Chapter 2: Introduction to the 2007 UK Renal Registry Report

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The UK Renal Registry (UKRR) is part of the UK Renal Association and provides independent, professionally led, audit and analysis of renal replacement therapy (RRT) in the UK. The Registry is funded directly by participating renal centres through an annual capitation fee, currently £16 per patient per annum (2007).

The Registry receives quarterly electronic data extracts from information systems used for clinical and administrative purposes within each renal centre, and has developed expertise in mapping data items from each local system to the UKRR database. All but 5 UK renal centres provided such electronic data extracts in 2006; these 5 provided summary data on incident and prevalent patients.

Geographical areas covered by the UK Renal Registry

The Scottish Renal Registry provided demographic and also haematology and dialysis dose data from the whole of Scotland.

All the reporting renal centres in England & Wales and also the Scottish Registry run the CCL Proton software, except:

Table 2.1: Centres in the 2007 Registry Report

	Hospital	Estimated population (millions)
England		**46.14**
Basildon	Basildon Hospital	0.50
Birmingham	Heartlands Hospital	0.60
Birmingham	Queen Elizabeth Hospital	1.82
Bradford	St Luke's Hospital	0.60
Brighton	Royal Sussex County Hospital	0.98
Bristol	Southmead Hospital	1.50
Cambridge	Addenbrookes Hospital	1.42
Carlisle	Cumberland Infirmary	0.36
Carshalton	St Helier Hospital	1.80
*Chester	Countess of Chester Hospital	0.24
Chelmsford	Broomfield Hospital	0.50
Coventry	Walsgrave Hospital	0.85
Derby	Derby City Hospital	0.48
Dorset	Dorchester Hospital	0.71
Dudley	Russell's Hall Hospital (previously Wordsley)	0.42
Exeter	Royal Devon and Exeter Hospital	0.75
Gloucester	Gloucester Royal Hospital	0.55
Hull	Hull Royal Infirmary	1.04
Ipswich	The Ipswich Hospital	0.33
Leeds	St James's Hospital & Leeds General Infirmary	2.20
Leicester	Leicester General Hospital	1.80
*Liverpool	University Hospital Aintree	0.64
Liverpool	Royal Liverpool University Hospital	0.98

Table 2.1: (continued)

	Hospital	Estimated population (millions)
London	St Barts & The Royal London	1.79
London	Guys & St Thomas' Hospital	1.70
*London	Hammersmith, Charing Cross & St Mary's	2.11
London	Kings College Hospital	1.01
London	Royal Free, Middlesex, UCL Hospitals	1.43
Manchester	Hope Hospital	0.94
Middlesbrough	James Cook University Hospital	1.00
Newcastle	Freeman Hospital	1.31
Norwich	James Paget Hospital	0.84
Nottingham	Nottingham City Hospital	1.16
Oxford	Churchill Hospital	1.80
Plymouth	Derriford Hospital	0.55
Portsmouth	Queen Alexandra Hospital	2.00
Preston	Royal Preston Hospital	1.48
Reading	Royal Berkshire Hospital	0.60
Sheffield	Northern General Hospital	1.75
Shrewsbury	Royal Shrewsbury Hospital	0.40
Southend	Southend Hospital	0.35
Stevenage	Lister Hospital	1.25
Sunderland	Sunderland Royal Hospital	0.34
Truro	Royal Cornwall Hospital	0.36
Wirral	Arrowe Park Hospital	0.31
Wolverhampton	New Cross Hospital	0.49
York	York District Hospital	0.39
Wales		**2.96**
Bangor	Ysbyty Gwynedd	0.18
Cardiff	University of Wales Hospital	1.30
Clwyd	Ysbyty Clwyd	0.15
Swansea	Morriston Hospital	0.70
Wrexham	Maelor General Hospital	0.32
Northern Ireland		**1.69**
Antrim	Antrim Hospital	
Belfast	Belfast City Hospital	
*Derry	Altnagelvin Hospital	
Newry	Daisy Hill Hospital	
Tyrone	Tyrone County Hospital	
Ulster	Ulster Hospital	
Scotland	(via the Scottish Registry)	**5.10**
Aberdeen	Aberdeen Royal Infirmary	
Airdrie	Monklands District General Hospital	
Dunfermline	Queen Margaret Hospital	
Dumfries	Dumfries & Galloway Royal Infirmary	
Dundee	Ninewells Hospital	
Edinburgh	Royal Infirmary	
Glasgow	Royal Infirmary, Western Infirmary & Stobhill General Hospital	
Kilmarnock	Crosshouse Hospital	
Inverness	Raigmore Hospital	

*Renal centre included in the report for the first time.

