

UK Renal Data Collaboration White Paper v2

Background

The UK Renal Data Collaboration was formed at a meeting in The University Department of Medicine, The Royal Infirmary Edinburgh on 29 Nov 2012.

The current organisations in the UKRDC are the UK Renal Registry, the Scottish Renal Registry, the Northern Ireland Nephrology Forum, the Welsh Renal Clinical Network, Patient View (PV), the UK Registry for Rare Kidney Diseases (RaDaR) and the British Association for Paediatric Nephrology. The initial meeting was chaired by Dr Afzal Chaudhry who is the Chair of the Renal Information Exchange Group (RIXG). This organising group is called the Guiding Coalition (Programme Board). The background, roles, authority, accountability, composition and organisation of the UKRDC and the guiding coalition are set out in a paper [Registry Development Guiding Coalition](#). The UKRDC members are a strategic alliance with each organisation retaining their own governance structures through their respective accountable officers.

The Problem

Renal units in the UK started using computerised electronic patient records (EPRs) in the 1960s. Every adult renal unit in the UK now has a well-developed electronic patient record (EPR) provided by a variety of 3rd party software suppliers. The early versions were very powerful and flexible. They were mostly configured by enthusiastic nephrologists and were very successful at supporting and recording care of patients dependent of renal replacement therapy (RRT).

This has resulted in great expertise around the UK but because they were deployed before standards had been developed, many systems were hand crafted with individual schemes for communication, coding, naming conventions, definitions, error trapping and validation. Most renal EPR systems cannot support modern, now often mandatory processes for security, patient identification, clinical coding (diagnoses and procedures) or the use of granular hierarchical schemes that allows data to be grouped automatically. Few current systems can store the meta data which are required to interpret data correctly (e.g. assay method and reference range), secondary uses of data are limited and it is impossible to transfer records electronically between renal units or other specialties when a patient changes address or status. In some cases word of mouth and local knowledge are required to interpret the data and operate the systems. It was acknowledged that in 2013 better use could be made of existing knowledge, collaborations, patient involvement and new information technologies.

Proposal Aim

Improve and standardise the scope and detail of data recording in renal units; move to paperless electronic patient records; improve and standardise data communications between the UKRDC member organisations and between renal units allowing rapid transfer of a full patient record as required and full access to data by patients. Furthermore it is hoped to improve the use made of available data and thereby improve efficiency.

To this end the UKRDC made the following proposals for IT developments in the renal community in the UK. These have been approved by the UK Renal Information Governance Board, the SRR Steering committee, RaDaR, PV and BAPN and they have been discussed in outline with the suppliers of IT systems and EPRs to the UK renal units at a meeting in Bristol on 19 Sept 2012 and subsequently at meetings in their offices. The original version of this paper was presented at a second meeting with the IT suppliers in Birmingham on 06 June 2013.

1. Adopt standard terms using SNOMED CT and LOINC with advice from the UK Renal Terminology Committee. The NLMC has been developed by the Royal College of Pathologists and the HSCIC. It supports lab requests and results reporting and includes SNOMED-CT identifiers and metadata. The Terminology Committee includes a professional terminologist from the HSCIC and has close links with the HSCIC, NLMC and the ERA-EDTA Registry and its coding scheme.
2. Adopt standard methods for labelling and formatting data via creation of a data model and standard messaging systems. A data model has been created for the UKRDC which is available on request.
3. Develop two way communication between all participants including patients via PV. This will require clear rules about data primacy, provenance, distribution and version.
4. Build and maintain a data repository with suitable operating system, security, communications and database. This will act as the communications hub for the organisations in the UKRDC.

The repository will:

- Provide secure, fast, high capacity data storage with validation and version control.
- Support a query language with output to other renal systems and external analysis software.
- Adhere to relevant principles specified in the RIXG renal database recommendations/operational requirement.
- Manage data with sufficient granularity and associated meta data to support the needs of the most exacting requirement set by a UKRDC member.
- Identify data records with a unique id e.g. using a Global Unique Identifier (GUID).

This will facilitate the inevitable corrections required.

- Collaborate closely with the UK Renal IT/EPR suppliers.
- Improve renal unit clinical and data governance and accept standardisation of clinical terminology and message structure.
- Adopt fully electronic records that will support the highest standards of care, decision support, embedded prompts, error and pattern detection, full access for patients, reuse of data for secondary purposes including quality improvement, service development, clinical and epidemiology research and teaching. The systems adopted must be fast and flexible. A powerful database and server will be required for the warehouse with a sophisticated query system.

Dataset

The dataset required to satisfy the needs of all the participating organisations will be large and will likely change frequently. A spread sheet listing the datasets submitted by the UKRDC members and an initial core dataset for the warehouse and data model will be maintained by the UK Renal Terminology Committee Data Set Group. The data model noted above has been based on this spread sheet. A list of common abbreviations, and useful websites is also available there.

Clinical Governance

Clinical Governance for the core work of the UKRDC will be managed through the current governance arrangements of the UKRDC members. These however may need to be bolstered as new uses are found for the data warehouse. Local clinical governance arrangements are key to ensuring that data are accurate and valid and this route will be used to encourage clinicians and managers to improve data quality. In some places this will be reinforced through commissioner contracts.

Pilots

Volunteers now are invited to join the pilot. Applications should be made jointly by renal units using a modern and capable EPR and the IT company supporting their EPR. Applications should be sent by email Ron Cullen, Director UKRR ron.cullen@renalregistry.nhs.uk.

Links to the UKRDC members

The current organisations in the UKRDC are:

UK Renal Registry	www.renalreg.com
The Scottish Renal Registry	www.srr.scot.nhs.uk
Patient View	www.patientview.org
The Renal Association	www.renal.org
The British Association for Paediatric Nephrology	www.renal.org/bapn
Rare Renal Diseases Registry	www.renalradar.org
Northern Ireland Nephrology Forum	
Welsh Renal Clinical Network	www.wales.nhs.uk/sites3/home.cfm?orgid=773

Communication

Good communication will be required with:

- Renal IT suppliers. All such companies currently active in the UK attended a meeting in Bristol in 2012, the UKRDC has visited them all at their offices (WebEx with Cybernius who are based in Canada) and a second general meeting was held on 06 June 2013 in Birmingham.
- Renal units and renal unit staff will be kept up to date via newsletters, the UKRDC members' internal communications and by presentations at the RA and SRA meetings.
- Health and Social Care Information Centre (HSCIC) in Leeds via contacts and meetings with staff there.
- UK Renal Terminology Committee (for SNOMED CT). The Chair is Dr Afzal Chaudhry who is on the UKRDC Guiding Coalition.

Comments about this document are requested from the UKRDC members, UK renal units, renal IT suppliers and are invited from any reasonably interested parties should be sent to Ron Cullen (Director UKRR) (ron.cullen@renalregistry.nhs.uk).