

Barriers to community involvement in health and medical research

Researcher perspectives on consumer and community involvement in research: a qualitative study



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Definitions and acronyms:

Consumer and community involvement	consumers, community members and researchers working together in partnership to make decisions about research priorities, policies and practice
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NHMRC	National Health and Medical Research Council
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*I think part of the attitude as well might be, **'I'm not going to put too much time into this until I know it is funded'** because I can't afford to dedicate time to something that is not going to happen.*



SUMMARY

This qualitative study was undertaken by the Consumer and Community Involvement Program at The University of Western Australia's School of Population Health and Telethon Kids Institute (the Involvement Program), with a researcher from the University of Notre Dame Australia and a UK consultant on patient and public involvement. The study used two focus groups and four telephone interviews to explore researcher perspectives on consumer and community involvement in research.

Key findings about barriers to consumer and community involvement could be categorised into the following areas:

- ▶ Time and effort
- ▶ Funding
- ▶ Finding the 'right' people
- ▶ Sensitivity and confidentiality
- ▶ Organisational and policy barriers
- ▶ Personal barriers
- ▶ Research fatigue
- ▶ Group dynamics

At the conclusion of the focus groups and interviews, researchers were asked to name one main benefit of involving consumers and community members in research.

Main benefits included:

- ▶ Increased relevance and appropriate ways to disseminate findings
- ▶ Wider community support and long-term beneficial relationships
- ▶ Unique perspectives being brought to a research topic

It was also apparent from the level of discussion that the training workshops provided by the Involvement Program for researchers, consumers and community members were considered to be important by many researchers and consequently a section on this topic has been included.

BACKGROUND

The Consumer and Community Involvement Program is a joint initiative between The University of Western Australia School of Population Health (the School) and the Telethon Kids Institute (the Institute). The Involvement Program has provided key deliverables in the area of consumer and community involvement in health and medical research at the School since 1998 and jointly with the Institute since 2002. These four key deliverables are advocacy and advice, education, community links and leadership. The National Health and Medical Research Council (NHMRC) and Consumers Health Forum of Australia published a joint *Statement on Consumer and Community Participation in Health and Medical Research* in 2002 which was designed to encourage the involvement of consumers and community members in health and medical research, not just as 'research participants', but also as partners in the research process itself.

The Involvement Program held consultation forums during 2004/5 and organised and hosted the Involving People in Research Symposium in 2008. Anecdotally and from feedback after these events, it was apparent that many researchers did not have the confidence, skills or resources to fully implement consumer and community involvement. Anne McKenzie, Consumer Advocate and Manager of the Involvement Program, collaborated with Bec Hanley, a patient and public involvement expert in the UK, in responding to this perceived need. Together they developed and facilitated training workshops for researchers. The researcher training workshops were piloted in 2009 and continue to be an integral component of the work of the Involvement Program. The workshops include a session on addressing barriers to implementing consumer and community involvement.

The qualitative study entitled *Barriers to community involvement in health and medical research* was undertaken in 2012 by Involvement Program staff, in collaboration with Bec Hanley, Caroline Bulsara from the School of Nursing and Midwifery at the University of Notre Dame Australia and Rachel Skoss, a researcher at the Institute, provided support during the focus groups. The study aimed to determine factors that may act as barriers to involving consumers and community members in health and medical research from a researcher's perspective and potential strategies and methods that may be implemented to overcome these barriers. The University of Western Australia Human Research Ethics Committee provided ethics approval.

Feedback forms, provided at training workshops for researchers, consistently show that over 80% of attendees intend to change their practices to increase consumer and community involvement as a result of attending a workshop. It is expected that by having a greater understanding of the barriers, the Involvement Program can tailor training, resources and support to address barriers raised by researchers.

METHODOLOGY

A qualitative methodology used an in-depth interviewing technique and focus groups approach to collect data. Focus groups were organised at the School and the Institute. Four researchers who agreed to participate but who were unable to attend a focus group were interviewed by telephone asking the same questions as those asked in the focus groups. The interviews and focus groups were recorded digitally and transcribed. The focus group or interview schedule was based on barriers that had been identified in previous workshops and events held by the Involvement Program. Details can be found in the Appendix.

The focus group or interview schedule covered the following areas:

- The impact of funding issues
- Sensitivity and confidentiality issues
- Qualities of effective consumers and community members
- Managing group dynamics
- The time and effort required
- Benefits and barriers

Sample population

Researchers from all academic levels were recruited from the School and the Institute via an email circulation using professional contact information in the public domain. The email was sent by Anne McKenzie, the chief investigator, with those interested in participating being asked to contact her for more information on the study. Researchers expressing interest were sent a study information sheet and contacted by the investigators to discuss study requirements and timing. Signed informed consent was gained prior to data collection. To avoid conflicts of interest, researchers supervised or managed by the investigators did not participate in the study. All researchers who participated were actively involved in research involving humans.

Data collection

A total of twenty four researchers participated in the study. Twenty of these researchers attended focus groups, one held at the School and one at the Institute. Four one-to-one telephone interviews with researchers who were unable to attend either focus group were conducted. The sound files were transcribed by Involvement Program staff and the researcher Caroline Bulsara.

Data analysis

Data were analysed thematically using the software NVivo version 10.

RESULTS

In the focus groups and interviews, researchers identified factors and issues that have been organised into broad categories of;

1. Barriers to consumer and community involvement
2. Benefits of consumer and community involvement
3. Attitudes and perspectives on training

It was noticeable that both understanding and level of consumer and community involvement was dependent on the type of research being conducted. Those involved in qualitative research appeared to have greater understanding of the value of consumer and community involvement in research. This may be due to the methodological requirements of qualitative research. Some who were conducting epidemiology-based or laboratory / clinical research were less engaged in the process. Nonetheless, all of the researchers felt that there was value in having meaningful consumer and community involvement. Many also believed that there was potential to have consumers and community members more fully involved.

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Barriers of consumer and community involvement

Key findings:

The two key barriers identified by researchers were **time** and **funding**. These barriers impacted on the implementation of consumer and community involvement in the planning and conduct of research, as well as building trust and relationships over the long-term.

Finding the 'right' consumers and community members to be involved was clearly a major barrier for researchers, as indicated by the extensive discussion on the topic.

Building trust and relationships over time, with senior level support and clear organisational policies, were seen as ways to address these barriers.

Other barriers to consumer and community involvement identified by researchers included:

- ▶ Funding
- ▶ Finding the 'right' people
- ▶ Sensitivity and confidentiality
- ▶ Organisational and policy barriers
- ▶ Personal barriers
- ▶ Research fatigue for consumers and community members
- ▶ Group dynamics

Time and effort

The time and effort required from both researchers and consumer and community members to implement involvement was identified as a major barrier. Researchers also mentioned time as a potential barrier for consumers and community members becoming involved in a study.

