CONSUMER ENGAGEMENT IN THE AGENCY FOR CLINICAL INNOVATION (ACI):
Key stakeholder perspectives
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EXECUTIVE SUMMARY

The Agency for Clinical Innovation (ACI) is the lead agency in NSW for engaging clinicians, promoting innovation and developing and supporting implementation of new models of care. This report documents a study of consumer engagement amongst ACI’s staff and consumer representatives.

In March – April 2013, ACI in conjunction with the Australian Institute of Health Innovation (AIHI) invited feedback from individual patients, carers, community members and representatives of non-government organisations (NGO) that participate in the activities of ACI clinical networks, taskforces and institutes. The methods used were online surveys, focus groups and individual interviews. Simultaneously feedback was invited from ACI staff. This report summarises the feedback provided by both consumers and staff.

The key points in the report are as follows.

- There is a high degree of agreement between consumers and staff about what constitutes consumer engagement and what is required to ensure its success in ACI.

- The working definition used by staff is a direct and active input and collaboration in the decision making processes and projects by non-clinicians or health care professionals as equal partners at all levels and in all aspect of activities from their inception of those activities, to their closure. Staff spoke of the role of consumers in steering of health services as a whole.

- The study explored the recruitment and retention process for consumer engagement in ACI, along with the perceived barriers and enablers. Word of mouth, including networking and contact with NGOs figured prominently in recruitment strategies.

- Factors which motivate existing consumers, include obtaining information, helping others, positive and negative experience with health services, and wanting a voice. All relate to the desire to contribute to significant health system improvements.
• Being valued was the strongest theme expressed by consumers. Core to the experience of engagement is whether the consumer has a sense of being valued. The visible support of ACI Senior Executive (through their presence at consumer events), the work of Network Managers, and the input of ACI staff in general were highly prized. Such support was viewed as both tangible and symbolic evidence of the recognition of the contribution of consumers.

• Staff recognised both the value of their contributions to consumers, and the cost of participating. A range of support strategies was identified by both consumers and staff, most centred around practicalities of attending meetings, orientation and training. Others dealt with more complex issues, such as the attitudes of some clinicians towards consumers, and the need for more extensive engagement, which was seen as requiring modifications to existing strategies.

• The importance of effective communication was emphasised. Such strategies include the need to develop stronger networks between consumer representatives, and between consumers and the ACI Consumer Council.

• Participants’ overall experience of consumer engagement with ACI was positive, although along with staff, they were able to articulate a number of concerns, including the cost of participation to the individual consumer. The need for ACI to make special efforts to access more vulnerable individuals and communities (including Aboriginal and Torres Strait Islander peoples, Cultural and Linguistically Diverse communities, people with disabilities, and rural consumers) was noted.

• Suggestions to inform an ACI Consumer Engagement Framework included: ‘True’ representation, genuine partnership based on equity and equality, integrity and trust, transparency of procedures, collaboration, cooperation, consultation, constant communication and clarity, the valuing of contributions through respect and recognition, and ongoing evaluation.
I. **INTRODUCTION**

The Agency for Clinical Innovation (ACI) is committed to the active engagement of consumers. Individual patients, carers, community members and representatives of Non-Government Organisations (NGOs) currently play an essential part in ACI’s clinical networks, taskforces and institutes. This report presents the results of a study examining the perspectives of consumers and staff about the scope of, processes for, and impact of consumer engagement within ACI. They reflected on the values and principles that underpin consumer engagement in ACI, and described their visions for a Consumer Engagement Framework for ACI. The results are presented via direct quotes from consumers and staff. Aggregated results are presented to show patterns. Not all responses are quoted, rather a representative sample is provided, indicating both agreement and contrasting or contested views.
II. METHODS

Data collection

The research team from the Australian Institute of Health Innovation utilised a mixed method approach for the collection of data from ACI’s consumer and community representatives and staff. The methods included a survey, focus groups and interviews. The researchers in conjunction with staff at ACI developed the study questions.

A formal invitation to participate in this project, an information sheet explaining the purpose and process of data collection, and a link to an anonymous online survey was sent to all consumer representatives and staff by ACI’s Chief Executive Officer via email. The survey period was set from 22\textsuperscript{nd} March to the 10\textsuperscript{th} of April, 2013. A reminder was sent on 3\textsuperscript{rd} April, 2013. The survey questionnaire is presented in Appendix A, and details of respondents (consumers and staff) in Appendix B and Appendix C.

Participants

A total of 31 consumers and 32 staff completed the online survey. Individuals who responded to the survey were asked if they wished to participate in focus groups or interviews, intended to probe questions raised in the survey in greater depth. Of the 31 consumers, 26 agreed to participate in follow up group or individual interviews. There were 14 of the 32 staff who indicated that they were happy to be individually or collectively interviewed.

The consumer focus group was conducted on the 18th April, 2013 and the interviews between 17\textsuperscript{th} April, 2013 and 3\textsuperscript{rd} May, 2013. The same questions were asked in both the group and individual interviews, although they varied slightly between staff and consumers. The interview questions are presented in Appendix D.

Of the 26 consumers who provided their contact details, six participated in a focus group and an additional eight participated in individual interviews. The rest were either unable
to participate due to competing demands, did not respond to requests for interviews, or were unable to be contacted.

The staff focus groups were conducted on the 18th and 24th April, 2013 and the interviews between 17th April, 2013 and 29th April, 2013. Of the 14 staff who provided contact details, two were interviewed, 10 participated in focus groups, one individual was on leave at the time of the interviews and the remaining individual did not respond.

**Consent and analysis**

All interviews except one were recorded with the explicit or implicit consent of the participants. The recordings were transcribed. Survey data were analysed using a combination of descriptive statistics and thematic analysis. Individual and group transcripts were analysed using thematic analysis. Individual researchers analysed the interview and survey data independently, a third researcher reviewed and compared results.

**Reporting of results**

The term ‘interviews’ in the Findings section is used to denote both individual and focus group interviews. While each section includes an analysis and summary of data, a large number of direct quotes are included. This is done to both reflect and align this report with the specific philosophy of consumer engagement – which aims to ensure that people’s actual voices are heard, and also because the quotes chosen reflect the varied detailed and nuanced, and at times contrasting (or even contradictory) understanding of and desires for consumer engagement in ACI.
III. FINDINGS

As the purpose of this project was to garner an overview of consumer engagement from key stakeholders, the results from the surveys and individual and group interviews with both consumers and staff have been integrated. Each section indicates the source of the data, origins of the responses (ie consumers or staff are indicated at the beginning of each paragraph). Differences in perspective and or experiences between groups have been highlighted.

1. What is consumer engagement?

*(Interview and focus group question: staff)*

One of the key issues in the consumer and community engagement literature is a lack of consistency in the definition of the terms utilised in this field (Baggott and Forster, 2008, Contandriopoulos, 2004). Staff were asked to define and describe consumer engagement as a way of clarifying the differences and similarities in the way this strategy was understood at a network level.

Participants’ responses pointed to the centrality of consumer engagement in ACI. Consumer engagement was defined most simply as the direct input by non clinicians or health care professionals into network activities. This process involves ACI actively seeking, collecting and being informed by, consumer input. This input is facilitated by the participation of consumers and community members in ACI’s projects from their inception.

The notion of active involvement at all levels of ACI was one of the determining characteristic of consumer engagement. For example:

Consumer engagement is “… consumers actively being involved in making decisions with regards to their care and also in regards to what care they want, and also in terms of …services, planning and development as well” at an individual and strategic level (Staff Interview) and “I think it's about having the input into any projects that...”
we commence and deliver and having them as active participants so that we tailor it for them. Because ultimately that's what we're here for, for the patient who is a consumer of the service” (Staff Focus Group).

Participants agreed that consumers should be considered equal partners in ACI’s networks of participants, active in shaping and improving health care services and delivery. These participants saw effective consumer engagement as harnessing and maximising the opportunity for consumers, community members and carers to contribute to and collaborate in steering the development and shaping of services and delivery systems. This involved a range of heterogeneous activities and ranged from long-term involvement in project working parties to completing one-off, on-line surveys.

The notion of collaboration, along with those of partnership and teamwork emerged strongly in participants’ definition of consumer engagement, as indicated in the following examples:

Consumer engagement is about “... maximising the opportunity for people to have their say and participate with steering the service delivery systems. Which doesn't mean that they've got maximum say which I think is sometimes a confusion for a consumer who wants to be on a working group because they want to be engaged and have an outcome that meets their agenda. So I think it’s maximising the opportunity for them to participate and be involved collaboratively with the steering” (Staff Focus Group) and while consumers were “... not the end gatekeeper. They are part of the collaborative decision making process“ (Staff Focus Group).

The importance of feedback as a component of defining consumer engagement was clearly articulated. For this staff member:

“... it’s about starting a two way dialogue. We all too often go out and ask people what they think of what we’re doing and we invite those comments back. But we don’t give them much feedback back the other way. I don’t think we close loops very well in terms of consumer and community engagement, because we see it as a
dialogue of just we ask them a question and they answer and that's it. I think if we could close that loop, I think that would be good engagement really” (Staff Interview).
2. Recruitment of consumers into ACI’s activities

Recruitment was examined in three ways. The consumer survey asked how individuals had heard about ACI and why they chose to be involved. The staff surveys asked participants what strategies they had used to recruit consumers. The interviews with both consumers and staff focused on recommendations for strategies that ACI should use to engage consumers. The responses fell into two categories: strategies to engage (recruit) consumers; and strategies to engage (involve) consumers once they had been recruited. The issue of recruiting members of specific communities was an identifiable issue of concern for interview participants.

2.1 How do consumers and community representatives find out about ACI?

(Consumer Survey)

Consumers identified eight ways in which they learnt about ACI. These can be grouped into three categories: word of mouth (healthcare professionals, other organisations); direct contact with ACI either personally, or through other consumers or staff; and the media (newspaper advertisements, calls for Expressions of Interest, ACI’s newsletters and website).

The largest single source of referrals to ACI membership is through healthcare professionals (26%) coupled with and other organisations (9%). This would indicate that ‘word of mouth’ is an important source of consumers. The direct contact route consisted of either current (17%) or previous experience of ACI (9%). The last group, media, (39%) shows a greater impact for newspapers, and in particular, of local media, followed by electronic information.
2.2 Current recruitment strategies

*(Staff Survey)*

Respondents to the staff survey identified five strategies for recruiting consumers or community members. These matched the consumers’ responses quite closely. Staff utilised: networking or word of mouth; advertising; forums or workshops; links with NGOs (other organisations); and internal ACI mechanisms. A number of staff also noted that they were not involved in recruiting consumers.

**Networking and word of mouth:** Staff responses agreed with those of consumers (presented in Figure 1 above) that word of mouth and networking were major strategies for recruitment. Word of mouth operated through clinicians, clinical services, NGO and peak organisations, contacts in the field, support groups, hospital consumer groups, by contacting consumers directly, including speaking to people in waiting rooms,
approaching consumers directly or via referrals from other consumers. Some individuals were nominated either by their community group or by clinicians who were asked to approach “consumers who may be interested” and “proactively identifying key people for engagement”.

**Advertising:** Staff provided examples of advertising strategies, which included “Advertised for consumers to provide their views to government and paid consumers for their time input”. Others made explicit reference to ACI’s newsletter and website, to the use of NGOs and community organisations, and others “placed ads in the community newspaper, posters and flyers” or some elements of all these.

**Forums and workshops:** Several respondents mentioned forums and workshops, of which there were two types of recruitment. The first type involved inviting consumers or community members to ACI activities, for example “in our forums and workshops, consumer representatives occasionally attend” or “I held three Forums in Sydney and five in rural cities, consulting [community members]. Forums were advertised in advance through … networks and local papers when conducting regional forums” and the second group involved “being [a] guest speaker at support group forums” or “attend[ing] consumer events and invit[ing] future involvement”.

**Links with NGOs (other organisations):** NGOs were identified as a main source of consumers. Respondents commented on seeking direct input through organisations, including one who specified that “…I worked with key NGOs (usually through formal and informal correspondence) to identify new representatives, although there was limited success with this. I had similar experiences engaging potential consumers to networks as well. Generally I would do an intro email and ask/look for an opportunity to speak with them in person - just to personalise the ACI, the network and our request for them to be involved”. It was noted that “ensuring regional and rural representation by contacting appropriate organisations in relevant areas to nominate someone” demonstrated a positive and proactive engagement with consumers.
Utilising ACI services: Several respondents mentioned utilising ACI services to attract consumers, including those who: “utilised the services of the ACI Communications Team”; publicised Expressions of Interest (EOIs); approached another network manager for contacts; or made a “request to SACC”.

Not recruiting: Several participants indicated that they had not recruited consumers. Several simply said that recruitment had not taken place. Others seemed to infer that although this process had not happened in the past (or as one responded noted ‘yet’) active recruitment was not precluded. “We have not previously attempted to recruit consumers” was one such statement, while another was more specific in claiming that they “would be keen to consider strategies to invite clients”. Other reasons for non-recruitment included an individual who was new to the network, respondents who felt that recruitment did not apply to their role, and those that thought that active recruitment of consumers was not required because they were “already on network”.

2.2.1 Improving recruitment to ACI (Consumer Survey)

Respondents to the consumer survey were asked how ACI may improve the way they recruit consumers. These closely matched the more detailed discussions of the interviews and included newspaper and related advertisements (particularly local papers, on television and radio), clinician referrals, links with and advertising through NGOs and other consumer organisations (in particular ‘specialty” organisations and Local Health Districts (LHD) Consumer Participation Networks), and using consumers currently involved in networks.

The following consumer quotations expose the rationales behind the choice of these strategies. For these consumers (all participants in the consumer survey):

“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”

“Ask clinicians to recommend them. They usually have had the benefit of observing them over a period of time to be able to gauge their suitability”

“Maybe looking at more health groups that are around - the health consumer groups are good however there are probably online support groups who may welcome the opportunity to be involved. Recruitment somehow needs to be done so it is not seen as scary to people - not easy”

“Seek consumers already actively engaged at coal face level in collaborative type positioning in ACI relevant activities”

“Make them (consumers and community members) aware they have a voice let them know through surveys and health care providers or the direct approach”

“Personally visit as a guest speaker to forums and workshops where consumers are most likely to be attending. For example HACC conference (with a table in the foyer to speak to carers although many non carers attend these forums). [Community] association holds many forums per year, both in Sydney and rural locations, so ask if you can speak for 30 minutes max on the work of ACI at one of these venues”

Consumers provided a range of suggestions for strategies aimed at involving specific consumer groups. These included conducting forums in country areas for rural consumers, looking at meeting times suitable for those in full time employment, and the following:

“Perhaps consider ways of also contacting people who are not already 'professional' or 'serial' volunteers on committees and who come from outside other voluntary bodies - for example, some sort of advertising in relevant patient / consumer areas - perhaps brochures in waiting rooms or on notice boards or in hospital information brochures. I am not sure if it would work and there are ethical and practical issues
with this but possibly target or 'head hunt' specific clients / consumers on a personal level via letter or personal suggestion ... say people who have had long, prolonged or otherwise significant contact with the system?"

2.2.2 Increasing the profile and awareness of ACI

(Consumer and Staff Interviews)

“Then we've also got the problem of recruiting consumers because the public absolutely have no idea about ACI”

(Consumer focus group)

One of the most frequently articulated suggestions offered as a strategy to engage consumers was to increase the profile of ACI. Participants identified that a large number of people are unaware of the existence and work of ACI.

“You say ‘they’re one of the four pillars’, and they say ‘hey?’ It’s health speak and the average consumer doesn’t know about that”

(Consumer focus group)

Increased advertising, using a range of mediums, was the preferred mechanism to “educate” the public and clinicians about the role of ACI. Specific suggestions in relation to advertising consumer engagement with ACI included Facebook, webinars, Twitter, local newspapers, newsletters in locations such as Local Health Districts (LHDs), aged care facilities, school newsletters, and local support groups. A novel suggestion was that competitions be used to provide an alternative method of attracting applicants and raising the profile of ACI. As one participant noted:
The need for education about ACI was extended to the involvement of clinical staff (echoing the strategies already identified as successful in the consumer survey) in the process of recruitment. The rationale was to “… educate clinical staff about spotting consumers who would like to be engaged and who would like to contribute to the ACI … teaching them the best ways of recruitment” (Consumer Interview).

Logo advertising, emphasising the role of consumers in improving healthcare, and outlining ways in which consumers could be involved were raised as potentially useful strategies. Raising awareness that consumer involvement with ACI takes a number of different forms - from formal engagement in committees to less formal and intermittent activities such as one off focus groups, individual patient interviews, or anonymous patient experience trackers – would ensure that consumers understand that they have a range of commitment opportunities open to them.

“I suppose newsletters, people always like newsletters. It doesn’t have to be specific to ACI. Lots of organisations have newsletters. Health has newsletter, like the Local Health Districts have newsletter. Most aged care places - because I’m at an aged care facility … we have our own newsletter. So little spiels in about what ACI do and some of the projects would be good to get the message out … There’s lots of different groups that have their own newsletters … Schools have their own newsletter, that’s a good source. All parents of young children read the newsletters. Sometimes Pop and Nan read too” (Consumer Interview)
Participants wanted to emphasise not only the benefits that consumers themselves gain from the engagement process, but also the benefits to ACI and the health system of the consumers’ participation. Related to this was the idea that the development and progress made by ACI should be advertised both to consumers and to the general public. For example, “when a new guideline is developed they should Tweet it” (Consumer Interview). Getting quick runs on the board and advertising quick wins, good news stories and providing a positive spin on stories were also suggested strategies to increase the profile of ACI in the community as depicted in the following excerpts from an interview:

“Facilitator: So positive stories in - you think are important in engaging consumer and community involvement?

Participant: Yes, I do think so. To start a discussion, especially ... one should do those talks or you're presenting or you're putting something out there, that we are always looking for ways for improving. So please, if you feel there’s something we could do better, let us know. If they have a local number to go to, people will tend to” (Consumer Interview)

As with the consumer survey, interviewees felt that collaboration with other organisations provided an effective way of recruiting consumers. Dissemination of the work of ACI through related organisations and the utilisation of points of contact that are external to ACI were seen as valuable sources of new consumers. More specifically, it was suggested that ACI not only use existing structures and networks outside ACI, but link those across ACI. An example offered was that ACI could work into existing structures such as the Leeds University Disability Group which is only currently accessed by those in the disability sector. Strategies such as these could overcome some of the issues in recruiting individuals from specific target groups. The theme of working with
other organisations to recruit consumers for ACI is illustrated in the following selection of quotations:

“But there’s a lot of support groups around in the community for consumers with that type of illness – ongoing illness – whether people are working or not. Maybe that’s a point of contact for recruiting consumers” (Consumer Focus Group)

“A good one is the Cancer Council runs Relay For Life. They get really good community involvement with that. But that’s a good opportunity. People are walking around a track. Give them something to think about as they’re going or give them some information or tell us about your experiences. So you can tap into those sorts of things because they sleep over, it’s a 24-hour event” (Consumer Interview)

“I guess you’d start with maybe the NGOs and the Heart Foundation and cancer people. I guess - and the ACI is very good at doing that to a certain degree I think, in terms of priority groups because they’ve got the specialist networks. So they’ve got the clinicians out there who often, as well - obviously they’re with the patients and they know of good people or good consumers to get involved” (Staff Interview)

ACI may need to tap into and collaborate with the work other organisations are already doing. The rationale for this was that consumers might wish to contribute to ACI, but due to time limitations many cannot or choose not to engage with several organisations. If they need to choose, they may not select ACI unless it is seen to be relevant.

As the consumers indicated in the survey, they themselves are seen to play an active role in advertising and recruitment for ACI. ACI Consumers who are also consumer representatives on other bodies spoke about how they advertise ACI.
One final comment provides a new perspective on the recruitment process. For this consumer:

“I actually have an agenda item. So I bash the ACI story at every meeting. Now that ensures that all the senior clinicians in the health district are aware, and one would hope that maybe it’ll filter down. So consumers can do something towards getting the message across” (Consumer Focus Group).

