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UK Renal Registry 19th Annual Report: Introduction

Fergus Caskey, Retha Steenkamp, Karen Thomas

UK Renal Registry, Bristol, UK

Background

Fair processing is a key principle of the Data Protection Act and requires organisations to be clear and open with individuals about how their information will be used. This is particularly important where data are collected without individual patient consent with support under section 251 of the Health and Social Care Act, as is the case for the UK Renal Registry (UKRR).

As part of ongoing efforts to communicate its work to patients and clinicians, in 2017 the UKRR worked with its Patient Council to update its information leaflets and posters. It also produced a video animation explaining the varied work of the UKRR (see www.renalreg.org/about-us/) and published a more technical "Strategy on a Page" series (see www.renalreg.org/about-us/strategy-mission/). The framework used by the Strategy on a Page series arranges activity into three broad areas: audit, research, improvement and innovation and clinical informatics. The same framework has been adopted here.

Audit

The UKRR collects data primarily for national audit. For this purpose it is essential that high risk populations are not excluded and on this basis it continues to receive support under section 251 of the Health and Social Care Act to collect data without individual patient consent. With the recent expansion of the scope of the UKRR to include acute kidney injury (AKI) and pre-dialysis chronic kidney disease (CKD) in England, Wales and Northern Ireland, the Confidentiality Advisory Group of the Health Research Authority requested two new applications from the UKRR in 2016:

1. An updated non-research application, i.e. to allow audit and quality assurance
2. A new research application.

These applications both sought a legal basis for linking the UKRR data to the Hospital Episode Statistics and Office for National Statistics databases at NHS Digital (figure 1). Separate arrangements are required for Scotland and Northern Ireland.

Since the UKRR secured the necessary legal bases in December 2016 and March 2017 respectively, the next step has been to apply to NHS Digital to link the main UKRR database to the Hospital Episode Statistics and

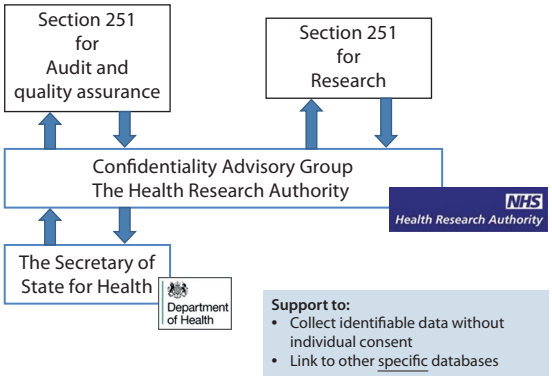

Fig. 1. Section 251 approval process

KARGER

Fax +41 61 306 12 34
E-Mail karger@karger.com
www.karger.com/nef

Fergus Caskey
UK Renal Registry, Southmead Hospital, Southmead Road, Bristol, BS10 5NB, UK
Email: renalregistry@renalregistry.nhs.uk

Office for National Statistics databases. This has the potential to enhance the UKRR data in a number of ways, by:

- enabling adjustment for case-mix in centre survival comparisons
- providing information about differences in rates of hospital admission between renal centres
- making it possible to study equity of access to other non-renal services, such as cardiology, stroke and orthopaedic
- transforming the AKI database from a 'master patient index' of all cases of AKI in primary and secondary care into one with information about admissions to hospital, reasons for admission to hospital, admissions to intensive care units and mortality
- providing hospital admissions and mortality data to support efficient clinical trials in nephrology.

This linkage is likely to take six to twelve months to agree, but has the potential to transform the way the UKRR works.

In the meantime, during the Summer of 2016, one new chapter (Home Therapies) and one revamped chapter (Dialysis Access) were prepared for this year's Annual Report. Dr Matt Tabinor and Dr Barny Hole, Academic Clinical Fellows affiliated with the UKRR from Stoke and Bristol, led the work in a series of task and finish groups with UKRR statisticians and expert co-authors. The aim of these, to explore and present the data in new ways. For example, the dialysis access chapter explores the counter-intuitive finding in last year's report of higher permanent vascular access rates in older people and those with a very high body mass index and concludes that these are likely explained by lower rates of transplantation and peritoneal dialysis in these groups. At the same time, however, these new analyses lead to as many new questions and ideas for how we should study the structure and process differences behind the variation in outcomes. The feedback on this approach has been positive and therefore there are plans to do something similar for future reports.

