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Opportunities to enhance consumer and community engagement training for researchers and healthcare providers: a qualitative study

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ABSTRACT

Objective To identify key training content for the education of researchers and healthcare providers in consumer and community engagement.

Design A qualitative descriptive design, underpinned by pragmatism, involved semi-structured interviews and a focus group. We conducted a thematic analysis using a framework approach.

Setting Community, hospital and university settings in Australia.

Participants This study involved 28 individual interviews with researchers, ethics officers, leaders from consumer organisations and a focus group with six people working in health service settings.

Results Key findings from our study reveal a wide scope of consumer and community involvement (CCI) training content recommended for researchers and healthcare providers. Four main themes for training content were identified: (1) Embedding consumer and community involvement in research and health improvement projects; (2) Connecting with consumers and the community; (3) Considerations for consumer and community involvement; and (4) Progressing CCI in research and healthcare. Participants emphasised the importance of building foundational relationships with consumers and community, as well as connecting with experts. While how to partner authentically with consumers and the community was another important training topic raised, so too were the administrative considerations involved in CCI partnerships. Furthermore, the identification of training content including reducing duplication of effort, embedding CCI training into the education of healthcare and researchers and building an evidence base for CCI, shows the importance participants placed on investing in and advancing the field.

Conclusions A wide scope of training content is required to support CCI capacity building in researchers and healthcare providers. Key training content is recommended to cover practical, relational, administrative, ethical and logistical aspects of CCI as well as guidance about how to advance CCI practice and its evidence base. Future work needs to focus on how the training content can be successfully implemented, evaluated and updated.

STRENGTHS AND LIMITATIONS OF THIS STUDY

⇒ Multiple perspectives and methods were used in this study.
⇒ Consumers engagement occurred through interview and write up of the study.
⇒ To ensure trustworthiness of the analysis, data triangulation, detailed records and project debriefing were used.
⇒ A limitation was the lack of scientists and laboratory researcher perspectives in this study.

INTRODUCTION

Consumer and community involvement (CCI) is an important and evolving area in research and healthcare improvement. CCI in healthcare refers to the active partnership between researchers, healthcare providers and those affected by or who may benefit from the research or healthcare improvement.1 In Australia, consumers, the community and other funders of research and healthcare are increasingly calling for active CCI in research and healthcare improvement planning and conduct.2-6 Indeed, training in consumer involvement for researchers has been core for international organisations leading in this area including the National Institute for Health and Care Excellence in the UK, Strategy for Patient-Oriented Research in Canada and Patient-Centered Outcomes Research Institute in the USA. All have successfully embedded CCI (also known as patient and public involvement) as a core component in research processes.5-9 Training has an important role to capacity build and ensure researchers and healthcare providers are appropriately prepared to engage with consumers. Training in this study refers to the process of developing knowledge, skills and behaviours to undertake CCI.
Underscoring the importance of CCI training for researchers and healthcare providers are the barriers that many Australian researchers and healthcare providers report when working with consumers and the community, despite its value and importance. In Australia CCI has not traditionally been a core component of research or health training, yet policymakers, research funders and consumer groups are increasing calls for CCI training. Most published literature about CCI training has focused on tailored programmes for individual projects or organisations, providing little guidance for broader systems level capacity building initiatives. While important and useful documents for developing and implementing training and support for CCI exist, these were designed to be general in advice and for systems that have established process, funding and support for patient and public involvement. There is also a gap around detailed content on topics specific to the needs of researchers and healthcare providers. While training consumer and researchers/healthcare providers together is frequently advocated, it is also important to understand the training requirements of different stakeholders.

Monash Partners Academic Health Science Centre is a National Health and Medical Research Council accredited Research Translation Centre comprising 12 health service, research and teaching organisations serving the health and well-being of ~3.2 million Australians throughout the south and east of the metropolis of Melbourne with reach into regional Victoria. Monash Partners has established an enabling platform to strengthen capacity for meaningful CCI, undertake research, identify best practice and develop strategies to prioritise and facilitate CCI to improve healthcare and outcomes for Australians. To support Monash Partner’s CCI strategy and broader CCI implementation, this study aimed to identify key training content for the education of Australian researchers and healthcare providers in consumer and community engagement.

