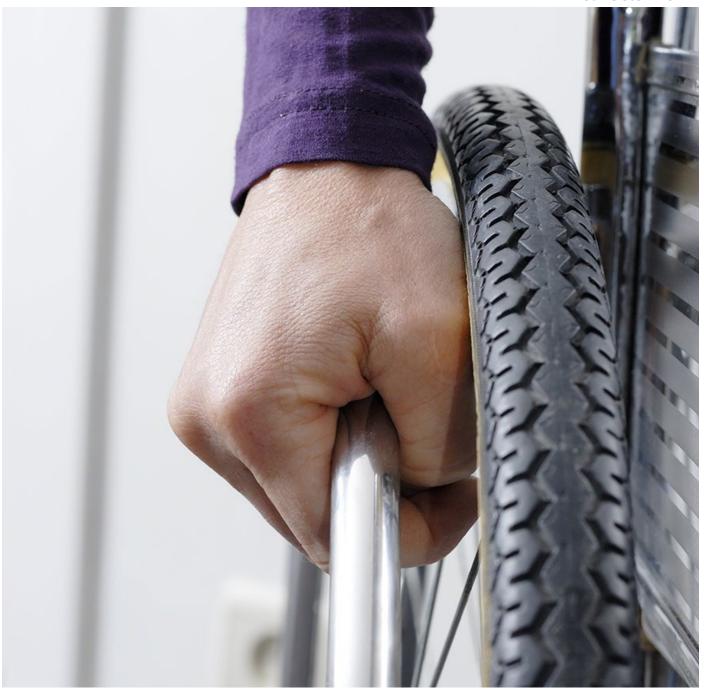Spinal Cord Injuries Australia

SCIA Research Framework

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SCIA Research Strategy and Framework

Spinal Cord Injuries Australia is a member based for-purpose organisation working with people who have a spinal cord injury, neurological condition and other physical disabilities. Key services include advocacy, member support, NeuroMoves Exercise and Therapy Services, Peer and Family Support Program, Support Coordination and Plan Management, CHOICES accommodation and Occasional and Emergency Services.

SCIA strives to be at the forefront in provision of high-quality services that assist people with SCI and other neurological conditions to overcome the barriers of living with a disability. Research underpins all SCIA's services as we strive to have the best possible outcomes for the people in our community. Research can:

- Underpin a better quality of life and a healthier lifestyle for those living with SCI and similar neurological conditions by reducing the burden of their impairments, and discovering how to lower costs.
- Guide SCIA's services through the translation of research-into-practice, so that that SCIA offers high quality services that are research informed "best practice".

For SCIA, research is crucial to improve the wellbeing of those within our community, to enhance the quality of our services, measure their impact and ultimately contribute to improved clinical practice and policy changes. These research-led outcomes will enhance the lives of people with SCI and other disabilities.

This Framework sets out a general overview for Research at SCIA. Guiding the annual decision making is the *Bi-annual Research Plan*, which outlines key focus areas and budget for a two year period. The *Plan* will be drafted by the Clinical Governance and Research Committee and endorsed by the SCIA Board of Directors.

Vision for Research
Based on SCIA's vision, the research supported by SCIA must contribute to a society without barriers for people with spinal cord injuries. This means that the aims of research developed within, or supported by, SCIA must be person-centred, without bias, promoting, diversity and inclusion and readily translated to improve outcomes for people in three key areas:

- Body function and Structure
- Independence and Mobility
- Psychosocial (wider participation in the community).

Mission for Research
Aligned with SCIA's overall mission, the research mission is to engage with high-quality scientific evidence for novel strategies to improve care and advance the rights, choices and entitlements of people living with spinal cord injury and similar conditions.

Objectives for Research
Research promoted by SCIA should:

- Fully align with SCIA's Strategic Plan and Three Year Operational Plan

- Evaluation of internal data to ensure that services are relevant and practices are research informed.
- Translate into quality improvement for SCIA services.
- Be readily deployed for people with spinal cord injury and similar conditions (translational research-into-practice).

Approach of our Research

Through engagement with world-recognised research centres, clinical institutions and Universities, we aim to:

- Pursue local, national and international partnerships to complement and enhance the key areas of research described below.
- Build mutually beneficial collaborations.
- Pursue shared goals with SCIA's clients (community-end users) to maximise the delivery of solutions and ultimately return on investment.

SCIA is proudly a member organisation and a provider of services. There are a variety of ways in which we engage with research to support our community.

Promotion: SCIA has a wide member and client base who are keenly interested in research that could lead to improved outcomes for them or for others within the community. Research that is aligned to our vision, mission and key focus areas may be supported and promoted by SCIA.

Support: Among SCIA's members and employees there is a wealth of knowledge that can contribute to research projects through engagement on reference or advisory groups and active participation in consultations.

Partnership: Where a project falls within our Bi-Annual Research Plan and is assessed by the committee as a priority, a partnership will be formed which may include in-kind support such as employee engagement, access to clients and members, fundraising or other contributions for the shared project.

