MEETING OF THE LEICESTERSHIRE, LEICESTER AND RUTLAND JOINT HEALTH SCRUTINY COMMITTEE

DATE: **MONDAY, 11 DECEMBER 2017**
TIME: **2:00 pm**
PLACE: **Meeting Rooms G.01 and G.02, Ground Floor, City Hall, 115 Charles Street, Leicester, LE1 1FZ**

Members of the Committee

Leicester City Council

Councillor Cutkelvin (Chair of the Committee)
Councillor Chaplin
Councillor Corrall
Councillor Sangster
Councillor Fonseca
Councillor Osman
Councillor Waddington

Leicestershire County Council

Mr L Breckon CC (Vice-Chair of the Committee)
Mrs H Fryer CC
Mrs A J Hack CC
Dr S Hill CC
Mr T Parton CC
Mrs L Richardson CC
Mrs D Taylor CC

Rutland County Council

Councillor Dr L Stephenson
Councillor Miss G Waller

Members of the Committee are invited to attend the above meeting to consider the items of business listed overleaf.

For Monitoring Officer

Officer contacts:
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Tel: 0116 454 6357, e-mail: Julie.harget@leicester.gov.uk
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Tel: 0116 454 6344, e-mail: Kalvaran.Sandhul@leicester.gov.uk)
Leicester City Council, City Hall, 115 Charles Street, Leicester, LE1 1FZ

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If you have any queries about any of the above or the business to be discussed, please contact Julie Harget**, Democratic Support on (0116) 454 6357 or email Julie.harget@leicester.gov.uk** or call in at City Hall, 115 Charles Street, Leicester, LE1 1FZ.

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PUBLIC SESSION

AGENDA

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1. APOLOGIES FOR ABSENCE

2. DECLARATIONS OF INTEREST

Members are asked to declare any interests they may have in the business on the agenda.

3. MINUTES OF PREVIOUS MEETING **Appendix A (Pages 1 - 18)**

The minutes of the meeting held on 27 June 2017 are attached and the Committee is asked to confirm them as a correct record.

4. PETITIONS

The Monitoring Officer to report on the receipt of any petitions submitted in accordance with the Council's procedures

5. QUESTIONS, REPRESENTATIONS, STATEMENTS OF CASE

The Monitoring Officer to report on the receipt of any questions, petitions, or statements of case in accordance with the Council's procedures

6. NHS ENGLAND'S DECISION ON CONGENITAL HEART DISEASE SERVICES AT UNIVERSITY HOSPITALS OF LEICESTER NHS TRUST

Appendix B (Pages 19 - 48)

To consider NHS England's decision on the Congenital Heart Disease Services Review with particular reference to outcome for the East Midlands Congenital Heart Centre at Glenfield Hospital.

NHS England launched a national consultation on its proposals for the future commissioning of Congenital Heart Disease services on 9 February 2017 and this closed on 17 July 2017. The decision has been made on 30th November 2017 by NHS England's Board, with reference to the East Midlands Congenital Heart Centre as follows:

"Continuing to commission University Hospitals of Leicester NHS Trust to provide level 1 CHD services, conditional on achieving full compliance with the standards in line with their own plan to do so and demonstrating convincing progress along the way"

The NHS England's Board paper outlining the decision is attached for the Committee's reference and the consultation responses can be found on the following link: https://www.england.nhs.uk/wp-content/uploads/2017/11/06-pb-30-11-2017-annex-a-congenital-heart-disease-consultation-report.pdf

The Committee is to receive a verbal update from University Hospitals Leicester NHS Trust on the impact of the decision and their planning to maintain the standards.

7. NHS ENGLAND'S PAEDIATRIC CRITICAL CARE AND SPECIALISED SURGERY IN CHILDREN REVIEW

Appendix C (Pages 49 - 112)

To consider NHS England's review of paediatric critical care and specialised surgery for children launched in October 2016.

Several engagement events were held between January and March 2017 – bringing clinicians and experts in paediatric critical care together to discuss the areas they see as the greatest challenge facing services and to get their ideas on how things could be improved. Following these events, NHS England are developing a proposed new model of care in response to these issues, while also looking at existing data on paediatric critical care which highlights the pressures on critical care services.

NHS England has produced an analytical pack containing some of the review's early work which examines why there is pressure on paediatric intensive care units. They are also currently looking at the data available on specialised surgery in children.

Following the outcome of the Congenital Heart Disease services review, this

provides the Committee with the opportunity to consider the current position of the paediatric critical care and specialised surgery for children review.

The committee is to receive a verbal update from University Hospitals Leicester NHS Trust on the review and its impact on the Paediatric Intensive Care Unit (PICU) and Extra Corporeal Membrane Oxygenation (ECMO) Unit at Glenfield Hospital.

Supporting Information

The following supporting information is supplied to assist the committee to comment upon the information in the analytical pack.

a) Dr Gale Pearson, Intensive Care Consultant at Birmingham Children's Hospital and Chair of the Clinical Reference Group for Paediatric Intensive Care, Blog dated 23 June 2017.
b) Dr Peter Wilson, Paediatric Intensive Care Consultant at University Hospital Southampton NHS Foundation Trust, and the Clinical Chair of the Women and Children's Programme of Care Board at NHS England, Blog dated 11 October 2017.
c) Paediatric critical care and specialised surgery review: issues to address.
d) Paediatric critical care and specialised surgery review: Frequently Asked Questions.

8. ANY OTHER URGENT BUSINESS

Appendix A

Leicester
City Council

MINUTES OF THE MEETING OF THE
LEICESTERSHIRE, LEICESTER AND RUTLAND JOINT HEALTH SCRUTINY COMMITTEE

Held: TUESDAY, 27 JUNE 2017 at 10.00am

P R E S E N T :

Councillor Cutkelvin – Chair of the Committee
Mr L Breckon CC – Vice Chair of the Committee

Leicester City Council

Councillor Cassidy Councillor Chaplin
Councillor Dempster

Leicestershire County Council

Mrs H Fryer CC Mr T Parton CC
Mrs A J Hack CC Mrs L Richardson CC
Mrs D Taylor CC

Rutland County Council

Councillor Miss G Waller

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34. WELCOME AND INTRODUCTIONS

The Chair welcomed everyone to the meeting and asked those present to introduce themselves.

The Chair reminded everyone that the primary purpose of the meeting was to hear from patients' and stakeholders about their experiences and for them to give their views on NHS England's proposals. The level of frustration expressed by the public in relation to accessing the consultation process was well understood by Members. Although the meeting was open to the public to attend it was not a 'public meeting' as such and only those that had registered to speak would be allowed to do so. It would not be possible, therefore, to hear comments from the other Members of the public who were in attendance at the

meeting. NHS England had arranged a public consultation meeting at Glenfield Hospital for Saturday 1 July 2017 and that would be the opportunity for the public to participate in the process.

The Chair also welcomed Michael Wilson, Programme Director for CHD, NHS England and Catherine O'Connell, Regional Director Specialised Commissioning - Midlands and East who were attending the meeting to hear the submissions by the public and stakeholders.

35. APOLOGIES FOR ABSENCE

Apologies for absence were received from:-

Councillor Corrall	Leicester City Council
Councillor Fonseca	Leicester City Council
Dr S Hill CC	Leicestershire County Council
Councillor Sangster	Leicester City Council
Councillor Stephenson	Rutland County Council

36. DECLARATIONS OF INTEREST

Members were asked to declare any interests they might have in the business on the agenda. No such declarations were made.

37. MINUTES OF PREVIOUS MEETING

RESOLVED:-

That the minutes of the meeting held on 14 March 2017 be confirmed as a correct record.

38. PETITIONS

The Monitoring Officer reported no petitions had been submitted in accordance with the Council's procedures.

39. QUESTIONS, REPRESENTATIONS, STATEMENTS OF CASE

The Monitoring Officer reported that no questions, petitions, or statements of case in accordance with the Council's procedures.

40. CHAIR'S INTRODUCTION

The Chair stated that given there were a number of new members on the Committee and the Programme Director for the CHD was attending his first meeting of the Committee; she felt it would be useful to set the scene and recap on the points raised at the previous meeting of the Committee.

The Chair mentioned the following points:-

NHS England stated that it wasn't for them to mandate to patients where to have surgery at a particular centre and that it was for parents/patients to determine where they wished to receive treatment.

- UHL disputed this stating that it was NHS England's responsibility to organise these services and whilst they did not choose where a patient was treated, these proposals were seeking to determine where they would not be treated.

The outstanding issue with regards to Glenfield hospital's plans from NHS England's perspective related to their ability to reach 375 operations (125 each for 3 surgeons) per year.

- UHL also argued that small adjustments to the catchment area would enable them to meet the required number of operations.

- Members commented that the destabilising effect of the ongoing proposals may also be having a negative effect and would no doubt influence patient choice if they thought the centre may close whilst not realising the high quality of care that they would receive.

- There was anecdotal evidence that people in Northampton were being directed further south when Glenfield was a much closer option.

It was debated as to whether the figure of 125 surgeries had been applied fairly across all CHD sites in the consultation proposals; given that Newcastle, in particular, had been given no time frame within which to reach the standards.

- UHL argued that if it was safe for Newcastle to continue providing Level 1 services whilst providing considerably less surgeries than Glenfield; then why should it be unsustainable for Glenfield to continue with higher levels of surgeries and still also provide the National ECMO service.

- NHS England stated they would revisit Newcastle if they couldn't meet the required number of surgeries in an agreed timeframe; although no timeframe had been agreed. Also, Newcastle were being treated separately, as they also undertook heart transplant services, the only centre to do so one outside of Great Ormond Street Hospital to perform them and it would be unsafe to only have that service on one site.

- Committee members argued that given the 125 surgeries was not backed by any real scientific evidence for it to be an absolute criteria to provide a resilient service and, given that Newcastle were being given an indefinite time period to meet the required number of surgeries, Leicester should also been given extra time.

If, like Newcastle, they subsequently didn't meet the required number of surgeries in an equal timeframe, then NHS England should review the situation at that time.

- UHL's CHD unit was rated as 'outstanding' by the CQC; the only one in the country and this should not go unrecognised.

- Also, the fact that there were 200 standards, and some were being weighted more than others, felt arbitrary to committee members and they seemed to be chosen to help push a pre-determined decision. The fact that the standards were being implied retrospectively rather than from their approval date in July 2015 was also questioned.

NHS England's proposal would result in an entire region not having CHD surgical services. This would be the only region not to have them and would leave a large geographical gap across the country.

- NHS England suggested that Glenfield could perform Level 2 services as part of the proposals which would still offer a service in the East Midlands
- UHL questioned whether they would be able to perform Level 2 services without a Level 1 service, as they would not have cardiac anaesthetists on site without a Level 1 service and currently no model of what a Level 2 service would look like existed.

The Committee also raised the issue of travel times not being considered properly and the burdens of travel on families seemed nonsensical given there was a service in the East Midlands already providing good outcomes.

The Committee had also been advised of the following prior to the meeting:-

Background Information

NHS England had launched a national consultation on its proposals for the future commissioning of Congenital Heart Disease services on 9 February 2017.

This consultation period was originally intended to end on Monday 5 June, but was subsequently extended to close on Monday 17 July 2017 as a result of the recent Parliamentary Election.

This Joint Committee was the appropriate body to be consulted by NHS England on the proposals in accordance with Regulation 30 of the Local Authority (Public Health and Wellbeing Boards and Health Scrutiny) Regulations 2013. The regulation provided that where the appropriate person (NHS England) had any proposals for a substantial development or variation of a health service in an area they must consult the local authority. Where the

consultation affected more than one local authority in an area, the local authorities were required to appoint a Joint Committee to comment upon the proposal and to require a member or employee of the responsible person to attend its meeting and respond to questions in connection with the consultation.

The Regulation did not prevent constituent Councils of the Joint Committee considering the issues separately; but it was the responsibility of the Joint Committee to formally respond to the consultation process.

The Regulations also provided that a Council may refer a proposal to the Secretary of State where:-

- it was not satisfied that the consultation has been adequate in relation to content or time;

- it was not satisfied with the reasons given for the change in services; or

- it was not satisfied that that the proposal would be in the interests of the health service in its area.

This referral must be made by the full Council unless the Council has delegated the function to a Committee of the Council. Currently, only the City Council had delegated the powers to refer the NHS proposals to the Secretary of State. Leicestershire County Council and Rutland County Council would need to approve any referral at their respective Council meetings.

Supporting Information

The Joint Committee had first met on 29 September 2016 and received the following supporting documents:-

- NHS England's proposals published on 8 July 2016.
- Extracts of decisions taken by Leicester City Council and Leicestershire County Council's Cabinet in response to NHS England's proposals.
- A report from NHS England and a submission from the University Hospitals of Leicester NHS Trust (UHL) submitted to the City Council's Health and Wellbeing Board at their meeting on 18 August 2016, together with the Minutes of the Meeting.
- A report of NHS England and their Assessment of UHL submitted to the Board and updated to reflect the subsequent meeting held with UHL on 16 September 2016 and the revised high level timetable for the consultation and decision making process.
- A letter to the City Council's Deputy City Mayor from NHS England in response to questions asked at the Health and Wellbeing Board.
- Evidence base for new standards & specifications in relation to the 125 cases per surgeon that was requested by the Health and Wellbeing Board.

The second meeting on 14 March 2017 had received the following documents:-

- The “Proposals to Implement Standards for Congenital Heart Disease Services for Children and Adults in England - Consultation Document”
- Minutes of the Meeting of the Joint Committee held on 29 September 2016 when the Joint Committee considered the proposals in the pre-consultation engagement stage.
- A letter from Will Huxter responding to issues raised by the Joint Committee on 29 September 2017.
- Proposals to implement standards for Congenital Heart Disease Services for Children and Adults in England - Consultation Summary.
- Congenital Heart Disease Equality and Health Inequalities Analysis – Draft for consultation.
- Congenital Heart Disease Provider Impact Assessment: National Panel Report.
- NHS England Congenital Heart Disease Provider Impact Assessment.
- Congenital Heart Disease Consultation – Events List.

The agenda, reports and minutes of the Joint Committee’s meetings referred to above can be found at the following link:-

http://www.cabinet.leicester.gov.uk/ieListMeetings.aspx?CId=420&Year=0

41. UHL'S VIEW ON NHS ENGLAND'S PROPOSALS FOR CONGENITAL HEART DISEASE SERVICES

The Chair welcomed the following representatives of University Hospitals of Leicester NHS Trust (UHL) to the meeting:-

John Adler, Chief Executive.
Dr Aidan Bolger, Consultant Cardiologist & Honorary Senior Lecturer and Head of Service East Midlands Congenital Heart Centre.
Mark Wightman, Director of Communications Integration and Engagement.
Alison Poole, Senior Manager Special Projects.

John Alder thanked the Committee for the opportunity to address the Committee. He stated that UHL were opposed to the proposals in NHS England’s Consultation Documents for the Congenital Heart Disease (CHD) Review; particularly as the Trust had made good progress in meeting the standards required and NHS England had formally acknowledged that the only point of issue was the standard for each surgeon to perform 125 procedures a year. The Trust had submitted a Growth Plan to NHS England, at their request, in May 2017 which had clear and robust plans to meet the target standard specified in standard B10 (L1) and demonstrated that the Trust had already begun to put this plan into place to meet the required target. It was understood that NHS England had been considering the growth plan since it was submitted and had promised a meeting with UHL during the consultation period to discuss it. However, no formal response had been received from NHS England.

Dr Bolger gave a presentation on their current view of the proposals and a copy of the presentation is attached to these minutes.

During the presentation the following points were noted:-

a) The announcement that NHS England were minded to decommission Level 1 services in Leicester was made in July 2016. It was not until February 2017 that the public consultation was launched and in may not be until 2018 that the outcomes will be known. This was having a destabilising effect on those centres put forward for decommissioning.

b) This destabilising effect had already impacted upon Level 1 services in Manchester as the unit had recently closed prematurely at short notice. This was the result of senior staff leaving because of the uncertainty over its future and, as the Trust could no longer provide Level 1 congenital heart services. NHS England has had to form a crisis team to manage the situation externally, calling on other Level 1 providers in the North of England and Queen Elizabeth Hospital in Birmingham to provide care for Manchester's patients. It was of concern that this had been allowed to happen, particularly as NHS England did not have a contingency plan in place for this eventuality during the consultation process. This uncertainty remained and there was still a danger that other centres, such as UHL, could be susceptible to the same pressures. If UHL was forced to close prematurely then patients would be at risk as there were no plans in place to absorb their caseload at short notice.

c) The national picture in relation to CHD services has transformed immensely since the concerns associated with Bristol in the 1980's and 1990's. At that time, Bristol had a 30 day post-operation mortality rate of 28% in those under a year of age compared to the national average of 14% and Leicester's 13%. In 2015-16, the national mortality rate was 2% for all children's heart surgery compared to Leicester's 0.6%. The number of CHD centres in the UK had reduced from 17 in 1991 to the current 12 centres and there was now far more regulation, governance and audit in place to monitor safety and outcomes than in 1991, when there was very little overview.

d) After a self-assessment exercise in early 2016, UHL were informed that they were non-compliant with 8 out of 14 "core standards". NHS England's "minded" decision was based on this analysis. After UHL challenged this position, further discussions took place with NHS England, after which NHS England revised UHL's compliance to 13 out of 14. Despite this, it didn't alter NHS England's "minded" decision to decommission Level Services from UHL. According to NHS England, UHL failed to achieve the surgical activity standard by April 1st 2016. The standard refers to a centre having a team of three surgeons undertaking 125 operations per year (i.e. 375), averaged over three years. UHL objected to NHS England's retrospective application of this standard. They pointed to the fact that this was never agreed by the

working group of stakeholders who proposed the standards, to the fact that current surgical activity was now significantly higher than the historical data NHS England used and to the fact that the rate of increase in surgical activity will mean that for the current year, (2016-17), 375 operations would be undertaken. UHL also submitted a robust growth plan to NHS England in May 2017 that described how the network would grow in order to reach the 2021 standard of four surgeons/500 cases per year. Despite UHL providing them with a detailed growth plan that described how the 500 cases per year would be achieved, and agreeing to meet them to discuss that plan, NHS England had failed to reply to enquiries from UHL about when, or even if, those discussions would take place.

e) UHL had demonstrated unequivocally to NHS England that 500 operations per year are undertaken on patients from this region already with many having to travel outside the region to receive specialist care. NHS England had undertaken its own analysis of activity in the region and agreed with UHL's conclusions. UHL, therefore, stated that the issue was not one of a centre situated in a small geographical area with a small population of patients, as is found elsewhere in the country where there is no threat of decommissioning, but one of improving access to care for a large and populous region.

f) In addition to activity growth from existing network partners, UHL had been working with Chesterfield, Peterborough and Northampton hospitals who had expressed clear support for the continuance of CHD services in Leicester and the desire to explore network relationships in the future. These new referral pathways would accelerate the surgical activity in Leicester so that the target of 500 operations per year by 2021 would be comfortably achieved. However, critically, the fact that it was now a year since NHS England had announced that it was minded to decommission Level 1 services in Leicester and the fact that NHS England had still not decided when it would finally make a decision on future commissioning had created such instability and uncertainty that providers up and down the country were struggling to move forward with developing care pathways for paediatric and adult congenital heart services.

g) UHL had also held informal discussions with clinicians in Milton Keynes and Warwickshire Hospitals who were currently outside Leicester's Network but which were geographically close and had short journey times. There was interest in exploring network membership further. Any referrals from these centres had not been included in the UHL's Growth Plan adding further confidence to UHL's firm belief that they will reach the required target for operations in the required time.

h) UHL felt that there should be much more consistency with respect to the approach NHS England was taking. For example, UHL had asked NHS England to consider its world leading ECMO programme in the same light as the cardiac transplant service in Newcastle. NHS England had

stated that ECMO was subject to a separate review as it was not in the terms of reference for the congenital heart review and yet heart transplantation was not in the terms of reference for the congenital review but was given due consideration. That included an open-ended derogation on achieving the surgical activity target and co-location of paediatric cardiac services with all other children's services with respect to the Newcastle service. As another example, UHL had been required to submit a detailed Growth Plan to NHS England to demonstrate their ability to reach 500 operations per year by 2021. Other centres for whom this target is equally challenging, but who were not earmarked for decommissioning, had not been asked to provide anywhere near this level of detail. Through Freedom of Information requests, UHL was aware that at least one other centre had stated in its impact assessment that they would achieve the 500 target only by other centres closing. This was felt to be inequitable. Many patients would have to travel further than their nearest centre for this to be achieved, something highlighted by the Independent Reconfiguration Panel (IRP) that reviewed the Safe and Sustainable decision as being highly undesirable.

i) UHL had demonstrated the largest sustained percentage growth in operations for CHD services over the last 8 years compared to other Level 1 centres where the number of operations has remained static or declined in the same period.

j) UHL's provision of regional and local PICU and regional and national ECMO services should have received equal consideration to Newcastle's heart transplant services. The PICU and ECMO provision should have been part of the CHD Services Review from the outset as had been recommended by the IRP in their report to the Secretary of State for Health in 2013 on the matter of the Safe and Sustainable Review.

k) UHL questioned the ability of other centres to cope with the additional workload that would result from decommissioning in Leicester. Consideration seemed to have only been given to cardiac surgery whereas PICU capacity, catheter interventions ("key hole" procedures), non-cardiac surgery, ECMO, obstetric cardiology (the care of expectant mums with heart conditions), education, training and research seemed to have been given far too little attention; if any at all. The point was made that many of the complex patients need outpatient review in the Level 1 centres and the NHS England model that describes outpatient review in a Level 1 centre only on a single occasion before surgery and a single occasion after surgery just was not accurate. UHL expressed concern that waiting lists in other Level 1 centres were already under pressure and moving patients out of the East Midlands would make this worse. Patients from the East Midlands were therefore likely to have to wait longer for operations and catheter procedures than they do now and by default so would patients in the receiving centres. This must be seen as a risk to implementing the current proposals. UHL also stated that the surgical activity data sent to other Level 1 centres to test their

capacity expansion plans was years out of date, again adding significant and unnecessary risks to implementation.

l) UHL raised the prospect of a shortage in human resources, particularly PICU nurses as a serious concern with respect to the transfer of surgical services to another centre. Indeed it was highlighted that Birmingham Children's Hospital had already expressed their concerns over recruiting sufficient staff to accommodate the increase workload in the event of UHL ceasing to provide Level 1 services. It was stated that the issue at hand was not whether other centres could build a hospital big enough to accommodate all the patients from the East Midlands with congenital heart conditions but whether they should.

The Chair thanked UHL for their presentation and commented that this was a regional issue and not just a local issue to Leicester. There was a great deal of concern across the East Midlands about the current proposals.

The Chair offered the representatives of NHS England the opportunity to comment upon the points raised by UHL. The representatives indicated that they did not wish to comment as they were attending the meeting to hear the views put forward by the public and stakeholders.

The Chair then asked Members to refrain from asking questions until the Committee had heard the representations and submissions from patients and stakeholders as there may be some duplication of questions arising from UHL's presentation and representations and submissions still to be heard.

42. REPRESENTATIONS FROM THE PATIENTS, PATIENTS' GROUPS AND OTHER STAKEHOLDERS

The Chair stated that the Commission had previously invited members of the public, patients groups and other stakeholders to submit their views on NHS England's proposals for Congenital Heart Disease Services. A number of individuals and stakeholders had registered their interest to address the Committee and had submitted written submissions.

Leicester University had been invited to attend the meeting and although Professor Philip Baker, Pro-Vice Chancellor and Head of College Medicine, Biological Sciences and Psychology was unable to attend, he had submitted a representation on behalf of the University. A copy of the letter is attached at Appendix A to these minutes.

Lincolnshire Health Scrutiny Committee had submitted their response to NHS England's Consultation on the Congenital Heart Disease Review and a copy of their submission is at Appendix B to these minutes.

The Chair stated that the primary purpose of people presenting their submission was for the Committee to hear at first hand the views being expressed and, as such there, would be no opportunity for members of the Committee to ask questions on the submissions. Representatives of NHS

England were present but they would not be asked to respond to the submissions. They would, however, consider the submissions as part of the consultation process.

The Chair stated that each person would be given 5 minutes to present their submission and it would be published with the minutes of the meeting unless the person presenting the submission indicated they did not wish it to be made public. The submissions could also be included as part of the Committee's evidence to the Consultation process. All those who were intending to make a presentation to the Committee were then asked to indicate if they wished their submission to remain private. No such indications were received and the Chair confirmed that all the submissions would be published with the minutes of the meeting.

The Chair then invited the following patients and stakeholders to address the Committee for a maximum period of 5 minutes each:-

a) Shirley Barnes, a parent of child with a congenital heart disease. A copy of the submission is attached as Appendix C to these minutes.

b) Olivia Barnes, a parent of child with a congenital heart disease. A copy of the submission is attached as Appendix D to these minutes.

c) Jess Whitehouse, a parent of child with a congenital heart disease. A copy of the submission is attached as Appendix E to these minutes.

d) Dr Sally Ruane, Health Policy Research Unit, DeMonfort University. A copy of the submission is attached as Appendix F to these minutes.

e) Katy Weatley, Leicester Mercury Patient Panel. A copy of the submission is attached as Appendix G to these minutes

f) Karen Chouhan, Chair of Healthwatch Leicester, representing Healthwatch Leicestershire and Healthwatch Rutland. A copy of the submission is attached as Appendix H to these minutes.

g) Eric Charlesworth submitted a question, a copy of which is attached as Appendix I to these minutes.

