Objective 5 – Phase 1 Report

To establish a system for the provision of information about the performance of congenital heart disease services to inform the commissioning of these services and patient choice.

Contents

Contents ........................................................................................................................................... 1
1 Background .................................................................................................................................... 2
2 Approach ...................................................................................................................................... 2
3 Sources of information .................................................................................................................. 3
4 Activity/Finance ............................................................................................................................ 4
5 Mortality ......................................................................................................................................... 6
6 Morbidity ......................................................................................................................................... 10
7 Quality of Life ............................................................................................................................... 12
8 Patient Experience ......................................................................................................................... 14
9 Reporting ....................................................................................................................................... 16
10 Conclusion ..................................................................................................................................... 17
11 Next Steps .................................................................................................................................... 18
1. Background
Throughout the review we have heard that work is needed to develop the information provided to both patients and commissioners about the performance of congenital heart disease services. There are also other stakeholders, such as networks, clinicians and managers, who have a legitimate interest in better information on congenital heart disease services. Clinicians, providers, charities and patient groups have all identified that the data currently available regarding congenital heart disease services is not sufficient and that work is needed to develop the accuracy, reliability and usefulness of information about the performance of CHD services.

This issue was raised in the Independent Reconfiguration Panel’s review of the Safe and Sustainable review which made two specific recommendations relating to information. These were

- **NHS England must establish a systematic, transparent, authoritative and continuous stream of data and information about the performance of congenital heart services. These data and information should be available to the public and include performance on service standards, mortality and morbidity; and**

- **NHS England and the relevant professional associations should put in place the means to continuously review the pattern of activity and optimize outcomes for the more rare, innovative and complex procedures.**

2. Approach
This report documents the findings from the first phase of the work on this objective and covers the following areas:

- the current information being provided on congenital heart disease services;
- what we heard from those currently using the information; and
- Potential areas for development to improve the information provided.

Members of our Clinician, Provider and Patient and Public engagement groups were invited to comment on the currently available information. In addition to these discussions we also met with people currently involved in collecting, analysing or using information on congenital heart disease. A full list of people/groups consulted as part of the preparation of this report can be found in Appendix A of this report.

This report presents an analysis of the gap between the information currently available and that required by patients, commissioners and other stakeholders.

Phase two, working with relevant stakeholders, will develop proposals for addressing the gaps identified. This will include making specific recommendations and producing action plans to describe the process and timeframes for making this information available.

The report begins by describing the key sources of information and is then separated into six sections to reflect five largely distinct areas of information which were highlighted throughout our discussions and a general concern which applies to all areas about the way information is made available.
3. **Current Sources of Information**

3.1 **National Congenital Heart Disease Audit (NCHDA)**

The NCHDA is performed by the National Institute for Cardiovascular Outcomes Research (NICOR) and reports on 30 day mortality for a list of 57 procedures. This information is published on their website and a report on 30 day mortality is produced for paediatric interventions. The NCHDA reports mortality to provide assurance over the safety of specialist centres and to measure improvement both within centres and nationally. NICOR has been commissioned by HQIP on behalf of NHS England to manage six national clinical cardiac audits until March 2016.

3.2 **Hospital Episode Statistics (HES)**

HES data is the generic data used to record all hospital activity, not simply that for congenital heart disease. Hospitals are required to submit a large amount of HES data and as such have teams of coders who are responsible for coding activity based on the case notes. HES data is largely used by commissioners to establish the activity of centres and inform their payment of providers.

3.3 **Quality Dashboard**

The Clinical Reference Group (CRG) for congenital heart disease has established a ‘Quality Dashboard’ for adult and children’s services. This is part of NHS England’s strategy to provide better information on all specialised services, which has resulted in two batches of quality dashboards being produced to date. The congenital heart disease Quality Dashboard was part of the second batch of quality dashboards, which were due to be implemented from April 2014. However, due to NHS England going through a procurement exercise for the management of these dashboards, the launch of the congenital heart disease dashboard has been delayed and no quality dashboard information has yet been published. Data will be submitted on a quarterly or annual basis.

The Quality Dashboard consists of 15 metrics, four of which are populated from NCHDA data, one of which is from CQC submissions, four of which are based on the Somerville Foundation patient experience questionnaire (for adults with CHD) and six of which are submitted directly from the unit. These measures are split into four categories, neonate, infant, child and adult with certain metrics only being required for certain categories.

The Quality Dashboard is intended to provide both commissioners and the public with a broader range of appropriate information to assess the quality of the services being provided by each unit.

3.4 **Transition Dashboard**

The purpose of the Transition Dashboard is to provide a mechanism to test the current health of the system by collecting specific information on defined operational delivery aspects of the Children’s Congenital Heart Services in England. The metrics were developed in the Midlands and East with input from Provider Units. The Transition Dashboard was rolled out to all units during the course of 2013/14 and is now fully operational in all Area Teams.