One researcher also spoke of the ethics of justifying the use of consumers' and community members' time.

“As for barriers, it’s probably time, not just our time but time of the community members and it can be difficult to get people together, especially because we want people from very diverse areas.”

“So for me the greatest barrier is sort of the rationality... justifying of taking people’s valuable time.”

One researcher noted that there is a difference in the amount of time required when involving one or two consumers or community members on a reference group compared to involving many more consumers in a community forum.

“Once again it depends on the method you use, one or two token community representatives on a reference group is much easier than something like [what] one of my colleagues is doing at the moment which is 100 odd people in a forum; it depends on which way you are going, on what level. From my point of view it’s a massive time burden. It’s something I do on top of everything else because we don’t have a dedicated person to do it. To get 12 is fine, to get 30 means you have to ask 100 and it’s time.”

Researchers noted that some grant applications include consumer and community involvement as a requirement. Consequently, they felt pressured to have this component ready to move forward at the commencement of the project and this required extra time commitment. In response to this, however, researchers also acknowledged that having consumer and community involvement from the outset could save time and money as the research was more closely guided and assisted.

Onerous requirements from funders during grant writing season was perceived as a barrier to involving consumers and community members in the planning stages, before the grant application was sent in.

“Yeah, I think the hard thing is that really when people need to come in is the planning stages... A lot of this is getting put together in January before NHMRC goes in. No one has got the time to do it properly. You are struggling to get it all in and that is why it goes by the wayside. Everyone is trying not to kill themselves with the workload in January.”

Some researchers spoke further about difficulties with timeframes,

“Absolute and meaningful involvement takes time and those relationships take time to establish as well, you have a couple of weeks to throw that sort of stuff together and yeah, I think people need to be planning six months out from an application to get meaning from the community.”

Other researchers believed that there was also a ‘great deal’ of time and effort expected from the consumers and community members involved, in terms of reading documents and commenting. It was perceived that the success of a grant application was uncertain and that there was some degree of unwillingness to invest a lot of time.

“I think part of the attitude as well might be, ‘I’m not going to put too much time into this until I know it is funded’ because I can’t afford to dedicate time to something that is not going to happen.”

A researcher suggested that preparation during the year for consumer and community involvement in future research grants would enable activities to go beyond a planning phase when grants were being written. It was also acknowledged by researchers that this is a suggestion which is rarely implemented.

Funding

Some researchers described consumer and community involvement in research as a ‘bit of a luxury’. This was due to receiving funding purely for the ‘scientific part’ of the research. If they were awarded NHMRC funding, however, researchers said they were better able to provide consumer and community involvement components in their research. Researchers were asked to discuss funding priorities and the allocation of funds for involving consumers and the community. Those who worked with either laboratory-based research or linked datasets were less likely to involve consumers fully in their research projects. They were open, however, to including consumers and community members. One explained,

“From our experience we haven’t actually involved any consumers in any of our projects and I guess the reason for that is probably because our work is based on data from medical labs rather than going out to people or focus groups which is more suitable for consumer research. At the moment we are looking at ways that we can incorporate consumers into our research.”

Others saw that it was important to include consumer and community involvement activities within the proposed budget and to allocate funds at that time.

“We went right in and dedicated a line in the budget around two things. One sort of project advisory group which has consumer participation but then also a sort of consumer advisory group themselves.”

Another researcher felt that it should be a responsibility of the research team and that it was a ‘non-negotiable’ aspect of the funding application.

“I think it’s a public responsibility that we should involve consumers and inform consumers about what they are doing. It has to be a priority.”

The importance of involving consumers and the community from the beginning of the research process, prior to funding applications, was acknowledged.

“Well, I think just keeping people informed about what we are doing and getting their input. I mean, we’ve had consumer input from the very beginning in this grant so before we even applied for the grant we held you know, workshops and asked people what they thought we should be using the data for and things like that.”

In some research teams there appears to be a tendency to make budget cuts, if necessary, in areas of consumer and community involvement.

“The research team will say, well we need money to actually pay for data or recruitment or salaries or we can run an advisory group on the cheap. So that’s where the budget gets cut.”

Another researcher noted that research budgets were not really geared to requesting generous amounts for consumer and community involvement and there was researcher expectation that a budget allocation would often be cut by funders.

“So, I think things like, you know, setting costs and paying consumers for their time as well as travel and other things for other professionals, catering properly, those sort of things tend not to get done anyway, and I would worry that would be the sort of thing that people cut down on.”

Budget cuts to consumer and community involvement was perceived by some to allow for the researcher-perceived ‘essential’ research to be carried out. One said,

“I would love to say it’s very high priority but I suspect its low down the list. I suspect it gets shunted. It’s considered nice but not necessary. I imagine data costs and salary would be prioritised over that. And I think I would be guilty of that too.”

Nonetheless, others argued that the actual costs of consumer and community involvement were relatively minor compared to the rest of the research budget.

One researcher spoke of priorities in terms of how established the research ‘team’ might be. Funding to support involvement was on a list of priorities and a track record needs to be established before larger grants are awarded. Some researchers felt that it was harder to draw funding from smaller projects and that larger projects were much more able to have budgets for consumer and community involvement. In contrast, another researcher in the same group said that she would not conduct any research without consumer and community involvement and that doing so was regarded as ‘unethical’ in some research circles.

Researchers who had experienced collaborative grant writing with representatives of not-for-profit or non-government organisations, were positive about the experience. One said,

“I’d say we have nothing but a positive, a really positive relationship with our industry partners, we’ve had no problems at all.”

However, it was acknowledged that many more non-government organisations should support research and engage as research partners within Australia.

Finding the ‘right’ people

The barrier of finding consumers or community members to be involved in research projects generated a great deal of discussion amongst the researchers. They identified qualities that they considered advantageous for effective consumer or community representatives to possess. Researchers also described some qualities that contributed to the challenges of involvement.

Some of the sensitive research areas were particularly problematic in terms of getting consumers and the community involved. These areas, which included mental health and Aboriginal health, required care in selecting consumers and community members. Actually finding anyone willing to take on the role was also a challenge for the researcher.

“Generally you find, even with the sensitivity of the topic, if people have had a bad experience [they] like to come to give their opinion. That was one thing, we tried for 3 months, we’ve given it our best shot, let’s leave it at that and I am not going to try it again. So the resources and availability [of consumers] I guess.”

Another difficulty identified was that of having a health issue portrayed negatively in the media, which could result in reluctance on the part of consumers or community members to become involved due to self-perceived guilt and fear of stigma.

“But barriers, time and money as everyone has mentioned. But also for me the stigma of having a genetically transmitted disease.”

