

Public portal, latest funnels

Data from 2006/7 was added to the public portal early this year. There are still no red liners. One centre approached the green line for the first time for arterial shunts – difficult to interpret as these patients are so heterogenous. We think it's probably a good idea to continue to show funnels for arterial shunt operations as it would look strange to exclude such a common operation from the website. The data analysis/procedure algorithms are already complex and we do not yet have the resources to analyse outcomes using permutations of procedures and pre-procedure diagnosis. User defined data analysis on line remains an aim for the future. We will, however do some work in house to look at the complexity of analysing shunts for specific diagnoses such as tetralogy and pulmonary atresia.

Norwood 1 year data

Andrew Parry pointed out an error in the 1 year calculation of survival after the Norwood operation. This had arisen as a result of a large number of cases being censored from 1 year analysis due to reoperation. In future data will be analysed with the Norwood 1 operation remaining as the primary procedure even after reoperation. We did not feel we currently have the resources to analyse all our data according to diagnosis (as opposed to procedure), but as the Norwood cases are so unique we will no longer censor patients from the long term survival data for this particular group of patients.

Improving timeliness of 30 day survivals

After previous discussion at the January RCS meeting, we agreed it was time to implement earlier release of provisional (ie non validated) 30 day survivals on the public portal. It should be possible to do this within a few months of the end of the financial year, but publishing non validated data will be a break from tradition for us. We will initially do this in the private (password protected) section of the portal to allow centres a couple of months to check that no major errors appear to have occurred before we move the data to the public part of the portal. There will be a clear explanation of the provisional nature of the data and it will, of course, be updated after validation. This approach is likely to encourage improvement in early data quality. The private section of the portal should be up and running within the next two months

Timing of data submission

Our last funnel update was late – largely due to some centres being very slow in submitting their full year's data in a timely fashion. We have been asked by the CQC (Care Quality Commission) to fix a date for all centres to submit their data. They suggested that we should come in line with adult cardiac surgery – the 1st July each year. We felt that was a bit short notice for this year, so agreed on 1st August for 08/09 data but 1st July for 09/10 data. **Please note this deadline** – if you do not send your data by the 1st August you are likely to find your latest data missing from the portal and it will be made clear who is responsible!

Antenatal diagnosis

We have been encouraged by various DH bodies and patient support groups to highlight areas of inequality of care. We are not aware that there are any inequalities in access to care in childhood, but have no doubt that there are big variations in quality of data submission and quality of care in antenatal diagnosis. We are adding a new “tab” to the public portal home page for antenatal diagnosis and we will be publishing information on each cardiac centre’s data quality in this area as well as the % of cases under 1 year of age who have undergone procedures other than duct closure or ASD closure. The analysis shows a wide variation across the UK. We will show data according to PCT. There is some very embarrassing data there, so this is likely to be picked up by the press. If your area is performing badly it might be wise to enter early discussions with your PCTs and networks to pre-plan what you and your local obstetricians are going to do about it.

In future we are not going to include the antenatal diagnosis field in patients over 1 year of age in your data quality indicator figure (it’s really only relevant to infant procedures)

Individual operator data

Our work on individual operator data is nearly completed, with only the password protection side of things to be sorted now. The data available will include survival analysis for each year as well as for the most recent 3 years’ amalgamated data (in line with adult cardiac surgery). We will provide raw data without individual operator comparative statistics as numbers will be small and we are keen to promote the concept of centre performance rather than individual performance. Centres will need to register with CCAD and each individual user will need a password even though this will allow access to all of their own centre’s data. This should be up and running within 2 months

Endocarditis

Only 3 centres have submitted any endocarditis data, with a total of 17 cases. We realise that automated submission will be delayed if your software developer has not yet updated with the new endocarditis dataset and data export, but please bear in mind that you can submit data directly on line with Lotus Notes and the dataset is small, so it should not prove too time consuming. Could be part of a local audit of IE for a keen SpR? Please give your software developers a hard time if they are not keeping up to date with the national dataset. And bear in mind that from April 2010 the IE dataset will be included in your data validation visit.

ACHD

Data submission from non tertiary centres carrying out procedures in ACHD is slowly but surely improving, but there is a long way to go. Ongoing national work on ACHD centre designation will hopefully help. At BCCA’s suggestion Gruschen Veldtman has succeeded Mike Gatzoulis as ACHD representative on the CCAD steering committee. Thanks to Mike for his years on the committee.

PROMS

The CHF and GUCH had replied to our request for ideas on Patient Reported Outcome Measures. Both groups agreed that it is very difficult to know what data could be collected that would genuinely reflect quality of care, and although both groups felt there were certain areas (such as patient or parent perception of quality, physical exercise capacity after treatment and quality of life scores) we were probably not at the stage of including such complex and difficult to interpret data in the national dataset at present. GUCH have already undertaken some patient surveys on patients' perceptions, which are currently being analysed professionally, and we hope they will let us know their results.

NICOR

The administration of the national cardiac audits is to be put out to tender in May. Roger Boyle has been leading work on a collective bid for the administration to be taken over by NICOR (National Institute of Clinical Outcomes Research). This has unanimous support from congenital CCAD, the BCCA and the SCTS. JG has joined the NICOR executive committee and board (DC is already a member) and we are collaborating in the group bid. The timescale is short with bids having to be in by August 1st.

Postoperative procedures

At the request of BCCA and SCTS we are adding one new data field for "post operative procedures". The field will include a choice of the specific EU codes relating to procedures such as ECMO, LVAD and the like. We will be updating the dataset on the website in the next few months and we will be writing to software developers letting them know. We anticipate the new field being active by April 2010. Again, please do your best to make sure that your local software is updated.

NCEPOD

We were delighted that the BCCA/SCTS application to for the National Confidential Enquiry into Post Operative Deaths has been accepted. CCAD will be collaborating with NCEPOD as appropriate.

NICE and CCAD

Our collaboration with NICE continues. Our first choice of topic is transcatheter closure of perimembraneous VSD. NICE want to look at our data as well as HES data to maximize pickup of late events, but are delayed by one government body wanting to charge another a large sum of money to come up with HES data. NICE can't afford it. Isn't bureaucracy wonderful!

1 year tracking for latest data

Some of you have noticed the high number of untracked 1 year survivals for the latest portal data. This is due to even dafter bureaucracy, with us being temporarily (we hope) stopped from tracking survival because of confidentiality issues. This is affecting all the national cardiac audits and we hope some common sense will be brought to bear in the near future.

JLG 29/4/2009

jl gibbs@mac.com