

# Sharing information safely and securely: the foundation of a modern health care system

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My Health Record will foster a more connected health system that will help prevent avoidable harm

In November 2015, a Coroner's case revealed the details of a patient who died after complications that arose from routine cancer treatment. Four days earlier, a scan showing signs of potentially fatal lung toxicity had been faxed by the hospital to an incorrect number, and neither the treatment team nor the patient were aware of the results — vital information that may have prevented a further fatal dose of chemotherapy.<sup>1</sup> This failure of information sharing resulting in an avoidable death is not an isolated case in our Coroners' courts.<sup>2</sup>

The position statement of the Royal Australian College of General Practitioners raised the need to end our reliance on the fax machine, stressing the threat to patient safety, and called upon the entire health care sector to make secure electronic communications a priority.<sup>3</sup> The National Digital Health Strategy has also highlighted electronic communication as a fundamental issue to deal with if we want a safe, seamless and secure system that meets the needs of modern Australia.<sup>4</sup> The My Health Record system is a step towards addressing the current system failures related to information sharing, supporting people in accessing their own health information, and allowing them to share these data with their clinicians.

Australia is not alone in this respect. The safe transmission of data around a connected health care system — interoperability — is a concern shared by many countries around the world. A new collaboration of the World Health Organization, governments and agencies — the Global Digital Health Partnership — has prioritised interoperability as a shared international challenge and opportunity.<sup>5</sup>

Providing patient care in collaboration with other clinicians requires the safe and timely sharing of their health information — the importance of which is acutely highlighted when we are faced with an avoidable tragedy. In the above Coroner's case, the use of an outdated technology such as the fax machine to share medical information contributed to a preventable death. In both the Australian and international contexts, communication among health care providers has been a major contributor to patient safety incidents.<sup>6,7</sup> In summarising the case, the Coroner called for the development of national standards around the communication of clinical information.

Australia is recognised as a world leader in its delivery of personally controlled health records<sup>8</sup> — tools that allow individuals to access, manage and share their health information in a private, secure and confidential environment.<sup>9</sup> The My Health Record system is a secure, personally controlled online platform that collects key summary information from health care providers. The system does not aim to capture detailed clinical notes from all settings. However, by simply allowing visibility of real-time data, including test results, medicines, hospital and general practitioners' summaries, it mitigates the safety risks faced when we encounter a health system that has not yet succeeded in allowing data to flow safely and securely between providers.

In February 2019, a My Health Record was created for all Australians, unless they chose not to have one. In line with expectations, this opt-out participation model resulted in a large number of Australians now having access to My Health Record, with 90.1% of Australians participating in the system at the time of record creation (<https://www.myhealthrecord.gov.au/statistics>). While a national electronic summary record has been available since July 2012, the move to an opt-out system with the ongoing option to permanently delete their record at any time offers Australians an important choice about how they wish to interact with their personal health information.

In this Supplement, there are a number of case studies and reviews that show the growing evidence supporting the role of digital technologies in modern clinical practice, including My Health Record, telehealth, and mobile health applications (apps).<sup>10–13</sup> Jackson<sup>10</sup> describes the way clinicians are using My Health Record to support patient-centred care and the advantages of a digital handheld antenatal record for improved clinical communication and patient safety. Face-to-face consultation via video conferencing and direct supervision of patient examinations are delivering better health outcomes for patients in remote East Arnhem communities, while also providing the additional benefit of education for both patients and clinicians.<sup>12</sup> McCullagh and colleagues<sup>13</sup> concluded that there are gaps in the effective implementation of mobile apps in health care. Nevertheless, they found that staff are supportive of apps, perceiving them to be of value to their patients and families. Case studies such as these are important indicators of success for digital health initiatives, but we need to ensure that rigorous academic evaluation supports such claims in the longer term.

A number of articles in this Supplement suggest that building the evidence base that guides the development of our digital health services is a high priority in Australia and internationally. Westbrook and Baysari<sup>14</sup> highlight the need to adopt a more evidence-based approach in the design of decision support tools for medication management, and Andrade and Roughhead<sup>15</sup> call for more evidence that specifically supports the effectiveness of emerging consumer-directed technologies. Miles and colleagues<sup>16</sup> evaluation of electronic health records in emergency departments (EDs) indicates the general paucity of studies in the application of digital systems in the ED setting. To improve our approach to this problem, it is important to consider the methods that can be applied to evaluate systems and deliver evidence of digital health benefit, as described by Biggs and colleagues<sup>17</sup> — evidence that can be used to guide policy makers and funders of our national digital infrastructure and direct future improvements of our systems.

Realising the benefits of digital health technologies will require not only the provision of digital technologies that support safer care and better health outcomes but also education and other strategies that support behaviour change for clinicians to use these technologies. Shaw and colleagues<sup>18</sup> sought to understand the attitudes of health and informatics professionals towards using data in electronic health records for performance feedback and professional development. The outputs of their study will inform future programs in this important research area, particularly when the secondary use of data may be considered.

The quantity of health data that clinicians have access to is constantly increasing and will continue to grow in the future, and digital health tools will be vital to support the ability of clinicians to analyse this information in a meaningful way that contributes to their ability to provide better, safer care. In this Supplement, Pearce and colleagues<sup>19</sup> — who have developed an algorithm to predict a patient's risk of ED presentation while undergoing a GP consultation — describe the application of big data analytics and machine learning. The tool demonstrated its utility, with the ability to create real-time “in consultation” warnings. Canaway et al<sup>20</sup> note the growing momentum in Australia to establish big data repositories of primary care clinical data to enable new frontiers in primary care and population health research, but they acknowledge that before potential benefits to evidence-based health care practices, policies and improved health outcomes can be realised from such research, Australians need to be well informed of the risks and benefits.

This acknowledgement of the balance between risks and benefits when developing digital health technology is further emphasised by Hansen and colleagues,<sup>21</sup> who highlight the work of Australian Genomics as it shapes a coordinated, national approach to the curation, storage and sharing of genomic and related clinical data. As we work towards the promise of a future that delivers precision medicine to Australians, we need to bring together the expertise of health care users, clinicians, researchers, information technology and data security specialists, ethicists, regulators, policy makers and lawmakers — all playing integral roles within an interdependent digital health care system. Evolving Australia's system will rely on co-design and collaboration between these groups to achieve a sustainable and effective digital health care infrastructure that achieves the shared objective of improving health care outcomes for patients into the future.

Given our use of outdated communication technology, there is a compelling argument that we need to modernise our systems,

improve our ability to share health care information and embrace the benefits that digital health systems can offer. We know that Australia delivers a world class health system ranked among the highest globally for efficiency and health outcomes.<sup>22</sup> However, we know from consultations with thousands of Australians who contributed to the National Digital Health Strategy that we could do better, that people want access to their own health information and that they want their health care providers to have access to it too.<sup>4</sup>

This Supplement highlights many of the advances and new technologies that are being developed and applied in the Australian health care system. Furthermore, it considers our need to support behaviour change and education among clinicians, while acknowledging and measuring the risks and benefits of new digital health services that support information sharing and better health outcomes. As we see increasing connections and use of the My Health Record system,<sup>23</sup> it is anticipated that its value will increase along with the richness of its clinical content. My Health Record is not the whole answer to solving the challenges of data sharing. However, it is a piece of the broader digital health ecosystem that will empower Australians by giving them access to their own health data and will help us take a step towards a better connected health system. Achieving this is key to the most important objectives of a modern health care system: to prevent avoidable harm for the people trusting us with their health information, and to provide patients with safe and high quality health care.

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