Developing a patient-led electronic feedback system for quality and safety within an existing electronic health record

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Background

• Capturing and incorporating the viewpoint of the patient as a service-user has increasingly been a key message in health policy (Berwick 2013, Francis 2013, NHS England 2014, AHRQ 2016)
• It is recognised that patients are both able to and in a unique position to identify patient safety concerns
• BUT the patient voice is largely absent from current incident reporting systems
• Renal Patient View (RPV) (Patient View) is a novel shared electronic health record for all dialysis and transplant patients in the UK. It provides patients with web-based access to their blood results, referral letters, and the provision of specific health advice.
(http://rixg.org/patientview)
• Renal Patient View (RPV) provided an ideal opportunity to adapt an existing Electronic Patient Record (EPR) and incorporate a patient reporting system.

Aims

1. Explore the feasibility of renal patients, health care professionals and researchers working in partnership to develop a patient-led quality and safety feedback system within an existing EHR (i.e. RPV).
2. Adapt an existing technology (RPV) to accommodate a patient-led quality and safety feedback system and collect a range of qualitative data from patients and staff to establish the main principles and components of the patient feedback system prototype, and assess usability.

Setting and Design

Where did the research take place?

• Four renal units in the North of England

Design of the research

• Renal patients, carers, researchers and health care professionals acted as co-creators, and co-evaluators (Bate & Robert 2006).
• A patient led-steering group consisting of renal patients, health care professionals and the research team.
• Guided by the first two phases of Catwell and Sheikh’s (2009) model for evaluating eHealth interventions:
  • Inception (Phase 1), Requirements (Phase 2).

Method

• Phase 1 (inception): Focus groups with patients (including one non-English speaking) (n= 4), healthcare professionals (n = 3) and two combined focus groups.
  • A Joint Services Expert Panel (JSP) (front line staff and governance leads from the renal units) to review the findings from phase 1 focus groups and agree on the core principles and components for the system prototype.

• Phase 2 (requirements): cognitive walkthroughs using the patient reporting system prototype and 1:1 qualitative interviews were conducted with patients and healthcare professionals.
Participants

- Participants were purposively sampled from four renal units in Northern England. They included patients from the various stages of kidney disease and different modalities of renal treatment, and healthcare professionals from nursing, medical and administration.
- Phase 1: participants (n=57) included 29 patients/carers or relatives and 28 health care professionals.
- Phase 2: Participants (n=34) included 24 patients and 10 members of staff.
- JSP: 14 participants including three renal patients, one carer, a renal sister, a pre-dialysis nurse, a renal matron, a renal consultant, the RPV specialist, three members of the research team, a Cultural and Health Improvement Officer and a Risk Manager.

Phase 1 Results

- Patients were enthusiastic about the idea of feeding back quality and safety concerns within RPV.
- Could encourage openness between staff and patients within the renal units, and lead to service improvements.
- Concerns particularly around the accessibility of a computer based system for certain patient groups (i.e. the elderly, people who have learning difficulties), and the potential lack of feedback from the units regarding their reports if such a system were live.

Phase 1 Results

- Key facilitators to patient reporting
  - Anonymity
    - “If something is set up anonymously you would probably get a lot more back…”
  - Feedback from reports
    - “…I think when you report something you always want to see the outcomes or something come of that report…”
  - Being able to give positive feedback
    - “You have to be able to make a complaint which would be positive.”
  - Independent voice for patients
    - “We need a voice, we need a patient representative that can go around and write down the concerns the patients have.”

Phase 2 Results

The JSP were able to agree on seven core principles and components for the patient feedback system prototype:

1. The title of the system - "Sharing thoughts about my care: the renal patient confidential quality and safety feedback system"
2. The inclusion of separate forms for positive experiences and concerns
3. Anonymity
4. A two-tier filtering system for health care professionals
5. Individual feedback acknowledgment
6. Unstructured feedback forms
7. Inclusion of a severity score.

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Key barriers to patient reporting

- Language barriers
  - “There are a lot of patients and I don’t think they have the English a lot of them to actually put across you know…”
- Computer literacy
  - “The only thing is – especially on dialysis and pre-dialysis you’re got a lot of elderly people who won’t go near a computer”
- Consequences of reporting
  - “Some doctors are so rude and when you do complain about them they do put their back up…”
- Perception that the information won’t be dealt with
  - “Because if it’s going to nursing staff then they probably don’t have time to deal with it.”
Conclusion

• This study highlights the willingness of patients and health care professionals to work collaboratively to design a system that could be mutually beneficial. Other specialties and health care systems could use the same approach to develop or adapt their own patient feedback systems.
• Tensions arose due to competing priorities, particularly around anonymity and feedback.
• Careful consideration should also be given to whether it is feasible/possible to integrate a new element with differing priorities into an existing system with established functions and objectives.

Next steps

• Apply for funding to test the patient reporting system more widely and with different groups of patients.

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References:
