

# Partnership in Action: An Innovative Knowledge Translation Approach to Improve Outcomes for Persons with Fibromyalgia

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## WHAT IS KNOWLEDGE TRANSLATION?

The creation of new knowledge through health research often fails to translate into appropriate changes in health care practice.<sup>1</sup> In fact, it may take 10 to 20 years for information gained through research to be implemented in routine clinical practice.<sup>1</sup> The difference between the best (evidence-based) care and traditional care was referred to by Graham and colleagues as the “knowledge to action (KTA)” gap.<sup>2</sup> This gap accounts for a significant number of patients who do not receive the best possible care or, in some cases, receive care that is potentially harmful.<sup>2</sup> The Canadian Institutes of Health Research (CIHR) seek to close the KTA gap by accelerating the translation of new research knowledge into improved health care practices and outcomes—a process known as *knowledge translation* (KT).<sup>3</sup>

Below we introduce the concept of KT, as defined and used by CIHR, and outline an innovative project to disseminate the results of a 2007 Cochrane Systematic Review on the effects of exercise in fibromyalgia (FM).<sup>4</sup> The collaborative work conducted by a small CIHR subgroup to disseminate research priorities, as identified by review authors, in a user-friendly format to the FM research community should be of particular interest to physiotherapists.

## THE CIHR AND KNOWLEDGE TRANSLATION

CIHR was created in June 2000 as Canada’s premier health research funding agency.<sup>5</sup> Its mandate is “to excel,

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according to internationally accepted standards of scientific excellence, in the creation of new knowledge and its translation into improved health for Canadians, more effective health services and products, and a strengthened Canadian health care system.”<sup>5</sup> Embedded within this mandate, CIHR defines KT as “a dynamic and iterative process that includes synthesis, dissemination, exchange and ethically sound application of knowledge to improve the health of Canadians, provide more effective health services and products, and strengthen the health care system.”<sup>3</sup> KT takes place within a complex system of interactions between researchers and knowledge users that depends on the nature of the research (e.g., biomedical, clinical, health services, population health) and its findings, along with the needs of individual end users.<sup>3</sup> For example, knowledge gained through biomedical research may inform the next research question toward unravelling a complex diagnostic puzzle, while information gained through clinical research may lead to an improved treatment approach for clinicians and patients, supported by updated health policy.

At CIHR, KT is divided into two main categories: end-of-grant KT and integrated KT.<sup>3</sup> The former involves the traditional dissemination and communication strategies undertaken by researchers, including publication in peer-reviewed journals and conference proceedings, along with newer approaches such as tailoring the message and medium to a specific audience.<sup>3</sup> The term “integrated KT” refers to a collaborative approach in which researchers and users of research (end users) work together to set the research agenda, determine

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project methodology, collect data, interpret findings, and share research results with the broader health community.<sup>3</sup> The ultimate aim is to facilitate the translation of knowledge into action that leads to improved health outcomes and quality of life for Canadians.<sup>3,5</sup>

### **THE INSTITUTE OF MUSCULOSKELETAL HEALTH AND ARTHRITIS—KNOWLEDGE EXCHANGE TASK FORCE**

The Institute of Musculoskeletal Health and Arthritis (IMHA), one of 13 institutes within CIHR, “supports research to enhance active living, mobility and movement, and oral health; and addresses causes, prevention, screening, diagnosis, treatment, support systems, and palliation for a wide range of conditions related to bones, joints, muscles, connective tissue, skin and teeth.”<sup>6</sup> To achieve this goal, IMHA focuses on three strategic research priorities: (1) physical activity, mobility, and health; (2) tissue injury, repair, and replacement; and (3) pain, disability, and chronic disease.<sup>6</sup>

Recognizing the importance of ongoing and effective information sharing between researchers and stakeholders IMHA created a forum for these groups to interact and strategies for disseminating research information to a wider audience. This forum, known as the Knowledge Exchange Task Force (KETF), was created in 2004 to bring researchers, consumers (i.e., patients), clinicians, students, community partners, and other end-users together to discuss current research, either completed or in progress.<sup>6</sup> The knowledge arising from research is translated by KETF members into language and approaches suitable for dissemination within their own organizations, to other stakeholders, and, ultimately, to the broader Canadian public. The KETF also seeks to identify research priorities of primary importance to the groups it represents to ensure that IMHA supports research that addresses the most pressing needs of Canadians. The active partnership between creators and users of knowledge facilitates the dissemination, uptake, and implementation of research results toward evidence-based practice and best health outcomes for Canadians.

