

The impact of changing workforce patterns in UK paediatric intensive care services on staff practice and patient outcomes

Report for the National Institute for Health Research Service Delivery and Organisation programme

March, 2009

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Acknowledgements

This study was funded by the NIHR SDO Programme (grant number SDO/96/2005), and the work endorsed by PICANet. We thank the members of our advisory group for their valued contributions and advice.

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Without the support of staff in all UK paediatric intensive care units and PICANet this study would not have been possible. We thank staff in the 12 units who agreed to take part in the prospective data collection phases and notably the link research nurses, nurse managers and clinicians who collected data on our behalf. We are grateful for the work of secretarial and data management staff at the Universities of Aberdeen, Leicester and Leeds for their support: Genevieve Cseh, Sylvia Clement, Thomas Fleming, Julie Faulkes and Pauline Hatty.

In particular we thank those parents and individual staff members who agreed to be interviewed about their views of the service, and members of voluntary organisations in adult and neonatal intensive care who participated in our consultation exercise. We are very grateful to Dr Jeremy Dawson and the NHS Staff Survey group at Aston University who generously gave permission to use NHS Staff Survey items and their continued support and advice about analysis. We thank Dr Alex Greene at HSRU, University of Aberdeen, for her qualitative methodological advice. Also the PIC nurse managers group who advised and shared their experience and previous research on recent staffing issues and nursing roles, in particular Renee Adomat, Joy Grech, Mary Chadwick and Angela Grange.

Ethical and NHS R&D Approvals

The census (2005) was undertaken by the PICANet nurse Nicky Davey. Collection, management and disclosure of unit-level data was undertaken following the policy and procedures of PICANet (Universities of Leeds and Leicester). The prospective study was approved by Trent Multi-centre Research Ethics Committee (06/MRE04/50), and by the appropriate NHS R&D authorities for each of the 12 participating PICUs.

The Report

Introduction

Skilled staff are central to performance and the NHS prioritises workforce policies and initiatives towards sustaining high quality service delivery. Shortage of skilled manpower, NHS recruitment and retention difficulties, implementation and amendment to the European Working Time Directive (EWTD) for doctors in training (Department for Business, Enterprise and Regulatory Reform (BERR), 2003), the need for flexible working, and work-life balance issues and staff wellbeing, are all driving NHS workforce policies.

The NHS Plan (Department of Health (DH), 2000a) and Agenda for Change (DH, 2004a) focus on improving patient care. This aimed to invest in the NHS, by tackling health care manpower issues of clinical and nursing capacity and designing new ways of working. They raise the importance of human resources management and professional role redesign as key parts of the strategy to achieve NHS goals (DH, 2004b).

A review by Hewitt *et al* (2003) notes that role redesign in the UK has, to a large extent, meant an increasing range of extended nursing roles that includes role specialisation and task-level substitution for doctors, with limited evidence to date suggesting equivalence in outcomes for patients. There is some evidence that higher educational attainment levels in trained nurses improve outcomes (Aiken, 2003). Many previous descriptions of workforce in studies of staffing and health care have tended to use high-level structural staffing definitions and measures. These have been underpinned by assumptions that specific workforce characteristics and recommended staffing levels (often based on grade-IV level of evidence) will lead to improved performance. This is an approach perhaps most closely aligned to "the Universalist" model of human resources management (see below).

Three main theoretical approaches to human resource management strategy (HRMS) towards improving performance are discussed in the literature (Torrington *et al*, 2002):

1. The *Universalist* approach is prescriptive and achieved by integration of HRMS into the organisation's strategy, and by attaining commitment, flexibility and high quality of staff.
2. The *Fit or Contingency* approach recognises external and internal fit, i.e. the importance of external factors and people to achieve the organisation's goals, and still requires human resource strategy to fit with the demands of the organisational strategy

3. The *Resource-based* approach focuses clearly on human capital, with the skills, knowledge, attitudes and competencies underpinning the required human resources and roles to ensure performance and sustainability.

Buchan (2004) and the consultation document of the National Workforce Taskforce and HR Directorate (DH, 2002) recommend the fit or contingency approach and suggest that single HRMS interventions are unlikely to be effective. They cite evidence that "bundles" of HRM interventions in health settings are indicators of "better" staffing, and that these have, in turn, been associated with improved quality of care. Buchan reports key workforce attributes for "better staffing" as interventions that:

- Fit with the organisation's priorities
- Support autonomous working by nurses
- Enable participation in decision-making
- Facilitate career development
- And enable high level skills to be deployed effectively

These attributes are also represented in the HRM evidence and theory-base of the work of Michie and West (2004a) in the 2003 NHS staff survey, in *"an architecture for understanding the links between the context of work, management of people practices, psychological consequences for staff, staff behaviour and performance and patient care in the NHS."*

However, Hewitt *et al* (2003) noted that there was little evidence about:

- contextual factors that support and effect change in care team configuration to include extended nursing roles;
- the impact of extended nursing roles on the wider care team;
- the impact of extended nursing roles on direct patient care, or "who cares" in hospital;
- and whether extended nursing roles in care teams result in similar or improved quality of care and performance in terms of patient outcomes and user views or satisfaction.

Rationale

The conceptual rationale for this project draws on the above HRMS theoretical approaches, suggesting that:

- there is likely to be variation between organisations in staffing configurations and the adoption of new extended nursing roles that extended nursing roles:
 - are more likely to have arisen in organisations where human resource management and strategy is sensitive and responsive to external forces (e.g. manpower/ skills shortages or the need for flexible or part-time working by women)

- have a resource-based approach to human resource management strategy to redesign teams with enhanced, autonomous and extended nursing roles to sustain quality of care and service provision. and are more likely to arise in organisations that also better support staff and staff wellbeing (in terms of a supportive work and management context, job satisfaction, workload and stress, intention to leave and reported performance (Michie & West, 2004a)

Furthermore, the defined extended nursing roles examined in this study will include nurses undertaking clinical tasks outside their normal practice and in substitution for doctors (Srivastava *et al*, 2008). It follows that adoption of additional specialist clinical tasks would increase overall patient-centred direct care time by the nurse and time spent on the extended tasks, while, conversely, reducing doctor direct attendance time.

Finally, the conceptual framework of Sidani & Irvine (1999) is used in linking the delivery of extended nurse activities to quality of care process and outcomes. Teams with nurse extended roles may be less, more or equally effective and efficient as those without. We hypothesise that those teams with extended nursing roles will be associated with improved care process and patient-centred outcome measures such as:

- shorter length of stay and lower unplanned readmission rates (because, as Fairley (2005) highlights, the strategic activities of nurses are aimed at restoring critically ill patients to an optimal level of functioning for discharge)
- reduced risk of nosocomial infection (because fewer clinicians performing invasive procedures and better nurse compliance with infection control measures (Hugonnet *et al*, 2007)
- and improved user satisfaction with care (because it is well-recognised that already nurses are most responsive to the patient and their families in delivering patient-centred care (Frampton *et al*, 2008).

Aim

The study aims to assess the impact of changing workforce patterns and skillmix on staff, staff practice and patient outcomes in paediatric intensive care.

Objectives

1. To identify new workforce models arising from role redesign for nurses
2. In a stratified random sample of units (by higher vs. lower extended nursing roles), to compare:
 - a. the impact of new or changing workforce models on staff including:

- skillmix and task substitution
 - staff well-being
 - staffing costs
- b. explore unit context and human resources management strategy (HRMS)
3. and to compare:
- direct care time between units with higher and lower levels of nurses in extended roles
 - impact of higher and lower levels of nurses in extended roles on clinical care process and patient outcomes
 - and total direct care time and different staff groups' direct care time on clinical care process and patient outcomes

Study design and setting

Following a census of all UK Paediatric Intensive Care Units (PICUs), a prospective observational study of risk-adjusted clinical process and outcomes in a randomised sample of 12 PICUs, stratified by units higher and lower new extended nursing roles and staff groups' direct care time; with parallel assessment and monitoring of context, HRMS, and impact on staff wellbeing and staffing costs.

The selected clinical service model for the study is UK Paediatric Intensive Care. This is "a *low volume, high-cost service providing care for critically ill children, most of whom will be artificially ventilated. It requires a highly trained multidisciplinary team, together with tertiary expertise and diagnostic facilities*" (DH, 1997).

Findings from this study about new care team configurations will have relevance for comparisons with wider critical and acute hospital settings which demand twenty-four hour staffing for delivery of highly specialist and technical advanced life support systems. Examining findings about unit context and HR management attributes against theory-based criteria will allow theoretical generalisability of the findings.

Measures of care process and patient outcomes

- Risk-adjusted outcomes of length of stay, unplanned re-admission, and probable ventilator-associated pneumonia.
- Parent / child views and experience of care

The following chapters present data sources and the findings for each of the study objectives in turn.

1 Objective 1: To identify new workforce models arising from role re-design for nurses

Background

A review of contemporary UK policy and scientific literature about nursing role re-design and definition of terms was undertaken to inform identification of defined roles or skills within UK intensive settings to date and PICUs in particular (Srivastava *et al*, 2008).

We note that previous reports highlight the lack of clarity over definitions of the advanced nursing role, and the lack of firm distinction between different nursing roles. It is important to note that both advanced and specialist practitioners can undergo role expansion, or undertake extended tasks; where expansion refers to pushing the boundaries of nursing role development, and where extension focuses usually on one area of practice or skill, or on a specific task (Frost, 1998). However, many reports also describe the development of the extended nursing role in terms of the rise and development of the Advanced Nursing Practitioner (ANP).

Designated Advanced Nursing Practitioner Roles

Pearson and Peels (2002a-c) suggest the ANP role combines five key areas: clinical, research, teaching, consultancy and leadership. According to Fairley (2005), the Workforce Development Confederation have defined an ANP as an experienced non-medical registered professional who has developed theoretical knowledge (often characterised by Masters Degree level attainment) and skills to a very high standard in a specific and often specialised area of practice. Fairley reports that in critical care, ANPs embraced skills, previously within the domain of medicine, provided that they could be performed effectively to enhance patient care and management in this substitution. There have been a number of studies assessing the effectiveness of advanced neonatal nurse practitioners (ANNPs) compared with paediatric staff, mostly in task specific or single site studies. Findings to date suggest equivalent outcomes for patients achieved by ANNPs compared with doctors. Whereas in neonatal intensive care, the development of an additional advanced nurse staffing tier is supported and continuing apace (British Association of Perinatal Medicine, 2001), there is little information about the extent of extended nursing roles, particularly in paediatric and adult intensive care.

Extended Specialist Nursing Roles in critical care settings

Neenan (1997) argues that nurses' roles in critical care are already more expanded than in other areas of nursing, for example, in relation to advanced life-support skills and invasive cardiac procedures. Hind *et al*

(1999) found substantial support for developing the role of critical care nurses in a number of activities: cannulation, venepuncture, ordering blood tests and X-rays, performing physiotherapy, inserting arterial lines, performing elective cardioversion, thrombolysis treatment and intubation.

Outline staffing surveys had been conducted by the Paediatric Intensive Care Audit Network (PICANet) previously in September 2003, March and October 2004 that collected outline information on medical and nurse staffing establishments (Chater *et al*, 2005).

Methods

A census of all UK PICUs participating in PICANet was undertaken in October 2005 using a postal and telephone questionnaire (Appendix 1). It collected data on medical and nursing establishments, designated advanced nursing posts, and extended nursing roles with grades and numbers of nurses undertaking 24 specified clinical nursing tasks (Chadwick, 2005; Figure 1).

Figure 1. 24 specified clinical tasks and skills undertaken by nurses

24 skills/tasks	
• Taking blood samples, CPV/ART*	• Venupuncture†
• Processing blood samples*	• Cannulation arterial/venoust
• Altering oxygen levels*	• Titration of analgesia*
• Altering ventilator settings	• Weaning off analgesia*
• Chest assessment	• Titration of inotropes*
• Broncho-alveolar lavage	• Setting up CFAM
• Setting up CPAP driver*	• Advanced life support skills*
• Initiation non-invasive ventilation	• Nurse ordering investigations
• Planned nurse-led extubation	• Insertion of NJ tube*
• End of life extubation	• Nurse-led retrieval†
• Intubation†	• Haemofiltration/dialysis†

Nurse skills: * Tasks undertaken in nearly all units; † tasks rarely undertaken in any units; **BOLD, variation in respiratory tasks undertaken**

Results

Of 27 eligible PICANet units, 26 completed the survey. Of those, only four units reported having a designated advanced post of Nurse Consultant or ANP.

There was substantial variation in the array of clinical tasks undertaken autonomously by nursing staff. Whereas some tasks* (Figure 1: blood sampling and processing, setting up CPAP drivers and titration and weaning off analgesia) were routinely reported as undertaken by specified grades of trained nurses in nearly all units, other tasks† (Figure 1: haemodialysis, cannulation or nurse-led retrieval) were rarely undertaken and then only by

those very few nurses in designated advanced posts. However, data indicated that there was a situation of equipoise around six clinical tasks associated with respiratory support (Figure 1, bold; Figure 2).

Figure 2. Skills Analysis

<p>Identified which units had nursing staff performing specific tasks: 6 respiratory support tasks</p> <ul style="list-style-type: none">▪Altering ventilator settings▪Chest assessment▪Broncho-alveolar lavage▪Initiation of non-invasive ventilation▪Planned nurse-led extubation▪End-of-life extubation
--

Stratified random sample of PICUs

Since three quarters of all children admitted to paediatric intensive care receive respiratory support by mechanical ventilation during an admission (Chater *et al*, 2005), the selected tasks represent an important clinical skills requirement in the care team.

The marked variation between units in whether nurses were reported to undertake six identified respiratory support tasks was used to stratify units into higher (nurses undertake five or more of the six respiratory support tasks) and lower extended nursing skills (nurses undertake only one or none of the six respiratory support tasks). Nine units were categorised as those with higher extended respiratory support nursing tasks and seven as lower. Notably there was internal consistency in that those nine units in our higher extended task category also included the few PICUs with designated advanced posts.

Summary and conclusions

Twelve units (six with higher extended nursing respiratory support tasks and six without) were randomly selected and invited to participate in the next phases of the study. The selected tasks represent an important clinical skills requirement in the care team since three quarters of all children admitted to paediatric intensive care receive respiratory support by mechanical ventilation during an admission.

All PICUs invited agreed to participate in the prospective observational study.

2 Objective 2: To compare context and the impact of new or changing workforce models on staff

To compare context and impact on staff of extended nursing roles in the stratified random sample of 12 participating units identified by the census (six with higher extended nursing and six without). Four strands of data collection and analysis assess impact on:

- **2.1.1 Skillmix and task substitution:** census data (2005) and unit profile data (2007)
- **2.1.2 Staff wellbeing:** staff survey data in 2007
- **2.1.3 Staff costs:** economic costing data

And in the final section of Part 2,

- **2.2 To explore and compare unit context, Human Resource Management Strategies (HRMS) and staff views:**

The recent impact on PICUs of policy, contextual labour market change and NHS workforce data are reviewed and the views of staff working in PICUs are presented.

2.1 Unit context, skillmix and staffing

2.1.1 Unit establishments, staffing configurations and activity

Census (2005)

Results of the PICANet census of October 2005 (Appendix 1) that describe and compare bed and staffing establishments between units reporting higher/lower extended nursing tasks are shown in Table 1. Units in the higher group tend to be larger, although there was a wide range of throughput in both types of unit. Information about nurse establishments indicates a highly trained workforce. Nearly all nurses (93%) have paediatric training and around 1/3 are senior nurses at or above Grade F in both types of unit (pre NHS KSF (Knowledge and Skills Framework, Department of Health, 2004c)). However, attainment of recommended standards of nurse staffing provision for bed establishment number tended to be a little lower in the units in the lower extended nursing role group (Appendix 2.1). There was evidence of task substitution by nurses for Junior Doctors in the reported medical establishment pattern in the higher

units. Whereas all but one unit with lower nursing extended roles had some Junior Doctors, higher units tended to have more Middle-Grade Doctors, and only two had any Junior Doctor posts.

Table 1. 2005 unit establishment census information

Establishment	Lower Median (range)	Higher Median (range)	PICU total response/12
Beds			
Total	8 (5-17)	13.5 (5-28)	12
Intensive Care	7 (5-17)	12 (5-25)	-
High Dependency	0 (0-2)	1.5 (0-15)	-
Annual throughput	445 (355-909)	496 (336-1017)	12
Mean WTE nurse establishment	64 (36-114)	79 (32-133)	12
% Paediatric trained nurses	93% (89%-97%)	93% (84%-98%)	12
% Senior paediatric trained nurses(\geq F grade)	32% (28%-52%)	27% (22%-31%)	12
Number WTE nurses per IC bed*	6.4 (5.2-6.9)	6.7 (6.3-7.2)	12
Number of units with Junior Doctors (<i>JHO, SHO</i>)	5/6	2/5	11 (1 higher missing)
Junior Doctors (WTE) (<i>JHO, SHO(now F1,2)</i>)	3.5 (0-6)	0 (0-6)	11 (1 higher missing)
Middle-Grade Doctors (WTE) (<i>Fellows, Trust doctors, SPRs</i>)	8.5 (6-20)	9.6 (5-12)	10 (2 higher missing)
Consultants (WTE)	6 (4-8)	6 (3-12)	10 (2 higher missing)

* see Appendix 2.1

On average the lower units reported slightly lower levels of whole-time equivalent (WTE) nurse staffing per bed (at 6.4, compared with 6.7 for the

higher units). Standards recommend seven per intensive care unit (ICU) bed and 3.5 per high-dependency unit (HDU) bed (Appendix 2.1).

It is important to note that reports of bed and staffing establishment may change within units, depending on counts of establishment beds or available staffed beds, the season, the use of annualised nurse staffing WTEs and attribution of total or shared staff establishments between sites (Appendix 2.1). Nurse Managers further commented on their beds and identified staffing pressures in 2005 in one open item. Lower units noted additional nurse staffing pressures that included: diluted skillmix, sickness rates (3% to over 5% in some units), long term sickness and maternity leave, not being able to support study leave or support emergencies/surgical lists, specific high nurse staffing requirements for ECMO (extracorporeal membrane oxygenation), and to cover increased bed establishments to meet winter demands.

Those in the higher extended role group noted even higher sickness rates (6 to 10% reported) and maternity leave, skillmix dilution due to difficulties recruiting experienced senior staff, and the new enhanced leave entitlement for long-serving staff (from *Agenda for Change*). Some evidence of flexibility in bed use and staffing was also reported. This included seasonal establishment changes, sharing nurse staffing across sites, delivering support for study leave; and staffing establishments were judged to be improving (although still only moving towards seven WTE per ICU bed). Capping on establishments, beds and agency staff use was described in one area.

Unit Profile (2007)

Methods

A unit profile questionnaire was self-completed by Nurse Managers and Medical Directors for each of the 12 units in the prospective part of the study in 2007. The questionnaire (Appendix 2.2) included items about:

- bed and staffing establishments and throughput
- perceived recent change in sources of pressures on staffing and workforce
- staff education and training
- on-site facilities for staff
- on-site facilities for parents/visitors.

The results are described and compared between unit groups of higher/lower extended nursing role.

Unit profile results 2007

Unit establishments, staffing configurations and activity

As in 2005, units in the higher group in 2007 had more establishment beds (median 15, range 8 to 23) than in the lower group (median 9, range 8 to 20) (Table 2). However, the average maximum number of beds staffed is lower than establishment, at 13 in the higher group compared to eight in the lower group. Some units in the higher group also have more beds in cubicles (median 3.5, range 1 to 10) than the lower group (median 3, range 2 to 4). More beds in cubicles implies further increased pressure for nurse staffing requirement to maintain at least 1:1 nursing in each cubicle.

Table 2 shows more Middle-Grade Doctors in higher units by 2007 (note only one or two units reported having any Junior Doctors by 2007, and they were on the rota for supervised day shifts and did not contribute to the resident 24 hour cover rota). More units with higher extended nursing roles reported wide fluctuation in activity and dependency levels in their units, although on average lower units reported more unplanned admissions. Most units reported that there was one Medical Consultant designated to direct and manage the unit. The lower group tended to report more Consultants on the emergency on-call (median 7, range 5 to 8) than the higher group (median 6, range 4 to 7).

All units in the lower group reported having no ANP or Nurse Consultant posts. Only 3 units in the higher group reported having such posts, and that they were all matched to a national job profile and were locally evaluated and specified. For units that reported no ANP posts, only one unit from each group reported plans to create the posts. There were no reports of any previous ANP or Consultant posts that had been discontinued or unfilled in the returned unit profiles.

10/12 units had retrieval teams (all six units from the lower group but only 4/6 units from the higher group). None of the retrieval teams were supernumerary nor were they nurse-led.

Table 2. Establishments, medical staffing and activity by 2007

Bed and medical staffing	Lower Median (range)	Higher Median (range)
Total beds	9 (8-20)	15 (8-23)
Beds In open ward	7 (5-16)	10.5 (6-13)
Beds In cubicles	3 (2-4)	3.5 (1-10)
<i>Doctors providing resident 24 hour cover</i>		
Junior Doctor (SHO)	0 (0-6)	0 (0-5)
Middle-Grade Doctors	10.5 (5-14)	12 (7-17)
Consultants on PIC emergency on-call rota	7 (5-8)	6 (4-7)
Activity	Num Units	Num Units
V.High-High fluctuation day-to-day	1/6	4/6
V. High-High fluctuation week-to-week	1/6	3/6
V. High-High variation in dependency day-to-day	2/6	3/6
V.High-High variation in dependency week-to-week	1/6	3/6
Unplanned admissions	353 (167-535)	210.5 (57-546)
Transfers accepted to unit	129 (91-323)	151.5 (121-193)

Pressure on staffing and workforce

A range of questions asked the extent to which the unit had experienced change in the year 2006/7. Reported recent changes in units were scored '0' for no change, '1' for increase and '-1' for decrease for each item of change. Scores were summed in groups of items representing key sources of additional pressure on units:

- bed demands
- staffing pressures (unfilled posts, turnover, etc.)
- training need and activities
- long-term sick leave, maternity and suspensions.

Positive scores indicate an increase in pressures on staffing and workforce; and negative scores indicate a decrease in pressures. Assuming that each pressure source is of equal weight, an overall pressure score on the unit is presented.

Table 3 shows aggregated scores for seventeen items within the four areas and overall. These data suggest that units in the lower group tended to report experiencing more pressure on their staffing in 2006/7 compared with those units in the higher group.

Table 3. Pressure on staffing

Perceived change in pressure on staffing	Lower Median score (range)	Higher Median score (range)
Increased pressure on beds (score/4) ¹	3 (-1-4)	1.5 (0-3)
Increased pressure on staffing (score/6) ²	1 (-2-5)	-1.5 (-5-5)
Increased pressure for training (score/4) ³	0.5 (-2-3)	-1.0 (-5-5)
Increased pressure from long-term sick (score/3) ⁴	2.0 (0-2)	0.5 (-2-2)
Total staffing pressure score (score/17) ⁵	8 (-1 - 11)	3 (-5 - 12)

¹ score of increased bed demand (HD, ITU beds, variation in occupancy and transfer in requests)

² score of increased pressure on staffing (unfilled medical and nursing posts, staff turnover, use of agency/bank, use of unqualified staff)

³ score of increased pressure from training (training need, in-house training, off-site training and secondments)

⁴ score of increased pressure from long-term sick, maternity leave and suspensions

⁵ Overall summed scores

Education and training

Seven items explored training and development in units. Table 4 shows that the majority of units in both groups "ticked all the boxes" for nurse training, although one or two fewer lower units seconded staff for training or offered training for nurses from alternative backgrounds. It is also of note that although all 12 units agreed that there was a specific identified nurse to coordinate training and education, later interviews show that not all of these posts were filled (see Section 2.2.2, page 51). Large reductions in nurse training budgets were also noted in 4/6 lower units compared with 2/5 higher units.

Table 4. Education and training

	Lower Number of Units "yes"	Higher Number of Units "yes"
Specific/identified nurse to co-ordinate training and education	6/6	6/6
In-house training programmes for staff	5/6	6/6
Secondments for own staff	3/6	5/6
Host for secondments	5/6	6/6
Funds for nurse education and development at courses/conferences	5/6	6/6
Training for nurses with alternative backgrounds	4/6	5/6
Multi-professional training courses	6/6	6/6
Total training and education score (median)	6/7 (3-7)	7/7 (6-7)
Budget change in last 2 years?*		
Large reduction	4/6	2/5
No Change	2/6	3/5

* Total units responded n = 11

All six units from the lower group reported that there has been a change in the need for education, compared with only two units from the higher group. Opinions also differed between unit groups on the effect of the Knowledge and Skills Framework (KSF) on overall training needs. Not one unit from the higher group reported that the KSF had changed their focus or introduced less flexibility in training, although four units from the lower group did.

Facilities for staff

Units in the higher group have more facilities for staff and reported higher quality facilities, compared to the lower group (Table 5).

Table 5. On-site facilities for staff

	Lower Number of Units	Higher Number of Units
Facilities* within immediate proximity to unit		
Median	5/6	6/6
Range	(4-6)	(5-6)
Facilities upgraded within last 2 years		
Median	1/6	3/6
Range	(0-3)	(1-4)
Facilities often used		
Median	5/6	6/6
Range	(2-6)	(4-6)
Facilities good quality & often used		
Median	2/6	4/6
Range	(0-3)	(2-5)

*Staff facilities included changing area, sitting room, cooking facilities, study area, computer

Facilities for families

Table 6 shows little difference between the two groups in their facilities for parents/families. Accommodation was free of charge at all units. Units in the higher group have more accommodation available for parents and families, even though their through-put is only slightly greater than that of the lower group. The higher group also reported fewer problems than the lower group with finding parental accommodation.

Parking charges for parents/visitors and problems finding parking spaces were reported by nearly all units. Many units did not complete the items about whether there was discretion and financial support for families, dependant on their ability to pay parking charges during their child's stay (Table 6).

Table 6. On-site facilities for parents and relatives

	Lower Number of Units	Higher Number of Units
Facilities for relatives		
Parent/relatives quiet sitting area within the unit	6/6	4/6
Sibling play area within the unit	3/6	4/6
Unit has overnight accommodation for parents/guardian	5/6	6/6
Accommodation is close to the unit	3/6	5/6
Hospital-provided accommodation is free of charge	6/6	6/6
Parental accommodation is often used	6/6	6/6
Parental accommodation is often full	4/6	5/6
There are often problems with finding accommodation	3/6	0/6
Parking		
Visitors pay to park	5/6	6/6
<i>Discretion in charges linked to:</i>		
Ability to pay	0/6	1/6
Length of illness	2/6	1/6
There are usually problems in finding parking spaces	6/6	6/6

Summary and conclusions

In 12 randomly selected PICUs stratified by extended nursing roles (six with extended nursing roles (higher) and six without (lower)), the census (2005) and unit profile data (2007) was used to describe and compare the context of the units in terms of self-reported:

- unit establishments, staffing, skillmix and activity
- pressures on staffing and workforce
- education and training
- facilities for staff
- facilities for parents/visitors.

Census data and further detailed unit profile data indicated the higher group tended to be bigger units, with more beds and more beds in cubicles. Whereas all but one of the lower units had Junior Doctors, units in the higher group tended to have more Middle-Grade Doctors and only two had Junior Doctor posts. Substitution of nurses for Junior Doctors was likely to be more required in the higher units.

Only three units, all in the higher group, reported designated advanced nursing posts (ANP or Nurse Consultant). These posts were matched to a national job profile and locally evaluated and specified.

More units in the higher group reported extreme fluctuations in activity, but there was wide variation in numbers of unplanned admissions and in-transfers in units of both types. Yet it was units in the lower group which tended to report recent increased pressures on their staffing, such as: increased bed demand, unfilled posts, sick leave, staffing turnover, and training requirements.

Slightly fewer units in the lower group seconded staff for training or offered training for nurses from alternative backgrounds, and only the units in the lower group thought there had been a change in the need for education and training and that the impact of the NHS Knowledge and Skills Framework (KSF) had changed their focus and introduced less flexibility in nurse training.

Finally, there appeared to be more and higher quality facilities for staff in higher units compared to units in the lower group. Fewer higher units reported having problems finding accommodation for parents, although otherwise there was little difference between the two groups of units in their reported facilities for parents/visitors. Both types of units reported parking problems and charges for parents and most did not reply about whether parking charges were waived in relation to illness severity, duration of stay or ability to pay. These main findings are shown in summary Table 7.

Summary Table 7. Comparing contextual characteristics of lower/higher units from census (2005) and unit profile data (2007)

Characteristic	Lower (6)	Higher (6)
Establishment		Bigger units, more beds, more beds in cubicles
Staffing models	More Junior Doctors	Few Junior Doctors, more Middle-Grade Doctors
Task substitution	Uncertain	Uncertain, but more likely to be required with few or no Junior Doctors
Advanced nursing roles	None	A few
Nurse staffing	93% Specialist Paediatric-Trained Nurses	93% Specialist Paediatric-Trained Nurses
	32% (28%-52%) on Senior Nurse bands	27% (22%-31%) on Senior Nurse bands
WTE nurse per Intensive Care Bed (establishment)	Lower than recommended (n=7) at 6.4	Slightly lower than recommended (n=7) at 6.7
Reported changing pressures on staffing	Increased	Same or slightly decreased
Training needs and Knowledge and Skills Framework (KSF)	Increased needs and KSF negatively viewed	Same needs and KSF viewed as neutral
Facilities for staff		Tend to be higher quality, and more recently refurbished
Facilities for parents	Accommodation available free and close to unit	Accommodation available free and close to unit
	Some reported problems finding accommodation for parents	Fewer reported problems finding accommodation for parents
	Parking charges in place and problems finding spaces	Parking charges in place and problems finding spaces

2.1.2. Staff wellbeing

To compare the staff-reported work context and impact of higher vs. lower extended nursing roles on staff wellbeing.

Background

Staff wellbeing vs. workforce wellbeing

This quantitative part of the study used a postal survey of staff in the stratified sample of 12 participating PICUs arising from the phase 1 census (six with higher extended nursing tasks (higher), and six with few or no extended nursing tasks (lower)). This study did not use psychological scales to test negative mental states (such as depression, anxiety or burn-out in individual staff "wellbeing" measurement) as clearly further contributory factors from outside the workplace may also impact on staff mental states. Instead, directly alterable factors affecting workforce wellbeing were used from the theoretically derived HR management models of Michie & West (2004a).

Sibbald *et al* (2004) suggest that change in work patterns, job design and extended roles may have positive and negative contributions to staff wellbeing. The hypothesis being explored is that working in units with higher extended nursing roles may be associated with working in a more supportive work context and organisation, with higher job satisfaction, job performance, and improved staff commitment and hence retention. These indicators of workforce wellbeing in units with higher and lower extended nursing roles are described and compared.

Workforce wellbeing and performance

It is suggested in the annual programme of the NHS Staff surveys (Health Care Commission, 2004-2008) that staff with positive attitudes to work, provided with a good working context, management and leadership are more likely to perform better and so improve the outcomes of patients. Conversely, staff who feel overworked or stressed may perform less well, have more time off work due to illness and are more likely to intend to leave their job. This may lead to staff shortages, threaten service sustainability and the organisation as a whole, and therefore may negatively impact on the quality of patient care.

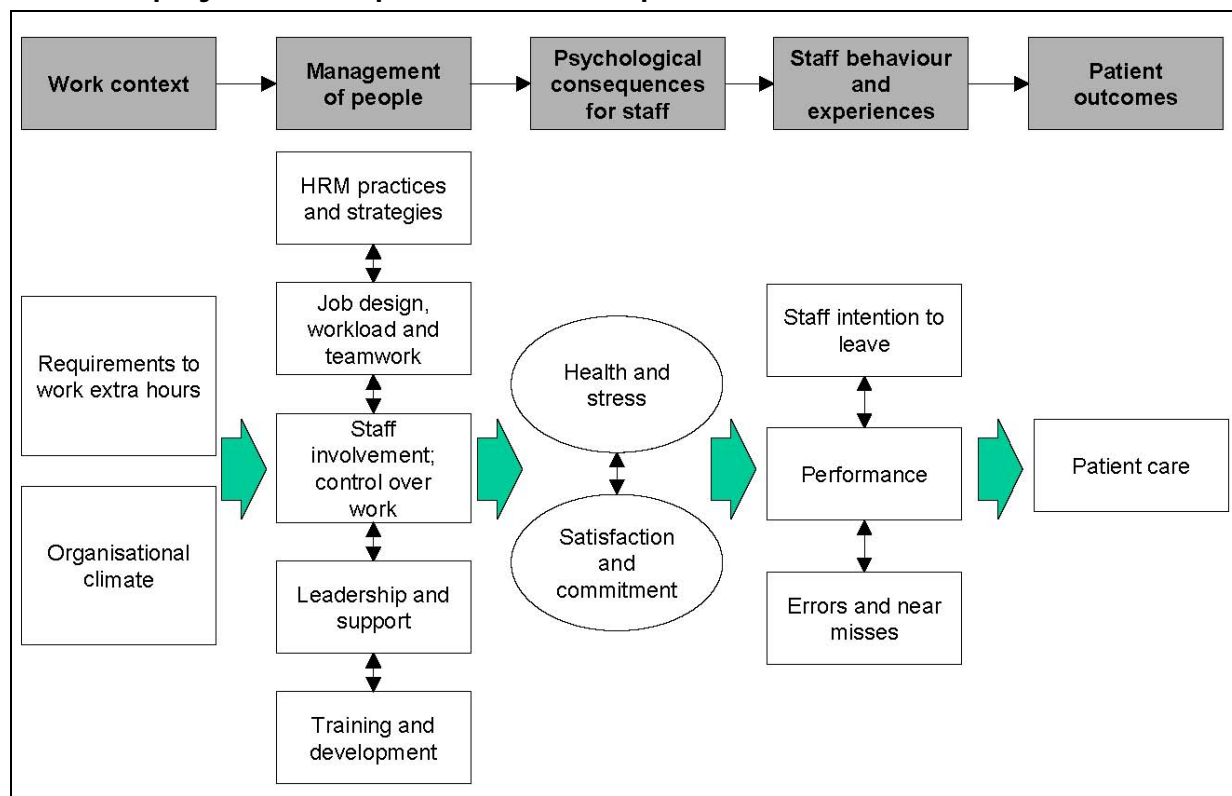
Measuring workforce wellbeing

Michie & West (2004b) propose a theoretical model that incorporates four main aspects of the experience of staff at work. Michie & West's model is shown in Figure 3 below and includes:

1. work context (work-life balance, leadership, and culture)
2. management of people (job design, management, workload and training)

3. psychological consequences and staff behaviour (job satisfaction, stress, intention to leave)
4. performance and care for patients.

Figure 3. An architecture for understanding the links between the context of work, management of people practices, psychological consequences for staff, staff behaviour and performance, and employee health, performance and patient care in the NHS



The model suggests that factors and domains related to work context and management of people may impact on staff, internal health and safety and hence on outcomes for patients. Although the evidence-base for this final connection is limited and mainly from US studies, the link from staff wellbeing to quality of care was highlighted in previous scoping exercises for SDO (Carr-Hill *et al*, 2003; Elliot *et al*, 2003; Hewitt *et al*, 2003; Sheldon *et al*, 2005).

Methods

The questionnaire

Our questionnaire used selected theory-based items previously developed and tested in the NHS Staff Surveys with permission from Aston University (Appendix 3.1). It contained demographic questions, and the NHS Staff Survey closed binary choice (Yes/No) items, and Likert scale items to rate staff views and agreement with statements to derive scores in specific factors. Likert items used a five-point scale ranging from strongly disagree to strongly agree. Scores ranged from 1 to 5 with one indicating low

agreement or satisfaction and five high. The questionnaire was designed to include items on factors in the four main domains in the workforce wellbeing model:

1. *Work context* – Work-life balance is an important factor for staff. Poor work-life balance can result in a higher level of sickness absence and a greater proportion of accidents or near-misses. The questionnaire asked staff to indicate how many hours they work a week, how many paid hours they work over their contracted hours and how many hours are unpaid. Staff were also asked to indicate why they worked extra hours.
2. *Management of people* – This section included items on team-working, autonomy and job satisfaction and views on unit leadership and support. For example, staff were asked to indicate whether they work in a team. Thereafter a number of Likert scale questions contribute to a team-working score that indicates the extent to which the team is structured and functions well. There were further questions to explore staff views on their control over their work, whether they felt recognised and valued for good work and about whether management dealt effectively with bullying or harassment.
3. *Staff wellbeing and commitment* – High workload (or work pressure without adequate time or resources) is one of the main causes of stress. Stress is known to be linked with absence from work, staff turnover, and less effective working and so poorer quality of patient care. Four Likert scale items were included that contribute to a score for pressures at work. Further questions explored whether staff had suffered injury, work-related stress or harassment or bullying at work. These items asked whether staff felt supported at work, and their future intentions about staying in their current post and staying working in the NHS.
4. *Staff performance and unit safety* – Items on errors and near misses asked whether the staff have seen any incidents, their knowledge of reporting procedures, and their experiences of whether such incidents actually were reported when witnessed. Finally the questionnaire included items on the unit provision and staff behaviour in relation to hand-washing and infection control.

Following a pilot study of 10 PICU nurses, only minor changes were made to the draft questionnaire. These included typographic corrections and the addition of named staff roles specific to paediatric intensive care sub-specialty.

