



Kidney Care

**Evaluation of New Features of
Renal Patient View:
Phase 1 Report**

Better Kidney Care for All

Reader Page

Title	Evaluation of New Features of Renal Patient View: Phase 1 Report
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Introduction

Renal PatientView (RPV) is a secure internet based personal health records system which enables kidney patients to view their live test results online and obtain information about their kidney disease¹. The system was designed specifically for patients to use by themselves and is available to all kidney patients at participating units. The service is free and registration does not affect the routine care available to the individual from a renal unit. Patients who sign up for this service are provided with a personal 'webpage' displaying details which can be accessed from any computer². Access to the site is controlled by the patient who may choose to give permission for family, and others to view their data. RPV is now available in 51 of UK Renal Units³ with over 16000 registered users. It is anticipated that RPV will be installed in all renal units in the UK.

NHS Kidney Care commissioned the development of enhanced interactive capabilities to support the improvement of RPV. These new features include:

1. An online discussion forum
2. Patient entered data (eg Blood Pressure (BP), Weight, and Glucose readings)
3. Patient entered 'blog' (dated comment).

By August 2010, the online discussion forum and the ability for patients to enter data had come live. The patient entered blog went live in March 2011.

NHS Kidney Care is now carrying out a service evaluation of RPV. The purpose of this evaluation is to assess the utility and usefulness of the new features to the patients and health care professionals. Findings will be used to further develop RPV.

This evaluation is conducted in two phases. Phase 1 involved web analytics and thematic analysis of online forum comments, while phase 2 will involve surveys and interviews with patients and healthcare professionals (Table 1). The first phase of this evaluation has been completed and a summary of the preliminary findings is presented here. The second phase commenced in July 2011.

¹ www.renal.org/rpv

² Taylor J (2010). Analysis of patient use of 'Renal Patient View' (RPV) – An online patient records system (unpublished)

³RPV report to Renal Association Trustees June 2011

Table 1: Methods of Evaluation.

Phase I	Phase II
<p>Web analytics of usage data six months after the new features go live, and monthly for the next consecutive three months.</p> <p>Thematic analysis⁴ of anonymised patient discussions on discussion forum up to nine months of going live</p>	<p>A survey of 375 users of RPV⁵</p> <p>A survey of health care professionals directly involved in patient care/ care planning in 10 renal units in England⁶</p> <p>In-depth individual interviews with a purposive sample of 15 RPV active users</p> <p>In-depth individual interviews with a sample of at least 15 professionals across the sampled renal units</p>

Methods of Phase 1 evaluation

Web Analytics: Custom reports were extracted from Google Analytics from 1st March 2011 to 31st May 2011, to:

- Obtain basic measures of users and usage data including, number of users, visits, repeat visits and resources accessed.
- Identify trends and changes in usage

The report used the following information to measure Renal PatientView utilization:

⁴ The constant comparative method of data analysis was used as described below in the section 'Analysis of data'.

⁵ A random sample of 375 RPV users will be included in the survey. Sample size has been calculated on the basis of 16000 registered users in England.

⁶ Ten renal units will be chosen on the basis of one being selected randomly from each Strategic Health Authority (SHA) region in England that uses RPV.

Page View

A page view is counted with the successful loading of any full web page document that was requested by a visitor either by opening or reloading a web page. Page views to an individual page can be defined as the number of times the web page was viewed in a given period. This reflects the traffic patterns over specified time periods.

Visit

A visit is counted when a visitor creates activity on a web page by opening or navigating around the website. A visit persisted until 30 minutes of inactivity or 12 hours of continuous activity. A single visit could include multiple page views.

Unique Visitor

Unique visitors represent the number of different web browsers that were used to visit the site over a specified period. A unique visitor is counted when a web browser is used to visit the site regardless of the number of pages visited or the duration of the visit. Visitors who have returned at any time during the reporting period are counted only once on their first visit between the specified start and end date. The presence of a cookie stored in the visitor's web browser helps to determine the individuality of the visitor.

