

IMPROVING HEALTH IN WALES



Caring for Critically Ill Children

Standards



Llywodraeth Cynulliad Cymru
Welsh Assembly Government

Thanks to Jonathon and his parents for letting us use his photographs

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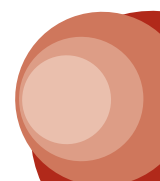
Caring for Critically Ill Children *Standards*

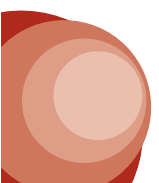


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1. Introduction

1.1 This booklet sets out the Welsh Assembly Government's standards for caring for critically ill children. The standards have been developed by health professionals, in partnership with parents, and have been consulted upon widely. They form part of the Welsh service framework to improve outcomes for critically ill children by ensuring they receive the level of specialist care needed, regardless of where they live.

1.2 These standards are being published ahead of other parts of the service framework so that immediate action can be taken to improve patient care. Standards have been produced for the whole patient pathway, as the quality of care at each stage counts towards achieving the best outcome for the child:

- Receiving a critically ill child
- Paediatric high dependency care and initiating paediatric intensive care
- Paediatric intensive care
- Lead-centre paediatric intensive care
- Retrieval
- Clinical audit and information requirements

1.3 Work is also underway to develop standards for:

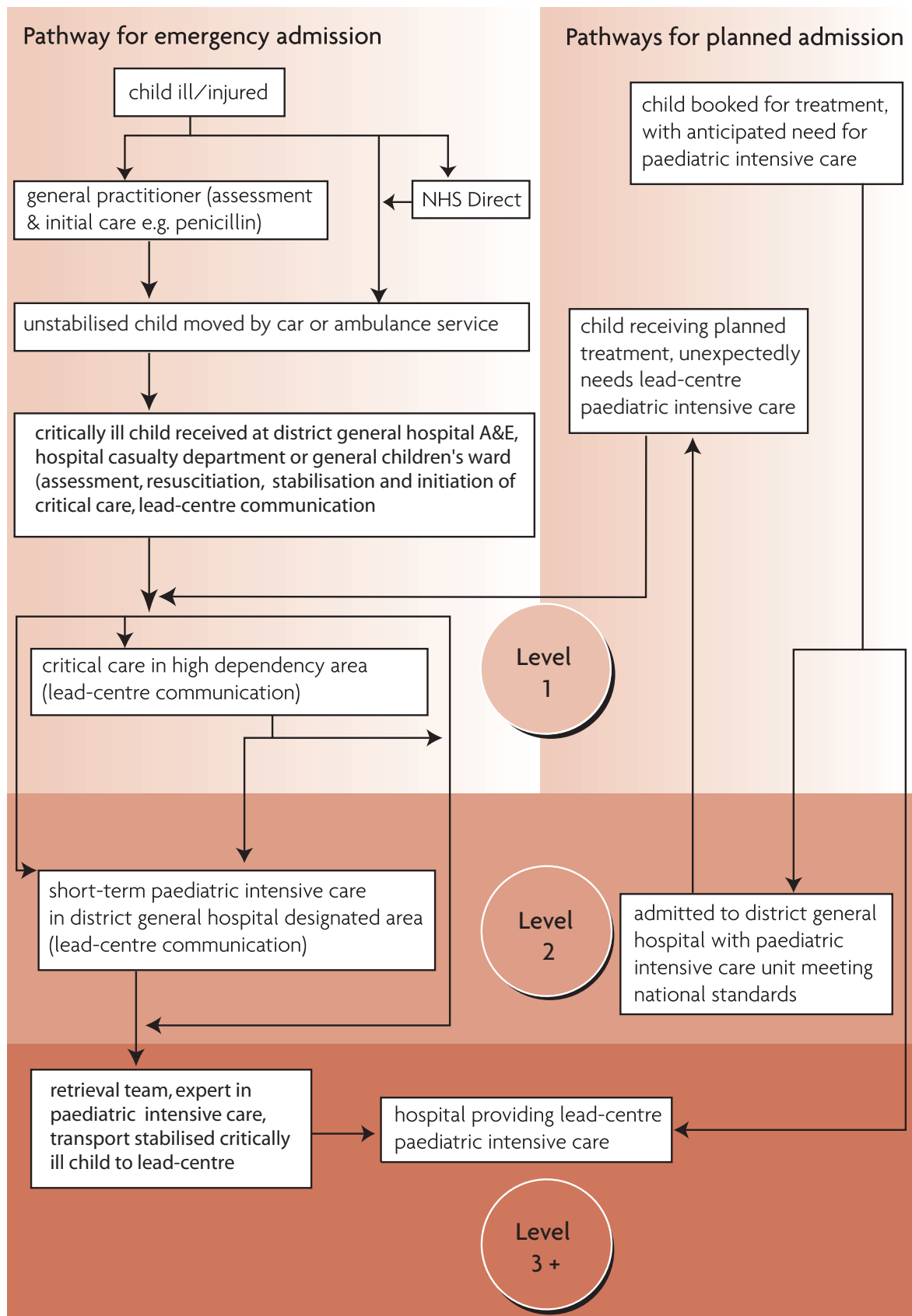
- Critically ill children and young people aged 16-18 years
- Children and young people who need long-term ventilation
- Preparing for the unexpected event of a critically ill child
- Critically ill children with burns
- Critically ill children with complex trauma, which will cover severe head injuries and spinal injuries




1.4 The completed service framework will include:

- the baseline service review, showing how the service in Wales initially measured up against these standards and the areas where changes are required, published by the Specialised Health Services Commission for Wales in 2001 (1); and
- a commissioning framework.

1.5 The pathway diagram overleaf shows that the care of a critically ill child can start at numerous points. Condition-specific clinical protocols are being developed for acute respiratory failure, severe head injury and meningococcal meningitis.

2. General pathways of care for critically ill children and definitions



Dependency level and location	Definition
<div data-bbox="284 304 475 495" style="text-align: center;">  <p>Level 1</p> </div> <p>All hospitals admitting children must be able to provide high dependency care.</p>	<p>Child in need of closer observation and monitoring than is usually required on an ordinary children's ward because of one or more of the following:</p> <ul style="list-style-type: none"> single organ support, excluding respiratory support; step down from ICU; following major surgery; cardiac, neuro, spinal etc; advanced analgesic techniques; non-intubated children with moderately severe croup, bronchiolitis etc.; recently extubated child.
<div data-bbox="284 898 475 1088" style="text-align: center;">  <p>Level 2</p> </div> <p>All hospitals potentially admitting children who are, or who may become, critically ill must be able to initiate paediatric intensive care.</p>	<p>Children requiring continuous nursing supervision because of:</p> <ul style="list-style-type: none"> advanced respiratory support or two or more organ systems requiring support or one acute organ failure receiving support, plus one chronic failure. <p>-----</p> <p>A child meeting level 2 criteria should be treated within a PIC lead-centre, except in a case where it is agreed between the DGH and lead-centre consultants that the child can be cared for safely locally.</p>
<div data-bbox="284 1547 475 1738" style="text-align: center;">  <p>Level 3 and above</p> </div> <p>Lead-centre and specialist units</p>	<p>Children needing intensive care nursing supervision at all times, because of:</p> <ul style="list-style-type: none"> two or more organ systems requiring technological support, including advanced respiratory support as one of these systems, e.g. renal support/ haemofiltration. <p>Extra corporal membrane oxygenation (ECMO) is also provided at three centres in the UK.</p>

The Human Rights Act defines a child as a person below the age of 18, although there needs to be flexibility in practice to meet the needs of individual children. This framework does not cover neonatal intensive care.

3. Background

3.1 This section outlines:

- the three year, £45 million, programme that has accelerated change in England;
- the development of services for critically ill children in Wales, including a new lead-centre serving southern Wales;
- and the opportunity to build on the English experience and develop a pattern of services in response to the needs of critically ill children throughout Wales.

3.2 Paediatric intensive care is a high cost service, for a very small number of children, and is dependent upon scarce specialist skills (2),(3). In February 1999 responsibility for it transferred to the Specialist Health Service Commission for Wales (SHSCW). In June that year, SHSCW was tasked with developing a service framework to improve outcomes for critically ill children in Wales.

3.3 The situation SHSCW inherited was complex and differed from the position in England significantly.

The situation in England

3.4 In the UK the care of critically ill children developed in an ad hoc and fragmented way until about five years ago. During the 1990s evidence began to emerge suggesting that the most critically ill children were least likely to die if treated in a paediatric intensive care tertiary centre (3),(4),(5). Research also showed there were low risks if such children were cared for, during ambulance journeys, by doctors trained in paediatric intensive care (known as "retrieval") (6), (7). Studies into admission rates for PIC showed strikingly similar results, ranging from 0.9 - 1.3 admissions per 1000 children. It was judged that a population of approximately 500,000 children aged 0-16years was needed in order to develop a tertiary centre (or lead-centre) (8),(9). The size of lead centres was also determined by Royal College requirements that medical staff should see a minimum number of children each year in order to maintain skills (10). It was also suggested that larger centres would be better able to maximise the use of highly skilled staff; deploy scarce resources flexibly at times of high demand; and provide an appropriate training environment (8). During this period there was also growing acceptance that children should be cared for by appropriately trained and equipped staff, in specially designated facilities, in a way involving parents (11), (12).

3.5 Professional bodies such as the Intensive Care Society and the then British Paediatric Association voiced concern about the standard of care for critically ill children and campaigned for improvements (13), (14). Following the death of the young patient Nicholas Geldard the Department of Health in England issued "Paediatric Intensive Care: A Framework for the Future" in 1997 with a three year implementation plan, backed by £45 million to accelerate change (8). The document drew together evidence on the ways of achieving the best quality of care and outcomes for critically ill children. In essence, it:

- set standards for all hospitals initiating and providing paediatric intensive care;
- proposed the centralisation of care for the most critically ill children into designated specialist centres in each region and recognised the role of these centres in supporting and advising the network of hospitals they served;
- advanced the development of specialist retrieval services in each region;
- announced more specialist education and training, in particular nurse training;
- initiated the development of detailed clinical protocols for the management of each stage of acute respiratory failure, severe head-injury and meningococcal meningitis/septicaemia, as a way of ensuring consistent care;
- supported the collection of data on the outcomes of critically ill children and the number of children needing, as opposed to receiving intensive care; and
- required an assessment of how many children would need long-term ventilation in each region.