Sample and setting

A questionnaire, letter of invitation and two reminders were sent at three-weekly intervals to all staff working in the 12 participating PICUs in the last quarter of 2007. Staff establishments included doctors, nurses, allied health professionals, technicians, administrative, management and other support staff. Questionnaires were anonymous except for unit serial number, and with prepaid-postage envelopes to return to the study centre.

Analysis

Data were collated and descriptive analysis used SPSS for Windows. Results are presented as percent response for Yes/No items and mean scores for summed Likert-scale items (scaled one to five) following the methods of the NHS Staff Survey. Health Care Commission (2007) results are presented as differences in percent response, crude and adjusted scores (and 95% CIs) between the two groups of units (higher vs. lower nurse extended roles). As different occupational groups tend to answer some questions in different ways, scores were adjusted only to take account of unit-level variation in occupational group responder proportions (Appendix 3.2; Healthcare Commission, 2007).

Results

Of 1222 staff, 57% (700) completed and returned the questionnaire. Response rates varied within and between unit groups (lower and higher extended nursing roles) and by occupational staff group (Tables 8 and 9). There was a higher response from units with higher extended roles compared with lower units. By occupational group, there were higher response rates from nurses compared with doctors.

Table 8. Response rates (n) by unit stratified by higher/lower extended nursing roles

Unit Number Extended nursing role	Respondents n	Total Staff n	% response
Lower			
1	97	191	50.8
4	110	176	62.5
6	26	57	45.6
7	23	46	50.0
9	33	80	41.3
10	54	87	62.0
Total	343	637	54.0
Higher			
2	88	137	64.2
3	41	50	82.0
5	49	56	87.5
8	110	191	57.6
11	29	51	56.9
12	40	100	40.0
Total	357	585	61.0

Table 9. Response rates n (%) by staff groups stratified by higher/lower extended nursing role

	Medical	Nursing	Allied	Scientific/ technical	Admin/ clerical	Other	Total
Lower	44/104 (42.3)	269/480 (56.0)	15/33 (45.5)	0/1 (0.0)	10/13 (76.9)	1/6 (16.7)	339/637 (53.2)
Higher	38/65 (58.5)	300/498 (60.2)	3/8 (37.5)	1/1 (100.0)	10/10 (100.0)	0/3 (0.0)	352/585 (60.2)
Total	82/169 (48.5)	569/978 (58.2)	18/41 (43.9)	1/2 (50.0)	20/23 (87.0)	1/9 (11.1)	691*/1222 (56.5)

*9 missing

Table 10. Demographic characteristics of respondents stratified by higher/lower extended nursing role

	Lower (%)	Higher (%)	Total (%)
Gender			
Male	42(13%)	45 (13%)	87 (13%)
Female	287 (87%)	305 (87%)	592 (87%)
Age (yr)			
<20	-	4 (1%)	4 (1%)
21-30	100 (29%)	93 (26%)	193 (28%)
31-40	159 (47%)	118 (33%)	277 (40%)
41-50	68 (20%)	94 (27%)	162 (23%)
>50	13 (4%)	44 (13%)	57 (8%)
Ethnicity			
White	297 (88%)	311 (88%)	608 (88%)
Asian	25 (7%)	31 (9%)	56 (8%)
Black	6 (2%)	7 (2%)	13 (2%)
Chinese/other	7 (2%)	-	7 (1%)
Mixed	3 (1%)	3 (1%)	6 (1%)
Total Yrs in PICU			
<1	38 (11%)	24 (7%)	62 (9%)
1-5	109 (32%)	119 (34%)	228 (33%)
6-10	91 (27%)	74 (21%)	165 (24%)
>10	103 (30%)	137 (39%)	240 (35%)

There were no differences between the respondent groups from lower and higher units in terms of gender or ethnicity, but, in comparison with lower units, higher units had fewer staff with less than one year experience, and more experienced (more than 10 years) and older staff (aged over 40) (Table 10).

Work Context

More than two thirds of all respondents reported working more than their contracted hours. Of those, nearly all indicated that was due to elements of work pressure and demand. Table 11 shows that significantly more staff from units with higher extended nursing roles reported working extra hours (77%, working both unpaid and paid) compared with respondents from units with lower extended roles (66%).

There were few differences between the groups in the individual reasons for working more than contracted hours (Table 12). Despite nearly 10% more respondents in the lower group indicating it was impossible to do the job without working extra hours, the overall summary report score showed most staff in both types of units were working extra hours to meet demand (Table 12, items*) with no difference between higher (87%) vs lower (89%) units (Table 11).

Management of people

Only around one fifth of staff were judged to be working in a well-structured team environment from the aggregated responses to the team-working items. Staff reported varied team size from small (2 to 5) to more than 15. Interestingly, in the scored item on quality of work-life balance, the level of unit management support for maintaining work-life balance (as perceived by staff) was significantly higher in units with higher extended nursing roles than in the lower units (Table 13).

Table 13 presents the findings from items relating to unit management practices, staff control over their work, and their satisfaction with the recognition given to them by management. There were no differences in staff scores between higher vs. lower extended nursing role groups for satisfaction with these aspects of their jobs and the effective unit action on staff bullying/harassment.

Psychological consequences for staff and commitment

On staff wellbeing, staff in higher units had a statistically significantly higher adjusted work pressure score (3.13 (95%CI 3.07-3.18)) compared with staff in the lower unit group (3.01 (95%CI 2.95-3.07)), indicating higher perceived work pressure in the former. Similarly, significantly more respondent staff from higher units (36%) reported experiencing work-related stress in the past 21 months compared with those in lower units (24%) (Table 11). In the recently reported NHS Staff Survey findings for 2007, the average percentage of staff reporting work-related stress was 33% (Healthcare Commission, 2004-2008).

There were no other differences in the staff wellbeing items by unit group, and no difference in their job commitment from the scored items on intention to leave.

Unit performance and safety

Tables 11 and 13 show no differences between unit types in self-reported behaviour and units' performance related to reporting errors, incidents and near misses, hand-washing and infection control. Staff in both groups of units scored their units highly for ensuring availability of amenities, and as effective environments for hand-washing.

Table 11. Percent agreement (n (%)) with domain items by lower and higher extended nursing role units.

Items	n/total item response (%)	Lower	Higher	% Diff (95% CI)
I Work Context				
Staff working more than contracted hours (paid)	263/677 (38.9%)	104/331 (31.4%)	159/346 (50.0%)	18.6% (7-22%) p=0.000
Staff working more than contracted hours (unpaid)	405/679 (59.5%)	185/332 (55.7%)	220/347 (63.4%)	7.7% (0.3-15%) p=0.041
Staff working more than contracted hours (total)	500/698 (71.6%)	227/342 (66.4%)	273/356 (76.7%)	10.3% (4-17%) p=0.002
Staff working extra hours due to pressure and demands of job*	438/500 (87.9%)	201/227 (88.5%)	237/273 (86.8%)	-1.7% (-7.5-4%) p=0.558
II Staff Wellbeing and Commitment				
Staff suffering a work-related injury in the last 12 months	147/697 (21.0%)	66/342 (19.3%)	81/355 (22.8%)	-3.5% (-3-10%) p=0.255
Staff suffering work-related stress in the last 12 months	212/697 (30.4%)	83/342 (24.3%)	129/355 (36.3%)	12% (5-19%) p=0.001
Staff experiencing violence, harassment, bullying or abuse	259/697 (37.3%)	124/339 (36.6%)	135/356 (37.9%)	-1.3% (-6-9%) p=0.714
III Management of People				
Staff working in a well-structured team environment	142/662 (21.5%)	68/329 (20.7%)	74/333 (22.2%)	1.5% (-5-8%) p=0.626
IV Unit Performance and Safety				
Staff witnessing an error, near miss, or incident in the last month that could harm staff or patients	439/693 (63.3%)	232/355 (65.6%)	207/338 (61.2%)	-4.4% (-3-11%) p=0.262
Staff reporting error, near miss or incident	597/627 [†] (95.2%)	301/316 (95.3%)	296/311 (95.2%)	-0.1% (-3-3%) p=0.964

(see Table 12)* Of those working extra hours, reasons included at least one of the following: a) necessary to meet deadlines, b) expected by their line manager, c) expected by their colleagues, d) impossible otherwise to do the job, e) don't want to let down the people they work with

[†] excludes "don't know" or "never seen"

T

Table 12. Percent agree (n (%)) with reasons for working more than contracted hours by lower and higher extended nursing role units.

I work more than my contracted hours in this unit because....	n/total item response	Lower	Higher	% Difference (95% CI)
*It is necessary to meet deadlines	255/493 (51.7)	119/222 (53.6)	136/271 (50.2)	-3.4% (-12.3 - 5.4) p = 0.452
It is necessary to get ahead in my career	76/497 (15.3)	39/225 (17.3)	37/272 (13.6)	-3.7% (-10.1-2.7) p = 0.250
I also work bank shifts	168/498 (33.7)	73/226 (32.3)	95/272 (34.9)	2.6% (-5.7 - 10.9) p = 0.537
*It is expected by my immediate manager	84/495 (17.0)	35/225 (15.6)	49/270 (18.1)	2.5% (-4 - 9.2) p = 0.444
*It is expected by my colleagues	114/497 (22.9)	50/226 (22.1)	64/271 (23.6)	1.5% (-5.9 - 8.9) p = 0.694
I enjoy my job	244/492 (49.6)	114/224 (50.9)	130/268 (48.5)	-2.4 (-11.3 - 6.5) p = 0.598
*It is impossible to do my job if I don't	277/493 (56.2)	138/224 (61.6)	139/269 (51.7)	-9.9% (-18.7 - -1.2) p = 0.027
I want to provide the best care I can for patient/service users	415/496 (83.7)	189/225 (84.0)	226/271 (83.4)	-0.6% (-7.1 - 5.9) p = 0.856
*I don't want to let down the people I work with	379/496 (76.4)	174/225 (77.3)	205/271 (75.6)	-1.7% (-9.2 - 5.8) p = 0.659
I want to earn extra money	187/495 (37.8)	77/224 (34.4)	110/271 (40.6)	6.2% (-2.3 - 14.8) p = 0.156

Table 13. Mean (95% CI) domain scores for staff by lower and higher extended nursing role units.

Scored Items	Respondents n			Crude score (95%CI)		Adjusted score (95%CI)	
	Total	Lower	Higher	Lower	Higher	Lower	Higher
Work-Life Balance							
Unit context : perceived support for work-life balance	694	339	355	3.25 (3.15-3.34)	3.39 (3.3-3.48)	3.23 (3.17-3.30)	3.36 (3.30-3.41)
Management of People							
Satisfaction with responsibility, recognition and control over work	687	335	352	3.50 (3.43-3.58)	3.49 (3.42-3.55)	3.49 (3.44-3.54)	3.48 (3.43-3.52)
Unit takes effective action against bullying /harassment	687	339	348	3.58 (3.5-3.66)	3.61 (3.54-3.69)	3.57 (3.51-3.63)	3.60 (3.55-3.65)
Staff Wellbeing and Commitment							
Work pressure	689	338	351	3.06 (2.97-3.15)	3.10 (3-3.18)	3.01 (2.95-3.07)	3.13 (3.07-3.18)
Intention to leave	692	338	354	2.63 (2.52-2.75)	2.60 (2.49-2.72)	2.64 (2.57-2.72)	2.59 (2.52-2.66)
Unit Performance and Safety							
Hot water, soap and towels availability	685	336	349	4.72 (4.65-4.78)	4.74 (4.66-4.78)	4.73 (4.69-4.78)	4.72 (4.68-4.76)
Unit effective environment for hand- washing	696	342	354	4.01 (3.93-4.1)	4.08 (3.99-4.17)	4.04 (3.98-4.10)	4.11 (4.06-4.17)
Staff role in infection control	696	342	354	4.67 (4.59-4.75)	4.53 (4.45-4.61)	4.68 (4.62-4.74)	4.58 (4.53-4.63)

Summary and conclusions

57% of PICU staff completed and returned the questionnaire. There was a higher response from units with higher extended roles compared with lower units. There was a higher response rate from nurses (~60%) than doctors (~50%). Clearly we cannot exclude the possibility of response bias and the main findings below relate to respondent replies.

Context

- Most reported working extra hours.
- Nearly all said they worked extra hours to ensure the best care possible for patients.
- Nearly all attributed extra hours worked to perceived demands and pressure of the job.
- More respondents from units with higher extended nursing roles reported working extra hours (77%, both unpaid and paid) compared with staff from lower extended role units (66%).

Management of People

- No difference between higher and lower units in job satisfaction score.
- No difference between higher and lower units' for working in well-structured teams.
- Respondents in higher units had a higher average work pressure score compared to those in lower units.
- Respondents in higher units scored their unit management more highly for support to maintain a work-life balance.

Psychological Consequences for Staff

- More respondents from higher units had suffered work-related stress in the last 12 months.
- No difference between higher and lower units in terms of work-related injury or experiencing bullying/harassment.
- No difference between higher and lower units in average score for intention to leave.

Unit Performance & Safety

- No difference between higher and lower units in respondent views relating to errors/incidents and hand-washing/infection control practice

Compared with the lower units, respondents from units with higher extended nursing roles were more likely to work extra hours and report work-related stress. They had a higher mean work pressure score, but also recognised their unit management's supportive approach for a work-life balance.

From these data, working in units with extended nursing roles was not associated with any discernable improvement in team-working, job satisfaction, self-reported performance, but neither was it associated with increased intention to leave.

2.1.3 PICU staff cost analysis

Objective

To compare unit context and the impact of higher/lower levels extended nursing roles on staff costs (medical and nursing staff) in PICUs in the UK.

Method

We used a top-down approach to measure total salary costs of the nursing and medical staff, and related this to measures of unit size and activity and tested for association with higher/lower extended nursing role.

Data

We used detailed data about staffing from surveys (in 2005 and 2007) of the stratified random sample of 12 participating UK PICUs arising from the census (six designated as having higher extended nursing roles (higher), and six with few or no extended nursing tasks (lower)). Each unit employed a mix of doctors and nurses. The doctors included Consultants, Senior House Officers (SHOs), Specialist Registrars (SPRs), Trust Doctors, and Associate Specialists. The units also employed different grades of nurses, namely: Nurse grades A to H, including clinical and non-clinical nurses in grades F to H, as well as a few designated Nurse Consultants.

Data on unit size was captured by total number of ITU beds available within the unit in 2007. This data, taken from a survey of PICUs undertaken as part of this study in 2007, reflects the units' potential level of activity.

Estimating staff salary costs

Method

Staff salary costs were calculated as the product of total staff whole-time equivalent (WTE) and the average annual salary for the two occupational groups (doctors and nurses) at the mean point for the appropriate scale or grade/band. Whole time equivalent measures the total number of contracted working hours supplied by staff. Data on staff WTE per PICU was obtained from our surveys of 12 units in both 2005 and 2007. Data on doctors' WTE was provided by the 2007 survey data. However due to incomplete data on nurses' WTE in 2007 and the on-going *Agenda for Change* transition at some units from grades to banding, nurse WTE was taken from the baseline 2005 data (Department of Health (DH), 2004a, 2004d).¹ Table 14 reports the total WTE recorded for each staff group by the study definition of higher and lower level units.

¹ We also adjusted nurses' WTE in 2005 by a factor of the ratio of establishment size in 2007 and 2005, to obtain an estimate of nurse WTE figures for 2007. This takes into consideration any change in unit size/bed establishment between 2005 and 2007 (see Appendix 4.1).

Table 14. Nurse and Doctors Total WTE in 12 PICU study sites

Staff group	Unadjusted	
	Lower units	Higher units
Doctors		
Consultant	30.00	32.00
Senior House Officer	1.00	7.00
Specialist Registrar	46.00	52.00
Trust Doctor	22.00	18.00
Associate Specialist	0.00	0.00
Nurses		
Nurse A	10.29	12.06
Nurse B	10.53	8.33
Nurse C	3.60	3.00
Nurse D	109.33	121.10
Nurse E	117.13	175.60
Nurse F (clinical)	81.75	63.43
Nurse F (non clinical)	4.70	2.00
Nurse G (clinical)	41.64	39.99
Nurse G (non clinical)	12.10	6.00
Nurse H (clinical)	4.20	9.34
Nurse H (non clinical)	2.15	5.84
Nurse I	1.20	1.00
Nurse Consultant	0.00	2.00
Other Nurse (category 1)	1.00	9.34
Other Nurse (category 2)	0.00	1.00
Other Nurse (category 3)	0.00	1.00

Doctors' salary costs were calculated directly using 2007 salary scales for all identified training and non-training grades while nurse costs were calculated from 2005 salary scales and inflated to 2007 values representing nurses' salary uplifts of 2.5% consecutively for 2006 and 2007 as recommended by the NHS Pay Review Body (NHSPRB, 2007). Mean points for the relevant salary scales for staff groups were taken. Information on nursing staff grades in 2005 were given in terms of pre-*Agenda for Change*, Whitley salary scales while 2007 salary scales were in terms of *Agenda for Change* bands. The marking up of 2005 mean point at grade level according to annual pay increases to estimate salaries in 2007 assumes no significant effects of movement on the salary scales due to possible regrading in the *Agenda for Change* job evaluation exercise. Any such re-adjustment between grades to bands will therefore not be reflected in the estimation of

2007 grade/band WTE. In addition, taking mean points will not capture variations between units in the placing of staff within staff grades/bands. Information on staff salaries were obtained from several sources, including Review Bodies on Doctors' and Dentists Remuneration, NHS Pay Review Body, the NHS Staff Earnings Survey and Advance Letters from the Department of Health (NHS Information Centre for Health & Social Care, 2004; DH, 2004e; Doctors' and Dentists' Review Body (DDRB), 2007; NHSPRB, 2007).

Results

Descriptive statistics of staff salary costs

Table 15 reports the average crude costs for both nursing and doctor occupational groups for all 12 PICUs within the study and the average total nurse and doctor staff cost. These costs are further broken down to compare the differences in these average staff costs between units with extended roles and those without extended roles. The costs are based entirely on staff WTE and are therefore (at this stage) not adjusted for factors such as unit size, activity or other potential confounding factors.

Table 15. Average staff costs in PICUs

	All PICUs	Lower	Higher
Nurse costs	£1,537,905.00 (£831,478.40)	£1,439,010.00 (£852,672.70)	£1,636,799.00 (£877,759.20)
Doctor costs	£873,171.80 (£278,834.40)	£845,621.70 (£353,312.20)	£900,721.90 (£210,714.70)
Total nurse and medic costs	£2,411,076.00 (£1,021,054.00)	£2,284,632.00 (£1,152,549.00)	£2,537,521.00 (£962,742.70)

For all 12 PICUs, on average, nurse staff costs represent 63.8% of the total nurse and medical salary costs. Doctor salary costs contribute the remaining 36.2% of the total. Average total nurse and doctor staff costs were higher in the higher extended role units than in the lower extended role units. Within this total, both nurse and doctor average costs were higher in the higher extended role units compared to the lower extended role units. There was slightly more variation in the higher extended role units in terms of nurse costs, with much more variation in doctor costs in the lower extended role units. In terms of both nurse and doctor costs, higher extended role units reported less variation in total costs.

Adjustment for activity (size, volume and illness severity)

Descriptive statistics

Salary costs were also considered in relation to measures of unit size and activity. Unit size was measured by the maximum number of beds that can be occupied, and unit activity measured in terms of the number of bed days. The relationship between patient profiles as measured by illness severity and staff salary costs is also considered.

Table 16 illustrates the differences in these potential confounding factors in the explanation of the different staff costs across the units and between the higher and lower extended role units. Extended role units were larger (on average) than lower extended role units in terms of the reported number of ITU beds. Table 16 reports however that there was more activity in the lower units (on average) than in the higher units as measured by bed days. In addition, there were also greater variations in bed day activity among lower units, compared to higher units. Illness severity comparisons also showed differences between units with higher and lower extended roles for nurses. The lower units recorded higher proportions of admissions for risk categories 3 (5 to <15%) and 4 (15 to <30%), compared with the higher units. The higher units admitted a higher proportion of patients in the lowest two risk categories (<1% and 1 to <5%).

There were however wide variations in the percent of admissions by risk categories at unit level, particularly in the lower compared with the higher group (although the greatest variation in percent of admissions in the most risky group (30%+) was among units with higher extended roles).

Table 16. Descriptive statistics of independent variables

Variable	All PICUs	Higher	Lower
Mean (standard deviation)			
Total ITU beds	13.50 (5.85)	14.50 (5.82)	12.50 (6.25)
Total bed days	4234.92 (1949.05)	3763.17 (1678.92)	4706.67 (2237.07)
Mortality risk categories*			
1) <1%	17.67 (6.90)	20.50 (5.99)	14.83 (10.19)
2) 1-<5%	47.83 (8.46)	48.50 (6.35)	47.17 (10.78)
3) 5-<15%	26.67 (11.34)	23.67 (6.31)	29.67 (14.88)
4) 15-<30%	5.58 (1.98)	5.00 (1.55)	6.17 (2.32)
5) 30%+	2.33 (1.37)	2.33 (1.37)	2.33 (1.51)

*This variable presents the percent of admissions within 5 different mortality risk groups

In summary, lower units recorded more activity (total bed days) and greater variations in activity than higher units. They also recorded fewer

ITU beds and greater variations in ITU beds compared to higher units. Also, compared to the higher units, the lower units recorded larger percentages of patients in high mortality risk groups (5 to <15% and 15 to <30%) and greater variation for most of the mortality risk categories. Despite these, the higher units employed 10% more doctors and 31% more nurses than the lower units. Consequently, staff costs were 28% more for nurses and 7% more for doctors among higher units compared to lower units. There were also greater nurse cost variations in higher units and greater doctor cost variations among lower units.

Cost per maximum bed occupation

Salary costs were first adjusted for unit size. Unit staff salary cost per maximum number of beds that can be occupied are shown in Table 17 by unit and the group average cost for units with higher/lower extended roles.

Table 17. Cost per maximum beds that could be occupied in 2007

UnitID	Staff cost per maximum bed (GB£)
Lower	
10	170,547.40
1	196,296.00
7	203,100.70
4	226,848.50
6	297,517.30
9	351,579.10
Higher	
12	173,242.40
2	174,089.40
3	187,734.30
8	209,379.30
5	244,257.80
11	273,141.80
Means (sd) by extended role	
Higher	£210,307.50 (£40,735.11)
Lower	£240,981.50 (£69,311.71)

On average and after adjusting for unit size, the lower extended role units tend to have higher cost per maximum bed and also have a higher variation around this mean than the higher extended role units. This is illustrated further in the following diagrams. Figure 4 indicates the variation of cost per maximum number of bed across each of the 12 units in the study (ranging from £170,547.40 to £351,579.10). Figure 5 and 6 illustrate the differences in the extent of variation within the higher and lower extended role PICU groups. There appears to be greater variation in the lower extended role units in terms of cost per maximum bed than in the higher extended role units. This suggests that, after accounting for unit size, the higher units remain more uniform in terms of staff costs than the lower units.

Figure 4. Radar chart showing variation of cost per maximum number of beds that can be occupied (all PICUs in 2007)

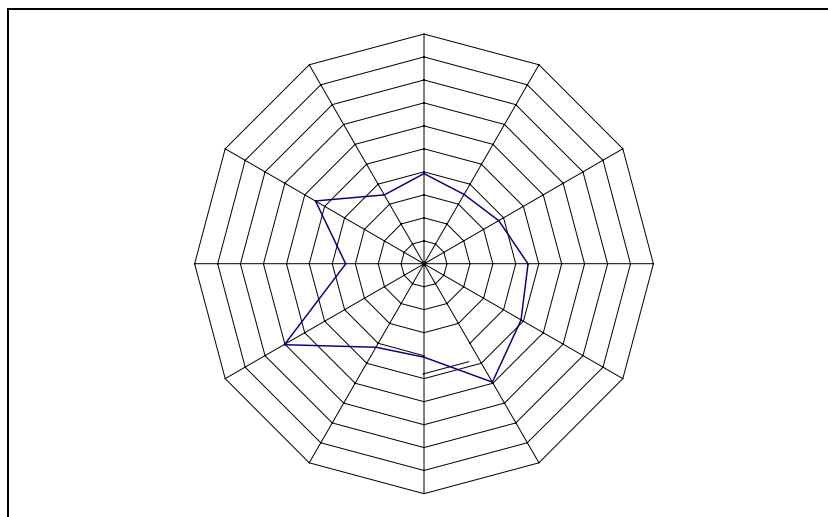


Figure 5. Radar chart showing variation of cost per maximum number of beds that can be occupied (lower PICUs in 2007)

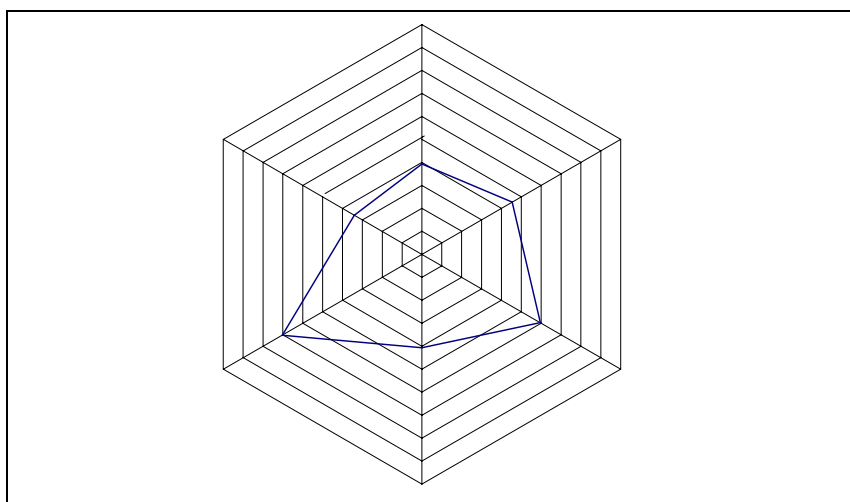
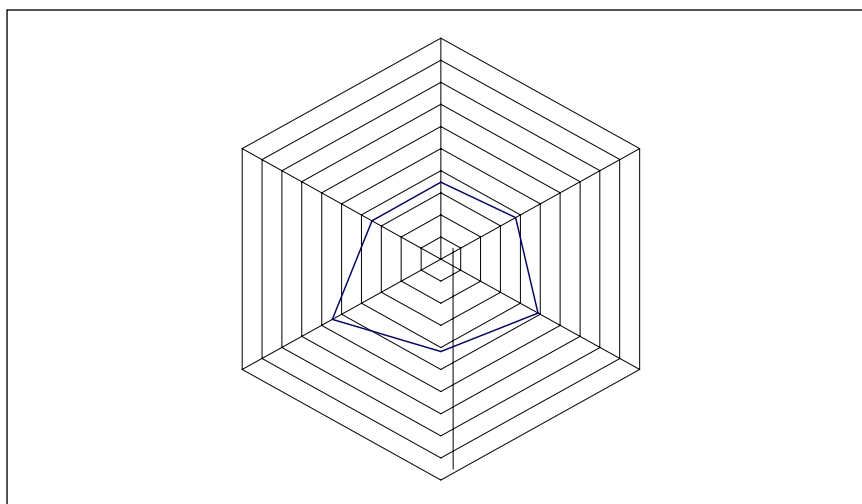


Figure 6. Radar chart showing variation of cost per maximum number of beds that can be occupied (higher PICUs in 2007)



In summary, higher units had higher and more variable staffing salary costs, but also were on average larger units. Once unit size was taken into consideration, the higher extended role units tended to have lower average cost units than the lower units and exhibited less variation in staff cost per bed.

Cost per bed day

Staffing costs were also explored in relation to a measure of unit activity as given by the total number of bed days. Table 18 shows there is wide variation in staff cost per bed day from £176.98 to £1747.74. There is also marked variation in the average cost per bed day between the higher and lower extended role unit groups. The higher extended role units have average staff costs per bed day of £818.28 compared to £581.45 in the lower extended role units. However there is also more variation around the mean in the higher extended role units.

Table 18. Staff costs per number of bed days

UnitID	Total costs per bed day (GB£)
Lower	
7	176.98
6	278.73
1	448.68
4	773.45
9	812.90
10	997.94
Higher	
11	307.07
5	455.86
2	582.63
3	703.45
12	1112.91
8	1747.74
Means (sd) by extended role	
Lower	£581.45 (£327.65)
Higher	£818.28 (£531.43)

Validation

We found no reports in the literature for external validation of our estimates of staff costs in PICUs. However, in UK adult intensive care units as the most comparable clinical setting, the *Critical Care National Cost Block Programme* collects data on resource use for critical care units in the UK (Dean *et al*, 2002). The data covers resource use of consumables, staff, clinical support services as well as other defining unit characteristics. Staff costs (nursing and medical staff) are reported as 51.7% of all costs based on data collected for 1996/97 (Edbrooke *et al*, 2001). Total mean costs per patient day for the Cost Block Programme are £1028 (2001 price year, £1318 inflated to 2006/7 price year using inflation indices from Unit Costs of Health and Social Care). An alternative estimate is given by a study by Hibbert *et al* (2004) which covers a wider range of resources and a higher

mean cost per day of £1302 (2003 price year, £1535 inflated to 2006/7 prices). The PICU study (nursing and medical) staff costs per day are estimated on average as £699.86 (2007 price year). Assuming that nurse and medical staff costs remain 52% of the total costs, this would correspond to a total mean cost per day of £1346. This figure lies between the two figures quoted in the literature for adult intensive care. This suggests that the staffing cost figures reported in this study are reasonable.

Regression analysis of staff costs

We now analyse total nursing and doctor staff costs as a function of unit size and activity. Independent variables include measures of unit size (maximum number of beds), illness severity (percent of admissions by mortality risk group) and a dummy variable indicating whether the PICU was a lower or higher (extended role for nurses) unit. We also consider a model which replaces the maximum number of beds in the unit with a measure of unit activity as given by the number of bed days. This alternative measure reflects the difference between actual activity (number of bed days) and potential activity (maximum beds) where high fluctuations in demand for beds will tend to suggest a greater divergence of potential activity from actual activity.

The two regression results (on the analysis of total medical and nursing staff salary costs) are presented in Table 19. The difference between the two models is in the measure of unit size or throughout. Model A uses the maximum number of beds as an explanatory variable (model A) and this is replaced with total bed days in model B. Both models used the same measures of the percent of admissions within five mortality risk groups to adjust for illness severity. Model A was statistically significant ($p < 0.05$), while model B was not ($p > 0.66$). The corresponding coefficients of determination were 0.93 for model A and 0.66 for model B. This means that while model A's independent variables were able to explain most of the variations in direct staff costs among PICUs, model B's independent variables were not. All the same, both models suffered from small samples and small degrees of freedom.

As would be expected, model A reports a significant effect of the maximum number of beds on total medical and nursing staff salary cost, reflecting a strong positive relationship between establishment size and subsequent staffing costs. In model B, the alternative measure of unit activity (the number of bed days) showed no statistically significant variable including that of the number of bed days. The breakdown of this relationship between staff costs and number of bed days may be due to fluctuating demand for beds and subsequent fluctuations in bed occupancy with no parallel ability to adjust staffing and therefore staff costs. This suggests that establishment staff costs represent a large fixed cost for the units irrespective of bed occupancy, hence any changes in occupancy do not

significantly add to staff costs. There were no significant effects in either model of any of the measures of illness severity on direct staff costs. Again, this may indicate the nature of the unit staffing costs that are incurred as fixed costs with any changes in illness severity not effecting total direct staff costs. Neither was there any evidence of any significant effect of extended roles on total direct staff costs while controlling for activity (maximum beds), throughput (bed days) or illness severity.

Table 19. OLS regression analysis of staff costs in PICU Units

<i>Variable</i>	Dependent variable is total cost (doctors & nurses)	
	Coefficient (P> t)	
	Model A (maximum number of beds)	Model B (total bed days)
Maximum number of beds	0.075 (0.011)**	-
total bed days	-	0.001 (0.371)
<i>Mortality risk</i> [#]		
<1%	-0.112 (0.704)	0.296 (0.672)
1-<5%	-0.148 (0.659)	0.249 (0.736)
5-<15%	-0.139 (0.674)	0.328 (0.664)
15-<30%	-0.064 (0.799)	-0.137 (0.810)
30%+	-0.111 (0.738)	0.510 (0.480)
Extended role (Higher)	-0.074 (0.704)	0.293 (0.535)
Constant	26.989 (0.415)	-13.398 (0.853)
<i>Sample</i>	12	12
<i>F-stat (probability)</i>	7.72 (0.033)	1.12 (0.485)
<i>R</i> ²	0.93	0.66

[#]this variable presents the percent of admissions by mortality risk categories

** α =at least 0.05; * α =0.10

Note that the dependent variable (cost) was transformed to logs for the regression analysis.

Summary and conclusions

Care should be taken when comparing costs across the higher extended and lower extended role units as depending on the confounding factor that is considered, the comparison may change in favour of one unit "type" to the other. Once correction of crude staff costs is made for the size of the unit in terms of the maximum funded available beds, figures indicate that, on average, the lower extended role units tend to have higher cost per maximum bed and have a higher variation around this mean than the higher extended role units. However, when considering unit size in terms of activity, higher extended role units have higher average staff costs per bed day of £818.28 compared to £581.45 in the lower extended role units. Regression analysis suggests that a model using maximum number of beds days explains more variation in costs than one using bed activity data.

This finding reinforces the view that staffing is very much a fixed cost in these units and the difference in costs per maximum number of funded available beds and costs per bed day is due to differences in demand for beds that are not reflected in the variation in staffing observed and therefore staff costs.

2.2 Unit context, human resources management strategy (HRMS) and staff views

Objective

To explore and compare unit context and human resources management strategy (HRMS) against Contingency theory-derived criteria.

In considering the context we review, first, the wider contextual policy, labour market and healthcare workforce of PICUs in the UK, and second, present an in-depth analysis of staff views and experience of their work context, professional roles (including extended nursing roles in the PICU care team) and issues of sustainability, acceptability, and training.

2.2.1 Contextual labour market and healthcare workforce for UK Paediatric Intensive Care Units

The labour market for PICU staff

This first section presents the wider contextual labour market conditions in which the selected PICUs operate. Issues relating to the recruitment and retention of both medical and nursing staff employed to deliver care, and trends in employment numbers for medical and nursing staffing groups in the NHS and for the paediatric specialty are considered. There may also be regional differences in terms of the number of medical and non-medical staff, recruitment and retention difficulties, as well as competition from the private sector.

There are also medical labour supply implications from policy that have impacted on all PICU units: the new Consultant and GP contracts, with substantial increases in pay and reduced hours for Consultants; the implementation of policies such as the European Working Time Directive, limiting training doctors' weekly working hours to no more than 48 hours per week; and Modernising Medical Careers (Department of Health, 2005), which emphasised that care should be delivered by fully trained doctors, with more narrowly focussed training and recruitment and retention of sufficient training-grade doctors in PICU Units.

Available data obtained from the NHS Information Centre (for data on England) and the Information Services Division (ISD) NHS Scotland are presented.

Number of medical and non-medical staff

Considering training-grade doctors and nurses most commonly employed in PICUs, the Royal College of Paediatrics and Child Health (2006) highlight the increasing dependence on these professional groups to support the delivery of children's services. National trends in this group are an indication of their availability, and also an indication of ease of access to supply in the

delivery of care in PICUs. Trends for these groups, showing headcounts (HC) and whole-time equivalents (WTE) are presented in Figures 1 to 6 in Appendix 5.1. Headcounts measure the absolute number of staff in post, while whole-time equivalents measure the equivalent number of full-time staff that would be employed at the standard number of hours for full-time employed. The greater the difference between headcount and whole-time equivalent, the greater the number of part-time staff.

Registrars

There was a steady increase in the number (HC) and WTE of Registrars in England over a ten year period from 1995 to 2005 (Appendix 5.1, Figure 1). Statistics show a 57% increase in headcount, compared with a 60% increase in WTE in England over the period, possibly an indication of a slight increase in the number of Registrars working full time (or a decrease in Registrars working part-time).

The picture for Scotland (Appendix 5.1, Figure 2) showed a steady decline in both headcount and whole-time equivalent Registrars between the years 1997 and 2000, and a gradual, steady increase from 2000 up until 2006. There was a sharp increase in both headcount and WTE in 2007, possibly following the implementation of a revised programme of specialty training under the Modernising Medical Careers (MMC) programme (Department of Health, 2005). The introduction of MMC resulted in two cohort years of medical graduates being eligible to go into Registrar level in 2007, i.e. SHO3s (from old system) and Foundation Year 2 (new MMC). Prior to 2007, doctors usually spent at least 3 years as House Officers before competing for limited Specialist Registrar numbered training posts. MMC shortened not only the years in Registrar training (middle-grade posts before becoming a Consultant) but also cut the Junior Doctor years (to only Foundation Year 1 and Foundation Year 2). We would also expect this MMC adjustment in England since this training re-alignment was introduced across the UK.

MMC has implications for the supply of medical labour, as many PICUs regularly use training-grade doctors to deliver care in their units. The impact of the MMC on medical staffing levels would therefore be a function of the proportion of training-grade doctors currently employed by any individual PICU. Any differences between the PICUs in terms of their reliance on training-grade doctors may mean that the effects of the implementation of MMC will be felt differently across the units.

Other training-grade doctors

These 'other training-grades' include Senior House Officers (SHOs) and House Officers, currently referred to as Foundation Year 2 and Foundation Year 1 under the Modernising Medical Careers scheme.

