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**TITLE: Barriers and Enablers to Consumer and Community Involvement in research and healthcare improvement: Perspectives from consumer organisations, health services and researchers in Melbourne, Australia.**

## **ABSTRACT**

Partnering with consumers and patients and the community and public is a research and healthcare improvement imperative. Consumer and community involvement (CCI) requires behaviour change at the individual (researcher, health professional, manager), organisational (health service, university, medical research institute) and system level (funding policies, collaboration between organisations). To understand the barriers and enablers to meaningful CCI, a qualitative descriptive study was undertaken with researchers, health professionals, representatives from consumer organisations, and health services and ethics committees in Melbourne, Australia. Twenty-eight semi-structured interviews and one focus group were conducted in May-August 2019. Ethics approval was obtained. Thematic analysis was guided by the Capability, Opportunity and Motivation and Behaviour model (COM-B). Training of researchers and health professionals in CCI, benefits and systems and processes to undertake CCI, alongside incorporating CCI as a requirement for funding were identified as enablers. Lack of time and resources for CCI, challenges in finding consumers for projects and a perceived lack of evidence of the impact of CCI were barriers. These identified barriers and enablers will inform strategies to build the capacity of CCI at the individual, organisation and system-level within the Australian Health Research Alliance.

### **What is known about this topic?**

- Consumer and community involvement (also termed patient and public involvement) is working in partnership with consumers and the community in research and healthcare improvement projects.
- Consumer and community involvement is a policy and funding imperative.
- CCI requires behaviour change at the individual, organisation and system level yet understanding of barriers and enablers and behavioural strategies to build stakeholder capacity, opportunity and motivation for CCI is limited.

### **What this paper adds**

- Key barriers and enablers in CCI include building capability through training, opportunity through systems and processes, and motivation through funding requirements, enhanced research and evidence on CCI benefits

- These tangible, actionable outcomes are informing systems, organisational and individual level behaviour change strategies to advance CCI

## INTRODUCTION

The community funds and benefits from healthcare improvement and research and hence deserve integration and partnership with researchers and health services to ensure optimal, evidence-based health care that meets their needs and priorities (Miller et al., 2017). This is unlikely to occur without genuine consumer and community involvement (CCI). Hence, CCI is a priority in research and healthcare improvement and has increased significantly over the past decade. CCI is a policy directive in countries including Australia (NHMRC, 2016), the United Kingdom (UK) (National Institute for Health and Care Excellence, 2020), Canada (Canadian Institute of Health Research, 2019), and the United States (US) (Patient-Centered Outcomes Research Institute, 2019). Different terminology is applied internationally, with the US adopting *patient engagement* and *patient-centered outcomes research* (Patient-Centered Outcomes Research Institute, 2019); Canada uses *patient-researcher engagement* (Canadian Institute of Health Research, 2019); the UK employs *patient and public involvement* (INVOLVE, 2019; NIHR, 2019) and Australia utilises *CCI* (NHMRC, 2016). Despite differences in terminology, involvement is a partnership between patients, consumers, the public and the community and researchers and health professionals (Ocloo & Matthews, 2016). CCI may also include relevant communities, such as organisations, services and settings (e.g., community health centres, hospitals, cultural groups) that may play a role in informing interventions. Optimal methods, approaches and strategies to increase and promote effective and evidence-based CCI, are in their relative infancy (Manafa, Petermann, Vandall-Walker, & Mason-Lai, 2018; Staniszewska, Denegri, Matthews, & Minogue, 2018).

Hence while CCI is increasingly recognised as important, there is slow and inconsistent progress and many CCI activities remain tokenistic (Ocloo & Matthews, 2016; Staniszewska et al., 2017). CCI in healthcare improvement and research requires changes in perceptions, behaviours and actions of health professionals and researchers. Understanding the perceived challenges and barriers that impede the process of effective and meaningful CCI and identifying enablers to promote and enhance CCI is required.

This study applied the Capability (physical and psychological), Opportunity (social and environmental opportunities) and Motivations (reflective and automatic) to Behaviour Model (COM-B) model. This model synthesised concepts from 19 frameworks of behaviour change (Michie, van Stralen, & West, 2011). Using the COM-B model, we aimed to identify barriers, enablers and strategies to enhance capability, opportunity and motivation for behaviour change to

improve CCI. We sought to identify the physical and psychological factors (capability); environmental and social contexts (opportunity); and reflective and autonomic processes (motivation) that are perceived to be barriers and enablers to CCI. Our ultimate aim was to inform evidence-based strategies to advance CCI at the system, organisation and individual levels among researchers and healthcare improvement leaders, organisations and policymakers, across the Australian Health Research Alliance (AHRA). AHRA encompasses the 10 National Health and Medical Research Council (NHMRC) accredited Research Translation Centres, which cover 95% of the country's health and medical researchers and over 80% of acute health services.

