Increasing community awareness of Advance Care Planning

Report

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cohealth

Merri Health

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AIM

The aim of this project was to deliver age and culturally appropriate information about Advance Care Planning (ACP) to local community groups of older or culturally and linguistically diverse individuals across nine Local Government Areas in the north and west of Melbourne.

METHOD

DESIGN

A short presentation on ACP was delivered to local community groups of older or culturally and linguistically diverse individuals. This was session one. Participants were invited to complete a questionnaire comprising pre and post questions to evaluate session one. See Appendix A for the session one questionnaire.

A small number of these local community groups were then revisited and participants were invited to complete a second questionnaire exploring behaviour change inclusive of ACP conversations and completion of written Advance Care Plans. This was session two. See Appendix B for the session two questionnaire.

DATA ANALYSIS

Quantitative data from the session one and session two questionnaires were collated and analysed. Qualitative data were analysed thematically.

RESULTS

SESSION ONE

ATTENDANCE

A total of 58 groups comprising 1068 participants attended the session one ACP presentation. Attendance in session one groups ranged between 2 - 50 participants.

SAMPLE

Participants comprised community based individuals attending local community groups across the nine Local Government Areas. A total of 278 participants completed the session one questionnaire – giving a response rate of 26%.

Local Government Area by group

Session one groups by Local Government Area in Table 1 below.

Table 1. Session one by Local Government Area

	n	%
Brimbank	8	14
Maribyrnong	3	5
Moreland	9	16
Yarra	8	14
Darebin	9	16
Hobsons Bay	4	7
Melbourne	10	17
Moonee Valley	4	7
Wyndham	3	5
Total	58	100

This project delivered session one to 58 local community groups, across nine Local Government Area's in the north and western suburbs of Melbourne.

Partner organisations

This project was supported by a partnership with cohealth and Merri Health. Session one groups were recruited from cohealth, Merri Health and local community groups coded as 'other'. Session one groups by partner organisation in Table 2.

Table 2. Session one by partner organisation

	n	%
cohealth group	19	33
Merri Health group	9	16
other	30	52
Total	58	100%

Results indicate that just over half of the session one groups were recruited from local community groups – that were not cohealth or Merri Health groups.

Of the session one groups 59% (n=34) were culturally and linguistically diverse groups. Interpreters were used in 48% of the groups (n=28), indicating that some CALD groups did not require an interpreter.

Session one attendance and pre and post questionnaire

Session one groups by attendance and number of participants in each group completing a pre and post questionnaire are detailed in Table 3 below.

Table 3. Session one attendance and questionnaire completions

	Attendance session one		Completed pre and post questionnaire	
Group name	n	%	n	%
West Sunshine walking group	8	1	8	3
Afghani/Iranian Community group	6	1	4	1
Older Italian Fri Brunswick	14	1	6	2
English Ladies Fri Brunswick	19	2	12	4
Aus Yugoslavian Pensioners	33	3	10	4
Bone Boosters	16	1	5	2
Young people ID	20	2	2	1
Older Italian Mon Brunswick	10	1	4	1
Older Italian Fri Glenroy	12	1	12	4
cohealth Fri community	8	1	8	3
Turkish Womens	7	1	6	2
Strong Leaves	33	3	20	7
English Ladies Mon Glenroy	20	2	5	2
Older Men Thurs Brunswick	8	1	2	1
Older Mixed Thurs Brunswick	11	1	3	1
Chinese carer Fri Kensington	16	1	10	4
Westvale Mens Shed	16	1	5	2
Kensington Mon Chinese Seniors	42	4	2	1
Church of All Nations Wed	15	1	4	1
Chinese Wed North Melbourne	29	3	2	1
Flemington Chinese Seniors Thurs	26	2	3	1
OPHR Mon Flemington	5	0	5	2
Somali Thurs Collingwood	5	0	5	2
Deer Park Senior Citizens	45	4	2	1
Vietnamese Elderly Collingwood	14	1	6	2
OPHR Fri Kensington	2	0	2	1
OPHR Thurs Carlton	9	1	3	1
Indian Friendship group	45	4	19	7
Chinese Friendship group	15	1	6	2
English Language Duke Street	16	1	2	1
Chinese Thurs high rise North Melbourne	14	1	6	2
Vietnamese Chinese Seniors Fri Ascot Vale	50	5	10	4
Stronger Living exercise Niddrie	4	0	3	1
Older Mixed Thurs Glenroy	12	1	3	1
STACC group	22	2	3	1
Italian Social Mon Preston	22	2	5	2
Shine	8	1	1	0
OPHR Thurs Williamstown	10	1	3	1
Mandarin Older and Active Reservoir	8	1	3	1
Vietnamese Elderly Wed Kensington	31	3	4	1
CALD Horn of Africa Seniors group	42	4	3	1
Laverton Probus Club	38	4	3	1

Rec West exercise group Pryme movers	11	1	0	0
PANCH mixed Thurs group	19	2	4	1
Rushall Park	11	1	4	1
OMNI Span House	16	1	3	1
PAG STACC	20	2	5	2
PANCH Ladies Fri	28	3	2	1
Gateway Williamstown	14	1	4	1
Preston Reservoir Indochinese elderly	41	4	5	2
German aged Westvale	13	1	3	1
Indochinese Elderly Refugees Friday	16	1	3	1
Mandarin Diabetes support group	11	1	2	1
Indochinese Elderly Refugees Thursday	16	1	3	1
DIVRS	7	1	0	0
SPAN community group	2	0	2	1
Indochinese Elderly Refugees Monday	27	3	5	2
Darebin Life Activities Club	30	3	3	1
Total	1068	100%	278	100%

^ Note. No pre or post evaluation data was collected from participants in the Pryme Movers or DIVRS group.

