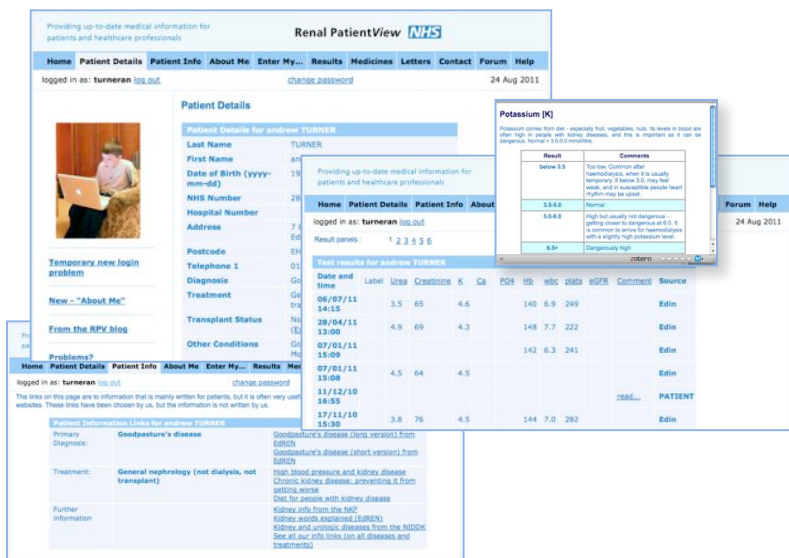


1,000 renal patients looked up their records online yesterday



Renal PatientView (RPV) began giving renal patients access to live test results and info about their diagnosis and treatment in 2005. It has grown steadily and had 17,000 registrants in August 2011.

51 of the UK's 72 renal units have joined, with more on the way. See www.renal.org/rixg/units.html

Patients like it

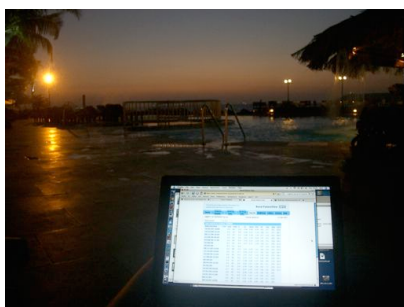
Patient users give enthusiastic responses both spontaneously and in surveys. They reported that they know more about their condition and feel in better control.

And they use it heavily

10,000 visitors make 30,000 visits to the site each month.

Users log in frequently at first, settling down to an average of about twice each month. These levels are much higher than reported in other records access systems. We cannot prove whether this is because of the condition or the system design, but we suspect both.

Most logins occur around test results, and therefore around visits for outpatients.



Patients report using it at all times of day and from all over the world.

Staff like it too

Remarkably, staff responses are just as positive.

RPV is quietly revolutionary. Staff report that patients become more knowledgeable, not more but less anxious, and that it leads to fewer phone calls and better quality consultations. They no longer start with bad/good news, instead spending more time on what's to be done.

Isn't this just for a minority?

Not any more. In 8 units, enrolment in patients on dialysis or transplanted is over 50%, and in one (Bristol) it has reached 65%. We think that a key factor in enrolment is the level of face-to-face advocacy within different units.

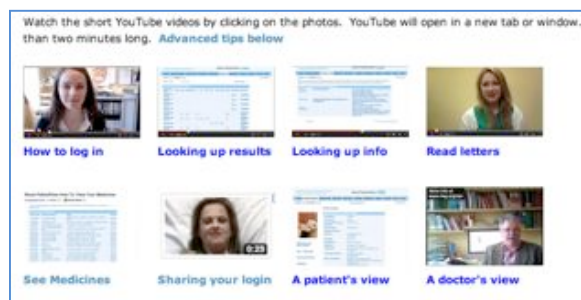
The difference in median age between users and non users has fallen to just 3 years. We can detect no difference in usage between men and women. There is however an apparent association between user status and lower deprivation.

Any renal EPR can connect to RPV

There are now interfaces with just about every kind of renal electronic patient record system: Proton, eMed, Vitaldata, RenalPlus, Clinical Vision, as well as with several non-renal or bespoke systems, including iSoft's Clinical Manager.

Scope for further uptake

The level of uptake varies widely across the UK. Experience in Bristol and recruitment campaigns at Guy's, Edinburgh and Salford, units with high to moderate enrolment, show that there is still scope for significant further recruitment even in high enrolling units. Aids to increase uptake and early retention are being developed.



Online patient hints and help at www.rixg.org/rpv

Can other specialties do the same?

Almost certainly. We have provided advice to regional projects across the UK including diabetes, haematology, oncology and HIV.

Could RPV do it for [specialty X]?

Possibly. We are close to defining a way to switch the view from Renal to other specialties, at the patient's choice. You would just need to have

1. A way to send relevant data
2. A way to issue logins
3. A (specialty?) group to sort the info links

How does it work

A local server or PC receives and then sends new or changed info to the webserver as an encrypted XML file at least twice each day. Patients have a username/password login that they can choose to share. 40% have shared their logins and some are dependent on family or friends to log in for them.



Chris was able to give his login to doctors in Aberdeen when he was flown there after developing serious problems while on holiday in Orkney.

What next?

Patients can now enter some of their own data and comments, use a forum, and soon will be able to give anonymous feedback. We are working on feeding data back into Unit EPRs.

In 2011 RPV is being integrated with **RADAR**, a Renal Rare Disease Registry, so that with patients' permission data may be shared anonymously for audit and future research into specific diseases. Patients and clinicians will get extra information and expert contacts.

We are discussing sharing logins with similar projects, and how to use RPV to give access to approved local apps or projects.

About Me



Things people should know about me

I don't have such serious kidney disease. Just do everything, but up to a point. I really like to know everything

Things I'd like to talk about

What should my blood pressure be

Save

Print this page

About me allows you to write down and show or print out important information about what staff or others should know about you, or what worries you, or what you would like to happen to you.

History

The Renal Information Exchange Group (RIXG) was formed in 2004 with representatives from patient groups and all renal organisations and professions. The intention was to coordinate IT initiatives to improve patient experience and care. RIXG commissioned RPV as its first major project.

Cost

RPV was piloted with support from the Departments of Health of England, Scotland and Wales and has had further development funding from NHS Kidney Care and the Scottish Government, giving total development funding of about £120,000. However its main continuing income comes from renal units. Each pays an average of about £2000 per annum to use RPV, depending on size. It is free to patients.

Further information

RPV news – renalpatientview.blogspot.com

www.rixg.org/rpv – 'How To ...', with links to brief introduction, and **Recruitment Toolkit**

www.renal.org/rpv – More info including technical details, and **contact details** – how to get more leaflets and posters or other information. Or email neil.turner@ed.ac.uk, or keith.simpson@nhs.net