

Notes from meeting on 23 August 2023

Legislative Assembly Legal and Social Issues Committee (Chair and Deputy Chair) meeting with Ethnic Communities' Council of Victoria Policy Advisory Committee on Health & Wellbeing

The Chair and Deputy Chair of the Legislative Assembly Legal and Social Issues Committee met with representatives from the Ethnic Communities' Council of Victoria (ECCV) Policy Advisory Committee on Health & Wellbeing (PACHW) to discuss the Inquiry into increasing the number of registered organ and tissue donors.

ECCV is the peak body for migrant and refugee communities in Victoria. It works with over 220 member organisations, including ethnic associations, multicultural service providers and eight regional ethnic communities' councils. Its mission is to be the voice of multicultural Victorians by strengthening and building community through advocacy and leadership.

General

- Not all cultures are comfortable talking about death, dying and donation.
- There are many differences between multicultural communities. One approach will not fit all communities.

Encouraging multicultural communities to register to be donors

- Education and awareness raising material and activities should:
 - share powerful stories of people who have gone on to live full lives after receiving a successful transplant
 - use simple, clear language (including for translated materials)
 - include resources like short online videos in different languages that can be shared on TikTok, Instagram and YouTube
 - include 'influencers' or trusted people from different community groups
 - include radio programs in different languages, translated information and attendance of bicultural workers at community events
 - be aware of cultural sensitivities but simultaneously not shy away from promoting donation, including highlighting the need for donation and using practical examples
 - encourage family conversations about donation
 - consider tailoring materials to connect with different cohorts, for example culturally diverse people with disabilities.
- Registration options may need to be broader than drivers licences because many people in multicultural communities do not drive. Registration options could include Medicare, healthcare cards or other methods that are meaningful to people.
- In regard to potentially moving to an opt-out model, it is very important to make sure everyone is informed and knows that they can change their mind. It could be damaging if people do not know they can opt out and raises questions about informed consent. It is also important that decisions are confidential and people do not feel guilty about opting out.
- Acknowledge family living overseas or family of choice, because multicultural people may be detached from family.
- Encourage GPs to discuss donation with diverse patients.

Build trusted relationships in multicultural communities

- In-person attendance at community events or visits to local groups is important. This includes bicultural health workers or translators to assist with communication and partnering with local councils.
- Active engagement with communities, like talking directly to people and sharing facts or stories often has a greater impact than one-way sharing of translated resources.
- Invest in reciprocal relationships in multicultural communities, by spending time, being genuine, having a presence and building personal connection. Community leaders are a good starting point to building these relationships.

Multicultural young people

- Social media is a good tool.
- Schools are a great platform to engage students to think about organ donation.
- Have conversations with young people early because you never know what will happen.
- Young people can be leaders and have conversations about donation, see resource prepared by the Centre for Multicultural Youth: [Invisible Leaders: How Multicultural Young People Served as Bridges and Brokers During the COVID-19 Pandemic in Victoria](#)
- Young people can be 'brokers' and positively convey health messages received through schools or other programs.
- Young people can encourage multigenerational discussions with family and community. While it can be hard to broach the subject with community members, young people can be more approachable.
- Young people who are more exposed to western views may find it challenging to talk to older generations about donation.

Family conversations about registration in multicultural communities

- People from multicultural communities wanting to register as donors should be encouraged to have the conversation with their family before registration, rather than afterwards, so it is not a surprise. People need help to be able to articulate how they feel about the issue and the facts to inform their family discussions.
- Another option is to have a dedicated team to answer questions from families based in Australia and overseas. Information on a website is not enough, particularly for people from oral cultures.
- Campaigns should provide culturally safe spaces for discussion about donation.
- In relation to family conversations in hospitals, a donation decision happens very quickly in hospitals and conversations about donation can be hard; they are often impacted by culture and language barriers. More preparation or education ahead of time could benefit families having to make that decision.