

Consumer engagement Agency for Clinical Innovation (ACI)

Giving a voice to key stakeholder perspectives

This is a brief summary of the *Consumer Engagement in the ACI: Key stakeholders perspectives* report produced by the Australian Institute of Health Innovation (AIHI) for the NSW Agency for Clinical Innovation. It highlights key findings of that report through quotations from consumer members of ACI clinical networks, taskforces and institutes interviewed as part of this project.

I realised that knowing the patient perspective would be beneficial to clinicians and would contribute to their sense of job satisfaction, as well as encouraging them in that the work they do is greatly appreciated by their patients.

To continue to help provide an improved health system for all stake holders i.e. Clinicians, Health Managers and Patients.

What motivates consumers to become involved in the activities of the ACI?

To improve the lot of ... patients, improve the effectiveness of [community organisations] and create synergy between the two organisations.

To contribute to significant change in the health system through:

- Obtaining information
- Helping others
- Having a voice.

Just that I am really grateful as a consumer that something like ACI exists where I can contribute and if I have got an idea or – not necessarily a complaint, but some constructive criticism or whatever, that there is somewhere where I can air that.

What experiences do consumers have, once they are engaged with ACI?

Ranged from:

- Highly commended to feeling of tokenism
- Overall experience of consumer engagement was positive with some areas noted for improvement.

"Opportunity to contribute to a body which has the potential to make actual changes to practice on the basis of initiating new ideas - in effect a 'think tank' with hopefully some clout to introduce these"

An annual meeting and or training would help empower us (because mostly we are a very small percentage on a board where clinicians etc are very acute focused and are very medicalised/use jargon etc)

What helps consumers to become engaged?

- Consumers considered active partners driving change across the health system
- Tangible and symbolic recognition of the importance of consumer contribution
- Process specific efforts to access and engage more vulnerable individuals and communities
- Clarity about whether consumer representatives should collect input from and feedback back to the community
- Clarity of role and expectations of consumers
- Clear and transparent processes (e.g. administrative, feedback, change, reporting, communication)
- Empower consumers to participate (e.g. glossary of terms and acronyms; actively seek input; provide safe space; accommodate needs; training)
- Mechanisms to network consumers with each other across ACI
- Champions and passion
- Funding
- Collaboration with organisations external to ACI
- Raising the profile of ACI.

I became a member of a health council years ago after seeing a small ad in a local paper. Since then we have had feature articles in the local paper when we need to recruit and that always works well in getting people with no previous contact with a consumer body to apply and who also represent a specific minority group not yet represented on the health council e.g. young people or Aboriginal or disability.

I would like to see us being given specific tasks, rather than just tagging along on the perimeter of the medical personnel's debates.

At least 2 and possibly 3 consumers should be invited to participate because it can be very intimidating for some consumers to participate at this level" because "(I need) fellow network members to act as "sounding boards" for ideas and checks of my understanding

... it makes such a difference to say thank you for coming

How can ACI engage and retain consumers once recruited?

"Once every 4 months, it would be very helpful if ACI could send a letter or ring the engaged consumers to ask if they are OK – a "checking in" – are you resourced enough, are you still OK to participate – how are you going etc and then once a year to see if the committee they are on is still the most appropriate"

Some consideration needs to be given to a carer's lot or consumer because if they are at the ACI after hours for meetings they still have to meet their caring needs and work commitments. Financially it is tough enough with reduced work hours without getting some compensation for our time and effort to attend meetings. Please pay consumers; this helps us feel that you really value our contribution. Consider these costs and make it part of the budget

- Ensuring consumers feel valued
- Ensuring consumers feel supported
- Reassurance
- Representativeness
- The willingness of clinicians to engage
- Reimbursement
- Transport
- Information and communication
- Timing and location of meetings
- Improvements to meetings and workshops
- Monitoring engagement

- “Basic” training
- Team work
- Overview of ethics
- Media training
- Small group facilitation
- Coaching and mentorship
- Participation in meetings
- Terminology education
- Expectations of Consumers
- Interaction and meeting skills
- The skills required to be a good communicator
- Skills in how to participate in ACI and its networks
- Reasons for confidentiality and privacy, complaint system.