Table 2.2: Progress in centres not included in this report

	Hospital (indicates IT system used by hospital)	Estimated population (millions)
Stoke – submitted 2007	North Staffs (Cybernius system)	0.70
Manchester – submitted 2007	Royal Infirmary (CCL clinical vision)	2.51
Canterbury	Kent & Canterbury – Renalplus	0.91
London	St George's (CCL clinical vision)	
Colchester	Colchester General Hospital (new renal centre Fresenius, software not chosen)	

Ipswich and Bangor (Baxter system);
Aberdeen, Brighton and Newcastle (CCL clinical vision);
Kings, The London and Royal Free (Renalware);
Airdrie, Basildon, Chelmsford, Dorset, Dundee, Norwich and all six Northern Ireland centres (Mediqal eMed);
Shrewsbury & Stevenage (Renalplus);
Birmingham, Cambridge, QEH, Hammersmith and Hope Hospital (own systems).

Three renal centres were created in 2006 and two in 2007:

1. Liverpool Aintree (previously a satellite of University Hospital Liverpool renal centre)
2. Chester (previously a satellite of the Wirral renal centre)
3. Derry (previously a satellite of Tyrone renal centre)
4. Doncaster (until 2007 a satellite of Sheffield renal centre)
5. Colchester

In 2007, Derby changed their renal IT system from Proton to Vitaldata and Wrexham changed from Proton to Renalplus.

Future coverage by the Registry

From the analyses presented here, it can be seen that the report on the 2006 data covers over 90% of the UK with the remaining centres sending electronic data returns for 2007. With the recommendation in the Renal National Service Framework (NSF) that all renal centres should participate in audit through the Registry, all renal centres in England, Wales and Northern Ireland have invested in the IT technology and local support infrastructure to undertake returns to the UK Registry. To support the Renal Registry, continuing local investment is required in the additional local resources to maintain the clinical data within these systems.

The Health Care Commission (HCC) wishes to use the Registry as one vehicle for monitoring implementation of the NSF.

Centres not returning data electronically in 2006

All adult renal centres have moved to implementation of a Registry compatible renal IT system.

Completeness of returns for four important data items

The Registry has again included a table of completeness for four of the important data items for which it has been trying to improve returns. Centres have been ranked on their average score (Table 2.3). Ethnicity, date first seen by nephrologist and co-morbidity are not mandatory items in the Scottish Renal Registry returns so these centres have been listed separately.

Table 2.3: Completeness of data returns

Centre	Ethnicity	Primary diagnosis	Date 1st seen	Co-morbidity	Average completeness	Country
Nottm	100.0	100.0	100.0	90.4	97.6	England
Swanse	98.2	91.2	100.0	94.7	96.0	Wales
Bradfd	93.9	89.8	100.0	100.0	95.9	England
Glouc	100.0	100.0	82.2	87.7	92.5	England
York	95.7	87.2	97.9	87.2	92.0	England
L West	100.0	91.5	89.7	67.3	87.1	England
Bristol	88.4	80.9	80.9	84.4	83.7	England
Wolve	97.8	80.6	100.0	45.2	80.9	England
Sheff	73.7	86.8	99.4	46.1	76.5	England
Ports	71.8	96.6	94.3	34.5	74.3	England
Newc	98.2	96.4	99.1	0.9	73.7	England
ManWst	100.0	100.0	87.4	6.3	73.4	England
L Kings	93.7	98.2	0.0	99.1	72.8	England
L Barts	96.6	99.4	22.3	72.6	72.7	England
Bangor	52.5	97.5	100.0	40.0	72.5	Wales
Leic	95.4	79.3	53.1	61.0	72.2	England
Shrew	81.5	98.1	100.0	0.0	69.9	England
Carlis	92.6	100.0	0.0	81.5	68.5	England
Truro	58.0	80.0	56.0	78.0	68.0	England
Middlbr	95.9	93.8	77.3	0.0	66.8	England
Sund	82.8	94.8	0.0	84.5	65.5	England
Wirral	87.5	96.4	73.2	1.8	64.7	England
Stevng	100.0	100.0	46.1	0.0	61.5	England
Leeds	47.3	55.9	83.9	51.6	59.7	England
Dudley	100.0	97.8	37.8	2.2	59.5	England
Derby	45.8	100.0	4.2	69.4	54.9	England
Liv RI	69.7	99.3	0.0	46.5	53.9	England
Sthend	20.5	97.7	0.0	95.5	53.4	England
Camb	72.8	100.0	35.9	0.0	52.2	England
Redng	100.0	100.0	0.0	0.0	50.0	England
Hull	5.1	96.9	1.0	94.9	49.5	England
B Heart	94.1	100.0	0.0	0.0	48.5	England
Covnt	80.8	98.1	0.0	0.0	44.7	England
Prstn	90.1	86.8	0.0	0.0	44.2	England
Exeter	22.8	62.3	50.9	24.6	40.2	England
Oxford	60.1	96.9	2.5	0.6	40.0	England
L Guys	57.9	99.2	0.0	0.0	39.3	England
Liv Ain	55.6	100.0	0.0	0.0	38.9	England
Chestr	50.0	100.0	0.0	0.0	37.5	England
Plymth	32.3	97.8	0.0	8.6	34.7	England
B QEH	97.3	38.5	0.0	0.0	34.0	England
Crdff	26.7	99.0	0.5	3.4	32.4	Wales
Clwyd	11.8	100.0	0.0	0.0	28.0	Wales
L Rfree	99.5	0.0	0.0	0.0	24.9	England
Wrexm	0.0	88.0	0.0	0.0	22.0	Wales
Brightn	21.4	49.6	0.8	0.8	18.2	England
Carsh	9.5	56.8	0.0	1.6	17.0	England
Centres whose co-morbidity data was excluded from this report due to incorrect data returns*						
Basldn	100.0	97.7	100.0			England
Chelms	40.0	100.0	86.0			England