New, returning (repeat) and one time visitors

All unique visitors are counted only once and then classified as "First Time" or "returning" visitors. A returning (repeat) visitor is one who has visited the website at some time prior to the selected date range/reporting period. First Time (new) visitors are those that are visiting the website for the first time during the selected date range. So when somebody uses a web browser to access the site for the first time, the visit is categorized as "Visit from a new visitor." If this same web browser has been used to browse the website before, the visit is categorized as "Visit from a returning visitor."

One time visitors refers to the web browsers that were used to access the site only once during the reporting period (between the specified start and end dates).

Thematic analysis of forum discussions: The forum discussion posts were extracted and subjected to thematic analysis to:

- Evaluate the utility of the forum for the users – to understand the ways the patients use the forum
- Investigate whether or how the users benefit from the process of sharing information with other patients.

Analysis of data

Web analysis data were exported from Google Analytics into Excel where summary tables and simple charts were produced. These were then subjected to descriptive analysis.

The forum discussion posts were extracted and subjected to thematic analysis using the 'constant comparative method' of qualitative data analysis⁷. Working independently, two researchers, FM and MB, reviewed the forum extract line by line, categorizing comments and quotations that appeared to embody distinct concepts into themes and subthemes. During the categorisation process, each quotation or comment was compared with previous entries in same category, and categories were expanded or combined as comments were analysed. The forum extract was reviewed several times to ensure all entered comments were accounted for and appropriately categorised. The identified themes were discussed and agreement was reached between the researchers where there were differences in the analysis.

Summary of Findings

Overview of RPV Usage

Access statistics

Between 1st March 2011, and 31st May 2011, Renal PatientView received 74673 visits from 20543 unique visitors (averaging 3.6 visits per visitor), resulting in 655067 page views (Table 2).

