

IMPACT REPORT

2024





The Spinal Research Institute acknowledges the
Traditional Owners of the land on which we work, the
Wurundjeri People of the Kulin Nation.
We pay our respects to Elders past and present.

Cover: Kristine Hendry, SRI CEO (far left) with 2023 SCI
Research Collaboration Grant recipients (clockwise)
Kamrunnaher Koly, Dr Bakhtawar Qureshi, Jacob Schoffl,
Dr Haleluya Moshi, Robert Buren, and Keira Tranter.

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Chair of the Board's message

As Chair of the Spinal Research Institute (SRI), I am deeply honoured to be part of a dedicated team that tirelessly collaborates with those who share our passion for advancing spinal cord injury research.

I want to acknowledge our Patron, Lady Southey AC, whose commitment and support continues to inspire us. I also extend a warm welcome to **Michèle Whittle** (right), who joins our Board of Directors and has also taken on the role of Company Secretary. Michèle is a Senior Lawyer at the Australian Securities & Investments Commission. She has more than a decade of experience in law, regulation and policy, having worked in both corporate and public sector roles. She has a Bachelor of Arts and a Bachelor of Laws (Hons) from the University of Melbourne.



Our busy year has yielded significant progress, and I'd like to focus on three key areas:

Consumer Engagement

The SRI is transforming research culture through an innovative approach. We upskill both individuals with lived experience of SCI

and researchers, enabling them to participate in and contribute to co-designed research. By connecting these stakeholders effectively, we aim to improve treatment and care for those living with SCI.

Collaborative Research

Our Spinal Cord Research Hub brings together national and international researchers, transcending borders. This collaborative network helps facilitate larger-scale trials and enhances research outcomes. Importantly, it aligns with our Consumer Engagement Program, ensuring that those with lived experience actively shape research, knowledge translation, and policy decisions.

Supporting Early Career Researchers

The future lies with our young researchers. Through our Patron's Program, we offer initiatives including the Mentor Program and SCI Research Collaboration Grants.

The SRI remains a leader in this field, and our thanks go to the dedication of our team, board, ambassadors, volunteers, donors and supporters. Your ongoing support empowers us to make a difference in the lives of those with SCI. Thank you.

Fi Slaven
Chair, Board of Directors



Fi Slaven
Director & Chair



Associate Professor Doug Brown AM
Director



Nick Morris OAM
Director



Dr Mario D'Cruz
Director



Craig Macaulay
Director



Professor Marc Ruitenberg
Director



Grant Norton
Director



Dr Caroline McFarlane
Director



Frank Nigro
Director



Chief Executive Officer's message

Once again, we have had a very exciting year at the Spinal Research Institute (SRI) and I am delighted to share with you our 2024 Impact Report. Below are some of the highlights that can be found in the report - examples of the work we are doing to scale research collaboration, capacity, and community engagement - to help improve health and quality of life outcomes for the 20,800 Australians, and those around the world, living with spinal cord injury.

- Three researchers share how the SRI's Research Group Facilitation service on the Spinal Cord Research Hub has enabled their collaboration groups to advance their research projects.
- We introduce you to the three new participants in the SRI's Mentor Program, and the six recipients of our SCI Research Collaboration Grants - future leaders in spinal cord injury research and clinical care.
- Explain how the SRI is helping shape and drive research through consumer and community engagement initiatives and our partnerships with several research projects as a consumer advisor.
- Present the new report published by the SRI, The Landscape of Spinal Cord Injury

Research in Australia 2018-2023, which identifies significant opportunities for new approaches to SCI research in Australia.

As always, I extend my heartfelt gratitude to our donors and philanthropic partners, without whose support and commitment to the SRI our work would not be possible. Many of our philanthropic relationships are longstanding and I want to thank these partners for their continued loyalty and shared vision in the work we do.

I would also like to thank and recognise the contributions of my wonderful team, passionate and engaged Board, inspiring Patron Lady Southey AC, our dedicated Ambassadors and Consumer Advisory Network, and the members of the research and spinal cord injury community who generously give their time to act as judges, reviewers, advisors and mentors for our programs.

Please enjoy reading about the impact we are creating by driving research collaboration, investing in the next generation of researchers, and transforming research through consumer engagement, to improve health outcomes and quality of life for people with spinal cord injury.

Kristine Hendry
Chief Executive Officer



Above: SRI team. Front row: Emma Peleg, International Research Collaborations Manager; Fiona Low, Office Administrator and Program Support; Associate Professor Linda Barclay, Research and Knowledge Translation Lead; Antonio Vecchio, Community and Consumer Engagement Manager. Back row: Claire Backhouse, Marketing and Communications Manager; Deirdre Mori, Development Manager; Kristine Hendry, Chief Executive Officer



Spinal Research Institute strategy for impact 2023 - 2026

Our purpose and vision

- Building research collaboration and consumer engagement, to improve the lives of people with spinal cord injury.

Our role

- Facilitate collaboration and cooperation within national and international spinal cord research to drive innovation and scale.
- Build consumer participation within research through understanding, confidence and experience.
- Influence and advocate for more research with an agenda shaped by the voices of lived experience.

Our beliefs

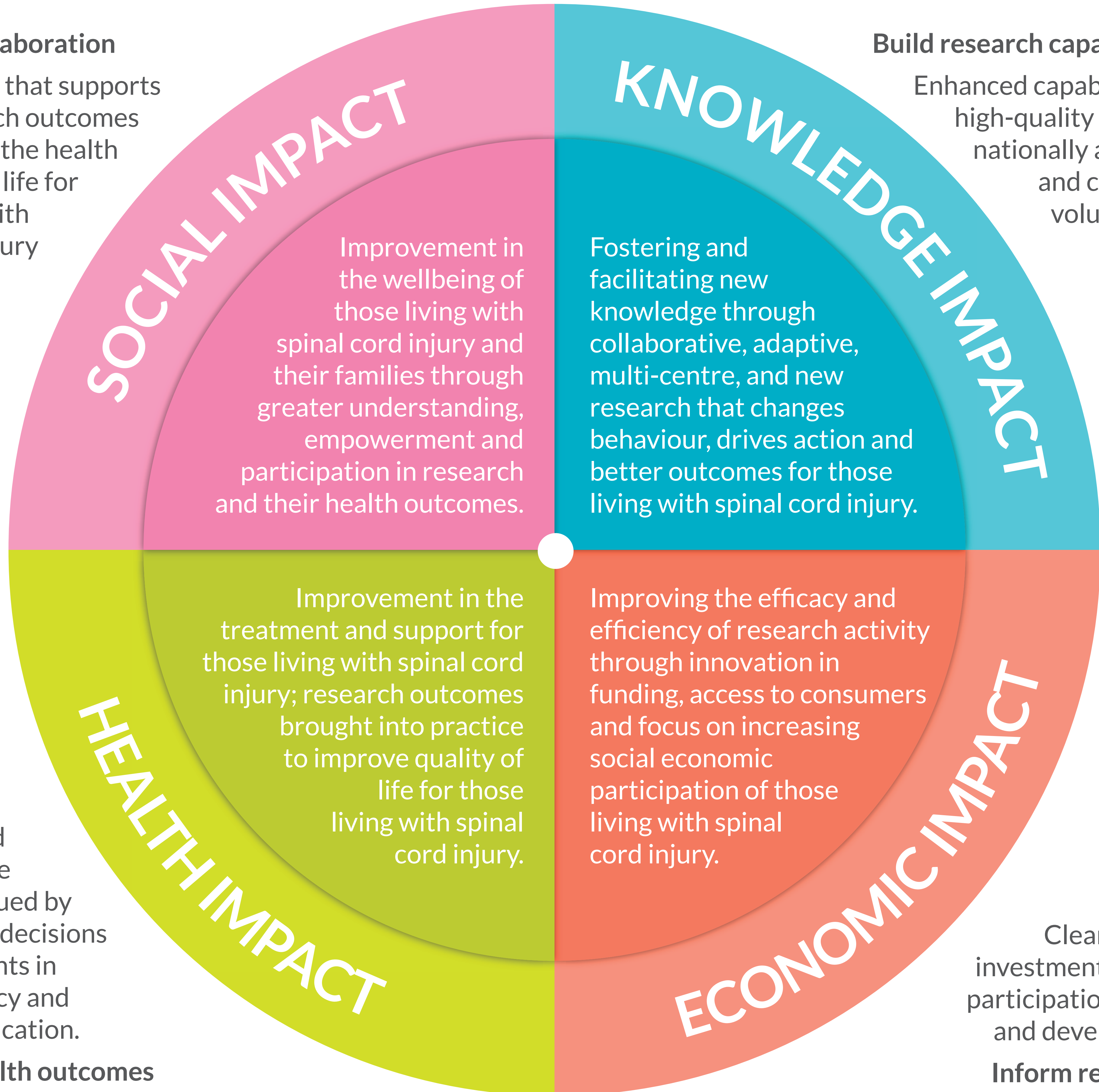
- We believe in the value and power of research to drive better health outcomes and improve the lives of people with spinal cord injury.
- We believe in the critical importance of collaboration from discovery to translation, and that alone we will not be as successful.
- We believe in the value of bringing together the voices of lived experience, researchers, clinicians and funders to drive relevance and better results.

