Role of Renal Registry in audit of UK Renal services

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History of UK CKD studies

Age <65
Urea > 35mmol/l
52 per million pop

Hospital Practice

SURVEY OF CHRONIC RENAL FAILURE IN SCOTLAND


Scottish Home and Health Department and Medical Renal Units of Aberdeen Royal Infirmary, Dundee Royal Infirmary, Edinburgh Royal Infirmary, Glasgow Royal Infirmary, and Stobhill General Hospital, Glasg

THE LANCET

Volume 299, Issue 7745 , 5 February 1972, Pages 304-307

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Age <60
Urea > 35mmol/l
38 per million pop

Hospital Practice

CHRONIC RENAL FAILURE IN NORTHERN IRELAND, 1968-70

A Prospective Survey

Mary G. Mcgeown

Renal Unit, Belfast City Hospital, Belfast., Northern Ireland
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- 72 adult and 13 paediatric units
- 1990s Renal association initiated UKRR
- 1995 Standards and guidelines
- 1998 1st report
- 2012 14th report
- ~50,000 prevalent patients end 2010
ROLES OF A REGISTRY?

- Record and compare activity for all
- Achievement of clinical markers of care
- Outlining differences between units
- Exploring differences between units
- Changing practice
  - Education on practice and differences
  - Stimulating change
  - Measuring the change
Audit questions within the registry.

Use of existing Renal Association Standards:
http://www.renal.org/clinical/GuidelinesSection/Guidelines.aspx

The committee comprises the leaders of each of the guideline modules of the current edition of the guidelines shown below, chaired by Dr Robert Mac tier. robert.mactier2@ggc.scot.nhs.uk

The guidelines provide a template for the management of patients with kidney disease in the UK and define the data collected by the Renal Registry.

The Fifth Edition of the Clinical Practice Guidelines

<table>
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<tr>
<th>Module</th>
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<td>Blood-borne viruses - Colin Geddes, Elizabeth Lindley &amp; Neil Duncan</td>
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<td>Peritoneal dialysis - Dr Graham Woodrow &amp; Prof Simon Davies</td>
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<td>Planning, Initiation &amp; withdrawal of RRT - Ken Farrington &amp; Graham Warwick</td>
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<td>Assessment for transplantation (FINAL DRAFT) - Chris Dudley &amp; Paul Herden</td>
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<td>Nutrition in CKD - Dr Mark Wright &amp; Dr Colin Jones</td>
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In commissioning the fifth edition of the guidelines the Clinical Affairs Board considered the term Clinical Practice Guidelines more appropriate than the previous term Clinical Guidelines.
Annual reports

“A resource in the development of patient care in renal disease......comparative data for audit, benchmarking, planning, policy and research.”
Growth in prevalent patients, by treatment modality at the end of each year 1982-2010

Year

Number of patients
0 10000 20000 30000 40000 50000 60000

Changes 2005-2009 as pmp
5.1% PD,
+5.7% HD,
+5.6% Tx

Growth of home haemodialysis +23% (2010 data)
1st Renal Registry Report: 9 units

Chapter 4 All patients receiving Renal Replacement Therapy in 1997

Median age of dialysis stock 1997

Median Age

Treatment Centre

B I F D A G C H E
Fig. 1.3. UK incident RRT rates between 1980 and 2009
Median age of new patients by centre 2009 range 57-73 years of age.
Fig. 1.11. Late presentation rate by year 2004–2009
Restricted to centres reporting continuous data 2004–2009
Benchmarking between units improves care

Dialysis blood pressure

UK Renal Registry Interactive Data Portal - Motion Charts
HD - BP pre < 140/90 mmHg

Antrim
Tyrone
Ulster
Belfast City
Newry

Order: Percent achieving criteria
3/03/2005
Survival in dialysis patients - unadjusted
Centre variation in Survival: Funnel plot-how to interpret?
The effect on 1 year survival after sequential adjustment for age, primary renal disease and comorbidity, 2004-2008 cohort.
Decline in comorbidity reporting

Percentage of patients with co-morbidity data
Linkage to Hospital Episodes data

- **RR**
  - 21,637 Incident RRT Patients
  - 2002 – 2006
  - UKRR Data until Oct 2009

- **HES**
  - 2.9 Million Episodes
  - 290,000 Hospital Admissions (~13 per patient)
  - 2 Million Outpatient Appt.

- **Office for National Statistics**
  - 11,547 Deaths up to 31/12/2010
  - 14.4% At Home

---

**Hospital Associated Mortality**
- Renal Centre & Hospital Level

**Length of Stay & Freq. of Admission**
- Start of RRT & End of Life

**Comprehensively Adjusted Survival**
- Late presentation, Comorbidity &
Mean Comorbid Score derived from HES according to year of start of RRT
Comprehensively Adjusted Survival

Adjustment for Age, Sex, Ethnicity, IMD, 16 Comorbidities

12 outliers (6 high / 6 low) → 4 outliers (2 high / 2 low)

Length of Stay & Freq. of Admission
1st year models

Despite adjustment there is great variation in the number of admissions patients have in the first 12 months of RRT between centres

Hospital Associated Mortality
Renal Centre & Hospital Level

Using recognised methodology we can determine the likelihood of a patient surviving an admission – Dr Foster HSMR

Understand how inpatient care interacts with overall survival
Fig. 2.1. Prevalence rates per million population by age group and UK country on 31/12/2009
Figure 17.2e: Incidence of RRT pmp, 75+ years in different countries
Modality and treatment options
Welcome to Renal PatientView

Renal PatientView is a project of RIXG a UK group representing renal patients and the renal team. It aims to provide online information about renal patients' diagnosis, treatment, and their latest test results. Patients can share this information with anyone they want, and view it from anywhere in the world.

