Takin’ it to the Streets: A Community-University Partnership Approach to Physical Activity Research and Knowledge Translation

Kathleen A. Martin Ginis

Over the past decade, researchers have faced increasing pressure to bridge the gap between the generation of new knowledge and the translation of that knowledge into applications and products that can benefit society. SCI Action Canada is an example of a community-university partnership approach to bridging the research generation-knowledge translation gap. It is an alliance of 30 community-based organizations and university-based researchers working together to increase physical activity participation among people living with a spinal cord injury (SCI). This paper provides an overview of activities undertaken by SCI Action Canada, presented within the framework of key principles of effective knowledge translation. Recommendations are made for the cultivation of successful community-university partnerships to develop, evaluate, and implement physical activity innovations.

Keywords: spinal cord injury, knowledge mobilization, exercise, implementation science, paraplegia, tetraplegia

The term *spinal cord injury* (SCI) refers to damage to the spinal cord that results in a loss of motor and/or sensory function (Rick Hansen Institute, 2012). Injuries are classified in terms of the location of the spinal cord lesion; people who have a lesion in the thoracic segments of the spinal cord or lower are classified as having **paraplegia**. People who have a lesion in the cervical segments of the spinal cord are classified as having **quadriplegia** or **tetraplegia** (these terms mean the same thing and are interchangeable). What most people do not realize is that there is tremendous variability in residual function after an SCI. Residual function all depends on the severity (i.e., “completeness”) of the injury. As a result, some people—a small minority—will regain almost full sensation and function below their level of injury; some people will not regain any function or sensation, and the majority end up somewhere in between. For example, over the years I have met several quadriplegics who can walk almost as well as I can. I have also met quadriplegics who cannot move a muscle below their chins. Most people with quadriplegia fall somewhere in between those extremes; consequently, the SCI population is very heterogeneous in terms of physical functioning.

It is estimated that 85,000 Canadians and 1.25 million Americans are currently living with a SCI (Christopher and Dana Reeve Foundation, 2012; Farry & Baxter, 2010). These numbers may not seem particularly large, but consider the tremendous impact that a SCI has on a person’s quality of life (QOL; Post & van Leeuwen, 2012). In addition, the costs of treating SCI in Canada alone are $3.6 billion/year (Rick Hansen Institute, 2012). If you consider the personal and financial burdens associated with SCI, clearly, this is a population where physical activity interventions have the potential to make a powerful difference.

Numerous meta-analyses and systematic reviews have shown that physical activity has significant physical and psychosocial benefits for adults with SCI (Hicks, Martin Ginis, Pelletier, Ditor, Foulon, & Wolfe, 2011; Jacobs & Nash, 2004; Martin Ginis, Jetha, Mack, & Hetz, 2010; Noreau & Shephard, 1995; Rimaud, Calmels, & Devillard, 2005; Wolfe, Latimer, Eng, & Hsieh, 2008). Yet, despite these benefits, people with SCI are the most inactive segment of society. Indeed, in a population-based sample of nearly 700 people living with a SCI, we found that 50% reported no leisure time physical activity (LTPA), not even a single minute of sport, exercise, or other leisure activity (Martin Ginis, Arbour-Nicitopoulos et al., 2010). When we looked at the amount of activity performed by those reporting at least some LTPA, we found that 50% reported no leisure time physical activity (LTPA), not even a single minute of sport, exercise, or other leisure activity (Martin Ginis, Latimer et al., 2010). However, the standard deviations were massive; a finding that further attests to the heterogeneity of the SCI population.

It is also important to note that given the number of physical activity barriers faced by people with SCI,
those who are active face an ongoing struggle to stay active over the long haul. Looking across an 18-month observational study period, in a cohort of 541 adults with SCI, we found that about 1/3 of our sample stayed active over the entire 18 months. Another third started out active, but by 18 months, they were not reporting any LTPA (Sweet, Martin Ginis, Latimer-Cheung, & The SHAPE-SCI Research Group, 2012). These data suggest that the SCI population would benefit from strategies and support to help both with the initiation and the maintenance of an active lifestyle.

