ACP Steering Group Meeting Minutes
5 April 2018

Present

Jane Goodwin (Chair)

Arthur Te Anini
Carla Arkless
Ellen Fisher
Helen Rigby
Jane Large
Kate Grundy
Kate Orange
Kirstin Pereria
Rachel Haggerty
Sue Cooper

Commission staff

Clare O'Leary
Deon Walsh
Jenny Hill
Leigh Manson
Lizzie Price
Ricki Smith

Apologies

Barry Snow
Kendra Saunders

1. Welcome and apologies

Jane Goodwin welcomed everyone to the meeting, and group members introduced themselves, and talked about their particular interest in ACP.

2. Matters arising from meeting 13 March 2018

2a The terms of reference were confirmed, with one minor correction (6th bullet on pg 2 to read 'Clinical leads from regions'). It was clarified that we are awaiting a clinical lead for Midland.

Action: Commission to make change to ToR and finalise them.

2b. There was discussion about further potential members of the group, and their bios were handed out. They were:

- Noel Tiano
- Jason Kerehi
- Marianna Churchward
- Jane Pou
- Te Rina Ruru
- Courtenay Mihinui.

There was agreement that it would be great to have these different perspectives as part of the group, but also some concern about how this would affect the size of the group, which is already large.

It was agreed those proposed would be invited to join the group, and the Commission would manage the logistics of a bigger group.

It was also agreed that there was a need for another face-to-face with the expanded group.

In terms of having a NZ Aged Care Association representative on the group, Lizzie Price will continue to try to contact CE Simon Wallace. If she cannot contact him, or if the NZACA does not want to be a member of the group, they will be kept in the loop as a key stakeholder.

2c. The minutes of the teleconference on 13 March 2018 were confirmed.

Actions

- Commission to invite those proposed above to join the steering group.
- Commission to work with the group to find a date for another face-to-face meeting.
- Commission to continue to try to contact NZACA.

3. Key themes from regional workshops

3a. There have been four workshops around the country in the last six weeks, looking at local and regional needs for ACP support. Leigh talked to the summary of key themes (see appendix).

There have been a mix of responses from DHBs about the proposed train-the-trainer model. There is a risk that if the train-the-trainer programme for the DHB ACP trainers is not adequately supported with FTE and training course logistics/administration, this would negatively affect the ACP programme.

In response to the concerns raised by the DHBs and as a mitigation strategy it was proposed we work with the DHBs that are ready and willing as pilot sites, take the lessons learnt and adapt the approach for the next group of DHBs to do the training. While this staged approach is undertaken, the national programme will deliver L1A training to DHBs who are not part of the pilot.

There was discussion that we need to be aware that the programme is being funded by 18 DHBs and a pilot could be seen as subsidising some DHB to be trained, while training doesn't go to others who have also provided funding. This is a significant risk.

Following discussion, it was agreed that the ACP DHB train-the-trainer to all 18 DHBs and a staged roll out undertaken. In addition, it was agreed that we reflect to DHB Planning & Funding the issues raised by many of the DHB ACP implementation teams so that they can

address the needs and concerns of their ACP teams to ensure they maximise the Train-the-Trainer programme they have purchased.

Status reports about uptake of the train the trainer will be provided to DHB Planning & Funding and shared with this group for wider distribution. Action: Leigh

Enhanced clinical communication train-the-trainer – the Commission has secured the opportunity to bring the Serious Illness Conversation Guide (SICG) and associated training to New Zealand in November 2018. We have the opportunity to train 32 trainers – senior clinicians with experience in having conversations in acute environments who would then be capable of training clinicians in DHBs on how to effectively use the Serious Illness Conversation Guide. The SICG training is an enhanced clinical communication training programme aimed at non-palliative clinicians in secondary care environments required, it sits between basic clinical communication training and advanced clinical communication training.

