UK Kidney Association
UK Renal Registry

Q&A Summary
The UK Renal Registry Informatics Meeting
Monday 6th February 2023

Q. = Question
A. = Answer
C. = Comment

Vision for the UKRDC
James Medcalf, UKKA

Q. Are there plans or discussions for Cerner Millennium joining (submitting data to the UKRDC)?
A. Yes, we are in conversation with them, although there are no specific plans that we are aware of.

Q. Should we send patients that have a high EGFR (50), that drop to a low EGFR briefly (<30) then go back to an EGFR 50?
A. In practice the only group of people which are likely to be included in an audit measure in the foreseeable future are people with advanced CKD (eGFR <20 ml/min) under the care of a renal centre. These people need assessment for kidney replacement therapy, kidney transplantation, and symptom control. So this is the group of people we need reliable information about.

It is not always easy to separate out people with AKI and CKD – so historically we have pragmatically just requested the results on any patient who ever had an eGFR <30 ml/min. Some will indeed have had AKI and recovered, but others will hover around an eGFR of 30 and it would be unhelpful to include/not-include them.
So yes – do please continue to include people regardless of whether their eGFR improves.

Q. How do we identify & provide data for patients with an EGFR between 20-30 that are cared for by non-renal staff as they are not on renal systems?
A. This is a similar challenge to the 'what to do if a patients eGFR improves above 30' question above. As the above answer – it is those with CKD and an eGFR < 20 under follow-up by a renal centre we are most interested in for comparative audit and improvement.

Some centres will be able to distinguish people under follow-up by a kidney centre, and those who are not (perhaps discharged or lost-to-follow-up). If it is possible to limit the group to just those under care – that is ideal. If that is not possible then we will attempt to do the same using linkage to hospital episode statistics.

Q. Will there be a capitation fee on AKI & CKD patients?
A. Fee is and will continue to be charged for KRT patients as it has been for many years.

Q. What is the aspiration to link data from primary care systems to pick up CKD patients that are receiving non specialist care?
A. Yes – even just counting the numbers of people in a region who have advanced CKD but not under a kidney centre would be a useful improvement measure. Separately considering quality of earlier CKD care (measurement of BP and albuminuria, and prescription of certain medications) would also direct efforts to improve wider population health. The latter is included in an ongoing audit run by

CVDprevent. The former group the UKRR hopes to better understand by continuing to work with OpenSafely – and are currently sharing identifiers of people known to be receiving KRT with them to correctly identify these patients.

Q. How many CKD patients are not being seen in specialist care?

A. This is not currently known except for estimates of the prevalence of CKD taken from the previous National CKD audit, and the regular Health Survey for England. Please see answer above relating to working with OpenSafely to try to measure this more accurately in different regions.

Dataset Version 5

James Medcalf, UKKA

Q. How do we provide co-morbidity start dates if exact date is not available on system?

A. This has been a dilemma for as long as the UKRR have collected data. A suggestion was mooted in the meeting of having a 'this date is only an estimate' flag. Whilst this would be ideal in a motivated centre, it is not the approach taken in the wider NHS (for example GP systems) where the best guess date is entered. We suggest that when a precise date is not known reverting to 01-01-YYYY (or 01-MM-YYYY) is the best compromise.

Q. What are the symptoms of Peritonitis and how do we submit them?

A. The role of this item is to improve the interpretation of any PD fluid microscopy and culture result that we receive. The definition of PD peritonitis is classically 2 from 3 possible features (symptoms, WCC > 100, positive culture). A practice approach to this data item therefore is simply to record a 'Y' or 'N' every time a PD sample is sent to the microbiology department.

In the case of a blank answer to this question the assumption will be that the patient did have symptoms (the most common reason for sending a sample after all).

Q. Care plan – No option for unpredicted. On the care plan we do have undecided patients – what to do with them?

A. There are always people who cannot make a decision about KRT until the moment that they need it – either because they present late with symptoms, or they struggle to decide. So 'best' care will never be 100% of people with a care-plan at KRT start. However, even after KRT start, it is not unreasonable to think that every patient still has an assessment about whether they could do dialysis at home.