**Jake’s Story**

In the Department of Kinesiology at McMaster University, we operate a community-based exercise program for people with SCI. This program is known as the “MacWheelers” and it was established in 2002 when one of our randomized controlled trials (Hicks et al., 2003) ended and the participants did not want to stop exercising. My colleague, Dr. Audrey Hicks, used this opportunity to establish the MacWheelers exercise program. Adults with SCI come into our program twice per week and a small army of student volunteers work with our clients, serving as personal trainers.

When the program first opened, one of our most motivated, regular exercisers was a young man named Jake. When Jake was 24 years old he fell from a roof that he was working on, broke his neck, and instantly became a C4 quadriplegic. His injury was incomplete, which means that he had some residual function and sensation below his injury. Ten years ago, when Jake started working out in our program, he did not have sufficient hand strength to grip the cranks of an arm ergometer; his hands had to be tethered to the cranks.

Spending so much time in the gym, Jake became good friends with many of the student volunteers. And after months of listening to stories about their undergraduate lives, Jake came to the conclusion that if they could get an undergraduate degree, so could he. One day Jake told me that he had decided to go back to school and become a French teacher. I thought that was great. The only problem was: Jake did not know how to speak French.

Jake did not see this as a barrier and he enrolled at McMaster University and faithfully continued to work out at the MacWheelers program. Now at that time, Jake’s level of function was such that every morning, a nurse had to come into his apartment, get him out of bed, showered, dressed, and into his wheelchair. Then at the end of the day, a nurse had to come back to his apartment, help Jake out of his wheelchair, get him undressed and into bed. Try to imagine for a moment, being 20-something years old, and having to be home by 8:00 every night so that somebody can put you to bed. Jake told me that with that type of routine, he was never going to meet a woman. For Jake, exercise became the means to achieving a vital personal goal; to regain enough strength, so that he could come home whenever he wanted, get himself out of his chair, undressed, and into bed.

Over the next seven years, Jake earned two undergraduate degrees from McMaster University, completed teacher’s college and became a full-time French teacher in an elementary school. And two summers ago, I had the honor of watching him fulfill that second life goal as he stood and exchanged marriage vows with his beautiful bride, Lynn.

For the past ten years, I have seen the small but significant role that physical activity can play in helping people with SCI move forward with their lives. Consequently, my research interests have gradually shifted from questions that can be addressed in typical randomized controlled trials or other experimental-based protocols, to the bigger question of how to replicate Jake’s story among the tens of thousands of people living with a SCI. In 2007, an opportunity arose to begin answering that question.

**SCI Action Canada**

SCI Action Canada is a community-university research alliance (CURA) that was established in 2007 through a CURA grant from the Social Sciences and Humanities Research Council of Canada (Martin Ginis et al., 2012). The purpose of the alliance is to advance physical activity knowledge and participation among Canadians living with SCI. Our partnership includes 16 community-based organizations. These are organizations that have a primary focus on providing services to people with SCI, such as SCI Ontario and SCI Alberta (formerly known as Canadian Paraplegic Association Ontario and Alberta, respectively); organizations that provide adapted physical activity opportunities to people with disabilities, such as the Canadian Paralympic Committee and the Canadian Wheelchair Sports Association; and organizations with a vested interest in public health and physical activity such as ParticipAction and the provincial government. Our research partners are 15 investigators (including several NASPSPA members) from eight institutions (see Table 1 for a complete list of partners). We have come together with the common mission of developing and mobilizing evidence-informed strategies that inform, teach, and enable people living with a SCI to initiate and maintain a physically active lifestyle.

