

UK Renal Data Collaboration

18 November 2015

Dear Clinical Directors

UK Renal Data Collaboration (UKRDC) data repository & file format.

This letter is to alert you to two separate but necessarily coincident initiatives in UK renal information technology and to seek your support in making the changes required.

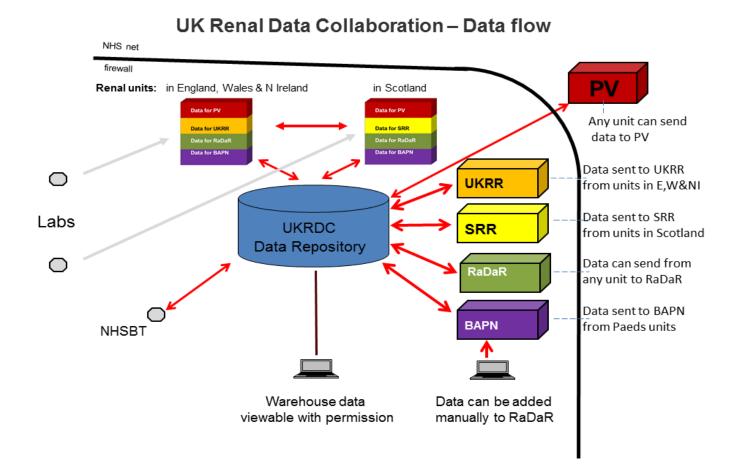
The first is the introduction of the UKRR version 4 data set.

This affects all renal units in England, Wales and Northern Ireland. Clinical Directors in relevant renal units were notified of this change in a letter from the UKRR on 03 Sept 2014. Updates have been issued by letter and in the RA-News. A further letter from the Directors of the UKRR will be sent soon.

The second change is that the UKRDC Board has established a powerful and secure computer data repository. The project was announced in 2012 and updates have been published regularly since then. The data repository will receive data from all UK renal units at least daily making national audit and quality assurance in almost real-time, possible – something that renal units have been requesting for years. Standard formats will be used for data file transfer and for both clinical and administrative terminologies. The data repository will validate and forward the data to its members (PV, UKRR, SRR, BAPN, RaDaR, Welsh Renal Clinical Network & Northern Ireland Nephrology Forum) on a need and right to use basis. It will also enable patient data to be transferred quickly between renal units when care is transferred or a patient is admitted in an emergency.

This single link will replace the existing methods for retrieving and transmitting data from renal units to these organisations It will also be possible to create links with other computer systems and for patients to save a copy of their records via PatientView.

The Terminologies we are using are in line with those being adopted and in some cases mandated by the NHS in the four home countries.



For renal units that have previously sent quarterly files, the UKRR will arrange for the data it requires to be collected from the UKRDC data repository and it will not be necessary to run separate quarterly data extraction and reporting routines. Data from the UKRDC will also be used for PatientView and RaDaR for patients who have registered.

Data transmission to the UKRDC can start from 01 Jan 2016 and should be running by 01 June 2016 for units wishing to send data in the new UKRR ver 4 dataset. After June, arrangements will have to be made for a one-off transmission of data required for the UKRR which you will have stored from 01 Jan 2016.

Data from renal units in Scotland will be sent to Scottish Renal Registry, PV and RaDaR daily from the UKRDC.

If specialised data required for a Rare Renal Disease Group or any other purpose are stored on an EPR, they can be included in the regular transmissions to the UKRDC from where they will be forwarded to RaDaR. If the data are not stored on an EPR, they will have to be entered manually.

Six renal units have asked to work with us as pilot sites and we are in active discussions with all of the main renal system suppliers.

Once satisfactory data transmission has been confirmed, the UKRDC technical team will ask you to stop sending data via the current mechanisms.

UK Renal Data Collaboration, UKRR Office, Third Floor, Learning and Research Building Southmead Hospital, Bristol, BS10 5NB t +44 (0)117 414 8150 https://www.ukrdc.org This will mean that you only have to use one file format and one data transmission method.

We hope that you will now arrange with your local electronic patient record support staff and your renal IT supplier to implement the daily transmission of data to the UKRDC.

Kind regards

April CI

Dr Afzal Chaudhry Chair UKRDC

Rue

Dr Wendy Metcalfe Chair SRR

Dr James Chess Chair WRCN

Dr Fergus Caskey Chair UKRR

Dr Detlef Bockenhauer Chair Renal RaDaR

togety

Dr Damian Fogarty Chair NINF

Van

Mr Ron Cullen Director UKRR

Net

Prof Neil Turner Chair PatientView

Dr Sinha Manish Chair BAPN

Ms Tess Harris CEO, Polycystic Kidney Disease (PKD) Charity