Q. Care Planning - How would a patient be classified if they would be suitable for transplant if they lost weight? How to classify unsuitable patients for RRT.

A. This is a very good question – to which the first answer should be – 'the priority of the clinical and operational team locally should take precedence in this decision'. So if a local service continues to keep people under the care of the transplant assessment service whilst they lose weight then the assessment is ongoing.

Much more commonly though is that people are 'referred back to their nephrologist' and in practice the transplant assessment is finished until the person becomes suitable and is re-referred. A patient will then have two or more care-planning episodes.

Q. Is transplant listing data being captured?

A. Yes

Q. How many centres are using Snomed?
A. At present only one centre (Oxford) is submitting the 'primary renal disease' code using SNOMED. It is likely this will increase in time however, as increasing numbers of centres use generic EPR systems which will be coded using SNOMED (in keeping with NHS guidance).

Q. How may centres have stopped collecting comorbidities other than diabetes and malignancy now that the UKRR is using HES data?
A. About 50% of centres send data on co-existing conditions, with few centres each year.

Q. Will the old co-morbidity list be updated to a more sensible list?
A. We all suspect that there is a much longer list of co-existing conditions which affect the outcomes of patients with CKD than the (old) UKRR list. Frailty, mental health conditions, learn disabilities and cognitive impairment are all likely to. This would need further research to prove and would be a justification for getting more data from linkage (to GP systems or Hospital Episode Statistics for example), as it would become increasingly unlikely that a kidney unit would maintain such a list separately.

UKRDC User Interface – Clinical viewer

George Swinnerton, UKKA

Q. Who corrects errors and what happens?
Q. If I am advised of an error & I make a change on the renal system, do I need to do anything else?
A. Errors are corrected at individual units. At present the whole file is rejected, the data corrected at unit, and that prompts a file re-submission. We are working on different levels of 'rejection' where the error is not critical enough to prevent the data-loading but needs to be updated. The process would be similar however – with the renal systems administration correcting the data in the local system which would trigger a further file send.

C. George – *Error checks will be different to current validation - not as severe – for example, a patient with no HD sessions or an incorrect PD modality, this type of error will not cause the working file to be rejected.*

Q. What will happen with smaller errors i.e., dates a year out?
Q. As we are using real time data, do I need to do anything with future errors / observations?
A. Some dates can clearly not happen in the future (a date of birth, or even anticipating a date of death). Sometimes a future data is possible. Future dates will not result in the file being rejected – but in the future these errors will be highlighted and should be resolved with the handling of real-time data and looking at treatment records/timelines.

Q. What happens once corrected on renal system and the new file sent? Will it overwrite the incorrect data? For example, wrong date of starting dialysis – how does it remove the wrong date?
A. The file got rejected and the new files are loaded and will overwrite the wrong information. In the case of data such as the 'timeline' the entire new timeline is resubmitted and overwrites the previous.

In the case of blood results (in most systems) the results between the two dates specified in the file removed and replaced.

Q. What do we do with temporary HD sessions for a PD session? Is my renal unit going to get a lot of errors for PD patients that have HD session data but do not change treatment modality as it is not a permanent treatment change?
A. *These will be highlighted in the GUI, and data managers will query with the site and it won't reject the file.*

Q. How is it best to identify renal patients on a multi-speciality system and how would you get RR numbers added?
A. *The UKRR will not issue patient RR numbers to kidney units as these will no longer be the most important way of correctly identifying a patient – NHS number will be used instead. The kidney centre will need to work with their EPR system to define who is either on KRT, or under the care of the kidney unit (see answers to identifying patients with advanced CKD above)*

UKRDC User Interface – Clinical viewer

Joel Collins, UKKA

Q. Can Networks access the data? Interested in seeing the metrics & stats rather than individual patient identifiable information.
A: The design of the permission structure would allow this – with an individual in the network being able to see summary statistics from several individual centres (but not the patient identifiers)

Q. Can I produce statistics from this platform?
A: Not currently – although we expect that the majority of questions will be similar or identical between units and regions, so we are instead anticipating agreeing an increasing range of measures at a national/regional level and displaying those for everyone.