The Dashboard is completed by the 10 current service providers on a monthly basis. The Dashboard is submitted to the relevant Area Team Service Specialists each month with information relating to the preceding month. The area team review the Dashboard and have discussions with the providers either as part of their normal contract review meetings or as a specific Transition Dashboard discussion.
The aim is for the Area Team to confirm and challenge the data with providers in order to gain assurance that the service is functioning appropriately and that any risks to patient care and safety are identified, mitigated and escalated where appropriate. In addition, following feedback from the Congenital Heart Services CRG, a SitRep process has been established, led by the Congenital Heart Accountable Commissioner. The purpose of the call is to ensure that there is national triangulation of any issues which may be emerging from the Transition Dashboard, to verify that the Dashboard has been returned and reviewed by the Area Team and to identify any issues which require escalation.

The Transition Dashboard consists of 15 operational metrics designed to enable commissioners to establish if there is significant strain on paediatric centres. The dashboard was intended to give longitudinal comparisons for an individual service, not to provide comparison between children’s centres or to provide the public with a view of the quality of any particular centre. As a result the metrics involved have not been subject to tight definition.

4. Activity/Finance

4.1 Current Provision

Two of the sources of information described above are important for measuring CHD activity: the NCHDA and HES.

National Congenital Heart Disease Audit (NCHDA)

The NCHDA collects information on interventional activity relating to three areas:

- Catheter Interventions
- Bypass Surgery
- Non Bypass Surgery

This information is submitted by the Trusts and then validated by NICOR through visits to the centres, during which they check a sample of entries with the hospital records in order to confirm that appropriate information has been recorded. They currently capture all paediatric (0-15 years old) interventional activity and an estimated 80% of the adult (16+) interventional activity. This shortfall occurs because a number of providers of adult CHD services (including some of the biggest providers) do not make returns to NICOR, though they may participate in other audits. Participation in the NCHDA is now mandatory for all centres in England as set out in the NHS contract. Section 26.1 (26.1.2) states that the provider must “participate in the national clinical audits within the National Clinical Audit and Patient Outcomes Programme (NCAPOP) relevant to the Services.”

NICOR does not collect any information on non-interventional activity. This means outpatients as well as patients who do not get to treatment or who do not undergo one of the procedures captured by the NCHDA are not included in the audit. The information from the audit does not play any role in determining the income that provider trusts receive for their activity.

Hospital Episode Statistics (HES)

HES Admitted Patient Care (APC) data is the data which records congenital heart disease activity and is based on two levels of codes entered by coders within each hospital.

- OPCS codes are used for classifying interventions/procedures and therefore identify the specific activity performed at the hospital.
Item 9

New Congenital Heart Disease Review

- ICD (International Classification of Diseases) codes are used to record the diagnosis of the patient to whom the activity relates. Patients may have multiple diagnoses and therefore multiple ICD codes applied to them.

The combination of the OPCS and ICD codes place the activity within a specific Healthcare Resources Group (HRG) each of which results in a particular tariff being paid to the provider trust. OPCS and ICD codes are then filtered using a list of codes called the 'Identification Rules' developed by NHS England to determine whether the activity is specialised or not. Specialised activity is paid for by NHS England as the national commissioner and non-specialised activity by local Clinical Commissioning Groups (CCGs). The lack of granularity within the ICD codes makes the identification of congenital heart disease activity problematic. This was especially apparent in adult congenital heart disease, where identifying activity relating to congenital heart disease, as opposed to acquired heart conditions, was often difficult.

While activity is measured at episode level, payment is made using ‘spells’ which may include a number of episodes which are then sorted into a hierarchy to determine how the spell is categorised. As such, some congenital heart disease activity may not be included in the congenital heart disease ‘spells’ which are paid.

4.2 What we heard

The validation of the paediatric and adult information submitted to NICOR for the NCHDA was seen as an important part of ensuring the accuracy of the activity reported through this audit. The accuracy was considered high due to the data entry being performed by clinicians. The activity reported through this system was considered to accurately reflect the interventional activity performed within the hospitals who currently reported their activity to the audit. Despite the requirement within the NHS contract for all providers to submit information to the appropriate national clinical audits this is not currently pro-actively enforced by commissioners.

There was some concern that the list of procedures reported through this audit (57 in the annual report for 2010-13) was not comprehensive enough, meaning that some activity for more infrequent procedures was not reported at all. Whilst statistical analysis of these procedures may be problematic, due to the low number of procedures, it was generally considered that these should still be reported to enable users to identify where these procedures are performed and their outcomes. Patients stated that this would help them to identify centres which are more experienced in these rare procedures and avoid concerns over the competency of their local centre to perform these procedures.

The accuracy of HES data was regarded as of a lower quality than that reported through the NCHDA. The fact that the data was entered by coders, who were not clinically trained, was seen as a key reason for the inferior quality of this information. There was a significant concern that outpatient activity for congenital heart disease was still not being captured consistently in HES data and that there was no uniform process for recording this activity. This is because outpatient data is not coded using OPCS or ICD-10, but rather treatment function codes for which adult congenital heart disease falls into the more general group of adult cardiac of which congenital heart disease would only represent a very small part. The coding of critical care data is also an issue as it does not record OPCS and ICD-10 codes so again it is not possible to identify which activity related to congenital heart disease.