Research

As part of the re-application for section 251 support, it was necessary to cease all research activity for a number of months in 2016. The UKRR is very grateful to all researchers whose work was affected for their patience during this time. At last, in April 2017, advertisements for applications from researchers interested in analysing the UKRR data to answer specific research hypotheses were placed. Going forwards, there will be four such calls a year, timed to allow peer-review of the applications by clinician researchers and members of the UKRR's Research Methods Study Group before a recommendation is made regarding release of the data. Establishing such formal assessments of scientific quality and risk of re-identification and being transparent to patients about the use of their data were key requirements for the UKRR's ongoing section 251 support. For further information see www.renalreg.org/about-us/working-with-us/.

Despite the restrictions placed on UKRR research activity in 2016/2017, several papers have been published from work that pre-dated the temporary halt in research activity and these are listed in appendix 1 of this chapter.

The need to reapply for section 251 support has not held up applications for primary research, and there have been a number of recent successes (table 1). Most notable amongst these are two NIHR HTA-funded

Table 1. Grant and fellowship income in 2016/2017

Reference	Title	Applicant/Chief investigator	Value (Period)
NIHR HTA 15/80/52	The High-volume Haemodiafiltration vs. High-flux Haemodialysis Registry Trial (H4RT).	F J Caskey	£1,500,276 (2017–2021)
NIHR HTA 15/57/39	Prepare for Kidney Care Trial – a randomised controlled trial of preparing for responsive management versus preparing for renal dialysis	F J Caskey	£2,538, 968 (2017–2021)
NIHR HTA 14/216/01	Bioimpedance guided fluid management in dialysis patients – the BISTRO trial.	S Davies	£1,403,368 (2016–2019)
NIHR DRF	Why do children with severe chronic kidney disease present late to specialist services? A mixed-methods observational study.	L Plumb	£331,496.00 (2017–2022)

NIHR National Institute for Health Research; HTA Health Technology Assessment; DRF Doctoral Research Fellowship

individual patient level randomised controlled trials:

1. The Prepare for Kidney Care Study – a randomised controlled trial of preparing for responsive management versus preparing for dialysis (£2.5m)
2. The High-volume Haemodiafiltration versus High-flux Haemodialysis Registry Trial (£1.5m)

Both are currently in set-up phase, with sites opening to recruitment in July 2017 and November 2017, respectively. This as a significant development at the UKRR and alongside the quality improvement work provides a new set of tools and opportunities to generate evidence that will improve patient care and outcomes for people with kidney disease.

UKRR data have impact in other ways too, and throughout 2016/2017 a number of requests for data sharing for audit, commissioning and research have been approved. Several previously approved projects also remain open. For details see table 2.

Table 2. UKRR work requests received 2016–2017

Originator: person & organisation	Aims & objectives	Date			Funding?
		Original application	Data shared	End	
David Milford, Birmingham Children's Hospital[a]	A list of hospitals that report AKI data to the UKRR by month.	Feb 2017	Feb 2017	Feb 2017	None
Aric Bendorf, Centre for Value, Ethics and the Law in Medicine (VELiM), the University of Sydney[a]	Data requested for the time period of 2003–2015 by age group and year included: • Number of patients in each dialysis group • Number of patients in each diagnosis group • Number of deaths while on dialysis	Aug 2016	Mar 2017	Mar 2017	None
Hanna Meredith, BBC[a]	Incident and prevalent numbers by year (2011–2015), for Leicestershire, Derbyshire and Nottinghamshire	May 2017	May 2017	May 2017	None
Su Sheti, NHS England[a]	Incident and prevalent numbers in 2015, by CCG in the North-West of England	Dec 2016	Mar 2017	Mar 2017	None
Matthew Katz, Department of Health[a]	Incident numbers in 2013 and 2014, by age-group, gender and referral for each treatment modality	Aug 2016	Aug 2016	Aug 2016	Health Foundation (ASSIST-CKD grant)
World Health Organisation (via Andrew Hughes, Public Health England)[a]	Global Burden of Disease update	Nov 2016	Dec 2016	Dec 2016	None
Neil Ashman, NHS England (London Region)[a]	Information on a variety of measures for London – suggested by their 'Quality Review Service'	Jul 2016	Oct 2016	Oct 2016	None
Deborah Duval, Kidney Life[a]	Information for the spring issue 2017 publication of Kidney Life	Jan 2017	Jan 2017	Jan 2017	None
Zandra Richards[a]	Information for a patient forum	Nov 2016	Dec 2016	Dec 2016	None
Hannah Burton, Kings College London[b]	Information for research on cause of graft failure.	Sep 2016	Nov 2016	In progress	None
John Wilson, Liverpool CG[a]	Number of AKI-alerts in April'15-March'16, by month and AKI-stage, from Liverpool laboratories	July 2016	July 2016	July 2016	None

