# Enhancing Community-Based Physical Activity Participation Among Adults with SCI: The SCI Action Canada Story

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Professor, Dept. of Kinesiology, McMaster University
McMaster Physical Activity Centre of Excellence

McMaster University
Inspiring Innovation and Discovery

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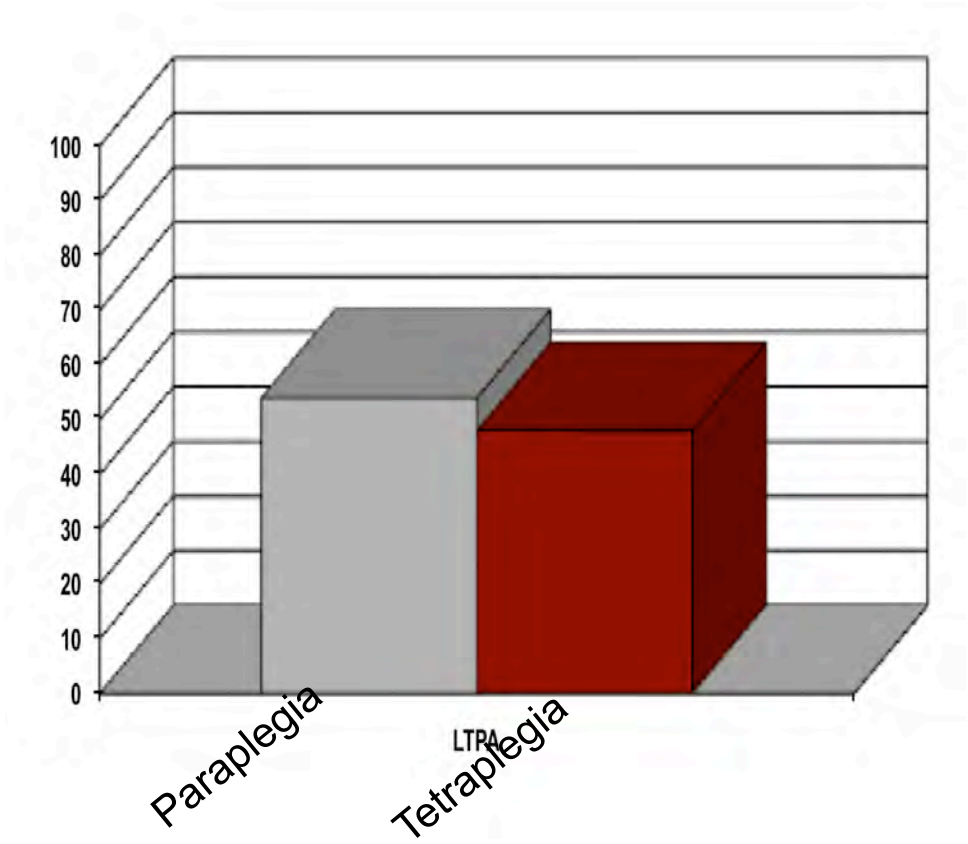
# MacSeniors

# Activity Levels Among Canadians with SCI

% Reporting Any Leisure Time Physical Activity (N = 695)

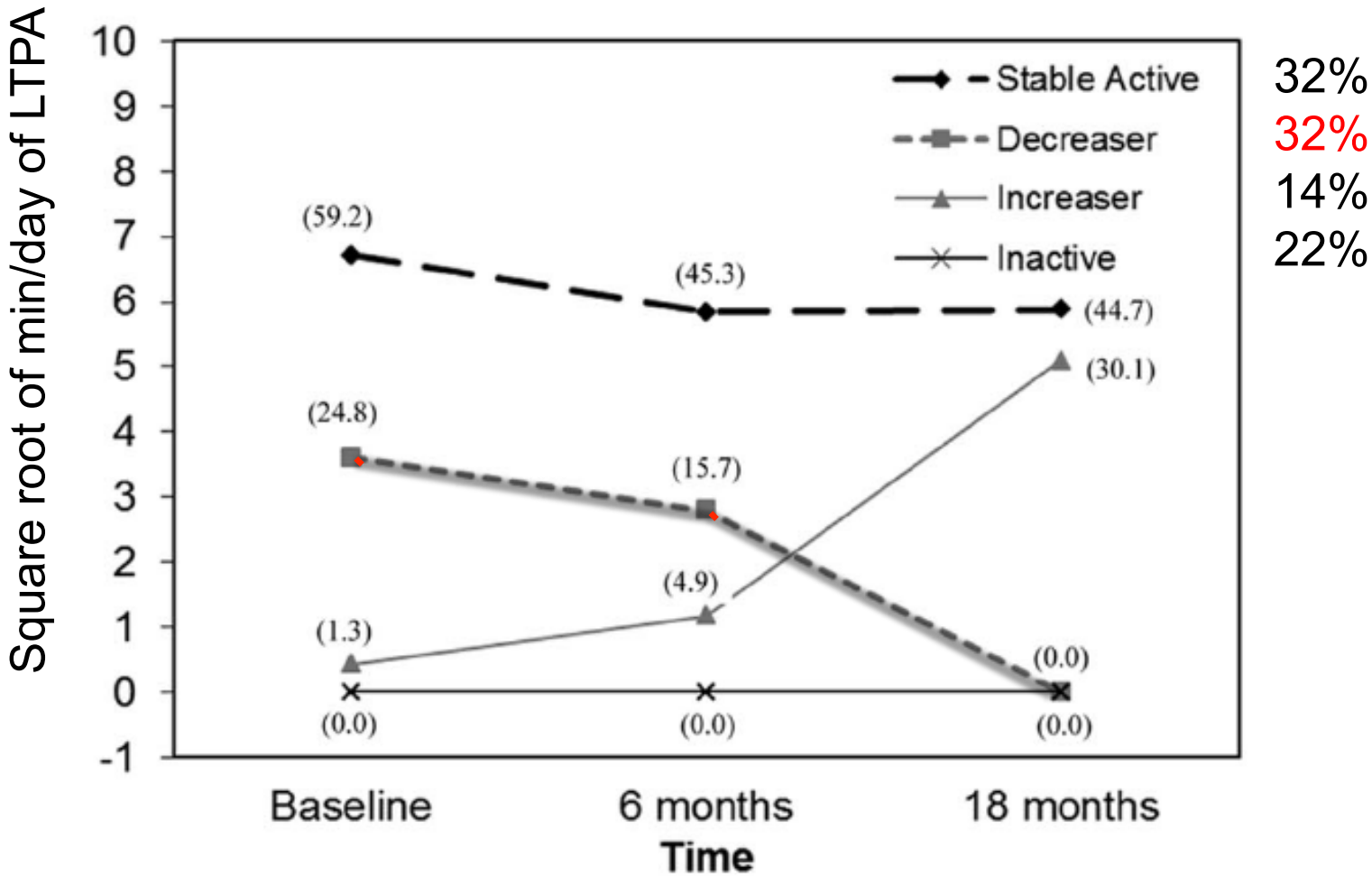



Martin Ginis, Latimer, Arbour-Nicitopoulos et al. (2010a).
*Arch Phys Med Rehabil*

Similar findings in:

- Netherlands
  (van den Berg-Emons, 2008)
- United Kingdom
  (Tasiemski et al., 2005)
- Switzerland
  (Rauch et al., 2014)
- Germany
  (Anneken et al., 2010)

