



# VALUING THE DIVERSITY WITHIN THE SPINAL COMMUNITY IN SHAPING CONSUMER ENGAGEMENT PROGRAMS

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## 1. BACKGROUND

The involvement of consumers in health and medical research has increasingly become more central to research policy in Australia. With health and medical research being a matter of public interest, the outcome of the research should be to improve human health<sup>1</sup>.

The Spinal Research Institute (SRI) is committed to a paradigm shift in clinical spinal cord injury (SCI) research. This shift is where people who were research subjects in the past, now play an active role in collaborating with researchers in the research process, from study aims and design to implementation into the lives of people with spinal cord damage.

Consumer engagement programs should seek to close the disconnect between people living with SCI and the research community. They also need to ensure that they represent the diverse views within the spinal community.

The SRI has developed a Consumer Engagement Program (CEP) to close this gap and ensure that research outcomes represent consumers' diverse views. The CEP then developed a Consumer Advisory Network (CAN) to provide the program with input from the broader SCI community to ensure the program represents the diverse views within the SCI community.

## 2. METHOD

In August 2020, after the scope of a consumer engagement program had been outlined, the SRI hired a Consumer Engagement Lead to lead the program development. The successful candidate was a person with lived experience of SCI with expertise working in community-based engagement programs. The candidate was also selected based on extensive networks established within the broader SCI community.

Terms of Reference were developed for the CAN. The Terms of Reference outlined the purpose of the advisory network in its role in program development.

The Terms of Reference outlined selection criteria for the appointment of members. The clauses mandate that the CAN should, where practical, reflect the diversity in the spinal cord injury community, and membership shall aim to include, where possible:

- At least 50% people living with spinal cord injury.
- At least one consumer is defined as a FLEx (Family member/Friend with lived experience).
- Gender diversity.
- A diverse range of skill sets, education levels, and professional experience.
- At least one member of the SCI research community.

A shortlist of candidates was established based on the selection criteria. The SRI approached individuals, and preliminary discussions were held between shortlisted members and the consumer engagement lead.

## 3. RESULTS

A CAN was formed consisting of seven (n=7) members recruited specifically for diverse skill sets to provide valuable feedback in program development, and each offers diverse experiences of living with SCI or working with the SCI community.

Membership consists of five (n=5) persons with lived spinal cord injury experience representing a diverse range of ages and various lengths of time living with SCI. One member of the advisory network is a family member (wife) of a person living with SCI. The advisory network also recruited an active SCI researcher who is also an experienced physiotherapist in the area.

## 4. CONCLUSION

Consumer Engagement Programs need to ensure that they receive feedback from the broader SCI community so that the programs' direction reflects their values and addresses the barriers to consumer involvement in the research process.

When establishing consumer engagement programs, organisations need to be mindful that although they may be modelled off similar programs to ensure maximum impact they engage directly with the local SCI community. They must include stakeholders' perspectives in the development stage of their program to give a greater chance of program success and sustainability.

Organisations must seek to clearly define diversity parameters such as gender, age, and background and ensure that a framework is put in place to ensure the diversity standards are met. It is also important to acknowledge the diverse experiences individuals have living with their disability (or as a family member or researcher). This individuality also shapes their perspective in how consumer engagement programs should approach the development and engage with the SCI community.

Through the formation of the advisory network, the SRI has been able to and will continue to gather valuable feedback and consumer perspective, ensuring that the CEP is given every opportunity to deliver a positive impact and change in generating consumer engagement and SCI research.

If you'd like further information about our Consumer Engagement Program please email Antonio Vecchio at [antonio.vecchio@thesri.org](mailto:antonio.vecchio@thesri.org)

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## References

1 Miller, Caroline L, Mott, Kathy, Cousins, Michael, Miller, Stephanie, Johnson, Anne, Lawson, Tony & Wesselingh, Steve 2017, 'Integrating consumer engagement in health and medical research - an Australian framework', Health Research Policy and Systems, vol. 15, no. 1, pp. 1-6.