Advance Care Planning

Grant recipient: Ethnic Communities' Council of Victoria

Project Title: The Advance Care Planning 'have the conversation' consumer project

Final Report

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The Voice of Multicultural Victoria

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INTRODUCTION

The Advance Care Planning (ACP) 'have the conversation' consumer project is a partnership between Department Of Health And Human Services and the Ethnic Communities' Council of Victoria (ECCV). The project was initiated to support the Department of Health and Human Services Advance Care Planning Strategy for Victorian health services 2014-2018. The Advance Care Planning 'have the conversation' consumer project aims to increase consumer capacity to engage in discussion around advance care planning at home and within health services.

The project raised awareness of advance care planning among culturally and linguistically diverse (CALD) communities. Successful in-depth consultation with the Macedonian and Filipino community ascertained the current understanding of advance care planning in the targeted communities, it identified cultural beliefs and values that needed to be considered when initiating conversations about advance care planning and it developed culturally relevant key messages for each of the communities. Consultation also provided what key communication methods were needed to disseminate the information using a suite of delivery mechanisms; based on specific sub-groups within each community.

This report provides a summary of findings including a model and communication framework which recommends approaches to future engagement with the Macedonian and Filipino cultural groups.

ETHNIC COMMUNITIES' COUNCIL OF VICTORIA

ECCV multiculturalism our commitment

ECCV is the peak advocacy body for ethnic and multicultural organisations in Victoria. It is a community based, member driven organisation committed to empowering people from diverse multicultural backgrounds. ECCV are proud to have been the key advocate for culturally diverse communities in Victoria since 1974. For over 40 years ECCV have been the link between multicultural communities, government and the wider community. Our full-time professional staff is engaged in representation, advocacy, policy development and capacity building.

Project experience

ECCV has considerable experience in managing projects which educate and build the capacity of the ethnic and multicultural community sector. This project has developed a community education model to raise awareness of palliative care among culturally and linguistically diverse communities.

Relationships of trust

ECCV represents over 210 ethnic and multicultural organisations in Victoria and has often acted as a link between the public and ethnic sector (e.g. Home and Community Care - Access and Support), due to its relationship of trust with ethno-specific community organisations. ECCV has close ties to ethnic communities and faith-based organisations through our membership and a network of Regional Ethnic Communities' Councils through which we have developed strong relationships with ethnic communities in regional and rural Victoria. Further, ECCV has been cooperating closely with ethnic media organisations.

ACKNOWLEDGEMENTS

Funders:

- Department Of Health and Human Service

Lead ethno specific organisations:

- Australian Filipino Community Services
- Macedonian Community Welfare Association

PROJECT MODEL

Project Aim

This project aimed to deliver culturally appropriate information about advance care planning to two ethno specific communities and to understand and overcome taboos, fears and stigmas surrounding advance care planning in the targeted communities. Each of the communities was selected due to a number of factors, including the community size, the average age within the community (each of these communities has a large ageing population) as well as the community's capacity to participate and interest in participating.

Governance

ECCV was the lead agency and the contract holder responsible for meeting this project's reporting, project deliverables, evaluation and budgetary requirements.

The project was guided by a project Advisory Group convened by the Department of Health and Human Services consisting of a range of representatives. ***See Appendix A - List of Advisory Group***

Deliverables

- Ascertain participant's knowledge and understanding of advance care planning
- Deliver advance care planning workshop
- Explore cultural considerations
- Identify key messages
- Review resource
- Identify a model of approach and a communication framework

Design

A qualitative approach has been used for this Project, which uses the same methodology as is used in all of the ECCV projects. The project uses an evidence based framework for in-depth consultations to develop a strategic model to increase advance care planning that will ensure advance care planning messages, resources and information dissemination methods are relevant, appropriate and meet the needs of the Macedonian and Filipino communities.

LITERATURE REVIEW

Advance care planning

Both international and national literature suggests that there is a lower rate of end-of-life planning and decision making in people from culturally and linguistically diverse (CALD) backgrounds (Johnstone & Kanitsaki, 2009; Sinclair, Smith, Toussaint & Auret, 2014).