Retention of consumers and community members was noted as a challenge, particularly in groups which are considered to be over-researched. Although it was perceived that everyone started out ‘enthusiastically’, retaining consumers and community members could be ‘difficult’ in terms of engaging and maintaining their interest over time.

“I think you start with a good idea. But then after a while maybe the momentum dies off a little bit.”

Agenda-pushing

One repeated concern was the perception, by some researchers, of agenda-pushing by consumers or community members. One researcher noted that this was more likely to come from what she termed ‘career consumer representatives’ who are usually paid for their involvement. This researcher felt that the approach of these consumers was different to others who ‘donated their time’ and that there could potentially be some ‘in-fighting’ for positions on panels. This view was not endorsed by other researchers. Another concern was expressed by researchers about aggressive or overtly critical consumers or community members in public settings and was seen as a problem that could ‘derail researcher confidence’.

One researcher noted that researchers needed to carefully consider which consumers or community members had a genuine concern for their community and those who had a broader and less intensive experience.

“This is where a problem might come when you have a reference group and you have one or two community representatives on there and then you get people who have a real interest from the community and others not truly representative of the community. So it is part of the issue I have with the agenda [pushing].”

Other researchers also felt that sometimes consumers or community members might use the research setting as a support for personal problems.

“...using it as a kind of counseling thing for themselves.”

“Some consumer groups out there are also like therapy groups, support groups. So there is a distinction between kind of joining a consumer group and just talking or... consumer reference groups.”

Other researchers did not see agenda-pushing as an issue, with one highlighting that,

“We all have agendas. Doesn't it annoy you when people say ‘Oh that consumer has an agenda’ So what? We [researchers] have an agenda.”

Another issue that arose for researchers was having a balance of opinions. Several researchers noted that consumers and community members with strong voices and opinions did not necessarily provide this. She explained,

“I mean you need everyone's viewpoint and if they were all the same it could be indicative of that [agenda-pushing] or it could be just that the people who come forward have a particular viewpoint. But when you are discussing issues you want any idea to be debated regardless of peoples' particular agendas.”

Negative experiences

There was a perception that negative experiences might recur with each requirement to involve consumer and community members such as,

“The scary stories that tend to get repeated and people tend to be more aware of the bad example.”

One researcher explained that other researchers in her group refused to engage with a consumer she had managed to recruit. This researcher continued,

“I just had to sort of say.. a bit of a fib really.. that the research was not progressing and that we would contact her if we needed her. It made my relationship with the other researchers difficult.”

This caused many issues for the researcher with the team and she explained further,

“I definitely feel that what is missing from our project is the patient voice that is not there, and I don’t think there is much I can do about it.”

Balance of power

Some researchers highlighted difficulties in the power differential between some health professionals, in particular, and consumers or community members. The perception that some health professionals lack awareness of their paternalistic or ‘superior’ attitude was noted by a researcher who explained,

“So, we are all in this together. If you live in a world where you think you are superior, and feel that, ‘we have invited you and aren’t you lucky?’ then it’s absolutely evident. The biggest issue for me has been that people haven’t understood how transparent, how obvious it is, that they have views that are often quite disparaging or paternalistic, which is also just as bad.”

Another researcher stated that she felt that the main problem was with professionals and researchers accepting consumers as equals in the research partnership. Setting an example for the research team was noted as facilitating mutual respect. One researcher related the following as an example of lack of respect amongst research staff.

“But when I look at the way that the senior researchers treat their junior researchers I get scared”.

Her comment was about the balance of power between senior and junior researchers and she continued,

“What I now wanted to say about that is it actually demonstrates powerfully for me... two things. One, that consumers aren’t stupid. Talking to them about ethics and then behaving unethically. The other thing is it shows me that in the moment that strength can sit anywhere in the room. So you know the real strength of observations was sitting with us in a wiser older woman whose son had schizophrenia and she had a depressive illness.”

Having a smaller base of people willing to participate is challenging for some researchers, with one describing consumer and community involvement in research in Australia, and in Western Australia specifically, as ‘in it’s infancy’. Getting new consumers ‘on board’ can prove difficult. One explained,

“We have just had a thing recently trying to get people for a study for media involvement, but no one wants to talk about it.”

Managing expectations

Many consumers and community members join a research group with great expectations of what can be achieved by the research. Managing these expectations over the lifecycle of the project can be challenging.

“I think you also need to manage their expectations of what we can deliver and how long it takes. Research takes a long time and I think a lot of people don’t realise how long it takes. It’s something you are wanting to feed back and you know, thank them with something tangible but it can take two years. And so they think ‘They have just used us and forgotten about us.’ and that is not necessarily the case. It’s taken, you know, a long time.”

Two researchers further highlighted the need to have consumer and community members who were unafraid of expressing their opinions and having their expectations out in the open. In addition to this, it was seen as important that consumers and community members had expectations of researchers as well. One said,

“I suppose if you get too good a match and someone is just going to say ‘Yeah that’s a good idea.’ rather than actually challenge you a bit to come up with something.”

A balance of viewpoints

Researchers noted various qualities as important for consumers and community members to possess. These included having a balance of viewpoints and being collaborative, confident, knowledgeable and understanding.

The importance of having a balance of views and someone who was able to accept other viewpoints within the group was regarded as very important. Key concepts were objectivity and the ability to listen to different viewpoints. One researcher explained,

“So if you do have to get someone who has had a bad experience in whatever [research] then you are kinda limited by only having that or if you have two or a group then perhaps you have more of an even spread if they have the background of what you are researching about.”

For this reason it was suggested that a representative of an organisation (community, non-government or support group) might be preferable as they would bring a number of viewpoints and thus be more balanced. Another researcher suggested that engaging consumers who were some years from an initial, emotional diagnosis / illness stage would be preferable.

“We want someone who is more settled into their routine and who is not in that emotional place and they can step back.”

As another researcher described it, ‘someone who is middle of the road and with no huge sways for and against’. Balance also meant having all perspectives considered. For example, males should also be represented in a project about women’s health. One researcher also highlighted the difference for her between consumers who represent the community rather than those who are representational of the community.

Collaborative

Another quality spoken of by researchers was collaboration. It was perceived as important that consumers and community members would avoid being ‘argumentative’ and to be collaborative in working with not just the research team but also with any other consumers in the group.

“To work well in a group dynamic they need to work well regardless.”

Confident

Confidence was regarded as very important to researchers. Although perceptions of confidence were varied, generally it was agreed that this was the ability to ‘speak up’ in meetings, even if the consumer or community member was in the minority. One researcher explained it thus,

“I think that’s the thing; most people have been to a committee meeting where there’s a consumer representative who effectively has to shout to be heard. So that’s in the back of your mind. My experience is that actually they are not like that at all but in a bigger level committee then they need to be very stern and strong.”

