Programme Board

28 July 2014

AGENDA

2:00pm – 4:00pm

Room 6B2, Skipton House

Members in attendance:
Ian Dodge, National Director: Commissioning Strategy (Chair)
Wayne Bartlett-Syree, Assistant Head of Planning and Delivery (Specialised Commissioning);
Will Huxter, Regional Team representative, Head of Specialised Commissioning (London)
Michael Macdonnell, Head of Strategy, Specialised Commissioning Taskforce
Mr James Palmer, Clinical Director, Specialised Services *(via teleconference)*
Professor Sir Michael Rawlins, Chair of Clinical Advisory Panel
Professor Peter Weissberg, Chair of the review's Patient and Public Group *(until 3:30pm)*
Giles Wilmore, Director for Patient & Public Voice & Information
Michael Wilson, Programme Director
Eleri de Gilbert, Area Team representative, Area Team Director (South Yorkshire and Bassetlaw);
Linda Prosser, Area Team representative, Director of Commissioning (Bristol, North Somerset, Somerset and South);

Apologies:
John Holden, Director of System Policy
Professor Deirdre Kelly, Chair of review's Clinicians' Group
Professor Sir Bruce Keogh, National Medical Director
Sam Higginson, Director of Strategic Finance
Chris Hopson, Chair of the review's Provider Group

Additional attendees:
Penny Allsop, Project Manager
Caroline Gillespie, Project Manager
Joanna Glenwright, Analytical Lead
Lauren Phillips, Programme Development Manager (Secretariat)

Item	Agenda Item	Action	Lead
1.	Welcome and apologies	To note	Chair
2.	Minutes of the previous meeting (10 June 2014)	To agree	Chair
3.	Declarations of interest (verbal)	To note	Chair
4.	Action log	To discuss	Michael Wilson
5.	Programme Board Revised Terms of Reference	To agree	Michael Wilson

Item	Agenda Item	Action	Lead
6.	Consultation products: • Annex A: Consultation document, consultation questions • Annex B: Outline of the consultation reference pack • Annex C: Initial financial assessment • Annex D: Initial equalities analysis • Annex E: Governance paper • Annex F: Engagement paper	To agree	Michael Wilson/ Caroline Gillespie
7.	Analysis output: • Annex A: Slide pack	To note	Joanna Glenwright
8.	Engagement during consultation	To agree	Michael Wilson
9.	Consultation launch criteria	To agree	Caroline Gillespie
10.	CCG engagement (verbal)	To note	Michael Wilson
11.	Risk and issues review	To note	Caroline Gillespie
12.	Highlight report	To agree	Michael Wilson
13.	Children and Young People Engagement Events (video)	To note	N/A
14.	Any other business	To discuss	All
	Next meeting: 8 September 2014	To note	

Minutes of the Programme Board held on 10 June 2014

Present:

- Bill McCarthy, National Director: Policy by V/C
- John Holden, Director of System Policy (Chair)
- Professor Sir Michael Rawlins, Chair of Clinical Advisory Panel
- Giles Wilmore, Director for Patient & Public Voice
- Michael Wilson, Programme Director

Apologies:

- Chris Hopson, Chair of the review's Provider Group
- Professor Deirdre Kelly, Chair of the review's Clinician Group
- Professor Sir Bruce Keogh, National Medical Director
- Professor Peter Weissberg, Chair of the review's Patient and Public Group
- Ann Sutton, Director of NHS Commissioning (Corporate)
- Mr James Palmer, Clinical Director, Specialised Services

In attendance:

- Caroline Gillespie, Project Manager (Secretariat)

Item	Agenda item
1	**Welcome and apologies**
	The Chair welcomed everyone to the meeting. Apologies were noted from: Chris Hopson, Professor Deirdre Kelly, Professor Sir Bruce Keogh and Professor Peter Weissberg. It was noted that the meeting was not quorate. Those present agreed to continue with the meeting; any decisions would be reviewed by absent members and agreed post-meeting by correspondence. They would be ratified at the next quorate meeting.
2	**Minutes of the previous meeting**
	The Programme Board approved the minutes of the last meeting (13 May 2014).
3	**Declarations of Interest**
	There were no specific declarations of interest in relation to today's agenda. The Chair requested that the declarations of interest for the current Programme Board members be made available on the NHS England website in advance of the next meeting.
ACTION	**Declarations of interest forms to be made available on the NHS England website in advance of the July 2014 Programme Board meeting.**

Item	Agenda item
4	**Action Log**
	The Programme Board considered the action log and discussed the following in more detail: **Action 65:** Colleagues from finance are now working with the programme team on the assurance of the Financial Impact Assessment and are currently looking at ways to source some further support to deliver this assessment. **Action 66:** An additional resource has been sourced from a Commissioning Support Unit (CSU) to lead engagement with NHS England Area and Regional teams and Clinical Commissioning Groups (CCGs).
5	**Timeline update**
	Michael Wilson introduced this item. The Programme Board were reminded of the March 2014 paper outlining possible timeline scenarios, and were provided with a brief narrative overview of the slides tabled for this item. This included confirmation that all the expected activities that need to take place, including the assurance process which will provide approval to launch consultation, have been identified and planned in detail. Michael Wilson reported that the key message within the slides was that whilst it is currently expected that the consultation will launch in September, this is still an optimistic target. The programme team are confident that the work can be delivered, however there are still some significant risks in terms of the governance process. Therefore a September launch cannot be guaranteed. In order to meet a consultation launch date of September the Programme of Care (POC) board would need to meet as expected in August, the POC and Clinical Priorities Advisory Group (CPAG) would need to accept papers in parallel (as the meetings are so close together) and the Directly Commissioned Services Committee (DCSC) of the NHS England board would need to review by correspondence. It was noted that board sub-committees approving by correspondence is not the organisation's preferred approach and a new exception process has been put in place. Michael Wilson advised that in order to launch in September the consultation products would need to be approved at the first time of asking. Bill McCarthy advised that this needs to be a shared priority across the organisation to ensure it succeeds and to provide the level of assurance required. All areas of NHS England must collectively support the programme to launch consultation in September as: ○ there are significant resilience risks associated with the time it takes to conduct the review; and ○ if consultation is launched any later than September it will include the Christmas period which will require an extension, resulting in no possible way to respond by the end of the financial year. The Programme Board agreed that the current plan looked suitable and that

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	consultation launch should not be any later than September. Bill McCarthy advised that this should be raised at the Task and Finish Group (T&FG) on 23 June 2014 and the Chair may wish to issue a request to the decision making groups to advise them that support should be provided to ensure this timescale is met.
ACTION	**John Holden was asked to contact the Chair of the Task and Finish Group (T&FG) to advise of the risk associated with the timeline and to recommend that this issue is discussed at the 23 June 2014 meeting.**
6	**Engagement and communications plan: consultation and beyond**
	Michael Wilson introduced this item. Michael advised that the details of the papers had been brought to the Programme Board for discussion in order that they understood what the new CHD review team would be delivering for the consultation and could contribute to and approve the plans. Specific discussions were held around Annexes A and B: o Engagement during consultation o Consultation documents Annex A identified an intention to hold four regional events plus targeted initiatives (not necessarily events) for adults; for black Asian and minority ethnic groups; patients with learning disabilities; and bereaved parents. It is expected than an active role will be played by our partners (charities, patient support groups, professional colleges, providers, regional teams and area teams). Work is ongoing with the engagement and advisory groups to shape this work and it is expected to include awareness raising and facilitating conversations. As the nature of the information that will be consulted on is complex and detailed, the feedback the review has received is that “town hall” style events may not be the best approach. The Patient and Public Group have advised that a dialogue, with an opportunity for questions and answers, would be required. An opportunity must also be provided for local government and Healthwatch to play a role. Giles Wilmore advised that it may be possible to work with charities for the specific targeted engagement and to attend events already scheduled rather than develop specific additional sessions, and that the regional sessions must be an open invitation. These sessions must be participative and facilitative. People will need to give their views as groups or communities and also must have an opportunity to communicate and share views with others. Giles advised the team that four regional events would take significant work to both plan and facilitate and that the effort required should not be underestimated. It may also be possible to join up the plans for social media with the events possibly live streaming, providing a hash tag and tweeting out

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	key messages on the day. The Programme Board agreed that these events should ideally be held in cities that do not contain a CHD surgical centre, to mitigate any perception of bias. Discussion took place around potential provider input and the programme board asked the review team to consider the possibility of groups of clinical leaders working together across a region to present the problem as one section of the regional events. A brief overview of Annex B was provided outlining the intention to create a brief and easy to read consultation document, which might nonetheless be 30-40 pages, complemented by a detailed reference document containing all the standards and other supporting materials. In addition a simple audio/visual version will be created. Giles Wilmore advised it would be possible to do a short film and suggested the team look at that produced for the 6C's. He also strongly advised that a true 'easy read' version would not be 30-40 pages; it would be much shorter and contain symbols and pictures. The Patient Voice team could help advise on the production of this. Professor Sir Michael Rawlins advised that it would be necessary to flag up the areas within the standards that advice is required on and Michael Wilson confirmed that there was an intention to 'spotlight' certain issues within the consultation document. Bill McCarthy reminded the review team to ensure that the process was checked through by the legal team.
ACTION	**Michael Wilson to contact the legal team to arrange for a lawyer to check the process.**
7	**Activity analysis update**
	John Holden introduced this item and gave a brief overview of the paper outlining both the qualitative and quantitative information being used to forecast the activity. A combination of factors are driving activity increases and this means it will not be easy to forecast. The review will, as a minimum, present two scenarios, population growth only and population growth plus other factors. The T&FG have advised that it may be necessary to illustrate the effective of different sensitivities, so the review is looking at what else is possible, however the level of data available may mean this is not possible. As a minimum two scenarios will be presented. The programme board were advised that there is no comprehensive reliable data available about the number of people living with CHD, only the number of procedures carried out. Discussion was held on the consequences of over or under estimating the

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	volume of future activity, and the programme board noted that there is a risk that the analysis will be revisited post-consultation. The Programme Board agreed that tracking of the volumes carefully in future would need to happen regularly, particularly as this is no longer solely a children's service and much growth may come from adult procedures in future. Bill McCarthy advised the review team to map out the process it is going through and which deliverables are part of the consultation and which are not. The analysis of the data is taking place as NHS England's role as a commissioner rather than something that will be consulted upon. John Holden explained to the board that the quantitative data available is coming from two sources hospital episode statistics (HES) data and data from NICOR (National Institute for Cardiovascular Outcomes Research) and the two are being compared to look for material differences in order to validate the data that is being used. The Programme Board were advised that getting access to the data has proven challenging and the adult data will be partial. By the end of July 2014 the review will have a current baseline and a ten to fifteen year paediatric and adult forecast for activity. Giles Wilmore confirmed that whilst it would not be appropriate for a consultation on standards to focus on the activity data, this data nonetheless needs to be publicly available, and there should be a place for an open debate about the forecasts and their interpretation.
8	**Transition dashboard**
	Michael Wilson introduced this item on behalf of Julia Grace, the accountable commissioner. Michael advised the board that this update was in response to the risk to safety associated with no change happening whilst the services are under review. The dashboards provide early warning measures to NHS England commissioners in Area Teams. Their purpose is to facilitate a conversation between the unit and the commissioner which will lead to an improvement plan where necessary. The Programme Board were advised that the dashboard is in place in all units and a monthly "sitrep" telephone call happens across commissioners in all areas to enable identification of themes. Bill McCarthy advised that this information should be routinely shared with the Care Quality Commission (CQC) and asked the review team to advise the accountable commissioner of this view and ensure that the sharing of this information was investigated. Giles Wilmore advised that an appropriate narrative should be developed around the data, prior to sharing. Discussion then followed around the ownership of the data and sharing it

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	publicly. This resulted in a steer from Bill McCarthy that the only circumstance in which the data should not be shared would be a strong argument based on patient interest. John Holden confirmed that Objective 5 of the review would resolve the issue of data availability in the long term. The Programme Board agreed that a judgement needs to be made by the NHS England board, via the review T&FG, about how and when the transition dashboard data should be made publicly available.
ACTION	**Michael Wilson to discuss the routine sharing of dashboard data with the CQC and more widely, with the accountable commissioner.**
ACTION	**Public sharing of the transition dashboard data to be considered by the Task and Finish Group, in order that a judgement can be made by the NHS England Board.**
9	**Programme Board membership**
	John Holden introduced this item which was in response to the action from the previous meeting to build in resilience and some changes due to members leaving NHS England. John Holden advised that in the paperwork provided for this meeting, the omission of the Director of NHS Commissioning from future membership was an error. However this job role/title may change due to internal NHS England discussions about management of specialised services. John outlined the recommendation to both expand the membership to include commissioners and a finance representative, and to allow named deputies to be included in the quoracy. The Programme Board were asked if the membership had been adjusted appropriately and whether these changes would make it more resilient. All board members in attendance agreed that the inclusion of named deputies for quoracy was appropriate as they are acting with the authority of the member who has nominated them. It was recommended that both a regional and area team commissioner should be asked to join the board plus CCG leaders who will need to be close to some of the commissioning decisions. Bill McCarthy recommended that the review team seek advice from Rosamond Roughton about the most suitable body to approach for nominations.
ACTION	**Contact Rosamond Roughton to advise on Area Team, Regional Team and CCG representatives to join the programme board.**

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10	**Progress report to the NHS England Board**
	John Holden outlined the intention of the review team to issue a paper to the Task and Finish group on 23 June, which will in turn report to the NHS England board on 3 July reporting back on the board's ambition set out on 12 June 2013 to deliver an "implementable solution" within twelve months. The review team will provide both the NHS England board and the public with an update on progress to date. This will advise where the review is in the lifecycle of the work. It will describe that this is a task and finish project which should in the normal course of events be "mainstreamed" – i.e. handed on to NHs England's direct commissioners by the end of the financial year. John proposed that the paper will report the challenge set by the board and the progress made against each of the 6 objectives and the overall timeline. The Programme Board members were asked for a steer on both the content and the approach being taken to this report. Professor Sir Michael Rawlins advised that an appendix of all the events, meetings and trust visits that have taken place should be included. Advice was also provided that the report should focus on the need for the review to start with the rebuilding of trust, and that this has been successful in large part because it was not rushed, even though this makes it harder to meet the ambitious timeline set. Bill McCarthy advised that the report should be framed in terms of decisions made within the first twelve months, and the very different approach to the previous review particularly highlighting: ○ a different and more extensive approach to engagement; ○ an increased scope, covering the full lifetime pathway from screening through to adults and palliative care; and ○ additional standards such as bereavement and care. The review team were also advised to ensure the approach which has been to capture information and make decisions throughout the process, is clearly represented. John Holden advised that if it timescales allowed a draft would be shared with programme board members before submission to the T&FG.
11	**Risk and issue registers**
	The Programme Board noted the risk and issue registers. Their attention was drawn to the mitigation action against risk 1 (delivered by item 8 at this meeting) and to the issue raised from risk 10, referring to the lack of resource to deliver the required Financial Impact Assessment.

Item	Agenda item
12	**Highlight report**
	John Holden introduced this item and drew the Programme Board's attention to the visits that Professor Deidre Kelly and members of the programme team have been making to the trusts delivering CHD services. The initial planned visits are now completed, however a number of additional visits are planned to trusts delivering second tier adult services. Following an approach from a trust for the team to visit, a commitment has been made by the team to visit up to three trusts delivering this type of service. In addition the patients and families in three areas will be met with again. Families of Ocean ward at Southampton were visited by Michael Wilson and Claire McDonald on 31 May 2014, as they have so far been unable to contribute to the Patient and Public Group due to logistical challenges. A similar arrangement is being considered for Newcastle patients and families. An additional session will be arranged in Bristol to meet families, who were not in attendance when the review team visited the unit. It is important for the review to hear from these families. John Holden expressed his concern that any or all of these sessions could be misconstrued as preferential treatment. Giles Wilmore advised the review team that they are taking the right approach. It is critical that all voices are heard and the approach taken must be flexed to allow that to happen and to meet on the terms of stakeholders. There are justifiable reasons to carry out these additional sessions and whilst this may leave the team open to challenge about consistency or even-handedness, it is nonetheless the right thing to do. Bill McCarthy raised a risk around workforce issues associated with the review. He asked the team to confirm the plans that are in place to engage with Health Education England (HEE) and the Royal Colleges. John Holden confirmed that work is ongoing and meetings are planned. Bill McCarthy asked about progress on the equalities impact assessment and John Holden confirmed that the review team are working with the equalities team to ensure the approach meets their requirements. The Programme Board noted the highlight report.
13	**Any other business**
	No other business raised.
14	**Next meeting**
Date of next meeting	Thursday 10 July 2014, 10pm – 12pm, Skipton House, London ***[subsequently rescheduled]***

Action Log: Programme Board

Action no.	Meeting date	Action description	Responsibility	Progress details	STATUS	Date closed
24	14/01/2014	**Invitation to be sent to senior commissioner in Wales to join / become a member of the Programme Board.**	Michael Wilson	Invitation sent. Follow-up contact initiated.	IN PROGRESS	
25	14/01/2014	**Write to Scotland, Northern Ireland and the Republic of Ireland to offer an official meeting with NHS England along with the option of representation on the Programme Board.**	Michael Wilson	Letters sent. Initial meetings with NHS Scotland and Northern Ireland held and further sessions being scheduled to agree the details of engagement.	IN PROGRESS	
50	16/04/2014	**Discussions to take place with relevant members of the Clinical Advisory Panel regarding the training of anaesthetists and nurses.**	Professor Sir Michael Rawlins and Michael Wilson	In the April Programme Board, it was agreed that the issue of anaesthetists should be discussed with Dr J P Van Besouw (Royal College of Anaesthetists) and the issue of nursing with Fiona Smith (Royal College of Nursing). Conversations in relation to workforce will be scheduled once work on objective 4 is underway in October.	ON HOLD	
51	16/04/2014	**Michael Wilson to connect with Jo Lenaghan, Director of Strategy and Planning at Health Education England (HEE) regarding perfusionists, nursing and other technical staff.**	Michael Wilson	Introductory email to Jo Leneghan sent. Will be followed up further when we have a clearer, more comprehensive picture of workforce and training issues in October.	ON HOLD	
61	13/05/2014	**Seek advice from the Independent Reconfiguration Panel (IRP)**	John Holden	Call to be scheduled at a later point in the review as appropriate.	ON HOLD	
62	13/05/2014	**A note to be prepared on behalf of the Programme Board to Health Education England (HEE) updating them on the potential issues in relation to workforce and training in respect of the early diagnosis work, once they are identified.**	Michael Wilson	This action links to action 51. This topic is due for discussion at the next Fetal Leads Group meeting in July 2014.	ON HOLD	
63	13/05/2014	**A summary report of the children and young people's engagement events to be produced and published via John Holden's bi-weekly blog.**	Michael Wilson	A summary video is scheduled for viewing at this Programme Board (item 13). The summary report was used to inform the pre-consultation paper, 'Review of proposed CHD standards', which went to the Clinical Advisory Panel on 18 June 2014 (item 6) and was highlighted in John Holden's 26th blog. The report is likely to be published as a standalone item via John Holden's 29th blog on 4 August 2014.	IN PROGRESS	

64	13/05/2014	**The review team to scope the whole spectrum of potential external support required for analysis of the consultation responses.**	Michael Wilson	Business Case has been approved by the Department of Health as of 17th July. Specification for external support being written. Engagement with suppliers expected to start w/c 28th July.	IN PROGRESS	
65	13/05/2014	**At a future meeting, the Programme Board should consider the drivers of costs in the new standards and the potential savings.**	Michael Wilson	Finance have assisted the team to source a new member of staff to look at finance specifically. The initial finance assessment is included in the papers for this Programme Board (item 6 annex C).	IN PROGRESS	
66	13/05/2014	**Discuss options for working with clinical commissioning groups (CCGs) on the commissioning of Tier 3 of the standards with colleagues in the Commissioning Development Team.**	Michael Wilson	Additional resource has been secured into new CHD review team whose remit is to focus on both the commissioning model and relationship/engagement with CCGs. A brief update will be given at the Programme Board (item 10).	IN PROGRESS	
68	10/06/2014	**Declarations of interest forms to be made available on the NHS England website in advance of the July 2014 Programme Board meeting.**	Michael Wilson	Declaration of interest forms can now be found at: http://www.england.nhs.uk/ourwork/qual-clin-lead/chd/dec-of-int/	CLOSED	11/07/2014
69	10/06/2014	**John Holden was asked to contact the Chair of the Task and Finish Group (T&FG) to advise of the risk associated with the**	John Holden	This action has been completed.	CLOSED	23/06/2014
70	10/06/2014	**Michael Wilson to contact the legal team to arrange for a lawyer to check the process.**	Michael Wilson	An initial meeting was held and the team were advised that no specific legal advice is required at this time in relation to the proposed consultation. Consideration will be given at a later date to the need for legal advice on objectives 3 and 4 of the consultation and the process post-consultation.	IN PROGRESS	
71	10/06/2014	**Michael Wilson to discuss the routine sharing of dashboard data with the CQC and more widely, with the accountable commissioner.**	Michael Wilson	Discussed with accountable commissioner. Proposals for onward reporting of concerns to be discussed with area teams and providers.	IN PROGRESS	
72	10/06/2014	**Public sharing of the transition dashboard data to be considered by the Task and Finish Group, in order that a judgement can be made by the NHS England Board.**	Michael Wilson	Discussed at the June Task and Finish Group meeting.	CLOSED	23/06/2014
73	10/06/2014	**Contact Rosamond Roughton to advise on Area Team, Regional Team and CCG representatives to join the programme board.**	Michael Wilson	Area and Regional Team representatives have been named and invited. CCG representatives are still being sourced via colleagues in Commissioning Development.	IN PROGRESS	

Programme Board Revised Terms of Reference

At its meeting in June 2014 (item 9), the Programme Board considered and approved changes to the core membership of the Programme Board as the work of the review moved into its next phase including consideration of implementation of the standards and in order to give appropriate focus to the financial impact of the change that will be brought about as a result of the review and to ensure involvement within NHS England specialised commissioning. This recommendation was then taken to the Board Task and Finish Group on 23 June 2014, where it also received sign off.

Enclosed with this paper is a copy of the revised New Congenital Heart Disease Review Programme Board Terms of Reference (Annex A).

Representatives have been sourced from finance and the regional and area team functions of specialised commissioning, and have been included in all communications regarding future Programme Board meetings.

The review team are still in the process of identifying and inviting two clinical commissioning group (CCG) representatives to join the Programme Board. Advice has been taken from Rosamond Roughton (National Director: Commissioning Development) and the review is working with the Commissioning for Service Transformation team to encourage members to take up the opportunity.

In light of this, current quoracy of the Programme Board rests at eight members until the CCG representatives have been recruited.

Nominated deputies who attend Programme Board on behalf of members will now count towards meeting quoracy.

The Programme Board is asked to review and agree the amended Terms of Reference.

NHS England

New Congenital Heart Disease Programme Board Terms of Reference

Information Reader Box

Directorate	
Medical	Commissioning Operations
Nursing	Commissioning Strategy
Patients & Information	Transformation and Corporate Operations
Finance	

Document Purpose	To describe the terms of reference of the New Congenital Heart Disease Review Programme Board
Document Name	New Congenital Heart Disease Review Programme Board Terms of Reference
Author	NHS England, Commissioning Strategy Directorate
Target Audience	General
Additional Circulation List	Website; Intranet
Description	Terms of Reference
Cross Reference	n/a
Superseded Document	n/a
Action Required	As described
Timing/Deadlines	See programme plan
Contact Details (for further information)	Jennie Smith, Programme Co-ordinator jennie.smith5@nhs.net NHS England Quarry House Quarry Hill Leeds LS2 7UE Direct Line: 0113 8248232

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New Congenital Heart Disease Review Programme Board: Terms of Reference

Version number: 2

First published: 17 October 2013

Updated: 28 July 2014

Prepared by: Michael Wilson, Programme Director

Contents

1 Purpose

1.1 The purpose of this document is to define the Terms of Reference for the 'New Congenital Heart Disease Review Programme Board'.

2 Background

2.1 Following the outcome of judicial review, the report by the Independent Reconfiguration Panel (IRP) and the Secretary of State's announcements relating to the Safe and Sustainable review of children's congenital heart services, in summer 2013, NHS England established a new review to consider the whole lifetime pathway of care for people with congenital heart disease.

2.2 The aim of the review is to ensure that services for people with congenital heart disease are provided in a way that achieves the highest possible quality within the available resources:

- To secure the best outcomes for all patients, not just lowest mortality but reduced disability and an improved opportunity for survivors to lead better lives.
- To tackle variation so that services across the country consistently meet demanding performance standards and are able to offer resilient 24/7 care.
- To ensure great patient experience, which includes how information is provided to patients and their families, considerations of access and support for families when they have to be away from home.

2.3 The Programme Board has been established to support the SRO (Senior Responsible Owner) in managing all aspects of the review's work, taking day-to-day decisions on the running of the review. It is responsible for ensuring that the programme delivers its objectives, manages risk and for ensuring that there is a comprehensive and effective approach to stakeholder participation and involvement.

2.4 The Programme Board will have regard for the views of the provider group, the patient and public group, the clinician group and the clinical advisory panel.

2.5 The Programme Board will make recommendations to the Board Task and Finish Group.

3 Role and Responsibilities

3.1 The programme board will support the SRO (Senior Responsible Owner) in managing all aspects of the review's work, taking day-to-day decisions on the running of the review:

- Take overall responsibility for the effective running of the programme;

- Approve the:
  - Programme initiation document;
  - Programme plan and milestones;
  - Communications and engagement plan; and
  - Plan for evaluation.

- Agree significant variations to the programme plan;

- Monitor and manages programme progress;

- Provide visible leadership, direction and commitment to the programme, promoting effective communication of the programme's goals and progress;

- Ensure availability of essential programme resources;

- Report to the Board Task and Finish Group.

3.2 Ensure that the programme delivers its objectives:

- Develops standards to give consistent services, improved outcomes, and improved patient experience for people with CHD;

- Analyses the demand for specialist inpatient CHD care, now and in the future;

- Makes recommendations about the function, form and capacity of services needed to meet that demand and meet quality standards, taking account of accessibility and health impact;

- Makes recommendations on the commissioning and change management approach including an assessment of workforce and training needs;

- Establishes a system for the provision of information about the performance of CHD services to inform the commissioning of these services and patient choice;

- Improves antenatal and neonatal detection rates.

3.3 Manage risks and issues:

- Own risks and issues and develop proposals for mitigation / resolution;

- Ensure that all material risks and appropriate mitigating actions are recorded in the risk register;

- Escalate risks and issues to the Board Task and Finish Group as necessary.

3.4 Ensure that there is a comprehensive and effective approach to stakeholder participation and involvement.

4 Membership

4.1 The Chair of the Programme Board is the National Director: Commissioning Strategy as appointed by the Board Task and Finish Group, and has particular responsibility for providing effective leadership.

4.2 The Director of System Policy is the Vice Chair and is responsible for chairing Programme Board meetings and providing leadership if the Chair is unavoidably absent, or is not able to chair the meeting due to a conflict of interest for specific items on the agenda.

4.3 **Core Membership**
The core membership of the Programme Board is as follows:

- Ian Dodge, National Director: Commissioning Strategy (Chair);
- John Holden, Director of System Policy (Vice Chair);
- Wayne Bartlett-Syree, Assistant Head of Planning and Delivery (Specialised Commissioning;
- Eleri de Gilbert, Area Team representative, Area Team Director (South Yorkshire and Bassetlaw area team);
- Sam Higginson, Finance representative, Director of Strategic Finance;
- Chris Hopson, Chair of the review's Provider Group;
- Will Huxter, Regional Team representative, Head of Specialised Commissioning (London);
- Professor Deirdre Kelly, Chair of the review's Clinician Group;
- Professor Sir Bruce Keogh, National Medical Director;
- Michael Macdonnell, Head of Strategy, Specialised Commissioning Taskforce;
- Mr James Palmer, National Clinical Director, Specialised Services;
- Linda Prosser, Area Team representative, Director of Commissioning (Bristol, North Somerset, Somerset and South Gloucestershire area team);
- Professor Sir Michael Rawlins, Chair of the Clinical Advisory Panel;
- Professor Peter Weissberg, Chair of the review's Patient and Public Group;
- Giles Wilmore, Director for Patient & Public Voice & Information;
- Michael Wilson, review Programme Director; and
- two CCG representatives, to be identified.

4.4 The meeting will be quorate if nine members are present.

4.5 Where members are unable to attend a meeting, they may field a nominated deputy. Such deputies in attendance will count toward the meeting being quorate.

4.6 **Additional attendees**
The additional attendance at the Programme Board is as follows:

- Secretariat.

5 Frequency

5.1 The New Congenital Heart Disease Review Programme Board meeting will be held monthly and on such other occasions as the Chair shall deem necessary.

6 Secretariat

6.1 The Programme Board Secretariat function will be provided by the new congenital heart disease review team.

7 Agenda and papers

7.1 The agenda and all papers will be normally be distributed via email to members and those in attendance in advance of the meeting by the new Congenital Heart Disease review team. The agenda and papers will be published on the NHS England website in advance of the meeting.

7.2 The actions to be taken will be recorded in the Programme Board's minutes which will be circulated to all members of the Programme Board.

7.3 The Chair is responsible for ensuring that the minutes of meetings, produced by the Secretariat, and any reports to NHS England accurately record the decisions taken, and, where appropriate, that the views of the individual members have been taken into account. Once agreed by the Chair the minutes will be published in draft on the NHS England website.

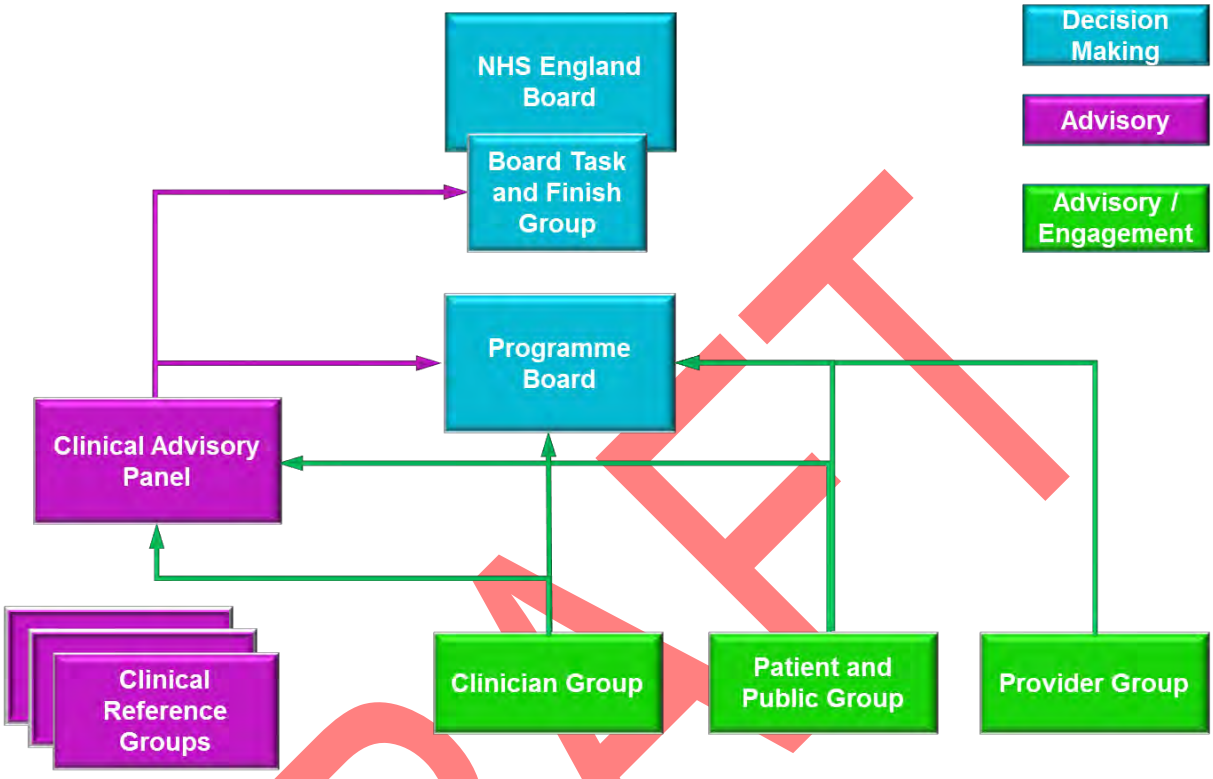
7.4 Minutes will be formally approved at the subsequent meeting. Approved minutes will be published on the NHS England website.

8 Reporting line(s)

8.1 A report will be provided by the SRO at each meeting of the Board Task and Finish Group on the work of the review.

8.2 The Programme Board will make recommendations to the Board Task and Finish Group of any decisions requiring full Board approval and at the end of phase 3.

8.3 A diagram illustrating the governance structure is shown below:



9 Declaration of interests

9.1 Members must comply with the document "Managing potential and perceived conflicts of interest" which details the approach and broad principles for the management of potential and perceived conflicts of interest, specifically in relation to the new Congenital Heart Disease review.

10 Public services values for members

10.1 Members must comply with the NHS England Standards of Business Conduct Policy at all times. Available here: http://www.england.nhs.uk/wp-content/uploads/2012/11/stand-bus-cond.pdf

Consultation Products

In preparation for consultation the new CHD review team have drafted the consultation document and an outline for the associated reference pack. In addition, impact assessments and assurance papers have been completed as previously agreed with the Programme Board.

Governance processes are in place to assure the following:

- that the standards, specifications and impact assessments meet the expectations for NHS England as commissioner for these services (specialised commissioning governance); and
- to assure the process the review is undertaking and the consultation materials and plans are appropriate and take into account everything we have learned to date (programme governance).

Attached to this paper are drafts of these documents, and the Programme Board is asked to review, comment and approve as follows:

Annex A – Consultation document including consultation questions

The Programme Board is responsible for assuring the content of this document and the consultation questions. Further amendments will be made to both the document and consultation questions following advice from the Programme Board and the review's key stakeholders, and in relation to how the responses to the consultation can be analysed.

The Programme Board is asked to review and comment, and to delegate final approval of the content to John Holden, Vice-Chair of the Programme Board following that advice being obtained and reflected in the document and questions.

Annex B – Outline of the consultation reference pack

This document will contain all the appropriate reference material for the consultation. These are reference materials which have been previously produced and published gathered together for ease of access. They will provide background and context for the consultation.

The Programme Board is responsible for assuring the content of this pack, and is asked to advise whether this is a full and appropriate list of materials required to support the main consultation document.

Annexes C and D - Initial financial impact assessment and initial equality analysis

These documents will be considered by the specialised commissioning governance groups. They are designed to outline the potential impact of implementing the standards and specifications in their current draft form, to inform the consultation process.

The Programme Board is asked for advice and comment, and to approve for onward submission to the Programme of Care (POC) board as the first step in the specialised commissioning governance process.

Annexes E and F – Governance and engagement papers

The documents will be considered by the specialised commissioning governance process. They are designed to support the requirement by the POC board, the Clinical Priorities Advisory Group

(CPAG) and the Directly Commissioned Services Committee (DCSC) that both the governance and engagement processes that have been undertaken in the development of the standards and specifications have been full and appropriate, and that they reflect the views of the stakeholders involved.

The Programme Board is asked for advice and comment, and to approve for onward submission to the POC board as the first step in the specialised commissioning governance process.

Foreword from Chairman, Professor Sir Malcolm Grant

To follow

The foreword will

- acknowledge importance of the issues, and thank contributors for their work, and
- set this review in context of current NHS England work on specialised services, and broader "forward look" strategic review for publication in the autumn"

Introduction

Babies born with congenital heart disease (CHD) are amongst the most vulnerable patients the NHS cares for. We must ensure that CHD patients receive the best care we can provide from diagnosis and early treatment through to lifelong care and support.

Although relatively small in terms of numbers and expenditure, congenital heart disease is a matter of great public concern. Confidence in the service has been undermined by many years of repeated review and investigation (even though services in England are considered to be as good as those in any country in the world).

New standards for congenital heart disease services are proposed for consultation. These will ensure consistent best practice across all providers in terms of how services should be organised and delivered but do not introduce new clinical interventions or change the threshold for treatment.

In this consultation, we are seeking your views on draft standards and service specifications for the delivery of congenital heart disease services for children and adults in England. We are also asking for your views and contributions to the draft financial impact assessment and draft equality analysis that sit alongside this consultation.

This document summarises the issues and lists the consultation questions. The detailed standards can be found in our reference document [insert link].

This consultation forms part of the work of the new congenital heart disease review ('the new review'). NHS England's Board set up the new review in June 2013 to consider the whole lifetime pathway of care for people with congenital heart disease; and to make sure that services for people with congenital heart disease are provided in a way that achieves the highest possible quality within the available resources. The Board saw the new review as a real chance to bring about lasting improvements for some of the most vulnerable NHS patients.

The aims of the new review are to ensure:

- the best outcomes for all patients, not just lowest mortality but reduced disability and an improved opportunity for a better quality of life for survivor
- variation is tackled so that services across the country consistently meet demanding performance standards and are able to offer resilient 24/7 care; and
- great patient experience is delivered, which includes how information is provided to patients and their families and consideration of access and support for families when they have to be away from home.

This consultation on draft standards and service specifications is one part of the review. We are also

- analysing current and future demand for services,
- looking at the overall “shape” of the service that is provided,
- considering how best to commission any required improvement and support the necessary change,
- reviewing how better, more timely information can be provided
- looking at ways to achieve better earlier diagnosis of congenital heart disease.

The proposed standards

Developing the standards

When we started our work, stakeholders (patients, public, clinicians and providers) told us that the best way to improve congenital heart disease services was through clear service standards, consistently applied.

"The aim of the review is to ensure that services achieve the highest possible quality within the available resources, now and for future generations…the standards [must] set out what is needed to achieve this"
Professor Sir Bruce Keogh

The fact that NHS England has sole legal responsibility for buying specialised (including congenital heart disease) services, gives NHS England an opportunity not open to any of our predecessors, to drive consistently high standards right across England.

Work on congenital heart disease standards was already underway for children's and adult services when the new review was set up. The review team has continued to work with the professionals involved to draw the different pieces of work together into one coherent set of standards that describes the whole patient pathway from fetal diagnosis through children's and adult services including transition and pregnancy, to end of life care and bereavement.

During this process, the team has worked with those who were involved in the earlier development of standards, with new engagement and advisory groups (patients and public, clinicians and providers) and a national, expert Clinical Advisory Panel; and has regularly reported its progress through the use of a fortnightly blog

The proposed standards in detail

The proposed service standards will ensure that patients across the country receive the best possible care, within the available resource, now and in the future. The standards have been designed to ensure that there is a joined up system where care is provided through a network of services with the patient at the centre. Networks rely on agreed ways of doing things, and the standards focus on how services are delivered, what is needed to support effective joint working and what is needed to ensure the best patient experience.

There are 13 sections, listed from A-M (networks to dentistry):

Section A: The network approach
Section B: Staffing and skills
Section C: Facilities
Section D: Interdependencies
Section E: Training and education
Section F: Organisation, governance and audit

Section G: Research
Section H: Communication with patients
Section I: Transition
Section J: Pregnancy and contraception
Section K: Fetal diagnosis
Section L: Palliative care and bereavement
Section M: Dentistry

The standards have been developed by groups of practising clinicians from most congenital heart disease specialist surgical centres in England and by patient representatives.

The service specifications (the way in which NHS England ensures that the standards are part of its contracts with hospitals) have been developed by the Congenital Heart Disease Clinical Reference Group.

During the pre-consultation period, we have conducted extensive engagement with the groups who created the draft standards our engagement and advisory groups, and with patients and staff in all specialist surgical centres.

In developing these standards, we have tried to show what we have heard and what we are proposing as a result. A paper summarising all we have heard is available here.

There is broad agreement on most of the proposed standards. But there are some areas where we have heard different views. For example, people have different views about the number of surgeons required in each centre, the volumes of work they undertake, which services must be near each other ("interdependencies") and the case for some procedures to be restricted to a very few larger centres ("sub-specialisation").

Where relevant we have also highlighted the different views. In each case, we make clear the approach we prefer, and why.

In the following pages we summarise what we are proposing for each section of the standards, and the specific topics where we have heard different views.

There are consultation questions at the end of each section, and these are all listed together at Annex A.

Section A: The network approach

Section A sets out how all hospitals treating people with congenital heart disease will work together to deliver the best possible outcomes within existing resources. Networks include all congenital heart services, both adult and paediatric, at all three levels of the service

What we have heard

We have heard that networks are essential to good outcomes and patient experience. Networks provide a way of bringing hospitals together around congenital heart disease to improve services, shared learning, deliver efficiencies and improve patient outcomes. Networks should bring together children's and adult services. Networks need to have clear leadership including a single clinical leader, and be properly resourced and supported. Clinicians have a key role in making networks work locally and nationally.

Local networks

Networks of local hospitals can work together at an operational level to meet local needs and can also work as quality improvement networks by helping each other and encouraging shared learning and skills development.

Hub and spoke networks centred on specialist surgical centres ensure that patients can move smoothly between locations, with information being shared and with hospitals working together using the same policies and protocols.

We have heard mixed views on whether it is good to have fixed, geographical network boundaries. The advantage of fixing boundaries is that patient numbers can be managed across specialist surgical centres; the disadvantage is that it could be argued that it does not encourage adequate choice and competition. However, fixing network boundaries could also affect the number of centres, or whether patients are able to use their closest centre.

Regional or national level networks

Networks at a regional or national level offer the opportunity for specialist surgical centres to work more closely together to share learning and skills and to provide important quality assurance and mutual challenge, enhanced training and research opportunities.

They could also have a role in ensuring that the congenital heart disease standards are being met and would provide an element of peer review.

We have heard that one of the effects of the congenital heart disease service having been under review for more than a decade is that centres are not always working together as closely as they might. Emphasising the importance of networks at all levels in future contracts could set the direction for future working.

What makes a good network?

We have heard that good networks need to:

- be clearly defined, including role and responsibilities, and needs to cover children's and adult services
- include all elements of congenital heart disease care – not just surgery
- comprise high quality services
- be large enough to be sustainable, but small enough to manage
- have adequate resourcing, clear leadership and named contacts
- develop consistent care pathways for children and adults to identify how hospitals work together – patients need to get the right care in the right place
- invest in developing individual relationships across the network
- ensure that there is a shared understanding of how each part of the network works with each other
- ensure that there are shared information systems including clinical IT systems and videoconferencing

What we are proposing

In Section A we propose the creation of congenital heart networks that include both children's heart services and adult congenital heart services. These will be based around specialist surgical centres, with strong clinical leadership care that will mean that all care and treatment is delivered by the most appropriate professional in the most appropriate setting as close as possible to home. This includes an expectation that congenital heart surgery for children and adults is only undertaken in specialist surgical centres. The networks will consist of:

- specialist children's surgical centres and specialist adult congenital heart disease centres
  (level 1)
- specialist children's cardiology centres where these exist – it is not mandatory for all networks to include level 2 provision, but where there is level 2 it, must meet the standards and specialist adult congenital heart disease centres (level 2) local children's cardiology centres and local adult congenital heart disease centres (level 3)

Networks will be required to have formal working relationships with cardiothoracic transplant centres, the national Pulmonary Hypertension Service and a children's and adult cardiac pathologist with expertise in congenital cardiac abnormalities.

The precise shape of each congenital heart network will be determined by local need and local circumstances, including geography and transport. It will be important for congenital heart networks to work closely with other local networks, including

maternity and fetal. Networks will be hosted by an agreed lead provider and that organisation will provide appropriate managerial and administrative support for the effective operation of the network, ensuring that all organisations in the network also provide management and administrative support. Networks will be expected to organise weekly specialist multi-disciplinary team meetings to consider case management and cover second opinions and referrals. (We consider multi-disciplinary teams in section B)

The standards propose that a new standard health records summary is developed to improve information sharing across and between networks giving the responsible clinician's name and a management plan; and shared telemedicine and information technology across networks.

In addition, the standards propose the development of a nationally consistent system of 'patient-held records'. The standards include an expectation of regional and national networking that will allow patients to receive the most appropriate care from the most appropriate person with the required skills at all times.

What this will mean

- Hospitals and clinicians will work together locally, regionally and nationally to provide the best possible care for patients
- Patients, their families and their carers will have a better experience as the services they receive will be more joined-up and will work around the patients
- Networks will ensure that the new standards are implemented in all their hospitals and lead quality improvement

Consultation questions

- Do you agree with local (i.e. single centre) networks?
- Do you agree with regional (i.e. multi centre) networks?
- Do you agree with national (i.e. all centre) networks?
- Are there any important aspects of network working that we have missed?
-
- Could fixed geographical network boundaries improve outcomes?

  Please explain your answers

Section B: Staffing and skills

Section B sets out the staff and skills needed in teams to deliver a world class service across all parts of the network to deliver excellent outcomes within existing resources. This covers all three tiers of the service

What we have heard

We have heard that it is important to ensure that all centres are adequately staffed and that staff have the skills they need. We have heard that there is a need to ensure that people with congenital heart disease, their families and carers are supported by a multi-disciplinary team.

We have heard that care and treatment also includes making sure the emotional needs of patients of all ages are addressed. Patients and their families need help to understand the health system, and to sort out other important areas like benefits and education.

In our discussions about staffing, we have heard different views about surgeon numbers in each specialist surgical centre; and about how many cases a surgeon needs to do each year. We cover the points that have been raised and what we are proposing in more detail in xxxxx.

A common theme that came up in our conversations was concern about current and future staffing levels, in particular capacity in paediatric intensive care units and intensive therapy units.

What we are proposing

In Section B we propose the staff and skills (surgeons, cardiologists, paediatricians with expertise in cardiology, cardiologists with an interest in congenital, specialist nurses, psychologists and others) needed to ensure that a world-class service is provided across the country.

We set out minimum staffing and activity levels for surgeons and interventional cardiologists, including out of hours cover; specifications for staffing of catheter labs, electrophysiology, imaging and echocardiography, anaesthesia and intensive care, nursing including paediatric, adult, fetal and transition specialist nurses, psychology and requirements for administrative support, safeguarding leads and named bereavement officers.

We describe what needs to be in place to ensure that there is all year round, 24 hour staffing, including on-call arrangements to ensure consistent high quality care.

The standards remind professionals that they must only provide care that they are competent to give and make clear that they must seek support from a colleague or refer the patient to another centre, if they do not have the necessary skills.

We also include a requirement that all centres and networks must work together to develop and support national, regional and local collaborative arrangements.

