Paediatric critical care and specialised surgery review: issues to address

Purpose

1. This paper sets out the proposed key issues for NHS England's paediatric critical care and paediatric specialised surgery review, which will also consider extracorporeal membrane oxygenation (ECMO) and transport for children requiring paediatric critical care (PCC). In reading it, expert stakeholder panel members are asked to consider:

    - Whether we have correctly identified the pressing issues that critical care and specialist surgical services are facing;
    - Whether any issues are more pressing than others; and
    - Whether there are additional, major issues to address, that are not discussed in this paper.

Introduction to the review

2. NHS England has responsibility for 149 specialised services, with a total budget of £15.6bn for 2016/17 and £16.4bn for 2017/18. Reforming how these specialised services are provided and supporting new models of care will be central to improving quality of services for patients and supporting longer-term financial sustainability.

3. Two years ago the NHS *Five Year Forward View* announced a rolling programme of service reviews. The programme is aimed at identifying opportunities to transform the way that specialised services are provided on a national scale. The reviews are intended to support all aspects of our triple aim – improving population health, improving quality or services and improving value for money.

4. In 2016 NHS England identified paediatric critical care (PCC) and paediatric specialist surgery as priorities for service reviews. This decision was reinforced by the *Independent Review of Children's Cardiac Services in Bristol,* published in June 2016 which recommended a national review of paediatric intensive care units (PICUs). Given the interdependencies between these reviews, they are being taken forward jointly, with the aim of commencing implementation in September 2017. This is particularly opportune as early findings around PCC should inform the consultation for the review of congenital heart disease (CHD) services.

5. This paper sets out some of the key issues that we have identified so far and that we will aim to tackle through the review process.

Background and context

Critical Care and transport for children requiring critical care

6. PCC has changed significantly over the last few decades. There has been a large degree of centralisation of PICUs since the 1990s, achieved by the expansion of 'lead centres' – there are now around 30 PICUs across the country providing care to the 1 in 1000 children over 5 who require PICU admission per year.[1] Previously, outcomes were not monitored but research suggested that fragmentation of intensive care services for children was associated with inadequate provision and excess mortality. Since centralisation of care, outcomes have improved and deaths on PICU are now very rare: in 2016 96% of children were discharged alive.[2]

7. Levels of PCC are defined as below[3]:

    - Level 1 paediatric Critical Care Units (PCCUs): located in all hospitals providing inpatient care to children.

    - Level 2 PCCUs: formerly classified as High Dependency Units (HDUs), these are provided in tertiary or specialist hospitals, and a limited number of district general hospitals (DGHs). They deliver levels 1 and 2 care.

    - Level 3 PCCUs (PICUs): usually located in tertiary centres or specialist hospitals, level 3 services can provide all 3 levels of PCC. Level 3 units provide care for children requiring intensive care and monitoring, including medically unstable patients requiring intubation or ventilation, single or multi-organ support, and continuous or intensive medical or nursing supervision. PCC level 3 units also provide routine planned post-operative care for surgical procedures, or during some planned medical admissions.

8. Whilst significant progress has been made in the delivery of paediatric intensive care (PIC), ongoing care of critically ill children has not progressed to the same degree. *High Dependency Care for Children – Time to Move On* outlined a number of issues and proposed potential solutions to improve management of critically ill children in acute hospitals, and much remains to be done on this front.[4] Provision of level 2 PCC is variable across the country and commissioning arrangements differ: whilst level 2 care is commissioned by NHS England in specialist hospitals and in a limited number of designated high dependency units, CCGs are responsible for commissioning level 1 care in acute hospitals but in some areas of the country it is reported that there is no commissioned level 1 care.

---

[1] PICANET 2016 Lay Report – available at: http://www.picanet.org.uk/Documentation/Annual-Reports/

[2] PICANET 2016 Annual Report – available at: http://www.picanet.org.uk/Documentation/Annual-Reports/

[3] NHS England, Level 3 Paediatric Intensive Care Service Specification. Available at: https://www.england.nhs.uk/commissioning/spec-services/npc-crg/group-e/e07/

[4] RCPCH, High Dependency Care for Children: Time to move on. Available at: http://www.rcpch.ac.uk/high-dependency-care

9. There is a weight of evidence to support the use of specialist retrieval teams in relation to paediatric intensive care. These services were once provided by PICUs using staff that would otherwise be working on the unit. Increasingly transport services are standalone, independently staffed services, although they remain linked to and endorsed by regional PICUs. There are now 10 PCC transport teams in England providing a service to their designated geographical region, though the level of services they are commissioned to provide varies and air transport is usually undertaken with a number of charitable organisations. There is one combined neonatal and paediatric service (Embrace).

