

North American Spinal Cord Injury Consortium: (NASCI): Meeting Report

Miami, Florida

October 12th, 2017



*Prepared by: Mike Tomlinson
Strachan-Tomlinson*

Contents

Introduction	1
Meeting Overview.....	1
Pre-Conference Survey	2
Presentations: The Value of Collaboration.....	2
NASCIC Charter	4
Project Selection Process	5
Conclusion: the Founding of NASCIC	6
NASCIC Partners.....	7
Appendix 1: NASCIC Agenda	10
Appendix 2: Pre-Meeting Survey Summary.....	12
Appendix 3: Meeting Feedback Report	16

Introduction

On October 12th, 2017 people living with spinal cord injury, their caregivers, and those who work for organizations that represent their interests gathered in Miami. This was the first meeting of the North American Spinal Cord Injury Consortium (NASCIC). The purpose of the meeting was to bring together organizations in North America that advocate, represent, or communicate with people living with spinal cord injury to create a project-focused consortium.

Objectives were to:

1. Convene North American organizations focused on people living with SCI
2. Come to agreement on a proposed governance charter for NASCIC
3. Come to agreement on a method for identifying promising projects to support.

While there are many potential issues to address with SCI such as rehabilitation, independent living, secondary conditions, and employment, NASCIC's initial focus is on research, and in particular, strengthening the connections between the research and SCI communities across the full continuum of research.

This initial focus on research is closely linked to NASCIC's role as an advocate for people living with SCI. Advocating for research that more accurately reflects the needs of the SCI community and includes members of the SCI community as equal partners is an important first step in NASCIC's evolution.

SCI research is quickly progressing in North America, and SCI consumers need to be equitable partners along the continuum of research to ensure the end results are oriented toward consumer needs, clinically relevant, and transparent to better enhance uptake.

Meeting Overview

Kim Anderson, Director of Education for the Miami Project to Cure Paralysis and Organizing Committee Chair welcomed all to the meeting. She commented on how while there were many familiar faces in the room, this was the first time everyone had been gathered for the sole purpose of strengthening the voice of the consumer.

Jen French, Executive Director of the Neurotech Network and Preparation Committee Chair also welcomed all. Jen introduced the founding members of NASCIC, as well as the members of the preparation and organization committees, who led the work to prepare for the meeting:

Barry Munro, Canadian & American Spinal Research Organization

Craig Williams, Conquer Paralysis Now

Annie Hambleton, Facing Disability

Rob Wudlick, Get Up Stand Up 2 Cure

Megan Moynahan, Institute for Functional Restoration

Kim Anderson, Miami Project to Cure Paralysis

Jen French, Neurotech Network

Tara Jeji, Ontario Neurotrauma Foundation

John Chernesky, Rick Hansen Institute

Matthew Rodreick, Unite 2 Fight Paralysis

Marilyn Smith, Unite 2 Fight Paralysis

Sharon Drennan, United Spinal Research Committee.

After highlighting the generosity of NASCIC's sponsors (see p8-10), Jen introduced Mike Tomlinson, the facilitator for the day. Mike outlined the work ahead on the agenda and spoke to several key assumptions for the work leading up to the inaugural meeting:

- NASCIC is not intended, nor will it endeavour to, merge with, take over, or absorb any member organizations.
- The consortium must not be dependent on any one person. Once a structure is in place projects can be selected for others to rally around.
- Sustainable funding and a secretariat are key features of the success of consortia.
- NASCIC will be "project focused, not committee driven". Projects will be member driven, and each project requires a realistic budget based on shared goals.
- NASCIC is intended to gather representatives of all voices in the community of people living with SCI, regardless of size; the bringing together of different (and potentially disparate) points of view will strengthen the voice of the whole. All members will have equal weight in decision-making.
- NASCIC considers the phrase "people living with SCI" to also include their caregivers and their families and friends.
- While other stakeholders (such as hospitals and industry) are involved, NASCIC will be driven by, and representative of, people living with SCI.
- Collaboration and joint participation by all are hallmarks of NASCIC's approach.

