16 November 2017

Australian Government Department of Health
C/- HealthConsult,
3/86 Liverpool Street
Sydney NSW 2000

By email to: MyHealthRecorddata@healthconsult.com.au

Dear Sir/Madam

Re: Development of a framework for the secondary use of My Health Record Data

The Royal Australian and New Zealand College of Psychiatrists (RANZCP) welcomes the opportunity to provide feedback to the Australian Government Department of Health with regard to its development of a framework for secondary use of My Health Record Data.

The RANZCP is the principal organisation representing the medical speciality of psychiatry in Australia and New Zealand and is responsible for training, educating and representing psychiatrists on policy issues. The RANZCP represents more than 4000 qualified psychiatrists in Australia, many of whom have specific interest and expertise in this matter.

Secondary health data constitutes a significant resource and it makes economic and ethical sense to use this data as much as possible to improve the effectiveness and efficiency of health services in Australia.

However, the RANZCP asserts that, in the main, the secondary use of health data requires a balance to be struck between the public interest and the very important need to protect the privacy of individuals. This is particularly so in the context of mental health where an individual's health data is likely to include sensitive information.

With minor exceptions, almost all of the data within the My Health Record system is originally acquired during the clinical care of a patient - not for administrative or planning purposes. Therefore, if the data are to be used for secondary reasons, clear definitions of the circumstances in which this is allowable must be articulated and well understood. Such circumstances where it may be appropriate for the data to be used for secondary purposes include:

- health service commissioning
- risk stratification
- audit – financial and health care
- health service management and planning
- health research
- public health surveillance.
That said, the needs of the health system for information are constantly evolving and responding to new challenges meaning that future needs for data are difficult to anticipate. In particular, this means that data needs can never be fully anticipated in advance and that the data ‘net’ may need to be thrown quite widely, even where there is no obvious benefit to doing so.

With regard to ensuring a robust process is in place for their use, the RANZCP further adds that at this stage of the development of the My Health Record, organisations and individuals should be able to access My Health Record data for secondary purposes only in the event that they agree to hold the data in Australia, as well as agreeing to a framework that ensures:

- no data must be retained longer than is necessary
- data must be de-identified
- the minimum amount of data required for the purpose should be disclosed
- data must be held securely
- information should also be obtained about whether the data will be stored in or outside Australia
- assurances should be sought (preferably in writing) that information will not be transferred to a third party and it will only be used for the specific purpose for which it was disclosed.

While agreeing and codifying principles for the release of information will provide a framework respect to the secondary release of health information, as with any system, safeguards need to be included to ensure compliance.

To this end, the RANZCP asserts that:

1. its support for the secondary use of data is conditional on any governance arrangements pertaining to the release of data being approved by, and preferably including senior level representation from, the Office of the Australian Information Commissioner
2. under the system being mooted by government, there is a high degree of trust placed in those given access to data. Accordingly, any breach of agreement must be penalised commensurate with the potentially significant impact that the breach may have
3. following ‘2’, any breach must be recorded and reviewed, with any learnings incorporated to prevent a reoccurrence to the extent possible.

The RANZCP also notes the previous position it has articulated with respect to e-health systems. In particular, the RANZCP cannot state strongly enough the importance of doctors and representative medical bodies being included in system design, to ensure accessible and useful information is available without a need for doctors to perform onerous data entry activities. In addition, the need for software to be compatible with all medical practice software systems is crucial.
Also, the RANZCP restates its previously articulated concerns around the need for special consideration of sensitive health information, which are especially relevant concerns for people living with mental illness. Providing clarity around mechanisms to ensure the privacy for individuals should be an immediate priority. Issues that require your consideration in this regard include matters that relate to:

- particularly sensitive information to do with sexual health, trauma or mental health being recorded, and whether this information warrants additional protection above that that applies to other health information
- whether a person with a carer or guardian will have access to the My Health record and whether the person has the ability to withhold sensitive information from their carer and not their doctor
- protections beyond those codified in the release principles and governance regime to ensure health information is not misused, for example in family law or other settings.

Finally, the RANZCP notes that the recording and analysis of mental health diagnoses require special consideration as they are often changeable and less clear cut than their physical health equivalents. Any system would need to be mindful of this reality.

If you would like to discuss any of the issues raised in this letter, please contact Rosie Forster, Executive Manager, Practice, Policy and Partnerships via rosie.forster@ranzcp.org or by phone on (03) 9601 4943.

Yours sincerely

Dr Kym Jenkins
President

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