The inaccuracies and variances in the information available through HES data made it extremely difficult to identify congenital heart disease activity in its entirety. The issues over the
granularity of the codes, and accuracy of the coders and the activity picked up by the identification rules means that actual congenital heart disease activity is unlikely to be identical to the congenital heart disease activity for which providers are paid.

ICD-11 is currently being developed and includes a larger number of cardiac codes which should enable clearer identification of activity relating to congenital heart disease. As the NCHDA information is generally considered to be more reliable than that reported through HES, certain centres chose to check their interventional activity as recorded in their HES data with that submitted to the audit. This would enable them to identify any inconsistencies between these two data sources and determine whether or not there were any errors which required further investigation or correcting within the HES data. Due to the differences between the information collected using HES data and for the NCHDA there are limitations to the benefit to be gained from comparing HES and NCHDA information.

4.3 Potential areas for development
4a) Percentage of adult intervention activity captured by the NCHDA.
4b) Number of procedures against which outcomes are reported by the NCHDA.
4c) Methodology for coding congenital heart disease activity using HES codes.
4d) Ability to compare NCHDA interventional activity with that reported by HES data.
4e) A process for monitoring and enforcing the submission of information to the NCHDA

5. Mortality
5.1 Current Provision
Mortality information is considered to be the primary measure when judging the quality of congenital heart disease services. Patients may use mortality information for particular centres and procedures to inform their choice of specialist centre, and commissioners will use it to help determine the quality of the services provided by the units from which they are commissioning the service. Mortality information could also be used by clinicians and networks to identify areas where they could improve and inform where learning between centres may be beneficial.

The NCHDA currently measures survival at 30-days after each of the 57 surgical and transcatheter cardiovascular interventions most frequently undertaken to treat congenital heart disease in children for all centres, undertaking major congenital heart disease procedures in England, Scotland, Wales and Republic of Ireland.

Partial Risk Adjustment in Surgery (PRAiS) software has been developed which estimates the risk of death within 30 days of a primary surgical procedure, based on specific procedure, age, weight, recorded diagnoses and comorbidities. The PRAiS model can only be applied to paediatric cardiac surgery.

Each paediatric centre’s actual 30 day mortality rates is compared with those predicted by the PRAiS software. An actual survival/predicted survival ratio is produced which allows actual survival within centres to be compared to that predicted by the risk model. Both aggregate survival rates and survival rates for individual procedures are reviewed to identify if centres have a statistically significant lower survival rate than that predicted either overall or for
specific procedures. Where centres’ actual survival rates are below their predicted survival rate, to a statistically significant extent, letters are written to the hospitals involved as well as the relevant professional societies. Commissioners are not formally informed of this or involved in responding to any divergence.

Annual reports are produced by NICOR which report paediatric 30 day mortality rates for the previous three years (e.g. 2014 report would be for the financial years 2010/11, 11/12 and 12/13). The 2014 report, which included information from 1 April 2010 to 31 March 2013, was not published until 25 September 2014. NICOR state that this delay has been due to it taking them a year to check the quality of data in all hospitals. However, they acknowledge that this delay is too large and have streamlined their visits to larger centres with a view to completing these within 6 months and publishing their report within 12 months. By 2016, NICOR aim to publish results within 6 months of the audit deadline.

Currently the NCHDA do not produce a report on adult 30 day mortality. Unadjusted mortality rates can be reviewed through their website, but no analysis or narrative is provided to help this information be interpreted in a meaningful way. The Review performed some analysis\(^1\) of the adult data to seek an assurance that all centres were working safely. This is not a risk adjusted analysis and so is significantly limited and the results must be treated with caution, but it was concluded that the data did not suggest any providers had results that were meaningful outliers compared to the national average.

The NCHDA website also includes 30 day mortality rates for each procedure to enable a centre’s mortality to be reviewed for specific procedures as well as percentages of patients being treated by surgery or intervention in the first year of their life, who were diagnosed antenatally.

5.2 What we heard

30 day Mortality

The 30 day mortality information which is available is generally considered to be very good. Users of the information are confident that it reports on all paediatric mortality and that steps have been taken to ensure that in future it will be collecting all adult mortality information as well. Assurance that the NCHDA is now collecting information from all centres performing adult congenital heart disease procedures is still required to ensure that mortality rates for all centres are being reported.

Concern was voiced over the provision of unvalidated mortality information by NICOR in 2013 which had presented Leeds General Infirmary as having a lower survival than was actually the case. This had resulted from incomplete data being provided; however, most people were confident that appropriate steps had been taken to reduce the risk of this happening again.

