Scleroderma Canada

Understanding the Burden of Scleroderma on Canadians

2024-2025 SCLERODERMA PATIENT IMPACT SURVEY SUMMARY REPORT

Scleroderma Canada | Sclérodermie Canada

Thank you to everyone who completed the patient impact survey. Your support and willingness to share your lived experience has provided us with truly invaluable information that will move us closer to creating a better future for those affected by scleroderma.

Published February 2025
Scleroderma Canada
scleroderma.ca

Table of Contents

A Message from Scleroderma Canada

We excited to share the results of our recent Patient Impact Survey. Your voice, along with that of many others, has provided invaluable insights into the experiences and needs of patients. The findings are both eye-opening and motivating, shedding light on areas where we can create meaningful change together.

We hope that these results inspire you to join us in our mission to improve the lives of Canadians living with scleroderma. The work we do is driven by the dedication and passion of people like you who believe in the power of advocacy, collaboration, and compassionate care. Together, we can turn these survey insights into action—whether by amplifying patient voices, advocating for essential policy changes, or developing new resources and programs that truly make a difference.

Your involvement can help us build a future where patients' needs are heard, understood, and met. Let's create a better world for those who need it most.

Thank you, again, for your continued support.

John Malcolmson
Executive Director, Scleroderma Canada

All About Scleroderma

What is Scleroderma?

Scleroderma is a rare, progressive, chronic, and multi-symptom autoimmune disease, which involves an overproduction of collagen. This results in a thickening, hardening, and scarring of connective tissues, which includes the skin, blood vessels, and internal organs. The challenges of living with scleroderma are exasperated because the course of the disease can vary widely from person-to-person.

There are two types:

Localized	Systemic
Primarily affecting the skin Minimal organ involvement Progresses more slowly Better long term prognosis	Affects the skin and underlying organs Progresses more quickly Less desirable long term prognosis

Symptoms may include:

- Thickening/tightening of skin
- Raynaud’s Phenomenon
- Joint and muscle pain
- Gastroesophageal reflux
- Renal crisis
- Fatigue
- Dry mouth
- Fibrosis of the lungs

Who gets scleroderma?

Anyone can get scleroderma. In Canada, 1 in 2500 people develop the disease. Women are four times more likely to develop scleroderma than men. However, men typically have a less desirable long-term outcome. The average age of disease onset is between 25 and 55 years old. It affects people of all races and ethnicities, although, Indigenous peoples and those of African decent have a higher incident rate than Caucasians.

What treatment is available?

There is currently no cure for scleroderma. Treatments that are available aim to alleviate symptoms and to slow the progression of scleroderma. Medications currently target four key factors:

1. Inflammation
2. Autoimmunity
3. Vascular disease
4. Tissue fibrosis

Primary disease management is typically provided by a rheumatologist that specializes in autoimmune and musculoskeletal disorders. Other specialists may also be needed, depending on organ involvement. This can include gastroenterologists (for the digestive tract), pulmonologists (for the lungs), and cardiologists (for the heart).

About the Survey

In 2024, Scleroderma Canada undertook a Canada-wide survey examining the physical, social, financial, and psychological impacts on individuals diagnosed with scleroderma.

The Patient Impact survey was completed between August of 2024 and January of 2025. The goal of the survey was to assess the physical, social, financial, and psychological impacts of living with scleroderma.

Exploring these disease impacts in a Canadian context will ultimately update the understanding of the effects of scleroderma disease burden. Additionally, it will help to give a voice to those impacted by disease, therefore enabling organizations, such as Scleroderma Canada, to direct funding, support efforts, and steer research strategies.

The survey was promoted through Scleroderma Canada as well as provincial partners (Scleroderma Atlantic, Scleroderma Ontario, and Scleroderma Alberta). The survey was designed to take 30 minutes and includes 160 questions spanning across all impacts. There were 358 respondents in total.

Gaps In Treatment

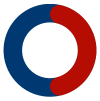
35% of respondents said they were not confidant in the Canadian healthcare system to fully support their scleroderma management. In the Canadian healthcare system, while there are various treatments available for scleroderma, gaps in treatment can emerge due to a number of factors.

Limited Access to Specialized Care

- Lack of Specialists: Scleroderma often requires management by specialists, such as rheumatologists, pulmonologists, cardiologists, and dermatologists. In some regions of Canada, access to these specialists may be limited, especially in rural or remote areas. Delays in diagnosis and treatment may occur due to these shortages.
- Regional Disparities: Larger urban centres may have more access to multi-disciplinary care teams, whereas rural areas might have fewer specialized healthcare providers, limiting patients' access to necessary expertise.
- Fragmented Care: Scleroderma often requires a coordinated, multidisciplinary approach to treatment, involving a variety of specialists, physical therapists, mental health support, and more. If communication between different healthcare providers is poor or fragmented, patients may experience disjointed care and lack holistic treatment plans.
- Patient Navigation Support: There may be limited resources to help patients navigate the complex healthcare system and coordinate their care, especially in non-urban areas. This can lead to challenges in accessing timely treatment and follow-up.

Healthcare System Strain

- Wait Times: Canada is known for having longer wait times for specialists and certain treatments, which can be problematic for scleroderma patients who need timely intervention. Waiting for diagnostic tests, procedures, or new medications may lead to worsening of symptoms and even irreversible damage to organs.
- Variation in Provincial Guidelines: Different provinces and territories may have varying guidelines for the treatment of rare diseases like scleroderma, leading to inconsistency in care standards.



50% of respondents reported feeling that the wait time to see their family physician is too long

40% of respondents reported feeling that the wait time to see their rheumatologist is too long

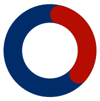
Early Diagnosis and Intervention

- Delays in Diagnosis: The symptoms of scleroderma can be subtle at first and overlap with other conditions. In some cases, it may take time before the correct diagnosis is made. Early intervention is critical in preventing irreversible organ damage and diagnostic delays could hinder effective treatment.

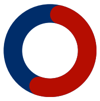
Gaps In Treatment

Patient Education and Awareness

- Lack of Awareness Among Healthcare Providers: While scleroderma is a known condition within rheumatology and some other specialist fields, general practitioners or healthcare providers outside of these specialized settings may have limited knowledge about the disease. This can result in misdiagnosis, delayed referrals to specialists, and a lack of understanding about the most current treatment protocols.
- Patient Education: Educating patients on managing their condition, understanding the progression of the disease, and navigating treatment options is essential. However, resources for patient education may be scarce and there may not be enough emphasis on self-management strategies, which are important for patients to cope with their disease daily.



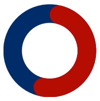
40% of respondents did not feel well informed about all of the treatment options available to them



59% of respondents feel that there are no/limited informational resources about treatment options

Access to New and Expensive Treatments

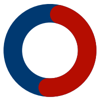
- Availability of Advanced Therapies: While Canada provides universal healthcare, the approval and funding for certain biologics or targeted therapies can vary across provinces and territories. Some newer treatments, such as biologics (e.g., rituximab, tocilizumab), may not be immediately available in all provinces or may be restricted based on specific criteria, creating gaps in treatment access.
- Cost Barriers: Though public healthcare covers many aspects of treatment, some therapies, particularly newer or experimental ones, may require out-of-pocket payments or insurance coverage, which some patient may not be able to afford.



57% of respondents reported feeling that there were not a lot of treatment options for scleroderma

Research and Clinical Trials

- Limited Access to Clinical Trials: Although Canada is involved in research, there may be limited access to clinical trials, particularly for patients living in rural areas. Clinical trials offer the possibility of cutting-edge treatments, but geographical and logistical factors may hinder participation.