Pre-Conference Survey

In preparation for the meeting a survey was sent to all participants. The purpose of the survey was to determine the level of comfort with the meeting objectives, generate ideas as to NASCIC's potential, and identify factors to support that potential.

Responses were used to adapt sections of the agenda as well as the overall approach to the meeting. Advice from respondents regarding the success of the meeting was key, and included:

- Open, respectful, and inclusive communication is essential;
- Keep the meeting and meeting follow-up focused;
- Don't get too heavy and keep it fun. Encourage and enable people to dream big;
- Establish measurable goals for the meeting.

Presentations: The Value of Collaboration

Three presentations covered the value of collaboration:

1. The Praxis Experience

John Chernesky, Consumer Engagement Lead, Rick Hansen Institute

John gave an overview of the RHI hosted conference "Praxis 2016", speaking to the diversity of attendees at the conference, along with a consumer driven focus as evidence of a shift to researchers and clinicians asking the consumer community to take more of a leadership role. John discussed some of the history of the path to NASCIC, including initial meetings on site at Praxis 2016 with Jen French and Kim Anderson that led directly to the foundation of NASCIC.

2. Examples of Successful Collaborations

Kim Anderson, Director of Education for the Miami Project to Cure Paralysis

Kim discussed two examples of successful collaboratives: The European Spinal Cord Injury Federation (ESCIF), and the Medical Device Innovation Consortium (MDIC). While different in terms of their areas of operation, both ESCIF and MDIC are examples of how much can be accomplished through a collaborative grouping of like-minded organizations.

3. Landscape Search, Results, and Recommendations

Barry Munro, Chief Development Officer, Canadian/American Spinal Research Organization (CSRO); Matthew Rodreick, Executive Director, Unite 2 Fight Paralysis.

Barry and Matthew presented the results of their landscape search, having spoken with and researched a field of similar groups to NASCIC in order to better understand key success factors. Successful examples presented of collaborative consortia were the Health Charities Coalition of Canada and the ESCIF. Based on their analysis, Barry and Matthew made seven recommendations for the formation and operation of NASCIC:

1. Dedicate resources to some type of secretariat/office person;
2. Be project focused, not committee driven;
3. Have projects driven by members that best fit the project description;
4. Structure the consortium so that all members are recognized equally;
5. Start by identifying a common project as a test case (i.e., cure) and then develop a mandate as the project comes to fruition;
6. Create a memorandum of understanding;
7. Create a realistic budget to drive the chosen project.

NASCIC Charter

A proposed Charter for NASCIC was presented for review and approval. The proposed Charter was prepared and discussed extensively by the Organization and Preparation Committees prior to the meeting. On-site, participants worked in table groups to review the proposed Charter section by section. In plenary, tables indicated with a card whether they were comfortable (green), had reservations or questions (yellow), or completely opposed (red) with each section.

Each yellow and red section was then discussed by the group. Changes were noted, and proposals were made to amend the proposed Charter and move forward. Changes then went back to the Organization and Preparation Committee for further discussion and revision post-meeting.

One important section of the Charter that was the focus of discussion was regarding the three membership categories:

1. Principal;
2. Patron;
3. Advisory.

In keeping with NASCIC being a consumer-led and consumer-focused advocacy consortium, principal members are North American SCI consumer-based organizations; each has one vote.

Patron members are individuals living with SCI or those directly representing a person living with SCI, such as a family member or caregiver; each has one vote.

Advisory members are organizations or individuals who don't meet the requirements for Principal or Patron memberships. For example, this could include clinical care facilities, professional associations, research centers, funding agencies, for-profit entities, etc. There are no voting rights for Advisory members. This decision was made because of the importance of establishing and maintaining an autonomous SCI consumer voice.

Following Charter discussions at the meeting, input was gathered from participants. The Organization and Preparation committees reviewed all feedback and amended the charter. As of time of writing, the next version of the Proposed Charter was under final review, with a vote to adopt a revised Charter by NASCIC members to be held November 30th, 2017.