2.2.3 Difficulties in recruiting consumers from specific communities

(Consumer and Staff Interviews)

A number of interviewees commented on the difficulties associated with recruiting consumers who are representative of a community, particularly from difficult to reach communities. The essence of this issue is captured in the following quote.

“So like recruitment I think that’s the really difficult one because if you want to get representative consumer and you want it to be representative of community that is really, really hard ... 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. They tend not to get to be the consumer representatives. They tend to be middle-class, more educated, often have a health background or have an agenda of their own. Yeah so that is really, really hard from your point of view to recruit” (Consumer Interview)
While acknowledging the difficulties in this process, most participants acknowledged the importance of recruitment strategies which targeted a range of groups e.g. mothers, women, men, members of Aboriginal communities, people with disabling conditions, people who are homeless and youth, so as to ensure broad community representation in ACI. Participants in interviews went on to identify a range of strategies to improve consumer engagement in general.
3. Motivation for joining ACI Networks, Taskforces or Institutes

(Consumer Survey)

Recruitment is one element of engaging consumers. Another is what motivates them to actually participate in ACI activities, especially given the cost in time and in some cases, money. Respondents to the consumer survey identified four specific motivations: helping others; having had either a good or bad experience in healthcare; wanting to make a change by having a voice; and wanting to access information. One individual added a very personal response: “looking for retirement activities and interests”.

The major motivation for participating in ACI was the desire to help others. Beyond the simple (but valued) desire to ‘do good’, consumers specifically identified their role as a consumer voice in service improvement as the key issue. They felt strongly that their perspective could contribute to the increased efficacy of health organisations, improvements to inter-organisational collaboration, to “… get better services for people in rural areas” and to the work of clinicians.

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

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

One respondent specified not only the importance of consumer involvement, but the actual input they provide to ACI. For this person, the:
“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”

Both good and bad experiences formed the basis for the second motivation to engage in the work of ACI. One consumer stated that a community organisation had “helped me so I wanted to help others in pain”. For others it was “…because I have had more than one bad experience with the Public Health system”, or as this person describes the situation:

“I have had [a chronic illness] for over 30 years and have experienced difficulties with the health system because of it, so decided I wanted to try to help others navigate it and if I could help improve it on the way - it benefits us all. Having also been a nurse I have an understanding of both sides of the system which helps me as a consumer”

Making a change to the system was also coupled with the concept of ‘having a voice’ for both individual consumers and community representatives. For this respondent: “I joined [ACI] because I felt that I could have a voice and make a difference and bring about change in current practices most of all improve services.”

“1 in 5 people in Australia has arthritis and yet the issue of musculoskeletal disease often seems to be overlooked in favour of higher profile conditions such as cancer and heart disease. I believed that joining the Musculoskeletal Network would enable my organisation to raise the profile of the impact of arthritis in adults and children and also increase awareness about osteoporosis including prevention strategies. I believed that services for this population could be improved”

A small number of participants added very specific insights into why they thought their participation in ACI was important. For one person it was about giving a voice to rural people, for another “I knew I represented a fairly uncommon demographic in the [condition x] world and I wanted to be a voice for people like me”.
The desire to have a direct access to information about either the specific health issues or ACI in general was the final motivator mentioned. “... I thought membership of a Network would help in my understanding of the ACI system of Networks”. 
4. Engaging and retaining consumers once recruited

*(Consumer and Staff Interviews)*

Engagement and retention of consumers and community representatives included both strategies common to recruitment e.g. the need for information, but also other more sustained issues. These included: addressing the motivational aspects of engagement, such as ensuring people feel valued and supported throughout the engagement process; the cost of engagement to the consumer (a commonly identified issue in the literature); the need for information; the timing and location of ACI activities; changes to meetings and workshops; and an ongoing evaluation of engagement experience.

4.1 Ensuring consumers feel valued

Participants talked about the significance of keeping consumers engaged with ACI. When engaging consumers, one participant identified that “*it is important that peoples’ readiness to engage is assessed or considered to actively avoid the potential for PTSD*” *(Consumer Interview).*

The importance of feeling valued and making a difference to outcomes underscored strategies aimed at keeping consumers engaged. A thread through discussions and responses spoke to the necessity of having engagement processes in place. These processes included structures and activities that acknowledge, value and respect consumers’ input and that ensure consumers’ voices (a key motivator as identified in the previous section) were heard and acted upon.

Strategies suggested included having: clinicians on the networks who listen and seek input from the consumers on that network; mechanisms in place to feedback to consumers information that shows that their contribution is important and valued, that they are being heard, they are influencing change, and that they are making a difference.
4.2 Ensuring consumers feel supported

Establishing and facilitating a supportive environment was identified as a key issue. For these participants holding such views, for example: “... the disincentive for going and coming back, a person in a wheelchair who arrives to what is supposedly an accessible venue and finds a step in the middle of it. The person with epilepsy that says ‘look, I've got photosensitive epilepsy, I can't deal with flickering lights’ and things and comes to a setup where there's a large waterfall at the end of the room with a light flickering through the water as a part of your thing, the staff member doesn't necessarily know or doesn't necessarily check the venue or anything like that, to check that the venue is actually when it says it's accessible, it is accessible. The blind person who got the handout, they say well sorry, I'm not coming back” (Staff Focus Group).

As well as a supportive environment participants suggested two specific support strategies. These included providing mentoring or peer support processes for consumers who would like to be mentored and having training or support programs available for consumers in relation to the meeting procedures and terminologies. The current mechanisms and need for consumer support will be addressed in more detail in the next sections, which address this issue from the perspective of consumer and staff surveys.

4.3 Reimbursement

While some engagement strategies were very simple, “... it makes such a difference to say thank you for coming” (Consumer Interview), others highlighted a more nuanced understanding of how engagement could be valued, and included having mechanisms in place to allow consumers to be compensated (not just reimbursed). Reimbursement needed to be proactive and transparent with clear explanations. Comparisons were made between the reimbursements made to clinicians (for example the hourly rate paid to General Practitioners who participated in a panel) compared to reimbursement for consumers on the same panel. Other suggestions included the need to organise and fund travel for participants.
4.4 Information

As with recruitment processes, engagement and retention processes require a constant flow of information. Producing a newsletter that informs consumers of the projects that ACI is involved in and that includes feedback on what is happening as the result of ACI’s work, rather than just those in their network, was considered a useful resource for consumers. Related to this was the need to provide consumers with an overview of ACI activities.

Several participants suggested one other, very specific information strategy. This was to provide consumers with a list of acronyms and glossary of terms, some of which are general and others network specific. The jargon of healthcare is a perennial problem for consumers.

4.5 Timing and location

As with recruitment, timing and location of meetings were raised as variables affecting consumers’ ability or willingness to continue their engagement with ACI. Offering a range of meeting times so that people can indicate what suits them best would overcome a situation where “... a lot of people work so they can’t get involved so we’ve cut them off ... some people hold their meetings later” (Consumer Focus Group). Moving meeting locations to overcome “... meetings [that] are not geographically good for everybody” (Consumer Focus Group) was identified as an important approach.

4.6 Changes to meetings and workshops

Specific improvements to the way in which ACI meetings and workshops are conducted were identified. This included utilising a range of tools to “avoid being didactic” so as to be “fun, interactive and enjoyable” were considered important. This was considered to be a particularly important strategy in making participation less intimidating for those consumers who are new to ACI.
Other participants suggested a restructuring of meetings to facilitate involvement of consumers, although this might be different for different networks and at different times. A number of participants noted that it would be useful to conduct meetings in a culturally sensitive manner or engage clinicians who have a similar background to the consumer group that is targeted. Having structures and rules of engagement that take into account the special needs of some of the consumers, such as allowing more time for someone with a speech difficulty to speak, was raised.

The need for ACI to facilitate different forms of engagement was thought to be one way of both encouraging and supporting engagement. Examples included involving consumers in providing services such as peer support, participation in focus groups, surveys and data collection, as well as their more traditional and substantive role in networks.

One participant suggested that it might be appropriate to take the time to look at current network models that are working well in terms of consumer engagement. The purpose of this would be to see which parts of those could be adopted and translated across the networks.

4.7 Monitoring engagement

There was support for the idea that ACI should introduce mechanisms that allow regular evaluation of consumers’ willingness to continue with the same level and type of engagement.
“One way that it could be improved is that from time to time it would be good if ACI would ask the consumer if they are still happy to be on the particular committee they are on. Sometimes they may have joined a committee but over time another committee may be more appropriate, either because they become more aware that their contribution better fits with another existing committee or a new committee/network is formed). Alternatively their situation may have changed and they may need to step down or have other needs.” … “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” (Consumer Interview).
5. **Supporting consumers and community representatives**

During the interviews, the need to support consumers and community representatives was identified in response to a general question about ensuring ongoing engagement in ACI. In this section we present findings from the staff and consumer surveys as to the current strategies utilised by networks to facilitate this process.

5.1 **Staff perspectives on support of consumer and community representatives**

*(Staff Survey)*

Eight different types of support strategies were identified. These included providing support for new consumers and community representatives through: support of attendance at meetings; provision of information; and structural modifications to meetings. Strategies to encourage engagement included: actively inviting consumers and community representatives to forums and meetings; individualising communications with consumers; and providing transport and financial support.

As well as these approaches a ‘no strategy’ response was identified. This category included respondents who stated that they either did not know about such strategies, that they did not utilise such strategies, or that they already had or did want to develop such strategies. None had yet been successful or that as one individual described the situation, they were “Proposing social media strategies to get consumer input. These are hard to get off the ground, none functioning yet”.

**Providing support for new consumers and community representatives**: several respondents mentioned providing support for new consumers. These ranged from: “phone conversations” through to the provision of “information packs and orientation to the network” induction and “orientation” including “introduction to the activities of the network (at the start)” to more comprehensive approaches including: “When people have joined networks, I have tried to provide them with a lot of support at their first few meetings to encourage them to speak up (e.g. making sure you/or the chair seek their
opinion on an issue)” and providing an “initial orientation for new consumer, taking them to the three units and introducing to key staff/clinicians. Explaining role and opportunities, directing them to information on the website”.

The importance of welcoming and including new members to the network was underscored by two respondents who noted that “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” and that “introductions at each meeting so all know who each is - along with everyone else, having a living document with common terms we use including acronyms, placing a clinical person with them at the table to help explain any topic being discussed, pre presentation discussions, celebrating their successes”.

Providing support for consumers and community representatives’ attendance at meetings: was identified as a strategy by a number of respondents. Preparatory strategies were highly valued and ranged from the general “Welcome, pre-meeting discussions” including “[discussing] concerns on the phone and provided information they require pre meetings” to more sophisticated strategies such as holding “Pre-meeting discussions, ensuring minutes are not full of abbreviations and acronyms without explanation. Currently compiling a glossary of frequently used terms with meanings and explanations” and “making sure [consumers and community representatives] are clearly identified, welcomed and feel part of the meeting, briefing when required (eg consumer is co-chair of Transition Executive and is briefed prior to meetings)”. Post meeting discussions “to discuss concerns (esp where consumers have not felt comfortable talking up during the meeting” were also held.

A sub-set of this area of provision of support was the facilitation of support between consumer and community representatives. This included networking strategies and facilitating and fostering peer support.
Structural modifications to meetings: were required to encourage continued involvement in meetings. Some strategies included “Standing agenda item for the consumer to speak at the committee meeting” providing “opportunities to listen at meetings and then invitation to comment from consumer perspective”, “ensuring that they are comfortable during meetings, understand what is happening (no acronyms etc), are given the opportunity to speak etc.”

Provision of information: is an important part of consumer engagement. One respondent indicated: “specifically ask consumers for their feedback on relevant agenda items”. A proactive approach included asking “... the consumer for her preferred mode of participation and methods of receiving information. She liked to attend meetings and receive hard copies of materials” and “consumers [receiving] all meeting information well before meeting”. Other strategies included the provision of research summaries to members of networks and explanations on progress.

Actively inviting consumers and community representatives to forums and meetings: including their involvement in “forums targeting ACI consumers”, focus groups, as well as face to face meetings “... every now and then for 1:1 catch up to check how things are going” and creating “Informal opportunities for consumers and clinicians to interact to increase rapport in bid to feel comfortable and 'equal' at meetings”.

Individualise communications with consumers: a total of five respondents said their networks or areas utilised this approach. Variations included: asking for individual feedback on specific issues: “Occasionally, if specific consumer feedback was needed I have individualised the process by writing to them specifically to ask for advice” most often by email or phone and holding a “… separate working group which is made up of consumers - have had input into the statewide flyer and service directory”.

One respondent felt that processes went beyond seeking and providing the information. For this respondent, the process of individually contacting consumers so that if the consumers’ “input is out of scope, this is explained personally to the consumer by the
network manager. *The personal relationship formed by the network manager is further indication to the consumers that their input is valued.*”

**Providing transport and financial support:** including reimbursements and cab vouchers.

### 5.2 Consumer perspectives on support of consumer and community representatives

**Consumer Survey**

Consumers were asked about the support they required for participation in consumer engagement. Most of the suggestions made by consumers addressed the pragmatic aspects of engagement, including issues such as training, travel support, assistance in meetings and so on. But deeper issues were also identified. Consumers discussed not only what they needed to be engaged, but reflected on what engagement actually meant and why it was important to support consumers through the process.

“I think the question should be posed the other way, i.e.: *what should ACI do to ensure consumers are at the forefront of everything ACI does?*” “Because people / clients need to be at the centre of everything the caring professions do, not the other way around (as can often happen); clinicians are caring people, but with the growing complexity and specialised nature of clinical practice and research, and with the budgetary and other pressures on the medical system, clinicians can end up taking less account of clients’ needs and individual circumstances than is desirable, this needs to change”

As well as various types of engagement activities, a number of respondents to the consumer survey identified the **conditions** which should be in place in order to improve the process of consumer engagement and recruitment of new consumers. Two major types of conditions were identified: the structural conditions including providing additional support for consumers and dealing with structural challenges to involvement and the philosophical including: ensuring that the involvement of consumers is ‘real’;
combining both NGO and individual consumer representatives; and ensuring cultural diversity.

Structural issues or conditions for engagement included the common concerns of **financial assistance** for consumers, including paying a fee when consumers attend activities on behalf of ACI. One respondent wanted “financial assistance for consumer representatives to participate in person at meetings and forums more frequently than annually (e.g. transport, accommodation, meals etc)”.

Additional financial consideration included reimbursement for resources used in their work with ACI for example, “contribution towards printing and toner costs” because “cartridges are expensive and run out too quickly if all documentation has to be run off at home”. The costs for carers raised a particular mention, along with pensioners and others. As this person mentioned:

“There is an issue however than applies to volunteer generally. It relates to out of pocket expenses. Again this does not bother me personally and I am aware that specified travel expenses of a defined nature are claimable it could be that many don’t benefit from and there are general expenses that are not recoverable e.g. the telephone, this could be discouraging some retired people, low income earners etc, from being consumer reps. The Minister assisting the Health Minister made reference to such disadvantages at the recent Carers Conference. I suggest this issue needs some research”

“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”
As with transport costs the process for reimbursements seems to be a particular issue. “... getting reimbursements was a nightmare, all the paperwork was lost and also getting statements of tolls in order to get reimbursed for tolls was too much effort”.

One response which was uncommon, but needs recording on that basis is the following: “Individual consumers should be paid for representation”.

**Transport** was a significant and recurring concern for consumers and reflects the current literature on barriers to consumer engagement. The issue of “time spent waiting for buses and connections can be onerous as we have busy lives and it is difficult to fit everything in, especially when you have your own ongoing medical appointments to attend” was a commonly identified problem.

Most individuals identified support for travel a priority: “Help with transport, yes always”. People travelling from rural areas or “anyone at a distance from the meeting places will have the same problems” (including requiring assistance with flights and accommodation), people with a disability “I think transport is likely to be a concern for many consumers, especially those with disabilities” and people coming to meetings at night being identified specifically.

**Cab vouchers** and **travel allowances** were an area where there seemed to be a significant difference in practice across ACI, and one which is leading to some confusion. The following an indicative sample of responses:

“The cab vouchers are great”

“I get cab vouchers and papers when I remember to ask for them”

“I asked for cab vouchers instead and was told that I could not get any but would be reimbursed for public transport and I do not have the time to work across Sydney by public transport”

“I also think it to be essential that consumers are informed of travel allowance being paid, and equally important, that they be encouraged to claim it”
“Individual consumers should be: provided with subsidy for transport”

“Most ACI consumer reps are involved in several other organisations and naturally freely give time, effort and stationery costs. However, to date claims for mileage expenses are paid ‘eventually’ and usually after the need to pursue claims for same”

“And at least two trips to Sydney to meet face to face with the team. I don’t mind paying half the ticket as it’s a flight. But I would appreciate getting around $80 compensation or just under for one half of the return fair. A 50/50 relationship is ok with me, I am not in paid work and have not been for over two years so some assistance is good otherwise I will lose interest through loss of connection in a more meaningful way with the committee”

“I have had one trip paid for last year, and one trip the year previous”

Some consumers provided suggestions for support systems required in relation to network meetings. These included “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” and providing an orientation to the purpose of the committee (or network) “… preferably by the Chair, so again they feel comfortable to speak up at meetings” because “… not knowing the other members are [an] obstacle”.

There was strong praise for some network managers. “The networks need to maintain the network managers as these people provide the greatest support” and “we have an excellent Network Manager in X - is outstanding in every way”. For one individual, this direct support does not seem to be forthcoming, as they required “person[al] contact and support from facilitator or coordinator of network”.

One individual spoke to a more fundamental concern about their involvement in the network. “I would like to see us being given specific tasks, rather than just tagging along on the perimeter of the medical personnel’s debates”.
Support for participation in network meetings and ACI activities also included improved mechanisms for information and communication including issues common to those identified by the consumer interviews. For example, “despite best efforts of ACI members, particularly the project managers, one often gets lost in the maze of acronyms which change & extend perpetually. I would much appreciate some education/training.” For another, the request was quite specific: “I would need a terms of reference with aims and goals with finite beginning and end, talking without purpose is of no interest”.

Pragmatic suggestions to overcome both issues of time and communication included video and teleconferencing. For several consumers this is already underway “A good video conference link which is just starting to happen thanks to X and her work in getting me more tech savvy”, although “some may need assistance or advice on how to participate in teleconferencing”. One individual articulated both the pros and cons of this approach:

“My personal extra support needs are not materially great. They mainly rest with available time. A major issue is travel time to meetings, particularly [a] short meeting, and the lack of face to face follow up opportunities including the workplace operatives. I am aware that this is somewhat contradictory and teleconferencing can be arranged but this is cumbersome and frequently of low productivity. Video conferencing can be a part answer in formal meetings but beyond that no easy solution. It seems to be a problem for all such activated retirees”.

Broader requests for information included “more information about what you do and have done”. Another respondent felt that “individual consumers should be given some more formal orientation to the sector they represent - not just to ACI”.

Some respondents wanted hard copies of documentation at all meetings. One respondent felt that “It would be helpful if all papers could be mailed double-sided without having to ask for them each time”.

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Another commonly expressed concern was the timing of network meetings. For this person, “... it is disappointing however, when meeting times are made to suit health service staff e.g. surgeons and then these people often do not attend”. A more common response was that consumers needed to be consulted about meeting times and that advanced and adequate notice of meetings was required.

ACI consumer meetings were also raised and a potential support structure. “Meetings are so infrequent - I believe all consumers should meet monthly or two monthly” and “it is worthwhile for consumers from different networks to interact from time to time to share ideas to improve effectiveness” and have “the opportunity to mix with other consumers at times”.

A more specific request had to do with the engagement procedures. “I think we all like to know we have a go to person for inquiries and comprehension checks”.

