Paediatric High Dependency Care in West, North and East Yorkshire

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Acknowledgements

Abstract

A 36 item, measurement tool to establish the volume of paediatric high
dependency care (PHDC) activity was developed from inpatient episode data (n =
24,540) collected in 14 hospitals in West, North and East Yorkshire in 2005. The
PHDC measurement tool was subsequently applied to the inpatient episode data
(n = 24,540) to estimate the amount and location of PHDC by hospital ward type
(District General Hospitals, (DGHs), paediatric intensive care units (PICUs),
specialist hospital wards and a DGH with specialist paediatric facilities). A total of
9,077 episodes of PHDC for 1,763 children were measured. The majority (55%) of
children receiving PHDC were male and 25% were infants (aged 29 days to 1
year). The specialist hospital wards provided the majority (42%) of episodes of
PHDC.

Clinical staffing data to determine the number and level of skills of doctors and
nurses providing care was also collected in 2005. A total of 7.5% of shifts were
without a Registered Children's Nurse (RN (Ch)). A further 4.5% of shifts worked
with only one RN (Ch), of which, 76% was for the period of the night shift. Over
one-quarter (28%) of all shifts were without a nurse with valid advanced paediatric
life support (APLS) skills, and 43% of all doctors were without valid APLS skills.
When the skills of nurses were matched to the dependency needs of children a
disproportionate number of qualified nurses to children was most noticeable at
night on all hospital ward types, excluding the PICUs.

This study is unique, firstly, in its ability to quantify PHDC in the Yorkshire region,
and, secondly, to match the dependency needs of children to the available skills of
the workforce. This information has provided important information to assist with
the organisation, planning and delivery of PHDC in Yorkshire.

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List of Abbreviations

Abbreviation	Description
A&E	Accident and Emergency
AGH	Airedale General Hospital
ANZPIC	Australia and New Zealand Paediatric Intensive Care
APACHE II	Acute Physiology and Chronic Health Evaluation II
APACHE III	Acute Physiology and Chronic Health Evaluation III
APLS	Advanced Paediatric Life Support
AVPU	Alert, Voice, Pain, Unresponsive
BMA	British Medical Association
BMTU	Bone Marrow Transplant Unit
BRI	Bradford Royal Infirmary
CCC	Critical Care Course
CCU	Coronary Care Unit
CPAP	Continuous Positive Airways Pressure
CPR	Cardiopulmonary Resuscitation
CRH	Calderdale Royal Hospital
CSW	Clinical Support Worker
CT	Computerised Tomography
CVP	Central Venous Pressure
DGH	District General Hospital
DoCDat	Directory of Clinical Databases
DOB	Date of Birth
DoH	Department of Health
DNS	Daily Nurse Staffing
DPA	Daily Patient Activity
ECG	Electrocardiogram
EN	Enrolled Nurse
ENB	English National Board
EPLS	European Paediatric Life Support
FA	Factor Analysis

GCS	Glasgow Coma Score
HBN	Health Building Note
HCA	Health Care Assistant
HD	High Dependency
HDC	High Dependency Care
HDCC	High Dependency Care Course
HDU	High Dependency Unit
HES	Hospital Episode Statistics
HO	House Officer
HRGs	Health Resource Groups
HRI	Hull Royal Infirmary
HSR	Health Services Research
Hudd RI	Huddersfield Royal Infirmary
IC	Intensive Care
ICA	Intermediate Care Area
ICU	Intensive Care Unit
KMO	Kaiser – Meyer Olkin
LOS	Length of Stay
LGI	Leeds General Infirmary
MCRN	Medicines for Children's Research Network
MMS	Monthly Medical Staffing
MNS	Monthly Nurse Staffing
NCSW	Non Clinical Support Worker
NEYNL	North East Yorkshire and Northern Lincolnshire
NGT	Nominal Group Technique
NHS	National Health Service
NSTS	National Strategic Tracing Service
NYCRIS	Northern and Yorkshire Cancer Registration and Information Services
OT	Overtime
PACU	Post Anaesthesia Care Unit
PALS	Paediatric Advanced Life Support
PbR	Payment by Results

PCT	Primary Care Trust
PCCMDS	Paediatric Critical Care Minimum Data Set
PH	Pinderfields Hospital
PHDC	Paediatric High Dependency Care
PHDU	Paediatric High Dependency Unit
PIAG	Patient Information Advisory Group
PIC	Paediatric Intensive Care
PICANet	Paediatric Intensive Care Audit Network
PICS	Paediatric Intensive Care Society
PICU	Paediatric Intensive Care Unit
PIM II	Paediatric Index of Mortality II
PPA	Paediatric Patient Activity
PRISM	Pediatric Risk of Mortality
PSI	Physiologic Stability Index
RBC	Regional Burns Centre
RCN	Royal College of Nursing
RCT	Randomised Controlled Trial
RGN	Registered General Nurse
RN (Ch)	Registered Nurse (Child)
RoM	Risk of Mortality
RSCN	Registered Sick Children's Nurse
SAPS II	Simplified Acute Physiology Score II
SHA	Strategic Health Authority
SHO	Senior House Officer
SJUH	St James University Hospital
SpR	Specialist Registrar
SWACIC	South West Audit of Critically Ill Children
TISS	Therapeutic Intervention Scoring System
ULTHT	United Leeds Teaching Hospitals NHS Trust
UK	United Kingdom
UKCC	United Kingdom
USA	United States of America
WTE	Whole Time Equivalent

Publications arising from this thesis

Rushforth K, McKinney PA. (2005). Issues of patient consent: A study of paediatric high dependency care. *British Journal of Nursing.* 14: 519-523.

A local report was submitted to the Paediatric Critical Care Network of the Yorkshire and Humber Specialist Commissioning Group (North):

Rushforth K. (2006). A study of paediatric high dependency care in West, North and East Yorkshire: A report of paediatric staffing and patient activity. January – December 2005. University of Leeds. ISBN 0 85316 171 0.

1   Background

1.1   Introduction

This chapter describes high dependency care (HDC) and outlines how paediatric high dependency care (PHDC), as a level of care, is organised and delivered, for children, within the UK and West, North and East Yorkshire. It concludes with a description of Health Services Research (HSR), the theoretical framework underpinning this research.

Critical care is a term used to describe HDC and intensive care (IC) (Department of Health, 1997a; Munro, 1999). HDC is a level of care located between IC and usual ward care. In the UK, individuals requiring IC are extremely sick and require support for one or more system organ failures. IC patients are usually cared for in designated intensive care units (ICUs) by specialist nursing and medical personnel with additional training in critical care. Although IC may be initiated in other settings, such as accident and emergency departments and operating theatres, all IC takes place in the ICU. The same cannot be said for HDC, where HDC is not synonymous with the high dependency unit (HDU). Patients requiring HDC may be very sick and require a high level of medical and nursing intervention but this level of care is provided by a diversity of healthcare personnel in a variety of hospital settings including:

- Intensive care units (ICUs).
- Emergency care units or accident and emergency units (A&Es).
- High dependency units (HDUs).
- Specialist wards or units (such as renal units, oncology wards).
- General wards.
- Post operative theatre recovery units.

HDC is delivered to patients of all ages, including the newborn, at acute general hospitals, at regional specialist centres and also at tertiary centres.

1.2   Organisation of the Delivery of Paediatric Critical Care in the UK

Although IC and HDC are not new modes of care delivery in the adult medical and nursing services, paediatric intensive care (PIC) and PHDC are relatively new specialties in the delivery of hospital care for critically ill children. The importance of specialist care for critically ill children has been recognised over the past 25 years by the medical profession, but in 1995 after the death of a child, Nicholas Geldard, the provision of appropriate care became a focus of debate (Department of Health, 1997a; Department of Health, 1997b). Nicholas Geldard died in a paediatric intensive care unit (PICU) after being transferred many miles from the hospital to which he was first admitted. The inquiry into this child's death outlined problems inherent within the NHS, and in particular focused upon the ability of PIC services to cope with peaks in demand (Ashworth W, 1996). The result was the publication of two reports to be read in conjunction with each other (Department of Health, 1997b):

1. *A Framework for the Future* outlined standards for achieving the best quality of care and outcomes for critically ill children, and described an organisational framework to unify PIC services in four types of hospital in England (Department of Health, 1997a). These hospitals included:

- District general hospitals (DGHs). These hospitals were to provide PHDC and initiate resuscitation and stabilisation of the critically ill child.

- Lead centres. These were designed to provide all PIC, PIC advice and guidance to all paediatric hospital ward staff within the lead centre and at DGHs, and to provide an expert retrieval service for the safe transfer of children within a defined geographical area.

- Major acute general hospitals. These hospitals had large adult intensive care units that provided some PIC to children. Provided these hospitals met with predetermined standards they would be allowed to continue to provide IC to children.

- Specialist units. These were to provide IC for adults and children for that particular specialty where appropriate (e.g. burns).

2. *A Bridge to the Future*. The Chief Nursing Officer's taskforce summarised actions to be taken to improve levels and training of nurse staffing for children requiring PIC and PHDC at the four types of hospitals (listed above). This included the development of courses for intensivist nurses to enable them to attain qualifications in the delivery of IC, and to ensure that critically ill children were nursed by suitably trained staff (Department of Health, 1997b).

The term critical care was used within *A Framework for the Future* (Department of Health, 1997a), yet little attempt was made to differentiate between PIC and PHDC (Department of Health, 2001a). The difficulties associated with the definition of PIC and PHDC were acknowledged by the national coordinating group responsible for *A Framework for the Future*; therefore, the following definitions derived from the Paediatric Intensive Care Society (PICS) (1996) were used (Appendix 1).

- Level 3 care, or PIC, is needed for a child that requires support for two or more system organ failures including advanced respiratory support from a ventilator, or life support machine. A child requiring level 3 care will be extremely ill, and consequently, require more than one nurse to provide care.
- Level 2, also PIC, is defined by intubation and subsequent care of the ventilated child. This child requires one to one nursing.
- Level 1, or PHDC, is defined as a child that requires 'closer observation and monitoring than is usually found on an ordinary children's ward' (Paediatric Intensive Care Society, 1996).

The result of the Nicholas Geldard inquiry and subsequent publications ensured that substantial resources were set aside to improve PIC services in England. The reports set out ways of achieving improved quality of care and outcomes for children, and recommended standards for all units treating intensively ill children (level 2 and 3 care) (Department of Health, 1997a; 1997b) . The definition of PIC was clear, but the definition of PHDC, or level 1 care, was left open to interpretation. Therefore, 'closer observation and monitoring' which traditionally had been provided on most children's wards, with higher staffing levels, failed to receive any attention. Thus, there were no clear guidelines with respect to who should deliver this level of care and no guidance as to what combinations of conditions, interventions and treatments distinguished PHDC from any other level of ward care.

Following those earlier reports (Department of Health, 1997a; Department of Health, 1997b) both the NHS Executive (NHS Executive, 2000) and the Department of Health (DoH) (2001a) endeavored to define PHDC. The NHS Executive used the original PICS definition (Paediatric Intensive Care Society, 1996), but in addition suggested a number of criteria to be reached prior to admission to a dedicated PHDU. Many of these specified criteria were vague, for example, 'patient with multiple system problems' and 'circulatory instability due to hypovolaemia'. Nevertheless; the document offered guidance for best practice in the North West of England and amalgamated ideas from a number of experts (NHS Executive, 2000).

The Department of Health (2001a), in the report *High Dependency Care for Children – Report of an Expert Advisory Group for the Department of Health,* commented upon the lack of clarity with the earlier definition of PHDC (Department of Health, 1997a), and therefore, attempted to provide criteria that would identify children in need of PHDC in acute and specialist hospitals. For this purpose the DoH used illness classifications to define children in need of PHDC with specific reference to diabetic ketoacidosis, bacterial meningitis and meningococcal septicaemia (Department of Health 2001a). However, this method of identifying children in need of PHDC is unsatisfactory as it cannot be assumed that a child requiring PHDC is necessarily a consequence just of their illness. A child may be admitted and discharged from hospital with the same diagnosis, for example bacterial meningitis, yet move between all three levels of care during a single admission to hospital (Appendix 1). This classification is therefore too simplistic for the purposes of identifying children who need PHDC during their hospital stay. From the perspective of service delivery this loose and inadequate definition also fails to allow any assessment of the number of children receiving PHDC and the duration of time that children receive that level of care. Such information is essential for service planning to ensure that critical care (including PHDC) activity levels are planned for and resourced over and above normal commissioned activity for paediatrics.

1.3   Paediatric Critical Care Activity in the UK

The amount of PHDC activity in the UK is currently unquantified in contrast to PIC. The Paediatric Intensive Care Audit Network (PICANet), a national audit network of PIC, was established in 2002 to provide information on PIC activity across England and Wales. Led by the clinical PIC community, through the PICS, it is funded by the Department of Health, Health Commission Wales Specialised Services, Royal Hospital for Sick Children Edinburgh and the Pan Thames Commissioning Consortium (Paediatric Intensive Care Audit Network, 2007). Thirty one intensive care units in 25 NHS Trusts in England, Wales and Scotland submitted data to PICANet between January 2004 and December 2006. The total number of PICU beds within the network was 257, the mean number of beds for each PICU was eight, this ranged from one to 21 beds, 57% of all admissions to the PICUs were

boys and children less than one year of age accounted for 48% of all admissions. The median length of stay for all Hospital Trusts and age groups ranged from one to six days.

The data collected by PICANet related to PICU admissions irrespective of the level of care delivered in that setting. However, some PICUs have beds identified for children in need of PHDC. Only 33 (13%) of PICU beds were designated for PHDC in 13 (42%) PICUs, yet of the 42,221 admissions to the PICUs 11,092 (26%) did not require invasive ventilation, but this varied by Trust between 6 and 95% over three years, with the lowest rates of invasive ventilation occurring in Central and Eastern England and the highest rates occurring in Wales (Paediatric Intensive Care Audit Network, 2007). A further 1,632 (3.9%) admissions received non-invasive ventilation only. Children admitted to the PICU for support, but not invasive ventilation, may have received PHDC; however, this cannot be confirmed because a number of children that do not require invasive ventilation may still require PIC. For example, children will require PIC, but not invasive ventilation, if they require observation for acute airway problems and are at risk of airway obstruction. Other children with serious rhythm disturbances require anti-arrhythmia drugs and may progress to intubation if treatment is not successful. This further highlights the difficulties associated with classifying PHDC.

Despite the detailed documentation of PICU activity in the UK, the extent to which that activity may have been PHDC is not known. Similarly, the amount of PHDC delivered on general children's wards is not known. According to the Department of Health (2001a) the majority of children requiring PHDC are cared for on paediatric wards in DGHs, 5 to 15% of all DGH admissions require PHDC, yet only 0.5% to 1% of these children will require stabilisation and transfer to a PICU. Hence, many children receive PHDC on ordinary children's wards at DGHs where extra staffing resources may not be in place.

The South West Region of the UK has collected data for critically ill children including PIC and PHDC from 16 hospitals, since 2000 (The South West Region Critical Ill Children's Audit, 2007). The South West Audit of Critically Ill Children

(SWACIC) provides information for both individual hospitals and commissioners on the volume of critical care and identifies areas of concern and good practice. Between 2006 and 2007, 17 PHDC beds were located within the region in seven hospital locations, six of these hospital locations were DGHs. Of all admissions to the paediatric wards, 3% of children were admitted to the seven designated PHDUs and bed occupancy varied from 32% to 46%, with a median length of stay of 1 day or less. Only two large DGHs were without a dedicated PHDU in the region and PHDC was provided on the general children's ward. The South West Region continues to collect the only comprehensive data set on critically ill children across a region as recommended by the Department of Health in the publication a Framework for the Future (Department of Health, 2007a).

1.4 The Child Requiring High Dependency Care

Patient acuity, staff concern and nursing intensity are some of the variables that characterise PHDC. Many children in need of PHDC are acutely ill and are easily identified because they require single organ support, excluding respiratory support, for example, acute peritoneal dialysis (Department of Health, 1997a). This level of acuity demands an extensive nursing resource because of the time and effort involved in the fluid management and the continuous monitoring of vital signs. Although continuous monitoring of vital signs may distinguish high dependency care from usual ward care, not all children requiring PHDC will require this practice. However, all children requiring PHDC will require close visual (and auditory) nursing observation. This direct and indirect observation of the child is an extremely important activity associated with PHDC and resources to provide this should not be underestimated.

The child requiring PHDC will be more dependent than for usual ward care and may (but not always), be confined to bed. An example is a child that becomes physically more dependent, as a result of his illness, in the post operative period; this may require fluid management, intravenous analgesia and regular administration of intravenous drugs. This type of child requires a high level of nursing and medical intervention and will cause concern for staff providing PHDC. However, it is important to distinguish between the child that requires PHDC and

close observation, from the child that is highly dependent. The latter situation may be misleading for inexperienced staff because the patient needs considerable nursing time but is not necessarily at risk of physical deterioration (Sheppard and Wright, 2000).

Assimilation, interpretation and evaluation of a child's physiological status requires the experience of skilled nursing and medical staff to recognise and promptly treat critical illness. Skilled staff are not only aware of minute changes to a child's condition, but they are able to predict and prevent complications often when instinct tells them that something is wrong. The importance of direct and indirect observation should not be undervalued on any hospital ward where PHDC is delivered. This need for close observation clearly requires that PHDC can only be effectively delivered with a high number of skilled nurses available to care for patients.

1.5   The Workforce and Paediatric High Dependency Care

Irrespective of where PHDC is delivered to children, it is vital that all areas have the correct equipment, and that trained staff are available day and night to care for patients who may suddenly deteriorate. As children progress from usual ward care to PHDC and PIC the continuum of care should be as smooth as possible. However, the distinguishing feature between all three levels of care is the number, level and skill mix of health care professionals necessary to provide optimum care (Sheppard and Wright, 2000).

1.5.1   Nursing Staff

A number of DoH publications have provided guidance for the quantity, level and skills of healthcare professionals to enable the structure of the workforce, in paediatric ward areas, to be optimised in relation to critical care (Department of Health, 1991; Department of Health, 1997a; Department of Health, 1997b; Department of Health, 2001a; Department of Health, 2004a; Department of Health, 2006). Appendix 2 provides a summary of this guidance. One of the recommendations is that two registered children's nurses (RN (Ch)) should be on duty at all times in any 24 hour period; however, in areas such as emergency care

units and specialist non primary paediatric areas (adult wards where children are nursed) it was recommended that a RN (Ch) only needed to be available for advice and guidance 24 hours a day (Department of Health, 1991). Although the standards set down by the Department of Health (1991) were audited by the Audit Commission in 1993, it was found that expectations fell short of the 1991 guidance and the Audit Commission declared that the basic qualification for nursing children was a RN (Ch) (Audit Commission, 1993). This has subsequently been interpreted as all nurses caring for children should be RN (Ch); however, this may be unrealistic and unobtainable without a redistribution of resources (Smith and Long, 2002). In non-primary paediatric hospital ward areas where children are nursed, difficulty is experienced by nurse managers in retaining children's nurses as the nurse often lacks job satisfaction and looks towards the primary paediatric ward for fulfillment (Smith and Long, 2002). In a UK survey conducted by the Royal College of Nursing (1999), 71.6% of all organisations had two RN (Ch) on duty on each shift, but this varied considerably from region to region. More recently the Royal College of Nursing (2003) specified that two children's nurses on duty in any 24 hour period was no longer sufficient for most general children's wards, and that where very young children, i.e. under two years of age, were nursed the ratio of children's nurses to children should be 1:3 (Royal College of Nursing, 2003).

There were 672,897 nurses, midwives and health visitors registered in the UK on March 31st 2005 of which 21,466 were registered on Part 8 of the register (registered sick children's nurses RN (Ch)) and 17,604 were registered on Part 15 (RN (Ch)) of the register (Nursing and Midwifery Council, 2005). Notably, the register lists the total number of nurses who are registered to practice not the numbers actually practicing. A national shortage of nurses became apparent in the late 1990s and early 2000s (Culley and Genders, 2003) but this problem was not confined to Britain; globally the picture was much the same (Buchan, 2002). This causes problems for the recruitment of nurses to some specialties.

Concerns regarding the number of RN (Ch) was highlighted in 1976 by the Department of Health and Social Security (Fit for the Future) and again, in 1994, by the Department of Health (The Allitt Inquiry (The Clothier Report), 1994); however,

despite a number of government initiatives to resolve the problem there remained an estimated shortfall of 2,770 Whole Time Equivalents (WTE) in children's nurses (Elston and Thornes, 2002). Although the Home Office Border and Immigration Agency (2006) held a shortage occupation list for nurses of all specialties, this was changed in July 2006 to include nurses at Band seven or eight in a number of specialties only. From July 2007, children's nursing as a specialty was not listed as a shortage occupation yet, critical care remained on the Home Office shortage occupation list (Home Office Border and Immigration Agency, 2006). Thus, a shortage of nurses for the critical care areas remained in existence.

Although RN (Ch) are essential to the care of hospitalised children, the DoH have made further recommendations that nursing and medical staff working with children in acute areas should undertake extra training in advanced paediatric life support (APLS) courses (Department of Health, 1997a; 1997b; 2001a; 2004a; 2006). The APLS courses include the:

- European Paediatric Life Support (EPLS) course, this has recently superseded the Paediatric Advanced Life Support (PALS) course. This is a two day course.
- Advanced Paediatric Life Support (APLS) course. A three day course. This course also has a multiple trauma component.

The APLS courses employ a variety of techniques such as lectures, skills stations and scenarios to teach early recognition of the child in respiratory and circulatory failure and the knowledge and skills to intervene and prevent further deterioration (European Resuscitation Council, 2004). The courses are assessed through written testing procedures and rigorous clinical assessments. These courses are costly, require large amounts of training equipment, have a high instructor to student ratio and are valid for four years only whereupon a full course has to be undertaken to update (Jewkes and Philips, 2003). Despite the cost, intensity and periodic updating of these courses, recommendations by the DoH are that a child in an emergency situation should have access to a nurse that has APLS skills during any 24 hour period (Department of Health, 1997b; Department of Health, 2001a).

In settings where patient activity can be unpredictable such as the ICU and the HDU it is difficult to plan the numbers of staff, particularly nursing staff, required to provide the necessary care (Sheppard and Wright, 2000). This problem also exists for general paediatric wards where children are admitted acutely and may require PHDC. Little mention is made of the variability in the workload on general children's wards and the increase in staffing levels that are required to meet with the child's immediate PHDC or increasing dependency needs. Documented evidence suggests that the majority of children in need of PHDC are cared for on ordinary children's wards at DGHs (Department of Health, 2001a), at times, with extra staff in place (Department of Health. 1997a). However, ordinary children's wards are not always adequately, or routinely, staffed to care for the extremely sick child recently admitted, or for a growing number of patients with PHDC needs, and staffing demands for children requiring PHDC may compromise the care of other children on the ward (Doman, Prowse and Webb, 2004).

The recommended nurse to patient ratios for children requiring PIC and PHDC in ICUs have been taken from the adult literature. According to the Department of Health (1996), the minimum recommended nurse to patient ratio in the ICU for a patient requiring IC is 1:1 and for HDC in the ICU and the HDU is 1:2. There have however, been calls to establish a scientific basis to examine the association between dependency and nursing resource (Department of Health, 1996; Endacott, Wilkinson, Harrison and Ellis, 1996). Despite the recommendation of a ratio of one nurse to two patients, for HDC, Sheppard and Wright (2000) identify a number of situations where a greater level of dependency in the care of adults may be required:

- Sudden deterioration in physiological status of the patient.
- Confusion and disorientation of the patient.
- Recently extubated patients who may have associated airway/breathing problems.
- The level of expertise at the bedside is junior.

This suggests that the recommendation of one nurse to two HDC patients should not be automatically and rigidly applied. Although a minimum recommendation has been set for the care of adult patients requiring HDC, nurses make minute by minute assessments of their patients and each nurse should exercise clinical discretion before applying any aspect of the recommendation. The PICS (Paediatric Intensive Care Society, 2001) recommended the above adult nurse to patient ratios, but also advocated increasing the dependency of a child if the child was isolated in a cubicle. For example, a sick child requiring PHDC, or level 1 care, and nursed in a cubicle should have their dependency increased to level 2 (a ratio of one nurse to one child). Children require isolation in addition to PHDC because they may be infective or they may require protective isolation for a severely compromised immune system. Isolation increases the dependency level of the child because if left unattended, deterioration in condition would go unnoticed and the sounding of monitoring alarms would not be heard.

1.5.2 Medical Staff

In 2005, in the UK, there were 4,417 (3,997 WTEs) doctors in the paediatric medical workforce, of these, 2,723 were consultants, 1,337 were staff and associate specialist grade doctors and 357 were other grades (Royal College of Paediatrics and Child Health, 2006). Although reference was made to the changing paediatric medical workforce where women outnumbered men in the career grade workforce (53.6% to 46.45), and to an increase (40% since 2003) in the number of nurses participating in the medical rota, no mention was made of the qualifications and training of paediatricians (Royal College of Paediatrics and Child Health, 2006). Subtly, the Royal College of Paediatrics and Child Health advise that paediatricians should undertake an APLS course through the advertisement of APLS and instructor courses on their website (http://www.rcpch.ac.uk). Other documents concerned with the quality of care recommended that medical staff in hospitals treating trauma in children should be 'familiar' with the APLS guidelines (National Confidential Enquiry into Perioperative Deaths, 1999).

The skills and training requirements for doctors in PHDC in England were recommended seven years ago by PICS they include:

- Where PHDC is provided, within hospitals, there must be a lead Consultant with responsibility for the provision of PHDC, paediatric resuscitation and for the initiation of treatment and stabilisation of the critically ill child.
- Consultant paediatrician cover during a 24 hour period by staff with advanced paediatric resuscitation skills.
- 24 hour consultant anaesthetic cover by staff with advanced paediatric resuscitation skills.
- 24 hour resident cover on-site by medical staff with APLS/PALS or equivalent (Paediatric Intensive Care Society, 2001).

The Department of Health (2001a) guidance recommended a lead clinician to establish and develop all aspects of care relating to PHDC who could be a paediatrician, an anaesthetist, a surgeon or a senior children's nurse. The guidance recommended that both medical and nursing staff should have APLS skills; for nursing staff the recommended training was specific i.e. APLS qualification, yet for medical staff the recommendation was less specific requiring 'appropriate competency in advanced paediatric life support' (Department of Health, 2001a). The wording of the guidance for medical staff may potentially be misconstrued, permitting doctors to develop their competency through experience and not through a taught course. It is difficult to establish that children have an improved outcome when cared for by clinicians who have an APLS qualification, yet evidence suggests this may be the case (Jewkes and Philips, 2003). Successful completion of an APLS course does not ensure adequate experience for caring for critically ill children, and both nursing and medical staff need regular refresher courses to prevent the decay of skills (Jewkes and Philips, 2003; Gemke et al, 2007).

More recent evidence from Department of Health (2004a ; 2006) also specified that at least one member of staff (no distinction was made between nursing and medical staff) or where a member of staff was working as part of a hospital resuscitation team to be trained to APLS, PALS or equivalent on each shift where children were admitted acutely. Regular teaching and scenario training was also

suggested for the maintenance of skills at DGHs (Department of Health, 2006). Surgeons operating on children were required to have basic training in resuscitation and life support (Department of Health, 2004a); although it was not clear what specific courses were required and how often surgeons should attend such courses. It was likely that 'surgeon' referred to all those operating on children including those that performed both adult and paediatric surgery.

1.6   Organisation of the Delivery of Paediatric Critical Care in West, North and East Yorkshire

The study area for the research reported in this thesis was the Strategic Health Authorities (SHAs) of West and North East Yorkshire and North Lincolnshire (NEYNL) (Appendix 3) which, since reorganisation of boundaries in 2006, has become the northern part of the Yorkshire and Humber SHA. The childhood population base of the study area was 629,100, in 2005, for children aged 0 to 14 years (Office for National Statistics, 2006). Originally, paediatric critical care in the region was delivered to children admitted to 41 hospital wards, in 14 hospitals, in 10 NHS Trusts straddling all paediatric specialties. However, during the conduct of this study some wards stopped treating children requiring PHDC as a consequence of reorganisation, reducing the number of wards to 36 (Appendix 4). The DoH template for a *Framework for the Future* (Department of Health, 1997a) identified four types of hospital required to unify critical care services all of which were represented within the region (table 1.1).

Table 1.1   Types of Hospital required to unify critical care services within the study region

Types of hospital*	Hospitals in the study area
1 Lead Centres for PIC (PICUs that provide most of the PIC regionally and offer support and guidance to DGHs through training and education)	Leeds General Infirmary St James University Hospital
2 District General Hospitals	Airedale General, Bradford Royal, Calderdale Royal, Dewsbury District, Friarage, Harrogate District, Huddersfield Royal, Pinderfields, Pontefract General, Scarborough District, York District.
3 Major Acute Hospitals	Hull Royal Infirmary
4 Specialist Units	Burns unit located at Pinderfields Hospital

* recommended by the Department of Health (1997a)

The study area included different settings where PHDC was delivered. The three PICUs, across two hospital sites, in Leeds included the children's cardiac ICU and all three units were known by the researcher and medical colleagues to admit children requiring PHDC, despite having no designated PHDC beds. These three PICUs served the 11 DGHs in addition to the 14 specialist hospital wards at the Leeds General Infirmary (LGI) and the St James University Hospital (SJUH) (table 1.1).

At the DGHs the pathway of care for children admitted requiring resuscitation and stabilisation of their condition is that staff are expected to intubate and provide PIC for the ventilated child until the PIC retrieval team arrives. The medical staff at the DGHs contact the lead centre (PICU) for the following:

- Help and advice regarding a critically ill, deteriorating or collapsed child.
- The retrieval service to collect and transport the child safely into the lead centre.
- Availability of a bed on one of the three PICUs.

All 11 of the DGHs and the 14 specialist hospital wards at the lead centres were known to care for children requiring PHDC without extra resources for this level of care. Children were generally not transferred from a DGH to the lead centre in Leeds for PHDC unless for specialist care such as renal, liver, or cardiac care, or for deteriorating PHDC and initiation of level 2 care (PIC). Within the study region most children were likely to begin and end their period of PHDC on a general hospital ward.

Further sites where PHDC was known to be delivered were Hull Royal Infirmary (Hull and East Yorkshire Hospitals NHS Trust) and the supra regional specialist Burns Unit at Pinderfields Hospital of the Mid Yorkshire Hospitals NHS Trust. Hull Royal Infirmary is a major acute trust with a large adult ICU with two paediatric ICU beds, three general paediatric wards and a designated PHDU. Children requiring PHDC for a burns injury were cared for at the regional burns centre at Pinderfields Hospital; however, children requiring PIC for burns were transferred to the paediatric burns unit at Alder Hey Children's Hospital at Liverpool.

At the outset of the study 12 PHDC beds existed within the region at the following locations:

- Hull Royal Infirmary (HRI) – Ward 200 comprised four designated PHDC beds for children with general and neurological conditions providing 'step down' care from the mixed adult and PICU.
- Leeds General Infirmary (LGI) – Ward 10, six cardiac PHDC beds only for cardiac patients.
- St James University Hospital (SJUH) – Plastics/orthopaedic HDU, two PHDC beds were designated for children requiring complex plastic/orthopaedic surgery on the mixed paediatric and adult unit. Following completion of the study the designated ortho/plastic PHDC beds were relocated to the LGI and were managed by RN (Ch) on a plastics/orthopaedic children's ward.

As a designated provider of PHDC, only ward 200 (PHDU) at HRI charged a tariff for PHDC, this tariff was setting dependent. All other PHDC beds provided care at usual ward care rate.

1.7 Health Services Research as a Conceptual Framework

Health Services Research (HSR) is the conceptual framework that is woven throughout this study because HSR aims to improve the 'quality, efficiency and management of health care' (Black, 1997). This study has selected a methodology which addresses the delivery of the healthcare needs of children not at an individual level but at a population level (Long, 1996). For HSR the end results should translate into action to influence policy and positively benefit the care that children receive. An essential aspect of paediatric hospital care is recognising and treating children with a developing critical illness, yet without an adequate definition of what constitutes PHDC the recognition of children requiring PHDC becomes difficult. The ultimate goal of this research is to improve the care of critically ill children by deriving a definition of PHDC that could be subsequently adopted by paediatric hospital wards nationally. This would then facilitate the assessment of provision that is needed so that the service can be adequately resourced to intensify the care that is offered to children.

A further reason for adopting this HSR framework is the potential for promoting research across organisational boundaries and disciplines (Long, 1996). For

example, HSR spans areas such as sociology, epidemiology, statistics, economics, psychology and history with input from medicine, nursing, other clinical areas, universities and research institutes (Black and Davies, 1999). HSR is published in a wide variety of journals, which makes HSR output difficult to monitor (Black and Davies, 1999). Despite this, HSR has improved knowledge through clinical databases for comparative audit in paediatric critical care (Paediatric Intensive Care Audit Network, 2007); it has identified service users and the reasons for their uptake, recently reporting on patients' outcomes in the independent sector compared with NHS providers (Browne et al, 2008). HSR has recognised ways of improving the organisation and management of services for example improving the management and organisation of care for obese people (Harvey, Glenny, Kirk and Summerbell, 2008).

1.8   Summary

Although PHDC is a recognised level of care, the boundary between PHDC and usual ward care is unclear. The lack of a precise definition restricts clear identification of individual children requiring PHDC and therefore, causes problems when planning and providing for their needs. Although the SWACIC is able to determine the volume of PHDC for the South West Region, the total number of children requiring PHDC, either within PICUs or on ordinary children's wards, in the UK, has not been estimated. This is in contrast to children requiring PIC where detailed audit information is available and published by PICANet. One of the principle reasons for the lack of information on PHDC activity is the absence of a clear definition of what constitutes PHDC.

The characteristics of PHDC are influenced by patient acuity, staff concern and nursing intensity, however the needs of each child are as individual as the child himself and what is characteristic of PHDC for one child is not characteristic for another. Children that require closer 'observation and monitoring' on hospital wards are different according to the type of ward and the regional specialties available (Department of Health, 2001a). Despite ward and specialty variation it is expected that all hospital wards that admit children acutely will provide level 1 care (PHDC) and initiate level 2 care (PIC) until a dedicated retrieval team arrives to escort the

child to the PICU. With only a small number of children requiring transfer for PIC, the majority of children will start and end their period of PHDC stay on an ordinary children's ward where, at times, the resources necessary for care may not be in place.

Clinical guidelines for the recommended number and level of skills of staff that should be available to care for children requiring PHDC were published by the Department of Health (1991; 1997a; 1997b; 2001a; 2004a; 2006), the Royal College of Nursing (2003) and the Paediatric Intensive Care Society (1996; 2001). The wording of the guidance has changed over time with the most recent publications from the Department of Health (2004a; 2006) making no distinction between the availability of doctor or nurse with APLS skills. These guidelines should be interpreted with caution. The availability and responsibilities of doctors may vary from hospital to hospital. The responsibilities of APLS competent SpRs, particularly out of hours, may also be to neonatal ward areas and accident and emergency departments that may be geographically isolated from general paediatric wards. In these situations nurses with APLS skills are vital to initiate and lead the resuscitation situation until such a time that medical assistance becomes available. Without national audit it is uncertain if NHS Trusts conform to the guidance for the number and skills of clinical staff although there is evidence from the Royal College of Nursing (1999) to suggest that adherence to national guidelines is poor. However, there are concerns that the setting of minimum staffing levels provides a number for maximum staffing levels which do not respect the individuality of hospital ward activity (Royal College of Nursing, 2006).

The HSR framework employed by the study sought to answer questions about the processes and structures associated with the delivery of PHDC (Lilford, Brown and Nichol, 2007). HSR has provided an underpinning methodology for a project whose findings aim to inform the understanding of the management of PHDC particularly at the boundary between level 1 and level 2 care.

2   Literature Review

2.1   Introduction

This literature review will outline some of the difficulties associated with the definition of a 'child', describe the organisation and delivery of critical care services, explain how the service is funded and how much critical care is available particularly for the paediatric population, nationally and internationally.

One of the difficulties in research on children is defining the age range of those who are included under this heading. Children have been defined by the DoH by their age as less than 19 years (Department of Health, 2004a). However, this definition cannot always be applied in the paediatric services. Some paediatric hospital wards admit children older than 19 years for the purposes of continuing care, especially those children and young people with complex conditions who now survive into adult life (Department of Health, 2004a). Some hospital wards have policies to admit children up until their sixteenth birthday; therefore, the delivery of care to children may require the definition of 'children' to be those who are treated on a paediatric ward. Consequently, the setting; the paediatric ward probably defines the child.

Children and young people with critical illness differ from adults with respect to their clinical, psychological and social needs. Therefore, they require a dedicated approach to care which in the UK is generally provided on children's wards by specialist children's healthcare professionals. One in 10 to15 children from the general population will be admitted to hospital in any single year; the majority of admissions will be unexpected, or unplanned, and most children will spend a short period of time as an inpatient (Department of Health, 2004a). A small, but unknown proportion of these admitted children will require critical care, a relatively new sub-

specialty of paediatric hospital care. Published research in the field of critical care overwhelmingly relates to the adult population although some can be generalised to children. In the following literature review reference will be made, where possible, to papers relating to paediatric services.

Although the volume of literature pertaining to the HDC component was greater for adults than children, the overall volume of primary research was low. It was not possible to grade the primary studies for review according to their design as studies that provided the strongest evidence, for example well designed randomised controlled trials (RCTs) (grade 1) and prospective cohort studies with concurrent controls (grade 2) (NHS Centre for Reviews and Dissemination 1996) have never been published for HDC. According to McPherson (2001) 'intensive care remains outside of the evidence base paradigm'. From this McPherson (2001) concluded that randomisation did not occur in IC for ethical reasons. As a result there were no rigorous studies to provide the evidence required to contribute to the improvement of critical care services. In view of this weaker designs had to be reviewed. This is set to change in the paediatric critical care arena with RCTs being encouraged through groups such as the Medicines for Children's Research Network (MCRN) available at http://www.mcrn.org.uk and the Paediatric Intensive Care Society (PICS) available at http://www.UKPICS.org.

2.2   The History of Critical Care

Florence Nightingale, in 1852, was probably the first person to make reference to HDC when she commented about the benefit of having a designated area where postoperative and other patients requiring observation could be watched (cited by Jennett, 1990). Such rooms were introduced in the 1940's as post operative recovery rooms, which significantly reduced the morbidity and mortality of post-operative patients (Oh, 1996). The ICU came into being after ventilatory support for respiratory failure was given to patients during the polio epidemic of the 1950's (Oh, 1996). Complication rates were notably reduced when such patients were nursed together on one ward (Oh, 1996). A report from the British Medical Association (BMA) in 1967 (*Report of the Working Party on Intensive Care in the United Kingdom)* came at a time when most hospitals were considering setting up

an ICU, this report outlined the advantages of care for the seriously ill in specialised units and encouraged the development of IC. The types of patients to be admitted to the ICU were not specified at this time but those requiring 'heavy nursing', frequent monitoring or those requiring mechanical treatment were types of patient that made excessive demands of nursing staff on traditional wards (British Medical Association, 1967). The focus on the development of the ICU concealed the need for HDC although specialised forms of HDUs were introduced such as Coronary Care Units (CCUs) and Renal and Bone Marrow Transplant Units (Sheppard and Wright 2000). In the general hospital environment HDC continued on general hospital wards with the patient nursed in close proximity to the 'nurses' station'. At times some of these patients were 'specialled', a term given to the care that patients received when the nurse to patient ratio was increased; hence, a recognition that at times patients required an increase in nursing resource and close observation (Sheppard and Wright, 2000).

As ICUs grew in character, and with advances in technology, but increases in cost, their use came under scrutiny for two types of patient; firstly the patients that were 'too sick' to benefit from ICU (these were patients whose condition had deteriorated to such an extent that despite all efforts, death was inevitable) and secondly; the inappropriate admission of 'well' patients; consequently, preventing genuine patients from gaining access (Sheppard and Wright, 2000). This second group of patients posed problems; where should patients that were too sick for a general ward, but not sick enough for IC be cared for? An awareness for the effective use of the ICU was growing.

In 1988, Franklin et al, published work on the reduction of morbidity and mortality by 'facilitating access to critical care' through the opening of a HDU and rationing IC for low risk patients. This small prospective cohort study compared medical service admission, cardiac arrest and mortality rate in a single hospital in the year preceding and for one year post opening of a 12 bedded HDU. The results suggested a decrease of 13% in medical service hospital mortality rate in the first year of opening the HDU, a 25% decrease in deaths on medical wards in the second year of opening, a 40% decrease in ward cardiac arrests and a 7%

decrease in admission to ICU. Although this study was revolutionary in providing information to support the notion that ICU for low risk patients was not appropriate and could be rationed with improved outcomes, it was not without its limitations. Severity of illness was not measured and other confounders such as changes in staff or medical case mix were not accounted for.

In 1988, the first attempt at the definition of HDU was made in a Report by the Association of Anaesthetists (1988) as 'an area for patients who require more intensive observation and/or nursing care than would be expected on a general ward. It would not normally include patients requiring mechanical ventilation or invasive monitoring'. By prohibiting intubation and mechanical ventilation from a HDU, a definition for intensive care was fashioned, but the question was raised for HDC as to how much observation would define intensive observation and observation of what? As the use of HDUs became more commonplace a study for the DoH conducted in 1993, to investigate the provision of IC in England revealed that there were considerable disparities in the provision of HDC across the country (Metcalfe and McPherson, 1995). Only 34 (20%) of the acute hospitals in England, with an ICU, also had a HDU, although the number of beds were variable and not always known (Metcalfe and McPherson, 1995). At this time other small single centre prospective observational studies were published on the value of HDUs and effective use of ICUs (Nehra, Crumplin, Valijan and Edwards, 1994; Kilpatrick, Ridley and Plenderleith, 1994; Leeson-Payne and Aitkenhead, 1995; Donnelly, Sandifer, O'Brien and Thomas, 1995).

By 1996 evidence had mounted for the need for HDC but uncertainty remained as to its definition. The Department of Health (1996) produced 'Guidelines on admission to and discharge from Intensive Care and High Dependency Units' and although this report endeavored to typify HDC, ambiguity with regard to the definition remained. For example it was suggested by the Department of Health (1996) that HDC was appropriate for:

- 'Support for circulatory instability due to hypovolaemia from any cause which was unresponsive to <u>modest</u> volume replacement'.

- 'Patients <u>recently</u> extubated after a <u>prolonged</u> period of intubation and mechanical ventilation'.

The terms modest, recently and prolonged were subjective and without distinguishing parameters or boundaries; therefore, the definition of HDC remained arbitrary.

Accurate figures provided by the Department of Health (2003) suggested that, of the 3,097 adult critical care beds available, just over one third (1,351) were used for HDC on 15th January 2003 (http://www.dh.gov.uk/PublicationsAndStatistics/PressReleases). These figures reported only on the small number of beds available for HDC within the adult critical care areas and did not reflect the true estimation of HDC occurring on adult hospital wards and departments within NHS Trusts in England. As with paediatric services the problem encountered in determining the number of patients requiring HDC was with the lack of a precise definition. Although HDC for adult is not a new concept, attempts have been made to clarify the intensity of this level of care, but with no clear definition for any group of patients the situation with regard to HDC in the UK has remained confused (Sheppard and Wright, 2000).

2.3   Cost of Critical Care Services

Costing health services is important to aid political and administrative decision making and to enable optimal use and allocation of resources (Gyldmark, 1995). There are no precise figures for the cost of IC as the methodologies used for costing care are considered flawed; most studies fail to effectively specify a study question and the cost concept is not adapted to the purposes of the study (Gyldmark, 1995). A further problem with describing the costs of IC is the poor consistency of the costs to be measured and with the methods of measurement (Wernerman and Flaatten, 2004). A number of studies have attempted to report on cost; from the early 1990's to 2004 the cost per patient per bed day had not increased and was estimated to be between £1,000 to £1,500 (Singer, et al, 1994;

Coggins and de Cossart, 1996; Audit Commission, 1999a; Jacobs, Rapoport and Edbrooke, 2004). This relative agreement on the cost of an ICU bed day per patient over the period of 10 years may possibly be due to inaccurate determining of costs. Although significant variation in costs are attributable to differences in costing methodologies other factors are also at play; these being advances in technology, ICU size and differing treatment options offered (Seidel, Whiting and Edbrooke, 2006).

In 2004 a large retrospective data analysis concluded that the cost per patient per day of IC for six beds, running at 80% capacity, was £1,165, yet with economies of scale, 10 beds at 80% occupancy, the cost was reduced by 12% to £1,022 (Jacobs et al, 2004). A number of methodological flaws with this study need to be acknowledged; severity of illness was never taken into account as a scale variable, and the average length of stay was used in place of this; large ICUs were not represented in this study, particularly those in London; therefore, the study was not representative of ICUs nationally, and it was not clear where the scale of economies ceased to occur. An American study performed by Dasta, McLaughlin, Mody and Piech (2005) reported on the costs of IC in 253 hospitals in the US and found that the daily costs were higher on the first day of care ($7,728) than subsequent and stable days which occurred from day three ($3,436). It was not clear what costs were reported upon as fixed costs were not described. Singer et al (1994) compared the costs of intensive care and HDC and found that on average HDU costs were £437.83 per patient per bed day, while IC costs averaged £1,149 per patient per bed day. HDC costs were; therefore, estimated to be just over one third of those for IC.

The cost of a PIC bed was estimated to be between £950 and £1,200 in 1997 (Department of Health, 1997a) irrespective of the treatment or level of care provided, PIC or PHDC. Three early prospective evaluations of costs undertaken in single PICUs commented upon the increased cost of non survivors to survivors where non survivors cost between twice and three times the amount of survivors (Klem, Pollack and Getson, 1990; Pon, Notterman and Martin, 1993; Garcia et al, 1997). Two studies used the Physiologic Stability Index (PSI) to find that daily

expenditure grew with the level of physiologic instability (Klem et al, 1990; Garcia et al, 1997), while Pon et al (1993) used paediatric risk of mortality (PRISM) and calculated Risk of Mortality (ROM) as a measure of the severity of illness. Although PSI and PRISM were used to calculate the severity of illness, calculating non survivor and survivor costs may not reflect true IC costs. Never ventilated patients for example in one study (Pon et al, 1993) contributed more than half (56%) of the resident population of PIC. The threshold for admission to PICU will vary between units many children may be admitted for PHDC diluting the true cost of PIC, and thereby diluting the cost of non survivors. Arguably, low risk patients may not influence cost when 50% of all PICU cost is attributed to non survivors.

The national average cost per bed per day, in 2003 -2004, for all levels of care and unit types are seen in table 2.3.1 (The United Kingdom Parliament House of Commons Hansard written answers for 15th June 2005 (http://www.publications.parliament.uk).

Table 2.1   Cost per patient bed day by unit type in 2003 – 2004 (£)

Type of unit	National average cost per unit per day 2003-2004 (£)
Intensive Care Unit (Adult General)	1,328
Intensive Care Unit (Adult Cardiac)	1,025
Coronary Care Unit (Adult)	457
Intensive Care Unit (Paediatric)	1,702
Intensive Care Unit (Neonatal)	
Level 1*	838
Level 2	721
Special Care Baby Unit	353
High Dependency Unit (Adult)	584

*note level of care is reversed for the neonate with level 1 being intensive care

A PIC bed day was allocated more resources than an adult intensive care bed day, and the average cost of a HDC bed for the adult population was between 44 to 57% of that of an intensive care bed (table 2.1). Within the Leeds Teaching Hospitals NHS Trust the cost of a PIC bed was £648 more expensive per night than that of an adult IC bed and £1,123 more expensive per night than a neonatal IC bed in 2006/7 (table 2.2). A tariff was applied for adult and neonatal HDC but

not for PHDC (Jayne Bullas, 23.2.2007) (table 2.2). These figures were determined in consultation with the Clinical Director and the Matron for paediatric critical care (Jayne Bullas, 23.2.2007).

Table 2.2   Cost per night (£) for all critical care services at The Leeds Teaching Hospitals NHS Trust

Service description (per night)	Unit price (£)	Fixed price (£)	Variable price (£)
Neurosurgery - ICU	1,370.43	1,096.34	274.09
Cardiothoracic surgery - ICU	1,370.43	1,096.34	274.09
General - ICU	1,370.43	1,096.34	274.09
General- HDU	684.70	547.76	136.94
Paediatric - ICU	2,018.23	1,614.58	403.65
Paediatric - ICU cardiac	2,018.23	1,614.58	403.65
Neonatal - ICU	894.83	715.86	178.97
Neonatal - HDU	537.10	429.68	107.42
Neonatal - Special Care Baby Unit (SCBU)	357.73	286.18	71.55

Taken from: The Leeds Teaching Hospitals NHS Trust SLA monitoring report as at period 3 financial year 2007/08. LTHOO Trust Summary.

Costing for critical care is exceptionally difficult, and variation in the estimates of cost may reflect the lack of definition and provision of PHDC as this varies considerably between setting and NHS organisation. Until there is agreement on the methodology for costing purposes and an accurate definition for critical care including PHDC, the true costs will remain variable and inaccurate.

2.4   Support for High Dependency Care in the UK

Nine out of 10 acute hospital trusts had a general ICU in 1999 and although the number of ICUs was not increasing the median number of beds within them increased from four to six (Audit Commission, 1999a). In 1999, 45% of hospitals had a HDU (Audit commission, 1999a), yet this figure was contradicted by Garfield, Jeffrey and Ridley, (2000), who concluded that only 10% of hospitals in the UK in 1999 had HDU facilities. Furthermore, according to the Department of Health (2000), HDU development has been unplanned and haphazard. Some 40% of hospitals from which deaths were reported had no HDU and within some hospitals access to HDC facilities was denied (National Confidential Enquiry into

Perioperative Deaths, 2001). With concerns over bias and inequitable distribution of resources calls to extend and improve HDU facilities were made (National Confidential Enquiry into Perioperative Deaths, 2001).

The impact of the lack of HDC facilities and inappropriate use of ICU provided the impetus for a number of studies (Kilpatrick et al, 1994; Bodenham, et al,1995; Leeson-Payne and Aitkenhead, 1995; Ryan, Bayly, Weldon and Jingree, 1997; Turner, McFarlane and Krukowski, 1998; Loughrey, Fitzpatrick, Connolly and Donnelly, 2002). Only one of theses studies was multi-centre in approach and used survey research methods to collect data on the number, length of stay and severity of illness of patients admitted to 18 ICU's in North, West and East Yorkshire, to determine the provision of services for the future (Bodenham et al, 1995). A good response rate was achieved (96%) during the six month study period which found that 36% of all admissions were categorised as low nurse dependency or spontaneously breathing patients requiring simple monitoring .Twenty seven percent of patients required no therapeutic interventions. In conclusion the introduction of HDC services would have a major impact on costs and pressure on ICU beds (Bodenham et al, 1995). The five remaining studies conducted prospectively in single centres also identified a need for HDU care. Between 21% to 25% (Ryan et al, 1997; Loughrey et al, 2002) and 40% (Kilpatrick et al, 1994) of ICU patients could be managed in an HDU. Hospital mortality was greater in those patients that did not receive optimum requested care (Turner et al, 1998). Although patient activity and dependency level was not observed on the ICU, one study predicted that an eight bedded HDU would fulfill their ward based HDC needs (Leeson-Payne and Aitkenhead, 1995). A Welsh consensus study conducted in five hospitals aimed to define the number of critical care beds required for a population of 500,000 (Lyons et al, 2000). During one calendar year, on every 12th day, 10 intensivists, using summary sheets, made consensus decisions about each patient admitted for critical care to establish if care was provided in an appropriate place. The results suggested that 41% of patients required HDC, 21% required intensive care and the number of beds required to meet the needs, 95% of the time, was 30 IC beds and 55 HDC beds (Lyons et al, 2000).

Collectively the studies described (Kilpatrick et al, 1994; Bodenham et al, 1995; Leeson-Payne and Aitkenhead, 1995; Ryan et al, 1997; Turner et al, 1998; Lyons et al, 2000; Loughrey et al, 2002) make a convincing argument for the need for a HDU in hospitals that do not have such a facility, or for the opening of more HDC beds. While all of the above studies have reported the need for HDC facilities or the impact of opening a HDU on ICU, one early prospective observation study described the impact of the closure of a HDU on critical care facilities (Byrick, Mazer and Caskenette, 1993). By reversing the graded care approach the admission of low dependency, or short stay (one and two days) patients to the ICU increased from 92 to 423 over a period of nine months, and after closure of the HDU, mean APACHE II (severity of illness scoring system) scores reduced from 21 to19 (Byrick et al, 1993). Although collectively this information has attempted to provide support for greater numbers of HDC beds the efficacy and cost effectiveness of this level of care was never proven.

2.5 Organisation of the Delivery of Critical Care: The International Perspective

It is extremely difficult to compare critical care between countries without information from national databases and participation in national registers (Wild and Narath, 2005). Little systematic information is available concerning the need and appropriateness of critical care, organisation and methods for costing (Wild and Narath, 2005).

2.5.1 The United States of America

The United States of America (USA) has over the years allocated more resources to providing critical care than Britain (Singer et al, 1994; McPherson, 2001). According to McPherson (2001) the USA has spent more than 1% of its gross national product to providing IC though Britain spent only 0.05%. The average critical care unit in America boasted 11-12 beds, while the average number of beds in the UK was six (Jacobs et al, 2004). High dependency care in the USA is also known as 'intermediate care', or 'step up' and 'step down' care (Popovich, 1991; Junker, et al, 2002). Intermediate care areas (ICAs) were developed to care for specialist populations such as patients undergoing surgery and those requiring

coronary care that required additional monitoring and a level of nursing care more intensive than that provided on a regular nursing unit (Popovich, 1991). Yet some units developed were multipurpose (Junker et al 2002). Although there have been a number of publications related to the advantages of ICAs these being early ICU discharge (Byrick et al, 1993), a decrease in the hospital ward mortality rate (Franklin et al, 1988) and decreased costs (Krieger, Ershowsky and Spivack, 1990), one large multi-centre retrospective, cohort study concluded that between 20% to 70% of low risk patients admitted to ICU could be monitored in an ICA with concentrated nursing care (Zimmerman et al, 1996). Selection criteria for admission to one of the 42 ICUs within 40 hospitals were not set, but patients receiving 'ventilatory support' and high risk monitoring patients were excluded from the study (Zimmerman et al, 1996). A total of 6180 (35%) of all ICU admissions from 40 hospitals required monitoring, but no active treatment. As IC and HDC beds were not as abundant in Europe and particularly in the UK this study was not generalisable to countries outside of the USA. Patients admitted to IC in the UK have a greater illness severity and risk of mortality than those admitted to ICUs in other countries (Bion and Bennett, 1999). A further limitation is that the units taking part in this study were not randomised and therefore may not be representative of ICUs in the US. However this study has outlined the number of inappropriate admissions that occur in many ICUs in the USA.

The cost of a paediatric intermediate care bed in the USA was greater than that of a usual ward bed ($534 $\pm$ $60 V 381\pm$ $42), but less expensive than a PICU bed ($764 $\pm$ $99) (Lawless et al, 1991). In 95% of paediatric ICAs the registered nursing staff to patient ratio was 1:2 or 1:3 (Lawless et al, 1991). Paediatric critical care services were provided in level 1 and level 2 units in the USA where guidelines were in existence for the scope of care (American Academy of Pediatrics, 2004). Level 2 units should be equipped to deal with moderate to low acuity of critical illness, but all level 2 PICUs should be able to provide stabilisation of the critically ill child before, if necessary, being transferred to another centre. These guidelines also expressed the desirability for all nursing staff working in level 1 and level 2 PICUs to obtain a critical care and a PALS or equivalent qualification. The range of nurse to patient ratios were recommended at 1:3 to 2:1 depending

upon patient acuity (American Academy of Pediatrics, 2004). A further set of guidelines for the admission and discharge of children requiring intermediate care were published in 2004 by Jaimovich. The criteria used to determine admission were system based and included respiratory, cardiovascular, neurological, haematological, oncological, endocrine, gastrointestinal, surgical, renal and multi-system diseases. Each system heading contained a list of between three and seven criteria, but as with other lists to define PHDC no upper and lower limits or severity parameters were set, hence many of the criteria were imprecise.

Three recent surveys conducted throughout the USA have provided information on the number of PIC and paediatric ICA beds available (Randolph, Gonzales, Cortellini and Yeh, 2004; Odetola, et al, 2005; Vandeburgh, Hutchinson and Parshuram, 2007). Data from the American Hospital Association (AHA) and described by Randolph et al (2004) suggested that a shift in bed distribution for children towards high acuity beds and fewer general ward beds had occurred in the USA during three survey periods between 1980-2000. The reason for the growth was unclear, yet the number of PIC beds increased by 26% from 1980 to 1989, 19% from 1990 to 1994 and by 12.9% between 1995 and 2000. General paediatric ward beds decreased by 22.4%, 10.8%, and 15.7% during the same periods respectively. Although the purpose of this survey was to describe the growth and distribution of PIC beds from 1995 to 2001 and the characteristics of PICUs in 2001, Randolph et al (2004) found that of the 501 hospitals (with PICU facilities) surveyed in 2001 there were 140 stand alone ICAs, with 1,342 ICA beds, and 31 (22%) ICAs had $\geq$ 15 beds. The number of ICA beds per paediatric population varied between regions, from 1/34,269 in the mountainous states to 1/81,656 in New England. Unfortunately there was no data available to compare the growth of ICA beds between the study periods.

Odetola et al, (2005), found that the number of hospitals in the US with specialist paediatric critical care facilities was 337, but these hospitals did not provide equivalent care. Smaller units of one to six beds were found to have a greater ratio of nurses and doctors to beds, but lower availability of technological monitoring equipment. The proportion of PHDC to PIC provided in all units was not specified.

A recent cross sectional telephone survey identified 181 hospitals that met with detailed criteria (two or more paediatric wards or greater than 50 acute paediatric beds) across 51 states or commonwealths of the United States of America and 12 provinces of Canada (Vandeburg et al, 2007). Of these hospitals all had a PICU and more than half (99, 55%) had an ICA. The median number of ICA beds per hospital was four (range two to seven), and almost half (47%) of the ICAs were located within the PICU. These three surveys suggest that paediatric intermediate care is well recognised and provided for in the USA although uncertainty remains to the criteria used for admission and discharge to these units.

2.5.2   Europe

Britain also contrasts to mainland Europe. Fewer beds were available in Britain, per 100,000 population, than the rest of Europe; therefore, the patients admitted to these beds were sicker and almost always required intubation and ventilation (Singer et al, 1994). IC beds in the UK were rationed to such degree that by the time the patient had deteriorated to warrant IC organ system dysfunction was irreversible and recovery remote (Bion and Bennett, 1999). Only two papers written in English were found that reported upon adult HDC in two parts of Europe (Prien, 1998, Germany; Zakynthinos and Vassilakopoulous, 1999, Greece). Although these articles were related to the adult services and were not recent it was possible to draw some conclusions on the state of HDC in certain areas of Europe. In Germany the delivery of all health care was required to be more efficient without increasing costs; one area of care that demanded change was the critical care services (Prien, 1998). Guidelines were developed in 1974 for West Germany to determine the number of HDC beds according to hospital size; however with the increasing need for IC the concept of short term IC or HDC was realised with the advent of the post anaesthesia care unit (PACU). PACUs were developed as a subdivision of HDC to care for patients on a short term basis (24 hours) in post operative recovery units. These areas offered a combination of reasons for admission; buffer (holding area until the patient could be admitted to ICU), switch (the patient was evaluated for type of care) and upgrade (as the patient's condition improved or deteriorated the patient was transferred to the IC, HDU or general ward).

Although the UK had fewer beds than the rest of Europe the call to increase the number of HDUs and HDC beds in existence and the need to establish the effective use of resources in the ICU remained the same (Zakynthinos and Vassilakopoulous, 1999). In Greece recommendations were made for the creation of new HDUs in peripheral hospitals with less than 150 beds and in areas that had a high incidence of accidents. No information was available regarding staffing and training in ICUs in European countries (Timmermann, 1996).

2.5.3 Australia and New Zealand

The Joint faculty (Australian and New Zealand College of Anaesthetists, Royal Australasian College of Physicians) have published *Minimum Standards for Intensive Care Units* (2003) and *Recommendations on Standards for High Dependency Units Seeking Accreditation for Training in Intensive Care* (2002). Intensive Care units were determined by facilities, support services, severity of illness and the number of admissions per year. The levels of intensive care ranged from level 3 (greater than 300 mechanically ventilated patients per year for mechanical ventilation and provision of complex multi system life support), to level 1 ICUs that were able to provide resuscitation and short term cardio respiratory support. The staffing and operational requirements, design, equipment and monitoring and suitability for training were set out for each level of ICU. The medical and nursing requirements were similar to those recommended in the UK. A nursing ratio of 1:1 for mechanically ventilated patients and greater for patients requiring complex management was required and the nurse co-ordinating care in the ICU along with the majority of staff were required to have a post registered qualification in IC. A medical director with clinical practice principally in IC was required for the management of the unit. Similar standards also applied for PICU but a minimum of 300 admissions, irrespective of ventilatory status, were required to meet with the guidelines.

The Joint Faculty of Intensive Care Medicine (2002) recommended the following guidelines for HDUs involved in the training of medical staff for critical care to:

- Be adjacent or within the ICU complex.

- Possess defined referral, admission and discharge policies.

- Have formal audit of HDU and outcomes.

- Appoint a medical director who is a Fellow of the Joint Faculty of IC Medicine.

- Ensure that the nurse coordinating HDU has a post registered qualification in IC.

- Have all senior nurses with a post registered qualification in IC or HDC.

- Make certain that the nursing staff to patient ratio is 1:2.

- Have a minimum of four beds.

No reference was made to the inclusion or exclusion of children for PHDC.

In 1997 the Australian and New Zealand Paediatric Intensive Care (ANZPIC) Registry was established to describe PIC practices and outcomes and to report upon performance in nine PICUs and six ICUs (Report of the ANZPIC registry, 2005). In 2005 the rate of admission for PICU was 1.4 per 1000 children similar to the rate documented by PICANet (Paediatric Intensive Care Audit Network, 2007), the majority of admissions were for children less than five years of age and infants (less than 12 months of age) accounted for 37% of all paediatric admissions to the PICU. The percentage of ventilated patients admitted for PIC ranged from 9.7% to 85% with the median length of stay (LOS) for non intubated admissions being 0.85 days in comparison to intubated admissions whose median LOS was 2.1 days (Report of the ANZPIC registry, 2005).

2.6   Models of High Dependency Care

The English Dictionary definition of 'model' is a representation of a designed or actual object, proportioned in all dimensions (Oxford Dictionary, 1974). Therefore models of HDC are a representation of the floor space, bed numbers and staffing requirements for a resource intensive type of health care. One model of HDC will not fit all; each model will have its advantages and its limitations, however the favoured model should be that which produces the best outcome with greatest patient satisfaction at the lowest cost (Gerber, 1999; Wachter, 1999).

The aim of HDC is to provide a level of care between that of IC and usual ward care. This means providing advanced (invasive) monitoring equipment, skilled nurses with adequate nurse-to-patient ratios and access to skilled medical staff (Cheng, Byrick and Noble, 1999). Although with any hospital ward, shape, size, layout, lighting, air conditioning and many other factors require consideration, the location of the HDU requires serious thought particularly when access to HDU may be responsible for determining the efficiency of both the HDU and ICU (Cheng et al, 1999).

Three structural design models described as 'freestanding', 'parallel' and 'integrated' by Cheng et al, (1999) have their advantages and limitations, yet these models are described in relation to IC and HDC not to usual ward care and HDC. The description of the design options provided by Cheng et al (1999) have little validity, the literature provided by these authors is not based on empirical research but, on subjective opinion. Different hospitals may have different requirements. For example no mention is made of a model of general hospital ward based HDC that would be multiple in number and provide seamless care for the patient from general ward to HDC. Post anaesthesia care units (PACUs) as described above by Prien, (1998) have no place in the description of models for HDC provided by Cheng et al (1999), and the views of users were not taken into account.
Two models of PHDC have been described by Crawford and Powell (2004):

- Peripheral PHDU: managed as specialist units separate to PICU. These units may be managed by general paediatricians or surgeons with an interest in acute care.
- Central PHDU: adjacent to PICU but care may be managed at three levels:
  - general paediatric or surgical subspecialty approach.
  - combined approach, intensivists and general paediatricians/surgeons.
  - intensivist managed in consultation with subspecialties.

Regardless of the model to be used for HDC, patients and their families should be consulted with regard to the way they would like services to develop (Gerard et al, 2006; King and Meyer, 2006; Mayor, 2006). Therefore, the views of children and

their carers should be sought prior to the development of PHDUs. United Kingdom government policy over recent years has been dedicated to promoting user involvement, this has been evident in a number of policy documents (Department of Health 2000; 2001b; 2004a). Service planning in the 21st Century includes listening to the views of users and implementing ideas; however involving and listening to users is not easy and requires skill (Mayor, 2006). Although there are many areas of PHDC development where child and family views cannot be taken into account, comments and views regarding unit design and patient facilities are vital.

