

Initial analysis – scoping note

1. Analytical support is required to support the new Congenital Heart Disease review. In scope of this review is all adults' and children's cardiac surgery for congenital heart disease in England¹.
2. Initially we propose to:
 - a) set out the historic and current prevalence and incidence of congenital heart disease, and consider the likely future trend;
 - b) set out volume and characteristics of current cardiac surgery activity for congenital heart disease in England (including patient population characteristics and geographic spread); and
 - c) set out a number of “what if” scenarios for future activity, including:
 - demographic pressure only (population growth and changes in age, gender and ethnicity mix);
 - demographic pressure plus continuation of historic trends in prevalence and activity; and
 - other scenarios following discussion with clinician(s) e.g. changes in future incidence and prevalence and changing clinical practice.
3. We will seek to deliver the above in autumn 2013. Delivery is dependent on step a) below. The key risk to this work is the quality of the data we draw down and ensuring we capture the relevant activity– we need to work with a clinician as soon as possible to mitigate this risk.
4. To deliver the above we will take the following steps:
 - a) Obtain the necessary data (by October 2013 – now by November 2013)
 - Work with clinician(s) to understand relevant population variables, data sources and clinical codes for interrogation of HES.
 - Access National Institute for Cardiovascular Outcomes Research (NICOR) data and compare with HES.
 - Speak to Public Health England (PHE) cardiovascular disease leads.
 - Review of academic literature and trials.
 - b) Establish the baseline (October/November 2013 – now December 2013)

¹ Whether or not Wales, Scotland and Northern Ireland activity and populations should be included and to what extent is yet to be decided

- Set out and describe current activity based on cross sectional data obtained
- c) Model future activity projections (November 2013 – now January 2014)
- Conduct simple time series analysis of population trends and historic trends in congenital heart disease activity
 - Consider other relevant variables and trends that make impact congenital heart disease surgical activity in the future
 - Basic high level modelling of four to five feasible scenarios for future activity
 - Sensitivity analysis of assumptions
5. The above will be subject to the following quality assurance processes:
- Regular sharing of outputs and discussion with policy leads and clinical experts
 - Internal peer review (other analysts and experts)
6. Once the above initial analysis is complete we will consider what, if any, further analysis is required, such as:
- More complex/detailed modelling of the above
 - Modelling of supply side constraints (e.g. specialist workforce, minimum volume of surgery per consultant)

UPDATE: 20/09/13

7. Work to obtain the necessary data (step a). above) is well under way. Specifically:
- Initial literature review has been undertaken.
 - ONS 2011 based subnational population projections have be obtained.
 - Relevant leads in PHE have been contacted – a lot of information they have relates to cardiovascular disease in general rather than congenital heart disease specifically but they are going to look into this to see what else is available.
 - Relevant clinicians have been contacted.
 - An initial list of relevant diagnoses and procedures for congenital heart disease have been shared with clinicians for review.
 - A draft HES specification has been shared with the Information Centre (owners of HES data) and clinicians for review.
 - It is agreed that the proposed analysis will be discussed at the next clinical advisory panel meeting on 15 October 2013.
8. Obtaining the data (step a) is taking longer than initially envisaged as there are multiple parties and sources of information to engage. However, as this step is critical to the overall quality of results we will take the time necessary.

9. Once we have the agreed data specification it may take up to two weeks for the data to be extracted. Obtaining the data (necessary to start the analysis) by mid to end October 2013 is looking the most likely timescale at this stage. As a result much of the analysis may be undertaken end of October and November 2013.

10. The immediate next steps for the next two weeks are:

- Access NICOR data
- Receive relevant information and contacts from PHE
- Receive clinician views on proposed list of diagnoses and procedures
- Agree final list of diagnosis and procedure codes
- Receive clinician's views on draft HES specification
- Agree final HES specification

UPDATE: 11/10/13

11. Further work to obtain the necessary data (step a. above) is well under way. Specifically:

- I have dialogue with clinicians who are providing clinical advice on the list of relevant diagnosis and procedure codes required for the analysis. In particular:
 - Dr Kate English (a consultant in Adult Congenital Heart Disease at Leeds Teaching Hospitals NHS Trust) has provided initial advice
 - Dr Rodney Franklin (the Clinical Lead for NICOR Congenital Audit and a Consultant and Lead Paediatric Cardiologist at Royal Brompton & Harefield NHS Trust) has provided initial advice. He is providing further advice on a list updated for his comments over the next few days.
 - Other clinicians contacted have indicated that Dr Rodney Franklin is the expert on clinical coding in this area.
- I have shared a draft list of codes with the Information Centre so they can understand the likely size of the HES data request.
- I am seeking access to other data sources that are highly regarded by the profession; NICOR and SCTS data.
- The proposed analysis and initial list of diagnosis and procedure codes was shared publicly via the John Holden's 7th blog update.
- It is agreed that the proposed analysis will not be discussed at the next clinical advisory panel meeting on 15 October 2013 as it is not the appropriate audience. Instead the analysis will be presented to the programme board on 13 November 2013.
- The scope of the review will be discussed at the CAP on 15 October 2013 and this will directly influence the scope of the analysis and the relevant diagnosis and procedure codes (for example surgical vs. non-surgical, congenital vs. acquired paediatric diseases).

12. The immediate next steps are:

- Access NICOR and SCTS data
- Agree final list of diagnosis and procedure codes

- Agree final HES specification
- Submit HES data request

UPDATE 26/11/13

13. Work to obtain the necessary data (step a. above) is nearly complete. Specifically:

- The scope of the new review has been agreed, and this informs the scope of the analysis.
- The Programme Board agreed the proposed approach for the activity analysis
- The high level definition of the scope for analysis has been checked and agreed as “specialist inpatient care for congenital heart disease” which is to be defined as “all cardiac and intrathoracic great vessel procedures carried out in patients under the age of 16 years, and all adults where they are performed for a cardiac defect present from birth”.
- Based on this high level definition, I have list of relevant diagnosis and procedure codes required for the analysis and these are being tested with the congenital heart disease clinical reference group (CRG). There may be procedures included which we later want to exclude but this is straightforward once we have the data.
- I have applied for the data from NICOR CCAD and they are working to provide it by the end of November 2013.
- Once we have this data we will seek the SCTS data to fill the gap for adult activity.
- On receipt of the NICOR data we will begin to estimate the current baseline of activity (step b. above).
- I have applied for the HES data. This is currently awaiting approval by the HSCIC before the data extraction exercise can begin – this has been delayed due to volume of work at the HSCIC.

14. Work to think about how to model future activity (step c. above) has begun. Specifically:

- An operational research analyst has joined the work and is investigating various modelling options.
- We are considering the potential drivers of future activity and the available data

15. The immediate next steps are:

- Receive NICOR CCAD data
- Access equivalent data from SCTS
- Start estimating baseline activity (step b.)
- Receive comments from congenital heart disease CRG on the list of procedures considered in scope of analysis – adjust analysis and data accordingly.
- Set out drivers of future demand and investigate other data sources (step c.)
- Consider analytical approaches to modelling future demand (step c.)