In England, there was a steady increase in both headcount and WTE of other training-grade doctors over the period 1995 to 2005. There was a 58% increase in the number of other training-grade doctors, followed by a

slightly lower increase in WTE over the same period (Appendix 5.1, Figure 3). In Scotland, statistics show a steady increase in the number and WTE of this grade of doctors from 1997 to 2006, similar to changes in England during the period, and a sharp decrease in 2007 (Appendix 5.1, Figure 4). Again, the sharp reduction in total number of SHOs coinciding with the sharp increase in Registrars in Scotland reflects the adjustment of the pre-MMC SHO3s into the Registrar category.

Nurses and Midwives

Differences in the statistics reported for England and for Scotland mean that while England report numbers and WTE for qualified nurses alone, in Scotland midwives were included in the total number of qualified nurses. Statistics on registered nurses show an increase in the number of registered nurses (England) and in the number of registered nurses and midwives (Scotland). There were larger increases in headcount and WTE of nurses in England (Appendix 5.1, Figure 5), compared to Scotland (Appendix 5.1, Figure 6). For example, headcount and WTE increased by 28% and 25% respectively in England, compared to increases of 9% and 11% respectively in Scotland over 10 year periods.

Medical staffing in paediatric specialty

A report by the Royal College of Paediatrics and Child Health (2006) highlighted reductions in the number of academic paediatricians for three consecutive censuses, and also expressed concern for the slowing of the annual growth rate for Consultants from 7.3% (between 2001 and 2003) to 4.0% (between 2003 and 2005). Also reported were declines in the number of staff and Associate Specialist grades, an increase in Trust Doctors and an increase in the number of nurses in the SHO (1st on-call) since the 2003 census. A recent report by the Royal College of Obstetrics and Gynaecology and the Royal College of Paediatrics and Child Health (2008) showed that good progress had been made towards ensuring compliance towards the EWTD for Junior Doctors, but not for Consultants. Also, to comply with the EWTD, many units had chosen to increase their medical staff and redesign their rotas.

Recruitment and retention difficulties

Vacancy rates

The number and proportion of unfilled vacancies, and the subsequent use of agency and bank staff (especially within the nursing profession) are considered as indicators of recruitment and retention difficulties. Appendix 5.1, Figure 7 shows qualified nurses' vacancy rates in England between 2003 and 2007. There were generally decreasing vacancy rates for qualified nurses in England, both at the national level and for all the Government Office Regions (GORs). Regional differences show that the highest vacancy rates were in London while the lowest vacancy rates were recorded in the West Midlands. The average vacancy rates for Paediatric Nurses in England

were also falling within the same period, although there were less clear regional patterns (Appendix 5.1, Figure 8). Again, the highest Paediatric Nurse vacancy rates were recorded in the London GOR, while the West Midlands recorded the lowest rates.

Statistics for qualified nurses' vacancy rates in Scotland covered the period from 2001 to 2007. These rates have been decreasing since 2005, following increases between 2003 and 2005 (Appendix 5.1, Figure 9).

Competition within and outwith the NHS

Doctors and nurses operate within very different labour markets. There are differences in scope, for example, for movement between careers (nursing occupation to alternative non-nursing employment) and within the profession (changing specialty and/or location of employment). There is evidence that doctors operate in a national labour market while nurses operate in local (regional) labour markets. This suggests that the effect of competition on the demand for nurses would be greater as nurses tend to be significantly more responsive to local labour market differences in pay between the NHS and the private sector (Elliott *et al*, 2005). There are regional differences in the level of competition for medical and non-medical staff, with greater competition, especially for nurses (due to greater presence of the private health care sector, other occupations and other local NHS labour markets) in London and the South East regions. National pay scales also mean that trusts operating in the context of a tight labour market (where there are more jobs than suitable employees) relative to other trusts are not always able to adjust pay accordingly, although *Agenda for Change* (Department of Health, 2004d) has provision for trusts to be able to apply recruitment and retention premia to the national pay scales.

Other labour market factors

Recruitment from abroad

In this sub-section, we look at trends in recruitment of training-grade doctors from abroad and the proportion of females within these grades. Data from 2000 to 2005 (Appendix 5.1, Figure 10) show an increase in the number of Registrars (working for the NHS in England) who qualified from outside the European Economic Area (EEA), as well as a corresponding decrease in the number of those who qualified in the UK and the EEA. Similar comparisons were made between House Officers qualifying from outside the UK and EEA and those who qualified from the UK (Appendix 5.1, Figure 11). These trends point to potential problems of sustainability, especially since recent changes in immigration rules have led to restrictions to recruitment of doctors from abroad.

Proportion of females

There was an increase in the proportion of female House Officers and those in Foundation Year 1 over the period 1995 to 2005 (Appendix 5.1, Figure 12). Females may be more likely to work part-time, and may be more likely to take career breaks for family reasons. Therefore such an increasing trend in the female workforce may have implications for the planning for doctor

numbers. The divergence of WTE from HC may make planning future numbers of WTE less reliable as will the higher potential of career breaks.

Summary and conclusions

The labour market that the NHS operates in is not static. Over the last decade there has been significant investment into the NHS and a number of policy initiatives affecting both the medical and nursing professions. The general increase of resources into the NHS has seen a general trend of increasing staff in the nursing and medical professions. At the same time, external effects such as the new European Working Time directive and internal structural changes to the medical training programme have also affected the staffing resource available to the NHS and have impacted on all specialities including paediatrics. Many of these new initiatives are still to be fully reflected in national statistics, and the full impact of the new initiatives will still take time to work their way through the system.

It is also clear that there are many different influences on the amount of staffing resource available to the NHS and the net effect of these is difficult to predict as we move forward into the future. For instance, changes in the gender balance of medical staff increases the uncertainty of both labour market participation and the number of hours that are supplied by any individual. For nursing staff, there is the added uncertainty of their relationship with the private sector and alternative professions. Working conditions, including pay, in relation to the private sector and indeed competing nursing positions can impact on their participation in their particular nursing labour market.

The sustainability of any model of staffing relies on the availability of the correct and skilled staffing groups. That is the case on average, but if there are differences across regions in the influences on staffing, as we have previously highlighted, this suggests that there may not be one sustainable model for all areas of the UK.

2.2.2 PICU staff views on their work context, staffing and professional roles

The aim of this second section was to explore, through interviews, staff experiences and views about their work context, professional roles in the PICU care team, human resource management issues, local recruitment retention and training and views relating to extended nursing roles. This qualitative part of the study used semi-structured interviews with staff in the stratified sample of PICUs arising from the census (six with higher extended nursing tasks (higher), and six with few or no extended nursing tasks (lower)).

Methods

Sampling

Eleven of the 12 units agreed to a site visit and staff interviews. The researcher (NS) was blind to whether the unit was in the higher or lower extended nursing role group at site visits. A sample of clinicians was drawn from all the health care professionals employed in each PICU. The sampling approach purposively aimed for diversity in gender, discipline, experience and responsibilities. Medical and nursing personnel at different levels of seniority were selected in each unit. The aim was to interview the Clinical Lead/Director, Nurse Manager, one Staff Nurse (Band 5/6) and one Junior/Middle-Grade Doctor (Senior House Officer or Registrar). Some appointments with senior staff were made before the site visit by the researcher, whereas junior staff were approached during the site visit. All staff invited to interview took part. In total 21 nurses and 21 doctors were interviewed between October 2006 and July 2007. The characteristics of those interviewed are shown in Table 20.

Table 20. Staff interviewed at 11 units

Extended nursing role	Profession	Total	Characteristics
Lower (5 units)	Clinical Lead/Directors	4*	Gender: 3 male, 1 female Ages: 35 -54 Time in current PICU: 1-10+ yrs Time in current post: < 1 – 10+ yrs Time in PIC altogether: 6 - 10+ yrs Specialties: 2 Paediatrics, 1 Anaesthesia, 1 Anaesthesia/Intensive Care
	Nurse Managers	4*	Gender: 2 male, 2 female Ages: 25 – 44 Time in current PICU: 1 – 10 yrs Time in current post: < 1 – 5 yrs Time in PIC altogether: 6 – 10+ yrs
	Staff Nurses	5	Gender: 1 male, 4 female Ages: 25 - 54 Time in current PICU: < 1 – 10+ yrs Time in current post: < 1 – 10 yrs Time in PIC altogether: < 1 – 10+ yrs 3 'Band 5/Grade E', 1 'Band 6', 1 'Band 7'
	SHO/Registrars	5	Gender: 3 male, 2 female Ages: 25-44 Time in current PICU: all < 1 yr Time in current post: < 1 – 5 yrs Time in PIC altogether: < 1 – 10 yrs Specialties: 4 Paediatrics, 1 Anaesthetics
Higher (6 units)	Clinical Lead/Directors	6	Gender: 4 male, 2 female Ages: 35-55+ Time in current PICU: 1 -10+ yrs. Time in current post: < 1 – 10+ yrs Time in PIC altogether: all 10+ yrs Specialties: 3 Anaesthesia, 2 Paediatrics, 1 Paediatrics/Anaesthesia
	Nurse Managers	6	Gender: 1 male, 5 female Ages: 35-54 Time in current PICU: 6 -10+ yrs Time in current post: 1-10+ yrs Time in PIC altogether: all 10+ yrs
	Staff Nurses	6	Gender: 1 male, 5 female Ages: <25 – 44 Time in current PICU: < 1 -10 yrs Time in current post: < 1 yr – 10 yrs Time in PIC altogether: < 1 – 10+ yrs 5 'Band 5', 1 'Band 6'
	SHO/Registrars	6	Gender: 4 male, 2 female Ages: 25-44 Time in current PICU: all < 1 yr Time in current post: < 1 – 5 yrs Time in PIC altogether: < 1 – 5 yrs Specialties: 4 Paediatrics, 1 Paediatrics/Neonatal, 1 Anaesthesia

* Two of the units had one Nurse Manager and Clinical Lead/Director common to both units.

Conduct of interviews and analysis

Individual face-to-face interviews were conducted in a private room in or near the PICU. The interviews followed a topic guide (Appendix 5.2) that had been developed by the researcher (NS) after consultation with the investigators, clinicians and the advisory group. Topics included the main challenges faced by the unit, the workforce and planned changes or future role development. It also included: staffing issues and human resource management, team working, existing extended nursing roles and the perceived advantages and disadvantages of those roles. The interviewer invited and probed any other issues raised by the interviewees.

The interviews lasted between 40 and 90 minutes and were audio-recorded with consent. They were transcribed verbatim and managed in NUDIST (QSR N6). Analysis was undertaken using a framework approach. This involves a pragmatic approach to qualitative analysis for policy research (Richie & Spence, 1994). Charting and sorting of material according to key issues and themes was undertaken and developed into a framework. Members of the team (NS, EP, JT, LM, DS, ED) read the transcripts individually and verified the emerging themes. The framework analysis was circulated throughout the team, comments received, and these comments used for further interrogation of the data. In the final iteration, mapping and interpretation was undertaken. Findings and themes arising from the transcripts of interviews in units with lower extended nursing tasks were considered and compared along the key dimensions to those in the higher group. Any new issues arising solely from the higher group were noted.

Consent

Participants had read the information sheet and were well-informed about the study before participation. Written consent was obtained from volunteers.

Anonymity and confidentiality

Assurances of anonymity and confidentiality were given to participants before data collection. Narrative quotes are commonly used in qualitative research reports to give readers an insight into the data and demonstrate credible links between these and the interpretation. Participants were assured that, although they might be able to identify themselves from quotes in reports or publications, neither their name nor any other uniquely identifiable characteristic would be used. The names and contact details of the participants were stored electronically and password protected. The data were managed in accordance with the Data Protection Act (1998). All audio recordings were transferred onto a compatible computer software package and then erased from the recorder. These data were password protected and access was limited to the researchers and the transcriber.

Findings

Three over-arching themes emerged. The first concerns the way staff characterise their work context: aspects and challenges of working in paediatric intensive care and their PICU in particular. The second is about how staff work together: professional roles, interactions, teamwork and communication. The third is about relative professional roles: extended nursing practice, the interfaces between professional groups and professional boundaries. All the main features of working in PICU arising from interviews in units with lower extended nursing roles also appear in accounts from staff working in the units with higher extended nursing roles. However, some differences and new issues did arise in the higher extended nursing role group, and these are highlighted in the findings throughout. The main findings and themes arising are summarised in Figure 7.

Figure 7. Outline of main findings and themes

- | |
|---|
| <ol style="list-style-type: none"> 1. Context- how PICU staff describe and explain their workplace <ul style="list-style-type: none"> ▪ what PICUs do ▪ PICU types and casemix ▪ workforce and staffing establishments ▪ shift staffing and skillmix ▪ recent NHS workforce and training policies ▪ HR management – PICU management, hospital HR management ▪ Regional management 2. How staff work together <ul style="list-style-type: none"> ▪ team work and communication ▪ professional roles and teamwork 3. Relative roles and professional boundaries <ul style="list-style-type: none"> ▪ professional boundaries and relative roles ▪ definitions of extended nursing roles ▪ nurse extended role practice in respiratory support tasks in lower/higher units ▪ lower units and culture of the unit ▪ higher units and professional development, new ways of working, education and training ▪ role blurring ▪ benefits of and barriers to extended nursing roles ▪ comparing extended nursing roles in PICU with neonatal and adult intensive care settings |
|---|

1. Context - How PICU staff describe and explain their workplace

What PICUs do

Staff in their interviews described how paediatric intensive care units provide highly technical life-support interventions for very sick children. They emphasised that working in an intensive care setting they are already

specialist, to the extent that they are working in an environment that requires not only knowledge and understanding of the technology, but also child/family health nursing.

One other characteristic of PICU noted by nurse interviewees in units in the higher extended nursing role category was the emotional demands made on staff of working with children who were critically ill and their families.

...Go through very sad periods on the ward....although I'm a very hardened ICU nurse, typical of my breed, I'd say that's still an extremely difficult part of working here.

(Band 6 Nurse, Higher)

And, describing potential burn-out in senior nurses:

You're the most senior member of staff, here you go, ... you always look after the patients that are the sickest, and then when they get well, somebody else has them, and you go on to the next sickest patient ... I rarely discharge anybody to the ward.

(Band 5 Nurse, Higher)

The impression given is of a very focused, technology-dependent and emotionally demanding environment reliant on highly specialised professionals dealing with life-threatening conditions on a continual basis. Variation is limited as all patients are very sick.

PICU types and casemix

The interview data suggest that PICUs are not all the same. There is variation in throughput and casemix between units. Some staff described having more trauma admissions than other chronic complex conditions requiring respiratory support, or further differentiation of sub-specialty surgery, e.g. cardiac, hepatic or neurosurgery. These differences in casemix appear to impact on staff experience of working in PICUs in two ways. First, some staff in the lower group units reported continually having to respond to unpredictable peaks and troughs of emergency admissions, whereas others have more planned admissions for elective surgery, or more children with chronic long-term conditions. Staff in the higher group described similar fluctuating demand, but those with substantial elective caseloads in the higher group (sub-specialty surgical) further emphasised their struggle to avoid cancelling planned elective admissions when faced with high demand from emergencies. Second and to deal with fluctuating demand, senior clinical managers in all units highlighted PICU bed management systems and networking with other PICUs in their region to find appropriate places. They also described working hard with paediatric wards and other

units to free up ICU beds by discharging children judged suitable, e.g. back to hospitals nearer their homes, or calling on staff to work extra shifts.

Workforce and staffing establishments

In the same way that there was variation in casemix and activity between units, there was also continual variation in workforce availability and staffing provision. However, senior staff in all but one unit noted recent improvement in that they had attained and maintained the nursing establishments required by PICS standards at the time of the interviews.

We've hit easier times ...we couldn't recruit and retain, and we were running with vacancies all the time. And that changed when we had the NHS recession, when Trusts were going bust and laying people off, and that has changed.

(Clinical Lead/Director, Lower)

Within the last year, we've changed a lot within our intensive care unit, we're now up to full complement of nursing staff, which is fantastic.

(Nurse Manager, Lower)

Nevertheless, most also described continual churn and pressure of nursing staff turnover (often from younger but recently skilled-up staff leaving to take up new posts or work abroad) but also due to maternity and long term sick leave. There was pressure to avoid using agency or bank nurses wherever possible, although metropolitan units reported greater pressures and the use of bank nurses more frequently.

Recruitment will remain... the biggest problem that we have. It's a young workforce in ITU, they do end up settling down and having families, therefore can work part-time or travelling the world...and this experience that they have in [place] will take them anywhere else in the world.

(Nurse Manager, Lower)

Every year you expect some people to leave, and maternity obviously is a huge consumption of your staff as well, and ... the [other hospital] have advertised for a [senior skilled] nursing post ... that would be a concern, an opposition unit, you know, for staff.

(Nurse Manager, Lower)

Shift staffing and skillmix

Maintaining skills balance for each shift was evident in reports of both medical and nurse shift staffing provision. Both doctors and nurses described ensuring two-tiered provision was in place for their staff. More

junior staff work alongside more senior practitioners with longer experience, and are also allocated patients or tasks within competencies. One Clinical Lead/Director (lower) explains a medical 'two-tier' system:

Because we have the national grid trainees, we're able to run a two-tier rota. So we run an upper tier and a lower tier ...we always have one on the upper tier present ...someone who has done some intensive care, usually done some anaesthetics as well. So we are able to skill mix the Junior Doctors' rota....we always have one that's more senior.

(Clinical Lead/Director, Lower)

Similarly, most units had a core of more senior experienced nurses who had worked in the unit for many years. Thus, a less experienced nurse will be allocated a patient in the bed next to a patient being cared for by a more senior experienced nurse, allowing supervision and advice. Maintaining adequate staffing levels of bedside nurses appears to be a perennial problem across all units, although many units (both higher and lower) emphasised a much greater problem during winter months when bed occupancy is higher.

Recent NHS workforce and training policies

Recent NHS workforce and training policies were never referred to in a positive light. It was suggested that *Agenda for Change* caused unrest for experienced nurses at re-grading. It was perceived as limiting opportunities for future promotions and creating inequality in acute settings compared with community posts.

But the perception of our nurses is that Agenda for Change short-changed them...we lost a whole pile of very good nurses to the community, because the community seemed to be better graded. So they could get the same money without the unsocial hours. Agenda for Change was bad for morale on our unit.

(Clinical Lead/Director, Lower)

As far as promotion and development of nursing goes... and this is where Agenda for Change, I think, sadly ...we may have outpriced ourselves at Band 7....I think that that top tier will go... Band 6, which are considered our junior sisters, will be as far as they go in the management structure on a ward.

(Nurse Manager, Lower)

I'm desperate to finish my degree, but there's no time, or funding...yet if I worked in the community... It's like... they take the lion's share of all the money for training and there's very little that gets through to areas like this.

(Band 6 Nurse, Higher)

Many units are recruiting newly qualified nurses who must then be trained up to work independently at the bedside. This means that, in many units, the pool of nursing staff now has a lower level of skills than in previous years. The onus is now on units to provide increased levels of training for junior nurses in order to address this potential skills shortfall.

One manager describes the training programme for newly qualified nurses:

There aren't very many people well enough qualified to come in up and running in PICU. And that's a national thing...We have had an education program for our new starters ... a rotation program running through Critical Care ...

(Nurse Manager, Lower)

Even though the recruitment pool has been widened in this way, some managers report difficulties in 'finding the right sort of person for PICU' (Nurse Manager, Higher). Others find difficulties in educating and training nurses who have been recruited; a few of the units do not have educators in post. The skill-mix on the units can become diluted, as there is a 'big influx of newly qualified staff who need training' (Nurse Manager, Higher). Where there are no nurse educators, there were added pressures on senior nursing staff:

Well, we don't have educators at the moment, that's the problem. Which means that there is inherent stresses on the senior nursing staff, because there are less able staff, or less skilled staff in the skill mix.

(Clinical Lead/Director, Higher)

Medical Directors were uncertain about the sustainability of providing medical cover. They described a service that was progressively Consultant-delivered, not just Consultant-led. Training-level medical staff rotate through PICU at regular intervals and the recent changes arising from MMC had yet to bed down and make their impact felt. It was uncertain for example whether Middle-Grade Doctors in national grid training posts linked to paediatrics rather than the PIC sub-specialty would continue, although paediatric (and anaesthetist) trainee doctors, both destined to work in wider non-PIC settings, reported PIC training as important for them to be able to effectively stabilise and manage acute paediatric emergencies they might meet in future. There was no mention of the new PEM (paediatric emergency medicine) as part of emergency medicine specialty training.

[Doctors] aren't going to get exposure to intensive care anymore, which, some would say, well, they don't need it, but to have experience in care of the acutely ill, very acutely, severely ill child is very important.

(Clinical Lead/Director, Lower)

Both new nurses and in-coming medical trainees were perceived by senior staff in both higher and lower units to be less skilled than before. Academic training as opposed to clinical apprenticeship was suggested as a cause of the initial skills shortfall. Senior nurses spoke of 'growing their own' PIC specialist nurses in-house from new starters. The new MMC training pathways and European Working Time Directive raised concerns from senior doctors (who themselves had trained for more years and for longer hours) about skills levels of new doctors, and whether this cohort of medical trainees would accrue the requisite expertise with more limited exposure time and less frequent experience of procedures and cases. Although this was a problem across the board, the issue was highlighted more in interviews with staff from lower units:

*Junior Doctors are more and more junior as time's gone past.
(Clinical Lead/Director, Lower)*

*They do less hours, therefore they're less experienced, they're more frightened, they're less capable...
(Clinical Lead/Director, Lower)*

*I think we've responded to the fact they get more junior and we've had to up induction, we've had to... partly because of the increased busyness of the unit, partly because of the increased dependency of the patients, the increased complexity of the patients. And partly because the Junior Doctors are getting more junior...the Consultants have responded by being around more.
(Clinical Lead/Director, Lower)*

HR Management - PICU management, Hospital HR management, Regional management

Senior staff in both types of units discussed their unit's contribution and function (and sometimes competition) for skilled staff. Financial constraints were often noted as the main barrier, not just to progress further professional development of the nursing staff (by paying for backfill during nurse release for courses), but also just to stand still and sustain current nursing establishments. Different clinical areas within hospitals were noted to be effectively in competition for limited resources for retaining staff posts.

*Every time somebody leaves [PICU] - we have to go to operations board to justify why we need to recruit back to that post.
(Nurse Manager, Lower)*

Human Resources (HR departments at hospital level) were not seen as providing any strategic management or support role (particularly in the lower group units), but rather undertook the administrative tasks of the recruitment process which was judged bureaucratic and slow. Structural changes to HR departments across boundaries or a deficit of leadership in HR departments could be seen to impede local recruitment.

HR fill in forms and sort out your packs etc but actually sitting there and fighting your corner?

(Nurse Manager, Lower)

They do [recruit for us], but they are not really good. They are an impediment to us.

(Clinical Lead/Director, Lower)

Human Resources has gone from just being within this hospital [to covering a group of hospitals] just made it a more laborious and convoluted practice.

(Clinical Lead/Director, Higher)

[HR]...don't have a good reputation in this particular hospital...they're slow and inefficient.

(Clinical Lead/Director, Higher)

Senior staff talked about PICU management being self-sufficient to some extent dealing with HR management at unit-level, and most effort was on fire-fighting the challenges in recruitment, retention and training. Strategic planning appeared difficult, particularly in units in the lower extended role group.

I'd say our HR is our Matron.

(Clinical Lead/Director, Lower)

Units in the higher extended roles group experienced the same difficulties outlined above, but they reported some initiatives to tackle the nurse staffing issues and support staff wellbeing, both within the unit and also by harnessing wider hospital HR expertise. Examples of the types of HR initiatives that were only reported in the higher group are shown in Figure 8.

Figure 8. Human Resources management initiatives in units with higher extended roles

- a strategic decision to recruit above the nurse establishment standard to allow a margin for maternity and sick leave and so avoid the winter bed crisis (Clinical Lead/Director, Higher)
- Hospital Human Resource management back-up for managing staff who were frequently reporting in sick (Nurse Manager, Higher)
- self-rostering for nursing staff, to allow choice of shifts (Nurse Manager, Higher)
- breaking up a very large establishment to form nursing teams..(with relatively small group numbers) ... *'so people feel less overwhelmed'* and also to ensure mentoring, assessment and annual formal annual career progression addressed (Nurse Manager, Higher)
- flexible working for nurses with family commitments (Nurse Manager, Higher)
- a new and more responsive Hospital HR retention section and advisor in the hospital (Nurse Manager, Higher)
- offers of secondments or *'year-out and return'* to retain staff (Nurse Manager, Higher)
- shared hospital HR recruitment to intensive care nursing with colleagues from neonatal, cardiac, neurosurgery, and adult IC settings (Nurse Manager, Higher)

Compared with one of five units in the lower group, five of the six units in the higher group reported planned, major changes for their units in the next 2 to 5 years. These included new builds, reconfiguration of PICU provision, increasing bed number, or adding high dependency units. As management they were already scoping the implications for staffing.

A new unit... there is also a certain unsettling aspect to that. And I know we're going to lose some staff when we move...to my surprise, but if you live out [place] it's the other side of the city, some people may go and work at [other unit], rather than cross to get to the brand new, sort of shining unit.

(Clinical Lead/Director, Higher)

These findings suggest that the units categorised as having higher extended nursing roles in respiratory support tasks in this study also appeared to

demonstrate more proactive HR practice in a context of forthcoming service changes and development.

2. How staff work together

Teamwork and communication

Despite the challenges of an intensive care setting, and the problems with staffing and training noted thus far, nearly all the interviewees in both higher and lower units were positive about the good teamwork, good communication and supportive environment of working with colleagues in their PICU. There was respect between the medical and nursing professionals. There is evidence of considerable professional pride in the distinctive features of nursing and medical practice and also evidence of high mutual regard in the reported close teamwork in most units, whether higher or lower.

This unit really impresses me and I think that one of the nicest things I like about the unit is that the nurses and doctors do work as a team here.

(Middle-Grade Doctor, Lower)

Registrars, SHOs joining the unit, nurses take them to heart as well, so I think it's a very very close-knit unit. It's a very strong and dynamic team.

(Nurse Manager, Lower)

We've always had good teamwork within [named unit]. It's good communication links, the Consultants work well and information's fed up and information's fed down.

(Nurse Manager, Higher)

All the staff are... really are supportive... if you've got any problems, you will be listened to and a solution will be found...it is a good unit to work on.

(Band 5 Nurse, Higher)

Professional roles and teamwork

Nurses tended to clearly articulate their role in terms of their one-to-one bedside nursing, their direct care and their views on relative professional roles and new tasks. Nurses described their responsibility for the technical monitoring, recording and understanding the importance of observations throughout shifts. They were clear about their goals in holistic care and achieving optimal outcomes for the child. They communicated concerns to doctors and were invited and expected to contribute their views of the child's condition at ward round. These were perceived by nurses as highly

valued contributions and incorporated in decision-making. Nurses described having insights about children's progress from being at their bedside, e.g. a "feeling" whether a child was not ready for weaning from the ventilator irrespective of favourable blood gas measures.

Because the doctors are looking after the entire unit and also patients elsewhere...as the bedside nurse...you get to know that patient very well, and that can give you sort of inside knowledge ...[on] the progress for a patient, whether it be that you need to slow down a bit or speed up, say, when you're weaning ventilation.

(Band 5 Nurse, Higher)

Communication with patients and their families is also of central importance in all units. Whereas doctors also communicate information to relatives, this is generally seen as one of the key functions, and strengths, of a nurse. The nurse, in particular, performs the role of explaining details and ensuring the family become partners in the care process:

And I think that's an important part of what nurses do, and it is actually making sure that the family are involved with care ... and become part of the process of the care.

(Nurse Manager, Lower)

Any of the doctors do speak to the families, the Consultants would tend to do sort of any major updates, whereas a nurse is kind of there, you'll be kind of explaining things, and what drugs are...

(Band 6 Nurse, Lower)

Nurses are seen by several units (higher and lower) as having an important role as a patient advocate. One staff nurse from a higher unit explains:

As a nurse...you're supposed to be aware of how your patient's feeling and your family's feeling...psychosocially as well as physically, because if they're frightened, that changes the whole thing. And so I think it's very important for the nurse to stick up for their patient when they can't speak for themselves. Or for the families...

(Band 5 Nurse, Higher)

Doctors' comments on nurses showed clear appreciation of the high levels of clinical expertise of experienced nurses, and the dedication of nursing staff when occupancy and events were pressing, although in these circumstances they wanted more doctors too.

I think the nurses stretch themselves beyond endurance, I mean, they did, they're so hard-working and they just do so much... But because, again, it's so busy, we could do with some more doctors, really.

(Middle-Grade Doctor, Higher)

Doctors described their direct care role in dealing with medically unstable patients and emergencies, instigating investigations and recording results, undertaking interpretation of test results, diagnosis, considering treatment options and prescribing treatment and care. Nurses' comments on doctors noted that whereas they (nurses) were dedicated to one patient, doctors had responsibility for the safety of all those on the unit and in all lower units that final decisions rested with doctors. Clearly doctors are directly accountable for clinical governance in the quality of their service and for formally ensuring high standards of clinical care are attained. This contractual reality of medical accountability was acknowledged in the accounts of both medical and nurse interviewees.

The nurses have only one, one patient....then the doctors are making the major decisions, chasing up blood results and sorting scans....they can have 10 patients and they have a huge role to...work out what's going on everywhere and making sure everyone's safe, every 10 patients.

(Band 5 Nurse, Lower)

Doctors still need to be aware [of any procedure or change]...because they're ultimately...they'll take the fall for anything that is going on in the unit.

(Band 6 Nurse, Lower)

Only some units had Junior Doctors below middle-grade medical trainee level. These Junior Doctors appeared less forthcoming about their role compared to nurses, and noted their limitations and aspirations.

...chase up outstanding investigation results, instigated new investigations, organised prescriptions and make assessments.

(Junior Doctor, Lower)

If children become unwell there's always at least a Registrar and often the Consultant to go to for advice.

(Junior Doctor, Lower)

Would like more of a chance to be supervised in doing the more difficult, advanced or risky things. Which is what I'm, like, wanting to learn...

(Junior Doctor, Lower)

Several nurses, in both higher and lower units, said that trainee doctors are dependent for guidance on nursing staff. One staff nurse said:

Most of the medical staff tend to... realise that the nurses have had a lot of experience, probably do know a little bit more about PICU than they do, and they tend to respect that. I think it's a two-way street, you know, as long as we respect that doctors put the hours in and the work, yeah, we get along fine.

(Band 5 Nurse, Lower)

On at least one unit (lower), nurses act as mentors to incoming Registrars, as one nurse described:

They [Registrars]'ll ask about stuff... because obviously every unit has slightly different policies, protocols. So, all the doctors when they first start have a nurse mentor.

(Band 6 Nurse, Lower)

Relative roles and professional boundaries

As well as the mutual regard between professions and enthusiastic reports of good teamwork and workplace reported above, some conflicting views within the team also became apparent. First there were reports of some lack of cohesion and perceived potential inequality within the nursing team in relation to the possible introduction of advanced nursing roles in lower units. This was confirmed by those higher units that had introduced ANPs.

We had a meeting when we were talking about advanced nurse practitioners. And some people are interested in doing that role, others aren't. But...are they seen as 'higher-up', you know, than a ward sister, for example? And I think it can, potentially, produce a little bit of conflict and competition in the [nursing] team.

(Nurse Manager, Lower)

We've got ANPs. It's been difficult – they're still not accepted by a heck of a lot of nursing staff in the place as being kosher.

(Clinical Lead/Director, Higher)

I think advanced nurse practitioner is just a very different role to nursing, [don't] expect them to sort of interchange between the two roles. I do think you have to handle with caution, because I think you're in danger of upsetting existing nursing staff, [and] upsetting the people you've trained...by not being careful.

(Clinical Lead/Director, Higher)

Second, there were comments indicating some friction between professional groups in the care team in both higher and lower units. This was at both the interface between nurses and Junior Doctors and between unqualified Health Care Assistants (HCAs)/clinical support workers and nurses. Between nursing staff and medical staff, there were comments suggesting that nurses may exert their longer experience and power in relation to each new cohort of Junior Doctors. Trainee doctors themselves observed that in units with large numbers of nursing staff, many working part-time, it takes a long time to even meet all the nurses and this hinders abilities to 'gel' as a team.

There are usually tensions when...the Junior Doctors join. They're doctors, and they feel they should be able to lead...But nurses have seen a lot, know a lot about intensive care. There's usually a clash between the two until things settle down.
(Clinical Lead/Director, Lower)

I've always been teaching them [doctors] as well as student nurses...Though I think some nurses are bothered...I feel like it's a responsibility for nurses now to not really be mean to them, because I think it's a tendency, I think we can be.
(Band 6 Nurse, Higher)

As an SHO...we have nurses who are specialised...we change every six months, they stay at the unit many years, and they are much more skilled than us. They tend to boss over us.
(Junior Doctor, Higher)

Trainees find it intimidating and there's always a bunch of nurses that have been doing it a long time that are going to make it very difficult for trainees. We don't do too well with that. But I think most places don't do too well with that...
(Clinical Lead/Director, Higher)

In a few lower units clinical support workers/HCAs had an extended role, with reported benefits of increasing staffed beds available. But this had met opposition from qualified nurses.

CL/D: So, my opinion of the clinical support workers... if you've got the right person in the job, they are brilliant. Double up on level 1 beds an extra pair of hands. It was [Nurse Manager] who championed it, and championed it against a lot of resistance from bedside nurses on the unit.

Interviewer: Why do you think that was?

CL/D: Taking their jobs. Agenda for Change was bad for morale on our unit.
(Clinical Lead/Director, Lower)

Other staff voiced some concern.

I've concerns about an unregistered group of practitioners practicing.

(Nurse Manager, Lower)

I was a bit shocked when... I mean, there was a couple of patients who were really quite sick, ventilated patients, who were being... I don't know if this happens on other units or... but their nurse for the day, as it were, was an HCA.

(Junior Doctor, Lower)

Similarly units in the higher group varied in the extent to which they had implemented extended roles for HCAs and support staff. Staff in higher units also had widely different opinions about the benefit of extending unqualified roles that might include direct patient care. A few reported enthusiastically about HCAs already trained, e.g. giving patients personal care, leading parents to take over some of the child's care around time of discharge and looking after high dependency patients. Other staff were supportive of such roles in theory and if supervised, although it was not undertaken in their units. Finally some staff, both doctors and nurses, remained sceptical.

We've got two Critical Care Practitioners, who are NVQ level 3 trained, and they take patients. They just take HDU patients; they don't take any ITU patients. I think if you choose the right person and give them the right training and the right support, then they're really good.

(Nurse Manager, Higher)

Our HCAs, well, they are very valuable... to assist the trained nurse, but in no way can they replace them. It takes 3 years to train a nurse and another 6 months to a year to train a PICU nurse. And an HCA by no means replaces that. But, everybody's looking for the cheap option...until something goes wrong; then it costs us a lot of money.

(Clinical Lead/Director, Higher)

I don't think, without further training, I don't think really they should be doing anything [in direct care], in my opinion.

(Band 5 Nurse, Higher)

Definitions of extended nursing roles

All staff were asked how they might define extended nursing roles. It should be noted that technically 'extension' refers to nurses taking on new clinical tasks, whereas 'expansion' or 'advanced nursing' refers to a role that may include leadership, management, education, and research, as well as expert clinical skills (Srivastava *et al*, 2008). Some of these roles may be formally designated as Advanced Nursing Practitioners (ANPs) or Nurse Consultant. However, some interviewees used the terms 'extended', 'expanded' and 'advanced' interchangeably. It was also unclear if some staff used these terms informally in relation to experienced or senior nurses who had accrued expert clinical skills or additional areas of responsibility over time, or whether they applied them only to nurses who had moved into a new, defined and designated role.

Definitions varied widely, but interviewees described extended roles based on five different elements:

- doing extra tasks
- skills and competencies
- expanding professional role development
- patient-centred care
- unit requirements

Extended roles based on tasks

Mostly lower units defined extended/advanced nursing in terms of taking on new and extra tasks:

Shared tasks, tasks which can be easily performed.

(Clinical Lead/Director, Lower)

Our team, nursing team here are very proactive in things like gas sampling, interpretation of blood results, all the bits and pieces that go along, like cannulation, IV therapy. We have to go to the next step and look at what advanced nurse practitioners are going to be able to do.

(Nurse Manager, Lower)

Extended roles based on skills and competencies

Some clinical managers believed extended nursing should be given a competency-based definition: indeed, the best person for the job should do it, whether a doctor or a nurse. Notably, staff from higher units predominantly held this view:

I mean, basically for us it's about competence; and, to me, I don't even think 'doctor', 'nurse', I just think competence.

(Nurse Manager, Higher)

It's very much about the best person to do the job...working inside of legal and professional guidelines.

(Nurse Manager, Higher)

Another manager stressed the role of training to achieve the required competencies, although she feels a PICU nurse already takes on more decision-making in care than a general nurse:

The PICU nursing role is quite proactive in having a significant decision-making input to the sort of patient process in terms of their clinical care. But I think the extended role goes over and above that, usually in fairly well-defined areas. So that, one could define competencies, give appropriate training.

(Clinical Lead/Director, Higher)

Some nurses implied that extended nursing was not just competence on tasks but about having higher skills, perhaps suggesting critical thinking or synthesis:

Not just what we do with our hands as our role. I think it's just as much about how you think and how you approach things.

(Band 6 Nurse, Higher)

Expansion based on professional role development

Others (in both higher and lower units) use a definition of an expansion of role, rather than 'adding on' specific tasks:

Roles that traditionally haven't been done by the nursing profession.