2.6.1 Critical Care Outreach

Critical care outreach is an approach that has changed the way that critical care is provided in England and Wales (Ball, Kirkby and Williams, 2003). In 1999 a recommendation was made to support hospital ward staff in managing patients that were at risk of deterioration through outreach services (Audit Commission, 1999a). Critical care outreach is used to identify patients at risk on hospital wards using early warning tools. Early warning tools allow the calculation of a score from a set of physiological observations for example respiratory rate, oxygen saturation level, and heart rate. When physiological observations are outside of the normal range, or extreme, the total score will activate a response or 'trigger' to ensure that patients are provided with timely treatment and where possible avert admission to the critical care unit. Early warning tools were developed initially for the adult population to identify patients at risk of deterioration (Goldhill, et al, 1999; Subbe, Kruger, Rutherford and Gemmel, 2001). As a result critical care outreach teams have developed with support from the Department of Health (2000) with three main aims, to:

- Avoid or ensure timely admission to intensive care.
- Facilitate discharge from intensive care.
- Share knowledge and skills.

Since the introduction of early warning systems a number of authors have demonstrated a positive effect on patient outcomes with a reduction in unplanned

transfers to the ICU from wards, length of ICU stay (Pittard, 2003) and hospital mortality (Buist, et al, 2002; Pittard, 2003). Despite this, more recent evidence from the Cochrane database of systematic reviews suggests that studies investigating outreach are of poor methodological quality with no evidence to support the effectiveness of outreach or reduction in mortality rates (McGaughey, et al, 2007).

Adult early warning tools have been adapted for use with children, yet concerns have been raised about the need to validate such tools as it cannot be assumed that children deteriorate physiologically in the same way as adults (Tume and Bullock, 2004). The development and use of two paediatric early warning tools have been published (Monahan, 2005; Haines, Perrot and Weir, 2006). Only one of these tools claimed to be validated (Haines et al, 2006). Unfortunately this claim was disputed because 'specificity' and 'sensitivity' or the tests use to confirm the accuracy of the tool were not correctly performed and reported (Tibballs and Kinney, 2006).

Although early warning tools and the implementation of outreach teams have been successful, particularly in adult areas, further work is necessary to determine if outreach teams have achieved their objectives on children's wards. Has identifying children at risk early averted admissions from or ensured timely admission to the PICU, and has this affected paediatric mortality rates? Funding attributed to outreach services will be dependent upon the ability to measure the benefit and the effectiveness of the outreach role, and although it may be difficult to assess the effectiveness of outreach services constant evaluation of this service is vital.

2.7   Scoring Systems and Mortality Prediction

2.7.1   Therapeutic Intervention Scoring System (TISS)

Children in need of critical care require numerous interventions, and therefore demand careful observation and technological monitoring (Department of Health, 2001a). The Department of Health (2001a) identified a core set of categories for paediatric critical care with a mix of therapeutic interventions and illness classifications. For example 'nebulised adrenaline for upper airway obstruction

after two doses or more' and 'cardiopulmonary resuscitation' are interventions, yet bacterial meningitis, diabetic ketoacidosis with drowsiness and meningococcal septicaemia are illnesses. An illness classification for a child may not change during a single admission to hospital, yet the level of care may fluctuate between PIC and usual ward care. During an admission, therefore, therapeutic interventions will change according to the level of care; this may make interventions a reliable indicator of dependency care levels.

The Therapeutic Intervention Scoring System, or TISS 76, was first described in the literature in 1974 by Cullen, Civetta, Briggs and Ferrara to classify the severity of illness, or the level of dependency of critically ill adult patients regardless of diagnosis and to predict the use of nursing manpower in the care of patients. A total of 76 items were scored on a one to four basis. The classification of patients ranged from Class 1, those less sick that received ≤ 10 points, to Class 4 patients those severely ill and receiving ≥ 40 points (Cullen et al, 1974). Since this time the development of more precise scoring systems such as Acute Physiology and Chronic Health Evaluation II (APACHE II (Knaus, Draper, Wagner, Zimmerman, 1985), APACHE III (Knaus, et al, 1991) and Simplified Acute Physiology Score II (SAPS II) (Le Galle, Lemeshow and Saulnier, 1993) to determine severity of illness has seen the demise of TISS for these purposes (Miranda et al, 1996). Despite being a reliable, validated tool for quantifying nursing resource criticisms of the TISS 76 were aimed at the time taken to complete the form and of the unreliability because of the varying interpretation of the interventions; therefore a simplified version was developed and called the TISS 28 (Miranda, de Rijk and Schaufeli, 1996). Despite criticisms, TISS 76 was used to determine the severity of illness of patients in hospitals where it was found that patients discharged from the ICU with high TISS had higher mortality rates (Smith, et al, 1999; Beck, McQuillan and Smith, 2002). Beck et al, (2002) used a retrospective cohort study in one DGH to compare patients discharged from the ICU to either hospital ward or the HDU. The results demonstrated that patients with TISS scores ≥ 30 points discharged to a hospital ward had a higher risk of in-hospital death compared with patients discharged to HDUs. Late time of discharge from the ICU to the ward was also associated with increased mortality (Beck et al, 2002). With pressures for precious

ICU beds and few HDC facilities, decisions have to be made about who has available ICU/HDC beds and who is transferred to the ward. Yet, it was inappropriate for patients with high TISS scores to be discharged to hospital wards when HDC facilities were available and at times during the night when ward staff were unable to manage the care of patients that required greater observation and monitoring.

Intermediate TISS was developed in 1994 by Cullen, Nemeskal and Zaslavsky, for use with medical adult patients requiring HDC in HDUs but also on hospital wards. Intermediate TISS varies from original TISS in the number of interventions listed, 75 items were developed for use in ICAs, 49 of which were retained from original TISS, 10 of which were re-weighted and 26 items were added. Changes for the new TISS were agreed by nurse managers and clinicians using consensus methods to agree new items and re-weightings. Although intermediate TISS was developed to measure HDC workload, two studies failed to use this as measure of nursing workload in HDC areas (Garfield et al, 2000; Pirrett, 2002). Garfield et al, (2000) provided an explanation for not using intermediate TISS, this being that it did not perform well on surgical patients (Cullen et al, 1994).

Without an explanation for not using intermediate TISS, Pirrett (2002) used TISS 76 to report upon the effectiveness in distinguishing between ICU and HDU patients. This study occurred in a small three bedded, predominantly, HDC area where it was required to immediately distinguish the level of care in order to put the correct skills and resources into place to provide safe patient care. Despite identifying groups of HDC patients with a TISS score of ≤10, modifications (e.g. insertion of oxygen therapy as an intervention) were made to the original TISS 76 by Pirrett (2002) to meet the needs of the study site, yet intermediate TISS did retain 49 items from the original TISS 76 and one of the 26 new items added was oxygen therapy via mask or cannula and given a score of two points (Cullen et al, 1994).

Criticisms of scoring systems developed to determine requirements for nurse staffing and nurse to patient ratios suggest that they are too restrictive as they do

not quantify all aspects of nursing workload, for example overall ward co-ordination of care and the support of relatives (Chellel, Dawson, Endacott and Andrews, 1995; Department of Health, 1996). Although both TISS 76 and 28 have been shown to correlate well (Miranda et al, 1996; Moreno and Morais, 1997) criticisms were levied at the TISS 28 for not accounting for the basic aspects of patient care such as general hygiene and the psychological aspects of patient and family care, and for underestimating therapeutic interventions in the HDU patient (Garfield et al, 2000; Kwok, Chau Low and Thompson, 2005). TISS 76 and 28 were also criticised for determining nursing workload with the use of medical interventions (Adomat and Hewison, 2004). This claim is outdated. Nurses are performing duties once performed by doctors. The arrival of the Scope of Professional Practice (United Kingdom Central Council, 1992) facilitated the expansion of nursing roles with changes in responsibility occurring to serve the interests of patients. This coupled with the reduction in junior doctors' hours has changed the traditional patterns of work (NHS Executive, 1998). Opportunity has arisen for nursing staff to share certain clinical duties with medical staff. Even without the expansion of nursing roles many procedures such as intubation, which is performed more routinely by the medical staff, would require the presence of a skilled nurse to assist with the process.

Although developed for use in adult patients, TISS have been found to perform and correlate well with reputable mortality prediction scores (Paediatric Risk of Infant Mortality (PRISM)) for determining the severity of illness in children with cancer (Heying, et al, 2001; Tamburro et al, 2004). To determine the efficacy of ICU for newly diagnosed oncologic children, a retrospective analysis within a single PICU was conducted using TISS and PRISM scores (Heying et al, 2001). Intensive care was found to be beneficial for this group of patients with TISS and PRISM scores higher in children that did not survive. Median TISS scores of survivors to non survivors were 29 vs. 47.5. Although the generation of PRISM was documented the TISS scoring system, 76 or 28, was not clearly documented or referenced.

2.7.2   Mortality Prediction

Mortality prediction scores are widely used in intensive care units and are valuable tools. The Pediatric Risk of Mortality (PRISM) (Pollack, Ruttiman and Getson, 1998) and the Paediatric Index of Mortality (PIM) (Shann, Pearson, Slater and Wilkinson, 1997) are used in PIC to assess the mortality risk in various groups of children. Both these tools have been updated to PRISM III (Knaus et el, 1991) and PIM 2 (Shann, Slater and Pearson, 2003). The purpose of such systems is to allow comparison of the severity of illness between different treatment arms in clinical trials, to observe trends within units and to evaluate the efficiency of PICUs (van Keulen, Polderman and Gemke, 2005). Both were developed and validated in tertiary PICUs (Pollack et al, 1988; Shann et al, 1997).

2.7.2.1   Pediatric Risk of Mortality (PRISM)

PRISM consists of 14 physiologic variables and 23 variable ranges and was developed from the Physiologic Stability Index (PSI) to predict mortality in PICUs (Pollack et al 1988). The initial PSI scoring system, which consisted of 34 variables with 75 variable ranges, required reduction and the re-weighting of variables to simplify and to reflect the severity of illness for children. Admission day PSI scores (first 24 hours from the time of admission), outcome (survival or death), diagnosis and demographic data were collected from nine participating PICUs. The PRISM score was remodeled by splitting the dataset into two parts; part A was used for model derivation and part B for data validation. The score was evaluated in each institution in the validation group along with the aggregate of all institutions. Used extensively in the USA, PRISM III is the most recent addition to the family which provides the risk adjustment tool for the United States based Paediatric Intensive Care Unit Evaluations system reporting to participating units under a licensing arrangement (Brady, et al, 2006).

2.7.2.2   Paediatric Index of Mortality (PIM)

A mortality prediction model PIM was developed in 1996, by Shann et al, to predict the expected probability of death in children, less than 16 years of age, in PICUs. The score was initially developed using 10 variables collected at the time of admission to PIC. The 10 variables identified for the model from three prospective

cohort studies, from 1988 to 1995, in one hospital in Australia were subsequently reduced to eight variables using data from part of the third cohort and from a fourth cohort study and located in eight PICUs (seven in Australia and one in Britain). The PIM was recently updated to PIM 2 using data from 10 PICUs in Australia and four PICUs in the UK (Shann, Slater and Pearson, 2003). None of the tools have been externally validated for use in UK PICUs (Pearson, Stickley and Shann, 2001). The PIM differs to PRISM in the timing of data collection and in number of items that make up the score. Although PRISM was the only mortality prediction score available for effective general use in PICUs for nine years it was accurate and widely accepted (Shann et al, 1997). An alternative score (PIM) was developed because it was difficult to collect the most abnormal values of 14 variables during a 24 hour period. Many non survivors die within the first 24 hours after admission to PICU and poor quality of care may be unnoticed if a child deteriorates within the first 24 hours (Shann et al, 1997, Gemke and van Vught, 2002).

Although valuable, both tools have their limitations. Both tools require in-depth training of medical staff before they can be applied in the PICU. Chronic disorders characterised by differences in acute physiology are not accounted for (Gemke and van Vught, 2002). For PIM it may be difficult to gain all scores for physiological variables within one hour of admission to the PICU. Default scores are provided by Shann et al (1997), yet underestimates or overestimates of expected probability of mortality is likely to occur when missing information for PIM is replaced with the default scores.

2.8   Summary

Although there is limited information in relation to adult HDC the literature available for PHDC is meagre. A plethora of governmental guidance has been published which spans all age groups and relates to the standards of care particularly for staffing and training in critical care including HDC. Policy documents and guidelines were also accessible for children and adults in the USA and in Australia and New Zealand. Standards were not available regarding the admission to and discharge from the paediatric critical care areas and for the level of training and skills for staff in other parts of Europe. This was despite the availability and

accessibility of the website for the European Society for Paediatric and Neonatal Intensive Care (http://www.espnic.org.htm). In the UK the current situation for critical care for both adult and paediatric services has similarities to Europe and the USA with regard to the lack of definition and the problems in quantifying the volume of HDC. Nevertheless the USA was able to quantify the volume of PHDC beds but the threshold for admitting to those beds was not clear.

Regardless of efforts to refine the boundaries between HDC and usual ward care and HDC and IC, HDC remains subjective, and it appears that clinical discretion is applied by health care professionals when admitting patient's to ICUs or HDUs for HDC. Differences also exist between countries and regions with regard to the amount of HDU provision. Owing to geographical and international disparities and availability of HDC, confusion exists when planning for HDC. In countries with a low ICU bed density (Great Britain, Australia, Canada), planners argue for an increase in critical care provision, but in countries with a high ICU bed density (USA, Germany, Austria) arguments focus upon the better use of existing resources (Wild and Narath, 2005). Although arguments that centre upon an increase in HDC provision may appear to be justified from the limited literature, further research is required to prove the efficiency and effectiveness of HDC.

Costing for critical care currently remains inconsistent across the UK and worldwide owing to the variation in the methodologies used. Treatment options available and the size of units also impact on the variability of costing figures. Clearly the cost per day of a PIC bed in Leeds was listed as £2,018. 23 but this was irrespective of the treatment modality or the level of care provided. The same cost was attributed to PHDC if that care was provided in the PICU. Costs for PHDC were not separated from that of usual ward care, presumably, because no designated PHDU existed in Leeds for children and because no accurate definition of PHDC exists on which to base costs. Tariffs were listed for neonatal HDC and adult HDC in Leeds, yet HDUs existed for these groups of inpatients. If a substantial amount of PHDC is being provided on acute paediatric wards at Leeds then revenue is lost for the PHDC that is being provided.

The information describing models of HDC determine ways of grouping and managing HDC work in combination with IC and not with usual ward care. Critical care outreach has a different approach to the management of critically ill patients which involves providing ward based HDC. Critical care outreach requires a trigger or early warning score to identify patients at risk of deterioration and a team of health professionals to support and educate ward nurses in the care of critically ill patients. Where a patient cannot be maintained in the ward environment timely admission to the ICU is arranged. Despite government support for critical care outreach (Department of Health, 2000) the evidence does not support its effectiveness.

Scoring systems such as TISS and mortality prediction tools such as PRISM and PIM have been used extensively in the critical care setting and have been shown to be reliable and valid. Although each of the tools described has limitations the usefulness and simplicity of the TISS has provided the impetus for the development of a scoring tool to define PHDC.

3 Plan of Investigation

3.1 Aims and Objectives of the Study

The aims of this study were twofold. Firstly to develop definitions of PHDC in order to determine PHDC activity, and secondly to estimate the number and level of skills of nursing and medical staff required to ensure that the dependency needs of children were matched by the skills of the workforce.

The study commenced in September 2003 with the following specific objectives:

- To develop a measurement tool to define PHDC.
- Report on the number of children requiring PHDC in West, North and East Yorkshire during a one year period from January 1st to December 31st 2005.
- Conduct a nurse staffing survey to determine the number, qualifications and advanced life support skills of nursing staff available to care for children in need of PHDC during the months of May and November 2005.
- Conduct a survey of medical staff to provide information on the number and grade of medical staff with valid certification in advanced paediatric life support skills available to each ward during the month of May 2005.

3.2 Setting up for the Study

The study of PHDC was the idea of the Paedaitric Critical Care Network from two Strategic Health Authorities (SHAs), West Yorkshire and North East Yorkshire and Northern Lincolnshire (NEYNL). From this initial idea, a Steering Group Committee of doctors, nurses, hospital managers and commissioners formed to brainstorm and plan for the study of PHDC. Owing to the size of the geographical area and the amount of work the study was to create, a job description for a full time research

nurse was written by the Steering Group and approved by the Paediatric Critical Care Network.

In 2003, the researcher a specialist children's nurse with a paediatric critical care course, advanced life support skills and more than 10 years experience of managing children with a critical illness on PICUs, applied for the position of research nurse to conduct the study of PHDC and as the successful candidate, inherited the study with the specific aims and objectives as described above. A part time audit clerk, who input all returned data, joined the study late in 2004.

The funding for this study was provided by the Paediatric Critical Care Network. Participating hospitals within this region included 11 NHS Trusts and 16 hospitals incorporating lead centres for paediatric intensive care, DGHs, major acute hospitals and specialist units all with paediatric hospital wards and services. Two DGHs (Scunthorpe General Hospital and the Diana Princess of Wales Hospital, Grimsby) both of the Northern Lincolnshire and Goole Hospitals NHS Foundation Trust were affiliated to Sheffield Children's Hospital for PIC services where an audit of PHDC had already been undertaken, and both hospitals opted not to take part.

The infrastructure and progress of the research process is summarised below and in figure 3.1.

Feasibility study. This is described in chapter four. The development of, and the acceptability and validity of the data collection forms is explained. The feasibility of this study was explored on two hospital wards within two NHS Trusts.

The pilot study is explained in chapter five. The 38 hospital wards involved in the study provided information to refine the data collection forms.

Expert consultation in chapter six used the results from chapter five and the opinions of 10 experts within the region to determine consensus for tool items thought to represent PHDC. The expert consultation study was adapted from the Delphi technique and applied to assist in the reduction of tool items.

The main study unites chapters seven, eight and nine where data was collected for children, patient activity and staff during one calendar year.

The development of the PHDC measurement tool is summarised in chapter seven. Five iterative phases describe tool development, data collection, assessment of data quality, data analysis, modification and process and testing of the 36 item tool. The use of the measurement tool in clinical practice is explained.

Representation of ward activity in chapter eight was provided by the number, qualifications and skills of clinical staff and the number of children requiring care. The measurement tool developed was applied to the existing dataset in chapter nine to marry the information provided on the volume of PHDC that occurred in the region and the skills of clinical staff.

The discussion and conclusion are presented in chapter 10 and compares opinion about PHDC.

Figure 3.1   Flow chart outlining the process for the development of the paediatric high dependency care study

Interviews with clinical staff Steering group committee Literature review to develop data collection forms

Feasibility study	Pilot study	Expert consultation

Refinement of data collection forms

Development of the PHDC measurement tool	Clinical nurse and medical staffing survey

Phase 1 Data collection Phase 2 Development of complex tables Phase 3 Modification Phase 4 Test retest	Data validation	**Number and level of skills of nursing and medical staff quantified** **Quantity of PHDC determined**

36 item measurement tool developed

4   **A Study of Feasibility**

4.1   Introduction

This chapter discusses the development and introduction of five PHDC data collection forms in the Yorkshire region. Consideration was given to the processes and procedures undertaken to ensure the reliability and credibility of the PHDC data here and throughout the study. Questionnaires are just one method of collecting data: their design and method of administration has a direct bearing on the response rate achieved but also on the quality of data collected (Williams, 2003). Therefore, all data collection forms were introduced into practice for completion by nurses to determine their performance and to ensure that the data collected was meaningful. This rigorous approach adopted for the development of the forms and their introduction into clinical practice, permitted errors to be rectified before they were subject to further testing on all hospitals and sites in the region. A basic analysis of the data was undertaken to ensure that the data collection forms collected all necessary information relevant to PHDC and ward workload in the paediatric area. This was essential before progression to the pilot study.

4.2   Aim

The study of feasibility aimed to establish tools for collecting clinical and intervention data for:

- Children requiring PHDC, or paediatric patient activity.
- The nursing staff employed to care for them.

4.3   Method

4.3.1   Study Population

Inclusion Criteria: All infants, children and young persons, irrespective of age, admitted to hospital that met with one or more of the predetermined criteria were eligible for inclusion into the study (Appendix 5). All nurses, qualified and unqualified, that assisted with the care of children.

Exclusion Criteria: Infants who had not been discharged home after birth and were less than three months corrected age, or less than five kilograms. These children were excluded because members of the steering group for PHDC believed these children were akin to the neonatal population and would therefore require neonatal criteria to meet with PHDC.

4.3.2   Study Period

Data were collected over a two week period 24/11/2003 to 7/12/2003.

4.3.3   Location

Two hospital sites and five ward areas were recruited for the feasibility study (table 4. 1).

Table 4.1   Hospital sites involved in the feasibility study

Hospital	Ward
Leeds General Infirmary (LGI) of The Leeds Teaching Hospitals NHS Trust.	48A Paediatric Neurosurgery 48 Paediatric Surgery
Bradford Royal Infirmary (BRI) of The Bradford Teaching Hospitals NHS Foundation.	2 Paediatric Surgery 17 Paediatric Medicine 16 Paediatric Medicine

These sites were chosen because the LGI was the lead centre for PIC and admitted children from the Yorkshire region in need of PIC /PHDC. Some children were transferred back to their referring hospital after discharge from PICU but some children remained in Leeds for specialist treatment. Therefore, two busy hospital wards at the LGI were chosen to determine the performance

of the data collection forms within a large teaching hospital, specifically, in two specialist surgical areas, these being neurosurgery (ward 48A) and general surgery (ward 48). Ward 48 admitted children for all types of surgery but it was a referring centre for major bowel and chest surgery.

Routine acute admission data to the PICU is collected by an audit clerk for the PICU at the LGI. This data was accessed by the researcher to provide information on the number of acute admissions from the regions DGHs in 2002 and 2003. These results showed that Bradford Royal Infirmary (BRI) was an extremely busy DGH and the largest referrer of critically ill children to the PICU in the region (PICU database) (figure 4. 1); therefore BRI was chosen to test the data collection forms during the feasibility study. In contrast to the wards at Leeds, testing the data collection forms at BRI would measure their performance in an area of acute general paediatric medicine and surgery.

Comment sheets were provided for nursing staff to critically appraise all data collection forms.

Figure 4.1 **Frequency of retrievals from referring hospitals within West, North and East Yorkshire during 2002 and 2003 to the paediatric intensive care units at Leeds (PICU Database)**
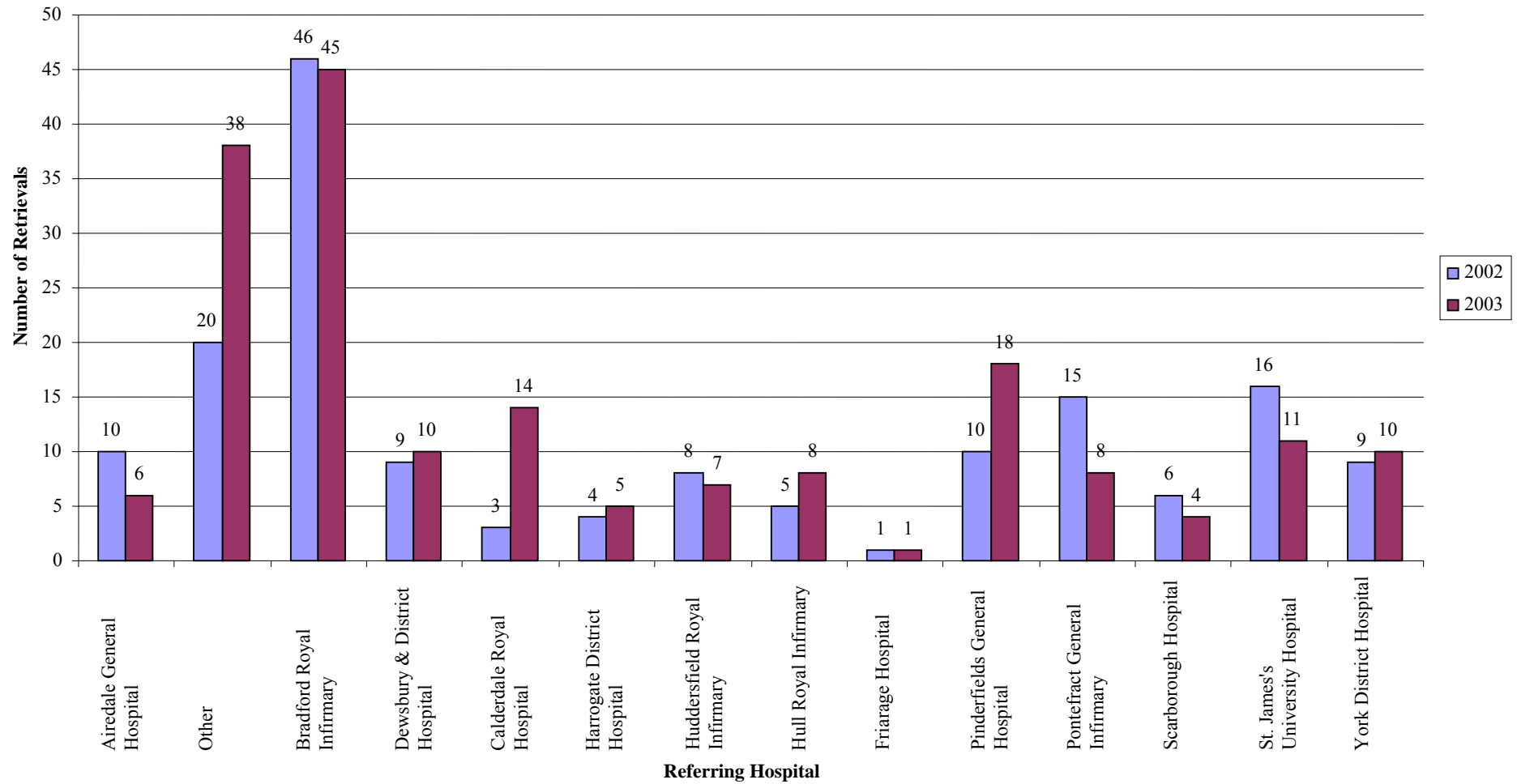
4.3.4 Data Collection

Data items selected to represent the concept of PHDC, for inclusion into the data collection, were informed from the limited literature available (Department of Health, 2001a) and from discussions with matrons/nurse managers and/or senior nurses from every hospital and ward in the Yorkshire region. Appointments were made with 24 individual nurses and or matrons/nurse managers; they were asked to provide an overview about the following:

- The range of diagnoses/conditions of children and young people that presented to their area requiring PHDC.
- The interventional care and monitoring that was given to individual children requiring PHDC.
- Their nursing establishment, qualifications of nursing staff, number of shifts in a 24-hour period and the number of beds available.

From these interviews the admission diagnoses, types of monitoring available, interventions performed and shift types and times were listed to develop the data collection forms. At the interview each nurse manager/matron was also asked to identify a link nurse for each ward to:

- Take responsibility for effective data collection.
- Act as a resource for other members of staff.

Some nurse managers were responsible for more than one hospital ward and encouraged senior nurses to be present at the interview. The nurses that were interviewed worked on hospital wards that differed in the numbers, the range of conditions and the treatment of children they admitted. Some wards were extremely specialised, and for example only admitted children with cardiothoracic, renal, oncological, neurological, plastic or orthopaedic problems. Shift patterns for nurses also varied by hospital ward.

4.3.4.1 Data Collection Forms

Five data collection forms were designed by the researcher for purposes of this study (Appendix 5). The first two paediatric patient activity (PPA) forms were designed using the limited literature available and from interviews with nurses

from around the region. Criteria for the staffing forms were guided by the Paediatric Critical Care Network because of information that was required by them to determine the number and level of skills of nurses available each shift. These five forms included:

- Paediatric Patient Activity (PPA) Form A.
- Paediatric Patient Activity (PPA) Form B.
- Monthly Nurse Staffing (MNS).
- Daily Nurse Staffing (DNS).
- Daily Patient Activity (DPA).

All forms for the feasibility study were designed to be completed by nurses.

4.3.4.1.1   Paediatric Patient Activity (PPA) Forms A and B

As each ward relied upon subjective methods of assessing PHDC, and because diagnosis does not assume PHDC status (Leeson-Payne and Aitkenhead, 1995) the concept of PHDC for the PPA was not defined by specific diagnoses or diseases, but defined by clinical interventions with severity parameters that were written into each intervention and into the guidance notes (Appendix 6) to assist nurses with form completion and with the capture of accurate data. Severity parameters prevented nurses from using their own judgement. Examples of the clinical interventions and their severity parameters (underlined) used for the PPA forms were:

- 'Four apnoeic episodes within four hours'.
- 'Frequent position changes' (2 hourly or more frequent).

The severity of PHDC illnesses may be quantified by the number of clinical interventions provided for a child. However, some single interventions may necessitate a higher level of care than usually given on a children's ward, for example 'cardiopulmonary resuscitation' (CPR) and 'continuous positive airway pressure' (CPAP) may singly represent PHDC (or a higher level of care). Other items although individually do not reflect the concept of PHDC the cumulative effect of the interventions may weigh in favour of a child requiring PHDC.

Identification of the criteria defining the need for PHDC, usual ward care or PIC required the comparison of children at each level; therefore, the clinical interventions ranged from care of the child with an intravenous infusion (possibly usual ward care) to intubation and subsequent care of the intubated child (PIC). Some children will move between all three levels of care and require specialist care and transfer to a ward or hospital from which they were first admitted.

Two separate forms were developed to collect data on the number and type of clinical interventions performed, for a child, during a shift (Appendix 5). Two separate forms were developed to identify form superiority. Form A was administered to both surgical wards at the LGI. Form B was administered to all wards at BRI. PPA forms A and B had many similarities these included:

1.   Data items.

The following information was required for both PPA forms:

• Demographic details	Full name
	Date of birth
	Unit number
	Sex
• Geographical information	Hospital
	Ward
	Home postcode
• Diagnosis (according to category)	Cardiovascular
	Respiratory
	Renal
	Oncology
	Neurological
	Metabolic
	Trauma/Accident
	Post-op care
	Other
• Location of child on ward	High dependency area
	Cubicle

The clinical interventions developed were arranged under eight, largely system, headings; these were:

- Observations.
- Airway.
- Breathing.
- Infusions.
- Renal.
- Circulation.
- Neurological.
- Other.

For example under the heading 'airway' was a list of interventions that may be performed for a child during a shift and the corresponding response box for nurses to annotate the correct option. The check/tick box was reported to be the quickest method for form completion and the easiest to read and interpret by data entry clerks (Avey, 2000).

2.   Completion and Completion Times

To determine the quantity of PHDC the PPAs required completion for children that fulfilled the PHDC criteria at any time during a shift. Children were not followed from admission to discharge: data collection forms were completed when children fulfilled the PHDC criteria specified; this is outlined below and is slightly different for each of the data collection forms.

The data was collected twice during a 24 hour period; once during the day and once during the night at 03.00hrs and 15.00hrs. It was vital that assessment of the child and completion of the audit form did not conflict with other duties and nursing responsibilities. At various time points during a shift nurses were bound to certain routines, for example lunch time for the children was around midday; nurses must serve lunch and feed some children. At 2pm intravenous antibiotics and oral drugs must be administered; therefore, 03.00hrs and 15.00hrs appeared suitable times to ensure maximum response rate.

Error is introduced if there is a lack of response levels (Streiner and Norman, 2001); therefore, to identify form superiority, the PPA forms A and B, differed in the way nurses were asked to respond to the interventions listed:

PPA Form A

Form A listed 58 clinical interventions. Completion was required once during the day (15.00 hrs) and once during the night (03.00 hrs) for all children that required any one of the 58 items/ interventions listed. Some children required form completion for a single intervention e.g. for a continuous drug infusion yet, other children required form completion for multiple interventions. A response was required only to the intervention that was provided for the child by annotating the box alongside the intervention.

PPA Form B

Form B listed 51 interventions, although it appeared that there were a reduced number of items for form B, some of the items were subdivided. Completion was required once during the day (15.00 hrs) and once during the night (03.00 hrs) for any child who fulfilled any one of the criteria on the data collection form excluding intervention one. Intervention one asked the nurse to mark the appropriate box for the frequency of nursing observations the child was receiving. The reason for excluding intervention one was 'Daily Observations' would permit inclusion of every child admitted to a ward into the PHDC study. A response to all of the 51 interventions was required by marking each intervention with an answer of 'Yes', 'No' or 'Not Known'.

4.3.4.1.2   Monthly Nurse Staffing (MNS)

The following information, regarding nurse staffing levels and grades, was required for a two week period within the month (24/11/2003 - 7/12/2003):

- The numbers of established Whole Time Equivalents (WTE) and actual WTE's in post according to grades A,B,C,D,E,F,G and H.
- The numbers of nurses according to grade with APLS skills.
- The numbers of nurses with a critical care course (English National Board (ENB) 415, 405, 160, 100).
- The number of nurses with a PHDC course or modules.
- The number of funded beds and the number of funded beds actually open.

4.3.4.1.3   Daily Nurse Staffing (DNS)

The following information was required for each shift:

- The numbers of RN (Ch), RGNs, ENs and HCAs.
- The numbers of bank agency or overtime nurses used.
- To acknowledge the presence of a nurse with A (APLS/PALS training), H (HDC modules) and C (critical care course). Numbers were not required; nursing staff were asked to mark the appropriate box with ✓ if a member of staff was on duty with the relevant qualification.

4.3.4.1.4   Daily Patient Activity (DPA)

DPA collection forms required completion daily and the following number of:

- Admissions to ward.
- Day cases.
- Ward attenders.
- Children for pre-assessment or admissions to an assessment area.
- Transfers to PICU or ICU.
- Transfers to PHDU (internal/external).
- Transfers to the ward.
- Discharges home.
- Deaths.
- PPA forms collected during the day and during the night.
- Beds occupied at the times the data forms were collected.

Guidance notes, with severity parameters documenting the definitions for each intervention,(Appendix 6) and for staff/patient categories were produced for all

data collection forms to assist with completion and to facilitate the capture of clean accurate data (Wood, 2000; Arts et al, 2003).

4.4   Results

During the short period of time that the data collection forms were tested the nursing staff responsible for form completion made many criticisms regarding the form format using the comment sheets provided. These are outlined first, followed by a basic analysis of the feasibility data.

4.4.1   Criticisms and Comments from Nursing Staff

4.4.1.1   Paediatric Patient Activity (PPA) Forms A and B

1.   All items regarding PHDC for both forms were designed to fit one sheet of A4 paper. The form was double sided. The font, Comic Sans MS, size 10 was used for both forms. Items were ordered under their respective group headings (observations, airway, breathing, infusions, renal, circulation, neurological, other). Nursing staff using the comment sheets provided noted that the forms were not user friendly; the font was difficult to read and the response boxes small. PPA form B used at BRI required more response boxes for nursing staff to indicate a response of 'Yes', 'No' or 'Not Known'. Some items were subdivided. Form B appeared extremely crowded. Nurses had difficulty reading the items which may increase the likelihood of response errors; these can be minimised by providing a workable form (Moser and Kalton, 1971).

2.   Two ward staff from separate areas (ward 48 LGI and ward16 BRI) were of the opinion that the PPAs would not be completed if nursing staff had other priorities at 03.00hrs and 15.00hrs.

3.   The reason for a child's admission was categorised (cardiovascular, respiratory, renal, oncology, neurological, metabolic trauma/accident post-op care and other) for nursing staff to indicate a response. Nurses remarked that this was subjective; it was possible for a child with meningococcal disease to be categorised under any of the following headings; cardiovascular, neurological, metabolic or renal, depending upon the severity of symptoms, and this did not really reflect a child's true diagnosis.

4.4.1.2 Daily Patient Activity (DPA) and Daily Nurse Staffing (DNS)

The design of the PPA and DNS caused problems for nursing staff. Their criticisms centred on the size of the data set. Both forms were to be collected on a daily basis. To avoid having two sheets of paper both data collection forms were placed on one side of A4 paper with identical tables for completion on the reverse side. Nurses reported that the information they were documenting on these forms was small and crowded. They confessed that mistakes, made by themselves, in recording numbers caused them confusion; they worried that the information documented would be recorded incorrectly during data input.

4.4.2 Basic Analysis of Feasibility Data

4.4.2.1 Paediatric Patient Activity (PPA) Forms A and B

The number of PPAs returned for the total study population was157 for 48 children (figure 4. 2). Leeds General Infirmary (ward 48) returned the largest number of data collection forms n= 60 (38%) for 12 children. Ward 2 at BRI returned the smallest number of forms n= 5 (3%) for three children.

Figure 4.2 The number of paediatric patient activity forms returned by hospital and sex (feasibility study)

Hospital ward
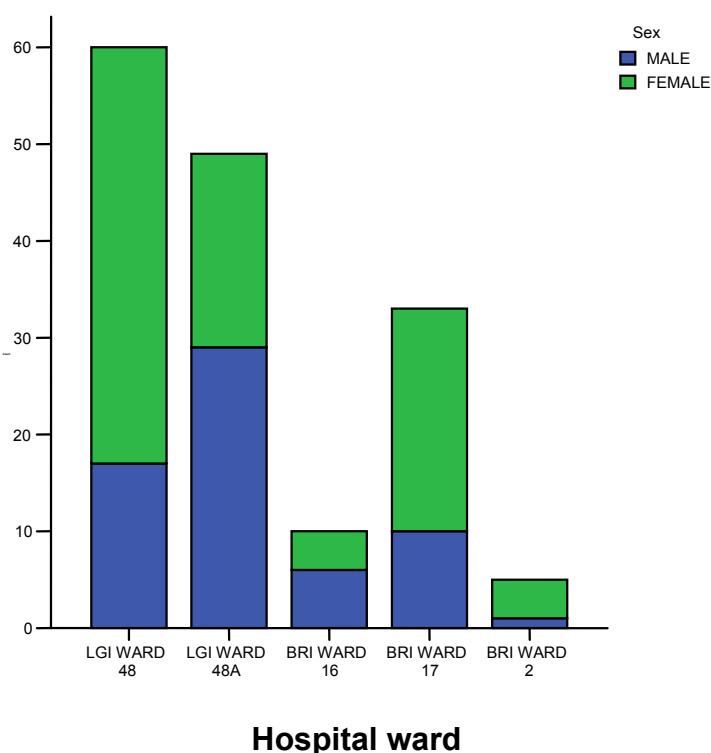
The number of children for whom forms were completed were evenly split by sex (n= 24, 50%), yet more forms were returned for analysis per female n= 94 (60%). Three girls accounted for 37 (24%) of the total episodes of care or 40% of all female episodes. The majority of forms were completed during the night shift (n= 89, 57%).

The most common category for a child in need of PHDC to be admitted to one of the hospital wards was neurological n= 60 (38%). Only three (2%) data collection forms were completed for a child with a metabolic disorder.

The majority (57%) of episodes of care on the ward areas required general nursing observations less frequently than hourly. Only 12% of episodes required general nursing observations greater than hourly (table 4.2).

Table 4.2   Frequency of nursing observations (feasibility study)

Observation frequency	Number of episodes (%)	Number of children (%)
Greater than hourly	19 (12.1)	9 (18.8)
Hourly	43 (27.4)	17 (35.4)
Less frequent	90 (57.3)	20 (41.7)
Missing	5 (3.2)	2 (4.2)
Total	**157 (100)**	**48 (100)**

Seventy seven (49%) episodes of care for 34 (71%) children required oxygen saturation monitoring. Of the 58 possible clinical interventions; oxygen saturation monitoring was the most common either as a single intervention, or one of many (table 4. 3). Forty percent of episodes required an intravenous infusion for 60% (n =29) of children and 16% required multiple intravenous drug therapy for one quarter (n= 12, 25%) of all children.

Table 4. 3   Most frequent clinical interventions performed by episode of care and child (feasibility study)

Intervention	Number (%)	Children (%)
Oxygen saturation monitoring	77 (49)	34 (71)
Intravenous infusion	61 (40)	29 (60)
Oxygen less than 50%	36 (23)	17 (35)
Nasogastric tube chronic	35 (22)	8 (17)
Multiple bolus of intravenous drugs	26 (16)	12 (25)
Domiciliary ventilation	24 (15)	3 (6)

The least common interventions (0.6%) included intubation, recent extubation, CPAP, bag and mask ventilation and sedation for a ward procedure. The following interventions failed to be recorded:

- Care of the child with a new tracheostomy.
- Nebulised adrenaline for upper airway obstruction (up to 2 doses).
- Nebulised adrenaline for upper airway obstruction (more than 2 doses).
- Apnoeic episodes (4 within 4 hours requiring stimulation).
- Vasoactive drug therapy (e.g. dopamine, dobutamine, adrenaline).
- Blood transfusion/transfusion of platelets/fresh frozen plasma.
- Acute renal failure (less than 1ml/Kg of urine in 24 hours).
- Renal replacement therapy (haemofiltration/haemodialysis).
- Acute hourly cycle peritoneal dialysis.
- Arterial line.
- Central venous pressure (CVP) monitoring.
- Cardiac pacing new on this admission.
- Cardiac arrhythmia responded to first line therapy.
- Cardiac arrhythmia failed to respond to first line therapy.
- Dressing changes greater than three this shift or complex dressing changes.
- Warming or cooling blankets/ambient temperature monitoring/incubator.

The maximum number of interventions received by a child was 15; however, the majority of forms were completed for children receiving one to three interventions. The median number of interventions for the study population was three (range 1-15) (figure 4.3). No child under five years of age required more than seven interventions, yet four children aged five and over required eight or more than eight interventions.

Figure 4.3   Frequency of interventions for each episode of care (feasibility study)

Total number of interventions
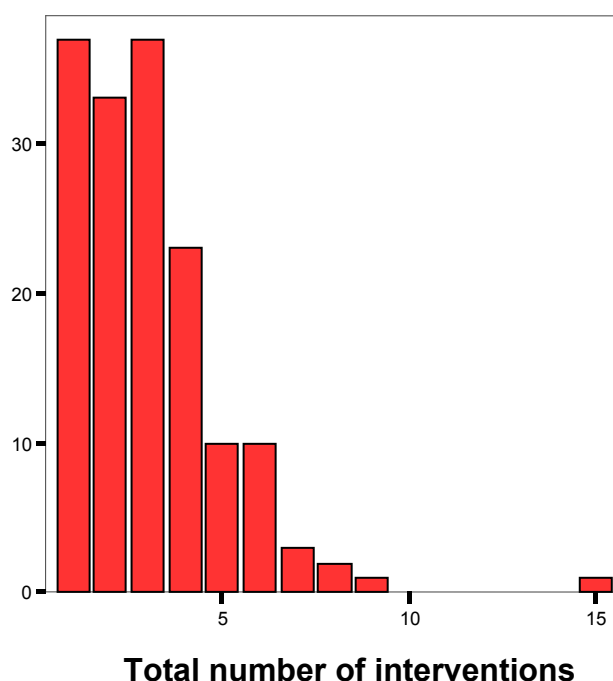
Missing data for both PPAs was minimal (table 4. 4).

Table 4.4   Missing data by variable (feasibility study)

Variable	Number (%)
Diagnosis	15 (9.6)
Frequency of nursing observation	5 (3.2)
Location of the child on ward	11 (7.0)
Date of birth	18 (11.5)
Date	3 (1.9)

It was impossible to determine if intervention data were missing from form A as the form required a response to the intervention only if performed for the child. No data was missing for any of the 51 intervention variables (Form B).

4.4.2.2   Monthly Nurse Staffing

Only four monthly MNS forms were returned for analysis. Ward 2 at BRI failed to return a monthly data collection form. Total staffing numbers for the feasibility study are shown in table 4.5. A discrepancy between the nursing establishment, particularly at D and E grade, and the actual number of nurses that were available to work existed.

Table 4.5   Total establishment and actual numbers of nursing staff according to grade (feasibility study)

Grade	Establishment Whole Time Equivalents	Established Whole Time Equivalents available to work
A	13.8	12.5
B	3.8	3.0
C	1.0	1.0
D	31.4	28.5
E	44.2	40.5
F	8.1	7.8
G	3.0	3.0
H	0.9	0.9
I	0	0

The majority of nursing staff with APLS skills were employed at BRI (table 4.6). Eighteen nurses with APLS or PALS were employed on wards 16 and 17 at BRI. Only one member of nursing staff (F Grade) was employed with APLS or PALS skills on ward 48, and no member of staff was recorded for ward 48A with APLS or PALS training. Nineteen (17%) nurses had APLS skills to care for children requiring PHDC, or critical care in four of the ward areas.

Table 4.6   Total number of nursing staff with advanced paediatric life support training according to grade (feasibility study)

Hospital	Ward	A	B	C	D	E	F	G	H	I	Total
BRI	2				Failed to return form						
	16	0	0	0	0	8	0	0	0	0	**8**
	17	0	0	0	2	6	1	1	0	0	**10**
LGI	48	0	0	0	0	0	1	0	0	0	**1**
	48A	0	0	0	0	0	0	0	0	0	**0**
Total		**0**	**0**	**0**	**2**	**14**	**2**	**1**	**0**	**0**	**19**

Only one nurse had undertaken a critical care course (ENB 405,415,100,160); this nurse was employed at BRI on ward 17. A total of seven nurses employed at BRI on ward 16 had training, or had completed university courses in relation to HDC.

4.4.2.3 Daily Nurse Staffing (DNS)

A total of five DNS forms were returned. An example of the number of nurses and their qualifications for one day is presented in table 4.7

Table 4.7   Daily nurse staffing for Thursday 4th December (feasibility study)

		Clinical Staff							
Hospital	Ward	RN (Ch) [1]	RGN [2]	APLS [3]	HD [4]	CCC [5]	EN [6]	HCA [7]	Bank Agency OT [8]
BRI	2	7	1	0	0	0	0	2	0
	16	4	0	1	0	0	0	0	0
	17	4	0	1	0	0	0	0	0
LGI	48	3	0	0	0	0	0	0	0
	48A	4	0	0	0	0	0	1	0
Total		**22**	**1**	**2**	**0**	**0**	**0**	**3**	**0**

KEY
(1) RN (Ch) Registered Children's Nurse
(2) RGN Registered General Nurse
(3) APLS Advanced paediatric life support course
(4) HD High dependency modules
(5) CCC Critical care course
(6) EN Enrolled Nurse
(7) HCA Health Care Assistant's or team support worker
(8) OT Overtime

The maximum number of nursing staff with APLS skills on a shift was four; this occurred at BRI (ward 17). Thirty three (79%) shifts on ward 17 (BRI) and 39 (93%) on ward 16 (BRI) were covered with a member of staff with APLS skills. Ward 48A (LGI) never recorded a member of staff with valid certification in APLS skills. The maximum number of RN (Ch) on duty, during a single shift, was nine; this was 75% of the workforce total during the period of a morning shift (ward 2 BRI). The minimum number of RN (Ch) available, on a shift, was one; this occurred on both ward 2 (BRI) for the night shift and ward 48 (LGI) for the morning shift. Ward 48 required two nurses, for bank, agency or overtime, to staff the ward during a shift (Saturday 6th December 2003). The maximum number of bank, agency or overtime nurses required, during a shift, was during Monday 1st December 2003; two extra nurses were required for the morning and night shift at LGI (ward 48).

Missing data varied between 0 to 40% for all variables. Unfortunately data was missing for one complete week from ward 2 at BRI.

4.4.2.4   Daily Patient Activity (DPA)

Ward 2 (BRI) admitted the maximum number of children in week one and week two (44 admissions and 65 admissions respectively) (table 4.8). Large numbers of children were also seen on ward 2 for pre-assessment; 36 during week one and 39 during week two. Fifty six and 51 ward attenders were also seen during week one and week two respectively on ward 2 (BRI). During the two week period of the feasibility study a total of 253 children were seen in the assessment area of ward 16 (BRI). One death occurred during this period on ward 16 at BRI.

Missing data for the DPA was evident during the study period. Minimum missing data on various days was 20% for pre-assessment and ward admissions. Maximum missing data was 100% on Thursday 4th December for total beds occupied during the day. For the total number of data collection forms collected, by day and night, missing data ranged from 40-100%. No data was provided for ward 48 for one full week.

Table 4.8   **Daily patient activity for the duration of the feasibility study (2 weeks)**

	Week (1) commencing 24/11/03					Week (2) commencing 1/12/03				
Hospital	BRI			LGI		BRI			LGI	
Ward	2	16	17	48	48A	2	16	17	48	48A
Admissions to ward	44	31	35	0	38	65	43	43		22
Children seen pre-assessment	36	0	0	0	1	39	0	18		0
Day cases	13	0	0	0	0	12	1	6		0
Ward Attenders	56	0	2	1	7		0	10		6
Children seen (assessment area)	No data	101	40	0	0	51	154	94	No data returned	0
Transfers to PICU	No data	0	0	0	3	No data	0	0		0
Transfers to HDU (internal)	No data	0	1	0	7	No data	0	1		3
Transfers to ward	No data	1	1	2	4	No data	0	1		0
Discharges home	33	29	35	2	27	61	42	45		16
Deaths	No data	1	0	0	0	No data	0	0		0

4.5   Discussion

The size and design of a feasibility study is a matter of convenience, time and money which should result in improvements to the data collection forms (Moser and Kalton, 1971). Often surveys are carried out with little thought for the design ensuring that weaknesses remain unrecognised until the results subsequently have to be interpreted (Oppenheim, 1992). The aim of this feasibility study was to detect early weaknesses in the design of the data collection forms to ensure formatting and content for the pilot study. Two weeks of data collection during the busy winter period provided sufficient information to determine:

- Interpretation and response by nursing staff to the data items listed.
- The completeness of the data recorded, evaluating the amount of missing data and the reasons for this.
- Design of the forms.
- If the concept of all levels of care (usual ward care, PHDC and PIC) was captured.
- A population for the next phase i.e. the pilot study.

These are discussed below:

4.5.1   Interpretation and Response by Nursing Staff to the Data Items

The feasibility study suggested that the data items were understood by nurses well on the wards where they were tested. General medical and surgical and specialist neurological and surgical nurses were able to respond to each of the data items with no comments made regarding item wording or failure to understand any of the interventions listed.

Nursing staff on wards 16 and 17 (BRI) expressed concerns regarding the exclusion criteria of the PPA. Infants who were not discharged home after birth and were less than three months corrected age, or less than five kilograms were excluded because they were expected to fulfill neonatal PHDC criteria. Nursing staff on the wards admitted infants from the neonatal area that fulfilled the exclusion criteria but also the inclusion criteria; these infants regularly required more than one level of care and expended a large amount of nursing time and resource. For this reason the exclusion criteria was removed from the PPA for the pilot study.

Some of the data items listed on the PPA may not individually represent a child requiring PHDC for example naso-gastric tube (chronic or acute), intravenous infusion and oxygen saturation monitoring. This information may have reflected children requiring usual ward care rather than PHDC. Although more critical interventions for example, intravenous fluid resuscitation greater than 20mls/kg and cardiac arrhythmia, which may singly represent PHDC, occurred infrequently; many of the PHDC interventions were not reported; for example

the care of a child with a new tracheostomy and nebulised adrenaline (up to two doses). The pilot study was expected to provide more information regarding the frequency with which each of the interventions occurred.

It was not possible to determine the number of children missed yet fulfilled the criteria for form completion yet, more PPAs were completed per female. Three girls accounted for 24% of all data collection forms. It is possible that the three girls received complex care and therefore required form completion over a number of days. More PPAs were completed during the night shift than the day shift. This was not easily explained but may have been due to several factors; children may have been sicker during the night, therefore, the level of care may have been stepped up; nurses may not have been as busy during the night, therefore, time was taken to complete the forms; or the link nurse responsible for data collection in the area may have been working night duty and encouraged other nurses to complete the forms.

The majority of PPAs were returned for children with a neurological disorder (38%) owing to the high return rate from ward 48A, a specialist neurological ward. General hospital wards also admit children that have seizures or minor neurological problems also categorised as 'neurological' for data collection purposes. This distribution was expected to be very different once data was collected for all hospital and ward areas.

4.5.2   The Completeness of Data Recorded, Evaluating the Amount of Missing Data and the Reasons for This

A missing data analysis confirmed that 0 to 56% of data was missing. Fifty six percent of the PPA forms were returned without the child's unit number recorded. No missing data was evident for any of the nursing interventions (1 to 51) listed. However it was impossible to determine if nursing staff completing form A had failed to respond to some of the nursing interventions provided for the child during their shift. Nurses were not asked to respond to all items with yes, no, or not known, but to check the boxes only for the nursing interventions performed. Nursing staff completing form B had to respond to each nursing intervention with 'Yes', 'No' or 'Not Known'. Form B; therefore, made it easier to determine if any nursing interventions were overlooked as one of the response

boxes ('Yes', 'No' or 'Not Known') would not be checked. Consequently, it was decided by the Steering Group for the PHDC study to use data collection form B for the pilot study.

Although the PPAs were completed moderately well, with varying amounts of missing data for some variables (0 to 56%), a missing data analysis for the variables used in the DNS and DPA provided evidence of large amounts of missing data. No information was recorded on the DNS for the number of nurses on duty with a critical care course. It was not clear if this data was missing or if nurses with this qualification were not working on these wards. Of the 140 shifts worked by nurses, 85 (61%) shifts had no record of a nurse with advanced life support skills, however 80% (n= 111) of shifts worked with a RN (Ch) on duty. Missing data was also recorded on the DPA. A total of 70 days of data was recorded for the five hospital wards; 91% (n=63) of data was missing for the number of forms collected at 03.00 hrs and 15.00 hrs, yet 83% (n= 58) of data was complete for the number of admissions to the ward. The completion of the DNS and DPA was labour intensive for nursing staff. The DPA form required a detailed and accurate record of the movement of children during a 24 hour period. This information required constant updating by all ward co-ordinators during the early shift(s) and night shift; thus, it was vital for each co-ordinator to maintain accurate records to guarantee that the night co-ordinator had accurate patient information at midnight to complete the form. If this information was not maintained by previous co-ordinators, a night co-ordinator could spend a great deal of time checking patient registers for the admission, discharge and transfer information.

The DNS required the nurse co-ordinator to determine the qualifications and extra training that each nurse had undertaken by asking each individual nurse on duty. A list of qualifications and extra training that nurses had undertaken was developed for each hospital ward to save the co-ordinator time.

Nursing staff were asked to indicate using ✓ if there was a member of staff on duty with APLS/PALS or HDC or critical care courses on the DNS. Nurses indicated the actual numbers of staff in response. Therefore nursing staff were

asked to document the actual numbers of staff on duty rather than ✓ when completing this form during the pilot study.

The comments made by nursing staff were addressed to improve the quality of the data for the pilot study. Further education of nurses was required regarding completion of forms. One of the reasons for poor data quality within the NHS is the lack of understanding by doctors and nurses of the reasons and benefits of the information they are collecting (Kmietowicz, 2004, Audit Commission, 2004). DPA and nursing staff information may be seen as irrelevant to the needs of the child, and may be believed to be focused upon the needs of the institution rather than frontline service delivery (Kmietowicz, 2004, Audit Commission, 2004). Strategies were developed to increase awareness and for involving staff in validating and using the information they collected (Audit Commission, 2004). A detailed monthly account of the information collected by staff, including information about the amount of missing data, assisted in the reduction of missing data during the main data collection.

4.5.3   Design Issues

The data collection forms required changes to make them workable. To encourage nursing staff to complete all forms for the pilot study, (PPA form B, the DNS and the DPA) the following changes were made, the first five changes were made in response to nursing staff comments;

1. Small response boxes (PPA form B) that made it difficult for nursing staff to check the correct one required enlarging.
2. Comic Sans MS font was difficult to read; therefore the font required changing to one that was easily readable (Times New Roman).
3. The response boxes for completion times (03.00hrs and 15.00hrs) of the PPA were labelled 'DAY' and 'NIGHT'. This allowed nursing staff to complete the forms when time allowed during a shift and prevented nurses from recalling events that happened retrospectively, potentially creating time memory bias (Williams 2003). The end of the shift was ideal as the nurse had to provide a written record of the care and interventions s/he had performed for the child; the child data collection form was for completion at the same time.

4. To ensure that a diagnosis along with a category diagnosis was available. A diagnosis free-text box, for nursing staff to write the admitting diagnosis, was created. The categories were slightly modified to include the following: surgical illness, respiratory illness/croup, diarrhoea/vomiting, shock, poisoning/metabolic disorder, fits/reduced conscious level, asthma, trauma, sepsis and other. These categories remained subjective; more than one response was possible; however a text box clarified the diagnosis.

5. Small DNS and DPA data collection forms required enlargement. These were placed onto one side of paper. The font was changed, to Times New Roman, from Comic Sans MS to standardise all data collection forms.

6. Grid lines that aligned response boxes and item/intervention (PPA form B) added to the disorder of the page; therefore grid lines were removed to create a 'less busy' data collection tool.

7. Sub-questions (PPA form B) required slight indentation and the response boxes were realigned.

8. The request for the number of audit forms collected during the day and night was removed for the pilot study due to the large amount of missing data present on the DPA.

The MNS appeared satisfactory; no comments were recorded by the nurses completing them. The font was changed; however, to Times New Roman to ensure standardisation of all data collection forms.

It was not possible to determine the non-response rate (how many children did not have data collection forms completed that fulfilled the criteria), or falsification of forms; however it was noted that falsification of entire data collection forms is rare (Moser and Kalton, 1971). Time did not permit checks for validity with notes and patient records during the feasibility phase of the study; data validation occurred during the main data collection phase.

4.5.4 Was the Concept of all Levels of Care Captured?

As PHDC cannot be studied in isolation, a role of the feasibility study was to determine if usual ward care, PHDC and up to PIC for stabilisation purposes were captured. Were any important nursing interventions relating to PHDC missed? At this stage no missing interventions were evident. All interventions

that nurses performed for children during a shift appeared to be listed (Appendix 5).

4.5.5 The Population of the Pilot Study

The total number of PPA forms returned during the feasibility study was 157 of which the maximum, 60 (38%), were returned from ward 48. A large return was therefore estimated for the pilot study. For example if 38 wards returned 120 PPA forms during the 4 week period of the pilot study; 38 x 120 = 4,560 PPA forms is estimated.

4.6 Conclusion

This feasibility study provided valuable information regarding face validity of the investigation. Although face validity is no longer considered acceptable evidence for validity, the forms' appearance and the willingness of nurses to complete the instrument was vitally important for this phase (Burns and Groves, 1993). The feasibility study has suggested that the forms were used to collect information regarding the levels of care, including PHDC, provided to children in Yorkshire and for the nursing staff caring for them. Problems were identified through feedback given by nurses and the forms were modified appropriately.

Some education of nurses was required, particularly in relation to the completion of the DNS and DPA. It was emphasised that completion of all forms was necessary to obtain a full representation of PHDC, but methods of assisting nursing staff to record this information were devised to make data collection easier and less time consuming. Therefore key nurses to 'train the trainers' were sought and provided with in depth training sessions, include the importance of collecting complete and accurate information; to improve the quality of data collected (Armstrong et al, 1994; Arts et al, 2003).

The data collection forms required slight modification for the pilot phase of the study. The suggestions for improvement were provided by the nursing staff involved in their use. This exercise revealed that nurses were willing to use the data collection forms and provide feedback for improvement which suggested that they were willing to co-operate, support the researcher and, importantly, the PHDC study. Their enthusiasm and determination to provide useful information

was overwhelming. A supportive, co-operative network of nurses, the most influential group concerned with the development of this study, was established. Meeting regularly and developing a rapport with them was essential for the future of the PHDC study.

5   The Pilot Study

5.1   Introduction

After the feasibility study the modified data collection forms (Appendix 7) were distributed to all 14 hospitals and 40 hospital wards for completion during the pilot study. The hospitals and wards are listed at Appendix 4. Immediately prior to the start of the study one hospital ward closed, consequently children requiring ear nose and throat surgery were relocated to another children's ward and data collection forms were not returned from this ward. As a pilot study is frequently defined as a smaller version of a proposed study the subjects, locations and data collection techniques were developed to mimic the proposed main data collection (Burns and Grove, 1993).

5.2   Aim

The pilot study aimed to establish the:

- Level of delivery of PHDC in West, North and East Yorkshire.
- Reliability and validity of the data collection tools.
- Response rate.
- Efficiency of researcher instruction.
- Data analysis techniques.

5.3   Method

5.3.1   Study Population

5.3.1.1   Paediatric Patient Activity (PPA)

All infants, children and young persons irrespective of age that were admitted to a paediatric ward within region and met with one or more of the numbered

interventions listed on the form. Table 5.1 outlines the data collection forms specifying the type and frequency of the information required.

5.3.1.2 Monthly Nurse Staffing (MNS)

The monthly clinical nursing staff (qualified and unqualified), grade A to I, employed to work on each of the hospital wards within the region (table 5.1).

5.3.1.3 Daily Nurse Staffing (DNS)

The nursing qualifications and training held by each member of staff, each shift, on all hospital wards taking part in the study (table 5.1).

5.3.1.4 Daily Patient Activity (DPA)

All admissions, discharges and transfers of children within a 24 hour period on all of the hospital wards taking part in the study (table 5.1).

5.3.2 Study Period

Data were collected over the period of one month (January 1st - 31st, 2004).

5.3.3 Location

Fourteen hospitals and 39 hospital wards located in West, North and East Yorkshire were recruited for the pilot study (Appendix 4).

5.3.4 Education of Nursing Staff

The education of nurses within the region was essential before the pilot study began to ensure that the paediatric and staffing information was recorded appropriately.

During the month of December 2003, visits were arranged at 12 hospitals to discuss completion of the data collection forms with nursing staff. Some hospitals required more than one visit to capture as many nursing staff as possible. Example copies of the forms were circulated for discussion and given to nurses to further debate, with all nursing staff, at local staff meetings.

Owing to the number of paediatric wards at SJUH and at the LGI a number of training sessions were organised at both hospitals. Dates for training sessions

were posted on all ward areas on each of the two sites and senior sisters, interest group members and key trainers were e-mailed a copy of the training dates. On the morning of the training sessions the co-ordinator, for each ward area within the hospital, was contacted by telephone and reminded of the training session, time and the venue. This was to ensure that as many staff, as possible, attended the training session. The length of time taken to discuss all forms and completion was three quarters of an hour; therefore one hour was the time allocated to each of the training sessions to include time for questions.

Ward co-ordinators (senior members of staff) at all hospitals were keen to attend the training sessions as they assumed responsibility for completing the MNS, DNS, DPA forms and for motivating and guiding junior nurses in completion of the PPA.

The role of the researcher during the pilot study was to:

- Provide information, education and support to staff.
- Facilitate continued development of the research study and the research tools.
- Collect and analyse the data.
- Monitor and evaluate the study.
- Feedback and communicate with nurses throughout the region.

5.3.5   Data Collection

Four highly structured data collection forms were developed and used during the pilot study to collect unambiguous data that was easy to count (Bowling, 2000) (Appendix 7). The information required from each of the data collection forms is listed in table 5. 1.

5.3.6   Data Analysis and Coding

Data was stored in an Access database which was developed by a database programmer at the University of Leicester and analysed using SPSS v 12 (SPSS. Inc. V12.0.1, 2003). Coding, or the process of converting questionnaire data into meaningful categories, was discussed and developed by both the researcher and the database programmer for both the PPA and for the input of

staffing and DPA information. For example each hospital ward was coded with a number between one and 41. Further examples of coding used for the PPA and for the staffing forms can be seen below:

General observations code (PPA).

Code	Description.
1	Greater than hourly.
2	Hourly.
3	2 Hourly.
4	4 Hourly.
5	BD.
6	Daily.
9	Not known.

Shift period code (PPA).

Code	Description.
1	Day.
2	Night.
9	Not known.

Missing data code (Nurse staffing).

Code	Description.
99	Missing data (no data represented on line.
999	Missing data (data present on line).
888	Ward closed.

Table 5.1   Data collection forms and the type and frequency of information recorded by nursing staff during the pilot study

Data collection form	Information required	Inclusion criteria	Frequency of information recorded
Paediatric Patient Activity (PPA)	• Demographic details • Geographical information • Diagnosis according to category • Location of child on the ward • A response to the interventions performed	Any child that meets with 1 or more than one of the numbered interventions listed	Once during the day and once during the night (a child in need of PHDC will require two forms completing in 24 hours)
Monthly Nurse Staffing (MNS)	• Numbers of established WTE and actual WTE's according to grades A-I	Staffing establishment for the ward	Monthly

Daily Nurse Staffing (DNS)	Number of
	• Registered General Nurses
	• Children's Nurses
	• Enrolled Nurses
	• Health Care Assistants
	• Registered Nurses with
	    APLS courses(APLS, EPLS, PALS)
	    HDC modules
	    Critical care courses
		Staffing establishment for the ward	Each shift (early, late and night shift)

Daily Patient Activity (DPA)	Number of • Admissions to the ward • Day cases • Ward attenders (not admitted) • Transfers to PICU or PHDU (internal/external) • Transfers to ward • Discharges home • Deaths • Children seen in pre-assessment area	All patient movement	Once per day. Form to be totaled at midnight

5.4 Results

5.4.1 Paediatric Patient Activity (PPA)

The data presented relates to 5,213 episodes of care for 1,337 children admitted to all hospital wards from 1st - 31st January 2004. The largest proportion of inpatient episodes occurred for children admitted to two specialist hospital wards, ward 10 (SJUH) n = 619 (12%) and ward 10 (LGI) n = 461 (9%), both located at The Leeds Teaching Hospitals NHS Trust (figure 5.1). Eight percent (n = 415) of data collection forms were returned from ward 120 (Hull Royal Infirmary); this hospital ward admitted children less than one year of age. Two hundred and ninety four (6%) data collection forms were returned from a DGH (Ward 17 BRI) admitting children, of all ages, with medical conditions. No data collection forms were returned from ward 59 (SJUH), a regional specialist hospital ward, that admitted both children and adult patients with renal conditions.

