



Royal College
of Physicians



Personal health record (PHR) case study

PatientView

Acknowledgements

This case study is based on a review of published PatientView research reports (see references), information provided on the PatientView website, copies of leaflets and letter templates, responses to an online survey and a request for user comments, conducted as part of the landscape review.

It is also informed by discussions with Keith Simpson¹; Beverley Pearce², renal and transplant data co-ordinator; Ann Donnelly³, assistant renal services manager; Liz George³, renal transplant sister; and Cesarina Santos³, renal outpatient administrator. Many thanks to all for their help.

Overview

PatientView is run by the Renal Association and operations are overseen by the PatientView Committee. It is funded by a grant from the Scottish government and a capitation fee from the Department of Health in England.

The aim of PatientView is to give patients a better experience by enabling them to access the information held about them on electronic patient record (EPR) systems. PatientView has been in operation for 10 years and is used by 90% of UK renal units. There are currently more than 50,000 registered users, of which 10,000 use it every month. It was initially known as Renal PatientView and used by patients with chronic kidney disease and receiving renal replacement therapy (ie dialysis) in dedicated renal units. It is now used for a wider range of patients with kidney disease and for people with other conditions, notably inflammatory bowel disease (IBD), heart failure and diabetes.

The tool started by providing patients with access to their test results (including tables, graphs, help information and reference ranges). The types of information available have been extended over time and now include diagnoses, transplant list status, vital signs and observations, hospital (and in some areas primary care) medication records and clinical letters. Patients can also add their own information to PatientView, but this information cannot as yet be uploaded to the clinical system. Secure messaging with clinicians is available, but not yet widely used. PatientView can be accessed via the internet, on a mobile app and on interactive TVs (using the 'Looking Local' system).

Key recommendations

- > Collaboration is required between patients, professionals, IT specialists and patient and professional organisations.
- > Focus on what patients really want.
- > Use an agile approach to development, with services built up incrementally.
- > Keep things simple, avoid complex solutions.
- > Clinical champions are instrumental in driving implementation locally.
- > Local responsibility is needed for user recruitment, support and data quality.

Methods and lessons learnt

Implementation

Plans for Renal PatientView began to be developed in 2003, with a pilot in 2004. This was followed by a national project, launched in 2005. Since then, roll-out across renal units, integration with different renal clinical systems and the development of additional services (eg secure messaging, discussion forum) have taken place.

By 2011 there were 17,000 registered users. In 2012, extension to other conditions began, starting with IBD, and the system was renamed PatientView. In 2015, a major update, PatientView 2 was launched with new functions and better support for mobile devices.

Design and development

The initial content of the system was agreed in meetings between patient groups, clinicians, and renal IT specialists, to work out what would be most useful to patients, what was feasible technically, and what was likely to be practical and implementable. Focus groups with patients were also arranged by Kidney Research UK.

An agile approach was taken to development as the full set of requirements was not clear. This meant that the work was split into small packages, each of which was agreed with the developer, completed, and reviewed before moving on to the next. This reduced the level of risk and increased flexibility to change the plan where necessary. With difficult issues, a simple solution was piloted first, rather than building in complexity from the start. The services offered by PatientView have increased incrementally over the 10 years of operation.

¹ PatientView Committee

² Leicester General Hospital

³ Guy's and St Thomas' NHS Foundation Trust

User recruitment and registration

Recruitment is the responsibility of individual units and rates vary between units. Research shows that the main reason why patients don't become users is that they are unaware of PatientView.

Demographic factors, such as age, gender and social background do not play a major part, but people who are supported at first, for example, with a demonstration of the system, are more likely to become regular users. Leadership by health professionals – doctors, nurses and others in the unit – is key to a successful implementation. Various approaches to recruitment are recommended, such as:

- personal recommendation from the doctor or one of the team
- team members spending time in the waiting room with patients, giving them leaflets, enrolment forms and having a tablet or laptop to demonstrate the system
- prominently displayed posters and leaflets and/or information on the trust website
- YouTube videos showing how to use PatientView
- incremental registration of users, eg Guy's started with transplant patients, who for the most part were relatively well and interested in their results, before extending it to other patients
- quick turnaround on setting up users, which can be achieved by spreading administration rights across the team.