Project Selection Process

After reviewing the proposed Charter, participants trialled a project selection process for the Consortium. Three presentations from external researchers seeking to engage NASCIC's members were given. Meeting participants took notes, and had the opportunity to ask questions of each presenter in turn. With presenters absent from the room, meeting participants then rated each presentation based on their potential to bring about positive change toward persons living with spinal cord injury and their care and quality of life.

NASCIC members provided feedback on the proposed projects using the following criteria:

1. The potential to form relationships between the individuals and organizations representing spinal cord injury;
2. The potential for the exchange of valid, trustworthy, and useful information, experience, and knowledge;
3. The potential for promotion of and involvement with 'best practices' in research, treatment, and care;
4. The potential to create and/or strengthen a unified voice for SCI in North America;
5. The potential to promote collaboration among experts in the fields of research, clinical care, and advocacy of participating members
6. The resources required of NASCIC*, and
7. The potential impact (considering both breadth and depth) of the proposed project.

Criteria given a score from 1 (low) to 5 (high), with the opportunity given for open comment provided to NASCIC members as well.

**Note that criteria #6, which evaluates the resources required of NASCIC was a subject of discussion at the meeting. It was determined in the moment to use 1 as requiring a great deal of resources and 5 as requiring few resources.*

In the future, projects may be proposed by NASCIC members or by those external to NASCIC. There are no deadlines for proposing projects.

Following the meeting, project feedback was shared with each presenter, in the hopes of establishing a collaborative connection in order to improve each project's potential impact.

The criteria, scoring, and overall project selection process will be updated and adapted as appropriate in the months to come.

Conclusion: the Founding of NASCIC

Jen French and Kim Anderson put the question to meeting participants: “Given our discussions today, do you agree to the foundation of the North American Spinal Cord Injury Consortium?” Participants were asked for a show of either their green (yes) or red (no) card.

Participants were unanimous in electing to move forward with NASCIC, and a new consumer-led advocacy organization was formed.



Both Jen and Kim stressed that timely follow-up to the meeting was critical, pledging to share a timeline for the work required to get NASCIC off the ground following the meeting. They thanked the preparation and organization committees for their work leading up to and following the meeting, as well as all those present for their contributions to the formation of NASCIC.

NASCIC Gold Sponsors

Asterias Biotherapeutics

Asterias Biotherapeutics is a biotechnology company pioneering the field of regenerative medicine, focused on employing our pluripotent stem cell and cancer immunotherapy platforms to develop therapeutics addressing significant unmet medical needs in neurology and oncology.

<http://asteriasbiotherapeutics.com/>



Neurotech Network

Neurotech Network of The Society to Increase Mobility, Inc. is a 501(c)(3) non-profit organization focusing to improve the education of and the advocacy to access neurotechnology devices, therapies and treatments for persons with impairments.

<http://www.neurotechnetwork.org/index.html>



Rick Hansen Institute

The Rick Hansen Institute is a Canadian-based not-for-profit organization committed to accelerating the translation of discoveries and best practices into improved treatments for people with spinal cord injuries.

<http://www.rickhanseninstitute.org>



Rick Hansen Institute
Institut Rick Hansen

The Miami Project to Cure Paralysis

The Miami Project to Cure Paralysis, a Center of Excellence at the University of Miami Miller School of Medicine, is considered the premier investigative research program conducting cutting edge discovery, translational, and clinical investigations targeting spinal cord and brain injuries. The Miami Project's international team includes more than 200 scientists, researchers, clinicians, and support staff who take innovative approaches to the challenges of spinal cord and brain injuries.

<http://www.themiamiproject.org/>



Vertex Pharmaceuticals

Vertex creates new possibilities in medicine to cure diseases and improve people's lives. We work with leading researchers, doctors, public health experts and other collaborators who share our vision for transforming the lives of people with serious diseases, their families and society.

