

UK Renal Data Collaboration (UKRDC) Programme Board

Terms of Reference v4

Introduction

The UKRDC was set up to improve and standardise data recording scope and detail in renal units, move to paperless electronic patient records, improve and standardise data communications between the UKRDC members, between renal units allowing rapid transfer of a full patient record when a patient moves between renal units and full access to data by patients, improve the use made of available data, improve efficiency.

Renal units in the UK started using computerised clinical records in the 1960s and every adult renal unit in the UK now has a well-developed electronic patient record (EPR).

The early versions of renal systems were very powerful and flexible and were mostly configured by enthusiastic nephrologists. They were very successful at supporting care and this has resulted in great expertise around the UK.

However, because such IT systems were developed before common standards had been developed; many systems were hand crafted with individual schemes for communication, coding, naming conventions, definitions, error trapping and validation.

Most systems cannot support modern and in some cases mandatory systems for security, patient identification, clinical coding of diagnoses and procedures or the use of granular hierarchical schemes that allows data to be grouped automatically. Few current systems can store the metadata 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. In some cases local knowledge is required to interpret the data and operate the systems.

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 the Chair of the Renal Information Exchange Group (RIXG). This organising group was initially called the Guiding Coalition and is now known as the UKRDC Programme Board. The background, roles, authority, accountability, composition and organisation of the UKRDC and the programme board were 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.

Purpose and Vision

The primary aim of this board is to deliver and implement a structure and tools within 3 years that will lead to the formation of a renal data repository. Member organisations will be responsible for their own areas of work but the UKRDC will be responsible for designing the data set, data analysis, publication and research. The UKRDC will adhere to international standards where possible.

At the end of 3 years the aim is to:

- Develop two way communications between all participants (including patients via PatientView). This will require clear rules about data primacy, provenance, distribution and version.
- 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.
- Provide secure, fast, high capacity data storage with validation and version control.
- Support a standardised messaging system 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 metadata to support the needs of the most exacting requirement set by a UKRDC member.
- Collaborate closely with EPR suppliers.
- Encourage improvements in renal unit clinical and data governance and accept standardisation of clinical terminology and message structure. Units will undertake their own clinical governance.
- Encourage adoption of 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.
- Standardise methods for labeling and formatting data via creation of a data model and standard messaging systems. A data model has been created for the UKRDC by HSCIC.
- At national and local level provide the data flows to allow timely audit and quality improvement.

Programme Objectives

The objectives of the UKRDC are to:

- Facilitate improvements and standardise data recording scope and detail in renal units.
- Encourage and support movement to paperless electronic patient records.
- Improve and standardise data communications between the UKRDC members, and between renal units allowing rapid transfer of a full patient record when a patient moves between renal units.
- Facilitate full access to their data by patients
- Improve the use made of available data.
- Take responsibility for the delivery of the overall programme plan.
- Take responsibility for the preparation of any business cases to be presented to the Renal Information Governance Board (RIGB) or appropriate governance boards for approval.
- Take responsibility for and oversee the allocated programme budget once the budget has been agreed by the RIGB.
- Advise on the establishment of work packages and agree deliverables including coordinating timescales and prioritisation of activity.
- Ensure alignment of the programme with the health service priorities of the constituent members and the emerging renal communities.
- Provide strategic and practical advice and act as co-ordinator to the work packages, on significant changes to programme deliverables and/or delivery timescales Approve all deliverables from work packages and monitor the progress of the work packages whilst providing coordination across the project.
- Ensure positive and constructive engagement with the renal community and renal IT suppliers, external partners and other key stakeholders to communicate and influence the development and implementation of programme strategy. Ensure that relevant work, which is undertaken by members, is acknowledged and incorporated where appropriate.
- Identify and manage risks and issues, and to support workstream leads, the renal community, renal IT suppliers, external partners and other key stakeholders in the resolution of workstream level risks and issues escalated to RIGB.
- Ensure that advice is obtained from experts and organisations as and when appropriate to assist in ensuring that informed decisions can be arrived at.

Parameters

Any recommendations by the UKRDC Programme Board will be:

- Affordable and offer best value for money in the use of resources.
- Set within the context of other policy initiatives.
- Focussed primarily within the NHS but also link across to social care and other providers.

The Board will be responsible for the work packages outlined below. Priorities are to be set based upon resources.

Work Packages

- Terminology
- Technology
- Communications
- Messaging
- Dataset

Governance

Meeting Schedule

It is anticipated that the UKRDC Programme Board will meet four times a year. Additional meetings will be scheduled should an urgent business need arise. The majority of meetings will take place using WebEx/conference call facilities but at least 1 physical meeting will be held per year.

Board Members

The chair will be elected by members of the programme board. The board is to be comprised of the members listed below:

- UK Renal Registry
- The Scottish Renal Registry
- Patient View
- The British Association for Paediatric Nephrology
- UK Registry for Rare Kidney Diseases - RaDaR
- Northern Ireland Nephrology Forum
- Welsh Renal Clinical Network
- Patient Representatives
- Representatives from renal units

Members may consider a substitute where possible, for those meetings where they are unable to take part. It is assumed that these representatives have the authority to speak and act on behalf of their organisations.

For any meetings to be quorate then a minimum of 3 of the 7 members of the UKRDC must be present.

If a vote is required a consensus will be looked to be achieved. There will only be one vote per organisation.

Additional attendees will be invited as and when appropriate.

Secretariat

The UK Renal Registry will provide the secretariat for the Board meetings.

Agenda Items

The Secretariat will maintain a series of planned agenda for the scheduled meetings. Members are urged to submit items for inclusion on the appropriate agenda as early as possible to assist with the management of the meeting schedule.

The secretariat will also trawl for agenda items approximately three weeks before each meeting and confirm the agenda approximately one week before the meeting. Papers will be circulated by email to members at least five working days before the meeting; therefore, any papers need to be with the secretariat at least five days before the meeting.

The above will be subject to review.

Minutes & Actions

Outstanding Actions will be reviewed at each Board meeting.

Minutes of the meeting will be prepared and will include actions agreed and ownership assigned to individual attendees. Minutes of each Board meeting will be distributed 10 days after each meeting. Links to the approved and publicly available version of the minutes will be available publicly on appropriate websites.

All members will declare any conflicts of interest.