   Mr Charlesworth commented that a number of questions previously asked at public meetings had not received a response from NHS England. It was important that the public were given the answers or, if not, an explanations as to why the questions have not been answered. He was also concerned that the PICU and ECMO review proposals were only made public on the previous Friday and he questioned how this could realistically be incorporated in the CHD Review at this stage, which was not in keeping with the previous IRP finding on this issue.

The Chair thanked everyone for their contributions and submissions, which provided a valuable insight to the effect of the proposals on patients.

The Chair then invited questions from the members of the Committee. The following comments/statements and questions were received (these have been grouped into general themes for ease of reference). NHS England responded to some the comments/statements and questions and these are shown below each themed area.

GENERAL

a) It was disappointing that NHS England had not responded to the questions asked by the public and patients at previous public meetings. It was important that the members of the public were given an explanation why these questions had not been answered. A Member had been unable to find NHS England's Q&A on the website during the meeting which indicated the difficulties the public were having in accessing the information. There was frustration that, in common with other NHS consultations on the STP and health care in general, it was impossible to receive forthright answers to questions asked during the process; which added to the concerns over openness and transparency. It was felt important that NHS England should demonstrate at the forthcoming public meeting how to access this link and that show that the questions had been answered. It was not reasonable to expect that patients and families who were already under stress should have to make tortuous searches to find the answers they were seeking.

b) NHS England should publish its risk analysis to patients in areas where they were proposing to close a Level 1 centre, particularly in relation to the vulnerable groups already identified by NHS England.

c) It was worrying that some centres were being allowed to continue as Level 1 centres based upon an assumption that they would achieve the 125 operations per surgeon simply by other Level 1 centres closing. This was inequitable in relation to how UHL, in particular, were being treated and raised grounds for judicial review in relation to the process used for carrying out the review and the consultation, particularly the disparity of treatment between UHL and Newcastle, the poor travel modelling and the assertion that 125 operations per surgeon was an essential requirement to provide a safe and sustainable service in the future. There were also concerns over questions relating to the transparency and conflicts of interest of some of those involved in the process of putting forward the proposals in the review who were working in Trusts that would benefit from the proposals.

d) The uncertainty of the timeline for the review and the taking of the final decision was considered detrimental and damaging to the current provision of services as it created uncertainty and worry for those staff and their families working in the current centres put forward for closure. It was also considered that it was unsettling for patients and families and caused additional anxiety at a time of extreme stress for them. This uncertainty had already led to the early closure of Manchester Level 1

services.

e) There was enough evidence already to indicate that the proposal to cease Level 1 services at UHL was not sustainable and that the proposal should be dropped now. Services had previously been regionalised and the outcomes at Glenfield were excellent compared to other units. It was the only centre between Newcastle and London on the eastern side of the country and if it closed it would disadvantage patients in the East Midlands for ever more.

f)

g) NHS England had still not put forward an EIA in relation to specific individual vulnerable groups, such as people of south Asian origin, and this was of particular concern as there were large numbers of this vulnerable group in the east midlands generally and in Leicester in particular. The proposals did not make sense in proposing to close a Level 1 centre in Leicester when there was such a large identified vulnerable group in the region.

h) The personal accounts submitted to the meeting by parents and the patient panel had emphatically demonstrated families faced difficult situations over long periods of time and it was clear that the proposals would only add to these difficulties.

i) There were concerns at the previous meeting that if UHL did not provide Level 1 services they would not be able to provide Level 2 services. NHS England had indicated that they would discuss the issue with UHL and they were asked if any progress had been made.

j) It was still not clear why an excellent unit such as UHL with low mortality outcomes was being put forward for closure. Given the predicted growth rates in the region, it was questioned how the larger centres would cope with the additional demand from the areas where centres were closed in addition to the increased demand from their own catchment areas, particularly when these large centres had been fairly static in terms of the number of operations for some years. It was also questioned how the larger centres would recruit the additional specialised staff required to meet the increased demands. There were concerns that waiting times for operations in the larger centres could increase as a result of these proposals, particularly if they could not recruit sufficient numbers of staff, and this could also impact upon mortality rates.

k) When the review started it was expected that the decision would be made by 30 November 2017 but there had been no indication when the decision would now be made as a result of suspending the consultation during the general election period. It was also unknown who or which body would be involved in making the final decision, and this further added to concerns over transparency.

NHS England's Response

Michael Wilson thanked Members for the invitation to attend the meeting and hear the contributions made by parents and stakeholders. He stated that the prime purpose of NHS England's attendance was to note the contributions to the meeting and to relay these back to NHS England.

Although NHS England were not attending to specifically respond to comments made at the meeting it was felt helpful to make the following responses:-

a) NHS England had received UHL's growth plan and were considering it and a response would be sent to UHL. This issue had now been passed to John Stewart, Acting Director of Specialised Commissioning NHS who was the new Programme Director for the CHD Review.

b) NHS England aimed to respond to all FOI enquiries within the 20 day target but this was not always possible.

c) NHS England had updated the information on the Q&A area of the website to take into account questions raised during the consultation. If anyone did not feel their question had been answered they should contact the Review Team and Mr Wilson would make sure that the question was answered.

d) The NHS England Board would take the final decision in the light of the responses to the consultation responses.

e) The concerns surrounding the 125 cases per surgeon were noted but NHS England believed they had set out the basis for the figure of 125 cases in the documentation when standards were agreed. NHS England believed the figure to be a fair representation based upon the recommendations of surgeons working in this particular speciality and they also felt that they had provided an explanation of the evidence they had used.

f) The EIA and Impact Assessment had been published as part of the review and consultation and it was unclear to them what was meant by the comments that they had not been published. It would be helpful if the specific details could be made known to NHS England after the meeting.

g) The frustrations about straight answers to questions were understood and NHS England needed to make sure that the link to the Q&As was more easily accessible. NHS England intended to answer the questions asked even though the answers may not always be what the questioner wanted to hear.

h) The NHS Board, in making the final decision, would need to consider whether the proposals were appropriate and whether any changes

outweighed the cost of those changes, including the question of having no Level I services within the East Midlands in the future.

i) It was expected that those centres taking on increased workloads as a result of the proposals would need more staff. NHS England would want to work with staff in Level 1 centres that would close to have the opportunity to transfer to another Level 1 centre that would have additional workloads. However, it was recognised that not all staff would want to move and, therefore, a good number of the additional staff required by a Level 1 centre with increased workloads would have to be recruited by that centre.

j) The modelling for the Review for the growth in numbers was most affected by the numbers of births rather than the overall number of people in an area. UHL's growth plan took into account their view of the growth in the population in the East Midlands and NHS England's work had also taken into account how the demand for CHD services would change in response to changes in population.

k) It was not possible to indicate with any certainty when the final decision would be made; it could be late in 2017 or early in 2018. The volume of responses to the consultation had been high and NHS England needed time to analyse these and assess what they indicated in relation to the proposals.

UHL's Comments

a) It was not UHL's desire to become embroiled in a legal dispute with NHS England through the courts as both bodies were part of the wider NHS system. However, UHL had taken legal advice on the proposals and were of the view that there was significant scope for challenge in relation to what was expected of public bodies and the process of how they should do it.

b) If UHL were a Level 2 centre as a result of the proposals, they would be the only Level 2 centre in the country that did not have a Level 1 centre in their region. The other Level 2 centres in the country were Cardiff, who were in a partnership with Bristol, Oxford were in partnership with Southampton and Edinburgh with Glasgow. This would mean that UHL would need to create a partnership and a network with Level 1 centres outside of the region. This network would include Birmingham Children's Hospital, Queen Elizabeth Hospital Birmingham for adult patients and also Leeds. It was also likely to include one or more centres in London. This model for providing Level 2 services and care was untested as it did not exist anywhere else in the country.

c) The idea that a Level 2 centre is a Level 1 centre without surgery was erroneous. It had been suggested that a Level 2 would undertake the simpler catheter interventions for example. The existing Level 2 centres at Cardiff, Oxford or Edinburgh did not undertake the catheter

intervention in children as they don't have the surgical expertise in the centre to intervene should there be any complications from the procedure. UHL would not wish to undertake keyhole procedures if there was no the surgical expertise available as this would not be safe for the patient if they had to be transferred to another Level 1 centre many miles away.

d) Existing Level 1centres also saw patients from Level 2 centres because they had the specialist equipment for specific imaging or scanning techniques that were required for Level 2 patients. Level 1 specialist services and equipment were also required for Outpatients as they often need to undergo further tests on the day of their appointment provided by a Level 1 centre. UHL felt that NHS England were unaware of these practicalities and the current proposals would mean that even more patients would be required to travel out of the region to attend a Level 1 centre.

ISSUES RELATING TO STANDARDS

a) The points made by Sally Ruane in relation to the lack of published evidence to support the selection of 125 operations per surgeon as being a definitive figure needed to be addressed and fully evidenced by NHS England; rather than rely on a figure arrived at by the consensus of specialist clinicians, many of whom would benefit from these proposals.

b) Few studies had been carried out and their findings differed and offered contradicting viewpoints. One study suggested 250 operations per centre was a recommended level of activity. Other studies showed that small centres could perform better than large centres and also that centres of equal size could perform differently. These studies demonstrated that the evidence was mixed and complex and that there were many factors that contributed to good outcomes. The outcomes of these studies suggested that focussing solely on the number of operations was not the best approach to providing a high quality service.

c) The focus should be on the mortality rates of Level 1 centres as this was evidence of good outcomes for patients. It was difficult to understand how a well performing centre such as UHL with mortality rates better than most was being proposed for closure.

ISSUES RELATING TO TRAVEL

a) NHS England had not sufficiently considered the impact of travel of for severely ill children and the effect this could have on the mental wellbeing of parents, other family members and close relatives. Mental health was a crucial aspect of the whole process. The focus should be on the patient and the family and the care and support that is given to the family and not on the number of operations carried per surgeon. It had been expressed many times that UHL gave excellent care and support and these proposals were putting more stress on people who

are already under stress.

b) There was still concern that the proposals did not adequately consider the impact of people in outlying areas such as Boston having to travel long distances many times during the duration of their care.

c) The impact of the proposals upon other members of family, children parents and grandparents needed to be fully considered as they could cause life changing effects to the family. It could not be assumed that the immediate family would be on hand to provide support at a time of stress and crisis. Not all families lived close by to their relatives and the proposals did not seem to consider its impact on the increased costs to families in maintaining the household, extra travel and accommodation away from home. It was vitality important that children were not disadvantaged by choices which not of their not of their making and the proposals should also take into account their impact upon the social aspects of family and extended family life.

The Chair echoed members thanks to the parents and stakeholders for attending and giving the Committee their representations. The representations clearly demonstrated that the issue was not simply a number game or about the number of procedures as quality of care was much broader than that. The patient experience was integral to the whole process and should be recognised and all the representations had emphasised that the consistency and continuity of care was essential and that the support the staff that UHL provided was far beyond that which could be expected and they were almost part of the extended family and support network. The importance of having care as close to home was important for families especially on the impact for other family members attending local children. It was important that normal family life was maintained as far possible for all family members whilst coping with the demands placed upon them from caring for a child with CHD. The emotional needs of the child and the family also needed to be considered; none more so than where a child also had other special needs.

The views expressed at the meeting would be incorporated into the Committee's submission to the consultation process. There was obvious frustration expressed by both the public and Members with the whole consultation process and the particular concerns over its equity and fairness. The overall impression from the Committee's meetings on this issue has been that NHS England had been put in the position of defending the proposals, which Members feel were indefensible for the reasons put forward. This process had not been helped by a new Programme Director being appointed part way through the consultation process and, whilst that was not the fault of NHS England, they now needed to undertake considerable work to reassure the public about the process.

AGREED:-

That the members of the public and the various stakeholders be thanked for their submissions and that NHS England take the views expressed at the meeting in account as part of the

consultation process and when considering the final decision.

43. NEXT STEPS IN RESPONSE TO THE CONSULTATION PROCESS

The Chair commented that based on the discussions of this and previous meetings a response to NHS England's consultation would be prepared. The consultation response would be shared with the constituent Council's for comment prior to it being submitted before the deadline on 17 July.

The Chair also commented that the City Council would be writing to the Secretary of State expressing concerns in relation to the inequality of the proposals and the way in which the standards had been determined and applied in the consultation process. The proposals were also not considered to be in the best interests of health services in Leicester and the wider region. The letter would also indicate that, because of those concerns, a referral would be made to the Secretary of State in the future should Level 1 services no longer be commissioned from UHL.

44. ANY OTHER URGENT BUSINESS

There were no items of Any Other Urgent Business to be discussed.

45. CLOSE OF MEETING

The Chair declared the meeting closed at 7.47 pm.

Appendix B

NHS ENGLAND – BOARD PAPER

Paper: PB.30.11.2017/06

Title:

Congenital Heart Disease Services for Adults and Children: Future Commissioning Arrangements

Lead Directors:

Paul Baumann - Chief Financial Officer

John Stewart - Acting Director of Specialised Commissioning

Purpose of Paper:

To take final decisions on the commissioning of congenital heart disease services for adults and children across England following full public consultation on proposals.

Summary:

The introduction of a standards-based approach to commissioning congenital heart disease services for adults and children responds to calls from patients, patient groups, clinicians and professional bodies, and will ensure the highest quality of care is provided to patients within resilient and sustainable services. Already, this approach has driven significant improvements across the country to out of hours and seven day cover, the number of specialist nurses and rates of antenatal diagnosis. Occasional and isolated practice has now almost entirely been eliminated.

However, in line with the standards, there is both scope to secure further improvements and, crucially, the opportunity to make some further adjustments that will ensure services are able to respond rapidly to future clinical, technological and scientific advances and, in doing so, maintain their world leading status. The recommendations in this paper, if agreed, will further support us in moving towards full national compliance with the standards through:

- Commissioning Liverpool Heart and Chest Hospital NHS Foundation Trust to provide level 1 adult CHD services in the North West, with Manchester University Hospitals NHS Foundation Trust providing the full range of level 2 adult CHD services as an integral part of a North-West CHD Network;
- Continuing to commission University Hospitals of Leicester NHS Trust to provide level 1 CHD services, *conditional* on achieving full compliance with the standards in line with their own plan to do so and demonstrating convincing progress along the way;
- Backing the Royal Brompton and Harefield NHS Foundation Trust's ambitious

new outline proposal for achieving full compliance with the standards and continuing to commission level 1 services from them in the meantime, *conditional* on demonstrating convincing progress along the way;

- Continuing to commission Newcastle upon Tyne Hospitals NHS Foundation Trust to provide level 1 CHD services until at least March 2021, with further consideration to be given, by NHS England, to the future commissioning of both the Trust's advanced heart failure and transplant service and its level 1 CHD service;
- Ceasing to commission level 2 CHD services, including cardiology interventions in adults with CHD, from Blackpool Teaching Hospitals NHS Foundation Trust, Imperial College Healthcare NHS Trust, Nottingham University Hospitals NHS Trust, and University Hospital of South Manchester NHS Foundation Trust[1].

The Board is invited to:

- Note the results of the consultation;
- Note the assurances that due process has been followed and that it may appropriately proceed to take decisions;
- Agree the recommendations for changes to the provision of level 1 and level 2 adult and paediatric CHD services and the associated implementation schedules; and,
- Agree the proposals for full implementation of all the standards, and in particular confirm its support for the recommendations relating to better information, formal CHD networks and peer review.

[1] University Hospital of South Manchester has now merged with Central Manchester University Hospitals to form Manchester University Foundation Trust. Under the recommendations the newly merged Trust would provide level 2 services from its Royal Manchester Infirmary site.

Congenital Heart Disease Services for Adults and Children: Future Commissioning Arrangements

Purpose

1. In February 2017, a full public consultation was launched on proposals for the future commissioning of congenital heart disease services for adults and children in England. The purpose of this paper is to provide feedback to the Board on the responses received during consultation and, in light of this, present a set of recommendations on future commissioning arrangements for final decision by the Board.

2. This paper should be read in conjunction with the supporting materials set out in **Table 1.**

Table 1	Title	Description
Annex A	Congenital Heart Disease Consultation Report.	Independent analysis of consultation responses provided by Participate Ltd.
Annex B	Decision Making Business Case.	A detailed consideration and analysis of the impact of consultation proposals and alternative proposals presented during consultation.
Annex C	Notes of a meeting of the Liverpool and Manchester Trusts, chaired by Professor Huon Gray, National Clinical Director, Heart Disease.	Record of discussions and agreements reached between the Trusts at the meeting on 23 October 2017.
Annex D	Letter from the Liverpool Trusts.	Letter supporting the delivery of level 2 services in Manchester.
Annex E	Leicester Growth Plan.	Growth Plan materials supplied by the Trust.
Annex F	Letters from referring hospitals in response to Leicester's Growth Plan.	Compendium of letters supplied by the Trust.
Annex G	Joint consultation response from the Royal Brompton & Harefield NHS Foundation Trust and King's Health Partners.	Proposals for a collaborative approach that would meet the requirement for RBH paediatric care to be delivered in a holistic children's environment.

Background

3. Congenital heart disease (CHD) is the most common birth anomaly, and affects between 5 and 9 in every 1,000 babies born in the UK, meaning 3,500 to 6,300 babies are born with CHD in England and Wales each year. Not every baby will need surgery, but when it is needed, it is both life-saving and life changing. As such, a great deal of focus is often placed on the surgical episode. However, although surgery can represent a critical and life-saving intervention, for most, this will not be

a final cure. Congenital heart disease is a lifelong condition, and patients and their families will need monitoring, support and care throughout their lives.

4. Services for CHD in England are very good, and survival after surgery is as good as, if not better than, anywhere in the world[1]. A recent review has shown that UK mortality rates are low, compare favourably internationally[2], fell over the 10 years between 2000 and 2010, and more recently we have seen a continuing trend to improved survival[3]. About 80% of children with congenital heart disease will now survive into adulthood, with the result that for the first time, the number of adults living with CHD is thought to exceed the number of children and young people.

5. Despite these improvements, the origins of this review, which stem from the publication in 2001 of the public inquiry into concerns about the care of children receiving complex cardiac surgery at Bristol Royal Infirmary, remind us of the importance of not being complacent. We believe there is both scope to secure further improvements and, crucially, the opportunity to make some further adjustments that will ensure services are able to respond rapidly to future clinical, technological and scientific advances and, in doing so, maintain their world leading status. In doing so we are also seeking to ensure that services are more resilient, and will be sustainable for years to come.

6. When NHS England launched its review into congenital heart disease services, following previous failed attempts to put in place a coordinated programme of change, we listened to patients, their families and the clinicians who provide these services to understand what needed to be done.

7. They asked us to do two things. Firstly, they wanted to see national standards that set out what excellent care looks like and which every hospital would be expected to follow. Secondly, they asked us to deal with the uncertainty that had been allowed to develop about the future of individual centres providing these services, because it was affecting patient confidence and staff morale. So working with doctors, nurses, psychologists and patient representatives from across the country we developed a comprehensive set of service standards which, if implemented, would mean that hospitals providing this care were brought up to the level of the very best in every aspect of care.

8. In July 2015, the NHS England Board agreed the standards - almost 200 in total that covered the entire patient pathway, from diagnosis through to treatment and then on into care at home. The standards describe three levels of CHD service provision:

[1] See Annex B, Decision Making Business Case, Table 1: Survival Rates (paediatric surgery 2012-2015) before risk adjustment.

[2] Brown KL, Crowe S, Franklin R, et al. Trends in 30-day mortality rate and case mix for paediatric cardiac surgery in the UK between 2000 and 2010. Open Heart 2015;2:e000157.doi:10.1136/openhrt-2014-000157

[3] See Annex B, Decision Making Business Case, Figure 2: Variable Life Adjusted Display (VLAD) Chart for all 14 centres undertaking procedures in patients under 16 years of age, 2012-15.

- **Level 1 Specialist Surgical and Interventional CHD Centres**: manage all patients with highly complex CHD and provide the most highly specialised diagnostics and care, including all surgery and interventional cardiology.
- **Level 2 Specialist Medical Cardiology Centres:** provide the same level of specialist medical care as a level 1 centre, but not surgery or interventional cardiology (except for one specific minor procedure at selected adult centres). They focus on diagnosis and ongoing care and management. Not every network will include a level 2 centre: this will depend on local requirements for access and capacity.
- **Level 3 Local Cardiology Services :** accredited services in local hospitals run by general paediatricians / cardiologists with a special interest in CHD. They provide initial diagnosis, ongoing monitoring and care, including joint clinics with specialists from the level 1 or 2 centres, so allowing more care to be given nearer to home.

Using the standards to ensure services improve for patients

9. NHS England does not consider there to be a 'right number' of CHD surgery centres, nor that a certain number of centres should close. Rather, our aim is to ensure that every centre that offers CHD services meets the standards and, in doing so, provides the highest quality of care to patients on a sustainable basis. By setting standards that make clear what is required for an excellent service we have already seen improvements. For example, when NHS England completed its initial assessments, only seven centres had full out of hours cover for adults undergoing cardiology interventions (1 in 3 rota, specialist adult CHD interventionists); now all centres providing this service have full cover. Similarly, all now have full specialist adult cardiologist out of hours cover (1 in 4 rota). In addition, every centre now has consultant-led ward rounds seven days a week. These are important improvements that make a difference to the quality of care for patients. We have also seen increases in the number of specialist nurses and steady improvements in antenatal diagnosis of CHD; with targeted action becoming possible we expect to see more improvements.
10. The standards do not permit occasional and isolated practice (small volumes of surgery and interventional cardiology being undertaken in institutions that do not offer sufficient specialist expertise in this field). This has been of particular concern to patients and their representatives. We have worked with the hospitals involved and we are well on the way to completely eliminating occasional practice.
11. Patients and their families told us that while it was a good thing to have standards, they only really mattered if we ensured that they were met. Otherwise, they were a waste of time.
12. We therefore set out proposals to implement the standards, and asked for views in a full, formal, public consultation that ran between 9 February 2017 and 17 July 2017.

13. At the heart of our proposals was our aim that every patient should be confident that their care is being delivered by a hospital that meets the required standards. To achieve this, we proposed that in future, NHS England would only commission CHD services from hospitals that are able to meet the standards. The recommendations that the Board is now being asked to consider will, over time, ensure we achieve that aim and, more specifically, that:

    - **Every operation or cardiology intervention for CHD patients will be carried out by specialist doctors** with a volume of practice sufficient to develop and maintain their skills;
    - **All children with heart disease will receive their inpatient care in a holistic children's environment** so that they can receive optimum care for any non-cardiac clinical problems without either the child or the specialist having to travel to another hospital with the potential compromises involved;
    - **Daily interaction between teams will be facilitated,** which is particularly important for children with complex conditions and multiple medical needs;
    - **Resilience will be enhanced** through larger level 1 centres, with bigger teams, providing an assurance of full 24 hour seven day specialist care and the ability to cope with challenging clinical events or fluctuations in specialist staffing;
    - **Care will be delivered as close to home as possible**, through networked specialist level 2 centres, level 3 services and outreach clinics, all co-ordinated by a network team;
    - **Occasional and isolated practice will no longer be permitted**, so low volume surgery or interventional cardiology in institutions without sufficient specialist CHD expertise will cease.

14. **The recommendations set out in this paper modify NHS England's original consultation proposals, because we have listened to the views expressed and considered new proposals and information that has emerged as part of the process**.

Assurance of readiness for decision making

15. In taking final decisions as to whether to implement the consultation proposals or whether to take an alternative course of action the Board must:

    - give conscientious consideration to the results of the consultation;
    - ensure that NHS England has met the requirements of the Secretary of State's Four Tests for reconfiguration (and the fifth test set by the Chief Executive of NHS England) and has followed NHS England's Service Change Guidance;
    - ensure that NHS England has met its legal duties including those set out in sections 13C - Q of the NHS Act 2006 and in the Equality Act 2010, the Human Rights Act 1998 and the Children Act 2004;

- take into account all the relevant factors and no irrelevant factors; and,
- satisfy itself that due process has been followed.

The results of consultation

16. We received 7673 online consultation responses (survey) and 78 'other responses' in the form of letters/emailed documents. These were independently analysed by Participate Ltd and a report of their analysis accompanies this paper at **Annex A**. Further detail from the responses and the way they have influenced our thinking can be found in the relevant sections of the Decision Making Business Case (DMBC), also accompanying this paper at **Annex B**.

The five reconfiguration tests

17. NHS England has ensured that it has met the requirements of the five tests. This is described in Part 3 of the Decision Making Business Case (DMBC) accompanying this paper. In reviewing and accepting the DMBC, both the Oversight Group for Service Change and Reconfiguration and the Investment Committee have provided assurance that this requirement has been met.