Table 2.3: (continued)

Centre	Ethnicity	Primary diagnosis	Date 1st seen	Co-morbidity	Average completeness	Country
Dorset	100.0	96.4	100.0			England
Ipswi	73.8	97.6	100.0			England
Norwch	44.5	100.0	18.2			England
Antrim	61.3	100.0	25.8			N Ireland
Belfast	77.0	93.8	52.2			N Ireland
Derry	100.0	100.0	100.0			N Ireland
Newry	7.1	100.0	71.4			N Ireland
Tyrone	90.0	100.0	96.7			N Ireland
Ulster	75.0	100.0	100.0			N Ireland
Scotland						
Abrdn	0.0	82.0				Scotland
Airdrie	94.5	94.5				Scotland
D&Gall	0.0	86.4				Scotland
Dundee	16.0	94.0				Scotland
Dunfn	2.9	97.1				Scotland
Edinb	1.9	100.0				Scotland
Glasgw	1.1	84.5				Scotland
Inverns	22.2	96.3				Scotland
Klmarnk	0.0	84.6				Scotland

*See chapter 5.

Software and links to the Registry

It is apparent that there are now 13 systems in use by renal centres, some of them commercial and some in-house. The Registry has worked with the relevant companies to provide appropriate software links to the Registry. As new data items (eg those relating to vascular access) are defined and the need for collection by the Registry accepted, there will be a continuing requirement that these companies provide the necessary enhancements to their systems to permit collection of these items and maintenance of an interface with the Registry for the new items. The NHS Information Centre has developed a National Renal Dataset, with the intention that collection of these data items within electronic care records provided by Local Service Providers under Connecting for Health will be mandatory; the feasibility of collection of data items defined within the dataset is now being tested using existing renal centre IT systems and this project will also require software development to permit collection of data items not currently collected by the Registry.

Paediatric Renal Registry links

The BAPN were unable to return their data analyses in time to be included in this years report. In the UK in 2005 there were 768 patients under 18 years old at the 13 UK paediatric renal centres who were on renal replacement therapy. In order to integrate with the adult Registry and also benefit from funded resources for data management, the BAPN is intending to develop the means to collect the paediatric data electronically.

Relationship with the Renal Association

The UK Renal Registry is represented by the Chairman on the Renal Association Clinical Practice Guidelines Committee, which is in the process of producing a modular, 4th edition set of audit measures relating to all aspects of care of patients with kidney disease. Where possible, the Registry will adapt its data collection procedures so as to be able to report on performance against these audit measures. Many of the data items cannot be collected electronically

from renal centre IT systems and for those measures, centres will have to develop local audits. The Chairman also represents the Registry on the Clinical Affairs Board.

Links with other organisations

NHS Blood & Transplant and the British Transplantation Society

Close collaboration has developed with the NHS Blood and Transplant Authority (previously UK Transplant, www.nhsbt.nhs.uk) and with the British Transplantation Society (www.bts. org.uk), to produce analyses utilising the coverage of both the NHS BT and Renal Registry databases. The 2005 report included a full chapter of these analyses. New analyses for 2006 include the survival benefit of patients after having received a renal transplant when compared to a patient who remained on the transplant waiting list. The results were presented at the British Transplantation Society meeting and a paper is in preparation. The current report includes a centre specific analysis of access to the transplant waiting list and these analyses will be included in all future reports.

This years report (chapter 11) also includes a report from the BTS/RA national survey of clinical practices at transplanting and non-transplanting centres.

Departments of Health

Registry reports are sent to the Department of Health in each UK country in the expectation that the analyses will inform policy relating to the care of patients with established renal failure. Such analyses were important in the development of the National Service Framework. The DoH for England is represented on the Registry Committee.

