2024-2025 Scleroderma Patient Impact Survey Research Proposal

Karol Bedoya-Carvajal and Carly Burow
Scleroderma Canada
August 9th, 2024

Introduction and Research Rationale

The area of investigation for this research proposal is the multifaceted impacts that scleroderma can have on Canadians living with this rare disease. The question being, "How does scleroderma impact individuals physically, socially, financially, and psychologically?" We hope to measure these impacts by conducting a comprehensive survey.

Scleroderma is a rare, progressive, chronic, and multi-symptom autoimmune disease in which an individual's immune system works against itself, resulting in excess tissue collagen throughout the body. This overproduction results in a thickening, hardening, and scaring of tissues. Reduced blood flow through small blood vessels can also further compromise affected tissues. The most characteristic feature of scleroderma, and the source of its name, is the hardening of the skin. However, the effects of scleroderma on the body do not end there. Less visible are the vascular lesions that can occur in small blood vessels, which may affect major organs (Scleroderma Canada, 2020). The challenges of living with scleroderma is often exasperated by the fact that the course of the disease tends to vary so widely from person-to-person.

Scleroderma can be categorized into two primary forms: localized and systemic. Scleroderma primarily affecting the skin without major organ involvement is referred to as "localized." It progresses more slowly than systemic scleroderma and has a more positive long-term prognosis. Localized scleroderma typically affects skin of hands, fingers, lower arms, and face. When this form of scleroderma does have internal organ involvement, it typically affects the esophagus and lungs. It is also more typical for this form of scleroderma to develop in children (Scleroderma Canada, 2020). Systemic scleroderma, on the other hand, affects the skin as well as the underlying tissues, progresses more rapidly, and tends to be more severe with less desirable long-term outcomes. This form of scleroderma is typically categorized by vascular lesions in small

blood vessels and major organs, often resulting in organ damage (Scleroderma Canada, 2020). While medications are available to slow disease progression and provide symptom relief, there is no known cure.

Scleroderma Canada's mission as an organization is "to advance heath care options and enrich the lives of those living with scleroderma" (Scleroderma Canada, 2020). The organization is committed to serving the Canadian scleroderma community by engaging in activities aligned to its core pillars; Patient Support, Research, and Awareness. These core pillars drive the activities that the organization engages in. This research is important for two reasons. For one, Scleroderma Canada hopes to use the data collected through this comprehensive survey to shed light on the physical, social, financial, and psychological impacts of Scleroderma on Canadians living with the disease. In addition to this, Scleroderma Canada is also looking to use this data to evaluate its strategic goals and priorities to ensure the organization is successful in meeting its mission. With a disease like scleroderma, rare and extremely personalized, surveys of this kind are of the utmost importance. They give those closest to the disease an outlet through which to speak on their experience and the chance to voice the kind of help they need from patient advocacy groups such as Scleroderma Canada.

Scleroderma patients in Canada rely on Scleroderma Canada to provide them with resources aimed to improve their quality-of-life day to day, as well as to conduct advocacy work on their behalf and to distribute grants to researchers hoping to find a cure for scleroderma. Being able to take the thoughts and experiences of individuals suffering from scleroderma into consideration is incredibly important to Scleroderma Canada and its activity.

Literature Review

There have been calls on patient advocacy organizations to take action to ensure that their current and future value frameworks take into consideration patient value (Addario et al., 2018). In order to accurately gauge patient values, organizations must employ a concept known as "patient engagement." In healthcare this is defined as "the facilitation and strengthening of the role of those using services as coproducers of health, and health care policy and practice" (Valderas Martinez et al., 2016). Patient engagement is cited as crucial to improving health outcomes and overall quality of life patients (WHO, 2023). Given the direct role that non-profits play in health care policy through their advocacy work and their responsibility to provide resources for patients it is essential that they recognize their responsibility to elevate patient voices.