Meeting our legal duties

18. Our external legal advisers have reviewed our compliance with sections 13C to 13Q of the NHS Act 2006 and the public sector equality duty. This is described in Part 3 of the DMBC accompanying this paper. We have completed a full Integrated Equalities Impact Assessment. This is described in the DMBC accompanying this document. In reviewing and accepting the DMBC, the Oversight Group for Service Change and Reconfiguration and the Investment Committee also provided assurance that this requirement has been met.

Taking account of the relevant factors

19. NHS England has received advice on the current (as at August 2017) assessment of each hospital providing level 1 and 2 CHD services against the standards, the impacts of implementing NHS England's proposals and appropriate mitigations of any potential adverse impacts. These assessments were undertaken by a specially convened National Panel including national and regional commissioners, clinical and patient representatives and chaired by Dr Vaughan Lewis. The panel met in August 2017. The report of its work is included at **Annex 6 of the DMBC** accompanying this paper. Its advice is reflected throughout the accompanying DMBC. The National Panel confirmed that there have been no changes in the assessment of any of the centres where change has been proposed which could imply that the original proposals would no longer be appropriate. It has also confirmed that the original proposals could, in principle, be implemented by the NHS England Board and that the impacts of doing so could be appropriately managed. The National Panel also considered alternative proposals that emerged during consultation.

20. NHS England has also received advice on a range of clinical issues in the light of consultation, including issues raised by respondents from a specially convened Clinical Advisory Panel chaired by Professor Sir Michael Rawlins. The panel met in August 2017. The report of its work is included at **Annex 5 of the DMBC** accompanying this paper. Its advice is reflected throughout the accompanying DMBC.

21. A full assessment of the financial impact, both revenue and capital, of NHS England's proposals is included in the DMBC accompanying this paper. In developing and agreeing the CHD standards, NHS England has been clear throughout that no additional funding will be provided to meet compliance costs for those providers wishing to offer these services and that no specific central funds are available for capital investment. The Investment Committee has confirmed that implementing the standards is affordable for NHS England under tariff and that risks around the capital funding requirement are minimal. The Investment Committee has also endorsed pump priming the development of CHD networks for a limited period in a similar way to other Operational Delivery Networks and using similar funding mechanisms from within the Specialised Commissioning budget.

Consideration and Recommendations

22. Having confirmed that NHS England has in its work on CHD followed due process, this paper now considers the proposals for change and whether the Board should decide to implement the proposals on which it has consulted, or, in light of the consultation response and all the other relevant factors, take a different course of action.

23. It is worth noting that the majority of standards can be met at every hospital currently providing level 1 services with the right focus, attention and in some cases some extra investment. However, there are two very important areas covered by the standards that have proved more challenging for certain hospitals, as follows:

    - **Surgical activity standards** require that each level 1 centre has a team of three surgeons from April 2016, increasing to four surgeons from April 2021. Each surgeon must undertake at least 125 operations per year. CHD surgeons work across paediatric and adult practice, and all these operations count. Only a small number of centres already undertake more than 500 operations a year. Requiring each surgeon to undertake 125 operations per year (equivalent to about three operations a week) will enable them to maintain and develop their skills and will ensure the best possible outcomes for patients. Bigger teams, more effectively networked with other centres will be more resilient, providing an assurance of full 24 hour seven day care and the ability to cope with challenging events, for example the loss of a surgeon. They will be better for training, and because less onerous for

surgeons, better for patient care. There is good evidence, from a large number of studies, for a link between centre size and outcomes.

Professor David Anderson, Consultant Heart Surgeon and Professor of Children's Heart Surgery, Guy's and St Thomas', past President of the British Congenital Cardiac Association (BCCA) and member of the Clinical Advisory Panel has said: *'125 really is a minimum number. It equates to three operations a week, per surgeon. Practice makes perfect … Some of the operations we do only come up once or twice a year…we must set a minimum standard in order to ensure that a surgeon has an acceptable level of skill refined and maintained through regular practice.'*

- **Paediatric co-location standards** require that level 1 centres delivering paediatric cardiac care must have a range of other paediatric specialties on site from April 2019. This means that specialist children's cardiac services will only be delivered in settings where a wider range of other specialist children's services are also present on the same hospital site. This determines what medical care is available by the bedside for a child in a critical condition, which is important because many children with CHD have multiple medical needs. It also facilitates daily interaction with the wider paediatric multidisciplinary team which is of significant benefit to patients. This approach brings paediatric cardiac services into line with expectations in other specialist children's services and with paediatric cardiac services in other countries. Having all tertiary specialties on one site means neither the child nor the specialist has to travel, and it avoids the potential compromises involved - in the care environment, access to the full team and equipment, and timeliness of advice and intervention. This works in both directions in that similar advantages are also gained by children under the care of other specialists who need access to the advice or care of a paediatric cardiologist.

  The Clinical Advisory Panel has said: *'care for children should be provided in a holistic children's environment with on-site access to the full range of paediatric specialties and services'.* And the Royal College of Paediatrics and Child Health has told us that *'Isolated children's services are unacceptable; specialist children's cardiac services must be delivered within a hospital providing a broad range of other specialist children's services."*

24. Having assessed all existing providers of level 1 services against the standards, four Trusts were identified as being unlikely to meet the standards and were the focus of our proposals for change and our formal consultation. These are now considered in turn. In each case we describe the original proposal and the reasons for that proposal, we then go on to discuss what we are now recommending, and if that differs from the original proposal we say why.

Level 1 and 2 Services: North-West England

25. In North-West England, specialist inpatient services for people with CHD (level 1) have, to date, been divided between two cities: Liverpool where children received their care at Alder Hey Children's Hospital; and Manchester where adults received their care at Manchester Royal Infirmary.

26. Running the service in this way inevitably required compromises, because it meant the adult service depending on a single surgeon. He could not be there all the time, and the distance between the cities was such that cover could not be provided from Liverpool. There also wasn't enough surgical work to allow him to meet minimum volume expectations – just 92 operations in 2016/17. On 19 June 2017 the service in Manchester was suspended by the Trust, when their surgeon moved to a new post at a different hospital. As a result, patients who previously received their care from the Manchester team currently receive much of that care from the clinical teams at Leeds, Newcastle and Birmingham under interim arrangements.

27. As such, NHS England's proposal was to bring the level 1 service together so that care for adults and children could be delivered in one city, by teams of surgeons, cardiologists and interventionists big enough to give full, consultant led, 24 hour, seven day care. Choosing which city should be the level 1 centre was always going to mean some people would be dissatisfied. We proposed that level 1 services should be centred in Liverpool, because around 80% of the operations are done in children and so moving the much larger children's service from Liverpool (Alder Hey Children's Hospital carried out 415 operations in 2015/16) to Manchester would be more difficult and potentially a greater risk than moving the smaller adult service to Liverpool. An important part of our proposal was that adults with CHD should still be able to get much of their care in Manchester if that is better for them. Inpatient care related to surgery and cardiology interventions is important, but it's something that happens only occasionally - sometimes just once in a lifetime - but outpatient appointments and investigations are a regular part of life for a person with CHD. So we wanted to make sure that people could still get that care in Manchester, without having to travel to Liverpool all the time if that's not convenient for them.

28. We've listened to concerns raised during the consultation and can confirm that Manchester can and should provide level 2 care for adults with CHD as part of a North-West England CHD Network (NWCHDN). That will mean they will still be able to provide maternity care to most women with congenital heart disease. It will also be possible to have some of the more straightforward interventional procedures conducted there. As such, Manchester will continue to play a pivotal role in the network of care for adults with CHD, and when a patient does need an operation or more complex intervention, the new service at Liverpool Heart and Chest Hospital will be able to provide it. Critically, all these services will meet the national standards, giving patients an assurance of the best care.

Recommendation for consideration by the Board:

After careful consideration of consultation responses and other supporting materials, the Board is asked to confirm that it is content to proceed with implementing its 'minded to' decision to commission adult level 1 CHD services from Liverpool Heart and Chest Hospital NHS Foundation Trust, with the full range of level 2 services to be commissioned from Manchester University Hospitals NHS Foundation Trust, as part of a North-West England CHD Network.

Under these network arrangements, we would expect Manchester University Hospitals to continue to play a leading role in providing maternity care for women with CHD, including the development of care pathways and the coordination of multidisciplinary discussions of maternity care. We would expect that care for women with complex needs would be discussed at the NW CHD Network multidisciplinary team meeting to determine the best place for delivery.

The Board's decision to support these network arrangements should be conditional on the Liverpool Trusts providing robust and adequate support for level 2 services in Manchester.

Assurance:

- Professor Huon Gray, National Clinical Director for Heart Disease, met with clinical and managerial leads from the Liverpool and Manchester Trusts on 23 October 2017. At this meeting there was agreement on the provision of maternity care for women with CHD, with services continuing in both Manchester and Liverpool: place of birth for women with complex needs would be discussed and determined at the NW CHD Network MDT. This could mean a bespoke arrangement to ensure that all aspects of care were 'wrapped around' the patient, including the relevant adult CHD support being provided at St Mary's Hospital if that was the most appropriate place for the woman to deliver. There was also agreement for continuing adult CHD interventions in Manchester, within the level 2 standards, subject to NW CHD Network MDT oversight. Professor Gray has confirmed that in the north-west, providers will work together to establish a robust network with strong level 1 and 2 centres providing ACHD and paediatric cardiac care to patients in the north-west (**Annex C**).
- We have received written confirmation from the Liverpool Trusts that they are committed to ensuring that Manchester University Hospitals NHS Foundation Trust (MFT) will be able to provide the full range of level 2 adult CHD services as described in the National Standards, including facilitating the delivery of obstetric care for women with CHD and adult CHD interventions at a level two centre in Manchester as part of the North West CHD Network (**Annex D**).
- The impacts of implementing this recommendation have been assessed. The full assessment is reported in the Decision Making Business Case accompanying this paper. This confirms that the recommendation could be implemented by the

NHS England Board and the impacts of doing so could be appropriately managed.

Implementation

NHS England will monitor progress in the North-West towards meeting the standards and take commissioning action, if it becomes clear that the standards will not be met according to the timescale set out in the implementation schedule. These timescales are informed by the Trusts' own plans and the original timetable set out in the standards.

Alder Hey Children's Hospital Trust, Liverpool Heart and Chest Hospital, The Royal Liverpool and Broadgreen Hospitals, Liverpool Women's Hospital and Manchester University Hospitals will be required to re-provide all level 1 and level 2 services for adults with CHD within the NW CHD Network by January 2019. A detailed implementation schedule can be found at **Appendix 1 to this paper**.

Level 1 Services: University Hospitals of Leicester NHS Trust

29. In the East Midlands, specialist inpatient services for people with CHD (level 1) have been provided by University Hospitals of Leicester NHS Trust (UHL) from its Glenfield Hospital site in Leicester. This is one of the two smallest level 1 CHD services in the country, and this has meant that, to date, the Trust has cared for too few patients for its surgeons to be able to fully develop and maintain their skills. In recent years the service has grown, but it still is not big enough to allow each of its three surgeons to do at least 125 operations per year, a minimum requirement that came into effect on 1 April 2016. In addition, Glenfield is a mainly adult hospital, so the other specialists whose care and advice are sometimes needed for children with congenital heart disease were not all immediately at hand. When their help was needed they were usually at one of the Trust's other hospitals, the Leicester Royal Infirmary (LRI), and that meant either the doctor or the child would need to travel to a different hospital. It also meant that the specialist heart doctors at Glenfield were not so easily available to the children with other conditions, who were at the LRI.

30. UHL has produced plans to address these concerns, so that the standards could be met. Although we were happy with their plan to move children's services all under one roof at the LRI, we did not think, at the time, that we could be sure that their plan to increase the number of patients they care for would be enough for them to be able to meet the surgical activity standards. As a result, NHS England proposed that UHL should not provide level 1 CHD services in future, and patients needing surgery, cardiology interventions and specialist inpatient care or investigations would go to another hospital, generally in either Birmingham or Leeds. Under those proposals, it would still have been possible for patients with CHD to have most of their care - most outpatient appointments and investigations and some inpatient admissions and cardiology interventions - in Leicester because it would still have provide level 2 services.

31. Since that time, and in response to that prompt, UHL has further developed its plans to attract more patients to its service (**see Annex E**), and gained support from many of the surrounding hospitals (**see Annex F**). We also know from the consultation that, assuming UHL is meeting the standards, people want to see them continue to provide a level 1 CHD service.

32. Taking these developments into account we think it is now reasonable to give the Trust the opportunity to prove that it can implement its plans to meet the standards. To succeed, it will need to change the choices made by referring doctors and their patients, so neither we nor the UHL leadership can be absolutely certain what will happen. We plan, therefore, to monitor UHL's progress against their plan closely, and should it become clear that it is not going to be able to deliver its commitments and so meet the requirements, we will take the necessary action.

33. If UHL succeeds in attracting additional patients as planned, it will, of necessity, mean that activity levels at other hospitals will fall. Our analysis shows that the greatest impact is likely to be on Great Ormond Street and the Birmingham hospitals. The scale of the likely impact should not materially affect any other hospital's ability to meet the standards.

Recommendation for consideration by the Board

After careful consideration of consultation responses, other supporting materials and the additional evidence supplied by University Hospitals of Leicester NHS Trust around plans for achieving the co-location standard and meeting the surgical volumes standards, the Board is asked to confirm if it is content to continue to commission level 1 services from Leicester, conditional on the Trust achieving full compliance with the standards within the required timeframes, as described in its new plan to do so, and the Trust demonstrating convincing progress in line with the implementation milestones and key performance indicators (KPIs) set out in the implementation schedule at Appendix 1. Should this not be achieved, referral to the Specialised Services Commissioning Committee will be made to confirm that the process of decommissioning level 1 services should begin, with alternative arrangements put in place to ensure patients are able to benefit from receiving care from centres compliant with the required standards.

Assurance

- University Hospitals Leicester has provided a detailed plan for increasing the number of operations to be undertaken by its surgeons to allow it to meet the requirement of having a team of four surgeons, each undertaking 125 operations per year, from 1 April 2021 (**Annex E**). It has also provided statements of support from many of the hospitals that would be required to increase referrals (**Annex F**).
- The impacts of implementing this recommendation have been assessed. The

full assessment is reported in the Decision Making Business Case. This confirms that the recommendation could be implemented by the NHS England Board and the impacts of doing so could be appropriately managed.

Implementation

NHS England will monitor UHL's progress towards meeting the standards and take commissioning action if it becomes clear that the standards will not be met according to the agreed timescale and KPIs. These timescales and KPIs are informed by the Trust's own plans and the original timetable set out in the standards.

University Hospitals of Leicester NHS Trust will be required to achieve full compliance with the standards within the timeframes set out in the detailed implementation schedule which can be found at Appendix 1 to this paper. This includes achieving full co-location for all inpatient paediatric CHD care by April 2020 and increasing surgical activity so that it has a team of at least four surgeons, each undertaking at least 125 operations per year, from April 2021.

Level 1 Services: Royal Brompton and Harefield NHS Foundation Trust

34. The Royal Brompton and Harefield NHS Foundation Trust has provided specialist inpatient services for both adults and children with CHD (level 1) from its Royal Brompton Hospital (RBH) site in Chelsea. RBH is a mainly an adult hospital, so the other specialists whose care and advice are sometimes needed for children with congenital heart disease are not all immediately at hand. When their help was needed they were usually at another hospital, often Chelsea and Westminster Hospital, and that meant that either the doctor or the child would need to travel to a different hospital. RBH did not, at the time, produce any plans to address these concerns, so that the standards could be met. As such, NHS England proposed that RBH should not provide level 1 CHD services in future, and patients needing level 1 CHD care, including surgery, cardiology interventions and specialist inpatient care or investigations, would go to another hospital, generally still in London.

35. Since that time, and in response to our 'minded to' decision, RBH has begun to develop a proposal to work closely with another of the hospitals that provides level 1 CHD services in London, Guy's and St Thomas', part of King's Health Partners (**see Annex G**). They propose bringing together the CHD services offered by the two hospitals. Cardiac services for children would be provided from new buildings to be developed as part of the Evelina Children's Hospital and CHD services for adults from a newly created specialist heart and lung centre (both developments forming part of St Thomas' Westminster Bridge Campus).

36. We also know from the consultation that many aspects of RBH's service are held in high regard, with a special emphasis placed on the way their teams work together, and people want to see those teams kept together if possible.

37. Taking all that into account, we think it is reasonable now to allow the Trust to develop its plans further to the stage where they can be properly evaluated. The advantages of the proposed model (or one like it, involving another partner), if it could be delivered, would be very significant. Amongst these advantages is that this solution also addresses the parallel challenge relating to paediatric respiratory services, and that it facilitates keeping together the Royal Brompton's clinical and research teams. Although the proposal submitted involved Guy's and St Thomas', other partnerships might also be possible, so we will not make our decision specific to this one partnership arrangement. In any case, developing plans of this sort will mean RBH considering and fully evaluating a range of options, in terms of strategic fit, clinical quality, value for money and affordability (capital and revenue), and deliverability, to make sure that it is pursuing the best one.

38. It is important to note that the specific proposal presented in response to the consultation is ambitious and would require a great deal of money to fund the necessary new buildings and equipment, much, if not all, of which would probably need to be found by the Trusts themselves, including from surplus land disposals. So, if this option is pursued it would need to go through the exacting scrutiny that the Government requires of such projects. We plan, therefore, to monitor progress closely and provide appropriate support to the evaluation of options. However, if it becomes clear that RBH is not going to be able to meet the requirements through such an initiative, or that the solution cannot be put in place within a reasonable timescale, we would begin the process of decommissioning level 1 CHD services for children from the Royal Brompton site at this point.

Recommendation for consideration by the Board

After careful consideration of consultation responses and other supporting evidence, the Board is invited to note the outline alternative solution presented by the Royal Brompton and Harefield NHS Foundation Trust, for how full compliance against the standards might be achieved and, in light of this, confirm that NHS England should work with RBH and other potential partners on the full range of options for delivering a solution that could deliver full compliance with the standards and ensure the sustainability of other connected services. Progress should be reviewed by the NHS England Board over the next two years. Should a credible solution not have been presented by the end of November 2019 in the form of a submitted Outline Business Case, supported by NHS England, referral to the Specialised Services Commissioning Committee will be made to confirm that the process of decommissioning level 1 services for children should begin, with alternative arrangements put in place to ensure patients are able to benefit from receiving care from centres compliant with the required standards.

Assurance

- Royal Brompton & Harefield NHS Foundation Trust in collaboration with

King's Health Partners has submitted a proposal to develop a model for CHD services that brings together the existing Royal Brompton Hospital and Guy's & St Thomas' Hospital services to deliver a joint service that would meet the paediatric co-location standards (**Annex G**).

- The impacts of implementing this recommendation have been assessed at a level commensurate with the level of detail in the plans. The assessment is reported in the Decision Making Business Case. Further assessment of the plan, its impacts and appropriate alternatives will be undertaken as the plan passes through the public sector business case development process through to potential Outline Business Case approval.

Implementation

NHS England will monitor RBH's progress towards meeting the standards, and take commissioning action, if it becomes clear that the standards will not be met according to the timescale set out in the implementation schedule. These timescales are informed by the Trust's own plans and a realistic planning schedule.

RBH will be required to develop and deliver a credible solution for meeting the co-location requirements for its paediatric services. RBH should develop its plans (working with potential partners as appropriate) following Treasury guidance for preparing a Public Sector Business Case and using the five case model.

RBH will be required, as part of its planning process, to develop and deliver a detailed plan with clear milestones, that will achieve full co-location for all RBH paediatric specialist services by April 2022 at the latest.

A detailed implementation schedule can be found at **Appendix 1** to this paper.

Level 1 Services: Newcastle upon Tyne Hospitals NHS Foundation Trust

39. In the North-East of England, specialist inpatient services for adults and children with CHD (level 1) have been provided by Newcastle upon Tyne Hospitals NHS Foundation Trust (NUTH) from its Freeman Hospital site in Newcastle. This is one of the two smallest level 1 CHD services in the country, and this has meant, to date, that the Trust has cared for too few patients for its surgeons to be able to fully develop and maintain their skills, as it is not big enough to allow each of its three surgeons to do at least 125 operations per year, a minimum requirement that came into effect on 1 April 2016. In addition, the Freeman Hospital is a mainly adult hospital, so the other specialists whose care and advice are sometimes needed for children with congenital heart disease were not all immediately at hand. When their help was needed they were usually at one of the Trust's other hospitals, the Great North Children's Hospital (GNCH), and that meant either the doctor or the child would need to travel to a different hospital. It also means that the specialist heart doctors at the Freeman Hospital were not so easily available to the children with other conditions, who were at the GNCH.

40. The Trust has told us that it is confident it will reach the minimum 375 operations needed to meet the current requirement, but it does not consider it likely that it will have enough activity to be able to support a team of four surgeons each undertaking at least 125 operations a year as required by the standards from April 2021. In addition, while the Trust had looked at options for moving its paediatric cardiac services to the GNCH, they had not identified funding, or made definite plans, partly because of the uncertainty about the service's future. Under these circumstances NHS England would normally have proposed that NUTH should not provide level 1 CHD services in future. However, it was clear that if it did not provide level 1 CHD care, NUTH would also have to stop providing its advanced heart failure and heart transplant service for children and for adults with CHD. There are only two hospitals that do heart transplants for children and NUTH is also the main hospital for transplanting hearts for adults with CHD. These services could not be replaced in the short term without a negative effect on patients. Because of the way these services are intertwined, we cannot make a decision on one without also making a decision on the other, and heart transplants were outside the brief of our work on CHD services. Taking this into account we originally proposed that surgery and interventional cardiology for adults and children should continue to be provided by NUTH for the time being, with further consideration given to the commissioning position beyond 2021.

41. We are now recommending that NUTH should continue to provide a level 1 CHD service, until at least March 2021, which will allow us time to further consider our commissioning approach for both the CHD and the advanced heart failure and transplant service at the Trust from April 2021 onwards.

42. Whilst this consideration should assess the potential for moving the advanced heart failure and transplant service to another provider, it is possible that we could conclude that it is in the overall interest of patients to maintain current arrangements with permanent derogation against the 2021 surgical activity standard. If this were to be the case NUTH would still be required to meet the other standards, including having a team of at least three surgeons, each carrying out at least 125 operations a year, and to achieve full paediatric co-location.

43. Although NUTH has considered how it would achieve co-location of children's services, we think it would be premature to move to implementation of this until the commissioning position beyond 2021 is confirmed. As such, derogation against the co-location standard, for a time limited period, will be needed from April 2019.

Recommendation for consideration by the Board

After careful consideration of consultation responses and other supporting materials, the Board is asked to confirm that the commissioning of level 1 CHD services at Newcastle upon Tyne Hospitals NHS Foundation Trust should continue until at least March 2021.

Recognising the importance of the quality and sustainability of both the CHD service

and the interdependent advanced heart failure and transplant service, the Board is invited to agree that further consideration should be given to the future commissioning of both. This will inform our commissioning approach from 2021 to ensure services meet the required standards. Until the outcome of this work is known, derogation against the 2019 co-location standard should be assumed.

Assurance

- The impacts of implementing this recommendation have been assessed. The full assessment is reported in the Decision Making Business Case. This confirms that the recommendation could be implemented by the NHS England Board and the impacts of doing so could be appropriately managed.

Implementation

NHS England will further consider its commissioning approach for both the CHD and the transplant service at NUTH from April 2021 onwards. It will confirm its plans by no later than April 2019.

NHS England will monitor NUTH's progress towards meeting the standards, and take commissioning action, if it becomes clear that the standards will not be met according to the timescale set out in the implementation schedule, and subject to the relevant derogations. These timescales are informed by the Trust's own plans and the original timetable set out in the standards.

NUTH will be required to develop and deliver a plan to increase surgical activity so that it has a team of at least three surgeons, each undertaking at least 125 operations per year from 2019/20, in line with the detailed implementation schedule which can be found at **Appendix 1** to this paper.

NUTH will not be required to meet the 2019 deadline for full co-location for paediatric cardiac services, but will be required to meet these standards if NHS England confirms a plan to commission level 1 CHD services beyond March 2021.

44. If implemented, these revised proposals will mean that in future level 1 CHD services in England will be provided by the following hospitals:

- Alder Hey Children's Hospital NHS Foundation Trust (children's services) and Liverpool Heart and Chest Hospital NHS Foundation Trust (adult service) – subject to the conditions described above;
- Birmingham Women's and Children's Hospital NHS Foundation Trust (children's services) and University Hospitals Birmingham NHS Foundation Trust (adult service);
- Great Ormond Street Hospital for Children NHS Foundation Trust (children's services) and Barts Health NHS Trust (adult service);
- Guy's and St Thomas' NHS Foundation Trust (children's and adult services);

- Royal Brompton & Harefield NHS Foundation Trust (children's and adult services) – subject to the conditions described above;
- Leeds Teaching Hospitals NHS Trust (children's and adult services);
- Newcastle upon Tyne Hospitals NHS Foundation Trust (children's and adult services) – subject to the conditions described above;
- University Hospitals Bristol NHS Foundation Trust (children's and adult services);
- University Hospitals of Leicester NHS Trust (children's and adult services) – subject to the conditions described above; and
- University Hospital Southampton NHS Foundation Trust (children's and adult services).

