

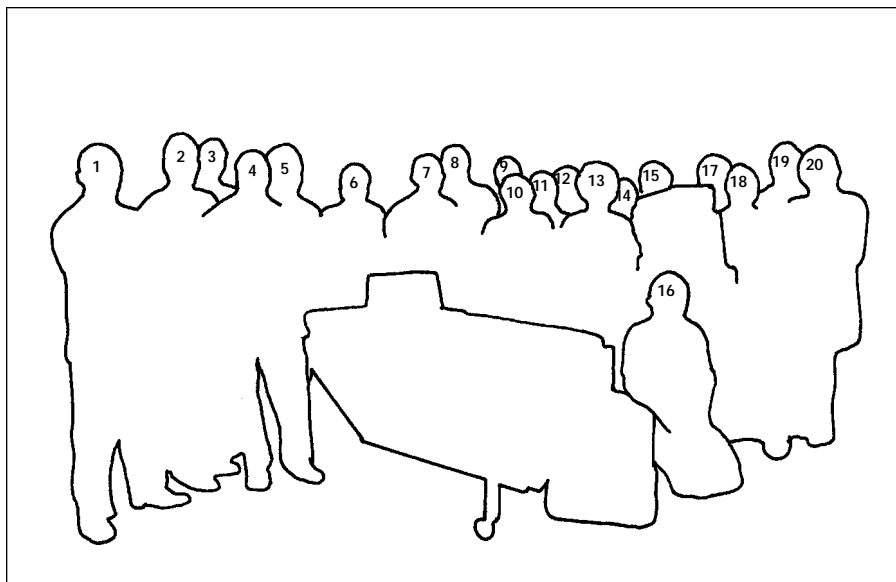
# Paediatric Intensive Care “A Framework for the Future”

Report from the National Coordinating Group on  
Paediatric Intensive Care to The Chief Executive  
of the NHS Executive

**ACTION**

Matters requiring action

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**Photograph, courtesy of Medical Illustration: CSUHT Sheffield**

The typical number of staff needed to look after one critically ill child. The photograph was taken in Sheffield Children's Hospital.

*Left to right:*

- |   |                                       |
|---|---------------------------------------|
| 1. Paediatric Intensive Care Equipment Technician | 11. Social Worker                     |
| 2. Registrar Paediatric Medicine                  | 12. Sister Paediatric Intensive Care  |
| 3. Senior Registrar Paediatric Medicine           | 13. Paediatric Radiographer           |
| 4. House Officer Paediatric Medicine              | 14. Domestic                          |
| 5. Consultant Paediatrician                       | 15. Paediatric Intensive Care Fellow  |
| 6. Consultant in Paediatric Anaesthesia           | 16. Sister Paediatric Intensive Care  |
| 7. Consultant in Paediatric Intensive Care        | 17. Paediatric Surgeon                |
| 8. Anaesthetic Senior Registrar                   | 18. Consultant Paediatric Radiologist |
| 9. Staff Nurse Paediatric Intensive Care          | 19. Paediatric ENT Surgeon            |
| 10. Paediatric Physiotherapist                    | 20. Hospital Dietician                |

Medical and ancillary staff are shared between several beds. In addition to those staff shown input may be required from paediatric surgical sub specialties - Neuro, Cardiothoracic, Orthopaedic, also from paediatric Cardiologists, Neurologists, Haematologists/Oncologists, Microbiologists, Chemical Pathologists. Input also from Paediatric Intensive Care Secretary, Business Manager and Nurse in charge of in-service training.

Photograph also shows portable monitor, ultrasound machine and rucksacks (foreground) containing drugs and equipment used during retrieval.

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# Executive Summary

## **Paediatric Intensive Care: A Framework for the Future**

The report of the National Coordinating Group on paediatric intensive care describes the features of the paediatric intensive care service as it is now, draws together the evidence on ways of achieving the best quality of care and outcomes for critically ill children, suggests standards which should apply in all hospitals providing paediatric intensive care and describes an organisational framework to provide a unified paediatric intensive care service in each area of the country.

## Facts and Definitions

### **Paediatric Intensive Care:**

- delivers care to the most critically ill children, most of whom will be artificially ventilated;
- is a low volume, high cost service;
- cannot be provided in every locality;
- requires highly trained specialist staff;
- should be available to all children who need it regardless of where they live.

### ***The key features of the current service are:***

- It has developed in an ad hoc unplanned way during the past 20 years;
- It is currently provided in a wide range of different settings, in designated paediatric intensive care beds, general children's wards, adult intensive care units, single specialty hospitals, and special care baby units;
- Until very recently, there has been relatively little evidence in the UK on the standards which provide the best outcomes for critically ill children, and no such standards have as yet been laid down;
- The number of *designated* paediatric intensive care beds is 223, of which many are in small units with less than 3 beds;
- Around half of all children needing intensive care are under 2 years old;

- Specialist retrieval services, needed to transport critically ill children to the nearest specialised centre, are still relatively few and are often not provided on a continuous 24-hour basis;
- There are too few clinicians and nurses with paediatric intensive care skills.

## Recommendations

### AUDITS OF THE CURRENT SERVICE

Health Authorities and hospitals in each area need to carry out a study to assess how many children in their area are likely to need intensive care each year, and where they are receiving care now. The study should establish:

- The numbers of children per 1000 in the population who need intensive care each year;
- The profile of demand throughout the year;
- The current configuration of the service;
- The average length of stay in each hospital providing the service;
- The percentage of intensive care which can be predicted in advance (eg as a result of major elective surgery);
- The numbers of children needing long-term ventilation;
- The extent of need for high dependency care to relieve pressure on intensive care beds.

The National Coordinating Group's report summarises the current evidence in each of these areas.

### ORGANISATION OF THE SERVICE

The National Coordinating Group recommends that in future the paediatric intensive care service should be delivered in 4 types of hospitals:

- **District General Hospitals** admitting children, which must be able to *initiate* intensive care;
- **Lead centres**, providing most of the intensive care needed in the area and supporting the whole service for the area through the provision of advice and training;
- **Major acute general hospitals** with large adult intensive care units, which already provide a considerable amount of paediatric intensive care;
- **Specialist hospitals** providing some intensive care in support of the speciality, eg cardiac, neurosurgery, burns.

- Each of these types of hospital should in future comply with certain standards, within each of the following categories:
- Training and experience of medical and nursing staff;
- Competencies and equipment for specific forms of treatment;
- Access to specialist services on site or access to advice on particular specialties;
- Facilities for families and an environment for the successful care of children;
- Supporting services on site or on call;
- Requirements for training, quality control and management.

## Action Plan

The National Coordinating Group recommends that Health Authorities and hospitals should follow a timetable for introducing the necessary changes to the paediatric intensive care service:

- As an **immediate** first step, **provision of extra single, isolated beds should cease**;
- All areas should now carry out **a prospective study** to establish the extent of need for paediatric intensive care and where it is currently provided;
- Within one year after publication of this report, **children needing intensive care should no longer be looked after in the inappropriate location of general children's wards**;
- A **lead centre** should be designated in each area;
- A **retrieval service** should be funded and staffed on a 24 hour basis in each geographical area;
- **Protocols** should be developed describing how the service is to be organised and managed across the whole area to provide the best possible outcomes for critically ill children;
- Steps should be taken within 3 years to **stop caring for children in centres which do not meet the standards set out in the report**.

# Introduction

## ***The National Co-ordinating Group's Terms of Reference***

- 1.** The National Co-ordinating Group on Provision of Paediatric Intensive Care was set up in June 1996. It was tasked with drawing up a policy framework for paediatric intensive care and asked to report to the Chief Executive of the NHS Executive by 30 April 1997.
- 2.** Throughout the past months, we have focused on a long-term vision of a high quality, integrated service, organised and run around the health needs of individual children. Meeting the needs of children and their families means seeking to balance ways of getting the best outcomes for children against ease of access to a local service - since specialised services cannot be provided in every area. We have borne in mind, in writing this report, the pattern of the service as it is now and that, in the past, the majority of critically ill children have received a high standard of care from the NHS. The paediatric intensive care service has enormous strengths. Our aim has been to focus on those strengths, and whilst we are critical of some aspects of the present service and we acknowledge that there have been some problems in providing the service, we wish to build on its *strengths* in setting a direction for the future.
- 3.** Our terms of reference, set out in an Executive Letter on 5 July 1996<sup>1</sup> - included a number of detailed tasks, in particular to:
  - i.** Produce a set of principles which command broad managerial and professional support, to assist the rational development of services nationally and regionally;
  - ii.** Describe the key features of a paediatric intensive care service to meet the needs of the population which makes the best use of limited resources, staff expertise and of specialised facilities and which can respond to fluctuating demand;
  - iii.** Indicate the role of adult intensive care units and of high dependency beds within the paediatric intensive care service;
  - iv.** Describe the implications of these principles for medical and nurse staffing, training and development and for retrieval services;
  - v.** Provide a focal point for dissemination of information on research and other studies into various aspects of paediatric intensive care which are taking place in, or planned for, 1996/97 regionally and nationally;

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<sup>1</sup> EL(96)53: Executive Letter to Chief Executives of Health Authorities and Chief Executives of NHS Trusts, Headed "Paediatric Intensive Care : The Way Forward"

- vi Describe the information required by all parts of the NHS which would permit the best use to be made of the paediatric intensive care service.

4. This report discharges our remit. It provides a picture of the paediatric intensive care service as it is now, describes the work done by the National Co-ordinating Group on standards of care and service configuration, and sets out some pointers for the future. Our report should be read in conjunction with that from the Chief Nursing Officer's Task Force which considers the nurse staffing and training issues for the paediatric intensive care service.<sup>2</sup>
5. We are grateful to everyone who has helped with this work. A list of their names and a list of the names of members of the National Co-ordinating Group is at Annex 1.

### ***What Do We Mean By Paediatric Intensive Care?***

6. The report of the Chief Executive of the NHS Executive <sup>3</sup>, published in May 1996, described a number of reasons why children - whom we define as those up to age 16 may need intensive care. These include following an accident, major surgery, or in medical emergencies. That report also described the categories of care, as defined by the Paediatric Intensive Care Society.<sup>4</sup> Our work has focused on the differing needs of children requiring the highest two categories of care.
7. Intensive Care is defined as "a service for patients with potentially recoverable diseases who can benefit from more detailed observation and treatment than is generally available in the standard wards and Departments".<sup>5</sup> Intensive care is usually reserved for patients with threatened or established organ failure, which may have arisen as a result of an acute illness, trauma or a predictable phase in a planned treatment programme.
8. Intensive care for children is part of a network of health and other services meeting the needs of children. All such services must focus on the particular needs of the child. Health services for children are delivered in a variety of settings, including in the community, in general hospitals, and in specialist hospitals. The health needs of children can only be met by close collaboration between many agencies, including health, social services and education. Some of the conditions which may lead to children requiring paediatric intensive care are preventable by appropriate delivery of services by other parts of the health, social care or education systems. For example, the number of injuries to children as passengers in cars has reduced through a variety of measures. There are similar prospects for a reduction in the number of accidents affecting children in the home and elsewhere. Conversely, the improvement in medical techniques in recent years and the availability of new drugs have led to the survival of premature babies who

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<sup>2</sup> "A Bridge to the Future - Future nursing workforce and education in paediatric intensive care" - Report of the Chief Nursing Officer's Task Force, June 1997.

<sup>3</sup> "Paediatric Intensive Care" submitted to the Secretary of State for Health; NHS Executive, May 1996

<sup>4</sup> "Standards for Paediatric Intensive Care" Paediatric Intensive Care Society 1996.

<sup>5</sup> "Intensive care in the United Kingdom": King's Fund Panel; May 1989

can make high demands on both neonatal and paediatric intensive care services.

9. Children are not adults scaled down in size. Their relative immaturity (in all respects - physiological, anatomical, functional, developmental and psychological) creates greater vulnerability to a variety of adverse influences and they should be looked after by specifically trained staff, familiar with the changes characteristic of each stage of development. The pattern and range of illnesses affecting children are also different. Intensive care may be required for acute illnesses in otherwise healthy children or for complex congenital malformations - which are most unusual in adults. Children can become acutely ill very rapidly, but have greater potential for full recovery than adults. Children's greater vulnerability means that the effects of delay in intervening or commencing treatment, or of errors in treatment can be amplified to a considerable degree.
10. Provision of intensive care is not simply to do with equipment and facilities, although these are important as their range and size must be geared to the needs of children. In addition, the surrounding environment and contact with their families are crucial to promote recovery.
  - Some procedures in intensive care, for example vascular access, are particularly difficult in younger children and staff must be competent in them;
  - Physiological immaturity requires particular expertise in fluid balance and use of drugs;
  - Manifestations of distress, deterioration or recovery differ, and expertise in interpretation is needed.
11. While these factors apply to children of all ages, they are particularly relevant in the youngest. In later childhood and adolescence, psychological factors and the involvement of a young person in their own care require particular sensitivity.
12. This report does not cover **neonatal intensive care**, which is delivered to babies who require intensive care shortly after birth. Such babies have a restricted group of conditions including complications of prematurity, birth asphyxia, birth injury, congenital infection and congenital abnormality. Treatment of these babies is delivered by neonatal paediatricians and is quite separate from paediatric intensive care. However a proportion of the babies who require neonatal intensive care will require transfer for paediatric surgery, including paediatric cardio-thoracic surgery, and, following this, will probably be cared for on a paediatric intensive care unit. In addition, some premature babies who have received neonatal intensive care will, in later months, require admission to general paediatric intensive care units because of other problems, for example, bronchiolitis.
13. Although we have assumed that a "child" is someone up to the age of 16, some health authorities, social services authorities, and hospitals have policies of delivering children's services up to the age of 19, whereas others assume that 15 and 16 year olds are already "adults". Within the older age range,

children's needs can vary widely and there needs to be flexibility in policies to meet the needs of individual children. Older adolescents, for example, will often be appropriately cared for on adult intensive care units. There will, however, need to be sensitivity to their particular emotional, educational and family needs. Some of these adolescents will feel out of place in a paediatric intensive care unit, which may contain predominantly very young children, often with the majority being under 1 year old. Other adolescents may feel equally out of place in an adult intensive care unit, which may contain a large number of elderly patients.

