**Purpose:**

To provide the Consortium Management Group with information and rationale for allocating funding for facilitation of a culturally diverse focus group to inform Consortium member agencies on perceptions regarding death and dying of an emerging community and next steps to developing culturally appropriate palliative care and resources.

**Context**

In January 2021, the Consortium assembled a small Focus Group comprising representatives from our three community palliative care services to explore opportunities to strengthen knowledge and practice when providing palliative care to culturally diverse communities. This objective is consistent with three of the five priorities of Victoria’s end of life and palliative care framework priorities this project supports:

* delivering person-centred services
* engaging communities, embracing diversity
* strengthening specialist palliative care

**Work undertaken to date:**

The Focus Group was asked to identify cultural resources across member agencies to aid identification of gaps in resources and knowledge regarding the provision of culturally appropriate palliative care. From this information, the Consortium identified key goals and undertook a range of activities:

***Goal 1: Comprehensively review and refresh the Consortium’s current resources and information on its webpage.***

In April 2021, the Consortium undertook a comprehensive review of the ‘CALD’ information and resources on our website and repositioned the information as a quick link on our home page. Feedback from the Focus Group in response to this improvement is very positive. The Consortium has also implemented systems to ensure the information on our website regarding the provision of culturally appropriate palliative remain accurate, relevant and current.

***Goal 2: Identify culturally diverse communities in the Consortium’s catchment, in particular emerging communities where information and knowledge around death and dying and palliative care is unknown or limited.***

Focus Group members consulted their colleagues who identified people from Somalia, the Middle East and Africa, Aboriginal and Torres Strait Islander People and Vietnamese and Chinese communities to be a priority in relation to emerging communities.

***Goal 3: Identify capacity building opportunities for the workforce e.g. identify existing education and training on cultural diversity and palliative care and facilitate access to same; link with culturally diverse community organisations to explore how to identify expectations and needs of culturally diverse communities regarding death and dying and palliative care.***

* The Consortium negotiated with PEPA to conduct a workshop on 11 May 2021 for Consortium member agencies on culturally-responsive palliative care for people from culturally and linguistically diverse backgrounds workshop. This was well attended and well received. Repeat workshops (which are free of charge) can be negotiated with PEPA
* The Consortium sought to identify and meet with community based culturally diverse organisations that could provide education and training in cultural diversity. Work completed includes:
  + The Consortium met with the Manager of the Centre for Culture, Ethnicity & Health (CEH) <https://www.ceh.org.au/> which provides specialist resources and training to improve health and wellbeing in a culturally diverse society. They offer expertise in areas of diversity, health, community education and resource development and training in Cultural Competence, Health Literacy, Language Services. CEH advised the first step is to understand how communities think about death and dying before moving to exploration of and demystifying palliative care with diverse communities. They suggested the key elements of the approach should include:
* The Consortium identify the language groups/communities we wish to know more about.
* CEH would conduct some focus groups contacting relevant community associations and negotiating recruitment of participants (no more than eight people (gender mix to be determined by community norms). CEH together with representatives from the Consortium develop focus group questions that will elicit the information we require. Participants are paid (usually by voucher)
* Focus group questions will be developed with the literacy of the community in mind and whether an interpreter is required for the focus groups.
* Representatives from the Consortium may attend focus group as observers.
* CEH provides a written report of key information and themes arising from focus groups.
* Community Associations involved in the recruitment of participants are reimbursed which is included in the cost of the work undertaken by CEH.
* The Consortium may wish to offer focus group participants the opportunity to be involved in development of resources and tools.
  + Feedback from the Focus Group on the CEH approach was positive suggesting this would be an appropriate method for deepening and strengthening the perceptions of emerging communities around death and dying and implementing a culturally appropriate palliative approach to care.
  + CEH were invited to provide a quote for this scope of work.

**CEH quote for work**

CEH provided a quote for the scope of work (attached below). They have advised that:

* The proposal shows the cost and process for one focus group with one selected language groups.
* Some of the costs will be reduced if you choose to engage us to do multiple focus groups.
* Not all listed costs may be incurred depending on the English proficiency of the participants.
* The presence of an palliative care clinician at the focus group would be encouraged in case the discussion raises issues for participants.
* Recruitment can be the slowest and most difficult of all the tasks and lockdown has not made that any easier.  Focus groups work better if people are all in the same room, requiring a COVID safe approach.



**Proposal:**

* The Consortium consider the CEH proposal regarding funding work on identifying cultural perceptions around death and dying and palliative care needs of one emerging community.
* The emerging community nominated to be part of this approach is decided by the Consortium by consensus.
* The focus group is designed to include at least one palliative care clinician.
* The usefulness of the work undertaken is evaluated by applying agreed performance measures to determine if this exercise should be repeated for other emerging communities. The following performance measures and targets are proposed to support evaluation of the focus group, outputs and information.

|  | **Strongly Disagree (1)** | **Disagree**  **(2)** | **Neither agree nor disagree**  **(3)** | **Agree**  **(4)** | **Strongly agree**  **(5)** |
| --- | --- | --- | --- | --- | --- |
| **Statement 1:**  Documented outputs from focus group are comprehensive and reflect the content of the discussion. (Target is rating of 4/5) |  |  |  |  |  |
| **Statement 2:**  Feedback from community palliative care representatives attending and observing the focus group demonstrates the information was useful, relevant and informative.  (Target is rating of 4/5) |  |  |  |  |  |
| **Statement 3:**  The information gathered as part of the focus group will provide a strong foundation to inform practice and resource development.  (Target is rating of 4/5) |  |  |  |  |  |
| **Statement 4:**  This approach should be repeated for other emerging communities. (Target is rating of 4/5) |  |  |  |  |  |
| **Statement 5:**  Palliative care representatives attended and observed the focus group. | YES – Note how many and which organisations were they from  NO | | | | |
| **Statement 6:**  Focus group participants actively sought information and asked questions of palliative care clinician/s | YES – Themes from questions  NO | | | | |
| **Statement 7:**  Feedback from focus group participants demonstrated they found the experience useful, informative and appropriately conducted (if appropriate, will seek to obtain this information through a short survey) |  | | | | |