Level 2 Services

45. Changes were also proposed to the provision of level 2 CHD services. These follow the same principle of only commissioning from hospitals that are able to meet the standards. We found a number of hospitals had been providing aspects of level 2 services, particularly cardiology interventions in adults with CHD, which were not able to meet the full level 2 standards. Common findings were that there were not enough doctors with specialist expertise in caring for CHD patients and that the doctors doing the interventions were not doing enough in CHD patients to develop and maintain their skills as required by the standards.
46. Since we made these proposals the situation has not really changed, except in one case, that of Papworth. Papworth Hospital has taken action in response to our assessment and as a result it now either meets or has good plans to be able to meet all the requirements.
47. With that in mind we consider that four hospitals, listed below, should no longer provide level 2 services for adults with CHD, including interventional cardiology.

Recommendation for consideration by the Board

After careful consideration of consultation responses and other supporting materials, the Board is asked to confirm that the commissioning of level 2 CHD services, including cardiology interventions in adults with CHD, should no longer continue at the following hospitals:

- *Blackpool Teaching Hospitals NHS Foundation Trust*
- *Imperial College Healthcare NHS Trust*
- *Nottingham University Hospitals NHS Trust*

- *University Hospital of South Manchester NHS Foundation Trust*[4]

Assurance

- The impacts of implementing this recommendation have been assessed by the National Panel which has confirmed that the recommendation could be implemented by the NHS England Board and the impacts of doing so could be appropriately managed.

Implementation

NHS England's regional teams will give notice on any contracts for the provision of level 2 services, and will no longer reimburse such services from the providers named above.

48. If implemented, these proposals will mean that in future level 2 CHD services in England will be provided by the following hospitals:

- Brighton and Sussex University Hospitals NHS Trust (adult service)
- Manchester University NHS Foundation Trust (adult service)
- Norfolk & Norwich University Hospitals NHS Foundation Trust (adult service)
- Oxford University Hospitals NHS Foundation Trust (children's and adult services)
- Papworth Hospital NHS Foundation Trust (adult service)

Further action to support full implementation of the standards

49. We are clear that all of the standards are important in ensuring excellent patient care and we are committed to ensuring that the NHS in England continues to work to see them all implemented in practice. A lot of the work we have done so far has concentrated on the challenge of meeting those standards that could not be met at every hospital working as they were. However, most of the standards are not of this type, and they can be met at every hospital with the right focus, attention and in some cases some extra investment. We are therefore putting in place a range of mechanisms to support the full implementation of all the standards.

Better information

50. Surviving surgery (or a cardiology intervention) is clearly vital for patients, but that is not the whole story when considering how good services are or the quality of life they achieve for patients and their families. Unfortunately, to date, few other reliable measures have been available. To address that shortfall we have:

- Developed a measure of patients' experience of their own care.

[4] University Hospital of South Manchester has now merged with Central Manchester University Hospitals to form Manchester University Foundation Trust. Under the recommendations the newly merged Trust would provide level 2 services from its Royal Manchester Infirmary site.

- Worked with the Congenital Heart Services Clinical Reference Group to introduce a dashboard that makes available a much wider range of measures of the quality of care than has ever been available before.
- Worked with the National CHD Audit to encourage reporting on a wider range of procedures and with a wider range of measures.
- Developed a research proposal to investigate longer term outcomes by diagnosis, which will now be commissioned by the Department of Health. This will use linked data from the national CHD audit and paediatric intensive care network databases, and other sources.

Networks

51. While most level 1 CHD surgical centres already have informal networks, the extent to which these networks have been developed varies. The standards place great emphasis on networks, and we believe they have a vital role to play in ensuring standards are met across the board. That's why we have agreed to provide funding to support their development.

Peer review

52. Peer review provides a mechanism by which centres are required to provide evidence to show that they meet the standards. The emphasis is on improvement and learning from other centres. NHS England's Specialised Commissioning Quality Surveillance Team (QST) will support the development and delivery of a rolling peer review programme that will cover all of the standards at all hospitals.

Conclusion

53. We have made a series of recommendations for changes to services for people with CHD. Ultimately, the aim of all our work has been to improve the care that patients receive. We believe that if these recommendations are implemented they will mean that, in time, every hospital will be brought up to the level of the very best in every aspect of care. It will mean that every child with CHD receives their care in a hospital that offers a holistic children's environment, with all the facilities and other specialists on site and readily able to contribute to their care. It will mean that all CHD surgeons and interventional cardiologists are doing enough procedures to develop and maintain their skills, and they will be part of teams large enough to provide full 24 hour / seven day care, resilient enough to continue to do so, even if one of the team leaves or is away for some reason. Occasional practice by non-specialists will be a thing of the past. Over time the full range of standards will be implemented with the help of more formal networked working, and including better information, communication and support which patients told us is so important. Commissioners, hospitals and patients alike will have access to a wider range of measures that can tell us all how well services are doing and help inform further improvements.

54. The Board is invited to:

- **Note** the results of the consultation;

- **Note** the assurances that due process has been followed and that it may appropriately proceed to take decisions;

- **Agree** the recommendations for changes to the provision of level 1 and level 2 adult and paediatric CHD services and the associated implementation schedules; and
- **Agree** the proposals for full implementation of all the standards, and in particular confirm its support for the recommendations relating to better information, formal CHD networks and peer review.

Appendix 1: Implementation Schedules

North West of England

- NHS England will monitor progress in the north-west towards meeting the standards and take commissioning action if it becomes clear that the standards will not be met according to the timescale set out in the implementation schedule. These timescales are informed by the Trust's own plans and the original timetable set out in the standards.
- Alder Hey Children's Hospital Trust, Liverpool Heart and Chest Hospital (LHCH), The Royal Liverpool and Broadgreen Hospital, Liverpool Women's Hospital and Manchester University Hospitals (MFT) will be required to re-provide all level 1 and level 2 services for adults with CHD within the North-West England CHD Network (NWCHDN) by January 2019.

Milestone- no later than	**Deliverable**	**Commissioner action if not delivered**
		Trust required to produce, and agree with NHS England, a recovery plan.
January 2018	NWCHDN Network MDT meets at least weekly.	If milestone missed.
April 2018	NWCHDN Network Board established.	If milestone missed.
September 2018	All outpatient appointments for adults with CHD delivered within the NWCHDN at both LHCH and MFT (and outreach), excluding patients whose care is delivered elsewhere because of patient choice or for clinical reasons.	Less than 85% outpatient appointments for adults with CHD delivered within the NWCHDN at both LHCH and MFT, excluding patients whose care is delivered elsewhere because of patient choice or for clinical reasons.
November 2018	All cardiology interventional procedures for adults with CHD delivered within the NWCHDN at both LHCH and MFT, excluding patients whose care is delivered elsewhere because of patient choice or for clinical reasons.	Less than 85% interventional procedures for adults with CHD delivered within the NWCHDN at both LHCH and MFT, excluding patients whose care is delivered elsewhere because of patient choice or for clinical reasons.
January 2019	All cardiac surgery for adults with CHD delivered within the NWCHDN at LHCH, excluding patients whose care is delivered elsewhere because of patient choice or for clinical reasons.	Less than 85% cardiac surgery for adults with CHD delivered within the NWCHDN at LHCH, excluding patients whose care is delivered elsewhere because of patient choice or for clinical reasons.

January 2019	All non-cardiac surgery for adults with CHD delivered within the NWCHDN at the appropriate centre, excluding patients whose care is delivered elsewhere because of patient choice or for clinical reasons.	Less than 85% non-cardiac surgery for adults with CHD delivered within the NWCHDN at the appropriate centre, excluding patients whose care is delivered elsewhere because of patient choice or for clinical reasons.
January 2019	All inpatient admissions for adults with CHD delivered within the NWCHDN at the appropriate centre, excluding patients whose care is delivered elsewhere because of patient choice or for clinical reasons.	Less than 85% inpatient admissions for adults with CHD delivered within the NWCHDN at the appropriate centre, excluding patients whose care is delivered elsewhere because of patient choice or for clinical reasons.

University Hospitals of Leicester NHS Trust

- University Hospitals of Leicester NHS Trust will be required to achieve full compliance with the standards within the required timeframes and specified milestones. This includes achieving full co-location for all inpatient paediatric CHD care by April 2020 and increasing surgical activity so that it has a team of at least four surgeons, each undertaking at least 125 operations per year from April 2021.
- NHS England will monitor UHL's progress towards meeting the standards and take commissioning action if it becomes clear that the standards will not be met according to the timescale set out in the implementation schedule. These timescales are informed by the Trust's own plans and the original timetable set out in the standards.

Milestone- no later than	**Deliverable**	**Commissioner action if not delivered**	
		Trust required to produce, and agree with NHS England, a recovery plan.	**Referral to Specialised Services Commissioning Committee for decision whether to terminate the contract to provide level 1 CHD services.**
April 2018	Surgical activity for the year 2017/18 at least 375 operations.	Surgical activity less than 356.	Surgical activity is less than 337.
	Surgeons undertaking at least 125 operations per year.	One or more surgeons undertook fewer than 125 operations in 2018/19.	Fewer than three surgeons in post; no appointment made for replacement(s).
April 2019	Surgical activity for the year 2018/19 at least 403 operations.	Surgical activity less than 382.	Surgical activity is less than 362.
	Three surgeons undertaking at least 125 operations per year.	One or more surgeons undertook fewer than 125 operations in 2018/19.	Fewer than three surgeons in post; no appointment made for replacement(s).
April 2020	Surgical activity for the year 2019/20 at least 435 operations.	Surgical activity less than 418.	Surgical activity is less than 402.

	Three surgeons undertaking at least 125 operations per year.	One or more surgeons undertook fewer than 125 operations in 2019/20.	Fewer than three surgeons in post; no appointment made for replacement(s). One or more surgeons undertook fewer than 125 operations a year averaged across 2018/19 or 2019/20.
	Full co-location achieved for all inpatient paediatric CHD care.		Full co-location not achieved for all inpatient paediatric CHD care.
April 2021	Surgical activity for the year 2020/21 at least 471 operations.	Surgical activity less than 453.	Surgical activity is less than 435.
	Three surgeons undertaking at least 125 operations per year.	One or more surgeons undertook fewer than 125 operations in 2020/21.	Fewer than three surgeons in post. One or more surgeons undertook fewer than 125 operations a year, on average across the years 2018/19, 2019/20 and 2020/21.
	Fourth surgeon appointed and in post.		No appointment made for fourth surgeon.
April 2022	Surgical activity for the year 2021/22 at least 500 operations.	Surgical activity less than 487.	Surgical activity is less than 475.
	Four surgeons undertaking at least 125 operations per year.	Fewer than four surgeons in post. One or more surgeons undertook fewer than 125 operations in 2021/22.	Fewer than three surgeons in post.

Royal Brompton and Harefield NHS Foundation Trust

- The Royal Brompton and Harefield NHS Foundation Trust will be required to develop and deliver a credible solution for meeting the co-location requirements for its paediatric services. RBH should develop its plans (working with potential partners as appropriate) following Treasury guidance for preparing a Public Sector Business Case and using the five case model.
- The Royal Brompton and Harefield NHS Foundation Trust will be required, as part of its planning process, to develop and deliver a detailed plan with clear milestones, that will achieve full co-location for all RBH paediatric specialist services by April 2022.

NHS England will monitor RBH's progress towards meeting the standards, and take commissioning action if it becomes clear that the standards will not be met according to the timescale set out in the implementation schedule. These timescales are informed by the Trust's own plans and the original timetable set out in the standards. NHS England will expect the following:

- Strategic Outline Case prepared by the Trust, supported by NHS England and submitted for approval by 30 June 2018
- Outline Business Case prepared by the Trust, supported by NHS England and submitted for approval by 30 November 2019
- Full Business Case approved by 30 August 2021

Milestone- no later than	**Deliverable**	**Commissioner action if not delivered**	
		Trust required to produce, and agree with NHS England, a recovery plan.	**Referral to Specialised Services Commissioning Committee for decision whether to terminate the contract to provide level 1 CHD services.**
June 2018	Strategic Outline Case (SOC) prepared by the Trust, supported by NHS England, and submitted for approval.		SOC not submitted.
April 2019	Early priorities for joint working implemented.		

	Detailed plan to achieve full co-location for all inpatient paediatric specialist services.	Co-location plan not delivered.	Further slippage to delivery of co-location plan vs recovery plan.
November 2019	Outline Business Case (OBC) prepared by the Trust, supported by NHS England, and submitted for approval.		OBC not submitted.
August 2021	Full Business Case.		Approved FBC not delivered.
April 2022	Full co-location achieved for all inpatient paediatric specialist services.	Full co-location not achieved for all RBH paediatric specialist services.	Full co-location not achieved for all inpatient paediatric CHD care.

Newcastle Upon Tyne Hospitals NHS Foundation Trust

NHS England will further consider its commissioning approach for both the CHD and the heart transplant service at NUTH from March 2021 onwards, and will confirm its plans by no later than April 2019.

- NUTH will be required to develop and deliver a plan to increase surgical activity so that it has a team of at least three surgeons, each undertaking at least 125 operations per year, within the required timeframes, and specified milestones.
- NUTH will not be required to meet the 2019 deadline for full co-location for paediatric cardiac services but will be required to meet these standards, if NHS England confirms a plan to commission level CHD services beyond April 2021.

NHS England will monitor NUTH's progress towards meeting the standards, and take commissioning action if it becomes clear that the standards will not be met according to the timescale set out in the implementation schedule. These timescales are informed by the Trust's own plans and the original timetable set out in the standards.

Milestone- no later than	**Deliverable**	**Commissioner action if not delivered**	
		Trust required to produce, and agree with NHS England, a recovery plan.	**Referral to Specialised Services Commissioning Committee for decision whether to terminate the contract to provide level 1 CHD services.**
February 2018	Growth plan to increase surgical activity to at least 375 operations a year by 2019/20.	Plan not delivered.	Further slippage to delivery of plan vs recovery plan.
April 2019	NHS England to produce a commissioning plan for CHD services including advanced heart failure and heart transplant for children and adults with CHD.	n/a	n/a
April 2020	Surgical activity for the year 2019/20 at	Surgical activity less than 365.	Surgical activity is less than 356.

	least 375 operations.		
	Three surgeons undertaking at least 125 operations per year.	One or more surgeons undertook fewer than 125 operations in 2019/20.	Fewer than three surgeons in post.
To be confirmed if long term commissioning of level 1 CHD confirmed.	Full co-location achieved for paediatric cardiac services.		Full co-location not achieved for all inpatient paediatric CHD care.

NHS England

Paediatric Critical Care and Specialised Surgery in Children Review

Appendix C

Paediatric critical care and ECMO: interim update

June 2017

Contents

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Executive summary

NHS England is undertaking a review of paediatric critical care and specialised surgery in children. This pack focuses on critical care, as well as Extracorporeal Membrane Oxygenation (ECMO). Data on specialised surgery in children is the subject of a separate analysis.

Paediatric critical care is a highly valued specialised service that saves the lives of children, costing around £230m per year. It delivers high quality outcomes, but there is evidence to suggest that critical care services are not sustainable in their current form. Significant peaks in winter and high average occupancy creates real pressures on units during some parts of the year.

To further understand these pressures, the review has undertaken analysis of data supplied by paediatric intensive care units to the Paediatric Intensive Care Audit Network (PICANet). The analysis shows that demand for these services is changing, with relatively stable admissions but increasing average length of stay. There are significant seasonal peaks, driven largely by unplanned respiratory admissions, and a small number of technology-dependent children accounting for a large proportion of resources. Most of the increased demand seen over recent years has been for the most basic levels of intensive care.

This data suggests that some children could be moved out of paediatric intensive care units into more appropriate settings. These settings may also be closer to the child's home. To enable this shift, however, a new model of care for these services is needed.

Additional modelling has been undertaken to understand what the impact of these pressures would be if patients continued to be treated in the same place. This shows that the model of care in its current form will not be sufficient to meet future demand. Developing a new model of care that ensures that patients are treated in the right place could improve patient experience as well as make services affordable in the future.

The review is now using the data presented in this pack, as well as extensive stakeholder engagement, to develop a proposed future model of care. Comments on the analysis are welcomed and can be sent to england.paedsreview@nhs.net.

1. Introduction

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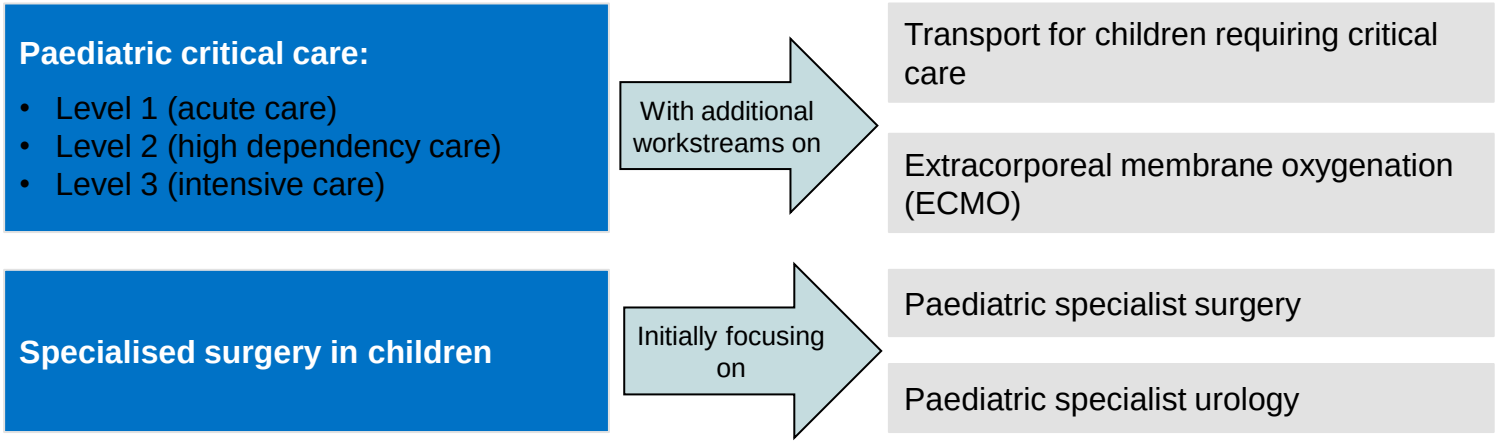
1.1 NHS England is conducting a review of paediatric critical care and specialised surgery in children

NHS England's review aims to develop a sustainable model of care for paediatric critical care and specialised surgery in children that enables the current high quality of services to be delivered in an affordable way into the future.

The review is focusing on the following areas:



The review aims to develop a vision and proposals for these services, including the shape of a future model of care, and consult on these proposals by the end of the year.

The review's terms of reference can be found on the NHS England webpage.

This slide pack focuses on paediatric critical care and ECMO. The review has been able to make quicker progress in assessing demand and capacity in these areas because it has analysed existing data from the Paediatric Intensive Care Audit Network (PICANet).

Data on specialised surgery in children is currently the subject of separate analysis.

1.2 So why do we need a review, and what elements of these services need to change?

Paediatric critical care is a highly valued service that saves the lives of children in England every day. It is a specialised service, meaning that it is commissioned centrally by NHS England, although some care delivered outside of Paediatric Intensive Care Units (PICUs) is commissioned by CCGs. It is high cost, with annual expenditure of around £230m for the specialised elements alone, and delivers outcomes that are globally recognised as high quality through 23 units spread across England.

There is, however, evidence to suggest that, although quality is high, the services themselves are not sustainable in their current form. Significant peaks in winter and high average occupancy creates real pressures on units during some parts of the year. Early discussions with stakeholders identified a number of challenges that the review needs to address.

Paediatric critical care	• Significant seasonal pressures every winter • Balancing emergency / elective demand • Possible variation in admissions criteria across England • Increasing morbidity in those children who survive • Variable provision of high dependency care • Staffing critical care units to the appropriate levels
ECMO	• Reported inequity of access to respiratory ECMO • A need to transfer patients a significant distance to receive care • Lack of agreement about the model of service provision, the role of mobile ECMO, and the need for minimum standards • Variable referral arrangements • Seasonal demand for ECMO services

To explore these challenges further, the review has undertaken analysis of critical care activity using data from the Paediatric Intensive Care Audit Network (PICANet), the national clinical audit which has been collecting data on paediatric intensive care since 2002. The analysis presented here therefore focuses on care delivered in PICUs. Data on high dependency care is also included in this analysis where that care has been delivered on a PICU.

1.3 Our analysis of the data draws highlights the current pressures on critical care

NHS England's analysis supports an initial hypothesis that – if the model of paediatric critical care does not change – the services will not be sustainable or affordable in the medium to long term. It demonstrates that, although admissions to paediatric critical care have remained relatively stable over the last three years, the service is facing increasing pressures:

- Some of these pressures are seasonal, with peaks in winter, driven largely by unplanned respiratory admissions, and troughs in the summer.
- The nature of the PIC population appears to be changing, with an increasing average length of stay and a small number of technology-dependent children accounting for a significant proportion of resources.
- Most of the increase in bed days seen over the last five years has been in those children who require the most basic levels of intensive care.
- Units vary in their size and case mix, which may affect their ability to absorb unplanned demand. Units also vary in their rates of ventilation, which may suggest differences in admissions criteria as well as variation in case mix.

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To further determine the extent of these pressures, the review has undertaken modelling to project what the impact of these pressures would be if the model of care does not change. It shows that **the model of paediatric critical care in its current form will not be sufficient to meet future demand.**

The review has noted the following from this analysis:

- Some children could be moved out of PICUs into more appropriate settings that are enhanced in order to manage ill children outside of intensive care
- These settings are likely to be a better environment for children and closer to the child's home
- **A new model of care is required in order to facilitate this shift.**

1.4 NHS England would welcome your comments on this analysis to support the next stage of the review

The review is now using the data presented in this pack, as well as extensive engagement with stakeholders, to develop proposals for a future model of care that delivers the high quality of services that we currently see in a way that is affordable into the future.

We will be developing and testing this model over the coming months, working with the commissioners, providers and clinicians that will be involved in its delivery, as well as the patients and parents who will experience these services. We will be considering how a future model of care could enable those patients who could more appropriately be treated outside of intensive care, such as those patients on long term ventilation, to move to a more appropriate environment that may also be closer to home.

Comments on this analysis and our initial conclusions are welcomed, and can be sent to england.paedsreview@nhs.net. They will be considered as the review develops. There will be further opportunities to engage in the review over the coming months; please visit NHS England's webpage or send an email to the address above and ask to be added to our mailing list.

A note on the data

- This information pack uses data from the PICANet which has been analysed and interpreted by NHS England.
- It is important to note that the current analysis only considers English patients being treated in English units. NHS England is aware that some patients from Scotland, Wales and Northern Ireland travel to English units for treatment, but this initial analysis focuses on English demand. Further analysis may consider patient flows between administrations.
- Data submitted to PICANet, and therefore this analysis, is on the basis of funded beds reported by the units. We are aware that, at times, capacity may vary within a unit depending on staff resource and case mix but also on local commissioning arrangements.
- The methodology used by NHS England in this analysis can be found in appendix 2.

