

2019 Resource Review table for Driving Consumer Engagement in the spinal cord research process: A review of the available resources

<p><u>SA Health</u> Partnering with consumers and the community (Framework)</p> <p>Policy Guideline: Consumer and Community Advisory Committee / Group (CACAC / CAG) Policy Guideline and Toolkit</p>	<p>Provides SA Health's Governance Framework, guides and toolkits to assist in partnering with consumers, carers and the community.</p>
<p><u>Health Issues Centre</u> Safer Care Victoria - A guide to Consumer Remuneration</p>	<p>Includes Remuneration Guidelines for Group c: advisory committees, registration board and management of small organisations.</p>
<p><u>The Healthcare Improvement Studies Institute (THIS), UK</u> <u>Resource from Health Issues Centre, Australia</u> Patient and public involvement and engagement in research.</p>	<p>Report on what is known and knowledge gaps of evidence base in patient and public involvement (PPI) in research. Helps inform The Healthcare Improvement Studies Institute (THIS Institute) efforts to establish and implement an effective PPI strategy. THIS Institute - www.thisinstitute.cam.ac.uk</p>
<p><u>WA health translation network</u> Consumer and Community Health Research Network (CCHRN)</p>	<p>Governments, funding bodies and research organisations across the world are increasingly recognising the importance of including the 'lived experiences', values and priorities of consumers into research policies and practice. This supports an aim of increasing translation of research evidence to improve health outcomes. The CCHRN support consumers, community members and researchers to work in partnership to make decisions about health research priorities, policy and practice.</p>
<p><u>Clinical Trial Refer, NSW</u> ClinTrialRefer</p>	<p>Clinical trial finder app. To increase participation in clinical trials research.</p>
<p><u>International Association for Public Participation (IAP2)</u> <u>Australasia</u> Consumer Engagement Model</p>	<p>Determining where the community, where your organisation intersects. Who is leading and who is acting on the purpose.</p>

<p><u>Centre for Healthcare Innovation - George & Fay Yee</u> Patient & Public Engagement in Health Research - Interactive Map Tool</p>	<p>Active and meaningful patient and public engagement can occur at all phases and stages of the research process. It's never too late to start engaging people with lived experience in your health research project. The interactive tool helps decide which participatory approach to use in your engagement strategy.</p>
<p><u>Monash Partners Academic Health Science Centre</u> Consumer and Community Involvement – presentation from conference.</p>	<p>Presentation discussing the need for research to be approached differently in Australia. The Australian Health Research Alliance <i>Disruption through collaboration, overcoming system challenges.</i> Current system makes researchers work against the translation. The publish or perish approach is embedded in our culture of research.</p>
<p><u>National Health Service (NHS), UK</u> UK standards for public involvement</p>	<p>A framework for what good public involvement in research looks like and is adaptable to different situations. Designing to encourage reflection and learning, including where lessons have been learned when public involvement has failed to lead to expected outcomes. A tool to help people and organisations identify what they are doing well, and what needs improving. Intended to be used with any method or approach to public involvement.</p>
<p><u>European League Against Rheumatism (EULAR)</u> Patient involvement in research – a way to success</p>	<p>7 Reference Cards. Patient representatives are engaging with researchers to improve methodology and research outcomes, to give credibility to the results. Cards have an introduction, points for a researcher, points for a patient research partner. Preparation During Meetings Debriefing Grant Review process Patient review form - Project evaluation rating form</p>

<p>Publication Developing a spinal cord injury research strategy using a structured process of evidence review and stakeholder dialogue. Part III: outcomes.</p> <p>Middleton JW, Piccenna L, Lindsay Gruen R, et al. Developing a spinal cord injury research strategy using a structured process of evidence review and stakeholder dialogue. Part III: outcomes. <i>Spinal Cord</i>. 2015;53(10):729-737. doi:10.1038/sc.2015.87</p>	<p>To develop a unified, regional spinal cord injury (SCI) research strategy for Australia and New Zealand. Four themes emerged: (1) Collaborative networks and strategic partnerships to increase efficiency, reduce duplication, build capacity and optimise research funding. (2) Research priority setting and coordination to manage competing studies. (3) Mechanisms for greater consumer engagement in research. (4) Resources and infrastructure to further develop SCI data registries, evaluate research translation and assess alignment of research strategy with stakeholder interests.</p>
<p>Publication Engaging Patients and Other Non-Researchers in Health Research: Defining Research Engagement.</p> <p>Frank L, Morton SC, Guise JM, et al. Engaging Patients and Other Non-Researchers in Health Research: Defining Research Engagement. <i>J Gen Intern Med</i>. 2020;35(1):307-314. doi:10.1007/s11606-019-05436-2</p>	<p>Increase in patients serving as active advisors and co-leading or leading clinical research. A consortium of individuals from these countries formed a Multi-Stakeholder Engagement (MuSE) consortium to examine critical issues in engaged research, establish consensus on definitions, and provide guidance for the field, beginning with an overview of how to involve stakeholders in health research</p>
<p>Publication Consumer engagement critical to success in an Australian research project: reflections from those involved.</p> <p>Synnot AJ, Cherry CL, Summers MP, et al. Consumer engagement critical to success in an Australian research project: reflections from those involved. <i>Aust J Prim Health</i>. 2018;24(3):197-203. doi:10.1071/PY17107</p>	<p>Describes the people, activities and methods of consumer engagement in a complex research project, and reflects on the influence this had on the research and people involved, and enablers and challenges of engagement.</p>
<p>Publication Facilitators and Barriers to Spinal Cord Injury Clinical Trial Participation: Multi-National Perspective of People Living with Spinal Cord Injury.</p>	<p>The purpose of this research study was to learn more about the factors that encourage or interfere with the decision to participate in clinical trials from the perspective of people living with SCI.</p>

<p>Anderson KD, Cowan RE, Horsewell J. Facilitators and Barriers to Spinal Cord Injury Clinical Trial Participation: Multi-National Perspective of People Living with Spinal Cord Injury. <i>J Neurotrauma</i>. 2016;33(5):493-499. doi:10.1089/neu.2015.4064</p>	
<p>Melbourne Disability Institute / Melbourne University Co-research training program</p>	<p>Awaiting release.</p>