Figure 5.1   Number of paediatric patient activity forms returned by hospital ward during the pilot study
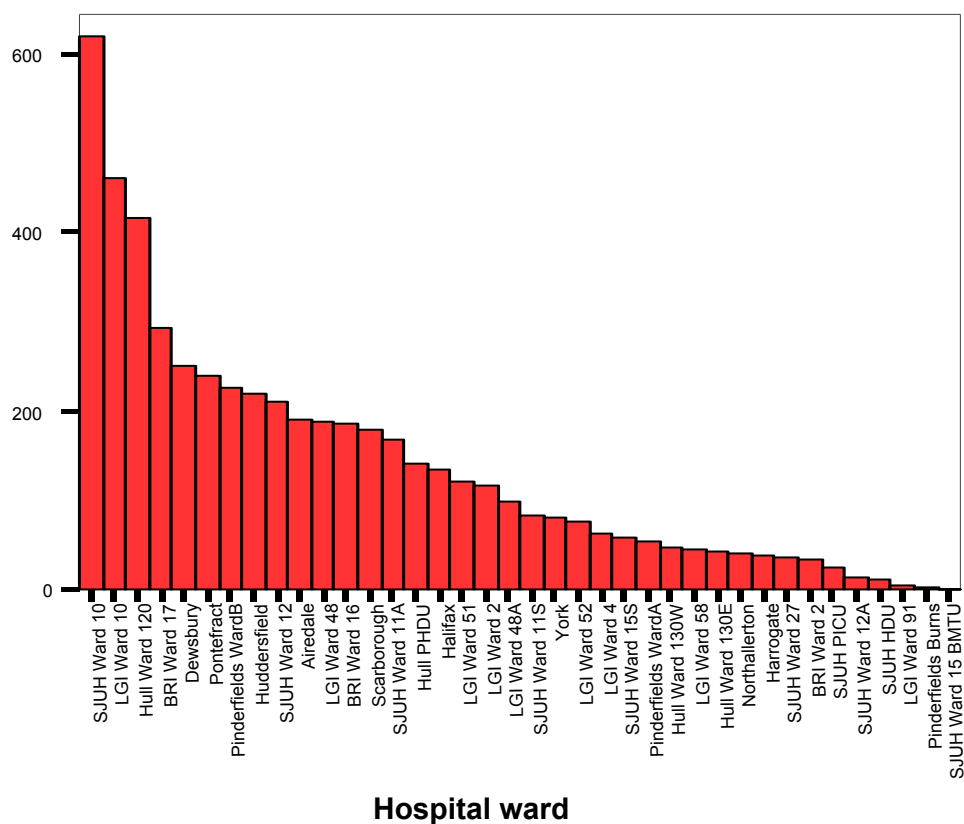
More forms were returned for males (52%) than females and more males were admitted for care (52%). Just over half of all forms were returned for the period of the night shift (53%) and more children had forms completed by night (55%) (table 5.2).

Table 5.2   Paediatric patient activity forms returned by sex and time period during the pilot study

Sex	Day (%)	Night (%)	Missing (%)	Total (%)
Male	1223 (45)	1454 (54)	39 (1)	**2716 (100)**
Female	1087 (46)	1266 (53)	26 (1)	**2379 (100)**
Missing	58 (49)	56 (48)	4 (3)	**118 (100)**
Total	**2368 (45)**	**2776 (53)**	**69 (1)**	**5213 (100)**

The primary reason for admission was categorised into 10 diagnostic groups. The two most common reasons for admission were 'respiratory' illness and 'other' with 39% (n = 2,030/5213) and 26% (n = 1,339/5213) of forms returned respectively (figure 5.2). Nearly half (543/1,337, 41%) of all children were

admitted with a 'respiratory' illness and 19% (n= 256) of all children were admitted for 'other'. Sixty percent (n= 1,223) of episodes for 288 children (67%) with respiratory illness were for infants (29 days to 1 year of age). 'Asthma', 'fits/reduced conscious level', 'poisoning/metabolic disorder', 'shock' and 'trauma' all occurred more frequently in the group of children aged one to four years.

Figure 5.2   Percentage of data collection forms returned and number of children by reason for admission during the pilot study
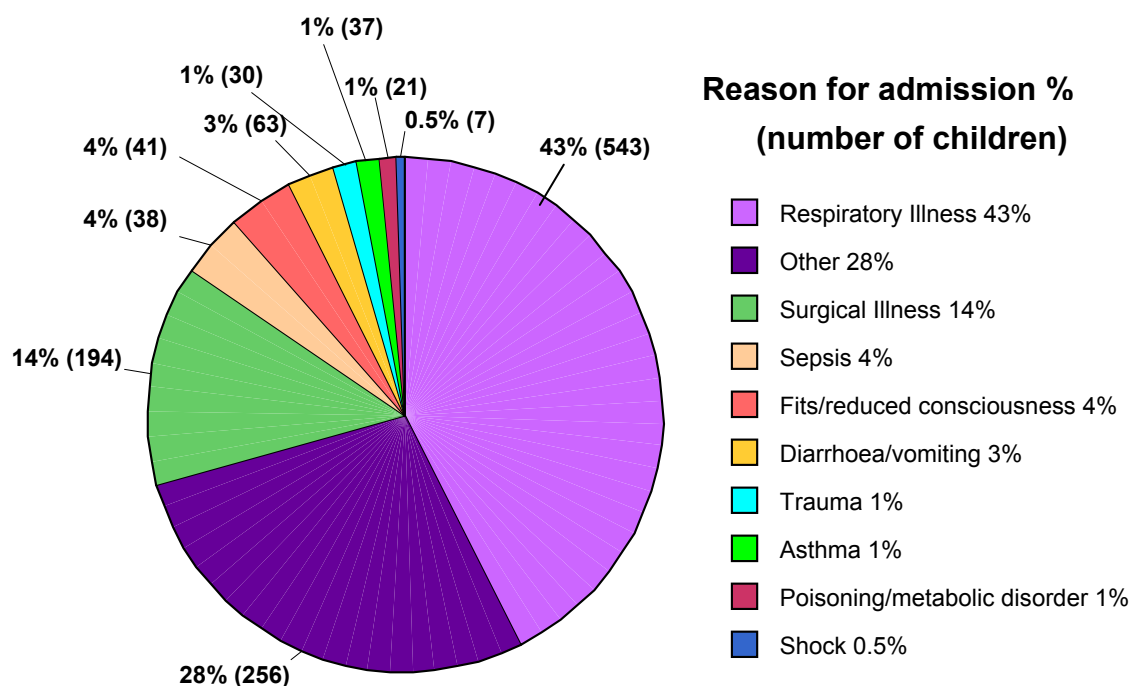
Few data collection forms were returned for children with 'shock' (0.5%), 'poisoning/metabolic disorder' (1%), 'asthma' (1%) and 'trauma' (1%). The majority of these inpatient episodes were returned for children aged one to four years.

Forty four percent (n = 2,302) of inpatient episodes were for children under the age of one year (figure 5.3). From the age of three years onwards inpatient episodes decreased, but increased slightly for 10, 14 and 16 year old males and 9, 15 and 16 year old females (figure 5.3). More data collection forms were returned for males throughout all the age ranges with the exceptions of 4, 9,11,12,15 and16 year olds (figure 5.3).

Figure 5.3   Inpatient data collection forms returned by sex and age during the pilot study
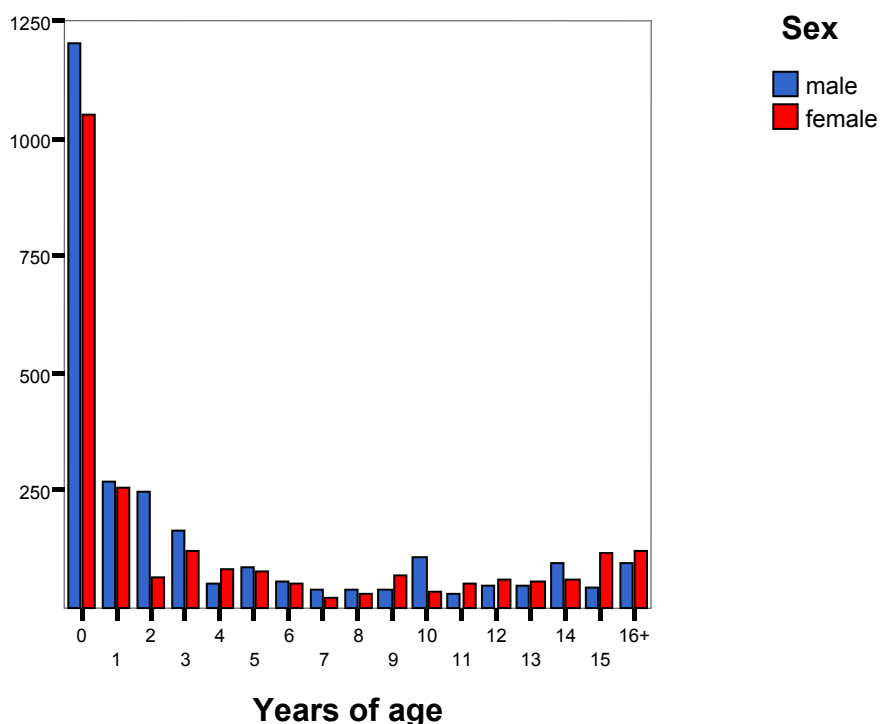
The majority of episodes of care received two hourly general observations (table 5.3). There was a correlation between increased frequency of observation and total interventions performed for episodes r_s = 0.4; n = 5098; p<0.01.

Table 5.3   Frequency of observations during the pilot study

Frequency of observations	Number (%)
Greater than hourly	81 (1.5)
Hourly	74 (1.4)
2 Hourly	2950 (56.5)
4 Hourly	538 (10.3)
Twice daily	1233 (23.6)
Daily	222 (4.2)
Missing	115 (2.2)
Total	**5213 (100)**

A total of 756 (57%) children required oxygen saturation monitoring. Just over half of the data collection forms (51%) were returned for children requiring 'oxygen saturation monitoring' as a single intervention, or one of many. Thirty seven percent of inpatient episodes required 'oxygen therapy less than 50%'

and 32% of inpatient episodes required an 'intravenous infusion of maintenance fluid' as a single intervention, or one of many.

Very few data collection forms were returned for episodes of care requiring 'more than two doses of nebulised adrenaline', or for 'care during the first 24 hours following a tracheostomy', n= 2 and n= 1 respectively. No data collection forms were returned for episodes of 'cardiac pacing new on this admission'.

A total of 1,655 (32%) of forms were returned for episodes of care where children received one intervention only. Of the episodes of care where children received one intervention 295 (18%) forms were returned for care of an 'intravenous infusion of maintenance fluid', 243 (15%) forms were returned for episodes of 'continuous oxygen saturation monitoring' and 219 (13%) forms were returned for 'nasogastric / gastrostomy /nasojejunal feeding-chronic' (table 5.4). The mean number of total interventions was 2.8.

Three episodes of care required 19 or more interventions, these all occurred in the infant group (29 days to 1 Year). Twenty six interventions were performed for a female child aged two months admitted with 'respiratory disease'. This child was extremely sick and required 'intubation and subsequent care of the intubated child'. This intervention would never occur alone, and would involve many other interventions. In total 25 children required 'intubation and subsequent care of the intubated child'.

Table 5.4   Frequency of interventions where total number of interventions is 1, 2 and 3 during the pilot study

Intervention	Frequency of interventions where total number of interventions = 1, 2 and 3		
	1(%)	2(%)	3(%)
Intravenous infusion of maintenance fluid	295 (18)	292 (23)	314 (35)
Continuous oxygen saturation monitoring	243 (15)	606 (47)	604 (68)
Nasogastric tube feeding (chronic)	219 (13)	212 (16)	164 (19)
Nasogastric tube feeding (acute)	164 (10)	91 (7)	158 (18)
Intravenous drugs bolus > 3 per shift	160 (10)	165 (13)	132 (15)
Nebulised medication < 1/hour for > 4 hours	137 (8)	130 (10)	167 (19)
Oxygen < 50%	119 (7)	464 (36)	477 (54)

5.4.1.1   Data Analysis

Exploratory factor analysis (FA) was applied to the PHDC data set to:

- Summarise patterns of correlations among variables.
- Reduce the large number of variables to a smaller number of factors each measuring the same dimension. (Tabachnick and Fidell, 2001).

FA explains the maximum amount of common variance in a correlation matrix using the smallest number of explanatory concepts or dimensions (Field, 2003). Data reduction involves looking for variables that correlate very highly with a group of other variables, but correlate very badly with variables outside of that group (Field, 2003). FA usually involves three procedures:

1. Extraction of factors.
2. Rotation of factors to assist with interpretation.
3. Naming and interpretation of each factor with estimated values for the factor loadings (Field, 2003).

To prepare the data set for analysis the guidance offered by Field (2003), was used. This involved removing variables with a small number of values or missing values. The following variables were removed for analysis:

- Cardiac pacing new on this admission.
- Care of the child with a new tracheostomy (less than 24 hours old).
- Nebulised adrenaline more than two doses.
- Haemofiltration/haemodialysis.

The following options were used in SPSS (SPSS. Inc. V12.0.1, 2003) for analysis of the variables:

- Descriptives.
  - o Univariate descriptives, provides means and standard deviations for each variable.
  - o Initial solution, displays initial communalities, eigenvalues and the percentage of variance explained.

- o Co-efficients, produces the R-matrix or squared multiple correlation.
- o Significance levels, generates a matrix indicating the significance value of each correlation in the R-matrix.
- o Determinant, is vital for testing multicollinearity (variables highly correlated) or singularity (variables perfectly correlated) within the R-matrix and should be greater than 0.00001.
- o Kaiser-Meyer Olkin (KMO) and Bartlett's Test, creates a measure of sampling adequacy. The KMO statistic is a ratio of the sum of squared correlations to the sum of squared correlations plus the sum of squared partial correlations. Bartlett's test is a test of the hypothesis that the correlations in a correlation matrix are zero.
- o Inverse, this supplies the inverse of the correlation matrix and is useful only if the calculations for factor analysis are required.
- o Reproduced, a correlation matrix, used to show the differences between the matrix based on the model and the matrix based on the observed data.
- o Anti-imaging, shows a matrix containing measures of sampling adequacy for each variable along the diagonal and the negatives of the partial correlation on the off diagonals. Diagonal elements should be greater than 0.5 and the off diagonal elements should be close to zero.
- Extraction.
  - o Correlation matrix, this is a standardised version of the covariance matrix. Variables measured using different scales will not affect the analysis.
  - o Unrotated factor solution, is useful in assessing the improvement of interpretation due to rotation.
  - o Scree plot, aids decision making. It is used to establish the number of factors to be retained in the analysis although this is a matter of interpretation.
  - o Eigenvalues over option, selects and retains all values greater than (user specified) to assist with the retention of factors. Eigenvalues greater than one was set for this study (default option) as recommended by Field (2003).

- Rotation, makes clear which variables relate to which factors and works by changing the absolute value of the variables by keeping their differential values constant.
    - Rotated solution, essential for interpreting the final analysis.
    - Loading plots, provide a graphical display of each variable plotted against the extracted factors.
    - Varimax is an orthoganol rotation and works by loading a small number of variables highly onto each factor. This is a general approach that simplifies the interpretation of factors.
- Options.
    - Suppress values less than 0.4. This option ensures that factor loadings within ± 0.40 are not displayed in the output.

Principle factors extraction with varimax rotation was performed on 50 items from the PHDC study for a sample of 5,213 episodes of care. Data was assessed for the presence of multicollinearity and singularity using the *R*-matrix. Multicollinearity and singularity are present if the variables on the R-matrix or squared multiple correlation are equal to one, or near to one respectively and should be deleted (Field 2003). No further variables were deleted at this stage. The Kaiser-Meyer-Olkin (KMO) measure was greater than 0.6, confirming the data were suitable for factor analysis (table 5.5).

Table 5.5   Kaiser-Meyer Olkin (KMO) and Bartlett's test

Kaiser-Meyer-Olkin Measure of Sampling Adequacy		.706
Bartlett's Test of Sphericity	Approx. Chi-Square	31833.109
	df	1225
	Sig.	.000

With eigenvalues greater than one, 18 factors were extracted (figure 5.4). Thirty of 50 variables did not load onto any factor. Failure of numerous variables to load onto a factor reflected the heterogeneity of items (Tabachnik and Fidell, 2001). However two of the variables in the solution, 'intubation' and 'bag mask' were complex i.e. the variables loaded onto more than one factor (figure 5.4). Before rotation most variables loaded highly onto Factor 1. Factor 1 accounted for 8% of the variance, yet all 18 factors accounted for only 56% of the variance.

Figure 5.4   Order, by size of loadings, in which variables contribute to factors

<u>Factor 1</u> Arterial pressure monitoring Bag/mask ventilation CVP monitoring ECG monitoring Complex fluid balance Hourly urine output measurement Intubation	<u>Factor 2</u> Bag/mask ventilation CPR Intubation	<u>Factor 3</u> Oxygen saturation monitoring Oxygen < 50%
<u>Factor 5</u> Cardiac arrhythmia responded to first line therapy	<u>Factor 6</u> Cardiac arrhythmia	<u>Factor 7</u> Frequent position changes
<u>Factor 9</u> NG Tube chronic	<u>Factor 11</u> Domiciliary ventilation	<u>Factor 12</u> Nebulised adrenaline < 2 doses
<u>Factor 13</u> Peritoneal dialysis	<u>Factor 16</u> Transfusion of blood	<u>Factor 18</u> Frequent dressing changes

The scree test plots the eigenvalues against factors and is just one method of assessing the adequacy of extraction and number of factors (Tabachnick and Fidell, 2001) (figure 5.5). The scree plot was negatively decreasing, with the eigenvalue highest for the first factor and decreasing before reaching small values for the last factors. The reference line at the point of inflection on the curve suggested that a stable plateau was reached after only four factors and that four factors should possibly be retained (figure 5.5). Although the scree test is usually accurate to within one or two factors, it is not exact and requires careful judgment at where discontinuity of eigenvalues occurs.

Figure 5.5   Scree plot to determine factors with eigenvalues of one and above
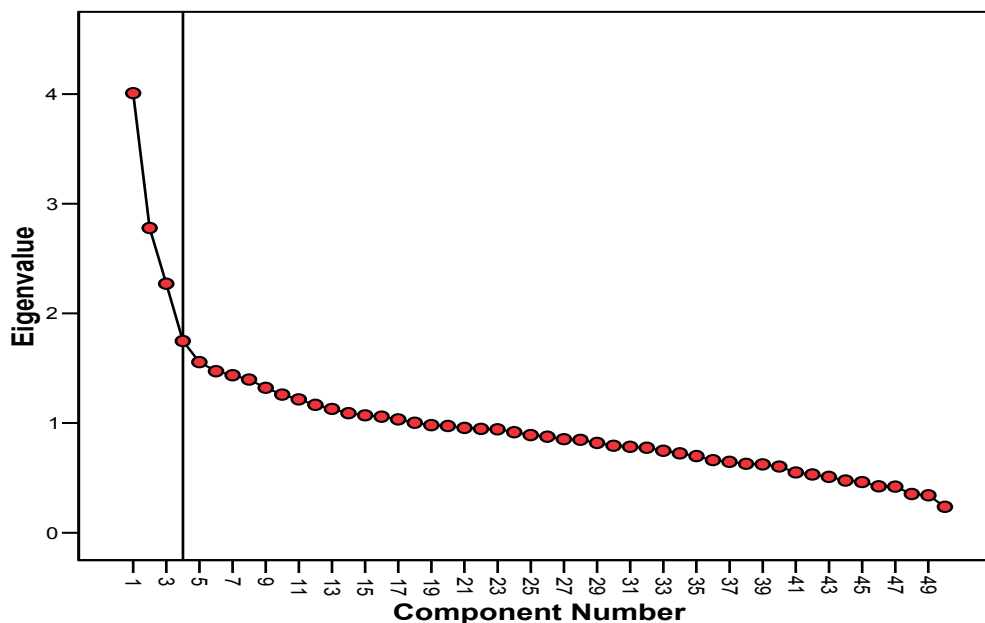
5.4.1.2   Completeness and Missing Data

Little missing data was apparent from the PPA (table 5.6). All data was more than 95% complete with the exception of reason for admission. However, only 30 (0.6%) episodes of care were missing both 'reason for admission' and 'diagnosis'. Diagnosis was written in the free text box.

Table 5.6   Missing paediatric patient activity data for the pilot study

Variable	Number analysed	Number missing (%)
Date	5193	20 (0.4)
Date (DOB)	5103	110 (2.1)
Sex	5095	118 (2.3)
Day/Night	5144	69 (1.3)
Reason for Admission	4772	441 (8.5)

On some hospital wards nurses neglected to write the child's name in full, and initials only were given. This occurred for 65 (1.2%) episodes of care. All occurrences were for children admitted to ward 12A and ward 15S at SJUH. Ward 12A returned 13 (100%) and ward 15S returned 52 (90%) data collection forms with initials only and no patient name.

A response of 'Yes', 'No' or 'Not Known' was available in the access database for all but the following numbered interventions:

- Oxygen therapy (greater than or equal to 50%).
- Nebulised medications (more than 1 per hour for more than 4 hours).
- Chest drain in situ (greater than 24 hours).
- Cardiac arrhythmias (responded to first line therapy).
- Nebulised adrenaline (more than 2 doses).
- Care of the child with a new tracheostomy (less than 24 hours).
- Cardiac pacing (new on this admission).

These seven interventions were sub categories of other interventions; therefore missing and not known were merged.

A hand search of the data collection forms provided the following information:

- The not known box was checked on 274 occasions on 61 data collection forms. Of the 61 data collection forms:
    - Forty seven forms contained the response not known under the systems based heading 'neurological'.
    - Seven forms contained the response not known under the systems based heading 'neurological' and 'other'.
    - Six contained the response not known just under the systems based heading 'other' (not neurological). However four of these were for the intervention urine output less than 1 ml/kg/hr.

5.4.2   Monthly Nurse Staffing (MNS)

The MNS was poorly completed. Fifteen hospital wards failed to return the MNS. Telephone reminders were given to each ward, but data was either 'lost' or 'in the mail'. Over half of the data was missing for all variables, this included the hospital wards that failed to return their data collection forms (table 5.7). All data collection forms returned contained gaps where potentially a zero should have been placed, this was counted as missing.

Table 5.7   Missing data analysis for the monthly nurse staffing during the pilot study

Variable	Number analysed	Number missing (%)
APLS courses	119	241 (67)
WTE in post established	158	202 (56)
WTE available to work	144	216 (60)
CCC	122	238 (66)
HDCC	117	243 (67)

Key
APLS Advanced paediatric life support
WTE Whole Time Equivalent
CCC Critical care Courses
HDCC High dependency care courses/modules

From the data that was returned during the month of January 2004, all grades in the region were under established with the exception of grade C, who, were slightly over established (table 5.8). Nurses with APLS, critical care courses and HDC modules were concentrated at the E, F and G nursing grades. Sixty nine percent of senior nurses working at G grade had valid APLS skills, and a large proportion of nurses (62%) at this level also had a critical care qualification (table 5.8).

Table 5.8   Regional nursing establishment according to grade during the pilot study

Grade	Establishment WTE	Established WTE available to work	APLS (%)	CCC (%)	HDCC (%)
A	67	52.7	0	0	0
B	28	24.6	0	0	0
C	4	4.4	0	0	0
D	120	101.0	1 (1)	0	0
E	231	173.2	32 (18)	22 (13)	4 (2)
F	73	59.6	22 (37)	29 (48)	4 (7)
G	35	29.1	20 (69)	18 (62)	2 (7)
H	4	3.0	2 (50)	1 (25)	0
I	0	0	0	0	0

Key
WTE Whole Time Equivalent
APLS Advanced Paediatric Life Support
CCC Critical Care Course
HDCC High Dependency Care Course/modules

Those nurses with a critical care qualification were concentrated on the ICUs and the HDU at The Leeds Teaching Hospitals NHS Trust. Only one nurse was available to work with a critical care course at a DGH (Friarage Hospital).

Of the hospital wards that returned data, two mixed wards that admitted both adults and children (Bone marrow transplant unit and HDU), and two paediatric wards (ward 27 and ward 11) all situated within the Leeds Teaching Hospitals NHS Trust, recorded no staff, at any grade, with an APLS course.

Only one hospital ward (ward 11 at the LGI) showed a discrepancy in the number of beds funded (10 beds) and the number of beds open (6 beds).

5.4.3 Daily Nurse Staffing (DNS)

5.4.3.1 Registered Children's Nurses RN (Ch)

The DNS was also poorly completed (table 5.9).There were 112 (3.1%) shifts either, early, late or night where no RN (Ch) was on duty. These shifts occurred on the mixed adult and paediatric hospital wards. No primary paediatric ward worked without an RN (Ch) on duty. Two hundred and twenty eight (7%) shifts worked with one RN (Ch) on duty only. The maximum number of RN (Ch) on duty, for a shift, was 12, this occurred on two occasions on a PICU (ward 2 at the LGI).

5.4.3.2 Registered General Nurses (RGNs)

RGNs were concentrated on the mixed adult and paediatric wards (Bone marrow transplant unit and HDU at SJUH and the regional burns centre at Pinderfields Hospital). Five RGNs were recorded on the HDU at SJUH on one occasion only. No record of RGNs was made on two hospital wards on any shift.

5.4.3.3 Enrolled Nurses (ENs)

No EN was working for 898 (28%) shifts. No record was made of ENs on any shift at eight hospitals. One shift at a DGH recorded one occurrence of three ENs working.

5.4.3.4 Health Care Assistants (HCAs)

HCAs were working on 1,313 (39%) shifts. Eleven (0.3%) shifts had three HCAs working; these shifts all were at various DGHs around the region.

5.4.3.5   Advanced Paediatric Life Support (APLS) Skills

Six hospital wards recorded no member of staff on duty on any shift with APLS skills. The maximum number of staff with valid certification in APLS, on duty at any one time, on a shift was seven. This occurred at a DGH, on ward B, at Pinderfields Hospital. Slightly more than one quarter (n= 930, 28%) of shifts on hospital wards did not have a member of staff on duty with APLS skills.

5.4.3.6   Critical Care Courses (CCC)

Fifteen hospital wards had a member or members of staff with a CCC. The majority of nurses with a CCC were concentrated on the PICU (ward 2 at the LGI) where the maximum on duty at any one time was eight.

5.4.3.7   High Dependency Care Courses (HDCC)

Only 235 (7%) shifts had a member of staff on duty with a HDCC. Two shifts at a DGH (ward 2 at the Bradford Royal Infirmary) had five members of staff on duty, at one time, with such a course.

5.4.3.8   Bank, Agency or Overtime

A maximum number of four staff, on one shift, was used for overtime at a DGH (ward 17 at York District General Hospital). The same DGH was the largest bank/agency/overtime user with a total of 52 members of staff, either qualified or unqualified, booked to undertake extra duties owing to a shortage of staff. Only three hospital wards failed to record any bank, agency or overtime nurses.

5.4.3.9   Missing Data

The DNS was not well completed. Five variables contained greater than 50% of missing data (table 5.9), and two hospital wards (ward 4 and ward 91 at the LGI) failed to complete the DNS.

Table 5.9   Missing data for the daily nurse staffing during the pilot study

Variable	Number analysed	Number Missing (%)
Registered children's nurses (RN (Ch))	2606	749 (22)
Registered general nurses (RGNs)	1325	2030 (60)
Enrolled nurses (ENs)	1106	2249 (67)
Critical care courses (CCC)	1477	1878 (56)
Advanced paediatric life support (APLS) courses	1847	1508 (45)
High dependency care courses (HDCC)	1299	2056 (61)
Bank, agency, overtime (OT)	1194	2161 (64)
Health care assistants (HCAs)	1795	1560 (46)

5.4.4   Daily Patient Activity (DPA)

The total number of admissions, including day cases, for the region during the pilot study was 3,381. The maximum number of admissions during a single shift was 18, this occurred on ward B at Pinderfields Hospital.

Ward attenders seen on many hospital wards totalled 910 during the pilot study, nearly one quarter (24%, n= 214), of which, were seen on ward 7 at Dewsbury District General Hospital.

There were 69 children transferred to the three PICUs within the region. One hospital ward (ward 10 at the LGI) transferred 17 children to ward 4, the Children's Cardiac Intensive Care Unit, post operatively. This was for children that were listed for surgery and for children requiring emergency surgery. Bradford Royal Infirmary transferred nine children for PIC within the month. Forty four (64%) children were internal transfers to one of the three PICUs. Sixty eight children were transferred to an internal HDU and 14 children were transferred to an external HDU. Children transferred to other wards but not a PICU/ICU or a HDU was 238, 20% (n= 49) of which were transferred to a hospital ward from one of the PICUs. During a 24 hour period the maximum discharges from a hospital ward was 16, this occurred four times at three DGHs.

There were 14 deaths in the region during the study period. Seven (50%) of these were from the ICUs and HDU at the lead centres. Four were located at the DGHs and the remainder from specialist wards within the tertiary centres.

The maximum number of beds occupied at midnight on a hospital ward was 23 (ward 10 SJUH).

The maximum number of children seen in a pre-assessment area, either for triage, before being admitted or discharged, or prior to list admission was 27.

A large amount of missing data was evident (table 5.10). Seventy five percent of data was missing from the number seen in pre assessment areas and the number admitted to the ward from pre-assessment units.

Table 5.10   Missing data for the daily patient activity during the pilot study

Variable	Number analysed	Number missing (%)
Ward admissions	774	342 (31)
Ward attenders	654	462 (41)
Number transferred to PICU	580	536 (48)
Number transferred to HDU internal	519	597 (53)
Number transferred to HDU external	491	625 (56)
Transfers to other ward	580	536 (48)
Discharges	683	433 (39)
Deaths	537	579 (52)
Number of beds occupied at midnight	736	380 (34)
Numbers seen in Pre-assessment unit	272	844 (76)
Numbers admitted to ward from pre-assessment unit	283	833 (75)
Number of audit forms returned by day	448	668 (60)
Number of audit forms returned by night	504	612 (55)

5.5   Discussion

The pilot study ensured that content and construct validity, reliability and acceptability were tested (Williams, 2003). The PPA, the MNS, DNS and the DPA forms were used for the period of one month on all hospital wards involved in the study. Content validity was assessed by nursing staff and the Steering Group Committee by judging that the interventions listed on the PPA were representative of PHDC and the personnel listed on the MNS, DNS and DPA were exhaustive. Rarely are empirical approaches used as acceptance of a measure for content validity (Streiner and Norman, 2001). The PPA was used in conjunction with guidelines where a definition of each of the interventions was listed.

The information presented in this chapter builds upon the work undertaken for the feasibility study. It has provided a description of paediatric usual ward care and PHDC up to and including intubation and stabilisation for transfer to a PICU in West, North and East Yorkshire. Whilst it is recognised that intubation and subsequent care of the child requires PIC or level 2 care as defined by the Department of Health (1997a) and not PHDC, DGHs are expected to stabilise a child prior to transfer to a lead centre for PIC. A number of children not intubated will still require PIC but what separate these children from children requiring PHDC is unclear. For these reasons intubation will remain as an intervention on the PPA for the main study.

Data collection occurred at one of the busiest times for all paediatric hospital wards, January, when wards were full to capacity and nurses struggled to cope with their demanding workload. The success of this phase of the study was largely dependent upon the goodwill of all nursing staff that completed data collection forms not only for the children in their care, but also to inform the study about nurse staffing and daily patient activity.

5.5.1 Paediatric Patient Activity (PPA)

Data collection was extremely successful with over 5,000 data collection forms returned for episodes of care with varying numbers of returns from wards. The wards that submitted the largest number of data collection forms were not an indication that a sicker population was resident as data collection forms were also returned for children receiving usual ward care. Although the PPA recorded interventions performed for children in need of usual ward care it also, importantly, captured children irrespective of illness in need of PHDC. The pilot sample therefore appeared to reflect PHDC and cover the PHDC domain in part of the Yorkshire region.

The largest number of inpatient episodes was for children admitted with a respiratory illness, and the majority of these were for infants under the age of one year. This was possibly attributable to bronchiolitis, a seasonal disorder that occurs in epidemics during the winter months, and affects infants of all ages (Boeck, 1996). Despite the success in the amount of forms returned a monthly total of 5,000 over the period of 12 months for the main study are

unmanageable and impractical. It is likely that a wealth of information for children receiving usual ward care is captured rather than information to establish the definitions and quantity of PHDC. It is estimated that between 2,000 to 2,500 data collection forms are an acceptable number to input each month.

The majority of data collection forms were returned for episodes of care that required one intervention only. The most frequently occurring single interventions were 'continuous oxygen saturation monitoring', 'intravenous infusion of maintenance fluid' and 'nasogastric feeding (chronic)'. Possibly these were more characteristic of usual ward care than PHDC.
Therefore the following questions were posed:

Question 1: How can the data set be reduced and the threshold criteria raised to determine PHDC?
Question 2: What outcome measure is to be used to summarise the pattern of correlations between the variables for usual ward care and PHDC?

Answer 1: Statistical reduction of the data was attempted using FA. Of the 18 factors extracted, only two, Factor 2 and Factor 3 had meaning in the combination of variables that correlated with these factors. Factor 2 contained the interventions 'bag and mask ventilation', 'intubation and subsequent care of the intubated child' and 'cardio pulmonary resuscitation' (CPR). All three interventions would occur simultaneously for a child that was extremely sick and had lost cardiac output. Meaning was attributed to Factor 3, 'continuous oxygen saturation monitoring' and 'oxygen therapy less than 50%'. Factor 1 despite accounting for a higher percentage of the variance contained variables that had little meaning as a group and also contained the complex variables 'intubation' and 'bag and mask ventilation'. Complex variables are to be avoided because they cause ambiguity in the interpretation of factors (Tabachnick and Fidell, 2001). Nine factors contained one intervention only and six factors contained zero interventions. Factors that accounted for one or two variables were considered unstable (Tabachnick and Fidell, 2001).

To assess the adequacy of extraction and number of factors the scree plot of eigenvalues was used (Tabacnhik and Fidell, 2001; Field, 2003). The point at which the line was drawn, where the points changed slope, indicated the justification for the retaining of factors, however this is a matter of interpretation and factor selection should not be made on this criterion alone (Field, 2003). For purposes of this study there was probable justification for retaining four factors only.

A mediocre KMO statistic of 0.7 and poor factor loading suggested that FA could not reliably be used to reduce the data set. In general 300 cases and above are required for FA (Tabachnik and Fidell, 2001). Despite 5,213 data collection forms returned for analysis not all combinations of variables received 300 responses. Therefore, reduction of the data set in readiness for the main data collection required methods other than FA, yet exploration of the data set using FA may be worthwhile upon completion of the main study. To reduce the data set for the main study and provide a manageable amount of data collection forms each month a number of experts were contacted and the Delphi methodology was adopted (chapter 6).

Answer 2: To summarise or group patterns of usual ward care and PHDC, nurses were asked their opinion when completing the PPA on their opinion of the level of care provided for the child during a shift period

5.5.1.1   Completeness of Data and Missing Data

Confusion existed over the interventions listed for the recording of neurological observations. An observation noted from the returned forms from one hospital ward and from the comment sheet provided by another hospital ward suggested that determining a Glasgow Coma Score (GCS) for children was difficult. One of the aforementioned hospital wards gave each child, for whom a PPA form was completed, a GCS of 9 to 12. This was despite no formal recording of neurological observations. Nurses working on this ward believed that a normal GCS was between nine and 12, not 15; therefore in the absence of non recording of neurological observations a guess of a GCS of 9 to 12 was made. After discussing this with all nursing staff, the GCS for this hospital ward was not input into the database.

The second specialist hospital ward that encountered a 'neurological' problem found that, despite using a neurological observation chart, a total coma score could not be calculated for the PPA as scores to add were not available on the neurological chart being used by them. To observe deterioration in a child's neurological status a dotted trend was used, not a falling numerical score, but a method of scoring brain function (encephalopathy score) was used alongside the neurological observation form. To assist nurses in interpreting a GCS examples of encephalopathy scores and a simple coma score, characterised by four letters or AVPU (to assess a child's neurological response quickly (A= Alert; V, responds to Voice; P, responds to Pain; U= Unconscious), were aligned to scores from the GCS. These were written into the guidance notes for use with PPA.

Forty seven of the data collection forms were checked 'Not Known' under the systems based heading of 'neurological' for the interventions relating to the GCS. If nurses were not recording neurological observations the GCS would not be evident. This highlighted a failing of the data collection form that did not manifest itself during the feasibility stage of the study. To correct this problem and address the issue of content validity the following questions were asked on the refined PPA:

'Is the child receiving neurological observations?'
        and the following sub categories were added:
'If yes is the GCS less than 8?'   or
'If yes is the GCS 9 to12?'

Four data collection forms recorded a response of 'Not Known' for the intervention 'urine output less than 1ml/kg/hr'. If urine output was not being recorded hourly or if the amount of urine was not being recorded this would not be calculable. Therefore the following question was posed:

Would the intervention 'hourly urine output measurement' capture children with 'urine output less than 1ml/kg/hr'?

This is highly likely as to know that urine output was less than 1ml/kh/hr hourly recording must be taking place. The intervention 'urine output less than 1ml/kg/hr' was removed for the refined data collection form for the main study and replaced with 'hourly urine output measurement'.

It was important to determine the relevance of the responses 'Yes', 'No' and 'Not known' on the PPA to establish if the same responses were to be used for the main study. An alternative to this would be to allow nurses to check only the interventions that applied thereby removing 'No' and 'Not Known' from the categories of response. Form completion is less likely if responses to a question are complicated (Williams, 2003).

The data suggested removing the 'Not Known' category, allowing nurses to check only the interventions that apply as:

- 49 boxes may be checked per single form for items 'Not Known'.
- 49 x total number of child data collection forms = 255,437.
- 255,437 possible responses for 'Not Known'.
- Only 274 (0.1%) responses of 'Not Known' were given during the pilot study.

Therefore 'No' and 'Not Known' categories were replaced with ✓ for a positive response only.

5.5.1.2   Data Quality and Accuracy

The researcher was actively involved in data entry. This provided an insight into the acceptability of all data collection forms, the early detection of problems associated with form completion, the amount of missing data and the coding schemes to assist with the input of data. The input screens developed for both Access databases, by the database programmer at the University of Leicester, mimicked the layout of the forms, and were easy to use with drop down boxes to facilitate speed and ease of inputting (Waterfield, 2000). Although optical scanners ease the burden and repetitiveness of inputting they are known to be subject to errors and are initially costly (Williams, 2003). Despite the estimated large number of PPA returns each month optical scanners were, therefore, not considered for the main data collection.

To assist with data entry the database was able to detect errors and offer help (van Bemmel and Musen, 1997). A flagging system in operation with the PPA database cautioned the data entry clerk if, for example, shift dates were not recorded with the year 2005, or if a child's date of birth prior to 1985 was entered. Data entry was performed once only despite the PPA database having a double entry facility. Although double entry increases accuracy by highlighting the differences between two data clerks (Waterfield, 2000) the process was considered labour intensive and therefore expensive. Transcription error is documented to be a minor cause of inaccuracy (Arts, de Deizer and Scheffer, 2002; Hogan and Wagner, 1997). The most common cause of inaccuracy (36%) is with the users who provide incorrect information (Hogan and Wagner, 1997).

Poor data quality exists when systems and processes are not managed appropriately or when data are missing (Audit Commission, 2004). Ten percent validity checks were performed on the computerised pilot data to confirm data accuracy. Twenty mistakes were evident. Time did not permit visits to each hospital ward to access and corroborate evidence from the medical notes and nursing rosters. However this was undertaken for the main study.

5.5.2 Monthly Nurse Staffing (MNS)

Few conclusions can be drawn from the information analysed owing to poor completion and return rate. Where there was failure to record staff with APLS courses, it was possible that, some wards admitting children for PHDC, had no member of staff with an APLS course, and therefore no member of staff with advanced skills to recognise and initiate life support for an extremely sick child, or that this was due to missing data.

The forms returned for the MNS, DNS and DPA were poorly completed throughout the region. Nursing staff explained that their completion was onerous. Consequently, the MNS, DNS and the DPA collection occurred at two time points within one year rather than each month, during the main study. The two months identified for the collection of this data was May 2005 (summer period) and November 2005 (winter period). Prior to completion of these forms

staff education was provided and the importance of form completion stressed to them.

5.5.3 Daily Nurse Staffing (DNS)

Despite a poor return on the DNS, all primary paediatric wards declared that an RN (Ch) was on duty to co-ordinate or provide care to children and guidance to other staff. However 10% of all shifts worked without or with only one RN (Ch) on duty. In the Yorkshire region, more than one quarter of shifts were without a member of nursing staff with APLS skills, and hence not in line with government guidance, yet because of the large amount of missing data these figures were potentially inaccurate. High quality data and a good response rate was required to draw firm conclusions on the number of qualified staff available with extra training. As it was not possible to determine if data was missing, or if staff had forgotten to write zero in the space provided, staff were encouraged to write in all spaces on the data collection forms during the main study.

Some problems existed with the clarification of the role of the HCA. Senior nurses assisted verification of content validity and returned comments complaining that some HCAs provided patient care while others assisted nursing staff with non nursing/general ward duties. It was requested that a distinction be made between the types of HCA; therefore an extra column was added to the refined data collection form to include both categories of HCA, and their names were changed to clinical support worker and non clinical support worker.

5.5.4 Daily Patient Activity (DPA)

A large amount of missing data was evident from analysis of the DPA as with the staffing data collection forms. This was not, therefore, a true reflection of patient activity within the region. Some data collection forms returned contained no information for one complete day, or for many complete days, this indicated that data was missing and not zero. Other forms contained some row data but no representation was made with a zero or dash and instead many spaces were left blank possibly to denote a zero. This was coded as missing data. With such a large amount of missing data the usefulness of collecting staffing and daily patient activity data, each month, for one year during the main study was

questioned. Members of the steering committee agreed to the staffing and the DPA data collection occurring for one summer month and one winter month during the year. Prior to the main study intense education for nurses regarding form completion and the importance of documenting the numeric zero was essential. Despite the large amounts of missing data many hospital wards were busy as identified by the large number of admissions, discharges, ward attenders and beds occupied during the month. During the Bank Holiday period, Christmas and New Year, some hospital wards amalgamated or closed because the number of children admitted, particularly for surgical reasons declined. Staff sickness at this time of year is a problem and another reason to amalgamate wards. Since ward closure or ward amalgamation has the potential to distort the data, November was chosen for the winter month of data collection for the MNS, DNS and DPA.

Nurse managers commented that midnight bed occupancy was not an indication of ward activity. It was suggested that an extra column was added to the DPA to determine bed occupancy at midday, a healthier indication of a busy ward.

There were a large number of ward attenders within the region who were possibly not captured because of the busy nature of the hospital wards during this time. Ward attenders were referred by General Practitioners or were self referred. Many of these children were not admitted and therefore, never appeared in the hospital statistics. Where resources were not in place these children generated a large amount of work for both nursing and medical staff. Not all hospital wards had a pre-assessment area, some of the children that were seen in this area were admitted and others discharged home. In some hospital wards children were pre assessed prior to surgery that was scheduled for another day at the hospital.

5.6   Conclusion

The piloting of data collection forms on each hospital ward taking part in the study provided further information to improve the PHDC data collection. The issues raised have improved and informed the next stages of the study.

The pilot study aimed to provide information on the levels of care within which PHDC occurred in the Yorkshire region. The data generated by this phase of the study provided a useful description of all levels of care including usual ward care, PHDC and PIC on many hospital wards. A further aim was to ensure that all data collection forms had items to reflect the levels of care including PHDC, the staffing for PHDC and patient movement. Concepts or items missed by the researcher were noted and added to the refined data collection tools for use in the main study; however the refined data collection forms were sufficient in length to answer the research question, but the length of the forms was limited with respect to the burden placed upon respondents (Armstrong et al, 1994). Only essential items were added to maintain brevity of the refined forms. Changes to the PPA, DNS and DPA were required. No changes were required to the MNS.

A larger response rate than anticipated by the feasibility study to the PPA was made. The vast response can be attributed to two causes:

1. Support from nursing staff and a willingness to complete the PPA.
2. A large number of forms completed for children receiving usual ward care indicating that the threshold criteria for PHDC was set too low.

The enthusiastic support of nursing staff who wanted to show the varying levels of care provided to children on each shift, was demonstrated by the large amount of data returned in the feasibility and the pilot phases. However these initial phases highlighted a number of practical difficulties related to data collection. The first problem was using busy clinical nurses to capture data for the PPA and for the staffing levels on each shift. Although nursing staff wanted to substantiate the care they provided with, at times, low numbers of staff; the combination of collecting data for the PPA and the staffing data sets was too burdensome. This was evident in the extensive amount of missing data, negative feedback and complaints from the nursing staff. As a consequence, it was agreed to reduce the burden by limiting the collection of staffing data (DNS and DPA forms) to a period of two separate months, during the summer and the winter. The PPA data collection was to continue as originally planned.

The second difficulty was the competing pressure from the funders, the Paediatric Critical Care Network, to produce timely results, counterbalanced by the researchers supervisor at the University of Leeds, for scientific rigor. Time was a key factor for the Paediatric Critical Care Network, who wanted information on the number of children receiving PHDC in the region. However, without a reduction in interventions to assist with a definition of PHDC, the main data collection was not possible. The importance of this aspect the complexities of PHDC and the negative effect that a 'quick answer' would have on the scientific rigor of the study was openly debated in meetings with the Paediatric Critical Care Network. These discussions resulted in a further 12 months, of the study being funded. This enabled the researcher to undertake further research that would maintain scientific credibility to fulfill the aims of the study that were clearly defined at the outset and changes to these were non-negotiable.

The third difficulty related to the required reduction of the data items on the PPA form and the specific need to remove some data items considered to represent usual ward care. Statistical analysis (FA) failed to reduce the data set and raise the threshold criteria for PHDC; consequently a further attempt was made using the Delphi approach in the following chapter. This expert consultation phase was not originally planned but the complexities of the patterns of correlations for PHDC and the associated difficulties in determining the boundary between usual ward care and PHDC meant that further work was required to clarify this. To assist with the reduction of data and in defining PHDC, two procedures were adopted. Firstly, the expert consultation, an additional phase, described in the next chapter, and secondly a further key question was added to the PPA asking nurses their opinion on the dependency needs of children in their care. In the absence of a gold standard to measure PHDC, a realistic way to assess levels of care during a shift period was to ask nurses their opinion of the level of care provided.

The completion of the PPA also highlighted a clinical concern regarding the inability of nurses to correctly record neurological observations on some hospital wards and the lack of understanding of the GCS. This problem was addressed with nurse managers in the respective hospitals.

The nursing staff remained dedicated to completing the PPA and wished to continue with the collection of data for staffing levels but not as often as was originally planned, therefore a compromise was reached between the clinical staff, the steering group and the Paediatric Critical Care Network to collect staffing data for 2 months of the year only. To guarantee that the study continued to progress, regular meetings with the Paediatric Critical Care Network, the steering group and the clinical staff to debate strategy was adopted for the main study.

The pilot study highlighted numerous problems to be addressed prior to the main data collection. To highlight these changes a list of recommendations was made.

5.7   Recommendations

5.7.1   Paediatric Patient Activity (PPA)

1. Increase the threshold criteria to reflect PHDC and reduce the number of PPA forms returned for usual ward care using the Delphi approach.
2. Add the following questions to the PPA:

    a. 'Is this child receiving neurological observations?' and the subcategories 'if yes is GCS<8?' and if yes 'is GCS 9-12?

    b. 'In your opinion is this child in need of HDC?' as the outcome measure to determine the dependency level.

3. Change the font type to Arial to improve the readability of the PPA (Avey 2000). Print the PPA on brightly coloured pink paper to capture the nurse's attention (Williams 2000).
4. Align GCS, encephalopathy and AVPU scores with assistance from the medical staff for neurological assessment and write into the guidance notes.
5. Provide education to all hospital wards with regard to changes made for neurological assessment.
6. Inform the relevant nurse managers of the difficulty that some nursing staff have in neurologically assessing a child.
7. Remove urine output less than 1ml/kg/hr.

8. Remove categories 'No' and 'Not Known' and allow nurses to check the intervention boxes that only apply to the child.

9. Add a response box for staff to write the NHS number.

10. Add the following categories to the 'reason for admission' :

    a. Diarrhoea and vomiting.

    b. Bone marrow transplant.

    c. Post cardiac surgery.

    d. Bacterial meningitis.

    e. Diabetic Ketoacidosis.

    f. Meningococcal septicaemia.

Point 10 is to ensure that the data collection is mapped to other geographical areas that use the Department of Health (2001a) guideline as a data collection tool to determine the quantity of PHDC.

5.7.2 Staffing and Daily Patient Activity (DPA)

1. Collect data for one month during May (summer month) and November (winter month).

2. Provide education on form completion prior to May and November's data collection.

5.7.2.1 Daily Nurse Staffing (DNS)

1. Add an extra column to include all categories of HCA; those that provide patient care and those that do not. Rename; clinical support workers and non-clinical support workers.

5.7.2.2 Daily Patient Activity (DPA)

1. Add an extra column to capture midday bed occupancy, an improved reflection on overall ward activity than midnight bed occupancy.

6   Expert Consultation

6.1   Introduction

The expert consultation phase was designed as an additional phase to this study with the aim of reducing the dataset for the PPA. The methodology adapted for the expert consultation was the Delphi technique.

The Delphi technique is a method of gathering information, opinions and ideas from a panel of experts, using a specific sequence, designed to transform opinion into consensus (Beech, 2001). Information is assimilated through iterative rounds that allow individuals to change their opinions; each round is summarised and feedback is given to group members (Jones and Hunter, 1995).

The Delphi technique is often used in health care settings as part of a larger study where there is little information on the subject of interest and where issues of a policy nature require prioritising (Mead and Mosely, 2001). It is considered to be highly adaptable and flexible, but modification of the process is not without its critics (Hasson, Keeney and McKenna, 2000; Beech, 2001). Regardless of the design used for the Delphi technique precision and research rigor are required, and Hasson et al (2000) have developed the following guidelines to address this:

1. Define the problem.
2. Identify the resources available.
3. Describe the definition of 'expert' and the sampling techniques.
4. Determine the medium to be used (written or electronic).
5. Establish the level of consensus.
6. Outline the structure of the initial round and the number of rounds.
7. Listen to group opinions and give thought to the organization of those opinions.
8. Consider how to present the final results.
9. Address the issues of ethical responsibility, anonymity, reliability and validity.

For purposes of this research the Delphi technique was adapted and called the 'expert consultation'. Expert consultation was necessary to refine the PPA (Appendix 8). The feasibility and pilot studies generated large amounts of information suggesting that data capture included children requiring usual ward care. The interventions characteristic of usual ward care required removal by experts defined to undertake the process.

The aim of the expert consultation was to:

- Obtain consensus between doctors and nurses in assigning levels of care (level 0 to usual ward care and level 1 to PHDC) to the items listed on the PPA.
- Reduce the data set to allow the threshold criteria to be raised for triggering completion of the PPA.

Each round is discussed following the Hasson et al (2000) guidelines.

6.2 Implementation of Guidelines

6.2.1 Definition of the Problem

No clear and precise definition of level 1 or PHDC exists. *A Framework for the Future* (Department of Health, 1997a) provides guidelines which are essentially open to interpretation. This study aimed to focus the data collection and recruit expert opinions on the variables to be collected.

The feasibility and pilot PPA data collection form contained a list of interventions performed for a child admitted to any paediatric ward in West, North and East Yorkshire, receiving any of the following levels of care:

- Level 2 care (PIC).
- Level 1 care (PHDC).
- Level 0 care (usual ward care).

A child may move between all levels of care during a single admission to hospital. Although a definition exists for level 2 care (PIC), the definition of level 1 care (PHDC) is vague and the boundary between level 0 (usual ward care) and PHDC is blurred.

Level 1 (PHDC) is provided on all paediatric wards taking part in the PHDC study, because of the lack of PHDUs within the region. Staff on any paediatric ward, providing PHDC, will be expected to initiate level 2 care (PIC) i.e. resuscitate, intubate and stabilise a child prior to transfer to a lead centre (Department of Health, 1997a). For these reasons the interventions listed on the PPA identified children requiring all levels of care (0, 1, up to and including intubation and stabilisation or level 2).

The more serious, or life threatening the illness the less frequent the occurrence of the illness. Hence, many pilot data collection forms were returned for the pilot study for children receiving usual ward care, but fewer forms were returned for children receiving PHDC, and relatively few were returned for children requiring PIC. In an attempt to eliminate the data items for children requiring usual ward care, but capture PHDC, a modified Delphi technique (expert consultation of two rounds) was adopted.

6.2.2 Available Resources

Careful thought, planning and relationship building was necessary for each round of the expert consultation (Hasson et al, 2000). Thirty eight paediatric wards in 14 hospitals and 10 NHS Trusts were involved in the pilot study. The same hospitals and hospital wards were to be involved with the main study. Great importance was attached to meeting staff, of all grades, in all of the

hospitals and wards taking part in the study; their opinions were valued and essential for the development of all phases of the PHDC study. However for purposes of this study a precise definition was required for the 'experts'.

The need for a wide range of 'experts' representing nursing and medical staff, from specialist hospital wards and from lead and tertiary centres and DGHs was necessary to reduce bias. A member of nursing and medical staff within the region had contributed to *High Dependency Care for Children-Report of an Expert Advisory Group for Department of Health.* (Department of Health, 2001a). One or both of these individuals were vital to inform the expert consultation.

6.2.3 Definition of Expert

A purposive sample of experts was identified using the criteria specified (table 6.1).

Table 6.1   Definitions of expert nurse and expert doctor

Expert Nurse	Expert Doctor
Must have five years experience or more in the care of children requiring PHDC.	Must be consultant paediatrician/intensivist with experience in dealing with critically ill/highly dependent children.
Must have one year at F/G grade level or above.	Is used to dealing with and evaluating clinical data associated with children receiving PHDC.
Is aware of illness severity scoring.	Is aware of and able to discuss severity of illness scoring.
Is computer literate.	Is computer literate.

Participants or experts cannot be selected randomly therefore representativeness is not guaranteed and bias may be introduced into the sample (Jones and Hunter, 1995; Hasson et al, 2000). A lack of representativeness or a homogenous like minded panel in the choice of experts

was likely to produce a skewed dataset (Hasson et al, 2000). Therefore; it was reasonable for this study to select a group of experts that were representative of the geographical area, clinical grade and specialty, that met with the pre defined criteria, were impartial, reflected current knowledge and were interested in the subject under consideration (Hasson et al, 2000; Mead and Mosely, 2001). Furthermore, bias is introduced if minority expert views are eliminated early in the process, consequently the range of experts, should be unknown to each other, able to express their views and not be inhibited by the more domineering personalities of the group (Mead and Moseley 2001). For the purposes of reducing bias, consideration was given to the way that information was communicated to prevent experts from identifying each other.

6.2.4 Medium to be Used

All information for Round 1 was communicated electronically. Information was sent by the researcher and returned by the experts via e-mail. As suggested by Hasson et al (2000) an outline of the Delphi process, details of what was expected of each 'expert', the time each member was expected to contribute and uses to which their information would be put was also sent electronically.

6.2.5 Level of Consensus

A universally agreed degree of consensus for the Delphi technique does not exist as this depends upon the aim of the research, the sample numbers and resources available (McKenna, 1994). Work performed by Greatorex and Dexter (2000) opted for greater than 80% consensus. Consensus set at the outset of the expert consultation was 70% as recommended by Summison (1998).

6.2.6 The Structure of the Initial Round and the Number of Rounds

Two rounds, only, of the expert consultation study for the PHDC study were agreed. For the initial round,10 experts (5 doctors and 5 nurses) were invited to indicate the level of care (level 0 or level 1) required for children using clinical scenarios. In total 140 case scenarios were randomly extracted from the pilot data and distributed between the five teams of one nurse and one doctor. There was overlap between some scenarios and all five teams received the same 20

scenarios, 20 scenarios were examined by two teams and 20 scenarios were unique to each team. This gave each team a total of 60 scenarios (table 6.2)

For purposes of analysis the experts were paired (doctor and nurse) to determine agreement between disciplines. Each doctor/nurse pair was located at separate hospitals to determine if their views clustered according to discipline or hospital culture (table 6.2).

Table 6.2   Team members, scenario numbers and experts place of work

Team number	Scenario number			Team members	Hospital
1	1-20	1-20A	1-20B	Doctor	Pinderfields Hospital [1]
				Nurse	Hull Royal Infirmary [2]
2	1-20	1-20A	1-20C	Doctor	Bradford Royal Infirmary [3]
				Nurse	Leeds General Infirmary [4]
3	1-20	1-20C	1-20D	Doctor	Leeds General Infirmary [4]
				Nurse	Bradford Royal Infirmary [3]
4	1-20	1-20D	1-20E	Doctor	Calderdale Royal Infirmary [5]
				Nurse	Hull Royal Infirmary [2]
5	1-20	1-20E	1-20F	Doctor	Hull Royal Infirmary [2]
				Nurse	Pinderfields Hospital [1]

Key
1 The Mid Yorkshire Hospitals NHS Trust
2 Hull and East Yorkshire Hospitals NHS Trust
3 Bradford Teaching Hospitals NHS Foundation Trust.
4 The Leeds Teaching Hospitals NHS Trust
5 Calderdale and Huddersfield NHS Trust

6.2.7   Group Opinions and Organisation of Opinions

Group membership was not disclosed to the experts, they were asked not to discuss the process or collude with colleagues. Experts were asked to read through 60 case scenarios each generated from the pilot data to establish if the scenario reflected a child in need of HDC, or routine ward care, by indicating their response with ✓ in the appropriate box (table 6.3). Experts were aware that more than one round of the process may be necessary, the researcher was conscious that sample fatigue was a consequence of many rounds (Schmidt, 1997).

Simple summary statistics were analysed using SPSS (SPSS. Inc. V12.0.1, 2003). The levels of agreement between doctor/nurse teams was tested using the Kappa statistic (Cohen 1960) (K) in SPSS V12 and Stata (StataCorp,

 2005). The Kappa statistic measures the amount of agreement beyond that expected by chance and has values ranging between zero and one (Becker, 1999). The values can range between < 0.4, 0.4 -< 0.75 and 0.75 - 1, representing poor, fair to good and excellent agreement respectively (Becker, 1999). The Kappa statistic is easily calculated and appropriate for testing whether agreement exceeds chance levels for binary data (Uebersax, 2002). The Kappa statistic as measure of agreement does not make distinctions between types and sources of disagreement and it is influenced by trait prevalence and base rates and is therefore not comparable across studies (Uebersax, 2002).

6.2.8 Presentation of the Final Results

Results were reported using textual presentation of statistics. Both rounds were reported upon together. The experts were informed of the results, and how to interpret and digest the findings in relation to the significance being placed upon them.

6.2.9 Issues of Ethical Responsibility, Anonymity, Reliability and Validity

During Round 1 the experts were known to the researcher only. Anonymity is one of the features which distinguish this method from other consensus methods (Hasson et al, 2000). In Round 2 respondents were known to each other; however opinions gathered from Round 1 remained anonymous.

Issues of reliability and validity, regarding the expert consultation, are discussed throughout this chapter.

Table 6.3   Example of the scenarios provided for the experts

Number	Age	Frequency of observations	Diagnosis (category)	Nursing Interventions	Usual ward care	HDC
1	6 Years	4 Hourly	Other	**1**Continuous intravenous drug infusion **2**Hourly intake and output measurement **3**Total parental nutrition		
2	4 Years	4 Hourly	Sepsis	**1**GCS 9-12 **2**Intravenous infusion of maintenance fluid **3** Oxygen saturation monitoring		
3	7 Months	4 Hourly	Diarrhoea and vomiting	**1**Regular blood sampling **2**Intravenous infusion of maintenance fluid **3**Hourly urine output measurement		
4	3 Years	Hourly	Respiratory	**1**Nebulised medications (less than 1 per hour) **2** Oxygen less than 50% **3**Oyygen saturation monitoring		
5	11 Years	4 Hourly	Other	**1**Intravenous infusion of maintenance fluid **2**Naso-gastric tube (chronic) **3**Oxygen less than 50% **4**Pain requiring epidural/intravenous analgesia/bolus infusion		
6	2 Months	2 Hourly	Respiratory	**1**ECG monitoring **2**Naso-gastric tube acute **3**Oxygen less than 50% **4**Oxygen saturation monitoring		
7	10 Months	4 Hourly	Respiratory	**1**Nebulised medication (less than 1 per hour) **2**Nasogastric tube (chronic) **3**Oxygen saturation monitoring **4**Oxygen less than 50%		
8	14 Years	Hourly	Diarrhoea and vomiting	**1**ECG monitoring **2**Continuous intravenous drug infusion **3**Intravenous drug bolus greater than 3 **4**Regular blood sampling		

6.3   **Method**

6.3.1   **Round 1**

The purpose of Round 1 was to determine those interventions that reflected PHDC. Some interventions were clearly representative of PIC and some were clearly representative of PHDC as defined by the Department of Health (2001). For other interventions, it was not clear of the level of care (usual ward care or PHDC) being represented; therefore those interventions thought to be ambiguous were presented to the experts for a consensus of opinion on the items thought to represent PHDC and to be retained for the main data collection.

An example of a PIC (level 2) intervention was:

'Intubation and subsequent care of the ventilated child'.

This did not require removal for the PPA but required removal for the experts because this intervention was performed by nursing and medical staff on any of the children's wards during the resuscitation and stabilisation period and prior to retrieval by a regional PIC team (table 6.4).

An example of a PHDC (level1) intervention as defined by the Department of Health 2001 was:

'Sedation during or after a procedure'

The interventions listed by the Department of Health (2001) did not require removal for the PPA but removal for the experts because these interventions had been previously defined as PHDC (table 6.4). The pilot data was used to generate 140 case scenarios of actual children admitted to a paediatric ward requiring three or more interventions, but not interventions known to be provided for children requiring level 2 (PIC) and level 1 care (PHDC) as defined by the Department of Health, (2001a). Table 6.4 identifies all of the interventions removed and retained for analysis by the experts.

Table 6.4   Data items from the paediatric patient activity (pilot study data) retained and removed for Round 2 of the expert analysis

Forms with the following interventions were retained for expert analysis	Forms with the following interventions were removed for expert analysis
2) continuous ECG monitoring	4) endotracheal intubation and subsequent care of the intubated child
3) continuous oxygen saturation monitoring	5) use of airway adjunct
7) care of the child with tracheostomy	6) child recently extubated
8) nebulised adrenaline for upper airway obstruction (< 2 doses)	7a) care of the child with a newly formed tracheostomy
9) oxygen therapy less than 50%	8a) nebulised adrenaline more than 2 doses
12) stable long term (domiciliary ventilation)	9a) oxygen greater than or equal to 50%
14) nebulised medications < 1 per hour for more than 4 hours	10) acute continuous positive airways pressure (CPAP)
15) chest drain/s	11) bag and mask ventilation
15a) if yes has chest drain/s been in situ > 24 hours	13) four apnoeic episodes within 4 hours requiring stimulation
16) airway suction more than once an hour	14a) nebulised medications > 1 per hour for more than 4 hours
17) continuous intravenous drug infusion	23) vasoactive drug therapy
18) intravenous infusion of maintenance fluid	28) peritoneal dialysis
19) replacement of fluid losses	29) haemofiltration/haemodialysis
20) complex hourly fluid balance	30) cardiopulmonary resuscitation
21) multiple intravenous lines > 3	31) intravenous fluid resuscitation
22) intravenous drug boluses > 3	32) invasive arterial pressure monitoring
24) total parental nutrition	33) central venous pressure monitoring
25) blood transfusion	35) cardiac pacing new on this admission
26) hourly urine output measurement	36a) cardiac arrhythmia that has not responded to first line therapy
27) urine output less than 1ml/kg for greater than 4 hours	37) GCS equal to or less than 8
34) regular blood sampling (4 hourly or more frequent including blood glucose levels)	39) deteriorating GCS (a fall of 2 points since commencement of observations)
36) cardiac arrhythmia that has responded to first line therapy	40) prolonged or recurrent seizures

Table 6.4   continued

Forms with the following interventions were retained for expert analysis	Forms with the following interventions were removed for expert analysis
38) CGS 9-12 43) frequent position changes 44) pain requiring epidural/intravenous analgesia 46) warming or cooling blanket 47) dressing changes greater than 3 per shift 48) hourly aspiration of naso-gastric or gastrostomy tube 49) naso-gastric/naso-jejunal/gastrostomy (chronic)	41) intracranial pressure monitoring 42) external ventricular device 45) sedation during after procedure

The child's age, category of diagnosis, frequency of observations and the type and number of interventions performed for the child during a period of duty (12 hrs) were tabulated and given to the experts (table 6.3).