ECCV reviewed literature relating to cultural issues and advance directives/advance care plans, including cultural attitudes and practices in relation to death and dying, ninety articles in total were reviewed. Cultures and communities may vary across space (e.g., urban

compared to rural). It is important to avoid generalization and stereotyping; the emphasis is on remaining sensitive and opens rather than having a prescription for each person based on their culture.

Conceptualisation of ACP in CALD communities

Anecdotal and empirical research evidence has shown that in multicultural countries, such as Australia, there is a lowered uptake and perceived benefits of engaging in ACP, including discussions and planning around end-of-life care and decision making, in people from CALD backgrounds.

There is even a lower prevalence of completion of relevant documentation and forms. Older people from CALD backgrounds and their carer's have a different conceptualisation and understanding of ACP. Some studies have found that ACP is perceived as a 'financial planning process' rather than a 'lifestyle related process', and is most commonly seen as creating a Will, or in some instances extended to include all financial planning for retirement as well as management of superannuation (Cultural & Indigenous Research Centre Australia, 2008, p. 21). It is rarely associated with other components of ACP including discussions around medical treatments when a person is unable to make decision themselves or completion of documentation such as Enduring Power of Attorney, Advance Care Plan/Advance Care Directives and other documentation.

CONSULTATIONS - COMMUNITY REFERENCE GROUPS

ECCV Framework

The project staff established two community reference groups consisting of ECCV project staff. Participants included:

- CEO and staff from service providers - primarily aged care services
- Volunteers in the organisation,
- Board members of the organisation,
- Community leaders - Minister
- Filipino Consul General
- Community members
- ECCV project staff
- These groups age ranged from 30 – 65+ years

In these groups we discussed community perceptions, or misperceptions of advance care planning, as well as culturally specific sensitivities around death, dying, illness and caring.

For many people on these reference groups this was the first time they had actually thought very much about, or discussed advance care planning in any detail. In some cases, participants had never before heard of advance care planning, even those of us who thought we had an idea of what it was, found that we had misperceptions.

These discussions and consultations assisted in the development of the 5 step model of engagement and the communications framework as well as the flyer on advance care planning. The model, framework and resource were tailored to incorporate insights specific to each of the key communities, including: cultural, religious, community and intergenerational perspectives and values, as well as attitudes towards health, illness, caring, death and dying. ***See Appendix B – Community Reference Group Meeting Structure***

FINDINGS FROM THE CONSULTATIONS IN THE FILIPINO COMMUNITY

Advance Care Planning In The Filipino Community

Cultural attitudes relating to illness, death and dying can be a barrier to discussing and initiating a conversation around advance care planning in the Filipino community. There is a strong reluctance to discuss death and dying as it is believed that it may be harmful and contagious to the person. Thinking about, and considering, issues such as death, illness and loss of mental ability was 'bad luck' and could accentuate the like-hood of these things occurring.

> *'It's not easy because of our culture we don't discuss death'.*
>
> *'We trust our older people, our parents, brothers and sisters and death for us is nothing to be talked about - you shush, that's what death is for us'.*

Representatives from the Filipino community organisations have expressed concerns about the limited resources and infrastructure in place to support the emerging ageing population.

> *'Filipinos are ageing in Australia and we are not preparing for the future. While there is an increasing awareness of services there has been no systematic approach in preparing the 55 plus for the future. It is important that we are getting education and information on how to prepare for future care needs of our population.'*
>
> *'We had information sessions in the past year about wills, with 70 or 80 year old plus. They look at the booklet and say "I don't need this". And they would tell me "I don't want to see that again". But recently someone in a clubs is saying can I have it again but we need someone experienced to talk to us'.*
>
> *'Wills, powers of attorney and advanced care planning are not commonly discussed or understood'. Filipinos can be uncomfortable with impersonal bureaucratic systems and processes. Families may not know the obligations associated with powers of attorney and guardianship'.*

Involvement in the project

Participants indicated they wanted to be involved in the project for a variety of reasons, primarily to support their community.

