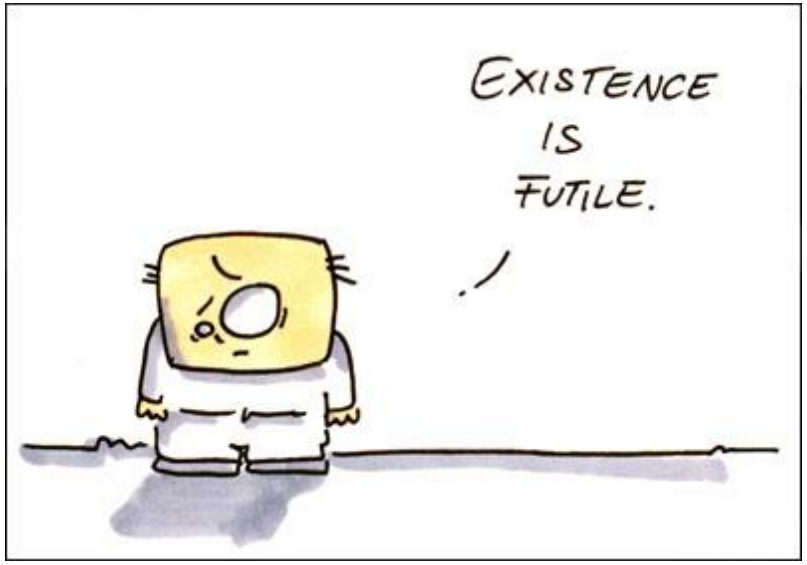
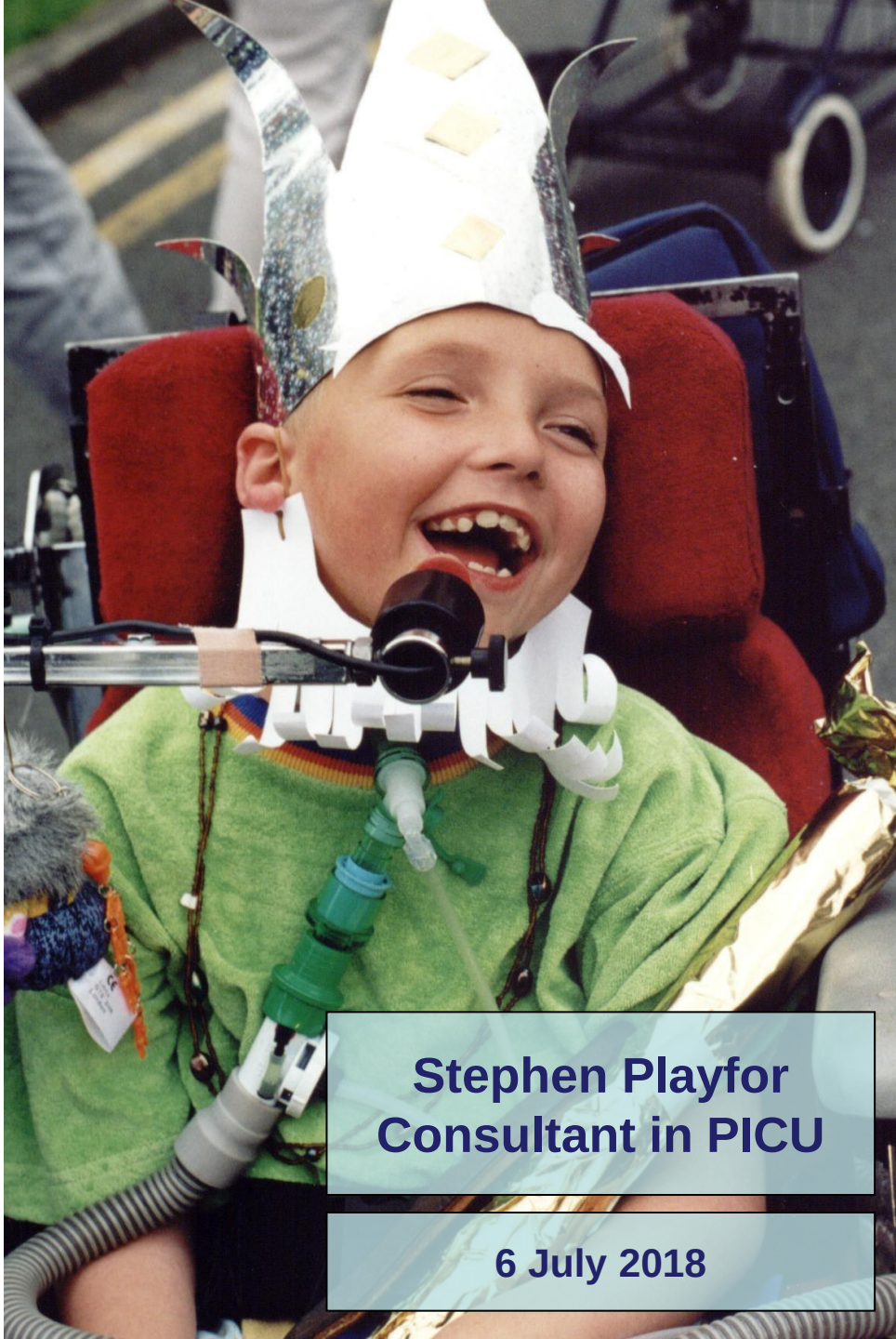


ROYAL MANCHESTER CHILDREN'S HOSPITAL

Impact of potentially inappropriate care in PICU



Stephen Playfor
Consultant in PICU

6 July 2018

Impact of potentially inappropriate care in PICU

- Definitions
- Incidence
- Manchester experience
- UK experience
- Impact of prolonged PICU admission

Impact of potentially inappropriate care in PICU

DEFINITIONS

AMERICA
DOCUME

An Official AT **nent:**
Responding t **eatments in**
Intensive Car

Gabriel T. Bosslet, Tha nda H. Rushton,
J. Randall Curtis, Dee Brody,
Brenda G. Fahy, Jesse uglas B. White;
on behalf of The Amer opriate Care

THIS OFFICIAL POLICY STATEME AMERICAN ASSOCIATION FOR
CRITICAL CARE NURSES (AAC THE EUROPEAN SOCIETY FOR
INTENSIVE CARE MEDICINE (ESICM), SEPTEMBER 2014, AND THE SOCIETY OF CRITICAL CARE MEDICINE (SCCM), DECEMBER 2014

The term "potentially inappropriate" should be used, rather than "futile," to describe treatments that have at least some chance of accomplishing the effect sought by the patient,
The term "futile" should only be used in the rare circumstance that an intervention simply cannot accomplish the intended physiologic goal.

American Journal of Respiratory and Critical Care Medicine Volume 191 Number 11 | June 1 2015

Making decisions to limit treatment in life-limiting and life-threatening conditions in children: a framework for practice

Vic Larcher,[1] Finella Craig,[2] Kiran Bhogal,[3] Dominic Wilkinson,[4] Joe Brierley,[1,5] on behalf of the Royal College of Paediatrics and Child Health

BMJ

The RCPCH believes that there are three sets of circumstances when treatment limitation can be considered because it is no longer in the child's best interests to continue, because treatments cannot provide overall benefit

1. When life is of limited quantity
2. When life is of limited quality
3. Informed competent refusal of treatment

Larcher V, *et al*. *Arch Dis Child* 2015;**100**(Suppl 2):s1–s23

Impact of potentially inappropriate care in PICU

INCIDENCE

Arch Dis Child 2001;**84**:265–268

Identifying futility in a paediatric critical care setting: a prospective observational study

A Y Goh, Q Mok

34 of 662 patients ‘futile’ (5%)

Accounted for only 3% of bed days

Table 2 Comparison between patients who fulfilled criteria for medical futility and other non-futile patients

Characteristics	*Futile (n = 34)*	*Non-futile (n = 628)*
Age (mth)*	40.1 (59)	35.4 (54)
Length of stay (days)*	4.6 (4.3)	5.1 (8.4)
PRISM*	20.5 (11.7)	10.7 (6.7)
Mortality (%)	56	5.1
Treatment limitation in non-survivors (%)	79	37.5
Precipitating cause of admission (%)		
Postoperative	2.9	32.2
Respiratory	17.7	30.3
Sepsis	38.2	9.1
CNS	23.6	13.8
Trauma	2.9	4.7
Others	14.7	9.8

*Values are mean (SD).
PRISM, Paediatric Risk of Mortality Score; CNS, central nervous system.

Arch Dis Child 2001;**84**:265–268

Identifying futility in a paediatric critical care setting: a prospective observational study

A Y Goh, Q Mok

34 of 662 patients ‘futile’ (5%)

Accounted for only 3% of bed days

Table 2 Comparison between patients who fulfilled criteria for medical futility and other non-futile patients

Characteristics	*Futile (n = 34)*	*Non-futile (n = 628)*
Age (mth)*	40.1 (59)	35.4 (54)
Length of stay (days)*	4.6 (4.3)	5.1 (8.4)
PRISM*	20.5 (11.7)	10.7 (6.7)
Mortality (%)	56	5.1
Treatment limitation in non-survivors (%)	79	37.5
Precipitating cause of admission (%)		
Postoperative	2.9	32.2
Respiratory	17.7	30.3
Sepsis	38.2	9.1
CNS	23.6	13.8
Trauma	2.9	4.7
Others	14.7	9.8

*Values are mean (SD).
PRISM, Paediatric Risk of Mortality Score; CNS, central nervous system.

Pediatric Anesthesia 2006 **16**: 309–313

Futility and inappropriate care in pediatric intensive care: a cross-sectional survey

GOPI VEMURI MBBS AND STEPHEN DEREK PLAYFOR MD

Paediatric Intensive Care Unit, Royal Manchester Children's Hospital, Pendlebury, Manchester, UK

Methods: A prospective cross-sectional survey was carried out using a data collection form distributed by mail to the directors of all PICUs in the UK. Respondents were asked to give details of all patients on their unit on a specific day including age, reason for admission and any preexisting medical conditions. An assessment was made by respondents of whether the care being provided in each case was, in their opinion, appropriate, futile or inappropriate according to standard definitions.

Definitions used in 2006

The following definitions were used.

1 Futile treatment: The care being provided will not have the desired outcome or accomplish its intended goals (no physiologic effect).

2 Inappropriate treatment: Treatment is extremely unlikely to be beneficial, is extremely costly or is of uncertain benefit.

Consensus statement of the Society of Critical Care Medicine's Ethics Committee regarding futile and other possibly inadvisable treatments

Critical Care Medicine. 25(5):887-891, May 1997.

Consensus statement of the Society of Critical Care Medicine's Ethics Committee regarding futile and other possibly Reproduced with permission from the Society of Critical Care Medicine.

Futility and Inappropriate Care in PICU

Dr G Vemuri and Dr S D Playfor

Central Manchester and Manchester Children's University Hospitals NHS Trust

Paediatric Intensive Care Unit, Royal Manchester Children's Hospital, Pendlebury, Manchester M27 4HA, United Kingdom

Introduction

Over recent years there have been increasing concerns regarding an increase in the number of futile and inappropriate admissions to Paediatric Intensive Care Units (PICUs) in the United Kingdom (UK). These patients are staying on the PICU for long time and consume up to 1/3 of resources and as intensivists we have ethical obligation to avoid treatments that are not beneficial to the patient. This prompted us to obtain a snapshot opinion of the paediatric intensivists across UK to determine the extent of futile and inappropriate admissions.

Methods

A postal questionnaire was sent to the directors of all UK PICUs identified through the Paediatric Intensive Care Society. Respondents were asked to give details of all patients on their unit at the time including age, reason for admission and any pre-existing medical conditions. Finally an assessment was made by respondents of whether the care being provided in each case was, in their opinion, either futile or inappropriate. All questionnaires were completed on the same day in order to obtain a snapshot of current practice. The following definitions were used.

1) Futile treatment ;

The care being provided will not have the desired outcome or accomplish its intended goals (no physiological effect).

2) Inappropriate treatment ;

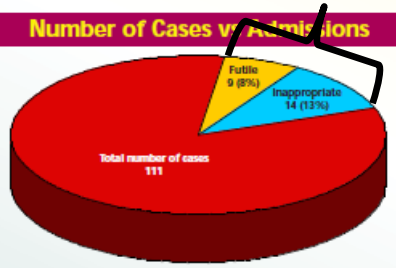
Treatment is extremely unlikely to be beneficial, is extremely costly or is of uncertain benefit.

Results

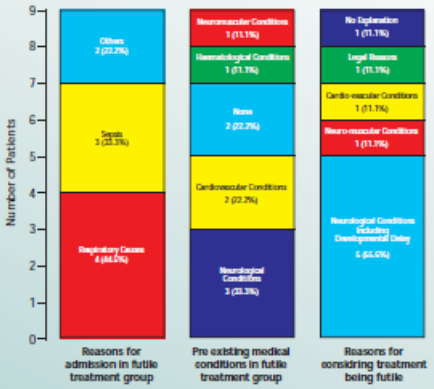
We received responses from 21 units (68%) who reported the details of 111 patients. Care was felt to be futile in 9 of these cases (8%) and inappropriate in a further 14 cases (13%). Futile cases were most commonly admitted with respiratory failure and had pre-existing medical conditions, most commonly neurological and neuromuscular conditions including developmental delay. Where care was felt to be inappropriate, respiratory failure was the most common reason for admission and ALL ha… co…

21% Futile or Inappropriate

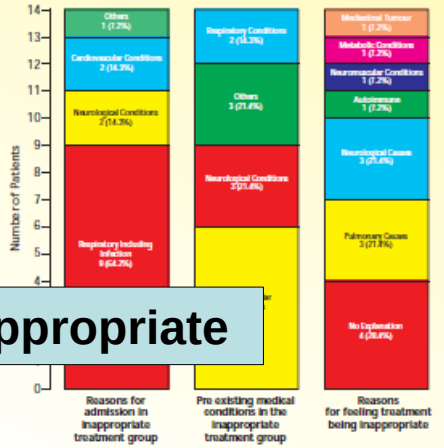
Number of Cases v… …ions



Futile Treatment Group (9 Cases)



Inappropriate Admission (14 cases)



Conclusion

The care provided in 21% of the PICU admissions described in this study was felt to be either futile or inappropriate by the directors of those units. Facilities and resources for intensive care treatment for paediatric age group are limited in UK. Identification of patients where treatment was felt to be futile has shown to be cost effective in adult ICU and as intensivists we should avoid unnecessary prolongation of the suffering of the child. Although we as doctors are not very good at predicting the outcome in a given patient we have an ethical obligation to avoid those treatments where there is no net benefit to the patient. Futile and inappropriate PICU admissions could easily fall into this category.

RMCH PICU 05/07/18

Bed	Name DOB	DOA+ Base Hospital	Diagnosis and Relevant Background	Reason for admission	Current Issues	Systems	Plan
Bed 7 Day 16		17/04/18 Stepping Hill	Trisomy 21 AVSD repair at AHCH- May 2017 MV stenosis & regurg	Pneumonia and effusion Pul. hypertention LAVV stenosis – for surgery	**Pseudomonas in ETA(27/04)** Persistent RML collapse/consol Awaiting transfer to Alder Hey PRBC transfusion(28/4) NPA : negative	**A:** nETT micro cuffed 4.0 @ 14cm, grade 1 **B:** BIPAP/ASB 16/10 f 16 FiO2 0.50 **C:** no support **D:** Chloral QDS **F:** 80% maint, NG feeds furosemide & spiro **S:** Ceftaz, gent ; CRP 6	Chase AHCH bed Referred to NWTS (1890) Daily child profile, CRP Twice weekly FBC Chase rpt ETA Discuss abx with micro **If FiO2 >0.6 rpt CXR** ***Summary updated 01/05/18***
Bed 8 Day 3		01.05.18 PED	Beare-Stevenson Syndrome and visual difficulties VP shunt	Seizure	CT : increased ventricular size → shunt revision catheter noted to be stuck in ventricle→ new catheter passed	**A:** tracheostomy **B:** BIPAP/ASB (20/10 f20/ 21%) **C:** stable **D:** no further siezures, CSF normal **S:** nil	
Bed 9 Day 20		14/04/18 Blackpool	Infantile Pompe's Cardiomyopathy Muscular weakness Microcephaly Gross motor delay Paroxysmal SVT Sleep disorder breathing Recurrent Tonsillitis	Transfer AHCH Respiratory wean – Parainfluenza CAP (RLL) Own portable vent from Respiratory	R diaphramatic palsy Pseudomonas in ETA Failed extubation 18/04 Extubated 12.30 01/05 -reintubated 02/05 RLL collaspe	**A:** nETT 5.0 microcuff 18.5cm **B:** BIPAP/ASB 22/10, FiO2 0.5 **C:** Atenolol 15mg BD (SVT) **D:** Appropriate/PRN chloral **E:** Full EN **S:** Afebrile, ceftazidime for pseudomonas- complete 14/7 (started 26/04)	Saline neb for thicker secretions ***Summary updated 01/05/18***
Bed 10 Day 3		1/5/18 Theatres	Ex-prem 32/40 Oesophageal atresia Multiple anastomosis GORD- Fundo CLD Recurrent LRTI	Post op right bronch-oesophgeal fistula repair, re-anastomosis & R throacotomy	Post op recovery 50ml/kg plasmalyte+ 15ml/kg PRBC intraop Self extubation- reintubated 2.5.18	**A:** 4.5 uncuffed 13cm **B:** BIPAP/ASB 20/6/22RPM/0.60 **C:** stable **D:** Midaz 300mcg, fentanyl 4mcg, **F:** 70% maintaince IVF **S:** Cefurox+ metronidazole 5/7	Start steroid – after d/w surg For 48hr pre ext Surg review re TAT and feed
Bed 11 Day 35 **MS**		24/03/18 Blackburn	Term Poor foetal weight gain VSD + ASD Ch 16 microdeletion	Collapsed neonate – presumed secondary to cardiac failure	Cardiac failure Cardiomegaly+ pulm vasc dilatation Cerebral haemorrhages Failed extubation twice Yeast on ETAs 9/4	**A:** nETT 3 mm cuffed 11cm **B:** BIPAP/ASB 14/5, R10, 21% **C:** Unsupported **D:** Reg chloral + alimem **F:** 120ml/kgNG feeds (wt 2.7kg) Furosemide, spironolact	Chase AHCH bed Abx + micafungin if unwell For MR at 6months or before cardiac surgery Referred to NWTS (1891) ***Summary updated 25/4/18***
Bed 12 Day 4		30/04/2018 PED	Left side intracranial space occupying lesion and Rt side midline shift Subfalcine herniation Thymidine phosphorylase deficiency Mitocondrial Neurogastrointestinal encephalopathy Diabetes BMT Nov 2017 TPN dependent	ICP management	Intracranial hypertension Subfalcine herniation Post brain bx + ICP monitor insertion	**A:** oral ETT at 20cm **B:** Vol control, low vent settings **C:** Noadr. + Adr **D:** Mida 300, Fent 4, Roc 1000 Thio infusion 3mg/kg/hr Temp 35, Paracetamol **F:** NBM **S:** mero/metronidazole/acyclovir a/w tissue/CSF micro	TPN when available Thio boluses Monitor UO
Bed 13 Day 6		27/4/18 HDU	Raised ICP 4th ventricle tumour – debulked 26/4 VAP resolved	Post EVD/ICP bolt insertion.		**A:** COETT **B:** CPAP/ASB in air **C:** CPP >50mmHg, **D:** off Midaz/fent, EVD at 10cmH2O, dex, **NBM**, IVF 70% maint Na 142 **S:** min secretions pip/taz (29/04 to 2nd May	? extubation ***Summary started 28/4/18***
Bed 15 Day 26 **CG**		2/4/18 (ward 85)	Infantile Pompe's Hypoplastic lungs- LTV PEG fed Unsafe swallow Social	Resp failure ?HAP	New tracheostomy Rhinovirus+ve Pseudomonas in ETA (11/04) Possible new VAP NPA : Adenovirus PCR +	**A:** Trachy 4.5 cuffed Shiley **B:** NIPPY 20/8 FiO2 0.23 **C:** Unsupported **D:** Alert **F:** Feeds 36ml/hr **S:** IV Ceftazidime (01/05)	***Summary started 24/4/18***
Bed 3 Day 3		30/04/2018 A&E	Methyl malonic acidemia	Acute decompensation	Metabolic acidosis Dehydration Loss of weight 10% Lactic acidosis NH3 235 –130 – 82 Na 163	**A:** Own **B:** SVIA/ acidotic **C:** Unsupported **D:** Appropriate **F:** 120% IV maint + 10% dehydration correction IV levocarnitine	BG before ward to check Potassium and Ca Discharge to ward ***Summary started 02.05.18***
Bed 18 Day 2		01.05.18 PED	Out of hospital VF arrest Incidental finding of Chiary malformation	Neuroprotection	Hypothermic Troponin 59 (1-14) Tox neg	A: OETT B: SIMV TV 350mls, PEEP 5 rate 20, 0.25% C: HR 95 SR with ventricular ectopics, Noradrenaline D: Fent 2.5, Midaz 3.5mg/hr F: 70% IVF G: ranitidine S: acyclovir, ceftriaxone	**Clarfy timeline of events** Neuroprotect 48 hrs Keep electrolytes up 24 hour ECG tape (on) ?? may need ICD pre discharge (Krasi) Brugada screen/test Genetic screen for LQTS Cardiomyopathy screening MRI brain
Bed 20 Day 12 **DG**		22/4/18 HDU	Meningomyelocele repaired Arnold chiari 2 malformation VP shunt Tracheomalacia Neuropathic bladder Gastroesophageal reflux Unsafe swallow Post aortoplexy (Dec 2017)	- LRTI - recurrent apnoeas (? obstructive)	**Rhinovirus +ve** Increased WOB since 18/4/18 UTI / temp spikes since 12/4/18 Fungal balls b/l kidneys CT brain : no shunt dysfunction Enoxeparin for left femoral thrombus	A: 4 NETT 14 cm B: BIPAP/ASB 15/6 f15 30% C : stable, left femoral thrombus - enoxaparin D : Chloral F: 100% feeds S : Ambisome 19/4/18 Tazocin 30/4/18 PICC line culture sterile CRP 12	Wean ventilation ***Summary updated 24/4/18***
Bed 21 Day 3		30/4 Theatres	Ex 29/40 Subglottic stenosis GORD NG fed Rt sided aortic arch + aberrant subclavian	Post-op: single stage laryngeal reconstruction	I+V Keep paralysed 48hrs Low BP PCT < 0.1 (03/05)	**A:** nETT 4.5 uncuffed, 14cm **B:** BIPAP/ASB 14/5, FiO2 0.3 **C:** stable **D:** fent, midaz, roc Chloral + clonidine **F:** NG feeds **S:** co-amox	Keep I+V until end of week with dex pre-extubation Reduce IV sedation ?stop roc 03/05 pm

