

ECCV Response to the Victorian Government's Review

In relation to

Community Information about Voluntary Assisted Dying

November 2018

The Ethnic Communities' Council of Victoria Inc. (ECCV) is the voice of multicultural Victoria and the peak advocacy body for eight regional ethnic community councils and 240 member organisations including ethnic and multicultural organisations across Victoria. For over 40 years, we have been the link between multicultural communities, government and the wider community.

ECCV has a strong history in advocating for the rights of multicultural communities, informing industry practice and influencing Government on a range of issues including health, aged care, workforce participation, equitable access and community harmony.

This submission builds on previous activities conducted by ECCV including the *ECCV Response to Victorian Government Discussion Paper on the proposed Voluntary Assisted Dying Legislation* and *ECCV's Position Paper on Advance Care Planning and Palliative Care*.

ECCV is providing its feedback on community information on Voluntary Assisted Dying of the Victorian Government upon request.

Summary of responses on draft community information on Voluntary Assisted Dying (VAT) in Victoria

Community Organisation Feedback Form: Understanding voluntary assisted dying

Introduction

The Ethnic Communities' Council of Victoria (ECCV) states that it is neither in favour and neither against the notion of Voluntary Assisted Dying (VAT) as an organisation, as this is the personal decision of each individual. ECCV believes that culturally appropriate access to palliative care, advance care planning, and VAT is important if the individual wishes to make use of them. ECCV points out that all Victorians should have appropriate access to good qualitative palliative care and advance care planning and that Victorians would only access VAT under specific circumstances in the context of end-of-life care. ECCV emphasises the need to better inform culturally diverse communities on end-of-life care choices to raise people's awareness and to avoid confusion amongst palliative care, advance care planning, and Voluntary Assisted Dying.

Thinking about the information presented in 'Understanding voluntary assisted dying' and the information needs of people your organisation represents, and/or who use your services, please answer the following questions:

1. Which sections of the information do you think people would find hardest to understand? Why?

The ECCV emphasises that some culturally diverse communities are not familiar with the concept of Voluntary Assisted Dying (VAT) as it not a common concept in their country of origin. People may be distrustful of public institutions facilitating VAT. ECCV, however, reaffirms that VAT is an individual choice and people may access VAT irrespective of their cultural or religious backgrounds values or beliefs.

ECCV highly recommends community education facilitated by multicultural organisations to outline what VAT is and also the safeguards associated with VAT. ECCV community feedback indicated that some culturally diverse people are neither familiar with the concept of palliative care, advance care and VAT and that some people may feel confused about these significant differences in concept, partly due to the lack of awareness or the difficulty to literally and culturally *translate* such concepts. ECCV states that culturally diverse communities are especially not familiar with VAT, and therefore more ‘work on the ground’ needs to be done to engage with culturally diverse communities including on how to culturally appropriately and respectfully communicate VAT related issues.

Recommendation 1:

ECCV recommends that the Victorian Government consults specifically with culturally diverse community members on how to effectively and appropriately deliver culturally sensitive information on end-of-life care issues to culturally diverse people and communities, including on VAT.

Recommendation 2:

ECCV recommends that the Victorian Government facilitates and provides resources for culturally sensitive community education sessions, delivered face-to-face, to local culturally diverse communities on the suite of end-of-life care issues.

2. Were there particular terms in the information that needed further explanation? If so, which ones?

ECCV recommends providing clearer and more specific information on available safeguards including where exactly to seek help in case people or community members are concerned that VAT could be *misused*. ECCV is also concerned about culturally diverse people who experience severe loneliness who wouldn't legally be permitted to access VAT, but may be under the impression that VAT would be an option to alleviate their psychological and physical pain. This might apply to terminally ill and severely lonely people, including people in residential aged care settings.

Further, ECCV highlights that there is limited information in the draft on ‘Understanding voluntary assisted dying’ about the roles and responsibilities of family members, especially if the person speaks little or no English. Often people from culturally diverse backgrounds make health-related issues a topic of family conversations, even to the point that in some families decisions are made for family members. For example, in some cultures the older person wouldn't be told that she/ he has cancer to avoid ‘unnecessary suffering or preoccupation’. ECCV emphasises that in many culturally diverse families decision making is rather a collective and not an individual process and therefore family and carers support issues need be taken into

consideration. ECCV reiterates the importance of the family and carers, especially as the terminally ill person may receive support or comfort from them as they accompany the terminally ill person on their end-of-life journey.

Recommendation 3:

ECCV recommends the promotion of culturally sensitive lifestyle programs and activities in residential aged care facilities and more government investment to ensure access of isolated people to community and social participation activities. This should also include supporting family members, carers, and community organisations who visit very isolated and terminally ill people.

Recommendation 4:

ECCV recommends that the Victorian Government creates an information sheet on the role and responsibilities of families in the context of VAT, including on safeguards and issues related to personal and physical safety (in cases where people are concerned about these), and considerations on family and carer support during the terminal stage of the illness or when accessing VAT.