Depends on the individual’s background. If they have never attended meetings they will need training on how to behave at meetings, how to communicate with others, listening skills and clear channels of support for the carer should be provided

What should consumer engagement training include?

“Confidence boosting to encourage consumers to speak up but there should also be guidance on diplomacy and realistic expectations”.

... we could do with some media training to promote the work being done by ACI for local community

I would need a terms of reference with aims and goals with finite beginning and end, talking without purpose is of no interest

What improves consumer’s experience of engagement?

- Ease of engagement
- Making a difference and a valued contribution
- Positive impact of visible support by the senior executive
- Program/Network Managers are pivotal.

I am very happy with my involvement on one of the committees because my involvement on that committee visibly and definitely leads to change, that is there are visible results due to the work of the committee. However, the other committee does not seem to have as much impact. It is very frustrating ... if the only experience I had of consumer involvement on a committee was that of the one in which not much is achieved, I would become very disengaged

The courtesy shown to the consumers indicates their value, both to the other ... members and to the consumers themselves. Their input is included in documents, wherever possible”

Whereas really it’s really hard to recruit say from aboriginal communities, from disadvantaged groups, from disabled groups or disempowered groups - really hard for a whole range of reasons

What are common barriers to engagement?

We welcome the attempts to engage in consumers of the services but feel that due to the terminological and other barriers, and also what appears to be tokenistic efforts to involve consumers, that there’s a long way to go

- Uncertainty about the role
- Attracting hard to reach groups
- Disempowered consumers
- A lack of awareness of consumer engagement
- Feedback on whether consumer input has made a difference
- Apprehension around obligations

What are common enablers to engagement?

I've been involved with, and the Consumer Rep ... he's one of the co-chairs. He's very passionate about what he is doing, and the reasons for why he is doing it. So I think having someone - consumer leading it ... I think having good champions in the community - someone who's very involved with the community - is a good thing, because they know where to tap into different areas, different community organisations. You've got to have people who are open-minded, and don't come with their own agendas

- Characteristics of individuals (passionate champions)
- Cross representation
- Clear and transparent expectations
- Streamlined and transparent processes

I think, again, it's a mind shift change. Instead of the question being how does ACI involve consumers, I think the question should be how should ACI be directed by consumers? The first one is a very passive role; the second one is a very active role

- Paradigm shift
- Training and induction
- Clear communication
- Empowering and networking consumers in ACI
- Knowing who is involved in ACI and tapping into key information within ACI
- Utilising a variety of engagement mechanisms including online registers, Consumer Council representation and champions

How can ACI improve the consumer engagement process?

Giving people a true voice, by fostering an expert patient approach, by reducing the clinical nature of communications and interactions, by making their involvement less tokenistic

You need to be on the agenda you need to have a willingness of the group to want to pursue consumer interests" and "the consumer voice [needs to be] explicitly sought at meetings - and also debated if relevant

Therefore people who are representing consumers really should have a mandate of a consultative strategy around how they are going represent consumers in those forums...

What should the ACI Consumer Engagement Framework include?

- Vision and mission
- Recruitment and representation
- Induction and orientation
- Valued, respected and supported involvement
- Feedback
- Strong relationships
- Evaluation

...because the representatives that are representing consumers, they really should be - they should actually submit to ACI how they're going to do that in a clear and transparent way

ACI are great ... they are for consumers. We're always talking about maybe improving the way they go about it but you can't fault ACI on the consumer generally, you can. They pay lip service to consumers. That's the word, it's lip service, we're the token person and we're lucky to be invited in many cases

Because if we're all working for clinical innovation we want to know what the outcome is ... but does the normal consumer attending the committees, know what the pathway is to get to the change?

In summary...

I'm just wondering like I'm on the [de-identified] group - exactly how that tool will come out of that. How will that be evolved because it's a big committee - I sort of wonder what sort of useful tool will come out of it in the end

- Overall consumers feel valued and supported by ACI in their role
- Consumers see themselves as ambassadors for their specific causes/concerns but also the ACI
- Clarification of roles and best ways to engage, retain and support consumers still required
- Strengthening consumer engagement needs to involve both consumers and clinicians.

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