



## CKJ REVIEW

# The role of patient portals in enhancing self-care in patients with renal conditions

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## ABSTRACT

Web-based portals enable patients to access their electronic health records, including test results and clinical documents, from anywhere with Internet access. Some portals also serve as a means of two-way communication between patients and healthcare professionals and provide a platform for the recording of patient-entered data such as home blood pressure readings. Such systems are designed to encourage patient participation in the management of their condition, and ultimately to increase patient empowerment and self-management, which are associated with improved clinical outcomes. As an example of portal use in patients with renal conditions, we discuss the PatientView portal, which is offered free of cost to patients under the care of renal physicians in the UK. We present an account of its various features and briefly describe the user experience. Previous studies examining the impact of this portal on patient care have been very positive; it appears to be popular among users and overall levels of satisfaction with the service are high. As the use of patient portals increases, we discuss barriers to the more widespread use of portals. We offer suggestions on how the care of patients with renal conditions can be enhanced in the future by further developing the existing features, learning from experiences of other patient portals and providing better integration of portal use into the current model of care.

**Keywords:** chronic renal insufficiency, information technology, PatientView, quality of life, self-management

## INTRODUCTION

In patients who suffer from long-term conditions, such as chronic kidney disease (CKD), a key therapy aim is to integrate the management of their condition into routine daily life. The episodic and reactive nature of patient encounters with the 'traditional' physician-led healthcare system can result in suboptimal care in chronic diseases, whereas seeking their active involvement in the process of care is potentially advantageous in improving outcomes [1, 2]. Supporting patients in becoming confident self-managers of their care could help empower them in maintaining a good quality of life and taking preventive

measures against the complications associated with long-term conditions [3, 4].

The management of patients with CKD, including those receiving renal replacement therapies (RRTs), provides fertile ground for innovation and quality improvement. Clinical manifestations of CKD do not appear until advanced stages. A large proportion of subjects who are known to have CKD have no awareness of their diagnosis [5, 6] and generally lack the knowledge of its complications [7]. Poor health literacy in patients with CKD is associated with lower estimated glomerular filtration rate (eGFR), higher urinary protein excretion and higher

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self-reported rates of cardiovascular diseases [8]. With the increasing prevalence of CKD, web-based technologies may be able to assist in delivering more rounded care, while at the same time achieving enhanced patient participation in the process of care.

Web-based portals (also referred to as 'patient portals') enable patients to securely access their electronic health records (EHRs), usually maintained by healthcare providers, from anywhere with an Internet connection using either an Internet browser or a dedicated application (app). Patient portals usually make selected parts of the EHRs accessible to patients depending on technological limitations and the demands of the service being offered. Given the widespread availability of the Internet and a patient population that is increasingly proficient in the use of information technology (IT), such portals provide an invaluable opportunity to enhance communication with patients and actively engage them in the management of their condition as an adjuvant to routine care.

In this article we describe the characteristics and user experiences of a portal aimed at patients with renal conditions in the UK: PatientView ([www.patientview.org](http://www.patientview.org)) [9]. We then discuss how patients with renal conditions could benefit from the use of patient portals generally, highlighting the unique characteristics of this population that makes them a ready target for technological innovations. We then conclude by discussing how we envisage the future for patient portals and the measures needed to popularize their use.

## THE UK EXPERIENCE OF WEB-BASED PORTALS FOR RENAL PATIENTS

### The PatientView portal

The PatientView portal [9] is an education and self-management platform, accessible on the web and through an app on handheld devices, designed to promote patient engagement in their medical management. The service is funded by the National Health Service and is currently available for use to patients who are under the care of renal physicians. PatientView has now been implemented in >90% of all renal units in the UK. Although patient participation in the website is voluntary, it is expected that all eligible users are offered the opportunity to sign up for an account.