Facilitate collaboration

Collaboration that supports better research outcomes and improves the health and quality of life for those living with spinal cord injury (consumers).

Voices of lived experience are heard and valued by those making decisions and investments in research, policy and practical application.

Influence health outcomes



Our strategic framework

- 1. Invest in people**
The organisation identifies, retains and develops its talent; is prepared for succession and provides the support needed to excel.
- 2. Secure programs**
Existing programs have secured funding and can be scaled for impact; and new program opportunities through partnership are explored and realised.
- 3. Build resilience**
Financial diversification through new funding sources, supported by investment in operational support to keep pace with action and support impact.
- 4. Strengthen partnerships**
Developing and nurturing two-way and values aligned partnerships within the research sector and across the spinal cord field to support programs, investment and outcomes.



A word of thanks from our Patron, Lady Southey AC



It is my great pleasure to reflect on what has been a wonderful year of supporting our Future Leaders of SCI Research through the Patron's Program.

Your gifts to this Program over the last year have helped our young researchers to thrive.

I would like to thank all members of the Patron's Program for your wonderful gifts over this last year. Your donations are greatly valued for the impact they can make to support our young researchers. We are truly inspired and heartened by the contributions of each and every one of you and the impact that will ultimately flow from this spirit of giving.

For those of you who were able to join us for the morning tea at Cranlana in May of this year, it was a wonderful opportunity to meet some of our early career researchers in spinal cord injury. My thanks to our three speakers, Dr Marnie Graco, Talia Clohessy and Jacob Schoffl for joining us and sharing insights on their individual research studies. As they

explained, their research innovations have the power to transform the lives of those with spinal cord injury and this means improving health and independence, and advancing the day-to-day quality of life of community members.

Through your generous gifts this year to the Patron's Program for Future Leaders of SCI research, you have supported our best and brightest researchers of today, empowering them to find health solutions that will help people living with spinal cord injury live healthier and more active lives. I hope you feel proud of what we have achieved together and I look forward to you being a part of our Patron's Program next year.

Thank you again for your loyalty and wonderful support.

Lady Southey AC
SCI Patron



Lady Southey AC addresses a gathering of SRI supporters at Cranlana in May 2024.



Ambassadors

The Spinal Research Institute (SRI) is fortunate to work with a group of Ambassadors who champion our cause in the spinal cord injury community and beyond. Being able to draw on the diverse and rich lived experiences of our Ambassadors, in a range of settings, has enabled us to talk about the impact of our work in meaningful ways.

The SRI thanks all of our Ambassadors for the work they have done in promoting our work and raising awareness of the importance of collaboration and consumer engagement in research.



Jason Ellery



Dr Mario D'Cruz



Dr Gillean Hilton



Max Di Paolo



Stefania Di Paolo



Marc Brew



Lachie O'Brien



Martin Heng



Christine Tripp



Dr Leanne Rees



Ben Gruter



Campbell Message

Consumer Advisory Network

The Spinal Research Institute's (SRI) Consumer Advisory Network was established to inform and help shape our Consumer Engagement Program. It plays an important role in identifying key research knowledge gaps, helping us to improve our education and awareness resources. The Network also plays an important role in the evaluation of our Consumer Engagement Program to ensure that it meets the needs and priorities of the spinal cord injury community.

We are grateful to have a Consumer Advisory Network that is engaged, diverse and committed to improving levels of consumer engagement in research.



Our programs

Spinal Cord Research Hub (SCoRH)

SCoRH is a unique online hub developed by the Spinal Research Institute (SRI) to foster and facilitate collaboration between researchers and clinicians working in spinal cord injury around the world. SCoRH also offers research group facilitation and consumer engagement consulting services for members.

Mentor Program

The Mentor Program nurtures talented emerging researchers by matching them with an experienced mentor. Mentors are carefully selected according to the needs and research aims of participants. To date, all participants have reported improvement in their research skills.

SCI Research Collaboration Grants

These grants support researchers and clinicians to attend the International Spinal Cord Society Annual Scientific Meeting. Recipients have created global networks, generated opportunities for research collaboration, and presented their research to new audiences.



Consumer Engagement Program

This innovative program supports people with lived experience of spinal cord injury to co-design and co-deliver research that is relevant to their needs and priorities. Impact is achieved in a range of ways including creation and dissemination of educational resources.

SCI Research Writing Prize

Each year, we ask spinal cord injury researchers and clinicians to write about their research in a creative way. This provides an opportunity to present their research to a broad-ranging, non-scientific audience. Successful entries are featured in our publication, *Why Research Matters*.

Research & Collaboration

This program is all about connecting people, sharing practices, and disseminating information. It provides the SRI with an opportunity to collaborate with leading institutions in spinal cord injury research as well as connect with the international research community.



Spinal Cord Research Hub (SCoRH)

The Spinal Cord Research Hub (SCoRH) is an online platform for spinal cord injury research collaboration. This world-first Australian innovation was developed by the Spinal Research Institute (SRI), with support from leading local and international experts in spinal cord injury research. SCoRH enables researchers and clinicians to connect, share and collaborate in one easy-to-use online space, and to work across health disciplines and geographic boundaries to impact greater numbers of health outcomes for spinal cord injury.

In the past 12 months, two services were launched on the SCoRH platform. Both are free of charge for members. These services have been developed with researchers and clinicians in mind, to add quality and value to the work they are already doing in the field of SCI research. Through SCoRH, the SRI also offers Online Networking Events to foster networking and collaboration between researchers.

Research Group Facilitation service supports collaboration groups already established on SCoRH to overcome obstacles that prevent or hinder their progress. Researchers globally are time-poor, and organising meetings with group members in a range of international locations can be prohibitively time-consuming.

Additionally, group members are concurrently working on other projects and managing conflicting priorities. For these reasons, it can be difficult to maintain momentum, leading to a lack of clarity about group actions and goals. Research Group Facilitation provides structure and focus that can assist with these issues. Read more about this service and groups that use it on the following page.

Consumer Engagement Consultation service supports researchers who would like to know more about how to include consumers in the design and implementation of their research. Including the perspectives of consumers is best practice in SCI research and is increasingly required in order to secure grant funding. However, it is not always clear how researchers might approach this in their own projects. Consumer Engagement Consultation provides guidance about the ways in which consumers might be involved in different stages of the research process.

Online Networking Events: Introduced in 2023, attendees participate in 45 minute discussions facilitated by SRI staff. These events enable attendees to connect with other researchers and clinicians working in various SCI research fields around the world.



The Spinal Cord Research Hub (SCoRH) is supported by Freemasons Foundation Victoria



SCoRH member Jennifer Maher
University of Bath, United Kingdom



Research Group Facilitation supports research through SCoRH

The Spinal Research Institute (SRI) has been providing Research Group Facilitation to a number of groups on SCoRH, and these stories demonstrate the impact of this service.

Speech and Language Therapists group Dr Jackie McRae

There are very few Speech and Language Therapists (SLT) working with people with SCI, so the group was formed to provide connections and support, and also to gain an understanding of how problems might be addressed in different countries. Ideally, we want to raise standards for everyone and highlight the positive impact SLT can have.

Most group members are clinicians who have limited time outside of clinical practice to engage in research activity. Some are based in low and middle income economies so their challenges include restricted services.