Many health organizations and non-profits engage patients through studies and surveys which explore the impacts of disease. The results of which represent these patient values and can be used to guide patient advocacy organizations in their advocacy work, improving the quality of life of their patients, and meeting their mission statements. Canadian organizations such as The Pulmonary Hypertension Association of Canada, Arthritis Society Canada, and the Heart and Stroke Foundation have reported disease demographics, the impacts, and the burdens of their respective disease of focus.

By identifying these issues, the voices of those most affected by disease are heard, enabling organizations to better strategize future efforts that meet community needs. A similar survey on the impacts of scleroderma would be invaluable for assessing comparable impacts and outcomes. A review of the current literature further highlights this need.

Some studies have explored the psychological and social impacts of scleroderma (Benrud-Larson et al. 2002; Gumuchian et al. 2016). One qualitative study by Benrud-Larson et al. (2002)

identified sources of emotional distress. These include facing a new reality with scleroderma diagnosis, daily struggle of living with scleroderma, handling work and general financial burdens, and changing social interactions. Other studies have investigated the physical impacts of disease (Oreska et al. 2018; Oreska et al. 2019; Sandusky et al. 2009). Sandusky et al. (2009) found patients reporting greater pain also had greater levels of self-reported fatigue and depression, as well as poorer functioning. While both studies by Oreska et al. (2018; 2019) found that patients with systemic sclerosis tended to have an increased extracellular mass/body cell mass ratio in comparison to healthy controls. This reflects a deteriorated nutritional status and worse muscle predispositions for physical activity in systemic sclerosis patients. While these highlight the physical implications of disease, research by Bernatsky et al. (2009), Chevreul et al. (2015), López-Bastida et al. (2014), and Morrisroe et al. (2018) analyze the financial impact of scleroderma. In a study by Bernatsky et al. (2009) the average annual cost of living with systemic sclerosis was calculated from 457 Canadian systemic sclerosis patients. They estimated the total average annual cost (both direct and indirect costs) to be $18,543, represented in 2007 Canadian dollars. An Australian study by Morrisroe et al. (2018) also found that living with scleroderma often results in a significant financial burden. The study also found higher than average rates of unemployment and reduced productivity with systemic sclerosis patients, furthering the financial burden of the disease. These studies speak greatly to the multifaceted nature of disease burden.

Further qualitative research has attempted to describe the perspectives of patients and the diverse impacts of living with scleroderma.

One qualitative study by Cinar et al. (2012) used phenomenological analysis to determine the perspectives of 16 patients living with scleroderma. Data analysis revealed four categories; physical impacts of disease, emotional impacts of disease, social impacts of disease, and patient

behaviors for coping with disease. This study found that patients experience significant limitations in daily functioning due to problems in their hands. Patients also reported feeling disappointed in relation to their coping with the illness or their symptoms, anxiety for the future, and social isolation. Another qualitative study by Zigler et al. (2020) explored health related quality of life impacts on pediatric localized scleroderma patients. Major areas of impact identified in children include physical limitations, body image issues, bullying and teasing from their peers, and treatment side-effects and burdens.

The multifaceted nature of disease burden evident in these studies makes it paramount to continue to research the impact of scleroderma to identify areas of focus. Having significant impact on the psychological, social, physical, and financial aspects of life highlight how challenging managing a rare disease can be. Being able to quantify these impacts of disease in a Canadian context will help to give a voice to those most impacted by disease, as well as bettering our understanding of scleroderma disease burden and help to give a voice to those most impacted by disease. Data of this nature can play a vital role in guiding organizations such as Scleroderma Canada to direct funding, support efforts, and steer research strategies in more productive ways. By collecting and analyzing data pertaining to the psychological, social physical, and financial impacts of scleroderma, Scleroderma Canada would be able to improve its operations and productivity, therefore necessitating the proposed comprehensive survey.

Research Design

In this study, the independent variable is scleroderma and the dependent variables are the impacts of the disease. These impacts span across four dimensions; physical, social, financial, and

psychological impact. These impacts will be used to answer the central research question and to quantify the impacts of Scleroderma.

