Improving eRecord systems for People with Intellectual Disability

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Two studies


2. New research on EHR/EDRs
EHR/EDR?

EHR — Electronic Health Record
an artefact created and maintained by some or all of the people involved in a healthcare interaction

EDR — Electronic Disability Record
“contains the medical, occupational, financial, health support, and accommodation data necessary for disability payers to make a fair decision about an individual’s eligibility to receive health and benefit services, as well as the extent of those services.”
NDIS makes understanding how people with intellectual disability are represented in and by official records even more important.
How are people with intellectual disability included in eRecord systems?
To find out, we asked...

- People with intellectual disability
- Their families and carers
- Front-line management staff in large disability support organisations
We found…

• It’s (un)surprisingly complex
• But perhaps not for the reasons you might think
First study

- Participants were individuals, families and carers
- We asked about enrolling in PCEHR
  - (Australian Federal Government’s Patient Controlled Electronic Health Record)
- The PCEHR information is too complex
• Qualitative interviews (small \( n \); in depth)
• Experiences of going to the doctor
• How people handle information
  – mail
  – health information (e.g., paperwork)
• PCEHR recruitment paperwork
• Understanding and expectations of EHRs
Participants saw value in EHRs especially for managing a lot of health information but there are many barriers to entry
Recommendations

- Provide appropriate information for people
- Assist carers to explain eHealth records
  - Look internationally
  - Development and evaluation of easy English explanations
- EHRs could save time, avoid errors and improve communication
- Many barriers prevent some people from opting-in to a system that could benefit them
Second study

- People, families, front-line management staff
- Expectations of using eRecords
- Benefits unclear; enrollment complex
eRecords in this case

- 8 non-government providers collaborating to introduce a eRecord for their clients
- “off the shelf” software, adapted for intellectual disability context
- More than, more detailed than, PCEHR
Phase 1: How do expectations and experiences of people with intellectual disabilities, and their families, shape their understanding and adoption of eRecord systems?

Phase 2: How do people who work in disability support organisations understand the adoption of eRecord systems?
Findings

• Staff are on message
• Enrollment remains complex
• No time given for eRecord rollout
• GP signup is (perceived as?) a barrier
Staff expectations of eRecords are informed by who they understand their clients are and what they understand their client’s abilities to be.
Recommendations
Deciding if an eRecord is for you

- Do you have someone to help you look at your records?
- Do you have access to a computer?
- Do you know what information will be put into the records?
- Do you know who can see your information when it’s online?
- Have you been asked if the information online is correct?
Bigger questions

• who benefits from eRecords?
• who has the power?
• what are you gaining
• what are you losing?
More research is still needed on eRecords but also into wider systems of representation e.g. NDIS
How are people with intellectual disability included in eRecord systems?
Including people with intellectual disability in eRecords is unsurprisingly complex but possibly not for the reasons you think
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