[a]No input from the UKRR after supplying the data
[b]UKRR will perform most of the analysis and the write up

Improvement and innovation

A main component of UKRR work is quality improvement and innovation, which falls under the banner of our Think Kidneys brand. There are three main programmes of activity under Think Kidneys and significant progress has been made over the last year with respect to this work.

AKI national programme

This is a national NHS campaign to improve the care of people at risk of, or with, AKI. The programme was a partnership between the UKRR and NHS England, and then latterly, NHS Improvement, with the main programme of work concluding in March 2017. The AKI programme was established to address the need identified by the National Confidential Enquiry into Patient Outcome and Death (NCEPOD) and NICE. The national programme responded by raising awareness of AKI, improving access to education, developing effective resources and sharing best practice across the NHS and beyond.

More than 70% of laboratories in England are now submitting AKI data from primary and secondary care to the UKRR. Going forward, the focus of the work at the UKRR will be improving the quality of the data coming in and identifying other data sets to link with to provide more meaningful data. Running in parallel with these efforts, a working group has been set up to begin the process of agreeing a publication plan which will detail analyses and their interpretation together with a reporting structure appropriate for different audiences.

Transforming Participation in CKD programme

This programme is a further collaboration between the UKRR and NHS England. The programme supports a person centred approach to care where people with kidney problems are supported to build their skills, knowledge and confidence to better manage and make decisions about their own health to improve their quality of life. This programme has successfully piloted the collection of patient reported outcome measures and a patient's level of activation in 14 renal centres. Renal centres have been encouraged to test various ways to collect the data and work continues to test interventions that might have a positive impact on an individual's outcome.

A development of this programme has been the introduction of an annual Patient Reported Experience Measure Survey (PREM). This is a joint collaboration between the UKRR and Kidney Care UK. This collaboration has allowed the expansion of this survey outside of the original programme. A pilot survey was run last year which resulted in over 8,000 completed surveys. The survey has now been validated and rolled out to English and Welsh centres. For further information see www.renalreg.org/projects/prem.

Kidney Quality Improvement Partnership

The Kidney Quality Improvement Partnership (KQuIP) is a dynamic network of kidney health professionals, patients and carers who are committed to developing, supporting and sharing quality improvement in kidney services in order to enhance outcomes and quality of life for patients with kidney disease. It will improve the lives of adults and children affected by kidney disease by supporting healthcare professionals, kidney units, renal networks and commissioners across the UK to achieve the highest quality of care for patients. KQuIP builds on rather than replaces existing quality improvement structures.

It will do this by:

- focussing on embedding systematic quality improvement (QI) into everyday multidisciplinary paediatric and adult practice by clinicians and managerial staff within all renal services including kidney transplantation
- providing expert clinical strategic advice regarding QI within renal services to NHS England and the other UK countries
- facilitating education, project management and capture of outcome data for QI projects in collaboration with renal clinical networks/regional QI architecture and local renal units.

It is anticipated that this supportive framework will provide the freedom for clinicians to identify, foster and encourage local innovation (bottom up ideas and priorities) and to address education of clinical staff to improve the quality of practice with an expectation that this learning will be passed on and shared.

For more details and latest activities on any of these programmes please visit https://www.thinkkidneys.nhs.uk/.