(Nurse Manager, Lower)

Roles that were traditionally those of a doctor.

(Junior Doctor, Lower)

Expanding our role outside those roles which have been included in our training.

(Nurse Band 7, Higher)

One manager was particularly clear about how he saw the advanced nursing role in substitution for medics:

A nurse who can work more like a medic. So, go out – like the neonatal nurses, nurse practitioners – go out and do retrievals with another nurse, so they function as a medic, able to make management decisions, within certain guidelines and protocols, make changes on the ventilator, modify the drugs, drug doses, things like that. But currently the Registrars... somebody who can function at around a Registrar level.

(Clinical Lead/Director, Lower)

Extended role based on a patient-focus

Some staff (higher and lower units) felt an extended or advanced nursing role should be, above all, for the primary benefit of the patient:

That which the nursing profession identifies will allow the patient to have a more either comprehensive or satisfying journey through their illness.

(Nurse Manager, Lower)

Taking more responsibility for patients, for care and treatment.

(Middle-Grade Doctor, Higher)

Extended role based on unit requirements

Unit managers from two units, both higher, commented that the development of nursing roles was in response to the specific needs of that unit, for example, occupancy rates and casemix:

No one definition - depends on a unit's needs at the time.

(Clinical Lead/Director, Higher)

Workforce establishment issues could be dealt with by introducing extended or advanced nursing roles, for example, clinical expert cover at difficult times:

[Nurses could be] supporting the medical rota to a certain extent.

(Nurse Manager, Higher)

Extended nursing roles in respiratory support tasks in lower and higher units

Lower units

All the interviewees in units grouped as lower nurse extended roles by our criteria noted that they had no designated Advanced Nursing Practitioners and no Nurse Consultants. Senior management nurses in the lower group could take on a number of roles including clinical expert practice or an education and training function. Interviewees noted that the extended respiratory support tasks identified by the study were not autonomously decided upon by their nurses (at least not officially) although nurses clearly did contribute significantly to team decision-making and team-working to do these tasks.

Weaning is usually a medical decision. We called it collaborative weaning but it's... for some patients it's nurse-led weaning. For some patients it's a bit of doctor, a bit of nurse, a bit of doctor, a bit of nurse... if the bedside nurse isn't a weaner, the doctor will do it in its entirety.

(Clinical Lead/ Director, Lower)

Senior girls ...or whoever will be busy twiddling knobs and making it so, but officially, they're not allowed to change ventilator settings unless it's part of the weaning programme, unless it's a weaning process. But they do, yeah.

(Clinical Lead/ Director, Lower)

Now, I say that [doctors decide ventilator settings] slightly cautiously because I'm sure that sometimes, many cases the doctors are led by the nurses, you know particularly senior nurses and Junior Doctors.

(Clinical Lead/Director, Lower)

The culture of the unit

In discussing nursing roles in the lower units, some noted that the culture of the unit had not previously supported modernising nursing careers, or that there had been previous initiatives by key senior nursing staff advocating and demonstrating extended tasks but that those leading nurses had left. It is clear that a conservative hospital environment or the loss of clinically expert and innovative nursing staff can jeopardise nursing practice development. Some of the units in the lower group of units did aspire to further extending qualified nursing roles, but leadership and commitment appeared equivocal and future plans clearly uncertain as shown in the quotes in Figure 9.

Figure 9. Quotes from staff in lower units that suggest equivocal attitudes to extended nursing roles

[Hospital] hasn't necessarily led with management initiatives, and modernising nursing careers.

(Clinical Lead/Director, Lower)

The management of the unit had built up a superb unit, but a unit which I felt didn't empower nurses.

(Clinical Lead/Director, Lower)

Had some nurses before doing BAL, cannulation + blood gases and respiratory support but they've moved on now.

(Clinical Lead/Director, Lower)

...Historically doctors, SHOs had to do it because it was a learning progression for them...nurses didn't do it...But now nurses are going to start doing it now because of the working time directive and with less doctors... And from that will come weaning ventilation. But I think initially with them [nurses] taking the blood gases and interpreting them.

(Nurse Manager, Lower)

...That [advanced/extended roles] wasn't high on anybody's agenda, because they were focussing on the fact that they were losing staff. If we take this role forward, then we have to do it as a multi-disciplinary PICU team.... We have a steering group now...

(Nurse Manager, Lower)

I don't see at this moment in time, the support for big whole scale changes. And that's not that I'm averse to them, actually, because as I tried to say... there is scope for changing the way nurses approach patients, except that I just think that, I mean, ultimately it's for the future, isn't it?

(Clinical Lead/Director, Lower)

I think the whole career pathway for extended nursing roles is not properly sorted out.

(Clinical Lead/Director, Lower)

Clinical Leads also noted that nurse-led protocolised extended tasks are only appropriate for a particular casemix (for example, nurse-led weaning post-surgery where 'nurses act almost like recovery nurses' (Clinical Lead/Director, Higher) and this is different from collaborative weaning for complex respiratory cases).

A routine post-op patient [with] no other problems, the nursing staff would probably be able to manage them pretty much on their own, and just go through a protocol-driven kind of formula.
(Middle-Grade Doctor, Lower)

Higher units

All six units in the higher group had previously reported that their nurses undertook five or more of six specified extended respiratory support tasks (Phase 1). Of these six units, three had designated advanced posts of Consultant Nurse or ANPs, although one Consultant Nurse post was unfilled at time of interview, and a handful of ANPs in total were in post. Senior Nurse Managers and Clinical Lead/Directors interviewed in the higher group units were consistently positive about the culture of their unit to empower nurses (within competence and regulations) and enthusiastic about extended and advanced nursing roles. There was also more frequent reporting of nurses undertaking advanced roles of leadership, professional development and education, change management, research and quality evaluation in the higher units that were intended to support service change. Some interviewees in this group thought many of the specified respiratory support tasks were not extended tasks but expected competencies in PICU. Notably however, nurses undertaking the extended respiratory support tasks also continued to do so as medically prescribed and instructed in the higher units.

PICU nursing role is quite pro-active in having a significant decision-making input.

(Clinical Lead/Director, Higher)

Well, I believe...that the role here is quite extended already... they feel they've got license to do things to the patients in their care... not everything, but... it probably empowers them, and it's quite time-saving [not waiting for doctors].

(Clinical Lead/Director, Higher)

I think the difficulty for - and it's particularly difficult for...the Registrar grade - is that the nurses are so empowered...it's a perennial complaint here that it's difficult for the medical staff to fit in this niche between quite an active nursing cohort and ...Consultants who want things run a certain way.

(Clinical Lead/Director, Higher)

Because we do not have a Junior Doctor, it's all middle-grade - the nurses have to take on more.

(Middle-Grade Doctor, Higher)

We [nurses] already do quite a lot in terms of non-invasive ventilation, which I think, that probably needs to be formalised a little bit more ...nurses actually making decisions about pressures.

(Band 6 Nurse, Higher)

Some senior doctors in higher units saw ANPs and nurse extended tasks as a straight substitute for trainee doctors, who, because of MMC 'could no longer deliver the quality of care we achieved by Registrars a few years ago.' The senior doctors of these units, if not unsympathetic to trainee doctors, were champions of fostering the required skills in a permanent staff tier as direct support for the Consultants, thus:

ANP's another profession - no longer a nurse and I want more ...
(Clinical Lead/Director, Higher)

Like if there were ANPs already cooked out there, and there was money, we would employ them now.
(Clinical Lead/Director, Higher)

The advantages [of ANPs]...to me as a Consultant, I think, is that I - 24x7 - will have hands, eyes, and a voice on the ward that...so that I know whether I've sort of got to run and get back or whether actually everything's under control. It's a question of having someone you trust on the ward.
(Clinical Lead/Director, Higher)

But in addition to undertaking expert delivery of clinical tasks, ANPs and Consultant Nurses were also reported as leaders in practice development and educators for nurses (and doctors) and so were spanning professional boundaries:

One of the ANPs has set a course that people have to go through to alter the ventilator – weaning ventilation – [although] probably the minority of nurses would do that now.
(Clinical Lead/Director, Higher)

ANPs aren't just surrogate doctors, but looking at developing [nursing and medical] practice across the whole unit...and enabling and empowering staff to do more.
(Nurse Manager, Higher)

I have two (nurse) teacher practitioners, who do a lot of education for junior medical staff. And it's just because we're

such a big team, and you've got to have well-educated staff to deliver quality staff. At the end of the day, that's what it's all about.

(Nurse Manager, Higher)

Whereas junior medical staff rotates, the ANPs ...develop practice, clinical practice, not just nursing practice, but clinical practice, within the unit, across the multi-professional team.

(Nurse Manager, Higher)

Professional development and new ways of working

Nurse starters' skills at entry to all PICUs have already been described and were judged to be lower now, but new starters after orientation do undertake supervised practice and are no longer supernumerary at virtually all units. It was also noted that in general:

Nurses' roles have generally extended over the last 10 years – nurses much more involved in ward rounds and actively contribute information and opinions about treatment plans

(Nurse Manager, Lower)

Role blurring

There was frequent mention of "blurring of roles" between doctors and nurses in interviews of staff from units with lower extended roles. There was no simple substitution. Blurring here means overlapping roles, where a task might be undertaken by either a doctor or a nurse, depending on who had the competency and the other competing demands on the unit. Blurring might mean there is no longer a clear definition of who does what procedure in the team. Blurring of roles was used as a positive attribute of interdisciplinary team working. At other times blurring of role boundaries was described but with the caveat that the underpinning traditional professional models remained intact. Finally blurring was used to mean a potential weakening or diminishing of basic nursing care as nurses took on extended tasks previously within the remit of the doctors. Each of these is presented below.

Blurring roles – a positive force in team working

I think you can't do this kind of a job unless you have a proper team, and respect, mutual respect ...you know...another unit I worked in was very much into extended roles of nurses, they used to talk about role blurring, and, you know, I think all those things are very important.

(Middle-Grade Doctor, Lower)

I think, you know, the boundaries that we have with our medical team are slightly blurred. And I think that makes for the team dynamics that are so good at the moment.

(Band 6 Nurse, Lower)

Blurring boundaries but maintaining traditional roles

So I think the margins are blurred, but if you didn't have the line, there's a... doctor prescribing role, nurse doing role, which isn't that different from the traditional one.

(Clinical Lead/Director, Lower)

Here's a list of tasks [extended nursing tasks]. Well, that's fine, but actually, medicine is much more than just doing tasks, it's about making assessments and being able to act on those assessments, and that's where the difficulty might come.

Because presumably there is a difference between a doctor and a nurse, no matter how much we try to blur those edges.

(Clinical Lead/Director, Lower)

One of the disadvantages [of extended roles] are there are different professions. Nurses aren't doctors and doctors aren't nurses. The ethos and philosophy is very different...I don't think we can replace the other.

(Nurse Manager, Higher)

Blurring - diluting of basic nursing care

A number of nurses raised concerns about losing their focus on nursing care in undertaking extended roles. One nurse described this as blurring of their profession.

But I think, yeah, just, are we blurring our profession too much, you know...That's probably the danger, that we move so far away from basic nursing care that we forget about the things that really matter.

(Nurse Manager, Lower)

These good and bad descriptions of role blurring in NHS care team working are not new. They may be considered in relation to the theoretical analysis of Rushmer (2005). She argues that "effective inter-disciplinary working" is not role blurring. It may include a sub-set of agreed shared skills and competencies and allow overlapping on those tasks, whilst still maintaining and respecting the overall separate skills set and boundaries of each professional. She emphasises however, that "blurred role" boundaries may threaten good team-work and effective inter-disciplinary working. This is because clear parameters about the shared tasks and maintained

boundaries have not been wholly agreed or not made explicit between professionals. Potential negative consequences of such theoretically defined "role blurring" threaten relationships between team members due to role ambiguity, stress and anxiety, and possibly feelings of being unprepared, inadequate or resentful.

Benefits of and barriers to extended nursing roles

Some respondents were very positive about the benefits of extended roles. Staff in one or two of the lower units already reported realised benefits of extended roles for HCAs and clinical assistants already undertaken, and saw potential for future extended qualified nursing roles. The main benefits envisaged were that advanced roles and extended tasks undertaken by nurses would improve patient care. Examples of tasks undertaken by nurses included cannulation, ventilation control, weaning, removing chest drains, all, it was envisaged, could be done *'without having to wait on a doctor who is looking after a whole side...'* (Nurse Grade 5, Lower). Further positive benefits anticipated and beliefs were:

- that the role would fit the context
- that it offered career progression for highly skilled and clinically experienced nurses in direct clinical care roles as opposed to management roles
- that any changes would maintain quality and be of benefit to patients
- that it would support Consultants who wanted a permanent staff tier with expert skills in clinical tasks
- that it would be cost effective and efficient
- that it would increase the capacity of the unit.

The main barriers noted to extended nursing roles were primarily financial with no funding for backfill during nurse training. In the lower units, there was also real concern about what exactly the extended nursing roles were and whether extended or advanced roles meant becoming divorced from basic nursing care to become a 'mini-doctor vs. maxi-nurse.' It was acknowledged that one way of overcoming the shortage of doctors, due to newly limited medical working time and their lower accrued skills, could be by task substitution by nurses, but only for the most Junior Doctors. Some senior staff were enthusiastic in principle and indicated an intention to future development of extended roles, whereas others were more sceptical and uncertain of whether they would work, be sustainable and be of benefit. Thus from staff interviews a long list of uncertainties arose about how extended and advanced roles might work. These included:

- A. Uncertainties about defining the extended roles, tasks and skill base
 - a need to more clearly define the role
 - whether sufficient nurses want to undertake extended and autonomous roles
- B. Uncertainties about the impact and effect of extended nursing roles in substitution for doctors
 - the perceived inadequacy and limitations of protocolised practice undertaken by nurses as a replacement for doctors
 - whether it is sustainable
 - whether it is cost effective
- C. Uncertainties about training, regulation and career pathways and pay
 - whether existing nurse training courses are fit for purpose (and could it be done in-house?)
 - the career pathway and pay associated with new nursing roles
 - the lack of regulation by NMC for a legal framework for the new roles and the hierarchical nursing management structures for practice
 - the limitations on nurse prescribing
- D. Uncertainties about professional identities, professional demarcation and role conflict
 - whether the care team will accept nurses with new mini-doctor roles and tasks undertaken
 - whether nurses are concerned about loss of the core ethos of nursing by undertaking more clinical and invasive tasks
 - whether the dilemma of further reducing access to skills training for Junior Doctors can be overcome to support medical succession
 - despite devolving some tasks, doctors maintained their ownership and responsibility in the traditional role of assessment, diagnosis and care management decision-making
 - despite devolving some tasks to clinical assistants or health care assistants, nurses maintained their ownership and responsibility for the traditional nursing role

Comparing extended nursing roles in PICU with neonatal and adult intensive care settings

Only doctors drew on their experiences of observing alternative extended and advanced nursing roles from their times working in neonatal and adult IC settings.

My experience is slightly coloured by my experience with anaesthetic nurses in the States, whereby they're seen as... a cheaper, better, more efficient option. But you get less hours out of a nurse than you get out of a doctor ...you may have an ANP, but there's always going to be somebody [medical practitioner] backing them up. So... how it all works and the finances therefore I have to be convinced about.

(Middle-Grade Doctor, Lower)

There were different opinions about advanced nursing contributions and their limitations. One suggestion was that in adult intensive care, the nurses already just got on with extended respiratory support tasks and didn't see them as extended or additional tasks. The experiences of the advanced neonatal nurse practitioner were generally described positively as circumscribed working within protocols (for example, to retrieve ventilated and already stabilised babies), or with admiration for their expert-level skills (e.g. in siting long lines). But salutary tales were also put forward to demonstrate where the ANP skills were not sufficiently developed in assessment, selection of alternative procedures or interventions to avoid a poor outcome that might be judged to have been avoidable.

Summary and conclusions

Staff in hospitals with lower extended nursing roles described how their existing collaborative care team worked together very well, although some friction between staff groups (Junior Doctors and nurses in particular) was mentioned. Some units had already introduced extended roles, but for HCAs or clinical support staff, to ease the pressure on their qualified nurse staffing. This new role had met some resistance from qualified nurses.

Experienced senior nurses were reported by some of these interviewees to make a significant contribution to collaborative weaning and could undertake the procedures we had identified as extended respiratory support tasks, but not autonomously, and notably - not officially.

Some described potential benefits of extended nurse roles, but there remained differences in intention and commitment to introduce extended nurse roles in the future. There were many reasons given for not implementing extended or advanced roles. These included the culture of the unit, difficulties of funding and training, inequality for nursing staff, loss of skills training opportunities for future doctors, sustainability in the nurse staff establishment, dilution of the traditional nurse role, etc. Individuals in one unit could have widely different opinions about the likely impact of extended nurse roles, both on staff and patients, and misgivings could be articulated by either nurses or doctors.

Staff from PICUs in the higher extended tasks group raised similar issues to those arising from interviews in lower units: good collaborative team-working, some evidence of friction between professional groups, more autonomous protocolised care for nurses, but ultimately a similar adherence to the traditional medical prescribing and nurse performing roles. Higher units clearly had not approached saturation in trained nurses with the extended respiratory tasks, and the extent to which they had introduced advanced nursing roles in substitution was patchy. Higher units, however, did appear to differ in terms of the culture of their unit in empowering nursing staff. Their clinical leaders were consistently enthusiastic and keen to obtain further staff with extended and advanced nursing roles, although they highlighted the scarce availability of such highly-skilled staff in the workforce. Furthermore, managers and staff at these units were more likely to report responsive HRM initiatives aimed to support and develop staff in line with contingency HRM theory. These managers believed it would sustain delivery of high quality care, develop practice for both nurses and doctors across the whole unit and enable and empower staff to do more.

Staff interview findings are compared between study units with lower or higher extended nursing roles in Table 21. This summary comparison highlights the main factors arising from the staff interviews, as those driving or hindering changes in staffing configurations and wider adoption of extended or advanced nursing roles.

These findings can be considered alongside the structural comparisons between the two types of units from the analysis of unit profile, staffing establishments and census data (see Section 2.1.1, p 13).

Our findings showed all PICUs faced similar difficulties to acquire and maintain the right skillmix in their clinical team, but widely divergent views around definitions of extended nursing practice, and varying views on the desirability or feasibility of implementation of extended roles in local contexts. There is some evidence that, so far, no PICUs have attained 'saturation' with enough trained and competent staff in extended nursing roles to ensure significant impact or be sustainable. There were some different patterns of skillmix in the staff establishments emerging from higher and lower units, but it remains patchy.

Table 21. Comparing key characteristics of lower/higher units

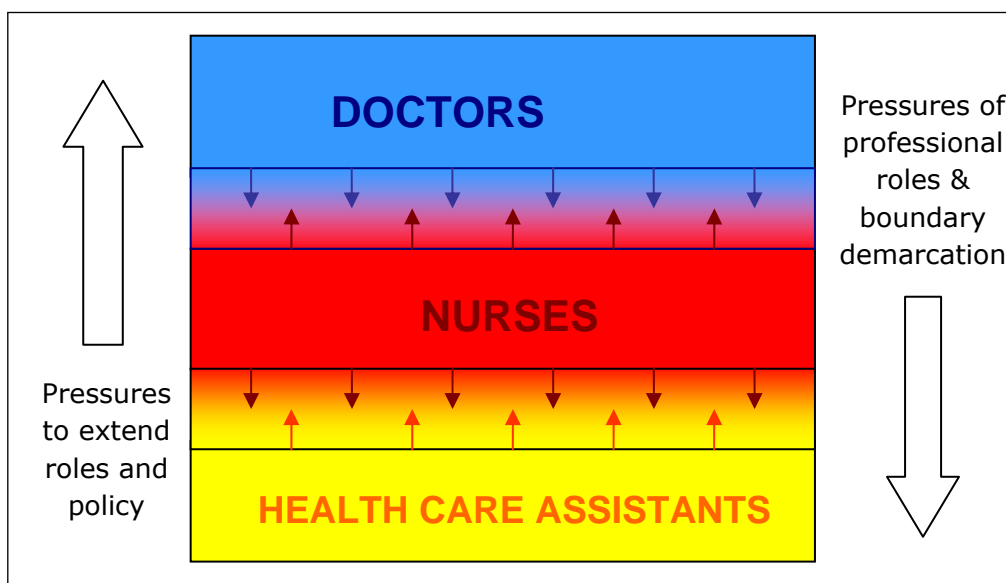
Characteristic	Lower (5)	Higher (6)
Anticipated forthcoming structural change (new units etc)	few	Anticipated in all but one unit
Census self-reported array of nurse extended respiratory support tasks	Consistently low nursing extended tasks (<2)	Consistently high nursing extended tasks (>5)
Advanced nursing roles	None	A few
Extended use of HCAs	Some	Some
<i>Contextual factors</i>	Improved	Improved
Recruitment & retention Nurse staffing establishment	Achieved PICS standard (still churn in retention)	Achieved PICS standard (still churn in retention)
Degree of nurse-led innovation and empowerment	Low	High
Workforce policies (<i>Agenda for Change</i> and MMC and European working time)	Negatively viewed created unrest and uncertainty about sustainable medical cover	Negatively viewed created unrest and uncertainty about sustainable medical cover
Human resources management	Inertia/passive	Pro-active/initiatives
<i>Organisational functioning</i> Teamwork	Good, flat structures with nurse participation for care decision-making Collaborative working	Good, flat structures with nurse participation for care decision-making More devolved working - giving responsibility to nurses
	Clinical governance - still doctors	Clinical governance still doctors
Communication	good	good
Education and training	Mixed – some had no educators	Good in all but one, often multidisciplinary
Professional interfaces	Some conflict	Some conflict
Doctor/ nurse roles and boundaries	More (formal) adherence to clear traditional roles/ demarcation.	Less adherence to demarcation
	Defence of professional boundaries	Defence of professional boundaries
Degree of support and nurse-led empowerment of nurses	low	high
Intention and leadership to innovate new staffing models	low	high
Nurse/ unqualified assistant boundary	Nurses defend qualified nurse boundary	Nurses defend qualified nurse boundary

Implications for policy and practice

For policy and practice, one striking feature of the findings is the continuing uncertainty and controversy related to professional role demarcation. There is pressure to re-organise the division of labour and tasks within the PICU as in other health care settings. In this already technical IC setting, the pressure is to further up-skill personnel to enable them to undertake new extended roles and tasks previously outwith their remit. One approach is to devolve tasks that are closely prescribed, supervised and protocolised and are a part-substitution for ever-scarcer professional staff in the clinical hierarchy. Thus HCAs may undertake tasks previously within the remit of nurses, and nurses may undertake clinical skills tasks previously within the remit of doctors. At the same time many staff restated the need to maintain and support the unique professional identities of doctors and nurses. There was evidence of downward resistance to define and limit the extent of encroachment at professionally-defined boundaries.

This is summarised below in Figure 10, where the blurred boundaries between HCAs and nurses and between nurses and doctors is represented in the graded boundary areas. Workforce imperatives may exert upward pressure to develop extended roles (upward arrows). And although some tasks may be devolved (from doctors to nurses, or from nurses to HCAs), there is also evidence of strong adherence to core professional roles in both doctors and nurses in order to limit substitution only at the boundaries and restate professional role demarcation (downward arrows).

Figure 10. Conflicting pressures at the boundaries between professional groups



The differences between extended roles in task substitution and advanced roles to support professional development and high quality care should be clearly distinguished. The lack of recognition of defined extended and advanced roles by the professional councils in relation to scope of practice is clearly a major barrier. Similarly, a nationally-agreed skillset for extended practice that is recognised between units would support the nurse workforce skills development and wider expert workforce sustainability and avoid local demarcations that currently vary widely.

This comparison has highlighted the main factors arising from the staff interviews as those driving or hindering changes in staffing configurations and wider adoption of extended or advanced nursing roles. These findings should be considered alongside the structural comparisons between the two types of units from the analysis of unit profile, staffing establishments and census data (see Section 2.1.1, p 13).

For policy-makers, the findings suggest that units are seeking local solutions to local workforce conditions. There is a continuing uncertainty and controversy related to effective inter-disciplinary working with agreed overlap vs potentially negative effects of role blurring that creates role ambiguity and resentment within the care team and erosion of professional role demarcation, questions about capacity and sustainability of specialist experienced nurses to fully take on the new extended roles, and the potential unforeseen consequence of further limiting specialty medical training opportunities.

3 Objective 3: Staff direct care time

To compare staff practice and staff groups' time spent in direct patient care between units with higher and lower levels of trained nurses in extended roles.

Background

Adomat (2001; Adomat & Grech, 1998) reported observation and analysis of nursing activity in relation to patient dependency in one PICU. Observation by closed circuit video of two bed spaces over a period of 90 shifts took place. The data recorded were analysed by an expert nurse panel and the following activity categories defined:

1. Nursing interventions
2. Observing the patient
3. Preparing for patient's admission
4. Preparing for patient's discharge
5. Talking to the patient
6. Talking to visitors at the bedside
7. Teaching students/juniors
8. Charting observations/record keeping
9. Domestic work
10. Nurse not present

Adomat used this activity tool to measure nurse time spent in direct and indirect care to inform more accurate assessment of nursing requirements, rather than using patient clinical illness severity levels or categories (Adomat & Hewison, 2004).

Methods

We used Adomat's activity categories (Appendix 6.1). Time spent on direct patient care included: (1) Nursing interventions, (2) Observing the patient, (5) Talking to the patient and (8) Charting observations/record keeping. We further distinguished between the six extended respiratory support tasks (1A) and other nursing interventions (1B) in category one. A final additional category (11) was added for nursing interventions outside the ward area, e.g. taking a child to CT scan, retrieval, resuscitation in A&E (all of which were also extended tasks; see Appendix 6.1).

Shadowing and observation

The researcher (NS), after orientation and training by an expert PICU nurse in one centre, undertook structured observation and shadowed staff to record nurse activity data during a 'typical' shift. Three to five volunteer and consenting nurses were observed at each unit. Each nurse was observed for two hours during a typical 12-hour shift at 11 of the 12 PICUs (one PICU in the lower extended nursing role group refused to participate in observational on-site activity). The researcher recorded the grade of nurse, primary diagnosis of patient and time at start of observation, and thereafter the timing and activities of the nurse. The researcher also recorded any other staff present at the bedside (Appendices 6.1 (Checklist for nursing activities classification) and 6.2 (Observation schedule)).

Shift Diary

All nursing staff on the shift when a nurse was shadowed were also invited to complete a shift diary (Appendix 6.3). This was to be completed at the end of their shift. It was a summary of their activities throughout that shift and aimed to explore their self-reported task activity breakdown. Activities were grouped in the same categories as those used in the researcher observation. Doctors were not invited to complete shift diaries.

Results

Shadowing and observation

Table 22 shows the number and grades of nurses observed at each site. Of 46 nurses observed (21 lower and 25 higher), most were shadowed during the day, but at least one observation per unit was undertaken during a night shift. Overall around two thirds of observations were during day shifts and the remainder during night shifts in both higher and lower units. Primary diagnoses for the patients of the observed nurses varied widely and included: infection, respiratory, neurological, trauma, cardio-vascular, hepatic, gastro-intestinal, or congenital abnormality diagnoses. All but five patients required some respiratory support. Of those without respiratory support, four were in higher units and one in lower.

Observation data were entered directly into SPSS with multiple records per nurse observed, each record represented one task and its time. Data were aggregated to describe the amount of nurse direct patient care time in each unit. Direct care time was further divided into non-extended and extended role tasks. Nurse direct care time estimates and extended tasks direct care time (minutes, % time) were calculated for each unit and compared between unit type (lower vs. higher extended nursing roles), including and excluding nurse break time (Tables 23 and 24 respectively). Comparison between unit types was adjusted for within unit-level variation.

Table 22. Number and grades of nurses observed at each site.

Unit	Number of observed nurses	Observed nurses band
Lower extended roles		
1	4	5/6
4	5	5
6	4	5/7
7	4	5
10	4	5/6
Higher extended roles		
2	4	5
3	4	5/6
5	3	5
8	6	5
11	4	5/6
12	4	5

Total direct nursing care time between the two groups of units.

Table 23 shows that in the lower extended roles group, from a total of 2585 minutes that nurses were observed, 1734 minutes (67.1%) were spent providing direct care. In the higher extended roles group, from a total of 2996 minutes, 2139 (71.4%) were spent providing direct care. Adjusting for variation by unit level, this represents a non-significant difference in the odds of a nurse being in direct care between the two groups of 1.22 (95% CI 0.65 to 2.3, $p = 0.528$).

Table 24 shows that in the lower extended roles group, excluding breaks and from a total of 2471 minutes that nurses were observed, 1734 minutes (70.2%) were spent providing direct care. In the higher extended roles group, from a total of 2928 minutes, 2139 (73.1%) were spent providing direct care. Adjusting for variation by unit level, this represents a non-significant difference in the odds of a nurse being in direct care between the two groups of 1.15 (95% CI 0.65 to 2.05, $p = 0.629$).

Figure 11 summarises findings for total nurse direct care time by higher and lower extended role groups, and Figure 12 for each unit within group. Figure 12 shows wide variation of estimates of total nurse direct care time within and between units in both groups.

Total time on extended and non extended tasks between the two groups of units

Table 23 shows that in the lower extended roles group, from a total of 2585 minutes that nurses were observed, 75 minutes (2.9%) were spent providing direct extended care. In the higher extended roles group, from a total of 2996 minutes, 62 (2.1%) were spent providing direct extended care. Adjusting for variation by unit level, this represents a non-significant

difference in the odds of nurse time spent in providing direct extended care between the two groups of 0.71 (95% CI 0.37 to 1.37, $p = 0.304$).

Table 24 shows that in the lower extended roles group, excluding breaks and from a total of 2471 minutes that nurses were observed, 75 minutes (3.0%) were spent providing direct extended care. In the higher extended roles group, from a total of 2928 minutes, 62 (2.1%) were spent providing direct extended care. Adjusting for variation by unit level, this represents a non-significant difference in the odds of a nurse providing direct extended care between the two groups of 0.69 (95% CI 0.36 to 1.32, $p = 0.262$).

Figure 13 summarises the findings for total nurse direct care time on extended tasks by higher and lower groups, and by each unit within group. Figure 14 shows wide variation of estimates of total nurse direct care time on extended tasks within and between units in both groups.

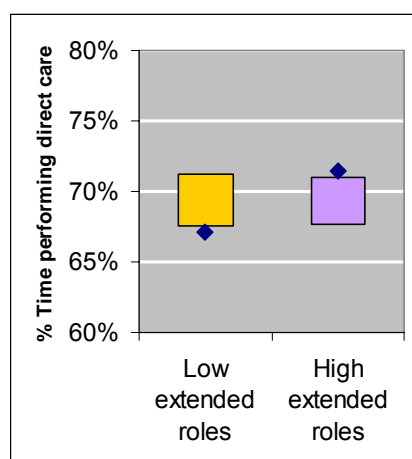
Table 23. Nurse time (minutes) and % of total nurse time spent providing direct (non-extended and extended) care and non-direct care

PICU	Direct Care			Non-Direct Care	Break	Total
	Non Extended	Extended	Total			
Lower extended roles						
1	364 (75.8%)	14 (2.9%)	378 (78.8%)	102 (21.3%)	0 (0%)	480 (100%)
4	365 (56.8%)	21 (3.3%)	386 (60.0%)	162 (25.2%)	95 (14.8%)	643 (100%)
6	294 (57.1%)	9 (1.7%)	303 (58.8%)	193 (37.5%)	19 (3.7%)	515 (100%)
7	381 (81.4%)	21 (4.5%)	402 (85.9%)	66 (14.1%)	0 (0%)	468 (100%)
10	255 (53.2%)	10 (2.1%)	265 (55.3%)	214 (44.7%)	0 (0.0%)	479 (100%)
Total	1659 (64.2%)	75 (2.9%)	1734 (67.1%)	737 (28.5%)	114 (4.4%)	2585 (100%)
Higher extended roles						
2	365 (78.7%)	18 (3.9%)	383 (82.5%)	81 (17.5%)	0 (0%)	464 (100%)
3	366 (76.3%)	9 (1.9%)	375 (78.1%)	105 (21.9%)	0 (0%)	480 (100%)
5	247 (68.8%)	10 (2.8%)	257 (71.6%)	102 (28.4%)	0 (0%)	359 (100%)
8	509 (74.4%)	22 (3.2%)	531 (77.6%)	153 (22.4%)	0 (0%)	684 (100%)
11	275 (54.3%)	0 (0%)	275 (54.3%)	186 (36.8%)	45 (8.9%)	506 (100%)
12	315 (62.6%)	3 (0.6%)	318 (63.2%)	162 (32.2%)	23 (4.6%)	503 (100%)
Total	2077 (69.3%)	62 (2.1%)	2139 (71.4%)	789 (26.3%)	68 (2.3%)	2996 (100%)

Table 24. Nurse time (minutes) and % of total nurse time spent providing direct (non-extended and extended) care and non-direct care (excluding break time)

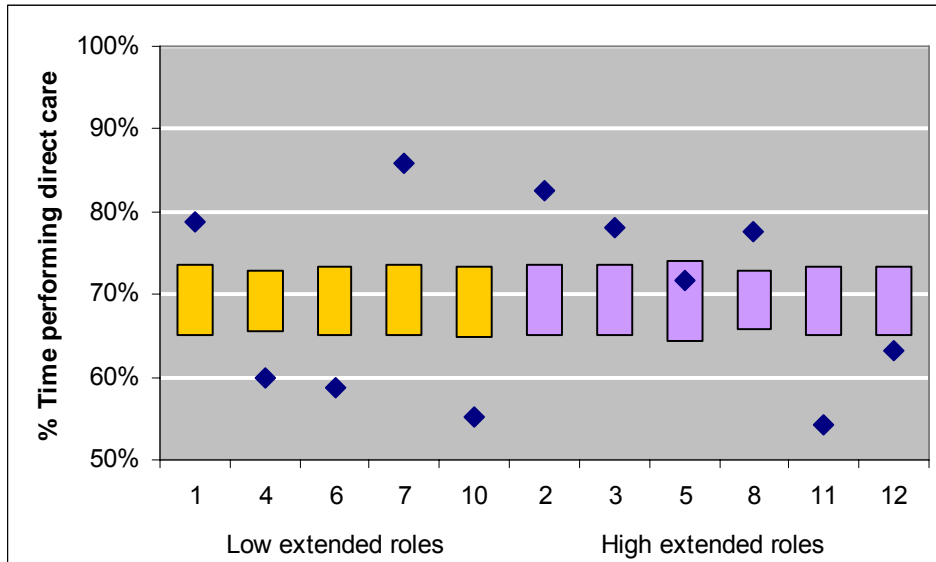
PICU	Direct Care			Non Direct Care	Total
	Non Extended	Extended	Total		
Lower extended roles					
1	364 (75.8%)	14 (2.9%)	378 (78.8%)	102 (21.3%)	480 (100%)
4	365 (66.6%)	21 (3.8%)	386 (70.4%)	162 (29.6%)	548 (100%)
6	294 (59.3%)	9 (1.8%)	303 (61.1%)	193 (38.9%)	496 (100%)
7	381 (81.4%)	21 (4.5%)	402 (85.9%)	66 (14.1%)	468 (100%)
10	255 (53.2%)	10 (2.1%)	265 (55.3%)	214 (44.7%)	479 (100%)
Total	1659 (67.1%)	75 (3%)	1734 (70.2%)	737 (29.8%)	2471 (100%)
Higher extended roles					
2	365 (78.7%)	18 (3.9%)	383 (82.5%)	81 (17.5%)	464 (100%)
3	366 (76.3%)	9 (1.9%)	375 (78.1%)	105 (21.9%)	480 (100%)
5	247 (68.8%)	10 (2.8%)	257 (71.6%)	102 (28.4%)	359 (100%)
8	509 (74.4%)	22 (3.2%)	531 (77.6%)	153 (22.4%)	684 (100%)
11	275 (59.7%)	0 (0%)	275 (59.7%)	186 (40.3%)	461 (100%)
12	315 (65.6%)	3 (0.6%)	318 (66.3%)	162 (33.8%)	480 (100%)
Total	2077 (70.9%)	62 (2.1%)	2139 (73.1%)	789 (26.9%)	2928 (100%)

Figure 11. % Nurse time performing direct care by lower/higher extended nursing group (including break time)



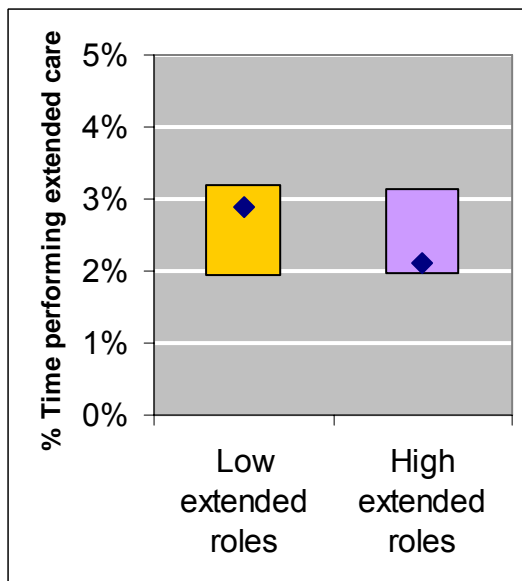
◆=observed % time, and expected variation range within unit type

Figure 12. % Nurse time performing direct care by unit by lower/higher extended nursing roles group (including break time)



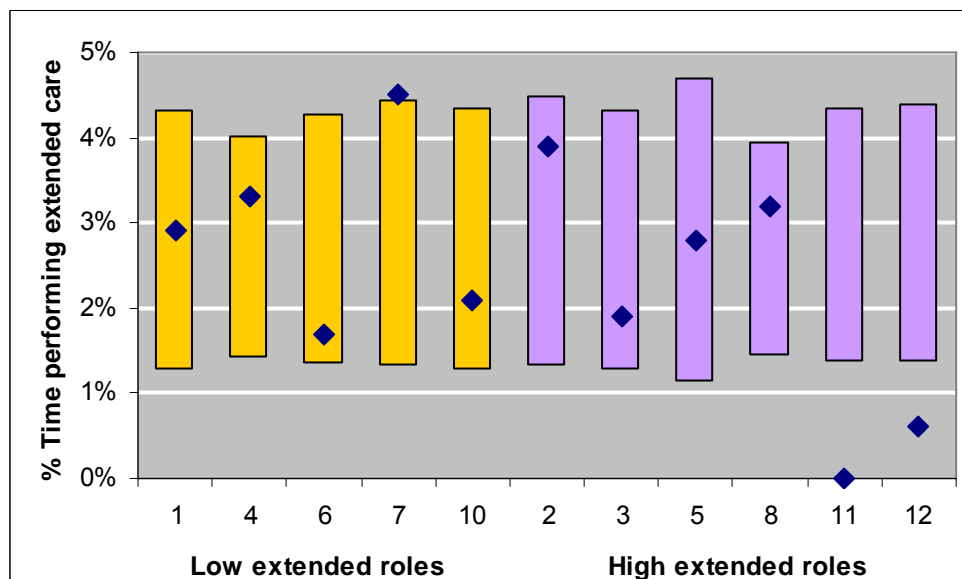
◆=observed % time, and expected variation range within unit

Figure 13. % Nurse time performing extended care by unit and by lower/higher extended nursing group (including break time)



◆=observed % time, and expected variation range within unit type

Figure 14. % Nurse time performing extended care by unit by lower/higher extended nursing group (including break time)



◆=observed % time, and expected variation range within unit

Presence of other staff groups

There were no other staff at the bedside for 74% (4138/5581 minutes) of the total observation time (68% (1759/2585 minutes) in the lower extended role group and 79% (2379/2996 minutes) in the higher extended role group). The number of staff at the bedside, in addition to the index observed nurse, is summarized in Table 25 below.