Importantly, SCI Action Canada is not just a research organization. Knowledge translation is at the foundation of all of our activities and is vital to our mandate and fulfillment of our mission. In Canada, one of our national funding agencies uses the term knowledge translation—and the other uses the term knowledge mobilization—for what NIH refers to as “dissemination and implementation.” Essentially these three terms mean the same thing: getting the right information, to the right people, in the right format, at the right time.

The community-university partnership is at the heart of all SCI Action Canada research and knowledge...
Table 1  SCI Action Canada Community and Research Partners

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<th>Community partners</th>
<th>Research partners</th>
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<td>• Bridging the Gap</td>
<td>• Dr. Larry Brawley, University of Saskatchewan</td>
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<td>• Canadian Paralympic Committee</td>
<td>• Dr. Steven Bray, McMaster University</td>
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<td>• Spinal Cord Injury Alberta</td>
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<td>• Dr. Julie Horrocks, University of Guelph</td>
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<td>• MacWheelers (McMaster University)</td>
<td>• Dr. Amy Latimer-Cheung, Queen’s University</td>
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<td>• Ontario Neurotrauma Foundation</td>
<td>• Dr. Lori Letts, McMaster University</td>
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<td>• ParaSport Ontario</td>
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translation activities. Our activities are guided by the blueprint shown in Figure 1. Specifically, partners work together to conduct research that is subsequently translated into products, tools, and services that are then implemented into the SCI community.

The SCI Action Canada Research and Knowledge Translation Program

To operationalize the blueprint, we have constructed a research and knowledge translation program carefully structured around Lavis and colleagues’ five principles of effective knowledge translation (Canadian Health Services Research, 2004; Lavis, Robertson, Woodside, McLeod, & Abelson, 2003).

Principle 1: Know Your Audience and the Issues

The first principle of effective knowledge translation is to know your audience and the key issues faced by that audience. Early in our program, we conducted studies to determine what is available and what is needed in the SCI community, in terms of tools and resources for physical activity promotion. We also spent time examining whether there was adequate community capacity to deliver any new tools, products or services that we might develop (Bassett, Martin Ginis, Latimer, & Wolfe, 2010; Latimer, Brawley, Conlin, & Martin Ginis, 2010).

From a psychosocial perspective, we devoted resources to determine what psychosocial variables and behavioral skills should be targeted to enhance LTPA in the SCI population. For example, in one study we used Bandura’s Social Cognitive Theory (Bandura, 1997) to examine predictors of LTPA in 160 people with SCI (Martin Ginis, Latimer et al., 2011). The results were consistent with what has been found in the general population.
skills as well as their self-efficacy. Tools to help people with SCI develop their self-regulation—Arbou, 2006—highlighted the need for us to develop delivery strategies, tools and techniques for providing pilot projects, developing and testing various information and skills people need to be active, and who should be delivering this information. We conducted over a dozen pilot projects, developing and testing various information delivery strategies, tools and techniques for providing LTPA-enhancing information and skills to people with SCI. I will highlight a few of our projects that best exemplify how the partnership worked together.

A key accomplishment was the development of the first evidence-based physical activity guidelines for adults with SCI (Martin Ginis, Hicks et al., 2011). We also developed a supporting physical activity guide—the SCI Get Fit Toolkit (Arbour-Nicitopoulos et al., 2012). To develop these products, we first pulled together an evidence base consisting of systematic reviews and needs surveys [e.g., (Foulon, Lemay, Ainsworth, & Martin Ginis, 2012; Hicks, Martin Ginis, Pedletier et al., 2011; Wolfe, Martin Ginis, Latimer et al., 2008)]. That evidence was presented to a consensus panel comprised of researchers, clinicians and community members. The panel made recommendations and those recommendations were translated into the Physical Activity Guidelines for Adults with SCI and the SCI Get Fit Toolkit.

