

Spring 2011

Issue No 2

# Registry News



## Welcome to issue number 2 of Registry News

It gives me great pleasure to make my first contribution to our newsletter-increasing communication between renal units and the registry is a key goal to our shared aims.

I would first like to thank all the staff in the units and the registry who together feed and process the data that forms the Annual Report for assessing clinical performance in UK Renal Units. You should feel great pride in contributing to one of the highly regarded renal registries worldwide. I would also like to thank Dr David Ansell for his many years of hard work as Director of the Registry. His efforts with many others have brought us to where we are today.

There are many millions of data items that are used at some point in the generation of the Renal Registry annual report. This is a large and complex task collecting clinical details from over 80 renal units using almost 20 different Information Systems for almost 50,000 patients each year. This work has been revised this year with additional validation steps and thus a delay in the publication of this year's report. However this improved process is overdue and will assist us in getting more accurate data in the report and back to you in as timely a way as possible in future years. As ever we thank you for your help and this year especially, your patience.

As we move into a financially constrained NHS environment we are going to face some challenges but also some opportunities: firstly reductions in resources for coal-face activity will probably happen even if unintentional; secondly the new government agenda is explicitly planning to use more information to help assess patient outcomes. For both reasons registries will assume a greater role in the collection and analyses of summary data on unit performance. We already use our annual report to highlight that the UK Renal Services offer high quality renal replacement therapy to many more patients in more locations and in a more holistic way than ever before. That said there is still significant variation in aspects of this care which raises the possibility of better use of our resources. Before this step however it is critical to know that the variation in say patient survival is 'real' and does not reflect variation over which we have no control; in other words our analyses need to correct (adjust) for the so-called case-mix of patients before interpreting these differences. We can only do this with your help to complete as much of the relevant information in the areas that we use in such analyses. The important areas for this adjustment are age, gender, race, primary renal disease and co-morbidity. The registry has high rates of completeness for age and gender; understandably the other factors are seen as less relevant to day to day management and are thus more often incomplete in Renal Information Systems. Another related issue is the need for completed dates in the systems: many aspects of care require measuring the time between events (first appointment, first dialysis, listing for transplant etc). If units have higher rates of late-presentation they can hardly be expected to plan dialysis access in the same proportion of patients as units with a low rate of late-presentation.

The Registry recognises that collecting clinical data needs to fit, as much as possible, with routine clinical practice and increasingly the collection of other information for trust and other reporting bodies. The majority of these pieces of information are important for our patients to get the best care. Renal staff in all clinical and administration areas are already filling the role of patient advocate in their own way. We should also demand for our patients and units higher quality data and audit management systems to help assist the units and thus patients.

*Damian Fogarty*

## Informatics Meeting 2011

The next Registry Informatics meeting is to be held at the Queen Elizabeth Hospital, Birmingham on Wednesday 6th July 2011.

Please contact Ceri at the Renal Registry to book your place.

### **The Registry, the National Renal Dataset and Vascular Access Audit: lessons for the future.**

The National Renal Dataset (NRD) was designed to enable a detailed description and audit of Renal Services. It was developed at a time when it was envisaged that hospitals would be acquiring clinical information systems which would then send data to the Secondary Users Service (SUS) through Connecting for Health. It was "mandated" for use, which means that the suppliers of clinical information systems are obliged to provide the capacity for these data to be recorded in those systems.

The NRD dataset was to come from a variety of sources including hospital theatre systems, renal unit IT systems, primary care IT systems, pathology IT systems and many others. It was not envisaged that it would be the responsibility of Renal Units to assemble and enter all these data into their own systems.

Sadly the investment envisaged in hospital clinical information systems, and the development of Connecting for Health, has not taken place and we have an NRD without the envisaged support. We are left with the situation that most renal units do not have IT systems capable of collecting the whole dataset, and have not received the investment to purchase such systems or to provide staff to assemble the data.

In many quarters there is an expectation that the UK Renal Registry, together with UK Transplant, will be collecting these data, as is shown in the following extract from the NHS Information Centre website: "*The dataset extends the existing collections of the UK Renal Registry, UK Transplant and the British Association of Paediatric Nephrologists. Data collection and submission of the NRD will be included within these existing collection mechanisms*". This is not strictly correct, as it is not the primary responsibility of the Renal Registry to collect these data, and it is certainly not the role of the Registry to pass such data onto any other body. The Registry can easily provide the capacity within its database to store the data items from the NRD for subsequent audit, but the Registry has not been resourced for the enormous workload of validating and cleaning such data, and furthermore it can only collect data which are being stored on Renal Unit IT systems; most of these data items are not yet available on these systems.