In this study, the independent variable, scleroderma, is a dichotomous nominal variable. In the survey, individuals will be asked to self-identify whether they have been formally diagnosed with scleroderma. The dependent variables, impacts of disease, are primarily ordinal variables.

The survey will contain questions designed to assess and quantify these impacts. It will be delivered as an online survey through the platform, Survey Monkey. The survey will be comprised of ranking, short answer, and yes or no questions. For example, "please rank the following statement on a scale of 0 (not true at all) to 5 (definitely true): I feel that my scleroderma diagnosis has limited my career options". A full list of proposed survey questions is available in Appendix A. The survey will take approximately 20-30 minutes to complete and will be anonymous. The sample size would be ideally around 100 participants, with a representative distribution from across provinces and territories in Canada. This sample size was chosen based on the fact that scleroderma is a rare disease, therefore, not extremely prevalent in the Canadian population. To achieve a representative sample from across Canadian provinces and territories, provincial Scleroderma associations will be included in the survey distribution.

This survey will be primarily distributed through Scleroderma Canada emails, marketing from provincial partners, social media campaigns, and at the 21st Bi-Annual National Scleroderma Conference in St. John's, Newfoundland and Labrador. The inclusion criteria for this study will be individuals formally diagnosed with scleroderma who currently reside in Canada. Individuals will be informed that participation is voluntary and that they are able to withdraw at any point without consequence.

To disseminate the findings of this survey, a formal report will be published through Scleroderma Canada. These findings will be shared with stakeholders, provincial partners, researchers, clinicians, and the general public. In doing so, this report aims to support and encourage increased advocacy efforts, funding, and support services for those living with scleroderma.

One limitation of this study may be ensuring inclusion of a broad geographic range of respondents across all provinces and territories in Canada. To combat this, we are partnering with provincial organizations for survey distribution and considering population size in each province or territory when analyzing the final study results. Another foreseeable limitation is the inherit bias in self-reported survey data. In order to combat this, question design will involve neutral, non-leading questions and a range of response options. We will also be including diverse recruitment strategies to reach a broad range of respondent demographics.

Statistical Methods

The appropriate measure of association for this study is the Spearman rank-order correlation coefficient. This is because we are measuring the strength of a monotonic association between two variable that are measured on a ranked scale (Likert-scale). Pearsons's correlation coefficient r takes on the values of –1 through +1, where values –1 or +1 indicate a perfect linear relationship between the dependent and independent variables. A value of 0 indicates no linear relationship. A value that is neither –1, 0, or +1 indicates a linear relationship that is not perfect.

A measure of significance is important because it determines the likelihood that the results were due to chance. A separate t-test would be most appropriate for this study in order to measure

the difference between the observed *r* and the expected *r* under the null hypothesis (*r* being Pearsons's correlation coefficient).

References

Addario, B. J., Fadich, A., Fox, J., Krebs, L., Maskens, D., Oliver, K., ... & Turnham, T. (2018). Patient value: perspectives from the advocacy community. Health Expectations, 21(1), 57-63.

Arthritis Society Canada. (2023). *The State of Arthritis in Canada* [Review of *The State of Arthritis in Canada*]. https://arthritis.ca/getmedia/0c7b1abc-8f14-4fea-bc8d-3225b6d30e53/Arthritis-Canada-Report-Card_Final_Oct5.pdf

Bernatsky, S., Hudson, M., Panopalis, P., Clarke, A. E., Pope, J., Leclercq, S., St. Pierre, Y., & Baron, M. (2009). The cost of systemic sclerosis. *Arthritis Care & Research*, *61*(1), 119–123. https://doi.org/10.1002/art.24086

Benrud-Larson, L. M., Haythornthwaite, J. A., Heinberg, L. J., Boling, C., Reed, J., White, B., & Wigley, F. M. (2002). The impact of pain and symptoms of depression in scleroderma. *Pain*, *95*(3), 267–275. https://doi.org/10.1016/S0304-3959(01)00409-2