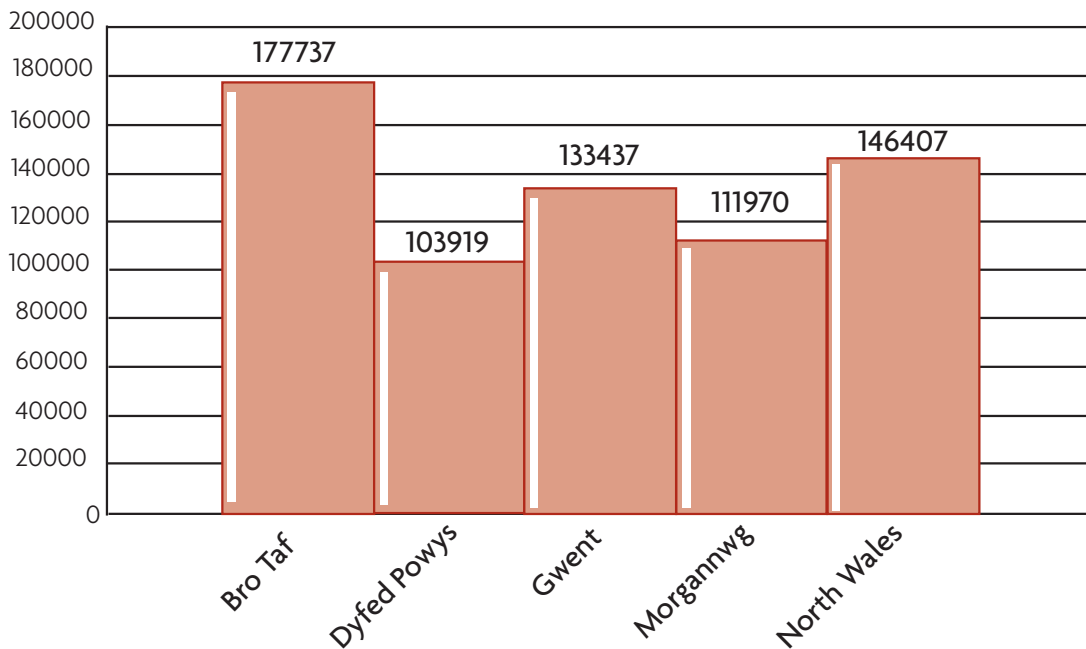
The position in Wales and the need for change

3.6 The geography of Wales is such that it is not possible to have a single paediatric intensive care lead-centre. An information system has been launched which will show where all children with critical illness are cared for in Wales. However, as yet information is incomplete. Children from hospitals in North Wales, and some from Aberystwyth, are referred to the lead-centre at Alder Hey in Liverpool and thus form part of the Northwestern PIC regional network. A small number of children from Powys receive intensive care in Birmingham, and paediatric cardiac surgery patients in southern Wales are transferred to Bristol. A small number of children go to highly specialised centres elsewhere in the UK, such as Great Ormand Street.

3.7 A new lead-centre was opened at the University Hospital of Wales (UHW) in 2000, serving southern Wales. The centre covers a threshold population of over half a million children aged less than 18 years old (15).

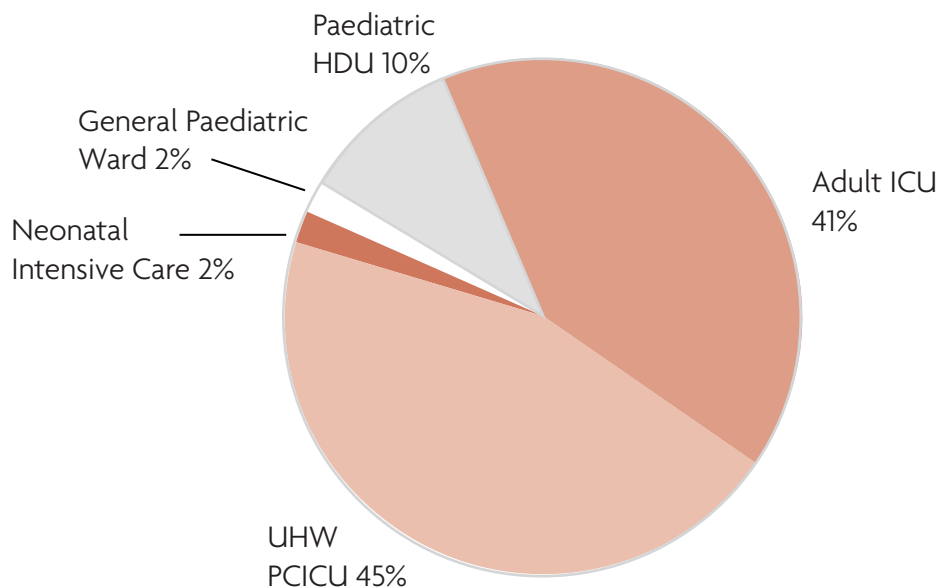
Even though services in Wales are thus divided between north and south, the UHW lead-centre plays an important role in ensuring there are strong links with the north, for example over issues such as training.

Children 0-17 years in Wales (population estimates mid 1999)



3.8 A study of the care of the most critically ill children was presented to the Welsh Intensive Care Society and the Welsh Paediatric Society in 1997 (using 1995/6 data) (16). The study was used to support the argument that a lead-centre should be developed in the south (data for North Wales was incomplete). It was also thought to be an underestimate because it was not possible to visit every hospital to search for children fulfilling entry criteria who had not been managed on an intensive care unit. Nor was it possible to trace all children referred outside the region, unless they were reported to the study. However, the study does provide a fairly recent, and one of the only, pictures of paediatric intensive care in Wales.

Locations in which children received intensive care



3.9 The main findings of the study were that:

- A few children were being referred to lead-centres in England (London, Birmingham and Bristol). However, the majority of those children needing tertiary care went to the UHW Paediatric Cardiac Intensive Care Unit (PCICU), even though 43% did not have a primary cardiological diagnosis.
- The 284 children fulfilling entry criteria for the study were receiving paediatric intensive care in 17 hospitals in West, Mid and South Wales. Locations where the most critically ill children were being treated included neonatal intensive care units, general children's wards, paediatric high dependency units, adult intensive care units, and the UHW PCICU.
- Importantly, the study found a death rate in Wales of 11.3% of all admissions. This compares to a death rate of 7.3% in Trent and 5% in Victoria, Australia (3).
- The majority of PIC admissions occur in the very youngest children (8): 80% of the children were pre-school age; 55% were under 2 years old; and 44% were aged less than a year old (which is consistent with the rest of the UK).

3.10 The 1997 English framework was circulated by the Welsh Office, and was generally well received, although never formally adopted. The Welsh Office asked the NHS in Wales to prioritise paediatric intensive care. In 1998, recognising that the situation was sub-optimal, Chief Executives supported recommendations to develop services in South Wales (17), (18). This was followed by a ministerial commitment to develop a lead-centre at the UHW. A business case was developed in response, but changes to the provision of paediatric cardiac services, meant that the basis of this had to be reassessed. Thus, whilst progress was being made, by June 1999, there was:

- no agreed business case for a Welsh lead-centre and retrieval service;
- no basic information, such as the numbers of critically ill children in Wales and their need for intensive care;
- no way of comparing outcomes for Welsh children with others;
- no commonly agreed standards;
- no specialist training and education available in Wales, with a knock-on effect to recruitment and retention;
- no inter-hospital clinical protocols for managing the most critically ill children;
- and the distribution of specialist services for children, requiring the back up of PIC, was spread over a number of sites, e.g. burns and neurosurgery.

- Whilst medical groups vigorously attempted to raise the standard of paediatric intensive care in Wales there was no multidisciplinary network for sharing good practice and building professional relationships.

3.11 Work is now underway in all these areas co-ordinated by SHSCW. The business case for development of a lead-centre at the University Hospital of Wales was approved in September 1999. At this stage in development the unit does not meet the criteria for approval by the Intercollegiate Committee for Training future consultants in Paediatric Intensive Care Medicine (10). The following has already been achieved:

- a new unit with six staffed beds and a seventh for retrieval;
- the flexibility to open a further two beds in periods of peak demand;
- a 24hour, 7 day a week, consultant delivered retrieval service;
- initiation of the paediatric intensive care network;
- publication of an annual report on activity, referral patterns and outcome;
- and the £1.3 million funding originating from the paediatric cardiac intensive care has been secured, in addition to the £2.019 million identified to support the new development.

3.12 The development of a lead-centre in southern Wales has been a recent achievement and is a major stride along the route to improving services here. However, the investment in paediatric critical care in Wales is not yet comparable with that in England. Building on the experience there, it has been recognised in Wales that the best outcomes for critically ill children will be achieved by developing the quality of the service along the whole pathway of care.

4. Developing evidence-based standards

4.1 This section covers:

- the evidence-base for the standards
- the methodology used
- multidisciplinary participation in their development
- the process for ensuring critical scrutiny of the standards and widespread consultation
- establishing a process for monitoring compliance and keeping the standards under review

4.2 A Steering Board, chaired by Mrs Margret Price, led the work on the service framework, learning from the English approach, but taking account of the circumstances in Wales. Steering Board representatives were nominated from the official advisory committees to the National Assembly for Wales, such as Welsh Medical Committee. The balance of the membership reflected:

- the need to involve closely front-line clinicians, both paediatricians and intensivists;
- a multidisciplinary approach;
- geography;
- the need to work closely with neighbouring English regions;
- and the desire to strengthen the voice of parents and some of the voluntary groups working with them.

4.3 The Steering Board received exceptionally generous help from the clinical directors of neighbouring English lead-centres and the Chair of the Paediatric Intensive Care Society.

Evidence

4.4 The Steering Board reviewed the evidence-base from which these standards are derived in a three-stage process.

- Firstly, a literature search was undertaken and research underpinning the English framework identified. Overviews of the information on need, although limited, and of the research findings, were presented to the first meeting of the Steering Board.
- Secondly, Dr Gale Pearson, Chair of the UK Paediatric Intensive Care Society, and one of the authors of the Trent Victoria study

(a central piece of research relied upon in England and internationally)(3), agreed to present a review of the available evidence and to discuss his findings with clinicians in Wales.

- Thirdly, the Director of SHSCW, Dr Gillian Todd, sought the advice of Dr Jane Ratcliffe, the Chairman of the Intercollegiate Committee for Training in Paediatric Intensive Care Medicine, on the messages from research and the implications for clinical governance. Dr Ratcliffe confirmed that the evidence supported the safety of retrieval and improved outcomes, for the most critically ill children, if cared for in a tertiary centre. All the evidence cited had already been used in the development of the standards in Wales (3), (5), (7). She confirmed that respiratory support, up to 24 hours, may be sustainable outside a lead-centre with the correct protocol and structure in place, including discussion with and advice from the lead-centre. With regard to clinical governance she stated: *"If a life threatening event occurred in a previously well child with one organ system failure which resulted in death or neuro-disability, there would be a very far-reaching investigation involving clinical governance issues. If parents were asked whether they wished their child to be cared for in an ICU which regularly cared for critically ill children or in an ICU which occasionally did so, their response would be predictable and unanimous."*

4.5 Recently, a prospective study of paediatric intensive care for critically ill children has recently been completed in the South West region. The research findings support a model of care in which the most critically ill children are transferred to a tertiary PIC unit. The hazards of transport do not appear to confer added risk in terms of mortality outcome. The study findings also support the care of critically ill children with a low mortality risk locally, including in general intensive care units with appropriate facilities (19).

Methodology for developing the standards

4.6 A small subgroup of clinicians and nursing staff initially drafted the standards (Annexe 3, Contributors). The clinicians involved from across Wales worked together effectively and objectively on this complex task.

4.7 The evidence considered is listed in Annexe 2. Where there was no formal evidence to support a standard, a clinical consensus was established. Careful consideration was given to the evidence used in the English framework and the expert opinion of some leading clinicians in the field. The subgroup included the chairman of the Paediatric Intensive Care Society to ensure harmony with the English approach. This is especially important given that a significant number of children from Wales will continue to receive tertiary care in England. It will facilitate inter-regional communication and comparison, and will ease joint training. Where a standard differing from England was proposed, the variance had to be highlighted, justified, and a consensus achieved.

4.8 An attempt was made to identify *essential* standards, that is, those standards without which the service would be unsafe or would be failing to address the rights of the child. It was also recognised that because of constraints, such as the difficulty in recruiting highly sought after specialists, some short-term compromises would be inevitable. In such instances the commissioning framework should include a target time-scale for achieving compliance. Some standards labelled as "desirable" were included. These are matters, which would not prevent a hospital from providing paediatric intensive care, but would enhance the service.

4.9 Parents and the Association for the Welfare of Children in Hospital were then asked to contribute, and essential standards for all children in hospital were included.

