

ARTICLE



Consumer engagement in doctoral research – what difference does it make?

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STUDY DESIGN: Qualitative reflective descriptive study.

OBJECTIVE: To evaluate a consumer engagement experience in the context of doctoral research.

SETTING: Full time doctoral research at an Australian university.

METHOD: A reflective evaluation of consumer engagement was completed, presented using the Guidance for Reporting Involvement of Patients and the Public, and frameworks of the research cycle, levels of consumer participation and integrated knowledge translation guiding principles providing theoretical background. Seven people with SCI ($n = 6$ men, $n = 1$ woman) replied to an expression of interest to join a Consumer Advisory Group for a doctoral researcher. Activities included: four 90-minute meetings, formal and ad-hoc email exchanges, and one-to-one conversations as required. Data sources included meeting transcripts, email correspondence, researcher's notes, and a short consumer survey.

RESULTS: Consumer engagement occurred at each stage of the research cycle and met all guiding principles. Consumers participated at consultation and involving levels, however, collaboration evolved. Enablers included a common interest for the research topic, rapport with the researcher, using a virtual platform to disseminate research findings, supervisory support, and availability of funding. Challenges included complexity in harnessing different perspectives, using a virtual platform for group meetings, time, and consumers' negative experiences of media.

CONCLUSION: Consumer engagement informed doctoral research by promoting nuanced perspectives on the unique experiences of living with SCI, providing unanticipated richness to data analysis. Building trust, and being responsive, led to in-depth consumer participation.

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INTRODUCTION

Involving people that research affects can introduce knowledge and perspectives not necessarily held by researchers, enhancing quality and relevance of research [1]. Including people with lived experience, such as those with spinal cord injury (SCI), in research decision-making is considered best practice in health and disability studies and improves public confidence and understanding of research [2, 3]. The research relationship requires activity is done 'with' or 'by' persons with lived experience of a health issue rather than something that is done 'to', 'about' or 'for' them [4]. Consumer engagement in research is increasingly required by ethics committees and funders [5], and documenting how consumer engagement impacts research can facilitate better understanding of methods and processes, fostering good research practice [1, 6].

Consumer engagement can happen at each stage of the research cycle, starting with developing a research question through to dissemination of research findings [7]. The level of consumer participation throughout the research cycle ranges from informing through to consumer led activity (Fig. 1) [8]. It is recommended consumer engagement activities are conducted according to the Integrated Knowledge Translation

(IKT) Guiding Principles [9]. IKT is a collaborative model that can be used to promote engagement between researchers and research users [10] leading to 'relevant, useful and/or useable' [9] research. The IKT Guiding Principles were co-developed to support SCI researchers and research users (including consumers) and comprise eight guiding principles: build relationships; share decision-making; facilitate communication; diversity in expertise and knowledge; allow tailored research to match project aims and context; meaningful partnerships; address ethical considerations; and, respect financial and practical constraints [9] (Table 1). Adopting IKT Guiding Principles during the research process and respecting the experiential knowledge people with lived experience bring to research fosters 'meaningful SCI research partnerships' [9] and quality research.

People with SCI want to engage in research, with increasing advocacy for people with SCI to advise and collaborate on research activity [11–15]. Engaging people with SCI throughout the research cycle can facilitate SCI research purpose and efficiency, and promote translation of new knowledge, potentially enabling research outcomes to reach people with SCI more readily [9, 11–13]. People with SCI are now consulted to a

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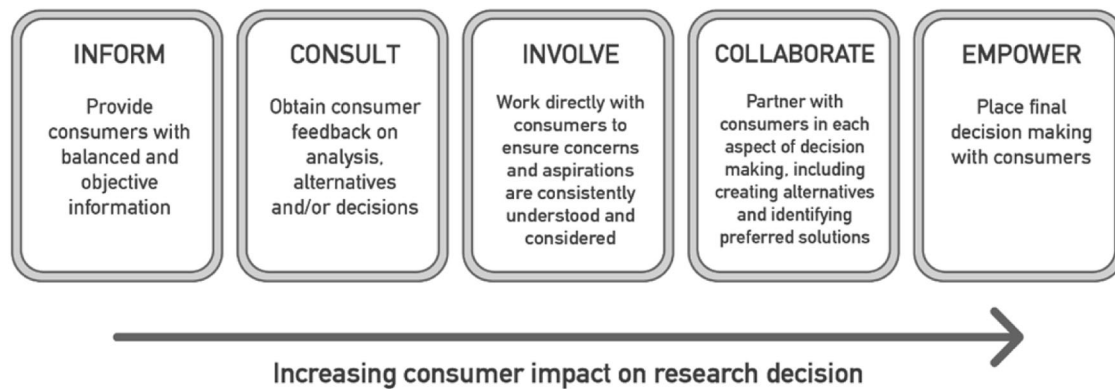