In 2007, the DoH for England invited bids for funding of new audit projects. The Registry submitted three bids and was awarded funding for each of these totalling just under £200K. The bids involved:

1. The development of software to enable the Registry to produce centre-specific audit packs, designed to encourage use of Registry analyses of individual centres' performance compared to other centres' performance in local audit activities. These centre-specific reports will include pdf documents and powerpoint slides in which each centre's results are highlighted.
2. Upgrading of the Registry database.
3. Collaboration with the East Midlands Public Health Observatory on use of graphical mapping software to present Registry analyses.

The Information Centre, Connecting for Health, and the Secondary Uses Service

The Registry Chairman is a member of the National Renal Dataset project board. Following the definition of a proposed national renal dataset, the Registry has been awarded funding by the Information Centre to test the collection of several new data items defined within the dataset, including vascular access, peritoneal dialysis access and complications relating to these. Software is being developed for the Proton, Clinical Vision and Mediqal systems to enable collection of these data items.

The Registry, together with other professional organisations, provided input into a working party to define the scope of an audit of care of patients with kidney disease in England. A tender document focusing on transport for haemodialysis and vascular access for haemodialysis was subsequently developed by the Information Centre. The funding for this audit has now been awarded by the Healthcare Commission to the Information Centre. The Registry expects to be a key partner in the performance of the audit of vascular access.

Detailed negotiation continues with the Information Centre on how data will flow to the UKRR as the work of Connecting for Health evolves. The present model of data extraction from specialty-specific IT systems in each renal centre, would not be sustainable if such specialty-specific systems were no longer supported or used. The Registry, together with the Renal Information Exchange Group, takes the view that specialty-specific systems, fully interoperable with the main electronic care record,

will continue to be necessary to support the care of patients with kidney disease. The alternative view is that full implementation of the solutions currently being developed by Local Service Providers will make such specialty-specific systems redundant. If that view were accepted, the data currently collected by the Registry would be available within the Secondary Uses Service, which replaces the Hospital Episode Statistics database as the repository of all data collected by the NHS in England. The role of the Registry in validating data, correcting errors and then in the design, performance and interpretation of clinically meaningful analyses, would remain to be defined.

The Registry is also keen however, to be able to use data from the Secondary Uses Service, for instance on hospitalisation, surgical procedures and discharge diagnoses. Under current arrangements, this would require approval from the Patient Information Advisory Group under Section 60 of the Health and Social Care Act, 2001.

The Health Protection Agency

Web-based collection of an extended dataset by the Health Protection Agency (HPA) on patients on RRT with methicillin resistant Staphylococcus Aureus (MRSA) bacteraemia was piloted in eight renal centres in 2006–7. This programme is now being extended to the whole of England. The Registry has collaborated with the HPA and the Cleaner Hospitals Team of the Department of Health for England in providing details of main and satellite centres, to ensure that all patients on RRT developing MRSA bacteraemia can be accurately identified. The Registry will provide denominator data for future analyses of MRSA rates and will be able to produce reports jointly with the HPA.

Agreement in principle has been reached with the HPA on work to describe the clinical epidemiology of all types of bacteraemia in patients with established renal failure, by linking the Registry dataset with the Lab-Base dataset held by the HPA. The latter contains reports of positive blood cultures submitted by nearly all microbiology laboratories in England.

EDTA-ERA Registry

The UKRR sends fully anonymised data to the European Renal Association Registry. Several representatives have participated in discussions regarding the ERA nephroQUEST programme for European countries, which intends to initiate quality initiatives, similar to many of those already undertaken by the UKRR. The nephroQUEST initiative has recently been granted funding by the European Union; the first phase will involve the specification and development of a standardised renal IT data interface for electronic exchange of data (HL7v3). The nephroQUEST group is also investigating the feasibility of funding and co-ordinating pan-European collaboration in anaemia, mineral metabolism and cardio-vascular risk studies.

Commissioning of renal services and PCTs

An Executive summary of the 9th Annual Report was published (as a pdf file) and distributed to all specialised commissioners in the UK. Feedback has been positive.

The East Midlands Public Health Observatory (www.empho.org.uk) has a statutory responsibility on reporting to the Department of Health for England on renal services.

The Registry has reported some demographic analyses based on Local Authority and PCT areas. Only some of the boundaries of the PCTs and Local Authorities in England are similar. In 2007, the Office for National Statistics has been re-aligning the PCT boundaries with those of Local Authorities.

The Registry and clinical governance

There is a need for clarity on the role of the Registry's responsibilities under the principles of clinical governance, particularly if an individual renal centre appears to be under-performing on one or more key measures of clinical activity. The process set out below has been agreed by the Clinical Affairs Board of the Renal Association.

