



Part-time or Full-time Data Manager and Analyst: Patient-engaged Health Research and Novel Clinical Trials with the Scleroderma Patient-centered Intervention Network

Dr. Brett Thombs (www.thombsresearchteam.ca/) and Dr. Andrea Benedetti (<https://www.mcgill.ca/epi-biostat-occh/andrea-benedetti>) of McGill University and the Scleroderma Patient-centered Intervention Network (SPIN; www.spinsclero.com) are seeking a Data Manager and Analyst to contribute to observational studies and novel trials of patient-centered interventions in a rare disease context.

Background: Scleroderma is a rare autoimmune connective tissue disease that causes significant disability and disfigurement. SPIN was created to bring together people living with scleroderma, health professionals, and scleroderma researchers from around the world to develop, test, and disseminate accessible support tools for people with scleroderma, including self-management, rehabilitation, psychological, and educational tools. Rare conditions like scleroderma are often under-studied, and patients usually have few or no tested support options, including the kind of support programs that are typically available to people with more common conditions. One reason for this is that the small number of patients with any given rare disease is a barrier to effectively developing, testing, and disseminating such programs. SPIN has addressed these barriers by (1) fostering a high level of patient and community engagement in all aspects of its research; (2) adapting well-tested patient support strategies from other chronic diseases to meet the needs of people with scleroderma and delivering them via the internet to increase accessibility; and (3) utilizing novel trial designs to conduct large, efficient, trials in a resource-starved rare disease environment.

A unique data infrastructure: SPIN maintains a large cohort of over 1,600 scleroderma patients, recruited by scleroderma clinicians from 47 clinical sites in 7 countries (Canada, USA, UK, France, Spain, Australia, Mexico). Through the cohort, patients complete regular online questionnaires about psychological aspects of living with scleroderma, important challenges they face, and what their support needs are. SPIN uses this data to develop specific online tools and help people manage and cope with the disease.

Role of the Data Manager and Analyst:

- Acting as the data custodian for the large SPIN database, including for local trainees and staff, as well as external collaborators requesting data for additional studies;
- Exporting data from the SPIN platform and merging participant data from regular assessments and specific trials;
- Preparing data for use in specific projects, based on existing codebooks and study protocols;
- Conducting data analyses, including descriptive statistics and generalized linear models, accounting for participant clustering and missing data;
- Contributing to drafting manuscripts for publication (particularly methods and results sections);
- Assisting with the design and oversight of clinical trials.

The ideal candidate will meet the following qualifications:

- A Master's degree in Epidemiology, Biostatistics, Public Health, Quantitative Psychology or any other field focused on data management and quantitative analysis.
- Strong analytical skills.
- Research experience, including data management
- Good interpersonal skills and a strong capacity for teamwork
- Basic programming skills (e.g., SPSS, Stata, R)
- Excellent organizational and communication skills

Opportunities: Trainees and employees with Dr. Thombs and Dr. Benedetti take on significant responsibility and have published extensively. In the last 5 years, student and staff trainees under their joint supervision have first-authored approximately 65 peer-reviewed articles and have co-authored articles more than 150 times (for details, see <https://www.thombsresearchteam.ca/>). The Data Manager and Analyst will gain experience in the design and management of large international trials, and in manuscript development (including authorship on publications).

Salary and Duration: Salary to be negotiated based on relevant experience and training. This is a one-year position with the possibility of extension based on mutual agreement and funding. There is flexibility in the number of hours to work in this position.

Location: The Data Manager and Analyst position is at the Jewish General Hospital in Montréal, Québec, but working remotely from outside of Montréal is possible.

Start Date: Start date is flexible, and applications will be considered on a rolling basis.

To apply: Applicants should send (1) a cover letter, (2) a curriculum vitae, (3) an unofficial transcript, (4) a writing sample, and (5) contact information for three references to Ms. Marie-Eve Carrier (carrier.marie.eve@gmail.com).