A qualitative study of Australians’ opinions about Personally Controlled Electronic Health Records

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Background

- Medical and medication errors are associated with poor coordination of care.
  - 2-fold increase when seeing 2 or more specialists.
  - 3-fold increase if hospitalised in the past 2 years.¹

- Other countries have implemented shared electronic health records.²,³

- Evaluation studies of small scale PCEHR show mixed results.⁴-⁵

What is a Personally Controlled Electronic Health Record?

A secure, electronic record of your medical history, stored and shared in a network of connected systems. The PCEHR will bring key health information from a number of different systems together and present it in a single view.\textsuperscript{6}

\textsuperscript{6}What is a PCEHR? National E-Health Transition Authority
Study Aim

- To explore the:
  1. Knowledge
  2. Understanding
  3. Views

of healthcare providers and consumers regarding personally controlled electronic health records.
Research Method

- **Study population**: Healthcare providers and consumers.

- **Sample size**: Recruit until saturation of themes.

- **Recruitment**: Flyers posted in public areas, information about the study was included in newsletters sent out in several Divisions of General Practice.
Research Method

- **Interview guide design**: Based on the interview guide used by Greenhalgh *et al*\(^5\) two interview guides were designed.

- **Data collection**: Interviewed once either face-to-face (individually or in small groups) or over the phone.

- **Data analysis**: Preliminary data analysis alongside data collection. Thematic analysis once data collection finished.

Results

- 26 consumers aged between 21 and 78 years.
- 22 healthcare providers aged between 27 and 71 years.
  - Doctors n=9
  - Pharmacists n=8
  - Nurses n=5
- 56% female participants.
Knowledge about and understanding of PCEHR

**Facilitator:** “Have you ever heard of a personally controlled electronic health record?”

**Consumer 16:** “Yes”

**Facilitator:** “Where did you hear about it?”

**Consumer 16:** “On the TV”

**Facilitator:** “What do you know about it?”

**Consumer 16:** “Very little. I believe it’s where your doctors can just grab your information up off the computer anywhere in Australia”
Type of information

Healthcare providers: As much information as possible.

Consumers 22: “I’m having an MRI every four months still. Whether they include the actual MRI results I wouldn’t think necessary but the fact that I had one would be just a salient point”
Purpose of the PCEHR

Healthcare providers:
- A tool for them to use, many failed to mention patients.
- Monitor patients (adherence, doctor shopping).

Consumer 2: “The purpose of it (PCEHR) is not for me, it’s for the medical profession”
Anticipated benefits with the PCEHR

- No more lost records
- Ability to electronically search a record
- More information
  - More holistic approach
  - Prevent misadventures
  - Safer healthcare
Anticipated drawbacks with the PCEHR

- Privacy concerns
  
  **Consumer 18:** “I have HIV and hep C... so I am very nervous about having my information stored in a single place”

- The system crashing
- Training of staff
Discussion

- Participants’ knowledge and understanding of the PCEHR was poor.

- Several benefits were identified but few would opt-in.

- Fear of unauthorised access.
Conclusions

- Strong opinions (despite poor knowledge and understanding).

- Challenge to achieve consumer opt-in.

- A quantitative study is needed to make more generalisable conclusions and recommendations.
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