RMCH PICU 05/07/18

Bed	Name DOB	DOA+ Base Hospital	Diagnosis and Relevant Background	Reason for admission	Current Issues	Systems	Plan
Bed 7 Day 16		17/04/18 Stepping Hill	Trisomy 21 AVSD repair at AHCH- May 2017 MV stenosis & regurg	Pneumonia and effusion Pul. hypertention LAVV stenosis – for surgery	**Pseudomonas in ETA(27/04)** Persistent RML collapse/consol Awaiting transfer to Alder Hey PRBC transfusion(28/4) NPA : negative	**A:** nETT micro cuffed 4.0 @ 14cm, grade 1 **B:** BIPAP/ASB 16/10 f 16 FiO2 0.50 **C:** no support **D:** Chloral QDS **F:** 80% maint, NG feeds furosemide & spiro **S:** Ceftaz, gent ; CRP 6	Chase AHCH bed Referred to NWTS (1890) Daily child profile, CRP Twice weekly FBC Chase rpt ETA Discuss abx with micro **If FiO2 >0.6 rpt CXR** ***Summary updated 01/05/18***
Bed 8 Day 3		01.05.18 PED	Beare-Stevenson Syndrome and visual difficulties VP shunt	Seizure	CT : increased ventricular size → shunt revision catheter noted to be stuck in ventricle→ new catheter passed	**A:** tracheostomy **B:** BIPAP/ASB (20/10 f20/ 21%) **C:** stable **D:** no further siezures, CSF normal **S:** nil	
Bed 9 Day 20		14/04/18 Blackpool	Infantile Pompe's Cardiomyopathy Muscular weakness Microcephaly Gross motor delay Paroxysmal SVT Sleep disorder breathing Recurrent Tonsillitis	Transfer AHCH Respiratory wean – Parainfluenza CAP (RLL) Own portable vent from Respiratory	R diaphramatic palsy Pseudomonas in ETA Failed extubation 18/04 Extubated 12.30 01/05 -reintubated 02/05 RLL collaspe	**A:** nETT 5.0 microcuff 18.5cm **B:** BIPAP/ASB 22/10, FiO2 0.5 **C:** Atenolol 15mg BD (SVT) **D:** Appropriate/PRN chloral **E:** Full EN **S:** Afebrile, ceftazidime for pseudomonas- complete 14/7 (started 26/04)	Saline neb for thicker secretions ***Summary updated 01/05/18***
Bed 10 Day 3		1/5/18 Theatres	Ex-prem 32/40 Oesophageal atresia Multiple anastomosis GORD- Fundo CLD Recurrent LRTI	Post op right bronch-oesophgeal fistula repair, re-anastomosis & R throacotomy	Post op recovery 50ml/kg plasmalyte+ 15ml/kg PRBC intraop Self extubation- reintubated 2.5.18	**A:** 4.5 uncuffed 13cm **B:** BIPAP/ASB 20/6/22RPM/0.60 **C:** stable **D:** Midaz 300mcg, fentanyl 4mcg **F:** 70% maintaince IVF **S:** Cefurox+ metronidazole 5/7	Start steroid – after d/w surg For 48hr pre ext Surg review re TAT and feed
Bed 11 Day 35 **MS**		24/03/18 Blackburn	Term Poor foetal weight gain VSD + ASD Ch 16 microdeletion	Collapsed neonate – presumed secondary to cardiac failure	Cardiac failure Cardiomegaly+ pulm vasc dilatation Cerebral haemorrhages Failed extubation twice Yeast on ETAs 9/4	**A:** nETT 3 mm cuffed 11cm **B:** BIPAP/ASB 14/5, R10, 21% **C:** Unsupported **D:** Reg chloral + alimem **F:** 120ml/kgNG feeds (wt 2.7kg) Furosemide, spironolact	Chase AHCH bed Abx + micafungin if unwell For MR at 6months or before cardiac surgery Referred to NWTS (1891) ***Summary updated 25/4/18***
Bed 12 Day 4		30/04/2018 PED	Left side intracranial space occupying lesion and Rt side midline shift Subfalcine herniation Thymidine phosphorylase deficiency Mitocondrial Neurogastrointestinal encephalopathy Diabetes BMT Nov 2017 TPN dependent	ICP management	Intracranial hypertension Subfalcine herniation Post brain bx + ICP monitor insertion	**A:** oral ETT at 20cm **B:** Vol control, low vent settings **C:** Noadr. + Adr **D:** Mida 300, Fent 4, Roc 1000 Thio infusion 3mg/kg/hr Temp 35, Paracetamol **F:** NBM **S:** mero/metronidazole/acyclovir a/w tissue/CSF micro	TPN when available Thio boluses Monitor UO
Bed 13 Day 6		27/4/18 HDU	Raised ICP 4th ventricle tumour – debulked 26/4 VAP resolved	Post EVD/ICP bolt insertion.		**A:** COETT **B:** CPAP/ASB in air **C:** CPP >50mmHg. **D:** off Midaz/fent, EVD at 10cmH2O, dex, **NBM**, IVF 70% maint Na 142 **S:** min secretions pip/taz (29/04 to 2nd May	? extubation ***Summary started 28/4/18***
Bed 15 Day 26 **CG**		2/4/18 (ward 85)	Infantile Pompe's Hypoplastic lungs- LTV PEG fed Unsafe swallow Social	Resp failure ?HAP	New tracheostomy Rhinovirus+ve Pseudomonas in ETA (11/04) Possible new VAP NPA : Adenovirus PCR +	**A:** Trachy 4.5 cuffed Shiley **B:** NIPPY 20/8 FiO2 0.23 **C:** Unsupported **D:** Alert **F:** Feeds 36ml/hr **S:** IV Ceftazidime (01/05)	***Summary started 24/4/18***
Bed 3 Day 3		30/04/2018 A&E	Methyl malonic acidemia	Acute decompensation	Metabolic acidosis Dehydration Loss of weight 10% Lactic acidosis NH3 235 –130 – 82 Na 163	**A:** Own **B:** SVIA/ acidotic **C:** Unsupported **D:** Appropriate **F:** 120% IV maint + 10% dehydration correction IV levocarnitine	BG before ward to check Potassium and Ca Discharge to ward ***Summary started 02.05.18***

Bed 18 Day 2		01/05/18 PED	Out of hospital VF arrest Incidental finding of Chiary malformation	Neuroprotection	Hypothermia Troponin 59 (1-14) Tox neg	A: OETT B: SIMV TV 350mls, PEEP 5 rate 20, 0.25% C: HR 95 SR with ventricular ectopics, Noradrenaline D: Fent 3.5, Midaz 3.5mg/hr F: 70% IVF G: ranitidine S: acyclovir, ceftriaxone	Clarify timeline of events Neuroprotect 48 hrs Keep electrolytes up 24 hour ECG tape (on) ?? may need ICD pre discharge (Krasi) Brugada screen/test Genetic screen for LQTS Cardiomyopathy screening MRI brain
Bed 20 Day 12 **DG**		22/4/18 HDU	Meningomyelocele repaired Arnold chiari 2 malformation VP shunt Tracheomalacia Neuropathic bladder Gastroesophageal reflux Unsafe swallow Post aortoplexy (Dec 2017)	- LRTI - recurrent apnoeas (? obstructive)	**Rhinovirus +ve** Increased WOB since 18/4/18 UTI / temp spikes since 12/4/18 Fungal balls b/l kidneys CT brain : no shunt dysfunction Enoxeparin for left femoral thrombus	A: 4 NETT 14 cm B: BIPAP/ASB 15/6 f15 30% C : stable, left femoral thrombus - enoxaparin D : Chloral F: 100% feeds S : Ambisome 19/4/18 Tazocin 30/4/18 PICC line culture sterile CRP 12	Wean ventilation ***Summary updated 24/4/18***
Bed 21 Day 3		30/4 Theatres	Ex 29/40 Subglottic stenosis GORD NG fed Rt sided aortic arch + aberrant subclavian	Post-op: single stage laryngeal reconstruction	I+V Keep paralysed 48hrs Low BP PCT < 0.1 (03/05)	A: nETT 4.5 uncuffed, 14cm B: BIPAP/ASB 14/5, FiO2 0.3 C: stable D: fent, midaz, roc Chloral + clonidine F: NG feeds S: co-amox	Keep I+V until end of week with dex pre-extubation Reduce IV sedation ?stop roc 03/05 pm

RMCH PICU 05/07/18

Bed	Name DOB	DOA+ Base Hospital	Diagnosis and Relevant Background	Reason for admission	Current Issues	Systems	Plan
7 Day 16		Stepping Hill	AVSD repair at AHCH- May 2017 MV stenosis & regurg	effusion Pul. hypertention LAVV stenosis – for surgery	ETA(27/04) Persistent RML collapse/consol Awaiting transfer to Alder Hey PRBC transfusion(28/4) NPA : negative	@ 14cm, grade 1 B: BIPAP/ASB 16/10 f 16 FiO2 0.50 C: no support D: Chloral QDS F: 80% maint, NG feeds furosemide & spiro S: Ceftaz, gent ; CRP 6	Referred to NWTS (1890) Daily child profile, CRP Twice weekly FBC Chase rpt ETA Discuss abx with micro If FiO2 >0.6 rpt CXR Summary updated 01/05/18
Bed 8 Day 3		01.05.18 PED	Beare-Stevenson Syndrome and visual difficulties VP shunt	Seizure	CT : increased ventricular size → shunt revision catheter noted to be stuck in ventricle→ new catheter passed	A: tracheostomy B: BIPAP/ASB (20/10 f20/ 21%) C: stable D: no further siezures, CSF normal S: nil	
Bed 9 Day 20		14/04/18 Blackpool	Infantile Pompe's Cardiomyopathy Muscular weakness Microcephaly Gross motor delay Paroxysmal SVT Sleep disorder breathing Recurrent Tonsillitis	Transfer AHCH Respiratory wean – Parainfluenza CAP (RLL) Own portable vent from Respiratory	R diaphramatic palsy Pseudomonas in ETA Failed extubation 18/04 Extubated 12.30 01/05 -reintubated 02/05 RLL collaspe	A: nETT 5.0 microcuff 18.5cm B: BiPAP/ASB 22/10, FiO2 0.5 C: Atenolol 15mg BD (SVT) D: Appropriate/PRN chloral E: Full EN S: Afebrile, ceftazidime for pseudomonas- complete 14/7 (started 26/04)	Saline neb for thicker secretions Summary updated 01/05/18
Bed 10 Day 3		1/5/18 Theatres	Ex-prem 32/40 Oesophageal atresia Multiple anastomosis GORD- Fundo CLD Recurrent LRTI	Post op right bronch-oesophgeal fistula repair, re-anastomosis & R throacotomy	Post op recovery 50ml/kg plasmalyte+ 15ml/kg PRBC intraop Self extubation- reintubated 2.5.18	A: 4.5 uncuffed 13cm B: BIPAP/ASB 20/6/22RPM/0.60 C: stable D: Midaz 300mcg, fentanyl 4mcg, F: 70% maintaince IVF S: Cefurox+ metronidazole 5/7	Start steroid – after d/w surg For 48hr pre ext Surg review re TAT and feed
Bed 11 Day 35 MS		24/03/18 Blackburn	Term Poor foetal weight gain VSD + ASD Ch 16 microdeletion	Collapsed neonate – presumed secondary to cardiac failure	Cardiac failure Cardiomegaly+ pulm vasc dilatation Cerebral haemorrhages Failed extubation twice Yeast on ETAs 9/4	A: nETT 3 mm cuffed 11cm B: BiPAP/ASB 14/5, R10, 21% C: Unsupported D: Reg chloral + alimem F: 120ml/kgNG feeds (wt 2.7kg) Furosemide, spironolact	Chase AHCH bed Abx + micafungin if unwell For MR at 6months or before cardiac surgery Referred to NWTS (1891) Summary updated 25/4/18
Bed 12 Day 4		30/04/2018 PED	Left side intracranial space occupying lesion and Rt side midline shift Subfalcine herniation Thymidine phosphorylase deficiency Mitocondrial Neurogastrointestinal encephalopathy Diabetes BMT Nov 2017 TPN dependent	ICP management	Intracranial hypertension Subfalcine herniation Post brain bx + ICP monitor insertion	A: oral ETT at 20cm B: Vol control, low vent settings C: Noadr. + Adr D: Mida 300, Fent 4, Roc 1000 Thio infusion 3mg/kg/hr Temp 35, Paracetamol F: NBM S: mero/metronidazole/acyclovir a/w tissue/CSF micro	TPN when available Thio boluses Monitor UO
Bed 13 Day 6		27/4/18 HDU	Raised ICP 4th ventricle tumour – debulked 26/4 VAP resolved	Post EVD/ICP bolt insertion.		A: COETT B: CPAP/ASB in air C: CPP >50mmHg, D: off Midaz/fent, EVD at 10cmH2O, dex, NBM, IVF 70% maint Na 142 S: min secretions pip/taz (29/04 to 2nd May	? extubation Summary started 28/4/18
Bed 15 Day 26 CG		2/4/18 (ward 85)	Infantile Pompe's Hypoplastic lungs- LTV PEG fed Unsafe swallow Social	Resp failure ?HAP	New tracheostomy Rhinovirus+ve Pseudomonas in ETA (11/04) Possible new VAP NPA : Adenovirus PCR +	A: Trachy 4.5 cuffed Shiley B: NIPPV 20/8 FiO2 0.23 C: Unsupported D: Alert F: Feeds 36ml/hr S: IV Ceftazidime (01/05)	Summary started 24/4/18
Bed 3 Day 3		30/04/2018 A&E	Methyl malonic acidemia	Acute decompensation	Metabolic acidosis Dehydration Loss of weight 10% Lactic acidosis NH3 235 –130 – 82 Na 163	A: Own B: SVIA/ acidotic C: Unsupported D: Appropriate F: 120% IV maint + 10% dehydration correction IV levocarnitine	BG before ward to check Potassium and Ca Discharge to ward Summary started 02.05.18

