

How and to what extent do patients with kidney disease value the use of PatientView in their self-care practice?

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Introduction

An increasing prevalence of long-term illness such as chronic kidney disease (CKD)^{1,2} is necessitating changes to health care provision. Patients are being encouraged to take a more active role^{3,4}, with greater responsibility for making decisions about their own self-care activities. Technology has been identified as a means not just to supply information⁵, but to provide patients with the ability to control and manage self-care. PatientView, encourages patients to be more actively involved in the monitoring and managing of their long-term care. It is thought that the use of PatientView, will improve long-term management through better self-care but there is a lack of evidence to support this claim.

Aims

To gain an understanding of:

- How patients value the use of PatientView in their own care
- How and why engagement in self-care differs
- How factors such as key care relationships and use of technology influence self-care behaviours

Method

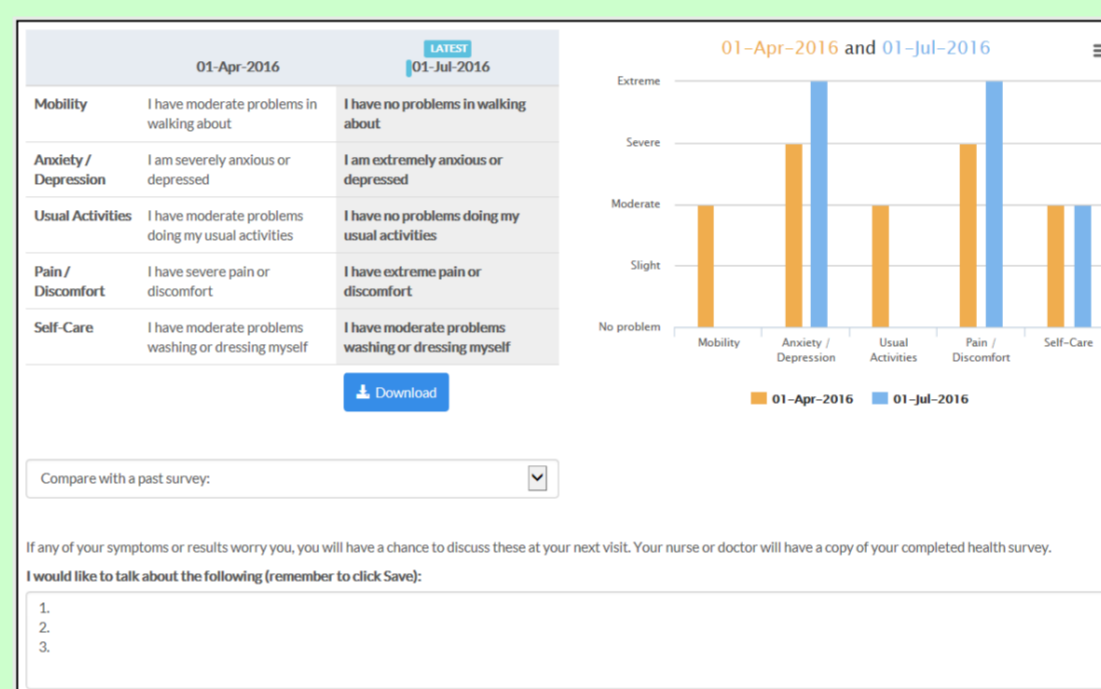
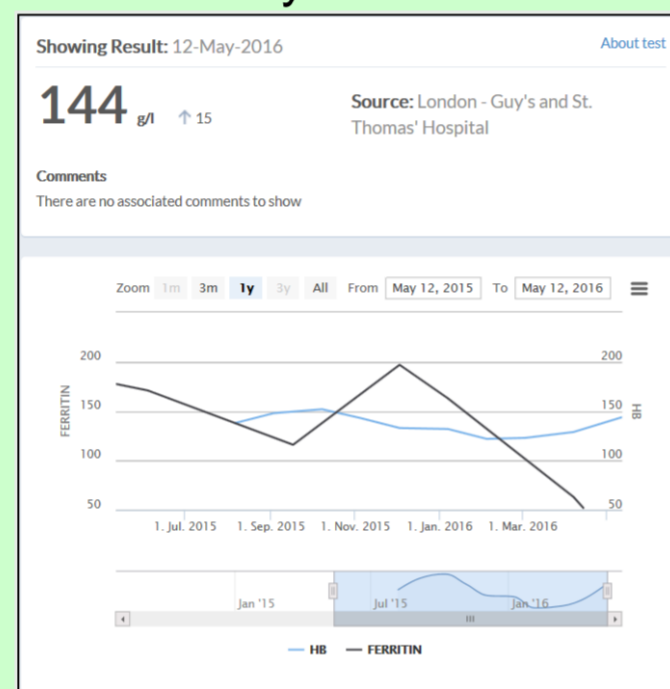
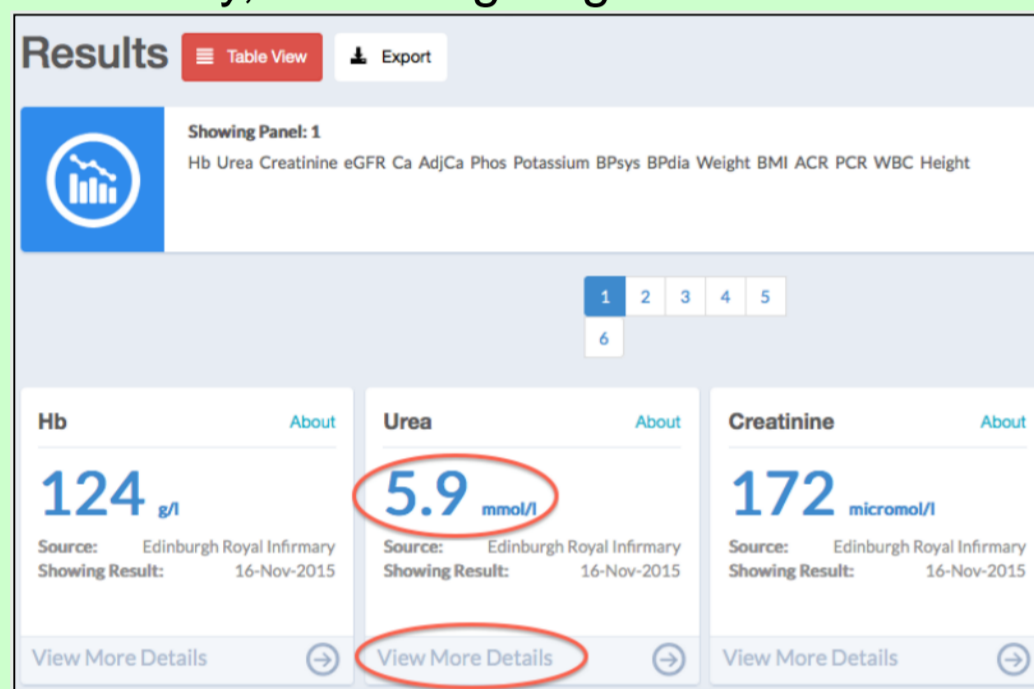
A qualitative, practice-based approach that draws on ethnographic methods was used to support understanding of how the use of technology and activities of self-care inter-relate. In practice theory, social reality is created through the interactions that occur as part of everyday life. This allows for an understanding of how patients 'do' self-care, what enables them to change behaviours and why this is important.