Provider units record their data for submission to the NCHDA using different databases. These were often custom built and, when NICOR’s requirements for data change, each unit needs to arrange for their database to be updated to record the necessary information. One centre told

\(^1\) This was done by determining the range of values around the national average that could be reasonably expected, all else being equal, for each level of activity. Where values are outside this range they are considered statistical outliers compared to the national average. This analysis identified five statistical outliers compared to the national average for the relevant procedure. However, in these five cases the provider has carried out only one procedure and therefore the possible survival rate is constrained to being 0% or 100%. Considering this very low volume, although technically an outlier, the numbers are too small to draw a robust conclusion. Patient factors have not been controlled for and therefore the true outliers may be different.
us that they had concerns that the interface between their systems and NICOR could result in incomplete data extraction into the NCHDA database, so they ran additional checks to ensure that all of the submitted information is included in their reports. Further work is required to understand which systems need to be developed to gain sufficient assurance that the systems used for submitting information to the NCHDA are reliable. Formalising procedures relating to the submission of information, validation, reporting and communication would also be beneficial.

**Longer Term Mortality**

Whilst the quality of the 30 day mortality information based on procedure was generally accepted as an indication of the quality of congenital heart disease services, it was seen as insufficient. Although it is a useful measure, the reliance upon it was largely a reflection of a time where 30 day mortality was considerably worse that it currently is. Advances in surgical techniques, facilities and intensive care have made this a less useful measure than it used to be, as keeping a patient alive for 30 days can now be more straightforward than in the past, making this a less useful measure of any real differences between centres. Some have also been concerned that the intense scrutiny on 30 day mortality could influence clinical practice by acting as an incentive to delay inevitable deaths until after this milestone has passed, or to favour interventions with the best 30 day outcomes rather than prioritising long term outcomes. Measuring longer term mortality could therefore provide very helpful additional information as well as countering this unhelpful incentive.

90 day mortality was seen as having the potential for providing useful procedure based information; however, one year mortality was the measure which was seen as offering the most benefit. There were differing views on whether one year mortality should continue to be analysed by procedure or whether, for longer term mortality rates, it would be more useful to analyse these by diagnosis. There was some concern voiced over the fact that, as the length of the period was extended, other factors such as socio-economic conditions impacted mortality figures, making the link between the quality of the procedure (and aftercare) and the outcome less significant. However, there was widespread agreement that one year mortality information should be provided in addition to the 30 day mortality currently reported. It was noted that one year mortality was a better indicator that a child would survive into adulthood than 30 day mortality and, as such, was a more significant piece of information for parents.

Diagnosis based information was seen as being of value for patients and parents in understanding the mortality outcomes associated with specific diagnoses. However, it was noted that there would be some diagnoses which are so rare that any statistical analysis of outcomes would not be possible. The Clinical Operational Research Unit (CORU) are currently undertaking a project to analyse and report on the long term outcomes of two diagnostic groups. This is due to be completed in the autumn of 2015. This will provide useful information in evaluating both the ease of collecting this information and the degree to which it provides useful information for patients, commissioners or providers of congenital heart disease services.

**Partial Risk Adjusted in Surgery (PRAiS)**

The PRAiS software was generally viewed as a positive addition to 30 day paediatric mortality but it was noted that the methodology has an inherent limit to risk adjustment that could lead to under-estimating the risk adjustment needed for very high risk procedures. The absence of a risk model for adult congenital heart disease means that adult mortality can only be reported in raw form with no adjustments for case mix or other factors. NICOR does not produce a
Item 9

New Congenital Heart Disease Review

comparative safety report for adult CHD centres as a result, simply publishing individual centre and procedure data. This is a significant concern for commissioners and patients.

NICOR have shied away from doing any analysis of adult congenital heart disease mortality information due to the absence of a risk model for this data. They are concerned that the impact of such analysis could be considerable for a unit. They are keen to develop a risk model for adult congenital heart disease.

Practitioner results

NHS England currently publishes individual surgeon mortality outcomes for adult cardiac surgery on NHS Choices; however, individual paediatric cardiac and adult congenital heart disease surgeon mortality outcomes are currently not required. NHS England states that publication of surgeon data means consultants' performance can be compared openly for a given specialty to help spread best practice and identify any issues that need investigating.

The potential for publishing mortality outcomes for individual surgeons was an area of much discussion with stakeholders, with a number of concerns being voiced. There was concern that publishing individual surgeon mortality rates could lead to additional stress on surgeons and potential risk-averse behaviour where they would be unwilling to operate on patients with a higher risk of mortality. The focus on the surgeon could also be unhelpful as the care of a patient is the responsibility of a much wider team. It was, however, noted that individual surgical outcomes should be reviewed and discussed within the trust to ensure that any areas of concern are identified and addressed.

