

Reference Number: UHB 334	Date of Next Review:
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<p>PAEDIATRIC ADVANCE CARE PLAN (PAC-PLAN) POLICY FOR PATIENTS UNDER 18 YEARS OF AGE WITH LIFE THREATENING OR LIFE LIMITING ILLNESS</p>	
<p>Policy Statement</p> <p>To ensure the Health Board delivers its aims, objectives, responsibilities and legal requirements transparently and consistently, we will support children and families with life threatening or life limiting illness in advance care planning.</p> <p>Cardiff and Vale University Health Board is committed to implementing the guidance for Paediatric Advance Care Planning for children and young people with life threatening or life limiting illness as supported by the reference list.</p> <p>The policy has been written to support the use of the PAC plan document as a summary of recommendations to guide immediate decision making in case of future deterioration or emergency. This policy aims to provide a framework for doctors and others in the patient's care team to approach and document decisions regarding emergency care and treatment, cardiopulmonary resuscitation and admission to intensive care for mechanical ventilation. It provides health and care professionals responding to a future emergency with a summary of recommendations to help them to make immediate decisions about that person's care and treatment. PAC Plans can be complementary to a wider process of advance/anticipatory care planning.</p> <p>Please note that the PAC plan process and document are not solely aimed at decisions about limiting treatment; the process is intended to support people to articulate and share their views about treatments and approaches to care that they do want, as well as about those that they don't. The process and document can cover recommendations about both specific treatments (such as clinically-assisted nutrition) and approaches to care (such as whether or not a person would want to be taken to hospital in an emergency).</p>	
<p>Policy Commitment</p> <p>The Health board is committing to supporting high quality Paediatric advance care planning. This will be done through:</p> <ul style="list-style-type: none"> - Good communication with children and families, - Clear documentation of discussions and wishes - Dissemination of the above with family consent to key agencies. <p><i>We commit</i></p> <ul style="list-style-type: none"> • To implement a consistent approach to Advance Care Planning in children. • To ensure children receive appropriate and effective resuscitation when necessary and without delay 	

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- To ensure children are treated with dignity and their human rights are respected⁶
- To ensure appropriate, correct and respected application of United Nations Convention on Rights of the Child⁷
- **To promote current best practice in children’s palliative care and specifically in the area of advance care planning based on current national guidance from Together for short lives¹, Royal College of Paediatrics and Child Health ², National institute of clinical excellence ³ Royal College of Physicians ⁹, Department of Health¹⁰, General Medical Council¹¹, Welsh Assembly Government ¹², National Service Framework for Children¹³.**
- **To comply with Department of Health requirements**
 - To provide support for clinical staff
 - To provide written information for children and relatives
 - To satisfy legal and professional requirements
 - To minimise clinical risk, litigation and material loss
 - To comply with UHB requirements for formal organisation-wide policies.
 - To ensure the PAC-Plan procedures are monitored and audited
 - To facilitate improving end of life care as a key performance indicator of all NHS Health Boards and Trusts in Wales

Supporting Procedures and Written Control Documents

This Policy describe the following with regard to Paediatric Advance Care Plan (PAC-Plan) Policy for patients under 18 years of age with Life threatening or Life limiting illness

Other supporting documents are:

- This policy should be read in conjunction with the All Wales advance and future care planning / All Wales DNACPR Policy in adults⁵, and Guidance from RCPCH ^{2,8}, NICE³, the GMC, BMA⁴, RC (UK), RCN.

Scope

This policy applies to all of our staff in all locations including those with honorary contracts who are involved in planning of patient care, review and decision making in relation to children or young people with life threatening or life limiting illness requiring paediatric advance care planning with regards to active treatment and/or symptom control and cardiopulmonary resuscitation.

Equality and Health

An Equality and Health Impact Assessment (EHIA) has been

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Impact Assessment	completed and this found there to be a positive impact. Key actions have been identified and these can be found in incorporated within this policy/supporting procedure.
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Policy Approved by	Board/Committee/Sub Committee
Group with authority to approve procedures written to explain how this policy will be implemented	For example: Health System Management Board
Accountable Executive or Clinical Board Director Director [insert title of post holder]
<p>Disclaimer</p> <p>If the review date of this document has passed please ensure that the version you are using is the most up to date either by contacting the document author or the Governance Directorate.</p>	

Summary of reviews/amendments			
Version Number	Date Review Approved	Date Published	Summary of Amendments
1	Date approved by Board/Committee/Sub Committee dd/mm/yyyy	TBA <i>[To be inserted by the Gov. Dept]</i>	<i>State if either a new document, revised document (please list main amendments). List title and reference number of any documents that may be superseded</i>
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1. EXECUTIVE SUMMARY

1.1. Purpose of Policy

For every person there comes a time when death is inevitable. For a child with life threatening or life limiting illness that time is expected to arrive during childhood.

The purpose of the Paediatric Advance Care Plan (PAC-Plan) policy is to outline the legal and ethical standards for planning patient care and decision making at the end of a child's life, particularly in relation to interventions that might delay death at the cost of pain or discomfort to the child. **The policy has been written to support the use of the PAC plan document as a summary of recommendations to guide immediate decision making in an emergency.**

2.0 INTRODUCTION

"Palliative care for children and young people with life-limiting or life-threatening conditions is an active and total approach to care, from the point of diagnosis or recognition throughout the child's life and death. It embraces physical, emotional, social, and spiritual elements, and focuses on enhancement of quality of life for the child/young person and support for the family. It includes the management of distressing symptoms, provision of short breaks and care through death and bereavement."¹

The palliative phase for children is often longer than for adults with specialist support needed over years rather than months.

Paediatric palliative care services must meet the needs of children and young people with a wide range of differing conditions including neurodisability, neurodegenerative conditions and chronic conditions such as cystic fibrosis, cardiac disease and cancers.

Decisions regarding interventions at the end of life should form part of a holistic end of life planning for a child or young person with a life threatening or life limiting illness.

Use of a Paediatric Advance Care Plan (PAC-Plan) including options regarding resuscitation should alert readers to the beginning of a process of discussion and individualised care for that particular child and family. ²

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It is vital to encourage the involvement of the patient, their family, the health care team and people close to the patient in decision making, and to ensure the communication of decisions to all relevant health and multiagency professionals. (GP, Community Nursing service, Respite, Education, Social Services, Ambulance, Police, Coroner, Bereavement Services) ³

3.0 AIMS OF POLICY

- To implement a consistent approach to Advance Care Planning in children.
 - To provide a framework for doctors and others in the care team to approach early decision making and emergency care planning to ensure that the most appropriate resuscitation plan is provided for the patient. This is not only intended for use at end of life, but may be appropriate for people with stable but life limiting illness.
 - To facilitate documentation of discussion and agreed plans between the lead clinician and family/patient, which may include a limitation of resuscitation but may also document that full resuscitation is still appropriate.
 - To support the use of the Recommended PAC Plan document as a summary of recommendations to guide immediate decision making in an emergency, ensuring children receive appropriate and effective resuscitation when necessary and without delay
 - To ensure children are treated with dignity and their human rights are respected⁶
 - To ensure appropriate, correct and respected application of United Nations Convention on Rights of the Child⁷
 - To promote current best practice in children's palliative care and specifically in the area of advance care planning based on current national guidance from Together for short lives¹, Royal College of Paediatrics and Child Health ², National institute of clinical excellence ³ Royal College of Physicians ⁹, Department of Health¹⁰, General Medical Council¹¹, Welsh Assembly Government ¹², National Service Framework for Children¹³.
- **To comply with Department of Health requirements**
 - To provide support for clinical staff
 - To provide written information for children and relatives
 - To satisfy legal and professional requirements
 - To minimise clinical risk, litigation and material loss
 - To comply with UHB requirements for formal organisation-wide policies.
 - To ensure the PAC-Plan procedures are monitored and audited

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- To facilitate improving end of life care as a key performance indicator of all NHS Health Boards and Trusts in Wales

This policy supports fully the national guidance on CPR decisions published by the British Medical Association, the Resuscitation Council (UK) and the Royal College of Nursing (2016) and the latest General Medical Council guidance (2010), as well as NICE End of Life care for Infants, children and young people with life-limiting conditions: planning and management (NG61). For children and young people age under 18 years the policy should also be read in conjunction with guidance from the Royal College of Paediatric and Child Health: 'Making decisions to limit treatment in life-limiting and life-threatening conditions in children: a framework for practice' 2015.

4.0 DEFINITION OF TERMS

4.1 'DNACPR' ('Do Not Attempt Cardiopulmonary Resuscitation) was a term historically used to record a decision that in the event of a sudden deterioration resulting in cardiorespiratory failure, no resuscitation would be carried out.⁴ Developed in adults, 'DNACPR' is not appropriate in the context of a child/young person with life threatening or life limiting illness, for three main reasons:

- DNACPR is often seen to represent a unilateral decision on the part of the doctor or healthcare team. Where there are multiple family members and carers involved, as is usual in the care of a child with a life-limiting condition, other views (especially those of parents) must be solicited before such a decision is made.
- DNACPR offers only binary options ("do everything/do nothing") and its scope is limited to cardiopulmonary resuscitation, rather than to life-saving or life-sustaining treatments more generally. In children, it is more important to set out the range of options that have been discussed and an indication that consensus has been reached. Effective communication is key to the success of paediatric advance care planning.
- Parents do not have the same right to refuse treatment on behalf of their child as an adult patient would have to refuse her own treatment. Conclusions about end of life care in children represent preferences on the part of a child, young person and/or their family. that are agreed by healthcare professionals to be reasonable.

