

**Renal PatientView (RPV)** is the UK renal community's pioneering project that gives patients rapid access to their results, information about their diagnosis and treatment, and in many units also clinic letters, via a secure Internet login.

## 6000 registrations in 33 units

By the time you read this we expect to have registered 6000 patients in units covering more than half of the UK. A dozen more units are lined up to join including the first units in Northern Ireland. This is nearly a doubling in numbers over the last 12 months. See below for more about recruitment.



Installed in progress (February 2008)  
See [www.renal.org/rixg/units.html](http://www.renal.org/rixg/units.html) for an update

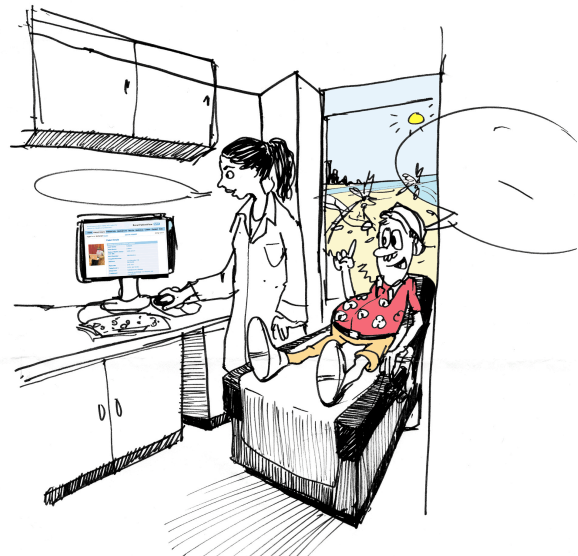
**eMed (Mediqua)** – is now fully integrated after piloting in Norwich. If your unit has eMed you should have heard from us already, but you should be able to ask Mediqua to switch it on, plus contact us to start using Renal PatientView. We will send our usual info packs, posters and patient info leaflets.

**Guy's/St Thomas'** has integrated its own system and is enrolling fast.

**Clinical Vision (CCL)** – CV4's interface is almost ready, test data has been sent successfully.

**Cybernius, RenalPlus** – also imminent, ask them about progress.

**Proton** - there are now very few Proton units that are not using RPV, but if you are in one that isn't, but are now keen to start, let us know.



Use RPV even on holiday (Beth Shortt)

## Tell your colleagues

In addition to patient info materials, we can supply modifiable posters and presentations for medical or patient audiences so that you can show how ahead Renal are in your area. Contact us.

The first manuscript describing RPV is currently under review and we will circulate it when we can. Others should follow.

## What's New?

**News Module** - The News module allows local RPV admins to post notices that can be read only by patients in your unit. Should be useful for patient info events, patient association info, etc. If you would like something posted more widely, contact us, we can post notices that can be seen by all units, or by all RPV local admins, or by everyone including the public who just come to have a look at the home page and demo logins.

**Results from other units** - RPV has always been able to amalgamate info from multiple units, for instance if a patient goes to another centre for transplantation. Previously demographic info and diagnosis etc would switch according to whichever unit sent the last info; and there was a bug that meant that some results could disappear if their date range overlapped. That is now corrected with some important consequences. The login the patient uses (i.e. which unit has issued it) will determine which unit's demographic

info, diagnoses, 'other conditions' and contact info are shown, so the patient can use this mechanism to determine which unit is dominant. Test results and letters from all units sending data will be shown, with their origin indicated by colour coding. To come: Medicines from *both* units will be shown, clearly distinguished and with appropriate cautions.

## What's next?

**Statistics extraction** and a patients' **discussion forum** are coming soon. During 2008 we intend to add **new tests**, including ferritin, Fe, uric acid and LFTs. We're hoping to introduce some **graphics**, and to trial **patient enters their own BP** – their values will be clearly differentiated. We are seeking a way for units to send **occasional or unusual tests** for which there is no consistent format. Examples might include tissue typing, virology or microbiology results, dietary assessment, etc. Each would require some work on your local info system to configure data extraction, but at the RPV server there would be a standard way of presentation.

**Links review** – we're reviewing all the info links we provide again this Summer. Please let us know if you'd like to help, or know someone who should, or have any particular links to suggest.

## Funding and governance

**Budget and funding** – last year units who were in their second year of using RPV were invoiced at an average of £1500 (based on RRT numbers), contributing to a total budget of £30,000. The expanded patient base means that while charging less per patient in 2008/9 we will be able to undertake more development and put the administration on a more regular footing. In future years the cost per patient will fall, and it may be possible to collect these sums via the Registry's capitation fee (except Scotland). A universal charge would add about £1.50 per RRT patient to give a total budget of £60,000. If restricted to enrolling units it would add £3 this year, falling as more units join towards £1.50. The system is of course available to non-RRT patients too, so the cost per eligible patient is lower than this. For new units there is a one-off installation cost of approximately £3,000.

**Governance** Now that RPV is a success and here to stay, and larger than the pilot project it started out as, the best arrangements for administration and governance are under review. The Renal Association is currently the project's banker, and one option is to establish an arms-length body attached to the Renal Association, akin to the Renal Registry. A governing board would have representation from the groups that contribute to RIXG, including strong patient representation.

## Your involvement

**Meet the developers meeting** We'd like to invite an admin from each unit to 'meet the developers' along with another advocate - doctor, nurse, transplant coordinator, or whoever. This will give us a chance to hear your feedback, and you a chance to influence further development.

**Enrolment - how's yours?** Levels and rates of enrolment vary enormously between centres. Some have very high levels of enrolment while others haven't taken off. Responses to the patient survey suggested that unawareness was the major reason that patients hadn't enrolled, so we are interested to test the effect of being more proactive. One notion is a project to train and employ local advocates for 1 day per week for 6 months with the aim of seeing 'how high can you go' – and to establish how useful and used is this in 2008. More to follow.

## RPV and HealthSpace

**Connecting for Health's 'patient portal'** is called HealthSpace. RPV anticipated one of CfH's visions by enabling access to records online. Viewing of Summary Care Records is being trialled now through HealthSpace, and we are discussing the possibility of also making RPV viewable through a HealthSpace login. These logins are more difficult to get and use than ours, but also more secure. It would enable patients to see details from primary care via the 'Spine', their RPV record, and any other secondary care records via one route. It wouldn't alter the content or management of RPV, just provide an alternative way of logging in.

### FURTHER INFO

**Contact us** The RPV project has a small steering group under the auspices of RIXG. Contact Neil Turner, 0131 242 9167, [neil.turner@ed.ac.uk](mailto:neil.turner@ed.ac.uk); or Keith Simpson, 0141 211 4946, [keith.simpson@nhs.net](mailto:keith.simpson@nhs.net)

**Where did this come from?** RIXG, the Renal Information Exchange group, commissioned RPV in 2004. More information at [www.renal.org/rixg](http://www.renal.org/rixg)

**Need more leaflets or posters?** Contact Emma Farrell, [emma.farrell@ed.ac.uk](mailto:emma.farrell@ed.ac.uk) 0131 242 9167

**Download this and other newsletters and further info** including recruiting tips, patient feedback etc, [www.renal.org/rixg/patientview.html](http://www.renal.org/rixg/patientview.html)

**Try the system** [www.renalpatientview.org](http://www.renalpatientview.org) – demo logins are available from the foot of the home page (limited; no letters, TP status etc).

**More info and help for local administrators** is available from [www.renal.org/rixg/adminhelp.html](http://www.renal.org/rixg/adminhelp.html)