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

To contribute to significant change in the health system through:
- Obtaining information
- Helping others
- Having a voice.

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.
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.

How can ACI engage and retain consumers once recruited?

- 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
What should consumer engagement training include?

- “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.

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?

- 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

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.

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.

“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 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.

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.

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.

What can ACI improve the consumer engagement process?

- 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.

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.

How 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

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…

...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.

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

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?

- 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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