

9-16-2022

Engaging Stakeholders as Advisors on the Design of a Large-Scale Calibration Study of the Spinal Cord Injury Movement Index (SCI-MI) Item Pools

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Biller, OTDc, Olivia M.; Biundo, BS, Jason; Mitchell, MBA, Edward S.-L.; Ofori, MB ChB, LMCC, Ernest; Richardson, Bonnie; Kim, OTD, OTRL/L, Rachel Y.; Gerhardt, MS, OTR/L, CBIS, Nicole; and Mulcahey, PhD, OTR/L, FASIA, M.J., "Engaging Stakeholders as Advisors on the Design of a Large-Scale Calibration Study of the Spinal Cord Injury Movement Index (SCI-MI) Item Pools" (2022). *Department of Occupational Therapy Posters and Presentations*. Paper 74.

<https://jdc.jefferson.edu/otpresentations/74>

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Introduction

People living with spinal cord injury (SCI) in North America are involved in the following as stakeholders in research:

- identifying priorities for research¹,
- planning interventions^{2,3,4}, and
- implementing rehabilitation³ or peer-support interventions⁴.

The best practice is for partnerships to span the continuum of research⁵.

Project purpose: to collaborate with an advisory board of individuals living with SCI, to make recommendations for the methods of a large-scale calibration study of the Spinal Cord Injury Movement Index (SCI-MI).

The SCI-MI is being developed as a SCI clinical trial outcome assessment to evaluate the construct of movement in the context of function using item-response theory.

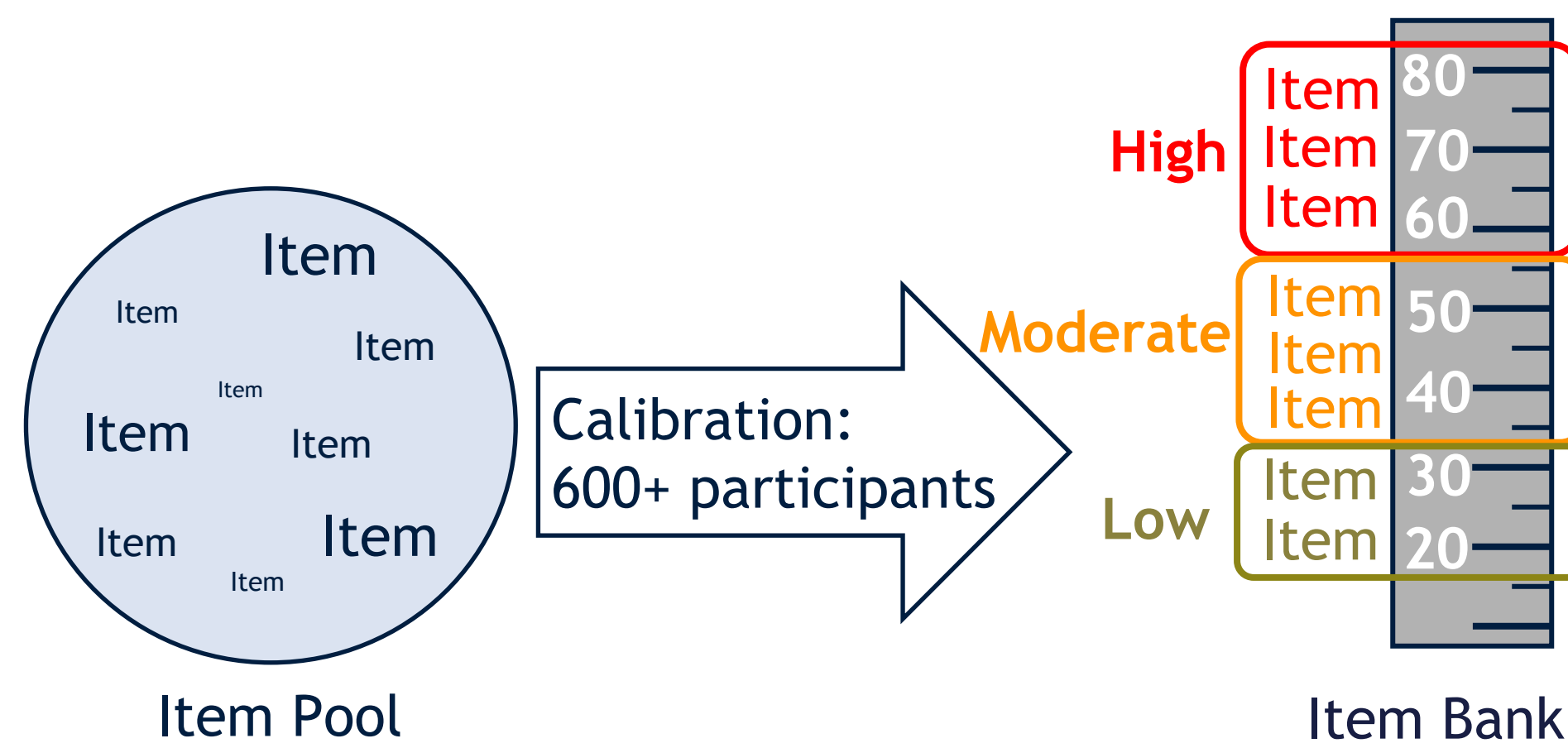
- Performance-based assessment with standardized administration and scoring
- Large candidate item pools for fine and general movement, as well as buckets for early administration after SCI and for those who walk (Figure 1)
- Calibration study involving recruitment of at least 600 participants internationally (Figure 2)