4.2 Life-limiting Conditions

Life-limiting conditions are those for which there is no reasonable hope of cure and from which children or young people are expected to die before reaching adulthood. They typically cause progressive deterioration, rendering the child increasingly dependent on parents and carers as adulthood approaches¹.

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4.3 Life-threatening Conditions

Life-threatening conditions are those for which curative treatment may be feasible but can fail, such as children with cancer.¹ Children or young people in long-term remission or following successful curative treatment are not included.

4.4 End of Life

The 'end of life' phase ends in death. Definition of its beginning is variable according to individual child/young person/family and professional perspectives. In some cases it may be the child/young person or family who first recognises its beginning. In other cases the principal factor may be the judgement of the health/social care professional/team responsible for the care of the patient. Since it is rarely clear at the outset of an acute deterioration whether or not it will result in death, it is usual for children with complex chronic conditions to have several 'end of life' episodes.

4.5 Paediatric Advance Care Planning

Paediatric advance care planning begins when a child or fetus is at risk of life threatening deterioration, whether following an acute event or a more gradual decline. It includes discussing life-sustaining (active) treatments and establishing long-term care goals. The child/young person, their parent/carers and the child's paediatrician should agree on the most appropriate care in an emergency or slow deterioration and sign a pathway form (see Appendix 1). Paediatric advance care planning may conclude that any of a range of options be in the child/young person's best interests, from full resuscitation including invasive ventilation through active treatment which might be life-prolonging (e.g. IV antibiotics) but stops short of invasive ventilation support or CPR, to measures where the aim of treatment is to relieve symptoms without prolonging life.

4.6 Child

There is a clear legal distinction, in terms of treatment decision-making between those who are 16 years of age and over and those who are under 16. In this Policy, reference to a child means a patient who is under 16 years of age. Patients who are 16 and 17 years old are referred to as young people. Children are presumed not to be competent to make their own treatment decisions, unless they have been assessed to be *Gillick* competent. In contrast, patients aged 16 years and over are presumed to have capacity to make their own decisions.

A child or young person may have a PAC-Plan or begin the discussions about completing a PAC-Plan at any point in time while they remain under the primary care of a lead child health professional.

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Professionals should be aware that the legal framework and systems for assessing capacity are different for adults. Professionals should seek appropriate advice regarding this matter.

4.7 Cardiopulmonary Resuscitation (CPR)

Cardiopulmonary Resuscitation: may include artificial respiration chest compressions and defibrillation in an attempt to restart the heart.⁴

5. ROLES AND RESPONSIBILITIES

Cardiff and Vale UHB aims to comply with national guidance to healthcare professionals both through the development of this policy and the production of an information leaflet for children and relatives.

5.1 Health Board

The UHB Board carries overall responsibility for Cardiff and Vale UHB. It has delegated powers from the National Assembly for Wales in respect of the ownership and management of hospitals and other health facilities; it is responsible for the performance of the UHB. The Chief Executive must ensure the UHB has an agreed Resuscitation Policy that respects Children's Rights and that any decisions made by staff are informed via the Paediatric Advance Care Planning policy and relevant child/young person/family information.

5.2 Resuscitation Group

The UHB Resuscitation Group, led by its chairperson, meets on a regular basis. Its role is to ensure that UK Resuscitation Council guidelines for the resuscitation of victims of cardiopulmonary arrest are implemented effectively. Group members should be conversant with contemporary issues related to new developmental knowledge, and be aware of the need to specify them appropriately for the particular issues of children through discussion with specialists in paediatric end of life and intensive care.

5.3 Resuscitation Service

The Resuscitation Service is answerable to the Resuscitation Group in terms of its clinical lead. It is responsible for implementing decisions made by the Resuscitation Group and promoting good practice primarily through training and audit. The Resuscitation Service is responsible for assessing those it teaches and ensuring that they meet standards that reflect UK Resuscitation Council guidelines. The Resuscitation Service develops policies using guidance to ensure full multidisciplinary representation. It monitors cardiac arrest outcome and team response as well as adherence to resuscitation policies (including PAC-Plan policy). The Senior Resuscitation Practitioner will maintain, manage and develop the service, within available resources, to meet the needs of the Health Board.

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5.4 All-Wales Network in Paediatric Palliative Care

The PAC-Plan subgroup is convened under the All-Wales Network in Paediatric Palliative Care. The Network meets on a regular basis. Members should be conversant with contemporary issues related to new developmental knowledge and review and update this policy annually through regular clinical governance procedures.

5.5 Clinical Board Directors and Line Managers

While the UHB has the responsibility to ensure that resuscitation policies and relevant patient information are developed through the UHB Resuscitation Service, those who manage staff, particularly clinical staff, have a responsibility to ensure that staff and, where relevant, children and their relatives have access to and understand resuscitation policies, especially the PAC-Plan policy.

5.6 Individual Staff Members

While the UHB has a responsibility to provide a Resuscitation Service and its managers are responsible for ensuring staff have access to and understand resuscitation policies and relevant patient information leaflets, each individual is responsible for their own actions and professional practice. Paediatric health care practitioners have an obligation to educate themselves about this aspect of medical care. Individual staff members should familiarise themselves with UHB resuscitation policies and, with respect to the PAC-Plan policy ensure that children and their families have access to and understand it. Staff must respect patient rights to confidentiality whilst ensuring that decisions relating to PAC-Plan are communicated to appropriate colleagues with informed consent.¹⁴

6. PAEDIATRIC ADVANCE CARE PLANNING DECISION MAKING

Advance Care Planning is an extension of usual discussions about plans for treatment, which have conventionally focused on curative measures and on what will be provided rather than what will not. Paediatric advance care planning broadly encompasses both short-term and long-term health care goals and treatments. It may include the drafting of formal advance options, which specify what treatments will or will not be provided for the child/young person. The benefits of Advance Care Planning are both procedural, in that two-way communication is improved, as well as substantive, in that the actual details of the plans for care are clarified. When paediatric advance care planning is executed well it ensures that shared goals of care, be they curative or palliative, are aligned with the planned course of treatment.

6.1 Advance Care Planning for Children/Young People with Life Threatening or Life Limiting Conditions – a New Standard of Care
Advance care planning in paediatrics is most important among children with life-limiting or life-threatening conditions. Among such children, the expected

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mode of death is often an acute deterioration in respiratory, brain or bowel function. The stimulus for discussion is usually recognition that some interventions, especially those associated with intensive care, will do harm to the child that cannot be justified because the chance that they will prolong the child's life is too small. Such discussions represent a transition from a curative to a palliative focus of care that can be abrupt if the discussions are left too late. Health care providers should be aware that palliative care is appropriate at any point following diagnosis of a life-limiting or life threatening condition, and can proceed alongside treatments which may have cure as their goal.

6.2 Timing of Initiating the Advance Care and Emergency Pathway Process

- As a general rule, the earlier PAC-Planning begins in the trajectory of an individual child's illness, the better prepared the family and healthcare team can be at the time of the child's death.
- Each family is different, however, and the most appropriate timing will depend on the readiness of the family to engage with the process. A significant minority of families will never be willing to do so, while others will feel comfortable with having the discussions but will never sign the form.
- PAC-Plan discussions take place over many weeks and months. Even in the paediatric intensive care setting, in which decision-making often occurs on a compressed timeline, one Canadian study¹⁵ found that two or more meetings were required to achieve consensus in 46% of cases involving decisions to forego life-sustaining therapy.
- Effective communication includes being open and available for feedback, having ongoing discussions and re-evaluating treatment goals.
- Emotional and psychological needs of child/young person/family must be considered at all times. Available counselling and psychological support services should be accessed when appropriate e.g. parent counselling service.

6.3 Ethical issues in Advance Care Planning

The ethical principles that underlie Advance Care Planning include respect for autonomy, beneficence, non-maleficence and justice. Any course of action should only be undertaken when the benefit to the child/young person proportionately outweigh the burden¹⁶. Since it is not possible precisely to predict benefits and burdens, the PAC-Plan is designed to encourage 'parallel planning'; that is, an exploration of different scenarios that might occur at the end of life, and a record of preferences in each. Those preferences result from values as well as medical facts, and the PAC-Plan accommodates views that are subjective. Health care professionals should be aware of differences in how burden is perceived, looking from the perspective of the child/young person in isolation versus being embedded in a family unit. It may even be difficult to separate the interests of the child from those of their caregivers and

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extended family members. The best interests of the child, however, should be of paramount consideration¹⁷.