PatientView is only available from some UK renal units, and for patients who have chosen to participate. Here is a list of units involved so far. The information comes directly from existing databases within units, so if you suspect a mistake, you should check with your own unit. Links are provided after you log in.

You can view our information links without logging in.

You can view a demo as if you were a patient.

- Automatic lab results download
- Letters and medications available to see
- ~16,000 patients registered UK wide
- Patient entered information possible e.g Blood pressure, patient symptoms
1st Tranche rare disease groups - £12k Administration funding for 5 years

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<td>Dr Graham Lipkin</td>
<td>Birmingham Queen Elizabeth Hospital</td>
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<td>Prof Fiona Karet</td>
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<td>Prof Neil Turner</td>
<td>University Of Edinburgh</td>
<td>Alport RDWG</td>
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<td>Prof Tim Goodship</td>
<td>University Of Newcastle</td>
<td>Atypical Haemolytic Uraemic Syndrome (aHUS)</td>
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Integrated models of care
- Background
- The chronic care model
- Care pathways
- Disease-specific working groups

Diagnosis
- Monogenic disorders and genetic testing
- Non-genetic investigations

Proposal for Renal RaDaR:
- Research
- Audit
- Empowering patients and families

Costs and Efficiencies
- Financial support KRUK/BKPA, approx £0.5m
- Fast track ethics
Renal RaDaR
(Rare Disease Registry)

- Secure database
- Moving to similar technology as Renal Patient View
  - Plan for semi-automated data capture/sharing with RRT systems, Labs etc
  - Local administration
- Consent gives permission to be contacted by RDWG.
- Patient accessible section, hosts information for patients/carers
- Research section, exclusive to RDWG
RaDaR

Welcome to the homepage of the UK Registry for Rare Kidney Diseases, eponym RADAR.

The purpose of the registry is to assemble cohorts of patients whose kidney disease is thoroughly investigated and characterised. Patients in the registry can then be approached to participate in "translational" research. Translational research aims to connect the basic scientific investigation of a disease to tangible benefit for the patient. Benefits might include better diagnosis, patient information, treatment trials, and ultimately better care.

Patient involvement in the registry is strongly encouraged.

RADAR is an initiative of the Renal Association and the British Association for Paediatric Nephrology. It operates within the UK Renal Registry, and its governance lies with the Renal Association. The initiative is supported by the Medical Research Council and Kidney Research UK.

To go to the Disease Index NEXT
Case finding via coded diagnoses

- General Practice Research Database covers 8 million in the UK-expanding to 20M in 2012/13

- Merged with Hospital Episode Statistics 1st April

- Alport disease (renal disease in all)
  - 264 patients/8M= ~32 pmp prevalence (in NI ~60)
  - On NI renal system 23 noted

- Fabry disease (renal disease does not affect all)
  - 125 patients/8M= ~16 pmp prevalence (in NI ~30)
  - On NI renal system 5 noted
  - 43 registered within NI genetics service
Challenges

- Defining data sets, nosology, and coding
- Avoiding duplicating data entry-
  - CfH “do once and share”
  - Or ............ “enter data once for best patient care”
- Workload for local investigators
- Sustainable activity, sustainable funding
- Interfaces, interfaces, interfaces
- Interface with disciplines beyond nephrology
Mandatory data qualifier
1 - DIALMAKE option set
2 - DIALFLOW option set

**Treatment Timeline** - **TXT** Data Block(s)

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<td>Y1</td>
<td>Access for haemodialysis (code list VA02)</td>
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<td>Site of haemodialysis access (VA41)</td>
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<td>Bag size (litres) if on PD [range 0.25 - 9.5]</td>
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**Haemodialysis Session - QHD**

Data from every haemodialysis session during a quarter should be collected where possible. Each session has a unique date attached. There should be approx 20-39 nested returns for each quarter (depending upon no of dialysis sessions in the quarter).

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<td>Post HD systolic BP</td>
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**Transplant Waiting List Status - TXP** Data Block

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Renal Registry Database - System Specification Version 3.14
~400 items ~50% of the National Renal Dataset
Predicting the implications of demographic change

- Prevalence growing
- Vintage and RRT complications growing
- More elderly pts living on HD
  - Nutrition, BP targets, access, age for Tx
- Better dialysis systems for collective and individual
- We need data on CKD stage 5 patients to understand Conservative and withdrawal issues to allow adjustment for survival and other outcomes
- For this UKRR methods to capture more relevant data closer to the time of RRT initiation are needed.
Where next

- Patient reported outcomes
- Empowerment
- Self-determination
- Support for NHS
- Support for patients
Sir Bruce Keogh
medical director of the NHS

"For too long clinicians have thought NHS data is someone else's business. I am quite clear that quality of data on clinical services in the NHS should rest squarely with those who deliver the service and responsibility for accuracy should lie with medical directors and clinical service leads. After all, as a professional if you can't describe what you're doing and define how well you're doing it, you have no right to be doing it at all.

I expect all NHS organisations to have assurance processes in place to ensure that the data in their systems reflects the reality of clinical activity."
Death not dialysis follows CKD for most patients.
Adding Insult to Injury

A review of the care of patients who died in hospital with a primary diagnosis of acute kidney injury (acute renal failure).
Admitting specialty

Figure 3.2 Specialties of admitting consultants
1. Make data entry a priority

2. Make data management easier

3. Educate staff and patients about the importance of data

4. Educate yourself about interpreting data

If you want to improve quality you have to record what you do