Clinical informatics

The UK Renal Data Collaboration (UKRDC) is a new process for collecting data for kidney patients, whereby data will flow into a central data repository and flow

out to various organisations with approved access to the data. The main advantages of implementing the UKRDC are:

- reducing unnecessary data flows and increasing efficiency
- storing all renal data in a central warehouse
- obtaining more granular data and meta data
- timely data for the renal community and NHS England
- renal units will have the ability to access and interrogate their data in almost real time
- improving the use made of available data

The implementation of the UKRDC requires IT developments, such as:

- adopting standard terms using SNOMED CT and LOINC
- adopting standard methods for labelling and formatting data via the creation of a data model and standard messaging system
- developing two way communications between all participants including patients via Patient View (PV).

There has been major progress in the implementation of the UKRDC over the last 12 months:

- PatientView: laboratory results are now flowing through the UKRDC to PV on an almost real time basis
- the National Registry of Rare Kidney Disease (RaDaR): data is now being transferred in both directions between the UKRDC and RaDaR. This has allowed the UKRR to provide researchers from several renal disease groups with data extractions that include both manually entered data and PV data which has been received electronically
- the Transforming Participation in Chronic Kidney Disease (TP-CKD) project: TP-CKD is supported by the UKRDC and scanned PAM and PROM survey results are uploaded into the UKRDC and stored in the central repository. Reports are generated and sent to PV where they can be viewed by patients registered on PV and to renal centres
- SNOMED CT: SNOMED codes have been added into the updated UKRDC schema and the implementation of SNOMED successfully tested in an anonymised dataset of primary renal diseases
- clinical trials: the UKRDC is supporting the NIHR HTA-funded SIMPLIFIED clinical trial of cholecalciferol versus placebo to reduce all-cause mortality in dialysis patients (led by Dr Thomas Hiemstra in Cambridge). Particularly novel from a UKRR perspective is the ability to provide laboratory data such as blood calcium level in real-time to the clinical trials unit
- UKRDC pilot sites: these have been identified and agreed to work with the UKRR to develop an extract to the UKRDC. UKRDC test files have been received from the first pilot site and from one of the renal system suppliers and work is underway to finalise the extraction. As a result of working on the UKRDC extract with pilot sites and renal system suppliers, the UKRDC schema documentation has been updated, refined and published on the website (*www.ukrdc.org*). Some pilot sites are expected to submit some of their 2016 data via the UKRDC.

The concept of the UKRDC has been proven and data are flowing through the UKRDC in two directions. Work with pilot sites is progressing but the success of the UKRDC depends on support and commitment from renal centres and the renal community.

Completeness of data returns from UK renal centres

Data completeness remains fairly static for returns on ethnic origin, primary renal diagnosis and date first seen by a nephrologist (table 3). Comorbidity at the start of RRT remained poor, with almost half (30/62) of the adult renal centres in England, Wales and Northern Ireland having less than 75% completeness for comorbidity data. Twelve renal centres submitted comorbidity data on less than 10% of their incident patients. This makes it impossible for the UKRR to adjust survival analyses for case mix, something that is particularly relevant to outlying centres [1]. The UKRR and NHS Digital have agreed that there could be considerable benefits for patients from routine linkage with Hospital Episode Statistics data [2].

For the first time since the UKRR gained full coverage of the UK in 2008, one renal centre, Cambridge, was unable for technical reasons to provide patient level data in time for inclusion in the Annual Report. As a temporary measure, aggregate data were provided to allow estimation of treatment rates and work is ongoing within