**METHODS**

**Study design**

A qualitative descriptive design, underpinned by pragmatism, involved semi-structured interviews and focus group, and applied inductive thematic analysis. An interpretive framework based on pragmatism focuses on practical understandings, what is useful and ‘what works’. This approach enables the most appropriate methods to be selected to answer the research question and recognises that knowledge is always based on experience. Qualitative description design and framework analysis align with pragmatism as an interpretive framework and with the involvement of stakeholders (eg, consumers) in the analysis.

**Setting**

This study was set in metropolitan Melbourne, Australia, where Monash Partner’s member organisations are situated.

**Participants and recruitment**

The estimated information power required to generate new knowledge from this project was based on the focused aim, sampling a range of participants with specific experiences and employing established and appropriate analysis methods. The study inclusion criteria required participants to have experience with consumer and community involvement in research/health service delivery. Participants were purposively sampled based on: having a role in consumer engagement in a Monash Partners health service; employment as a researcher in a partnered university; and being part of a consumer organisation known to Monash Partners aligned to one of their seven clinical themes. University-based researchers from varied clinical research settings known to Monash Partners through their consumer engagement work, and representatives from consumer organisations, were emailed an invitation to participate in an interview as well as an explanatory statement. Representatives from consumer organisations were identified through known networks, recommendations or information on websites. All email addresses and phone numbers were available in the public domain or contact was enabled through Monash Partners’ networks. Potential participants were asked to respond to the email if they were interested in the study. A mutually agreed interview time and date were subsequently organised. No response was received from the email invitation within 2 weeks, a second invitation was emailed. If no response was recorded after 4 weeks from the first email, attempts were made to contact the potential participant by telephone. Once a leader from a consumer organisation was recruited in each of the seven clinical themes, no further invitations were emailed. To recruit people working in a health service with CCI experience, an email invitation was sent to participate in a focus group. To make participation in the focus group accessible for in-person attendance, the session was scheduled to commence half an hour after a Monash Partners Consumer and Community Advisory Committee meeting. Interested people replied to their email invitation to confirm attendance at the focus group before its commencement.

**Data collection**

Two trained qualitative researchers conducted all interviews in English at a time convenient to the participants. One interviewer has nursing and education qualifications and experience (SR) and the other has public health qualifications and education experience (DA). Both were employed as researchers and had experience in qualitative research and working with consumer organisations and as healthcare consumers. The semi-structured interview guide for individual interviews and focus group was developed from the aims of the research and included six questions and topics: experience and understanding of CCI; knowledge and skills in CCI; barriers and facilitators of CCI; engagement; training and support for CCI; and future directions for CCI.
main areas. Topic areas included experiences with CCI and how consumers and the community were involved in health research, what was valued and working well or not so well with CCI in health research, how any issues were overcome, what formal or informal CCI training was being undertaken including the content covered, what resources and supports were available or needed to conduct CCI and how any activity was reported. To encourage participants to explain or expand on their responses, probes were used throughout the interviews.

Semi-structured interviews and a focus group were conducted between July 2019 and April 2020. Interviews were completed face-to-face or by telephone and the focus group was held in-person. Consent to participate was verbal if completed over the phone and written consent was obtained for face-to-face interviews and the focus group. All interviews and the focus group were audio recorded and professionally transcribed.

**Data analysis**

Data were managed in NVivo 12 (QSR International, Doncaster). Using a framework approach, a thematic analysis was undertaken.24 After reading the transcripts multiple times, inductive coding was undertaken which involved coding any text that appeared relevant to the aim of the study, for example, attitudes (eg, CCI should occur in all research projects), values (eg, CCI is important in research) and ideas (eg, how to evaluate CCI). Coding to classify data was both iterative and inductive. Both SR and DA independently coded the transcripts. Codes with similar content or meaning were grouped together into categories, and then organised into main categories and subcategories to create an analytical framework, which was developed through discussion. The remaining transcripts were then indexed (through the application of codes, categories and subcategories) to the framework, which was revised as additional codes were identified. Data were then charted into a framework matrix, which involved summarising data from each category while retaining the links back to the original data set. A person with lived experience of acute and chronic health conditions contributed to the analysis and results presented in this manuscript and met the requirements for authorship. The consumer was known to the Monash Partners consumer network and expressed an interest in the topic and contributed to the manuscript. When engaging with consumers we worked with an ethical framework for consumer and community involvement by applying standards relevant to our project and country such as those outlined by Pandya-Wood et al.25 Principles included, for example, avoiding tokenism, communicating clearly with consumers, working sensitively, operating fairness of opportunity, being conscious of confidentiality and remunerating consumers for their involvement.25

