Patient portals: furthering the reality of patient partnership

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Patient-held medical records are not new. Shared notes for antenatal care and patients with cancer have been studied since the 1980s. However, these records are censored and only certain details are available, usually limited to a short time span. They become out-of-date over longer time frames.

A review of publications on patient-held medical records in chronic disease management found no benefits in patient outcomes. However, the authors stressed the low methodological quality of the evaluations, poor consistency across studies and a lack of detail of what information was shared with patients as limitations to the studies.[1]

Doctors are now in a climate of patient-centred care, patient partnership and shared decision making.[2] There is an increased emphasis on individuals taking responsibility for their own health. While doctors still widely control access to patients' records, many doctors now turn their computer screens to face patients in consultations, write referral letters with the patient's input and print out copies of test results for their patients. My preference would be for patients to have full ownership of their medical records. This can lead to improved continuity of care as the patient moves between healthcare providers, who frequently distrust personal memories of medical histories. The Australian Government introduced the PCEHR (personally controlled electronic health record) in 2012, which enables healthcare providers to access and share patients' health information, including diagnoses, allergies and medication history. However, patient uptake has not been as extensive as predicted, with only around one million individuals signing up to view their personal record.[3]

Australia's PCEHR gives patients limited access to their health information. What might the effect of having full access to patient-held medical records be? A symposium at the Mayo Clinic in Minnesota focused on patient-held medical records and included a presentation from hospitals in Boston, Massachusetts that use the PatientSite (www.patientsite.org/login.aspx) and OpenNotes systems. Patients log on to the password-protected portal to see their doctors' and other health professionals' notes. Blood and X-ray results are also available as soon as they are uploaded. The referring family physician has access to this record. There is no waiting for clinic or discharge summaries (which are available within 24 hours) and test results are included. This is in contrast with a small Australian audit sample of hospital–primary care communication. The study showed half the discharge summaries included no drug information, and only one in five had full details of radiology and pathology investigations.[4]

The presenters stressed patient-held medical records should be considered an intervention like any other and should be researched for potential adverse effects. Their system had very positive responses from patients and health professionals. The preliminary study involved 20,000 patients and concluded that:

'Patients accessed visit notes frequently, a large majority reported clinically relevant benefits and minimal concerns, and virtually all patients wanted the practice to continue. With doctors experiencing no more than a modest effect on their work lives, open notes seem worthy of widespread adoption.'[5]

Only 2% of patients stated they did not understand the notes and 87% felt better prepared for subsequent consultations.

At the presentation, two patients spoke about their experience with this system and felt access to their own health records helped them feel part of the healthcare team. Patients were given the option of whether they wanted to view X-rays and other results before their follow-up appointment. The conversation can begin with discussions around the results they have already seen, and perhaps discussed with family, when

they attend follow-up consultations after the tests. Patients can also check back on the interaction of the consultation and any advice given.

Doctors are more likely to write clearer notes, with less jargon, as a consequence of open records. They need to fully inform patients on the reasons for particular tests and prepare them for the findings. However, there are concerns about bad news being unfiltered and delivered in one chunk without personal support, with different patients having variable levels of health literacy.

Care would need to be taken to avoid the 'inverse care law'.[6] These are situations where patients who are more in need are disadvantaged because of their social and financial circumstances. For example, it is important to note not all Australians have access to the internet.

There have been no trials on an open system for patient-held medical records in Australia. The PCEHR review in 2013 included feedback from key stakeholders about access. Patients stated they feel the system will support their involvement in their own care, but found the enrolment process to be 'time consuming and clunky'.[3] General practitioners (GPs) felt the current system does not add anything of use to a patient's regular GP and noted the large amount of effort required to implement the process.[3]

However, Australia's PCEHR is a much restricted version of what is available in parts of the US. Certainly, further work is required on the longer term impact, while security and confidentiality need to be assured. The patient portal in Boston cost US$50,000 to develop, which was compared favourably with the high costs of other complex interventions.

Is it time in Australia to debate the wider patient-held medical record and to pilot portals in general practice and secondary care?

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