4.10 In all, the package of draft standards was circulated to health authorities, trusts and clinicians three times for critical scrutiny. A workshop of representatives of a wide range of organisations, involved in paediatric intensive care, also scrutinised the standards. Between February and March 2000 the Specialised Health Services Commission for Wales undertook an extensive consultation where the views of all the stakeholders were sought. A small number of amendments were then made to reflect views expressed during the consultation process. Finally, the completed draft documents were circulated by the Welsh Assembly Government in a formal, and final round of consultation, resulting in a few further amendments. Thus the final set of standards include those which are specific to the care of critically ill children and those which apply to all children in hospital. The standards take into account the findings of the Kennedy Report on paediatric cardiac surgery at Bristol Royal Infirmary; the Redfern Report on organ retention at Alder Hey Hospital, Liverpool; and the Carlile review of safeguards for children within NHS Wales.

Review and compliance

4.11 The Paediatric Critical Care Commissioning Advisory Board will keep the standards under review. (Please see next section.) However, it is the strong view of those involved in drawing-up the standards that compliance monitoring should involve a combination of:

- site visits
- reports
- clinical audit
- statistical returns
- and patient/parent views

4.12 The most important measure of the success will be improved outcomes for critically ill children in Wales.

5. Implementation

Expert advisory board for paediatric critical care

5.1 On completion of the main set of draft standards, the Paediatric Intensive Care Steering Board was replaced by the Paediatric Critical Care Commissioning Advisory Board ("the Advisory Board"), which is a subcommittee of the SHSCW Board. The Board advises SHSCW on commissioning paediatric intensive care and oversees the implementation of the standards of care for all critically ill children, within the service framework. It will in the future advise Health Commission Wales (Specialist Services)(HCW(ss)) and Local Health Boards (LHBs) about action to ensure compliance with the standards and upon proposed business cases. An implementation plan, with identified costs and resources, will form part of the service framework.

5.2 The Advisory Board has two permanent subgroups, one on education and training and one on clinical audit. In addition, it will be tasked with ensuring effective communication with stakeholders; addressing the needs of adolescents and the interface with adult critical services; and monitoring safeguards for critically ill children. The Advisory Board will keep the standards under review and will recommend modifications where necessary.

5.3 It is essential that an audit against all these standards is reported to the trust clinical governance committee every six months and to the trust Board on an annual basis. Exception reporting to the Trust Board should occur when patient safety is compromised. A system should be in place for reporting, investigating and learning from adverse incidents.

Clinical audit

5.4 SHSCW is working with clinicians to improve the information routinely collected about critically ill children, and to establish a common approach. The aim is to ensure that the care of all critically ill children is audited from the onset of care, as opposed to arrival in a designated unit. The anonymised information needed by SHSCW and the Welsh Assembly Government will be derived from this data set, to reduce clinicians' form-filling burden. The data set should cover information about:

- numbers of critically ill children;
- illness severity;
- method, type and source of admission;
- case-mix;
- length of stay;
- main therapeutic interventions;
- and the outcome for critically ill children who have been treated in hospital (including morbidity and mortality).

5.5 All units caring for the most critically ill children from Wales must be able to provide information about death-rates adjusted for risk. In partnership with the NHS in England, outcome measures should be developed which reflect quality of life – including morbidity, disability, and functional health of the child after a period of intensive care. Such outcome measures need to take account of the severity of the child's condition prior to paediatric intensive care and retrieval beginning.

5.6 Wales will work with the Department of Health and English National Co-ordinating Group to agree a process for inter-regional comparison. Wales must also ensure that the information it receives from English hospitals about patients from Welsh health authorities matches that required in Wales.

5.7 This approach to paediatric intensive care information should help:

- identify best practice;
- monitor and review outcomes of treatment episodes;
- monitor compliance with national standards;
- reveal the pattern of critical illness;
- monitor need and equality of access;
- and compare the performance of hospitals in Wales with others in the UK.

5.8 Clinicians in Wales have also suggested starting a continuous Confidential Inquiry into paediatric deaths, as a way of bringing to light unmet need or areas where clinical practice needs to be improved.

Education and training

5.9 It is recognised that education and training are of crucial importance in achieving the standards for the care of critically ill children. A subcommittee of the Advisory Board will develop a multidisciplinary education and training implementation strategy spanning the whole pathway of care covering:

- need (including basic and post-basic qualifications and training)
- maintenance of skills
- education and training capacity
- access
- the "messages" for education and training from research and clinical audit
- evaluation
- recruitment and retention of staff with specialist skills

Clinical network and communication

5.10 Led by the University Hospital of Wales, the multidisciplinary clinical network for critically ill children will also play a key role in sharing best practice and developing a unified service operating to a uniform standard of care. Each DGH will have a designated clinician representing them in the network. These individuals will play a crucial role in ensuring there is effective communication within the network.

5.11 The key elements of the clinical network will be

Managed clinical network for the care of critically ill children

- Designated lead-clinician for network
- Designated lead staff at local level
- Agreed standards
- Shared approach to clinical audit
- Joint education and training
- Agreed clinical protocols
- Identified funding and clear commissioning arrangements
- Links with supra regional network
- Agreed approach to monitoring compliance
- Management resource

Action already taken

5.12 A service review was undertaken in 2000, to show how Wales initially measured up against these standards and the action required to ensure compliance (1). Steps to improve the care of critically ill children have been taken in advance of the publication of these standards including:

- New lead-centre commissioned in Cardiff, with retrieval service, formally opened on 11th March 2001
- Independent clinical audit shows the new unit is achieving outcomes which compare well with the best in the UK (The crude mortality rate in 1999-2001 was 5.4% and the standardised mortality ratio was 0.43)
- A lead consultant for paediatric critical care has been identified in each District General Hospital in Wales
- Paediatric Critical Care Commissioning Advisory Board established

- Education and training programme underway to improve paediatric airway skills in each trust in Wales and to increase the number of Registered Sick Children's Nurses caring for critically ill children
- Regional training and practice educator nurse appointed
- Clinical Audit group established
- Clinical audit feedback sessions held in each DGH in South Wales and clinical audit information for the four main lead-centres serving Wales reported (including risk adjusted mortality outcomes)
- Paediatric Critical Care Clinical Audit form approved by the Assembly's Information Requirements and Standards Subcommittee, piloted and launched
- Regional clinical audit co-ordinator appointed
- Working with Department of Health to establish a clinical database to compare the performance of lead-centres
- Participation in UK project to develop risk adjusted morbidity outcome indicators
- Reciprocal arrangements agreed with Bristol for retrieval
- Investment in transport ventilators for children under 10kg in each DGH in Wales, to equip hospitals for the rare event of retrieval being inappropriate/unavailable
- Routine reporting system for all critical incidents in South Wales lead-centre established and arrangements initiated for North Wales
- Draft standards for long term ventilation agreed and audit completed
- Interim arrangements agreed for the care of critically ill children with burns in Wales, including testing the use of Telemedicine, is a "first" for the UK.

6. Standards

6.1 This section sets out the standards for:

- A) receiving a critically ill child
- B) paediatric high dependency care and initiating paediatric intensive care
- C) paediatric intensive care
- D) lead-centre paediatric intensive care
- E) retrieval
- F) clinical audit and information requirements
- G) relevant essential standards for all children in hospital

6.2 Standards have been developed within the following categories:

- critical mass
- support for children, parents, and siblings
- staffing
- access on site to other specialities
- equipment and facilities
- communication
- responsibilities of the lead-centre
- education and training
- quality and management of services
- audit
- commissioning

6.3 A successful outcome for the critically ill child depends upon the quality of care received from the first contact with the health service. Thus, there should be a seamless system of care from the onset and diagnosis of the critical illness, to the outcome. Critical care for children must be provided within a managed clinical network offering a collaborative approach based upon common standards, protocols, shared training, and effective communication. It is essential that there is equity of access throughout Wales to the different levels of critical care for children.

6.4 Some of the standards listed in this section, which were accepted during widespread consultation, will be the responsibility of local health boards to implement, and should be reflected in local plans. SHSCW and its successor HCW(ss) is responsible for commissioning paediatric intensive care and through the Paediatric Critical Care Commissioning Advisory Board, oversees the implementation of the service framework for the care of critically ill children. The PCCS Advisory Board includes representation from each DGH in Wales, the ambulance trust, professions allied to medicine and parents. Two permanent subgroups have been formed. One deals with education and training, the other is the All-Wales Paediatric Critical Care Clinical Audit Group, which has an independent chairman, who is a clinician experienced in caring for critically ill children.

6.5 The arrangements for monitoring compliance with these standards are set out in section 5 of this document. An initial service review has been carried out to see how Wales measures up against these standards, which was published in 2001 (1). An implementation plan will be published. Progress in achieving the implementation plan will be reported publicly, together with any changes needed.

6.6 With regard to the standards below, it is assumed that arrangements are in place for staff cover in times of annual leave and sickness. The standards apply to all NHS funded care.

Please see care pathways and definitions on pages 4 and 5.

A) Receiving a critically ill child

Standard A1

1a). It is *essential* that all hospitals, with on site in-patient medical paediatric facilities, are able to:

- receive, assess, resuscitate, stabilise the child and immediately refer to the high dependency care or paediatric intensive care team on site;
- or have the ability to initiate and maintain paediatric intensive care until the retrieval team arrives.

1b). It is essential that all other hospitals (including those with minor injury departments) receive only children with minor clinical conditions and have in place a protocol for use in the unexpected event of a critically ill child, or potentially critically ill child presenting.

Standard A2: environment and support for children, parents and siblings

It is *essential* that all accident and emergency departments and minor injury departments:

- comply with the published guidance for A&E departments in relation to children (this is also desirable for minor injury units);

- have a child and family focused environment with separation (out of sight and sound) from adult patients;
- give parental access to the child at all times, except when this is not in the interests of the child (written child protection procedures must be in place);
- ensure parents have access to support services, including bereavement support e.g. social workers, chaplains, translation and counsellors;
- up-date the parents regularly on the child's condition, care plan and if relevant, retrieval.
- In the case of retrieval, immediate family members must be given all possible help, and arrangements made for transport by ambulance or taxi. The name of the admitting hospital/ward and directions should be given to parents arranging their own transport.

Please see also section on general standards for children.

Standard A3: medical staffing

In accident and emergency departments it is:

- *essential* that there is 24 hour, on-site, cover by medical staff and always a doctor on duty with APLS/PALS or approved equivalent resuscitation training
- desirable that there is a consultant with recognised training in paediatric A & E responsible for protocols, assessment, and management of the critically ill child.

Standard A4: access/provision of advice between lead-centre and referring hospital

It is *essential* that all hospitals in the catchment area of a lead-centre have:

- access to advice from the local paediatric medical inpatient unit and the lead-centre;
- an agreed protocol in place for accessing advice 24 hours a day. The protocol must be discussed, agreed and regularly reviewed by all the hospitals in the catchment area including the lead-centre.

Standard A5: nurse staffing

It is *essential* that accident and emergency departments have:

5a. a senior nurse on part 8 or 15 of the register responsible for ensuring that the care of children is appropriate and undertaken in the correct environment. This nurse must ensure there is ongoing education and training for the nurses in A&E in APLS/PALS/PLS or equivalent paediatric resuscitation skills and good liaison arrangements in place with hospital and community based nurses caring for children.

- 5b. at least one registered nurse on duty with APLS/PALS or equivalent paediatric resuscitation skills.

