nephron Clinical Practice

Nephron 2016;132(suppl1):1–8
DOI: 10.1159/000444814

Published online: April 19, 2016

UK Renal Registry 18th Annual Report: Introduction

Fergus Caskey, Ron Cullen

UK Renal Registry, Bristol, UK

Activity since the last Annual Report

Registries have the potential to improve the health of the population in so many ways. Their data can be used to generate and refine hypotheses that require testing, to inform optimal study design, to provide the evidence of need for the research to help secure funding, to provide an efficient framework for sampling and data collection in trials, to track changes in practice and finally and most importantly to monitor changes in population health outcomes (figure 1). We believe we have a responsibility to work across this translational public health spectrum [1], achieving the maximal benefit from observational data as well as interventional trials, and developing methods to cover the full range of complexity of interventions that are required in health care. We believe we have made a little more progress towards doing this over the last 12 months.

The UK Renal Data Collaboration

Essential for the progress of the UK Renal Registry (UKRR) is an upgrade in the basic mechanisms by which data is collected. As information technology continues to advance, this is going to be a journey rather than a single step or leap. In the introduction to last year's report we set out the proposed new data collection infrastructure for the UK Renal Data Collaboration

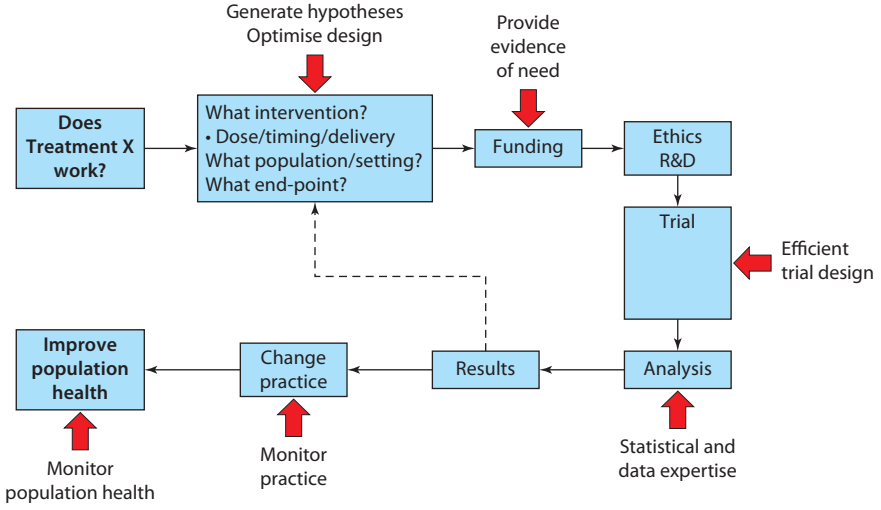

Fig. 1. Translational Public Health Research: block arrows show the potential role of registries at various stages

KARGER
Fax +41 61 306 12 34
www.karger.com/nef

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

(UKRDC), a partnership between seven of the main UK renal organisations – The UK Renal Registry, The Scottish Renal Registry, The British Association of Paediatric Nephrology, PatientView, The UK Registry for Rare Kidney Diseases (RaDaR), The Northern Ireland Nephrology Forum and The Welsh Renal Clinical Network.

There has been major progress with the UKRDC over the last 12 months. The schema for transmitting data has been published and a range of sites have expressed an interest in piloting the extraction and transmission of UKRR data. PatientView data is now flowing through the UKRDC, with plans for this to feed RaDaR in early 2016, demonstrating the ability of the UKRDC to capture real-time data from renal centres – a huge advance for the UKRR. Further evidence of the opportunities this creates is provided by the fact that for the first time the UKRR is able to support an efficient randomised controlled trial (SIMPLIFIED) by providing daily feeds of laboratory data for patients consented into the trial.

Changes in eligibility for reporting to the UKRR and the dataset: dialysis and plasma exchange for AKI and CKD stages 4 and 5

From January 2015, renal centres in England were required to submit data to the UKRR on all cases of dialysis or plasma exchange (PEx) for acute kidney injury (AKI). The first files containing this data started to be uploaded in late 2015. Over the coming months we will be reporting compliance with reporting these data at the renal centre level and we hope to publish some of the initial data on dialysis or plasma exchange for AKI in the 2016 Report.