The Registry Report is sent to the Chief Executives of all Trusts in which a renal centre

is situated, since the responsibility for clinical governance within the Trust lies formally with the Chief Executive.

In the event that Registry analyses of data from a renal centre give rise to professional concern (eg mortality or transplantation rates), the data will first be validated internally by the Registry and then the source data checked with the reporting renal centre.

If the findings and analyses are robust and concern appears warranted, the Registry Chairman will notify the President of the Renal Association and will write to explain the findings to the clinical director or specialty lead of the relevant centre, asking that this information be passed to the Chief Executive of the Trust concerned and also to the Clinical Governance lead for that Trust. Written evidence of the internal hospital transfer of information should be received by the Renal Association within 8 weeks. If such evidence is not forthcoming the President will write to the Medical Director and Chief Executive of the Trust. The Renal Association can offer support (in terms of senior members providing advice) if requested by the Medical Director.

Anonymity and confidentiality

In the first few Registry Reports, all centres were anonymised. Anonymity was removed from all the adult data apart from survival in 2002 and in the 9th Annual Report anonymity for survival was also removed. It is now possible for any member of the healthcare community or general public to see centre-specific analyses on each audit measure, including survival. The response to this de-anonymisation has been uniformly positive, even from centres whose results are at the lower end of the distribution.

Data security and confidentiality

There has been recent concern in the UK over loss and insecure access to confidential information. The UK Registry is a recipient of patient identifiable data. The Caldicott guardian's job in each Trust is to make sure that any identifiable patient data that leaves the Trust site is authorised and complies with the Trusts current responsibilities and that the data held externally will remain secure.

The UKRR is registered under the Data Protection Act and this should be verified independently within the Trust using the following website (registration number Z8096557) http://www.esd.informationcommissioner.gov.uk/esd/search.asp.

The Registry also must apply for annual exemption under the Health and Social Care Act 2001 and Trusts may independently verify this listing on their official register using the following link below (http://www.advisorybodies.doh.gov. uk/piag/register.htm).

When a data file has been created on the local hospital Trusts system, this is encrypted using an approved public/private key 256 bit encryption system prior to transmission to the Registry (www.pgp.com), then emailed as an attachment to the Registry. The Registry is able to provide a software licence for sites whose IT departments will not provide this package.

The data file is transferred to the Renal Registry server based in Southmead Hospital's secure computer room and is then decrypted. There is no external hospital access to the Renal Registry server and there is also no internet access to the server (even through the NHSnet). Access to the Registry server has been configured so that it is restricted to the hub that supplies the building housing the Renal Registry staff. All Registry staff have signed data confidentiality agreements.

Data extraction for statistical analysis excludes identifiable data and relies in the unique Renal Registry number allocated by the Registry.

The 'Health and Social Care Act 2001: section 60 exemption

The Registry has been granted temporary exemption by the Secretary of State to hold patient identifiable data under section 60 of the Health and Social Care Act. This exemption allows the registration of identifiable patient

information from renal centres without first asking the consent of each individual patient, avoiding a breach of the common law on confidentiality.

This exemption is temporary and is reviewed annually. The progress towards collection of anonymised data or obtaining permission of the individual patient is monitored by the Patient Information Advisory Group (PIAG). The third annual report on progress by the Registry towards anonymisation has been submitted to the PIAG and the fourth review is due in March 2008.

Quality Improvement

In the Introduction to the 9th Annual Report, details were given of a planned quality improvement collaborative, the aim of which was to identify and spread best practice in the management of serum phosphate concentration and the correction of renal anaemia. A half-day meeting was held at the British Renal Society meeting in May 2007 to start this work. In preparation for this, 'change packages' were developed by a faculty of clinicians from some of the renal centres with sustained high performance on these two performance indicators. This work was complicated by the changing definition of high performance relating to the management of anaemia: those centres with the highest proportion of patients with a Hb >10 g/dl were not the same as those with the highest proportion of patients with a Hb between 10.5 and 12.5 g/dl, which is the new audit measure introduced by the Renal Association – as many centres with a high proportion of patients with Hb >10 g/dl have, as a consequence of shifting the distribution to the right, a high proportion of patients with Hb >12.5 g/dl as well. Those centres that perform well on both measures have a narrower distribution of Hb values. Despite these difficulties, a number of clinical processes were identified both by the anaemia and phosphate faculties and were presented to participants after a brief intensive session on improvement methodology delivered by a senior clinician from the NHS Institute for Innovation and Improvement. The meeting generated a great deal of interest and enthusiasm. The intention had been to promote active collaboration between improvement teams in each participating renal centre, using a web-based social network. However, the intended website for this purpose proved unsuitable. The Renal Association provided a discussion forum within its website, but this has not proved conducive to improvement teams posting and sharing their experiences and to date there is little evidence of genuine collaboration between teams, although it is clear that some improvement teams have continued to work hard to improve their own results.