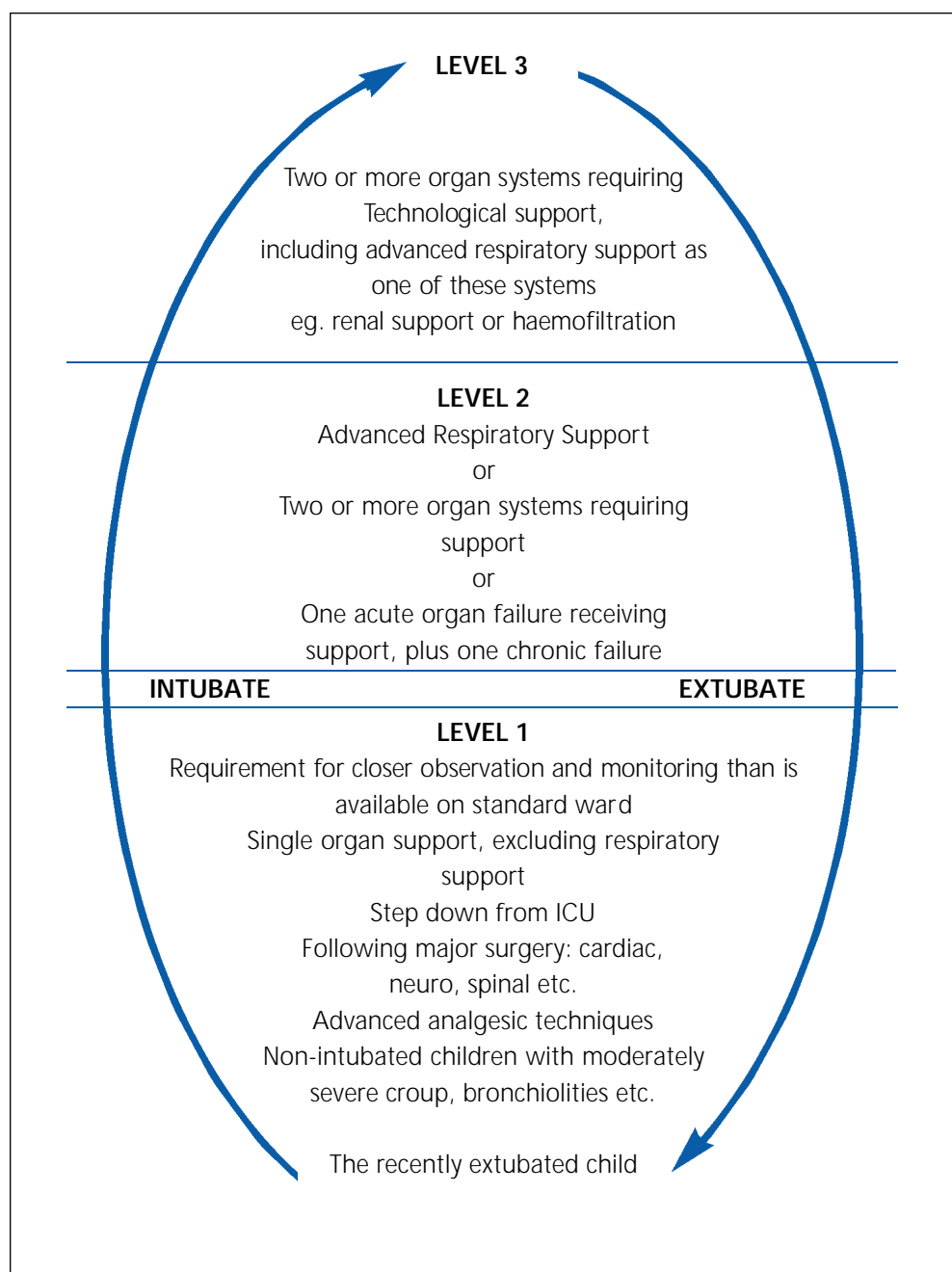
14. Intensive care is a low volume, high cost specialty, which requires a highly trained, multidisciplinary team together with specialised tertiary expertise and diagnostic facilities.
15. In many of the previous discussions about paediatric intensive care, there has been little attempt to differentiate between intensive and high dependency care - and indeed the definitions are often blurred. A critically ill child may need more than one of the three types of care - as defined by the Paediatric Intensive Care Society - *during a single period* of treatment in hospital:-

- **High Dependency** Care (often described as Level 1) -
  - This describes care provided to a child who may require closer observation and monitoring than is usually available on an ordinary children's ward, although much of this care is already provided, with higher staffing levels than usual, in such locations. For example the child may need continuous monitoring of the heart rate, non-invasive blood-pressure monitoring, or single organ support (but not respiratory support). The child may, for example, be suffering from moderately severe croup, suspected intestinal obstruction or suspected poisoning.
- **Intensive Care** (Level 2) -
  - These children will always need continuous nursing supervision. They may need ventilatory support, or support for two or more organ systems. Sometimes the child will have one organ system needing support and one other suffering from chronic failure. Usually children receiving level 2 care are intubated to assist breathing.
- **Intensive Care** (Level 3 or above) -
  - Children with two or more organ systems needing technological support, including advanced respiratory support, will need intensive nursing supervision at all times and will be undergoing complex monitoring and/or therapeutic procedures. They would, for example, include ventilated children undergoing advanced renal support, those who have suffered multiple trauma in major road accidents, or those who have undergone very complex major surgery. Children receiving treatment by extra-

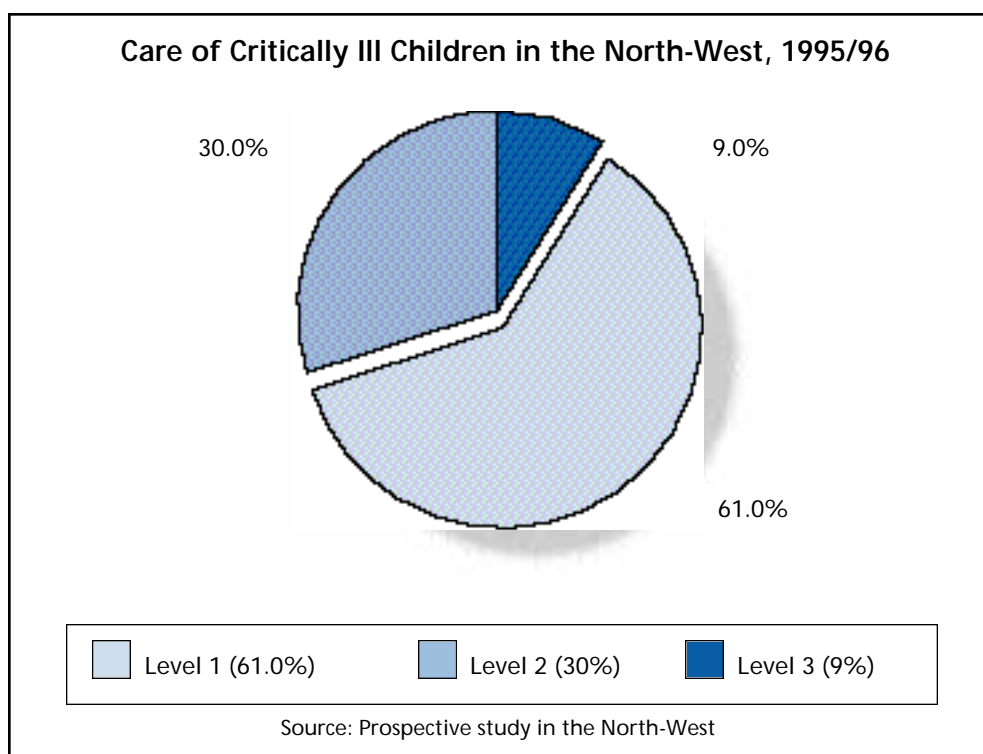


corporal membrane oxygenisation (ECMO), which is provided in a very small number of hospitals, are sometimes described as needing Level 4 intensive care.

- 16.** A critically ill child may need a number of different levels of high dependency or intensive care during a single period of treatment in hospital. For example, children admitted with acute respiratory illness such as bronchiolitis, and provided with high dependency care, can deteriorate rapidly so that they need ventilation and Level 2 or even Level 3 care. Equally, children who, perhaps following complex major surgery, may initially need a very high level of intensive care including ventilation, can recover very rapidly so that the level of care provided can be reduced over a period of only a few hours. This is illustrated in the following diagram.



17. High Dependency Care is sometimes provided as a step down from intensive care, where high dependency beds are provided on the same site and adjacent to the beds dedicated for intensive care. They may be used, for example following major surgery, where a child is stable, is recovering rapidly but continues to need monitoring.
18. We focus, in this report, on *paediatric intensive care* - by which we mean care at Level 2 or above.<sup>6</sup> A small number of the totality of critically ill children need care at this level. The chart below shows the proportion of critically ill children in one area of the country<sup>7</sup> who needed care at Levels 2 and 3 in 1995-96:



19. It is likely that the pattern of all care for critically ill children in England is similar to this, and that the proportion of care at Level 2 or above, as compared to Level 1, reflects this pattern across the country.

## Progress Since May 1996

### ***The Extent of Provision of Paediatric Intensive Care***

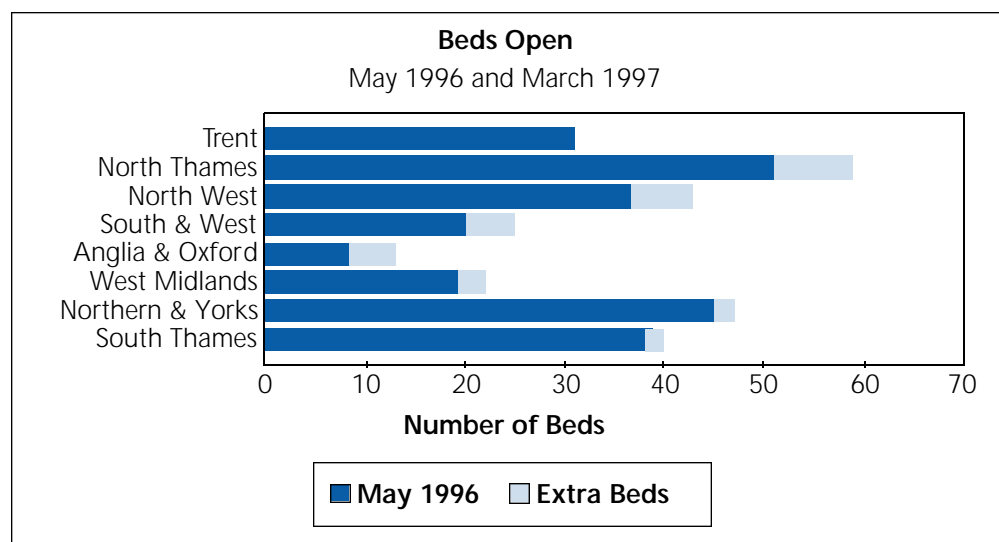
20. The Chief Executive's report of May 1996 identified a total of 249 dedicated intensive care, specialist intensive care and high dependency beds for children in England. Since then, additional beds have opened. The number of beds open in March this year are shown in the table; the following chart illustrates the proportion of new beds in each region as compared to the number at May 1996.

<sup>6</sup> A number of previous documents (eg the 1993 report- "The Care of Critically Ill Children"- by the British Paediatric Association) have described "paediatric intensive care" as including high dependency care (Level 1), but we consider that this is misleading since high dependency care differs in a number of important respects from paediatric intensive care.

<sup>7</sup> "Report on a Prospective Study of Intensive Care Utilisation in the North West Region", Royal College of Paediatrics and Child Health, London, October 1996.

<b>BEDS OPEN - MARCH 1997</b>				
<b>Paediatric Intensive Care</b>				
	General PIC	Specialist	High Dependency	TOTAL
<b>Trent</b>	21	5	5	31
<b>North Thames</b>	28	19	12	59
<b>North West</b>	27	12	4	43
<b>South &amp; West</b>	12	7	6	25
<b>Anglia &amp; Oxford</b>	9	1	3	13
<b>West Midlands</b>	20	0	2	22
<b>Northern &amp; Yorks</b>	17	14	16	47
<b>South Thames</b>	26	5	9	40
<b>TOTAL</b>	160	63	57	280
* Some centres combine general and specialist provision, without designating them separately.				

21. The Chief Executive's report stated that 18 additional dedicated general paediatric intensive care beds, 5 additional specialist beds and 7 additional high dependency beds (associated with intensive care beds) were due to open in 1996 - 1997. These plans have been implemented.






### ***The Pattern of Provision***




22. The available dedicated general paediatric intensive care beds are spread across England in 29 centres of differing sizes. The map overleaf shows the location of the larger (with 4 or more dedicated beds) centres. Where specialist beds are incorporated within a centre covering both general and specialist paediatric intensive care, the centre size is calculated on the overall total.

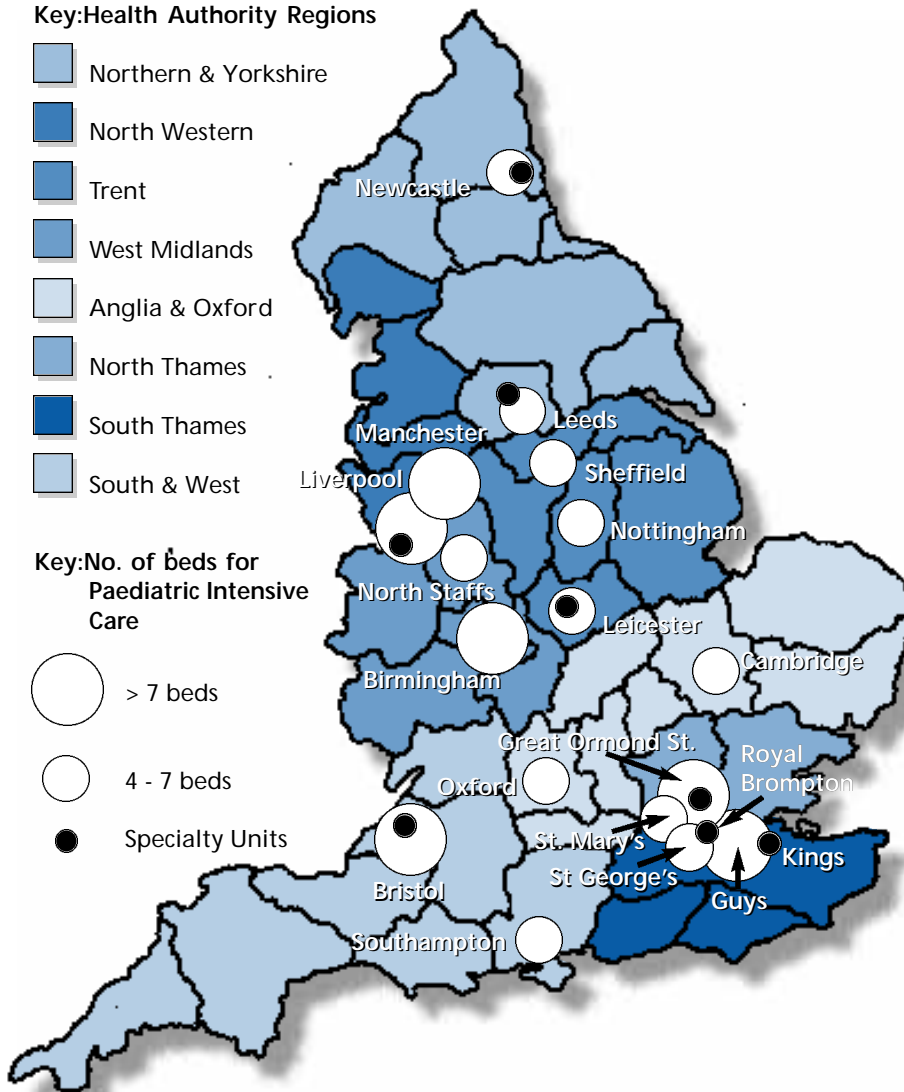
### Location of Paediatric Intensive Care

#### Key:Health Authority Regions

-  Northern & Yorkshire
-  North Western
-  Trent
-  West Midlands
-  Anglia & Oxford
-  North Thames
-  South Thames
-  South & West

#### Key:No. of beds for Paediatric Intensive Care

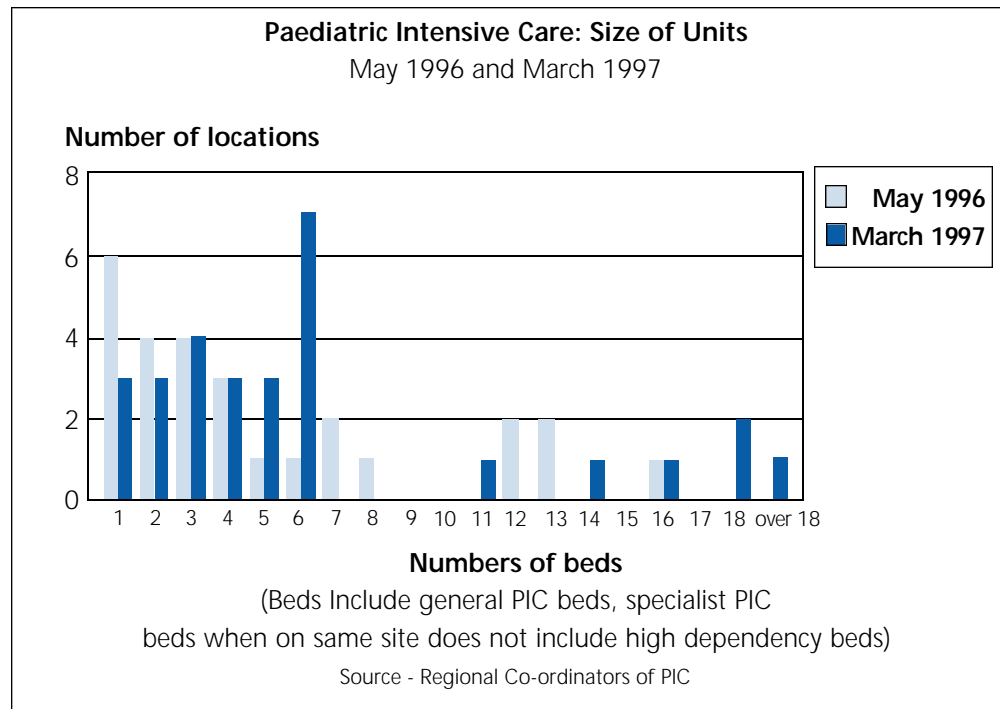
-  > 7 beds
-  4 - 7 beds
-  Specialty Units



NB. There are a number of additional single speciality centres not shown here.  
 Some hospitals operate on split sites.  
 The smallest centres with general Paediatric intensive care are excluded.