Fig. 1 Levels and goals of consumer engagement (adapted from IAP2 Spectrum of Public Participation).

greater extent on SCI research priorities, however, they are still less likely to be engaged in the research process itself [14]. Potential avenues for greater engagement include promoting positive attitudes towards the inclusion of people with experiential knowledge, building environments that foster relationships between researchers and people with SCI, and promoting the work of peers and champions of consumer engagement in SCI research as future role models [13].

Research context is important for consumer engagement planning and evaluation because it helps establish how consumer engagement can be achieved [1, 6]. The context of doctoral research creates unique challenges for consumer engagement, including a responsibility to complete an independent body of work, limited agency in the research topic, time, funds, and/or no prior consumer engagement experience [16–19]. Despite these challenges, consumer engagement in doctoral research can add value when planned early, with clear aims, and by being flexible to circumstances [16–20]. Consumer engagement in doctoral research can be facilitated by early access to experienced consumers, funding for remuneration, and consumer engagement training [16–20]. It can occur at the informing, consultative and involving levels, at different stages of the research cycle [17–20]. Methods of engagement include formal and informal, one-to-one and group activity via online and face to face meetings [16–20]. Postgraduate study is an entry point for people embarking on research, yet no identified studies have described the consumer engagement process in the context to doctoral SCI research.

The overall aim of this study was to evaluate the consumer engagement experience within the context of doctoral research. Specific aims were: to describe the consumer engagement activities, to assess how the consumer engagement activities met the IKT Guiding Principles, to describe the outcomes of the consumer engagement activities, and to identify enablers and challenges to consumer engagement. This paper is presented according to the Guidance for Reporting Involvement of Patients and the Public Short Form (GRIPP2-SF) [21] (see Supplementary Appendix 1). The findings of this evaluation, a consumer engagement experience within the context of doctoral research in the field of SCI, may also be applicable to other research projects and contexts.

METHOD

Research context

This full-time doctoral research aimed to investigate media portrayal of SCI. The doctoral candidate (the primary researcher) worked as a physiotherapist in SCI rehabilitation for 17 years prior to commencing the doctoral research and continued working part-time during the research. The primary researcher had no prior experience of consumer engagement in research, other than informal engagement with people with SCI in the clinical setting

and formal engagement with the Burwood Academy Consultation Network, New Zealand [22] prior to commencing the doctoral research to help establish a relevant research topic. The primary researcher had two supervisors, one of whom had prior experience in consumer engagement. Two and a half years of the doctoral research was carried out during the Covid-19 pandemic and all communication was performed via a virtual platform (Zoom). The aim of consumer engagement was to embed experiential knowledge of SCI, not possessed by the primary researcher, to the overall doctoral thesis, in particular, two qualitative research studies (hereafter referred to as study one and study two respectively). Ethics approval was obtained to use the data produced from the Consumer Advisory Group activities in a published paper. This doctoral research centred SCI as the experiential knowledge of relevance [6], hence consumers were people with SCI [2]. Consumers and the primary researcher engaged in a bi-directional relationship, herein known as engagement [23].

Consumer Advisory Group

A Consumer Advisory Group was established comprising people with SCI (Table 2). Members were recruited through an advertisement calling for expressions of interest distributed by a local SCI peer agency. Acknowledging the diverse range of experiences of people living with SCI, all of which could influence perspectives and opinions, the expression of interest collected information about the number of years living with SCI, gender, and type and level of SCI. Potential members were also asked if they had prior consumer engagement experience, why they wanted to be involved, and what they could bring to the group. Four people applied and all joined the group. Eighteen months into the doctoral research another three people expressed interest after participating in study one and joined the group. Terms of reference for the Consumer Advisory Group were agreed upon at the first meeting. One group member resigned from the group after 24 months. All group members were full-time wheelchair users and acquired their SCI from traumatic aetiology.

Consumer engagement activities

Consumer Advisory Group activities centred on four meetings, the timing of which was determined as the doctoral research progressed and corresponded to key points when formal advice was indicated. Each meeting was scheduled for 90 minutes, at a time convenient to members. If a member was unable to attend, the primary researcher offered a one-on-one meeting instead. The primary researcher emailed an agenda to the group one week prior to each meeting, highlighting key discussion points and any associated reading material. Meetings were audio recorded and transcribed verbatim, and the primary researcher also made handwritten notes. A summary of the meeting was emailed to members about one week later. The first meeting occurred six months after the doctoral research commenced and the final meeting was held six months prior to thesis submission. Between meetings, the group was emailed any follow-up tasks, updates on research progress, and information about outcomes such as publications and conference presentations, highlighting their contribution [9, 24, 25].

