Specialist in Supportive Care Complex Children's Team Southampton City Community Healthcare.*

Ita Kelly, *Senior Paediatric Resuscitation Officer ORH NHS Trust.*

Dr Susie Lapwood, *Lead Doctor, Helen and Douglas House hospices for children and young adults, Oxford.*

Dr Abigail Macleod, *Consultant Paediatrician/Oncology, Royal Berkshire Hospital NHS Trust.*

Dr Liz McCaughey, *Consultant Paediatrician Community Child Health, Southampton Community Healthcare.*

Katrina McNamara-Goodger, *Head of Policy & Practice, ACT, Association for Children with Life-threatening and Terminal Conditions and their Families.*

Dr Marie-Louise Millard, *Consultant Paediatrician/Palliative Care PH NHS Trust.*

**Legal and Ethical Advice**

Mr Robert Wheeler, *Consultant Neonatal & Paediatric Surgeon, Specialist Advisor in Clinical Law SUHT.*

**Additional Contributors**

Dr Rebecca Ferris, *Consultant Community Paediatrician, Winchester.*

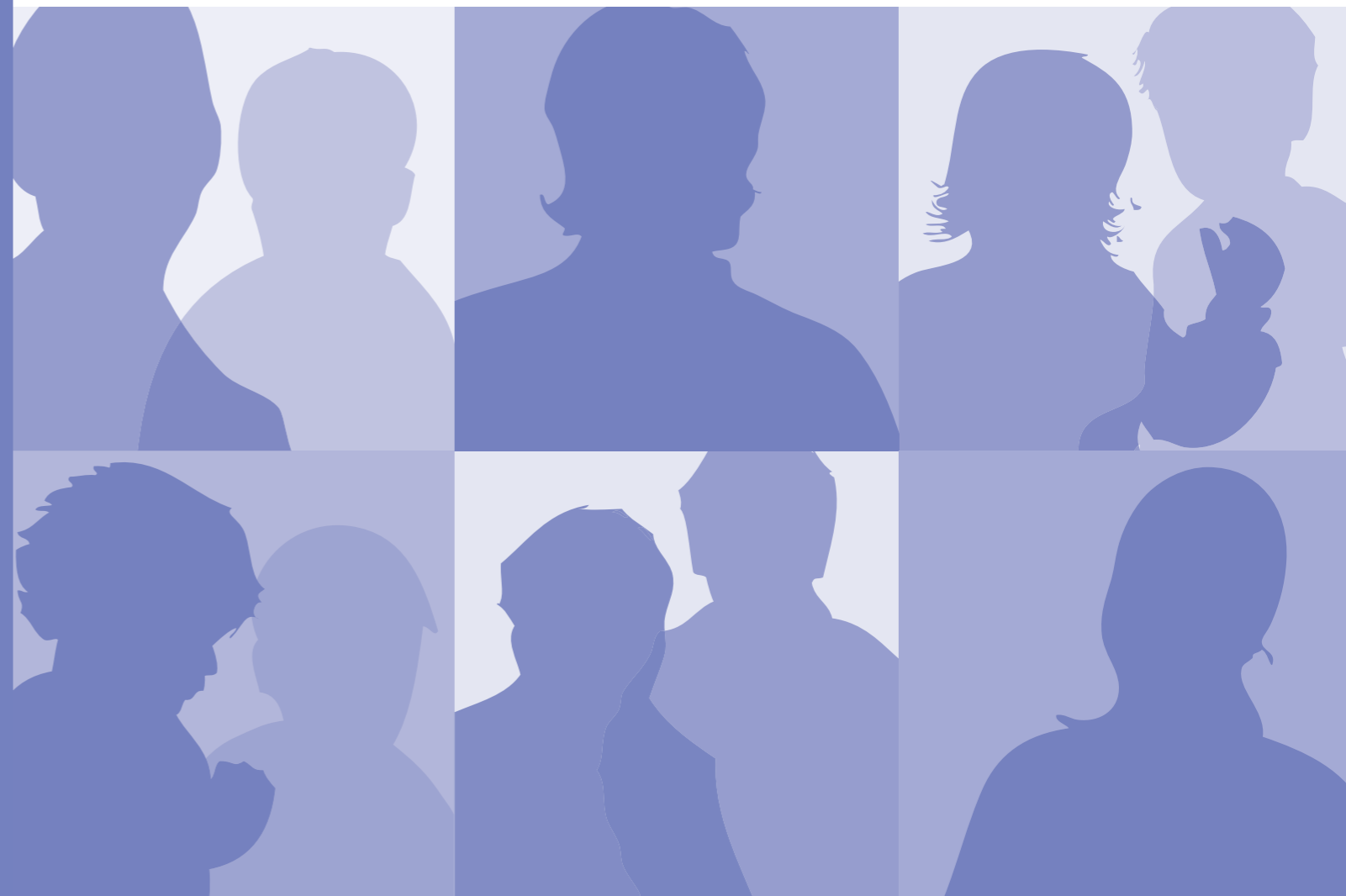
Rachel Hayes, *Paediatric Commissioner, Isle of Wight.*

