

Our healthcare systems are currently going through vast changes; possibly some of the most significant transformations since the Enlightenment. The medical establishment, the technology industry, and patients are integrating in a manner not previously seen. The technological changes in patient online access to Electronic Patient Health Records (EPHRs) is potentially more convenient for patients, empowers and enables them to take better control of their health and health behaviour, helps them to navigate a complex system, and may make services more efficient and cost-effective.

But there is also the possibility for unintended harm, particularly related to privacy and confidentiality, and patients with complex needs or potential vulnerabilities could potentially experience significant impacts to their health care and relationship with their providers.

EQUAL FOOTING

These changes bring exciting new possibilities. It is hoped that patients are likely to experience a greater sense of self-autonomy and equal footing in their health care. Instead of working in silos, healthcare providers will be able to access networks and collaborations of data in ways not previously accessible. Traditionally, a reductionist philosophy has meant that patients often take a passive role within their health care. These developments could change the nature of the patient-clinician relationship as the patient takes a more central role in the heart of these systems. An increase in life expectancy, chronic conditions, condition self-management, and the rise of the internet have meant that many patients are eager for, and are able to have, an increased involvement in their health care.

PATIENT EXPERTISE

Some clinicians are embracing this change and attempting to accommodate not just the practicalities of merging technology into their daily working lives but also using it to establish 'Partnerships of Trust' with

their patients.¹ They firmly believe that patients are also experts in the consultation and can bring knowledge of context and personal requirements to the consultation, working together to produce patient-centred planning. This means having care plans that utilise the holistic attributes of personal circumstances and preferences, as well as diagnostic expertise. This context can play an important role in understanding risk and condition management.

CONCERNS AROUND CONFIDENTIALITY AND ACCESS

However, with all these exciting changes there are likely to be some challenges. Keeping this technology safe, inclusive, and accessible to diverse populations is one of these. Patients will experience these changes in a variety of ways. Those enduring domestic abuse have expressed concerns that their healthcare data could potentially be controlled and used for personal gain by partners or carers.² Concerns around confidentiality may mean patients experiencing abuse are less likely to disclose information.

Patients with dementia may experience challenges with the technology with the onset of their condition, and could be particularly vulnerable to their data being accessed and used in a way that had not been intended. Young people may worry about a parent finding out about a sexually transmitted infection they may have or a record of them seeking contraceptive advice.³ There may be patients who are not able to embrace this new technology. Some may have learning difficulties or not be able to read English or gain access to the internet.

INCLUSION

It is important to remember that our relationship with and expectations of health services are fluid and will change over the course of our lives. Some patients will be living in a permanent state of vulnerability, while for most this will be something that surfaces periodically. Vulnerability isn't just

dependent on our diagnostic condition but also our situation or circumstances, which will vary with each case. It is this context and complexity that needs to be brought to the forefront of health care. Perhaps the technological changes in EPHRs could help marry the flexibility, diversity, and complexity of different lifestyles of patients into alignment with the well-founded, evidence-based, established modernity of biomedicine. Each discourse brings different understandings, attributes, and challenges to the sector.

The technological healthcare revolution can usher in an exponential amount of exciting possibilities, but it's essential that it is researched and understood so that health care can be kept as safe, inclusive, responsive, and dynamic as possible. Listening to a diverse range of patient and clinician voices is vital. This way, experiences and concerns are represented, benefits can be maximised, and the risks reduced.

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