Attendance numbers at the session one groups varied greatly with 12% of groups recording attendance of 35 participants or over. Of the session one groups, two groups were attended by only two participants each. Both of these groups were advertised sessions inviting community members to attend but were not linked to an existing community group. This finding reinforces the usefulness of linking in with existing community groups.

Pre and post evaluation data was collected from 56 out of 58 of the session one groups (97%). Due to time constraints no pre or post evaluation data was collected from participants in the Pryme Movers exercise group or the DIVRS group (Darebin Information Volunteer Resource Service).

Of note, is that no more than 7% of the sample who completed a pre and post evaluation came from one community group. This suggests the pre and post evaluation data came from a wide range of groups.

Demographics

Session one demographic data is detailed in Table 4 below.

Table 4. Session one demographics

	n	*%*
Gender		
Male	88	32
Female	190	68
Total	278	100%
Age		
20 - 29	5	2
30 - 39	5	2
40 - 49	8	3
50 - 59	17	6
60 - 69	71	26
70 - 79	69	25
80 - 89	88	32
90 - 99	14	5
100 - 109	1	0
Total	278	100%
Local Government Area live		
City of Melbourne	34	12
Moreland	47	17
Moonee Valley	23	8
Maribyrnong	25	9
Brimbank	33	12
Darebin	23	8
Wyndham	32	12
Hobsons Bay	16	6
Yarra	28	10
Banyule	5	2
Melton	3	1
Casey	2	1
Hume	2	1

Frankston	1	0
Whitehorse	1	0
Boroondara	1	0
Whittlesea	2	1
Total	278	100%
Region of birth		
Asia	126	45
Australia	74	27
Europe	64	23
Africa	11	4
South America	1	0
Oceania	2	1
Total	278	100%
Main language		
English	98	35
Vietnamese	48	17
Mandarin	29	10
Italian	25	9
Cantonese	17	6
Punjabi	10	4
Gujarati	9	3
Somali	8	3
Serbian	7	3
Turkish	6	2
German	5	2
Dari	4	1
Croatian	2	1
Arabic	1	0
Filipino	1	0
Malaysian	1	0
Maltese	2	1

Macedonian	2	1
Indonesian	2	1
Cambodian	1	0
Total	278	100%
Income		
Pensioner	200	73
Government payments (ie Centrelink)	25	9
Employee	17	6
Visitor visa	17	6
Self funded retiree	11	4
Self employed	2	1
None	1	0
Total (Missing = 5)	273	100%

Results indicate that of those who completed an evaluation 62% were aged 70 years of age and over – while 37% were aged 80 years of age and over. More than two thirds of participants (68%) were female. The largest percentage of participants lived in the Local Government Areas of Moreland (17%), Brimbank, (12%), City of Melbourne (12%) and Wyndham (12%). Forty five percent of participants were born in Asia. The main language spoken by participants was English (35%) and Vietnamese (17%). While more than a third of the sample nominated English as their main language – this project involved participants citing nineteen languages other than English as their main language.

The overwhelming majority of participants were pensioners (73%). Of note is that only a small percentage of participants (4%) identified as self funded retirees. Future projects may consider exploring how self funded retirees access information about Advance Care Planning.

Heard about ACP

Session one participants were asked 'Have you ever heard before today about Advance Care Planning?' and 'Has any health professional ever talked to you about Advance Care Planning?'. Results are detailed below in Table 5.

Table 5. Ever heard or talked to about ACP pre session

	Yes		*No*	
(n = 276)	*n*	*%*	*n*	*%*
Have you ever heard before today about Advance Care Planning?	62	22	214	78
Has any health professional ever talked to you about Advance Care Planning?	42	15	234	85

Note. Missing = 2

Results indicate that of those who completed an evaluation, 214 participants had not ever heard of ACP. Additionally, 20 participants had heard about ACP but had not heard about it through a health professional. Some participants were then asked if they recalled how they had heard about ACP. Responses indicated that those who heard about ACP, other than through a health professional, heard about this through a range of sources:

> Read about ACP on the internet. No health professional talked to me about this. (Vietnamese Elderly Collingwood)

> I heard about it on the radio. (Vietnamese Elderly Wed Kensington)

> My family is medical and talked to me about this plan. (Gateway Williamstown)

> Someone from the Office of Public Advocate spoke to our group one year ago about this. (German Aged Westvale)

Future projects may consider exploring why some community based individuals are not hearing about ACP through a health professional.

Knowledge of ACP pre session

In the session one questionnaire participants were asked to rate their level of agreement with a number of statements relating to their knowledge of Advance Care Planning *before* attending this presentation. Response options were “Strongly Disagree”, “Disagree”, “Uncertain”, “Agree” and “Strongly Agree”. Results are detailed in Table 6.

Table 6. Session one agreement with pre statements about Advance Care Planning

	Strongly Disagree		Disagree		Uncertain		Agree		Strongly Agree	
	n	*%*	*n*	*%*	*n*	*%*	*n*	*%*	*n*	*%*
I understand what Advance Care Planning is #	17	6	177	64	15	5	63	23	3	1
I understand why it may be useful to have an Advance Care Plan^	15	5	176	64	10	4	64	23	9	3
I feel able to think about my values, beliefs and preference about my future health care^	17	6	163	59	14	5	69	25	11	4
I understand how an Advance Care Plan may be used if I cannot make or communicate my decisions^	15	5	179	65	11	4	63	23	6	2
I feel confident to talk to my family or friends about Advance Care Planning^	12	4	169	62	12	4	62	23	19	7
I understand what a medical decision maker is in Advance Care Planning^	11	4	161	59	10	4	76	28	16	6
I feel confident to talk to my doctor about Advance Care Planning^	13	5	179	65	12	4	56	20	14	5
I know who to ask if I have questions about Advance Care Planning^	11	4	180	66	16	6	58	21	9	3

Note. Some percentages do not total 100% due to rounding off.
Missing = 3 ^ Missing = 4

The majority of participants before the session one presentation did not understand ACP (70%), how it may be useful (69%) or how it may be used (70%). While more than a third (34%) understood what a medical decision maker was, the majority did not feel confident talking to family and friends (66%) or their doctor (70%) about ACP before session one.