This train-the-trainer opportunity is being seen as more manageable by DHBs and we are rolling it out between 14 and 20 November 2018. As part of this roll out, we will also develop New Zealand capability to train more trainers in the future.

Actions:

- The Commission will provide Rachel Haggerty with a summary of the DHB ACP train-the-trainer issue to raise at the GMs Planning and Funding meeting on Monday 9 April.
- The Commission will provide ongoing feedback to DHB P&F, CEs and ACP contacts about the issues noted above, with specifics on what is being offered to DHBs, and uptake.
- The Commission will draft a letter for DHB P&F to send to DHB HR managers about what DHBs have purchased in terms of training.

3b. IT solutions for joined up ACP

DHBs in regions are doing different things around IT solutions to join up ACPs. The Ministry of Health's standards team has offered to support the Commission to develop standards for electronic sharing of ACPs. The Commission will also talk to the Ministry team about having a national alert on people's records showing they have an ACP.

MedTech has added an ACP to its practice management system (PMS) ManageMyHealth so people do their own ACP. MedTech will make this available to all MedTech practices. It is web-based, so anyone with permission can access it. The group noted that this was an exciting development. Concern was raised about lack of a quality assurance step to ensure the plan did not contain conflicting wishes. If conflicts were seen frequently in plans by the clinicians who read and attempt to use plans, this may discourage clinicians from looking for or relying on plans in the future.

Another concern is that, at this stage, ManageMyHealth doesn't link to electronic medical records used by acute hospitals and ambulance teams.

It was suggested the Commission provide an update of these IT developments to DHB chief information officers.

Actions

- The Commission will write to DHB chief information officers, on behalf of the steering group, making them aware of the Ministry's involvement in potentially developing standards for the electronic sharing of ACPs, and of the MedTech ACP developments.
- The Commission will report back to the steering group on its meeting with the MoH.

3c. Insufficient facilitator/project resource for local implementation

There was discussion about the differences across DHBs in terms of the FTE available to drive local ACP implementation. Some DHBs have full time staff, others have .5 of a person, and others have no available FTE.

It was agreed that a minimum 'critical mass' was needed to make ACP work locally and regionally, including across settings (not just in hospitals).

This lead to a discussion about the need for a minimum package of what DHBs need to provide for successful local/regional implementation of ACP. Investing only in some components of ACP delivery is ineffective. For example, a minimum package might include 1 FTE for implementation, protocol of how to capture and retrieve ACPs for the DHB, inclusion of information about ACPs in staff orientation etc.

Actions

- Ellen Fisher, Jane Large, Ricki Smith and Carla Arkless will form a subgroup to develop the 'minimum package' concept further and bring it back to the next meeting for further discussion.
- The Commission to include in its communications with DHB P&F that they won't get full value for their investment unless staff with dedicated time are made available for local implementation.

4. ACP promotion

Lizzie Price and Clare O'Leary presented a communications plan to raise general public and sector awareness about ACP. This included the suggestion of a social marketing campaign, using paid media, PR and stakeholder work.

Clare discussed a number of PR ideas. These included working with Defence, ambulance staff, Department of Internal Affairs, when people get their gold card, mayors and council community development teams with a 'building resilience' focus; champions, leaders and celebs; and the health of older people.

Other ideas and comments from the group included:

- work with NZ Police, lawyers, first aid providers, there is a euthanasia bill before Parliament and we need to be aware of how the ACP conversation will change if the law changes (see the link to David Seymour's physician assisted suicide bill; http://www.legislation.govt.nz/bill/member/2017/0269/latest/DLM7285905.html?src=qs)
- Stan Walker as a champion?
- RNZCGP to proactively promote ACP and sharing what practices are doing
- take famous NZers and ask them three questions (Australian palliative care site) http://palliativecare.org.au/dr-philip-lee-dying-talk http://palliativecare.org.au/amy-sagar-dying-talk
- insurance companies and funeral directors to offer reduced prices if someone has an ACP.