Table 3. Percentage completeness of data returns for 2015 and 2014

	Ethnicity Year		Primary diagnosis Year		Date first seen Year		Comorbidity Year		Cause of death Year		Average completeness Year		
Centre	2015	2014	2015	2014	2015	2014	2015	2014	2015	2014	2015	2014	Country
Newry	100.0	100.0	100.0	100.0	100.0	94.7	100.0	94.7	100.0	93.3	100.0	96.6	N Ireland
L Kings	100.0	100.0	100.0	100.0	99.4	100.0	100.0	100.0	96.7	98.7	99.2	99.7	England
Oxford	99.0	76.2	100.0	97.4	98.5	97.9	99.5	95.2	96.9	98.3	98.8	93.0	England
Swanse	100.0	100.0	99.2	100.0	100.0	100.0	99.2	100.0	94.9	82.6	98.7	96.5	Wales
Hull	99.2	100.0	99.2	99.0	97.6	95.3[b]	99.2	100.0	97.3	91.7	98.5	97.2	England
Leeds	98.6	100.0	99.3	100.0	98.0	99.4	99.3	100.0	96.4	99.2	98.3	99.7	England
Bangor	100.0	100.0	100.0	81.8	100.0	90.9	100.0	59.1	90.0	95.0	98.0	85.4	Wales
Ulster	100.0	100.0	96.9	100.0	96.9	94.7	100.0	100.0	96.0	90.0	98.0	96.9	N Ireland
Middlbr	100.0	100.0	99.3	99.0	98.5	98.1	98.5	97.1	93.4	95.1	97.9	97.9	England
Wrexm	97.8	100.0	100.0	97.6	93.3	97.6	100.0	100.0	97.4	87.0	97.7	96.4	Wales
B Heart	100.0	100.0	99.2	83.7	95.9	92.8	98.4	99.0	93.8	65.6	97.4	88.2	England
Bradfd	96.6	98.8	98.9	100.0	100.0	100.0	98.9	100.0	90.2	98.0	96.9	99.4	England
Dudley	100.0	95.1	100.0	87.8	95.9	95.1	93.9	87.8	94.3	95.5	96.8	92.3	England
West NI	100.0	97.1	100.0	100.0	96.5[b]	97.0	86.5	97.1	100.0	93.9	96.6	97.0	N Ireland
York	90.2	93.8	100.0	98.4	98.4	90.5[b]	98.4	95.3	94.7	97.4	96.3	95.1	England
Dorset	100.0	100.0	98.7	100.0	94.6	98.7	97.3	100.0	90.2	90.6	96.1	97.8	England
Sund	96.8	100.0	95.2	96.8	96.8	100.0	93.7	95.2	98.0	97.4	96.1	97.9	England
L Guys	95.0	93.7	93.9	64.8	93.3	81.5	100.0	1.9	92.4	0.0	94.9	48.4	England
Exeter	93.4	97.8	99.2	97.1	99.2	91.9	93.4	93.5	85.3	96.5	94.1	95.4	England
Cardff	93.7	100.0	100.0	99.4	98.1	95.8	94.9	89.9	80.9	96.7	93.5	96.4	Wales
Newc	100.0	100.0	99.2	100.0	99.2	98.1	94.3	97.2	74.1	51.8	93.4	89.4	England
Redng	93.0	93.5	100.0	99.1	100.0	97.2	94.2	92.5	76.7	79.7	92.8	92.4	England
Antrim	100.0	100.0	100.0	100.0	94.3	97.1	71.4	100.0	93.9	100.0	91.9	99.4	N Ireland
Derby	96.8	98.7	98.4	98.7	98.4	97.3	79.0	94.7	86.4	73.7	91.8	92.6	England
Kent	100.0	94.7	61.2	96.7	100.0	100.0	100.0	100.0	95.3	86.6	91.3	95.6	England
Wolve	100.0	100.0	98.8	87.3	97.6	92.4	94.0	16.5	62.5	85.2	90.6	76.3	England
Donc	100.0	100.0	100.0	100.0	94.4	98.2	63.9	70.4	91.7	96.8	90.0	93.1	England
B QEH	99.2	100.0	99.6	99.6	98.8	97.9	98.8	96.7	53.4	90.4	90.0	96.9	England
Chelms	78.3	71.2	89.1	100.0	95.7	98.1	82.6	92.3	96.2	85.7	88.4	89.4	England
Clwyd	100.0	89.7	96.6	79.3	72.4	78.3[b]	72.4	55.2	100.0	90.0	88.3	78.5	Wales
Wirral	93.7	98.2	93.7	73.2	92.2[b]	96.4	84.1	30.4	69.0	68.5	86.5	73.4	England
Stoke	99.1	97.3	83.2	57.1	92.5	90.1	75.7	81.3	75.0	53.5	85.1	75.9	England
Plymth	100.0	100.0	96.2	32.1	94.3	26.9	52.8	41.5	74.0	24.5	83.5	45.0	England
Colchr	78.6	78.9	78.6	64.2[a]	67.9	44.7	100.0	100.0	90.0	77.3	83.0	73.0	England
Glouc	100.0	100.0	100.0	96.1	92.2	66.7	28.1	15.7	94.2	88.1	82.9	73.3	England
Norwch	99.1	77.2	94.5	93.7	94.2[b]	49.9[b]	76.2	43.0	48.6	74.0	82.5	67.6	England
Basldn	93.5	95.7	73.9	100.0	97.8	95.7	54.4	89.1	86.4	90.0	81.2	94.1	England
Truro	100.0	100.0	98.8	94.9	96.3	97.4	3.8	0.0	98.0	97.1	79.3	77.9	England
L West	100.0	99.7	99.7	100.0	97.7	98.6	0.0	0.3	96.7	93.8	78.8	78.5	England
Bristol	89.6	100.0	96.5	85.1	77.8	95.2	64.6	84.5	61.2	90.0	77.9	91.0	England
Nottm	100.0	100.0	97.6	100.0	94.4	97.3	0.8	95.5	95.7	98.9	77.7	98.3	England
Shrew	100.0	98.5	100.0	90.8	83.7[b]	98.4	67.7	18.5	34.9	0.0	77.3	61.2	England
Carlis	100.0	100.0	57.3	100.0	97.7	92.1	45.5	55.3	82.4	92.0	76.6	87.9	England
Prestn	99.4	99.3	100.0	99.4	96.9	97.4	4.4	4.6	80.3	95.2	76.2	79.2	England
Sthend	94.3	63.3	100.0	100.0	88.6	100.0	0.0	76.7	97.0	95.7	76.0	87.1	England
Liv Ain	97.0	98.5	100.0	100.0	95.5	98.5	72.7	56.7	12.5	0.0	75.5	70.7	England
Sheff	95.8	96.7	100.0	99.3	92.7	98.7	79.2	78.8	0.8	0.9	73.7	74.9	England
Leic	90.5	93.7	76.6	78.0	98.2	98.0	29.3	42.9	57.7	55.2	70.4	73.6	England
Belfast	69.7	100.0	77.5	95.2	89.9	91.9	45.5	77.8	47.8	51.1	66.1	83.2	N Ireland
L Rfree	97.0	94.8	96.2	96.1	96.2	96.1	8.5	22.3	16.1	15.9	62.8	65.0	England
M RI	93.6	93.2	95.5	59.5	92.3	43.4	25.9	34.2	2.0	1.4	61.8	46.3	England
Stevng	87.8	90.1	68.4	80.3	87.8	94.1	1.4	0.7	62.1	9.3	61.5	54.9	England

