

ACP Advisory Group Meeting Minutes 10 April 2018

Present

Sarah Clark (Chair)	Chief Executive, Social Workers Registration Board
Marj Allan	Consumer representative
Hector Matthews	Executive Director, Māori and Pacific Health, Canterbury DHB
Sara Rishworth	Palliative Care Specialist, Mercy Hospice
Michelle Main	Programme Manager, Palliative Care Programme, Ministry of Health
Jane Large	South Island regional ACP, South Island Alliance Programme Office
Anna Stevenson	Public Health Physician, Canterbury DHB
Stephanie Clare	Chief Executive, Age Concern
Sue Cooper	Consumer representative
Helen Mason	Chief Executive, Bay of Plenty DHB
Sue Ineson	Executive Director, Council of Medical Colleges
Chris Walsh	Director, Partners in Care, Commission
Leigh Manson	Senior Programme Manager, Commission
Lizzie Price	Director of Communications, Commission
Clare O'Leary	ACP Promotions Coordinator, Commission

Apologies

None

1. Welcome and introductions

Sarah Clark welcomed the group and opened the meeting with a karakia. Each group member then introduced themselves, and briefly talked about what they hoped to get out of their involvement in the advisory group, and their advance care planning experiences.

2. Confirmation of the minutes of the last meeting 21 March 2018

The minutes of the last meeting were accepted without amendment.

Actions from the minutes:

- The group agreed that a second face-to-face meeting would be useful. Lizzie is going to check the budget and look at other options, such as videoconferencing. **Action: Lizzie Price**
- Sarah is meeting with Vivienne Jenner from the seniors' policy team at MSD to talk about her possible participation on the advisory group. **Action: Sarah Clark**

3. Matters arising from previous meeting:

- The revised terms of reference were discussed, and the following amendments suggested:

On page one:

- add that the group will report regularly to DHB chief executives

On page two:

- change 'consumer representatives' to 'consumer perspectives'
 - change 'representatives' of the various groups to 'perspectives'
 - clarify that Ministry of Health representation includes coverage of palliative care, HWNZ and older people's Health Quality & Safety Commission
 - add 'district health boards' as having their perspectives represented
 - under 'Required skills/attributes, add 'proactive champion of ACP'
 - correct top of page 3 to read "The committee has a deputy chair...'
- There was also discussion on whether the advisory group had more of a 'think tank' role, than an advisory role. The former means more freedom for 'blue sky' thinking, without connotations of making commitments on behalf of organisations.
 - The membership discussion for the increased need for Māori and Pacific perspectives was held over until the group agreed its purpose.

4. Election of deputy chair

Dr Sara Rishworth was elected deputy chair of the group.

5. Overview of ACP development, and workplan

Leigh Manson gave an overview of the development of the 2018-2022 National ACP strategy and road map of actions and outlined the ACP programme's work plan for 2018-2019 (the first two years of committed funding).

Eighteen DHBs have committed to two years of funding for the National ACP programme, to end 2019. We are in discussions with Counties Manukau Health and Waitemata DHB on their contributions towards the elements of the programme they will benefit from, such as the website and resources.

There was discussion about the impact to the national programme from not having those two DHBs on board, particularly in terms of their large Pacific (CM) and Asian (Waitemata) populations.

There was also discussion about how we integrate ACP into the approaches and policies of other organisations and aligned topics – for example, the Healthy Ageing Strategy, Pharmacy Action Plan, Palliative Care Action plan etc. See Appendix 1 for more detail.

6. Promotion of ACP

Lizzie and Clare O'Leary presented thoughts about raising public and sector awareness about ACP. This include 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.

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.

Group discussion included:

- target audiences, and how messages would need to be delivered in very different ways to these audiences. I.e, the approach for Māori would be very different to the approach for those who have grown up in a European culture
- we need to engage with stakeholders outside the health sector, such as pharmacists and lawyers. We need to find the touchpoints of ACP along someone's life journey when the ACP conversation can be instigated
- do we need a campaign at all? Should the focus instead be on talking to relevant groups and resource development?

Overall, there was support for a campaign approach. Communications need to be appropriate to our different audiences.

7. Monitoring and evaluation

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 – emerging international evidence is finding that when given the opportunity to develop care and treatment preferences consumers choose less aggressive treatment than clinicians ordinarily provide. We are exploring an opportunity to look at whether this has happened in New Zealand with two DHBs – is there a difference in use of health services in the last year of life between consumers with ACPs and consumers without ACPs.
- patient experience – we are looking at the current inpatient and primary care patient experience surveys to 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 experience – Voices research data is being analysed and will provide insight into the experience of family following the death of their loved one including specific questions about ACP.

