

Module 12 – SCI 101 for Researchers

Getting Started as an SCI Researcher

NASCIC is continually active in partnering on research projects that bring about positive change for persons living with SCI. We have programs designed to facilitate the engagement of people with lived experience, and we can help you develop and run a successful engagement program. We also promote recruitment for clinical trials.

Ian Burkhart – We review any active projects to make sure that the goals and conditions of individuals with lived experience are in mind and are active priorities of the project.

The review criteria include the likelihood that a project will:

1. Form relationships between individuals and organizations representing SCI;
2. Exchange valid, trustworthy, and useful information, experience, and knowledge;
3. Promote best practices in research, treatment, and care;
4. Create and/or strengthen a unified voice for SCI in North America;
5. Promote collaboration among experts in the fields of research and/or clinical care and/or advocacy;
6. Impact the lives of people living with SCI; and
7. Meaningfully and actively engage persons with lived experience of SCI.

NASCIC has two programs to facilitate engagement of people with lived experience in research projects: Letters of Support, and Project Partnerships.

A Letter of Support provides a commitment to you that if your project is funded, NASCIC will work with you to ensure that the SCI community is engaged. If the project is funded, NASCIC will work with the requesting group on a Project Partnership Submission; however, a Letter of Support is not a guarantee that a Project Partnership will be approved.

NASCIC helps researchers engage people with SCI directly through Project Partnerships. Project Partnerships may include but are not limited to establishing consumer advisory boards, recruiting for focus groups or in-depth interviews, and advisors for community survey design and recruitment.

You may request a Letter of Support or propose a Project Partnership by filling out the appropriate form on our website at <https://nasciconsortium.org/projects/application/>.

NASCIC's Project Review Committee (or "PRC") will review the application and respond to the applicant within three business days.

The PRC is a voluntary committee chaired by NASCIC's Vice President that includes people with lived experience of SCI, researchers, and SCI community organization representatives. The PRC works iteratively with applicants, if needed, to suggest revisions or clarifications that the submitting group may make to the proposal to ensure alignment with NASCIC's project partnership criteria.

NASCIC also supports and practices the Integrated Knowledge Translation (or IKT) Guiding Principles described in the previous module titled "SCI 101 for Researchers." We strongly encourage all applicants to review these principles and apply them to your proposal.

For both Letters of Support and Project Partnerships, the PRC scores the final submission from 1-5 on each of the NASCIC criteria, for a maximal score of 35. Submissions that score above 23 will advance to review by the NASCIC Executive Council. Submissions that score under 23 will not be approved, but the applicant will receive an explanation of the PRC's score. The applicant can use this feedback to refine and resubmit the project.

Approval is based on a simple majority vote of the Executive Council. A submission that is not approved can be returned to the PRC to request further modification by the submission team.

If a Project Partnership is approved, NASCIC's Vice President will work with the submitting group's project lead to establish specific recruitment criteria and will query the Project Engagement Database of research advocates. If needed, NASCIC may make an open call to partner member organizations to fulfill the specific needs of the project.

NASCIC must be acknowledged for its role in the project in any publications, promotional material or other project-related communications. At project completion, NASCIC surveys participants including both the project lead and SCI advocates. The survey helps NASCIC evaluate the effectiveness of the engagement and identify lessons learned. Additionally, post-project surveys help NASCIC refine its processes and guidelines for engagement.

Research Recruitment

In addition to facilitating community engagement, NASCIC can assist in promoting recruitment for clinical trials by leveraging its 400+ members and social media channels. To request NASCIC's assistance with research recruitment, complete the form on NASCIC's website at <https://nasciconsortium.org/projects/application/>. The PRC will review your request and respond within 3 business days. The PRC requires a review of recruitment materials, IRB or ethics board approval, and, if applicable, the research instrument or the listing on clinicaltrials.gov.

Now, let's review questions that advocates and researchers should ask before agreeing to participate in a research engagement.