Another researcher felt that having a consumer who was well versed in the area of research was beneficial and that this person would be willing to advocate and use their own experiences without embarrassment or guilt to provide depth of perspective.

“She feels that by her being public it actually helps others.”

Although having the confidence to ‘speak out’ in a group setting was noted as desirable, it was considered less so by some researchers. One researcher explained this by noting that it ‘settled’ researchers to have a consumer or community member who had ‘got it together’ in terms of their issues and had the ability to express themselves without too much of a personal agenda. This was not, however, agreed upon by all researchers with others preferring someone with a strong personal agenda whose richness of experience was a valuable contribution to researchers’ understanding.

“I think it does help [researchers] and people who are struggling to see that confidence.”

In regard to confidence, another researcher felt that different consumers or community members may be required for different activities. Being a single representative in a large group of academics and researchers may require someone with a great deal more confidence. She explained,

“We often put one consumer representative in a room full of policy people and professors and I think we ask an incredible amount of them and I think the skills that we need from them are very different from that skill set if you like (or qualities is probably more an appropriate word) than that base level when we are trying to decide what research to do. So I think there are different qualities depending on how they will be used.”

Another researcher echoed this by talking about the ‘power discrepancy’ and that this can be a barrier to ensuring that consumers and community members are confident in speaking to senior academics. She added that if she feels a little intimidated by more senior academics then consumers and community members may potentially feel even more so. As a mechanism for having their voice heard, this researcher suggested that one-on-one conversations between a research team member and the consumer or community member might be a way to promote confidence.

Overall, it was generally noted that having the ‘courage of their convictions’ was the overarching quality sought from those representing the consumer and community voice,

“Yeah, or sometimes just the altruism of not caring about the way that they are portrayed to make sure that the message is out for others.”

Knowledgeable

Most researchers acknowledged that it was very important for consumers to be knowledgeable about the particular area of research they are involved in. One researcher gave an example from the area of asthma and medications,

“So we were able to delve into their medications, how does that happen, how do they get those medications, what do the doctors tell them about them, how do they actually use them, and so they were obviously knowledgeable because it’s their own experience.”

Another suggested keeping a database of consumers and community members, including some information regarding their willingness to help. Some of the skills were outside of the research setting but were nonetheless valuable. For example,

“We are trying to keep a database of people we have spoken to who have skills....So if we ever need help we could ask that person. I am trying to keep a little internal list of people who have said ‘well if you ever want [skill set] I know someone’.”

Identifying people with varied expertise in a particular health area was recommended by some researchers. One said that she would seek out not just the woman with the health issue but also a health professional and possibly a spouse or partner who would provide complementary but slightly different perspectives on the same problem. One researcher explained it in this way,

“I think we should really take a lesson out of the indigenous book, if you want knowledge it is a different sort of knowledge than the academic knowledge but it is as every bit as important.”

Understanding

Some researchers spoke of the importance of a consumer or community member being aware of the aims and objectives of the research team in carrying out the research and to be an integral part of the team whilst providing their perspective. One said that she felt that consumers had a very ‘good grip’ on what was appropriate and what was not.

Another said that it was important for researchers to remember that we are all consumers in some way or another and support mutual understanding and respect.

“I mean consumers and community representatives are not a rare breed. We are all people in there together doing the very best that we can for the community, children and families. We all need to be natural and normal with each other I think.”

Some researchers suggested that to help find consumer and community members it was important to look at what is needed for the study. This may be understanding and knowledge within an area specific to the research or a more general community awareness.

Confidentiality and sensitivity

Researchers reiterated that they all take confidentiality 'very seriously' and that breaches were extremely rare. Researchers believe they can offer reassurance about the confidentiality of consumers' data and medical information. There is greater awareness and openness of procedures in this area which has built consumer confidence.

"It's not so much about confidentiality, it's more about why we do the things we do and who owns this information and why would you share some things and not other things."

Confidentiality of topics and findings, which consumers and community members are privy to as members of a research team was, however, seen as a potential barrier.

Establishing ground rules at the commencement of a consumer, community member and researcher partnership was seen as very important by many researchers. As noted by one, it is part of a 'shared understanding'.

The importance of establishing ground rules around confidentiality was noted. This was especially important given that many community members would relay information back to their community groups. This was highlighted as a learning experience for many novice consumer and community members. Other researchers pointed out that most researchers are very aware of what the 'ground rules' are and 'take it for granted' that confidential information would not be 'leaked'. It was noted that researchers who are new to the process of involving consumers and community members in research may be more concerned with this issue.

One researcher noted that whether researcher, consumer or community member, everyone should abide by the same confidentiality rules,

"So it applies to everybody, rather than say that because you are from the community we need to make special note of you."

Another barrier identified was related to consumer and community involvement in sensitive research areas which might involve vulnerable consumers or community members. Two researchers noted that it was a fine balance between asking consumers and community members to share their experiences and in not making them feel uncomfortable. In relation to this, another researcher said that the responsibility rested with the researcher. She explained,

"I think if you are going to involve consumers, then you need to do your own research about how to do it. Not to put anybody who is vulnerable in a vulnerable position. It takes some care, people volunteer and want to be in it and you need to manage it"

first at the start. I mean people are very happy to help, but if they find they are in a situation that might be uncomfortable for the room I think that then you as a manager [research leader] have an obligation to find that out beforehand.”

Some researchers working in areas considered sensitive or ‘high risk’ noted that they had a more difficult task when seeking to recruit and inform consumers and community members,

“I think women rely a lot on more anecdotal information during pregnancy than they should because the researchers keep telling them all the things they are doing wrong. They listen to each other.”

Building relationships and trust over time was discussed as a way of addressing these barriers of confidentiality and sensitivity, from both a researcher’s perspective and that of consumers or community members. Having support to develop trust was seen as crucial to successfully implementing consumer and community involvement in research. Lack of support, from senior researchers in particular, contributed to confidentiality and sensitivity barriers, which can become more problematic over time. Examples of trust between researchers and consumers or community members were provided, such as,

“They [researchers] give them their manuscripts to read and proofread, that I think that requires a very high level of trust. Because if that manuscript gets leaked and you know potentially the data won’t be published, there could be devastating effects.”

Researchers with longer term relationships with consumers and community members noted how important trust is. One researcher said that it would be helpful in trust-building to share a few rows of qualitative or quantitative practice data to demonstrate data confidentiality methods.

“I think it builds the relationship, you know we talked about relationship building, it allows people in the community to understand research more, they actually have participated in it rather than [it just being] a study. They are contributing to it. I think the scientific and ethical standards are enhanced. And our group found it’s fantastic when you are tackling difficult issues.”