The requirement for English renal centres to submit data on dialysis or PEx for AKI was set out by the National Clinical Director for renal services and the chair of the Clinical Reference Group for dialysis in England. However, it then became part of the UKRR's core data set from January 2016 (version 4) and so applies to adult and paediatric renal centres in Wales, Scotland and Northern Ireland from this date. Also new in this data set is the requirement to submit data on patients known to renal centres with an estimated eGFR of less than 30 ml/min/1.73 m^2. This will allow the UKRR to identify a cohort of pre-dialysis patients with stage 4 or 5 chronic kidney disease whose care and outcomes can be audited including their decision to receive conservative care or their transition onto dialysis. With the acute dialysis data, this should for the first time allow us to report on quality of care and outcomes during a very high risk period for patients.

National Programmes working with NHS England

Data on cases of AKI in primary and secondary care are now flowing from 70 of the approximately 120 laboratories in England as part of the Acute Kidney Injury National Programme being run in collaboration with NHS England. This work is being managed through the measurement work stream of the National Programme and is part of a range of activities including education, risk assessment and commissioning. The first analyses of these data should become available in 2016.

The other collaboration with NHS England is called 'Transforming Participation – CKD'. It aims to pilot the routine collection of patient reported outcomes, initially in 10 renal centres but scaling up to 23 renal centres over 12 months. Renal centres are being encouraged to test various ways to collect the data from patients on all forms of treatment – CKD, dialysis and transplant. The NHS England sponsored work is focussed on quality of life and patient activation. Closely linked to this is a piece of worked supported by the British Kidney Patient Association to measure and report the patient experience.

For more details on either of these programmes please visit the Think Kidneys website www.thinkkidneys.nhs.uk.

Research

There has been some exciting progress with research. Dr Thomas Hiemstra of Cambridge Clinical Trials Unit has obtained funding from the NIHR HTA for the UKRR's first registry trial – where all follow up is being carried out remotely with linkage to routine databases. The trial is called SIMPLIFIED and tests the hypothesis that ordinary vitamin D given to dialysis patients reduces all-cause mortality. What is particularly novel about this collaboration is that the UKRDC is providing daily reports back to the Clinical Trials Unit on all calcium laboratory results reported for participating patients, providing an efficient mechanism for serious adverse event monitoring.

More challenging has been the evolving information governance landscape. Permissions for the UKRR to undertake research and linkage with data have had to be (re-) established and it has become clear that research ethics committee approval is needed for all work that is not audit or quality assurance, holding up several analyses this year.

Output since the last Annual Report

The UKRR is keen to become formally included in research grant applications, with early involvement to ensure appropriate integration in the study design and consideration of its costs. In the last 12 months it has been a co-applicant on four grant applications:

- NIHR HTA: the SIMPLIFIED trial, led by Dr Thomas Hiemstra of Cambridge, an individual level randomised controlled trial of ergocalciferol versus placebo in dialysis patients.
- Health Foundation: Tackling AKI, led by Dr Nick Selby of Derby, a stepped wedge cluster randomised controlled trial of a complex intervention to reduce harm from acute kidney injury.
- NIHR HTA: BisCKD, led by Dr Daniel Prieto Alhambra of Oxford, a linkage study exploring the risks and benefits of bisphosphonate use in patients with chronic kidney disease.
- NIHR HS&DR: Risk modelling in the critically ill, led by Dr David Harrison of the Intensive Care National Audit and Research Centre London, to develop risk prediction models for quality improvement.

A number of requests for data sharing have been approved in the past 12 months (table 1) and a number of projects previously approved remain open. Data are shared for specific analyses only and securely destroyed at the end of the agreed period. For further details or to enquire about accessing UKRR data please visit the UKRR's website (www.renalreg.org).