Dr Gillian Watterson, *Consultant Neurodevelopmental Paediatrician, Dorset.*

<p><b>Local Information</b></p> <p><b>ACP Coordinator</b></p> <p><b>ACP Lead</b></p>
--



# Child and Young Person's Advance Care Plan Policy



**Contents**

Page	Content
3	Introduction
3	Definitions
4	Policy Statement
4	Purpose
4	Scope
4	Legislation and Guidance
6	Ethical and legal background
8	Roles and Responsibilities
10	Process
10	DNACPR
11	Review
11	Situations where there is lack of agreement
11	Cancellation of a DNACPR Decision
11	Exclusions from and suspension of DNACPR Decision
12	Audit
	<b>Appendices</b>
14	<i>Appendix 1</i> Child and Young Person’s Advance Care Plan
22	<i>Appendix 2</i> Parent and Young Person Information Leaflets
26	<i>Appendix 3</i> Audit Form
27	<i>Appendix 4</i> Equality Impact Assessment

**1 Introduction**

This document was written by the Child and Young Person’s South Central Advance Care Plan Working Group for a launch date of 18th March 2010. This group is a subgroup of the NHS SC eolc (National Health Service South Central end of life care) programme board. Details of this group can be found on the South Central Strategic Health Authority (SCSHA) website. This policy is valid until its review. The policy will be reviewed initially at 1 year and then at three yearly intervals thereafter.

This policy is supported by a package which consists of:

- An Advance Care Plan proforma (Appendix 1)
- A Guide to using the Child and Young Person’s Advance Care Plan SCSHA [www.southcentral.nhs.uk](http://www.southcentral.nhs.uk) (eolc) webpage
- An information leaflet for parents and carers about Advance Care Plans (Appendix 2)
- An information leaflet for young people about Advance Care Plans (Appendix 2).

A Child and Young Person’s Advance Care Plan (ACP) is designed to communicate the health-care wishes of children or young people who have chronic and life-limiting conditions (a different ACP is used in adults). 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. This ACP can be used as a resuscitation plan or as an end-of-life care plan. It remains valid when parent(s) or next of kin cannot be contacted.

**2 Definitions**

- 2.1 A Child and Young Person’s Advance Care Plan (ACP)** is a document that records the advance wishes of a child or young person and/or those with parental responsibility for them. A different ACP can be used in adults. An ACP will include whether the child’s resuscitation status has been discussed, and the outcome of that discussion.
- 2.2 Cardiopulmonary Arrest** is the cessation of breathing and loss of cardiac output.
- 2.3 Cardiopulmonary Resuscitation (CPR):** Interventions delivered with the intention of restarting the heart and breathing. These will include chest compressions and ventilations and may include attempted defibrillation and the administration of drugs.
- 2.4 Do Not Attempt Cardio Pulmonary Resuscitation (DNACPR)** refers to not making efforts to restart breathing and/or the heart following a cardiopulmonary arrest.
- 2.5 Valid DNACPR:** A DNACPR is only valid if it 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 SCSHA Child and Young Person’s ACP Working Party.
- 2.7 ACP Co-ordinator:** is responsible for ensuring that all ACPs in his or her area are appropriately completed, regularly reviewed and that all relevant parties have the most recent copy of the ACP. This role can be undertaken by a senior clinician, an advanced nurse practitioner or consultant nurse.
- 2.8 Child Death Overview Panel (CDOP):** This group monitors and reviews the deaths of all children, and a rapid response team is activated to initiate a review within a designated time frame each time a death occurs.
- 2.9 Adult:** A person aged 18 years or over  
**Young Person:** A person aged 16 or 17.  
Anyone under this age is regarded as a child.

**For the purposes of this document when the word child is used it can be read as child/young person.**

### 3 Policy Statement

The SCSHA Child and Young Person's Advance Care Plan policy will ensure that:

- 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 will be used. (See appendix 1).
- 3.4 The existence of an ACP for a child will be communicated to all affected members of the child's multidisciplinary team and to all relevant settings.
- 3.5 The Child and Young Person's Advance Care Planning process is measured, monitored and evaluated to ensure a robust governance framework.
- 3.6 Training will be available to enable staff to meet the requirements of this policy.

### 4 Purpose

- 4.1 This policy will provide guidance for staff responsible for providing or organising health care for children within the South Central region.

### 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 SCSHA.
- 5.2 This policy is appropriate for all children up to 18 years of age. Once initiated the Child and Young Person's ACP may be extended beyond the 18th birthday, with discretion, for young adults within the special education or hospice environment.