Whilst there was no appetite amongst those we talked to for surgeon specific mortality information there were a number of people who felt that specific surgical outcomes could be measured using the Technical Performance Score (TPS) method. TPS uses echocardiography to assess the surgical outcome based on predetermined criteria. This is currently being used in certain centres in the USA and UK and a paper has been produced in America which demonstrates the link between these surgical outcomes and mortality and complications.i

Accessibility of Information

It was noted that NICOR has improved the presentation of their 30 day mortality information and made it easier for people to access reports and information, which they are interested in. However, more work could be done to ensure that information on mortality was easy to find, and understand, by the range of stakeholders who use this information. It was observed that one size cannot fit all due to the range of people using the information with significantly different requirements and levels of understanding. A multi-layered approach to the information was therefore seen as desirable to enable people to access the information at an appropriate level.

The timeliness of the reporting of mortality outcomes was also seen as a significant issue, to ensure that users are able to review information which reflects recent performance. This would also give centres appropriate opportunities to review the accuracy of reported outcomes and to ensure that the context of these results can still be discussed.

Divergence

The NCHDA report includes a warning limit and an alert limit against which centres can be measured. The statistical likelihood of breaching the warning limit by chance is approximately 1 in 40, with the chance of breaching the alert limit around 1 in 1000. There was concern that there is no agreed process for when centres breach the warning or alert limit and that the responses made could be inappropriate.
Following the most recent paediatric report which found that the warning limit had been breached in two centres, NICOR validated more recent 2013/14 data for the centres concerned and undertook a preliminary analysis. This showed that in this more recent period, the predicted 30 day survival rates are now within the pre-specified limit. NICOR also wrote to both hospitals and the relevant professional societies to inform them about the warning limit being breached. Both hospitals provided a response to NICOR’s letter; these were published on the NCHDA website.

There is no independent review of centres that have breached limits and commissioners are not involved in the process, limiting the usefulness of the process for either decision making or to improve services.

5.3 Potential areas for development
5a) 90 day mortality by procedure with risk model
5b) Systems used by units for recording the information required for the NCHDA.
5c) Procedures for recording, submitting, validating and reporting on information relating to the NCHDA.
5d) 1 year+ mortality by diagnosis.
5e) PRAiS software for adult congenital heart disease 30/90 day mortality.
5f) A measure for assessing the outcomes of individual surgeons
5g) The website used to communicate mortality information.
5h) Timeliness of reports on validated mortality information
5i) Processes for responding to centres which breach the warning or alert limits.

6. Morbidity
6.1 Current Provision

There is currently no method for providing national information on morbidities to patients or commissioners. Rather morbidities are reported and discussed at the provider trusts where regular meetings (such as Mortality and Morbidity (M&M) meetings) are used to review information on key morbidities. Whilst there is no uniform way to perform these meetings or specific content which must be covered, key morbidities such as complications, re-interventions, surgical site infections, neurological seizures, use of ECMO and length of stay are reviewed and information is produced to enable centres to effectively monitor this. Where morbidities are identified, discussions are then held to understand the issues and identify whether any further measures are needed or there are lessons to be learned.

The NCHDA has been collecting information on neurological seizures but has found the data submitted to be too unreliable to provide any useful information.

The Quality Dashboard requires units to submit numbers for ‘unplanned re-interventions within 30 days’, both for surgical and catheter interventions, and ‘1 or more significant procedure-related complication (stroke, tamponade, unresolving complete heart block, device embolisation, vessel rupture, lost pulse, pseudoaneurysm)’ for catheter interventions only.
6.2 What we heard

Neurological Seizures

The attempt to monitor neurological seizures has been difficult as it is not always easy to identify whether or not a patient has had a neurological seizure and at what point in the pathway of care this occurred. There is no way to verify that a centre has identified, or reported, all neurological seizures and therefore there is a significant risk of incomplete reporting with this measure. As such, those centres which are better at identifying and reporting neurological seizures appear to have higher rates than other centres, which may be simply failing to identify that these have occurred.

Length of Stay

It was considered that length of stay was an easy metric to measure; however, there was less agreement over its usefulness. For parents/patients the question of how long the spell in hospital is likely to be is of some concern but the primary concerns are always the quality of care they receive and the recovery they are likely to make. It is also difficult to know what judgments could be made from one centre having a longer average length of stay than another centre as this could be impacted by so many factors (e.g. the patient’s wishes, the patient’s condition, the availability of other services etc.). It was noted that an American study had created a risk model for different procedures in children to create indicative lengths of stay. It was suggested that time to definitive treatment may be a better measure of hospital performance; however, this is much more complicated information to collect and clear definitions would be required to ensure comparative information was reported.

Quality Dashboard

There was widespread support for the idea of a quality dashboard among the units; however, significant concern and confusion over the current dashboard being proposed. Units were unsure whether the metrics within this were final and therefore were nervous about creating the necessary mechanisms to start collecting this information. They were also unclear as to whether they were required to resubmit the data from the NCHDA, which was required on the dashboard, and whether or not retrospective information was required. For certain measures, retrospective information would not be possible as they had not previously been collecting the necessary information. There was also significant concern over the definitions of the morbidity requirements included in the quality dashboard, with a number of units stating that the definition for unplanned re-interventions within 30 days was required to ensure that comparable information was submitted by all units.