6.3.1 Assessment of Best Interest.

- (1) General guiding principles are set out by the General Medical Council (GMC) 'Respect for human life and best interests, (see paragraphs 9-11). There is specific guidance in children¹¹ (0-18 years: guidance for all doctors. General Medical Council 2007, **paragraphs 12-13**)

An assessment of best interests will include what is clinically indicated

in a particular case. You should also consider:

- a) The views of the child or young person, so far as they can express them, including any previously expressed preferences
- b) The views of parents
- c) The views of others close to the child or young person
- d) The cultural, religious or other beliefs and values of the child or parents
- e) The views of other healthcare professionals involved in providing care to the child or young person, and of any other professionals who have an interest in their welfare
- f) Where there are a number of options, that which will least restrict the child or young person's future options should be selected.

This list is not exhaustive. The weight attached to each point will depend on the circumstances, and all other relevant information should be considered. One should not make unjustified assumptions about a child or young person's best interests based on irrelevant or discriminatory factors, such as their behaviour, appearance or disability.

In cases of acute critical illness where the outcome of treatment is unclear, as for some children who require intensive care, survival from the acute crisis would be regarded as being in the patient's best interests¹⁸

6.3.2 Capacity to Consent

Guidance is set out by the GMC re decisions on capacity to consent (see paragraphs 24-29)¹¹ (see Paragraph 68-72)¹⁸ See also the UHB's Consent to Examination or Treatment Policy.

The capacity of paediatric patients to consent ranges from those who lack capacity altogether to those who are fully capable of consent. The latter defines the mature or 'Gillick Competent' minor, who is legally not

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an adult according to chronological age criteria, but has the cognitive ability to consider treatment choices and alternatives and weigh the consequences and, other than by age, would be considered to have capacity as defined by the Mental Capacity Act 2005.

The authority of the expressed preferences of a Gillick competent minor are essentially those of an adult and cannot usually be overridden, even if they are seen to be perverse or irrational, without express permission from the Court.

Where minors lack 'Gillick Competence' but are capable of expressing a preference, that preference is important and should be given weight in end of life decision-making, even if it is ultimately necessary to override it on the grounds of the child's interests.

A Scandinavian study¹⁹ found that a quarter of parents regretted not talking about death with their child who was dying of cancer, suggesting that one of our responsibilities is to help parents address this issue. Providing information is consistent with the duty to be honest with our children. We respect their dignity by only administering treatments that they have freely chosen and desire. A more recent UK study²³ found advance care plans to be relevant to a diverse group of children and families as a resource to plan care. Research participants described numerous positive outcomes and anticipated benefits.

6.4 When to Attempt CPR

Where no explicit advance decision has been made about the appropriateness or otherwise of attempting resuscitation prior to a patient suffering cardiac or respiratory arrest, and the express wishes of the child and/or family are unknown and cannot be ascertained health professionals should make all reasonable efforts to attempt to revive the patient.

Ideally, decisions about whether to attempt to resuscitate an individual are made in advance as part of overall care planning for that patient and, as such, are discussed with the patient along with other aspects of future care. Neither children, nor those close to them, can demand treatment that is clinically inappropriate.

In an emergency situation and in the absence of the patient's consultant/GP, the doctor on duty should attempt CPR unless:

- The Paediatric Advance Care Planning suggests alternative management
- The patient is clearly in the terminal phase of illness
- Sufficient information is available to make a judgement that CPR would not be in the child/ young person's best interest.

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Where CPR may restart the heart and breathing for a sustained period but there are doubts about whether this is in a child's best interest, the views of the family, child or young person should be taken into consideration in deciding whether it should be attempted.³

6.5. Refusal of Treatment

- Adults with parental responsibility are the usual proxy decision makers for children who are unable to decide for themselves.
- Whenever possible, children or young people should be fully involved in all decisions affecting them, even if they are not Gillick competent or lack capacity.¹¹
- The views of children and young people must be taken into consideration when making decisions about end of life interventions, even when they are not able to make the decisions for themselves.
- Competent children can consent to treatment in England and Wales⁹.
- Refusal of treatment by a Gillick-competent minor cannot usually be overturned without express permission from the Courts¹¹. In the past, the Courts typically supported the treatment preferences of parents over those of the child, but that is becoming increasingly uncommon and should not be assumed.
- Parents cannot require doctors to provide treatment contrary to their professional judgement, but doctors must try to accommodate parental wishes as far as they are compatible with the child's best interests.
- If there is disagreement between those with parental responsibility and the health care team, advice from the Clinical Ethics Committee and/or legal advice must be sought in a timely fashion¹¹.

7. TEMPORARY SUSPENSION OF A PAC-PLAN ORDER RECORDED IN AN ADVANCE & EMERGENCY CARE PATHWAY

- The PAC-Plan discussions include exploration of the possibility that cardiac or respiratory arrest will occur in a child with a life-limiting condition, but from a readily reversible cause such as choking, induction of anaesthesia, anaphylaxis or blocked tracheostomy tube. In such situations CPR will usually be appropriate while the reversible cause is addressed. A specific example is where an intervention carries the risk of cardiopulmonary arrest. General or regional anaesthesia, for example, may cause cardiovascular or respiratory instability that should usually be treated, irrespective of the conclusions recorded in a PAC-Plan.

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- It is good practice to review the PAC-Plan as part of the clinical preparation for surgery, and again once the child has returned to base-line health afterwards.

8. RESPONSIBILITY FOR PAEDIATRIC ADVANCE CARE PLANNING DECISION MAKING

- The conclusions recorded on a PAC-Plan are to guide clinicians making decisions about the appropriateness or otherwise of certain interventions at the end of a child's life. They are not legally binding, and do not replace discussions with patients/families at the actual time of an acute deterioration.
- They do not obviate the need to make a decision in the interests of the child at the point of an acute deterioration. 'Standard rules' or 'blanket policies' that restrict interventions for reasons other than the interests of the child at the time are unlawful and cannot apply.
- Overall responsibility for decisions about what interventions are appropriate rests with the physician in charge of the patient's care, who may be the specialist with primary responsibility for the most significant illness at the time (e.g. oncologist for a child/young person with cancer).
- Where responsibility for a child/young person's care is shared (e.g. between general paediatrics and paediatric palliative care) decisions should be made together. However, one individual should take the lead in the PAC-Plan process, ensuring discussions are properly recorded and communicated to those who need to be aware of them.
- If it becomes clear that there is important disagreement within the team (or between the team and parents, for example), legal advice should be sought. from the Clinical Ethics Committee and/or a legal representative. This should be timely enough to allow the possibility of resolution before a life-threatening episode.
- PAC-Plan conclusions must be based on reliable, up-to-date clinical guidelines.
- The language needs of children and their families must be met; interpreters should be used when necessary.
- Decisions about what interventions are appropriate should be undertaken in compliance with the Cardiff and Vale UHB's Policy Consent to Examination or Treatment Policy.²¹

9. COMMUNICATING PAEDIATRIC ADVANCE CARE PLANNING DECISIONS

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- Decisions regarding PAC-Plans in children need to be clearly communicated to all involved with their care, for example; schools, hospice, respite carers, etc. Consent to share this information must be sought from the patient/ someone with parental responsibility for them/ in their best interests.
- A leaflet should be made available to children and people close to them explaining PAC-Plans, how decisions are made and what their involvement would be in the process.
- Any decisions about CPR should be communicated between health professionals whenever a patient is transferred between establishments, between different areas or departments of the same establishment, or is discharged home.
- Transfer of children between facilities: It is the responsibility of the clinical team caring for the patient to review the patient's resuscitation status at the earliest opportunity following transfer between healthcare settings or out into the community. This may mean review after transfer by the transferring lead clinician or handover to and review by receiving team (e.g. other speciality team neurology, respiratory, renal, cardiac, community Consultant).

10. RECORDING PAEDIATRIC ADVANCE CARE PLANNING (PAC-PLAN) DECISIONS

- All decisions relating to resuscitation should be clearly documented with the date of the decision and the reason for it.
- Any PAC-PLAN decision and the reasons for it must be recorded in the medical notes*. The documentation must be dated and signed by the most senior member of the team.
- *The use of the dedicated PAC-Plan form is recommended; this form should be completed and filed in the front of the medical notes.
- Any decision relating to attempting CPR should be clearly recorded in the nursing notes by the primary nurse or the most senior member of the nursing team whose responsibility it is to inform other members of the nursing team
- Any decision about the provision of attempted CPR must be readily accessible to all relevant health care professionals.
- In acute hospitals the consultant making the decision may delegate the communication of this decision to his/her colleagues.
- Where GPs make this decision, they are responsible for its appropriate dissemination.