Its origins can be traced back to the National Service Framework (NSF) for Renal Services 2005 document [10], which aimed to define the vision for future care of patients with renal conditions in the UK and stated that 'patients with CKD are to have access to information that enables them, with their carers if desired, to make informed decisions on their care and encourages partnership in decision making'. Later that year, the Department of Health published a Renal Services Information Strategy [11], which expanded further on the support structures that were required at the time to aid in the implementation of the above NSF objectives. In this document, the commissioning of 'Renal PatientView' [9] was first announced; this was to be supported by the Departments of Health of England, Wales and Scotland, representatives of the renal medical community and patient groups. Under the umbrella organization, Renal Information Exchange Group [12, 13], these 'stakeholders' in the care of renal patients in the UK first developed the PatientView [9] website (originally called the 'renal PatientView'). This service is now run by the UK Renal Association [14].

### Functionality and user experience

Eligible patients are encouraged to request a PatientView account, which gives them access to their latest blood test results and medical information, such as the name of their condition, recent renal clinic letters (available at some units only) and a list of current medications. Patients can also use PatientView to document their home blood pressure (hBP) readings, capillary blood glucose (BG) levels and weights; these data can then be used to detect temporal changes in these parameters that can potentially enable a more comprehensive patient assessment during routine follow-up clinic visits.

PatientView also directs users to expertly written patient information articles, which are specific to their diagnosis and treatment. Finally, patients can use this service to communicate with members of their multidisciplinary team, which may include care providers such as dialysis nurses, dieticians or their general practitioners; the choice of who can access and communicate with them depends entirely on patient's discretion. The key features of the new PatientView website are explained in Figures 1 and 2.

When users first log in, they enter a 'dashboard area' that highlights key personal information including their identity and details of previous logins (see Figure 1). Prominent headings on top of this page provide links for navigation to other sections of the website. These sections include MyConditions, listing patient diagnoses; Results, for reports of blood results and Letters, for the latest clinic letter. The website does not require any special user training; however, basic computer and Internet skills such as opening Internet browsers, navigating different webpages and entering usernames and passwords are a prerequisite for its use.

The data relating to blood test reports and clinic notes that populate the PatientView portal come from a back-end system. It takes up to 24 h for new results to become available on PatientView. Abnormal results are highlighted against a darker background. Of note, the system currently does not notify patients if the abnormal results have been seen or acted on by their physicians. Hospital-based physicians work directly from the EHR software to document any actions taken. Currently this information is not automatically displayed on PatientView since, at our hospital at least, the document format currently used in the EHR software (Lorenzo, DXC Technology, Tysons, VA, USA) is incompatible with PatientView unless converted into a Portable Document Format; this process has not yet been automated. Constraints on physicians' time certainly impact greatly on the popularity of PatientView. There is no dedicated time built into the physician's routine to communicate with patients through this medium. Hence, currently all communications take place using conventional measures (letters or telephone calls if urgent). This is clearly an area in need of further work.

### Outcomes of PatientView use

Studies examining the utility of PatientView describe high levels of user satisfaction with the service. Mukoro [15] used online questionnaires and face-to-face interviews to examine the usefulness and impact of PatientView. Participants included patients and staff from 10 renal units across the UK. A total of 507 patients were e-mailed questionnaires and 257 (50%) responded. Nearly all respondents (94%) found it very valuable to have access to their health records from home. The Results section was by far the most valued as well as the most frequently visited part of the service; other sections of the website

