

It is just over 1 year since Renal PatientView (RPV) opened enrolment to all areas. This newsletter describes some important new features, and gives an update on progress and plans for the next year, including anticipated costs for 2007.



Imminent new features

Transplant status will come directly from UKT – provisionally from **Sept 4th**. This means that for the first time it is possible that information on RPV may be different from that shown on the local electronic record (EPR) – *but the status shown on RPV will be the operational one*. Status changes will be checked with UKT at least twice weekly. This feature was requested by patient groups at the outset of the project and agreed with the BTS and UKT. Further information will be sent via BTS and Renal Association email lists.

Historical information can be sent Proton users can now electively send historical information (results, letters if available, or both) for a specified date range for a patient who is enrolled in RPV. Previously the system automatically sent just the last 10 items under each heading (e.g. Urea, Creat) at the time of enrolment, except for letters, which are only sent prospectively unless you use this manual option.

New data items The range of items routinely shown is being extended to include HCO₃, eGFR, Protein/Creat ratio (PCR) and Alb/Creat (ACR), sirolimus, INR, and one or two others. RPV can only show an item if you have it on your renal EPR.

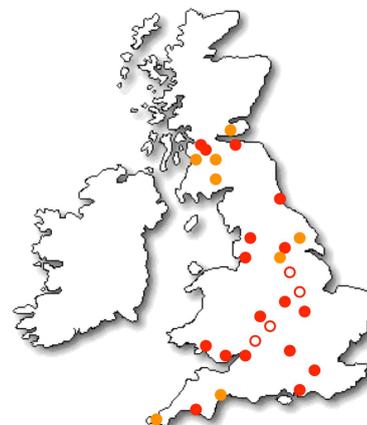
Login analysis Unit Admins can now analyse the use of any account, and it will soon be possible to download summary data on usage by all staff and patient users in a unit. Further information will be sent to Unit Admins.

We won a prize!

RPV won 1 of 5 awards at the NHS CfH Health IT Accolades Awards in May. The award was accepted by Cherry Bartlett (IT manager at the St James' renal unit) on behalf of RIXG at a ceremony during the NHS IT Professionals Conference in Leeds Town Hall. The £5000 prize goes towards the project.

Over 2000 patients now use RPV

RPV enrolments crossed 2,000 earlier this month, with Bristol going into the lead as the top recruiter. Two centres have over 300 users each. RPV will soon be installed on 21 systems, supporting 29 units and potentially over half of the UK's renal patients, with more to follow.



● Available ○ Near completion
For an update, see www.renal.org/rixg/units.html.

Proton units

Most Proton units have joined RPV but a few haven't yet. You can join any time, contact us.

Non-Proton units

Non-Proton system providers are telling us that they are now ready to provide interfaces to RPV. There is not a significant technical hurdle, but one explanation offered for slow pace has been 'users haven't requested it' – so PLEASE ASK YOUR SUPPLIER DIRECTLY – repeatedly if necessary – and tell us of any problems, we may be able to help. Our target is that at least two other systems should be integrated before the end of the year. If you are commissioning an upgrade or new installation, please ask for RPV functionality to be built in.

Feedback

Cherry Bartlett (Leeds) has undertaken a formal survey of several hundred patients, and a smaller number of non-users from the same units. This has yet to be fully analyzed, but some highlights:

Users were divided roughly evenly between dialysis, transplant, and general nephrology. Their average age is below the average age of ESRD patients, but 10% are over 65 and quite a few patients over 80 are enrolled.

Non-users – 64% stated that it was because they didn't know about the system! Not having access to a computer was next.

Value – 95% described it as valuable or very valuable (65% very). Positive answers to 'makes me feel more in control'; and 'gives me better understanding'. 24% reported 'I read things that worry me' – but perhaps it would be abnormal if they didn't.

Most useful item – Results.

Most desired item – copies of clinic letters, where these were not available. These are now online in several units, but were not in many at the time of the survey.

Useability, amount of information – patients generally found the site easy to use. We have had many requests for more information, none for less.

Security 7% of patients were 'very anxious' about the security of the system before they enrolled, but this fell to 1% after they became users. 82% have never changed passwords.

User comments: "I felt like a pest keeping ringing the hospital for my results after I had attended clinic – I now feel that my results belong to me". "The website is excellent. It is one of the best innovations I have encountered in the NHS in my 50yrs involvement". "Patients don't always take in what the medics say, and to be able to take time to read it properly in the comfort of your own home is wonderful."

Staff experience

Is it a lot of extra work? Not a lot. Use is made of data that is already stored. Patient and staff enrolment are simple and are carried out locally. RPV Unit Admins deal with enrolment and queries about passwords etc and this is generating some work, but the task can be divided between multiple individuals.

Advance concerns were expressed that RPV might lead to more anxious patients and more phone calls. The reported experience has been contrary to this – fewer phone calls, and no increase in anxiety or length of consultations.

Other benefits Look up results from home when on call, or when at another hospital or out-of-centre meeting. Patients can show their information to staff at other clinics, hospitals, etc.

Funding

Funding so far The development costs of RPV were met by the Departments of Health of England, Scotland, and Wales, as a pilot project to test feasibility and acceptability. Further dissemination has been funded from this resource plus a supplement to aid integration of non-Proton systems. All other costs have been covered by an installation charge of £2000 per unit for joining. The whole project has spent less than £100,000 for all its development work and implementation so far.

Funding 2007/8 No further central funding is on offer, and we are not keen to become dependent on commercial or other fickle external support, so next year we will need to be self-supporting. While we hope that in the longer run the cost could be integrated into other schemes (such as the Registry), at first we will need to invoice participating units annually. RIXG will discuss this soon, and invoices are likely to be sent by March 2007, to permit payment in either financial year. The cost in 2007 is likely to average about £1500, probably modified up and down according to unit size. This is probably about £1 per eligible patient (including long-term outpatients). More news will follow.

Background

The project was developed by RIXG, the Renal Information Exchange Group. A pilot project began testing in two centres in January 2005. After a favourable reception, in mid 2005 the project was extended much more widely. Read more about RIXG at www.renal.org/rixg.

FURTHER INFO

Contact us The RPV project has a small steering group under the auspices of RIXG. Please contact Neil Turner or Keith Simpson with feedback or questions: Neil Turner, 0131 242 9167, neil.turner@ed.ac.uk; Keith Simpson, 0141 211 4946, keith_simpson@compuserve.com

Need more leaflets or posters? Contact Dawn Hibbert, dawn.hibbert@ed.ac.uk 0131 242 9167

Download this and other newsletters and further info including recruiting tips etc from first newsletter, at www.renal.org/rixg/patientview.html

Try the system www.renalpatientview.org – new demo logins are now available from the foot of the home page.