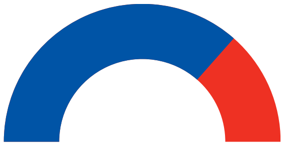


55% of respondents reported having considered participating in a clinical trial for scleroderma treatment

Only 24% of respondents reported having participated in a clinical trial for scleroderma treatment

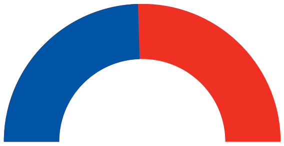
Gaps In Treatment

51% of respondents felt that treatment side effects have lowered the quality of their life



73%

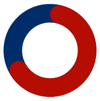
Of respondents reported that when choosing treatment, the number or type of side effects is one of the most important things they consider



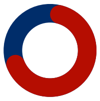
49%

Of respondents reported that where the treatment is administered (e.g. home, clinic, hospital) is one of the most important things they consider

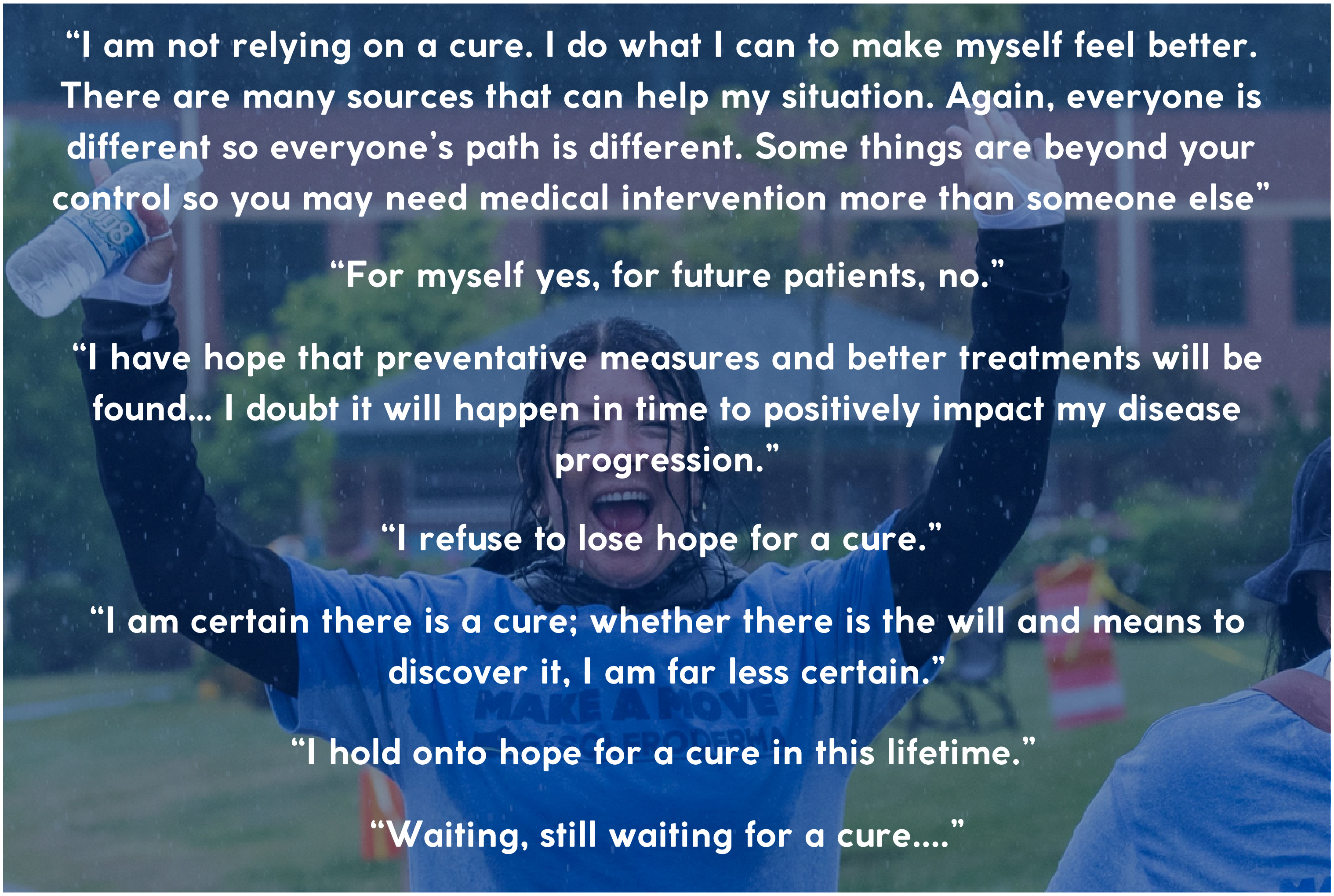
56% of respondents reported having lost hope in a cure



70% of respondents reported not knowing what ongoing research for a cure there is



73% of respondents reported feeling that there is not enough funding or support for researching a cure



“I am not relying on a cure. I do what I can to make myself feel better. There are many sources that can help my situation. Again, everyone is different so everyone’s path is different. Some things are beyond your control so you may need medical intervention more than someone else”

“For myself yes, for future patients, no.”

“I have hope that preventative measures and better treatments will be found... I doubt it will happen in time to positively impact my disease progression.”

“I refuse to lose hope for a cure.”

“I am certain there is a cure; whether there is the will and means to discover it, I am far less certain.”

“I hold onto hope for a cure in this lifetime.”

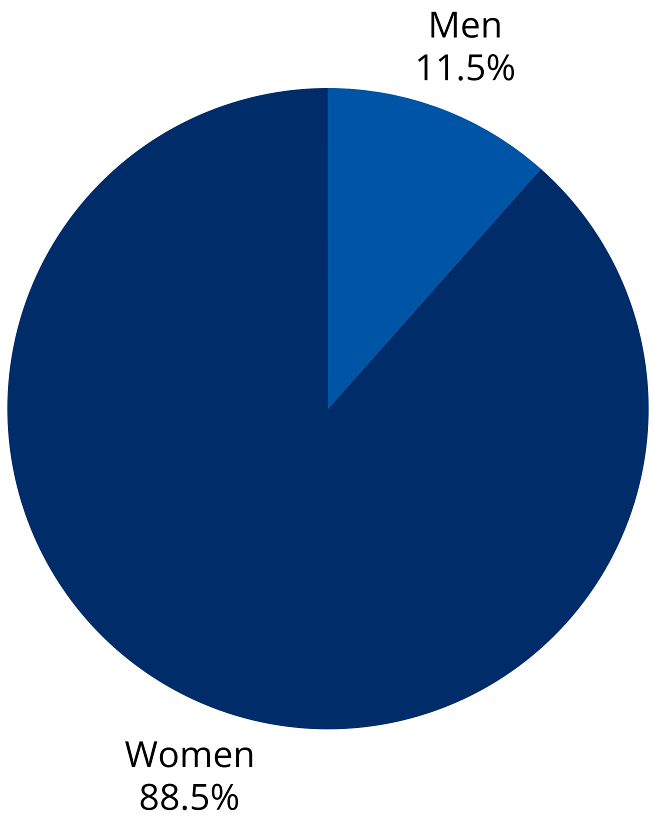
“Waiting, still waiting for a cure....”