<https://www.vrtx.com/>



NASCIC Silver Sponsors

BioAxone Biosciences

BioAxone is committed to applying a deep understanding of axon regeneration and neuronal signalling pathways to transform the lives of patients afflicted with neurotrauma or neurovascular disorders. Led by a passionate management team augmented by 20 years of pioneering research, the company has identified and is developing a pipeline of drugs focused on nerve repair and regeneration.

<http://bioaxonebio.com/>



Cleveland FES Center

The Cleveland FES Center is a consortium of four nationally recognized institutions: Louis Stokes Cleveland VA Medical Center, Case Western Reserve University, MetroHealth Medical Center, and University Hospitals of Cleveland. With the support of these partners, the Cleveland FES Center is able to be at the forefront of academic and clinical research, furthering the advancement of neural technology into clinical standards of care.

<http://fescenter.org/>



DP Clinical

DP Clinical, Inc. (formerly DP Clinical Associates, Inc.) is a privately-held, minority and woman owned contract research organization (CRO) located in the I-270 Technology Corridor in Rockville, Maryland serving pharmaceutical and biotechnology clients. DP Clinical was established in 1994 and is a Maryland corporation.

<http://www.dpclinical.com/home.html>



Reeve Foundation

The Reeve Foundation is dedicated to curing spinal cord injury by funding innovative research, and improving the quality of life for people living with paralysis through grants, information and advocacy.

<https://www.christopherreeve.org/>



NASCIC Bronze Sponsors

Craig Hospital

The Craig Hospital is a world-renowned, premier center for specialty rehabilitation and research for people with spinal cord injury and traumatic brain injury. Craig has a remarkable atmosphere and culture that is casual but professional, active and upbeat. We're a 93-bed inpatient/outpatient, non-profit hospital that offers acute, short and long-term care.

<https://craighospital.org/>



Restorative Therapies

Restorative Therapies provides people with a neurological impairment or critical illness to achieve their full recovery potential. We help transform the way people understand and treat neurological impairment. We innovate and market a range of FES therapy systems.

<https://www.restorative-therapies.com/>



Shepherd Center

Shepherd Center, located in Atlanta, Georgia, is a private, not-for-profit hospital specializing in medical treatment, research and rehabilitation for people with spinal cord injury and brain injury.

<https://www.shepherd.org/>



Appendix 1: NASCIC Agenda

North American Spinal Cord Injury Consortium (NASCIC) Inaugural Meeting Agenda

October 12, 2017

Hilton Miami Airport Hotel

Miami, FL

Introduction

The **purpose** of the meeting is to bring together organizations in North America that advocate, represent, or communicate with people living with spinal cord injury to create a project-focused consortium.

Objectives are to:

1. Convene North American organizations focused on people living with SCI
2. Come to agreement on a proposed governance charter for NACSIC
3. Come to agreement on a method for identifying promising projects to support

Agenda

7:00AM	Continental Breakfast and Registration
8:00AM	Welcome, Introductions, Agenda <ul style="list-style-type: none">• Kim Anderson, Professor, Department of Neurological Surgery, Director of Education, The Miami Project to Cure Paralysis• Jennifer French, MBA, Executive Director, Neurotech Network• Meeting process and agenda: Mike Tomlinson• Participant Introductions
8:40AM	Collaboration: The Praxis Experience <ul style="list-style-type: none">• John Chernesky, Lead, Consumer Engagement, Rick Hansen Institute
9:00AM	Landscape Search: Results and Recommendations <ul style="list-style-type: none">• Barry Munro, Chief Development Officer, CSRO• Matthew Rodreick, Executive Director, Unite 2 Fight Paralysis• Q&A
10:00AM	Break
10:30AM	For review and approval: Proposed NASCIC Charter
12:00PM	Lunch

1:00PM	NASCIC: Potential Projects <ul style="list-style-type: none">• Clinical trials matching registry (SCITT)• Guidelines for consumer engagement in research• Consumer engagement in neurotechnology
2:15PM	Break
2:30PM	NASCIC: Potential Projects (continued)
4:00PM	Adopting the Charter, Determining Membership
4:30PM	Summary and What's Next
5:30-7:00PM	Social

Appendix 2: Pre-Meeting Survey Summary

Note:

- Wherever possible, respondents' original words and phrases are used to represent what a number of responses indicated.
- When "e.g.," appears after a statement, the points that follow are examples expanding the main point and represent the range of responses provided in that area.
- Unless noted otherwise, main-points are presented starting with those with the most support from respondents; sub-points are arranged in alphabetical order.