KETF members, known as Research Ambassadors, are committed to (1) fostering a culture of inquiry, cooperation, and communication; (2) maintaining a climate of mutual respect, consideration, and inclusiveness; and (3) embodying the highest standard of integrity and ethics. While the majority of Research Ambassadors are patient representatives from national voluntary health organizations relating to IMHA’s six focus areas (e.g., the Arthritis Society, Osteoporosis Canada, Muscular Dystrophy Canada), others represent professional associations such as the Canadian Physiotherapy Association (CPA).

### **PARTNERSHIP WITH COCHRANE MUSCULOSKELETAL REVIEW GROUP**

Recognizing the value of the high-quality health information found in Cochrane Systematic Reviews and a shared interest in engaging consumers (i.e., patients) in research relating to pain, musculoskeletal health, and arthritis, IMHA–KETF partnered with the Cochrane Musculoskeletal Group (CMSG) in 2006 to disseminate information arising from their systematic reviews. The CMSG has a strong track record in working with organizations such as the Arthritis Society (to develop and share plain-language summaries of Cochrane Reviews on arthritis interventions) and the Canadian Arthritis Patient Alliance (to engage patients in activities such as consumer peer review).

In 2006, KETF sub-groups were asked to choose one CMSG Cochrane Review on which to base a knowledge-transfer or dissemination project. Our group consisted of arthritis consumer representatives (MB, ME, PS), an Arthritis Society staff member (LM), and a physiotherapy graduate student (VD). We chose “Exercise for Treating Fibromyalgia Syndrome (FM),” a fibromyalgia (FM) and exercise Cochrane review published in the Cochrane Library in 2002 (updated October 2007) by University of Saskatchewan physiotherapy researcher Dr. Angela Busch and her colleagues.<sup>4</sup> This review was chosen because FM affects between 1% and 2% of the population and causes significant pain, disability, and loss of quality of life.<sup>4</sup> While exercise is an important part of a healthy lifestyle, the optimal intensity, frequency, and duration levels of exercise for people living with FM are not yet defined.<sup>4</sup> We felt that providing information about exercise and FM to persons with this condition could help empower them to take a more active role in their care and achieve an optimal quality of life.

Our first goal was to share information found in the exercise and FM review<sup>4</sup> with the Canadian public. To this end, we worked with the CMSG Knowledge Translation Specialist (TR) to develop a plain-language summary of the review, along with a poster titled “Got Fibro, Get Fit.” Next steps involved working with high-profile organizations such as FM Canada, the Arthritis Society, and CPA to disseminate this information in French and English through the Internet, newsletters, and other communication networks within these organizations. Immediately prior to our launch date, however, a small revision to the October 2007 exercise and FM review was published in the Cochrane Library (April 2008). The revision reported less significant findings than the 2007 review. Given the need for clear, actionable, positive messages about the role of exercise for persons with FM, we chose not to proceed with our dissemination plan to the lay audience. However, plain-language summaries of this review, and of other Cochrane Reviews on FM or arthritis interventions, are

found in the Cochrane Library and on the Arthritis Society Web site.<sup>7,8</sup> They are an excellent source of high-quality, easy-to-understand health information suitable for clinicians and patients.

While Cochrane Systematic Reviews summarize the current evidence base in an identified area of interest, they also play an important role in identifying gaps in the literature and recommending what research is needed to fill these gaps. Recognizing that Busch et al.<sup>4</sup> clearly outlined the recommendations for further research needed to understand the best ways for persons with FM to exercise, our second goal was to facilitate the dissemination of these research priorities to the broad, international FM research community.

