New Congenital Heart Disease Review

Data, analysis and evidence

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Evidence for standards

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Evidence to inform the service standards

- A key source of evidence for this review is advice from experts; patients; providers and clinicians.

- We are gathering this from our groups and wider engagement.

- In addition to this we have:
    - commissioned a systematic literature review; and
    - asked NICOR to investigate their data.

Literature review

- We have asked the NHS National Institute for Health Research (NIHR) to commission a literature review under their Health Services & Delivery Research (HS&DR) Programme.

- This programme is contracting with The University of Sheffield, School of Health and Related Research (ScHARR) who have expertise in academic literature reviews of health care service design.

- ScHARR, on our behalf, will undertake a review of the literature to understand how organisational factors may affect patient outcomes.

Literature review questions

ScHARR will focus on two key areas:

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

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

Literature review approach

- ScHARR will review:
  - papers since 2003, looking further back if few papers
  - papers on congenital heart disease services for children and adults, and if there is a lack of these, papers on other clinically similar services as feasible and where relevant.

- ScHARR will apply inclusion criteria to papers – details in their final proposal which is available via the blog.

- If you know of any relevant papers please provide us with the full references.

Literature review report

- ScHARR will provide NHS England with a draft report on 1 April 2014.
- This will then need to be subject to ScHARR's peer review and quality assurance processes.
- This timeframe means we will be able to revise any standards in light of the additional evidence .

NICOR data analysis

- The National Institute for Cardiovascular Outcomes Research (NICOR) run the Congenital Heart Disease Audit using patient information collected by the Central Cardiac Audit Database (CCAD).

- We have 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.

- We are currently in discussion with them about what can be delivered.

NICOR data analysis

- As it stands, NICOR have advised they could provide analysis of the following:

By 30 April 2014 –

The association between 30 day mortality rates and:

- ✓Patient ethnicity
- ✓Patient deprivation
- ✓Volumes of procedures by unit
- ✓Procedure and complexity

Possible, would require further discussion–

The association between 30 day mortality rates and:

- ✓Volume of procedures by surgeon
- ✓Patient proximity to surgical unit
- ✓Timing of procedures

Not feasible –

- ✗Analysing any association between 1 year mortality rates or other outcome measures and any other factor
- ✗Proximity to related services (patient time to access)

NICOR data analysis

- There are limits to this analysis which mean there are risks to be addressed in interpreting any future results:
  - Outcome measures are restricted to mortality which is quite crude, unlikely to see as much variation as morbidity.
  - Any analysis could only show association not causality (and there may be some complicated inter-relationships).
  - The amount of data may be insufficient to give reliable (statistically significant) answers.

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Activity Analysis

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Activity analysis

The aim of this activity analysis is to estimate how much specialist inpatient congenital heart disease care NHS England will need to commission up to 2025.

Activity analysis – Initial analysis

- This analysis requires data from a number of sources, in particular for data on activity relating to adults.
- There have been delays in obtaining some of this data, as a result we have progressed analysis of children's activity using data from NICOR's congenital database (the aim is to have the equivalent analysis for adults activity over the next month or so).
- This initial analysis is to provide a building block for further analysis and to facilitate discussion and engagement about what should be considered when forecasting demand for future services and what can, and cannot be, modelled.
- The projections here will be superseded as the analysis evolves and is subject to further discussions, scrutiny and quality assurance. The projections in this paper do not form a final understanding of how much activity NHS England will need to commission in the future.

Activity analysis – Initial analysis

The coverage of the analysis so far…

Baseline year	2012
Population	England residents, aged 0-16 – (Children) (includes private patients)
Procedures included	Surgical and catheter interventions reported to NICOR/CCAD congenital database - (All bypass and non-bypass procedures, excluding minor and non-cardiac procedures)
Historic data	2003-2012
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 congenital database • ONS 2012 based projections for England • ONS 2011 based subnational projections by local authority