# 18-month LTPA Trajectories in 541 Adults with SCI
## (bracketed values are min/day of LTPA)




32%
32%
14%
22%

Sweet, Martin Ginis & Latimer-Cheung (2012). *Health Psychol*

# What's the Problem?


Jaarsma et al., 2014; Williams et al., 2014

# PubMed Citations on Physical Activity and Spinal Cord Injury

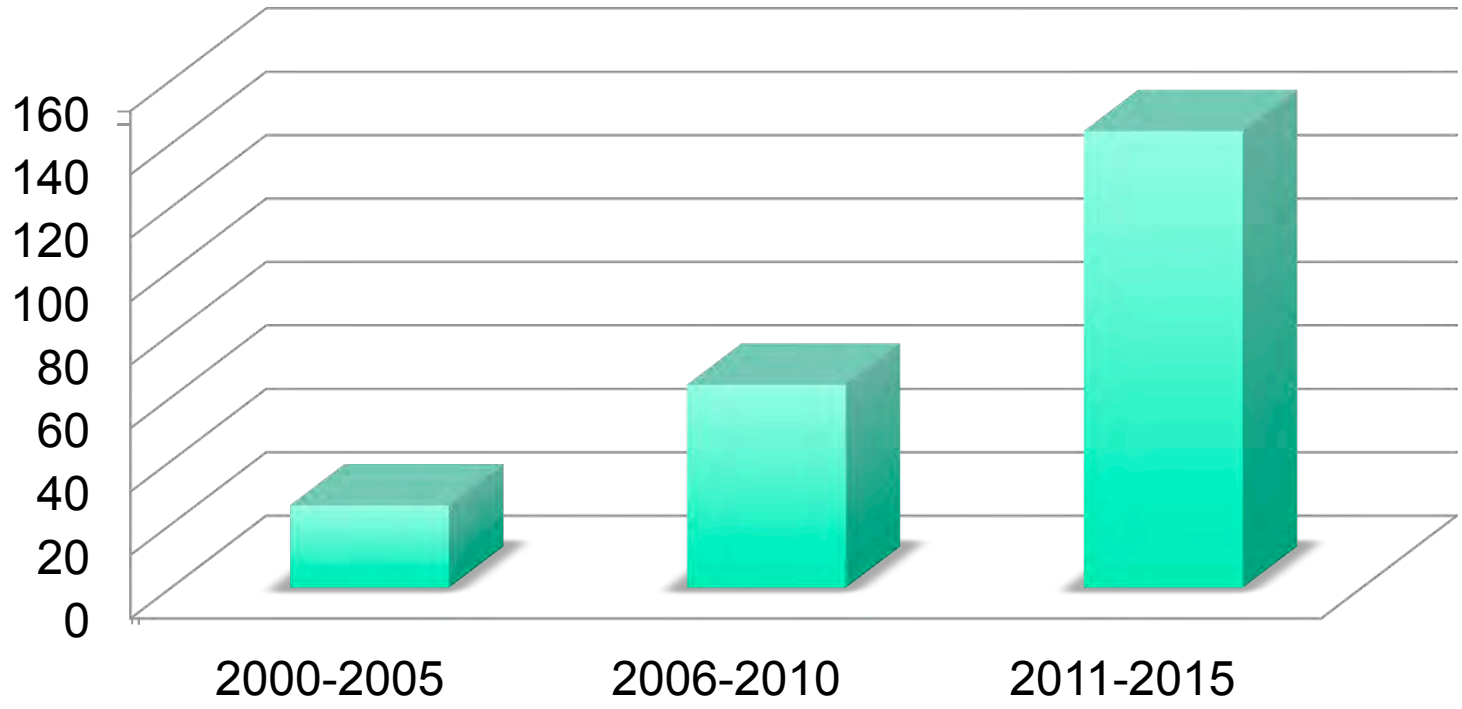
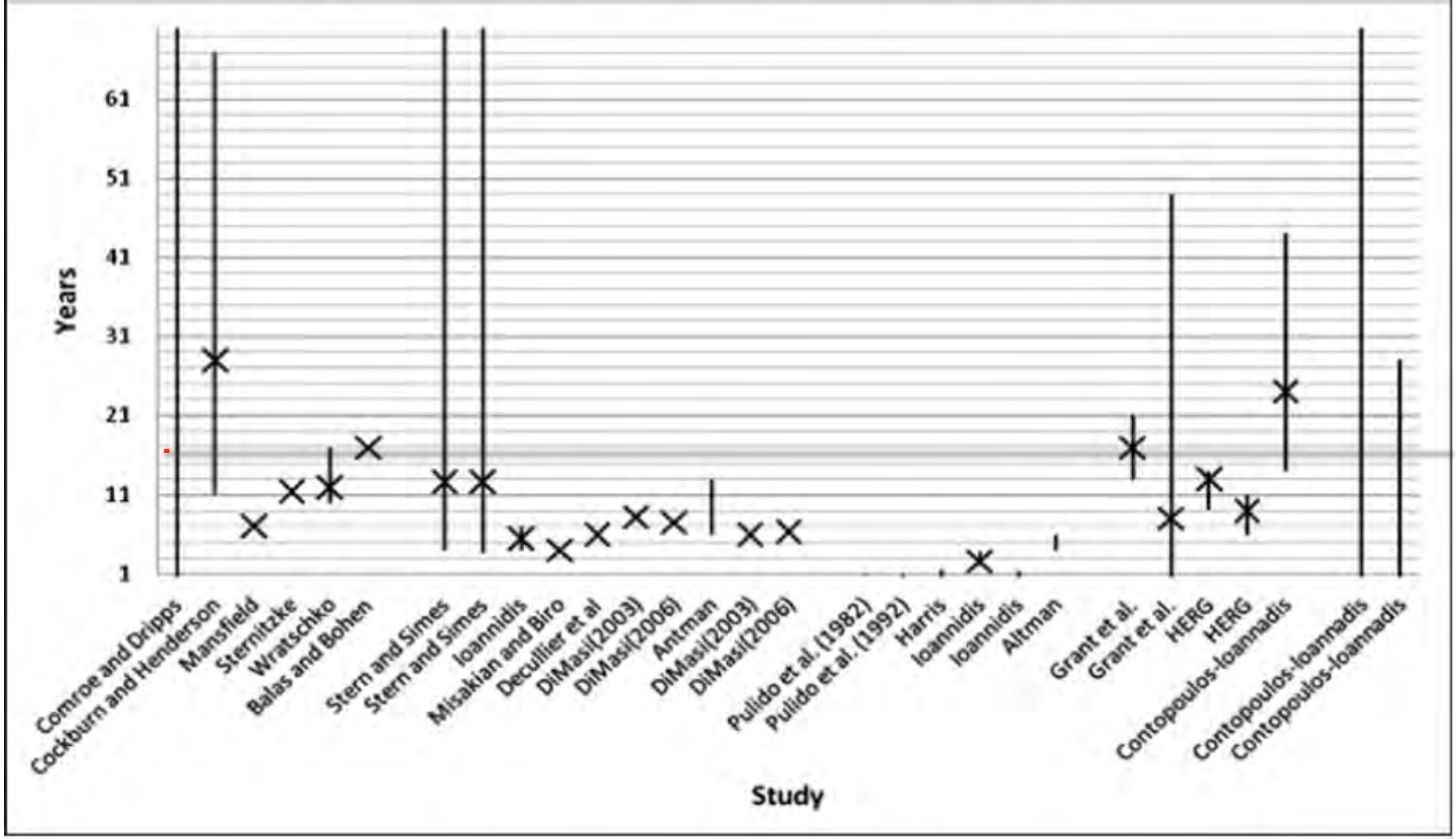


**Chart showing the approximate range and average time lag reported in studies of time lags in health research.**




Morris, Wooding & Grant, 2011

TBM

ORIGINAL RESEARCH

# Assessing the research use and needs of organizations promoting healthy living for adults with disabilities

Shane N Sweet, PhD,[1,2] Amy E Latimer-Cheung, PhD,[1] Chris Bourne, MA,[3] Kathleen A Martin Ginis, PhD[4]

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Cite this as: *TBM* 2014;4:86–94
doi: 10.1007/s13142-013-0231-2

**Abstract**

The uptake of research in community-based organizations (CBOs) is low and still unknown in CBOs that promote active and healthy living in adults with a disability. Using the knowledge to action framework, the objectives of this study were to determine if a gap exists regarding the use of research in CBOs, to learn about the preferred method to receive/read research evidence and to identify the barriers and facilitators of research use. Sixty-two employees of CBOs answered an online questionnaire. A research use gap was found as only 53 % of employees indicated they often or always use research. Conferences, emails and short research summaries were the favoured method of receiving/reading research information. Education, time and financial resources were important barriers to research use, while attitudes, intentions and self-efficacy were facilitators. More efforts are needed to develop tools to help CBOs use research.