### 6 Legislation and Guidance

**Legislation** [www.opsi.gov.uk/acts](http://www.opsi.gov.uk/acts)

- 6.1.1 Under the 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: Clinician's are expected to understand who has parental responsibility to consent to treatment in a child.
- 6.1.3 Mental Capacity Act- 2005.  
Particularly pertaining to 16 and 17 year olds (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.

- 6.1.4 Working Together to Safeguard Children 2006 as this pertains to responsibilities to report child deaths to the Child Death Overview Panel (CDOP) and the role of the local Rapid Response Team.
- 6.1.5 The following sections of the Human Rights Act (1998) are relevant to this policy:
  - the individual's right to life (article 2)
  - to be free from inhuman 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: Clinicians are expected to know the circumstances when a death must be discussed with the District Coroner.
- 6.1.7 Equality Impact Assessment (See Appendix 4)

### Guidance

- 6.2.1 European Resuscitation Guidelines.  
[www.resus.org.uk/siteindx.htm](http://www.resus.org.uk/siteindx.htm)
- 6.2.2. Advanced Paediatric Life Support Group Guidelines.  
[www.alsg.org/en/?q=en/apls](http://www.alsg.org/en/?q=en/apls)
- 6.2.3 Royal College of Paediatrics and Child Health (1997, 2004) Withholding or Withdrawing Life Sustaining Treatment in Children: A Framework for Practice.  
[www.rcpch.ac.uk/Publications/Publications-list-by-title#W](http://www.rcpch.ac.uk/Publications/Publications-list-by-title#W)
- 6.2.4 Resuscitation Council (UK) Recommended standards for recording "Do not attempt resuscitation" (DNAR) decisions (2009).  
[www.resus.org.uk/siteindx.htm](http://www.resus.org.uk/siteindx.htm)
- 6.2.5 Decisions relating to Cardiopulmonary Resuscitation, A Joint Statement from the British Medical Association(BMA), the Resuscitation Council (UK), and the Royal College of Nursing. (October 2007, updated November 2007).  
[www.bma.org.uk/ethics/cardiopulmonary\\_resuscitation/CPRDecisions07.jsp](http://www.bma.org.uk/ethics/cardiopulmonary_resuscitation/CPRDecisions07.jsp)
- 6.2.6 BMA (2006) Parental Responsibility: Guidance from the BMA  
[www.bma.org.uk/ethics/consent\\_and\\_capacity/Parental.jsp](http://www.bma.org.uk/ethics/consent_and_capacity/Parental.jsp)
- 6.2.7 General Medical Council (2007) 0-18 years: guidance for all doctors.  
[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  
[www.aagbi.org/publications/guidelines/docs/dnar-09.pdf](http://www.aagbi.org/publications/guidelines/docs/dnar-09.pdf)
- 6.2.9 Withholding and withdrawing life-prolonging medical treatment 3rd Ed BMA 2007  
[www.bma.org.uk/ethics/end\\_life\\_issues/Withholdingwithdrawing.jsp](http://www.bma.org.uk/ethics/end_life_issues/Withholdingwithdrawing.jsp)

## 7 Ethical and legal background

(Mr Robert Wheeler Consultant Neonatal & Paediatric Surgeon, Specialist Adviser in Clinical Law (2009)).

### 7.1 18 year olds and older (*terminology for this age group is adult*)

- 7.1.2 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.
- 7.1.3 In the majority of circumstances the Child and Young Person's Advance Care Plan for the child should not 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.
- 7.1.4 The MCA provides a test for 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.
- 7.1.5 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.
- 7.1.6 The SCSHA adult DNACPR document and the MCA provide clarification on decision making in adults.

### 7.2 16 and 17 year olds (*terminology for this age group is young person*)

- 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 For persons under 16 years of age

- 7.3.1 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 (CA). 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' competence. 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.
- 7.3.2 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 the 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.
- 7.3.3 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.



**8 Roles and Responsibilities**

- 8.1 Chief Executive of South Central Strategic Health Authority is responsible for:
  - ensuring that this policy adheres to statutory requirements and professional guidance
  - supporting unified policy development and the implementation within other organisations
  - ensuring that the policy is monitored and reviewed
  - review of policy.
- 8.2 National Health Service (NHS) Commissioners must ensure that commissioned services implement and adhere to the policy and procedure and provide funding to ensure staff training.
- 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 the policy is implemented and 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 and the audit details fed back to nominated Director at the SCSHA.
- 8.5 Local Lead Clinician for ACPs liaising with the SCSHA Child and Young Person's Advance Care Plan Working Group and are responsible for:
  - disseminating information about the ACP package to all SCSHA staff in their area who are affected by it
  - feeding back queries about the contents and application of the package to the 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 an ACP 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 ACP Co-ordinator is responsible for ensuring that all ACPs in their area are appropriately completed, regularly reviewed and that all relevant parties have the most recent copy of the ACP.
- 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 DNACPR / ACP 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 dentistry, should be aware of this policy and consider its implications when commissioning or providing services.
- 8.10 The Ambulance service will:
  - adhere to the policy and procedure
  - notify line manager of any training needs
  - ensure they are aware of the existence of a DNACPR/ ACP 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/ ACPs
    - 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 ACP is available and followed
  - in an acute event, an ambulance is called and the presence of the ACP highlighted to ambulance staff (follow protocol including giving home postcode)
  - parents immediately contacted by phone.