18 Day 2		PED	arrest Incidental finding of Chiary malformation		Troponin 59 (1-14) Tox neg	B: SIMV TV 350mls, PEEP 5 rate 20, 0.25% C: HR 95 SR with ventricular ectopics, Noradrenaline D: Fent 2.5, Midaz 3.5mg/hr F: 70% IVF G: ranitidine S: acyclovir, ceftriaxone	Neuroprotect 48 hrs Keep electrolytes up 24 hour ECG tape (on) ?? may need ICD pre discharge (Krasi) Brugada screen/test Genetic screen for LQTS Cardiomyopathy screening MRI brain
Bed 20 Day 12 DG		22/4/18 HDU	Meningomyelocele repaired Arnold chiari 2 malformation VP shunt Tracheomalacia Neuropathic bladder Gastroesophageal reflux Unsafe swallow Post aortoplexy (Dec 2017)	- LRTI - recurrent apnoeas (? obstructive)	Rhinovirus +ve Increased WOB since 18/4/18 UTI / temp spikes since 12/4/18 Fungal balls b/l kidneys CT brain : no shunt dysfunction Enoxeparin for left femoral thrombus	A: 4 NETT 14 cm B: BiPAP/ASB 15/6 f15 30% C : stable, left femoral thrombus - enoxaparin D : Chloral F: 100% feeds S : Ambisome 19/4/18 Tazocin 30/4/18 PICC line culture sterile CRP 12	Wean ventilation Summary updated 24/4/18
Bed 21 Day 3		30/4 Theatres	Ex 29/40 Subglottic stenosis GORD NG fed Rt sided aortic arch + aberrant subclavian	Post-op: single stage laryngeal reconstruction	I+V Keep paralysed 48hrs Low BP PCT < 0.1 (03/05)	A: nETT 4.5 uncuffed, 14cm B: BiPAP/ASB 14/5, FiO2 0.3 C: stable D: fent, midaz, roc Chloral + clonidine F: NG feeds S: co-amox	Keep I+V until end of week with dex pre-extubation Reduce IV sedation ?stop roc 03/05 pm

RMCH PICU 05/07/18

Bed	Name DOB	DOA+ Base Hospital	Diagnosis and Relevant Background	Reason for admission	Current Issues	Systems	Plan
7 Day 16		Stepping Hill	AVSD repair at AHCH- May 2017 MV stenosis & regurg	effusion Pul. hypertention LAVV stenosis – for surgery	**ETA(27/04)** Persistent RML collapse/consol Awaiting transfer to Alder Hey PRBC transfusion(28/4) NPA : negative	@ 14cm, grade 1 **B:** BIPAP/ASB 16/10 f 16 FiO2 0.50 **C:** no support **D:** Chloral QDS **F:** 80% maint, NG feeds furosemide & spiro **S:** Ceftaz, gent ; CRP 6	Referred to NWTS (1890) Daily child profile, CRP Twice weekly FBC Chase rpt ETA Discuss abx with micro **If FiO2 >0.6 rpt CXR** ***Summary updated 01/05/18***
Bed 8 Day 3		01.05.18 PED	Beare-Stevenson Syndrome and visual difficulties VP shunt	Seizure	CT : increased ventricular size → shunt revision catheter noted to be stuck in ventricle→ new catheter passed	**A:** tracheostomy **B:** BIPAP/ASB (20/10 f20/ 21%) **C:** stable **D:** no further siezures, CSF normal **S:** nil	
Bed 9 Day 20		14/04/18 Blackpool	Infantile Pompe's Cardiomyopathy Muscular weakness Microcephaly Gross motor delay Paroxysmal SVT Sleep disorder breathing Recurrent Tonsillitis	Transfer AHCH Respiratory wean – Parainfluenza CAP (RLL) Own portable vent from Respiratory	R diaphramatic palsy Pseudomonas in ETA Failed extubation 18/04 Extubated 12.30 01/05 -reintubated 02/05 RLL collaspe	**A:** nETT 5.0 microcuff 18.5cm **B:** BIPAP/ASB 22/10, FiO2 0.5 **C:** Atenolol 15mg BD (SVT) **D:** Appropriate/PRN chloral **E:** Full EN **S:** Afebrile, ceftazidime for pseudomonas- complete 14/7 (started 26/04)	Saline neb for thicker secretions ***Summary updated 01/05/18***
Bed 10 Day 3		1/5/18 Theatres	Ex-prem 32/40 Oesophageal atresia Multiple anastomosis GORD- Fundo CLD Recurrent LRTI	Post op right bronch-oesophgeal fistula repair, re-anastomosis & R throacotomy	Post op recovery 50ml/kg plasmalyte+ 15ml/kg PRBC intraop Self extubation- reintubated 2.5.18	**A:** 4.5 uncuffed 13cm **B:** BIPAP/ASB 20/6/22RPM/0.60 **C:** stable **D:** Midaz 300mcg, fentanyl 4mcg **F:** 70% maintaince IVF **S:** Cefurox+ metronidazole 5/7	Start steroid – after d/w surg For 48hr pre ext Surg review re TAT and feed
Bed 11 Day 35 **MS**		24/03/18 Blackburn	Term Poor foetal weight gain VSD + ASD Ch 16 microdeletion	Collapsed neonate – presumed secondary to cardiac failure	Cardiac failure Cardiomegaly+ pulm vasc dilatation Cerebral haemorrhages Failed extubation twice Yeast on ETAs 9/4	**A:** nETT 3 mm cuffed 11cm **B:** BiPAP/ASB 14/5, R10, 21% **C:** Unsupported **D:** Reg chloral + alimem **F:** 120ml/kgNG feeds (wt 2.7kg) Furosemide, spironolact	Chase AHCH bed Abx + micafungin if unwell For MR at 6months or before cardiac surgery Referred to NWTS (1891) ***Summary updated 25/4/18***
Bed 12 Day 4		30/04/2018 PED	Left side intracranial space occupying lesion and Rt side midline shift Subfalcine herniation Thymidine phosphorylase deficiency Mitocondrial Neurogastrointestinal encephalopathy Diabetes BMT Nov 2017 TPN dependent	ICP management	Intracranial hypertension Subfalcine herniation Post brain bx + ICP monitor insertion	**A:** oral ETT at 20cm **B:** Vol control, low vent settings **C:** Noadr. + Adr **D:** Mida 300, Fent 4, Roc 1000 Thio infusion 3mg/kg/hr Temp 35, Paracetamol **F:** NBM **S:** mero/metronidazole/acyclovir a/w tissue/CSF micro	TPN when available Thio boluses Monitor UO
Bed 13 Day 6		27/4/18 HDU	Raised ICP 4th ventricle tumour – debulked 26/4 VAP resolved	Post EVD/ICP bolt insertion.		**A:** COETT **B:** CPAP/ASB in air **C:** CPP >50mmHg. **D:** off Midaz/fent, EVD at 10cmH2O, dex, **NBM**, IVF 70% maint Na 142 **S:** min secretions pip/taz (29/04 to 2nd May	? extubation ***Summary started 28/4/18***
Bed 15 Day 26 **CG**		2/4/18 (ward 85)	Infantile Pompe's Hypoplastic lungs- LTV PEG fed Unsafe swallow Social	Resp failure ?HAP	New tracheostomy Rhinovirus+ve Pseudomonas in ETA (11/04) Possible new VAP NPA : Adenovirus PCR +	**A:** Trachy 4.5 cuffed Shiley **B:** NIPPV 20/8 FiO2 0.23 **C:** Unsupported **D:** Alert **F:** Feeds 36ml/hr **S:** IV Ceftazidime (01/05)	***Summary started 24/4/18***
Bed 3 Day 3		30/04/2018 A&E	Methyl malonic acidemia	Acute decompensation	Metabolic acidosis Dehydration Loss of weight 10% Lactic acidosis NH3 235 –130 – 82 Na 163	**A:** Own **B:** SVIA/ acidotic **C:** Unsupported **D:** Appropriate **F:** 120% IV maint + 10% dehydration correction IV levocarnitine	BG before ward to check Potassium and Ca Discharge to ward ***Summary started 02.05.18***