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11. COMMUNICATING PAEDIATRIC ADVANCE CARE PLANNING DECISIONS TO THE MULTIAGENCY TEAM

11.1 Ambulance

- Clinical guidelines issued by the Joint Royal Colleges Ambulance Liaison committee (JRCALC) advise ambulance staff that they should always initiate CPR unless:
There is a formal PAC-Plan conclusion, which has been seen by the ambulance crew, and the circumstances in which CPR may be attempted are consistent with the wording of the PAC-Plan conclusion; or the child/young person is known to be terminally ill and is being transferred to a palliative or terminal care facility (unless specific instructions have been received that CPR should be attempted)
- To enable the ambulance staff to comply with these guidelines, procedures must be in place to notify the ambulance staff of the child/young person's CPR status, and provide them with the necessary documentation before the transfer commences.
- If a child/young person is being transferred from hospital to a palliative care facility for terminal care then it is the responsibility of the transferring clinician to ensure that the ambulance crew have viewed a copy of the child/young person's PAC-Plan prior to transfer.
- If an ambulance crew is called to attend a child/young person with a PAC-Plan in the community – e.g. at home the ambulance control system will alert the crew that a PAC-Plan exists. The crew will receive no information about the contents of the PAC-PLAN; it will be the responsibility of the child/young person's carer to show the crew the most up to date copy of the child/young person's PAC-Plan.
- The ambulance control system will only communicate information to the ambulance crew about the existence of a PAC-Plan if the 999 call is made from the child/young person's home address. If an ambulance is called from an address other than the home – e.g. school; it will be the responsibility of the child/young person's attending carer to show the crew the most up to date copy of the child/young person's PAC-Plan
- When attending the child/young person professionals must be aware that the patient, parents/carers of a child or young person with a PAC-Plan may change their mind and request resuscitation for their child.

11.2 General Practitioner (GP)

- The child/young person's GP will be invited to contribute to the PAC-Plan planning process.

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- It will be the child/young person's GP's responsibility to ensure that details of the individual's PAC-Plan are communicated to the Out of Hours GP service.
- It remains the GP's responsibility to ensure that the child is on the practice palliative care register information, so that the information available to the Out of Hours GP service is up to date and that they are in receipt of the child/young person's current PAC-Plan.

11.3. Education

- Timely and sensitive use of the PAC-Plan should also facilitate discussion around the limitations of its use, for example in the school setting where education staff have a duty to call an ambulance and initiate resuscitation

11.4. Child Health and Disability (CHAD) Social Services

- Any child/young person with a PAC-Plan is likely to have an appointed Special Needs Health Visitor (SNHV) or CHAD Social worker (SW)
- Some children/young people requiring a PAC-Plan would benefit from accessing the services of the National Youth Advocacy Service (tel. 029 2066 8956) to ensure their participation in decision-making is optimised.
- Advocacy needs may be discussed with the child/young person/family and their respective Special Needs Health Visitor or CHAD social worker
- It will be the responsibility of the named SW/SNHV to disseminate information about a PAC-Plan to respite carers other than Community Children's Nurses.

11.5. The Coroner

- The Coroner investigates all deaths the cause of which is unknown or unnatural. A child/young person with a PAC-Plan may die unexpectedly or the cause of their death may not be known. If a child/young person has a PAC-Plan this does not negate the need to involve the Coroner.
- Families should be made aware that if an ambulance is called to attend a child/young person's death the police and therefore also the Coroner will automatically be informed of the child/young person's death. The Coroner then has a duty to investigate the death.
- The aim of the Coroner's investigation is to establish the cause of a child/young person's death. This may only involve seeking this information from a doctor who knows this child. For deaths that occur out of hours this may not be possible until the next

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working day. If the cause of death is unclear from discussions with health professionals the Coroner may proceed to further investigations which may include a post mortem examination of the child/young person.

- If a death is being investigated by the Coroner the child/young person's body must reside in the local mortuary. The child/young person should not be washed or changed and equipment, such as indwelling tubes or lines must not be removed without her permission.
- Creating a PAC-Plan should provide an opportunity to prepare parents and carers for possible Coroner involvement when their child dies. It does not negate the need for a Coroner's investigation of an unexplained death.

11.6 Police

- When a child dies at home (or elsewhere in the community) the police may have a duty to investigate the circumstances of the death.
- The existence of a PAC-Plan cannot remove the obligations that the police have or limit their investigative responsibility. The police should be made aware at the earliest opportunity of the existence of such a PAC-Plan as this will assist information sharing between professionals and support the decision making process.
- Creating a PAC-Plan should provide an opportunity to prepare parents and carers for possible police involvement when their child dies.

11.7 Ty Hafan Children's Hospice

- The team at Ty Hafan Children's Hospice have a wealth of experience of caring for children/young people with life-limiting illnesses and their families; throughout life, through death and into bereavement. The team are able to share this expertise with families and professionals to support the end of life care planning process.
- The hospice has their own documentation in relation to family wishes, and processes in place to ensure they know a families preferred place of care in the event of an acute deterioration during a hospice stay. This is usually used when a PAC plan is not in place but could also be used alongside an existing PAC Plan.
- The hospices offer emotional and psychosocial support to families and most families will have a named contact engaged in delivering this support. This resource can be used by the wider team to support PAC planning discussions but also to support the family in the event of a sudden deterioration or death.

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- The Family Support team at Ty Hafan offer a 24-hour on call service to families known to them, in the event of sudden deterioration or death outside of normal working hours when other professionals may not be contactable. This might involve the Ty Hafan family support worker supporting the family at home if needed and liaising with professionals from other agencies.
- All PAC-Plans drawn up for children/young people in Cardiff and The Vale of Glamorgan must be copied (subject to consent) to The Assistant Director of Care at Ty Hafan.
- If professionals need to access information from a child/young person's PAC-Plan outside of normal working hours and in the absence of being able to access any other copy of the PAC-Plan such as the parent-held copy, they could contact the family support team at Ty Hafan to access Ty Hafan's copy.
- The Ty Hafan family support team are contactable on Tel. (029) 20532200

12. REVIEWING THE PAEDIATRIC ADVANCE CARE PLANNING DECISION

- PAC-Plan documentation must be reviewed regularly. The frequency of the review will be determined by the child/young person's health care needs and professional in charge and may be influenced by:
 - Changes in the child/young person's condition
 - Changes in patient or family wishes
 - Transfer from one facility to another
 - Changes in the consultant or GP in charge
- Every PAC-Plan document should include a review date.
- PAC-Plan discussions should occur early and regularly throughout the course of treatment, ideally before crises arise, and as the goals of care are clarified or change over time. Decisions should be reviewed on a regular basis and revised as necessary as the medical condition and knowledge of treatment and prognosis evolve.
- Paediatric palliative care professionals should be involved early in discussions of treatment goals. Discussions about palliative care should ideally take place well before the child is at imminent risk of dying.

13. RAISING AWARENESS OF THE PAEDIATRIC ADVANCE CARE PLANNING POLICY

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At Health Board induction, all newly employed health professionals will be made aware of the Cardiff and Vale UHB paediatric advance care planning policy and their responsibilities according to the policy. Staff must have access to this document. The Resuscitation Service will provide this information. Existing staff will be made aware of the Cardiff and Vale advance care planning policy for children through the Resuscitation Service and attending regular health professional scheduled meetings.

14. REVIEW OF THE PAEDIATRIC ADVANCE CARE PLANNING POLICY

It is the responsibility of the Child Health Paediatric Advance Care Planning Focus Group in liaison with the Resuscitation Group of Cardiff and Vale UHB to review and update the PAC-Plan policy, taking into account new guidelines, changes in the law, and/or recommendations arising from audit following the implementation of the policy. Review of the policy will occur routinely once every three years and more frequently if required. These amendments will be presented to The Quality, Safety and Experience Committee

15. IMPLEMENTATION

All newly employed health professionals will be made aware of the Cardiff and Vale UHB policy on PAC-Plan and their responsibilities according to the policy at their local induction. Existing staff will be made aware of the policy through training and dissemination of this information to all appropriate Clinical Boards and managers in accordance with the management of policies and procedures for Cardiff and Vale UHB.

16. RESOURCES AND FUNDING

The policy will be distributed electronically and introduced to doctors as part of the in-house training programme when being appointed to work for Cardiff and Vale UHB. Full printed forms will be available as a download from the Intranet.

17. AUDIT

Compliance with this policy and the completion of PAC-Plan forms will be assessed through a process of spot-check audit. Professionals using the PAC-Plan may be asked to complete an audit form through the All Wales managed clinical network Data manager. Audit data will be examined by the All Wales Paediatric Advance Care Planning Focus Group and presented to

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the network and to relevant Quality, Safety and Experience Meetings at regular intervals.

18. CONTRIBUTORS

These have contributed to the original policy, or to the updated policy, or to both. Some have moved on to other roles since making their contribution.

Dr Richard Hain	Consultant Paediatric Palliative Medicine (CVUHB)
Dr Jo Griffiths	Consultant Paediatric Palliative Medicine (ABMU)
Dr Sian Moynihan	Consultant Community Child Health
Dr Charlotte Mellor	Paediatric Palliative Medicine SpR
Dr Michelle Jardine	Consultant Paediatric Intensive Care
Dr Helen Fardy	Consultant Paediatric Intensive Care
Dr Cath Norton	Associate Clinical Director Consultant Community Child Health
Dr Louise Hartley	Consultant Paediatric Neurologist
Dr Graham Shortland	Consultant Paediatrician
Cath Thompson	Assistant Director of Care , Ty Hafan
Liz Pendleton	Lead Nurse Community Children's Nursing Cardiff
Mary Glover	Senior Nurse Neonatal Unit
Dr J Calvert	Consultant Neonatologist
Carys Davies	Special Needs Health Visitor
Wendy Herbert	Head of Health Visiting
Diane Rogers	Head of Paediatric Physiotherapy Services
Nuala Mahon	Lead Nurse School Health
Dr Rhodri Lewis	General Practitioner
Chris Horrocks	Service Manager Child Health and Disability
Ms ME Hassell	HM Coroner for Cardiff and The Vale of Glamorgan
Mrs Hillary Valle	Parent representative
Mr Edward O'Brien	Welsh ambulance Service
DCI Leigh Holborn	DCI Gwent Police

We would like to acknowledge the work of Neath Port Talbot Safeguarding Children's Board Management Group in initiating this work and all subsequent teams working towards the single Welsh Pac plan.