Consumer engagement evaluation

The consumer engagement evaluation adopted a reflective descriptive approach and was performed by the primary researcher. In a reflective

Table 1. Consumer engagement guiding principles: how this research achieved meaningful outcomes*.

Guiding principles	How were these guiding principles met by the researcher?	CAG ^a members' engagement survey responses
Build and preserve relationships based on trust, respect, dignity, and transparency	<ul style="list-style-type: none"> • Researcher** maintained communication with CAG throughout doctoral research, including checking in on how members were going during the Covid-19 Pandemic. • Researcher communicated early the expectations and aims of the CAG. 	'I was given the opportunity and platform to add my voice. I felt my voice (and dis experience) was valued and used to assist with shaping the research program. It was a very different feeling to being a participant in research' (M ^b 4) 'The content and findings were extremely motivating. The dynamics and conversation within the group was also a driving factor as there was a robust discussion which personally was extremely motivating' (M3).
Share decision-making	<ul style="list-style-type: none"> • CAG assisted in the interpretation of findings for study 1. • CAG consulted on interview schedules for study 1 and 2. • CAG consulted on potential participants for study 2. • CAG consulted on all public facing material such as infographics summarising each study; recruitment advertisements; and conference presentation material. • CAG members collaborated with a conference presentation and script for the VYT^d competition. 	'Engagement with the other participants as well as [the researcher]. It was great to hear others and contribute' (M5). 'Believing in the research direction, and being made to feel like my contribution was valued and incorporated' (M4).
Facilitate open, honest, and responsive communication	<ul style="list-style-type: none"> • Formal meetings conducted at key points during the doctoral research. • Researcher provided updates in-between meetings, including study outcomes and feedback from presentations and supervision meetings. • Researcher followed up with members one-to-one if information was taken out of context with ad-hoc emails between members. 	'People were genuine and passionate, and it is a subject matter that is enormously influential' (M1).
Recognise, value, and share diversity in expertise and knowledge	<ul style="list-style-type: none"> • CAG members given equal opportunity to provide input during meetings, and to share reflections and thoughts. • Researcher equally respected and valued each members' input. • Researcher aimed to be responsive to members' skills, capacity and expectations as the doctoral research evolved and opportunities rose. 	'There was a tangible feeling of sharing power and contributing to the direction of [the researcher's] work.' (M4) 'I feel I've been able to express my thoughts along the way, and for them to be taken on board. This has been a particularly satisfying aspect of my participation, and I felt like a significant contributor to the study' (M6).
Be flexible and receptive to allow tailored research to match project aims and context	<ul style="list-style-type: none"> • Studies comprising the doctoral research were directed by the doctoral research topic and responsive to gaps in knowledge. • Studies were presented to the CAG, which facilitated shared understanding of research aims and goals. 	'Gave me the chance to think in a new way about the issues, and to feel my thoughts had weight. I also appreciated the qualitative approach, where our contributions evolved over time' (M6).
Participate through meaningful partnerships	<ul style="list-style-type: none"> • CAG members participated at informing, consultative, involving and collaborative levels at appropriate times and for appropriate activities pre and during the doctoral research. • Researcher aimed to be responsive to member's skills, capacity and expectations as the doctoral research evolved and opportunities rose. • CAG members were invited to participate in dissemination activities. 	'To contribute to the discussion, and the collective effort to better portray/understand SCI in media' (M1) 'It is a very important subject, and I felt the need to get language in the community correct. It's important to be heard and seen by the media and others as a person and not a number. Correct terms need to be used by them' (M5).
Address ethical considerations, such as research that is relevant, useful and/or useable	<ul style="list-style-type: none"> • Researcher engaged with people with SCI pre doctoral research to consult on the doctoral research topic. • Researcher engaged with people with SCI throughout the doctoral research to ensure studies comprising the doctoral research were relevant and were a valuable contribution to a better understanding of the lived experience of SCI. 	'To help studies that will benefit people like myself' (M2) 'I value the opportunity to be part of a project which may seek to one-day change how people with spinal cord injuries are portrayed which in turn impact the quality of life of people with spinal injuries' (M3).
Respect financial and practical constraints	<ul style="list-style-type: none"> • CAG members were offered remuneration as an appreciation for their time and to cover out-of-pocket expenses. • Researcher arranged meetings for times that suited majority of members. If someone could not attend the researcher arranged a one-to-one meeting. 	CAG members did not describe remuneration as an enabler, however, during the doctoral research members expressed gratitude for remuneration offered and was accepted.