Before session one the majority (65%) did not think about their values, beliefs and future health care preferences. In response to this question an individual participant stated:

Never thought of it. It is not part of our culture. (Chinese Friendship Group)

This response indicates that cultural factors may influence some participant's awareness or beliefs regarding planning for future health care.

Knowledge of ACP post session

In the session one questionnaire participants were asked to rate their level of agreement with a number of statements relating to their knowledge of ACP *after* attending this presentation. Response options were "Strongly Disagree", "Disagree", "Uncertain", "Agree" and "Strongly Agree". Results are detailed in Table 7.

Table 7. Session one agreement with post statements about Advance Care Planning

	Strongly Disagree		Disagree		Uncertain		Agree		Strongly Agree	
	n	*%*	*n*	*%*	*n*	*%*	*n*	*%*	*n*	*%*
I understand what Advance Care Planning is#	1	0	6	2	16	6	215	79	34	13
I understand why it may be useful to have an Advance Care Plan#	1	0	5	2	10	4	218	80	38	14
I feel able to think about my values, beliefs and preference about my future health care^	1	0	5	2	25	9	202	75	38	14
I understand how an Advance Care Plan may be used if I cannot make or communicate my decisions#	2	1	7	3	18	7	210	77	35	13
I feel confident to talk to my family or friends about Advance Care Planning#	4	1	14	5	22	8	146	54	86	32
I understand what a medical decision maker is in Advance Care Planning#	1	0	7	3	19	7	190	70	55	20
I feel confident to talk to my doctor about Advance Care Planning#	1	0	11	4	19	7	147	54	94	35
I know who to ask if I have questions about Advance Care Planning^	2	1	7	3	15	6	200	74	47	17

Note. Some percentages do not total 100% due to rounding off.
Missing = 6 ^ Missing = 7

Findings indicate that after attending the session one presentation more than 90% of respondents understood what ACP was (92%), why a plan may be useful (94%) or how it may be used (90%). The overwhelming majority (90%) reported after session one that they now understood what a medical decision maker is. Further, the majority reported feeling confident talking to their family and friends (86%) or doctor (89%) about this issue. This is reinforced by the following participant quotes:

> This is not difficult to talk to doctors about. (Mandarin Diabetes Support group)

> Very nice doctor. I can talk to my doctor. (Indochinese Elderly Refugees Thursday)

> I talk to my kids. Yes very confident talking to my doctor. (Preston Reservoir Indochinese Elderly)

While the majority reported feeling comfortable talking about this issue after session one, a small number still did not feel comfortable talking to family and friends (6%) or their doctor (4%) about this. This finding is supported by the following qualitative data:

> Would feel confident talking to my psychologist but not my doctor. (Deer Park Senior Citizens)

> No. I don't have a doctor I trust enough. (Mandarin Older and Active Reservoir)

The first participant indicated a willingness to talk to another health professional about ACP but not her doctor. With the second participant issues around lack of trust hindered his willingness to talk about this issue with a doctor. These findings support the concept of an ACP team-based model that includes health professionals such as nurses, social workers, allied health professionals and medical staff (Dixon and Knapp, 2018). While team-based models offer a cost effective alternative to entirely physician led ACP, this shared approach has the potential for increasing consumer choice around who they talk to about ACP and enhancing accessible healthcare. Future projects may give consideration to development and piloting a tailored ACP team-based model in the community setting.

> My doctor is so busy. (PANCH Ladies Fri)

> Vietnamese family doctor is so busy. They don't have time to fill in the form. (Vietnamese Elderly Wed Kensington)

Results indicate that individuals reported a perceived “busyness” of the doctor for not feeling confident talking to their doctor about ACP. In addition, feedback from a few individuals highlighted a perception that some Vietnamese speaking doctors were too busy to fill in these forms. This reinforces findings that physicians report lack of time as a barrier to ACP (Dingfield & Kayser, 2017; Dixon & Knapp, 2018; Patel et al., 2012). Further exploration around why some individuals don’t feel confident talking to their doctor about ACP may be warranted.

Take action

Attendance at session one prompted a number of participants to detail action they planned to initiate as a result of this presentation. This is highlighted in the qualitative data below:

> Have already done so but will review. (cohealth Fri community group)
>
> I am seeing my doctor next week. I will definitely talk to him about this. (Shine group)
>
> I will do it. I will talk to my children. (Indochinese Elderly Refugees Friday)
>
> After this I will ask my kids about this. Yes I will talk to my doctor. (Indochinese Elderly Refugees Monday)

This suggests that attendance at the session one presentation prompted a small number of participants to plan action regarding ACP. Two of these four participant quotes indicate a willingness to discuss this issue with their children. Our findings supports research by Lum et al., (2017) that found individuals can be motivated to participate in ACP by a desire to discuss this with family.

Level of understanding

Session one participants were asked ‘How much did you understand in today’s presentation?’. Results detailed in Table 8 below.