There was discussion about how we measure concordance – that is, how closely were the wishes of someone with an ACP followed? Leigh agreed that this would be ideal and something for us to work towards. There are concerns with the resource intensity for DHBs with this kind of research as it would require qualitative audits by healthcare professionals.

8. ACP training

Leigh gave an update on the planned train-the-trainer programmes that will be rolled out in 2018/19:

- DHB ACP trainers – this programme will train trainers in DHBs to be able to deliver ACP training to people across the districts. The focus of this training is on what ACP is, the benefits of ACP, the legal framework for ACP, initiating and documents ACP conversations, using ACP to inform care.
- Serious Illness Conversation Guide training – this is a short and focused enhanced communication training programme been developed by Ariadne Labs with Atul Gawande. Ariadne Labs trainers will be coming to New Zealand in November to support the training of New Zealand Uber trainers and the training of 32 DHB-based trainers. This will provide DHBs with the capability to improve the communication confidence of non-palliative healthcare professionals in the acute environment.
- Volunteer training – a focus for 2019, this programme will build on the conversations that count communicators training programme with the aim of increasing the numbers of volunteers that can support ACP conversations in communities.

9. Implementation

Leigh gave an overview of the implementation strand of work. Regional workshops have been undertaken with ACP facilitators, trainers, educators and managers, DHB planning and funding, leaders/champions etc. The purpose of these workshops was to familiarise DHB ACP teams with the 5-year strategy and roadmap of actions, support them to work through a DHB plan for delivering on the local actions in the roadmap, and support them to maximise train-the-trainer opportunities.

She also advised the group that the Commission is working with the Ministry of Health on the potential development of standards for electronic ACPs, so information can be shared, and an ACP alert that different providers will get.

10. Clarifying the role of the group

a. *Leading Large Scale Change*

Leigh shared some key points from work on leading large scale change out of the NHS:

“Power to create change no longer comes through positional authority, power comes from connection and ability to influence through networks”

3 dimensions of large scale change:

1. Wide spread – across groups, industries and sectors
2. Deeply challenging mental models and ways of thinking
3. Broadly impacting on what people do in their lives or in their time at work

Is ACP or people-powered health a large scale change?

- Are we envisioning a very different future
- Does it require co-ordinated changes in structures, processes and patterns of behaviour
- Do the three dimensions above apply to ACP?

Agreed ACP is a large scale change – for more information here is the link to the practical guidelines developed by the NHS:

<https://www.england.nhs.uk/publication/leading-large-scale-change/>

b. *Environmental Scan* - A high level environment scan was done with the group to identify activities currently underway across Health and Social sector

- **Ministry of Health** DSS Transformation programme, primary care suite of changes – not just GPs but a suite of actions. GP fees, gold cards. 9 funds, hopefully broad review. www.moh.govt.nz
- **Healthy Ageing Strategy** <https://www.health.govt.nz/publication/healthy-ageing-strategy>
- **Carers Action Plan** <https://www.msd.govt.nz/about-msd-and-our-work/work-programmes/policy-development/carers-strategy/>
- **Residential Aged Care Review**, E & Y – funding review. Where the dollar will drive the outcome. Accommodation vs services. Just beginning the process. Mechanisms of care, not just responding to the funding outcome, but health care services. A broader view of models of care and quality of care.
- **MSD: Positive Ageing Strategy** – Stephanie 2001, just doing a refresh of it. The new Minister wants to do a whole review and will do a systems review, so

workshops will be developed. <http://www.superseniors.msd.govt.nz/about-superseniors/office-for-seniors/positive-ageing-strategy.html>