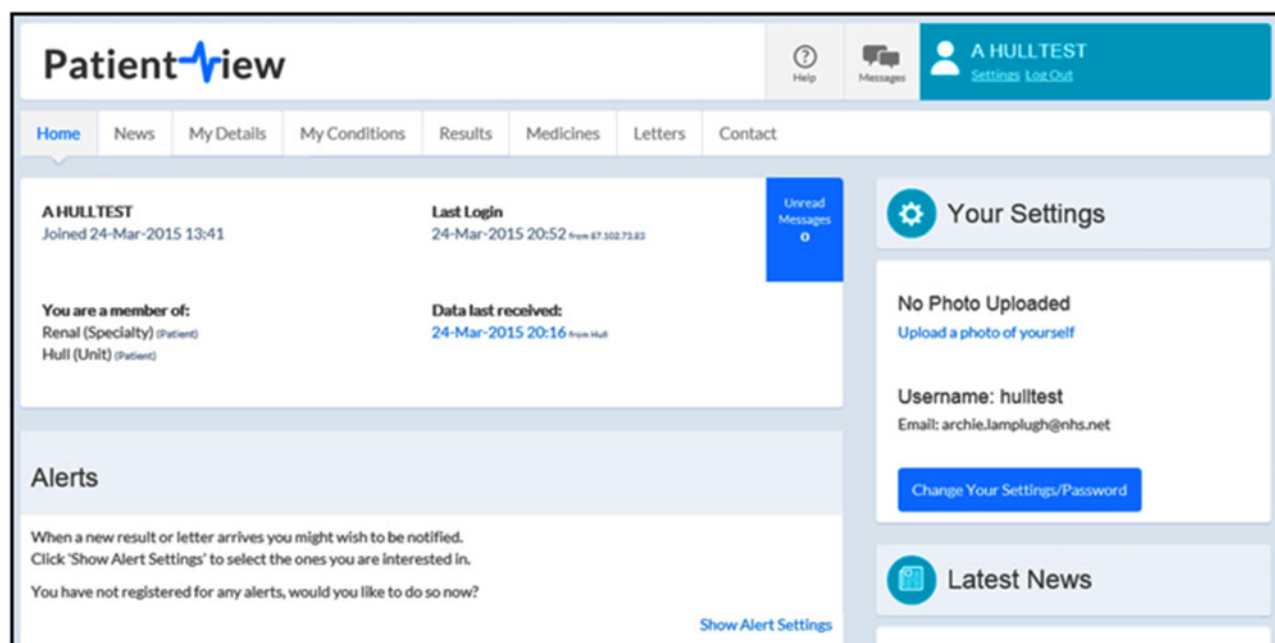


FIGURE 1: Home page of the PatientView website, personalized to each individual patient.

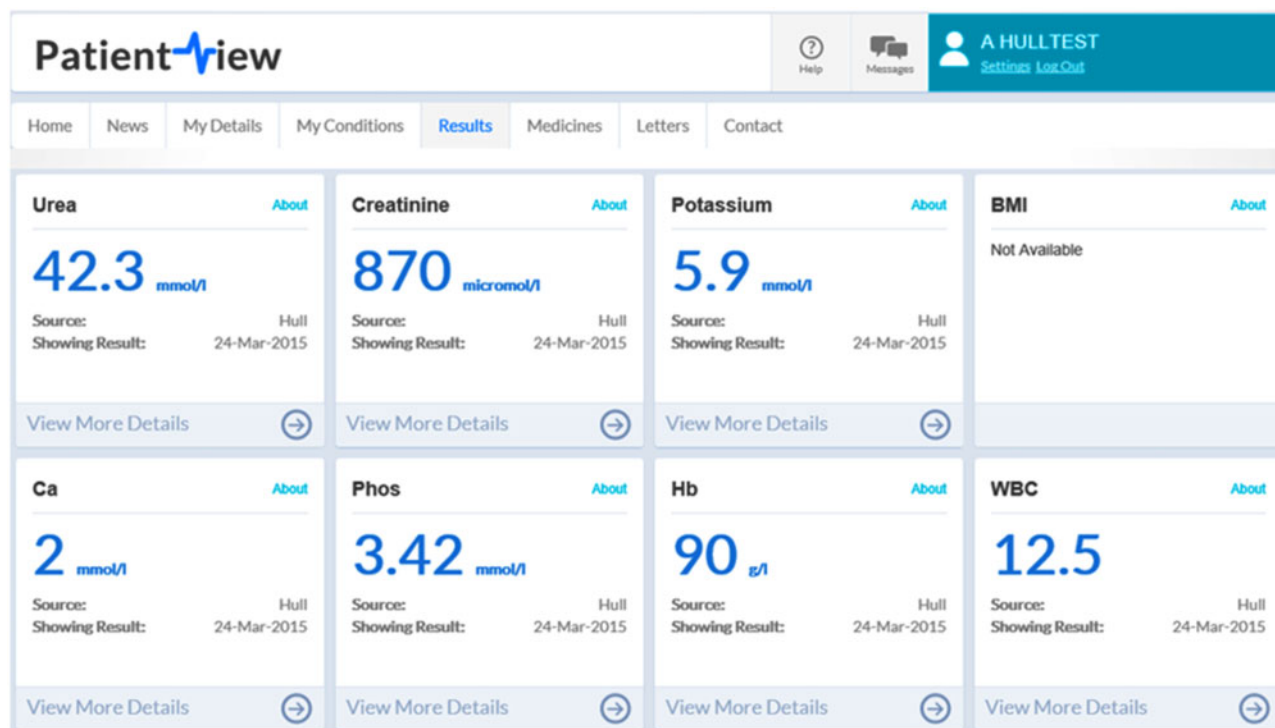


FIGURE 2: The Results page of the PatientView website. Individual results are displayed in large tiled format for ease of use with touchscreen devices.