^aConsumer Advisory Group, ^bCAG member (members completed survey anonymously), ^cSpinal Cord Injury, ^dVisualise Your Thesis.

*Data for this table came from meeting transcripts, email correspondence, primary researcher's handwritten notes diarised throughout the doctoral candidature, and responses to the Consumer Advisory Group engagement survey.

**Primary researcher.

analysis, the researcher adopts 'self-understanding about the biases, values, and experiences that [they] bring to a qualitative research study' [26]. Qualitative data sources included meeting transcripts, email correspondence, the primary researcher's handwritten notes on

consumer engagement activities diarised throughout the doctoral candidature, and a Consumer Advisory Group engagement survey. The survey comprised four open questions about what was valued, enablers and challenges to engagement, and feedback on the consumer

engagement experience. It was completed by six group members anonymously after the final Consumer Advisory Group meeting. Following an iterative process, data from these sources were deductively coded according to: the steps of the research cycle [7], the levels of consumer participation [8], the eight IKT Guiding Principles [9], outcomes and effects of consumer engagement [21], and enablers and challenges to consumer engagement [21]. Descriptive analysis was performed on data coded as enablers and challenges and presented as themes. Following a constant comparison process [27] the remaining coded data were mapped according to a theoretical framework acknowledging the connection between the research cycle [7], levels of consumer participation [8] and IKT Guiding Principles [9] (Fig. 2) and presented descriptively in table form (Table 2, Table 3). This iterative process was cross-checked with Consumer Advisory Group members and research supervisors. Pseudonyms have been given to consumers throughout the reporting to maintain confidentiality.

Table 2. Consumer Advisory Group members.

Group member ^a	Age (years)	Gender	SCI ^b level	Years living with SCI	Previous consumer engagement experience
David	66	Man	T10	10	No
Nigel	50	Man	C6	30	Yes
Peter	37	Man	C5	21	Yes
Tom	32	Man	C4	11	No
Andrew	36	Man	C7	17	Yes
Heather	75	Woman	C7	36	Yes
Chris	47	Man	T12	45	Yes

^aMember pseudonyms.

^bSpinal Cord Injury.

RESULTS

Consumer engagement occurred at each stage of the research cycle and members participated at consultation, involving, and collaborative levels (Table 3). Research outcomes and effects were identified (Table 3). Analysis showed all IKT Guiding Principles research were met by the primary researcher (Table 1) [9]. To determine convergence with Consumer Advisory Group members, a sample of responses from the evaluation survey (Table 4) were mapped to each principle (Table 1).

Enablers of consumer engagement

Shared interest in the research topic. Members said that bringing lived experience to the research was important for them; they wished to introduce ‘the perspective from someone who has lived life in and out of a wheelchair’ (Tom), and ‘a lived experience of growing up while having an SCI’ (Craig). Members said they wanted to be involved because they had an interest in the topic and a desire to shape a better understanding of SCI and living with disability - ‘participating in the advisory group can help assist others with a better understanding of the impact [SCI] has on a person’ (David). Members described how they were motivated by the robust discussion of the research topic, and the opportunity to have their voices heard. For the primary researcher, group interaction supplemented formal academic supervision by providing a forum to explore new ideas directly related to the doctoral research as the research evolved.

Primary researcher's rapport and understanding of the SCI community. Embarking on doctoral research as an experienced clinician meant the primary researcher was able to leverage established relationships and networks within the SCI community. This enabled the primary researcher to confidently propose the