Chevreul, K., Brigham, K. B., Gandré, C., Mouthon, L., & and the BURQOL-RD Research Network*. (2015). The economic burden and health-related quality of life associated with systemic sclerosis in France. *Scandinavian Journal of Rheumatology*, *44*(3), 238–246. https://doi.org/10.3109/03009742.2014.976653

Cinar, F. I., Unver, V., Yilmaz, S., Cinar, M., Yilmaz, F., Simsek, I., Erdem, H., Pay, S., & Dinc, A. (2012). Living with scleroderma: patients' perspectives, a phenomenological study. *Rheumatology International*, *32*(11), 3573–3579. https://doi.org/10.1007/s00296-011-2230-2

Gumuchian, S. T., Pelaez, S., Delisle, V. C., Carrier, M.-E., Jewett, L. R., El-Baalbaki, G., Fortune, C., Hudson, M., Impens, A., Korner, A., Persmann, J., Kwakkenbos, L., Bartlett, S. J., & Thombs, B. D. (2016). Exploring Sources of Emotional Distress among People Living with Scleroderma: A Focus Group Study. *PLoS ONE*, *11*(3). http://doi.org/10.1371/journal.pone.0152419

Heart and Stroke Foundation. (2018). *Lives Disrupted: The Impact of Stroke on Women* [Review of *Lives Disrupted: The Impact of Stroke on Women*]. https://www.heartandstroke.ca/-/media/pdf-files/canada/stroke-report/strokereport2018.pdf?rev=8491d9c349f7404491f36be67f649c0b

López-Bastida, J., Linertová, R., Oliva-Moreno, J., Posada-de-la-Paz, M., & Serrano-Aguilar, P. (2014). Social Economic Costs and Health-Related Quality of Life in Patients With Systemic Sclerosis in Spain. *Arthritis Care & Research*, *66*(3), 473–480. https://doi.org/10.1002/acr.22167

Morrisroe, K., Sudararajan, V., Stevens, W., Sahhar, J., Zochling, J., Roddy, J., Proudman, S., & Nikpour, M. (2018). Work productivity in systemic sclerosis, its economic burden and

association with health-related quality of life. *Rheumatology*, *57*(1), 73–83. https://doi.org/10.1093/rheumatology/kex362

Oreska, S., Spiritovic, M., Cesak, P., Cesak, M., Storkanova, H., Smucrova, H., Hermankova, B., Ruzickova, O., Mann, H., Pavelka, K., Senolt, L., Vencovsky, J., Becvar, R., & Tomcik, M. (2019). P167 Association of changes of body composition in scleroderma patients with disease activity, physical activity and serum levels of inflammatory cytokines. *Annals of the Rheumatic Diseases*, *78*(Suppl 1), A74-. https://doi.org/10.1136/annrheumdis-2018-EWRR2019.149

Oreska, S., Spiritovic, M., Cesak, P., Cesak, M., Storkanova, H., Smucrova, H., Hermankova, B., Ruzikova, O., Mann, H., Pavelka, K., Senolt, L., Vencovsky, J., Becvar, R., & Tomcik, M. (2018). AB0799 Alterations of body composition in scleroderma patients are associated with disease activity and physical activity but not with lung involvement. *Annals of the Rheumatic Diseases*, *77*(Suppl 2), 1531-. https://doi.org/10.1136/annrheumdis-2018-eular.6978

Pulmonary Hypertension Association of Canada. (2024). The Socioeconomic Burden of Pulmonary Arterial Hypertension in Canada [Review of The Socioeconomic Burden of Pulmonary Arterial Hypertension in Canada]. https://www.phacanada.ca/_files/ugd/f4d8ca_f05ae73fe7034349ad8ff0e085f95ad1.pdf

Sandusky, S. B., McGuire, L., Smith, M. T., Wigley, F. M., & Haythornthwaite, J. A. (2009). Fatigue: an overlooked determinant of physical function in scleroderma. *Rheumatology*, *48*(2), 165–169. https://doi.org/10.1093/rheumatology/ken455

Scleroderma Canada . (2020). *Scleroderma Canada Infographic* . Hamilton , Ontario .

