

NeuroMatters

Connecting YOU to the Research

New Clinical Guidelines For TBI

Imagine being asked to develop clinical guidelines for the best way to provide rehabilitation for adults with moderate to severe traumatic brain injury. Where would you start? How long would you expect the process to take? Who would be part of the discussion? The development of new Guidelines for Rehabilitation of Adults with Moderate to Severe TBI is taking almost 2 years. Intended for clinicians and program managers providing TBI rehabilitation in settings across Ontario and Quebec, the clinical practice guidelines (CPG) will improve both the quality and consistency of care in both provinces.

The comprehensive development process depended on the expertise from a broad range of stakeholders. It is being overseen by a governing committee and a project team composed of research and clinical

leads, and two Canadian organizations: Institut national d'excellence en santé et en services sociaux (INESSS) in Quebec and the Ontario Neurotrauma Foundation (ONF).



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Ontario Neurotrauma Foundation
Fondation ontarienne de neurotraumatologie

Naming the Expert Panel

As part of its planning responsibilities, the project team named a 60 member expert panel, to assist in the development of the clinical practice guidelines. Members were recruited from rehabilitation centres, hospitals, universities, brain injury associations, TBI community programming, ABI program management, and health-care operations. Their clinical, administrative, personal (consumer), programming, research and system expertise is invaluable to the process.

"We ensured that the recommendations will be truly relevant in helping people recover from a brain injury, reintegrate into the community and work life", says Dr. Mark Bayley, Ontario co-lead for the project, "by putting a team in place representing the breadth of the stakeholder experience, from leading researchers to clinicians across the continuum, including mental health and addiction, to consumers

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with expertise in living with a brain injury.”

The Consensus Conference

A major milestone took place last November at a Consensus Conference held in Montreal. Facilitated by Dr. Bayley, the Expert Panel met to select, adapt and develop recommendations for the CPG. Their work was to:

- Review previously published best practice guidelines in TBI rehabilitation;
- Develop new recommendations that could be implemented in TBI rehabilitation programs in Québec and Ontario during the next phase of the project;
- Identify methods for evaluating the recommendations.

The list of previously published recommendations (405) were reviewed and organized by working groups under two sub headings:

- 1) Organization of rehabilitation services, and
- 2) Rehabilitation of specific brain impairments.

“The conference was abuzz with activity, networking and productivity,” noted one participant. “Panel members from Quebec and Ontario made a lot of effort to learn about

“ We ensure that the recommendations will be truly relevant in helping people recover from a brain injury, reintegrate into the community and work life. ”

Dr. Mark Bayley

the health system and organization of the other province, and conversed as much as possible in both languages.”

Voting on the Best

During June and July, the list of recommendations were sent out again to the expert panel for two voting rounds with the following questions:

- **Round 1:** Which recommendations should be included in the INESSS-ONF Guideline?
- **Round 2:** From the “included” recommendations, which should be identified as a “key” recommendation for implementation?

With the help of the expert panel, the project team then narrowed the number of recommendations to 325.

Approximately 80 key recommendations have been identified as being key recommendations for implementation and will be highlighted this way in the guidelines. There is more work to be done, including writing about the recommendations and producing the guideline in English and French. Once again, the expert panel will be called upon to review these recommendations. The guidelines are expected to be completed in the next several months.

Implementation

The final phase of the project is implementation, which depends heavily on the broad network of experts and stakeholders who have been involved from the beginning of the process. This ensures that as the CPGs are developed, the content and format meet the needs of a clinical setting.

“Creating networks during the two-year process is part of the overall strategy for getting the guidelines into use in clinical settings,” explains Dr. Shawn Marshall, Ontario co-lead for the project. “By being in constant communication and engaging with stakeholders, we set the environment

for implementation and uptake of the guidelines.”