Morbidity Study

Through discussions with the Clinical Operational Research Unit at University College University we were made aware of a study entitled ‘Complications after heart surgery in children’ which is currently being undertaken to better understand surgical morbidities. The project is funded by the National Institute of Health Research (NIHR) and includes representatives from Great Ormond Street Hospital, Evelina Children’s Hospital, Bristol’s Royal Hospital for Children, Birmingham Children’s Hospital, Glasgow’s Royal Hospital for Sick Children, The Children’s Heart Federation and University College London. The project is planned to run from 1 January 2014 to 30 June 2017. A list of ten morbidities, on which information will be collected and analysed has been agreed to establish if these do provide useful, comparable information. A definitions panel has been put in place to establish sufficiently robust definitions for each morbidity. NICOR has agreed to begin collecting the necessary information for some of these morbidities from April 2015.
New Congenital Heart Disease Review

It is noted that the American study, referred to in the Length of Stay section, has also created a risk model for major surgical complications for different procedures in children which allows morbidity to be adjusted to reflect the case mix of different units. It may be possible to use this as a basis for a UK based model.

Adult Morbidities

It was noted that there is no comparable study being performed for adult congenital heart services and that much work is needed in establishing a list of morbidities which apply to adults receiving care for congenital heart disease.

Barriers

There were a number of common issues raised in collecting further morbidity data. Some units were concerned about the amount of data that they were already being asked to collect and concerned about the time and staffing required to collect more data on congenital heart disease services. A more robust software infrastructure would help alleviate some of the demands on staff time. The lack of clear direction as to what NHS England would like to be collected, the purpose of the information and tight definitions were considered to be the most significant barriers to making better information available to commissioners and patients.

6.3 Potential areas for development

6a) Definitions for any new measures units are required to submit as part of the Quality Dashboard.
6b) Provision of morbidity information recommended by the paediatric morbidity study.
6c) System used by units for recording morbidity information required for the NCHDA. (see 5b)
6d) Risk models for morbidities
6e) Adult morbidities which could be used to measure outcomes for adults with congenital heart disease.

7. Quality of Life

7.1 Current Provision

Currently, no systematic, nationwide information on the quality of life of people with congenital heart disease is produced. Some studies have been undertaken where a sample of people with congenital heart disease has been used to establish some of the quality of life issues faced by people with congenital heart disease. For example, a paper entitled ‘Neurodevelopmental Outcomes in Children With Congenital Heart Disease: Evaluation and Management’ was produced in 2012 which concluded that ‘Children with CHD are at increased risk of developmental disorder or disabilities or developmental delay’. However, with the exception of these sporadic studies, there is no ongoing work to monitor or report on outcomes relating to the quality of life of people with congenital heart disease.

In addition, questionnaires have been produced to enable Patient Reported Outcome Measures (PROMS) to be collected. These include Paediatric Quality of Life Inventories for 5-7, 8-12 and 13-18 year olds as well as parent reports for 1-12 months, 13-24 months, 2-4, 5-7, 8-12 and 13-18. In addition to these generic quality of life surveys we also saw examples of Paediatric Cardiac Quality of Life Inventories for 8-12 and 13-18 year olds produced by
New Congenital Heart Disease Review

Cincinnati Children's Hospital Medical Center. However, there was no evidence of these being used or of information from these being reported on. Although it is not entirely clear why these surveys have not been adopted, a number of centres commented on the fact that without the appropriate infrastructure, centres are not set up to assess PROMS and lack the resources to both collect and analyse information on PROMS.

7.2 What we heard

PROMS

As survival rates among people with congenital heart disease have continued to improve, there is a recognition that information on the quality of life of people who have undergone procedures is increasingly important. This would not only be useful information for patients seeking to better understand the implications of their condition, but also in assessing the quality of the services provided by different centres. There was, however, some concern over the subjectivity of the information gathered through patient reported outcome measures and the potential impact each patient’s expectations and personality may have on the results. It was suggested that asking teachers/carers to report on quality of life outcomes might lead to more objective results.

The use of both general surveys and condition specific surveys was advised to enable comparison of people with congenital heart disease both with the wider population and with those with similar conditions.

Concerns were raised that there was not a lot of work being undertaken in this area, the study looking at surgical morbidities (referred to in section five) has also identified feeding problems as one of the ‘morbidities’ it plans to collect information on. Although they have not yet determined how they will collect information on this, it is likely that this will be patient reported.

An app called ‘My Heart’ was demonstrated by the Somerville Foundation, which could provide a valuable tool for collecting PROMS. Patients would be able to download the app which would include their key medical information, appointments, messages and could be used to host questionnaires on quality of life which they could be prompted to use following appointments or on a periodic basis.

Other Quality of Life Measures

There was a strong desire for there to be a measure which could assess the neurological development of people with congenital heart disease. As a result of studies which have been undertaken, as well as anecdotal evidence, a clear link between congenital heart disease and neurological developmental disorders, including behavioural issues is recognised. There is currently no clear process for the creation of any metric which could show this, however, it continues to be a high priority for both patients and parents of people with congenital heart disease.