**Implications**

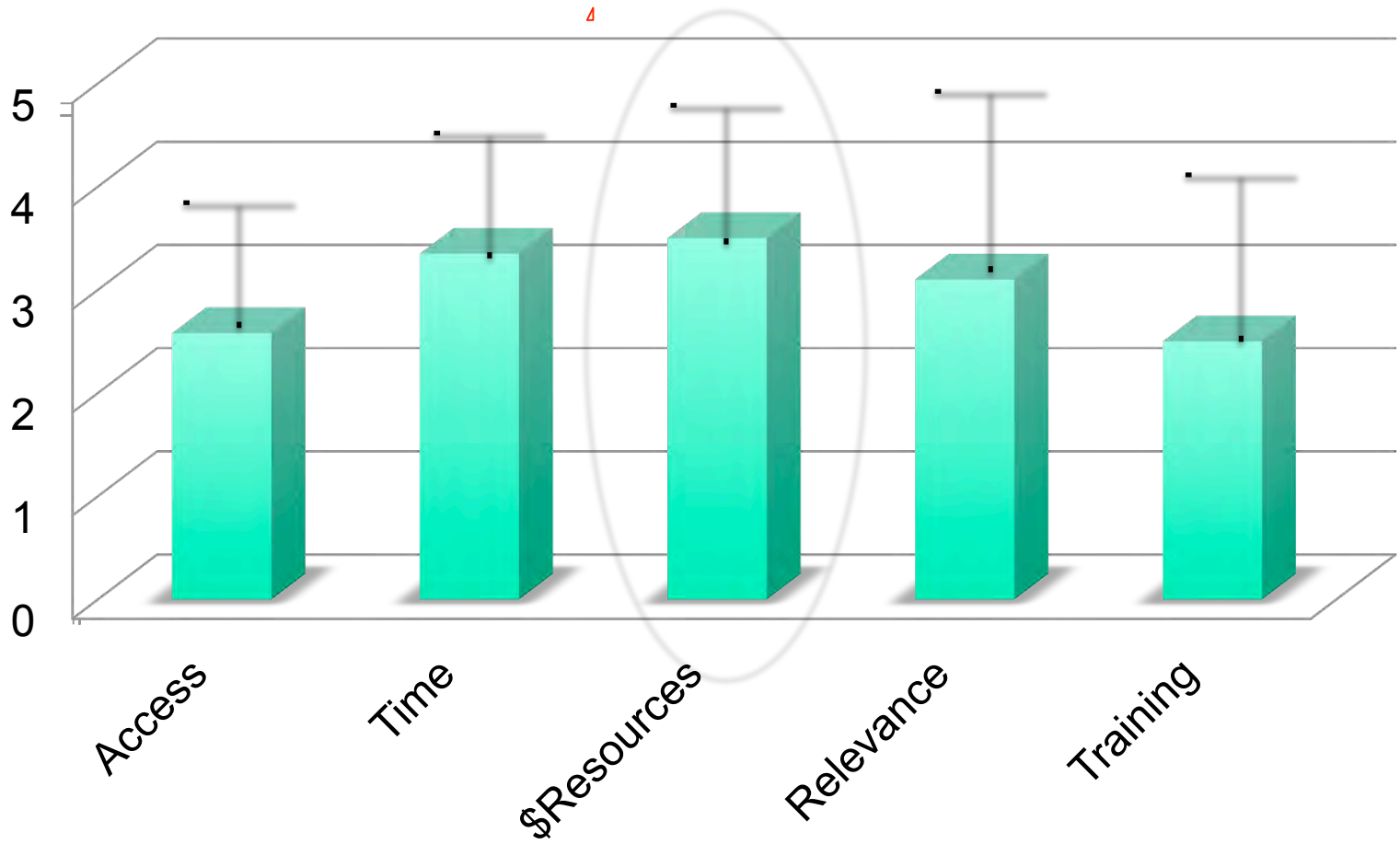
**Practice**: Community-based organizations promoting healthy living in adults with a disability should provide more training and opportunity for their employees to use research.

**Policy**: Funding should be provided to develop a knowledge product and associated training to facilitate the integration of research into programs.

**Research**: Research is needed to understand how individual and organizational factors interact to influence knowledge translation for adults with a disability.

vices to their community members who are often

# Barriers to Research Use in Community-Based Organizations

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***ADVANCING PHYSICAL ACTIVITY KNOWLEDGE AND PARTICIPATION AMONG CANADIANS LIVING WITH SPINAL CORD INJURY***

Social Sciences and Humanities
Research Council of Canada

# Community Partners
















***ADVANCING PHYSICAL ACTIVITY KNOWLEDGE AND PARTICIPATION AMONG CANADIANS LIVING WITH SPINAL CORD INJURY***

# University Partners











***ADVANCING PHYSICAL ACTIVITY KNOWLEDGE AND PARTICIPATION AMONG CANADIANS LIVING WITH SPINAL CORD INJURY***

# Research Partners

| | |
|---|---|
| Kathleen Martin Ginis (PI) | McMaster University |
| Larry Brawley | University of Saskatchewan |
| Steve Bray | McMaster University |
| Dave Ditor | Brock University |
| Guy Faulkner | University of Toronto |
| Keith Hayes | University of Western Ontario |
| Audrey Hicks | McMaster University |
| Steve Hanna | McMaster University |
| Julie Horrocks | University of Guelph |
| Amy Latimer-Cheung | Queen's University |
| Lori Letts | McMaster University |
| Kelly Arbour-Nicitopoulos | McMaster University/U of T |
| Harry Prapavessis | University of Western Ontario |
| Brett Smith | Loughborough University |
| Christopher West | University of British Columbia |
| Dalton Wolfe | Parkwood Hospital/UWO |

# Our Mission

To develop and mobilize evidence-informed strategies that inform, teach and enable people living with SCI to initiate and maintain a physically active lifestyle.

SCI ACTION CANADA

*ADVANCING PHYSICAL ACTIVITY KNOWLEDGE AND PARTICIPATION AMONG CANADIANS LIVING WITH SPINAL CORD INJURY*

# Knowledge Translation/Mobilization

Activities used to transfer knowledge generated from research into products, services, and changes in practice.

*"Getting the right information, to the right people, in the right format, at the right time"*

Ontario Neurotrauma Foundation
Fondation ontarienne de neurotraumatologie

# Blueprint for Research and Knowledge Translation Process


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# Five Principles of Effective Knowledge Translation

Lavis, Robertson, Woodside, McLeod & Abelson (2003)
Canadian Health Services Research Foundation (2004)
Grimshaw, Eccles, Lavis, Hill & Squire (2012)


***ADVANCING PHYSICAL ACTIVITY KNOWLEDGE AND PARTICIPATION AMONG CANADIANS LIVING WITH SPINAL CORD INJURY***

# 1. Know Your Audience and the Key Issues

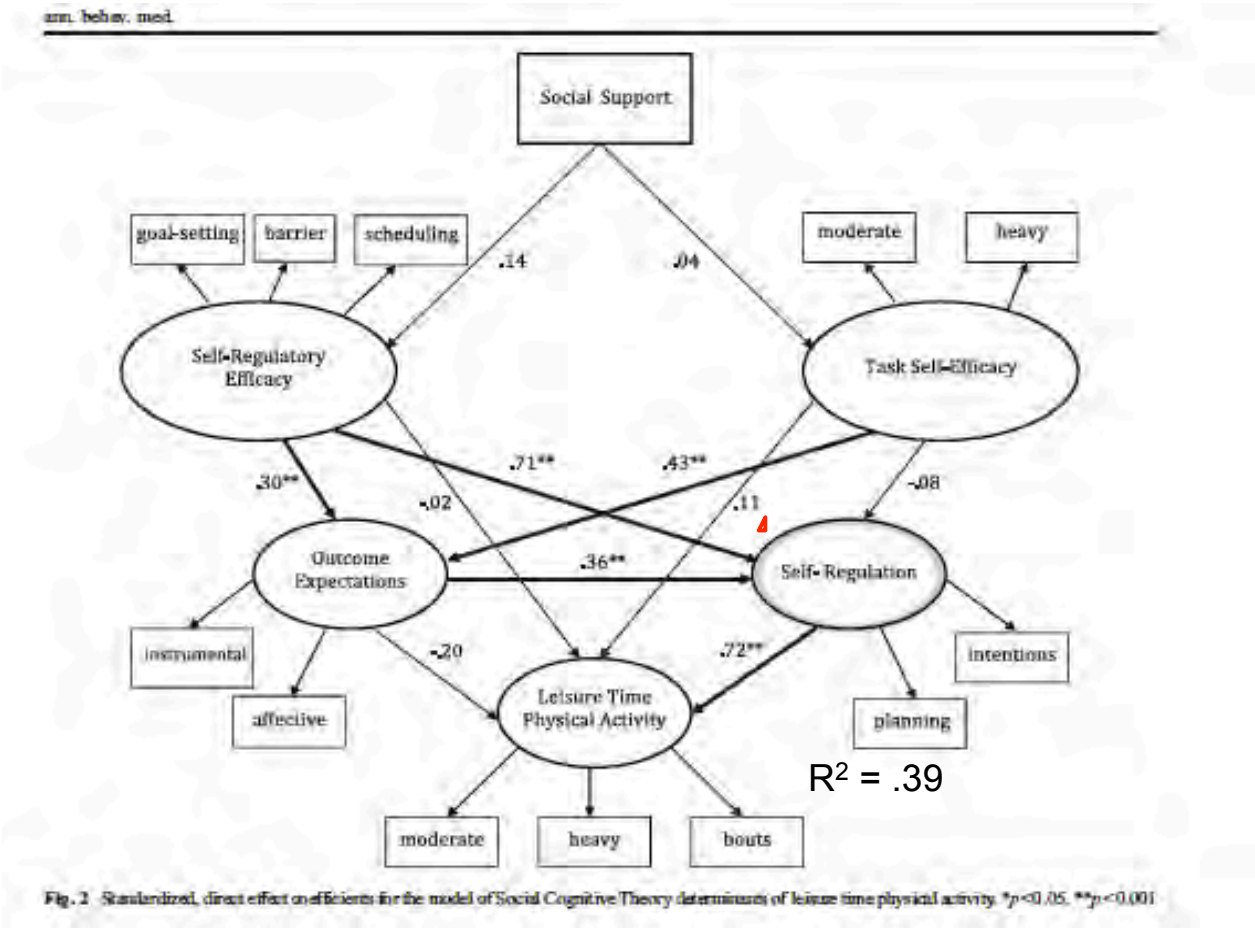
What's available?

