



Renal PatientView is easy enough for young and old to use!

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What I tell my patients about the Renal PatientView system

Have you ever wanted to find out your test results after you've been to a clinic? Or find information about your disease or treatment? Or show some of that information to someone somewhere else? Renal PatientView makes it possible to do all of these things. It may be at a renal unit near you already – or if not, it could be soon.

How does it work?

Most renal units have a special renal computer system for showing results and other information on their patients, separate from other hospital IT systems. However, you can usually only use them within the hospital, and sometimes only from certain computers. Although these systems were introduced mainly to show blood tests, they almost always have a lot of extra information about your diagnosis and treatment too. In some units they include lists of medicines, and letters and summaries about you.

Renal PatientView takes information from your renal unit's computer system once a day, and puts it onto a webserver so that you can look it up on the internet yourself, from home or from anywhere in the world.

How do I get to it?

You are given a username (for example, smithjane) and a password. It's just like logging in to use an email account.

When you log in you will first see your name and address – to confirm that it's you, and that your unit has your details recorded correctly. As Figure 1 (overleaf) shows, you will also find links to useful explanations about your kidney condition and its treatment. The figure shows just some examples of what it does.

Who can read it?

You can, your GP can, and staff from your renal unit can. Also, you may share your password with anyone you want. So, you could show it to relatives in other parts of the country or even the world. When you are seen at another clinic, or at an unfamiliar hospital or surgery, you could show it to staff there, even if you are away on holiday. You can change your password at any time to restrict access again.

Who can see what?

The information shown is the same for all users. Thus, staff can read patient information, and patients can read medical information.

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Figure 1. How to use Renal PatientView

1 - LOG IN at www.renalpatientview.org
With your username and password

2 - click on the 'tabs' at the top to go to, for example Patient Info

It will show **your** diagnosis and treatment

3 - then follow the links (blue lines) to read about ...

a your kidney disease

b your treatment

c ... and more

4 - you can read your Blood Results here

5 - click on any of the other tabs. They include info for healthcare staff who don't work in renal units, contact information (routine and urgent), medicines (if a reliable list is kept in your unit), and letters and summaries in some units.

Date and time	Urea	Cr&E	eGFR	Ca	PTH	PTHrP	HbA1c	HbA1c	Urea
28/12/04	4.8	139	5.8	1.25	1.52	11.2	5.6	109	213
02/12/04	6.5	134	3.9	1.02	1.49	100	6.0	106	153
29/11/04									205
26/11/04	5.6	126	3.8	1.26	1.23	94.9	6.3	183	
18/11/04								114	5/8
10/11/04									
10/11/04	POST	12.4	308	3.0	1.09	1.36			
10/11/04	PBE	17.8	493	3.2	1.08	2.03			
03/11/04		16.3	467	6.5	1.65	2.04			
22/10/04							123	6/3	199
22/10/04	POST	22.0	503	4.8	1.52	1.52			
22/10/04	PBE	29.4	1100	5.2	1.64	1.90			

Patients see only their own results and other information. GPs have a unique login for each of their PatientView-registered patients. Unit staff who have PatientView logins may see the records of any PatientView patient from their unit.

What if I don't use the internet?

It can still be very useful for you. Friends or other members of the family can look it up for you, and

a major benefit is that if you are on holiday, or at another clinic or hospital, your record can still be available to the staff you see there. Also, your own doctors and some other staff can get to your record when they aren't at the right computer – for instance, if they are telephoned at home, or while at another hospital. Transplant co-ordinators may find this very useful. However, only the people who are already allowed to look



up your record in hospital will be able to look it up on Renal PatientView.

Is it safe?

It is very safe. It uses security systems like the ones used for internet shopping, and has been thoroughly checked. The main risk is probably that someone might find or guess a password. If you think someone may have discovered your password, you can change it at any time. We've chosen a password system that is safe but still quite simple to use. See Box 1 for some tips on making a safe password.

What if I don't like the idea of having my information on the internet?

We think it's quite safe, and that there will be real benefits. But your information is only put onto Renal PatientView at your request, and you can have all of your information removed if you change your mind. If you don't want to use Renal PatientView, it will not affect the records held by your renal unit but, as now, people will only be able to read them within your unit (usually).

Where has this come from?

Renal PatientView has been produced by the Renal Information eXchange Group (RIXG). This is a group representing patients and renal teams, which was formed in 2003 to make advances in IT work to help renal patients. The PatientView pilot project began in 2004, funded by the Department of Health. Additional support has come from the Scottish Executive and the Welsh Assembly Government. There is no private or industrial sponsorship involved.

Where does the information about diseases come from?

RIXG has set up a group to choose the information links that go with different diseases and treatments. The group includes patients, GPs, renal consultants and representatives of others on the renal team, including dietitians, nurses, social workers, and others. Almost none of the information been written specially for PatientView; the links are chosen from existing websites. We use a set of rules to help us decide what we should and shouldn't use, but the quality of the information is the most important factor. As well as accuracy, and coming from a reliable source, we look at how easy the information is to understand. We do not use sites that carry adverts if there are good alternatives.