For another respondent, the issue was the complexity of the organisation and the lack of genuine engagement. This consumer felt that “... consumers would be put off by the number of Networks and the confusing structure of ACI. Even after a few years, I do not really understand it all. There are a lot of people with a lot of opinions so you do not get to know anyone. It may be different if I attended meetings in person, but when I did attend one, I found the medical people talked among themselves, there was a lot of business for the meeting, so I was in the dark about many of the topics. Also, the meeting times are unusual/inconvenient - late afternoon, or right on dinner time for consumers who are at home and join by teleconference.” For another respondent however, the desire was to find “opportunities to contribute more broadly to core issues across networks”.

The need for training also emerged as an issue, although opinions were divided. As one individual commented: “Training is of course helpful, although in my opinion not absolutely necessary”, whereas others not only wanted training but specified the contents they wished included, such as the expectations of consumers, communication
skills, how the health system works and media training “... we could do with some media training to promote the work being done by ACI for local community”.

The reasons for these choices of skills were telling: “We are in effect advocates for consumers, who deserve the best possible representatives” and “Consumers have demonstrated they can have a powerful advocacy role. They can add value and relevance to health messages and specific health campaigns e.g. warning signs of heart attack and breast cancer awareness campaigns”.

The principles underpinning consumer engagement were varied but spoke to issues of genuine engagement and representation. ‘Real involvement’ was described as “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”.

The willingness of clinicians (and networks as a whole) to listen and proactively pursue consumer concerns was a common theme. This willingness needed to be displayed both prominently and consistently. “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”. One respondent went further: “Yes [there is a need for support] For a while to come there is probably going to be a level of pushback from the medical profession to consumer involvement, so continuing support will be necessary”.

This willingness to listen and be driven by the perspective of consumers was linked closely to issues identified throughout this report that is the support, encouragement and assistance needed by consumers to allow their voices to be heard. For one individual:

“See my previous point about degree of functional literacy and confidence in communicating as a minority in the context of such sophisticated other members - whether someone might be intimidated by the range of highly educated professionals who make up the bulk of the membership”
For a number of respondents, the issue was one of **reassurance**. One of the most important underpinning principles was for consumers “just to be received with respect” and provided “Assurance that a consumer’s viewpoint and contribution is valid and valuable. Assistance to help those professionals who may not feel that way respect the consumer voice”.

The comments on this aspect varied. While for most respondents support and reassurance was “definitely [provided] in the working group I have been involved in” for some individuals, engagement has not been an entirely positive experience and this assurance has not been forthcoming. The following response, though not typical is telling:

“I feel like it doesn't really matter that I am there, I have not achieved the things I would have liked to achieve and I really question my value”

The issue or reassurance is also related to representation. For another person,

“Consumers need to feel they ARE making a valuable contribution to their community and are not just token representatives”

The question of representation was addressed by a range of respondents. For the following individual, their network model of engagement was so effective that they felt it should be utilised across ACI: “[our] network has an excellent mix of consumers - by this I mean three extremely articulate individual consumers as well as the NGO (my organisation) which represents this target group. This is the ideal combination. If they are not already doing this, I recommend other networks use this model”.

For other respondents the current model is less successful. They felt that “… ACI doesn’t seem to capture as representative a cross-section of the community as it should there should be a more multicultural consumer base”. For another the question was the difficulties of networks responding to broader issues in healthcare “Geographical isolation often means what is relevant to metropolitan areas has no place in remote areas where services are limited or nonexistent”.

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Specific support for consumers with disabilities was mentioned several times. This included consideration of the location of meetings “... both of my networks were held upstairs (not accessible independently) and in the auditorium that is not accessible”. This spoke to the need for a companion, and support for special transport.

A novel, although individual response to representation was provided by one individual: “There almost needs to be social workers who work at health and can collect comments and feed them back into the system. This could be done using smart phones!”

Additional suggestions raised some personal, although not unique support requirements. These included: “support from your healthcare team and spouse” and “others might have dietary needs if a meeting is going in the evening”. 
6. Consumer Engagement Training

(Consumer Survey)

6.1 The value of training

As well as being asked about their own individual needs for support, consumers were asked several questions specifically about training. The first question addressed the issue of whether training did or could assist consumers in their role at ACI. Nearly half of consumers said that training had contributed to their role (48%). Of the remaining respondents, 10% were unsure (Figure 2).

Figure 2: Contribution of training to consumers’ role at ACI

Participating in training appears to have assisted both as a form of socialisation into ACI as a whole and a source of information. In the experience of the following consumers:

“I think the consumer training I have done has been of massive benefit and provided the added bonus of meeting other consumers”

“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)”
For consumers who answered that they were not sure, additional comments provided a range of perspectives. For some it was a question of the nature of training, “It should be offered and it can be the choice of the consumer if they want to take up the offer” and “This depends what it is?” One respondent commented that “I have not received any ‘consumer training' so do not know if it could assist with my role”.

For others it was a question of expertise. “I think it is very valuable - not necessarily for myself, because I worked in the health service for nearly my whole career, but certainly for others if we are to ensure it is an empowering experience”; or another respondent was “not sure that personal training would be necessary but a basic induction program would be sufficient”.

A small number of respondents questioned the rationale behind the training, rather than its particulars. For these individuals:

“I think the basis of this question is flawed, in line with my previous answers; the question assumes that consumers are somehow flawed and need to be fixed, and that the clinicians have all the answers; this is the underlying flawed assumption in the medical model of disability as well”

“It is really the ACI that needs to include consumers in its processes in a real way”

6.2 What should be included in consumer engagement training?

The second question addressed what content should be included in consumer engagement training. For one respondent it was simply the training as it is currently conducted. For another, the training should not be directed at consumers, but that “…there needs to be more training for service providers on how to engage consumers”.

This perspective was mirrored by another individual who thought that “Perhaps a consumer email list/forum should be available for consumer-wide issues - e.g. the overuse of jargon with patients”.

Several themes emerged as suggestions for content. A number of respondents also identified preferences for particular training models.

The need for ‘basic’ training for consumers was identified by a number of participants, although for one respondent this was qualified: “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”.

Information on roles, policies and organisational structures of both ACI (including its history and purpose, selection criteria for consumers, objectives of ACI) and the health system (sector orientation, hierarchies, different levels of government, health language and policy) in general was considered useful, as well as information about changes to health systems structures and services. For example:

“For some consumers a deeper understanding of the complexity of the health care system and the various health care delivery settings may be beneficial”

“The role and structure of ACI and other supplementary bodies. The role of consumers in ACI. Perhaps a mentoring role”

Closely aligned to this was training related to participation in networks. “A brief about the committee or whatever the group is. A meeting with Chair. An explanation about the type of reports the committee will see. An overview of the purpose of the group and the contribution expected from consumer. Meeting the other consumers including the NGO before the first meeting”.

Part of the information requirements that were specified addressed very specific aspects of engagement in the work of ACI. For example:

- “Reasons for confidentiality and privacy, complaint system”
- “Overview of ethics”
• “Team work”

• “Importance of reading notes and gathering problem solving information to contribute”

• “… setting realistic goals to achieve in their group”

• “Media training”

• “Terminology education”

• “Expectations of Consumers”

• “Work-shopping ideas to take to your networks”

Skills training also emerged as a priority. This included communication skills, “disease specific but also consumer specific. Skill to speak up when things get very medicalised”. Other suggestions included

• “Interaction and meeting skills”

• “How to ask questions, expectation”

• “The skills required to be a good communicator”

• “Small group facilitation”

• “Participation in meetings”

A sub set of skills training was confidence training. Several individuals identified the need for training in this area specifically. For these respondents the issue is “Confidence in the long term outcome. A degree of optimism and the knowledge that a great number of people are suffering in the same or similar manner and help is at hand, it is not the end” and “confidence boosting to encourage consumers to speak up but there should also be guidance on diplomacy and realistic expectations”.

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The final group of respondents addressed the issue of **training methods**. Two additional approaches, mentorship and discussions came to the fore:

- "**Consumer mentors - those who have been consumers and involved in ACI to talk about how they perceive they help**"

- "**Rather than a one on one approach what about a group discussion approach with a few new consumers? Perhaps give a few scenarios of issues they might face? Facts were adequate but discussion of application of these issues could be encouraged**"
7. Attributes required by consumers and community representatives

(Staff Survey)

Staff identified several characteristics and skills required by consumers and community representatives for consumer engagement. These included knowledge, skills and attitudes, along with personal attributes incorporating courage, and open mindedness.

7.1 Attitudes

**Interest and commitment** was seen as an expression of the willingness of consumers to contribute their time and effort to ACI over a period of time. One aspect of this commitment was described as consumers’ willingness to “... have a high level of interest in the area and be able to talk in meetings where there are mainly clinicians” and their desire to learn more about the area. Other expressions of commitment included reliability in taking on tasks and finishing them, and reading documents, which was seen as important so that they “[are] able to voice an educated opinion as required”. Those who felt that a high level of health literacy was necessary echoed this sentiment.

**Sharing the vision and perspectives of ACI** was identified as an important attribute by numerous respondents. Demonstrations of this ability ranged from “the ability to understand and set priorities without bias”, to “see the bigger picture” and to “have a broad view”. This broad view includes being able to step outside personal experiences and “to understand the issue in the broader sense and therefore not always relate it only to their personal condition, because everyone is different even if they have the same health issue. This is a skill, because many people can only see it through their own experience”. This particular skill was extended by one respondent to include the ability to “think laterally ... [and to see beyond] their personal goals” and to be “open minded”.

Other perspectives that were valued in consumers and community representatives were also valued by staff. These include “having a whole person perspective to health care”, understanding that “change moves slowly”. Experience, a positive attitude and
engagement with the health system and their own communities were also prized “experience and understanding of the system and expectation of improvement to services and treatment in future” and “education, engagement with the health system and a good understanding of their own community” “would allow them to contribute a useful insight”.

This understanding of their community needs was coupled with the ability to “articulate the needs/concerns/viewpoint of consumers relevant to the issues”. This was considered especially important for community representatives who were also meant to have “good links with target consumer group”, to have the skills to gather information from that consumer base, the knowledge of other relevant support groups and organisations that might include stakeholders, and to have the desire to “learn more of what is needed in the specific health issue”.

A strong ethical stance is required. This includes issues such as awareness of confidentiality. At a deeper level this attitude also related quite closely to the issue of being ‘even handed’ in their role.

“A broad and fair perspective that demonstrates that they are not there to gain personally, or to retaliate for past grievances. The betterment of all clients should be at the forefront of your thinking, but underpinned by your personal experiences. A non-judgmental position in discussions, good listening skills, respect for the value of each participant regardless of their status in position or in paid or unpaid work. Above all a healthy respect for social justice in all its forms”.

7.2 Knowledge

Knowledge of the field, included knowing both the specific and broad issues addressed by their network, having an understanding of ACI’s goals overall and understanding the processes involved in the decision making. Several respondents identified the need for specific medical and health system knowledge. As they put it “they really need a high level of medical knowledge and understanding to get anything out of the discussions”
and “because of the nature of the work/problems/events that are discussed, and usually expressed in medical language (which is to be expected)”.

As well as knowledge of ACI and its systems, **health literacy** was identified as an important skill. This included the “ability to read and interpret a range of written material plus a degree of information literacy”. One respondent felt that “Although it is possible that a person with poor literacy could make a positive contribution, on the whole the very nature of the organisation would really benefit from a consumer who has good functional literacy so they can contribute on equal terms with the bulk of professional members who are mostly highly educated. Most important would be the ability to interpret the bigger picture by understanding concepts and moving with empathy beyond their own experience and 'agenda' to embrace and represent other consumer points of view. They don’t have to have professional health skills but they do need to be able to extrapolate from skills and knowledge they have acquired in other contexts”.

Health literacy also included the ability to **understand reports and decipher jargon**, a commonly articulated concern within this report. “My experience has shown me that it is possible for some consumers to feel completely overwhelmed at health service meetings because of the jargon used and reports presented. Some reports can be difficult for even health service staff to decipher, so it can be extremely intimidating for some consumers. Everything possible needs to be done to ensure consumers feel their view is as important as anyone else’s around the table”.

**Procedural knowledge also mattered.** “Consumers need to be able to contribute to a meeting and therefore need meeting procedure skills. Consumers need to be able to understand the reports provided and therefore to develop this skill they may again need orientation and explanation”.
7.3 Skills

The primary skills required by consumers was to be able to communicate effectively. This was because all “... consumers need to be strong communicators” although as one person noted “... not necessarily good English because the ACI can use interpreters to engage consumers”.

Communication skills in all their variety were seen as essential to consumer participation. These skills ranged from effective listening, through the ability to gather information from fellow patients in hospitals, to the ability to articulate their own, the patient for whom they are a carer and community concerns (and distinguish between them), facilitate effective feedback, and to “explain their status”.

7.4 Attributes

Personal attributes varied widely. These included the ability to “be able to be flexible and negotiable” to being computer literate and “being active participants in the treatment of their own medical condition or that of someone they care for”.

An underlying and somewhat unexpected attribute was that of courage and confidence. These attributes were expressed in a variety of ways, but essentially related to three key issues: overcoming the fear of public speaking both within networks and in public forums; the ability to ‘speak up’ (that is be confident enough to articulate their own views and those of their community); and having the deeper levels of courage and confidence to not be intimidated by clinicians and other individuals with strong opinions, “Maybe have some experience advocating and be able to speak up in a setting with very strong personalities. If they have never done this work they will need training and support for this.” “These skills are important to be able to contribute effectively and participate in the forums/work of the ACI”.

One respondent was able to articulate the rationale behind the need to have courage: “It can be quite a daunting environment to be working with medical professionals who are not always comfortable having to include consumers in discussions”.

Other attributes included the ability to be “passionate but not angry” or argumentative, to be proactive and to be self-reflective. This meant the “ability to reflect on their role in a thoughtful and non-egocentric way”.
8. Experience of consumer engagement with ACI

*(Consumer and Staff Interviews)*

Participants acknowledged the value of consumer engagement to the work of ACI. Most respondents reported a positive experience of consumer engagement with ACI and were able to identify those features that were influential for that experience. The articulation of the unique aspects of consumers’ involvement with ACI was often markedly framed by their experience with other organisations.

Issues arose in relation to the: use of medical jargon and acronyms; lack of transparent processes around role expectations; inflexible meeting times and choice of meeting venues; incomplete feedback loops; and isolation of consumers as potentially undermining the experience of consumer engagement with ACI.

8.1 Consumer experience of consumer engagement at ACI

Interviews and focus groups with consumers identified that for most the experience of consumer engagement with ACI had been positive including reports of *feeling valued and welcomed*. The following excerpts provide illustrative examples:

“I’m very pleased with the way my involvement has gone with the ACI. I have a background in the health system. Although I’ve worked for another NGO my career has predominantly been across area health services. So I have sat on the other side and tried to establish good consumer participation structures and processes. So I feel that I have a good understanding of what a good structure is. So now sitting on the other side as a consumer I actually think that what the ACI have in place is excellent” (Consumer Interview)
“... 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 ......but 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”
(Consumer Focus Group)

“But you were acknowledged and respected and that hasn’t changed, but we’re now into huge groups and – but that’s the difference, that one is acknowledged and respected and welcomed” (Consumer Interview)

“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”
(Consumer Interview)

“What has actually struck me right from the beginning is how enthusiastic they are and really sort of keen. Well the message I seem to get is they’re really keen to have the consumers on board which is a good thing” (Consumer Interview)
While overall consumers reported positive experiences of consumer engagement with ACI, there were some participants who, while acknowledging ACI’s efforts to engage consumers, suggested that there was still room for improvement: “ACI is good but in a way it’s still tokenistic” (Consumer Focus Group) and 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” (Consumer Interview) and “… there doesn’t seem to be a clear consumer strategy that I have ever seen” (Consumer Interview).

For some a paradigm shift was needed in the way ACI and the broader community view consumer engagement, to move from tokenistic to meaningful consumer engagement. In this consumer’s perspective:

“… 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” (Consumer Interview).

8.2 Factors influencing consumer experience of consumer engagement with ACI

(Consumer and Staff Interviews)

Ease of engagement

Experience of consumer engagement with ACI was influenced by access to a holistic overview and processes that supported active engagement. For some, participation was not well supported by current ACI processes, “... I think the reality is had I not been proactive in trying to get more involvement I probably wouldn’t have been involved. Really it was off my own initiative” (Consumer Interview). Other participants specified an uncertainty of what was expected of them and a lack of clarity about the role of the consumer, particularly in relation to wider consultation and community engagement as
influential in their experience of consumer engagement with ACI. For example, their consumer engagement experience would be improved with “… a little bit more information in advance about how the overall contribution would be structured and how hands on the actual processes are, what exactly is involved … I’m finding, because I’ve got other commitments as well, that there seems to be lots of little add-ons” (Consumer Interview).

**Making a difference and a valued contribution**

An important influence on how consumers experienced consumer engagement was linked with feeling that their participation makes a difference, has an impact, and leads to change. This underscores the significance of feedback in relation to effective consumer engagement and is illustrated in the following examples:

“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” (Consumer Interview)

“I’m very happy with my involvement, as long as they consider the suggestions I’ve made” (Consumer Focus Group)

Participant’s experience of consumer engagement was also mitigated by their perception of whether or not their input was valued and whether they were able to meaningfully contribute. One source of concern that was identified by multiple participants (staff and consumers) related to a difficulty understanding the medical
terminology and use of acronyms. Examples of views articulating positive and negative experiences of consumer engagement with ACI are offered below.

“I have been, as have the other consumers, on the network, actively engaged at every point. We’ve always been sought after in terms of our opinions and our views. We’ve never felt like we were lesser of a member because we were from a consumer group and not a health representative” (Consumer Interview)

“The really nice thing about being an ACI consumer is that you do feel valued and you can speak on sort of a peer level with people that are much smarter than you are or much more educated in the area” (Consumer Interview)

“I’m involved in a couple of networks. It’s good because I’m able to have my experiences from one network translate to the other … it has given me, I suppose, a broad knowledge of more of the whole system” (Consumer Interview)

“The thing is, we don’t have the same, naturally, we don’t have the same clinical knowledge. The acronyms change from meeting to meeting, there’s something new … it’s a bit of a challenge and I hate the way people come and say, I don’t know what that means. Sometimes I decide it wasn’t relevant to ask. I do - I wonder how the committees see me as a consumer rep, because I don’t often say much” (Consumer Interview)
Consumers and staff expressed acknowledgement of the positive impact of visible support by the senior executive on their experience of consumer engagement with ACI. Attendance and participation at consumer events was noted as particularly reinforcing. The importance of this executive support is conveyed in the following quotes:

“One of the things they’ve [consumers] found valuable and still report to this day, even though it happened several months ago, was having senior management of ACI acknowledge them and their worth. So we hold our meetings on a weekend and we had the portfolio director attend on the weekend in his own time to meet with them and engage with them and it really provided a sense of worth for them” (Staff Focus Group)
Program managers were identified as pivotal to consumers’ experiences of consumer engagement. In relation to meetings, the role of the Chair, availability of information that was clearly presented, and the attitudes of the group members were critical to participants’ experience of consumer engagement with ACI. Participants praised the commitment and diligence of the project managers, the network managers, clinicians and other health professionals in ACI. However, in one focus group with consumers, concern was expressed that when the Chair of the network is a clinician, the focus might be on more concrete and immediate things rather than on ongoing community issues, which may inhibit debate, and an interview participant offered:

“I suppose it would be nice for some of the execs or ACI Director or whatever it is, to come out and meet people sometimes. That’s a good way of feeling that your input’s valuable and your area - where you are - is quite valuable. That you come - even if it’s a forum, to come to that. Sometimes you get them, and they’ll come and they’ll do the introduction and they’ll disappear. Sometimes it’s nice if they stay around a bit and actually chat to people. Because that way it just makes people feel a bit more valued”

(Consumer Interview)
8.3 Staff experience of consumer engagement at ACI

*(Consumer and Staff Interviews)*

While staff and consumers generally expressed positive experiences of consumer engagement with ACI, shortfalls were also recognised. Some participants suggested that ACI needed to **shift their focus** so that consumers were not considered “add-ons” but essential players from the outset: “*I think we don’t yet see consumers as the integral part of our work. We see them as oh yeah we need a consumer, let’s get a consumer. We would never do that with clinicians, because we would always develop something with a clinician involved*” (Staff Interview). Participants suggested that at times they were frustrated by the lack of sophisticated methods of engaging consumers describing processes as “**clunky**”, “**confusing**” and “**slow to respond**”. Instead, “... at ACI we need to be a bit more responsive ... it can take six months for a consumer to get onto a network” (Staff Focus Group).