As a small group, it helps to be seen and be given encouragement to continue our work. Some members are starting research training, co-authoring papers and gathering data for abstract submissions. We want to see more activity but we are definitely moving in the right direction.

Dietitians group Kate Desneves

In 2021 a number of dietitian researchers with a particular interest in SCI formed a group on SCoRH, the Spinal Research Institute's online collaboration platform. The founding members hoped it would become a place for professional conversations, something that did not exist previously.

Soon after it was founded, the group took advantage of the platform's Research Group Facilitation Service and had an initial meeting with the SRI's Associate Professor Doug Brown and Emma Peleg. Group founders Kate Desneves, Amy Nevin and Priya Iyer credit that meeting as being fundamental in assisting the group to clarify where to start and how to proceed.

Through challenges and success, the early groundwork in clarifying goals and identifying necessary steps was essential in maintaining momentum. The group has achieved significant outcomes such as complex case support, conference presentations, and research publications.

Low and Middle Income Countries group Nishu Tyagi

We created a low and middle income country (LMIC) research working group on SCoRH given the higher burden of SCI-related complications due to limited healthcare resources. Initially, working towards a unified goal presented challenges stemming from disparities in healthcare quality, resource availability, as well as time differences between our countries. However, SCoRH's Research Group Facilitation service played an instrumental role in mitigating these issues.

Our team comprises members from Bangladesh, India, Nepal, Pakistan, and South Africa. Together, we have developed a draft to examine the COVID-19 response and the management of individuals with SCI in LMICs. Our objective was to expand our efforts by engaging and collaborating with interdisciplinary professionals in the field of SCI.

Building local capacity through collaboration can foster more sustainable and autonomous research practices within LMICs, ensuring that the benefits of research are disseminated more broadly.

Right: Nishu Tyagi



Mentor program

The Spinal Research Institute's (SRI) Mentor Program is now in its fifth year. It began as a pilot program in 2019 and was run as a full program in 2021. The third round of the program opened for applications in March 2023 and the participants in this round have now been matched with a mentor.

The program has four aims:

1. Progress the research careers of talented emerging researchers.
2. Provide guidance and support to strengthen their specific research projects.
3. Produce the next generation of leaders in the field to advance spinal cord injury research more broadly.
4. Enhance international collaborations in spinal cord injury research.

The mentor/mentee relationship has great potential to be successful because it is not bound by geographical limits, meaning that the SRI can facilitate matches across the globe based on the needs of the mentee and any deficits faced in their particular locations.

Meet the newest participants in our Mentor Program to the right.



Dr Sungchul Huh, South Korea

Dr Sungchul Huh is a Medical Doctor and Director of Spinal Cord Injury Program at Pusan National University Yangsan Hospital, Department of Rehabilitation Medicine, South Korea. Sungchul completed a PhD in 2022 and has published in a number of journal articles on SCI.

The SRI has matched Sungchul with a well established, highly-regarded physician and expert researcher in the United States of America. Sungchul's goal is to be a leading clinician in the field of spinal cord medicine, with a focus on clinical practice and research.



Margaret Mungai, Kenya

Margaret Mungai is the Deputy Director of Nursing at Moi Teaching & Referral Hospital in Kenya. Margaret has an interest in research around the spinal cord injury, skin integrity and continence compromise triad that is the basis of distress among the patients admitted in the teaching hospital where she works.

The SRI has matched Margaret with an exceptional clinician researcher from the United States of America, who not only has a decorated career in the SCI field, but has a long standing affinity with Africa from his early years of life and research.



Anjita Khadka, Nepal

Anjita Khadka is an ambitious early career researcher from Nepal, who is a Registered Nurse by background and has completed further studies in Nutrition. Anjita is currently working as a part time Nutritionist at Spinal Injury Rehabilitation Center Nepal and is involved in several research projects.

The SRI has matched Anjita with an exceptional clinician researcher from Australia who is well published in the area of nutritional health in SCI, and will support Anjita with collaborative connections and funding approaches.



SCI Research Collaboration Grants

Each year, the Spinal Research Institute (SRI) offers SCI Research Collaboration Grants to enable early and mid-career researchers to attend the Annual Scientific Meeting of the International Spinal Cord Society (ISCoS). In 2023, the meeting was held in Edinburgh, Scotland, and the SRI supported six researchers to attend. The 2023 recipients (pictured on the front cover of this report) highlight the impact of their grant below:

Keira Tranter, Australia: Attending ISCoS 2023 afforded me the unique opportunity to meet and connect with a diverse range of researchers, stakeholders and clinicians from across the globe. Informal networking has been invaluable to me.

Dr Haleluya Moshi, Tanzania: Engaging with the psychosocial special interest group expanded my perspective. I established contacts with individuals interested in collaborating on addressing psychosocial needs, an area that has received limited attention in Tanzania.

Kamrunnaher Koly, Bangladesh: Attending ISCoS 2023 provided me with a great opportunity to enrich my knowledge, foster collaboration in the area of SCI, connect with researchers around the world in my field of returning to work after SCI.

Dr Bakhtawar Qureshi, Pakistan: Attending ISCoS 2023 was crucial for developing collaborative research ideas and networks. Engaging with esteemed researchers enriched my understanding and fostered collaborative initiatives.

Jacob Schoffl, Australia: I had the honour of presenting some of my work, solidifying my presence within the academic community. I joined the quality of life and psychosocial health Special Interest Groups, connecting with like-minded individuals.

Robert Buren, Canada: Presenting my initial work and participating in specialised groups not only exposed me to a broader audience but also facilitated insightful discussions. The conference was an invaluable platform for networking.