Organisational and policy barriers

Government policy was cited by researchers as a barrier to achieving full consumer and community involvement. One believed that the guidelines set out by the NHMRC were in need of further revision. She said,

“[In regard to] the NHMRC. Now, would you believe that because they have produced a statement about consumer participation in 2002, they have produced the model framework for CCP in health and medical research in 2005, produced the Australian code of responsible conduct for research in 2007, even a report in 1998 to support consumer and community representation? They have definitely got the underlying requirements but I think some of the statements in the framework could be revised.”

Further to this, another researcher noted that the guidelines as they currently stand should be promoted and referred to more widely by the universities and funding bodies. Another researcher went on to say that the guidelines should be mandatory. This would establish awareness and encourage researchers to develop consumer and community involvement before funding is awarded, embedding it in a research project or program from the outset. Rewarding researchers who fully engage in outlining involvement in a grant application and conducting meaningful consumer and community involvement was suggested.

“The NHMRC don’t reward researchers who undertake it, like it’s not really counted I don’t think. So what gets rewarded gets done. It’s sort of an academic thing, it’s not really part of a researcher’s track record or for their academic record.”

Organisational barriers were also noted. One researcher cited a study from 2009 which had found that only 43% of institutions and organisations have policies and practices for consumer and community involvement in place. Although novice researchers and those not having previously involved consumers and communities in research had some anxieties about this, most could see the value in policies and practices. As this study has also noted, anxieties amongst researchers centred mostly on the time and effort required, along with funding.

Some researchers felt that they had little control over whether research findings were translated into recommendations and policy changes. This was noted as a difficult balance between making commitments to the consumers or community members and what they could realistically provide and achieve at the end of the research project.

“I can faithfully represent what I am, you know, what they say, but then I don’t personally have a lot of control over what recommendations or any findings, even if I feed them back to the community and the community says ‘yeah that’s right’, or ‘this is what we need’, or ‘you need to include this in that’. Which is how I work constantly, but then if ultimately at the end whoever you are giving that report to does not act on those recommendations, then I feel as a researcher that I have let down those [people]. So to me there is a lot of emotional sort of stuff tied in with that.”

A junior researcher noted that they would include consumers and community members but if they do not, ‘then no one else on the team will’. This creates a great deal of pressure on the junior researcher for the consumer and community involvement to succeed. She explained,

“I have to drive it and I feel that if it doesn’t go well it is going to go badly for me. It would be good if it was just part of a protocol that we were all contributing to. Like budgets or anything else. At the moment it still feels like an ‘add on’ I am suggesting.”

Personal barriers

Some researchers identified the biggest barrier as their own mindset and lack of knowledge. They were aware that engaging with consumers and community members could benefit their research. One researcher did not think the issue was about getting researchers to agree to consumer and community involvement but it now largely involved

a move beyond rhetoric to the instituting of a defined process. Others mentioned that researchers can be defensive or anxious,

“I think as a researcher we have to not be defensive as well because sometimes people are going to bring up issues with the research that has got problems, and that is why they are there, why we want them there, to hear their voice. But I think sometimes researchers can get a bit defensive, you know. ‘Don’t tell me what to do’ and ‘I’m doing this for the good of you’.”

“I am a bit nervous with some consumer reps who feel quite antagonistic towards researchers. I find that a little off-putting. I can understand why some people are motivated to get involved because they feel that researchers have really done the wrong thing by them and I think that’s a really strong motive. It makes me a bit nervous.”

Another researcher, however, felt that differences of opinion should be viewed in a positive light so that diversity of perspectives can be taken ‘on board’. She advised others to,

“Not to be defensive of it. You can choose to take it in a positive light. It’s valuable.”

One researcher spoke of barriers that need to be broken down on both sides and identified one barrier as ‘they [researchers] don’t like consumers telling them’. Another felt that those who had most issue with this were PhD and masters students who had a great sense of ownership over their projects.

“I think that might be relevant for students like this doing honours or PhD, it’s very much like it’s my project and this is what I am going to do, to go to someone and then they [consumers] say ‘no I think you can take it in that direction’, it can be a bit of barrier to getting them involved in research.”

In terms of keeping updated with current communication pathways, one researcher spoke of social media and the need for researchers to become more engaged with this. She justified this by saying,

“I think with social media and social networking that there is a lot more propensity for misinformation to get circulated and get around. And we are not really addressing or sort of getting the facts through on those sorts of mediums.”

Research fatigue

Another barrier identified was, as one researcher termed it, ‘research fatigue’ among groups who were widely researched. She explained that this proved difficult and additionally so if consumers or community members had not been involved in the area of research before. Also, those struggling with a health condition or caring for someone are less likely to prioritise involvement in research. She explained,

“The barriers are generally dealing with a group who have extreme research fatigue and often their daily life is such that priority of the researcher takes a very lower priority and as much as they may see a benefit, they have daily experiences that block them being able to assist you.”

And another,

“We advertised through the Health Consumers’ Council and through a number of [non-government organisations] and widely through papers and radio and we haven’t got any sort of consumers with relevant expertise.... we have tried for 12 months to get a group together.”

Particular areas of potential research fatigue were Aboriginal communities. Some researchers noted that they had a few core community members but that it could be challenging to find others.

“One we haven’t talked about much is about the Aboriginal consumers, and the availabilities; there is small number of very good and active members. Then how do you find others?”

Some researchers working with Aboriginal communities highlighted the importance of the cycle of consumer and community involvement. The key is in ‘meaningful’ engagement. This cycle also includes feeding back information to the community during and after the research.

“One aspect that is really important to us is not just the participation but the feedback aspect of going back to community and telling them what we’ve found. This is a big aspect because Aboriginal people feel that time and time again everybody wants to come in and ask them what the issue is, get all their views and then they disappear and they never know quite what happens to that. So we are sort of now making that a mandatory aspect of our work.”

Another researcher highlighted problems with the guilt of returning to the same willing communities time and time again. For this reason, she noted the importance of feeding results and findings ‘regularly’ back to the communities. Assessing how satisfied a community is with results is about openness and sharing, whether the results reflect the research question and the community perspective.

“You ask them. Show them that you have actually done what they have asked you to do. So if you go and get their opinion on something and they say ‘Please don’t do this’, so you don’t do it, you come back and say thank you.”

This approach was noted as having the added benefit of reassuring the community in regard to their health information. In addition, it was explained that referring to community advice and input was greatly valued in the research process. This should take place regardless of how busy the ‘lifecycle’ of research projects becomes.

“I think it’s just communication sometimes, even if it’s just an informal email to say, ‘Hey, you know when you suggested this? We changed it and it worked really well. We did this because of your suggestion and this is how it worked out’.”

Group dynamics

A barrier to fully implementing consumer and community involvement in research projects is establishing and maintaining good relationships between all parties involved.

