

## Congenital CCAD Newsletter July 2008

### ONS tracking

JG received a letter from the BCCA Council expressing their concerns about the quality of our data on the public portal. This related to the high proportion of patients for whom we had no trackable life status at 30 days and 1 year. CCAD have looked at this in detail. We found that the latest data return from ONS had been missing the date, rendering the information useless. This data has been requested again. It accounts for only a very small proportion of unknown patient status. A further small proportion is due to foreign national patients who one would not expect to have an NHS number. The huge majority of the unknown status patients are due to missing NHS numbers. CCAD can only use data which is submitted to us and responsibility for sending us NHS numbers can only lie with the centre themselves. You will see from the attached table that centre's efficiency at including the NHS number varies greatly. If we have the NHS number it is very rare for ONS to fail to track survival. Please look at the table and put your house in order!

There was much discussion on how we might improve matters at our end.

We have decided to:

- a) Remove patients known to be foreign nationals from the 30 day and 1 year survival analyses (by censoring those identified as private with no NHS number submitted or by excluding those with a pseudo postcode). This will allow information on survival at 30d and 1 year to more closely reflect the healthcare demands of UK residents as well as reducing the number of untrackable patients.
- b) Publish an additional set of statistics on all patients survival at discharge from hospital. This will include foreign national patients.
- c) Give a 3 month period for all centres to resend their data with the NHS numbers.

### Other data quality issues

Tables are attached showing variable data quality for duration of ventilation and for PCPC (paediatric cerebral performance score). There is no reason why ventilation time data quality should be so poor – it is routinely collected by Picanet and should be available from their local databases, and it is still felt by the SCTS that it is an important surrogate for morbidity. Collecting PCPC data simply requires local discipline. Please look at your data quality in the attached tables and take action to improve your DQI.

With the changes (above) in data analysis it is of particular importance to identify foreign national patients. Please be aware of the importance of ensuring that the patient status (NHS/Private) is submitted accurately – if a PP has no NHS number we can then safely assume that they are foreign nationals and should not be included in our ONS tracked data. If you don't identify the patient as private and you don't send an NHS number your Data Quality Index will fall. Please also note that pseudo postcodes are a useful way of identifying foreign nationals. They are freely available for importing into database systems.

### **Potential outliers**

Funnel plots show there are still no “red liners”. The SCTS and BCCA will draft a brief document on process for green and red liners. They feel that reaching the green line should provoke local detailed audit rather than direct involvement of the specialist societies, with only the red line being reached instigating the societies’ involvement.

### **Data analysis in different age groups**

The Heart Hospital’s results for Fontan operations appeared on the green line last year, but there seemed little doubt that this was due to them being the only centre reporting purely adult data. In future we will produce 2 funnel plots specifically for the Fontan operation – for under and over 16s. At present the data does not suggest that other adult procedures carry significantly different risk to those in children.

### **Hybrid procedures**

The dataset has been adjusted to allow for hybrid procedures to be identified using the updated EU short codes supplied by Rodney Franklin. The new short codes have now been published on the portal (under “technical information”). Until the new EU short codes were released this Spring, there was no code for a hybrid procedure. We recommend that centres performing this procedure should, once they have updated their coding systems, recode the small number of patients who have had a hybrid procedure and to then resubmit that data to ensure we can identify the procedure reliably.

### **Endocarditis**

The dataset (also on the portal now under “Technical information”) has been adjusted to include the new IE dataset. A guide for developers has also been placed on the portal, with instructions for export file format. Endocarditis data can be submitted in the usual way if your local software has been appropriately updated, but it can also be entered on line. Please contact our helpdesk if you need help with this - [helpdesk@ccad.org.uk](mailto:helpdesk@ccad.org.uk)

### **Portal improvement**

The dataset, the algorithms for procedure allocation and the Project Board meeting minutes are now all available directly on the public portal (previously only available on the main CCAD website).

As agreed at the last RCS contributors’ meeting, we are working on password protected access to individual operator results. This has been delayed because of limited resources at CCAD but we hope will be available later in the year. Similarly, work on freedom from reintervention and actuarial survival plots await further resources.

### **Mortality index**

The North American led international work on mortality index is progressing. CCAD have agreed to test the index on CCAD data. A very provisional analysis had, however, suggested that the index may not accurately predict mortality in our patients. A full analysis is awaited.