SCI Research Collaboration Grant statistics

97

total number of grants awarded since 2016

43

recipients from low and middle income countries

57

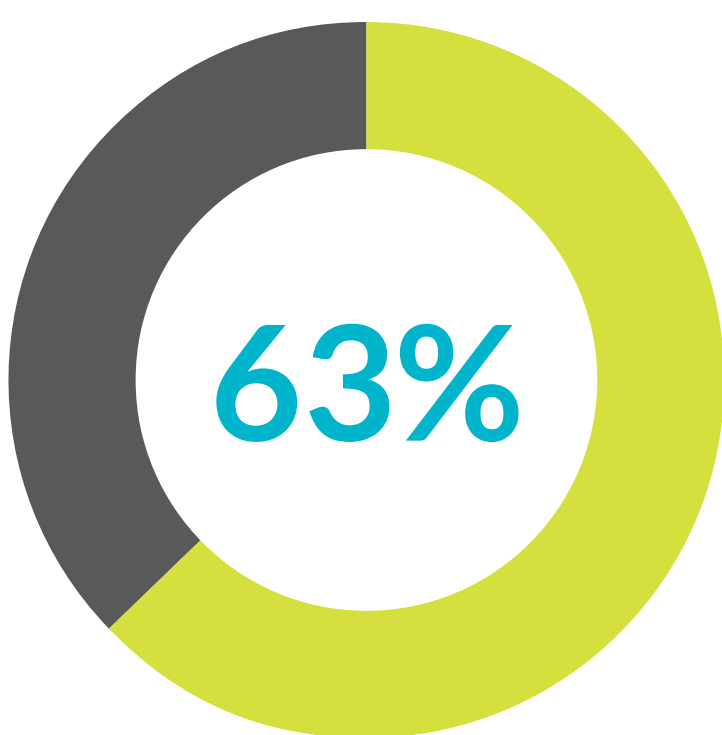
grants awarded to women since 2016

24

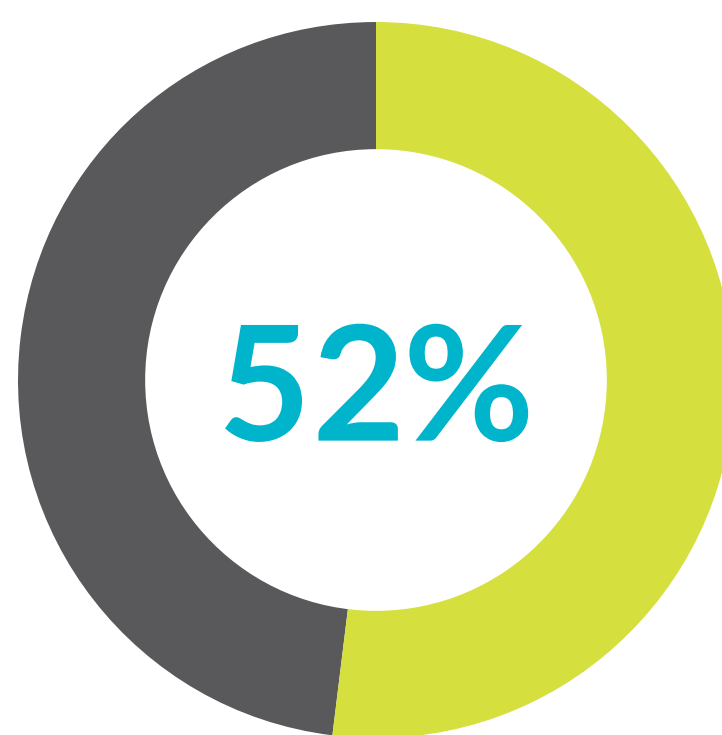
countries represented

In December 2023, the SRI sought longer term impact feedback via a survey sent to all past grant recipients from 2016 to 2021. 2022 and 2023 recipients were not surveyed due to the short time that had elapsed since their ISCoS conference experience. Survey respondents described how the opportunity

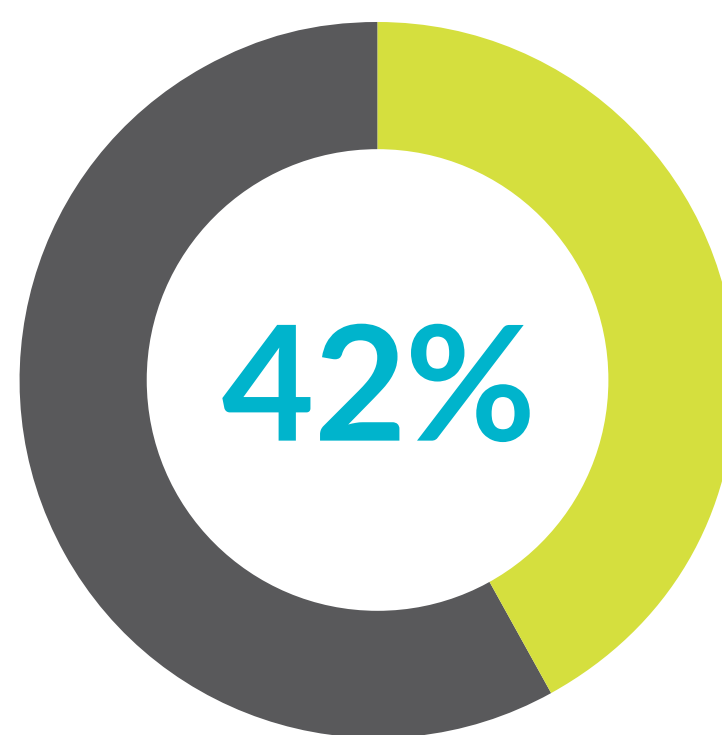
enabled them to make new connections in other countries and connect with researchers in the same field or discipline. Recipients also described generating new ideas and directions for their own research and forming ongoing collaborative relationships. Survey results are shown below.



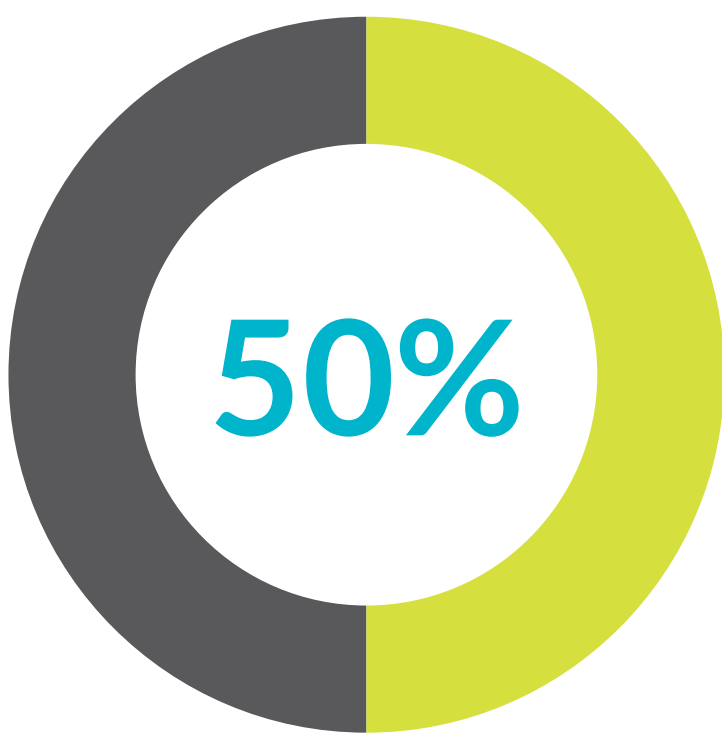
have progressed a research or project idea initiated at the ISCoS conference



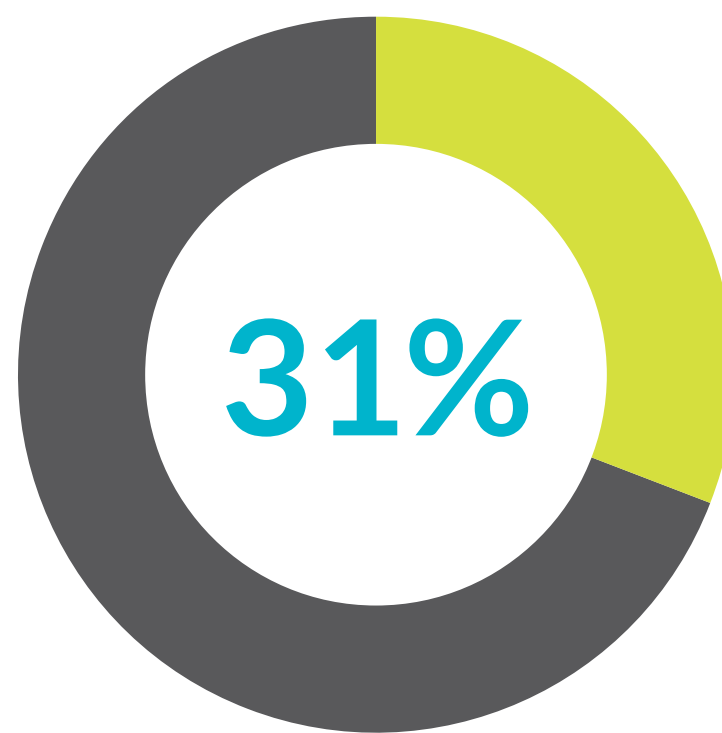
have applied skills and information they learned at the conference into their clinical practice



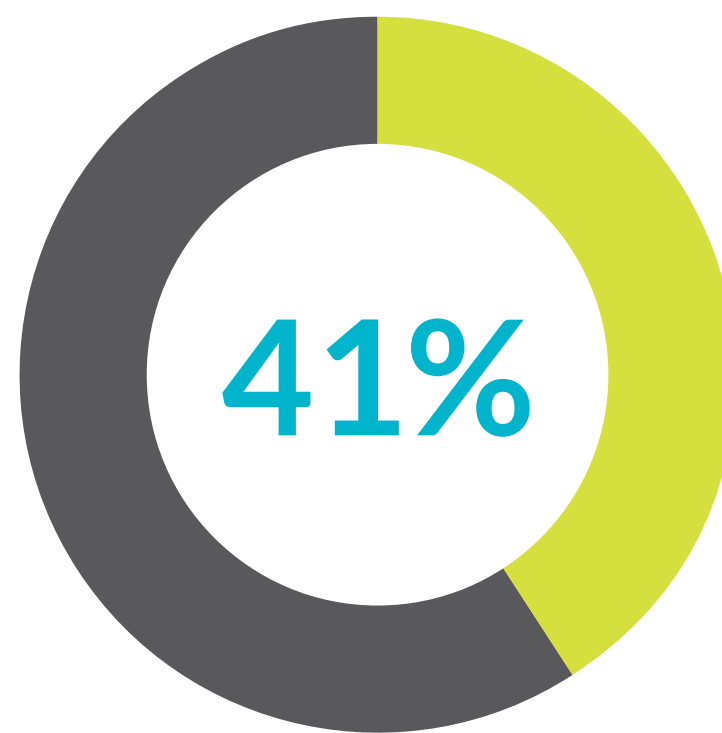
said their research has gained wider exposure as a result of conference attendance



formed collaborative relationships at the ISCoS conference



have been involved in collaborative research with people that they met at the conference



made 3-5 new networking connections at the conference and 22% made 6-10 new connections



Consumer Engagement Program

The Spinal Research Institute (SRI) is committed to placing people with lived experience of spinal cord injury ('consumers') at the forefront of research. Consumer engagement can help generate more meaningful research that improves health and quality of life outcomes for the spinal cord injury community.