Information from the following questions was required from the analysis in Round 1:

- Were the number of interventions important in determining a child in need of PHDC?
- Was a single intervention within a scenario crucial in determining a child in need of PHDC?
- Do differences in agreement occur between expert doctors and expert nurses?
- Do differences of opinion exist between hospitals?

The scenarios were sequenced, 20 were common to all teams, 20 were common to two teams and 20 were unique to each team. Table 6.2 outlines the sequence of the numbered scenarios. This sequencing was adopted to determine if an estimation of unobserved data or latent traits could be made on the basis of available responses (Smits, Mellenbergh and Vorst, 2002). For example was it possible to estimate responses in the unobserved data using the sequencing of scenarios when each team received only 60 scenarios rather than 140 scenarios? Planned missingness or missing by design is used in longitudinal, psychological and educational research, this design is used to save money and lighten the respondent load (Graham, Taylor and Cumsille, 2001; Smits et al, 2002).

6.3.2   Results of Round 1

A response rate of 100% was achieved and all scenarios were returned by the deadline set. Data were entered into an Access database and exported to SPSS (SPSS. Inc. V12.0.1, 2003) and Stata (StataCorp, 2005) for analysis. Basic frequencies were tabulated for the frequency of interventions. From the 600 responses to the case scenarios more (n= 398, 66%) children were admitted for usual ward care. Only 186 (31%) responses were in favour of admitting the child for PHDC. Sixteen responses were missing. The

percentages of interventions that occurred for children admitted to either ward or PHDC area are seen in table 6.5.

Nebulised adrenaline (less than 2 doses) occurred only twice in the 600 scenarios. The children receiving this intervention in both scenarios were admitted for PHDC by the experts. Warming or cooling blanket/ambient temperature monitoring/incubator occurred nine times in the scenarios, eight (80%) of the nine children were admitted for PHDC, one (20%) child only was admitted for usual ward care. Blood transfusion (88.5%), urine output less than 1ml/kg (78.6%), and neurological observations for a child with a GCS of 9 to 12 (70%) were interventions received by children more frequently admitted to PHDC.

In total, 140 case scenarios were mailed to the 10 experts, of the 20 case scenarios received by all experts, 12 scenarios achieved 70% or greater agreement as to where the child should be nursed (table 6.6). There was 100% agreement that patient seven and patient four should receive usual ward care. There was 90% agreement that patient 14, 17 and 20 should receive PHDC. There was 80% agreement that patient one, three, five, and 16 should be nursed on the ward and 70% agreement that child 12 should be nursed in a PHDC area and child six on the ward.

On hundred and twenty case scenarios were delivered between the 10 experts. There was overlap between 20 scenarios for two groups of experts and a unique set of case scenarios were mailed to each group of experts. Of the 120 scenarios, only 5 (4%) reached total (100%) agreement that the child should receive PHDC, these were child 16B, 17B, 18B, 1E and 2F.

Table 6.5   Allocations of interventions into paediatric high dependency care and usual ward care

Intervention	PHDC n (%)	Ward n (%)
2) continuous ECG monitoring	64 (42)	85 (56)
3) continuous oxygen saturation monitoring	127 (31)	271 (67)
7) care of the child with an established tracheostomy	12 (44)	15 (56)
8) nebulised adrenaline for upper airway obstruction	2(100)	0
9) oxygen therapy less than 50%	83 (28)	213 (71)
12) stable long term (domiciliary ventilation)	5 (36)	9 (64)
14) nebulised medications less than 1 per hour for more than 4 hours	31 (22)	109(78)
15) chest drain/s (first 24 hours)	*	
15a) chest drain/s (greater than 24 hours)	*	
16) airway suction more than once an hour	8 (68)	4 (33)
17) continuous intravenous drug infusion	69 (40)	97(57)
18) intravenous infusion of maintenance fluid	124 (37)	197 (59)
19) replacement of fluid losses	36 (50)	34 (47)
20) complex hourly fluid balance	58 (56)	81 (40)
21) multiple intravenous lines greater than 3	10 (42)	13 (54)
22) intravenous drug boluses greater than 3	48 (31)	96 (62)
24) total parental nutrition	17 (24)	49 (70)
25) blood transfusion/transfusion of platelets/fresh frozen plasma	23 (89)	3 (12)
26) hourly urine output measurement	39 (50)	37 (47)
27) urine output less than 1ml/kg for greater than 4 hours	22 (79)	5 (18)
34) regular blood sampling (4 hourly or more frequent including blood glucose levels)	47 (56)	36 (43)
36) cardiac arrhythmia that has responded to first line therapy	*	
38) CGS 9-12	28 (70)	12 (30)
43) frequent position changes	22 (50)	20 (46)
44) pain requiring epidural/intravenous analgesia	22 (39)	33 (59)
46) warming or cooling blanket	8 (80)	1 (10)
47) dressing changes greater than 3 per shift	2 (50)	2 (50)
48) hourly aspiration of naso-gastric or gastrostomy tube	9 (38)	14 (58)
49) naso-gastric/naso-jejunal/gastrostomy (chronic)	53 (28)	129 (68)
50) naso-gastric/naso-jejunal/gastrostomy (acute)	18 (23)	57 (75)

*Did not occur in the scenarios mailed to experts.

Table 6.6   Scenarios 1-20. Children admitted for paediatric high dependency care or usual ward care according to expert opinion

	Scenario 1-20			Scenario 1-20A			Scenario 1-20B			Scenario 1-20C			Scenario 1-20D			Scenario 1-20E			Scenario 1-20F	
	PHDC %	Ward %		PHDC %	Ward %		PHDC %	Ward %		PHDC %	Ward %		PHDC %	Ward %		PHDC %	Ward %		PHDC %	Ward %
1	20	80	1	0	100	1	0	50	1	25	75	1	75	25	1	100	0	1	0	50
2	60	40	2	0	100	2	50	50	2	75	25	2	75	25	2	0	100	2	100	0
3	20	80	3	0	75	3	0	100	3	0	100	3	75	25	3	75	25	3	50	50
4	0	100	4	25	75	4	50	50	4	0	100	4	0	100	4	75	25	4	50	50
5	20	80	5	25	75	5	0	50	5	0	100	5	0	100	5	50	50	5	50	50
6	30	70	6	25	75	6	50	0	6	0	100	6	0	100	6	25	75	6	0	100
7	0	100	7	50	50	7	50	50	7	25	75	7	0	100	7	25	75	7	50	50
8	60	40	8	0	100	8	50	0	8	0	100	8	25	75	8	0	75	8	50	50
9	50	50	9	75	0	9	0	50	9	25	75	9	0	100	9	0	100	9	50	50
10	10	90	10	25	75	10	50	50	10	25	75	10	50	50	10	75	25	10	0	100
11	40	60	11	25	50	11	0	100	11	50	50	11	75	25	11	0	100	11	50	50
12	70	30	12	50	50	12	0	100	12	25	75	12	25	75	12	0	100	12	0	100
13	50	50	13	50	50	13	0	100	13	0	100	13	0	100	13	50	50	13	0	100
14	90	10	14	75	25	14	0	100	14	0	100	14	75	25	14	0	100	14	0	100
15	30	60	15	25	50	15	50	50	15	0	100	15	0	100	15	25	75	15	50	50
16	20	80	16	0	75	16	100	0	16	25	75	16	0	100	16	0	100	16	50	50
17	90	10	17	0	100	17	100	0	17	25	75	17	0	100	17	25	75	17	0	100
18	40	60	18	0	75	18	100	0	18	0	100	18	25	75	18	0	100	18	50	50
19	60	30	19	0	75	19	50	50	19	0	100	19	0	100	19	0	100	19	0	100
20	90	10	20	75	25	20	0	100	20	0	100	20	0	100	20	0	100	20	50	50

Cohen's Kappa (Cohen, 1960) (K) was used to measure individual agreement within and between disciplines for the 20 scenarios. Data returned from Doctor 1 contained five missing values, yet Kim and Lemeshow (2001) suggest the cross-table provided by SPSS should contain no row or column data with zero elements; therefore Doctor 1 was excluded from the analysis. Inter rater agreement for all nine experts are displayed in table 6.7. Results of agreement within and between disciplines were not statistically significant. Good agreement existed between Doctor two with Doctor three, Doctor three with Nurse four (K = 0 .588, p= 0.007; n= 20) and Doctor two with Nurse four (K = 0.596, p= 0.008; n=20).

Stata (StataCorp, 2005) was used to calculate total inter rater agreement. Doctor 1 was eliminated from the analysis for reasons as discussed above. The proportion of total agreement and agreement between disciplines, after chance had been excluded, was poor (total agreement was 24%), (K = 0.245, p<0.0005: n= 9), between doctors agreement was 31%, (K = 0.315, p<0.0005; n= 4) and between nurses 20%, (K = 0.199, p<0.005; n= 5).

After allowing for chance, the proportion of total agreement was poor between the 20 scenarios that were sent to groups of 4 members:

Team two and three
Doctor two, Doctor three, Nurse two, Nurse three (total agreement was 8%), (p<0.2; n= 4).

Team three and four
Nurse three, Nurse four, Doctor three, Doctor four (total agreement 33%), p<0.0005; n=4).

Team four and five
Nurse five, Nurse four, Doctor four, Doctor five (total agreement 23%), (p<0.05; n= 4).

Missing data were present from Doctor one and Doctor two from Team one and Team two; therefore Team one and Team two were excluded from the analysis.

The findings from Round 1 were not helpful in guiding the process of reducing the set of items for data collection as agreement was relatively poor. Although planned missingness by design was intended to enable variations in case scenarios to be randomly administered to different subsets of experts, this was not pursued in this analysis. To assign plausible values for missing data one must be assume that non-missing values are good predictors of missing values (Morales and Bautista, 2008). It was not possible to determine from the PPA data the predictors of PHDC, as it was not clear if the predictors of PHDC were single or multiple interventions in combination, or if the age of the child, the diagnosis or the frequency of interventions were influencing the agreement decisions of the experts; consequently further analysis was not attempted on the data during Round 1 and a different format was agreed for Round 2.

Table 6.7　**Agreement for the level of care between doctors and nurses during the expert consultation**

Discipline	Discipline	Kappa statistic	
Doctor 2	Nurse 1	(n=20) = 0.010	p= .964
	Nurse 2	(n=20) = 0.118	p= .582
	Nurse 3	*	
	Nurse 4	(n=20) = 0.596	p= .008
	Nurse 5	(n=20) = 0.314	p= .142
	Doctor 3	(n=20) = 0.558	p= .007
	Doctor 4	(n=20) = 0.208	p= .343
	Doctor 5	(n=20) = 0.255	p= .178
Doctor 3	Nurse 1	(n=20) = 0.381	p= .018
	Nurse 2	(n=20) = 0.038	p= .848
	Nurse 3	*	
	Nurse 4	(n=20) = 0.588	p= .007
	Nurse 5	(n=20) = 0.340	p= .085
	Doctor 4	(n=20) = 0.417	p= .043
	Doctor 5	(n=20) = 0.390	p= .061
Doctor 4	Nurse 1	(n=20) = 0.406	p= .064
	Nurse 2	(n=20) = 0.082	p= .714
	Nurse 3	*	
	Nurse 4	(n=20) = 0.406	p= .064
	Nurse 5	(n=20) = 0.490	p= .028
	Doctor 5	(n=20) = 0.151	p= .369
Doctor 5	Nurse 1	(n=20) = 0.468	p= .013
	Nurse 2	(n=20) = 0.268	p= .068
	Nurse 3	*	
	Nurse 4	(n=20) = 0.255	p= .178
	Nurse 5	(n=20) = 0.107	p= .494
Nurse 1	Nurse 2	(n=20) = 0.314	p= .142
	Nurse 3	*	
	Nurse 4	(n=20) = 0.394	p= .078
	Nurse 5	(n=20) = 0.510	p= .170
Nurse 2	Nurse 3	*	
	Nurse 4	(n=20) = 0.314	p= .142
	Nurse 5	(n=20) = 0.375	p= .094
Nurse 3	Nurse 4	*	
	Nurse 5	*	
Nurse 4	Nurse 5	(n=20) = 0.510	p= .017

* No statistic computed

6.3.3　Round 2

Round 2 was performed using a face to face structured meeting. Lack of time prevented the use of the existing 10 experts and scenarios for a further round to achieve congruence; therefore three experts (a nurse, the researcher; a paediatrician from a DGH and a member of the expert advisory group for *High Dependency Care for Children-Report of an Expert Advisory Group for*

Department of Health (Department of Health, 2001a) and a consultant intensivist from the PICU) came together to discuss the results of Round 1 with the aim of reducing the data set. No limits are set for the number of experts used in a Delphi study and as few as three experts are acceptable if the small group has in depth knowledge of the subject (David and Sutton, 2004). Each expert had plenty to say and they were able to feed off each other. A face to face meeting of the existing five consultants and five nurses would have proved difficult to co-ordinate due to scheduled work demands.

6.3.4   Results of Round 2

Simple summary statistics and the results from the exploratory FA both obtained from the pilot data and the simple summary statistics gained from the expert consultation data were used to assist the experts with deletion of interventions in Round 2 (Appendix 8). Following Round 2 of the expert consultation the following seven items were decided not to be indicative of PHDC and removed from the criteria for form completion:

- 2) ECG monitoring.
- 3) Continuous oxygen saturation monitoring.
- 9) Oxygen therapy less than 50%.
- 18) Intravenous infusion of maintenance fluid.
- 27) Urine output less than 1ml/kg for greater than 4 hours.
- 48) Hourly aspiration of naso-gastric or gastrostomy tube.
- 49) Naso-gastric/naso-jejunal/gastrostomy tube (chronic).

6.4   Discussion

The expert consultation study was undertaken to refine the items/interventions necessary to define PHDC (level 1care) and, subsequently, to remove any interventions that did not pertain to PHDC up to the point of stabilisation and intubation for transfer to PIC (level 2 care). The effect of this was to raise the threshold criteria to include level 1 and 2 care and exclude any child receiving usual ward care (level 0 care), and therefore reduce the monthly data return by half.

This study demonstrated good motivation and interest of doctors and nurses for defining PHDC. During Round 1, nurses and doctors from specialist and general paediatric ward areas were willing to invest time to refine the list of interventions that they believed were used to care for children in need of PHDC. A 100% response rate was achieved and all information was submitted to the researcher via e-mail before the deadline set.

Round 1 required a great deal of time for the:

- Researcher to extract 140 case scenarios from the pilot data.
- Experts to complete the case scenarios.

Yet, this work provided very little useful information.

Nebulised adrenaline for upper airway obstruction (less than 2 doses) received PHDC status (100%) but this was only observed in two scenarios by two experts. As the intervention occurred so infrequently it was impossible to categorise as PHDC or usual ward care. Blood transfusion/transfusion of platelets/fresh frozen plasma, urine output less than 1ml/kg, GCS 9 to 12 and warming cooling blanket/ambient temperature monitoring were interventions performed for children admitted more frequently to PHDC. Difficulty was encountered in determining if each of the interventions was responsible for admission to PHDC independently, or because they occurred in combination with other interventions, or because of factors such as age of the child, diagnosis and frequency of observations, that also were provided to assist with the process.

Of the 20 case scenarios given to all experts there was 100% agreement for scenario four and seven that both children could be nursed on the ward. Scenario four contained three interventions, scenario seven contained four interventions, the interventions were identical (nebulised medications less than 1 per hour, oxygen less than 50% and oxygen saturation monitoring). Care of the child with naso-gastric tube (chronic) was extra to scenario seven.

The majority of experts (90%) placed patient 14, 17 and 20 into a PHDC category. All scenarios had greater than six interventions; patient 20 required 10 interventions (singly, possibly, all representing usual ward care). It was not possible to determine if the number of interventions or a single intervention caused the response. Intravenous infusion of maintenance fluid was the only intervention common to all scenarios.

With 80% agreement for child one, three, five, and 16 to be nursed on the ward, each of the scenarios contained six or less than six interventions. The interventions were varied and a total of 16 interventions occurred between all scenarios.

There was 70% agreement that child 12 should be nursed in a PHDC area, the scenario contained five interventions only, however the child's diagnosis was categorised as fits/reduced conscious level and this may have impacted upon the experts in their decision of where this child should be nursed. Fits/reduced conscious level as a category of diagnosis occurred only once in the 20 scenarios received by all experts. Scenario 6 received 70% agreement that the child should be admitted to a ward area. This child required only four interventions.

Of the 120 case scenarios that were distributed to the experts (some with overlap between two groups and some unique to each group), only five established 100% agreement that the child should be cared for in PHDC area. All five of these scenarios contained between five and seven interventions and the only intervention unique to all scenarios was continuous oxygen saturation monitoring.

Due to the number of factors affecting the different scenarios it was extremely difficult to determine the influencing dynamic for the experts; the planned missingness was therefore not pursued. A greater number of scenarios were required in order to identify the items that most influenced the experts to admit a child for PHDC or for usual ward care. It is not a trivial task to rationalise this, given the 29 combinations of interventions (minimum) x 6 frequencies of observations x 10 categories of diagnosis = 1,740 scenarios per expert.

Assuming each judgment takes 20 seconds this equated to 580 minutes or 10 hours of work which experts would not agree to. A further issue is that the clinical scenarios extracted from the pilot data did not capture the information necessary to generate this number of scenarios.

Total inter rater agreement for both disciplines was poor; however agreement between doctors was better than agreement between nurses. The reasons for this are unclear. Greater agreement existed between Doctor two and Nurse four and Doctor three and Nurse four. No explanation is presented for the greater agreement that existed between Doctors two and three and Nurse four, Nurse four was not employed at the same hospital as Doctors two or three. One explanation for the differences between all nurses and doctors is that nurses focused upon age, diagnosis category and frequency of observations while doctors concentrated upon the interventions. It was possible that the lack of consensus for Round 1 demonstrated a lack of opportunity for discussion and clarification (not inherent within the Delphi technique). Further discussion may have resolved uncertainties, encouraged consensus and strengthened opinion, yet this approach is more akin to nominal group technique rather than the Delphi approach (Mead and Mosely, 2001; Allen, 2004).

Face to face meeting in Round 2 proved useful to reduce the items listed on the PPA. The reasons for removing the PPA items after discussion are presented below:

- Intervention 2: ECG monitoring. Results from Round 1 did not suggest overwhelmingly that a child receiving this intervention should be placed for usual ward care or PHDC; 56% of children receiving this intervention were admitted for usual ward care. Singly, during Round 2, this intervention was not felt to be indicative of PHDC but the importance of ECG monitoring was discussed. A child requiring ECG monitoring was thought by the experts to be at risk of cardiac arrhythmia and therefore had the potential to deteriorate. Listed as intervention number 36, on the PPA, cardiac arrhythmia would be captured by the data collection form. Although ECG monitoring as an intervention was removed from the criteria for form completion (i.e. the intervention was not numbered) 'continuous ECG

monitoring' was placed under additional information on the back of the revised PPA form for nursing to staff to indicate if a child was receiving this intervention.

- Intervention 3: Continuous oxygen saturation monitoring. Evidence from the simple summary statistics of the pilot data suggested that this was the most common of all interventions, 2,661 (51%) PPA forms were returned for children receiving this intervention either as a single, or one of many interventions. As a single intervention, 243 (5%) data collection forms for 96 (7%) children were returned. During Round 1 experts placed the majority of children with this intervention for usual ward care (66.7%). During Round 2 of the expert consultation the experts believed that a child in need of PHDC and receiving continuous oxygen saturation monitoring was determined from other interventions (for example oxygen therapy, pain requiring epidural/intravenous analgesia).

- Intervention 9: Oxygen therapy less than 50%. The data from the experts in Round 1 suggested that the majority of children requiring this intervention (71%) could safely be nursed on the ward. After discussion in Round 2 the experts concluded that a child in need of PHDC required a greater concentration of oxygen (greater than 50%).

- Intervention 18: Intravenous infusion of maintenance fluid. During the pilot study, 295 PPA forms were returned for children receiving this as a single intervention. The data from Round 1 did not assist with the decision making process, 59.3% of occurrences of this intervention were for usual ward care. Singly it was not defined as PHDC by the experts in Round 2.

- Intervention 27: Urine output less than 1ml/kg (for greater than 4 hours). This intervention was removed as the experts in Round 2 agreed that this was determined from intervention 22 on the PPA (hourly urine output measurement) and did not require separate categorisation.

- Intervention 48: Hourly aspiration of naso-gastric or gastrostomy tube. In Round 1 usual ward care was indicated for the majority of children (58.3%) requiring this intervention. Singly this was not seen to be an intervention associated with PHDC in Round 2.

- Intervention 49: Naso-gastric/naso-jejunal/gastrostomy tube (chronic). Sixty eight percent of children with this intervention were admitted to the ward for usual care by the experts in Round 1. During Round 2 the experts agreed that singly this intervention did not ensure PHDC status.

Each one of the 29 items/interventions (non-PHDU or PIC) that was retained for the expert consultation was discussed to determine its relevance to PHDC. Although seven interventions were identified for removal with ease from the PPA, two interventions caused considerable debate:

- Intervention 24: Total Parental Nutrition. This intervention was seen as highly specialised by one member and not routine PHDC; however this intervention was performed in specialist areas and therefore retained.

- Intervention 50: Naso gastric/naso-jejunal/gastrostomy tube (acute). As a single intervention this accounted for 164 returned PPA forms during the pilot study. According to the results of Round 1, 75% of children were admitted for usual ward care with this intervention, yet all experts in Round 2 agreed that to pass a naso-gastric tube acutely to feed or to decompress the stomach of a child was an indication of deterioration and a child in need of care at a greater level than usual ward care. This was therefore retained.

6.4.1   A Critique of the Delphi Technique

The Delphi technique has an important place in research to synthesise information where there is lack of, or contradictory information. It is commonly used as a consensus method for medical and health services research and as statistical methods proved ineffective in refining the data set for the PHDC study this methodology was exploited. Despite being flexible there are difficulties inherent within this technique. This critique will discuss those difficulties and

provide details of the approaches that were used to ensure validity of the expert consultation study.

There is no evidence of the reliability of the Delphi technique; the same results may not be obtained if identical information were given to two or more panels (Hasson et al, 2000). The Delphi operates upon the supposition that many group members are better than few (Hasson et al, 2000). However there are no hard and fast rules, and there is the suggestion that the more group members know about the subject the smaller the group needs to be (David and Sutton, 2004).

To increase the content validity of the PHDC study, participants with knowledge and an interest in the topic of PHDC were gathered together (Goodman, 1987). Listening, organising and listing nursing and medical opinions from a mix of participants and backgrounds using predefined expert criteria was performed to ensure credibility in the interpretation of findings. A homogenous group of nurses or doctors was not convened as this was likely to produce a skewed data set and pose a threat to the validity of the study (Mead and Mosely, 2001).

The assessment of content validity is a matter of judgment which may be made by the researcher or judges engaged for the purpose (Moser and Kalton, 1971). To ensure content validity items definitely relating to PHDC and PIC were removed by two judges (a nurse and a doctor) to determine if the interventions retained for the experts were classified as requiring PHDC or usual ward care. To assist this process the literature relating to PHDC, although limited, was examined for information to validate the removal of certain interventions by the nurse and doctor. The document *High Dependency Care for Children –Report of an Expert Advisory Group for the Department of Health* (Department of Health, 2001a) provided a list of useful interventions that were used to aid the decision making process.

The definition of expert is problematic and subjective and ranges from an informed individual to a specialist in the field (Keeney, Hasson and McKenna, 2001). Difficulties are encountered in finding relevant individuals with a

knowledge and interest on the subject. Pre-defined criteria were clearly set at the outset of the expert consultation.

As each round of the process progresses complexities exist where there are conformists and also individuals that refuse to budge. Both individuals are damaging to the decision making process, but removing experts from a panel are only undertaken after careful consideration (Greatorex and Dexter, 2000). One of the great mysteries of this methodology is determining if the increase in agreement between rounds is due to feedback aiding agreement in a positive way or if experts have conformed to the majority view (Greatorex and Dexter, 2000). Threats to validity arise, principally, from pressures for convergence of predictions (Hill and Fowles, 1975). During Round 2 of the expert consultation study, despite some disagreement, respondents were able to express their opinions and refine their judgment using feedback from the facilitator and the descriptive statistical results.

Response rates affect the validity of a study (Hasson et al, 2000). The response rate for Round 1 was 100% although 16 missing responses were noted. Individuals who failed to respond to scenarios were removed for statistical analysis using Cohen's Kappa to maintain the Kappa rule (Kim and Lemeshow, 2001). Although successive Delphi rounds help to increase concurrent validity the same technique using case scenarios was not adopted for Round 2 of the expert consultation. A modified version of the Delphi technique was used. Adapting the method is open to criticism from other researchers as there are implications for the trustworthiness of the findings (Hasson et al, 2000).

Although a result was achieved from Round 2 of the expert consultation the same approach would not be used again. The methods were extremely complex and daunting and time was an important factor for this phase of the study. During Round 1, planned missingness by design was aborted because of the lack of clear predictors for identifying PHDC which prevented gaps to be filled in unobserved data. In addition, Round 1 did not permit discussion which was desperately required for clarification of the responses. In Round 2 discussion and clarification were vital to achieve agreement, consequently other

consensus methods, such as the Nominal Group Technique (NGT) may have proved more useful as a methodology for this phase.

The NGT is a highly structured meeting to gather information from experts. This group is facilitated by an expert and has two rounds involving nine to 12 experts (Allen, 2004). The advantages of the NGT include:

- Reaching consensus during the 2nd round.
- Elimination of ambiguity through group discussion.

Although difficult to organise a group meeting of nine to 12 experts, for four hours or more, group discussion would have allowed individuals to probe and clarify issues. However the group facilitator requires a clinical working knowledge of PHDC and good interpersonal skills to tease out the beliefs of the quieter group members, thus allowing them not to be swayed by more vocal members.

6.5 Conclusion

The Delphi technique was adapted to gather information from nursing and medical experts in the Yorkshire region, to determine consensus for items thought to be reflective of PHDC. Despite criticisms, this design was adapted for the PHDC study because characteristics of PHDC could not be determined from statistical analysis of the pilot data and therefore the expert consultation was developed later to assist in the reduction of data items. As a methodology the Delphi technique allowed the researcher to network with and involve individuals working across all paediatric specialties within the Yorkshire Region.

Two Rounds of the Delphi process were undertaken using a variety of methods; Round 1 used electronic communication as a medium, and Round 2 brought experts together for a meeting to discuss opinions generated during Round 1.

Round 1 required a good deal of time and resources to develop the definitions of expert, a level of consensus, the case scenarios and a database to analyse the information. Unfortunately the 10 experts (5 nurses and 5 doctors) did not achieve consensus. Many factors possibly accounted for this:

- Scenarios were too few with some interventions occurring on few occasions.
- Scenarios were based on clinical findings, these were not hypothetical situations. Too much information may have blurred the response of some experts, for example, the age of the child, the category of diagnosis and the frequency of observations.
- No means for discussion or clarification.

Whilst this study indicated the difficulties encountered in reaching consensus using case scenarios the researcher is not at liberty to criticise the methodology, but her approach in the way written information was provided to the experts. If this study was performed again; a different consensus approach, the NGT, would be adopted to determine agreement on items characteristic of PHDC.

Following Round 2 the PPA was refined to include all items thought to be characteristic of PHDC and PIC (to the point of stabilisation) for the main study purposes.

The expert consultation represents one stage in the knowledge development of the PHDC study and the findings do have certain limitations. However, despite a complex area of study, an attempt was made to ensure that there was reliability in the outcome. A diagrammatical representation of the Delphi process is presented in Appendix 8.

7 Main Study: Development of the Paediatric High Dependency Care Measurement Tool

7.1 Introduction

Chapter seven combines with chapters eight and nine to describe the main study. Chapters seven and eight outline the development of the PHDC measurement tool and the assessment of hospital ward staffing and daily patient activity. The quality of data is discussed in each of the chapters. Chapter nine details how the final PHDC measurement tool was applied to the original data set; firstly to quantify the volume of PHDC which was delivered to the study population and secondly, to establish the volume of care delivered by individual ward nurses at the bedside.

The PPA data collection form was used to collect demographic and clinical intervention data irrespective of the level of care (Appendix 9). This detailed information was exploited to develop a measurement tool to assess the dependency needs of hospitalised children. This chapter describes the five sequential phases of the development of the PHDC measurement tool with the methods and results evaluated at each phase.

7.2 Aim

To develop a final tool using data from the PPA for measuring PHDC activity on all types of hospital wards; DGHs, PICUs, specialist hospital wards and a DGH with specialist paediatric facilities.

7.3 Patients, Methods and Results

7.3.1 Population

Children of any age receiving one or more of 42 pre-specified treatment interventions on a hospital ward.

7.3.2   Study Design

The project was designed as a prospective cohort study of paediatric inpatients, collecting twice daily episode data from 36 hospital wards in 14 hospitals and 10 NHS Trusts in West, North and East Yorkshire over a single calendar year (2005) (Appendix 4).

7.3.3   Ethics Approval

Ethics approval was given by the Riverside London Multi-centre Research Ethics Committee (Approval number 04/Q001/7). Management approval, research governance and honorary contracts were obtained from 10 Local Research Ethics Committees from each of the 10 NHS Trusts involved by September 2004. Posters and parent information leaflets, in five languages, were distributed to all hospital wards (Appendix 10).

7.3.4   Patient Information Advisory Group: Section 60 Support

The Patient Information Advisory Group (PIAG) (http://www.advisorybodies.doh.gov.uk/piag/index.htm) granted exemption from gaining signed parental consent, for holding personally identifiable data, under Section 60 of the Health and Social Care Act (Stationary Office, 2001) in August 2004 (Approval number PIAG 2-07(m)/2004). Class support enabled the collection and processing of information for auditing and analysing the PHDC data. Section 60 was a temporary measure until pseudoanonymisation of the data could take place. The process of obtaining ethics approval and Section 60 support took a great deal of time which delayed the start of the PHDC study by 8 months (Rushforth and McKinney, 2005) (Appendix 11).

7.3.5   Phase 1: Data Collection

Demographic and clinical data were collected by nurses on the double sided A4 PPA data collection form (Appendix 9). Items recorded included hospital, ward and sex in addition to patient identifiable information collected, including name, date of birth, postcode, NHS number and hospital unit number. This latter information allowed identification of multiple admissions for the same child permitting data to be both patient and episode based. The PPA form also included a specific yes/no question for the nurse completing the form 'in your opinion is this child in need of HDC?' The PPA forms were completed for an

episode defined as the period of a day shift or a night shift and effectively covered the 24 hour day.

The decision to complete a form for any episode of a child's care was based on whether they met with one or more of the inclusion criteria (Appendix 9). Children were eligible if they had received one or more of the 42 specified intervention criteria. These intervention criteria with subdivisions for five interventions (n= 49) were identified during the expert consultation (see chapter 6). Subdivisions were provided for five interventions when two or more answers for the same intervention were possible. The 42 interventions were grouped under seven clinically appropriate headings; airway, breathing, circulation, renal, neurological, IV fluids/infusions and other (Appendix 9). For example, 'child recently extubated', was listed under the heading 'airway'.

Training sessions on form completion were delivered to staff on each hospital ward. This was facilitated by providing guidance notes (Appendix 6) with descriptors for each intervention for reference.

A total of 24,540 PPA forms, relating to 3,252 children were returned (figure 7.1). Each form represented an episode on the ward which was assessed by nurses completing the form as either PHDC or usual ward care. Forms were returned from all ward types including PICUs and episodes were assessed as PHDC or usual ward care from all these locations. It was anticipated that some children on PICU would receive PHDC as their level of care was stepped up or stepped down depending on their condition. Usual ward care was also delivered in the PICUs, as a consequence of the demand for general and specialist ward beds elsewhere and the inability to return children to these wards.

The monthly return rate for the PPA ranged from 1,726, in February, to 2,285 in October. Of the 24,540 PPAs returned 13,580 (55%) were for males, and nearly half, 12,129 (49%) were for the period of the night shift. A specified shift period was missing on 432 (1.8%) forms. Over half of all forms returned (12,696, 52%) were for episodes where children received a single intervention. Eighty six percent (n= 21,154) of all episodes of care were for children receiving three or less interventions. The maximum number of interventions a child received

during a single episode of care was 18. Of the 24,540 forms returned 10,362 (42%) were judged to be episodes of PHDC and 14,178 (58%) judged to be episodes of usual ward care by nurses. The median number of interventions received during an episode of PHDC was two (range 1-18) and during an episode of ward care was one (range 1-11). The number of episodes of care per child ranged from one to 685 this was during a single admission to hospital. Of the episodes where children received a single intervention 3,353 (26%) were for children requiring PHDC as assessed by nurses. Therefore the nurses' assessment of a child requiring PHDC could be based, either on a single or multiple interventions.

Figure 7.1   Flow chart outlining the process for the development of the measurement tool
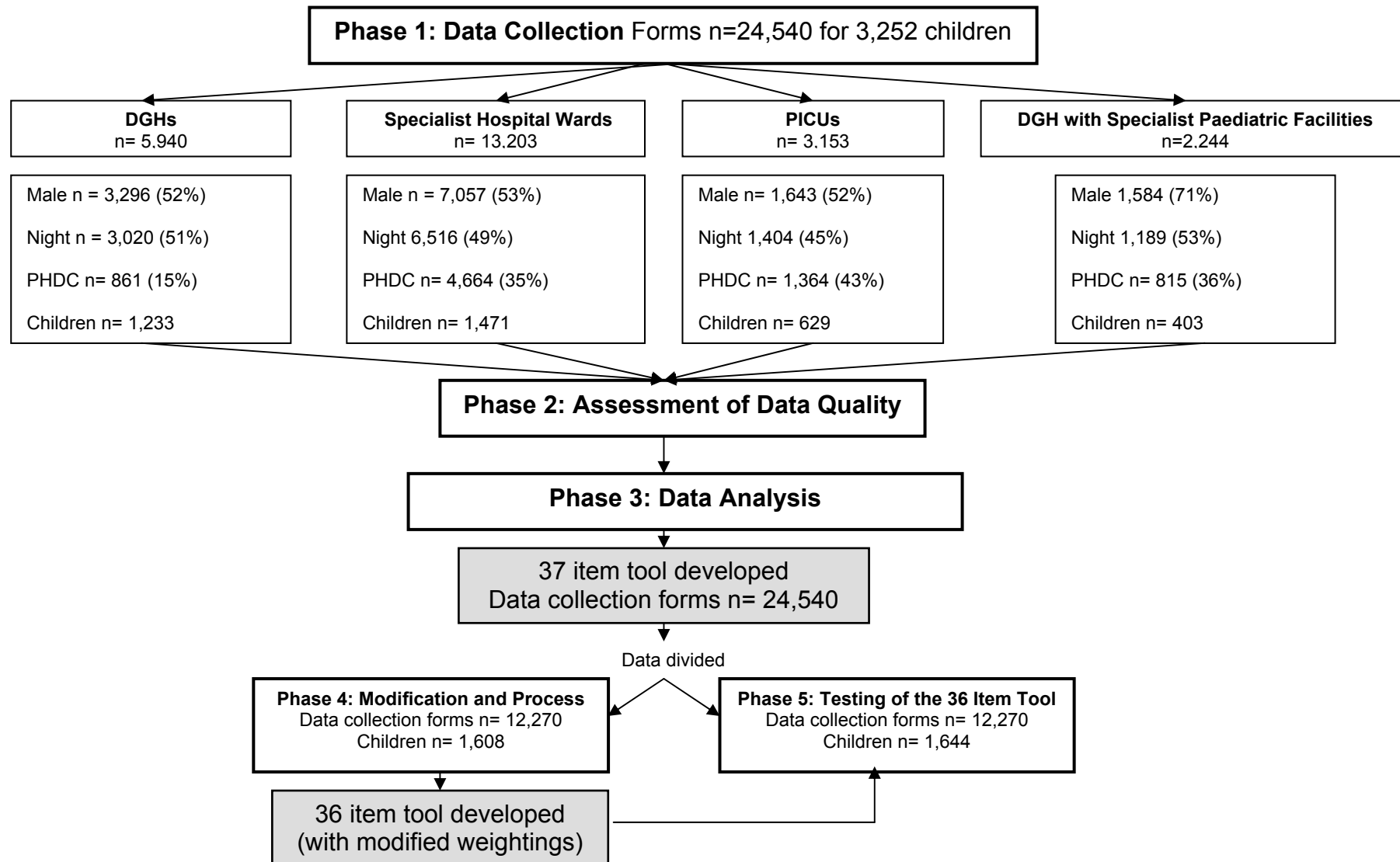
7.3.6   Phase 2: Assessment of Data Quality

Each form was subject to visual inspection prior to data input into a customised Access database with input validation and logical checks. Additional validation was undertaken through hospital visits; cross checking information on individual forms with hospital records. Both of these methods are discussed below.

7.3.6.1   Validation Checks

Monthly, on return, all PPA forms were consistently visually checked for missing demographic data. Problems with illegible handwriting were individually cross checked by the data entry clerk with the source of the data.

The NHS number was vital to map all children in the database and was frequently missing. Although the NHS number was developed for identification purposes within the health and social services, it was apparent it was not used routinely in many hospitals at the bedside, for nursing purposes. The NHS number was not recorded if it was not listed in the child's medical case notes. The child's unit number which is a unique hospital generated number was, at times, mistakenly recorded in place of the NHS number. Even when the NHS number was available within the child's case notes, it was time consuming for nurses to locate and many forms were returned for input without the NHS number. To overcome this problem of missing NHS numbers, permission was granted by the Leeds Teaching Hospitals NHS Trust for the researcher and a data entry clerk to access to the NHS Strategic Tracing Service (NSTS) for online tracing. The NSTS is a database of people, places and NHS organisations in England and Wales which informs NHS staff of the NHS number. Strict security procedures were put in place to obtain information from this electronic database. Passwords were issued by the Leeds Teaching Hospitals NHS Trust for the period of one year, and online access was limited to the 'simple' tracing service. To obtain the NHS number from the electronic database the child's name, date of birth and postcode, were required; data items that were well documented on the form. When many forms were returned for the same child, the NHS number was often only completed on a single form. The nurses expected this would be filled in by the data entry clerk. To improve accuracy and completeness of the data the NHS number was traced using NSTS.

Of the 24,540 PPA forms returned 227 (0.9%) for 27 children could not be
traced using NSTS. An NHS number was not available for children living in
Scotland, Ireland or for overseas visitors. Only 12 PPA forms for 10 British
children were without a NHS number (table 7.1).

**Table 7.1   Children remaining untraced by the National Strategic
Tracing Service**

Nationality	Availability of NHS number	Episodes of care (%)	Number of children (%)
Scottish	No	51 (0.2)	4 (0.1)
Irish	No	1 (<0.1)	1 (<0.1)
Overseas visitors	No	163 (0.6)	12 (0.4)
British	Yes	12 (<0.1)	10 (0.3)
Total		**227 (0.9)**	**27 (0.8)**

After data input the PPA data were uploaded on a monthly basis from the
Access database into SPSS V 12 (SPSS. Inc. V12.0.1, 2003) for cleaning. Data
were systematically checked for missing, inconsistent and out of range data
values and further examined by hospital ward for inconsistencies. Simple cross-
tabulations exposed anomalies in data patterns (Arts et al, 2002). Scrutinising
data by hospital ward area allowed a check to be performed of the interventions
expected for that ward area. For example, the intervention 'cardiac pacing' was
unique to two hospital wards, ward 4 and ward 10 at the LGI. Where 'cardiac
pacing' was recorded elsewhere, checks of the paper forms were undertaken to
identify input or recording errors.

Each month a PPA data quality report was returned to each hospital ward
showing the number of forms mailed to the researcher for input and the
percentages of missing variables (Arts et al, 2002). This provided the hospital
ward with a monthly feedback summary of PPA data quality and ensured a
constant review of the data by nursing staff.

An audit trail, a step by step record, by which data changes are made and
traced back to the source (Tollenare, 2000), was built into the PPA Access
database. This was a simple design that automatically recorded the date and
time of any correction, but not the operator making those changes and the

changes were not explicit, i.e. differences between the original and corrected data had to be deduced by comparing the trail and the audited data.

Examination of the missing data for all 10 demographic variables from the entire dataset of PPA forms (n= 24,540) varied as shown in table 7.2.

Table 7.2   Missing data for paediatric patient activity variables

Variable	Missing (%)
Day or Night	432 (1.8)
Date of birth	5 (0.1)
Diagnosis (free text)	3940 (16.0)
Gender	4 (<0.1)
NHS number	227 (0.9)
Patient name	0
Postcode	30 (0.1)
Reason for admission	5999 (24.0)
Shift start date	258 (1.0)
Unit number	292 (1.2)

The highest proportion of missing data was found for 'reason for admission' (5,999, 24%) (table 7.2). This information could not be inferred because the diagnosis may not have been clear on admission or the reason may have changed throughout the hospital stay. In comparison, the free text box containing information about the diagnosis was more complete with fewer missing responses (n= 3,940, 16%). A relatively small proportion of PPA forms had data missing for the remaining variables which could not be inferred from other data items.

At the outset of the study, Leeds Primary Care Trust had requested not only the number of episodes of PHDC but also an estimate of the number of children receiving PHDC living outside the Leeds area. In order to locate children by their PCT of residence, their postcode was linked to the PCT using All Fields Postcode Directory (Office for National Statistics, 2004). Postcodes were missing or invalid for 157 (2%) episodes of PHDC and for 43 (3%) children.

7.3.6.2   Hospital Visits to Assess Data Accuracy

Visits were made to each submitting ward in October 2005 to check the data on a random sample of PPA forms against patient case notes and to discuss data

collection procedures. The purposes of these visits, was to control and evaluate data quality (Arts et al, 2002).

PPA forms for validation were randomly chosen using the 'exact' option from 'random samples' in the drop down box', data' and 'select cases', in SPSS. This was a user specified method that requested an exact number of cases to generate a sample. Data received prior to the month of June was used to generate the random cases. The PPA forms were selected by NHS Trust and by the total number of patient interventions. Three categories of patients from 10 Hospital Trusts were created:

- Category A   1-3 interventions.
- Category B   4-8 interventions.
- Category C   9 interventions or greater with 'intubation and subsequent care of the ventilated child' listed as one of the nine interventions. Intubation was selected as an important variable because this would never occur as a single intervention but as one of many. A child that required this intervention would be expected to have certain other interventions as a matter of routine.

Three child PPA forms were randomly selected from each category giving a total of nine episodes per NHS Hospital Trust. Randomisation was undertaken by episode rather than by child to reduce the time and resources spent on the validation across different sites. For example one child may have received many episodes of care and the validation exercise was designed to examine different children with different care needs. Validation was limited to reviewing case notes from each of the 10 Hospital Trusts, not each hospital, to improve efficiency. Fewer than nine sets of patient case notes were requested from some NHS Trusts for the following reasons; 1) Not all hospital wards had any episodes of 'intubation and subsequent care of the intubated child' recorded before the data validation period. 2) Some randomly generated episodes related to care performed for the same child on different days or admission episodes. Eleven variables were selected to be checked for accuracy, covering missingness or incongruity as detailed in table 7.3.

Table 7.3   Paediatric patient activity variables checked for accuracy

Variable	Missing	Incongruity
Shift start date	✓	✓
Shift period (day or night)	✓	✓
Sex	✓	✓
Unit number	✓	✓
NHS number	✓	✓
Postcode	✓	✓
Date of birth	✓	✓
Diagnosis (free text)	✓	✓
Reason for admission	✓	✓
All numbered interventions		✓
Frequency of observations		✓

A total of 15 hospital visits were made to validate 73 episodes of care, for 61 children, comparing patient case notes with the PPA forms. A number of problems were encountered in obtaining patient case notes and also validating some of the variables. Seventeen (21%) sets of patient case notes were either lost, in other departments or unavailable for review. Only three (30%) Hospital Trusts were able to provide all the notes requested for review (Airedale Hospitals NHS Trust, Scarborough and North East Yorkshire Health Care NHS Trust and York Hospitals NHS Trust). Two Hospital Trusts were able to provide less than 45% of patient case notes requested (The Leeds Teaching Hospitals NHS Trust and South Tees Hospitals NHS Trust).

Certain variables on the PPA form were impossible to validate. For example, information on whether a child was nursed in a cubicle was not documented routinely in the medical or nursing notes unless there was a risk of cross infection. Also, in some instances, use of an ECG monitor was not recorded; a heart rate was noted, but the method (cardiac monitor, stethoscope or pulse rate) was not present in the notes. Of the variables checked for accuracy the following was found:

- Five (8%) shift start dates did not correspond to the dates for delivery of care in the case notes.

- Two (3%) shift periods were not entered.

- Three (5%) unit numbers were not provided but were found in the patient case notes.

- Three (5%) unit numbers were written incorrectly on the PPA form. Only one (2%) was grossly abnormal i.e. more than one digit out.

- Twenty one (34%) NHS numbers were not recorded on the PPA, with 5 (8%) of these not recorded in the patient case notes.

- Four (6%) postcodes were not recorded. Of all the recorded postcodes every one (100%) was consistent with the patient case notes.

- Sixty two (100%) dates of birth were identical for both sources.

A summary breakdown of the validation process including the overall numbers of missing and incongruous items for the 11 variables (table 7.3) is shown in table 7.4 by each NHS Hospital Trust. Missing values and incongruity were most prevalent at Bradford Teaching Hospitals NHS Foundation Trust and least prevalent at South Tees NHS Hospital Trust. However the latter hospital only made two sets of patient case notes available for review (table 7.4).

Table 7.4   **The data quality of paediatric patient activity data by Hospital Trust**

Hospital Trust	Number of visits	Number of case notes requested	Number of case notes reviewed (%)	Number of episodes of care reviewed against patient case notes	Missing values	Incongruity	Total
Airedale NHS Trust	1	7	7 (100)	9	4	10	**14**
Bradford Teaching Hospitals NHS Foundation Trust	1	9	7 (78)	7	8	17	**25**
Calderdale and Huddersfield NHS Trust	2	9	5 (55)	5	5	6	**11**
Harrogate and District NHS Foundation Trust	2	9	8 (89)	8	9	13	**22**
Hull and East Yorkshire Hospitals NHS Trust	1	8	7 (87)	8	4	12	**18**
Scarborough and North East Yorkshire Health Care NHS Trust	1	6	6 (100)	9	8	8	**16**
South Tees Hospitals NHS Trust	1	5	2 (40)	5	1	0	**1**
The Mid Yorkshire Hospitals NHS Trust	3	9	7 (78)	8	3	17	**20**
The Leeds Teaching Hospitals NHS Trust	2	9	4 (44)	4	5	6	**11**
York Hospitals NHS Trust	1	8	8 (100)	9	10	11	**21**
Total	**15**	**79**	**61**	**72**	**57**	**100**	**159**

Validation of interventions recorded for the 73 episodes of care showed that only 37 (76%) of the possible 49 interventions were recorded on the PPA forms. Table 7.5 illustrates that of the 37 interventions recorded, 18 (49%) interventions were correctly recorded on the forms according to the information in the patient notes. For 55 (20%) interventions, inconsistencies were found between the PPA forms and the patient case notes. The intervention with the greatest discrepancy (n= 10) recorded on the PPA form but with no record in the patient case notes was complex fluid balance. Two interventions, bag and mask ventilation and GCS 9-12, were noted in patient case notes, without being recorded on the PPA.

Table 7.5   Inconsistencies between paediatric patient activity forms and patient case notes

Intervention	Number of form positives	Number of patient case note positives	Inconsistencies
Oxygen therapy	20	20	0
Seizures	8	8	0
Airway suction	5	5	0
Vasoactive drug	5	5	0
Sedation	5	5	0
Apnoeas	3	3	0
Recent extubation	3	3	0
Deteriorating conscious level	3	3	0
CPR	3	3	0
Multiple lines	3	3	0
CVP monitoring	2	2	0
Chest drain <24 hrs	2	2	0
Chest drain ≥ 24 hrs	1	1	0
Tracheostomy care (est)	1	1	0
Nebulised medication	1	1	0
Domiciliary ventilation	1	1	0
Transfusion	1	1	0
Cardiac pacing	1	1	0
Intubation	12	11	1
Pain relief (IV, epidural)	11	10	1
Bag mask ventilation	8	9	1
GCS<8	6	5	1
GCS 9-12	4	5	1
Warming/cooling	3	2	1
CPAP	2	1	1
Nasogastric feeding	20	18	2
Blood sampling	13	11	2
Frequent position changes	11	9	2
Dressing changes	5	3	2
Arterial line monitoring	4	2	2
Multiple IV bolus	17	14	3
Fluid resuscitation	11	7	4
Continuous drug infusion	18	13	5
Hourly urine output	13	8	5
Replacement of fluid losses	12	7	5
Airway adjunct	8	2	6
Complex fluid balance	24	14	10
Total	**270**	**219**	**55**

* Number of inconsistencies will not add to number of patient case notes to equal number of total PPA form positives.

7.3.7   Phase 3: Data Analysis

The range and complexity of interventions provided to children requiring PHDC were known to vary by hospital ward types. The DoH in 1997 (Department of Health, 1997a) outlined four hospital types that unified PIC services and this template was used to stratify the hospital wards (see chapter 1, table 1.1) into four separate categories; 1, district general hospitals (DGHs); 2, paediatric intensive care units (PICUs); 3, specialist hospital wards and 4, DGH with specialist paediatric facilities. An example which illustrates the need for separate categories is PHDC delivered within a PICU where treatment is potentially likely to be more clinically invasive, than in other settings such as a DGH general children's ward, because of the number of routinely used arterial and CVP lines.

A number of formal statistical methods were applied to the data to distinguish PHDC from usual ward care and intensive care. Exploratory FA was attempted, but proved unhelpful as consequence of the inability of many variables to load onto a factor (Tabachnick and Fidell, 2001). Regression Tree Analysis was then considered as an alternative approach for analysis because of its ability to deal with complex interactions and to classify patients into clinically important categories (Lewis, 2000). However, because of the complexity of the statistical analysis, the difficulties in understanding the software and the software costs (Lewis, 2000), this method was not pursued. In the absence of a suitable formal statistical method a pragmatic, but systematic and complex approach was developed based on the data combined with expert knowledge of the clinical setting. This ensured that the final measurement tool made 'good clinical sense'.

The first step in the process was to make sense of the data. Letters (a-z, A-W, n= 49) were assigned to each intervention or subdivision of interventions. These letters were strung together to form a 'cluster code' for an individual episode (table 7.6). Each cluster of letters was then given a unique numerical code which made it possible to quantify the number of combination of interventions and the frequency with which each combination occurred. Table 7.6 gives an example of this procedure.

Table 7.6   Example of assigning cluster codes and unique numerical codes

Episode of care	Intervention				Cluster code	Unique code
	Position change	Oxygen therapy	Frequent suction	CPAP		
1	A	b	C	d	AbCd	73
2	A		C		AC	20
3		b	C	d	bCd	21
4			C		C	5
5		b	C		bC	19

The results of this procedure gave a vast number of unique combinations of interventions (n= 3,255). Some combinations of interventions occurred only once. The maximum number for a combination of interventions was 2,562.

The next step in the process was to look at each intervention to examine its coexistence with other interventions and to determine the relative importance of each intervention with the outcome measure i.e. whether nurses had assigned the episode of care to usual ward care or PHDC. This exercise was completed independently for the four categories of ward type.

An illustration of this procedure is given in table 7.7, an example from DGHs where the PPA form recorded the intervention 'care of a child with an established tracheostomy'. This was recorded as occurring as a single intervention for 407 episodes of care, of which 41% required PHDC as assessed by nurses. When this was recorded in combination with frequent suctioning (i.e. for 126 episodes of care), 87 (69%) were assessed as requiring PHDC. When the care of a child with an established tracheostomy was recorded with 'frequent suctioning' and 'oxygen therapy', although this was only recorded for seven episodes, 100% required PHDC according to nurses. Established tracheostomy never occurred as an intervention with more than 3 coexisting interventions (table 7.7).

Table 7.7   Example of a cluster table for an established tracheostomy (ward group: DGHs)

Number of interventions	Frequency of total occurrence	Co-occurring interventions (unique code)		Frequency of combined occurrence (%)	Requiring PHDC as assed by nurses (%)
1	407	Trachy (est) (1070)			168 (41)
2	304	Trachy (est) + S (1224)		126 (41)	87 (69)
		Trachy (est) + P (1076)		110 (36)	0
		Trachy (est) + DV (1182)		45 (15)	1 (2)
			Total	**281 (92)**	
3	401	Trachy (est) + S + P (1227)		342 (85)	168 (49)
		Trachy (est) + S + NG (1230)		23 (6)	19 (83)
		Trachy (est) + S + O^2 (1231)		7 (2)	7 (100)
			Total	**372 (93)**	
4	31	Trachy (est) + S + P + DV (1195)		12 (39)	12 (100)
		Trachy (est) + S + NG + O^2 (1133)		5 (16)	4 (80)
		Trachy (est) + S + NG + BMV (1179)		5 (16)	5 (100)
			Total	**22 (71)**	

Key
S = Frequent suction
P = Position change
DV = Domiciliary ventilation
NG = Nasogastric tube
O^2 = Oxygen therapy
BMV = Bag mask ventilation

The cluster tables for each intervention (example in table 7.7) permitted the quantification of interventions and their combinations that occurred for the majority of episodes that required PHDC. The cluster tables also informed the weight and place of importance of interventions on the measurement tool. Clinical expertise was also an important factor as interventions were known not to be of equal importance in the context of PHDC. Interventions could be defined not only by the number of interventions delivered together, but also by a clinically important single intervention. For example where care was provided for a child requiring CPAP as a single intervention, 70%, 79% and 82% were assessed as requiring PHDC by

nurses at the DGHs, the specialist hospital wards and the DGH with specialist paediatric facilities respectively.

These cluster analyses and expert clinical evaluation showed that PHDC was represented by 37 interventions that may occur singly or in combination. From this a 37 item measurement tool was developed which put each intervention into one of three differently weighted categories. The system of weighting was developed for the following reasons:

- Some children required only one intervention to meet with PHDC, according to nurses, as described with the intervention CPAP in the above paragraph.
- Some children required a combination of interventions to meet with PHDC as assessed by nurses.
- The majority (86%) of all episodes of care were for children receiving three or fewer interventions of varying clinical significance.
- To maintain simplicity of the tool.

There were two sources of evidence for categorising the relative importance of weights for the different interventions in the assessment of PHDC. Firstly, the PPA data where nursing assessment of PHDC was linked to intervention information (see table 7.7) and secondly, the clinical experience of the researcher. In order to distinguish between the more and less important interventions it was theoretically appropriate to assign a weight to the interventions (Streiner and Norman, 2001). In situations where large numbers of items are present within a scale (≥ 40) weighting contributes very little but with fewer than 40 items weighting may have an effect (Streiner and Norman, 2001).

Each intervention was assigned to one of three groups, A, B or C. Group A, was assigned the maximum weighting and represented the most clinically serious interventions and included 'intubation and subsequent care of the ventilated child' and 'CPAP'. Group B contained interventions with a medium weighting for example use of 'airway adjunct'. Interventions in group C had the lowest weighting and

included for example 'continuous IV drug infusion'. Individual interventions within the groups A, B and C were given the same numerical weight. The assignment of the figure to each group was a somewhat arbitrary procedure as no such tools previously existed for reference or with which to make a comparison (Streiner and Norman, 2001). For any single form, the scores were added and a score of six points or more, for an episode of care, was deemed to require PHDC. Less than six points indicated usual ward care. The total score was accumulated from any of the A, B or C groups; three interventions in group C scored six points.

In order to test agreement between an assessment of PHDC from the total scores of the 37 item tool with nursing opinion, the Kappa statistic (Cohen, 1960) (K) was applied. This measured levels of agreement or concordance between the two sources. The results of applying the test to the entire dataset (n= 24,540 episodes) are given in table 7.8. Overall the Kappa value reached moderate agreement (K = 0.4), but the results varied considerably by hospital ward type, ranging from poor agreement for PICUs (K = 0.1) and DGHs (K = 0.2) to moderate agreement at the DGH with specialist paediatric facilities (K = 0.5). Overall the 37 item tool had reasonable levels of agreement between data sources but it failed when testing within ward areas. To improve the levels of agreement, particularly in the PICUs and the DGHs, the 37 item tool was re-examined and modified with a view to further testing of agreement.

Table 7.8   Levels of agreement (Kappa values) between nursing opinion and the 37 item measurement tool by ward location

Number of data collection forms	Number of tool items	Kappa values by hospital ward type				
		Overall	District general hospitals	Paediatric intensive care units	Specialist hospital wards	District general hospital (specialist paediatric facilities)
24,540	37 items	0.38	0.22	0.10	0.39	0.50

7.3.8   Phase 4: Modification and Process

To further refine the measurement tool with the aim of improving concordance between the tool assessment and nursing opinion it was decided to split the data (n= 24,540) into two separate datasets. This would allow modification and testing on one set of data with a view to re-testing and confirming on the second dataset. The data was randomly separated, taking account of patient demographics, geographical location, ward type and level of care as assessed by nurses.

The first 50% dataset was subjected to two separate processes:

- Binary logistic regression (Kinnear and Gray, 2000) was applied in an attempt to group the data by predicting the odds of a certain event happening. The outcome or dependent variable was the opinion of nurses as to whether the episode was PHDC or usual ward care. All independent variables (each intervention) were included in the model and parameter estimates were calculated.

  The results of the analysis failed to provide any additional information to support the grouping of interventions because the ranking of the odds ratio similarly compared to the ranking of interventions by nursing opinion (table 7.9). Despite this, it was used as a guide to establish the precision of estimates. For example, the odds ratio for established tracheostomy was 2.50 with a 95% confidence interval (2.22 to 2.81). This suggested that established tracheostomy was one of the stronger predictors for PHDC (table 7.9).

- Focused expert evaluation and inspection of the discordant data from the two ward locations DGHs and PICUs, where nursing opinions and tool did not agree. This is further discussed.

Table 7.9 **Binary logistic regression, rank of Odds Ratio and PHDC according to nursing opinion, for each intervention (50% data)**

OR Rank	Intervention	OR	CI		PHDC rank	Number of episodes	Nursing opinion for PHDC (%)
			Lower	Upper			
1	EVD	6.68	3.83	11.63	1	87	72 (83)
2	Vasodrug	6.18	4.70	8.14	2	339	275 (81)
3	Bag mask	5.22	3.49	7.84	3	142	112 (79)
4	Apnoeas	5.03	2.89	8.77	4	74	58 (78)
5	Cardiac pacing	4.76	2.27	10.01	5	40	31 (77)
6	Dressing changes	4.72	3.65	6.12	6	327	251 (77)
7	Domiciliary ventilation	4.61	3.66	5.81	7	407	310 (76)
8	GCS< 8	4.24	2.37	7.61	8	61	46 (75)
9	CPAP	4.20	3.31	5.34	10	175	130 (74)
10	Fluid resuscitation	4.05	2.88	5.70	9	362	270 (74)
11	Hourly urine output measure	3.99	3.49	4.58	13	242	178 (73)
12	Warming/cooling	3.92	2.95	5.24	11	358	262 (73)
13	CVP	3.90	3.08	4.95	12	1123	808 (72)
14	Complex fluid balance	3.84	3.46	4.27	17	44	31 (70)
15	Arterial line	3.41	2.79	4.18	15	465	327 (70)
16	Nebulised adrenaline <2 doses	3.29	3.30	6.30	14	130	91 (70)
17	GCS 9-12	3.25	2.23	4.74	16	1914	1327 (69)
18	Recent extubation	3.11	3.11	3.09	18	450	308 (68)
19	Chest drain <24 hrs	2.77	1.82	4.22	21	9	6 (67)
20	Intubation	2.77	1.81	4.25	20	96	64 (67)
21	Replacement of fluid losses	2.77	2.41	3.20	22	99	66 (67)
22	Nebulised adrenaline >2 doses	2.75	0.69	11.01	19	898	585 (65)
23	Sedation during after procedure	2.61	2.05	3.33	23	294	191 (65)
24	Established tracheostomy	2.50	2.22	2.81	25	395	248 (63)

Table 7.9 continued

OR Rank	Intervention	OR	CI		PHDC rank	Number of episodes	Nursing opinion for PHDC (%)
			Lower	Upper			
25	Multiple IV lines	2.38	1.94	2.94	24	1317	819 (62)
27	Oxygen > 50%	2.34	2.08	2.64	26	1242	757 (61)
27	Frequent suction	2.20	1.86	2.61	27	590	358 (61)
28	Seizures	2.00	1.57	2.56	28	275	162 (59)
29	New tracheostomy	1.87	0.86	4.09	29	26	15 (58)
30	Pain management	1.85	1.67	2.05	30	1641	907 (55)
31	ICP monitoring	1.72	0.46	6.41	46	28	15 (53)
32	CPR	1.58	0.76	3.34	31	58	31 (53)
33	Cardiac arrhythmia responded	1.58	0.48	3.93	32	98	52 (53)
34	Nebulised medications	1.56	10.05	2.33	33	422	212 (50)
35	Chest drain >24 hrs	1.40	1.16	1.71	34	14	7 (50)
36	Multiple IV bolus	1.40	1.26	1.56	38	375	186 (50)
37	Frequent position changes	1.39	1.20	1.63	37	689	344 (50)
38	Cardiac arrhythmia not responded	1.37	0.99	2.66	35	1533	757 (49)
39	GCS 13-15	1.36	1.11	1.68	36	345	169 (49)
40	Airway adjunct	1.33	1.08	1.65	39	3018	1345 (44)
41	NG feeding	1.14	1.05	1.24	40	837	359 (43)
42	Continuous IV drug infusion	1.06	0.96	1.17	42	2243	974 (43)
43	Frequent blood sampling	1.03	0.90	1.19	41	47	18 (38)
44	Haemodialysis	0.85	0.47	1.54	43	645	199 (31)
45	Peritoneal dialysis	0.68	0.35	1.34	45	39	13 (33)
46	Blood transfusion	0.59	0.50	0.71	44	9	3 (33)
47	TPN	0.41	0.37	0.47	47	1698	429 (25)

Focused expert evaluation and inspection of the DGH and PICU discordant data

The intervention data from the two most discordant subsets (PICUs, DGHs) was examined to identify the underlying reasons for the poor level of agreement between the tool and nursing opinion. Firstly, the letters or cluster codes (see table 7.6) for the discordant episodes were examined. These identified the interventions or combination of interventions that were most common in the discordant data. The letters or sequence of letters that were, most often, not in agreement with nursing opinion are shown in table 7.10.

Table 7.10   Comparison of concordant and discordant data on assessment of PHDC in DGHs and PICUs for the first 50% dataset

Letter and Intervention	Episodes of care in PICUs (n= 1,592)		Episodes of care in DGHs (n= 2,937)	
	Concordant data (n= 1066) n (%)	Discordant data (n= 526) n (%)	Concordant data (n= 1913) n (%)	Discordant data (n=1024) n (%)
B CPR	4 (0.4)	3 (0.6)	7 (0.4)	10 (1.0)
j Bag/mask ventilation	54 (5.0)	8 (1.5)	33 (1.7)	19 (1.9)
a Endotracheal intubation	27 (2.5)	10 (1.9)	24 (1.3)	20 (2.0)
i CPAP	175 (16.0)	65 (12.0)	31 (1.6)	5 (0.5)
E CVP monitoring	206 (19.0)	90 (17.0)	0	0
c Child recently extubated	230 (22.0)	119 (23.0)	21 (1.0)	16 (1.6)
D Invasive arterial line pressure monitoring	264 (25.0)	135 (26.0)	8 (0.4)	1 (0.1)
s Complex fluid balance	326 (31.0)	142 (27.0)	112 (6.0)	89 (8.7)
h Oxygen ≥50%	134 (13.0)	57 (11.0)	135 (7.0)	226 (22.0)
R Frequent position changes	7 (0.7)	3 (0.6)	135 (7.0)	246 (24.0)

The concordant and discordant interventions will not total because an episode of care may involve more than 1 intervention.

Of the 1,592 (50% data) episodes delivered within the PICUs, a total of 526 (33%) episodes were discordant. For situations where nurses had not assessed an episode of care as requiring PHDC, examination of individual interventions showed that five variables, bag and mask ventilation, endotracheal intubation, recent extubation, CPAP and CPR were considered, in the opinion of the

researcher, to be of high intensity. They would only have been performed on very sick children and were considered separately to represent PHDC or a higher level of care. Further episodes that could only have been delivered to very sick children involved combinations of interventions; these included 142 (27%) discordant episodes which required five or more interventions. Of the 142 episodes, 95 (67%) episodes required an arterial line and 73 (51%) episodes required a CVP line, 69 (49%) of the 142 episodes required both arterial line and CVP line.