Q. I want to look at metrics in a different way to the annual report, is that possible?
A. This functionality is perhaps best achieved in the existing UKRR data-portals available from the ukkidney.org website. Whilst the statistics are not 'real-time' they can be grouped or separated by patient group/treatment type or other characteristics.

Q. How are numbers generated on the UI? Number of patients or records?
A. It will be numbers of patients in the majority of cases.

Q. What plan is in place for EPIC integration?
A. Since the meeting the UKKA has co-hosted a meeting of all the EPIC sites with Dr Afzal Choudhry to discuss ways that the EPIC sites could work together to the benefit of all.

Q. Can you view more than one error for an individual patient at one time?
A. This is currently in development and a priority – at the moment you can only view one error at a time and resubmit each time an error is fixed until the file is accepted.

Q. The Annual Report isn't in real time – how will this work with the UKRDC data?
A. *Although the data source is separate, the data items are the same as that reported in the Annual Report. In the future that will mean we could present innovative measures of kidney care, but initially the measures based on the UKRDC data will be of similar design to either a) the UKRR annual report b) the RSTP dashboard or c) the measures we have co-produced with renal GIRFT.*

Q. Can UKRDC viewer be linked to other patient portals?
Q. PKB – Oxford have moved from PV to Health for me. Can this data feed be used?
A. At the moment, only Patient Knows Best because the priority was to replace the 'PatientView' platform with a similar alternative. In the future renal centres may well send data to other patient portals because their trust has either subscribed to an alternative portal or has developed on themselves.

Q. EPIC. Will have a similar statistical tools within EPIC, can we integrate with them?
A. Not directly – but if measures are created on data which is also in a UKRDC feed then it is likely the UKRR will design very similar measures (and would always be open to hearing good ideas for them).

UKRDC User Interface – Data Visualisations

Philip Main, UKKA

Q. Is there a way of obtaining numbers / summary of report rather than just view the graphs?
A. Yes – the dashboard will have an export button.

Q. Can you use the graphs to drill down on an error to find out more information about any outliers?
A. Yes this will be available.

Lab AKI Update

Beth Carter-Crosby, UKKA

Q. Is the AKI lab data linked to the quarterly data collection, for example are we combining data with CKD, and are we including the AKI from kidney centres to look at how many of AKI patients are dialysed?
A. Not as yet in routine statistics. The UKRR do use the data we hold on patients on KRT to exclude them from the AKI warning score data before we calculate AKI rates. The next priority is routinely linking to Hospital Episode Statistics to identify hospitalised vs. community AKI. If we received good quality data in the UKRDC feed about dialysis sessions for AKI we could generate a combined measure in the future.

Q. Who is the contact for the AKI data?
A. Data comes directly from pathology labs - for queries at UKKA please email ukrr.akiregistry@nhs.net

Lab AKI Results

Shalini Santhakumaran, UKKA

Q. With multiple alerts becoming one episode – how do you calculate the peak stage if there are multiple alerts (do we use highest alert value or the first alert value)?
A. We have looked at both peak and first but not done much to look into progression as of yet.

Q. Is there a formula to calculate eGFR in children that doesn't use height?

A. No

Q. **Creatine and kidney function – is it not only valid in steady state?**

A. We agree that serum creatinine is only an appropriate measure of kidney function in a patient when the concentration in their blood is relatively constant. This is in part why we are cautious about creating AKI measures based on change in AKI warning score, or duration of scores.

Information Governance and National Data Opt-out

Tom Gray, UKKA

Q. Is it justifiable for full medication record to be included e.g. contraceptives, medication for mental health etc?

A. *It is correct to point out that there are several medications which we are unlikely to use to make a quality improvement measure of kidney care, or that would be sufficiently accurately recorded. We would be happy for a unit to limit the types of medication which they sent to the UKRR to a) Treatments for anaemia, b) immunosuppression, c) Treatments for CKD-mineral bone disease, d) treatments for cardiovascular risk reduction (including BP medication, treatments for diabetes, anti-platelet medication, statins, SGLT2 inhibitors or treatments for heart-failure).*

Many centres will find this difficult to achieve however, especially as the same data-feed will also be used for the patient-viewer in many cases (where a patient may well expect to see all their medications listed).