Valderas Martinez, J. M., Ricci-Cabello, N., Prasopa-Plazier, N., Wensing, M., Santana, M. J., Kaitiritimba, R., ... & Murphy, M. (2016). Patient engagement: WHO technical series on safer primary care. World Health Organisation.

World Health Organization. (2023). Engaging patients for patient safety: advocacy brief. World Health Organization.

Zigler, C. K., Ardalan, K., Hernandez, A., Caliendo, A. E., Magee, K. E., Terry, M. A., Mann, C. M., & Torok, K. S. (2020). Exploring the impact of paediatric localized scleroderma on health-related quality of life: focus groups with youth and caregivers. *British Journal of Dermatology*, *183*(4), 692–701. https://doi.org/10.1111/bjd.18879

Appendix A – Potential Survey Questions

Demographics	
What is your age?	What is your gender?
What is your relationship status?	What kind of community do you live in?
Province?	Age at diagnosis?
Years since diagnosis?	How long did it take you to be diagnosed?
How many specialists did you see prior to diagnosis?	What specialty diagnosed you?
What type of scleroderma were you diagnosed with?	Are you a member of a patient support group?
Would you be interested in joining a patient support group?	In the past year, how many times have you been admitted into the hospital due to scleroderma?
In the past year, how many days have you spent in the hospital due to scleroderma?	In the past year, how many days have you spent in a clinic due to scleroderma?
Career and Education	
What is your employment/education status?	On average, how many scheduled hours do you miss weekly from work or school because of your health problems? Include hours you missed on sick days, times you went in late, left early, etc., because of your health problems.
How many hours over the past year have you miss from work or school because of any other reason, such as vacation or holidays?	How many hours over the past year did you actually work or attend school?
Has scleroderma affected your ability to work (switched to part time, retired early, accommodated schedule, etc) ? If so, please specify.	

Rank each of the following statements on a scale of 0 (not true at all) to 5 (definitely true). Please select not applicable if the question does not apply to you. If you would like to expand on an answer, select the dropdown box. All responses are anonymous:

Rank each of the following statements on a scale of 0 (not true at all) to 5 (definitely true). Please select not applicable if the question does not apply to you. If you would like to expand on an answer, select the dropdown box. All responses are anonymous:

I feel that my scleroderma diagnosis has limited my academic options

I feel that my scleroderma diagnosis has limited my academic success

I feel that my scleroderma diagnosis has prevented me from being able to keep up with my grades

I feel that my scleroderma diagnosis has stopped me from wanting to attend school

I feel that my scleroderma diagnosis has stopped me from be able to attend school

I feel that my scleroderma diagnosis has prevented me from continuing onto further education

I feel that my scleroderma diagnosis has stopped me from wanting to continue onto further education

I feel that my scleroderma diagnosis has changed the way my educators treat me at school

I feel that my scleroderma diagnosis has changed the way my peers treat me at school

I feel that my scleroderma diagnosis has prevented me from being excited for school

I feel that my educational institution has provided adequate supports and accommodations for my scleroderma diagnosis

I feel that my scleroderma has lowered the number of hours I am able to dedicate to school work

I feel that my scleroderma has lowered my productivity at school

I feel that my scleroderma diagnosis has limited my career options

I feel that my scleroderma diagnosis has limited my career progress

I feel that my scleroderma diagnosis has prevented me from being able to keep my job

I feel that my scleroderma diagnosis has stopped me from wanting to work

I feel that my scleroderma diagnosis has stopped me from be able to work

I feel that my scleroderma diagnosis has prevented me from obtaining a promotion

I feel that my scleroderma diagnosis has stopped me from wanting to accept a promotion