Source: Regional PIC Co-ordinators, January 1997

- 23.** A large number of the available dedicated general and specialist paediatric intensive care beds are provided in small units. Ten out of the 29 units with dedicated paediatric intensive care beds have 3 beds or fewer - and only six units have 8 beds or more. The position now is similar to the position last year, as described in the Chief Executive’s report of May 1996, although the number of very small units has fallen somewhat and the number with 5 or 6 beds has risen.



#### ***Regional Coordinators for Paediatric Intensive Care***

- 24.** In July 1996, a group of Regional Coordinators for Paediatric Intensive Care was established. The Regional Coordinators were responsible for coordinating implementation of the planned additional intensive care beds within each region, as described in the Chief Executive’s report of May 1996. They were also given the task of ensuring, wherever possible, that the necessary medical and nursing staff were available to meet paediatric intensive care needs and of facilitating the production of medium term plans to develop the provision of paediatric intensive care within each region.

#### ***Additional Funding in 1996-97***

- 25.** To assist the development of the service, the Secretary of State for Health announced in May 1996 that he was providing additional funding to assist development of the paediatric intensive care service, and specifically to allow training of more specialist paediatric intensive care nurses and to provide an improved service for moving critically ill children to the nearest specialised unit. £2 million of additional funds were distributed through the Regional Coordinators, to finance specific projects with these priorities in mind. Funding was particularly used to provide cover for nurses who were away from their normal jobs undergoing specialist paediatric intensive care training.

**26.** Overall, the allocation of £2 million was used as follows:

- Increased specialist nurse training £903,000
- Purchase of additional equipment to open new paediatric intensive care beds £685,000
- Enhanced patient retrieval services £293,000
- Other pump priming, including temporary nursing and medical staff cover £119,000

**27.** Part of the funds was used to stimulate further development of retrieval services and all regions now have at least one such service, although most do not operate for 24 hours a day throughout the year. Since retrieval services tend to cover a wide geographical area, a secondary beneficial effect of the injection of additional funds for retrieval was that health authorities and hospitals in particular areas came together in groups to discuss the use of the additional money. This has reinforced the links between the health authorities and hospitals of this highly specialised service.

<b>Hospitals which have some form of retrieval service</b>
<p>John Radcliffe, Oxford Addenbrooke's, Cambridge Portsmouth Bristol North Staffordshire Royal Infirmary, Stoke Birmingham Children's Hospital Alder Hey, Liverpool Manchester Children's Hospital United Leeds Teaching Hospitals Newcastle General Hospital Guy's and St Thomas' King's St Georges, Tooting St Mary's, Paddington Great Ormond Street Sheffield Children's Leicester Royal Infirmary</p>
<p><b>Source:</b> Regional Coordinators for Paediatric Intensive Care</p>

***Intensive Care Bed Register***

**28.** From 1 December 1996, an intensive care bed register has been in operation nationally, covering all intensive care beds, including dedicated paediatric intensive care beds, in England. Any clinician wanting to locate an available paediatric intensive care bed and failing to find one locally can now use the service to find the closest options for the placement of a critically ill child.

### **Nurse Staffing**

- 29.** In May 1996, it was announced that the Chief Nursing Officer would lead a multi-disciplinary task force to ensure that arrangements are in place which will improve nurse staffing in the paediatric intensive care service and to advise and provide guidance on staffing, training and development of staff. The terms of reference of the group were:
- i.** How to encourage the development of skills and competency-based training for paediatric, adult, neonatal and specialist intensivist nurses, which allows them to use their technological expertise in a range of settings, according to fluctuating service needs and their personal development plans.
  - ii.** The development of part-time and modular courses for intensivist nurses, which allow them to combine continuing training to attain qualifications with experience in intensive care units.
  - iii.** How to ensure the best quality care is given by the most appropriate person from the clinical team, in line with the changing needs of the intensive care service.
  - iv.** How suitably qualified children’s nurses can be used to provide specialist advice and consultancy input at all times in paediatric intensive care settings, whilst ensuring the best use of all available staff and that all highly dependent and critically ill children are nursed by an appropriately trained intensive care nurse.
  - v.** The feasibility of fast-track accreditation for paediatric intensive care nurses who have adult intensive care experience and experience with children.
- 30.** The Task Force report, “A Bridge to the Future”, summarises the actions taken to respond to the urgent short-term need for paediatric intensive care nurses last winter. More substantially, it also addresses the nursing issues of standards, education and workforce planning involved in achieving the framework envisaged for the paediatric intensive care service in future.
- 31.** As background to its work, a survey of nurses working in hospitals with dedicated paediatric intensive care beds was carried out on 22 May 1996. It showed that, of the employed qualified nurses working in these settings on that day:
- 85% were trained children’s nurses, and
  - of those, 48% had also undergone intensive care training.
- 32.** The proportion of trained children’s nurses was higher than anticipated and exceeded the standard quoted by the British Paediatric Association (70%)<sup>8</sup>. However, it was generally agreed that the proportion of nurses with a qualification in paediatric intensive care was too low. The survey was repeated on 22 January 1997 and the position on the two dates is shown in the table overleaf:-

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<sup>8</sup> “The Care of Critically Ill Children”, British Paediatric Association, December 1993.

# **NURSES WORKING IN PAEDIATRIC INTENSIVE CARE - whole-time equivalents**

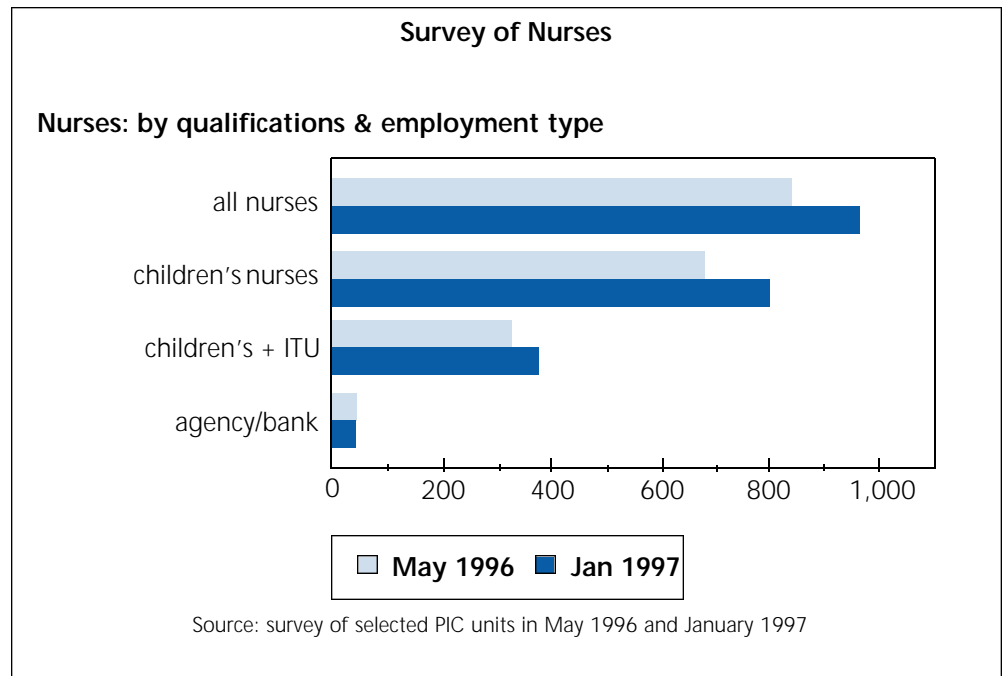
Region	Total employed qualified nurses		Number children trained nurses		percentage children trained nurses		number children and intensive trained nurses		percentage children and intensive trained nurses		agency/bank nurses (wte)	
	May '96	Jan '97	May '96	Jan '97	May '96	Jan '97	May '96	Jan '97	May '96	Jan '97	May '96	Jan '97
Northern & Yorkshire	83.41	99.86	69.63	90.22	83%	90%	27.40	30.40	39%	34%	4.24	0
North West	164.5	204.7	150	186.1	91%	91%	68.75	83.07	46%	45%	12.67	2.67
Trent	89.65	94.4	89.12	94	99%	100%	39.64	42.61	45%	45%	3.06	3.66
West Midlands	120.04	131.9	78.18	100.1	65%	76%	39.53	58.86	51%	59%	0	0
Anglia & Oxford	54.83	62.67	48.08	59.67	88%	95%	16.16	19.83	34%	33%	1.63	0
North Thames	104.3	116.6	88.7	97.4	85%	84%	60.10	62.40	68%	64%	6.46	17.07
South Thames	128.4	132.2	114.1	122.1	89%	92%	53.48	56.02	47%	46%	9.24	11.8
South & West	48.69	59.67	39.89	46.87	82%	79%	19.15	21.15	48%	45%	0	1
All England	793.8	902	677.6	796.4	85%	88%	324.2	374.3	48%	47%	37.3	36.2
Percentage Increase		13.63%		17.53%				15.45%				

Source: Hospitals with dedicated paediatric intensive care beds which responded to both the May 1996 and January 1997 surveys

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- 33.** The National Coordinating Group was encouraged by the increase in qualified nursing staff working in hospitals with designated paediatric intensive care beds, revealed by this survey. The increase of 17.5% in the number of trained children’s nurses and of 15.5% in the number of children’s nurses with intensive care training was needed to allow the additional paediatric intensive care beds to open during the past winter. The chart shows the increase in diagrammatic form:



- 34.** The proportion of nurses with intensive care training remains, however, low. The same survey of hospitals with dedicated paediatric intensive care beds revealed that 114 nurses have commenced intensive care training (ENB 415) since May 1996, and also that the hospitals involved in the survey have provided an additional 48 places for this type of training since that date. This suggests that the proportion of nurses trained in intensive care will increase further, since the length of the training period means that there is a time delay in increasing the numbers of these nurses.

### **Medical Training**

- 35.** There was, prior to this year, no formally recognised training in England for medical staff who wish to undertake a career in paediatric intensive care. Some of the consultants currently working in paediatric intensive care (who trained initially in paediatric medicine, paediatric anaesthesia and paediatric surgical specialties) obtained their intensive care training in Australia, America or Canada. The Royal Colleges of Physicians, Anaesthetists and Surgeons, with the support of the British Paediatric Association (now the Royal College of Paediatrics and Child Health), therefore established a joint committee (the Intercollegiate Committee for Training in Paediatric Intensive Care Medicine) to consider the issue of paediatric intensive care training. The Committee has produced advice to the Royal Colleges on the duration, content and assessment of training of paediatric intensive care and on the skills which



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clinicians, drawn from different disciplines, should hold. The Intercollegiate Committee has also defined specific criteria for the recognition of training posts in paediatric intensive care. It stated that the training programme and participating hospital will need to:

- “have a sufficiently wide case mix and patient throughput to provide wide experience in all aspects of paediatric intensive care. The Committee anticipates that this would normally be in units with at least 8 paediatric intensive care beds and managing a minimum of 250 intubated patients each year;
- have at least 10 fixed notional half days each week when a designated consultant experienced in paediatric intensive care is in attendance on the unit to supervise patient management;
- provide a fully operational paediatric inter-hospital retrieval service.”

- 36.** Training will only be recognised if it is carried out in centres approved by the Intercollegiate Committee or in training programmes based in those centres, (although there may be links with other centres where training may be carried out).
- 37.** The aim is to establish sufficient recognised training posts for individual clinicians who intend, ultimately, to pursue a consultant career in paediatric intensive care. Specialist registrars with training in paediatric medicine, anaesthesia or surgery will be eligible to apply for posts - these will entail a minimum of a two-year programme for those intending to become full-time paediatric intensivists and at least a one-year programme for those aiming at a lower sessional commitment.

# Work Done by the National Coordinating Group

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## ***Work done by the National Coordinating Group***

38. The National Coordinating Group carried out most of its work by dividing into three subgroups, covering:

- data issues, including the information required to assess need for the paediatric intensive care service;
- the standards of care required for children;
- organisational issues, including those which will affect health authorities.

39. This next section of the report draws together the work which has been done. It is designed to be useful to health authorities and hospitals in assessing the future need for, and shape of, the service.

## ***Numbers of children needing intensive care***

40. Relatively few studies have addressed the need for paediatric intensive care, particularly in the UK. However a number of studies have been initiated in this country over the last three years. These, together with major studies in the USA and Australia, suggest that the number of admissions for paediatric intensive care at Level 2 or above ranges from 0.9 to 1.3 per 1000 children in the population per year, with an average of 1.2 admissions per 1000 children per year. A summary of the research which leads to this conclusion, and a list of the references, is at annex 2.

41. It is not possible accurately to compare the results and conclusions from the various studies without introducing caveats about the lack of detail in many of them on case mix and the severity of illness of the children concerned. The criteria for admission to or exclusion of a child from paediatric intensive care vary from country to country - and, particularly in the USA, from area to area. There is also evidence that, within the UK, there can be wide regional variations. Some of these may result from differences in need - for example emergencies caused by accidents are affected by socio-economic factors. Some may be caused by different usage of beds. It is, therefore, imperative for each group of health authorities to carry out research into their local requirements in order to assess the extent of need for the service.

## ***Increases in need for paediatric intensive care, year-on-year***

42. No data has yet been collected nationally showing increases in need, year-on-year, for paediatric intensive care per thousand children in the population. Some increases might be expected because of advances over recent years in the technology and therapeutic interventions which are now available for critically ill children. In some hospitals there is anecdotal evidence of an increase in the number of *emergency* admissions requiring paediatric intensive care, although this data can be affected by factors such as the number of beds available and the reputation of the hospital. In others, there has been a clear increase in *elective* admissions. Changes in the demand for paediatric intensive care at individual hospitals will be affected by decisions

of referring clinicians on where children should best be cared for. There is a lack of published data on trends in demand for paediatric intensive care.

***Factors Affecting Demand***

43. Translating an annual estimate of the likely number of admissions, based on the number of children in the population, into the number of paediatric intensive care beds needed in any particular locality is not straightforward. To do so requires consideration of a number of different elements:

- The profile of demand through the year;
- The average length of stay (which in itself will vary according to the severity of illness of the children concerned and the expertise of the hospitals caring for them );
- Whether some beds are occupied by long-term ventilated children who might be more appropriately cared for elsewhere;
- The configuration of the service - including the size of the different units and the flexibility within which they can operate;
- The availability of high dependency beds adjacent to paediatric intensive care units which can free intensive care beds more quickly than might otherwise be the case.

More information about calculating the number of beds required is in Annex 5.