One explanation of why nurses in PICU did not assess many episodes as requiring PHDC was they considered them as high intensity and requiring PIC (bag mask ventilation, endotracheal intubation, recent extubation, CPAP, CPR) and arterial line monitoring and CVP monitoring, when reported with four or more interventions. For locations outside PICUs, 116 (92%) of episodes of invasive arterial pressure monitoring were judged by nurses to require PHDC.

The other location where there was a high proportion of discordant data was at the DGHs, where 1,024 (35%) discordant episodes occurred. The main interventions which accounted for lack of agreement were 'oxygen therapy' (n= 226, 22%), 'frequent position changes' (n= 246, 24%) and 'complex fluid balance' (n= 89, 9%) (table 7.10). The discordant episodes for 'oxygen therapy' and 'complex fluid balance' were positive for nursing opinion of PHDC with the 37 item tool not scoring PHDC. In contrast the discordant episodes of 'frequent position changes' were positive for the PHDC measurement tool but nursing opinion suggested usual ward care. The interventions, that were in the opinion of the researcher, thought to be intensive in the PICUs ('CPR', 'CPAP', 'bag and mask ventilation', 'endotracheal intubation' and 'child recently extubated') were also reported as discordant at the DGHs (table 7.10). For example 10 (1.0%), 19 (1.9%), 20 (2.0%), 5 (0.5%) and 16 (1.6%) of episodes were discordant for nursing opinion and the 37 item tool for the interventions 'CPR', 'bag and mask ventilation', 'endotracheal intubation', CPAP and 'child recently extubated' respectively.

In the opinion of the researcher, for the DGHs, three interventions were assigned incorrect weightings because complex fluid balance, oxygen greater

than 50% and frequent position changes comprised; 8.7%, 22% and 24% of all discordant episodes respectively (table 7.10). Complex fluid balance and oxygen therapy had been given a low weighting of two points, yet the discordant episodes were positive for nursing opinion. Frequent position changes had also been given a weighting of two points, yet the discordant episodes were positive for the 37 item tool. Therefore, a decision was made to remove frequent position changes from the PHDC measurement tool and to re-assign oxygen therapy and complex fluid balance to group B giving a medium weighting of four points.

In summary, the focused assessment of discordant data from the PICUs and the DGHs provided evidence for four recommendations for change to the 37 item measurement tool (table 7.11).

Table 7.11   Recommendations for changes to be made to the 37 item measurement tool

Change	Description of the changes made to the 37 item measurement tool
1	Recode all episodes of care for interventions thought to require IC (bag mask ventilation, endotracheal intubation, recent extubation, CPAP and CPR) as PHDC.
2	Recode all episodes of care for invasive arterial pressure monitoring and CVP monitoring as PHDC.
3	Reassign complex fluid balance and oxygen therapy to medium weighting (the primary PHDC measurement tool gave a low weighting) to both of these interventions (discordant episodes of care were positive for nursing opinion).
4	Remove frequent position changes (discordant episodes of care were positive for the PHDC measurement tool) from the PHDC measurement tool.

These recommended modifications were implemented resulting in the 36 item tool (Appendix 12).

7.3.9   Phase 5: Testing of the 36 Item Tool

The purpose of phase five was to test the modified 36 item tool using the Kappa statistic on the second half of the dataset to determine whether the levels of agreement between nursing opinion and the modified tool were improved. Table 7.12 shows that the Kappa values improved both overall and at all locations of care; the greatest improvement was seen in the PICUs with the Kappa statistic increased from 0.1 to 0.4. Therefore, although the practical decision taken to evaluate and inspect the discordant data, in 50% of the data, was the only option for the researcher, the resulting recommended changes to the 37 item tool brought the levels of agreement between the 36 item tool and nursing opinion closer.

Table 7.12   Levels of agreement (Kappa values) between nursing opinion and the 37 and 36 item measurement tool by ward location

Number of data collection forms	Number of tool items	Kappa values by hospital ward type				
		Overall	District General Hospitals	Paediatric intensive care units	Specialist hospital wards	District general hospital (specialist paediatric facilities)
24,540	37 items	0.38	0.22	0.10	0.39	0.50
*12,270	36 items (test retest)	0.49	0.39	0.40	0.41	0.53

*second 50% dataset

7.4   Discussion

The evolution of the final PHDC measurement tool accounted for issues of design and usability, but more importantly the difference in the acuity of interventions representing paediatric care within each of the three groups labelled A, B and C (Appendix 12). The 14 interventions in group A were assigned a maximum score of six points, the 15 interventions in group B, were assigned a medium score of four points and the seven interventions in group C, the lowest score of two points. The weighting of interventions allows a score to be given to an episode of care with a total score of six points indicating PHDC. This can range from a single intervention in group A to a number of interventions from group B or C (Appendix 12). This scoring system is

innovative in that it allows quantitative comparison between PHDC and usual ward care based on a 'number' with six points or more indicating PHDC and any lower figure representing usual ward care.

The clinical experience of both the researcher and other nursing and clinical experts from the region was fundamental to the process of developing the PHDC measurement tool. Collaboration between disciplines and organisations is key to good health service research (Black, Barker and Payne, 2004), and this project provides a successful example of cross discipline and multi-organisation research within the NHS.

One of the important aspects of research using patient identifiable data was the protection of clinician and patient privacy and the rights of patients' or their guardians. This project obtained approval from the MREC, LREC, and the PIAG for Section 60 support and although this process was time consuming and costly, it had many positive benefits. It raised awareness for the researcher and all healthcare professionals involved in the study regarding the legislative requirements to protect confidentiality (Rushforth and McKinney, 2005) (Appendix 11). A detailed account of the application process for ethics approval, and Section 60 support, the legislation and guidance affecting consent and confidentiality in the UK and the adverse events surrounding consent and confidentiality in clinical paediatric practice has been published from this thesis (Appendix 11).

The experience of clinical staff was exploited and used in conjunction with the interventions recommended by the Department of Health (2001a), to develop the data collection forms and subsequent measurement tool. At the commencement of this study criticisms were levied by the researcher on the subjective nature of the interventions defining PHDC in the literature. As a consequence particular attention was paid to the severity parameters for the study of PHDC which set time, or volume limits for all interventions listed on the data collection forms, and thus, prevented nurses from using their own judgment (see guidance notes, Appendix 6). Views, particularly, of nursing staff in 11 DGHs, where many children received not only PHDC but also PIC until a transport team retrieved the child for admission to a PICU, were sought before

and during the development of the measurement tool. This ensured that the tool was relevant for clinical practice.

The study was conducted for one full year to include the winter peak, and associated increase in respiratory problems, and the summer trough in admissions. The data collection period was particularly onerous for nursing staff, yet the hard work and dedication afforded to the collection process generated a large quantity of high quality data that were fit for purpose (Sheldon, 2003). The constant feedback from the researcher to clinical staff on the wards, via monthly feedback reports, played a key role in motivating the continuing efforts of the staff over a long data collection period.

Planned and systematic procedures to promote data quality and rigor were continued throughout the project with regular validation checks on computerised data and a separate validation exercise with patient hospital records involving hospital visits. The range of completeness showed high variability depending on the type of PPA data. Incomplete (missing) demographic data ranged from less than 0.1% (date of birth, sex, NHS number) to 24% (reason for admission). Date of birth, sex and NHS number contained small amounts of incomplete data, but the incomplete data for 'reason for admission' appeared extreme when compared to a data quality study by Arts et al (2002) who found only 3% of these data, incomplete in a large medical registry for a hospital with manual data entry. Other registers report variable data quality. For example cancer registration data collected from 1998 to 2000, by the Northern and Yorkshire Cancer Registration and Information Services (NYCRIS), found that 15.5% of data was incomplete for the stage of cancer and 19.5% was incomplete for grade of cancer at diagnosis (Adams, White and Forman, 2004). This suggests that there are variations in the quality of registers and clinical databases and it cannot be assumed that they are complete and reliable.

The hospital visits made by the researcher to validate the PPA forms against patient case notes revealed variable quality of patient records. Although it was relatively easy to validate the demographic variables (e.g. NHS number, date of birth) recorded on the PPA with the patient case notes, the interventions noted on the PPA forms, performed on a daily basis were not always recorded in the

case notes by the clinical staff. In total, 20% of all interventions failed to be validated against patient records. At times, clinical entries for treatment and care on specific days was missing and nursing paperwork, drug and fluid prescription charts, fluid and observation charts were not dated or present in the patient case notes. This exercise of validating interventions against documented evidence in the patient case notes, served to highlight the lack of detail written about the daily care for many children and the lack of order within case note folders. Loose sheets also added to the chaos of case notes. Although problems associated with case note filing and record keeping have been documented (Audit Commission, 1999; Mann and Williams, 2003) the standard is variable (Mann and Williams 2003). The validation process revealed that none of the NHS Hospital Trusts within the Yorkshire region achieved a high standard of record keeping; all could have improved their record keeping and the content of their case notes. This highlights a need for paediatric services to improve the overall quality and organisation of information in patient case notes.

Specific difficulties were encountered validating essential items for the project. Some of the more serious of interventions such as CPR, apnoeic episodes and tracheostomy care were recorded and signed, but some information on interventions had to be gleaned from other paper sources (fluid balance charts, prescription charts etc), this made validation difficult and in some cases impossible. A further problem for the researcher was validating a 12 hour period of care either a day or a night shift when only one record of care was made in a 24 hour period by medical staff. Owing to the poor state and lack of structure of many patient case notes, it was impossible to determine if the source of discordance was a result of nurses incorrectly completing the PPA or the lack of information in the patient notes. Time may have been a limiting factor for staff in completion of the nursing and medical notes particularly with respect to the intricacies of multiple clinical interventions.

There were many limitations and unanticipated difficulties that occurred during the course of the development of the measurement tool. The complexity of the data did not lend itself to standard statistical testing, and consequently a systematic evaluation was undertaken grounded in expert clinical knowledge of clinical practice. The definition of PHDC for an episode of care was based on

nursing opinion as the outcome measure. No gold standard was available and the only realistic way to record whether an episode was PHDC was to ask nursing staff as they provided care. The limitations of this are acknowledged. The expert consultation (chapter 6) established that agreement between clinical staff, particularly nursing staff, on the assessment of episodes of care was poor. However the expert consultation itself had limitations as the Delphi exercise looked at paper based specific theoretical scenarios with a limited number of interventions. In clinical practice, at ward level decisions may be different to those presented in written scenarios. Other scoring tools, for example early warning scores, developed in the adult and paediatric areas to detect deterioration in physical status have reported similar difficulties in assessing clinical outcomes (Ball et al, 2003; Buist et al 2002; Monahan, 2005; Haines et al 2006; Morgan, Parslow and Whiteley, 2008; unpublished); yet once scoring tools are introduced into the clinical setting, validation becomes extremely difficult (McGaughey et al, 2007).

The inability of statistical methodology to group interventions defining PHDC resulted in a pragmatic, but systematic and clinically based approach to examine the co-dependence of interventions and the assigning of weighting to interventions within the tool.

The first 37 item tool showed considerable variation in performance by location of care with poor concordance between nursing opinion and the assessment of PHDC especially in DGHs and the PICUs. This was possibly due to two factors:

1. Differences in the local experiences and expertise of the nurses with those in DGHs 'over assessing' PHDC, and those in PICU 'under assessing'.
2. A fault in the original questionnaire which did not ask the question 'is this child in need of PHDC or higher level care?'

Thus an explanation for the poor agreement between the PHDC 37 item measurement tool and nursing opinion may have been that some children were assessed by nurses as being in need of PIC, not PHDC.

Close examination of the data accounting for the poor agreement resulted in refinement of the tool, reducing the number of interventions to 36, and changing the weighting of some interventions. The performance of the refined 36 item tool improved assessment of PHDC, to become more uniform across the whole region, particularly at the extremes of paediatric care, i.e. in the PICUs and the DGH general hospital wards. This improvement was demonstrated in the Kappa scores where overall and at all locations values of the test statistic were increased with the 36 item tool.

The Kappa statistic values showed that agreement between nursing opinion and the measurement tool in assessing PHDC represented 50% (overall) of the potentially achievable agreement beyond chance or 'moderate agreement'. This level of 'moderate agreement' has been generally acceptable in this type of research (dos Santos Silva, 1999). One of the advantages of this project was the ability to compare Kappa values before and after modification of the tool on independent sections of the data.

One of the questions for this project was whether any of the children on the wards who fulfilled the criteria for PPA form completion failed to have forms submitted. The possibility of addressing this was discussed, but it was agreed by the study Steering Group this was not a priority, principally because of time constraints. The resources for conducting such an evaluation for 36 separate hospitals were not available. Therefore it was not determined whether the case mix of children missed and children reported was different. A large volume of data was accrued by the study from many different locations from a wide range of staff and it was deemed unlikely that systematic differences in form submission would have occurred for any particular subgroup of children, or types of episodes. Examination of the data by ward location showed that the distribution of the demographics of the children and their reasons for admission were not substantially different.

7.5   Conclusion

The need to define PHDC has evolved in response to the need for the recognition of children at risk of deterioration and their management. The study was undertaken with the support, encouragement and oversight of local

commissioners and a wide range of healthcare professionals who recognised the potential usefulness of the project both locally and nationally. A key outcome was the 36 item tool to measure PHDC across all locations of care including care provided in the PICUs and the DGHs. It was developed from a large empirical dataset, and as a process measure is likely to aid judgment with respect to the quality of PHDC provided to children (Lilford, Brown and Nichol, 2007).

The design of the tool made it relatively easy to use with small numbers of listed recordable interventions, easily summed to provide a total score. Six points or more defines a child in need of PHDC; a score of less than six points defines usual ward care. Thus; the boundary between PHDC and usual ward care has been defined by the tool although the boundary between PHDC and PIC was not established. The facility to distinguish between PHDC and PIC was not the one of the fundamental aims of this study.

The collection of large amounts of high quality data offers the opportunity to provide accurate information to clinicians, researchers and patients to improve the outcomes of care (Audit Commission, 2002). Nevertheless, no data base will be completely free from errors and some will remain regardless of the systematic procedures in place (Arts et al, 2002). A great deal of time and attention was devoted to data quality issues for the PHDC study. The process of data cleaning was ongoing throughout the data collection period (2005). Gaining access to the NSTS and patient's NHS numbers was a vital component of this study's commitment to data quality, overcoming the absence of this data item in patient case notes.

The data validation exercises were important to assessing data quality but the extent of the cross checks of forms with patient records was limited by available resources. One important finding from this process was the inadequacy of the information available in patient records. Twenty percent of the interventions recorded as being performed for children receiving care on the PPA forms could not be confirmed because the information was not dated or not present.

One of the difficulties encountered in analysing the data has been the assessment of PHDC in the absence of a definitive measurement or 'gold standard'. The outcome was dependent upon the interpretation of the meaning of PHDC by nurses completing the forms. This may have been affected by local practice, nursing grade and clinical experience. With such a large number of paediatric ward specialities involved in the study many nurses of all grades and levels of experience completed forms. Therefore, they were likely to be representative of the 'nursing population', however; it would be advisable for future studies to take account of the grade and experience of nurses completing the forms to ensure consistency of nursing opinion. The final 36 item PHDC measurement tool was developed from a large primary dataset subject to rigorous data quality checks. Although formal statistical testing failed to support its evolution, the importance of clinical expertise and clinical relevance underpinned all phases of the work. The application of the tool to a wider setting in the UK is feasible but the need to take account of the variations in clinical practice in different locations would be an important adjunct to using the tool outside Yorkshire.

8 Main Study: Assessment of Ward Staffing and Daily Patient Activity

8.1 Introduction

For parents there can be few events more worrying than the admission of their child to hospital with a critical illness. When this occurs it is expected that there will be sufficient technical resources available for continuous monitoring of vital signs, but also that the correct number of skilled clinical staff will be present on the ward to intervene quickly, prevent further deterioration and where possible promote a fast recovery, or ensure timely admission to the ICU. The standards provided by the Department of Health (1991; 1997b; 2001a; 2004a; 2006) for the number and skills of children's hospital ward staff will be taken as the baseline for comparison with all hospital wards taking part in the study to demonstrate areas of good practice, and to identify where staffing improvements could be made to improve the delivery of care. This chapter provides information to facilitate health care planning and quantify resource requirements, particularly, with respect to staffing, staff development, training and education within West, North and East Yorkshire.

8.2 Aim

To investigate hospital ward activity in relation to the number and level of skills of nursing and medical staff providing care.

8.3 Method

8.3.1 Location

Fourteen hospitals and 36 hospital wards from 10 NHS Trusts (Appendix 4)

8.3.2   Data Collection Forms and Study Period

Data was collected on four separate data collection forms in 2005 (Appendix 13). Nurse staffing data was collected for the two months of May and November to cover activity in the summer and winter periods. Medical staffing data was collected during May 2005 only. All forms are described below:

1. **Monthly Nurse Staffing (MNS):** Forms were completed by the senior nurse for each ward recording the monthly nursing establishment, according to grade (A to I), in whole time equivalents (WTEs) and the number of available funded beds (Appendix 13).

2. **Daily Nurse Staffing (DNS):** Forms were completed by the nurse ward co-ordinator for each of three shift periods at the following times: 12 midday, 18.00 hrs and 12 midnight. Numbers of nursing and non nursing staff according to qualification and training were recorded (Appendix 13).

3. **Daily Patient Activity (DPA):** Forms were completed by the nurse ward co-ordinator recording the number of admissions, ward attenders and discharges. Bed occupancy was recorded at 12 midday and 12 midnight (Appendix 13).

4. **Monthly Medical Staffing (MMS):** The lead clinician recorded the number of WTEs of consultants, specialist registrars (SpRs), senior house officers (SHOs), house officers (HOs) and other doctors in post. The number of doctors with valid certification in advanced paediatric life support skills training was also requested. This information was only completed for May (Appendix 13).

8.4   Results

8.4.1   Monthly Nurse Staffing (MNS)

The largest numbers of nursing establishments (WTE) were nurses at grade D and E in both May and November 2005 (table 8.1). Agenda for Change (Department of Health, 2004b) required the implementation of a new pay structure for all NHS employees which was rolled out nationally in December 2004. Many hospitals classified their nurses into the new banding structure between the first survey performed in May 2005 and the second survey performed in November 2005. As D and E grades were banded together (as

band 5), under the new pay structure, many nurse managers returned questionnaires with D and E nurse numbers combined. Therefore, to ensure consistency of the data, D and E grade nurses were combined for analysis. There was a shortfall between the establishment, the number of nursing staff that were funded to work, and the nurses available to work at all grades (table 8.1). Proportionately G grade posts had the greatest shortfall (28%) in May and C and F posts (14%) in November. Numerically D and E grades had the greatest shortfall in May and November with 533.7 and 477.8 WTE respectively. Only 8.4 WTE and 5 WTE were employed at H grade in May and November respectively. There were no posts reported at I grade (table 8.1).

Table 8.1   Nursing establishment by grade available to work on all hospital wards

Grade of nurse	May 2005			November 2005		
	WTE establishment	WTE available to Work (Shortfall %)		WTE establishment	WTE available to Work (Shortfall %)	
A	125.1	113.5	(9)	84.4	83.3	(1)
B	32.9	26.3	(20)	27.6	24.6	(11)
C	11.3	10.3	(9)	14.6	12.5	(14)
D + E	582.1	533.7	(8)	525.5	477.8	(9)
F	95.0	93.1	(2)	92.4	79.8	(14)
G	50.7	36.7	(28)	47.8	44.6	(7)
H	8.4	7.5	(10)	5.0	4.8	(4)
I	0	0	0	0	0	0
Other	5.3	3.0	(43)	1.8	1.8	0
Total	**910.8**	**824.1**	**(9)**	**799.1**	**729.2**	**(9)**

The majority of nurses with extra training in APLS, CCC and HDCC were concentrated at senior level, F, G and H Grade (table 8.2). Although the largest proportion of nurses were employed at D and E grade, relatively few had extra training in APLS, CCC and HDCC in both May and November (table 8.2).

Table 8.2   Nurses with extra training and qualifications according to grade during May and November

Grade of nurse	May 2005			November 2005		
	APLS (%)	CCC (%)	HDCC (%)	APLS (%)	CCC (%)	HDCC (%)
A	0	0	0	0	0	0
B	0	0	0	0	0	0
C	0	0	0	0	0	0
D + E	91.7 (16)	25 (4)	8 (1)	75.0 (14)	40 (8)	12 (2)
F	60.5 (64)	34 (36)	5 (5)	61.1 (66)	25 (27)	3 (3)
G	32.8 (65)	25 (49)	2 (4)	34.0 (71)	16 (33)	6 (12)
H	5.0 (59)	1 (12)	0	3.0 (60)	1 (20)	0
I	0	0	0	0	0	0
Other	0	0	0	0	0	0
Total	**190 (26)**	**85 (11)**	**15 (2)**	**173.1 (26)**	**82 (12)**	**21 (3)**

KEY
APLS Advanced paediatric life support courses
CCC Critical care courses
HDCC High dependency care courses

There was no record of a nurse, at any grade, with APLS skills on ward 58 (May), Bone Marrow Transplant Unit (BMTU) (May and November) and ward 27 (May and November) all of the Leeds Teaching Hospitals NHS Trust. The largest number of nurses with APLS skills was in the critical care areas. Thirty-six (45% qualified total) nurses between ward 2 (PICU at the LGI and PICU at SJUH) held a valid APLS course in May and 51 (56%) in November. These two wards were staffed by nurses as one ward. The hospital ward at a DGH that reported the greatest proportion of nurses with APLS skills was ward 17 at BRI. Ward 17 (BRI) recorded 17 (71% qualified total) nurses with APLS courses in May and 15 (62% qualified total) nurses in November.

The majority of nurses with a critical care course were employed between ward 2 (PICU) LGI and PICU (SJUH). Forty two nurses (52%) were employed in May and 51 (47%) in November. Eight nurses (28%) were employed with a critical care course at the Regional Burns Centre (RBC), Pinderfields Hospital (PH) in May and eight (28%) in November. Five (31%) nurses were employed on ward 200 at the Hull Royal Infirmary (HRI) in May and four (23%) in November. Outside of the HDC and IC areas 16 nurses had critical care courses in May and eight in November.

Few nurses were employed that had completed HDC courses (table 8.2). In May only a total of 15 (2%) nurses had completed such a course, the majority of these nurses (n= 8, 53%) were concentrated on ward 200 (HRI). In November a total of 21 (3%) nurses had completed HDC courses of these, the majority of nurses (n= 7, 33%) were employed at the RBC (PH).

8.4.1.1 Bed availability

The total number of beds available in the region varied according to the day of the week. Two wards, ward 27 and the HDU, both at SJUH, decreased the number of beds available in May and November at the weekend, and a further ward, ward 2 BRI, admitted children as day cases mid week; therefore bed numbers were possibly reduced at the weekend. All three hospital wards admitted children requiring surgery. Five hospital wards, wards 2, 4, 48A (LGI), 5 and 11 (SJUH) did not run to full capacity in May and on days reduced their bed numbers. This was recorded by nurses to be due to staff shortages. Two hospital wards only, ward 48 (LGI) and ward 11 (SJUH) were not running to full capacity during the month of November. Wards A and B (PH) combined to function as one ward at the weekends in May and November.

8.4.2 Daily Nurse Staffing (DNS)

Data for the number of RN (Ch), Registered General Nurses (RGNs), Enrolled Nurses (ENs), Clinical Support Workers (CSWs), Non Clinical Support Workers (NCSWs) and nurses with APLS courses will be presented. Reference is made to the best case scenario and the worst case scenario for the number of RN (Ch) and for the number of nurses with APLS courses. The best case scenario does not infer results from missing data (coded 99, 88 or 999) to determine shifts without a RN (Ch) or a nurse with an APLS course. The worst case scenario uses the missing coded data 99, 88 and 999 to infer that more shifts were without a RN (Ch) or a nurse with APLS skills.

8.4.2.1 Registered Children's Nurses (RN (Ch)). Best case scenario

Of the 3,140 shifts worked by nurses in May 2005, 230 (7.3%) were without a member of staff with a RN (Ch) qualification (figure 8.1). In November, of the 2,970 shifts worked by nurses, 228 (7.7%) shifts were without a RN (Ch) on duty.

Three hospital wards that admitted both adult and paediatric patients (mixed hospital wards) were included in the survey (BMTU and HDU (SJUH) and the RBC (PH). If these three hospital wards are removed from the analysis, in May (n = 2,871 shifts), one shift only was without a RN (Ch). In November (n= 2,700 shifts) one shift was not covered by a RN (Ch) on ward 3C Calderdale Royal Hospital (CRH). In November (n= 2,700 shifts), one shift was not covered by a RN (Ch) this occurred on ward 52 (LGI) but an extra member of staff was recruited on overtime, bank or agency. The data was not specific enough to determine the qualifications of the nurse working overtime, bank or agency.

Figure 8.1   Registered children's nurses on duty each shift (all hospital wards)
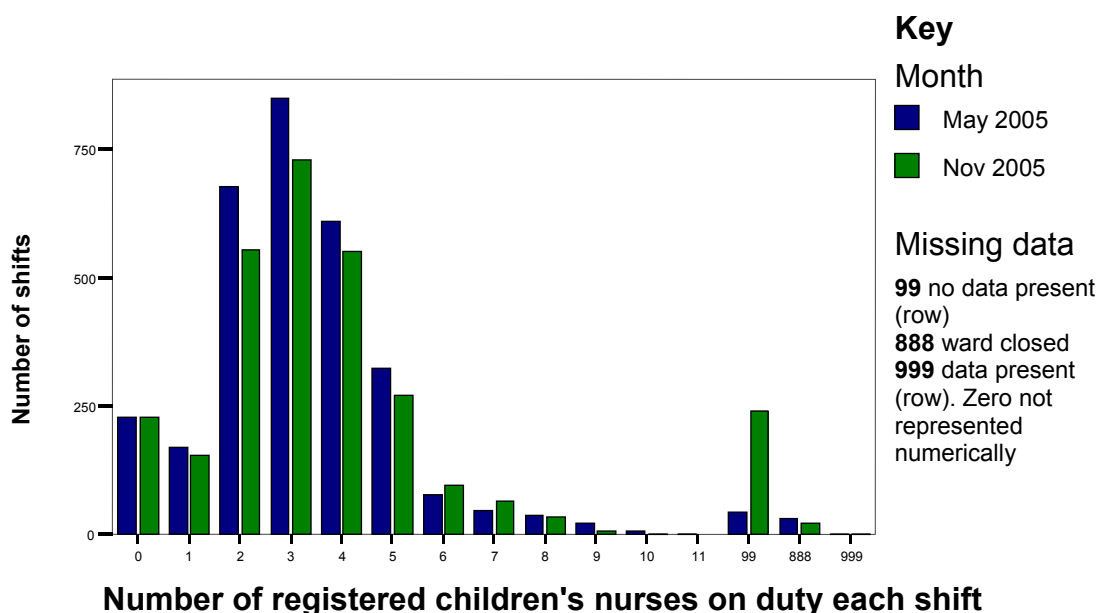
On the mixed hospital wards a RN (Ch) was on duty during 39 (14%) shifts in May and during 42 (15%) shifts in November. The RBC (PH) provided RN (Ch) cover for 42% and 35% of its shifts in May and November respectively. For all wards the majority of shifts (851, 27%) were worked with three RN (Ch) on duty on a single shift in May and 731 (25%) in November (figure 8.1). Nine (0.3%) shifts were worked with 10 and greater numbers of RN (Ch) on each shift in May and three (0.1) in November (figure 8.1).

Of the 3,140 shifts worked by nurses during May, 170 (5.4%) shifts worked with one RN (Ch) per shift, and in November, of the 2,970 shifts, 154 (5.2%) shifts

worked with one RN (Ch) per shift (figure 8.1). If the three mixed hospital wards are removed from the analysis, of the 2,871 shifts, 138 (4.8%) shifts in May worked with one RN (Ch). Of the 2,700 shifts in November, 112 (4.1%) worked with one RN (Ch) per shift. Of the 250 shifts worked with one RN (Ch) on duty 191 (76%) were for the period of the night shift. The following hospital wards had two or more RN (Ch) on duty, each shift, in May and November where questionnaires were completed; ward 5 and ward10 (SJUH), ward B (PH), children's unit (Airedale General Hospital, AGH), ward 2, ward 4, ward 10 and ward 48A (LGI), ward 200 (HRI), ward 17 Huddersfield Royal Infirmary (Hud RI)) and ward 120 (HRI).

8.4.2.2   Registered Children's Nurses (RN Child). Worst case scenario

Of the 3,140 shifts worked by nurses in May, a further two shifts were coded to 999 suggesting that no RN (Ch) was on duty for a total of 232 (7%) shifts (table 8.3). In November, of the 2,970 shifts worked, one shift was coded to 999 suggesting that 229 (8%) of shifts were not covered by a RN (Ch) (figure 8.1, table 8.3).

If the three hospital wards that admit both adult and paediatric patients are removed from the analysis two shifts were coded 999 or missing (a total of three shifts were without a RN (Ch) on duty in a primary paediatric area in May, figure 8.2). In November, one shift only was recorded as 999, a total of five shifts therefore were without a RN (Ch). Of the five shifts without a RN (Ch) three (60%) shifts were covered with overtime where a RN (Ch) was possibly recruited to work the shift. It is possible; therefore that only two shifts in total were without a RN (Ch) during May and November.

Table 8.3 **Coding system for nurses without a Registered Children's Nursing qualification or advanced paediatric life support skills**

Qualification or skill	May 2005 (%)			November 2005 (%)		
	coding		Total number of shifts	coding		Total number of shifts
	0 (zero recorded)	999 (missing)		0 (zero recorded)	999 (missing)	
RN (Ch)	230 (7)	2 (.06)	232	228 (8)	1 (.03)	229
APLS skills	1,159 (37)	513 (16)	1,672	878 (30)	552 (19)	1,430
Total number of shifts worked			**3,140**			**2,970**

Figure 8.2 **Registered children's nurses on duty each shift (excluding mixed hospital wards)**
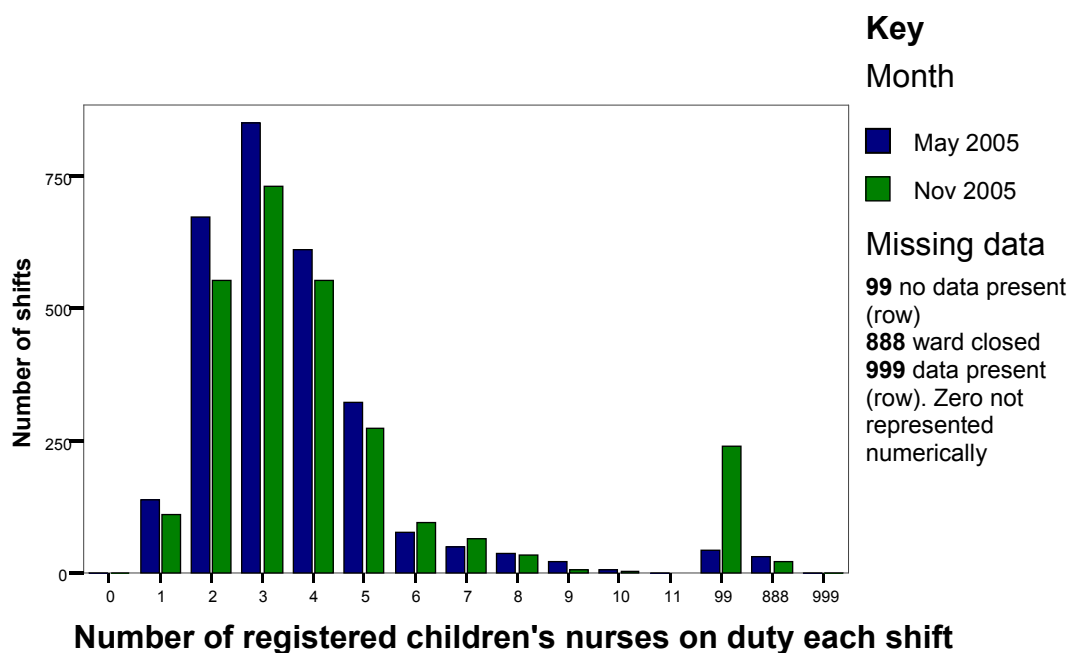
8.4.2.3 Registered General Nurses (RGNs)

Registered General Nurses (RGNs) provided nursing care for children on 29 (82%) hospital wards in May and 28 (85%) hospital wards in November. In May 736 (23%) shifts worked with one or more RGNs and in November 597 (20%) of shifts worked with one or more RGNs. On the mixed hospital wards (n= 3) 264 (98%) shifts worked with one or more RGNs per shift in May, and during November 270 (99.6%) shifts worked with one or more than one RGN per shift.

8.4.2.4 Enrolled Nurses (ENs)

In May 12 (34%) hospitals recorded a member of staff on duty with an Enrolled Nurse (EN) qualification and 15 (45%) hospitals recorded a member of staff with an EN qualification in November. ENs provided care on 140 (4.5%) shifts during the month of May and on 106 (3.6%) shifts in November.

8.4.2.5 Clinical Support Workers (CSWs)

A total of 1,202 and 990 shifts worked with between one to three CSWs during May and November respectively. Slightly more CSWs were employed for the period of the morning shift in May (n= 455) and in November (n= 396) (table 8.4).

Table 8.4   Clinical support workers on duty each shift

Month	Number of clinical support staff	Shift			
		Morning	Afternoon	Night	**Total**
May 2005	1	358	336	348	1042
	2	95	60	1	156
	3	2	2	0	4
	Total	**455**	**398**	**349**	**1202**
Nov 2005	1	296	285	237	818
	2	93	66	0	159
	3	7	6	0	13
	Total	**396**	**357**	**237**	**990**

8.4.2.6 Non-Clinical Support Workers (NCSW)

A total of 447 and 545 shifts had between one and three NCSWs during May and November (table 8.5). The majority of NCSWs were employed for the period of the morning shift in May (n= 259) and November (n= 308). Only 38 night shifts in May and 49 night shifts in November had one NCSW. Three night shifts had two NCSWs in November (table 8.5).

Table 8.5   Non-clinical support staff on duty each shift

Month	Number of clinical support staff	Shift			
		Morning	Afternoon	Night	**Total**
May 2005	1	233	141	38	412
	2	23	9	0	32
	3	3	0	0	3
	Total	**259**	**150**	**38**	**447**
Nov 2005	1	282	169	49	500
	2	25	16	3	44
	3	1	0	0	1
	Total	**308**	**185**	**52**	**545**

8.4.2.7   Advanced Paediatric Life Support (APLS) Courses. Best case scenario

The maximum number of nurses on duty during a shift on a hospital ward with training in APLS was seven in May and five in November. There were however; 1,159 (37%) shifts in May and 878 (30%) shifts in November without a nurse with a valid APLS course (table 8.6). Excluding the three hospital wards that admitted both children and adults from the analysis; in May 915 (32%) shifts were without a member of staff with a valid APLS course (n= 2,871) and in November 646 (24%) shifts were without a member of staff with a valid APLS course (n= 2,700, table 8.7).

Table 8.6   Number of shifts without nurses with APLS (all wards)

Month	Shift	Number of shifts without APLS (0)	Number of shifts with APLS	Missing data (99, 999, 888)	Total shifts
May 2005	Morning	332	553	161	
	Afternoon	355	519	173	
	Night	472	319	256	
	Total	**1,159**	**1,391**	**590**	**3,140**
Nov 2005	Morning	245	501	244	
	Afternoon	273	455	262	
	Night	360	319	311	
	Total	**878**	**1,275**	**817**	**2,970**

Table 8.7   Number of shifts without nurses with APLS (excluding non primary paediatric hospital wards)

Month	Shift	Number of shifts without APLS (0)	Number of shifts with APLS	Missing data (99, 999,888)	Total shifts
May 2005	Morning	256	540	161	
	Afternoon	277	507	173	
	Night	382	319	256	
	Total	**915**	**1,366**	**590**	**2,871**
Nov 2005	Morning	172	484	244	
	Afternoon	198	440	262	
	Night	276	314	310	
	Total	**646**	**1,238**	**816**	**2,700**

8.4.2.8   Advanced Paediatric Life Support (APLS) Courses. Worst case scenario

In May 513 (16%) responses were coded 999 suggesting that no member of staff with a valid APLS course was on duty (table 8.3). In November 552 (19%) shifts were coded 999 (figure 8.3). In total 1,672 (53%) shifts in May and 1,430 (48%) shifts in November were without a member of staff with a valid APLS skills course (figure 8.3).

Excluding the three hospital wards that admitted both children and adults from the analysis; in May 513 (18%) and in November 552 (20%) were coded to 999 suggesting that these shifts were without a member of staff with a valid APLS course (figure 8.4). In total 1,428 (50%) of shifts were without a member of staff with a valid APLS course in May and in 1,189 (44%) in November (figure 8.4).

The three PICUs taking part in the study work each shift with a high staff to patient ratio. Many of these nurses will have APLS courses and possibly bias the shifts with large numbers of nurses with APLS courses. A total of 21 (3.9%) shifts, four (1.5%) in May and 17 (6.3%) in November, were without a member of nursing staff with a valid APLS course (figure 8.5). Thirteen (2.4%) of these shifts were on ward 4 at the LGI.

Figure 8.3   Number of nurses on duty with APLS courses (all wards)
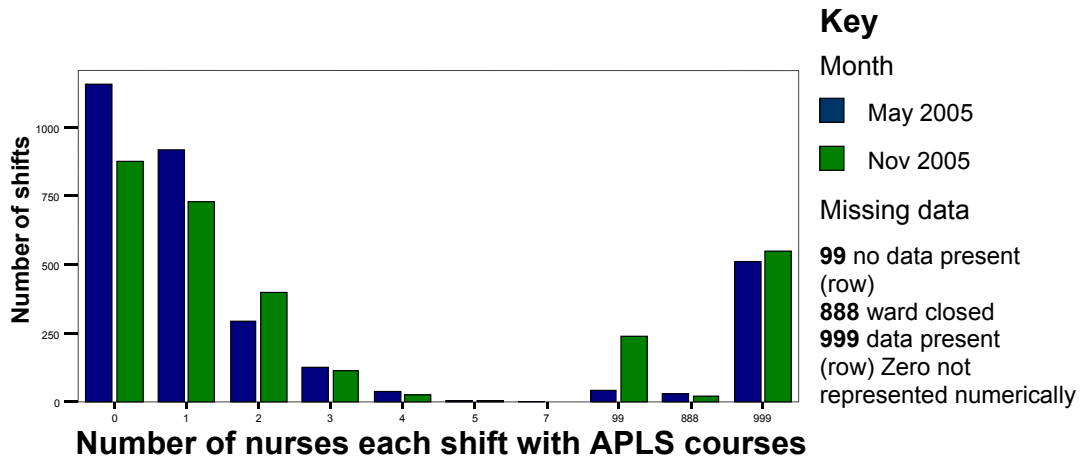
Figure 8.4   Number of nurses on duty with APLS courses (excluding mixed hospital wards)
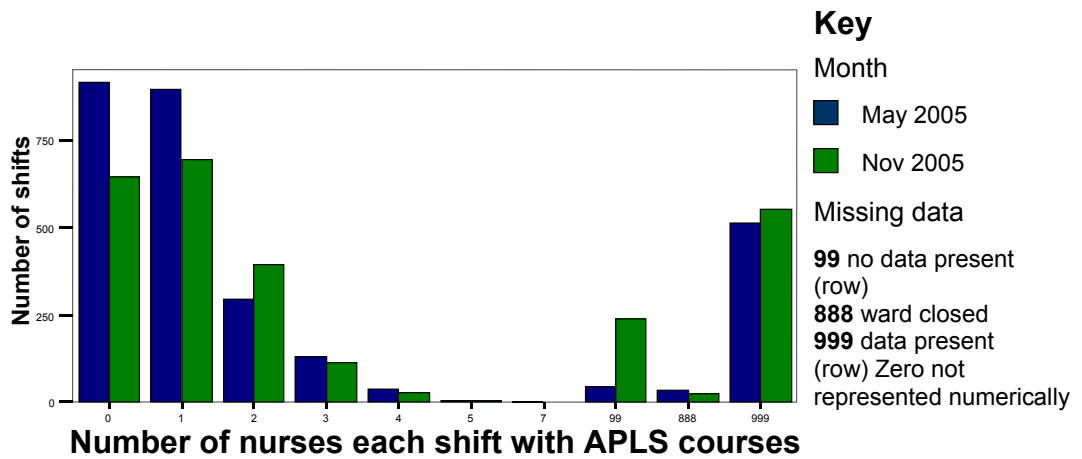
Figure 8.5   Number of nurses on duty with APLS courses (excluding paediatric intensive care units)
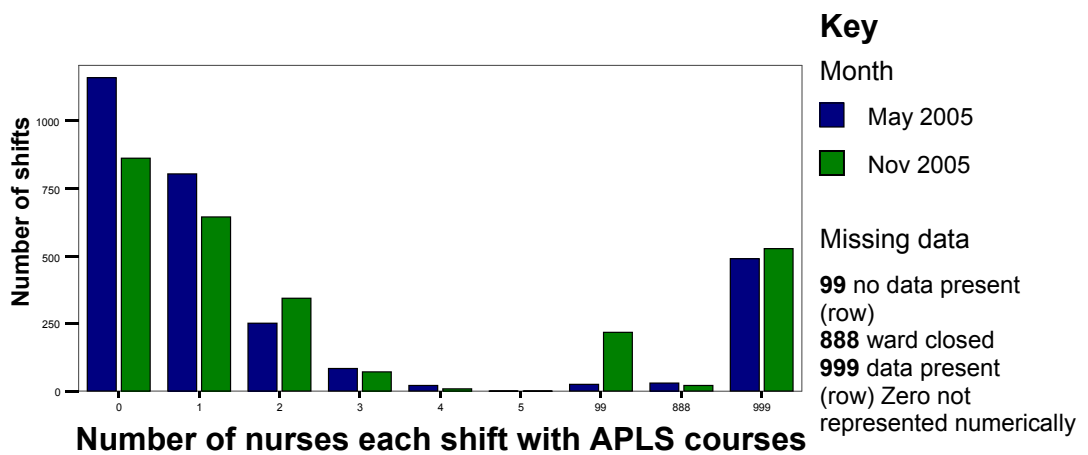
Although the majority of nurses without APLS were on duty at night in both May and November (n= 472 and n= 360) this was not exclusive to the night shift (table 8.6 and table 8.7).

No hospital ward managed to cover every shift with a member of staff with APLS skills, yet two hospital wards came very close to achieving this. Ward 2 (LGI) could not provide APLS cover on one shift in May and two shifts in November. Ward B (PH) could not provide APLS cover on two shifts in May and one shift in November. In May the following four hospital wards did not provide APLS cover on any shift; Woodlands ward at Harrogate District Hospital, ward 2 (BRI) and HDU and BMTU (SJUH).

8.4.2.9   Critical Care Courses (CCC)

Seventeen percent (n= 543) of shifts had one or more members of staff on duty with a critical care course (CCC) in May. Of the 543 shifts 251 (46%) shifts were in the critical care areas. In the critical care areas no shifts were without a member of staff with a CCC. This information was not requested during the month of November.

8.4.2.10   High Dependency Care Courses (HDCC)

A total of 336 (10%) shifts worked with one or more than one member of nursing staff with a course, or module, in HDC in May. This information was not requested during November.

8.4.2.11   Overtime/Bank/Agency

Throughout the region a total of 321(10%) shifts during May and 389 (13%) shifts during November required between one and three members of overtime, bank or agency staff (table 8.8). Eight shifts required three members of staff for overtime, bank or agency and six shifts required three members of staff for overtime, bank or agency in May and November respectively (table 8.8).

The largest user of overtime, bank and agency during both months was ward 17 (BRI) who used between one and two members of staff on 71 shifts. Information regarding the grade of the nurse employed as extra was not requested and thus, could range from grade A to Grade G. In May and November more

overtime, bank and agency nurses were required for the period of the night shift (n= 140 and n= 188) than the morning or afternoon shift (table 8.8). There was no difference between day of the week and the amount of overtime, agency or bank used.

Table 8.8   **Overtime, bank or agency used by shift in May and November 2005**

Month	Number of bank, agency,OT	Shift			
		Morning	Afternoon	Night	**Total**
May 2005	1	80	86	117	283
	2	2	8	20	30
	3	4	1	3	8
	Total	**86**	**95**	**140**	**321**
Nov 2005	1	87	83	165	335
	2	12	16	20	48
	3	1	2	3	6
	Total	**100**	**101**	**188**	**389**

8.4.3   Daily Patient Activity (DPA)

More children were admitted to hospital (including day cases) in November (n= 4, 325) than in May (n= 4,293), and fewer children were admitted on Saturday and Sunday (table 8.9).

Table 8.9   **Total number of ward admissions by day of the week and month**

Day of the week	Ward admissions by month	
	May 2005	Nov 2005
Monday	734	712
Tuesday	836	817
Wednesday	665	836
Thursday	542	577
Friday	667	614
Saturday	408	370
Sunday	441	399
Total	**4,293**	**4,325**

The ward with the greatest number of admissions was ward 2 (BRI) with 742 (9%) of all admissions during May and November. Ward attenders seen throughout the region totalled 1,227 in May and 1,337 in November (table 8.10). The largest number (n= 556 (22%)) of these children were seen on ward 3C (CRI); however this ward has six assessment beds.

Table 8.10   Ward attenders by day of the week and month

Day of the week	Ward attenders by month	
	May 2005	Nov 2005
Monday	221	235
Tuesday	242	253
Wednesday	215	238
Thursday	173	230
Friday	211	184
Saturday	76	103
Sunday	89	94
Total	**1,227**	**1,337**

The total number of discharges from hospital wards in the Yorkshire region in May was 712, and in November 752. The maximum number of discharges in May from a hospital ward during a 24 hour period was 21; this occurred on ward B (PH). In November, 25 discharges occurred twice on ward 2 (BRI).

Nine deaths occurred in May. Four deaths occurred on the paediatric wards at the DGHs and five deaths occurred on three wards at a tertiary centre. In May the transfer of a critically ill child to a PICU/ICU occurred on 30 occasions. Nine of these were children transferred from ward 10 (LGI) to ward 4 (LGI). This information was not requested in November because it had no relevance to the study.

8.4.4   Monthly Medical Staffing (MMS)

Data collected was restricted to the month of May because the time spent by doctors finding this information took them past the next data collection point of November. Of the 26 MMS data collection forms, that were dispatched for completion, 22 (85%) were returned for analysis. The total number of doctors available in the Yorkshire region providing care for children during May, was 314 (table 8.11). Of the 314 doctors 179 (57%) had an up-to-date APLS course (table 8.11). Senior house officers (SHOs) working in the paediatric area were the grade of medical staff that were least trained in advanced paediatric life support; 70 (55%) were without APLS courses. Of the consultants (general paediatric, anaesthetic, specialist paediatric and paediatric intensivist) 38 (40%) were without valid certification in APLS. Eight (15%) SPRs in general paediatrics were without valid certification in APLS.

Table 8.11   Number of medical staff available with APLS courses by grade

Grade of medical staff	Total Number	Total WTE in post	APLS courses (% of total number)
SHO general paediatrics	126	126	57 (45)
SHO anaesthetics/equivalent	1	1	0
SPR general paediatrics	52	49	44 (85)
SpR anaesthetics/equivalent	10	9	7 (70)
SpR PICU training/equivalent	0	0	0
Consultant general paediatrics	78	76	48 (61)
Consultant anaesthetics/equivalent	2	-	1 (50)
Consultant paediatric specialist	14	14	7 (50)
Consultant paediatric intensivist	1	1	1 (100)
Other	30	23	14 (47)
Total	**314**	**299**	**179 (57)**

KEY
SHO Senior house officer
SpR Specialist paediatric registrar
PICU Paediatric intensive care unit
WTE Whole time equivalent

A telephone survey was undertaken during May of anaesthetic departments at all hospitals taking part in the study to determine if 24 hour resident anaesthetic cover was available on site. No hospital was without 24 hour resident anaesthetic cover.

8.5   Response Rates

A good response rate for the MNS, DNS and DPA was achieved overall, but this was higher in May (table 8.12). In May only one (3%) hospital ward (Scarborough and District Hospital) failed to return all parts of the survey that were to be completed by nurses (MNS, DNS and DPA). In November three (8%) hospital wards failed to return all three forms, the PPA, the DNS and the MNS (Scarborough District Hospital, York District General Hospital and Huddersfield Royal Infirmary). Other hospital wards failed to return parts or part of the DNS and DPA. MMS questionnaires were returned with four outstanding non-returns (table 8.12).

Table 8.12   Response to the daily and monthly clinical staffing survey

Forms	May 2005 (%)	November 2005 (%)
Monthly nurse staffing (MNS)	31 (86)	28 (77)
Daily nurse staffing (DNS)	35 (97)	33 (92)
Daily patient activity (DPA)	34 (94)	33 (92)
Monthly medical staffing (MMS)	22 (85)	N/A

8.6   Discussion

The quality of the information from all the 36 hospital wards was high and therefore provided a robust description of daily patient activity alongside the number and level of skills of clinical staff. This type of information is rarely collected for such a complete group of hospital locations and is essential for local managers in establishing priorities for ward management, skill mix review, training and education, but also to assist them in reflecting upon ward routine and practice. The information also provides commissioners with crucial evidence for resource requirements.

The data collection periods were resource intensive for both medical and nursing staff and required commitment and dedication. The excellent response rate suggested that staff did not feel threatened by the request for detailed data, but wanted to share the good and bad areas of practice. Although the Department of Health recommendations (1991; 1997a; 1997b; 2001a; 2004a, 2006) with respect to the number and level of skills of nurses and skills of medical staff available for care on acute hospital wards, was purely 'guidance', it served to provide information against which to measure and it set standards for hospital wards to strive to achieve. The DoH guidance provided a baseline for comparison of available staffing activity recorded in the study region, but there was very little information with which to compare results. A report by the Royal College of Nursing (1999) found that of 290 hospitals taking part in a UK wide study of acute health care provision for children in 1998, over one quarter of organisations (n= 83, 28.4%) did not achieve the DoH standard to have two RN (Ch) on every shift. Although this data was not of sufficient quality to determine the shift frequency by which each organisation failed to meet with the DoH guidance, it was reported that achieving the standard at night was a 'particular problem' (Royal College of Nursing, 1999). In comparison 68% of hospital wards, within the study location, did not achieve the standard of two RN (Ch) per shift during May and November for only 5% of shifts. It was not clear

why the level of non adherence to a national recommendation was so striking for the number of hospital wards that failed to achieve the standard for two RN (Ch) in the Yorkshire region. However the results from the UK study (Royal College of Nursing, 1999) and the Yorkshire study were in agreement; the gaps in service provision occurred at night. Skill mix cuts and the recruitment and retention of children's nurses contribute to the lack of children's nurses, particularly at night.

It was not possible to compare the APLS study data directly with hospital wards outside of the region because no published data was found either from the literature or through personal contacts. The lack of available comparative information restricted evaluating the national context of this Yorkshire study.

Although some differences existed between summer and winter hospital ward activity large variations were not observed. The following discussion examines each set of data independently with a final overall conclusion.

8.6.1 Monthly Nurse Staffing (MNS)

The nursing grade results clearly show that for all grades there was a shortfall in the number of staff available to work. Possible reasons for the shortfall were not elicited by the questionnaire and so it was impossible to identify if this was due to maternity leave, long term sickness or unfilled posts. Overall the shortfall for May and November was the same at 9%. However despite a reduced number of WTE equivalent establishment posts, in November, there was an increase in the employment of G grade nurses and a reduction in F grade nurses.

Despite government recommendations regarding the presence of a nurse with APLS skills, during a 24 hour period, on all paediatric wards where children are admitted acutely, three hospital wards were without any nurses with valid certification in APLS. Although some hospital wards, because of the nature of their specialty, admitted children that were more likely to deteriorate, any sick child has the potential to rapidly worsen and become acutely ill. To provide recommended levels of care it is necessary for more nurses to undertake APLS courses, particularly, to identify and promptly treat children that begin to show signs of deterioration. Nurses with APLS skills should be available to take the

lead for scenario training and act as a resource for other/junior staff within their own area. Over 60% of senior nurses, at F, G and H grade had valid certification in APLS skills, yet only 15% of the backbone of the workforce, at D and E grade, had certification in APLS. Many nurses at E grade on general hospital wards co-ordinate ward activity for a shift period it would therefore be appropriate to invest in these nurses and expect a number of them to become skilled in APLS.

Only 2% and 3% of the regions nursing workforce in May and November, respectively, had undertaken a HDC course or modules relating to the care of a child in need of stabilisation. This is, possibly, due to the fact that no such course was available, locally, within the study region at the time. Whilst high dependency care courses are not a substitute for APLS courses these courses can provide experience, confidence and competence for nurses in the care of children with increasing dependency needs. It is vital however that the skills gained during APLS and HDC courses are maintained. Provision of HDC courses locally may address some of the educational and professional development needs of nurses, but the provision and monitoring of the maintenance of acquired skills may prove more difficult.

8.6.2 Daily Nurse Staffing (DNS)

Almost all primary paediatric wards that took part in the study had sufficient numbers of RN (Ch) to ensure that a children's nurse was on duty per 24 hour period. Of the two primary paediatric hospital wards that did not provide children's nurse cover for two shifts, two (100%) were for the period of the night shift. Where only one RN (Ch) was on duty on a shift (n= 250, 4%), 191 (76%) were for the period of the night shift. Twenty four hour availability of a RN (Ch) in a primary paediatric area should be the gold standard; however the DoH recommendation (Department of Health, 1991) that two RN (Ch) on duty each shift is shown, by the findings, to be difficult to achieve for some hospital wards. This may be a consequence of more generalised nursing shortages. It is nevertheless a goal that primary paediatric hospital wards in West, North and East Yorkshire should strive to achieve.

Ideally a RN (Ch) should be available to care 24 hours a day, or children should be cared for on primary paediatric wards (Department of Health, 1991). Three mixed adult and paediatric hospital wards were present within the region and these wards found it particularly difficult to provide a RN (Ch) for each shift. The Regional Burns Unit (PH) covered more than a quarter of shifts with a RN (Ch). The problem faced by the three mixed hospital wards may be a consequence of their high levels of specialisation, and because they admit relatively small numbers of children. The specialist skills and expertise in caring for these children are not available on general children's wards. A compromise is necessary to ensure that children are, either, managed by RN (Ch) without the relevant specialist skills and the skilled specialist general nurse is called for advice, or children are managed by non children's nurses, with specialist skills, and the (RN (Ch) is called for advice. It is possible that the data from the study appears to overstate the gaps in provision; staff from these mixed wards may have consulted appropriately outside their area for specialist advice, but this was not recorded by this study.

Extremely small numbers of ENs were employed to work on children's wards. Fewer than 5% of shifts were worked with an EN on duty during both months. This is because training for EN ceased to exist in 1991 with the introduction of Project 2000 (United Kingdom Central Council, 1986), and since this time many EN nurses have either retired, or enrolled on a conversion course to become a RN (Ch).

CSWs provided care under the supervision of a registered nurse. Hospital wards taking part in the study had the support of these workers during 35% of all shifts. Whilst CSWs are trained to become competent at performing certain basic cares, care must be taken not to dilute hospital wards with unqualified nurses, leaving fewer qualified nurses with even greater responsibility.

Nearly 50% of shifts in West, North and East Yorkshire were without a nurse with valid certification in paediatric advanced life support skills, yet on some hospital wards up to seven nurses with APLS skills were on duty on a single shift. On the primary paediatric hospital wards, just over one-quarter (28%, n= 1561) of all shifts were without a nurse with valid certification in APLS. Two

issues regarding APLS competencies for nurses come to the fore after analysis of both the MNS and DNS data:

- That insufficient nurses were trained to provide paediatric advanced life support.
- The planning of shifts did not extend to providing APLS cover (there were situations where more than one nurse was on duty during a shift with APLS training and other shifts were without).

Although the cost of providing each acute paediatric hospital ward with sufficient APLS trained nurses is substantial, to meet with government guidance it is suggested that more nurses particularly senior staff nurses (grade E) are given the opportunity to attend APLS courses. To meet with the workforce guidance nurse managers should plan nursing rotas for each ward to ensure that the skill mix for each shift includes, not only two RN (Ch), but a nurse with APLS training. Nurses working on mixed adult and paediatric wards should not be an exception to the documented guidance.

Ten and 13% of all shifts used a bank, agency or overtime nurse in May and November respectively. The increase for the winter period of November may have been due to a reduction in the establishment and corresponding nurses available to work; however sickness during the winter months also contributes to staffing shortages. The 2005 Royal College of Nursing (RCN) employment survey found that the expenditure on temporary nurse staffing tripled in England between 1998 and 2003 (Ball and Pike, 2005). Although the target by NHS Plan (Department of Health, 1999) to increase the number of nurses working in the NHS has been achieved, healthcare services have expanded, new roles have been introduced and patient acuity and dependency levels have increased. Increasing the number of nurses has not had the effect of reducing the workload for nurses on some hospital wards (Ball and Pike, 2005).

8.6.3 Daily Patient Activity (DPA)

November saw a larger number (n= 4,325) of paediatric admissions to the regions hospital wards than May (n= 4,293). At the outset of the study an excess of winter admissions was predicted; it is possible that November did not

capture the winter peak which is more likely to occur in January (Paediatric Intensive Care Audit Network, 2007).

Fewer children were admitted at the weekend because planned surgery did not take place on Saturday and Sunday.

Large numbers of children were seen on the majority (89%, n= 32) of hospital wards as ward attenders during both May and November. On some wards adequate provision, in terms of funded beds and extra nursing resources, were in place for these children. On other wards ward attenders remained a hidden workload which added substantially to the demands placed upon a ward.

8.6.4 Monthly Medical Staffing (MMS)

Just over half of the doctors in the region had undertaken APLS training with the largest proportion concentrated at SpR level. A limitation of the data collection form was that the APLS information did not identify whether medical staff had lapsed in their certification of APLS skills, or if an APLS course had ever been undertaken. The data on medical staffing for the first study month of May was difficult to accrue. The time taken to return forms was excessive and some locations failed to return the forms despite active chasing. Therefore the information was not requested for a second month (November). One explanation for the delayed return was possibly due to the lack of recorded information on APLS competencies for each member of medical staff. This exercise ought to have alerted consultant medical leads involved to the fact that:

- Serious untoward incidents may occur if APLS qualifications are lacking.
- It is useful information to clarify at interview.

Notably, 40% of consultants who provided general paediatric, specialist paediatric, paediatric anaesthetic and paediatric intensivist care did not have valid APLS certification. It is impossible to establish from the data if any of the consultants required revalidation of a course or if they had never attended such a course. As the government guidance is vague and contradictory for doctors within the various types of hospital (Lead centres, DGHs, Specialist centres and

Major acute general hospitals), and because daily information was not collected for the skills of medical staff, it was impossible to establish the achievement of any standard.

8.7   Conclusion and Summary

The following summarises the conclusions from this chapter which have been difficult to contextualise in the absence of comparative information:

- The medical and nurse staffing audit was extremely successful with large amounts of high quality data on the level of inpatient activity and the number and qualifications of medical and nursing staff for each hospital ward submitted for analysis.

- This study was made possible by the dedication and enthusiasm of the nursing and medical staff employed within West, North and East Yorkshire.

- The findings show that children's wards in the region varied greatly in size (range 4 to 31 beds) alongside considerable variation in the number of qualified nurses available to cover these beds.

- Some primary paediatric hospital wards where sick or extremely sick children were admitted did not have adequate cover from nurses with APLS skills and no hospital ward in the study was found where all shifts were covered with a nurse with APLS skills. Data from three adult specialist hospital wards who also admitted children showed the absence of adequate RN (Ch) and APLS qualified support.

- For hospital ward attenders, rather than admissions, some primary paediatric hospital wards provided adequate nursing resources to support the needs of these children attending for minor care or assessment. Other hospital wards saw ward attenders without extra nursing resources. This practice placed a considerable burden on an already stretched workforce.

- Although it was very rare for a primary children's ward to be without a RN (Ch) it did occur for two shifts at a DGH. Nurse managers' should adjust nursing rotas to ensure that RN (Ch) cover is available at all times during a 24 hour period.

- There were some occurrences where the DoH recommended guidance requiring two children's nurses on duty at all times in a 24 hour period was not adhered to: this was most noticeable at night.

- Nearly half (43%) of all doctors were without valid APLS skills. Some shifts may have been without medical APLS cover. Without a detailed breakdown of medical APLS skills by shift it was impossible to draw firm conclusions on this.

This study has provided a wealth of information on the complex interplay between the number and skills of staff available, the number of inpatient children admitted and the perceived dependency needs of those children. The following chapters of the thesis will merge the information from this chapter with data derived by applying the PHDC measurement tool to quantify PHDC activity in the region.

9 Main Study: Paediatric High Dependency Care, Patient Activity and Clinical Staffing

9.1 Background

This chapter describes:

- The application of the PHDC measurement tool (see chapter 7) to the 24,540 episodes of the PPA collected for the study during one full year (2005), to quantify PHDC in the region.
- The merging of three datasets, the PPA, the DPA and the DNS to provide a comprehensive assessment of PHDC patient activity and related staffing.

As part of their programme to highlight areas of potential concern and to provide information to assist with the planning of critical care services, the Paediatric Critical Care Network of the Yorkshire and Humber Specialist Commissioning Group (North) commissioned a detailed evaluation of the quantity of PHDC and the corresponding staffing levels for the entire region. Consequently, activity had to be measured for every hospital ward. As the delivery of critical care varied by hospital ward type, activity needed to be measured for every hospital ward. Evaluation was made for the entire dataset and then broken down by the four hospital ward types; DGHs, PICUs, Specialist Hospital Wards and the DGH with specialist paediatric facilities. Differences between hospital ward type and shift period are highlighted in relation to the nurse to patient ratios as determined by the Department of Health (1996). To put the findings in context the emphasis shifts slightly in parts of this chapter to include information on children requiring usual ward care and not critical care. This is to demonstrate that outside of the critical care arena, clinical staff are responsible for another group of inpatient children, those requiring usual ward care, who are equally entitled to care and treatment. To simplify the workforce skills and the dependency needs of children this information will be represented

diagrammatically for the data as a whole and again for each of the hospital ward types.

Few attempts have been made to quantify PHDC in the UK. HES reports that 1,725,863 children aged 0-14 years were admitted to hospital in England and Wales during the financial year 2004-2005 (http://www.hesonline.nhs.uk). However, only a small number of these episodes are likely to require PHDC. HES does not provide information at a sufficient level of detail to estimate what proportion of activity relates to PHDC. Limited evidence is available from other sources:

- The Information Standards Board (2007) provided extrapolated evidence from two 'pilot' studies to suggest that:
    - In PICUs, in England, approximately 80,000 inpatient bed days per annum were devoted to PHDC (based on data contained in the PICANet report- date not specified).
    - Outside of PICUs, approximately 73,000 inpatient PHDC bed days per annum were provided on children's wards based on data collected by Rushforth (2006). These figures were extrapolated from an early report written for the commissioners of the Yorkshire and Humber Specialist Commissioning Group prior to the final development of the PHDC measurement tool and were therefore potentially inaccurate.
- The Department of Health (2001a) has estimated the amount of PHDC occurring in DGHs to be between five and 15% of all admissions.
- A small audit by Watchorn (2006) during a four week period in Scotland, involving four hospital wards estimated, using their own PHDC criteria, that 30% of all average admissions per week (n= 51.5) required PHDC with an average PHDC inpatient time of 28.7 hours per patient.
- Information from the South West Audit of Critically Ill Children (2007) reported that 2.9 of paediatric admissions to 16 hospitals in the South West of England required admission to one of seven PHDUs where the median length of stay was 1 day or less.

Despite the existence of numerous government standards published on the number and level of paediatric clinical staffing skills that should be available to provide usual ward care and PHDC (Department of Health 1991; 1997a; 1997b; 2001a), no information was found which provided insight into the achievement of the key recommendations for PHDC elsewhere in the UK. There are no published or available studies describing the matching of skilled clinical staff to the dependency needs of children.

9.2 Aim

The aims of this part of the study were twofold:

- To estimate the level of PHDC patient activity occurring in the region by applying the 36 item PHDC measurement tool (Appendix 12) to the collected episode data (n= 24,540).

- To take the estimated levels of PHDC and the related staffing levels and match them to the dependency needs of children during the months of May and November.

9.3 Method

Application of the tool to the existing data allocated each of the 36 interventions listed on the PHDC measurement tool a respective score of two, four or six points (see Chapter 7) to each reported episode. An episode of care was defined as the period of a day shift or night shift. The total scores for each episode of care (n= 24,540) was calculated in SPSS (SPSS. Inc. V12.0.1, 2003). A score of six points or more assigned an episode of PHDC, and a score of less than six points indicated usual ward care. The NHS number was used as the unique identifier to map all children from hospital to hospital and ward to ward.

The DNS and DPA data collected in May and November, 2005, provided a detailed set of data on the number and skills of qualified and unqualified nurses and the number of children admitted, discharged and seen as ward attenders on each hospital ward (see chapter 8). The nurse staffing and patient activity data collected in May and November was of good quality but incomplete data items were visible for many hospital wards at the beginning of May. May 1st was a Sunday and May 2nd a Bank Holiday. Therefore, to reduce capture of blank

items, 28 days of data in May and 30 days of data in November was selected to investigate whether the number and levels of skills of nursing staff on each shift matched the number and PHDC activity of children on the ward.