such as Medicines, Letters and Enter My sections were of considerably less value to the survey respondents. Only 37% of respondents had used the Enter My section, which allows users to enter their hBP, capillary BG and weight measurements; these features are aimed at promoting self-management. A high proportion of patients agreed or strongly agreed with the statements 'Renal PatientView makes me feel more in control of my care' (88%), 'Gives me a better understanding of my renal

disease' (86%), 'Helps me communicate better with my doctor' (79%), 'Reassures me about my treatment' (77%) and 'Makes me more prepared for my hospital visits' (69%).

Woywodt *et al.* [16] have also described similarly positive experiences for their users in a single-centre study. A paper questionnaire was sent to 651 PatientView users. The response rate was 45%. The majority of patients used PatientView either just before or just after their clinic visits; a trend also seen in the

Mukoro study [15] described above. Patients primarily used the website to monitor their kidney function: creatinine, potassium, haemoglobin and eGFR being the most commonly accessed results. The level of patient satisfaction with the service was high; on a scale of 1–5 (5 being ‘most satisfied’), the majority of patients rated the service as either 4 (32%) or 5 (53%).

We studied PatientView from the perspective of inactive account holders—patients who originally signed up for the service but were not actively using it [17]. We identified 190 PatientView account holders at our centre (of a total of 468 registered accounts) who had not logged in for the previous 6 months. Our survey response rate was 39%. The majority of our inactive users had problems accessing their accounts due to loss of login credentials and did not know whom to contact to get this information back. It was also clear that some patients had lost their passwords through non-use. A proportion of patients indicated that PatientView did not add to their existing care. They were able to obtain their blood test results through alternative means. Patients in our survey made very little reference to using other sections of the website—particularly the ones aimed towards self-management.

In summary, renal patients use PatientView mainly as a portal to check blood test results. This helps them prepare for clinic visits and monitor their results when they have blood taken during their visit. Between clinic visits, the website is used less frequently. Also, sections of the website other than the Results section are not as frequently accessed. Negative experiences are uncommon in association with PatientView use.

## THE DIRECTION OF FUTURE INNOVATIONS IN WEB-BASED PORTALS

### Improvements in communicating test results

Perhaps the most readily available opportunity to enhance patient engagement is to communicate to them the results of their investigations. Modern laboratory and radiology reporting systems are already computerized and the technology to access this information through web-based systems already exists. Such measures are associated with increased patient satisfaction [18, 19] and high uptake rates [20, 21]. Renal patients can use test results to track their disease activity and progression as well as monitor the effects of diet, exercise and changes in medications. Those receiving RRT can monitor the adequacy of their dialysis and the blood levels of anti-rejection medications as appropriate.

Patients’ interpretation of their test results can vary widely. In a trial involving 20 renal transplant recipients who were presented with lab test results (in graphical format) to test their ability to differentiate between different risk categories, misinterpretation of risk occurred in 65% of instances [22]. Hence the displaying of test results alone is unlikely to be enough in promoting self-care and increased understanding among users [23]. Witteman and Zikmund-Fisher [24] suggest that online communication of test results must contain a clear takeaway message (i.e. an indication if changes in figures are meaningful or not), should provide thresholds for concern and must enable patients to use the data as they wish. Here the renal community can lead innovation, given a patient population that is relatively static (e.g. renal transplant recipients or those on long-term maintenance dialysis), a range of laboratory tests with clear links to the patient’s condition (e.g. creatinine, eGFR, haemoglobin level, potassium and phosphate) and the long-term nature of interactions between care providers and patients

(i.e. opportunities to promote self-care and engaging patients in their chronic disease management).