What's needed?

Community capacity

Latimer, A. E., Brawley, L. R., Conlin, C., & Martin Ginis, K. A. (2010)
Bassett, R. L., Martin Ginis, K. A., Latimer, A. E., & Wolfe, D. (2010).
*Rehabilitation: Mobility, Exercise and Sports.* Amsterdam: IOS Press.

# What Tools Do People with SCI Need to Start and Maintain an Active Lifestyle?




Martin Ginis, Arbour-Nicitopoulos, Latimer et al. (2011). *Ann Behav Med*

***ADVANCING PHYSICAL ACTIVITY KNOWLEDGE AND PARTICIPATION AMONG CANADIANS LIVING WITH SPINAL CORD INJURY***

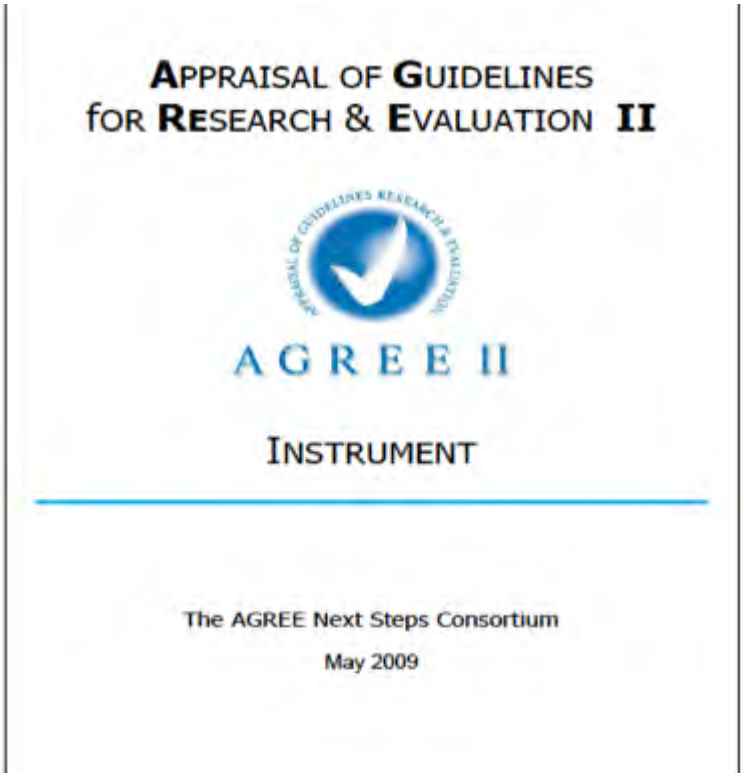
# 2. Identify Credible Messengers


Faulkner, G., Gorczynski, P., Arbour, K., et al. (2010). *Spinal Cord Injuries: Types, Treatments and Prognosis.* Nova Science Publishers.
Letts, Martin Ginis, Faulkner et al. (2011). *Rehab Psychol*

# 3. Create Audience-Specific Messages and Practices


Martin Ginis, Hicks, Latimer, Warburton et al. (2011). *Spinal Cord.*
Arbour-Nicitopoulos, Martin Ginis, Latimer-Cheung et al. (2013). *Spinal Cord*

# Guideline Development Process



APPRAISAL OF GUIDELINES
FOR RESEARCH & EVALUATION II

AGREE II

INSTRUMENT

The AGREE Next Steps Consortium

May 2009

| |
|---|
| **Domain 1: Scope and purpose** |
| The overall objective(s) of the guideline is (are) specifically described. |
| The clinical question(s) covered by the guideline is (are) specifically described. |
| The patients to whom the guideline is meant to apply are specifically described. |
| **Domain 2: Stakeholder involvement** |
| The guideline development group includes individuals from all the relevant professional groups. |
| The patients' views and preferences have been sought. |
| The target users of the guideline are clearly defined. |
| The guideline has been piloted among end users. |
| **Domain 3: Rigour of development** |
| Systematic methods were used to search for evidence. |
| The criteria for selecting the evidence are clearly described. |
| The methods for formulating the recommendations are clearly described. |
| The health benefits, side effects and risks have been considered in formulating the recommendations. |
| There is an explicit link between the recommendations and the supporting evidence. |
| The guideline has been externally reviewed by experts prior to its publication. |
| A procedure for updating the guideline is provided. |
| **Domain 4: Clarity of presentation** |
| The recommendations are specific and unambiguous. |
| The different options for management of the condition are clearly presented. |
| Key recommendations are easily identifiable. |
| **Domain 5: Applicability** |
| The guideline is supported with tools for application. |
| The potential organizational barriers in applying the recommendations have been discussed. |
| The potential cost implications of applying the recommendations have been considered. |
| The guideline presents key review criteria for monitoring or audit purposes. |
| **Domain 6: Editorial independence** |
| The guideline is editorially independent from the funding body. |
| Conflicts of interest of members of the guideline development group have been recorded. |

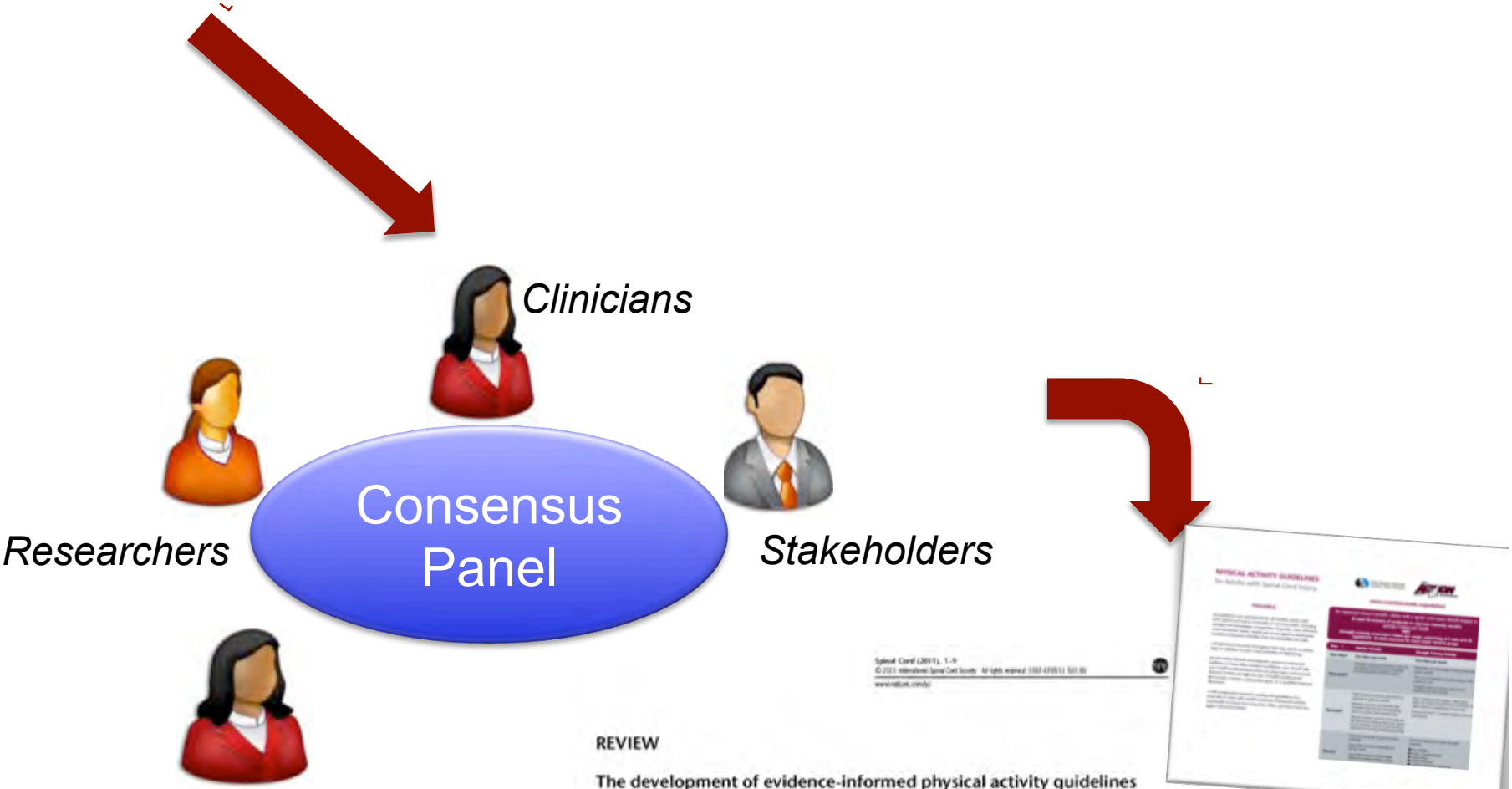
Spinal Cord (2011), 1–25

www.nature.com/sc

ORIGINAL ARTICLE

**The effects of exercise training on physical capacity, strength, body composition and functional performance among adults with spinal cord injury: a systematic review**