Table 25. % time by number of additional staff at bedside by lower/higher group

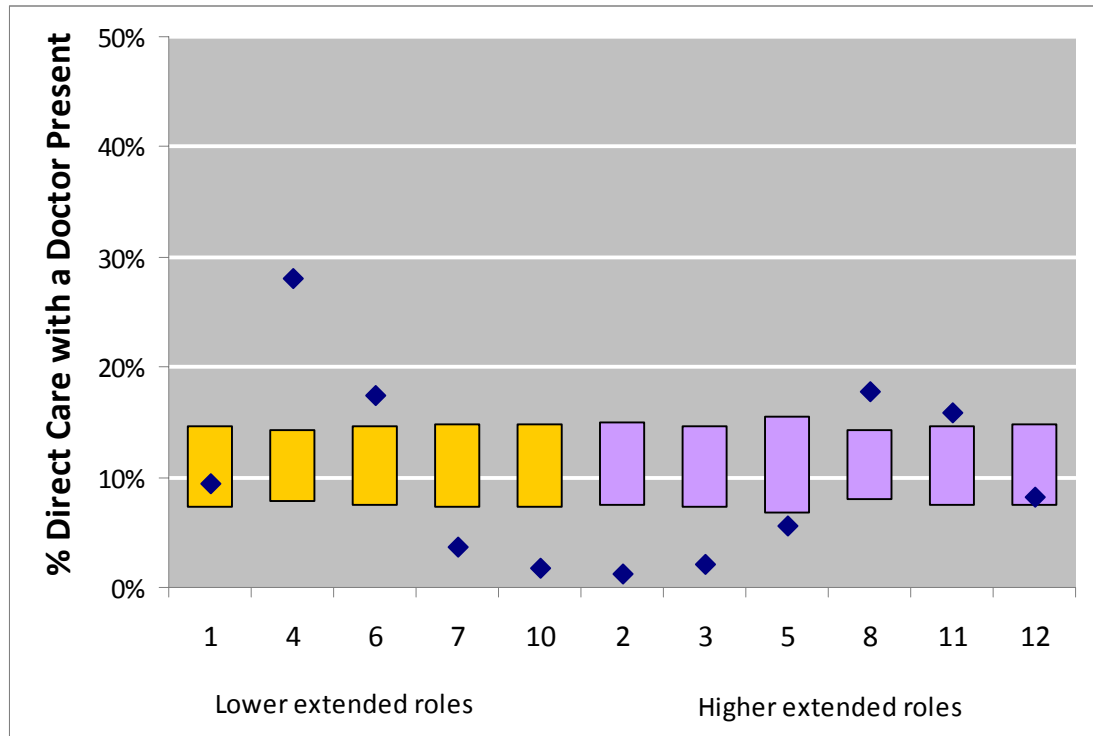
Additional staff	Lower extended roles		Higher extended roles		Total	
	minutes	% time	minutes	% time	minutes	% time
0	1759	(68%)	2379	(79%)	4138	(74%)
1	572	(22%)	509	(17%)	1081	(19%)
2	174	(8%)	98	(3%)	272	(5%)
3	32	(1%)	10	(1%)	42	(1%)
4	48	(1%)	0	(0%)	48	(1%)
Total	2585	(100%)	2996	(100%)	5581	(100%)

Overall, at least one doctor was at the bedside in addition to the nurse 11% of the time (618/5581 minutes). In the lower extended role group this was 13% of the time (340/2585 minutes), whereas in the higher extended role group it was 9% (278/2996 minutes) (Table 26). However, Figure 15 shows very wide variation of % time by doctor at bedside within and between units in both groups. Adjusting for variation at unit level, this represents a non-significant difference in the odds of a doctor being present at bedside between the two groups of units of 0.80 (95% CI 0.32-1.99).

Table 26. % time by doctor at bedside by lower/higher group

PICU	Doctor attending (minutes %)		
	No doctor	Doctor	Total minutes
Lower extended roles			
1	435 (90.6%)	45 (9.4%)	480
4	463 (72.1%)	180 (27.9%)	643
6	425 (82.5%)	90 (1.8%)	515
7	451 (96.4%)	17 (4.5%)	468
10	471 (98.3%)	8 (2.1%)	479
Total	2245 (86.8%)	340 (13.2%)	2585 (100%)
Higher extended roles			
2	458 (98.8%)	6 (1.2%)	464
3	470 (97.9%)	10 (2.1%)	480
5	339 (94.4%)	20 (5.6%)	359
8	536 (82.4%)	121 (17.6%)	684
11	426 (84.2%)	80 (15.8%)	506
12	462 (91.8%)	41 (8.2%)	503
Total	2691 (90.6%)	278 (9.4%)	2969 (100%)

Figure 15. % Doctor at bedside by units and by lower/higher extended nursing group



◆=observed % time, and expected variation range within unit

Shift Diary

Table 27 shows the numbers of shifts observed, nurses on shift to give clinical care, nurse respondents and response rates.

Table 27. Response rates (n %) for completed shift diaries by nurses by higher/lower group

Unit	shifts observed (n)	Total n nurses on observed shifts	Nurse diary Completed n	Nurse diary completed %
Lower extended roles				
1	4	82	24	29%
4	2	36	13	36%
6	2	12	5	42%
7	4	33	12	38%
9	-	-	-	-
10	4	32	18	56%
Total		(195)	(72)	(37%)
Higher extended roles				
2	4	46	23	50%
3	4	28	13	46%
5	2	15	6	40%
8	4	60	16	27%
11	4	24	13	50%
12	5	58	17	29%
Total		(231)	(88)	(38%)
Total	37	426	160	38%

Thirty-eight percent (160/426) of nurses on shift to deliver clinical care completed and returned a shift diary. Of the 160 respondents, 87% were Band 5 and 6, 10% Band 7, and 3% unqualified HCAs. Excluding HCAs, and those with wide outlier values of total activity time (total range 7% to over 500%) there were 115 remaining cases. Of those, only 61 gave estimates of percentage time for their activities that totalled 100%. The majority of the completed diary data records were internally inconsistent. Nurses wrote comments that they usually did more than one activity at any time; for example, nurses reported observing their patient for 100% of the shift when also undertaking other tasks. Some also reported that they had spent some

shift time teaching students or junior staff but could not quantify that overlap time.

Estimates of self-reported direct and indirect care time, or time on extended tasks, cannot be reliably calculated from these diary data. The low response rate and poor compliance with instructions suggests that self-reporting in a simple shift summary of work activities was not acceptable to the majority of these nurses. This finding is in line with a recent report by Ampt *et al* (2007) comparing observational and (prospective electronic) self-report work sampling of nursing tasks in a ward setting. That report suggested that self-report work sampling was poorly accepted by nursing staff. Furthermore their comparison of observational and self-report methods of data collection concluded that self-report technique was not a reliable method to obtain an accurate reflection of the work tasks undertaken by ward-based nurses.

Methodological issues arising

There are other practical and methodological concerns about observational studies to estimate direct/indirect care time of staff in these settings. Practical issues include our uncertainty about, not just the casemix or diagnostic category of the patients being cared for by the staff, but the rapidly fluctuating levels of illness severity and the nursing dependency measures of acutely ill patients.

On methodological issues, first is potential selection bias due to only volunteer nurses being observed. The second is potential bias due to the Hawthorn effect, where staff may alter their behaviour because they are being observed. It is also of note that staff in paediatric intensive care units were already sensitised to external observation in relation to future funding for specialty, as this study was being undertaken at the same time as observational work to estimate DRG costs for the DH *Payment by Results* programme.

Finally there are questions about validity or what estimates of direct care time mean. In terms of direct care time by medical team members, it has been suggested that increasing illness severity is positively associated with increased total direct care doctor time, so lack of robust measures of illness severity clearly detract from us being able to interpret or control for medical staff direct care times. Second it could be suggested that direct care time may also be a function of skill level and competence. Those who are highly skilled and expert will take less time to undertake well-practised tasks compared to those less skilled. Unknown variation in skills levels within and between nurses and doctors observed adds further uncertainty to the reliability and meaning of the findings on direct care time presented here.

Summary and conclusions

Contrary to expectation that units with higher extended nursing roles would have increased nurse direct care time, while conversely doctor direct attendance time would be reduced, these data (adjusted for variation at unit level) show:

- a non-significant difference in the odds of a nurse being in direct care in higher vs lower units (adjusted odds 1.22 (95%CI 0.65-2.3))
- a non-significant difference in the odds of a nurse being in direct extended care in higher vs lower units (adjusted odds 0.71 (95% CI 0.37-1.37))
- a non-significant difference in the lower odds of a doctor being in attendance in higher vs lower units (adjusted odds 0.80 (95%CI 0.32-1.99))

Thus, although nurses in higher units spent more (71%) of their overall time in direct care (vs 67% in lower units), and doctors were attending for less (9% of the time (higher)) vs 13% in the lower units, these differences were not significant because of wide variation in observed staff groups' direct care time between units within the higher/lower groups.

Furthermore, of only 2 to 3% of time overall spent on the extended respiratory support tasks, nurses in the higher units appeared to spend less time (2.1%) vs 2.9% in the lower units on these tasks; although again the difference was not significant because of wide variation at the unit level.

There remain significant methodological challenges to measuring NHS staff and work activities. First, there is the potential of selection bias (due to nurses observed being volunteers) and also observer bias (nurses possibly altering their practice during observation). Second, there remain questions about the validity and meaning of "direct care time". For example confounders of observed direct care time may include: rapidly deteriorating condition of patients in PICU that result in doctors attendance; or longer time spent on tasks related to lower skill-levels or competence. Finally, the self-report diary for ward-based nurses to give account of their work activities on shift appeared to be unacceptable to the majority nurses and an unreliable method.

4 Objective 4: Outcomes for patients

To test the relation between the twelve units, stratified by higher and lower extended nursing roles, on outcomes for patients. Proxy outcomes include risk-adjusted care process variables of length of stay, unplanned re-admission, and a health care associated infection (HCAI), namely ventilator-associated pneumonia (VAP) (National Institute for Health and Clinical Excellence (NICE), 2007).

4.1 Clinical outcomes for patients

Methods

Data are routinely collected by the Paediatric Intensive Care Audit Network (PICANet) (2008) for all consecutive admissions to participating UK PICUs. These data include length of stay (LOS), destination at discharge, variables for unplanned re-admission, diagnoses and diagnostic categories and PIM2 (Paediatric Index of Mortality), an adjustment tool to account for variation in illness severity in children (Slater *et al*, 2003; Brady *et al*, 2006). LOS was the primary outcome.

There were no routinely collected PICANet data relating to HCAI. We assessed probable ventilator-associated pneumonia (VAP) and collected data prospectively from participating units throughout the study period. Eligible infants were aged <12 months at admission and were invasively ventilated. Although there are a number of definitions in the literature for nosocomial pneumonia (CDC, 2003; Tablan *et al*, 2004; Langley & Bradley, 2005; Elward *et al*, 2002; NICE, 2007), we use definitions derived from CDC (Garner *et al*, 1988; CDC, 2003; Langley & Bradley, 2005). We defined probable ventilator-associated pneumonia (VAP) as *'an infection not present or incubating at the time of PICU admission, with onset after 48 hours of ICU stay. The child was required to have received at least 48 hours of mechanical and invasive ventilation and develop new and persistent radiographic evidence of focal infiltrates 48 hours or more after the initiation of mechanical ventilation. In addition, the child had to have at least one of the following signs and symptoms or laboratory test findings (a-f): a. increased production of respiratory secretions; b. new onset of purulent sputum; c. organism isolated from blood culture or single antibody titre; d. isolation of pathogen from tracheal aspirate; e. isolation of virus or viral antigen; f. histopathologic evidence of pneumonia.'*

Link study-research nurses were appointed and trained from each PICU to collect information by casenote review. Data included information from laboratory and X-ray reports. The data collection form is shown in Appendix 7.1.

We used a cross-sectional approach to explore if unit type (of higher or lower extended nursing tasks) were related to care process/outcomes.

Analysis used multiple regression methods with LOS (using a log transformation), unplanned re-admission and VAP respectively as the dependent variable. Illness severity and casemix was taken into account using PIM2 (transformed from a simple probability into a PIM2 log odds) and diagnostic categories. Destination at discharge (including death or discharge to hospice) was included as a further independent variable that could contribute to the variation observed in LOS. Random effects models, to take account of clustering within units, were used in all cases with robust standard errors calculated.

In estimating sample size, previous reports had suggested that average UK PICU length of stay can vary between units by as much as 72 hours and that the intraclass correlation coefficient (by PICU) for length of stay is 0.0167 (Chater *et al*, 2005). Assuming an average of 300 children per PICU, and assuming 80% power to detect a 24-hour difference (SD=103) between units with higher and lower extended nursing roles at 5% significance, then 12 PICUs (six higher vs six lower) will be required. This would correspond with a total sample of 3466 children. For probable ventilator-associated pneumonia (VAP), the proportion of eligible <1 year-olds consecutively admitted and developing VAP is suggested to be around 8% to 10%. An average cluster size of 150 patients (per PICU) admitted to all 12 PICUs with an overall ventilator pneumonia rate of 10%, at 80% power and 5% significance, would be sufficient to detect a difference of between 10% and 16% in one direction and 10% and 5% in another direction, assuming an intraclass correlation coefficient of 0.004 and PICUs are in two groups of six units. Due to variations in throughput of eligible children, the larger units applied a sampling ratio over the study period.

Results

A total of 6707 children were consecutively admitted to the participating 12 units in the study period. Annual throughput per PICU ranged from 301 to 1171.

Of those, 357/6690 (5.3%) died before discharge, and 6686 children had complete data to estimate length of stay in PICU.

Length of stay (LOS)

Overall, children's length of stay varied widely and the distribution was right skewed. Table 28 shows mean and median LOS by units with higher and lower extended nursing role, where the lower group appear to have slightly longer LOS (median 48.8 hours) compared with 45.1 hours for the higher group (although the IQRs are wide (21.7 to 122 and 20 to 166.8 hours respectively). Our findings of an average LOS of around 2 days is also similar to that reported by Marcin *et al* (2001) of a median length of stay of two days for 32 US PICUs.

Table 28. Mean (SE) and Median (IQR) of length of stay (LOS, in hours) by higher/lower extended nursing role

PICU type	LOS		
	N	Mean	SE
Lower	3443	109.9	3.9
Higher	3243	103.5	3.3
Total	6686	106.8	2.6
	N	Median	IQR
Lower	3443	48.8	(21.7, 122.0)
Higher	3243	45.1	(20.0, 116.8)
Total	6686	47.1	(20.8, 119.8)

Median LOS ranged between units from 29.9 to 84.8 hours (Table 29). Clearly LOS varies widely within and between units and we were concerned to take account of potentially confounding factors such as death, or the availability of step-down beds in high dependency (HDU/SCBU level) that might allow units with access to discharge earlier.

Table 29. Median (IQR) of length of stay (LOS, in hours) by unit and higher and lower extended nursing role

PICU	LOS		
	N	Median	IQR
Lower extended roles			
1	1171	50.6	(22.7, 124.3)
4	921	43.8	(19.8, 104.0)
6	337	43.3	(16.7, 137.0)
7	357	57	(22.1, 129.2)
9	312	41.5	(20.6, 96.5)
10	345	84.8	(33.2, 181.0)
Total	3443	48.8	(21.7-122.0)
Higher extended roles			
2	649	63.4	(22.1, 135.5)
3	409	29.9	(18.8, 96.6)
5	301	44.3	(20, 111.2)
8	1091	47	(21.7, 115.5)
11	301	36	(16.0, 95.9)
12	492	42.8	(18.5, 117.0)
Total	3243	45.1	(20.0, 116.8)
Total	6686	47.1	(20.8-119.8)

Table 30 describes average LOS by all destinations at discharge for higher/lower groups of units. Destination (at the same or another hospital) following PICU discharge was grouped as NICU/PICU/ICU, HDU/SCBU, Ward/normal residence, Died/hospice or Other. LOS by destination at discharge by unit within unit type is shown in Appendix 7.2. The unadjusted data do not suggest a consistent relationship between higher/lower units' LOS by the different destinations at discharge.

Table 30. Mean (SE) and Median (IQR) of length of stay (LOS, in hours) by destination at discharge* by higher and lower extended nursing role group

Destination at discharge	Higher/ lower	N	Mean	S.E.	Median	Quartiles
NICU/ICU/PICU	Lower	215	157.8	16.5	80.8	(18.8, 182.0)
	Higher	113	151.2	24.2	51.3	(21.2, 187.3)
	Total	328	155.5	13.6	69.9	(20.1, 183.3)
HDU/SCBU	Lower	239	116.3	9.6	62.3	(23.0, 155.6)
	Higher	725	128.3	7.5	70.0	(23.2, 156.8)
	Total	964	125.3	6.2	67.7	(23.2, 156.5)
Ward/normal residence	Lower	2770	98.8	4.3	46.6	(21.7, 113.8)
	Higher	2187	81.5	2.9	37.8	(19.0, 93.6)
	Total	4957	91.2	2.7	43.1	(20.4, 104.5)
Died/hospice	Lower	200	204.2	22.2	73.6	(22.2, 271.6)
	Higher	168	230.5	34.1	94.4	(28.4, 266.4)
	Total	368	216.2	19.7	87	(25.1, 266.6)
Other	Lower	19	101.1	27.4	44.8	(22.8, 135.0)
	Higher	50	168.4	30.7	110.3	(33.2, 172.4)
	Total	69	149.9	23.6	94.7	(28.7, 165.0)
Total		6686	106.8	2.6	47.1	(20.8, 119.8)

*All destinations at discharge in index and other hospitals

Table 31. Summary of the regression model of the relation of extended nursing roles and Length of Stay (LOS, in hours)

Variable	Log (LOS)	S.E.	P	INVLOG (LOS)*	95% C.I.	
Admission						
Planned	ref					
Unplanned	0.05	0.03	0.109	1.12	0.98	1.29
Destination at discharge						
ICU/NICU/PICU	ref					
HDU/SCBU	0.21	0.11	0.053	1.62	1.00	2.63
Ward/Normal residence	0.03	0.10	0.788	1.07	0.66	1.70
Died/Hospice	-0.33	0.11	0.003	0.47	0.28	0.78
Other	-0.08	0.33	0.806	0.83	0.19	3.72
Interaction PIM2/Destination at discharge						
PIM2 ICU/NICU/PICU	0.13	0.03	<0.001	1.35	1.17	1.55
PIM2 HDU/SCBU	0.03	0.03	0.340	1.07	0.93	1.20
PIM2 Ward/Normal residence	0	0.03	0.993	1.00	0.89	1.12
PIM2 Died/Hospice	-0.19	0.03	<0.001	0.65	0.55	0.76
PIM2 Other	-0.08	0.08	0.356	0.83	0.58	1.23
Primary Diagnostic Group						
Respiratory	ref					
Blood/lymphatic Body wall and cavities	-0.24	0.09	0.011	0.58	0.38	0.89
Cardiovascular	-0.06	0.05	0.256	0.87	0.69	1.10
Endocrine/metabolic	-0.22	0.02	<0.001	0.60	0.55	0.66
Gastrointestinal	-0.31	0.08	<0.001	0.49	0.35	0.69
Infection	-0.17	0.02	<0.001	0.68	0.62	0.76
Multisystem	-0.17	0.03	<0.001	0.68	0.59	0.78
Musculoskeletal	-0.15	0.09	0.096	0.71	0.47	1.07
Neurological	-0.20	0.05	<0.001	0.63	0.51	0.78
Oncology	-0.33	0.03	<0.001	0.47	0.42	0.54
Trauma	-0.20	0.05	<0.001	0.63	0.50	0.79
Other	-0.26	0.04	<0.001	0.55	0.46	0.65
Other	-0.28	0.03	<0.001	0.52	0.46	0.60
Higher Ext Roles	ref					
Lower Ext Roles	-0.09	0.09	0.304	0.81	0.55	1.20
Interaction Ext Roles/Destination at discharge						
Lower Ext Roles HDU/SCBU	-0.04	0.10	0.726	0.91	0.58	1.48
Lower Ext Roles Ward/Normal residence	0.08	0.10	0.433	1.20	0.78	1.82
Lower Ext Roles Died/Hospice	0	0.13	0.975	1.00	0.55	1.78
Lower Ext Roles Other	-0.16	0.23	0.497	0.69	0.25	2.00
Constant	2.27	0.10	<0.001	186.21	120.23	295.12

Number of children with complete data for this model = 6663

*To interpret the inverse log results, for example 'Lower Extended Roles' is associated with an LOG(LOS) estimate of -0.09. The Inverse log of this is 0.81 (95% CI 0.55, 1.20), which means that the LOS of patients in the lower extended roles group is 0.8 or 81% (95% CI 55%, 120%) that of patients in the higher extended roles group.

For adjusted comparison of length of stay (LOS), the model included type of admission, PIM2, primary diagnostic category and destination at discharge, as well as selected interaction terms, before fitting the term for higher/lower extended nursing role. Table 31 (above) shows the regression model. There is no significant independent association between units with higher/lower extended nursing or interaction terms of higher/lower extended nursing and destination at discharge and risk-adjusted LOS. It is of note that, in comparison with admissions for primary respiratory conditions, nearly all the other primary diagnostic categories (except for body wall and cavities) are independently related to a shorter LOS.

Unplanned re-admission

Any re-admission into the index PICU within seven days of discharge was designated an unplanned re-admission. We note that Kossovsky *et al* (1999), exploring readmission rates in adult intensive care settings over 31 days, noted that re-admission risk peaks by seven days and decreases rapidly thereafter. Overall, approximately 3% of children had an unplanned re-admission to PICU within seven days of discharge. Destination at discharge and number (%) re-admissions from each destination by higher/lower extended nursing role are shown in Table 32. Total unplanned re-admission rates by unit type are 2.7% (lower) and 3% (higher). These data show that the largest number of re-admissions are from wards or home but readmissions are proportionally highest from HDU/SCBU.

Table 32. Number (%) of unplanned readmission to PICU within 7 days by source of re-admission, by higher/lower extended nursing role

Total	ICU/NICU/ PICU	HDU/SC BU	Ward/Normal residence	Died/ Hospice	Other
Low extended roles					
93/3458 (2.7%)	8/216 (3.7%)	20/239 (8.4%)	64/2772 (2.3%)	0/201 (0%)	1/30 (3.3%)
High extended roles					
98/3249 (3%)	2/114 (1.8%)	46/726 (6.3%)	47/2187 (2.1%)	0/168 (0%)	3/54 (5.6%)
Total					
191/6707 (2.8%)	10/330 (3.0%)	66/965 (6.8%)	111/4959 (2.2%)	0/369 (0%)	4/84 (4.8%)

Table 33. Summary of regression model of the relation of extended nursing roles and unplanned re-admission.

Variable	LOG Re-ad	Std. Err.	P>z	Odds	[95% Conf.	Interval]
Planned	ref					
Unplanned	0.034	0.195	0.861	1.03	0.71	1.52
ICU/NICU/PICU	ref					
HDU/SCBU	0.553	0.402	0.169	1.74	0.79	3.82
Ward/Normal residence	-0.703	0.420	0.094	0.50	0.22	1.13
Other	0.200	1.079	0.853	1.22	0.15	10.13
PIM2						
ICU/NICU/PICU	0.322	0.227	0.156	1.38	0.88	2.15
PIM2 HDU/SCBU	-0.246	0.260	0.344	0.78	0.47	1.30
PIM2 Ward/Normal residence	-0.264	0.232	0.256	0.77	0.49	1.21
PIM2 Other	-0.245	0.463	0.596	0.78	0.32	1.94
Respiratory	ref					
Blood / lymphatic	0.614	0.975	0.529	1.85	0.27	12.48
Body wall and cavities	-1.065	0.633	0.093	0.34	0.10	1.19
Cardiovascular	-0.379	0.178	0.033	0.68	0.48	0.97
Endocrine / metabolic	-0.236	0.393	0.547	0.79	0.37	1.70
Gastrointestinal	-0.188	0.280	0.502	0.83	0.48	1.43
Infection	-0.382	0.343	0.266	0.68	0.35	1.34
Multisystem	1.185	0.460	0.010	3.27	1.33	8.06
Musculoskeletal	-2.442	1.047	0.020	0.09	0.01	0.68
Neurological	-0.261	0.217	0.228	0.77	0.50	1.18
Oncology	-1.479	0.553	0.007	0.23	0.08	0.67
Other	0.416	0.412	0.313	1.52	0.68	3.40
Trauma	-2.339	1.105	0.034	0.10	0.01	0.84
Higher Ext Roles	ref					
Lower Ext Roles	0.116	0.182	0.523	1.12	0.79	1.60
Constant	-2.666	0.373	0	0.07	0.03	0.14

Number of children with complete data for this model = 6295

Unplanned re-admission rates by destination at discharge for units within higher/lower groups are shown in Appendix 7.3. Overall, only small numbers are re-admitted from the various settings at individual unit level.

For the adjusted comparison of unplanned re-admissions in relation to higher/lower extended nursing roles, the model included type of admission, destination at discharge, an interaction term for PIM2 and destination at discharge, and primary diagnostic category, before fitting the term for higher/lower extended nursing role. Table 33 (above) shows the results of a logistic regression model with unplanned readmission as the dependent variable. In order to provide a more parsimonious summary, the model shown includes only the main effect terms because none of the interaction terms were significant.

The model suggests that compared with children admitted for respiratory conditions, some primary diagnostic categories had significantly lower odds of unplanned re-admission (cardiovascular 0.68 (95% CI 0.48-0.97), musculo-skeletal 0.09 (95% CI 0.01-0.68), oncology 0.23 (95% CI 0.08-0.67), trauma 0.1 (95% 0.01-0.84)), whereas multi-system diagnoses had significantly higher odds of unplanned readmission (3.37 (95% CI 1.33-8.06)). However, there is no significant independent association between units with higher/lower extended nursing roles and risk-adjusted unplanned re-admission. This finding is in line with previous reports that suggest patient characteristics (of, for example older age, and clinical diagnoses such as congestive heart failure) may explain more of the variation around unplanned readmissions than quality of care issues (Kossovsky *et al*, 2000).

Probable VAP (ventilator-associated pneumonia)

Lower respiratory tract infection detected in the first 48 hours following admission was designated as probable community-acquired infection (CAP). The definition of CAP included specified symptoms of lower respiratory tract illness, and fever and initial/progressive radiograph opacity. Probable VAP as defined above, was designated if an infection was not present at time of PICU admission, with onset only after 48 hours of ICU stay and at least 48 hours after the start of invasive ventilation in the unit.

Data were returned for a total of 1171 eligible cases throughout the study period from the 12 units (616 (52.6%) from lower units and 555 (47.4%) from higher units). In total 93/1156 (8%) of cases were designated as probable community-acquired pneumonia CAP (33/608 (5.4%) in lower units and 60/548 (10.9%) in higher).

Table 34 shows the number of eligible cases and number (%) of probable VAP by unit by higher/lower extended nursing role. Overall, there were 12.9% (152/1171) designated VAP cases with similar percentages in both the higher/lower groups of units (83/616 (13.5%) in lower and 69/555 (12.9%) in higher units). However, variation between units within groups was wide in both higher/lower unit types.

Table 34. Probable VAP (n, %) by eligible infants by unit and higher and lower extended nursing role

PICU	Probable VAP		
	N	Total	%
Lower extended roles			
1	157	10	6.4%
4	150	21	14.0%
6	118	28	23.7%
7	22*	2	9.1%
9	55	8	14.5%
10	114	14	12.3%
Total	616	83	13.5%
Higher extended roles			
2	177	10	5.6%
3	21*	2	9.5%
5	67	12	17.9%
8	150	19	12.7%
11	59	12	20.3%
12	81*	14	17.3%
Total	555	69	12.4%
Total	1171	152	12.9%

*Estimated missing cases (based on previous annual throughputs of eligible ventilated 1-year-olds from PICANet: unit 3 (13); unit 7 (78); unit 12 (3))

Of 1171 VAP records, PICANet data were available for 1029 (88%). The results of the logistic regression model are shown in Table 35 for the adjusted comparison of probable VAP in relation to extended nursing role. The model included type of admission, PIM2 and the primary diagnostic category before fitting the term for higher/lower extended nursing role. Again, whereas some primary diagnostic categories in the model had a significantly lower likelihood of VAP (endocrine, infection, neurological,

oncology), only unplanned admissions are significantly more likely to develop VAP and there is no significant independent association between extended nursing role and risk-adjusted probable VAP (adjusted odds of VAP in units with lower compared to higher extended roles 1.23, 95%CI 0.61-2.46). In a sensitivity analysis removing unit 7 from the model because of potential bias due to missing cases, the results remained similar (adjusted odds 1.31, 95% CI 0.61-2.82).

Table 35. Summary of regression model of the relation of extended nursing roles and probable VAP.

Variable	LOG			Odds	[95% Conf. Interval]	
	VAP	S.E.	P>z			
Planned	ref					
Unplanned	0.801	0.408	0.050	2.23	1.00	4.96
PIM2	0.070	0.094	0.457	1.07	0.89	1.29
Respiratory	ref					
Body wall and cavities	-0.184	0.588	0.754	0.83	0.26	2.64
Cardiovascular	-1.775	1.037	0.087	0.17	0.02	1.30
Endocrine / metabolic	-1.162	1.037	0.003	0.31	0.15	0.67
Gastrointestinal	-1.398	0.392	0.176	0.25	0.03	1.87
Infection	-1.309	1.032	0.001	0.27	0.12	0.60
Neurological	-0.918	0.405	0.003	0.40	0.22	0.74
Oncology	-1.375	0.313	0.043	0.25	0.07	0.96
Other	-0.322	0.679	0.629	0.72	0.20	2.67
Higher Ext Roles	ref					
Lower Ext Roles	0.205	0.354	0.562	1.23	0.61	2.46
Constant	-1.835	0.736	0.013	0.16	0.04	0.67

Number of children with complete data for this model = 989

Summary and conclusions

We hypothesised that that extended nursing roles would be independently associated with significant improvement in the specified quality of care process and outcomes to be tested of length of stay (LOS), unplanned readmission and health care associated infection, (namely probable ventilator-associated pneumonia (VAP)). We found no significant

independent effect of extended nursing roles on the tested care processes/outcomes for patients of LOS, unplanned re-admission or probable VAP.

Findings were:

- **Length of Stay:** Units with lower extended nursing roles appear to have slightly longer crude LOS (median 48.8 hours, IQR 21.7 to 122) compared with 45.1 hours (IQR 20 to 166.8). However, the IQRs are notably wide. After taking account of illness severity, primary diagnostic category, destination at discharge and unit-level variation, we found no significant independent effect of extended nursing role on LOS. Compared with the higher group, adjusted LOS of patients in lower extended roles group is 81% (95%CI, 55% to 120%).
- **Unplanned re-admission:** Overall, approximately 3% of children had an unplanned re-admission to PICU within seven days of discharge. Crude unplanned re-admission rates by unit type are 2.7% (lower) and 3% (higher). After taking account of illness severity, primary diagnostic category, destination at discharge and unit-level variation, we found no significant independent effect of extended nursing role on the likelihood of readmission (compared with the higher group, the odds of readmission for patients in the lower extended nursing role group are 1.12, 95% CI 0.79-1.6)
- **Ventilator-associated pneumonia:** Overall, there were 12.9% (152/1171) designated probable VAP cases with similar percentages in both the higher/lower groups of units (83/616 (13.5%) in lower and 69/555 (12.9%) in higher units). However, variation between units within groups was wide in both higher/lower unit types. After excluding community-acquired pneumonia and adjusting for admission type, illness severity, primary diagnostic category and unit-level variation we found no significant independent association between extended nursing role and risk-adjusted probable VAP (adjusted odds of VAP in units with lower compared to higher extended roles, 1.23, 95%CI 0.61-2.46).

Our overall estimates of average LOS at two days, unplanned re-admission at 3% and probable VAP rates (at 13% of eligible ventilated patients) are broadly similar to previous reports in the literature (Marcin *et al*, 2001; Kollef, 1993).

Caution is required in interpreting the regression model for probable VAP for three reasons: first, because of cluster sample sizes not achieving the target size of 150 at each unit over the one year period; second, potential selection bias due a markedly incomplete series from one unit (although a sensitivity analysis excluding that unit showed similar results); and third,

from potential selection bias due to a 12% VAP sample loss in matching with PICANet records.

Although we have compared nurse and medical groups' time spent in direct care time in Section 3, further comparisons of higher/lower total staff direct care time and higher/lower staff groups' direct care time are not tested. This is because the variation in estimates of staff direct care time between units within groups is extremely wide and unreliable. It would not be valid to arbitrarily assign categories of higher/lower direct care time as the meaning of any such groupings to practice would be unclear.

4.2 User views and satisfaction

To explore the relationship between units with higher and lower levels of nurses in extended roles and user views and satisfaction

4.2.1 Parents' views and experiences of PICU

Interviews were conducted with parents of children in intensive care between October 2006 and March 2008 in the 12 participating PICUs across the UK.

Methods

Participants

Parents present on PICU when the researcher (NS or CJ) was on the ward were invited to take part in semi-structured interviews about their experiences and views. Parents were not approached if the person in charge of the ward felt that this would be inappropriate. Everyone who agreed to take part, after being given the opportunity to take some time to decide, was interviewed after giving written consent. Informed consent and methods to ensure anonymity and confidentiality were maintained were the same as those used in the staff interviews (see Section 2.2, p 46).

Interviews

Researchers at site visits were blind to the higher/lower extended role category of the unit. All participants were interviewed on hospital premises (private room on ward or parents' room). The methods and interview schedule guide (Appendix 8.1) was used to guide the interviews. The guide was designed to prompt participants to articulate their views and experiences of the PICU in their own terms. It was used flexibly in response to the direction in which participants wanted to take the interview. It was revised in later interviews in response to emerging themes. All interviews were digitally-recorded and transcribed verbatim.

Analysis

The complete dataset was first analysed using the constant comparative method (Glaser & Strauss, 1967) 'open' codes to describe each unit of meaning within the transcripts were initially generated by CJ who organized the codes into a coding framework of thematic categories and subcategories. Data was assigned to the coding framework with the assistance of QSR N6 software. The coding framework was checked and modified as the analysis progressed to ensure a satisfactory fit with the data and JT independently validated the assignment of the data to the categories. Findings were drafted for the overall data then the coded data was reviewed again, split into two halves for higher/lower extended nurse role units. It was reviewed to explore if there were any unique issues or differences within themes in the two sections of data that might indicate

any differences in parents' satisfaction or experiences in the two types of units.

The sample

Nineteen interviews took place. Parents reported a wide variety of conditions for which their child was admitted to PICU. These included respiratory problems (9), heart problems (4), injuries resulting from a traffic accident (2) and a variety of other conditions. Twelve of the paediatric patients were admitted to PICU following surgery. The children were 13 male and 6 female patients, admitted for both chronic (8) and acute conditions (11) and had been in PICU at this admission for between less than 24 hours and up to 11 days. For some parents the current admission was the first time their child had been admitted to PICU (10), for others the child had been admitted previously on 1 to 7 occasions with one child having been admitted on more than 60 occasions. Most commonly (16) children were admitted to PICU as an emergency. Although it was planned to invite a subset of children aged >8 years to take part in parent/child pair interviews, this proved not to be possible. Children in PICUs were too young, too ill, unconscious, suffered from multiple severe disabilities or not competent.