Financial Support: Where a project falls within our Bi-Annual Research Plan and is assessed by the committee as a priority, SCIA may fund or partially fund research.

Successful Research Project Examples

Examples of existing research at SCIA has included:

Higher Degree Research

To date, SCIA has financially supported the completion of two PhD projects that sought to improve rehabilitation outcomes for those living with a SCI; and to provide evidence on the outcomes of participating in the NeuroMoves program. This initiative resulted in the implementation of the research findings into NeuroMoves clinical practice improving the quality of the service and to provide better outcomes for clients. Research findings were disseminated in more than 8 National and International Conferences, increasing the exposure and public knowledge about SCIA and resulted in 4 scientific journal publications, to date. Furthermore, SCIA is currently supporting 3 PhD and 1 Master project at the University of Sydney, Edith Cowan University and University of Technology Sydney.

Research Partnerships

SCIA is currently engaged in a number of research partnerships which are aligned to our research

mission and vision. Support is in-kind utilising our knowledge, consumers and member base to advertise and recruit for several research projects from various universities. Partnerships are varied and cover subjects such as: paediatric support enhancements, wellbeing, breathing techniques and accessibility.

Key Research Areas:
As a member-based organisation, our research is grounded in a commitment to improve the wellbeing of our community. SCIA's focus is research that translates into practice, upskills its employees, produces quality practitioners, improves services and service-delivery, and seeks innovative approaches towards better quality of life. Research should improve SCIA's competitive advantage as a provider of services and long term improvements to our financial position, will be passed on to the people we support. There are six research areas that outline how this may be achieved.

1. Validation of SCIA services and measurement of its impact in the lives of people living with SCI or other neurological conditions.
   o Apply research methodology to gather and analyse quantitative and qualitative data on client-centred outcomes for SCIA programs, for example NeuroMoves, Peer Support or EmployAbility.
   o Participate in a range of projects from quality assurance schemes (small scale) to large randomised controlled trials.

2. Support research aimed at improving outcomes for people living with an SCI in the acute, subacute or chronic phases in the areas of:
   o Body function and structure (impairments from SCI)
   o Activity limitations (mobility and accessibility)
   o Social Participation (work, leisure, well-being and quality of life)

3. Support translational research to build upon policy influence and advocacy capacity.
   o Large cohort studies evaluating the problems faced by people with SCI and prognostic factors that could support changes of practice and policies in the health care and social aspects for people with SCI.

4. Support projects that explore the future potential for cure-care of SCI through testing the effectiveness of:
   o New and innovative technologies
   o Enhanced surgical management
   o Biological approaches to spinal repair (eg. stem ceslls and similar vectors)
   o Neuromodulation

5. Support research aimed to evaluate and implement strategies for the prevention of traumatic SCI and other neurological injuries.

6. Support multidisciplinary research targeted at improving client-centred outcomes holistically.

Research Strategies

To achieve the above, we aim to collaborate and support recruitment, development and/or funding of:

- High Degree Research student scholarships in partnership with leading Universities in the field.
- Research partnerships
- Small Honours student projects in partnership with educational institututions.
- Funding for grants

Operational Oversight

The Clinical Governance and Research Committee will oversee the implementation of the Research Framework including drafting for approval by the CEO and Board of Directors the Bi-Annual Research Plan. The Plan will target specific focus areas for SCIA's research within the key areas outlined above. The *SCIA Clinical Governance and Research Committee* is composed of:

- 3 experienced clinicians in the rehabilitation of neurological conditions (Physiotherapist / Occupational Therapist / Nurse/ Psychologist/ Social worker/ Exercise Physiologist / rehabilitation specialist/ spinal cord medical clinician).
- 2 members of the community with a disability from a neurological condition
- 1 member of the community who is a disability-carer.
- 1 academic (researcher) in the field of clinical rehabilitation of neurological conditions.
- Internal membership from the executive and SCIA Board.

The committee has the delegated responsibility of the SCIA Board to advise on clinical and research matters. The committee is bound by a confidently agreement and much seek CEO and Chair approval to speak publicly on SCIA-related matters.

The Committee has a number of key research responsibilities including, but not limited to:
- Proposing a Biannual Research Plan to the SCIA Board that reflects the priorities of the Strategic and Operational Plans
- Assessing research projects, partnerships and research engagement including high degree research student projects, honours projects, grants and partnerships with in-kind contributions.
- Identifying 'best practice' in service provision out of the scientific literature and from information-gathering from medical and allied health professionals for possible implementation within the Clinical Governance Committee.
- Actively seek contributions from research priority areas that are in line with the Research Plan, for the best interests of the SCIA community, that can 'up-skill' SCIA teams, promote novel developments in practice and enhance the operations of SCIA.

Monitoring and Review

SCIA has not previously had a Research Framework. The above will be monitored by the Committee and sercrateriet Support team and updated in twelve months if required

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