AL Hicks[1], KA Martin Ginis[1], CA Pelletier[1], DS Ditor[2], B Foulon[1] and DL Wolfe[3]




Spinal Cord (2011), 1–9

www.nature.com/sc

REVIEW

**The development of evidence-informed physical activity guidelines for adults with spinal cord injury**

KA Martin Ginis[1], AL Hicks[1], AE Latimer[2], DER Warburton[3], C Bourne[4], DS Ditor[5], DL Goodwin[6], KC Hayes[7], N McCartney[1], A McIlraith[8], P Pomerleau[9], K Smith[10], JA Stone[11] and DL Wolfe[7]

# RICHTLIJNEN VOOR LICHAAMSBEWEGING

## voor volwassenen met ruggenmergletsel

### VOORWOORD

Deze richtlijnen zijn geschikt voor alle gezonde volwassenen met al dan niet traumatisch chronisch ruggenmergletsel, waaronder tetraplegie en paraplegie, ongeacht het geslacht, ras, etniciteit of sociaal-economische status. Volwassenen worden aangespoord om diverse lichamelijke activiteiten te beoefenen, die aangenaam en veilig zijn.

Naast uw gebruikelijke dagelijkse activiteiten moet u proberen de hele dag door op een gevarieerde manier actief te zijn.

Als u onlangs letsel heeft opgelopen, zwanger bent, neiging heeft tot autonome dysreflexie of andere medische problemen heeft, dan dient u uw gezondheidswerker te raadplegen over de voor u geschikte soorten en hoeveelheid lichaamsbeweging. Een gezondheidswerker is bijvoorbeeld een arts, een fysiotherapeut of een bevoegde trainer.

Om de richtlijnen veilig en progressief te bereiken is het beter om met kleine hoeveelheden lichaamsbeweging te beginnen en geleidelijk de tijd, frequentie en moeilijkheidsgraad ervan op te bouwen.



Rick Hansen Institute
Institut Rick Hansen

SCI ACTION CANADA

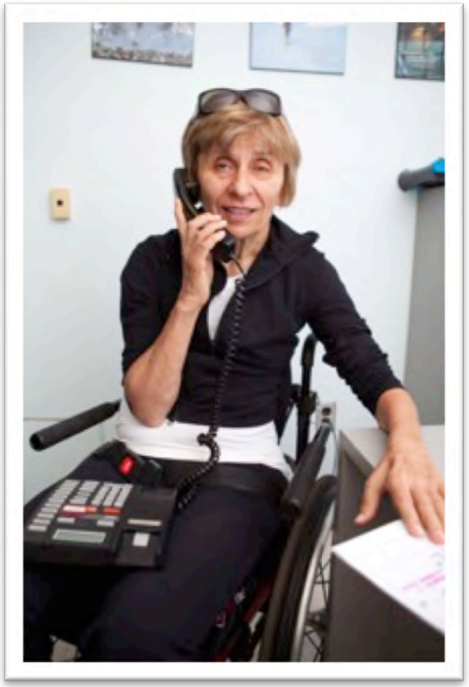
www.sciactioncanada.ca/guidelines

**Voor aanzienlijke fitnessvoordelen zouden volwassenen met ruggenmergletsel het volgende moeten doen:**
**2 maal per week ten minste 20 minuten matig tot zeer intense aerobe beweging,**
**EN**
**2 maal per week krachttrainingsoefeningen, bestaande uit 3 series van 8-10 herhalingen van iedere oefening voor iedere belangrijke spiergroep.**

| Hoe...? | Aerobe Activiteit | Krachttrainingsactiviteit |
|---|---|---|
| **Hoe vaak?** | **Tweemaal per week** | **Tweemaal per week** |
| **Hoe vaak?** | Bouw uw activiteit geleidelijk op, zodat u tijdens iedere training ten minste 20 minuten aan aerobe beweging doet. | Herhalingen zijn het aantal keren dat u een gewicht optilt en neerlaat.<br>Probeer 8-10 herhalingen voor iedere oefening. Dit geldt als 1 serie.<br>Bouw dit geleidelijk op tot 3 series van 8-10 herhalingen voor iedere oefening. |
| **Hoe moeilijk?** | Deze activiteiten dienen matig tot zeer intens te worden uitgevoerd.<br>Matig intens: activiteiten die ietwat moeilijk aanvoelen, maar die u een tijd lang kunt volhouden zonder moe te worden.<br>Zeer intens: activiteiten waarbij u zich echt hard aan het werk voelt, bijna op uw maximale niveau, en die u niet erg lang kunt volhouden zonder moe te worden. | Kies een weerstand (vrije gewichten, kabelkatrollen, banden enz.) die zwaar genoeg is om net, maar wel veilig, 8-10 herhalingen van de laatste serie te kunnen afmaken.<br>Zorg ervoor dat u tussen iedere serie en oefening 1-2 minuten rust. |
| **Hoe?** | Er zijn veel manieren waarop u dit doel kunt bereiken, zoals:<br>Bovenlichaamsoefeningen: rolstoeloefeningen, armfietsen, sport<br>Onderlichaamsoefeningen: Lopen op de loopband met ondersteuning van het lichaamsgewicht, fietsen<br>Oefeningen voor het hele lichaam: ligstepper, wateroefeningen | Er zijn veel manieren waarop u dit doel kunt bereiken, zoals:<br>■ Vrije gewichten<br>■ Elastische weerstandsbanden<br>■ Kabelkatrollen<br>■ Gewichtsapparaten<br>■ Functionele elektrische stimulatie |