> *'I would like to gain understanding and practice on how to facilitate discussion groups about future planning.'*
>
> *'I want to learn and understand advance care planning, because in my family there is no planning. My mum told me when I was a child, don't worry your aunty will look after you. I don't want to tell my children don't worry, I would like to know what it is in Australia that I can use and understand what advance care is planning.'*
>
> *'I think it's great to have a conversations associated with death and dying it's about making sure that your wishes are going to be respected'*
>
> *'It is very good that we are involved with this advance care planning project especially for Filipinos because it's time for us to accept that our seniors are passing/dying'.*

'I have seen some fight with a property so it is very good that we are now into this project.

Individualistic versus family decision making

Many migrant communities in Australia come from cultures that emphasise the importance of family in decision-making, and the importance of maintaining harmonious relationships where respect and dignity take precedents over any behavior which could threaten these roles. Individuals might feel that communicating their rights and preferences for future medical needs may indicate that they do not trust their family members to be able to make decisions themselves.

'We don't think in individual terms, we always think in terms of the group, family, the tribe, the town'.

'If there is a problem solve it within a family. If there is an accident or heart attack or stroke. Or somebody did something wrong we don't talk about that outside the family, we deal with that inside the family'.

'There is this strong tradition of trusting our own family members and this is whole positive cultural trait but it can lead to making arrangements with a actually discussing the expectation of that person, or planning for things may actually go wrong and getting independently getting financial advice is not so common'.

'If a family members needs assistant and goes to a friend it can brings a lot of conflict, because the person who needs assistant is seen to trust the friend more than a family member which in some situations can be very, very difficult'.

'Within the family situation the trust can go overboard, for example with my mum or dad they say - I trust my oldest daughter or son (usually the oldest person makes the decision for everybody after mum and dad). That person says- Don't worry I got you - but there are different opinions already and if you have somehow got into the Australian way of doing things then there is - oh no this is mine or this is your or I tell you when to do that or don't step on my boundaries-. Trust is fragile and when there is no discussion that trust can be shaken'.

'This really is a huge one. How do you have a conversation when there is understanding that my oldest daughters or my oldest son would just know what I need, what I want and what is important to me, how would they just know'.

'You really need to have an understanding of the family network and once you understand how it is for that family, every single aspect of the family network, then you can go forward'.

'An understanding for the family network is very very primary'.
'And it gets more complicated with blended families'.

'I had a call from Filipinos lady who was so distressed just before Christmas, she said I need to help her because her husband passed away. She is new to Australia, her husband had a stroke and she had to decide about life support, also he donated his

organs to hospital and they won't allow her to see him or have a funeral. She asks me what am I going to do'.

'The pain this causes and the conflict, imagine having to turn the life support off or not, but if we don't do what the person that you love wants then imagine the grief that if you turn it off maybe to the rest of your life you have because you don't know if it was a right thing or not. But if it's written down to turn off the light support then it's not about me it's about me respecting this person that I love and what they want'.

Provision of care - expectations about being looked after in old age

The Filipino elderly are highly respected in the Filipino community and co-reside with their children. It is common for them to support their children by helping them care for their children and help with household while their children are able to care for them.

In Australia most Filipino women aged 60 and above are carers of grandchildren and it is not uncommon for the Filipino society to have three generations living in the same household. Evidence and community consultations suggest there is an expectation for children to alter their lives and take role of a carer for their loved one.

'It is traditional that older are looked after by their children as they reach older in our homes'.

'So you know these are there expectations of being looked after at the old age that is not so much about choosing a nursing home or not'.

'It's also about reputation. If people knew that family wasn't looking after the parents it means I am not a good enough daughter or maybe it means I don't love my mother enough'.

'It's about keeping face and reputation and being seen to do the right things, so even if it's not a best care it's still just keep trying to do that because that's expected. You are not supposed to bring people to do it for you'.

It's always when I get old will you take care of me?
'I think of my mum who says - oh I may go back to Filipinas when I'm old - but it's like, even then its assumed family will look after her. But if she gets a condition or something happens I don't know what she wants, for a funeral or how she wants to be taken care off if something happens, what she wants, but she says - oh you take care of me'.