Researchers mostly felt that consumers and community members are aware of their role as part of a research project. One researcher did acknowledge that if there were issues, they should be addressed before they escalate, to 'try to deal with it sooner rather than later'. Researchers were aware of the diversity of involvement, ranging from individuals sitting on panels and advisory groups through membership of steering panels to forums with larger numbers of consumers and community members.

It was noticeable that some researchers, such as qualitative researchers who worked more closely with communities, were more amenable to the roles and value that each team member contributed.

"I don't see the researchers as above the consumer and community representatives in knowledge or experience. I think the knowledge is equivalent and their experiences are equivalent to those who have studied a subject. That takes a reasonable amount of emotional maturity and ability to lead, and if you are thinking about people who are starting out on their research career, sometime they have got enough on their plate with all the things they need to deal with."

Closeness of researchers to consumers and communities can however become pressured in terms of how and when results, recommendations and responses are shared. One researcher highlighted the issue with,

"The interesting thing that I find really hard is you can't really give results until you are published. I find that a real bugbear and I find that you really want to reward, you really want to give, and you really want to share. You know that you are just not able to. You need to explain that. People who have been with you on a three year project, trust is developed and they understand that."

This researcher noted that she will address the issue by sending drafts of papers for comment to consumers and community members, providing updates of research status and acknowledging their contributions in her publications.

"With the projects that I have, that is how the acknowledgements are going to be written. I have three quarters of a page of acknowledgements. So they [consumers and community members] know that they are going to be acknowledged in those papers. There will not be a surprise to them. I think [it is important] to keep them informed of things coming on the horizon. If they are not wanting to be a part of it, I respect that too. I know we move on in circles of our lives."

The diversity in approach between qualitative and quantitative researchers was noted by one researcher who felt that qualitative researchers, by nature of their approach, would be less likely to regard themselves as 'removed' from the community. This was attributed in part to the 'one to one approach', as defined by some data collection techniques in qualitative research.

“I do think there is an attitude that you don’t really need to talk to any people to do a lot of quantitative research. So, I think qualitative researchers are less likely to do that.”

When asked what the ‘right time’ to involve consumers and community members might be, opinions varied. Some researchers felt that it largely depended on the type of research being conducted and others said it was highly important to ask consumers and community members for direction at the start of the research process. Those involved in clinical studies felt that it was worth re-examining levels of involvement within their work, given the perception that the levels are lower in this area of research than in studies dealing directly with the community. One end of the spectrum of involvement was described by a researcher as being a ‘co-researcher’ with her community partners. This researcher noted that research always includes collaborators, and consumers and community members should be regarded as such.

“I feel committed as much as I am ever able because you know in a research team you are not an individual, you have collaborators. So I would definitely seek to have my consumer representative sitting right at the table with researchers in the steering group in the research that I undertake. You really do have equal voices”

The community co-researcher examined the findings with the main researcher, who received ethical approval to do this. Given that the translation of the results by a community member was crucial, the researcher justified this as follows,

“Because she is part of such a tiny group, involvement is essential as to how this particular topic is viewed. I felt it was important and so I had to reapply to ethics and she had to put [her comments] into writing.”

Another issue raised by some researchers was the need for clear roles and respect between researchers, consumers and community members. It was noted that this could be best achieved through open and ongoing communication between all parties. In relation to communication, one researcher highlighted the importance of researchers being able to manage strong personalities during meetings.

“It’s also managing the meeting... if someone is talking all the time, to say, ‘Ok that’s fine but now we are moving on to something else.’ You know, don’t let someone with a really strong opinion dominate. Stop people putting each other down. Make it a nice happy environment. Don’t let anyone feel that they are being victimised or that they haven’t got a voice.”

Researchers were asked to consider any rules and/or guidelines that they had used or encountered in working with consumers and community members. Terms of reference were noted as an important starting point for any group. As one explained,

“So that everyone knows what they are doing... We used to read out a terms of reference at the start of every meeting, it was like a little prayer. Every meeting, because we only met 3 monthly, we were in agreement, this is what we are here for and what we have agreed.”

However, there was a caveat that any terms of reference should be set up and agreed upon by everyone and not imposed upon the consumers or community members after the commencement of the research.

Keeping people engaged and feeling included was also highlighted as potentially challenging. One researcher said that she ensured consumers were able to contribute and asked at the end of meetings if anything had been omitted during discussions. This enabled them to have a voice at each meeting. In practical terms, agendas were also noted as very important.

Representation

Diverse representation was highlighted as important. There were some groups which were acknowledged as more likely to engage with research, such as retirees. As one researcher said, 'It's a bit skewed to retired persons'. There was variation in the proportion of consumers and community members that were seen by researchers to be required for a project. One researcher said,

"I think 20% is fair. I mean my research is quite connected to the community so I probably feel different to others. But I am definitely aware that I am not going to get much further with my results unless I have people on board."

Another commented,

"On the consultation we did with mental health consumers, carers and health professionals we did some years ago we had 50 people representing the five professional groups and we had 50 consumers and carers because we needed equal representation as it was such a serious message."

Having a consumer or community member who could represent a group on a high level research advisory team was suggested. This was noted as someone prepared to 'stand up and speak' as a representative of their community. The level of experience, training and 'representational history' were seen as important for the success of this.

Another researcher cautioned about expecting one person from a specific cultural background to represent the views of an entire community. He said,

"We have that with some of my Aboriginal colleagues who are continually asked to be on steering committees and represent Aboriginal views as if there is just the one view, and they find that very challenging particularly if they are in a room where they are the only Aboriginal representative which is generally the case and they are asked to speak on the behalf of an entire population. You can train that person to be more general in their views but at the end of the day their experience is based on their personal history. I think a lot of us make that mistake with cultural backgrounds, as we think one person can just tick a box and represent an entire population or group or cultural experience and it's very simplistic."

A more general question about community representation was raised by one researcher.

"It's like when you send out surveys, only the people who are really interested send them back. So it's hard to know that you are getting true community representation when you only have two [consumers] on a larger reference group."

Key findings:

Consumers and community members can provide increased relevance and appropriate ways to disseminate findings.

Endorsement from consumers and community members can lead to wider community support and long-term beneficial relationships.

Consumers and community members can provide unique perspectives to a research topic and to pinpoint issues that are not obvious to the researcher.

Most researchers acknowledged the ethical justification for involvement and that there are significant benefits that consumer and community perspectives can contribute to research.

“The bottom line for benefit is that most of us are doing research that will benefit people in the community and using money that has come from the community and it is almost morally wrong not to involve them in the research.”

One noted that having strong and knowledgeable consumers and community members was of great benefit in sending a message about trust back to the community.

“So they know if it’s been passed by these two people [consumer members] then it’s A-OK, it’s sort of like ‘Oh those people keep the scientists under control’ so the research is worthwhile.”