- **Heather McLeod** is due to complete her research on *Trajectories of Care* for Min of Health in the last year of life. What services have they been through and where they end up. Where people end up – data collection story, especially in the hospital, hospices have more sound data collection than anywhere else.
- **Auckland research on ACP, Te Arai Palliative Care Team**
<https://www.fmhs.auckland.ac.nz/en/son/about/our-research/research-groups/the-palliative-and-end-of-life-care-research-group.html>
- **Ageing Well Science Challenge, Ak University**
<https://www.ageingwellchallenge.co.nz/>
- **The Cancer Plan**, as a living document.
<https://www.health.govt.nz/publication/new-zealand-cancer-plan-better-faster-cancer-care-2015-2018>
- **Health Workforce NZ Development Plan** <https://www.health.govt.nz/our-work/health-workforce>
- **Pharmacy Action Plan – conversations around new contracts with DHBs.**
<https://www.health.govt.nz/publication/pharmacy-action-plan-2016-2020>
- **Digital Technology – equity – business case.**
- **National Funding review on patient travel.** <https://www.health.govt.nz/new-zealand-health-system/claims-provider-payments-and-entitlements/national-travel-assistance>
- **InteRAI** – Have you got an advance care plan question. The way that is reported is non-standardised. So we should have an interest in that.
<http://www.interrai.org>
- **TAS** is doing a piece of work about aligning PHO and ARC access.
www.tas.govt.nz
- **Inpatient and Primary Care Patient survey** – Liz/Leigh are talking to Richard Hamblin about that.
- **Palliative Care Action Plan** – <https://www.health.govt.nz/publication/palliative-care-action-plan>
- **Long Term Conditions and Acute Demand** work – integrating ACP into these workstreams
- **The Commission:** Mortality Review Committees, Deteriorating Patient – has goals of care as part of it. Partners in Care Programme: consumer voices; Falls Programme – facilitating ACP conversations after an acute fall. Also, Leading national ACP Implementation Team.

The CEO promoted ACP by giving all staff an ACP booklet and CEO encouraged all to complete it and talk with families as part of 'walking the talk' and ACP Day. Also through key stakeholders, oopū, the Commission's Māori advisory group and Te Tumu Whakarae – Māori Advisory groups for the Commission.

c. **Role of the advisory group** in this context

There was general discussion on what the role of the group might be. Within the discussion the following was raised:

- need to engage more broadly beyond health and influence broader thinking
- important to normalise death and dying as part of health and well-being
- there was discussion on NZ having a death denying culture. The group felt it was important to recognise that this comes from a more dominant Anglo-

Saxon culture. Māori culture embraces death more readily demonstrated through tangi and tikanga.

- need be very responsive to specific groups, such as Māori, Pacific, Asian, lgbgti, people with disabilities, ageing demographic
- ageism was a challenge – the need to support positive messaging and attitudes to getting older
- we need to always be cognisant of the perspective of Māori. It would be useful to focus on universal values such as aroha, manaakitanga, respect, dignity and compassion, integrating the values at the heart of what we use. Using these values, messages can then be communicated in different ways
- it would be useful to capture the key messages, stakeholders and touchpoints of ACP in a visual map (see appendix)
- it would be useful to have standard national presentations and resources about ACP that can be adapted for local use, and use key messages (for further discussion)
- enduring power of attorney – the cost barrier to access was discussed and there were different views on this
- Michelle Main talked about her meeting with a local app developer, who had developed the advance directive app 'My Say'. The developers are looking for partnerships and endorsement of the app. Action: The secretariat will meet with the app developers
- develop key messages for a toolkit for others to use.

AGREED - the role of this group was to normalise ACP with integrity (thinking about use of language, the audiences and agreeing key messages); to influence (within member networks, integrating into policy and strategies, talking to people about ACP); and walk the talk (to do our own ACPs and start conversations with the important people in our lives).

Actions:

Secretariat to:

- **develop a standard national presentation about ACP**
- **meet with the developers of the advance directive app 'My Say'**

11. Carried over to next meeting

These items will be carried over to the next meeting.

- How do we engage and share ideas with the steering group?
- Determining what we hope to achieve in the first two years (three core things) – for further discussion
- How will we measure our success?
- What reporting do we want to do and to whom?

The meeting ended at 2pm.

Appendix - Stakeholder engagement map from ACP Implementation Team

Stakeholder	Engagement / participation method
Consumers	Consumer representatives on Programme Advisory Group, include in all project teams
DHB CEs and P&F managers	Quarterly reporting, include P&F in regional workshops
MoH and HWNZ	Build relationships with key people, agree national measures, regional and annual planning requirements, support with wider communication development
HOP	Work with portfolio and regional managers to find opportunities to support each other
Acute care teams	Understand and respond to their needs
Community teams (including GPs and PHOs)	Understand their needs/barriers and respond with adapted training and resources
ARC and retirement villages	Increase awareness of the positive impact good ACP has, understand barriers and work with them on resolving these
Hospice	Build strong relationship and look for mutual benefits around volunteers and community support for ACP
NGOs	Build strong relationship and look for mutual benefits around volunteers and community support for ACP
MSD	Find common ground and build a shared understanding, look for opportunities to promote ACP through MSD
Aged Concern/Grey Power	Build strong relationship and look for mutual benefits around volunteers and community support for ACP
Lawyers/CAB/Financial advisors	Build a shared understanding and look for opportunities for lawyers to support clients with ACP/promote the importance of ACP
Carers	Build strong relationship and look for mutual benefits around volunteers and community support for ACP