18 Day 2		PED	arrest Incidental finding of Chiary malformation		Troponin 59 (1-14) Tox neg	B: SIMV TV 350mls, PEEP 5 rate 20, 0.25% C: HR 95 SR with ventricular ectopics, Noradrenaline D: Fent 2.5, Midaz 3.5mg/hr F: 70% IVF G: ranitidne S: acyclovir, ceftriaxone	Neuroprotect 48 hrs Keep electrolytes up 24 hour ECG tape (on) ?? may need ICD pre discharge (Krasi) Brugada screen/test Genetic screen for LQTS Cardiomyopathy screening MRI brain
Bed 20 Day 12 **DG**		22/4/18 HDU	Meningomyelocele repaired Arnold chiari 2 malformation VP shunt Tracheomalacia Neuropathic bladder Gastroesophageal reflux Unsafe swallow Post aortoplexy (Dec 2017)	- LRTI - recurrent apnoeas (? obstructive)	**Rhinovirus +ve** Increased WOB since 18/4/18 UTI / temp spikes since 12/4/18 Fungal balls b/l kidneys CT brain : no shunt dysfunction Enoxeparin for left femoral thrombus	A: 4 NETT 14 cm B: BIPAP/ASB 15/6 f15 30% C : stable, left femoral thrombus - enoxaparin D : Chloral F: 100% feeds S : Ambisome 19/4/18 Tazocin 30/4/18 PICC line culture sterile CRP 12	Wean ventilation ***Summary updated 24/4/18***
Bed 21 Day 3		30/4 Theatres	EX 29/40 Subglottic stenosis GORD NG fed Rt sided aortic arch + aberrant subclavian	Post-op: single stage laryngeal reconstruction	I+V Keep paralysed 48hrs Low BP PCT < 0.1 (03/05)	A: nETT 4.5 uncuffed, 14cm B: BiPAP/ASB 14/5, FiO2 0.3 C: stable D: fent, midaz, roc Chloral + clonidine F: NG feeds S: co-amox	Keep I+V until end of week with dex pre-extubation Reduce IV sedation ?stop roc 03/05 pm

RMCH PICU 05/07/18

- Appropriate treatment; 4/12 = **33%**
- Inappropriate treatment; 6/12 = **50%**
  - Treatment is extremely unlikely to be beneficial, is extremely costly or is of uncertain benefit
- Futile treatment; 2/12 = **17%**
  - The care provided will not have the desired outcome or accomplish its intended goals

Futile or inappropriate treatment; 2006 = 21%, 2018 = 67%

Intensive Care Med (2015) 41:1330–1332
DOI 10.1007/s00134-015-3873-3

EDITORIAL

Rachel S. Agbeko
Jeffrey P. Burns
Mark J. Peters

Tools for revealing uncomfortable truths? Measuring child-centred health-related quality of life after paediatric intensive care

Received: 5 May 2015
Accepted: 6 May 2015
Published online: 3 June 2015

R. S. Agbeko (✉)
Department of Paediatric Intensive Care, Great North Children's Hospital, The Newcastle upon Tyne Hospitals NHS Foundation Trust, Institute of Cellular Medicine, Newcastle University, Newcastle upon Tyne, UK
e-mail: rachel.agbeko@ncl.ac.uk

J. P. Burns
Division of Critical Care Medicine, Department of Anaesthesia, Perioperative and Pain Medicine, Boston Children's Hospital, Harvard Medical School, Boston, MA, USA

M. J. Peters
Respiratory, Critical Care and Anaesthesia Unit, Paediatric Intensive Care Unit, UCL Institute of Child Health, Great Ormond Street Hospital NHS Trust, London, UK

The benefits of paediatric intensive care are self-evident. Mortality rates for critically ill children have declined dramatically [1]. The greatest gains are occurring in higher-risk groups in whom admission to critical care was previously considered futile. Even those with malignancies [2] fare better and require a more optimistic approach than in the past [3].

In this edition of *Intensive Care Medicine*, Aspesberro et al. [4] further this point: that mortality per se has ceased to be a meaningful outcome measure for the majority of paediatric intensive care admissions. Their response is to attempt to identify more meaningful outcome measures from the health-related quality of life (HRQL) literature published between 1980 and 2015 in the context of paediatric critical care.

The review is timely, important and uncomfortable. Timely, because there is a growing appreciation that the provision of paediatric intensive care is associated with increased morbidity [5]. Why? Perhaps at least in part because there has been a shift in PICU casemix from 'acute' to 'acute on chronic' critical illness. A recent study from the USA identified that 53 % of critically ill children had pre-existing chronic complex illnesses [6]. This change has many implications. One major implication is that the HRQL outcomes that might be hoped for many of our patients are becoming more distinct from those of previously healthy children [7].

This subject is important, because paediatric intensive care is costly: for the child, their family and society. Equally, the association of increased morbidity with improved mortality should make intensivists uncomfortable. [illegible] hard "objective, binary 'life or death' outcome to the more "fuzzy" concept of HRQL.

[illegible] being and not merely the absence of disease or infirmity" [8].

[illegible] healthy most of the time as the emphasis is on "complete" well-being. Moreover, the WHO definition of [illegible] This understanding prompted a group of international [illegible] tributes to successfully navigate through childhood, and self-management is increasingly relevant to children as [illegible] measurement, in order to better advance our clinical practice to meet these new outcome goals.

Other high-risk paediatric medical specialties have previously confronted this same challenge of evolving a more empirical basis by which to assess the potential

'Paediatric intensive care is transitioning from a specialty that deals with acute illness to one that is part of the multidisciplinary team that looks after children with chronic illness'

Impact of potentially inappropriate care in PICU

MANCHESTER EXPERIENCE

Judicial resolution; RMCH experience

Family Law Week

keywords search

- Home
- Create account
- Subscribe to our CPD
- Current CPD Courses
- News
- Judgments
  - 2016 archive
  - 2015 archive
  - 2014 archive
  - 2013 archive
  - 2012 archive
  - 2011 archive
  - 2010 archive
  - 2009 archive
  - 2008 archive
  - 2007 archive
  - 2006 archive
  - 2005 archive
  - Pre 2005 judgments
  - Case Digests
- Articles
- Podcasts
- PDs & Guidance
- Monthly Newsletters
- Recruitment
- Advertising on FLW

An NHS Foundation Trust v R (Child) & Ors [2013] EWHC 2340 (Fam)

Application concerning the medical treatment of a 14 month old child and in particular the removal of the child from hospital to live at home and the continuation of artificial ventilation.

The child, R, aged 14 months old at the date of the original judgment, was born with profound developmental delay. It was found early on that R was unable to suck and he was diagnosed with Down's Syndrome and mitochondrial myopath,; suffering from, inter alia, profound neurological problems and severe and progressive muscle weakness. R was moved into the Paediatric Intensive Care Unit when he was two months old and remained there. He was unable to breathe for himself and required continuous artificial ventilation. The prognosis given was that if the ventilation was continued, R's life expectancy was reduced but uncertain. If ventilation was withdrawn, he would rapidly die.

R's parents and family wanted R to move to live at home with a package of care which included long-term ventilation. The treating doctors considered that this would be too much for R and that it would be in R's best interests if ventilation were withdrawn, thereby allowing him to die in comfort. In March 2013 the NHS Trust responsible for R's care made an application to withdraw ventilation.

It was the unanimous view of the treating clinicians that continuing R's life by long-term ventilation was "delaying his death without significantly alleviating his suffering".

The family did not consent to the withdrawal of treatment on the basis that R shared a loving bond with the family and had a quality of life which enabled him to interact. He experienced pleasure when held by a family member and his heart rate would slow down when cradled by his family, indicating comfort. He would move his eyes towards the sound of their voices. As practising Muslims they held conscientious beliefs about the sanctity of life.

Judicial resolution; RMCH experience

Family Law Week

keywords search

- Home
- Create account
- Subscribe to our CPD
- Current CPD Courses
- News
- Judgments
  - 2016 archive
  - 2015 archive
  - 2014 archive
  - 2013 archive
  - 2012 archive
  - 2011 archive
  - 2010 archive
  - 2009 archive
  - 2008 archive
  - 2007 archive
  - 2006 archive
  - 2005 archive
  - Pre 2005 judgments
  - Case Digests
- Articles
- Podcasts
- PDs & Guidance
- Monthly Newsletters
- Recruitment
- Advertising on FLW

Admission; 11 months

Legal process 7 months

Home > Judgm

An NHS F

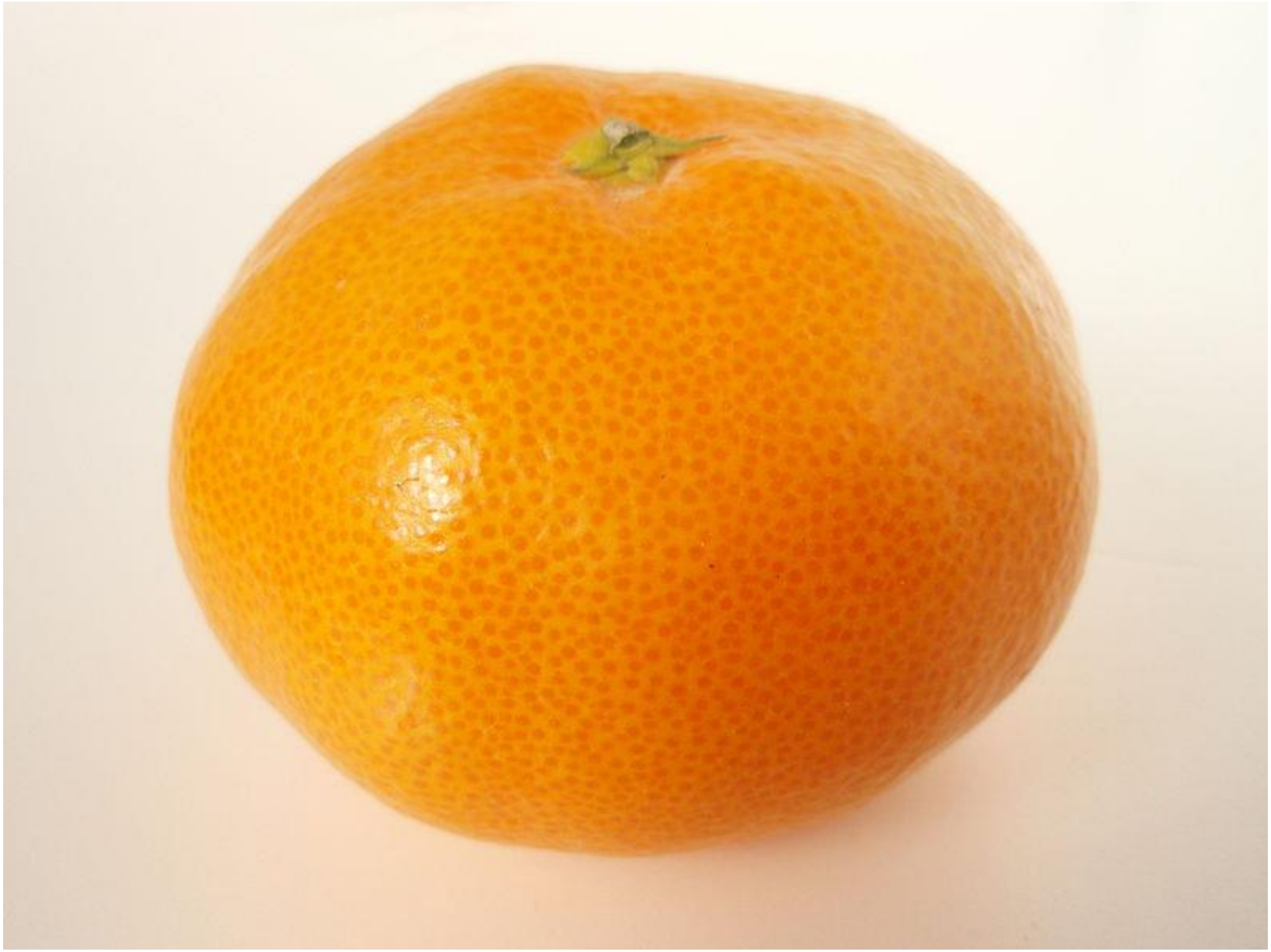
Application ... he removal of the child from hospital to live at home

The child, R, aged 14 months old at the date of the original judgment, was born with profound developmental delay. It was found early on that R was unable to suck and he was diagnosed with Down's Syndrome and mitochondrial myopath,; suffering from, inter alia, profound neurological problems and severe and progressive muscle weakness. R was moved into the Paediatric Intensive Care Unit when he was two months old and remained there. He was unable to breathe for himself and required continuous artificial ventilation. The prognosis given was that if the ventilation was continued, R's life expectancy was reduced but uncertain. If ventilation was withdrawn, he would rapidly die.