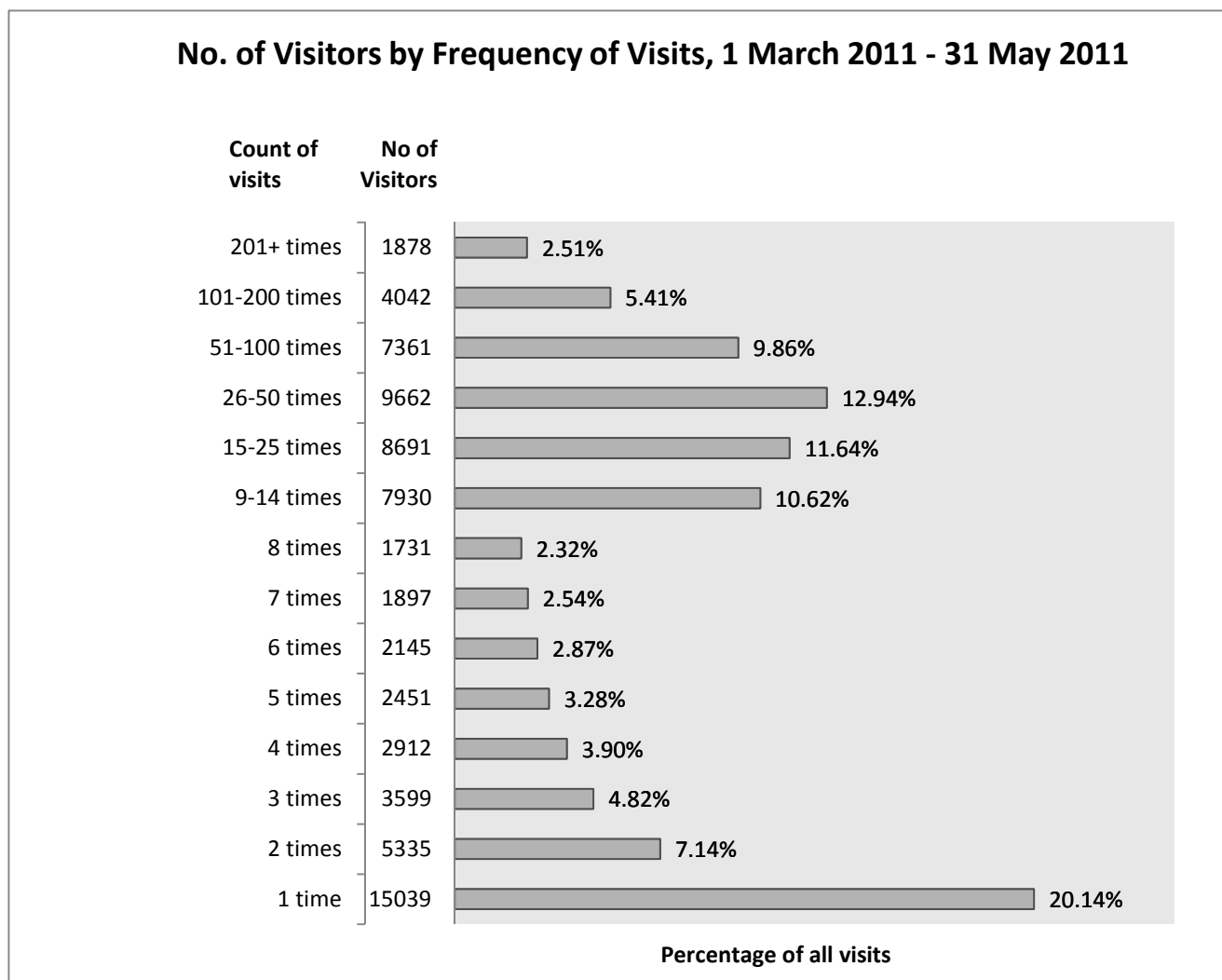
Table 2: Access to RPV

Accesses	Month 1	Month 2	Month 3	Month 1 - 3
Visits	25265	23348	26060	74673
New Visits	5200	4627	5212	15039
Unique Visitors	9039	8399	9215	20543
Pageviews	216809	206598	231660	655067
Pages/Visit	8.6	8.8	8.9	8.8
Avg. Time on Site (min:secs)	04:46	04:39	04:45	04:43

⁷ Boeije, Hennie (2002). A purposeful approach to the constant comparative method in the analysis of qualitative interviews. *Quality & Quantity* Vol 36 number 4, 391-409, DOI: 10.1023/A:1020909529486

The majority of visits to Renal PatientView were from returning visitors (repeat visitors), with just over 20% made by one time visitors (Figure 1).

Figure 1: Frequency of visits to RPV



User interest in six of the ten sections of Renal PatientView is shown by aggregating the page views of individual web pages within the section (Table 3). The “Results” section had the greatest number of page views accounting for 10% of the total for the period. This is followed by the “Letters” section (3.7%), “Patient Details” (2.8%), “Medicines” (1.7%), “Patient Info” (1.6%) and “Enter My” (1.2%).

Table 3: User interests

Section of RPV	Number of Page views	Percentage of site total
Results	68879	10%
Letters	24513	3.7%
Patient Details	18480	2.8%
Medicines	11089	1.7%
Patient Info	10638	1.6%
Enter My	7733	1.2%