'It is the most common things, there is an expectation that because I love you and you love me and we are family you will know what I want, what I need and what is important for me and you will do that'.

Religion

In some religions it is believed that God will take care of the person and therefore end of life planning and discussions around advance care planning is not required. Factors such as illness, timing and nature of one's death are felt to be the responsibility of a God rather than the individual, and not something to "plan ahead" (Cultural and Indigenous Research Centre

Australia, 2008). There is a sense that people will view their final outcome as being in God's hand.

> *'Not my role to decide that is God's role - God is the substitute decision-maker'*
> *'Fate is important to most of the community and has to be incorporated in the advance care planning'*
>
> *'In many cases when it comes to dying and grief there are many stages. The young community doesn't follow these stages and most elderly rely on their friends when it comes to this stage of their life'.*
>
> *'Friends are very important when honouring spiritual beliefs because most of the time only they understand the needs of the person dying'.*
>
> *'Not knowing the wishes and the rituals is a problem ….'*
>
> *'It's important for community to know that advance care planning can protect and honour a person's religious believers and values'.*

Migration

Individual's migration experiences have an impact on their attitudes towards advance care planning. Many Filipino women wished to escape the poverty in Philippines and came to Australia under a spouse sponsored visa. The notion of "mail-order bride" and "email-order bride" phenomena can reflect this.

These women are more vulnerable to complex issues around advance care planning, arising from how their marriages were contracted and stereotypes.

In many of the "mixed marriages" understanding of family and the way that family interacts with each other adds a degree of tension in many of the marriages. This can be exacerbated by the outside status of the Filipino women and the age difference between many of the women and their partners.

> *'Lots of woman married non Filipino's, Australian residents. Those women are now in their 60 or 70 and have husband 20 years older than them, nearly in palliative care'.*
>
> *'When it comes to estate, women are told; don't go there; the moment you ask about money and property my trust towards you is diminished'.*
>
> *'When there are children in the marriage from previous relationships, the women are told' don't worry my children already have it, don't worry trust your husband. Then the husband passes away, which is already painful; but then the women are left with no knowledge or access to assets, I have seen this'.*
>
> *'Because the money go to the children, rather than to her'.*
>
> *'I think in a past 10-15 years I have been in this field, I have seen those entire woman who said after 15-20 years I am homeless. I have to rent out. I have no money.*
> *'There is no point us Filipino woman talking about advance care planning with partner if we are not afforded rights and access to assets/estate/money/inheritance'.*
>
> *'It more layered than a Filipino man and Filipino woman, it can still be an issue because the power imbalances, men are kings and the woman keeps the king happy.*

So even then it is hard to Filipino woman to talk to her Filipino husband about advance care planning but this is more complex, the additional considerations are more about Aussie -Filipino framework'.

'It also depends if the woman is sponsored by older men. For the sake of equality it is better to have information for both so they can clarify what the level of openness is'.

GP

'It is possible that a third party, a medical practitioner is a key to release advance care planning information. Filipino women need a third party, someone who understand the wider social issue'.

'The GP has an influence particularly in those situations. It is a start of the conversation, we can't get to it because it is too hard'.

Some other Australians will not let their wives to drive a car, will not let her to participate in this kind of organization because is some organization will power them. That's why they prohibited.

What it doesn't mean

Advance care planning and associated documentation is associated with death planning, many community members think that future planning is death planning.

'Advance care planning is not for people dying it's for everyone'.

'Advance care planning IS NOT about dividing family wealth and property, we have to be very sensitive about the way we present advance care planning so it doesn't look like children are after parent's money'.

'Advance care planning is about strengthening existing plans not overriding them. Advance care planning is for our life, it's not a death treaty, we need to reassure family and friends, talk about the now, what is important to me now and put in action'.

'We are planning for life this is not death wish and is not only for elderly'.

