

ACP Advisory Group Meeting Minutes 24 July 2018

Present

Sara Rishworth (Deputy Chair), Ann Coughlan	Palliative care medical practitioner, Mercy Hospice CE Mercy Parklands and NZ Aged Care Association board member (left the meeting at 9.30am)
Anna Stevenson	GP/public health physician, Canterbury DHB
Hector Matthews	Executive director, Māori health, Canterbury DHB
Lisa McNab	Consumer representative, Northland
Tess Huia Moeke-Maxwell	Research fellow, Auckland University
Vanessa Eldridge	Manager, day hospice, Mary Potter Hospice

Commission

Lizzie Price	Director of communications
Chris Walsh	Director, partners in care
Leigh Manson	ACP programme lead
Ricki Smith	ACP implementation manager
Clare O'Leary	ACP promotions coordinator

Apologies

Helen Mason	CE, Bay of Plenty DHB
Jane Large	ACP facilitator, SIAPO
Marj Allan	Consumer representative
Michelle Main	Palliative care lead, Ministry of Health
Sarah Clark (Chair)	Social Workers Registration Board
Stephanie Clare	CE, Age Concern
Sue Cooper	Consumer representative
Sue Ineson	Executive director, Council of Medical Colleges
Ofa Dewes	Research fellow, University of Auckland

1. Welcome and apologies

Sara Rishworth welcomed the group, and Clare O'Leary opened the meeting with a karakia. Sara welcomed the four new members – Lisa McNab, Vanessa Eldridge, Tess Huia Moeke-Maxwell and Ann Coughlan.

2. Confirmation of minutes

The minutes of the last meeting were confirmed without amendment.

Matters arising from previous meeting:

- Leigh is in the process of finding a member for the group from the Ministry of Social Development.

- Clare and Leigh are developing a presentation about the ACP programme that members of the advisory group will be able to use in the community.
- Clare is meeting with paramedic lecturer Sean Thompson and developers on Thursday about MySay, an advance directive app.
- Leigh gave an update that Counties Manukau and Waitemata DHBs are now both providing partial funding to cover the benefits they receive from the national ACP programme, excluding training. We will continue to have discussions with them about fully funding the programme in the future.
- Following the last advisory group meeting, Ricki and Leigh looked at concordance evidence internationally. There will be a report back on concordance research following the next international conference for ACP, being held in Rotterdam in March 2019.

3. Future of ACP survey

A survey of advisory group members was undertaken to find out what they see ACP looking like in the future – eg, by 2025. Key findings are below.

If you had three wishes for the future of ACP what would they be?
Key messages <ul style="list-style-type: none"> • Culturally appropriate resources, conversations and engagement • Community and primary care driven • Increased public awareness and understanding
Describe how you see ACP in 2025? Don't think of a statement but instead a vivid picture (like a blueprint) of what is happening for consumers, health and social providers, the wider community, NGOs, lawyers, systems, etc.
Key messages <ul style="list-style-type: none"> • ACP is culturally responsive • ACP is business as usual (BAU) in the health sector • ACP is BAU in the community
What are the major differences in 2025 when you compare it to the current situation?
Key messages <ul style="list-style-type: none"> • ACP is developed and accepted for and by Māori • Compassionate communities is embedded across New Zealand • Consistent IT systems for ACP documentation • Tailored resources for diverse audiences i.e. Māori, Pacific, Asian, people with disabilities etc.
What obstacles and uncertainty stand in the way of that future?
Key messages <ul style="list-style-type: none"> • Sustainable funding • Change management processes and DHB engagement • Current level of community understanding
What do we need to do as a group to move toward that future?
Key messages <ul style="list-style-type: none"> • Explore new ways to create community awareness and engagement • Explore ways to increase ACP uptake and support in DHBs • Discuss opportunities for future funding
What are the three things you can do within your circles of influence that would move us towards that future?
Key messages <ul style="list-style-type: none"> • Continue to promote and raise ACP awareness within our networks and health sector and build on these relationships • Identify equity issues at every stage of the programme that can be proactively targeted to Māori and Pacific populations • Continue to engage communities to increase ACP awareness

There was general discussion about the topics raised in the survey and the summary of responses included:

- Strong endorsement from the group of the focus on equity, particularly Māori
- Conversations being initiated at every point in one's health journey, it's not just about the health sector in crisis or ill health
- ACP needs to reach well beyond the health sector – out there in the community
- How do we change the dialogue around illness, eg, not necessarily being a fighter, battling but about dying naturally? 'It's OK to go. We'll be OK' reassuring – allowing family/whānau to let people go with grace. We need to shift the language.
- Our society needs to change its relationship around death and dying. Death and dying is not a health issue, it's a society issue
- How can we get whānau to have conversations about death and dying...and how to best prepare for that?
- Peeling back those layers of fear and trepidation – it is a tino rangatiratanga issue. We who work in health should be supporting what the community wants.
- Is the concept of 'community' a bit of a myth? Some people have strong communities but others don't. We have to be realistic. What is important is the choices people have, and that family/whānau are empowered to make those choices.
- There is a holistic swing happening, with people open to looking at holistic approaches, and this should be supported by this group, particularly rongōa, Māori traditional healing. Need to swing more towards the spiritual aspect of the Te Whare Tapa Whā model, and away from the tinana/physical – embedding wairuatanga/spirituality throughout our approach.
- Death has become very medicalised, similar to birth – in some cases this has been a good thing, but in others not so. We have lost capability to deal with it – need to go back to traditional knowledge of death and dying to empower communities to own it again.
- The ACP conversation doesn't just end in death. ACP can contribute to doing loss and grief better; we need to do things properly so nothing is lost.
- We have the opportunity to make tools available to family/whānau that are contemporary; to help capture diverse stories and get engagement in a way that works for them.
- Need to have conversations well before an ACP needs to be put into action. 'Have you had the conversation?'
- Māori and European have very different approaches to death – person going back to the marae rather than to the undertaker. Iwi own the wairua or spirit of the person to take home – the tūpāpaku (body) remains in the physical world.
- Need to consider care for children at end of life. Important to have a relationship with that child's family/whānau.
- What happens when family/whānau are overseas? What are considerations within different hapu and iwi after death? We can't resolve all these issues with ACP. What we do need to be saying is that you need to have these conversations before they are needed. Look at all the issues.
- Should we have a 'John Kirwan' type media champion, or a mix of individuals?
- What are the distinguishing things in people's stories that would get the public thinking? Eg, oral will, one mokupuna heard – others disagreed – ongoing distress within the whānau. Specific preference for body preparations and whether you have to have a coffin.
- You can't treat everyone the same. Everyone has different needs. Not one size fits all. How do we convey that – that it's OK to be flexible and go outside the boundaries. Bring these messages into a multimedia campaign.

Where to from here?

- The Commission will take the comments from today and align them with the ACP five-year plan, to consider where the gaps are and what can be amended and changed to address the vision that is emerging.
- The notes from today will be sent to those who couldn't make the meeting, and their further comment sought.
- There was discussion about what level of detail from the steering group should go to the advisory group. It was agreed that the steering group minutes would be circulated to the advisory group.
- Agreed that the advisory group minutes would be shared with the steering group before the steering group meeting 2 August 2018 to inform the discussions around 2019 programme activities.

Next Meeting:

A date and time has not yet been agreed.

Karakia (at the beginning).

*Whakataka Te Hau
Whakataka te hau ki te uru
Whakataka te hau ki te tonga
Kia mākinakina ki uta
Kia mātaratara ki tae
E hii ake ana te atakura
He tio
He huka
He hau hū
Tihei Mauri Ora!*

Cease the winds from the west
Cease the winds from the south
Let the breeze blow over the land
Let the breeze blow over the ocean
Let the red-tipped dawn come with a
sharpened air
A touch of frost, a promise of a
glorious day.

[Karakia from Hector]

Waiata

*Te Aroha
Te Whakapono
Me te rangimarie
Tatou tatou e*

*Love
Faith and
Peace
Be amongst us all.*

Glossary of Māori terms

Aroha – love, compassion, empathy

Iwi – tribe

Hapu- pregnant/sub-tribe

Haere Mai - welcome

Hinengaro – emotional/mental well-being

Marae - courtyard - the open area in front of the *wharenuī*, where formal greetings and discussions take place.

Whakapapa - to recite in proper order (e.g. genealogies, legends, months), recite genealogies.

Karakia – prayer, chant

Karanga – to call out, summon

Kaumatua – elder male

Kuia – elder female

Mokupuna - grandchildren

Tangi – to cry, weep, mourn / funeral

Te whare tapa wha – Māori health model

Tinana – physical health and well-being

Tino rangatiratanga – self-determination for Māori

Tūpāpaku – deceased body

Waiata – song/to sing

Wairuatanga – spirituality/spiritual well-being

Whānau – family (could be immediate whānau or extended whānau)

Whenua – land, ground (also placenta)

For further information

www.māoridictionary.co.nz