We understand that there is concern about staffing levels, in particular in paediatric intensive care units and intensive therapy units, and we will work with the Royal Colleges, professional associations and Health Education England to make recommendations in relation to workforce and future training strategies as a later part of the work of the review.

What this will mean

- The standards are designed to ensure that wherever patients receive their care, the centres will have the right staffing with the right skills, and if necessary will refer patients to another unit if they need more specialist care, or will bring in expert support
- We expect that there will need to be an increase in the number of some staff groups at some centres to meet the standards, for example, surgeons, specialist nurses and psychologists
- Networks will need to ensure that each centre has the right staffing levels, and the right skill mix at all times

Questions

- Will these standards ensure consistent high quality 24 hour care at all centres?
- Are there important staff groups that we have not included or need to say more about?
- Are there particular staff groups where training, recruitment or retention may be an issue? If so, what is your concern?

Section C: Facilities

Section C sets out what facilities and equipment are needed to deliver care and treatment to people with congenital heart disease, to support families and carers, to deliver the best possible outcomes within existing resources. This covers all three tiers of the service.

What we have heard

We have heard that having good facilities makes a huge difference to patient and family experience.

What makes a difference

We have heard:

- It would be helpful if hospitals provided a 'How to find us/About Us' booklet with information about where to park, eat and sleep (for people who are not local)
- Facilities need to be welcoming and clean. They need to be age appropriate
- Play rooms need to be staffed so children can use them with separate facilities for young people and adults
- Living in hospitals is expensive and can be unhealthy. There need to be facilities where people can make their own meals and shops/cafes where people can get inexpensive and nutritious food (taking into account intolerances, allergies and religious restrictions)
- Wi-Fi needs to be available at all times for patients to let them keep in touch with friends and family, for entertainment, education and work
- Facilities to keep up with schooling need to be available for children and young people
- Parking charges need to be reasonable or removed
- Facilities need to be wheelchair friendly

What we are proposing

In Section C we set out what will be required in the different centres. This includes standards that relate to the provision of hospital information booklets; age appropriate facilities; Wi-Fi; catering facilities; schooling; reasonable cost parking; and dedicated room space for therapeutic work.

What this will mean

- Networks and centres will need to ensure that they are able to offer the facilities that will improve the overall experience of patients, their families and carers
- Patients, families and carers will be able to live as normally as possible during times spent in hospital

Questions

Have we identified the most important improvements that will make the biggest difference to patient and family experience? Are there others?

Is there any risk that in seeking these improvements we might inadvertently compromise clinical care/best outcomes for patients?

Section D: Interdependencies

Section D sets out the relationship congenital heart disease services (children's and adults) have with each other and with other services to deliver the best possible outcomes within existing resources. This covers all three levels of the service

What we have heard

We have heard that when done well, the relationship between maternity services, fetal and paediatric cardiology, fetal medicine, neonatal intensive care unit and adult congenital heart disease cardiology can make a real difference both to the care delivered and to patient experience.

Having services for children and adults all on one site was considered by some to improve efficiency and to promote the sharing of expertise. But this alone is not the answer. The services must work together with the patient at the centre – and this means different services having positive relationships and excellent communications, wherever they are located.

We also heard that some children have multiple morbidities and will need access to a range of other specialists, for example, paediatric surgery and renal specialists. As the care of patients with congenital heart disease has improved, pregnancy is becoming more commonplace, emphasising the importance of a close relationship between maternity and adult congenital heart disease services.

We heard that triple co-location is ideal, that is, to have all the following services on the same site:

- Paediatric congenital heart surgery with other paediatric services
- Adult congenital heart surgery with other adult services
- Paediatric cardiac with adult congenital heart services

We heard that while this is ideal, other arrangements may be acceptable with appropriate responsiveness (time it takes between services to provide advice or take over care) and good working relationships. Everyone did not agree on exactly which services need to be on the same site. Everyone did agree, however, that wherever they are located, excellent and timely communication and information sharing between specialists is essential as part of the network.

We heard that because of shared rotas, joint working and the need to minimise losses to follow up at transition mean that children's cardiac and adult congenital heart services need to be close to each other and work as a fully integrated service.

We asked the University of Sheffield's School of Health and Related Research (ScHARR) to look at the research on the benefits of co-location of services in relation to mortality and reducing health complications. They found few good studies to inform our thinking so the standards are based on expert opinion.

What we are proposing

The standards recognise that triple co-location is ideal, but where this is not possible, they set out which services must be on the same site, and the required levels of responsiveness for all services (call to bedside within 30 minutes, 24 hours a day, all year round).

The standards propose a new requirement that children's congenital heart surgery should only take place in hospitals that also have other children's services on the same site, in particular paediatric surgery, surgeons with skills in repairing vascular damage in children, paediatric renal specialists, paediatric gastroenterologists, paediatric physiotherapists and paediatric pain management services. This recognises the importance of multidisciplinary care for children with complex heart disease and addresses concerns about the safety of caring for children with complex conditions (a high proportion of whom will need input from other specialties) in settings without other paediatric services.

What this will mean

- The interdependency standards are designed to ensure that wherever patients receive their care, all the experts they are likely to need are on site or available very quickly

- Not all current centres as presently arranged will be able to meet the requirements: this includes the integration of children's and adult congenital heart disease services; which children's services are available on the same site; and the responsiveness of other specialties. Centres will need to consider how to arrange services to ensure that they meet these standards. The relationships between specialties and the way they work together for patients will also need to be examined.

Consultation questions

Will these standards ensure that all the services needed by patients are available when they need them and that they work together with patients as their focus? If not, why not.

Do you agree with our proposals for which services must be on the same site? Please explain any areas of disagreement.

Do you agree with the levels of responsiveness described for each service? Please explain any areas of disagreement.

Are there any unintended risks/consequences which NHS England must bear in mind in commissioning the service against the proposed new standards?

If hospitals need to make changes how much time should be allowed by the specification to achieve compliance with the inter-dependency standards?

Section E: Training and education

Section E sets out what continuing training and education all healthcare professionals involved in the care of those with congenital heart disease need to do, in order to deliver the best possible outcomes within existing resources. This covers all three tiers of the service

What we have heard

The feedback we have received specifically about ongoing training and education has been limited.

We heard that it is important to ensure that trainees are able to communicate effectively with patients, their families and carers and listen to the patient.
We also heard that nurses in level 2 and 3 services need specific help to maintain their skills and knowledge because they do not see congenital heart disease patients all the time. We heard that this was less of an issue for level 2 cardiologists as they see congenital heart disease patients more frequently.

In our discussions about networks – we heard about the important role networks can play in enabling all members of multi-disciplinary teams to learn from each other.
We also heard that there are pressures on junior staff and training, particularly in smaller units.

What we are proposing

We are proposing that all centres need to ensure that all healthcare professionals involved in the care of people with congenital heart disease stay up to date through continuing training and education.

Congenital cardiology networks will have a formal annual training plan in place.

Networks are required to have cardiac clinical nurse educators to deliver standardised training and education that is competency based across the network. The training and education will cover clinical knowledge and skills, as well as teaching, research, audit and management.

There is a requirement that all members of cardiac medical and nursing teams will complete mandatory training on end of life care, breaking bad news and supporting families and carers through loss.

What this will mean

- Patients, families and carers will be cared for by staff who are appropriately trained in the skills needed to perform their jobs
- Networks and centres will need to ensure that they have the right processes in place to train staff appropriately

Consultation questions

- Will the standards help ensure that all health care professionals involved in the care of CHD patients have the skills they need to provide high quality compassionate care? If not, why?

Section F: Organisation, governance and audit

Section F sets out systems to ensure good decision making and quality improvement, including learning from local data and experience to deliver the best possible outcomes within existing resources. This covers all three tiers of the service

What we have heard

We have heard that the way information is collected and used varies across centres – and some centres have more advanced systems than others. The best systems are being used to improve quality. We have heard that the multi-disciplinary team needs to make decisions on surgery and intervention (except where they are covered by protocols) to deliver the best outcomes.

While recognising that there will always be emergencies, some people told us that they felt too many operations were cancelled at short notice.

We heard that systems for reporting adverse incidents are not clear.

There need to be stronger links between GPs, hospitals, workplaces and schools so that everyone has all the information they need in relation to the patient.

What we are proposing

We are proposing that specialist surgical centres have a dedicated management group for the internal management and coordination of service delivery.

The standards require the development of a robust and documented clinical governance framework that includes:

- Clinical audit
- Regular network multidisciplinary team meetings to discuss patient care pathways, guidelines and protocols
- Regular network meetings, to discuss mortality, morbidity and adverse incidents
- Regular audit days that include discussion of adverse incidents and follow up action plans

The Specialist Surgical Centres will be responsible for reporting on adverse incidents and for sharing information throughout the local and national networks.

The standards set out systems to ensure that:

- Networks keep up to date with new technologies and new treatments
- Networks and centres plan workforce needs
- Waiting times and cancellations are noted and acted upon
- Audit is used to drive improvement.

What this will mean

- Patients, families and carers will benefit from clearly organised systems focused on patient care and improved outcomes
- Networks and centres will need to ensure that they have the right processes in place to deliver quality outcomes based on robust information and audit systems

Consultation questions

- Do you agree that the standards will help ensure there are systems in place which support excellent patient care through a consistent approach to clinical governance and information sharing? If not, why?
- What further improvements may be required?

Section G: Research

Section G sets out a requirement for networks to have and regularly update a research strategy and research programme to deliver the best possible outcomes within existing resources. This covers all three tiers of the service

What we have heard

We have heard that many centres have close links with academic institutions.

What we are proposing

We are proposing a new commitment to research that ensures that all services are continually focused on improvement and development. Networks will be required to have, and regularly update, a research strategy and research programme to better clinical practice and outcomes. In addition, they will be required to demonstrate close links with one or more academic department(s) in Higher Education Institutions.

What this will mean

- Patients, families and carers will benefit from research that adds to the understanding of congenital heart disease now and in the future
- Networks and centres will be able to keep adding to their knowledge and understanding

Consultation questions

- Do you agree that the standards appropriately reinforce the importance of a research strategy and programme? If not, why?

Section H: Communication with patients

Section H sets out the importance of ensuring that patients of all ages, family and carers are able to participate actively in decision making at every stage in their care to deliver the best possible outcomes within existing resources. This covers all three tiers of the service

What we have heard

We have had more feedback in relation to communication than any other standard. We have heard that patient information (including personal needs and preferences) as well as medical notes, need to be in one place and available to all the professionals involved. This would mean that people do not have to repeat their story to different health professionals.

Communication with patients: what matters

Discussions need to be:

- With the appropriate person(s): patient and/or parent/carer and age appropriate
- Honest about diagnosis and ongoing care plan
- Two-way and respectful
- Understanding and understandable
- Empathetic and sympathetic

Information needs to be presented so that it is:

- Clear and understandable and needs to cover, for example:

- information about patient choice
- what it feels like before and after operations
- better support to deal with anxiety and depression
- a clear process for providing feedback and for making complaints

There needs to be

- improved sharing of patient information within and between centres and networks
- more information about, and help with, living with congenital heart disease including:

- liaison with childcare providers and schools
- lifestyle choices for young people
- what happens at transition
- follow on health care and checks; and
- benefits and allowances.

What we are proposing

We are proposing that all centres put in place arrangements to ensure that patients, parents and carers are able to participate actively in decision making at every stage.

Every patient will be given a detailed written care plan that sets out the follow-up process and setting. The plan must be copied to all involved clinicians and the patient's GP.

Patients, families and carers must be supported to understand the patient's condition and the effect it will have on their health and future life and the treatment they will receive, including involvement with the palliative care team if appropriate.

Interpreters and/or advocates must be provided where patients do not have English as their first language or have other communication difficulties such as deafness or learning disabilities. There must be access (for patients and family members and carers) to support services including faith support and interpreters.

Information will be provided on all aspects of life that are relevant to the condition, including social and community services; benefits; sex, contraception and pregnancy; dental care and endocarditis; and school and careers.

The standards emphasise the need for two way communication and encourage concerns and complaints to be raised and to be dealt with in an open and positive way that is followed through with the person who has raised the complaint. Patients will be supported if they request a second opinion.

We have proposed increased sharing of information within and across centres and networks. Children's Cardiac Nurse Specialists and Adult Congenital Heart Disease Nurse Specialists will liaise between the clinical team, the patient, family and carers throughout their care. Patients who are going to have surgery will be given the chance to visit the specialist surgical centre before the operation.

What this will mean

- Patients, families and carers will have a better understanding of congenital heart disease, the care provided and what the options are. They will also be encouraged to offer feedback and complain if they need to
- Networks and centres will work with patients, families and carers to help and support them at all times, giving them the information they need in a form that makes sense

Consultation questions

- Will the standards ensure consistently good communication in support of better patient care? If not, why?

Are there any other ways in which communication might be improved?

Section I: Transition

Section I sets out the importance of ensuring that young people can move smoothly from children's to adult services in a way that respects individual circumstances and needs to deliver the best possible outcomes within existing resources. This covers all three tiers of the service

What we have heard

We have heard that transition needs to be planned carefully and be personalised. It needs to be accompanied by information for everyone that is clear and easy to understand. There needs to be a gradual introduction to the new staff and ward/building. In a centre offering children's and adult congenital heart disease services, parents like being able to keep in touch with both teams. Transition needs to be a time of joint-working between the children's and adult congenital heart disease services.

We have heard that the time for transition will depend on the young person – some will need more support than others and this needs to be recognised and listened to.

With young people who have more complex needs including learning disabilities, there needs to be more support in adult services as well as help to understand the health and social care systems which can be complicated.

We heard that around the age of 14 young people feel like they are stuck between the child and adult worlds. People have suggested having young people's wards and young people's services that are targeted to young people's needs, including lifestyle choices as well as education/employment opportunities.

We have heard that that there are a number of things that help young people transition well:

- Dedicated transition nurses
- Young adult clinics
- Transition days
- Being able to speak to someone who has already gone through it if you want (buddy system)
- Meeting the new consultant and ward staff before transition
- Teenage and young adult wards

What we are proposing

In Section I, we propose consistent linked standards for children's and adult services. All services in the local Congenital Heart Network must have appropriate arrangements in place to ensure a seamless pathway of care, led jointly by paediatric and adult congenital cardiologists.

The standards emphasise the need for transition to be tailored to meet individual needs, but the process of transition will be started no later than age 12, taking into account individual circumstances and special needs. Transfer will normally be completed by age 18.

Approaching transition the patient will be seen at least once for consultation by an adult congenital heart disease cardiologist and an adult congenital heart disease specialist nurse. Clear care plans/ transition passports will be agreed and relevant records transferred. Young people, parents and carers need to be fully involved and supported in discussions about the clinical issues and the young person must be fully heard and their views considered. The particular needs of young people with learning disabilities and their parents/carers need to be considered.

What this will mean

- Young people will have the help and support they need as they grow up and move from children's into adult services
- Networks and centres will need to work together to ensure that all young people experience a seamless transition and those young people who need ongoing support and treatment continue to receive it

Consultation questions

- Will the standards help ensure consistently good transition arrangements? If not, why?
- Are there any other elements of transition that need to be covered?

Section J: Pregnancy and contraception

Section J sets out the importance of appropriate (age, culture, developmental) discussions during transition to deliver excellent outcomes within available resources. This covers all three tiers of the service

What we have heard

As the care of patients with CHD has improved, pregnancy is becoming more commonplace, emphasising the importance of a close relationship between maternity and ACHD services, and the importance of decisions about place of delivery and the levels of CHD cardiology support available.

What we are proposing

In Section J we propose that:

- women with CHD of child-bearing age will be given the opportunity to discuss their child-bearing potential and contraception with a consultant cardiologist and specialist nurse
- Men with CHD will also have access to genetic counselling and information about contraception and recurrence risks
- specialist genetic counselling will be available for those with heritable conditions

Discussions about family planning will begin during transition (from age 12 in line with national curriculum requirements, but taking into account culture and level of understanding).

Patients will be offered access to a Practitioner Psychologist, as appropriate, throughout family planning and pregnancy, and when there are difficulties with decision-making, coping or the patient and their partner are concerned about attachment.

Each Specialist Adult Congenital Heart Disease Surgical Centre must be staffed by Specialist Adult Congenital Heart Disease cardiologists with expertise in pregnancy, with appropriate arrangements for cover within the centre. And patients considering pregnancy who carry a medium/high risk, must receive joint pre-pregnancy counselling with the cardiologist and a maternal medicine specialist (consultant obstetrician) with expertise in pregnancy in women with congenital heart disease.

Pregnant women with congenital heart disease must have the opportunity for access to termination of pregnancy services. The individualised care plan must cover the antenatal and postnatal periods as well as pregnancy. It must include clear instructions for shared care with other services as needed.

Each Specialist Adult Congenital Heart Disease Surgical Centre must be linked to a specialist maternity unit staffed by a multi-disciplinary team. Ideally they would be on the same site but must be no more than 30 minutes away.

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What this will mean

- Patients will be able to make informed choices in relation to contraception, termination, pregnancy and maternity
- Pregnant women who are at risk will be cared for in the most appropriate setting
- Networks and centres will be able to plan services and staffing appropriately and ensure that support services are to hand in high risk pregnant women

Consultation questions

- Do the standards set out a comprehensive and helpful approach to issues concerning pregnancy and contraception? If not, why?

Section K: Fetal diagnosis

Section K sets out the importance of networks, and providers working together to ensure that national standards are consistently applied and results reported

What we have heard

Early detection is important but is not as good as it could be and there are differences in detection rates between different parts of the country.

We have heard that national standards for the screening programme to test for congenital heart disease at 18-20 weeks were only introduced in 2010 and they have not been fully implemented yet. This means that there is variation across the country. New standards are expected in 2015, but we have heard that some units are struggling to even offer the 18-20 week scan.

We heard that standards are not the full answer and that the following areas are also important:

- adequate and continuous training for sonographers
- a national fetal anomaly register to show performance across units
- ultrasound funding
- fetal network

We have heard that this is a very worrying time for parents and that everything possible needs to be done to minimise the time between the first suspicion of a problem and final diagnosis. We have also heard how important it is that parents are provided with support at this time and are given all the information they need to make the best decisions. In particular we have heard that:

- the time between 18-20 week scan and a specialist scan needs to be as short as possible (the ideal would be for women to be able to see both the fetal medicine and fetal cardiology specialists on the same day)
- specialist nurses play an important role in supporting patients

What we are proposing

All Congenital Heart Networks must work with all providers of maternity and paediatric cardiac services in their network to ensure that NHS Fetal Anomaly Screening Programme (FASP) standards are consistently met and results reported. This will include putting in place arrangements to ensure that all women with a suspected or confirmed fetal cardiac anomaly are seen more quickly by a specialist.

Where there is a concern that a baby in the womb may have abnormalities of the heart, a firm diagnosis will be made as quickly as possible and expert advice and support will be made available at this difficult time.

At diagnosis, a plan will be developed that gives information about arrangements for delivery of the baby. The plan will be updated during pregnancy. Where appropriate,

the delivery will be arranged at or close to a Specialist Surgical Centre. Where the plan is for delivery at the local maternity unit, arrangements need to be put in place in case early intervention or assessment is required.

What this will mean

- **Patients will receive the same high quality fetal anomaly screening wherever they live and will receive the support care, and information they need if an anomaly is suspected**
- **Networks and centres will need to ensure that they are meeting FASP and BCCA standards and have the support in place for women who have a suspected or confirmed cardiac anomaly**

Questions

- Do you agree that the standards will help to ensure consistent provision of fetal screening and high quality support. If not, why?

Section L: Palliative care and bereavement

Section L sets out how to provide support at end of life and how to manage communication with families around the end of life

What we have heard

We have heard that when a patient with congenital heart disease is becoming progressively ill or dies, families and carers depend on psychological, social, spiritual and practical support. And that excellent and open communication is key.

We have heard that staff need to be trained in how to break bad news. In our discussions about bereavement and poor outcomes, we heard that the way in which this is handled is not always as sensitively as it might be.

We heard that families and staff needed to be able to express grief and sadness within a supportive culture – and not one of blame/denial. They want to be able to understand what has happened and why..

What we are proposing

In Section L, we have developed standards that relate to all levels of the service and are consistent for children and adults.

We describe how CHD services should support patients and families at this time with the help of other existing teams (like palliative care, pain and bereavement specialists). All CHD services must be able to provide appropriate support to patients who are dying and to their families.

This will include bereavement follow up and referral for ongoing emotional support of the family/carers.

When a patient enters the end of life pathway, a lead doctor and named nurse will be chosen by the multi-disciplinary team and the patient and their family/carers. The lead doctor and named nurse will make sure that the patient and their family/carers are supported up to, and beyond death. They will also ensure that an individual end of life pathway is developed and that that is written down and agreed with all medical, nursing and psychological support team members.

A key element of this standard is the need for communication and end of life care discussions with patients and their families/carers to be open, honest and accurate.

The standards cover care in the hospital as well as the arrangements to be made if a patient wishes to be at home.

The standards also set out the support that must be given to bereaved families and carers at the time of death and afterwards.

What this will mean

- **Patients, families and carers will receive all the support they need once on the end of life pathway whether that be in the hospital or in the community, including at home**
- **Networks and centres will work together to agree and deliver appropriate care and support which will include care and support for families and carers after the patient's death.**

Consultation questions

- Do the standards help to ensure consistently good palliative and bereavement care? If not, why?

- Are there any other ways in which care might be improved?

Section M: Dental

Section M sets out how to ensure that congenital heart disease patients receive good dental care

What we have heard

We heard that it is important for people with congenital heart disease to receive appropriate dental care

What we are proposing

Each Congenital Heart Network will be responsible for having a clear referral pathway for urgent dental assessments for certain patients. All patients admitted and diagnosed with infective endocarditis must have a dental assessment within 72 hours.

We are proposing standards that relate to the provision of dental services in Specialist Children's Cardiology/Adult Congenital Heart Disease Services. Centre's will be required to ensure that any dental needs have been addressed prior to referral (where possible) and any outstanding needs are shared with the interventional/surgical team.

Centres must be able to provide access to theatre facilities and appropriate anaesthetic support, or refer patients to the Specialist Surgical Centre.

What this will mean

- **Patients who are at risk because of dental problems will be identified and treated**
- **Networks and centres will need to ensure that they have the facilities to undertaken dental surgery on congenital heart disease patients where needed**

Consultation questions

- Do the standards help to ensure the provision of appropriate dental care? If not, why?

FOCUS ON THE 'KNOTTY' ISSUES

We have heard broad agreement with the great majority of standards. At the same time there are a small number of issues where people disagree. Because of this we have given them more attention here. In each case we have clear proposals to be considered in consultation, but we have tried to set out the arguments on both sides so that you can make up your own minds. Please take the time to weigh the arguments and to let us know what you think.

Surgical caseloads and size of surgical teams

Surgery is carried out in Specialist Surgical Centres. In section B of the standards we consider staffing and skills. During pre-consultation, we discussed the ideal number of operations per surgeon each year, and how many surgeons there should be in surgical teams. We set out here what we have heard. We ask for your views on what the standards should say about the number of surgeons and their caseloads in each centre in order to deliver the best possible outcomes within existing resources.

What we have heard

During pre-consultation we heard continuing debate about the ideal number of surgeons in a team, but a clear consensus about the individual caseloads needed to ensure that skills are maintained.

Number of operations per surgeon (a year)

We have heard that it is important that each surgeon does enough operations on a regular basis to maintain their surgical skills (this is the case in all types of surgery, but is especially important in congenital heart disease because of the range and the complexity of procedures undertaken). All surgeons support a minimum of 125 operations. They told us that this must be seen as a minimum.

Surgeons are clear that the number of operations they each do is more important for achieving the best outcomes than the number of surgeons in a team and that increasing the number of surgeons in a team must never be at the expense of minimum levels of activity.

Some surgeons consider that maintaining skills is not just about numbers but also about the kinds of cases being done so some considered that short and long procedures should be counted differently.

Some thought that senior surgeons don't need to do so much surgery to maintain skills and that they could do more adult work but would still be competent to tackle paediatric work because of their accumulated experience.

Surgeon numbers

We have heard that surgeons in some centres are under great pressure and because of this few long-standing surgeons are still working. We heard about the risk of burnout and the potential for safety to be compromised.

In our discussions everyone was agreed that two surgeons in a team is not enough. This is because for around 20 weeks of the year (when the other is away) there is only one surgeon available to cover.

Most of the discussion we have heard has centred on whether a minimum of three surgeons in a team is enough or whether there needs to be at least four. Surgeons have mixed views about whether the minimum number of surgeons in a team should be three or four.

We have heard that a number of centres currently have teams of three surgeons and consider this to be acceptable and safe. It enables teams to plan holidays and training; on-call is not onerous (except in transplant centres) and surgeons tend to look after their own patients whether they are on-call or not. The key is good relationships within the team to work well together. There is no direct evidence that results are any less good.

We have also heard arguments in favour of bigger surgical teams – four surgeons or more. It has been argued that teams of at least four surgeons are needed to enable centres to:

- protect against fatigue and burnout among surgeons
- be more resilient to the loss of one surgeon (for example in the event of illness)
- provide 24 hour clinical cover all year round, with appropriate work-life balance and holiday cover
- provide a greater range of skills range with a greater chance to sub-specialise
- increase the opportunities for training, mentorship, dual consultant operating and professional development

Bigger surgical teams are also associated with bigger units which some consider to provide better supporting facilities and staffing, more attractive units for recruitment and greater opportunities for training and research. These are not seen as ends in themselves but as important contributors to higher quality services that will improve outcomes.

The idea that bigger units are associated with better outcomes was supported by the review of published evidence commissioned by the review which identified a substantial number of studies reporting a positive relationship between volume and outcome. However, while many studies showed better patient outcomes with larger volumes of surgery, this was not consistent and not all studies showed this. The relationship was stronger in studies of single complex conditions or procedures. The evidence did not tell us the best size for a CHD surgical centre. As a result our Clinical Advisory Panel told us that while the evidence was broadly supportive of the relationship between volumes and outcomes, by itself it did not provide a compelling argument for change.

The Clinical Reference Group advised that with increasing sub-specialisation, the number of surgeons was not the only issue. Each hospital needs to make arrangements to ensure the availability of surgeons with the required skills at all times including the ability to do surgery on new-born babies (the most frequent out of hours emergency), undertake complex congenital operations and to set up cardiac ECMO. Emergencies out of hours are however rare.

What we are proposing

Taking all this into account, we are accepting the advice we received from the Clinical Advisory Panel that the standards should state that teams should be made up of a minimum of four surgeons. This would reduce fatigue and burnout; secure consistently good outcomes; and enable surgical teams to adequately cover children's and adult services (which may be located in different centres). We are also proposing that congenital cardiac surgeons must be the primary operator in a minimum of 125 congenital heart operations a year (in adults or children) averaged over a three year period. This will enable surgeons to maintain their skills and will ensure the best possible outcomes for patients.

We are clear that we would not want to see teams of four or more in a unit too small to provide them with sufficient activity.

What this will mean

- Bigger surgical teams, with each surgeon doing enough operations to maintain their skills will provide greater assurance of quality.
- They will be better able to provide 24 hour clinical cover all year round, and be more resilient to events.
- Not all of the existing surgical centres have enough work for four surgeons each doing at least 125 operations per year.
- While we expect the number of operations being done to continue to rise, it is possible that this will mean that the way services are provided will need to change.
- This might mean fewer surgical centres in future, but other solutions are possible including managing the case load at each centre to ensure sufficient activity or creating multi-centre networks with larger surgical teams working across more than one centre.

Questions

Do you agree that it is important to ensure the number of surgeons is not increased at the expense of activity levels of individual surgeons?

What is your view on managing the activity levels at each centre to ensure that centres have sufficient cases? How will this support or undermine quality of care and patient choice? Would you support this if it meant that some patients received their care at a centre that was not their closest?

What is your view on surgeons working across more than one unit in multi-centre networks? What would need to change to make this work?

Sub-specialisation

Our proposals for bigger surgical teams are intended to ensure that, in every centre, the skills are available to perform most operations. Rare and complex cases would be managed either by referral to an appropriate specialist or by inviting a specialist to provide support at the patient's usual centre. However, some people have suggested that at least some centres should be bigger and that they should be designated to undertake more specialist work. We note here what we have heard, and what we are proposing, to deliver the best possible outcomes within existing resources.

What we have heard

We heard that the standards must ensure that congenital cardiac surgeons and consultant interventional cardiologist only undertake procedures for which they have the appropriate competence because not all cardiac surgeons and consultant interventional cardiologists are trained to perform all procedures.

Views are mixed on whether or not it would be appropriate to formally designate sub-specialist centres (so that they are identified as the ones that perform particular operations). While this would offer certainty in terms of competence, a two-tier service could result which would affect the service available in the other centres and might affect their long term future.

Doctors told us that they preferred a system to ensure that support is brought in from within the network or another specialist surgical centre or to refer the patient to an alternative specialist surgical centre where a surgeon/interventionist has the appropriate skills.

We heard that networks have an important role to play in ensuring that:

- there is free movement of surgeons to mentor and work alongside other surgeons in difficult cases
- the introduction of new techniques is managed.

What we are proposing

The staff and skills standards (Section B) require that all congenital heart surgeons and consultant interventional cardiologists only undertake procedures for which they have appropriate competence. The proposals relating to the number of surgeons in a team are aimed to make sure that there is an adequate skill mix and that at least one surgeon in a team can do most operations. The network standard (Section A) sets out what needs to happen if there is not competence within the team. In these cases:

- support needs to be sought within the network or another Specialist Surgical Centre or the patient must be referred to an alternative Specialist Surgical Centre where a surgeon has the appropriate skills.
- arrangements for services out of hours must also meet the requirement that surgeons and cardiologists only undertake procedures for which they have appropriate competence.
- arrangements must be in place in each Specialist Surgical Centre both for consultant interventional cardiologists and for congenital cardiac surgeons to operate together on complex or rare cases, within compliant rotas
- specialist surgical centres and networks must work together to support national, regional and network collaborative arrangements that facilitate joint operating, mentorship and centre to centre referrals.

We believe that the above will ensure adequate cover in all cases and so we are not proposing formal designation so that already specialist surgical units become more specialist.

What this will mean

- Patients can be assured that their care will only be provided by a doctor with the appropriate skills and training
- Surgical teams will need to recognise competences
- Surgeons and centres will need to work closely and collaboratively to ensure that all patients receive the best care possible
- Networks will need to manage competence through peer review and audit
- Networks will need to work together to ensure that surgeons can move between units to support each other as needed.

Questions

Do you agree that we can deliver the best possible outcomes without subspecialisation? If not, why?

Will the proposed standards ensure that all patients are cared for by the most appropriate surgeon for their needs?

The role of level 2 cardiology centres

The standards propose that all decisions regarding CHD patients are made through the MDT meeting and that congenital interventional cardiology are only be undertaken at Specialist ACHD Surgical Centres to assure safety while increasing the sustainability of services. During pre-consultation some argued that this approach was too inflexible. We set out here what we heard and what we are proposing. We ask your views on what we have proposed.

What we have heard

We heard different views on whether, in a specialist ACHD cardiology centre, it should be possible to undertake interventional congenital cardiology procedures.

Some considered the standards too inflexible and that these centres should be permitted to continue to undertake congenital interventional cardiology procedures (as long as the cardiologists have been appropriately trained and meet the minimum volume thresholds) because the outcomes are good and it is more convenient for patients.

Others considered that this would not be appropriate because we need to ensure that low risk procedures have zero mortality. Concentrating this work at Specialist ACHD surgical centres ensures:

- Appropriate surgical back-up for complications only available at congenital surgical centres
- Congenital interventionists meet minimum activity levels
- Cases for congenital trainees

We heard that the argument was not about the technical competence of non-congenital cardiologists. Rather the argument was that all surgery and catheterisation in CHD patients needed to be part of the network, discussed at the MDT and with the appropriate expert CHD surgical back up if there were complications. The requirement for specialist congenital surgical back-up in particular was considered essential and surgical members. We heard that congenital surgeons based at specialist surgical centres would not and could not provide this.

The standards extend the opportunity for cardiologists from level 2 units to continue to undertake catheterisation at the level 1 unit.

What we are proposing

We are proposing that:

- All decisions regarding CHD patients to be made through the MDT meeting
- Congenital interventional cardiology must only be undertaken at Specialist ACHD Surgical Centres

- Cardiologists from level 2 units will be given the opportunity to continue to undertake catheterisation at the level 1 unit (but must meet standards for minimum numbers)

What this will mean

Patients with CHD can be assured that any decision to undertake an interventional cardiology procedure will have been agreed by the MDT and will take place in the safest environment.

Questions

Do you agree that interventional congenital cardiology procedures should only be carried out at specialist CHD surgical centres? If not, why? What are the implications?

Model of care for congenital heart services

The standards are based on having three levels of congenital heart disease services for children and adults working as part of networks. These are:

- specialist children's surgical centres and specialist adult congenital heart disease centres (level 1)
- specialist children's cardiology and specialist adult congenital heart disease centres (level 2)
- local children's cardiology centres and local adult congenital heart disease centres (level 3)

The standards set out the different requirements for each level of the service and the way in which they need to work together in a network relationship.

What we have heard

Patients and their families should be able to receive as much of their care as locally as possible. For this to be possible networks need to ensure that local services work closely with specialist services to ensure that patients receive their care in a setting with the right skills and facilities.

As people with CHD live longer, the number of adults receiving long term care will continue to rise, so we need to make sure that there is enough provision for their care. As adults have fewer operations, more of their care can be done at non-surgical centres.

What we are proposing

We are proposing three levels of care over and above that provided in general hospitals and general practice.

Level 1: Specialist surgical centres

All congenital heart surgery and catheter interventions will be carried out in specialist surgical centres by trained congenital cardiac surgeons with anaesthetic cover provided by those with congenital heart disease training. Specialist surgical centres will also manage very complex patients who need to have access to anaesthetists with congenital heart disease experience.

Specialist surgical centres will provide leadership and clinical support of congenital heart networks, making sure services are better coordinated and working to common protocols. They will proactively lead training, development and research across the network.

Level 2: Specialist cardiology centres

Specialist cardiology centres will provide a broad range of medical cardiology services, but not surgery or catheter interventions. They will be able to care for patients before and after surgery in a specialist surgical centre including ongoing patient care and management. Not all networks will necessarily include level 2 centres, but because of the increasing number of adults living with CHD, specialist ACHD cardiology centres will be more common. Wherever they exist, specialist cardiology centres must meet the standards.

Level 3: Local cardiology centres

Local cardiology centres will be members of congenital heart networks and will be the front line of the new congenital heart networks, bringing expert care closer to home. Local centres will be staffed by a cardiologist with an interest in congenital heart disease to provide care for adults with CHD and paediatricians with expertise in cardiology to provide care for children and young people. Local centres will perform tests and provide ongoing expert cardiac care for pregnant women whose babies have been diagnosed in the womb, so that they can give birth locally with the support of a paediatrician with expertise in cardiology if safe to do so. They will provide inpatient care where appropriate.

What this will mean

Patients will be able to receive as much of their care as is appropriate in a centre closer to their home. Each centre will have clear roles and responsibilities and will work together within a congenital heart network.

Patients are able to move between service levels as appropriate. This will not necessarily be between all three or from one to the other, but will depend on patient need.

Questions

Do you have any comments on the roles identified for the different service levels in the standards?

Can we afford to implement the standards?

The aim of the review is to ensure that services achieve the highest possible quality within the available resources. The available resources are not open ended and it is the duty of the NHS to ensure both that it lives within its means and that it achieves the maximum value for every pound it spends.

If recent trends continue it is expected that, whether or not new standards are introduced, activity will increase and therefore spending by commissioners can be expected to increase. Some of the costs of meeting the specification, particularly those arising from additional consultant surgeons, are directly linked to activity and so will only rise if there is enough activity to justify it.

INSERT GRAPHIC OF EXPECTED ACTIVTY RISE?

Our assessment of the financial impact of introducing the standards (available here) indicates that the costs of providing the service to the new standards should be met from the additional funding hospitals receive as activity levels increase. While the new specification could be expected to increase some costs at individual providers, many of the requirements are already included in the existing paediatric service specification so these do not represent additional costs for commissioners as they have already been committed. This includes, for example, the requirement for congenital surgeons to work in teams of at least four and for each network to have a minimum of seven children's congenital specialist nurses. Our finance impact assessment gives further consideration to other ways of managing costs while still ensuring that the standards are achieved.

In considering whether any increased costs represent good value it is important to consider what benefits come from the higher spending. Introducing the standards ensures that the NHS delivers higher quality and not just more activity.

There will be wide ranging benefits for patients, their families, NHS England and other commissioners, and also to provider organisations.

Patients and their families

Effective implementation of the standards will provide assurance to patients and their families that the care they receive will be of consistently high quality wherever they live in England. It will be delivered in the context of a specialist network dedicated to improving quality, with decisions about their care taken by an appropriate multidisciplinary team and delivered by specialist staff who are supported to maintain their skills and knowledge in specialist centres with the right equipment and close links to the other services they might need.

Effective implementation of the standards will also ensure that patients receive the information they need to participate actively in decisions about their care. It will be provided in a way that they can understand. They will receive the support they need throughout their care, from diagnosis through to end of life.

Commissioners

Adoption of the standards through the service specifications will give commissioners the tools they need to hold providers to account for the quality of care they deliver and to be able to take action if standards are not met.

Variation between providers will be reduced. Occasional practice will be eliminated, thereby addressing an obvious risk to patient safety.

As activity continues to rise, commissioners will be assured that additional expenditure is directed to services of increasing quality and not just quantity.

Providers

Providers will benefit from increased clarity about what is expected of them, and will be able to confidently plan for the future.

Relationships between providers will be improved by working as part of formal managed networks.

Improved information and support to patients will result in fewer complaints, time consuming investigations and potentially costly litigation.

What happens next?

Consultation

This consultation will run from xxx to yyy. While our focus is on services for patients resident in England, we recognise that there are children and adults living in Wales, Scotland and Northern Ireland who use congenital heart disease services in England. We have agreed with our colleagues in the other countries that they will make people aware of this consultation. We welcome all responses and will make the other health services aware of the responses we get from their countries.

During consultation we will run a number of regional events to raise awareness of the standards and to provide an opportunity for discussion. We will also support charities, patient groups, clinicians and provider units to run their own events through the provision of materials etc.

To find out where and when your nearest event will be held please refer to the new congenital heart disease review website at

http://www.england.nhs.uk/ourwork/qual-clin-lead/chd/

Once consultation ends

We are asking an independent company to collate all the responses and to produce an analysis of what respondents have said. The analysis will be published in due course and will include information about the number, type and other characteristics of the responses giving us a good picture of the views expressed. But it is important to note that the consultation is not a vote. NHS England will consider all the responses to the consultation and where appropriate will amend the draft standards and specifications. These will then be agreed through the relevant committees and approved by our Board.

Preparing for change

Once the new specifications are agreed, we expect to develop the business case for change to set out what we intend to commission and how we will do this.The business case will bring together all of the work of the review to set out:

- The assessment of need
- The clinical priorities
- What service users and carers want
- The standards and specification
- The resources needed to deliver the new service
- The benefits that will be delivered by the new service

As with any other service, we would expect to prepare a technical document called 'commissioning intentions' to inform current and any potential new providers how we intend to shape the healthcare system for congenital heart disease that serves the population of England.

The "commissioning intentions" document provides the context for constructive engagement with providers, seeking innovative solutions to meet the requirements of the new specifications to improved patient outcomes and experience, within the fixed resources available. To support patient-centred care, we shall be working with our own area teams, local clinical commissioners, partner NHS bodies and Local Authorities to ensure that emerging solutions have wide ownership and commitment. We will encourage innovative and flexible approaches provided that they meet our requirement of delivering the service improvements required. As part of this work we will consider the best approach to commissioning and how long contracts should be awarded for.[1] The business case and commissioning intentions will be agreed by the NHS England board.

Commissioning the new services

Once the appropriate approach has been agreed, we expect that NHS England will work with clinical commissioners to complete the commissioning of the agreed service specification during 2015/16 and award contracts to the successful providers for delivery in 2016/17. There may need to be a period of transition during which the changes are supported and co-ordinated at a national level. However it should be noted that many of the service improvements required to meet the new standards are already beginning to happen as a result of the work undertaken to date and that this work can and should continue.

[1][1] Technical note: NHS England will consider the right combination of commissioning tools to deliver the improvements required by the service specifications, ranging from at one end of the spectrum disinvestment and contact penalties if services fail to meet specifications, to positive financial incentives for providers such as CQUINs (commissioning for quality and innovation payments) through to a full procurement exercise which gives both existing and new providers the opportunity to create innovative solutions to solve operational challenges.

Responding to the consultation

1. This document launches a consultation on congenital heart disease services in England for children and adults.

2. The consultation is being run in accordance with the Cabinet Office guidance

   https://www.gov.uk/government/publications/consultation-principles-guidance

3. The closing date for the consultation is xxxx

4. This 12 week consultation is open to everyone

5. There is a full list of the questions we are asking in Annex A.

6. You can complete the response form on line, by email or by posting it to us at xxxx

7. Hard copies of the consultation document and response form are available by contacting xxxxx. We have also produced a video version that explains the main elements. This can be found at xxxx on NHS England YouTube

8. When you are replying, please let us know whether you are replying as an individual or whether you are representing the views of an organisation.

9. If you are replying on behalf of an organisation, please make it clear who the organisation represents, and where appropriate, how the views of members were assembled.

10. The consultation coordinator is Michael Wilson, Programme Director. If you have any queries or complaints on the consultation process, please write to him at:

    Xxxxxxxxx

    Or email xxxxxxxx

Outline of the consultation reference pack

Draft flat plan

	Content
1	Introduction • what is included • what we are asking for comments on • links to the website and blog
2	Financial assessment (draft)
3	Equality analysis (draft)
4	Activity analysis (draft)
5	Original letter to the Secretary of State
6	NHS England Board paper announcing the review (item 13 on 18 July 2013)
7	Task and Finish Group of the NHS England Board, terms of reference and membership
8	Programme Board terms of reference and membership
9	Standards groups terms of reference and membership
10	CAP terms of reference and membership
11	Engagement and Advisory Groups terms of reference and membership
12	Externally commissioned research papers
13	*What we have heard* paper, presented to the Clinical Advisory Panel on 18 June 2014
14	*One year on* paper, presented as item 10h to the NHS England Board on 3 July 2014
15	Glossary

The Programme Board is responsible for assuring the content of this pack, and is asked to advise whether this is a full and appropriate list of materials required to support the main consultation document.

Draft financial impact assessment of draft new standards for paediatric cardiac and adult congenital heart disease services

1. Background

Babies born with congenital heart disease (CHD) are amongst the most vulnerable patients the NHS cares for. We must ensure that CHD patients receive the best care we can provide from diagnosis and early treatment through to lifelong care and support.

Although relatively small in terms of numbers and expenditure, congenital heart disease is of huge public and political interest. It is a bellwether of the health service, and 14 years after the Kennedy Report, of the ability of commissioners to effect change in the interests of patients. Confidence in the service has been undermined by many years of repeated review and investigation (even though services in England are considered to be as good as those in any country in the world). Investment in the service has been held back because of continuing uncertainty. It is therefore important that this review is brought to a successful conclusion.

2. Introduction

New standards for congenital heart disease services are proposed for consultation. These will ensure consistent best practice across all providers in terms of how services should be organised and delivered but do not introduce new clinical interventions or change the threshold for treatment.

If recent trends continue it is expected that, whether or not new standards are introduced, activity will increase and therefore spending by Specialised Commissioning will need to increase. The reimbursement to providers for the costs of most elements of clinical care covered by the consultation falls within the scope of Payment by Results (PbR). The costs of providing the service to the new standards should therefore be met by providers from the additional funding they receive through the tariff system as activity levels increase.

The approach taken in this assessment is to consider the current and projected costs that are likely to be required from Specialised Commissioning budgets to meet expected demands using current tariff prices and future activity projections. Future changes in tariff prices reflecting wider system approaches to inflationary and other cost pressures as well as efficiency improvements have been excluded. The consideration of the net impact on providers is not within the scope of this consultation, and thus this assessment.

Consideration of the net impact on providers is not within the scope of this consultation. However, it is noted that the number of procedures undertaken at individual centres has an impact on their efficiency and thus the overall cost of these services. As this is outside the scope of the consultation it has not been considered further here.

At this stage in the consultation process, the objective is to consider the proposals described in the main part of the consultation document to help inform the responses from the consultees. Once a preferred option is confirmed using the financial information presented here, the implementation of this option can be further considered and the preparation of a more detailed financial Business Case will be appropriate.

3. Current CHD Commissioning Spend

The start point for an assessment of future activity and spend is the current estimated level of both. Establishing this has been hampered by a lack of nationally available data and consistency in the identification by commissioners and providers of the relevant activity and associated cost to commissioners.

The base period chosen is 2012/13 as this is the most recent full year for which Hospital Episode Statistics (HES) and Secondary Uses Service (SUS) data are available.

The best information available to NHS England on total paediatric cardiac and adult congenital heart disease specialised activity and spend is that identified through SUS. NHS England is working on improved data flows in this area but this data represents the best estimate currently available. It is important to note that these estimates will underestimate total activity and spend on these services as they do not include spend on the following: high-cost devices (e.g. pacemakers), critical care (e.g. paediatric intensive care), any activity paid for by local prices, and adult CHD outpatient activity. There are also a number of caveats around the quality of the data that is included:

- *Coverage*: The Identification Rules (IR) are used to identify specialised activity within SUS data. However, not all specialised activity can be flagged by the IR, owing to a significant amount that either doesn't flow through SUS or requires cross-referencing with a range of external datasets (to which NHS England has extremely limited access).
- *Source*: Any SUS data underpinning this analysis has been sourced from the PbR-Mart extract, provided by the Health and Social Care Information Centre (HSCIC). This data is freeze data and may contain provider errors that have not been corrected during the reconciliation period. Any coding errors in provider-submitted fields and inconsistencies will remain.
- *Data Enhancements*: The NHS England Analytical Service has enhanced the SUS data to maximise quality and the amount of specialised activity identified. While improving the value of intelligence produced, these enhancements will result in difficulties reconciling the data back to national SUS extracts or local activity data processed by Data Services for Commissioners Regional Offices. Modifications have been applied to the IR to maximise the amount of activity that can be identified and designated as specialised, however these do not account for local deviations in the IR. The data has also been subjected to a light deduplicated algorithm, which removes a limited amount of erroneous data.