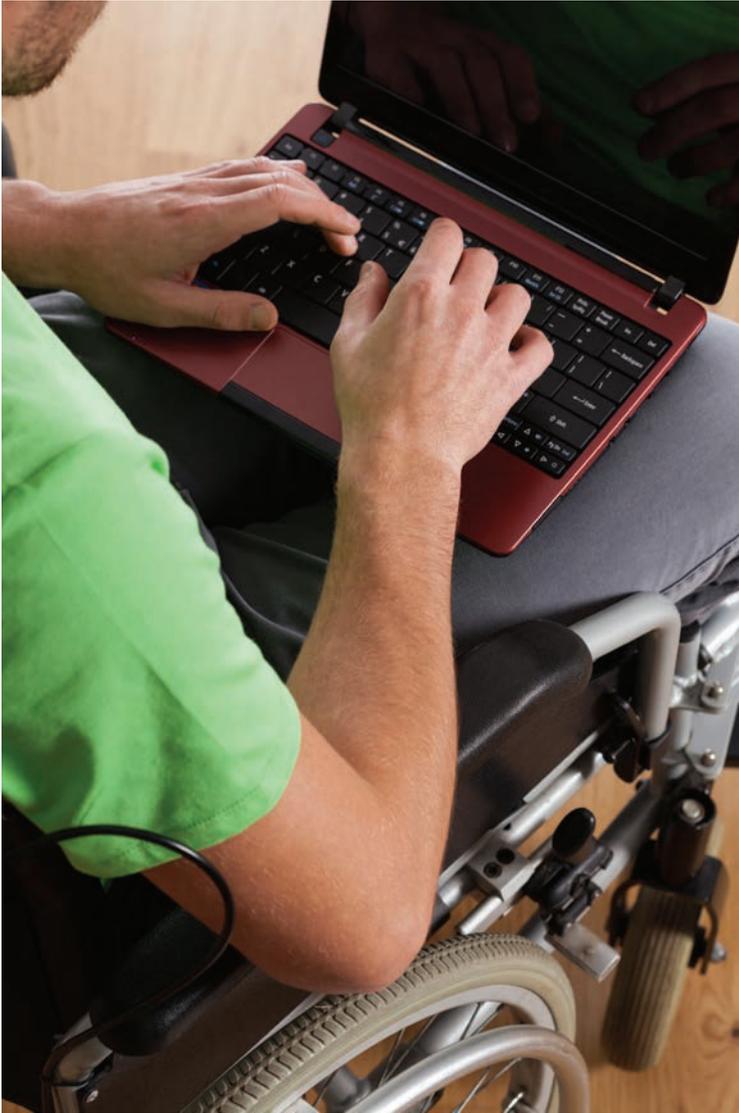
Both Quebec and Ontario have an Implementation Advisory Committee in place to guide and advise as the guidelines are rolled out. The implementation will begin in 2016.



There has been growing interest in Clinical Practice Guidelines (CPGs) for traumatic brain injury. Guidelines are a very helpful tool in taking the research evidence in TBI and turning it into treatment guidelines. One of the most important benefits of CPGs is their potential to improve both the quality and consistency of care throughout the province.

In Ontario, the leads are Drs. Mark Bayley and Shawn Marshall, working with ONF, and in Quebec, Professors Bonnie Swaine and Marie-Eve Lamontagne, working with INESSS.





How GRASSP is changing lives and treatments

Every Small Movement Counts

For the individual with tetraplegia, being able to enhance even the smallest movements in the hands and wrists represents progress toward an improved quality of life. For the researcher, being able to measure such movement is the only way to tell if a new research discovery, perhaps a new drug or surgery is making a detectable difference. But until the development of GRASSP at University Health Network, the field of SCI was without a valid and reliable measurement tool.

"We have always been able to measure large changes in impairment," says Dr. Sukhvinder Kalsi-Ryan (Sukh), "but for the individual with SCI, it is the small changes where we can make some of the biggest difference in quality of life. And for researchers, small changes in function may be the only way we can be certain that some treatments are working.

"By measuring the subtle improvement in movement, we can significantly improve someone's life. With reliable and validated measurements, we can create standards that mark progress and measure the impact of treatment."