Activity analysis – changes over time

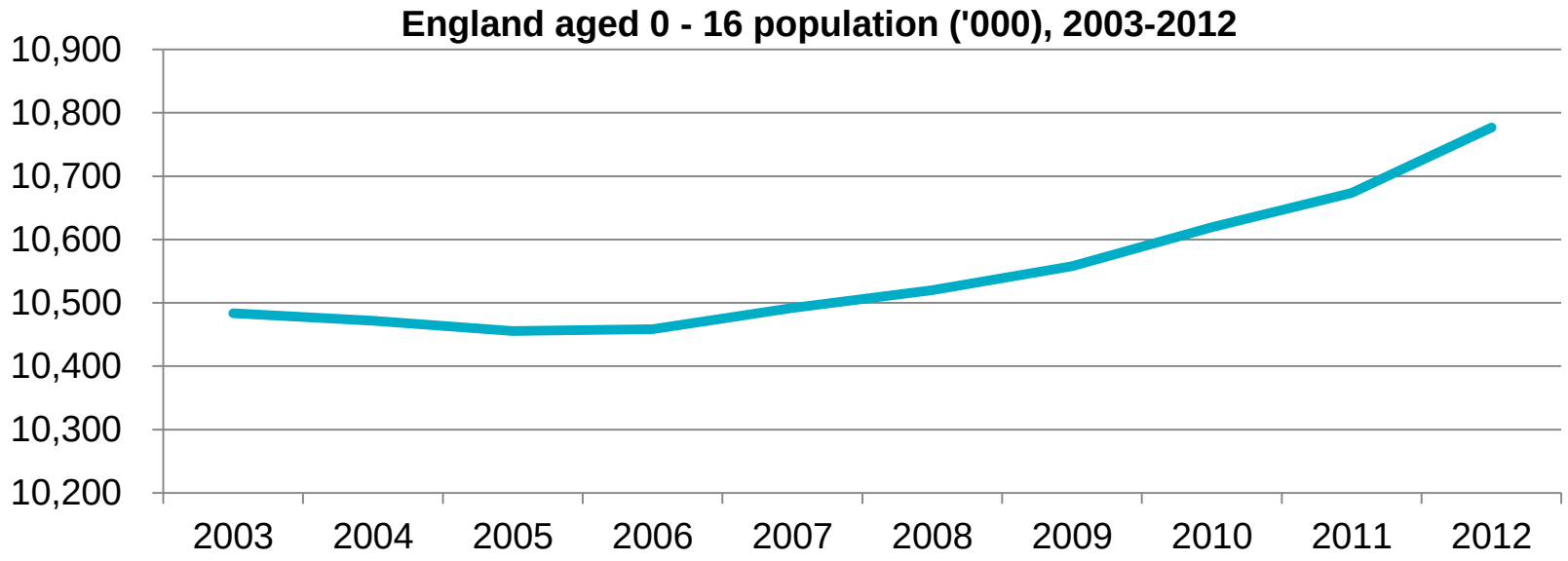
- Using NICOR data we have estimated the number of congenital heart disease procedures on children living in England from 2003-2012

	Actual data: NICOR/CCAD Congenital Database										
Year	2003	2004	2005	2006	2007	2008	2009	2010	2011	2012	Change
Procedures (surgeries and catheterisations)	4,670	4,440	4,650	4,850	4,620	4,800	5,060	5,200	5,330	5,430	+16%