Medical staff were asked to complete the Monthly Medical Staffing (MMS) in May only, but not on a shift by shift basis; therefore it was impossible to determine if continuous medical availability of APLS skills were present at all times, during a 24 hour period, for hospital wards. However it was possible to assess the skills of the medical staff by hospital ward type.

9.4 Results

9.4.1 Estimate of Paediatric High Dependency Care Patient Activity

Applying the PHDC measurement tool to all the episode data (n= 24,540) gave an estimated 9,077 episodes of PHDC corresponding to 4,538 bed days for 1,763 children. The median length of PHDC stay was one day (range 1-125 days) (table 9.1). The maximum length of PHDC stay for a child was 125 days; this was on a hospital ward at a DGH and was defined as a continuous day/night period (table 9.1). The hospital ward with the greatest number of episodes (n= 1,466, 16%) of PHDC for 249 children was ward 2, PICU, at the Leeds General Infirmary (LGI) where the median length of PHDC stay was three days (range 1-34) (table 9.1). The majority of all children requiring PHDC were male (n= 967, 55%) and one quarter (n= 436, 25%) of all children requiring PHDC were infants (aged 29 days to 1 year). Only 72 (4%) young people aged 16 years and over admitted to hospital required PHDC. Slightly more episodes of PHDC were provided for the period of the day shift n= 4,627 (51%). December was the busiest month for children receiving PHDC (n= 192, 11%) and just over one quarter (n= 449, 26%) of all children requiring PHDC were admitted with a surgical problem. Scores for episodes of PHDC ranged from six to 72 (table 9.2). One third (n= 2967, 33%) of all episodes of PHDC received a score of six; while just over half (n= 4893, 54%) of all episodes scored eight points or less (table 9.2). Only one episode of PHDC received 72 points; this was for a child on ward 4 (children's cardiac intensive care unit, CCICU). PHDC defined by single intervention only accounted for 877 (10%) episodes.

Table 9.1   Episodes and number of children receiving paediatric high dependency care by location (2005)

Hospital Trust	Hospital	Ward	Episodes of PHDC (%)	Mean length of PHDC in days	Median length of PHDC stay in days (Range)		Number of children requiring PHDC by ward	Total number of children requiring PHDC by hospital
Airedale NHS Trust	Airedale General Hospital	Children's Unit	130 (1.4)	2	1	(1-4)	48	48
Bradford Teaching Hospitals NHS Foundation Trust	Bradford Royal infirmary	2	8 (0.1)	1	1	(1-2)	6	117
		16	196 (2.2)	2	1	(1-8)	74	
		17	238 (2.6)	2	1	(1-13)	39	
Calderdale and Huddersfield NHS Trust	Calderdale Royal Hospital	3C	397 (4.4)	5	1	(1-125)	37	37
	Huddersfield Royal Infirmary	17	106 (1.2)	1	1	(1-4)	54	54
Harrogate and District NHS Trust	Harrogate District Hospital	Woodlands	151 (1.7)	2	1	(1-22)	57	57
Hull and East Yorkshire NHS Trust	Hull Royal Infirmary	120	70 (0.8)	1	1	(1-6)	24	166
		130 E	76 (0.8)	2	2	(1-4)	24	
		130 W	10 (0.1)	1	1	(1)	7	
		200 (PHDU)	505 (5.6)	2	1	(1-12)	135	
Scarborough and North East Yorkshire Health Care NHS Trust	Scarborough and District Hospital	Duke of Kent	106 (1.2)	2	1	(1-16)	36	36
South Tees Hospital NHS Trust	Friarage Hospital	Children's Unit	44 (0.5)	1	1	(1-3)	24	24
The Mid Yorkshire Hospitals NHS Trust	Dewsbury District Hospital	7	158 (1.7)	2	1	(1-11)	61	61
	Pinderfields Hospital	A	9 (0.1)	1	1	(1)	6	101
		B	123 (1.4)	2	1	(1-10)	52	
		Burns (RBC)	326 (3.6)	2	1	(1-45)	45	
	Pontefract General Infirmary	Hydes	135 (1.5)	1	1	(1-3)	71	71

Table 9.1 continued

Hospital Trust	Hospital	Ward	Episodes of PHDC		Mean length of PHDC stay in days	Median length of PHDC in days		Number of children requiring PHDC by ward	Total number of children requiring PHDC by hospital
				(%)	days		(Range)		
The Leeds Teaching Hospitals NHS Trust	Leeds General Infirmary	2	1466	(16.2)	3	3	(1-34)	249	749
		4	803	(8.8)	2	2	(1-7)	267	
		10	572	(6.3)	3	2	(1-17)	89	
		48A	501	(5.5)	2	1	(1-9)	146	
		48	344	(3.8)	3	2	(1-18)	44	
		51	192	(2.1)	2	1	(1-11)	44	
		52	81	(0.9)	2	1	(1-6)	29	
		58	137	(1.5)	2	1	(1-6)	51	
	St James University Hospital	5	42	(0.5)	2	1	(1-4)	18	323
		10	535	(5.9)	2	1	(1-14)	78	
		11	487	(5.4)	3	2	(1-9)	66	
		12	161	(1.8)	3	2	(1-25)	29	
		15	123	(1.4)	2	1	(1-5)	41	
		15 BMTU	184	(2.0)	3	1	(1-22)	13	
		PICU	476	(5.2)	2	2	(1-14)	116	
		27	15	(0.2)	1	1	(1)	15	
		HDU	105	(1.2)	2	2	(1-10)	25	
York Hospitals NHS Trust	York District Hospital	17	65	(0.7)	2	1	(1-6)	28	28
	Total		**Episodes**					**Children**	
			9077	**(100)**				**1673**	

KEY

☐ **DGHs**   ☐ **PICUs**   ☐ **Specialist hospital wards**   ☐ **DGH with specialist hospital facilities**

Note total children requiring HDC by ward will not equal total children requiring HDC by hospital because children were duplicated across hospitals and wards. The total number of children requiring PHDC was 1763.

Table 9.2   **Points scored using the paediatric high dependency care measurement tool for each episode of care by hospital ward type**

Total number of points scored using the PHDC measurement tool	Hospital ward type				
	DGHs (%)	PICUs (%)	Specialist hospital wards (%)	DGH with specialist paediatric facilities (%)	Total (%)
6 points	941 (50)	297 (11)	1518 (40)	211 (32)	**2967 (33)**
8 points	290 (16)	676 (25)	828 (22)	132 (20)	**1926 (21)**
10 – 19 points	496 (27)	1005 (37)	1311 (34)	287 (43)	**3099 (34)**
20 – 39 points	114 (6)	646 (24)	144 (4)	28 (4)	**932 (10)**
40 – 59 points	22 (1)	114 (4)	4 (0.1)	3 (0.5)	**143 (2)**
60 – 72 points	3 (0.2)	7 (0.3)	0	0	**10 (0.1)**
Total (%)	**1,866 (100)**	**2,745 (100)**	**3,805 (100)**	**661 (100)**	**9077 (100)**

9.4.2   Clinical Nurse Staffing

Overall, for the 36 hospital wards, the mean number of all inpatient children, irrespective of their dependency needs, per shift, was 11 at midday and 10 at midnight. The mean ratio of qualified nurses to children, requiring HDC, per shift was 4.2 : 0.4 at all times of the day and 3 : 0.4 at all times during the night. The nurse to child ratios did not take into account the additional need for a nurse to co-ordinate the care of the entire ward. Usually this task is performed by one senior member of staff who may or may not, depending upon the size of the ward, also care for patients. The following figure (9.1) illustrates the recommended child to qualified nursing ratios for all 36 hospital wards (Department of Health, 1996) when one qualified nurse, not providing patient care, was removed to co-ordinate the ward.

Figure 9.1   Mean nurse to child ratios for all 36 hospital wards for high dependency care and usual ward care by shift period
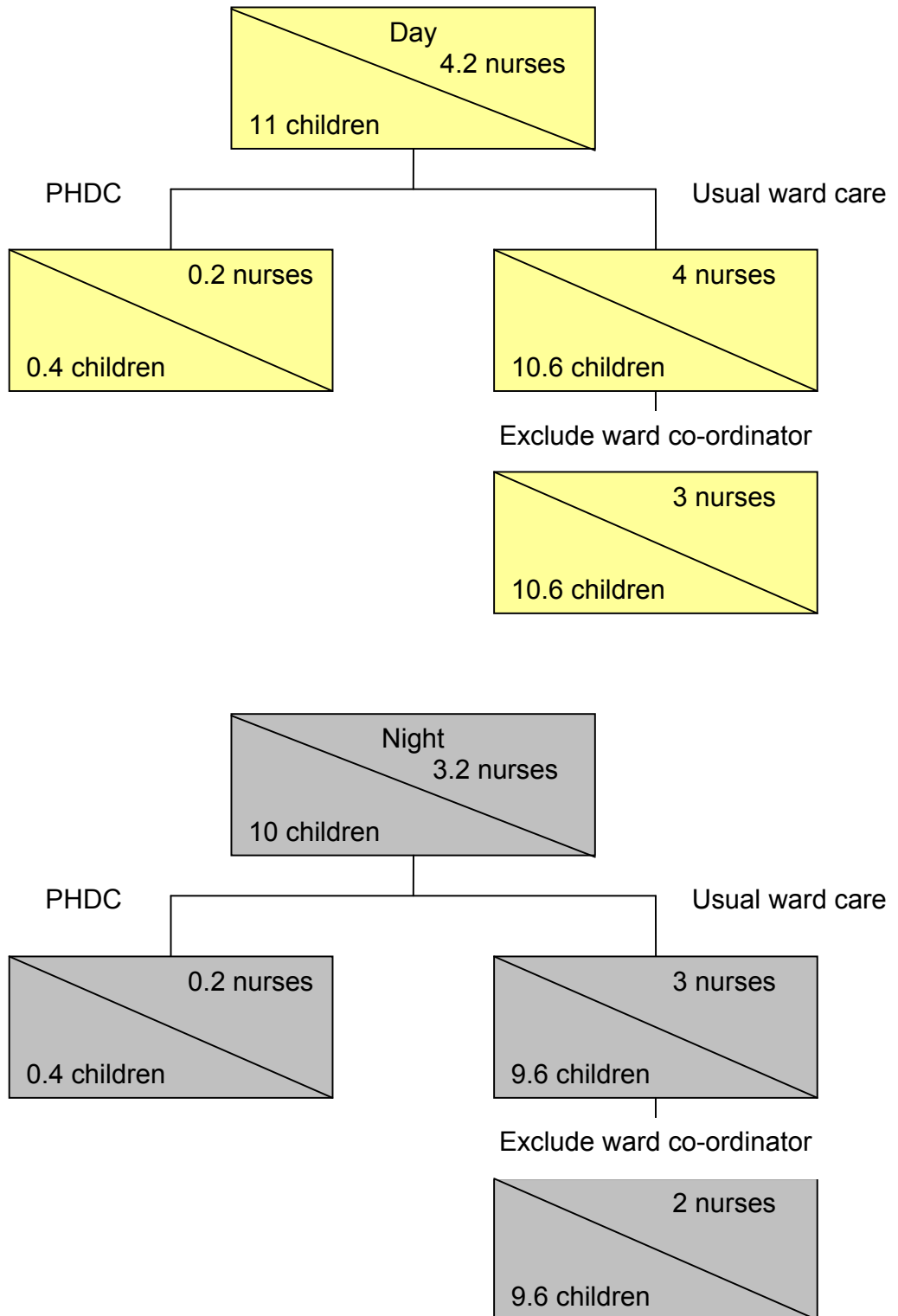
9.4.3 Estimate of Paediatric High Dependency Care Patient Activity at District General Hospitals

Eleven DGHs and 14 hospital wards were assessed as providing PHDC for 1,866 episodes for 589 children (table 9.1). Bradford Royal Infirmary (BRI) admitted critically ill children to three hospital wards where the majority of episodes (n= 442, 24%) of PHDC for 116 children were performed (table 9.1). The majority of children admitted for PHDC were male (n =323, 55%) and infants between 29 days to one year of age (n =157, 27%). More children were admitted with a respiratory illness/croup (n =134, 23%) at the DGHs. The PHDC scores ranged from six to 62 points. Half (n =941, 50%) of all PHDC episodes were for children who received a score of six points (table 9.2). Children who scored eight points or less accounted for 66% (n= 1231) of episodes (table 9.2). Only one child scored 62 points.

9.4.4 Clinical Staffing at District General Hospitals

Hospital wards at the DGHs varied in size from 16 to 31 beds (mean 23) in May to 17 to 31 beds (mean 22) in November (table 9.3). Mean daily admissions were slightly greater in November (n= 8) than in May (n= 7). The mean number of children seen, per day, on hospital wards as ward attenders, in both May and November, was three.

In May, during the day, the mean number of qualified number nurses available to care for all children was 4.5 (figure 9.2). At night the mean qualified number of staff was reduced to 2.6 (figure 9.2). For both shift periods in November, the mean number of staff available to care did not vary greatly from May, with 4.4 and 2.6 qualified nurses available to care morning and night respectively (figure 9.2). Eight percent (n= 89) of shifts in May worked with one RN (Ch), only, of which 72 (81%) shifts were for the period of the night shift. Similar figures were obtained in November, 85 (9%) shifts worked with one RN (Ch), of which, 79% (n = 67) were for the period of the night shift. A total number of 241 (29%) shifts were without a member of nursing staff with a valid APLS course in May and 205 (25%) in November.

The combined data for the DGHs showed that November was the busiest month; the mean bed occupancy by day was 15 and by night was 13 in comparison to May (by day 12, by night 11) (figure 9.2). The mean number of qualified nurses remained the same by day in May and November and also by night in May and November. The number of children's nurses available to care was reduced at night in both months (figure 9.2). At the DGHs the following grades of medical staff had valid certification in APLS courses:

- Senior House Officers (SHOs)   n= 32 (46%).
- Specialist Registrars (SpRs)   n= 24 (96%).
- Consultant Paediatricians   n= 39 (74%).

Table 9.3   A summary of all clinical nurse staffing and patient activity data at District General Hospitals by shift period for May and November (2005)

Month	Shift and time	Bed availability	Registered nurse (child)	Registered general nurse	Enrolled nurse	Clinical support worker	Non clinical support worker	Bank/ agency/OT	APLS courses	Critical care courses	HDC courses	Admissions daily	Attenders daily	Beds occupied midday	Beds occupied midnight	[1]Number of forms returned	[2]Number of PHDC bed shifts
							Mean (range)									Actual numbers	
May (2005)	Morn 12MD	23 (16-31)	4 (1-8)	0.4 (0-3)	0.08 (0-1)	1 (0-3)	0.4 (0-1)	0.2 (0-2)	1 (0-5)	0.07 (0-2)	0.5 (0-6)	7 (0-23)	3 (0-17)	12 (2-25)	11 (3-24)	212	79
	Aft 18.00		3 (1-7)	0.5 (0-3)	0.1 (0-1)	1 (0-3)	0.2 (0-2)	0.2 (0-2)	1 (0-4)	0.1 (0-1)	0.4 (0-4)						
	Night 12MN		2 (0-4)	0.5 (0-3)	0.1 (0-1)	0.6 (0-1)	0.04 (0-1)	0.3 (0-3)	0.8 (0-3)	0.1 (0-2)	0.2 (0-2)					228	75
Nov (2005)	Morn 12MD	22 (17-31)	4 (1-7)	0.3 (0-3)	0.1 (0-1)	1 (0-3)	0.6 (0-3)	0.2 (0-2)	1 (0-5)	Information not requested in November		8 (1-26)	3 (0-22)	15 (1-29)	13 (1-27)	347	132
	Aft 18.00		3 (1-6)	0.3 (0-2)	0.1 (0-1)	1 (0-3)	0.4 (0-2)	0.3 (0-3)	1 (0-5)								
	Night 12MN		2 (1-5)	0.5 (0-2)	0.1 (0-1)	0.3 (0-1)	0.2 (0-2)	0.5 (0-3)	1 (0-3)							343	127

Key
Data analysed for the period of 28 days in May and 30 days in November
[1] Total number of forms returned was irrespective of the level of care (PHDC or usual ward care)
[2] PHDC bed shift is either a day shift or a night shift
Morn = Morning
Aft = Afternoon

Figure 9.2   Mean nurse to child ratios for all District General Hospitals by shift period and month

May

4.5 nurses
12 children

2.6 nurses
11 children

PHDC

0.1 nurses
0.2 children

0.1 nurses
0.2 children

Usual ward care

4.4 nurses
11.8 children

2.5 nurses
10.8 children

Exclude ward co-ordinator

3.4 nurses
11.8 children

1.5 nurses
10.8 children

November

4.4 nurses
15 children

2.6 nurses
13 children

PHDC

0.15 nurses
0.3 children

0.15 nurses
0.3 children

Usual ward care

4.25 nurses
14.7 children

2.45 nurses
12.7 children

Exclude ward co-ordinator

3.25 nurses
14.7 children

1.45 nurses
12.7 children

Key
Day (12 midday)
Night (12 midnight)

9.4.5 **Estimate of Paediatric High Dependency Care Patient Activity on the Paediatric Intensive Care Units**

The three PICUs of the Leeds Teaching Hospitals NHS Trust were assessed as providing PHDC for 2,745 episodes for 608 children (table 9.1). Two of these PICUs were located at the Leeds General Infirmary (LGI), ward 2 (general PICU) and ward 4 (children's cardiac intensive care unit), and one PICU was located at St James University Hospital (SJUH). Within this Trust the PICUs accounted for 44% (n= 2,745) of all episodes of PHDC. Ward 2 (LGI) provided the majority of PHDC for 1,466 episodes for 249 children. Of the 608 children receiving PHDC on the PICUs, the majority (n = 344, 57%) were male and 181 (30%) children were infants. Admission following cardiac surgery was the reason for the majority (n= 181, 30%) of children receiving PHDC. Fifty-two percent (n= 1,427) of all episodes of PHDC were for the period of the day shift. According to the PHDC measurement tool the PHDC scores ranged from six to 72 yet only 11% (n= 297) of episodes scored six points and only 35% of episodes (n= 973) scored less than eight points. Sixty eight percent of episodes scored 16 points or less (table 9.2).

Sixty percent of all admissions to the PICU at SJUH in 2005 were never intubated (PICU database) (table 9.4). In comparison, 40% of all admissions to ward 2 PICU, at the LGI, and 19% on ward 4, at the LGI, in 2005 were never intubated (PICU database) (table 9.4). In 2006 there was an increase to 65% in the number of never intubated children admitted to the PICU at SJUH and a decrease in the number of children never intubated to 36% and 16% on ward 2 and ward 4 at the LGI respectively.

Table 9.4 **Comparison of data for intubated and never intubated patients admitted to the paediatric intensive care units in Leeds (2005)**

Month	Paediatric Intensive Care Unit								
	St James PICU			Leeds General Infirmary Ward 2			Leeds General Infirmary Ward 4		
	Intubated children (n)	Intubated children (n) shift period	Never intubated children n (% of total admissions)	Intubated children (n)	Intubated children (n) shift period	Never intubated children n (% of total admissions)	Intubated children (n)	Intubated children (n) shift period	Never intubated children n (% of total admissions)
		Day	Night			Day	Night			Day	Night	
Jan	3	3	2	12 (80)	17	17	16	13 (43)	30	30	25	5 (14)
Feb	4	4	2	15 (79)	14	14	14	18 (56)	26	26	26	2 (7)
Mar	6	6	4	6 (50)	19	18	19	12 (39)	22	21	22	1 (4)
Apr	6	6	5	4 (40)	18	18	16	18 (50)	22	22	22	4 (15)
May	6	6	6	6 (50)	22	21	22	8 (27)	18	18	17	10 (36)
Jun	8	8	8	10 (56)	15	15	15	12 (44)	17	17	14	3 (15)
Jul	5	5	3	7 (58)	21	18	21	9 (30)	25	25	19	4 (14)
Aug	4	4	3	7 (64)	10	4	10	8 (44)	23	23	20	1 (4)
Sept	4	4	4	9 (70)	11	11	11	11 (50)	25	25	20	7 (22)
Oct	3	3	3	12 (80)	20	20	19	10 (33)	23	23	19	7 (23)
Nov	10	9	10	7 (41)	15	15	14	6 (29)	33	33	28	3 (8)
Dec	12	12	9	6 (33)	25	25	25	9 (26)	19	19	18	8 (30)
Total	**71**	**70**	**59**	**101 (60)**	**207**	**196**	**202**	**134 (40)**	**283**	**282**	**250**	**55 (19)**

9.4.6 Clinical Staffing on the Paediatric Intensive Care Units

The mean number of beds available for the three PICUs was eight in May and November (range 5 to 10 in May and 5 to 11 in November) (table 9.5). The beds on the general PICUs (ward 2) at LGI and SJUH were flexed, nursing staff moved to the location of the new admission as beds became few and, therefore, both units were staffed as one. Five beds were available on ward 4 (CCICU). The mean bed occupancy for all PICUs was four by day and by night in May and November (table 9.5). The range of occupied beds varied by month (table 9.5). The mean number of qualified staff available to care for both shifts in May was slightly greater than in November (table 9.5). Up to two Clinical Support Workers (CSWs) were available by day and one by night to care for the long term ventilated children in both months. No shift period was worked in the PICUs without a nurse with a critical care course (CCC) in May. This information was not requested in November. A total of four (2%) shifts were without a nurse with APLS skills in May, but 17 (8%) shifts were without APLS cover in November. There were a total of 14 (3%) shifts where one RN (Ch) was available to work. Of the 14 shifts, 100% were located at the PICU at SJUH because in the absence of patients on the PICU, at SJUH, nurses were relocated to the busiest hospital wards leaving one RN (Ch), on site, to attend paediatric crash calls for the hospital.

The number of qualified nurses by day and night remained constant in the PICUs in May and November (figure 9.3). Mean bed occupancy irrespective of the level of care remained constant in both months (n= 4) (figure 9.3). The children not requiring PHDC on the PICU required PIC and a ratio of 1:1.

Medical staff, according to grade, with valid APLS certification on the PICUs was:

- Senior House Officers (SHOs) anaesthetics and paediatrics   n= 8 (89%).
- Specialist Registrars (SpRs) anaesthetics and paediatrics   n= 7 (71%).
- Consultant, intensivists and anaesthetics   n= 3 (67%).

No MMS data was returned from the PICU at SJUH.

Table 9.5 A summary of all clinical nurse staffing and patient activity data on the paediatric intensive care units by shift period for May and November (2005)

Month	Shift and time	Bed availability	Registered nurse (child)	Registered general nurses	Enrolled nurses	Clinical support worker	Non clinical support worker	Bank/ agency/OT	APLS courses	Critical care courses	HDC courses	Admissions daily	Attenders daily	Beds occupied midday	Beds occupied midnight	[1]Number of forms returned	[2]Number of PHDC bed shifts
							Mean (range)									Actual numbers	
May (2005)	Morn 12MD	8 (5-10)	5 (1-11)	0.7 (0-3)	0.04 (0-1)	0.5 (0-2)	0.6 (0-1)	0.5 (0-)	2 (0-7)	3 (1-6)	0.2 (0-1)	0.8 (0-3)	0.04 (0-1)	4 (0-10)	4 (0-10)	123	105
	Aft 18.00		5 (1-11)	0.8 (0-3)	0.05 (0-1)	0.5 (0-2)	0.5 (0-1)	0.5 (0-3)	2 (0-7)	3 (1-6)	0.2 (0-1)						
	Night 12MN		5 (1-10)	0.7 (0-3)	0	0.2 (0-1)	0.1 (0-1)	0.1 (0-1)	2 (0-4)	3 (1-6)	0.04 (0-1)					115+ 4[M]	91 + 3[M]
Nov (2005)	Morn 12MD	8 (5-11)	5 (1-10)	0.5 (0-2)	0	0.5 (0-2)	0.6 (0-1)	0.6 (0-2)	2 (0-5)	Information not requested in November		0.8 (0-4)	0.02 (0-1)	4 (0-8)	4 (0-9)	106	98
	Aft 18.00		5 (1-8)	0.4 (0-1)	0	0.5 (0-2)	0.6 (0-1)	0.6 (0-2)	2 (0-5)								
	Night 12MN		5 (1-8)	0.5 (0-2)	0	0.5 (0-1)	0	0.7 (0-2)	2 (0-5)							78+ 1[M]	71+ 1[M]

Key
Data analysed for the period of 28 days in May and 30 days in November
[1] Total number of forms returned was irrespective of the level of care (PHDC or usual ward care)
[2] PHDC bed shift is either a day shift or a night shift
[M] Missing data (day/night)
Morn = Morning
Aft = Afternoon

Figure 9.3   Mean nurse to child ratios for all paediatric intensive care units by shift period and month

May

5.8 nurses
4 children

5.7 nurses
4 children

PHDC

PIC

0.6 nurses
1.25 children

0.5 nurses
1.1 children

5.2 nurses
2.75 children

5.2 nurses
2.9 children

Exclude ward co-ordinator

Key
Day (12 midday)
Night (12 midnight)

4.2 nurses
2.75 children

4.2 nurses
2.9 children

November

5.5 nurses
4 children

5.5 nurses
4 children

PHDC

PIC

0.5 nurses
1 child

0.4 nurses
0.8 children

5 nurses
3 children

5.1 nurses
3.2 children

Exclude ward co-ordinator

4 nurses
3 children

4.1 nurses
3.2 children

Note in the PICUs the IC ratio of nurses to children is 1:1

9.4.7   Estimate of Paediatric High Dependency Care Patient Activity on the Specialist Hospital Wards

The specialist hospital wards were the largest group of hospital ward types and included all hospital wards at the LGI and SJUH (excluding the PICUs) and the regional burns centre (RBC) at Pinderfields Hospital. These wards were assessed as providing 3,805 episodes of PHDC for 685 children on 15 hospital wards (table 9.1). The majority of children receiving PHDC were male (n =361, 53%). Children aged 10 to 16 years were the group that accounted for the majority of PHDC (n =168, 26%). Of all children requiring PHDC, the majority (299, 44%) were admitted with a surgical problem and for the period of the day shift (n= 1,909, 50.2%). The PHDC scores ranged from six to 58. Forty percent (n= 1,518) of episodes of PHDC received a score of six points and 62% (n= 2,246) received a score of eight points or less (table 9.2).

Of the 6,224 episodes of PHDC provided on the Leeds hospital wards 1,951 (31%) episodes of care were for children with a Leeds postcode, and 4,381 (70%) episodes of PHDC were for children with a West, North and East Yorkshire postcode. One quarter (n= 11) of all children admitted for PHDC, to the RBC at Pinderfields Hospital, with a burns injury during 2005 were from the Leeds area, or had a Leeds postcode. Children most commonly admitted to the RBC were aged one to four years (n = 16, 36%).

9.4.8   Clinical Staffing on the Specialist Hospital Wards

The specialist hospital wards had a mean availability for May and November of 14 beds (range 5 to 23 in May and 5 to 27 in November). Daily mean ward admissions and ward attenders were slightly greater in November (n= 3 and n= 0.8) respectively (table 9.6). This group of hospital wards included the three mixed adult and children's wards that employed small numbers of RN (Ch) and therefore these three wards had 216 (86%) shifts in May and 227 (84%) shifts in November where a RN (Ch) was not available for duty. A maximum of three nurses with CCCs were available on the RBC at Pinderfields Hospital.

On the primary paediatric specialist wards only 44 (2%) shifts worked with one RN (Ch), but 38 (80%) were for the period of the night shift. Sixty percent (n= 444) of shifts were without nurses with valid APLS skills in May and 52% (n =259) in November. All primary paediatric specialist hospital wards were located between the two hospitals in Leeds at the LGI and SJUH.

The mean bed occupancy irrespective of care level on the specialist hospital wards was higher in November (by day n= 10, by night n= 9) than May (by day n= 9, by night n= 8) (figure 9.4). The mean number of children receiving PHDC was higher by both day and night in November. The qualified nurses providing the care did not increase accordingly in November (figure 9.4). A greater proportion of qualified nursing staff to children was available to work during the day in both months.

On the specialist hospital wards 42% (n= 13) of consultants, 88% (n= 15) of SpRs and 29% (n = 11) of SHOs held valid certification in APLS.

Table 9.6 **A summary of all clinical nurse staffing and patient activity data for specialist hospital wards by shift period for May and November (2005)**

Month	Shift and time	Bed availability	Registered nurse (child)	Registered general nurse	Enrolled nurse	Clinical support worker	Non clinical support worker	Bank/ agency/OT	APLS courses	Critical care courses	HDC courses	Admissions daily	Attenders daily	Beds occupied midday	Beds occupied midnight	¹Total no of forms returned	²Total no of PHDC bed shifts
						Mean (range)										Actual numbers	
May (2005)	Morn 12MD	14 (5-23)	3 (0-9)	1 (0-7)	0.04 (0-1)	0.4 (0-2)	0.3 (0-2)	0.08 (0-1)	0.5 (0-3)	0.3 (0-3)	0.1 (0-2)	2 (0-11)	0.6 (0-5)	9 (0-26)	8 (1-23)	578	111
	Aft 18.00		3 (0-8)	1 (0-5)	0.03 (0-1)	0.4 (0-2)	0.2 (0-2)	0.09 (0-1)	0.4 (0-2)	0.2 (0-3)	0.1 (0-2)						
	Night 12MN		2 (0-6)	0.8 (0-5)	0.07 (0-1)	0.4 (0-2)	0.08 (0-1)	0.2 (0-3)	0.1 (0-1)	0.1 (0-2)	0.1 (0-2)					576 + 9ᴹ	119 + 2ᴹ
Nov (2005)	Morn 12MD	14 (5-27)	3 (0-10)	1 (0-7)	0.04 (0-1)	0.6 (0-2)	0.5 (0-2)	0.08 (0-2)	0.6 (0-3)	Information not requested in November		3 (0-10)	0.8 (0-7)	10 (1-24)	9 (0-25)	507	164
	Aft 18.00		3 (0-8)	1 (0-4)	0.02 (0-1)	0.5 (0-2)	0.3 (0-2)	0.07 (0-2)	0.5 (0-3)								
	Night 12MN		2 (0-6)	1 (0-4)	0.08 (0-1)	0.4 (0-1)	0.06 (0-1)	0.2 (0-2)	0.2 (0-2)							603 + 12ᴹ	189 + 8ᴹ

Key
Data analysed for the period of 28 days in May and 30 days in November
¹ Total number of forms returned was irrespective of the level of care (PHDC or usual ward care)
² PHDC bed shift is either a day shift or a night shift
ᴹ Missing data (day/night)
Morn = Morning
Aft = Afternoon

Figure 9.4   Mean nurse to child ratios for all specialist hospital wards by shift period and month
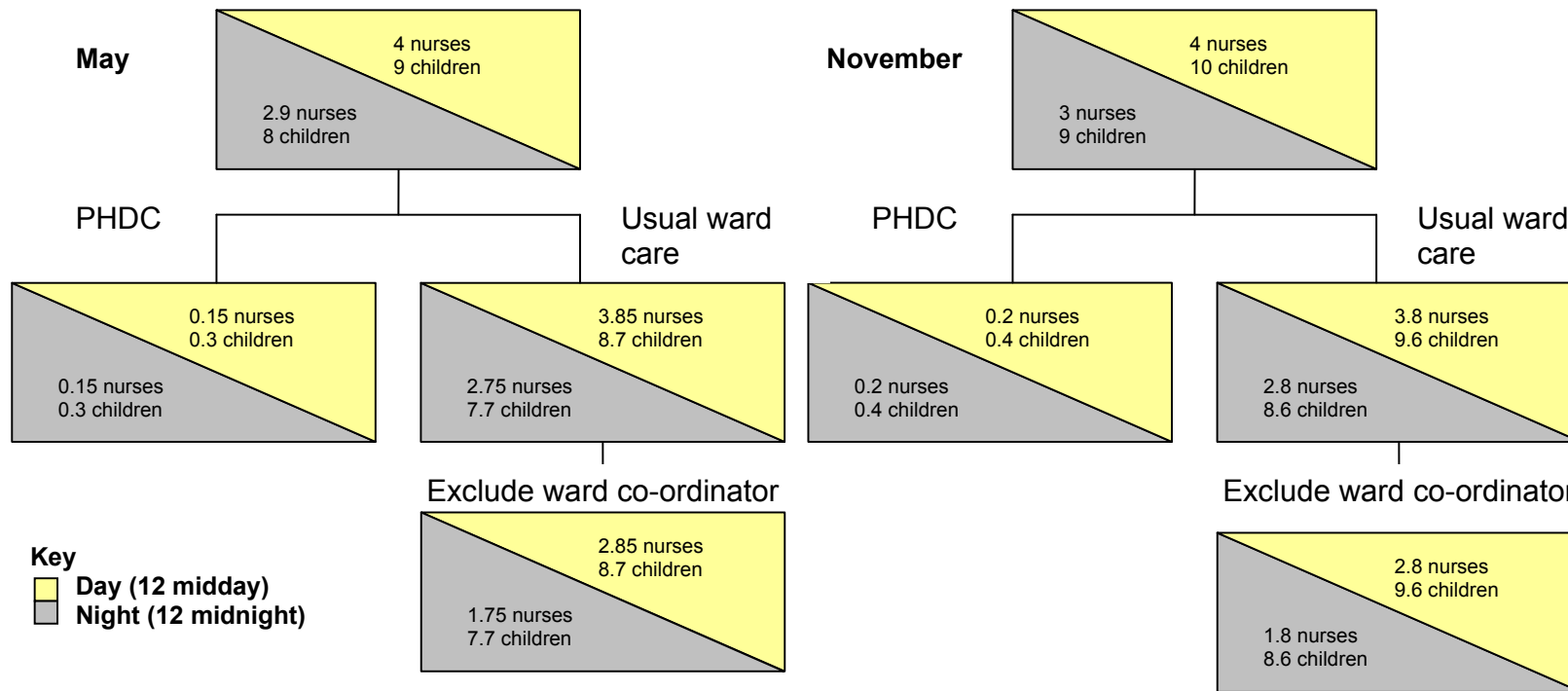
9.4.9 Estimate of Paediatric High Dependency Care Patient Activity at a District General Hospital with Specialist Paediatric Facilities

The four children's wards at Hull Royal Infirmary (HRI) were assessed as providing a total of 661 episodes of PHDC for 166 children (table 9.1), yet 156 of PHDC episodes were outside of the dedicated PHDU. The majority of children admitted to HRI were male (99, 60%) and were infants (42, 25%). Surgical problem was the most common (n= 45, 27%) reason for PHDC admission. The PHDC scores at HRI ranged from six to 54 (table 9.2). Thirty two percent (n= 211) of episodes of PHDC were given a score of six points and 343 (52%) episodes of HDC scored eight or less points (table 9.2). Within the PHDU at HRI 47% (n= 236) of episodes of PHDC scored eight points or less (table 9.2). Outside of the PHDU 60% of children received PHDC for a surgical problem.

9.4.10 Clinical Staffing at a District General Hospital with Specialist Paediatric Facilities

Beds available for the wards at HRI ranged from four to 25 (mean n= 16) for both data collection periods (table 9.7). Four beds were designated for PHDC on ward 200. Hospital wards were better staffed with qualified nurses for the period of May than November both by day and by night. In November 3.11 mean qualified staff were available to care by day and 2.11 by night. In May 164 (49%) shifts were without a nurse with APLS skills and 169 (47%) in November. Eight (9.5%) shifts on the PHDU were without a nurse with APLS skills in May and only one shift was without APLS skills in November. For all wards at HRI only one (0.3%) shift was worked with one RN (Ch) in May and 5 (1.4%) in November. All six (100%) shifts with one RN (Ch) were for the period of the night shift. During both months all nurses with HDC courses were employed on the PHDU at HRI, 79 (45%) shifts on the PHDU worked with a member of staff with a HDC course. Sixty six (38%) shifts on the PHDU were worked with a nurse with a critical care course in May and November.

At night, fewer mean qualified nurses were available to care and this was particularly noticeable in May when, after exclusion of a ward co-ordinator, only

one mean qualified nurse was available to care for 11 children requiring usual ward care (figure 9.5).

Although the MMS was returned for the Hull wards with the number of medical staff according to grade documented, no information was documented on the number of doctors with valid APLS skills.

Table 9.7   **A summary of all clinical nurse staffing and patient activity data at a District General Hospital with specialist paediatric facilities by shift period for May and November (2005)**

Month	Shift and time	Bed availability	Registered nurse (child)	Registered general nurse	Enrolled nurse	Clinical support worker	Non clinical support worker	Bank/ agency/OT	APLS courses	Critical care courses	HDC courses	Admissions daily	Attenders daily	Beds occupied midday	Beds occupied midnight	¹Total no of forms returned	²Total no of PHDC bed shifts
							Mean (range)									Actual numbers	
May (2005)	Morn 12MD	16 (4-25)	4 (2-6)	0.1 (0-1)	0.1 (0-1)	0.5 (0-2)	0.5 (0-3)	0.2 (0-3)	0.6 (0-3)	0.2 (0-2)	0.3 (0-3)	4 (0-15)	1 (0-8)	9 (0-25)	9 (0-20)	74	30
	Aft 18.00		4 (2-6)	Missing (0)	0.1 (0-1)	0.4 (0-2)	0.2 (0-1)	0.1 (0-2)	0.6 (0-3)	0.2 (0-2)	0.3 (0-3)						
	Night 12MN		3 (1-4)	Missing (0)	0.01 (0-1)	0.3 (0-1)	0.04 (0-1)	0.2 (0-2)	0.5 (0-3)	0.2 (0-2)	0.1 (0-1)					83	26
Nov (2005)	Morn 12MD	16 (4-25)	3 (2-5)	0.06 (0-1)	0.05 (0-1)	0.5 (0-2)	0.2 (0-2)	0.1 (0-1)	0.8 (0-3)	Information not requested in November		5 (0-16)	1 (0-6)	12 (0-25)	11 (0-25)	62	25
	Aft 18.00		3 (2-5)	0.06 (0-1)	0.04 (0-1)	0.5 (0-2)	0.1 (0-1)	0.1 (0-2)	0.7 (0-3)								
	Night 12MN		2 (1-4)	0.1 (0-2)	0.01 (0-1)	0.3 (0-1)	0.03 (0-1)	0.3 (0-1)	0.5 (0-3)							98	32

Key
Data analysed for the period of 28 days in May and 30 days in November
¹ Total number of forms returned was irrespective of the level of care (PHDC or usual ward care)
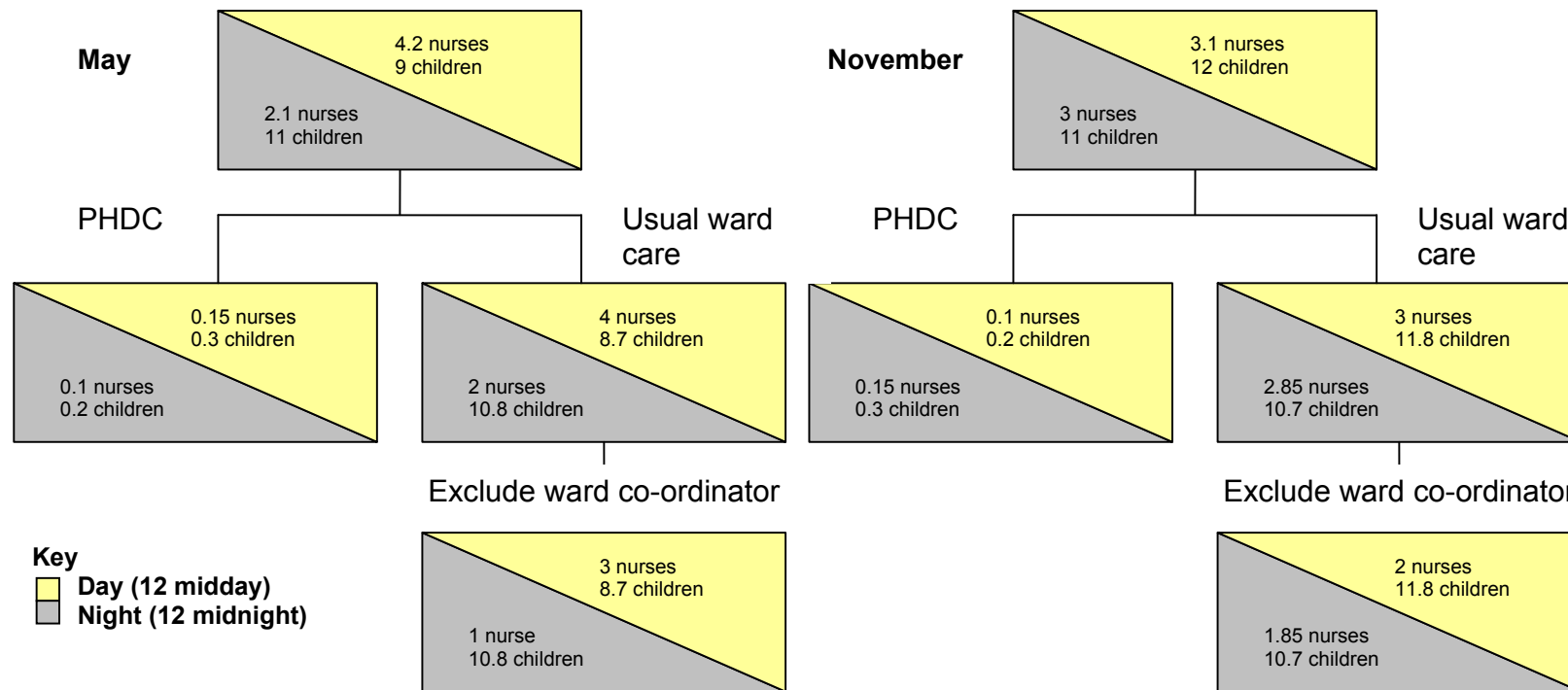**² PHDC bed shift is either a day shift or a night shift**
Morn = Morning
Aft = Afternoon

Figure 9.5   Mean nurse to child ratios for the District General Hospital with specialist paediatric facilities by shift period and month

9.5   Discussion

In the UK this study is the first of its kind to report estimates of PHDC using a PHDC measurement tool. The findings are unique in their coverage of all hospital ward types delivering paediatric hospital care and also the use of staffing data to match the dependency care needs of children to the available skills of the workforce. Overall the results have provided information to facilitate improved health care planning across the region, for all hospital wards, with specific details to permit the quantification of resource requirements. For the Paediatric Critical Care Network of the Yorkshire and Humber Specialist Commissioning Group (North) the outputs of the study have raised issues that require resolution in order to support the delivery of improved critical care services for children in the region. Specific concerns were highlighted in relation to staffing levels and the need for staff development, training and education.

9.5 1   Estimate of Paediatric High Dependency Care Patient Activity

Application of the 36 item final PHDC measurement tool to the paediatric patient activity episode data (n= 24,540) estimated 9,077 inpatient episodes or 4,538 PHDC bed days for children in the region. All of the hospital wards included in the study delivered some PHDC, but there was considerable variation between the volume of episodes of PHDC by hospital ward ranging from eight to 1,466 episodes per ward. The minority of episodes (n= 8, 0.1%) occurred on ward 2 (BRI) and the majority (n = 1466, 16%) occurred on ward 2 (PICU) at the LGI. Where PHDC activity was low this possibly represented a true situation or may have been a consequence of incomplete form completion and submission. Admission for PHDC affected 1,763 children; one quarter (n= 436) of whom were infants aged 29 days to one year, possibly reflecting health problems associated with immature physiological development.

Extrapolation of results from this study to the national picture estimated that 63,434 PHDC inpatient bed days per annum were required for children aged 0 to 14 years in England. This was slightly less than the figure (n= 73,000) reported by the Information Standards Board (2007). The discrepancy in the figures may be explained by the lack of age restriction in the Information Standards Board (ISB) figures which applied to all admissions to children's wards. The findings for the Yorkshire region are therefore similar to the ISB

estimates. For the PHDC length of stay, the median, in Yorkshire was one day (range 1 to 125 days). This figure was broadly consistent with data from the small audit undertaken in Scotland by Watchorn (2006), where the average length of PHDC stay was 28.7 hours and with the figure reported by the South West Audit of Critically Ill Children (2007) of 1 day or less. The Yorkshire study did not record exact admission and discharge times so it was not possible to produce precise lengths of stay.

While this study quantified PHDC occurring by hospital ward, by hospital and within each hospital trust, a wide range of scores for individual episodes of PHDC (range 6 to 72) showed that within any single episode there were wide ranging needs for individual children. One third of all episodes of PHDC scored six points, 10% of which was for a single intervention only. For the higher scores it was possible these were children requiring PIC but the tool was not able to discriminate this higher level of care. High scores were likely to reflect a child who was becoming increasingly unwell but the tool may have measured greater provision of non critical interventions. The number of interventions scored by the tool does not necessarily reflect how unwell a child may be. For example a child receiving 10 interventions with as score of 50 may not necessarily be more unwell than a child receiving 12 interventions with a score of 50. The inability of the tool to assess how sick children are does not impact on its applicability to measure PHDC which will be given to children with a wide range of needs; the original purpose was to discriminate between PHDC and usual ward care.

9.5.2   Estimate of Paediatric High Dependency Care Patient Activity by Hospital Ward Type

PHDC activity was assessed by the type of hospital ward to provide the Paediatric Critical Care Network of the Yorkshire and Humber Specialist Commissioning Group (North) with data on the quantity and locality of PHDC and the corresponding staffing skills available for the delivery of care. The specialist hospital wards (n= 15) were the commonest type of hospital ward delivering the majority of PHDC episodes (n = 3,805). These wards, collectively, differed from the three other hospital ward types, particularly, in the age range of children treated for PHDC. The majority of PHDC episodes on the specialist

hospital wards were delivered to those aged 10-16 years, compared to the other hospital ward types, where infants were the most common age group. One possible explanation for the different age profiles by ward type is that the specialist hospital wards cared for young people with chronic conditions which required repeated treatments and frequent admissions.

The 11 participating DGHs had an estimated total of 1,866 episodes of PHDC for 589 children, equating to 933 inpatient PHDC bed days. Of all children admitted to a DGH, 8% and 12% required PHDC in May and November respectively. This volume was consistent with the report by the Department of Health (2001a) who estimated that between 5% to 15% of all admissions to a DGH required PHDC. Although 0.5% to 1% of children admitted to a DGH require stabilisation and initiation of PIC Department of Health (2001a), the Yorkshire study reported the majority of children as completing their PHDC at the DGH to which they were first admitted.

Within the DGH with specialist paediatric facilities there was one hospital with a dedicated PHDC facility; this was the only one within the region. It was notable that, despite the availability of a PHDU, almost one quarter (n = 156, 24%) of all episodes of PHDC occurred on the three other children's wards at this hospital; the majority (60%) of which, required PHDC for a surgical problem. Further investigation of this issue attributed this distribution to a preference of the surgeons for ward care rather than PHDU care. Informally the surgeons working at the hospital inferred that specialist surgical skills were lacking in the PHDU. This inappropriate referral pattern for children requiring PHDC raised issues for hospital managers.

PICUs admitted children requiring PIC but also children that required step down care from PIC and step up care from PHDC. Findings for the three PICUs, at the Leeds Teaching Hospital NHS Trust, showed that 2,745 episodes of PHDC were provided, nearly half (44%) of all episodes of PHDC for the entire Trust. The PICUs did not have any beds dedicated to PHDC but all of the units admitted children who were never intubated with 60% of all PICU admissions at SJUH never being intubated. This was nearly double the national average proportion, reported by the Paediatric Intensive Care Audit Network (Paediatric

Intensive Care Audit Network, 2006), where 34% of admissions to a PICU did not require invasive ventilation. However there was considerable national variation ranging between 12% and 95%. Although the number of never intubated children admitted to the PICUs in Leeds was variable, evidence from this study and the Paediatric Intensive Care Audit Network (2006) suggested that many children were admitted to the PICUs for PHDC. This was, possibly, to prevent deterioration to PIC and reflected the concentration of available clinical skills and technological monitoring at any one location.

For individual children the mean PHDC scores varied by different ward types. Children in PICUs had higher mean scores (16 points) compared to children treated at DGHs (10 points), specialist hospital wards (9 points) and a DGH with specialist paediatric facilities (10 points). The higher scores occurring in the PICUs may be explained by the fact that children were actually more unwell but there is also the possibility, in this setting, that clinical staff may have intervened more frequently because of availability of their skills and technological resources. Across all of hospital ward types the maximum PHDC scores were high. At the DGHs the maximum score was 62 points, in the PICUs 72 points, at specialist hospital wards 58 points and at the DGH with specialist paediatric facilities the maximum score was 54 points. High scores cannot identify those requiring PIC as the measurement tool does not provide a threshold for the boundary between PHDC and PIC. However it can be seen that all hospital ward types were, at times, treating children, who were extremely ill and measured as requiring a vast amount of nursing and medical intervention.

9.5.3 Clinical Staffing

It is not the intention here to discuss in detail the results of hospital ward activity and the achievement of the government standards set for the number of skilled nurses and doctors in practice. At macro level this information was presented in chapter 8. Nevertheless themes such as the lack of APLS trained staff and the reduced number of qualified children's nurses on some shifts will be alluded to. The nurse to child ratios will be compared for each hospital ward type in relation to patient acuity. At micro level the impact of PHDC and usual ward care needs of children on individual nurses on the ward will be discussed below.

9.5.4 Clinical Staffing and the Hospital Ward Types

As would have been expected the number of available qualified staff, per shift, varied between hospital wards; although overall, for the total combined data set, irrespective of ward type, the requirement for PHDC remained constant day and night (n= 0.4 children). Irrespective of dependency level the mean total bed occupancy rates varied slightly by shift period (n= 11 by day, n= 10 by night). Hence, the mean number of qualified nurses providing care on each hospital ward by day was 4.2 for 11 children (figure 9.1) and 3.2 nurses for 10 children at night. Using the recommended HDC nurse to patient ratios of 1 : 2 (Department of Health 1996), 0.2 qualified children's nurses were required for 0.4 children both day and night. It was suggested that the needs of children requiring PHDC were provided at the expense of other children on the ward (Doman et al, 2004). Therefore as a result, on removal of the PHDC component (0.4 children and 0.2 nurses), individual nurses delivered usual ward care to four children during the day and five children during the night Overall these results indicate that sufficient staff were available to manage the volume of usual ward care work.

All hospital ward types reduced the mean number of nurses on duty at night with the exception of the PICUs where mean nurse staffing levels remained relatively constant (n= 4), both day and night, in summer and winter. Reduced staffing levels at night were reported elsewhere (Ball and Pike, 2005). The RCN employment survey of 2005 found that only 2.4 qualified nurses at night cared for 21 patients (a ratio of 8.7 patients per nurse) this was in contrast to the day where 3.3 qualified nurses delivered care to 20 patients (a ratio of 6 patients per nurse) (Ball and Pike, 2005). This survey achieved only a 55% response rate, collected data from all types of hospital wards in the UK irrespective of age group and specialty, and the dependency needs of these patients were not taken into account.

Reducing qualified nursing staff at night without a corresponding reduction in the total number of patients and the number of patients requiring PHDC increases vastly the workload on individual nurses. It is not clear why the standard of two RN (Ch) was achieved during the day but was a problem at night. This may be due to the employment of permanent night staff, poor nurse

roster management or inadequate number of RN (Ch). Whatever the reasons, the lack of RN (Ch) at night had a major impact on the delivery of safe and effective care for children on the hospital wards in the region. The disproportionate number of staff to children was particularly noticeable at night on wards at the DGH with specialist paediatric facilities where in May the number of children per nurse was 10.5. In addition in May nearly half of all shifts on these wards were without a nurse with APLS skills and no record of APLS skills was provided for doctors. In November the DGHs fared only slightly better, the number of children per nurse was 8.7 yet, comparably, one quarter of shifts (201, 25%) was without a nurse with APLS skills, but nearly three quarters (n= 39, 74%) of Consultants and nearly all SpRs (n = 24, 96%) had valid APLS skills. While it is acknowledged that other (unqualified) staff members carry out some nursing duties, it is the responsibility of qualified nurses to assess, plan, implement and evaluate all care and recognise anomalies in the age related physical parameters (such as respiratory and pulse rate) that aid recognition of the deteriorating child. Unqualified staff are unable to apply competent judgment for children of varying ages and therefore, qualified nurses need to be sufficient, in number and skills, to be able to prioritise their workload, support children and families that require usual ward care but importantly identify the critically ill and intervene.

Of the 15 specialist hospital wards, 14 wards were situated within the two hospitals (LGI and SJUH) of the Leeds Teaching Hospitals NHS Trust. These hospital wards were the most incompetent with regard to nursing shift cover for APLS skills. Over half of all shifts in May and November were without the presence of such a nurse. This may be due the fact that a PICU was located on both sides of the city from which a nurse and doctor attended crash calls or reviewed deteriorating children on the hospital wards. If the reason for the lack of APLS skills on specialist wards was due to this factor, two important issues must be raised for these wards:

- The paediatric crash teams were not designated. Doctors and nurses performed this duty alongside other duties. When the PICUs are busy it is possible that staff will not be free to attend, leaving ward staff to manage any scenario.

- What action is taken by clinical ward staff at the time a child presents in extremis is vital to the outcome of the child.

Therefore; skilled, trained clinical staff should be available to follow correct procedure and where possible, prevent progression, to a respiratory or cardiopulmonary arrest.

9.6   Conclusion

A large, clear and precise description of PHDC for all hospital wards was presented to the Paediatric Critical Care Network of the Yorkshire and Humber Specialist Commissioning Group (North). This comprehensive depiction of PHDC united paediatric patient activity and hospital ward staffing levels and is the first of its kind nationally. The detailed feedback presented to the commissioners, the hospital managers and the ward staff that collected the data, provided an assessment of the quantity of PHDC, in relation to the skills of nurses. All reports were enthusiastically received and all comments were fed back into the project. The information presented enabled commissioners and managers to address, resource priorities and staffing and training issues in specific locations where the achievement of government standards was poor.

Without designated PHDC beds, PHDC has to be provided on the hospital wards. However care must be extended to all children on hospital wards, irrespective of level, and therefore must include PIC (stabilisation and initiation of level 2 care), PHDC and usual ward care. The substantial amount of PHDC that occurred on all hospital ward types compromised the ability of some hospital wards within the region to deal safely and effectively with the complex level of care needs for all children admitted. This had a considerable impact on the workload of nursing staff and the delivery of care within the region, particularly at night. The DGHs and the DGH with specialist paediatric facilities were in excess of the one nurse to five children ratio during the night as suggested by the Royal College of Nursing (2003). The DGHs were only able to

provide 1 : 7.2 and 1 : 8.7 nurse to child ratios in May and November respectively and the DGH with specialist paediatric facilities only provided nurse to child ratios of 1 : 10.8 and 1 : 5.7 in May and November respectively. Both an increase in the skills and numbers of staff are required if children requiring PHDC are to be safely cared for outside of the PICUs and PHDUs. Hospitals that have PIC facilities and general paediatric hospital wards should not be an exception to the Department of Health (1997a; 1997b; 2001) guidance.

The PICUs delivered a significant amount of PHDC. They were well resourced to manage critical care and almost achieved the standards set by the Department of Health (1997a). A lack of designated PHDC facilities within the region, large numbers of skilled clinical staff within the PICU and few skilled nursing staff on the general and specialist hospital wards may have fostered the need for the admission of children with PHDC needs to the PICUs. This may be a national problem and not a local one if evidence from the Paediatric Intensive Care Audit Network (2006) is to be used for the number (34% in 2005) of children admitted to a PICU, not requiring invasive ventilation.

This study concurs with evidence from the Royal College of Nursing (1999) who report on the poor adherence to national guidelines. Yet without data from other regions within the UK it is difficult to put this work into a national context. Shortages of qualified and skilled children's nurses have serious implications for the care and safety of all children irrespective of the level of care being provided. The commissioners for children's services and hospital managers were confident that the results reflected PHDC and believed that this work would have great value for informing health care policy for children in the region.

10 Discussion and Conclusion

In this chapter a statement of the key findings related to PHDC activity and clinical staffing are presented and their implications put into the context of health care delivery. A critical evaluation of each phase of the study was provided in the discussion of each chapter however the overall strengths and limitations in relation to the study design and the minimisation of bias will be discussed here. Suggestions for future work and a final conclusion end this chapter and provide closure for the study.

10.1 Key Findings

The aims of the study were achieved with the design, development and validation of a novel measurement tool developed for quantifying PHDC in a variety of hospital settings in the English NHS. Application of the tool to clinical and demographic data collected from DGHs, PICUs, specialist wards and DGHs with specialist paediatric facilities across West, North and East Yorkshire has provided vital information on the volume of PHDC being delivered across the region, irrespective of the type of hospital. Of all paediatric hospital admissions in the region, approximately, 5% (398 children) were estimated as requiring PHDC according to the PHDC measurement tool developed for this project.

This study was novel firstly in its ability to formally assess the dependency needs of children using the PHDC measurement tool and secondly to then match them to the skills of the available workforce. The question of whether qualified staff were available to treat the children identified as needing PHDC was addressed by the workforce and staffing component of the project. This showed that the vast majority (96%) of shifts were covered by the recommended number of RN (Ch). However it was notable that over one quarter of shifts were without a nurse with APLS skills.

These results showed that the delivery of PHDC was not restricted to any location of care and took place on all paediatric hospital wards within the region, although management of care for children with varying dependency needs differed by location. Overall this study has provided an essential information base for organisational and strategic planning of PHDC across the region and has therefore fulfilled the aim of improving the delivery of care to sick children.

10.2 Implication of the Findings

Some difficulties were experienced in focusing both the original appraisal of the literature and the subsequent contextualising of the study findings. Appraisal was hampered by the dearth of published evidence pertaining to the delivery of HDC, particularly PHDC. In addition, information highlighting the attributes of HDC such as staff concern, patient acuity and severity of illness concentrated upon the individualistic nature of HDC and it was not possible to disentangle one attribute from another to provide a clear description of the group of characteristics that defined HDC. There was, by comparison, a substantial amount of informative literature to critique on health care policy allied to HDC available to critique. Although the literature relating to PHDC was meagre the wealth of clinical knowledge and skills within the region and nationally were vital for driving the study forward.

10.2.1 Paediatric High Dependency Care Activity

As a result of a highly successful data collection procedure, children admitted to hospital in West, North and East Yorkshire for general and specialist PHDC in 2005 were identified and quantified using the 36 item PHDC measurement tool. A total of 1,763 children were estimated as receiving PHDC during 9,077 episodes of care. This equated to 4,539 beds days for the region. The resident study population in 2005 for children aged 0-14 years was, 629,100 (Office for National Statistics, 2006), of which 1,433 (0.2%) children (0-14 years) with West, North and East Yorkshire postcodes were admitted for PHDC. The Yorkshire region is representative of the rest of England and Wales in terms of population demography and socio-economic status (Feltbower, Lewis, Picton and Richards et al, 2004), therefore assuming that healthcare services and inpatient profiles are also equivalent, these results are generalisable to the country as a whole.

The findings from this study were similar to the national estimate provided by the Information Standards Board (2007). Applying the results to the national population, 63,434 national PHDC inpatient bed days for children aged 0-14 years were estimated compared to 73,000 national bed PHDC bed days projected by the Information Standards Board (2007). This inconsistency may be attributed to the different upper age ranges in the two assessments; the Office for National Statistics employed a precise upper age of 14 years compared to the lack of an upper age restriction in the Information Standards Board report.

Length of stay for PHDC had comparable estimates for the Yorkshire study to the audit undertaken in Scotland by Watchorn (2006) and the South West Audit of Critically Ill Children (2007). Although the Scottish study calculated an average length of PHDC stay of 28.7 hours, this was only four and a half hours longer than the median length of PHDC stay, of one day (24hours) (range 1 to 125 days), found for the Yorkshire region.

No published figures for the number of resourced PHDC beds or suggested ratios of PIC to PHDC beds are available nationally. The total number of paediatric beds available for the study region, irrespective of the level of care, was 580. Of the 580 beds, 15 (3%) beds were designated for PIC. Twelve (2%) beds at three hospitals were provided for PHDC; four only were actually designated and resourced for PHDC. Figures for adult critical care services suggest ratios of HDC to IC beds should be 2:1 and for a population of 500,000 the number of IC beds should be 21 (Lyons et al 2000). Although these figures should not be generalized to the paediatric population, 30 PHDC beds (2 PHDC : 1 PIC) would be required to serve the population of West, North and East Yorkshire, based on the formula given by Lyons et al (2000). In comparison, using data from this study, 21 beds (60% occupied) were estimated to serve the needs of the region (Rushforth, 2007; unpublished) slightly less than the figure of 30, as recommended by Lyons et al (2000).

The four bedded PHDU located at HRI provided only 5.6% (n= 505) of the total episodes of PHDC for the region. This highlights the small amount of PHDC occurring within the designated PHDU in the region. Although the PICUs cared

for critically ill children, some requiring PHDC, the number of episodes of PHDC provided on the general and specialist wards was estimated to be 5,827 (64%). Some of these children were extremely ill, with PHDC scores ranging from six to sixty-two, however the association between illness severity and tool scores were not verified during the study.

10.2.2 Locations of Paediatric High Dependency Care

An important finding of this study was clear demonstration of the variation in the amount of PHDC occurring by hospital ward but also by hospital type. It was estimated that 8% of all children admitted to the DGHs in May and 12% of children in November required PHDC. These findings are consistent with those of the Department of Health (2001a) who estimated that between 5% to 15% of all children admitted to a DGH required PHDC. The majority of PHDC estimated by this study, was provided by the specialist hospital wards in the region, yet 20% (n= 751) of the total volume of episodes of care were for children resident outside the region. Of the 6,224 (69%) episodes of PHDC occurring within the two Leeds Teaching Hospitals, 44% (n= 2,745) of all episodes of care took place on the three PICUs. A total of 1,372 bed days of PHDC represented 30% of the PICUs total occupancy. In 2005, 151 children were denied access to one of the three PICUs at the Leeds Teaching Hospitals NHS Trust (Leeds Hospitals NHS Trust Database, 2008) suggesting that PHDC was possibly, inappropriately delivered in a PICU. According to the national Paediatric Intensive Care Audit Network (2007) in England and Wales, 26% of all admissions to the PICUs (in 2005) were never intubated; this varied by NHS Trust; ranging between 11% and 81%. Although difficult to clarify, it is therefore possible that some children were admitted to PICU for PHDC in other regions of the UK and in addition to providing step up care from PHDC and step down care from PIC use the PIC beds flexibly to admit children for PHDC. If this situation is familiar to PICUs, it is not clear if the reason to admit children to a PICU for PHDC is due to the lack of PHDUs, the lack of nursing skills or shortages of nursing staff on the hospital wards.

10.2.3 Variability in the Provision of Care

As expected there was variability in the provision of care by hospital ward type, but within the region as a whole poor adherence to national guidelines, with

respect to the number of children's and trained APLS nurses available to care, was evident.

Just over one quarter (28%, n=1,561) of shifts on primary paediatric wards in the region were without a nurse with APLS skills. National comparisons in relation to the number of children's nurses with APLS skills cannot be made because no other studies exist that give this information. Nevertheless this study concurs with the work performed in the adult services by Ball and Pike (2005) and by work performed in children's services by the Royal College of Nursing (1999). Both studies reported a lack of qualified nursing and qualified children's nursing provision, respectively, particularly at night. Although only 4% (n= 250) of shifts on primary paediatric wards in region were without two RN (Ch), the majority (n= 191, 76%) of these were for the period of the night shift.

The number of children overall, in region, requiring usual ward care varied little by day and night. PHDC, overall, did not vary at all by day and night (0.4 children per hospital ward), yet some hospital wards varied in their ability to provide usual ward care. The DGHs and the DGH with specialist paediatric facilities managed the care of children with large ratios of children to small numbers of qualified nurses, particularly, during the night. For example in May at the DGH with specialist paediatric facilities one RN (Ch) was available to care for 10.8 children requiring usual ward care. Despite the variability of hospital ward types to provide PHDC and usual ward care, the staffing numbers and skills remained constant in the PICUs which were well resourced to manage the amount of PHDC. This, combined with a lack of designated PHDC facilities and available skilled staff on general and specialist wards possibly attracted a large volume of PHDC to the PICUs.

10.3   Evaluation of the Study Methods

At the start of this prospective cohort study an outline research proposal set out the aims, study design, analysis techniques, and the responsibilities of the research advisory group to lay the foundations for the PHDC study (Appendix 14). In a desire to measure PHDC, the pre-specified study design had to be flexible to manage the challenges of a complex and ill defined concept while providing opportunity for a large number of diverse hospital wards within the

region to take part. All study designs have potential pitfalls. The strengths and limitations of the cohort study in relation to other methodologies is discussed here. Additionally, because this study was dedicated to the development of a measure, each step was concerned with the reduction of measurement error. Therefore the strengths and limitations of the study in relation to the minimisation of bias are also discussed.