Over the past 12 months, we have continued to raise awareness of the benefits of research, and educate consumers to equip them to partner in research co-design and co-delivery. During this time the SRI has worked closely with the Victorian Spinal Cord Service to deliver regular education sessions to patients and family members. The SRI was also invited to present at researcher forums on the importance of consumer engagement and how to involve consumers in research. These forums were conducted by Neuroscience Research Australia (NeuRA) and the John Walsh Centre for Rehabilitation Research at the University of Sydney. These partnerships are invaluable to the Program and we're grateful for these organisations' support.

At the Annual Scientific Meeting of the International Spinal Cord Society (ISCoS) 2023, the SRI co-presented a workshop on leveraging digital media for research

communication with researchers from Australia and the USA (photo at right). The workshop was very well received and demonstrates the SRI's leadership in this space.

In early 2024, the SRI launched 'Ask the SRI', a new series of short videos accompanied by fact sheets. Each video focuses on a single question about research generally, or spinal cord injury research specifically, and is no longer than 90 seconds. The intention of this series is to generate greater consumer engagement in research through education and increased awareness.

The SRI continues to help shape and drive consumer engagement in research projects. We have been invited to partner with several projects in a consumer advisory capacity to ensure that the research is representative of consumer needs and accessible for consumer participation. The SRI has also recently launched a Consumer Engagement Consultation service through the SCoRH platform where researchers can seek advice about involving consumers in their research.

[View Ask the SRI resources](#)



Dr Anjali Forber-Pratt (USA), Dr Anne E Palermo (Australia), Antonio Vecchio (SRI, Australia), Dr Leanne Rees (Australia), Dr Jennifer Coker (USA)



The Landscape of Spinal Cord Injury Research in Australia 2018 - 2023

In 2023, the Spinal Research Institute (SRI) commenced a mapping project to obtain a comprehensive understanding of the spinal cord injury research landscape in Australia (January 2018 - May 2023). Having a clear understanding of the current landscape for SCI research within Australia is important to inform and support efforts to minimise duplication of research, reduce financial waste, and help make strategic decisions around investment. Gaps and challenges can then be identified, and opportunities addressed.

Two methods were used to identify the scope and breadth of current and recent SCI research - a web-based search of recent funding and a scoping review of recently published literature.

Funding

The total publicly identifiable funding for SCI-related research in Australia was \$48,662,255. 87.5% of funding was allocated to clinical research, and 12.5% to pre-clinical research. The SRI's landscape report provides additional breakdowns of funding, including funding by state, source, and research category (e.g. clinical - rehabilitation; pre-clinical - neuroprotection).

Published research

Of the 196 publications included in the literature review, the majority reported clinical research (87%), consistent with funding allocations. The landscape report provides additional breakdowns of publications, including by state, study design (e.g. qualitative inquiry, randomised controlled trial), and research category. Of note, only 16% of clinical studies published recruited participants from outside their own state; and only 9 publications (all clinical) included people with lived experience other than as research participants.

The SRI's report concludes that research models that promote greater links between laboratory-based researchers and clinical researchers, and funding incentives for multi-state collaboration, could more adequately address pressing healthcare needs, reduce duplication, maximise recruitment participation, and more efficiently engage consumer advisory panels. Our report highlights that significant opportunities exist for new approaches to advance the reach and impact of SCI research in Australia.

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THE LANDSCAPE OF SPINAL CORD INJURY RESEARCH IN AUSTRALIA 2018-2023

Associate Professor Linda Barclay
Research and Knowledge Translation Lead, Spinal Research Institute; Associate Professor, Monash University

Dr Marnie Graco
Implementation Scientist, Institute for Breathing and Sleep, Austin Health; Senior Research Fellow, Department of Physiotherapy, University of Melbourne

Professor Marc Ruitenberg
Professor of Neurotrauma, The University of Queensland; Non-Executive Director, Spinal Research Institute



SCI Research Writing Prize: Why Research Matters

The Spinal Research Institute's (SRI) 2023 Spinal Cord Injury Research Writing Prize asked entrants to write about their research in a compelling and creative way that would appeal to, and be easily understood by, a broad-ranging, non-scientific audience. Entrants must explain their research in 800 words or less, keeping in mind the question "Why does my research matter?" Shortlisted entries are published in an annual anthology called *Why Research Matters*.

Why Research Matters 2023 contains the top eleven entries from the 2023 Spinal Cord Injury Research Writing Prize. The entries presented showcase a diverse range of research interest areas and their authors are working in six different countries. They cover a diverse range of topics, including sexuality, blood pressure, anxiety, recovery of arm function, and rugby-related SCI in Australia.

The SCI Research Writing Prize aims to engage researchers, foster clear writing skills and champion research to a local and international audience. Writing a clear and concise synopsis of often complex research, is a vital skill for communication with other researchers, clinicians, grant makers, and the SCI community.

Why Research Matters provides a forum for Australian and international researchers to showcase their work outside of traditional academic publications and enables engagement with the SCI community through an accessible, 'storytelling' format. This makes research more accessible and enables all stakeholders to engage in discussion, debate and decision making about the application of research outcomes. Most importantly, it puts research into the hands of the people who will benefit from its impact, in our case, people with spinal cord injury.

Our 2023 Judges' Choice winner was Merna Seliman with her piece titled 'Let's talk about sexuality and intimacy for women with spinal cord injury.' Merna's research aims to explore the lived experiences of women with SCI and their needs related to sexuality and intimacy, for which practical knowledge and resources are severely lacking. In Merna's words, "Every single woman who has participated in the study expressed gratitude that this research was being done."

Read all eleven pieces in *Why Research Matters 2023*. We are sure you will be impressed by the scope of the research, and the engaging style of the articles. Read previous editions of *Why Research Matters* on the [SRI's website](#).

Click
to read



11 AUTHORS
6 COUNTRIES



Funded Research & Clinical Trials Partnership

Funded Research

In the past year the Spinal Research Institute (SRI) has supported the 5-year follow up to the International Spinal Cord Injury Survey, the first international community survey that focuses both on the lived experience of people with spinal cord injury and the societal response to their needs. The SRI is co-funding the Australian arm of the survey (Aus-InSCI).



Aus-InSCI represents the largest and most comprehensive survey of health related issues, functioning, social inclusion, economic participation and support needs of people with spinal cord injury ever conducted in Australia. Results from the survey will be used to improve clinical practice, increase community support and change policies and systems to enhance the lived experience of people with spinal cord injury in Australia.

The SRI is proud to support this leading collaborative national and international initiative to help improve the health and quality of life of people with spinal cord injury.

Clinical Trials Partnership

The SRI is currently partnering with several SCI research projects in a consumer advisory capacity, including Aus-InSCI. Another project is the neurostimulation clinical trial being led by Professor David Berlowitz (right), University of Melbourne Chair in Physiotherapy at Austin Health.

Professor Berlowitz is testing the effects of transcutaneous spinal stimulation, therapeutic acute intermittent hypoxia and intensive muscle training on upper limb and respiratory function after cervical spinal cord injury (tetraplegia).

Antonio Vecchio, the SRI's Community and Consumer Engagement Manager (far right), is a member of the trial's consumer advisory committee, providing the perspectives and input of a person living with spinal cord injury. Consumer engagement is vital to increasing research impact, and the consumer advisory committee is integral to the project's governance, trial design, research translation, and disseminations of outcomes.

The SRI is proud to be a consumer partner of this world-leading trial with the potential to return function to people with SCI.