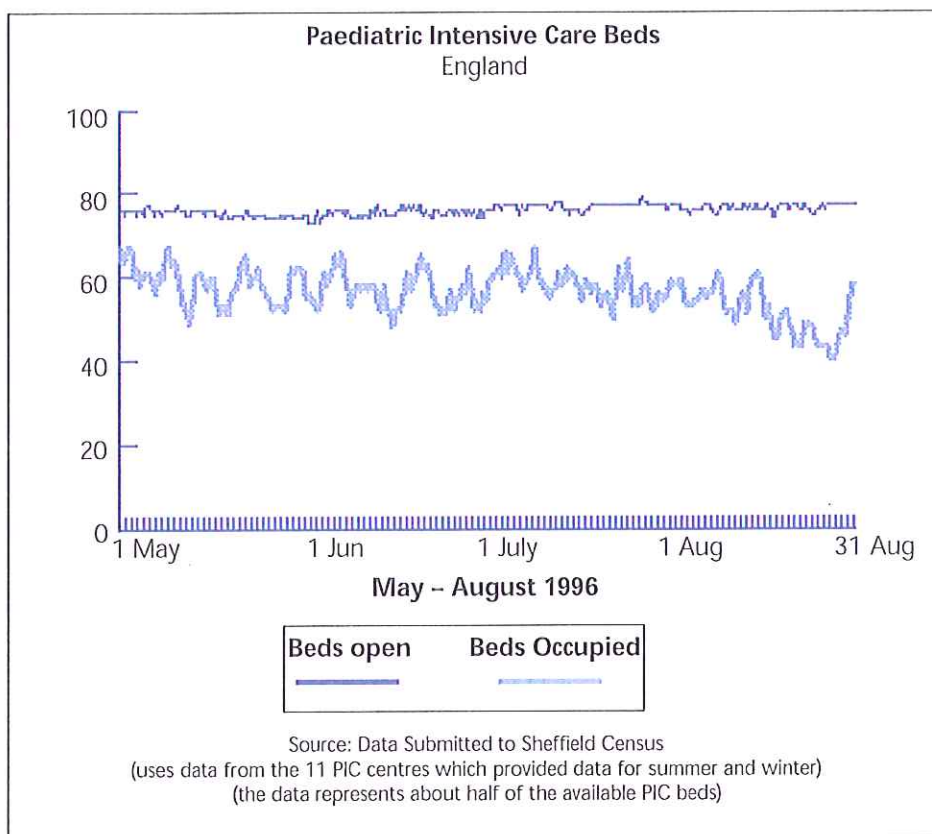
***The Pattern of Demand for Intensive Care***

44. The Chief Executive's report of May 1996 included an illustration of the varying demand for paediatric intensive care between 17 February and 31 March 1996. The report pointed out that:

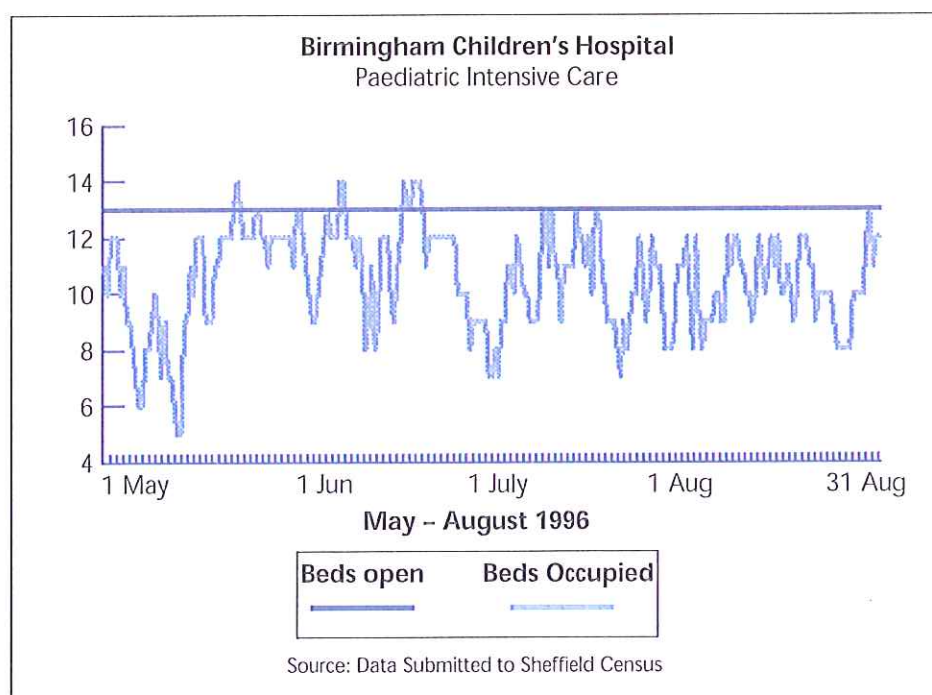
- the national picture concealed some wide variations locally, with some hospitals fully occupied most of the time when others were not;
- the variation of demand during the year suggested that the available number of dedicated paediatric intensive care beds was probably sufficient to meet demand at current levels for most of the time (probably about 9 months of the year); and
- a full assessment of supply and demand required a much longer survey over at least a full year.



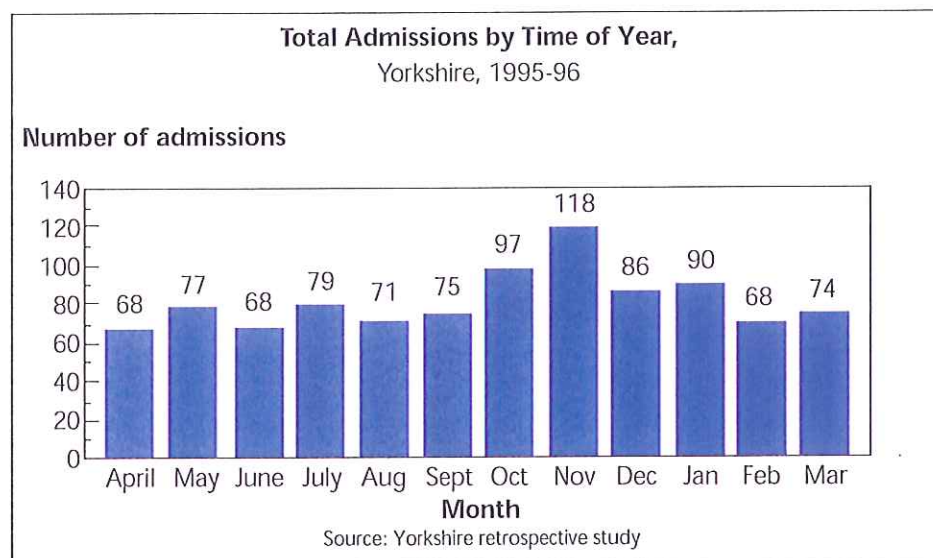
45. A survey over a full year has now been done. First, we have analysed data collected during the summer months (April - September 1996). The graph which follows shows the outcome for England as a whole.



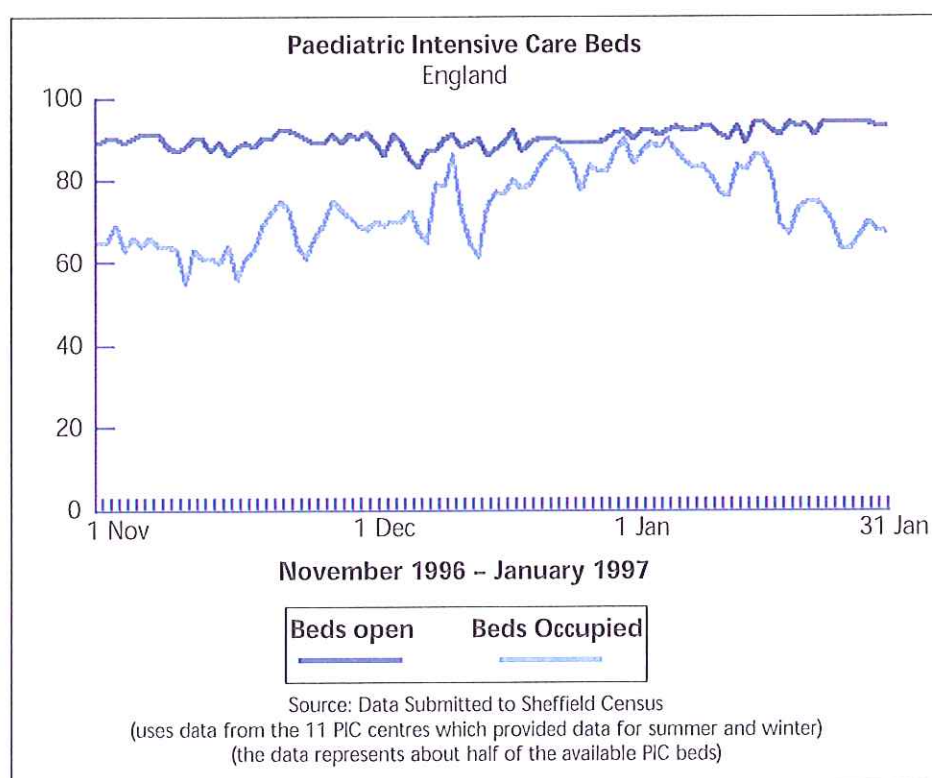
46. This national picture again conceals some wide local variations. For example, some of the larger paediatric intensive care centres were fully occupied during last summer, when demand might be thought to be lower. The following chart (which may not be typical for all hospitals and for all years) illustrates this:

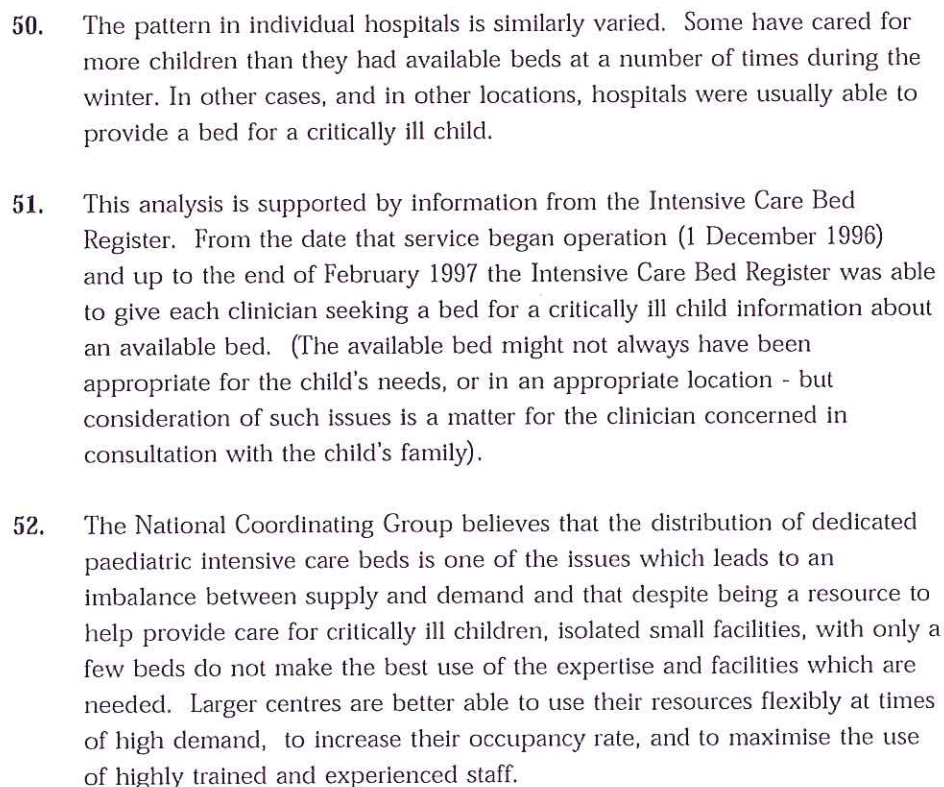


47. Peaks of demand do not only occur in the winter. Secondary peaks in summer may occur at different times. The prospective study in the North West showed that there were 1.7 times more episodes of intensive care at the time of highest demand (in December) than at the time of lowest demand in that region that year (in May). Apart from the peaks in demand in December and January, (mainly caused by an increase in the number of children suffering from respiratory infections), there was a secondary peak in August, caused mainly by an increase in trauma cases. A retrospective study in Yorkshire<sup>9</sup> revealed exactly the same ratio (1.7 times) between the number of admissions at times of highest and lowest demand although, again, the peaks occurred at different times than in other regions. The chart below profiles the total number of admissions in Yorkshire in 1995-96:-



48. Nationally, the time of highest demand is in the winter. Demand begins to increase from October onwards, and can show considerable variation:-

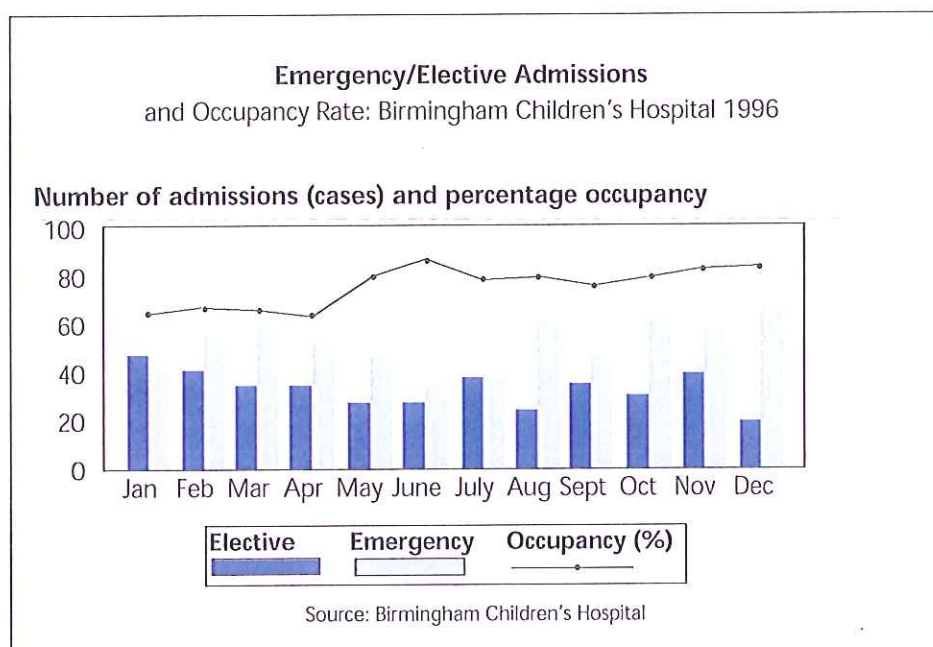






### Emergency and elective admissions

53. Apart from the emergencies, resulting, for example, from an increase in the extent of respiratory diseases or accidents, demand for paediatric intensive care is also affected by the number of *elective admissions* - those of children who have undergone surgery or complex medical interventions in hospital and whose needs for intensive care can be predicted in advance. The Chief Executive's report last May suggested that good management of overall demand for paediatric intensive care could be aided by management of elective demand, such that the work was carried out (wherever possible) at times when there were fewer emergencies. There is limited scope for this (operations on children often need to be done at the "optimum" time - for example, where the child is suffering from congenital heart disease or has a brain tumour). The proportion of elective to emergency admissions for paediatric intensive care varies from area to area, depending on where various specialties are practised. The Yorkshire retrospective study revealed that 38% of admissions to paediatric intensive care in that area were elective but a proportion of these were accounted for by the fact that the area provides supra regional cardio thoracic services. In other areas, 50% of admissions may be elective.
54. The amount of emergency work which has to be accommodated has knock on effects on the amount of elective work that can be undertaken. Hospitals make every attempt to care for children admitted in an emergency; when the paediatric intensive care centre is full, less elective work can be undertaken. In order to maximise the use of resources, the surgeons normally adopt a flexible approach to their schedules. The chart shows the interactions between emergency and elective work and occupancy levels at one paediatric intensive care centre.



### Assessing overall demand

55. The information provided above on demand in summer and in winter reflects only the position in dedicated paediatric intensive care beds. A large proportion of critically ill children are not currently cared for in these beds but in a wide range of other facilities, such as on children's wards and in general (adult) intensive care units. The only way to make an overall

- several attempts might be made to admit the same child to more than one paediatric intensive care centre on the same day (and it is difficult to avoid multiple counting);
- clinicians tend to know when most beds in a particular centre or region are full and so they may continue to treat critically ill children locally rather than try to obtain admission to a dedicated paediatric intensive care bed;
- as networks develop between regions and areas of the country, demand for admission to key centres providing paediatric intensive care tends to increase as children are “displaced” from hospitals where they would previously have been cared for. This may suggest an increase in the number of refused admissions, but is not necessarily indicative of an increase in demand.

57. The available studies provide some information on the length of stay of children in intensive care. This ranges from just over two days (in Australia) to five days (in California). Information from the UK is limited. However, both the prospective study in the North West Region and the retrospective study in Yorkshire indicate that the average length of stay was 4.3 days for intensive care. The length of stay for differing levels of care in the North West was broken down as follows:

58. The mean length of stay at Level 2 or above in the North West and in Yorkshire is - at 4.3 days - somewhat higher than the length of stay of just over 3.9 days calculated for Trent region in a recent study<sup>10</sup> and a great deal higher than in Australia. However, the circumstances in Australia, which have brought the length of stay in paediatric intensive care units down to just over two days, seem unlikely to be realised in the UK, mainly because of the configuration of the service (in Australia there is a very small number of very

25



large units) and because the Australian figures include a large number of admissions for cardiac surgery, which involved a length of stay in paediatric intensive care of only a single day. It is therefore suggested that health authorities should, for the purposes of planning, estimate the average length of stay at around four days - although this should be checked by audit.