Participant Demographics

Age

Average Age	59 Years Old
Youngest	17 Years Old
Oldest	90 Years Old

Gender

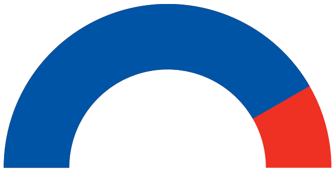


Participant Demographics

Scleroderma Subset

16.62%

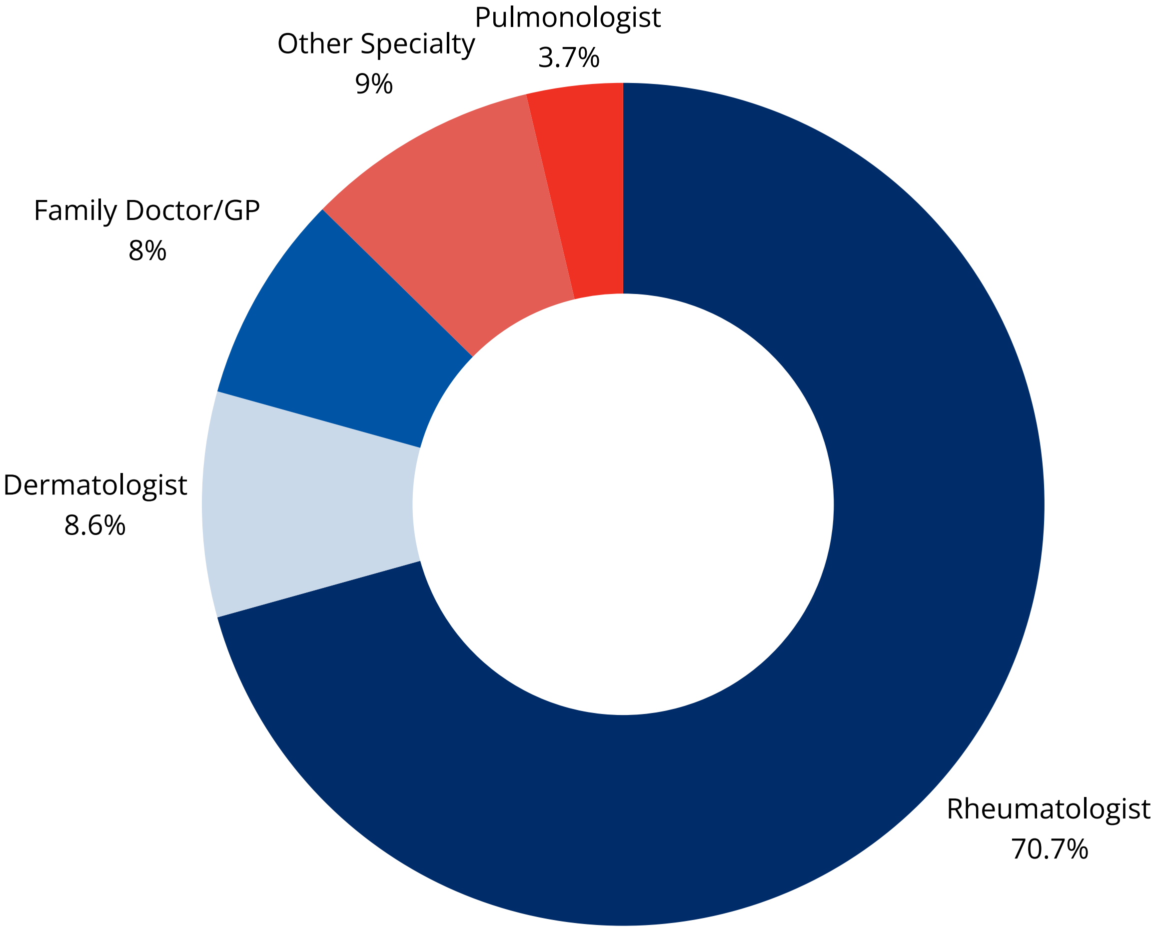
Localized



83.38%

Systemic

Patients reported being diagnosed by the following specialists

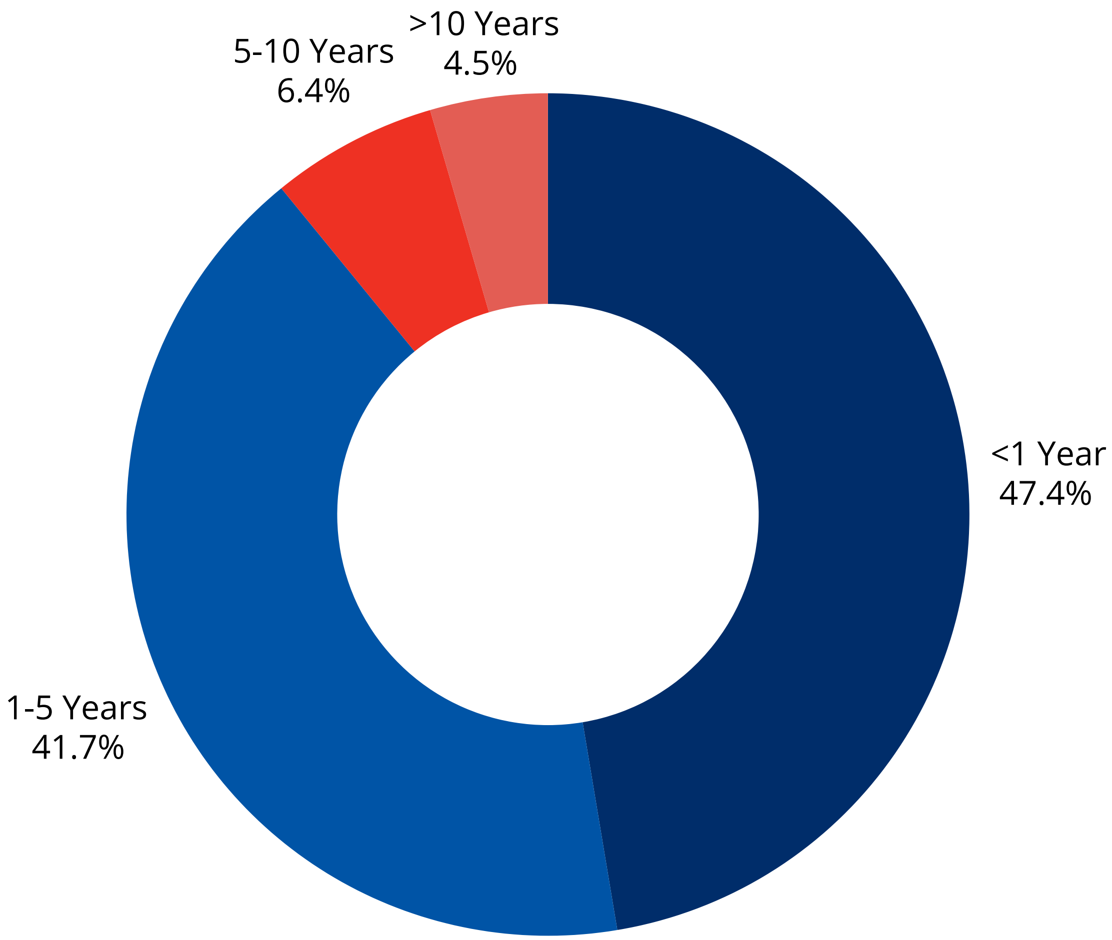


Participant Demographics

Average Age at Diagnosis: 45 Years Old

Youngest	7
Oldest	82

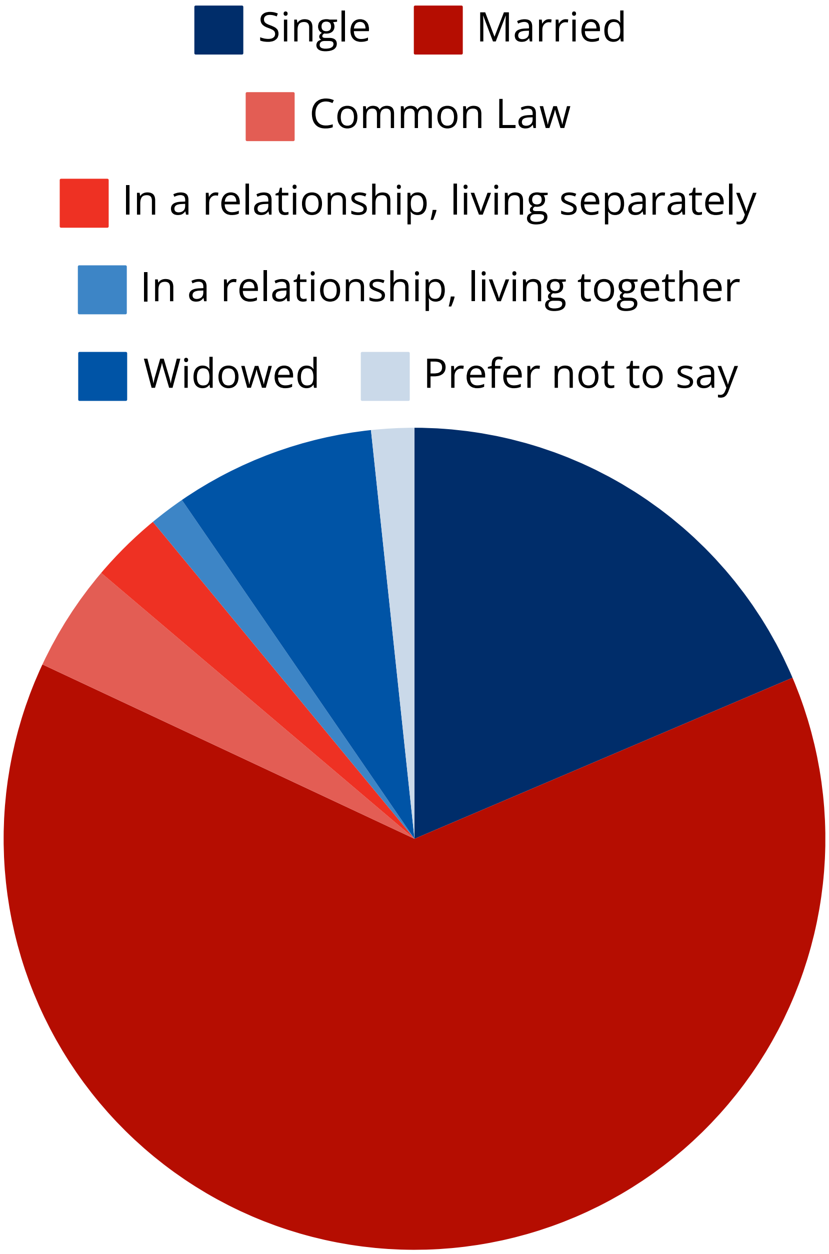
Reported Length of Diagnosis



Patients reported seeing an average of 2 specialists prior to being diagnosed.