Standard A6: equipment and facilities

It is *essential* that accident and emergency departments ensure:

- there is a separately designated and equipped area for resuscitation and stabilisation of critically ill children of all ages;
- children are looked after in a designated critical care area whilst awaiting retrieval, which is known to the retrieval team;
- access to appropriate support services;
- there are facilities for parents and siblings, including a quiet room.

Standard A7: quality and management of services

It is *essential* that accident and emergency departments have:

- a system within the hospital alerting staff to the arrival of a critically ill child;
- protocols in place (covering resuscitation, stabilisation, transfer, admission, discharge, care of parents and treatment of all major conditions) for use in the department. These need to be developed in conjunction with local consultant paediatricians, the lead centre and other appropriate specialities.
- There must be a critical incident reporting system in place and a clinical audit system.

B) Paediatric high dependency care and initiating paediatric intensive care

Standard B1

It is *essential* that all hospitals potentially admitting children who are, or who may become, critically ill as a result of their treatment, surgery, dental surgery, or disease process are able to provide:

- resuscitation;
- paediatric high dependency care; and
- paediatric intensive care prior to retrieval or transfer.

Standard B2: medical staffing

It is *essential* that on the hospital site there is for the care of critically ill children:

- a designated lead-consultant;
- a lead consultant for anaesthetics and paediatrics, one of whom is the designated hospital lead;

- 24 hour consultant paediatric cover;
- 24 hour consultant anaesthetic cover;
- 24-hour resident cover by doctors with PALS/APLS or equivalent resuscitation training.

Standard B3: access on site to other paediatric sub specialities and services

It is *essential* that the same hospital site has:

- a general medical paediatric inpatient unit;
- paediatric dieticians, physiotherapists, speech therapists and pharmacists;
- a general intensive care unit;
- 24-hour availability of biochemistry, haematology, microbiology and radiology services.

It is also *desirable* that there is

- a neonatal unit where babies are ventilated.

Standard B4: nurse staffing

It is *essential* that for the provision of paediatric high dependency care and initiation of paediatric intensive care there is:

- a senior nurse on part 8 or 15 of the register and an ENB 415/160 or equivalent with 24 hour responsibility;
- care provided by registered children's nurses and at least one nurse per shift with APLS/PALS or approved equivalent resuscitation skills;
- a nurse staffing ratio of
 - 0.5 to 1 per child or
 - 1 per child if in a cubicle.

Standard B5: equipment and facilities

It is *essential* that the hospital has:

- an ability to provide high dependency care, which may be in a designated HDU facility or side-room/s that can be appropriately equipped, which includes the provision of facilities for parents;
- an area for resuscitation and stabilisation of critically ill children of differing ages within (or with easy access to) the HDU, out of sight of the rest of the children in the HDU;
- a designated critical care area suitable for the care of the child awaiting retrieval, which is known to the retrieval team.

Standard B6: environment and support for children, parents and siblings

It is *essential* that the hospital and HDU provides:

- a child-friendly environment, including toys and play specialists;
- a multidisciplinary approach to care;
- sufficient and appropriate information to enable children to share decisions about their care;
- parental access to the child 24 hours per day, except when this is not in the best interests of the child (written child protection procedures must be in place, and implemented at ward level);
- information, encouragement and support for parents to enable them to fully participate with staff in the care of their child;
- access to support services, including bereavement support e.g. social workers, chaplains, translation and counsellors;
- up-to-date information available to the parents on the child's condition and care plan.

In the case of retrieval, immediate family members must be given all possible help, and arrangements made for transport by ambulance or taxi. The name of the admitting hospital/ward and directions should be given to parents arranging their own transport.

A child meeting level 2 criteria should be treated within a PIC lead-centre. However, prior to retrieval, or where the DGH and lead-centre consultants agree that a level 2 child can be cared for safely locally, a child may be treated in a general intensive care unit. The care of such children must comply with the standards in this document and the recommendations of the Carlile Review and the Kennedy Report.

Standard B7: access to and provision of advice between lead-centre and referring hospital

It is *essential* that there is 24 hour access to medical and nursing lead-centre advice for the consultant staff and the senior nursing staff involved in the care of the critically ill child.

Standard B8: education and training

8a) It is *essential* that a multidisciplinary training plan is agreed by each hospital for their own staff, addressing the needs of each discipline, so ensuring:

- access to PALS/APLS/PLS or approved equivalent resuscitation training;
- ongoing professional training for all groups involved in the care of critically-ill children, including maintenance of skills;
- access to RN 15, RSCN 8 and ENB 415/160 or equivalent courses for high dependency care;
- provision of a hospital based basic life support training programme.

8b) On an all-Wales basis it is *essential* that:

- a training plan is agreed for all staff involved in the provision of critical care to children;

- there is a training plan to ensure the ongoing provision of appropriately trained specialist staff in the future;
- there is a plan to ensure access to APLS/PALS/PLS or equivalent resuscitation courses and ENB 415/160 or equivalent for high dependency care.

Standard B9: quality and management of services

It is *essential* that the hospital:

- develops and uses protocols (including for resuscitation, stabilisation, transfer, admission, discharge and treatment of all major conditions) within the framework agreed by the Paediatric Critical Care Advisory Board;
- has a programme of clinical audit in place within the framework agreed by the Advisory Board;
- has a critical incident reporting system.

C) Paediatric intensive care

Standard C1

It is *essential* that all hospitals providing paediatric intensive care, excluding those that just initiate paediatric intensive care prior to retrieval:

- are designated to do so;
- and can demonstrate compliance with these standards.

Standard C2: critical mass/workload

The following thresholds are indicative of the throughput such hospitals require in order to maintain skills. Intensive care should be provided for:

- 50 ventilated children a year, with a median of 2 days length of stay in a functionally separate critical care area;
- 500 adults requiring intensive care.

The skills of the staff should be shared to ensure staff involved are kept up to date and that the service is appropriate and cost effective.

Standard C3: medical staffing

It is *essential* that the hospital has:

- a lead consultant with 2 years approved training in paediatric intensive care working on the paediatric intensive care unit, with one session in the lead-centre (lead-centre consultants should have designated sessions for training those within the network of paediatric intensive care units within the catchment area);

- 24 hour cover, on the same site, from named consultants with APLS/PALS or equivalent resuscitation training (future consultants should be appointed with at least 1 years approved training);
- 24 hour dedicated resident cover for the unit from doctors who are approved as having the appropriate skills (PALS/APLS or equivalent resuscitation);
- each child under the care of an on site consultant paediatrician;
- each child assessed by a consultant intensivist and a consultant paediatrician within 1 hour of admission, and jointly with any other appropriate consultant within 4 hours.

Standard C4: access on site to other paediatric sub specialities and services

4a. It is a *essential* that on the same site there is:

- a medical paediatric inpatient unit;
- a general intensive care unit;
- paediatric anaesthetists;
- a comprehensive 24-hour paediatric radiology service;
- paediatric physiotherapy, dietetics, speech therapy and pharmacy;
- 24-hour pathology support.

4b. If the following are not on site, it is *essential* that protocols are in place for 24-hour access to support and/or advice from:

- paediatric renal service support;
- a consultant paediatric neurology service;
- paediatric cardiology support;
- paediatric general surgery support.

Standard C5: nurse staffing

5a. It is *essential* that the paediatric intensive care unit has:

- 24-hour cover by a senior nurse on part 8 or 15 of the register and who is educated in paediatric intensive Care ENB 415/160 or equivalent;
- a ratio of 1 registered nurse to each child or higher;

5b. It is *essential* that children on the paediatric intensive care unit are looked after by:

- a minimum of 70% of staff on part 8 or 15 of the register and at least 50% with ENB 415/160 or equivalent;
- nurses with APLS/PALS or approved equivalent for resuscitation.

Standard C6: equipment and facilities

It is *essential* that the paediatric intensive care unit provides:

- a designated intensive care facility for children, equipped for children of differing ages;
- facilities and accommodation for parents;
- access to support services.

Standard C7: multidisciplinary team

It is *essential* that the paediatric intensive care unit has a multidisciplinary approach to care involving:

- medical staff;
- paediatric nursing staff;
- psychologists;
- play specialists;
- paediatric physiotherapists;
- paediatric pharmacists;
- paediatric clinical psychologists;
- paediatric dieticians;
- paediatric occupational therapists;
- paediatric speech therapists;
- social worker;
- chaplain;
- general paediatric staff;
- and other appropriate staff, including health visitors.

Standard C8: environment and support for children, parents and siblings

It is *essential* the paediatric intensive care unit provides:

- a child-friendly environment, including toys and play specialists;
- a multidisciplinary approach to care;
- sufficient and appropriate information to enable children to share decisions about care;
- parental access to the child 24-hours per day, except when this is not in the best interests of the child (written child protection procedures must be in place and implemented at ward level);
- information, encouragement and support for parents to enable them to fully participate with staff in the care of their child;

- access to support services, including bereavement support e.g. social workers, chaplains, translation and counsellors;
- up to date information available to the parents on the child's condition and care plan.
- In the case of retrieval, immediate family members must be given all possible help, and arrangements made for transport by ambulance or taxi. The name of the admitting hospital/ward and directions should be given to parents arranging their own transport.
- There should be written guidelines covering organ donation.

Standard C9: access to and provision of advice by lead-centre

It is *essential* that the consultant and nursing staff involved in the care of the child have:

- 24 hour availability of medical and nursing advice from lead-centre

Standard C10: education and training

10a) It is *essential* that there is a multidisciplinary training plan for the paediatric intensive care unit, agreed in conjunction with the lead-centre for the network, addressing the needs of each discipline, ensuring:

- access to PALS/APLS or approved equivalent resuscitation training;
- ongoing professional training for all groups involved in the care of critically-ill children, including maintenance of skills;
- access to RN 15, RSCN 8 and ENB 415/160 or equivalent courses;

10b) On an all-Wales basis it is *essential* that there is a multidisciplinary training plan to:

- ensure the ongoing provision of appropriately trained specialist staff;
- ensure access to APLS/PALS or equivalent resuscitation courses and ENB 415/160 or equivalent.

Standard C11: quality and management of services

It is *essential* that the paediatric intensive care unit:

- develops protocols (including resuscitation, stabilisation, transfer, admission, discharge and treatment of all major conditions) within the framework agreed by the PCCS Advisory Board and jointly with the lead centre;
- has a programme of audit and research in place in partnership with the lead centre and within the framework agreed;
- has a critical incident reporting system in place.

D) Lead centre paediatric intensive care

Standard D1

It is *essential* that all hospitals providing lead-centre paediatric intensive care conform to these standards to ensure that comparative audit is possible.

Standard D2: critical mass/workload

It is *essential* that all lead centres providing care for the children of Wales must:

- treat 500 children per year, of whom 250 must be intubated/ ventilated children;
- have 8 beds;
- be able to respond to fluctuating demands for paediatric intensive care.

Standard D3: medical staffing

It is *essential* that PIC lead centres have:

- a lead consultant with approved training in paediatric intensive care of 2 years;
- 5-7 consultant staff trained in paediatric intensive care and all with identified sessional commitments to paediatric intensive care and the on-call rota (core training may be in paediatrics, paediatric surgery or anaesthesia);
- a designated deputy to the lead consultant;
- 24 hour cover by consultants with no other commitments while on the duty rota;
- 24 hour cover from dedicated resident doctors with no other commitments who are approved as being appropriately trained to work on the unit;
- each child under the care of a consultant paediatrician, recognising that some children will also be under the care of consultants in another speciality;
- each child attended by a consultant intensivist within one hour of admission and by any other appropriate consultant within 4 hours.