### Towards more integrated care

Web-based portals all differ in what they offer patients. From enabling simple access to the latest laboratory test results [18, 25] to facilitating active participation in integrated care networks [26, 27], the diversity found in the implementation of patient portals is extensive. In settings where an organization might handle multiple aspects of care, including primary care, hospital-based services and a system of internal referrals, patient portal use is associated with high levels of participation and user satisfaction [21, 28]. Conversely, when the delivery of care is fragmented between different providers, the proliferation of web portals in the same patient population can potentially lead to underutilization of individual portals. In the UK, for instance, patients using primary care services can request appointments and ask for prescription refills using their general practices’ (GP) online service [29, 30]. Separate from GP services, some hospitals now provide their own portals that enable patient access to their EHRs [31, 32]; using these, patients can manage hospital appointments, view test results and communicate with their hospital care teams. Portals provided by specialist services, such as renal medicine’s PatientView, are in addition to these, and their suboptimal use could be due to the crowded field of online services being offered to patients. Hence a more integrated approach is needed in designing web portals to ensure that users can access all relevant information on a single platform. Instead of each service offering its own portal, a single patient portal is needed with data links to each relevant organizational database.

### Offering the service more widely

In the USA, most healthcare providers are mandated to provide patient access to EHRs through certified patient portals and to demonstrate their ‘meaningful use’ [33]. Providers commonly deploy commercially available software rebranded to the organization’s specifications. One widely used patient portal software is MyChart (Epic Systems, Verona, WI, USA), which enables users to engage in messaging with providers, renew prescriptions, manage appointments, receive clinical updates and view billing information. In one example, a large academic medical centre based in Ohio (USA) offered a version of the MyChart portal, OSUMyChart, to a potential 491 288 eligible patients over a 3-year period, 98 023 (20%) of whom became active users. Active use was most common among those ages 31–45 years. Those >65 years of age were more likely to be active users than those 18–30 years of age, contrary to the popular belief that older patients are less likely to engage in online services. Active users were also more likely to be of white ethnicity, female and employed [34].

Research into approaches to increase participation and active use of patient portals is limited. New strategies specifically targeting those who are traditionally considered less likely to use Internet-based portals are urgently needed. It should also be acknowledged, however, that not all patients will want to use such portals. In a survey of a sample of patients from the USA who were offered online access to their EHRs, just over half (53%) logged in to their account at least once in the previous year [35]. Most of these patients gave ‘speaking to healthcare professionals directly’ as the main reason for non-use. Future

development of patient portals will need to progress in parallel with developments in routine care.

### A more personalized experience

Patients with CKD make frequent visits to see specialists and allied healthcare professionals (dietitians and specialist nurses). Clinic encounters are routinely recorded as 'clinic letters', which are usually addressed to other healthcare professionals. Making clinic communications available to patients via web portals can aid in the promotion of more personalized care [36]. Clinic letters can help enhance patients' understanding of their condition and improving their accessibility, using appropriate encryption and protection methods, can potentially make patients feel more empowered in managing their own condition. Community health professionals, such as GPs and community nurses, will find the availability of clinic letters particularly useful, for example, when visiting patients, as a guide for specialist plans.

Patient portals for renal patients, such as PatientView, could include time and venue of future clinic appointments, clinic maps and consultant profiles. The model of social media websites, where users can create and share their profile, can also be an interesting way of increasing participation. This may particularly suit transplant or dialysis patients who may find interacting with other patients with similar conditions helpful and supportive. Discussion forums could perhaps have an expert with sufficient skill to reply to comments and encourage patients to learn more about their condition. Indeed, a single resource for reliable unbiased information could perhaps reduce the impact of confusing messages often associated with surfing the net [37].

### Building in interactivity

A systematic review of literature recently cited patient-provider communication as the most common reason for positive experiences associated with patient portal use [38]. In the UK, there is a national shortage of renal dietitians [39]. In the management of CKD, the reduced availability of dietetic input may lead to suboptimal potassium and phosphate control [40, 41]. Dietitians play a critical role in the management of renal transplant recipients who may experience dramatic changes in dietary requirements and sometimes receive conflicting information from their previous dialysis regime. Increasing patient demand for dietetic input without an increasing dietetic workforce requires innovative ways of working. Patient portals can provide a convenient platform for interactions to take place between dietitians and renal patients. This would ensure that users who want to engage in dietetic services can access advice when it is convenient for them rather than waiting for a referral to be made to the dietitian and a subsequent appointment arranged.