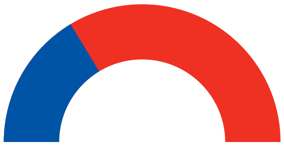
Participant Demographics

Relationship Status

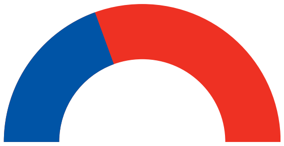


Participant Demographics

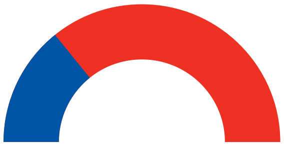
Type of Location



32.7%
Large Urban Centre
(>500,000)

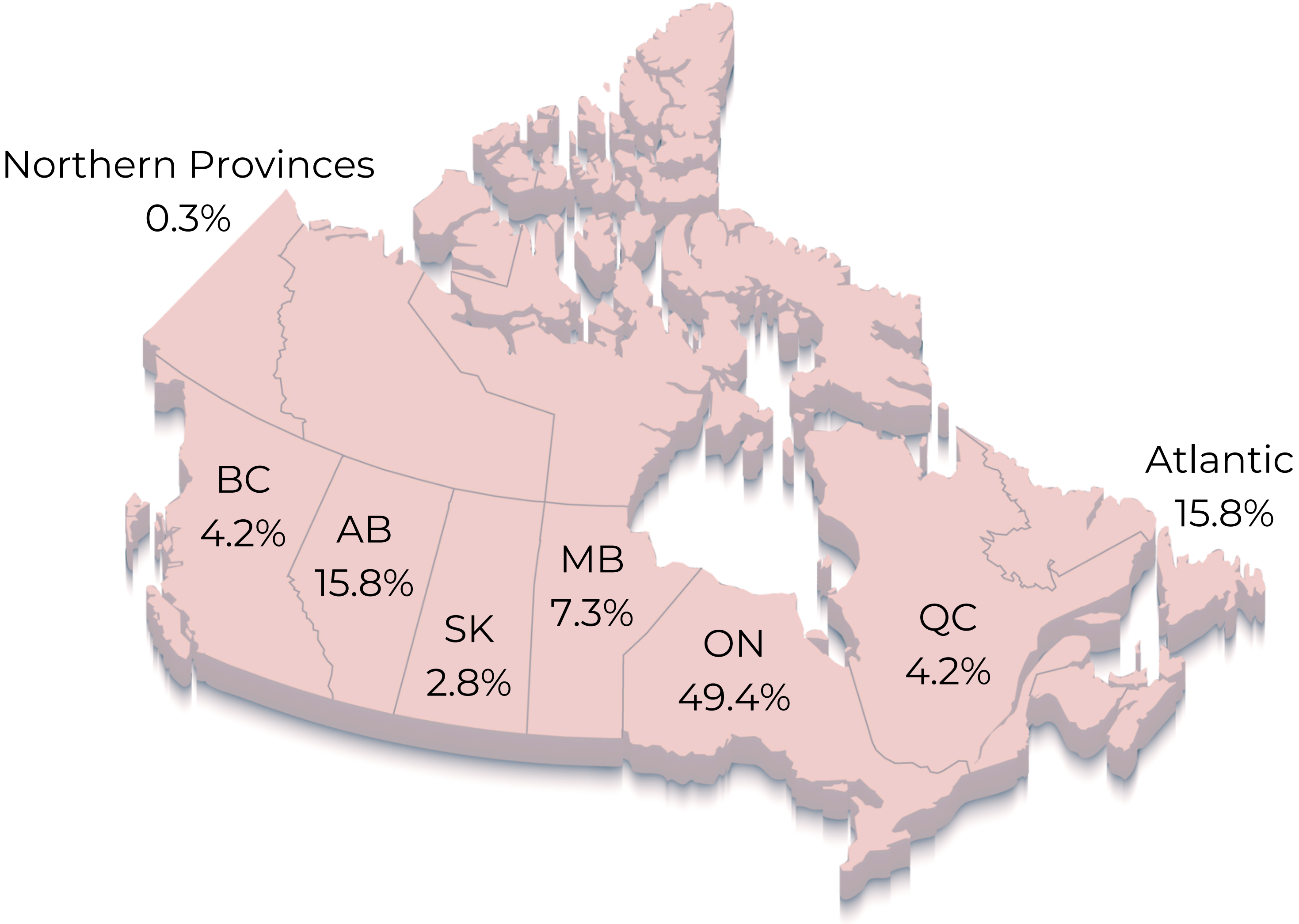


38.9%
Small or medium urban centre
(10,00-500,000)



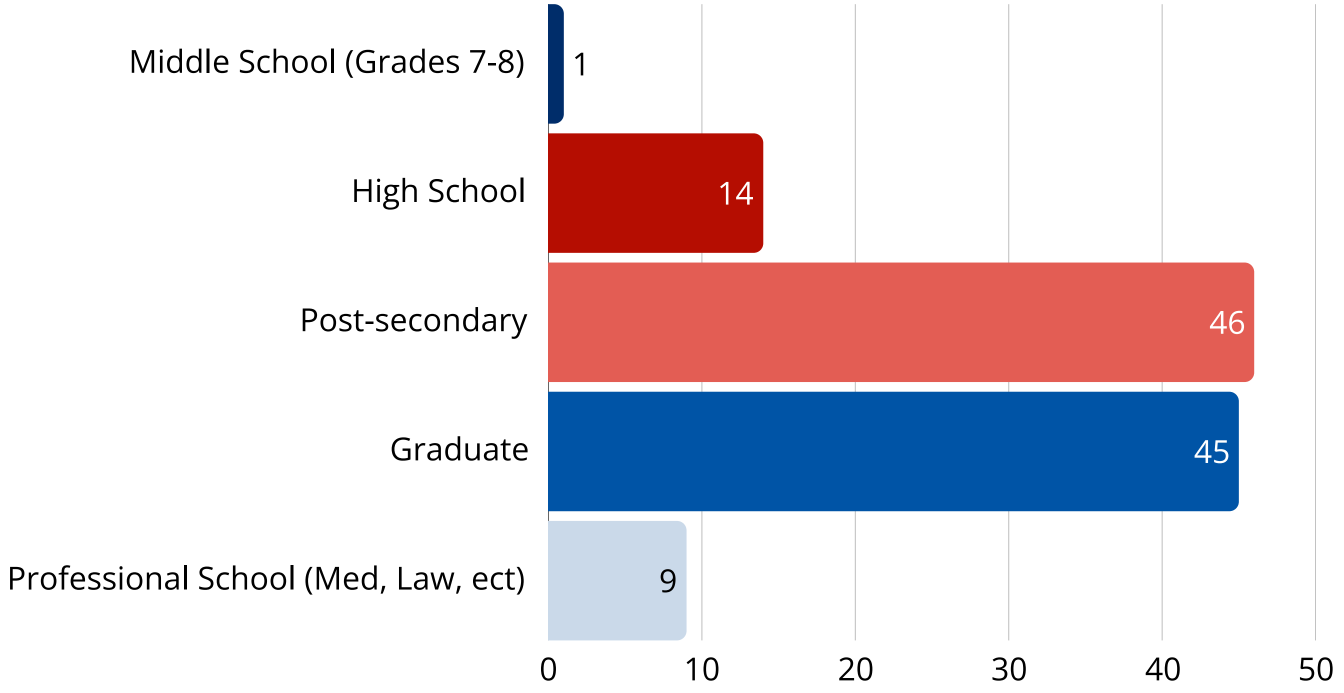
28.4%
Rural or small suburban
(<10,000)