R's parents and family wanted R to move to live at home with a package of care which included long-term ventilation. The treating doctors considered that this would be too much for R and that it would be in R's best interests if ventilation were withdrawn, thereby allowing him to die in comfort. In March 2013 the NHS Trust responsible for R's care made an application to withdraw ventilation.

It was the unanimous view of the treating clinicians that continuing R's life by long-term ventilation was "delaying his death without significantly alleviating his suffering".

The family did not consent to the withdrawal of treatment on the basis that R shared a loving bond with the family and had a quality of life which enabled him to interact. He experienced pleasure when held by a family member and his heart rate would slow down when cradled by his family, indicating comfort. He would move his eyes towards the sound of their voices. As practising Muslims they held conscientious beliefs about the sanctity of life.



Neutral Citation Number: **[2015] EWHC 443 (Fam)**

IN THE HIGH COURT OF JUSTICE
FAMILY DIVISION
MANCHESTER DISTRICT REGISTRY

Civil Justice Centre
1 Bridge Street West
Manchester
M60 9DJ

Thursday, 12th February 2015

Before:

THE HONOURABLE MR JUSTICE HAYDEN

In the matter of:

Re: A (A Child)

Counsel for the Applicant NHS Trust: MISS CAVANAGH

The First Respondent Father, Mr A, appeared In Person

The Second Respondent Mother did not appear and was not represented

Counsel for the Third Respondent the Senior Coroner for Manchester: MR BURROWS

DAILY Mirror

'It's the right right thing to do': Judge orders life support machine keeping toddler alive is switched off

12:44, 16 FEBRUARY 2015 | BY GLEN KEOGH

Doctors said the boy was unresponsive and declared him "clinically dead" after he was rushed to hospital after choking on a satsuma

Distressed: The boy's parents argued for him to be kept alive but a judge ruled that his life support should be switched off

DAILY Mirror

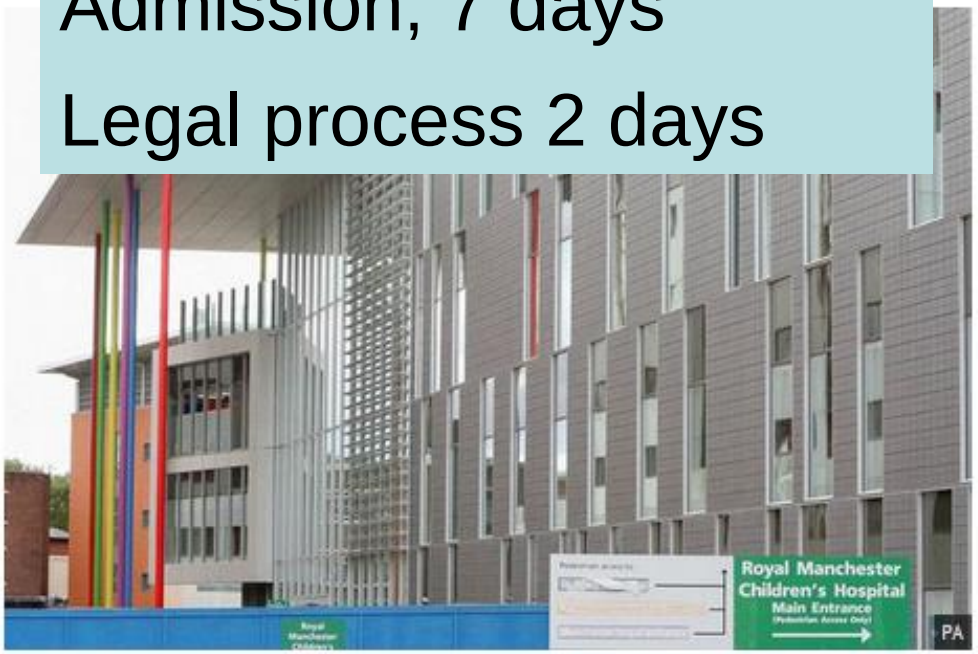
'It's the right right thing to do': Judge orders life support machine keeping toddler alive is switched off

12:44, 16 FEBRUARY 2015 | BY GLEN KEOGH

Doctors said the boy was unresponsive and declared him "clinically dead" after he was rushed to hospital after choking on a satsuma

Admission; 7 days

Legal process 2 days



Distressed: The boy's parents argued for him to be kept alive but a judge ruled that his life support should be switched off

Twins die as court rules for life support to be withdrawn

Two 14-month-old boys died after their life support was withdrawn following a court case where Mr Justice Holman ruled in favour of doctors' judgement

By Marcus Johns

Royal Manchester Children's Hospital is part of the Central Manchester University Hospitals NHS Foundation Trus Photo: The Labour Party @Flickr

Two 14-month-old boys have died after a court ordered their life support to be switched off against the wishes of the parents. The court case Central Manchester University Hospitals NHS Foundation Trust vs A and others took place on the 2nd of October 2015. The boys died around five days later in the presence of their parents and an Imam.

Posted **16 October, 2015** in **Manchester, News, University** by **Marcus Johns**

Related posts

7th October 2013 **Concerns raised over discrimination in GP exam** University of Manchester report raises concerns over discrimination against ethnic minority doctors

23rd February 2016 **Nigerian student faces deportation to death** Master's student Luqman Onikosi faces deportation back to Nigeria where he will not receive critical Hepatitis B treatment

25th October 2015 **Medical Students Left Out of Contract Negotiations** Medical students feel their voices are not being heard in the attempt to reject

POPULAR

Album: David Bowie – No Plan EP

NUS Vice-President caught on film planning to oust President

Fish out of Water: Bowie Binge

PlayStation hacked again

Baroness Deech's claims that UoM is a 'no-go' for Jewish Students criticised

Why Manchester Students' Union supports BDS

Manchester students get cheeky for charity: The 2015 naked calendar is here!

MUFC Player Ratings: Manchester United vs Sunderland

Trainspotting: Book vs. film

Why Daley Blind can be United's next Michael Carrick

@THEMANCUNION

Tweets by @THEMANCUNION

The Mancunion
@THEMANCUNION
An undercover investigation filmed Vice-President of the NUS admitting to plans to oust
theguardian.com/2017/01/11/nus...

Twins die as court rules for life support to be withdrawn

Two 14-month-old boys died after their life support was withdrawn following a court case where Mr Justice Holman ruled in favour of doctors' judgement

By Marcus Johns

Royal Manchester Children's Hospital is part of the Central Manchester University Hospitals NHS Foundation Trus Photo: The Labour Party @Flickr

Two 14-month-old boys have died after a court ordered their life support to be switched off against the wishes of the parents. The court case Central Manchester University Hospitals NHS Foundation Trust vs A and others took place on the 2nd of October 2015. The boys died around five days later in the presence of their parents and an Imam.

Admission; 7 months

Legal process 6 months

raised over discrimination in GP exam University of Manchester report raises concerns over discrimination against ethnic minority doctors

23rd February 2016 **Nigerian student faces deportation to death** Master's student Luqman Onikosi faces deportation back to Nigeria where he will not receive critical Hepatitis B treatment

25th October 2015 **Medical Students Left Out of Contract Negotiations** Medical students feel their voices are not being heard in the attempt to reject

POPULAR
Album: David Bowie – No Plan EP
NUS Vice-President caught on film planning to oust President
Fish out of Water: Bowie Binge
PlayStation hacked again
Baroness Deech's claims that UoM is a 'no-go' for Jewish Students criticised
ester Students' Union
students get cheeky for
15 naked calendar is here!
r Ratings: Manchester
erland
Trainspotting: Book vs. film
Why Daley Blind can be United's next Michael Carrick
@THEMANCUNION
Tweets by @THEMANCUNION
The Mancunion
@THEMANCUNION
An undercover investigation filmed Vice-President of the NUS admitting to plans to oust


CASE NO. LV17C00739

IN THE HIGH COURT OF JUSTICE
LIVERPOOL DISTRICT REGISTRY
FAMILY DIVISION

BETWEEN:

CENTRAL MANCHESTER UNIVERSITY HOSPITALS NHS FOUNDATION TRUST

Applicant

-and-

NARGAS YOUSAF

1st Respondent

INDEX TO BUNDLE FOR HEARING ON 9 & 10 MAY 2017 AT 10:30AM

BEFORE THE HONOURABLE MR JUSTICE FRANCIS

CASE NO. LV17C00739

IN THE HIGH COURT OF JUSTICE
LIVERPOOL DISTRICT REGISTRY
FAMILY DIVISION

BETWEEN:

CENTRAL MANCHESTER UNIVERSITY HOSPITALS NHS FOUNDATION TRUST

Applicant

–and–

NARGAS YOUSAF

1st Respondent

IN[illegible]

Admission; 14 months

Legal process 9 months

No.	Document	Date	Page Nos.
Section A – Preliminary Documents			
1.	Applicant's Position Statement	02.05.17	A1 – A7
2.	Proposed Witness Template		A8
3.	1st & 2nd Respondents' Position Statement		To be added
4.	3rd Respondent's Position Statement		To be added

Impact of potentially inappropriate care in PICU

UK EXPERIENCE

UK PICU experience

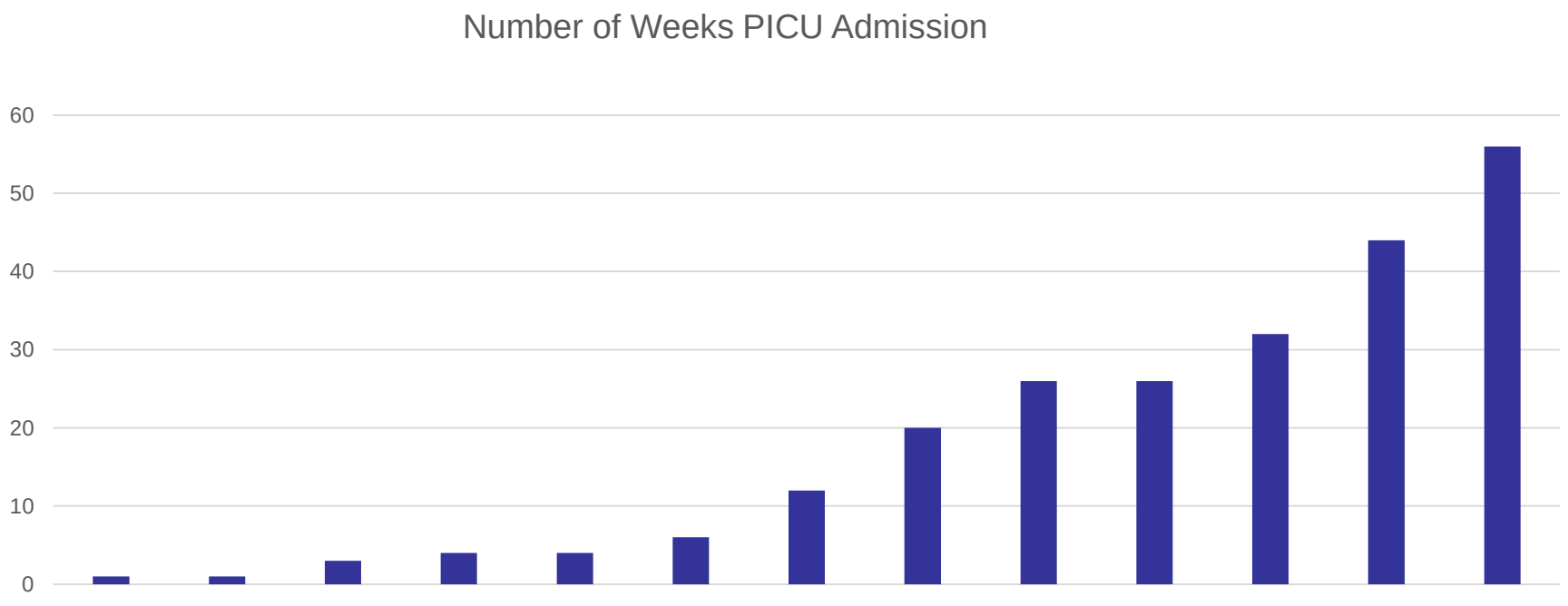
- Paediatric Intensive Care Society (PICS)
- Child Health Ethics and Law Special Interest Group (CHELSIG)
- Retrospective review;
  - Increasing numbers (esp last 5 years)
  - Duration of legal process
    - Either a few days or 5-9 months
- Prospective database