## 9 Process

The guide to using the Child and Young Person's Advance Care Plan ([www.southcentral.nhs.uk](http://www.southcentral.nhs.uk) under eolc webpage) 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 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 rapidly reversible causes such as choking or anaphylaxis, or causes specific to the individual child specified in the Advance Care Plan).
- 10.2 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.
- 10.3 If an ambulance is called then Ambulance Control must be told about the existence of an ACP.
- 10.4 If the death is anticipated, the GP should be called.
- 10.5 A DNACPR decision does not mean withdrawal of care. Every attempt will continue to be made to make the child as comfortable as possible, and to fulfil his or her and the families' wishes.
- 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 The ACP will only apply to situations described within the care plan and only when it is current, dated and signed by the child's parent or legal guardian (see section 7 on ethical and legal background). If the young person has capacity for the decision, his or her signature may also appear on the form, although this is optional.
- 10.9 The Child and Young Person's ACP 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 no longer required.
- 10.10 In all circumstances not covered by the ACP 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.

- 10.11 A valid ACP should be followed even when the parent or legal guardian is NOT present at the time of the child's acute deterioration or collapse.
- 10.12 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.

**Note: For further guidance on how to complete the Child and Young Person's Advance Care Plan, please see Staff Guidance leaflet. [www.southcentral.nhs.uk](http://www.southcentral.nhs.uk) (eolc webpage)**

### 11 Review

The ACP should be reviewed regularly, and in good time to ensure there is always a current valid plan. The local ACP co-ordinator is responsible for distributing the latest version of the ACP.

### 12 Situations where there is lack of agreement

Where the clinical decision is seriously challenged and agreement cannot be reached, legal advice must be sought.

### 13 Cancellation of a DNACPR Decision

In rare circumstances a decision may be made to cancel or revoke the Advance Care Plan or DNACPR decision. In this situation the plan should be crossed through with 2 diagonal lines in black ball-point ink and the word '**CANCELLED**' written clearly between them, dated and signed by the senior clinician, and the reasons clearly documented. It is the responsibility of the ACP Co-ordinator to inform all parties and to organise and urgent review so that a new ACP can be completed.

### 14 Exclusions from and suspension of DNACPR Decision

- 14.1 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.
- 14.2 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 ACP 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.

**15 Audit**

- 15.1 The SCSHA will measure, monitor and evaluate compliance with this policy through audit and data collection.
- 15.2 All organisations will have clear governance arrangements in place which indicate individuals and committees who are responsible for the governance of this policy at a local level and that can respond to the SCSHA request for audit purposes.  
  
This includes:
  - data collection
  - ensuring that approved documentation is implemented
  - managing risk
  - sharing good practice
  - monitoring of incident reports and complaints regarding the DNR process
  - developing and ensuring that action plans are completed
  - (see Appendix 3 audit tool).
- 15.3 Frequency and information
  - compliance with the policy will be audited annually using the SCSHA Audit Tool (see Appendix 3)
  - local leads will decide number of Advance Care Plans to be examined.
- 15.4 Information will be used for future planning, identification of training needs and for the policy review.

<p><b>Local Information</b></p> <p><b>ACP Coordinator</b></p> <p><b>ACP Lead</b></p>
--

# Child and Young Person's Advance Care Plan

## Policy Appendices

**Appendix 1**

*This form will be printed in lilac.*

**Advance Care Plan for a Child or Young Person**

This document is a tool for discussing and communicating the wishes of a child / parent(s) or young person. It is particularly useful in an emergency, when the individual cannot give informed consent for themselves and / or next of kin / parent(s) cannot be contacted.

<b>Name:</b>	<b>Date of Birth:</b> ____ / ____ / ____
<b>Known as:</b>	<b>Hospital Number:</b>
<b>First Language:</b>	<b>NHS Number:</b>
<b>Home Address:</b>	
<b>Postcode:</b>	
<b>Telephone Number:</b>	

**NB: If the child or young person becomes unwell and needs an ambulance, inform ambulance control that the child has an Advance Care Plan. Ambulance Control will have an electronic copy of the ACP flagged under the child's home address and postcode. Don't forget to give ambulance control the child or young person's current location as well, if they are away from home.**

Name of person/people with parental responsibility (and address if different from above):

Emergency contact number for person with parental responsibility: \_\_\_\_\_

Other emergency contact numbers: \_\_\_\_\_

Other key people (e.g. family and friends): \_\_\_\_\_

Name: \_\_\_\_\_ Relationship: \_\_\_\_\_ Tel: \_\_\_\_\_

Name: \_\_\_\_\_ Relationship: \_\_\_\_\_ Tel: \_\_\_\_\_

Primary diagnosis and background summary:

Advance Care Plan for use in:			
Home	School	Hospital	Hospice
Other, please state:			

**Date Plan Initiated** \_\_\_\_ / \_\_\_\_ / \_\_\_\_      **Date Review is due** \_\_\_\_ / \_\_\_\_ / \_\_\_\_

Date reviewed/amended	Name & title of lead reviewer	Next review due

**Advance Care Plan: Management of cardio-respiratory arrest**

Name \_\_\_\_\_ Date of Birth: \_\_\_\_ / \_\_\_\_ / \_\_\_\_

Regardless of the patient's resuscitation status, the following immediately reversible causes should be treated: **choking, anaphylaxis, blocked tracheostomy tube, other** (please state):

**RESUSCITATION STATUS**

- Resuscitation status has not been discussed – **attempt full resuscitation**
- Resuscitation status has been discussed and the following has been agreed:

**Clearly delete actions not required**

For full resuscitation	Attempt resuscitation with modifications below:	Do not attempt cardiopulmonary resuscitation DNACPR
OR	OR	
Attempt resuscitation as per standard RC(UK) guidelines	<b>Patient-specific modifications to standard resuscitation guidelines</b>  AIRWAY:  BREATHING:  CIRCULATION:  DRUGS:  OTHER:  PICU/HDU:	Patient-specific supportive care is documented on pages 3 and 4   In the event of sudden death 24 hour emergency number for doctor who knows the child:

**Ambulance directive: (eg transfer to home/ward/Emergency Department /hospice)**

Reason(s) for decision

Senior Clinician Signature \_\_\_\_\_ Name \_\_\_\_\_ GMC No \_\_\_\_\_

Date Initiated \_\_\_\_ / \_\_\_\_ / \_\_\_\_

Review Date (see page 1)



**Advance Care Plan: Intercurrent illness/acute deterioration**

Name:	Date of Birth: ____/____/____
Main Diagnoses:	<b>Known Allergies:</b>
Signs/Symptoms to expect:	

In the event of a likely reversible cause for acute life-threatening deterioration such as choking, tracheostomy blockage or anaphylaxis please intervene and treat actively. Please also treat the following possible problems actively e.g. bleeding (please state):

If a cardiac or respiratory arrest is not specifically anticipated, decisions about resuscitation would normally be made on a 'best interests' basis at the time of such an event. Unless a separate resuscitation section has been completed, the presumption would normally be for attempted resuscitation initially unless this seemed futile, unlikely to be successful, not in best interests, or otherwise directed.

**In the event of acute deterioration:**

(Clearly delete all options NOT required. Add comments to clarify wishes):

- support transfer to preferred place of care if possible (specify): \_\_\_\_\_
  
- maintain comfort and symptom management, and support child / young person and family
- clear upper airway
- face mask oxygen if available
- bag and mask ventilation
- emergency transfer to hospital if doctor considers appropriate in the specific situation
- intravenous access or intraosseous access
- consider nasogastric feeding tube (insertion or removal)
- non-invasive ventilation
- intubation
- consider stopping feeds
- consider stopping fluids
- other; please state: \_\_\_\_\_

**Advance Care Plan: Intercurrent illness/acute deterioration** *continued*

Name: \_\_\_\_\_ Date of Birth: \_\_\_\_/\_\_\_\_/\_\_\_\_

**Specific treatment plans if indicated**

**Management of seizures**

Description of usual seizure pattern / types: \_\_\_\_\_

Rescue medication: (drug name, dose and route)

First line	after _____ mins
Second line	after further _____ mins
Third line	after further _____ mins

Call 999 for emergency transfer to hospital?  Yes  No

If yes, at what stage? \_\_\_\_\_

Other instructions for seizures: \_\_\_\_\_

**Management of infection** *(prompt, check for known allergies recorded p3)*

Preferred antibiotic or regime for recurrent infections – drug dose, route, duration:

Intravenous antibiotics will normally require transfer to hospital for investigation and initiation of treatment.

Other instructions/comments regarding infection-related symptoms e.g. nebulisers, steroids.