**RESULTS**

Participants in the 28 semi-structured interviews included 8 researchers (of which five were researcher-clinicians) from a university, 4 people from ethics offices of two health services and 16 leaders from 15 consumer organisations (advocates for cancer, cardiac, neurological, renal, endocrine, women’s, orthopaedic and mental health conditions). Researchers and researcher-clinicians interviewed worked in diverse health contexts (eg, trauma, mental health, women and children’s health, disability). Participants had a range of experience with CCI. Some researchers had only engaged with consumers on a small

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<th>Table 1</th>
<th>Strategies to ensure trustworthiness of the analysis</th>
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<td>Detailed records</td>
<td>Detailed records were maintained about analytical and methodological decision-making to ensure a transparent audit trial.34</td>
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<td>Project debriefing</td>
<td>Regular project and peer debriefings provided opportunities for detailed discussion and feedback, enhancing the conceptualisation of the developing analytical framework.34</td>
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<td>Data triangulation</td>
<td>Data triangulation was achieved by two researchers working to develop the framework of themes and subthemes.34</td>
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<td>Monitoring for bias</td>
<td>The potential bias was regularly monitored through discussions at project meetings including checking if particular outcomes were anticipated.36</td>
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number of projects, but most participants reported extensive CCI experience over several years. Interview length ranged from 18 to 58 min. Interviews were supplemented with one focus group involving six participants from five Victorian metropolitan health services and ran for 50 min. No person participated in both an individual interview and the focus group. Four main themes and multiple subthemes were identified from the analysis. Each theme is discussed below and additional quotes for each theme are available in the online supplemental table.

Embedding consumer and community involvement in research and health improvement projects

Rationale, value, and benefits proposition of CCI

To embed CCI in research and projects, many participants reported that training programmes should provide a rationale for ‘why’ CCI is important, as well as highlight the benefits and opportunities it can bring from multiple perspectives. Suggestions included addressing CCI from a moral and ethical perspective, noting ‘there is a rights element to this, of wherever possible ensuring that focus on ‘Nothing About Us Without Us’” (Researcher 2). Others proposed motivating researchers to embed CCI in their work by taking a practical and value perspective to emphasise the ‘logic’ and importance of incorporating CCI.

Some participants expanded on how CCI training content could communicate the value of CCI in research and projects. Participants suggested highlighting that consumers can help to ensure research was fit for purpose, identify new research ideas, recruit participants, design appropriate interventions and translate findings for impact. The following participant summarised these benefits of CCI by noting, ‘... it stops you from doing kind of wasted processes. And ... from following a path... that may not end up being implemented” (Leader_from_consumer_organisation 1).

Early partnering to plan, prioritise and conduct research and healthcare improvement activities

To embed CCI in the practice of researchers and healthcare providers, participants recommended CCI training content incorporating information about connecting with consumers early and throughout the research process. Participants suggested that if researchers and healthcare providers understood the advantages of early partnership then the positive impacts of collaborative planning and prioritising research would resonate throughout the research project. Many considered such early engagement to be ‘the best model’ and one that enabled ‘consumers [to] inform research directions... and research priorities’ (Leader_from_consumer_organisation 8).

Ways of involving consumers and the community

Participants suggested that to embed CCI into the practice of researchers and healthcare providers, they required training content about the diverse roles consumers could perform in research and healthcare improvement projects. Participants suggested training should include how to involve consumers at different ‘levels’ of engagement (such as inform, participate, consult, involve, collaborate, lead), in different ways and settings (eg, laboratory based) and at different stages of the research. Without this knowledge and understanding, it was suggested that tokenistic engagement would likely to result.