The apprehension about increased workload expressed by clinicians features highly as a theme in one study exploring negative experiences related to the use of web portals [42]. Spending additional time to make enquiries on behalf of patients and addressing concerns when results create unnecessary anxiety can all lead to increased workload. Payment reform to reimburse the providers for time spent interacting with patients on portals has been suggested as a means to increase their use [43]. In the MyHealthGroup patient portal, as implemented in Washington and Idaho (USA) by Group Health Cooperative, providers were given an incentive of \$5 per message beyond their salary to encourage electronic patient-provider messaging [21].

### Promoting self-management

Patients' belief in their own ability to manage their condition, known as self-efficacy, is associated with health-seeking behaviours such as increased communication with caregivers, partnership in care, self-advocacy and improved adherence to medications [44]. Can patient portals influence and enhance self-efficacy? Although this remains to be proven, Ong *et al.* [45] have proposed key principles that future IT solutions could follow in promoting self-management in patients with CKD. These principles include the advancement of patient education, promotion of specific behaviours such as downloading and tracking blood test results, forming collaborations with others (including clinicians) through direct messaging and community interactions and setting individual goals. Based on these principles, they have developed self-management stations (kiosks) in their patient areas. These enable patients to enter symptoms self-assessment questionnaires, create notes on issues and concerns that they wish to discuss at clinics (accessible by clinicians), print-out summary reports of identified learning needs and forward plans for the period between clinic visits, as well as allowing physicians to enter 'take-home' messages for patients.

Weight management is an important aspect of care in patients with CKD [46, 47]. Weight loss improves BP control, reduces reliance on antihypertensives [48], decreases proteinuria in patients with established CKD [49] and may help prevent further decline in renal function [50]. Web-based interventions aimed at increasing physical activity have been successfully implemented in the sufferers of other chronic conditions [51]. In one study, Liebreich *et al.* [52] designed a web-based intervention aimed at patients with type 2 diabetes. On the website 'Diabetes NetPLAY', they posted weekly updates under five sections: weekly topic, education, research, fitness tips and physical activity myths. They also included interactive features including a physical activity logbook, message board and weekly e-mail counselling from coordinators. Compared with the control group ( $n=24$ ), who only received static links to online educational guides, a significant improvement in total vigorous and moderate minutes of physical activity was observed in the Diabetes NetPLAY users ( $n=25$ ) after 12 weeks of this activity. A similar model may also be employed in web-based portals such as PatientView, to help implement targeted exercise programmes in patients with renal diseases.

Documentation of hBP measurements have been shown to reduce the need for antihypertensives [53]. Patient-recorded data such as home capillary BG levels, hBP readings and weight measurements can help health professionals in proactively managing patients' glycaemic control, may improve adherence to antihypertensive medications [54] and may help with the monitoring of fluid load in patients with renal conditions. A degree of oversight and encouragement will be necessary for such an exercise; clinicians could review and refer to these readings during outpatient consultations with patients to promote their use. Data collected through web portals, with appropriate consenting procedures and data safeguarding measures, could, in the future, prove a useful resource for outcomes research [55].

### CONCLUSION

The care of patients with long-term conditions such as CKD can be enhanced if they are actively engaged in the management of their condition. Increasing patient knowledge, seeking their participation in decision making and equipping them with tools that enable them to monitor and react to changes in their

condition could lead to improved outcomes and prevent complications associated with long-term conditions. The widespread availability of the Internet and the vast array of devices that make it accessible offer a ready avenue for achieving this goal in patients with renal conditions. Although Internet-based portals are being increasingly used, their potential as a self-management tool has yet to be fully realized. Future research needs to focus on identifying and addressing the barriers to patient participation in the use of portals. Better integration of their use into routine care, widening participation among the subset of patients who are traditionally considered less likely to use new technologies, providing a more personalized experience in the use of patient portals and supporting patients in using the available information to understand and monitor their conditions could all help in increasing patient portal use.

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## CONFLICT OF INTEREST STATEMENT

None declared. The results presented in this article have not been published previously in whole or part.

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