Additionally, days at home in the first year would help to demonstrate something of the quality of life experienced by patients following procedures.

7.3 Potential areas for development

7a) Quality of life surveys for all ages of people with congenital heart disease.
7b) An app which can be used by patients/parents to gather PROMS information.
7c) Mechanisms for delivering PROMS surveys via post and email.
7d) Processes for ongoing analysis of the information provided through the PROMS surveys.
7e) A tool for measuring neurological development in people with congenital heart disease.

8. Patient experience

8.1 Current Provision

There is a growing awareness across the NHS of the need to collect patient reported experience measures (PREMS) as demonstrated by the requirement that the opportunity to provide feedback through the Friends and Family Test should be given to all patients. In addition to this, provider trusts are required to report on patient experience within their centres, although each unit is free to do this as they choose. The proposed standards for both adult and paediatric congenital heart disease clearly state that patients, partners, children, young people, families and carers must be encouraged to provide feedback on the quality of care and their experience of the service. *(H10 (L1) and H7 (L2 and 3) - Paediatric and Adult Standards)*

It was noted that, within each trust, there was a process for collecting and reporting on patient experience, although this was generally done at a hospital or ward level rather than for particular services. Many centres used paper based questionnaires to gather their PREMS, although some used apps such as ‘Fabio the Frog’ which include a bank of questions on patient experience from which wards can choose those most appropriate to them.

Trusts also monitor and discuss a number of operational measures which play a significant part in a congenital heart disease patient’s experience. These include measures such as operations which have been cancelled (along with the reason for cancellation) and waiting times/lists.

A questionnaire for adult congenital heart disease patients has been developed by the Somerville Foundation and is currently being given to patients by centres providing adult congenital heart services. The Somerville Foundation have reviewed this with a number of clinicians and completion rates and positive responses for this questionnaire have been included as metrics to be reported through the Quality Dashboard.

8.2 What we heard

PREMS

There was a general acceptance that PREMS were important and that a greater understanding of patient experience of congenital heart disease services is needed. It was however, acknowledged that the subjectivity of PREMS impacts the degree to which the information can be used for comparing centres.

It was noted that communication with patients/parents was incredibly important to the overall patient experience and that this was regularly raised as an area around which patients would like more information. This has been included as a measure within the study looking at surgical morbidities (referred to in section five). It was noted that there was no objective way to judge this and therefore PREMS would be relied on to ascertain the quality of communication with patients and whether or not they received the information they required. It was suggested that the percentage of patients discharged with a named cardiologist, paediatrician (including %
with expertise in cardiology), specialist nurse/nursing team, and with all relevant training and information could provide useful measures of units’ performance in enabling effective communication.

The adult survey which has been developed by the Somerville Foundation was developed in consultation with both clinical and patient representatives. Following its initial implementation, this survey has been reviewed and refined by the Somerville Foundation to reflect comments from users. However, no formal process for reviewing and approving this questionnaire within the adult centres has been performed and a formal review process may be beneficial prior to it being used as an official measure of adult patient experience. One of the primary problems with the Somerville Foundation questionnaire is that it relies on the units to give the surveys to patients and on the patients to then complete these and return them to the freepost address. This has led to relatively poor completion rates, which impacts the credibility of any findings. The majority of people stated that, in order to get the highest quality of patient experience, information surveys should be done in a timely manner, after discharge and outside of the centre which provided care, with results sent to an independent third party. The use of an app such as ‘My Heart’ referred to in section seven as well as email and postal reminders could provide valuable ways of improving completion rates.

There is currently no nationally used congenital heart disease paediatric survey for patient experience; however, it was acknowledged that one should be developed as a matter of high priority to provide information on patient experience.

**Operational Measures**

Patients/parents are concerned about the number of interventions which are cancelled and the reasons for this. Whilst they recognise that more urgent procedures may lead to disruption in planned interventions they are aware that cancellations (particularly last minute cancellations) are stressful for families and can have a detrimental impact on the patient experience. Concern was also voiced that often these cancellations are not due to more urgent cases but rather more operational issues such as the availability of beds in ICU. Cancellations, along with the reasons for these, are reviewed by Trusts but this information is not currently available in the public domain and may provide an important indicator of patient experience. The proposed adult and paediatric standards for congenital heart disease require specialist and local centres to record same day cancellations and discuss these at multidisciplinary team meetings. (F16 (L1) - Paediatric and Adult Standards)

Among both trusts and patient and public groups there was a concern that waiting times may be increasing and having a negative impact on patient experience. Although information on waiting lists is currently required by the Transition Dashboard, the quality of information provided varies significantly and this information is not publicly available. Commissioners are currently able to review the information on waiting times reported through the Transition Dashboard and, to date, they have not identified any concerning trends. Again, it was stated that waiting times impacted patient experience significantly and, therefore, this information should be made available to the public.