### **Adult congenital data**

The number of adult cardiac centres sending us data is steadily increasing, although some of them appear to be carrying out small numbers of procedures. There are still a good few centres who choose not to send us data on adults (Scotland in particular stand out). All centres sending data will receive validation visits, even if their numbers are small.

**Additional procedures for analysis**

Heart transplantation, heart and lung transplantation, ablation for arrhythmias and permanent pacing (surgical and transvenous) will be added to the procedures analysis on the portal.

10/07/2008

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CCAD Missing NHS numbers in complete data from 2000, by hospital

Hospital	n Patient
ACH. Alder Hey Hospital	15
BCH. Birmingham Childrens Hospital	499
BHL. Cardiothoracic Centre Liverpool	2
BRC. Bristol Children's Hospital	200
FRE. Freeman Hospital	7
GEO. St George's Hospital	3
GOS. Great Ormond Street Hospital for Children	845
GRL. Glenfield Hospital	26
GUY. Guy's Hospital	628
HSC. Harley Street Clinic	1461
LGI. Leeds General Infirmary	190
MRI. Manchester Royal Infirmary	9
NHB. Royal Brompton Hospital	1033
QEB. Queen Elizabeth Hospital, Edgbaston	180
RAD. John Radcliffe Hospital	40
RHS. Royal Hospital for Sick Children	641
RSC. Royal Sussex County Hospital	29
RVB. Royal Victoria Hospital	1027
SGH. Southampton General Hospital	164
THH. The Heart Hospital	316
UCL. University College Hospital	39
UHW. University Hospital of Wales	2

## CCAD duration of ventilation data quality index by hospital

<b>Hospital</b>	<b>CCAD Identifier</b>	<b>2006 DQI %</b>	<b>2007 DQI %</b>	<b>2008 DQI %</b>	<b>Comments</b>
Alder Hey	ACH	60	45	50	
Birmingham	BCH	57	65	60	
Bristol	BRC	57	62.5		Not yet visited for 2008
Liverpool Heart and Chest Hospital	CTC	n/a	n/a	50	
Freeman	FRE	62.5	88	93	
Great Ormond Street	GOS	93	46		Not yet visited for 2008
Glenfield	GRL	87.5	46		
Guys	GUY	89	0		Not yet visited for 2008
Harley Street Clinic	HSC	n/a	n/a		Not yet visited for 2008
Leeds	LGI	83	0	0	
Manchester	MRI	n/a	45	50	
Brompton	NHB	69	31	33	
QEB	QEB	57	65	60	
Oxford	RAD	44	73		Not yet visited for 2008
Glasgow	RHS	0	100		Not yet visited for 2008
Brighton	RSC	n/a	n/a	0	
Belfast	RVB	100	100		Not yet visited for 2008
Southampton	SGH	72	14	80	
UCL	UCL	n/a	46		Not yet visited for 2008
Cardiff	UHW	n/a	n/a		Not yet visited for 2008
		931	826.5	476	
<b>DQI</b>		<b>66.5</b>	<b>51.65625</b>	<b>47.6</b>	

PCPC data quality by hospital

Hospital	CCAD Identifier	2006 DQI %		2007 DQI %		2008 DQI %	
		Pre	Post	Pre	Post	Pre	Post
Alder Hey	ACH	52	44	42	42	57	52
Birmigham	BCH	90	93	84	80	96	96
Bristol	BRC	55	47	88	93		
Liverpool Heart and Chest Hospital	CTC					57	52
Freeman	FRE	88	88	100	100	73	65
Great Ormond Street	GOS	48	91	56	26		
Glenfield	GRL	86	100	81	66		
Guys	GUY	95	95	90	90		
Harley Street Clinic	HSC						
Leeds	LGI	91	91	40	60	68	68
Manchester	MRI			42	42	57	52
Brompton	NHB	96	92	96	96	100	100
QEB	QEB	90	93	84	80	96	96
Oxford	RAD	96	100	93	93		
Glasgow	RHS	91	100	93	93		
Brighton	RSC					0	75
Belfast	RVB	100	100	100	100		
Southampton	SGH	93	100	87.5	87.5	93	93
UCL	UCL			56	26		
Cardiff	UHW						
<b>DQI</b>		<b>83.64</b>	<b>88.14</b>	<b>77.03</b>	<b>73.41</b>	<b>69.7</b>	<b>74.9</b>