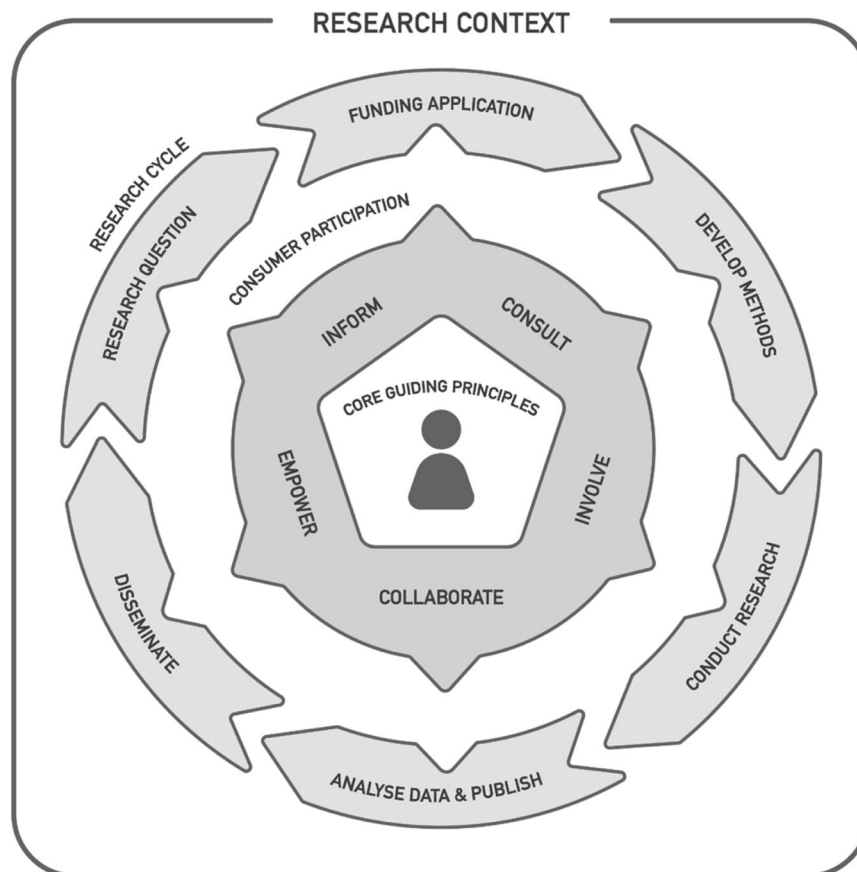


Fig. 2 Theoretical framework for relevant quality research.

Table 3. Consumer engagement outcomes and effects at each stage of the research cycle.

Research cycle stage	Level of consumer participation	Outcomes*	When	Effects**
Research question	Consultative	<ul style="list-style-type: none"> As a clinician in SCI^a, the researcher*** involved people with SCI to consult on the research question. Research question reviewed by a SCI consumer consultation committee, BAC (Burwood Academy Consultation) Network, New Zealand. 	Pre doctoral research	<ul style="list-style-type: none"> Consumer engagement helped identify and develop a relevant and useful research topic. BAC commended the research topic.
Doctoral funding application	Consultative	<ul style="list-style-type: none"> Anecdotal evidence and BAC feedback included in doctoral scholarship application. 	Pre doctoral research	<ul style="list-style-type: none"> Researcher successfully received doctoral scholarship.
Develop methods	Consultative Involving	<ul style="list-style-type: none"> CAG^b consulted and involved in creation of interview schedule for study one - a qualitative study interviewing people with SCI to understand perceptions of media portrayal of SCI and the impact on lived experience. CAG consulted and involved in creation of interview schedule for study two - a qualitative study interviewing journalists and sources to understand how media stories on SCI are created. Some members participated in practice interview sessions with the researcher for both studies. 	Meeting 1 Meeting 3 In-between meetings	<ul style="list-style-type: none"> As representatives of the target group of study one, CAG introduced lived experience to study one interview schedule. Unlike study one, group members were not representatives of the target group for study two, however, were able to recount personal experiences as subjects of media stories to inform study two interview schedule.
Conduct research	Consultative Involving	<ul style="list-style-type: none"> CAG consulted on and disseminated advertising material to their peers for study one. CAG consulted on timeliness of recruitment for study one given Covid-19 concerns CAG involved with identifying potential participants for study two. 	Meeting 3 In-between meetings	<ul style="list-style-type: none"> Wide distribution of recruitment material for study one. The Covid-19 pandemic and subsequent national lock down during study one recruitment had the potential to stall the research. The researcher was mindful of Covid-19 concerns within the SCI community and felt it may not be appropriate to drive recruitment. Consultation with CAG was positive and listening to their perspectives gave the researcher confidence to continue recruitment, minimising delays. Study one recruited 24 participants to help reach data saturation. To facilitate better understanding of systemic processes and practices in the creation of media content on SCI, CAG's advice was to only invite individuals with SCI who in their professional capacity were an identified source or journalist to participate in study two. Study two recruited 20 sources and journalists to help reach data saturation.
Analysing data and publish	Consultative	<ul style="list-style-type: none"> Researcher presented preliminary findings of study one. CAG involved in the interpretation of findings and refined themes. 	Meeting 2	<ul style="list-style-type: none"> CAG informed thematic analysis of study one included in published paper.
Disseminate	Consultative Involving Collaboration	<ul style="list-style-type: none"> CAG consulted on public facing material facilitating dissemination of research findings. CAG consulted on conference presentations. CAG members invited to collaborate on international conference presentation. CAG members invited to collaborate on script for university VYT^c competition. Researcher invited by CAG member to present doctoral research to peer group. CAG member invited the researcher to write article on doctoral research in peer agency newsletter. CAG member invited the researcher to collaborate on a presentation on consumer involvement at a philanthropic event. CAG member invited the researcher to collaborate on a webinar on consumer involvement. 	Meeting 3 In-between meetings	<ul style="list-style-type: none"> CAG comments included in public facing material and conference presentations. Successful conference presentation, co-created and delivered with two CAG members. Script written for VYT competition in collaboration with three CAG members, however video not made due to pandemic restrictions. Presentation of research to wider SCI peer group. Article in a SCI peer agency newsletter. Consumer involvement presentation successfully presented with CAG member at a philanthropic event. Consumer involvement webinar presented with CAG member.