Figure 1. Example SCI-MI Candidate Items



Abbreviation: SCI-MI, Spinal Cord Injury Movement Index.

Figure 2. Calibration of an Item Pool into an Item Bank

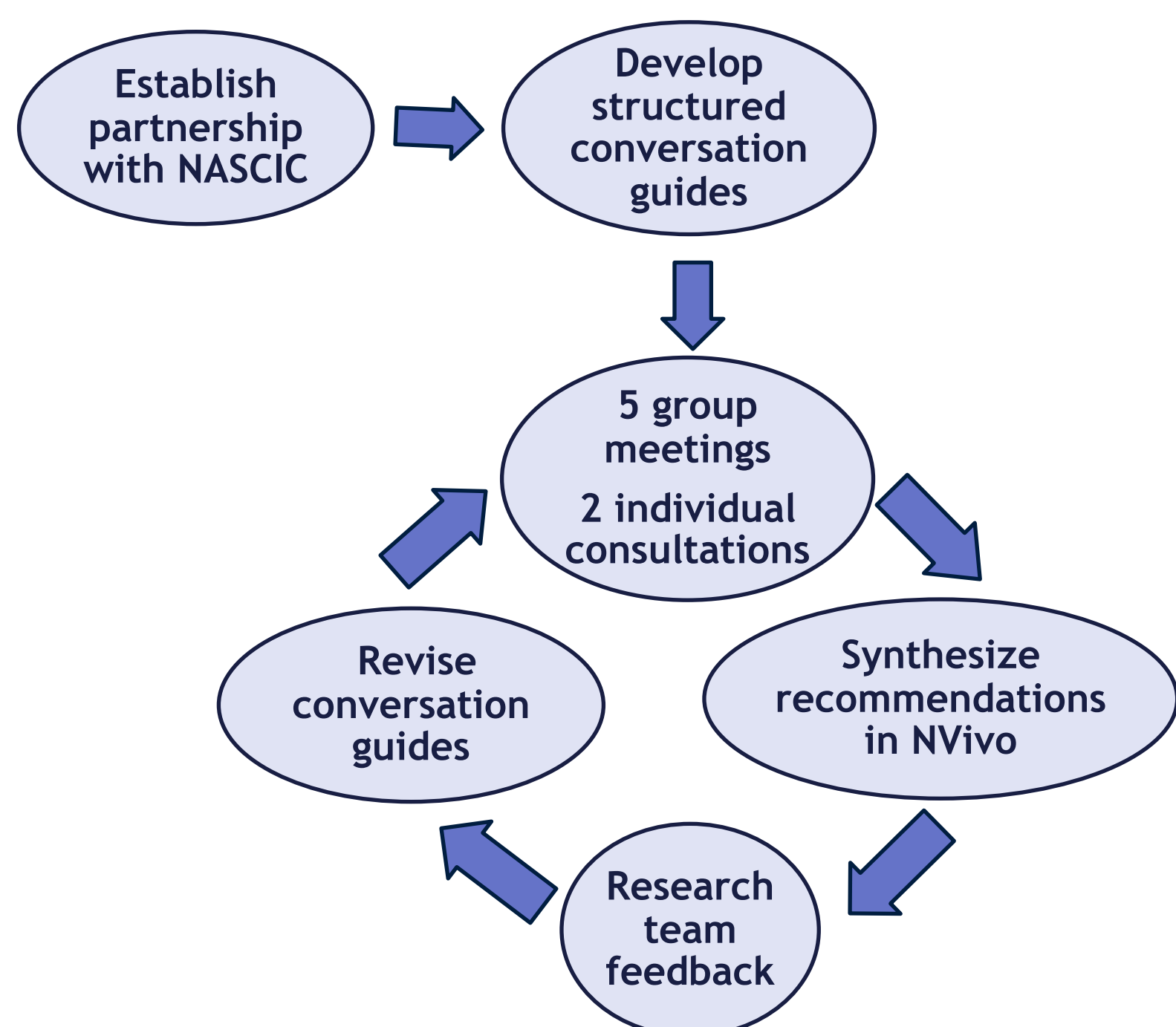


Methods

The research team used the formal process set forth by the North American Spinal Cord Injury Consortium (NASCI) to create and engage the advisory board.

- Virtual meetings followed structured conversation guides (Figure 3).
- There were five 1-hour group meetings and two 1-hour consults per advisor (Figure 4).
- Meetings were recorded, transcribed, and imported into NVivo (Release 1.6.1, QSR International Ltd., US) to synthesize advisor recommendations.
- Advisors revisited and clarified recommendations at each meeting.
- Advisors provided feedback about the partnership with a modified self-report survey⁶, and results were analyzed in Microsoft® Excel (Version 16.60).

Figure 3. Flow Diagram of Creating and Engaging the Advisory Board



Abbreviation: NASCI, North American Spinal Cord Injury Consortium.

Figure 4. Schedule and Agenda for Advisory Board Meetings

Month	Activities	Key
Month 1	Overview of the SCI-MI Data collection	Group meeting <input type="checkbox"/> Individual consultation <input type="checkbox"/>
Month 2	Participant enrollment Reduce participant burden	Feedback via self-report survey
	Future stakeholder engagement Finalize recommendations	
Month 3	How to disseminate findings	Modified Stakeholder-Centric Engagement Evaluation ⁶ Likert Scale 1-Poor 2-Neutral 3-Good 4-Very Good 5-Excellent

Abbreviation: SCI-MI, Spinal Cord Injury Movement Index.

Results

12 individuals applied to serve on the advisory board, and 4 applicants were selected (Figure 5).

- 3 advisors lived throughout the United States, and 1 lived in Canada.
- All advisors had incomplete spinal cord injuries.
- Qualifications included experience with neuroscience, medicine, governmental programs, legislative advocacy, and stakeholder engaged research.

The advisory board generated 30 recommendations for the future calibration study, falling into 6 discrete areas of research methods (Figure 6).

The results of the modified Stakeholder-Centric Engagement Evaluation showed engagement areas were rated Very Good to Excellent (Table 1).

- Lowest rated area: "The advisory board and the research team learn from each other's expertise" (average item score = 4.5)
- Highest rated area: "Deal with conflict and disagreement effectively" (average item score = 4.79)

Figure 6. Recommendations from the Advisory Board for the SCI-MI Calibration Study Methods (Abbreviated)