Offering fresh perspectives to a research question was cited by a number of participants as being a main benefit. One researcher explained it this way:

“I think the benefit is getting the perspective of, for lack of a better term, the end users I guess, on what the whole research process is about. If you are doing something that has patient-ended outcomes, you want input of what is actually happening. Unless you have actually experienced it, it can seem very easy giving 4 doses of medication a day; that’s a piece of cake but if you have actually gone through and met a carer of a patient with dementia you might have quite a different view. So that’s the main benefit from my perspective.”

The unique perspective that consumers and community members provide was highlighted by several other researchers. One noted that the views that consumers and the community have on research direction and results can be missed by mainstream research processes and protocol and for this reason are invaluable.

“Its good for them to see that they can actually have a guiding hand in directing where the research is going so they have got a voice. Because otherwise participants

feel distanced. It's nice for them to actually say, 'This is a bit of a problem for us, is there any way you can do a research project on that?'. It's bringing a real world experience to the research."

"I think about valuing their lived experiences. So I would be looking for someone who has had their own regular person experiences with whatever disease or condition or whatever the content is. I am looking for that lived experience because that's the part I can't get from reading or from any amount of data. Someone who has been there, done that."

In terms of the actual research, one researcher said that consumers and community members often were able to pinpoint issues that were not obvious to the researcher, ensuring that the research remains relevant and the approach feasible.

"Even if it's just to confirm that you are on the right track I think that is hugely valuable. I think they will pick up things that you have missed because you don't know what you don't know."

Other researcher comments about perspectives and experiences included:

"I think the one main benefit is that it offers a perspective that I just can't get within my own resources."

"And from my limited experience it is the information that they can contribute up front that can inform how the project proceeds and that's based on their own personal experiences and the effects of the burden of the disease."

Another researcher noted that, regardless of research plans, sometimes consumers and the community will convey that the approach is not appropriate for them and that researchers need to reconsider. She added,

"And that's an extremely humiliating and also humbling experience but a very good one to learn as a researcher."

Another of the key perceived benefits was the endorsement of the research by having meaningful consumer and community involvement. One researcher emphasised that it improved the integrity of the research and validated the results through translating the research and giving results a 'community voice'. Keeping researchers 'grounded' and remaining within 'context' were also highlighted by a researcher.

"The main benefit to consumer and community involvement is that we keep grounded, doing what we are doing. That it's not out of context, and for me it's the constancy of that."

Increasing relevance by involving consumers and the community was another of the main benefits noted by the researchers. One explained it as,

"So we have to keep reminding ourselves that this is not for you to make your life better, not doing it for the glory of winning a Nobel prize or getting grants or what have you. So it's a good reality check. Ultimately, if your goals are to improve a

situation in a community or on supporting a community with your research and you have already gone in there with your ideas of what that is, you've sort of missed the boat."

Another researcher explained that aside from a personal and in-depth perspective, consumers and the community were also invaluable in advising how a research project might be received by the wider community and how best to get a message across. One researcher described it as 'putting people at their ease' through community input. Another liked the idea of being able to 'bounce ideas' off consumers and community members, ensuring the relevance of future research. One researcher said that consumer and community involvement was valuable in intervention studies, particularly at the time when the intervention is about to be applied.

Several researchers commented on ways consumer and community involvement can benefit the dissemination of research findings.

"Dissemination of your results - if you have got consumer involvement that is a good step and they have ideas about how you are going to get the message out. I think that things like record linkage at the beginning look incredibly dry and something that consumers wouldn't be interested in but it is something that they are passionately interested in. To have them involved in research you have to explain your research in ways that they can understand and it's good for us."

As was expressed here, sometimes with the 'drier' subjects the consumer or community input was invaluable in making the results more accessible to the wider community. As one researcher said,

"It brings a richness to it."

Similarly, groups such as young adults were more likely to 'listen to someone of their own age and stage in life' than a researcher's approach to disseminating results. In addition, it was also believed that there was wider support for research through consumer and community involvement in all stages, including dissemination of results. Researchers reiterated the value of having consumer and community involvement in their research areas, regardless of the type of research. One spoke of holding consumer workshops at the end of a project to decide which way to disseminate the findings most effectively to the community.

"We have got people there who are actually experiencing what the data are telling the researcher and might be able to provide some insights."

One researcher noted that the involvement of consumers and community members helped researchers to 'break down the paternalistic view of medicine that people have, particularly if you have a highly medicalised condition'. This researcher explained this view as,

"You know we need to develop new therapies and medications that our consumers will actually be able to use and take. Because compliance is a massive issue so it's no good having a medication that must be taken three times a day at six hour intervals because that is never going to work."

On a more practical note, one researcher spoke of the benefits to future studies of retaining consumer and community interest, 'so we know what they will and what they absolutely won't do.' In long-term areas of research, word of mouth was noted as an effective way of engaging with communities.

"For one of our recent studies, the majority of people who came back were actually families or previous participants or friends from kids at school and stuff like that so we have found that word of mouth is very good promotion."

A researcher described consumer and community input into research as 'eloquent in their simplicity' even when meeting with government and other funding bodies. Long-term development of trusting relationships was seen as important for continuity. A database of consumers and community members who want to be involved was again highlighted as an important strategy for meaningful engagement. One researcher described the process,

"[you say] well, unfortunately they can't take part in this study. But would you be happy to hear about any future studies that we are doing? And if they say 'yes' then we forward them our newsletter with the database forms. They can go on the website, see what we are doing. Then if they are happy, they come back to us."

Another researcher raised the importance of involving consumers early on and also regularly seeking their input in order to have their support into the longer term. This contributes to what one termed as 'the longevity of the research' due to having more stakeholders invested in it.

The Consumer Advocate role within the Involvement Program was commended for supporting the development of strong relationships between researchers, consumers and community members. In addition, the Involvement Program's Involvement Network, formerly known as the Participation Network (a database of consumers and community members interested in research) was noted as a valuable future strategy,

"That is something that I think is really fantastic that researchers have support with [involvement] until they get experience with it. That is where [the Consumer Advocate] has also been very helpful for us with contacts, that's where having the database is going to be much easier."

Key findings:

The role of the Consumer Advocate in training consumers to be involved in research was highlighted as extremely beneficial to researchers. Consumers gain confidence to meaningfully contribute to a research area following training.

Most researchers felt that researcher training was beneficial - even though confronting at times - to challenge some long held beliefs about consumers and community members.

Although not included on the schedule of topics, the training offered by the Involvement Program at that time to researchers, consumers and community members was discussed by researchers in considerable detail. Ten of the twenty four researchers who took part in the focus groups and interviews had attended a training workshop provided by the Involvement Program at the School or the Institute. There was awareness amongst the researchers of the benefits of training in in this area.