Table 8. Level of understanding session one

	Nothing at all		Not much		Some		Most		All	
(n = 272)	*n*	*%*	*n*	*%*	*n*	*%*	*n*	*%*	*n*	*%*
How much did you understand in today's presentation?	2	1	11	4	38	14	89	33	132	49

Note. Missing = 6

The results found that the majority of participants understood 'All' (49%) or 'Most' (33%) of session one. These findings are supported by qualitative data highlighting level of understanding, relevance of this session and individual learnings.

> I am very happy I came today. I have not heard of this topic in the past. I have learnt a lot. (Chinese Thurs high rise North Melbourne)

> Your explanation through the interpreter was 1000%!! You speak slow so very interesting for the people. (Vietnamese Chinese Seniors Fri Ascot Vale)

> It was very clear. I understand perfectly. (STACC group)

> It was a good meeting for me. It helped me. (STACC group)

> Very clear. Very good. (Mandarin Older and Active Reservoir)

> Fully understood this. (Indochinese Elderly Refugees Thursday)

> First time hearing this information. (Preston Reservoir Indochinese Elderly)

> It's very important for me. (Preston Reservoir Indochinese Elderly)

Of the two that reported understanding 'Nothing at all' – one participant advised he did not understand the presentation as he spoke Cantonese and no Cantonese interpreter was present during this talk.

Further analysis on those not confident talk to doctor

Participants were asked how confident they felt talking to their doctor about ACP after attending session one. Those participants who 'Strongly disagreed', 'Disagreed' or felt 'Uncertain' talking to their doctor about ACP after attending session one were then selected (n = 31). Further analysis then examined how much this subgroup understood in session one. Results are detailed in Table 9.

Table 9. Level of understanding those not confident talk to doctor

How much understand	n	%
Nothing at all	2	6
Not much	3	10
Some	10	32
Most	11	35
All	5	16
Total	31	100%

Findings indicate that of those who 'Strongly disagreed', 'Disagreed' or felt 'Uncertain' talking to their doctor about ACP after session one – 51% understood 'Most' or 'All' of session one. These results suggest that lack of understanding about ACP may not be a factor for at least half of this cohort regarding their reluctance to talk to their doctor about ACP. Of note is that 68% of this subgroup reported Asia as their region of birth, compared to 45% born in Asia for the whole sample group.

What would stop you talking about this?

During session one group participants were asked 'What would stop you from talking about this [ACP]? A range of responses were offered from the group. Qualitative data were coded thematically and outlined below.

Some participants viewed ACP as a future concept that may not be relevant to their current situation and may stop people talking about this:

> Might think things will only happen in the future – not now. (cohealth Community group)

> You might feel like you're 21 on the inside and you're actually 94 on the outside. And you think it won't happen to you. (Older men Thursday Brunswick)

Conversely one participant reported this as an issue best addressed in the current rather than in the future.

> Better to talk about this now rather than in the future when we are unwell. (Chinese Thursday high rise North Melbourne)

Others voiced concern about worry or stress as to why they may not talk about this issue:

> If I talk about this it might worry them [the children]. (Merri Health Glenroy Ladies)

> I don't want my children to worry about me so I don't talk to my children about this. (Indochinese Elderly Refugees Thursday)

> I might cause stress. (Mandarin Older and Active Reservoir)

> I might worry that I am a burden to others. (Older person high rise Mon Flemington)

Our findings suggest that some participants worried that talking about ACP might cause stress or be a burden. These results contrast with the literature that indicates ACP discussions can decrease stress and the burden for caregivers (Dingfield & Kayser, 2017).

In addition one participant reported that in his culture he had a responsibility to the family and this would stop him talking about this issue (Indian Friendship group).

Some participants voiced concerns that if they talked about this issue it may lead to unwanted consequences:

> I might not have a choice where I go after I am sick. (Merri Health Glenroy Ladies)

> Fear of loss of independence. (Older Person high rise Thursday Carlton)

> I worry if I talk about this they will send me to aged care [residential facility].

> If I fill this plan in, can it be used to move me into a nursing home? I want to stay living in my own home. (Indochinese Elderly Refugees Thursday)

> This might be used to make me move from where I live and to live in a nursing home. (Mandarin Older and Active Reservoir)

Some reported talking about this issue may trigger uncomfortable feelings:

> Shyness (Older men Thursday Brunswick)

> Scared (cohealth Community group)

> Pride (STACC group)

> Fear (STACC group)

> Shame

> Lack of confidence

> Embarrassment (STACC group)

I might feel embarrassed. (Older person high rise Mon Flemington)

In contrast others suggested that a feeling of embarrassment would not stop them talking about this:

Nothing to be embarrassed about. (Mandarin Diabetes Support group)

Others reported that lack of trust, understanding or differing viewpoints may stop them talking about this issue:

Trust. If I felt I couldn't trust the other person. (German aged Westvale)

They [the family] might not understand. (Older mixed Thurs Glenroy)

If I thought the other person might have a different viewpoint of what I have. (OMNI)

In a community group male participants talked about how they were raised may impact on their willingness to talk about some issues (Older men Thursday Brunswick). One participant reported that when he was growing up he was told 'big boys don't cry' and that made him feel he shouldn't talk about certain issues and he should hide his feelings. Another participant stated: "Yes we were given those messages but now we know that it is wrong. It is okay to cry." (Older men Thursday Brunswick)

Others voiced concerns that if they talked about this issue the family may not be willing to engage or try to stop the conversation:

If you talk about this with the family they will say 'oh we don't want to talk about that'. (Westvale Men's shed)

If I try to talk to the kids about this they say 'stop talking about this'. (Deer Park Senior Citizens)

> The children stop you talking. (Williamstown Thurs OPHR)

> They [the family] might just talk on top of you. (Older mixed Thurs Glenroy)

> The children don't want to listen. (Italian Social Club)

> Communication with the children is difficult. (Williamstown Thurs OPHR)

> I think the family might just brush it [the conversation] off.