I feel that my scleroderma diagnosis has made me want to retire early

I feel that my scleroderma diagnosis has lowered the number of hours I can work

I feel that my scleroderma diagnosis has changed the way my boss treats me at work

I feel that my scleroderma diagnosis has changed the way my peers treat me at work

I feel that my scleroderma diagnosis has prevented me from being excited for work

I feel that my workplace has provided adequate supports and accommodations for my scleroderma diagnosis

I feel that my scleroderma has lowered the number of hours I am able to work

I feel that my scleroderma has lowered my productivity at work

Financial	
Scleroderma patients must budget for many out-of-pocket expenses, including travel to clinic appointments, parking, and professional caregiver costs. Do you feel that this has taken a toll on you financially?	On average, how much do you spend on travel (to the doctor, health clinics, hospital) per year?
Have you received financial support from the government because of the effects of scleroderma? If yes, please specify.	On average, how much do you spend on parking fees at pharmacy, hospital, or health related visit per year?
On average, how much do you spend on professional caregiving services per year?	

Rank each of the following statements on a scale of 0 (not true at all) to 5 (definitely true). Please select not applicable if the question does not apply to you. If you would like to expand on an answer, select the dropdown box. All responses are anonymous:

Since being diagnosed with scleroderma, my financial situation has been negatively affected

I feel that my scleroderma diagnosis has directly caused financial hardship

Since being diagnosed with scleroderma, my income has decreased

Since being diagnosed with scleroderma, my medical expenses have increased significantly

Since being diagnosed with scleroderma, I have found it more difficult to manage my finances

Since being diagnosed with scleroderma, I have found it more difficult to financially support my children

Since being diagnosed with scleroderma, my spending habits have changed

Since being diagnosed with scleroderma, I have had to make significant changes to my investment portfolio

Since being diagnosed with scleroderma, I have felt stressed over my financial situation

Since being diagnosed with scleroderma, I struggle to afford my prescribed medication

Since being diagnosed with scleroderma, I struggle to afford a paid professional caregiver (PSW, nurse, etc.)

Since being diagnosed with scleroderma, I struggle to afford everyday expenses

Since being diagnosed with scleroderma, I have not been able to save as much money

Since being diagnosed with scleroderma, I have had to take money from my savings to support myself

Since being diagnosed with scleroderma, I have sought additional financial planning assistance

Since being diagnosed with scleroderma, I have had to rely more on financial supports related to my diagnosis (grants, loans, government support programs)

My health insurance has been adequate for managing scleroderma related expenses

I have experienced denials or delays in insurance coverage for my scleroderma-related treatments and medications

I have applied for disability benefits relating to my scleroderma diagnosis

I feel there are adequate government financial supports for individuals with scleroderma

Since being diagnosed with scleroderma, I have incurred additional debt due to my diagnosis

I am optimistic about my financial future given my scleroderma diagnosis

Quality of Life

Rank each of the following statements on a scale of 0 (not true at all) to 5 (definitely true). Please select not applicable if the question does not apply to you. If you would like to expand on an answer, select the dropdown box. All responses are anonymous:

Since being diagnosed with scleroderma, my mental or emotional health has declined

Since being diagnosed with scleroderma, I have had a new mental health diagnosis

Since being diagnosed with scleroderma, I need more mental health support

I feel that I have limited access to mental health supports

I feel that the expense of mental health supports prevents me from using them

I feel that the geographic location of mental health supports prevents me from using them

I feel that stigma surrounding seeking mental health supports prevents me from using them

I feel that there are not enough mental health supports for scleroderma patients

I feel that there is a large social stigma with scleroderma

I feel there are many misconceptions about scleroderma

I feel more socially isolated since being diagnosed with scleroderma

I feel that people avoid interaction with me due to my scleroderma diagnosis

I am likely to seek information about scleroderma from my doctor

I am likely to seek information about scleroderma from peers with scleroderma

I am likely to seek information about scleroderma from organizations like Scleroderma Canada