Another example is Get In Motion, a service through which we provide telephone-based physical activity counseling, at no charge, to people living with a SCI anywhere in Canada. This service began with two randomized controlled trials (Arbour-Nicitopoulos, Martin Ginis, & Latimer, 2009; Latimer, Martin Ginis, Arbour, 2006). In these trials, we demonstrated the efficacy of a telephone-based counseling intervention for increasing physical activity in adults with SCI. During the counseling, participants were taught an important self-regulation strategy—how to develop action plans and/or coping plans. With funding and promotional support from community partners, we were able to translate those trials into a service that has now been up and running for three years. The counseling is structured around the Physical Activity Guidelines for Adults with SCI, and is heavily focused on teaching clients those key self-regulatory strategies that we have found to be so important for the initiation and maintenance of physical activity. We have just completed a preliminary evaluation of the service and we are seeing significant increases in the proportion of clients regularly participating in LTPA (Arbour-Nicitopoulos, Tomason, Latimer-Cheung, & Martin Ginis, 2012).

A third example is Dr. Amy Latimer-Cheung’s Active Homes pilot project. Through Active Homes, we wanted to capitalize on what we had learned about the importance of peers for promoting physical activity. In this project, we sent a peer with a SCI and a fitness trainer who had extensive experience working with people with SCI, into the homes of people with paraplegia. Peers were drawn from the peer support program of one of our partners, SCI Ontario. The fitness trainer came from our partner, Fusion Fitness. Participants were people who were not currently meeting the physical activity guidelines for strength training. The peer and the trainer went into each participant’s home. Once there, the fitness trainer prescribed an individualized strength-training program using resistance bands or other equipment in the person’s home and helped the participant develop an action plan for adhering to the exercise program. The peer demonstrated the exercises, and talked to the participant about barriers he or she might face when carrying out the action plan, and strategies that could be used to overcome those barriers. The response to this intervention was fantastic. From baseline to four weeks after the visit, we saw
nearly a threefold increase in the number of minutes people were spending on strength training each week (Latimer-Cheung et al., 2012). We are currently working with partners to implement elements of this pilot project in the community. In addition, we have translated the study materials into resources that are available to the public, for free. On our website (www.sciactioncanada.ca) manuals and corresponding exercise videos can be downloaded, providing home-based strength training programs for people with paraplegia and tetraplegia.

**Principle 4: Select Methods of Delivery and Implementation to Targeted Audiences**

The fourth principle of effective knowledge translation is to select methods of delivery and implementation to targeted audiences. Given that we had only five years of funding for all phases of this project, it was important to zero in on a couple of key audiences that we felt confident in reaching within the final two years of our funding mandate. As such, we decided to focus our efforts on reaching people with SCI as well as reaching health care professionals.

Here are some examples of strategies we are using to reach these audiences. Our website (www.sciactioncanada.ca) has downloadable versions of all of our resources, tools and services, as well as links to our partners' websites, and layperson summaries of our research projects. A key feature of our website is our Question and Answer Log (i.e., a “QLog”). We use the QLog as another means for leveraging the influence of peers to enhance physical activity. Specifically, two of the QLog bloggers are physically active men who have an SCI—one has paraplegia and the other has tetraplegia. Every month, they are asked to write about their own physical activity experiences with reference to a particular topic such as “how do you stay active in the winter?” or “how do you find time to be active?” Our readers are able to learn from our bloggers' personal experiences. In addition, our research coordinator, Adrienne Sinden, provides a layperson summary of a journal article on the Qlog topic so that we ultimately provide a blend of experiential and empirical information on each issue.

SCI Ontario, SCI Alberta and SCI British Columbia have played a central role in helping us reach people with SCI by facilitating direct mailings of SCI Action Canada Get Fit Tool Kits to their members. In addition, with the logistical support of SCI Ontario and SCI Alberta, we sent a team across the provinces of Ontario and Alberta to 19 communities where we put on “The SCI Action Canada Roadshow.” The purpose of the Roadshow was to bring together people with SCI, their families, health care providers and support workers, to present the SCI Physical Activity Guidelines. During the Roadshows, we taught people how to do some basic exercises that would help them meet the guidelines, showed them where to find the exercise videos and manuals on our website, and a peer with SCI spoke to the audience about his/her own experiences and challenges with being physically active in that particular community. Importantly, the Roadshow also provided an opportunity for people within a community to come together and exchange information and ideas on how to be active within their community.