The proposed timeframe for the campaign was to appoint a preferred provider by end June 2018, with the campaign to start at the beginning of 2019.

It was agreed that Lizzie and Clare will develop a campaign brief which they will take to the group, and provide that to the preferred agency, who will then develop the creative and advise on other aspects of the campaign. The creative will be presented back to the group as an FYI, unless the group has major issues with it.

Other

There was discussion about whether we have another national ACP hui / forum. An alternative suggestion was that we find a way to be part of the health of older people national forum.

All content from the existing ACP website is being moved onto ACP pages on the Commission's website. This means the look and feel has changed somewhat. Hosting ACP on the Commission's site means changes can be made much more quickly and for no cost. The Commission will request feedback on the navigation of the new site in April and incorporate that feedback before we go live with redirecting website traffic from the old website.

- Decision: It was agreed that a national campaign was important and should go ahead.
- Action: Commission to develop a campaign brief and send it to members of the steering group for comments.
- Action: Commission to look into ways of being part of the health of older people national forum.
- Action: Commission to seek and use feedback about the navigation of the new website before going live.

5. ACP resource development

5a. Clare updated the group on the task of creating a national ACP resource for Māori that is appropriate for all iwi. A Māori project manager will be appointed to manage the process. We will be linking in with people we already work with to get a resource that speaks to everyone.

5b. Pacific and Asian resources will be in the next phase of development.

5c. Review of ACP guide and plan. Different feedback about the ACP Plan continues to be received – don't change it because it's in our systems, along with it's too long and confronting.

There were comments from Arthur Te Anini and Sue Cooper that the plan was too long, making it hard to fill in. They said it needed to be kept very simple – simple to understand and simple to do. Kate Orange commented that, as a GP, she encouraged people to start with the last page, which was less confronting. She also felt the plan was too long. Other members of the group including Kate and Jane Goodwin commented that their experience was that people loved the plan and that clinicians required to interpret these plans found them invaluable. They felt that it was more an issue of people understanding how to use the plan than the plan itself. It was also commented that for DHBs and regions that had digitised the current plan, changing it would have a substantial financial and required change management cost.

The group agreed that it was important to understand what the real issues with the use of the current plan is for people so that we can formulate a response that addresses the root causes. This was included in a key project for this year – ACP Plan and Guide use review - what works, what doesn't, how we can address issues.

Action: Commission to look at pros and cons of current plan, consulting widely with different groups. Recommendations for how we address the causes would then come back to the steering group.

6. 'State of the nation' resource

One of the regions suggested that it would be useful to develop a mechanism to gauge how DHBs are doing on various aspects of ACP implementation. So a 'state of the nation' table was developed for discussion, with questions such as, Are clinicians aware of their role in ACP?

There was comment that these questions were very subjective, and it might be better to focus on more concrete measures, for example, amount of FTE allocated to ACP implementation.

It was agreed that the group needed to do more thinking about potential DHB-level process measures, including what the purpose of getting this information would be and how it would be used. This item will be held over to the next meeting.

- Action: Commission to put 'State of nation' resource on agenda for next meeting.

Leigh updated the group on the plans for national measurement and evaluation of the ACP programme. Nationally we are looking at three outcome measures:

- outcomes for the system – reduction in use of various services in the last year of life, based on Commission's intelligence team work on last year of life. Compare population with an ACP to population without an ACP and what the difference is
- patient experience surveys – inpatient and primary care, see if we can use one of the existing questions or a combination to indicate a difference in experience and satisfaction for those who have an ACP
- family impact – Voices research, experience of family following the death of their loved one.

