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Committee Secretary
Senate Standing Committees on Community Affairs
PO Box 6100
Parliament House
Canberra ACT 2600

My Health Record system

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 strives to ensure that the needs and aspirations of Australians from diverse cultural and linguistic backgrounds are given proper recognition in public policy.

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 would welcome the opportunity to expand on this submission as required. For enquiries please contact FECCA CEO Dr Emma Campbell at emma@fecca.org.au or on (02) 6282 5755.

Recommendations

FECCA recommends that:

- adequate resources and funding be allocated to community engagement, including practical training for individuals on how to use the MHR with a particular focus of that engagement being CALD persons with disability.
- the MHR be offered in other languages.
- default settings for the MHR should be set at maximum security and privacy with a prompt that offers individuals the choice to allow for their health data to be shared with others including caregivers and medical professionals should they wish.
- adequate resources and funding be allocated to the ongoing education of new migrants who arrive after the opt-out period, so they can make informed choices about whether or not to cancel the record which has been created for them, should they wish.
- all translated materials in relation to the MHR are community reviewed.
- the MHR system be updated to include fields 'interpreter required' and 'preferred language' to support the needs of CALD consumers.

The expected benefits of the My Health Record system

FECCA has been funded by the Australian Digital Health Agency (ADHA) to assist with their communication strategy for CALD Australians and migrants about the My Health Record (MHR) and the opt-out period. This includes disseminating information in culturally and linguistically appropriate ways and through preferred channels, to provide community review

of translated materials and to provide assistance to Primary Health Networks (PHNs) to improve their messaging about the MHR for CALD Australians. Based on community feedback, FECCA has advised the ADHA on alleviating CALD concerns regarding the MHR and how to provide adequate and appropriate information. FECCA advised the ADHA on providing information that enables CALD Australians to make an informed choice about whether or not to opt-out of the MHR.

FECCA believes that the MHR has benefits for CALD Australians including:

- supporting individuals with low English language proficiency, by having information on their health readily available to medical professionals attending to their needs, particularly in cases of emergency.
- assisting people with low English language proficiency to more efficiently and accurately provide information on their medical histories, conditions, treatments, allergies, hospital discharge information, and current medications.
- providing instructions relating to organ donation and advanced care planning.
- supporting CALD carers in maintaining immunisation and other records for the children and others they care for.
- supporting migrant Australians who change address frequently due to work or other requirements, particularly early in the settlement period when this is more likely to occur.
- assisting recent migrants and refugees who may have lower levels of English language proficiency and who lack knowledge of the Australian health system.
- supporting older CALD Australians and their healthcare providers to monitor and manage treatment.

FECCA understands that there are longer-term plans to extend the MHR program for use in Aged Care and fully supports the ADHA in efforts to extend the program in this way.

FECCA commends the work of the Government and ADHA in creating a tool that will allow Australians, including those of CALD background, to more easily manage and access their health data.

The decision to shift from opt-in to opt-out

As a consumer organisation FECCA believes that schemes such as the MHR, as a matter of principle, should be opt-in. However, FECCA recognises that many harder-to-reach CALD communities may not have opted in to the MHR, due to a lack of targeted communication, or lower levels of English language proficiency or digital literacy. Considering the significant benefits for CALD Australians, FECCA acknowledges that an opt-in system may have resulted in some of the key beneficiaries of MHR missing out on having a record created.

Prior to the roll out of the MHR, FECCA consistently raised concerns with the ADHA that the opt-out period was too short and should be extended to ensure that CALD communities were adequately informed. FECCA welcomed the August 2018 decision by the Government to extend the opt-out period, but argues that such an extension could have been avoided had the relevant stakeholders taken into consideration FECCA's feedback from the outset.

Considering that the MHR was shifted to an opt-out system and is based on the assumption that individuals have a high level of digital literacy, FECCA recommends that:

- increased resources and funding be allocated to community engagement, including practical training for individuals on how to use the MHR and how to opt-out.
- the MHR be offered in other languages.
- default settings should be set at maximum security and privacy with a prompt that offers individuals the choice to allow for their health data to be shared with others including caregivers and medical professionals should they wish.

- resources and funding should be allocated to the ongoing education of new migrants who arrive after the cessation of the 2018 opt-out period, so they can make informed choices about whether or not to opt-out of having a MHR or can delete the record which has been created for them, should they so choose.

FECCA has long advocated for the collection of disaggregated and longitudinal data on CALD Australians to inform better public health policy and believes that the secondary use of data will positively contribute to this aim. However, FECCA believes that the default setting for consent to secondary data usage should have been set in the negative, with a prompt or option for users to consent, should they wish. FECCA strongly opposes the use of any mechanisms that oblige consent to the secondary use of data, or MHR scheme participation as a condition of service access or usage. Whether or not individuals opt-out of the MHR scheme should never affect the quality or continuity of healthcare service provision. This message should be clearly communicated to all Australians.

Privacy and security

While CALD communities may be some of the key beneficiaries of the MHR system, they are also more vulnerable to the misuse or release of healthcare information. Preceding the roll out of the MHR, FECCA repeatedly expressed concerns to ADHA, including to the CEO and relevant stakeholder relations representatives directly, that the *My Health Records Act* did not preclude use of MHR data for the purposes of compliance checks or law enforcement with regards immigration and visa status. These concerns were supported by experiences in the UK, where health records were used in cases of deportation.¹

FECCA supports a strong immigration system and the need for consequences to apply when the rules relating to visa status are not complied with. However, FECCA does not believe it is appropriate or in the best interest of community safety to use data gathered in the provision of healthcare services for this purpose. FECCA was consistently assured by the ADHA that legislation (prior to amendment) did protect against usage in this way. This was later proven not to be the situation. The ADHA dismissed and downplayed FECCA's concerns and when pressed for a formal response, provided an obfuscatory letter.