Location



Impacts on Education

Of 358 respondents, 115 reported to still be enrolled in:



25% of respondents felt that their diagnosis has limited their academic progress

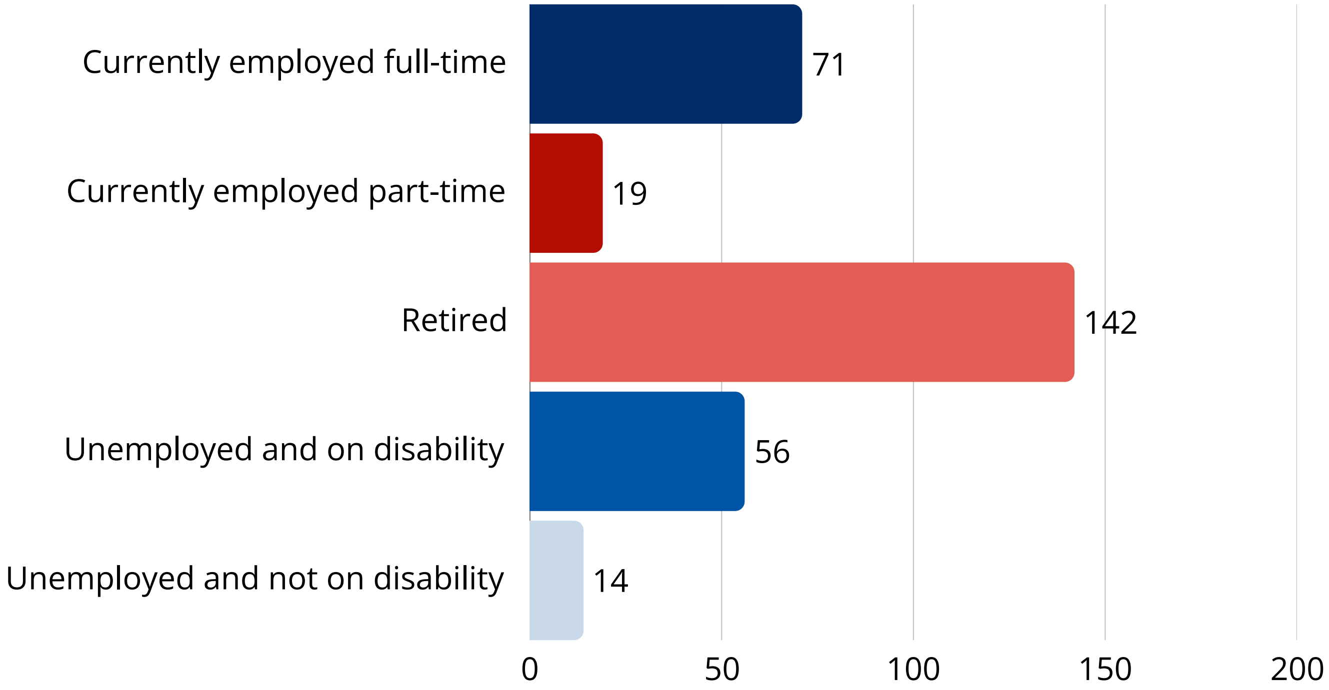
21.43% of respondents felt that their diagnosis has stopped them from <u>wanting</u> to continue their academic career

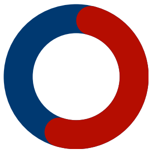
21.35% of respondents felt that their diagnosis has stopped them from <u>being able</u> to continue their academic career

24% of respondents felt that their diagnosis has lowered the amount of hours they are able to dedicate to their academic work

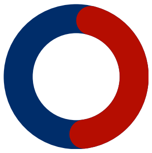
Career Impacts

Employment Status

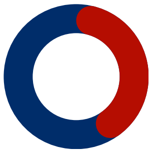




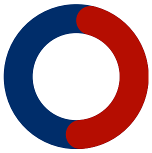
58.8% of respondents felt that their diagnosis has limited their career options



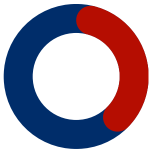
51.9% of respondents felt that their diagnosis has limited their career progress



44% of respondents felt that their diagnosis has prevented them from being able to keep their job



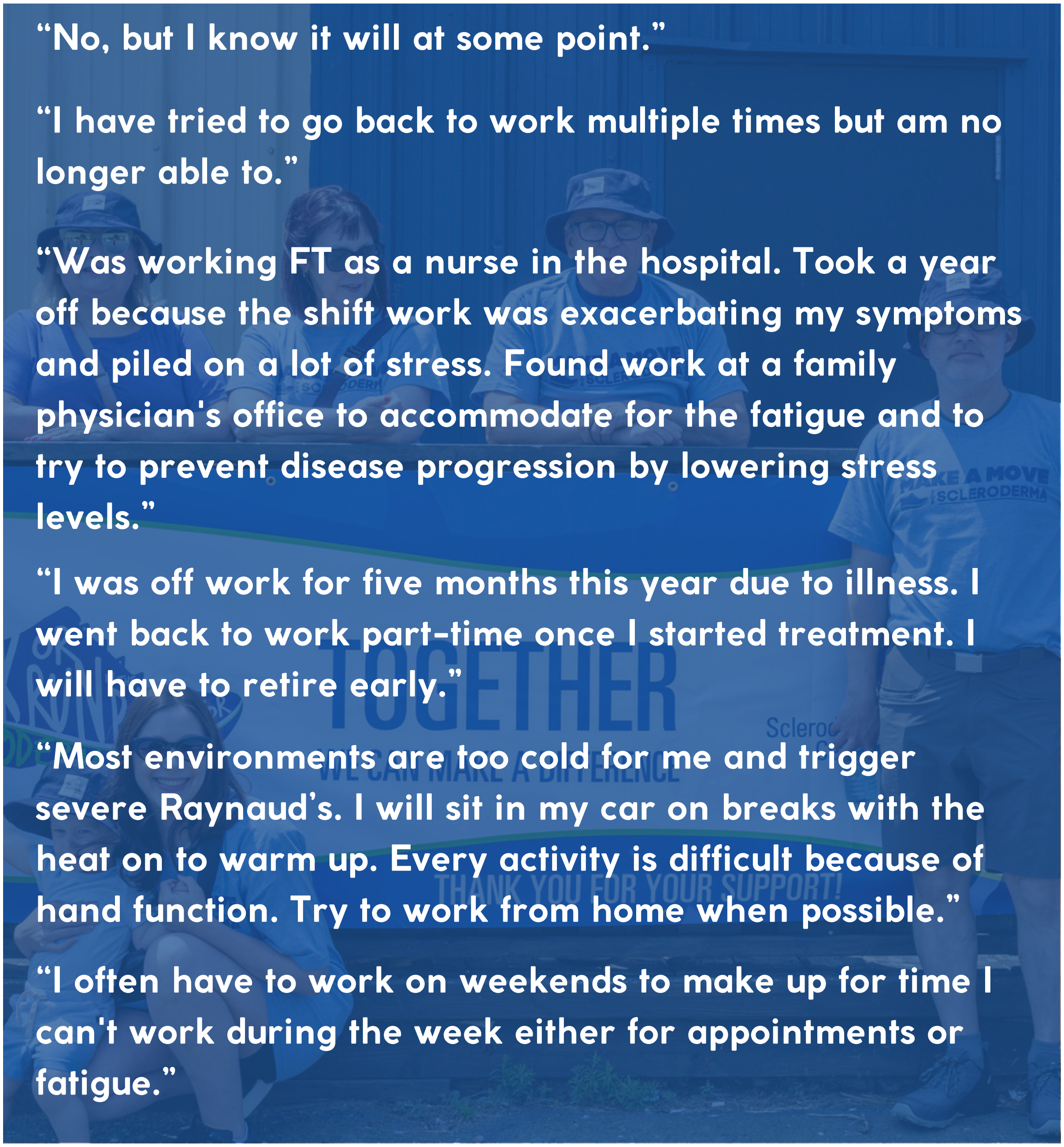
52.9% of respondents felt that their diagnosis has lowered the amount of hours they are able to work



41.4% of respondents felt that their diagnosis has lowered the amount of hours they are able to work

Career Impacts

When asked if they felt scleroderma had affected their ability to work (e.g. had to switch to part-time, forced to retire early, had to accommodate their schedule, etc.), respondents left the following comments:



"No, but I know it will at some point."