Developing GRASSP

The need for a new measure sparked the beginning of a multi-

national project in 2007; based out of Toronto Rehabilitation Institute.

The project's purpose was to produce an assessment tool:

- Highly responsive (sensitive) to the smallest changes in movement, over time;
- Able to assess the extent of spontaneous (natural) recovery; and
- For use in clinical trials to evaluate the effect of new treatments, new drugs and surgical procedures.

Led by Sukh, the team of 6 researchers developed GRASSP (Graded and Redefined Assessment of Strength, Sensibility and Prehension). GRASSP (Version 1.0) is the first clinical tool of its kind in the world that easily and precisely measures the small changes in movement in

the upper limbs following an SCI.

After extensive clinical testing in Europe, Canada and the USA, GRASSP has been proven to be reliable when measuring upper limb impairment for individuals with complete or incomplete tetraplegia. One of its big advantages is that it can be administered early after injury (in the intensive care unit), throughout rehabilitation, and at outpatient clinics.

Today, GRASSP has been implemented as a standard of care at Toronto Rehab Institute Lyndhurst Centre, where all patients with SCI are tested to track change and evaluate treatment. It is currently licensed and being implemented in three sponsored drug trials and

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being used in multiple studies in Europe, Canada, Australia, Asia and the USA.

What does the GRASSP look like?

GRASSP comes as a kit that contains everything a clinician requires. It is easy to use and the clinician can bring everything to the patient's side in order to administer a test. Included is the GRASSP manual, instructional CDs, a set of monofilaments or fibres used to measure the sense of touch, "prehension" materials that can detect the ability to grasp, and a scoring and graphing program to record results. GRASSP is also affordable compared to most healthcare equipment and completely non invasive for the consumer.

"The idea behind GRASSP was not complicated," says Sukh, "but until we had an adequate tool like this, there was an incomplete step in the rehabilitation and research process. We were able to develop treatments – now we can tell whether or not they are working."

For the Individual with SCI

GRASSP is also being implemented by clinicians in hospitals and rehabilitation centres to demonstrate progress in recovery. This is particularly important for the individual with SCI and their family. Regaining hand function in all or some of the fingers or wrist movement means being able to perform simple tasks such as feeding oneself and brushing teeth as well as accessing technology, opening doors, pushing buttons and operating a power wheelchair.

"We hear back from clinicians at Toronto Rehab and Toronto Western

“By measuring the subtle improvement in movement, we can significantly improve someone's life”



Upcoming Events

2015 Acquired Brain Injury Provincial Conference
Nov. 11-13, 2015

Sheraton on the Falls Hotel
Niagara Falls, ON

Theme: Innovate, Integrate, Motivate

For more info, contact: OBIA
ontarioabiconference.ca

Save the date!

2016 Mild Traumatic Brain Injury Conference
Jan. 29, 2016

Allstream Centre
105 Princes' Blvd, Exhibition Place
Toronto ON

Registration opens October 15.
For more info, contact: UHN
Toronto Rehabilitation Institute:
conferences@uhn.ca

that when GRASSP is applied, it raises the awareness of the consumer concerning their ability," says Sukh. Over time, the consumer and their families see improvements in what they are now able to do, compared to the last test. Consumers ask, 'when can I try the test again?'

ONF funded the testing of GRASSP at six Ontario rehabilitation sites: St. Michael's Hospital, Sunnybrook Health Sciences Centre, Toronto Western Hospital, Toronto Rehabilitation Centre, London Health Sciences Centre and Hamilton Health Sciences Centre.

The GRASSP research and design team continues to work together on new versions and modifications.



Concussion Champions for Change

This past June, the power of individual voices speaking out about kids and concussion became a massive collaboration for future change.

One Voice: The First International Symposium on Pediatric Concussion launched a conversation about pediatric concussion – a conversation that quickly spread far beyond the 60 participants gathered for two days at Holland Bloorview Kids' Rehabilitation Hospital in Toronto.