ISCoS Partnership

International Spinal Cord Society (ISCoS) partnership

In 2023, the Spinal Research Institute (SRI) continued its partnership with the International Spinal Cord Society (ISCoS). This partnership enabled streamlined facilitation of the SCI Research Collaboration Grants, cross-promotion of a range of activities, and sharing of resources relating to spinal cord injury research.

Partnering with ISCoS provided an opportunity to add more value to the conference experience for our 2023 SCI Research Collaboration Grant recipients. Dr Haleluya Moshi, Jacob Schoffl, Keira Tranter were invited to participate in the *SCI Care: What Really Matters* podcast series, talking with SRI CEO Kristine Hendry about their experiences as first time attendees at ISCoS, and the importance of the SRI's grants program in supporting their attendance.

 **Listen to the podcast with Dr Haleluya Moshi (3 min)**

 **Listen to the podcast with Jacob Schoffl and Keira Tranter (3 min)**

MENTOR PROGRAM DEVELOPING & STRENGTHENING EMERGING SPINAL CORD INJURY RESEARCH TALENT INTERNATIONALLY

PELEG E¹, HENDRY K¹, BROWN DJ¹, GRACO M², & BARCLAY L¹

INTRODUCTION

Structured mentoring over an extended period of time provides significant benefits to those who participate and equips individuals with skills that might not be available within their own organisation or institution. The SRI's Mentor Program is now in its fourth year. The program aims to progress the research careers of talented spinal cord injury (SCI) early career researchers (ECR's) and clinician researchers, particularly those from developing countries, and with limited access to experienced researchers.

METHODS

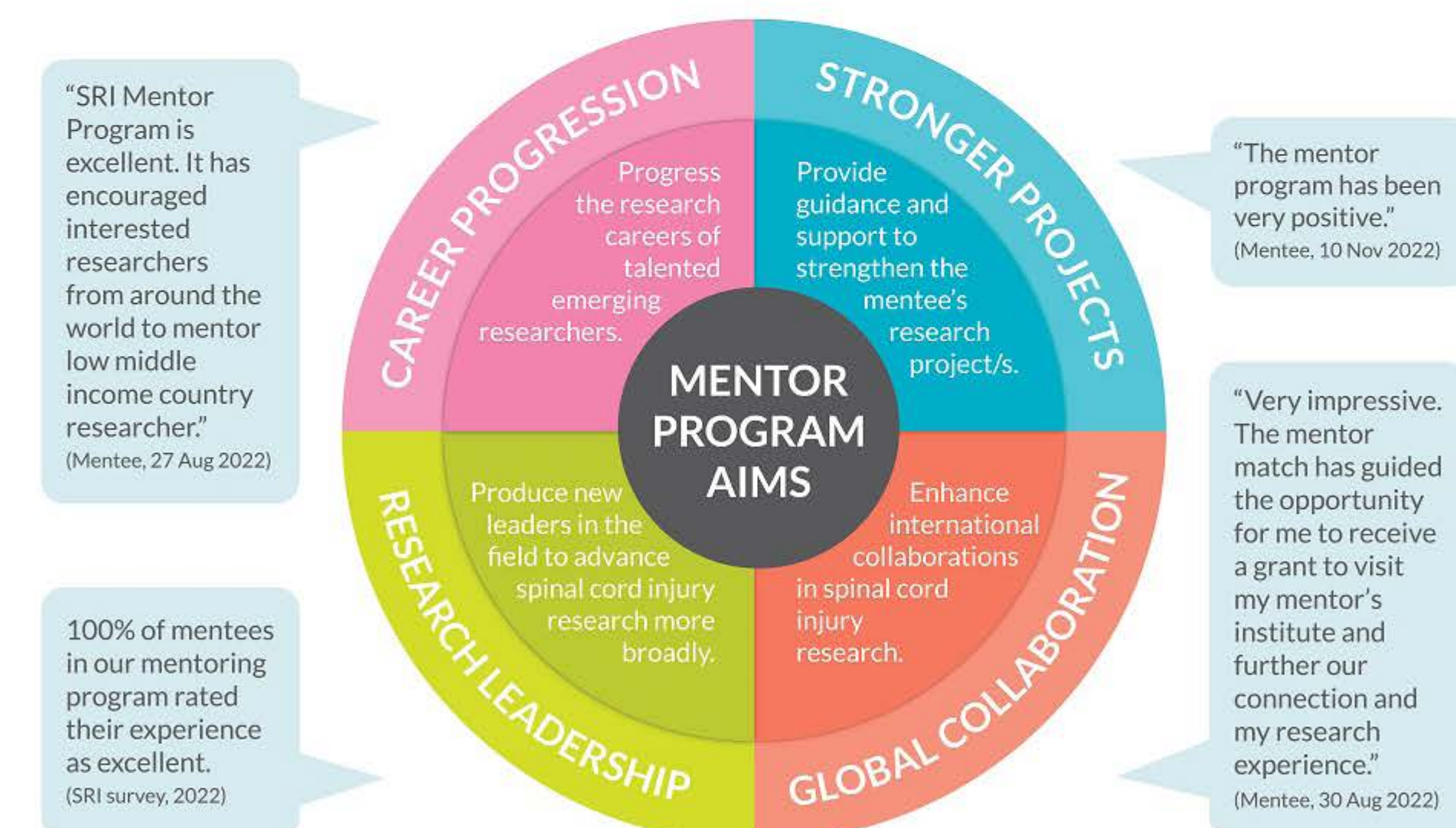
Eligibility for mentee participation is assessed through a competitive application process. Once a mentee is accepted into the program, significant consideration is given to finding a mentor who aligns with the mentee's research area and objectives. A baseline survey and follow-up surveys every six months are conducted to gain feedback to help improve the program, and determine whether or not the program is achieving its objectives.

RESULTS

Mentees from eight countries have been paired with mentors across the world. 100% of mentees reported feeling strongly connected with the SCI research field and were confident to progress their research after the mentor program. This is a 40% increase from baseline reporting. 100% of mentees reported that the mentor program had improved their SCI research skills.

CONCLUSION

Applications for the Mentor Program doubled in 2023, indicating that this program is fulfilling a need within the SCI research community. Our Mentor Program equips researchers with skills that might not be available within their own organisation or institution.



anzscos
Australian & New Zealand Spinal Cord Society

Author affiliations:
¹Spinal Research Institute, Australia
²Institute for Breathing and Sleep, Austin Health, Melbourne, Australia



Scan the QR code to find out more about the Spinal Research Institute and our Mentor Program. There are also links to sign up for our newsletter and follow us on social media.



UTILISING SOCIAL AND DIGITAL MEDIA TO ENGAGE THE BROADER SPINAL CORD INJURY COMMUNITY AND CREATE RESEARCH AWARENESS

VECCHIO A¹ & BACKHOUSE C¹

INTRODUCTION

Increasingly, consumers of health services expect to have greater input into research that affects their lives. This creates challenges for organisations and researchers to ensure that they engage with the consumer community. Social and digital media provide opportunities for engagement that traditional forms of dissemination lack.

METHODS

A series of ten short videos was created during the International Spinal Cord Society (ISCoS) 2022 Annual Scientific Meeting in Vancouver. Eight of the videos were recorded live and released to the audience to provide real time updates. Key topics addressed in the videos included an explanation of how ISCoS provides a forum for researchers and clinicians to share their work and creates opportunities for collaboration.

Social media analytics were collected for each video within a specific time frame. Results were recorded for the series and captured one week after the release of the final video.

RESULTS

The series had a total of 3,232 views over the data collection period. The most watched video was the third in the series: "Inukshuks - Consumer Voice" (461 views). The least watched video was the seventh in the series "Posters - why are they great" (203 views).

The strongest performing platform was LinkedIn (1,157 views), followed by Twitter (1,013 views) and then Facebook (1,013 views).

CONCLUSION

Organisations and researchers have a responsibility to communicate with consumers, however traditional means of dissemination such as email and websites are becoming less effective. Social media provides a platform to engage consumers with whom researchers might not otherwise have had the opportunity to do so.



anzscos
Australian & New Zealand Spinal Cord Society

Author affiliation:
¹Spinal Research Institute, Australia



Scan the QR code to find out more about the Spinal Research Institute and our Consumer Engagement Program. There are also links to sign up for our newsletter and to follow us on social media.