#### ***Long-term Ventilation***

59. There is a small, but growing, number of children who require long-term ventilation. This may be carried out either at home or in hospital. It is most important that these children should have a physical environment suitable for their age and development and frequent access for their families. The need can arise from, for example, head injury, leading to the child, although in a stable condition, being dependent on care for many months or for the rest of his or her life; neuromuscular disease; an injury to the spine; or severe infection. A survey by the British Paediatric Respiratory Society in 1995 estimated that there were 110 children receiving long-term ventilation in Britain - an average of one in each Health Authority area - two thirds of whom were cared for in their own home. An ad hoc survey<sup>11</sup> in November 1996 has shown that there were 21 children needing long-term ventilation in dedicated paediatric intensive care beds.
60. Ventilation of children at home may be for the whole period of 24 hours or only during sleep. It raises questions of who should supervise and care for the child (who may need supervision throughout the whole 24 hour period), although experience shows that parents and care assistants, as well as qualified nurses, can all contribute after training. Caring for these children in their own homes requires collaboration by and input from a number of different agencies - not only from Health Authorities which may provide nursing care and equipment, but also from Social Services Departments which may provide care assistance as part of the care team, or perhaps home help support to free the time of the parents to allow them to care for the child. Aids and adaptations may be needed - involving housing departments in local authorities - to allow houses to accommodate oxygen or other equipment. It is the view of the National Coordinating Group that children needing long-term ventilation should be cared for in their own homes or as near to them as possible.
61. For most children needing long-term ventilation, the use of a paediatric intensive care bed is not appropriate. Such children are not acutely ill but attention must be paid to their wider development and education. Moving them to a more suitable location or home, allows appropriate care for other critically ill children. In some hospitals, a long-term ventilation unit is being developed alongside the paediatric intensive care unit, where support from experienced intensivist nurses and clinicians is readily available. Community nursing teams helping to care for children in their own homes may also need such support.

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<sup>11</sup> From survey by Regional Coordinators.

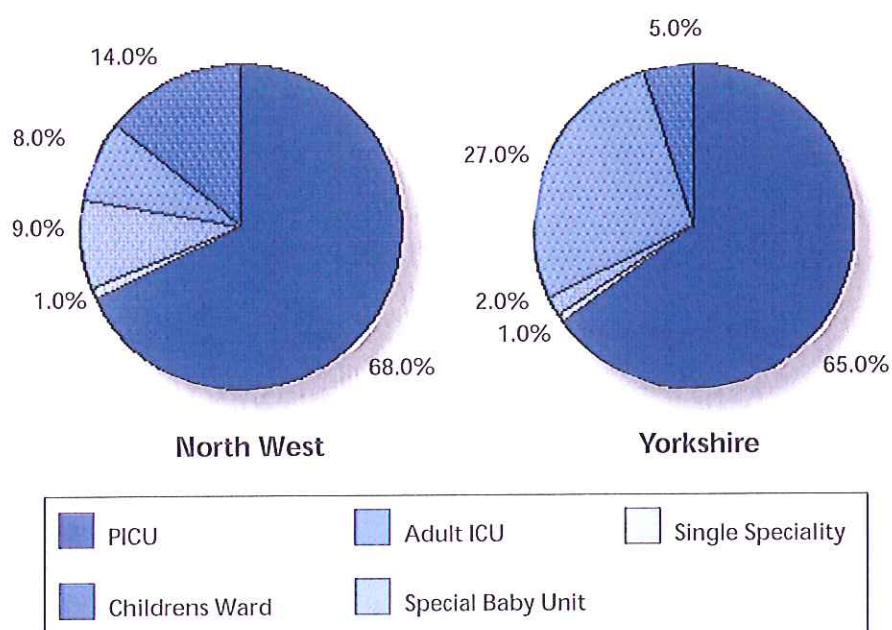
### Advantages of a Long-Term Ventilation Unit

- Better provision for children's needs than accommodation in either a dedicated paediatric intensive care centre or on a general children's ward
- Provides a less acute but highly supportive environment, focused on longer-term needs.
- Allows education and training and support for families who may later care for the child at home.
- Provides respite care for children normally cared for in their own homes and for their families.
- Running costs per bed less than half (sometimes only one-third) of those in a dedicated paediatric intensive care centre.
- Allows more appropriate use of dedicated PIC beds - for those with acute needs.

### Where children are cared for

62. It has always been the case that a considerable number of critically ill children do not receive their care in a hospital bed which is dedicated to paediatric intensive care. Since the Chief Executive's report was published in May last year, more information has become available about where children are treated. The surveys in the North West and in Yorkshire have shown what proportion of care is provided on general children's wards, in single speciality children's wards, in general (adult) intensive care units, and in the paediatric intensive care centres.

**Location of Paediatric Intensive Care at level 2 and above in the North West and in Yorkshire, 1995/96**



Source: Prospective study - North-West, retrospective study Yorkshire

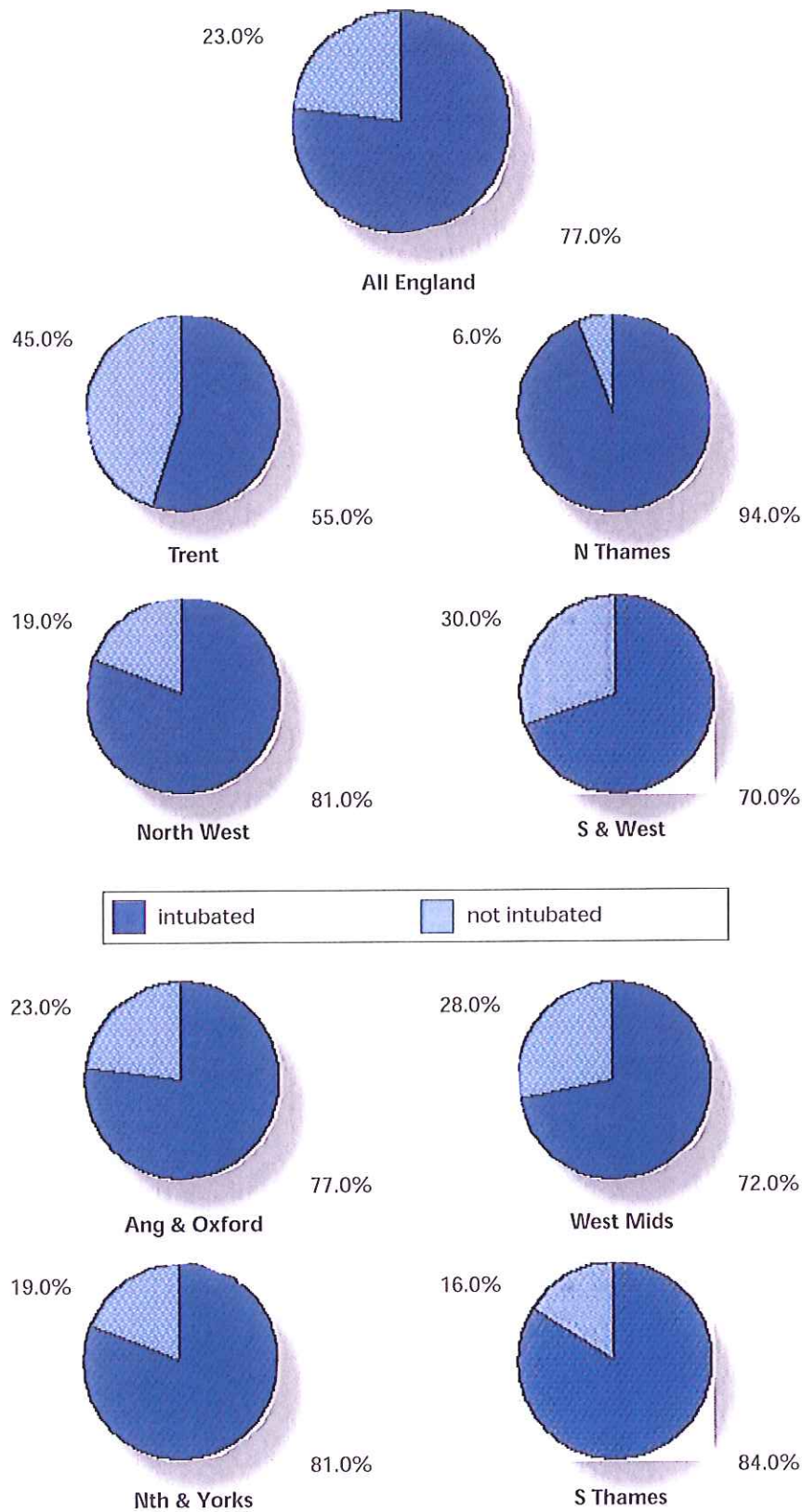
63. This chart shows that a significant proportion of care at Level 2 or above is provided *outside* paediatric intensive care centres. Twenty-two per cent of intensive care in the North West (at Levels 2 & 3) was provided on general children's wards and in general (adult) intensive care units, despite the fact that the region has two large paediatric intensive care centres and is relatively well provided with beds in relation to its child population. In Yorkshire, the pattern of provision of intensive care is similar but reveals fewer children treated on children's wards and a much higher percentage in adult intensive care units.

***Provision of high dependency care in dedicated paediatric intensive care beds***

64. The North West Survey shows that 55% of all high dependency (Level 1) care - as defined for that report - was provided on general children's wards. A further 35% was provided on single specialty wards. 8% of Level 1 care was provided in the two paediatric intensive care centres (this was mainly at times of low demand for intensive care at Levels 2 and 3). In Yorkshire 9% of all Level 1 care was provided in dedicated paediatric intensive care beds.
65. The ratio of intubated to non-intubated patients can provide an approximate indication of the amount of high dependency care provided in *dedicated* paediatric intensive care beds. This ratio shows wide variations between the different regions, as the chart overleaf (which is only for dedicated *general* paediatric intensive care beds), illustrates:



**Percentage of patients intubated / not intubated in dedicated PIC beds**



Source: survey carried out in Sheffield Children's Hospital, 1996-97

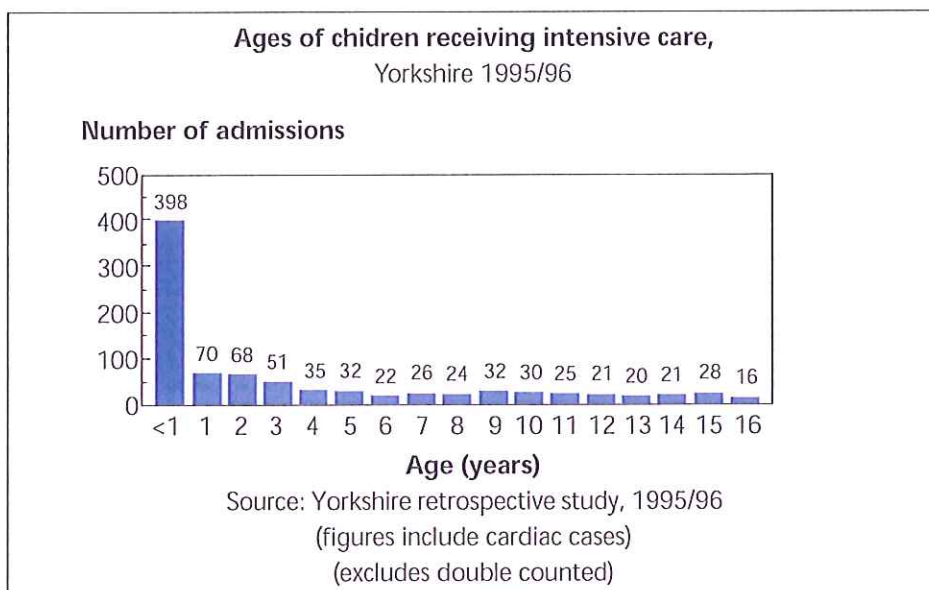
66. A child who is not intubated may occasionally be receiving paediatric intensive care at Level 2 or above. Nevertheless, the variations shown in this chart raise questions about the appropriateness of the care currently being provided in some dedicated paediatric intensive care beds, and about the cost-effective use of those beds.

#### *Causes of admission for intensive care*

67. The study in the North West also revealed the main causes of children needing intensive care at levels 2 and 3. These were respiratory (27%), neurological (12%), trauma (11.5%), and cardiac (11%). The study showed that 2.2% of all acute paediatric admissions needed either high dependency or intensive care and just over 1% of them needed intensive care at Level 2 or above. Thirty per cent of paediatric intensive care admissions were following major surgery. Of this last group, nearly 80% of the operations were elective rather than emergencies. Fifty per cent of all episodes of paediatric intensive care at Level 2 or above arose in the tertiary or regional hospital, and the other 50% in District General Hospitals. A third of all paediatric intensive care at Level 2 or above arose from tertiary practice (including because of major surgery).

#### *Ages of children needing Intensive Care*

68. Most children needing intensive care at Level 2 or above are very young. The age profile revealed by the study in Yorkshire provides helpful information on the ages of children cared for in that area in 1995-96. It shows that over half of the children were under two years old.



69. The age distribution of critically ill children raises questions about the appropriateness of providing paediatric intensive care on a general (adult) intensive care unit.

# Delivering a high quality paediatric intensive care service

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## **Service Delivery**

70. The most important factor for any family whose child needs intensive care is that the child should recover fully, and as quickly as possible. We believe that this is far more important to families than the distance that they may have to travel to visit a child who is being treated in intensive care.
71. Intensive care is an expensive facility because of the need for sophisticated equipment, trained specialist staff and accessibility of a wide range of support and other services. It therefore cannot be provided in every locality. The National Coordinating Group believes, however, that children should have equal access to an appropriate standard of care for their needs, regardless of where they live.
72. There are a number of components of a high quality paediatric intensive care service. What is needed depends to a certain extent on the severity of the child's illness.

## **Skills and Experience of Staff**

73. The most important element, by far, is the skills and experience of the medical and nursing staff who will be caring for the critically ill child. They need both skills and knowledge in managing children and in provision of intensive care. In paediatric intensive care, specialist skills have been shown to be important in achieving the best possible outcomes for children<sup>12,13</sup>. For both nurses and clinicians, approved training is provided in two stages:

	Nurses	Clinicians
<b>A) Core Training</b>	Registered Children's Nurse	Paediatrics Anaesthesia Paediatric Surgery
<b>B) Intensive Care Training</b>	English National Board Course, ENB 415, in Paediatric Intensive Care	<i>Now:</i> Training in USA, Canada, or Australia  <i>In future:</i> Approved Training in the UK under the proposals of the Intercollegiate Committee on Training in Paediatric Intensive Care Medicine

74. The second important element for staff caring for critically ill children is that they should retain and develop their knowledge and skills. The small numbers of very critically ill children needing intensive care, and the complexity of the problems involved in treating them, suggest that staff should manage sufficient numbers of children needing Level 2 care or above each year to keep their skills and experience up to date. In addition, it is

<sup>12</sup> M M Pollack, T T Cuerdon, K M Patel, UE Ruttiman, PR Getson, M Levetown: "Impact of quality-of-care factors on paediatric intensive care unit mortality" JAMA 1994;272

<sup>13</sup> G A Pearson, F Shann, P Barry etc op.cit



essential that nurses and clinicians treating critically ill children should have access to specialist, multi-disciplinary expertise whenever it is needed.

- 75 The evidence on the skills of staff and the caseload they need in order to maintain and develop their competence, taken as isolated examples, is not absolutely conclusive. But taken together, it suggests the need to concentrate skills and expertise in larger centres. The National Coordinating Group has noted that there has never been any suggestion that there was merit in moving to a service where fewer staff working in smaller, more localised settings, had the necessary skills.
- 76 Apart from the skills and experience of the staff, the treatment of a critically ill child requires:
- Availability of other tertiary services on site (depending on the type and severity of the child's illness);
  - Child-friendly accommodation and facilities;
  - Facilities for the family to visit and stay with the child;
  - Specialist equipment for children of differing ages;
  - Support services, such as paediatric pathology, laboratory services and paediatric radiology;
  - Provision of safe transport to other appropriate facilities if needed.
77. The families of critically ill children (and the children themselves when they are old enough), have a right to an explanation of the treatment proposed for them and what it will entail <sup>14</sup>, and enough information so that they can agree to the care which is being proposed.