2. Context

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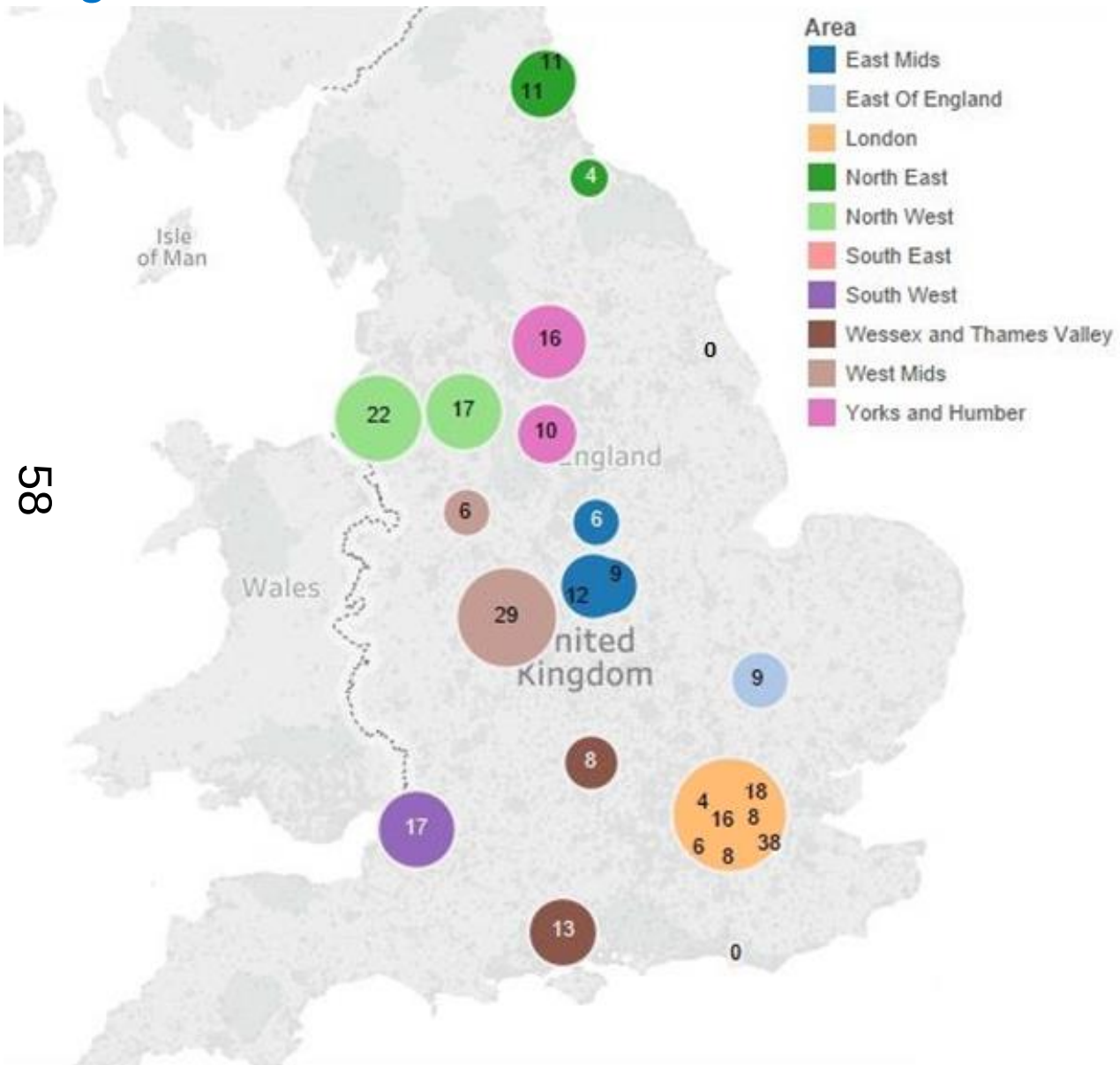
2.1 There are 23 Paediatric Intensive Care Units (PICUs) in England



The circles on this map represent the location of funded PICUs.

The numbers, and the diameter of the circles, reflect the number of funded beds in the unit, as reported to PICANet in May/June 2015.

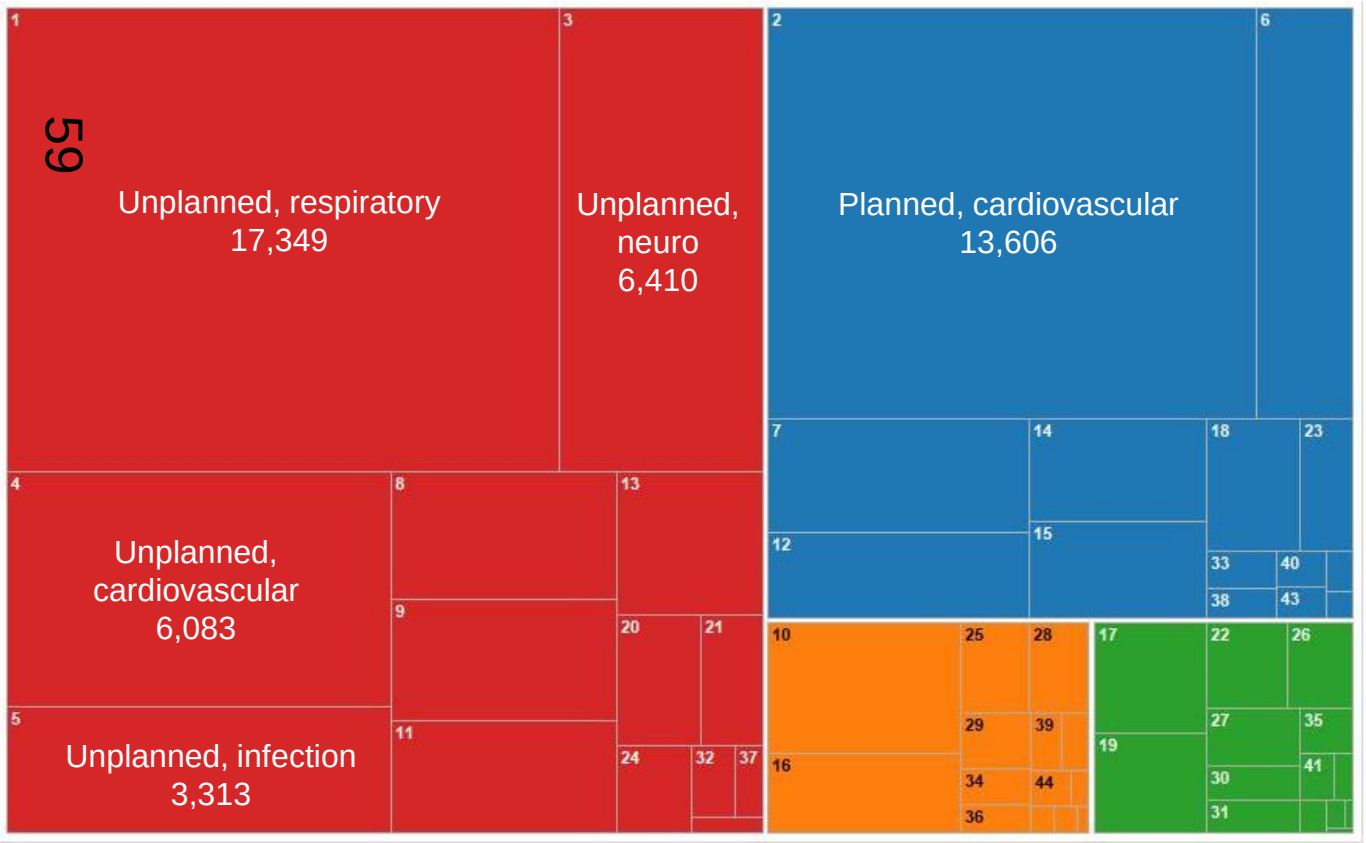
Some units have been grouped together due to their geographical proximity. It is possible that during busy periods the number of beds on units may be increased.

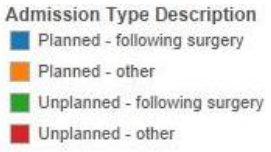
The units have been colour-coded according to the hub in which they sit. There are ten specialised commissioning hubs across England, which are listed next to the map. Some of the analysis in the remainder of this pack is undertaken at hub level.

2.2 Children with cardiac and respiratory conditions make up the majority of admissions to PIC services

2011 – 2015 data shows that there were both planned and unplanned admissions to PIC services. Planned admissions include those resulting from children admitted following surgery (elective procedure), and unplanned admissions can result from children being admitted in an emergency, for example from A&E, another ward or another hospital, or unexpectedly following surgery.

- For **unplanned admissions** the main users are children with respiratory conditions.
- For **planned admissions** the main users are children with cardiovascular conditions.





This infographic shows the five largest diagnostic categories. The other diagnostic categories that can not easily be shown here are listed in appendix 3 and correspond to the numbers in this infographic. They are ranked from 1 to 56 based on the number of admissions to PICUs.

3. Why are units under increasing pressure?

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3.1 Demand for PICU is changing: admissions have remained relatively stable whilst bed days have increased

In order to understand the reasons for changing pressures on PICUs, the growth in admissions and growth in bed days were examined. The graph below demonstrates that between 2011 and 2015:

- The increase in admissions is in line with the national demographic growth rate (0.8%) and therefore represents a negligible real increase in admissions; however
- There was a 5% increase annually in bed days used.

This suggests that pressures on PICUs are caused by an increasing average length of stay as opposed to treating a greater number of children on PICUs. The review will need to explore the reasons for this, which may include the changing needs of children, particularly those who require mechanical support, and other factors such as delayed discharges.

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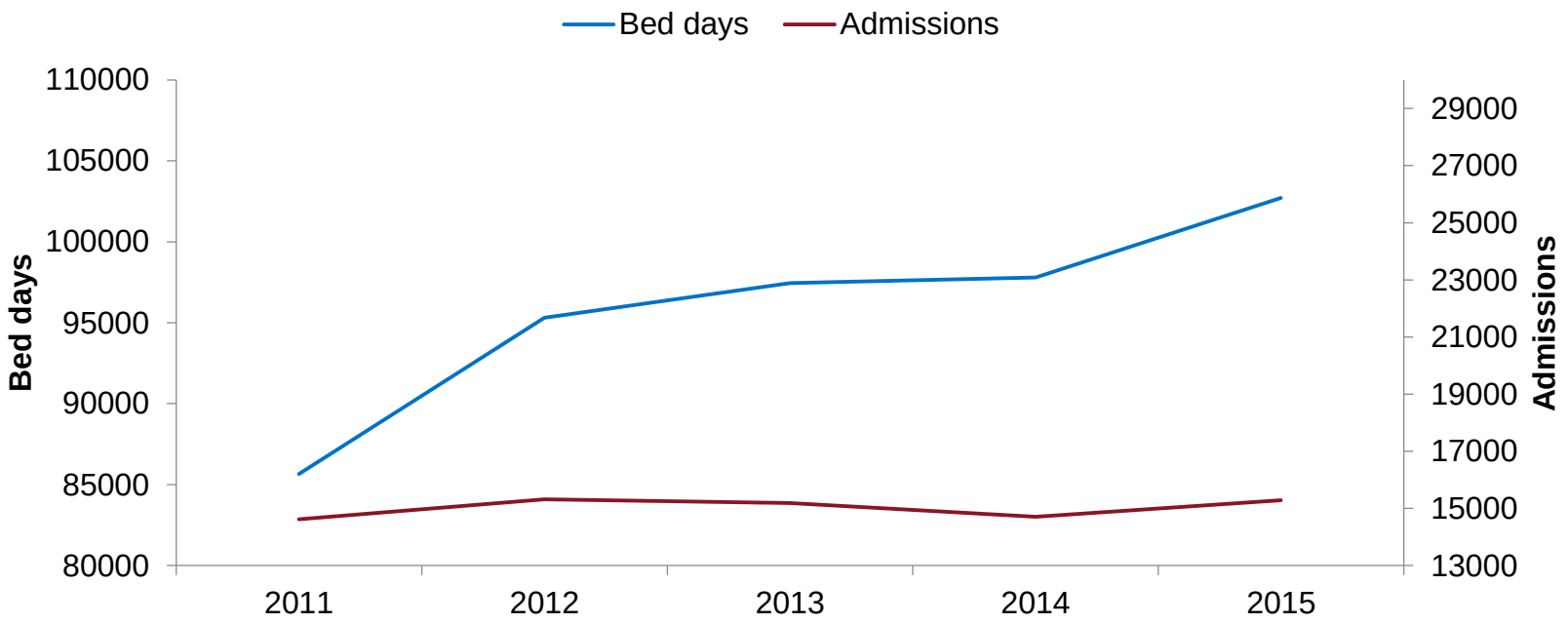
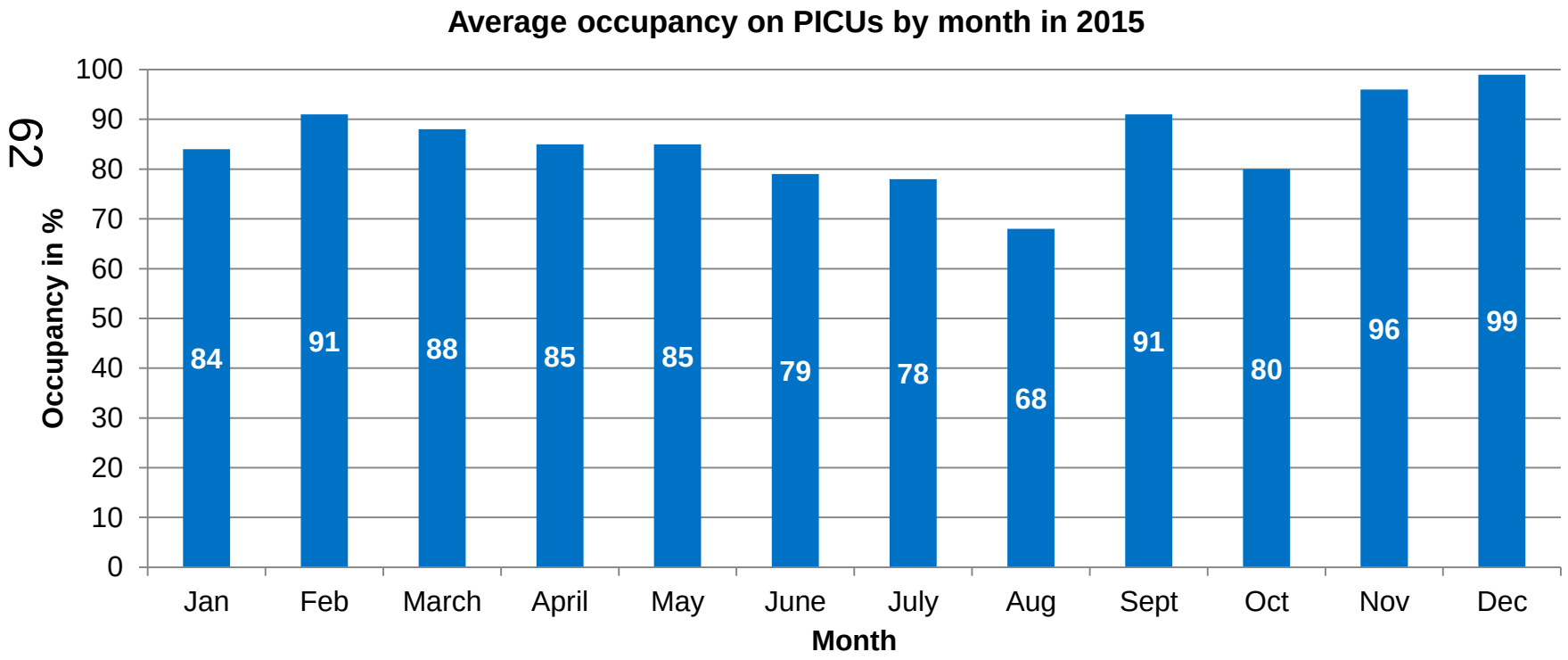
2011 to 2015 increase in bed days and admissions to PICUs



3.2 On an annual basis, PICU activity peaks in the winter months

There is seasonal variation in demand for PICU beds across the country. This graph shows that, in 2015, there was a peak in November and December. We know from PICANet data that these peaks occur annually; this graph shows data from a single year, however, because showing a longer time series would not account for the changes in bed numbers over that period.

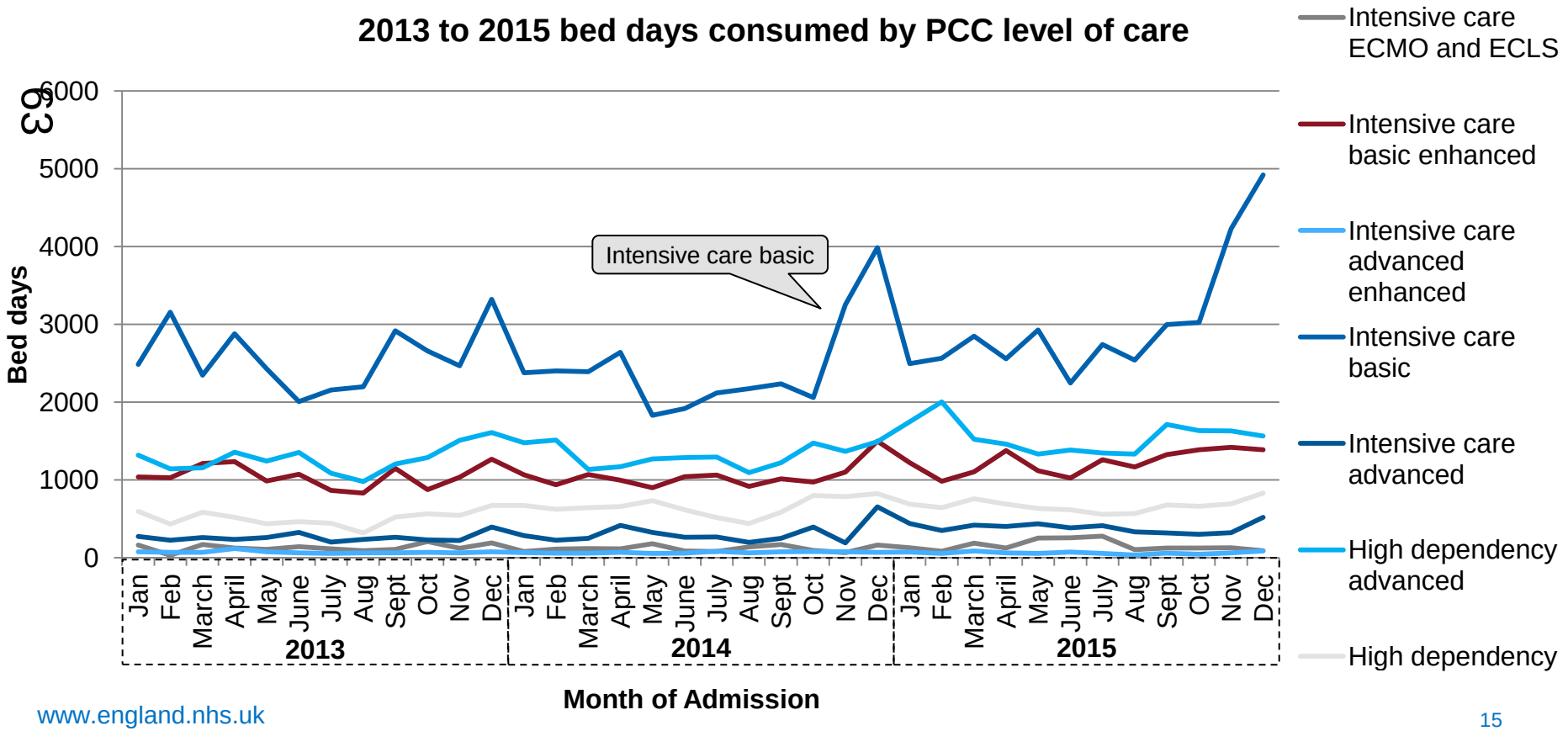
The graphs on subsequent slides show what is driving these seasonal peaks.



3.3 The winter admissions peak is driven by an increase in the number of children requiring basic intensive care…

Between 2013 and 2015, the highest proportion of bed days used on PICUs were occupied by children requiring basic intensive care. The seasonal demand was driven by an increase in the number of children requiring this level of care.

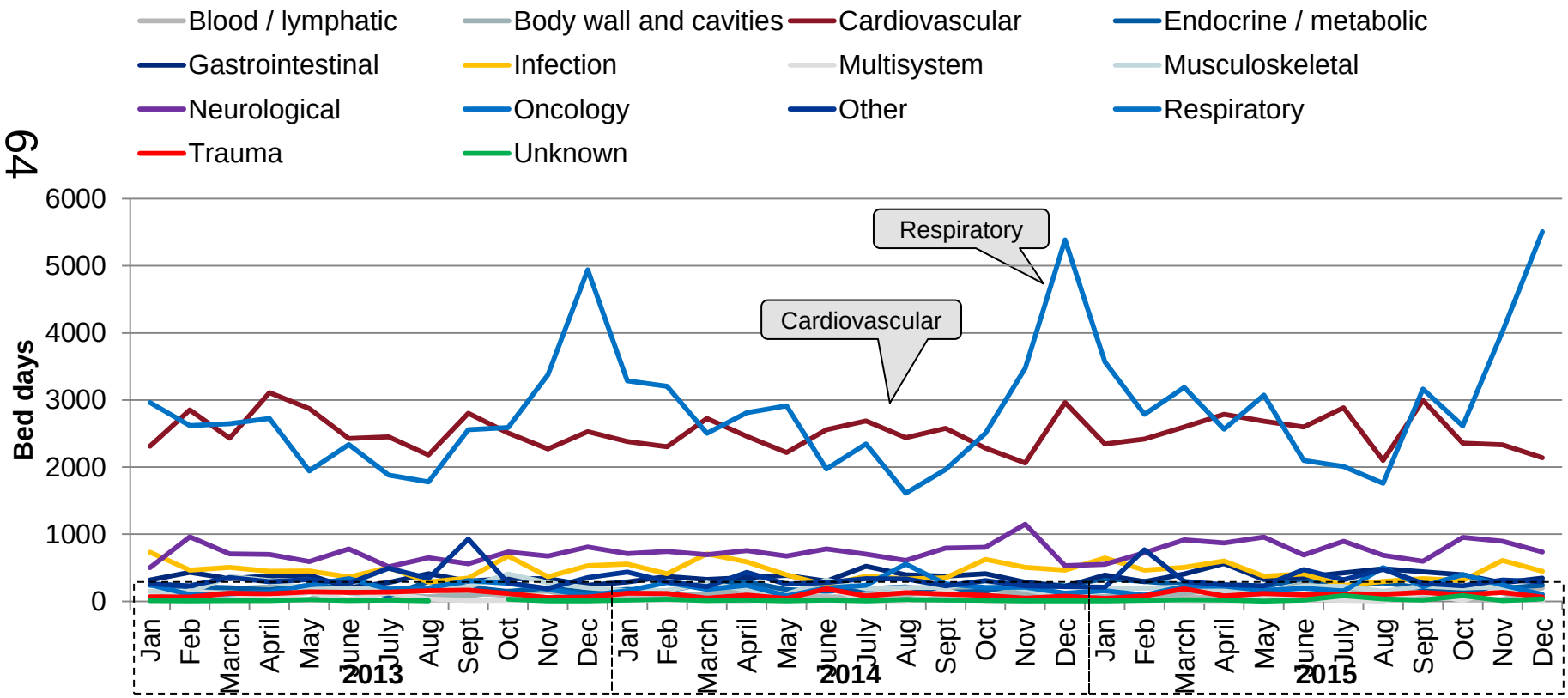
As can be seen from the graph below, children requiring the highest levels of intensive care (ECMO, advanced, and advanced enhanced) occupied the lowest volume of beds on PICUs between 2013 and 2015, and there was significantly less seasonal variation amongst these groups. As part of the development of a new model of care, the review will consider the optimal location for the provision of basic intensive care throughout the year, and how the increased demand for basic intensive care in winter can best be met.



3.4 …and is also driven by increases in respiratory illness during the winter months

The graph below shows the bed days used on PICUs for each diagnostic category between 2013 and 2015, and shows that the highest number of bed days used was due to respiratory infections such as bronchiolitis or pneumonia. An increase in these respiratory infections also drives the peak in admissions seen in November and December. Cardiovascular admissions accounted for the second highest volume of bed days used, but the data shows a small decrease in cardiovascular admissions in winter; this may be due to a reduction in the number of elective operations carried out over this period.