Table 3. Continued

	Ethnicity Year		Primary diagnosis Year		Date first seen Year		Comorbidity Year		Cause of death Year		Average completeness Year		
Centre	2015	2014	2015	2014	2015	2014	2015	2014	2015	2014	2015	2014	Country
Brightn	88.7	93.2	90.1	100.0	97.9	98.6	4.2	11.6	7.0	0.9	57.6	60.9	England
L Barts	99.7	99.4	89.8	82.6	1.1[b]	28.7	40.8	55.2	49.2	82.7	56.1	69.7	England
L St.G	94.1	86.8	51.3	75.8	67.2	24.2	31.1	42.9	32.8	57.1	55.3	57.4	England
Covnt	100.0	98.4	64.2	88.0	88.1	84.8	15.6	15.2	4.7	6.7	54.5	58.6	England
Ports	84.8	84.9	69.5	86.7	67.0	59.5	17.3	26.7	33.8	38.8	54.5	59.3	England
Liv Roy	93.2	94.2	46.6	85.4	91.1	97.8	28.1	48.2	11.0	19.0	54.0	68.9	England
Salford	98.6	99.3	95.7	98.6	5.8	0.7	0.0	0.0	0.0	0.0	40.0	39.7	England
Carsh	93.1	87.9	17.3	23.8	42.3	41.4	4.0	11.4	24.9	16.3	36.3	36.2	England
Ipswi	80.3	0.0	34.9	61.2[a]	16.7	90.9	7.6	0.0	25.0	83.3	32.9	47.1	England
Camb		86.6		57.3[a]		68.5		4.7		42.3		51.9	England
Abrdn			100.0	100.0					46.7	67.7			Scotland
Airdrie			100.0	100.0					97.5	97.6			Scotland
D&Gall			100.0	100.0					69.2	100.0			Scotland
Dundee			100.0	100.0					66.7	52.8			Scotland
Edinb			100.0	100.0					92.6	96.2			Scotland
Glasgw			100.0	100.0					91.4	100.0			Scotland
Inverns			100.0	100.0					100.0	100.0			Scotland
Klmarnk			100.0	100.0					97.4	100.0			Scotland
Krkcldy			100.0	100.0					54.8	92.3			Scotland