## **METHODS**

***Design:*** A descriptive qualitative study.

***Setting:*** Monash Partners Academic Health Science Centre (Monash Partners) is a partnership between six hospitals (public and private), three medical research institutes (MRIs) and Australia's largest university (Monash University), working together to improve the health and wellbeing of almost three million people in Melbourne, Australia (Monash Partners, 2020). Accredited by the NHMRC as an Advanced Health Research Translation Centre, the purpose of Monash Partners is to connect researchers, clinicians and the community to innovate for better health. Monash Partners includes clinical themes: linking cancer and blood diseases; cardiovascular disease; critical care, trauma and perioperative medicine; infection and inflammation; metabolic medicine; neuroscience, mental health and sleep; and women's and children's health, across clinical, academic and community partners. The clinical themes aim to enhance interaction and collaboration and to improve healthcare and health outcomes. Monash Partners also has multiple platforms including CCI. Monash Partners is a member of the AHRA and works with other centres in promoting evidence-based approaches to CCI.

### ***Participants and recruitment:***

#### ***Eligibility:***

Representatives from consumer organisations if the organisation represented consumers with a health condition that mapped to a clinical theme for Monash Partners. Consumer organisations (n=32) were identified via Monash Partners networks and a Google search. Researchers were eligible if they worked for the University or medical research institutes associated with Monash Partners and their research area mapped to one of the Monash Partners clinical themes. Representatives from ethics committees were eligible if the committee was from one of the six Monash Partners health services or the University.

*Semi-structured interviews.* Purposive sampling was used to identify and invite representatives from 18 consumer organisations mapped to the Monash Partners clinical themes. Researchers from three MRIs and the University mapped to the Monash Partners clinical themes were also invited to participate alongside members of partner research ethics offices.

Emails were sent to either a publicly available email address or via Monash Partners' network contacts, who were known to the research team. The email to participate included the Participant Information and Consent Form (PICF) as an attachment and the contact details of the researchers (DA and SB). Interested participants were asked to contact the researchers to express their interest in participating. Once the study team had been contacted by a potential participant, the interview was organised. If no response was gained from the initial invitation, a follow-up email at two weeks was sent and a phone call (at four weeks) was made to determine interest in participating.

*Focus groups.* Patient experience officers/coordinators from each of the six health services were invited to participate in a focus group following a Monash Partners CCI Advisory Committee meeting. These representatives are known to each other, work in similar roles within the health services and have been meeting regularly via the Monash Partners CCI Advisory Committee. The rationale for conducting a focus group instead of individual interviews was to capture the interaction between the participants as they shared their experience of CCI in their health service.

**Data collection:** The interview guide was designed to identify the opportunities, motivations and barriers to CCI using the COM-B framework (Michie, van Stralen, & West, 2011), understand how CCI is conducted, and obtain information about training programs to elicit contextual factors, experiences, and processes for CCI (Appendix 1). Data related to training will be analysed and reported in a separate paper. Interviews were conducted by DA and SB either face-to-face or via telephone. The focus group with representatives from the health services was conducted by DA and AJ following a Monash Partners CCI Advisory Committee meeting. All interviews and the focus group were audio-recorded and transcribed verbatim by a professional transcription company. Transcripts were available for review on request and this was taken up by one participant.

**Data analysis:** Transcripts were uploaded to NVivo (QSR International 2020) for data management. Analysis was guided by the three COM-B domains and deductive codes for capability (e.g. knowledge, experience and skills related to CCI); opportunity (e.g. resources, funding, partnerships with organisations) and motivation (e.g. attitudes and beliefs about CCI, organisational policies and funding requirements). Thematic analysis was conducted via three rounds of inductive and deductive coding – open, axial and selective outlined in Table 1 (Saldana,

2016; Vaismoradi, Turunen, & Bondas, 2013). DA and SB were the primary coders, all authors were involved in developing the conceptual links and development of themes. Table 2 outlines author positionality.