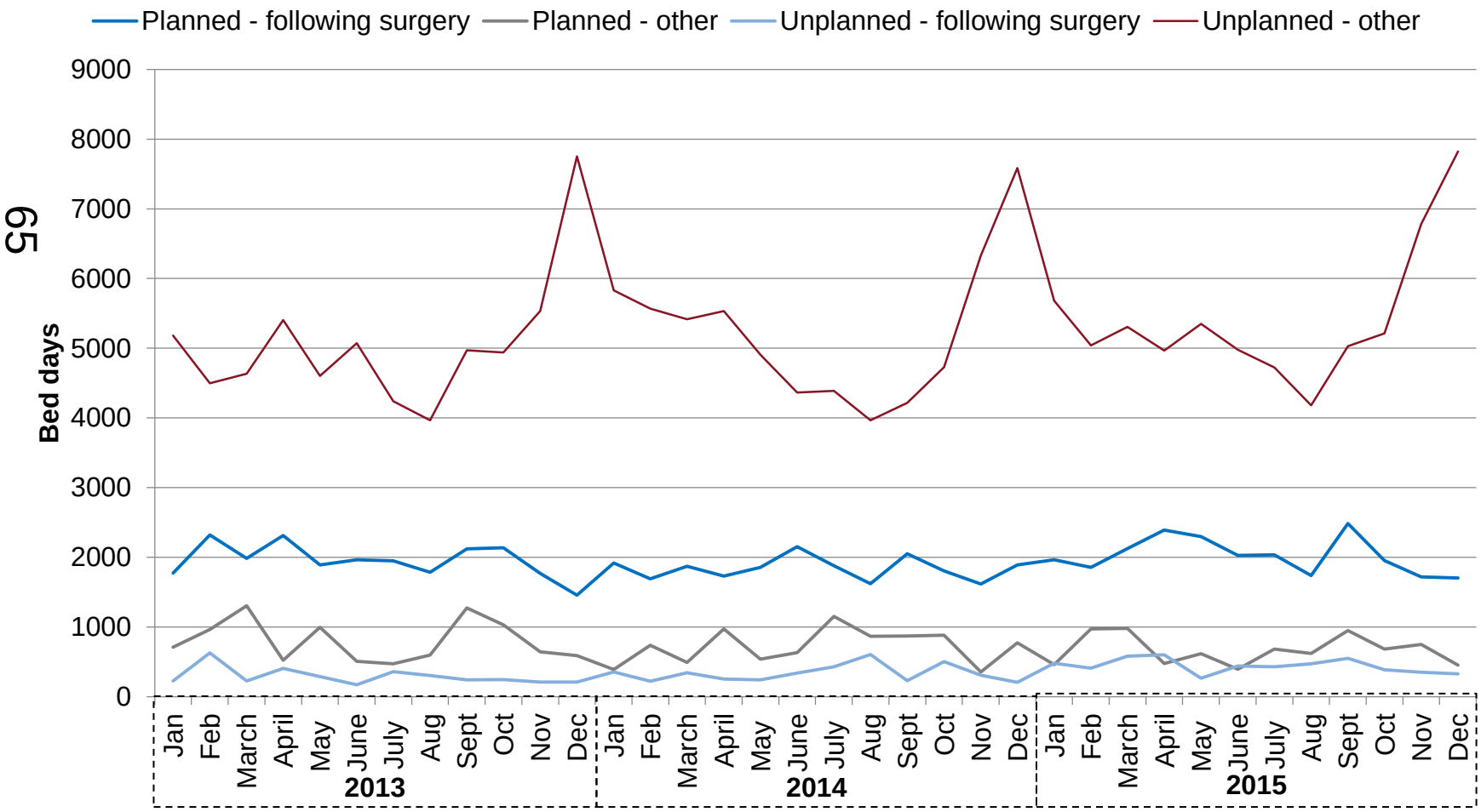
Bed days consummed by diagnostic category from 2013 to 2015, by month



3.5 The number of unplanned admissions significantly increases during winter

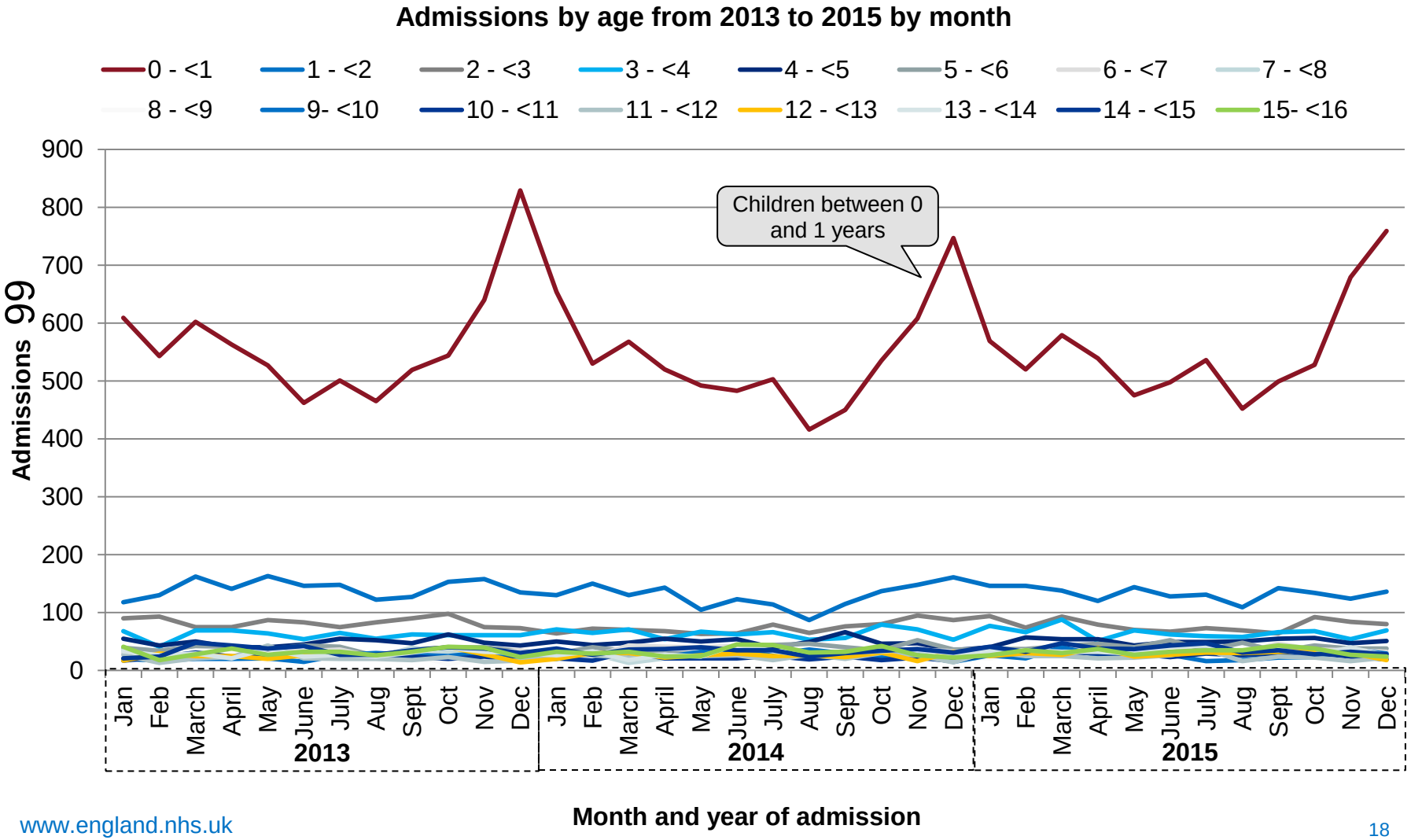
The previous slides show that peaks in demand for basic intensive care, and respiratory conditions, drive seasonal pressures. The graph below demonstrates that this activity is largely unplanned.

Bed days consumed by planned and unplanned admissions from 2013 to 2015



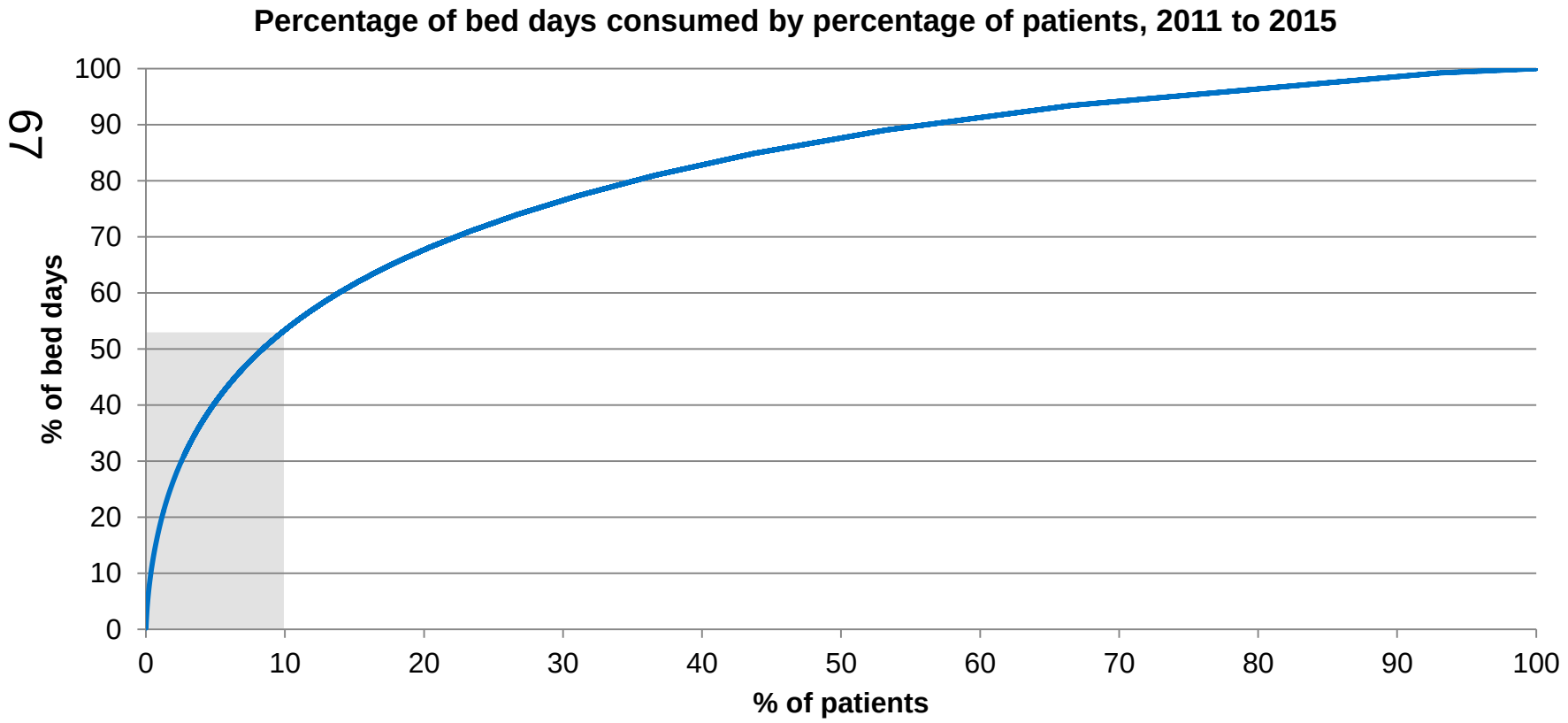
3.6 Most of this seasonal peak in activity is seen in children under the age of one

The data shows that the peaks in demand for unplanned, basic intensive care are largely driven by children who are under one year old.



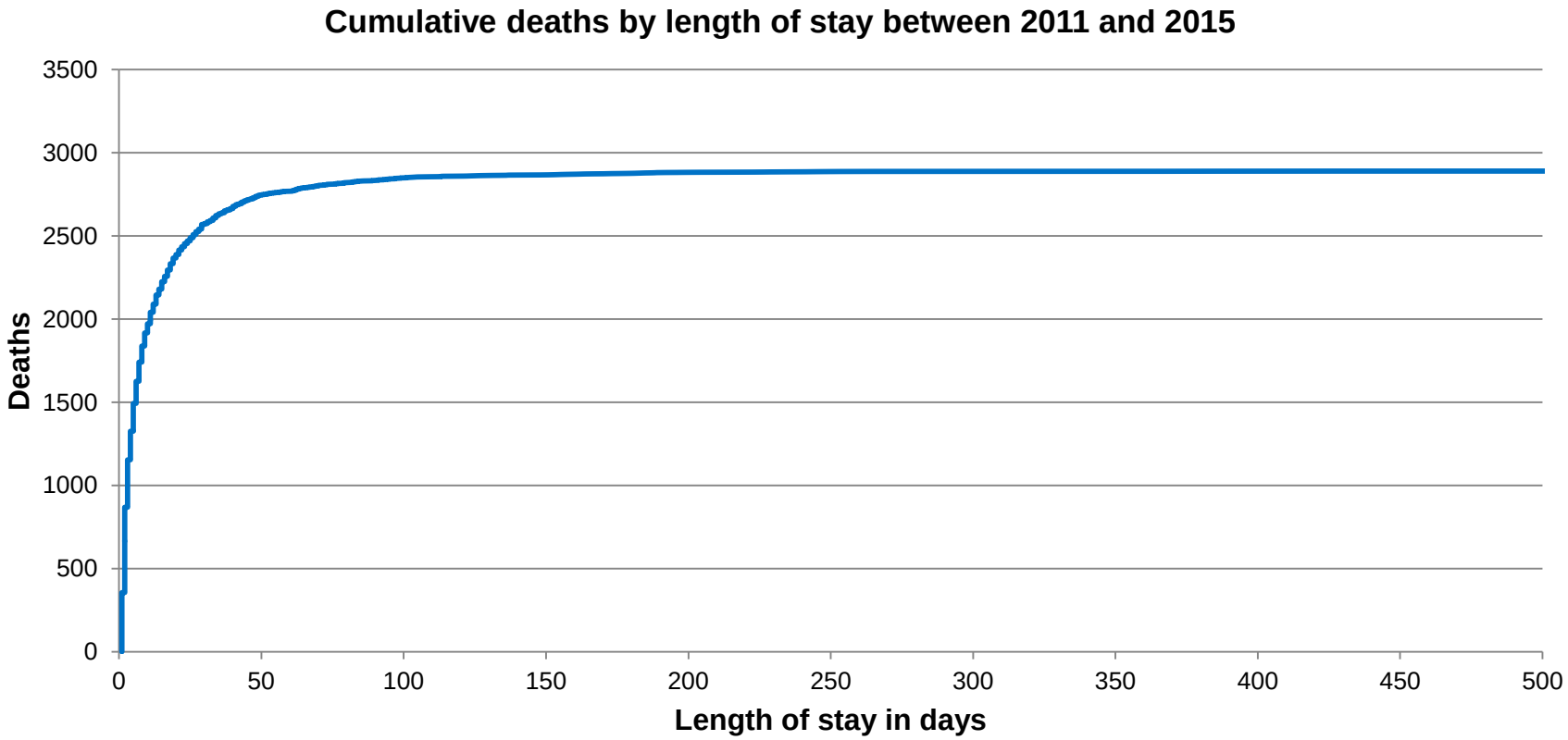
3.7 Ten per cent of children admitted to PICUs use more than half of resources

2011 to 2015 data from PICANet shows that 10% of children admitted to PICUs used over 50% of PICU resources . The review will be considering the nature of this cohort of patients, which is likely to be children with long-term, complex needs, and whether alternative care settings could benefit these children and their families as well as help to optimise the use of PICU beds. This is particularly important given the potential for further increased demand for critical care from children who have a life-limiting illness but who are surviving longer.



3.8 Most deaths that occur on PICUs happen after a relatively short stay

The graph below shows cumulative deaths of English patients on PICUs in England, between 2011 and 2015, arranged by length of stay. The steep slope on the left hand side of the graph suggests that most deaths occur after a relatively short stay on a PICU.



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3.9 The number of bed days used to care for very poorly children who do not survive is growing

From 2011 to 2015, there was a 6% growth in the proportion of total days that were dedicated to caring for very poorly children who did not survive because of the terminal or complex nature of their condition. This could be a result of patients with more complex care needs being treated on PICUs.

Where individual units have a higher number of days spent caring for children who did not survive, this could indicate that they provide more complex care and admit children who are much sicker, compared to elsewhere.

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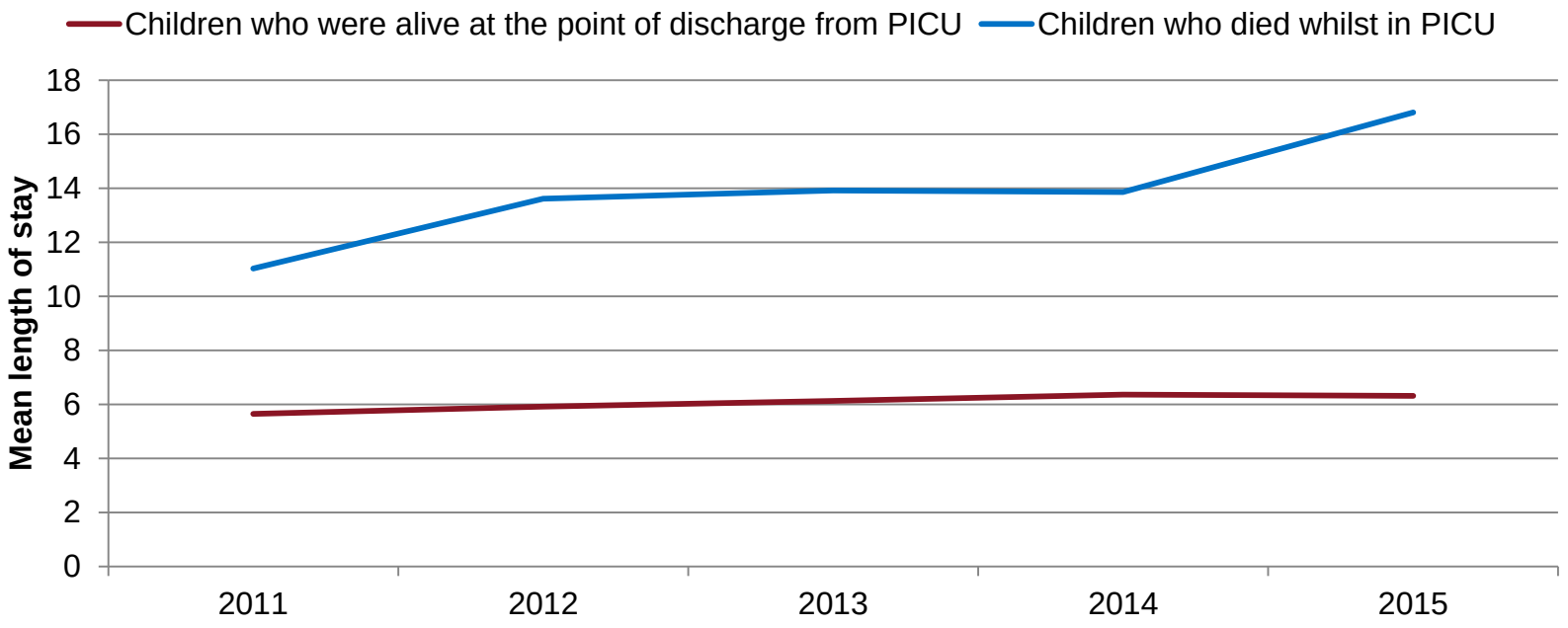
Mean length of stay on PICU for children who survived and children who died between 2011 and 2015



4. Variation in the provision of care

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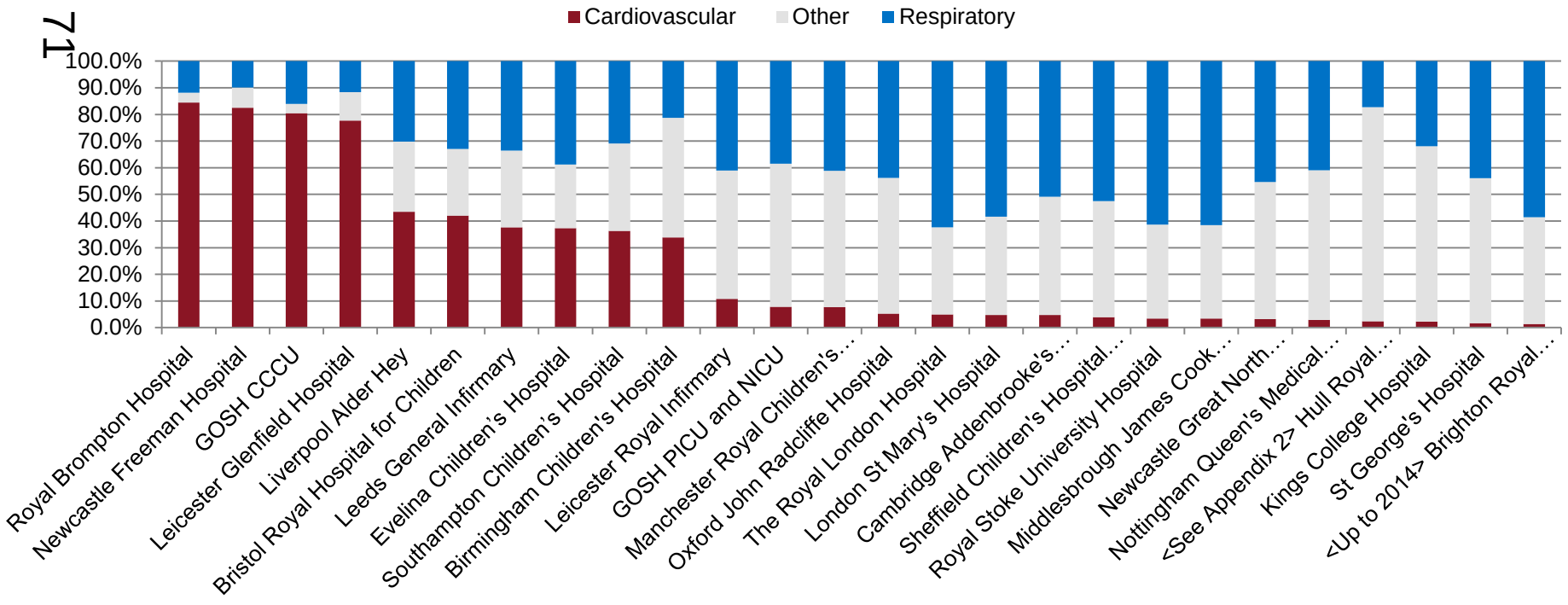
4.1 Units have a different case mix of patients, something that may affect their ability to absorb unplanned demand

The graph below shows the proportion of bed days used by the two main diagnostic categories, cardiovascular and respiratory, on PICUs. Most units are dominated by either cardiac or respiratory patients. The four PICUs to the left of the graph are primarily cardiac PICUs.

Cardiac admissions tend to be predominantly planned following surgery, whilst respiratory admissions tend to be unplanned. Different PICUs will therefore have different abilities to respond to increases in emergency admissions, for example in winter.

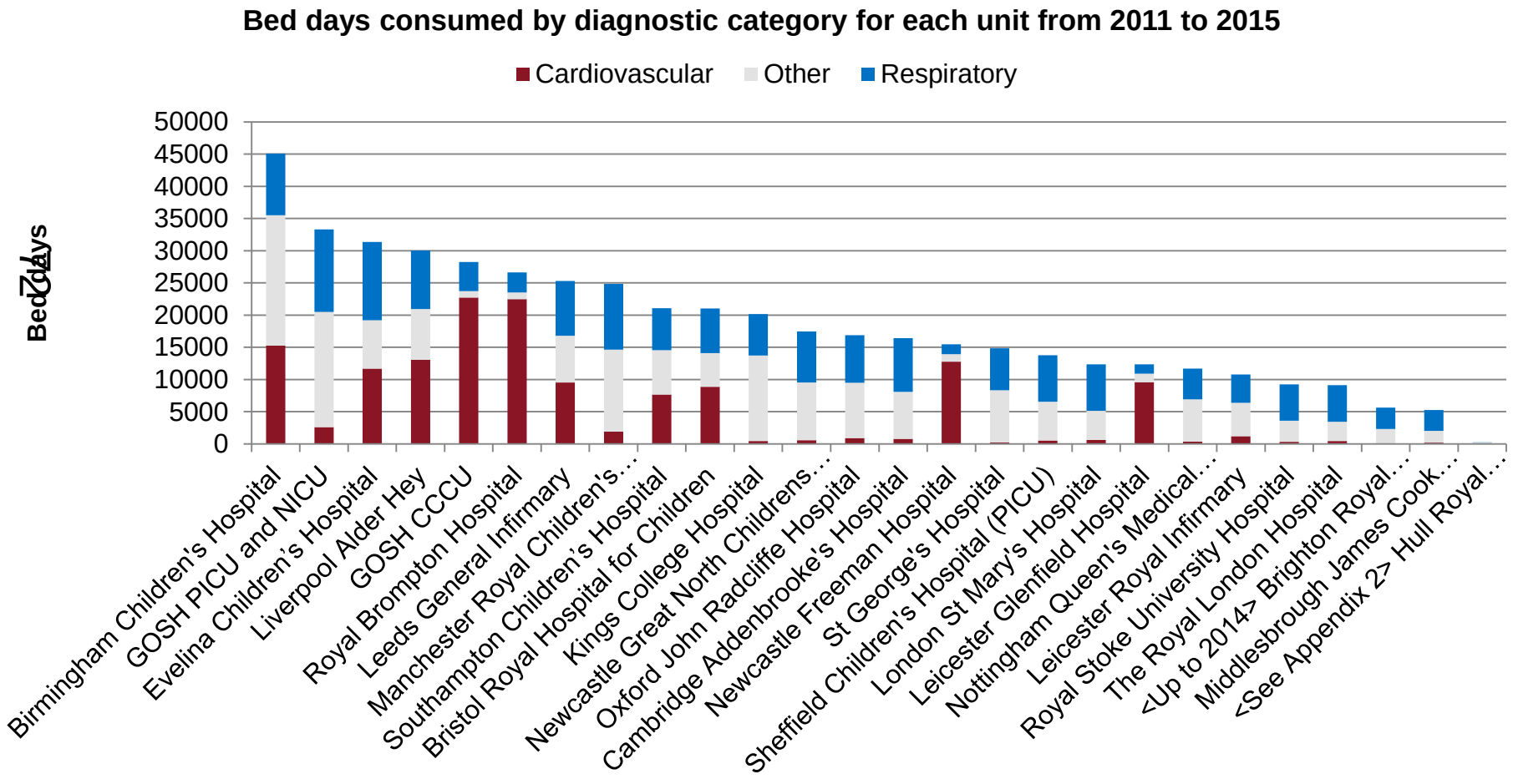
Percentage of bed days by diagnostic category for each unit from 2011 to 2015



