Introduction

This describes building a data feed to the UKRDC that covers the requirements of PatientView and the UKRR v4 dataset. We suggest that you “Watch” our repository on GitHub (<https://github.com/renalreg/ukrdc> ) to be notified of any changes to the schema.

An annotated copy of the UKRR v4.2 is included alongside this to show how different items of data should be transmitted. The categorical copy of the UKRR dataset remains the one published on the UKRR website.

If you have any technical questions about the schema or the process please contact [George.Swinnerton@renalregistry.nhs.uk](mailto:George.Swinnerton@renalregistry.nhs.uk)

Comments on all aspects of the UKRDC’s work are welcome and can be sent via  [Karen.Thomas@renalregistry.nhs.uk](mailto:Karen.Thomas@renalregistry.nhs.uk" \t "_blank)

Exports / Transmission

# Export to the UKRDC

A single XML file should be exported for each patient that meets the criteria for collection by at least one of the member organisations of the UKRDC.

If a patient does not meet the criteria for any collection (for example they have asked that they not be included in the UKRR and are not a member of PV or RADAR) then they should not be submitted. You should not submit them with anonymised demographics.

It is suggested that files should be exported at least daily to allow timely analysis and in particular to support its use by PatientView.

The files should either contain:

* The full record of the patient
* A partial record indicating which date ranges the file covers (as currently used by PV XML)
* Only changes (Additions, Updates and Deletions)

It is expected that all patients will have an NHS identifier. The “SendingFacility” should be the one where the system is being run (Sent as CNT02 in current UKRR files).

The first transmission to the UKRDC should contain full records for all patients held on the system that meet the criteria for transmission (including historic records).

It should be possible for a user to trigger a re-send of data from the System – such as in the event of problems or to reflect a future schema change.

# Transmission to the UKRDC

We intend to initially offer transfers via SFTP as sites will be familiar with this from sending data to PV.

Other methods of transfer such as web services will also be possible.

# Exports from the UKRDC to the UKRR

A schedule will be published of dates on which the UKRR will do extracts of data from the UKRDC. These will be a period of time after the end of each quarter to accommodate late-loading and local data quality processes.

Once the extracts have been done these will be processed by the assigned data manager for the unit in the same way that happens now. If the data manager identifies any problems with the data the unit would amend the records on the renal system which will then be transmitted to the UKRDC via the standard feed. The UKRR will then produce another export from the UKRDC.

We intend to make units aware of data quality issues as data is received, in addition to the quarterly process.

# Exports from the UKRDC to PV

Data will be made available to patients who are members of PatientView as soon as it is received. This will initially be the current dataset but it is intended to expand this as new screens to display the information are developed.

# Exports from the UKRDC to RADAR

Data will be made available for patients who are members of RADAR as soon as it is received.

Common Objects

# Coded Data Items

Throughout the schema there are points where we ask for a coded data item. Instead of a single field we ask for three:

**CodingStandard:**

This is the code list (SNOMED, ICD10, READ etc.) that the code comes from.

**Code:**

This is the value itself.

**Description:**

This should be the term that was displayed in the UI when the value was picked.

Prefixes used in UKRR files such as “%EDTA1=” and “%RR=” should not be included in the Code field.

# ExternalID

This should be a consistent reference by which you refer to an item of data. This then allows the item of data to be deleted or updated.

If you have obtained the data item from another system then where possible you should use the identifier that came from that system – such as a test number from a LIMS. This allows us to detect duplicate items that may be submitted via multiple renal systems. Otherwise a possible value would be the row identifier from your database.

# UpdatedOn

This should contain the date that the item was created or modified within your system. If we receive the same item of data from multiple systems then in places the item with the most recent UpdatedOn date will be used.

Changes

# Communicating Changes (“PV Method”)

This works similar to how PatientView operates now. Most of the record is re-sent each time with the exception of the LabOrders, Observations and Procedures sections.

Within these nodes Start and End date attributes can be supplied to indicate that the sections only contain the part of the patients record that falls between those two dates.

If the attributes are supplied then any items of that type that have been received from the unit between those dates are deleted before the items received in the file are loaded.

The date span should be wide enough to cover the longest typical period between an activity (such as a blood sample being taken) and the data being loaded on the system (such as when the result is returned from the lab).

The date values used should be the date range which was used by the extraction tool when querying the database and NOT the earliest and latest dates of items it found. The later behaviour is seen in some current PV feeds.