Staff further proposed that in order for consumer engagement activities to be meaningful they needed to **assess and accommodate to the needs of the consumers** as individuals, ensuring that engagement strategies are “**fit for purpose**”. Staff explained that the formal interview process, while important when used to engage consumers, may need to be flexible and appropriate to the consumer target e.g. young people, and the homeless, to avoid it acting as a deterrent. Other examples discussed included:

- developing a prompt sheet to consider specific needs of the consumers you are inviting and actively engaging e.g. need for Braille, only ramps, non-flickering lights, child care needs
- going to where the consumers are e.g. Facebook for adolescents, Aboriginal networks for that group; self help groups; ethnic minorities
- engaging with hard to reach groups across ACI, not just within some networks
• thinking outside the square and using different methods to recruit and engage consumers depending on the group and project

As explained by one participant, “Sometimes in organisations that I’ve worked in, you have to kind of jump through loops. I know obviously, some kinds of standards and procedures have to be followed but I think from ACI we need to make it easy for the consumers to be involved and easy for us working here to get consumer feedback and input. I think we have to be clever about the way that we get that. It doesn’t have to be someone sitting on a steering committee necessarily or - that's one way” (Staff Interview).

The staff identified positive experiences of consumer engagement, of “… getting a fresh idea from their [the consumer] perspective about what the problems are and what the solutions are, because they often have completely different solutions that the staff have never thought of” (Staff Focus Group) and at the same time iterated the tension between wanting to involve consumers throughout the whole process and the awareness of the costs of that to the consumer. They identified that consumer participation incorporated different types of activities and varying degrees of difficulty depending on the circumstances for the consumer. For example, turning up for a meeting might be difficult with children. Their experience was that consumers identified engagement as rewarding and supportive and that they formed visible networks.
9. Integration of consumer voices in the work of ACI

(Staff Survey)

Staff were asked their perspectives on how consumers voices had been integrated into the work of ACI. Apart from those who responded that they had not integrated consumer perspectives because it is not the main focus of their work, there were eight different approaches to this question.

The most common approach was involving consumers on committees. Examples ranged from membership on executive committees, working groups, taskforces, network committees, working groups and project steering committees, advisory bodies and more general ‘meetings’. More detailed examples include:

- “We have two consumers that are part of our executive committee that have participated actively (although less so of late)”

- “Consumers are members of working groups, advisory committees, executive”

- “We engage consumer representative on our ‘executive’ committee. Always give the consumer representative opportunity to contribute to discussions at the committee meetings and have their own agenda item on the meeting agendas”

- “Three consumer representations on Taskforce (would like more, but no takers)”

- “We have consumer participation in all working groups that involve patient care. Also we have consumer representation on our network's executive committee. Our consumers are well-informed and their input at meetings is highly regarded”
• “Try to ensure that consumers and community groups are always represented at meetings and have the opportunity to participate in discussions and comment on documents”

• “Our ECI committees have a consumer representative on them. This is a biased view and only one person though who is clearly a motivated consumer from either good or bad experiences”

Consumers are also actively involved in the development of network resources, models and plans. This ranges from the general “seeking input from consumer groups when developing resources” through to “semi structured patient interviews as a component of diagnostic phase for model of care development” and consumers’ “involvement in the development and endorsement of the … work plan and communication and engagement strategy” and “filming of their stories”. A more detailed approach was outlined by the following respondent:

“In our methods for developing Models of Care we emphasise the importance of having a consumer/carer on the group developing the model, and the importance of gathering patient views in the diagnostic phase. This can consist of patient stories, interviewing patients, shadowing patients and reviewing patient complaints”

A more general source of consumer engagement was the seeking of feedback on the work of networks and ACI. As in the broader range of inputs, the type of feedback sought and the methods to gather this input varied significantly in terms of focus and sophistication:

• “Asking for comment on relevant matters”

• “Current project also uses PETs to track patient experience feedback regarding their perception of services received”
• “These representatives are provided discrete pieces of work to review from the [de-identified] Advisory Committees - example is reviewing the [de-identified] patient fact sheets”

• “Providing opportunities for consumers to provide feedback on program development and implementation strategies, evaluation including surveys”

• “Consultation with individual consumers, consumer advocacy groups and consumer policy organizations”

• “Attend Outpatient Clinics and meet with patients and carers”

• “They also provide feedback on documents, reports, work plan and policy development. Their input influences the direction of our network activities, and influences priorities”

**Involvement in research projects and data collection** was a secondary source of ‘engagement’. For most respondents, this meant collection of information from consumers, for example annual surveys or focus groups with consumers or NGOs as one way of gaining their input. The value of this approach, despite the associated difficulties was noted: “The network has a project looking at patient and carer experiences - although it has been difficult identifying people willing to be interviewed, it has been a thought provoking experience for the network's clinicians”.

For a smaller group, consumer engagement involves the active engagement of consumers in the research process. In the case of one network it was noted that “We have had a consumer initiated project that received funding for development and piloting through ACI”.

For some ACI staff members, there were difficulties in the engagement process. These included:
• “I know of no actual consumers of the Program who are represented in the decision making process at ACI (as consumers) … I know of no avenue of input from the actual consumers (people with … a disability)”

• “Currently attempting to engage consumers for review of current guidelines but are having difficulty”

• “I should and I think it is important but I don’t do so at all”

• “Struggling to choose consumer rep and unsure what it will add”

• “In my ED capacity I find significant administrative hurdles and obstruction in setting up consumer communication strategies, we continue to battle on this front. In hospitals there is significant ‘fear of finding out’”

Several respondents mentioned consumer involvement in forums. This included both specially organised forums for consumers and facilitating the attendance of ACI consumers in conferences and related gatherings: “Holding forums and conferences either specifically targeted at consumers or involving them in presentations” and “Consumer representatives are invited to the … Annual Symposium and other [meetings]”.

A small group identified the role of the internet as a place for engagement. Staff commented that consumers could share “… their stories on our website”. One group already had a dedicated consumer resources section, while another was in development.
10. Improving consumer engagement: general perspectives

*(Consumer and Staff Interviews)*

Participants were asked to indicate ways that consumer engagement could be improved with ACI. For the most part, respondents applauded ACI for their focus on consumer engagement and their current consumer engagement strategies, while others offered suggestions on how consumer engagement could be improved with ACI.

In relation to consumer engagement

ACI needs to be “bold” and “to take a lead”

"I think ACI has to be pretty bold here. I think ACI as the Agency for Clinical Innovation probably needs to take a lead and this is a really good area in which we could really take quite a strong lead" (Staff Focus Group)

10.1 Paradigm shift

For some participants, improvement in consumer engagement both in the broader community and ACI requires a shift in thinking such that consumers are consulted as partners in driving change, as co-producers, rather than as passengers of change.

“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”

(Consumer Interview).
This mind shift change would be reflected in involvement of more consumers, with a more powerful voice, involved at every level and from the outset. The following are examplar quotes that articulate this idea:

“Well, talking from our point of view, I think we need to have the consumers of the clinical services having a much stronger voice, and that it’s not being engaged as an afterthought or being engaged as one of many. As the ultimate consumers of the services, I think the consumers should have a much stronger voice and a lot more power and control” (Consumer Interview)

“We’ve actually said there should be a consumer on every working body because our network is so big there’s not so many consumers in contrast with lots and lots of specialists and doctors. So I guess sometimes a consumer force is not as large as it should be. Then we’ve also got the problem of recruiting consumers because the public absolutely have no idea about ACI” (Consumer Focus Group)

“I think that’s important ... bringing them in from the start rather than bringing them in later, and helping them identify what their concerns are rather than trying to assume what their concerns are and then fit the consumer engagement to fit the project rather than allowing the consumer to drive the body of work in the first place, or the community” (Staff Focus Group)

“... you’ve already set the agenda and then you’re asking them to comment on our agenda. It really is a very different slant to saying what are your issues as opposed to this is what we see as your issues, now tell us if we’ve got it right. So I think health is going down that track in some areas where we start with a blank page and ask them, you direct what you see as the issues” (Staff Focus Group)
“I think we don’t yet see consumers as the integral part of our work. We see them as oh yeah we need a consumer, let’s get a consumer. We would never do that with clinicians, because we would always develop something with a clinician involved. I think that there’s this tag-on effect with consumer engagement as a second” (Staff Interview)

“I think we really probably would do well to see consumers as almost part of our staff, an extended staff that we engage. They do so on a voluntary basis. But we do see our clinicians a bit like that. I don’t think we’ve made that step for consumers on the whole” (Staff Interview)

There was also an acknowledgement that ACI are open to change in relation to consumer engagement. As one staff member expressed “So I think sometimes it’s challenging the system and I’m glad to see you’re [researchers] doing this work on it because that’s an indication that the organisation is prepared to make changes in just doing this” (Staff Focus Group).

10.1.1 Clarification and process improvement

Improvement in consumer engagement at ACI requires the development of a systematic approach to consumer engagement. Participants’ responses supported the need to develop and adhere to a strong framework to involve a broad spectrum of consumers. The following points and illustrative quotes present areas highlighted for attention for improving consumer engagement by ACI. Respondents identified that ACI could improve consumer engagement through introducing transparent and streamlined processes from the outset of the engagement process that enable:

Clarity about the role and expectations of consumers in relation to activities with ACI and expectations of ACI of consumers was raised by both staff and consumers.

“I’d like to know more clearly, what are the expectations of us? I don’t know that necessarily other people know either” (Consumer Interview)
“But we also need to understand what it is that we can expect from consumers. Then also for consumers, what it is that they are - what is it that they're signing up for and what can they expect of ACI?” (Staff Interview); “their time and then the expectations if you want people to contribute to specific meetings or conferences it’s being mindful of our expectation” (Staff Interview).

Clarity about the question of representation: in those forums and articulation of processes by which consumers feedback to the wider community.

“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 ... 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 ... One of the issues that has come up there has been that people get on to committees because they have a particular lobby or they have a particular passion and they tend to push their passion or their lobby. They don’t actually represent the, I guess the varied views of the consumers that they actually represent ... People who are invited to be consumers or who are opted in as being consumers should present even just a half a page outline of how they will actively represent the consumers for the group that they - how they will get information back out to the consumers and how they’ll bring information in” (Consumer Interview)
Clarity about the role of consumers in engaging the wider community:

“I don’t know how one would do that and I actually do not understand my role there, is there a role? Because our - we’re confidential, et cetera ... But to my knowledge it’s not my role and how could it be my role to engage the wider community? But I would be happy to do whatever is advised and support it”  
(Consumer Interview).

Clear processes and structures in place to encourage consumers to report back to their LHDs:

“The other thing about networks I find strange. At no time since I’ve been on either two networks I’m on ... has anyone ever said to me, make sure you take that back to your LHD”  
(Consumer Focus Group).

Clarity about the pathway by which consumer input influences change:

“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?” (Consumer Focus Group)

“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” (Consumer Interview)
Clear feedback about changes that are the result of their participation: “So if you can feedback the results of what you’ve done in a way that’s meaningful to the people who have participated, then that’s sometimes much stronger than some other incentive which might be a bit more ethically challenging” (Staff Focus Group); “… it is more than just saying they have a voice, but making sure that we’re recognising their contribution and developing that into something that they can say yes, it really was worth my while going to effort of sharing my story and going through that challenging time and taking time off and getting a babysitter because I really feel like it did result in …” (Staff Focus Group).

Setting clear goals:

“… you need to meet all the SMART goals. Be specific, measurable - what’s the other one? Achievable. Nothing worse than going to something you know it’s never going to be achieved” (Consumer Interview)

Streamlined and clear processes that enable ACI to be responsive: ACI should be more responsive with simple and streamlined processes that enable a consumer to engage. “I think at ACI we need to be a bit more responsive. Because I know, that’s the criticism of our system at the moment. It can take six months for a consumer to get onto the network just because our office processes seem to be - whereas I think we should, somebody rings and says I want to be on the network we should make it as simple as possible and say yes. Can we just go through this and we make it easy” (Staff Focus Group).

Clarity of communication processes within ACI: “So that support when they’re first touching base with ACI, I don’t think that’s been that well done either. Then sorry, then once they are part of my taskforce then I mean I have no idea how internally ACI communicates to my consumers who are involved in my working groups because I don’t
get copied ... Again another disjointed set of communications that goes to the consumer and the consumer kind of thinks, well how does this organisation work and not link up. It can potentially become a burden I think” (Staff Interview).

**Clarity about the endorsement of social media use by ACI staff:** it is important that ACI consider and specify the acceptable and endorsed processes and training requirements for using social media appropriately, “We need the skills, the social media skills. Because I think that's an important one.” “If I was going to do something on Facebook to engage with consumers, I wouldn't know how I should go about that. That's why I would do it rightly or wrongly and whether I would be likely to get into strife about it et cetera. There's all those things that for me just goes, ‘woah’ I don't think I want to go in” (Staff Focus Group).

**Improve the recruitment process:** “I don't feel we have a sophisticated enough way of engaging consumers. I mean I've recently recruited consumers to one of my taskforce that I work with and I found the process incredibly clunky” (Staff Interview).

**Clear processes put in place to evaluate** the recruitment and engagement processes to identify where these are not appropriate or not working so that they can be improved: “Then we got five people interested in the group. Then we sent out the packs and one person applied. I have no idea why those other four people didn’t apply. To me this kind of when you try and get more information out, I feel like things go off into the ether and that we haven't understood exactly you know that loop again. We haven't understood why those people didn't apply. Was it the fact that the pack that you received, the set of forms you receive is actually not very friendly to consumers? Is it a bit overwhelming to receive that pack or is it that they just when they read more about the role, they just thought oh that's actually not for me. We don't know those answers. Therefore when we go to do another EOI, we don't know whether we're making the same mistakes that we've made before because we don't have that information” (Staff Interview).
10.2 Empowering and networking consumers in ACI

Participants discussed the importance of empowering consumers through the provision of training, communication of information in a way that is appropriate, and structures and processes that support their active involvement. There were also suggestions that linking consumers with each other would empower consumers and improve engagement.

Participants recounted that networking consumer representatives with each other across ACI would be beneficial and would offer opportunities for mentorship and peer support. It was identified that it would be good to have more than one consumer on each working group so that they could support each other.

Some consumers described feeling that everyone else in the group knew each other.

“It probably has no bearing on our input, but it's difficult in a huge group because all the clinicians know each other, they know their roles, they have other meetings and we feel - or I feel that I don't - I don't always feel I contribute anything at all, just by being there”

(Consumer Interview)

There were suggestions that mechanisms to facilitate networking with other consumers in ACI would be helpful.

“... with consumers backing one another up and learning from one another if, and with people’s permission, that contact details were shared amongst all the consumer people, like the 50 people? If we could get in touch with another, if we have permission”

(Consumer Focus Group)

A number of participants outlined the benefits of being networked with other consumers in their network.
There were suggestions that it would be useful to integrate consumers across the networks, to establish a central consumer group onto which are nominated one or two representatives from each group with this group having “... an overall idea of what’s going on at ACI to bring their general issues to the table” (Consumer Focus Group). It was proposed that the group meet twice a year and consider issues raised by their respective groups and then feed that information back to their group.

Respondents appreciated strategies, such as the Consumer Forum, that ACI was making to facilitate consumer networking.

“I think the idea I said about the peer support thing, having connections with other consumers, I think that’s really important. The consumer forum, which I’m not sure how often it happens now, but it’s really important for that because if you don’t have that consumer forum where all the consumers get together and you can discuss what the different networks are doing, you just feel like you’re a consumer on one network and there’s no bigger picture network ... The consumer forums just gives you the chance to meet other consumers in different disciplines and work out how their networks do things, if they’re maybe doing it a different way that could be better for you” (Consumer Interview).
10.3 Training and induction

Participants suggested that training should be made available for consumers.

“It think there's been a huge gap - some many years ago, there was some consumer training and - I can't remember why - but I wasn’t able to go - the one that would have been available to me and there was always going to be another one”

(Consumer Interview)

It was suggested that training may be beneficial particularly in relation to meetings and language, “I think the other thing that we need to consider with consumers is having some kind of training or support program for them, because often they may not necessarily have experience of going to meetings where there’s agendas and how issues are raised, et cetera. As you were saying, even the terminology, so I’ve started developing a glossary of things that I find when I do my minutes, writing them for the consumer” (Staff Focus Group).

There were also suggestions that there be a comprehensive orientation and induction that include an overview of NSW Health, the structure of ACI and how they fit together, policies and processes, lines of communication, issues around confidentiality, Code of Conduct, how the work of ACI influences change and the role of consumers in that. While orientation is available, some participants noted that it could be improved, “Then when the consumers are recruited and they did an orientation. That's great that we have a process for orientation. But my consumer went away from the orientation not understanding how she would be reimbursed” (Staff Interview).