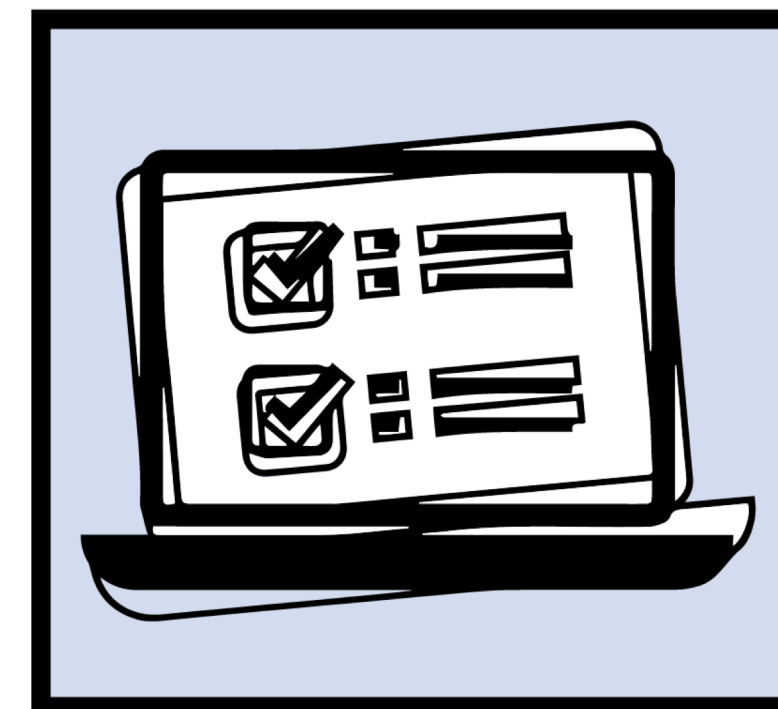


RECRUITMENT AND ENROLLMENT

- Recruit from Major SCI centers like SCI Model Systems.
- Recruit from specialized gyms like the NeuroRecovery Network.
- Share materials to social media and SCI advocacy organizations.
- Home data collection not a priority but could be necessary for certain demographics.

INTAKE

- Create an accommodations intake questionnaire.
- Let participants know what accommodations are possible.
- Participants should have the ability to decline the International Standards for Neurological Classification of Spinal Cord Injury physical exam.
- Note medications or secondary conditions that impact movement.



MAKING PARTICIPATION EASIER

- Coordinate and reimburse accessible parking options.
- Make a team member available and responsible for assisting participants.
- Offer a flexible schedule for data collection.
- Have a separate space/waiting area for participant caregivers.

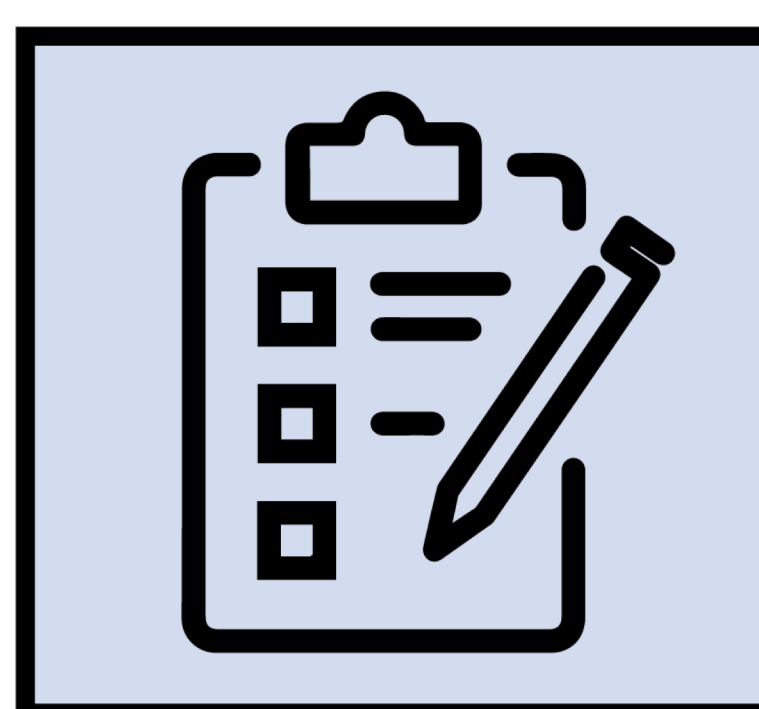
COMPENSATION

- Appropriately compensate participants for their time spent.
- Have compensation available in multiple forms (including an ABE account).
- Acknowledge participants in publications.
- Provide clear methods for participants to stay connected regarding the study.
- Educate participants about the data collected about their SCI during intake and their performance on the SCI-MI.



TEST ADMINISTRATION

- Include authentic, encouraging language in any scripts.
- Prevent fatigue by offering optional rest breaks between test items.
- Offer standardized walking devices (walker, crutches, etc.).
- Clinicians and students with SCI experience should administer the test.
- Create an optional feedback survey for participants to take after completing data collection.



FUTURE ADVISORY BOARDS

- The advisory board should include diversity in stakeholder roles, identities, geographic locations, etc.
- Advisors should try SCI-MI items and participate in the calibration study.
- Advisors should serve as recruitment liaisons.
- Advisors should create and review educational and feedback survey materials.
- Advisors should co-author publications and publicity materials.