Standard D4: responsibilities of the lead-centre

It is *essential* that the lead centre:

- provides a 24 hour fully equipped and resourced retrieval service;
- provides 24 hour access to and provision of advice to all hospitals in the catchment area of the unit;
- establishes a multidisciplinary clinical network of staff from hospitals within the catchment area within the agreed framework;

- ensures that regular meetings are held with the DGH paediatric critical care professionals who work in hospitals in the catchment area of the lead centre to discuss issues of communication, the updating of guidelines, training and to ensure that the whole of the service to critically ill children is regularly reviewed and audited;
- and publishes an annual report including all aspects of the work of the clinical network.

Standard D5: access on site to other paediatric sub specialities and services

- 5a. It is *essential* that the same hospital site as the lead-centre has:
- an inpatient medical paediatric unit;
 - consultant paediatric anaesthetists;
 - consultants in the paediatric tertiary specialities of paediatric nephrology, paediatric surgery, paediatric cardiology, paediatric neurology and neurosurgery, ENT and/or maxillofacial surgery, paediatric endocrinology and paediatric radiology;
 - access to consultants in orthopaedic surgery;
 - 24 hour access to paediatric physiotherapy and pharmacy;
 - 24 hour access to microbiology, biochemical and haematological facilities;
 - and 24 hour access to all routine radiological and imaging facilities.
- 5b. There is a need to have access to advice from:
- consultants in the paediatric subspecialties of immunology, hepatology, cardiac surgery, transplant surgery, ECMO and plastic surgery;
 - a paediatric nutrition care team, including a paediatric gastroenterologist
 - occupational therapy and speech therapy (for the assessment, management, training and advice in relation to swallowing, feeding and communication difficulties).

Standard D6: nurse staffing

It is *essential* that the lead-centre paediatric intensive care unit has:

- a clinical nurse manager, H or I grade, on part 8 or 15 of the register, with ENB 415/160 or equivalent. (This key nurse must provide the focus for the development of a joint approach to nursing staffing and education for the whole paediatric critical care network.);
- an establishment of 6.4 WTE nurses per bed, as a minimum 70% must be on part 8 or 15 of the register, and 50% must have ENB 415/160 or equivalent; care for each child must be provided by registered children's nurses;

- a dependency related staffing ratio of 1 registered nurse to 1 child or higher;
- access to and mutual support from nurses with adult and neonatal intensive care skills;
- a programme of on-going education and training, including children's nursing and access to Part 8 or 15 of the register;
- and appropriately trained nursing staff to staff the retrieval team.

Standard D7: environment and support for children, parents and siblings

It is *essential* that the lead-centre paediatric intensive care unit provides:

- a child-friendly environment, including toys and play specialists;
- a multidisciplinary approach to care;
- sufficient and appropriate information to enable children to share decisions about their care;
- parental access to the child 24 hours per day, except when this is not in the best interests of the child (written child protection procedures must be in place and implemented at ward level);
- information, encouragement and support for parents to enable them to fully participate with staff in the care of their child;
- access to support services, including bereavement support e.g. social workers, chaplains, translation and counsellors;
- and regular and up to date information to the parents on the child's condition and care plan.
- In the case of retrieval, immediate family members must be given all possible help and arrangements made for transport by ambulance or taxi. The name of the admitting hospital/ward and directions should be given to parents arranging their own transport.
- There should be written guidelines covering the issue of organ donation.

Standard D8: equipment and facilities

It is *essential* that the lead-centre for paediatric intensive care provides:

- a separately designated and equipped unit for the entire paediatric age group and for a retrieval service;
- equipment continuously available through a programme of appropriate service, maintenance and storage;
- training for all staff in the PICU for use of equipment;
- appropriate facilities for parents;
- a quiet room for interviewing and bereavement counselling;
- The lead-centre must comply with the general published children's standards.

Standard D9: multidisciplinary team

It is *essential* that the lead-centre has an established 24 hour multidisciplinary approach to care from staff trained to work with children involving:

- medical staff;
- nursing staff;
- paediatric clinical psychologists;
- paediatric physiotherapists;
- paediatric occupational therapists;
- paediatric speech therapists;
- paediatric dieticians;
- paediatric pharmacists;
- community children's nurses;
- play specialists;
- social workers;
- chaplains;
- and any other appropriate staff including liaison with health visitors, medical physics and ICU technicians.

Standard D10: designated HDU facility

It is *essential* the hospital with the lead centre PICU has an associated HDU meeting the standards of care for those children not requiring intensive care.

Standard D11: quality and management of services

It is *essential* that the lead-centre paediatric intensive care unit develops:

- evidence based protocols including resuscitation, stabilisation, transfer, admission, discharge and treatment of all major conditions within the agreed framework;
- clear management policies covering all aspects of activity;
- protocols in collaboration with the whole network, including those to assist training and peer support;
- protocols for drug therapy, medication, drug doses, respiratory therapy, sedation regimes and organ donation;
- clear guidelines for daily investigations, practical procedures and policies for infection control and health and safety at work.

Standard D12: education and training

It is *essential* that the lead-centre paediatric intensive care unit has a multidisciplinary education and training plan addressing the needs of each discipline including:

- junior doctor training;
- APLS/PALS or equivalent resuscitation courses;
- the ongoing supply of appropriately trained nursing, medical and other professional staff;
- the lead-centre role in the provision of training within the paediatric critical care network.
- At an all-Wales level there should be planning to secure specialist skills.

Level 4

Arrangements must be agreed and in place for retrieval of children requiring ECMO (extracorporeal membrane oxygenation). Centres providing ECMO must have, in addition to the facilities described above:

- the support of cardiothoracic perfusionists, cardiothoracic surgeons and paediatric cardiologists;
- a robust retrieval system;
- a 2:1 or even greater nurse to patient ratio.

E) Retrieval of the most critically ill children

Standard E1

It is *essential* that:

- the lead-centre retrieval team retrieves children within the agreed catchment population, who need transfer to the paediatric intensive care lead-centre;
- the lead-centre team retrieves children with conditions not treated at the local lead-centre, when paediatric intensive care is required;
- there is an agreed protocol in place, for use when the local lead-centre cannot retrieve for whatever reason;
- and there is an agreed protocol in place for the transfer of children requiring specialised intensive care not available in the local lead-centre.

Standard E2 availability

It is *essential* that the lead-centre:

- retrieval service is 24-hour, 7 days a week;
- retrieval service is available on at least 95% of days (with an agreed back up plan in place for those occasions it is not available);
- plans and agrees arrangements with referring hospitals covering what happens when the local lead-centre is full and the retrieval team cannot function (including partnership arrangements with neighbouring lead-centres);
- retrieval service ensures equity of access.
- It is essential that the appropriate local consultant takes the decision as to whether a child needs to be transferred, in consultation with a lead-centre consultant.
- There must be agreement of the transport standards to be applicable when the child's condition is such that it is inappropriate to wait for the retrieval team, such as a child with burns.

Standard E3: medical staffing

It is *essential* that the lead-centre:

- service is consultant-led and whenever appropriate consultant provided;
- PIC consultants are responsible for deciding which medical staff are appropriately trained and experienced to carry out retrieval.
- The decision on the level of medical input to the retrieval team will be made after discussion between the lead centre and referring DGH consultants and must always include doctors who have skills to intubate and ventilate children electively, as well as in an emergency situation.

Standards for the retrieval of children with burns, head injury or intracranial bleeding is the subject of more detailed work.

Standard E4: nurse staffing

It is *essential* that:

- the staffing ratios at the lead-centre should be such to allow 24-hour availability of registered nurses educated to perform paediatric retrieval.

Standard E5: environment and support for children, parents and siblings

It is *essential* that hospitals where the child is initially resuscitated and stabilised, in conjunction with lead-centre, ensure:

- parents are given information about the retrieval process as early as possible;

- immediate family members are given all possible help and arrangements are made for transport by ambulance or taxi. The name of the admitting hospital/ward and directions should be given to parents arranging their own transport.
- Wherever possible the child should undergo one retrieval journey only.

Standard E6: equipment and facilities

It is *essential* that the retrieval team:

- is able to retrieve from a designated area within each referring hospital, which should be agreed with the retrieval consultant;
- and is fully equipped to deal with children of different ages.

Standard E7: quality and management of services

It is *essential* that the lead-centre and referring hospital:

- develop compatible protocols;
- and ensure arrangements are in place locally and at the lead-centre, so there is clarity about how the retrieval team can be contacted.

It is *essential* that the lead-centre:

- provides adequate information to users;
- includes the retrieval service in reporting and clinical audit processes;
- and ensures the critical incident reporting system covers the retrieval service.

F) Clinical audit and information requirements

Standard F1

It is *essential* that all hospitals admitting children (under 18 years old) resident in Wales collect data on the admission of all critically-ill children to:

- a holding area prior to retrieval;
- paediatric high dependency care;
- an adult intensive care unit;
- an adult intensive care unit prior to retrieval or transfer;
- a paediatric intensive care unit;
- a paediatric intensive care lead centre.

Standard F2: data collection

It is *essential* that each trust identifies a named individual, in each hospital, who is responsible to the Clinical Governance Lead for the comprehensive capture of information on all critically ill children admitted. The responsible person will:

- ensure the use of the attached agreed form, approved by the Assembly's Information Requirements Standards Subcommittee (Annexe 1);
- produce an annual audit report for the trust on the care of critically-ill children;
- be a member of the all Wales Audit Group for the care of critically-ill children;
- submit the validated data to the all Wales Group for analysis as individualised, but anonymised, data.

Standard F3: hospital audit group

It is *essential* that all hospitals admitting critically ill children (including those hospitals in England that regularly provide care to Welsh children):

- set up a clinical audit group or use an existing audit group, to consider the audit report produced by the lead clinician and to recommend improvements within the trust;
- ensure that appropriate information about each child is made available to the Paediatric Critical Care Advisory Board by the lead clinician on a monthly basis;
- include in their audit report information on all children refused admission to a HDU or ITU (including the reasons, what happened to them, and where they were ventilated), as well as sending it to the all-Wales Paediatric Critical Care Audit Group on a monthly basis.
- The retrieval teams retrieving children who are Welsh residents are also required to complete an audit form and the data should be part of the lead centres' audit reports.
- All parents of children discharged from intensive care should have appropriate written information and be issued with a parent-held record or equivalent, in order to ensure appropriate follow up, continuing care and rehabilitation.

It is essential that:

- An audit against all these standards is reported to the trust clinical governance committee every six months and to the Trust Board on an annual basis.
- Exception reporting to the Trust Board occurs when patient safety is compromised.
- A system should be in place for reporting, investigating and learning from adverse incidents.

Standard F4: All Wales PIC Clinical Audit Group

It is *essential* that the Paediatric Critical Care Clinical Audit Group:

- ensures that the critically ill children of Wales receive a high quality audited service;
- produces an annual audit report for Wales, identifying any issues requiring action by commissioners and/or trusts.
- SHSCW and its successor HCW(ss) will support the audit group's work in aggregating the data for Wales and by ensuring that it is comparable with other UK regions. Such comparisons are essential for effective clinical governance.

Standard F5: equipment, staffing and facilities

It is *essential* that trusts report to SHSCW and its successor HCW(ss) each year on the service provided to critically ill children, including details of the progress they have made in achieving the agreed standards of care for critically ill children. This includes those hospitals in England providing care to children normally resident in Wales.

Standard F6: commissioning

It is *essential* that SHSCW and its successor HCW(ss):

- Commissions paediatric intensive care within the agreed standards and service framework for critically ill children;
- Implements a monitoring framework for the care of all critically ill children;
- Establishes the Advisory Board for the care of critically ill children with a clinical audit sub committee which will be independently chaired;
- is informed of all untoward incidents.
- The audit group must ensure that SHSCW and its successor HCW(ss) is aware of the findings of paediatric critical care clinical audit.