BRIDGING THE GAP BETWEEN CONSUMERS & RESEARCHERS THROUGH EDUCATION TO PROVIDE GREATER CONSUMER ENGAGEMENT

VECCHIO A¹, BACKHOUSE C¹, HENDRY K¹, & BROWN DJ¹

INTRODUCTION

Research institutions and funding bodies increasingly require demonstration of consumer engagement in research projects, beyond only trial participants. However, consumers often feel they do not have enough knowledge about the research process to get involved. Through its Consumer Engagement Program, the Spinal Research Institute (SRI) aims to bridge this gap by providing consumers with education about involvement in all stages of the research process.

METHOD

In 2022, the SRI developed a four-part webinar series delivered at six week intervals. The purpose was: 1. to provide people with lived experience of spinal cord injury (SCI) a foundation knowledge of the research process, and 2. to increase researchers' awareness of the value of consumer engagement and provide strategies for incorporating consumer engagement into their research practice. The recordings from the series were repackaged as a series of 16 short, single topic videos that have been posted on YouTube as a permanent resource.

RESULTS

The webinar series was successfully completed in August 2022. The first two webinars focused on the role research has on the quality of life of the consumer community and highlighted strategies for greater consumer engagement. The third webinar provided an opportunity for consumers to engage with researchers directly and showcased the diversity of research within the SCI field. The fourth webinar focused on a current PhD candidate who explained how they incorporated consumer engagement in their doctoral research. The mean series viewer registration was 57.

CONCLUSION

Education plays a vital role in facilitating consumer engagement in SCI research. Increasing researchers' knowledge and skill sets allows them to work together in partnership to ensure research outcomes represent the needs of the consumer community. However, the education should be explicitly targeted to each audience rather than broadly disseminated.



anzscos
Australian & New Zealand Spinal Cord Society

Author affiliation:
¹Spinal Research Institute, Australia
Spinal Research Institute Consumer Engagement Program:
thesri.org/consumer-engagement



The Spinal Research Institute thanks the following organisations for their support of the Consumer Engagement Program and the webinar series:
IQOF Foundation
Marion's Ed Fick Trust
John T Reid Charitable Trusts
Brian M Davis Charitable



A full list of the SRI's publications is available on our website.

Visit website

The three posters above were presented at the 2023 Meeting of the Australian & New Zealand Spinal Cord Society in Adelaide, Australia. The Mentor Program poster was also presented at the 62nd Annual Scientific Meeting of the International Spinal Cord Society in Edinburgh, Scotland. Click the poster to see or download a larger version.



Spreading our message

To coincide with World SCI Day on 5 September 2023, the SRI's Founder and Director Associate Professor Doug Brown AM was interviewed for The House of Wellness TV and radio programs. The impacts of spinal cord injuries are profound and far-reaching, touching the lives of many Australians each year. Raising awareness about spinal cord injuries is vital in driving prevention, supporting research, enhancing medical care, and fostering social inclusion. Through ongoing awareness building, we can make a positive difference in the lives of those

affected by spinal cord injuries, ultimately promoting a healthier, more compassionate Australia.



Antonio Vecchio presenting to William Buck staff

International Day of Persons with Disabilities

To mark International Day of Persons with Disabilities on 3 December 2023, SRI's Community & Consumer Engagement Manager, Antonio Vecchio, was invited by William Buck (accounting and advisory services firm) to present on the impact of spinal cord injury (SCI). Antonio spoke about the challenges to employment when you have a disability and the benefits of workplace flexibility to help overcome barriers to inclusion. It's great to see businesses interested in learning about SCI, educating their employees, and valuing diversity.



International
Day of
**Persons with
Disabilities**
3 DECEMBER



Acknowledgements

The Spinal Research Institute (SRI) relies on external expertise to ensure our program selection processes are robust and transparent. We would like to thank all of our reviewers and judges for their generosity in providing their time, guidance and knowledge. We would also like to thank the researchers who have shared their experience and insight as mentors in the Mentor Program.

We would like to particularly acknowledge the contribution of Dr Harvinder Chhabra, for his input to Board matters in an advisory capacity.

SCI Research Collaboration Grants reviewers

- Professor Graham Creasey, Stanford University, USA
- Campbell Message PLY, Paralympics Australia, Australia
- Dr Colleen O'Connell, Stan Cassidy Centre for Rehabilitation, Canada

Mentor Program reviewer and mentors

- Dr Marnie Graco, Austin Health, Australia (reviewer)
- Professor Graham Creasey, Stanford University, USA
- Dr Priya Iyer, University of Sydney, Australia
- Dr Steven Kirshblum, Kessler Institute for Rehabilitation, USA

SCI Research Writing Prize judges

- Dr Emily Bray, Griffith University, Australia
- Stephen Muldoon, Muldoon Consultancy, Ireland

Board Advisor

- Dr Harvinder Singh Chhabra, Sri Balaji Action Medical Institute, India



SRI-hosted breakfast at the 2023 ISCoS Annual Scientific Meeting

Each year at the ISCoS meeting, the SRI hosts a networking breakfast for our SCI Research Collaboration Grant recipients, many of who are attending the ISCoS meeting for the first time. The breakfast is an opportunity for the grant recipients to meet each other, as well as past grant recipients, senior researchers and clinicians, and the SRI team.



Celebrating the vision of our donors and supporters

As we reflect on the SRI’s significant impacts of 2023/24 in this report, it’s essential to express our sincere gratitude to our generous community of donors and supporters.

In collaboration with our donors we have been able to propel SRI’s vision to advance spinal cord injury research so that we can transform the everyday lives of those with a spinal cord injury. Our success is a testament to the collective commitment of our donors to bring about this positive change.

In 2023 this included the renewal of two philanthropic grants that transformed into multi-year partnerships, joining our other highly valued long term multi-year donors. These partnerships underscore our strong relationship with donors and our shared commitment to tackling our three pillars of support: consumer engagement, collaborative research and support for emerging researchers.

All our donors have demonstrated vision and a drive for impactful change in 2023 whether this be in striving for transformative co-designed research, joining together researchers on the SRI’s innovative online

Hub to cross geographical borders and build networks capable of advancing research; or by supporting our future generations of researchers to thrive. Working with our inspiring and committed philanthropic community has been a pleasure and a privilege.

Thank you!
Deirdre Mori, Development Manager

Founding Donors

Ms Joanna Baevski
Mr Geoff Handbury AO
Dr Peter Kingsbury
Mr Irving Lenton
Mrs Rae Rothfield
Lady Southey AC
Mr Zich Woinarski KC