19. REFERENCES

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- (3) End of life care for infants, children and young people with life-limiting conditions: planning and management. NICE guideline [NG61]. 2016
- (4) Decisions relating to Cardio.pulmonary resuscitation. Guidance from the BMA, Resuscitation Council (UK) and the Royal College of Nursing. Resuscitation Council (UK). 3rd edition 2016
- (5) All Wales DNACPR policy [2020]
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- (7) UN Convention on the Rights of the Child (United Nations,1989) Articles 12 – 14
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- (9) Advance Care Planning - concise guidance to good practice. A series of evidence-based guidelines for clinical management, no 12. The Royal College of Physicians 2009
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- (11) 0-18 years: guidance for all doctors. General Medical Council 2007
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- (23) Shaw KL, Spry JL. Evaluating advance care plans: Listening to families and professionals. Short Report. September 2020. University of Birmingham.

Equality & Health Impact Assessment for

PAEDIATRIC ADVANCE CARE PLAN (PAC-PLAN) POLICY FOR PATIENTS UNDER 18 YEARS OF AGE WITH LIFE THREATENING OR LIFE LIMITING ILLNESS

Please read the Guidance Notes in Appendix 1 prior to commencing this Assessment

Please note:

- The completed Equality & Health Impact Assessment (EHIA) must be
 - Included as an appendix with the cover report when the strategy, policy, plan, procedure and/or service change is submitted for approval
 - Published on the UHB intranet and internet pages as part of the consultation (if applicable) and once agreed.
- Formal consultation must be undertaken, as required¹
- Appendices 1-3 must be deleted prior to submission for approval

Please answer all questions:-

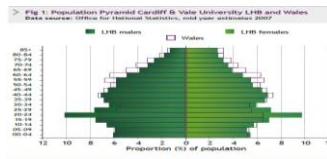
1.	For service change, provide the title of the Project Outline Document or Business Case and Reference Number	PAEDIATRIC ADVANCE CARE PLAN (PAC-PLAN) POLICY FOR PATIENTS UNDER 18 YEARS OF AGE WITH LIFE THREATENING OR LIFE LIMITING ILLNESS
2.	Name of Clinical Board / Corporate Directorate and title of lead member of staff,	Child Health Dr Jo Griffiths, All Wales managed clinical network.

¹http://www.cardiffandvale.wales.nhs.uk/portal/page?_pageid=253.73860407.253.73860411&_dad=portal&_schema=PORTAL

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	including contact details	Jo.griffiths@wales.nhs.uk
3.	Objectives of strategy/ policy/ plan/ procedure/ service	<p>The objectives of this policy and associated plan are to provide a rational and practical framework by which to support children and families affected by life-limiting or life threatening conditions.</p> <p>For most, deterioration towards death is slow, taking place over several years. The acute episode causing death is typically preceded by several similar episodes in which death is possible or even expected, but does not occur. The Paediatric Advanced Care Planning (PAC-Plan) provides a structured approach to discussions about end of life in children that are initiated by clinicians in a timely fashion when there is still time for parents and clinicians to explore a consensus about what is in the child's interests</p> <p>By supporting families to engage with meaningful PAC planning we hope the following outcomes will be achieved:</p> <ol style="list-style-type: none"> 1. An Increase in the proportion of families who are able to care for their child in the place of their preference at the end of life. 2. A Decrease in the number of irreconcilable disagreements between families and healthcare team about what interventions are appropriate for a child at the end of life.
4.	Evidence and background information considered. For example	The most recent prevalence studies (fraser et all 2020) estimated that there were 5933 children living with LLC in wales. The research in

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<ul style="list-style-type: none"> • population data • staff and service users data, as applicable • needs assessment • engagement and involvement findings • research • good practice guidelines • participant knowledge • list of stakeholders and how stakeholders have engaged in the development stages • comments from those involved in the designing and development stages <p>Population pyramids are available from Public Health Wales Observatory² and the UHB's 'Shaping Our Future Wellbeing' Strategy provides an overview of health need³.</p>	<p>England identifies a steep rise in the number of babies, children and young people with life-limiting or life-threatening conditions with the absolute number of these children almost trebling in the last 17 years. There is no reason to suspect that this isn't also the case in Wales. At least 450 children in Cardiff and the Vale University LHB have a chronic medical condition that is expected to lead to their death within childhood and many more life limited children from across south Wales access specialist care provided by paediatricians in the health board.</p> <p>Cardiff & Vale University Local Health Board (LHB) area is the smallest and most densely populated LHB area in Wales, primarily due to Wales' capital city: Cardiff. 72.1 and 27.9 percent of the LHB area population live within Cardiff and the more rural Vale of Glamorgan respectively</p>  <p>Advance care plans can help people with a life-limiting condition plan for and receive care at the end of their life that is in line with their wishes. Talking with the child or young person, and their parents or carers, at appropriate stages allows them to influence the care that they receive and improves their experience of care. This includes involving parents and carers when a potentially life-limiting condition is diagnosed in a</p>
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² <http://nww2.nphs.wales.nhs.uk:8080/PubHObservatoryProjDocs.nsf>

³ <http://www.cardiffandvaleuhb.wales.nhs.uk/the-challenges-we-face>

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		<p>baby during pregnancy. Advance care plans should be appropriate to the circumstances and continuously updated throughout the delivery of care and support.</p> <ul style="list-style-type: none"> - NICE Quality Standard QS160 states that services should have evidence of local arrangements to ensure that children with life limiting illnesses (where possible) and their parents are involved in developing an advance care plan, acknowledging that this may start as early as prenatally. - The first all Wales PAC plan approved in 2016 following engagement with acute, community and critical care paediatric team alongside WAST, Police, social care and voluntary sector colleagues. <p>For this review stakeholders included</p> <ul style="list-style-type: none"> - Representative clinicians from the All Wales childrens palliative care network - Children and families with experience of using PAC plans. - Welsh ambulance service - South and North Wales police forces - Coroner's representatives. <ul style="list-style-type: none"> - Changes to the PAC plan reflect engagement and comment from users including children and families, health care professionals and partner agencies. - The UHB's usual arrangement with regard to consultation will be followed (ie. 28 days on the intranet) and any queries explored.
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		- As part of good practice, other policies from different organisations across the UK were considered. Key changes in the PAC plan reflect similar changes across advance care planning documents in other areas of the United Kingdom.
5.	Who will be affected by the strategy/ policy/ plan/ procedure/ service	The policy applies to all UHB staff involved at any stage in the process of advance care planning. As an All Wales document, the policy will be replicated across Wales, with agreement encouraged in all LHBS. The voluntary sectors, most notably the Childrens hospices (Ty Hafan, Ty Gobaith and Hope House) will be aware of and participate in supporting children and families with PAC planning.

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6. EQIA / How will the strategy, policy, plan, procedure and/or service impact on people?

Questions in this section relate to the impact on people on the basis of their 'protected characteristics'. Specific alignment with the 7 goals of the Well-being of Future Generations (Wales) Act 2015 is included against the relevant sections.

How will the strategy, policy, plan, procedure and/or service impact on:-	Potential positive and/or negative impacts	Recommendations for improvement/mitigation	Action taken by Clinical Board / Corporate Directorate. Make reference to where the mitigation is included in the document, as appropriate
6.1 Age For most purposes, the main categories are: <ul style="list-style-type: none"> • under 18; • between 18 and 65; and • over 65 	The policy relates only to those younger than 18 years. Caution is required for those aged 16-18 years where the MCA and best interest's decision making should be key parts of decision making.	N/A	
6.2 Persons with a disability as defined in the Equality Act 2010 Those with physical impairments, learning disability, sensory loss or impairment, mental health conditions, long-term medical conditions	The policy is aimed at improving dying in children with life-limiting conditions, around two thirds of whom are significantly cognitively and/or physically impaired. Many will have visual and hearing impairment and 70% will have learning disability as well as physical disability. The UHB is aware from its demographic	N/A	