Standards for children in hospital

6.7 The care of all children in hospital must comply with the law and published guidance on the provision of health services for children. (Unless stated otherwise, all the standards listed are **requirements**.) The term 'children' applies to all children and young people under 18 years of age and 'parents' includes any person having care of the child at the time.

6.8 Most importantly hospital care should reflect the needs of children of different ages and should be provided in partnership with parents and other agencies involved with the child. *The Human Rights Act 1998*, the *UN Convention on the Rights of the Child*, and the six principles highlighted in "*The Health of Children in Wales*"(20), (21), (12) have guided the development of these standards. This section is not intended as a comprehensive list but as a "sign-post" to the relevant standards (bearing in mind that the majority of children in PIC units are unconscious babies and toddlers).

6.9 The Paediatric Critical Care Advisory Commissioning Board has been tasked with monitoring safeguards for critically ill children and will take account of the recommendations of the Carlile Review of Safeguards for children in the NHS in Wales, the Kennedy Report and other guidance.

Children's rights include:

- Best interests of the child being of paramount importance
- Right to life
- Prohibition of degrading treatment
- Respect of family and private life
- Protection from abuse
- Protection from discrimination
- Freedom of expression
- Help based upon need

The six guiding principles in "The Health of Children in Wales"

- Appropriate hospitalisation
- Easy access to hospital
- A child centred service
- A family centred service
- A high standard of care
- Well-managed discharge

6.10 Recent guidance on safeguards states that a child under the age of 16 should not be placed on an adult ward except in major extenuating circumstances. This guidance makes clear that there are specific circumstances when it is appropriate to care for a critically ill child on an adult ward, for example in an adult intensive care unit whilst awaiting retrieval. However, the care of such children must comply with the standards in this document and the recommendations of the Carlile and Kennedy Reports. Specifically Kennedy states: "Children should always (save in exceptional circumstances, such as emergencies) be cared for in a paediatric environment and always by healthcare professionals who hold a recognised qualification in caring for children. This is especially so in relation to paediatric intensive care." Carlile emphasises the importance of applying standards for children and young people to children who, in exceptional circumstances, are cared for on adult wards and stresses that such patients should be transferred to a children's ward as soon as possible (11) (21) (22) (23).

6.11 Guidance stresses the importance of addressing the special needs of adolescents both as a group and as individuals. The young person's circumstances should be taken into account when deciding whether care on a PIC or adult intensive care unit is appropriate.

6.12 The framework for the assessment of children in need and their families provides a systematic basis for collecting and analysing information to support professional judgements about how to help children and families in the best interests of the child. Practitioners should use the framework to gain an understanding of the child's developmental needs; the capacity of caregivers to respond appropriately to these needs and to keep the child safe from harm; the impact of wider family and environmental factors on the parents and child.

The provision of appropriate services need not and should not, wait until the end of the assessment process, but should be determined according to what is required and when, to promote the welfare and safety of the child.

6.13 The importance of making child protection an integral part of critical care and links to clinical governance, are stressed. This is because it is recognised that some of the children requiring intensive care will have been the victims of abuse. Also the PIC environment presents the opportunity for "Allitt-like" harm of children by staff or visitors which must be guarded against. Children may also be harmed, inadvertently if those caring for them are not up-to-date, appropriately trained or are ill equipped. The standards in this service framework are designed to reduce the risk of harm.

6.14 The standards in this section also touch upon what should be in place to ensure that children are discharged appropriately and successfully (back home, to their local hospital or to some other form of continuing care). The importance of support for those requiring long term care and for those who face the death of a child is dealt with in greater detail in the booklet on long term ventilation.

6.15 The caring responsibility of parents with disabled children is over and above those of normal parenting. The needs of carers of disabled children are likely to vary during their child's development. Key periods of stress are likely to occur at times of change. Parent carers are likely to spend the longest time caring and the cumulative effects of caring on emotional physical health must be considered. The likely impact on the whole family in particular on siblings, of disabled children should be considered. The assessment process should consider the needs of carers and direct them to appropriate services.

Standard 1: the interests of the child

It is *essential* that all those providing NHS services to children ensure that:

- in all actions concerning children the interest of the child is paramount;
- the interests of children of all abilities, from all groups and socio-economic and cultural backgrounds, are valued equally;
- each child is treated as a whole and not simply for the condition needing treatment or care;
- children and their parents should receive information about their rights, complaints procedures, helplines and advocacy services in a form and language they can understand;
- a paediatrician with the lead role for providing the service and a lead-nurse for the care of children is identified within each unit;
- provision is made for children's play and educational needs, as appropriate;
- and interpretation services are provided when required.

Standard 2: children are different

It is *essential* that all those providing NHS services to children ensure that:

- staffing, facilities and equipment are appropriate to the needs of children and separate from those provided for adults;
- children under 16 are not treated on adult wards, except in extenuating circumstances (written guidelines must be in place and implemented) and the needs of adolescents are recognised;
- all staff are trained to work with children and are familiar with their emotional and development needs;
- each child is cared for under the supervision of a paediatrician.

Standard 3: the child's right to be heard

It is *essential* that all those providing NHS services to children ensure that:

- the consent of the parent/guardian is wherever possible, obtained to treat children under 16 years old. Where a child has sufficient understanding and intelligence to give or withhold consent a note should be made of the factors taken into account.
- Children should receive information appropriate to their age, understanding, communication ability and language and play an appropriate role in decisions about their care. "Play" techniques may be helpful. When the child is unable to communicate verbally, augmentative/alternative forms of communication should be made available if appropriate.
- Children have a right to have their privacy and dignity respected.

Standard 4: the importance of the family

It is *essential* that all those providing NHS services to children ensure that:

- parents have access to their child unless exceptionally this is not in the interests of the child (guidelines for these circumstances must be in place and implemented);
- parents are able to stay with their child and help care for them, in the location where the child is treated (there should be adequate facilities- including overnight accommodation, encouragement and support);
- visiting arrangements allow contact with other family members, such as siblings;
- all professionals are trained in the skills necessary to work in partnerships with parents, including the ability to counsel effectively;
- there is compliance with national guidance on the issue of organ removal and retention/disposal (during surgical procedures or at post-mortem);
- all those with parental responsibility should be fully informed and involved in making decisions about the care and treatment of their child;
- the views of parents and children should influence the planning of services;

- families should have easy access to children's hospital facilities without needing to travel significantly further than to other similar amenities;
- there is support for the family on the death of a child;
- parents are given the opportunity to be present at resuscitation of the child.

Standard 5: protecting children from harm

It is *essential* that all those providing NHS services to children ensure that:

- staff are trained in their duty to protect children and are familiar with signs and symptoms of abuse and local child protection procedures; all staff with substantial or unsupervised access to children should be police-checked;
- policies and procedures, consistent with "Working Together" and local Area Child Protection procedures are in place and implemented where abuse or neglect is suspected;
- the service is managed with the aim of reducing risks for children (a comprehensive approach complying with all the standards in this service framework is needed, spanning the safe selection, training and management of staff; multidisciplinary care; health and safety; the involvement of patients and families; clinical audit and effective planning, management and monitoring);
- procedures should be in place for investigating and reporting complaints and untoward incidents;
- health commissioners and providers should be aware of what is considered best practice and have access to sources of information and advice on effective health care;

Standard 6: continuity of care and working with others

It is *essential* that all those providing NHS services to children ensure that:

- the need for partnership between the child, parents, health, education, social services and other agencies is recognised;
- the local authority, where the child is normally resident is notified if the child is/maybe accommodated in hospital for twelve weeks consecutively;
- in particular arrangements are in place to co-ordinate care for children with multiple needs such as those with learning disabilities or mental health problems;
- when "stepped-down" from paediatric intensive care, older teenagers are admitted to "teen" units if available;
- the continuing health care needs of children who have received paediatric intensive care are recognised and discharge (including between hospital departments, inter-hospital and into the community) is carefully planned.

7. The consultation process and conclusion

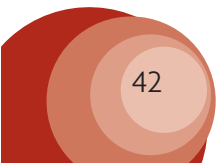
7.1 The standards in this document have been the subject of extensive consultation including:

- clinicians in the fields of paediatric intensive care, paediatrics, anaesthetics, burns and accident and emergency;
- Welsh Medical Committee;
- Royal College of Paediatrics and Child Health;
- Welsh National Board for Nursing, Midwifery and Health Visiting;
- Royal College of Nursing;
- Advisory Sub-Committee in Paediatric and Child Health;
- Welsh Intensive Care Society;
- Paediatric Intensive Care Society (UK);
- clinical nurse leaders in intensive care;
- officials at the Welsh Assembly Government;
- neighbouring English lead-centres;
- representatives of professions allied to medicine (including All Wales Committee for Speech and Language Therapy Managers, Chartered Society of Physiotherapy);
- the ambulance service;
- parents;
- Association for the Welfare of Children in Hospital;
- health authorities and trusts.

Conclusion

7.2 In order to improve the outcomes and quality of care for critically ill children in Wales, common standards must be implemented along the whole pathway of care that at least match those for children in England. There must be equity of access and equity of care for children across Wales. Within paediatric critical care a collaborative approach based on effective communication, is essential for a successful service.

7.3 Whilst much has already been done in Wales, further work is necessary. Future developments should take place within the framework agreed by providers, commissioners and the Assembly. As part of the service framework an implementation plan for achieving the standards will be published. The recommendations in this paper are intended to secure improvements in the way Wales cares for some of its most vulnerable children.



Annexe 1

All Wales Audit of Critically Ill Children

To be completed by all departments (other than intensive care units) caring for critically ill children

Attach addressograph here

Code

All Wales Audit of Critically Ill Children

A1

To be completed by all departments (other than intensive care units) caring for critically ill children

Hospital
Ward
Code
Date of birth

Instruction for use:

Please:

- use a new form in each ward/unit to which the child is admitted/transferred. NB the form does not follow the child;
- use 24 hour clock and dd/mm/yy format when answering time and date question
- answer all questions;
- do not file with medical or nursing notes

Sex **Male** **Female**

Initial diagnosis	
Date and time of admission to ward	
Date and time of initiation of high dependency care	

Source of admission: Home Ward PICU
to your department: G.P. P/HDU NICU
(Please tick appropriate box) A+E ITU Theatre Other
If other, please specify
Was the child transferred from another hospital? Yes No
If yes, name of hospital

Has a critical incident form been completed within your trust whilst the child was in your care? Yes No

Did your department contact a PICU lead centre? Yes No
Date and time of first contact
Was admission to/ retrieval by PICU refused? Yes No
If yes reason for refusal
If more than one refusal please use sheet E1
Was the child retrieved by PICU lead centre team? Yes No
Was the child transferred by the DGH team? Yes No
Date and time of acceptance of retrieval/transfer
Date and time of arrival of retrieval team
Date and time of discharge/transfer
Discharge destination
Ward Hospital
Home Yes No Other
Status on discharge: Alive Died
Was discharge/transfer delayed? Yes No
Reason for delay in discharge/transfer
Diagnosis on discharge




All Wales Audit of Critically Ill Children

A2

To be completed by all departments (other than intensive care units) caring for critically ill children

Please identify with a tick the diagnostic and/or interventional criteria that matches the child

