

ACP Steering Group Meeting Minutes 2 August 2018

Present

Jane Goodwin (Chair)
Carla Arkless
Noel Tiano
Helen Rigby
Kirstin Pereira
Ellen Fisher
Arthur Te Anini

Commission

Leigh Manson
Lizzie Price
Ricki Smith
Chelsea Sirs
Clare O'Leary
Deon York

Apologies

Barry Snow
Courtenay Mihinui
Kate Grundy
Mariana Churchward
Rachel Haggerty Jane Pou
Kate Orange
Kendra Sanders
Jane Large
Sue Cooper
Ellen Fisher
Karlynn Earp

1. Welcome and apologies

Jane Goodwin opened the meeting with a karakia and welcomed everyone.

2. Matters arising from meeting 3 May 2018

The minutes from the 7 June meeting were confirmed. Moved Kirsten, seconded Carla.

Jane asked if there were any questions from the pre-meeting update document.

- It was noted that it was really useful to have updates on the different stakeholder work underway; having reports on this makes it much easier to avoid duplication.
- Ricki gave an update on a meeting between her, Leigh, Margaret Milne from Central TAS and a national interRAI trainer, Jenny Allen. Issues such as ACP being clearly defined in interRAI, and the accuracy of the data about ACP coming out of interRAI were discussed. We will send some recommendations to interRAI about better capturing ACPs "completed/not complete" to support getting more reliable information from the system about ACP. Leigh will arrange training the 28 national InterRAI trainers as part of the December meeting.
- There was a suggestion that it would be useful to send interRAI some information about the difference between various terms such as 'advanced directives' and an

ACP. Ellen has something similar at Bay of Plenty DHB and will send it to Ricki.
Action Ellen

3. Education and training

- There was discussion about the document developed by Central Region that clarifies the difference between the train-the-trainer programmes – the ACP workshop and Serious Illness Conversation Guide. There is a need to amend the doc so that it works across different settings.
- Jane G asked who the course owner of the SICG was – at the moment it is down as the DHB's ACP facilitator. She has concerns about the workload of facilitators. Leigh suggested that the organisational logistics of DHBs' training could potentially be managed nationally, and that funding could be allocated for this next year. This would also help with the quality of what is being delivered.
- Next steps: Ricki and Leigh will draft a role description for national management of arranging the logistics of SICG and ACP training. **Action Ricki and Leigh**

4. Implementation

4a. There was further feedback on the website. Comments included:

- it seems fine
- there is a lot of information on the site and would take people a lot of time to get through
- the website is too complex
- we need to make sure it is primarily consumer focused
- we need to make it equally consumer and health professional focused
- we need to make sure the language is consumer-friendly
- some of the language used in the site will change as elements of the promotion campaign are integrated.

Lizzie will revise the site using consumer friendly language and then it will be reviewed by health literacy expert Susan Reid. **Action: Lizzie**

4b. Minimum package for DHBs

There was discussion about whether the minimum package for DHBs document was useful. We need to ensure te ao Māori is captured in the document – ie, the Māori engagement within the DHB with ACP training. An equity box could be added. Ricki to draft and send to SG for sharing. **Action: Ricki**

There was agreement that we will ask for comment on the package from DHBs' GMs Planning and Funding. Leigh will set up a meeting with Rachel Haggerty from Planning & Funding to look at best mechanisms for doing this. **Action: Leigh**

5. Planning session

There was discussion around the five workstreams, looking at:

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- what we have or will have achieved in 2018
 - plan for 2019
 - what steps, projects, other activities will we need to do to achieve our 2019 goals?

Promotion

- Arthur said that when he was in hospital recently, very few people knew what an advance care plan was
- This is why a promotional campaign is so important. The more widely ACP is known by the public, the more the health sector will know about and encourage ACPs.
- Discussion about ambulance services also finding it difficult when ACPs are not captured. The Commission is meeting with St John and Wellington Free Ambulance for discussions on working together on knowing about and accessing ACPs.
- Options include using an app (like the one developed in Canada) to verbally record your wishes and putting a 'lifetube' in the fridge. Could look at these things nationally.
- In terms of stakeholders, would be good to develop a central list of stakeholder liaison that regions can also feed into.
- By end of 2019 we hope to have:
 - raised awareness in the public about advance care planning, a selection of resources in different languages, local events and engagement
 - ambulance staff aware of ACP and what they need to do once they arrive at someone's house
 - funding so the campaign can continue to be run
 - alignment across government, with other agencies working in similar areas
 - engaged with lawyers and financial advisors
 - engaged with faith communities about future health care planning
 - engaged with Asian populations.

Resources

By end of 2019 we hope to have:

- an updated ACP guide and plan based on the feedback from the health literacy review. We are going to look at the things we can change easily in the short term, and things we can work in longer term
- short form ACP template with culturally appropriate design
- explored digital options for advance care plans
- a guide for clinicians about the legalities of ACP. This could be a one-pager, diagram or animation.

Education and training

By the end of 2019 we hope to have:

- trained ACP trainers from 18 DHBs
- trained at least 24 additional DHB SICG trainers
- started to adapt the SICG for the primary care sector
- developed a plan and piloted how we can ensure quality and consistency of the training at local level through mentoring and communities of practice

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- found funding for advanced communications training. We have currently got a registration of interest in for the Health Workforce NZ development fund, but haven't heard back yet. If unsuccessful the plan will be to develop a proposal for funding from DHBs
 - a clinical communications training advisory group formed and advising the Commission
 - developed and piloted a training programme for the community, NGOs etc

It was noted that people need to 'sing from the same song sheet' in the delivery of advance care planning. It is important the message isn't watered down.