The following excerpt from a focus group discussion offers some suggestions of potential form and content to be included in the induction:
**10.4 Clear communication**

The need for communication of information in a way that supports engagement was raised repeatedly in interviews and focus groups. Participants spoke to the need for careful thought as to the most appropriate medium of communication (e.g. braille, electronic, paper), the layout (e.g. not in three columns for people with an intellectual disability), and provision of support to understand the information to enable time to process and digest the information. Most importantly, it was emphasised that a “one size fits all” approach was not appropriate and that effective engagement of consumers requires “fit for purpose” engagement approaches including communication. This concept is presented in the following exemplar excerpts from interviews and focus groups with staff:

“If we are going to engage consumers then let’s do it and let’s do it well and make sure they are actively engaged in what it is we’re working on, that they have a voice and we act upon what their suggestions are. But also we have to have - be able to give them the information in a way that they understand what it is we’re asking them for their input on. So I think in terms of strategies that’s really important. So I
think in terms of our strategies we’ve got an important role to play in making sure that they can make decisions and input. So we have to give them the information in a way that they can understand that ... often in health things are so complex. If you don’t understand the bigger picture then I think that’s when it's hard for consumers because they are often not able to see globally what’s happening. I think that’s our role, in terms of the ACI, making sure that we are able to communicate properly so that they can make informed decisions” (Staff Interview)

“I think that’s what is really critical for people and actually also for the other people, if it's on a high level committee or if it’s a regular working group, how the other members of that committee interact with a person, particularly if they have any communication issues or an intellectual disability that there are [barriers] to communication or allowing people more time to be able to have their say. So those kind of facilitators to help that person to be involved in the process can be very helpful. I don’t think we do that very well in terms of educating even the consumer or other people on the working groups” (Staff Focus Group)

The positive effect of well thought out communication was also noted appreciatively,

“She actually crafts her emails. She puts a lot of effort into them”
(Consumer Interview)

Consumer and staff participants made particular mention of the disempowering effect of the use of acronyms and medical terminology that were not readily understood. The following excerpts from interviews offer more explanation of this:
“It’s hard to avoid, and I’m sure this isn’t people’s intention, but certainly, the appearance is somewhat - our area of involvement is somewhat tokenistic. As I say, I’m sure that’s not people’s intention but it certainly - actions speak louder than words; certainly, in terms of the numbers of people on the committee and the relative weighting between the clinicians et cetera versus the community. It’s also quite - and I hear this from our people as well - daunting to deal with the clinical world because of the way, as with most professions, the terminology and the acronyms and the - it’s almost exclusive by its nature, in that it’s a world that is very hard to penetrate for people that haven't had the experience and training that the major participants have”

(Consumer Interview)

“If people aren’t given the right information it’s very easily to be daunted as well in terms of - we have to make sure that people don't feel intimidated by big words and clinical words. I have been on groups where I've seen the consumer never speaks because the clinicians get into the nitty-gritty and don't explain properly what it is they're talking about” (Staff Interview)

“It's sort of, are you going to speak up? The thing is, we don't have the same - naturally, we don't have the same clinical knowledge. The acronyms change from meeting to meeting, there's something new. I just - but it's a bit of a challenge and I hate the way people come and say, I don't know what that means. Sometimes I decide it wasn't relevant to ask. I do - I wonder how the committees see me as a consumer rep, because I don't often say much. But if I was asked and I knew something about the subject matter, of course I would. Having said that, I think we're well respected and acknowledged, et cetera”

(Consumer Interview)

“So in terms of the consumer to make it empowering the process evaluation needs to measure that, were they empowered, did they understand the discussion, was there no use of jargon or acronyms, did they understand what was taking place?” (Consumer Interview)
Participants suggested that an alphabetical list of the meanings of acronyms and terms that are commonly used across ACI as well as a list of network specific terms would be invaluable:

“They speak in a language that is very specific to a condition or a particular environment and I found right the way along through my experience that sometimes I just don’t know what the acronyms mean. The things that I would have really liked from the word go would have been a list of common acronyms in health” (Consumer Interview)

“Ideally it should be part of the orientation. It only needs to be a one page sheet and to ask the people on the executive or on the network to put together a one page list of acronyms they use and what the meanings are of them. Then after the initial orientation phase if there’s stuff that they want more information about then they know they can either ask for it or they can at least go and Google it” (Consumer Interview)

“They have to - where possible - a simple language for the consumers. I can’t speak for the others and I should have a better understanding because of a nursing background. So it might be harder for the others ... Not just the acronyms, but some terms that you wouldn’t - or I would never think, oh, is that what that means” (Consumer Interview)

10.5 Knowing who is involved in ACI and tapping into key information within ACI

Participants identified that it would be helpful to improve the database of consumers who are involved and how they are involved. It was also suggested that a register of carers or consumers who are happy to be surveyed or to participate in various activities (e.g. focus groups) would be beneficial as well as a mechanism by which consumers are able to indicate that they are unavailable to participate for the time being.
Staff also proposed that within ACI, existed a wealth of information that could expedite and streamline future engagement. For example, knowledge of who the gatekeepers may be in external organisations and ideas on how to best approach particular issues. It was suggested that facilitated sharing of that information would be useful to improving consumer engagement, “So it would probably be worthwhile maybe within ACI having a day or half day for the network managers to talk about what works and what they've tried to engage consumers and have a bit of a focus on that” (Staff Focus Group).

**Tapping into other organisations external to ACI**

A common theme that arose across interviews and focus groups with staff and consumers was that of tapping into organisations external to ACI to improve consumer engagement, “... not just keeping it insular ... let’s use Consumer New South Wales and see what they can help us with and how we can work with them. I don’t think we have to just rely on building things within the ACI. I think we need to look outside and see what other groups there are and how we can use their input. That's one way. We don't necessarily have to own all the kind of, if you like the processes that we have for engaging consumers within ACI ... Obviously we work with the LHDs and they have processes and patient groups. So it’s knowing what’s out there and tapping into what’s out there to get what we need in terms of consumer input ... But I think it is good to link with other consumer groups that maybe within say housing or the police have. I think there's probably a lot of untapped consumer resources that we can maybe link into” (Staff Interview). Thus participants observed that ACI needs to be encouraged to see the relevance and benefits of working with other agencies and those in the non-government sector. Tapping into external organisations was not limited to accessing the consumers themselves but also their use of consumer engagement strategies that ACI may not have yet considered, “... other agencies and maybe councils, local councils, in terms of how the engage consumers or what kind of groups they’ve got already” (Staff Interview). In addition it was suggested that strategies that non health organisations use to engage consumers, ones that may not have been tried in health yet, may also prove useful and warranted consideration.
10.6 Other engagement mechanisms

*Consumer Council representation*

It was noted that currently there are networks that are not represented on the Consumer Council. It was therefore suggested that one area for improvement would be to increase the number of consumers on the Consumer Council. It was acknowledged that this may require constitutional change such that there would be “... *at least ten consumers with an alternate five and five year arrangement*” (Consumer Focus Group). Furthermore, it was suggested that the relationship and communication mechanisms between ACI Consumer Council and ACI network consumer representatives be improved so that these groups can benefit each other.

*Champions*

Participants proposed that consumer engagement could be improved by using the voices of existing consumers and clinicians who have seen the value of consumer engagement (good news stories). There were suggestions that champions may be recruited from among those clinicians who are also consumers and “... *from the point of view of ACI employees who've had an experience of a service and what they could say about that experience*” (Staff Focus Group).

*Funding*

There were suggestions that improvements in consumer engagement could be made through funding technology development, assistance, infrastructure and resources that support the engagement of consumers with ACI. For example, use of web cams for meetings with consumers who are located in rural areas, provision of reams of paper for consumers to print out meeting documents at home, or posting meeting documents to them. In addition, some participants were uncertain of the reasons for different funding rates for staff and consumers for meetings (meeting rates (staff) versus casual rates (consumers)): 
“I was just going to say with the reimbursement, I do think we need to be a lot more upfront about it and probably a bit more proactive. For instance, one of my consumers, it is a childcare issue but it’s also an issue that she’s invited onto interview panels for my network but it doesn’t fit the - there’s no hourly rate. So she’ll change her working schedule to meet that commitment but there’s no payment for her time, as opposed to a GP who comes onto an interview panel who changes their time around but gets an hourly rate. That’s why I think is it a real acknowledgement of the value when we’re not meeting it in that way, but also I think it’s not just the money but it’s also showing them that this is a real value we place on their time and their opinion” (Staff Focus Group)

10.7 Improving consumer engagement: consumer perspectives

(Consumer Survey)

Consumers identified four key areas that they felt would help improve consumer engagement in ACI. These included: providing support for consumers; enhancing communication; supporting connections between consumers; and expanding the roles for consumers.

The examples of additional support for consumers echoed those identified in previous sections, ranging from the pragmatic (dictionary of acronyms, draft documents in print, training) to the more conceptual “Nurture consumers to achieve realistic and achievable goals”, and personal “Educate us about what we are supposed to be achieving, and facilitate personal attendance at meetings”, “somehow get me more motivated but sometimes my time is also very limited” and “If the process intends to use my time, make sure it’s done in as way that is as time efficient as possible”.

With issues of communication, similar patterns were seen. Central issues related to keeping consumers informed through newsletters, forums, phone calls, online forums and webinars.
Supporting connections between consumers reflected dual concerns of exchange of information and personal support. For example:

“Hearing how other consumers have contributed to improvements. When you are new you have little idea of what you might say that would be helpful. I have found listening to other very experienced consumers enlightening and it makes me less afraid to speak up”

“I think the work is valuable and I would love to see a few more consumers on each committee, consumers gain and give so much more if they are connected also to each other. And not just annually. But in person.... in order to build up relationships.... first then to connect using technology more so to ensure economies are build into the cost of gaining consumer feedback”

An expanded role for consumers included an opportunity for ACI networks to be chaired or governed by consumers and clients, but also wider participation in the health agenda “opportunity for involvement and discussion re impacts of future changes in government funding to NGO's both in the Health and Disability sectors”.
11. Barriers to engagement

11.1 Barriers to engagement: general perspectives

*(Consumer and Staff Interviews)*

Participants identified potential and actual barriers to consumer engagement with ACI. While there was considerable overlap in the types of barriers to consumer engagement that consumers and staff identified, there were also barriers that were acknowledged uniquely by each group. Lack of familiarity with technology, costs (time, fiscal, energy), distance, isolation and the business of life were commonly offered barriers to consumer engagement. There was also a shared view that uncertainty about what the role involved and unrealistic expectations both on the part of the consumers and of ACI, and a lack of feedback in relation to outcomes resulting from involvement, were barriers to engagement.

Hard to reach groups were identified specifically as having multiple barriers to engagement.

“*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*”

*(Consumer Interview)*

“... *some of the groups that you most want to get to input are the disadvantaged groups. So the CALD group, the Aboriginal group, the trauma group, the refugee group ... homeless group and they’re the ones that you can’t get to really because they don’t, they’re not represented through - they don’t turn up to focus groups. They’re just not there*” (Staff Focus Group).

Participants also conveyed that processes that disempowered consumers were also potential barriers to ongoing engagement. These included: use of language that
excludes those without that specific vocabulary; inappropriate meeting venues and communication methods; and meeting structures that do not support specific needs of consumer populations e.g. braille; timing of meetings; short notice of meeting times. It was explained that it may be difficult for consumers to engage in a meeting in which all of the clinicians know each other and know their roles but the consumers are alone and do not know anyone else. Illustrative examples are captured in the following quotes:

“Well I think what I just spoke about was if people aren’t given the right information it’s very easily to be daunted as well in terms of - we have to make sure that people don’t feel intimidated by big words and clinical words. I have been on groups where I’ve seen the consumer never speaks because the clinicians get into the nitty-gritty and don’t explain properly what it is they’re talking about” (Staff Interview)

“Well, I think the way it’s structured where the clinicians are the experts and the consumers are engaged in not a deep enough way” (Consumer Interview)

“Often what I see when consumers share in meetings are clinicians dismiss that opinion because it’s over from their world view or it’s so - often what consumers will do will share at the very fine and granular level - like they’ll share experience right. I think often what clinicians will try and do is share group level, data driven views. I think that some sort of communication about how you value both of those things equally. So you don’t see one as the lesser because it’s not necessarily data driven or it’s anecdotal, all those kind of things. That the experience has real value” (Staff Interview)

“In some way our chairperson only reports the more concrete immediate stuff so the real consumer voice is ... [not heard]” (Consumer Focus Group)
A lack of awareness of the work of ACI, illness and uncertainty about whether or not their input made a difference were also cited as potential barriers to engaging consumers, “But then if consumers don’t see anything delivered that’s meaningful for them either, then I think it’s a negative experience. It’s like we just touch them and do what we were going to do anyway and I think it’s really important that it’s - that we get, that consumers believe that their outcomes and their unmet needs are actually being built into and we are actually getting traction in those areas that are important for them. We need to do that feedback thing as well” (Staff Focus Group).

“I find our consumers, because we don’t talk in the technical language, you sort of doubt yourself a bit like what I’m saying maybe it’s as important or life-saving for what they’re talking about because the focus of my network is managing acute and saving lives but they give very little attention to community living” (Consumer Focus Group)

“I think that’s a really important part of the meeting, because it’s intimidating to be in a room full of really smart people. If the floor’s not open to you and you’re not given that moment to say something, you might be too frightened to say anything because you don’t want to look silly” (Consumer Interview)

“I think there were about 50 people there and they were except for one other man they were all health professionals for middle management and above. That would be - so the consumer voice is a very small voice. That could be very intimidating for a lot of people and yeah so the consumer voice can get lost in there. I’m not sure how you make sure it’s heard” (Consumer Interview)
Apprehension around obligations and expectations of consumers once issues had been exposed were deliberated in relation to engagement of consumers. Discussion in relation to this issue centred on the huge untapped needs and uncontained obligations that could not be met with limited resources. Participants talked about their concerns connected to opening expectations that cannot be met with the potential of creating stress, anxiety, disappointment and anger. The following focus group discussion illustrates this issue:

“P1: It’s like opening a Pandora’s Box. So I think that's one of the other questions about barriers. I think that some of the boxes that we haven't opened in the consumer world actually are very big pieces and work and mean that you've got uncontained obligations. Like how do we fix this problem now we ... So to some extent it's a bit too hard. So I think that is a barrier is what out there the big consumer world there's huge issues that are untapped.

P2: You can open expectations.

P1: That’s exactly the problem - you turn up, open the door and go find a solution.

P2: That then creates stress, anxiety and disappointment and sometimes anger that they've told you what they need and all and what the problem is...

Facilitator: You can’t do anything.

P2: You can't do anything about it. Yes, so I think you need to have a way of ...

P1: I think you do - containing.

P2: ... approaching and putting it in context from the beginning so that you don't meet those sorts of issues” (Staff Focus Group)

11.2 Barriers to engagement: staff perspectives

(Staff Survey)
Staff identified seven different types of barriers to consumer engagement. These barriers included both attitudinal and structural issues.

Attitudinal issues included both those related to clinicians and consumers. **Clinician attitudes** formed the first barrier. This revolved around two inter-related concerns, clinicians monopolising proceedings and the under-valuing of consumers and their input.

Some clinicians were described as being “close minded” and “monopolising meetings.” This was attributed by one individual to the “hierarchical nature of health care - e.g. doctor knows best NOT seeing the patient as part of the team”.

In terms of the valuing of consumers, staff felt that some clinicians did not recognise the ‘true value’ of consumers or their input, or that they privileged or focused on clinician engagement, “the perception that clinician engagement is more highly valued”. But the valuing was not just about acceptance. As one respondent argued, “ACI needs to value and act on consumer in-put”.

“If consumers felt their contribution was taken for granted, or that the consumer engagement process was tokenistic, I am sure this would be detrimental to the input that consumers were willing to provide”

For **consumers**, attitudinal issues focused on fear. That is, the consumer being the “sole voice amongst learned professionals / clinicians” and “fear of rebound if critical of health services ie vulnerable population”.

The characteristics of consumers were identified by certain respondents as forming a barrier to participation. The notion of the ‘right’ **consumer** related to two separate aspects. The first concerns the question of how to identify an appropriate consumer. This related to relatively simple administrative details, such as having an up to date database of consumers to invite into ACI activities or more complex notions of “[needing] information about how to think strategically about who and how to engage people and maximise their contribution”.
The second relates to notions of representation. For example “I feel that it's sometimes difficult to find the right person to be truly representative, but I see that as a challenge rather than a barrier and should not be an excuse for not trying to find someone appropriate. Also feel that the same people keep putting their hand up to be consumer participants and feel that efforts need to be made to ensure new consumers are identified to avoid 'stagnation’” or the “failure to source consumer feedback directly from consumers (not organisations purporting to represent them)”. Identifying consumers from a diverse range of backgrounds continues to prove problematic. “Additional barriers to access the regional and rural/multicultural/ Indigenous consumer perspective”.

Part of being the right consumer from the perspective of ACI staff, are the knowledge, skills, attitudes and availability of consumers. Knowledge related to “consumers often underestimate the complexity of the work conducted by the ACI” or not knowing about the work of ACI. This was thought to be important because “being in the minority on groups can be intimidating as well, if they are not fully aware of what is needed from them this will act as a barrier”.

Attitudinal issues were mainly concerned with questions of bias. For some staff a consumer who has “… a specific personal issue they are pursuing and not able to look at the bigger picture. Having a consumer that is not mentally stable post their injury” or one who makes ‘biased comments’ are of particular concern.

Availability, the amount of time consumers are able to commit to ACI, and commitment also plays a part in sustained engagement. “Successful outcomes can take a long time in health and require commitment and patience to stay the distance - this may be a barrier for some impatient for improvement.” A more pragmatic concern was that “many consumers are older or have fluctuating health status - unable to travel and attend meetings”.
One last response puts the need to find consumers within the organisational context of ACI and points to barriers outside those of the characteristics of consumers. “Insufficient mechanisms/policies/guidelines to guide wider consumer/community engagement as standard practice, i.e. going beyond waiting for people to express interest or approaching consumer/NGO organisations”.

The **language and information** included the oft-repeated concern of jargon and acronyms. “Technical nature of information and solutions”, “too much medical jargon/medico speak/focus in meetings, relevance of issues” and “jargon, alphabet soup, we often speak in alphabet soup and for non clinicians it can be overwhelming and intimidating”, “not having things in clear language” and “long, wordy documents”.

**Engagement mechanisms** were thought to act as a potential barrier. These included both activities that occurred within networks “being rushed so don’t take the time to seek their input appropriately” and the need for appropriate feedback. As this respondent argues “Some of the barriers come from the consumers not feeling that they are making a valuable enough contribution but making sure that they receive feedback and have an opportunity to debrief etc can help overcome this”.

A secondary issue for engagement mechanism is the **bureaucracy** associated with participation. Many of these issues were identified in earlier sections as being of concern to consumers. They include:

- “All the paperwork to sit on a committee is seen as a barrier to some”
- “Formal structure of meetings”
- “Difficulty of reimbursement procedures”
- “Slow progress of projects” and “Slow progress to make a difference on the ground”
- “Talk and no action”
• “The ACI process for a consumer to join the network is off-putting for many - especially younger consumers who are time poor”

• “Sometimes confusing relationships between MOH, LHDs and ACI”

• “Vague generalised administrative concerns without precedent”

The cost of engagement to the consumer took several forms. This included the issue of burnout or conflicting priorities. In the case of burnout, this was seen as resulting from consumers being asked “to be involved in too many things within the ACI or ACI consumers being accessed by other groups for input”. The “added expectations outside of the Network business. If individuals are active within the Network then their involvement in other activities can be a burden. They will sometimes come to us asking do they really need to participate in other activities”.

Location loomed as a concern: “ACI office location, accessibility of consumers”; “Parking/ access to action from regional / rural areas”.

Lack of support from both ACI and consumers’ own organisations was a recurrent theme. “Consumers need support to participate and without this they can feel disengaged. “The lack of strong robust consumer organisation to support participation”.
12. Enablers to consumer engagement

12.1 Enablers to consumer engagement: general perspectives

*(Consumer and Staff Interviews)*

Participants were asked to identify factors that helped or enabled consumer or community engagement with ACI. That ACI was widely embracing consumer engagement and looking at ways to improve such engagement was considered an enabler.

> “I think their willingness to be looking at consumer engagement is a great help, so it helps reduce the barriers” (Consumer Interview)

**Corporate acknowledgement** that health needs to be consumer driven was also identified as enabling engagement, “… we do have a dedicated communications and consumer engagement group and I think that does put it on the agenda for all of us. Having [de-identified] team being there does remind you that you can’t really let the consumers out of your thinking. So I think having that corporate acknowledgement meant that health needed to be consumer driven” (Staff Focus Group).

The scope of factors that were suggested as facilitators of consumer engagement was broad ranging, from attitudes or virtues to more practical enablers. Demonstrating that consumer input was **valued and respected** and providing a **safe space for that input** were commonly identified as important to facilitating consumer engagement. **Valuing the consumer** as an individual, and **structuring engagement** to take those needs into account and acting on consumer contributions and feedback of outcomes were also considered imperative to encourage participation. In addition shaping the message for the target audience was raised as an important enabler. These concepts are exemplified in the following excerpts from focus group discussions and interviews.
P1: “That’s why I think it’s a real acknowledgement of the value when we’re not meeting it in that way, but also I think it’s not just the money but it’s also showing them that this is a real value we place on their time and their opinion”

P2: “If you communicate more the value, then you might not have to be so going out to people all the time. The people might identify themselves through you. If we can communicate ACI’s value to consumers a bit more, then we might self identify and be part of it” (Staff Focus Group)

“To facilitate that I think it’s really important to have a safe environment where consumers feel that they can actually say what they think and not feel like they’re saying something that may be dumb or maybe inappropriate and feel that they are respected, as [de-identified] was saying, part of the team” (Staff Focus Group)

“Or just inviting the consumer, do you have any feedback on that? Because it’s scary, sometimes, you don’t want to break into a conversation that’s between some really high level professionals or whatever. You don’t feel qualified to have much of a say. But if they make space and ask you for that input, then it’s a lot easier” (Consumer Interview)

“I don’t know what words you would use for this, but it’s kind of like a person centred and just making sure that you don’t just have easy rules of thumb, that you do think about the consumer that you’re working with and what they need, and ask them, involve them in some of that planning for their engagement” (Staff Focus Group)

“But I think the key is we need to actively act on what consumers want but obviously we need to enable them to have the voice and to be able to tell us what they want.” ... “I’m sure if they are involved and feel like they have some input, that must be very positive for them. Also if you’re working with consumers and - I
think it's just in terms of getting it right. If you feel like you've worked on a project
and you've had good consumer input and you've developed something that you
think is going to be useful and that you've got the consumer saying yes that's
going to be effective. It's positive feedback and input. It's tricky. It's very difficult
the whole enabling consumers be actively involved I think” (Staff Interview)

“So rather than just come up with a big policy document you need
to think creatively about who the message is going to and how
they can feel involved” ... “pictures and diagrams”
(Consumer Interview)

The characteristics of individuals involved also enable consumer engagement. This is
particularly evident with passionate champions.