I am likely to seek information about scleroderma from the internet

I feel that I haven't been able to participate in my usual social activities because of scleroderma

I feel that I am treated differently due to the physical manifestations of scleroderma

I feel that others define me based on my scleroderma diagnosis

I define myself based on my scleroderma diagnosis

I feel that scleroderma has lowered the quality of my social relationships

I feel that scleroderma has increased the quality of my social relationships

I feel that scleroderma has impacted my parenting in a positive way

I feel that scleroderma has impacted my parenting in a negative way

I feel that my scleroderma diagnosis has prompted me to reconsider my family planning in a positive way

I feel that my scleroderma diagnosis has prompted me to reconsider my family planning in a positive way

I feel that scleroderma has lowered the number of social relationships that I have

I feel that scleroderma has increased the number of social relationships that I have

Since being diagnosed with scleroderma, I am physically unable to participate in daily activities

Since being diagnosed with scleroderma, I am physically unable to participate in my regular exercise regime

I am less physically active since being diagnosed with scleroderma

I am less likely to participate in outdoor activities since being diagnosed with scleroderma

I have been able to make adaptions to my exercise routine or physical activities so that I can participate with scleroderma

My joint pain from scleroderma prevents me from being physically active

My skin involvement from scleroderma prevents me from being physically active

My shortness of breath from scleroderma lung involvement prevents me from being physically active

My fatigue from scleroderma prevents me from being physically active

I have difficulty with fine motor skills due to symptoms of scleroderma (eg. holding pencil, fastening a button)

I have difficulty in cooking and related activities (opening cans, using utensils) due to symptoms of scleroderma

Scleroderma Management

Rank each of the following statements on a scale of 0 (not true at all) to 5 (definitely true). Please select not applicable if the question does not apply to you. If you would like to expand on an answer, select the dropdown box. All responses are anonymous:

I feel that I am in control of my scleroderma and disease management

I feel confident when going into my scleroderma health appointments

I feel that my physician and I work together as a team

I am confident in my healthcare provider to help manage my scleroderma

I am confident in the healthcare system to support my scleroderma management

I feel that the wait time to see my family physician is too long

I feel that the wait time to see my rheumatologist is too long

I feel that my scleroderma symptoms are well managed

I feel that I have an adequate number of appointments with my healthcare provider

I feel that my current treatment regime is effective

I feel like I am able to follow my current treatment regime easily

I feel that there are lots of treatment options for scleroderma

I feel well informed about all of the treatment options available to me

I feel that treatment side effects have gotten in the way of optimal treatment results

I feel that treatment side effects have lowered my quality of life
I feel that there are no/limited informational resources for treatment options
I feel like I have no one to ask about my current treatment
When choosing a treatment, the number or type of side effects is one of the most important things I consider
When choosing a treatment, where the treatment is administered (home, clinic, hospital) is one of the most important things I consider
When choosing a treatment, how the treatment is administered (pill, infusion) is one of the most important things I consider
I have lost hope in a cure
I don't know what current research for a cure is happening
I feel like there is not enough funding and support going into research for a cure
I have had to seek support from a paid caregiver (PSW, nurse) in the past six months for scleroderma
I have had to seek support from an unpaid caregiver in the past six months for scleroderma
I feel comfortable asking my friends for support with things scleroderma related
I feel comfortable asking my family for support with things scleroderma related
Since being diagnosed with scleroderma, I have made adjustments to my diet
Since being diagnosed with scleroderma, I have participated in a clinical trial for scleroderma treatments
Since being diagnosed with scleroderma, I have considered participating in a clinical trial for scleroderma treatments

Who is most commonly your caregiver?	What support do you require from your caregiver?
How many hours per week does your caregiver spend supporting you with daily activities?	which professionals are included in your disease management / health team?