

# The Scleroderma Patient-centred Intervention Network (SPIN): An Innovative Cohort-Based Initiative for Scleroderma

By Claire Fedoruk; Marie-Eve Carrier; Linda Kwakkenbos; and Brett D. Thombs

**S**cleroderma is a rare autoimmune disease characterized by the hardening of connective tissues, which can substantially damage the skin, blood vessels, muscles, and internal organs. Common problems include lim-

itations in hand function and mobility, pain, fatigue, and emotional distress from disfiguring aspects of the disease, among other challenges.

Although rare diseases collectively affect one in 12 Canadians, the small number of patients at any given location is a barrier to developing and testing disease-specific support programs. Thus, people with scleroderma and other rare diseases must often cope without the kind of support programs that are generally available to people with more common diseases.

To develop and rigorously test patient programs in a rare-disease context, SPIN maintains a cohort of more than 1,800 scleroderma patients, who complete quarterly on-line assessments that help the SPIN team to understand their challenges and support needs. SPIN cohort patients are recruited by rheumatologists and other scleroderma health professionals from 40 clinical centres in seven countries.

The SPIN cohort also serves as an infrastructure for conducting clinical trials of SPIN's on-line support programs. Each program addresses a problem that scleroderma patients have identified as important, with programs currently in development to support: (1) disease self-management; (2) hand function; (3) emotional coping and; (4) body image distress.

## The SPIN Cohort

1,807  
scleroderma  
patients

7 countries

40 clinical  
recruiting sites



Knuckle Bending



Mild to Moderate →

Severe →

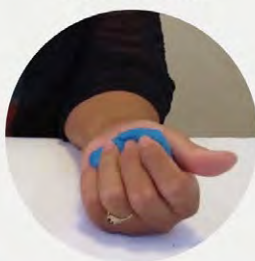
Finger-by-Finger  
Bending



Mild to Moderate →

Severe →

Grip Strength



Mild to Moderate →

Severe →

SPIN's first online program provides rehabilitation exercises to support hand function in people with scleroderma.

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# The Rheumatoid Arthritis Pharmacovigilance Program and Outcomes Research in Therapeutics (RAPPORT)

By Walter P. Maksymowych, MD, FRCPC

The Rheumatoid Arthritis Pharmacovigilance Program and Outcomes Research in Therapeutics (RAPPORT) Prospective Inception Cohort became operational in 2004 with two primary aims:

- A. To enhance the education and care of patients receiving biologics for the treatment of rheumatoid arthritis and;
- B. To systematically capture data on the safety, effectiveness, and cost-benefit of treatment with biologics.

The program was launched province-wide with the same database at the Universities of Alberta and Calgary. Since then, the program has accumulated data on almost 3,000 patients from both academic and community-based practices, expanded the scope of patient-care activities to include routine vaccination and management of disease-related comorbidities, and embraced patients receiving an ever-expanding array of complex therapies for rheumatoid arthritis. Efficacy outcomes are those routinely employed in clinical trials while safety has been systematically assessed using the Outcome Measures in Rheumatology Clinical Trials (OMERACT) framework. Cost-benefit analysis has been possible because of a unique linkage between outcomes captured in the clinic and administrative data provided by Alberta Health and Wellness. A major finding of analyses from the RAPPORT

database has been the extraordinary health-care expenditures incurred in the management of both RA-related and non-RA-related comorbidities, especially in patients failing treatment with their first biologic. Conversely, this analysis has also shown dramatic reductions in health-care utilization related to surgery, outpatient costs, physiotherapy, and in-patient stays in patients who do respond to treatment.

Two recent enhancements to the program have included direct online data entry on a tablet PC by patients at the time of the clinic visit and provision of real-time outcomes data for the attending rheumatologist to enhance treat-to-target management strategies. The program has been possible and continues to be successful because of the dedication and expertise of our allied health professionals. It will continue to grow because it has clearly been shown to serve a vital need for our patients and health care providers.

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The first of SPIN's online programs will be available free-of-charge to the public in 2019. SPIN also recently pilot tested a videoconference-based program to provide training and resources for scleroderma peer support group leaders.

For information about getting involved with SPIN Cohort recruitment and/or research, please consult SPIN's website ([www.spinsclero.com](http://www.spinsclero.com)) or email [spin@jgh.mcgill.ca](mailto:spin@jgh.mcgill.ca).

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