Patients are given a copy of an enrolment form in clinic. The form is signed by the patient and witnessed by a member of staff to confirm their identity. The form records the patient's name, date of birth and NHS number and this data is used to match the patient to their record on the local renal clinical system and to register the patient on PatientView. A login identifier and password are emailed to the patient, who can reset the password at first login.

Children and young adults are also registered on PatientView. Parents can register on their behalf, where necessary.

User support

Management of users is handled locally, given that the units know and are also able to verify the identity of their patients. As data is taken from local IT systems, management of the data and interfaces is also handled at a local level and this also ensures appropriate responsibility for data quality. A requirement was to keep local effort to a minimum to ensure sustainability and it was found to be possible for the work to be absorbed by existing local staff.

An administrator usually handles user queries (mainly relating to forgotten login details). Where a patient has not logged in for over 3 months, some units send out a reminder, offering individual support if they are having any problems.

Information sharing

As PatientView uses a national identifier (NHS number or CHI number in Scotland) as the key identifier, and as there is a single standard core dataset, patients can continue to see their record even if they move between renal units. Patients can see both current and previous records, which are also available to clinicians. This helps, for example, during transition from paediatric to adult services.

A patient leaflet is provided giving information about privacy and security. Patients can decide who they share their information with (family, carers, etc) and can do so by showing people their record on PatientView or as a printout or by giving them their login and password. Up to 40% of users share their login details with others and some are dependent on someone else to log in on their behalf (for example if they do not have a computer).

A patient's GP is provided with a login for PatientView, unless the patient requests for them not to.

Reporting test results

The results are uploaded from the clinical unit electronic record soon after they are reported by laboratory systems. They are shown as received and are not filtered or pre-screened by a clinician prior to upload to PatientView. The decision was made not to pre-screen as it would delay results being available to patients and would add a burden on clinicians.

All test results in a patient's clinical record are made available through PatientView, except in exceptional circumstances. Some results are not currently available to patients as these are technically more complex to set up. For example, microbiology results are technically more complex and often contain a mixture of predefined and free text, are of variable length and often come in instalments with later versions either supplementing or replacing previously received reports. There are plans to implement microbiology and virology data in time. Imaging reports are not included at present, but important findings would usually be discussed in clinic letters which are available on PatientView.

Patients may on occasion read bad news (such as deterioration in kidney function) or even dangerous results (such as high potassium) before their clinicians. Initial concerns about this turned out to be unfounded. Patients are anxious to know results and would rather have bad news sooner than wait for clinicians to deliver it. Information on high potassium is accompanied by appropriate patient information on how to seek help, so provides a safety feature.

Social networking

A discussion forum was originally provided in PatientView, but has been discontinued for various reasons, including:

- > the availability of other more sophisticated patient support groups run by patients (eg Polycystic Kidney Charity)
- > sometimes users inadvertently identified themselves in the posts and occasionally a user would offer well-intentioned but bad advice. The discussion forum was not moderated and even if it had been, this would not have prevented these problems.

Links to information sources

Information sources are linked to diagnostic and treatment codes and to test results, so that information about a specific condition, treatment or test can be accessed by the patient when they are looking at a specific diagnosis, treatment or test result. Further unlinked information is also provided.

The information is selected and reviewed by a patient and multi-professional panel. Selected information sources need to be:

- > high quality
- > appropriate for the audience
- > readable
- > from a trusted source
- > not associated with advertising
- > reviewed.

However, there has had to be some flexibility where few information sources exist, eg inclusion of sources with unobtrusive advertising that doesn't mislead.

The aim is that information should be readable by those aged 14 or under and the Wiki Flesch-Kincaid tool has been used to help measure readability. Initially, separate sources were signposted for professionals and patients.

However, since more patients read the professional pages than professionals, they have been combined and instead the plan is to offer different levels of detail, from easy to advanced/professional.

Patients checking and getting their records corrected

If a patient identifies incorrect information in PatientView, (eg their address has changed), they can contact a local administrator and the information is corrected on the local clinical system, this amendment is then uploaded onto PatientView.

In 2014, a project was set up to enable patients to check their renal unit and GP medicine records to see whether they were correct. Patients were invited through PatientView to 'opt in' to see their medication records. They were able to compare the renal unit and GP medications and send a secure message to their renal consultant identifying where there were differences. The consultant was notified by email and could contact the GP (and if necessary the patient) to discuss and both could then update their prescriptions.