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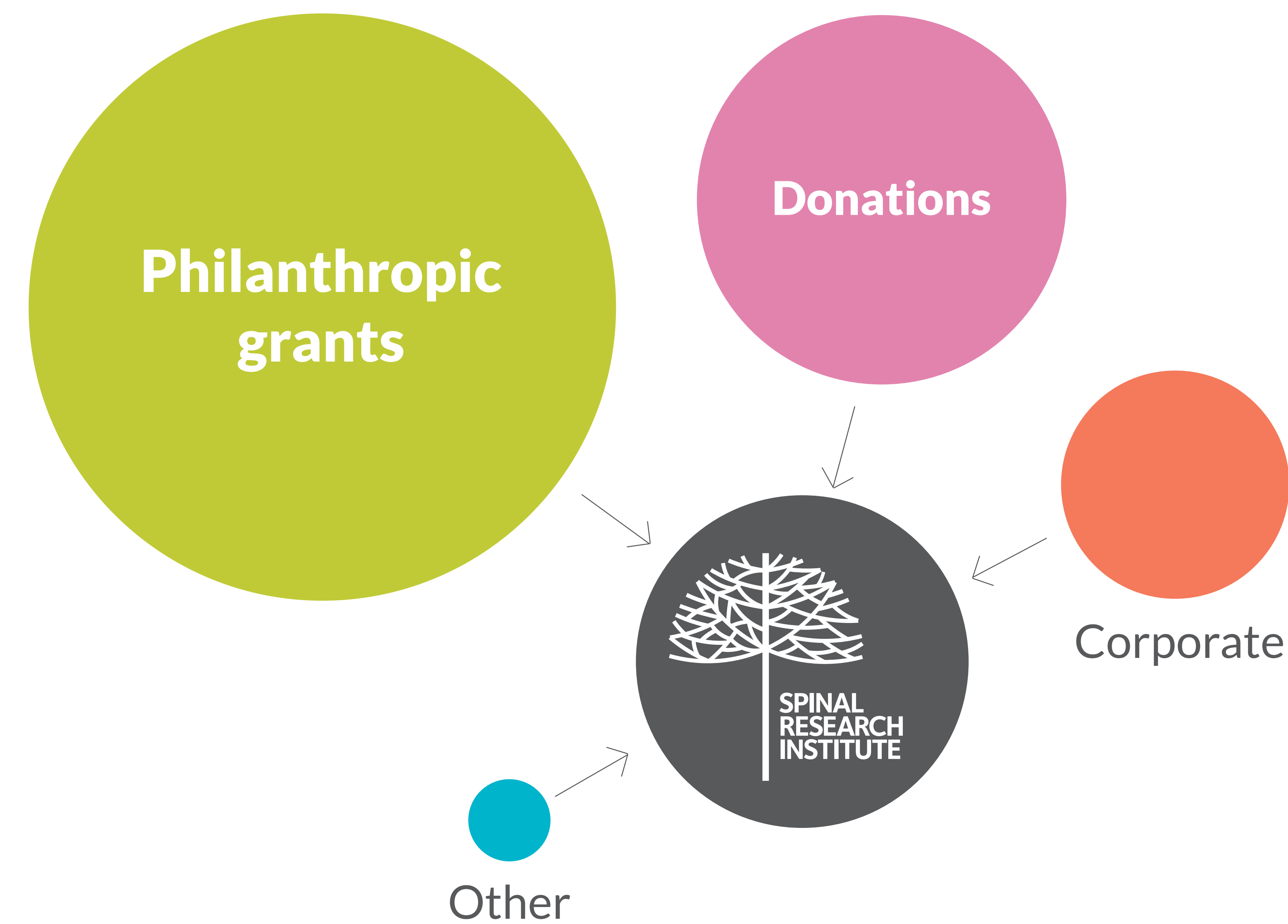
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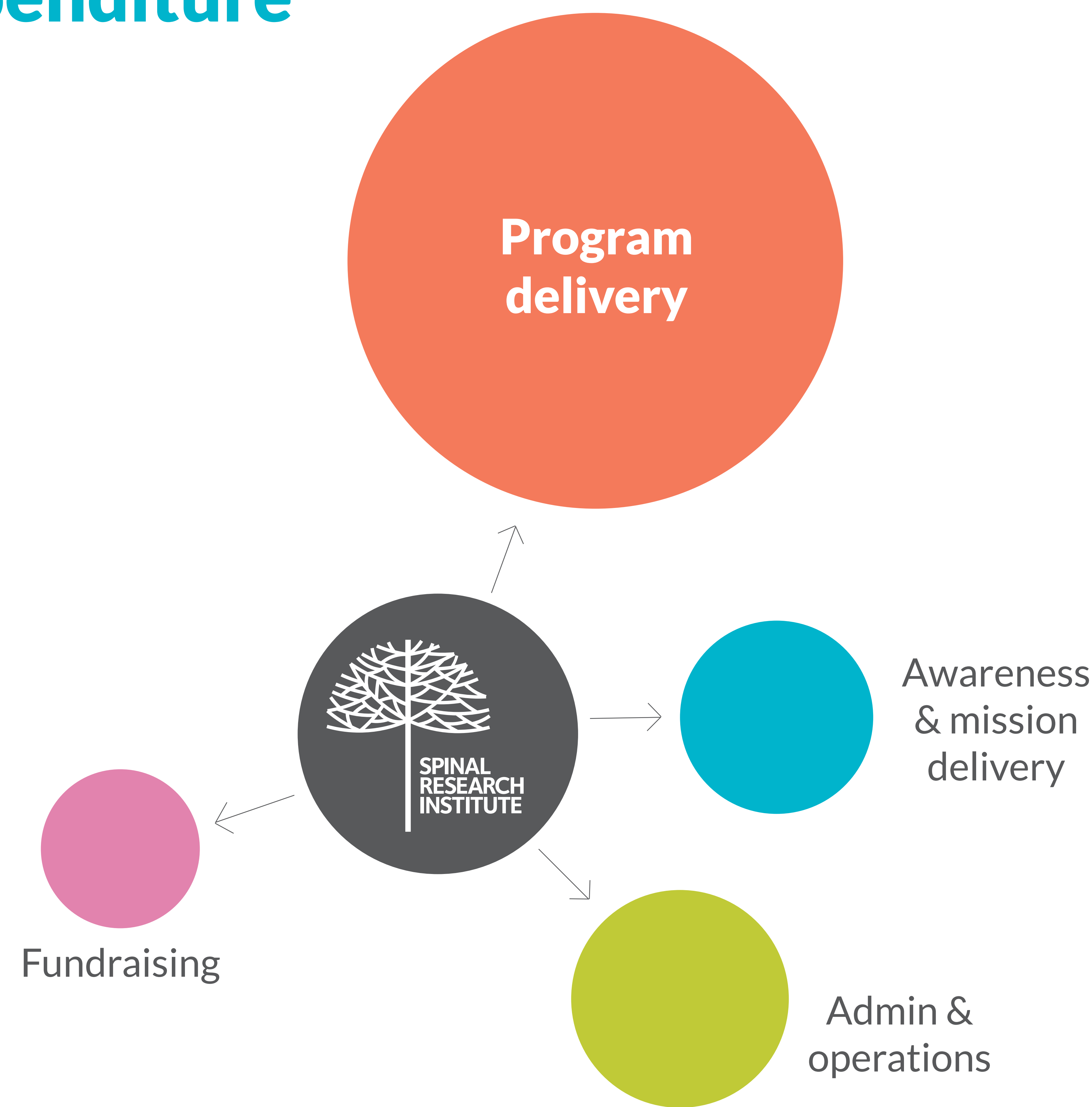
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FOUNDATION

Austin
HEALTH

Funding sources



Expenditure



This information is based on figures from the 2023 financial year.
Our financial reports can be found on the [Australian Charities and Not-for-profits Commission website](#).



Where to next?

While this report has focused on the recent achievements and impact of the Spinal Research Institute (SRI) there are also many exciting things planned for 2024/25.

In September, members of the SRI team travelled to Antwerp, Belgium, to attend the 63rd International Spinal Cord Society Annual Scientific Meeting. The team presented posters and workshops, met with recipients of the 2024 SCI Research Collaboration Grants (who you will meet in next year’s Impact Report), established new relationships, and reconnected with international colleagues.

In addition to our continued support for early career researchers through our SCI Research Collaboration Grants and Mentor Program, we have exciting plans to introduce a new grant to support an Australian-based student undertaking PhD research within the spinal cord injury field.

With the launch of the SRI’s report, The Landscape of Spinal Cord Injury Research in Australia 2018-2023, we look forward to engaging with the local SCI community to delve into the opportunities identified for new research approaches and models.

Following the release of new service offerings on the Spinal Cord Research Hub (SCoRH) this past year, we are excited to advise that a complete refresh of the platform will commence soon, with a fresh new user experience. Existing SCoRH features will be enhanced and new features introduced, providing even greater opportunities to connect and collaborate with colleagues around the world.

With increasing demand for consumer engagement in research, we are also looking forward to helping more researchers embed co-design principles into their research projects, and to partner on projects in a consumer advisory capacity. As we grow our database of consumers who have an interest in participating and partnering in research, we will develop additional resources to support them in these roles.

Year on year we are increasing our impact, helping us achieve our goal of improving health outcomes and quality of life for people with spinal cord injury.

If you want to hear about these developments as they happen, follow us on social media or subscribe to our Plexus mailing list.

Stay in touch

Contact details

Address
Spinal Research Institute
Royal Talbot Rehabilitation Centre
1 Yarra BoulevardKEW 3101

Telephone
+61 3 9496 2579

email
info@thesri.org

Website
<https://www.thesri.org/>

Connect with us on social media



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This list is for people with lived experience of SCI, although everyone is welcome.

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SCoRH

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