What was the research about?
Scleroderma is a rare health problem that causes the skin and internal organs to harden. Symptoms can include joint pain, heartburn, or trouble swallowing. Scleroderma has no cure. Learning to manage it can help patients ease their symptoms. But few programs exist to teach patients how to do so.

In this study, the research team tested an online program to help patients manage scleroderma. The program covered topics such as coping skills, body image, exercise, and pain management. The team wanted to learn if patients who received the program had greater confidence in their ability to manage their health problem compared with those who received a book. The book had information on types of scleroderma, what causes it, its effects on the body, coping skills, and patient resources.

What were the results?
Patients using the online program and patients who received the book didn't differ in their confidence in their ability to manage their health problem.

Compared with patients who received the book, patients using the online program reported

- Better health after four and six months
- Feeling less tired after six months

Who was in the study?
The study included 267 adult patients with scleroderma who had access to a computer and the internet. Of these, 83 percent were white, 8 percent were African American, 6 percent were multiracial, and 3 percent were other races. The average age was 54, and 91 percent were women. Also, 79 percent of patients had at least a college degree and 60 percent reported the highest level of confidence to manage and improve their health at the start of the study. On average, patients had lived with scleroderma for nine years.

What did the research team do?
The research team assigned patients by chance to either take part in the online program or receive the book. Patients in the online program viewed 15 lessons over four months. Those who received the book had four months to read it.

Patients completed surveys at the start of the study and four and six months later.

Patients with scleroderma and staff from scleroderma foundations gave input throughout the study. A patient co-led the project.
What were the limits of the study?
Most patients in the study were white, well-educated women with confidence in their ability to manage and improve their health. Also, most patients had lived with their disease for about nine years. Results may differ for people from other backgrounds.

Future research could test the program with patients who are less confident in their ability to manage and improve their health. Studies could also include patients at earlier stages of disease and with more diverse backgrounds.

How can people use the results?
Clinics that treat patients with scleroderma can use these results when considering how to help patients manage symptoms at home.

To learn more about this project, visit www.pcori.org/Poole196.