^aSpinal Cord Injury.^bConsumer Advisory Group.^cVisualise Your Thesis.

*Outcome of consumer participation at the research cycle stage.

**Effect of consumer engagement to subsequent research activities.

***Primary researcher.

Table 4. Consumer Advisory Group evaluation survey.

Survey question	Responses
What did you most value about being a member of the Consumer Advisory Group?	<ul style="list-style-type: none"> • 'To contribute to the discussion, and the collective effort to better portray/understand SCI in media' (M^a1). • 'To help studies that will benefit people like myself' (M2). • 'I value the opportunity to be part of a project which may seek to one-day change how people with spinal cord injuries are portrayed which in turn impact the quality of life of people with spinal injuries' (M3). • 'I was given the opportunity & platform to add my voice. I felt my voice (and dis experience) was valued and used to assist with shaping the research program. It was a very different feeling to being a participant in research. There was a tangible feeling of sharing power and contributing to the direction of [the researcher's] work' (M4). • 'Engagement with the other participants as well as [the research]. It was great to hear others and contribute' (M5). • 'Gave me the chance to think in a new way about the issues, and to feel my thoughts had weight. I also appreciated the qualitative approach, where our contributions evolved over time' (M6).
Please tell us any challenges you may have had being a member of the Consumer Advisory Group.	<ul style="list-style-type: none"> • 'The obvious challenge is the subjective subject matter; that it was a challenge for a consensus to be agreed on' (M1). • 'Remembering to respond to emails' (M2). • 'No challenges' (M3). • 'It was a great experience. Quite significant differences of opinion were valued equally. While Zoom in some ways made for a less personal experience, it also seemed to provide a safety zone for people to talk honestly from their home/ places of work' (M4). • 'I didn't have any challenges. I felt very comfortable and relaxed. It was presented and facilitated very well' (M5). • 'None in particular' (M6).
What enabled or motivated you to stay involved in the Consumer Advisory Group?	<ul style="list-style-type: none"> • 'People were genuine and passionate, and that it is a subject matter that is enormously influential' (M1). • '[The researcher's] passion for the subject' (M2). • 'The content and findings were extremely motivating. The dynamics and conversation within the group was also a driving factor as there was a robust discussion which personally was extremely motivating' (M3). • 'Two main things. Believing in the research direction, and being made to feel like my contribution was valued and incorporated' (M4). • 'It is a very important subject, and I felt the need to get language in the community correct. It's important to be heard and seen by the media and others as a person and not a number. Correct terms need to be used by them' (M5). • 'The researcher's genuine curiosity and respect. The conversations with them and the group' (M6).
Please provide any further comments about your experience and/or advice on how your experience could have been made better.	<ul style="list-style-type: none"> • 'Keep the conversation going!' (M1). • 'Overall it was an enjoyable experience' (M3). • 'My experience was good. [The researcher] is amazing and passionate about the subject and wanted to make the research true and valuable' (M5). • 'I feel I've been able to express my thoughts along the way, and for them to be taken on board. This has been a particularly satisfying aspect of my participation, and I felt like a significant contributor to the study' (M6).

^aConsumer Advisory Group member.

research topic, knowing it was relevant to the SCI community. The primary researcher's familiarity and confidence communicating with people with SCI helped develop rapport with members, and from members' perspectives, the primary researcher's respect and curiosity for the research topic and lived experience facilitated this engagement.