“[the network] 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”
(Consumer Interview)

Co-chairs with a good grip on the agenda and who ensure that consumer input is given
the same space and importance as the input from other members of the meeting were
also identified as facilitators of engagement, according to one participant:

“So it's really about the co-chairs having a good grip on the agenda
before they get there and then being able to construct the way the
meeting flows so that all the points are covered and there is time
for just general discussion” (Consumer Interview)
When asked about enablers to engagement, one of the participants highlighted the importance of **cross representation**.

“**So you need individual consumers to bring to the table their experience but you also do need the not-for-profit organisations that might represent that community to also be at the table. I don’t think it’s a successful model when you only use one or other of those. I actually think you need both**” (Consumer Interview)

Participants reported that **clear and transparent expectations** about roles and responsibilities, knowing what is involved and knowledge of how beneficial their contribution to ACI could be were also facilitators of engagement with consumers. Thus, emphasising the important role that consumers play was considered an enabler.

“**Thinking about when you advertise to consumers, fear of the unknown or people have got no idea what they’re getting themselves into being involved with ACI. I suppose if they’ve got no knowledge of ACI then it’s coming back the other way in that they don’t know and understand what benefit they could be to ACI ... I think it’s about trying to make the consumers feel comfortable in the role and to actually get across when you’re trying to get consumers the possible benefits to them and the benefits they can be to ACI**” (Consumer Interview)

**Streamlined and transparent processes** that made it easy for consumers to get involved were also emphasised as important facilitators of engagement. This point is evident in the following excerpts:

“**It needs to be easy for consumers to be involved. Sometimes in organisations that I’ve worked in, you have to kind of jump through loops. I know - obviously some**
kinds of standards and procedures have to be followed but I think from ACI we need to make it easy for the consumers to be involved and easy for us working here to get consumer feedback and input. I think we have to be clever about the way that we get that. It doesn’t have to be someone sitting on a steering committee necessarily or - that’s one way” (Staff Interview)

“I think at ACI we need to be a bit more responsive. Because I know, that’s the criticism of our system at the moment. It can take six months for a consumer to get onto the network just because our office processes seem to be - whereas I think we should, somebody rings and says I want to be on the network we should make it as simple as possible and say yes. Can we just go through this and we make it easy” (Staff Focus Group)

“What is available to a consumer [for] car expenses or travel expenses. That needs to be an easy process for people to claim their money back” (Consumer Interview)

Participants also highlighted pragmatic facilitators (reimbursements, changes in meeting times) to consumer engagement. It was suggested that not only were such actions helpful, but they also conveyed a message that the consumer’s input was valued and important. It was also identified that having a specified “go to” person was beneficial. Examples of practical enablers included: adjusting meeting times to accommodate involvement; organising and paying for travel to attend ACI events including meetings; provision of hard copies of meeting documentation; and providing ways to support people to use technology such as training, back up, and availability to trouble shoot problems with that technology. The following extracts are offered to illustrate:
“But I think the important one is that people shouldn’t be out-of-pocket because of their involvement because they’re doing it on a voluntary basis and I think their generosity in flying people down if that’s what’s needed is really good” (Consumer Interview)

“I would hate this to become, we must provide all consumers with hard copies of everything. But where they know it's a draft and it's a huge thing, it would be great just to have that posted to the consumers. We're talking say two or three consumers on a committee that's got 40 clinicians, so I don't think that would be a huge cost, but that's not my judgment, that's not my call to make” (Consumer Interview)

“But people are involved in costs of doing it, we're in a stage when they're going to make a consideration. At a level where they're pensioners or they're self-funded retirees and they're battling, that's going to be a consideration. Now you don't want them also filling in an expense form every time they turn around. That's not a desirable thing to do” (Consumer Focus Group)

“I think sometimes we take for advantage the - we use technology quite a lot. Sometimes our consumers are retired and perhaps they didn't use technology so much in their workplace or in their current day-to-day life. So providing a supportive environment for people to use the technology so that they're not always having to travel to meetings. One example, I just worked with a consumer recently in order for her to have access to WebEx at home. We struggled a little bit and she sort of said ‘oh, does it matter? I won't have it.’ We worked hard so that she could use that technology because she should be able to use it and be able to see what other people see in the meeting and those kinds of things. I think she found it really valuable and it requires quite a lot more effort than joining someone
else up by that same technology. But it was definitely worthwhile I think. I think being mindful of that. Not just saying here's the technology…” (Staff Interview)

12.2 Enablers to consumer engagement: staff perspectives

(Staff Survey)

Staff identified a series of factors that contribute to effective consumer engagement. As with barriers they reflect a mixture of principles, personal experience and pragmatic approaches or strategies.

Clarity of aims and objectives was seen as pivotal to the success of engagement processes. “Be clear what you want from community engagement. The engagement needs to cascade down from the rationale of why you need engagement. Engagement for the sake of engagement is pointless. Think where you want it to end”. For example “We are here to get your views on X, Y, Z or we want your assistance in A, B, C)”.

The concept of “real engagement” was based on the principle of “Being genuine, not just tokenistic” but went beyond that axiom. Treating consumers as equals and “not just ticking boxes but valuing their input”, “[ensuring] that they are a valued member of the network with an equal voice” was seen not only to be an important stance, but to have tangible outcomes:

“Treating all the same, listening to their points of view at meetings - these are very powerful - I have evidence of change of practice by surgeons because of the obvious concern expressed”

Closely related to the issue of treating consumers as valuable members of ACI, was the need to empower consumers and engage them in meaningful ways, that is in “more than just being invited to sit in a meeting periodically. Actually providing suggestions about innovations and care improvements, sitting on working groups, and promoting the activities they have been involved in to other community members”.
“Empower the community member, not just having them as static members. Look for genuine community roles, enthusiasm and freshness. Care with community members who are really just part of the public sector network indirectly. The so-called ‘usual suspects’ in community development speak. They just reflect what you know already”

The importance of ‘real engagement’ was linked to that of ‘real’ and ‘representative’ participants. “Very different input is provided by Consumers and professional bodies representing consumers. Effective consumer engagement requires both provide input”. Enablers in this space closely resembled barriers as staff identified what attributes were required by consumers to participate in consumer engagement. The list of characteristics was long and included attributes such as the ability to be broad and open minded, informed on issues, to understand how the ‘system’ works, to be confident and assertive, have undertaken training and be available.

“The appropriate selection of the consumer, not all consumers are necessarily personally capable of contributing depending on their personal circumstances so careful selection of the consumers is necessary. Can the consumer look at issues from a broader consumer perspective than their own personal issues?”

“From a network perspective finding the appropriate consumer who is prepared to attend meetings and to understand the way the system works”

“Selecting the ‘right’ consumer voice - a certain level of confidence and understanding of the wider system is needed”

“The consumers are informed on issues. Their input is sought, and is valued. They have reassurance that they are expected to be assertive”

“Willingness of the clinicians in the room to listen and engage with consumers”

Good communication and information appears as a key enabler as well as a key barrier. As an enabler, good communication is about the interpersonal as much as it is
about informational, and the individual as well as the organisational. For the respondents, good communication was about “taking the time and effort to regularly communicate with consumers and the community in order to build and maintain trust, relationships and enthusiasm” as well as “Providing support not just financially but through providing consumer targeted education opportunities, listening and responding when possible to their needs, including them at every level of the organization”.

Alternative approaches to the collection of information/engagement of consumers were also suggested. “Having community/user representatives on committees is just one approach. Surveys of the community ... and also other things are just as important”.

Once engaged with ACI, communication with consumers and community representatives was about “good support from co-chairs and network managers to engage with them”, “clearly explaining (ensuring the consumer is familiar with) meeting procedure/rules of engagement”, “providing orientation” and ensuring that “consumers being respected and given sufficient time to express opinions and have a voice”. The reason for this was that “consumers feeling like they are "part of the team" (ie alongside clinicians, managers, academics etc) support for attendance/travel regular communication with consumers”.

The two-sided nature of communication is explored in the following quotation. Here a staff member reflects not just on the approaches for communicating with consumers, but what it is that clinicians are communicating, either consciously or unconsciously.

“The welcome (or otherwise) that they are given by clinicians is critical. If clinicians have not fully embraced the concept that services should be focused around the patient then the consumer will either be heard and ignored, or not given the opportunity to contribute meaningfully”
A respondent summarised the various aspects of effective communication as they related to the engagement process. For this person:

“Communicating with them in their frame of reference in language they understand, cutting out all the medical jargon and the acronyms we use and no one else understands! Advising them that their input is valuable and just as important as clinicians and that they have a right to a voice and a right to be heard because it is about them. Making them feel welcome”

Acknowledgement is required of the impact of consumers’ involvement. Both explicit recognition and effective feedback loops are required.

• “Outcome driven forums and initiatives. Follow up/feedback to flag what is subsequently being done”
• “Consumers feel that their voice is being heard through the demonstrated action of the network/taskforce/institute”
• “Providing feedback on outcomes following discussions/engagement”
• “Providing feedback about their contributions”

Organisationally, respondents felt that it was important to provide “acknowledgement that consumers and the patient journey is incredibly important for the work that we do” because “consumers have unique perspective on the specialty services that our network support and are key in providing feedback on what could be improved”.

Physical and resource enablers included both the meeting environment and physical needs of consumers. “Ensuring the consumer’s needs are catered to (e.g. The building is accessible with an accessible toilet for consumers in wheelchairs, meetings have breaks for those unable to concentrate for longer periods, meals are provided that meet specific needs (Halal food, vegetarian etc)” and “providing the necessary resources to participate - transport costs, accessible venues, suitable meeting times”.

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13. Evaluating the impact of consumer engagement

(Staff Survey)

As a way of assessing the overall impact of consumer engagement in ACI, staff were asked whether they had been able to measure the impact of consumer engagement in their Network. The results are presented below in Figure 3.

Figure 3: Measure of impact of consumer engagement

![Pie chart showing 10% Yes and 90% No]

Only ten percent of respondents had measured the impact of consumer engagement. Those who had done so utilised some form of evaluation. Although as one individual noted "subjective – yes; objective – complicated".

Those respondents who had not evaluated the impact of engagement reflected on various aspects of assessing consumer impact:

“Have not evaluated consumer engagement in the network meetings etc -I guess from my perspective the fact that they continue to contribute is a measure that they feel valued - one of our consumer reps has been a network member for 9 years and another for 5 and this young person is also a member of another network”
“No - it would require a well-designed research project to capture the data and develop the conclusions. However, I have seen evidence of our consumers’ input affecting policy decisions in Ministry of Health. Also, I have seen our consumer input change the focus of development of healthcare information for consumers. Also, consumer input has identified issues for inclusion in our network’s work plan”

“Not formally. But I see it happening with clinical change, added information for developing models of care that are acceptable to consumers”

“Not actually measure, but the amount of beneficial information has been enough to swing opinions and decisions”

“Not as far as I am aware. We probably need to clarify what the purpose/intended outcome of consumer engagement is first and then look for/develop tools that can support measurement/evaluation”
14. The ACI Consumer Engagement Framework

*(Consumer and Staff Interviews)*

Participants were informed that ACI would be developing a Consumer Engagement Framework to describe how ACI will work with consumers and communities. This section reports on the findings of that specific question.

14.1 Principles of the ACI Consumer Engagement Framework

Before describing what elements the ACI Framework should include, participants stressed that the Framework itself must place an emphasis on the value of the consumer and carer input. ACI’s consumer engagement processes must be **person centred** with the consumer involved in planning for their engagement – “... *making sure you don't just have easy rules of thumb, that you do think about the consumer that you're working with and what they need*” (Staff Focus Group). Consumers should be **included from the beginning** “Consumers should be there from day one with all the other elements in the community. Rather than people put a proposal together and then come and say, are you happy with that, when you don’t really know the background of what’s put together” (Consumer Focus Group).

“We should be on the terms of reference. Where something’s going to happen they get the terms of reference and there should be one or two. It’s better for two consumers – one consumer on their own you’re lonely” (Consumer Focus Group)

The Framework should offer practical guidance and be informed by **high-level principles**. “I think one of the big dangers in producing a Framework is that it provides no practical guidance on how to behave, on how to act, on what to do. I think in term of style, I think it should be very practical. It should provide people with some really practical ways that they can increase engagement with consumers. I think to start with that's a really important thing. I think some high level principles are also really...”
important, because sometimes people don't even know that they're not doing these things” (Staff Interview).

Principles that participants identified as key to the ACI Consumer Engagement Framework are presented in Table 1. The results closely reflect the findings across this study, with examples and discussion of each of these dimensions present in previous sections.

Table 1: Key principles of the ACI Consumer Engagement Framework

<table>
<thead>
<tr>
<th>Principles for a Consumer Engagement Framework</th>
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<tbody>
<tr>
<td>True representation of consumers</td>
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<tr>
<td>Equity: open to all people</td>
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<tr>
<td>Equality: the consumer is an equal player at the table</td>
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<tr>
<td>Transparency</td>
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<td>Respect</td>
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<td>Recognition</td>
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<td>Empowering</td>
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<td>Partnership</td>
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<td>Value contribution</td>
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<td>Cooperation</td>
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<td>Consultation</td>
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<tr>
<td>Communication: shared, total, transparent, respectful</td>
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<tr>
<td>Clarity: clear definitions, processes, outcomes, policies, communication</td>
</tr>
<tr>
<td>Evolving and improving with ongoing evaluation for process improvement</td>
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</table>
15. Suggested components of the ACI Consumer Engagement Framework

*(Consumer and Staff Interviews)*

Consumers were asked to identify the key principles that should be emphasised in the Framework and what elements the ACI Consumer Engagement Framework should include. Responses have been grouped and presented under the headings: Vision and mission; Recruitment and representation; Induction and orientation; Valuing, respecting and supporting consumers; Feedback; Relationships; and Ongoing evaluation.

15.1 Vision and mission

Participants were clear as to the components of the Consumer Engagement Framework. Essential to the Framework is a **clear definition of consumer engagement**. This includes defining who a consumer is, what is expected of them, and the difference between consumers, peers and carers’ perspectives and roles.

The Framework should include clearly articulated and well advertised **vision and mission** statement and objectives that clearly inform process and goals. Part of this process is the clear articulation of the role and benefits of consumer engagement for consumers and ACI.

Each ACI project must have **clearly articulated goals and objectives** that are in line with the overarching Framework mission statement and organisational vision and goals, and the objectives should be ‘SMART’ (specific, measurable, achievable, relevant and timely).

The following interview excerpts provides illustration of this component:
Participants also discussed the importance of the Framework including a mechanism to articulate realistic expectations so as to avoid consumer engagement strategies leading to disappointment and despondency. The following selected excerpts from a focus group discussion capture the essence of the discussion in relation to this point:

“P: Create those sorts of expectations. But then if consumers don’t see anything delivered that’s meaningful for them either, then I think it’s a negative experience. It’s like we just touch them and do what we were going to do anyway and I think it’s really important that it’s - that we get, that consumers believe that their outcomes and their unmet needs are actually being built into and we are actually getting traction in those areas that are important for them. We need to do that feedback thing as well.

...
Facilitator: Just to touch on what you were just briefly saying before about that whole idea of expectations. So is it also an important component in the Framework that there is something that upfront says…”

P: Yes, this is out of scope for this at the moment. There has to be some things that are out of bounds” (Staff Focus Group)

There needs to be processes in place that enable projects to continue progressing when people go on leave.

“There’s nothing worse than being on a project and the timeframe gets extended, extended, extended. I guess one of my pet hates is you’re working on something, and then someone goes on holiday. Everything gets put on hold while that person’s away. Be realistic, they’ve got to have planning in place. So if someone’s on holidays, it still continues. Because that will turn people off instantly”

(Consumer Interview)

15.2 Recruitment and representation

The Framework needs to address issues of consumer recruitment. The first step in this process was considered to be an assessment of whether the consumer is ready for engagement. This was considered to be especially important when consumers were entering an area of work which reflected their own experience.

“It is important that peoples’ readiness to engage is assessed or considered to actively avoid the potential for PTSD”

(Consumer Interview)
Linked to the issue of readiness was finding ways of conducting targeted and ‘fit for purpose’ recruitment of consumers. This it was felt, would ensure appropriate representation from the community including the more difficult to access groups. Supporting this approach was the use of a variety of engagement methods that do not limit consumer engagement to those who have access to computers, are highly literate, empowered and educated (which minimises engagement with vulnerable populations e.g. CALD, homeless etc).

When discussing how it might consider recruitment of consumers, ACI was urged to think through the implications, “… if we’re going to go down this path that we have to start asking ourselves. That is, do we go to the easy route and go to established groups and people who probably have a regular voice that’s heard by a number of forums, or do we ask difficult questions such as is it appropriate to go to clients, is it appropriate to go to people in hospitals and appropriate to go to people and how do we assess whether it’s an added burden to ask them to participate in another means, or whether they are receptive to being involved in something they might not necessarily otherwise have thought to put their hand up for” (Staff Focus Group).

Some respondents felt that it was important that consumers submit information to ACI on how they represent the constituent of consumers, that is, make it clear and transparent how they are representing the consumers. The aim was to ensure that the consumer is able to present the varied views of the consumers they represent, how they will garner information from the consumers they are representing, and how they will provide feedback to those consumers.

“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” (Consumer Interview)
15.3 Induction and orientation

Once recruitment has occurred, the next issue to be addressed in the Framework is that of orientation to ACI’s processes, networks, goals, allocation within the health system, and then the location of consumers within ACI. Key contact people should be nominated for each consumer.

“It’s like at work you have a boss don’t you. You have your line supervisor and I think that needs to be made clear”
(Consumer Interview)

Clarity about the role of consumers, what was expected of them and what was beyond their brief was raised by several respondents: “But also I think on one side we want to think about what it is that we at ACI do. But we also need to understand what it is that we can expect from consumers. Then also for consumers, what it is that they are - what is it that they're signing up for and what can they expect of ACI” (Staff Interview).

When discussing the need for role clarification one participant articulated that, “You’ve got to be careful with that because people can take it on and then not realise that - some people might think it involves more but some people might be surprised at how much it does involve and I’ve been a bit surprised I suppose at how much it does involve. It’s not a criticism and perhaps I was free to say no to those ad-ons, but it maybe is a strength actually because that gives greater opportunity for contributions” (Consumer Interview).

Background and information about the network the consumer is getting involved in is required, and this information was felt to be best supplied at orientation. This should include a code of conduct, a ‘job description’, information about confidentiality issues,
the commitment required (in terms of time and travel) and a discussion of that role in relation to wider consultation and community engagement. A glossary of acronyms, terms and definitions, some general and others specific for a particular network, should be provided at orientation.

A more detailed discussion of the change agent role of ACI and consumers working with the ACI was considered to be important so that consumers understand both the processes and the value of their input.

“Does the normal consumer attending the committees, know what the pathway is to get to the change?” (Consumer Focus Group)

Issues of ethics, including information about the processes by which consumers are required to declare conflict of interest about issues being discussed were raised. This was considered particularly significant because several consumers identified the seeming disjoin between their role in wider community engagement and requirements for confidentiality, for example, they may be a consumer representative on an ACI network and also for another organisation (such as an NGO). The participants felt that there should be collaborative relationships between the organisations, but felt that there are restrictions imposed by the need for confidentiality. Other concerns about confidentiality issues were raised in several staff and consumer interviews and focus group discussions. One participant suggested that small group scenario type discussion would be very helpful for thinking through issues about confidentiality.

