CCAD Congenital heart disease newsletter

November 2007

The Public Portal

Feedback on the public portal has, on the whole, been supportive. But we have had calls just in recent weeks from a few centres concerning undercounting of some procedures. It is a pity that this was not flagged up in the pilot two months before the portal went live to the public! It seems that only a few centres actually bothered to check their data on line as requested before we went live.

CCAD staff and the Project Board have spent many hours looking at thousands of individual records to seek the causes of undercounting. Other than one error in translation of old "pick list" codes to the EU short codes explaining undercounting of cavopulmonary shunts (and consequent over counting of Fontans), the explanation was predictable and due to the complexity of using EU codes.

We had been aware that coding practice varies enormously between centres and had thought we had anticipated this sufficiently in our complex algorithms designed to ensure that specific codes took priority within long strings of codes to make sure that, for instance, all tetralogy repairs (even when long strings of codes were submitted) appeared in the tetralogy repair "bin". This involves deciding exactly which codes should be "allowable" within a string to allocate a procedure to a given procedure bin. It turns out we had not anticipated quite how many codes some centres were generating for some procedures. For instance, one centre was submitting "diagnostic catheterisation procedure" along with some (but not all) of its catheter interventions. We had not guessed that this might happen, and those cases were undercounted because "diagnostic catheterisation procedure" did not appear in our list of allowable codes for any intervention.

Similar problems were encountered for some operation coding strings including codes for "echocardiographic examination", and we had overlooked the possibility of some but not all surgeons including coding for transoesophageal echo within the operation codes. We are pretty confident we have sorted these problems by revision of our coding algorithms. We are now checking these against individual records for a wide selection of cases before we implement the new algorithms on the public portal. We hope to do that by Christmas – so expect to see some changes in the data then. There will be an explanatory note on the update on the portal.

Additional problems have arisen from some local software packages allowing export of codes which are incompatible with the agreed short EU codes. This is not something that CCAD can or even wishes to sort out centrally – it is each centre's responsibility to ensure their software manufacturers deliver the nationally agreed coding format. Codes which are incompatible will be excluded from our analyses.

We are also working on making the portal a little easier to navigate through, at the request of the Children's Heart Federation. It is inevitable that our data will be more complex to navigate as we are reporting on some 52 separate procedures in contrast to the very limited number of different procedures in the adult surgical portal (which the public find easier, we hear). We will be pleased to receive suggestions for making the portal more user friendly.

Developing the database

In the coming months we hope to rationalise the number of procedures analysed. We have decided to group all transcatheter duct closures into a single category (rather than the present separate categories for coils & plugs). The arterial switch categories will change to switch for simple TGA and switch with VSD closure. There has been debate as to whether it is useful to have a third "complex switch" category – for discussion at our next contributors' meeting. Surgical opinion appears to be that we include tetralogy with DORV repair within the overall tetralogy repair category, and that "mechanical AVR" should be included in a general category of "AVR – non Ross."

Work has been progressing on freedom from reintervention. We have chosen a series of specific procedures where one would hope not to reintervene early (VSD repair, switch, AVSD repair, coarctation repair & coarctation angioplasty/stenting and transcatheter ASD closure). We will be showing some of these plots at the RCS meeting in January.

NICE have asked us to ensure we are collecting data on hybrid procedures. We are keen to do this – we think the most logical way of easily identifying them is to add to the procedure categories – at present surgery, catheter, thoracic or other. We will need to discuss how to avoid double counting these procedures as they could potential appear as catheter procedures and surgical procedures.

We are also keen to collect data on endocarditis treatment – particularly taking into account the new NICE guidelines due for publication in March. This will also be discussed at the next RCS meeting, with a view to starting data collection in April 2008.

Consent and validation visits

We understand that all paediatric centres have now putt in place a process for consent which covers both data submission to CCAD as well as validation visits which involve non Trust staff inspecting medical records. As we have previously reported, the Healthcare Commission have been advised by PIAG (the Patient Information Advisory Group) that validation visits are potentially illegal, and that consent is essential. This will apply to those centres treating adult congenital heart disease that are just beginning to send their data to us. *If you do not have a consent process in place we will not be able to continue validation visits to your centre.* It will be made clear on the portal if any centres data is not validated.

Next Contributors' meeting at RCS London

The next contributors' meeting will be at the Royal College of Surgeons in London, as usual. It will be held on Friday 18th Jan 2008 with a 10.30 am start (coffee available from 10.00). You will be sent an agenda nearer the time, but please put the date in your diaries now and make sure that your centre is represented, ideally by a surgeon, a cardiologist and someone from your IT or audit dept.

Nov 26th 2007

John Gibbs
Lead clinician for congenital heart disease, CCAD
Consultant paediatric cardiologist
E floor Jubilee Wing
Leeds General Infirmary
Leeds LS1 3EX
0113 392 5757
0787 650 1305
jlgibbs@mac.com