1. How comfortable are you with the purpose and objectives? Please rate each one:

a. Convene North American organizations focused on people living with a Spinal Cord Injury (SCI)

Response Choice	Number of Responses	Percent of Total
<i>Uncomfortable</i>	0	0
<i>Somewhat Comfortable</i>	5	20.83%
<i>Comfortable</i>	19	79.17%

N=24

b. Come to agreement on a proposed governance charter for NASCIC

Response Choice	Number of Responses	Percent of Total
<i>Uncomfortable</i>	3	12.5%
<i>Somewhat Comfortable</i>	5	20.83%
<i>Comfortable</i>	16	66.67%

N=24

c. Come to agreement on a method for identifying promising projects to support

Response Choice	Number of Responses	Percent of Total
<i>Uncomfortable</i>	0	0
<i>Somewhat Comfortable</i>	5	20.83%
<i>Comfortable</i>	19	79.17%

N=24

Please comment:

- Key factors for success, e.g.,
 - A willingness by all involved to engage in frank discussions about their own missions and internal operations
 - Coordinated communication and a clear focus on outcomes
 - Define goals/timelines for effective leadership, including removal/replacement criteria
 - Inclusion: NASCIC should be comprised of organizations that represent the true needs and best interests of people living with SCI from a lived experience perspective
 - Methods for discussing, collecting and organizing our thoughts
 - Open communication and compromise to guide agreement.
- This is a great first step, e.g.,
 - Great potential for positive action and collaboration on SCI issues and discoveries
 - I have long been an advocate of bringing this community together
 - The objectives are good and the timing is right.
- Can we get it all done? e.g.,
 - Coming to agreement may be a tall order
 - Finding consensus in the time available is a potential concern.

Single Mention Comments

- Consumer-driven organizations fall on a continuum between making funding decisions based on a pre-existing relationship with an institution or researcher and convening a scientific advisory panel to make those decisions. How might we improve this process? It could be shared among members to reduce costs and increase funds for research.
- Does the term "focused on people living with SCI" include all the SCI trauma centers, rehabilitation centers, etc.?
- Include all significantly large SCI/D (Spinal Cord Injury/Disorder) organizations in North America that advocate for, represent, or communicate with people living with spinal cord injury/disorder at the NASCIC table. Greater inclusion of all such groups would serve to improve the validity of the meeting outcomes, and eventually, the SCI/D Consortium's outcomes.
- It's important to partner together to: create a strong voice to direct research into areas we deem important; be involved in research design and administration to ensure projects are relevant and feasible; assist with recruitment (getting the word out); assist with knowledge dissemination and translation into practice; assist with policy change; and assist with fundraising initiatives/lobbying government for research dollars.

2. Imagine it is three years from now and NASCIC has been a great success. What have been the key factors in that success? For example, size of membership, communications, completed projects, etc.