PICS Paediatric Intensive Care Society

Methods

- All UK PICUs over last 5 years
- Focus on England
  - situations different in Scotland & Ireland
- 26 centres initial response including Manchester
- Currently have data on 17 cases
- 13 cases under 1yr of age
  - 2 children aged 2yrs, 1 child aged 14yrs

PICU Admission Duration



Impact of potentially inappropriate care in PICU

IMPACT OF PROLONGED PICU ADMISSION

Impact of prolonged PICU admission

- Ethical
  - Child; prolonged treatment not in their best interest
  - Families; disruption, siblings, costs
  - Staff; medical and nursing staff
- Financial
  - 1 day of PICU admission = £2,400
  - Legal costs
- Resources
  - Median PICU admission = 3.5 days
- Performance indicators for PICU

Impact on nursing staff

Louise Harrison, Year 5 Medical Student, APEP Project

Qualitative research into the impact on nursing staff
Semi-structured interviews with 24 members of staff

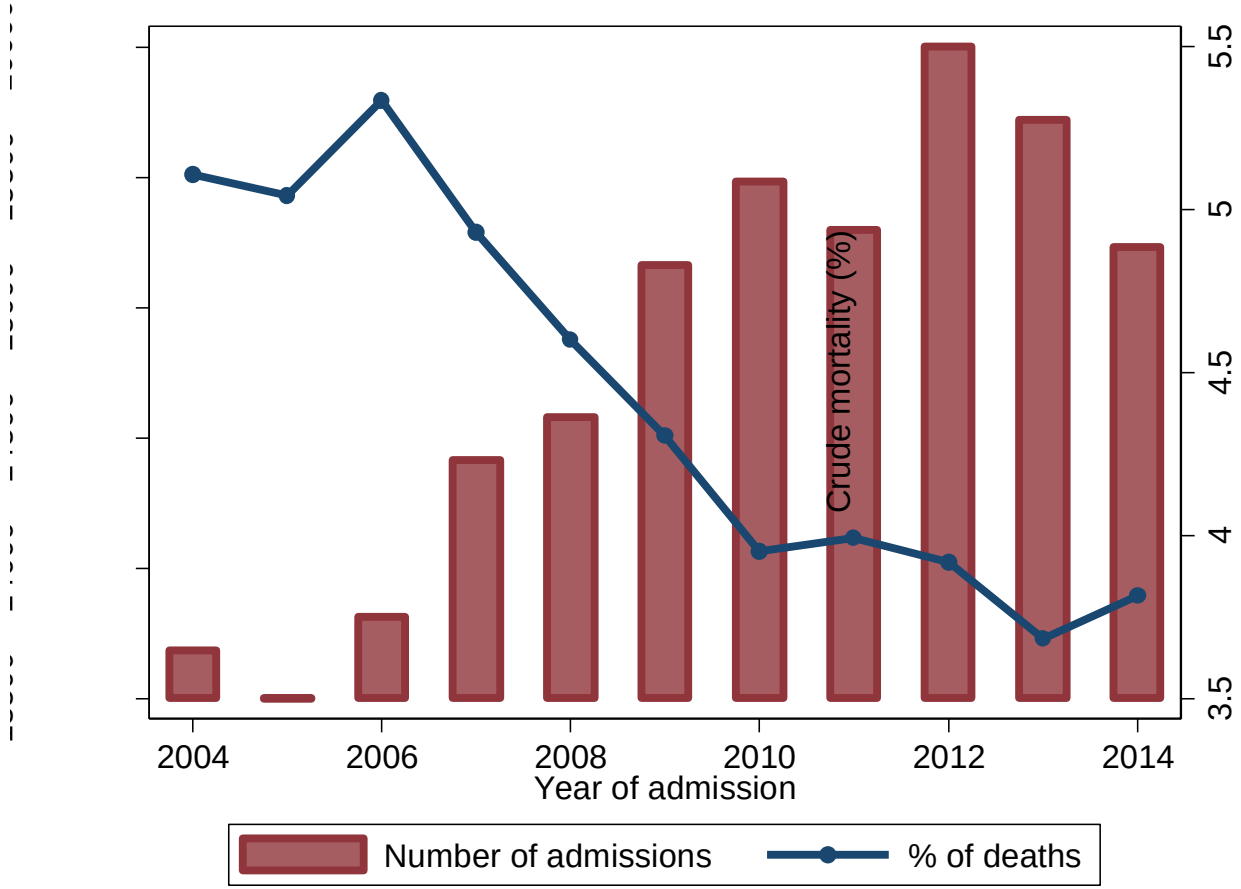
1. Does caring for these children impact on your mood, and if so how?
2. Do you have any personal or religious beliefs that may influence how you view these situations?
3. Have you ever considered changing jobs due to the nature of these cases?

Themes identified

- Emotional impact
  - More impact on the most junior nurses
- Mood
  - Negative impact on mood
    - Sadness, helplessness, frustration
  - Prolongation of suffering & ‘torture’

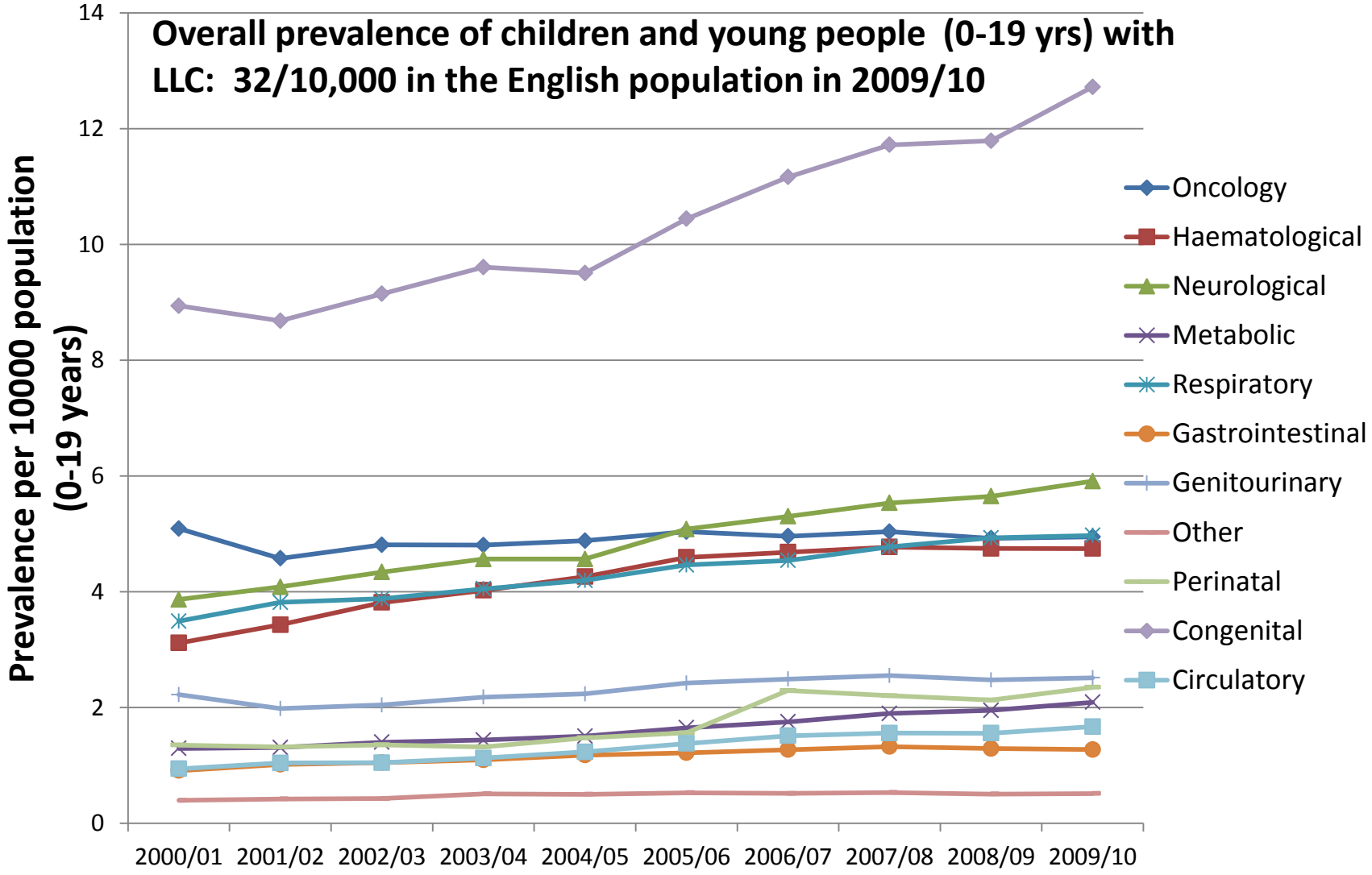
‘Can you imagine how it feels when you know your actions are causing a child to suffer?’