3. *Do you think people would find the tone of the information appropriate given the sensitivity of the topic of voluntary assisted dying?*

ECCV believes that the tone of the information is appropriate as such but emphasises that many culturally diverse people will not be able to understand the text, for *language* reasons or because the concept of VAT is not known to their culture.

ECCV is aware of the translations into a number of community languages on VAT and we recognise the effort of the Victorian Government to improve understanding on VAT in culturally diverse communities. ECCV believes, however, that such information, as a stand-alone resource, is not very effective and culturally sensitive.

Recommendation 5:

ECCV recommends face-to-face community information sessions in language to culturally diverse community members on end-of-life care issues including on access to palliative care, advance care planning, and VAT, in conjunction with translated materials.

4. *Do you think people would need more or less information in any of the sections?*

ECCV highlights that this will depend on the degree of an individual's English language literacy, the person's ability to read (some people are illiterate in their own language), and the level of formal or informal education that people may have had access to. ECCV reinforces the importance that VAT translations are used in conjunction with face-to face culturally sensitive community information sessions to culturally diverse communities.

5. *Do you think the information addressed people's general questions about voluntary assisted dying? If not, what additional questions should be added (you don't need to know the answers)?*

ECCV highlights that many culturally diverse people speak little or no English. ECCV believes that regulations and guidelines need to be in place in cases where people can't access an interpreter in their first language. ECCV states that access to face-to-face interpreters can be difficult and that access to some languages, especially languages of recently arrived communities and for people in regional Victoria, is often very limited.

Recommendation 6:

ECCV asks that the Victorian Government ensures appropriate access to face-to-face interpreting services for culturally diverse people who wish to access VAT, including for communities in regional Victoria and members from recently arrived communities.

6. *'Understanding voluntary assisted dying' is currently located on a publicly available website and people can also print a pdf of the information. Given these existing formats, what could be changed in the presentation of the information that would make it easier for people to read?*

ECCV reiterates the need for more culturally appropriate community information on end-of-life care issues including provided through ethnic and multicultural agencies and ethnic media.

7. *What other formats would people find helpful for presenting this information (e.g. video, audio, other)?*

ECCV recommends the development of in-language and simple English video clips on end-of-life care issues in conjunction with face-to-face community information sessions. ECCV also recommends that the Victorian Government consults with ethnic and multicultural community members and communities on online video messaging contents to ensure cultural appropriateness of the content.

Recommendation 7:

ECCV recommends the development of culturally sensitive in-language online video clips and ethnic media engagement on end-of-life care issues in conjunction with face-to-face community education sessions through multicultural organisations

8. *Where do you think people would expect to find this information (e.g. on a government website, provided by a doctor, other)?*

ECCV emphasises the need for culturally appropriate VAT information and resources to be accessible through their GP upon request. In those cases where people wish to access VAT, ECCV also highlights the importance that information should be provided to appropriate representatives of organisations that culturally diverse communities trust and with whom people have had a previous and ongoing relationship with.

9. Are there any further comments you wish to add?

ECCV is concerned about some of the translated VAT materials. As in some countries the concept of VAT doesn't exist, the translations have a tendency to cause distress and concern to people, rather than to inform them. This is the case for example with the translation into Somali.

Case example: Somali translation and cultural context

ECCV received community feedback that some of the terminology used in the translated resource into Somali is ambiguous.

It was questioned whether VAT related issues can actually be correctly translated if the concept of VAT itself doesn't exist in the public health setting of that country, such as the case in Somalia. As an example, the words *substance* (In Somali: walax) and *safeguards* (In Somali: ilaalin) have not been translated into Somali in a way people understand in a VAT context and therefore lack meaning. It was indicated to ECCV that *ilaalin* is more about monitoring rather than safeguards.

Whereas the English text was considered to be clear, translating the Somali text on the point of the *substance* back into English (section on 'What is voluntary assisted dying' of the translation) would read:

"Voluntary Assisted Dying means managing something (walax) that can bring death when looking at the written law."

Overall, while reading the translated Somali version, it was necessary to read the English text repeatedly in order to understand what the text in Somali is conveying. The text was perceived to be too close to the English text as it attempted to translate word by word which made it difficult to follow the text naturally (*text flow*).

It was also pointed out to ECCV, that in Somali culture, community members believe that "people have their specific time for dying which is beyond human control." People of Somali culture would "talk about dying but not in a sense that you have an option on how you want to die".

ECCV is further concerned that interpreters may not have sufficient subject matter expertise on end-of-life care issues, especially on VAT, which can make interpreting difficult and of poor quality.

Recommendation 8

ECCV recommends that translated materials are checked by relevant ethnic community members or groups as well as by health professionals who are fluent in that respective community language.

Recommendation 9

ECCV recommends interpreter training on end of life care issues to accredited interpreters.

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