Uptake of new features

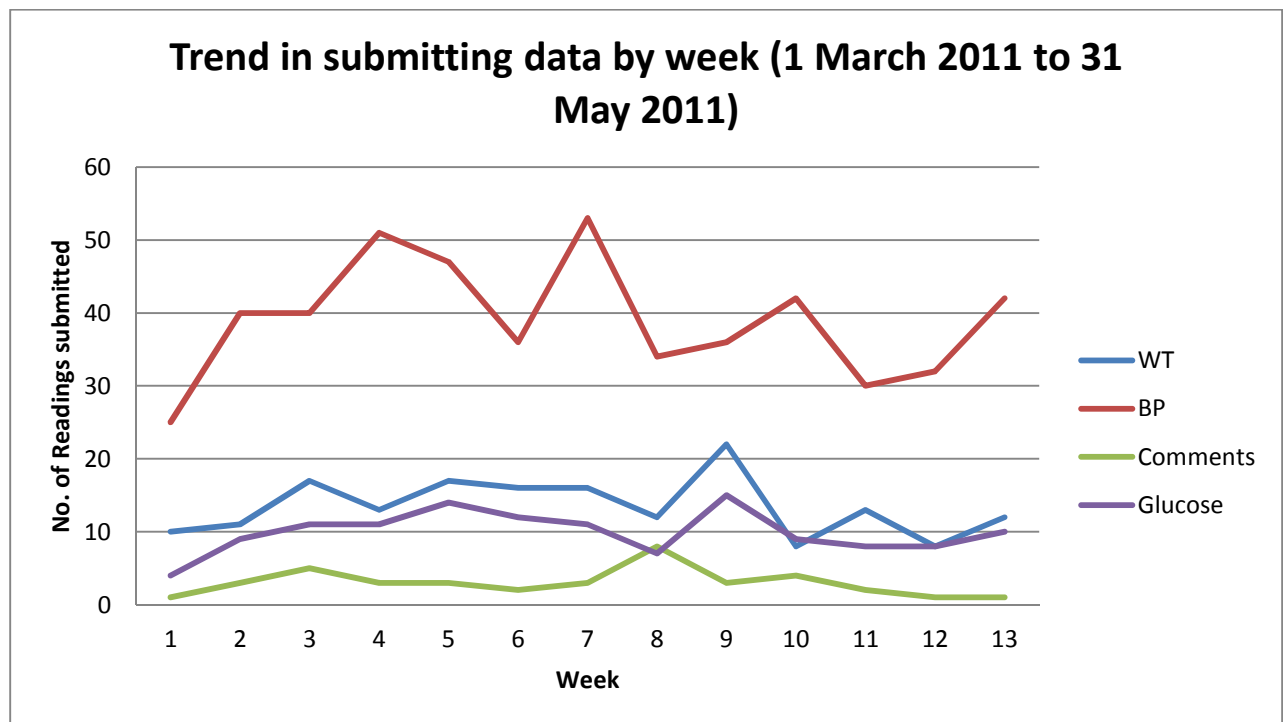
Over the three-month period, there were 13304 unique user logins to Renal PatientView (Table 4). Of these, 4040 users accessed the 'Enter My' section on Renal PatientView (30%). 7% (282) of the users accessing this section actually submitted data.

Table 4: uptake of patient entered features

RPV Section	Number of users			
	Month 1	Month 2	Month 3	Month 1 - 3
Logged in	5859	5432	5899	13304
Enter My	1551	1449	1554	4040
Submitted	134	103	99	282

Over the three-month period, the most frequently submitted data in "Enter My" section was "Blood Pressure" followed by Weight readings (Fig 2). There was no obvious change in trend of submitted readings over the period.

Figure 2: Weekly submission of data



Utility of Online Discussion Forum

Data were extracted from the RPV online forum in May 2011, nine months after the forum came live. The forum had 1753 registered users, representing almost 11% (1753/16400) of the total registered users of Renal PatientView. Since going live, a total of 513 messages have been posted by members in 17 discussion streams. On the whole, about 15% (258/1753) of the registered patients have posted at least one comment on the forum (Figure 3).