**Insert Table 1 here: “Table 1: Coding process”**

**Insert Table 2 here: “Table 2: Author positionality”**

**Ethics:** This study was approved by Monash University Human Research Ethics Committee (project ID 19514). Verbal consent was audio-recorded for interviews conducted over the phone. If the interview was conducted face-to-face, written consent was obtained.

## **FINDINGS**

Twenty-eight semi-structured interviews were conducted —16 representatives from 15 of the consumer organisations; eight researchers (five of them researcher-clinicians) mapped to six of the seven Monash Partners clinical themes; and four representatives from three ethics offices (two health service and the University). Interviews ranged from 18-58 minutes in length. One focus group was conducted with six participants from five health services (one member from four health services and two members from one health service). The focus group was 50 minutes in duration.

The COM-B domains and arising sub-themes are described in Table 3. CCI activities (opportunity enablers) described by participants have been summarised in Table 4. Below themes are presented in bold text and supporting quotes in italics.

**Insert Table 3 Here:**

**“Table 3: Mapping of barrier and enabler themes to COM-B domains”**

## Capabilities

**Researchers and health professionals having an understanding of, and experience in, CCI** was identified as a capability enabler for CCI as these researchers had “*skill of being able to engage (Consumer Organisation 6)*” to be “*a negotiator, the power broker (Researcher 3)*”. However, for the most part, participants across all the organisations felt that a lack of researcher experience in CCI results in tokenistic consumer involvement. The practice of CCI was perceived as being “*dependent on the experiences of the researchers (Consumer Organisation 8)*”. Researchers and health professionals reflected that CCI was not something that was in their “*DNA (Focus Group)*” and was not taught in their health degrees or training where the focus was on health risk factors and problems, which was dehumanising to the person or patient.

*“We’re trained as health professionals through this at risk’ lens. How you learn is through population statistics and the risk factors that you might have. That clouds the way we see and hear people. (Researcher 6)*

*“[Health services have] a long way to go. It is not in [the health professionals] DNA yet to think that I will, I can, and [CCI] will add value. (Health Service 5, Focus Group)*

Without experience or training, many participants felt that CCI becomes a “*tick box*” that becomes more “*tokenistic*”. One consumer organisation representative highlighted the need for “*training ... of researchers and even before that there’s the how do we better articulate the benefits so that there is buy-in and it stops being tokenistic.*” (Consumer Organisation 1)

**Training of consumers, researchers and health professionals was identified as an enabler to CCI.** Participants identified training in CCI as important, not just for consumers, but researchers and health professionals as well. The benefits of such training included a shared language and understanding of principles CCI.

*“Training for the people who are involved in the research endeavour is important...there’s an ability to speak a common language ... if a consumer is identifying risks or barriers or raising resistance, then you need to pause and understand that...you need some skills to be able to do that.” (Consumer Organisation 1)*

*“Developing [a] training or repository of resources would be enormously helpful. I think a lot of researchers probably accept that consumer engagement would be really good for their research, but just don’t know how to go about it, especially if you don’t have a lot of consumer participant or patient engagement in your research.” (Researcher 1)*

One researcher talked about the need for reflection and an open mind.

*“I think [researchers] need to have an open mind and they must not tick the box, and they need to have some deep reflection. If you’re doing a training resource, you need to make [researchers] feel uncomfortable and so that they actually can understand.” (Researcher 6)*

One of the health services expressed caution of training consumers and the need to balance training the consumer so they can be involved but not too much that they lose their consumer voice.

*“[Consumers] need training but it’s that double-edged sword— do you start creating professional consumers and then you’re not hearing the actual true consumer voice...” (Health Service 5, Focus Group)*

**Researchers and health professionals need to consider and address the health literacy needs of consumers.** Participants recognised that consumers either needed to have a high level of health literacy and professional skills and abilities or support to assist them in their involvement activities.

*“If you want [a consumer] sitting on a steering committee for a research project, unless you navigate somebody with poor health literacy through that process, you’re only really going to get a certain demographic of consumer there, the more professional consumer.” (Consumer Organisation 8)*

One researcher recognised that “*de-jargonising*” language is also a skill that researchers need.

*“It’s actually about you, [the researcher], developing a whole other set of skills around de-jargonising your language, even deconstructing what you are doing or thinking. Rather than problem-solving, it’s first about negotiation and communicating first.” (Researcher 3)*

Providing training to consumers was identified as a strategy to address health literacy challenges and to increase diversity in consumer representation.