New data items

Pre-RRT care

In order to provide some description of the care prior to start of RRT, the Registry is developing software to extract data on laboratory variables at 1, 2, 3, 6 and 12 months prior to start of RRT.

Vascular access and PD access

As part of the testing of the National Renal Dataset, UK nephrologists have supported the Registry in developing definitions of data items to describe the construction and use of both vascular access for haemodialysis and PD access, along with software to enable these items to be extracted from renal IT systems.

Irrespective of this work and the possible Healthcare Commission-funded national renal audit, the Registry plans to collect data on vascular access from all UK renal centres as soon as possible. This will require that all centres develop and implement software enabling the collection of these data items. It is proposed to achieve this by asking all centres to record the type of vascular access actually used for each and every haemodialysis session, preferably by recording this at the point of care along with the pre- and post-dialysis blood pressure and weight. Those centres that also wish to record vascular access construction, complications and use using a 'timeline' approach should continue to do so, as this approach gives additional information that will be useful for local audit and may become suitable for national data collection at some point in the future; however, the former approach is considered simpler and more likely to be widely adopted.

Non-RRT care of patients with stage 5 CKD

The Registry has been awarded funding from Kidney Research UK and the Edith Murphy Foundation to run a pilot project in 8 renal centres, involving collection of data on patients with stage 5 CKD who are not currently receiving RRT. Data will include laboratory variables; co-morbidity, the patient's decision about future RRT (if possible), any form of RRT subsequently initiated and the date and cause of death. If successful, these data will allow analysis of the outcomes of 'conservative', 'palliative' or 'supportive' care as well as an estimate of how many patients enter this pathway.

Peritoneal dialysis

The Registry Committee is acutely aware of the limitations of its analyses of the outcome of peritoneal dialysis. The Registry is unable to report on membrane function, peritonitis rates, residual renal function, prescription of peritoneal dialysis, net ultrafiltration or delivered peritoneal dialysis dose. Other Registries have reported on these – for instance, the ANZDATA Registry has reported on the association between peritoneal transport status and outcome (Rumpsfeld M, McDonald SP, Johnson DW). Higher peritoneal transport status is associated with higher mortality and technique failure in the Australian and New Zealand peritoneal dialysis patient populations (J Am Soc Nephrol 2006; 17: 271–278) and the outcome of peritoneal dialysis after failed kidney transplantation (Badve SV, Hawley CM, McDonald SP, Mudge DW, Rosman JB, Brown FG, Johnson DW: Effect of previously failed kidney transplantation on peritoneal dialysis outcomes in the Australian and New Zealand patient populations. *Nephrol Dial Transplant* 9:9, 2005). With the publication of revised peritoneal dialysis clinical practice guidelines by the Renal Association (http://www.renal.org/guidelines/module3b.html), it is time to put this right.

The problem is not due to lack of willingness of the Registry to report on these data items – the relevant fields have been defined in the Registry dataset for years. The Registry has written software within Proton to support calculation of PD KT/V and PET testing. Uptake to use this software by PD teams at Proton sites rather than their commercial standalone PC based system, has been poor. Other non-Proton based renal system IT suppliers have also not integrated such a product into their software having focused, at least initially, on haemodialysis rather than peritoneal dialysis. The calculations required are also more complex in peritoneal dialysis than in haemodialysis: whereas urea reduction ratio can be calculated simply from the pre-dialysis and post-dialysis urea concentration, calculation of peritoneal dialysis dose requires 13 pieces of information, including the results of biochemical tests on each exchange, drain volumes, plasma biochemistry, height, weight and residual renal function. Consistent practice between centres is also required in measurement of dialysis dose in APD patients, accounting for overfill in the calculation of ultrafiltration in CAPD patients and the correction for glucose interference in the measurement of dialysate creatinine concentration. Reliance on commercially provided software for calculation of dialysis dose is not a solution, since different software packages use different approaches to this calculation.

The UK Peritoneal Dialysis Research Network was formed to study encapsulating peritoneal sclerosis, but is now developing a clinical tool, derived from the GLOBAL fluid study (http://medweb.uwcm.ac.uk/globalfluid/), which accommodates different clinical practices and which will use methods of calculation recommended by the Renal Association Clinical Practice Guidelines committee. It is anticipated that this Network will provide a series of recommendations for the uniform collection of relevant data items in each centre, which will lead rapidly to the development of an agreed dataset in a uniform electronic format suitable for extraction and analysis by the Registry.