There has been a tremendous amount of progress over the past decade regarding concussion care and management. However, there is concern among some that stakeholder groups do much of their work in “silos”. As a result, there are varying messages and resources, which cause confusion, particularly among kids, families and those in the community dealing with pediatric concussions.

The purpose of One Voice was to create an action plan that would get everyone connected with pediatric concussion talking and working together. The event was supported through the ONF-REPAR partnership, formed in 2007 between two provincial research organizations; the Ontario Neurotrauma Foundation and REPAR (Réseau provincial de recherche en adaptation

réadaptation). ONF-REPAR grants encourage the kind of cross-provincial research and collaboration in neurotrauma envisioned by both organizers.

Listening to every voice

Two researchers came up with the idea after attending various conferences on concussions: Dr. Nick Reed from Holland Bloorview Kids Rehabilitation Hospital in Ontario and Dr. Phil Fait from Université du Québec à Trois-Rivières.

“We dreamed up an idea where we would bring together as many different voices as possible with experience dealing at some level with pediatric concussion,” says Reed.

Named “concussion champions”, the individuals invited to attend had demonstrated outstanding

dedication and contributions to pediatric concussion. The diverse group included sports coaches and teachers, representatives from school boards, sports organizations and clubs, policy makers, youth who had experienced concussion and their parents, in addition to health-care professionals and researchers. Key organizations in concussion, like ONF, were present.

“We heard from teachers, who may see five or six concussions in a year to people like myself, who deal with pediatric concussion every day,” Reed explains.

A concrete, feasible action plan

In the weeks leading up to the event, a pre-symposium webinar series provided an overview of

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current research and knowledge so that when the event began, everyone would arrive “on the same page”.

The event itself was designed to be discussion not presentation-based, with panels featuring parents and kids, and facilitated discussions. The symposium adopted the objective: “To create a 3-5 year action plan to help kids with concussion do the things they need, want and love” in order to address the purpose of creating a single, strong network for conversation.

“The action plan had to be feasible,” says Reed, “not pie in the sky.” Delegates focused on visioning, strategy, overcoming obstacles and action planning before they created the final plan. The resulting action plan had three strategic directions that covered;

- setting up a national network,
- getting the word out to more people, and
- making sure kids find the right concussion care.

Actions listed under each direction were related to building and sustaining continued conversation and networking, unifying research, a standardized approach to resources, and models of care. One action named the creation of a pediatric concussion knowledge toolkit; another called for a national network of concussion education experts.

Tweet your live experience

One of the most inspiring aspects of the symposium for Reed was the enthusiasm of the group. “Many had never met before, but as soon as we were gathered in one place, the drive to work together was incredible. I was absolutely blown away by the level of collaboration and drive to make a difference for the kids.”

Interest also spread through social media, which encouraged a larger group to join the conversation and spread the word. Through



“In the next 3-5 years, what do we need to do to help children with concussions do the things they need, want and love to do”



#TalkKidsConcussion, the online conversation was featured on a tweet wall at the event as well as leading up to and after the event. In just over a week, there were 1,000 tweets, with an estimated 600,000 individuals reached.

Next steps: Keeping up momentum

All aspects of the symposium were evaluated using three different survey tools. The results will help in the planning of future events, which are included as one of the specific action items. For those involved in moving the action items forward, the next steps are to ensure that what has been spoken about now gets done.



Fall Prevention Community of Practice



November is Fall Prevention Month

In partnership with 14 injury prevention organizations, the Ontario Neurotrauma Foundation has helped initiate Ontario's first Fall Prevention Month for November 2015. We invite other organizations to participate and join the movement! A toolkit with programming and event suggestions, promotional materials, statistics and printable fall prevention resources is available for download at www.oninjuryresources.ca/fall-toolkit.

Introducing Loop: An online communication platform for fall prevention

The Fall Prevention Community of Practice (CoP) is excited to launch Loop in September 2015. Loop connects you with your peers and experts in fall prevention. Loop helps with:

- Networking – search members to find an expert, mentor or collaborator

- Finding Answers – harness the collective knowledge of 1700 CoP members or ask our Information Specialist
- Working Together – work smarter with collaboration tools and private groups

Visit www.fallsloop.com for more information.