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How will the strategy, policy, plan, procedure and/or service impact on:-	Potential positive and/or negative impacts	Recommendations for improvement/mitigation	Action taken by Clinical Board / Corporate Directorate. Make reference to where the mitigation is included in the document, as appropriate
such as diabetes	information that it employs staff who have disabilities as defined within the Act. As such, the Policy has been made accessible to staff in both electronic and paper copy.		
<p>6.3 People of different genders: Consider men, women, people undergoing gender reassignment</p> <p>NB Gender-reassignment is anyone who proposes to, starts, is going through or who has completed a process to change his or her gender with or without going through any medical</p>	The number of children and young people treated for gender dysphoria is rising 4 and this will be reflected in the population of children with life-limiting conditions as in the population at large. The sexuality of most patients affected by the Plan will not be known with certainty because of cognitive impairment, and lack of congruence between body sex and gender identity will not be knowable in most. That is least likely to be true in the group with Duchenne Muscular Dystrophy and those with cancer. The Plan focuses, however, on the needs of		

⁴ <http://www.telegraph.co.uk/news/health/news/11519603/Rise-in-child-transgender-referrals.html> (accessed July 2016)

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How will the strategy, policy, plan, procedure and/or service impact on:-	Potential positive and/or negative impacts	Recommendations for improvement/mitigation	Action taken by Clinical Board / Corporate Directorate. Make reference to where the mitigation is included in the document, as appropriate
procedures. Sometimes referred to as Trans or Transgender	the individual child and makes minimal assumptions about sexuality		
6.4 People who are married or who have a civil partner.	The Plan makes minimal assumptions about marital status. Its only relevance is indirect (because it impacts on who has parental responsibility over the child). The Plan refers to parental responsibility, because that is relevant to the authority of the person completing the form. Marital status and parental responsibility are linked in that if an unmarried father is not present and does not sign the register of births, his details will not be included on the birth certificate and he will not automatically have parental responsibility for his child. It's important to point out that the Plan is not a legal document, and the lack of parental responsibility does not preclude someone from expressing a view, though it would preclude them from giving consent for the		

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How will the strategy, policy, plan, procedure and/or service impact on:-	Potential positive and/or negative impacts	Recommendations for improvement/mitigation	Action taken by Clinical Board / Corporate Directorate. Make reference to where the mitigation is included in the document, as appropriate
	<p>information to be disseminated.</p> <p>With that in mind, it's extremely unlikely that the Pac-Plan will impact differently on people in marriages or civil partnerships and those who are not.</p>		
<p>6.5 Women who are expecting a baby, who are on a break from work after having a baby, or who are breastfeeding. They are protected for 26 weeks after having a baby whether or not they are on maternity leave.</p>	<p>Instances in which end of life care needs to be provided alongside antenatal care during pregnancy are rare but well-recognised.⁵ The Pac-Plan relates to end of life care in the child, and will not impact on the care of a mother. The Plan might, however, impact on the care of babies who have not yet been born but are not expected to survive (such as those with anencephaly or some severe chromosomal abnormalities). The discussions represented by the Pac-Plan might result in a mother deciding to proceed</p>		

⁵ Best Pract Res Clin Obstet Gynaecol. 2001 Apr;15(2):323-31

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How will the strategy, policy, plan, procedure and/or service impact on:-	Potential positive and/or negative impacts	Recommendations for improvement/mitigation	Action taken by Clinical Board / Corporate Directorate. Make reference to where the mitigation is included in the document, as appropriate
	with a pregnancy she would otherwise have chosen to terminate, since the Plan allows her to be confident that the dying baby will receive good palliative care and be comfortable during his or her short life. ⁶		
6.6 People of a different race, nationality, colour, culture or ethnic origin including non-English speakers, gypsies/travellers, migrant workers	Despite being over-represented among the families caring for children with life-limiting conditions, there is evidence that BME groups are under-represented among those using palliative care services. ⁷ It is known that the palliative care needs of Romany families in the UK are not always well met. ⁸	If a child, family member or member staff was known to have difficulties with the written word, good management would dictate that alternative	

⁶ Hain R. Teddy Houlston's short life tells us so much about what it is to be human. Observer. 2015 26th April 2015

⁷ Fraser LK, Miller M, Hain R, Norman P, Aldridge J, McKinney PA, et al. Rising national prevalence of life-limiting conditions in children in England. Pediatrics. 2012 Apr;129(4):e923-9. PubMed PMID: 22412035. Epub 2012/03/14. eng.

, Fraser LK, Miller M, Aldridge J, McKinney PA, Parslow RC, Hain R. Life-limiting and life-threatening conditions in children and young people in the United Kingdom: national and regional prevalence in relation to socioeconomic status and ethnicity. Leeds: University of Leeds/Children's Hospices UK, 2011.

⁸ Jesper E, Griffiths F, Smith L. A qualitative study of the health experience of Gypsy Travellers in the UK with a focus on terminal illness. Primary Health Care Research & Development. 2008;9(02):157-65.

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How will the strategy, policy, plan, procedure and/or service impact on:-	Potential positive and/or negative impacts	Recommendations for improvement/mitigation	Action taken by Clinical Board / Corporate Directorate. Make reference to where the mitigation is included in the document, as appropriate
	<p>These studies are mainly of adults and do not relate directly to children, but it is reasonable to extrapolate their findings. The main impact of the Pac-Plan would be to help reduce that unequal access to services by encouraging clinicians to recognize the need to offer end of life care in a timely and sensitive fashion.</p> <p>The Plan is, however, currently available only in English, so that although it will still support the care of families whose first language is not English, it will be less effective in those families.</p>	<p>arrangements be made, such as individual meetings. Members of the public would be supported by staff or family members as appropriate.</p>	
<p>6.7 People with a religion or belief or with no religion or belief. The term 'religion' includes a religious or philosophical belief</p>	<p>There is evidence that poor access to palliative care services is related to cultural concerns about the ideology represented by palliative care itself (ie the belief that it can be acceptable to allow death to occur without intervening to try to stop it) and about its ethos, which is often seen to be</p>	<p>Access to spiritual leaders should be a core component of good end of life care.</p>	

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How will the strategy, policy, plan, procedure and/or service impact on:-	Potential positive and/or negative impacts	Recommendations for improvement/mitigation	Action taken by Clinical Board / Corporate Directorate. Make reference to where the mitigation is included in the document, as appropriate
	rooted in a Christian worldview ⁹ Religious belief is also often thought by clinicians to be the cause for difficulties in reaching consensus with families regarding care at the end of life ¹⁰ . To the extent that that is true, this policy will also offer particular benefits.		
6.8 People who are attracted to other people of: <ul style="list-style-type: none"> • the opposite sex (heterosexual); • the same sex (lesbian or gay); • both sexes (bisexual) 	There is evidence that adult members of the LGBT community feel excluded from good quality care at the end of life. ¹¹ Many concerns centred around reluctance of LGBT to engage with services for fear of heteronormative assumptions about relationships (especially in relation to defining who is next of kin) and language.		

⁹ Gatrad AR, Brown E, Notta H, Sheikh A. Palliative care needs of minorities. *BMJ*. 2003 Jul 26;327(7408):176-7. PubMed PMID: 12881234. Pubmed Central PMCID: 1126563. Epub 2003/07/26. eng. And Gatrad AR, Sheikh A. Palliative care for Muslims and issues before death. *International Journal of palliative nursing*. 2002;8(11):526-31.

¹⁰ Brierley J, Linthicum J, Petros A. Should religious beliefs be allowed to stonewall a secular approach to withdrawing and withholding treatment in children? *J Med Ethics*. 2012 Mar 30. PubMed PMID: 22465877. Epub 2012/04/03. Eng.

¹¹ <http://www.ncpc.org.uk/lgbt> (accessed July 2016)

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How will the strategy, policy, plan, procedure and/or service impact on:-	Potential positive and/or negative impacts	Recommendations for improvement/mitigation	Action taken by Clinical Board / Corporate Directorate. Make reference to where the mitigation is included in the document, as appropriate
	The PAC-Plan makes no such assumptions, referring throughout only to mother, father or parent. It is unlikely that members of the LGBT community would feel reluctant to engage with the process on those grounds, and it is plausible that one result of having the Plan available will be to encourage clinicians to be more proactive in involving parents generally, whatever their sexual orientation, improving access to specialist palliative care services.		
6.9 People who communicate using the Welsh language in terms of correspondence, information leaflets, or service plans and design Well-being Goal – A Wales of vibrant culture and thriving Welsh	Paper copies are currently available only in English, so that although it will still support the care of families whose first language is Welsh, it will be less effective in those families. Translation will be need to be sought.	The policy prompts staff to ask patients which language the patient/service users would like to communicate in, where staff can offer this as an option.	

Commented [RH1]: Julia, presumably CVUHB will have to have this translated ?