Completeness of data returns from UK renal centres

Data completeness has improved over recent years for returns on ethnic origin, primary renal diagnosis and date first seen by a nephrologist (table 2). Comorbidity at the start of RRT remains poorly returned, with almost half (29/62) of the adult renal centres in England, Wales and Northern Ireland having less than 75% completeness for comorbidity data. For a number of centres this limits the UKRR's ability to adjust their survival for casemix, something that is particularly relevant to outlying centres [2]. The UKRR and the Health and Social Care Information Centre (HSCIC) have agreed that there could be considerable benefits for patients from routine linkage with Hospital Episode Statistics [3], although as with everything linked to the HSCIC the delivery of this will depend on the outcome of the ongoing inquiry by the House of Commons Health Select Committee on Handling of NHS Patient Data [4] and the work programme arising from the Partridge Review [5].

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.

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. In 2011 (2010 data) the UKRR sent letters to six centres with lower than expected survival at one year after 90 days for incident patients starting on RRT; in 2012 (2011 data) this was required for only three centres; in 2013 (2012 data) two centres, and; in 2014 (2013 data) four centres. This year (2014 data) only one centre had to be contacted because of lower than expected survival in patients starting dialysis, although their results may

Table 1. Data sharing projects commenced during 2015

Originator: name and organisation	Aims and objectives	Dates			
		Original application	Data shared	End	Funding?
Ken Farrington Lister Hospital, Stevenage[b]	Ethnicity and End of Life Care in Haemodialysis Population	Jan 15	Jan 15	N/A – only aggregated data provided	None
Rishi Pruthi on behalf of the ATTOM Group[b]	Access to Transplantation and Transplant Outcome Measures (ATTOM) – Linkage with UKRR	Jan 15	April 15	According to ethics permissions	NIHR PGfAR
Cecily Hollingworth, NHS England	Information on late-referred in West Midlands 2012–2013 incident patients	Feb 15	March 15	N/A – only aggregated data provided	None
Jay Nath, Queen Elizabeth Hospital NHS Trust[b]	Does Cold Ischaemia Time matter in live donor renal transplantation?	Feb 15	June 15	Dec 16	None
Richard Fluck, Royal Derby Hospital	Plot of home therapies (Home HD + PD) by % urbanisation of catchment population by centre	March 15	March 15	N/A – only aggregated data provided	None
Andrew Bentall, Queen Elizabeth Hospital Birmingham[b]	Differentiating waiting/dialysis time for transplant outcomes in kidney transplants with immunological barriers	March 15	June 15	Sept 16	None
Maria Hernandez-Fuentes, King's College London[b]	DECISIONS study – information on previous haemodialysis	April 15	Sept 15	Apr 17	None
Neil Ashman, NHS England (London Region)	Pan London Peer Review	Jun 15	June 15	N/A – only aggregated data provided	None
Tamara Mallett, Bristol Children's Hospital[a]	Trends in PRDs in children starting RRT from 1995 onwards	Aug 15	Sept 15	N/A – only aggregated data provided	None
Bernadette Li, London School of Hygiene and Tropical Medicine[b]	Analysis of survival for historical cohort of patients on the transplant waiting list as part of the Access to Transplantation and Transplant Outcome Measures (ATTOM) study	Aug 15	Dec 15	Dec 17	NIHR PGfAR
Jenny McKinley, Queen's University Belfast[c]	Trace element abundance and renal disease	Aug 15	Nov 15	Sept 20	Department for Employment and Learning
Charlotte Sarmouk, NHS England	Percentage of dialysis patients who were receiving dialysis in the home	Nov 15	Feb 16	N/A – only aggregated data provided	None
James Hollingshead, Public Health England	Incidence rates and standardised rate ratios, modality usage and other information for CCG profiles	Dec 13	Feb 16	Annual	None

[a]UKRR will perform most of the analysis and the write up
[b]no input from the UKRR after supplying the data
[c]some support with statistics and interpretation required from the UKRR

Table 2. Percentage completeness of data returns for ethnicity, primary renal diagnosis, date first seen by a nephrologist, comorbidity at start of RRT (incident patients 2014) and cause of death (for deaths in 2014 amongst prevalent patients on 31/12/13)