CNS			
Bacterial meningitis			
Central nervous system depression sufficient to compromise the protective airways reflexes/respiratory drive or potential to progress			
Glasgow coma score 8 to 12			
Prolonged (e.g. over 1 hour) or recurrent convulsions			
CVS			
Arrhythmia which fails to respond to first line therapy			
Cardiac arrhythmia which has responded to first line therapy (other than cardioversion)			
Post cardiac surgery			
The need for intravenous infusion of vasoactive drugs to support cardiac output or control BP			
Resp			
Any airway intervention			
Asthma on IV bronchodilators or hourly nebulisers			
Cardiopulmonary resuscitation			
FiO2 > 40% via facemask, headbox, nasal cannulae or CPAP for bronchiolitis			
Long term tracheostomy (or dependent long term non-invasive ventilation)			
Mechanical ventilation or assisted respiration (other than during recovery from anaesthetic)			
Nebulised adrenaline for upper airway obstruction after 2 doses or more			
Patients recently extubated following prolonged ventilation			
Post op patient with multiple chest drains requiring hourly fluid replacement			
Recurrent apnoeas, upper airway obstruction, possibility of progressive deterioration to the point of needing ventilation.			
Renal			
Acute renal failure (urine output <1ml/kg/hour for 12 hours)			
Other			
After/during sedation for procedure			
Circulatory instability due to hypovolaemia other than meningococcal disease			
Continuous intravenous drug infusion			
Diabetic ketoacidosis with drowsiness			
Intravenous fluid resuscitation >10ml/kg & <30ml/kg			
Meningococcal septicaemia (stable state)			
Patient receiving multiple drug therapy (e.g. complex chemotherapy)			
Poisoning/substance misuse with potential for significant problems			
Pre or post-operative patients with complex fluid management, analgesia, bleeding, complex surgery (Booked or emergency)			
Patient with pain which is difficult to control			
If none of above, please specify:			
Specialist Care Code (Please tick appropriate box)			
Nurosurgical care	<input type="checkbox"/>	Renal care	<input type="checkbox"/>
Burns/Plastic surgery	<input type="checkbox"/>	Cardiac Care	<input type="checkbox"/>
Spinal Care	<input type="checkbox"/>	Oncology	<input type="checkbox"/>
Other (please specify)	<input type="text"/>		

Dependency level and location	Definition
<p data-bbox="284 344 480 533">  </p> <p data-bbox="236 629 564 786">All hospitals admitting children must be able to provide high dependency care.</p>	<p data-bbox="612 271 1305 383">Child in need of closer observation and monitoring than is usually required on an ordinary children's ward because of one or more of the following:</p> <p data-bbox="612 416 1273 450">single organ support, excluding respiratory support;</p> <p data-bbox="612 483 884 517">step down from ICU;</p> <p data-bbox="612 551 1251 584">following major surgery: cardiac, neuro, spinal etc;</p> <p data-bbox="612 618 1011 651">advanced analgesic techniques;</p> <p data-bbox="612 685 1310 741">non-intubated children with moderately severe croup, bronchiolitis etc.;</p> <p data-bbox="612 775 932 808">recently extubated child.</p>
<p data-bbox="284 882 480 1070">  </p> <p data-bbox="236 1133 564 1368">All hospitals potentially admitting children who are, or who may become, critically ill must be able to initiate paediatric intensive care.</p>	<p data-bbox="612 831 1246 909">Children requiring continuous nursing supervision because of:</p> <p data-bbox="612 931 991 965">advanced respiratory support</p> <p data-bbox="708 999 740 1032">or</p> <p data-bbox="612 1055 1193 1088">two or more organ systems requiring support</p> <p data-bbox="708 1122 740 1155">or</p> <p data-bbox="612 1178 1267 1256">one acute organ failure receiving support, plus one chronic failure</p> <p data-bbox="612 1279 1326 1435">----- A child meeting level 2 criteria should be treated within a PIC lead-centre, except in a case where it is agreed between the DGH and lead-centre consultants that the child can be cared for safely locally.</p>
<p data-bbox="284 1525 480 1713">  </p> <p data-bbox="236 1805 448 1883">Lead-centre and specialist units</p>	<p data-bbox="612 1469 1305 1547">Children needing intensive care nursing supervision at all times, because of:</p> <p data-bbox="612 1581 1273 1659">Two or more organ systems requiring technological support,</p> <p data-bbox="612 1693 1321 1771">including advanced respiratory support as one of these systems</p> <p data-bbox="612 1805 1070 1839">e.g. renal support/ haemofiltration.</p> <p data-bbox="612 1906 1299 1984">Extra corporal membrane oxygenation (ECMO) is also provided at three centres in the UK.</p>

The Human Rights Act defines a child as a person below the age of 18, although there needs to be flexibility in practice to meet the needs of individual children. This framework does not cover neonatal intensive care.

All Wales Audit of Critically Ill Children Intensive Care

Attach addressograph here

Code

All Wales Audit of Critically Ill Children Intensive Care	C1
--	-----------

Hospital		
Ward		
Code		
Date of birth		
Sex	Male <input type="checkbox"/>	Female <input type="checkbox"/>

Initial diagnosis	
--------------------------	--

Date + time of admission to P/ICU
--

<p>How to use this form</p> <p>Please:</p> <ul style="list-style-type: none"> - use a new form for each ward/unit to which the child is admitted/transferred. NB the form does NOT follow the child - answer all questions - use 24 hour clock and dd/mm/yy format when answering time and date questions - do not file with medical or nursing notes <p>Please return both sections of the completed form (following the discharge of the child) to local audit link nurse - tel: -</p> <p>For further information or advice please contact: Ian Langfield, Clinical audit Co-ordinator, SHSCW, Hensol Castle, Pontyclun, CF72 8YS.</p> <p>Tel: 01656 753400 Mob 07773 343180</p>

Source of admission:	Home <input type="checkbox"/>	Ward <input type="checkbox"/>	PICU <input type="checkbox"/>
	G.P. <input type="checkbox"/>	P/HDU <input type="checkbox"/>	NICU <input type="checkbox"/>
	A+E <input type="checkbox"/>	ITU <input type="checkbox"/>	Theatre <input type="checkbox"/>
	Retrieval	Transfer by referring hospital <input type="checkbox"/>	
Origin of retrieval/transfer:	Hospital	<input style="width: 100%;" type="text"/>	
	Ward	<input style="width: 100%;" type="text"/>	

Has a critical incident form been completed within your trust whilst the child was in your care? Yes No

All Wales Audit of Critically Ill Children Intensive Care

C2

Was the child ventilated during P/ICU stay? Yes No

If yes, enter number hours of ventilation?

Did the child receive inotropes during P/ICU stay? Yes No

Did the child receive renal support during P/ICU stay? Yes No
e.g. CVVH or PD

Date and time of discharge from P/ICU

Was discharge delayed? Yes No

Reason for delay in discharge

Diagnosis on discharge

Status on discharge Alive Died

Discharge destination

PICU Ward (other hospital)

HDC/U (this hospital) Home

HDC/U (other hospital) Other

Was the child transferred to another hospital? Yes No

If yes, name of hospital

Was the child retrieved by another/specialist PICU team? Yes No

If yes, reason for retrieval

If yes, name of PICU retrieval team

if yes, date and time retrieval accepted

Date and time of arrival of retrieval team

Did your department contact a PICU lead centre? Yes No

Date and time of first contact

Was admission to/retrieval by PICU refused? Yes No

If yes reason for refusal

If more than one refusal please use sheet E1

All Wales Audit of Critically Ill Children Intensive Care

D1

This section should be completed for each P/ICU admission. Enter the observations at the first face to face contact between patient and doctor. Use the first variable measured within the period from shortly before the first contact to one hour after the arrival in the ICU. Do not leave blanks. Use X for any missing data.

Reason for admission

Diagnosis

Booked admission Yes No

PIM WEIGHTING	
1. Cardiac arrest outside hospital	8. Hypoplastic left heart syndrome
2. Cardiac arrest in hospital	9. HIV
3. Severe combined immunodeficiency	10. Inborn error of metabolism
4. Leukaemia/Lymphoma before/after induction	11. Muscular dystrophy
5. Malignancy after first induction	12. Severe developmental delay (IQ<35)
6. Cerebral haemorrhage (aneurysm AVM)	13. Neurodegenerative disorder
7. Cardiomyopathy	99. Chronic impairment of one or more organ systems
<p>If there is one of the underlying conditions described above, then record the appropriate number in the box below.</p> <p>If there is more than one present select from (1,3,5,6,7,8,9,12,13) first as these score as premorbid categories</p>	

↓

PIM Weighting	
----------------------	--

↓

Response of pupils to bright light (>3mm and both fixed = 1, other = 0, unknown = 0) As pupil responses are used as an index of brain function, do NOT record an abnormal finding if this is caused by drugs or a local eye injury. Response to bright light refers to the speed rather than the magnitude of response	
Base excess in arterial or capillary blood mmol/L -/+	
Pa O2 (state units)	
FiO2 at time of PaO2 sample (via ETT or headbox)	
Systolic blood pressure (mmHg)	
Intubated at any time?	
(yes = 1, no = 0)	
Ventilated at any time in first hour?	
(yes = 1, no = 0)	

All Wales Audit of Critically Ill Children Intensive Care		D2
Hospital		
Ward		
Code		
Date of birth		

Instructions for use:




At 1200 midday and 0000 midnight enter the child's level of critical care in the matrix below
The table overleaf describes the three levels of care for critically ill children.
If you are unsure about which criteria the child meets, please discuss with the local audit link nurse on ext _____, or the Clinical Audit Co-ordinator (please see below).
Once the child has been discharged, please return form C and D to the local audit link nurse.
Thank you for completing this audit form.

Please identify the highest level of care for each day of admission

	DAY	NIGHT		DAY	NIGHT		DAY	NIGHT		DAY	NIGHT
Day 1			Day 11			Day 21			Day 31		
Day 2			Day 12			Day 22			Day 32		
Day 3			Day 13			Day 23			Day 33		
Day 4			Day 14			Day 24			Day 34		
Day 5			Day 15			Day 25			Day 35		
Day 6			Day 16			Day 26			Day 36		
Day 7			Day 17			Day 27			Day 37		
Day 8			Day 18			Day 28			Day 38		
Day 9			Day 19			Day 29			Day 39		
Day 10			Day 20			Day 30			Day 40		

Ian Langfield, Clinical Audit Co-ordinator
SHSCW, The Stables
Hensol Castle
Pontyclun
CF72 8YS Tel: 01656 753400 Mobile 07773 343180

Email ian.langfield@shsc.wales.nhs.uk

Dependency level and location	Definition
<p data-bbox="359 342 552 533">  </p> <p data-bbox="309 622 639 786">All hospitals admitting children must be able to provide high dependency care.</p>	<p data-bbox="687 264 1382 387">Child in need of closer observation and monitoring than is usually required on an ordinary children's ward because of one or more of the following:</p> <p data-bbox="687 412 1350 510">single organ support, excluding respiratory support; step down from ICU;</p> <p data-bbox="687 535 1329 571">following major surgery: cardiac, neuro, spinal etc;</p> <p data-bbox="687 595 1090 631">advanced analgesic techniques;</p> <p data-bbox="687 656 1385 734">non-intubated children with moderately severe croup, bronchiolitis etc.;</p> <p data-bbox="687 759 1008 795">recently extubated child.</p>
<p data-bbox="359 882 552 1072">  </p> <p data-bbox="309 1126 639 1373">All hospitals potentially admitting children who are, or who may become, critically ill must be able to initiate paediatric intensive care.</p>	<p data-bbox="687 824 1323 902">Children requiring continuous nursing supervision because of:</p> <p data-bbox="687 927 1067 963">advanced respiratory support</p> <p data-bbox="786 987 815 1023">or</p> <p data-bbox="687 1048 1272 1084">two or more organ systems requiring support</p> <p data-bbox="786 1108 815 1144">or</p> <p data-bbox="687 1169 1342 1247">one acute organ failure receiving support, plus one chronic failure</p> <p data-bbox="687 1272 1406 1440"> <hr style="border-top: 1px dashed #c00; width: 100px; margin: 0 auto;"/> A child meeting level 2 criteria should be treated within a PIC lead-centre, except in a case where it is agreed between the DGH and lead-centre consultants that the child can be cared for safely locally. </p>
<p data-bbox="359 1525 552 1715">  </p> <p data-bbox="309 1800 520 1879">Lead-centre and specialist units</p>	<p data-bbox="687 1464 1378 1543">Children needing intensive care nursing supervision at all times, because of:</p> <p data-bbox="687 1579 1347 1657">Two or more organ systems requiring technological support,</p> <p data-bbox="687 1693 1398 1771">including advanced respiratory support as one of these systems</p> <p data-bbox="687 1807 1145 1843">e.g. renal support/ haemofiltration.</p> <p data-bbox="687 1890 1374 1968">Extra corporal membrane oxygenation (ECMO) is also provided at three centres in the UK.</p>

The Human Rights Act defines a child as a person below the age of 18, although there needs to be flexibility in practice to meet the needs of individual children. This framework does not cover neonatal intensive care.