Specialised surgical services

10. The current infrastructure and model for children's surgical services has also evolved over time, and in some areas has now become fragmented. Commissioners of specialised services have traditionally implemented services at a local level, in organisations that are able to meet the required specifications and co-dependencies for treatment. There are issues with this approach both regionally and nationally around service variation, co-dependencies, governance and treatment volumes.

11. The model of provision for general paediatric surgery (GPS) is also now impacting on specialised activity, as there has been a steady decline in the number of GPS cases operated on in non-specialist hospitals, whilst activity in specialised centres has increased. In 2004/5 specialist services were responsible for 39% of children's surgery compared with 24% in 1994/1995[5]. Exposure to elective GPS for surgeons and anaesthetists in district general hospitals (DGHs) has declined in recent years, posing a challenge in replacing the cohort of general surgeons who are nearing retirement and have traditionally provided this service.

Extracorporeal membrane oxygenation

12. Paediatric respiratory extracorporeal membrane oxygenation (ECMO) has been commissioned on a national basis since 1997. All of the children's cardiac surgery centres provide peri-operative cardiac ECMO to support surgery, whilst respiratory ECMO is provided by 5 centres across the country: Alder Hey Children's Hospital, Birmingham Children's Hospital, Great Ormond Street Hospital, The Newcastle upon Tyne Hospitals, and University Hospitals of Leicester.

13. Until now there has been no formal geographic network arrangement for the service, although these are now being established for Alder Hey and Birmingham. Local networks exist but these have been established on an ad hoc basis and there is variation in referral arrangements. Variation in access to respiratory ECMO across the country and the need to transfer critically ill children requiring this service a considerable distance have been cited by units as cause for concern.

[5] Royal College of Surgeons: Five Year Strategy for Improving Local Access to General Paediatric Surgery

14. There is only one provider of mobile ECMO in England, which may be affected by changes proposed as part of the CHD review. It is therefore opportune to consider both the clinical issues affecting current ECMO provision, and the optimal model of provision across England.

Issues to address

15. The following section sets out the main issues related to paediatric critical care, paediatric specialised surgery, extracorporeal membrane oxygenation (ECMO) and transport that we have identified as drivers for the review, and that we believe will require attention as part of the review process.

16. The predominant concerns leading to the establishment of the review centred on increasing pressures on services and variation in care, which we believe apply across all elements of the review.

Increasing pressure on services

Overall Pressures

17. The number of admissions to PICUs has remained largely stable over the last 3 years,[6] however the changing nature of work on PICUs, increasing average length of stay and workforce pressures place the service under considerable strain. These pressures are compounded over the winter months arising from increases in severe respiratory infections across the acute paediatric service.

18. Similarly, work by the Royal College of Surgeons has shown that there has been a year on year increase in the number of children's surgical procedures carried out in specialist hospitals[7]. The following section examines some of the contributing factors for the increasing pressure on services:

Changing nature of the population

19. Critical care services in particular have seen a dramatic shift in the nature of work undertaken on PICUs. Over the last three decades, there has been a substantial reduction in mortality on PICUs, however, morbidity has increased significantly, with a much higher proportion of children surviving with moderate or severe disability.[8]

20. An increasing number of children are living with long-term, complex conditions or on long-term ventilation (LTV). Despite the fact that PICU is unlikely to be the optimal environment to care for children with such needs, in many cases little alternative

[6] PICANET 2016 Annual Report – http://www.picanet.org.uk/Documentation/Annual-Reports/
[7] Royal College of Surgeons: Five Year Strategy for Improving Local Access to General Paediatric Surgery
[8] Namachivayam P, Shann F, Shekerdemian L et al. Three decades of pediatric intensive care: Who was admitted, what happened in intensive care, and what happened afterward. *Pediatr Crit Care Med.* 2010 Sep;11(5):549-55

provision is available outside of intensive care, to support discharge at home or to the community when children no longer require hospital care. This poses challenges for critical care services, with a small number of children using a high level of resources in PICUs: in 2015 10% of children used 58% of bed days provided.[9]