Therefore, in this research participant observations of patients using PatientView were combined with semi-structured interviews during which patients described the ways in which PatientView formed part of their care practice. An opportunity sample of 10 participants with chronic kidney disease, including both users and non-users of PatientView, were recruited to take part. Inductive thematic analysis was used to analyse the transcribed interviews and the observational data.



PatientView is an online portal which allows patients to access certain parts of their health care record. Patients can see tables and graphs of their blood results and look up reliable, accurate information about their illness and treatment.

Recently, screens giving feedback from PROM/PREM surveys have been added.



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Results

Patients valued the use of PatientView differently according to their historical experiences of health services, their situation at home and their personal situation within what is (for people living with CKD) a continuum of care. Within that continuum, the value of PatientView was that it simultaneously afforded opportunities for both independence and inter-dependence. Access to blood results enabled patients to feel less reliant on health professionals and supported them in sharing and developing new care practices with family members and informal carers.

In describing and demonstrating how they use of PatientView, patients described the 'hidden work' involved in making self-care practice part of daily life and sustaining this over time. At some points PatientView made patients feel less reliant on healthcare professionals, whilst at other times they felt it deepened their engagement, enabling them to prepare and think through questions to address during clinical appointments. It revealed how understanding how to act in response to changes in blood test results is a practice produced through trial and error coupled with ongoing conversations with clinicians, peers and family members

Contrary to what might be expected, patients who did not use PatientView were clearly users of technology who actively engaged in self-care. However, finding out and interpreting blood test results was a practice they specifically preferred to engage in with health care professionals.

It empowers me to be able to ask health professionals questions..... without lying back and thinking they know what's best

There's a number of times that I have changed something...because of PatientView results

..why do I need to keep asking because the nurses are really busy... if I have got it on a computer, I can just look it up

..it's not their problem, it's my problem...information is power...I'm interested in the whole process

Conclusion

Technologies such as PatientView are valued by the patients who use them because they enable them to sustain, share and take responsibility for their own care. Rather than categorising PatientView user types, a practice approach reveals the hidden work of sustaining self-care and how for most patients care practices change over time and are situation-specific.



Literature cited

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