As noted above this dataset does not identify adult CHD outpatient activity separately from other adult heart disease-related outpatient activity. To provide an estimate of the activity and thus commissioner expenditure it has been assumed that the ratio of outpatient to inpatient activity is 50% of the paediatric ratio reflecting the lower intensity of ongoing care for these patients. An alternative population-based approach, following a long term condition model, is not possible as the number of adult patients in such a cohort cannot be identified from the data available. The total activity in 2012-13 has been summarised as:

	Outpatient	Inpatient	Other (e.g. critical care)
Paediatric cardiac	91,500	10,800	No national data
Adult congenital heart diseases	24,900 (assumption)	5,500	No national data

The costs to Commissioners have been calculated using SUS data submitted by providers. The SUS data for 2012/13 and covers all spells for both procedural and non-procedural based CHD activity that have been paid via national Payment by Results tariff. For paediatric activity the data shows the figures for outpatient and inpatient episodes. However for adult activity outpatient episodes for congenital heart disease are not separately identifiable from outpatient activity for other cardiac conditions and an estimate has therefore had to be made based on an assumed relationship between inpatient and outpatient episodes.

The total spend in 2012-13 has been summarised as:

£m	Outpatient	Inpatient	Other (e.g. critical care)
Paediatric Cardiac	20.5	62.1	Unknown
Adult congenital heart disease	3.4	24.0	Unknown
Total	23.9	86.1	Unknown

Note: this baseline underestimates total spend on CHD services so as a result the increases in funding required may be higher than suggested above.

The costs to providers are not directly available however the PbR tariffs are based on the data sent providers that shows the full cost of providing their services including a share of all the overheads of the relevant organisation. The PbR tariff should therefore reasonably represent the average costs incurred by providers.

From the limited information available it is clear that the current quality standards, as required by the existing paediatric CHD service specification have not been uniformly implemented by all providers. Where this is not the case, providers will need to invest in staff and other resources in order to meet those elements of the standards that are defined by the resources required for a service, as opposed to those defined by outputs/outcomes. Providers cannot expect any additional income in the short term as the PbR tariff is intended to reflect the current standards, though over the medium term any additional investment could be expected to be reflected in an increase in the baseline cost and thus tariff, though this would not result in a material change in the tariffs. These costs would not be attributable to the proposed new service specification and standards.

4. Costs associated with the proposals

The principal costs associated with achieving the proposed quality standards arise from increased levels of staffing and from establishing networks.

Many of these costs are already inherent in the existing paediatric service specification, and therefore should not be attributed to the new standards. This includes:

- **Staffing**: additional congenital surgeons, paediatric cardiologists, paediatric nurse specialists and nurse educators.
- **Networks**: most costs including lead clinicians, lead nurses, network meetings etc.

As has already been noted elsewhere, given the projected rise in activity levels, it can be assumed that additional staff will be needed and that the associated costs would be met by the rise in income recovered by providers as a result of this higher activity (see section 5 below). Because of the way in which the standards have been written, the number of surgeons is expected to rise only in line with rises in activity levels. Additional surgeons who were unable to meet the minimum activity levels required would not be supported.

Some of the costs of the proposed new standards are however wholly new and are not included in the existing paediatric specification. This includes:

- Psychologists
- Adult CHD (ACHD) specialist nurses

Detailed costs have not been prepared because of the absence of an accurate baseline for comparison. It is known however that existing staffing levels vary considerably between providers. Commissioners would argue that the uplift in expenditure by providers is modest in the context of overall spend, lifts all providers to the same levels of staffing achieved by the best and that any additional costs should be covered by providers as a result of higher activity levels (see section 5 below).

The implementation of the new standards is not expected to result in new expenditure by either patients or their careers.

5. Benefits associated with the proposals

Commissioning against the standards will have wide ranging benefits for patients, their families, NHS England and other commissioners, and also to provider organisations.

Patients and their families

Effective implementation of the standards will provide assurance to patients and their families that the care they receive will be of a consistently high quality wherever they live in England. It will be delivered in the context of a specialist network dedicated to improving quality, with decisions about their care taken by an appropriate multidisciplinary team and delivered by specialist staff who are supported to maintain their skills and knowledge in specialist centres with the right equipment and close links to the other services they might need.

Effective implementation of the standards will also ensure that patients receive the information they need to participate actively in decisions about their care. It will be provided in a way that they can understand. They will receive the support they need throughout their care, from diagnosis through to end of life.

Commissioners

Adoption of the standards through the service specifications will give commissioners the tools they need to hold providers to account for the quality of care they deliver and to be able to take action if standards are not met. As a result, variation between providers will be reduced and occasional practice will be eliminated thereby addressing an obvious risk to patient safety.

As activity continues to rise, commissioners will be assured that additional expenditure is directed to services of increasing quality and not just quantity.

Providers

Providers will benefit from increased clarity about what is expected of them, and will be able to confidently plan for the future. Relationships between providers will be improved by working as part of formal managed networks. Further, improved information and support to patients will result in fewer complaints, time consuming investigations and potentially costly litigation.

6. Impact of changes to pathways

The implementation of the new standards is intended to increase the quality of the care provided to patients. This will improve the quality of their outcomes and their experience of that care.

The new standards are not expected to directly result in changes to the number, frequency or type of intervention, admission, outpatient attendance or investigation. There is no evidence to support assumptions that the standards will either increase or decrease overall costs.

7. Future levels of activity and expenditure

The need to ensure that consultant paediatric surgeons and their teams undertake a minimum of 125 operations per year limits the number of surgeons that can meet that target under the current levels of activity. The period over which this can translate into a minimum of 4 surgeons per congenital surgical centre depends on the growth rate in the relevant activity.

The PbR tariff paid to providers covers both variable and fixed costs. Therefore an increase in activity will increase the contribution to the fixed overheads of the provider, which will not increase at the same rate. An increase in activity will therefore provide an additional source of funds for providers to invest in the resources required to meet the standards set out in this consultation. The sufficiency of this funding will depend on the amount of additional activity, the proportion of the tariff consumed by variable costs and the level of investment required to meet the standards.

7.1. Future projections of activity

A decision has been made to use HES data for the activity modelling, and this has been triangulated with data from the congenital audit run by the National Institute of Cardiovascular Outcomes Research (NICOR) where possible. This approach has been used for the following reasons:

- HES data is available for both Paediatric and Adult CHD, whereas NICOR's data on adults activity is incomplete.
- The Identification Rule (IR) definitions can be applied to HES, particularly for adults, and it is this definition that is used to calculate payments for specialised services through the National Tariff system and that will drive future levels of Specialised Commissioning funding.
- As with all HES data there is a risk that providers do not code activity in a consistent manner, though in this instance this is not considered to pose a significant threat to the validity of the data when considered at a national level

Detailed analysis of historic trends in specialist inpatient activity for paediatric cardiac and adult CHD services (i.e. procedure-based activity; surgery and catheter interventions) has been used to identify a pattern of growth. This financial assessment considers all CHD activity which includes non-procedural based activity as well as activity which includes a surgical or catheter procedure, e.g. critical care, diagnostic tests and outpatient appointments. We have assumed that the relationship between specialist inpatient activity and all other CHD activity will remain stable and therefore the growth rates for all activity will follow the trend identified for specialist inpatient activity.

Scenario modelling based on Office of National Statistics (ONS) population projections and historic trends in activity per head of the patient population suggests that up to 2025:

Paediatric cardiac activity: 0.4% to 1% per annum up to 2025/6

- Could be expected to grow by 0.4% per annum as a result of Population changes
- Up to a further 0.6% per annum could be expected to arise from increasing activity per Head of Population

  To note: These figure are very sensitive to ONS birth rate projections which have been previously underestimated – under ONS high projections we would be looking at 1% per annum as a result of Population changes and up to a further 1% per annum could be expected to arise from increasing activity per Head of Population – giving a range of between 1% and 2% pa. This sensitivity is considered below in scenarios 1b and 2b.

Adult congenital activity increase will be between 0.7% and 4% per annum up to 2025/6

- ACHD activity could be expected to grow by 0.7% annum as a result of Population changes
- Up to a further 3.3% per annum could be expected to arise from increasing activity rates per Head of Population

Assumptions:

- Activity per head will continue to grow as it has in the past following a linear trend
- Population will grow as per ONS's 2012-based principal population projections
- There will be no changes to Clinical Thresholds or Pathways arising from the implementation of the new quality standards (i.e. any changes will be at levels consistent with changes seen in the past)
- The current case mix of interventions will not change (for example the relative proportion of surgical and cardiology interventions)

Based on evidence from data analysis, academic literature and speaking to clinicians, it is expected that the main drivers of CHD activity have been and will be:

1. Population growth (which is a function of birth rate, migration and life expectancy)
2. Increasing prevalence of CHD within the population as a result of an increase in the proportion of patients who are of Asian and Black ethnicity for whom CHD is more likely to occur and in whom more serious manifestations of CHD are more common
3. Advances in medical techniques and new technology
4. Increased patient longevity and survival
5. Increased complexity and severity of patients (possibly also driven itself by 2, 3, 4 and 5 above)

As 30-day post-operative survival rates are already very high the new quality standards are not expected to improve them. Improvements in long-term survival and quality of life are expected but in the absence of any longitudinal studies of this cohort of patients there is no evidence currently available as to the longer term impact on survival rates of the increase in intervention rates over the past 10 years.

Given the uncertainty over future growth rates, as described above, two scenarios have been developed, firstly where growth reflects only projected population growth and secondly where

growth reflects the continuation of the average historic growth rates (2003/4-2012/13 for paediatric activity, 2006/7-2012/13 for ACHD activity – due to data issues). The historic trend has been broadly linear, and therefore the rate of growth in the future is assumed to be linear under both scenarios.

Scenario 1 – Population growth only

		Growth	2012-13	2025-26
Paediatric	**Outpatients**	0.4%	91,500	96,400
	Inpatients	0.4%	10,800	11,400
Adult	**Outpatients**	0.7%	24,900	27,300
	Inpatients	0.7%	5,500	6,100

Scenario 2 – Population growth + Average historic growth rates

		Growth	2012-13	2025-26
Paediatric	**Outpatients**	1.0%	91,500	104,100
	Inpatients	1.0%	10,800	12,300
Adult	**Outpatients**	4.0%	24,900	41,500
	Inpatients	4.0%	5,500	9,200

7.2. Future projections of spend

Applying our activity growth assumptions (from section 5.1 above) to our estimate of baseline spend (section 2 above) allows us to generate our financial forecast for the adult congenital heart disease and paediatric cardiac specialised services from the perspective of commissioners paying for services under PbR.

This estimate considers only services paid for under PbR and in order to demonstrate more clearly the impact of activity growth, takes no account of deflation/inflation in PbR tariffs.

The following table presents a summary of estimates for baseline and projected commissioning spend by 2025/26 for the two activity growth scenarios presented.

Scenario 1 – Population growth only

£m		**Growth (per annum)**	**2012-13**	**2025-26**
Paediatric	**Outpatients**	0.4%	20.5	21.6
	Inpatients	0.4%	62.1	65.4
Adult	**Outpatients**	0.7%	3.7	4.1
	Inpatients	0.7%	24.0	26.2
TOTAL			**110.3**	**117.3**

Scenario 2 – Population growth + Average historic growth rates

£m		Growth (per annum)	2012-13	2025-26
Paediatric	**Outpatients**	1.0%	20.5	23.3
	Inpatients	1.0%	62.1	70.7
Adult	**Outpatients**	4.0%	3.7	6.2
	Inpatients	4.0%	24.0	39.9
TOTAL			**110.3**	**140.1**

For providers the financial impact in the intervening years will involve a linear increase for variable costs and series of step changes in cost for semi-variable costs and fixed costs. The detail of the calculation of these spending projections is available in Annex A.

By 2024/15 it is expected that additional funding within a range of £7.0m to £29.8m will need to be made available to commission CHD services to meet increased activity levels based on current configuration of providers.

8. Affordability

The implementation of the proposed quality standards is not currently estimated to result in new investment by commissioners, however the early stage in the development of the implementation plans and the assumptions that underpin them mean that more work is required later in the development and assessment process to confirm the expected actual financial impact.

Furthermore this review has not considered any actions providers could take beyond the scope of the standards to mitigate this financial pressure.

Affordability for commissioners:
The increase in commissioner expenditure for the population-only growth model appears to be within the likely increase in overall NHS funding given that it excludes the impact of any QIPP initiatives undertaken by commissioners.

The increase in commissioner expenditure for the population plus historic growth model is likely to be above the likely increase in overall NHS funding. In these circumstances options to increase affordability would be:

- additional Quality, Innovation, Productivity and Prevention (QIPP) schemes to reduce demand and reduce provider expenditure (in order to reduce the PbR tariff); or
- commissioners to increase the share of their budgets that are directed to CHD; or
- measures to increase efficiency, such as reducing the number of networks (for example, creating multi-centre networks) or reducing the number of surgical centres.

Affordability for providers:
The projected increase in activity will provide an additional contribution to semi-fixed costs and overheads built into the current PbR tariffs. These funds could be directed in a way so as to meet the new standards.

The principal additional cost to providers of the new standards is the investment in increasing the number of surgeons and their medical teams.

It is not possible to provide an exact estimate of the number of additional surgeons required. The number of surgeons at each centre remains fluid. Operative activity levels vary considerably between surgeons. There may be changes in the way services are delivered that affects the number of surgeons required. However for the purposes of prudent accounting, the 'worst case' would be to ensure that there were teams of four surgeons at each of the ten specialist surgical centres that currently account for around 80% of paediatric and adult specialist inpatient activity. The IRP reported that in October 2012 there were 34 surgeons practising in England with a maximum of four surgeons at each centre at that time. This would therefore require an increase of six further surgeons. NHS finance teams have historically assumed an estimated cost of an additional consultant (together with their associated supporting staff) to be £500k for the purposes of business planning, or £3m (£500k*6 additional surgeons) in this instance.

The table below shows that even with this investment, providers would still have significant remaining income as a result of rising activity to cover semi-fixed costs and the costs of the proposed standards. As has been discussed, the position for any individual provider may be different but cannot be determined at this stage.

The number of surgeons will only rise as and when activity rises because of the need to maintain surgical skills reflected in the standards. This means that there will be a lag between the increase in the activity and the surgical capacity, which further means that providers will have the additional income from that increased activity before they have to increase these staff costs. At the highest rate of growth projected (Population and Rate per Head), the table below demonstrates that after costs for additional surgeons are taken into account (estimated at £500k per Surgeon) and the variable costs associated with the increased activity, *on average* each of the 10 specialist centres retains up to £1.6m to meet additional internal costs arising. As has been discussed, the position for any individual provider may be different but cannot be determined at this stage, currently around 20% of activity occurs outside of these specialist centres and this would need to be considered.

Provider Cost Impact 2025/6				
	1a	1b	2a	2b
	£000	£000	£000	£000
Income from additional activity	£7,000	£14,000	£29,800	£42,700
Costs of 9 additional surgeons and team (£ ****k per surgeon/team)	-£4,500	-£4,500	-£4,500	-£4,500
Variable costs @ 30%	-£2,100	-£4,200	-£8,900	-£12,800
Remaining income available for semi-fixed costs and proposed standards	£400	£5,300	£16,400	£25,400

Note: numbers may not sum due to rounding

Scenarios:
1a - Population Growth only (principal paediatric pop growth)
1b - Population growth only (high paediatric pop growth) – sensitivity upper bound
2a - Population growth + historic activity increase (principal paediatric pop growth)
2b - Population growth + historic activity increase (high paediatric pop growth) - sensitivity upper bound

This allows for investment to meet the costs of:

- developing Education and Training and Networks
- ACHD Specialist Nurses
- Psychologists
- Offices and administrative support
- IT development and analytical support

8.1. Efficiency and Value for Money

As has been demonstrated, based on available information, the future of congenital heart disease services following the introduction of the new standards for CHD services:

- Will show expected increases in the quality of care of the patient's experience
- Will show improved health outcomes for patients
- Will show improved levers for commissioners to increase quality
- Will show improved clarity for providers as well as reduced adverse events and complaints
- Will not change the expected number of interventions on the various clinical pathways
- Requires more suitably trained Consultant Surgeons to undertake the additional activity
- Requires existing providers to respond with improvements to quality of service delivery and to increase resources where necessary - the costs of which will be available to them from additional tariff income
- Is estimated to require additional funding of £9m to £37m by 2024/25 to meet activity increases regardless of whether or not the standards are introduced.

A lack of suitable data on patient quality of life has not allowed a quality-adjusted life year (QALY) based calculation to undertake an economic assessment of the value of the proposed changes

The financial assessment has not considered the impact of potential changes to the number, location or capacity of individual providers as this is not in scope of this assessment. However, the opportunity to consider such cost mitigation strategies is available if desired at later stages in the review process. This may involve changes to the location, co-location and distribution of facilities and specialist staff for hospital based CHD activity. Implementation of the standards at a smaller number of centres could be expected to be more efficient as the required number of consultant surgeons, specialist nurses etc. across the country would be lower. Thus, increased volumes of activity could be performed within a lower overall funding cost thus introducing an opportunity to reduce additional funding if so desired. Non-recurrent funding would be required to complete a reconfiguration of services. This financial assessment has not addressed the magnitude or incidence of costs or benefits of reconfiguration, as it is outside scope.

9. Conclusions

The proposed standards of care for CHD services will improve the quality of patient outcomes and patient and carer experience without changes to the existing patient pathways.

Many of the items in the new specification that could be expected to drive costs for individual providers are already included in the existing paediatric specifications and they are not relevant costs for commissioners.

Activity is projected to increase whether or not the new quality standards are implemented. The actual rate of increase will reflect population growth and potentially would exceed this should the recent trend interventions continue.

The additional activity should increase the income of providers and this is expected to cover, on average, the costs of the wholly new aspects of the standards for providers.

10. Recommendations

The approval for the consultation process for the new standards should proceed to the next stage as we do not expect the proposed standards would require material extra funding beyond that needed in the 'Do Nothing' scenario given the existing service specification for specialist paediatric cardiac services and the projected increase in activity for both paediatric and adult CHD services.

ANNEX A

Figure 1: Activity and Expenditure Forecast Population Growth

SCENARIO 1a - POPULATION GROWTH ONLY (paediatric low growth)														
ADULTS														
Year	2012/13	2013/14	2014/15	2015/16	2016/17	2017/18	2018/19	2019/20	2020/21	2021/22	2022/23	2023/24	2024/25	2025/26
Inpatients														
Population increase		*0.7%*	*0.7%*	*0.7%*	*0.7%*	*0.7%*	*0.7%*	*0.7%*	*0.7%*	*0.7%*	*0.7%*	*0.7%*	*0.7%*	*0.7%*
Rate of intervention														
Total projected growth		*0.7%*	*0.7%*	*0.7%*	*0.7%*	*0.7%*	*0.7%*	*0.7%*	*0.7%*	*0.7%*	*0.7%*	*0.7%*	*0.7%*	*0.7%*
Activity	5,534	5,573	5,612	5,651	5,691	5,730	5,771	5,811	5,852	5,893	5,934	5,975	6,017	6,059
Expenditure	£23,962,792	£24,130,532	£24,299,445	£24,469,541	£24,640,828	£24,813,314	£24,987,007	£25,161,916	£25,338,050	£25,515,416	£25,694,024	£25,873,882	£26,054,999	£26,237,384
Outpatients														
Population increase		*0.7%*	*0.7%*	*0.7%*	*0.7%*	*0.7%*	*0.7%*	*0.7%*	*0.7%*	*0.7%*	*0.7%*	*0.7%*	*0.7%*	*0.7%*
Rate of intervention														
Total projected growth		*0.7%*	*0.7%*	*0.7%*	*0.7%*	*0.7%*	*0.7%*	*0.7%*	*0.7%*	*0.7%*	*0.7%*	*0.7%*	*0.7%*	*0.7%*
Activity (est)	24,903	25,077	25,253	25,430	25,608	25,787	25,967	26,149	26,332	26,517	26,702	26,889	27,077	27,267
Expenditure	£3,735,450	£3,761,598	£3,787,929	£3,814,445	£3,841,146	£3,868,034	£3,895,110	£3,922,376	£3,949,833	£3,977,481	£4,005,324	£4,033,361	£4,061,595	£4,090,026
Total adult expenditure	£27,698,242	£27,892,130	£28,087,375	£28,283,986	£28,481,974	£28,681,348	£28,882,117	£29,084,292	£29,287,882	£29,492,897	£29,699,348	£29,907,243	£30,116,594	£30,327,410
PAEDIATRICS														
Year	2012/13	2013/14	2014/15	2015/16	2016/17	2017/18	2018/19	2019/20	2020/21	2021/22	2022/23	2023/24	2024/25	2025/26
Inpatients														
Population increase		*0.4%*	*0.4%*	*0.4%*	*0.4%*	*0.4%*	*0.4%*	*0.4%*	*0.4%*	*0.4%*	*0.4%*	*0.4%*	*0.4%*	*0.4%*
Rate of intervention														
Total projected growth		*0.4%*	*0.4%*	*0.4%*	*0.4%*	*0.4%*	*0.4%*	*0.4%*	*0.4%*	*0.4%*	*0.4%*	*0.4%*	*0.4%*	*0.4%*
Activity	10,839	10,882	10,926	10,970	11,013	11,058	11,102	11,146	11,191	11,236	11,280	11,326	11,371	11,416
Expenditure	£62,103,081	£62,351,493	£62,600,899	£62,851,303	£63,102,708	£63,355,119	£63,608,539	£63,862,974	£64,118,425	£64,374,899	£64,632,399	£64,890,928	£65,150,492	£65,411,094
Outpatients														
Population increase		*0.4%*	*0.4%*	*0.4%*	*0.4%*	*0.4%*	*0.4%*	*0.4%*	*0.4%*	*0.4%*	*0.4%*	*0.4%*	*0.4%*	*0.4%*
Rate of intervention														
Total projected growth		*0.4%*	*0.4%*	*0.4%*	*0.4%*	*0.4%*	*0.4%*	*0.4%*	*0.4%*	*0.4%*	*0.4%*	*0.4%*	*0.4%*	*0.4%*
Activity	91,498	91,864	92,231	92,600	92,971	93,343	93,716	94,091	94,467	94,845	95,225	95,605	95,988	96,372
Expenditure	£20,469,865	£20,551,744	£20,633,951	£20,716,487	£20,799,353	£20,882,551	£20,966,081	£21,049,945	£21,134,145	£21,218,681	£21,303,556	£21,388,770	£21,474,326	£21,560,223
Total paediatric expenditure	£82,572,946	£82,903,238	£83,234,851	£83,567,790	£83,902,061	£84,237,670	£84,574,620	£84,912,919	£85,252,570	£85,593,581	£85,935,955	£86,279,699	£86,624,818	£86,971,317
TOTAL EXPENDITURE	**£110,271,188**	**£110,795,367**	**£111,322,225**	**£111,851,776**	**£112,384,035**	**£112,919,017**	**£113,456,738**	**£113,997,211**	**£114,540,453**	**£115,086,478**	**£115,635,303**	**£116,186,942**	**£116,741,411**	**£117,298,727**

SCENARIO 1b - POPULATION GROWTH ONLY (paediatric high growth)														
ADULTS														
Year	2012/13	2013/14	2014/15	2015/16	2016/17	2017/18	2018/19	2019/20	2020/21	2021/22	2022/23	2023/24	2024/25	2025/26
Inpatients														
Population increase		*0.7%*	*0.7%*	*0.7%*	*0.7%*	*0.7%*	*0.7%*	*0.7%*	*0.7%*	*0.7%*	*0.7%*	*0.7%*	*0.7%*	*0.7%*
Rate of intervention														
Total projected growth		*0.7%*	*0.7%*	*0.7%*	*0.7%*	*0.7%*	*0.7%*	*0.7%*	*0.7%*	*0.7%*	*0.7%*	*0.7%*	*0.7%*	*0.7%*
Activity	5,534	5,573	5,612	5,651	5,691	5,730	5,771	5,811	5,852	5,893	5,934	5,975	6,017	6,059
Expenditure	£23,962,792	£24,130,532	£24,299,445	£24,469,541	£24,640,828	£24,813,314	£24,987,007	£25,161,916	£25,338,050	£25,515,416	£25,694,024	£25,873,882	£26,054,999	£26,237,384
Outpatients														
Population increase		*0.7%*	*0.7%*	*0.7%*	*0.7%*	*0.7%*	*0.7%*	*0.7%*	*0.7%*	*0.7%*	*0.7%*	*0.7%*	*0.7%*	*0.7%*
Rate of intervention														
Total projected growth		*0.7%*	*0.7%*	*0.7%*	*0.7%*	*0.7%*	*0.7%*	*0.7%*	*0.7%*	*0.7%*	*0.7%*	*0.7%*	*0.7%*	*0.7%*
Activity (est)	24,903	25,077	25,253	25,430	25,608	25,787	25,967	26,149	26,332	26,517	26,702	26,889	27,077	27,267
Expenditure	£3,735,450	£3,761,598	£3,787,929	£3,814,445	£3,841,146	£3,868,034	£3,895,110	£3,922,376	£3,949,833	£3,977,481	£4,005,324	£4,033,361	£4,061,595	£4,090,026
Total adult expenditure	£27,698,242	£27,892,130	£28,087,375	£28,283,986	£28,481,974	£28,681,348	£28,882,117	£29,084,292	£29,287,882	£29,492,897	£29,699,348	£29,907,243	£30,116,594	£30,327,410
PAEDIATRICS														
Year	2012/13	2013/14	2014/15	2015/16	2016/17	2017/18	2018/19	2019/20	2020/21	2021/22	2022/23	2023/24	2024/25	2025/26
Inpatients														
Population increase		*1.0%*	*1.0%*	*1.0%*	*1.0%*	*1.0%*	*1.0%*	*1.0%*	*1.0%*	*1.0%*	*1.0%*	*1.0%*	*1.0%*	*1.0%*
Rate of intervention														
Total projected growth		*1.0%*	*1.0%*	*1.0%*	*1.0%*	*1.0%*	*1.0%*	*1.0%*	*1.0%*	*1.0%*	*1.0%*	*1.0%*	*1.0%*	*1.0%*
Activity	10,839	10,947	11,057	11,167	11,279	11,392	11,506	11,621	11,737	11,854	11,973	12,093	12,214	12,336
Expenditure	£62,103,081	£62,724,112	£63,351,353	£63,984,866	£64,624,715	£65,270,962	£65,923,672	£66,582,909	£67,248,738	£67,921,225	£68,600,437	£69,286,442	£69,979,306	£70,679,099
Outpatients														
Population increase		*1.0%*	*1.0%*	*1.0%*	*1.0%*	*1.0%*	*1.0%*	*1.0%*	*1.0%*	*1.0%*	*1.0%*	*1.0%*	*1.0%*	*1.0%*
Rate of intervention														
Total projected growth		*1.0%*	*1.0%*	*1.0%*	*1.0%*	*1.0%*	*1.0%*	*1.0%*	*1.0%*	*1.0%*	*1.0%*	*1.0%*	*1.0%*	*1.0%*
Activity	91,498	92,413	93,337	94,270	95,213	96,165	97,127	98,098	99,079	100,070	101,071	102,081	103,102	104,133
Expenditure	£20,469,865	£20,674,564	£20,881,309	£21,090,122	£21,301,024	£21,514,034	£21,729,174	£21,946,466	£22,165,931	£22,387,590	£22,611,466	£22,837,580	£23,065,956	£23,296,616
Total paediatric expenditure	£82,572,946	£83,398,675	£84,232,662	£85,074,989	£85,925,739	£86,784,996	£87,652,846	£88,529,375	£89,414,668	£90,308,815	£91,211,903	£92,124,022	£93,045,262	£93,975,715
TOTAL EXPENDITURE	**£110,271,188**	**£111,290,805**	**£112,320,037**	**£113,358,975**	**£114,407,713**	**£115,466,344**	**£116,534,963**	**£117,613,667**	**£118,702,551**	**£119,801,712**	**£120,911,251**	**£122,031,265**	**£123,161,856**	**£124,303,125**

Figure 2: Activity and Expenditure Forecast Population Growth and Rate per Head Increase

SCENARIO 2a - POPULATION GROWTH + INCREASED INTERVENTION RATE (paediatric low growth)														
ADULTS														
Year	2012/13	2013/14	2014/15	2015/16	2016/17	2017/18	2018/19	2019/20	2020/21	2021/22	2022/23	2023/24	2024/25	2025/26
Inpatients														
Population increase		*0.7%*	*0.7%*	*0.7%*	*0.7%*	*0.7%*	*0.7%*	*0.7%*	*0.7%*	*0.7%*	*0.7%*	*0.7%*	*0.7%*	*0.7%*
Rate of intervention		*3.3%*	*3.3%*	*3.3%*	*3.3%*	*3.3%*	*3.3%*	*3.3%*	*3.3%*	*3.3%*	*3.3%*	*3.3%*	*3.3%*	*3.3%*
Total projected growth		*4.0%*	*4.0%*	*4.0%*	*4.0%*	*4.0%*	*4.0%*	*4.0%*	*4.0%*	*4.0%*	*4.0%*	*4.0%*	*4.0%*	*4.0%*
Activity	5,534	5,755	5,986	6,225	6,474	6,733	7,002	7,282	7,574	7,877	8,192	8,519	8,860	9,215
Expenditure	£23,962,792	£24,921,304	£25,918,156	£26,954,882	£28,033,077	£29,154,400	£30,320,576	£31,533,400	£32,794,735	£34,106,525	£35,470,786	£36,889,617	£38,365,202	£39,899,810
Outpatients														
Population increase		*0.7%*	*0.7%*	*0.7%*	*0.7%*	*0.7%*	*0.7%*	*0.7%*	*0.7%*	*0.7%*	*0.7%*	*0.7%*	*0.7%*	*0.7%*
Rate of intervention		*3.3%*	*3.3%*	*3.3%*	*3.3%*	*3.3%*	*3.3%*	*3.3%*	*3.3%*	*3.3%*	*3.3%*	*3.3%*	*3.3%*	*3.3%*
Total projected growth		*4.0%*	*4.0%*	*4.0%*	*4.0%*	*4.0%*	*4.0%*	*4.0%*	*4.0%*	*4.0%*	*4.0%*	*4.0%*	*4.0%*	*4.0%*
Activity (est)	24,903	25,899	26,935	28,012	29,133	30,298	31,510	32,771	34,081	35,445	36,863	38,337	39,871	41,465
Expenditure	£3,735,450	£3,884,868	£4,040,263	£4,201,873	£4,369,948	£4,544,746	£4,726,536	£4,915,597	£5,112,221	£5,316,710	£5,529,379	£5,750,554	£5,980,576	£6,219,799
Total adult expenditure	£27,698,242	£28,806,172	£29,958,419	£31,156,755	£32,403,026	£33,699,147	£35,047,112	£36,448,997	£37,906,957	£39,423,235	£41,000,164	£42,640,171	£44,345,778	£46,119,609
PAEDIATRICS														
Year	2012/13	2013/14	2014/15	2015/16	2016/17	2017/18	2018/19	2019/20	2020/21	2021/22	2022/23	2023/24	2024/25	2025/26
Inpatients														
Population increase		*0.4%*	*0.4%*	*0.4%*	*0.4%*	*0.4%*	*0.4%*	*0.4%*	*0.4%*	*0.4%*	*0.4%*	*0.4%*	*0.4%*	*0.4%*
Rate of intervention		*0.6%*	*0.6%*	*0.6%*	*0.6%*	*0.6%*	*0.6%*	*0.6%*	*0.6%*	*0.6%*	*0.6%*	*0.6%*	*0.6%*	*0.6%*
Total projected growth		*1.0%*	*1.0%*	*1.0%*	*1.0%*	*1.0%*	*1.0%*	*1.0%*	*1.0%*	*1.0%*	*1.0%*	*1.0%*	*1.0%*	*1.0%*
Activity	10,839	10,947	11,057	11,167	11,279	11,392	11,506	11,621	11,737	11,854	11,973	12,093	12,214	12,336
Expenditure	£62,103,081	£62,724,112	£63,351,353	£63,984,866	£64,624,715	£65,270,962	£65,923,672	£66,582,909	£67,248,738	£67,921,225	£68,600,437	£69,286,442	£69,979,306	£70,679,099
Outpatients														
Population increase		*0.4%*	*0.4%*	*0.4%*	*0.4%*	*0.4%*	*0.4%*	*0.4%*	*0.4%*	*0.4%*	*0.4%*	*0.4%*	*0.4%*	*0.4%*
Rate of intervention		*0.6%*	*0.6%*	*0.6%*	*0.6%*	*0.6%*	*0.6%*	*0.6%*	*0.6%*	*0.6%*	*0.6%*	*0.6%*	*0.6%*	*0.6%*
Total projected growth		*1.0%*	*1.0%*	*1.0%*	*1.0%*	*1.0%*	*1.0%*	*1.0%*	*1.0%*	*1.0%*	*1.0%*	*1.0%*	*1.0%*	*1.0%*
Activity	91,498	92,413	93,337	94,270	95,213	96,165	97,127	98,098	99,079	100,070	101,071	102,081	103,102	104,133
Expenditure	£20,469,865	£20,674,564	£20,881,309	£21,090,122	£21,301,024	£21,514,034	£21,729,174	£21,946,466	£22,165,931	£22,387,590	£22,611,466	£22,837,580	£23,065,956	£23,296,616
Total paediatric expenditure	£82,572,946	£83,398,675	£84,232,662	£85,074,989	£85,925,739	£86,784,996	£87,652,846	£88,529,375	£89,414,668	£90,308,815	£91,211,903	£92,124,022	£93,045,262	£93,975,715
TOTAL EXPENDITURE	**£110,271,188**	**£112,204,847**	**£114,191,081**	**£116,231,744**	**£118,328,764**	**£120,484,143**	**£122,699,958**	**£124,978,371**	**£127,321,625**	**£129,732,050**	**£132,212,068**	**£134,764,193**	**£137,391,040**	**£140,095,324**

SCENARIO 2b - POPULATION GROWTH + INCREASED INTERVENTION RATE (paediatric high growth)														
							ADULTS							
Year	2012/13	2013/14	2014/15	2015/16	2016/17	2017/18	2018/19	2019/20	2020/21	2021/22	2022/23	2023/24	2024/25	2025/26
Inpatients														
Population increase		*0.7%*	*0.7%*	*0.7%*	*0.7%*	*0.7%*	*0.7%*	*0.7%*	*0.7%*	*0.7%*	*0.7%*	*0.7%*	*0.7%*	*0.7%*
Rate of intervention		*3.3%*	*3.3%*	*3.3%*	*3.3%*	*3.3%*	*3.3%*	*3.3%*	*3.3%*	*3.3%*	*3.3%*	*3.3%*	*3.3%*	*3.3%*
Total projected growth		*4.0%*	*4.0%*	*4.0%*	*4.0%*	*4.0%*	*4.0%*	*4.0%*	*4.0%*	*4.0%*	*4.0%*	*4.0%*	*4.0%*	*4.0%*
Activity	5,534	5,755	5,986	6,225	6,474	6,733	7,002	7,282	7,574	7,877	8,192	8,519	8,860	9,215
Expenditure	£23,962,792	£24,921,304	£25,918,156	£26,954,882	£28,033,077	£29,154,400	£30,320,576	£31,533,400	£32,794,735	£34,106,525	£35,470,786	£36,889,617	£38,365,202	£39,899,810
Outpatients														
Population increase		*0.7%*	*0.7%*	*0.7%*	*0.7%*	*0.7%*	*0.7%*	*0.7%*	*0.7%*	*0.7%*	*0.7%*	*0.7%*	*0.7%*	*0.7%*
Rate of intervention		*3.3%*	*3.3%*	*3.3%*	*3.3%*	*3.3%*	*3.3%*	*3.3%*	*3.3%*	*3.3%*	*3.3%*	*3.3%*	*3.3%*	*3.3%*
Total projected growth		*4.0%*	*4.0%*	*4.0%*	*4.0%*	*4.0%*	*4.0%*	*4.0%*	*4.0%*	*4.0%*	*4.0%*	*4.0%*	*4.0%*	*4.0%*
Activity (est)	24,903	25,899	26,935	28,012	29,133	30,298	31,510	32,771	34,081	35,445	36,863	38,337	39,871	41,465
Expenditure	£3,735,450	£3,884,868	£4,040,263	£4,201,873	£4,369,948	£4,544,746	£4,726,536	£4,915,597	£5,112,221	£5,316,710	£5,529,379	£5,750,554	£5,980,576	£6,219,799
Total adult expenditure	£27,698,242	£28,806,172	£29,958,419	£31,156,755	£32,403,026	£33,699,147	£35,047,112	£36,448,997	£37,906,957	£39,423,235	£41,000,164	£42,640,171	£44,345,778	£46,119,609
							PAEDIATRICS							
Year	2012/13	2013/14	2014/15	2015/16	2016/17	2017/18	2018/19	2019/20	2020/21	2021/22	2022/23	2023/24	2024/25	2025/26
Inpatients														
Population increase		*1.0%*	*1.0%*	*1.0%*	*1.0%*	*1.0%*	*1.0%*	*1.0%*	*1.0%*	*1.0%*	*1.0%*	*1.0%*	*1.0%*	*1.0%*
Rate of intervention		*1.0%*	*1.0%*	*1.0%*	*1.0%*	*1.0%*	*1.0%*	*1.0%*	*1.0%*	*1.0%*	*1.0%*	*1.0%*	*1.0%*	*1.0%*
Total projected growth		*2.0%*	*2.0%*	*2.0%*	*2.0%*	*2.0%*	*2.0%*	*2.0%*	*2.0%*	*2.0%*	*2.0%*	*2.0%*	*2.0%*	*2.0%*
Activity	10,839	11,056	11,277	11,502	11,732	11,967	12,206	12,451	12,700	12,954	13,213	13,477	13,746	14,021
Expenditure	£62,103,081	£63,345,143	£64,612,045	£65,904,286	£67,222,372	£68,566,820	£69,938,156	£71,336,919	£72,763,657	£74,218,931	£75,703,309	£77,217,375	£78,761,723	£80,336,957
Outpatients														
Population increase		*1.0%*	*1.0%*	*1.0%*	*1.0%*	*1.0%*	*1.0%*	*1.0%*	*1.0%*	*1.0%*	*1.0%*	*1.0%*	*1.0%*	*1.0%*
Rate of intervention		*1.0%*	*1.0%*	*1.0%*	*1.0%*	*1.0%*	*1.0%*	*1.0%*	*1.0%*	*1.0%*	*1.0%*	*1.0%*	*1.0%*	*1.0%*
Total projected growth		*2.0%*	*2.0%*	*2.0%*	*2.0%*	*2.0%*	*2.0%*	*2.0%*	*2.0%*	*2.0%*	*2.0%*	*2.0%*	*2.0%*	*2.0%*
Activity	91,498	93,328	95,195	97,098	99,040	101,021	103,042	105,102	107,204	109,349	111,536	113,766	116,042	118,362
Expenditure	£20,469,865	£20,879,262	£21,296,848	£21,722,784	£22,157,240	£22,600,385	£23,052,393	£23,513,441	£23,983,709	£24,463,384	£24,952,651	£25,451,704	£25,960,738	£26,479,953
Total paediatric expenditure	£82,572,946	£84,224,405	£85,908,893	£87,627,071	£89,379,612	£91,167,205	£92,990,549	£94,850,360	£96,747,367	£98,682,314	£100,655,960	£102,669,080	£104,722,461	£106,816,910
TOTAL EXPENDITURE	**£110,271,188**	**£113,030,577**	**£115,867,312**	**£118,783,826**	**£121,782,638**	**£124,866,351**	**£128,037,661**	**£131,299,356**	**£134,654,324**	**£138,105,549**	**£141,656,125**	**£145,309,251**	**£149,068,239**	**£152,936,519**

Draft national standards and service specifications for congenital heart disease services: draft equality analysis

Equality and diversity are at the heart of NHS England's values. Throughout the development of the policies and processes cited in this document, we have given due regard to the need to:

- reduce health inequalities in access and outcomes of healthcare services, integrate services where this may reduce health inequalities;
- eliminate discrimination, harassment and victimisation; and
- advance equality of opportunity and foster good relations between people who share a relevant protected characteristic (as cited in the Equality Act 2010) and those who do not share it.

What are the intended outcomes of this work?

Congenital heart disease is a term for a range of birth defects that affect the normal workings of the heart. The treatment for congenital heart disease depends on the defect. Mild defects, such as an atrial septal defect (a hole in the heart), often do not need to be treated, as they may improve on their own and may not cause any further problems, or will just need regular monitoring by a cardiologist.

If the defect is significant and is causing problems, surgery (or sometimes a less invasive procedure) may be required. Modern surgical techniques can often restore most or all of the heart's normal function.

However, people with congenital heart disease often do need treatment over their life and therefore require specialist review during childhood and adulthood. This is because people with complex heart problems can develop further problems with their heart rhythm or valves over time.

The new Congenital Heart Disease review
The new Congenital Heart Disease (CHD) review ("the review") was set up in June 2013 to consider the whole lifetime pathway of care for people with CHD to achieve:

- the best outcomes for all patients, not just lowest mortality but reduced disability and an improved opportunity for survivors to lead better lives;
- tackling variation so that services across the country consistently meet demanding performance standards and are able to offer resilient 24/7 care; and
- great patient experience, which includes how information is provided to patients and their families, considerations of access and support for families when they have to be away from home.

The development of national standards to be applied through a national service specification is at the heart of the review's approach. This reflects the views of stakeholders from across the spectrum and is recognised in the review's objectives.

The review's six objectives:

1. **to develop standards to give improved outcomes, minimal variation and improved patient experience for people with CHD;**

2. to analyse demand for specialist inpatient CHD care, now and in the future;

3. to make recommendations on function, form and capacity of services needed to meet that demand, taking account of accessibility and health impact;

4. to make recommendations on the commissioning and change management approach including an assessment of workforce and training needs;

5. to establish a system for the provision of information about the performance of CHD services to inform the commissioning of these services and patient choice; and

6. to improve antenatal and neonatal detection rates.

Draft service standards and specifications
We are consulting on draft standards and specifications for CHD services for children and adults (there is currently a set of standards and a service specification in place for children's services but standards only exist in draft form for adults).

This equality analysis sets out the evidence we have considered as we have worked with others to develop these standards.

Draft standards
The draft standards cover the following:

- the network approach;
- staffing and skills;
- facilities;
- interdependencies;
- training and education;
- organisation, governance and audit;
- research;
- communication with patients;
- transition;
- pregnancy and contraception;
- fetal diagnosis;
- palliative care and bereavement; and
- dentistry.

We are producing standards and specifications which will enable commissioners to describe and commission an excellent service, within the available resource, and which

will help ensure that services are all meeting the same criteria and in doing this, reduce inequalities in CHD service provision and outcomes.

While some standards could have a bearing on how/where services are delivered (insofar as they make proposals as to surgeon numbers, caseloads and mixes, interdependencies and sub-specialisation), there is no predetermined outcome about the configuration of provider units. We await responses from the consultation to inform the final form of the standards, and the future consideration of the subsequent shape of services.

Scope of this equality analysis
It is important to stress that the work on objectives 2-6 above is **not** the subject of the current consultation or this equality analysis, but our future work will be informed by what we hear in consultation.

Future thinking on, for example, function, form and capacity will be subject to the equality duty, in so far as it relates to the configuration of services to meet demand. We will consider feedback to this consultation, alongside future evidence and where appropriate, further equality analyses would be produced. Furthermore, as the sole national Commissioner, NHS England will need to ensure monitoring of the duty as part of contract management with service providers.

We hope that this draft equality analysis will demonstrate the information that has informed our thinking so far, and provide an opportunity for stakeholders, and the general public alike, to share this and to enhance their own understanding and ours, by:

- **considering and commenting on the evidence we have included, and**
- **helping us to fill in the gaps.**

Who will be affected by this work?
It is estimated that across England and Wales between 5 and 9 in every 1,000 pregnancies, or 1 in every 110 to 200, have some form of CHD. This includes pregnancies which lead to live or still births, those which die before birth and those which are terminated. This is based on information collected by the British Isles Network of Congenital Anomaly Registers (BINOCAR[1]) and cited by the British Heart Foundation[2], which currently only covers 36% of births in England and Wales. In 2011, the average for the six geographical areas covered is 6.1 per 1000 births, but this ranges from 4.5 in one area to 9.1 in another. BINOCAR does not cover key areas such as London. Some academic literature (which varies in scope) also suggests rates of around 5 to 8 per 1000[3].

[1] *Table 1.1 and 5.1, "Congenital Anomaly Statistics 2011, England and Wales",* BINOCAR, September 2013, found at: http://www.binocar.org/content/Annual%20report%202011_FINAL_040913.pdf
[2] *Children and young people: Statistics 2013* (2013) Townsend N, Bhatnagar P, Wickrama singhe K, Williams J, Vujcich D, Rayner M, British Heart Foundation: London found at: http://www.bhf.org.uk/publications/view-publication.aspx?ps=1002326
[3] "*Trends in hospital admissions, in-hospital case fatality and population mortality from congenital heart disease in England 1994- 2004",* Billet J, Majeed A, Gatzoulis M, Cowie M (2008) Heart, (2008) Mar; 94(3): 342-8,
"Comorbidity, healthcare utilisation and process of care measures in patients with congenital heart diseasein the UK: cross-sectional, population based study with case-control analysis". Billet J, Cowie MR, Gatzoulis MA, Vonder Muhil if, Majeed A (2008) Heart, 2008 Sep; 94(9): 1194-9
"*Survival with congenital heart disease and need for follow up in adult life*", Wren C, O'Sullivan JJ (2001) Heart, 2001 Apr; 438-43

There is limited evidence available on how this birth incidence is changing over time, but it is expected to be fairly stable. For a given rate of incidence, as more babies are born, the numbers of babies born with some form of CHD will increase. This, together with people with CHD living longer, means that the number of people living with CHD is increasing.

As well as people with CHD, this work will affect their families and carers, all members of the multidisciplinary clinical teams who support patients with CHD, and hospital managers, in particular those with specialist CHD units. Paediatric cardiac services also care for children with acquired and inherited cardiac diseases (although CHD accounts for most of their work). These children and their families and carers will also be affected.

Evidence

Our evidence has come from a range of sources. Key sources of evidence for the review in general, and the standards in particular, have been advice from:

- patients;
- clinicians;
- provider leaders;
- academics and other experts; and
- the wider public through correspondence and responses to our blog.

We have gathered evidence from:

- our patients' and public, providers' and clinicians' engagement and advisory groups;
- the groups that have developed the draft CHD standards;
- the Clinical Advisory Panel;
- visits to 13 Trusts with specialist CHD units where we had the opportunity to meet staff and patients; and
- nine meetings across England with children and young people.

A report is available at http://www.england.nhs.uk/wp-content/uploads/2014/07/chd-cap-6.pdf.