[a]Data from these centres included a high proportion of patients whose primary renal diagnosis was 'uncertain'. In some cases, this appears to have been because software in these centres was defaulting missing values to 'uncertain'. The value given for the completeness has been reduced in proportion to the amount by which the percentage of non-missing diagnoses being 'uncertain' exceeded 40%
[b]More than 10% of patients reported as starting RRT on the same date as first presentation, the percentage completeness shown excludes the amount by which this exceeded 10%

the Trust and with commissioners to ensure submission recommences as quickly as possible. This has however meant that it was impossible to audit the quality of care and outcomes for people with kidney disease in the Cambridge area and this has been made clear in each of the relevant tables and figures in this report.

Interpretation of centre-specific clinical measures and survival comparisons

The UKRR continues to advise caution in the interpretation of the comparisons of centre-specific attainment of clinical performance measures provided in this report. In general terms, the UKRR has not tested for a 'significant difference' between the highest achiever of a standard and the lowest achiever, as centres were not identified in advance of looking at the data and statistically this approach can be invalid. As in previous reports, the arbitrary 95% confidence interval is shown for compliance with a guideline. The calculation of this confidence interval (based on the binomial 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. However for many of these analyses no adjustment can be made for the range of factors known to influence the measured variable as outlined above.

For a number of years de-anonymised centre specific reports on survival of RRT patients have been published. The Francis and Keogh enquiries and the ongoing CQC inspections of patient care and outcomes at a number of hospital trusts highlight the ongoing need for such transparency. This year (2015 data) two centres had to be contacted because of lower than expected survival in patients starting dialysis. Although that centre's results may reflect the comorbidity of their patients, the UKRR was unable to adjust the main survival analysis due to missing key data from many other centres (as discussed above).

Centres are asked to report their outlying status internally at trust level and follow up with robust mortality and morbidity meetings. The UKRR has no statutory powers. However, the fact that the UKRR provides centre-specific de-anonymised analyses of important clinical outcomes, including survival, makes it important to define how the UKRR responds to apparent under-performance. The senior management team of the UKRR communicate survival outlier status with the renal centres in advance of publication of this finding. The centres are asked to provide evidence that the Clinical Governance department and Chief Executive of the Trust housing the service have been informed. In the event that no such evidence is provided, the Chief Executive Officer or Medical Director of the UKRR would inform the President of the Renal Association, who would then take action to ensure that the findings were properly investigated.

Information governance

At present the UKRR operates within a comprehensive governance framework covering data handling, reporting and research, including data linkages and data sharing agreements. The Chair of the Renal Association Renal Information Governance Board is the person responsible for ensuring good governance, with the UKRR Chief Executive Officer as data controller and accountable officer responsible for day to day management of governance compliance. The Chief Executive Officer is supported by the Senior Information Risk Officer and the Caldicott Guardian. The framework is based on good practice, as described in the Information Governance Framework [3] and the Research Governance Framework for Health and Social Care (2005).

Each year the UKRR completes the NHS Digital Information Governance Toolkit and for the 2016/2017 assessment period achieved a score of 94% (subject to audit) against the 'satisfactory' standard of 80%.

Summary

The big challenge for the UKRR in 2017 is the need to use its new permissions to link to other databases for efficient national audit, perhaps most excitingly in research through the AKI Master Patient Index and the delivery of efficient registry trials. The core purpose of the UKRR remains however, national audit with the ability to report patient survival on dialysis and kidney transplantation. To this end it must be a priority to use the new linkage permissions to derive information about patient comorbidity from hospital admissions data and report case-mix adjusted survival for each renal centre. Until this happens, the UKRR report could be inappropriately alarming patients and clinicians in some centres whilst falsely reassuring patients and clinicians in others.

Conflicts of interest: the authors declare no conflicts of interest

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