AUSTRALASIAN COLLEGE FOR EMERGENCY MEDICINE

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Committee Secretary Senate Community Affairs Reference Committee Department of the Senate PO Box 6100 Parliament House CANBERRA ACT 2600

Dear Chair

Re: Submission to the Senate Community Affairs References Committee: My Health Record inquiry

I am writing on behalf of the Australasian College for Emergency Medicine (ACEM) in response to the Senate Community Affairs Reference Committee (the Committee) undertaking the *My Health Records Amendment (Strengthening Privacy) Bill 2018* inquiry (the Inquiry). ACEM welcomes the Inquiry as it provides a timely opportunity to review the current approach to the introduction of My Health Record.

ACEM is responsible for the training and ongoing education of emergency physicians and the advancement of professional standards for emergency medicine in Australia and New Zealand. As the peak professional organisation for emergency medicine, ACEM has a vital interest in ensuring the highest standards of emergency medical care are maintained for all patients.

ACEM has been clear in its support for government to take action to improve the accessibility of healthcare information given the anticipated improvements for patient outcomes.¹ This is consistent with the statement made by the Council of Presidents of Medical Colleges, which supports the My Health Record system as a means to "...*improve the communication process between health care practitioners and minimise delays in patient access to health care.*"²

Patients understand and support the need for healthcare professionals to have access to medical results and related healthcare information.³ ACEM considers it a priority that the My Health Record system protect the patient-clinician relationship, which is essential to safe and effective practice in healthcare. This relationship is built on the community's confidence that health information will be collected, stored and shared in accordance with privacy principles and community standards

¹ Australasian College for Emergency Medicine, 2018. *Submission to the Australian Digital Health Agency: Safe, Seamless and Secure Framework for Action*. [Internet] Melbourne. As viewed on 10 September 2018. Available from https://acem.org.au/getmedia/d1555dee-3a4a-487c-a43f-

⁴⁹c5337ffa1f/20180423_ACEM_Submission_Digital_Health_Agency

² Council of Presidents of Medical Colleges, 2018. *Statement on the My Health Record*. [Internet] Published on 8 August 2018. As viewed on 11 September 2018 at <u>https://cpmc.edu.au/wp-</u>

content/uploads/2018/08/STATEMENT-OF-THE-MY-HEALTH-RECORD-8August2018.pdf

³ Armani, R et al 2016. *Current patient and healthcare worker attitudes to eHealth and the personally controlled electronic health record in major hospitals*. International Medicine Journal Jun: 46(6): 717-722. Royal Australasian College of Physicians, Australia

regarding privacy and confidentiality. These principles and standards apply regardless of the physical and digital environment for this health information. Accordingly, ACEM recommends that safeguards to protect the patient-clinician relationship must form a core component of the My Health Record system.

ACEM understands that the health information of individuals and communities is vulnerable to exploitation when effective security safeguards are lacking. The possibility of irretrievable breaches of patient privacy has been realised in the National Health Service's loss of hundreds of thousands of health records⁴ and the coordinated cyber-attack on the Singapore government's health database⁵. Recent examples in Australia have included the collection of patients' health information without the consent of users⁶ and the health information being publicly shared to question a public figure's credibility.^{7 8} We note also the experience in the United Kingdom where the *care.data* system was cancelled after sensitive medical information was shared with commercial companies without the informed consent of patients.⁹

ACEM considers that more time and support is required to understand the operational impacts of the My Health Record system and ensure collaborative engagement across the hospital environment. It is unclear to ACEM how the My Health Record system will be operationally and clinically integrated into the more than 300 emergency departments across Australia, the timing of this roll out and how the system will interface with other clinical care settings. There are multiple complex policy and procedural issues regarding, for example, communication between patients and their health care providers about the recording and accessibility of health information arising from care across primary, emergency and inpatient areas in multiple health settings.

ACEM considers that operational readiness and clinical capacity in emergency departments, and ensuring alignment with community expectations, is vital to the successful roll out of the My Health Record system. ACEM is concerned about the risk that possible shortfalls in the My Health Record system may negatively impact the interactions between emergency clinicians and patients at a time when health information is most urgently needed. Where the My Health Record system does not

⁴ Syal, R & Campbell, D 2017. *NHS data loss scandal deepens with further 162,000 files missing*. Guardian News and Media Limited, United Kingdom.

⁵ Ministry of Health, 2018. *Singhealth's IT system target of cyberattack*. Press Release: 20 July 2018. Government of Singapore.

⁶ McGrath, P, Blumer, C & Carter, J 2018. *Medical appointments booking app HealthEngine sharing clients' personal information with lawyers*. [Internet] Australian Broadcasting Corporation. As viewed on 10 September 2018. Available from http://www.abc.net.au/news/2018-06-25/healthengine-sharing-patients-information-with-lawyers/9894114

⁷ Media Release: *Statement on fabricated evidence to Senate Inquiry*. The Hon Peter Dutton MP, Minister for Home Affairs. Australian Government, Canberra.

⁸ Grattan, M 2018. Peter Dutton is now at war with his former *Border Force boss over the au pair affair*. [Internet] As viewed on 10 September 2018. The Conversation. Business Insider Australia. Available from <u>https://www.businessinsider.com.au/peter-dutton-au-pair-affair-roman-quaedvlieg-2018-9</u>

⁹ Department of Health and Social Care & Freeman, G, 2016. *Review of health and care data security and consent*. [Internet] United Kingdom. As viewed on 12 September 2018. Available from

https://www.gov.uk/government/speeches/review-of-health-and-care-data-security-and-consent

function as patients and families expect, the resulting confusion is likely to add to the stress on patients, families and emergency physicians.

ACEM's recent dialogue with the Australian Digital Health Agency (ADHA) presents an ongoing avenue to seek clarity on these and other issues and reiterates our willingness to engage with stakeholders to collaborate our efforts. ACEM has been actively involved in previous consultation initiatives undertaken by the ADHA regarding the My Health Record and the broader digital health framework. Fellows of the College are also involved with an Australian Commission on Safety and Quality in Health Care project identifying the infrastructure and support necessary in emergency departments to maximise the benefit of My Health Record for patient care. This project will provide significant insights and make recommendations to the Australian Health Ministers' Advisory Council regarding best practice in awareness raising and training, workflow integration and user experiences of the respective system platforms.

To summarise, ACEM recommends:

- Stronger privacy and data security protections of healthcare information given the sensitive nature of these records;
- Targeted communication and engagement strategies that better explain the My Health Record, and the impacts surrounding a centralised reference point of healthcare records;
- Extending the time available for patients and health professionals to understand the risks and benefits of My Health Record and how the system will work before the option to opt out closes; and
- Ongoing engagement with health professionals, consumers and carers to improve the effectiveness of the My Health Record system.

In conclusion, ACEM considers that recent media coverage of concerns in the community and amongst digital and privacy experts regarding the My Health Record system highlights the risks to the project if it loses the public's trust. Our recommendations are aimed at assuring the community that in principle and practice the system is patient focused and will continue to underpin community confidence in the primacy of the patient-clinician relationship.

Thank you for the opportunity to provide this submission to the Committee for consideration. If you require any clarification or further information, please do not hesitate to contact the ACEM Policy Officer Lee Moskwa on (03) 9320 0444 or lee.moskwa@acem.org.au.

Yours sincerely,

Dr Simon Judkins

President Australasian College for Emergency Medicine