**Instructions for emergency care in other specific circumstances**

*(Document here regimes specific to this child/young person, for example for management of metabolic disturbance etc).*

**Additional Comments:**



### Advance Care Plan

#### Who has agreed and supports the plan?

Name: \_\_\_\_\_ Date of Birth: \_\_\_\_/\_\_\_\_/\_\_\_\_

#### Senior Clinician e.g. Paediatric Consultant – I support this care plan

Name: \_\_\_\_\_ Signature: \_\_\_\_\_ GMC No: \_\_\_\_\_ Date: \_\_\_\_/\_\_\_\_/\_\_\_\_

#### Child / Young person – I have discussed and support this care plan (optional)

Name: \_\_\_\_\_ Signature: \_\_\_\_\_ Date: \_\_\_\_/\_\_\_\_/\_\_\_\_

#### Parent/Guardian – We / I have discussed and support this care plan

Name: \_\_\_\_\_ Signature: \_\_\_\_\_ Date: \_\_\_\_/\_\_\_\_/\_\_\_\_

#### Other e.g. CCN – I have discussed and support this care plan

Name: \_\_\_\_\_ Signature: \_\_\_\_\_ Date: \_\_\_\_/\_\_\_\_/\_\_\_\_

#### Other e.g. GP – I have discussed and support this care plan

Name: \_\_\_\_\_ Signature: \_\_\_\_\_ GMC No: \_\_\_\_\_ Date: \_\_\_\_/\_\_\_\_/\_\_\_\_

#### Other e.g. Hospice doctor – I have discussed and support this care plan

Name: \_\_\_\_\_ Signature: \_\_\_\_\_ GMC No: \_\_\_\_\_ Date: \_\_\_\_/\_\_\_\_/\_\_\_\_

**Other people informed:** see circulation list.

#### Clinicians have a duty to act in a patient’s best interests at all times.

If a parent or legal guardian is present at the time of their child’s collapse, they may wish to deviate from the previously agreed Advance Care Plan and under these circumstances their wishes should be respected, provided they are thought to be in the best interests of the child/ young person. The child/ young person or parents/guardian can change their mind about any of the preferences on the care plan at any time.

Name: \_\_\_\_\_ Date of Birth: \_\_\_\_/\_\_\_\_/\_\_\_\_

	Name and contact details
ACP Co-ordinator – responsible for distributing this Advance Care Plan.	
A copy of this ACP is held by:	
<input type="checkbox"/> Parents/guardians	
<input type="checkbox"/> General practitioner	
<input type="checkbox"/> Paediatrician (Community)	
<input type="checkbox"/> Paediatrician	
<input type="checkbox"/> Hospital (e.g. open access ward)	
<input type="checkbox"/> Hospice (please provide the name of the hospice)	
<input type="checkbox"/> Community Nurses (CCN)	
<input type="checkbox"/> CCN Specialist Nurses/School Nurse	
<input type="checkbox"/> GP Out of Hours Service	
<input type="checkbox"/> Ambulance Control/Rapid Response Team	
<input type="checkbox"/> Emergency Dept	
<input type="checkbox"/> School-Head Teacher (with consent to share with school staff)	
<input type="checkbox"/> Other e.g. Social Care	
<input type="checkbox"/> Short break care provider	
<input type="checkbox"/> Other e.g. CDOP, Police, Coroner	
<input type="checkbox"/> Other	

## Appendix 2

### Patient Leaflets;

#### Parent information Leaflet

**What happens if...?:** Planning ahead for the needs of children and young people with life-limiting or life-threatening conditions.

**Intro:** Sometimes families worry about what might happen if their child suddenly or unexpectedly becomes unwell. Talking through what might happen can help reduce some of these worries and concerns.

**NHS**  
South Central

### What happens if...?

Planning ahead for the needs of children and young people with life-limiting or life-threatening conditions

#### Who is this leaflet for?

This leaflet is for families who have a child or young person with a life-limiting condition. It provides information about an Advance Care Plan – what it is, how it is created and what it means for the child. There is a separate leaflet for young people to read.

#### What is an Advance Care Plan?

An Advance Care Plan is a document that sets out an agreed plan of care to be followed if/when your child's condition deteriorates. It is very difficult to make rational and informed decisions during a crisis, so the benefit of an Advance Care Plan is that a plan of action can be made before the situation occurs.

#### How does it work?

Everyone who plays an important role in the life and health care of your child or a young person, and if appropriate your child/ young person themselves, can be involved in the advance planning. The plan covers a variety of different circumstances including slow deterioration and sudden emergencies, but is specific to the needs of your individual child and your family.

A key feature of an Advance Care Plan is that it is shared with all professionals involved in the routine care of your child as well as those who might be called in an emergency. This means that everyone has clear information about the wishes and needs of your child and your family, so they can provide that care.

#### What does the process involve?

The first step in the process is deciding whether the time is right to make an Advance Care Plan, and you are likely to have questions about this. Your child's health care team will try to answer your queries and concerns as realistically and sympathetically as possible. You may also want to talk through the issues with friends or family, or your religious advisor, or have any of these people with you when you next talk to your child's doctors.

You may have very clear thoughts about some aspects of care, whereas other aspects may be

less clear to you. A member of your child's team can show you an Advance Care Plan and discuss the various options that might be suitable for your child. We will work together with you at your pace to put together a plan for your child/ young person.