10.3.1   Study Design

Careful consideration of study design is a prerequisite of project planning with decisions being made, balancing practicalities with available resources and scientific rigour. For this project, the primary methodological approach was quantitative rather than qualitative because it required the collection of large volumes of data across various locations and was not aimed at developing rich descriptive data regarding attitudes, behaviour, culture or beliefs (Crombie and Davies, 1997).

Of the three main quantitative methodological approaches in HSR, experiments, surveys and case studies, the gold standard study design is the experiment, or the randomised controlled trial (RCT) (Roland and Torgerson, 1998). Although this method has an important role in health care, an RCT was not appropriate for this project as the investigation was not planned to examine the relationship between an outcome and an intervention with respect to its clinical and cost-effectiveness (Sibbald and Roland, 1998).

Case studies were a potential approach for this study, they are usually applied to observe a condition of interest, to answer the question 'how' and 'why', often using triangulated methods such as questionnaires, data from records and observations (Bowling, 2002). Case studies were not employed by this study because the aim was to determine 'what' distinguished PHDC from usual ward care. Also, the use of detailed observations and abstractions from medical case notes were considered too resource intensive to establish exactly what represented PHDC on both general and specialist hospital wards. This type of information would have to have been collected in all locations, as patterns of care and interventions performed were different.

Survey methods can provide investigators with profiles, explanations or descriptions of situations or events and are considered systematic and robust strategies to adopt (Robson, 2000). The term 'survey' generally includes traditional survey research methods, secondary data analysis and cohort studies, all of which are applied to observe events over time and to clarify the history of disease (Hulley et al, 2007).

The specific survey method of a 'cohort study' was selected for this project in the context of a lack of available primary quantitative information for the region. In addition, no secondary data were readily available for analysis from any source such as routine NHS data, medical records or registries. It was envisaged at the outset that the investigation would need to access a large population over a wide geographical area, relatively cheaply and the power of the cohort study to assess the incidence or prevalence of a condition over a specified period of time was an additional factor in the choice of methodology (Crombie and Davies, 1997). A prospective cohort approach has the advantage of potentially permitting the high quality measurement of a large number of variables using a variety of techniques (interviews, questionnaires and observation) compared to a retrospective study (Robson, 2000). For this project, different approaches were selected and chosen at different stages to fulfil various aims; these included the semi-structured interview and the closed-ended questionnaire. Their advantages and disadvantages, with regard to the PHDC study, are discussed below.

Semi structured group interviews were preferred for this project because they were an excellent way to probe nurses and gain greater depth and understanding of the range of conditions and the complex interventions performed for children admitted to all of the varying hospital ward types. Semi structured interviews enabled the researcher to modify the interview questions, where appropriate, and give explanations to nursing staff or to clarify ambiguities regarding aspects of care (Bowling, 2000). Interviewing is time consuming, expensive and there is the potential for interviewer bias (Bowling, 2000). However an interviewer with a good knowledge of the subject under study, and the ability to establish a rapport with people, to put them at ease, is likely to reduce interviewer bias (Moser and Kalton, 1971; Bowling, 2000).

Closed-ended questionnaires are quick and easy to answer, the answers are easy to tabulate and they are suited with use for scales that provide a single score (Hulley et al, 2007). For these reasons this technique was considered the most appropriate way of gathering information on a large scale in order to allow for hospital ward, seasonal and daytime/night-time differences. The main disadvantage was that they might have led respondents, as opinions are not able to be expressed and the answers provided may not be exhaustive (Hulley et al, 2007). The testing of forms during the feasibility and pilot studies and the comments from nurses ensured that items were not restrictive.

The use of observation in survey research can compliment the interview or questionnaire, particularly where the actions and behaviour of individuals are central, observation is the most obvious technique for data collection (Robson, 2000). Classically systematic observation has long been used in the enquiry of natural science, particularly medicine, and the advantage of this technique lies in the richness of the description of routines (Bowling, 2002). It was decided not to employ observation as a method in the study of PHDC as the disadvantages were considered to outweigh the benefits. The observation of a process opens up the possibility of introducing the Hawthorne effect, characterised by the observer affecting the behaviour of the observed; for example in relation to the delivery of PHDC this might have prompted nurses to intervene more frequently than was necessary. Ethical problems can also exist with observation technique; for example a nurse researcher may be observing/assessing a situation but may not be detached from and may have to clinically intervene (Bowling, 2002).

Observation relates to what clinical staff 'do' in public, i.e. on the ward. On general and specialist paediatric hospital wards nurses care for five or more children in different ward locations. Therefore, to examine what PHDC means for an individual child would require an excessive amount of research time and resource. If regular attendance of clinical staff at the child's bedside was indicative of the need of a higher level of care (PHDC) this would be problematic to measure on a general hospital ward as it would not be clear to the observer whether regular attendance was due to concern about the child being at risk of deterioration or because the child was highly dependent per se,

i.e. in need of nursing time and resource, but not necessarily at risk of deterioration. For example children with chronic conditions such as short bowel syndrome require continuous infusions of total parental nutrition (TPN) and hourly fluid balance for the period of 20 hours per day. This requires time and interventions from nursing staff; yet the child may not be necessarily unwell. This negates observation as worthwhile for this study because nursing staff will be documented frequently at the bedside recording record hourly fluid balance, checking blood glucose levels daily and administering drugs. In addition, to verify that the correct infusion is given to the correct child, two nurses will check compatibility of the infusions, aseptically run the clean infusions of TPN through filtered giving sets and attach to the child, every 24 hours. This is time consuming and would ensure that nursing time is recorded at the bedside but for the wrong reasons.

Observing so many children in so many different ward locations would not be possible with a single observer because of the time necessary to be allocated to the technique (Hulley et al, 2007). Structured approaches, such as observation schedules or instruments, to assist with the reduction in observation time, only serve to correspondingly increase the time spent developing such an instrument and training the users to acquire proficiency in its use (Robson, 2000).

Thus with limitless resources, observation techniques might well have supplied useful supplementary information to the project. However both time and financial restrictions limited the possibility of pursuing this approach.

10.3.2 Development of the Paediatric High Dependency Care Measurement Tool

10.3.2.1 Devising Items

Items or interventions on the PPA had to be relevant, unambiguous and capture the concept of PHDC. A good starting point for this study was to determine if the audit tool originally developed by the Department of Health (2001a) was adequate and discriminatory and if it would reduce the necessity for creating new items. The PHDC measurement tool built upon the Department of Health (2001a) work and incorporated the clinical interventions that were listed.

However, the inability of the Department of Health (2001a) audit tool to differentiate between the varying dependency levels of care i.e. usual ward care, PHDC and PIC, was partially explained by their limited use of illness classifications. Furthermore the clinical interventions listed by the Department of Health (2001a) were not adequately defined which left them open to interpretation and therefore potentially ambiguous. Therefore, in order to meet the requirements for the PHDC measurement tool, derivation of interventions for PHDC were captured from the audit tool developed by the Department of Health (2001a) but also from the accumulated knowledge and clinical experience of senior doctors and nurses from within the region. Illness classifications that blurred the boundary between the levels of care were omitted by the researcher and each intervention listed on the PPA form was provided with a severity parameter and explicit definition. This was essential for this study to prevent staff from recording subjective opinions. These strict definitions contributed to the reduction of measurement error in the data recorded across all locations of care.

10.3.2.2   Selecting Items

Selecting items deemed to define PHDC proved to be the greatest challenge for this study because interventions possibly thought to be representative of usual ward care were intertwined with PHDC. Both levels of care were found to be represented by a single intervention but also by the co-dependency of a number of separate interventions. Statistical methods such as FA and consensus methods were employed during the pilot study and expert consultation phase in an attempt to discriminate between PHDC and usual ward care, without success.

Exploratory FA was applied to data collected during the pilot phase of the study, with the aim of clustering items into factors with the purpose of discovering a common underlying dimension or construct for PHDC (chapter 5). FA, a useful construct validity technique (Mishel, 1998) was unsuccessful at grouping together correlated variables or coherent subsets for the levels of PHDC and usual ward care, mainly because of the complexity of the data. A consensus methodological approach, or expert consultation (chapter 6), of two rounds, implemented to refine the dataset for the main study (chapter 6), also failed

during Round 1 to reach agreement on the relevant data items. The number of experts used (n= 10) and the limited value of the case scenarios presented to the experts prevented the gathering of workable information in Round 1. In consequence, in Round 2, and owing to time constraints, a smaller number of three experts and a round table meeting provided a consensus of opinion for the items to be listed on the PPA (the main data collection form). In view of these difficulties, which were experienced in the early phases of the study, a pragmatic method of clarifying the PHDC construct had to be sought for the PHDC measurement tool. Despite a proposed logical framework for identifying items necessary for the form, difficulties experienced in the early phases of the study necessitated a pragmatic approach to clarify the final content of the PHDC measurement tool.

Complex tables (see chapter 7) were produced from the main dataset and closely assessed to establish the relative importance of each intervention and the co-dependency of interventions generated to define PHDC. This process was grounded in clinical practice; it involved systematic evaluation of the data to make good clinical sense and was therefore qualitative in approach. Although the production of the complex tables was not part of the original study plan, they proved to be effective in the identification of necessary items for the PHDC measurement tool.

The failure of the PPA questionnaire during the main study to ask nurses to identify children in need of HDC or a higher level of care was not recognised until the final validation process during the main study (chapter 8). The reason for the poor agreement reached between the PHDC measurement tool and nursing opinion at the DGHs and the PICUs for high intensity interventions was detected and managed by the recoding of all episodes where these interventions were performed. The presence of the intervention 'intubation and subsequent care of the ventilated child', and the possibility for the multiplicity of high intensity interventions to tip a child into a higher level of care (PIC), should have been recognised during the development of the final questionnaire. However, the complex interplay of the interventions for usual ward care, PHDC and PIC were not appreciated at the outset of this study and the relationship between the interventions became more explicit as the study progressed. The

progress of this study was a dynamic process where adaptation to each stage of the development of the PHDC measurement tool was key to its evolution.

At the conclusion of the study it was considered that the application of the measurement tool was able to discriminate the boundary between PHDC and usual ward care. However the tool was not designed to establish the boundary between PHDC and PIC and therefore was not appropriate for this function.

10.3.3 The Study Population

Steps were taken during this study to reduce bias during the selection procedure, when nurses decided whether to complete a form for a child. Originally clear inclusion and exclusion criteria for episodes of care were defined although, as the study progressed, exclusion criteria were omitted with all children admitted to a hospital ward being eligible for inclusion. This maximised responses by reducing the need for nurses to verify eligibility and therefore minimised selection bias.

Despite the collection of large amounts of data from many hospital wards the study sample was non random. Criticisms are usually levied at non random studies because of the likelihood for the introduction of systematic bias (Moser and Kalton, 1971). This study was geographically defined and included all hospitals and wards where children were admitted acutely and therefore potentially captured a total population. Owing to the heterogeneous locations across a large geographical region, institutional selection bias was reduced, making the findings potentially generalisable to other geographical areas of service delivery. The application of the PHDC measurement tool could be important in a national context because of it potential to supply information on the total number of hospitalised children receiving PHDC in a population.

One limitation of the study which may have contributed to a systematic bias in the data collected by the PHDC measurement tool was the inability of the nurse researcher to check the number of children or episodes of care potentially missed during the data collection period at each hospital ward location. The consequences of this were a possible underestimation of the population requiring PHDC. Time did not permit the onerous and difficult task of requesting

case notes for all children admitted to all wards over the period of one year to quantify the number of children not included in the study. However it was unlikely that any substantial underestimation was present because large quantities of data were returned, month on month, over the entire year with little fluctuation, suggesting that effect of nurses not completing data collection forms was minimal.

10.3.4 Form Completion

Although data capture was arduous for nursing staff, the response in their continuing completion of forms was overwhelming; between 1,726 to 2,285 data collection forms were returned each month for input. The successful recording of episodes of care for both day and night shifts was attributed to the high level of motivation and support for the study by nurses. In particular the 'trainers' the nurses taking responsibility for form completion on all hospital wards, continuously maintained and motivated activity.

The decision of nurses as to whether to complete a form or not (i.e. was the care PHDC or usual ward care) may have been influenced by chance elements such as case mix intensity, time of night or staff shortages, therefore causing random errors in measurement (Mishel, 1998; Meininger, 1998). To improve reliability, data were collected for one full year and from all hospital wards within the region where children were admitted acutely. However no degree of study planning can prevent staff sickness or alter the case mix intensity for children requiring HDC, but these factors should have been constant across all types of ward locations.

Although systematic errors or biases are not easy to detect (Mishel, 1998), potential systematic biases may have been introduced by nurses with varying levels of skill and clinical experience over, or under interpreting the significance of PHDC. Bias from systematic misclassification may have resulted from the influence exerted by nurses of any grade or level of experience in their answer to the question 'in your opinion is this child in need of HDC?' It is plausible that senior nurses, because of their increased knowledge and ability, underestimated PHDC and junior nurses, owing to lack of experience, overestimated PHDC. Despite treating the episodes of care independently the

status of a child may have changed rapidly between episodes, but the opinion of the nurse as to whether the child required PHDC may have been influence by previous levels of care. It would not have been practical to restrict form completion to senior nurses, only, to complete data collection forms as a senior nurse on one hospital ward may have equated to a junior on another hospital ward. For example band six and seven nurses may care for patients on a PICU; however a band five nurse may be the most experienced nurse coordinating a general hospital ward. Possible criteria for 'seniority' may have been the ward co-ordinator, irrespective of band, yet time would have physically constrained a single nurse from completing forms and would therefore not have provided a solution to the problem. For future studies tests of consistency of opinion should be performed across locations and between nurses to inform the study of potential systematic errors.

The data collection months of May and November, which were chosen to combine the patient activity and clinical staffing data, may not have been a true reflection of differences between summer and winter activity. June and December may have provided better representation of summer and winter. However May was selected to represent summer, as it occurred immediately prior to the implementation of Agenda for Change (Department of Health, 2004b) and the switch from nurse grading to nurse banding. November was preferred to represent winter because it was thought to provide time for nurse managers to implement Agenda for Change (Department of Health, 2004b) on all hospitals sites. Also, it avoided the December public holidays where many hospital wards amalgamated to combine resources for the Christmas period.

10.3.5   Data Quality

In the initial stages of the study, the literature review and data collection form design assisted with the control of measurement error and data quality. Although form design is a matter of common sense, experience and practicability (Moser and Kalton, 1971) the technological development of the data collection forms was rigorous and systematically driven by the literature and pre-testing during the feasibility and pilot studies. Comments from the ward staff and scrutiny of the data contributed to the evolution of the forms and the detection of technical flaws. This ensured that problems, for example, those

concerned with the recording of and assessment for the GCS were detected early and rectified prior to the main study.

The main study data was implemented with strict attention to data quality, specifically with respect to completeness and accuracy. This is essential for data being evaluated in the assessment of health care provision (Audit Commission, 2002). A large amount of complex data was collected for children and clinical staff in a number of hospital ward types, across differing locations of care. Despite the wide geographical coverage large amounts of data on patient activity and clinical staffing were effectively and efficiently collected in a relatively short space of time. The reasons for this were attributed to a number of factors including the excellent organisational and communication skills of the staff involved. For example the link nurses on all hospital sites regularly checked data for amount and quality, and reminded nursing team members of the importance of accurate form completion and the correct processes for returning data. In addition the support of a research network, developed for this study, was fundamental in guiding the methods and processes underpinning the research. The research network involved a number of individuals from a variety of settings including university academics, hospital managers and clinicians, regional network leads from the Paediatric Critical Care Network of the Yorkshire and Humber Specialist Commissioning Group (North) and collaborating critical care commissioners. To achieve success across all these agencies a good deal of time was given up to managing the research network. This involved communicating with all the health professionals, and key to success was the handling of the differences in attitudes, beliefs and interests; this investment of time and energy proved extremely worthwhile.

10.3.5.1 Completeness

Extensive data quality checking by the researcher was performed to reduce the possibility of random errors. This was achieved during the main data collection period by the cleaning of data each month. The range checks of all variables, carried out with the estimation of missing values and the monthly ward returns summarising the input data and totals of missing data, contributed to improvements in the completion of variables. A greater than 75% response rate was achieved for all data collection forms (MNS, DNS, DPA, MMS) distributed

in May and November. Less than 0.5% of incomplete data was present for the key demographic variables on the PPA, such as the NHS number, postcode, date of birth and sex. A vital contribution to this study was the ability of the researcher to access the demographic variables listed on the PPA using the NSTS. Without this facility mapping and quantification of children requiring PHDC would not have been possible.

10.3.5.2   Accuracy

Both aspects of data quality, completeness and accuracy were important for this study to provide unbiased clinical evidence for the care that children receive within the region. Although precise, systematic checking of the data on a monthly basis was carried out, minor errors may have been missed. A custom built, Access, database guaranteed that the data were reliably coded and provided a basic range check for some variables (Wunch, Harrison and Rowan, 2005). Although the database was developed with a second data entry facility, double entry of data was not performed due to time and financial constraints.

In addition to the computerised checks on the data, some inconsistencies were immediately validated against patient case notes, at the hospitals involved in the study, to reduce sources of error. A further specific validation exercise was undertaken to check study data against hospital records. Although it was impossible to accurately confirm the presence or omission of some variables (such as ECG monitor in situ or the location of the child on a ward, cubicle or main area) some inconsistencies were found for the episodes of care. No inconsistencies for dates of birth and postcode were found, yet 8% of clinical interventions did not correspond to the care recorded in the case notes. It was impossible to establish if the recorded interventions had never been provided to children, or if the documented patient care recorded in the case notes was not detailed enough to provide sufficient evidence.

10.4   Paediatric High Dependency Care, Within a Local and
National Policy Context

The findings from this study have received considerable local and national attention with results presented not only at a number of national forums focused on PHDC and international meetings on paediatric critical care. The issues of

consent and ethics approval provided original work for a publication in the British Journal of Nursing (Appendix 11).

Owing to the dual aims of the study, the results have provided information on both the skills and the number of staff employed on the hospital wards and the volume of PHDC. Interest from various NHS agencies within the UK was generated in relation to the results and the measurement tool that was developed. A description of the impact of this research from a local and national perspective is reported below. From a local policy perspective the service and societal impacts are explained.

10.4.1 Local Policy Context

A local feedback process was arranged for each hospital Trust before the close of this study in 2007, where commissioners, hospital managers and clinicians were invited to attend. This dissemination strategy was agreed, *a priori,* by the Paediatric Critical Care Network of the Yorkshire and Humber Specialist Commissioning Group (North) to provide PHDC information by hospital ward and Trust. The information was presented in booklet form to incorporate the amount of PHDC and staffing data on the level of nursing and medical skills available. Comparison tables for each ward by hospital ward type were also provided. This information was well received with areas for review discussed and future plans for improved practice established. Such comparative data relating to critical care, for hospital wards outside of the PICUs, had never previously been recorded and described in such great detail. Although this exercise was bold and ambitious, highlighting both good and poor practice, it has improved our knowledge on how PHDC services are delivered within the region. More importantly, it has provided an evidence base on which service commissioners, managers and clinicians can change future practice to improve paediatric hospital care.

10.4.1.1 Service Impacts

In order to influence health care, the local planning of services has extended formally from the meetings and booklets described above with the development of a Service Specification for PHDC within the Yorkshire and Humber Strategic Health Authority. Data and information from this study have been used by the

Paediatric Critical Care Network of the Yorkshire and Humber Specialist Commissioning Group (North) to produce explicit standards that should be provided to commissioners, for the delivery of PHDC services, for inpatient children and young persons up to the age of 16 years. The service specification ensures that commissioners and service providers are clear about their responsibilities with respect to the management of critically ill children, the HDC physical infrastructure and environment, safe staffing levels and requirement for data collection and audit.

An example of the impact of the work at a local service level has been the commissioning of two PHDC beds at BRI. Since June 2007, BRI have continued to collect PHDC measurement tool data to provide continuous up to date monthly information on the number of children requiring PHDC. It is anticipated that two beds of PHDC will suffice in the short tem. In the long term extra beds, within a PHDU environment, configured according to the PHDC service specification, as outlined above, will be required as demand grows and staff gain confidence and competence in caring for children with specialist PHDC needs such as Continuous Intermittent Positive Airway Pressure (CPAP). Currently many children requiring such an intervention are transferred to a PICU for this and other types of respiratory support. BRI as explained in chapter four are the largest provider of children to the three PICUs in Leeds and provided a total of 442 episodes of PHDC in 2005.

Plans to reconfigure children's services at the LTHT have been ongoing since the inception of 'Making Leeds Better', a local program initiative to improve services in health and social care. Currently children's services at the LTHT are split between two hospital sites; the LGI and SJUH. PHDC occurs on all acute paediatric wards at the LGI and SJUH but it is proposed that children's services will be transferred to one hospital site within the next two years. This has caused difficulties for the planning of services because of the short term and long term PHDC needs of children which have to be met. A modeling exercise for PHDC outlined a number of models for both long and short term needs and suggested that 15 beds, at 60% occupancy, would be required to meet with the needs of PHDC (unpublished Rushforth, 2007). A decision has yet to be made on the most appropriate model for the needs of Leeds.

These data provide new evidence to suggest that West, North and East Yorkshire did not have the necessary resources to achieve the standards of care for children requiring PHDC. Outside of the PICUs the number and skills of the nursing workforce did not match the dependency needs of children as recommended by the Department of Health (1991, 1997a 1997b, 2001a). No hospital ward met with guidance from the DoH for a member of staff to be on duty in a 24 hour period with APLS skills (Department of Health 1997a, 2001a). Delays of seconds may seriously affect the outcome of children presenting to hospital in extremis and for these reasons children have the right to expect the logical, sequential and timely pre set standards that are taught on the APLS course (Jewkes and Phillips, 2003). The lack of APLS trained doctors and nurses on some hospital wards and on some shifts suggest that not all children are afforded this right. For the Paediatric Critical Care Network and for each Hospital Trust informed decisions may be made for the planning of effective services for the delivery of care and for the training and education of doctors and nurses. Funding became available for APLS training, particularly, at the DGH with specialist paediatric facilities after feedback to the Hospital Trust, where low numbers of APLS trained nurses were employed. No strategies were debated or implemented to increase the number of medical staff with APLS skills.

10.4.1.2   Societal Impacts

The results of this study have ensured a greater understanding of the necessity for reforming the process for PHDC and the cost effectiveness of health systems within Hospital Trusts. The postcode data of children requiring PHDC collected during the study was returned as requested to some commissioners by age, reason for admission and hospital ward locality. Their aim was to ensure that in areas of high incidence of certain types of illness or injury, such as respiratory illness and thermal injury, health prevention work could be undertaken.

This study has impacted on the clinical staff who from the PHDC study acquired a greater understanding of the concept of PHDC and of the health status of children i.e. the differences between the levels of care PIC, PHDC and usual ward care. Nurses have debated the concept of PHDC more confidently in

meetings. This awareness has enabled nurses to challenge and influence the number and level of skilled nurses available on a shift by shift basis. With the PHDC measurement tool still being used on many of the hospital wards where it was developed, nurses are becoming more assertive, arguing for improved staff to patient ratios, funding for APLS courses and regular resuscitation scenario training.

Raising awareness of the amount of PHDC on the mixed adult and paediatric wards, in association with a lack of appropriate nursing skills, has proven profitable for health equity. All inpatient children have the right to be cared for on a ward where two RN (Ch) are present at all times in a 24 hour period (Department of Health 1991, 1997b, 2001a). Where a child requires critical care the parents and child can expect nurses who have APLS skills to intervene and prevent deterioration (Department of Health 1997b, 2001a). Three mixed paediatric and adult hospital wards within the region, the regional burns centre (RBC) of the Mid Yorkshire NHS Trust and the orthoplastic and bone marrow transplant units at the Leeds Teaching Hospital NHS Trust, have addressed their delivery of care for children. At the RBC, 61% of shifts were worked without a RN (Ch), 65% of shifts were without a nurse with APLS skills, yet 3.2% (n = 326) of the regions total PHDC episodes were performed. Such explicit accounts of the quantity of PHDC and the skills available on the mixed adult and paediatric hospital wards have influenced traditional custom and practice by assisting managers in restructuring services. When the new hospital build is complete at Pinderfields Hospital, all children will receive equitable care on primary paediatric hospital wards. Until this time there is opportunity to plan, employ and train the children's workforce of the future based on the data provided by this study. Children on the plastic/orthopaedic mixed adult and PHDU at SJUH were relocated to a children's ward in 2006 where PHDC was provided by trained and skilled children's nurses. The adult population from the bone marrow transplant unit has, since this study, relocated to a new wing at SJUH. The children remain on the original unit cared for by children's nurses. Once the new build is completed at Pinderfields Hospital no children will be cared for on mixed paediatric and adult wards within the study region. Although this study has not been the only influence in facilitating change for children admitted to the mixed paediatric and adult hospital wards, it has highlighted the

lack of nursing skills in these locations and has fuelled debate for improved safety in the care of children and for the development of nursing staff.

10.4.2   National Policy Context

Nationally PHDC has recently received much attention with the introduction of Payment by Results (PbR) and the collection of data by the Paediatric Critical Care Minimum Data Set (PCCMDS) (Information Standards Board, 2007). Developed by an expert working group of PIC clinicians the PCCMDS records clinical information for children and young people admitted to a PICU, ward, PHDU or other location, and was mandated for collection from October 1st 2007. Where a child receives specific interventions for a period of greater than four hours the child will be counted as receiving paediatric critical care at one of the five levels of intensive care or two levels of PHDC (Information Standards Board 2007). It is expected that payment will be provided for children requiring PIC delivered in the PICU, but also those requiring PHDC in any location. With an adequate definition for all levels of critical care, variation in costs for the same treatment modalities should disappear. The presumption that reimbursement can be determined for children requiring different levels of critical care has provided a whole new impetus for clearly identifying children in need of PHDC, and is relevant to all settings where this level of care may be delivered.

There are however a number of concerns regarding the specific application of the PCCMDS outside of the PICUs. The PCCMDS was developed by an expert working group (EWG) of PIC clinicians and whose primary function was to create a dataset for the measurement of paediatric critical care. The pilot work of the EWG was conducted in a number of PICUs where some PHDC was delivered. However, the pilot work did not include general paediatric wards where a considerable amount of PHDC work is undertaken (Department of Health 2001a). The clinical interventions listed for PHDC on the PCCMDS may not accurately identify children in need of PHDC on general and specialist hospital wards, and may overestimate PHDC through the use of the interventions 'oxygen therapy irrespective of ventilatory state', 'ECG monitoring' and 'oxygen saturation monitoring'. Two of the three interventions are used routinely to monitor children on general and specialist hospital wards and do not automatically represent critical illness or deterioration in condition. A further

concern regarding the collection of the PCCMDS is that high quality data, which is fundamental to support the implementation of PbR, carries a considerable burden of resources ranging from staff recording the information to the availability of computers, software and IT support. This burden is particularly pertinent to general paediatric hospital wards outside of PICUs where information technology (IT) systems are not yet in place. Due to these concerns a number of national study days have been held to share knowledge and information regarding data collection for the PCCMDS. The results from the PHDC study have informed a national debate regarding those concerns.

Lastly national recognition was received for the commitment to PHDC by the researcher in March 2008. The 'Child Health Award' for outstanding nursing practice at the Nursing Standard's Nurse of the Year Awards was presented to the researcher at a ceremony in London where all finalists were invited to 10 Downing Street to meet with the Prime Minister, Gordon Brown.

10.4   Future Work

This study has provided a novel description of PHDC. The challenges remaining are to explore the further areas of work. These are to:

- Validate the PHDC measurement tool outside of the Yorkshire and Humber region.

- Define the boundary between PHDC and PIC using the PHDC measurement tool.

- Reassess the number of clinical staff and level of skills by shift period after the introduction of PbR.

- Analyse comparative data for the PCCMDS and the PHDC measurement tool and assess the differences between the numbers of episodes of PHDC by each tool. Exploration of the two levels of PHDC, PHDC basic and PHDC advanced, as established by the PCCMDS against the PHDC measurement too is justified.

- Model PHDC, for the region, by assessing the implications for the service and for families and children, if PHDC is accredited and designated in certain localities.

- Apply for a policy research program grant from the National Institute of Health Research (NIHR) to collect information from a number of regions on the delivery of critical care. This information would ideally link with data collected by the PICANet to increase the knowledge of critical care outside of the PICUs.

10.6 Conclusion

For the first time a high quality dataset of PHDC activity was produced for the Yorkshire region. This dataset was collected by frontline hospital ward staff to develop a measurement tool to establish the volume of PHDC activity in the region. Once finalised the tool was applied to the total dataset to quantify regional PHDC. PHDC activity in combination with ward staffing activity provided further evidence to identify whether the skills and number of both nurses and doctors complimented the dependency needs of children. These findings were important not just to the managed paediatric critical care network and children's services managers, but to all regional paediatric ward staff in relation to the delivery of care for children. The results have a number of implications:

Firstly the volume of data collected from all hospital wards was attributed to the enthusiasm of nurses. Their hard work and dedication to PHDC with the data

they collected has provided the evidence for the development of multiple designated PHDC facilities.

Secondly the data collected confirmed that PHDC was delivered to children on all acute hospital wards. Some hospital wards because of the nature of their specialty, or because of the way that paediatric critical care services have developed, admitted more children for PHDC than others. With evidence to support the Department of Health (2001) in the amount of PHDC occurring at DGHs, a robust argument could be built for the development of ward based resourced PHDC services at some DGHs where considerable amounts of PHDC was provided. In addition, at lead centres where a large amount of specialist PHDC occurred, there is probable justification for the development of one or more PHDUs where economies of scale would legitimate their existence.

Thirdly the data verified that government guidance was not followed for the most basic dependency needs of children i.e. usual ward care and for children requiring PHDC. This was illustrated by the lack of children's nurses, especially at night and the lack of nurses with APLS skills available to care each shift. To meet with national guidance careful planning is required in a number of areas. There is a need to increase the number of RN (Ch) to two per shift on each hospital ward. Mixed adult and paediatric wards should not be an exception to this rule. The use of existing nurses with APLS skills should be maximised by planning duty rota's to ensure that a nurse with the relevant skills is present at all times during a 24 hour period on all acute hospital wards. Both doctors and nurses should undertake APLS courses in areas where skills were low. Regular multidisciplinary, resuscitation scenario training for all hospital wards to maintain life support skills should be planned in-house, or through taught sessions, where possible, using the medical infant/child simulators. Sessions using simulators may be accessed through the clinical educator employed by the Paediatric Critical Care Network and are available to the region as a whole.

Fourthly a large amount of PHDC was being carried out in the region without the support of dedicated PHDC beds. PHDC was therefore provided in the PICUs where staff were skilled and able to provide the recommended critical care nurse to patient ratios of 1:1 or 1:2, or on general and specialist hospital

wards where at times the correct number of appropriately trained staff were not in place to provide care. 'Well' children admitted to the PICU for PHDC may have prevented genuine or level 2 intensively ill children from gaining timely access to one of the three PICUs in Leeds.

Although data is published for the volume and hospital location of PHDC in the South West Region, it is unclear how PHDC services including staffing resources have developed elsewhere in the country. In West, North and East Yorkshire, a decentralised model of care is in operation with PHDC occurring outside of PHDUs. In other localities centralised systems of PHDC may be in place where the majority of PHDC is provided in dedicated PHDUs. In time and with the introduction of the PCCMDS comparisons between regions may provide this information.

The ultimate aim of the study was to make a contribution to improving the delivery of care to the sickest of children within the region. The findings from this study have provided vital evidence to support the implementation of changes for the benefit of children requiring PHDC. It is gratifying that the work of this project has already resulted in improvements in structures and processes related to delivering PHDC in Yorkshire.

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Appendix 1: Definition of paediatric high dependency care and intensive care (Department of Health, 1977a)

Level 3 - Paediatric Intensive Care

This child requires technological support for two or more organ systems including advanced respiratory support as one of these systems. Complex therapeutic and monitoring systems for example ventilated children undergoing advanced renal support will be in place for a child in need of level three care.

Level 2 - Paediatric Intensive Care

This is a child that requires continuous nursing supervision. The child requires intubation and advanced respiratory support
or
support for two or more organ systems
or
one acute organ failure receiving support, plus one chronic failure

INTUBATE	EXTUBATE

Level 1 - Paediatric High Dependency Care

This is a child that requires closer observation and monitoring than is usually found on an ordinary children's ward. This child may require single organ support, excluding respiratory support
or
continuous monitoring of heart rate or blood pressure.
or
following major surgery: cardiac, neuro, spinal etc
or advanced analgesic techniques

HDC is at times provided as a step down from intensive care and will include the recently extubated child

A child may be in need of more than one category of care during one period of treatment in hospital
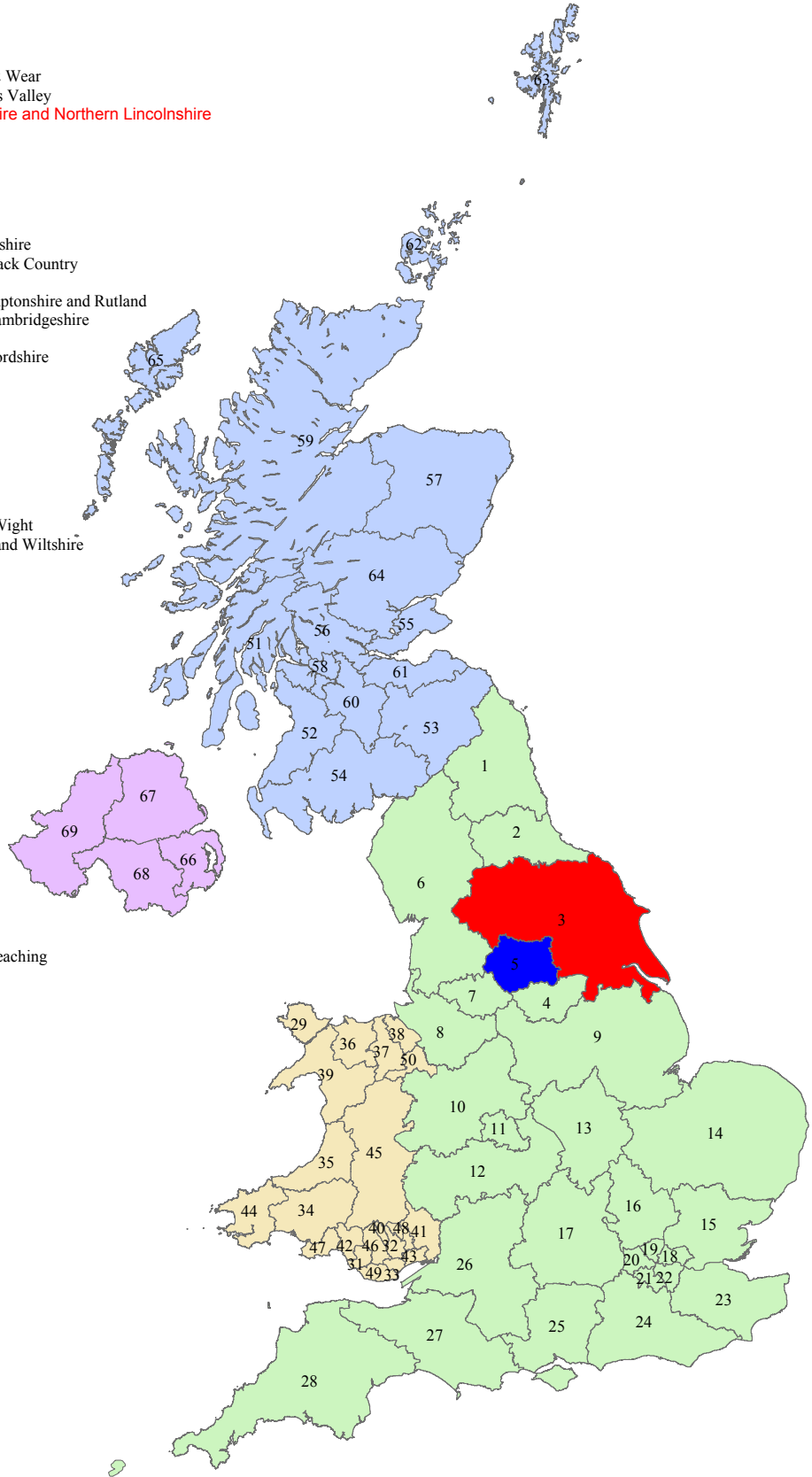
Appendix 2: Standards for the care of children requiring high dependency care

Year	Author	Publication	Standard
1991	Department of Health	The Welfare of Children and Young People in Hospital	At least 2 registered children's nurses on duty 24 hours a day on all children's wards and in all children's departments A registered children's nurse to be available 24 hours a day for advice and guidance in departments such as A&E The registered child nurse/child ratio to be proportionate to patient need and determined by a method of nursing manpower assessment
1997a	Department of Health	A Framework to the Future	Staff caring for children at all hospitals where paediatric HDC is delivered should be able to carry out emergency treatment and stabilisation of the critically ill child Nursing staff helping to stabilise and manage a critically ill child should have advanced paediatric life support or paediatric advanced life support skills A Specialist Registrar to be available immediately at all times with advanced paediatric resuscitation skills at all major acute general hospitals
1997b	Department of Health	A Bridge to the Future	At least 2 registered children's nurses to be on duty at any time in DGHs For each child in a DGH that requires HDC one registered children's nurse will carry out close observation and monitoring. This may mean a ratio of 1 nurse to 2 children Nurses at DGH who are required to resuscitate and establish level 2 care will have Advanced Paediatric Life support skills A registered children's nurse with a qualification in intensive care will be at the bedside to care for a level 2 and level 3 child. More than 1 nurse may be required for a child receiving level 3 care

Year	Author	Publication	Standard
2001	Paediatric Intensive Care Society (PICS)	Paediatric Intensive Care Standards Document	Where HDC is provided within hospitals there must be: • A lead Consultant with responsibility for the provision of HDC, paediatric resuscitation and for the initiation of treatment and the stabilisation of the critically ill child. • Consultant Paediatric cover during a 24 hour period with advanced resuscitation skills • 24 hour Consultant Anaesthetic cover by staff with advanced paediatric resuscitation skills • 24 hour cover on-site by medical staff with APLS/PALS or equivalent All HDC should be provided by registered children's nurses In HDU there should be at least one nurse per shift with APLS/PALS or equivalent. All children admitted to paediatric intensive care should have 24 hour access to a doctor with APLS/PALS or equivalent. All children requiring intensive care should be cared for by registered children's nurse with additional intensive care training
2003	Department of Health	Getting the Right Start: National Service Framework for Children	All hospitals that admit children should be able to provide HDC and initiate level 2 care Arrangements for the care of critically ill children should be in place for all hospitals admitting children. These arrangements should include 24 hour availability of clinical staff with advanced paediatric life support competency. In clinical areas, for example A&E and inpatient medical and surgical wards, there should be a member of staff on duty at all times with advanced paediatric life support training (APLS or PALS) In all acute hospitals where children are admitted a clinical rota must be maintained to ensure that emergency skills are available to resuscitate children Surgeons operating on children should have training in basic life support and emergency care in their chosen branch of service
2006	Department of Health	The acutely or critically sick or injured child in the District General Hospital	All clinicians involved in the care of children in the DGH should be: • able to recognise the critically ill child • able to initiate the correct immediate treatment • maintain and enhance skills The resuscitation team within the DGH should include doctors and nurses who have undertaken the paediatric life support (PLS) or European Paediatric Life Support (EPLS) courses

Appendix 3: Map showing 2004 SHA boundaries and the study region

England
1 - Northumberland, Tyne & Wear
2 - County Durham and Tees Valley
3 - North and East Yorkshire and Northern Lincolnshire
4 - South Yorkshire
5 - West Yorkshire
6 - Cumbria and Lancashire
7 - Greater Manchester
8 - Cheshire & Merseyside
9 - Trent
10 - Shropshire and Staffordshire
11 - Birmingham and the Black Country
12 - West Midlands South
13 - Leicestershire, Northamptonshire and Rutland
14 - Norfolk, Suffolk and Cambridgeshire
15 - Essex
16 - Bedfordshire and Hertfordshire
17 - Thames Valley
18 - North East London
19 - North Central London
20 - North West London
21 - South West London
22 - South East London
23 - Kent and Medway
24 - Surrey and Sussex
25 - Hampshire and Isle of Wight
26 - Avon, Gloucestershire and Wiltshire
27 - Dorset and Somerset
28 - South West Peninsula

Wales
29 - Anglesey
30 - Blaenau Gwent
31 - Bridgend
32 - Caerphilly Teaching
33 - Cardiff
34 - Carmarthenshire
35 - Ceredigion
36 - Conwy
37 - Denbighshire
38 - Flintshire
39 - Gwynedd
40 - Merthyr Tydfil
41 - Monmouthshire
42 - Neath Port Talbot
43 - Newport
44 - Pembrokeshire
45 - Powys Teaching
46 - Rhondda Cynon Taff Teaching
47 - Swansea
48 - Torfaen
49 - Vale of Glamorgan
50 - Wrexham

Scotland
51 - Argyll & Clyde
52 - Ayrshire & Arran
53 - Borders
54 - Dumfries & Galloway
55 - Fife
56 - Forth Valley
57 - Grampian
58 - Greater Glasgow
59 - Highland
60 - Lanarkshire
61 - Lothian
62 - Orkney
63 - Shetland
64 - Tayside
65 - Western Isles

Northern Ireland
66 - Eastern
67 - Northern
68 - Southern
69 - Western

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Appendix 4: Hospitals and trusts involved in the study

Trust	Hospital	Hospital ward
Airedale NHS Trust	Airedale General Hospital (AGH)	Children's Unit Mixed Medicine and Surgery
Bradford Teaching Hospitals NHS Foundation Trust	Bradford Royal Infirmary (BRI)	Ward 2 Surgery Ward 16 Medicine Ward 17 Medicine
Calderdale and Huddersfield NHS Trust	Calderdale Royal Hospital (CRH)	Ward 3C Mixed Medicine and Surgery
	Huddersfield Royal Infirmary	Ward 18 Mixed Medicine and Surgery
South Tees Hospitals NHS Trust	Friarage Hospital	Children's Unit Mixed Medicine and Surgery
Harrogate and District NHS Foundation Trust	Harrogate District Hospital	Woodlands Ward Mixed Medicine and Surgery
The Mid Yorkshire Hospitals NHS Trust	Dewsbury and District Hospital	Ward 7 Mixed Medicine and Surgery
	Pinderfields Hospital	Ward A Medicine Ward B Surgery ***ENT Surgery** Regional Burns Unit
	Pontefract General Hospital (PGH)	Hydes Ward Mixed Medicine and Surgery
The Leeds Teaching Hospitals NHS Trust	Leeds General Infirmary (LGI)	Ward 2 PICU Ward 4 Cardiac Intensive Care Ward 10 Cardiac Ward 48A Neurosurgery Ward 48 Surgery Ward 51 Medicine Ward 52 Medicine Ward 58 Surgery ***Ward 91 Surgery**
	St James University Hospital (SJUH)	Ward 5 Medicine Ward 10 Oncology Ward 11A Liver ***Ward 11S** Ward 12 Medicine ***Ward 12A** Ward 15 BMTU Ward 15S Medicine & Surgery PICU Ward 27 Surgery HDU Surgery ***Ward 59 Surgery**
Scarborough and North East Yorkshire Health Care NHS Trust	Scarborough and District Hospital	Duke of Kent Ward Mixed Medicine and Surgery
York Hospitals NHS Trust	York District Hospital	Ward 17 Mixed Medicine and Surgery
Hull and East Yorkshire Hospitals NHS Trust	Hull Royal Infirmary (HRI)	Ward 200 PHDU Ward 130E Medicine Ward 130W Surgery Ward 120 Under 1's

*Wards provided with information for data collection at the outset of the feasibility study but due to reconfiguration of services no data was collected during the main study

Appendix 5: Feasibility study: data collection forms

Paediatric Patient Activity Form A

YORKSHIRE REGIONAL PAEDIATRIC HDU STUDY

Hospital [_____]   Ward [_____]

Patient [_____]   Unit No [_____]   Postcode [_____]

Today's Date [_____]   DOB [_____]   Sex ☐   Time 03.00hrs ☐
15.00hrs ☐

Reason for Admission	Cardiovascular ☐	Respiratory ☐	Renal ☐	Oncology ☐
Neurological ☐	Metabolic ☐	Trauma/Accident ☐	Post-op Care ☐	Other ☐

Observations   Yes

1 Observations greater than or equal to twice per hour---------------------- ☐
2 Hourly nursing observations--- ☐
3 Continuous ECG monitoring--- ☐
4 Continuous Oxygen Saturation monitoring------------------------------------ ☐
5 Hourly non-invasive blood pressure recording------------------------------- ☐

Airway

6 Endotracheal intubation--- ☐
7 Use of airway adjunct / other artificial airway (e.g. guedel, nasopharyngeal,
nasal prong)   ☐
8 Care of new tracheostomy (1st week)-------------------------- ---------------- ☐
9 Care of established tracheostomy (after 1st week)-------------- ----------------- ☐
10 Nebulised adrenaline for upper airway obstruction (up to 2 doses)----------- ☐
11 Nebulised adrenaline for upper airway obstruction (more than 2 doses)--- --- ☐
12 Child recently extubated (less than 12 hours) after prolonged ventilation
(greater than 24 hours)   ☐

Breathing

13 Oxygen greater than or equal to 50%-------------------------------------- ☐
14 Oxygen less than 50%--- ☐
15 Acute Continuous Positive Airways Pressure (CPAP) including CPAP for physio ☐
16 Stable long term domiciliary ventilation (e.g. Nippy ventilator)--------------- ☐
17 Nebulised medications more than 1 per hour for more than 4 hours
(e.g. salbutamol)
                                                                             ☐
18 Nebulised medications 2-4 hourly-- ☐
19 Four apnoeic episodes within 4 hours (requiring stimulation)----------------- ☐
20 Bag and mask ventilation--- ☐
21 Care of chest drains (first 24 hours)-------------------------------------- ☐
22 Care of chest drains (after first 24 hours)--------------------------------- ☐
23 Frequent nasal / oral / tracheostomy suction greater than or equal to
4 times per hour   ☐

Infusions

24 Continuous intravenous **drug** infusions (e.g. aminophylline, salbutamol, octeriotide, prostin, midazolam, cytotoxic therapy, potassium, magnesium, phosphate , insulin) **except analgesia and inotropes** ❑

25 Intravenous infusion x 1 (maintenance fluid) --------------------------------- ❑

26 Replacement of fluid losses (e.g. from naso-gastric tube, drain, chest drain) ❑

27 Complex hourly intake and output (e.g. IVI's, wound drains, urine output, Ng/Gastrostomy losses) ❑

28 Multiple intravenous lines greater than 3 **except analgesia**--------------------- ❑

29 Intravenous drug boluses greater than 3 (including antibiotics)---- ----------- ❑

30 Inotropic support (e.g. dobutamine, dopamine or adrenaline)------------------- ❑

31 Total Parental Nutrition-- ❑

32 Blood transfusion / transfusion of platelets / fresh frozen plasma------------ ❑

Renal

33 Acute renal failure (less than 1ml/kg/hour for greater than 4 hrs)- ------------ ❑

34 Hourly urine output--- ❑

35 Acute renal replacement therapy (haemofiltration, haemodialysis)-------------- ❑

36 Acute hourly cycle peritoneal dialysis-- ❑

Circulation

37 Cardiopulmonary resuscitation-- ❑

38 Intravenous fluid resuscitation (greater than 20ml/kg in last 12 hours)----- ❑

39 Arterial line--- ❑

40 Central Venous Pressure (CVP) monitoring----------------------------------- ❑

41 Cardiac pacing--- ❑

42 Regular blood sampling (4 hourly or more frequent including blood glucose levels) ❑

43 Cardiac arrhythmia which has responded to 1st line therapy-------------------- ❑

44 Cardiac arrhythmia which fails to respond to 1st line therapy---------------- ❑

Neurological

45 Glasgow coma score equal to or less than 8------------------------------------ ❑

46 Glasgow coma score 9-12-- ❑

47 Deteriorating conscious level (a fall of 2 points since commencement of observations ❑

48 Prolonged or recurrent seizures (continuing for longer than 10 mins or repetitive short generalised seizures without consciousness regained between seizures, continuing for longer than 10 mins) ❑

49 Intra Cranial Pressure (ICP) monitoring--------------------------------------- ❑

50 External ventricular device (EVD)-- ❑

51 Frequent position changes (2 hourly)-- ❑

Other

52 Pain requiring epidural / intravenous or bolus infusion----------------------- ❑

53 Sedation during / after procedure (insertion of lines, drains, balloon septostomy, interventional cardiac catheterisation)--- ------------------------------------- ❑

54 Warming or cooling blanket/ ambient temperature monitoring/ incubator---- ❑

55 Dressing changes greater than 3 this shift------------------------------------ ❑

56 Naso-gastric / naso-jejunal feeding new on this admission-------------------- ❑

57 Naso-gastric / naso-jejeunal / gastrostomy feeding (chronic)--------- --------- ❑

58 Hourly aspiration of naso-gastric or gastrostomy tube------------------------ ❑

A child requiring close visual observation may include
- meningococcal sepsis in a stable state
- respiratory distress from any cause (e.g. asthma, upper airway obstruction)
- pre/post-operative if complex fluid management, analgesia, bleeding or complex surgery
- reduced conscious level from any cause (e.g. head injury, meningitis, DKA)
- pre/postoperative care
- severe neutropenia
- cyanotic congenital heart disease

Is this child nursed in a cubicle   yes☐   no☐

Is this child nursed in a designated high dependency area   yes☐   no☐

Paediatric Patient Activity Form B

YORKSHIRE REGIONAL PAEDIATRIC HDU STUDY

Hospital [   ]   Ward [   ]

Patient [   ]   Unit No [   ]   Postcode [   ]

Today's Date [   ]   DOB [   ]   Sex ☐   Time 03.00 ☐   15.00 ☐

Reason for Admission	Cardiovascular☐	Respiratory☐	Renal☐	Oncology☐
Neurological☐	Metabolic☐	Trauma/Accident☐	Post-op Care☐	Other☐

Observations

1 Observations ≥ twice per hour ☐   Hourly ☐   Daily☐ BD ☐   4 Hourly ☐   2 Hourly   ☐

	Yes	No	NK
2 Continuous ECG monitoring---	☐	☐	☐
3 Continuous oxygen saturation monitoring-----------------------------	☐	☐	☐
4 Hourly non-invasive blood pressure recording-------------------------	☐	☐	☐

Airway

	Yes	No	NK
5 Endotracheal intubation, subsequent care of the intubated child---	☐	☐	☐
6 Use of airway adjunct/other artificial airway (e.g. guedel,nasopharyngeal, nasal prong)	☐	☐	☐
7 Child recently extubated---	☐	☐	☐
8 Care of child with tracheostomy-------------------------------------	☐	☐	☐

*If yes   new tracheostomy first 48 hours --------------- *   ☐

tracheostomy after first 48 hours---   ☐

	Yes	No	NK
9 Nebulised adrenaline for upper airway obstruction-------------------- ---	☐	☐	☐

If yes   up to 2 doses--------------------------   ☐   *more than 2 doses---------------* ☐

Breathing

	Yes	No	NK
10 Acute Continuous Positive Airways Pressure (CPAP)-----------------	☐	☐	☐
11 Bag and mask ventilation---	☐	☐	☐
12 Stable long term domiciliary ventilation (e.g. Nippy ventilator)----	☐	☐	☐
13 Four apnoeic episodes within 4 hours requiring stimulation--------	☐	☐	☐
14 Oxygen therapy--	☐	☐	☐

If yes   greater than or equal to 50%----------   ☐   *less than 50%--------------------* ☐

	Yes	No	NK
15 Nebulised medications (e.g. salbutamol, saline)-------------------- -	☐	☐	☐

If yes   more than 1 per hour
        for more than 4 hours----------------   ☐   *2-4 hourly---------------* ☐

	Yes	No	NK
16 Care of the child with chest drains-----------------------------------	☐	☐	☐

If yes   first 24 hours------------------------   ☐   *after first 24 hours------*☐

17 Frequent nasal/oral/tracheostomy suction greater than or equal to 2 times per hour

☐   ☐   ☐

Infusions

18 Continuous intravenous **drug** infusions (e.g. aminophylline, salbutamol, octreotide, prostin, midazolam, cytotoxic therapy, potassium*, insulin) **except analgesia and inotropes** ❑ ❑ ❑

19 Intravenous infusion x1 (maintenance fluid)----------------------- ❑ ❑ ❑

20 Replacement of fluid losses
(e.g. from naso-gastric tube, drains, chest drain) ❑ ❑ ❑

21 Complex hourly intake and output
(e.g. IVI's, wound drains, urine output, NG losses) ❑ ❑ ❑

22 Multiple intravenous lines greater than 3 **except analgesia**-------- ❑ ❑ ❑

23 Intravenous drug boluses greater than 3 (including antibiotics)--- ❑ ❑ ❑

24 Vasoactive drug therapy(e.g. dobutamine, dopamine, adrenaline)-- ❑ ❑ ❑

25 Total parental nutrition-- ❑ ❑ ❑

26 Blood transfusion /transfusion of platelets /fresh frozen plasma- ❑ ❑ ❑

Renal

27 Acute renal failure (less than 1ml/kg for greater than 4 hours)--- ❑ ❑ ❑

28 Hourly urine output measurement----------------------------------- ❑ ❑ ❑

29 Acute renal replacement therapy (e.g. haemofiltration, haemodialysis)
❑ ❑ ❑

30 Acute hourly cycle peritoneal dialysis---------------------------- ❑ ❑ ❑

Circulation

31 Cardiopulmonary resuscitation------------------------------------- ❑ ❑ ❑

32 Intravenous fluid resuscitation (greater than 20 ml/kg in last 12 hours)
❑ ❑ ❑

33 Arterial line-- ❑ ❑ ❑

34 Central Venous Pressure (CVP) monitoring------------------------- ❑ ❑ ❑

35 Cardiac pacing (new on this admission)--------------------------- ❑ ❑ ❑

36 Regular blood sampling (4 hourly or more
frequent including blood glucose levels) ❑ ❑ ❑

37 Cardiac arrhythmia--- ❑ ❑ ❑

If yes responded to 1ˢᵗ line therapy ❑ *failed to respond to 1ˢᵗ line therapy* ❑

Neurological

38 Glasgow coma scale equal to or less than 8----------------------- ❑ ❑ ❑

39 Glasgow coma scale 9-12--- ❑ ❑ ❑

40 Deteriorating conscious level (a fall of 2 points since
commencement of observations) ❑ ❑ ❑

41 Prolonged or recurrent seizures (continuing for longer than 10 mins
or repetitive short generalised seizures without consciousness regained
between seizures, continuing for longer than 10 mins)-------------------- ❑ ❑ ❑

42 Intra Cranial Pressure (ICP) monitoring-------------------------- ❑ ❑ ❑

43 External ventricular device (EVD)-------------------------------- ❑ ❑ ❑

44 Frequent position changes (2 hourly)---------------------------- ❑ ❑ ❑

Other

45 Pain requiring epidural / intravenous or bolus infusion-------------- ❑ ❑ ❑

46 Sedation during/after procedure (insertion of lines drains, balloon
septostomy interventional cardiac catheterization/radiological investigation) ❑ ❑ ❑

47 Warming or cooling blanket / ambient temperature monitoring / incubator ❑ ❑ ❑

48 Dressing changes greater than 3 this shift or complex dressing changes ❑ ❑ ❑

49 Hourly aspiration of naso-gastric or gastrostomy tube------------ ❑ ❑ ❑

50 Naso-gastric / naso-jejunal /gastrostomy feeding (chronic)------- ❑ ❑ ❑

51 Naso-gastric / naso-jejunal feeding (new on this admission)-------- ❑ ❑ ❑

A child requiring close visual observation may include
- meningococcal sepsis in a stable state
- respiratory distress from any cause (e.g. asthma, upper airway obstruction)
- pre/post-operative if complex fluid management, analgesia, bleeding or complex surgery
- reduced conscious level from any cause (e.g. head injury, meningitis, DKA)
- pre/postoperative care
- severe neutropenia
- cyanotic congenital heart disease

Is this child nursed in a cubicle? Yes ☐ No ☐

Is this child nursed in a designated high dependency area? Yes ☐ No ☐

Daily Nurse Staffing (DNS) and Daily Patient Activity (DPA) Form

YORKSHIRE REGIONAL PAEDIATRIC HDU STUDY   Hospital [＿＿＿＿]   Ward [＿＿＿＿]   Week commencing [＿＿＿＿]

Hospital Census

Daily Nurse Staffing (DNS) levels	Early							Late							Night						
	Lead Nurse Sign:							Lead Nurse Sign:							Lead Nurse Sign:						
	RSCN	RGN	Please ✔ if a member of staff has **A,H, C** may ✔ more than 1 **A H C**	EN	HC	Bank Agency OT		RSCN	RGN	Please ✔ if a member of staff has **A,H, C** may ✔ more than 1 **A H C**	EN	HC	Bank Agency OT		RSCN	RGN	Please ✔ if a member of staff has **A,H, C** may ✔ more than 1 **A H C**	EN	HC	Bank Agency OT
Monday																				
Tuesday																				
Wednesday																				
Thursday																				
Friday																				
Saturday																				
Sunday																				

A = APLS/PALS) currently valid ie pass and in date   EN = Enrolled Nurse   C = CRITCAL CARE COURSE for example 100,415,405,160

H = HIGH DEPENDENCY COURSE for example 920 or HD modules   HC = Health Care assistant/Nursing auxillary/Clinical support worker

Daily Patient Activity (DPA) levels	Admissions to Ward	Pre-assesment	Day Cases	Ward Attenders	Admissions Assessment Area	Transfer to PICU/ ICU	Transfer to HDU Int Ext	Transfer to Ward	Discharged Home	Deaths	Total Audit Forms Collected 03.00 15.00	Total Occupied Beds 03.00 15.00
Monday												
Tuesday												
Wednesday												
Thursday												
Friday												
Saturday												
Sunday												

Monthly Nurse Staffing (MNS) Form

YORKSHIRE REGIONAL PAEDIATRIC HDU STUDY

Hospital Census   Ward [   ]

Hospital [   ]

Month/Year [   ]

Monthly Nurse Staffing (MNS)

Grade of nursing staff	Established WTE	Actual in post WTE	Number with APLS/PALS (valid)	Number with critical care course	Number with HDU course (modules)	Comments
A						
B						
C						
D						
E						
F						
G						
H						
I						
Other please specify						

Number of funded beds

Number of funded beds	
Number of funded beds open	

For further information or advice please contact

Kay Rushforth Research Nurse, Room 195, B Floor Clarendon Wing. The General Infirmary at Leeds. Belmont Grove. Leeds. WestYorkshire. LS2 9NS

T: 0113 3928650. **M**: 0777 1667761 **E**: Kay. Rushforth@leedsth.nhs.uk

Form YRPHDUS (monusbed 1) Kay Rushforth

Guidance notes
for use with the high dependency scoring tool

Yorkshire Regional
Paediatric High Dependency
Study

Kay Rushforth

EXPLANATION OF ITEMS (SCORING TOOL)

A. All children requiring high dependency care should be scored twice per day towards the end of the day shift and towards the end of the night shift.

B. The nurse scoring the child will need to look back from commencing duty/shift to identify the interventions performed for the child.

C. Please place a (x) or (✓) in the boxes provided to indicate the interventions you have performed for the child within the specified time period. All points 1-50 will need a (x)or (✓) in the box provided.

D   The reason for admission categories require a (x) or (✓) in the appropriate box. May (✓) more than one category

E. When completed please place data collection forms in the ring binder file provided

F. To assist you with the completion of this form a definition is available for all items. If you have any further queries please contact Kay Rushforth on **t:** 0113 3928650 **m:**0777 1667761 or
    e: kay.rushforth@leedsth.nhs.uk

G. Only complete data collection forms for children that are requiring high dependency care (that is all children who meet any one of the 51 criteria (excluding point 1) not all children admitted. Do not complete a form just because a child is nursed in a cubicle. The child must fulfil any 1 of the 51 criteria (excluding point 1).

CONTENTS

OBSERVATIONS

1 General nursing observations including non-invasive blood pressure and neurological observations

This includes:

- Any observations TPR recorded once or more than once per day
- Circulation observations that are performed as above.
- Neurological observations that are performed and recorded as above
- Blood pressure monitoring using a cuff via the conventional auscultation method (listening for the sound of the artery below the inflated cuff) or via an oscillometer (Dinamap) or Doppler instrument.

This does not include:

- ECG and oxygen saturation monitoring
- Invasive blood pressure monitoring via an arterial line is scored separately.

2 Continuous ECG monitoring

This includes the continuous standard 3 lead ECG monitoring to measure the rate and regularity of the heart beat.

3 Continuous Oxygen Saturation monitoring

This includes:

- The child that requires continuous oxygen saturation monitoring or pulse oximetry (a non-invasive method of measuring the arterial oxygen saturation).
- The child that is nursed in oxygen or in air.

This does not include:

- The child that requires a 'one off' oxygen saturation reading.

AIRWAY

4 Endotracheal intubation and subsequent care of the intubated patient

This includes:

- The placement/insertion of an oral or nasal endotracheal tube.

This does not include:

- The insertion of a short tube (nasal prong) for Continuous Positive Airways Pressure (CPAP)
- The insertion of a nasopharyngeal tube to remove secretions
- The child that has a tracheostomy

5 Use of airway adjunct / other artificial airway (guedel, nasopharyngeal, nasal prong)

This includes:

- Any device which passes from the lips or nose to the back of the throat to support the child's airway e.g. guedel, nasopharyngeal, or short endotracheal tube (nasal prong).

This does not include:

- The child that requires short tube Continuous Positive Airways Pressure (CPAP). This is scored separately.

6 Child recently extubated (less than12 hrs) after prolonged ventilation (greater than 24 hours).
This includes:
- A child that requires close observation following recent extubation (removal of the endotracheal tube)

Recent extubation is within 12 hours.
Prolonged ventilation refers to any child intubated and connected to a mechanical ventilator for longer than 24 hours.

This does not include:
- The child that has had removal of a nasal prong or other airway adjunct

7 Care of the child with a tracheostomy
 This includes:
- The child that has an opening surgically created through the neck into the trachea. The tube placed through the opening provides an airway and a means of clearing secretions.
- Observation of the tracheostomy site, observation of the child.
- Cleaning of, tying in of and dressings to the tracheostomy

This does not include:
Suction of the tracheostomy this is scored separately.

7a Care of the child with a tracheostomy less than 48 hrs old
This includes:
- The child that has an opening surgically created through the neck into the trachea (less than 48 hours ago). The tube placed through the opening provides an airway and a means of clearing secretions.
- Observation of the tracheostomy site, observation of the child.
- Cleaning of, tying in of and dressings to the tracheostomy

This does not include:
Suction of the tracheostomy this is scored separately.

8 Nebulised adrenaline for upper airway obstruction
This includes:
- Adrenaline 1 in 1000 (1mg/1ml) mixed with saline given via a nebuliser.

This does not include:
- The administration of any other drug but nebulised adrenaline.

8a Nebulised adrenaline for upper airway obstruction (more than2 doses)
This includes:
- The child that requires more than 2 doses of adrenaline only.

This does not include:
- The administration of any other drug but nebulised adrenaline.
- The child that requires up to and including 2 doses of nebulised adrenaline

BREATHING
9 Oxygen therapy
This includes:
- The child that requires oxygen therapy.
- The delivery of oxygen via a face mask, headbox, or nasal cannula

This does not include:
- The child that is nursed in air humidified or not
- The child that requires low flow home oxygen

9a Oxygen therapy greater than or equal to 50%
This includes:
- The child that requires 50% or in excess of 50% oxygen. This may be delivered via a mask or via a headbox.

10 Acute Continuous Positive Airways Pressure (CPAP)
When lung volume is diminished in certain disease states i.e. neurogenic disease, hyaline membrane disease and interstitial pneumonia CPAP is indicated.
CPAP will increase the end expiratory lung volume (functional residual capacity) to allow easier alveolar ventilation and mobilise secretions

This includes:
- the child that requires CPAP with nasal prong and nasal flow driver
- the child that requires CPAP via mask continuously (short term only).

This does not include:
- CPAP delivered for physiotherapy only.

11 Bag and mask ventilation
This procedure is reserved for the child with respiratory failure and requires the use of a hand operated self-inflating ventilation bag with a mask and high oxygen flow to control or assist ventilation. A gas filled anaesthetic T-piece may also be used.
Clinical criteria for the development of respiratory failure include:-
- Severe increase in respiratory effort including severe retractions or grunting, decreased chest movement.
- Depressed level of consciousness
- Cyanosis despite supplemental oxygen
- Absent or significantly decreased breath sounds
- Cardiovascular signs of distress – tachypnoea, peripheral vasoconstriction, mottled colour
- Apnoea, gasping, bradycardia, hypotension.

12 Stable long term CPAP/Biphasic Positive Airways Pressure (BIPAP) ventilation (Domiciliary ventilation).
This includes:
- The child that is chronically ventilated via a tracheostomy or mask and requires assistance with breathing via a Nippy ventilator, Breas ventilator or other domiciliary ventilator.