Findings

The findings describe a care setting with anxious and fearful parents of critically ill children. Three main themes describe satisfaction with care, attributes of the unit and care team, and meeting the needs of the family. We found no discernable differences in parents' views when comparing whether parents were interviewed in units with higher or lower levels of nurses in extended roles. The main themes and outline of the findings are summarised below.

Figure 16. Outline of main findings in themes arising (parent interviews)

<p><u>Background:</u> Admission, stage of treatment, reason, experience</p> <p><u>The unit and team:</u></p> <p><i>The team:</i> Team working, mutual support, knowledge and skills sharing, communication, trust, clarity of roles, nurses roles, expertise, views of individual staff, decision making and parental involvement</p> <p><i>The unit:</i> Atmosphere, function of the unit, challenges in the unit, physical environment, organisation, financial considerations, charities</p> <p><u>Patient care and satisfaction with care:</u> Quality of the care received, what makes care good?, parental involvement in care, delays, meeting the child's needs</p> <p><u>Needs of families:</u> Visiting, accommodation, staff caring for parents too, priorities, communication, information requirements, information sources and shortfalls, sources of anxiety and sources of comfort to parents, complaints and satisfaction, wider impact on family</p>
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Admission

The decision to admit their child to PICU was seen by parents either as a source of additional anxiety, where it was seen to demonstrate the seriousness of the child's condition, or as a source of comfort where the admission was viewed as access to superior care.

And we knew that she's very seriously ill, we knew that something serious had happened, because you don't transfer a new baby to a heart and lung hospital unless there is something very serious wrong with the baby.

(16Mother, Lower)

All right, I just wanted it all over, I just wanted my little girl safe, if you know what I mean, so... she was getting transferred over to [name of hospital 2], so I felt good about it, because [name of hospital 2]'s a nice hospital, and I like it.

(18Mother, Lower)

The child's admission to the PICU was frequently characterised by a period of uncertainty. During this time parents described feelings of fear, panic and confusion, particularly those parents who had no experience of PICU.

It was just basically very scary, because it happened all of a sudden [...] And they came to see him and they said "we might have to take him down" and then they came again an hour later to take him down, and it was like, panic stations and... basically I just remember it as panic station,it was just completely going over my head. I just didn't understand ... I think the first couple of days in ICU are more of a blur, because it's just horrible seeing your child lying there, basically.

(03Mother, Lower)

Not surprisingly, the primary source of distress for parents was their child's medical condition and the ensuing threat to their child's life. Parents' first priority, therefore, was to obtain the best possible medical care for the child, as quickly as possible. The PICU was invariably seen as providing this. Parents were generally happy with the speed of admission to PICU, although four parents reported a significant delay.

PICU was full on the Sunday, full because... there were some beds available but they didn't have the staff. The nurses were just totally stretched, so they phoned up quickly and asked for

one of the nurses to come in, and she agreed, and so, on that... because there was talk upstairs to transfer us out, as soon as they had a, as soon as they had the situation controlled, because [child's name] was life-death situation. But by the time they brought her downstairs, they had phoned around, got a nurse in, and fortunately enough we didn't have to go anywhere else.

(07Mother, Higher)

Being kept away from your child during the admission process was a feature of several accounts (11). Parents described being separated from their child during the transfer to PICU and during surgery, as well as being kept away during the initial period on the PICU. Whilst separation was seen by most all parents as particularly distressing and a source of anxiety they appeared to accept the reasons they were given for being kept from their child, given that their first priority was the child's care. Contact during this period of separation was reported in one account and welcomed.

They were. Fantastic. And they got him here, then we came here, we followed down, because you know, you can't go in the ambulance, because there are so many machines and too many people. So we came here. They got him settled in the bed before they allow you to go in, and they got him nice and stable here before they came and let us in, so, it was a scary time, but the main, they did make you feel at ease, but at the same time, they were very honest with us, which we liked. Because you've got to be honest at times like this really. So that was the transfer process. It took quite a few hours from start to finish, but it was, it was a smooth transfer, I would say. [...] From the anaesthetist, to the team coming up, tell us what they were going to do. They kept letting us go in to see him. You know, bit by bit. So we weren't worried too much.

(01Mother, Higher)

Whilst during admission to PICU any perceived delay in admission, and being kept away from their child, was stressful, this could be lessened to some extent by the provision of information. Being kept informed was particularly important to parents and was a feature of 12 accounts. Lack of information at this point was reported by one parent.

Mhmm. As well... once we got here we felt, we just felt a lot more relieved, and put at ease basically, because you know, they come to us, they explained everything, explained he was stable and the fact they had everything under control, so we were put quite at ease, really, once we got here.

(06Mother, Higher)

No. I mean, obviously, when your child is going into intensive care, you think any time is too long, you just want to be with them, but no, they kept coming and telling us what they were doing and how long they would be, no, they were very nice. No complaints whatsoever.

(01Mother, Higher)

It was more a case of the, okay, they took him into PICU, and we kind of hung around for probably about two hours, waiting for them to put in femoral lines, and kind of doing everything else they were doing, just cleaning him up. It was more a case of that, and we weren't kind of sure what was happening. I mean, they came out every now and again and said "Look, everything's okay and we'll let you in just now to come and see him" but it was, yeah, it was about two hours probably that we waited and things, two... [...] You know by the time you get to kind of two hours, you know, 15 minutes is fine, half an hour kind of okay, but when it starts stretching like an hour or two you tend to get a bit worried and things as well, you know, is it kind of... well they're not... they were very forthcoming with information.

(13Father, Higher)

The unit

Parents were generally very positive about the unit to which their child had been admitted, with some seeing it as providing superior care for their child.

I think they're prob-, I think they're more organised than the other wards I've been on. And the fact that there's always a nurse in the room, compared to other wards where you have to... you know, press a buzzer and wait for somebody to come, there's always somebody here. So you can just kind of go out for a drink or something, knowing that somebody's there.

(12Mother, Lower)

All parents who commented on the organisation of the units described them as being well organised (11).

Yeah, yeah, I think it is really good, well-run unit.

(06Mother, Higher)

Yeah, that's true, it's very well organised. People always come to help if an emergency came up, I mean the suction or changing the line, or something else.

(14Father, Higher)

No, I think it's good. It all seems like a drilled routine that they know very well, looking at it... you could sort of, you sort of get to speak up yourself,, oh, what's going to happen next? Yeah, I think it's, I think it's very good.

(09Father, Lower)

Organisation is as well as can be expected. This is the intensive care unit, and the unexpected just jumps up. And it's dealt with promptly, efficiently, you know, you see across the line of all the beds, and you see everybody works together, everybody helps. You know, and there's always one eye on that child, on every child, at all times. And it's very busy, very busy, but everything seems to work well.

(17Mother, Lower)

Where parents referred to the atmosphere on PICU they generally appreciated it being relaxed, comfortable and welcoming, with staff who were friendly and could have a laugh. For first time users of the service, the admission to PICU was viewed with fear. The positive atmosphere on the ward did much to allay those fears.

I, it's funny... I was very nervous about coming onto an intensive care unit, because he'd never been on one. And I know with a child like [child's name} being severely handicapped, you're told that, you know, he does get chest infections, we'd go into hospital regularly, but we've never been to intensive care. So when I came on the unit, it's, I thought it would be quite a dismal, you know doom-and-gloom place because of the place that it is. But I just, I don't know, there's like an overwhelming team feeling, when you go on there, and it's, even though it's quite intense, it's relaxed at the same time. There's no panic. That makes a parent feel good. There is no panic.

(01Mother, Higher)

I find that people actually... went out of their way to make you feel welcome and helpful and not getting in the way and...

(08Father, Higher)

Yeah, it's nicer than I thought, actually. I don't mind it at all and... I'm surprised at how relaxed, even though it's intensive care, family can come and... I didn't think they'd let anybody in at all, actually. But they're quite, they're quite good like that, they've let all the family see her.

(11Mother, Lower)

It's not nice seeing sick children, but they can still have a laugh and joke, as well as being professional. And, just, you pick up on it, how they are with each other, all the staff in here. And you can see that it's a real... they've really got, like, a passion for what they're doing, and it's really important. But they are at work. No one wants to come to a job that they don't like, do they? And it shows that they, you just pick up on it, it's hard to explain, but you just pick up on it. And that makes you feel more at ease as a parent.

(17Mother, Lower)

Negative comments about the unit concerned the physical state of the building (6), including decoration and lack of air-conditioning but these were considered to be minor concerns. Noise was also mentioned by some parents (2).

Obviously it's an old building, it's... I think the staff do very well in respect of moving people about in the wards. It could always be better, bigger an area and things like that, (especially) the parking.

(08Father, Higher)

I mean, it's an old hospital, so, I mean, you've kind of got to look at that. And we should have been in a camp where, we're not buying, well we're not buying, you're not getting sort of a cosmetic hospital and things, you're actually getting knowledgeable staff and things, and you know, they know what they're doing, and so you kind of turn a blind eye to a bit of the cosmetic things around here. You know there's other parents I think would come in here and say "oh, you know, this is not as great", I mean, we've been to [other hospital] as well, and [other hospital] was quite a lot smarter, but at the end of the day, their staff weren't as knowledgeable, so... you know, that's kind of the trade-off. It would ni- yeah, you basically are getting the knowledgeable staff, you know, who really know what they're doing, and I think that's what they're good at. So, and that's fine.

(13Father, Higher)

Charity funding was mentioned in 6 accounts, mainly relating to the provision of accommodation for parents (5) but also in one account, relating to the provision of staff and equipment.

When we were here last, we were given accommodation at... They've got a Ronald McDonald... Ronald McDonald is basically a charity that funds accommodation for parents. They've got a house with about rooms here, which, especially if

you're far away and this is not your local hospital, and your child is critical, and they need intensive care, they give priority to their parents.

(07Mother, Higher)

Father: But there's also the people on the [charity name], we see [name] and [name] a lot as well, so, which they're quite...

Mother: They come and make sure we were all right, didn't they? [...] Give you a cuddle and (laughs)...

(19Mother & Father, Lower)

Father: Well, they have... they can't buy equipment when they need to, and they have to try and fix it and hold it together until they get the money [...] That's the one thing that really annoys us...

Mother: And that the people do donate money, and they just do it to [name of this hospital], it doesn't necessarily go to [name of this hospital] because...

Father: ...it gets put in the Trust pool.

Mother: ... it doesn't necessarily go for what you want to buy. So we had to buy it through...[charity name]... To make sure that the things we wanted to buy for the ward got bought for the ward. Which is just... we just find that all a bit crazy really.

(19Mother & Father, Lower)

The team

Without exception, parents had something positive to say about the team caring for their child (19).

Well, staff-wise, just no complaints, just fantastic; you can ask them anything, they'll say to us, "(?)", if you want to do it your way, just do it your way," whatever suits us, you know. Couldn't praise them enough though, I think they're great.

(04Father, Higher)

Overall, I mean, I don't know how they do it. I mean, they're looking after these people as well and helping us and telling us things, and they work all hours, it's incredible. I don't know how they do it. I've said it before, and I'll say it again. I've said it every time. They are special people.

(05Mother, Lower)

I think it's been brilliant. But I might be probably biased, as well, because they've brought my son back....from the brink of death to stable, so I'm probably singing their praises, but I've got nothing but praise for them, you know, so...

(10Father, Higher)

Occasionally parents referred to particular members of staff when talking about their experiences on the unit but frequently they spoke about the staff as interchangeable.

They are all good, so it doesn't matter [which nurses care for her].

(18Father, Lower)

[Name of nurse], the [charity name] research nurse, they've been fantastic, haven't they? Mhmm. All of them! Just generally, really, so...

(19Mother, Lower)

We were fully supported, completely supported I have a say by the whole surgical team on the PICU department of [name of hospital].

(16Mother, Lower)

Rarely parents suggested dependency on a particular member of staff.

One of the nurses said, "Oh, she's gone off duty now, she's been on since Saturday on the night, and she's here Saturday, and then she's (not back until ?) the 21st," ... But I want them back. I think "I don't want you to go" I get really panicky and I think "no, I don't want any other, I want you." There were one in particular, not yesterday, the day before and she were absolutely fantastic. And I knew as soon as I met her that I could trust her, and she's been doing this... I asked her how long she'd done it, and she'd trained for intensive care 15 years ago.

(11Mother, Lower)

Invariably staff were reported as working well together as a team.

Yeah, in a team. They're like, it's like a family atmosphere between them. They help each other all the time. I've not seen anything, you know, to say, mm, that wasn't, that wasn't quite right... they just, they're very good, they work very very well in a team.

(01Mother, Higher)

I think it's, I think, I think they all work extremely well together, they're a good team. And it's just... Doctors and nurses together, it's just teamwork. Nobody's pretentious, you know how you can get some doctors that can be... think because they're called doctor they can be just a little bit....there's none of that here.

(05Mother, Lower)

The precise roles of doctors and nurses were ill-defined in the accounts. Where roles were discussed, doctors were generally seen as the directors, providing the expertise to make the decisions about the child's care, which was put into practice by nurses. In addition to providing the one-to-one care for the child, nurses were seen as relaying information from the doctors to the patient in terms they could understand, at the point at which the information was required by parents, acting as the parents' advocate and facilitating access to the doctors. Accounts suggested that doctors were responsible for the decisions about care, including any changes to current care. In the single account suggesting that nurses could make changes to the child's care, this was considered acceptable in limited circumstances and dependant on the nurses' training and experience. It was also seen as offering the benefit of providing best care quickly by virtue of the nurses' constant contact with the child.

Mother: The doctors come and sort of... look at what's been going on and all the stats and things and...Tweak it if necessary.

Father: But the nurses tweak as well as they're going along, which is...

Mother: To a certain extent.

Father: Yeah, I mean, if it's a major sort of...

Mother: I think it depends on how experienced the nurse is to.

Father: I think if it's a major sort of tweak, they get a doctor. But if it's a minor tweak, the nurses are free to do that themselves.

Interviewer: HOW DO YOU FEEL ABOUT NURSES TWEAKING?

Father: If they know what they're doing, it's fine.

Mother: I trust their...

Father: Yeah. Trust their judgement at the end of the day. I mean, that's what they're paid to do, and what they've got the qualification for, so...[...] Well, because the nurse is there all the time. The doctor, obviously, like I said before, he's going round...

Mother: He sees all the patients.

Father: Where the nurse is, she's there, and she'll well, if I tweak that, oh no, it's not working, I can put it back.

(19Mother & Father, Lower)

As well as providing constant care for the child, accounts suggested (12) that staff were also available to the parents, particularly when needed to provide support or information.

Unless... unless something major is blowing off on ICU, something's crossed them, that obviously takes priority. But when they don't, they're not too busy to talk to me. If I needed to talk to somebody, yeah.

(02Father, Higher)

No, no, no, they're... it seems like they're always, like, available, even when they're really busy, seems like they've always got time for us, so... it's really good if you need them.

(09Father, Lower)

Staff were presented as heroes where they either saved the life of the child or were seen to be doing more than what might be expected of them.

I think it's been brilliant. But I might be probably biased, as well, because they've brought my son back....from the brink of death to stable, so I'm probably singing their praises, but I've got nothing but praise for them.

(10Father, Higher)

Get more beds, get more staff. It's the same in any hospital, though, isn't it? They work - excuse my language - bloody hard. And they... yeah. Never, I've never been in a situation like this before, I've never seen it before. They work hard.

(17Mother, Lower)

Occasionally parents (2) had a problem with the attitude of particular members of staff. One doctor was described as blunt, not forthcoming with information and uncaring, another parent described some staff as ignoring the parents.

Mother: Mhmm. Because it should be the doctors that are coming and telling you about the tests and the X-rays and all that. I do find that I have to ask.

Interviewer: SO THE DOCTORS DON'T ALWAYS TELL YOU WHAT THEY...

Mother: Really, I've only met one doctor so far. So whether it's just his way, I don't know.

(01Mother, Higher)

Occasionally staff were presented in a particularly unfavourable light where they: ignored the parents; failed to communicate; failed to provide adequate care for the child; or hurt the child. These accounts frequently served as a contrast to the care usually received on PICU and usually involved new staff and outsiders.

We've only had one peculiar episode, and it was a nurse that absolutely gouged him on the ward with a needle. One nurse. And one of the other nurses said to him, "Don't worry, she can

be a bit like that sometimes." And you know, he's had all this surgery and they've done all that to him, and where this nurse gouged him is the most horrendous mark.[...] It wasn't on this ward. They're lovely on here.

(05Mother, Lower)

Mother: Last year they had a lot of staff from the [name of other hospital] because they were short-staffed. And I think that standards aren't quite the same at all the...hospitals [...] They're very spot-on here. Things are very by the, by-the-book. Which is how it should be, in my opinion. You know, this is how it should be done. But, the [name of other hospital] tend to be not quite so... spot-on. [...] I mean, we only had an issue with one nurse from the [name of other hospital], but I just didn't... I just wasn't happy was I ...I did say something to the sister that was on, because I just...

Father: You didn't feel that she was listening to you.

Mother: No. I mean, two hours we were saying.... things weren't right, weren't we, and ... I was just, it stressed me out, didn't it?

(19Mother & Father, Lower)

Yeah, it's just one particular nurse. We felt [child's name] was quite distressed this one day, and we just felt that he was a bit more interested in his [professional administrative business] than what he was... nursing... You know, we felt [child's name] was distressed and I said all the nurses, apart from this particular one, they've done everything they can until they've got [child's name] settled.And my partner brought it up to one of the nurses who went to the coordinator and, you know, explained our issues and it has been followed up.

(06Mother, Higher)

Patient care

Quality of care

All accounts (19) included at least one statement suggesting that the parent was generally happy with the standard of care on the PICU. When asked about the overall standard of care on the ward parents typically responded as the parents quoted below.

I think it's really, it is excellent, yeah. Like my partner says, it's a credit to them. The actual unit itself.

(06Mother, Higher)

I'd say it was excellent, really.

(09Father, Lower)

Brilliant. I'm just so happy that she were brought here.

(11Mother, Lower)

The main factors associated with quality of care were speed of access to medical expertise and care (8), and the constant presence of the nurse caring for the child (13).

They do respond straight away and, I'd say yesterday is a good example. He just would not sleep, not settle all day, and they never gave in, until they got him settled. They do, always do really well.

(06Mother, Higher)

I'm quite impressed with that. How there's always somebody on hand. I've noticed if the nurses need anyone, there seems to be a doctor here immediately.

(11Mother, Lower)

No. Not one thing. We were both, my husband and I, we're just amazed at how quickly they came, how many people came.

(16Mother, Lower)

They're still there, by [child's name]'s side, they're looking after her, they know what they're doing. If anything were to go wrong, they'd be by her side at all times. And that's what I want, so that's what I'm happy with.

(18Mother, Lower)

And the fact that there's always a nurse in the room, compared to other wards where you have to... you know, press a buzzer and wait for somebody to come, there's always somebody here. So you can just kind of go out for a drink or something, knowing that somebody's there.

(12Mother, Lower)

Expertise was highly valued but less frequently stated explicitly.

You're actually getting knowledgeable staff and things, and you know, they know what they're doing, and so you kind of turn a blind eye to a bit of the cosmetic things around here.

(13Father, Higher)

They're just as good as [hospital 2] basically. They... you know, they're just as good. They do the job right; they know what they're doing.

(18Mother, Lower)

Meeting the child's needs

Parents generally reported that the needs of their child were being met. Most frequently parents reported that their child appeared to be kept comfortable (11) or staff persevered until the child was made comfortable (3).

I think he's very comfortable. Yeah, he's stable, oh, yeah, he's very comfortable now. [...] In pain? I wouldn't know whether he's... because he's been, he's been comatose since last Monday, so pain, I really wouldn't know how they've dealt with that. But he seems settled. And if...they've informed us over certain numbers on the chart, and that's how you can tell whether they're in pain or not, and everything's been below their threshold... they tell us if he's below 20, he's fine, if he's over 20 it's... so we've been watching and monitoring it very closely, and everything's... not that we're medical people, but a little bit of information's quite dangerous sometimes, because you're watching those monitors and...everything's all right.

(10Father, Higher)

Obviously because he can feel he's uncomfortable and they have to do the physio on him. But they're very quick to make him feel comfortable, whether it means a little bit more sedation if he's getting a little bit distressed, they're very quick. They don't leave him distressed, which is another good thing. Because that puts you at rest as well. So he is, you know, he is comfortable, and they move him, they turn him, so he doesn't get sores, and change his position all the time, pad him out, so he's, I've no complaints whatsoever.

(01Mother, Higher)

Some parents (2) were unsure whether their child was comfortable or not and others (2) felt that their child could be uncomfortable at least some of the time.

Well, I don't know if it was comfortable for [child's name] because she was on sedation, right? But we didn't have any other choice, anyway. But I think she was very well, considering the outcome of the treatment, she's very good now.

(14Father, Higher)

Mother: He's got like a little tube up his nose to help him breath, didn't they, and just came off his ventilator... And he was lying on his front.

Father: Obviously he's got the...

Mother & Father: ...scar down his front.

Father: So that's going to be uncomfortable for him.

(19Mother & Father, Lower)

No. The only thing I don't like is all this plastic. He keeps complaining he hates plastic, it makes him feel poorly, it makes him hot and sticky. But they need that to try and combat bugs and germs, it's easy to clean isn't it?

(05Mother, Lower)

Generally, parents (13) reported that the psychological needs of the child were being taken care of. Whilst most of the children were sedated, parents reported that nurses talked to their child, played with their child or exposed them to familiar sound and music or encouraged the parents to do so.

I think he will [need more stimulation], but they've said they wanted, they don't want to kind of bombard him with everything at the moment, just because he's just woken up, so...

(12Mother, Lower)

He's physically disabled, he cannot communicate, he cannot speak unless somebody knows him really well is there to look after him. So when he's on ICU, there's always somebody there with him. If he wakes up, they'll play with him, they'll put the radio on. When he goes from ICU to ordinary wards, because of the staff shortage on ordinary wards, I don't feel I can walk out and leave [child's name] on his own.

(02Father, Higher)

Parents of older children particularly appreciated staff taking care to treat their child with respect by not exposing their naked body unnecessarily.

Yeah, and why I say that is because yesterday... I hadn't really thought about it until yesterday, but we came down to his room, and the doors were shut. And I thought, oh, I can't believe it... it was about 6 o'clock in the morning. And we banged on the door, and we thought... oh... and all it was, said "oh, yeah, no problem, just washed him." And why they shut the door was to cover his dignity...Because he's lying nude. Which was very nice. ...I mean, 10 year-old boys don't wish all their little bits to be shown all over the ward.

(10Father, Higher)

You know, they're, like, keeping her dignity at all times, you know, and... like I say, apologising and making sure that she, if she can hear, I mean, she knows... 'cause, you know what teenagers are like, she's, at home she won't let me see her with no clothes on, so... they understand that. Like making sure... you know, they'll never pull the cover back fully. They only ever pull one side up slightly to have a look at what they're doing, they're doing it under the cover, it's really nice. And they're real kind when they're touching her face or cleaning her mouth. And they're telling her what they're doing, and they're telling her that she's beautiful, and they're going to do everything nice to her. So, they're lovely. And there've been different staff on the ward, so... they all speak to her like that.

(11Mother, Lower)

Where parents felt that their child had special needs due to learning difficulties (2) parent felt that their child was well cared for.

On the occasions we've been here, we've always been treated with the utmost respect and the one thing I do appreciate is the understand- the accepting (of the limits?) of [child's name].

(02Father, Higher)

The parents of a child who had no English felt that they were unable to leave her because she would be frightened if she woke up.

Most parents did not report that their child had any particular spiritual needs. One parent reported the provision of support from a chaplain, including a christening service. A mother reported how the nurses kept the Koran at her child's head. Additional parents believed that if they had any religious need, they would be accommodated.

Yeah, we said we went down to the chapel and we asked them to come up and say a prayer over our son, and they put the curtains round and gave us 15 minutes of privacy.The most upsetting time was when the surgeon came to us on the Thursday and said that... [child's name]... it's looking very bad and...that's why we had him christened.

(10Father, Higher)

No. No, I mean, [child's name]'s a Muslim, but she's just lying there, and she's got a little Koran on her head and when they change the beds or whatever, that just goes back on her head, by her bed head, and that's nothing, you know, nothing, you

know, special, so... they do respect other people's religions, I have to say, which is very nice. Very very good.

(15Mother, Lower)

Decision making

Some accounts (6) suggested that the parents had some involvement in decisions regarding their child's care although it was not particularly clear what kinds of decision they were involved in. Usually (5) these were parents whose child had been admitted to the PICU on at least one previous occasion. There are occasional reports (4) of parents knowing best when it comes to the care of their child, based on either their knowledge of what was normal for the child or previous experience of the medical problem.

Well, like here is, like when they do the ward rounds, we'll come, we'll speak to the nurse, we'll speak to the reges [registrars], and then they always ask our opinion. So, to me, everybody's consulted, and we work together, and that's how it's always been, and... I always feel like I could turn around and say, "I disagree with that, I think you're wrong" and they will listen to me, and... I think we work well as a team – me and the staff. We've always worked well when we're...never really had any... I've disagreed with them, but then we sort of spoke about it, and come up with a plan, so yeah...

(02Father, Higher)

Well, staff-wise, just no complaints, just fantastic; you can ask them anything, they'll say to us, "If you want to do it your way, just do it your way," whatever suits us, you know. Couldn't praise them enough though, I think they're great.

(04Father, Higher)

In other account (6), parents were happy for doctors to decide on the most appropriate treatment and to be informed of their plans. Usually, these parents had no prior experience of PICU. For these parents, they considered the doctors experts and trusted them to act in the best interest of their child.

Not really. But I'd rather not be [involved in the decisions]. I'd rather leave it to them. They know what they're doing. I feel comfortable, I feel confident that they know what they're doing, and they should make the decisions. [...] But they do discuss it with me before they go ahead to do what they're going to do, if you get my meaning. You know, they don't just do it, they just tell us what they're going to do and...

(11Mother, Lower)

I don't feel they've kept anything from me. You know, it's like, it wasn't very nice when they told me they've got to intubate him again. But you know, they talked me through it, but they was also, while they was explaining why they was having to do it, everyone was also checking that I was okay with that, checking that, you know, how I felt about it, and making sure that I was okay. [...] I will say they're the specialists, they know what's what, and I just agreed with them.

(17Mother, Lower)

Parental involvement in care

A few parents (6) talked about being encouraged or allowed to take a role in caring for their child whilst in the PICU. There was no suggestion of any pressure on parents to do this. The types of care they mentioned typically included washing their child, cleaning teeth and changing nappies. There was a single report of a parent being involved in giving medication, blood pressure and temperature monitoring and the changing of bed sheets.

Yeah, they always ask us, do you, you know, we want to help them give him a wash, change his nappy, keep his eyes and lips moist and things like that, yeah, we do that every day.

(06Mother, Higher)

Oh, absolutely, they're brilliant. They've asked me from day 1, would you like to... and I've been doing it ever since now, so, you know? Not one nurse... I mean, I don't know what they do once I've gone to the hotel to sleep. But while I'm here, I like, they know I like to get that sorted, you know [...] There's, you know... my job as a mother is to be here for [child's name], you know, I wash her face, I brush her teeth, I comb her hair, and I plait it up and I oil her and massage her, and they say to me, because sometimes she'll be lying on her back, for most of, for a couple of hours or whatever. And she'll say to me, "Don't be scared, would you like to oil [child's name]'s back" because obviously she's been lying for a, and you know, we don't want it to get all (greasy) and peely off? And they do, they turn [child's name] on her tummy and I, you know, I give her a nice rub, a nice massage, which I think is nice, you know. But I don't like to ask them, you know, but they suggest it. You know, give her a nice wash, give her a whatever, and she goes off for the day, you know, she's relaxed, which is nice, you know?

(15Mother, Lower)

Being involved in the care of their child was viewed very positively by those parents who mentioned it.

Oh yeah, yeah. You just feel as if... 'cause if you just sit there all day, you just feel so helpless. Especially because they're not awake, and they still let you do the feeds and things like that, so you do feel as if you're doing something for them.

(06Mother, Higher)

And also, whenever we can involve ourselves into....even if it's just changing a nappy, that means quite, quite a lot. Or just holding her hand or something, at least we feel as if we're, you know, part of it.

(07Mother, Higher)

Erm... psychologically... yeah, yeah. He doesn't require a great deal, to be fair. He does on the care side, but everything else... my wife's been sort of wiping him down, because she feels like, as a motherly thing, it's really nice that she can get involved. She's been moving his joints, all the joints what she's allowed to move, his hand, stroking his hand. She's been cleaning his eyes, she's been brushing his teeth. So, yeah, I think everything's been [...] We're just a normal family, you know,... But they've, they've said, 'yeah, you wash him, you move his joints' so...

(10Father, Higher)

The extent of their involvement was, for some, limited by wires and tubes. Additionally, parents found it difficult where medical equipment prevented them from holding their child.

I like to help out as much as I can. Just..yeah, just cleaning and changing her nappy and...but all the rest...there's too many tubes and wires and I just stay away, really, because there's just too many things. Especially with the ventilator, I just... but, if I can just give her a wash or wipe her eyes down or, you know, wipe her mouth down, and things like that, just, those are the only things.

(07Mother, Higher)

Oh, they've got facilities; like washing him this morning... you know, just kind of, like, washing his face and bits of his body. But I'm happy they're doing it, there's that many wires and things, you know. So, they know what they're doing.

(17Mother, Lower)

She looks me in the eyes and says, "Pick...", she looks you in the eyes to want pick-ups, but you're just like... you can cuddle her, but you can't pick up, if you know what I mean. You have to wrap your arms around her, and it is difficult. It's upsetting.
(18Mother, Lower)

Concerns

When presenting concerns about their child's treatment, parents tended to be apologetic and quick to moderate the degree of concern by referring to the generally good standard of care received.

But otherwise I have no problem with the staff here, no.
(02Father, Higher)

But apart from that, no [problems].
(03Mother, Lower)

Delays were one area of concern. Delays were experienced in either admission (4), discharge (2) or in obtaining treatment (3).

Not really. I mean, yesterday she was off the ventilator, and then she'd come off for about four hours, didn't she, and then she took really bad again. But they left it a little bit too late, they could have put it on earlier, but they turned around and says "If we don't get her on now, she won't pull through." They said, "We have to get her back on the ventilator, like, within the half an hour." Which to me, I think they could have done sooner.

(18Mother, Lower)

The only thing I wasn't happy about was that I knew Thursday night [child's name] needed to go into ICU, because it's happened so many times in the past, but otherwise, no, not had a problem at all.

(02Father, Higher)

Lack of PICU beds was reported in some accounts (4) and equipment deficiencies in one further account.

Get more beds, get more staff. It's the same in any hospital, though, isn't it? They work - excuse my language - bloody hard. And hey... yeah. Never, I've never been in a situation like this before, I've never seen it before. They work hard.

(17Mother, Lower)

Mother: Yeah. I mean, I think the only way they fall down is lack of equipment and things, which isn't their fault. Because they have to raise money to buy it, which is absolutely outrageous.

Interviewer: WHAT KIND OF THINGS ARE THEY SHORT OF?

Father: Oh, well, you'd need to get the wish list off them, to find that out. Which we were a bit shocked by.

Mother: Infusion pumps...

Father: Incubators.

Mother: Beds.

Father: Beds, suction units.

Mother: Specialist beds.

Father: I think there was all sorts on the list.

Mother: There was... it was just unbelievable, wasn't it?

Father: Yeah. There's an A4 sheet.

Mother: An A4 sheet full of...

Mother & Father: ...the equipment that they needed...

Father: ...and they still need. Yeah. Well, it's like, there's also like that travel suction unit, I mean, I don't know if he used one from here or if it was one from...

Mother: Oh yeah... [name of another hospital].

Father: But the one that they had here, it was being...

Mother & Father: ...held together by sticky tape.

Father: Because it was that old and they didn't have the money to...

Mother & Father: ...buy a new one.

Father: So we had to buy one, well, we bought one for them. I just think it's outrageous, you know, that they have to...

Mother: ...buy equipment themselves.

Father: Well, they have... they can't buy equipment when they need to, and they have to try and fix it and hold it together until they get the money.

Mother: It's crazy. [...]But that's something that's not really in their control. So it's not their fault, it's the grander scheme of things, isn't it?

Interviewer: WHO DO YOU BLAME?

Mother: The government.

(19Mother & Father, Lower)

Sometimes parents were concerned about their child's treatment on PICU. One parent reported that her child had been hurt by a nurse taking blood, another reported her child's distress was ignored. Another account reported a nurse failing to wash her hands between patients and there was a report of a machine being set up incorrectly and a line been accidentally removed from a child's foot.

Just...not this occasion, but the last occasion... one of the nurses, the nurse that was looking after my daughter then just had to be

called away for something and at the moment [child's name]'s alarm's going, and the other nurse is supposed to put the gel on their hands, or put the gloves on, and this nurse, because she was in a rush, hadn't. So that's the only occasion where I've had to say "Please can you put some gel on, 'cause you've just been with another patient"... Apart from that, I can't think of anything else.

(07Mother, Higher)

Mother: Sorry. I was just going to tell you about, there's only been one thing that really worried me. On Sunday... she's got, she's monitored ...and they were really pleased all day Sunday and said the pressure was settled,.... And then, Sunday evening, the doctor came in to (?) very serious and very worried, and his words to us were "The machine hasn't been set up properly"I didn't, I didn't ask who'd done it..... So that's quite upsetting. It's still in my mind, that I don't know whether they're at fault for that. I feel awful really. Because I don't want to make it sound as if I'm cross with them, because they've been so good in other ways. But that's quite worrying

Interviewer: DO YOU THINK YOU COULD APPROACH STAFF IF YOU WANTED TO COMPLAIN ABOUT THAT? DO YOU THINK YOU'D BE ABLE TO?

Mother: I could probably, yes, but I don't really...No, I don't really want to.

Interviewer: HAVE YOU BEEN TOLD HOW TO COMPLAIN, IF YOU WANT TO?

Mother: No. Don't think so, no. But because they've been so fantastic since, I feel a bit awkward.

(11Mother, Lower)

Voicing complaints was something that parents generally found difficult but the parents who raised complaints were satisfied with the outcome.

Father: It was difficult...In the beginning it was, but now, because like, so we know...

Mother: Because we had such good care up until that point as well...But I think because we had had such good care up until that point, I felt I had to say something, because... I don't know. It was awkward having to, and I felt really horrible having to do it, but I felt that they needed...needed told...

(19Mother & Father, Lower)

Yeah, the Matron's come to us a couple of times since, to check that we're happy and... you know, they've assured us he won't have anything to do with [child's name] and things, so...

(06Mother, Higher)

Shortcomings tended to be excused by parents on the grounds that staff were busy or doing their best, it wasn't the hospitals fault or their expectations may have been unreasonably high.

Well, complaints, let me think... not of any importance. There were minor details, on the job at the same time, people listened to us, do their best, and we forget everything about it.

(14Father, Higher)

No. Not at all. But I appreciate they were busy and it were night time, but no, we're quite happy with the care that we received.

(11Mother, Lower)

The majority of accounts explicitly stated that parents had no complaints.

I've just got no complaints about anything, you know.

(04Father, Higher)

No, I have no complaints at all about anything. They've all been lovely. It is stressful, and you do go onto another level, it's weird. Like, you said, what day is it? What day? What day? I couldn't tell you. It's peculiar.

(05Mother, Lower)

I've been 200% satisfied with the care he's been given.

(17Mother, Lower)

Needs of the family

Apart from the medical care of their child, the priorities of parents were proximity to their child and being kept informed of the child's condition.

Visiting and accommodation

Being close to their child was very important to most parents and was mentioned in the majority of accounts (16).

We were waiting here. We had been given a room, a [name of] room, which is in another building, but we wanted to be here, because we knew the surgery was serious, and there was a high risk of losing [child's name], so we wanted to be near him, we wanted to be here in case anything untoward happened.

(05Mother, Lower)

The need to be close to their child was reflected in the accounts of parents relating to accommodation and visiting. Most parents reported that an open visiting system was in operation (12). Sometimes parents were asked to leave so that they could get some rest themselves.

They let us be with her 24 hours a day. That's why I'm taking turns with my wife, with my wife. Uh, yes, they le- , they didn't restrain us from anything from our own daughter.

(14Father, Higher)

Yeah, yeah, I did, no one's stopped me from coming and going. I've been, like, yeah, I've been here from like 1, 2 o'clock in the morning and they just said, "Why don't you go and rest or go into the parents' room, and (straighten your back out?)" sometimes I've been there overnight.

(03Mother, Lower)

Parents, even those who saw visiting as open, identified some restrictions. Restrictions to the number of visitors permitted to be by the child's bedside at one time were a feature of more than half of the accounts (10). Sometimes this was inconvenient, particularly where other family members were involved in caring for the sick child, where siblings visited and where the parents' room was crowded. Parents invariably considered this restriction to be reasonable.

Of course, yes, yeah. They don't have a problem. I think the only thing they like is, you know, not to... because you've got to remember there's other children there as well, and it's not fair when you've got like a bunch whole of family coming in and standing over, you know, over the bed of the person they're going to visit. So, for them to say two at each bed is, you know, is fair enough, you know. Otherwise the other people will get overwhelmed. Some people might not get visitors, and to see somebody getting so many, you know, probably upsetting to them as well. So, I think the way they do their rules is very good, so no problems with that at all.