> The children say 'Oh you'll be alright'.

Future projects may consider further exploration of the barriers to communication about ACP between adult children and their parents.

A couple of participants reported how cultural factors may impact on their willingness to discuss future plans for individuals or family:

> In our culture from an early age we make a plan who would be in charge if something happened to me. (Somali Thursday Collingwood)

> I can remember during the war my mother saying to me, if anything happens to me you are in charge of the children, the family. (Somali Thursday Collingwood)

One participant from a Mandarin and Vietnamese speaking group reported perceptions of bad luck may impact on other's willingness to speak about this issue:

> This plan sounds like making a will. Some people will feel it sounds like jinxed, like bad luck. (Strong Leaves group)

Another individual reported on general perceptions about Vietnamese people's lack of willingness to plan for their healthcare.

Sometimes Vietnamese people don't plan ahead for their healthcare. I think this is a good idea and we should all think about it. (Indochinese Elderly Refugees Monday)

Conversely others in a range of Mandarin and Vietnamese speaking groups reported that they felt free to talk about this:

No issue talking about it. Please go on. (Vietnamese Elderly Collingwood)

Very interesting this topic. (Vietnamese Elderly Collingwood)

We okay to talk about this. (Chinese Friendship group)

Nothing would stop us. (Chinese Friendship group)

I am happy to discuss this. (Chinese Thursday high rise North Melbourne)

We are okay to talk about this. (Indochinese Elderly Refugee Friday)

I am okay to talk about it. (Preston Reservoir Indochinese Elderly)

Not very difficult thing. We have already communicated to our children about this. (Mandarin Diabetes Support group).

Better to be open and upfront about this. (Indochinese Elderly Refugees Thursday).

We are not hesitant to talk about this. (Indochinese Elderly Refugees Thursday).

I am happy to talk about this with my children. (Indochinese Elderly Refugees Monday).

These findings suggest that while there may be cultural factors that impact on the willingness of some participants to engage in this topic – these are not homogenous cultural groups but groups with a diverse range of views on this topic.

How to get people talking about ACP

Session one participants were then asked 'So how do you think we can get people talking about this?' Participants offered a range of strategies to get people talking about this topic. Some suggested they would take the initiative to start the conversation:

> Oh, I'd just start talking.
>
> Just start talking about it. (Older mixed Thurs Glenroy)
>
> Introduce it yourself. (cohealth Stronger Living exercise group Niddrie)

While others suggested practicing this conversation with a friend before introducing the idea to family:

> I might talk to one of my friends from this group before I talk to my family.
>
> Practice with a friend.

Additionally, other participants reported that increased understanding and awareness of this topic may assist.

> Start to talk about this issue from time to time. (cohealth Community group)
>
> The more we understand about this topic there is less worry. (Vietnamese Elderly Collingwood group)

An individual participant further suggested taking the personal out of this conversation by using others as an example.

> Use others as an example. (cohealth Community group)

SESSION TWO

ATTENDANCE

A total of five groups were attended for session two.

SAMPLE

Five local community groups from session one were revisited and invited to complete a questionnaire about behaviour change after attending the session one presentation. This was session two. A total of 25 participants completed the session two questionnaire.

This project planned for the delivery of sixty session one presentations – with each group revisited a second time for session two. Due to time constraints the session two plan was downgraded resulting in the delivery of session two in five groups - instead of the planned sixty. Future projects may give consideration to allowing more time in the project for follow up sessions.

In this project the date of session one is Time 1 (T1) and the date of session two is Time 2 (T2). The timeframe between T1 and T2 was grouped by weeks and coded. Results in Table 10.

Table 10. T1 – T2 timeframe

	n	%
0-8 weeks	1	20
9-16 weeks	1	20
17-24 weeks	2	40
25-32 weeks	0	0
33-40 weeks	1	20
Total	5	100

Although the sample size was small, there were considerable differences in the T1 – T2 timeframe between the session two groups which potentially limits the comparability of

findings. Future projects may consider designing the project plan to ensure more uniformity in the timeframe between T1 and T2.

Local Government Area by group

Session two groups by Local Government Area are detailed in Table 11 below.

Table 11. Session two by Local Government Area

	n	%
Melbourne	2	40
Maribyrnong	1	20
Brimbank	1	20
Moreland	1	20
Total	5	100

Partner organisations

Session two groups by partner organisation are detailed below in Table 12.

Table 12. Session two by partner organisation

Group by partner org	n	%
cohealth group	3	60
Merri Health group	1	20
Other	1	20
Total	5	100

Demographics

Session two demographic data is detailed in Table 13 below.

Table 13. Session two demographics

	n	*%*
Gender		
Male	10	40
Female	15	60
Total	25	100%
Age		
60 - 69	5	20
70 - 79	10	40
80 - 89	8	32
90 - 99	2	8
Total	25	100%

Results indicate that all session two participants were 60 years of age and over. The majority of participants (60%) were female.

Session two participants were asked if as a result of attending the talk on ACP they thought about or talked to someone about this issue. Findings are set out in Table 14.

Table 14. Think or talk about Advance Care Planning

		Yes		No	
	(n = 25)	*n*	*%*	*n*	*%*
Think about Advance Care Planning		19	76	6	24
Talk to someone about Advance Care Planning		17	68	8	32

Results indicate that the majority of session two participants thought (76%) and talked (68%) about ACP after the presentation. This finding suggests that a single short presentation on ACP to a local community group is helpful in prompting attendees to think and talk about this issue.