Communication methods

- Flyers
- Booklets
- Use SBS Filipino is always open for interviews.
- Priest to promote advance care planning in churches to open up discussion
- Community education page in newspaper to launch poster

Resources

Project staff provided a range of existing advance care planning information to the community reference group as a guide to identify a resource and key messaging on advance care planning

The examples were from:

- Palliative Care Victoria information flyer
- Northern Hospital advance care planning resource
- Austin Hospital respecting patients choices booklet
- Austin Hospital 'Taking Control of YOUR Health Journey' booklet for indigenous communities
- Chinese Cancer Council, 'My Farewell Wishes'
- 5 Wishes Australia Booklet

Austin Hospital 'Taking Control of YOUR Health Journey' booklet for indigenous communities was identified as a very good resource, due to it being colorful and visual, there was not a lot of identification with the messaging in this booklet. Instead community members developed 5 key messages specific to the Filipino community.

Participants from the community reference groups suggested developing a flyer introducing advance care planning in Filipino based on the Northern Hospital 'conversation bubbles flier' and promote it as a prelude to a more in-depth resource. Northern Hospital's flyer was identified as a great preliminary resource to incorporate the key messages about advance care planning to begin conversations about advance care planning. ***See Attachment A & B – Filipino flyer - advance care planning***

FINDINGS FROM THE CONSULTATIONS IN THE MACEDONIAN COMMUNITY

Advance care planning in the Macedonian community

Advance care planning is not a well-known concept in the Macedonian community, there is limited knowledge and awareness of the concept of and what information is out there are misconceptions of advance care planning being associated with death and dying and giving up hope.

> *Death is very rarely spoken about outside the family home, especially in cases where a person is diagnosis with cancer'.*
>
> *'When my father came few years ago and saw commercial on television about choosing your funeral insurance he asked me to change the channel'.*
>
> *'If you talk about death it will come earlier. Don't mention it because it is going to come quicker. We younger generation are telling them life is changing and we need to be prepared'.*
>
> *'We don't want to talk about death, it hurts when we thing about the people we love dying. To talk about the benefit of the advanced care planning we have to find way to make this topic gentle'.*

Involvement in the project

Macedonian Community Welfare Association (MCWA) is very interested in participating in a project that will raise awareness and knowledge about advance care planning. Macedonian seniors are continuing to request information on topics such as their health and assets outside of the information received from their family and friends that may not have all the correct information.

'Everyone has different opinion on what you should do when its end of life and people might say you should do this or that and how you could have done that. But if I have the advanced care plan and know what my parents wants it is so much easier to deal with the whole process. It helps with family cohesion when it is clear what the person wants.''
'Becoming more aware of the meaning of advance directives'.

'Gaining knowledge and expertise in Advance Care Planning and advanced directives'.

'Disseminating consistent messages to the community and MCWA clients on this topic that will assist community members to make informative decisions and make own choices when it comes to medical, social or physical decisions'.

'In the past we had a project and developed resource about death and dying. I am looking forward to be part of the reference group'.

I work as access and support officer full time. I work directly with the elderly and very often one of the questions I ask is do you have power of attorney or guardian. Many people only know about wills'.

'I said to my mother I am going to do my will and she asked me if I am hiding something or if I am sick'.

'I had an uncle who lived in Australia 43 years and never went back to Macedonia. He has wife and son in Macedonia however he had an affair with other lady in Australia and had another child, a son. We had good relations he was visiting us casually. One year ago he passed away. He passes away in the hospital. I started the process to organize his funeral. He was at the hospital for one month after death. I took my cousin from Macedonia and start the process for the estate. Then I found out that my uncle only recognised his son in Australia for the estate. I was questioning if I was doing the right thing helping my cousin from Macedonia and getting my self-involved. When I found out about advanced care planning I was thinking how helpful would have been in this situation.
I found out from my uncles friends that his last wish was to give his son in Macedonia the power of attorney and sell all the property and give all the money to him. I felt relieved. I think ACP is amazing and will be solution for many people. I am not sure how people in our community will accepted this process but this is good choice to know about'.