Connecting with consumers and the community

Linking with leaders and quality resources

Several participants suggested training content should include how to connect with people knowledgeable about CCI (eg, people in consumer organisations, consumer or patient experience officers/managers, researchers with CCI experience, other experts or leaders). To support this topic, participants recommended including links to high quality CCI resources that provide guidance for connecting and engaging with consumers and the community. A researcher highlighted the need for connection to such information, ‘...because there aren’t really clear guidelines ... and no policy or anything at a university or school level; and I didn’t really know where to start’ (Researcher 2).

Understanding the role of consumer organisations

Participants from consumer organisations noted that training content should incorporate information about the role consumer organisations can play in connecting researchers and healthcare providers to consumers and the community. Participants from consumer organisations highlighted their work as knowledge brokers and relationship builders, as their role encompassed establishing community research priorities, conducting consumer training, providing consumer support, maintaining up-to-date consumer databases and facilitating consumer ‘matching’ with a research topic or task. Knowledge of the unique role consumer organisations play in connecting and aligning the interests of all stakeholders was suggested to ultimately support simplified processes and optimal consumer connections for researchers. Participants from consumer organisations also recommended CCI training content should guide researchers and health professionals to prepare and communicate the desired outcomes from CCI because ‘... we can let consumers down if we set false expectations’ (Leader_from_consumer_organisation 12).

Connecting with the ‘right’ consumer and consumer organisations

Participants stated that training content should address processes for connecting with the ‘right’ consumer (eg, skills, interests, abilities, attributes, connections) for a project, research topic, role and team. Finding the right consumer was not always a fast or straightforward process and participants recommended training content should include a variety of recruitment strategies to support connection. To find the most appropriate person, participants suggested training content should include how to prepare a consumer role description, where to publicise
the role or who to contact to facilitate connection. Additionally, information about how to select and interview suitable consumers for a role was advised as a role ‘that’s going to be in an advisory capacity [needs to ensure] the consumer is fitting that correct category – that is, they’re empowered and they’re connected into community’ (Leader_from_consumer_organisation5).

Consumer ‘representation’ and accessing underserved consumers in health systems
Most participants emphasised the importance of CCI training content encompassing how to connect with people who are underserved in health systems, such as culturally and linguistically diverse communities, Indigenous communities, gender diverse individuals and people living in remote, rural and regional areas. Multiple participants expressed concern that some researchers and healthcare providers might not seek connection with underserved communities if they “… assume that one individual can be all things to all people… [because] you cannot have somebody who doesn’t understand that experience representing that experience’ (Researcher 3). While many participants reported barriers to connecting with underserved consumers, some described the value of a ‘different approach [to] get people from different cultural backgrounds’ (Leader_from_consumer_organisation 3). Suggested strategies to include in training content were challenging the idea that one consumer can ‘represent’ others, being flexible with methods of involvement, ‘… talking with underserved communities around, ‘How can we engage with you more effectively?’’ (Leader_from_consumer_organisation 5), using plain language at an appropriate health literacy level, and meeting communities rather than expecting them to respond to publicised roles.

Considerations for consumer and community involvement

Logistical and resource considerations when engaging with consumers
How to navigate logistical and resource issues when engaging with consumers was raised as important considerations for CCI training content. Knowing that CCI ‘… is resource intensive and people have got to recognise that upfront […] if you want a good outcome at the end for patients’ (Health_services_focus_group), participants recommended CCI training content include information about the time, cost, administration, personal and personnel impacts of CCI. Content that informed how CCI can extend research timelines and cost considerations such as paying consumers and supplying equipment (eg, iPads, computers) was suggested. Furthermore, information about administrative processes such as managing organisational information technology systems (eg, logging onto a computer) and considering the impacts of research on consumers’ personal life (eg, privacy, emotional state), health and financial status (eg, impacts of payment if receiving government allowances) were noted as important training content. The need for personnel was also recommended to ensure appropriate documentation was prepared (eg, orientation manuals, position descriptions), and that a person was available to provide ongoing support and engagement to consumers of all abilities.

Valuing consumers through remuneration
Participants stated an important consideration in CCI training was how to appropriately acknowledge consumer expertise and time through remuneration and/or reimbursement. A participant explained “[consumers] have to have training, they have to be respected, they have to be paid for that’ (Researcher 3). To ensure consumers are ‘respected’, recommended training topics were how to prepare a budget to pay or reimburse consumers, understanding tax implications when paying consumers and how to administer consumer payments through their organisation.