Those who did talk to someone about ACP were then asked who they talked to. Participants were invited to select multiple options. Results in Table 15.

Table 15. Who did you talk to about Advance Care Planning?

	Yes
(n = 17)	*n*
My children	11
My partner, husband or wife	8
A friend	8
My doctor	6
Another relative	3
Another health professional	-

Participants reported that they talked to a range of individuals inclusive of children (n=11), partner (n=8) and a friend (n=8). No participants reported talking about ACP to a health professional, other than their doctor. Future projects may explore potential barriers that hinder individuals talking about ACP to health professionals, other than their doctor.

Those who did talk to someone were then asked how many conversations they had about ACP. Results in Table 16.

Table 16. How many conversations about Advance Care Planning?

How many conversations?	n	%
One conversation	5	29%
Two conversations	6	35%
Three conversations	3	18%
Four conversations	1	6%
Five or more conversations	2	12%
Total	17	100

As a result of attending session one, participants had 40 conversations about ACP. Two participants reported having five or more conversations. This finding that a single short

presentation on ACP to local community groups has generated numerous conversations about ACP is encouraging. While this project did not undertake a detailed analysis of the specifics of these conversations - recent research found that talking with others about ACP is helpful and that older adults are willing to discuss a range of topics related to ACP (Lum et al., 2016).

Participants were asked as a result of attending the talk on ACP 'Did you complete a written Advance Care Plan?' and 'Did anyone else you know complete a written Advance Care Plan?'. Results in Table 17.

Table 17. Complete a written Advance Care Plan

		Yes		No	
	(n = 25)	*n*	*%*	*n*	*%*
Did you complete a written Advance Care Plan?		1	4	24	96
Did anyone else you know complete a written Advance Care Plan?		0	0	25	100

One respondent completed a written Advance Care Plan as a result of attending the talk on ACP. The participant reported that her son was involved in this process:

> My son filled in the papers and took me to the doctor to fill in the form. (English Ladies Fri Brunswick)

This concurs with a recent study by Detering et al., (2015) that found 68% of discussions around ACP occurred with family members present and that inclusion of family was an important factor for effective ACP discussions. Additionally, this data supports research that visit companions are influential in patient's satisfaction with healthcare appointments and can be a valuable resource to enhance the healthcare interaction (Wolff & Roter, 2008). Visit companions are defined as family members or friends that accompany individuals to healthcare appointments. Future projects may give consideration to exploration of the role of visit companions in community based ACP appointments. Further work may examine healthcare professionals' confidence in interacting with and supporting visit companions in community based ACP appointments.

One other member of a participating local community group did not attend the talk on ACP. However, after session one she was given the forms by the group facilitator and did complete a written Advance Care Plan with her doctor. Feedback from this participant:

> It [Advance Care Planning] is very valuable to me. I have no family, you do everything yourself, this plan lets me do that…it makes me complete. (Carlton OPHR)

This finding reinforces that presentation of ACP information to local community groups can assist with dissemination of this information to others and has the potential to lead to completion of a written Advance Care Plan. In particular, this individual reported that having no family made the Advance Care Plan helpful to her. This is an important finding as increasing our understanding of patient motivations to participate in ACP can assist to tailor future interventions (Lum et al., 2017).

Reasons why participants did not write a plan

Participants who did not complete a written Advance Care Plan were asked why they didn't write a plan. One individual planned to complete a written Advance Care Plan but had not done so as yet:

> I said that I think we should do the plan. I haven't written any plan yet. (Chinese Seniors)

One participant reported a sense of responsibility for their own care as a reason for not initiating a written plan. In part, it was perceived that making a written plan may be onerous for others:

> I didn't make a written plan. We have a habitual thinking as long as we can do it our self, we do it our self. We don't want to make trouble for other people. (Strong Leaves)

Lack of time for the doctor to complete the ACP paperwork was cited as a reason why one participant did not initiate a written plan:

> It is a lot of effort to fill in the plan with a doctor so I'm not sure if I will do it. It will be a lot of trouble for the doctor to fill in a form. (Chinese Seniors)

These findings concur with current research that indicates time constraints form a significant barrier to ACP conversations (Dixon & Knapp, 2018). This suggests further exploration around why some individuals don't initiate a written Advance Care Plan with their doctor due to perceived busyness of the doctor may be warranted.

Some participants viewed ACP as a future concept that may not be relevant to their current situation to explain why they did not complete a written plan:

> I think it's still too early to write a plan. I am still healthy. (Chinese Seniors)

> I didn't make a written plan. I am still young. I am healthy. (Strong Leaves)

> I didn't write a plan. We think that we won't die so soon. My health is still okay so no written plan. (Strong Leaves)

> I didn't see the need to at the time. (English Ladies Fri Brunswick)

> I'm very confident when the need arises – I will be the first out there. But at the moment it's not there yet. (Carlton OPHR)

> I can't say why [I haven't filled out a written plan]. Maybe at this moment I'm not in a situation. We are not on our last breath. I don't even think of it. (Westvale Men's shed)

> Maybe my GP will think I don't need to fill in this form. I am still in good health. (Chinese Seniors)

The seven participants who viewed ACP as a future concept and not currently required were older individuals. Specifically, this cohort comprised 60-69 years (n=2), 70-79 years (n=4) and 80-89 years (n=1). Of interest is that one of these respondents suggested it is the role of the GP to decide whether this ACP paperwork was necessary. This reinforces the findings from Patel et al., (2012) that a potential barrier to ACP is an assumption by patients that clinicians will initiate the discussion around ACP and decide when it is needed. However, recent research suggests poor coverage of communication skills in medical training can leave physicians ill equipped to initiate and lead discussions around ACP (Dixon & Knapp, 2018). Additionally, many physicians undertake short training activities of limited depth around ACP which may be insufficient to upskill the physician in this complex area of healthcare (Dixon & Knapp, 2018). Future projects may give consideration to a series of tailored ACP GP education sessions to enhance physician confidence and skills around community based ACP conversations.