Get in Motion

# Physical Activity Counseling for Canadians Living with SCI

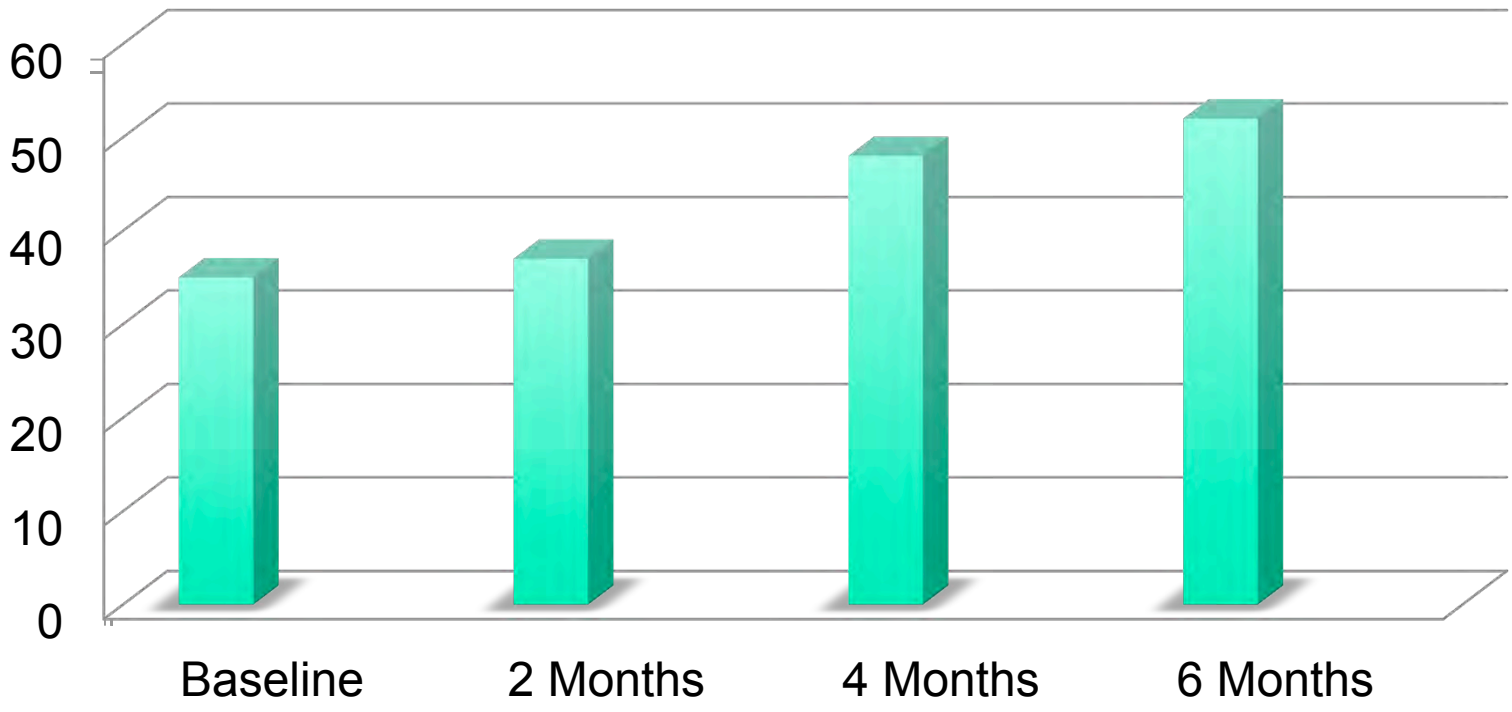
REPAR FRSQ

Ontario Neurotrauma Foundation
Fondation ontarienne de neurotraumatologie

McMaster University

Rick Hansen Institute
Institut Rick Hansen

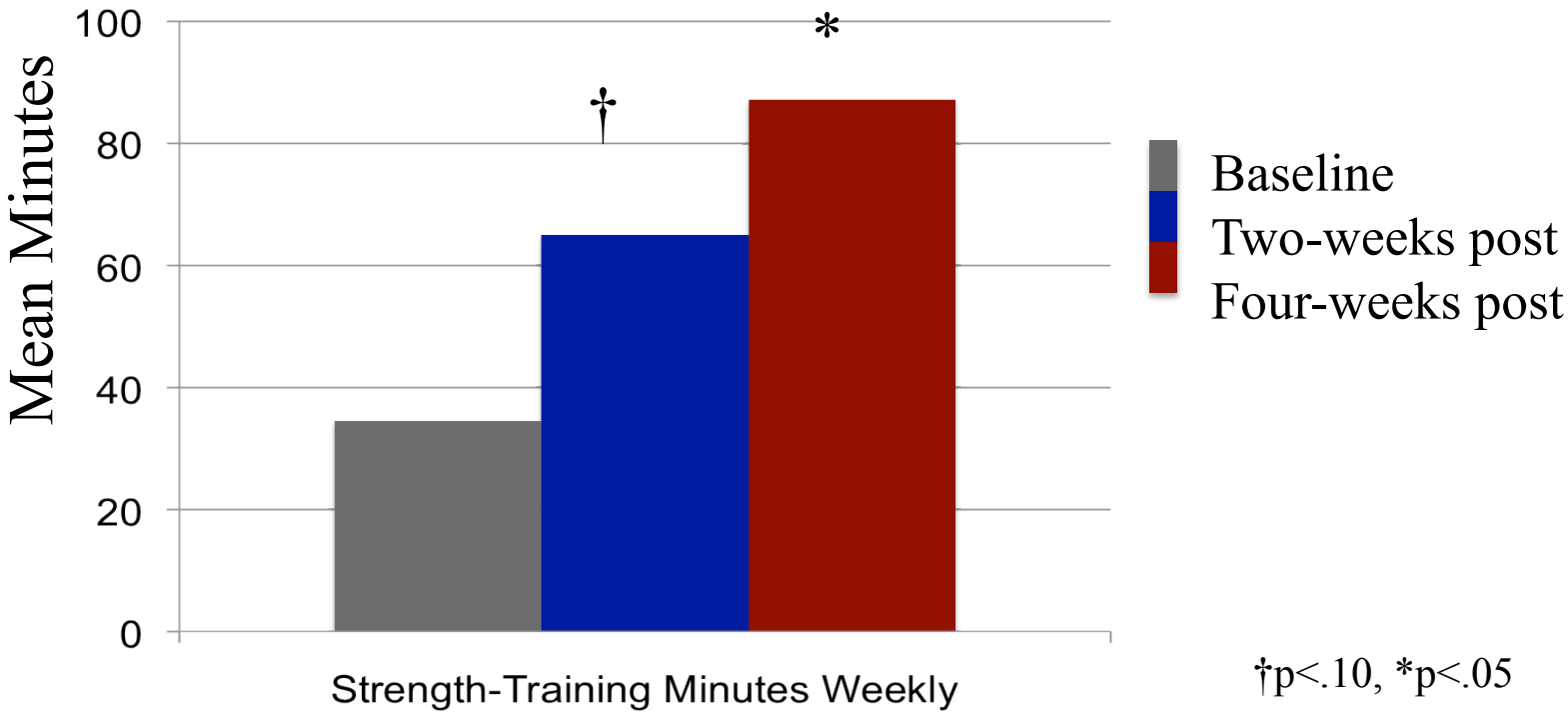
# Change in % of clients reporting ≥30 min of mod-heavy LTPA ≥3 days/wk




Arbour-Nicitopoulos, Tomasone, Latimer-Cheung & Martin Ginis (2014)

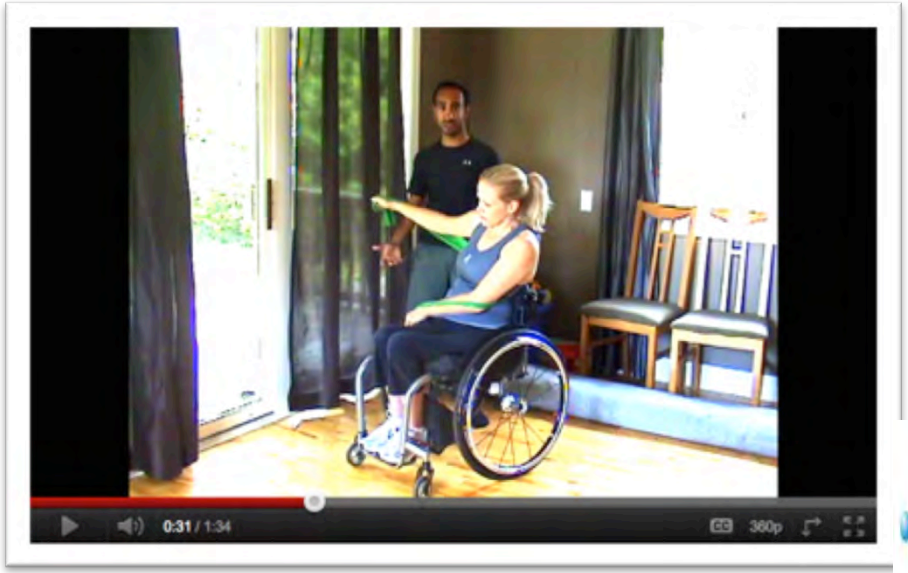
***ADVANCING PHYSICAL ACTIVITY KNOWLEDGE AND PARTICIPATION AMONG CANADIANS LIVING WITH SPINAL CORD INJURY***

# Active Homes: Changes in Minutes/ Week of Strength Training



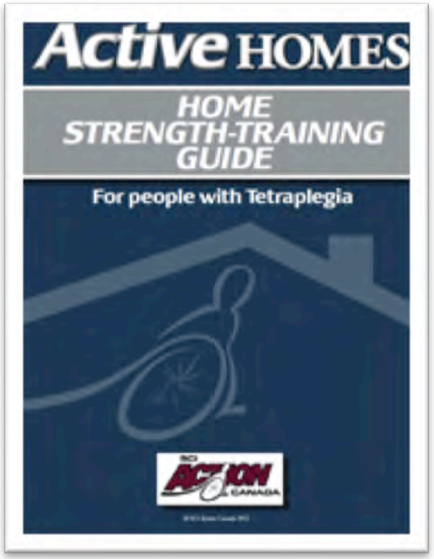

†p<.10, *p<.05

Latimer, Arbour-Nicitopoulos, Brawley, Gray, Wilson, Prapavessis, Tomasone & Wolfe (2013)


Canadian Paraplegic Association Ontario
Association canadienne des paraplégiques Ontario

fusionfitness FOR FUNCTIONAL LIVING




MacWHEELERS

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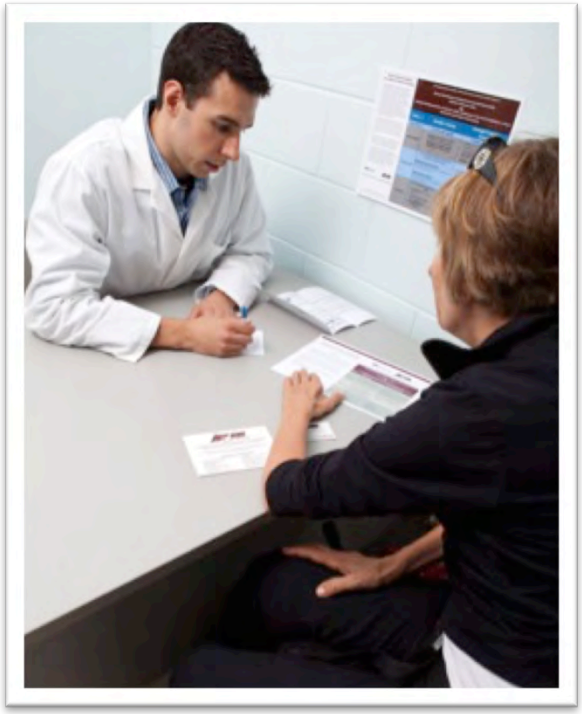
***ADVANCING PHYSICAL ACTIVITY KNOWLEDGE AND PARTICIPATION AMONG CANADIANS LIVING WITH SPINAL CORD INJURY***