Building strong relationships with consumers and the community
Many participants reported that a key consideration for CCI training content was how to build strong and equal relationships with consumers and the community. Given ‘a lot of [consumer involvement] is around relationship building’ (Leader_from_consumer_organisation 8), participants suggested that researchers and healthcare providers would benefit from training to support respectful and clear communication with consumers. Additionally, participants advised that good communication, particularly listening, was essential for minimising power imbalances and avoiding situations where consumers felt dismissed or disrespected.

Research integrity and ethical considerations
Several participants raised the need to consider training that addressed ethical issues in CCI. Suggested topics included when to seek approval from Human Research Ethics Committees to involve consumers, how to manage potential ethical issues (such as consumer and patient confidentiality) and identifying conflicts of interest and intellectual property. Furthermore, training content was recommended to cover ethical considerations from multiple stakeholder perspectives (eg, research participant, consumer, researcher, clinician). While many aspects of ethical conduct important for CCI training have been noted under other subthemes (eg, payment for consumers, inclusivity, building relationships), participants emphasised the importance of valuing consumer involvement by ensuring training content reflected how to conduct authentic, respectful, and meaningful CCI.

Progressing CCI in research and healthcare
Normalising CCI into research and healthcare
Several participants highlighted the importance of progressing CCI as a normal activity in research and healthcare and overcoming the idea ‘… that there has to be specific meetings and processes. [That] it has to be a formal, process-driven mechanism’ (Health_services_focus_group). As such, participants recommended
training content include ways to embed CCI into routine healthcare and research activities. Participants suggested integrating CCI training content into education and health policies, health administration and health research student curriculums and practice to normalise CCI. One participant proposed normalising CCI activities by quiet and careful ‘stealth techniques’ (Researcher 6) to create cultural shifts.

Collaborating and sharing CCI resources
Building an inclusive community of practice for researchers and healthcare providers was a vision for several participants that would help to progress CCI. Sharing resources, avoiding duplication and collaborating to enact CCI were considered important points for CCI training to ensure effective use of resources into the future, such as sharing access to established groups with culturally linguistically diverse community members.

Measuring and evaluating CCI impacts and outcomes
All participants recommended that to progress CCI practice training content should include how to evaluate the diverse impacts of CCI on research and healthcare projects. Measuring CCI impacts was considered important for evaluating its role in research outcomes, to support improvement process and to justify time and resources put into CCI. All recommended that impacts and experiences be evaluated from multiple perspectives so as to build an ‘evidence based on how you do this’ (Leader_from_consumer_organisation 8). Furthermore, participants advised that training content should include how to provide consumers with feedback about their impact as well as detail about a project’s outcomes.

**DISCUSSION**
This study is the first qualitative study to identify key CCI training content for Australian researchers and healthcare providers drawn from the perspective of multiple experienced CCI stakeholders. The findings reveal a wide scope of recommended training content to support CCI capacity building in researchers and healthcare providers. Importantly our study provides key practical, relational, administrative, ethical and logistical information to include in CCI training programmes, as well as guidance for training content that will advance CCI practice and its evidence base.

Capacity building for researchers and healthcare providers through training is an enabler of CCI10 26; yet little guidance specific to their training needs is available. Previous research has broadly suggested CCI training content for researchers,27–30 suggested training content was similar to our findings on websites is about how to do CCI training, but some suggested training content was similar to our findings including: ways to involve consumers,3 8 16 ethical considerations,3 8 16 accessing underserved consumers3 8 and evaluating engagement.3 8 However, overall these websites lacked detail about when their content was developed and/or updated. Our study contributes to the evidence base for CCI training through providing detailed information about the research processes used to develop the prioritised training content.

Key findings from our study will be used to inform a national CCI training knowledge hub that is currently underway to support all accredited National Research Translation Centres across Australia. However, the results can be used flexibly to tailor, update, develop or contextualise smaller scale CCI training programmes or to inform programmes for individual stakeholder groups or stakeholder groups being trained together. To facilitate the delivery of CCI training, education and/or implementation frameworks such as the Capability, Opportunity and Motivation Behaviour model31 could be applied to the recommended CCI training content to design effective behaviour change strategies.