- Between 2003 and 2012 the number of procedures has increased – around 16%

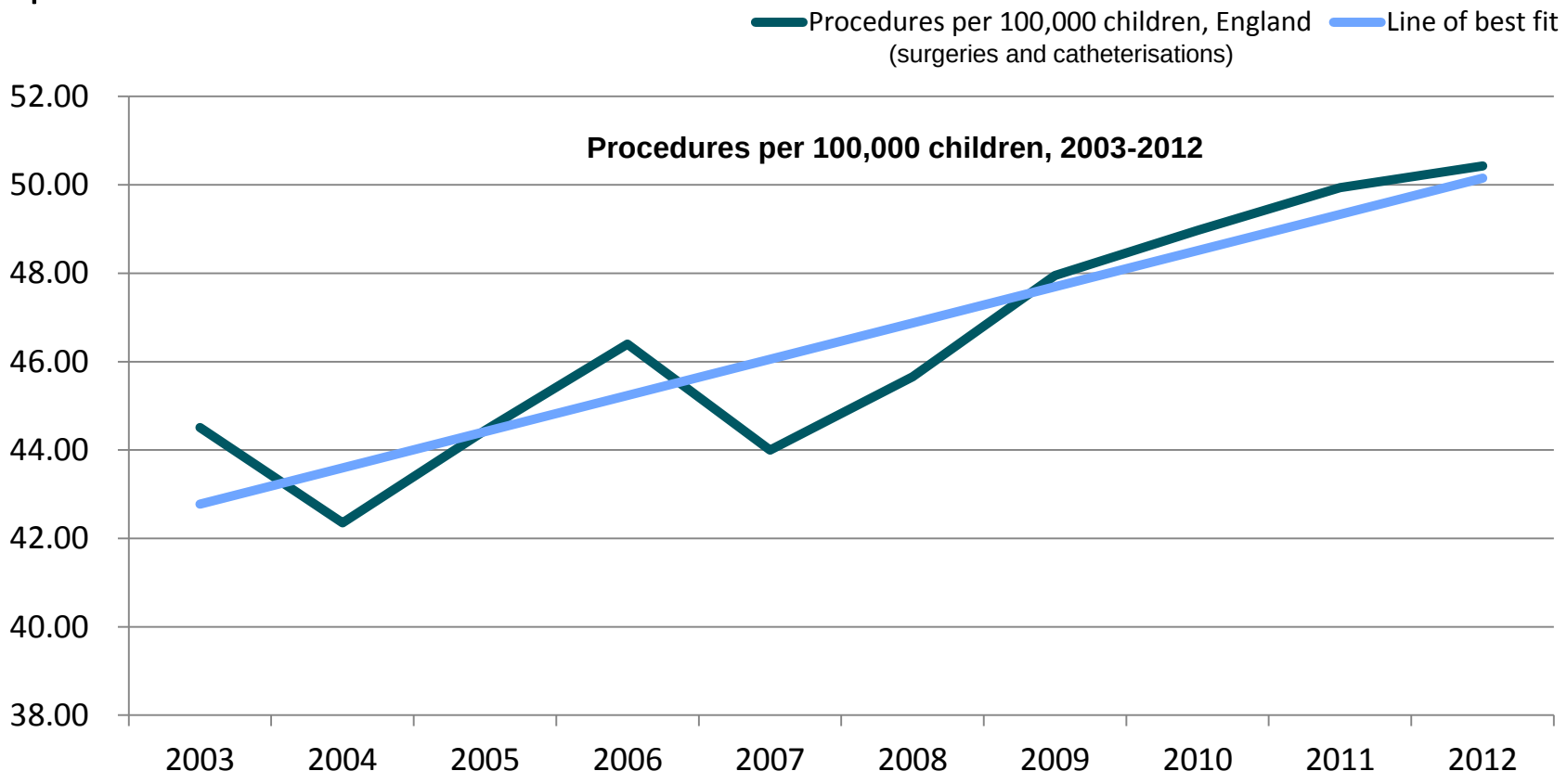
0 – 16 population – changes over time

- Around 3% of this growth can be accounted for by an increase in the number of children in England over the period; population growth in 0-16 year olds