*“We’re in this funny time where the health literacy demands on the consumer have never been higher and then [researchers] have this evidence process, which locks them out entirely. So even though we think we are getting closer to participation and representation, in a systematic sense we are getting further away. It’s really about skills and training, I think, of the consumer, in about understanding what that means.” (Researcher 3)*

**Acknowledgement that the consumer can only speak to their own experience** was a capability barrier. Participants described a wariness of how “*representative*” consumers were of the broader consumer population by both researchers and consumer organisations.

*“We identify a consumer who may not have much of a voice, or they’ll have a voice on a very narrow focus that could be a distraction to the research priority. It could potentially be misrepresentative of a group. Because someone has had a particular experience doesn’t necessarily mean that that represents everyone.”*  
(Consumer Organisation 1)

*“It’s such a challenging field. I’ve sat on a lot of committees and processes where you have your consumer perspective and the traps are you either get a person who has only their experience and they keep pushing that. You have the person that pretends they’re representative and they’re white, middle-class women from the suburbs. They’re not representative of some other woman in the western suburbs. If you want representation, you have to look at the demographic of patients that you are reflecting.”* (Researcher 3)

Strategies to address this challenge of representation included having “*rotational*” consumers, “*training*”, having a “*job description so they understand their role*” and also ensuring the consumer is connected to the voice of other consumers.

*“We had somebody from the [Consumer Organisation 15] come in and talk about, as a consumer, being a representative for other people and how you can broaden your experience through more than just your own [disease] experience. How you use your networks and their stories to inform the opinions that they give when reviewing our concepts.”* (Consumer Organisation 14)

One of the researchers countered the need for consumers to be representative of all consumers, rather their role was to provide the lens of the consumer’s lived experience.

*“I think, that there’s not a great expectation that they’re representing anything more than their lived experience.”* (Researcher 1)

## **Opportunity**

### **Involving consumers across the research and healthcare improvement project continuum.**

To create space and opportunities for CCI, several strategies were identified by the participants. These strategies spanned across the research and healthcare project continuum from developing the proposal to dissemination as adapted from the NHMRC self-assessment of consumer and community involvement in research (National Health and Medical Research Council, 2020) (see Table 4).

*“[Researchers] get consumer input at the start and it magically peters off once they’ve got money and they’re doing [the project]...For us, consumers must be embedded in every part of that research cycle.” (Consumer Organisation 14)*

**Insert Table 4 here: “Table 4: CCI strategies reported by consumer organisations, researchers, healthcare professionals and ethics committees”**

Another opportunity enabler for CCI is **consumer-centric research designs**. Consumer-centric research designs include participatory action research, co-design methodologies and qualitative research approaches.

*“Co-design is an obvious example ... if we do robust consumer engagement, then we can say, “What’s the problem that you’re experiencing? And what would be the best way for us to address that problem?” It stops you from doing kind of wasted processes. And also it stops you, potentially, from following a path, which is an area of interest that may not end up being implemented.” (Consumer Organisation 1)*

*“One of my colleagues just started doing her PhD and she is using a participatory research methodology and I’m on her advisory group, ...So this participatory approach is about understanding who needs to be in the room and are they the best person...In my heart, I feel like that’s going to be a useful place to start the decision-making power. (Consumer Organisation 12)*

While opportunity enablers were many and identified across the participant groups of consumer organisations, researchers and ethics committees, there were many opportunity barriers. The main barriers were challenges in finding consumers for a project, lack of diversity in consumers and a lack of time and resources to engage with consumers.

**Challenges in finding consumers for a project** was identified by the researchers as an opportunity barrier.

*“Well I understood that it was important but there had always been a bit of a difficulty in even identifying anyone” (Researcher 1)*

Researchers and consumer organisation representatives recognised the challenges of finding consumers to involve in laboratory-based research.

*“They don’t see people, they’re in a lab, [and] they’re working with either cellular models or animal models. It is hard when you’re thinking about a very physiological outcome to think about how you’re going to include consumers. If it’s not directly medical, clinical or at the coalface of engagement in terms of intervention specifically, then that would be hard.” (Consumer Organisation 4)*

However, the participants from the consumer organisations emphasised that they were well-positioned to find consumers for research projects (see Table 2).

When consumers were identified, there were concerns about a **lack of diversity in consumers**.