To meet all stakeholder CCI training needs, some suggest that training should be conducted with all stakeholders together.16 However, evidence to support this assertion is lacking and future work could explore the disadvantages and benefits of addressing CCI training for separate stakeholder groups (ie, researchers and healthcare providers). Future research is also needed on how CCI training content can be successfully implemented, evaluated and updated. The importance of such future work is highlighted by a recent scoping review on the conceptualisation of patient ‘centredness’ in healthcare.32 The authors found that only 15% of patient-centred frameworks involved consumer perspectives.32 High quality CCI training could ensure researchers know how to connect and engage with consumers effectively and ethically. This goal aligns with the work of national and international organisations that strive to embed and integrate CCI as a core practice in research and healthcare improvement activities.6–9

**Strengths and limitations**
A strength of the study was the inclusion of varying perspectives and rich experience of people working directly with consumers. A limitation of the study was a
lack of scientists and laboratory researchers whose experiences may vary from those included. Further, while we included some researchers and healthcare providers as potential users of the CCI training, additional interviews with a broader range of researchers and healthcare providers could have yielded more information about what they already know, and what they perceive are their knowledge gaps.

CONCLUSION

From the perspective of healthcare providers, researchers and leaders of consumer organisations, this study identified prioritised CCI training content for researchers and healthcare providers working across varying clinical areas and organisational settings. Our findings highlight comprehensive training content for researchers and healthcare providers and call attention to ensuring these specific stakeholder needs are considered and evaluated for future training improvement and capacity building.

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Contributors

SR and DA conceived of and led the study. SR and DA conducted data collection. SR, DA, HJT, HS, MS and AJ participated in qualitative data analysis and synthesis. All authors made substantive contributions to the manuscript and reviewed and approved the final submission. All authors had access to the data set in the study and can take responsibility for the integrity of the data and the accuracy of the data analysis. SR is the author responsible for the overall content (the guarantor).

Funding

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Competing interests

None declared.

Patient and public involvement

Patients and/or the public were involved in the design, or conduct, or reporting, or dissemination plans of this research. Refer to the Methods section for further details.

Patient consent for publication

Not applicable.

Ethics approval

This study involves human participants and was approved by Monash University Human Research Ethics Committee project 19514. Participants gave informed consent to participate in the study before taking part.

Provenance and peer review

Not commissioned; externally peer reviewed.

Data availability statement

Data are available upon reasonable request and subject to the approving institutional ethics committee for the project. The data that support the findings of this study are available from the corresponding author upon reasonable request. The data are not publicly available due to privacy or ethical reasons.

Supplemental material

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## Supplementary quotes

### Theme: Embedding consumer and community involvement in research and health improvement projects

<table>
<thead>
<tr>
<th>Subtheme</th>
<th>Supporting quotes</th>
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<tr>
<td>Rationale, value and benefits proposition of CCI</td>
<td>Researchers respond well to logic. So if you can explain the value proposition to them, then they will naturally incorporate [CCI]. It becomes less of a ‘I’m doing it because …I had to’, to a ‘I genuinely believe that this is improving my research outcomes’. (Leader_from_consumer_organisation_4)</td>
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<td>Early partnering to plan, prioritise and conduct research and healthcare improvement activities</td>
<td>Earlier is better… Researchers quite often approach us as an afterthought when they go to submit a grant application only to find that there are now requirements in a lot of the grant applications around ticking a box for consumer engagement. And they realise that they haven’t done it and they haven’t thought about it. They then come to us and consumers have had absolutely no input in the design of the project, setting priorities around what was an important area to study etc (Leader_from_consumer_organisation_8)</td>
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<tr>
<td>Ways of involving consumers and the community</td>
<td>I wish [researchers] would step back and think about how they can really incorporate consumers in their research and... not just... say ‘We’ve involved them, we’ve got one person sitting on a committee’. (Leader_from_consumer_organisation_5) I’ve moved towards more [work] including consumers giving international Delphi studies, which include consumers as a specific group to inform core outcome measures. I take consumers to conferences with me, we do co-presentations ... And now [consumers] sit on management committees and stuff as well. (Researcher_4) We have a couple of really interesting initiatives, one’s called The Human Library which is where we actually employ people from a whole range of experiences in life to come in and be an open book and students are invited to interview them, to talk to them about their life. (Researcher 2)</td>
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### Theme: Connecting with consumers and the community
### Linking with leaders and quality resources