Figure 3: Proportion of registered users posting comments on forum

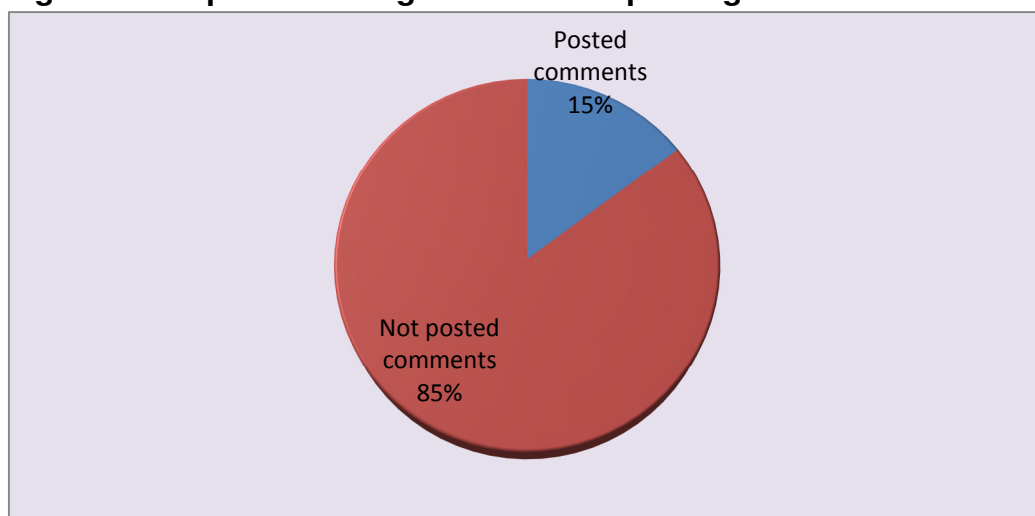


Table 5 shows the ten most read topics in the discussion forum by number of views.

Table 5: Most Read Topics in Discussion Forum

Forum Section	Topic	Responses	Views
Other health issues	Tiredness	26	1361
Travelling and insurance	Travel and Insurance	27	1133
About this forum	About the RPV forum	24	799
Having a transplant	Cross match transplant is an option I suppose	16	668
Life with a transplant	Exercise after transplant	18	662
Life with a transplant	water infections	16	623
Life on dialysis	Home haemodialysis	12	576
Life with a transplant	Problems getting Mycophenolate Mofetil (Cellcept)	18	550
Life with CKD	Life at 29 with PKD	8	548
Kidney diseases	IgA Nephropathy	11	474

Thematic Analysis of discussion forum comments

Based on qualitative analysis of the 513 messages posted on the forum, six main themes were identified (Table 6). The most frequent use of the forum was to share concerns (categorised 210 times), followed by information exchange (categorised 147 times) and providing advice and support (categorised 134 times). 93 of the forum entries were categorised under two or more themes, indicating more than one use.

Table 6. How patients use online discussion forum: themes, interpretations, and supportive Quotations

Major Theme	Sub-themes	Benefit to the user: Author's Interpretation	Supportive Quotes from Forum
Share concerns/problems (categorized 210 times)		Users are able to share their concerns and feel they are being 'listened to'	<i>I had a transplant 3yrs ago now, but due to constant water infections my kidney is in chronic rejection has anyone else suffered like this. I've been in and out of hospital constantly since Christmas and it's getting me so down that all I want to do is sit and cry. At the moment I'm recovering from yet another inpatient stay this time for pneumonia. When does it end?</i>
Information exchange (categorized 147 times)	Share opinion/viewpoint	Allow user to post information that may be of use to others without directly sharing experience or suggesting advice	<i>Don't know about you, but travel insurance always a problem. I am travelling to Canada in the Summer, and trying to find insurance. I have a transplant so obviously need to be covered. Just discovered a company lot cheaper than i have come across before if anyone interested. ____, give it a whirl.</i>
	Make suggestions		<i>I recently completed a 6 week programme held once a week for two and a half hours. It is made available through the NHS and teaches you how to better manage nutrition, pain, communication with health professionals and many other things to improve lifestyle choices and help understand your condition. The Expert patient course is well worth looking at.</i>

Table 6. How patients use online discussion forum: themes, interpretations, and supportive Quotations