Using a virtual platform to collaborate in dissemination of research findings. Due to the Covid-19 pandemic, an international SCI conference shifted to a virtual format, facilitating unanticipated collaboration with Consumer Advisory Group members in disseminating the research findings. Positive feedback from conference attendees identified the inclusion of consumers gave the presentation greater relevance and impact. Had the conference been face to face, members' attendance and collaboration may not have been feasible. A virtual platform also facilitated the

presentation of the doctoral research to a state-wide peer SCI group.

Supervisory support. The doctoral research supervisors encouraged consumer engagement from the outset and were supportive throughout. The supervisor with consumer engagement experience readily shared their experiences which helped shape group activity. Support and enquiry from the supervisors about the Consumer Advisory Group activities helped identify strategies for meaningful engagement as the research evolved and research findings emerged.

Funds. The primary researcher was able to apply for a student support grant to pay for member remuneration through their institution. Remuneration was calculated according to guidelines provided by Safer Care Victoria [28]. These funds were withdrawn

from the primary researcher's allocated funds dedicated to research related activity such as interview transcription, training courses and paying honoraria. While having access to funds for consumer remuneration was an enabler, the primary researcher was required to prioritise consumer remuneration over other research related costs such as attending conferences for presentations. The process revealed that systemic structures potentially hinder consumer engagement from being embedded practice in higher degree research, unless budgeted as part of a larger external research grant.

Challenges of consumer engagement

Complexity in harnessing varied perspectives. Engaging with people with SCI outside of a clinical environment enabled the primary researcher to listen openly. These interactions shaped a better understanding of the complexity of factors informing individual experiences. However, the interactions also revealed a complexity in collating perspectives when each perspective was unique. One member acknowledged the subjectivity of the research topic made the aim to reach group consensus challenging, however, overtime the experience enabled the primary researcher to recognise that reaching consensus need not be the goal. Despite these perceived challenges, the added richness to understanding lived experiences, together with heightened awareness to individual experiences and perspectives, was valued and appreciated by members and the primary researcher.

Time. A requirement to obtain ethics approval for consumer engagement inclusion meant Consumer Advisory Group activity commenced six months into the doctoral research. During this time, the primary researcher completed a newspaper content analysis of media portrayal of SCI without consulting with the Consumer Advisory Group, which would have been preferable. Instead, the primary researcher presented the findings from the content analysis at the first Consumer Advisory Group meeting. This provided a platform to initiate discussion on media portrayal of SCI and fuelled ideas for developing an interview schedule for study one. Advertising for Consumer Advisory Group members through one local SCI peer agency meant that only people with SCI associated with that organisation were invited to participate and others who might have been interested in taking part may not have been aware of the opportunity. Advertising through different channels would likely have attracted greater diversity, however three additional members were recruited following their participation in study one.

Using a virtual platform for meetings. Due to the Covid-19 pandemic, all communication was done online, which may have impacted members' ability to get to know each other. This mostly transpired through nuances in members' emails, at times misunderstood by fellow members and a challenge for the primary researcher to be 'responsive to diverse [member] perspectives' [24]. Relationship building activities such as social and research-directed gatherings [24] were not possible due to the Covid-19 pandemic. One member reported 'while Zoom in some ways made for a less personal experience, it also seemed to provide a safety zone for people to talk honestly from their home/ places of work'. The primary researcher followed up with members individually if something was misunderstood and/or to discuss a topic further. The one-to-one engagement enabled members to talk freely, which helped the primary researcher be more receptive to the varied member knowledge and expertise [9].

Consumers' negative bias towards media. Multiple members helped ensure the research was informed from varied experiences, however, the primary researcher was mindful the group's collective perspective of media portrayal of SCI weighed towards the negative. Members identified their understanding of SCI and

perceptions living with disability shifted over time and influenced their perspectives on media portrayal of SCI. Ethical considerations meant members had completed any inpatient rehabilitation and were living in the community. This omitted potentially valuable acute SCI perspectives. While group discussions and research findings reflected existing disability and media literature, to address potential biases, members were encouraged to reflect on perceived views of the wider population of people with SCI.

DISCUSSION

This reflective analysis offers an account of how consumer engagement added value to doctoral research, and the findings may also apply to other research projects. Consumer engagement helped inform the research topic, instil a lived experience perspective on two studies, and introduced experiential knowledge of SCI to the overall doctoral thesis. The primary researcher's rapport with the SCI community and group members facilitated engagement, as did access to a source of funding that could be used for remuneration. Consumers' perspectives provided unanticipated richness to the researcher experience, despite a perceived challenge to achieve consensus at times. Research activities empowering consumers to lead research was out of scope of doctoral research, however, building relationships and trust, and being responsive to opportunities, led to more in-depth engagement with dissemination of research findings.