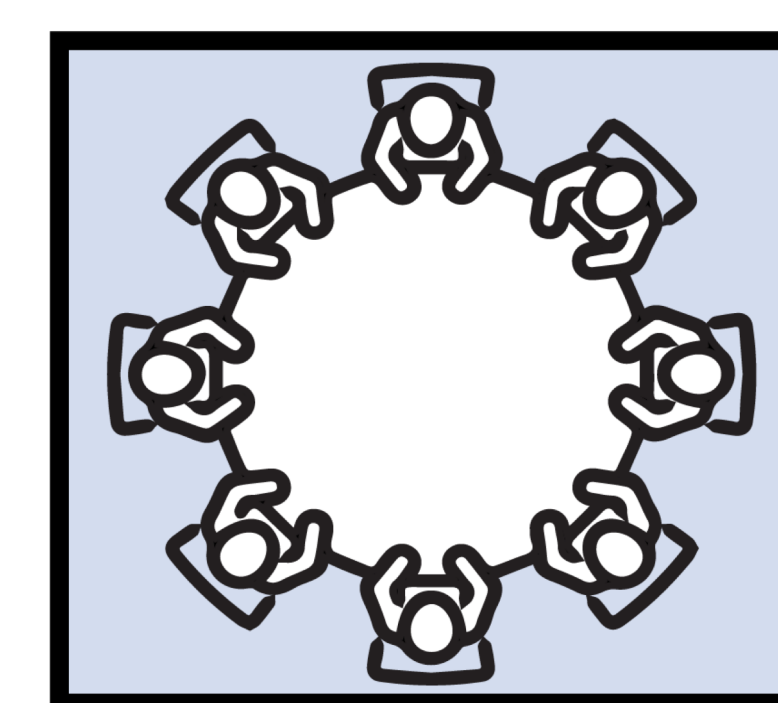


Figure 5. Members of the Advisory Board



Table 1. Modified Stakeholder-Centric Engagement Evaluation Results per Engagement Area

Engagement area	Mean score	Total score	Average item score	Average quality of engagement
Respect and value advisory board perspectives	37.75	40	4.72	Excellent
The advisory board and research team learn from one another's perspectives	31.5	35	4.5	Very Good/Excellent
Deal with conflict and disagreement effectively	28.75	30	4.79	Excellent
Communicate with advisory board members using effective methods	32.75	35	4.68	Excellent
Use a clear organizational structure	9.5	10	4.75	Excellent

Discussion

The recommendations for the methods of the SCI-MI calibration study:

- Will be used as guidelines when applying for grants and creating study protocols
- Have the potential to position the calibration study for greater success

Action items generated from the advisory board recommendations include:

- Developing a second partnership with NASCI to create the next iteration of the advisory board to provide guidance for the calibration study implementation
- Meeting with the institutional review board to determine:
 - Ethical methods of compensation for participants
 - How to appropriately involve board members in recruitment
 - How to provide named authorship to study participants
- Exploring future partnerships to support the calibration study, such as with the United Spinal Association and the Dana & Christopher Reeve Foundation

Although there was a widespread endorsement by SCI researchers to involve stakeholders in research⁷, it is still not the norm.

- Researchers can turn endorsement into action by pursuing options to partner with organizations like NASCI.

Conclusion

It was feasible to create and engage an advisory board of people living with SCI over a 3-month period.

- The advisors made recommendations for a large-scale, international study.
- NASCI's project review and implementation process facilitated success.

This project may serve as a case example for other research groups looking to involve people with lived experience in the research continuum.

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Acknowledgements

NASCI, Ian Burkhardt, Jen French, Namrata Grampurohit, PhD, OTR/L, Daniel Graves, PhD, MEd, Jenny Martinez, OTD, OTR/L, BCG, Maclain Capron, BA, Tina DeAngelis, EdD, MS, OTR/L, Lydia Navarro-Walker, OTD, OTR/L, Lauryn Jodoin, OTS.

The Jefferson College of Rehabilitation Sciences Center for Outcomes and Measurement provided support for engaging the advisors, and the Craig H. Neilsen Foundation (grant #597640, PI: Mulcahey) and the JEMS (2020-21, PI: Grampurohit) provides grant support for SCI-MI item pool development (grant #597640). This project was completed in partial fulfillment for the Doctoral Degree in Occupational Therapy at Thomas Jefferson University, Philadelphia, Pennsylvania (Biller).

NASCI website