Training for consumers and community members

The training provided by the Involvement Program for consumers and community members was seen as beneficial. One researcher highlighted the importance of the support provided by the Consumer Advocate. She explained,

“I think also we are both in the fortunate situation where we have a consumer [advocate] who provides training actually. They provide training so most of the consumers that we have on consumer research panels have received some training so they don't come into it cold.”

Another researcher acknowledged that most of the negative stories about consumer and community involvement were from ten years ago or more and that with greater training and awareness, understanding of requirements had improved significantly.

“We are in the fortunate position at the Institute where we have excellent training. We can have consumer and community representatives who have the opportunity to undertake that and we as researchers really seek to work as equal partners with them.”

One researcher spoke of the differences in research over the years when there was no training for consumers. Prior to the availability of training, the ability of consumers and community members to critique and offer constructive criticism could be very variable. As one said, ‘You know, some of it was valuable and some of it wasn't’.

Training for consumers and community members was seen as helpful in exploring how to express one's views more broadly,

“But also about training them in how to express your views more broadly as opposed to just always coming back to your own personal experiences and what exactly happened to you.”

Other perceived benefits of training included being able to voice one’s opinion in a constructive manner and having the ability to remain firm based on one’s experience.

It was felt that training for consumers and community members was partly the responsibility of an organisation or institution. Although consumers and community members were often ‘screened’ for sensitive projects, it was still important for them to receive appropriate training to enable them to fully contribute to a research program or project. It was also proposed that training be ‘tailored’, depending on the research approach and topic.

Training for researchers

Attitudes to training for researchers were varied. Many researchers felt that the training for researchers was of immense value in overcoming common misconceptions. Some said, with a sense of humour, that the training had been very ‘enlightening’ in terms of understanding issues from a consumer and community perspective. One added,

“Especially for researchers who haven’t been involved before.”

It was acknowledged that researchers often come to the training feeling very skeptical of the benefits of attending. Most agreed, however, that after completing the training they fully appreciated the value of it. It was also noted that everyone would benefit from training whether researcher, consumer or community member. One researcher said,

“I think all research should have consumer involvement even if it’s lab type of research ... I am going for training for researchers and also consumer reps. It’s good because it gives us new ideas.”

Some researchers can be ‘afraid’ of upsetting consumers and community members. A researcher noted that while one could seek justification and/or clarification about a research question amongst fellow researchers, one might be reluctant to question the consumer or community member about the same issue and training helps to address this.

“If a researcher said this question is not appropriate, you would say ‘Why? Justify that’. But if you say that to a consumer it looks like you are attacking them and [the consumer] doesn’t have the knowledge. So I think without that training it sort of adds to all those issues that could not derail the project as such but maybe complicate it.”

Two researchers suggested removing the academic approach to the researcher and consumer training workshops and making them more experiential. It was mentioned by a researcher that the consumer and community involvement aspect of research needed to be included in undergraduate units, be given by a consumer or community member and be supported by the university and/or institution.

CONCLUSION

Identifying and addressing barriers to involving consumers and community members in health and medical research has been part of the work of the Involvement Program since it began in 1998. The process became more structured with the development and facilitation of training workshops for researchers. Feedback from researchers attending the workshops identified time and funding as the major barriers to involving consumers and the community.

Researchers in this study, over half of whom had not attended a training workshop run by the Involvement Program, also identified time and funding as the main barriers. Addressing these barriers will, in many cases, need high level support from research organisations, government and non-government organisations and funding bodies. In addition, the researchers provided insights into other potential barriers that the Involvement Program may be able to address through the ongoing development of training and resources.

A second aim of the study was to identify perceived benefits of involving consumers and community members. Researchers described contributions made by consumers and community members at different stages of the research cycle. Some benefits, such as building trust with a community, require long term commitment.

Discussion by researchers on the topic of training offered by the Involvement Program indicates the level of interest in the workshops. The workshops for consumers and community members were particularly seen to be beneficial by researchers in the study. Researchers also highlighted the Involvement Program's leadership role in having staff to support consumer and community involvement in research, particularly in regard to the advice and assistance provided by the Consumer Advocate.

*... consumers and community representatives are not a rare breed. We are all people in there together doing the very best we can for the **community, children and families**. We all need to be natural and normal with each other I think."*

APPENDIX

Focus group and interview questions

Introduce myself and my background to the group. Explain a little overview to the project and how it came about. Finally, some housekeeping about talking over others, tape recorder etc....

Q1. I'd like to start by going around the group and just letting you say a little about who you are and your role here at SPH / THE INSTITUTE. Don't feel that you need to spend a great deal of time on this; it is really just a way of getting comfortable with the group today. Thank you for that.

Now, I have a number of areas for discussion today that have arisen from previous work in this area completed by Anne McKenzie and a number of researchers. I would really like your perspectives on these today in terms of whether you feel that they are major issues or not and why this might be the case.

Q2. I would like to begin the focus part of our discussion by asking you to consider some of the issues around FUNDING. As you know, funders often 'cut' budgets for research. Keeping this in mind, how much does this impact on the ability to engage consumers and communities effectively? Is this a major issue for you and your research environment? How great a priority is it for you to maintain funding in order to ensure consumers and communities are still involved?

Q3. When you think about the type of research that you are involved with, do you think that there are concerns around consumer and community involvement given sensitivity and confidentiality issues? Do you have ways of addressing this that you would like to share? Have you or a colleague you know ever had a situation where confidentiality of the research protocol has been compromised by consumer and community involvement?

Q3a. What would help in terms of training and / or awareness amongst consumer and community representatives involved in research around this particular issue of confidentiality?

Q4. With this in mind, what sort of qualities do you and / or colleagues seek out in a consumer and community participant? (Probing for confidence, education, background, level of engagement).

I would like to touch on a slightly more complex issue next. That is, group dynamics within a research project or program of research.

Q4. Firstly, in terms of numbers, would anyone like to share from experience what proportion of representation should come from consumers and community? How would you ensure that consumer and community are satisfied that their contribution has value in the research process? Could anyone share from experience any strategies that you might have used?

Q4a. Are any of you aware of the difficulties encountered when working with a number of different personalities and agendas within one project? How were these addressed?

Q5. We all acknowledge that getting the right sort of consumer and community involvement is essential for research. However, I would like to talk a little about the actual “nitty gritty” of engaging consumer and community representation in terms of disability, regularity and communication issues outside of the research environment that we share. Could anyone comment on this?

Q6. This topic really follows on from the previous question. What are your thoughts on the effort and time required of you and your team to get the most out of consumer and community involvement? Are there any time periods when the time and / or effort required seem to be greater than others, for example?

Q7. Finally, I would just like to ask if I can go around the group, for you to state briefly what is the one main benefit and one main barrier and / or concern for you as a researcher in effectively engaging consumer and community participation in research.

Q8. Any other issues we haven't spoken about that you feel are important to raise in this focus group?

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