Major Theme	Sub-themes	Benefit to the user: Author's Interpretation	Supportive Quotes from Forum
Provide advice and support (categorized 134 times)	Support and encouragement	Allow users to support peers by providing advice on the basis of their experience.	<i>I had my transplant in February when it was found that my husband could donate to me even though we were incompatible blood groups - he is AB and I am A+. Prior to that we were on the paired donor scheme. It hasn't been plain sailing for me by any means but that was nothing to do with the kidney. I keep getting infections! My husband recovered within a few weeks and is very fit and feels great. Luckily I didn't need dialysis which is always preferable for a good outcome.[____] look into all possibilities and if you [user being responded to] are offered a kidney by a friend, take it further if you can. 2 other people made genuine offers of kidneys for me! I was blown away, I didn't think people did that!! Keep your pecker up and stay positive and I hope things work out soon.</i>
	Make recommendation/sign post	Allows users to feel supported and benefit from the experiences and advice of peers	<i>Hi to you all, I've just this minute joined the forum and seen ____'s message regarding home dialysis taking a long time to arrange. ____, does your local council have Grants section? If so contact them and ask about a disability grant, contact your social services and ask for an assessment of your needs, ... If it turns out the garage is not suitable for conversion then ask about a porta-cabin being installed. Please don't be fobbed off by beauracrats. This is your choice for quality of life, it also frees up space in the unit for somebody unable to [do] home dialysis ... Keep in touch via the forum in the mean time I shall do some research of my own. Good luck</i>

Table 6. How patients use online discussion forum: themes, interpretations, and supportive Quotations

Major Theme	Sub-themes	Benefit to the user: Author's Interpretation	Supportive Quotes from Forum
Targeted questions to other users of the Forum (categorized 98 times)	Seek advice	Help users to make decisions when considering options for treatment	<i>... It's been two years since I was told I had kidney failure, and I can now see dialysis peeking at me over the horizon. I've started looking at dialysis options and, in an ideal world would opt for home dialysis. ... No doubt my renal unit will give me all the appropriate advice on medical aspects of dialysis, but I'll be interested to hear about everybody's personal experiences of all forms of dialysis - the advantages as well as the problems - so that it can inform my own decision, consequently I intend following this forum pretty closely now that I'm part of it.</i>
	Seek information	Allow users to seek clarity and understanding of issues/experiences relating to their health, for example their test results or symptoms they are experiencing	<i>Can anybody advise on the iron levels in the blood please? From a recent FBC [Full Blood Count] test I had, the ferr [iron] results was 12.95 which indicates as being low, hence anaemic. However when I have spoken to my nephrologist, he has said this is OK and is right for Stage 4 CKD... I'm lost now????</i>
Show good will (categorized 44 times)		Allow users to simply introduce themselves, thank others for their support and advice, or to wish others well	<i>Hi everyone I am stage 4 at present and very tired [and] sleep all the time. This is my first time to send a message to forum hope everyone well?</i>

Table 6. How patients use online discussion forum: themes, interpretations, and supportive Quotations

Major Theme	Sub-themes	Benefit to the user: Author's Interpretation	Supportive Quotes from Forum
Offer help and support to others (categorized 28 times)			<p><i>I've had my transplant now 6 years and get very tired even when working. I find an afternoon nap helps after work and when I'm not working. If anyone would like to talk about transplant problems please feel free to email me</i></p> <p><i>I'm fairly new to this forum. I also have PKD [Polycystic Kidney Disease] and had the inevitable "chat about my future" about a fortnight ago. I always knew this would be coming as my father had the same problems but it still rocked me quite badly. I am sure all the things you [another user with PKD who is having some concerns] are going through will be my problems soon enough, but I have seen it all first hand with my father. If I can be of any support etc to you let me know. I'd like to chat with fellow sufferers at least we can all compare notes</i></p>

Discussion

Summary of key findings

The demand for patients to have access to their own data is growing. This may have followed from a general assumption that increasing individuals' abilities to view and share their medical data will result in better self-care preparation and motivation, reductions in treatment and medication errors, and improved health^{8,9,10}. Yet, there is little information on how platforms designed to help patients access their medical information and share with others will be used. This evaluation provides an opportunity to explore how this system is utilized. Preliminary findings from this phase of the evaluation show that the uptake of this system is still growing. The finding that repeat users make up to 80% of all users suggests high visitor loyalty. This also highlights a need to further promote RPV to new users.