This child may require assistance with breathing at night time only and will only score for the shifts on which ventilation occurs.

13 Four apnoeic episodes within 4 hours (requiring stimulation)
This includes:
- The baby that stops breathing for 20 seconds and has an associated fall in heart rate to 80 or below.

This does not include:
- Apnoeas that are self correcting; the child must require stimulation to score.

14 Nebulised medications.
This includes:
- The administration of nebulised medications such as salbutamol, atrovent or saline

This does not include:
- The administration of adrenaline; this is scored separately

14a Nebulised medications more than 1 per hour for more than 4 hours
This includes:
- The administration of nebulised medications such as salbutamol, atrovent or saline more than 1 per hour for more than 4 hours

This does not include:
- The administration of adrenaline this is scored separately

15 Care of child with chest drain(s)
A chest drain is a conduit to remove air or fluid from the pleural cavity. Chest drains allow re-expansion of the lung.
Chest drain(s) may require suction, milking, observing for swing and bubbling, drainage (blood, haemoserous fluid, lymph fluid) and dressings to site.

15a Care of child with chest drain(s) first 24 hours
This includes:
- The child that has a chest drain(s) that may require suction, milking, observing for swing and bubbling, drainage (blood, haemoserous fluid) and dressings to site.

16 Airway suction greater than once an hour
This includes:
- The removal of secretions from the nose, mouth or tracheostomy to maintain a clear airway; more than once per hour.

INFUSIONS
17 Continuous intravenous drug infusion
This includes:
- The dedicated use of an intravenous line for continuous (**3 hours or more**) drug therapy.
- Drug infusion examples include potassium, salbutamol, aminophylline, prostin, octreotide, midazolam, phosphate, insulin, cytotoxic therapy.

This does not include:
- *Potassium, calcium etc that are added to maintenance fluid.
- An infusion of analgesia or vasoactive drugs

- The administration of bolus drugs ,those given as a short infusion (antibiotics anti-emetics, anticonvulsants) or those drugs given as a 'push'. Theses are scored separately.
- Arterial lines containing Heparin/sodium; these are scored separately.

18 Intravenous infusion (maintenance fluid)
This includes:
- The child that has an intravenous infusion for maintenance administered peripherally, via a central or Hickman line.

This does not include:
- The presence of a cannula. The child must have maintenance fluid running through the intravenous line

19 Replacement of fluid losses
This includes:
The measurement and replacement of fluid losses from 1 or more of the following:-
- Naso-gastric tube
- Gastrostomy tube
- Wound drains
- EVD devices
- Self retaining catheter (replacement of urine output-dehydrated child)
- Chest drains
This replacement could be hourly or 4 hourly

This does not include;
- The child who needs resuscitation fluid (HAS, saline) or requires a blood transfusion; these are scored separately

20 Complex hourly intake and output
This includes:
- The hourly charting of 3 or more continuous intravenous infusions, including maintenance and at least one hourly output measurement for example urine, NG, gastrostomy, wound drains, chest drains, EVD.
- The weighing of nappies.

21 Multiple intravenous lines greater than 3 except analgesia
This includes:
- Multiple intravenous lines that are in use not the number of peripheral or central cannula that are redundant.
- Intravenous lines with drug/fluid running continuously through it.
A double lumen central line is equal to 2 lines (if they are both in use)
A triple lumen central line is equal to 3 lines (if they are all in use)
A child may have three peripheral lines
A child may have analgesia via 1 line, inotropes via 1 line and maintenance fluid; the child will still score

22 Intravenous drug bolus greater than 3 types (including antibiotics)
This includes:
- The child that requires intravenous bolus drugs. These may be antibiotics, anti-emetics etc.

The drugs must be given as a bolus i.e. given as a push or given via an infusion pump over 1 hour/2hours and must be of 3 different types.
For example Gentamicin may be given twice per day but this is still one drug.
Flucloxacillin may be given 4 times per day this is still one drug.

23 Vasoactive drug therapy
This includes:
- The administration of one or multiple drugs to improve cardiac output. Examples of these drugs are dopamine, dobutamine, adrenaline, noradrenaline and dopexamine, flolan, glyceryl trinitrate, sodium nitroprusside.

24 Total Parental Nutrition (TPN)
This includes:
- The child receiving TPN either vamin and/or intralipid which is changed using a sterile/clean procedure daily. Intralipid may be administered as a separate solution or mixed with vamin.

25 Transfusion of blood / platelets / fresh frozen plasma (FFP)
This includes:
- The child that is receiving or has received a transfusion of blood, platelets or fresh frozen plasma

RENAL
26 Hourly urine output measurement
This includes:
- The child that has a self retaining catheter with which to measure urine output every hour.

27 Hourly urine output less than 1ml/kg/hr for more than 4 hours
This includes the child that has a urine output of less than 1ml/kg/ hr for 4 hours. The majority of children will be catheterised

28 Peritoneal dialysis
This includes:
- The child that is in acute renal failure.

This child requires peritoneal dialysis which is a method of removing waste products by passing a cannula into the peritoneal cavity, running in fluid (dialysate) and after an interval draining the fluid out. The peritoneum acts as a semi-permeable membrane allowing diffusion of electrolytes and water between the peritoneal capillaries and the dialysate.

This does not include:
- The presence of a peritoneal dialysis cannula. The child must be receiving peritoneal dialysis.
- The child that requires chronic peritoneal dialysis.

29 Haemofiltration, haemodialysis
Renal replacement therapy or dialysis is indicated for the child with acute renal failure when acute medical management has failed to control hypervolaemia, hypertension, bleeding, hyperkalaemia, hyperurecaemia or acidosis.
Dialysis is also indicated when uraemia produces cardiovascular or neurologic deterioration or when elimination of toxins or poisons is required.

This does not include:
- The child that is receiving chronic haemodialysis

CIRCULATION
30 Cardiopulmonary resuscitation
This includes:
- The child that has little or no spontaneous breathing requiring bag-mask ventilation and absent or collapse in ventricular rhythm (Ventricular Tachycardia VT, Ventricular Fibrillation VF, Pulseless Electrical Activity PEA).
- The child that needs bag/mask ventilation and cardiac massage.

31 Intravenous fluid resuscitation greater than 20mls/kg
This includes:
- The child that requires greater than 20mls/kg of fluid to restore effective circulating volume in hypovolaemic shock states. This is second and subsequent fluid boluses.

32 Invasive arterial pressure monitoring
This includes:
- The child that has an arterial line for continuous monitoring of blood pressure. A continuous heparinised flush system will maintain patency of the cannula. A transducer may convert the pressure waveform into an electronic signal.
The score includes the use of heparin flush infusion.

This does not include:
- The child that is receiving hourly or more regular blood pressure monitoring using a non-invasive technique.

33 Central Venous Pressure (CVP) monitoring
Central Venous Pressure monitoring is used to
- assess blood volume and venous return,
- evaluate right ventricular function
- Obtain direct information about the pulmonary vascular system.
For the child to score; the CVP should be measured by a transducer and monitor (continuous display) and a number recorded hourly.
This includes the use of heparin flush infusion.

34 Regular blood sampling (4 hourly or more frequent including blood glucose levels)
This includes:
- The child that is requiring frequent (4 hourly or more frequent) blood for any investigation (e.g. U+E's, FBC, clotting) from a central line, arterial line or skin stab.
- Blood taken for blood glucose levels, blood gas analysis

This does not include:
- The child that requires daily or twice daily bloods.

35 Cardiac pacing (new on this admission)
This includes the child that requires pacemaker therapy for
- bradycardia unresponsive to oxygen therapy, ventilation and drug therapy
- heart block with significant bradycardia

- The potential for sudden development of bradycardia or heart block (e.g. following cardiovascular surgery).

External demand pacing of children usually is accomplished using pacing leads placed on the epicardium in the operating theatre during cardiovascular surgery. A demand pacemaker allows the child's intrinsic cardiac rhythm to continue provided that the child's atrial or ventricular rate equals or exceeds the pacemaker demand rate. If the child's intrinsic rate falls below the pacemaker demand rate the pacemaker will initiate an electrical impulse.

This does not include:
- The child that is stable with an implanted pacemaker.

36 Cardiac arrhythmia
This includes:
- The child that has persistent cardiac arrhythmia (Supraventricular Tachycardia SVT, Ventricular Tachycardia VT, bradyarrythmias).

36a Cardiac arrhythmia which has responded to 1st line therapy
This includes:
- The child that has cardiac arrhythmia (supraventricular tachycardia, ventricular tachycardia, bradyarrythmias) that responds to first line therapy.

First line therapy is the administration of a pharmacological agent (e.g. adenosine, lidocaine, adrenaline, atropine).
Drugs may be repeated as prescribed

This does not include:
- The child that requires defibrillation or cardioversion (synchronised defibrillation) to correct the arrhythmia.

NERUOLGICAL
37 Glasgow coma scale equal to or less than 8
This scale is used in the evaluation of neurological disease
It evaluates, motor activity, verbal responses and motor responses to score the child's level of consciousness. The score can range between 3 - 15.
This includes:
- The child with a score of 8 or less that is unresponsive or responds to painful stimuli only.

38 Glasgow coma score 9-12
This includes:
- The child with a score between 9 and 12.

39 Deteriorating conscious level
This includes:
- The child that has had a deterioration in conscious level; a fall of 2 points since Glasgow Coma Scoring commenced.

40 Prolonged or recurrent seizures
This includes:
- A child that has a seizure lasting for 10 minutes without stopping or
- Repetitive short generalised seizures for longer than 10 minutes where consciousness is not regained between seizures

41 Intracranial Pressure (ICP) monitoring

This is a fibre optic or standard intraventricular catheter or subarachnoid bolt or screw that is placed through a burr hole in the skull into the ventricle, dura, cerebrum or subarachnoid space to monitor pressure within the brain.This device is attached to a fluid filled or fibre optic monitoring system and a number is displayed and recorded.

42 External Ventricular Device (EVD)

An external ventricular device is temporarily used to replace an infected ventriculoperitioneal (VP) shunt or to allow access and drainage of cerebrospinal fluid post-operatively.

The EVD allows the diversion of cerebrospinal fluid into an external reservoir relieving pressure within the brain. The reservoir is set at a prescribed level and the drainage of cerebrospinal fluid is measured hourly

43Frequent position changes (2 hourly)

This includes:

- The child that has limited mobility and requires frequent position changes

OTHER

44 Pain requiring epidural/intravenous or bolus/infusion

This includes:

- Epidural analgesia – a specialist technique of pain management obtained by the administration of local anaesthetic (bupivicaine) and other drugs (ketamine, clonidine and fentanyl) directly into the epidural space blocking sensory fibres. It can also affect motor and sympathetic nerve fibres.
- Continuous intravenous analgesia to maintain plasma concentration levels – this may be morphine, fentanyl or alfentanyl and administered via an infusion device.
- Bolus intravenous analgesia – examples are morphine sulphate, codeine phosphate, alfentanyl, fentanyl, remifentanyl, diamorphine, pethidine. These drugs may be given as a single bolus.
- Patient controlled analgesia (PCAS) – this method uses a computerised pump to deliver a specific amount of analgesia (usually morphine sulphate) continuously as a background. The child may also press a button to administer a small amount of analgesia to treat breakthrough pain. Lockout periods and dose limits can be programmed. This is only recommended for children over the age of 6 years that can understand the concept and have the dexterity to control the device.

45 Sedation during/after procedure (insertion of drains, lines, septostomy, interventional catheterisation, any radiological investigation)

This includes the child that requires oral/intravenous sedation for a procedure such as:

- insertion or removal of chest drains, wound drains,
- balloon septostomy
- interventional catheterisation
- dressing changes.
- any radiological investigation

46 Warming or cooling blanket/ambient temperature monitoring/incubator
This includes:
- The child that requires assistance to maintain normal body temperature. Devices that may be used include bear hugger/polar bear (warming or cooling blanket), incubator, open radiant warming bed or ambient temperature monitoring.

47 Dressing changes greater than 3 or complex (where more than 1 hour is spent performing dressing changes
This includes:
- The child that requires 3 or more dressings to skin, wounds, ostomy sites, drain sites. Dressing refers to any type of dressing dry gauze, alginate dressings (kaltostat), foam dressings (alevyn, lyofoam), hydrogel dressings (gelliperm, hydrosorb, intrasite) and adhesive film dressings (IV 3000, tegaderm).
- The child that requires complex dressing changes that take more than 1 hour to complete.

This does not include
- The child that requires a skin suit for dermatological reasons.

48 Hourly aspiration of naso-gastric or gastrostomy tube (NBM)
This includes:
- The child that requires hourly aspiration of a naso-gastric or gastrostomy tube.

49 Naso-gastric/gastrostomy/naso-jejunal feeding (chronic)
This includes:
- The child that is unlikely to be able to take adequate oral nourishment for a prolonged period of time
- The child that is admitted with the enteral feeding tube already in place

50 Naso-gastric/naso-jejunal feeding (new on this admission)
This includes:
- The child that requires a naso-gastric or naso-jejunal tube for the administration of nutrition acutely.

Appendix 7: Pilot study: data collection forms

Paediatric Patient Activity (PPA) Form

YORKSHIRE REGIONAL PAEDIATRIC HDU STUDY

Hospital [ ]   Ward [ ]   Date [ ]   Day [ ]   Night [ ]

Patient [ ]   Unit No [ ]   Postcode [ ]   DOB [ ]   Sex [ ]

Reason for admission	Surgical Illness	☐	Fits/reduced conscious level	☐
	Respiratory Illness/Croup	☐	Asthma	☐
	Diarrhoea/ Vomiting	☐	Trauma	☐
	Shock	☐	Sepsis	☐
	Poisoning/metabolic disorder	☐	Other	☐

Diagnosis free text [ ]

Observations

1. General observations (including non invasive blood pressure) performed

> Hourly ☐   Hourly ☐   2 Hourly ☐   4 Hourly ☐   BD ☐   Daily ☐

Additional Monitoring	Yes	No	NK
2 Continuous ECG monitoring	☐	☐	☐
3 Continuous oxygen saturation monitoring	☐	☐	☐

Airway

	Yes	No	NK
4 Endotracheal intubation and subsequent care of the intubated child	☐	☐	☐
5 Use of airway adjunct/other artificial airway	☐	☐	☐
6 Child recently extubated	☐	☐	☐
7 Care of child with tracheostomy	☐	☐	☐
7a If **yes**, is tracheostomy less than 48 hours old	☐	☐	
8 Nebulised adrenaline for upper airway obstruction	☐	☐	☐
8a If **yes** more than 2 doses	☐	☐	

Breathing

	Yes	No	NK
9 Oxygen therapy	☐	☐	☐
9a If **yes** FiO_2 > or equal to 50%	☐	☐	
10 Acute Continuous Positive Airways Pressure (CPAP)	☐	☐	☐
11 Bag and mask ventilation	☐	☐	☐
12 Stable long term (domiciliary) ventilation	☐	☐	☐
13 Four apnoeic episodes within 4 hours requiring stimulation	☐	☐	☐
14 Nebulised medications	☐	☐	☐
14a.If **yes**, more than 1 per hour for more than 4 hours	☐	☐	
15 Chest drains	☐	☐	☐
15a If **yes,** has chest drain been in situ less than 24 hours	☐	☐	
16 Airway suction more than once an hour	☐	☐	☐

IV Fluids Infusions and drug therapy	**Yes**	**No**	**NK**
17 Continuous intravenous drug infusions (other than analgesia and inotropes)	❏	❏	❏
18 Intravenous infusion maintenance fluid	❏	❏	❏
19 Replacement of fluid losses (e.g. naso-gastric tube, drains, chest drain)	❏	❏	❏
20 Complex hourly fluid balance (e.g. IVI's, drains, urine output, NG losses)	❏	❏	❏
21 Multiple intravenous lines greater than 3 **except analgesia**	❏	❏	❏
22 Intravenous drug boluses greater than 3 (including antibiotics	❏	❏	❏
23 Vasoactive drug therapy(e.g. dobutamine, dopamine, adrenaline)	❏	❏	❏
24 Total parental nutrition	❏	❏	❏
25 Blood transfusion / transfusion of platelets / fresh frozen plasma	❏	❏	❏
Renal			
26 Hourly urine output measurement	❏	❏	❏
27 Urine output < 1ml / kg for > 4 hours	❏	❏	❏
28 Peritoneal dialysis	❏	❏	❏
29 Haemofiltration / Haemodialysis	❏	❏	❏
Circulation			
30 Cardiopulmonary resuscitation	❏	❏	❏
31 Intravenous fluid resuscitation (> 20 ml / kg / hr)	❏	❏	❏
32 Invasive Arterial pressure monitoring	❏	❏	❏
33 Central Venous Pressure (CVP) monitoring	❏	❏	❏
34 Regular blood sampling (4 hourly or more frequent) including blood glucose	❏	❏	❏
35 Cardiac pacing (new on this admission)	❏	❏	❏
36 Cardiac arrhythmia	❏	❏	❏
36a.If yes, responded to 1st line therapy	❏	❏	
Neurological			
37 GCS equal to or less than 8	❏	❏	❏
38 GCS 9-12	❏	❏	❏
39 Deteriorating GCS (a fall of 2 points since commencement of observations)	❏	❏	❏
40 Prolonged or recurrent seizures	❏	❏	❏
41 Intra Cranial Pressure (ICP) monitoring	❏	❏	❏
42 External Ventricular Device (EVD)	❏	❏	❏
43 Frequent position changes (2 hourly)	❏	❏	❏
Other			
44 Pain requiring epidural / intravenous analgesia	❏	❏	❏
45 Sedation during / after procedure	❏	❏	❏
46 Warming or cooling blanket / ambient temperature monitoring / incubator	❏	❏	❏
47 Dressing changes greater than 3 this shift or complex dressing changes	❏	❏	❏
48 Hourly aspiration of naso-gastric or gastrostomy tube	❏	❏	❏
49 Naso-gastric / naso-jejunal /gastrostomy feeding (chronic)	❏	❏	❏
50 Naso-gastric / naso-jejunal feeding (new on this admission)	❏	❏	❏
Is this child nursed in a cubicle?	❏	❏	
Is this child nursed in a designated high dependency area?	❏	❏	

Daily Nurse Staffing (DNS) Form

YORKSHIRE REGIONAL PAEDIATRIC HDU STUDY   Hospital [   ]

Hospital Census   Ward [   ]   Week Commencing [   ]

Clinical Nurse Staffing Levels Please Record at Specified Times

	Early Shift (12 noon)							Late Shift (18.00 hrs)							Night Shift (12 midnight)						
	RSCN RN (C)	RG N	Numbers of staff with (A H C)			EN	HCA	Bank Agency OT	RSCN RN (C)	RGN	Numbers of staff with (A H C)			EN	HCA	Bank Agency OT	RSCN RN (C)	RGN	Numbers of staff with (A H C)			EN	HCA	Bank Agency OT
Monday																								
Tuesday																								
Wednesday																								
Thursday																								
Friday																								
Saturday																								
Sunday																								

Key
A = APLS/EPLS/PALS   H = High dependency care courses of modules   C = Critical care course

Daily Patient Activity (DPA) Form

Total daily activity numbers by week (to be completed at midnight)

	Admissions to Ward (including day cases)	Ward attenders (not admitted)	Transfer to PICU/ICU	Transfer to HDU		Transfers to ward	Discharges	Deaths	Total beds occupied at midnight		Admissions assessment area **or** Pre-assessment	Number admitted to ward
				Int	Ext							
Monday												
Tuesday												
Wednesday												
Thursday												
Friday												
Saturday												
Sunday												

Once forms are complete please return to the completed documents file   Int=Internal   Ext=External

Appendix 8: Diagrammatical representation of the development and refinement of the paediatric patient activity form

PRE-FEASIBILITY AND PILOT STUDY
Nurses were interviewed on each hospital ward or within specialties about the conditions and severity of illness of the children in their care.
Consultants were asked to discuss interventions used for HDC at steering group meetings

Lists of interventions were generated to assist with the development of the PPA for the feasibility and pilot study.

Large amounts of data generated suggesting that data capture included children receiving usual ward care

EXPERT CONSULTATION STUDY-ROUND 1
5 consultant paediatricians/intensivists and 5 nurses employed at DGHs and teaching hospitals used electronic communication to determine the level of care (usual ward care or high dependency care) for children represented in case scenarios

Interventions to be reduced for the refinement of the main study

Statistical independence (lack of agreement) achieved

EXPERT CONSULTATION STUDY-ROUND 2
3 experts to agree usual ward care intervention removal (1 nurse, 1 paediatric consultant, 1 paediatric intensivist)

7 interventions were removed for the revised PPA.

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Appendix 9: The main study: paediatric patient activity (PPA) form

NHS **YORKSHIRE REGIONAL PAEDIATRIC HDC STUDY** Data Collection Form

Hospital | Ward | Shift <u>Start</u> Date | Day
Night

{Affix patient sticker}
Patient
Name | NHS No

Unit No | Postcode | DOB | Sex

Reason for admission (please ✓ more than 1 category if applicable)

Surgical Problem ☐	Fits/Reduced Conscious Level ☐	Respiratory Illness/Croup ☐	Sepsis ☐
Asthma ☐	Bone Marrow Transplant ☐	Bacterial Meningitis ☐	Shock ☐
Diarrhoea/Vomiting ☐	Poisoning/Substance Misuse ☐	Meningococcal Septicaemia ☐	Trauma ☐
Metabolic Disorder ☐	Post Cardiac Surgery ☐	Diabetic Ketoacidosis ☐	Other ☐

Diagnosis (free text)

Place a ✓ in the box provided for all interventions performed (1-42) <u>during your shift only</u>

Airway	**YES**
1 Endotracheal intubation and subsequent care of the intubated child	☐
2 Use of airway adjunct/other artificial airway (e.g. guedel,nasopharyngeal, nasal prong)	☐
3 Child recently extubated	☐
4 Care of child with tracheostomy	☐
4A If **yes** is tracheostomy less than 48 hours old? ☐	
5 Nebulised adrenaline for upper airway obstruction	☐
5A If **yes** more than 2 doses? ☐	

Breathing	
6 Oxygen therapy greater than or equal to 50%?	☐
7 Acute Continuous Positive Airways Pressure (CPAP)	☐
8 Bag and mask ventilation	☐
9 Stable long term (domiciliary) ventilation	☐
10 Four apnoeic episodes within 4 hours requiring stimulation	☐
11 Nebulised medications more than 1 per hour for more than 4 hours	☐
12 Chest drains	☐
12A If **yes** has chest drain/s been in situ greater than 24 hours? ☐	
13 Airway suction more than once an hour	☐

IV Fluids Infusions and drug therapy	
14 Continuous intravenous drug infusions (other than analgesia and inotropes)	☐
15 Replacement of fluid losses (e.g. from naso-gastric tube, drains, chest drain)	☐
16 Complex hourly fluid balance (e.g. IVI's, wound drains, urine output, NG losses)	☐
17 Multiple intravenous lines greater than 3 **except analgesia**	☐
18 Intravenous drug boluses greater than 3 per (8 hour) shift (including antibiotics)	☐
19 Vasoactive drug therapy(e.g. dobutamine, dopamine, adrenaline, prostin)	☐
20 Total parental nutrition	☐
21 Blood transfusion / transfusion of platelets / fresh frozen plasma	☐

Renal   YES
22 Hourly urine output measurement   ❐
23 Peritoneal dialysis   ❐
24 Haemofiltration / Haemodialysis   ❐

Circulation
25 Cardiopulmonary resuscitation   ❐
26 Intravenous fluid resuscitation (greater than 20 ml / kg / hr)   ❐
27 Invasive Arterial pressure monitoring   ❐
28 Central Venous Pressure (CVP) monitoring   ❐
29 Regular blood sampling (4 hourly or more frequent including blood glucose levels)   ❐
30 Cardiac pacing (new on this admission)   ❐
31 Cardiac arrhythmia   ❐
    31A. If **yes**, responded to 1st line therapy?   ❐

Neurological
32 Hourly (or more frequent than hourly) neurological observations?   ❐
    32A. If **yes,** is GCS equal to or less than 8 ❐ GCS 9-12 ❐   GCS 13-15❐
33 Deteriorating GCS (a fall of 2 points since commencement of observations)   ❐
34 Prolonged or recurrent seizures   ❐
35 Intra Cranial Pressure (ICP) monitoring   ❐
36 External Ventricular Device (EVD)   ❐
37 Frequent position changes (2 hourly)   ❐

Other
38 Pain requiring epidural / intravenous analgesia   ❐
39 Sedation during / after procedure   ❐
40 Warming or cooling blanket / ambient temperature monitoring / incubator   ❐
41 Dressing changes greater than 3 this shift or complex dressing changes   ❐
42 Naso-gastric / naso-jejunal /gastrostomy feeding (new on this admission)   ❐

Additional Information (Please place a✓ in the box provided if the child is receiving any of the following:)

Observations
General observations (including non invasive blood pressure)   > Hourly❐   Hourly❐ 2 Hourly ❐

Monitoring   YES
Continuous ECG monitoring   ❐

Other
Is this child nursed in a cubicle?   ❐

Is this child nursed in a designated high dependency area?   ❐

In your opinion is this child in need of high dependency care?   ❐

Was this child transferred from another hospital?   ❐

Is all necessary equipment available to care for this child? If not please comment below   ❐

Any other comments?

Thank you for taking time to complete this questionnaire.

Appendix 10: Information leaflet for parents and guardians

THE YORKSHIRE REGIONAL PAEDIATRIC HIGH DEPENDENCY STUDY

Yorkshire Regional
Paediatric High Dependency
Study

Information leaflet for Parents and Guardians

This leaflet tells you about the Yorkshire Regional Paediatric High Dependency Study (YRPHDS). If after reading this leaflet you would like more information you can find contact details on the back page

What is High Dependency Care?

High dependency care is level of care provided for children and young people that is somewhere between Intensive care (for children who are very sick) and ordinary ward care. High dependency care may be described as close observation and monitoring and is provided on most children's wards.

What is the YRPHDS?

The YRPHDS is to collect information to find out how many children and young people require high dependency care in this area. Information will be collected by nursing staff once during the day and once during the night for all children and young people requiring high dependency care.

Why do we need to perform the YRPHDS?

To provide us with information:
- on the numbers of children and young people that require high dependency care
- to help our understanding of the illnesses that require high dependency care
- to help us plan care in the future.

At present there is very little information available to tell us about the numbers of children and young people requiring high dependency care and the best ways to provide this care.

What information do we hold?

For each child or young person we need to know about the reason for admission to hospital, their hospital number, postcode, how old they are and what sex they are. We also need to know what kind of equipment is being used in your care and what nursing involvement is necessary during your child's stay in hospital

Do I need to do anything?

No. You do not need to do anything. There are no forms to fill in and nothing to sign.

How do we ensure confidentiality?

All paper based and computer based records are kept under conditions of strict security, as required by law in the Data Protection Act. No personal information is ever released to unauthorised individuals, groups or companies. A Data Advisory Group monitors the security and release of data. No individual who takes part in this study will ever be directly approached. No individual is ever identified in any published material.

Is the data ever passed on to anyone?

Sometimes anonymous data that cannot identify individuals is given to other researchers. No personal information will be passed on to individuals, groups or companies.

Who will have access to the data?

A restricted number of staff working on the study. All staff will have been trained in confidentiality procedures.

Can I have access to the data?

Yes. You have a right to see all the information that is held about you or your child.

What if I do not want information recorded?

No personal details will be put onto the computer without agreement and no reason is required. This will NOT affect you or your child's medical care in any way. If you do not want information to be recorded please speak to the nurse in charge of the ward. It is possible to withdraw your child's personal details at any time either by contacting us directly or the ward who will contact us.

How do we know our work is ethical?

This work is carried out with the approval of national and local research ethics committees. The members of these committees include doctors, health professionals and lay people.

What are we asking for?

We are asking for your permission to collect store and use your child's details as described in this leaflet, for research into high dependency care.

For further information or answers to questions about this study please contact:

Kay Rushforth
Room 195
B Floor Clarendon Wing
The General Infirmary at Leeds
Belmont Grove
Leeds
West Yorkshire LS2 9NS

Tel: 0113 3928650
E-Mail Kay.Rushforth@leedth.nhs.uk

Appendix 11: Publication:Ethics and issues of patient consent

Issues of patient consent: a study of paediatric high-dependency care

Kay Rushforth, Patricia A McKinney

Health service and clinical researchers often require access to and use of confidential patient (or patient-identifiable) information as part of clinical audit or health service research which is designed to improve the quality of services that are provided. However, much confusion and ignorance surround the issue of informed signed consent which has become a fundamental principle governing the use of patient-identifiable information (Parkes, 2004). The current situation in the UK with regard to consent and confidentiality has been affected by the factors listed in *Table 1*.

This article will first define informed consent and confidentiality. It will outline the legislation and guidance affecting consent and confidentiality, including some of the adverse events that have occurred in practice and contributed to the concerns of service users. Finally, an overview of the experiences of a research nurse involved in a health service research study of paediatric high-dependency care will put this issue into a practical context.

Abstract

This article reports on the issues relating to obtaining informed, signed consent for a study of paediatric high-dependency care and provides practical guidance on confidentiality for health service researchers. Consent and confidentiality are not new concepts but recent changes to the legislation and guidance offered from nursing and medical regulatory bodies have caused concerns and confusion for researchers with respect to both issues. Balancing health service research and the development of services against the requirements of patients for confidentiality is essential yet challenging. This was a time consuming, costly exercise. Resource implications may ultimately mean that studies which are of benefit to patients in relation to the delivery of their care may not be undertaken. Health professionals need to be continually updated and made aware of the legislation and confidentiality requirements for health service research involving the collection of patient-identifiable details.

Key words: ■ Children: rights ■ Code of Conduct ■ Data protection
■ Ethics ■ Intensive care ■ Paediatric nursing ■ Patients: rights

Table 1. The factors that have affected consent and confidentiality in the UK

* Legislation (the Data Protection Act 1998; the Human Rights Act 1998; the Health and Social Care Act 2001)
* Guidance offered by medical and nursing regulatory bodies
* Adverse events in clinical practice

Informed consent: what is it?

Informed consent is the process of disclosing the risks, benefits and expectations of a research study to individuals to allow them to make an informed decision (McKeown and Weed, 2002). Competence, autonomy, lack of coercion and an understanding of the risks, burdens and benefits is vital to the process (McKeown and Weed, 2002). Some groups, such as children and individuals with a mental disorder, are considered vulnerable populations and may lack the decision-making capacity to provide informed consent. Consent may be considered either (Department of Health (DoH), 2003):

■ *Implicit:* an indication of agreement by an informed patient but not necessarily verbal or written
■ *Explicit:* patient agreement given orally or in writing after options and consequences have been made clear.

In addition, although children may give 'assent' or agreement to participate they may lack the intellectual capacity to provide true informed consent (McKeown and Weed, 2002).

The distinction should be made between consent for therapeutic and non-therapeutic research as determined by the Declaration of Helsinki (World Medical Association (WMA), 2002) as this contains the accepted recommendations for guiding physicians in biomedical research. Therapeutic research is defined as research that enrols patients to test interventions that may be of direct benefit to those patients. Non-therapeutic research is defined as research that enrols individuals with the aim of developing knowledge that may benefit future generations and not necessarily be of direct benefit to the individual taking part (WMA, 2002).

In health service research, where non-therapeutic research is used extensively, individuals do not give informed signed consent for personal details to be used and stored. Information regarding the use of patients' personal details is provided to patients/individuals with the aid of posters and patient information leaflets. This information includes details of how to withdraw participation at any time from the research. The Declaration of Helsinki (WMA, 2002) permits authorized representatives (parents or guardians) to enter children as subjects in non-therapeutic research but such research must not be 'harmful'.

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Informed consent: why do we need it?

Informed consent is required to provide assurance that patients are not deceived or coerced in any way (O'Neill, 2003). It is essential to give patients control over the amount and type of information that is shared with others and also provides an opportunity for them to withdraw participation at any time.

Confidentiality

Confidentiality covers information (private or sensitive) revealed to a chosen other but which is protected from being shared with others (McKeown and Weed, 2002). The common law of confidentiality is not framed in an Act of Parliament but built from case law where practice has been established by individual judgments. The key belief is that information confided should not be used or disclosed, except as formerly understood by the confider, or with his/her subsequent permission (Department of Health (DoH), 2003). Issues and responsibilities associated with consent and confidentiality are not new to practitioners; nevertheless, recent legislation and guidance in this area has had direct effects. Changes in the law are intended to benefit patients and ensure their rights are protected. However, in health service research, these new requirements can be thought of as both obstructing and inconveniencing the process. Academic researchers should be well aware of the new requirements but those new to the field may be unaware of the changes and how they have the potential to affect their practice.

Legislation affecting consent and confidentiality

The Data Protection Act 1998 became law in the UK in the year 2000, enshrining the principle that explicit consent from living individuals was necessary to enable the use, transfer and storage of data (Parkes, 2004). Essentially, the Data Protection Act 1998 differentiated between manual (including health records) and electronic records held about an individual. A health record relates to any information regarding the care of an individual (with the exception of anonymized information) made by a health professional. Therefore, all NHS information concerning patients, whether held electronically or on paper, falls within the scope of the Act (Parkes, 2004).

The importance attached to manual records marked a change from the Data Protection Act of 1984 and made the implicit assumption that the rights of the individual were to be protected while the autonomy of researchers was to be curtailed (Parkes, 2004). Personal data or patient-identifiable information 'processed' (i.e. data obtained, recorded, held, altered, retrieved, destroyed or disclosed) by individuals after the introduction of the Data Protection Act 1998 now required the consent of the patient.

The Human Rights Act 1998 also assisted the pro-patient debate with its stance over the rights of privacy. The Human Rights Act 1998 stated that transfer of data to third parties should only take place with identifiers removed or with explicit consent and that patient information could only be entered onto 'registers' with consent from those individuals concerned (Verity and Nicoll, 2002).

Many researchers believed that the passage of the Data Protection Act 1998 and the Human Rights Act 1998 would make life difficult for them, as a number of obstacles had been put in place to discourage medical research. It was felt that the extremely bureaucratic nature of the process would prevent the
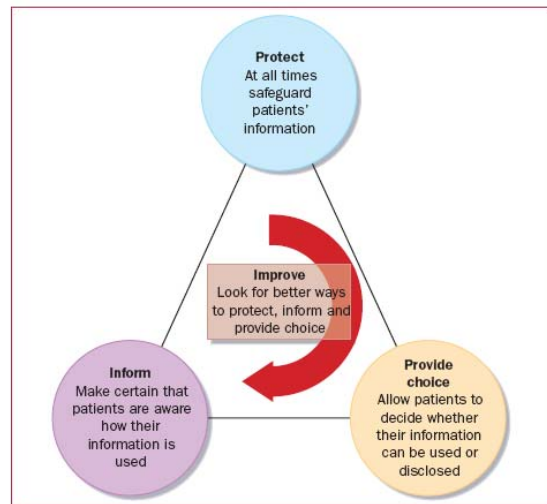

Figure 1. Confidentiality model (Department of Health (DoH), 2003).

development of future health care (Paterson, 2001; Verity and Nicoll, 2002; Peto et al, 2004; Ward et al, 2004).

The Health and Social Care Act 2001 ensures the control of patient information for medical purposes through the power of section 60. It negates the use of consent when the use of identifiable information clearly promotes the health and wellbeing of the public where:

■ Consent is not practicable
■ Anonymized information will not suffice (Lawlor and Stone, 2001).

The Patient Information and Advisory Group (PIAG) was established under section 60 of the Act to advise government to permit the use of patient-identifiable data in certain circumstances (Higgins, 2003). PIAG ensures annual review of each project approved and stipulates that section 60 support is intended as a provisional measure for studies until researchers develop consent or anonymization procedures (Higgins, 2003).

Section 60 of the Health and Social Care Act 2001 has been criticized for giving too much power to central government and for being unworkably bureaucratic (Verity and Nicoll, 2002; Peto et al, 2004). Peto et al (2004) argue that ethics committees (Multicentre Research Ethics Committees (MRECs) and local research ethics committees) are represented by all disciplines including any lay people and patients or their representatives. Therefore, there should be no necessity for further approval from the PIAG when the ethics committee is made up of multiprofessionals who each have a copy of the research protocol with which to make a decision.

Inconvenience is an insufficient justification for not gaining informed consent (Manning, 2002). The reason for gaining informed consent is for the benefit of the patient and the promotion of public health. Researchers may believe that they are acting in the best interest of their patients but without patient consent and involvement researchers could be seen to be investing in their own aims and self-interest (Lawlor and Stone, 2001).

Evidence suggests that the majority of patients are happy for their personal details to be used (Willison et al, 2003;

McKinney et al, 2005). However, most patients would prefer to be asked for consent either verbally or in writing (Willison et al, 2003). It is argued that the general public has been little informed in the development of the current legislation (Lawlor and Stone, 2001).

While the government talks about patients' rights, confidentiality and patient choice (DoH, 2000), it is unfortunate that the legislation concerned with these issues is written in a language that the general public would find difficult to understand (Lawlor and Stone, 2001).

Guidance affecting consent and confidentiality

The General Medical Council (GMC) in 2000 offered its own guidance to all members and prohibited the automatic reporting of cancer cases to the local registry without patient consent (GMC, 2000). This system of reporting cases to the registry had been in place for over 50 years with no adverse events and with great benefits (Parkes, 2004). New guidance from the GMC (2000) now implied that any doctor reporting patients to a
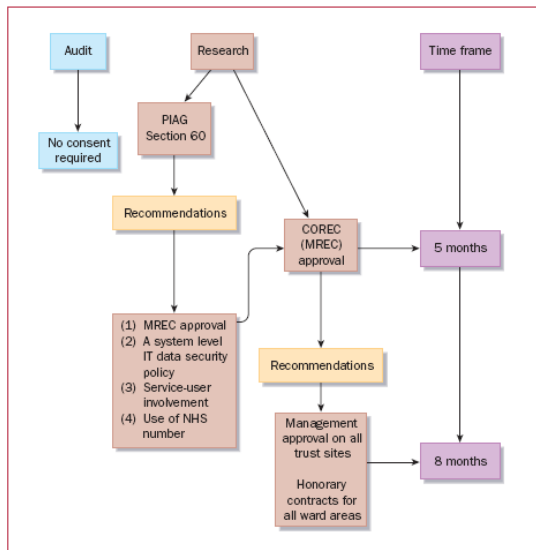
Figure 2. Flow diagram to outline the process and time frame involved in gaining section 60 support (from the Patient Information and Advisory Group (PIAG) and ethical approval; MREC = Multicentre Research Ethics Committee; COREC = Central Office for Research Ethics Committee; IT = information technology.

registry without consent would be prosecuted (Parkes, 2004). After much criticism the GMC bowed to pressure and modified its guidance in 2004 with the publication of *Confidentiality: Protecting and Providing Information* (GMC, 2004). This guideline now documents the importance of cancer registries and states that patients must be 'informed' if details are to be passed to any registry at the earliest opportunity (GMC, 2004).

Early guidance from the nursing regulatory body was established in the *Code of Professional Conduct* in 1992 (UKCC, 1992). The Code stated that each registered nurse should show consideration for confidential information and should refrain from disclosing any information without the consent of the patient. New guidance from the Nursing and Midwifery

Council (NMC) in 2002 expanded upon the previous Code and highlighted the impracticality of obtaining consent each time information has to be shared with others; however, others are referred to as health professionals within the team involved in the care of the patient (NMC, 2002). Specific reference is made to obtaining consent if information is to be disclosed outside of the team (NMC, 2002).

The DoH (2003) has also produced guidance to health workers using the aid of a confidentiality model to provide patients with a confidential service (*Figure 1*). The four processes are interlinked and should be ongoing to advance patient care.

Adverse events surrounding clinical practice

Confidence in healthcare professionals to protect the rights of patients and families decreased after the publication of two reports: *Learning from Bristol: The Report of the Public Inquiry into Children's Heart Surgery at the Bristol Royal Infirmary 1984–1995* (The Bristol Royal Infirmary Inquiry, 2001); and *The Report of the Royal Liverpool Children's Inquiry* (The Royal Liverpool Children's Inquiry, 2001). Lessons learnt from these two damning reports, both pertinent to the care of children and their families, prompted the necessity for radical change. Hospitals awash with data, a failure to use that data, flouting the need for consent and secrecy provided evidence of archaic practice. The NHS needed to be brought into the 21st century by adapting to change. Parents must now be provided with information and a culture of openness and accountability must be allowed to flourish (The Bristol Royal Infirmary Inquiry, 2001; The Royal Liverpool Children's Inquiry, 2001).

Much of the guidance and legislation pertaining to consent and confidentiality is relatively recent and, although health professionals are required to keep up to date on all aspects of their practice, consent and confidentiality are uninteresting topics for many. Owing to this it is possible that many researchers new to the field find out about the guidelines regarding consent and confidentiality well into their study and not at the outset when it would be beneficial.

A study of paediatric high-dependency care

This section describes the progress and pitfalls experienced in the early stages of implementing the paediatric high-dependency care study currently being undertaken in the Yorkshire region. The process can be seen in *Figure 2* and the aims of the project are listed in *Table 2*. The study was commissioned and funded by East Leeds Primary Care Trust in September 2003. Fourteen hospitals and 38 ward areas are taking part in this study. Data-collection forms are completed

Table 2. The aims of the Paediatric High-Dependency Care Study

- Provide a clinical definition of paediatric high-dependency care (HDC)
- Provide information on the number of children receiving paediatric HDC in Yorkshire
- Examine the relationship between HDC and ward staffing levels
- Present potential models for the delivery of HDC in the future

by nursing staff which collect identifiable and demographic information for individual children during their inpatient stay. In addition, staffing levels and ward activity are recorded.

At the outset of the HDC study the following question was posed: is the paediatric HDC study research or audit?

Confusion exists between healthcare professionals over what is audit and what is research (Smith, 1992; Close and Cheater, 1996). There are many similarities and the task of differentiating between the two is not easy (Closs and Cheater, 1996). *Table 3* provides a definition of both audit and research. Guidance was sought locally on the audit *vs* research issue and the study was first defined as audit. The clinical audit department at the Leeds Teaching Hospitals NHS Trust was notified and an appointment made to discuss the development of the data collection forms for the paediatric HDC study.

For the pilot phase of the HDC study, these forms were distributed to the 14 hospitals and 38 wards taking part. During this time, information identifying individual children was collected and transferred to the host organization for storage and analysis. It soon transpired that an essential component of nursing practice had been overlooked, i.e. that of patient confidentiality.

Consent from the children, young people and the parents or guardians taking part in this study would be impractical owing to the large numbers of children and study sites involved. Consequently, an application to the PIAG was made for section 60 support (class support to use and store patient–identifiable information). The identifiable information requested for all children taking part in the HDC study can be seen in *Table 4*. The paediatric HDC study was approved for section 60 support; however, the following recommendations were to be met: MREC approval must be sought; a system level information technology (IT) data security policy must be developed; there must be evidence of service–user involvement; and the use of the NHS number for patient identification must be phased in during a period of time that is to be negotiated with the PIAG. Each of the recommendations will be discussed in turn.

Table 3. Definition of audit and research

Audit

'Cyclical activity incorporating both systematic evaluation of the quality of clinical practice and action taken in response to the results of this evaluation' (Department of Health (DoH), 1994)

Research

'An attempt to increase available knowledge by the discovery of new facts or relationships through systematic enquiry' (Macleod Clark and Hockey et al, 1989)

Table 4. Identifiable information required for the child inpatient data-collection form

Demographic details

Name, date of birth, unit number, sex

Geographical information

Hospital, ward, home postcode

Diagnosis (according to category)

(1) Cardiovascular (2) Renal (3) Respiratory (4) Oncology (5) Neurological (6) Metabolic (7) Trauma/accident (8) Other (9) Postoperative care

Location of child on ward

High-dependency area; cubicle

Multicentre Research Ethics Committee approval

Before providing support the PIAG recommended that ethical approval be sought from the Central Office for Research Ethics Committee (COREC). This form completed online contains four sections (parts A, B, C and D). Part A outlines details of indemnity for the protection of participants and confidentiality of data. Part B relates to particular activities such as the use of stored tissue. Part C provides an assessment of the suitability of the lead researcher with regard to qualifications and research experience and adequacy of site facilities. Part D, although now withdrawn from the MREC process, is necessary for the LREC as this contains information relating to the funding of the project in an attempt to combine financial information for all research and development departments involved in the study (Pattison and Stacey, 2004).

Parts A and C were completed, yet part B was never activated as the questions were not relevant to the paediatric HDC study. Part D was not completed; however, on hindsight, initial completion would have proven useful. Part D required completion once MREC had given approval (see below). A helpline and question-specific guidance is provided by COREC to assist researchers with form completion.

MREC approval was granted in August 2004 but with the following recommendation:

■ That management approval is sought on each of the hospital sites taking part in the study. This involved completing further application forms for each of the eight research and development departments. The HDC study had no local investigator on each site; therefore, local research ethics approval was not required but research and development (R&D) approval was required. This involved completing further application forms for each of the eight trusts involved and obtaining honorary contracts to enable the validation of data on each ward. This was burdensome — no uniformity existed in what was required by each trust. Some trusts had developed their own documentation for research governance; however, other trusts insisted that part D of the MREC form be completed.

System level IT data security policy

A system level IT data security policy is essential to guide staff involved in the HDC study in the safe transfer, use, storage and destruction of identifiable patient information. Areas outlined by the policy are listed in *Table 5*. The development of this policy proved extremely difficult, as no clinician had experience of writing such a document and few had heard of section 60 support and the PIAG. The data protection officer and IT manager for the trust provided invaluable advice and guidance on all aspects of the policy.

Service-user involvement

To ensure patient–centred practice the PIAG requested information and evidence to show that service users had been involved in the HDC study and how their contribution and comments had been acted upon. A number of parent/guardian and patient information leaflets (for teenagers 12–16 years and teenagers 16 years and over) were designed. These were distributed to parents/guardians of children admitted to hospital and to children of the specified age groups. Parents were not critical of the study or of the information provided (all comments were in support of the study). Teenagers, however, were extremely

critical of the leaflets. The comments made were regarding the lack of colour, design and the wording of the information leaflet.

Use of the NHS number

The NHS number is a unique patient identifier which allows electronic access to patient details via secure online access. In turn, this national initiative is the key to improving data quality by allowing speedier updates to take place. The PIAG stresses the importance of temporary support and annual review and maintained that support for the paediatric HDC study would only be granted if the personal information requested for the inpatient child data collection form (see *Table 4*) was replaced over a period of time with the NHS number. This period of time is to be negotiated with the PIAG.

Conclusion

The paediatric HDC study has provided insight into issues of consent and confidentiality. Before commencing this study, the lead investigator had very little knowledge of the legislation surrounding consent and confidentiality and no knowledge of section 60 support and the PIAG. However, after discussing the issues outlined in this article with colleagues, presenting the paediatric HDC study at conferences and reading the literature surrounding consent and confidentiality, it has become clear that a great deal of education is required for nursing, medical and academic staff to remove the ignorance and confusion which still largely exists. It is believed that health professionals need to be continually updated and made aware of the legislation and confidentiality requirements for health services research involving the collection of patient identifiable details.

With regard to the HDC study the resource implications of the process were not budgeted for and the administration and obtaining of honorary contracts considerably delayed the audit by 8 months. This was a time-consuming, costly exercise which could have potentially jeopardized the HDC study. Resource implications may ultimately mean that studies which are of benefit to patients in relation to the delivery of their care may not be undertaken.

Despite criticisms of the process, the authors firmly believe that the role of section 60 and the PIAG is not a way to evade responsibility of obtaining consent but a way of improving the consent procedure and a way to provide information and education relating to the issues of informed consent and confidentiality. It is unfortunate that the process of obtaining PIAG and MREC approval is so lengthy and that no uniformity exists for obtaining management approval in hospitals.

There is a need to increase public awareness. The evidence suggests that the public is willing to allow researchers access to information from medical records and yet they are ill informed as to why their data is being collected and the ways in which their data is used. It is possible that patients and the public would be horrified at the amount of time, effort and resources being used to gain access to information they already believe is being used by researchers. **BJN**

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Table 5. Contents of the information technology data security policy

- The system's authorized users, manager and responsible owner
- The names of all hospitals and wards involved in the study and how data transit and storage is to be maintained
- The type of personal computer (PC) to be used and the firewall arrangements for the trust (firewall is a term used to describe a system that is designed to prevent unauthorized access to or from a private computer network)
- Details about users' accountability, dealing with public and media enquiries, the release of information to hospitals taking part and the right of access to personal details
- Details of the system's contingency/disaster recovery arrangements. Information regarding serious disruption or total system failure and resuming normal practice
- Details of the management of a security or confidentiality breech
- Details of the disposal of paper-based and electronic records following completion of the study

KEY POINTS

■ Informed consent and confidentiality are vital to protect patient privacy.

■ Legislation and guidance are in existence to protect the rights of patients; however, much of this is confusing.

■ A real threat to patient privacy is posed if researchers/ organizations are unaware of the legislative requirements to protect confidentiality.

■ A greater awareness by heathcare professionals and the public of the uses and ways in which data are stored is necessary.

Appendix 12: The paediatric high dependency care measurement tool

NHS
Paediatric High Dependency Care Assessment Form©

Hospital……………………………………Ward……………………… **Shift start date** ☐☐ ☐☐ ☐☐☐☐

Unit No…………………………………… Postcode…………………………………… **Day** ☐ **Night** ☐

Patient name…………………………………………… **DOB** ☐☐ ☐☐ ☐☐☐☐

NHS No ☐☐☐☐☐☐☐☐☐☐ **Male** ☐ **Female** ☐

Area A		**6 Point Interventions**		
	A1.	Acute Continuous Positive Airways Pressure (CPAP)	☐	6
	A2.	Bag and mask ventilation	☐	6
	A3.	Vasoactive drug therapy (e.g. dobutamine dopamine, adrenaline, prostin)	☐	6
	A4.	Intravenous fluid resuscitation (greater than 20/ml/kg/hr	☐	6
	A5.	Invasive arterial pressure monitoring	☐	6
	A6.	Cardiac pacing (new on this admission)	☐	6
	A7	Four apnoeic episodes within 4 hours requiring stimulation	☐	6
	A8.	GCS = 12 or less	☐	6
	A9.	Extra Ventricular Device (EVD)	☐	6
	A10.	Central Venous Pressure (CVP) monitoring	☐	6
	A11.	Child recently extubated	☐	6
	A12.	Nebulised adrenaline for upper airway obstruction	☐	6
	A13.	Endotracheal intubation and subsequent care of the intubated child	☐	6
	A14.	Cardiopulmonary resuscitation	☐	6
Area B		**4 Point Interventions**		
	B1.	Use of airway adjunct/other artificial airway (e.g. guedel, nasopharyngeal, nasal prong)	☐	4
	B2.	Care of child with a tracheostomy (new or established)	☐	4
	B3.	Stable long term (domiciliary) ventilation	☐	4
	B4.	Cardiac arrhythmia	☐	4
	B5.	Chest drain	☐	4
	B6.	Peritoneal dialysis	☐	4
	B7.	Haemofiltration/Haemodialysis	☐	4
	B8.	Warming or cooling blanket / ambient temperature monitor / incubator	☐	4
	B9.	Prolonged / recurrent seizures	☐	4
	B10.	Pain requiring epidural / intravenous analgesia	☐	4
	B11.	Sedation during / after procedure	☐	4
	B12.	Dressing changes greater than 3 this shift or complex dressing changes	☐	4
	B13.	Nebulised medication more than 1 per hour for more than 4 hours	☐	4
	B14.	Complex hourly fluid balance	☐	4
	B15.	Oxygen therapy greater than or equal to 50%	☐	4
Area C		**2 Point Interventions**		
	C1.	Airway suction more than once per hour	☐	2
	C2.	Multiple intravenous lines (greater than 3 except analgesia)	☐	2
	C3.	Continuous IV drug infusion (other than analgesia and inotropes)	☐	2
	C4.	Replacement of fluid losses (e.g. from naso-gastric tube, drains, chest drain)	☐	2
	C5.	Intravenous drug boluses greater than 3 per (8 hour) shift (including antibiotics)	☐	2
	C6.	Hourly urine output measurement	☐	2
	C7.	Regular blood sampling (4 hourly or more frequent including blood glucose levels)	☐	2

Total score ☐

Any child scoring 6 or more = high dependency care

Appendix 13: The main study: Data collection forms

NHS **YORKSHIRE REGIONAL PAEDIATRIC HDC STUDY**   Hospital [   ]

Hospital Census   Ward [   ]   Month/Year [   ]

MONTHLY NURSE STAFFING (MNS) **(Please complete for May 2005)**

Grades of nursing staff	Established WTE in post	Actual in post WTE (available for month)	Number with APLS/PALS/EPALS (valid)	Number with critical care course	Number with HDU course (modules)	Comments
A						
B						
C						
D						
E						
F						
G						
H						
I						
Other please specify						

Once forms are complete please return to the completed documents file

Number of funded beds

Number of funded beds	
Number of funded beds open	

For further information or advice please contact: **T**: 0113 3928650. **M**: 0777 1667761 **E:** Kay. Rushforth@leedsth.nhs.uk **Kay Rushforth** Research Nurse, Room 195, B Floor Clarendon Wing. The General Infirmary at Leeds. Belmont Grove. Leeds. West Yorkshire. LS2 9NS

Daily nurse staffing (DNS)
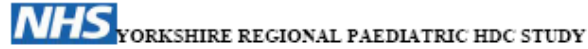
NHS YORKSHIRE REGIONAL PAEDIATRIC HDC STUDY   Hospital [＿＿＿＿＿＿]

Hospital Census   Ward [＿＿＿＿＿＿]   Week Commencing [＿＿＿＿＿＿]

Clinical Nurse Staffing Levels (Please complete daily at the specified times during May 2005)

Day of the Week	Early Shift (12 noon)								Late Shift (18.00 hrs)								Night Shift (12 midnight)							
	RSCN RN (C)	RGN	Numbers of staff with A H C			EN	NCS	CS	Bank OT	RSCN RN (C)	RGN	Numbers of staff with A H C			EN	NCS	CS	Bank OT	RSCN RN (C)	RGN	Numbers of staff with A H C			EN	NCS	CS	Bank OT
Mon																											
Tue																											
Wed																											
Thur																											
Fri																											
Sat																											
Sun																											

RSCN /RN (C) = Registered Children' s Nurse
RGN = Registered General Nurse

C = Critical Care Course for example 100,415,405,160
EN = Enrolled Nurse

OT = Overtime/Agency/Bank

A = APLS/PALS/EPALS
H = High Dependency Course for example 920 or HD modules

NCS = Non Clinical Support worker
CS = Clinical Support worker

28/09/2004Form 1 (KR)

Daily patient activity (DPA)

Total daily activity numbers by week (to be completed at midday/midnight) for May 2005

Day of the Week	ADMISSIONS to Ward (including day cases)	Ward ATTENDEES (not admitted)	EXITS Please include discharges, transfers and deaths	Total number of patients on the ward at MIDDAY	Total number of patients on the ward at MIDNIGHT (including overnight leave)		Comments
Monday 2/5/2005							
Tuesday 3/5/2005							
Wednesday 3/5/2005							
Thursday 4/5/2005							
Friday 5/5/2005							
Saturday 6/5/2005							
Sunday 7/5/2005							

Day previous plus the Yellow area minus the green area should equal the red area

KEY ☐ - ☐ = ☐

Once forms are completed please return to the address below

For further information please contact ;
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The General Infirmary at Leeds
Belmont Grove, Leeds
West Yorkshire LS2 9NS

Tel   0113 3928650
Mobile   0777 1667761
Email   **Kay.Rushforth@leedsth.nhs.uk**   **23/08/2005 Form 2 (KR)**

Hospital [＿＿＿＿＿＿＿＿]   Ward [＿＿＿＿＿＿＿]   Week commencing [＿＿＿＿＿＿＿]

Monthly Medical Staffing (MNS)

NHS **YORKSHIRE REGIONAL PAEDIATRIC HDC STUDY**

Medical Staff Survey

Hospital [   ]

Ward [   ]

Consultant [   ]

Monthly medical staffing levels **(please complete for May 2005)**

Grade of Medical Staff	Total number	Total WTE in post	*Number of staff with Paediatric Advanced Life support courses	Type of shift (numbers)				Other responsibilities (Cover for maternity services/neonates)
				Full	Partial	Hybrid	On-call	
SHO General Paediatrics								
SPR General Paediatrics								
Consultant on General Paediatric Rota								
Other, please specify								

Advanced Paediatric Life Support Courses include
APLS = Advanced Paediatric Life Support
PALS = Paediatric Advanced Life Support
EPLS = European Paediatric Life Support
Medical staff should have received a pass in the above courses and these should be valid (within the specified date period – 3 years)

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Appendix 14: Outline research proposal

KAY RUSHFORTH RESEARCH PROPOSAL (5/10/2003)

Title:
A STUDY OF PAEDIATRIC HIGH DEPENDENCY CARE IN YORKSHIRE

Purpose of the proposed study:
The aims of the study are to:
- Determine definitions of high dependency care.
- Perform a census on the number of children requiring high dependency care in Yorkshire.
- Determine the relationship between ward staffing levels and high dependency care in Yorkshire.
- Devise models of care to address problems identify need and determine priorities of care for the future.

Background to the project:
Children admitted to hospital require different levels of care, usual ward care, high dependency care or intensive care depending upon the severity of their illness. This care may be provided in a Paediatric Intensive Care Unit, a High Dependency Unit or provided on a children's ward. At times children may move between all 3 levels of care for specialist treatment.

The levels of care that can be expected in a Paediatric Intensive Care Unit have been recognised (DoH 1997). These are: High Dependency Care (often described as level 1 care), Intensive Care (level 2 care) and Intensive Care (level 3 care).

Despite this, paediatric high dependency care (PHDC) or level 1 care has no real definition (DoH 2001). A framework for the future (DoH 1997) advocates that a child in need of level 1 care may require 'closer observation and monitoring' than is usually available on an ordinary children's ward. However many children's wards already provide this (level 1) care with higher staffing levels but there is huge variation between hospitals and indeed wards within the same hospital in their approach to and provision of level 1 care. With no clear guidance or specified provision standardisation for PHDC is impossible.

Information to address ways of achieving quality of care, outcomes for children and standards for all units with critically ill children (level2/3 care or those children requiring mechanical ventilation) is documented (DoH 1997). This structured approach has ensured that District General Hospitals, lead centres and specialist hospitals have responsibilities to provide appropriate levels of care, in appropriate settings with guidelines that have implications for nurse staffing and training. The same approach is now essential for children who require PHDC.

Very limited literature is available on the subject of PHDC, however adult studies have reported upon issues such as reductions in morbidity and mortality (Davies et al 1999) and the impact upon the workload of intensive care units (Dhond et al 1998) following the opening of a high dependency unit. Scoring tools exist to quantify critical illness (level 2 and 3 care) in both adults and paediatric units. (Cullen et al 1974, Miranda et al 1996). No such tools exist for PHDC

Plan of the study including the research methodology proposed.
A steering group is in existence to provide guidance and structure to the PHDC study. The group includes Consultant Anaesthetists and Paediatricians, Nurse Managers and commissioners from the Yorkshire Region and researchers from the Universities of Leicester and Leeds.

A prospective cohort design will develop in 3 phases: a feasibility study, a pilot study and a main study.

1. The Feasibility Study
   The aim of the feasibility study is to establish validated tools for collecting clinical and intervention data on children requiring high dependency care. This will be conducted on two sites within the Yorkshire Region for the period of two weeks only.

Prior to the feasibility study informal discussions with all nurse managers/matrons/nurses from every hospital and ward in the region is to take place to identify the highly dependent children that present to each ward and area. These individuals will be asked to provide:

- information regarding children that diagnostically present for PHDC.
- information regarding the care or patient intervention that is provided for children requiring PHDC.
- information regarding nursing establishment, number of shifts throughout a 24-hour period and the number of beds available.
- a lead nurse to act as resource for other members of staff and to ensure effective data collection in their own area.

From informal discussions and the literature review items will be constructed to reflect the concept of PHDC.

2. The Pilot Study
The aim of the pilot study is to determine:
- the variability within the population.
- adequacy of the data collection forms.
- the response rate.
- the efficiency of instruction.

Data will be collected for the period of 1 month for all children aged 0-18 years of age requiring PHDC. Data will be collected on each ward area in every hospital in the former Yorkshire region by nursing staff (14 hospitals and 39 ward areas).
The education of all nurses will take place prior to the pilot study on all wards and hospital sites within the former Yorkshire region regarding completion of the data collection tools.

3. The Main Study
Data will be collected for the period of one-year using specifically designed forms these include:
- Child data collection forms to be completed by nursing staff twice per day (once during the day and once during the night) for all children requiring high dependency care. The following information is requested: demographic details (name, date of birth, sex); geographical information (hospital, ward and home postcode); diagnosis and the nursing interventions for any child requiring high dependency care.
- Medical and nurse staffing establishment forms to be completed by both nursing and medical staff monthly. This requires information regarding whole time equivalents (WTE'S) of nursing and medical staff in post, the number of nursing and medical staff with extra training (Advanced Paediatric Life Support – APLS, Paediatric advanced Life Support – PALS, and the number of funded beds open.
- Patient activity to be completed by nursing staff for the period of one month at two time points during the year (one-month during the summer period and one month during the winter period). For completion the following is requested: the numbers of children admitted to the ward, number of day cases, the number of children seen as ward attenders but not admitted, numbers discharged home and the numbers of children transferred to other areas (Wards, Paediatric Intensive Care Unit and High Dependency Unit).
- Nurse staffing according to qualification and training. To be completed by nursing staff for the period of one month at two time points during the year (one month during the summer period and one month during the winter period). The number of nurses with relevant qualifications (Registered Sick Children's Nursing – RSCN) and additional advanced life support training is to be recorded).

The same information is required for phase 1 and 2 of the study.

Data Analysis
A database application will be written in visual basic. The data will be stored in a database access file (Version 2000).

All data will be analysed using SPSS to describe simple totals and means of the population. Categorical variables or attributes such as gender, hospital site and ward and high dependency scores will be summarised using frequency tables, the proportion or percentages of samples

displayed. Chi Square and Fisher's exact test will be used to compare categorical variables. Factor analysis is the statistical technique to be employed to reduce the dataset to a small number of factors that measure PHDC.

A sample of completed data sheets will be 'cross-checked' with patient notes to check for accuracy of recorded information. Dummy abstraction will occur on every ward and hospital site to check data validity.

Proposed start date:
July 2004 (proposed duration 3 years). The Chief Investigator (Kay Rushforth) has been appointed as full-time research nurse to conduct the study as a secondment for 2 ½ years. At the end of this period it is possible that extra time may be required to write up and disseminate the research findings.

Research timetable:
Months 1-8
Literature review. Establish network of contacts. Application for MREC and Section 60 Support. Develop data collection tools. Develop database. Educate and train nurses regarding completion of data collection tools. Feasibility study and re-evaluation of data collection tools. Involve parents in the design and the information relating to high dependency care.

Months 9 - 11
Pilot study. Presentation of study results to Yorkshire Region.

Months 11 - 12
Refine data collection tools.

Months 12 – 24
Main data collection. Interim analysis performed at month 18. Data validation for completeness of data collection. Continued education and support for nursing and medical staff.

Months 24 – 28
Data validation and cleansing of data. Analysis of data.

Months 29 – 36
Report writing and dissemination or results.

Division of responsibility:

Name: <u>Kay Rushforth (KR)</u>   Job Title: <u>Regional Research Nurse</u>

Responsibility: KR as lead investigator will be responsible for literature review and developing links with hospitals and ward areas. KR will develop and refine the data collection tool. KR will train and educate all nurses with regard to the data collection tool. KR will be responsible for entering and analysing data. KR will be responsible for report writing and dissemination of study findings. KR will meet with Dr 1 and Nurse Manager every 2-4 months to review progress and procedure. KR will meet with the steering group every 3-6 months to review progress and strategy.

Name: <u>Doctor 1 (Dr 1)</u>   Job Title:

Responsibility: Dr 1 will act as clinical supervisor for the research nurse (KR). They will be responsible for advice regarding tool development and data collection. They will be accessible and available to discuss problems and they will ensure that milestones are met. Dr 1 will meet with KR every 2-4 months to review progress and procedure and meet with the steering group every 3-6 months to review progress and strategy. Dr 1 will ensure that KR carries out methods of intended dissemination.

Name: <u>Nurse Manager (NM)</u>   Job Title:

Responsibility: (NM) will act as support for KR. They will be responsible for advice regarding project management and workload planning. NM will meet with KR every 2-4 months to ensure

project deadlines are met. NM will meet with the steering group every 3-6 months to review progress and strategy.

Name: <u>Academic Supervisor (AS)</u>   Job Title:

Responsibility: AS will act as academic support for KR. AS will meet with KR every 3 months, they will advise on data collection methods, data analysis and reporting and interpretation of results. AS will meet with the steering group every 3-6 months.

Name <u>Steering Group (SG)</u>

Responsibility: The SG will meet every 3-6 months to offer support, advice and guidance for the development of the clinical aspects of the study. The SG will advise on ward staffing issues, the aspects of clinical care in different hospital ward locations and on the training and education of clinical staff.