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<sup>14</sup> "The Patients Charter: Services for Children and Young People"

### ***Support for Parents***

In focusing on the needs of the critically ill child, there is a risk that the needs of the parents and other family members may be neglected by paediatric intensive care staff. Admission of a child to intensive care represents a crisis situation for the family - often it is an emergency event which does not allow parents time for emotional preparation. Parents may also experience practical difficulties because of admission of a child to paediatric intensive care - such as financial demands, due to the need to visit or stay with a child who is a long way from their home.

Many steps can be taken<sup>15</sup> to help the parents and other family members, including:

- orientation to the intensive care unit, the waiting area, and other facilities which they can use, such as a telephone;
- an explanation that they can have continual access to their child;
- introductions to the key members of the intensive care team responsible for caring for the child, and explanations of the equipment and monitoring devices which are in use;
- encouragement to interact verbally and physically with their child, despite the medical interventions and monitoring equipment;
- encouragement to express their feelings and concerns (a social worker may be attached to the intensive care centre and would be in an excellent position to reassure parents and provide appropriate supportive counselling);
- referral to community agencies which may help with financial or other difficulties;
- help in preparing themselves and the child's siblings for the possible death or only partial recovery of the child.

### ***Providing care in the most appropriate place***

**78.** The evidence suggests that children in the highest risk groups are less likely to die if treated in a paediatric intensive care unit in a tertiary centre.<sup>16,17</sup> One study<sup>18</sup> comparing England and Australia also suggested that mortality (after adjustment for severity of illness on admission) will be lower in large tertiary centres with a full complement of trained specialist staff and a high throughput of patients.

<sup>15</sup> "Psycho-social Aspects of Paediatric Intensive Care: The Parent" Katherine Lipsky, from A Practical Guide to Paediatric Intensive Care (Lewin, Morris and Moore, New York)

<sup>16</sup> MM Pollock, SR Alexander, N Clarke, VE Ruttimann, HM Tesselaar, A Bachulis: "Improved Outcomes from Tertiary Centre Paediatric Intensive Care, A State-wide Comparison" Critical Care Medicine 1991;

<sup>17</sup> R J B J Gemke : G J Bonsel: "Comparative assessment of Paediatric Intensive Care: A national Multi-Centre Study". Critical care medicine 1995;23

<sup>18</sup> G A Pearson, F Shann. P Barry etc: op.cit note 10.

79. The number of very critically ill children (ie those at level 2 or above) is small. Our work suggests there are around 12,000 admissions each year in England - which would average 120 in each Health Authority area. The number of children needing the highest levels of care (Level 3 or above) may only be around 1000 in England as a whole. These numbers, together with the evidence that these children are best treated in tertiary centres, leads us to suggest that expertise in treating the very highest risk children should be concentrated, and that they should *only* be cared for in a tertiary centre covering a large population. It is difficult to justify the employment of a team of highly skilled staff for only small numbers of critically ill children - and we have argued that such a highly skilled team is needed to produce the best outcomes. To maintain expertise, the large centres should cover a population of at least 500,000 children aged between 0 and 16.
80. In an emergency, critically ill children need to be admitted to a local hospital so that their condition can be stabilised and they can be resuscitated if necessary. All District General Hospitals which admit children as inpatients should be able to carry out emergency treatment and stabilisation for any critically ill child. In other words, District General Hospitals, in addition to providing high dependency care on children's wards, must be able to establish intensive care - ie to ventilate children if necessary - prior to their transfer.
81. A number of hospitals have developed as single-specialty sites which need to provide some intensive care, for both adults and children, e.g. following cardio-thoracic surgery or treatment for severe burns. A number of reports have proposed that, because of the interdependence of specialties, small single speciality hospitals should gradually be amalgamated with others, so that a wider range of specialties is available on one site and, if they are caring for children, there should be on-site paediatric cover.<sup>19,20,21</sup> The National Coordinating Group supports this view and was pleased to learn that the British Burns Association has initiated a national review of care for people suffering from burns, with a view to advising the Department of Health about the most effective and cost-efficient pattern of burn care. This review will cover paediatric intensive care for children with burns. However, for the immediate future, it appears that single speciality hospitals, such as burns centres, will continue to provide some intensive care for critically ill children needing particular specialist treatments.

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<sup>19</sup> British Paediatric Association: "Purchasing Health Services for Children " Vol.1 1994

<sup>20</sup> "Tertiary Services for Children and Young People" BPA 1995

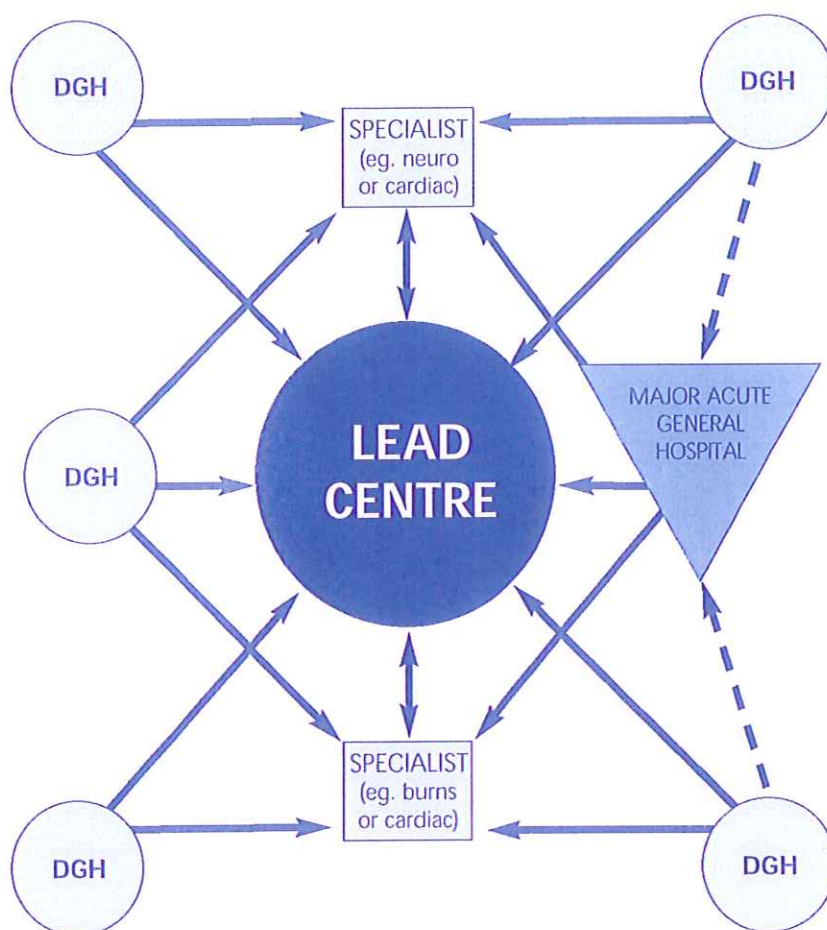
<sup>21</sup> London Implementation Group - Review of Children's Services, 1993



82. The analysis above leads us to suggest that, within any defined geographical area, there should be a service which provides care for each critically ill child in a facility which is best able to meet his or her needs. The system which is needed to care for critically ill children will involve accident and emergency departments and the ambulance service as well as hospitals. These hospitals, which should form part of a unified paediatric intensive care service, could be divided into 4 types:

- i      The **District General Hospitals** admitting children, which provide high dependency (Level 1) care, and which are able to resuscitate, intubate and stabilise children - ie initiate intensive (Level 2) care. This would allow the children to be stabilised prior to transfer (which sometimes may not be necessary - eg if intubation is only needed for a very short period (a few hours)).
- ii.    A large "lead centre" providing all Level 3 and most Level 2 care, supporting (eg through provision of advice and training) all intensive care provided across the geographical area and providing an expert retrieval service for critically ill children.
- iii.   In particular circumstances, **major acute general hospitals** with large adult intensive care units, which currently provide a considerable amount of intensive care for children. These will be able to continue providing Level 2 care and to initiate Level 3 care if they meet the standards.
- iv.    **Specialist units** providing intensive care (for both adults and children) in support of the individual speciality (eg, cardiac, neurosurgery, burns);

**PROPOSED ORGANISATIONAL STRUCTURE**  
 (for a hypothetical geographical area)



**Lead centre:**

providing all general and emergency level 3 and most level 2 care and the retrieval service.

**Major acute general hospital:**

with a large general intensive care unit and with paediatric provision. This will already provide a considerable amount of level 2 care, and be able to initiate level 3 care.

**Specialist centres:**

providing PIC only in association with the specialty.

**Network of DGHs:**

able to establish level 2 care prior to transfer to an appropriate PIC or specialist unit.

83. A District General Hospital which admits children as in-patients will provide high dependency care. Such care should be provided in a separate, identified, clinical area, usually within the children's department. A separately designated area will more easily be able to establish links with the paediatric intensive care service than a dispersed service. District General Hospitals should be able, by means of close collaboration between staff in their children's department and general (adult) intensive care department, to initiate intensive care. The National Coordinating Group recommends the following standards for District General Hospitals initiating intensive care:-

**STANDARDS: ALL HOSPITALS WHICH ADMIT CHILDREN (DGHs)**

**Facilities and Staffing for those initiating Level 2 care.**

- Acutely ill children should be taken to a hospital which has paediatric in-patient facilities, staffed by doctors and nurses trained to resuscitate children.
- In hospitals with an accident and emergency facility, there should be a separately designated and equipped area specifically for the resuscitation and stabilisation of children within that facility.
- Facilities for the *establishment* of intensive care of critically ill children should be designated (either in a high dependency area, on a children's ward or in the general intensive care unit), where they can be cared for until the arrival of the retrieval team.
- The facility must be physically sited where there is *immediate availability* of medical staff who have paediatric airway skills, supported throughout the 24 hour period by consultant paediatricians and anaesthetists.
- An area within the hospital should be identified for the high dependency care of children, and they should be physically separated from adult patients undergoing intensive care.
- Nursing staff should be registered children's nurses. Those helping to establish intensive care should have advanced paediatric life support or paediatric advanced life support skills.
- There should be access to, and support from, nurses within the hospital with general (adult ) or neonatal intensive care skills, as appropriate.
- There should be continuous access to specialist advice from clinicians and nurses trained in paediatric intensive care in the lead centre.
- The family must have access to the child at all times
- Protocols for the resuscitation and stabilisation of children, and their transfer, should be developed in conjunction with the lead centre.

84. All staff in District General Hospitals which treat critically ill children need close contacts with the lead centre for paediatric intensive care, and may need regular periods of training in the lead centre in order to maintain and update their knowledge and skills. Protocols should be developed in each geographical area covering the links between hospitals so that the *service* covers the whole of the geographical area and all children are able to access the care they need.

***The Lead Centres***

85. Identified centres which specialise in providing paediatric intensive care should be able to treat a wide range of illnesses in children needing Level 2 or Level 3 care, for a prolonged period if necessary. (Some very specialised treatments, such as extra corporeal membrane oxygenisation (ECMO), will only be available in a very few centres). Lead centres must be able to provide, not only for the clinical and nursing care of the child, but also for the child's wider needs. Responding to the needs of the child's family will be an essential element of the work of a lead centre; and families must be able to be with their child throughout the 24 hour period. The National Coordinating Group is of the view that lead centres should conform to a wide range of standards, as set out below.



## STANDARDS: LEAD CENTRE

### Medical Staff

- Lead Consultant (and deputy) with approved training (two years) in paediatric intensive care.
- All *future* Consultant appointments with sessional commitment to PIC and/or on call rota to have had approved training in paediatric intensive care.
- Cover in the unit for the whole working week by a consultant whose only clinical responsibility is to the centre and sufficient consultants to provide cover throughout the day and night.
- Resident specialist registrar (or equivalent) cover for the whole 24 hours by staff with advanced paediatric resuscitation skills, whose only clinical responsibility is to the centre.
- Access on site to consultants in paediatric tertiary specialties eg neurology, renal, surgery and radiology

### Nursing Staff

- Key nurse, providing the focus for the development of joint approaches to nursing standards, staffing and education for the whole PIC service.
- Intensive supervision and continuous observation of each child at all times by a registered children's nurse qualified in intensive care - some children may require 2 nurses at the bedside throughout the whole 24 hour period.
- Support and supervision by an experienced registered children's nurse with a recognised PIC qualification and several years' experience in PIC.

### Competencies and equipment required

- Appropriate equipment and the ability to undertake, for children of all ages, procedures including artificial ventilation, invasive cardio-vascular monitoring, renal support, intra-cranial pressure monitoring, intravenous nutrition, high frequency oscillation, nitric oxide administration.

### Access throughout the 24 hours to

- Paediatric microbiological, biochemical, haematological facilities
- All routine radiological & imaging facilities, including ultrasound & CT scanning

### Retrieval Service

- Fully equipped and resourced, and available at all times



STANDARDS: LEAD CENTRE	
<b>Facilities for families</b>	
	<ul style="list-style-type: none"> <li>• Access at all times</li> <li>• Lounge, kitchen and toilet facilities and a telephone adjacent to the centre</li> <li>• Accommodation for parents within the hospital</li> <li>• Restaurant facilities within easy reach of the centre</li> <li>• Child-orientated decoration and design</li> </ul>
<b>Supporting on site or on call</b>	
	<ul style="list-style-type: none"> <li>• Play specialists, social workers, chaplains, psychologists, physiotherapists, dieticians, pharmacists</li> </ul>
<b>Training</b>	
	<ul style="list-style-type: none"> <li>• Provision of ongoing education and training for all the centre's staff</li> <li>• Ongoing training for all staff in the PIC service covering the geographical area</li> </ul>
<b>Clinical Effectiveness and Management</b>	
	<ul style="list-style-type: none"> <li>• Protocols for admissions, discharges, resuscitation, stabilisation and the treatment of all major conditions</li> <li>• Data collection on illness severity, length of stay, outcomes</li> <li>• A commitment to research and audit</li> <li>• Protocols for retrieval into the lead centre and transfer to other centres</li> <li>• Critical incident reporting</li> </ul>

86. A lead centre should have at least 5-7 consultant staff with some commitment to the centre, who, together, will provide 24 hour cover (some of them may have responsibilities outside paediatric intensive care). The consultants' primary (core) training may be in either paediatrics or anaesthesia, but all of them, in due course, will have received approved post-graduate training and substantial experience (a minimum of 12 months) in paediatric intensive care. Ideally, the consultant team should have a mix of core skills. This number of consultant staff, (supported by at least 2 medical staff in training or equivalent middle grade medical staff at any one time), could manage from 8 up to around 20 patients at any one time, depending on the other responsibilities of the consultants. Provision of consultant cover will also need to take account of the responsibility for the retrieval service covering the geographical area.
87. To maintain the recommended levels of service and staffing, it is difficult to justify a lead centre having a throughput of fewer than 500 children a year who need care at Level 2 or above. These numbers may include children admitted as a result of specialist treatment on the same site - such as those recovering from cardiac or neuro-surgery. This number of admissions would also be sufficient to maintain the skills of the clinical and nursing staff. A lead centre with this throughput will probably have at least 8 beds.

#### **Major Acute General Hospitals**

88. Major Acute General Hospitals which have an *established practice* of caring for considerable numbers of critically ill children and which meet a number of standards may form part of the organisation of a paediatric intensive care service which covers a defined geographical area. Hospitals should not become part of the paediatric intensive care service covering the

geographical area unless they *currently* treat more than 50 children needing Level 2 care or above each year. Typically, such hospitals will be large centres with busy general (adult) intensive care units and large, appropriately staffed, existing inpatient paediatric facilities. The standards which should apply in these major acute general hospitals are set out below:

## **STANDARDS: MAJOR ACUTE GENERAL HOSPITALS**

### **Medical Staffing**

- A consultant with approved training in paediatric intensive care will lead the paediatric component of the intensive care service and will have a major sessional commitment to the unit.
- While children are being treated in intensive care, each clinical session and the on-call rota should be covered by a consultant who has training and continuing experience in paediatric intensive care.
- All the consultant staff providing cover should have completed advanced paediatric life support or paediatric advanced life support (instructor) training.
- Specialist Registrar (or equivalent) immediately available at all times with advanced paediatric resuscitation skills.
- Access to advice from a consultant with paediatric intensive care training at the Lead Centre.
- Access to Consultants in paediatric sub specialities eg neurology, renal, surgery and radiology.

