



Barriers to patient participation in a self-management and education website Renal PatientView: A questionnaire-based study of inactive users



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ABSTRACT

Objectives: The Renal PatientView (RPV) website is an information and education tool aimed at increasing patient involvement in their care. We have conducted this study to elucidate why some users remain inactive on RPV despite initially signing up for the service.

Methods: Patients at a teaching hospital in United Kingdom, who originally signed up for RPV but are no longer active (no logins during previous 6 months), were sent paper questionnaires. Responses were collected for up to 6 months.

Results: Of the 190 questionnaires, 69 (39%) were returned partially or fully completed. Majority of respondents could access computer (94%) and internet (91%) from home. Reasons for inactivity among survey respondents included: loss of login credentials (45%), perception that it did not add anything to existing care (37%), being too busy (13%) and anxiety of viewing results from home (10%). Thirty-seven respondents provided free-text comments. Thematic analysis of these reinforced above findings and also indicated that despite infrequent use, some patients valued RPV availability. Patients made very little reference to using sections of the website other than test results.

Conclusions: Patients find RPV a valuable resource. It is, however, mainly seen as a portal to check blood test results; other sections of the website aimed at promoting self-management remain underutilized. Several local and central level changes, such as a robust system of user accounts handling, improved promotion, and emphasis on further development of self-management sections of RPV may help improve participation.

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1. Introduction

Renal PatientView (RPV) [1] is a website aimed at promoting self-management and education in patients who are under the care of nephrology services in United Kingdom (UK). Patients who sign up for this free service can securely view their blood test results and monitor temporal changes in their laboratory parameters from anywhere with internet access. RPV also provides patients with a platform to document and monitor certain health parameters that are of interest to their renal physicians; these include weight changes between clinic visits, home blood pressures (hBP), capillary blood glucose and medication changes. RPV provides patients

with links to educational resources which are specific to their diagnosis and have been expertly written for patient use. The website was developed collaboratively by various health authorities, professional bodies and patient groups involved in the care of renal patients in the UK [2]. Access to RPV is strictly controlled using usernames and passwords. Patients can however authorize access to their account to other health professionals involved in their care which may include their general practitioner or community nurse. RPV has now been implemented in over 90% of all renal centers in UK.

Previous evaluations [3,4], conducted using an online survey and one-to-one interviews with patients and healthcare professionals, showed overwhelmingly positive views about the usefulness and impact of RPV. Patients reported feeling more engaged in their management and decisions regarding their treatment. Users felt more in-control and better prepared for clinic visits; their knowledge had expanded as a result of using RPV and they were more engaged in

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Table 1

Characteristics of the inactive Renal PatientView (RPV) members. 'Clinic type' represents the sub-section of renal service that the patient is registered with.

	All (n = 190)	Sub-groups	
		Respondents (n = 69)	Non-respondents (n = 121)
Male (%)	125 (66%)	43 (62%)	82 (68%)
Female (%)	65 (34%)	26 (38%)	39 (32%)
Median age (range)	53 (19–86)	58 (20–83)	52 (19–86)
Clinic type			
General nephrology	18	6	12
Haemodialysis	45	16	29
Peritoneal dialysis	19	5	14
Pre-dialysis clinic	26	10	16
Transplant follow-up	82	32	50

undertaking preventative exercises. Participants in this study however were chosen by a designated 'coordinator' at each center; the questionnaires were sent through email invitations and respondents were mainly current active RPV users with only 11% stating that they had not logged in to the RPV website during the previous three months. The use of online surveys and one-to-one interviews of the active RPV users may have excluded those who no longer use RPV for various reasons including those with possible negative experiences.

In order to help increase participation in RPV, we designed an initiative to look at the characteristics and experiences of those RPV members who are in-active on the website i.e., patients who have RPV user accounts but are no-longer using the website. The objective of this study was to understand the reason for in-activity in this group of RPV account holders.

2. Material and methods

Local RPV administration database was searched for records of user activity. Inactive user accounts were identified as those with no logins during the previous 6 months. Additional data on patient demographics and contact information were obtained using our hospital's electronic patient administration system. Paper questionnaires were posted to the inactive users along with stamped and addressed envelopes for postal return. Responses were collected for a period of up to 6 months in order to allow sufficient time for completion. Patients who did not respond to the survey were not sent further reminders to complete the questionnaire.

The questionnaire used in this survey (Supplementary Table) was developed locally by the study investigators and designed to capture information relevant to the stated objectives. The questions are based on our combined experiences of the most commonly cited issues with RPV use, from previous anecdotal discussions with patient in clinics and on the dialysis unit. The questionnaire underwent testing for its readability and ease of use by ten volunteer patients undergoing in-center haemodialysis. Questionnaire were given out to these volunteers during their regular haemodialysis treatment slots and were then interviewed shortly afterwards by an investigator (AMH) for feedback on any difficulties that they may have encountered understanding or filling any parts of the questionnaire; their results have not been included in the final analysis.

All statistical analyses were performed using MS Excel (Microsoft Inc., USA). Categorical variables have been presented as percentages or ratios, and continuous variables either as mean \pm standard deviations (SD) or median \pm range depending on data characteristics. The free text responses within the questionnaire were analyzed thematically; results are presented here as theme frequencies and representative quotes.

The project was approved by the audit section of the Clinical Governance department at Hull and East Yorkshire Hospitals NHS Trust (Audit reference: 2013.172). As this was deemed a quality

Table 2

The most commonly stated reasons for inactivity on the Renal PatientView (RPV) website. Common themes have been identified and presented here from responses given in the free-text section of the questionnaire.

Themes	Number of patients (%)
Login problems	14 (38%)
Used only when expecting blood results	8 (22%)
Value RPV availability despite infrequent use	7 (19%)
Information needs met by kidney care team	6 (16%)
Not updated in timely manner	2 (5%)

improvement project, ethical approval was not required. Confidentiality was maintained in accordance with Good Clinical Practice (GCP).

3. Results

RPV was introduced at our renal department (Hull and East Yorkshire Hospitals NHS Trust, United Kingdom) in 2009. The total count of registered users on the system stood at 468 by the end of June 2013. Of these, 47 (10%) user accounts were excluded since they belonged to patients who were deceased. Of the remaining 421 living RPV account holders, 195 (46%) were identified as in-active i.e., no logins to the RPV website during the previous 6 months. 190 paper questionnaires were sent out to the in-active RPV members whose contact details were available (no contact details could be found locally for 5 patients). Patient characteristics for this group are presented in Table 1.

By six months, 69 (36%) questionnaires were returned at least partially complete, 12 (13%) were returned indicating the member's unwillingness to participate, 10 (11%) did not reach the intended recipient as indicated on the returned mail labels and 99 (52%) questionnaires were never received back. Patients who completed at least one part of the questionnaire (n = 69) were more likely to be female (38% vs. 32%) and older (median age: 58 vs. 52 years) when compared to the non-responders (Table 1).

Analysis of the completed 69 questionnaires showed that the majority of in-active users have access to computer (94%) and internet (91%) at home. Levels of self-reported computer proficiency were high (Fig. 1). Loss of login credentials (username or password) was reported by a high proportion of respondents who also indicated not knowing who to contact to ask for help in retrieving this information (Fig. 2).

Participants were asked to select specific reasons for in-activity on RPV from a pre-specified list of responses. They could choose more than one option. Sixty members completed this section (9 survey respondents left this section blank). The commonest reasons cited for inactivity on the RPV website were difficulties using computers or with their password (45%) followed by the perception that it did not add anything to the members' existing relationship with their renal team (37%). The full breakdown of responses is presented in Fig. 3.

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