These problems are well demonstrated by the recent Vascular Access Audit. It soon became evident that relatively few renal units had IT systems with the capacity to store the vascular access data items from the NRD. The Registry did extract data from those units which did have that capacity, but it was soon clear that in many of those units only very few vascular access data items had been entered onto the system and most items were not available. As a result the NHS Information Centre resorted to sending spreadsheets to renal units to fill in some basic information, which, whilst it provided some insight on the current situation, did not move forward any means for the continuing collection of vascular access audit data. Work is progressing to define which are the most important items for vascular access audit which it is realistic to collect, and then to find ways of resourcing and enabling units to collect the data.

The NRD does offer the potential for good audit and the Registry will be working with the renal community to evaluate which items will be most important for critical audits and will then work with renal units to find ways of assembling those data, extracting them and performing the chosen audits. Terry Feest.

**Delays and exciting new developments.** Several factors have contributed to a delay in publishing the 2010 Annual Report. To give centres feedback on their 2009 data as soon as possible we are posting chapters on our website as they are completed: 8 are already available. The full Report will be at the printers at the end of June and be published online by Nephron Clinical Practice (NCP). Our whole process of data handling is being reviewed in depth. We hope the new process will be more accurate, quicker, and will improve our communications with the Renal Units. Within 2 years we hope to be able to produce the reports much earlier in the year.

A most exciting development is the work of Afzal Chaudhry enabling individuals to directly interrogate our anonymised database at [http://www.renalreg.com/n\\_portal/pages/main/registryportal.php](http://www.renalreg.com/n_portal/pages/main/registryportal.php). This means that it is now possible for you for the first time to obtain renal unit specific reports: in addition these reports will reflect changes in activity/performance over time.

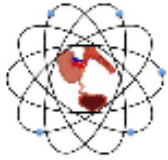
Terry Feest

## New Major Projects for 2011

### **ATTOM Project**

This is a multicentre UK-wide prospective study of access to transplantation in renal patients. The study will look at incident dialysis patients, a group wait-listed for transplantation and a third 'control group'. In addition to demographic and clinical data, patients will be asked to complete a number of quality of life questionnaires. Recruitment starts in late 2011 and ends after 1 year, with follow-up to the end of the study. Contact Dr Rommel Ramanan at Southmead Hospital, Bristol, for further information.

### **RCP (Research Capability Programme)**



RCP consists of about 10 projects exploring the possibilities of linking routinely collected data with clinical research. The Registry is working with a Specialist Registrar based in Sheffield to test the feasibility and quality outcomes of linking Registry data with Hospital Episode Statistics (HES) data. The linkage will be for Registry data between 2004 and 2010. Contact Dr James Fotheringham, Sheffield, for further information.

### **Staff Updates**

Professor Terry Feest is filling the role of Acting Director for a few months pending review of structures and appointment of a permanent Registry Director.

Professor Chris Maggs, the Deputy Director of the Registry retired at the end of February. He has played an important role in reviewing governance in the Registry, in bringing our procedures into the 21<sup>st</sup> century and in representing the Registry in the wider health community – we wish him a happy retirement. The role of his replacement will be considered together with that of the new Director.

Andy Langdon, our programmer has left the Registry: we wish him all the best in his new job.

Our most recent new member of staff, Sarah Wood, joined the Data Management team in December 2009. It is envisaged that the data management team and the IT team will need further additional help in the imminent future.

**RIXG**

## **Renal PatientView**

**NHS**

The administration of Renal PatientView is now managed by the Renal Registry.

If you require any information please contact Fiona at [Fiona.Braddon@renalregistry.nhs.uk](mailto:Fiona.Braddon@renalregistry.nhs.uk)

### **Name This Sheet!**

We would like to re name the newsletter and looking for bright ideas from its readers. If you have any good ideas for names please send them to [susan.shaw@renalregistry.nhs.uk](mailto:susan.shaw@renalregistry.nhs.uk) with your contact details no later than Friday 24th June. The winning idea will receive a box of chocolates and will be announced at the next Informatics Meeting.

If you would like to receive a personal copy of this news sheet and you are not on our mailing list please email your request to:- [renalreg@renalreg.com](mailto:renalreg@renalreg.com) - marking the subject line News sheet.



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