### **Nurse Staffing**

- Supervision and observation of the child at all times by a registered children's nurse with an appropriate intensive care qualification, age specific to the needs of the child.
- Supervision at all times by an experienced registered children's nurse with training and experience in paediatric intensive care.

### **Facilities**

- Appropriate equipment to enable artificial ventilation, invasive cardiovascular monitoring, intravenous nutrition, renal support etc for all ages of children.
- Access to expert microbiological, biochemical and haematological advice.
- Immediate access to radiological and imaging facilities including ultrasound and CT scanning.
- Access to appropriately trained professionals allied to medicine, for example, paediatric physiotherapists.
- Access to psychological and emotional support including social workers, psychologists, chaplains and play specialists.
- A child-orientated environment, physically separated from areas for adults.
- Access and facilities for families including lounge, kitchen, telephone and toilet facilities adjacent to the centre and restaurant facilities and accommodation within the hospital.
- The family must have access to the child at all times.

### **Clinical Effectiveness and Management**

- Protocols for admissions, discharges and the treatment of all major conditions.
- Data collection on illness severity, length of stay, outcomes.
- A commitment to research and audit.
- Protocols for retrieval into the lead centre, or to other centres.
- Critical incident reporting.



89. The major acute hospitals must have close links with their lead centre, should see sufficient numbers of children to maintain the skills of specialist staff and should not treat children needing Level 3 care (other than stabilising their condition when it is deteriorating). The National Coordinating Group believes that it would be difficult to justify the level of service and staffing described above on a throughput of less than 500 adults requiring intensive care *and* more than 50 critically ill children needing Level 2 care each year. Very few hospitals will be able to meet these standards - in some regions there will be no such hospitals. The National Coordinating Group believes that there should be no further development of paediatric intensive care in major acute general hospitals which do not currently meet the standards described in this report.

#### ***Single Specialty Hospitals***

90. Intensive care facilities in stand-alone single specialty hospitals currently treat children at dependency Levels 1,2 or 3. Intensive care should be linked directly to the specialty provided. Children with multi-organ failure should *not* be treated in single speciality hospitals which treat small numbers of children. There is evidence of difficulties in treating children in specialist facilities where most of the work is orientated towards adults, and which do *not* have an appropriate child and family-focused structure. For example, children who have suffered severe burns, and their families, often need a high level of social work and other support. The National Coordinating Group believes that surgeons and anaesthetists in single specialty hospitals should not undertake occasional work with children<sup>22</sup>.
91. Specialist facilities should have close links with the lead centre covering the geographical area, in particular for training purposes, and should develop arrangements on transfer of children in appropriate cases. Serious consideration should be given to ceasing, in the long term, provision of paediatric intensive care in specialist facilities which do not treat at least 50 children needing care at Level 2 or above each year. In planning service re-configuration, account must be taken of the need for specialties to have full on-site paediatric and intensive care support. In the meantime, specialist hospitals should aim to meet the standards set out below. The National Coordinating Group recognises that some of these will not be attainable in the smallest single-speciality hospitals. However they should be viewed as the goal for treating children in those specialties, and those standards that can be achieved should be included in the action plan for services in the geographical area.
92. Joint work should be undertaken between the lead centre and single speciality hospitals to determine how best to support intensive care for children needing treatment in the specialty.

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<sup>22</sup> National Confidential Enquiry into Perioperative Deaths and Perioperative deaths of children. Lancet 1990;335

## STANDARDS: STAND ALONE SINGLE SPECIALTY HOSPITALS

### Medical Staffing

- A paediatric consultant should be closely involved in the care of each child.
- While children are being treated in intensive care, each clinical session and the on call rota should be covered by a consultant who has training and continuing experience in paediatric intensive care.
- All the consultant staff providing cover should have completed advanced paediatric life support or paediatric advanced life support (instructor) training.
- Specialist Registrar (or equivalent) immediately available at all times with advanced paediatric resuscitation skills.
- Access to advice from a consultant with paediatric intensive care training in the Lead Centre.
- Access to advice from consultants in paediatric sub specialities eg neurology, nephology and radiology.

### Nurse Staffing

- Registered children's nurses with experience in intensive care will provide continuous monitoring and observation.
- A senior registered children's nurse with training and experience in paediatric intensive care available for support and advice.

### Facilities

- Appropriate equipment to enable artificial ventilation, invasive cardiovascular monitoring, intravenous nutrition, renal support, intracranial pressure monitoring, etc, for all ages of paediatric patients.
- Access to expert microbiological, biochemical and haematological advice.
- Immediate access to radiological and imaging facilities including ultrasound and CT.
- Access to appropriately trained professionals allied to medicine, in particular paediatric physiotherapists with intensive care experience.
- Access to psychological and emotional support including social workers, psychologists, clergy and play specialists.
- A child orientated environment, physically separated from adults.
- Facilities for families including lounge, kitchen, toilet facilities and a telephone adjacent to the unit and restaurant facilities and accommodation within the hospital.
- The family must have access to the child at all times.

### Quality and Management

- Clear documented management policies, agreed with the lead centre.
- Written protocols, agreed with the lead centre, for the treatment of major conditions.
- Protocols for transfer into the lead centre, especially for children with multi-organ failure.
- Protocols for prior resuscitation and stabilisation at referring hospitals.
- Data collection on illness severity, length of stay and outcome on all patients.
- Critical incident reporting.
- A commitment to research and audit.



### Organisation of the Service

93. A tiered service as described above could only function efficiently if those providing care for critically ill children in all locations and at all levels have close links with each other. It is essential that clinicians and nurses working in all hospitals within the area know:
- i. Which hospitals can admit critically ill children in emergencies;
  - ii. Where specialist care can be provided (eg neurosurgery);
  - iii. Where they can get help and advice from experts.
94. This suggests that all those providing care for critically ill children, and all health authorities responsible for arranging such care for their populations, should form groupings within each geographical area. The National Coordinating Group recommends that protocols should be developed setting out which types of care for critically ill children can be provided in which hospitals within the area, and when transfer of children should take place.

### Retrieval Services

95. Focusing care for most critically ill children in tertiary centres, which gain expertise from seeing a large number of such children, requires a safe, efficient retrieval service to bring the most critically ill children into those centres. Transfer of critically ill children requires special skills, and each child needs to be accompanied by a clinician and a nurse, both of whom should have had training in paediatric intensive care and have received additional training, followed by experience, in transporting critically ill children. The National Coordinating Group believes that retrieval services should be consultant-led. There have been several studies which demonstrate that the risks to children are low when they are cared for during transport by doctors trained in paediatric intensive care<sup>23</sup>. In contrast, ad hoc provision of transport services which may involve doctors with no paediatric training and/or no intensive care training carries risks of mortality of 20% or more.<sup>24, 25</sup>
96. The National Coordinating Group envisages that a transport service will be based at the lead centre, where there would be sufficient specialist paediatric intensive care consultants and nurses to provide the necessary staff. The transport service should cover the whole of a geographical area: it may, on occasion, be needed not just to bring children to the lead centre, but to transfer them to a specialist centre, which is able to provide care for the child's particular needs. If all beds in the lead centre are full, the retrieval service may need to take a critically ill child to a lead centre in another area.

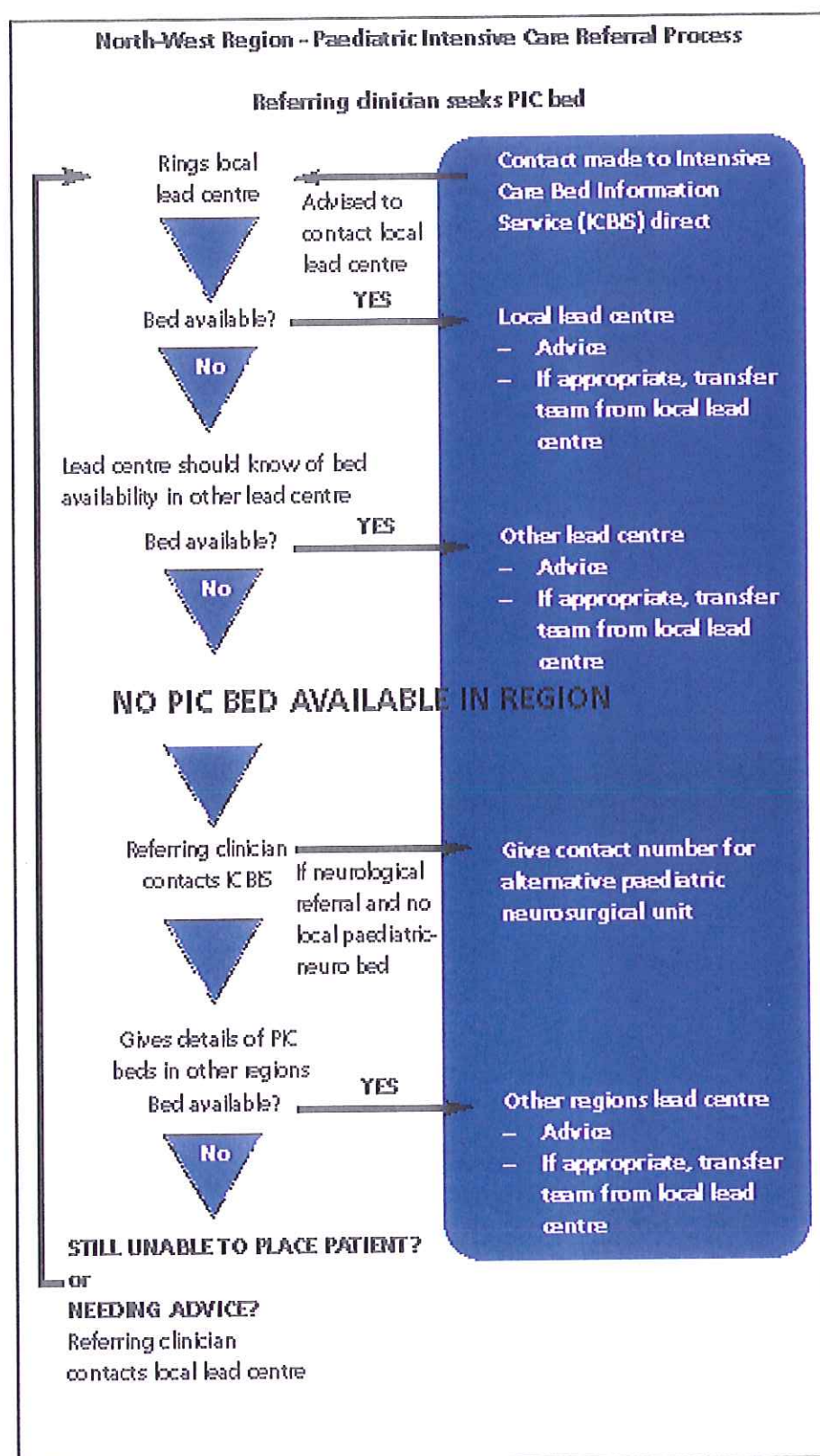
<sup>23</sup> A J MacNab: "Optimal Escort for inter-hospital transport of paediatric emergencies" *Journal of Trauma* 1991; 31

<sup>24</sup> W E Edge, R K Kanter, C G M Weigle, R F Walsh "Reduction of morbidity in inter hospital transfer by specialised paediatric staff", *Critical Care Medicine* 1992;20

<sup>25</sup> P M Sharples, A Storey, A Aynsley-Green, J A Eyre: "Avoidable factors contributing to the death of children with head injury", *British Medical Journal* 1991;300.

97. The National Coordinating Group has established that transport services already exist in some areas, although not all are properly funded. It is essential that health authorities in a defined geographical area should recognise the importance of 24-hour availability of a retrieval service and should arrange a service for all critically ill children in their area. The establishment of a 24-hour service influences the referral pattern for paediatric intensive care and this may cause increased use of the retrieval service itself.
98. In the North West, the retrieval service at Alder Hey, Liverpool collected 153 children over the year 1995-96 - around 3 a week. In Yorkshire, there were 125 retrievals into the Leeds paediatric intensive care centre in 1995-96, and retrieval could have been carried out for a further 112 admissions needing intensive care. Based on those studies, we have estimated that the need for retrieval services is for around 170 journeys per million children in the population per year. The service is therefore highly specialised and does not justify a team of staff devoted to this service alone. It can only be provided in a cost effective manner in the larger centres, where there is likely to be a pool of trained staff available to carry out a few retrievals each week, without detriment to the needs of other patients in that hospital.
99. Within each area there will need to be protocols governing the admission and transfer of critically ill children. In particular, each hospital providing care for critically ill children at whatever level should have a named individual who will liaise with the duty consultant in the lead paediatric intensive care centre. If the discussion between senior clinicians reaches the conclusion that the child should be transferred, the retrieval team should be despatched to collect the child, and transfer him or her either to the lead centre or, if it is full, to the nearest alternative lead centre with an available bed. The Intensive Care Bed Register may be used to locate the nearest available bed if necessary.

100. An example of a protocol is shown in diagrammatic form below.





101. Where a critically ill child is transferred to the lead centre by a retrieval service, or exceptionally is transferred to a specialist hospital or to a lead centre in another area, arrangements should be made to transport the immediate family members of the child to the hospital where treatment is being carried out. Similar arrangements should be made on discharge. This may involve arrangements with the ambulance service, or transport may be provided by taxi. Because of the need for critically ill children to be accompanied by at least 2 specialist paediatric intensive care trained staff, and because of the amount of equipment needed, there may not be space within the ambulance for family members to accompany the child. However, this does not mean that they should not be provided with all possible help in travelling to the hospital where the child is to be cared for.
102. Most children's hospitals provide for the overnight accommodation of parents<sup>26</sup> and this should be standard procedure for hospitals providing paediatric intensive care. The average stay in intensive care is around four days, during which time it is likely that family member(s) will wish to, and should be, accommodated at, or close to, the hospital. Where a longer stay is necessary there may be problems for families in meeting travelling expenses incurred by visiting. Assistance with travel expenses may be available from the Social Fund for families on certain social security benefits.

#### *Arranging Services*

103. It has already been suggested in this report that care for the most critically ill children is so limited that it should only be provided over a geographical area covering a large population of at least 500,000 children. This is far more than the number of children covered by any single Health Authority - and many health authorities will not need to arrange intensive care at Levels 2 and 3 for more than a 100 or so children each year. This suggests that it is imperative for health authorities to form groups, which together will arrange paediatric intensive care at Levels 2 and 3 in a relatively small number of hospitals. They might also collaborate to arrange high dependency care, especially where high dependency beds are linked to, and provide step-down care from, intensive care beds in a lead centre or major acute general hospital. Organisationally, groups of health authorities could be led by a lead Health Authority.
104. The Chief Executive's report of May 1996 stated that arrangements for meeting the need for paediatric intensive care should be explicit. Within each group of health authorities, each Health Authority would be expected to contribute towards the arrangement of a total volume of paediatric intensive care in the geographical area, according to the likely needs of its population. The likely level of demand in any one area can vary, and should be checked by means of a prospective audit. Explicit arrangements should also cover a retrieval service covering the whole of the geographical area (which will ensure that critically ill children receive care in a setting appropriate to their needs), and an audit system (to maintain clinical standards and provide data on outcomes).

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<sup>26</sup> "Children First: A study of Hospital Services" Audit Commission Report, 1993



105. On the basis of our work, we suggest that arrangements for paediatric intensive care at Levels 2 & 3 should be separated from those for general, tertiary and specialist paediatric services. Health authorities will need to consider the extent to which Level 1 (high dependency) care, when linked to paediatric intensive care provision, should be seen as separate or included in arrangements for general or specialist services - but would need to bear in mind the interaction between the different levels of care and their interdependence. A shortage of high dependency care could impact to the detriment of intensive care, where high dependency care is being used as a step down from Level 2 care.