# Communicating Changes (“UKRDC Method”)

This is where you only supply data which has been added, changed or deleted. This is the ideal.

Each main data item such as Procedures, LabOrders, Observations etc. has a field called ActionCode. This field can be populated with an instruction to Add, Replace or Delete the item of data. The ExternalID field is check if the data item already exists in the case of instructions to Replace or Delete.

Demographics must be sent in each file even if unchanged to allow us to check that the changes are being applied to the correct record.

# Communicating Changes (“Full Record”)

An alternative to both of the above may be to send the entire patient record each time. This is logically simpler but we would need to test the resource implications at both ends.

Data Items

# Allergies

These should be used to record any allergies the patient has.

# Clinical Relationships

These will initially be used by RADAR to record clinicians involved in the care of a patient. These do not need to be submitted by Renal Systems at the moment.

# Diagnosis - Generic

These should be used to record all diagnoses of the patient using SNOMED, including non-renal comorbidities.

# Diagnosis – Primary Renal Disease

These should be used to record the Primary Renal Disease (defined in the ERA‑EDTA PRD spreadsheet, notes for users, sections: ‘Description of PRD’ and ‘Selection of the most appropriate PRD’ <http://www.era-edta-reg.org/prd.jsp> ) for analysis by the UKRR, SRR and ERA. In order for the data to be comparable across countries it needs to be coded in using the EDTA code lists. Consequently we expect that some conditions may appear both as PRD objects and as generic diagnoses coded in SNOMED.

Patients who started RRT after 01/01/2014 should be coded using the 2012 EDTA code list. Patients who started before then can continue to be submitted using the older EDTA list. Systems should not automatically convert the older codes to the newer ones as this results in a loss of accuracy.

# Diagnosis – Cause of Death

These should be used to record the cause of death for analysis by the UKRR, SRR and ERA. In order for the data to be comparable across countries it needs to be coded in using the EDTA code lists.

Changes and additions that are made to a patient’s record after death (such as late loading of test results) should also be sent to the UKRDC.

# Documents

These should be used to transmit patient letters for use in PatientView.

In addition to the existing plain text option PV2 can also accept Base64 encoded PDF files sent using these objects.

# Encounters – Treatment

A Treatment record covers a period at which a patient is associated with a hospital and is classified as having a specific modality. It is possible for treatment records to overlap if a patient has multiple treatments (such as post-transplant dialysis).

A treatment record should exist for any period of time where they would be considered a patient (so for example code 900 record for pre-RRT CKD and a code 94 record for post-RRT Conservative care).

Systems should supply end dates to show when a record has ended, along with a reason for this happening.

Details of Transplants themselves should be recorded as Procedures but Treatment records should be used to record periods of Transplant related Inpatient/Outpatient care.

# Encounters – Transplant

These will be used to store Transplant Waiting List data from NHS B&T. Renal Systems should not use these records at the moment.

# Family Histories

These are used to record diagnoses which apply to a family member rather than the patient themselves. This would be used to record where there is a history of renal disease in the family for example.

# Lab Orders

Our EHR structure requires that all test results are associated with a lab order. If the details of the lab order are not received by the renal system then a generic lab order should be created to contain all results with a common sample time.

# Medications

All medications should be submitted whether or not prescribed for the purposes of renal care.

# Observations

As well as being used for physical observations these objects will be used to record other information about a patient such as their responses to surveys.

# Procedures – Vascular Access

These should be used to record the details of any Vascular Accesses that are created – including their dates of removal or failure.

# Procedures – Dialysis Session

These should be used to record any Dialysis sessions. Observations and Laboratory results that are associated with each session should be recorded in the standard places.

# Procedures – Transplants

These should be used to record any Transplants. A single Procedure should be recorded for each organ being transplanted, with multiple organ transplants being identified by multiple transplants occurring on the same day.

The record also contains information about the source donor for each transplant.

# Program Memberships

These are used to record whether or not a patient wishes to participate in one of the UKRDC’s member projects.

In the case of the UKRR and other projects where the right to hold the data is provided by law rather than individual consent, the records are used to record where a patient has asked that their data not be used by that project.

In the case of projects such as RADAR the Program Membership record should only be closed if the patient actively wishes to withdraw. It should not be end dated when they leave the unit or die.

If a patient decides to leave a project and then re-joins a new Program Membership record should be created (with a different ExternalID) rather than re-opening the original one.

# Social Histories

At present the only use of these is to record whether or not the patient is a smoker.