Support for renal systems managers and informatics staff

In 2005 and 2006, the Registry provided a forum for a renal informatics meeting supporting development of renal IS & IT staff. Topics included a discussion on current informatics, health informatics professionalism (eg UKCHIP), agenda for change and informatics related job profiles, ways

to enhance the role of IS managers within the MDT, an update from the NHS Information Centre on the national IT programme, provision by the UKRR of centre specific reports and examples of local renal audits. Encouraged by the feedback from those who attended, the Registry is planning a further meeting for September 2008.

Interpretation of the data within the report

It is important to re-emphasise that for the reasons outlined below, caution must be used in interpretation of any apparent differences between centres.

As in previous reports, the 95% confidence interval is shown for compliance with a Standard. The calculation of this confidence interval (based on the Poisson distribution) and the width of the confidence interval depends on the number of values falling within the Standard and the number of patients with reported data.

To assess whether there is an overall significant difference in the percentage reaching the Standard between centres, a Chi-squared test has been used. Caution should be used when interpreting 'no overlap' of 95% confidence intervals between centres in these presentations. When comparing data between many centres, it is not necessarily correct to conclude that two centres are significantly different if their 95% confidence intervals do not overlap. In this process, the eye compares centre X with the other 65 centres and then centre Y with the other 64 centres. Thus, 129 comparisons have been made and at the commonly accepted 1 in 20 level at least 6 are likely to appear 'statistically significant' by chance. If 65 centres were compared with each other, 2,080 such individual comparisons would be made and one would expect to find 104 apparently 'statistically significant' differences at the $p = 0.05$ level and still 21 at the $p = 0.01$ level. Thus, if the renal centres with the highest and lowest achievement of a standard are selected and compared, it is probable that an apparently 'statistically significant result' will be obtained. Such comparisons of renal centres selected after reviewing the data are statistically invalid. The Registry has therefore not tested for 'significant difference' between the highest achiever of a standard and the lowest achiever, as these centres were not identified in advance of looking at the data.

The most appropriate way of testing for significance between individual centres, to see where the differences lie, is not clear. The commonly used Bonferroni test is not applicable to these data, since the individual comparisons are not independent. In several chapters, funnel plots are used to identify significant outliers outside 2 and 3 standard deviations (see chapters 3, 4, 8, 9 and 11). The Registry is investigating further methods of performing such comparisons.

In chapters 3 and 4, charts are presented to allow PCTs and other organisations representing relatively small populations to assess whether their incidence and prevalence rates for renal failure are significantly different from that expected from the age and ethnic mix of the population they serve.

Future potential

Support for renal specialist registrars undertaking a non-clinical secondment

Through links with the Universities of Southampton and Bristol, training is available in both Epidemiology and Statistics. The Renal Registry now has the funding for 3 registrar positions. Dr Alex Hodsman and Dr Udaya Udayaraj started work at the Registry in February 2006 and Dr Daniel Ford started in August 2007.

Dr Raman Rao, Dr Az Ahmad, Dr Alison Armitage, Dr Catherine Byrne and Dr J Rajamahesh have previously completed two years working as a Registry registrar. It is hoped that their positive experiences and publication record will encourage other registrars who are interested in undertaking epidemiological work to consider working with the Registry.

New data collection and analysis

The survey on vascular access

The two national surveys on vascular access have been invaluable in establishing a baseline

for monitoring implementation of the renal NSF and in identifying the obstructions to improvement in the provision of vascular access services. It highlighted the wide variations between renal centres, with some centres managing to start 95% of renal replacement therapy patients with definitive access and others less than 50%. As discussed above, the Registry is working on collecting patient based access data electronically.

Surveys of facilities

After consultation with the Clinical Affairs Board and the renal Clinical Directors forum the Registry has carried out a fourth national renal facilities survey. The Registry has collaborated with the British Renal Society to collect data on non-medical staffing.