Centre	Ethnicity	Primary diagnosis	Date first seen	Comorbidity	Cause of death	Average completeness	Country
L Kings	100.0	100.0	100.0	100.0	98.7	99.7	England
Leeds	100.0	100.0	99.4	100.0	99.2	99.7	England
Antrim	100.0	100.0	97.1	100.0	100.0	99.4	N Ireland
Bradfd	98.8	100.0	100.0	100.0	98.0	99.4	England
Nottm	100.0	100.0	97.3	95.5	98.9	98.3	England
Sund	100.0	96.8	100.0	95.2	97.4	97.9	England
Middlbr	100.0	99.0	98.1	97.1	95.1	97.9	England
Dorset	100.0	100.0	98.7	100.0	90.6	97.8	England
Hull	100.0	99.0	95.3[b]	100.0	91.7	97.2	England
West NI	97.1	100.0	97.0	97.1	93.9	97.0	N Ireland
Ulster	100.0	100.0	94.7	100.0	90.0	96.9	N Ireland
B QEH	100.0	99.6	97.9	96.7	90.4	96.9	England
Newry	100.0	100.0	94.7	94.7	93.3	96.6	N Ireland
Swanse	100.0	100.0	100.0	100.0	82.6	96.5	Wales
Wrexm	100.0	97.6	97.6	100.0	87.0	96.4	Wales
Cardff	100.0	99.4	95.8	89.9	96.7	96.4	Wales
Kent	94.7	96.7	100.0	100.0	86.6	95.6	England
Exeter	97.8	97.1	91.9	93.5	96.5	95.4	England
York	93.8	98.4	90.5[b]	95.3	97.4	95.1	England
Basldn	95.7	100.0	95.7	89.1	90.0	94.1	England
Donc	100.0	100.0	98.2	70.4	96.8	93.1	England
Oxford	76.2	97.4	97.9	95.2	98.3	93.0	England
Derby	98.7	98.7	97.3	94.7	73.7	92.6	England
Redng	93.5	99.1	97.2	92.5	79.7	92.4	England
Dudley	95.1	87.8	95.1	87.8	95.5	92.3	England
Bristol	100.0	85.1	95.2	84.5	90.0	91.0	England
Chelms	71.2	100.0	98.1	92.3	85.7	89.4	England
Newc	100.0	100.0	98.1	97.2	51.8	89.4	England
B Heart	100.0	83.7	92.8	99.0	65.6	88.2	England
Carlis	100.0	100.0	92.1	55.3	92.0	87.9	England
Sthend	63.3	100.0	100.0	76.7	95.7	87.1	England
Bangor	100.0	81.8	90.9	59.1	95.0	85.4	Wales
Belfast	100.0	95.2	91.9	77.8	51.1	83.2	N Ireland
Prestn	99.3	99.4	97.4	4.6	95.2	79.2	England
Clwyd	89.7	79.3	78.3[b]	55.2	90.0	78.5	Wales
L West	99.7	100.0	98.6	0.3	93.8	78.5	England
Truro	100.0	94.9	97.4	0.0	97.1	77.9	England
Wolve	100.0	87.3	92.4	16.5	85.2	76.3	England
Stoke	97.3	57.1	90.1	81.3	53.5	75.9	England
Sheff	96.7	99.3	98.7	78.8	0.9	74.9	England
Leic	93.7	78.0	98.0	42.9	55.2	73.6	England
Wirral	98.2	73.2	96.4	30.4	68.5	73.4	England
Glouc	100.0	96.1	66.7	15.7	88.1	73.3	England
Colchr	78.9	64.2[a]	44.7	100.0	77.3	73.0	England
Liv Ain	98.5	100.0	98.5	56.7	0.0	70.7	England
L Barts	99.4	82.6	28.7	55.2	82.7	69.7	England
Liv Roy	94.2	85.4	97.8	48.2	19.0	68.9	England
Norwch	77.2	93.7	49.9 [b]	43.0	74.0	67.6	England
L Rfree	94.8	96.1	96.1	22.3	15.9	65.0	England
Shrew	98.5	90.8	98.4	18.5	0.0	61.2	England
Brightn	93.2	100.0	98.6	11.6	0.9	60.9	England
Ports	84.9	86.7	59.5	26.7	38.8	59.3	England
Covnt	98.4	88.0	84.8	15.2	6.7	58.6	England
L St.G	86.8	75.8	24.2	42.9	57.1	57.4	England