# 4. Select Methods of Delivery and Implementation to Targeted Audiences



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# Physical Activity Guidelines for Adults with SCI now available in Swedish, 12 languages total

The first evidence-based guidelines to be developed specifically to support people with Spinal Cord Injury in living healthier, more active lives is now available in 12 different languages:

- Chinese
- Dutch
- English
- French
- German
- Greek
- Italian
- Portuguese
- Punjabi
- Spanish
- Swedish
- Russian

To find out more click here

## Get In Motion Re-opens

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## My Perspective

*Which Paralympic sport have you tried in the past? Which sport would you like to try, and why?*

### Peer Perspective

Jake Lawless
Nawid Razvi
Neil Allen
Sheri-lyn Roberts

### Researcher Perspective

Adrienne Sinden

Financial support provided by

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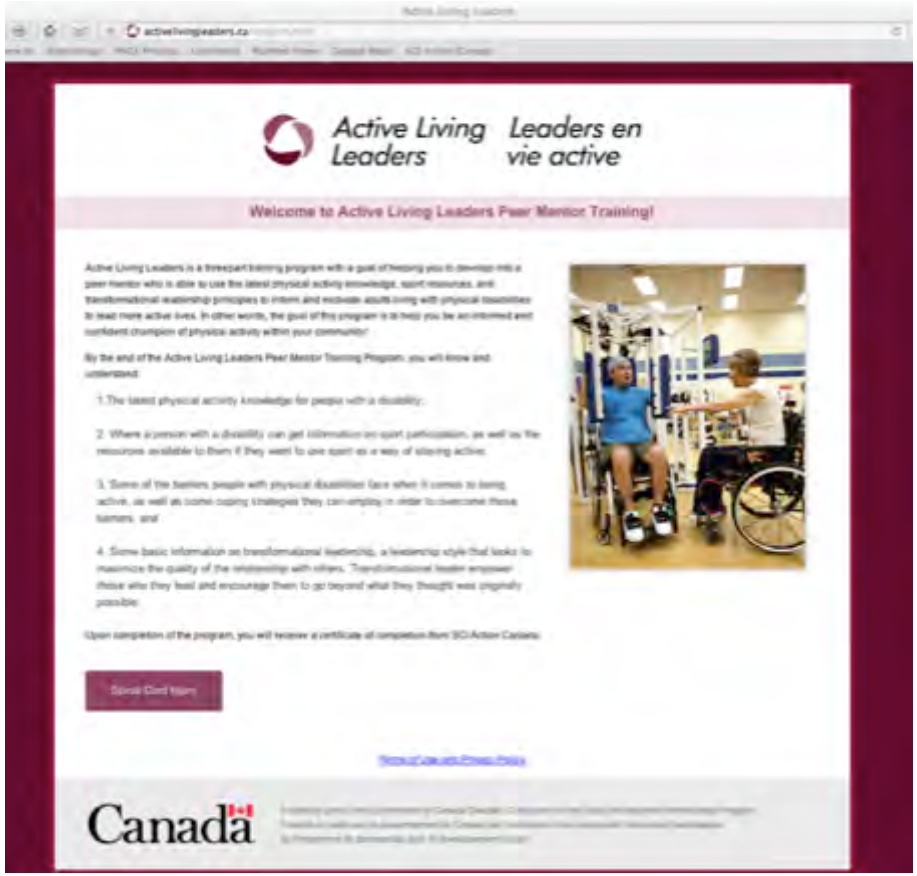
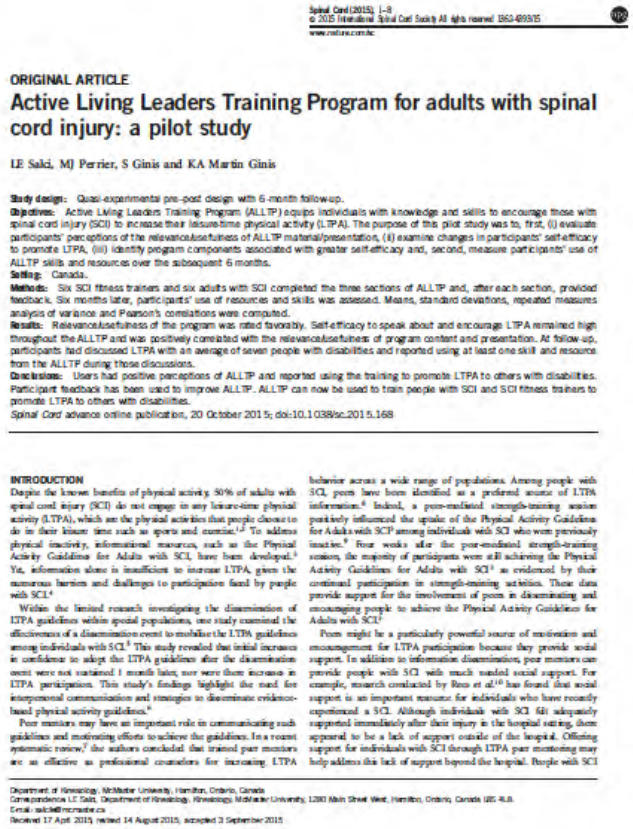
# CHANGING MINDS CHANGING LIVES

## Key Influencers

Canadian Paralympic Committee | Comité paralympique canadien

# activelivingleaders.ca



Spinal Cord (2015), 1–8
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ORIGINAL ARTICLE

## Active Living Leaders Training Program for adults with spinal cord injury: a pilot study

LE Salci, MJ Perrier, S Ginis and KA Martin Ginis

**Study design:** Quasi-experimental pre–post design with 6-month follow-up.
**Objectives:** Active Living Leaders Training Program (ALLTP) equips individuals with knowledge and skills to encourage those with spinal cord injury (SCI) to increase their leisure-time physical activity (LTPA). The purpose of this pilot study was to, first, (i) evaluate participants' perceptions of the relevance/usefulness of ALLTP material/presentation, (ii) examine changes in participants' self-efficacy to promote LTPA, (iii) identify program components associated with greater self-efficacy and, second, measure participants' use of ALLTP skills and resources over the subsequent 6 months.
**Setting:** Canada.
**Methods:** Six SCI fitness trainers and six adults with SCI completed the three sections of ALLTP and, after each section, provided feedback. Six months later, participants' use of resources and skills was assessed. Means, standard deviations, repeated measures analysis of variance and Pearson's correlations were computed.
**Results:** Relevance/usefulness of the program was rated favorably. Self-efficacy to speak about and encourage LTPA remained high throughout the ALLTP and was positively correlated with the relevance/usefulness of program content and presentation. At follow-up, participants had discussed LTPA with an average of seven people with disabilities and reported using at least one skill and resource from the ALLTP during those discussions.
**Conclusions:** Users had positive perceptions of ALLTP and reported using the training to promote LTPA to others with disabilities. Participant feedback has been used to improve ALLTP. ALLTP can now be used to train people with SCI and SCI fitness trainers to promote LTPA to others with disabilities.
*Spinal Cord* advance online publication, 20 October 2015; doi:10.1038/sc.2015.168

INTRODUCTION

Despite the known benefits of physical activity, 50% of adults with spinal cord injury (SCI) do not engage in any leisure-time physical activity (LTPA), which are the physical activities that people choose to do in their leisure time such as sports and exercise.[1,2] To address physical inactivity, informational resources, such as the Physical Activity Guidelines for Adults with SCI, have been developed.[3] Yet, information alone is insufficient to increase LTPA, given the numerous barriers and challenges to participation faced by people with SCI.[4]

Within the limited research investigating the dissemination of LTPA guidelines within special populations, one study examined the effectiveness of a dissemination event to mobilize the LTPA guidelines among individuals with SCI.[5] This study revealed that initial increases in confidence to adopt the LTPA guidelines after the dissemination event were not sustained 1 month later, nor were there increases in LTPA participation. This study's findings highlight the need for interpersonal communication and strategies to disseminate evidence-based physical activity guidelines.[6]