*Note that this data has been normalised and does not show volume per provider

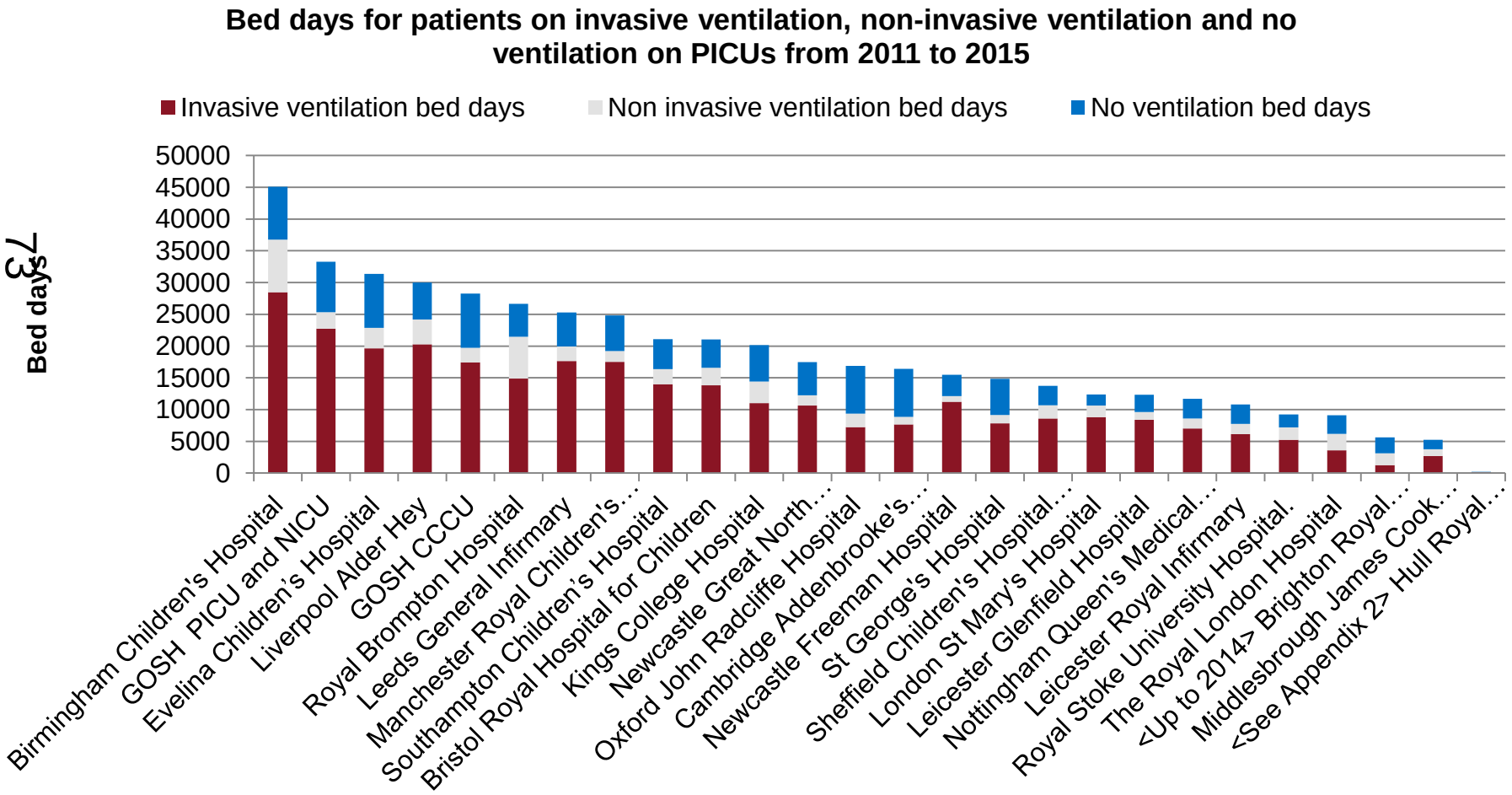
4.2 Different units also have varying capacity, which may in turn impact on their ability to absorb unplanned demand

The graph below shows the number of bed days consumed on each unit, subdivided by diagnostic category. The number of bed days may correlate with the unit's ability to absorb unplanned demand, with larger units possibly more able to do so. There can be significant differences in case mix and complexity of surgery carried out in the largest centres, which may increase the average length of stay for some patients.



4.3 The number of bed days used by patients undergoing invasive ventilation varies by unit

In 2011 to 2015, the number of bed days that included invasive or non-invasive ventilation varied across the country as shown in the graph below. This variation may reflect differing case-mix of patients, or different admissions criteria across the country.



5. Extracorporeal Membrane Oxygenation (ECMO)

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5.1 There is variation in the number of patients from each hub who receive ECMO

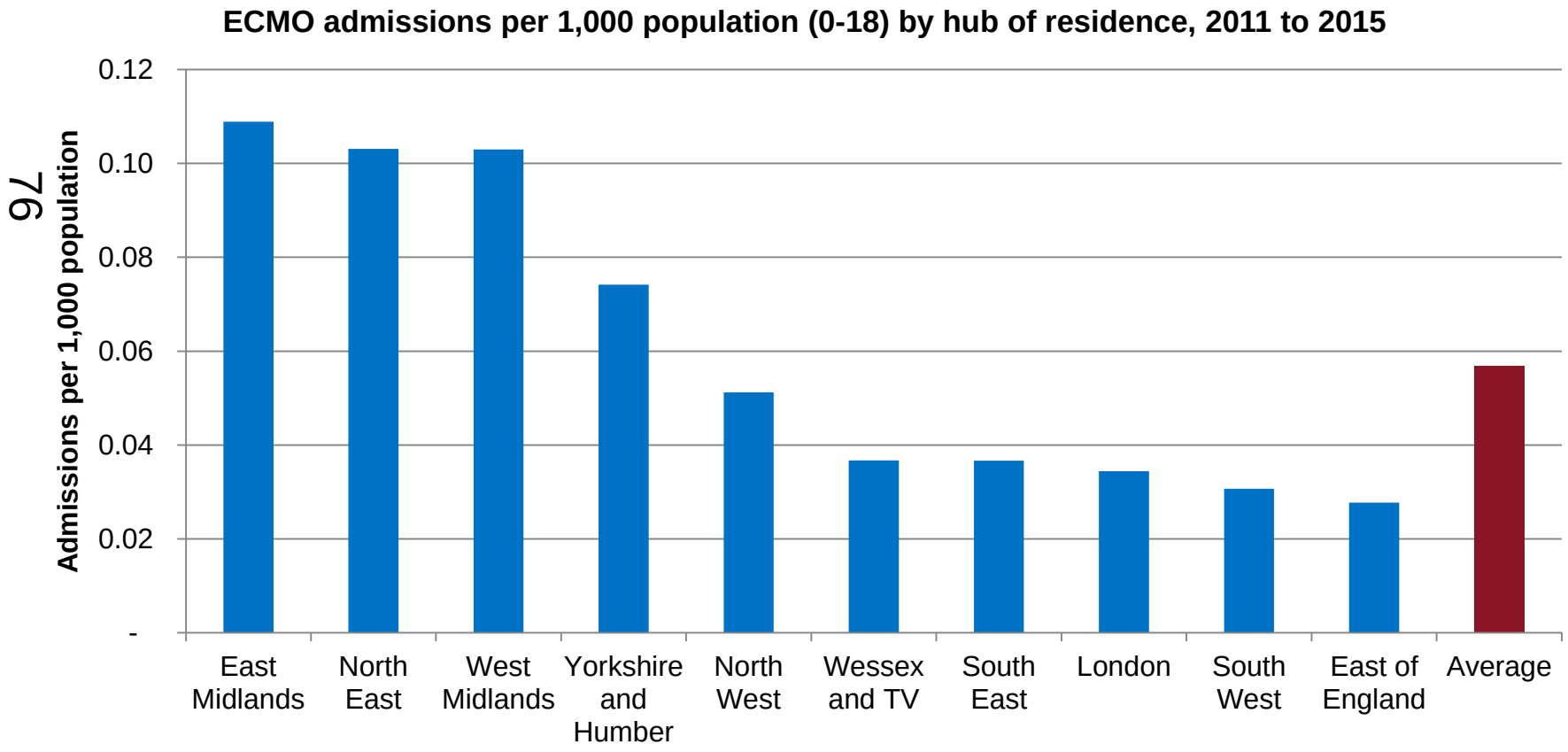
This matrix shows the volume of paediatric admissions from each hub who received ECMO (respiratory and cardiac) between 2011 - 2015, and where they were treated. For example, two children from the North East were treated in the East Midlands, and 62 within the North East. There is variation in the number of patients from each hub receiving ECMO. Note, however, that these are absolute numbers of admissions and are not normalised by population. See the next slide for the number of ECMO admissions by population.

Volume of ECMO admissions by hub of origin and hub of placement, 2011 - 2015

	Hub of placement								
Hub of Patient	East Midlands	London	North East	North West	South West	Wessex and Thames Valley	West Midlands	Yorkshire and Humber	Total
East Midlands	94	7	2	.	.	4	4	1	112
East of England	12	59	3	.	.	1	1	.	76
London	14	124	4	.	.	.	1	.	143
North East	2	.	62	.	.	.	.	.	64
North West	30	3	19	52	.	.	1	.	105
South East	5	42	2	.	.	1	.	.	50
South West	9	8	3	.	22	4	.	.	46
Wessex and Thames Valley	5	11	3	.	.	26	1	.	46
West Midlands	63	7	11	1	.	.	56	.	138
Yorkshire and Humber	45	1	14	3	.	.	2	23	88

5.2 Variation in the amount of ECMO activity still exists when hub population is taken into account

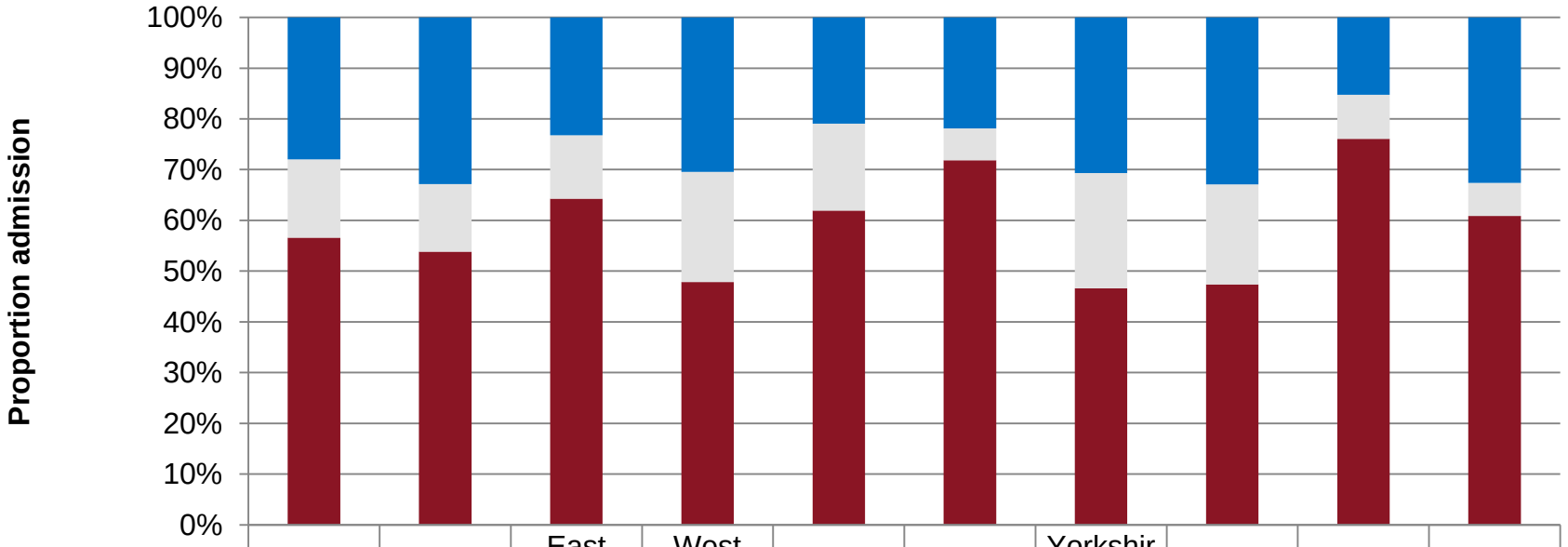
The analysis on the previous page shows ECMO admissions by hub of residence and hub of treatment. However, it is difficult to determine the extent of any variation without also looking at the population of that hub. The graph below therefore shows the level of ECMO admissions per 1,000 population between 2011 and 2015, by the patient's hub of residence. It shows that variation still exists, even when admissions are normalised by population. The review will need to consider whether there is clinical justification for these variations.



5.3 There is a greater proportion of patients receiving cardiac than respiratory ECMO

The analysis below demonstrates that a greater proportion of patients receiving ECMO have a cardiovascular presentation. Further work is being undertaken to determine the respiratory cases that may be counted in the 'other' categories in this data and the reason for any differences between datasets. These differences will be considered during discussions about a future model of ECMO care.

Proportion of ECMO admissions by type, by hub of treatment, 2011 to 2015



	Grand Total	London	East Midlands	West Midlands	North West	North East	Yorkshire and Humber	East of England	South West	Wessex and TV
Respiratory	243	47	26	42	22	14	27	25	7	15
Other	134	19	14	30	18	4	20	15	4	3
Cardiovascular	491	77	72	66	65	46	41	36	35	28

6. Future demand

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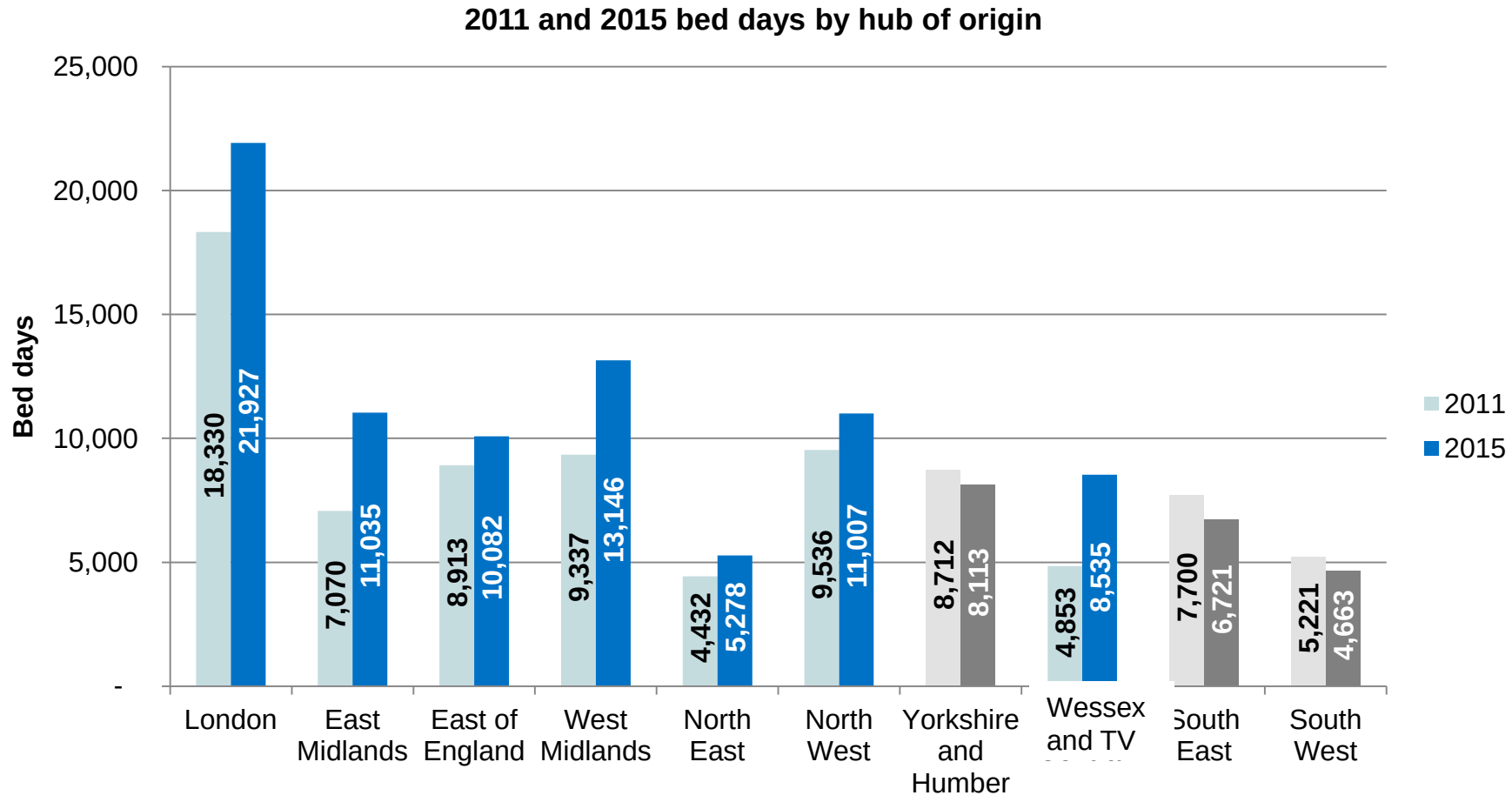
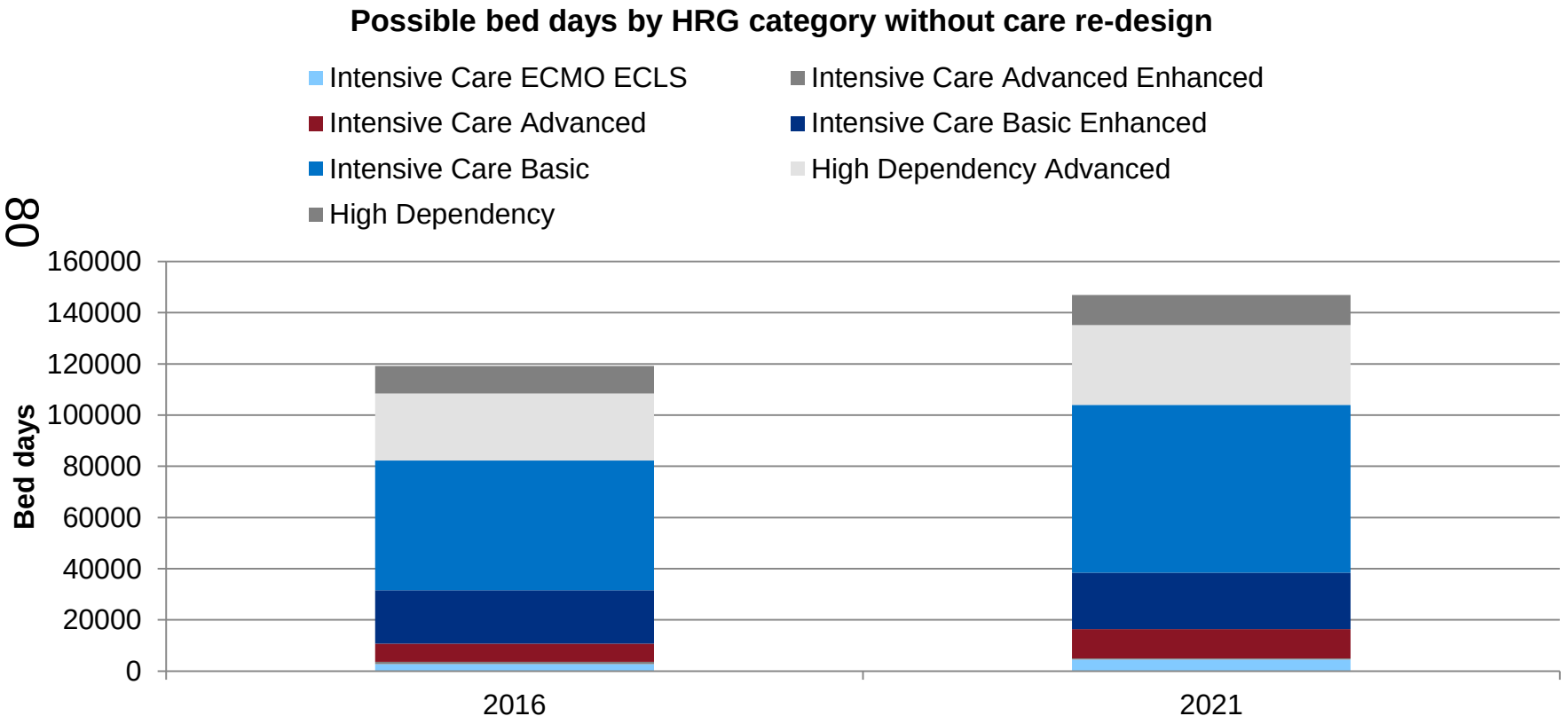
6.1 In most hubs, the number of bed days has increased between 2011 and 2015

This graph shows that the number of bed days consumed nationally increased between 2011 and 2015. Although there is variation by hub, with seven hubs increasing the number of bed days used (in blue) and three decreasing in the same time period (in grey), the overall increase is beyond the population growth rate for that period.



6.2 Our analysis suggests that a new model of care is required to enable us to meet future demand

A new model of care could enable some patients to be treated outside PICUs in an environment that is more appropriate to their needs and that may be closer to their home, which could help make services affordable as well as improve patient experience. This is supported by the modelling shown below, which suggests that most of the increased need would be for high dependency and intensive care basic and intermediate days, rather than for the highest levels of critical care.



(Note that the modelling has apportioned the number of uncoded bed days proportionately across each HRG)

7. Next steps for the review

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7.1 This analysis will help to inform the next stage of the review

The data and analysis in this pack will now be used by the review as it develops its proposals for a future model of care.

The review will be developing and testing this model over the coming months, working with a wide range of stakeholders including commissioners, providers, clinicians and patients and their parents and carers. It will be considering how a future model of care could enable those patients who could more appropriately be treated outside of intensive care, such as those patients on long term ventilation, to move to a more appropriate environment that may also be closer to home. It will also be thinking about the best way to deliver ECMO in future, taking into consideration the current distribution of activity.

This work will also take into account the review of Congenital Heart Disease (CHD) services in England, which is currently out to consultation. The CHD review has identified that, should its proposals be implemented, there would be an impact on both paediatric intensive care and ECMO. The review will therefore need to consider the best way of managing this impact, should the proposals be implemented. More details of the CHD review consultation can be found on the webpage.

The paediatric critical care and specialised surgery in children review welcomes comments on this analysis, and its initial conclusions. They can be sent to england.paedsreview@nhs.net and will be considered as the review develops. You can also use this email address to request to be kept informed of the review's developments, or alternatively please visit NHS England's webpage to find out about further opportunities to engage in the review.

This slide pack focuses on paediatric critical care and ECMO. The review has been able to make quicker progress in assessing demand and capacity in these areas because it has analysed existing data from the Paediatric Intensive care Audit Network (PICANet). Data on specialised surgery in children is currently the subject of separate analysis.

Appendices

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Appendix 1 – Terminology

Some of the terms commonly used in this document are defined below. Please note that cardiac centres order the levels care in the opposite order with Level 1 being highest level of acuity.

Terminology	Definition
Paediatric critical care (PCC)	• Provides care for children with a wide range of conditions who may need a high level of observation or more intensive therapies. There are three levels of critical care unit, as defined below.
Level 1 Paediatric Critical Care Units (PCCUs)	• Located in all hospitals providing inpatient care to children • Level 1 incorporates high dependency care provided in all acute hospitals which have inpatient facilities • Clinical Commissioning Groups (CCGs) are responsible for commissioning Level 1 services
Level 2 PCC units (High Dependency Units – HDUs)	• May be specialist or non-specialist • Level 2 services incorporate high dependency and high dependency advanced critical care. They are commissioned by NHS England when they are in specialist children's hospitals or designated district general hospitals, or if the unit is associated with a PICU.
Level 3 PCC units (Paediatric Intensive Care Units – PICUs)	• 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 • Level 3 units also provide routine planned post-operative care for surgical procedures, or during some planned medical admissions • They are usually located in tertiary centres or specialist hospitals and can provide all levels of care. • Level 3 units are commissioned by NHS England
Extracorporeal Membrane Oxygenation (ECMO)	• A potentially life-saving intervention for babies and children with reversible lung (respiratory) or heart (cardiac) failure, involving the use of an artificial lung (membrane) located outside the body (extra corporeal) that puts oxygen into the blood (oxygenation) and continuously pumps this blood into and around the body.
Bed Days	• As defined by the Quarterly Bed Availability and Occupancy Data Set: an occupied bed day is a hospital bed which has been used for at least one day case admission during the day
Regions	• NHS England has four regions from which services are commissioned. These regions are: North, South, Midlands and East, and London. Regional teams work closely with organisations such as clinical commissioning groups, local authorities, NHS trusts, GP practices etc.
Specialised Commissioning Hubs	• NHS England Specialised Commissioning has ten 'hubs' responsible for commissioning its ~140 services. These hubs sit within the four NHS England regions.

Appendix 1 – Terminology (2)

The following table identifies how the HRG definitions used in this document correspond with new HRG definitions and their description.