Recent UK Renal Registry peer reviewed publications

1. Burton C, Ansell D, Taylor H, Dunn E, Feest TG. Management of anaemia in United Kingdom renal units: a report from the UK Renal Registry. *Nephrol Dial Transplant* 2000;15:1022–1028.
2. Roderick P, Davies R, Jones C, Feest T, Smith S, Farrington K. Simulation model of renal replacement therapy: predicting future demand in England. *Nephrol Dial Transplant*. 2004;19:692–701.
3. Roderick P, Nicholson T, Mehta R, Gerard K, Mullee M, Drey N, Armitage A, Feest T, Greenwood R, Lamping D, Townsend J. A clinical and cost evaluation of hemodialysis in renal satellite units in England and Wales. *Am J Kidney Dis*. 2004;44:121–31.
4. Stel VS, van Dijk PC, van Manen JG, Dekker FW, Ansell D, Conte F, *et al*. Prevalence of co-morbidity in different European RRT populations and its effect on access to renal transplantation. *Nephrol Dial Transplant*. 2005;20:2803–11.
5. Tangri N, Ansell D, Naimark D. Lack of a centre effect in UK renal units: application of an artificial neural network model. *Nephrol Dial Transplant*. 2006; 21:743–8.
6. Feest TG, Rajamahesh J, Byrne C, Ahmad A, Ansell A, Burden R, Roderick R. Trends in adult renal replacement therapy in the UK: 1982–2002. *Quarterly Journal of Medicine* 2005;98:21–28.
7. Blank L, Peters J, Lumsdon A, O'Donoghue DJ, Feest TG, Scoble J, Wight JP, Bradley, J. Regional differences in the provision of adult renal dialysis services in the UK. *Quarterly Journal of Medicine* 2005;98:183–190.
8. Roderick P, Nicholson T, Armitage A, Mehta R, Mullee M, Gerard K, *et al*. An evaluation of the costs, effectiveness and quality of renal replacement therapy provision in renal satellite units in England and Wales. *Health Technol Assess* 2005;9:1–178.
9. Van Dijk PC, Jager KJ, Stengel B, Gronhagen-Riska C, Feest TG, Briggs JD. Renal replacement therapy for diabetic end-stage renal disease: data from 10 registries in Europe (1991–2000). *Kidney Int* 2005;67: 1489–99.
10. Caskey FJ, Schober-Halstenberg HJ, Roderick PJ, Edenharter G, Ansell D, Frei U, *et al*. Exploring the differences in epidemiology of treated ESRD between Germany and England and Wales. *Am J Kidney Dis*. 2006;47(3):445–54.
11. Ahmad A, Roderick P, Ward M, Steenkamp R, Burden R, O'Donoghue D, *et al*. Current chronic kidney disease practice patterns in the UK: a national survey. *Quarterly Journal of Medicine* 2006; 23:23.
12. White P, James V, Ansell D, Lodhi V, Donovan KL. Equity of access to dialysis facilities in Wales. Qjm 2006;99(7):445–52.
13. Caskey FJ, Roderick PJ, Steenkamp R, Nitsch D, Thomas K, Ansell D, Feest TG. Social deprivation and survival on renal replacement therapy in England and Wales. *Kidney Int* 2006;70:2134–2140.
14. Ansell D, Udayaraj UP, Steenkamp R, Dudley CR. Chronic Renal Failure in Kidney Transplant Recipients. Do They Receive Optimum Care?: Data from the UK Renal Registry. *Am J Transplant*. 2007 May; 7(5):1167–76.
15. van Manen JG, van Dijk PC, Stel VS, Dekker FW, Cleries M, Conte F, *et al*. Confounding effect of comorbidity in survival studies in patients on renal replacement therapy. *Nephrol Dial Transplant* 2007; 22(1):187–95.

The following have been submitted for publication:

16. Byrne C, Roderick P, Steenkamp R, Ansell D, Roderick P, Feest TG. Ethnic factors in Renal Replacement Therapy.
17. Nitsch D, Burden R, Steenkamp R, Ansell D, Roderick P, Feest TG. Diabetes in patients with established renal failure: demographics, survival and biochemical parameters.
18. Rao AVR, Ansell D, van Schalkwyk D, Feest TGF, Peritoneal dialysis technique survival in the UK: A UK Renal Registry data analysis.
19. Rao AVR, Ansell D, Steenkamp R, Williams AJ, Dudley CRK. Effect of 1st Year Renal Graft Function on Post Transplant Hemoglobin, Blood Pressure and Bone Metabolism: Data from UK Renal Registry.

Commissioned research and reports

1. Feest T, Rajamahesh J, Taylor H, Roderick P. The Provision of Renal Replacement Therapy for adults in the UK 1998. 1998 National Renal Survey, Report for Department of Health.

2. Roderick P, Armitage A, Feest TG, *et al*. An evaluation of the effectiveness, acceptability, accessibility and costs of renal replacement therapy in renal satellite units in England and Wales. Report for Department of Health, 2003.
3. Roderick P., Davies R., Jones C., Feest T., Smith S., Farrington K. Simulation model of renal replacement therapy: predicting future demand in England. HTA report 2003.
4. Feest TG, Byrne C, Ahmad A, Roderick P, Webber S, Dawson P. The Provision of Renal Replacement Therapy in the UK 2002. Report for the Department of Health, 2004.
5. Ansell D, Benoy-Deeney F, Dawson P, Doxford H, Will E. Welsh data validation exercise project report. Report for the Welsh Assembly 2005.

Distribution of the Registry Report

This report will also be distributed to Strategic Health Authorities and all PCTs in England and Commissioners throughout the UK.

Further copies of the report will be sent to individuals or organisations on request: a donation towards the £15 cost of printing and postage will be requested. CDs will also be available. The full report may be downloaded from the Registry website, www.renalreg.org.