Two respondents cited uncertainty as a barrier to filling in the written plan:

> I didn't write a plan. We don't know how to fill out the form. (Strong Leaves)

> I did start the written plan but I didn't finish. You don't know what you need to do. (English Ladies Fri Brunswick)

Others cited health issues as a barrier to filling in the written plan:

> My eyesight is limited. (Chinese Seniors)

> I didn't think about Advance Care Planning as my memory is not good. (Carlton OPHR).

> I didn't make a written plan because I was too full of other health issues. I didn't think about Advance Care Planning because I had other healthcare issues. (Carlton OPHR)

Talk about ACP

Participants who did to talk to someone else about ACP were asked if you did talk to someone, can you share a story of how that went?

Two participants reported talking to others about ACP but kept the information brief:

> I spoke to my husband but I didn't specify the information. (Chinese Seniors)

> When I talk to my children not much details. (Strong Leaves)

Several respondents reported feeling confident sharing this information:

> So I called a friend and I shared what the plan was about. The information shared was clear. (Chinese Seniors)

> I talked to my GP. My GP speaks Mandarin so it was okay. Doctor very good. (Strong Leaves)

> I talked to many friends about this - more than five friends. I talked to friends in China. (Chinese Seniors)

> I talked to my doctor. The conversation was good. (Carlton OPHR)

> I talked to two of my sons. (English Ladies Fri Brunswick)

Of interest is that one participant who talked to two people about ACP reported a discrepancy between his doctor and his brother as to how the information was received:

> I talked to my doctor. She was very sympathetic. And she went into it very much… I talked to my brother but he wasn't very interested. (Carlton OPHR)

One theme that emerged was discussion around whose role it is to care for older people in Australia. Some viewed the government as taking this role:

> The Australian Government takes good care of old people. (Chinese Seniors)

> We talked to friends in China that the Australian Government looks after older people with this plan. (Chinese Seniors)

> I talked to my husband. We've concluded that living here the government looks after us well. At the end of the day we will go to a nursing home. (Strong Leaves)

One participant reported the children have a role caring for older people:

> I talked to my daughter. My daughter said since you are old it is the children's responsibility to take care of you. (Strong Leaves)

Conversely, others reported the children are too busy to care for older people and that outside assistance should be considered:

> Our kids are all busy at work. (Strong Leaves)

> I talked to my children. My children asked me to seek help to help me do some of my work. (Strong Leaves)

Overall participants reported attendance at session one prompted a variety of discussions around current and future healthcare needs with partners, family members, friends and their doctor. This reinforces findings from Houben et al., (2014) that discussions around ACP can be valuable and productive.

Not talk about ACP

Participants who did not talk to anyone about ACP were asked why they didn't.

Two participants viewed this as a private issue and that they didn't feel the need to talk to anyone about this:

> I think it is my matter. I don't think I need to speak to anyone or write it down. I can make my own decision. (Chinese Seniors)

One individual cited social isolation as a barrier to talking to others about this:

> I didn't talk to anyone. I don't have anyone to talk to. (Strong Leaves)

Another individual cited lack of willingness to think or talk about this issue:

> I didn't talk to anyone. I didn't think about it. I don't want to think about it. (Strong Leaves)

Others cited a fatalistic approach to healthcare as influencing their decision not to make a written Advance Care Plan:

> I didn't make a written plan. As long as you are happy everyday you will be okay. (Strong Leaves)

> I didn't write a plan. I think death is a natural thing. There is nothing I can do about it. (Strong Leaves)

The second of these quotes reinforces the findings from Patel et al., (2012) that some patients believe deterioration is a normal part of ageing and inevitable. This belief has the potential to hinder and form a barrier to the ACP process.

ADDITIONAL OUTCOMES

A number of additional project outcomes are detailed below.

Information dissemination

This project facilitated the uploading of two Advance Care Planning Australia videos to Tonic TV – an audio visual system across cohealth waiting rooms playing rotational health promotional material. These videos include:

1. A doctor and patient discuss Advance Care Planning
2. A nurse introduces her patient to Advance Care Planning

This idea was initiated by Mary Natoli, Community Health Nurse Aged Care, cohealth Collingwood.

Sharing project learnings

Three cohealth FARREP Community Workers attended a session one presentation at cohealth Collingwood. Learnings shared with these workers:

- Content, formatting and delivery of the presentation
- Collection of qualitative responses during delivery of the presentation
- How the pre and post evaluation is undertaken

WHAT WORKED WELL

- Incidental dissemination of information (workers, kitchen staff, participants take resources for family or friends and disseminate to others)
- Linking in with existing local community groups proved to be a useful model
- Linking into partner organization existing local community groups was helpful
- Word of mouth referral from a local community group useful

CHALLENGES

- No key one point of contact when searching for local community groups across nine LGA's resulting in individualized contact to numerous groups
- Overwhelming majority of participants required assistance to complete evaluation thus adding time to the data collection process
- Some participants declined to complete the session one evaluation. This, in combination with time constraints, explains the smaller sample of completed evaluations compared to the total number of participants attending session one.

LIMITATIONS

This project planned for the delivery of sixty session one presentations – with each group revisited a second time for session two. Due to time constraints the session two plan was downgraded resulting in the delivery of session two in five groups - instead of the planned sixty.