What else will the system do?

At the moment we are still working through our initial list of objectives. However, spreading it to more units is a major priority. We hope in the

Box 1. Making passwords difficult to guess

1. These rules work anywhere you can make your own password. If you aren't too worried, you can stop at recommendation two. If you want the most secure password, go right up to eight.
2. Simple words or numbers can be easy for someone to guess. Maybe you don't mind? But if you do, you should make it harder – carry on below.
3. Make your password longer – more than six characters.
4. Don't make it easy to guess, so not 123456 or 777777, and certainly don't use 'password'! It is safer to avoid other simple words too (such as daffodil), but many people might be happy with that as a compromise to keep it simple to remember. Read further to make it safer still.
5. Using a mixture of numbers and letters makes it much safer; for example, daff271odil (daffodil + 271).
6. Using a mixture of capitals and ordinary letters is even better; for example, dAff271oDil – this would be a very difficult password to guess, and not impossible to remember.
7. Changing your password from time to time is wise if you have let other people know it. That stops other people finding it out from people you've told, accidentally or on purpose.
8. Use an advanced password for greatest security: think of a phrase first, then mix in a number. For example mysniHC comes from 'my sisters name is Helen Cameron'. Then make it harder by mixing in her birthday, 19th April 1951 (19/4/51) to make m1y9s4n5i1HC. That would be almost impossible to guess. On the other hand, you have to be able to remember how you made it.
9. Most systems allow just letters and numbers in passwords – not special characters such as ! - £ @ _ -.

future to alter the information shown according to how good your kidney function is – this will be particularly relevant to patients who may one day need dialysis or a transplant, and to patients who already have a transplant. We have had some additional suggestions. One is to give information for under-18s that is specific for children. Another is that it could send automatic text messages to tell you when to look at it. Both of these are technically feasible but we're keen to hear other ideas so that we know what would be really useful.

When will it get to my unit?

The project began on a small scale, as a pilot to test out the idea in four units. When this was successful, it proved possible to spread it to other units that used the most common type of renal unit IT system, 'Proton', at very little extra cost. At the moment, work is under way to make Renal PatientView available to units that use other IT systems – we hope that some will be able to join in beginning later in 2006.

The system was running in 12 units in January 2006, with a further ten installations



Table 1. Renal PatientView – participating units*

Planned go live	Centre	Actual go live
Oct 04	Leeds, York and Bradford	Nov 04
Nov 04	Birmingham Heartlands	Dec 04
Dec 04	Glasgow Western Infirmary and Crosshouse and Dumfries	Jan 05
Jan 05	Cardiff (Paediatric Unit)	Feb 05
Jun 05	Edinburgh and Dunfermline	Jun 05
Jun 05	Glasgow Royal Infirmary	Jul 05
Aug 05	Leicester	Aug 05
Oct 05	Preston	Sep 05
Nov 05	Swansea	Jan 06
Nov 05	Bristol and Exeter and Truro	Jan 06
Feb 06	Portsmouth	–
Feb 06	Plymouth	–
Feb 06	St Helier's Hospital	–
t.b.a.	Oxford	–
t.b.a.	Nottingham	–
t.b.a.	Gloucester	–
t.b.a.	Coventry	–
t.b.a.	Derby	–
t.b.a.	Sheffield	–

* Current plans (above) extend availability to units covering 50% of UK renal patients by May 2006. This includes the great majority of units using 'Proton'. Unfortunately, there are some units that do not have dedicated renal information systems, and it will not be possible for them to join the system yet.

under way or planned. However, for many of these places, installing it in one unit will make it immediately available to some other units that run from the same computer system. Examples include York and Bradford, using the Leeds system, and Fife, which uses the Edinburgh system.

See Table 1 for a list of units already enrolled, or soon to be enrolled. You can also get up-to-date information from the web page www.renalpatientview.org

Key points

- Renal PatientView is a computer system that has been developed so that you can access your test results, and information about diseases and treatments via the internet.
- Renal PatientView allows you to access your patient information from anywhere in the world, and to share this information with others.
- This new, secure system should be available in a number of major renal units this year.

What does it cost?

It is free to patients. Units pay a (usually) small fee for installation and long-term maintenance of the webserver.

Can I try it out?

Yes, if you go to www.renalpatientview.org you will see at the foot of the page 'you can view a demo as if you were a patient'. If you click on 'demo' you will find some test username and password combinations. Use these to log in at the top left to see the results for imaginary patients with different diagnoses and treatments ■

Further information

www.renalpatientview.org – go there to try it out

www.renal.org/rixg/patientview.html – more information about the system

www.renal.org/rixg/infolinks.html – how information links are chosen

If you would like to receive additional copies of this feature, please send your request to *BJRM* Patient Information, Hayward Medical Communications, Rosalind Franklin House, The Oaks, Fordham Road, Newmarket CB8 7XN.