#### What happens when the plan is agreed?

Once an Advance Care plan is agreed it will be signed by you and a senior doctor or clinician who knows your child/ young person. Copies of the Advance Care Plan are given to you and to each of the health care professionals who are routinely involved in your child's care, as well as those who might be contacted in an emergency.

Advance Care Plans are reviewed regularly to ensure that the plan of care is still appropriate and that everyone remains in agreement. The team caring for your child will discuss with you how often these reviews will take place.

#### What if I want to change an aspect of the Advance Care Plan once it has been agreed?

If you want the Advance Care Plan to be reviewed you do not have to wait for the next review date. Just talk to one of your child's care team, and the care plan can be reconsidered.

#### Where can I get further help or information?

ACT – The Association of Children with Life-threatening and Terminal Conditions and their families [www.act.org.uk](http://www.act.org.uk)

Child Bereavement Charity  
[www.childbereavement.org.uk](http://www.childbereavement.org.uk)

[www.specialchild.co.uk](http://www.specialchild.co.uk) is a book that has been reproduced on line; it is written by a mother who could not find the information that she needed when she needed it.

Through the contact a family scheme you can talk with other parents who are in a similar position: [www.cafamily.org.uk](http://www.cafamily.org.uk), or telephone **0808 808 3555**.

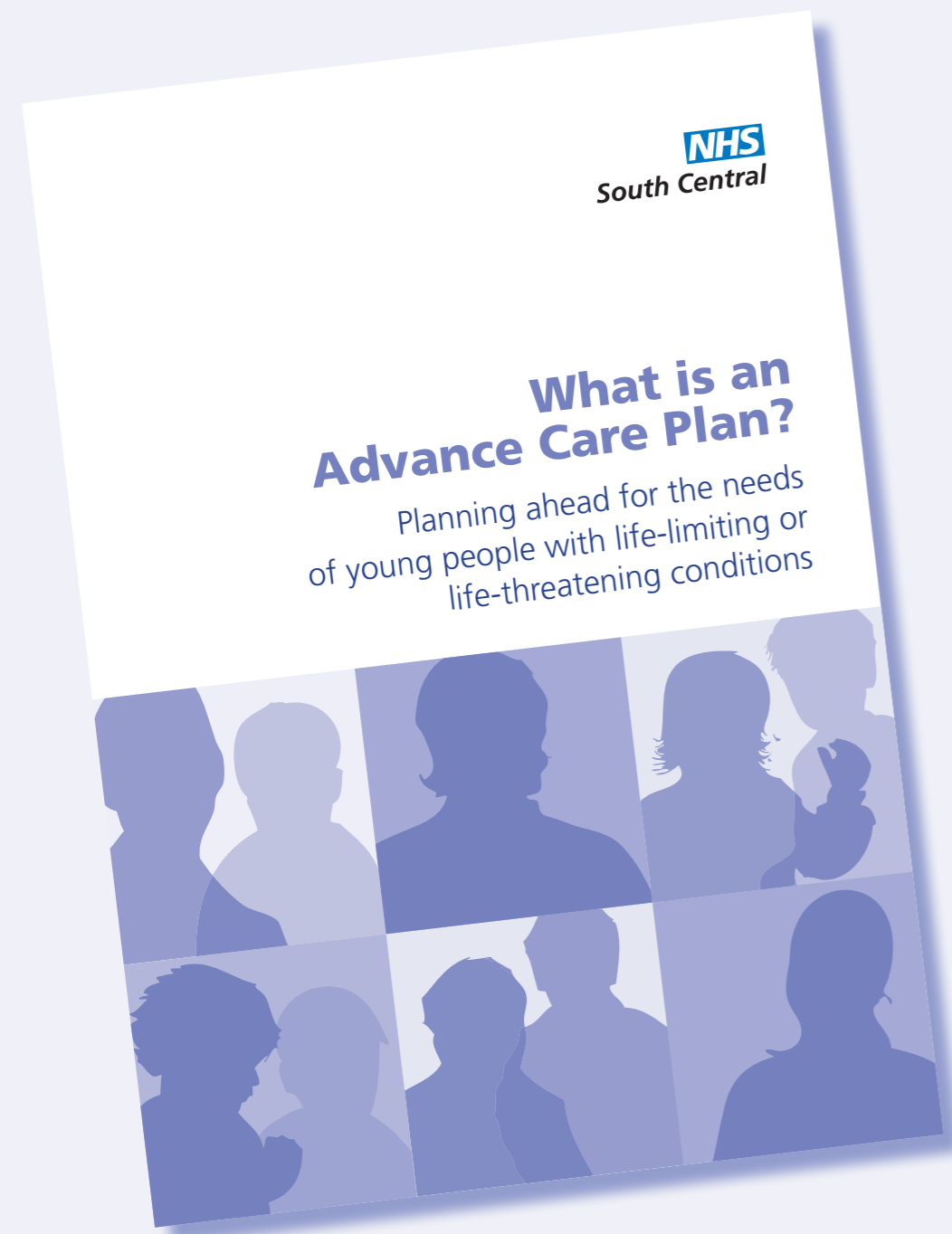
Each hospital has a Patient Advice and Liaison Service (PALS).