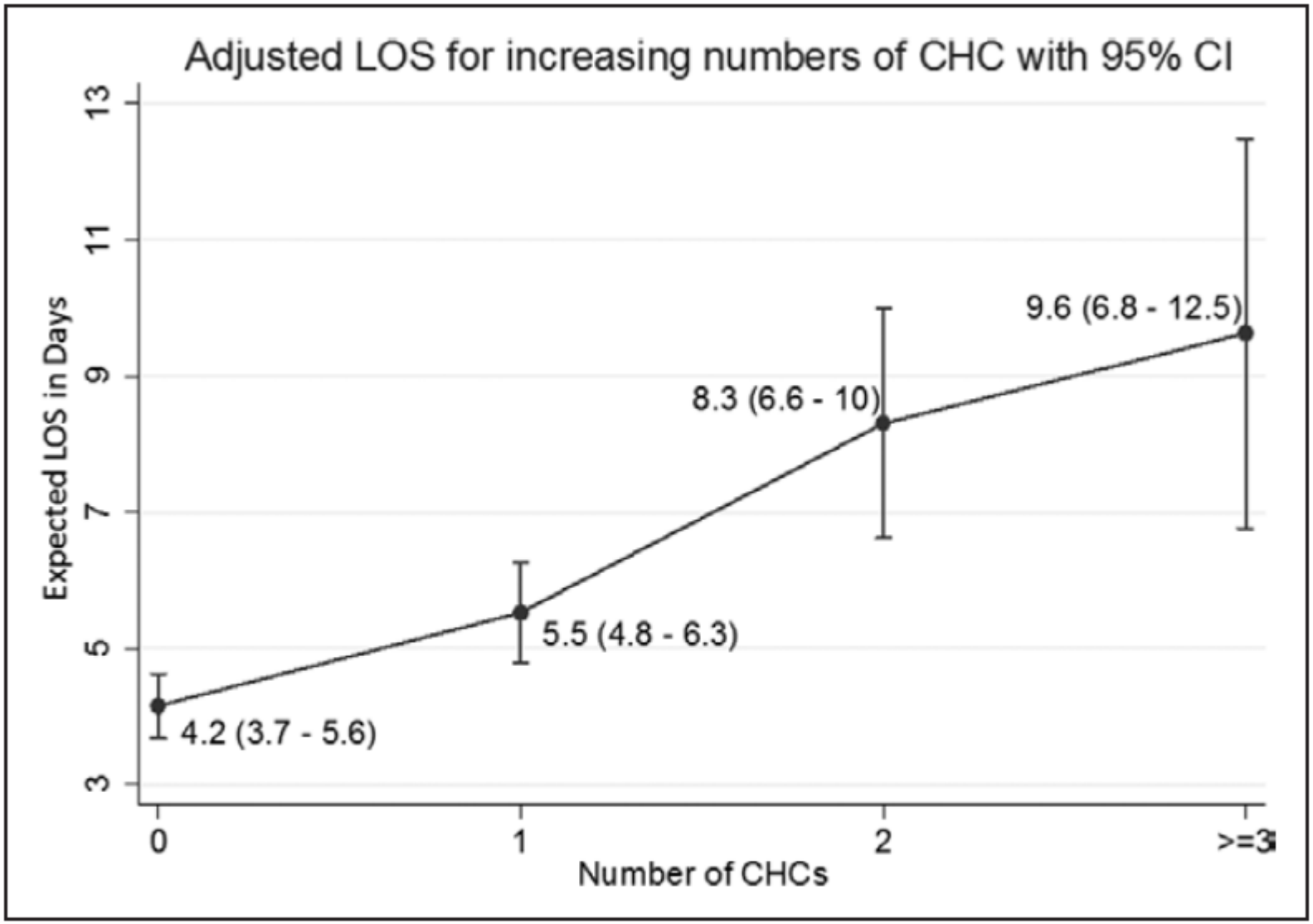
PICU Performance indicators



In 2015, UK and ROI crude mortality was 3.8%

Context: Increase in prevalence of life-limiting conditions (LLC)





The Impact of Chronic Health Conditions on Length of Stay and Mortality in a General PICU*

Scott O'Brien, MRes[1]; Simon Nadel, MD[1]; Ofran Almossawi, MSc[2]; David P. Inwald, PhD[1]

RCPCH
Royal College of
Paediatrics and Child Health
Leading the way in Children's Health

OPEN ACCESS

Children with life-limiting conditions in paediatric intensive care units: a national cohort, data linkage study

Lorna K Fraser,[1] Roger Parslow[2]

► Additional material is published online only. To view please visit the journal online (http://dx.doi.org/10.1136/archdischild-2017-312638).

[1]Department of Health Sciences, University of York, York, UK
[2]Division of Epidemiology and Biostatistics, Leeds Institute of Cardiovascular and Metabolic Medicine, University of Leeds, Leeds, UK

Correspondence to
Dr Lorna K Fraser, Department of Health Sciences, University of York, Area 2, Seebohm Rowntree Building, Heslington, York YO10 5DD, UK; lorna.fraser@york.ac.uk

Received 4 January 2017
Revised 16 May 2017
Accepted 28 May 2017

ABSTRACT

Objective To determine how many children are admitted to paediatric intensive care unit (PICU) with life-limiting conditions (LLCs) and their outcomes.

Design National cohort, data-linkage study.

Setting PICUs in England.

Patients Children admitted to a UK PICU (1 January 2004 and 31 March 2015) were identified in the Paediatric Intensive Care Audit Network dataset. Linkage to hospital episodes statistics enabled identification of children with a LLC using an International Classification of Diseases (ICD10) code list.

Main outcome measures Random-effects logistic regression was undertaken to assess risk of death in PICU. Flexible parametric survival modelling was used to assess survival in the year after discharge.

Results Overall, 57.6% (n=89 127) of PICU admissions and 72.90% (n=4821) of deaths in PICU were for an individual with a LLC. The crude mortality rate in PICU was 5.4% for those with a LLC and 2.7% of those without a LLC. In the fully adjusted model, children with a LLC were 75% more likely than those without a LLC to die in PICU (OR 1.75 (95% CI 1.64 to 1.87)). Although overall survival to 1 year postdischarge was 96%, children with a LLC were 2.5 times more likely to die in that year than children without a LLC (OR 2.59 (95% CI 2.47 to 2.71)).

Conclusions Children with a LLC accounted for a large proportion of the PICU population. There is an opportunity to integrate specialist paediatric palliative care services with paediatric critical care to enable choice around place of care for these children and families.

What is already known on this topic?

- The prevalence of children and young people with life-limiting conditions (LLCs) or life-threatening conditions is rising.
- Overall mortality in paediatric intensive care unit (PICU) is decreasing.

What this study adds?

- Children with a LLC accounted for the majority of admissions, bed-days and deaths in PICU.
- Children with a LLC were75% more likely to die in PICU than those without a LLC.
- There was 93% survival at 1 year for children with a LLC.

INTRODUCTION

Life-limiting conditions (LLCs) are those for which there is no reasonable hope of cure and from which children will ultimately die, for example, Duchenne muscular dystrophy or neurodegenerative disease. Life-threatening conditions (LTCs) are those for which curative treatment may be feasible but can fail, for example, cancer. LLC will be used to include life-limiting conditions and LTCs.

The prevalence of children and young people with a LLC is increasing[1] partly due to more aggressive treatment of complications and the use of medical technologies, including paediatric intensive care unit (PICU). These children often have repeated hospital admissions[2] and use increasing amounts of hospital resources.[3–5] Many of these children also die on PICU[6] when treatment fails or is withdrawn. This study aims to ascertain what proportion of admissions to PICUs are for children with a LLC and their outcomes in PICU and up to 1 year postdischarge.

METHODS

Datasets

The Paediatric Intensive Care Audit Network (PICANet) collects data on all children admitted to PICUs in the UK and Ireland. All admissions to a PICU in the UK between 1 January 2004 and 31 March 2015 were identified in the PICANet dataset.[7] Only children resident in England were included as only their inpatient hospital data (Hospital Episodes Statistics (HES)) were available for linkage.[8] Hospital data for the other nations of the UK were not available.

The Office for National Statistics (ONS) death record data in England were available with a censor date of 1 November 2015.[9]

Linkage of the PICANet dataset to the HES and ONS data was undertaken by the NHS Digital.[10] The standard deterministic linkage algorithm using National Health Service (NHS) number, date of birth, sex and postcode was used.

Clinical variables

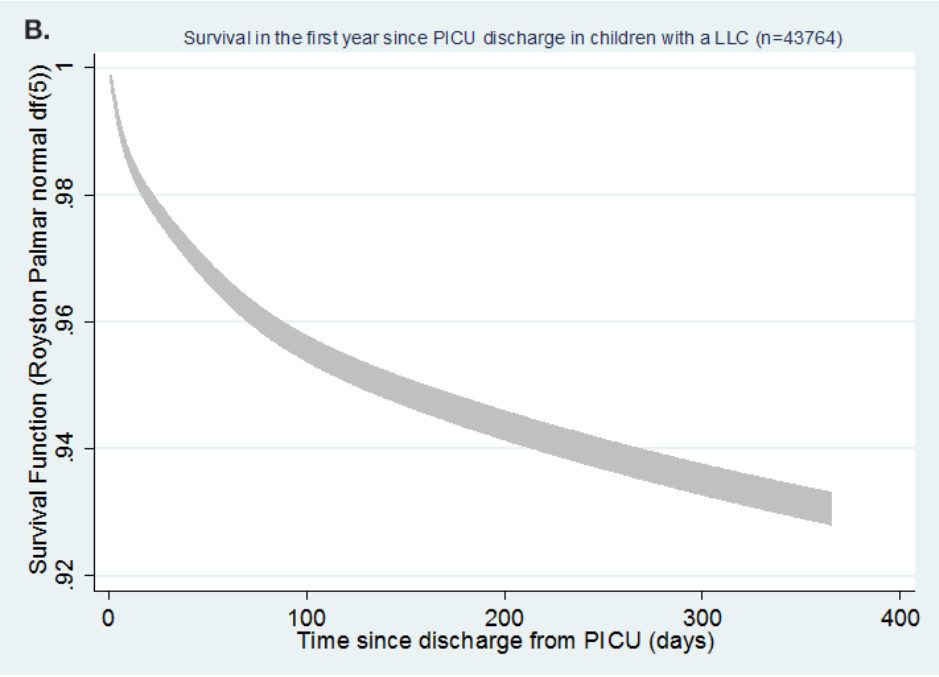
Inpatient HES data

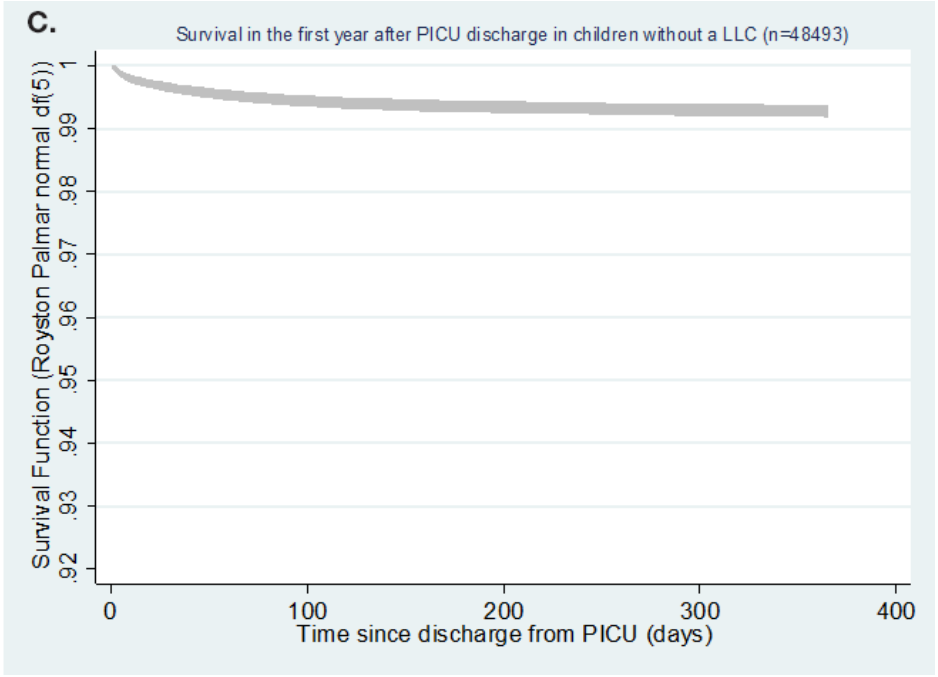
The PICANet data are of high quality and validated, but some of the non-mandatory fields, including comorbidities, are incomplete. Therefore, it is not possible to identify children with a LLC using the PICANet dataset alone. Linkage to the inpatient

CrossMark

To cite: Fraser LK, Parslow R. *Arch Dis Child* Published Online First: [*please include* Day Month Year]. doi:10.1136/archdischild-2017-312638

Impact of LLC on 1yr survival





Impact of potentially inappropriate care in PICU

- Definitions
- Incidence
- Manchester experience
- UK experience
- Impact of prolonged PICU admission

Any Questions?