Individualistic versus family decision making
Macedonians tend to rely on the extended family for support and problem solving and there is a general reluctance by Macedonians to go outside of these networks for support.
Macedonian families prefer to be informed first of the diagnosis and then decide if the ill person should be told. In those cases it might be the eldest son who would tell his parents of the diagnosis. However, attitudes to this issue are changing and this question should be discussed with the family to ascertain their views. Every family is different and if the patient wishes to know, the patient's wishes are paramount.

'Immediate family is most important but what is the definition of immediate family in different cultures (aunty uncles). Its culturally sensitive planning from the beginning before the planning goes further'.

'My father says he will leave me to inherit everything after his death and not include my brother. I refused this and we had a family meeting to discuss the decisions dad wants to make'.

'My mother wants to leave everything to my brother she thinks he should inherit everything because he is the male in the family which is not fair and is discrimination'.

'Cultural expectations (family members are responsible of the client's care), contrary on this, families often feel burdened by the concern that they will make a wrong choice not knowing the wish of their love ones'.

Provision of care - expectations about being looked after in old age

Traditionally in Macedonia it is the responsibility of the family to care for their older family members. They perceive this as their children's obligations because they came to Australia to provide a better life for them and if their sons and daughters don't take care of the parents in time of need it may be viewed as betrayal.

'Elderly Macedonians who migrated to Australia still have high expectations from their children and expect children to care for them'.

'Families remain the main support networks for elderly Macedonians and there is reluctance to seek help outside the extended family'.

Religion

Religion still plays a significant role in the Macedonian community, for older Macedonians whose experience may have been life in a communist country, their religion is culturally ingrained. Church groups and networks may be particularly important to the older generation who were instrumental in establishing the church in Australia.

'Religion is a stronger influence with older Macedonians than with the younger generation'.
'We place a high importance on talking to the priest'.

'We should have education sessions for our priest'

Migration

'The way the young people see the world is different to the way their grandparents see it maybe their children don't believe in the orthodox religion and may not organize their parent's funeral by the old traditions and customs. There is such an intergenerational separation'.

GP

'Talking to doctors about advance care planning is important'.

'Speak to your doctor, the biggest focus is medical treatment'.

Communication methods

MCWA sees this as an opportunity for advance care planning coordination and thinks that one trained professional should be leading the advance care plan for individuals using aged care services.

'Community awareness education and employee who can facilitate the advance care plans should go parallel'.

'Especially because there is no body to represent this idea it is critical to have workers who will know to explain advance care planning'.

MCWA suggested there could be training, for example a Certificate 3 & 4 with units of competency to provide advance care planning support, maybe a pilot project trialing staff position for advance care planning at MCWA, the organisation already works in partnership with a training organisation.

''This sort of conversation should be led by someone who speaks the language and know the culture''

Resource

Project staff provided a range of existing advance care planning information to the community reference group as a guide to identify a resource and key messaging on advance care planning

The examples were from:

- Palliative Care Victoria information
- Northern Hospital advance care planning resource
- Austin Hospital respecting patients choices booklet
- Austin Hospital 'Taking Control of YOUR Health Journey' booklet for indigenous communities
- Chinese Cancer Council, 'My Farewell Wishes'
- 5 Wishes Australia Booklet

The Austin Hospital 'Taking Control of YOUR Health Journey' booklet for indigenous communities was identified as a very good resource to talk about advance care planning. There were strong similarities identified between Aboriginal and Macedonian cultures and this was recognised as the best way to convey key information messages to disseminate information and the most relevant delivery mechanism and in the Macedonian community.

'This is a brilliant resource'.

'Strong correlation between Macedonian and Aboriginal culture'.

'Good trigger to prompt people to the right decisions pathways'.

Participants from the community reference groups suggested developing a flyer introducing key messages about advance care planning in language and to promote it as a prelude to a more in-depth resource. The Northern Hospital's 'conversation bubbles flier' was identified as a great preliminary resource to incorporate the key messages about advance care planning to begin conversations about advance care planning. ***See Attachment C & D – Macedonian flyer - advance care planning.***

RECOMMENDATIONS

5 step approach to increase awareness and understanding of advance care planning in CALD communities

This report recommends the following 5 step model and communication framework in order to increase awareness and understanding of advance care planning in the Macedonian and Filipino communities.