#### ***Meeting Fluctuations in Demand***

106. The Chief Executive's report of May 1996 suggested that predictable increases in demand might be met in a limited number of paediatric intensive care centres across the country, which were able to increase or decrease the number of intensive care beds they made available according to demand. Typically such centres would be large, would provide a wide range of paediatric services, and would undertake an elective workload which might require about half of their intensive care beds over the year as a whole.
107. Under the model which we have described, the lead centres in each area could be enabled, through agreement by health authorities and hospitals within the area, to meet fluctuations in demand. This would entail increasing and staffing the number of available beds during the winter months, and during other peaks in demand. If beds are unoccupied for some parts of the year, flexible methods of working will be necessary, eg staff may be redeployed to other parts of the hospital, encouraged to further their development and training, or to take leave.<sup>27</sup> The National Coordinating Group is of the view that predictable increases in demand, which occur particularly in winter, should be met by using the lead centres in this way.
108. Fluctuations in demand are probably being met now by caring for critically ill children in some places which will not meet the standards suggested by the National Coordinating Group. The National Coordinating Group is strongly of the view that this is not desirable. Health authorities will need to recognise explicitly the predicted fluctuations in demand and their extent, and state how they will be accommodated within the model for the paediatric intensive care service which is adopted within their area.

#### ***Education and Training***

109. The framework for the future of the paediatric intensive care service, described in this report, can only be established with the standards we consider essential if sufficient trained and qualified medical and nursing staff are available. The underlying principle is that children should receive clinical and nursing care from professionals who are trained in the care of children and who are appropriately prepared for their role when working in any setting which provides paediatric intensive care.

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<sup>27</sup> For further information, see the report of the Chief Nursing Officer's Task Force "Bridge to the Future"

110. The report of the Intercollegiate Committee on Training in Paediatric Intensive Care Medicine and the report of the Chief Nursing Officer's Task Force on paediatric intensive care, respectively, set out strategies for developing a skilled workforce of both clinicians and nurses.
111. Our proposals on the future organisation of the service will have a number of implications for training and development:
- We envisage that the lead centre should develop into a resource of the highest level of excellence in the maintenance of skills and the provision of advice and training covering the whole geographical area. In particular, lead centres are likely to become accredited centres for training in paediatric intensive care medicine and will provide intensive care training for nurses. We suggest that they should also be responsible for arranging placements for both doctors and nurses - in particular, those from centres which see relatively few critically ill children, to maintain their skills.
  - In some hospitals it will be necessary to develop skills in paediatric advanced life support for a number of different staff. This will particularly apply in the District General Hospitals admitting critically ill children, which are responsible for resuscitating and stabilising them prior to transfer to a more appropriate setting. The lead centre should assist in assessing training needs across the whole geographical area, in consultation with the professional staff involved.
  - Provision of paediatric intensive care is undertaken by multi-disciplinary teams of staff bringing different skills to this service. As teams, they can rely on each other's skills and expertise - and recognise that they do not all need to be trained in each and every aspect of the provision of the service. There is scope for multi-professional education in some aspects of paediatric intensive care - for example, bereavement counselling and clinical audit are two areas in which training can and should, in due course, be provided on this basis.

#### **Audit and Research**

112. The National Coordinating Group's proposals, described above, carry two key implications for audit. The first relates to the need for health authorities and NHS hospitals within any given geographical area, to build up a picture of the current pattern of care for critically ill children within that area. The second relates to ongoing clinical audit of the standards of care being provided. Both will require interaction between health authorities and hospitals within each defined area, and, as far as clinical audit is concerned, some wider comparisons to ensure that the highest possible standards are achieved and maintained.
113. Some regions have already carried out audits of provision (retrospective or prospective studies) for critically ill children within their area. The National Coordinating Group would recommend that similar studies should be



carried out across the country, as a basis for developing a model of service provision on the lines suggested in this report. The objectives of such studies should be:

- i. to review the current provision of care for critically ill children in both dedicated and non dedicated beds within the area, including occupancy levels in each centre providing care;
  - ii. to establish how many children require high dependency or intensive care each year;
  - iii. to establish how many of these children are currently cared for in dedicated paediatric intensive care beds;
  - iv. to establish the numbers of referrals and transfers between hospitals, and the extent to which admissions are inappropriately refused.
114. The North West, Anglia and Oxford, and Yorkshire have already undertaken a retrospective survey of provision and the North West has carried out a prospective study (from March 1995-March 1996). Similar exercises are currently being carried out in North and South Thames regions (due to report at the end of 1997) and in the South and West. These studies will continue to inform all health authorities and hospitals across the country and will assist other regions in planning and developing their own audits.
115. Some basic throughput information for paediatric intensive care will in future be collected at a national level through the Augmented Care Period data set, and will start to be available from October 1997.
116. Clinical audit is now a well established discipline within the NHS. The National Coordinating Group is of the view that all those providing paediatric intensive care should collect, as a matter of routine, information on case-mix, including illness severity, method, type and source of admission, the mean and median length of stay, main therapeutic interventions and the outcome for critically ill children who have been treated in the hospital. The Intensive Care National Audit and Research Centre (ICNARC) already collects information on some paediatric intensive care provided in England. Some hospitals have become involved in the case mix programme, a national comparative patient outcome audit coordinated by ICNARC, because of involvement by all intensive care units, both for adults and for children, within the region; others have joined voluntarily.
117. The advantage of centres which provide paediatric intensive care participating in the programme coordinated by ICNARC is that the information collected is standardised and allows an objective evaluation (by an independent organisation with charitable status) of the standard of care being provided. If more centres providing paediatric intensive care subscribe to the ICNARC programme now, we will, in future, have baseline information in areas where such information is currently lacking. It would also allow any changes resulting from this report to be monitored. There is a small cost to units which participate - both in terms of staff time collecting the data and in terms of computer equipment which is needed - but this is

small in comparison to the cost of providing intensive care. The National Coordinating Group recommends that as many hospitals and providers of paediatric intensive care should be covered by ICNARC as possible. There should also be mechanisms whereby the results of the evaluation of data can be shared between geographical areas and between lead centres.

118. The National Coordinating Group was pleased to learn that an audit tool is now readily available via the Internet to allow hospitals to monitor outcomes from paediatric intensive care using the paediatric index of mortality.<sup>28</sup> This will, once the research base has developed, be compatible with ICNARC.
119. The collection of data on outcomes from intensive care for children is not satisfactory, since at present the only outcome measures are mortality or survival. Fortunately, most children who undergo intensive care survive. However, the National Coordinating Group believes that other outcome measures should be developed which reflect quality of life - including morbidity, disability and the functional health of the child after a period in intensive care. These are more difficult to measure than mortality, and we may need a research base to develop new methods of measurement. In the longer-term we need to consider how to measure the humanity and equity of paediatric intensive care. Work on some of these issues is part of research proposals put forward through the Medical Research Council, which are covered in the following paragraphs.
120. The Chief Executive's report of May 1996 outlined research which, at that stage, was being discussed between the NHS Executive and the Medical Research Council. A joint working party on intensive care and high dependency care highlighted the need for high quality research for all age groups (not just children) aimed at evaluating how much care should be provided, to whom it should be provided, when it should be provided and how it should be provided. The report of the working party, published at the end of 1996, summarises the work which has already been carried out, and identifies a wide range of research needs, some of which need to be completed before others can begin. The report also points out that:
- high quality research is already being conducted in the UK on different aspects of intensive care. However, projects often tend to be fragmented;
  - the multi-disciplinary approach needed in such studies is not always present;
  - progress is hampered by a lack of accurate and objective methods that are usable and acceptable by a wide range of health care professionals, health authorities and policy makers.
  - methodological research is central and needs to build on existing work and include quality input from the professional groups who will eventually use its outputs.

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<sup>28</sup> Internet reference: <http://pedsccm.wustl.edu/clinical/software.html>.



- 121.** The working party report, therefore, suggests that a framework for future research needs to be applied.
- 122.** The Medical Research Council and the National Health Service Research and Development programme have expressed willingness to fund high quality research (subject to availability of funds and the number of high quality proposals in other fields) which fits within the framework set out in the working party's report. In particular, the Medical Research Council has indicated that it would welcome research proposals covering:
- Risk Assessment (the development and validation of risk adjustment methods for adult, paediatric and neonatal intensive care and high dependency care);
  - Costing methods (the development of methods for costing for adult, paediatric and neonatal intensive care and high dependency care);
  - Needs Assessment (methods of needs assessment to identify the need for, and appropriate targeting of adult, paediatric and neonatal intensive care or high dependency care);
  - Specific Interventions (a high technology assessment of specific interventions in adult, paediatric and neonatal intensive care and high dependency care).
- 123.** The NHS Health Technology Assessment programme has also advertised for research in this area. Proposals submitted to the Medical Research Council will be expected to complement work funded by the Health Technology Assessment programme
- 124.** The National Coordinating Group recognises that further research into paediatric intensive care is needed, but in the meantime, the service should not be permitted to continue to develop in an ad hoc manner.

***Pathway to the new service configuration***

- 125.** Moving from the existing position to our proposed new model of provision will take several years. It is important that health authorities and hospitals should keep the long term objective in view, and should consciously move towards the proposed service pattern which represents a vision for the longer term. The existing pattern of provision has evolved in an ad hoc way over a number of years - and without any national planning or long term consideration of the objectives. For this reason, the National Coordinating Group suggests an agenda for action, which might be followed by regional offices, hospitals and health authorities in working towards the future framework.
- 126.** As an *immediate* first step, we recommend that any additional designated paediatric intensive care beds opened from now on should be in the large centres which are likely to become lead centres and which will be accredited for medical training. It is crucial to an organised and planned framework for provision of this service that ad hoc developments, and provision of additional single, isolated paediatric intensive care beds, should cease.

127. By the end of March 1998, regional offices, health authorities and hospitals should have:-

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- i. identified the current pattern of provision, including the numbers of admissions of critically ill children to children's wards and general (adult) intensive care units, if this has not already been done as part of an audit;
- ii. set up a working group (to include a lead Health Authority, a manager, the regional coordinator and paediatric intensive care lead professionals from all centres providing the service across the geographical area concerned) to steer the work;
- iii. reviewed the existing pattern of service against the standards and proposals set out in this document;
- iv. identified the lead centre (and any major acute general hospitals meeting the standards) for the area concerned;
- v. identified the lead clinician and key nurse (in the lead centre) for the geographical area and the lead clinician in each other hospital involved;
- vi. decided the location of the retrieval service;
- vii. formed consortia of health authorities to organise the service (possibly with a lead Health Authority);
- viii. ensured that arrangements cover a 24-hour retrieval service and a system of audit of outcomes for the defined population;
- ix. decided where periodic increases in demand (such as occur in winter) are to be handled within the pattern of service provision covering the geographical area;
- x. assessed workforce and training provision in each area;
- xi. taken steps to ensure that no critically ill children needing Level 2 or Level 3 care, are treated on children's wards.
- xii. begun to develop local protocols on the organisation of the service, criteria for admission, discharge and for transfers between units.

The National Coordinating Group believes that, in moving towards a new pattern of provision, care for the most critically ill children should be removed from the inappropriate location of general children's wards in District General Hospitals. Many District General Hospitals will continue to provide high dependency care and should be able, in an emergency, to stabilise and intubate children needing level 2 care, in association with their general (adult) intensive care unit.



- 128.** Between March 1998 and March 2000, regional offices, health authorities, and hospitals should continue to develop their strategies for moving towards a more appropriate pattern of services across the region or area. Action should include:-
- i. reviewing future education and training needs for the new model of provision;
  - ii. ensuring that Level 2 and Level 3 care are not provided in an ad hoc way on general (adult) intensive care units, which do not meet the standards for the major acute general hospitals;
  - iii. establishing a system for collecting data on outcomes for critically ill children, perhaps through adopting the ICNARC system across all hospitals treating critically ill children within the defined area;
  - iv. assessing the requirements of children who need long-term ventilation.
- 129.** Regional offices, health authorities, and hospitals should also work together to review the need for and use of those designated paediatric intensive care beds in the defined area which are not in the designated lead centre, in a recognised specialist hospital, or in a major acute general hospital which meets the standards described in this report. They should ensure that critically ill children needing general or emergency care at Level 2 or above are not treated in beds outside the lead centre unless the hospitals concerned meet the appropriate standards.

#### ***Resources***

- 130.** The pathway towards the new service configuration, described above, will require, initially, investment of managerial and professional time in setting up the protocols and structures which must form the basis for any future work. Regions and areas which have not yet carried out an audit of their provision should be able to do so for a cost of around £50,000 - the approximate cost of the recent prospective study in North West Region.
- 131.** Within the first year, the National Coordinating Group has also suggested that health authorities should ensure that 24-hour retrieval services are established at appropriate lead centres. This will entail additional costs - the cost of equipping a retrieval service is approximately £40,000 (excluding the cost of an ambulance) - although many centres have already established such a service and have made use of the additional funds provided in 1996-97 to meet the start-up costs. Running costs of the retrieval service will include drugs, replacement equipment and other consumables - estimated at £40,000 a year - and the staff costs (although the clinicians and nurses may also be involved in other duties). To provide a consultant-led service covering the whole 24-hour period may entail recruitment of an additional consultant at the lead centre.
- 132.** The major cost for the National Health Service of the proposals in this report, both in the first few years and subsequently, is, however, in ensuring that critically ill children are given care of the right standard in the most appropriate location. In some parts of the country, this will entail opening

additional paediatric intensive care beds in the lead centre so that critically ill children are no longer treated in an ad hoc way on general children's wards or in adult intensive care units where the standards set out in this document are not met. Achieving the standards may also entail training costs.

133. Preliminary work suggests that the cost of a single bed-day of paediatric intensive care at Level 2 or above is between £950 and £1200. One centre has broken down the cost into 3 main areas:-

- Direct staff costs (pay and non-pay); 75%
- Indirect costs, eg radiology, biochemistry, haematology etc: 15%
- Overheads, such as capital charges, hotel services and administration: 10%.

134. We have found it impossible to say whether there are "enough" paediatric intensive care beds across the country as a whole to meet demand. This is mainly because, at present, a considerable proportion of critically ill children are treated in hospitals which do not have designated paediatric intensive care beds. It is only through prospective audits, covering all hospitals within an area, that it is possible to establish the exact extent of demand for paediatric intensive care in that area.

135. Equally, until regional offices, health authorities and hospitals together determine the service structure in particular parts of the country, it will not be possible to assess exactly how much of the existing provision will meet the standards we have described in this report. In particular, it is not clear how many major acute general hospitals will meet the standards and so become part of the organisational structure for provision of the paediatric intensive care service.

136. Expanding the larger paediatric intensive care centres will allow the NHS to maximise efficient use of resources through economies of scale. It is clear that (up to a certain number of beds) a large centre has lower costs per occupied bed than a number of small centres, because:

- a minimum number of consultants is needed to care for children throughout each 24 hours - but a team of this size can care for up to 20 critically ill children;
- there is likely to be a higher mean occupancy level, and more efficient use of beds;
- the extra cost of retrieval is spread more widely;
- management overheads are shared more widely;
- the number of nurses needed for supervision will be less;
- equipment can be purchased in bulk.



137. Moving some provision into larger paediatric intensive care centres, so that children are not inappropriately treated, will also reduce the workload in those hospitals where critically ill children are currently being treated. Local audits will reveal the pattern of care at present. There will, therefore, be some offsetting savings in those hospitals which are currently treating critically ill children and may not do so in the future, but these cannot be quantified. (The approximate cost of provision of paediatric intensive care within a general intensive care unit is very similar to the cost of a bed day in a designated paediatric intensive bed.)
138. In some areas of the country, regional or local audits will suggest that the overall amount of provision is not adequate. In these circumstances, additional paediatric intensive care beds will need to be provided. However, in almost all cases the additional beds will only be required at times of high demand - and it would be wasteful to calculate requirements on the basis of a full year, more information is given in annex 5.
139. There is a need for paediatric intensive care centres to develop the ability to manage the availability of provision such that it mirrors, as far as possible, the predictable fluctuations in demand. They should not waste resources because beds are unoccupied and staff are available but do not have patients to care for.

#### **Conclusion**

140. In this report, we have described our vision of the future shape of paediatric intensive care services in this country. We have also set out a pathway which, we believe, health authorities, hospitals and regional offices could use to make progress towards the longer term objective. All of this is achievable - given effort, co-operation, and goodwill - and all in the interests of critically ill children, whose needs must be at the heart of the service we are providing.
141. We, the National Coordinating Group, are grateful for the opportunity we have been given to contribute towards this work.



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