Maintenant disponibles en français:

- Lignes directrices et outils pratiques basés sur données probantes pour améliorer la gestion des commotions cérébrales pédiatriques.
- Trois versions des lignes directrices sont disponibles avec des recommandations spécifiques au type et rôle de l'utilisateur :
 - Pour les professionnels de la santé
 - Pour les écoles et les centres sportifs/organisations sportives ou communautaires
 - Pour les parents et/ou le responsable parental

- Lignes directrices, version originale, publiées en anglais le 25 juin 2014
- Version française publiée le 1er septembre 2015

Cette adaptation francophone a été réalisée avec la collaboration de l'Unité de traumatologie de l'Institut national d'excellence en santé et services sociaux (INESSS), ainsi que la contribution importante du Dr. Isabelle Gagnon, professeure adjointe à l'Université McGill et chercheuse-clinicienne à l'Hôpital de Montréal pour enfants.

Lignes directrices pour le diagnostic et la gestion des commotions cérébrales pédiatriques



What Motivates an Individual with an SCI to Exercise

Individuals with SCI keep hearing about the benefits of regular, moderate to vigorous exercise. This kind of leisure time exercise results in important physical and psychological benefits, including improved cardiovascular health and decreased depression. But despite various efforts by clinicians, participation rates for those with SCI remain low. Individuals find it difficult to remain motivated, particularly with barriers such as limited or no physical access to adequate exercise facilities, pain, transportation and lack of social support.

A recent pilot study supported by ONF asked the question, "Does developing brief action plans with a peer support counselor encourage more positive attitudes and feelings about leisure time physical activity?"

Action planning and coping strategies

A team led by Dr. Jessie Stapleton, Dr. Heather Gainforth and Dr. Kathleen Martin Ginis first identified techniques and factors from past studies that were effective: the development of a personal physical activity action plan as well as a coping plan to address barriers along the way. Two groups of individuals with SCI were then selected to be part of the study. Both groups were introduced to the value of making an action and a coping plan, and given instructions on setting up such plans. But only one group was guided through the process with a peer support counselor, using the online tool, Skype.

Using the right planning tool

The peer counsellor was given a structured, self-management tool called "Brief Action Planning (BAP) to use when working one-on-one with each individual. BAP asks a series of simple questions that makes the

planning process practical and easy to monitor.

As Stapleton explains, an action plan could be as straightforward as, "I want to go for a wheel, 3 times a week, 30 minutes at a time, at a moderate pace; I will go with my best friend, and I will take this specific route in my neighbourhood".

Social intervention with a peer counsellor

The peer support counsellor for this project was a para athlete, with an educational background in health and wellness, and experience working in a community gym for persons with SCI. Through facilitated, one-on-one sessions with the counsellor, individuals set up their own action plans that took in account individual needs and circumstances. They also created coping strategies with someone who understood their challenges and barriers. "The coping plans created," says Stapleton, "were not wish lists. They were realistic and practical solutions, such as; if I can't get transportation to get to the gym, here is what I'll do."

Each one also had the opportunity for follow-up with the peer counsellor to see how well they were doing with their plans. The results showed a difference between the two groups.



Is there anything you would like to do for your health in the next week or two?

How confident or sure do you feel about carrying out your plan (on a scale from 0 to 10)?

Would it be helpful to set up a check on how things are going with your plan?

Both action and coping planning was more effective for changing perceptions of peer support when participants worked with a peer counsellor.

"By making a concrete plan, individuals felt more confident to engage in their activities", explains Stapleton, "But those who had the peer counsellor felt more positive about sticking with their plan."

Next steps

Together with previous research, this pilot research provides evidence that incorporating peer support and planning techniques appear to be good strategies for increasing motivation for leisure time physical activities for the individual with SCI.