Table 2. Continued

Centre	Ethnicity	Primary diagnosis	Date first seen	Comorbidity	Cause of death	Average completeness	Country
Stevng	90.1	80.3	94.1	0.7	9.3	54.9	England
Camb	86.6	57.3[a]	68.5	4.7	42.3	51.9	England
L Guys	93.7	64.8	81.5	1.9	0.0	48.4	England
Ipswi	0.0	61.2[a]	90.9	0.0	83.3	47.1	England
M RI	93.2	59.5	43.4	34.2	1.4	46.3	England
Plymth	100.0	32.1	26.9	41.5	24.5	45.0	England
Salford	99.3	98.6	0.7	0.0	0.0	39.7	England
Carsh	87.9	23.8	41.4	11.4	16.3	36.2	England
Abrdn		100.0			67.7		Scotland
Airdrie		100.0			97.6		Scotland
D & Gall		100.0			100.0		Scotland
Dundee		100.0			52.8		Scotland
Edinb		100.0			96.2		Scotland
Glasgw		100.0			100.0		Scotland
Inverns		100.0			100.0		Scotland
Klmarnk		100.0			100.0		Scotland
Krkcldy		100.0			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]For these centres 10% or more of the dates returned were identical to the date of start of RRT. Whilst it is possible to start RRT on the day of presentation, comparison with the data returned from other centres raises the possibility, requiring further investigation, of incorrect data entry or extraction from these centres. The value given for completeness has been reduced in proportion to the amount by which the percentage exceeded 10%

reflect the comorbidity of their patients which we remain unable to adjust for in the main survival analysis due to missing data from many other centres (as discussed above).

For the present, 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, the Chief Executive of the Trust housing the service and their commissioner 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

The UKRR operates within a comprehensive governance framework which concerns data handling, reporting and research, including data linkages and 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 the accountable officer responsible for day to day management of governance compliance and the Head of Business Development and Support as the operational information governance lead. The framework is based on good practice, as described in the Information Governance Framework [6] and the Research Governance Framework for Health and Social Care (2005). The UKRR has temporary exemption, granted by the Secretary of State for Health under section 251 of The National Health Service Act (2006), to hold patient identifiable data. This exemption is reviewed annually. The UKRR has successfully completed the Connecting for Health information governance toolkit to a satisfactory standard.

Conclusion

It has been a very exciting twelve months at the UKRR with the receipt of new patient reported outcomes data and also AKI data beginning to flow directly from hospital laboratories. The first benefits are beginning to be seen from investments in the UK Renal Data Collaboration, with the real-time reporting of routine laboratory data to support an NIHR funded efficient randomised controlled trial. The mission for the next twelve months is to further demonstrate the potential of the UK Renal Data Collaboration and the unique opportunities that the UK Renal Registry offers to continue to underpin improvements in care for people with kidney disease.

Conflicts of interest: the authors declare no conflicts of interest

References

1 Ogilvie D, Craig P, Griffin S, Macintyre S, Wareham NJ. A translational framework for public health research. BMC public health 2009;9:116
2 Fotheringham J, Jacques RM, Fogarty D, Tomson CR, El Nahas M, Campbell MJ. Variation in centre-specific survival in patients starting renal replacement therapy in England is explained by enhanced comorbidity information from hospitalization data. Nephrol Dial Transplant 2014;29(2):422–30
3 Health and Social Care Information Centre. Release of health data to the UK Renal Registry (UKRR) Improvements in the analysis of renal care services for patients undergoing renal replacement therapy (RRT). 2014. http://www.hscic.gov.uk/casestudy/renalcareanalysis
4 House of Commons Health Select Committee. Handling of NHS patient data. 2014. http://www.parliament.uk/business/committees/committees-a-z/commons-select/health-committee/inquiries/parliament-2010/cdd-2014/
5 Partridge N. Data Release Review. 2014. https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/367791/HSCIC_Data_Release_Review_PwC_Final_Report.pdf
6 Health and Social Care Information Centre. 2014