Eight hospitals and 36 patients participated. Differences identified by patients included items that had different doses, items that were missing on the renal list or GP list and duplicates. They were scored by consultants to identify the impact that rectifying these issues would have on patient care. All of the findings improved the accuracy of the medicine records. Some of these improvements might have contributed to better care, optimised therapy and prevented major toxicity and/or organ damage. Doctors found that it took 5 to 20 minutes to rectify the issues per patient (by contacting the GP).

Patients were found to be knowledgeable about their medications (eg they were aware of inconsistent units of measurement), could spot errors and were happy to help resolve them. They liked the new service and said it made them feel more involved. However, participants included knowledgeable and motivated individuals and hence it cannot be assumed that the high level of patient participation and useful comments would be maintained if the service were made widely available.

User perspectives

PatientView is used by specific patient groups, who have a long-term condition and ongoing contact with the NHS. These patients tend to be more knowledgeable and interested in managing their condition.

The main use is obtaining blood test results, which are an important way of managing the condition and many patients take a close interest in them.

‘The most useful thing about PatientView is the removal of the wait by the telephone for days after clinic and wondering if there is a change to my health. By knowing outcomes quickly I find I am in more control’ – patient

The continuing usefulness of PatientView has meant that it is used routinely, mainly before and after clinics. Before clinics, it can be speculated that patients use it to prepare for the clinic (eg identifying things that they want to discuss) and after clinics, so that they can obtain their results and information in the clinic letter.

Users have found the site easy to access and use, reported the information available to be valuable, and that the contents gave them better understanding and empowerment. Patients have found it useful to share PatientView information to people involved in their care.

“I use PatientView on a tablet and mobile phone. This means should I take unwell I can provide the clinician attending me with a valuable overview of my condition’ – patient

Security is not a matter of concern to the majority of users, and the level of concern dropped after using the system.

Many of the benefits identified to date relate to the patient experience and are anecdotal rather than formally measured. Research in 2014 into patient outcomes indicated a possible link between use of PatientView and lowering phosphate levels, which is a mainly patient-led parameter.

Healthcare professional perspectives

Although PatientView is available to healthcare professionals, the number of renal unit users is relatively low (1,469 in total, including all staff groups). This may be because the same clinical information is available through the renal clinical system and currently only a small number of patients upload their own information into PatientView.

The majority of renal unit staff rate PatientView positively, considering that it has improved patient care and improved patients’ confidence in their care.

The implementation of PatientView has not added to clinician workload (in an evaluation carried out in 2012, 95% felt that it had no effect on the length of consultations). Evaluations of PatientView identified that some phone calls were being replaced by patients accessing their results online.

However, clinicians still review test results. In Guy’s Hospital, the nurses review results the morning they are available to patients so that they are prepared to discuss them, should patients phone in with concerns.

Renal units have not found that patient anxiety has increased by having detailed clinical information available – most of it would have been available anyway either by phone (test results) or via clinic letters. It seems that anxious patients remain anxious whatever medium is used to share information.

In general use of the system, the most frequent reason for contacting PatientView administrators was forgotten login details, followed by contact to amend demographic information or errors in data shown. These have included correcting contact numbers for patients on the transplant list, information about drugs prescribed, and observations on potassium levels and dialysis adequacy.

Technical perspective

PatientView software is supported by Solid State Group and is open source. Data is uploaded from local renal clinical systems to PatientView (now via a UK-wide renal data repository) and from NHS Blood and Transplant (NHSBT) for transplant list status. An encrypted XML file with a standard dataset is used for transfer of data.

All other communications with the web server are also encrypted. Records are based on a unique patient identifier (NHS number in England and Wales, CHI number in Scotland, and Health and Care number in Northern Ireland), enabling a composite record to be generated when data is received from more than one location, eg from the local renal unit and from a separate laboratory.

