Perspectives

e-Health records: beware of assumed benefit

Ray Moynihan rings some notes of caution coming from experiences elsewhere

Change is perennial in health care, but some changes are more significant than others, like the personally controlled electronic health record (PCEHR) currently being rolled out across Australia. An ambitious reform, its much-touted benefits are safer and more effective care, less duplication of unnecessary tests — and, of course, enhanced datasets for researchers. As with most things medical, potential adverse consequences can attract less attention than promises, so it may be timely to explore a few experiences elsewhere.

In 2007, the United Kingdom rolled out the Summary Care Record as part of the much bigger National Health Service National Programme for IT overhaul. Within the broader reform, a personal electronic health record system called HealthSpace was introduced, allowing people to view their record and record information like blood pressure readings. However, an independent evaluation of the system in 2010 was scathing.[1]

Of those invited to open an "advanced" HealthSpace account (which allows access to the summary record and opportunity to interact with health professionals, on top of the "basic" account containing an individual's data), only one in a thousand registered, compared with predictions of 5%–10% uptake. Many people found it "neither useful nor easy to use", and its "functionality aligned poorly with their expectations and self management practices".[1] Stressing the limitations of their evaluation — informed by experiences of very few patients — the researchers identified a fundamental flaw in the concept. HealthSpace was envisaged primarily as a "data container" to be "deployed", rather than part of a dynamic and interactive "sociotechnical" network.

Led by Trisha Greenhalgh from the Healthcare Innovation and Policy Unit at Barts and the London School of Medicine and Dentistry, the evaluation team argued that unless the e-records "align closely with people's attitudes, self management practices, identified information needs, and the wider care package … the risk that they will be abandoned or not adopted at all is substantial".[1] Early in 2012, Greenhalgh and colleagues published a wider evaluation of the experiences across England, Scotland and Wales,[2] explicitly offering lessons in introducing electronic health record systems. A key finding was that implementation had "rarely gone as planned".

The Emergency Care Summary in Scotland lists medication and adverse reactions. Its development was clinically led, and it was found to have strong clinical support, though weaknesses included important gaps in data collection, including prescriptions hand-written during home visits. In Wales, planners rejected the idea of a single large national database, and are developing their system iteratively, learning from its introduction region by region, without arbitrarily dictated deadlines, and stressing the importance of the "social architecture" at the local level. But it is the English approach that attracts the harshest criticism, for its enormity and top-down focus on technology, rather than on the people and systems that use it. Specifically, concern was expressed about large legally binding contracts with major IT suppliers, "in which small changes to specification came with large price tags", making the program "cumbersome and inflexible".[2]

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In the United States, a 2011 Institute of Medicine report on e-health safety cited case reports demonstrating that poorly designed health IT "can create new hazards in the already complex delivery of health care", including medicine dosing errors, diagnostic mistakes and life-threatening delays in treatment.[3] An accompanying review found errors are due to "inadequate staffing levels, lack of user experience, mislabeled barcodes on medications, human distraction, inaccurate data entry, system downtime, and missing data".[4] The report recommends mandatory reporting of "health IT-related deaths, serious injuries, or unsafe conditions" and it flagged possible government regulation. One author — Art Levin, director of the Center for Medical Consumers in New York — told me that shared electronic records have demonstrated "great potential", though he stressed the need for security, privacy and much better monitoring of safety.

An international authority — Enrico Coiera from the Australian Institute for Health Innovation at the University of New South Wales — is calling for a national system of safety governance here for e-health, which includes the PCEHR.[5] "I think it's disappointing we still don't have any clarity around the oversight of safety" he told me last month, "though it's pleasing to see the Chief Medical Officer and the Australian Commission on Safety and Quality in Healthcare may ultimately be responsible for it".

The person-centred nature of the PCEHR in Australia is welcome, with its opt-in function and facility to control what other users view. But as the inevitable promotional campaigns begin, rather than emphasising the assumed benefits, perhaps more effective may be an incremental, iterative rollout, with transparency about the cons and pros of this latest layer of complexity coming to health care.

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