“... the big word is confidentiality and I think that orientation’s important to make sure the consumers actually understand those issues because sometimes they don’t understand. They don’t really know what confidentiality means. Having a little discussion group I think up the front, right at the beginning, that is the entry point to the whole process” (Consumer Interview)
15.4 Valued, respected and supported involvement

A key purpose of the Framework is to ensure that consumer engagement has valued, respected and supported consumers. This is to be done through the principle of ‘visibly valuing’ the input of consumers, through both tangible and symbolic recognition.

The concept of ‘visibly valuing’ the work of consumers is recognised in the consumer engagement literature. This project has identified several variations and elements of this concept throughout the interview process. Visibly valuing consumers requires mechanisms and processes to ensure that the consumer voice is actively sought, heard, included, valued and respected. This includes time in meetings (not just at the end) that allows the contribution of the consumer – making space for the consumer to have input and then inviting them to do so (e.g. not one consumer on video conferencing and all of the clinicians in the room together).

Part of the process of visibly valuing consumers is the inclusion in the Framework of provision for educating clinicians as well as consumers. Clinician education, however, is to be directed at assisting them to recognise, actively seek out and incorporate consumer input.

“I think it is about educating the clinicians to value the consumers. I think they naturally do that, but it’s probably not a bad idea to have something down in writing in the Framework that suggests that the clinicians do need to listen to the consumers”

(Consumer Interview)

Part of the process of actively seeking consumer input will mean ensuring that required modifications are made to ‘standard’ ACI processes. For example, those providing information to consumers need to consider the best way that the recipient will receive the message and may need to be creative and innovative, to think outside
the square and to be flexible e.g. use of pictures and diagrams. Similar approaches were required for issues such as physical accessibility. The following excerpts provide illustrative examples from the discussions:

“So rather than just come up with a big policy document you need to think creatively about who the message is going to and how they can feel involved” (Consumer Interview)

“... it needs to be easy for consumers to be involved. Sometimes in organisations that I've worked in, you have to kind of jump through loops. I know - obviously some kinds of standards and procedures have to be followed but I think from ACI we need to make it easy for the consumers to be involved and easy for us working here to get consumer feedback and input. I think we have to be clever about the way that we get that. It doesn't have to be someone sitting on a steering committee necessarily or - that's one way” (Staff Interview)

Structural changes to procedures and activities including: modifying meeting times and locations; support for meeting involvement (e.g. print and send documentation); feedback and related processes that encourage consumer input; supportive environment; answering phone and email messages; executive support; ensuring accessibility of buildings and meetings; streamlining recompensing of consumers for time and travel; providing a range of mechanisms for and types of engagement:

“But I'm not saying everybody, I'm saying the consumers would find it just a touch helpful and considerate to get hard copies - where possible - of long documents ... I think it's a niggly thing, but I think if you want to make people feel we're cossetting you a bit and thank you for coming - where possible” (Consumer Interview)
Annual review and evaluation of the roles of consumers as part of a “check in process” were posited. The value of this was to assess whether the consumer is still able to participate, to be on the particular committee they are on, whether another committee is more appropriate, whether “they need to step back for a while” or if they require additional resources. A secondary rationale was that this type of regular checking would enable consumers to “opt out” and to exit gracefully (an EXIT strategy):

“Also avenues for consumers to opt out if they've been brought into a network, how they can gracefully retire without feeling that they need to stay on” (Staff Focus Group)

15.5 Feedback

Feedback was a commonly requested element of the Framework. Consumers are said to require clear and frequent feedback on changes that are made through the work of ACI so that it is clear that the consumer involvement is not just tokenistic.

“The feedback needs to be acknowledged, valued - and I'm sure that they're all good managers and it's not dismissed without consideration. I haven’t ever seen that happen, so that's not a criticism” (Consumer Interview)
One participant highlighted the positive effect of feedback and visible outcomes by describing her experience with ACI.

“There has been, as I've said, very clear outcomes, there has been models of care developed which hopefully can make change within the health system. So I feel when I turn up to one of the network meetings or participate in email discussion that we're actually getting somewhere, there's going to be an outcome from this level of activity, and that's immensely rewarding because we're all very busy people”

(Consumer Interview)

Part of that process is ensuring that consumers understand decision processes. They need to be made aware of the reasons why the ideas or suggestions they propose may or may not be taken up, and whether or not action on a particular issues has been taken.

15.6 Relationships

At the core of the engagement process is the notion of relationships, between consumers and ACI staff, consumers and ACI, between consumers themselves and between ACI and other organisations. For one person, support for the importance of building a relationship between the manager and the consumers needs to be made clear, and processes put in place to encourage this such as clear lines of communication.

“I think it's really important that the manager communicates well with the consumers, because again, if I have any questions, if something comes up in a meeting and I don't understand or whatever, the manager is the person that I go to, to get that information or to be directed to where I can get that information. I think that building a relationship between the manager and the consumers is really important ... It's kind of his role, I guess, to facilitate our involvement. If he doesn't - isn't able to do that or isn't aware that he is supposed to do that, that's obviously not going to happen”

(Consumer Interview)
Mechanisms to develop and support a sense of membership and belonging are required as part of the Framework.

“I don’t know if you can kind of make it compulsory – but maybe advisory to have a couple of consumers on every committee. Make that a general rule” (Consumer Focus Group)

For those concerned about relationships between consumers, the Framework needs to consider a variety of mechanisms to network consumers with each other (peer support) for example sharing email addresses or contact details, employing a “buddy”, mentoring, and increasing consumer forums. Generally, “I’m wondering if they should - I don’t know, I’m only asking - should the consumers each have each other’s email addresses or contact details?” (Consumer Interview) and specifically “Just peer support, I suppose you’d call it. This is my consumer buddy or whatever that I can call and they’ll listen and figure things out. For me, that was really good” (Consumer Interview).

The relationship between ACI and other organisations and in particular NGOs was raised by several respondents. For some individuals, the issue was that NGOs should be seen as “equal partners in the delivery of health and services” (Consumer Interview), for others it was expanding the ACI’s view of ‘community” that goes beyond the health sector including NGOs and other government agencies, so that everyone speaks the same language about a particular issue:

“I think it's being able to see NGOs as equal partners in delivery of health and services I think would be developing the Framework around that would be a really good thing for ACI to look at” (Consumer Interview)
A number of respondents raised specific ways of establishing relationships with other organisations. These included establishing clear goals and a clear pathway of how ACI are going to reach the LHDs, along with a broader definition of systemic partnerships with non-government organisations. New and diverse ways to disseminate information to the community, including TWITTER, and mechanisms to collaborate with other organisations are required.

15.7 Evaluation

A few individuals discussed the importance of building evaluation into the Framework. This includes evaluating ways in which the consumer engagement process and experience can be improved, how well the consumer feels they are operating with ACI, and a set of mechanisms to facilitate continuing consultation with consumers to allow ongoing evaluation of the processes of involvement and contribution. While noting that it would be beneficial, some participants identified that it would be difficult, and that they were unsure of the best way to do it. The following excerpts provide a snapshot of some of the issues identified in relation to evaluation that need consideration in the development of the Framework:

“I'm thinking do you have, I have no idea, but a Twitter thing going or is that against Health? How do we do that in a way where people, in a protected way and certainly to protect us as well, so all the dirty linen isn't out there for everyone to see so that at least we can get another source of feedback from people who don't have an organised voice” (Staff Focus Group)
“It made me realise that I need some evaluation tools because all of that feedback was initiated by them...” (Staff Focus Group)

Process evaluation is needed to assess consumers’ experiences of consumer engagement, including whether they felt empowered; whether they felt that their input mattered; participation in meetings; their perception of whether their views are acknowledged; their perceptions of the involvement process; and whether they have understood the information provided. Impact evaluation should include issues such as the level of involvement consumers have had in the work of ACI and their perceptions of the impact of the work.
16. Telling one’s story

(Consumer interviews)

ACI occasionally works with consumers to document their personal story about their experience of accessing care within the health system to help clinicians and others to understand a patient or carer’s perspective. Participants who were consumers were asked for their thoughts on whether it mattered who interviewed them when they related their story. Telling their story was seen by most participants as an opportunity to educate clinicians and benefit them and other health care consumers.

“I found my way through the maze and I wanted both clinicians and consumers to benefit by my experience of finding my way through” (Consumer Focus Group); “It doesn’t matter who I tell my story to because I want to tell it to everybody to get the message across so long as it’s within a health kind of setting and across my life span or experiences - there are quite a few different situations that could be helpful from an education point” (Consumer Interview)

The importance of differentiating between telling one’s story and being defined by one’s story was raised in a focus group discussion.

“I think that storytelling and the management should actually become separate because the management side of it doesn’t always have to do with your personal experience. So unless someone says I really want to share, I think they should be separate” (Consumer Focus Group)

This response was expanded “I think that’s where there’s much wider learning and like I said if you’re a panel member and you don’t really want to go down the road of seeing me as a personal story, maybe see me more as a business [partner] or strategic ...” and reinforced by another participant in the group, “I think the people on the committees..."
that I’m on, they don’t really know my personal story and I don’t know that that’s particularly relevant to what I’m saying. They can tell by what I say that I know what I’m talking about” (Focus Group Participant).

The significance of **ownership and control of one’s story** and it not being freely available for use without permission was deliberated. On the one hand a repository of the details of patient stories could avoid having to repeat the story.

> “... if I'm interviewed by someone and I tell my story and oh right you've had a rough trot. They might just file it away. Someone else wants to interview me from say a different network, wouldn't they check with someone who did the first interview? Find out what - rather than flying blind” (Consumer Focus Group)

However, there was a danger that stories would be reproduced without permission from the story owner.

> “You need to be told though. Actually my story was in the local newspaper and I didn't - been in the year before but they never asked me if they could put it in again the next year and they used it for National [de-identified] Week and I didn't even know it was there. Someone told me 'your story's in the paper’” (Consumer Focus Group).

Participants pointed out that what **would be done with the story** and the purposes for telling it also influence how it is told, “Well I find too that depending on who wants to know the story, where they’re coming from, that I'll tell it in a different way too from a different angle” (Consumer Focus Group), and the characteristics required of the person to whom it is being told.

> “We're just setting up a peer support program for our [de-identified] network for the main reason that people benefit from sharing their stories. I think from an individual's point of view where people had a particular journey, it sometimes helps them to express what they need to somebody who has had that journey also ... But it’s about trusting the relationship and what’s happening with the information really” (Consumer Interview).
Some respondents were not concerned about whom they told their story to, others articulated characteristics and skills they would like the story collector to have. Identified characteristics that the listener should possess included empathy, being non-judgemental and trustworthy:

“As a consumer, yes, I’d like to have someone who is empathetic. Who displays good skills. Someone you feel comfortable with. There’s nothing worse than trying to tell your story, and the person you’re telling it to is looking glazy-eyed and staring at the clock and... It’s often good to tell your story to the people it involved, but that is very hard to do.” (Consumer Interview)

Some of the participants expressed that they would not like to tell their story to those with an agenda that may influence how they heard and interpreted the patient story.

“Probably not to people that manage complaints, because they have a specific agenda when managing complaints. I’m thinking of the health [systems] now in the hospitals. They have a specific role in complaints management, where this is more about just telling a story as an overall.” (Consumer Interview)

It was suggested that given the personal nature of telling one’s story it would be ideal to tell it to someone with whom you have built a rapport and whom you trust.

“... that’s a fairly personal sort of thing to be asking someone about. Some people might take it like it doesn’t really matter, but I think for some people it’s really quite a personal thing. So you want to be interviewed by somebody that you’ve already developed a rapport with, that you sort of trust, I suppose ... I mean for some people, they may prefer somebody of the same gender. For me, that’s not an issue, but some people might find that confronting to be interviewed by somebody of the opposite gender or a different nationality or whatever.” (Consumer Interview).
Because of the potentially disempowering effect of relating one’s story, it was also suggested that a person who is independent from the health system may be the best person to tell one’s story.

“... because people who may feel somewhat disempowered, who perhaps haven’t worked in the health system like I have may be somewhat reluctant really to make certain comments to people that could be construed as criticism of that person’s profession or indeed of the health system or of their unit or something like that. So I guess that is an important factor to think about, and therefore talking to someone who’s completely independent may be more appropriate”
(Consumer Interview)

Some respondents identified desirable skills in the person to whom people told their stories. The following quotes highlight that people who collect the patient stories should be people who respect the person and their story, they should have an ability to validate the storyteller even if there are areas of potential discrepancy in their story, counselling skills, and for others clinical skills were important:

“Obviously needs to empathetic and not judgmental and probably it would be important that - it would be important they validated the person even if the story had some flaws to it”
(Consumer Interview)

“I would like it to be by someone with a clinical understanding”
(Consumer Interview)
17. General reflections on consumer engagement

(Consumer and staff survey)

Consumers and staff were asked if they wanted to make any final reflections or comments on consumer engagement. Consumers wanted primarily to voice their thanks and appreciation for their involvement in ACI, to provide a few additional suggestions.

17.1 Final consumer and community representative comments on consumer engagement

(Consumer Survey)

17.1.1 Expressing thanks

Quite a number of respondents wanted to express their thanks to ACI. An indicative sample of these are presented below.

- “It is great that the clinicians accept us as part of the team. I do feel respected”
- “I feel the ACI is endeavouring to consult and engage consumers and NGOs in a very constructive manner”
- “I think that we are an integral part of getting voices heard especially on a political level where the real, human voice is vital”
- “The network has always made me feel comfortable and supportive and encouraged participation at meetings etc”
- “I appreciate being given the chance to contribute to the development of Health Services in NSW”
- “You are doing very well so far - you are actively asking for input in a number of ways (this survey, upcoming special consumer forum and positively encouraging practical input for example)”
• “I think ACI is playing a vital role in bringing the medical profession, government and consumers together and doing a really great job! Well done and keep up the great work”

17.1.2 Suggestions for improvement

Respondents had some additional comments which had not been included in previous questions. The question of role definition arose “I think once my/our role has been discussed I personally might feel of more use”, along with the need to monitor consumers feedback.

More detailed, but atypical comments reflected on health culture and the skills of consumers. While atypical it is important to include such reflections to provide a balanced view of the consumer engagement experience and consumer attitudes:

“I have concluded over time that the principal management issue for Health is that its structure, associated education and training over the long term has led to an inward looking culture that amongst other things deters ready adoption of the 4C’s—communication, cooperation, collaboration, coordination, this naturally flows on to all parts of the enterprise in varying ways”

“I have only met a couple but have found they do not offer any sort of thoughts, etc just sit and listen, perhaps shy perhaps not encouraged? Although did meet one and she talked and talked ... Although she is an intelligent and articulate woman, just not fun to listen to. At least for me”

“I really think they are superfluous. Consumer experiences are so diverse, and the technical aspects of many of the discussions and topics are hard to grasp at times (and I am a Lawyer)”
17.2 Final staff comments on consumer engagement

(Staff Survey)

Staff comments reflected those of consumers, but included additional reflections on the consumer engagement process. These included, as with consumers the need for clarification, the need for more consumers, providing more opportunities for engagement, and the importance of consumer engagement.

Clarity was needed both for the objective of consumer engagement and the actual role. As these respondents noted:

“Only really think through what is the objective here - and the way of doing it spills easy from that. Don’t just get some random on the team to make up the community numbers”

“The demarcation line between consumer / community engagement is often blurred as many who are involved find the ACI accessible because they are also professionals, lobbyists, etc”

Respondents raised the need for more consumers. There was a division in the comments between the overall need to recruit and retain consumers, and the need for consumers from particular backgrounds:

“I think consumer engagement is a great strength of the ACI - however, on the whole, I’ve had quite a lot of experience in consumers leaving network/s, but not a lot in them joining - and I feel like the ‘pool’ of consumers has been slowly dwindling. It would be great to be able to address this (and before you ask, no, I have no bright ideas how)”

“Having worked with around 10 networks, I have only met one consumer representative”
“Stating the obvious I think people are motivated to engage and become involved for a range of reasons not always articulated - they cease their involvement for a range of reasons also not articulated. I think that's fine and attempts to keep them involved don't change this. Consumer turnover is probably a good thing”

“Because my background is in the disability sector I am very conscious of the input of consumers with disability. They represent 19% of the Australian population and their views may be more relevant to ACI/Health as, due to impairment, they are more likely than others to regularly require health services. The statistic (19%) suggests that if only 1% of ACI engagement was with consumers with disability it would be an underutilisation of the cohort. I'd like to see ACI (as the go to place) lead by example and ensure its research included the views of community members, that these views were accorded weight (rather than only the views of clinicians) and that closer to 19% of the community views gathered were gather from the 19% of the community with disability”

Some respondents offered suggestions of how to address the issue of recruiting and retaining consumers. For example:

“We need a consumer group that we can tap into when needed, and at the same time having a group may mean that they can support each other, because it can be really overwhelming trying to get your point across in front of a room full of clinicians that speak another language. We need to recruit more and provide information to them in clear English including the purpose of ACI and their role”

“From [our] point of view we have little understanding of consumers perceptions, I hope to be able to change that in time as the barriers from LHDs erode”

“Many people would be keen to have input into our work and therefore we need to have quite clear guidelines/structures for promoting opportunities to be involved and managing ongoing involvement. Local councils may be a good place to start to reach out to the “ordinary” consumer”
“We need to think quite carefully for each of our activities how to ensure there are the right consumers/ community members in the right numbers informing our work and how to maximise their contribution and make it attractive to them”

The concept of genuine engagement was considered important. This included ensuring that consumer engagement is not tokenistic and ensuring the time required to establish effective relationships:

“I think harnessing meaningful and representative consumer/ community engagement is critical to the work of ACI and our value to our stakeholders. This is an issue that many organisations and entities around the world are grappling with and therefore an opportunity for ACI to demonstrate our "innovation" in this area”

There was a close relationship between the idea of genuine engagement, and what respondents described as the need to provide more opportunities and better support for consumers. The following comments highlight a range of issues with the engagement process:

“I conducted an EOI recently and felt that it went into a vacuum. I received no feedback on the process. I was told 4 packs went out but only ever received the name of one potential member. My new consumer recently attended orientation and left without knowing how to claim for her out of pocket expenses. She was also not provided with any claim forms”

“Little collaboration with the Consumer Council to date. Requires varied levels of involvement - targeted consumer forums, consumers on committees, focused engagement for specific initiatives”

“ACI should provide training and support to assist consumers to be assertive. ACI should provide training and support to guide consumers to understand how they can be most effective in ACI projects. ACI should provide feedback to the consumers on projects where consumers have contributed. Consumers must be valued for the time
they give to our activities. They could be using their time for other pursuits, yet they
give of their time to our initiatives. Our consumers are Heroes!!”

The final group of comments related to **appreciation for the role of consumers and community representatives**. These were that:

“[Consumer engagement] *is essential and can be the difference between an initiative "working" or not*”

“I think that consumers are the key to getting the public involved and proactive on issues”

“No experience yet, but I understand that consumer input is valued at the ACI”
IV. DISCUSSION

This study shows that consumer engagement is a well understood and developing agenda in ACI. There is a high degree of agreement between consumers, community representatives and staff across the elements explored in individual interviews, focus groups and surveys, as to the nature of consumer engagement and what is required to ensure its success in ACI.

There are two common streams to answers to virtually every question asked in this study. The first stream is pragmatic. It deals with the how, where and when questions. These responses explored both the questions and answers to issues such as “how should consumers be reimbursed?” “where and when should meetings be held?” The second stream dealt with deeper and more complex issues. The progression of the consumer engagement agenda in ACI has meant that those involved, both consumers and staff, are asking “who, what and why”. Who should be targeted to be consumers? What do consumers contribute to the work of ACI and how can this contribution best be evaluated, recognised and valued? What is meant by ‘representative’ and ‘engagement’? And the most basic question of “why engage consumers?”