Unlike previous reports [16–20], consumers in this doctoral research were not recruited through an existing consumer engagement body and required approval from a university ethics committee prior to commencement. Mutual interest and passion for the research topic brought a dynamic group together, facilitating rapport otherwise impeded by time and funds [9]. Capacity to draw members from an existing consumer engagement program may have enabled earlier engagement, however, may have prohibited the diversity of experiences and perspectives captured [25]. Ability to provide remuneration was an enabler, however the process revealed potential systemic issues whereby remuneration for consumer engagement may not be prioritised. With consumer engagement aiding relevancy and usefulness in research, and consumer engagement and remuneration considered best practice [2, 3], institutions and community organisations advocating consumer engagement in research could look at models that encourage and support doctoral researchers to provide remuneration.

A strength of a consumer-informed approach to this doctoral research comes from centring lived experience of SCI as the primary experiential knowledge of relevance [6], allowing a variety of voices at the centre of the health condition examined to be heard [25]. Despite familiarity with SCI and the impact on lived experiences, engaging with people with SCI outside of a clinical environment enabled the primary researcher to listen openly, refining and complementing prior knowledge [20]. These unanticipated interactions shaped a better understanding to the complexity of factors that inform individual experiences, highlighting a common experience of SCI and disability does not necessarily infer a common perspective [29]. A smaller group may have helped streamline engagement, however, not knowing the direction of the overall doctoral research, early identification of what and whose experiences to capture would not have been possible. Recognising the spectrum of experiences was better than not recognising them, and despite being a perceived challenge, the added richness to understanding lived experiences, together with awareness to individual differences [29], strengthened the research.

Relationships and valuing other's opinion were fundamental in fostering meaningful activity during the research period. Working with consumers in this doctoral research started at consultative and involving levels of engagement, however, responding to

emerging consumer skills and opportunities, together with built relationships and trust, participation evolved into collaboration with the dissemination of research findings, an integral step in the research cycle [7]. This level of engagement was unanticipated, a result of being flexible and responsive to change [6] and likely enabled research findings to be shared with a larger, non-academic audience, with potentially greater impact [1]. Relationships are key [14], and maintaining communication with members can potentially facilitate research opportunities and a pathway to more in-depth consumer engagement, such as co-investigator, in the future [20, 30].

Reflective analysis highlighted the connections between the research cycle [7], levels of consumer participation [8] and IKT Guiding Principles [9] and how they work in combination in context of the research (Fig. 2). Recognising these connections prospectively may assist consumer engagement planning and evaluation activities. The IKT Guiding Principles [9] were published in 2021, two years after the doctoral research and Consumer Advisory Group activities commenced. We recognise the limitations in a retrospective reflective analysis, however, members' responses to the evaluation survey helped to address any perceived bias. It is recommended that IKT Guiding Principles are incorporated from the outset of future research activities. Promoting research knowledge and skills among consumers can facilitate consumer engagement [6]. While this was not the intent of the current evaluation, future research could investigate any difference to consumer advisory group member's perceptions and knowledge of research after their participation. The decision to only include people with SCI as members of the Consumer Advisory Group was important to the context of this research. In other research studies, other potential researcher users could be involved.

CONCLUSION

This paper provides a detailed account of a consumer engagement experience in the context of doctoral research in SCI. It contributes to the literature by advocating for the inclusion of lived experience of SCI to promote relevant, useful and quality doctoral research, as well as providing a framework that could apply to other research projects. Findings suggest consumer engagement can be facilitated through mutual interest in the research topic. Funding support for doctoral researchers to remunerate consumers may help embed consumer engagement in practice. Opportunity for consumers to voice, and for the primary researcher to listen to, experiences and perspectives was challenging yet valued. Building and maintaining relationships, while responding to opportunities can facilitate consumer engagement.

DATA AVAILABILITY

The datasets generated and analysed during the current study are not publicly available due to the possibility of identifying information occurring in the reflective data analysis, but are available from the corresponding author on reasonable request.

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AUTHOR CONTRIBUTIONS

LR, NS, and MS contributed to the study design. LR was responsible for conducting consumer engagement activity and performing the reflective data analysis. NS and MS provided critical feedback on the paper.

COMPETING INTERESTS

The authors declare no competing interests.

ETHICS APPROVAL

We certify that all applicable institutional and governmental regulations concerning the ethical use of human volunteers were followed during the course of this research. Ethics approval for this study was obtained from the La Trobe University Human Ethics Committee (HEC19185).

ADDITIONAL INFORMATION

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