The findings reported here show that the results pages are by far the most popular pages visited by the patients. This is reflected in the high numbers of page views to the results pages. It can be assumed from this that the test results are the main reasons for using RPV. Whether this is due to anxiety, or whether the patients are looking at new tests, not the same ones over and over, can be further explored through surveys and interviews.

The results of this study show that uptake of the patient entered features is still very low. Only 7% of users accessing this section of RPV actually submit any reading. The finding that patients who submitted their readings were more inclined to submit blood pressure readings than any other readings may be a reflection of how high blood pressure can impact on kidney disease (as a cause or consequence), which could be a cause for concern for patients.

Thematic analysis of the forum discussions revealed ways the patients used the forum. This offers insight into the potential value of patients sharing information within a community of fellow patients. It was evident from the analysis that the forum is used as a resource for information by

⁸ Mandl KD, Simons WW, Crawford C R, Abbett JM (2007). Indivo: a personally controlled health record for health information exchange and communication. *BMC Med Inform Decis Mak.* 2007;7(1):25. doi: 10.1186/1472-6947-7-25. <http://www.biomedcentral.com/1472-6947/7/25>

⁹ Detmer D, Bloomrosen M, Raymond B, Tang P. (2008) Integrated personal health records: transformative tools for consumer-centric care. *BMC Med Inform Decis Mak.* 2008;8(1):45. doi: 10.1186/1472-6947-8-45. <http://www.biomedcentral.com/1472-6947/8/45>

¹⁰ Bourgeois F T, Simons W W, Olson K, Brownstein J S, Mandl K D. (2008) Evaluation of influenza prevention in the workplace using a personally controlled health record: randomized controlled trial. *J Med Internet Res.* 2008;10(1):e5. doi: 10.2196/jmir.984. <http://www.jmir.org/2008/1/e5/>

the patients. The forum was also used as a place to share concerns/problems, as well as to find help. Uptake of the forum is only 11% of RPV users. This may be a reflection of a cohort of early adopters or individuals that are more likely to participate in online forums. What motivates patients to use the forum and the value of the forum to the individual will be further explored by surveys and interviews in the next phase of this evaluation. For example, viewing or posting messages in the forum may reduce a sense of isolation that could result from living with a disease or help individuals contextualize their own experience within a community of patients¹¹.

Limitations

The custom report data from Google Analytics may not have excluded internal traffic generated by developers and administrators who may have visited RPV during the reporting period. Our analysis assumes that internal traffic may not be a significant component of the traffic to the content areas of interest in this study, and therefore, findings reported here should be, to a large extent, representative of visitor's interest.

Conclusion

RPV is a novel system allowing patients to access their records online and share with whoever they choose. The new features introduced to RPV were developed to improve the capabilities of the system. Their benefits will be further explored in the second phase of this project through surveys and interviews of patients and healthcare professionals in ten of the Renal Units across England. The surveys and interviews will be asking their views around the usefulness of the system and its impact on care planning. This will contribute to the understanding of how this model of data access impacts patient participation in decisions about their own health and their capacity to self-care. The final report is due in October 2011.

¹¹ Frost, J., Massagli, M. (2008). Social Uses of Personal Health Information within PatientsLikeMe, an Online Patient Community: What Can Happen When Patients Have Access to One Another's Data. *Journal of Medical Internet Research*. 2008 Jul-Sep; 10(3): e15. Doi: 10.2196/jmir.1053.