



Response to the NIH NINDS RFI for the Research Themes resulting for SCI 2020

July 29, 2019

The [North American Spinal Cord Injury Consortium \(NASCIC\)](http://www.nasciconsortium.org) is a consortium representing all individuals living with SCI and their families in the countries and territories making up North America. We are very supportive of research impacting people living with SCI, their caregivers and family (collectively the SCI Community), and we fully understand that different types of research have different timelines associated with potential impact on the community. It is our mission to partner with various stakeholders to identify and develop effective means to ensure that SCI research **does** reach the community living with SCI.

Accordingly, we suggest that across all priorities, grant proposals should foster inclusion of at least 2 individuals living with SCI or a family member of someone with SCI as team members, as well as a plan for dissemination of grant outcomes in lay language to the community living with SCI. To this end, NASCIC is willing to help facilitate connections and resources for researchers with respect to these two endeavors.

We have suggested specific edits and/or additions to each of the 5 themes below.

Theme A should also include:

- the establishment of implementation strategies for evidence-based medical guidelines
- the implementation of new rehabilitation strategies for the inpatient setting
- the early onset of care/interventions targeted at preventing the development of future secondary health conditions
- learning from trauma triage care for other traumatic injuries such as stroke or TBI

Theme B should also include:

- the establishment of a mechanism to determine when findings related to repair and plasticity are ready to be moved to the next stage of translation; this mechanism should include input from scientists, clinicians, the SCI community, industry, and funders
- a plan for effectively moving research outcomes along the wheel of translation

Theme C should also include/revise:

- understanding how to effectively implement neuromodulation interventions in both the healthcare and community settings by partnering with healthcare providers, consumer-based organizations, technology vendors, and reimbursement specialists
- the inclusion of a plan for research outcomes to move along the wheel of translation



- revise bullet 3 to ‘Facilitate data sharing and aggregation to enable data science research (including machine learning) that can inform clinical care and improve cost effectiveness of interventions that target recovery’

Theme D should also include/revise:

- revise bullet 2 to ‘Understand the impact of behavioral, lifestyle, and environmental factors to reduce morbidity and mortality across the lifespan of people with SCI, with a special emphasis on pain, respiratory health, nutrition and metabolism, activity/exercise, and lean/fat mass as a biomarker of obesity’
- revise bullet 4 to ‘Understand the biology and impact of SCI on systemic health with emphasis on stressors that affect the immune function, the role of sensory and autonomic regulation, and physical, social, and mental health outcomes’
- include understanding and enhancing the utilization of tele-health technology in clinical studies and clinical care delivery
- include a mechanism to communicate and disseminate results to the clinical and SCI communities

Theme E should also include/revise:

- revise bullet 1 to ‘Demonstrate how assistive devices can be used to promote independence, prevention of secondary conditions, and improve recovery after discharge’
- revise bullet 2 to ‘Incorporate user input, comparative effectiveness research, and data sharing strategies to establish robust evidence for translation and adoption of assistive technologies’
- revise bullet 3 to ‘Improve the reliability and stability of devices and tissue interfaces to lower barriers to adoption and access as well as improve embodiment’
- add ‘understand how to effectively implement assistive technologies in the healthcare setting and community setting by partnering with healthcare providers, consumer-based organizations, technology vendors and reimbursement specialists’

In conclusion, the revisions and suggestions provided by NASCIC are founded in the integrated knowledge translation (IKT) framework that the SCI community will become partners in the research process. By definition, IKT engages end users throughout the entire research process. “By doing integrated KT, researchers and research users work together to shape the research process by collaborating to determine the research questions, deciding on the methodology, being involved in data collection and tools development, interpreting the findings, and helping disseminate the research results. This approach, also known by such terms as collaborative research, action-oriented research, and co-production of knowledge, should produce research findings that are more likely to be relevant to and used by the end users (<http://www.cjhr-irsc.gc.ca/e/29418.html>).”

Sincerely,

The North American Spinal Cord Injury Consortium Executive Council



North American
Spinal Cord Injury
— Consortium —

Tel: 1-800-361-4004

Email: info@nasciconsortium.org

Website: www.nasciconsortium.org

Kim Anderson, President (Case Western Reserve University)

Jennifer French, Interim Vice-President (Neurotech Network)

Barry Munro, Treasurer (Canadian/American Spinal Research Organization)

Bill Fertig, Delegate (United Spinal Association)

Alexander Rabchevsky, Delegate (University of Kentucky)

Matthew Rodreick, Delegate (Unite 2 Fight Paralysis)

Rob Wudlick, Delegate (GUSU 2 Cure Paralysis)

John Chernesky, Ad Hoc Delegate (Rick Hansen Institute)

C/O Canadian/American Spinal Research Organization
1623 Military Road, #271, Niagara Falls, NY 14304