Successful in-depth consultation with the Macedonian and Filipino community ascertained the current understanding of advance care planning in the targeted communities, it identified cultural beliefs and values that needed to be considered when initiating conversations about advance care planning and it developed culturally relevant key messages for each of the communities. Consultation also provided what key communication methods were needed to disseminate the information using a suite of delivery mechanisms; based on specific sub-groups within each community.

The model identifies five strategic steps to engage with culturally and linguistically diverse communities. This approach ensures culturally sensitive and appropriate delivery of information about sensitive topics such as advance care planning. This approach would be pertinent in any culturally and linguistically diverse community.

The Model


OUTCOME
INCREASE UPTAKE OF ADVANCE CARE PLANNING IN CULTURALLY AND LINGUISTICALLY DIVERSE COMMUNITIES
STEP 5 - COMMUNICATIONS FRAMEWORK
• Key communication approaches
STEP 4 - KEY COMMUNICATION MESSAGES
• Identify the key messages
STEP 3 - CULTURAL CONSIDERATIONS
• Identify cultural beliefs & values
STEP 2 - PARTNERSHIP & CONSULTATION
• Partner with multicultural and ethno specific organisations
• Instigate consultation with key stakeholders
STEP 1 - RESEARCH AND DATA
• Community profile Literature
• Review of existing resources and programs
OBJECTIVE
INCREASE AWARENESS AND UNDERSTANDING OF ADVANCE CARE PLANNING IN CALD COMMUNITIES

5 STEP APPROACH			
INCREASE AWARENESS AND UNDERSTANDING OF ADVANCE CARE PLANNING IN FILIPINO COMMUNITY			
Step 1 **Research & Data**	Literature Review of existing resources and programs on advance care planning Develop a community profile to build an understanding of the demographic & cultural profile	Build on existing knowledge of topic	Filipinos are an "emerging ageing" community.
		Size of community	At 2011 Census there were 37,957 Philippines-born persons in Victoria, increasing from 27,337 (39%) from 2006 Census.
		Migration history	1st/2nd generations
		Ageing population	Within the Filipino community there are 2000 persons over 60 years old
		Literacy & Health literacy	Anecdotal information that there is a move to the mother tongue in older age
		Religious composition of communities	Catholic
		Preferred languages spoken	Tagalog & English
Step 2 **Partnership & Consultation**	Identify and approach relevant individuals and organisations from multicultural and ethno specific organisations	Approach key stakeholders	
		Convene in-depth consultation with key stakeholders	
Step 3 **Cultural considerations**	Identify cultural beliefs & values	What are the considerations when initiating conversations about advance care planning	Individualistic versus family decision making Provision of care - expectations about being looked after in old age. Religion Migration experience What it doesn't mean
Step 4 **Key communication messages**	Cultural sensitive framing of advance care planning	Preparation for unexpected life events	
		Family/friend conversations	
		Peace of mind to secure your wishes	
		Honour religious beliefs	
		Support family unity in challenging times of loss and grief	
Step 5 **Develop a communications framework**	Key Communication Methods	Identify a suite of delivery mechanisms	

Target Population & Key Messages	COMMUNICATIONS FRAMEWORK –FILIPINO COMMUNITITY										
	Delivery mechanism's										
	Written Materials			Community Education				Formal Media			
	Posters/Postcards	Resource Kits	On-line Versions	Service Providers	GP's	Religious leaders	Bilingual Health Educators	Ethnic Press	Ethnic Radio	Main stream Press	Main stream Press
Frail aged 65 +	✓			✓	✓	✓			✓		
Active seniors 65 +	✓			✓					✓		
Adult children 45 + (carers)		✓	✓	✓	✓		✓			✓	
General population 45 +	✓	✓	✓						✓		✓