To inform our thinking on standards and the other objectives of the review, we have put in place other pieces of work to gather evidence. This has been done in parallel with the work of the review's lead analyst who has been progressing work on Objective 2 (including interrogating Hospital Episodes Statistics (HES) data).

We have also commissioned a systematic literature review; and asked the National Institute for Cardiovascular Outcomes Research (NICOR) to investigate their data.

Systematic literature review (papers since 2003 or earlier if few papers)
The independent systematic literature review, undertaken by The University of Sheffield, School of Health and Related Research (ScHARR) on our behalf, aimed to understand how organisational factors may affect patient outcomes focusing on:

- What is the current evidence for the relationship between institutional and surgeon volume and patient outcomes, and how is the relationship influenced by complexity of procedure and by patient case mix?

- How are patient outcomes influenced by proximity to/co-location with other specialist clinical services (e.g. co-location of services such as specialist paediatric intensive care)?

National Institute for Cardiovascular Outcomes Research - data analysis

The National Institute for Cardiovascular Outcomes Research (NICOR) was asked to examine its data and to advise on what this showed about service factors that could influence outcomes. Although the final write-up of this work is not yet available, NICOR has kindly supplied a summary of the main findings and these have been incorporated in this paper.

NICOR run the Congenital Heart Disease Audit using patient information collected by the Central Cardiac Audit Database (CCAD). We asked them to consider whether the information collected could be used to further understand the relationship between certain organisational or patient factors and patient outcomes. NICOR have helped us understand better the association between 30-day mortality rates in relation to ethnicity and social deprivation.

We see the gathering of evidence as part and parcel of our continuing work.

To this end, we propose to hold further engagement and advisory meetings and targeted work with some groups that share protected characteristics: BAME communities; people with learning disabilities and adults with CHD.

In the following sections we consider what impact our proposed standards for congenital heart disease might have on each of the nine protected characteristics:

- Age
- Disability
- Gender reassignment
- Marriage and civil partnership
- Pregnancy and maternity
- Race
- Religion and belief
- Sex
- Sexual orientation

We have also considered carers and geographical variations.

Age

The draft standards are intended to ensure that everyone with CHD gets the best possible care within the available resource.

Changing CHD population

CHD related episodes by age and as percentage of total (2012/13 HES data)

Age band	Age	Episodes	% total
Neonate	0 to 30 days	1297	12%
Infant	30 to 365 days	2318	21%
Child 1 -16	1 to 16 years	4296	39%
Child 17-18	17 to 18 years	695	6%
Adult 19-64	19 to 64 years	1856	17%
Adult 65+	65 years+	600	5%
Unknown	N/A	25	0%

Note: includes all episodes in NHS England providers for all patients (not just England and Wales)

Mortality from CHD has decreased over the past 30 years; between 1979-1983 and 2004-2008, absolute numbers of deaths from CHD in children under 15 years declined by 83% in the UK[4]. As the birth prevalence of CHD is thought to have remained more stable over this time period[5], it can be inferred that a large part of this decline in mortality is due to improved survival. Knowles *et al*. found that while deaths rates in the first year of life have been reducing throughout the period studied, drops in mortality in all age groups has only been observed for birth cohorts originating after 1989[6].

There is a suggestion from our own analysis and what we have heard that there has been an increase in demand for adult congenital heart disease care, not just among people in their twenties (i.e. birth cohorts originating after 1989).

Whereas in the past, mortality rates were higher in the early days and months, now more children in the UK with CHD benefit from advances in paediatric cardiac surgery and intensive care, and receive treatment and reach adulthood. The greatest decline in deaths from congenital heart disease has occurred in those aged less than one year.

This means that in the future, as more people survive, we are likely to see the service moving from one that is centred around children to one that is treating a growing number of young people and adults, who will continue to have (often complex) health needs.

This has consequences for the way in which services are delivered (and what sort of services are delivered) for both children and young people (and their different needs and expectations) through to transition for young people into adult services.

[4] *Mortality with congenital heart defects in England and Wales, 1959-2009: exploring technological change through period and birth cohort analysis* Knowles RL, Bull C, Wren C, Dezateux C (2012) Arch Dis Child, 2012 Oct: 97(10): 861-5

[5] *Temporal variability in birth prevalence of cardiovascular malformations* Wren C, Richmond S, Donaldson L (2000). Heart; 83: 414-9

[6] Op. cit.

For many defects treated in childhood, further problems can develop later in life which then require medical care or further surgery[7].

In *Children and young people: Statistics 2013*[8], the British Heart Foundation notes: 'Treatment of adults with congenital heart disease is relatively new as more children with congenital heart defects receive treatment and reach adulthood. As a result of the success of paediatric cardiology and cardiac surgery over the last four decades, it is thought that more adults with congenital heart disease will require medical care than children[9]' (page 15).

The report authors go on to highlight the importance of ensuring that facilities are adequate at transition.

Age and CHD: What we have heard during pre-consultation

Increasing need for adult congenital heart disease services
We have heard that there is a need for increasing capacity in adult congenital heart disease services and that some centres are expanding facilities and recruiting new staff.

Age-sensitive services
During pre-consultation, we have heard from patients, families and carers that services need to be age-sensitive and that effective transition is vital. This relates to effective and appropriate communication, but also to the facilities provided.

Young people have told us that they would like more information about sex and relationships and this needs to be away from parents – many teenagers are uncomfortable speaking about any of these things in front of their parents and some don't even like the idea of speaking with their regular doctors.

Our draft standards emphasise, in several places, the importance of open, honest communication in ways that are appropriate to the patient's needs. In addition we have also developed specific standards on:

- communication with patients;
- transition; and
- pregnancy and contraception.

We believe that the standards will have a positive impact on the experience and outcomes of all children and adults with CHD. For the first time services will be nationally commissioned using common service specifications across all ages.

We welcome more information/evidence.

[7] *Care and Treatment for congenital heart defects* (2011) American Heart Association http://heart.org/HEARTORG/Conditions/CongenitalHeartDefects
[8] *Children and young people: Statistics 2013* (2013) Townsend N, Bhatnagar P, Wickrama singhe K, Williams J, Vujcich D, Rayner M, British Heart Foundation: London
[9] *Task force on the management of grown up congenital heart disease of the European Society of Cardiology* (2003) European Heart Journal; 24: 1035-1084

Disability

The draft standards are intended to ensure that everyone with CHD gets the best possible care within the available resource.

Children and adults with congenital heart disease are at an increased risk of developing further problems. Many children with congenital heart disease experience delays in their development. For example, they may take longer to start walking or talking. They may also have lifelong problems with physical coordination.

Some children with congenital heart disease also have learning difficulties. These are thought to be caused by a poor oxygen supply during early life, which affects the development of the brain.

Natural intelligence is usually unaffected, but some children often perform well below the academic level they would be expected to reach. This is because of problems such as:

- impaired memory;
- problems expressing themselves using language;
- problems understanding the language of others;
- low attention span and difficulty concentrating;
- poor planning abilities; and
- poor impulse control – acting rashly without thinking about the possible consequences.

Recent research has found that children who have had surgery for transposition of the great arteries have significant problems related to a concept known as theory of mind (TOM). TOM is the ability to understand other people's mental states and recognise that they may differ from your own. In other words, to recognise that everyone has their own set of desires, intentions, beliefs, emotions, perspective, likes and dislikes. In simple terms, TOM is the ability to see the world through another person's eyes. An inability to recognise other people's mental states can lead to problems with social interaction and behaviour in later life.

<u>Congenital heart disease as a complication of Down's syndrome</u>
Around 50% of children with Down's syndrome have a congenital heart defect and around 60% of children with Down's syndrome who are born with a heart defect require treatment in hospital.

Septal defects account for 9 out of 10 cases of congenital heart disease in people with Down's syndrome. A septal defect is a hole inside one of the walls that separate the four chambers of the heart, often referred to as a 'hole in the heart'.

Less common but serious types of congenital heart disease in people with Down's syndrome include:

- tetralogy of Fallot (accounts for 6% of cases); and
- patent ductus arteriosus (accounts for around 4% of cases).

As noted above in relation to age, it is possible that in complex congenital heart disease cases, further problems (which could include a disability) will develop later in life that will require medical care or further surgery[10].

Disability and CHD: What we have heard during pre-consultation

We heard about the importance of ensuring the standards respect the needs of people with disabilities.

We have proposed standards that address the needs of all patients and have included particular standards that relate to learning disability, for example in relation to:

- communication with patients; and
- transition.

We believe that the standards will have a positive impact on the experience and outcomes of all children and adults with CHD, a number of whom have a disability. For the first time services will be nationally commissioned using common service specifications across all ages.

We welcome more information/evidence.

Gender reassignment (including transgender)

The draft standards are intended to ensure that everyone with CHD gets the best possible care within the available resource.

We have not identified any specific evidence relating to gender reassignment (including transgender) and CHD.

We welcome more information/evidence.

Marriage and civil partnership

The draft standards are intended to ensure that everyone with CHD gets the best possible care within the available resource.

We have not identified any specific evidence relating to marriage and civil partnership and CHD.

We welcome more information/evidence.

[10] *Care and Treatment for congenital heart defects* (2011) American Heart Association http://heart.org/HEARTORG/Conditions/CongenitalHeartDefects

Pregnancy and maternity

The draft standards are intended to ensure that everyone with CHD gets the best possible care within the available resource.

Cardiac disease is a leading cause of maternal death in pregnancy[11].

The Royal College of Obstetricians and Gynaecologists (RCOG) published a Good Practice guideline in 2011 which noted that pregnancy carries increased risks for women with congenital heart disease and particular efforts should be made to prevent any unwanted pregnancies. In particular teenage girls with congenital heart disease should have access to a specialist who can advise on contraception and later in life on preconception counselling. RCOG also noted the importance of ensuring that women with CHD:

- who go to their GP or midwife for advice are referred promptly to an appropriate high-risk pregnancy and heart disease team and see a cardiologist to establish how well the heart is working and discuss how pregnancy may impact their health.

- who want to become pregnant or who are pregnant visit their obstetrician and ideally should talk to them jointly with a cardiologist.

Fetal diagnosis
We are undertaking separate work (Objective 6) to improve fetal diagnosis of congenital heart disease.

Pregnancy and maternity and CHD: What we have heard during consultation

We have heard that there is a possibility that increased fetal diagnoses could in some cases increase terminations and reduce activity. But in other cases, it could increase the chance of survival and increase activity.

We have also heard that as a consequence of better care for people with congenital heart disease, more are going on to have their own children. This means that it is very important that there are close links between maternity services and ACHD services, and that deliveries are planned for safety.

We have developed specific standards on:
- pregnancy and contraception; and
- fetal diagnosis.

We believe that the proposed standards alongside our work to improve antenatal and neonatal detection rates (Objective 6) will have a positive impact on the experience and outcomes of women with CHD who are considering pregnancy, are pregnant or are receiving maternity care. For the first time services will be nationally commissioned using common service specifications.

We welcome more information/evidence.

[11] Royal College of Obstetricians and Gynaecologists (2011)

Race

The draft standards are intended to ensure that everyone with CHD gets the best possible care within the available resource.

CHD related episodes by ethnicity and as percentage of total (2012/3 HES data)

Ethnicity (%)	Specialist inpatient Episodes	Specialist inpatient Patients	ONS 2011 Census
Paediatric cardiac			
White	66%	66%	79%
Black	4%	4%	5%
White and Black	2%	1%	N/A
Asian	10%	10%	9%
White and Asian	1%	1%	N/A
Chinese and other	3%	3%	1%
Any other mixed	1%	1%	6%
Not Known	4%	4%	N/A
Not Stated	10%	11%	N/A
Ethnicity (%)	**Specialist inpatient Episodes**	**Specialist inpatient Patients**	**ONS 2011 Census**
ACHD			
White	79 %	79%	88%
Black	2%	2%	3%
White and Black	0%	0%	N/A
Asian	5%	5%	7%
White and Asian	0%	0%	N/A
Chinese and other	2%	2%	1%
Any other mixed	0%	0%	2%
Not Known	5 %	5 %	N/A
Not Stated	7%	7%	N/A

Note: ONS 2011 census do not use the same ethnic groups as HES so not directly comparable but give some sense of how the ethnic mix of activity for specialist inpatient CHD care compares to the general population of England and Wales.

The HES data above indicates that the majority of CHD episodes are among those patients classified as white, followed by those patients classified as Asian.

Ethnicity and prevalence

Research dating back to the 1980s[12] and 1990s[13] demonstrated higher prevalence among Asian communities in various UK cities including Manchester and Leeds, and in the West Midlands. In the 1980s research links were made between CHD and consanguinity in the Asian Muslim population. More recently in *Consanguinity and the risk of congenital heart*

[12] Gatrad AR, Reap AP, Watson GH Consanguinity and complex cardiac anomalies with situs ambiguous, *Arch.Dis Child 1984; 59: 242-5*

[13] Sadiq M, Stumper O, Wright JGC, de Giovanni JV, Billingham C, Silove ED Influence of ethnic origin on the pattern of congenital heart defects in the first year of life *Br Heart J 1995; 73: 173-176*

disease, (2012)[14] JT Shieh *et al.* undertook a systematic review of consanguinity in CHD, focusing on non-syndromic disease, with the methodologies and results from studies of different ethnic populations compared. They found that the majority of studies support the view that consanguinity increases prevalence of CHD, but found only three population-based studies controlled for potential socio-demographic confounding. The results suggested that the risk for CHD is increased in consanguineous unions in the studied populations, principally at first cousin level and closer.

For more precise risk estimates a better understanding of the underlying disease factors is needed. It has been suggested that we should consider whether and how to raise awareness of the risk of CHD within these communities.

Ethnicity and outcomes

We asked NICOR to see whether there was any link between ethnicity and the 30-day outcome after paediatric surgery. NICOR have used a 2009-12 dataset and a Partial Risk Adjustment in Surgery (PRAiS) model[15] recalibrated to evaluate the candidate risk factors for ethnicity. The PRAiS model assigns risk of death by 30 days after the first surgical operation (29 different specific procedures) in 30-day episodes of surgical management. NICOR's analysis of data from 13 paediatric surgery centres (12,186 episodes of care in paediatric heart surgery during April 2009 to March 2012 inclusive) showed that Asian ethnicity is associated with poorer outcomes (30-day post-operative mortality). This is a statistically significant finding. Other categories of ethnicity (Black, Chinese and Other) did not have statistically different risk from the Caucasian category.

Other factors beyond simple ethnicity may play a factor in this finding, such as deprivation and a higher incidence of consanguinity which is associated with more complex congenital heart disease and therefore less good outcomes.

Race and CHD: What we have heard during pre-consultation

We believe that the standards will have a positive impact on the experience and outcomes of children and adults from ethnic minorities with CHD. For the first time services will be nationally commissioned using common service specifications.

We welcome more information/evidence.

[14] Am J Med Genet A. 2012 May;158A(5):1236-41. doi: 10.1002/ajmg.a.35272. Epub 2012 Apr 9.

[15] (Sonya Crowe, Kate L. Brown, Christina Pagel, Nagarajan Muthialu, David Cunningham, John Gibbs, Catherine Bull, Rodney Franklin, Martin Utley, Victor T. Tsang**, Development of a diagnosis- and procedure-based risk model for 30-day outcome after paediatric cardiac surgery**, The Journal of Thoracic and Cardiovascular Surgery, Volume 145, Issue 5, May 2013, Pages 1270-1278, ISSN 0022-5223, http://dx.doi.org/10.1016/j.jtcvs.2012.06.023)

Religion or belief

The draft standards are intended to ensure that everyone with CHD gets the best possible care within the available resource.

We have not identified any specific literature relating to religion or belief and CHD.

Religion or belief and CHD: What we have heard during pre-consultation

We heard that religion and belief and culture could make it difficult for some people to engage with us in an open forum.

We welcome more information/evidence.

Sex

The draft standards are intended to ensure that everyone with CHD gets the best possible care within the available resource.

CHD-related episodes by gender and as percentage of total (2012/13 HES data)

Gender	**%**	**%**
Paediatric cardiac	**Episodes**	**Patients**
Male	56	55
Female	44	45
ACHD	**Episodes**	**Patients**
Male	50	50
Female	50	50

In terms of activity levels the HES data above shows that there are more episodes for males than females in paediatric cardiac procedures but the number evens out in adulthood.

In terms of outcomes, there is no evidence that outcomes differ by gender – based on analysis by NICOR – no statistical association between 30-day mortality and patient gender has been identified[16]. However, *Children and young people: Statistics 2013* (2013) notes that in children under five years of age, 3.5% of all deaths in boys and 4.8% of all deaths in girls are from congenital heart disease.

We have not identified any specific literature relating to gender and CHD.

Gender and CHD: What we have heard during pre-consultation

We did not identify any key messages about gender.

[16] Source: NICOR

We believe that the standards will have a positive impact on the experience and outcomes of children and adults of both sexes with CHD. For the first time services will be nationally commissioned using common service specifications.

We welcome more information/evidence.

Sexual orientation

The draft standards are intended to ensure that everyone with CHD gets the best possible care within the available resource.

We have not identified any specific evidence relating to sexual orientation and CHD.

Sexual orientation and CHD: What we have heard during pre-consultation

Young people have told us that they would like more information about sex and relationships and this need to be away from parents – many teenagers are uncomfortable speaking about any of these things in front of their parents and some don't even like the idea of speaking with their regular doctors. Our draft standards emphasise, in several places, the importance of open, honest communication in ways that are appropriate to the patient's needs.

We welcome more information/evidence.

Carers

The draft standards are intended to ensure that everyone with CHD gets the best possible care within the available resource.

It will be important to ensure that parents and carers of children with CHD have access to the information and any psychological support they might need.

Carers and CHD: What we have heard during pre-consultation

In addition, we have heard how important it is for parents and carers to be supported, particularly when they are away from home. They have told us about difficulties with finding their way round new hospitals, finding accommodation and eating balanced meals. They have also told us about problems with car parking.

We have also heard how important it is to have support for end of life and poor outcomes. This means having identified support structures that encourage and enable open and honest communication with families and carers at that time.

We have developed specific standards on:

- facilities; and
- palliative care and bereavement.

We believe that the standards will have a positive impact on the experience and outcomes for families and carers, ensuring that they are recognised and appropriately supported in their care of children and adults with CHD. For the first time services will be nationally commissioned using common service specifications.

We welcome more information/evidence.

Geographical variation

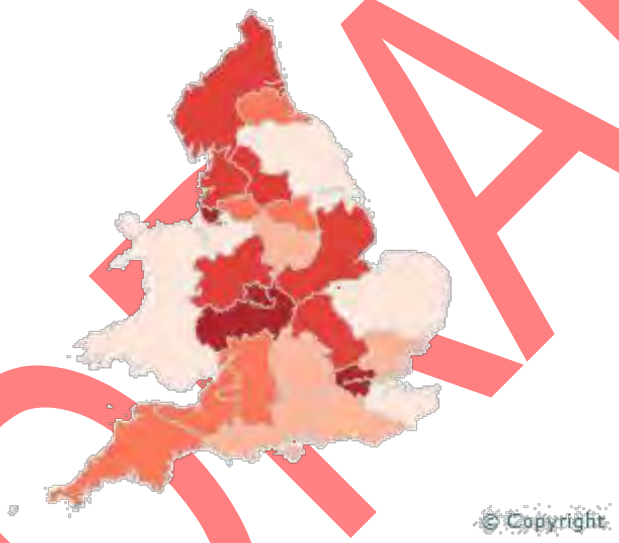
While not a protected characteristic, we have looked at CHD-related episodes (specialist inpatient activity) by area as percentage of total, and episodes per head of population (2012/3 HES data)

Area Team of patient residence	% of all specialist inpatient episodes	Specialist inpatient episodes per 100,000 (0-18) population	Specialist inpatient episodes per 100,000 (19+) population
Durham, Darlington and Tees	2%	60.0	4.9
Cumbria, Northumberland, Tyne and Wear	3%	69.0	3.9
Lancashire	3%	67.3	5.4
Greater Manchester	5%	63.1	6.3
Cheshire, Warrington and Wirral	2%	56.4	5.9
Merseyside	3%	72.4	10.5
West Yorkshire	4%	69.9	6.6
South Yorkshire and Bassetlaw	2%	59.8	3.4
North Yorkshire and Humber	2%	54.8	4.3
Leicestershire and Lincolnshire	3%	69.9	5.8
Hertfordshire and The South Midlands	5%	67.8	5.3
Derbyshire and Nottinghamshire	3%	59.7	5.1
Birmingham and The Black Country	6%	86.6	4.8
Shropshire and Staffordshire	3%	69.5	6.7
Arden, Herefordshire and Worcestershire	3%	72.2	5.7
East Anglia	4%	55.4	7.6
Essex	3%	59.5	3.9
London	16%	70.8	5.4
Kent and Medway	2%	53.7	4.5
Surrey and Sussex	4%	59.4	6.0
Thames Valley	3%	56.5	6.4
Wessex	4%	59.5	4.6
Bath, Gloucestershire, Swindon and Wiltshire	3%	59.8	8.8
Bristol, North Somerset, Somerset and South Gloucestershire	3%	63.9	6.9
Devon, Cornwall and Isles Of Scilly	3%	60.1	6.6

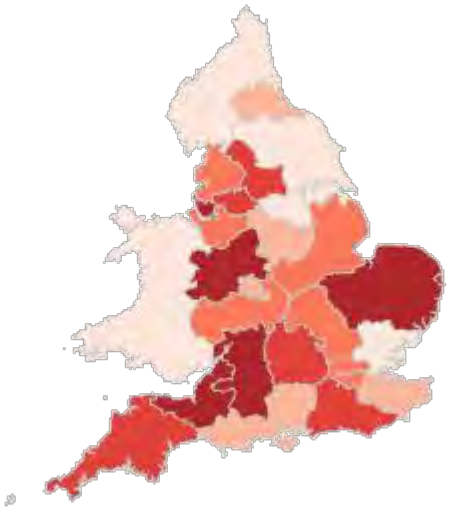
Wales	4%	52.6	2.0
Other (Scotland, N.I, Overseas etc.)	2%	N/A	N/A
Unknown	3%	N/A	N/A

The HES data above indicates that activity is fairly evenly spread across the country with the exception of London which has a much larger population, and Birmingham and Greater Manchester who are also slightly higher. However, once we account for different populations in each area we can see there is much more variation across the country in terms of relative activity. The episodes per 100,000 population show some differences from Wales at 52.6 and Kent and Medway at 53.7 to Merseyside at 72.4 to Birmingham and the Black Country at 86.6 (all paediatric services). In the case of adult services, the episodes per 100,000 population show differences from Wales at 2 and Essex at 3.9 to Bath, Gloucestershire, Swindon and Wiltshire at 8.8 and Merseyside at 10.5. This is demonstrated in the maps below; the darker the colour the higher the relative activity in that area.

Paediatric (0-18) 2012/13 HES specialist inpatient episodes per 100,000 population, by Area Team of patient residence (activity per head so controlled for different population sizes)



ACHD (19+) 2012/13 HES specialist inpatient episodes per 100,000 population, by Area Team of patient residence (activity per head so controlled for different population sizes)



Geographical variation and CHD: What we have heard during pre-consultation

The evidence we have received in relation to geographical variation has been limited. Where geography has been raised it has been in relation to how services are delivered now and how they might be delivered in the future. The focus has been on whether existing units will meet the standards and what it means to staff and patients if not; and travel times now and in the future.

We have noted the feedback we have received during pre-consultation on the concerns about how services will be delivered in the future, and will use this to inform our thinking in relation to future work on Objectives 3, 4 and 5.

We welcome more information.

Engagement and Involvement

Over the past 12 months we have been working with a wide range of stakeholders to develop the current draft standards. We have worked with and spoken to:

- children and young people with CHD and their parents and carers;
- adults with CHD and their parents and carers;
- groups representing people with CHD;
- clinicians and other members of the multidisciplinary team;
- providers; and
- local authorities and Healthwatch.

As well as regular meetings of formal engagement and advisory groups, we have undertaken visits to all specialist units, led by Professor Deirdre Kelly, Chair of the Clinician Group. During these visits, members of the new CHD review team had an opportunity to speak to clinical staff, and patients and their families. We also ran nine dedicated events for children and young people around the country.

The draft standards have been central to our engagement and involvement work from the outset and have informed the development of the draft service specifications. For the past year we have been working with experts to develop the draft standards, and then testing them out with our engagement and advisory groups and a wider audience.

We have adopted an approach of openness and transparency and all our papers are published on the NHS England Congenital Heart Disease Review website and John Holden's blog. Blog 23 contained the then-current version of the standards and so was open to everyone to see.

Launch of the consultation is the next step in the process and our work on engagement and involvement is ongoing. We plan to arrange four further regional visits during consultation and to do some targeted work with the stakeholders with an interest in the following protected characteristics:

- Age (specifically adults with CHD, with whom we have had less contact than children and young people)
- Disability (in particular, learning disability)
- Race

Summary of analysis

The evidence and engagement activity considered above has highlighted ways in which, subject to consultation and final agreement, our standards can help improve the way in which services are delivered to all those with CHD, including those in protected groups.

This is particularly so in relation to:

- Age
- Disability
- Pregnancy and maternity
- Race

The links between the standards and their impact on other protected groups is not so obvious. We hope to better understand how the standards might be used to support other protected groups through focused activities during the consultation – and also increase our understanding of the needs of adults with congenital heart disease.

The standards and the service specifications will, once agreed, set the framework through which CHD services will be delivered. It will be important for providers to ensure that they have regard to the equality duty in the provision of these CHD services.

Eliminating discrimination, harassment and victimisation

The draft standards apply to CHD services for children and adults – we currently only have agreed standards and a service specification for CHD services for children. The new draft

standards will ensure that everyone with CHD gets the best possible care whatever their age, thereby improving the consistency of our approach with adults.

Advancing equality of opportunity

The draft standards apply to CHD services wherever they are delivered in the country. They apply to all services (levels 1, 2 and 3). The draft standards will help ensure that all services are working to the same aims – and that people with CHD can receive a consistently high quality service.

Promoting good relations between groups

The standards will provide a consistent approach for all those with CHD in protected groups.

Our work to date has also enabled us to identify some areas that are common to all groups (and not solely applicable to CHD services) and improvements in these areas will benefit all:

- Effective communications
- Information sharing between professionals
- Transition

Evidence- based decision making

Our engagement and involvement to date has been invaluable in enabling us to develop the current draft standards and to hear from a wide range of people. It has at the same time allowed us to develop our thinking in relation to protected groups and to identify some gaps in relation to our understanding of whether people with CHD in some protected groups have a voice and are being heard.

Our work with children and young people and meeting patients and families at the hospitals we visited gave us a particular insight into issues around age (specifically children and young people, and the transition into adult services) disability, pregnancy and maternity, and race.

It has highlighted issues relating to three protected groups that would benefit from further consideration and research:

- How CHD services will develop to meet changing needs as the number of adults with CHD exceeds the number of children with CHD.

- The reason for the prevalence of CHD in some Asian communities and poorer outcomes at 30 days after first surgical procedure.

- How CHD services can best be developed to meet the needs of patients with a disability, in particular learning disability.

We are also keen during consultation to hear from people who can provide further evidence to inform our thinking in relation to those protected groups not mentioned above.

Sharing this draft equality analysis
As part of our assurance, this draft analysis will be shared with our programme board, the Specialised Commissioning Oversight Group, Programme of Care Board for Women and Children, the Clinical Priorities Advisory Group and the Directly Commissioned Services Committee.

The draft equality analysis will form part of the reference document that will accompany the consultation document, draft standards and service specifications.

As such it will be included in our communications and engagement activity at launch. We will send it to our engagement and advisory groups, our Clinical Advisory Panel and blog followers.

For your records **Name of person(s) who carried out this draft analysis:**	Penny Allsop
Name of Sponsor Director:	John Holden, Director of System Policy
Date analysis was completed:	July 2014
Review date:	TBC post-consultation

Governance Paper

Purpose

1. This paper provides assurance to the new Congenital Heart Disease (CHD) review Programme Board, Women and Children's Programme of Care (POC) Board, Clinical Priorities Advisory (CPAG) and Directly Commissioned Services Committee (DCSC) that the relevant and necessary governance has been in place during the development of the standards and specifications for congenital heart services.

Governance arrangements to date

2. The standards of care for patients with congenital heart disease from detection to end of life were created by specially formed groups of clinicians and patient representatives on behalf of a Clinical Advisory Panel (CAP) convened for the purposes of the review to advise the Board of NHS England. The CAP considered views from a wide range of stakeholders (see engagement paper, Item 6 Annex F).

3. The service specifications have been created and approved by the congenital heart disease Clinical Reference Group (CRG).

4. The overarching programme has been assured by a monthly-meeting Programme Board and a Task and Finish Group of the NHS England Board.

5. These groups are shown as the decision-making bodies in figure 1 below, along with links to the terms of reference for the various groups. Membership lists can be found in Annex A.

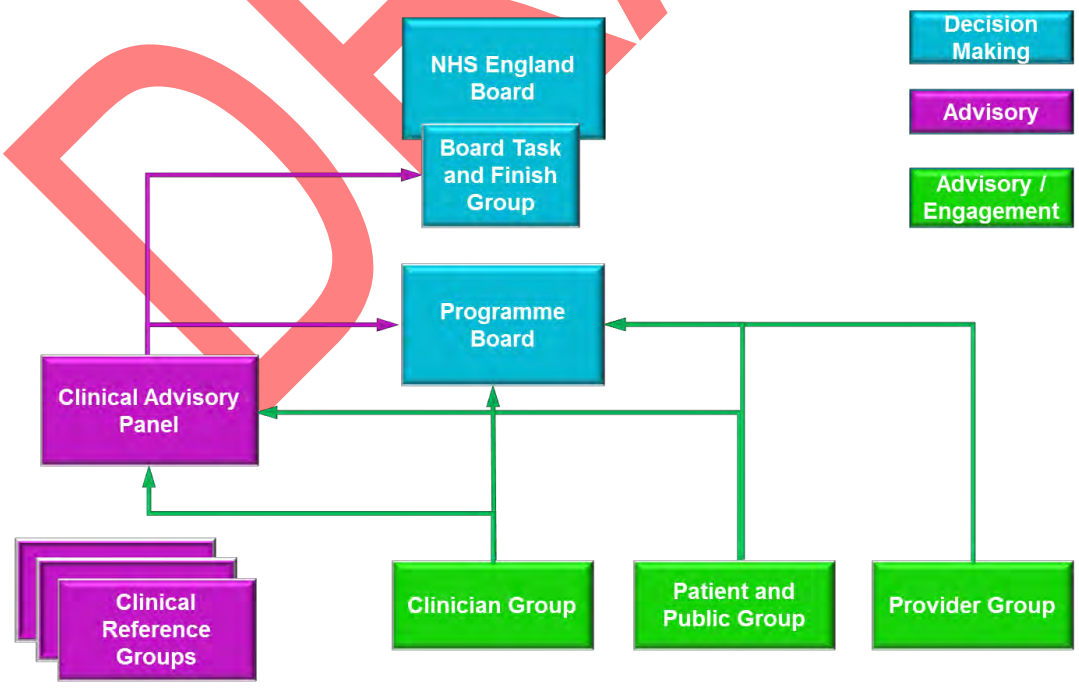


Figure 1

Board Task and Finish Group Terms of Reference
Programme Board Terms of Reference
Clinical Advisory Panel Terms of Reference

6. The CAP met on 18 June 2014 to review the standards. They considered the views expressed during pre-consultation and made amendments as necessary. Final approval for consultation will be given by correspondence by 8 August 2014.

Next steps

7. Prior to launching public consultation on the standards and specifications the review will go through the following process:
   - 22 July: **Specialised Commissioning Oversight Group** (SCOG) (to update on the review and engage with area and regional team colleagues)
   - 28 July: **Programme Board** (approval to apply to POC/CPAG/DCSC and approval of the content of the consultation documents)
   - 29 July: **Programme of Care Board** (to review draft specifications and update on impact assessment progress)
   - Early August: **Clinical Advisory Panel** (advice to the programme board on the alignment between standards and specifications by correspondence)
   - Mid-Aug: **Directly Commissioned Services Committee** (DCSC) (briefing by correspondence)
   - 20 Aug: **Programme of Care Board** (for approval/recommendation to CPAG)
   - 1 Sept: **Task and Finish Group of the Board** (briefing and approval to consult, subject to the remaining governance groups)
   - 2 Sept: **Clinical Priorities Advisory Group** (for approval/recommendation to DCSC)
   - 5 Sept: **DCSC** (approval by Chair's action)
   - 8 Sept: **Programme Board** (final approval to launch consultation)

8. Once the consultation closes the review expects the following next steps:
   - Analysis of the responses
   - Identification of required changes to the standards by the standards groups
   - Recommendation of changes made to the CAP
   - Sign-off on changes to the standards made by the CAP
   - Revisions to the specifications made by the CRG (Chair is a member of CAP)
   - Amended specifications to be subject to the specialised commissioning governance process, as defined by the Specialised Commissioning Taskforce
   - Public response to consultation published

9. Final decisions on the work of the review will be taken by the full NHS England Board meeting in public.

Annex A: Membership Lists

Task and Finish Group Members:

- Professor Sir Malcolm Grant, NHS England Chair (Chair);
- Margaret Casely-Hayford, NHS England Non-Executive Director;
- Ian Dodge, National Director: Commissioning Strategy;
- Professor Sir Bruce Keogh, National Medical Director; and
- Ed Smith, NHS England Non-Executive Director

Programme Board Members (as at 17 July 2014):

- Ian Dodge, National Director: Commissioning Strategy (Chair);
- John Holden, Director of System Policy (Vice Chair);
- Wayne Bartlett-Syree, Assistant Head of Planning and Delivery (Specialised Commissioning)
- Eleri de Gilbert, Area Team representative, Area Team Director (South Yorkshire and Bassetlaw area team);
- Sam Higginson, Finance representative, Director of Strategic Finance;
- Chris Hopson, Chair of the review's Provider Group;
- Will Huxter, Regional Team representative, Head of Specialised Commissioning (London);
- Professor Deirdre Kelly, Chair of the review's Clinician Group;
- Professor Sir Bruce Keogh, National Medical Director;
- Michael Macdonnell, Head of Strategy, Specialised Commissioning Taskforce;
- Mr James Palmer, National Clinical Director, Specialised Services;
- Linda Prosser, Area Team representative, Director of Commissioning (Bristol, North Somerset, Somerset and South Gloucestershire area team);
- Professor Sir Michael Rawlins, Chair of the Clinical Advisory Panel;
- Professor Peter Weissberg, Chair of the review's Patient and Public Group;
- Giles Wilmore, Director for Patient & Public Voice & Information;
- Michael Wilson, review Programme Director; and
- two CCG representatives, to be identified.

CAP Members:

- Professor Sir Michael Rawlins, President, Royal Society of Medicine (Chair);
- Mr David Barron, Society of Cardiothoracic Surgery;
- Dr J-P van Besouw, Royal College of Anaesthetists;
- Dr Hilary Cass, Royal College of Paediatrics and Child Health;
- Dr Jacqueline Cornish, National Clinical Director for Children and Young
- People (NHS England);
- Professor John Deanfield, Chair of Adult with Congenital Heart Disease Advisory Group;
- Professor Huon Gray, National Clinical Director for Cardiac Care (NHS
- England);
- Professor Deirdre Kelly, Chair of the review's Clinician Group;
- Dr Rob Martin, British Congenital Cardiac Association;
- Dr Andy Mitchell, Regional Medical Director (London), (NHS England);

- Professor Pedro del Nido, International Advisor;
- Mr James Palmer, National Clinical Director for Specialised Services (NHS
- England);
- Mr James Roxburgh, Society for Cardiothoracic Surgery;
- Dr Tony Salmon, Chair of the review's Standards Sub-group;
- Fiona Smith, Royal College of Nursing;
- Professor Terence Stephenson, Academy of Medical Royal Colleges;
- Dr Graham Stuart, Chair of the Clinical Reference Group for Congenital Heart Services;
- Professor Peter Weissberg, Chair of the review's Patient and Public Group; and
- Professor Norman Williams, Royal College of Surgeons

Congenital Heart Disease Clinical Reference Group (CRG) members:

- Graham Stuart, National Clinical Director Co-Chair
- Julia Grace, Accountable Commissioner

Senate representatives

- John O'Sullivan, North East (N1)
- Vaikom Mahadevan, Greater Manchester, Lancashire and S Cumbria (N2)
- Ram Dhannapuneni, Cheshire and Mersey (N3)
- Kate English, Yorkshire and Humber (N4)
- David Barron, West Midlands (M1)
- Giles Peek, East Midlands (M2)
- Clive Lewis, East of England (M3)
- Duncan Macrae, London NW (L1)
- Martin Elliot, London NE (L2)
- Gurleen Sharland, London S (L3)
- Mark Turner, South West (S1)
- Trevor Richens, Wessex (S2)
- Satish Adwani, Thames Valley (S3)
- David Hildick-Smith, South East Coast (S4)

Professional organisation representatives

- Gill Harte, Royal College of Nursing
- Rob Henderson, British Cardiovascular Society
- Andy Tometzki, British Congenital Cardiac Association
- Andrew Wolf, Association of Paediatric Anaesthetists of Great Britain and Ireland

Patient and carer representatives

- Jonathan Arnold
- Lois Brown
- Michael Cumper
- Penny Green
- Hazel Greig-Midlane
- Suzanne Hutchinson
- Anne Keatley-Clarke
- Samantha Lloyd

Engagement Paper

Introduction

1. This paper provides assurance to the new Congenital Heart Disease (CHD) review Programme Board, Women and Children's Programme of Care (POC) Board, Clinical Priorities Advisory (CPAG) and Directly Commissioned Services Committee (DCSC) that the necessary engagement has been carried out with all relevant individuals and groups in developing the standards, and that the views of stakeholders have been taken into account.

Action taken to date: Developing the standards and specifications

2. The standards of care for patients with CHD from detection to end of life were created by specially formed groups of clinicians and patient representatives. They have been reviewed by the Congenital Heart Disease Clinical Reference Group (CRG). See Annex A for CRG membership.

3. In March 2014 the standards were made public and have since been widely discussed as detailed below. Following this period of pre-consultation engagement, all comments received were considered by the Clinical Advisory Panel (CAP) and amendments made to the standards as necessary. The paper submitted to the CAP summarising what we heard pre-consultation can be found here: http://www.england.nhs.uk/wp-content/uploads/2014/07/chd-cap-6.pdf.

4. The CRG has prepared the service specifications to reflect the standards.

Action taken to date: Stakeholder Engagement

Engagement and advisory groups

5. The review has held regular meetings with its three engagement and advisory groups. All members received papers for meetings and blog alerts whether or not they attend a meeting. The following meetings have taken place:
   - five meetings of the patient and public group (with representation from national and local charities related to congenital heart disease and learning disabilities);
   - four meetings of the provider group (with representation from all providers of congenital heart services); and
   - four meetings of the clinicians' group (with representation from all trusts that offer congenital heart disease services).

   The standards have been discussed by each group and their views taken into account.

6. An additional visit has been made to Southampton representatives as they were unable to attend the main meetings due to timings.

7. These groups are shown as the engagement and advisory bodies in figure 1 below. Membership lists can be found in Annex B.

8. Each engagement and advisory groups has an independent chair (listed below). The chairs represent the views of their engagement and advisory groups at the Programme Board and CAP.

9. Chairs:
   - Chair, Clinician Group: Professor Deirdre Kelly, Professor of Paediatric Hepatology, Birmingham Children's Hospital,
     - Member of Programme Board and CAP
   - Chair, Patient and Public Group: Professor Peter Weissberg, Medical Director, British Heart Foundation,
     - Member of the Programme Board and CAP
   - Chair, Provider Group: Chris Hopson, Chief Executive, Foundation Trust Network,
     - Member of the Programme Board

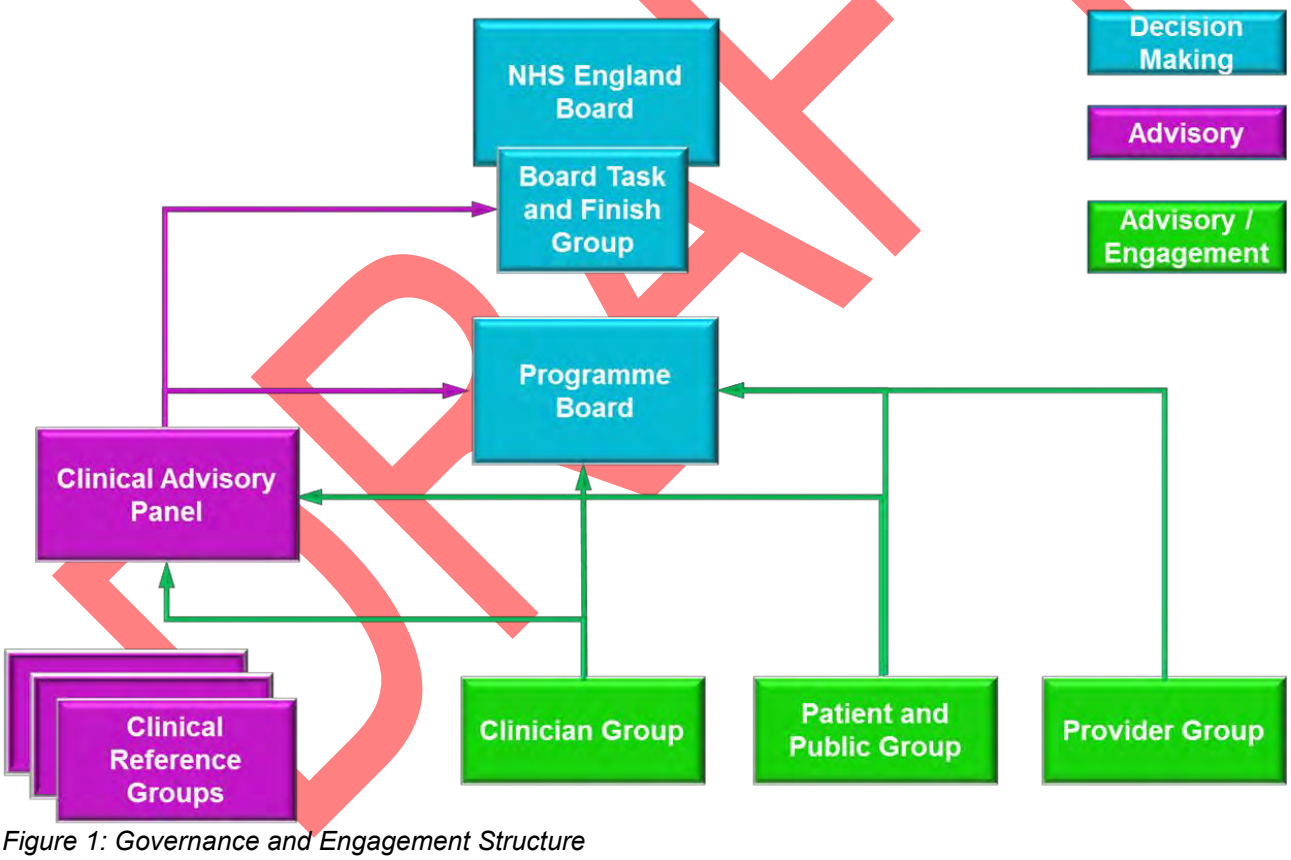


Figure 1: Governance and Engagement Structure

Children and young people

10. Nine events were held at venues around the country during the school holidays, for children and young people with congenital heart disease and their families, to ask them what mattered to them about CHD services. Over 100 children and young people aged between 2 and 24 years attended with their siblings and parents.

11. A parent/patient response form was used to gather comments and opinions on the draft standards.

12. Their views relating to standards were considered by CAP in their review of the standards.

Hospital visits

13. Professor Deirdre Kelly (Chair of the review's Clinician Group) supported by the review team undertook 13 visits to specialist services around the country including sessions with staff as well as with patients and families. The review team engaged directly with over 150 patients and families: adult patients, children and young people, parents of children of all ages in addition to hundreds of hospital staff.

14. Comments relevant to the standards were considered by CAP in their review of the standards.

Government, Local Authorities and Healthwatch

15. The review team has carried out the following engagement activities with government, local authorities and Healthwatch:
    - Two meetings at the House of Commons for interested MPs and Peers –
        - Professor Sir Bruce Keogh, NHS England Medical Director, presented at the All Party Parliamentary Group (APPG) to highlight the approach being taken to develop the standards in October 2013
        - Dr Mike Berwick, Deputy Medical Director, NHS England, presented at a meeting for MPs after the draft standards had been made public in April 2014
    - A combined meeting of local authorities and local Healthwatch groups connected with paediatric and adult services was also held in central England
    - A WebEx event was held for local authorities and Healthwatch
    - The team has responded to individual requests for Joint Overview and Scrutiny Committees and Overview and Scrutiny Committees attendance
    - Attendee lists can be found in Annex C

Next steps and plans for consultation

Regional Events

16. There will be a number of exhibition style events across the country to allow as wide an audience as possible to review the draft standards and respond to the consultation.

Engagement and advisory groups

17. A joint meeting of the three engagement and advisory groups to discuss current draft standards is arranged for 25 July.

18. We will offer the three engagement groups - Clinicians, Providers and Patient & Public – further opportunities to meet during the consultation process.

19. We plan to hold an additional event for all these groups to gather, listen to each other and share what they have been hearing during the consultation period. It will be run towards the end of consultation so that all attendees can report back what has been learnt / heard at the other events including stakeholder events and the regional events.

Hospital visits

20. There are three further visits planned to non-specialist adult CHD providers.

MPs, Peers, Local Authorities and Healthwatch

21. Prior to consultation all local and national government representatives will be informed of the forthcoming consultation at least three weeks in advance.

22. We are planning a further event for Local Government and Healthwatch during consultation.

23. We are having ongoing conversations with the Local Government Association, Centre for Public Scrutiny and Healthwatch England.

24. NHS England will respond to requests to attend JOSCs and OSCs during consultation.

25. There will be a briefing event for MPs and Peers during consultation.

Learning disabled adults

26. We plan to gather opinions on what matters to people with learning disabilities through existing routes rather than running specific events. It is likely that stakeholders who work with young people and adults with learning disabilities will incorporate questions and discussions about the standards, within already planned and existing events, to enable contribution to the consultation process.

Black and Minority Ethnic groups

27. Initial work with faith groups has not provided clear links to those in the communities that have an interest in CHD, but work continues with the providers who serve communities including significant numbers of people from ethnic groups more affected by CHD (see Draft Equality Analysis, Item 6 Annex D) to develop routes by which they are able to contribute to the process. This may include specific events during consultation or providing materials or spokespersons to events being run within these communities to encourage contributions to the review.