*“I’ve been trying to get different voices because we hear the same voices all the time. The term that I’ve bandied about...is professional consumers. They might have been academics or lawyers or engineers and you don’t get the average Joe, on the street...you don’t get to hear the voice of the average Joe.” (Health Service 3, Focus Group)*

To address challenges around diversity, one person from a health service established several consumer advisory groups that were not disease-specific, rather they were population specific.

*“We have 13 Consumer Advisory Groups (CAGs) and we’ve got an LGBTI [group] and thanks to them that we’ve got the Rainbow Tick accreditation. We’ve got an elderly people’s CAG, disability, mental health and they are the people who comprise committee members in the organisation.” (Health Service 1, Focus Group)*

Researchers and health professionals described a **lack of time and resources to engage with consumers** as barriers to CCI. Incorporating costs such as sitting fees, food and transport into funding applications or existing project budgets was not always feasible.

*“We run all our projects on the smell of an oily rag and the cost of training people and reimbursing them for their time, and as it is we provide gifts and things for people to come to conferences and speak with us, but it’s costly to provide the time and the training... time and money are the main barriers. The value that [consumers] add is immeasurable. But, it does come at a cost.” (Researcher 4)*

*“[CCI] is resource intensive but needs to have an out-front if you want a good outcome at the end for patients.” (Health Service 3, Focus Group)*

A consequence of not having “any dollars that are put into” CCI is that the engagement is “*tokenistic (Consumer Organisation 8)*”.

**Research ethics processes perceived as prohibitive.** One of the principles of CCI is to involve consumers and the community in the design and development of the research. Participants expressed confusion as to whether CCI at this stage of the research cycle required ethics approval and this was viewed as an opportunity barrier to CCI. However, the requirement for ethics approval seems to have been driven by consumer organisations rather than the ethics committees.

*“Always when we have a researcher come to us we say, ‘Do you have ethics...?’ before we even talk to them” (Consumer Organisation 9)*

Participants from ethics committees were supportive of involving consumers early in the design and development of the research protocol. The ethics committee participants also reflected that the majority of the applications they “receive have very little consumer input” and that for “collaborative group and investigator-led studies, there’s no good reason for not having [consumer] input into the protocol.” (Ethics Committee 1). For Ethics Committee 1, the stance was that consulting consumers in the research development and design does not require ethics approval (See Table 4).

There was some caution that while ethics approval may not be required that researchers need to be ethical in their processes of engagement and that any unequal relationships are addressed.

*“There [is] a potential conflict and what happens if the person’s known to them, or a colleague. I mean that’s one of the questions that’s asked in an ethics application. If you plan on enrolling people with whom you have an unequal relationship or a work colleague, the implications of you having access to that colleague’s medical information.” (Ethics Committee 3)*

## **Motivation**

A driving motivation for CCI for researchers and health services was the **requirement for research funding and health service accreditation**. National and philanthropic funding bodies increasingly required researchers to demonstrate consumer involvement in the development and conduct of the research.

*I saw a few funding schemes – I applied for six grants – and a few of them noted that consumer engagement was desirable. (Researcher 1)*

The Australian Commission on Safety and Quality in Health Care has a standard on partnering with consumers in the planning, design, delivery, measurement, and evaluation of health systems and services. Participants often referred to this “standard 2” as a motivator for consumer involvement. Standard 2 for CCI is typically translated into clinical governance, compliance and accreditation requirements.

*“I think one of the things with the new expectations of truly partnering with consumers, the compliance piece, I think there’s a sense that there has to be specific meetings and processes.” (Health Service 5, Focus Group)*

A key motivation barrier identified by participants was the **lack of evidence on the impacts of CCI on research outcomes and healthcare improvement**. Researchers and health professionals are taught in an evidence-based paradigm. Therefore, building the evidence-base for the benefits and impacts of CCI was considered important by participants. The challenge of creating the evidence-base was recognised along with the fact that there is enough evidence *“that suggests that consumer engagement in research is a good thing to do”* and that *“there are lots of tools... professional networks...checklists”* (Consumer Organisation 8) to help guide this work.

*“So we’re probably at a stage where there’s still a lot of work that needs to be done around the evidence-base on how you do this. If you read some of our papers we’re starting to pull together the evidence base around why this should be done and what consumers are seeking from us. But the how doesn’t have a great evidence-based yet. It’s very hard to test these sorts of things.”* (Consumer Organisation 8)

## **Cross-cutting themes**

A barrier that spans across capability, opportunity and motivation is the **power imbalance between consumers, researchers and health professionals**. Capability is required to negotiate between consumers and professionals (as described above); the opportunity to create an environment of safety and genuine engagement and the motivation to recognise and tackle power imbalances is important in CCI.