With regards to targeting health care professionals, the SCI Physical Activity Guidelines have been registered in the Canadian Medical Association’s Infobase of Clinical Practice Guidelines (www.cma.ca). We have also worked closely with two partners—the Canadian Paralympic Committee and the Active Living Alliance for Canadians with a Disability—to integrate the guidelines and other resources into existing educational programs that they deliver to health care professionals and trainees right across Canada.

**Principle 5: Evaluate Implementation Effectiveness**

The fifth knowledge translation principle is to evaluate implementation effectiveness. We are in the process of conducting a complete RE-AIM (Glasgow, McKay, Piette, & Reynolds, 2001; Glasgow, Vogt, & Boles, 1999) evaluation of SCI Action Canada’s knowledge translation activities. Although that evaluation is a work in progress, I can give you a small snapshot of some data, thus far. As of June 2012, our guidelines have been viewed 6,000 times on our website by people living in 89 countries; we have given presentations regarding the guidelines to over 800 health care professionals and service providers through our Roadshows and other educational initiatives; we have distributed 10,000 SCI Get Fit Toolkits; we have hosted Roadshows in 17 communities; and over 120 clients have received physical activity counseling through the Get In Motion service. Without a doubt, we would not have achieved this reach without the community-university partnership. In particular, the community partners played key roles in the development of our tools, products and services, and have been absolutely vital to during the dissemination and implementation processes.

**Cultivating Successful Community-University Partnerships**

Along the way, we have learned many lessons in terms of cultivating successful community-university partnerships (Martin Ginis et al., 2012). Perhaps the most important piece of advice I can offer, is to be patient. It takes time for multisector partnerships to develop into trusting, supportive and effective relationships. One of our community partners talks about how our early SCI Action Canada team meetings felt like high-school dances—the community partners would sit on one side of the room, the researcher partners would sit on the other, and there was a big awkward space in between. We did not really start to dance together until community partners were given specific roles in research projects,
and researchers were given specific roles in community projects. For example, community partners were invited to sit on research evaluation and recommendation panels. Researchers were invited by the community partners to help develop curriculum in some of their programs. It was during those projects that bridges were built, and the partnership really began to gel.

The second lesson is to remember that partnerships are about sharing. I know that there can be a tendency for researchers to think only about community partners in terms of facilitating study participant recruitment. Certainly that is important, but we also need to realize that one reason community organizations have come to the table, is because they want access to research. Our community partners want access to cutting-edge information that they can use to enhance their programs and to support their funding applications. They also have their own research questions that they want to address, but they need help to do so. Facilitating these needs goes a long way in strengthening the partnership.

The third lesson is to identify partnership champions. The partnership will not work unless there are people on both sides of the table—in the community organizations and in the universities—who truly believe in a partnership approach. I have been consistently amazed at the doors that have opened to us when we have identified those champions, particularly within the community organizations. They have facilitated opportunities for SCI Action Canada that have gone beyond my grandest ambitions.

Speaking of champions, 25 years ago, Rick Hansen, who is probably the world’s most famous paraplegic, wheeled around the world to raise money and awareness for SCI research. To mark the 25th anniversary of that accomplishment, the Rick Hansen Foundation organized a relay tour across Canada. Jake was seconded from his teaching position, to travel and work on the relay tour as an ambassador. He started in St. John’s, Newfoundland last August and finished in Victoria, British Columbia in May. Jake traveled 12,000 km and visited 600 Canadian communities, doing his own brand of knowledge translation, talking to people about the importance and possibility of being physically active after a SCI, and, incredibly, bringing his own story full circle.

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References