The working definition of consumer engagement used by staff who were interviewed for this project was the direct and active input and collaboration in the decision making processes and projects by non clinicians or health care professionals as equal partners at all levels and in all aspects of ACI’s activities from their inception of those activities, to their closure. The aim of this engagement went beyond ACI’s networks or even ACI itself. Staff spoke of the role of consumers in steering of health services as a whole.

There was a high degree of agreement between consumers and staff about sources of and strategies for consumer recruitment. Word of mouth, including networking and contact with NGOs figured prominently. Current or previous contact with ACI either individually or through another person, was less prominent but still effective. The use of media, and in particular local and social media, but also ACI’s own website and
newsletter has proven a useful recruitment tool and strategy. Other strategies included stronger contact with Local Health District consumer groups, and contacts with ‘specialty’ NGOs, in particular those who represent or have links to vulnerable communities.

It was within the context of the question of recruitment that the question of representation began to be raised. Within this context, the issue was couched as a question of how actively ACI should seek consumers with diverse perspectives, either because they represent ‘hard to reach’ communities, or because they are not ‘professional consumers’. This question echoes throughout the study, and though no clear conclusions were reached, it shows a considerable degree of reflection by consumers and staff not just on the consumer engagement process, but on the foundational questions of consumer engagement itself.

The question of recruitment also raised the issue of motivation for involvement in consumer engagement. It is clear from the study that involvement in consumer engagement has costs for the consumers involved, both personal and financial. Four factors motivate existing consumers, including wanting more information about specific issues. The remaining three (helping others, experience with health services, and wanting a voice) all relate to the desire to contribute to significant change to the health system.

Once motivated to join, the question arose of how to engage and retain consumers. A variety of strategies were offered, from the practical (reimbursement, information, address transport to and timing and location of services, the way network meetings are conducted) to the more personal (make people feel valued and supported). For many consumers and staff, these two areas were closely aligned. Questions of reimbursement for example, had both a practical element – of consumers, and in particular more vulnerable consumers, being able to attend – and a symbolic element of being valued and equal in their role at ACI (if clinicians are reimbursed for attending network meetings or speaking on behalf of ACI, why aren’t consumers?).
Here too, a more difficult question was raised. How can ACI encourage, facilitate and demonstrate the willingness of clinicians to accept consumers as partners, or even their equals, in the work of ACI? More specifically what types of modifications (including reducing the use of jargon, changing the time and place of meetings) were ACI willing to make in order to continue to attract and retain consumers?

The question of the types of support to be provided to consumers centred on issues similar to those discussed in relation to recruitment, but included a focus on how to encourage newly engaged consumers, including the importance of providing effective information and feedback, and personal contact and outreach. Almost half of the consumers surveyed felt that consumer training had benefitted them in some way.

Several suggestions were made about the type of training which could be provided. This included ‘basic’ training about the roles of consumers, policies and procedures of ACI, and general orientation to the work of ACI and the health system as a whole. Health literacy was clearly an issue. Additional training was required on skills such as teamwork. Consumers in particular wanted skills in how to participate in network meetings, including training on how to boost their confidence in working with clinicians. Some consumers noted that the training should not be confined to consumers themselves, but rather extend to clinicians as well.

As a way of understanding part of the relationship between clinicians and staff, staff were asked what types of attributes they looked for in consumers. The most frequent attribute identified was that of an interest in and commitment to ACI and its networks. Sharing the vision of ACI was part of this. A strong ethical stance, knowledge of the healthcare systems, procedural knowledge and skills on how to participate in meetings all closely mirrored consumers’ own desires for training. Closely aligned too was the need for courage, as both groups, consumers and staff, acknowledge the emotional and personal cost of engagement. Other forms of professional development, such as mentoring and a buddy system, were suggested as an alternative to face to face training.
Core to the experience of engagement with ACI was whether the consumer had a sense of being valued. Being valued was one of the strongest themes throughout this study. This went beyond a personal sense of engagement with ACI, although that was considered equally important. In a pragmatic sense this involved actions as simple as ensuring that consumers received timely feedback on the work of the Network or the outcomes of forums or meetings. But it related also to issues such as avoiding tokenism in consumer engagement and ensuring that consumers had all the information required to contribute equally to ACI’s processes. The visible support of the Senior Executive (through their presence at consumer events) and of Network Managers and ACI staff was highly prized, as it was tangible evidence of the recognition of the contribution of consumers.

Staff recognised both the value of the contribution from, and the cost to, the consumer of consumer engagement. While some staff noted that they had not actively sought out consumer input, for a variety of reasons, most were actively involved in the engagement process albeit to a variety of degrees. Most staff engaged consumers via standard processes, eg: inviting them on committees, asking them to participate in networks; inviting them to ACI forums and events; asking consumers and community organisations for feedback; inviting them to participate in research or data collection; and for a smaller group, seeking their opinions via the internet.

Suggestions for improving consumer engagement in ACI closely followed the patterns outlined in previous questions. Improvement to consumer engagement, argued respondents, should be based on a paradigm shift where consumers are seen as active partners driving change across the health system. In order for this to be achieved, ACI needs to put in place strategies to empower consumers to participate in this process. Clarity is required by all partners of the role of consumers, including as representatives of different communities. At the centre of consumer engagement improvement strategies is the need for effective communication processes (from ACI to consumers, from community representatives to their communities, and back to ACI). A key part of
this communication process is the need to develop strong networks between all consumer representatives, and between the consumers and ACI’s Consumer Council. Evaluation of existing and future consumer engagement activities and strategies, as well the impact of consumer engagement on ACI and the health system, was considered an important step in developing and supporting these activities.

Participants’ experiences of consumer engagement reflected the same structural, organisational and administrative concerns that were raised throughout the report. However, one significant additional barrier or potential barrier that arose around this question was that of the cost to the individual consumer. Personal concerns (illness, distances travelled, duties as carers, cost) contributed to the cost of participating in ACI activities. This was seen by some as being exacerbated by unclear or inappropriate expectations placed on consumers, as they struggled at times to meet what they felt were obligations placed upon them.

Barriers and enablers to consumer engagement followed similar patterns. The potential for disempowerment added a new perspective to understanding the consumer engagement process – here, similar issues that have been raised before (such as terminology, support for attendance at meetings, knowledge of the health system) were held up as having the potential not only to act as barriers, but to have significant negative impact on individuals as well. This question of vulnerability of individual consumers was reflected in the barriers to access to ACI for larger vulnerable communities. Engagement of people with disabilities, for example, was raised throughout the study. The issues ranged from questions of physical accessibility, to that of how to contact, reach out to and engage people with cognitive or intellectual impairments when much of the work of ACI revolves around complex concepts and forms of communication.

The question of enablers sparked reflection on issues such as the symbolic importance of the valuing of consumers through practical support. Increasing the role of consumer champions was suggested as a way of both promoting the work of ACI to the wider
community, and as a mechanism for recruitment of additional consumers. ‘Real engagement’ along with ‘real consumers’ remains a fundamental question to be settled in the consumer engagement dialogue in ACI.

In terms of evaluating the impact of consumer engagement, only 10% of staff who responded had been involved in this process in some way. Combined with repeated comments from consumers and staff that they want to know about both the short and long term impact of consumer engagement, within ACI and further across the health system, this would seem to be an area for consideration in the development of the consumer engagement agenda at ACI.

Suggestions for the ACI Consumer Engagement Framework followed logically and closely from respondents’ answers to all previous questions. The principles upon which the Framework is to be based were the same as those principles which reverberated across the findings. ‘True’ or real representation, genuine partnerships based on equity and equality, integrity and trust, transparency of procedures, collaboration, cooperation, consultation, constant communication and clarity, the valuing of contributions through respect and recognition, and ongoing evaluation. Many of these same values are present in the requirements for ‘telling one’s story’ to ACI.

The suggested elements of the Framework are the practical implications and applications of these principles. They include: targeting and responding to the needs of vulnerable or hard to access consumers; making consumer engagement a proactive activity; making modifications to current methods of engagement to ensure that consumers are able to contribute as fully as possible and eliminate barriers; empowering consumers by providing them with the skills and resources they require, when they require them; establishing and strengthening networks between ACI consumers, their communities and NGOs; creating and supporting consumer champions, not only so that they can represent their communities or ACI consumers, but so that they can represent ACI; providing constant feedback as to the impact of the decisions made by and with consumers; illuminating the system wide changes that occur as a
result of consumers’ involvement in ACI activities and carefully preparing and developing clinicians to understand and support a full engagement process.
V. CONCLUSION

ACI’s consumer engagement agenda has had an impact on the operations of ACI and on the individuals, consumer and staff, who participate in consumer engagement. To date this impact has been largely positive, and provides a strong base for the development of the Agenda and the ACI Consumer Engagement Framework. The high degree of agreement between consumers and ACI staff, and across all aspects of this study speaks to a few central issues. Some of these can be addressed relatively easily, for example the accessibility of information or offices. Others, such as the representative nature of consumers and the need for clinician as well as consumer education, will require investments and ongoing commitment. Such an approach is in accordance with the wishes expressed by consumers in this study, as consumers clearly articulated that they want to be included further, and in all levels of ACI’s initiatives. The involvement of ACI consumers in formulating, and not just responding to, a Consumer Engagement Framework responds to this request directly. So too does the inclusion of consumer engagement in any evaluation of ACI’s activities at both corporate and network level.
VI. REFERENCES


VII. APPENDICIES

Appendix A: Survey questions

Consumer survey

Consumer information
Which ACI clinical network, taskforce or institute do you contribute to (please check all that apply)? (List of current networks supplied)

What best describes your experience as a consumer (please check all that apply)?
  - Patient NSW public health system
  - Carer of a patient in the NSW public health system
  - Representative of a non government organisation
  - Other

Do you act as a consumer representative for other organisations or associations?
  - Yes
  - No
  - If so, which one(s)?

Recruitment

How did you find out about ACI?

What made you decide to join an ACI clinical network, taskforce or institute?

How can ACI improve the way they recruit consumers?

Types of involvement

  - What roles do you currently hold in ACI?
  - Member of a Network, Taskforce or Institute Committee
  - Co-chair
  - Other

Training, skills and support

From your perspective, what skills do consumers need to contribute to the work of ACI?

Why do you think this is so?

What support do you need to contribute to ACI?
Have you received that support?

From your perspective, do you think that other consumers might need similar or different support?

Do you think that consumer training did or could assist you in your role(s) in ACI?

What should be included in such training?

Apart from ACI, have you ever received training on how to participate as a consumer?

If so, from which organisation(s)?

In which year?

Experience

How does your involvement with ACI compare to your involvement with other similar organisations or groups (either now or in the past)?

What could ACI do to improve your involvement with its Clinical Networks, Taskforces and Institutes?

Final questions

Do you have any other comments or feedback about the role of consumers in ACI?

We would like to learn more about your experiences as a consumer with ACI. Would you be willing to participate in a telephone or face-to-face interview? If yes, please provide your contact details:

Name

Telephone

Email
Staff survey

How do you integrate consumer or community voices into your work at ACI? (Please be specific).

What strategies have you used to recruit consumer or community members? (Please be specific).

What strategies have you used to support consumer or community members to contribute? (Please be specific, e.g. welcome, pre-meeting discussions and information, etc)

What factors do you think contribute to the success of consumer or community engagement in ACI?

What factors do you think act as barriers or limit the success of consumer or community engagement in ACI?

Have you been able to measure the impact of consumer engagement?

Do you have any reflections or comments on consumer and community engagement in ACI?

The ACI acknowledges the important contribution carers make to our workplace and wider community, and is keen to play its part in increasing awareness of the NSW Health Carers (Recognition) Act. You are invited to indicate whether you combine caring responsibilities with work.

Please indicate your Portfolio

Please indicate your Clinical Network, Taskforce or Institute

Would you be willing to participate in a telephone or face-to-face interview? If yes, please provide your contact details:

Name
Telephone
Email
Appendix B: Consumer profiles

ACI clinical network, taskforce or institutes to which consumers contribute

Respondents participated in a wide range of ACI clinical networks, taskforces or institutes. Details are presented in Figure 4. ‘Other’ respondents were from Osteo-Arthritis and Rural Health Network Executive Committee/Co-Chair. A number of respondents are acting in different networks, taskforce or institutes at the same time.

Figure 4: Distribution of respondents across ACI clinical networks, taskforces or institutes
Consumers and community representatives of organisations other than ACI

The majority of respondents represented organisations other than ACI (Figure 5). The full list is presented in Table 2.

Figure 5: Respondents acting as consumers of organisations other than ACI

Table 2: Respondents acting as consumers of organisations other than ACI

<table>
<thead>
<tr>
<th>Organisations represented by consumers</th>
</tr>
</thead>
<tbody>
<tr>
<td>Australian Pain Management Association</td>
</tr>
<tr>
<td>Blind Citizen of Australia (BCA)</td>
</tr>
<tr>
<td>Cancer Council</td>
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<tr>
<td>Cancer Voices NSW</td>
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<tr>
<td>Clinical Excellence Commission</td>
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<tr>
<td>The City of Botany Access Committee for people with disability</td>
</tr>
<tr>
<td>Chronic Pain Australia</td>
</tr>
<tr>
<td>Consumers eHealth Alliance</td>
</tr>
<tr>
<td>Cooma Hospital Community Consultation Hub</td>
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<tr>
<td>Department of Health Local Health Council</td>
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<tr>
<td>IBD Support Australia</td>
</tr>
<tr>
<td>Kidney Health Australia</td>
</tr>
<tr>
<td>Macarthur Community Representatives Network</td>
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</tbody>
</table>
### Organisations represented by consumers

<table>
<thead>
<tr>
<th>Organisation</th>
</tr>
</thead>
<tbody>
<tr>
<td>NGO Roundtable</td>
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<tr>
<td>NSW Accessible Transport Committee</td>
</tr>
<tr>
<td>OACCP</td>
</tr>
<tr>
<td>Parenteral Nutrition Down Under</td>
</tr>
<tr>
<td>St George Hospital, Consumer Advisory Group</td>
</tr>
<tr>
<td>SWSLHD Consumer/Community Council</td>
</tr>
<tr>
<td>Translational Cancer Research Network</td>
</tr>
<tr>
<td>Young Stroke Group NSW</td>
</tr>
</tbody>
</table>

### Consumer and community representatives experience

Respondents had a variety of backgrounds in terms of their consumer experience. The majority had either patient or carer experiences, while one third represented a non-government organisation. Further details are given in Figure 6. The ‘other’ option describes a variety of situations such as being a past nurse, a member of a local health council, or community participation over many years.

#### Figure 6: Respondents’ experience

<table>
<thead>
<tr>
<th>Experience</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Patient NSW public health system</td>
<td>38%</td>
</tr>
<tr>
<td>Carer of a patient in the NSW public health system</td>
<td>17%</td>
</tr>
<tr>
<td>Representative of a non-government organisation</td>
<td>30%</td>
</tr>
<tr>
<td>Other</td>
<td>15%</td>
</tr>
</tbody>
</table>

### Roles held in ACI

Being a member of a Network, Taskforce or Institute Committee was the main role of respondents in ACI (Figure 7). The ‘other’ reply indicated being a member of the Consumer Council of ACI.
Previous consumer training

A total of 39% of consumers had undertaken consumer training outside of ACI (Figure 8). A list of organisations where the training had taken place is presented in Table 3.

Table 3: Previous consumer training and years undertaken

<table>
<thead>
<tr>
<th>Previous consumer training</th>
</tr>
</thead>
<tbody>
<tr>
<td>CEC; 2011</td>
</tr>
<tr>
<td>Articles from LHD; 2009</td>
</tr>
<tr>
<td>St George Intellectual Disability Service which is now called Sunny Haven Kogarah;</td>
</tr>
</tbody>
</table>
**Previous consumer training**

<table>
<thead>
<tr>
<th>Year</th>
<th>Organisation</th>
</tr>
</thead>
<tbody>
<tr>
<td>2004</td>
<td>Kidney Health Australia; 2006</td>
</tr>
<tr>
<td>2006</td>
<td>I can't recall the names; 1990’s</td>
</tr>
<tr>
<td>2012</td>
<td>HCNSW; 2012</td>
</tr>
<tr>
<td>1997</td>
<td>SWSAHS Consumer Network; 1997</td>
</tr>
<tr>
<td>1997</td>
<td>NSW Education</td>
</tr>
<tr>
<td></td>
<td>RACGP</td>
</tr>
<tr>
<td></td>
<td>University</td>
</tr>
<tr>
<td></td>
<td>Church related</td>
</tr>
<tr>
<td></td>
<td>Medical Training; 1965-2013</td>
</tr>
<tr>
<td></td>
<td>BCNA Cancer Council; last 5 years</td>
</tr>
<tr>
<td>2011</td>
<td>Cancer Council; 2011</td>
</tr>
<tr>
<td></td>
<td>Department of Health in my local region; since 2002</td>
</tr>
<tr>
<td></td>
<td>Department of Education</td>
</tr>
<tr>
<td></td>
<td>Department of Community Services</td>
</tr>
</tbody>
</table>
Appendix C: Staff profiles

Networks, taskforces or institutes of staff

Figure 9 shows the clinical network, taskforce or institute of the staff respondents. The ‘other’ category included individuals who worked across a number of networks, implementation teams.

Figure 9: Previous consumer training
**Staff undertaking the role of carers**

ACI acknowledges the important contribution carers make to its workplace and wider community, and is keen to play its part in increasing awareness of the NSW Health Carers (Recognition) Act. Staff who responded to this survey were asked to indicate if they undertake carer duties (Figure 10).

**Figure 10: Staff undertaking the role of carers**
Appendix D: Interview and focus groups questions

Interview and focus groups introduction and questions (staff)

Thank you for attending this focus group. As you know, the overall purpose of this focus group is to obtain information from staff, to aid in the development of an ACI Framework on consumer engagement. The Framework will set out how ACI designs, delivers and evaluates consumer and community engagement activities. As well as staff focus groups, we will also be conducting focus groups with consumers, who will provide feedback on their experience of contributing to ACI and suggestions on how we can improve the support we provide.

The purpose of this focus group is to help ACI assess current levels of involvement, and any gaps in representation of consumers and to invite your feedback and suggestions on how ACI can improve the support offered in the design, delivery and evaluation of CCE.

Questions

1. How do you define or describe consumer and community engagement?

2. What strategies should ACI use to involve consumers in the development and implementation of care?

3. What factors do you think act as facilitators or barriers to consumer or community engagement in ACI?

4. Have you been able to measure the impact of consumer or community engagement in your network?
   a. Prompt: Why, why not, how?

5. What should the ACI Consumer Engagement Framework include?
   a. Prompt: what is critical, what is optional?

6. What key principles that should be emphasized in the Framework?

7. Any other reflections?
Interview and focus groups introduction and questions (consumers and community representatives)

Thank you for attending this focus group. As you know, the overall purpose of this focus group is to obtain information from staff, to aid in the development of an ACI Framework on consumer engagement. The Framework will set out how ACI designs, delivers and evaluates consumer and community engagement activities. As well as consumer focus groups, we will also be conducting focus groups with staff to invite their feedback and suggestions on how ACI can improve the support offered in the design, delivery and evaluation of CCE.

The purpose of this focus group is to help ACI assess current levels of involvement, and any gaps in representation of consumers and to invite you to provide feedback on your experience of contributing to ACI and suggestions on how we can improve the support we provide.

Questions

1. How do you define or describe consumer and community engagement?

2. What strategies should ACI use to involve consumers in the development and implementation of care?

3. What factors do you think act as facilitators or barriers to consumer or community engagement in ACI?

4. What should the ACI Consumer Engagement Framework include?
   a. Prompt: what is critical, what is optional?

5. What key principles that should be emphasized in the Framework?

6. ACI is seeking feedback from patients, carers and consumers about their personal experience of healthcare (that is, your stories). As a consumer, does it matter who interviews when you are relating these experiences?

7. Any other reflections or points you would like us to share with ACI?