Bereaved parents

28. Parents who are bereaved may find contributing to the consultation difficult. The review has linked with the Child Bereavement Trust to assist in engaging bereaved parents during consultation: this may be through an event for bereaved parents

and/or using online and electronic methods of discussing comment and offering contributions. Members of the review team will meet with bereaved parents from the Bristol area at their invitation to seek their views.

Adults with CHD

29. Work is being undertaken to establish whether there is a requirement or desire to hold an event specifically for adults with CHD during the consultation period as this group has been relatively under-represented in the meetings held by the review to date.

Annex A: Congenital Heart Disease Clinical Reference Group members

National Clinical Director Co-Chair	**Accountable Commissioner**
Graham Stuart	Julia Grace, Leicester
Senate	**Representative**
North East (N1)	John O'Sullivan
Greater Manchester, Lancashire and S Cumbria (N2)	Vaikom Mahadevan
Cheshire and Mersey (N3)	Ram Dhannapuneni
Yorkshire and Humber (N4)	Kate English
West Midlands (M1)	David Barron
East Midlands (M2)	Giles Peek
East of England (M3)	Clive Lewis
London NW (L1)	Duncan Macrae
London NE (L2)	Martin Elliot
London S (L3)	Gurleen Sharland
South West (S1)	Mark Turner
Wessex (S2)	Trevor Richens
Thames Valley (S3)	Satish Adwani
South East Coast (S4)	David Hildick-Smith
Association of Paediatric Anaesthetists of Great Britain and Ireland	Andrew Wolf
British Congenital Cardiac Association	Andy Tometzki
British Cardiovascular Society	Rob Henderson
Royal College of Nursing	Gill Harte
Patient and carer representatives	
Samantha LLoyd	Lois Brown
Michael Cumper	Hazel Greig-Midlane
Suzanne Hutchinson	Jonathan Arnold
Penny Green	Anne Keatley-Clarke

Annex B: Engagement and Advisory Membership Lists

Clinician and Provider Engagement and Advisory Group
Alder Hey Children's NHS Foundation Trust
Barts Health NHS Trust
Basildon & Thurrock University Hospitals NHS Foundation Trust
Belfast Health and Social Care Trust
Birmingham Children's Hospital NHS Foundation Trust
Blackpool Teaching Hospitals NHS Foundation Trust
Brighton and Sussex University Hospitals NHS Trust
Cardiff and Vale University Health Board
Central Manchester University Hospitals NHS Foundation Trust
Great Ormond Street Hospital for Children NHS Foundation Trust
Guy's and St Thomas' NHS Foundation Trust
Hull and East Yorkshire Hospitals NHS Trust
King's College Hospital NHS Foundation Trust
Leeds Teaching Hospitals NHS Trust
Liverpool Heart and Chest Hospital NHS Foundation Trust
Newcastle upon Tyne Hospitals NHS Foundation Trust
NHS Greater Glasgow and Clyde
Nottingham University Hospitals NHS Trust
Oxford University Hospitals NHS Trust
Papworth Hospital NHS Foundation Trust
Plymouth Hospitals NHS Trust
Royal Brompton and Harefield NHS Foundation Trust
Royal Wolverhampton NHS Trust
Sheffield Teaching Hospitals NHS Foundation Trust
St George's Healthcare NHS Trust
University College London Hospitals NHS Foundation Trust
University Hospital of South Manchester NHS Foundation Trust
University Hospital Southampton NHS Foundation Trust

University Hospitals Birmingham NHS Foundation Trust
University Hospitals Bristol NHS Foundation Trust
University Hospitals of Leicester NHS Trust

Royal Colleges and Societies
Academy of Medical Royal Colleges
Association of Cardiothoracic anaesthetists
British Cardiovascular intervention Society
British Cardiovascular Society
British Congenital Cardiac Association
British Heart Rhythm Society
British Maternal and Fetal Medicine Society
British Psychological Society
Cardiothoracic advisory group
CATS
Extracorporeal life support association (ELSO)
Faculty of Intensive Care Medicine
Fetal Anomaly Screening Programme
PICS (Paediatric intensive care society)
Royal College of Nursing
Royal College of Obstetricians & Gynaecologists
Royal College of Paediatrics and Child Health
Royal College of Surgeons of England
Society for Cardiothoracic Surgery (STCS)

Clinical Reference Groups
Adult Critical Care CRG
Cardiac Surgery CRG
Complex invasive Cardiology CRG
Congenital heart services CRG
Fetal Medicine CRG

Heart and Lung Transplantation CRG
Neonatal critical care CRG
Specialised Maternity Services CRG
Paediatric Intensive Care CRG

Patient and Public Engagement and Advisory Group
Amelia Matters
Antenatal Results and Choices (ARC)
Asthma UK
Ben Williams Trust
BHA *(formerly the Black Health Agency)*
British Cardiac Patients Association
British Heart Foundation
Cardiac Risk in the Young (CRY)
Cardio and Vascular Coalition (CVC)
Cardiomyopathy Association
Children's Heart Unit Fund
Children's Heart Association
Children's Heart Foundation (CHF)
Children's Heart Support Network
Children's Heart Surgery Fund
Children's Heartbeat Trust
Cystic Fibrosis Trust
Down's Heart Group
Ebsteins Society
Elyon's Heart Foundation (EHF)
Evelina Children's Heart Organisation (ECHO)
Families of Oceanward
Fragile Hearts
Heart Link
Heart Rhythm UK

Heartline Families
Hearts 4 Teens
Heatlhwatch England
ICD Patient and Family Heart Support Group
Keep the Freeman Children's Heart Unit Open
KEEPTHEBEAT
Lagan's Foundation
Little Hearts Matter
Marfan Trust
Max Appeal !
National Voices
Oxford Heart Valve Bank
Race Equality Foundation
SADS UK Sudden Arrhythmic Death Syndrome
South Asian Health Foundation
South West Children's Heart Circle
The 22Crew
The Afiya Trust
The Brompton Fountain
The Somerville Foundation
Tiny Tickers
To Transplant and Beyond
Transplant Support Network
UK Health Forum *(formerly National Heart Forum)*
Wessex Children's Heart Circle
Young at Heart
Young Hearts

Annex C: Council Representatives

Council	Name	Position
Leeds City Council	Cllr Lisa Mulherin	Executive Member for Health & Wellbeing
Leeds City Council	Cllr John Illingworth	Chair of Health Scrutiny at Leeds City Council
Leeds City Council	Steven Courtney	Principal Scrutiny Advisor to the Leeds Health Scrutiny Board
Birmingham City Council	Cllr Susan Barnett	Chair of the Health and Adult Social Care Overview & Scrutiny Committee.
Leicestershire County Council	Cllr Ernie White	Chair of the Health & Wellbeing Board
Leicester City Council	Cllr Michael Cooke	Chair of Health and Wellbeing Scrutiny Commission
Southampton City Council	Cllr Dave Shields	Cabinet member for Health also Chair of the Health & Wellbeing Board
Southampton City Council	Cllr Paul Lewzey	Back bench member of the Health & Wellbeing Board
Southampton City Council	Jessica North	Senior Communications Officer, Public Health
Manchester City Council	Ged Devereux	Senior Strategy Manager, Public Health
Westminster City Council	Mark Ewbank	Scrutiny officer
Oxfordshire County Council	Claire Phillips	Senior Policy and Performance Officer
Cambridgeshire County Council	Jane Belman	Scrutiny and Improvement Officer
Cambridgeshire County Council	Cllr Kevin Reynolds	Member of Adults Wellbeing and Health OSC
Lincolnshire County Council	Cllr Christine Talbot	Chairman Health Scrutiny Committee

Lincolnshire County Council	Simon Evans	Health Scrutiny Committee

Healthwatch Representatives

Council	Name	Position
Manchester	Neil Walbran	Chief Officer
Birmingham	Paul Devlin	Chief Executive Officer
Leeds	Pat Newdall	Healthwatch officer
Leicestershire	Eric Charlesworth	LLR representative on the UHL Board and the East Leicestershire and Rutland Clinical Commissioning Group
Leicester	David Barsby	Policy & Partnership Officer
Liverpool	Edwin Morgan	Chair of Liverpool Healthwatch
Oxfordshire	Larry Sanders	Chairman
Healthwatch	Shona Johnstone	Public Policy and Partnerships Manager

Congenital Heart Disease Activity Analysis: An update

Purpose

1. Objective 2 of the new congenital heart disease review is "to analyse demand for specialist inpatient congenital heart disease care, now and in the future".
2. The outputs of this work are an understanding of:
   a) current service provision and demand;
   b) future activity pressures that all else being equal will translate into future spend pressures; and
   c) future required capacity for specialist inpatient care services.
3. At this stage of the programme's work, the main focus is on how this informs the Financial Impact Assessment we are preparing for the Programme of Care (POC) Board and the Clinical Priorities Advisory Group (CPAG) as part of the assurance process to approve our consultation on standards.
4. **This paper asks the Programme Board to note the future activity pressures suggested by the analysis, to understand how they were derived and to agree that they form an appropriate basis for undertaking the Financial Impact Assessment.**
5. To note, further work may continue over the consultation period to further refine and sensitivity test our analysis particularly as we receive comments from interested parties; as a result, the numbers may change.

Analysis - Data

6. There are two reliable national sources of data on paediatric cardiac and adult congenital heart disease (ACHD) inpatient activity. Both sources have some weaknesses and difficulties with interpretation and therefore this analysis draws on both sources, as appropriate, to triangulate the data and thus to increase confidence in our findings. The data sources used are:
   - National Institute for Cardiovascular Outcomes Research (NICOR) Central Cardiac Audit Database (CCAD) which reports procedure numbers.
   - Hospital Episode Statistics (HES) Admitted Patient Care (APC) which is derived from Secondary Uses Service (SUS) data and reports episodes of care.
7. Data for adult services is flawed from both sources:
   - Although reporting has improved, not all units undertaking adult surgery/interventional cardiology report that activity to NICOR; and

- the way in which Hospital Episode Statistics (HES) activity is coded means it is not easy to distinguish CHD activity from other cardiac services.

8. While there are therefore concerns about the quality of data for ACHD activity the information presented in this report is the best available and we consider it to be sufficiently robust for this purpose.

Analysis - Results

9. The key findings from our analysis are summarised below:
    - Currently, around 65-75% of congenital heart inpatient activity is for 0-18 year olds.
    - Paediatric activity has grown steadily by around 10% above population growth over the last 10 years.
    - ACHD activity has grown by over 20% above population growth over the last 7 years, but is from a much lower base (so big % change may be small in absolute numbers).
    - We think the key demand drivers include technology/medical advances, increased patient expectations and clinician's willingness to treat, increased patient survival and for paediatric activity in particular the increasing % of patients who are of BAME ethnicity (where there is some evidence of higher incidence and also of a greater proportion of serious anomalies).
    - Of the identified demand drivers the only one that can be separately modelled going forward is population growth (by age, sex and area). Modelling is based on ONS projections. While this is the best information available these have not always been accurate in the past because of unanticipated changes to the population and birth rates.
    - The effect of all the other demand drivers over the last 10 years is included in the historic trend in activity growth above population growth.
    - Therefore we have looked at two key scenarios for future activity:
        - Scenario A: Population growth only (England and Wales).
        - Scenario B: As for A but also allowing activity per head to increase at the same rate as it has in the past.
    - These scenarios suggest that up to 2025/6:
        - Paediatric activity could be expected to grow by between 0.4% and 1% pa However, this is very sensitive to the birth rate projections which ONS has previously underestimated – under ONS' high variant projections expected growth would be between 1% and 2% pa.
        - ACHD activity could be between **0.7%** and **4%** pa.

New Congenital Heart Disease Review

NHS England

Activity Analysis Update

(slides 44 and 45, showing historic patient flows, have been amended / corrected since these slides were first published and circulated to the Programme Board. This was due to an issue in the software used to generate the maps not an issue in the actual data)

Jo Glenwright
John Buckell
Charles Keenan

Key Messages

- We have more confidence in paediatric activity data than ACHD activity data. NICOR data is good for paediatric activity (0-16), HES can do both paediatric and ACHD
- Currently, we think around 65-75% of congenital heart inpatient activity is for 0-18 year olds
- Paediatric activity has grown steadily by around 10% above population growth over the last 10 years, this is driven by growth in activity for children under the age of 1
- ACHD activity has grown by over 20% above population growth over the last 7 years, but is from a much lower base (so big % change may be small in absolute numbers)
- We think the key demand drivers include technology/medical advances, increased patient expectations and clinician's willingness to treat, increased patient survival and for paediatric activity in particular the increasing % of patients who are of BME ethnicity
- Some simple scenarios suggest that up to 2025:
  - **Paediatric activity could be expected to grow by between 0.4% and 1%pa (this is very sensitive to the birth rate projections – under ONS High projections it would be between 1% and 2% pa)**
  - **ACHD activity could be between 0.7% and 4% pa**

New Congenital Heart Disease Review

NHS England

Datasets, data issues and the definition of congenital heart disease activity

Joanna Glenwright
John Buckell
Charles Keenan

THE NHS CONSTITUTION
the NHS belongs to us all

We have data from NICOR and HES

NICOR data: Central Cardiac Audit Database (CCAD)

- NICOR provided us with data by for Adults and Children (0-16), by area team of residence, provider category (NHS England etc.), type of procedure (surgery or catheter), for financial years 2003/4 to 2012/13
- NICOR have a list of procedures they include, these are coded using EPCC* list
- NICOR data is reported by procedure, procedure type (including catheter vs surgery is verified as part of audit) * European Paediatric Cardiac Code

HES data: Admitted Patient Care (APC) data

- We extracted data from HES based on the presence of select OPCS codes in any of the procedure fields. For each episode extracted we have a variety of fields including, patient area of residence and provider, for financial years 1997/8 to 2012/13
- The list of procedures included is based on the existing Identification Rules (IR) used for paediatric cardiac (23B) (age 0-18) and ACHD (13X) (age 19+) and clinician advice. For adults in particular it is not clear that this identifies all of the relevant activity e.g. due to coding issues etc.
- HES data is reported by episode of care, catheter/surgery split is based on definition set of codes.

We have data from NICOR and HES

- For adult services both NICOR and HES data sources are flawed for different reasons:

1. not all adult activity is reported to the national database run by the National Institute for Cardiovascular Outcomes Research (NICOR), and

2. the generic nature of Hospital Episode Statistics (HES) means it is not easy to distinguish CHD activity from other cardiac services

- Given 2, we have struggled to come up with a definitive list of codes that we are certain capture the relevant activity in HES. After using a series of wider definitions that captured "too much" activity we have settled on using the procedure codes in the current IR – this should be at least of subset of actual activity. However, we have dropped one code L13.3 (arteriography of pulmonary artery) as this was significant outlier affecting the data and where it is used alone it is likely to be diagnostic rather than therapeutic intervention.

- Further, in our HES extract for ACHD we found that the coding of activity pre 2006/7 looked odd. 2006/7 is a significant year for the Payment by Results system which relies on this data to pay hospitals for the activity they do. Therefore we have not used any of the ACHD data pre 2006/7 as it was distorting our analysis.

- **As a result we have some concerns about the quality of data for ACHD activity and interpretation of any results should bear this in mind.**

We have data from NICOR and HES

- Because of the different databases, different coding classifications used (EPCC vs OPCS), different coding practices and different currencies (procedures vs episodes) it is not possible to know if the activity covered by each dataset is an exact match. The next slides test how well the two datasets compare…

2012/13 data for patients in England and Wales:

Age	NICOR (procedures)	HES (episodes)
Paediatric (0-16)	5,700	7,500
Paediatric (0-18)	N/A	8,200
ACHD (17+)	2,400 (3,000*)	3,100
ACHD (19+)	N/A	2,400

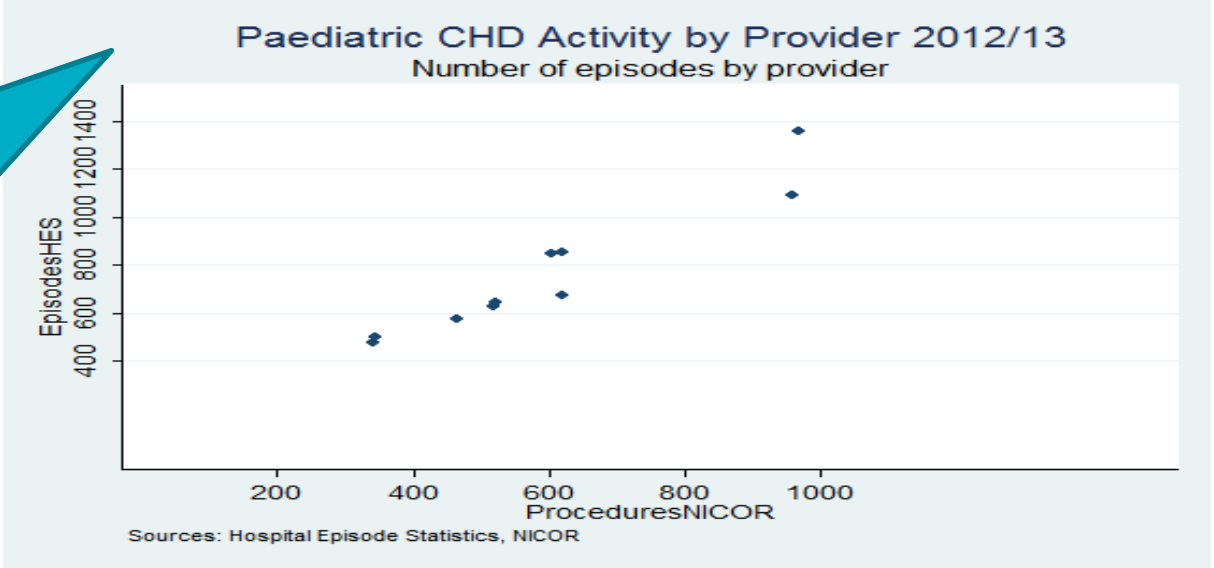
* Uplifted figure if we assume NICOR figure represents 80% of total
NICOR figures won't match website as only England and Wales residents treated in NHS E providers are included in figure above – website is all patients all reporting providers

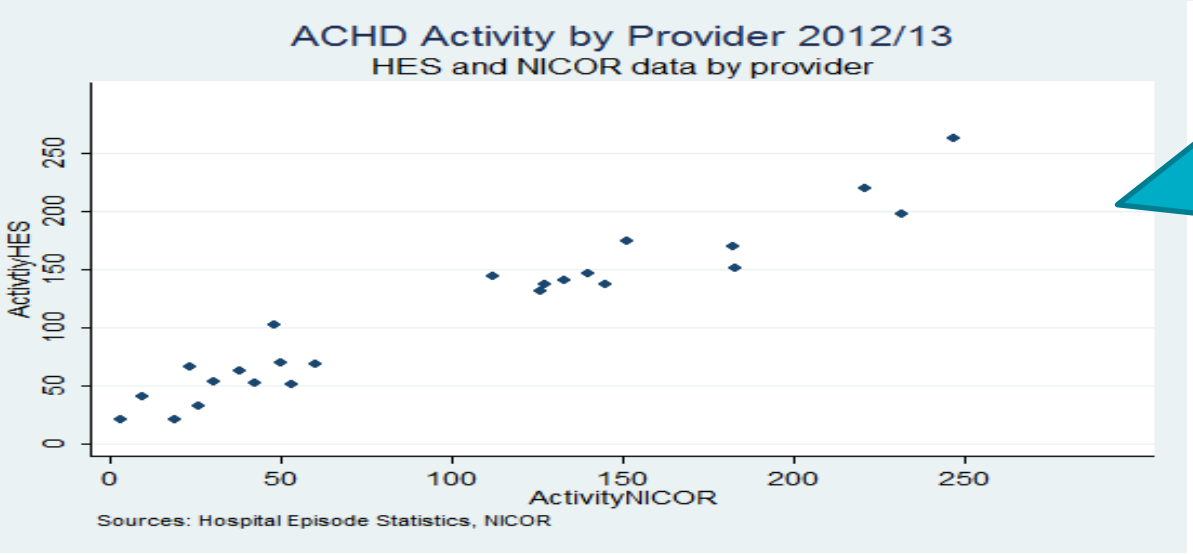
To note: definition of child vs adult. NICOR define a child as aged 0-16. The IRs for specialised commissioning define a child as aged 0-18. HES data is extracted on the latter, and will use this as the main definition going forward. Where using comparison with NICOR we compare activity for 0-16 only.

At provider level activity NICOR and HES data compare well

Paediatric (age 0-16 for comparison)
Strong results for rank correlation* and a correlation coefficient of 0.96

* Spearman's Rank and Kendall's Tau



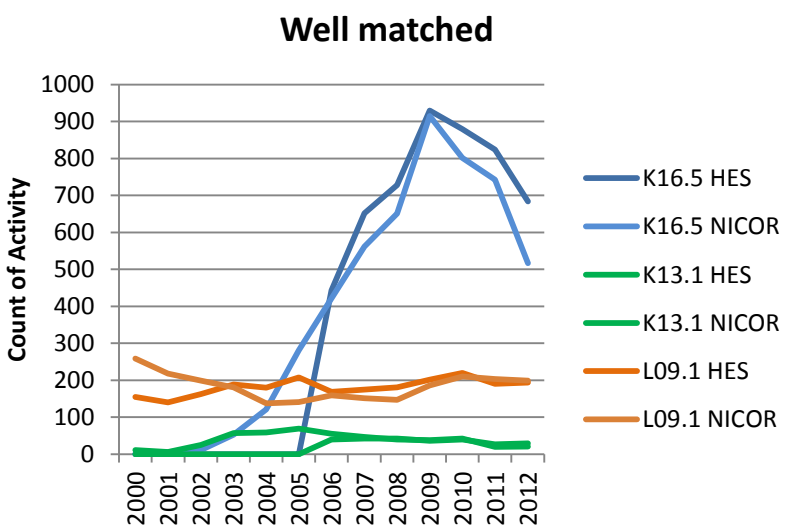


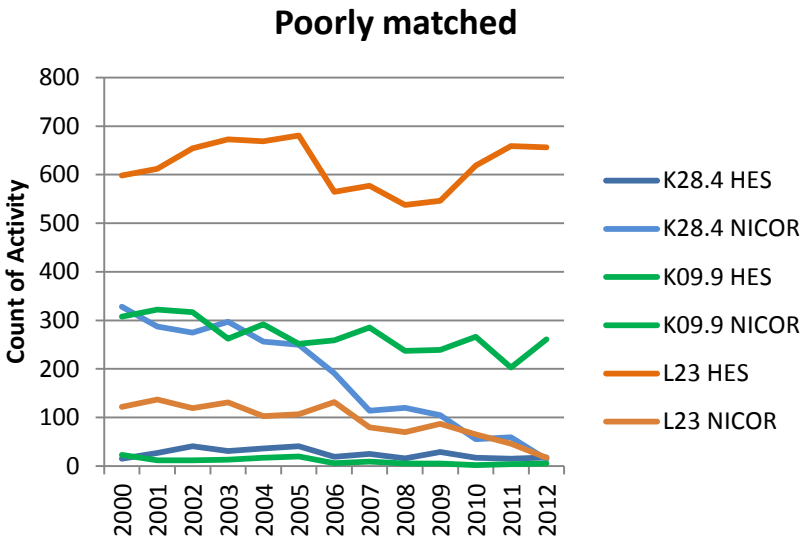
ACHD (age 17+ for comparison)
Strong results for rank correlation* and a correlation coefficient of 0.97

* Spearman's Rank and Kendall's Tau

At procedure level activity it is less clear

- Six procedures are chosen where the codes should map across the two data sets reasonably well; their activity is charted below for HES and NICOR
- Three of the procedures appear to have similar numbers and patterns in both data (left panel)
- Three appear to have very different numbers and patterns in both data (right panel)

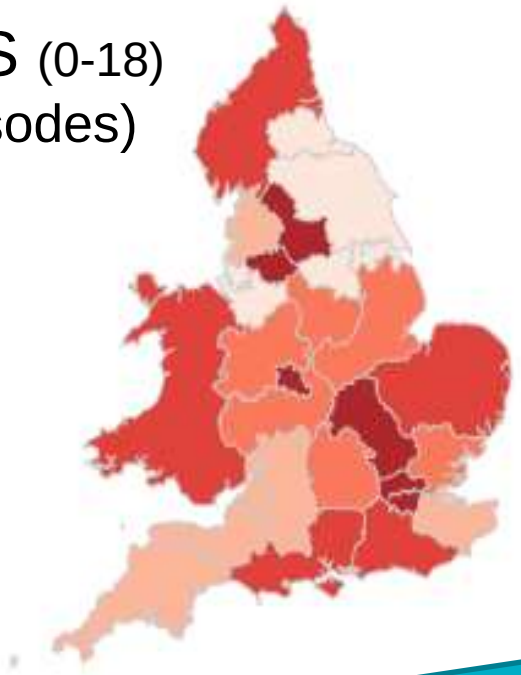


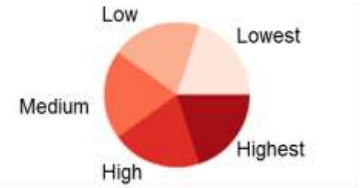


At Area Team of where the patient lives it looks OK

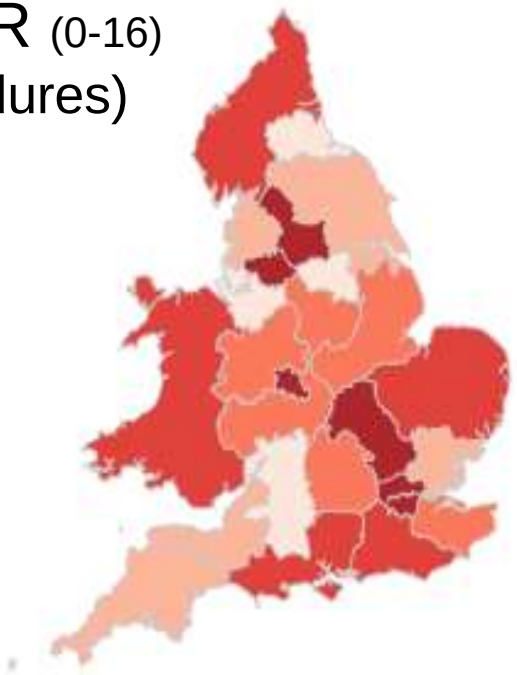
Paediatric 2012/13 activity by Area Team of patient residence

HES (0-18) (episodes)





NICOR (0-16) (procedures)

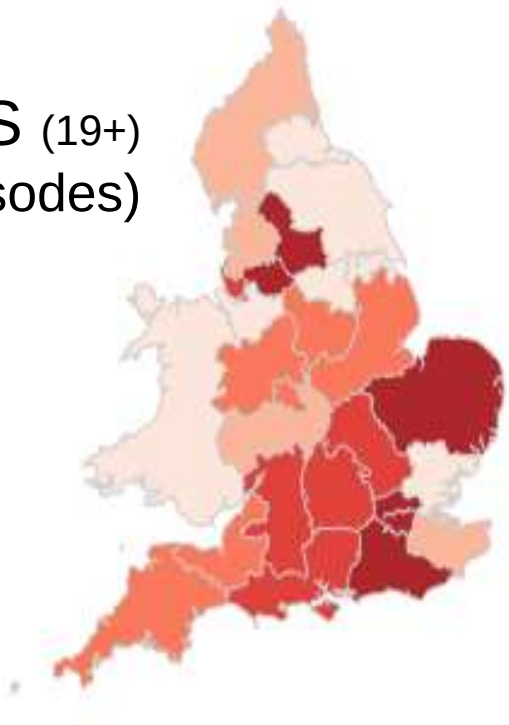


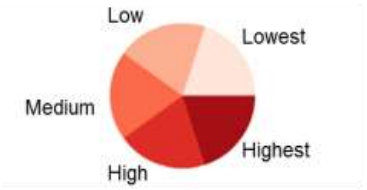
Similar patterns in which patient areas have the highest activity levels – paediatric activity 2012/13

At Area Team of where the patient lives it looks OK

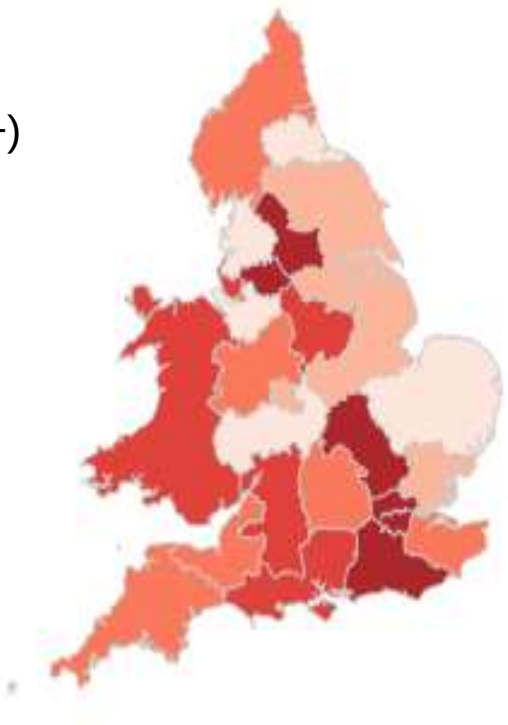
ACHD 2012/13 activity by Area Team of patient residence

HES (19+) (episodes)



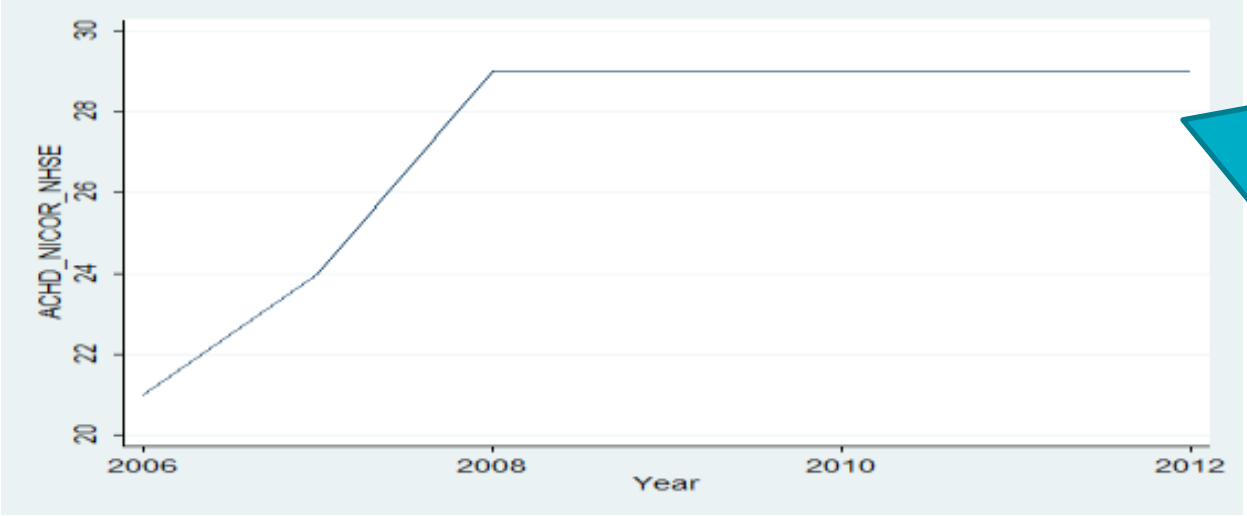


NICOR (17+) (procedures)



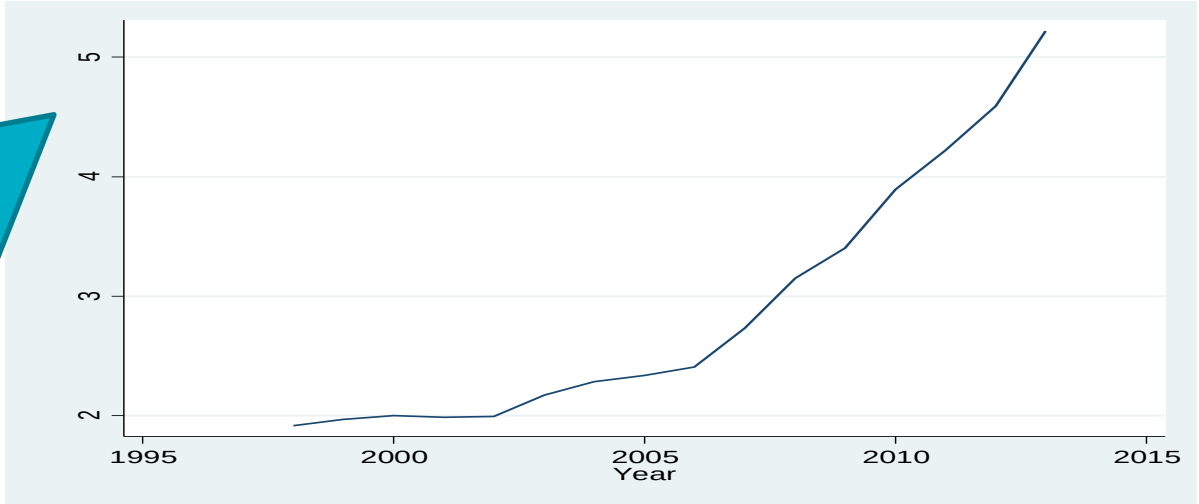
Similar patterns in which patient areas have the highest activity levels – ACHD activity 2012/13 - although comparison less reliable due to underreporting in NICOR data by some provider which **will bias certain areas.**

Both datasets may be affected by changes in reporting over time



NICOR ACHD data – not all NHS E and Wales providers report to NICOR but the number who do has increased over time from 21 in 2006/7 to 29 in 2012/13

HES data – Over time there have been changes in coding practice (especially with push to PbR payment in 06/07). The depth of coding has increased. For ACHD activity pre 2006/7 data was significantly distorted so has not been used.



This is a key caveat when considering past trends

Scope and coverage of the data and analysis:

Baseline year	2012/13
Population	England and Wales residents Paediatric = 0-18 (NICOR data only covers 0-16) Adult = 19+
Procedures included	NICOR: Surgical and catheter interventions reported to NICOR/CCAD congenital database HES: Procedures identified in the IRs and by clinicians as paediatric cardiac or ACHD procedures
Historic data	ACHD: 2006/07 -2012/13 Paeds: 2003/04– 2012/13
Projected data	• 2013-2025 (nationally) • 2013-2021 (sub nationally)
Projection Scenarios	• Population growth pressure only • Population growth plus continuation of historic trend
Sources	• NICOR CCAD database • HES APC data • ONS 2012 based projections for England • ONS 2011 based subnational projections by local authority

New Congenital Heart Disease Review

NHS England

2012/13 baseline activity

Joanna Glenwright
John Buckell
Charles Keenan

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2012/13 is our baseline year

2012/13 data for patients in England and Wales:

Age	NICOR (procedures)	HES (episodes)
Paediatric (0-16)	5,700	7,500
Paediatric (0-18)	N/A	8,200
ACHD (17+)	2,400 (3,000*)	3,100
ACHD (19+)	N/A	2,400

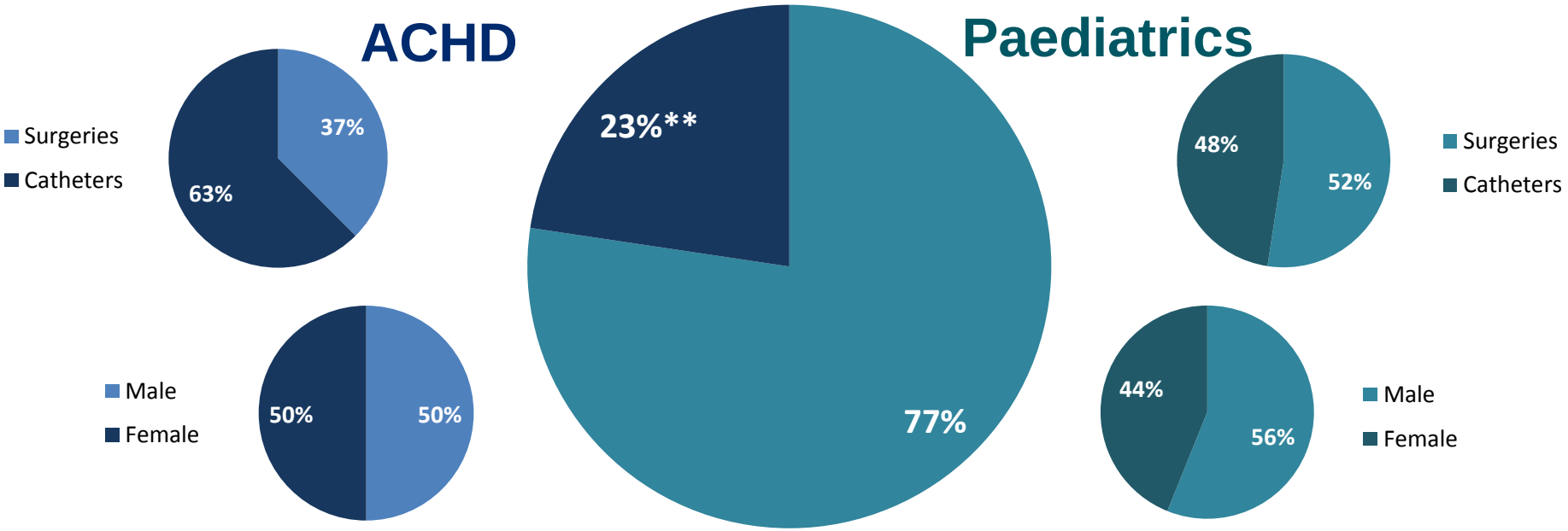
*Uplifted figure if we assume NICOR figure represents 80% of total

To note:
NICOR figures won't match website as only England and Wales residents treated in NHS E providers are included in figure above – website figures cover all patients for all reporting providers not just NHS England providers

In 2012/13…

Most episodes are for paediatrics (0-18), although the data could underestimate adult activity. According to our HES definition this activity is evenly split between catheters and surgeries, with more episodes for males rather than females

For adults most episodes are for catheter procedures and evenly split across males and females



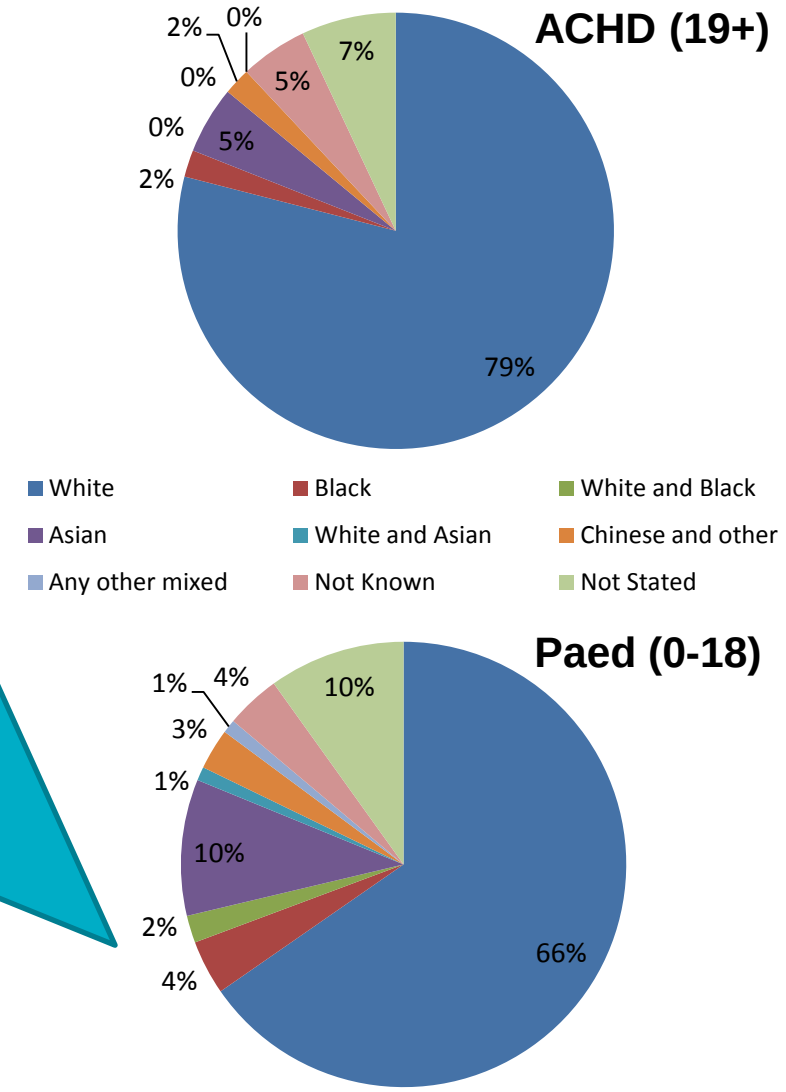
Source: HES data

** ACHD activity could be underestimated in the data. NICOR figures suggest activity for 17+= 34% so 19+ would be <34%

In 2012/13…

Ethnicity (%)	Episodes	England and Wales*
ACHD		
White	79%	88%
Black	2%	3%
White and Black	0%	N/A
Asian	5%	7%
White and Asian	0%	N/A
Chinese and other	2%	1%
Any other mixed	0%	2%
Not Known	5%	N/A
Not Stated	7%	N/A
Paed cardiac		
White	66%	79%
Black	4%	5%
White and Black	2%	N/A
Asian	10%	9%
White and Asian	1%	N/A
Chinese and other	3%	1%
Any other mixed	1%	6%
Not Known	4%	N/A
Not Stated	10%	N/A

A higher proportion of paed cardiac activity is for people from BME ethnic groups compared to ACHD activity, and for both it may be higher than the general population

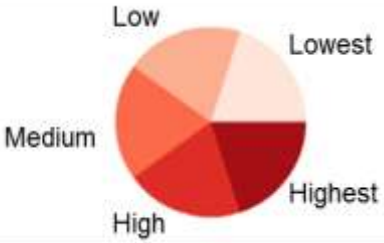


Source: HES data 2012/13 and ONS Census 2011

In 2012/13…

2012/3 activity (HES episodes) by area of patient residence

Paediatric (0-18)



ACHD (19+)

Activity varies by area of patient residence – some areas are "hotter" than others

In 2012/13…

Paed Cardiac Episodes	
GREAT ORMOND STREET HOSPITAL FOR CHILDREN NHS FOUNDATION TRUST	1388
BIRMINGHAM CHILDREN'S HOSPITAL NHS FOUNDATION TRUST	1104
ROYAL BROMPTON AND HAREFIELD NHS FOUNDATION TRUST	917
ALDER HEY CHILDREN'S NHS FOUNDATION TRUST	859
GUY'S AND ST THOMAS' NHS FOUNDATION TRUST	700
UNIVERSITY HOSPITALS BRISTOL NHS FOUNDATION TRUST	684
LEEDS TEACHING HOSPITALS NHS TRUST	682
UNIVERSITY HOSPITAL SOUTHAMPTON NHS FOUNDATION TRUST	606
UNIVERSITY HOSPITALS OF LEICESTER NHS TRUST	529
THE NEWCASTLE UPON TYNE HOSPITALS NHS FOUNDATION TRUST	518
OXFORD UNIVERSITY HOSPITALS NHS TRUST	59
OTHER PROVIDERS	560
TOTAL	8600*

ACHD Episodes	
PAPWORTH HOSPITAL NHS FOUNDATION TRUST	268
ROYAL BROMPTON AND HAREFIELD NHS FOUNDATION TRUST	166
UNIVERSITY HOSPITALS BRISTOL NHS FOUNDATION TRUST	164
UNIVERSITY COLLEGE LONDON HOSPITALS NHS FOUNDATION TRUST	151
LIVERPOOL HEART AND CHEST NHS FOUNDATION TRUST	146
LEEDS TEACHING HOSPITALS NHS TRUST	126
CENTRAL MANCHESTER UNIVERSITY HOSPITALS NHS FOUNDATION TRUST	121
OXFORD UNIVERSITY HOSPITALS NHS TRUST	112
UNIVERSITY HOSPITALS BIRMINGHAM NHS FOUNDATION TRUST	104
UNIVERSITY HOSPITAL SOUTHAMPTON NHS FOUNDATION TRUST	102
GUY'S AND ST THOMAS' NHS FOUNDATION TRUST	99
UNIVERSITY HOSPITALS OF LEICESTER NHS TRUST	81
THE NEWCASTLE UPON TYNE HOSPITALS NHS FOUNDATION TRUST	80
IMPERIAL COLLEGE HEALTHCARE NHS TRUST	80
UNIVERSITY HOSPITAL OF NORTH STAFFORDSHIRE NHS TRUST	62
BRIGHTON AND SUSSEX UNIVERSITY HOSPITALS NHS TRUST	58
BARTS HEALTH NHS TRUST	56
UNIVERSITY HOSPITAL OF SOUTH MANCHESTER NHS FOUNDATION TRUST	55
KING'S COLLEGE HOSPITAL NHS FOUNDATION TRUST	54
OTHER PROVIDERS	370
TOTAL	2500*

11 Paed Cardiac providers and 19 ACHD providers provided more than 50 episodes of care according to our **HES** dataset

(* Figures include ALL patients treated by these providers not just patients from England and Wales)

In 2012/13…

Paed Cardiac - Procedures	
GREAT ORMOND STREET HOSPITAL FOR CHILDREN NHS FOUNDATION TRUST	960
BIRMINGHAM CHILDREN'S HOSPITAL NHS FOUNDATION TRUST	930
GUY'S AND ST THOMAS' NHS FOUNDATION TRUST	620
ALDER HEY CHILDREN'S NHS FOUNDATION	610
ROYAL BROMPTON AND HAREFIELD NHS FOUNDATION TRUST	600
UNIVERSITY HOSPITALS BRISTOL NHS FOUNDATION TRUST	520
LEEDS TEACHING HOSPITALS NHS TRUST	510
UNIVERSITY HOSPITAL SOUTHAMPTON NHS FOUNDATION TRUST	450
UNIVERSITY HOSPITALS OF LEICESTER NHS TRUST	370
THE NEWCASTLE UPON TYNE HOSPITALS NHS FOUNDATION TRUST	340
OXFORD UNIVERSITY HOSPITALS NHS TRUST	15
TOTAL	5900*

11 Paed Cardiac Providers and 25 ACHD providers in NHS England reported to **NICOR** that they provided relevant activity

(* Figures include ALL patients treated by these providers not just patients from England and Wales)