*“The thing that people miss in consumer consultation is the power imbalance. You can have the most articulate and maverick consumers in there but they’re always going to be intimidated by health professionals and health professionals will always try and intimidate them, just by language, just by the privilege and the position the health professionals have. That’s naturally an unfair or uneven power dynamic.”* (Researcher 3)

*“How do you adapt, develop, reorientate meetings and process such that you have involvement? ...if [the consumer] wants to talk about [their] personal story and if [they] get really angry and it’s necessary for [them] to get red in the face and yell a bit... I think the challenge is finding ways to create models, processes, sequences, atmospheres that kind of, the milieu that enables those views to be expressed is a challenge.”* (Researcher 8)

*“Sometimes, there’s an element of fear for staff to be so candid. We’ve got a group of consumers that are not afraid to speak. They’re not afraid to say, exactly what’s on their mind. It’s quite refreshing, it keeps it real.”* (Health Service 4, Focus Group)

Another cross-cutting theme across the domains of motivation and capability was the concept of representativeness of consumers; **recognition of the lived experience and expertise of the consumer** was a motivation enabler. Participants described being experts in research methods and healthcare, however not being experts in the experience of being a patient or living with a condition. A few participants recounted the maxim “*nothing about us, without us*” to highlight the importance of involving consumers in research or healthcare improvement efforts that impact their treatment and care.

*“It’s nice that we are moving to a space where we’re starting to involve human beings living with the condition in the research.” (Consumer Organisation 3)*

*“The layperson goes: ‘I am not an expert in anything apart from...’, I’m like: ‘You don’t have to be the expert in everything. That’s the magic, it’s the jigsaw that comes together’. It’s a common theme that comes up.” (Ethics Committee 1)*

Increasing the relevance and translation of research by aligning projects to **consumer priorities** was a motivation enabler.

*“There is a potential for it to be done badly that makes everyone feel like they’ve wasted their time. The researchers feel like they’ve wasted their time because they don’t see the value the consumers are bringing, the consumers feel like they’ve wasted their time because they’ve just made this massive effort to get out of bed and go to this meeting and this guy just talked at them for 40 minutes about nothing that means anything to them, and then everyone feels a bit disheartened.” (Consumer Organisation 11)*

## **DISCUSSION**

CCI in healthcare improvement and research is a key priority and requires changes at the individual level for health professionals and researchers, at the organisational level and in systems and policies. We aimed to gain insight into barriers and enablers of CCI to inform strategies to build the capacity for CCI at the individual, organisation and system-level within the Australian Health Research Alliance. This study has identified a range of barriers and enablers to CCI from the perspective of researchers, health professionals and representatives from ethics officers, consumer organisations, and health services.

Participants identified training as a capability enabler to build the capacity of researchers and health professionals in CCI. Training for and about CCI has typically focused on consumers (Horobin et al., 2017) and less on equipping researchers and health professionals to implement CCI (Braaf et

al, under review). In particular, developing an understanding of CCI benefits, the technical skills in consumer-centric research designs, and implementing CCI across the research/project cycles were identified enablers. Additionally, participants identified the communication and interpersonal skills required for effective and meaningful CCI including addressing health literacy levels, creating an environment and processes to address power imbalances and recognising the lived experience and expertise of the consumer. In this case, individuals, organisations, and at the national level Research Translation Centres and AHRA, have prioritised training and endorsing the importance of this approach based on these results. This has also been the approach taken in the UK (INVOLVE, 2012; Staniszewska et al., 2018; Stephens & Staniszewska, 2017) and Canada (Manafó, Petermann, Mason-Lai, & Vandall-Walker, 2018; Manafó, Petermann, Vandall-Walker, et al., 2018).

Opportunity barriers — the physical and social resources impeding CCI — included challenges in finding consumers, a perceived lack of diversity in consumers, limited time and resources to do CCI and the research ethics process. Responses from the different participant groups highlighted the siloed and often individual nature of CCI efforts, with solutions posed by participants in one group to the challenges identified by another group. For example, researchers spoke about the challenge of finding consumers, yet consumer organisations and health service representatives stated they were happy to facilitate consumer and researcher connections. This again supports the need for an integrated approach to CCI targeting not only the individual level, but also the organisational and systems level. In this context, the Research Translation Centres and AHRA are seeking to use evidence to inform partner organisations and national system level approaches to addressing barriers and embedding CCI in research and health care improvement.