**Lost to Follow Up**

Where patients are ‘lost to follow up’ there is no way of continuing to assess their ongoing quality of life or experience of care and, therefore, our ability to provide quality information in these areas relies on patients who have been lost to follow up being identified. It was also acknowledged that the percentage of patients who are not being actively followed up by specialist centres following procedures is an important indicator of whether or not centres are providing an appropriate service to people with congenital heart disease. Concerns over
patients failing to be followed up by adult centres following transition, were raised with the risk considered to be greater where separate hospitals (sometimes in separate cities) provided adult and paediatric specialist care. A paper was obtained which reviewed the follow-up of a complete consecutive list of all 1085 UK patients with repair of tetralogy of Fallot from a single institution between 1964 and 2009 and found that 24% of these did not appear to be registered with specialist clinics. The report observed that ‘some patients not currently under follow-up want to be seen by specialist services but do not know how to access such services; the process of conducting the interviews has re-introduced half of those we spoke to who were not in specialist follow-up back into the system.’

Patient and Public groups were concerned that the lack of a register of people with congenital heart disease created a gap in their ability to understand the patient journey and it was noted that a register would allow better monitoring of the follow up care which is made available to each patient. Public Health England has begun work on developing a National Congenital Anomaly register which would include information on each person diagnosed with congenital heart disease. Further discussions are required to understand the information which will be collected within this register.

8.3 Potential areas for development

8a) The Somerville Foundation survey on adult congenital heart disease patient experience.
8b) Paediatric PREMS surveys for both children and parents.
8c) Appropriate mechanisms for collecting completed PREMS surveys
8d) Operational measures which clearly impact on patient experience
8e) A register of all people diagnosed with congenital heart disease

9. Reporting

9.1 Current Provision

The primary source of information on congenital heart disease is currently through the NCHDA website. This includes information on 30 day mortality, which can be presented by centre or by procedure. There is a simplified report, which is published annually, which presents the information in a more accessible format.

Other information on congenital heart disease can be accessed through reports published by a wide range of organisations but which are not made available in any consistent way. Trusts may also communicate information on areas such as patient experience; however, this is not normally specific to congenital heart disease.

9.2 What we heard

There is generally a high level of engagement from parents and patients with congenital heart disease, with a willingness to engage with numerical information. However, although the presentation of information from the NCHDA had improved, it was still considered necessary for this to be made more accessible.
Item 9
New Congenital Heart Disease Review

It was acknowledged that, when it comes to congenital heart disease information, ‘one size does not fit all’ and therefore there is a need for a multi-layered approach. A website offers the ability to provide information at a variety of levels which the user can access according to their needs/wishes. A single site, which included other information such as patient videos, information on different diagnoses, information on the facilities offered by different units as well as outcome information, would be greatly beneficial to patients and parents.

The Clinical Operational Research Unit has, recently started a project to develop a website for presenting information on 30 day mortality.

9.3 Potential areas for development
9a) The website used to present information on congenital heart disease services
9b) Processes for timely publishing of accurate information

10. Conclusion
Throughout the discussions which have contributed to this report there was an acceptance that better information was needed both for patients and commissioners to enable a better understanding of congenital heart services across the country. The lack of clear direction as to the information required was one of the chief barriers to providing this better information and it is the aim of this report to begin a process by which NHS England can provide clear direction as to the areas of information which are to be considered a priority for congenital heart services.

There was a high degree of concern among the provider trusts that any information which was to be published was tightly defined, comparable between centres and analysed in a meaningful way. There was also some concern as to the staffing required to provide better information, although it was acknowledged that a better IT environment for collecting the information may alleviate some of the demands on their staff.

Information on activity and cost continues to be problematic; however, this is clearly a wider issue than congenital heart disease and work is ongoing to further develop the codes used and the identification rules to make the activity recorded through HES data more accurate.

Although work on paediatric mortality and morbidity information was ongoing, it was apparent that more work was needed to develop information on adult mortality and identify appropriate morbidities. It was also clear that a process for providing national information on quality of life and patient experience had not yet been developed and that more attention was needed in this area before useful information would be available to patients and commissioners.

There is a great deal of work going on to develop congenital heart disease information; however, the lack of any national strategy or direction leads to a high risk that the information provided continues to be incomplete, incomparable and unfit for purpose. Therefore, the first priority for any work in this area must be to establish an owner of this information, who will clearly articulate the information which is required and ensure that this is both reviewed and made available in a timely manner.
**11. Next Steps**

Following this report there is a need for the potential areas for development to be prioritised to enable a more focussed approach to investigating how to best improve the information on congenital heart services. Following this specific recommendations and action plans will be developed for approval by NHS England.

This report has also not addressed what information may be required to help commissioners and patients assess centre’s compliance with the standards for congenital heart disease. These metrics will be developed following the outcome of the public consultation on the standards and specifications being known.

The Programme Board are asked to note the progress on objective 5 of the review and approve the potential areas for development.

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