### DISSEMINATING RESEARCH RECOMMENDATIONS TO THE BROADER RESEARCH COMMUNITY

In 2006, a *British Medical Journal* (BMJ) editorial team noted that “long awaited reports of new research, systematic reviews, and clinical guidelines are too often a disappointing anticlimax for those wishing to use them to direct future research. After many months or years of effort and intellectual energy put into these projects, authors miss the opportunity to identify unanswered questions and outstanding gaps in the evidence.”<sup>9</sup>(p.804)

In order to ensure that the potential of these recommendations is captured, the BMJ team recommended a specific organizational framework for recommendations on the effects of treatments. This framework uses the acronym EPICOT for the following compulsory headings: Evidence, Population, Intervention, Comparison group, Outcomes, and Time stamp.<sup>9</sup> Optional headings include Disease Burden or Relevance, Timeliness, and Study Type.<sup>9</sup> Our group worked with Dr. Busch to summarize the research priorities identified in the exercise and FM review in the EPICOT framework (see Table 1).

In spring 2008 we circulated our EPICOT dissemination tool via e-mail to a broad array of national and international FM and related organizations, including the Arthritis Society, CPA, Canadian Rheumatology Association, Arthritis Health Professions Association, American College of Rheumatology, Bone and Joint Decade Canada, and several national FM associations.

Recipients were asked to provide feedback via an online survey that could be completed quickly and easily.<sup>10</sup> Each of the six respondents who completed the online survey reported that the EPICOT summary helped them to understand the current evidence base (and gaps) surrounding FM and exercise. Five agreed that the information was presented in an easy-to-understand and useful way, was relevant to share with others, and was

**Table 1** Research Priorities to Understand the Effects of Exercise in Fibromyalgia Syndrome (FM)

Core Elements		
Evidence	What is the current state of evidence?	<ul style="list-style-type: none"> <li>• Sufficient studies are available to allow meta-analysis of six studies of moderate to high quality, aerobic-only protocols of American College of Sports Medicine (ACSM)-recommended intensity levels versus untreated controls.</li> <li>• There is limited evidence from two low-quality strength-training programs at ACSM level versus untreated controls.</li> <li>• There are no studies comparing flexibility-only exercise to non-exercise control groups.</li> </ul>
Population	Diagnosis, disease stage, co-morbidity, risk factor, sex, age, ethnic group, specific inclusion or exclusion criteria, clinical setting	<ul style="list-style-type: none"> <li>• Studies are needed on all age groups.</li> <li>• Future intervention studies should include more men.</li> <li>• Reviewers should consider expanding systematic reviews to include chronic fatigue syndrome.</li> </ul>
Intervention	Type, frequency, dose, duration, prognostic factor	<p>Future intervention studies should</p> <ul style="list-style-type: none"> <li>• use a standardized approach to describe the prescribed and performed exercise volume (i.e., ACSM-recommended exercise intensity classifications and corresponding ranges of physiological parameters for low-, moderate-, and high-intensity exercise) to ensure that researchers, clinicians, and individuals with FM have the same understanding of the exercise prescribed and performed.</li> <li>• evaluate leisure-time physical activity programs that meet Centers for Disease Control &amp; Prevention guidelines, monitoring both FM outcome measures and general health measures known to improve with regular physical activity.</li> </ul> <p>Future intervention studies should be designed to</p> <ul style="list-style-type: none"> <li>• assess dose-response curves for improvement of FM symptoms.</li> <li>• evaluate follow-up periods following completion of active intervention period. These studies should include ongoing, intermittent assessment of exercise behaviour and FM outcome measures to understand the stability of responses and program characteristics (intensity, duration, frequency) needed to maintain gains.</li> </ul>
Comparison	Placebo, routine care, alternative treatment or management	<p>Future intervention studies are needed that</p> <ul style="list-style-type: none"> <li>• compare one type of exercise (aerobic, strengthening, or flexibility) to untreated controls; once the understanding of the effects of each type of exercise is clear, mixed exercise can be evaluated.</li> <li>• evaluate the current strategies used to help people with FM engage in regular exercise.</li> </ul>