Activity analysis – changes over time

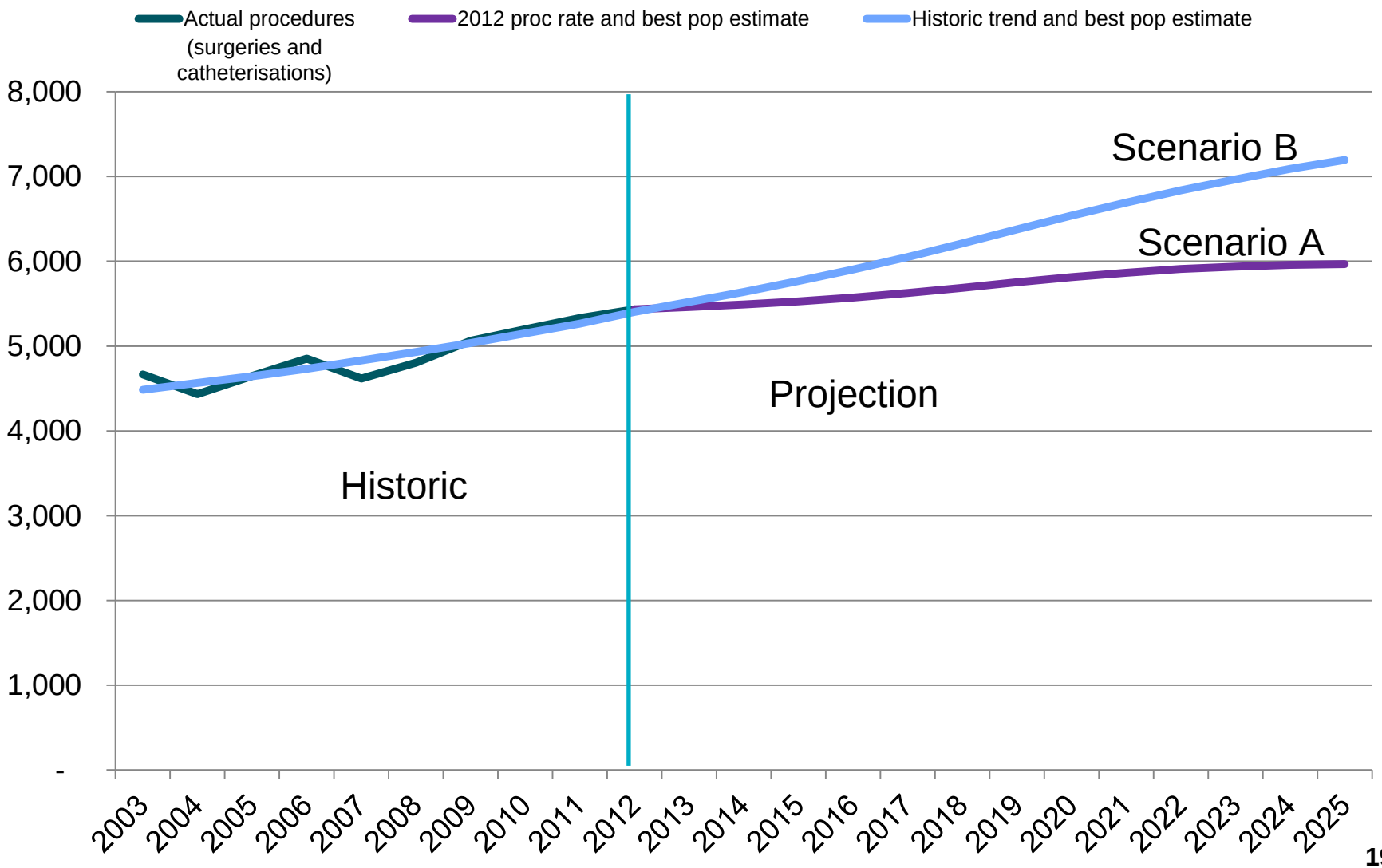
- But the number of procedures per head has grown by around 13% over this period



Activity analysis – future scenarios

- This suggests that forecasting future demand on population projections alone could underestimate future procedure numbers for children.
- However, we do not yet know what has driven the change in procedures per head over time.
- So we have just looked at 2 basic starting scenarios:
  - Scenario A: No change in procedures per head from 2012, only pressure is increase in number of children in England.
  - Scenario B: As A but allow number of procedures per head to increase as it has in the past.

Activity analysis – future scenarios



Activity analysis – future scenarios

- A more complex forecast will involve understanding what is driving the changes over time.

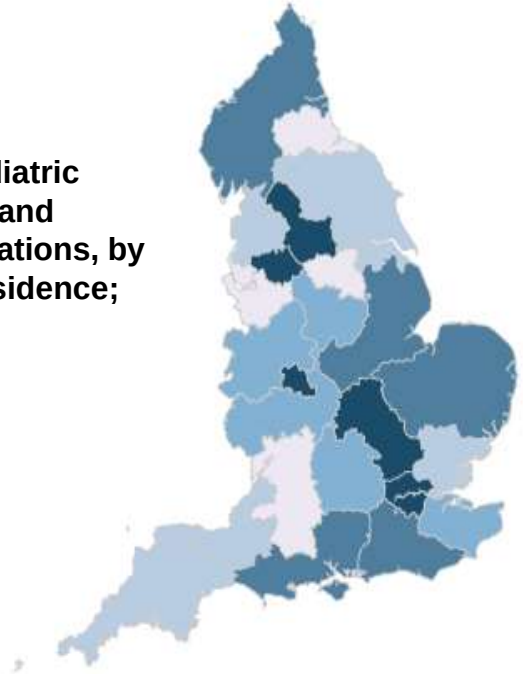
- We can then forecast each of those drivers going forward based on more specific assumptions.