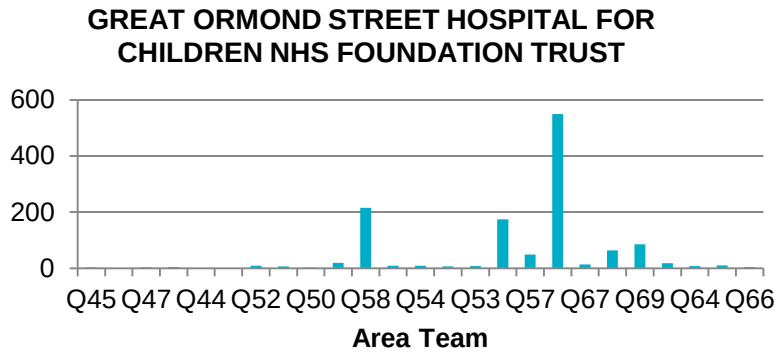
ACHD Procedures	
ROYAL BROMPTON AND HAREFIELD NHS FOUNDATION TRUST	250
LEEDS TEACHING HOSPITALS NHS TRUST	240
UNIVERSITY HOSPITALS BRISTOL NHS FOUNDATION TRUST	220
CENTRAL MANCHESTER UNIVERSITY HOSPITALS NHS FOUNDATION TRUST	190
UNIVERSITY COLLEGE LONDON HOSPITALS NHS FOUNDATION TRUST	180
LIVERPOOL HEART AND CHEST NHS FOUNDATION TRUST	150
GUY'S AND ST THOMAS' NHS FOUNDATION TRUST (GUY)	150
THE NEWCASTLE UPON TYNE HOSPITALS NHS FOUNDATION TRUST	140
UNIVERSITY HOSPITALS BIRMINGHAM NHS FOUNDATION TRUST	130
UNIVERSITY HOSPITAL SOUTHAMPTON NHS FOUNDATION TRUST	130
UNIVERSITY HOSPITALS OF LEICESTER NHS TRUST	130
OXFORD UNIVERSITY HOSPITALS NHS TRUST	110
BRIGHTON AND SUSSEX UNIVERSITY HOSPITALS NHS TRUST	60
UNIVERSITY HOSPITAL OF NORTH STAFFORDSHIRE NHS TRUST	50
IMPERIAL COLLEGE HEALTHCARE TRUST	50
ST GEORGE'S HEALTHCARE NHS TRUST	50
GREAT ORMOND STREET HOSPITAL FOR CHILDREN NHS FOUNDATION TRUST	40
GUY'S AND ST THOMAS' NHS FOUNDATION TRUST (St T)	40
BIRMINGHAM CHILDREN'S HOSPITAL NHS FOUNDATION TRUST	40
NOTTINGHAM UNIVERSITY HOSPITALS NHS TRUST	30
SHEFFIELD TEACHING HOSPITALS NHS FOUNDATION TRUST	30
KINGS COLLEGE HOSPITAL NHS FOUNDATION TRUST	20
ALDER HEY CHILDREN'S NHS FOUNDATION TRUST	15
BLACKPOOL TEACHING HOSPITALS NHS FOUNDATION TRUST	<10
UNIVERSITY HOSPITALS COVENTRY AND WARWICKSHIRE	<10
THE ROYAL WOLVERHAMPTON NHS TRUST	<10
BASILDON AND THURROCK UNIVERSITY HOSPITALS NHS FOUNDATION TRUST	<10
TOTAL	2500*

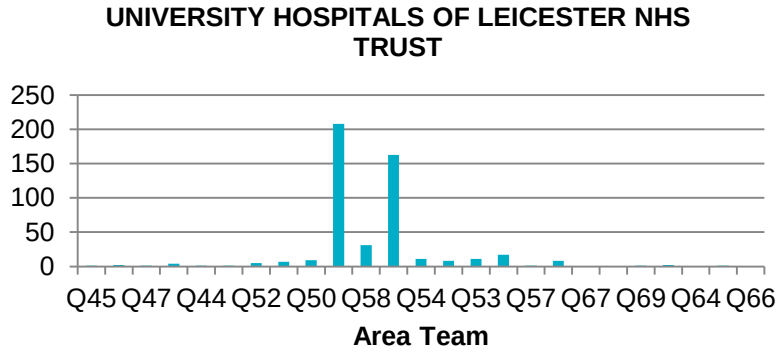
In 2012/13…

Paediatric activity by area of patient residence for different providers

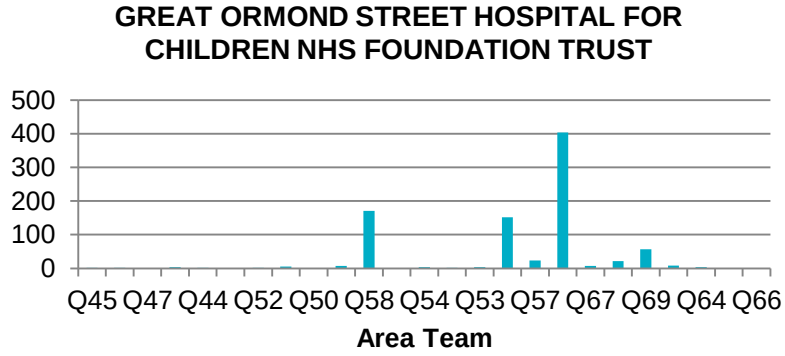
An example of how different providers have different "catchment" areas

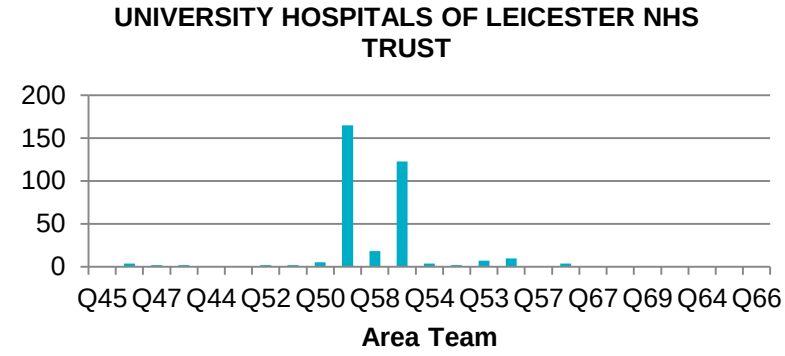
HES





NICOR





Similar patterns in both datasets

In 2012/13…

Paed Cardiac - HES		
OPCS code	*Procedure description*	*Count of episodes*
L02.2	Ligature of patent ductus arteriosus	1018
K63.1	Angiocardiography of combination of right and left side of heart	569
K10.4	Primary repair of defect of interatrial septum NEC	451
L03.1	Percutaneous transluminal prosthetic occlusion of patent ductus arteriosus	421
K61.1	Implantation of cardiac pacemaker system NEC	415
K11.2	Repair of defect of interventricular septum using pericardial patch	320
K11.1	Repair of defect of interventricular septum using prosthetic patch	305
L10.2	Repair of pulmonary artery using patch	294
K58.2	Percutaneous transluminal electrophysiological studies on conducting system of heart	290
K57.4	Percutaneous transluminal ablation of accessory pathway	274

ACHD - HES		
OPCS code	*Procedure description*	*Count of episodes*
K16.5	Percutaneous transluminal closure of patent oval foramen with prosthesis	665
K13.3	Percutaneous transluminal repair of defect of interatrial septum using prosthesis	332
K10.4	Primary repair of defect of interatrial septum NEC	188
L04.1	Pulmonary thromboendarterectomy	141
K10.2	Repair of defect of interatrial septum using pericardial patch	138
L13.2	Percutaneous transluminal embolisation of pulmonary artery	104
K16.6	Percutaneous transluminal chemical mediated septal ablation	72
L10.2	Repair of pulmonary artery using patch	52
L03.1	Percutaneous transluminal prosthetic occlusion of patent ductus arteriosus	50
K11.2	Repair of defect of interventricular septum using pericardial patch	43

2012/13 top 10 procedures by episode count according to our extract of HES data

In 2012/13…

Paed Cardiac (0-16) Procedures	
PDA closure (catheter)	**574**
PDA ligation (surgical)	**373**
VSD Repair	**351**
Radiofrequency ablation for supraventricular tachycardia	**333**
Tetralogy repair	**306**
Isolated coarctation repair	**281**
ASD closure (catheter)	**251**
Bidirectional cavopulmonary shunt	**243**
ASD repair	**228**
Pulmonary balloon valvoplasty	**225**

ACHD (17+) Procedures	
PFO closure (catheter)	**506**
ASD closure (catheter)	**421**
Pulmonary valve replacement	**257**
Radiofrequency ablation for supraventricular tachycardia	**158**
Aortic Valve Replacement - non Ross	**149**
ASD repair	**106**
Coarctation stenting	**77**
Aortic root replacement (not Ross)	**55**
Implantable Cardioverter Defibrillator	**44**
Transcatheter PVR	**41**

2012/13 top 10 procedures by count according to NICOR

(data taken from website 7th July 2014 – will include ALL patients and all providers not just NHS England)

In 2012/13…

From HES data:

Some episodes had a zero length of stay:

- 28% of episodes for Paediatric CHD patients
- 20% of episodes for ACHD patients

Of those episodes that covered at least one night, the average length of stay was around :

- 9 days for paediatric patients
- 8 days for ACHD patients

New Congenital Heart Disease Review

NHS England

Historic trends

Joanna Glenwright
John Buckell
Charles Keenan

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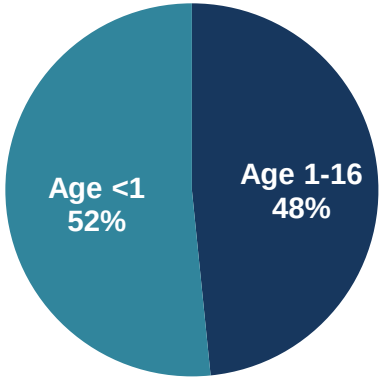
Historic trends: paediatric activity growth over time

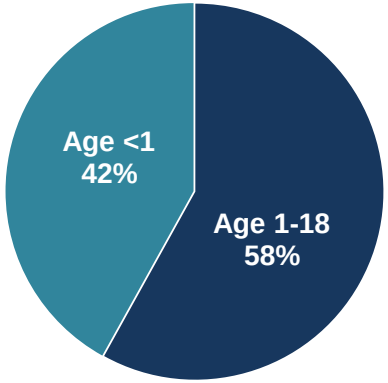
In the next slide we look at 2003/4 to 2012/13 growth in national paediatric activity over time

A significant % of paediatric activity is for children aged under 1 year (infants and neonates)

NICOR data (0-16)



HES data (0-18)



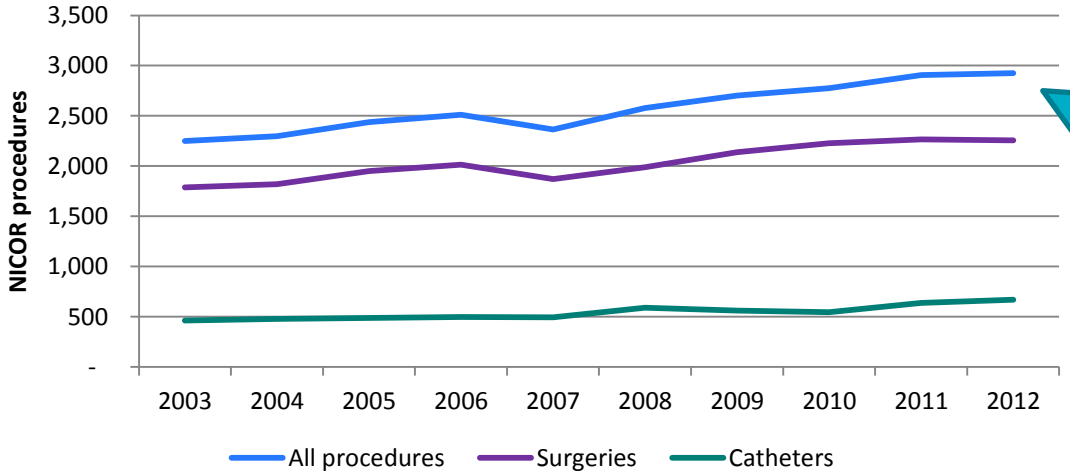
Therefore we consider paediatric activity growth over time by two groups:

1. aged under 1
2. aged 1+

Numbers may not sum due to rounding

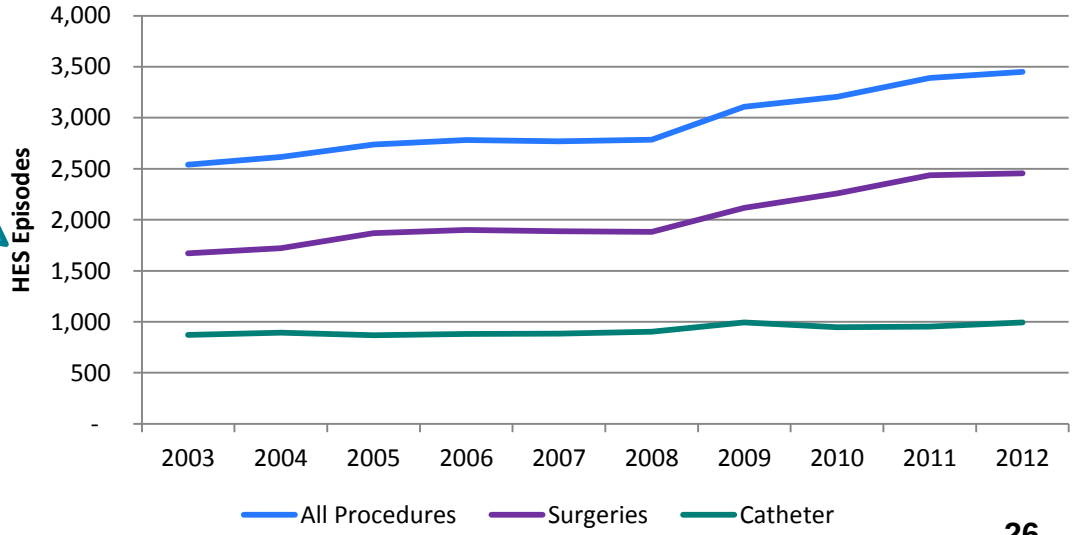
Historic trends: paediatric under 1 activity growth over time

2003/4 to 2012/13 growth in national paediatric under 1 activity over time



NICOR (<1) activity data counts reported procedure numbers – All procedures have increased steadily over time from around 2,200 in 2003/4 to 2,900 in 2012/13 (**30%**)

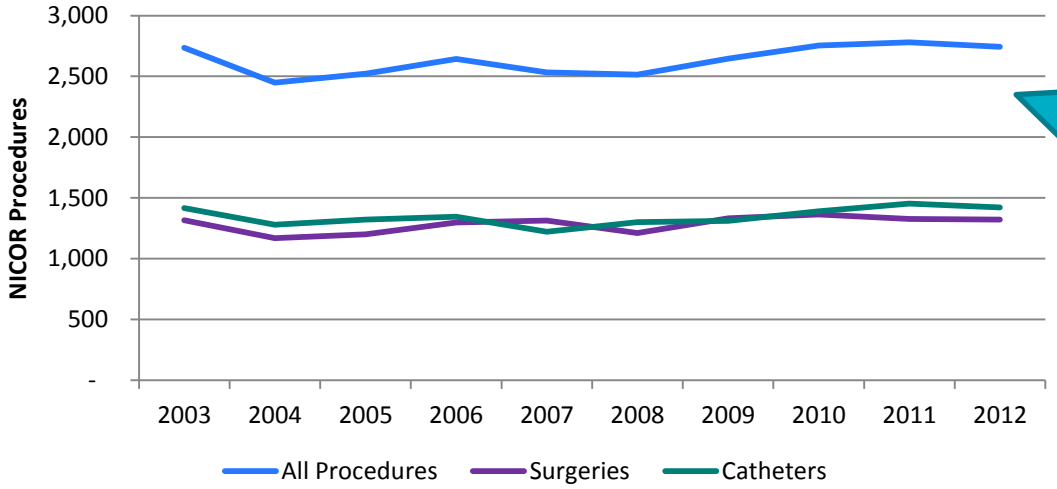
HES (<1) activity data counts episodes of care – Episodes for all procedures have increased steadily over time from around 2,500 in 2003/4 to 3,400 in 2012/13 (**36%**)



Numbers may not sum due to rounding

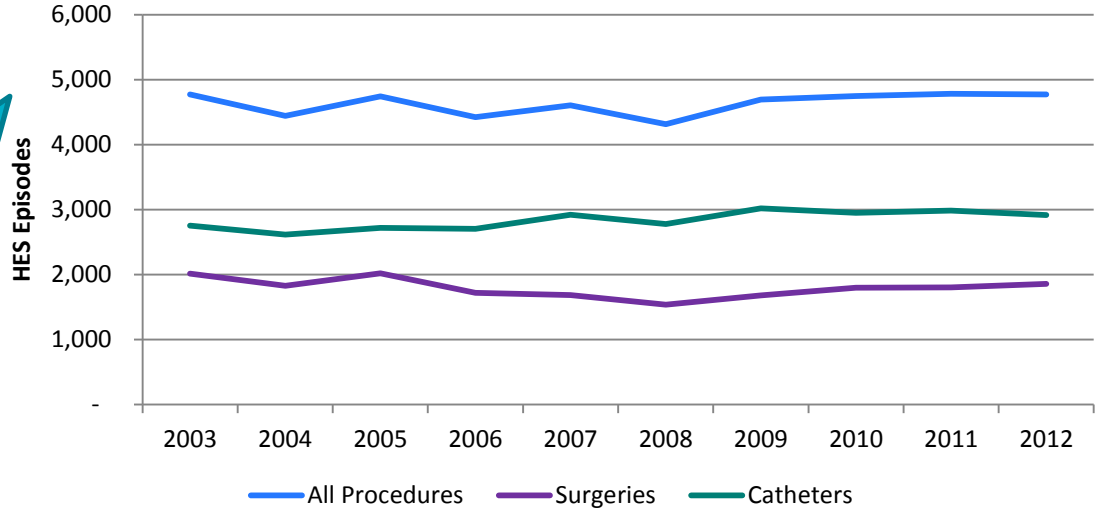
Historic trends: paediatric age 1 + activity growth over time

2003/4 to 2012/13 growth in national paediatric age 1+ activity over time



NICOR (1-16) activity data counts reported procedure numbers – All procedures have seen little change over the period, being around 2,700 in 2003/4 and 2012/13 (**0%**)

HES (1-18) activity data counts episodes of care – Episodes for all procedures have seen little change over the period, being around 4,700 in 2003/4 and 2012/13 (**0%**)

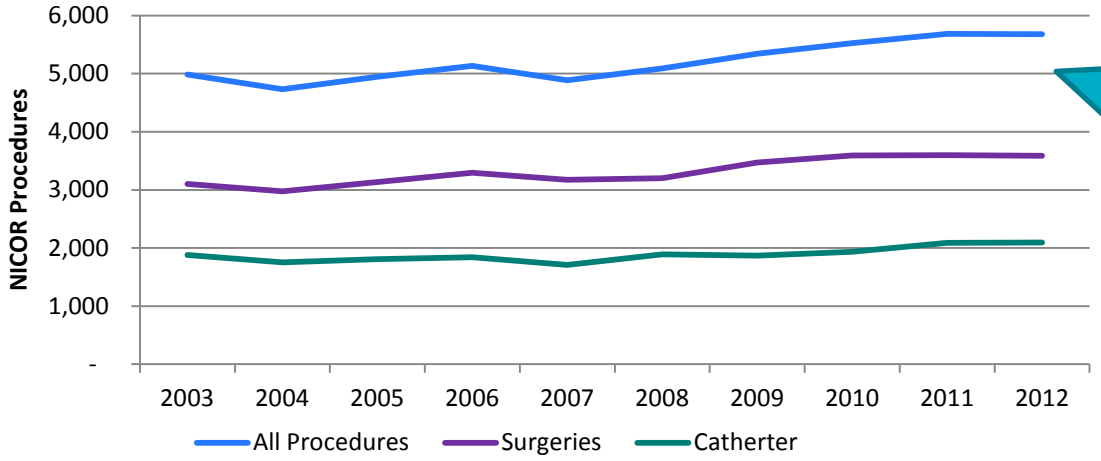


Numbers may not sum due to rounding

Driven by growth in activity for children aged under 1

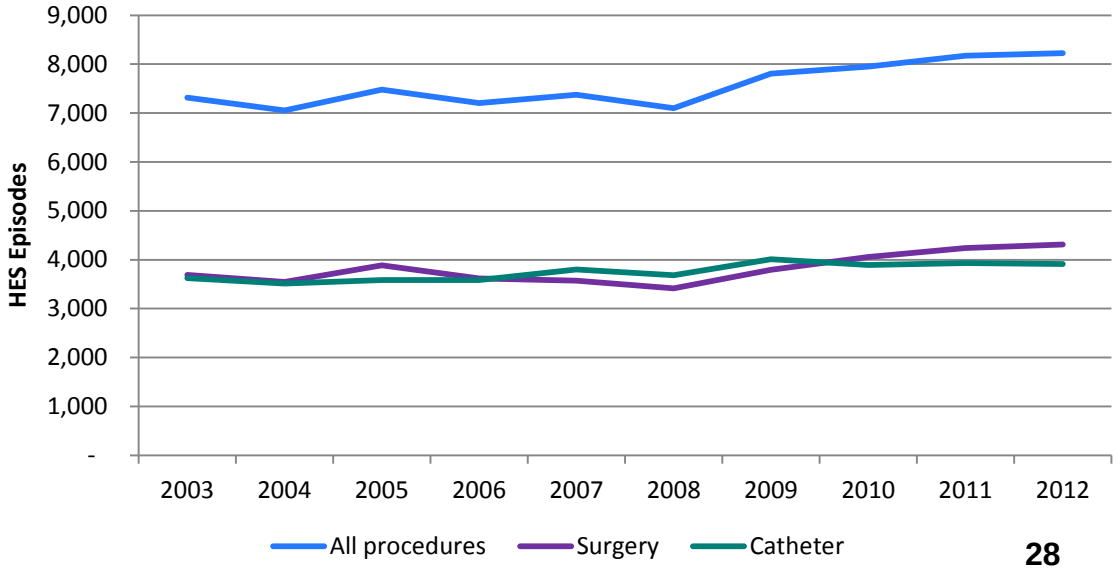
Historic trends: all paediatric activity growth over time

2003/4 to 2012/13 growth in national paediatric activity (all age) over time



NICOR (0-16) activity data counts reported procedure numbers – All procedures have increased steadily over time from around 5,000 in 2003/4 to 5,700 in 2012/13 (**14%**)

HES (0-18) activity data counts episodes of care – Episodes for all procedures have increased steadily over time from around 7,300 in 2003/4 to 8,200 in 2012/13 (**12%**)

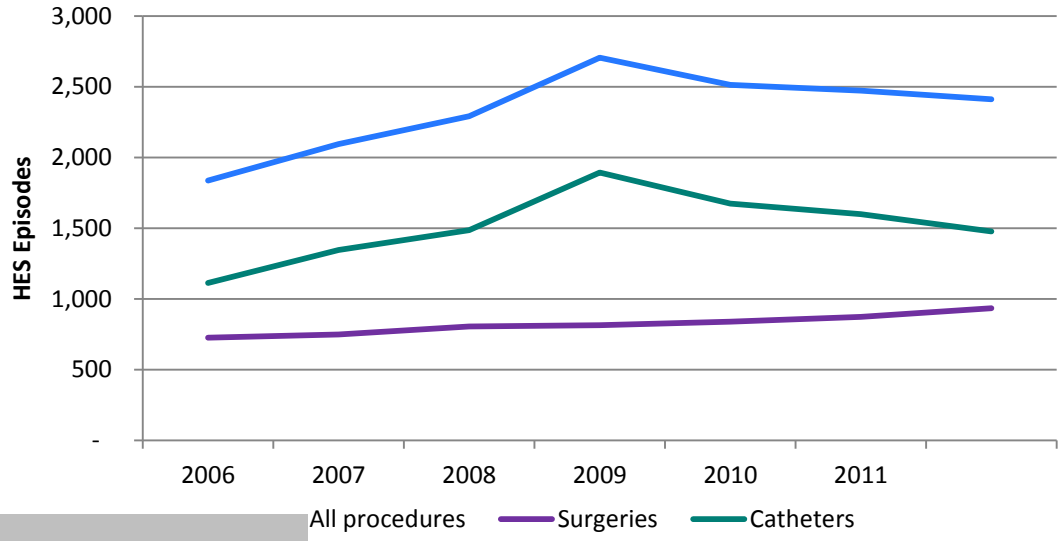


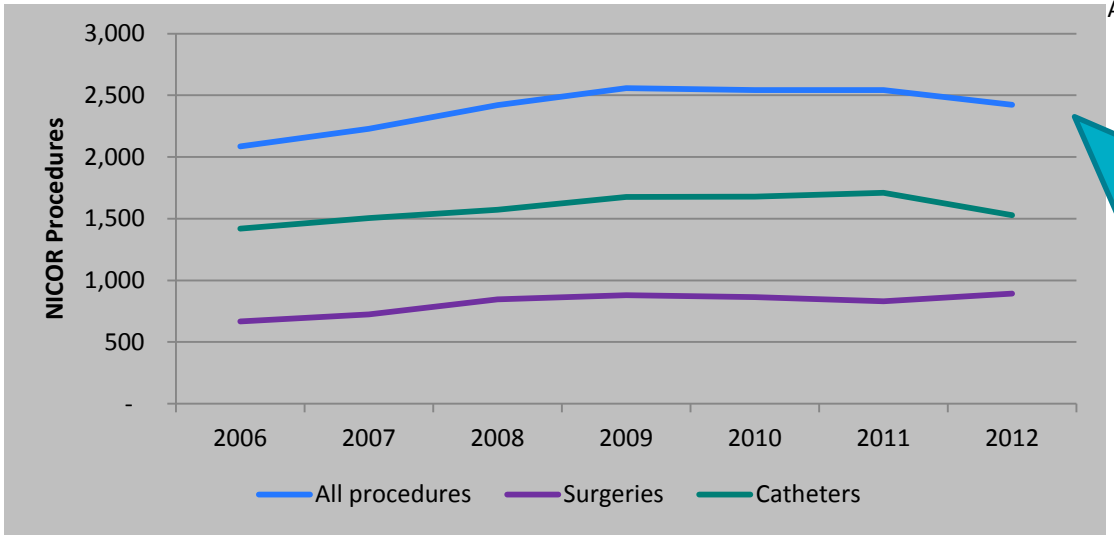
Numbers may not sum due to rounding

Historic trends: ACHD activity growth over time

2006/7 to 2012/13 growth in national ACHD activity over time

HES (19+) activity data counts episodes of care – Episodes have increased over time, mainly driven by increases in catheter procedures, from 1,800 in 2006/7 to 2,400 in 2012/13 (**31%**)

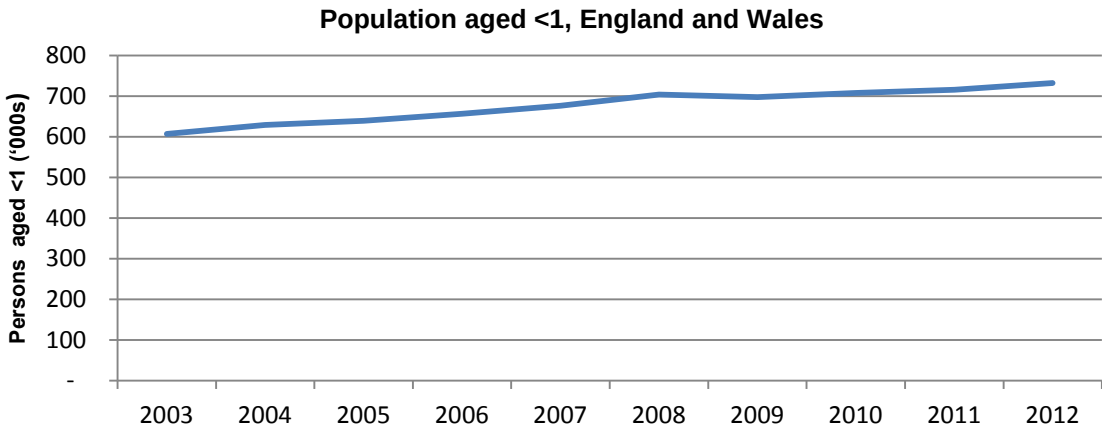




NICOR activity data counts reported procedure numbers – Over the last 10 years reporting has increased so the trend is distorted by this and cannot be used.

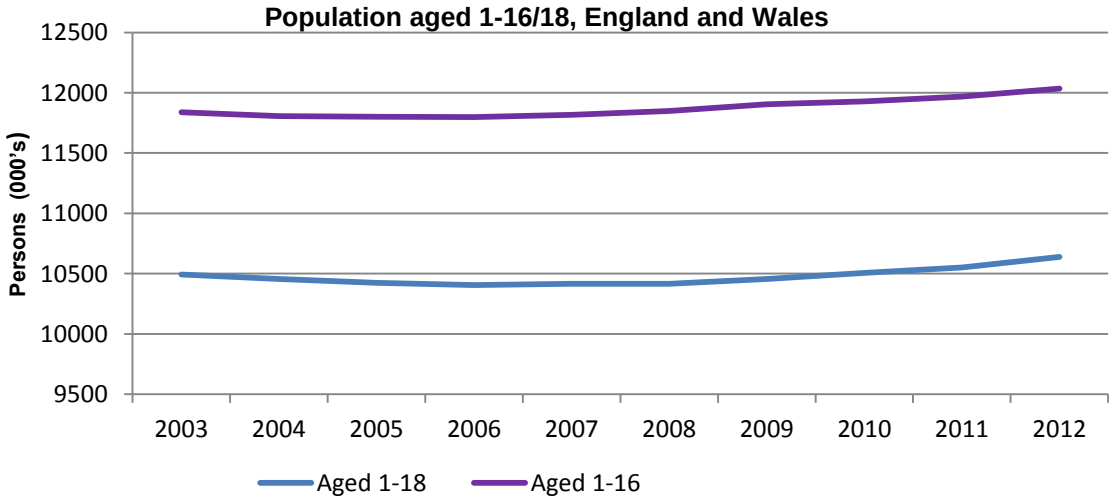
Historic trends: paediatric population growth (ONS data)

Paediatric population in total has grown over the last 10 years by around **3%,** but growth has varied by age within this

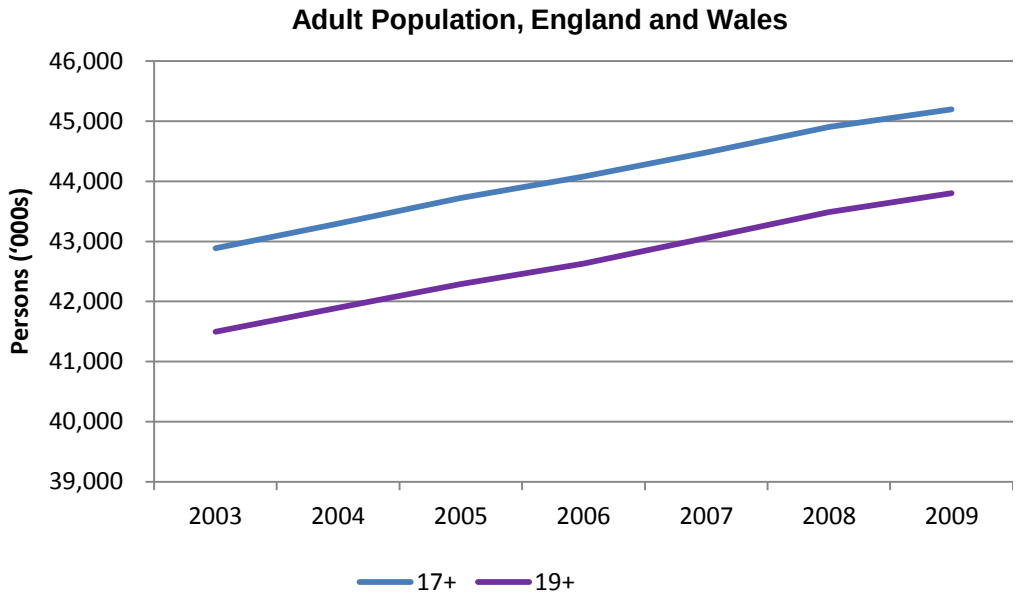


Over the last 10 years, the population aged under 1 has grown by **21%**

Over the last 10 years, the population of children over 1 has grown by **~2%**

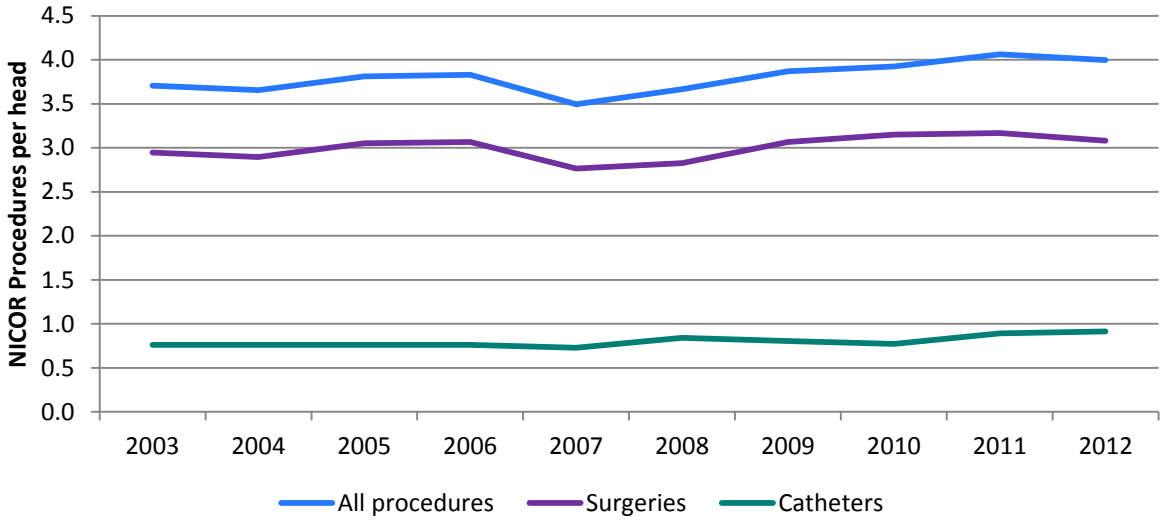


Historic trends: adult population growth (ONS data)



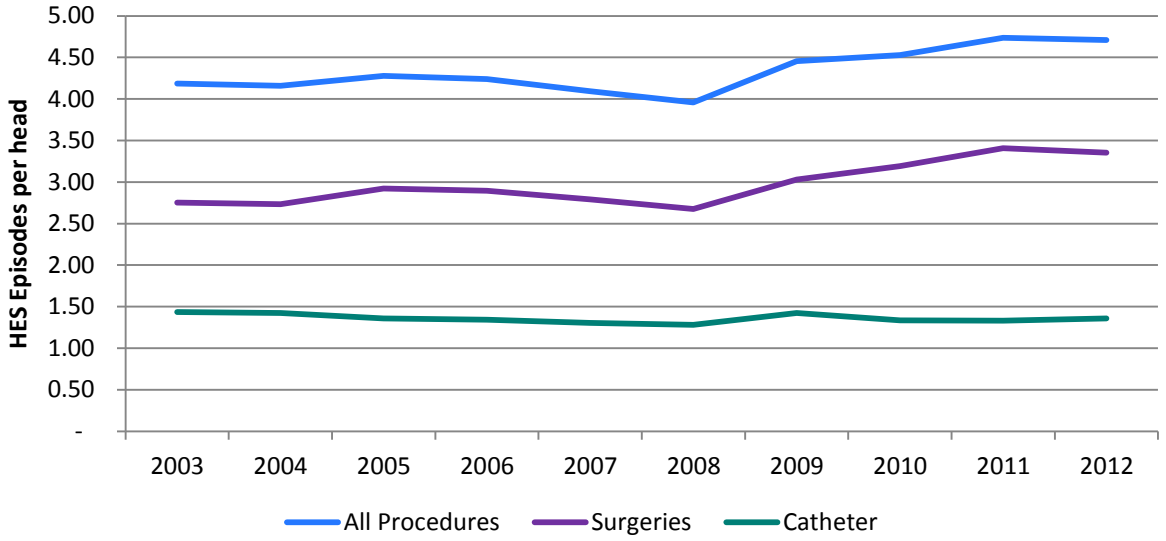
Adult population in England and Wales has grown over the last 7 years by around 6%

Historic trends: paediatric under 1 activity per head growth

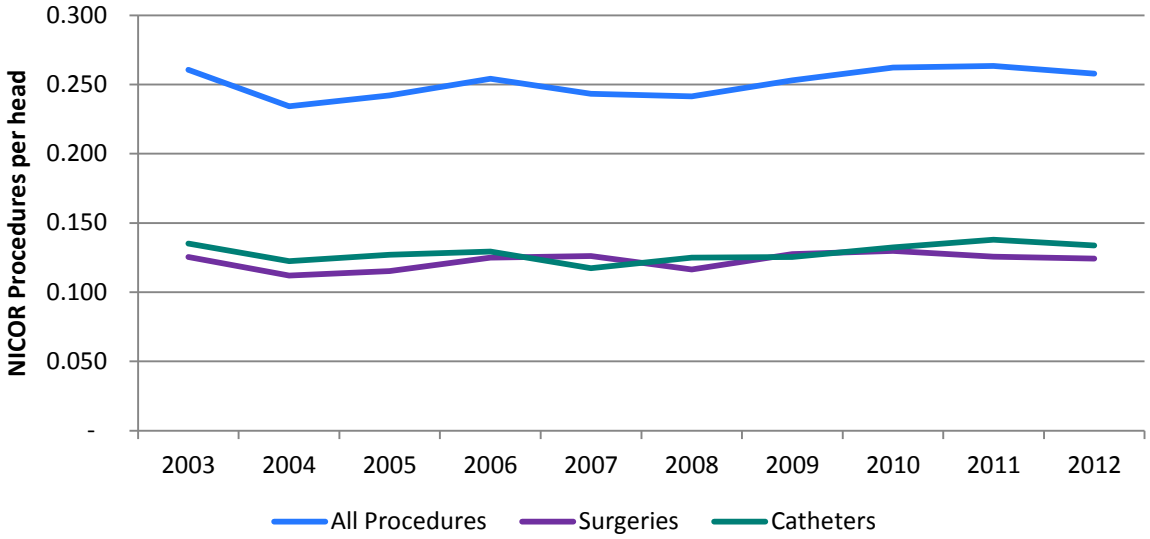


NICOR (<1) activity data – even once we have accounted for population growth there is still activity growth. Procedures per head of population grew by around **8%**

HES (<1) activity data – even once we have accounted for population data there is still activity growth. Episodes per head of population grew by around **13%**

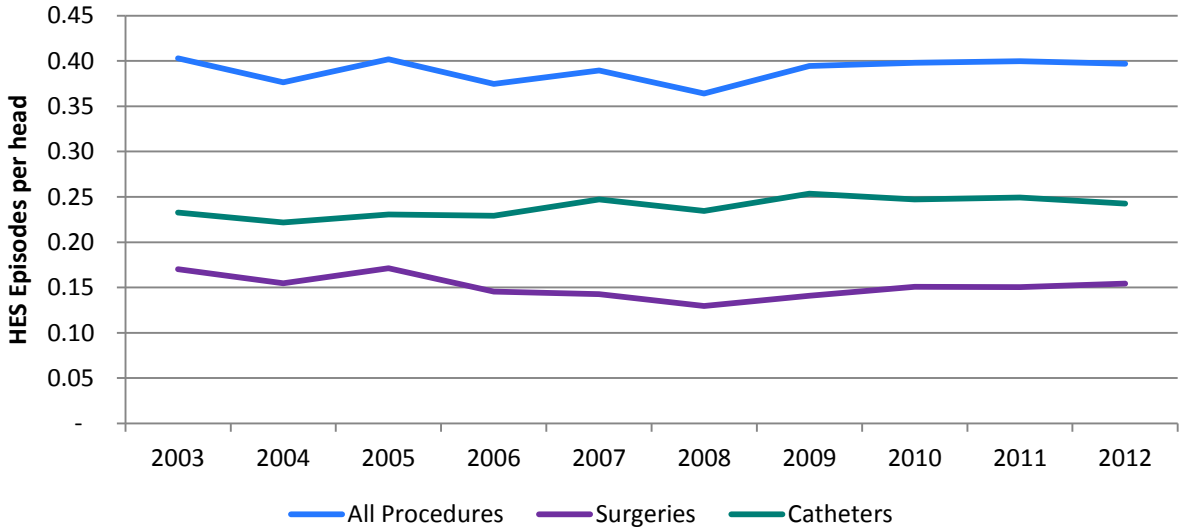


Historic trends: paediatric aged 1+ activity per head growth



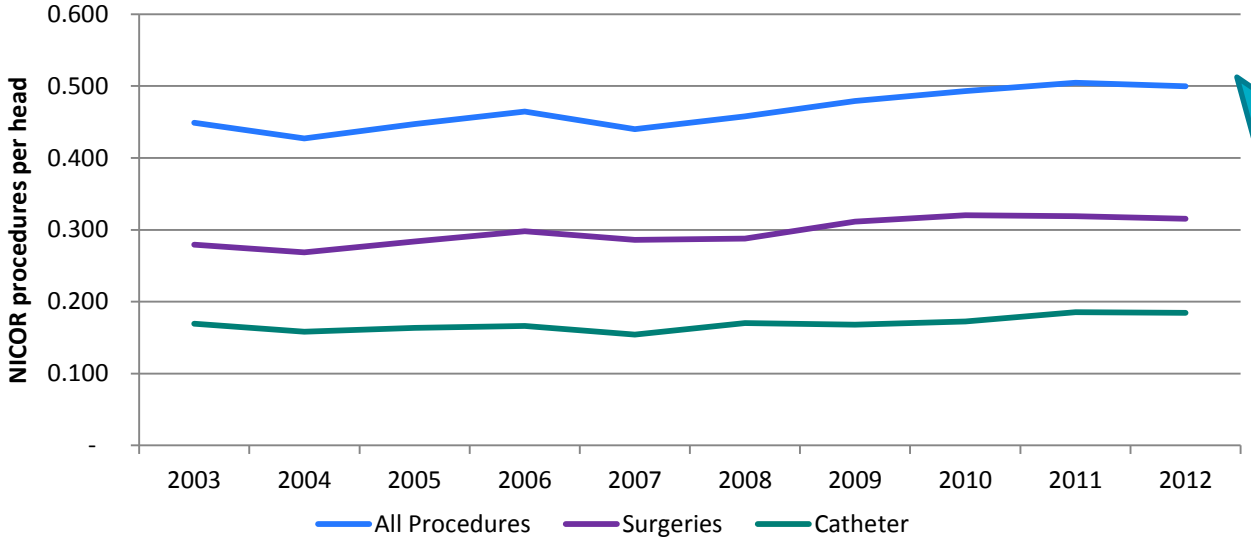
NICOR (1-16) activity data – once we have accounted for population growth activity look fairly stable with a slight decrease. Procedures per head of population grew by around **-1%**

HES (1-18) activity data – once we have accounted for population growth activity looks fairly stable with a slight decrease. Episodes per head of population grew by around **-2%**



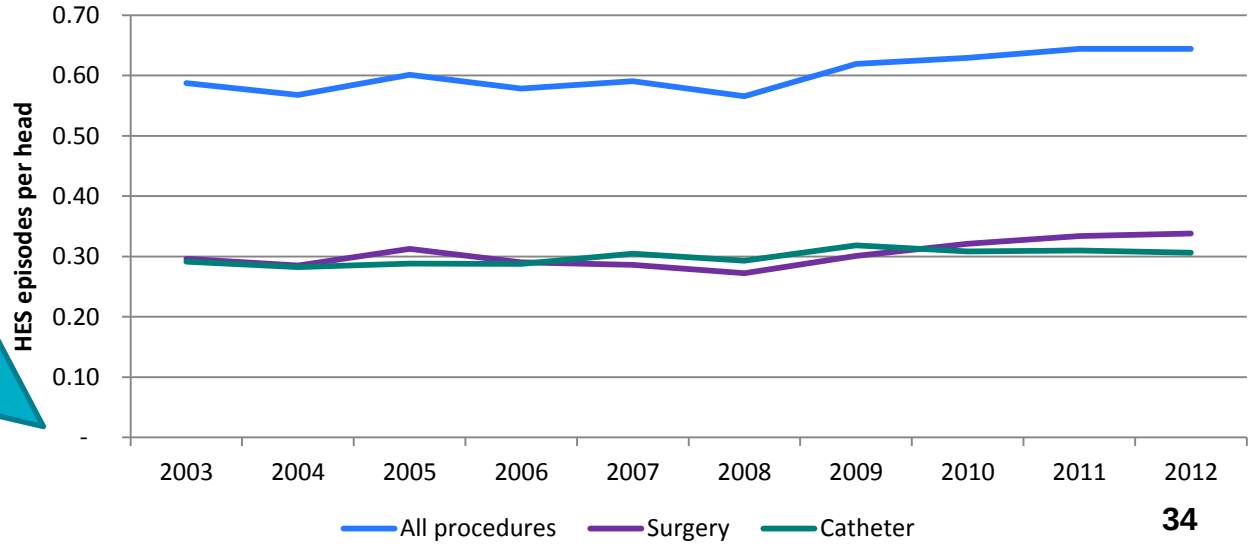
Driven by growth in activity for children aged under 1

Historic trends: all paediatric activity per head growth



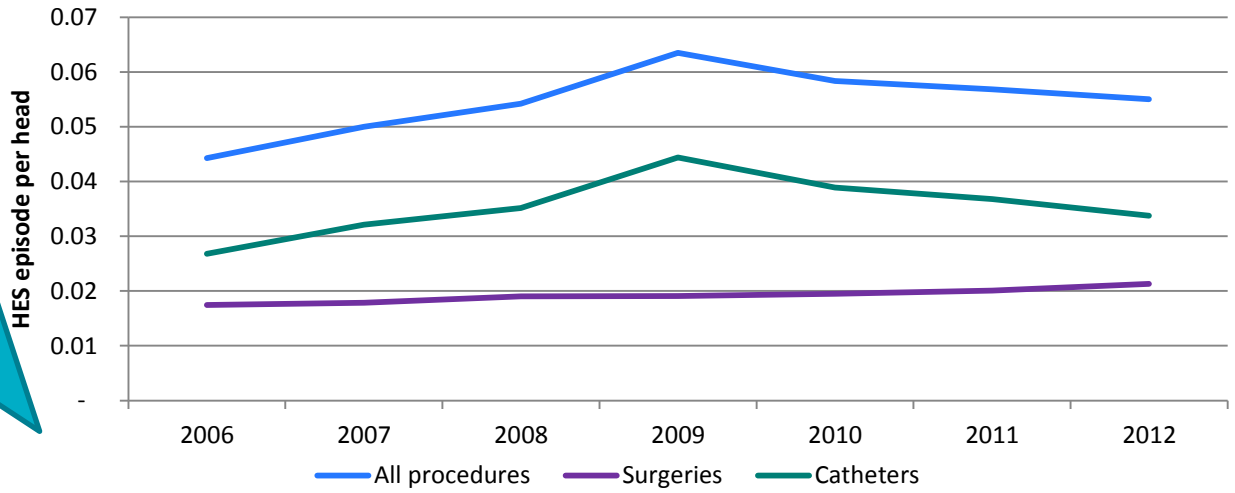
NICOR (0-16) activity data – even once we have accounted for population growth there is still activity growth. Procedures per head of population grew by around **11%**

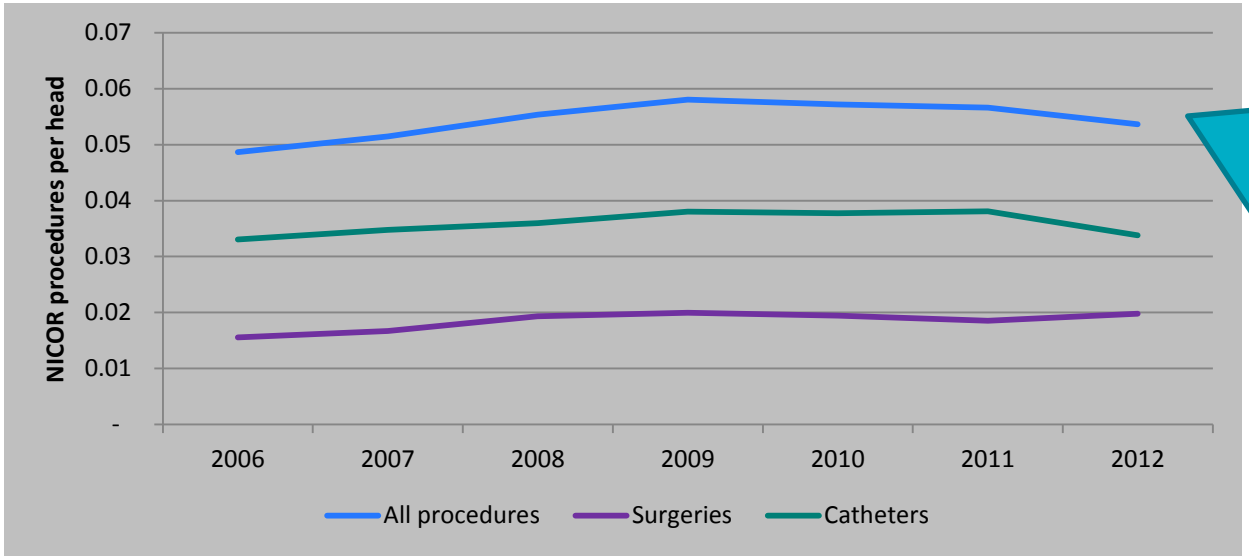
HES (0-18) activity data – even once we have accounted for population data there is still activity growth. Episodes per head of population grew by around **10%**



Historic trends: ACHD activity per head growth

HES activity data – even once we have accounted for population data there is still activity growth. Episodes per head of population grew by around **24%**





NICOR activity data counts reported procedure numbers – Reporting has increased over time so the trend is distorted by this and cannot be used.