(Continued)

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<i>Core Elements</i>		
<b>Outcomes</b>	Which clinical or patient-related outcomes will the researcher need to measure, improve, influence, or accomplish? Which methods of measurement should be used?	Research is needed that <ul style="list-style-type: none"> <li>• establishes a core set of outcome measures for research into non-pharmacological approaches for FM.</li> <li>• achieves a consensus on a standardized definition of adverse effects of exercise for FM; more extensive reporting of adverse effects is needed.</li> <li>• determines minimal clinically important differences and responsiveness of core measures.</li> </ul>
<b>Time stamp</b>	Date of literature search or recommendation	An updated systematic review is needed by January 2010.
<b>Optional Elements</b>		
Disease burden or relevance		FM affects 1–2% of population, causing significant pain, disability, and loss of quality of life.
Timeliness	Time aspect of core elements Mean age of population Duration of intervention or comparison Length of follow-up	Studies are needed on all ages: <ul style="list-style-type: none"> <li>• Interventions should be at least 6 weeks for de-conditioned individuals, although 12 weeks or more is preferable.</li> <li>• Researchers should report the level of participation in physical activity for subjects at study entry.</li> <li>• Follow-up of all study participants (including members of the control group) should be for at least one year.</li> </ul>
Study type	Study type and methodology	High-quality randomized studies are needed that <ul style="list-style-type: none"> <li>• have sufficient power (more than 50 per group).</li> <li>• include detailed description of the exercise intervention prescribed (mode, intensity, duration, frequency, exercise progression) and performed (adherence).</li> <li>• use methods to monitor exercise adherence (e.g., measuring exercise heart rate) throughout the study.</li> <li>• employ factorial designs (2 × 2) for interventions that combine exercise with other components (e.g., exercise and education) to allow assessment of the independent contribution of each component as well as any potential interactions between them.</li> <li>• investigate the barriers to regular exercise and physical activity for persons with FM.</li> </ul> Up-to-date systematic reviews will be needed that assess the effects of physical activity and exercise.

helpful either to them or to their organizations. Four concurred that it would help them make decisions about related research funding and felt that it would influence the way in which their organization would carry out future FM and exercise research. Comments included the following:

Very good for quick reference.

I will pass this along to my colleague who teaches rheumatology to health professionals.

I am not personally in a position to provide research funding or determine who receives it. My organization raises funds for research (and) researchers apply through CIHR. We feel that aspects of our programs are effective so may not change. We do not have adequate funding to carry out complicated research.

As we shift to more community management of FM it is essential to share best practice and not have these groups re-invent the wheel.

## LESSONS LEARNED

Effective KT facilitates the dissemination and uptake of research information so that appropriate action can be

taken by patients, clinicians, policy makers, voluntary organizations, other researchers, and research funding agencies. Stakeholder collaboration enhances information sharing to close the “knowledge to action” gap to improve health outcomes. Although we did not share our key messages with the Canadian public because of the lack of significant Cochrane Review findings, we hope that the broad dissemination of the research recommendations identified by the review’s authors in EPICOT format will increase their uptake within the international FM research community. The ultimate aim is to provide evidence-based information on effective exercise programs for persons with FM to achieve an optimal quality of life.

This small project reminds us that patient and consumer groups, along with other key stakeholders such as physiotherapists, play an important role in major health research organizations such as the CMSG and IMHA-KETF. Involving a variety of knowledge end users in health research and KT helps ensure that the most relevant research projects are conducted and that results are shared with the end users who can act on them to improve health practices and outcomes. For more information on the CMSG or KETF, or to learn ways in which you can contribute to either group, please visit the Web sites provided below.<sup>6,11</sup>

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