A key motivation enabler was having CCI as a requirement for funding for research or accreditation standards for health services – an example of a system-level driver for CCI. The Patient-Centered Outcomes Research Institute has adopted this approach and encourage patients to be co-investigators in studies and for patients and healthcare stakeholders to be actively involved throughout the research process (Patient-Centered Outcomes Research Institute, 2019; PCORI, 2017). In Australia, the NHMRC states that “*the active involvement of consumers and community members in health and medical research benefits the quality and direction of research*” (NHMRC, 2016). Funding applications often require researchers to state how they are involving consumers and the community across the research cycle in the proposed project. However, there is limited information about if and how these funding applications are scored for CCI. For health services, the National Safety and Quality Health Services standards — national statements of health service organisations levels of care for consumers — has a Partnering with Consumers Standard. This

standard encourages health services to have “*consumers as partners in the planning, design, delivery, measurement and evaluation of systems and services and patients as partners in their own care*” (Australian Commission on Safety and Quality in Health Care, 2019).

The perceived lack of evidence of the impact of CCI on research outcomes and healthcare improvement was a motivation barrier. While the majority of literature on CCI focuses on the how and why (Crocker, Boylan, Bostock, & Locock, 2017; Lalani et al., 2019; Manafo, Petermann, Vandall-Walker, et al., 2018), many of the literature reviews do identify the impact of involvement on research including process impacts on the research agenda, design and delivery, recruitment, data collection and analysis, ethics (Greenhalgh et al., 2019; Staley, 2015). CCI impacts are also described for the people involved in the research including researchers, participants and the community (Crocker et al., 2017). Implementation and change impacts are also described (Staley, 2015). Additionally, there are many checklists, reporting guidelines and frameworks to guide CCI which can be used to measure impact (Chudyk et al., 2018; Greenhalgh et al., 2019; Pandya-Wood, Barron, & Elliott, 2017; Staniszevska et al., 2017). Much of the evidence on impact is perceived as weak, potentially as the designs are qualitative or mixed methods and are descriptive. However considering the context of the research, the nature of knowledge gained through CCI and the complexity of CCI – quantitative and RCT methods may not be feasible (Staley, 2015). Hence this highlights another opportunity for AHRA and Monash Partners to provide support on the appropriate research designs for evaluating CCI impact and how to interpret the existing literature on impact.

In summary, operationalising the COM-B framework in the data collection guides and analysis process has produced actionable approaches to enhance CCI within Monash Partners and AHRA. Capability for CCI will be addressed through training programs, offered at pace and scale, the opportunity for CCI will be facilitated at the system-level through partnership and collaboration across sectors, and motivation will be enhanced via funding requirements and evidence of the impacts of CCI. The NHMRC accredited Australian Research Translation Centres are nationally coordinated through AHRA (Teede & Wesselingh, 2018), committed to CCI through a national system level initiative and are ideally placed to deliver recommendations from this research at systems, organisational and individual levels.

## **Strengths and limitations**

To our knowledge, this the first in-depth exploration of CCI barriers and enablers from key stakeholders in research, healthcare improvement and consumer organisations in Australia. The purposive sampling strategy and use of qualitative methods analysed using the COM-B framework (Michie et al., 2011) led to a deep understanding of how to build capacity and enhance CCI across Monash Partners and the AHRA. The inclusion of consumer organisations that represent the voice of consumers, and are often approached by researchers and health professionals for access to consumers, was valuable. These groups highlighted CCI processes and challenges that may not have been obvious to a researcher or health professionals and provided insights on how to partner with consumer organisations more meaningfully. Another strength of this study is the multiple lenses of the research team (see Table 2).

A limitation of this study is the lack of involvement of basic scientists and laboratory researchers who may have different attitudes to, and experiences of CCI. Data collection was conducted by two CCI fellows (DA and SB) and hence participants may have been cautious about sharing negative attitudes or experiences of CCI.

## **CONCLUSION**

This study has demonstrated that for researchers and health professionals, CCI requires behaviour change. To ensure meaningful CCI, understanding the perceived barriers and enablers is vital to inform evidence-based strategies at the system, organisation and individual levels. Monash Partners and AHRA are well-positioned to address these barriers at a local and national level in Australia.

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