(15Mother, Lower)

It can be, but it's space. There isn't the space, and if there's an emergency, you don't want to be chucking ten people out from around the side of the bed. So it's practical.

(17Mother, Lower)

Restricted access to their child was reported during the admission process (11). This was viewed as difficult but necessary by parents.

...Whilst they sorted her out. That was a good few hours whilst they sorted her out, and during that time, they just told us to wait, and we just waited until they had finished. And they were very busy in there, so...

(07Mother, Higher)

Being asked to leave during ward rounds was also accepted as reasonable by most parents due to confidentiality issues and the doctors' time being taken up with questions from parents. Units varied about parents being present during ward rounds. One parent who had been included at ward rounds in another hospital saw this restriction as being less acceptable.

When they do their rounds in the morning all the parents are asked to leave, because of confidentiality. Because they, they're close beds, aren't they....so it's not fair for everyone to hear about everybody else's child.

(19Mother, Lower)

Probably the only time that is a problem is kicking you out of there for ward round, which we understand why they do it, because they're obviously trying to do a bit of privacy and they don't want you, they want to talk openly about your own child's case and obviously they want to talk about other child's cases as well, and they don't want you listening in on that, sort of the whole confidentiality thing, it's fine. The problem with that tends to be is that they don't then necessarily disc – have a proper then ward round with you afterwards.... sort of then discuss with each parents individually,That's probably the only thing that we've seen... you know, it's obviously different when you go to [other hospital], because then you're actually included in the ward rounds.... you're able to ask questions right there and then...

(13Father, Higher)

Other restrictions to visiting included restricting visiting to parents only, after a particular time, or due to risk of infection. In one instance visiting was restricted to family only at the request of the parents overwhelmed by numerous teenage friends of their child.

Where visiting was restricted and where parents chose to leave the unit, access by telephone was often reported and very much appreciated by parents.

Parents spoke about accommodation both on the ward in parents' rooms and overnight accommodation. Facilities such as refreshments, comfortable chairs and a TV provided in day rooms on the wards were appreciated by parents as they allowed parents to remain on the ward. The main complaints about such facilities were overcrowding and lack of privacy. Overcrowding was often seen as being due to the restriction of two visitors only to each bed and the requirement for families to leave during ward rounds.

And they've got a parent room as well, so we don't have to go over to MacDonald House, you can just sit and watch the TV or make drinks and things in the parent room, so... Yeah, that's great, mmmm. Yeah [it's comfortable]. It can be busy at times, especially if the unit's full, ... you interact with the other relatives and, you know, just a little discussion, I think it's good.

(06Mother, Higher)

Adequate. Yeah. They're adequate; they probably could get a little bit more private, because there're only so many people you can hold in a room at any one time.

(10Father, Higher)

It does get a bit cramped at times, to be honest. Yeah, because what I've noticed is if there's a child that's... quite a lot of people along who come with the families and that... so there's sometimes people waiting outside, there's not enough room to be sitting inside, so...

(12Mother, Lower)

Generally, accommodation was reported as being available to those parents who required it. Frequently, accommodation appears to have been provided by a charity. Whilst two accounts suggested that parents went home because of the lack of suitable accommodation, there appeared to be other factors in this decision: in one case, the need to be with the child's sibling, and in the other, the fact that the child remained unconscious. What enable the parents to leave the ward was the provision of one-to-one, constant care for their child and the assurance.

In [name of hospital 2], it doesn't have the same family facilities as [name of hospital 1]. But if I wanted to stay here, I could, while [child's name]'s in the intensive care unit. I feel very confident that if there was, if I, if I did need to stay, I could stay, that would be no problem. But I feel happy that... because she is... she's got one-on-one nursing at the moment, but if she sneezes, they tell me how many times, they can tell me

everything I need to know. If I need to come back, they would ring me, so I feel happy about going home, and it enables me to spend time with my little boy. Which is very very important.

(16Mother, Lower)

Parents viewed positively accommodation that was provided on or close to the unit. Secondary considerations included the provision of kitchen facilities, a TV, and a comfortable bed in a quiet and private environment. Anything that enabled something resembling normal family life was especially valued.

The facilities were amazing. There was several family rooms, in the children's ward there was family rooms again, and there was a kitchen, and a washing machine, tumble drier, a microwave, a fridge and a freezer. So, you know, you could have a little bit more normality if you had other kids, or, you know, you wouldn't have to perhaps rely on the out[side] to have something to eat or eat in a restaurant, you have the option of maybe having a bowl of cereal in the kitchen that was there, or in your room, and that was very good,... a nice little bit of normality, and although it's nothing like being at home, it was a big enough slice for you to feel more relaxed about being there.

(16Mother, Lower)

Problems associated with accommodation included distance from the unit, lack of privacy, noise and lack of facilities, but parents were generally accepting of the limitations, didn't see the quality of accommodation for themselves as a high priority and expected very little.

Yeah. At the end of the day, that accommodation, you know, we're lucky to have it. So, you're just grateful that there's somewhere to get your head down...

(19Mother, Lower)

I'd like to have a parents' room just off of the ward, so you're there, instantly, seconds. Because they will, if there's any problems, ring down to the other wards to say... but you've still got to get, you know, up there. But that's just the mum thing, isn't it? You want to be there instantly. So I don't know, really. Because it's quite difficult, you know; it's so intense here, and you do need to have that break away, but it's finding the space. And to me, a room that stays empty maybe a few nights a week with a bed in it could be put to much more better use. So, sleep in the cleaning cupboard on a put-me-down bed, that's fine.

(17Mother, Lower)

Father: It's basic, isn't it, really? It's what you need, it's a bed and a chest of drawers.

Mother: Basic but clean, tidy.

Father: Yeah. It's all you need, really.

(19Mother & Father, Lower)

Staying close to the child was important for most parents and this made it very difficult for smoking parents. The stressful nature of the situation combined with need to go off hospital premises to smoke was seen as problematic.

Mother: Yeah. My only gri-, I have only one gripe. And it's not really...well. We have to go... and I know this is just something really minor, but, because we've been quite stressed, because he's been poorly, and we smoke, and we have to go off the premises to smoke now. And I just think, okay, not everybody smokes, whatever... but at times like this...you need that...

Father: ...you don't want to be leaving the hospital grounds.

Mother: ... and you don't want to have to go far away from your child. They used to have rooms where you could go and smoke. Non-smokers won't go in there, so I don't see what difference it makes.

Father: Well, as I've said before. Going into a smoking room... I don't particularly like that, so going outside I don't mind. It's the fact that I've got to go off hospital grounds. We have to go completely off the hospital grounds.

(19Mother & Father, Lower)

Care of parents

Staff, especially nurses, were widely reported as caring for parents and to a lesser extent members of the extended family, in addition to caring for the sick child. Most frequently (17) they provided emotional support.

Yeah, they do, yeah. And like, if you want to talk to them, about anything, really, (?) worries, or if you're just feeling down, they just... like, the liaison nurse we've got, and she says just ring her anytime, so they are good if you feel like you need to talk them, so...

(09Father, Lower)

Yes, yes. I'll tell you, they were comforting, personally, to me, when [another child's name on the ward] died.... You know, the assurance was there, all the time, I thought that was lovely. I mean, I'll remember that for the rest of my life, I really will.

(15Mother, Lower)

Everyone was there, everyone was incredibly supportive. But when we were in this room, my husband and I both felt that we were literally, we were very much in their hands, being protected.

(16Mother, Lower)

Yeah, if whoever needs a hug or a talk, then...

(19Father, Lower)

In a single account, emotional aspects of the time on the ward were considered to be private, and emotional support from staff was not considered necessary.

Interviewer: AND DID STAFF ACTUALLY PAY ATTENTION TO THE WAY YOU WERE FEELING?

Father: Well, we don't discuss many things about that with the staff, I mean that's private.

Interviewer: OH, YOU PREFER NOT TO DISCUSS YOUR FEELINGS?

Father: Yes.

(14Father, Higher)

Less frequently (7) staff were reported to have taken care of parents' physical needs, most commonly encouraging parents to get some rest, but on occasions, providing food, medication, and medical advice.

Father: And the doctors diagnosed you as well, when you came out with your rash.

Mother: Yeah, he said, "You're not under 18, so I shouldn't really be treating you, but it looks like it's just an allergic reaction to something" so he sent me to the doctors, and I got some cream.

Father: That's another good thing as well, that, you know, if you become, if you feel ill or anything like that, the doctors will look at the parents as well and...

Mother: So, here, they do look after you, and they do make sure that you're okay and they'll tell you if you need to go and get your rest. Because I was expressing as well, and they helped me do that... and everything. They were really good, they were really good.

(19Mother & Father, Lower)

Yes, very supportive. Silly things like bringing paracetamols for a headache, and a nurse brought me a slice of toast actually,

because she said, "You haven't eaten." So, yeah, they've... they've absolutely... I just, I can't praise them enough.

(11Mother, Lower)

Parental stress

Unsurprisingly, being on the PICU was a time of acute stress for parents.

It's traumatic, that is for sure. [...] it's just been really really difficult, just... because you do start fraying at the edges, I tell you.

(05Mother, Lower)

I think I went in shock, I couldn't even think. I didn't even know where I live, when they asked me. Yeah, the worst thing in the world.

(11Mother, Lower)

I mean, I did need support, the first couple of days I couldn't have been on my own. But now I'd be quite happy to sit at the side of the bedside talking to the nurse, you know, now she's stable.

(11Mother, Lower)

The main sources of stress, in addition to the child's medical condition, were periods of waiting (8), the child undergoing particular procedures (12) and in one case, witnessing the death of other children on the ward.

No, I think probably the most upsetting part of it all was probably just the waiting for the operation, to be completely... that's probably the most stressful process that we all... every time a door goes, you're always like looking... and obviously when the surgeon walks in, obviously you can see him walking through the door but it's like the silence before he goes to you. So I suppose that is probably the most worrying and most stressful time. Until you get him saying that everything's fine and it's (?) like a big relief. So then it's, it's... just the general (?) going day-by-day now really.

(09Father, Lower)

I find the whole procedure upsetting to watch, I really really do. I, [child's name]'s been in intensive care seven times and I find every single time even more difficult. I find this particular time more difficult, even just taking bloods is horrendous. I actually used to sit there, or stand there, and comfort the child, comfort [child's name]. Now I just move away, because I don't want her

to associate me with needles and pain. And I actually move away now, I will not stand there and comfort her, and put my hand on her head or... I just let the nurses and the doctors do that, and I actually walk away. Because, you can see it in her eyes, she's older and she's thinking "What the hell are you letting these people do to me?" you want to comfort her, you want to make sure she's okay, you have to walk away though, because I don't want her to associate, her not trust her own parents because...yeah.

(07Mother, Higher)

Very stressful, and I think the most stressful I think was, because [another child's name on the ward] died...And I think that's taken its toll on me, and it's very hard, it's very hard, because you get to know the mums here; we've been here for 15 days, so...when we're in the family room, you do, you talk about your children, you talk about your life, we get to know mums, mums and dads, you know?

(15Mother, Lower)

The main sources of comfort for parents included an improvement in their child's condition (7), open communication (11) and the knowledge that their child was in the best hands (11).

It's not going to be, it's not going to happen overnight, it's going to be a long process, but he looks a completely different colour. You see, I never noticed that he was navy blue. Mr [doctor's name] said he'd never had anyone as blue as [child's name]. But I didn't notice it. Possibly because I'm with him 24/7, you don't...but he looks like a piece of pastry now, with pink lips, he does. [...] Yes, it is, lovely.

(05Mother, Lower)

No, nothing, nothing that we were aware of. You know, we were given, we were kept informed all the time, and it was wonderful. There's nothing, we've not been, at any point, had anything hidden from us. [That's] very important, to be given realistic news; no false hopes, nothing... you know, and no... "I'm so sorry, there's nothing we can do" and you know, they continually tried, everyone. Everyone con- ... and so she's still here, thank goodness, and long may she be here.

(16Mother, Lower)

He came up to the ward and spoke to me privately with one of the nurses off the ward, explained everything in detail, everything so I could understand it, and yeah, I was... I've never

been so scared in my life as I was that moment, which any parent would be in that situation. But he was, they were fantastic, you know, totally. And as soon as I got up here, all the staff were brilliant, and the fear had gone, instantly. As soon as I'd seen him, you know, monitors, tubes, the fear had gone.

(17Mother, Lower)

Communication

Communication with staff was important to parents and a major feature of all accounts (19), with all including reports of parents being kept well informed.

They were great, to be honest, we had no problems whatsoever. They explained everything to us, all the machines, explained what the plan was, what they were doing, ever... they always kept us informed, up to date; you know, if we'd go home and come back, they'd tell us everything that had happened while we'd been at home.

(06Mother, Higher)

Yeah, they have. But...well...I think they've helped us in terms of just telling us what's happening, I think that's all they can do. They're not gonna... we're wise enough not to know that. They're not going say, "Oh, everything's going to be all right, there there" you know, it's more of just keeping us informed, and I think that's more important than anything for us. And just telling us what's going on.

(07Mother, Higher)

No, no, there was... obviously not ever experiencing anything like this before, but... it was, it was really good, no, everyone was, like, telling us everything they were doing and like, always saying if we've got any concerns, just ask, or... anything like that. So no, they've said us everything. So no, it was really good.

(09Father, Lower)

Parents generally reported that they felt able to ask questions and felt happy to do so.

Yeah. If we ever had any questions or worries, they've always sat down and gone through them with us. They've always got time for you. Yeah, yeah, with surgeons, they visit everyday, the surgeons come down, and (view him?) and they ask if I've got any questions, same with doctors, and same with the nurses,

and yeah, they've all... really open, and like, discuss anything, any worries you've got, or how things are progressing, and stuff like that.

(06Mother, Higher)

Not really, no. I've been concerned and, if I notice the machines beeping or... they'll explain everything to me, and say, "Don't look worried" because they can see sometimes I'm panicking and they'll explain it all, and show me what they're writing down, you know, because they record everything, it's all lots of figures and numbers and they explain what they're doing, all the time. So, you know, I can't think of a particular incident, just overall really good. And they've said, if I've ever got, if I've got a concern about anything, no matter how small or silly I think it sounds, just ask.

(11Mother, Lower)

Generally information was given in a form that parents could understand, though sometimes it took them some time to take information in and it was important that they felt they could ask the same questions more than once. Sometimes the nurse acted as a translator between the doctor and some parents. The continuous presence of a nurse appeared to act as an aid to communication.

Mother: Just, yeah, across the board, to be honest... everyone, you know, explains everything really well.

Father: In a nice manner.

Mother: Yeah.

Father: I mean, you know, they're very capable.

(08Mother & Father, Higher)

No, no. It was, it was fine. It was all quite simple to understand and they went through it well, so, no [complaints]...

(09Father, Lower)

It is, but our surgeon, [surgeon's name], was particularly good, because he would tell you in a way that was very clear, and you couldn't possibly misunderstand what he was saying. So, he wasn't blunt at all, but there was no way you could not understand what he was saying, with the language he was using, it was very clear.

(16Mother, Lower)

Yeah. And I ask them, I still ask them now, what that blue line means, you know. I've asked them probably half a dozen times in the last two days, and they still just, they tell me. It's so

much to take in, and you're worrying about your child at the same time. But they have never, you know, since I've been on here, they've never let me down, they've always explained something. And they were very good yesterday when they got a group of doctors. And my son's nurse was dealing with him. And while they were saying things, I was kind of listening, but they were talking in their terms, and she was relaying it back to me at the same time, what they meant, and that, you know, so that was... and then when they've gone, they say, right, well, they want to do this. And they just explain it better. I mean, the doctors are really good, you know, you can ask them anything, but the nurses, I can't fault them with... spot on.

(17Mother, Lower)

Communication problems were identified in some accounts (7). Problems associated with doctors included the failure to volunteer information, failure to provide comprehensible, timely or sufficient information. Where doctors' communication skills were found lacking, nurses generally appeared to make up for the deficiency.

Father: Sometimes. It is...

Mother: Yeah, I mean...

Father: They do that doctor-talking, you're like, "What?"

Mother: Yeah. They talk to the nurses and they talk to the other doctors before they talk to you, obviously, and then they come about 10, 15 minutes later and tell you what's happening and stuff like that, so...

(18Mother & Father, Lower)

Father: Yeah, there've been a couple of times. But when they look at your face and they see that it's gone...you know, you've got a blank expression, then they go back over it and re-, you know, retell you what it is. I mean, obviously...

Mother: Sometimes the nurses can explain things...

Father: ...things better than the doctors can.

Mother: ...a bit clearer.

(19Mother & Father, Lower)

Other barriers to communication identified by parents included the stressful nature of the situation and their inability to absorb and retain information and the parents' lack of medical knowledge.

Yeah, they were clear in my understanding of it, but to be fair, I'm not from a medical background, I'm an engineer by trade, so I don't really understand a lot of the terminology anyway. But it probably was just as well in a way, because I didn't realise how

ser-... I knew it was life-threatening, but I didn't take that on board, if you know what I mean, I just wouldn't accept that.

(10Father, Higher)

I think on the first day we got here, when [nurse] came out to talk to us, the nurse that was looking after [child's name] that day, she just got on with it, because she was very busy with [child's name], and we didn't ask,it was much later in the evening, we didn't even still ask questions, she just got on with her job because, it was just so critical to keep [child's name] on, on things. It's only when we know that there is some progress and we can see some light at the end of the tunnel that we will then start asking questions.

(07Mother, Higher)

Needs of the wider family and children

The time during which their child was in the PICU was generally reported as being stressful for members of the wider family and friends.

Our daughter, who's taking her A-Lev-, sorry, her O- Levels at the moment, she's not too good...she's come out in a... she's got a rash over her at present time,... and it's a stress rash, and they gave her some cream for the...she can't concentrate, she's more worried about her brother. Her GCSEs don't start till the 9th of May, ... she's not coping too good at the moment. Our son's slightly younger, he... or seems to be coping slightly better.

(10Father, Higher)

Yeah, it's caused quite a few problems, hasn't it? I mean, it's sort of upset my husband's side, and it's upset my side, because my mum's got a nine, ten year old daughter ...she were ventilated. But as soon as we told my mum what had happened to her granddaughter, [child's name], it really did upset my mum...and it's brought a tear to my dad's eyes a few times, so...

(18Mother, Lower)

In addition to reports of staff caring for the parents, the needs of other family members including children were generally considered well provided for by staff on the unit. Some parents preferred to keep their other children away from the PICU for fear of upsetting them.

Yeah, and the nurses, like, help her colour in and keeping her busy as well..., likes toys and stuff ...so yeah, she seems to be coping all right with it, like she's seen his little scar that he's got, and she's taking it all in as much as a 5-year-old can and so, yeah, it's, it's, it's fine, I think.

(09Father, Lower)

Parents with other children generally reported feeling torn between the need to be with their sick child and the needs of the other children.

There's been a bit of upheaval, and he's been passed around a lot. Just because it's been so difficult. You're up here, and you want to be there, and when you're at home, you want to be here as well. But we've got (good) family, and he goes to nursery and things other times, just...

(06Mother, Higher)

Discharge

Most parents were interviewed at a point in their child's treatment where discharge arrangements had yet to have been discussed. One parent was aware of plans to discharge their child and had been told what to expect.

It's difficult to know, but if all goes well, yes, if everything goes according to plan, we've been given a procedure, what's going to happen next. It's not written down on paper as yet, but when it happens, they just really told us what's expected of us next.

(10Father, Higher)

Some parents (5) either anticipated problems associated with the discharge process or reported on their prior experience. The main concern was leaving the caring environment of PICU, including the machines that monitored their child's condition and the staff who provided one-to-one care.

Yeah, I mean, we were always told sort of when, discharging, kind of, leaving PICU is always kind of a touchy time, because you tend to, PICU's a nice place to be because you've always got a nurse, you know, nurse all the time and things with them, and so you kind of feel a little bit unsure when you leave PICU. tend to be almost sort of thrown out into the open world kind of thing, so... and you're just not quite sure, are they going to cope? ...are they ready to kind of leave PICU?....., you'll never feel a right time to kind of leave PICU I think ...

(13Father, Higher)

One parent was concerned by the possibility of their child being in pain. Previous problems with the discharge process included lack of beds at the local hospital and being unable to be discharged to home.

Well, yes there is. If there's no beds at our local hospital, we get transferred to the ward here, until there is a bed. Because once your child is well enough to get out of intensive care, the bed's quite critical here, I presume, so the key is to transfer us

upstairs, if there's a bed upstairs, until there's a bed available at our local hospital.

(07Mother, Higher)

Those with previous experience generally reported being kept informed and a smooth transfer.

In the above account, these data were first analysed blind to type of unit. Reviewing the coded data split by units with higher/lower extended nursing roles, there were no discernable patterns or marked differences in parents' views of PICUs or staff.

Summary and conclusions

The main findings describe a care setting with anxious and fearful parents of critically ill children. Three main themes describe 1) satisfaction with care, 2) attributes of the unit and care team and 3) meeting the needs of the family. There were no discernable differences in parents' views when comparing interviews taking place in units with either higher or lower levels of nurses in extended roles.

1. Parents were all very positive about the units and staff and believed that they were getting the best and high quality care to ensure survival of their child. Waiting and separation from their child during admission, surgery or procedures were most distressing. They were appreciative of the continuous bedside nursing, immediate access to medical expertise and information on the units. There was evidence that the staff worked to ensure the comfort and dignity of the child as well as meeting psychological and spiritual needs. Parental involvement in care on the unit was well supported. There was some evidence of shared decision-making.
2. Without exception parents praised the unit and care teams. Although the precise roles of doctors and nurses were ill-defined by parents, doctors were seen as care directors with the expertise for care decisions, which nurses put into practice. Nurses provided one-to-one care, relayed (and interpreted) information from doctors, and acted as patient advocates. Only one account noted nurses making changes to the child's care. This was judged acceptable by parents within limitations, providing the changes were only minor and the nurse's training and experience were high. Occasionally parents did have a problem with the attitude of specific members of staff, either an uncommunicative doctor or individual nurses who failed to provide adequate care or hurt the child. Parents hesitantly

mentioned and tended to excuse any shortcomings such as long delays, bed shortages, noise and heat, poor building and equipment, or concerns or complaints about aspects of care.

Staff clearly cared for the needs of the family too and gave them emotional support. Main sources of distress for families were waiting and uncertainty during procedures and witnessing another child's death on the ward. Reports showed parents felt they were kept well informed and able to ask questions, although some communication problems were described. The majority of these parents were accepting of some restrictions of access to their child, and any limitations of old buildings, basic or overcrowded facilities.

4.2.2 Consultation with users and user groups in wider critical care settings in the NHS

Background

We undertook a consultation in June 2008 with users in other NHS intensive care settings. The overall project aims and lay summary were circulated to volunteer user representatives (5) and charity organisation representatives (4) of adult intensive care, paediatric intensive care and neonatal intensive care. Those who had agreed to participate in the consultation on the report (3 volunteer users and 4 charity representatives) were sent the full report *UK PICU Staffing Study: Families' views and experiences of PICU* (see Section 4.2.1). They were invited to take part in focus group meetings, or for those unable to attend a focus group, they were invited to give a telephone interview or to send a written response. Participants were asked to consider whether this PICU report was similar to their experiences of intensive care settings, or if there were significant differences or any gaps in the issues covered.

Four participants took part in one focus group, two sent written responses and one agreed to a recorded telephone interview. Four represented neonatal intensive care, two represented adult intensive care and one paediatric intensive care. The focus group proceedings and telephone interview were audio-recorded and transcribed verbatim. Transcripts and written responses were analysed to explore content and where there was broad agreement in the experiences and views of relatives of patients in wider critical care settings in the UK compared to those we report from PICU. Any noted differences, new issues or perceived gaps in the parents' PICU report are reported.

User satisfaction and generalisability of the PICU users' views to users in wider IC settings

Overall, the report was judged by the Paediatric Intensive Care Charity representative as a valid and a positive reflection of high quality care that showed staff were responsive to families' needs in PICU. With caveats, it was viewed as evidence of improvement in a family-centred service compared with some of the early reports of parents' experiences of intensive care for their children (Kasper & Nyamathi, 1988; Carter *et al*, 1985; Carter & Miles, 1989; Farrell & Frost, 1992; Smith *et al*, 2007).

I felt that there were very very many positive comments ...everybody now is much more aware of the situation for parents in PICU ...lovely comments, about some good teamwork, and about explanations as to what was happening. But I was also interested to note that during the whole of the report, there crop up all the usual concerns for parents that have been there over the years.

(Paediatric IC Charity representative)

The neonatal charity representative agreed that similarly for NIC: *"in this report the vast majority of parents are very appreciative of the (paediatric intensive) care, not at all critical of it. And I think, by and large, the same is true of parents of children, babies on the neonatal unit."*

The adult ICUsteps steering committee had also considered and discussed the report. One reported back:

Comments that have been made and members from the (adult intensive care) group themselves have said that... when reading the report, the items covered were so common to adult intensive care that I often forgot the study related exclusively to paediatrics.

(Adult IC user group representative)

All those consulted noted that these parents' experiences (e.g. separation or delay at transfer/admission, feelings of extreme stress or panic, instances of poor communication, anxiety around time of discharge, as well as heroic, helpful and supportive staff) were all recognisable for relatives of both Adult IC and NIC patients. Participants weighed up the PICU report against their own experiences. They highlighted some similar aspects of good practice in the report that they had found in Adult IC and NIC, but also disagreed on some points and used their own stories to illustrate their different experience. Different accounts and gaps in the report arising from the consultation are reported below.

User groups also highlighted the limitations of this study. They noted that all parents were interviewed in the units when their child was still receiving critical care. All children had quite short term stays in this episode when interviewed (<24 hours to 11 days (although some of the children had been in PICU many times previously)). There was no follow-up of parents' experiences after discharge. Due to ethical constraints, clinical staff were also the gatekeepers to parents invited for interview and no parents of children who had died were included. It was suggested that, clearly, these study design features might produce a more favourable report of PICU users' views by:

1. introducing selection bias (due to staff inviting only parents who were likely to be satisfied)
2. relatives avoiding criticism in case it compromised their child's on-going care (despite assurances of confidentiality and that any information given would not be disclosed to health care providers)

3. introducing temporal bias, as it does not take account of parents' longer term assessment of PIC in relation to follow up, rehabilitation and downstream quality of life measures.

Elaborating on the final point, one adult IC user explained that at the time of interview these parents were likely to be relieved to be in the best place possible for their critically-ill child. Parents were grateful for their child's survival and for the technical and clinical expertise and dedication of the critical care staff. He went on:

This euphoria may be cruelly shattered when the patient leaves intensive care and there is little or no support at ward level and at home.

(Adult IC user group representative)

Differences in views and experiences

Extended nursing roles and the care team

The team

Those consulted had noted our PICU parents' comments on good teamwork, but it was not an issue they had considered or had had brought to their attention. An adult ICU group representative described models of "team nursing" to improve continuity for patients, and 'shift teams' (or skillmix) being different by day and night. But the definition, boundaries and composition of the 'team' changed according to what was being described. The topic that did arise in relation to team work was communication (or lack of it) between staff in NICUs and Adult ICUs (see below).

Professional roles

Lay users of Adult and Neonatal IC generally had clear-cut views of the roles of doctors and nurses and everyone valued expertise. Doctors review plans, are directors of care, and give diagnoses. Doctors make medical decisions. These users noted that shocked relatives often did have difficulty absorbing medical information, sometimes feel they have limited access to doctors, and that Junior Doctors in particular could benefit from more '*people skills*' (Neonatal IC user group representative). These findings are broadly similar to those arising from the PICU parents' interviews.

An expert neonatal charity representative thought that experienced specialist nurses may be technically better at performing some procedures than the rotating cohort of Junior Doctors, especially those recently arriving in post. The short term nature of some placements of junior trainee doctors in critical care settings was questioned. However, it was also noted that

there were barriers to autonomous weaning by nurses and to ANPs attempting to implement nurse-led weaning in some adult ICUs.

Only a small number of very senior nurses who would tweak ventilators in adult IC and only where nurses not only feel competent but also confident.

(Adult IC user group representative)

In contrast, the possible blurring of roles between doctors/expert nurses was not clearly discerned by lay-users in this consultation. Nurses were seen as being by the bedside all the time, although in NIC the lack of one-to-one nursing was highlighted. Nurses built up relationships with the families and become advocates for the patient and family. Notably, lay-users with experience of NICUs and PICUs did not agree that medical/nursing staff were interchangeable for quality clinical care. They also had a negative view of the blurring of the roles between specialist IC nurses and unqualified health care assistants, thus:

There were loads of nurses with social care level training using intensive care equipment on which they had no experience or experience of.

(Neonatal IC user group)

Similarly parents did not agree that nurses could substitute for doctors when they wanted a consultation about their child's condition.

Finally, a neonatal user explained how she wanted "the best" expertise:

If we go (to an appointment), and don't get a Consultant, I feel really affronted. Because I just perceive a Consultant to be the 'best doctor' and if we get the Registrar I am not happy.

Well, you're looking for the expertise, aren't you? Expertise. That's what you're wanting. Because you, you see that person as being the person with the most expertise and experience. So...

(Adult IC user group representative)

Communication

Users and relatives from all IC settings agreed that most staff were good at giving them clear information and repeating information as often as they required. This appeared to be particularly true for senior doctors (Consultants, Surgeons, Registrars) and nurses. The problem that some doctors failed to communicate effectively (by giving information relatives

could not understand) was endorsed by neonatal users and it was suggested that Junior Doctors may seem to avoid talking to parents at all.

Researcher: So what should Junior Doctors be saying to parents about what they are doing, and why they might be unable to... enter into a dialogue about the child at the moment?

User Group Rep: Be truthful. 'I'm taking his blood, it then has to go up to pathology, it will then be read in pathology, and it will be assigned to MY senior, who is the Consultant, with whom we are working together, to help your child, and this is the best way of doing it.'

(Paediatric IC user group representative)

It was suggested this was an issue that might be improved by more and better training in communication for Junior Doctors, particularly when they were approached by relatives for an opinion when investigations were on-going. Those we consulted also gave examples from NICU of receiving conflicting advice or having their stated care preferences disregarded by nursing staff (e.g. bottle feeding despite maternal expressed milk being available).

Adult and NICU users also commented on their experiences of the detrimental impact of poor communication between staff, e.g. lack of continuity at handover, disrupted care plans, lack of continuity of staffing, use of bank nurses and staff shortages, lack of continuity after discharge. Interestingly, it was also suggested that there could be too much communication between either staff and parents, or staff members in front of parents. This might include indiscrete and unprofessional discussion of unit organisation/personnel/equipment/staffing shortages with users that can cause users concern.

This nurse I was telling you about.....she said, you have to maintain your own professionalism in terms of don't moan to somebody else, like, 'Oh, we're so short-staffed and now I've got to do another shift and dadadadada...'parents will pick up on that, and they will worry that their baby's not being cared for properly because they are short-staffed, and she said she's known parents who will choose to basically stay by their child's bedside all night because they fear that there aren't enough staff to maintain adequate care.

(Neonatal Charity representative)

Patient care: Quality of care

There were some shortcomings in quality of care and concerns described by NICU users. For example: it was suggested that nurses spent too much time on administrative tasks and arranging shifts and rotas; these users observed that there was wide variation in the caring attitude, skills and training of different nurses and that might depend to some extent upon the model of training in the country of origin of the nurse; it was believed that if there were staff shortages their child would miss out on some care unless parents were present and vigilant; and that specific procedures had been done incorrectly, inappropriately or inexpertly by staff.

In the PICU report, one parent of a child frequently admitted to PICU had previous experience and anticipated difficulties only after discharge from PICU to general wards. On general wards it was suggested that parents were needed by the bedside and to be vigilant on their child's behalf.

On decision-making or parental/relative involvement in care, there were no strong differences raised compared with the accounts in the PICU report. From the consultation the views varied about whether parents and relatives should/could/or would want to be present at transfers, during invasive procedures, or during ward rounds in a similar way to that found in the PICU report. But neonatal users suggested that parental presence at ward rounds was an important issue and can be achieved with thoughtful re-organisation and without compromising confidentiality in intensive care settings.

The unit

User representatives from other intensive care settings questioned our parents' report of good organisation in PICUs. They suggested that not all intensive care units are well organised, especially if they become busy and make mistakes.

They also described how the built environment was old and poor in some hospitals, and again unlike the PICU parents, these users judged some environmental conditions (such as uncontrollable ward temperatures or noise) to be unacceptable. In relation to accommodation for relatives, it was suggested this was not so much of an issue for more locally accessible adult intensive care units where relatives can go home. However, parents of newborns admitted to NICUs far from home did need accommodation in a similar way to parents with children in PICUs, and NICU parents reported finding it difficult to get and keep accommodation throughout their infant's stay.

In terms of funding and equipment, the charity representatives for both neonatal and adult intensive care felt that mostly there was no problem due to routine updating of the essential high-tech equipment in their settings.

Technical equipment yeah, I think a lot of neonatal units don't have a problem with equipment, although there is always something bigger and better out there, you know, if the budget allowed. ...units do choose to set up charitable funds of one sort or another, and ...sometimes that money isn't just used for equipment, it's used for staff training, and bursaries, which is sometimes a better use of it.

(Neonatal IC Charity representative)

I have to say equipment seems to be something which is updated regularly – at least in our unit.

(Adult IC user group representative)

But the focus group participants also agreed with the neonatal user who observed that any poor quality or shortages tended to be around the ward-based equipment: *'It's the non-medical, non-essential equipment, for example industrial-sized breast pumps, you know, and also the normal ones. There's so few of them'* (Neonatal IC user group representative).

Needs of the Family

It was reported from Adult ICUs that relatives start to look upon staff as friends and some say they miss ICU and the support received when they leave that environment.

A neonatal representative agreed but with qualification:

Certain staff are very supportive of parents and very welcominggive them lots of time to explain issues.... and other staff are much less so... some staff kind of give the impression (to parents) that they're getting in the way.

She also highlighted a particular dilemma for wider families to support parents with babies in NIC:

Often relatives don't really know how to celebrate or acknowledge that... baby is born very very early and critically ill.
(Neonatal Charity representative)

There is evidence of some support networks post-discharge for parents in neonatal intensive care, fostered by the neonatal intensive care charity, but that is rare for adult IC relatives.

Gaps in the PIC report

Overall there were six areas where (from their experience) the participants thought there were gaps or too little emphasis in the users' report about paediatric intensive care.

These were:

1. infection control
2. pain control
3. delayed access to the unit for relatives
4. timeliness of diagnosis and counselling
5. step-down to general wards or discharge home
6. equity of access.

1. Infection control

I think there's one big gap, and that's infection control, which wasn't really covered at all.there were some parents whomade a small complaint because a nurse didn't wash her hands, ... but one of the big issues in the (name of region) perinatal network for parents is infection control. The topic that comes up again and again.

(NICU user)

In contrast to the PICU report, NICU users were reported by these representatives to frequently voice strong concerns about infection control. NICU users gave details of variation in NICU visiting arrangements, provision for siblings, unit overcrowding, and examples of innovative infection control procedures, as well as failures of effective implementation. Adult IC representatives endorsed their specialty's approach to implement infection control procedures, but thought that higher levels of visitors in PIC and NIC posed those units more of a challenge.

2. Pain control

The PICU group representative was concerned about the quality of pain control for children:

There was an overarching problem, I think, throughout (the

report), the concern of pain. And they (the parents) didn't quite understand when the children might be in pain or not be in pain.

3. Delayed/difficult access to units

One lay user strongly emphasised receiving many user complaints about how delayed or denied access to neonatal intensive care units heightened relatives' panic and anxiety. These included: the universal car parking problems at hospitals, having long waits at security doors to intensive care units, or where close relatives (e.g. grandparents on behalf of parents at another unit) were denied access to neonatal units. Variation in rules and practice at different NICUs caused parents confusion and anxiety when transferred. Our report in the PICU setting had noted waiting and separation being a major source of anxiety to interviewed parents.

4. Timely diagnosis and counselling

In addition to clear information from doctors, users also noted the need for timely and early support following diagnosis. Early access to counselling to help interpret the diagnosis and prognosis was important.

5. Step down

It was emphasised that step down to general wards or community care was a very difficult time for relatives and adult patients. NHS staff in general settings might not appreciate the suffering/trauma undergone during IC care and the ongoing weakness, and support and rehabilitation still required.

Step-down from intensive care to the ward for I would say 97% of our patients is just such a huge trauma.
(Adult IC user group representative)

Most parents in the PICU report had yet to experience step-down.

6. Bed shortages, access and equity at admission

It was highlighted that neonatal transfers, because of cot shortages and full units, were commonplace. This may be due to shortages of cots, but was often due to shortages of trained nurses to staff the cots. One neonatal user raised questions about policy, management and spending decisions that allowed health care tourism or prioritised information translation services ahead of providing equipment and adequate staffing.

Users in the consultation reflecting on their stakeholder contribution

Finally, these users and representatives reflected on their roles and perhaps more experienced contribution as stakeholders to inform the service, policy makers and providers. One neonatal user representative had agreed with many of the positive aspects of the PICU report, but was also aware that her contribution to this consultation was more critical with more grievances and listed shortcomings.

My commentssound a bit negative but it's always the bad days you remember the most!

(Neonatal IC user group representative)

User representatives also reflected on their own representativeness, and whether some users in user support networks were so affected by their experience in intensive care (and perhaps particularly bad experiences) that they could continue to be involved for many years.

