



CONSUMER ENGAGEMENT IN SPINAL CORD INJURY RESEARCH: DEVELOPING A POLICY AND MODEL FOR CONSUMER REMUNERATION

HENDRY K¹, VECCHIO A¹, PELEG E¹, BROWN DJ¹

¹SPINAL RESEARCH INSTITUTE, MELBOURNE, AUSTRALIA

1. BACKGROUND

The Spinal Research Institute (SRI) has established a Consumer Advisory Network (CAN) to assist with development of the SRI's Consumer Engagement Program. The CAN is governed by a Terms of Reference.

The CAN currently comprises five people living with spinal cord injury (SCI), a partner/carer of a person with SCI, and a clinical researcher active in the field of SCI.

The SRI values the lived experience of the members of the CAN, who contribute and share their knowledge. Therefore, the SRI has chosen to acknowledge and support the skills and expertise brought to the SRI through this engagement by developing a policy and model for consumer remuneration.

2. METHOD

Consumer remuneration is not mandatory in Australia and is not legally required or expected. As such, the SRI developed a Policy for Consumer Remuneration to provide guidance on this matter.

The SRI leveraged resources from the consumer engagement toolkit developed by the VCCC - Victorian Comprehensive Cancer Centre¹ (an alliance of ten leading research, academic and clinical institutions), including the cost model and remuneration factsheets.

A review of Australian taxation and other financial implications required that consumers be classified as volunteers and paid in the form of an honorarium, which is not considered salary. CAN members are not eligible for remuneration if their involvement in the CAN is connected to their incoming-producing activities.

3. RESULTS

An SRI policy and model for remuneration of SCI consumers has been established. The policy encompasses guidance for payment of remuneration and expense reimbursement, information required by the Australian Tax Office, requirements for recording consumer participation, and the model (levels) for remuneration.

The consumer remuneration model is built on five levels of engagement – informing, consulting, involving, partnership and consumer-led. Consumer remuneration depends on the level of engagement and associated activity, and there is a defined cost schedule for each tier of participation to maintain consistency across projects and programs. CAN activities are classed as *partnership* level.

Remuneration can take the form of sitting fees for committee membership or an hourly rate dependent on the level of participation. Consumers also have the option to choose not to receive financial recognition for their involvement. As part of the policy, reimbursement of eligible expenses is available.



VCCC Alliance Model of Consumer Engagement²

4. CONCLUSION

To establish SCI consumers as partners in research programs, the value of the skills, expertise and knowledge they contribute must be acknowledged and supported with resources, including remuneration.

If you'd like further information about our Policy and Model for Consumer Remuneration please email Kristine Hendry at kristine.hendry@thesri.org

Sponsors

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References

- 1 viccompncancerctr.org
- 2 This resource is part of the VCCC Alliance Consumer Engagement Toolkit at viccompncancerctr.org/about-us/consumer-engagement/