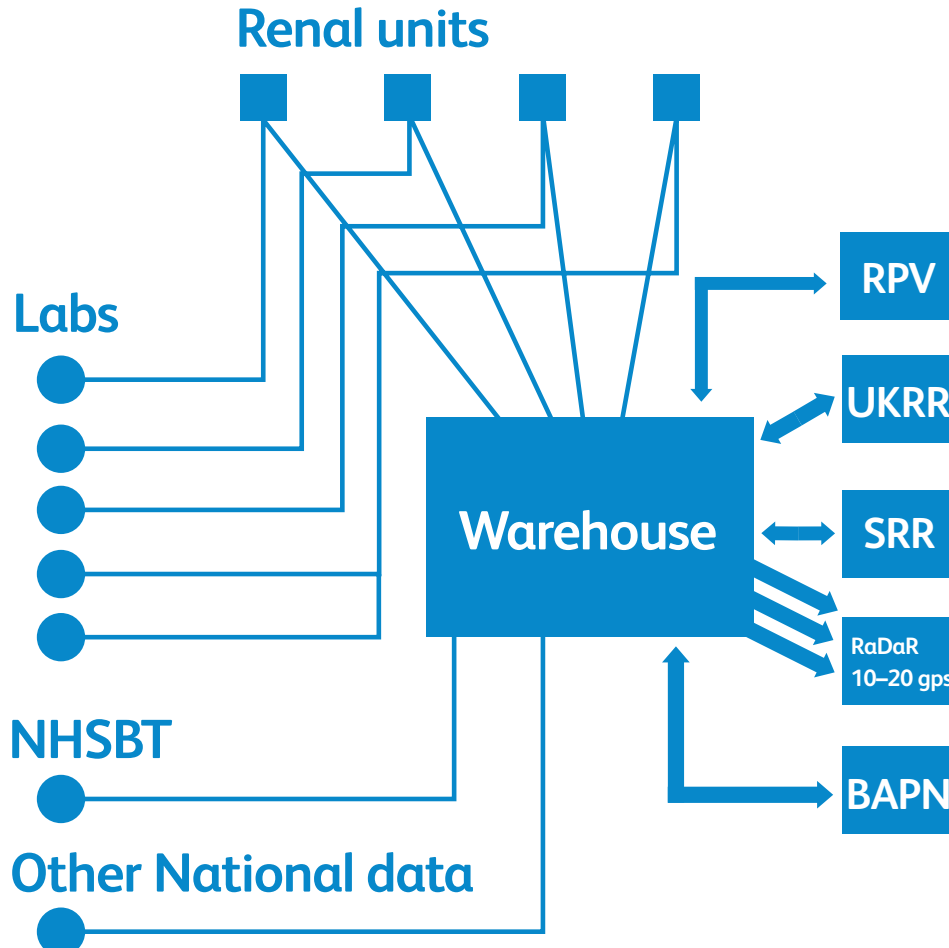
Security and confidentiality policies are in line with NHS policies and the Data Protection Act. Server security was verified by external specialists and regular penetration tests are carried out.

At present, although patients can record their own information on PatientView (eg blood tests outside the hospital, weight, blood pressure etc), it is not yet uploaded to the renal EPR. One of the challenges with older hospital systems, is that they do not record the metadata required to identify the source of the data. Secure messaging with clinicians became available with the latest version of PatientView.

PatientView is part of a wider UK Renal Data Collaboration technical infrastructure. As well as feeding PatientView, a central warehouse provides data to the UK and Scottish Renal Registries (UKRR and SRR), the Renal Rare Disease Registry (RaDaR) and the British Association for Paediatric Nephrology (BAPN).

The technical schema for PatientView is illustrated in figure 1 below.

Figure 1 PatientView technical scheme



References

Phelps RG, Taylor J, Simpson K, Samuel J, Turner AN. Patients' continuing use of an online health record: a quantitative evaluation of 14,000 years of patient access data. *J Med Internet Res* 2014;16(10):e241.

Phelps RG et al. *UK Renal Data Collaboration. Patients take the lead to reduce errors in medicine prescriptions* (unpublished, presentation abstract). 2015.

Bartlett C, Simpson K, Turner AN. Patient access to complex chronic disease records on the Internet. *BMC Medical Informatics and Decision Making* 2012, 12:87 (Open Access) <http://www.biomedcentral.com/1472-6947/12/87>

Rao A, Pitcher D, Phelps RG. *Patients that utilise a patient facing on line health record have better health outcomes* (unpublished, poster abstract). 2014.

Mukoro F. *Renal Patient View – A system which provides patients with on-line access to their test results – a final evaluation report*. NHS Kidney Care, 2012.

Health Informatics Unit

Royal College of Physicians
11 St Andrews Place
Regent's Park
London NW1 4LE
Tel: +44 (0)20 3075 1484
Email: informatics@rcplondon.ac.uk
www.rcplondon.ac.uk/hiu



**Royal College
of Physicians**