7. Online module access and learning management system

Leigh explained that there are four learning management systems (LMS) in the country. The online learning hosted by these LMSs are largely only accessible to DHB staff. For this reason, when the ACP modules were moved off the American LMS in 2017, that they were originally hosted on, they were placed in an open access LMS so everyone could access them – ARC, community providers, members of the public etc. As part of supporting DHBs with the implementation of ACP training locally and the SICG training, the Commission is developing course registration and evaluation capability into this LMS. This is aimed at reducing the administration burden of DHBs and will allow for national quality assurance and trainer coaching and support.

The Central region has asked that the ACP training modules are incorporated into DHBs' LMSs, as this will make it easier for training to be allocated to staff and to monitor the completion of modules. Helen Rigby said the main reason for wanting a local LMS platform is to give more control to DHBs which would significantly improve uptake. She said there should be ways of locking down the package so it doesn't get changed unless the national package changes.

Midland would also like to have the training within DHB LMSs, but noted some concerns with having ACP modules managed at a DHB level.

Leigh raised a concern about the national cost if each LMS has ACP online training, L1A /SICG training registration and evaluation, the software changes will need to be created five times

It was suggested that we look at understanding what the needs are of the four LMS's and to see whether there was a way to address those without creating 5 versions of the online learning and L1A/SICG training registration/evaluation.

Action: A sub group (including Leigh, Ricki and Helen) will work with LMS technical people to understand what the options are. We first need to understand the need and then see if it's possible to come to a solution that meets people's needs, without having to do five versions of the software package.

8. Risks and issues

This item was held over until the next meeting.

9. Other matters

There was discussion about sharing the agenda, minutes and papers from steering group meetings with people outside of the Steering Group membership. It was agreed minutes (once confirmed) would be placed on the ACP website together with other relevant documents on a case by case basis.

Key messages will be developed after each meeting and given to members to share with their networks. Action: Clare

Appendix

Themes from the 4 regional workshops – February/March 2018

1. Positives:
   1.1. Most DHBs reported an increase in ACP activities and awareness.
   1.2. ACP training, including online modules were reporting to be working well to support DHBs
   1.3. CTC Day works to focus promotion of ACP

2. Wishlist:
   2.1. Most common wish list item – Dedicated resource to drive ACP
   2.2. Second most common wish list item – a shared IT system

3. Questions raised:
   3.1. DHBs wanted to know how to get leadership/CEs/decision makers on board.
   3.2. DHBs asking “how can we measure our progress?” and “how can we capture data?”
   3.3. DHBs asking “how do we make the most of ACP with no dedicated budget?”
   3.4. How will we ensure national consistency and make sure we are all singing from the same song sheet

4. System/IT
   4.1. It seems most DHBs are now at a point where a shared IT system/digital strategy would help them progress and stream line their systems.

5. Barriers:
   5.1. communicating and linking between sectors
   5.2. Lack of local and national support for trainees post training
   5.3. Lack of understanding and knowledge by clinicians to create, review and use ACPs - wanting clarity and additional resources around legalities of ACP
   5.4. Feedback from some DHBs and individuals that ACP plan and guide is too long, not appropriate …etc.” Districts who have been working with an ACP template for some time report the new template has been well received and clinicians using the plans to guide care are reporting the greater depth of information collected invaluable.
   5.5. Consumers reluctant to put their wishes on paper
   5.6. Perceived barriers for the international workforce
   5.7. Lack of an ACP social media presence
   5.8. Concerns around gaps in health literacy

6. Concerns around TtT implementation –
   6.1. too much to ask for small DHBs to be able to find, support trainers and support administration of training
   6.2. 6 trainers were seen by some larger DHBs as not enough Trainers
   6.3. selected trainers not being given dedicated and ring-fenced time to develop their skills and/or deliver this training (concerns that it would just be added to their current full time roles)

6.4. lack of resource or systems/processes to support the administration/logistics of training
6.5. Trainer retention and ensuring quality/competency maintenance
6.6. regional and sub-regional models were explored
6.7. questioned whether it was too late to go back to a national delivery model for L1A training
6.8. Importance of training/resources and conversations being culturally safe