ASA – PS17

Position statement

My Health Record (MHR)

Preamble

The ASA supports the notion of an electronic health record that is ‘fit for purpose’, reliable, accurate, adequately resourced, consumer focussed, equitable, universally accessible, easy to use, maintains people’s privacy and safeguards against the misuse of data. The current 2018 My Health Record, (MHR), has attempted to address some of these concerns. The ASA will continue to collaborate with stakeholders to resolve the outstanding issues that present a barrier to the successful implementation of an effective e-health record.

Introduction

The practice of medicine in Australia has evolved organically from generic practitioners and bush hospitals to specialised generalists in primary care, specialists, sub-specialists in secondary and tertiary centres. Healthcare services are distributed geographically across rural, regional and metropolitan centres reflecting Australia’s population mal-distribution and across the public and private sectors. This healthcare practice is supported and augmented by pharmacists, nurses, allied health professionals and diagnostic technicians. The net result is often uncoordinated care occurring in silos that may be duplicative, unnecessary, wasteful and potentially harmful[1].

Having access to an accurate e-health record could theoretically improve this fragmentation of care. In 2012 the Personally Controlled Electronic Health Record (PCEHR), was introduced to improve health outcomes by sharing health information and increase consumer engagement through an ‘opt-in’ approach[2]. Low community uptake prompted further research, education and promotion culminating in the relaunch of MHR in 2016.

Potential advantages of an ideal e-health medical record

Reducing fragmented care

Medical information often exists in silos. This information should follow the patient[3], to allow healthcare professionals to provide timely, safe and appropriate care. This is particularly relevant for those with special needs, complex multisystem disease, chronic disease, the elderly and disadvantaged. Multiple medications may introduce the potential for drug interactions, allergic and adverse drug reactions. An up-to-date drug reconciliation tool would significantly reduce these potential errors particularly when patients are transitioning from one setting to another or changing geographical locations. Having an accurate current medical record assists with discharge planning and handover of care.

Safer care in emergencies

Emergency access to reliable, current medical information may be lifesaving.

Improved efficiencies

Uncoordinated care is wasteful. It often results in duplication of investigations and referrals. This is expensive and may result in increased exposure to risks.

Consumer centric

Allowing patients to have input into their medical record, how the data is managed and who has access to it, empowers them to take an active role in decisions about their care. It increases awareness, choice and control[4].

Advanced care plans and advanced care directives
These may be reliably located in the e-health record.

Increased engagement
Centralizing the consumer's information may stimulate healthcare providers to offer more acceptable, appropriate and useful products and services.

Area for research
De-identified data may be used by legitimate authorised entities to conduct quality improvement research, planning and policy development

Potential disadvantages of the My Health Record 2018

Incomplete, inaccurate record
Allowing consumers to alter their record potentially devalues the clinical integrity. Health professionals may not be able to reliably provide the best care for their patients if it is based on inaccurate information. Consumers may have an asymmetry of medical information that may compromise their ability to make the best decision regarding what to exclude[4]. When the MHR has been modified by a patient this is not visible. It should be made clear if a record has been altered by a patient even if the content of that change is not.

Access
Many health professionals, including many specialists, do not have access to the software required to engage with MHR[5]. Combined with 'on going' compliance obligations this presents a significant barrier to specialist participation. Incomplete healthcare provider participation below a critical mass, reduces the universality and overall value of the MHR. Adequate resources must be invested in the platforms that support and maintain the integrity and access at the bedside (ideally on a mobile device) of the MHR data.

Privacy and security
The potential for centralised personal data to be corrupted, stolen, used and stored inappropriately remains a valid concern for all stakeholders. Proposed government measures go some way to protect patient privacy. No IT system will ever be totally reliable yet this has not prevented the developments in e-banking or e-travel. There needs to be assurance that should such a data breach occur, the Federal Government assumes full responsibility. There needs to be consultation with the medical indemnity industry and some assurance on the limited liability of doctors utilizing MHR.

'Opt-out' may not be fully informed consent

PCEHR went from 'opt-in' to 'opt-out' in MHR to achieve a greater critical mass of consumer participation with benefits of scale, greater interconnected participation and the potential for transformational change[6]. However, consumers must be fully informed and have a degree of e-health literacy that permits them to make an informed choice about how to engage, and to what degree, with MHR.

Implementation barriers

There needs to be more effective targeted education and promotion to ensure MHR is acceptable and useful to healthcare providers and patients[7]. Evaluations of MHR have demonstrated low levels of usability amongst those with reduced e-health literacy[8]. Low levels of awareness and how to utilise the full capabilities of the MHR, may discriminate against the 'digitally naïve'. This may include the most vulnerable people with chronic, multisystem disease, the elderly, those with mental illness, non-English speaking and from lower socioeconomic backgrounds.

Conclusion

The ASA supports an e-health record that meets the clinical and consumer expectations. This includes respecting and protecting patient's privacy while maintaining the integrity of the clinical data. The implementation of MHR will require more resources to address and support these concerns.

References

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Promulgated	09/12/2018
Reviewed	29/01/2019
Latest Revision	29/01/2019