#### Local Contacts:

## Young Person Information Leaflet

**Advance Care Plans:** Planning ahead for the needs of young people with life-limiting or life-threatening conditions.

**Intro:** Sometimes people with life-limiting conditions worry about what might happen if they suddenly or unexpectedly become unwell and families will often share these worries. Talking through what might happen can help reduce some of these worries and concerns.



### Who is this leaflet for?

This leaflet is for young people who have a life-limiting condition. It provides information about an Advance Care Plan – what it is, how it is created and what it means for you.

### What is an Advance Care Plan?

An Advance Care Plan is a document that sets out an agreed plan of care to be followed if/when your condition deteriorates. It is very difficult to make decisions during a crisis, so the benefit of an Advance Care Plan is that a plan of action can be made before this happens.

### How does it work?

Everyone who plays an important role in your life and health care can be involved in the advance planning. The plan covers a variety of different circumstances, including a gradual decline in your condition and sudden emergencies, but is specific to your needs and, where appropriate, the needs of your family. A key feature of an Advance Care Plan is that it is shared with all professionals involved in your care as well as those who might be called in an emergency. This means that everyone has clear information about your wishes and needs so they can provide that care.

### What does the process involve?

The first step in the process is deciding whether the time is right to make an Advance Care Plan, and you are likely to have questions about this. Your health care team will try to answer your questions and concerns as realistically and sympathetically as possible. You may also want to talk through the issues with friends or family, or your religious advisor, or have any of these people with you when you next talk to your doctors.

You may have very clear ideas and feelings about some aspects of care, whereas other aspects may be less clear to you. A member of your team can show you an Advance Care Plan and discuss the various options that might be suitable for you. We will work together with you at your pace to put together a plan which suits you best.

### What happens when the plan is agreed?

Once an Advance Care plan is agreed it will be signed by you and a senior doctor (or clinician) who knows you and if appropriate your parent/s. Copies of the Advance Care Plan are given to you and to each of the health care professionals who are regularly involved in your care, as well as those who might be contacted in an emergency.

Advance Care Plans are reviewed regularly to ensure that the plan of care is still right for you and that everyone remains in agreement. The team caring for you will discuss with you how often these reviews will take place.

### What if I want to change an aspect of the Advance Care Plan once it has been agreed?

If you want the Advance Care Plan to be changed or re-looked at you do not have to wait for the next review date. Just talk to one of your care team, and the care plan can be looked at with you and altered if needed.

### Where can I get further help or information?

ACT – The Association of Children with Life-threatening and Terminal Conditions and their families [www.act.org.uk](http://www.act.org.uk)

Child Bereavement Charity  
[www.childbereavement.org.uk](http://www.childbereavement.org.uk)

[www.specialchild.co.uk](http://www.specialchild.co.uk) is a book that has been reproduced on line; it is written by a mother who could not find the information that she needed when she needed it.

Through the contact a family scheme you can talk with other families or young people who are in a similar position: [www.cafamily.org.uk](http://www.cafamily.org.uk), or telephone 0808 808 3555.

Each hospital has a Patient Advice and Liaison Service (PALS).

### Local Contacts:



Appendix 3

Child and Young Person’s Advance Care Plan Audit

Service: \_\_\_\_\_ Date: \_\_\_\_/\_\_\_\_/\_\_\_\_

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

Appendix 4

Equality Impact Assessment (EIA) - Evidence Form

South Central Strategic Health Authority strives to design and implement services, policies and measures that meet the diverse needs of our service population and workforce, ensuring that none are placed at a disadvantage over others. This form is designed to help you to consider the needs and assess the positive, adverse or neutral impact of your policy, protocol, proposal or service on all groups within our local communities, and to record the evidence that you have done so. Any proposal or policy submitted to the Board must have undergone EIA.

This form will be used as evidence of the assessment you have undertaken. It will need to be made available to the Board and Equality and Diversity Steering Group.

**Policy/Proposal/Service Title:** \_\_\_\_\_

Child and Young Person’s Advance Care Plan Policy \_\_\_\_\_

**Name of EIA Lead:** \_\_\_\_\_

**Others involved in assessment:** \_\_\_\_\_

**Date EIA commenced:** \_\_\_\_/\_\_\_\_/\_\_\_\_

**EIA Completed and Approved:** \_\_\_\_\_

**Signature (Lead Director):** \_\_\_\_\_

**Name (print):** \_\_\_\_\_

**Job Title:** \_\_\_\_\_

**Date:** \_\_\_\_/\_\_\_\_/\_\_\_\_

**ONCE COMPLETED, PLEASE SUBMIT TO EQUALITY AND DIVERSITY LEAD FOR EVIDENCE AND PUBLICATION.**