CCAD Congenital heart disease newsletter

April 2008

The new Endocarditis dataset is up and running

The new endocarditis dataset which was endorsed at the January contributors' meeting at the RCS has been implemented as planned and is now in action centrally at CCAD. The updated complete dataset is attached to the email with this newsletter. The dataset ahs been sent to software developers, but it is our experience that software only gets updated with persistent lobbying from customers. Please give your developers a hard time. The data required in addition to the usual demographic fields is pretty simple – just 15 new fields. This should not be difficult to collect as the number of patients with endocarditis in each centre is small. It is clearly best to collect this data via your current clinical databases and submit electronically to us in the usual manner. We recommend that you keep a separate simple record of patients with BE (in Leeds we now keep a book on the ward for all endocarditis cases to be entered) as this will give some material for validation other than a simple electronic record. If you can't submit this data via your current systems yet, please note it is possible to submit the data on line directly to CCAD.

If you would like more information, contact the helpdesk - helpdesk@ccad.org.uk.

Whilst it is a new thing for us to collect data on medical therapy as opposed to surgery or interventional catheterisation, there is a clear need for us to monitor endocarditis following the new NICE guidelines published at the end of March. Please do your utmost to ensure the data does get collected – for adults with congenital heart disease as well as children. If we are to validate endocarditis data you need to extend your data consent to patients treated for endocarditis.

Hybrid procedures

NICE have asked us to ensure we include new procedures in our National Audit and they have specifically requested we do this for the hybrid procedure for hypoplastic left heart syndrome. As you will see from the new dataset, this is relatively straightforward, requiring only a small change to the field relating to procedure type – as well as surgery or catheterisation there is now the option of "hybrid." Hybrids are defined as combined surgical and catheterisation procedures. Rodney Franklin has recently completed an update of the EU short codes, which include hybrid coding. The new codes will be circulated to software developers.

The Public Portal

The portal continues to improve ergonomically, but we have no doubt there is still plenty of room for improvement and feedback is welcome. We plan a full day meeting with the Children's Heart Federation later this year to optimise its usability from the patients' and parents' perspectives. Changes in the pipeline include showing serial years' data alongside the individual 5 year funnel plots to make trends over time more apparent. The funnel plots have recently been revised following the completion of validation of data from 05/06 (still showing 5 years' data, the 2000 data now being replaced by 05/06).

We have already received feedback from some centres who "green lined" for some specific procedures. It appears at first glance that there are still some errors in coding submissions from some centres – please note that data validation visits do not include scrutiny of every single diagnostic and therapeutic code submitted and it is each centre's responsibility to be scrupulous about accuracy, particularly where multiple codes are required.

Bill Brawn and Les Hamilton, as Presidents of BCCA and SCTS will be following up all green line results. This will be a valuable process which is likely to give us more insight into risk stratification and we hope will be viewed as such. It is likely that the review of deaths will lead to refinement of our future data analysis.

It is important to bear in mind that statistically it would be extraordinary if we did not have green liners popping up occasionally as we analyse 48 different procedures in 14 centres. Even at the 98% confidence limit we should expect some "potential" outliers each year. Happily we still have no "red liners" (99.5% confidence limit) for any procedures.

The steering committee plan to meet again by the summer to review our data analyses (for instance stratification by age and actuarial survival plots) and to consider adding further procedures to the current 48 included in the specific analyses. Suggestions would be welcomed.

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