Monitoring and evaluation

We aren't far off being able to map the Canterbury and Auckland DHB data against people's use of health services in the last year of life. We are also looking at the Voices research in Auckland. It was suggested that South Island Voices data also be looked at. It was noted the Bay of Plenty DHB is looking at doing the survey in their DHB. It was noted that Voices captures feedback from across the whole continuum – eg, hospice, hospital, GP, whanau etc.

Ellen talked about the health roundtable data, which can be used for quality improvement. She also talked about the compassionate communities approach – Clare went to this conference earlier in the year.

By the end of 2019 we hope to:

- be undertaking regular surveys of consumers about end of life and advance care plans
- have meaningful and informative interRAI measures
- have an increase in the number of DHBs that currently record advance care plans
- be looking at the results of Voices research and how we can use this research
- be measuring the difference in experience of the consumer when having a conversation with someone who has had training vs having a conversation with someone who hasn't; or applying for funding to do this.

Implementation

Ricki listed the many activities underway.

The 'How to guide' and ACP website

The Commission's advance care planning website went live in July 2018 and contains many different features. The landing page contains the information and tools for anybody to be able to commence their ACP journey. It also includes a 'How to guide' section for clinicians to use as a resource when planning, embedding and progressing ACP within their area of work. The guide explains steps and showcases case studies to assist in new ways and ideas for ACP implementation.

MSD – Ageing population strategy

Since 2001, councils and others have used the 2001 Positive Ageing Strategy to inform their own strategies and implementation plans so they can make a difference in people's lives at the local level. There have been a number of changes and trends identified that have happened since 2001. Technology has made huge advances and is embedded in most of our lifestyles. People of all ages are becoming more concerned about things like housing, secure employment and climate change and future planning. The new strategy for an ageing population will reflect these changes and align with other government strategies. Its purpose is to continue to provide a common platform to support central and local government, non-governmental organisations, businesses and communities to more easily work together to achieve better outcomes for older New Zealanders.

The new strategy will consider what should our vision for positive ageing be now and in the future? And what should we consider as we prepare for, and respond to, our ageing population?

The Commission is planning to send a written submission to included advance care planning as part of the 'Planning for the future' aspect of the strategy. Information will be shared as the plan progresses.

DHB bios

Ricki is meeting with and collating information of each DHB and their progress with ACP. This will help identify those DHBs who wish for more support and identify any barriers that are inhibiting uptake. This will help inform the Commission on what DHBs require for ACP to carry on into the future.

InterRAI

A recent meeting between the national ACP team and the national InterRAI team discussed ways that ACP can leveraged and better understood through the use of InterRAI. A recommendations document is currently being developed by the national ACP to inform InterRAI on suggestions for improvement.

LMS integration

This project was developed after hearing the concerns of DHBs and their inability to be able to organise and control ACP education within their organisation's framework. Meetings have been had with a sample of IT managers and DHBs to discuss ways that DHBs can better leverage existing learning management systems and ACP training to maximise efficiencies within individual organisations. Further discussions are planned and will be reported on as they eventuate.

Minimum package for DHBs

A document has been developed by a subgroup of the national ACP steering group to highlight the minimum requirements a DHB needs to ensure the successful implementation of ACP. This document is in its final editing stages and will be presented at an upcoming steering group meeting for final approval.

NHI review

The Ministry of Health is reviewing changes to the National Health Index (NHI) system and standard.

The national ACP team submitted a proposed change that was reviewed in June 18, requesting that an ACP alert be attached to a person's NHI.

The Ministry of Health is seeking public comment on various proposed amendments to the NHI system and standard and people are invited to review and provide comment. The public comment process is being carried out by Health Information Standards Organisation (HISO) and comments can be made on any or all of the 16 topics including the ACP alert.

The documents issued for public comment can be found online here:

<https://www.health.govt.nz/our-work/ehealth/digital-health-sector-architecture-standards-and-governance/health-information-standards/standards-open-public-comment>

The current version of the NHI Standard (HISO 10046:2017 – the Consumer Health Identity Standard) can be found here:

<https://www.health.govt.nz/publication/hiso-10046-consumer-health-identity-standard>

Please share this with your ACP networks and make your comment using the website provided above by the **closing date, Wednesday 22 August 2018.**

Digital ACP scoping project

As part of the five-year ACP strategy and plan, the national team is looking at ways to get ACP onto a national digital platform to make access to ACP consistent across the country.

The Commission has contract Jim Brown and associate Jo Jacobsen to scope out the current digital landscape to investigate platforms that already exist and whether these would be suitable to embed ACP.

Contact will be made by Jim and Jo with each DHB's nominated IT and ACP contact to discuss further. Progress will be reported on as the digital ACP scoping project progresses.

Standardised ACP

Preliminary planning to look at ways to standardise ACP nationally is underway. Initial discussions, ideas and planning will be worked on slowly over 2018 with the intention of looking at this more closely towards the beginning of 2019. Discussions with steering group and ACP networks will be discussed as process goes forward.

The group agreed that the focus for 2019 should be on consolidating all the work underway. It is important we line up the work happening locally and nationally.

Other matters

The group thanked Ellen for her fantastic contribution to the programme over the last two years and previous to that.

Close

Clare closed the hui with a karakia. The hui finished at 1pm. The next meeting is 4 July.

Closing karakia

Kia tau te manaakitanga
Ki runga I tēnā o tātou
Kia piki te ora, kia piki te māramatanga
Kia hoki pai atu, kia hoki pai mai
Tūturu whakmaua kia tina! (tina!)
Haumi e!
Hui e!
Tāiki e!