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PCEHR/Hi Discussion Paper Feedback
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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.

The Australian Bureau of Statistics reports¹ that as at 30 June 2014, 28.1% of Australia's estimated resident population was born overseas, that is, 6.6 million people. Over 4 million of these were born in non-English speaking countries. Cultural and linguistic diversity is significant aspect of the Australian population, and one of its defining factors. The needs of this large proportion of the population must be taken into account in the development, planning and implementation of government programs and services.

Participation

FECCA notes the primary change outlined in the Discussion Paper is to individual's participation; that is, the former 'opt in' system will be trialled as an 'opt out' system. This is an outcome of the review of the Personally Controlled Electronic Health Record (PCEHR) System in 2014.

Although FECCA made a submission to the former Department of Health and Ageing in relation to the PCEHR System in 2011, we did not participate in any consultations as part of the PCEHR Review in 2014. While FECCA supports the move to the PCEHR system ('My Health Record') in principle, we do not support an 'opt out' system, without appropriate information and education provided to CALD communities.

¹ Migration, Australia, 2013-14, Australian Bureau of Statistics 2015

The Discussion Paper notes that the stakeholders who were consulted strongly supported the move to an opt-out system, so long as it is 'accompanied by an effective public awareness and education campaign'.

FECCA would be interested in knowing the intention of the Department in terms of an effective public awareness and education campaign. Our consultations² with constituents have shown that, for instance, the My Aged Care information campaigns (such as 'Time to talk about aged care') have not been effective at reaching the CALD target group. Despite some limited ethnic radio advertising and print material in different community languages, almost no CALD person out of over 500 consulted in October-November 2014 had heard of My Aged Care.

Language is a major barrier to access to information, and to understanding systems and processes. Providing clearly identified information, online or in print, in community languages can be one way of making information available to people who are not literate in English, however agencies must take into account those many individuals who are not literate in their own language.

Feedback received from FECCA's consultations also emphasised the importance of having alternative means of accessing information. Face-to-face interaction, with a trusted person, or by using an on-site or phone interpreter is the preferred and most effective form of communication.

Governance

FECCA supports the establishment of a Commonwealth statutory authority, the Australian Commissioner for Electronic Health.

Privacy and security

Migrants and refugees may have lived in a country where the government systems are not trustworthy and thus are wary of anything which puts all of their personal information in one place, in view of privacy concerns. With an 'opt out' system, and with the intention to allow individuals access to set controls for their PCEHR should they wish to do so, it is imperative that individuals are able to understand how and why this could be done. The reasons for alerts when certain activities occur in relation to an individual's PCEHR would need to be clear.

While the privacy framework of the PCEHR system is described in the Discussion Paper, there is no information about an individual's rights should they be concerned about a notification of someone else accessing their PCEHR.

Conclusion

FECCA appreciates the opportunity to provide feedback. For further information, please contact the FECCA office on 02 6282 5755 or admin@fecca.org.au.

² FECCA undertakes annual consultations on equity of access to services and programs for migrants and refugees, in different States and Territories, and in metro, rural and regional areas.