- Communication, coordination, and shared goals, e.g.,
 - A common goal: positive impacts on people living with SCI and their care
 - A majority of people living with SCI are aware of the purpose and existence of NASCIC
 - Continuous communication among members; coordinated efforts for national or global SCI initiatives
 - Inclusive membership (e.g., people living with SCI, scientific, clinical, governments, etc.)
 - Surveys to evaluate progress and member satisfaction
 - User friendly/interactive website and Facebook page.
- Clear focus and actionable goals, e.g.,
 - Dollars raised for national/international initiatives, sponsorships obtained
 - Joint submission to National Institutes of Health (NIH) and Canadian Institutes of Health Research (CIHR) for SCI Randomized Control Trials (RCTs) guided by people with SCI
 - Meaningful outcomes from completed projects
 - Novel treatments and therapies incorporated into practice
 - Number of active members within NASCIC (the size matters less than the reach)
 - Promising research (relevant to people with SCI) moving at a steady pace.
- Meaningful input to completed or partially completed projects, e.g.,
 - A NA consumer prioritized and evidenced-based project
 - Best practices are adopted by all rehab centers: patients receive the best possible care
 - Higher percentage of American Spinal Injury Association Impairment Scale (AIS) B, C, D; higher conversion rates (A to B, C or D)
 - Neuro-recovery addresses chronic SCI population as well as acute
 - The size of membership does not necessarily matter as much as members' reach.
- Peer reviewed outcomes, e.g.,
 - Peer review of all research proposals ensures the robust involvement of people living with SCI, and that they are valued in the same way as the involvement of researchers and clinicians
 - Publications which can be cited by other groups (such as trial sponsors) as evidence of goals/opinions of people living with SCI.

Single Mention Comment

- Setting aside egos, self-interests and especially focusing on the needs of the future as opposed to merely continuing to work towards past goals and directions will guide success at the three-year mark. Setting ambitious yet attainable three-year goals, with six-month waypoints for evaluations of progress made toward the ultimate goals, may be key to overall

success. This would include the willingness to shift focus as needed based on a six-month evaluation finding.

What advice do you have for the organizers of this meeting to ensure it is a success for participants?

- Open, respectful, and inclusive communication is essential, e.g.,
 - Allow time for listening and engaging; success requires the participation of all members
 - Decisions made need to benefit all parties/organizations, regardless of size
 - Keep any one organization from dominating the process and discussions.
- Keep the meeting and follow-up focused, e.g.,
 - All are accountable for moving the agenda: keep focused and mindful of people's time
 - Drive the convening toward decisions and leave little for 'further discussion'
 - Hold people accountable for their commitments; this won't work without follow-through
 - Learn from other established organizations on paths to avoid.
- A productive and enjoyable process, e.g.,
 - Don't get too heavy and keep it fun. Encourage and enable people to dream big
 - Establish measurable goals for the meeting
 - Explore some digital solutions (mind mapping tools, open source, etc.)
 - Find a way to include all stakeholder opinions; do a stakeholder analysis for others with a significant impact on NASCIC activities
 - Is this meeting being held too close to hurricane season?
 - Share as much information as possible beforehand to allow time for reflection
 - Use consensus or voting for final decisions.

3. Further comments?

- This is a fantastic idea, e.g.,
 - A national network will help each of us help our clients more fully
 - Congratulations on making it this far – I am very excited to participate!
 - I'm excited to meet other SCI organizations and move things forward
 - The group from the Miami Project are well respected and are the right group to convene such a meeting. This could be very impactful if we prioritize our goals.
- It is exciting to see so many North American SCI/D organizations come together to form the framework of NASCIC. That said, if currently uninvited nationwide groups serving the SCI/D community are unwilling to participate in the initial NASCIC meeting, attending groups should press forward. Consideration should be given to developing an organizational structure and mission statement to encourage eventual group membership of the missing SCI/D groups. Moving forward, those additional organizations representing segments of the SCI/D population should be considered for addition to the consortium.
- The objective should be to gain the trust and confidence of participants so that information and opportunity are shared freely for years to come.

Appendix 3: Post-Meeting Survey Summary

- Wherever possible, respondents' original words and phrases are used to represent what a number of responses indicated.
- When "e.g.," appears after a statement, the points that follow are examples expanding the main point and represent the range of responses provided in that area.
- Unless noted otherwise, main-points are presented starting with those with the most support from respondents; sub-points are arranged in alphabetical order.