I think they rely on their network and if their network is equally naïve; and there are certain areas of research where there are very naïve areas around consumer engagement, then they don’t know how to move that forward. *(Leader_from_consumer_organisation_2)*

### Understanding the role of consumer organisations

I think there’s a lot of steps and stages for researchers that they need a background before they get into that [CCI]…. It’s nice having an organisation like ours that can facilitate that and they can also do some of that important legwork around finding that appropriate consumer for that person. *(Leader_from_consumer_organisation_7)*

### Connecting with the ‘right’ consumer and consumer organisation

They need to get the right consumers to do the job they’re asking for, just like they would a professional and that requires work. *(Leader_from_consumer_organisation_5)*

I did actually go to them a [community organisation] and they didn’t have a straightforward process even of identifying consumers for this [project’s] particular purpose. *(Researcher_1)*

### Consumer ‘representation’ and accessing underserved consumers in the health systems

The CALD [culturally and linguistically diverse] background people […] You have to have a really flexible range of methods for [involvement]…. If you are going to do it tokenistically, and if you are going to do it simplistically, just don’t do it. There’s no point. Actually, you are exacerbating the divide because you are saying, ‘We are representing you’ and you’re not and I think it’s really unethical. *(Researcher_3)*

Obviously, there’s an issue with that in the sense that no one person can ever really [represent]… and you can’t fully comprehend another person’s lived experience. *(Leader_from_consumer organisation 15)*

### Theme: Considerations for consumer and community involvement

### Logistical consideration when engaging with consumers

Depending on what you’re asking too, just even having people in a room who all had that shared experience with [a disease], you just need to be mindful that things may come up and what are you going to do about that, be prepared. *(Leader_from_consumer_organisation_7)*

### Valuing consumers

*Researchers need to* … understand HR [human resource] processes, understand some of the tax implications of gifts versus payment and thinking those through… being reflective on how you actually...
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<tr>
<th>Through renumeration</th>
<th><em>collaborate with someone in a respectful way without exploiting their expertise.</em> (Researcher_2)</th>
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<tr>
<td>Building strong relationships with consumers and community</td>
<td><em>You need to have good communication skills so that you are able to have effective communication and an effective conversation. So there is that aspect of the training for researchers.</em> (Leader_from_consumer_organisation_1)</td>
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<td></td>
<td><em>[Consumers] have to be treated like an equal member of the team and the input has to be valued just as much as anyone else’s.</em> (Researcher_6)</td>
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<tr>
<td>Research integrity and ethical considerations</td>
<td><em>It just depends on how consumers are involved and [if] they feel their involvement is meaningful. And that’s a metric for me, is that they all feel it’s not tokenistic; that we listen to what they say [...] it’s not really impact for me, it’s really about meaningful engagement.</em> (Leader_from_consumer_organisation_14)</td>
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**Theme: Progressing CCI in research and healthcare**

| Normalising CCI into research and healthcare | *It’s almost like if you do training that says, ‘Ok, we’re going to train you to work with consumers’, it’s almost like you need to do it via stealth technique, where you create these human library opportunities or you get a consumer in to talk or open a big event at hospital. So it becomes normalised ...* (Researcher_6) |
| Collaborating and sharing CCI resources | *When I look at my consumer base and I see that 30% of our patients come from a cultural and linguistically diverse background, yet I can’t even get a CALD [culturally and linguistically diverse] group going [...] but there are organisations out there who actually have links and to consumers... who can do the work or can help us to do the work.* (Health_services_focus_group) |
| Measuring and evaluating CCI impacts and outcomes | *One thing that kept coming up through our meetings was that [consumers] felt like they weren’t getting enough feedback about projects they provided input on. And so now we provide an annual summary and for each project we let them know which ones have now applied for funding, which funding has started, if any are published we provide them access to the publication. We try and give them a completely new summary of how everything moves forward after their input.* (Leader_from_consumer_organisation_14) |