

17th November, 2017

Australian Government
Department of Health
MyHealthRecorddata@healthconsult.com.au

Subject: Submission to Consultation on Secondary Use of Healthcare Data

The Federation of Ethnic Communities' Councils of Australia (FECCA) is the national peak body representing Australia's culturally and linguistically diverse (CALD) communities and their organisations. FECCA provides advocacy, develops policy and promotes issues on behalf of its constituency to Government and the broader community. FECCA supports multiculturalism, community harmony, social justice and the rejection of all forms of discrimination and racism so as to build a productive and culturally rich Australian society. FECCA's policies are developed around the concepts of empowerment and inclusion and are formulated with the common good of all Australians in mind.

FECCA welcomes the opportunity to provide input to the discussion around secondary use of healthcare data.

Key message:

FECCA acknowledges that while the secondary use of data available through My Health Record might be beneficial to the overall population, however, it can also have negative effects and raise privacy concerns. FECCA urges the government that the needs of vulnerable groups be taken into consideration when creating the relevant policy.

As an advocate and peak body for CALD communities in Australia, FECCA can confirm that as an 'at risk group', low health literacy is a major concern for Australia's multicultural

population. According to research, only 33 per cent of people born overseas have adequate or better health literacy compared to 43 per cent of the Australian-born population. This figure drops to 27 per cent for those who arrived in Australia during the past five years and to 26 per cent for people whose first language is not English. The impact of low health literacy on people from non-English speaking backgrounds means they are, among other, less likely to understand issues related to their health¹. Similarly, for ageing CALD populations, language is a major barrier as English as an acquired language is lost with isolation, age and with conditions affecting memory.

In order for a person's health literacy to be improved, they require access to health information that they are able to understand² and this is of great concern to FECCA. Although CALD communities may not necessarily be against secondary use of their data, they need to be informed and able to understand to enable them to make informed decisions.

Effective community engagement with most people from CALD backgrounds is recommended; face-to-face focus group consultation is considered to be the most effective way to gain participation.

A recently developed report on the uptake of the My Health Record portal suggested that people from CALD backgrounds, especially recently arrived immigrants, greatly appreciate the My Health Record system. The report suggests that the best approach is to work with key community leaders through interpreters in a train-the-trainer model so that they can convey messages and support use of the My Health Record system in their communities. In more established CALD communities, materials and resources translated into the key languages will also be necessary.³

FECCA supports this approach while at the same time recommends being mindful of the fact that migrants and refugees may have lived in countries where the government systems are not trustworthy and thus are wary of anything which places personal information in one place, in view of privacy concerns.

FECCA notes that the citizens of Australia are placing their trust in the Government to implement this process correctly and in their best interest.

FECCA is available to engage and contribute in more detail on matters relating to culturally and linguistically diverse communities and to undertake further discussions on this matter.

¹ http://www.eccv.org.au/library/An_Investment_Not_an_Expense_ECCV_Health_Literacy_Paper_FINAL.pdf

² http://www.eccv.org.au/library/An_Investment_Not_an_Expense_ECCV_Health_Literacy_Paper_FINAL.pdf

³ Siggins Miller Evaluation of the Participation Trials for My Health Records

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