1. Overall, how successful was this workshop from your perspective?

Response Choice	Number of Responses	Percent of Total
1 Not Successful	0	0%
2	0	0%
3	0	0%
4	7	43.75%
5 Successful	9	56.25%

N = 16, Average = 4.6

2. What did you like most about the workshop?

- The willingness to work together, e.g.,
 - Diverse organizations and individuals of varying backgrounds all lending their voice
 - Getting together in a room with a good majority of the spinal cord injury community leaders and coming to agreement on a structure to work together
 - The collaborative nature and enthusiasm of all attendees.
- The meeting was well-organized, e.g.,
 - Background documents supported thoughtful and informed discussions
 - Clearly stated objectives and an agenda designed to complement them
 - Very participatory event, with excellent flow and facilitation.
- The demonstration of collaboration was fantastic, e.g.,
 - A good balance between keeping things moving and allowing views to be shared. Everyone provided comments, and responses were friendly
 - Hearing the projects and doing a trial run on the project decision making process
 - Meeting people face to face for intelligent discussion of the issues, with consumers and industry hearing each other out
 - Open and productive discussions.

3. What did you like least about the workshop?

- Charter discussions, e.g.,
 - A lot of time was spent on the charter, with many comments by those unfamiliar with work done to date prolonging discussion
 - It was hard at times to stick to the big picture.
- Not enough time, e.g.,
 - An 8AM start is very early for people with SCI who need to access care services
 - We could have used two days – some parts felt rushed.

Single mention comments

- A seeming control and dominance by groups from Canada might not play well with USA audiences and groups going forward.
- It would be good to see more people living with SCI.
- Some folks dominated discussions: we need input from all members.
- The room was so cold.
- The task of agreeing on a charter at the conclusion of the workshop was not realistic. With so many participants sharing their insights requiring changes/updates, it would have been better to have spent more time on the charter rather than project proposals at this stage.
- There seemed to be a disconnect between the presenters and the review tool for projects. This needs some more work.
- There should have been more organizations represented.

4. What comments or suggestions do you have with respect to the project selection process?

- The process needs greater clarity and structure, e.g.,
 - Add a section for presenters to explain a project's potential significance
 - Clarify scoring and the process for project submission
 - Describe a more structured review process that assesses the project's approach, capability to complete the project, and which provides an overall score
 - Presenters seemed unclear about what they were asking for (endorsement, NASCIC member participation, money, etc.)
 - Provide room for positive feedback and encouragement for presenters
 - We need a clearer understanding of the implications of each request for NASCIC.
- Suggestions for the approach:
 - A four-point scale would force a positive or negative evaluation rather than allowing the selection of a three in the middle of the scale (which may signify indifference)
 - A good concept, and a good test to see how we'll move forward. It went well.
 - A laudable effort to make criteria as generalizable as possible and to train the proposers

- It might be useful to have a 'call for projects' from the general membership group prior to the next selection process.
- Project summaries need more detail regarding outcomes/metrics/accountability

Single mention comments

- Future updates to the charter shared via email may lead to many (and possibly slow) differing opinions that may slow the final adoption of the charter. Move forward any suggestions to streamline discussions.
- It is hard to keep bias out.
- Of the three projects presented, it was difficult to determine the long-term impact on people living with SCI. This may be part of the "growing pains" of the consortium.
- There is a lot of information available regarding SCI put out by different organizations. We should try to consolidate it and have it endorsed by the consortium.
- There seems to be a need to educate the researchers on consumers being partners rather than recipients.
- Tweaking the rating form to include a section devoted specifically to the depth of involvement of NASCIC in the project (i.e. involvement from initiation vs late-stage assistance) could be useful.

5. Further comments

- This is just the start – keep the group engaged, e.g.,
 - Kudos to the organizers and those with the vision to start this consortium – well done
 - NASCIC is a fantastic way for individuals living with an SCI to make an impact on the entire field. The hard part will be to keep things moving – don't lose momentum!
 - This is the beginning of something BIG, but only if we follow-up with charter and make action items happen.
- A job well done, e.g.,
 - A great first start for the consortium – looking forward to continued work
 - An overall success. It was a pleasure to be part of this meeting
 - Very well-organized event with a disparate group of participants.
- It was an excellent day and a great opportunity to meet others in our sector (which is now North America wide). I look forward to the opportunity to collaborate for collective impact as opposed to our current more regional or silo specific impact!