That the concerns of consumer representatives have, to date, only been acknowledged after broad public rejection of the MHR scheme, demonstrates the importance of responding to concerns of consumer representatives early on. This was particularly evident with regards the opt-out period extension and the changes to who has access to data in a MHR and for what purposes, which have only served to make CALD communities more wary and confused regarding the system.

Australians of migrant background may have had negative interactions with authorities in their country of origin and hold significant concerns about how their personal information is used and stored by government authorities. Building trust with CALD consumers requires that the Australian government explicitly communicate that MHR data will be used for healthcare matter only. This is important because the perception that MHR data may be used to the

¹ The Guardian UK, 'NHS hands over patient records to Home Office for immigration crackdown', (25 Jan 2017), available at <https://www.theguardian.com/uk-news/2017/jan/24/nhs-hands-over-patient-records-to-home-office-for-immigration-crackdown>; The Register, 'UK gov slammed for NHS data-sharing deal with Home Office', (17 Jan 2018), available at https://www.theregister.co.uk/2018/01/17/nhs_data_sharing_immigration_slammed/; Independent, 'Migrant women are being scared away from the NHS because the Home Office is taking data from patient records', (27 January 2018), <https://www.independent.co.uk/voices/immigration-nhs-patient-record-data-migrant-women-health-care-abortion-a8180906.html>; The Guardian UK, 'Home Office accessing NHS records to help track down illegal immigrants', (13 July 2014), available at <https://www.theguardian.com/uk-news/2014/jul/13/home-office-nhs-records-illegal-immigrants>.

detriment of an individual or community will lead to some CALD consumers avoiding healthcare services.

FECCA welcomes the eventual decision by the government to amend the MHR legislation to ensure that a court order is needed to access MHR data and to ensure that stored data is deleted if an individual chooses to cancel their MHR. FECCA believes that this change has been vital in signalling to CALD and migrant Australians that their personal data will only be accessed and used for healthcare purposes.

The Government's administration of the My Health Record system roll-out, including:

- i. **the public information campaign, and**
- ii. **the prevalence of 'informed consent' amongst users**

FECCA commends the government's efforts to engage CALD communities through targeted communication campaigns to engage harder-to-reach parts of the Australian population. FECCA's constituents have noted that targeted information sessions, in-language material and specialised content for CALD communities have been vital in assisting individuals to understand, manage and choose whether or not to opt out of the MHR system.

However FECCA believes that an advisory council should have been set up at the outset of the MHR process which would have included consumer representatives and privacy experts. Through working with an advisory council major concerns could have been addressed and mitigated as part of the development process and specific information inbuilt into the rollout of the education campaign.

FECCA welcomed the opportunity to conduct some community reviews of translated ADHA MHR materials and commends the ADHA for translating materials into key community languages. However, not all MHR translated materials were community reviewed and FECCA has received feedback from communities that these unreviewed translations were not of consistently high standard.

Community consultations revealed that some CALD Australians are deciding to not opt-out of MHR despite holding serious concerns about the system because the opt-out process appeared too complicated or adequate instruction on opting-out was not easily available in their preferred language. FECCA emphasises that all translated materials must be community reviewed and that more community education should be undertaken.

FECCA believes that community driven information campaigns are vital, however they should be complemented by above the line advertising campaigns. For CALD communities, delivery of information via SBS, in English and in-language, is particularly important. SBS is the media outlet of choice for CALD Australians and has unparalleled coverage and trust in communities. FECCA commends the ADHA for partnering with SBS to deliver information on the opt-out period in twelve languages on SBS Radio, but argue that SBS's reach into CALD Australia should be leveraged through the funding of further above the line advertising campaigns on SBS television.

Any other matters

FECCA has identified a number of additional challenges for CALD Australians interacting with MHR. The online system is currently only available in English, which makes it difficult for Australians with lower levels of English language proficiency to interact with the system and control their healthcare data. This is compounded for many older CALD Australians who also have lower levels of digital literacy.

The government needs to ensure that CALD Australians are provided with step-by-step instructions and training on how to manage their MHR. This information should be provided through a variety of channels (including ethno-specific media, SBS, and peak bodies). It

should also be provided in simplified English, utilise iconography and images, and languages other than English.

Need to include data collection on language

FECCA believes that there are many benefits for consumers from CALD backgrounds in using the MHR. However, FECCA understands that currently the data entry fields for MHR do not permit the input of information pertaining to consumer language needs. A MHR for CALD consumers would be significantly improved with the inclusion of fields 'interpreter required' and 'preferred language'.

The former would allow for practitioners to immediately identify situations when an interpreter is required. The data in the 'preferred language' field assists in the identification of appropriate language service professionals (interpreters and bilingual workers). These fields would also ensure that medical professionals are held to account if they fail to facilitate an interpreter for patients who have a need documented in their MHR.

FECCA also believes that language information data collection in the MHR would assist in developing nuanced analysis of CALD population health. Currently there is a lack of research available on almost all aspects of CALD health in Australia and this stems from a lack of CALD health data collection. Using language as a differentiation category could help segregate the de-identified data in the future (as per the Australian Government's Framework to Guide the Secondary Use of Data). Applying preferred language as parameter could provide more information on, for example, incidence of dementia in CALD communities, or specific chronic health conditions in CALD communities. Having such data readily available would support further research that could result in improved health outcomes for CALD Australians.

More specifically, the inclusion of these two items to the My Health Record system would ensure the delivery of more equitable and accessible health care services for CALD Australians. It would ensure that the provision of appropriate language support is integrated into health care service delivery.

FECCA has previously written to the Commonwealth Minister for Health calling for these changes to be made to the MHR system, and urges the Committee to endorse this recommendation.