"I have tried to go back to work multiple times but am no longer able to."

"Was working FT as a nurse in the hospital. Took a year off because the shift work was exacerbating my symptoms and piled on a lot of stress. Found work at a family physician's office to accommodate for the fatigue and to try to prevent disease progression by lowering stress levels."

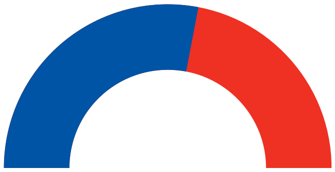
"I was off work for five months this year due to illness. I went back to work part-time once I started treatment. I will have to retire early."

"Most environments are too cold for me and trigger severe Raynaud's. I will sit in my car on breaks with the heat on to warm up. Every activity is difficult because of hand function. Try to work from home when possible."

"I often have to work on weekends to make up for time I can't work during the week either for appointments or fatigue."

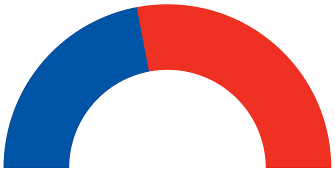
Financial Impacts

People living with scleroderma often face significant financial challenges due to the nature of the disease. Scleroderma can lead to costly medical treatments, frequent doctor visits, and hospitalizations. Patients may need ongoing physical therapy, medications, and sometimes surgeries, all of which can result in mounting healthcare costs. **77% of respondents reported a significant increase in medical expenses since their diagnosis**. Additionally, the debilitating symptoms of scleroderma, such as fatigue, joint pain, and difficulty with mobility, may impact an individual's ability to work or perform daily tasks, leading to lost income or job instability. **53% of respondents reported a decrease in income since diagnosis.** For many, the financial strain can be compounded by the need for home modifications, transportation assistance, or long-term care, creating a heavy economic burden. This can lead to increased stress and emotional strain, as individuals and families struggle to manage both the physical and financial demands of the disease. **Overall, 53% of respondents reported feeling stressed over their financial situation since being diagnosed.**



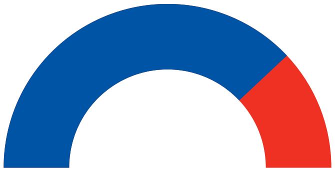
56%

Of respondents feel that since being diagnosed with scleroderma, their financial situation has been negatively affected



44%

Of respondents feel that their scleroderma diagnosis has directly caused financial hardship



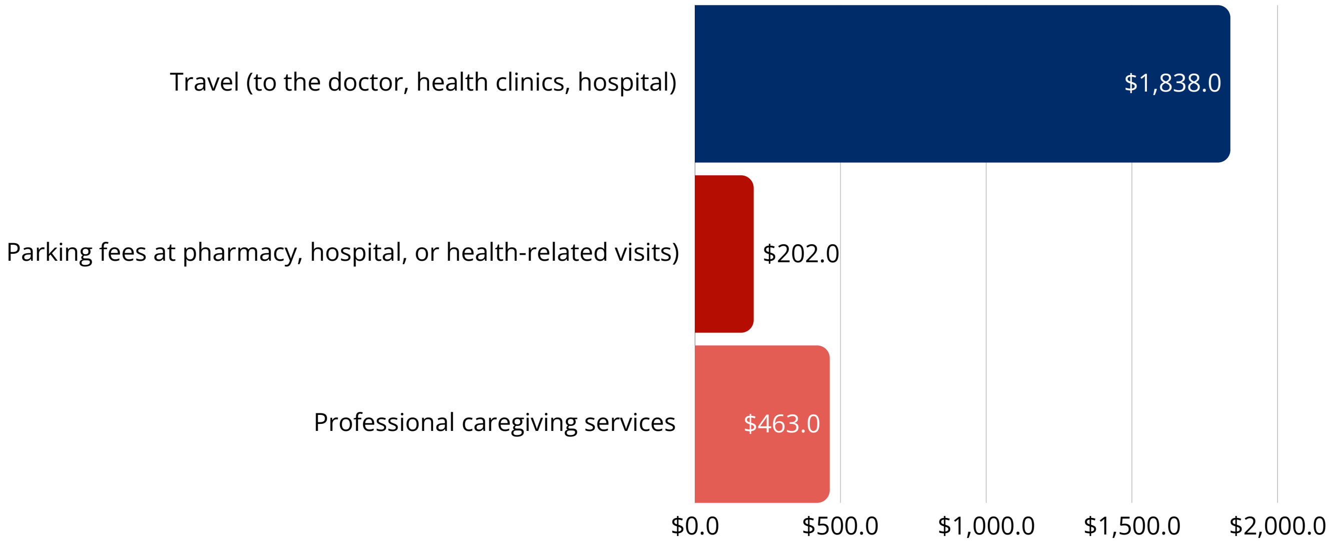
76%

Of respondents reported they were **not receiving** any financial support from the government

Financial Impacts

63% of respondents reported being negatively impacted financially as a result of out-of-pocket expenses, including travel to clinic appointments, parking, and professional caregiver costs, which are directly related to their scleroderma diagnosis.

Respondents reported the following average amounts spent for these expenses per year



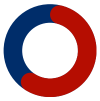
As a result of several factors and expenses, respondents reported the following changes to their finances since being diagnosed with scleroderma

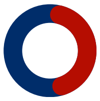

35% of respondents have found it more difficult to manage their finances


32% of respondents reported having to make significant changes to their investment portfolio


38% of respondents reported having to take money from their savings to support themselves


29% of respondents have sought additional financial planning assistance


63% of respondents reported a change in spending habits

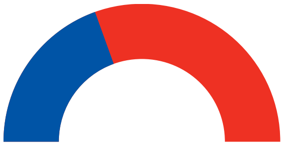

49% of respondents reported not being able to save as much money as they did prior to diagnosis


33% of respondents have incurred additional debt

Financial Impacts

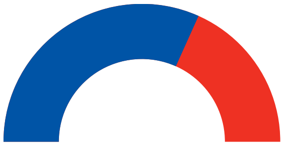
32% of respondents reported struggling to afford prescribed medication.

24% of respondents felt their private health insurance has been inadequate for managing scleroderma related expenses.

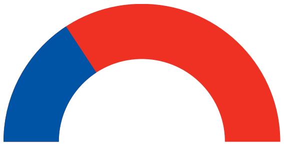


Of respondents have experienced denials or delays in private insurance coverage for their scleroderma related expenses

43% of respondents have applied for disability benefits relating to their scleroderma diagnosis.



Of respondents feel that government supports for individuals with scleroderma are **inadequate**



Of respondents felt that their provincial health coverage has been **inadequate** for managing scleroderma related expenses

Canada prides itself on its healthcare system, which, at its core, aims to provide equitable access to healthcare services for all residents. In addition to the universal healthcare system, it is important for the Canadian government to provide adequate support outside of healthcare services for those living with a rare disease such as scleroderma. Government support ensures that these individuals receive the specialized care they need, irrespective of their location or socioeconomic status.

Financial Impacts

Only **28%** of respondents reported feeling optimistic about their financial future given their scleroderma diagnosis.

“I am concerned as the disease progresses that I will need more aids and support. This may not be covered.”

“I have plowed through my savings. I have less capacity to earn. I have to look for other ways to earn money.”

“So much debt I'm not sure how to ever recover.”

“I have had to file for bankruptcy due to financial limitations due to my illness.”

“No luxuries no entertainment etc. We barely afford groceries.”

“I lost all my saving being off work the first year with no supports in place and no benefits.”

“Living in Northern Ontario, all my medical appointments are about 500 km away.”

“I had to use up my savings to live. I'm on social disability (AISH) to survive.”

“They don't give us enough to live on so we live in over draft and debt to get by.”

“It's the worst stress I go through, never knowing when we will reach a point of homelessness or not be able to eat.”

“I am terrified about the future how I will be able to live especially if my condition worsens, which it will over time, it's so difficult.”

“Meds first, housing second, food last. Clothing? Not a possibility. I’m ready to give up.”

“Reduced income, increased travel, increased spending on ways to improve health and life or daily living or existing. Supplements, different foods for gastrointestinal problems.”