RECOMMENDATIONS

It is recommended that future projects give consideration to:

- Allowing more time in the project for follow up sessions
- Aiming for greater uniformity of timeframe between session one and session two to enhance comparability of results
- Exploration of the barriers to communication about ACP between adult children and their parents
- Examining why some community based individuals are not hearing about ACP through a health professional
- Further exploration around why some individuals don't feel confident talking to their doctor about ACP
- Examining potential barriers that hinder individuals talking about ACP to health professionals, other than their doctor

- Development, implementation and evaluation of an ACP team-based model in the community setting
- Development, piloting and evaluation of tailored ACP GP education sessions to enhance physician confidence and skills around community based ACP conversations
- How information about ACP is delivered to those *not* linked into existing community groups – as this project primarily delivered information about ACP to those linked into existing community groups
- Exploration of the role of visit companions in community based ACP appointments
- Healthcare professionals confidence in interacting with and providing support to visit companions in community based ACP appointments
- Exploring how self funded retirees access information about ACP

APPENDICES

APPENDIX A

Advance Care Planning questionnaire: Session one

Please fill in this questionnaire to evaluate our presentation.

Your answers will be strictly confidential.

Name of your community group:

Age:	□ 20 – 29 years	□ 30 – 39 years	□ 40 – 49 years
	□ 50 – 59 years	□ 60 – 69 years	□ 70 - 79 years
	□ 80 - 89 years	□ 90 – 99 years	□ 100 – 109 years
Gender:	□ Male	□ Female	□ Intersex or Indeterminate
What suburb do you live?			
Country of birth:			
Main language spoken at home:			
Family Main Source of Income:			
□ Pensioner		□ Government payments (ie Centrelink)	
□ Employee (Salary/Wages)		□ Self employed	
□ Self funded retiree		□ Visitor visa	

Please fill in this page BEFORE the presentation

Have you ever heard before today about Advance Care Planning? □ Yes □ No

Has any health professional ever talked to you about Advance Care Planning? □ Yes □ No

Please circle the number that best describes how much you agree or disagree with the statement					
	☹ **Strongly Disagree**	**Disagree**	**Uncertain**	**Agree**	☺ **Strongly Agree**
I understand what Advance Care Planning is	1	2	3	4	5
I understand why it may be useful to have an Advance Care Plan	1	2	3	4	5
I feel able to think about my values, beliefs and preferences about my future health care	1	2	3	4	5
I understand how an Advance Care Plan may be used if I cannot make or communicate my decisions	1	2	3	4	5
I feel confident to talk to my family or friends about Advance Care Planning	1	2	3	4	5
I understand what a medical decision maker is in Advance Care Planning	1	2	3	4	5
I feel confident to talk to my doctor about Advance Care Planning	1	2	3	4	5
I know who to ask if I have questions about Advance Care Planning	1	2	3	4	5

Please fill in this page AFTER the presentation

Please circle the number that best describes how much you agree or disagree with the statement

	☹ Strongly Disagree	Disagree	Uncertain	Agree	☺ Strongly Agree
I understand what Advance Care Planning is	1	2	3	4	5
I understand why it may be useful to have an Advance Care Plan	1	2	3	4	5
I feel able to think about my values, beliefs and preferences about my future health care	1	2	3	4	5
I understand how an Advance Care Plan may be used if I cannot make or communicate my decisions	1	2	3	4	5
I feel confident to talk to my family or friends about Advance Care Planning	1	2	3	4	5
I understand what a medical decision maker is in Advance Care Planning	1	2	3	4	5
I feel confident to talk to my doctor about Advance Care Planning	1	2	3	4	5
I know who to ask if I have questions about Advance Care Planning	1	2	3	4	5

	Nothing at all	Not much	Some	Most	All
How much did you understand in today's presentation?	1	2	3	4	5

Thank you for completing this questionnaire

APPENDIX B

Advance Care Planning questionnaire: Follow up evaluation

Please fill in this questionnaire to evaluate our talk on Advance Care Planning.

Your answers are strictly confidential.

1. Did you attend the talk on Advance Care Planning a few months ago? □ Yes □ No

If NO, please STOP HERE. You do not need to answer any more questions.

Name of your community group:

Age:	□ 40 – 49 years	□ 50 – 59 years	□ 60 – 69 years
	□ 70 - 79 years	□ 80 - 89 years	□ 90 – 99 years
Gender:	□ Male	□ Female	□ Intersex or Indeterminate

As a result of attending the talk on Advance Care Planning did you:

1. Think about Advance Care Planning? □ Yes □ No
2. Talk to someone about Advance Care Planning? □ Yes □ No

3. If you talked to someone, please tick *who* you talked to about Advance Care Planning?

   (You can tick multiple options)

My children ☐ My partner, husband or wife ☐ Another relative ☐

My doctor ☐ Another health professional ☐ A friend ☐

4. If you talked to someone, please tick how many conversations you had about Advance Care Planning? *(Please just tick one option)*

1 conversation □ 2 conversations □ 3 conversations □

4 conversations□ 5 or more conversations □

5. As a result of attending the talk on Advance Care Planning:
Did you complete a written Advance Care Plan? □ Yes □ No

Did anyone else you know complete a written Advance Care Plan? □ Yes □ No

If YES to talk to someone else or YES to write a plan go to q. 6.

If NO to talk to someone else or NO to write a plan go to q. 7.

6. If you did talk to someone or you did write a plan, can you share a story of how that went?

_____
_____
_____
_____

7. If you didn't talk to someone or you didn't write a plan, can I ask why you didn't do anything?

_____
_____
_____
_____

Thank you for completing this questionnaire

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