There are people who will carry on being associated with various support groups for what most people consider to be an inappropriate length of time, (and for an) inappropriate reason.

(Neonatal IC Charity representative)

When we presented how we've set up and developed our (support) group, some of the professionals have actually raised that, in terms of... do people use this as a crutch, do they... are they disruptive? ...we haven't found that. We've found ...the new users... will almost look towards people (older users) as a sort of a stepping stone, as a goal ...18 months, 2 years down the road.

(Adult IC user group representative)

Evidence from both the neonatal and the paediatric charity representatives showed how their organisations' activities had evolved from initially funding support and equipment to undertaking a strategic advocacy role for policy in their specialty service area.

For years and years and we sort of spent millions of pounds on equipment....which we don't do anymore. It was a conscious decision of ours about 5 or 6 years ago not to do that. I mean, from our point of view the staffing issue is much more of a concern than the equipment issue... And (Charity name) is campaigning on it.

(Neonatal IC Charity representative)

*I'm on the (name) Supervisory Board in (city), they're looking at service reorganisation. And there are comments (on medical staffing sustainability and training needs) by senior people...
(Paediatric Intensive Care Charity representative)*

Summary and conclusions

Users and representatives of intensive care charities for adults, children and neonates were consulted on this report of parents' views of PICU. It was recognised as a valid and positive reflection of high quality care, well representing the experiences of relatives in wider intensive care settings. They agreed that the great majority of users and relatives in critical care settings were very appreciative and not critical. But it was suggested that there were limitations in the study design that might have produced this very favourable report, including staff as gatekeepers before approaching parents, and parents perhaps reluctant to criticise during their child's ongoing care.

On relative staffing roles, positive accounts of the way the care team worked together in PICUs was not an issue that the lay users we consulted had considered or had had brought to their attention before. One expert charity representative noted that specialist nurses may be more experienced and technically better at procedures than a rotating cohort of training doctors. Above all else, lay users valued expertise, but disagreed that medical/nursing staff were interchangeable, and had a negative view of blurring of roles between qualified nurses and unqualified health care assistants. Those consulted here were more critical of any shortcomings of care. They raised new issues and identified gaps in the PICU report from their perspective. New issues included too much or unprofessional communication between staff and relatives that could cause parents concern, and poor communication between staff e.g. leading to poor continuity or disrupted care plans. Six topics identified as gaps or as under-emphasised in the PICU report were: infection control, pain control, delayed access to the unit for relatives, timeliness of diagnosis and counselling, step down from IC, and equity of access.

5 Economic evaluation

In this section an economic evaluation approach is used to describe, synthesize and interpret the evidence from the different research strands to assess the impact of extended and non-extended nursing roles.

Evaluation of extended roles in PICUs

The most efficient mix of different types of staff is a prerequisite for an organisation or health care system that wants to maximise the health of its population from the available resources. Changes in the roles and activities of different staff groups need to be carefully evaluated to ensure any change in the way health care is provided is the best use of resources. We will use the framework of economic evaluation to frame the nature of information that is required to enhance the evidence-base to help make decisions about alternative workforce configurations (Kernick & Scott, 2002).

Design of the economic evaluation

We use a balance sheet approach to indicate evidence of impact and variation between the extended and non-extended nursing role units across a number of factors that this study covered. The study did not propose to undertake a full economic evaluation of extended roles within the paediatric intensive care setting. It is a partial economic evaluation focusing primarily on the effect of extended roles on staff costs. The study is concerned with the impact of new workforce models on staff. Alternative workforce models could be expected to have implications for salary costs but alternative workplace configurations may also impact on indirect staff costs such as job satisfaction, retention and absenteeism. We intend to identify all forms of staff costs, both direct and indirect, that would be relevant to compare across the extended and non extended workforce configurations. We will then consider the evidence from the study to identify where these factors may differ across the workforce configurations and where possible measure these effects from the study or report evidence from existing literature. We will consider the effects on staff costs along side the measures of care process and outcome used by the study. The objectives of the evaluation are:

- to compare staffing costs of units with extended roles to those with no extended roles
- to consider the impact of new workforce models on staff costs alongside risk-adjusted outcomes of length of stay, unplanned re-admission, and health care-associated infection and users' perceptions of care.

Evidence of impact on staff resource use

The relevant aspects impacting on the staff resource are listed in Table 36 alongside the source of measurement for that particular aspect. References to evidence from published sources are also reported.

Table 36. Identification of Staff resource costs

Staff related costs	Source
Staff contracted salary costs	PICU study census 2005 PICU unit profile 2007
Training costs	Unit profile
Replacement labour for tasks now not undertaken	Nursing activity observation component Staff interviews
Freeing of alternative labour input	Nursing activity observation component
Change in Professional motivation and job satisfaction	Staff survey Staff interviews
Use of material resources which may be indirectly related to staff configurations	Out with the scope of this study

Staff contracted salary costs

Section 2.1.3 reports the raw salary costs of nursing and medical staff within the 12 PICU units in the study and the salary costs adjusted for maximum number of beds that can be occupied. The mean cost per maximum bed (nurse and doctor staff costs) was reported in the higher extended role units as £210,307.50 and in the lower extended role units as £240,981.50. This represents a 14.6% difference between the unit groups. Taking total bed days into account, the higher extended role units have average staff costs per bed day of £818.28 with lower occupancy. This compares to £581.45 in the lower extended role units and represents a 28.9% difference in this measure of cost between the unit types. The closer measure of cost between the units in terms of maximum staffed beds that can be occupied is not surprising (given the similar levels of WTE nurses per bed adopted by PICUs to comply with PIC standards requirements). Staff

costs should be similar across units in terms of maximum number of beds since nursing staff make up nearly 64% of total nurse/doctor salary costs. Larger and opposite differences in average costs across the two groups of units emerge once adjustment is made for bed activity. This suggests that this measure of cost is being driven by variation in demand for the beds across the two unit types. However there is no evidence to suggest that these demand variations are factors in workforce configuration. But this does indicate that cost estimates are sensitive to controls for unit size and activity. This is confirmed by regression analysis that indicates more variation in costs is explained by a model using maximum number of bed days than a bed activity measure. This again indicates that costs are driven by a fixed cost related to number of beds and not activity within that bed. However this evidence should be treated cautiously as these figures are based on a small number of units and are based on contracted WTE figures and do not include paid overtime work. In addition, economies of scale may lead to differences in costs that are driven by a function of unit size rather than the alternative usage of extended roles within the units (Jacobs et al, 2004). In this study, the higher extended role units were on average larger units in terms of maximum number of beds but exhibit lower occupancy rates (lower number of bed days) and so it is not clear how any economies of scale may be impacting on the cost figures.

Training costs

Alternative staff configurations which are based around extended tasks should consider the additional training costs required for the alternative staff to undertake the tasks competently. If the task involves a direct substitution of one workforce for another, then, unless training costs for that task differ significantly across staff groups, there should be no consequences for cost. There would be a re-allocation of the cost of training from the original staff group to the new staff group. If the required training for the alternative staff group involves different methods and/or different time to train, then there may be cost implications. If a task is to be performed as an extended role for a new staff group but remain a role for the original staff group, then additional training for the new staff group will be over and above training costs for the original group.

The unit profile analysis suggests that 'role blurring' was commonly referred to by doctors and nurses in interviews of staff (Section 2.2) from units with lower extended roles. This suggests they do not regard extended tasks as a substitution of roles by one group for another but more of an overlapping of roles by staff groups. No views on this were stated from higher role units and so there is no evidence to suggest that higher extended role units have substituted training costs away from doctors (substitution) or added to training costs (overlapping roles).

There is evidence from the general views of the units on education and training that there are differences across the types of unit in terms of attitudes to training which may be reflected in differences in associated costs. Higher extended role units reported positive views on education and training with lower units reporting more mixed views. Lower units report increased needs for training and the *Knowledge and Skills Framework* (KSF) within *Agenda for Change* was viewed negatively. Higher units reported no change in training needs and KSF was viewed as neutral. Some lower units report having no educators within the unit. This suggests that higher extended units may already include some additional costs of training and support through additional staff and as such within their reported staff salary costs.

Replacement labour for tasks now not undertaken

Direct nursing staff impact

For nursing staff, increasing or extending the tasks assigned to nurses could either involve the need to hire additional nurses and/or will increase the workload of the existing nursing staff. An increase in the number of nursing staff should already be reflected in salary costs with nursing staff costs contributing a higher proportion of total staff costs. An increase in workload for existing staff should also be reflected in an increased use of overtime, both paid and unpaid. This should result in higher salary costs (contracted and overtime salary) and although unpaid overtime may not have a monetary cost it may be reflected in measures of staff well-being and satisfaction measures.

We must therefore first establish whether there is evidence that the presence of an extended role has any direct implications for staff activity. The observational component of the study (Section 3) sets out to compare staff practice including the time spent on direct patient care as well as type of activity within direct patient care between the higher and lower extended role units. It indicated that there was no evidence of significant differences between the unit types in terms of total direct nursing care time or the total direct care time on extended nursing tasks and therefore on non-extended tasks. However, the evidence from the observational component of the study could be considered unreliable with large variation of direct care time within the higher and lower extended role units around the point estimates.

What it does indicate is that on average a very small proportion of direct care time was spent on the extended task. This might explain why there is no evidence of a significant difference in terms of non-extended role direct-care time. This suggests that there is no need to backfill for tasks (non-extended) that are no longer able to be fulfilled. The smaller the proportion of time spent on an extended task, the more likely is it that it can be taken

on as an additional task without the need to substitute it for a non-extended role task. This would be even more the case where an extended task is more likely to be performed by an experienced nurse who again may be more likely to be able to take on additional tasks and operate at a more efficient level and thus absorb additional tasks (at the margin). However it should be stated that this may be a function of the small proportion of time spent on the extended task and may not hold if the proportion of time spent on an extended task increased.

We now consider overtime as an indicator of an effect of alternative workforce configurations on staff. There is some evidence of differences in use of overtime between the two groups of units. Evidence from the staff survey suggests that staff in units with higher extended nursing roles were significantly more likely to work more than their contracted hours in total and both paid and unpaid overtime. However there was no evidence of any significant difference in staff working extra hours due to pressure and demands of job which may have been a result of alternative workforce roles. The difference in use of overtime (and subsequent implications for cost) may instead reflect uncertainty in demand fluctuations and be an efficient way to adapt the staff resource to demand conditions. Observed differences in the use of overtime could also reflect underlying differences in x-inefficiency between units with respect to the management of rotas and the ability to adapt staff rotas in the face of demand fluctuations and uncertainty. For these reasons it would not be appropriate in this study to suggest differences in overtime use are a valid indicator of differences across the two unit types in terms of lower and higher extended roles.

Indirect (non-nursing staff)

In order to keep overall workloads constant, the assignment of extended tasks to nurses may therefore involve an additional substitution or extension of tasks between the nursing and Health Care Assistant interface. Such spill-over or knock-on effects do not need to be considered in this study as there is no evidence of need for replacement labour from the nurse activity observation component of the study.

Indirect (nursing staff)

There could also be indirect effects on staff if changes to nursing duties are perceived as a move away from what are considered core nursing duties. Alternatively it could be regarded as a positive addition to nursing duties and a positive influence of nursing on patient care. Evidence from the staff surveys indicate both views are expressed and there is no clear consensus on a dominating effect.

Freeing of alternative labour input

The benefit of the freeing up of labour resources is another area that should be considered. If a task or role is substituted away from one staff group to another, it frees up time for that staff group. With excess demand being faced on the NHS, the freeing up of staff by the substitution of tasks to others can not necessarily be measured by the reduction in the wage bill of that substituted labour. Any evaluation of the freeing up of medical labour is complicated by the EWTD which imposes restricted hours of work on doctors. This means any potential for the freeing of alternative labour can be hidden by the restriction in working of medical staff. However, the efficiency of a workforce configuration that does not require one particular individual or particular staff group to carry out a role should be considered as a potential cost-saving for extended roles. This study did gather some evidence on total direct doctor attending time within the nurse activity observation. However the same caveats on the reliability of this data hold as described above with no evidence that there were significant differences between the unit types in the total direct doctor attending time at bedside.

Change in Professional motivation and job satisfaction

Job satisfaction is a summary measure of an individual's experience of their working conditions. It has been shown to predict quitting (Freeman, 1978; Clark *et al*, 1999; Clark, 2001) and early retirement (Mein *et al*, 2000), and is associated with doctors' perceptions of their ability to offer high-quality care (DeVoe *et al*, 2002), as well as nurses' (Shields & Ward, 2001) and doctors' (Scott *et al*, 2006) intentions to quit. Job satisfaction is related with economic outcomes such as labour market participation rates (Akerlof *et al*, 1988; Laband & Lentz, 1998; Clark *et al*, 1999; Clark, 2001) and productivity (Grol *et al*, 1985; Levin & Stephan, 1991; Hamermesh, 1999, DeVoe *et al*, 2002). It is correlated with absenteeism (Steers & Rhodes, 1978; Clegg, 1983) and overall employment costs (Mirvis & Lawler, 1977). It is also reported to be one of the three most important predictors of overall well-being, apart from marriage and family satisfaction (Argyle, 1989), and may be the closest proxy measure of utility at work (Clark, 1997). Bailie *et al* (1998) and Grol *et al* (1985) confirm that job satisfaction is correlated with patient satisfaction and has an influence on patients' health outcomes. As such a measure of job satisfaction can be a summary measure that captures many potential indirect effects on staff costs. The staff survey reports no difference in the scores for job satisfaction between staff in higher and lower units. While staff in higher units did report a higher average work pressure score compared to those in the lower units, this may be balanced by the higher scoring of staff in higher units for their unit management supporting them to maintain a work-life balance. This indicates that a job satisfaction measure is indeed a summary measure and represents a net effect of smaller component parts. The significant and positive indication of support from unit management in maintaining a work-life balance however may not be attributable directly to the extended role

that the units exhibit. However it may be units with a management that embrace new workforce configurations may also embrace alternative human resource management strategies that are then reflected in staff satisfaction in this domain.

Evidence of impact on patient process and outcomes

Section 4.1 indicates that there was no evidence in this study data of an independent significant effect of higher extended nursing roles in the adjusted care processes/outcomes of length of stay, unplanned re-admission or probable ventilator-associated pneumonia. There is therefore no corresponding evaluation of these outcomes required across the unit groups. Neither were there any discernable differences in the views expressed in the interviews of parents of children in intensive care in the 12 participating PICUs across the higher and lower extended role units (although in consultation, lay users highly valued expertise and had a negative view of blurring of roles between qualified nurses and unqualified health care assistants.)

Implications for future service provision

One important aspect that ought to be evaluated is not just whether there is evidence for or against the alternative unit workforce configurations in terms of extended roles at this point in time, but whether the current and/or alternative workforce configurations are sustainable in the future.

Section 2.2.1 highlights the ever-changing labour market that the NHS operates within. Even within the time of this study there has been a substantial change to medical workforce training through the introduction of Modernising Medical Careers (MMC) that will have implications for both doctors in training and also the number of fully qualified specialists. Indeed recent changes to national policy regarding international medical graduates that may not impact directly on the pediatric specialty may impact indirectly through effects on other specialties. We have already considered implications for training in relation to extended roles for nurses and the possible cost implications of the substitution of training away from doctors as opposed to training nurses in addition to doctors. The need to substitute training costs towards nurses may be suggested by the introduction of Modernising Medical Careers and its impact on training-level medical staff rotating through PICUs. If the service relies on doctors in training to provide service while training, any impact on this staff group could have implications for service sustainability. In Section 2.2, the staff interview component of this study, Medical Directors are reported to be uncertain about the sustainability of providing medical cover with training-level doctors not getting the on-the job exposure to intensive care in general. If one driver behind extended roles is to substitute for staff who are no longer as available to carry out the role, then the reduction of training of training-

level doctors will require a substitution to training of nurses. The staff interviews also suggested that the new MMC training pathways and European Working Time Directive raised concerns from senior doctors (who themselves had trained for more years and for longer hours) about skills levels of new doctors, and whether this cohort of medical trainees would accrue the expertise with more limited exposure time and less frequent experience of procedures and cases. The potential impact of the new MMC training and the European Working Time Directive on the accumulation of skill levels by new doctors was seen as a problem across all units. However the issue was highlighted more in interviews with staff from lower units. This may suggest that units with nurse extended roles are seen as an appropriate substitute for reduced training in doctors and that this workforce configuration may be favoured in terms of sustainability of the service in the light of these external factors.

Limitation of this analysis

The analysis is limited in terms of the scope of its coverage of resource use. In addition, care must be taken in linking particular workforce configurations and/or extended roles with observed differences in workforce behaviour and subsequent cost implications. If one workforce configuration looks preferable it is not always clear whether the difference between that configuration and another is purely due to the workforce configuration under study or whether the difference is due to an alternative confounding factor. For example, a particular management style that is open to new ideas may implement extended roles but also implement other initiatives that could impact on resource use. The fact that some units allow extended tasks may itself be a proxy for a higher order difference in management/workforce context which is the true driver of any observed difference. If this is the case then simply allowing an extended task in a 'lower' unit may not achieve the same positive results as it does in the higher unit. In addition the findings are based on a small sample of 12 units which exhibit large variations across a number of different characteristics. Response rates to some components of the study may also be prone to response bias.

Conclusion

Evidence from staff costs indicate that there is little difference between the units when considering average cost per maximum bed. The higher average cost in the higher extended role unit once adjustment is made for bed activity suggests that this cost difference is driven by variation in demand for beds between the two unit types and as such is not related to the workforce configuration that is being considered. Other evidence presented suggests that on a number of different indirect staff related costs, there is little evidence to suggest a difference between the two unit types and where there is difference it may not be directly related to the difference in workforce configuration. However there is evidence that some of the factors that

feed into this net effect do differ between units. This illustrates that workforce is a complex area to evaluate with many conflicting influences on workforce outcomes and therefore costs. Where there is evidence of a difference between the types of unit in these indirect staff costs, the areas of difference may be related to issues regarding the ongoing sustainability of the service and its response to external pressures. This suggests that in an ever-changing environment, it may be important to also evaluate how workforce configurations can best adapt to these pressures.

6 Discussion

The main findings from the different strands of evidence comparing the impact of extended vs non-extended nursing role on staff and patients are presented and discussed, along with a parallel prospective assessment of workplace context and HR management, and conclusions drawn.

Main findings

New workforce models: identifying nurse role extension, skillmix and task substitution in UK PICUs

A survey of 27 UK PICUs showed wide variation between units in the extent to which they had designated advanced nursing roles or extended role clinical tasks undertaken by nurses. (Chater et al 2005) Since 75% of all PICU patients are mechanically ventilated, clinical tasks for respiratory support are core care-team skills. Nine units had five or more of six respiratory support tasks undertaken by nurses and were stratified as higher extended roles, and seven units with one or no respiratory support tasks as lower (notably those nine units in the higher extended group also included the four units reporting designated advanced posts). Of the stratified units, twelve units (six with higher extended nursing roles and six without) were randomly selected and took part the study.

All but one of the lower study units reported Junior Doctors in their medical establishment in 2005, whereas units in the higher group tended to have more middle grade doctors and only two reported Junior Doctor posts. This suggests substitution of clinical tasks by nurses for Junior Doctors was more likely to be required in the higher units.

Comparing the impact on staff of extended nursing roles

Workplace context

Units in the higher group tended to be bigger units, with more beds and more beds in cubicles. They tended to report more and higher quality facilities for staff and fewer problems finding accommodation for parents, compared to units in the lower group. All but one higher unit anticipated forthcoming structural changes for their units.

More units in the higher group reported extreme fluctuations in activity, but units in the lower group reported recent pressures on staffing, due to increased bed demand, unfilled posts, sick leave, staff turnover and training requirements.

Fewer units in the lower group seconded staff for training or offered training for nurses from alternative backgrounds. Units in the lower group thought the focus and need for training had markedly changed with the NHS Knowledge and Skills Framework (KSF) and introduced less flexibility in nurse training.

Staff wellbeing

Compared with the lower units, staff in units with higher extended nursing roles were significantly more likely to report:

- working extra paid and unpaid hours (77% vs 66%);
- suffering work-related stress (36% vs 24%);
- and having a higher mean work pressure score (3.13 vs 3.01).

However, staff from higher units also recognised their unit management's supportive approach to maintain work-life balance (3.26 vs 3.23). Furthermore, from these data, working in units with higher extended nursing roles, was not associated with any difference in reported team working, job satisfaction and performance, but neither was it associated with increased intention to leave.

The findings support the hypothesis that working in units with higher extended nursing roles may be associated with working in a more supportive work context and organisation, but not with improved job satisfaction, job performance, and staff commitment and hence retention.

The negative impact findings of higher workload and work-related stress for staff from higher units are of note. These findings could be interpreted to suggest that although more staff in the higher units experienced greater workload and stress, a local supportive organisation, team and management approach may have an ameliorative effect, securing work effort by staff, supporting retention and hence sustaining service delivery.

Staffing costs

The impact of higher vs lower unit types on nursing and medical establishment staff costs showed nurse costs represented 63.8% and doctor salary costs 36.2% of the total. Crude average nurse and doctor staff costs and average total staff costs were higher in the higher extended role units than in the lower units.

Taking account of staff salary costs in relation to unit size (maximum number of staffed beds available), unit activity (number of occupied bed days) and illness severity of cases (% admissions in mortality risk categories), there was no evidence of any significant independent effect of extended roles on total direct staff costs.

In comparing costs between the higher and lower units, findings may appear to favour one unit "type" or the other depending on the confounding factors considered. Taking account of unit size, higher (and larger) units tended to have lower average staff costs and less variation in those costs

than the lower units. Whereas, taking account of bed day activity (with wide variation in units' staff cost per bed day), higher units tended to have a higher average cost per day.

Regression models suggested that unit size explains more variation in staff costs than bed activity. This suggests that staffing, with recent closer attainment of contemporary prescribed staffing standards in both types of unit, is very much a fixed cost in these units.

Staff views on professional roles, extended nursing roles and HRMS

All PICUs faced similar difficulties to acquire and maintain the right skillmix in their clinical team. Recent training and workforce policy changes were not viewed positively. Human Resources (HR departments at hospital level) were generally not seen as providing any strategic management or support role (particularly in the lower group units), but rather undertook the administrative tasks of the recruitment process which was judged bureaucratic and slow. Structural changes to HR departments across boundaries or a deficit of leadership in HR departments could be seen to impede local unit initiatives and recruitment.

In *both* types of units staff described good inter-disciplinary team working and communication, but also some friction between nurses and junior doctors and professional role blurring. Blurring is where tasks might be undertaken by either a doctor or a nurse depending on competency, but where there was poor definition and agreement around who does what, difficulties in effective team working may arise and professional demarcation boundaries are eroded. Some units of both types had introduced extended roles, but for Health Care Assistants to ease the pressure on nurse staffing and this had met resistance from qualified nurses.

Staff held widely divergent views around definitions of extended nursing practice, and varying views on the desirability or feasibility of implementing extended roles in local contexts. Despite reporting that overall nurse recruitment and retention had improved, there was continual churn in the workforce and some evidence that, so far, no PICUs had attained 'saturation' with enough trained and competent staff in extended nursing roles to ensure significant impact or be sustainable.

Staff in units with *lower* extended respiratory support nursing roles tended to have more traditional doctor/nurse role demarcation. Experienced senior nurses might undertake the extended respiratory support tasks, but not autonomously and notably, not officially. Senior managers described potential benefits of extended nurse roles, but remained equivocal about extended nurse roles in the future.

Barriers to implementing extended or advanced nurse roles could be articulated by either doctors or nurses: low skills-levels of new in-coming nurses and doctors; difficulties in funding training and backfill; perceived inequality for nursing staff; loss of skills training opportunities for future

doctors; un-sustainability of such roles; dilution of the traditional nurse role as a mini-doctor, cost etc. Individuals in one unit could have widely different opinions about the likely impact of extended nurse roles, both on staff and patients.

Higher units, however, described more autonomous, protocolised care for nurses and reported a culture towards empowering nursing staff. Their leaders were enthusiastic to obtain more staff with extended and advanced nursing roles (although they highlighted the scarcity of such staff in their current staff and on the labour market). Furthermore, higher units reported responsive unit-level HRM initiatives to identify, develop and retain their staff. These managers believed that nurses in extended roles would sustain delivery of high quality care, develop practice for both nurses and doctors across the whole unit and enable and empower staff to do more.

These findings are in line with HRMS contingency and resource-based theory. As predicted, higher units appeared more sensitive and responsive to external factors, supported autonomous, extended and enhanced nursing roles and put in place pro-active local HRM initiatives towards improving recruitment, retention, staff development and new ways of working and sustain performance.

Strengths and Limitations

The setting and identification of new extended nursing roles took place in a well-organised speciality and network comprising twenty-seven PICUs that, as part of PICANet, had in place established clinical and staffing standards, robust mechanisms for structural and clinical data recording and detailed baseline staffing data.

The designated extended respiratory support tasks and advanced roles, used to stratify units into higher extended nursing role or lower extended nursing role type were of clinical significance. The comparative study design took place prospectively in 12 stratified and randomly selected units (six higher and six lower units).

Only descriptive unit profile information about unit structure, amenities, staffing challenges and change is presented for the two groups of six units. Data were derived in self-report from nurse managers only. We cannot exclude the possibility of reporting or temporal bias in those findings.

Indeed, triangulating descriptive findings and those arising from staff interviews and subsequent site visit data suggests wide variation between staff in units in their views and experience of evolving staffing models and on-going challenges to sustainable high-quality service. Furthermore, within the time of this study there was ongoing substantial change and challenges to units of new medical workforce selection and availability through the introduction of Modernising Medical Careers (MMC), reports of lower skills levels in-coming doctors and nurses and the impact of implementation of Agenda for Change and the KSF.

Only 57% of PICU staff completed and returned the staff wellbeing questionnaire. There was a higher response from units with higher extended roles compared with lower units. There was a higher response rate from nurses (~60%) than doctors (~50%). These response rates are similar to those achieved by the NHS Staff survey (Health Care Commission, 2008). The analysis is adjusted for differing proportions of staff groups, but we cannot exclude the possibility of response bias in these findings.

Staff cost estimates were derived from a top-down approach. Throughout the lifetime of the study, major policy and new initiatives were impacting on staff models and costs, e.g. to reduce bank nurse use, implementation of Agenda for Change, MMC etc. Our overall staff establishment cost estimates appear valid as, assuming they represent 52% of total cost per patient day, they were similar to those reported by Dean *et al* (2002) and Edbrooke (2001) for adult critical care.

Impact on Staff: Conclusions

Drawing together these strands of evidence to compare the impact of higher vs lower extended nursing role in PICUs on staff showed:

- higher units demonstrated responsiveness to external factors and change, with a culture to empower and retain nurses and more supportive human resources management initiatives
- staff views on extended nursing roles varied widely with many identified barriers. Despite overall improvement in nurse recruitment and retention, there was continual workforce churn and evidence indicated that, so far, no PICUs had attained 'saturation' with enough trained and competent staff in extended nursing roles to ensure significant impact or be sustainable.
- there was an increased risk of further limiting specialty medical training opportunities and hence threatening succession of medical expertise.
- role blurring occurred where tasks might be undertaken by either a doctor or a nurse according to competence, but there was also evidence of resistance to change and adherence to traditional professional role demarcation.
- more respondents working in higher units reported working overtime, higher work-related stress and work pressure, but they also recognized a supportive management
- no significant independent effect on direct staff costs. Staffing costs tended to be fixed and related to unit size.

Main Findings

Comparing the impact on patients of extended nursing roles

Impact on patients: direct care time by professional groups

Contrary to expectation that higher units with extended nursing roles would have increased in nurse direct care time, while conversely doctor direct attendance time would be reduced, these data (adjusted for variation at unit level) show:

- a non-significant difference in the odds of a nurse being in direct care in higher vs lower units (adjusted odds 1.22 (95%CI 0.65-2.3))
- a non-significant difference in the odds of a nurse being in direct extended care in higher vs lower units (adjusted odds 0.71 (95% CI 0.37-1.37))
- a non-significant difference in the lower odds of a doctor being in attendance in higher vs lower units (adjusted odds 0.80 (95%CI 0.32-1.99))

Thus, although overall nurses in higher units spent more (71%) of their time in direct care (vs 67% in lower units), and doctors were attending for less (9% of the time (higher)) vs 13% in the lower units, these differences were not significant because of wide variation in observed staff groups' direct care time between units within the higher/lower groups.

Furthermore, of only 2 to 3% of time overall spent on the extended respiratory support tasks, nurses in the higher units appeared to spend *less* time (2.1%) vs 2.9% in the lower units on these tasks; although again the difference was not significant because of wide variation at the unit level.

Impact on patients: care process and outcomes

We hypothesised that extended nursing roles would be independently associated with significant improvement in the specified quality of care process and outcomes to be tested of length of stay (LOS), unplanned readmission and health care associated infection, (namely probable ventilator-associated pneumonia (VAP)).

We found no evidence of significant and independent effect of extended nursing roles on the tested care processes/outcomes for patients of LOS, unplanned re-admission or probable VAP.

Our overall estimates of average LOS at two days, unplanned re-admission at 3% and probable VAP rates (at 13% of eligible ventilated patients) are broadly similar to previous reports in the literature (Marcin *et al*, 2001; Kollef, 1993).

Impact on patients: parents' views and satisfaction

Three main themes emerged from interviews with parents of children in PICU. They describe very positive views about 1) satisfaction with care, 2) attributes of the unit and care team and 3) meeting the needs of the family. There were no discernable differences in parents' views comparing interviews taking place in units with either higher or lower levels of nurses in extended roles.

Without exception parents praised the unit and care teams. Although the precise roles of doctors and nurses were ill-defined by parents, nurses making changes to the child's care was judged acceptable by PICU parents within limitations, providing the changes were only minor and the nurse's training and experience were high. Parents hesitantly mentioned and tended to excuse any shortcomings in care or mistakes. Communication by nurses and senior doctors and shared decision-making were praised, and only some communication problems were described, particularly with more junior doctors.

Users and lay representatives of intensive care charities for adults, children and neonates were consulted on the report of parents' views of PICU. It was recognised as a valid and positive reflection of high quality care, well representing the experiences of relatives in wider intensive care settings. Those consulted were more critical of any shortcomings of care. These lay users valued expertise, disagreed that medical/nursing staff were interchangeable, and had a negative view of blurring of roles between qualified nurses and unqualified health care assistants.

Strengths and Limitations

A strength of this observational work was the validity of the nursing activity categories arising from a report by Adomat *et al* using closed circuit television cameras in PICU (Adomat, 2001). However, there remain significant methodological challenges in observing and measuring NHS staff and work activities.

First, there is the potential of selection bias (due to nurses observed being volunteers) and observer bias (staff altering their practice during observation). Second, there remain questions about the meaning and interpretation of "direct care time". For example confounders of observed direct care time may include: rapidly deteriorating patients in PICU that result in more doctors attendance; or longer time spent on tasks related to lower skill-levels or competence by individual staff members. Finally, the self-report diary for ward-based nurses to give account of their work activities on shift appeared to be unacceptable to the majority nurses with poor internal consistency and the resulting data was judged unreliable.

Further comparisons of higher/lower total staff direct care time and higher/lower staff groups' direct care time on patient care process and outcomes were not tested. The variation in estimates of staff direct care time between units within type was very wide, inconsistent and unreliable. It was not valid to arbitrarily assign categories of higher/lower direct care time as the meaning of such groupings to practice would be unclear.

Some caution is required in interpreting the regression model for probable VAP for three reasons: first, because of cluster sample sizes not achieving the target size of 150 at each unit over the one year period; second, potential selection bias due a markedly incomplete series from one unit (although a sensitivity analysis excluding that unit showed similar results); and third, from potential selection bias due to a 12% VAP sample loss in matching with PICANet records.

Interviews with parents of children still in PICU might have influenced this very favourable report, due to staff selection of parents (as staff acted as gatekeepers before the researcher could approach parents), and parents possible reluctance to criticise during their child's ongoing care.

Impact on patients: conclusions

Comparing the impact of higher vs. lower extended nursing role in PICUs on patients this study showed:

- no evidence of significant and independent impact of higher extended nursing roles in PICUs on care process or outcomes for patients
- nor on parents' positive views of their child's care. Notably users valued expertise and were cautious or negative about devolving tasks in the professional care hierarchy.

Conclusions

The previous review of the literature suggested equivalence in previous comparisons of extended/ advanced nurse vs medically-led care models to date (Hewitt *et al*, 2003). Caution is required before interpreting the lack of discernable impact on patient care and outcomes as equivalence of the two models of care delivery in our findings.

Alternative interpretations arising from the in-depth evidence from site visits are: first, evidence from staff interviews and inconsistency in the staff groups' direct care time estimates suggest that higher units have not yet achieved fidelity (due to role blurring) nor saturation in implementation of trained nurses delivering extended respiratory tasks to make an impact; second, if these extended respiratory support tasks do require 2 to 3% of the total nursing care time, this could represent a small marginal time substitution, particularly if undertaken efficiently by an experienced nurse.

7 Implications for policy, local action and further research

Implications for Policy

What works and is sustainable?

There was no evidence of a significant independent effect of higher extended nursing roles in PICUs on staff group direct care time, care process or outcomes for patients.

However, in-depth site visit evidence suggested that, so far, no PICUs had attained 'saturation' with enough trained and competent staff in extended nursing roles to ensure impact or to be sustainable.

One important aspect for this evaluation is not just whether there is evidence for or against the alternative unit workforce configurations in terms of extended nursing roles at this point in time, but how they arise and whether the current and/or alternative workforce configurations, are acceptable and sustainable in the future.

Facilitators for implementation of extended nursing roles

These included:

- agreement, endorsement and regulation by professional bodies;
- belief that this role will fit the specific context and the care team, that it will be efficient and support high quality care;
- adoption and championing by both medical and nursing local leaders;
- a unit culture that is responsive to external pressures, anticipates change, is adaptive and innovative;
- a unit culture to empower and retain nurses with supportive human resources and management initiatives
- and has nursing workforce capacity for training and backfill.

Variation in adoption

There is continuing uncertainty about future medical workforce supply and nurse retention in the NHS and in the professions. The sustainability of particular models of staffing and supply-lines of appropriately skilled professionals remain in flux and variable in different regions of the UK. There may not be one model that fits all areas.

There is a notable difference in the extent to which extended and advanced nursing roles had been professionally endorsed in UK neonatal vs paediatric or adult intensive care settings, although the new neonatal nurse roles could vary widely (Srivastava *et al*, 2008).

Specialties are affected and respond differently to the workforce pressures. For example, whereas the RCPCH (2006) highlighted a recent increase in Trust Doctors and number of nurses in the SHO (1st on-call), the RCOG and RCPCH (2008) reported that to comply with the EWTD, many units had chosen to increase their medical staff and redesign their rotas.

Challenges to implementation: acceptability and impact on parents and staff

Parents had very positive views of a high quality critical care service, but valued expertise and were cautious about the devolving of tasks in the professional and care hierarchy.

There is evidence of staff resistance to some changes and adherence to traditional professional role demarcation.

There is perceived low skills levels of in-coming medical and nursing staff ie. in workforce supply.

The introduction of extended nursing roles may not support staff wellbeing in terms of increased workload and work-related stress.

A nationally-agreed skillset for extended practice that is recognised between units would support the nurse workforce skills development and wider expert workforce inter-disciplinary working and sustainability, avoiding local demarcations that currently vary widely.

There is a risk of further limiting specialty medical training opportunities and threatening succession of medical expertise.

Implications for local action

Support HR management strategic approaches. Undertake clinical care team workforce reviews and scoping. Identify external threats & opportunities including policy and regulatory developments, anticipate and plan for future supply and service sustainability and quality.

Deliver strategic NHS HR management expertise to support clinical managers, including:

- supply of local, regional and national workforce intelligence.
- Customized local HR management strategic initiatives to support recruitment, retention, workforce wellbeing, staff development and training and inter-disciplinary team working

Review how local NHS HR administrative recruitment service functions

Seek multi-professional consensus, and endorsement for implementing any coordinated workforce re-design initiatives in units.

Avoid role blurring that could undermine effective inter-disciplinary working due to lack of definition of shared overlapping tasks or skills and respect for professional boundaries.

Monitor and supervise staff to ensure competencies and competence and audit new staffing roles initiatives.

Continue to support:

- good clinical care team working and communication
- embedding and supporting nurse/trainee doctor relationships
- improving junior doctor communication skills
- professionalism in nurse communication with parents/carers

Further Research

Key areas where evidence was unclear and requires further investigation include:

- Defining reliable and required minimal datasets for ascertainment of probable VAP, as a major HCAI in IT settings
- Reliability, observer bias and acceptability to staff of direct care time studies of health staff work activity
- Staff stress relating to unit culture, team roles and impact on patient care and outcomes
- Sustainability of new models of staffing
- Effect of further extended or new roles e.g. health care assistants, physician assistants

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Addendum

This document was published by the National Coordinating Centre for the Service Delivery and Organisation (NCCSDO) research programme, managed by the London School of Hygiene & Tropical Medicine.

The management of the Service Delivery and Organisation (SDO) programme has now transferred to the National Institute for Health Research Evaluations, Trials and Studies Coordinating Centre (NETSCC) based at the University of Southampton. Prior to April 2009, NETSCC had no involvement in the commissioning or production of this document and therefore we may not be able to comment on the background or technical detail of this document. Should you have any queries please contact sdo@southampton.ac.uk.