Peer mentors may have an important role in communicating such guidelines and motivating efforts to achieve the guidelines. In a recent systematic review,[7] the authors concluded that trained peer mentors are as effective as professional counselors for increasing LTPA behavior across a wide range of populations. Among people with SCI, peers have been identified as a preferred source of LTPA information.[8] Indeed, a peer-mediated strength-training session positively influenced the uptake of the Physical Activity Guidelines for Adults with SCI[9] among individuals with SCI who were previously inactive.[9] Four weeks after the peer-mediated strength-training session, the majority of participants were still achieving the Physical Activity Guidelines for Adults with SCI[3] as evidenced by their continued participation in strength-training activities. These data provide support for the involvement of peers in disseminating and encouraging people to achieve the Physical Activity Guidelines for Adults with SCI.[3]

Peers might be a particularly powerful source of motivation and encouragement for LTPA participation because they provide social support. In addition to information dissemination, peer mentors can provide people with SCI with much needed social support. For example, research conducted by Rees *et al.*[10] has found that social support is an important resource for individuals who have recently experienced a SCI. Although individuals with SCI felt adequately supported immediately after their injury in the hospital setting, there appeared to be a lack of support outside of the hospital. Offering support for individuals with SCI through LTPA peer mentoring may help address this lack of support beyond the hospital. People with SCI

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Email: salcile@mcmaster.ca
Received 17 April 2015; revised 14 August 2015; accepted 3 September 2015

www.
sciactioncanada.ca

*Registry in Canadian Medical Association Infobase of Clinical Practice Guidelines*


*Educational Partners: Canadian Paralympic Committee Active Living Alliance*

*SCI Ontario & Alberta 'Roadshows' promoting the guidelines*

*SCI Get Fit Toolkits Directly Mailed to Spinal Cord Injury Ontario/BC Members*

# 5. Evaluate Implementation Effectiveness

*Guidelines viewed 10000+ times on our website*

*130+*
Get in Motion Clients

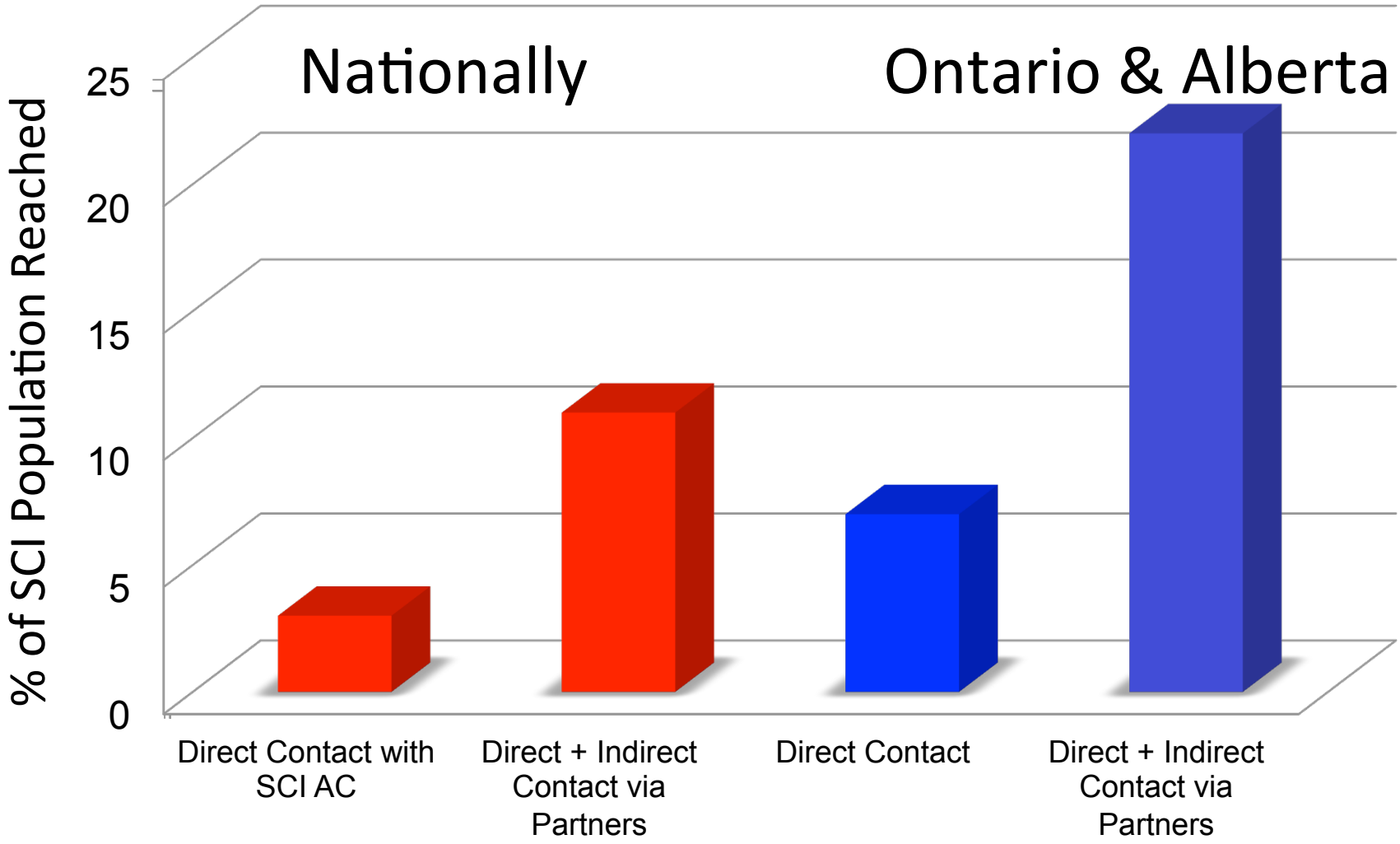
*800*
*Health Care Professionals & Service Providers*


*Roadshows in 17 communities*

*16,000*
SCI Get Fit Toolkits *Distributed*

*5-year Activity Monitoring Study*

# Do Partnerships Make a Difference?



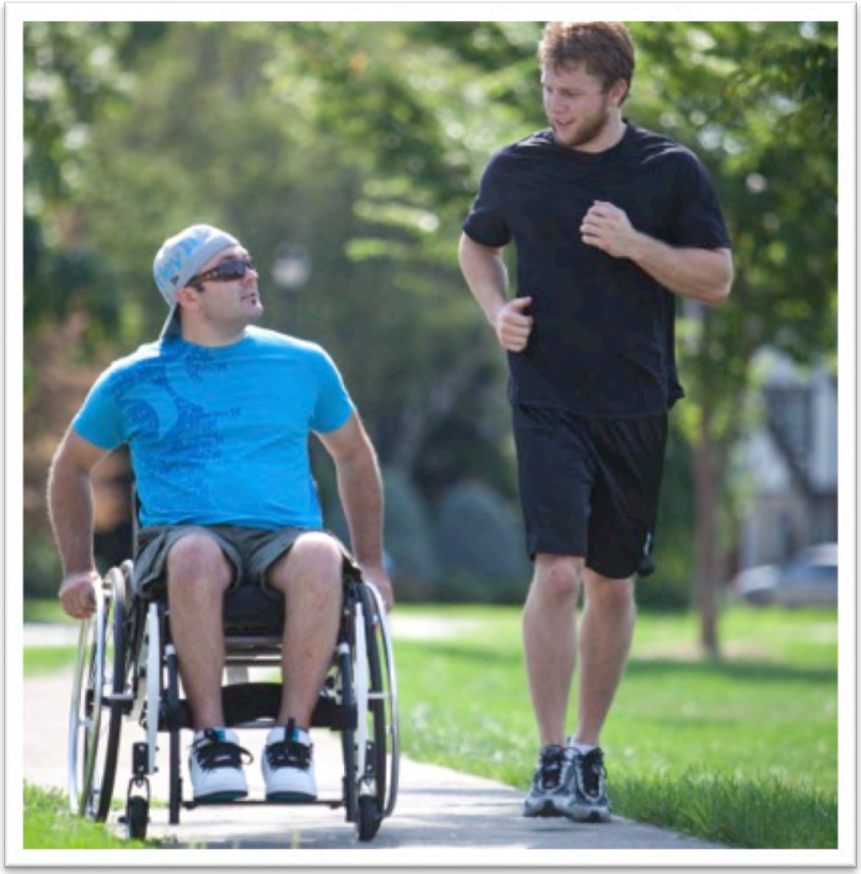

*Including website visits, reach = 18% nationally and 36% regionally.

# Lessons Learned: Cultivating Successful Community-University Partnerships

Martin Ginis et al. (2012). *Translational Behavioral Medicine*


***ADVANCING PHYSICAL ACTIVITY KNOWLEDGE AND PARTICIPATION AMONG CANADIANS LIVING WITH SPINAL CORD INJURY***

# Be Patient—Meaningful Partnerships Take Time to Develop



# Remember that Partnerships Are About Sharing

# Identify “Partnership Champions”

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