2016/17 HRG definitions (used in this analysis)	HRG	Current HRG definition	Description
PCC High dependency	XB07Z	Basic critical care	Monitoring and interventions
PCC High dependency advanced	XB06Z	Intermediate critical care	Monitoring and interventions
PCC Intensive care basic	XB05Z	Advanced critical care 1	Invasive ventilatory support and/or support for 2 or more organs systems
PCC Intensive care basic advanced	XB04Z	Advanced critical care 2	Invasive ventilatory support and/or support for 2 or more organs systems
PCC Intensive care advanced	XB03Z	Advanced critical care 3	Complex interventions / organ support
PCC Intensive care advanced enhanced	XB02Z	Advanced critical care 4	Complex interventions / organ support
PCC Intensive care ECMO ECLS	XB01Z	Advanced critical care 5	ECMO

Appendix 2 – Methodology (1)

General Notes

- All activity data sourced from PICANet, population data sourced from ONS, travel times calculated using the Google Maps API
- Unit bed capacities are as stated by each trust in their submissions to PICANet
- Where noted, analysis included admissions to PICU from 2011 to 2015, or just during 2015
- Admissions were attributed to regions/hubs on two different bases:
  - Hub of admission based upon the location of the unit to which the patient was admitted
  - Hub of origin, based upon mapping the LSOA of the patient's usual residence to the CCG within which the LSOA resides and from the CCG to the NHS England Specialised Commissioning Hub responsible for commissioning PICUs for those CCGs.
- Counts of admissions are based upon PICANet Event ID and, as such, individual patients may count as multiple admissions during any time period
- Diagnostic categories, admission types are as per PICANet definitions
- **Activity relating to patients whose usual residence is not within England are excluded from the analyses.**

Appendix 2 – Methodology (2)

Section-specific notes:

2.1

- Brighton and Hull are represented by zero on the infographic for the following reasons:
  - Brighton submitted data to PICANet up to 2014, but is only commissioned to provide 'step up' PIC for retrieval to other PICUs.
  - Hull is currently commissioned as a paediatric high dependency unit only and further analysis of the small number of higher care days delivered in the unit is currently under review by the regional team. It is likely that in future Hull will be excluded from reporting to PICANet.
- The bed numbers used in the infographic relate to May/June 2015 to try to best reflect the period included in the subsequent analysis. They may not represent current commissioned bed numbers which are subject to change.

2.2

- Source = PICANet
- Counts based on number of admissions to PICUs from Jan 2011 to December 2015
- Diagnostic types as defined by PICANet
- Admission types as defined by PICANet

3.1

- Source = PICANet
- Total bed days calculated by the sum of each patient's length of stay
- Year based on the date of the admission to PICU
- Years 2011 through to 2015 included
- Trend used to demonstrate growth

3.2

- Source = PICANet
- Year based on the date of the admission to PICU
- Month based on the date of admission to PICU
- 2015 admissions only used as occupancy is calculated against the bed capacities reported in 2015
- Occupancy is calculated as [total occupied days in 2015] / ([bed capacity] x 365)

Appendix 2 – Methodology (3)

3.2 continued:

- Bed days are assigned to month based upon the month of admission (i.e. all bed days incurred by patients admitted in January are counted against January)

3.3

- Source = PICANet
- Year based on the date of the admission to PICU
- Month based on the date of admission to PICU
- Bed days are assigned to month based upon the month of admission
- Level of care are as per PCCMDS as reported to PICANet
- No data included from Great Ormond Street Hospital or Alder Hey until 2015 as no PCCMDS submitted to PICANet
- Sum of bed days from 2011 to 2015 presented to demonstrate annual trend

3.4

- Source = PICANet
- Year based on the date of the admission to PICU
- Month based on the date of admission to PICU
- Bed days are assigned to month based upon the month of admission
- Diagnostic categories are as per PICANet definitions
- Three-year graph produced to illustrate cyclical nature of annual trend

3.5

- Source = PICANet
- Year based on the date of the admission to PICU
- Month based on the date of admission to PICU
- Bed days are assigned to month based upon the month of admission
- Admission types are as per PICANet definitions
- Three-year graph produced to illustrate cyclical nature of annual trend

Appendix 2 – Methodology (4)

3.6

- Source = PICANet
- Year based on the date of the admission to PICU
- Month based on the date of admission to PICU
- PICANet supplied age in admission to PICU as number of weeks, age in years derived by dividing by 52
- Three-year graph produced to illustrate cyclical nature of annual trend

3.7

- Source = PICANet

Period 2011 to 2015 used to maximise sample size

Resources are defined as bed days in this context

- Calculation = for each additional patient the sum of total bed days is calculated after sorting the patient records by length of stay (shortest first)

3.8

- Source = PICANet
- Period 2011 to 2015 used to maximise sample size
- Only those children who died in PICU included
- Calculation = for each additional patient who died the sum of total bed days is calculated after sorting the patient records by length of stay (shortest first)

Appendix 2 – Methodology (5)

3.9

- Source = PICANet
- Five-year graph produced to illustrate growth trend
- Average length of stay calculated as simple arithmetic mean (total bed days/total patients)

4.1

- Source = PICANet
- Period 2011 to 2015 used to maximise sample size
- Diagnostic categories are as per PICANet definitions
- Records with no diagnostic category recorded were excluded
- **Note:** Brighton submitted data to PICANet up to 2014, but is only commissioned to provide 'step up' PIC for retrieval to other PICUs.
- **Note:** Hull is currently commissioned as a paediatric high dependency unit only and further analysis of the small number of higher care days delivered in the unit is currently under review by the regional team. It is likely that in future Hull will be excluded from reporting to PICANet.

4.2

- Source = PICANet
- Period 2011 to 2015 used to maximise sample size
- Diagnostic categories are as per PICANet definitions
- Records with no diagnostic category recorded were excluded
- **Note:** Brighton submitted data to PICANet up to 2014, but is only commissioned to provide 'step up' PIC for retrieval to other PICUs.
- **Note**: Hull is currently commissioned as a paediatric high dependency unit only and further analysis of the small number of higher care days delivered in the unit is currently under review by the regional team. It is likely that in future Hull will be excluded from reporting to PICANet.

Appendix 2 – Methodology (6)

4.3

- Source = PICANet
- Period 2011 to 2015 used to maximise sample size
- PICANet data includes total length of stay, number of days with invasive ventilation and number of days with non-invasive ventilation for each patient. Non-ventilated days calculated as [Total LoS] - ([Invasive days]+[non-invasive days])
- The data that underpins this chart is captured as daily interventions, and as such a given patient may spend a part of a day ventilated and a part of a day unventilated and thus be counted twice in the data. As a result the most meaningful way to display this is as the total number of full or part days in each category, rather than as a proportion of total bed days.
- **Note:** Brighton submitted data to PICANet up to 2014, but is only commissioned to provide 'step up' PIC for retrieval to other PICUs.

  Note: Hull is currently commissioned as a paediatric high dependency unit only and further analysis of the small number of higher care days delivered in the unit is currently under review by the regional team. It is likely that in future Hull will be excluded from reporting to PICANet.

5.1

- Source = PICANet
- Hub of origin assigned by LSOA supplied by PICANet (see general notes)
- Count = number of admissions where the child received ECMO at any point during their stay on PICU
- Period 2011 to 2015 used to maximise sample size

5.2

- Source = PICANet
- Hub of origin assigned by LSOA supplied by PICANet (see general notes)
- Rate per population calculated as: number of admissions where the child received ECMO at any point during their stay on PICU for each Hub of origin, divided by the population for the CCGs within that Hub based upon the 2015 population projections from the 2014 ONS Census
- Period 2011 to 2015 used to maximise sample size

Appendix 2 – Methodology (7)

5.3

- Source = PICANet,
- Hub of origin assigned by LSOA supplied by PICANet (see general notes)
- Count = number of admissions where the child received ECMO at any point during their stay on PICU
- Period 2011 to 2015 used to maximise sample size
- Diagnostic categories are as per PICANet definitions
- Records with no diagnostic category recorded were excluded

6.1

- Source = PICANet
- Hub of origin assigned by LSOA supplied by PICANet (see general notes)
- Total bed days calculated by sum of length of stay for all patients from each hub of origin
- Bed equivalents calculated by [bed days]/365 rounded up to nearest whole bed

6.2

- Source = PICANet
- Level of care are as per PCCMDS as reported to PICANet
- Growth projections calculated by using MS Excel's line of best fit function to determine growth from 2011 to 2015, (total days per care level for each year 2011 through to 2015). This % growth factor was then applied to 2015 activity with an annual iteration to estimate future activity.
- Note – Alderhey and GOSH were excluded from the growth calculations as their PCCMDS submissions to PICAnet were only complete in 2015. Their quantum of bed days was included in the 2015 baseline to which the growth was applied.

Appendix 3 – Key for admissions by diagnostic category

This list follows on from the infographic in section 2.2

Admissions	Rank	Category	Admissions	Rank	Category
2704	6	Planned - following surgery - Musculoskeletal	176	33	Planned - following surgery - Infection
2006	7	Planned - following surgery - Respiratory	173	34	Planned - other - Body wall and cavities
1924	8	Unplanned - other - Gastrointestinal	170	35	Unplanned - following surgery - Trauma
1860	9	Unplanned - other - Other	143	36	Planned - other - Infection
1754	10	Planned - other - Cardiovascular	138	37	Unplanned - other - Unknown
1715	11	Unplanned - other - Endocrine / metabolic	135	38	Planned - following surgery - Trauma
1508	12	Planned - following surgery - Gastrointestinal	127	39	Planned - other - Oncology
1407	13	Unplanned - other - Trauma	123	40	Planned - following surgery – Endocrine/ metabolic
1254	14	Planned - following surgery - Oncology			
1156	15	Planned - following surgery - Other	115	41	Unplanned - following surgery - Body wall and cavities
1068	16	Planned - other - Respiratory			
866	17	Unplanned - following surgery - Respiratory	110	42	Planned - other - Endocrine / metabolic
842	18	Planned - following surgery - Neurological	102	43	Planned - following surgery - Multisystem
787	19	Unplanned - following surgery - Gastrointestinal	98	44	Planned - other - Musculoskeletal
			79	45	Unplanned - other - Multisystem
730	20	Unplanned - other - Oncology	71	46	Planned - following surgery - Blood / lymphatic
550	21	Unplanned - other - Blood / lymphatic			
483	22	Unplanned - following surgery - Cardiovascular	62	47	Unplanned - following surgery - Musculoskeletal
480	23	Planned - following surgery - Body wall and cavities	61	48	Unplanned - following surgery - Endocrine / metabolic
446	24	Unplanned - other - Body wall and cavities	47	49	Planned - following surgery - Unknown
430	25	Planned - other - Neurological	46	50	Planned - other - Blood / lymphatic
391	26	Unplanned - following surgery - Neurological	44	51	Planned - other - Trauma
375	27	Unplanned - following surgery - Other	42	52	Planned - other - Multisystem
369	28	Planned - other - Other	36	53	Unplanned - following surgery - Blood / lymphatic
272	29	Planned - other - Gastrointestinal			
223	30	Unplanned - following surgery - Oncology	21	54	Planned - other - Unknown
214	31	Unplanned - following surgery - Infection	18	55	Unplanned - following surgery - Unknown
206	32	Unplanned - other - Musculoskeletal	10	56	Unplanned - following surgery - Multisystem

Blog
Understanding the issues facing paediatric intensive care

23 June 2017

Dr Gale Pearson

Following the launch of the review of paediatric critical care and specialised surgery for children in October 2016, Dr Gale Pearson shares an important update on the progress so far.

Since the beginning of the year we have been working to identify and understand the issues facing paediatric critical care and specialised surgery in children in more detail so that improvements can be made for the benefit of patients. We held several engagement events between January and March 2017 – bringing clinicians and experts in paediatric critical care together to discuss the areas they see as the greatest challenge facing services and to get their ideas on how things could be improved. This has helped us to think about how a proposed new model of care could be developed in response to these issues, while also looking at existing data on paediatric critical care which highlights the pressures on critical care services.

We have just produced an analytical pack containing some of the review's early work which examines why there is pressure on paediatric intensive care units. Over the next few months, we will also be looking at the data available on specialised surgery in children and aim to publish an analysis report on these findings. The pack uses data submitted to the Paediatric Intensive Care Audit Network (PICANet) by the 23 paediatric intensive care units in England. It focuses on level three (intensive care) units because of the completeness of the data available. Level one and two critical care does not have the same level of data available. Some of the key findings from the data suggest that:

- Demand for paediatric critical care services is changing, with relatively stable admission numbers but increasing average length of stay
- There are seasonal peaks in demand for beds and emergency transport services, particularly during November and December, which are largely driven by unplanned respiratory admissions from children under one year of age.
- A small number of children account for a large proportion of resources. The data shows that 10% of children admitted to paediatric intensive care units (PICU) use more than half of the resources.
- Most of the increased demand seen over recent years has been for basic levels of intensive care. Units also vary in their rates of ventilation (artificial breathing), which may suggest differences in admissions criteria as well as variation in case mix

Through reviewing the results of this data, there are several things that we now know and will take into account as the review progresses. These are:

- Some children may be able to move out of PICUs into more appropriate settings, if the right skills and resources are available, to enable care to be delivered outside of intensive care;
- These settings may be a better environment for children and may be closer to the child's home; and
- We need to think about how a proposed new model of care could be developed in response to these issues.

The data and analysis in this pack will be used as the review develops its proposals for a future model of care and tests its emerging thinking with a wide range of stakeholders, including NHS England and CCG commissioners, providers, clinicians and patients and their parents and carers. This will include discussions about the best way to deliver extracorporeal membrane oxygenation in future.

We would really welcome your comments and feedback on the analytical pack. They can be sent to england.paedsreview@nhs.net and will be taken into account when decisions are taken as the review reaches its conclusions. You can also use this email address to ask to be kept informed in the review's developments, or alternatively please visit our website for more information on opportunities to get involved.

Dr Gale Pearson

Dr Gale Pearson has been an intensive care consultant at Birmingham Children's Hospital since 1995 and was involved in the preparation of the policy document on paediatric intensive care 'A Framework for the Future'. He is a former chairperson of the Paediatric Intensive Care Society and was involved in setting up the national audit PICANet. He was also a former National Director of Confidential Enquiries in Children at The Centre for Maternal and Child Enquiries (CMACE). Dr Pearson is the current Chair of the National Clinical Reference Group on Paediatric Intensive Care at NHS England.

Blog
Meeting the pressures of treating seriously ill children

11 October 2017

Dr Peter Wilson

Southampton Children's Hospital's Clinical Director gives an update on the Paediatric Critical Care and Specialised Surgery in Children review:

As we say goodbye to summer, we are moving into a new and exciting stage for the review.

The work we have undertaken in the first half of the year has helped us to develop a vision of what a future model of care could look like for paediatric critical care and specialised surgery in children.

We are fortunate to have services of excellent quality across all parts of the country but we all know that, as more and more patients have gravitated towards the specialist centres, this has left them under real pressure and has meant that some referring hospitals no longer feel that they have the skills or experience to treat more seriously ill children.

The model of care that is emerging is one that makes use of all levels of care so that capacity is not concentrated in one part of the system. It helps ensure that patients are not treated far from their home when this is not necessary, and that they return home, or to a hospital nearer to their home, as soon as possible.

It is a model that supports NHS staff to work flexibly across specialist centres and referring hospitals to maintain their expertise and confidence in dealing with critically ill children or children requiring surgery. And we hope it is a model that will help these services to become sustainable and affordable into the future.

We are calling this a 'managed system' of care, and I hope that doesn't sound too much like jargon. It essentially means that the secondary and tertiary centres in a geographical area work together to deliver a holistic package of care to the children for whom they are responsible. Some existing operational delivery networks work in a similar way currently, and we are looking at the best features of these to help inform the development of the managed system.

There are practical things that managed systems can implement in order to support the delivery of care in their area: flexible deployment of staff to encourage the sharing and maintenance of skills; the use of common equipment and protocols; agreeing clear step-up and step-down criteria.

However, in my view there are three elements of a managed system that are vital to its success: involving patients and their families is essential if we are to create a system that really works. We need to support managed systems to really understand what is important and not make assumptions about, for example, where patients

would prefer to be treated. In the review we have talked extensively to children who have experienced specialist paediatric services and their parents/carers, and it will be vital that each managed system does the same.

The managed system needs to work across commissioning boundaries: children and their families do not care about whether their services are commissioned by NHS England or by their local clinical commissioning group, provided they are joined up, good quality and patient-focused, so this should not be our main concern either. The managed system should be a joint endeavour between national and local commissioners, health and social care providers, clinicians, and patients and their families, and should be firmly rooted in the priorities and plans of Sustainability and Transformation Partnerships.

Whilst the managed system should adopt some of the features of the best clinical networks, it also needs to have real commissioning teeth and clear leadership. What this looks like will vary from region to region but, without clear responsibilities and accountabilities, it will not be able to affect the kind of change we are looking for.

So we have lots of work to do over the coming weeks to describe this in more detail, and achieve our goal for the managed system to be built into contracts by April 2019.

We have started work with our regional colleagues who are thinking about how this could look in their area, and over the autumn we will be seeking an even wider range of views to help test and develop the model.

As ever we would be grateful for any views on what you are hearing so far – even if it's just to tell us that you would like to be kept up to date. Just email england.paedsreview@nhs.net.

Look out for further blogs on the way from Dr Gale Pearson, Chair of NHS England's Paediatric Intensive Care Clinical Reference Group and Clinical lead at Birmingham Children's Hospital NHS Foundation Trust. There will also be an update blog from Mr Oliver Gee, Chair of NHS England's Specialised Surgery in Children Clinical Reference Group and Consultant Paediatric Surgeon, Birmingham Children's Hospital NHS Foundation Trust who will talk about the work the review is undertaking on the critical care and specialised surgery elements of the managed system.

Dr Peter Wilson

Dr Peter Wilson has been a consultant in paediatric intensive care medicine at the University Hospital Southampton NHS Foundation Trust since 2003 and has been involved in delivering critical care for 15 years.

Peter has been Clinical Director of Southampton Children's Hospital since 2010 and has created a number of regional networks to improve care and efficiency.

He is immediate past President of the Paediatric Intensive Care Society, a position that involved creating national standards, implementing national plans and working with commissioners around issues such as capacity management especially during winter pressures.

In 2015, Peter took up a post with NHS England delivering paediatric and women's specialist services nationally. He is involved in the national reviews of paediatric intensive care, neonatal intensive care, paediatric surgery and cardiac surgery.

NHS England

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.

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[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.

Paediatric Critical Care and Specialised Surgery in Children Review – Frequently Asked Questions

What services does the review cover?

The review is of paediatric critical care and specialised surgery in children. It also includes extracorporeal membrane oxygenation (ECMO), which can be a life-saving intervention for babies or children with severe heart or lung failure, and transport for children requiring critical care.

Why are you reviewing paediatric critical care?

Our analysis suggests that critical care services for children are under pressure due to increased demand, particularly in winter, and that some children that are currently being treated in paediatric intensive care units could be looked after in a more suitable setting that is closer to their home. Such a shift is likely to require a new model of care that helps ensure that services are sustainable into the future. This shift will also entail understanding the impact on paediatric critical care transport, and specifically how critically ill children could move up and down the patient pathway. We are reviewing ECMO for children to ensure the national service provides the best possible coverage for emergency support for children all over the country, whilst maintaining our excellent standards.

Why are you reviewing specialised surgery in children?

Specialised surgery in children is commissioned by NHS England and defined in NHS England's Manual for Prescribed Services. General Paediatric Surgery (GPS) is commissioned by Clinical Commissioning Groups. The Royal College of Surgeons (RCS) has identified a number of issues related to workforce and training that have an impact on the delivery of specialised and general paediatric surgery. These included concerns that children are travelling longer distances for general paediatric surgery which could be delivered closer to home, resulting in a rise in GPS being undertaken in specialist children's centres, which in turn may be resulting in increased waiting times for children requiring specialised surgery.

To address these concerns, NHS England is reviewing specialised surgery in children in order to understand whether there is a real increase in GPS activity within specialist children's centres and whether this is affecting the delivery of specialised services.

What is the scope of the review of specialised surgery?

Specialised surgery in children consists of a number of surgical specialties including specialist paediatric surgery services, specialist paediatric urology services, specialist ear, nose and throat services and specialist orthopaedic surgery services, amongst others. In order for us to meet the aims of the review, we are linking in with the work the RCS is undertaking, however we will be focussing on surgical activity that can only be carried out by paediatric trained surgeons, rather than general adult surgeons who have additional training in children. Working with the RCS, we will then be able to support commissioners and providers to plan more integrated surgical services for babies, children and young adults across other sub-specialities within specialised surgery for children using this as a template or model.

Who is conducting the review?

The review is being undertaken from NHS England's Specialised Commissioning Team with clinical leadership and input from a range of stakeholders including, clinicians, nurses, allied health professionals, professional organisations, providers, commissioners, patients and their families and the public. The review is supported by an Expert Stakeholder Panel which meets regularly; the minutes of their meetings are available on the NHS England website.

What is the timetable for the review?

The review will be engaging on its vision and case for change over autumn and winter 2017, with implementation beginning during 2018.

Who are you involving in the review?

We are working with a range of clinicians to ensure the review is clinically-led and informed by experts working in critical care and specialised surgery. We have set up an Expert Stakeholder panel that meets regularly and will be providing expertise and guidance throughout the review.

In addition to this core group, we engaged with a wider set of stakeholders in early 2017 including others working in paediatric critical care, surgical services, cardiovascular services, and third sector organisations. Through these webinars and events we have already engaged with around 250 people.

We will continue to engage with clinicians, managers, patients, their families and the public during 2017, as well as regional commissioning teams and Sustainability and Transformation Partnerships (STPs) who will be crucial in implementing the review's findings.

How can I get involved in the review?

We welcome comments on the initial analysis that we have undertaken and the review's overall direction of travel, as well as any of the other outputs available on the website. If you have any comments or want to be kept informed of new content, you can get in touch with the review team at england.paedsreview@nhs.net.

How long do I have to respond to the review and what will you do with my comments?

Any comments on the initial analysis and the review's early evidence and thinking are welcome. The website is updated periodically with the review's latest materials and responses to these are welcomed as soon as possible after they are published. If you want to be alerted to new content please email: england.paedsreview@nhs.net.

Any comments or feedback will be used to help inform the next stages of the review. We will not be replying individually to all comments or publishing them directly.

What is the difference between 'paediatric critical care' and 'paediatric intensive care'?

The term 'critical care' incorporates a range of care including basic critical care provided in all acute hospitals which have inpatient facilities (level 1), care that is often referred to as 'high dependency' (level 2), and intensive care (level 3). Level 3 services are provided in 23 paediatric intensive care units across the country.

Why is NHS England reviewing services that are commissioned by clinical commissioning groups?

Clinical commissioning groups (CCG) are responsible for commissioning level 1 paediatric critical care services. Level 2 services are often commissioned by CCGs, unless they are delivered in specialist children's hospitals or certain designated acute hospitals, in which case they are commissioned by NHS England. All paediatric intensive care units are commissioned by NHS England. We are reviewing the whole patient pathway, which includes CCG commissioned care, to ascertain the optimal models for the future provision of sustainable, high quality, responsive paediatric critical care and specialised surgery in children in England, considering critical co-dependencies with other essential services.

How is this work linked to the current review of congenital heart disease services?

NHS England consulted on proposals to implement standards for congenital heart disease (CHD) services in England over spring and summer 2017. NHS England's assessment has shown that, if the proposals were to be implemented, there would be an impact on paediatric critical care and extracorporeal membrane oxygenation (ECMO). This review will be considering the wider impact on the provision of non-cardiac paediatric intensive care and ECMO, should the CHD proposals be implemented. The implementation of the paediatric critical care review's proposals will need to take the outcome of the CHD review into account.

What evidence do you have to support the review?

In June 2017, we published our report: *Paediatric critical care and extracorporeal membrane oxygenation: Initial analysis and early update*. The data in the report shows that, whilst admissions to paediatric intensive care units are relatively stable, length of stay is increasing and there are significant seasonal peaks, meaning that services are under increasing pressure.

The analysis suggests that this pressure may be coming from children who require the most basic level of intensive care, and paediatric intensive care units vary in their ability to absorb this unplanned demand. Some of the data suggests that units may have different admissions criteria for paediatric intensive care, and the number of patients receiving extracorporeal membrane oxygenation also varies depending on where a patient lives. The biggest increase in demand in the future may be for high dependency and basic intensive care, rather than for the highest levels of critical care. The analysis suggests that there are some children that could be moved out of intensive care into other, more appropriate, environments that may be closer to their home.

The report is intended to stimulate debate and help support our discussions with stakeholders throughout the next stages of the review, and we are also keen to seek views on the analysis from stakeholders.

Where can I find out more about the review?

For more information about the Paediatric Critical Care and Specialised Surgery in Children review, visit www.england.nhs.uk/paediatricservicesreview/. Our web pages contain a range of information about the review, as well as terms of reference, blogs, a video and minutes from Expert Stakeholder Panel meetings. If you want to get involved, contact the review team at england.paedsreview@nhs.net.