UK Renal Registry
Learning & Research Building
Southmead Hospital
Bristol
BS10 5NB

13 Sept 2013

Dear CD

UK Renal Data Collaboration

I am writing to you at the request of the Renal Information Governance Board with information about the progress of the UK Renal Data Collaboration (UKRDC) which I hope will be of interest to the UK Renal CDs. The UKRDC is formed by the UKRR, SRR, BAPN, RPV & RaDaR and is chaired by Dr Afzal Chaudhry (Secretary UKRR and Chair RIXG). The aim is to develop a data warehouse that can act as a secure, high speed, real time hub for all the data that renal units in the UK wish to send to and receive from other renal units or the UKRDC members. Progress reports have been made at RA, UKRR and SRR meetings, in UKRR newsletters and a presentation is planned for this year's BAPN meeting.

Adoption of standard systems for data transmission and for medical terminology for diagnoses, procedures, medicines and lab tests based on SNOMED CT will enable messages from any renal unit to be generated and understood by any other unit or indeed, by colleagues anywhere without prior agreement about the file format or content. SNOMED CT incorporates the terms from the ERA-EDTA lists of Primary Renal Diagnoses and causes of Death, Medicines (dm+d) and the UK National Laboratory Medicine Catalogue (NLMC). The latter describes all lab tests and can include useful 'meta' data such as the reference range and the lab methods.

Security and confidentiality are key features. Patient groups have enthusiastically welcomed the plans and an extension has been granted to the UKRR's support from section 251 of the Data Protection Act. Patients participating in formal trials and Rare Disease Group projects under the auspices of RaDaR will sign consent agreements and those using RPV will sign a mandate instructing their renal units to provide the service.

Success obviously depends on widespread participation and adoption of comprehensive electronic patient records where all the data required for the care of a patient are recorded and can be made available in real time to patients via RPV and also reused for quality improvement, service planning, research and teaching. The potential benefits are obvious. They include transfer of full patient records between renal units, decision support, automatic links to literature, spotting trends, records for training, appraisal and revalidation and data linking eg as has successfully been done with NHSBT allowing RPV to display current transplant status. The system will replace all current links between renal units and the UKRDC members including registry returns and data for RPV. It will no longer be necessary for renal units to negotiate to send data to RPV through the secure

NHS data firewall because this will be done from the warehouse which will be inside the NHS firewall.

It is essential that renal units commission and use high quality electronic patient record systems with attractive and functional SNOMED CT browsers and near real time links to the UKRDC warehouse. This will require a commitment to near paperless working, a lot of training, effort and some financial investment. Renal units and their IT supplies are already volunteering to join the pilot phase of this project. The main UK renal IT suppliers fully support this development and are keen to participate. This letter is to alert you to the development and to invite you to discuss it with your hospital management and to make plans to participate. Links to the participants and to template specifications for a renal unit electronic patient record and SNOMED CT browser are given below Further information which is available from any of the UKRDC members eg the Registry to which you send data or me

Best wishes

Keith Simpson
Medical Adviser to UKRR

Further information - Links to:
UKRDC good summary & links on RIXG site
UKRDC White Paper – on RIXG site soon
PowerPoint presentation
UKRDC data model
RIXG Renal EPR specification based on SERPR Operational Requirement
UKRDC SNOMED CT Browser specification (expected at this URL 20 Sept 2013)
Info about SNOMED CT from IHTSDO and HSCIC
SNOMED CT Browsers - general
Info about dm+d
Info about NLMC NHS
Info about NLMC Royal Col Path
UKRR Newsletter Spring 2013