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How will the strategy, policy, plan, procedure and/or service impact on:-	Potential positive and/or negative impacts	Recommendations for improvement/mitigation	Action taken by Clinical Board / Corporate Directorate. Make reference to where the mitigation is included in the document, as appropriate
language			
6.10 People according to their income related group: Consider people on low income, economically inactive, unemployed/workless, people who are unable to work due to ill-health	Over the whole of the last decade, the prevalence of life-limiting conditions has been consistently highest for children in social deprivation category 5 and lowest in category 1. These figures show that the burden of caring for a child with an LLC is most likely to fall on those living in areas of high social deprivation, but that they are also the families least likely to access specialist palliative care services that can facilitate choices at the end of life.	The most important gap in these data is the extent to which the PAC-Plan achieves its aims of giving a voice to families, and therefore improving family choice at the end of life. The PAC-Plan documentation is designed to be audited over time so that this can be monitored.	
6.11 People according to where they live: Consider people living in areas	This policy is applicable to all in Wales regardless of residence and should thus		

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How will the strategy, policy, plan, procedure and/or service impact on:-	Potential positive and/or negative impacts	Recommendations for improvement/mitigation	Action taken by Clinical Board / Corporate Directorate. Make reference to where the mitigation is included in the document, as appropriate
known to exhibit poor economic and/or health indicators, people unable to access services and facilities	have a positive impact on people on low income as the policy is applicable to all people. The policy is applicable to community and acute settings.		
6.12 Consider any other groups and risk factors relevant to this strategy, policy, plan, procedure and/or service	People who speak other languages other than Welsh or English will be impacted as the policy is currently only available in English, pending translation into Welsh.		

7. HIA / How will the strategy, policy, plan, procedure and/or service impact on the health and well-being of our population and help address inequalities in health?

Questions in this section relate to the impact on the overall health of individual people and on the impact on our population. Specific alignment with the 7 goals of the Well-being of Future Generations (Wales) Act 2015 is included against the relevant sections.

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How will the strategy, policy, plan, procedure and/or service impact on:-	Potential positive and/or negative impacts and any particular groups affected	Recommendations for improvement/ mitigation	Action taken by Clinical Board / Corporate Directorate Make reference to where the mitigation is included in the document, as appropriate
<p>7.1 People being able to access the service offered: Consider access for those living in areas of deprivation and/or those experiencing health inequalities</p> <p>Well-being Goal - A more equal Wales</p>	<p>The aim of this policy is to enable those caring for children with life-limiting conditions to explore and articulate preferences for how their child should be managed at the end of life. When options become limited because of a child's deteriorating condition, it will provide an opportunity for sensitive and timely exploration of the reasons, irrespective of place of residence or health inequalities experienced. It is based on national multidisciplinary recommendations ¹. and informed by local experience.</p>		
<p>7.2 People being able to improve /maintain healthy lifestyles:</p>	<p>Due to the population who this is aimed at, there are limitations in how the policy</p>		

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How will the strategy, policy, plan, procedure and/or service impact on:-	Potential positive and/or negative impacts and any particular groups affected	Recommendations for improvement/ mitigation	Action taken by Clinical Board / Corporate Directorate Make reference to where the mitigation is included in the document, as appropriate
<p>Consider the impact on healthy lifestyles, including healthy eating, being active, no smoking /smoking cessation, reducing the harm caused by alcohol and /or non-prescribed drugs plus access to services that support disease prevention (eg immunisation and vaccination, falls prevention). Also consider impact on access to supportive services including smoking cessation services, weight management services etc</p> <p>Well-being Goal – A healthier Wales</p>	<p>can address this. However, good communication and dissemination of agreed best practice should reduce harm of inappropriate actions and support timely and supportive treatment where appropriate.</p>		
<p>7.3 People in terms of their income and employment status: Consider the impact on the</p>	<p>The policy is primarily aimed at children and thus any effect will be secondary on parents / carers. The policy</p>	<p>We recognise that for some PAC planning can be a stressful event and children / family and carers</p>	

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How will the strategy, policy, plan, procedure and/or service impact on:-	Potential positive and/or negative impacts and any particular groups affected	Recommendations for improvement/ mitigation	Action taken by Clinical Board / Corporate Directorate Make reference to where the mitigation is included in the document, as appropriate
availability and accessibility of work, paid/ unpaid employment, wage levels, job security, working conditions Well-being Goal – A prosperous Wales	aims to support carers in decision making which may in turn improve emotional well being impacting on ability to maintain employment.	alike should be supported during this time.	
7.4 People in terms of their use of the physical environment: Consider the impact on the availability and accessibility of transport, healthy food, leisure activities, green spaces; of the design of the built environment on the physical and mental health of patients, staff and visitors; on air quality, exposure to pollutants; safety of neighbourhoods, exposure to crime; road safety and	As a policy, there will be no impact.		

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How will the strategy, policy, plan, procedure and/or service impact on:-	Potential positive and/or negative impacts and any particular groups affected	Recommendations for improvement/ mitigation	Action taken by Clinical Board / Corporate Directorate Make reference to where the mitigation is included in the document, as appropriate
preventing injuries/accidents; quality and safety of play areas and open spaces Well-being Goal – A resilient Wales			
7.5 People in terms of social and community influences on their health: Consider the impact on family organisation and roles; social support and social networks; neighbourliness and sense of belonging; social isolation; peer pressure; community identity; cultural and spiritual ethos Well-being Goal – A Wales of cohesive communities	The ability to consider wishes for treatment at time of deterioration and death is shown to be important for emotional wellbeing. Opening discussions allows families to seek additional support from social networks and organisations. This in turn has the potential to reduce feelings of isolation and involve faith communities to better support the dying and bereaved.		

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How will the strategy, policy, plan, procedure and/or service impact on:-	Potential positive and/or negative impacts and any particular groups affected	Recommendations for improvement/ mitigation	Action taken by Clinical Board / Corporate Directorate Make reference to where the mitigation is included in the document, as appropriate
<p>7.6 People in terms of macro-economic, environmental and sustainability factors: Consider the impact of government policies; gross domestic product; economic development; biological diversity; climate</p> <p>Well-being Goal – A globally responsible Wales</p>	<p>As a policy, there will be no impact.</p>		

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Please answer question 8.1 following the completion of the EHIA and complete the action plan

<p>8.1 Please summarise the potential positive and/or negative impacts of the strategy, policy, plan or service</p>	<p>On reviewing the previous policy and writing the latest version, better engagement with the pac plan policy will support some of the more vulnerable in the health board, particularly those from BME communities or low socio-economic groups. Overall, there appears to be very limited negative impact on the protected characteristics and health inequalities as a result of this policy.</p> <p>The policy is likely to have the greatest positive impact among women, black and minority ethnic groups, families whose religious views are felt by professionals to be the cause of unreasonable care decisions at the end of life, and families from areas of high social deprivation.</p> <p>Because it focuses on the nature and needs of the individual child, and the individual members of the child's family, the sexual orientation of the child or parent (even if known and made explicit) is unlikely to be relevant to the impact of the Plan for most. The same is probably true for children of transgender parents or who are themselves transgender, but the data are not there and it is an issue that may become more important in the future as the incidence of gender incongruence in young people is rising.</p> <p>Its positive impact is likely to be less among those whose first language is not English, including those whose first language is Welsh.</p>
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Action Plan for Mitigation / Improvement and Implementation

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	Action	Lead	Timescale	Action taken by Clinical Board / Corporate Directorate
8.2 What are the key actions identified as a result of completing the EHIA?	Circulate to full all wales network and interested parties. Audit of equality impact on 3 yearly basis after launch	JG Pall care spr	May 2021 May 2024	
8.3 Is a more comprehensive Equalities Impact Assessment or Health Impact Assessment required? This means thinking about relevance and proportionality to the Equality Act and asking: is the impact significant enough that a more formal and full consultation is required?	No			

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	Action	Lead	Timescale	Action taken by Clinical Board / Corporate Directorate
<p>8.4 What are the next steps?</p> <p>Some suggestions:-</p> <ul style="list-style-type: none"> • Decide whether the strategy, policy, plan, procedure and/or service proposal: <ul style="list-style-type: none"> ○ continues unchanged as there are no significant negative impacts ○ adjusts to account for the negative impacts ○ continues despite potential for adverse impact or missed opportunities to advance equality (set out the justifications for doing so) ○ stops. • Have your strategy, policy, plan, procedure and/or service proposal approved • Publish your report of this impact assessment • Monitor and review 	<p>Translation into welsh when content agreed.</p>			

Appendix 1

Equality & Health Impact Assessment

Developing strategies, policies, plans and services that reflect our Mission of 'Caring for People, Keeping People Well'

Guidance

The University Health Board's (the UHB's) Strategy 'Shaping Our Future Wellbeing' (2015-2025) outlines how we will meet the health and care needs of our population, working with key partner organisations to deliver services that reflect the UHB's values. Our population has varied and diverse needs with some of our communities and population groups requiring additional consideration and support. With this in mind, when developing or reviewing any strategies, policies, plans, procedures or services it will be required that the following issues are explicitly included and addressed from the outset:-

- Equitable access to services
- Service delivery that addresses health inequalities
- Sustainability and how the UHB is meeting the requirements of the Well-being of Future Generations (Wales) Act (2015)¹²

This explicit consideration of the above will apply to strategies (e.g. Shaping Our Future Strategy, Estates Strategy), policies (e.g. catering policies, procurement policies), plans (e.g. Clinical Board operational plans, Diabetes Delivery Plan), procedures (for example Varicella Zoster - chickenpox/shingles - Infection Control Procedure) and services /activity (e.g. developing new clinical services, setting up a weight management service).

