

# The Scleroderma Research Topics Survey for Patients and Health Care Professionals: A Scleroderma Patient-Centered Intervention Network Project

Tao et al. (2019)  
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## For which topic were research priorities identified?

scleroderma

## In which location was the research priority setting conducted?

Australia - Australia; Europe - France; Europe - Spain; Europe - United Kingdom; North America - Canada; North America - Mexico; North America - USA

## Why was it conducted at all?

Involving patients and health care professionals in research has been shown to be a useful strategy to generate program development ideas and establish research priorities. Online surveys can be used to identify patient research priorities. The Scleroderma Patient-centered Intervention Network is an international collaboration dedicated to researching problems important to people with scleroderma and developing, testing, and disseminating educational, self-management, rehabilitation, and psychological tools to support coping within the disease.

## What was the objective?

to obtain input on online programs that Scleroderma Patient-Centered Intervention Network could develop, identify research topics important to members of the scleroderma community that could be addressed via the Scleroderma Patient-centered Intervention Network Cohort, and identify potentially understudied groups

## What was the outcome?

a list of 11 research topics

## How long did the research prioritization take?

April 2018 - August 2018

## Which methods were used to identify research priorities?

survey

## How were the priorities for research identified exactly?

Step 1: survey: participants were asked for suggestions for online programs: SPIN is dedicated to developing, testing, and disseminating programs to support people living with scleroderma. The types of programs that SPIN develops aim to increase quality of life by teaching coping and disease-management skills. Do you have any suggestions for online programs that SPIN could develop and provide, which you feel could make a difference in the lives of people living with scleroderma?, participants also asked for possible research questions: SPIN also investigates and answers research questions that are important to people living with scleroderma, using questionnaires via the Internet. Please note that we rely on patient questionnaires, thus the research questions that we can best address are related to the experiences of patients. We are not able to evaluate medical treatments. Do you have any specific research questions that you would like SPIN to address?, participants also asked about understudied groups: In your opinion, is there a specific group within the scleroderma community that is especially understudied?. Step 2: data processing: thematic analysis

## Which stakeholders took part?

Individuals with scleroderma, their caregivers, healthcare professionals, patient organization representatives. 125 participants: 100 patients, 24 healthcare professionals: 8 physicians, 5 rheumatologists, 3 physician-researchers, 5 research coordinators, 1 psychologist, and 1 caregiver.

## How were stakeholders recruited?

Eligible participants were individuals living with SSc and their caregivers, health care professionals, and patient organization representatives. Participants were recruited through news items on the SPIN website, online announcements to participants in the SPIN Cohort, and an email sent to 158 health care professionals from the over 40 SPIN recruiting sites in Canada, the United States, the United Kingdom, France, Spain, Mexico, and Australia.

## Were stakeholders actively involved or did they just participate?

Stakeholders were mere participants of the research prioritization process; they were not actively involved in the