UK Renal Data Collaboration

UK Renal Data Collaboration (UKRDC) Patient View Information

Dear Renal System Supplier

I am writing again on behalf of the UK Renal Data Collaboration (UKRDC) project. As a precursor to the ultimate goal of receiving the full UKRDC feed from all units, we would like renal units / their software system suppliers to modify their existing PatientView (PV) interface so as to transmit files for all of their patients (details below), in addition to those who are truly members of PV itself. As well as providing useful data for audit, quality improvement and research, the increase in the number of files processed will allow us to ensure that our systems have sufficient capacity for the planned new data feeds.

Patients should be included in the data feed if:

- they have asked to join PatientView itself – either directly or via their recruitment to the RaDaR rare disease registry, or
- if they meet the criteria for submission to the UK Renal Registry and have **not** withdrawn consent for their identifiable data to be transmitted, or
- if they meet the criteria for submission to the UK Renal Registry but **have** withdrawn consent for their identifiable data to be transmitted, then their data should still be submitted but stripped of its personal identifiers

For information governance reasons, the UKRDC would ask that the "Send to PV" flag (or equivalent) is still used within a system's user interface to accurately record true PV membership, and for this to continue to control the inclusion of patient letters within the submitted XML files data. Only those patients with true PV accounts will have their data transmitted to the PV server itself. Additional benefits for patients accruing from this change will be that the time between joining PV and data being available will be reduced, as well as them having access to more historical data.

The UKRDC is prepared to support this change in behaviour of your renal system where possible. To help us to understand what is and is not achievable, based on the information above please could you provide the following details:

a) is it possible for you to amend your system to reflect the change described?
b) if so, would this be a single change to cover all units that you supply, or a unit-by-unit change?
c) continuing from (a), if so, approximately, how long would it take for you to effect such a change in your system and then deploy this to a given unit (please assume that the renal unit itself has asked you to make such a change to their instance of your system)
d) continuing from (a), if so, what is the rough order magnitude of cost per change (either entire system or unit-by-unit as appropriate)?

Separate to the above but related to the move of some of the technical infrastructure underpinning the UKRDC, we will be asking renal units to work with you to re-point the destination IP address for the SFTP server receiving the XML data feed to the N3 endpoint 10.38.181.124. We have copied the accounts / credentials from the original server so you will only need to change the IP address but it is likely that the host renal unit will need to complete some local firewall changes before this change can be effected.

Many thanks in advance for your help with both of these items. If there are any particular difficulties / concerns then please do not hesitate to contact me either on 01223-254648 or by email: anc35@cam.ac.uk

Yours sincerely
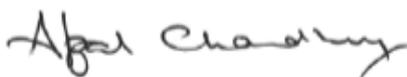
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Chair, UKRDC