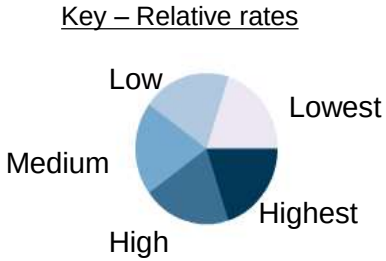
- This work will require clinician and patient input and we are aiming to be undertaking this in April-May 2014.

Activity analysis – sub national analysis

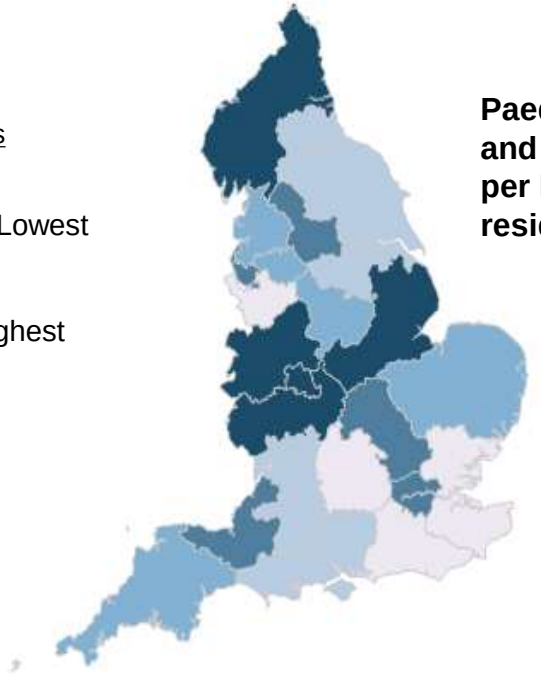
- As well as differences over time there are differences in areas across the country, even when accounting for population size.

Total paediatric surgeries and catheterisations, by patient residence; 2012





Paediatric surgeries and catheterisations per head, by patient residence; 2012



Activity analysis – future scenarios

- A more complex forecast will involve understanding what is driving the differences across the country.

- Again, we can then forecast each of those drivers going forward based on more specific assumptions.

- This work will require clinician and patient input and we are aiming to be undertaking this in April-May 2014.

Activity analysis – immediate next steps

- The above analysis needs extending to cover patients from Wales, and adults.
- The above considers procedure numbers only and needs to be repeated for other currencies of activity (patients, bed days and resource use).
- We also need to sense check across data sources.
- Then as mentioned we need to refine and test more complicated scenarios based on a better understanding of the observed changes over time and across the country.

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Impact Analysis

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Impact analysis – pre-consultation

- To accompany the consultation on standards we will provide an initial indication of the potential cost pressures.

- We will also provide an initial indication of any equality impacts.

Impact analysis – future work

- Once we have agreed standards and understand likely future activity we need to consider the full implications on any future service.

- At that stage we will assess the impact of future service proposals but this work cannot be done in advance.

Impact analysis – future work

- We will undertake capacity modelling and impact assessment of future services on all providers, patient groups, and interrelated services.

- This will involve:
    - agreeing an approach and obtaining the data;
    - analysing service options that meet forecasted demand and deliver standards and analysing patient flows; and
    - assessing workforce, affordability and value for money implications.

Impact analysis – questions

- Do you agree with our approach?
- What is useful and helpful to include in the partial impact assessment?
- Are there any gaps in what we are proposing? If yes, what are they?
- Can you suggest colleagues who could help us with this piece of work?

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NHS England

Further Analysis

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Further analysis

- We will be discussing with others (such as NICOR) how we can improve existing performance and outcomes data.

- We will undertake analysis to understand the performance variation in antenatal and neonatal detection rates.