21. As the Royal College of Paediatrics and Child Health (RCPCH) has previously noted,[10] when this group of children require hospital care, with appropriate resources and staff training they could be looked after in regional hospitals as opposed to PICUs. This would usually enable care to be provided closer to home, and may avoid the need to escalate care to facilitate a transfer from a regional to tertiary unit. It would also release valuable PICU capacity for cases requiring advanced critical care. The careful planning of how to look after children with complex, long-term needs, and contingency plans for looking after them in DGHs when they require hospitalisation, would not only ensure that those children were supported to stay well for as long as possible and be treated closer to home, but it would release PICU capacity for those requiring the highest level of critical care.

22. The current payment system does not promote the most appropriate use of PCC services, and it does not encourage providers to move patients swiftly from intensive to high dependency care. In some cases a standard rate is paid for a PICU bed, irrespective of the level of care received, and funding can be paid on a block basis irrespective of workload. For children with complex needs requiring a bespoke care package, NHS England currently incurs the cost associated with delayed discharges from tertiary units, except for in a small number of cases where there is a clear cut off for payment (when the child has been clinically stable for 90 days).

Increasing underlying demand

23. Overall the number of children operated on in DGHs has reduced from 410,000 children in 1994/1995 to 325,000 in 2004/2005. This is associated with a year on year increase in the numbers of cases being carried out in specialist hospitals.[11] Spend on specialised procedures also appears to have risen sharply over the last five years.

24. The reasons for this are not fully understood, and further analysis is required to understand whether activity in specialised centres is increasing due to an increase in the number of children with complex long-term conditions, who would require care in specialist centres even for non-specialised surgery, or whether there has been an increase in demand for specialised surgical procedures themselves.

[9] PICANET 2016 Annual Report – available at http://www.picanet.org.uk/Documentation/Annual-Reports/

[10] RCPCH, High Dependency Care for Children: Time to move on. Available at: http://www.rcpch.ac.uk/high-dependency-care

[11] Royal College of Surgeons: Five Year Strategy for Improving Local Access to General Paediatric Surgery

25. It is also likely that the increasing number of children – particularly those under five years old - being transferred from DGHs to specialised children's hospitals for non-specialised surgery is putting increasing pressure on specialist children's hospitals, and causes children and families to travel further than may be necessary. It may also result in children experiencing longer waiting times for planned specialised procedures.

Seasonal pressures

26. Every winter the number of children requiring PCC treatment peaks, largely due to a spike in prevalence of respiratory disease. Demand for ECMO services also increases during periods of respiratory illness, though data demonstrates that surges in demand are not always limited to winter months.

27. This pattern presents huge challenges for those working in PICUs and in emergency transport services, as demand often exceeds capacity during this time. Maximum throughput on PICUs can be compromised as units are unable to discharge children swiftly to ward level care. Children at times have to be transported considerable distance to a unit with an available bed or expertise to meet their needs.

Managing elective and emergency demand

28. Planning expected levels of emergency and elective procedures is a frequently cited challenge in managing PICUs, particularly in winter when emergency admissions peak. During this period it is not unusual for children undergoing specialised surgical procedures dependent upon the availability of a PICU bed to experience (potentially multiple) cancellations. Units sometimes report that the 18 week Referral to Treatment (RTT) target can lead to the repeated rescheduling of planned procedures.

Workforce challenges

29. Staffing critical care units to levels recommended by the Paediatric Intensive Care Society (PICS) often proves to be challenging. In 2015, 10 (29%) PICUs met the recommended nursing establishment levels, which was an increase from 5 units in the previous year.[12] In addition to well documented shortfalls in the nursing profession it can be difficult to ensure an appropriate skill mix on units, which also affects recruitment to paediatric critical care transport teams.