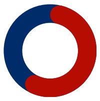
Quality of Life Impacts

78% of respondents reported a decline in their mental or emotional health since being diagnosed with scleroderma. Mental health and quality of life are deeply intertwined, and various factors can both enhance and undermine someone's sense of well-being. A decline in mental health often stems from these areas being compromised or disrupted. Following a diagnosis of scleroderma, a person's quality of life may be affected by various factors related to the disease itself, as well as the broader implications of living with a chronic illness.

Scleroderma can have large impacts on a persons interpersonal relationships

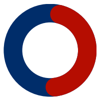
- Social Isolation: The physical limitations caused by scleroderma can lead to reduced social interaction. Pain, fatigue, and mobility challenges may prevent someone from engaging in social activities. This can result in feelings of loneliness and isolation, and subsequently a decline of their mental health.
- Relationship Strain: Chronic illness can place a strain on relationships with family, friends, and romantic partners. Caregiver fatigue, changes in roles and expectations, and difficulties in communication may lead to tension and emotional distress in relationships.
- Stigma and Misunderstanding: Because scleroderma is not widely understood, people with the condition may feel stigmatized or misunderstood, especially when it affects their appearance. This can contribute to social withdrawal, lower self-esteem, and anxiety about being judged.

34% of respondents feel that there is a large social stigma attached to scleroderma.

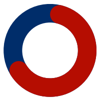


61% of respondents reported feeling more socially isolated since being diagnosed wth scleroderma.

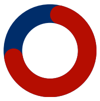
38% of respondents feel that they are treated differently due to the physical manifestations of scleroderma.



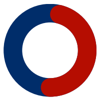
52% of respondents feel that scleroderma has lowered the number of social relationships they have.



70% of respondents felt that there are many misconceptions about scleroderma.



76% of respondents reported not being able to participate in their usual social activities because of scleroderma.

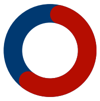


54% of respondents feel that scleroderma has lowered the quality of their social relationships.

Quality of Life Impacts

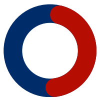
Physical Symptoms and Pain

- Chronic Pain: Scleroderma can cause significant pain, particularly in the joints, muscles, and skin, due to tightness and fibrosis. Persistent pain can affect mood, sleep, and overall functioning, contributing to mental health challenges like anxiety, depression, and irritability.
- Fatigue: Chronic fatigue is a common symptom of scleroderma and can have a significant impact on patients' mental health. Constant exhaustion can reduce the ability to participate in everyday activities, leading to frustration, isolation, and feelings of helplessness.
- Mobility Issues: If scleroderma affects the joints or internal organs (like the lungs or heart), it may cause difficulty with movement or breathing. Limited mobility can lead to loss of independence, creating emotional distress, anxiety, and a lower quality of life.

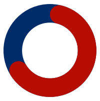


64% of respondents reported being physically unable to participate in daily activities since being diagnosed with scleroderma.

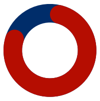
38% of respondents feel that they are treated differently due to the physical manifestations of scleroderma.



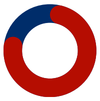
52% of respondents feel that scleroderma has lowered the number of social relationship they have.



70% of respondents reported being physically unable to participate in their regular exercise routine since being diagnosed with scleroderma.

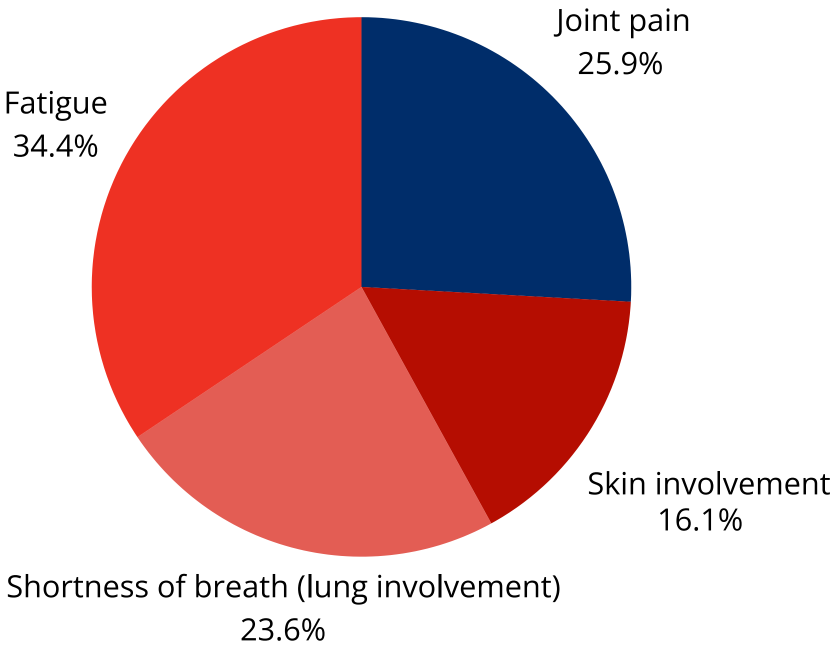


84% of respondents reported being less likely to participate in outdoor activities since being diagnosed with scleroderma.



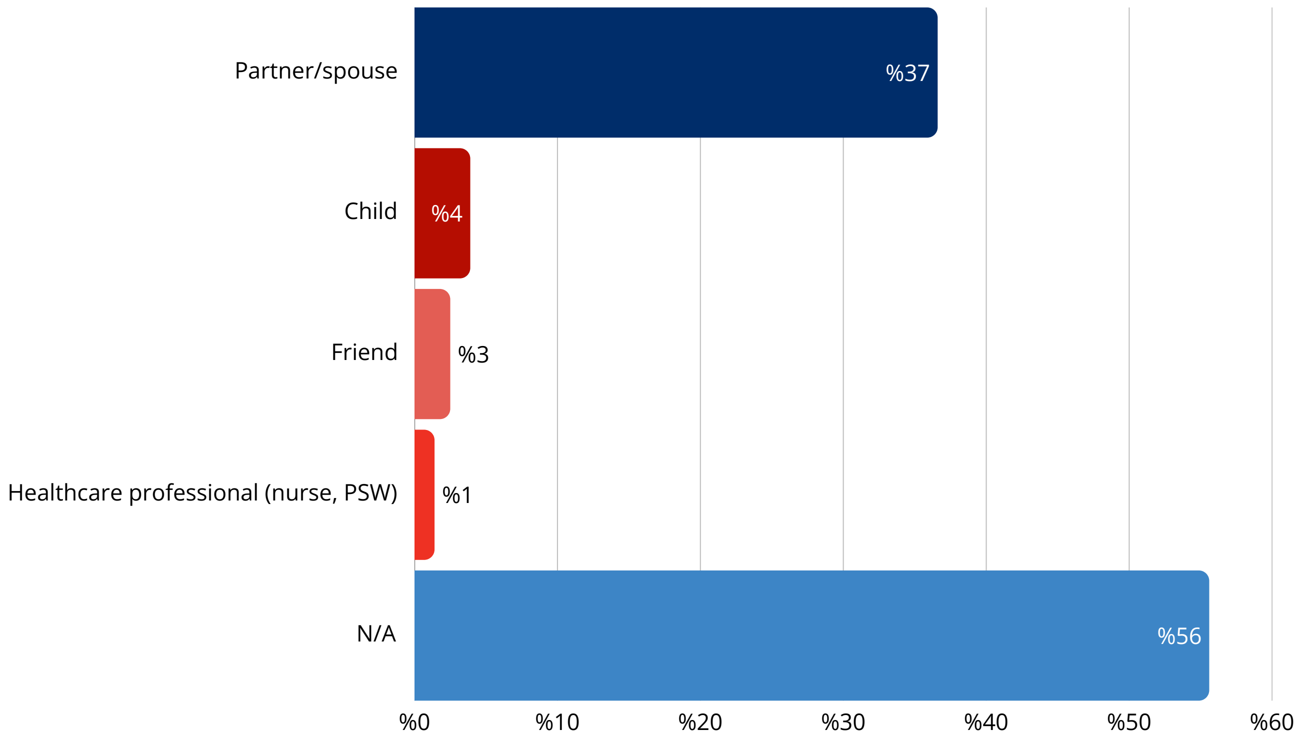
81% of respondents reported being less physically active since being diagnosed with scleroderma.