Considering and completing the Equality & Health Impact Assessment (EHIA) in parallel with development stages will ensure that all UHB strategies, policies, plans, procedures or services comply with relevant statutory obligations and responsibilities and at the same time takes forward the UHB's Vision, 'a person's chance of leading a healthy life is the same wherever they live and whoever they are'. This process should be proportionate but still provide helpful and robust information to support decision making. Where a more detailed consideration of an issue is required, the EHIA will identify if there is a need for a full impact assessment.

Some key statutory/mandatory requirements that strategies, policies, plans, procedures and services must reflect include:

¹² <http://thewaleswewant.co.uk/about/well-being-future-generations-wales-act-2015>

- All Wales Standards for Communication and Information for People with Sensory Loss (2014)¹³
- Equality Act 2010¹⁴
- Well-being of Future Generations (Wales) Act 2015¹⁵
- Social Services and Well-being (Wales) Act 2015¹⁶
- Health Impact Assessment (non statutory but good practice)¹⁷
- The Human Rights Act 1998¹⁸
- United Nations Convention on the Rights of the Child 1989¹⁹
- United Nations Convention on Rights of Persons with Disabilities 2009²⁰
- United Nations Principles for Older Persons 1991²¹
- Welsh Health Circular (2015) NHS Wales Infrastructure Investment Guidance²²
- Welsh Government Health & Care Standards 2015²³
- Welsh Language (Wales) Measure 2011²⁴

This EHIA allows us to meet the requirements of the above as part of an integrated impact assessment method that brings together Equality Impact Assessment (EQIA) and Health Impact Assessment (HIA). A number of statutory /mandatory requirements will need to be included and failure to comply with these requirements, or demonstrate due regard, can expose the UHB to legal challenge or other forms of reproach. This means showing due regard to the need to:

- eliminate unlawful discrimination, harassment and victimisation;
- advance equality of opportunity between different groups; and
- foster good relations between different groups.

EQIAs assess whether a proposed policy, procedure, service change or plan will affect people differently on the basis of their 'protected characteristics' (i.e. their age, disability, gender reassignment, marriage or civil partnership, pregnancy or maternity, race, religion, sex or sexual orientation) and if it will affect their human rights. It also takes account of caring responsibilities and Welsh Language issues.

¹³ <http://gov.wales/topics/health/publications/health/guidance/standards/?lang=en>

¹⁴ <https://www.gov.uk/guidance/equality-act-2010-guidance>

¹⁵ <http://gov.wales/topics/people-and-communities/people/future-generations-act/?lang=en>

¹⁶ <http://gov.wales/topics/health/socialcare/act/?lang=en>

¹⁷ <http://www.wales.nhs.uk/sites3/page.cfm?orgid=522&pid=63782>

¹⁸ <https://www.equalityhumanrights.com/en/human-rights/human-rights-act>

¹⁹ <http://www.unicef.org.uk/UNICEFs-Work/UN-Convention>

²⁰ <http://www.un.org/disabilities/convention/conventionfull.shtml>

²¹ <http://www.ohchr.org/EN/ProfessionalInterest/Pages/OlderPersons.aspx>

²² <http://www.wales.nhs.uk/sites3/Documents/254/WHC-2015-012%20-%20English%20Version.pdf>

²³ <http://gov.wales/topics/health/publications/health/guidance/care-standards/?lang=en>

²⁴ <http://www.legislation.gov.uk/mwa/2011/1/contents/enacted>

They provide a systematic way of ensuring that legal obligations are met and are a practical means of examining new and existing policies and practices to determine what impact they may have on equality for those affected by the outcomes.

HIAs assess the potential impact of any change or amendment to a policy, service, plan, procedure or programme on the health of the population and on the distribution of those effects within the population, particularly within vulnerable groups. HIAs help identify how people may be affected differently on the basis of where they live and potential impacts on health inequalities and health equity. HIA increases understanding of potential health impacts on those living in the most deprived communities, improves service delivery to ensure that those with the greatest health needs receive a larger proportion of attention and highlights gaps and barriers in services.

The **EHIA** brings together both impact assessments in to a single tool and helps to assess the impact of the strategy, policy, plan, procedure and/or service. Using the EHIA from the outset and during development stages will help identify those most affected by the proposed revisions or changes and inform plans for engagement and co-production. Engaging with those most affected and co-producing any changes or revisions will result in a set of recommendations to mitigate negative, and enhance positive impacts. Throughout the assessment, 'health' is not restricted to medical conditions but includes the wide range of influences on people's well-being including, but not limited to, experience of discrimination, access to transport, education, housing quality and employment.

Throughout the development of the strategy, policy, plan, procedure or service, in addition to the questions in the EHIA, you are required to remember our values of *care, trust, respect, personal responsibility, integrity and kindness* and to take the Human Rights Act 1998 into account. All NHS organisations have a duty to act compatibly with and to respect, protect and fulfil the rights set out in the Human Rights Act. Further detail on the Act is available in Appendix 2.

Completion of the EHIA should be an iterative process and commenced as soon as you begin to develop a strategy, policy, plan, procedure and/or service proposal and used again as the work progresses to keep informing you of those most affected and to inform mitigating actions. It should be led by the individual responsible for the strategy, policy, plan, procedure and/or service and be completed with relevant others or as part of a facilitated session. Some useful tips are included in Appendix 3.

For further information or if you require support to facilitate a session, please contact Susan Toner, Principal Health Promotion Specialist (susan.toner@wales.nh.uk) or Keithley Wilkinson, Equality Manager (Keithley.wilkinson@wales.nhs.uk)

Based on

- Cardiff Council (2013) Statutory Screening Tool Guidance
- NHS Scotland (2011) Health Inequalities Impact Assessment: An approach to fair and effective policy making. Guidance, tools and templates²⁵
- Wales Health Impact Assessment Support Unit (2012) Health Impact Assessment: A Practical Guide²⁶

²⁵ <http://www.healthscotland.com/uploads/documents/5563-HIIA%20-%20An%20approach%20to%20fair%20and%20effective%20policy%20making.pdf> (accessed 4 January 2016)

²⁶ <http://www.wales.nhs.uk/sites3/page.cfm?orgid=522&pid=63782> (accessed on 4 January 2016)

Appendix 2 – The Human Rights Act 1998²⁷

The Act sets out our human rights in a series of 'Articles'. Each Article deals with a different right. These are all taken from the European Convention on Human Rights and are commonly known as 'the Convention Rights':

1. Article 2 Right to life. NHS examples: the protection and promotion of the safety and welfare of patients and staff
2. Article 3 Freedom from torture and inhuman or degrading treatment. NHS examples: issues of dignity and privacy, the protection and promotion of the safety and welfare of patients and staff, the treatment of vulnerable groups or groups that may experience social exclusion, for example, gypsies and travellers, issues of patient restraint and control
3. Article 4 Freedom from slavery and forced labour
4. Article 5 Right to liberty and security. NHS examples: issues of patient choice, control, empowerment and independence, issues of patient restraint and control
5. Article 6 Right to a fair trial
6. Article 7 No punishment without law
7. Article 8 Respect for your private and family life, home and correspondence. NHS examples: issues of dignity and privacy, the protection and promotion of the safety and welfare of patients and staff, the treatment of vulnerable groups or groups that may experience social exclusion, for example, gypsies and travellers, the right of a patient or employee to enjoy their family and/or private life
8. Article 9 Freedom of thought, belief and religion. NHS examples: the protection and promotion of the safety and welfare of patients and staff, the treatment of vulnerable groups or groups that may experience social exclusion, for example, gypsies and travellers
9. Article 10 Freedom of expression. NHS examples: the right to hold and express opinions and to receive and impart information and ideas to others, procedures around whistle-blowing when informing on improper practices of employers where it is a protected disclosure
10. Article 11 Freedom of assembly and association
11. Article 12 Right to marry and start a family
12. Article 14 Protection from discrimination in respect of these rights and freedoms. NHS examples: refusal of medical treatment to an older person

²⁷ <https://www.equalityhumanrights.com/en/human-rights/human-rights-act>

13. solely because of their age, patients presented with health options without the use of an interpreter to meet need, discrimination against UHB staff on the basis of their caring responsibilities at home
14. Protocol 1, Article 1 Right to peaceful enjoyment of your property
15. Protocol 1, Article 2 Right to education
16. Protocol 1, Article 3 Right to participate in free elections
17. Protocol 13, Article 1 Abolition of the death penalty

Appendix 3

Tips

- Be clear about the policy or decision's rationale, objectives, delivery method and stakeholders.
- Work through the Toolkit early in the design and development stages and make use of it as the work progresses to inform you of those most affected and inform mitigating actions
- Allow adequate time to complete the Equality Health Impact Assessment
- Identify what data you already have and what are the gaps.
- Engage with stakeholders and those most affected early. View them as active partners rather than passive recipients of your services.
- Remember to consider the impact of your decisions on your staff as well as the public.
- Record which organisations and protected characteristic groups you engaged with, when you engaged with them and how you did so (for example, workshop, public meeting, written submission).
- Produce a summary table describing the issues affecting each protected group and what the potential mitigations are.
- Report on positive impacts as well as negative ones.
- Remember what the Equality Act says – how can this policy or decision help foster good relations between different groups?
- Do it with other people! Talk to colleagues, bounce ideas, seeks views and opinions.