5 STEP APPROACH			
INCREASE AWARENESS AND UNDERSTANDING OF ADVANCE CARE PLANNING IN MACEDONIAN COMMUNITY			
Step 1 **Research & Data**	Literature Review of existing resources and programs on advance care planning Develop a community profile to build an understanding of the demographic & cultural profile	Build on existing knowledge of topic	Macedonians are an "emerging ageing" community.
		Size of community	At 2011 Census there were 37,957 Macedonian-born persons in Victoria, increasing from 27,337 (39%) from 2006 Census.
		Migration history	1st/2nd generations
		Ageing population	Within the Macedonian community there are 2000 persons over 60 years old
		Literacy & Health literacy	Anecdotal information that there is a move to the mother tongue in older age
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Step 2 **Partnership & Consultation**	Identify and approach relevant individuals and organisations from multicultural and ethno specific organisations	Approach key stakeholders	
		Convene in-depth consultation with key stakeholders	
Step 3 **Cultural considerations**	Identify cultural beliefs & values	What are the considerations when initiating conversations about advance care planning	Individualistic versus family decision making Provision of care - expectations about being looked after in old age. Religion Migration experience What it doesn't mean
Step 4 **Key communication messages**	Cultural sensitive framing of advance care planning	• Decrease the vulnerability of the older people and give them control over their future.	
		• Provide a peace of mind by making wished known	
		• Give family consent to make difficult decisions	
		• Assist family/carer to provide the best possible care possible	
Step 5 **Develop a communications framework**	Key Communication Methods	Identify a suite of delivery mechanisms	

Target Population & Key Messages	COMMUNICATIONS FRAMEWORK – MACEDONIAN COMMUNITITY										
	Delivery mechanism's										
	Written Materials			Community Education				Formal Media			
	Posters/Postcards	Resource Kits	On-line Versions	Service Providers	GP's	Religious leaders	Bilingual Health Educators	Ethnic Press	Ethnic Radio	Main stream Press	Main stream Press
Frail aged 65 +	✓			✓	✓	✓	✓	✓	✓	✓	
Active seniors 65 +	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	
Adult children 45 + (carers)	✓	✓	✓	✓	✓		✓	✓	✓	✓	✓
General population 45 +	✓	✓	✓	✓	✓			✓	✓	✓	✓

APPENDICES

Appendix A - List of Advisory Group

- Colleen Pearce (Chair) – Public Advocate, Office of the Public Advocate
- Zoe-Austin Crowe – Project officer, Department of Health VIC
- Bill Barger, Ambulance Victoria
- Anthony Bartone, AMA Victoria
- Sam Brean, Advance care planning program, Eastern Health
- John Chesterman, Policy and Education, Office of the Public Advocate
- Charlie Corke, intensive care physician, Barwon Health
- Nicole Doran, Manager, Dept. of Health & Human Services VIC
- Barbara Hayes, palliative care physician, Northern Health
- Jackie Kearney – Manager, Dept. of Health & Human Services VIC
- Dr Lisa Mitchell - Geriatrician, Royal Melbourne Hospital
- Dr Julie Moran - Palliative Medicine, Austin Health
- Lisa Pearson - advance care planning program, Goulburn Valley Health
- John Rasa – CEO, Networking Health
- A/Prof Bill (William) Sylvester, Respecting Patient Choices, Austin Health

Appendix B – Community Reference Group (CRG) Meeting Structure

Meeting 1: **Introduction to the project and review existing knowledge of advance care planning**

- Introduction of CRG members/Project overview and project milestones
- Review what is known about advance care planning
- Identifying key issues around advance care planning.

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Info session: **Provide professional education session relating to advance care planning**

- Overview of Advance Care Planning by representatives from Northern Health, Austin Hospital and/or Office of the Public Advocate/legal representative

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Meeting 2: **Develop appropriate messages about advance care planning & review existing resources with CRG to identify any resources suitable for the community.**

- Review of existing advance care planning resources
- Discuss and explore gaps in the existing resources/suggestions for messaging
- Explore how to best develop resources (design, key message, format, delivery method)

↓

Meeting 3: **Identify the most appropriate advance care planning approach to raise awareness of advance care planning.**
Discuss evaluation of project/methodology

- Develop a strategy to talk to community about advance care planning.
- Seek input as to ways of collecting data to evaluate the impact of this project.

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