Historic trends: activity growth summary

Summary of the historic pressures in Paediatric Cardiac and ACHD activity

	Paed Cardiac 2003-2012		ACHD 2006-2012	
	HES (0-18)	**NICOR (0-16)**	**HES (19+)**	**NICOR (17+)**
Activity growth	12%	14%	31%	N/A
of which population growth	3%	3%	6%	6%
gives remaining activity per head growth	10%	11%	24%	N/A

With Paediatric split out into under 1 and 1+ age groups

	Paed Cardiac 2003-2012			
	HES (<1)	**NICOR (<1)**	**HES (1-18)**	**NICOR (1-16)**
Activity growth	36%	30%	0%	0%
of which population growth	21%	21%	2%	2%
gives remaining activity per head growth	13%	8%	-2%	-1%

To note: numbers will not sum due to compounding effect and rounding

Historic growth by patient characteristic

Paed (0-18) 10 year change

Gender Changes	
Male	19%
Female	12%
Age Band Changes	
Neonate (0-30days)	32%
Infant (31-365 days)	32%
Child (1-16 yrs)	-5%
Child (17-18 yrs)	41%
Ethnicity band changes	
White	16%
Black	101%
White and Black	333%
Asian	102%
White and Asian	306%
Chinese	89%
Other	3%
Any other mixed	137%
Not Known	66%
Not Stated	-39%

ACHD (19+) 7 year change

Gender Changes	
Male	38%
Female	24%
Age Band Changes	
Adult 19-64	26%
Adult Over 65	49%
Ethnicity band changes	
White	37%
Black	10%
White and Black	267%*
Asian	59%
White and Asian	100%*
Chinese	0%
Other	141%
Any other mixed	-29%
Not Known	14%
Not Stated	-20%

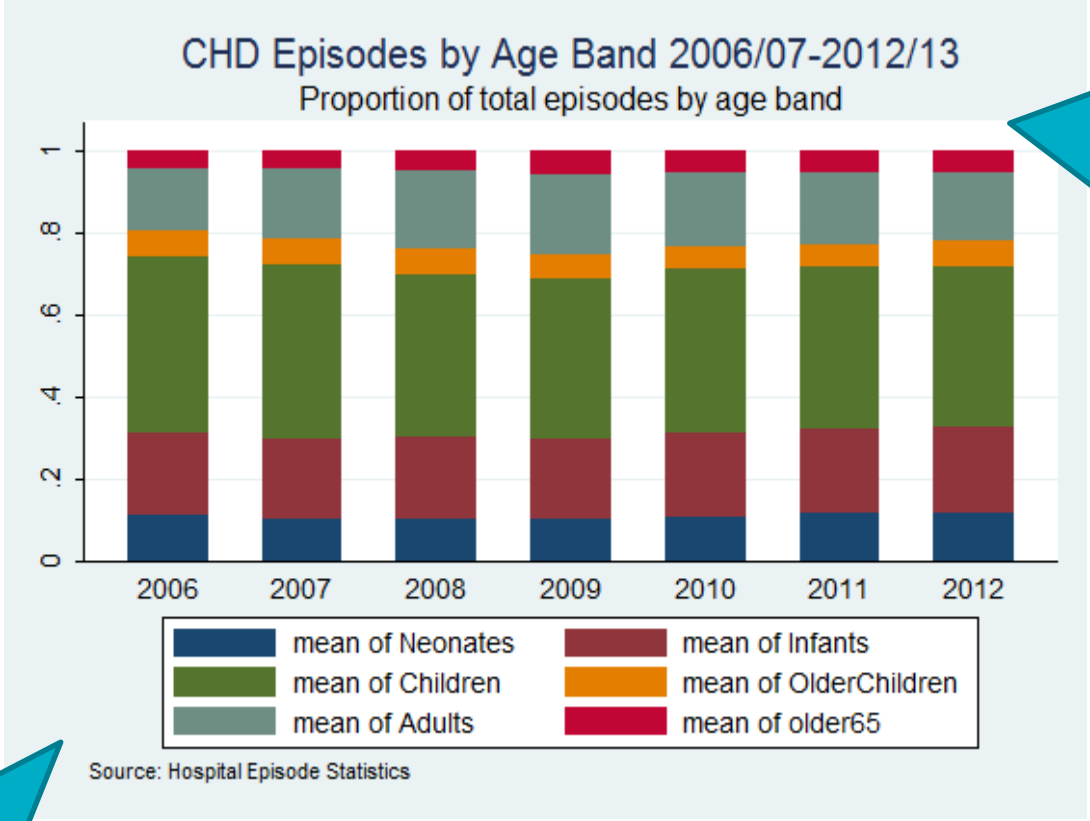
*very small numbers

Change in number of episodes with each patient characteristic between 2003/4 (Paeds) or 2006/7 (ACHD)and 2012/13 – interesting results circled. There has been higher growth in episodes for 17-18 yr. olds and over 65s, male episodes , BME paediatric episodes and Asian ACHD episodes.

See next slides for trends

Historic trends: activity by age

Neonate – 0-30 days
Infant – 30-365 days
Child – 1 – 16 years
Older child – 17-18 years
Adult - 19-64 years
Over 65 - 65+ years

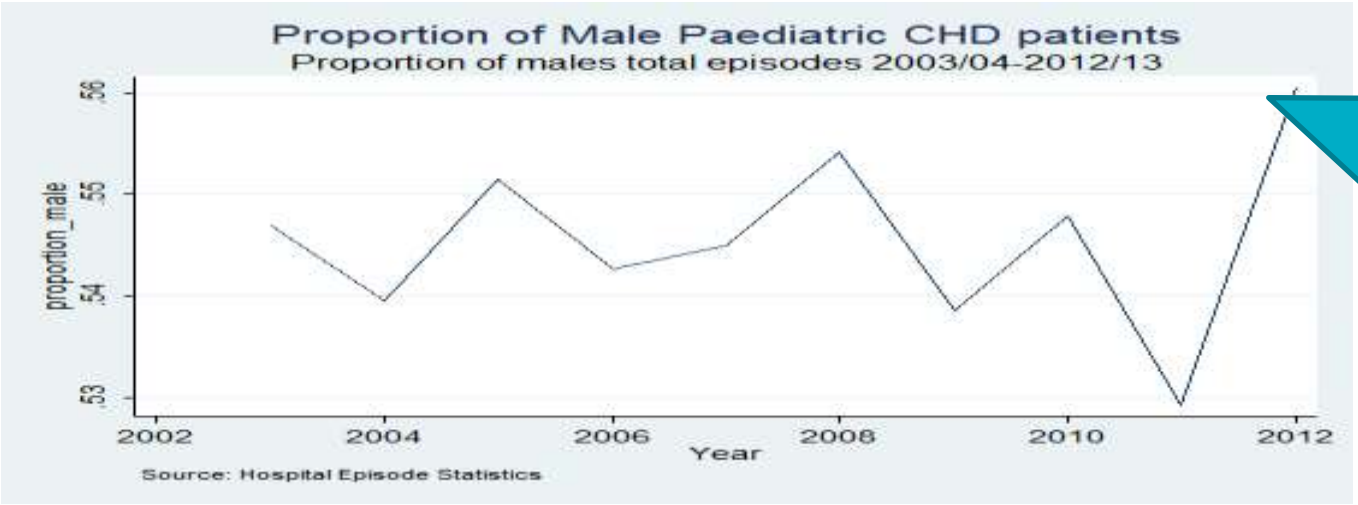


Most activity is for the child and infant age groups but both adult groups are growing

The % of episodes by age bands (neonate, infant, child, older child, adult, over 65) is stable over time with some increase in adults

We use a specific "older child" category to isolate the differences in the definition of child between NICOR (adults age 16+) and HES (adults age 18+)

Historic trends: activity by gender

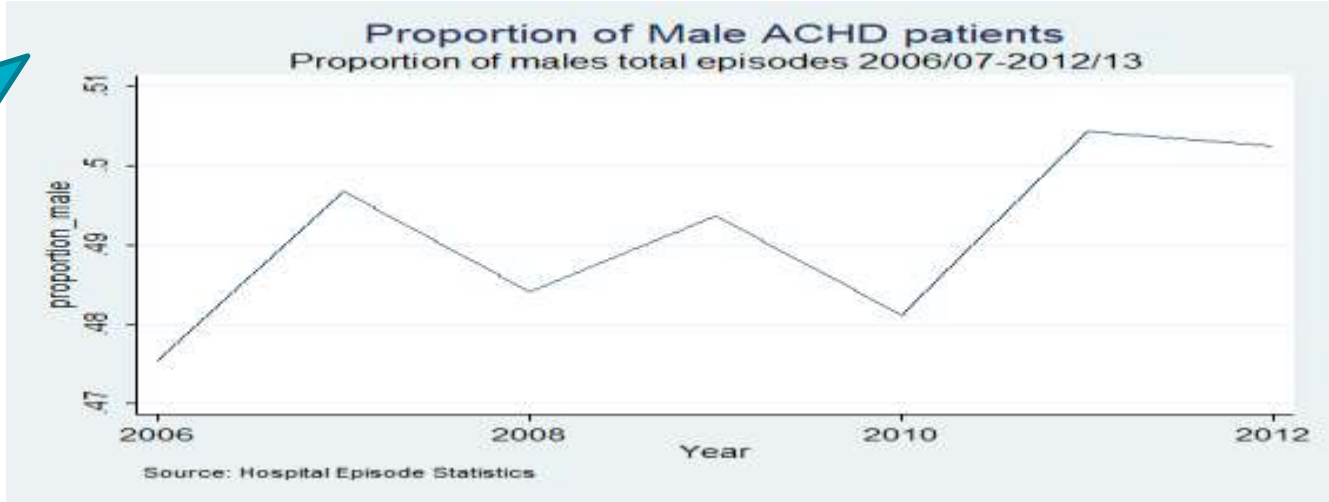


Paediatric activity - % of **males higher than females** in every year (males >50%)

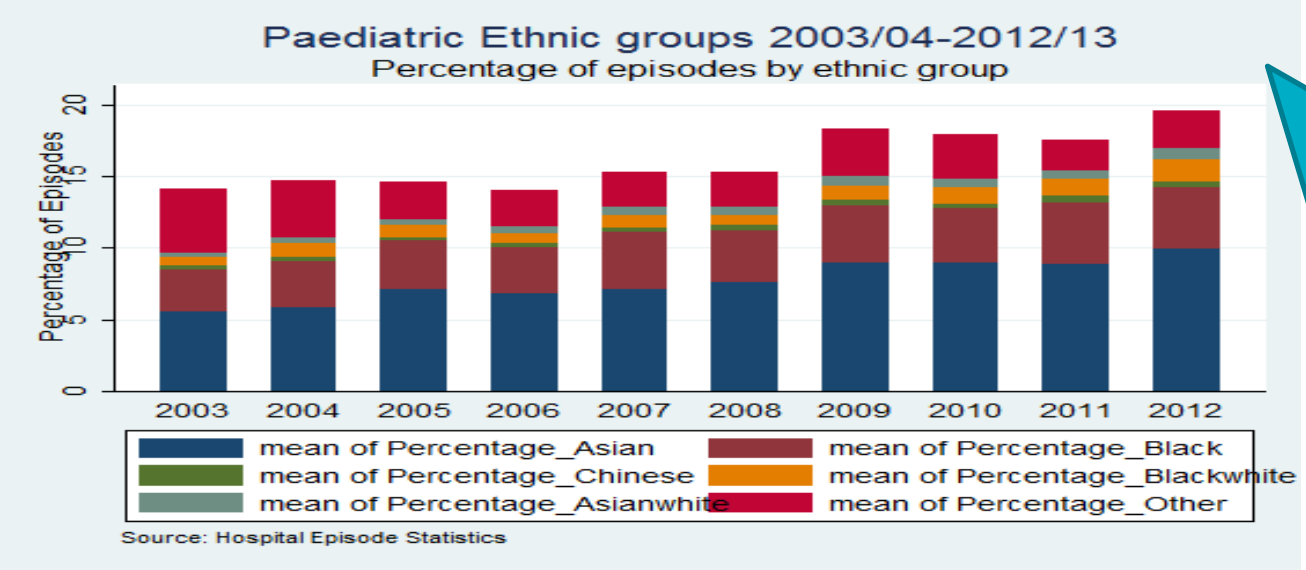
Range only 53%-55% - not much variation over time

ACHD activity - % of **females higher than males** in most years (males <50%)

Range 47%-51% - More variation than in Paeds activity



Historic trends: activity by ethnicity

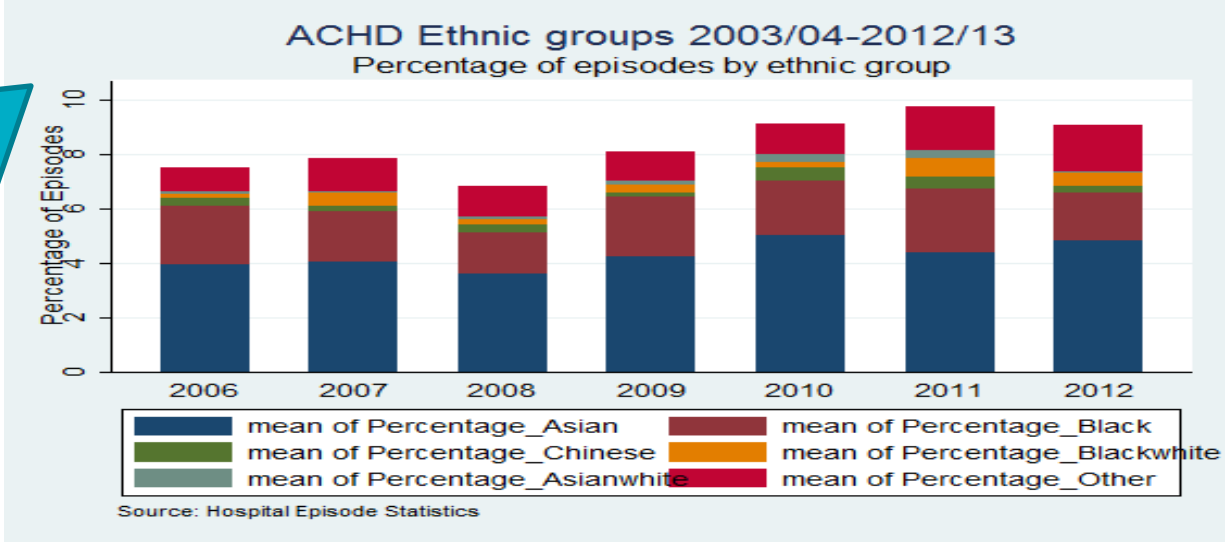


Paediatric activity:
% of activity for Asian, and Black ethnic groups has **increased** over time:

Asian from 6% to 10%
Black from 3% to 4%

ACHD activity:
% of activity for Asian ethnic groups has **increased slightly** over time but remains lower than for paediatric activity:

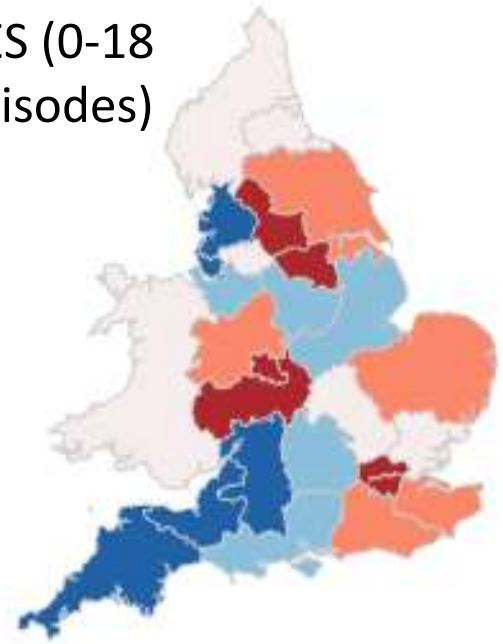
Asian from 4% to 5%



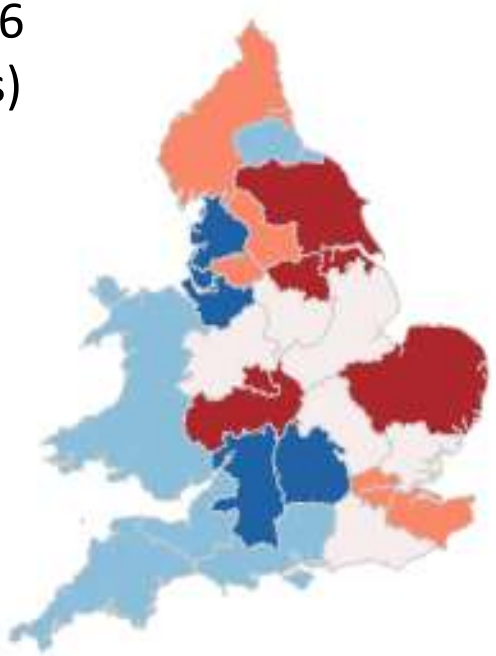
Historic trends: paediatric activity growth by area

2003/4 to 2012/13 growth in paediatric activity by area of patient residence

HES (0-18 episodes)



NICOR (0-16 procedures)

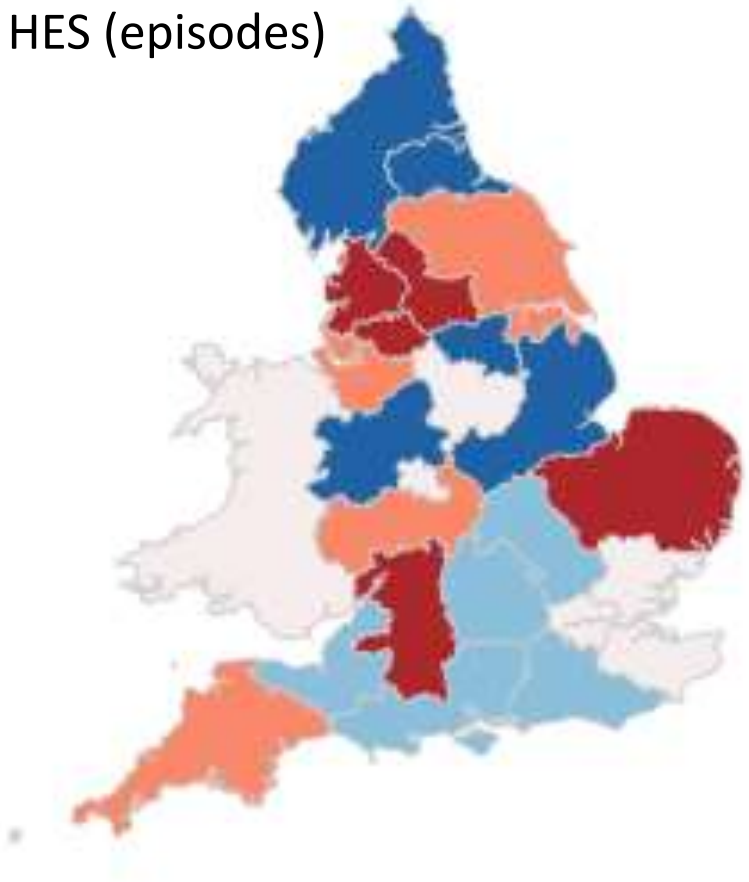


Heat Map:
Red = "Hot" = positive growth – higher growth darkest red
Blue = "Cold" = very low or negative growth – most negative growth darkest blue
NICOR and HES data suggesting similar "hot" and "cold" areas

Historic trends: ACHD activity growth by area

2006/7 to 2012/13 growth in ACHD activity by area of patient residence

HES (episodes)



Heat Map:
Red = "Hot" = positive growth – higher growth darkest red

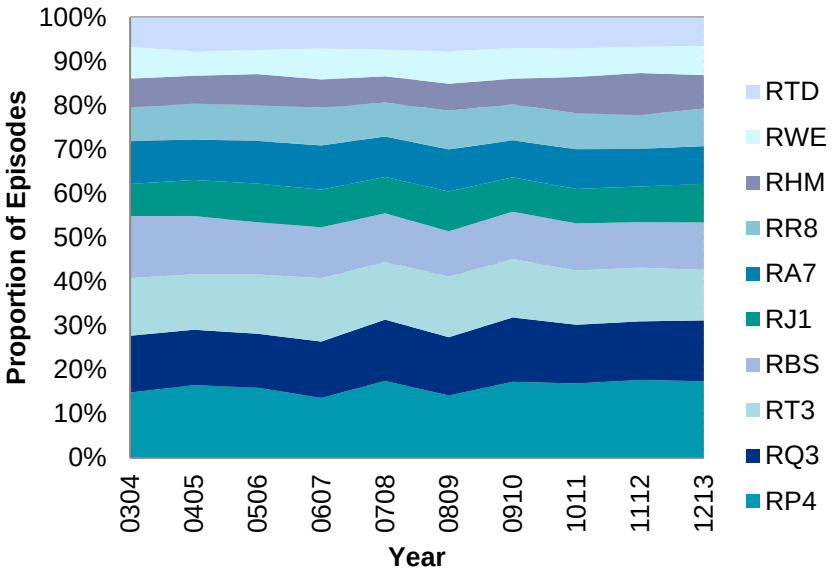
Blue = "Cold" = low or negative growth – most negative growth darkest blue

Cannot use NICOR data as geographical breakdown biased by changes in reporting over time.

Historic trends: activity by providers

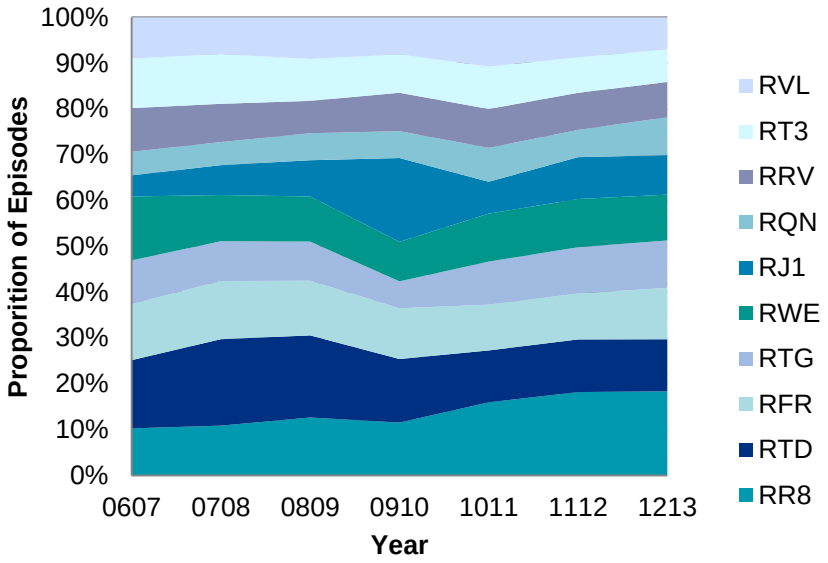
Changes in “market share” of the top ten (by activity) providers over time

Top ten (by activity) Paediatric Providers



Share of the activity by provider is fairly stable over time

Top ten (by activity) ACHD Providers



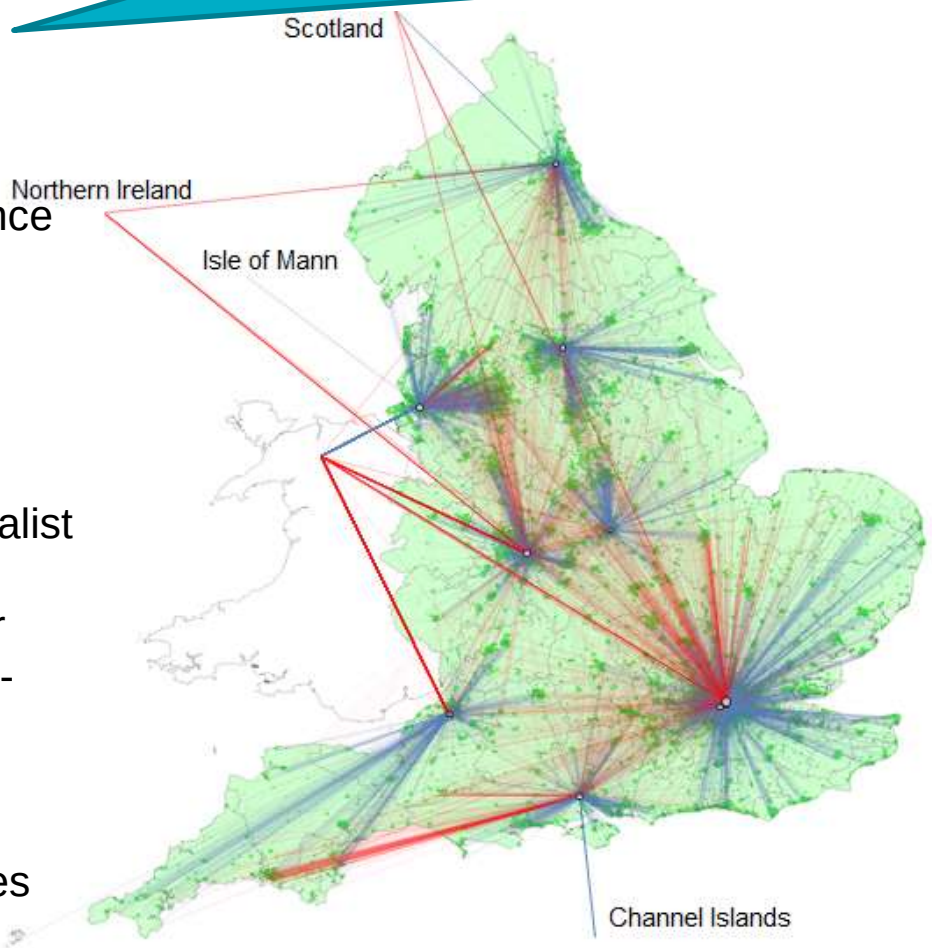
Share of the activity by provider is has changed over time

Historic trends: paediatric cardiac patient flows

Total episodes for the last 10 years by provider and patient residence. Different providers see patients from different areas.

Major Paediatric Providers

- 10 major centres
- 3 in London
- Lines denote activity flow from patient residence to provider
- Thickness of lines denote volume of activity
- Size of centroid denotes volume of provider activity
- Dark green areas are patient origins
- Most patients are going to their nearest specialist centre (as the crow flies -blue lines)
- Few centres are drawing patients from further than their nearest provider (as the crow flies - red lines)
- Only one point used for all activity from sites outside England
- Average distance per episode: 49km (excludes non England)
- Concentration ratio*, C_{10} = 0.91



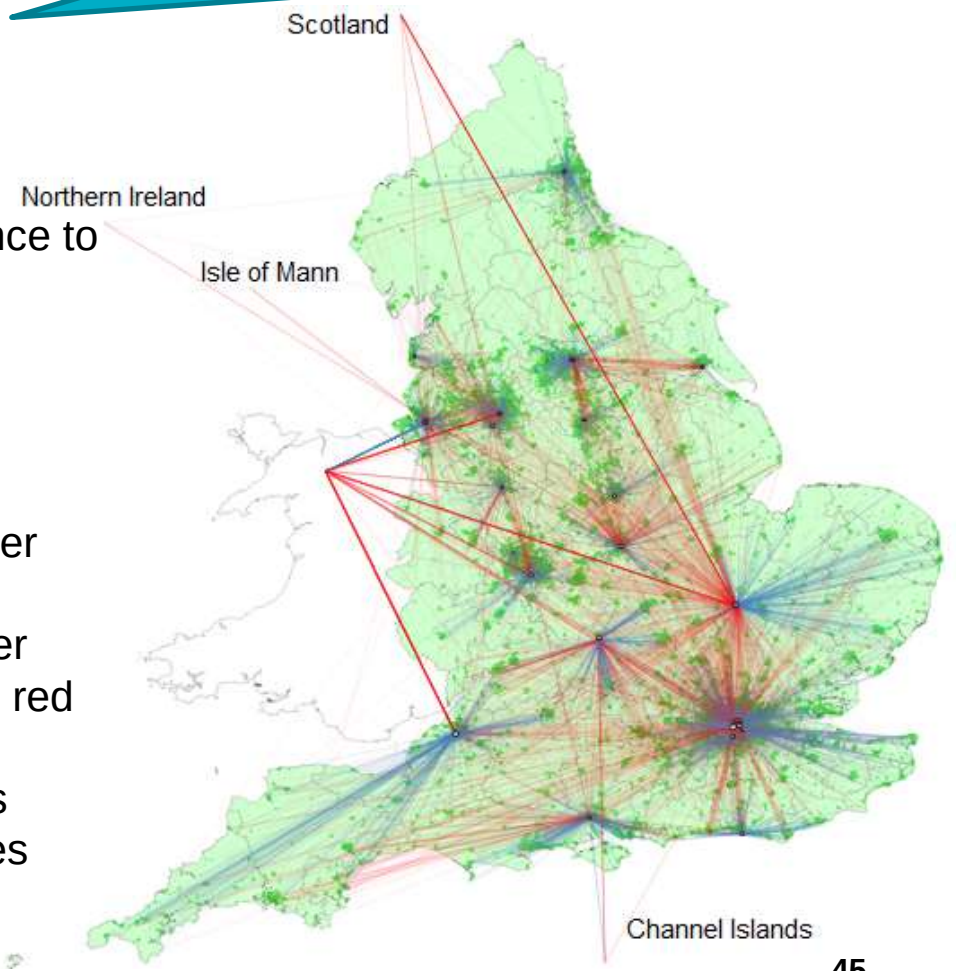
* the proportion of total activity provided by these centres over the last 10 years

Historic trends: ACHD patient flows

Total episodes for the last 7 years by provider and patient residence. Different providers see patients from different areas.

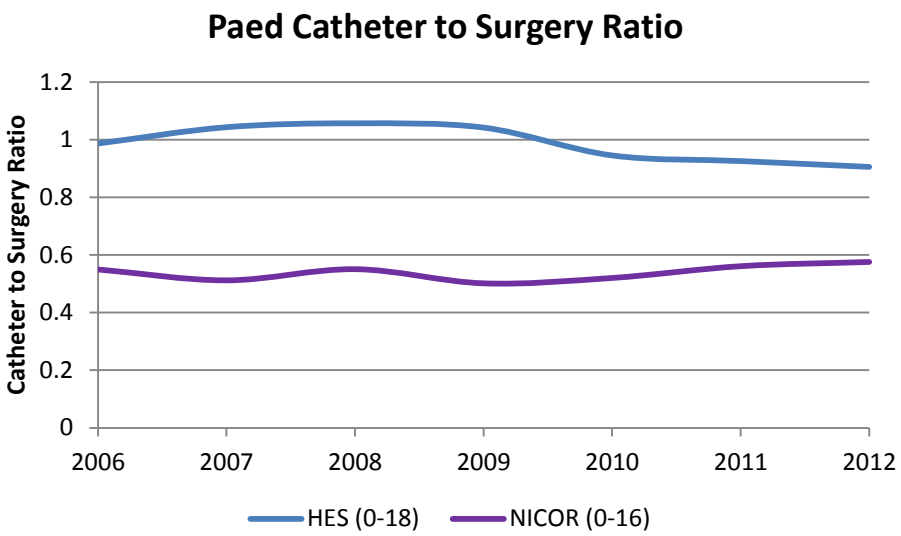
Major ACHD Providers

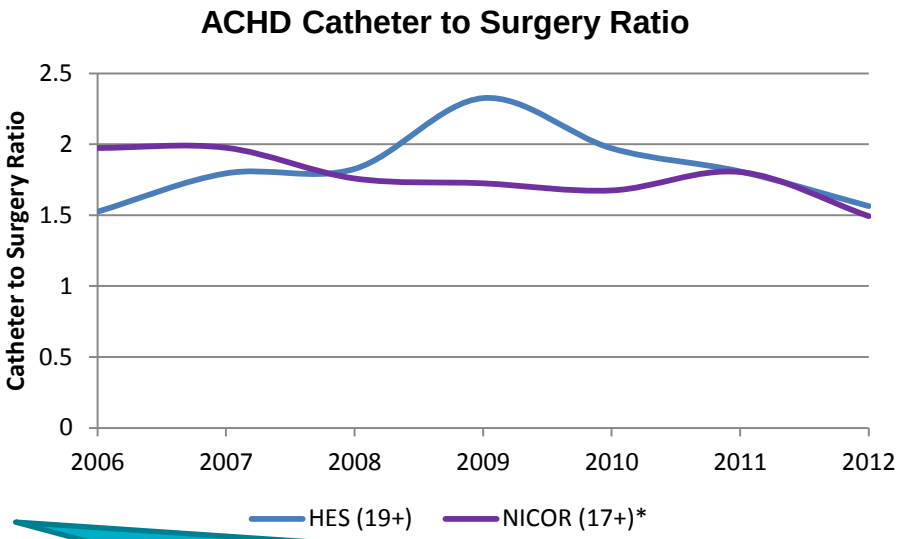
- Top 25 major centres
- 7 in London
- Lines denote activity flow from patient residence to provider
- Thickness of lines denotes volume of activity
- Size of centroid denotes volume of provider activity
- Dark green areas are patient origins
- Few patients are going to their nearest provider (as the crow flies - blue lines)
- Many centres are drawing patients from further than their nearest provider (as the crow flies - red lines)
- Only one point used for all activity from Wales
- Average distance per episode: 42km (excludes non England)
- Concentration ratio*, C_{25} = 0.92, C_{10} = 0.57



* the proportion of total activity provided by these centres over the last 7 years

Historic trends: Catheters vs Surgeries





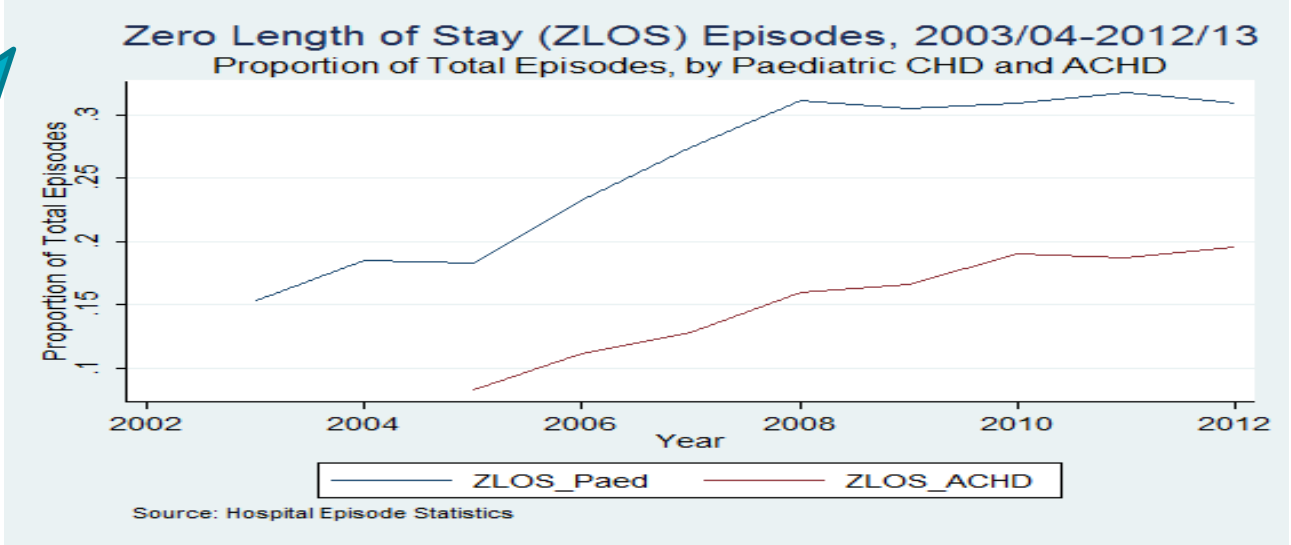
Paed: Both HES and NICOR suggest the catheter to surgery ratio has been stable over time. However, HES suggests a higher ratio than NICOR. This could be due to the differences in the two age groups (HES 0-18 vs NICOR 0-16)

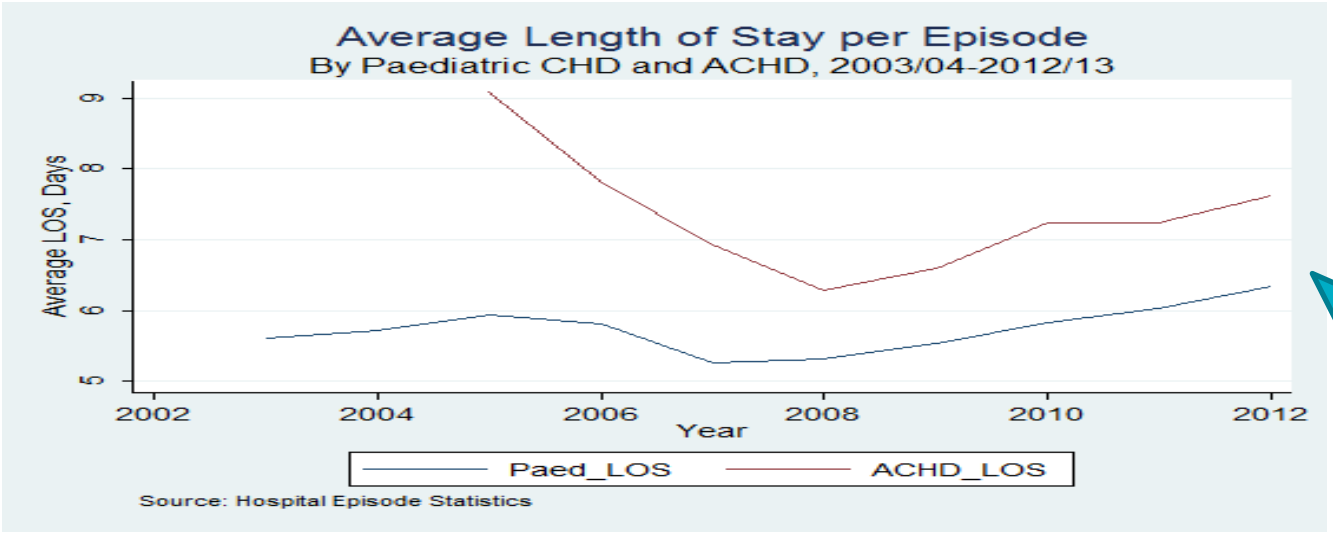
ACHD: Both HES and NICOR suggest a catheter to surgery ration of >1.5. There has been more variability over time according to HES. This could be changes in coding and difference in the two age groups (HES 19+ vs NICOR 17+)

To note: We have used a list of codes in HES to flag a procedure as a catheter – this is less reliable than NICOR who verify the procedures covered by the data. *For ACHD as NICOR data is missing for some provider the ratio may be bias depending on missing activity

Historic trends: Length of stay

Zero Length of Stay (LOS) episodes have been increasing as a proportion of the total number of episodes for both ACHD and Paediatric





For those episodes that are not zero LOS, the average LOS per episode looks to have declined for ACHD and looks to be fairly stable for Paediatric activity

New Congenital Heart Disease Review

NHS England

Activity Drivers

Joanna Glenwright
John Buckell
Charles Keenan

THE NHS CONSTITUTION
the NHS belongs to us all

We have investigated the possible drivers of activity

Levels of activity have changed over time and are different across patient resident areas beyond differences in population numbers

So we need to:

1. Understand what is driving the changes over time and the differences across the country

2. Make informed assumptions about what these drivers of activity are going to do in the future

To do this we have:

- ✓ Asked our clinician advisory group
- ✓ Reviewed academic literature
- ✓ Undertaken statistical analysis of HES data

What the clinician advisory group told us:

Factor	Relationship with activity	What has it done in the past?	What will it do in the future?
Population	Increased population = increased activity	Led to activity increases	Lead to activity increases
Patient longevity and survival	Increased longevity = increased activity	Led to activity increases	Lead to activity increases
Patient expectations and clinician willingness to treat	Increased expectations & willingness = increase activity	Led to activity increases	Lead to activity increases
Technology	Increased technology = increased activity	Led to activity increases	Lead to activity increases
Increased complexity of conditions	Increased complexity = increased activity	Led to activity increases	Lead to activity increases
Consanguineous relationships	Increased consanguinity = increased activity	Led to activity increases	Lead to activity increases
Maternal age	More mothers at edge of fertile age range = increased activity	Led to activity increases	Lead to activity increases
Deprivation	Increased deprivation = increased activity	Unclear	Unclear
Health tourism	Increased health tourism = increased activity	Unclear	Unclear
Early diagnosis and termination rates	Unclear	Unclear	Unclear

What some relevant literature suggests:

Driver of activity	References
Population	N/A
Patient longevity and survival	Hoffman, (1995), Wren (2001), Hoffman, Kaplan (2002), Billet (2007), Khairy (2010), Afalo et al (2011), Tutarel (2013), Mylotte (2014)
Patient expectations and clinician willingness to treat	Billet (2008), Irving (2011), Mylotte (2014)
Technology	Hoffman (1995), Wren (2001), Heart (2002), Marelli (2007), Khairy (2010), Irving (2011) ,Van der Linde at al (2011), 2013-CHD: International collaboration
Increased complexity of conditions	Wren (2001), Billet (2008)
Consanguineous relationships	Sadiq (1995), Sheridan (2013)
Maternal age	Reefhuis et al., (2004), Marelli (2007), Van der Linde at al (2011), Rankin (2012)
Deprivation	Sadiq (1995)
Health Tourism	N/A
Early diagnosis and termination rates	Wren (2001), Irving (2011), Rankin (2012), Sheridan (2013)
Other	Brown and Karunas (1972), Cullen et al., (1991), Jacobs (2000), Jenkins et al., (2007), Pinto (2007), Gilboa et al., (2010), Van der Linde at al (2011) Agay-Shay et al., (2013), Sheridan (2013), Zutphen et al., (2014)

The initial statistical analysis suggests:

We have applied a range of statistical techniques* to our HES data to investigate potential relationship between activity levels and possible “drivers”

For **paediatric** activity:

Covariate	Strong evidence	Some Evidence	Little Evidence	No findings	Association with activity	Relative Effect
Population	x				**Positive**	**Low**
Number of Diagnoses**	x				**Positive**	**High**
Age	x				**Negative**	**High**
Ethnicity: Asian	x				**Positive**	**Low**
Ethnicity: Black		x			**Positive**	**Low**
Ethnicity: Chinese			x		**Negative**	**Low**
Gender		x			**Positive**	**Low**
Time	x				**Positive**	**Low**

* A range of regression models: univariate and multivariate panel data models to look at data at Area Team level and hurdle models to look at patient level data, ** potential proxy for complexity but could be coding practice

The initial statistical analysis suggests:

We have applied a range of statistical techniques* to our HES data to investigate potential relationship between activity levels and possible “drivers”

For **ACHD** activity:

Covariate	Strong evidence	Some Evidence	Little Evidence	No findings	Association with demand	Relative effect
Population	**x**				**Positive**	**High**
Number of Diagnoses**	**x**				**Positive**	**High**
Age		**x**			**Positive**	**High**
Ethnicity: Asian			**x**		**Positive**	**Low**
Ethnicity: Black			**X**		**Positive**	**Low**
Ethnicity: Chinese			**X**		**Positive**	**Low**
Gender				**x**	**n/a**	**Low**
Time	**x**				**Positive**	**Low**

* A range of regression models: univariate and multivariate panel data models to look at data at Area Team level and hurdle models to look at patient level data** potential proxy for complexity but could be coding practice

Identified demand drivers but not quantified their effect

Based on the evidence considered we expect the main drivers of CHD activity are:

1. Population growth (which is a function of birth rate, migration and life expectancy)
2. Increasing proportion of patients who are of Asian and Black ethnicity
3. Technology and medical advances
4. Increased patient longevity and survival
5. Increased expectation (patients) and willingness (clinicians) to treat
6. Increased complexity and severity of patients (possibly also driven itself by 2,3,4 and 5 above)

All of these identified drivers are expected to continue to increase and drive up activity in the future

New Congenital Heart Disease Review

NHS England

Scenarios for future activity

Joanna Glenwright
John Buckell
Charles Keenan

THE NHS CONSTITUTION
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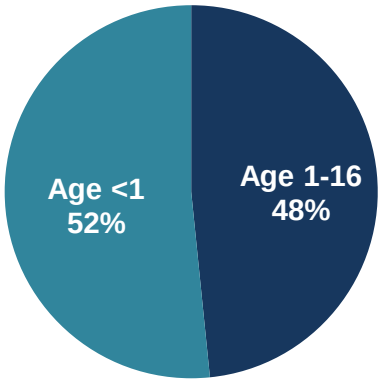
Future Activity Scenarios

- Of the identified demand drivers the only one that can reasonably be modelled going forward is population growth by age, sex and area
- The effect of all the other demand drivers over the last 10 years is wrapped up in the historic trend in activity
- Therefore we have looked at 2 key scenarios for future activity:
  - Scenario A: No change in procedures per head from 2012, only pressure is increase in number the population of England and Wales
  - Scenario B: As A but allow number of procedures per head to increase as it has in the past.