All Wales Audit of Critically Ill Children Refused Admissions/Retrievals

(continuation sheet)

E1

Hospital

Ward

Code

Date of birth

Sex Male Female

Instructions for use:

Please:

- use this form if there is more than one refusal of admission/retrieval
- once completed, return form to audit link nurse - Tel:

Thank you for completing this form

1	Name of unit approached	<input style="width: 95%;" type="text"/>
	Admission refused	Yes <input type="checkbox"/> No <input type="checkbox"/>
	Retrieval refused	Yes <input type="checkbox"/> No <input type="checkbox"/>
	Reason for refused admission/retrieval	<input style="width: 95%; height: 40px;" type="text"/>

2	Name of unit approached	<input style="width: 95%;" type="text"/>
	Admission refused	Yes <input type="checkbox"/> No <input type="checkbox"/>
	Retrieval refused	Yes <input type="checkbox"/> No <input type="checkbox"/>
	Reason for refused admission/retrieval	<input style="width: 95%; height: 40px;" type="text"/>

3	Name of unit approached	<input style="width: 95%;" type="text"/>
	Admission refused	Yes <input type="checkbox"/> No <input type="checkbox"/>
	Retrieval refused	Yes <input type="checkbox"/> No <input type="checkbox"/>
	Reason for refused admission/retrieval	<input style="width: 95%; height: 40px;" type="text"/>

4	Name of unit approached	<input style="width: 95%;" type="text"/>
	Admission refused	Yes <input type="checkbox"/> No <input type="checkbox"/>
	Retrieval refused	Yes <input type="checkbox"/> No <input type="checkbox"/>
	Reason for refused admission/retrieval	<input style="width: 95%; height: 40px;" type="text"/>

Annexe 2

References

1. The Specialised Health Services Commission for Wales "Caring for critically ill children: service review 2000" December 2001
2. MM Pollack et al "Impact of quality of care factors on paediatric intensive care unit mortality" JAMA 1994; 272.
3. Pearson G, Shann F et al "Should Paediatric Intensive Care be Centralised?- Trent versus Victoria"; The Lancet, Vol. 349, 1997
4. MM Pollock et al "Improved Outcomes from Tertiary Centre Paediatric Intensive Care, a State-wide Comparison" Critical Care Medicine 1991
5. RBJ Gemke et al "Comparative assessment of Paediatric Intensive Care: A National Multi-Centre Study"(PICASSO). Critical Care Medicine 1995; 23
6. A J Mac Nab "Optimal Escort for Inter-hospital Transport of Paediatric Emergencies" Journal of Trauma 1991; 31
7. Edge WE, Kanter RK, Weigle CG, Walsh RF "Reduction of Morbidity in Inter-hospital Transport by Specialised Paediatric Staff" Critical Care Medicine 1992
8. Department of Health (NHSE) "Paediatric Intensive Care: A Framework for the Future" July 1997.
9. E Milne, P Whitty "Calculation of the Need for Paediatric Intensive Care Beds" Archives of Disease in Childhood, 1995
10. The Royal College of Anaesthetists "The Intercollegiate Committee for Training in Paediatric Intensive Care Medicine." February, 2000
11. Welsh Office, "Welfare of Children and Young People in Hospital" 1991, WHC (91)97
12. Welsh Office "The Health of Children in Wales" 1997
13. British Paediatric Association, "The Care of Critically Ill Children", 1993
14. Paediatric Intensive Care Society, "Standards for Paediatric Intensive Care", 1996
15. Office of National Statistics *Mid year population estimates 1999*
16. Gajraj M, Shortland GJ, Smithies MS "A Regional Survey of the Requirement for the Care of Critically Ill Children" (unpublished)
17. Report from the Directors of Public Health Medicine in Wales "Paediatric Critical Care Provision" January 1997
18. South and Mid Wales PIC Policy Group "Paediatric Intensive Care – A Networked Service"
19. Warne S, Garland L, Bailey L, Edees S, Weir P, Henderson J "The Critically Ill Children Study". A Prospective Study of the Provision and Outcome of Paediatric Intensive Care in the South West." Glasper A, Ireland L (Eds) "Evidence Based Child Health Care; Challenges for Practice." Basingstoke, Macmillan 2000
20. "Human Rights Act" HSC (2000) 029
21. United Nations Organisation, "The UN Convention on the Rights of the Child" 1992. (CM1976) HMSO Welsh Office,
22. "A Review of Safeguards and Standards of Care" Hospital Advisory Service WHC (99)2 [The Secretary of State's letter contains action for all hospitals admitting children.]
- 23 "The Carlile Review: Too Serious a Thing" the National Assembly for Wales, March 2002

24 The Bristol Royal Infirmary Inquiry. *Report of the Public Inquiry into Children's Heart Surgery at the Bristol Royal Infirmary 1984-95*. Stationery Office: Norwich: 2001

Sources: general children's standards

Other references

Welsh Office, "Services for Children and Young People in Wales;" Patients Charter 1996, Central Office of Information

Children Act 1989, HMSO

"Carers and Disabled Children Act 2000. Guidance to Act" National Assembly for Wales, 2000

"Caring about Carers' - Carers Strategy in Wales - Implementation Plan"

National Assembly for Wales, 2000

"Practitioner guide to carers' assessment" National Assembly for Wales, 2001

"Moving Forward Listening to Children and Young People" National Assembly for Wales, 2001

"Children and Young People a framework for Partnership" National Assembly for Wales, 2001

Department of Health, "The Children Act 1989 –an Introductory Guide"

Welsh Office, "NHS Responsibilities for Meeting Continuing Health Care Needs" WHC (95) 7

Welsh Office, "Policy and Good Practice Advice on Hospital Discharge" and "The Hospital Discharge Workbook." 1996.

Welsh Office, "Working Together under the Children Act 1989" HMSO

Welsh Office, "Child Protection Clarification of Arrangements between the NHS and other Agencies" WHC (95)59

DHSS, "Child Protection; Medical Responsibilities" Addendum to Working Together

DHSS, "Child Protection: Guidance for Senior Nurses, Health Visitors and Midwives" Addendum to Working Together

The National Assembly for Wales "Working Together to Safeguard Children" September 2000

Audit Commission "Children First: A Study of Hospital Services" 1997

Clothier "The Allitt Inquiry" HMSO 1994 and subsequent guidance DGM(94)26

Welsh Office, "Protection of Children: Disclosure of Criminal Background of those with Access to Children." 1993 WO (54)

Welsh Office "Children's Safeguards: Choosing with Care" WHC(99) 38

Welsh Office, "People Like Us" WHC (97) 61

Welsh Office, "Reporting Untoward Incidents" DGM(98)30

Welsh Office, "A Guide to Consent for Examination and Treatment" 1993

Welsh Office, "Guidance on the Protection and Use of Information" DGM (96) 43

Action for Sick Children- the National Association for the Welfare of Children in Hospital "Emergency Health Services for Children and Young People" 1997

Welsh Office, "Disability Discrimination Act" DGM (96) 174

NHS Executive, "Working in Partnership to Implement Section 21 of the Disability Discrimination Act 1995 Across the National Health Service" M Freeny, R Cook, B Hale, and Dr S Duckworth. King Sturge and Co February, 1999

Welsh Office "Complaints: listening, acting and improving. Guidance on the implementation of the NHS complaints procedure." 1996.

Other sources

Colin Way, "Parental Stress in Paediatric Intensive Care." British Journal of Nursing (Vol. 2). 1993

Michael Farrell, "Support for Parents of Critically Ill Children." Paediatric Nursing, May 1994, Volume 6, No4, 16-18

Jane Noyes "The Impact of Knowing that your Child is Critically Ill; a Qualitative Study of Mothers" Journal of Advanced Nursing 1999 29(2)

Ann H Johnson "Death in PICU: Caring for the "Other" Families". Journal of Paediatric Nursing, 1997 vol. 12

Intensive Care Society "Standards for Intensive Care Units" 1997

Department of Health (NHSE) "A Bridge to the Future" Report of the Chief Nursing Officer's Taskforce. 1997

Paul Buss letter to the Lancet, July 5, 1997

Effective Health Care "Hospital Volume and Health Care Outcomes, Costs and Patient Access" Volume 2, Number 8, December 1996

NHS Centre for Reviews and Dissemination (CRD) "Which Way Forward for the Care of Critically Ill Children" CRD Report 1, University of York, January 1995

Royal College of Paediatrics and Child Health "Accident and Emergency Services for Children" June, 1999

The Royal College of Surgeons "Children's Surgery – A First Class Service", May 2000

Kendall L "A Comparison of Adult and Paediatric Intensive Care" Physiotherapy 73 (9) 49 1987

Annexe 3

Contributors

Paediatric Intensive Care	Standards Subgroup	Representing
Dr Gillian Todd	Director	SHSCW
Dr Helen Fardy	Consultant Paediatric Intensivist	PICU lead-centre, Southern Wales
Dr Gale Pearson	Consultant Paediatric Intensivist,	Chairman, Paediatric Intensive Care Society
Dr John Dunne	Consultant in Anaesthesia and Paediatric Intensive Care University Hospital of Wales	Welsh Advisory Subcommittee on Anaesthetics
Dr Gwyneth Owen (by correspondence)	Consultant Paediatrician	Welsh Advisory Subcommittee on Paediatrics and Child Health
Ms Alison Oliver	Paediatric Intensive Care Sister	PICU lead-centre, Southern Wales
Dr Craig Jerwood	Consultant in Anaesthesia and Intensive Care	Welsh Advisory Subcommittee on Anaesthetics
Dr Rupert Evans	Consultant in Accident and Emergency, University Hospital of Wales	A+E Consultants
Dr Paul Buss (information standards)	Consultant Paediatrician, Royal Gwent Hospital	Welsh Advisory Subcommittee on Paediatrics and Child Health
Dr Duncan Cameron (by correspondence)	Consultant Paediatrician Ysbyty Glan Clwyd	Welsh Advisory Subcommittee on Paediatrics and Child Health
Mrs Caroline Crimp	Chairman	Association for the Welfare of Children in Hospital
Parents of children who have had paediatric cardiac surgery		
Mrs Clare Lines	Specialised Commissioner	SHSCW
Mrs Jan Barbour	Information Manager	SHSCW