30. Additionally, part of the reason that children requiring surgery are transferred to specialist children's hospitals is that fewer adult surgeons and anaesthetists are trained in, or have enough exposure to children's general surgery compared to previous generations of clinicians who are now nearing retirement. In 2010 a RCS survey indicated that 38% (213/555) of surgeons and 42% (659/1561) of anaesthetists had less than 1 clinical session per week allocated to care of children

[12] PICANET 2016 Annual Report - http://www.picanet.org.uk/Documentation/Annual-Reports/

within their job plans. This was compounded by the fact that 20.3% (113/555) of surgeons and 23.3% (364/1561) of anaesthetists indicated that they did not have regular training that would maintain their skills in caring for children.[13]

Variation in care

31. The 2016 PICANET annual report indicates variation in the way that care for critically ill children is provided. Rates of invasive ventilation vary between 18% and 90% across all PICUs, and also by geographical region – reflecting different admission criteria and patient case-mix in different regions.[14]

32. There is also considerable inequity in how a child in the UK requiring level 2 critical care (high dependency) is cared for: in one part of the country a child may be cared for locally, whilst in another area they would be transferred to a PICU in another area, requiring the child to be anaesthetised, intubated and ventilated, adding complexity, cost and risk that may be potentially avoidable.[15] Data from previous years suggests that around 28% of children admitted to PICUs either do not require invasive or non-invasive ventilation – many of these children could be looked after in other critical care environments with the right staff resources and competencies.[16]

33. Whilst all critical care transport services transport critically ill children to PICU, some are additionally commissioned to provide repatriation after intensive care and relocation for high dependency care. Funding and commissioning models vary across regions and there is wide variation in access to and uptake of air transport between regions. Transport teams also reported, over a two year period (2013-2015) an unmet need totalling 806 transfers.[17]

34. In most regions repatriation is currently performed by local ambulance services by frontline or paramedic ambulances using two paramedics and a nurse from the tertiary centre. Repatriations are often assigned a low priority by the ambulance service with the result that they are substantially delayed and hence PCC capacity is not released in a timely fashion. These delayed discharges are a significantly impede effective utilisation of PCC capacity at times of peak activity.

35. Under the current model of provision for respiratory ECMO, inequity of access to services and the need to transfer patients a significant distance has been cited as a concern.[18] However, research from America suggests that mortality is significantly higher at centres providing low volumes of ECMO compared to those providing

[13] Royal College of Surgeons: Five Year Strategy for Improving Local Access to General Paediatric Surgery
[14] PICANET 2016 Annual Report, available at: http://www.picanet.org.uk/Audit/Annual-Reporting/
[15] Royal College of Paediatrics and Child Health. High Dependency Care: Time to Move On. 2014. Available at: http://www.rcpch.ac.uk/high-dependency-care
[16] As above
[17] PICS ATG & NTG Air Medical Transport Report 2015
[18] Paediatric ECMO Model of Care: Workshop Recommendations

higher volumes.[19] The Paediatric Intensive Care Society (PICS) is currently undertaking work to set standards for all respiratory and cardiac centres in the UK, reflecting the varying degrees of competence across the nursing and medical workforce currently involved in delivering this service. It is anticipated that these standards will inform commissioners about the optimal models to be considered for the future.

36. Children requiring surgery are likely to receive different care dependent upon regional or local arrangements and the extent to which DGHs are resourced and able to provide general paediatric surgery. In those areas where children are transferred to specialist hospitals in emergency situations – such as for treatment of torsion of the testes – there is the potential for this to lead to adverse patient outcomes in emergency situations.

37. More generally, there are numerous challenges involved in the planning of children's specialised services which can lead to variable provision across the country. The volume of children with specialist conditions is small, with a number of sub-specialties, which can result in complex and fragmented services both within specialised services as well as between different specialised services. Most specialised children's services are highly dependent on each other and taking account of interdependencies in the provision of services can be challenging.

Summary

38. Panel members are asked to confirm:
    - Whether we have correctly identified the pressing issues that critical care and specialist surgical services are facing;
    - Whether any issues are more pressing than others; and
    - Whether there are additional, major issues to address, that are not discussed in this paper.

[19] Freeman C, Bennett T, Casper T et al. Pediatric and Neonatal Extracorporeal Membrane Oxygenation: Does Center Volume Impact Mortality? *Critical Care Medicine*. March 2014, Vol 42, No 3.