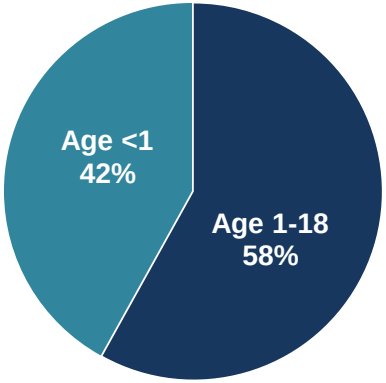
Future Activity Scenarios: Paediatric activity

As discussed a significant % of paediatric activity is for children aged under 1 year (infants and neonates)

NICOR data (0-16)



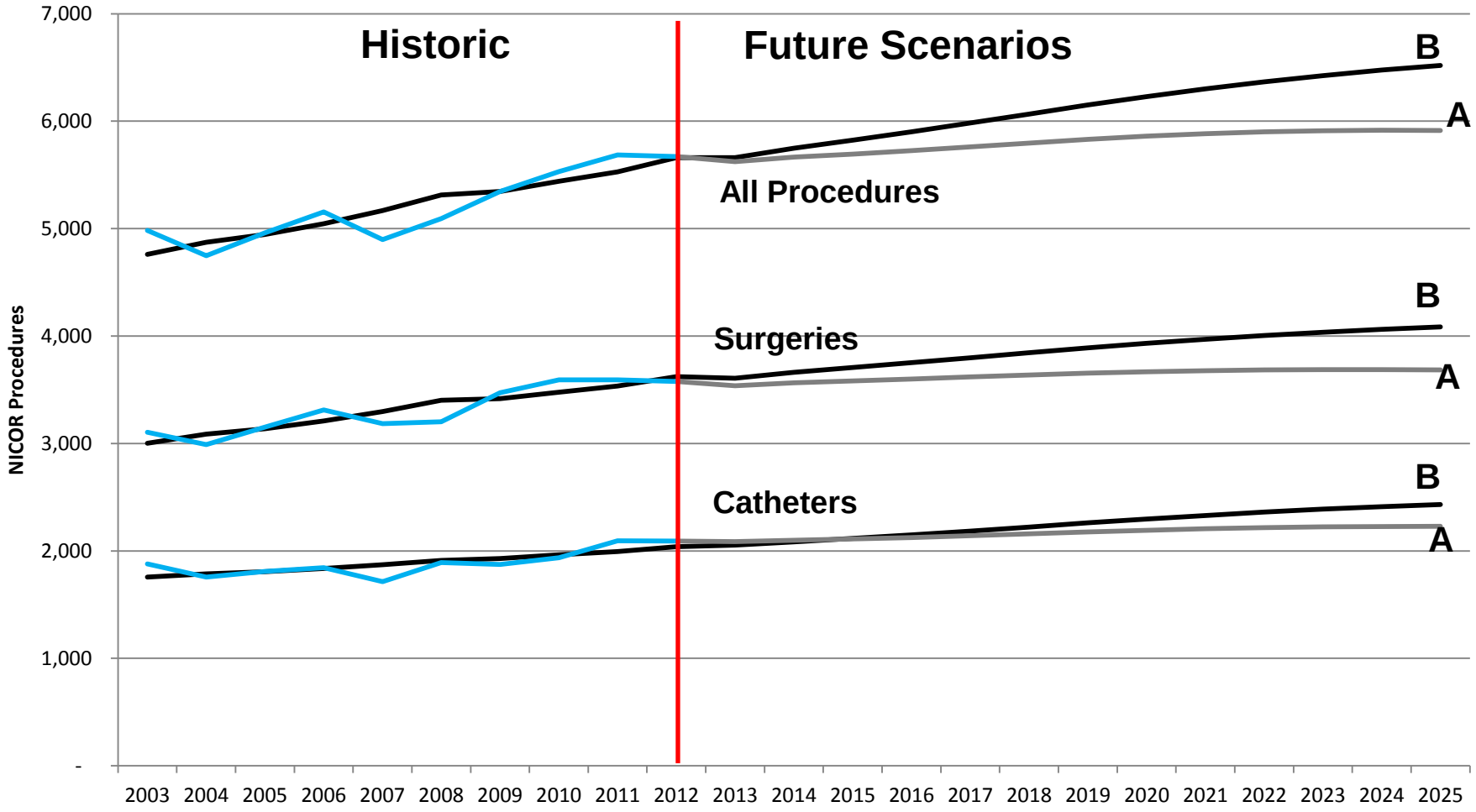
HES data (0-18)



As shown in previous slides activity trends differ significantly for those aged under 1 compared to those aged over 1, as do ONS population projections

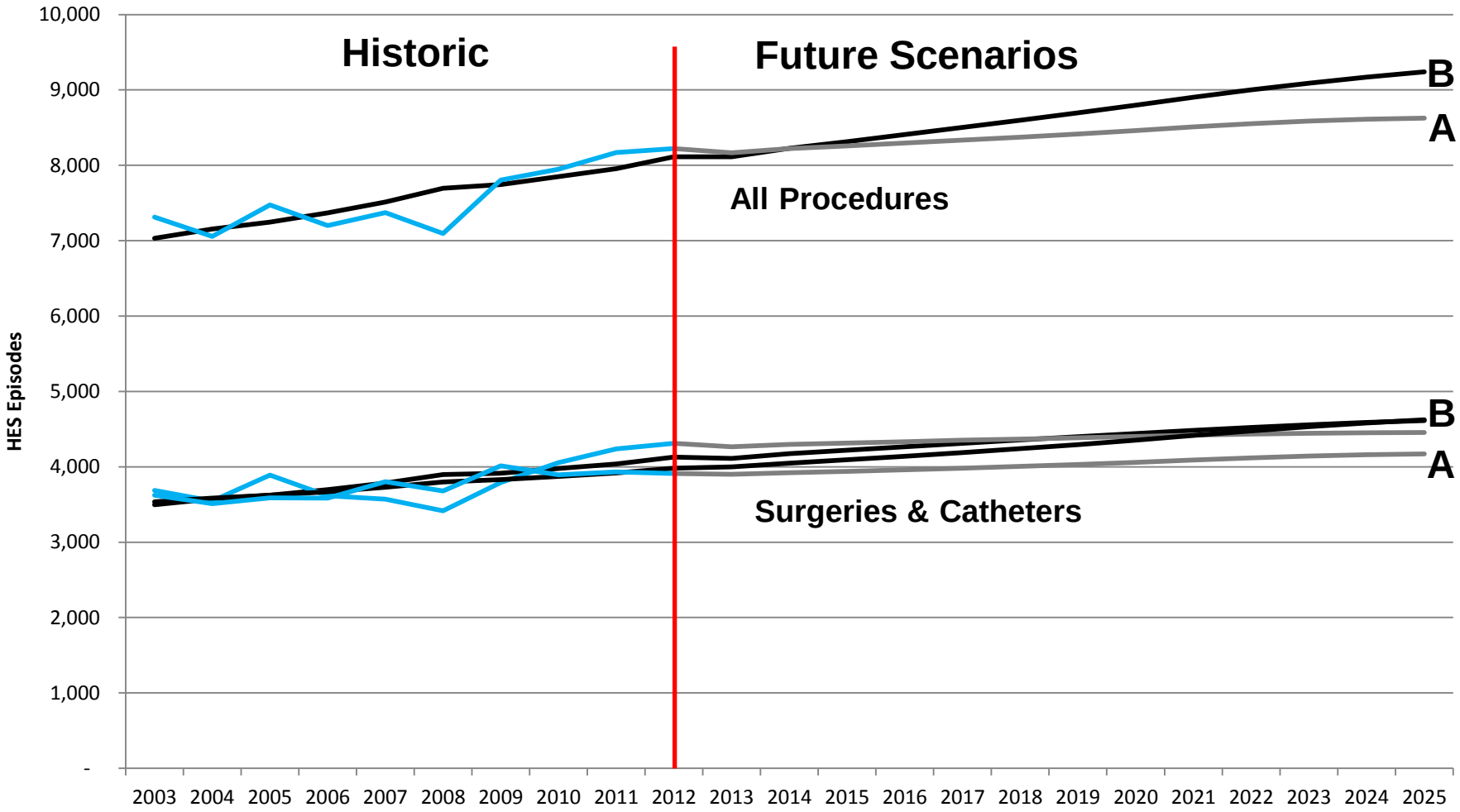
Therefore we have considered the future activity growth for these two groups separately and then brought them back together to give a total analysis for all paediatric activity

Future Activity Scenarios: paediatric (0-16) based on NICOR



NICOR data & ONS 2012 Principle Projections

Future Activity Scenarios: paediatric (0-18) based on HES



HES data & ONS 2012 Principle Projections

Using ONS Principal Population Projection

Future Activity Scenarios: paediatric activity pressure

	All Paed Cardiac (0-16) Procedure Based Activity – Based on ONS Principal Population Projections						
	2012/13 Baseline	Scenario A			Scenario B		
NICOR (0-16) CCAD data (procedures)							
Procedure Type	**2012/13**	**2025/26**	**13 yr growth**	**Per annum**	**2025/26**	**13 yr growth**	**Per annum**
All	5700	5900	4.3%	0.3%	6500	15.0%	1.1%
Surg	3600	3700	3.0%	0.2%	4100	14.2%	1.0%
Cath	2100	2200	6.5%	0.5%	2400	16.3%	1.2%
HES (0-18) APC data (episodes)							
Procedure Type	**2012/13**	**2025/26**	**13 yr growth**	**Per annum**	**2025/26**	**13 yr growth**	**Per annum**
All	8200	8600	4.9%	0.4%	9200	12.4%	0.9%
Surg	4300	4500	3.3%	0.3%	4600	7.0%	0.5%
Cath	3900	4200	6.7%	0.5%	4600	18.3%	1.3%

Baseline depends on activity currency and age group – HES episodes (0-18) vs. NICOR procedures (0-16)

Scenario A: Pressure is similar – it is driven by ONS population forecasts and the relative activity weight for each age group – around 3 - 7% up to 2025/26 or around **0.4% per annum**

Scenario B: Pressure is similar – around 10 – 15% up to 2025/26 or around **1% per annum**

To note: above calcs may not sum due to rounding and compound effects.

Using ONS High Population Projection

Future Activity Scenarios: paediatric activity pressure

	All Paed Cardiac (0-16) Procedure Based Activity – Based on ONS High Population Projections						
	2012/13 Baseline	Scenario A			Scenario B		
NICOR (0-16) CCAD data (procedures)							
Procedure Type	**2012/13**	**2025/26**	**13 yr growth**	**Per annum**	**2025/26**	**13 yr growth**	**Per annum**
All	5700	6500	14.8%	1.1%	7200	26.6%	1.8%
Surg	3600	4100	14.1%	1.0%	4500	26.5%	1.8%
Cath	2100	2400	16.1%	1.2%	2700	26.9%	1.9%
HES (0-18) APC data (episodes)							
Procedure Type	**2012/13**	**2025/26**	**13 yr growth**	**Per annum**	**2025/26**	**13 yr growth**	**Per annum**
All	8200	9400	14.5%	1.0%	10100	22.8%	1.6%
Surg	4300	4900	13.8%	1.0%	5100	18.6%	1.3%
Cath	3900	4500	15.3%	1.1%	5000	27.5%	1.9%

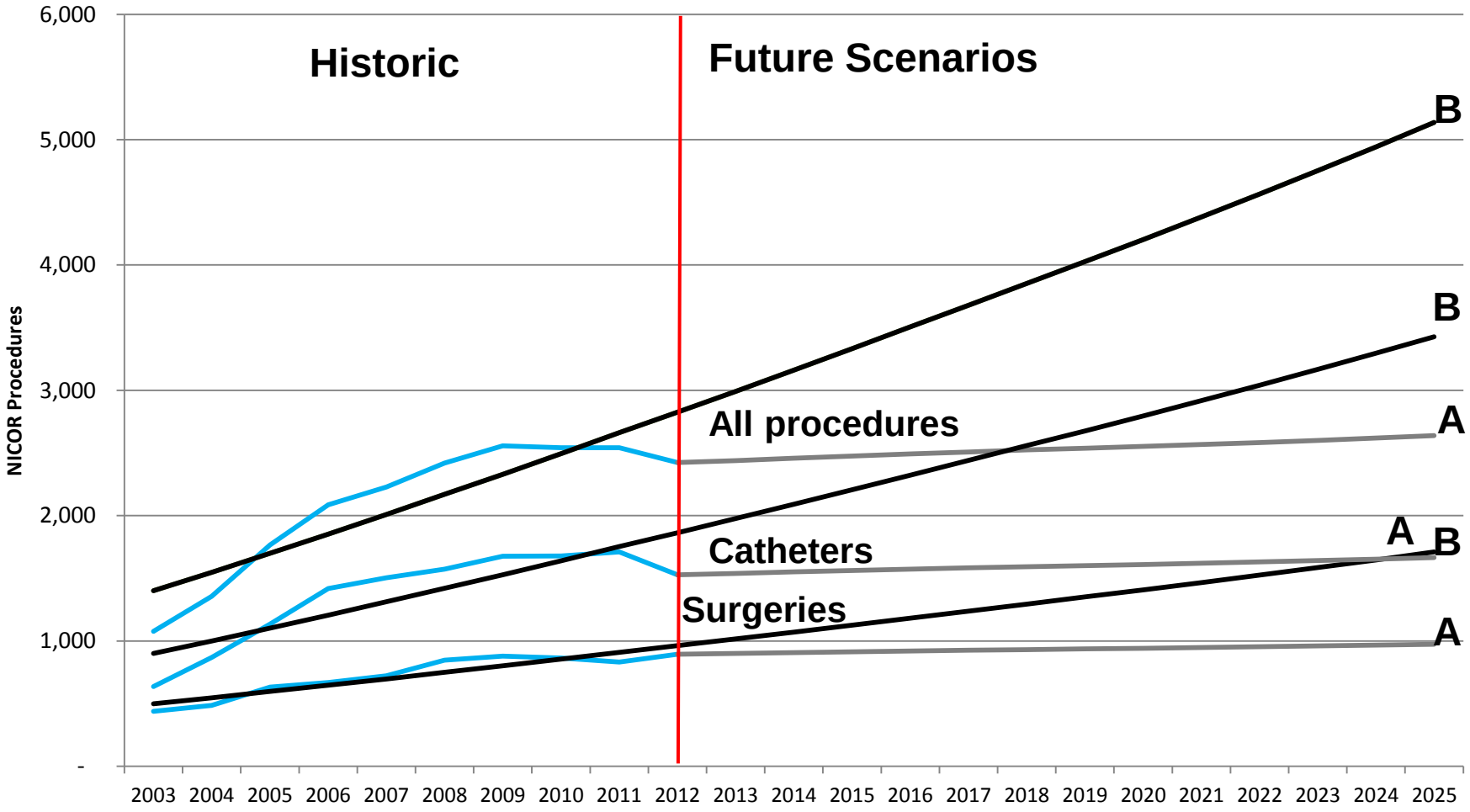
Baseline depends on activity currency and age group – HES episodes (0-18) vs. NICOR procedures (0-16)

Scenario A: Pressure is similar – it is driven by ONS population forecasts and the relative activity weight for each age group – around 15% up to 2025/26 or around **1% per annum**

Scenario B: Pressure is similar – around 20 – 25% up to 2025/26 or just under **2% per annum**

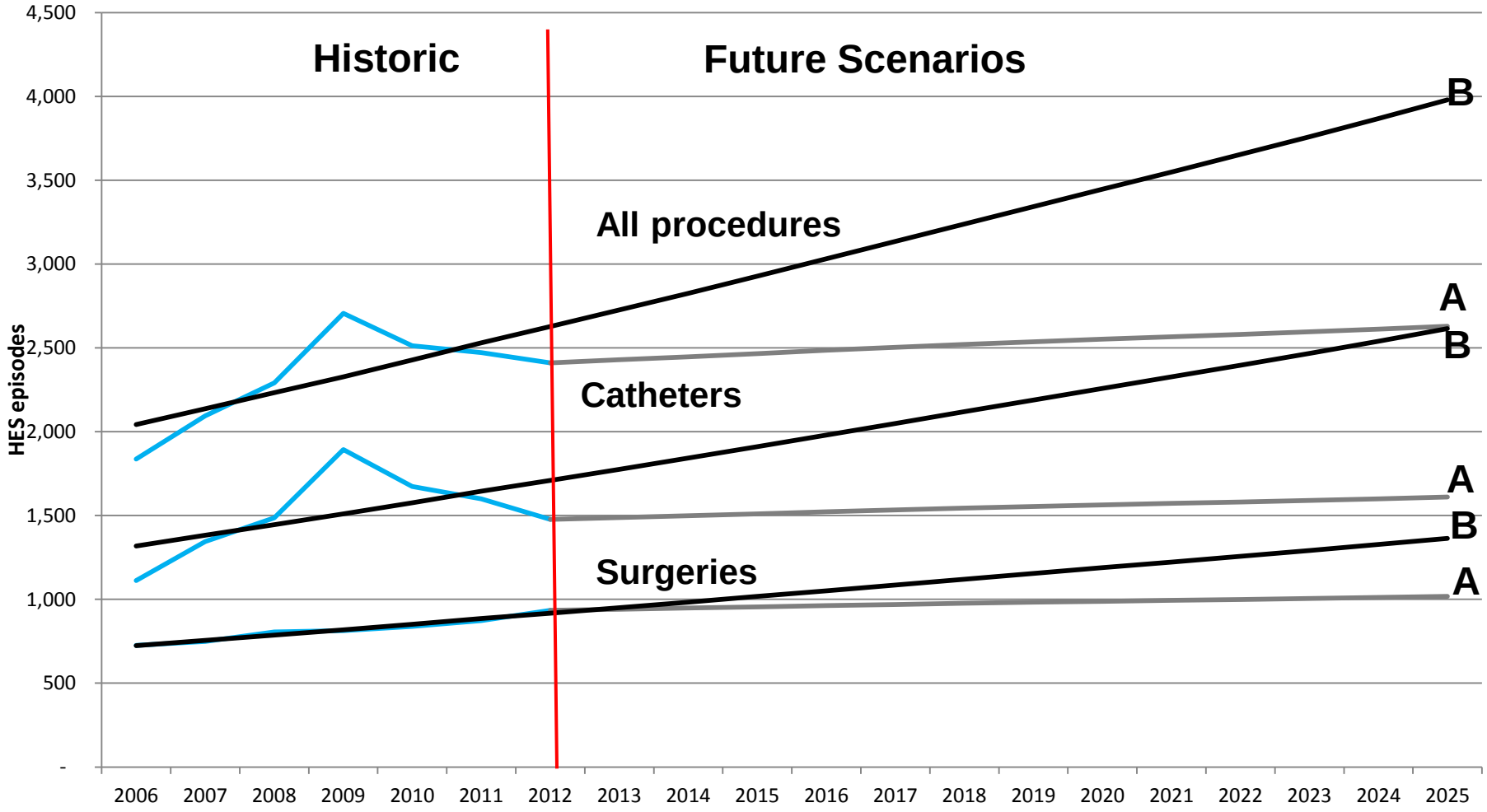
To note: above calcs may not sum due to rounding and compound effects

Future Activity Scenarios: ACHD 17+ based on NICOR data



NICOR ACHD data is affected by increases in the number of providers reporting over time so **Scenario B is distorted** by this and should not be used – included for completeness

Future Activity Scenarios: ACHD (19+) based on HES data



HES data and ONS 2013 Principle Projection

Using ONS Principal Population Projection

Future Activity Scenarios: ACHD (HES vs NICOR)

	ACHD Procedure Based Activity – Based on ONS Principal Population Projection						
	2012/13 Baseline	Scenario A			Scenario B		
NICOR (17+) CCAD data (procedures)							
Procedure Type	**2012/13**	**2025/26**	**13 yr growth**	**Per annum**	**2025/26**	**13 yr growth**	**Per annum**
All	2400	2600	8.9%	0.7%	5100	112.0%	6.0%
Surg	900	1000	8.9%	0.7%	1700	91.2%	5.1%
Cath	1500	1700	8.9%	0.7%	3400	124.1%	6.4%
HES (19+) APC data (episodes)							
Procedure Type	**2012/13**	**2025/26**	**13 yr growth**	**Per annum**	**2025/26**	**13 yr growth**	**Per annum**
All	2400	2600	9.0%	0.7%	4000	65.0%	3.9%
Surg	900	1000	9.0%	0.7%	1400	46.0%	3.0%
Cath	1500	1600	9.0%	0.7%	2600	77.0%	4.5%

Baseline numbers depends on activity currency and age – HES episodes 19+ vs NICOR procedures 17+. NICOR thought to cover around 80% of total

Scenario A: Pressure is driven by ONS population forecasts – around 9% up to 2025/26 or **0.7% per annum**

Scenario B: NICOR data unreliable due to reporting changes. But even for HES pressure is high and driven by catheter activity.
65-77% to 2025/26 or around **3-4% per annum**

To note: above calcs may not sum due to rounding and compound effect

- the way in which Hospital Episode Statistics (HES) activity is coded means it is not easy to distinguish CHD activity from other cardiac services.

8. While there are therefore concerns about the quality of data for ACHD activity the information presented in this report is the best available and we consider it to be sufficiently robust for this purpose.

Analysis - Results

9. The key findings from our analysis are summarised below:
    - Currently, around 65-75% of congenital heart inpatient activity is for 0-18 year olds.
    - Paediatric activity has grown steadily by around 10% above population growth over the last 10 years.
    - ACHD activity has grown by over 20% above population growth over the last 7 years, but is from a much lower base (so big % change may be small in absolute numbers).
    - We think the key demand drivers include technology/medical advances, increased patient expectations and clinician's willingness to treat, increased patient survival and for paediatric activity in particular the increasing % of patients who are of BAME ethnicity (where there is some evidence of higher incidence and also of a greater proportion of serious anomalies).
    - Of the identified demand drivers the only one that can be separately modelled going forward is population growth (by age, sex and area). Modelling is based on ONS projections. While this is the best information available these have not always been accurate in the past because of unanticipated changes to the population and birth rates.
    - The effect of all the other demand drivers over the last 10 years is included in the historic trend in activity growth above population growth.
    - Therefore we have looked at two key scenarios for future activity:
        - Scenario A: Population growth only (England and Wales).
        - Scenario B: As for A but also allowing activity per head to increase at the same rate as it has in the past.
    - These scenarios suggest that up to 2025/6:
        - Paediatric activity could be expected to grow by between 0.4% and 1% pa However, this is very sensitive to the birth rate projections which ONS has previously underestimated – under ONS' high variant projections expected growth would be between 1% and 2% pa.
        - ACHD activity could be between **0.7%** and **4%** pa.

Engagement during consultation

There will be a number of engagement events and activities during the 12-week consultation period to enable as many groups, organisations and individuals to contribute to the consultation on the new NHS England Congenital Heart Disease standards as possible.

We have reflected on the previous plan for a smaller number of events, in locations without congenital heart disease services and with a panel-style debate; we felt this would cause difficulties for attendees to get to the events, did not provide enough opportunity for engagement across the country and could distract from the standards consultation if providers were trying to explain how they would meet the standards in a debate, as this would be a likely question.

We are therefore asking the Programme Board to consider an alternative approach.

A number of strands of engagement are now being planned for during consultation and the detail of these is outlined below:

1. Regional Events

- **Purpose of events**
  To better equip and inform stakeholders and the wider public as a whole about the proposed standards for Congenital Heart Disease services, to enable them to make informed comment and responses. The purpose of the events is to assist in developing of their responses as opposed to gathering responses.

- **Timing**
  Timing of the events delivered by NHS England will be at least 4 - 6 weeks into the 12-week period of consultation (apart from the political events) to enable potential attendees to be able to read, understand and think about a response to the standards. Autumn half term will be avoided so that additional pressure is not put on providers and clinicians who may wish to attend, but will need to cover colleagues off over the half-term period.

  In order for as many people to be able to contribute, the timing of the event will be from mid-afternoon to early evening.

- **Location**
  The NHS England regional events will take place in locations around the country and possibly in cities associated with providers of paediatric CHD services, as that this is where the population will be available to attend events.

  The venues will be chosen with careful consideration to the transport links into the area and the provision of venues that can accommodate such an event and any specific requirements that attendees of the event may require (disabled parking etc.)

- **Attendees**
  The event will be open access but attendees will be required to log their interest in attendance prior to the event to manage logistics. All registered stakeholders will be

invited. The events will be advertised via providers and using NHS England and partners' websites and communication materials.

- **The event style**
  A main room will be laid out with exhibition-style wall boards/free standing boards with details of the standards presented. There will be boards additional to the information found in the consultation documents to extend the draw for the exhibition. There will be team members available to be able to guide attendees through the content and listen. Additionally, team members will guide all attendees to methods to respond to the consultation available.

  There will also be 'video stations' playing on loops for attendees to be able to listen and absorb the consultation content, and vox pop films of big questions answered and opinions from clinicians, providers, patient and public groups so that attendees can listen to opinions of those involved in the Clinical Advisory Panel (CAP), Standards groups, Clinical Reference Group (CRG) etc.

  There will be opportunity to gather responses at the events from attendees, in written or electronic form. iPads with 3G or wireless in the venue will allow participants to add their thoughts and opinions directly.

- **Benefits**
  The approach has been chosen as one that will provide an opportunity for those attending to find out more about the proposed standards and make a considered response at the events in written or electronic form.

  There will be time and opportunity for attendees to talk through the standards with others at the events. There may be fixed times during the event when NHS England Congenital Heart Disease review team members will walk through the proposed standards and answer questions in a presentation style format.

  Local area teams will be engaged prior to the events and it is anticipated that they will attend their local event/events to be able to provide answers to questions related to their role post-consultation and begin the natural handover of standards from the CHD programme team to specialised commissioners.

- **Next Steps**
  - Establish the best venues and logistics.
  - Develop a sliding scale of potential attendees in terms of numbers and ensure that the events/locations work within the scale.
  - Discuss with Giles Wilmore and the Patient and Public Voice team to assure the approach.
  - Establish how we manage responses to the consultation at the event in a manner that is secure and works with how the responses are being dealt with but doesn't dissuade attendees from contributing to the review process.
  - Inform a wider audience of the planned approach.

2. Panel debate and discussion-style event

In order to have one event where contributors can gather, listen to each other and share what they have been hearing during the consultation period, another event similar to the event on the 25 July will be run. It will run towards the end of consultation so that all attendees can report back what has been learnt/heard at the other events including stakeholder events and the regional events.

This would be an invitation event which would be offered to those stakeholders engaged with the review so far.

There is a possibility that the three engagement groups - Clinician, Provider and Patient and Public - will meet separately at some point during the consultation process; this will be delivered if there is a desire to have meetings and content to discuss.

3. Partner events

Stakeholders and partners to the review will be encouraged to hold their own events over the consultation period where they can engage with their employees, members and stakeholders to help inform them and encourage responses to the consultation.

Partners and stakeholders will plan the timing of their own events to fit with their members, employees and constituents.

We will offer support to partners for events by providing them with materials to include:

- All produced/printed materials for consultation
- Notes for social media engagement
- Speaking notes and crib sheets
- Narrated PowerPoint presentation
- Q&A
- Video vox pop of questions answered by the members of CAP, key surgeons, CRG, Standards groups etc.

4. Political Engagement

- **Local Government and local Healthwatch**
  An event will be run for local government and Healthwatch representatives in a central England location for all representatives who wish to attend who are linked to both paediatric and adult congenital heart disease services, during the consultation period.

  Prior to consultation all local government representatives will be informed of the forthcoming consultation at least three weeks in advance.

- **National political representatives**
  For national representatives we suggest that a mini exhibit is placed in the Houses of Parliament for MPs and Lords to 'drop in' during a fixed period to talk to CHD representatives and pick up consultation materials.

  Prior to consultation all national government representatives will be informed of the forthcoming consultation at least three weeks in advance.

- **Other political/government groups**
  Groups such as Healthwatch England, Local Government Association and the Centre for Public Scrutiny will be contacted in advance of consultation to enable them to communicate with their members.

  Communication will be sent to Health and Wellbeing Boards and representatives of Overview and Scrutiny Committees (OSCs) to inform them of the consultation period and the opportunity to contribute. It is anticipated that there will be a small number of requests to attend OCSs and Joint Overview and Scrutiny Committees (JOSCs) to which we will respond.

  Other groups that will be asked to engage with their members will likely include providers and Royal Colleges and Associations.

5. Specific engagement with special interest groups

There are a number of groups for whom the review needs to take a tailored approach to ensure that they are able to contribute to the consultation process.

- **BAME - Black and Minority Ethnic**
  Initial work with faith groups has not provided clear links to those in the communities that have an interest in CHD, but work continues with the providers who serve the largest communities of South Asians in the UK to identify parents and patients so that we can ensure that they are able to contribute to the process as 10% of paediatric cases of Congenital Heart Disease occur in the South Asian communities. This may include specific events during consultation or providing materials or spokespersons to events being run within these communities to encourage contributions to the review.

- **Adults with CHD**
  Work is being undertaken to establish whether there is a requirement or desire to hold an event specifically for adults with CHD during the consultation period as this group has been relatively under-represented in the meetings held by the review to date.

- **Learning disabled**
  We plan to gather opinions on what matters to people with learning disabilities through existing routes rather than running specific events. It is likely that stakeholders who work with young people and adults with learning disabilities will incorporate questions and discussions about the standards that are being consulted upon within already planned and existing events to enable contribution to the consultation process.

- **Bereaved parents**
  Parents who are bereaved may find contributing to the consultation difficult. The review has linked with the Child Bereavement Trust to assist in engaging bereaved parents during consultation: this may be through an event for bereaved parents and/or using online and electronic methods of discussing comment and offering contributions. Members of the review team will meet with bereaved parents from the Bristol area at their invitation to seek their views.

The Programme Board is asked to review, comment and approve the approach and plans for engagement during consultation.

Consultation Launch Criteria

At the next meeting of the Programme Board on 8 September 2014, the new CHD review team expects to ask for approval to launch the public consultation on new standards and specifications for the whole lifetime pathway of care for people with congenital heart disease.

The specifications and associated impact assessments are required to pass through the formal specialised commissioning governance process. Requesting approval from the Programme Board to launch the consultation will be subject to approval of those items by those groups (ultimately the Directly Commissioned Services Committee of the NHS England Board).

The expected timetable for those approvals is as follows:

- 20 Aug 2014: **Women and Children's Programme of Care Board** (POC) - for approval and recommendation to CPAG
- 2 Sep 2014: **Clinical Priorities Advisory Group** (CPAG) - for approval and recommendation to DCSC
- By 5 Sept 2014: **Directly Commissioned Services Committee** (DCSC) - by correspondence/Chair's action

The review team expects that in addition to this governance process, there are a number of other criteria that the programme board will need to feel are satisfied in order to support the review team to launch the consultation.

These are outlined below.

Assurance

- The review's Clinical Advisory Panel (CAP) have advised the Programme Board that they are satisfied with the final version of the standards for consultation, and with the alignment between the standards and the specifications.
- All required consultation products have been through the NHS England 'gateway' process and are cleared for publication.
- The NHS England Board Task and Finish Group are satisfied with plans for consultation and have delegated final sign-off to launch the consultation to the Programme Board, subject to the approval required by the Directly Commissioned Services Committee.

Briefings and Communications Planning

- The Specialised Commissioning Oversight Group (SCOG) and Patient and Public Voice Advisory Group (PPVAG) have received materials and been briefed on the review and plans for consultation.
- Consultation launch has an agreed date on the NHS England communications grid.

- A full communications and media launch plan has been developed and is ready to be implemented.
- Briefing packs have been created and are ready to be disseminated as per the launch plan.

Stakeholder Involvement

- Stakeholders from the review's Standards Groups, Clinical Advisory Panel and Engagement and Advisory Groups, and the Congenital Heart Services Clinical Reference Group (CRG) have had a chance to review draft impact assessments and supporting papers before they were issued to the specialised commissioning governance groups.
- The questions for the consultation have been tested with appropriate stakeholders.
- The consultation document has been reviewed by key programme stakeholders and revised in light of their advice.
- Engagement arrangements for the consultation are in place, and have been reviewed by colleagues within patient and public voice and revised in light of their advice.
- Clear arrangements with the devolved administrations in relation to their role in consultation are agreed and in place.
- Support materials have been developed to enable partners to run events during consultation.

Accessibility

- An easy-read version of the consultation document has been created and appropriately assured.
- Assurance that the plans for the running of the consultation have been designed in such a way as to ensure it is accessible by all has been provided by the NHS England equalities team.
- Arrangements have been made to support people for whom English is not the first language in engaging with and responding to the consultation, and the approach has been assured by both the NHS England patient and public voice and legal teams.

Consultation Mechanisms

- Response mechanisms for the consultation have been defined and meet NHS England standard requirements.
- A 'Citizen Space' consultation hub has been developed in line with the NHS England standard, and all documents and links are ready to be made live.
- A provider has been selected to analyse the responses to consultation.

The Programme Board is asked to review, and to advise of any additional requirements that would need to be met in order for them to approve the launch of the public consultation at their next meeting, on 8 September 2014.

New congenital heart disease review: Programme Risk Register

Risk Owner	Risk Ref	Potential Risk Description	Current Risk Score (note 1)			Mitigating Actions in Place	Further Mitigating Actions	Completion Date for Actions	Anticipated Risk Score Following Mitigation (note 2)		
			Impact	Likelihood	RAG Status	Systems and processes that are in place and operating that mitigate this risk	Additional actions required to mitigate this risk further	For each further mitigating actions a completion date must be provided	Impact	Likelihood	RAG Status
Programme Risk Register											
National Director: Commissioning Strategy Supported by: National Medical Director	**1**	**There is a risk that continued uncertainty may compromise the safety, quality, resilience and viability of services until the future configuration of the service is established.**	**4**	**3**	**AR**	1. NHS England has worked with providers to develop a 'transition dashboard' and this is now being rolled out across the country to give early warning of any emerging concerns and to allow commissioners and providers to respond promptly whenever concerns arise. 2. NHS England continues to drive an ambitious timeline to bring the period of uncertainty to an end as soon as possible.	Continue to progress the review at pace whilst being as open as possible, and maximising opportunities for engagement. The programme board and task and finish groups were updated on the transition dashboard in June. Further discussions will be held in relation to the potential to share this data in future.	ongoing	**3**	**3**	**A**
National Director: Commissioning Strategy Supported by: National Medical Director	**2**	**There is a risk that continued uncertainty for patients, families and staff may lead to concern about the future of particular units and the implications for individuals.**	**3**	**3**	**A**	1. Ensuring good communication and stakeholder engagement are at the heart of the review and that stakeholders are informed about the process, it's aims, objectives and ways of working and are enabled to participate in that process in a way that suits them. 2. Bi-monthly meetings of the engagement and advisory groups continue and a joint meeting of all 3 groups is taking place in July 2014. Visits to all paediatric surgical centres along with an opportunity to engagement with local patient and public groups have taken place.	Revision of stakeholder communications and engagement plan to ensure all stakeholder groups are identified and well informed. Development of a detailed communications grid for the lead up to consultation will ensure all stakeholders are engaged and up to date, and understand the details of the consultation. Plans are in development for engagement during consultation.	ongoing	**2**	**3**	**AG**
National Director: Commissioning Strategy Supported by: National Medical Director	**5**	**There is a risk that the review will not achieve the required level of stakeholder engagement and ownership of the processes and proposals of the review leading to mistrust of or opposition and delaying needed service improvements for patients.**	**4**	**3**	**AR**	1. Continuing to work closely with colleagues in the Patients and Information Directorate. 2. Communications and engagement plan drafted and considered by the Programme Board at its meeting on 21 October 2013. 3. A further update presented to the programme board in February 2014 to advise of the detail of the engagement currently taking place and planned.	The stakeholder communications and engagement plan to be constantly reviewed and updated following dialogue with stakeholders - reflective of how they want to be engaged.	ongoing	**3**	**3**	**A**
National Director: Commissioning Strategy Supported by: National Medical Director	**6**	**There is a risk that any proposed solutions will be formally challenged, for example through judicial review or referral to Secretary of State, delaying needed service improvements for patients.**	**3**	**3**	**A**	1. Open and transparent approach - bi-weekly blogs, new congenital heart disease (CHD) webpages, publishing all meeting papers etc. 2. Supplementary publication scheme for the new review approved by the Programme Board at its meeting on 21 October 2013. 3. Ensure both the new standards and specifications are created in collaboration with all established programme engagement groups and all established NHS England specialised commissioning groups.	Progress work to ensure that all information / documents are published in line with the agreed supplementary publication scheme. Continue to maintain an extensive plan of engagement and communications activity with all stakeholder groups. Advice has been taken from the NHS England Legal team. Areas of the commissioning process which may require legal advice have been identified and will be progressed as the commissioning and change model work develops.	ongoing	**3**	**2**	**AG**
National Director: Commissioning Strategy Supported by: National Medical Director	**7**	**There is a risk that if a challenge was raised against the programme (see risk 6) it could be successful if best practice in all processes has not been followed.**	**3**	**2**	**A**	1. Reflecting on the lessons learned from the challenges brought against the safe and sustainable process. 2. The new review is taking into account the recommendations made by the Independent Reconfiguration Panel (IRP) in their report and the Judicial Review. 3. Commitment has been made by NHS England to not leave all the key decisions until to the end of the process wherever possible. 4. The NHS England specialised commissioning process for the development of new service specifications is being followed and best practice standards will be consulted on and agreed before consideration is made as to how these can practically be applied. 5. Stakeholders are being engaged at every stage in an open and transparent way to allow input to the process in addition to the content of the review.	Ensure that all opportunities are taken to streamline governance processes to ensure the fastest possible route to consultation can be achieved whilst enabling all stakeholders and appropriate governance groups to input pre-consultation. Seek expert advice on the review's processes (e.g. Legal, Monitor, scrutiny) - as part of increased focus on Objective 4 (commissioning & change model). Undertake equalities analysis (including impact on protected characteristics groups and health inequalities).	July 2014 ongoing July 2014	**2**	**2**	**AG**
National Director: Commissioning Strategy Supported by: National Medical Director	**8**	**There is a risk that as NHS England is not the commissioner for the third tier in the proposed service standards, this may result in extended timescales to deliver change, or an inability to fully implement the new service model and standards.**	**4**	**3**	**AR**	1. Resource now identified to lead the engagement with Area Team commissioners and providers (update June 2014).	NHS England to work closely with CCG's to ensure that changes can be implemented across the pathway. Programme team to engage more closely with specialised commissioning colleagues to ensure handover to commissioning is seamless and that expert commissioners are advising on the implementation of standards for service areas outside of NHS England's direct commissioning reach.	End 2014 Oct 2014	**4**	**2**	**A**
National Director: Commissioning Strategy Supported by: National Medical Director	**9**	**There is a risk that the new standards and specifications result in higher cost services which will conflict with current work underway to reduce costs across all specialised service areas, which may result in the funding being unavailable to implement required changes.**	**3**	**4**	**AR**	1. An initial financial impact assessment is being carried out assessing areas of cost pressure within the standards and current delivery costs. - This initial assessment will now contain a much higher level of detail including modelling potential financial impact of all standards (update June 2014).	Consideration later in the review process will need to be made as to the likely cost of implementation of best practice standards by working closely with providers to understand costs, undertaking further financial assessment of the new standards, understanding the relationship and trade offs between higher standards, number of centres/access, payment systems and risk sharing and the impact of rising activity levels.	End 2014	**3**	**3**	**A**

Risk Owner	Risk Ref	Potential Risk Description	Current Risk Score (note 1)			Mitigating Actions in Place	Further Mitigating Actions	Completion Date for Actions	Anticipated Risk Score Following Mitigation (note 2)		
			Impact	Likelihood	RAG Status	Systems and processes that are in place and operating that mitigate this risk	Additional actions required to mitigate this risk further	For each further mitigating actions a completion date must be provided	Impact	Likelihood	RAG Status
National Director: Commissioning Strategy Supported by: National Medical Director	11	**There is a risk that clearance to consult on standards is delayed because of POC/CPAG uncertainty about the requirements of the financial impact assessment.**	4	3	AR	1. Working with NHS England finance to clarify requirements and quality assure the initial financial impact assessment.	Ensure that the requirements and clarified and then met in order that the POC board and CPAG can recommend to the DCSC that consultation is launched as per the target timeline. Work continues with stakeholders of POC and CPAG, however there remains a significant risk that the financial impact assessment may not be approved.	Sept 2014	4	2	A
National Director: Commissioning Strategy Supported by: National Medical Director	12	**There is a risk that a need to replicate a similar governance process to that required to launch consultation, prior to providing a formal public response to the consultation, will result in a delay to respond until after the general election.**	3	3	A		Define the work required post consultation in order to produce a formal public response and review this with specialised commissioning colleagues in order to develop an achievable plan.	Sept 2014	3	2	AG

Note 1 - Current risk score An assessment of the risk as it is today, taking into account the mitigating actions already completed and controls in place.

Note 2 - Anticipated risk score following mitigation An intended score to be achieved following the completion of all the further mitigating actions.

New congenital heart disease review: Programme Issue Register

Issue Owner	Issue Ref	Risk Ref	Date Reported or Escalated	Issue Description	Action already taken Actions taken to date	Actions to be taken Additional actions required to further address this issue	Completion Date for Actions For each further mitigating actions a completion date must be provided	Status
Programme Risk Register								
National Director: Policy Supported by: National Medical Director	**1**	**3**	**Programme Board March 2014**	**Due to the complexity and scale of the review and the need for broad and deep engagement it will not be possible to deliver implementable solution by June 2014 as initially recommended by the NHS England Board.**	The Task and Finish Group of the NHS England Board have been advised of the latest timeline scenarios and the expectation that NHS England will commission against the new standards and specifications in 2015/2016 following a full 12 week public consultation. The latest timeline scenarios have been made public on the blog and further updates will continue to be made available as and when appropriate. Risks 1 and 2 which are associated with the length of time the review process takes will continue to be closely managed. New CHD review current expected timelines for consultation are published within the NHS England business plan. Updated timeline issued to programme board June 2014.	Best case scenario **baseline** timeline to be agreed with the Programme Board and NHS England board Task and Finish Group for reporting against in future. Request to close this issue once the new baseline has been formally signed-off by the programme board. Programme Board agreed to close this issue following the 'end of year one' report which will go to the NHS England Board in June. **ISSUE CLOSED: Paper submitted to the NHS England board June 2014.**	30/06/2014	**Closed**
National Director: Policy Supported by: National Medical Director	**2**	**10**	**Programme Board June 2014**	**The initial financial impact assessment has not been delivered as per the target timeline. At present no resource is available to deliver the impact assessment and it is therefore on hold.**	NHS England Finance directorate have been approached and have: 1. allocated resource to quality assure the output of the financial impact assessment 2. begun looking to identify and secure resource from a Commissioning support unit (CSU) or area team to support the delivery of the financial impact assessment.	Further resource must be identified to lead the development of the financial impact assessment. The programme board will be asked for support in ensuring resource is made available. **ISSUE CLOSED: Finance resource has been identified via a Commissioning Support Unit (CSU) and an initial draft have been prepared for submission to the Programme Board in July 2014.**	20-Jun-14	**Closed**

HIGHLIGHT REPORT to the PROGRAMME BOARD

SRO: Professor Sir Bruce Keogh, National Medical Director
Programme Director: Michael Wilson

KEY UPDATES SINCE LAST MEETING OF PROGRAMME BOARD:

- Patient and Public Group meeting on 13 June 2014
- Clinical Advisory Panel meeting on 18 June 2014
- NHS England's Board Task and Finish Group meeting on 23 June 2014
- Attendance at the Specialised Commissioning Oversight Group on 22 July 2014
- Joint meeting of the review's three engagement and advisory groups on 25 July 2014
- Specialised commissioning governance group requirements clarified and planned
- Plans for consultation during engagement developed
- Additional trust visits scheduled for Professor Deirdre Kelly and team to Blackpool on 30 July 2014, Brighton on 13 August 2014, and Papworth on 15 August 2014
- Meeting confirmed with bereaved families in Bristol for 7 August 2014

KEY RISK

Description	Current residual risk rating
There is a risk that clearance to consult on standards is delayed because of POC/CPAG uncertainty about the requirements of the financial impact assessment. The programme team will ensure that the requirements are clarified and then met in order that the POC board and CPAG can recommend to the DCSC that consultation is launched as per the target timeline.	**Amber / Red**

ISSUES

Description
• No current reported issues.

NEXT STEPS:

COMMS AND ENGAGEMENT: A full and detailed plan for engagement during consultation is in development.

FUTURE KEY MEETINGS:

29 July 2014: **Programme of Care Board** (for update)
20 Aug 2014: **Programme of Care Board** (for approval/recommendation to CPAG)
1 Sept 2014: **Board Task and Finish Group of the Board**
2 Sept 2014: **Clinical Priorities Advisory Group** (for approval to consult)
By 5 Sept 2014: **Directly Commissioned Services Committee** (by correspondence)
8 September 2014: **Programme Board**

SUPPORT REQUIRED:

The Programme Board is asked to:

- approve next steps for both the assurance process and for preparation for consultation; and
- advise and support on management of risks.