



SPIN RESEARCH UPDATE

We **thank you** for your ongoing participation in SPIN research projects. Your invaluable time and effort are helping us make significant strides across multiple initiatives, advancing research for patient-centered care in scleroderma. Here's a snapshot of our current projects, how your contributions are driving progress, and what's on the horizon for SPIN in enhancing patient support

SPIN HAND

SPIN-HAND has been distributed free of charge to over 500 members of the scleroderma community

- Functional impairments of the hands are common in people living with scleroderma.
- The SPIN-HAND toolkit is the only program in the world designed specifically for scleroderma hands, with exercises to improve hand function.
- The toolkit includes instructional videos and sections to help patients develop a personalized routine, set goals and track their progress.

Some publications related to SPIN-HAND:

- Feasibility trial protocol: [here](#)
- Feasibility trial results: [here](#)
- Full-scale trial results: [here](#)



SPIN SELF

The full-scale randomized trial for SPIN SELF is ongoing, recruiting and enrolling participants

- Improving disease self-management is essential for people living with a chronic disease.
- The SPIN-SELF toolkit is specifically designed to help people with scleroderma better manage certain common symptoms (fatigue, pain, itching, skin care, changes in physical appearance, etc).
- The first SPIN-SELF feasibility trial was conducted with 40 participants, giving them access only to the online toolkit, but few used it. The second feasibility trial was launched in September 2021 (80 participants). This new iteration of the program includes 8 group videoconferences, in addition to online access to the toolkit.

Some publications related to SPIN-SELF:

- Feasibility trial protocol: [here](#)
- 1st feasibility trial results: [here](#)
- Feasibility trial protocol with progression to full-scale trial: [here](#)

SPIN SSLED

Over 200 support group facilitators have now been trained by SPIN, and post-training support is also provided monthly to SPIN-SSLED graduates.

- The SPIN-SSLED Support Group Leader Education Program (12 sessions) is the only evidence-based program of its kind for people living with a disease (all diseases included).
- SPIN-SSLED provides information, resources and training to effectively facilitate support groups for people with scleroderma.

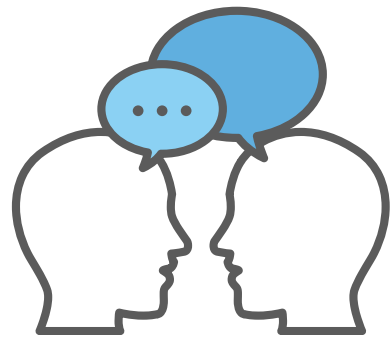
Some publications related to SPIN-SSLED:

- Non-randomized feasibility trial results: [here](#)
- Randomized controlled trial protocol: [here](#)
- Randomized controlled trial results: [here](#)

Recent SPIN Projects

SPIN CHAT

- The study is one the first trials of a mental health intervention during the COVID-19 pandemic to report results.
- This study tested a program to reduce isolation.
- A total of 172 participants from 12 countries were recruited for this trial.
- Divided into subgroups, the participants met virtually 3 times a week for 4 weeks.
- The results show that the program significantly reduced anxiety and depression symptoms.



MENTAL HEALTH

- This study was the first to report changes in the mental health status of vulnerable individuals with pre-existing illness.
- The study investigated levels of anxiety and depression among participants in the SPIN-COVID-19 cohort, many of whom are also participants in the regular SPIN cohort, for which we have pre-pandemic data.
- The results show that symptoms of depression remained more or less consistent, both before and during the pandemic.
- In contrast, anxiety symptoms increased in the early months of the pandemic and then declined to pre-pandemic levels in the summer of 2021.



SPIN DINE

- Many resources on nutrition are available, but very few are specific to the management of gastrointestinal symptoms in people with scleroderma.
- This study identified the resources used by scleroderma patients to obtain information about nutrition and diet, and the perceived advantages and disadvantages of these resources.
- This is the first study aimed at identifying nutrition information resources for people with scleroderma.



ORAL HEALTH

- Oral health is an essential component of overall health for people with scleroderma.
- SPIN has identified an array of academic articles to begin addressing oral health issues.
- This study aims to identify what research has been conducted on oral health and where the gaps are in the current literature.
- This will allow us to conduct relevant SPIN studies on oral health and will help other researchers to initiate clinical research.
- We are currently in the submission process of our first study on Oral health and scleroderma.



PATIENT ENGAGEMENT

- Patients are at the heart of everything we do, and SPIN is a leader in the development of research in partnership with patients and patient organizations.
- Despite this, SPIN hopes to do even better and aims to constantly improve the way we involve patients in our projects, as well as how we communicate the results of our research to them.
- This project includes 1) a synthesis of the evidence on patient involvement in research and on communication of results, and 2) the development and evaluation of various communication tools.
- This work will enable patients to participate more effectively in scleroderma research, and will help researchers and patient organizations better communicate research findings to patients.

CO-PRESENTING

- Sharing results with patients might help to build trust in research, increase the likelihood of research participation, and contribute to supporting patients to be knowledgeable partners in their own health care
- At the most recent, Canadian national scleroderma conference SPIN had the opportunity to co-present poster abstracts with patient partners.
- This opportunity has turned into various submissions and publications on the co-presenting experience for both patients and researchers.





What else has SPIN been up to?

SPIN VAX

This study investigated experiences and perceptions of vaccination among participants in the SPIN-COVID-19 cohort.

SPIN PAIN

This study measures pain levels among scleroderma patients. Results show that pain is very common and should be considered in the treatment of patients.

SPIN COPE

This program contains 7 modules addressing emotional management with scleroderma. The online program will be developed in the next coming years.

SPIN COACH

This project focuses on how changes in physical appearance impact people with scleroderma. This intervention has been developed and is next in line to best tested via the cohort.

SPIN PACE

We conducted interviews with patients to identify the barriers and facilitators to physical activity. These results will help us develop an online program to support physical activity.

EMPLOYMENT

This study will examine factors associated with employment and disability that could be targeted to improve the ability to work for people with scleroderma.

RESILIENCE

This study will first validate a questionnaire on resilience with participants of the SPIN cohort, and then identify factors that can positively or negatively influence resilience

The SPIN Cohort, established in 2013 and now comprising over 1,400 patients, owes its remarkable longevity to the dedicated work of over 90 researchers and clinicians in 51 treatment centers globally.

We express our heartfelt gratitude for your unwavering support throughout the years. Your commitment has been instrumental in SPIN's achievements. The collaborative efforts of experts, patients, and partner organizations have played a vital role in enabling SPIN to publish numerous studies derived from the comprehensive analysis of cohort data. We look forward to continued collaboration and success in advancing scleroderma research.

1,436 participants
7 countries
51 recruitment sites