Respondents reported the following barriers to physical activity

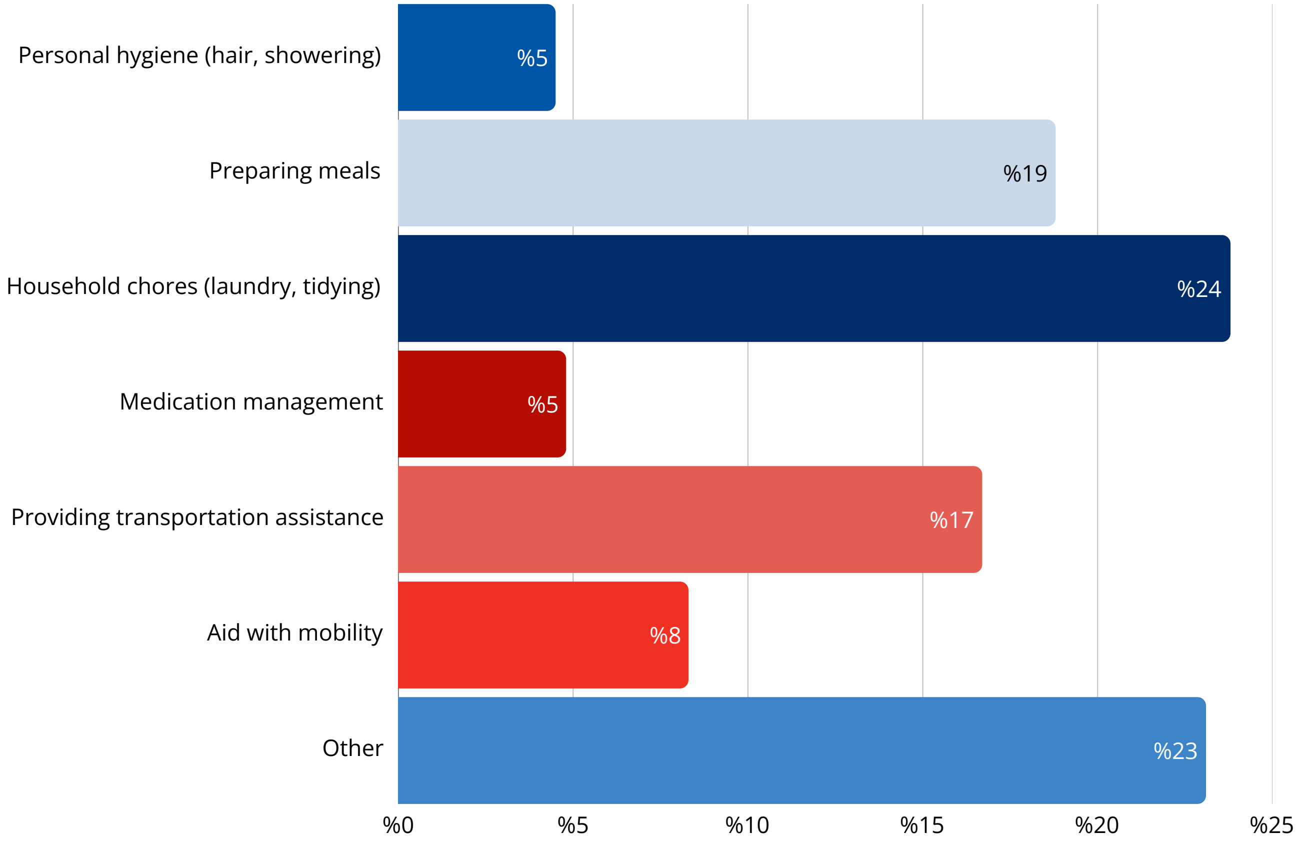


Quality of Life Impacts

44% of respondents reported having to rely on a caregiver

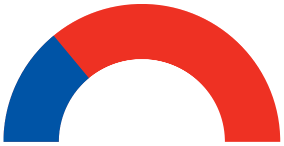


Respondents reported relying on a caregiver for the following supports



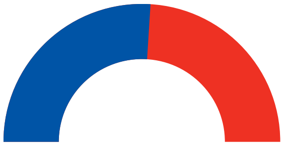
Quality of Life Impacts

While respondents reported serious impacts to their quality of life that have lead to a decline in mental or emotional health, access to mental health supports for those living with scleroderma remains a problem



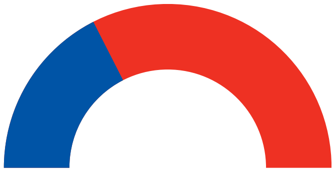
28%

Of respondents reported receiving a new mental health diagnosis since being diagnosed with scleroderma.



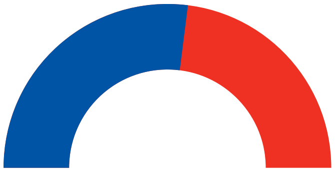
52%

Of respondents reported needing more mental health support since being diagnosed with scleroderma.



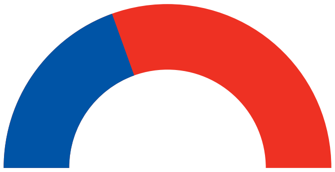
35%

Of respondents feel that they have limited access to mental health supports.



54%

Of respondents feel that there are not enough mental health supports for scleroderma patients.



39%

Of respondents feel that the expense of mental health supports prevents them from using them.

Quality of Life Impacts

Respondents left the following comments when asked about the impact of scleroderma on their quality of life...

“Unfortunately I am less active and also unsure of what is going to happen to me and thus more prone to be more down than before.”

“It is very difficult to accept what is happening to you, it's scary.”

“Not knowing what is to come is hugely stressful and scary. I want to inform myself to be prepared mentally and to accept and own it and try to find positivity in every day, but informing myself also opens doors to scary possibilities. I think the biggest hurdle thus far is not having a road map for this disease, not being able to plan how much longer I'll be able to work.”

“I'm early on in the disease course and starting an immunosuppressant soon. I'm very fortunate that my progression has been slow, but I think what impacts me most is the ‘what ifs?’ and the unknowns of the disease. The stress of worst case scenarios is what I find most heavy about the disease and what has led me to switch from full time to part time work, to allow myself to focus on my health and lower stress. The positive side of it all is that it has prompted me to focus more on exercise and healthy eating, to try to control the things I can.”

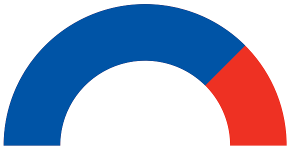
“It's a very difficult disease to cope with both physically and mentally. But I am doing my best to overcome the obstacles.”

“I'm tired and I hurt.”

“It is degrading and very painful, GI Issues. Sometimes, I can't leave the house.”

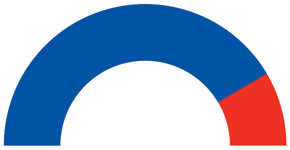
How Can We Help?

Scleroderma Canada recognizes its role and responsibility in providing necessary patient support for those living with scleroderma across Canada.



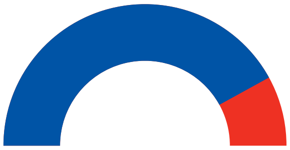
75%

Of respondents said they are likely to seek information about scleroderma from their doctor.



83%

Of respondents said they are likely to seek information about scleroderma from the internet.



84%

Of respondents said they are likely to seek information about scleroderma from organizations like Scleroderma Canada.

The results from this survey will serve as a cornerstone for guiding our strategic direction, ensuring that we are not only listening but actively responding to the needs and concerns of patients. By analyzing the valuable feedback shared with us, we can better understand the challenges and aspirations of the patient community. This insight will drive our efforts to create more effective programs, advocate for necessary policy changes, and provide resources that truly make a difference. We remain dedicated to fulfilling our promise of being an unwavering ally to patients and continuously improving the care and support they receive.

Your Support

Scleroderma is a highly unique and individualized disease - no two experiences are alike. Your support is crucial for raising public awareness, boosting research investment and interest, driving policy changes, and strengthening the scleroderma community.

Your support is invaluable. To learn more about how you can help, connect with us:

www.scleroderma.ca

Scleroderma Canada

@SclerodermaCAN

@SclerodermaCAN

Scan the QR code to sign up for our quarterly newsletter with updates from Scleroderma Canada.

Thank you to everyone who contributed to this report including those patients who took the time to share their stories and answer our questions.

Survey Authors

Karol Bedoya-Carvajal

Carly Burow